Achieving a connected health data system

The Current State in Canada: A Review

Contents

This report was commissioned by Roche Canada and created by Santis Health through independent review and analysis.

Canada needs connected health data **now**

It is difficult to overstate the importance of effectively modernizing Canada’s health data infrastructure, stewarding Canada’s health data resources, and achieving a connected health data system.

If patients want to take control of their health care journey, control their records, and effectively navigate the system – health data must be connected.

If providers want a complete picture of their patient’s health, access to the highest quality evidence to provide the best possible care, and the ability to manage their workload without being overwhelmed by the avalanche of system demands – health data must be connected.

If governments want to understand where services are needed, what resources are available, what is working, and what is not – health data must be connected.

And if Canada wants to continue to be at the forefront of research and innovation, leading the world in Artificial Intelligence (AI) and the use of revolutionary new medical technologies – health data must be connected.

The purpose of this report is to highlight the opportunities Canada has to achieve a connected health data system. It does this by assessing the connectivity of health data in Canada’s ten provinces, identifying opportunities for improvement, and highlighting successes that can be built upon. While there is also an important role for the federal government in data connectivity, the provinces are primarily responsible for the management of health data systems and the creation of health data policy, and the report’s assessment is accordingly focused at the provincial level.

The report includes both a snapshot of the current state, as well as an articulation of the highest-value opportunities to move the needle in the short- and long-term in each province and nationally.

The country has a long way to go, but there has been progress and pockets of success that provide a strong foundation moving forward. We want to celebrate these successes and build on this momentum.

Canada needs connected health data now, and we hope that readers of this report will join us in our efforts to achieve this critical goal.

Six key learnings

01

Achieving a connected health data system is essential, and Canada has fallen behind. This lack of connectivity is not the sole cause of Canada's health care challenges, but it exacerbates virtually all of them.

02

Canada has made tremendous strides in implementing a strong digital foundation – we have the technology in place to capture and share health data electronically, as well as the legal framework.

03

Canada is not yet capitalizing on the potential of this foundation. Data that is captured electronically is often not practically accessible by patients, shared by providers, used for research purposes, or used to support decision making.

04

Canada as a whole lags behind international comparators.

05

Every province has had its share of successes and challenges; there is a great opportunity for the provinces to learn from one another, leverage each other's progress, and improve health data systems to the benefit of all Canadians.

06

There is much work to be done, but the provinces have the foundational pieces in place to achieve a connected health data system and we can collectively make substantial progress in the next few years that will meaningfully improve the health care experience of patients and providers.

What do we mean by ‘connected health data’?

“Health data” is information related to a person’s health status and their interactions with the health care system. For instance, if an individual goes to a doctor’s office, is sent for a lab test, fills a prescription, and then receives care at home, their health data will include all of the information that is recorded at the doctor’s office (e.g. demographics, health concerns, doctor’s notes), at the lab (e.g. test results), at the pharmacy (e.g. prescription information), and by the home care provider in their home (e.g. ongoing monitoring of blood pressure).

Connected health data refers to the ability to integrate, access, and leverage all of this health data. With connected health data, individuals or organizations providing health care, managing the health care system, or conducting research have access to all of the data that they need, when and where they need it.

In the example provided, the doctor would be able to quickly and easily see when their patient’s lab test results are ready, when the prescription is filled, and how the patient’s blood pressure is responding to treatment at home. This information would also, in anonymized form, enable health system planners and researchers to understand how the health care system is performing and what impact different services and treatments are having on the population.

With connected health data, individuals or organizations providing health care, managing the health care system, or conducting research have access to all of the data that they need, when and where they need it.

Why connected health data matters

Health data is produced every day in the routine delivery of health services. This data has the potential to be leveraged for frontline care, clinical trials, AI innovations, and more. The diversity of Canada’s population means that our health data could be particularly valuable for research and innovation. But, with provincial fragmentation, siloed repositories, and outdated governance, the flow of this data is significantly limited.[1]

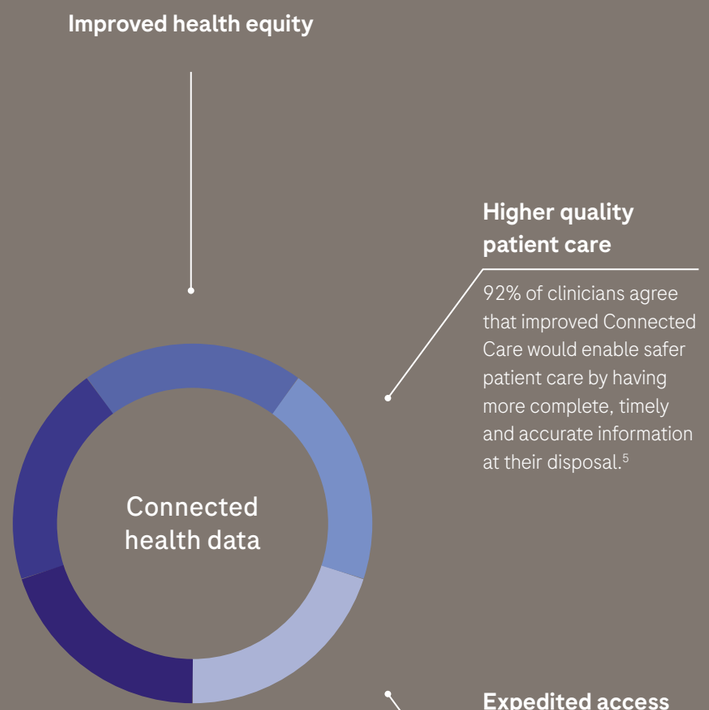
A Canada Health Infoway survey revealed only 29% of physicians share patient information outside their practice, and fewer than 40% of Canadians say they can see their own health records electronically.[2]

For our health care systems, accessible and connected health information means: more timely, evidence-based health care decision-making, better coordinated care, and greater health care system effectiveness. Health care workers would also see less duplication, increased productivity, and more collaboration with other health professionals.[3]

For Roche and other organizations that develop innovative medicines and technologies, connected health data enables more effective clinical trials, improved monitoring of the efficacy of treatments, and expedited access to life-saving innovations. This does not mean that innovators get unfettered access to an individual’s health data - it means access to high quality, anonymized information for research and analysis, with careful safeguards to respect individual privacy rights.

