Enabling Connected Care with a Person-Centred Data Foundation

COMMENTARY

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ABSTRACT

Having the right information at the right time and at the fingertips of the right individuals is not just a necessity for a well-functioning healthcare system but it is also the difference between life and death for Canadians. It is particularly critical to enable improved access to and quality of care for equity-deserving individuals because

these data eliminate blind spots for clinicians, policy makers and system planners. The COVID-19 pandemic put a spotlight on the health data challenges that exist across Canada and the tangible impact those have on the healthcare system's ability to meet the needs of underserved populations. It sparked unified urgency at the federal and provincial/territorial levels to build a learning health system powered by connected health data for clinical care, patient access, care organization operations, health system use and population/public health. Person-centric data content standards will lie at the foundation of Canada's learning health system, enabling the creation and exchange of data.

Patient Stories

A 20-year-old cancer patient does not have the funds to pay for the drug required for his treatment. His family doctor knows about his social and economic situation, but his oncologist does not. Because there is no ability to share this information between providers, this patient is left on his own to struggle through the transition gaps in the system.

An emergency department doctor in a remote hospital sends a virtual consultation request to a specialist at another hospital. Because their systems cannot exchange information, the consultation takes much longer than necessary, taking time away from both clinicians' days that could have been spent with patients.

A recent graduate who has lived her whole life in New Brunswick, Canada, has received a job offer in Alberta. This person has chronic conditions that require careful management but because of the fragmented nature of our health systems, coupled with the lack of interoperability, there is no easy way for her to access their data and take her history with her to her new home.

These stories demonstrate the harm that can occur when the right information is not available to the right person at the right time. When a patient-centric approach to healthcare and data flow is not put in place, the result is fragmented information and poor patient outcomes. This harm is further amplified for equity-deserving individuals for a variety of complex reasons.

While equity cannot be achieved by one solution alone, this paper will explore how increased access and availability of data across the healthcare system can make an impact and help us progress as a society.

Background

Good information that is accurate, reliable and fit for purpose is a prerequisite for meaningful data exchange, patient access to information, population health analytics and unlocking the power of emerging technologies such as artificial intelligence.

The ability to access and share health data is a key enabler for patients to receive and clinicians to provide high-quality, timely and equitable access to healthcare. Implementing inclusive data collection practices in digital health systems is a critical first step to eliminating data invisibility and addressing health disparities (McClure et al. 2022). This information will, in turn, support the ability to provide equitable and personalized patient care, advance health system research and shape evidence-based policy by enabling disaggregated reporting on health system performance – including access, utilization and quality of care – across key equity measures.

Over the past two decades, Canada has made extraordinary progress toward digitizing its paper-based processes in healthcare. However, in the current state, data in digital health systems have been generated to meet digitization needs and are not yet set up to enable timely and broad information sharing, also known as "interoperability." In addition, Canada's legislative frameworks have not been set up to empower patients to manage their own information and care. Finally, socio-demographic data to support the measurement of equity stratifiers are not comprehensively collected in digital health systems (Palacio et al. 2017). Over time, this has resulted in data that are not standardized, comprehensively patient-centric or shared across digital health systems.

Patient-centred care is defined as the ability of the healthcare system to meet "an individual's specific health needs and desired health outcomes" where "[p]atients are partners with their healthcare providers, and providers treat patients not only from a clinical perspective, but also from an emotional, mental, spiritual, social, and financial perspective" (NEJM Catalyst 2017). For providers to deliver care in this manner, they require timely and accurate access to fulsome data about the whole patient. In addition, the healthcare system and researchers also require the same in order to design programs and quality initiatives, set policies and investigate new technologies or techniques.

Current data collection practices in Canada's digital health systems largely misrepresent or underrepresent diversity across individuals' socio-demographic factors. This can lead to health inequalities and patients feeling unsafe when receiving care (Patterson et al. 2017).

Some socio-demographic information is collected through the federal census, administered by Statistics Canada, and some data are collected in various care settings across the provinces and territories. The data are also not shared consistently across provincial/territorial or federal levels (Menezes et al. 2022).

To correct this problem, Canada is developing person-centric data content and exchange standards to collect patient-centred, standardized data that follow the patient across care settings and geographies to enable more informed care provision and a connected health system (CHS), ultimately leading to better health outcomes for all Canadians. Based on the way Canada's health data infrastructure has been built up over time, data reside in a variety of different systems and applications and under the purview of organizations that operate largely independently of one another. Thus, interoperability is the only path to accessing comprehensive data about a person that addresses the full spectrum of health information needs for Canadians and their families, clinicians and care teams, health organizations, researchers and health system decision makers.