The diversity of Canada’s population means that our health data could be particularly valuable for research and innovation.

[1] Reference: https://www.theglobeandmail.com/opinion/article-without-integrating-our-health-data-canada-risks-being-left-behind/
[2] Reference: https://insights.infoway-inforoute.ca/2024-national-physician-survey
[3] Reference: https://www.cihi.ca/en/taking-the-pulse-a-snapshot-of-canadian-health-care-2023/better-access-to-electronic-health-information-key-to-improving-health-systems



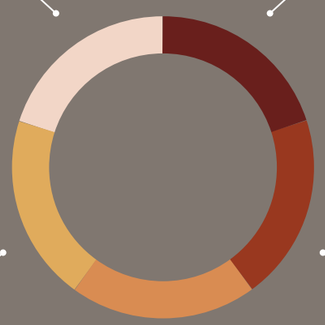
[4] Reference: https://www.infoway-inforoute.ca/en/component/edocman/resources/reports/benefits-evaluation/6443-quantifying-the-benefits-of-digital-health-interoperability?Itemid=103
[5] Reference: https://connectedcare.infoway-inforoute.ca/

Methodology

How did we measure ‘connected health data’?

There are many ways to measure the connectivity of a health system. For the purposes of this report, an independent, third party consulting firm conducted using the following process.

Developed a standard measurement framework to enable a direct comparison between provinces, measuring their progress across four domains: strategy, policy, technology, and accessibility of health data (see Appendix).



Spoke to subject matter experts across the country on an anonymous basis, including individuals who work or have worked in institutions responsible for the aggregation and sharing of data, to understand their on-the-ground experience in data access and use.

Conducted a six-week review spanning late 2024 and early 2025.

Focused the review on select data types – hospital clinical data, diagnostic imaging data, drug data, and EMR data from community-based physicians – and measured the extent to which this data is collected and can be shared and used across the system.

Reviewed publicly available information regarding the progress of each province in achieving a connected health data system.

The limitations of our analysis

- This analysis was limited to publicly available data. In many cases, what looks like a gap in progress may instead be a gap in the public reporting of governments or health care institutions.
- This analysis is informed by the perspectives of subject matter experts. This is a crucial supplement to the report’s quantitative analysis and served as the source of critical and rich insights, but it also means that the analysis likely reflects some degree of individual bias.
- This analysis is limited to four data types - hospital clinical data, diagnostic imaging data, drug data, and EMR data from community-based physicians. A truly connected health data system would capture all of these and more. The exclusion of other data types (such as lab data, home care data, spending data, and wait time data) was done to simplify and speed up the analysis. Future analyses that incorporate these other sectors would be a valuable supplement to the findings of this report.
- This analysis does not include Canada’s three territories, nor does it include federally-managed health care systems (e.g. the military health system), nor does it include health systems led by Indigenous nations across the country. A truly connected health data system would also include all of these, but they were not included because of time constraints in the development of the report and because in some instances (e.g. the military) public information is less available. Future analyses that also incorporate these other health systems would be highly valuable.

Unpacking Canada's progress

Where Canada has done well:

Digitizing core systems

This work is not "done" but, in all provinces, all or most of the necessary infrastructure is in place to capture health information electronically.

Implementing foundational data governance frameworks

These frameworks are not perfect, but in most instances, legislation and regulations create the rules needed to use and share data in a manner that respects patient privacy.

Building momentum

In recent years, leaders across the country have done well to draw renewed attention to the importance of health data in advancing Canada's health care system. The country has established a Health Data Charter which lays out common principles for data connectivity and the federal government has reached agreements with provinces and territories to enhance data systems.[6] There is an enthusiasm and energy in Canada that will be important to maintain progress.

Where Canada has fallen behind:

System usage

Canada has digital systems, but these systems are sometimes not used to capture all relevant information, or data is sometimes captured in a manner that limits its utility (e.g. scanned PDFs).

Fragmentation

Data remains mostly siloed in any given health care organization, with limited ability to share information between sectors.

A culture of data "protection"

Data is often not shared even when it is permissible and desirable to do so. For the provision of health care, this commonly leads to unnecessary delays (e.g. hospitals take months or years to negotiate data sharing agreements with provincial governments), while for research and innovation purposes the result is often, unfortunately, that research studies, clinical trials, and other forms of innovation work are simply abandoned or moved to other countries. This results in what is referred to as "health data related harm", in which the non-use of health data leads to sub-optimal patient care.[7]

Strategic direction and/or transparency

Most provinces do not have a clear, publicly available strategy to achieve a connected health data system. Such strategies may exist in some form, but their utility in guiding the sector is limited when they are not published.

Capacity in smaller settings

There is a very high degree of fragmentation in sectors like primary care and diagnostic imaging clinics, in which most care is provided by a large number of small, independent businesses. The connectivity of data from these sectors in particular lags behind others.

[6] Reference: https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html

[7] Reference: https://www.networkedhealth.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf

Key findings

How Canada compares internationally*

As part of this analysis, the overall progress of Canada and 10 peer countries in achieving a connected health data system was assessed. We found that, overall, Canada has fallen behind. In this analysis, we assessed the foundational interoperability of data systems and the accessibility of health data, but not the quality or usability of this data. We recognize that some countries scored high in terms of connected data, but they may have data that is not usable beyond patient care or quality improvement (e.g. not usable for AI applications). While Canada lags behind these peer countries on connected data readiness, we have the opportunity to learn from the experiences of these other countries to thoughtfully design systems that will collect/connect high quality, usable data.

For more details on this international comparison, including country-specific details and insights, see: https://healthdash.platformable.com/

Canada: Canada's federated structure creates challenges for interoperability, and jurisdictions across the country could do better in articulating their path forward and ensuring that these strategies align with one another. Canadian interoperability initiatives also tend to be narrowly focused on clinical care and thus often have less of an impact on health system planning, economic growth, and research.

Australia: Like Canada, Australia has a highly federated health system, but Australia has been more successful in defining integrated digital health strategies to coordinate work across multiple governance layers.

Brazil: Brazil's digital health strategy emphasizes equity and patient-centred care, with interoperability embedded in legislation to support a more collaborative digital health system.

Denmark: Denmark has done well to define a national strategy to ensure that data can be exchanged across services and is accessible to and understandable by patients to empower them to manage their own health.

*This research on international comparisons was conducted by Platformable.

Estonia: Estonia is a leader in connected health data with a digital health strategy that prioritizes EHR infrastructure and clear user experience metrics, though frameworks for non-government use of health data remain unclear.

Finland: Finland has developed a strong foundation for much of its health data sharing capabilities, and has often been at the frontier of global efforts. Finland was an early adopter of legislation that enables a wide range of secondary uses of health data.

Germany: Germany has demonstrated a clear commitment to interoperability, with a Health Data Act in place to provide regulatory data governance frameworks and a digital health strategy designed with patient input.

Singapore: Singapore's national digital health strategy has evolved into a complex web of strategies and agencies with limited coordination or clarity on future directions. Work to advance national legislation regarding data access, use, and sharing also appears to have stalled.

Slovenia: Slovenia's digital health approach establishes a hybrid governance model that strikes a balance between national responsibilities and state based health services delivery. This enables a national approach to interoperability and the adoption of health standards while recognizing the autonomy and delivery focus of regions.

Sweden: Sweden has not treated interoperability as a priority, nor has it created structures for patient participation. This has resulted in Sweden falling behind peer jurisdictions.

United Kingdom: While long a leader in digital health, the UK has struggled more recently because of issues with data sharing with third parties. The current government has not yet produced a revamped digital health strategy, and a series of reviews have slowed progress without subsequently driving tangible progress in this space.

*This research on international comparisons was conducted by Platformable.

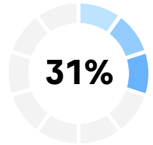
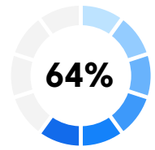
Sectoral comparison

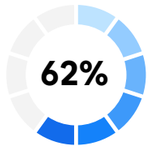
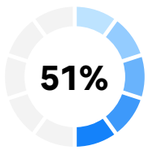
When we zoom in a little more closely, it is clear that performance in connectivity varies between different sectors of the health system. While Canada lags behind internationally, there are numerous areas where there has been good progress and there are opportunities to further build on these successes. Although we restricted our analysis to the clinical data from the below four sectors, one would likely find similar variation if the analyses were extended to other sectors (e.g. community-based care).

Sector & Performance	Findings
Acute care Above average	• Data is not perfect but there is a reasonable degree of standardization across the sector, largely driven by national reporting requirements. • Many provinces have either moved or are moving to a single hospital system, so it is likely that this data will be even better and more accessible by the end of the decade as these transitions are completed. By the end of the 2020s, there may be only two provinces that have more than one hospital information system. • Even where hospital information systems are fragmented, the infrastructure to connect these systems has matured considerably and data sharing between hospitals is now common.
Drugs Average	• Most provinces have fairly strong drug data, including some degree of data sharing with community-based and private pharmacies. • While Ontario does not yet have a provincial drug data system, considerable work is happening on both the technology and policy fronts to close this gap and once completed it may be the case that every province will have robust drug data that will be nationally comparable.
Diagnostic imaging Below Average	• Diagnostic imaging in acute care settings is usually quite standardized and well-integrated with provincial systems. • Community-based diagnostic imaging is a key gap, with some provinces not yet having a plan to integrate these into provincial systems.
Physician offices Well below average	• Physicians operate in many independently run, small clinics across the country, and their data is highly fragmented. PEI is an exception, with a single EMR used by many physicians, but in most provinces, physician offices select their own EMRs, data does not move easily between systems, and data is not readily shared with provincial systems. • Alberta has made good progress in connecting independent physician systems to a central system and other provinces are working on similar efforts, but this has proven challenging across the country. • This is particularly challenging in larger provinces, where the number of disparate systems is often very high.

Indicators of a connected health data system

Similarly, a closer look at Canada's performance across various dimensions of connectivity shows that the country is doing reasonably well in certain ways and what is needed is not a wholesale revamp but targeted improvements to address key gaps.