In addition, Canada's legislative frameworks have not been set up to empower patients to manage their own information and care.

Interoperability

Interoperability is the ability of health systems to *speak the same language* and exchange health information in a secure and timely manner.

Canada is taking a groundbreaking approach to achieving interoperability. Most countries have jumped straight to solving data exchange, without first taking the time to make sure that the data that are being exchanged are standardized so they can be understood and interpreted the same way by all senders and recipients. The Canadian Institute for Health Information (CIHI) and Canada Health Infoway, two pan-Canadian organizations, have established a partnership that combines expertise to define data content and enable data exchange.

In response to the recommendations laid out by a pan-Canadian Health Data Strategy Expert Advisory Group, Canada Health Infoway (2023) led the development of a *Shared Pan-Canadian Interoperability Roadmap*, which was released in May 2023 with official endorsement from the deputy ministers of health (except in Quebec). The roadmap was developed in close collaboration with all 13 provinces and territories, pan-Canadian health organizations including CIHI, federal agencies and the private sector. Learnings were also gleaned from other leading countries and their interoperability roadmaps, including the US, Switzerland, Australia and New Zealand.

The first step in the roadmap development process was to identify four key interoperability challenges, which led to the development of the following four strategic goals (Canada Health Infoway 2023):

- reducing data blocking and easing portability;
- improving provider access to patient data at point-of-care;
- enabling patient access to their health record; and
- improving care coordination and collaboration.

Canada's state-of-the-art approach to interoperability puts high-quality, accurate data that are fit for purpose at the foundation. By thinking about data first, the question of how it can be harnessed to improve equity, access, quality, safety and timeliness of care can be solved. Only with a strong data foundation can data be exchanged with confidence, knowing that it will mean the same thing to all senders and recipients.

The ability for digital health systems to talk to each other, using the same language, will enable the following:

- *continuity of care* by ensuring that clinicians and care providers know what happened to their patients as they navigate through various care settings;
- *patient access to records*, allowing patients to participate in the management of their own care and that of their loved ones;
- *improved patient outcomes and experience*, as they receive more efficient access to care and become empowered based on participating in their health management;
- *improved provider experience* because less time will be spent on administrative processes and paperwork that are currently contributing to clinician burnout and health workforce challenges and because providers will be able to maximize the cost investments they have made in their digital health systems;
- *person-centric, equitable healthcare*, by creating opportunities for individuals and communities to reach their full health potential without disadvantage due to race, ethnicity, religion, gender, age, social class, socio-economic status or other socially determined circumstances; and
- the availability of real-world data *for policy decision making and research purposes*.

In essence, Canada's data-first approach to interoperability addresses the Quintuple Aim (Nundy et al. 2022). It puts data at the heart of the solution, giving real meaning to the phrase "data save lives," and is what will lead to the realization of the goal to create an optimized and world-class health data system in Canada.

The Pan-Canadian Health Data Content Framework

As a foundational component of the interoperability roadmap, CIHI is leading the development of a Pan-Canadian Health Data Content Framework (pCHDCF), which will define all real-world concepts that are relevant to a person's health. As health information system vendors develop their products and technologies for Canada, they will be expected to build in the content of the pCHDCF. Over time, this will create standardized, high-quality data content based on a common architecture across vendor products. The pCHDCF will become the source of truth for all healthcare content and structure within vendor products. It will provide an openly available map for all data points across vendor products, thereby enabling semantic interoperability. Canada Health Infoway will leverage these data standards and architecture to develop data exchange standards to facilitate the secure and timely exchange of health information between systems.

The development of the pCHDCF will require extensive engagement across the country to ensure that perspectives "from the ground" are incorporated – for example, perspectives from initiatives such as those in provinces like British Columbia (BC) described later in this paper. This is crucial for ensuring that patient-centric data can be collected across the system without negatively disturbing existing clinical workflows and that the data will be useful in identifying system-wide strategies that reduce disparities (Palacio et al. 2017).

Approaches to Data that Enable Interoperability in Canada and Internationally

Canada's approach to interoperability leverages learnings from countries around the world that are tackling the same challenge and builds on successes that have been realized across the nation. While many provinces and territories are leading on various aspects of data and interoperability, this paper highlights work that has been done in BC.

British Columbia

In 2022, a new BC Digital Health Strategy and program was created with a focus on four strategic objectives: (1) empower patients, (2) improve the provider experience, (3) establish a CHS and (4) enable the business enterprise (British Columbia Ministry of Health and Provincial Health Services Authority 2023).