Indicator	Performance	Findings
Strategy Do Canada's provinces have a comprehensive, publicly available strategy to achieve a connected health data system, with measurable milestones and indicators of success?		• At the time of our review, only two of 10 provinces had a current, publicly available strategy to achieve a connected health data system. We understand through stakeholder discussions that such strategies often exist within the relevant bureaucracies/agencies, but these could not be evaluated and do not fill all of the functions of a public strategy (e.g. providing clarity to stakeholders around priorities and directions). • Most provinces have made various announcements that one could combine to form the outline of a strategy, but the currency of many of these was unclear and it was difficult to create a clear picture. • There are very few publicly available examples where clear milestones or other indicators of success have been robustly laid out in a fashion that would enable the public to measure progress against the goal of achieving a connected health data system.
Technology Is the digital infrastructure in place that would enable provinces to record and share digital information?		• For the most part, systems are in place across the country that enable providers to capture information digitally. Systems are also largely in place that enable the aggregation of data from the local to the provincial level. • The key gaps in Canada are in the actual flow of data between local and provincial systems – while both systems are in place, the connectivity between the two remains a work-in-progress, many organizations do not in practice share their data, and centralized data is often not very timely (e.g. research data, depending on the data set, can often take years before it is available for researchers).

Indicator	Performance	Findings
Policy Is there a legal framework that enables data sharing, does this framework drive improved standardization, and are there mechanisms in place to avoid data issues (e.g. duplication or privacy breaches)?		• The foundational legal framework for data sharing and privacy protection is essentially in place across the country. Every province has rules that articulate when and how data is used, and these generally encompass multiple purposes (e.g. clinical care, system planning, and research). • These policies, however, do a better job of protecting patient privacy than of ensuring that data is used effectively. Legislative frameworks are often perceived by policy experts as overly limiting, with numerous reports highlighting the potential for these policies to impede data sharing and cause health data related harms.[8] The provinces often have limited ability to drive data standards and/or ensure that data is shared when it is important to do so, meaning that data is more commonly held in a single setting than shared across the system.
Data accessibility In practice, are patients, providers, researchers, and innovators able to access the data that they need?		• The ability of patients and providers to access data is highly variable across the country.[9] Great strides are being made to enable patient access to their records, but this is inconsistent, while providers repeatedly express frustration at their inability to access data they need for patient care. • Academic researchers tend to have reasonably good access to data (albeit data that is somewhat old), while private sector researchers seeking to use data for clinical trials, real world evidence, or other innovative purposes tend to have somewhat poorer access to data. The distinction in this instance appears to be largely cultural, rather than legal, as data holders tend to be very hesitant to share data with the private sector, even when the data is aggregated or completely anonymous and even when it is legal to do so. This significantly limits the ability to evaluate the effectiveness of therapies, the development of new technologies, and the potential economic gains of Canada's data systems.

[8] Reference: https://www.networkedhealth.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf
[9] Reference: https://insights.infoway-inforoute.ca/2024-national-physician-survey

How the provinces are doing

Finally, when we zoomed in on each province, we found that there is progress happening everywhere. Each province has its own unique set of circumstances and challenges, but each province has moved the needle to some extent and has meaningful success on which to build. Given the progress that has been made and the capacity that is in place across the country, there is a great opportunity for the provinces to learn from one another, leverage each other's progress, and improve health data systems to the benefit of all Canadians.

Province	Strategy	Technology	Policy	Accessibility
British Columbia	Above average	Above average	Average	Average
Alberta	Average	Above average	Above average	Above average
Saskatchewan	Below average	Above average	Above average	Average
Manitoba	Below average	Average	Average	Average
Ontario	Below average	Average	Above average	Above average
Quebec	Below average	Below average	Average	Average
New Brunswick	Below average	Below average	Average	Average
Nova Scotia	Average	Below average	Average	Above average
Prince Edward Island	Above average	Above average	Above average	Below average
Newfoundland & Labrador	Below average	Average	Above average	Below average

Above average | Average | Below average

Provincial progress

British Columbia

- BC has a very clear and comprehensive digital health strategy – perhaps the most robust in the country – and has made strides in improving uptake and connectivity in recent years, especially in certain regions (e.g. Vancouver).[10]
- Fragmentation is a key challenge in BC. Although it is hard to measure, BC may have the most fragmented primary care EMR market in the country, and BC's regional health authority model likewise creates fragmentation and variation in approaches across the province.
- BC has a strong approach to enabling public sector researcher access to data. However, data holders and researchers indicated that there is high potential for greater data sharing with the private sector, given the useful data assets already within the province, but that the province is not taking advantage of this opportunity.

Alberta

- Alberta may have the most mature digital health system in the country, with widely used data systems and a high degree of integration. Alberta is currently a leader in the country for patient and provider access to data, and in terms of enabling access to data for the private sector.
- The province has not articulated a clear vision for what comes next, limiting the potential to leverage the progress that has been made to drive innovation.
- Alberta has very strong foundational technology, including the recently completed deployment of its province-wide Epic implementation, one of the largest clinical system implementations in the world. Alberta has an opportunity to become a health data research destination in Canada and more broadly, should they take the next steps of developing and articulating a comprehensive vision to leverage these assets.

Saskatchewan

- Saskatchewan has a long-standing and solid digital health foundation. The province generally does well across most major indicators, although it has some challenges in enabling community-based physicians to access the data they need.
- The province recently implemented measures to significantly simplify data sharing for research purposes, a model for the rest of the country.
- Like Alberta, the province has also not articulated a clear vision for the future and is not fully leveraging its assets. There is enormous potential for economic development and health innovation that is not being fully leveraged.

Manitoba

- Manitoba has leading research structures and systems that have long made the province a destination for academics and innovators looking to conduct research.
- The comprehensiveness of data is a challenge, however, driven by fragmentation, which in turn limits the potential impact of these leading research structures.
- Like Alberta and Saskatchewan, Manitoba has also not articulated a clear vision for the future and is not fully leveraging its assets. If the province bolstered its data foundation, it would be a very high potential destination for researchers and innovators.
- Manitoba also lags somewhat in providing patients and providers with access to data.

Ontario

- Ontario has a highly mature policy framework, with mechanisms to drive data standardization and sharing.
- Ontario has very high rates of digital adoption for local systems but also high degrees of fragmentation between these systems. Ontario has made significant progress in implementing systems to centrally consolidate data; however, gaps remain in practice.
- Ontario does not currently have a clear strategy or public vision outlining accountability and ownership to connect health data. There was a major push prior to and during the pandemic to establish this, such as the publication of the Ontario Health Data Council Report: A Vision for Ontario's Health Data Ecosystem,[11] but provincial direction has become unclear since.
- Primary care, community-based diagnostic imaging, and drug data are particularly fragmented, although Ontario recently implemented policy measures to bolster imaging and drug data sharing.

Quebec

- Quebec's data systems, like the health system more broadly, are currently quite fragmented. This is a known challenge in the system and has been the subject of considerable debate in recent years.
- Between system reorganization (e.g. the creation of a new provincial agency) and the procurement of a new provincial hospital information system, Quebec is implementing substantial measures to better integrate services and technology.
- While a number of reforms are in flight that will dramatically change the landscape in the coming years, a clear strategy for a connected health data system is not currently in place and the end-point is unclear.
- Quebec currently provides reasonably good access to data for patients, providers, and researchers; however, private sector access remains a challenge for the province. Recent reforms may change this but, as with system reforms more broadly, it is hard to predict what the future will be.

[10] Reference: https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/health-priorities/bc-digital-health

[11] Reference: https://www.ontario.ca/page/ontario-health-data-council-report-vision-ontarios-health-data-ecosystem

New Brunswick

- New Brunswick is working to make itself a destination for researchers and innovators and has implemented numerous reforms to support this local innovation agenda. In particular, New Brunswick has done substantial work to enshrine data access for research purposes into legislation, and ensuring all health data collected under different pieces of legislation is accessible for research.
- However, clinical systems lag somewhat behind the rest of the country, and work to modernize the technological foundation (e.g. procure a new EHR) are in their early days. This limits the potential impact of the province's innovation agenda.

Nova Scotia

- Nova Scotia is moving quickly to enhance systems, update policy, and provide patients with access to their records, with considerable progress made in recent years.
- Data systems remain somewhat outdated, but the upcoming launch of the province's One Patient, One Record initiative is likely to significantly bolster the province's data foundation. Current indicators of data connectivity (e.g. provider access to data from across the system; patient access to their own records) all lag somewhat, but the substantial work that has been done in recent years and is coming to fruition now are likely to change this.

Prince Edward Island

- PEI has implemented a single system for several sectors (acute care, home care, primary care, long-term care) and has a clear strategy to leverage these tools in the coming years.[12]
- Actual uptake of these systems has faced challenges and indicators of physician access to data lag behind much of the rest of the country. However, these indicators appear to be rapidly improving and PEI is emerging as a digital health leader in the country.
- Patient access to data is a significant challenge in the province, but the province is working towards the introduction of a patient portal that is intended to address this issue and the province has a data foundation that has the potential to make this the most useful portal in the country.

Newfoundland & Labrador

- The 2021 cyberattack in Newfoundland & Labrador caused substantial issues,[13] but the province has made major strides in recent years to improve its digital foundation and is working to implement a new provincial hospital system.
- Provincial rates of EMR adoption and data sharing are lagging, but a number of major initiatives are in-flight to bolster the province's technology in the near term and these indicators have been gradually improving in recent years.
- The province's policy framework is fairly robust with positive work in defining comprehensive health data standards.

[12] Reference: https://www.princeedwardisland.ca/en/information/health-and-wellness/digital-health-strategy
[13] Reference: https://www.gov.nl.ca/hcs/files/OVERVIEW-NL-Health-Cyber-Incident-March-2023.pdf

Grounding observations

- After conducting this review, the following picture emerged: Canada is lagging other countries in overall digital health performance, but specific sectors (e.g., acute care) and regions (e.g., provinces) are actually doing quite well. There are major successes, there are large challenges, and there is everything in between.
- However, simply saying "it's complicated" is not highly useful. While there is considerable variation across the country, there are also patterns that emerge from the data. In particular, a few key challenges arise repeatedly across the country, while a few interesting success stories point the way towards solving these challenges.
- Canada has the foundational pieces in place to achieve a connected health data system, and Canada's provinces have the capacity to make meaningful advances in the coming years. By learning from each other and building on our successes, there is an opportunity to substantially improve patient care, the provider experience, system management, and innovation in the coming years.

Challenges

Strategic direction + transparency

Improving Canada's digital health system requires many different players to make progress in the same direction. This includes multiple levels of government, of course, but it also includes health care providers and institutions (e.g. hospitals), vendors, academic organizations, and others.

Canada has a long history of fragmentation, and this worsens when these stakeholders move in opposite directions or try to solve problems in isolation.

This review revealed that there is really no practical way for most stakeholders in most places to know whether their work is well-aligned with a provincial strategy, because most provinces do not have a publicly accessible digital health strategy. We learned that in some cases strategies do exist internally, but if they are not publicly available and easily accessible, then each stakeholder is left to figure things out on their own.