BC's CHS is a set of digital tools that aims to provide end-to-end, seamless and widespread interoperability across BC and create more equitable access to care. For example, the Longitudinal Record Access project aims to standardize how provincial health records are accessed, stored and shared between clinical systems (Provincial Health Services Authority n.d.b.). It will enhance existing solutions by enabling care providers to more easily share and interact with provincial health data directly through their electronic medical record (EMR) or electronic health record (EHR) systems.

The provincial health record data will be used to generate on-demand patient summaries in alignment with pan-Canadian data content and exchange standards, giving providers a more holistic view of a patient's medical history and allowing them to make more informed and evidence-based decisions. It will also reduce the time a patient needs to spend repeating their health history, enabling the care provider to focus more on patient interaction and providing person-centred care.

The CHS tools will complement the work that is underway to advance patient access to their health data and their interaction with the health system through the BC Health Gateway (British Columbia Ministry of Health n.d.). Health Gateway is a provincial patient portal that enables patients to access their own health data, including labs, immunization records, medication history and more. This was an essential tool during the pandemic, providing patients with access to their COVID-19 vaccination records and the ability to book appointments. As interoperability is achieved through the CHS, Health Gateway can offer more data and services to be available to patients. In addition, the new provincial Digital Referrals & Orders program will improve transparency and engagement with patients, enabling automated status notifications, appointment reminders and secure communication channels where they can share information directly with their care providers (Provincial Health Services Authority n.d.a.).

Work is also underway to improve clinical service wayfinding in BC, enabling providers and patients to search for, locate and request health services more easily through visual, map-based search tools and up-to-date clinical service directories. These directories could also be used to identify care providers who offer health services in different languages and who have specific accessibility accommodations in place. Greater interoperability will allow care providers to keep this information up to date through existing systems and make it easier for patients to find and access the care they need using self-serve tools.

BC works in collaboration with CIHI and Canada Health Infoway to ensure that provincial standards are aligned with pan-Canadian data standards and, as relevant, provincial standards can be elevated to become pan-Canadian. Building a strong foundation based on pan-Canadian data standards that are adopted across the province will enable more equitable access to care and greater patient engagement throughout the health journey.

Lastly, BC has played a key role in pioneering the creation of standards that are in the process of being adopted as pan-Canadian data standards within the pCHDCF. Most notable is the Gender, Sex, and Sexual Orientation (GSSO) data standard, which provides a framework, concepts, definitions and guidance for how data elements can be integrated into EHRs, EMRs, pharmacies and other point-of-care systems to better support affirmative, culturally safe care and health outcomes for 2SLGBTQI+[1] communities (British Columbia Ministry of Health 2023). Modernizing GSSO information management practices involves separating social, administrative and clinical data elements in a way that supports person-centred, culturally safe communication and competent, affirmative care for all peoples.

International

Internationally, the US is a world leader in implementing large-scale initiatives that advance data interoperability and, thus, health equity. The United States Core Data for Interoperability (USCDI) provides standards for basic demographic data such as race, ethnicity, sexual orientation and gender identity data to ensure that they are consistently recorded across different health systems (Office of the National Coordinator for Health Information Technology 2023). Additional health equity-supporting data elements were recently added to the USCDI, including disability status, mental function and tribal affiliation. The USCDI also added health insurance information as a new data class (Office of the National Coordinator for Health Information Technology 2022), which allows insurance coverage information to be captured in a consistent and standardized way that is accessible through a central health information hub, rather than through individual digital health systems. Not only are these data helpful for patient care, but they also allow researchers and public policy makers to identify healthcare disparities and inequities related to insurance coverage.

The Gravity Project is another large-scale initiative in the US that focuses on standardizing how social determinants of health (SDH) data are captured in digital health systems. One of the main goals of the project is to create standardized codes and terminologies for SDH-related data elements so that healthcare providers can accurately collect and share this critical information (Gravity Project 2023). The work completed by the Gravity Project will be leveraged by Canada within the pCHDCF.

Conclusion and Next Steps

Canada's data-driven approach to interoperability, while building on lessons learned from other jurisdictions in Canada and internationally, is novel and bold. It attempts to correct legacy data issues that have been built into digital health systems over decades and leverages great progress that is being made across the country in provinces and territories, including BC. Getting the data foundation right will enable not only interoperability but also other advances in technology for decades to come. It will also help advance health equity by increasing access to and availability of socio-demographic data in clinical decision making. The patients and groups most impacted will be those currently underserved.

The time to act is now: the urgency and unity toward a shared goal of connected care for healthier Canadians has never been stronger across the country. It is time for Canada's healthcare systems to seize the day.

Note

[1] Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex and additional people who identify as belonging to sexually and gender-diverse communities (Government of Canada 2023).

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