There is an opportunity for provinces - beyond British Columbia and PEI, the two provinces who currently have clear and comprehensive public digital health strategies - to provide clarity on their data connectivity journey, to articulate a set of milestones, and to communicate their goals and progress more openly.

If the ultimate goal is to have data systems that "talk" to each other, then the humans that build these systems need to do the same.

Discomfort with data sharing beyond point-of-care

Canada has robust policy in place that enables data sharing for a wide variety of purposes – health data can be used for clinical care, to drive research and innovation, and to support health system planning. But beyond urgent clinician decision-making, data is not used to its full potential, especially for non-clinical purposes and secondary use of data.

The barrier is not primarily policy, it is the culture of health system stakeholders who, first and foremost, see themselves as "custodians" of data (responsible for ensuring that data is not misused) rather than as "stewards" of data (responsible for ensuring that *data is used well*).

In Canada, there is an almost exclusive focus on the harm that is caused when data is accessed inappropriately (i.e. privacy and security). But what is rarely considered is the harm that is caused when health data is not used to its fullest potential as articulated powerfully by Networked Health in their Data Disarray Report.[14]

When there is an urgent need to share data, such as when a patient has had a stroke and needs an urgent assessment from a remote physician, barriers to data-sharing largely dissipate and data goes where it is needed. However, when the impact of data sharing is longer-term, such as for years-long chronic disease management, or when the value of data is less direct, such as for research purposes, Canadian systems tend to move slowly.

Because of our diverse populations and expertise, Canada could be a leader in health data-driven research and innovation, with the secondary use of data enabled through responsible governance and patient empowerment. Instead, the health system focuses almost entirely on the negative potential of data misuse. While it is hard to quantify the negative impact of this, the country collectively bears the cost when life-saving research does not happen and when global innovators choose to conduct clinical trials and introduce technologies elsewhere.

We have the legal frameworks and technological capacity we need to enable data-sharing and innovation, but we do not have a policy framework that ensures that data is used when and where it is needed.

[14] Reference: https://www.networkedhealth.org/_files/ugd/3eb345_85ada6635d334c2ba6c102bdd57f20e2.pdf

Organizational fragmentation

A major barrier to connected health data in Canada is capacity, especially among smaller health care organizations. Health care in Canada is, in many cases, delivered by a large number of small, autonomous organizations (e.g. most of primary care), and this fragmentation of organizations is reflected in the fragmentation of Canada's data systems.

Progress has been strongest in larger, better-resourced entities like acute care, diagnostic imaging, and drugs, where data systems are relatively mature and better integrated than in other sectors.

But in primary care and smaller clinics, limited staffing, time, and technical support make it difficult to adopt new tools and ensure consistent entry of high-quality, structured data.

This is unsurprising. It is far easier to coordinate and connect a few well-resourced organizations than it is to coordinate and connect many less-resourced organizations.

There is often a lack of publicly-funded infrastructure to support these organizations and they are often left to make technology decisions and investments on their own. Without targeted support and direction, these capacity constraints will continue to impact the ability for Canada to be a leader in health data connectivity across the health care system.

While the challenges identified pose difficulties for provinces in achieving a connected health data system, this does not mean that this goal is unattainable.

Through this research, we also found numerous success stories – governments, health care organizations, and innovators who have made crucial progress in leveraging technology to improve the health and well-being of Canadians.

This report profiles select examples that illustrate the kinds of successes that are possible in a Canadian context, and highlight a path forward to address the key challenges identified.

Success stories

Building a national model for interoperability and stewardship

As a federation with multiple provincial, territorial, and other health systems, connecting health data across the country is a daunting task. Each of these health systems operates semi-independently, with each health system potentially having its own approach to technology, its own standards, and so on. Put simply, Canada's fragmentation makes connectivity more difficult.

However, "difficult" does not mean "impossible", and Canada has a major, proven success to build from.

The Canadian Institute for Health Information (CIHI) has demonstrated that pan-Canadian data sharing and use is feasible, even in our federated context. CIHI is responsible for a range of national data systems that capture administrative and other data from across the country.[15] Each independent health system feeds its own data to CIHI, at which point CIHI has a range of processes to aggregate and normalize this data so that it becomes useful for health system planning and research. Much of what we know about the challenges, successes, and costs of Canada's health system are underpinned by CIHI's work; without it, we would not have a clear, objective picture of how Canada's health system is doing, how we compare to other countries, where our system needs to improve, and where we have capacity.

CIHI's success has largely been driven by a mix of trust, collaboration, and patience. The systems that are in place today were not "quick wins," nor were they built unilaterally. CIHI's work has benefited from strong engagement through Deputy Ministers' tables, collective agreement on shared priorities, and the gradual transitioning of local systems to contribute data to national structures. Ensuring co-ownership, transparency, and shared accountability will be critical if Canada is to scale CIHI's model into new domains of care.

Together, CIHI's achievements illustrate an important lesson: that Canada's system, as messy as it is, already has the ability for a connected, pan-Canadian health data system. The challenge is continuing the patient, essential work of collaborating across the country to ensure that all levels of data are integrated to improve care delivery and health outcomes for all Canadians.

[15] Reference: https://www.cihi.ca/en

Unlocking the power of Canadian hospital data to advance patient care, clinical trials, and health AI

GEMINI, one of Canada's largest hospital data-sharing networks, brings together detailed clinical and administrative health data generated from routine medical care at hospitals covering 60% of Ontario's medical inpatient beds. Today, GEMINI houses data from over 2.5 million hospitalizations and more than 20 billion data points. Stored in a secure system, the data enables researchers and clinicians to study patterns of care, identify opportunities for improvement, conduct clinical trials, and carry out health AI research that no single hospital could accomplish alone.[16]

"GEMINI supports the work of more than 1,000 scientists, students, and health care leaders in a highly secure environment that protects the sensitive health data of Canadians while allowing innovation to flourish," says Amol Verma, Co-Lead of GEMINI, and Temerty Professor of AI Research and Education in Medicine, University of Toronto.

To advance this work, GEMINI partnered with the Vector Institute, one of the world's leading centres for AI. Through this partnership, Vector seconded a team of data experts to organize the data into a consistent architecture with standardized language for privacy-enabled AI research. Now, AI researchers can work with real-world Canadian hospital data within a secure environment designed specifically for compute-intensive applications such as machine learning. As a result, they can build and test new AI tools that are based on health data from Ontario's diverse populations, making them more accurate, relevant, and ready for use in practice across Canada. A recent global review by Vector recognized GEMINI as one of the best datasets worldwide for health AI research.[17]

This collaboration demonstrates the power of effectively connected and shared health data. By combining GEMINI's high-quality hospital data with Vector's AI expertise, researchers are able to create innovative tools that help doctors make better decisions, improve patient outcomes, and strengthen the health care system.

GEMINI also exemplifies how organizations can form unique partnerships, where the value of each organization's data grows as more groups join the network, generating insights and innovations far beyond what any one organization could achieve alone.

The collaboration between GEMINI and Vector leverages health data and AI innovation to drive improvements in clinical care and advance Canada closer to a connected health data system capable of realizing AI's full potential – from development to evaluation. By linking data, research, and innovation, it delivers improvements in patient care while laying the groundwork for a nationwide connected health data ecosystem. The next step is supported by an investment from the Government of Canada to create Version 2.0 of GEMINI, a multi-provincial platform called VITAL, that will extend coverage to approximately 20 million Canadians.

"VITAL will position Canada as a first-in-class jurisdiction for health AI and clinical trials," says GEMINI Co-Lead Fahad Razak, an internist at St. Michael's Hospital and Canada Research Chair at the University of Toronto. "It will accelerate access to new therapeutics and health care devices for Canadians, create algorithms and insights more tailored to our diverse population, and support innovation and economic growth that responsibly harnesses health data."

"Canada is the envy of the world for its diverse and representative data assets, but accessing these data for AI research was a long-standing challenge," says Roxana Sultan, Chief Data Officer and VP, Health. "Vector's partnership with GEMINI has been a critical step forward in addressing this challenge by creating a gold-standard resource that enables us to develop AI solutions designed for the Canadian health care context. Together, we've shown how to build the data infrastructure we need to really take advantage of AI's immense potential to improve care for patients."

[16] Reference: https://vectorinstitute.ai/research/health-research/
[17] Reference: https://geminimedicine.ca/partners/

Putting the building blocks in place in Nova Scotia

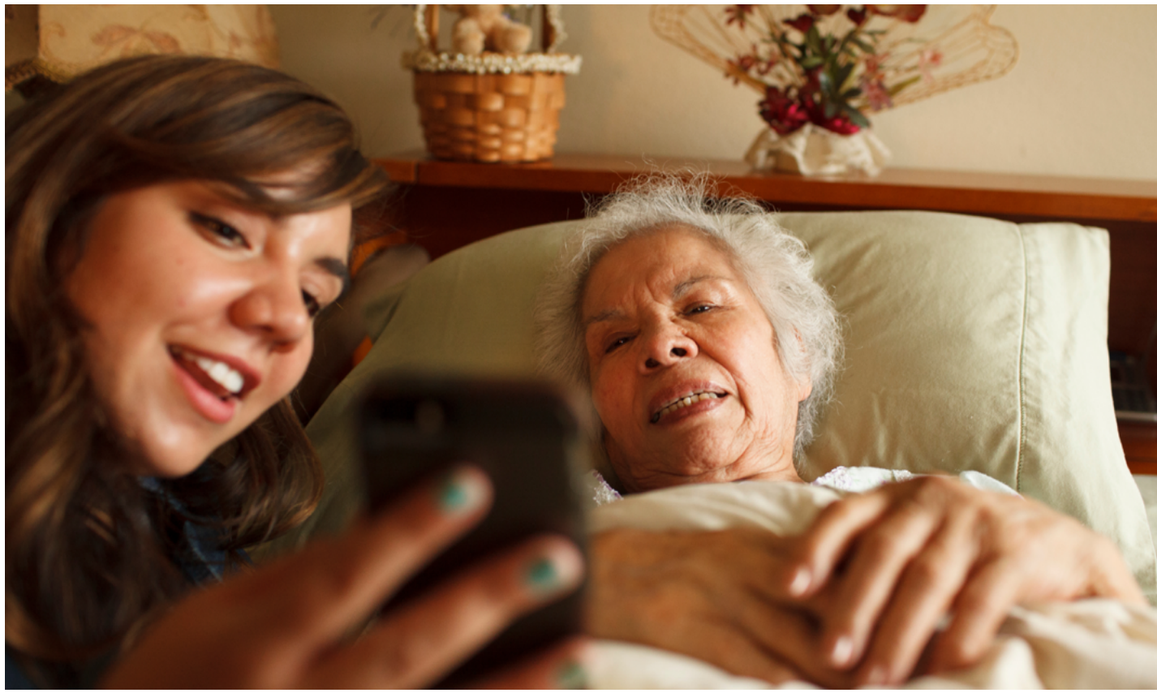
Nova Scotia has emerged as a leader in advancing a more connected health data system through a series of ambitious initiatives. The province is demonstrating what can be achieved in a fairly short amount of time when a health system prioritizes data connectivity and focuses efforts around the concept of improved data access.

Nova Scotia has a wide array of digital initiatives underway, but these are of particular interest:

- The province's One Patient One Record (OPOR) program is, after many years of delay, now progressing at a rapid pace. The initiative is replacing fragmented electronic systems with a single, integrated health record, which will enable health care providers across the province to access the same up-to-date information.[18]
- The YourHealthNS app extends data connectivity to patients themselves, acting as a digital front door. By giving Nova Scotians easier access to their health records, test results, and virtual services, the platform empowers patients to participate more actively in their care while also supporting more accessible communication with providers.[19]
- Nova Scotia is leveraging its health data to drive research and innovation. The NS Health Innovation Hub serves as a centre of excellence that brings together health system leaders, researchers, and industry to co-develop solutions to real-world challenges. These initiatives highlight how connected data can be mobilized to accelerate discovery.[20]
- Nova Scotia's role in the Atlantic Clinical Trials Network (ACTN) shows how the province is extending its impact beyond its borders, building capacity to attract and support clinical trials in the region. This not only provides patients with earlier access to innovative therapies but also strengthens data collaboration across Atlantic Canada.[21]

Together, these efforts demonstrate how Nova Scotia is moving towards a promising path of data connectivity. By linking data and making this data readily available for clinical care, patient empowerment, and research, the province is showing how a connected health data ecosystem can drive innovation and transformation.

[18] Reference: https://physicians.nshealth.ca/topics/nova-scotia-provider-digital-health-toolkit/one-person-one-record-opor
[19] Reference: https://www.yourhealthns.ca/
[20] Reference: https://innovationhub.nshealth.ca/
[21] Reference: https://innovationhub.nshealth.ca/clinical-trials/atlantic-clinical-trials-network



Canada has a long way to go to achieve a strong, sustainable connected health data system, and there are complex challenges that we will continue to face, however there is an opportunity for provinces to collaborate and learn from each other.

Together, we can make significant progress to achieve a connected health data system.

Final recommendations: Charting the future of connected health data in Canada

Clearly and transparently articulating a connected data strategy

All 10 provinces should publish, in a publicly accessible location, a strategy to achieve a connected health data system, including an articulation of who is accountable for achieving which elements of the strategy and milestones to measure success. These strategies will need to be unique to each province, reflecting the current state of their respective journeys, but should also align with and support the national roadmap and framework that has been articulated by the federal government to ensure national cohesion.

Public trust and data systems literacy

Governments across the country should articulate a clear set of principles for data sharing - that individual data will be shared for clinical care, that secondary usage of data for research and innovation (by both the public and private sectors) is needed to drive system improvements, and that individuals can opt out of any of this. Governments should also provide informational resources to ensure there is a clear understanding of what this means in practice, and should ensure that there is a high degree of accountability for any breaches of these principles.

The next steps for legislation

Policy in Canada enables data sharing and ensures that this data is protected, but it does not ensure that data is used when and where it is needed. Legislation across the country needs to be expanded upon to implement a data “steward” model that ensures that data is actually being used to drive improved patient care, research and development, and health system planning.

Stabilizing health data systems

While governments across the country have invested heavily in day-to-day clinical technology, investments in health data and research infrastructure have lagged behind (these often rely on short-term research grants). It is important for innovation and planning that these systems have long-term stability to maintain reliable access to timely and high-quality data, and resources are needed to achieve this goal.

Capacity support for small organizations

Small organizations, especially in primary care, are overwhelmed. For these providers to share their data, it needs to be easy. That means focusing efforts (including around policy, technology, and change management) on these organizations and likely providing funding to support transitions as needed.

Increased dialogue on the harms of not sharing or using data

The last decade has seen the emergence of a new dialogue across the country that highlights the importance of using data. This needs to continue. Patients expect that clinicians will have access to their health records, they expect that their data will be used to develop life-saving innovations for future generations, and they expect that governments are using real-world evidence to inform planning. Thought leaders across the system need to continue to highlight where this is not happening and emphasize the critical importance of using data to its fullest potential.

Next steps

The data in this review demonstrates three major things:

1. Canada is lagging behind our international peers in achieving a connected health data system.
2. Many successes have been achieved across Canada and the world that can be leveraged to accelerate progress.
3. While there is a lot of work to be done, the foundation is in place to achieve a connected health data system.

The provinces have the opportunity to make major strides towards data connectivity, building on what they've already done, using their existing capacity, and learning from the success of other provinces and countries. This report is intended to provide a range of insights and ideas to advance this conversation, and Roche is keen to collaborate to support stakeholders in making progress.

The advancement of health care depends on our ability to connect and harness data in ways that drive meaningful, measurable change. Steps are being taken across Canada, but now is the time for stakeholders to act together – we must acknowledge the urgency and impact on access to treatment and improving outcomes, which can mean the difference between life and death.

Appendix

Provincial scoring criteria

Strategy – Does the province have a clear and practical strategy in place to achieve a connected health data system?
Question
Is it clear who in the province is responsible for achieving a connected health data system?
Does the province have a connected health data strategy?
Does the strategy have clear targets, goals, and milestones?
Is the strategy current and is it actively driving work in the province?

Technology – Does the province have existing systems in place to collect and integrate health data?
Question
Have key sectors of the health system gone digital and are they able to share data within their own sector?
Does the province have systems in place that can centrally collect or aggregate data across the system?
Are some, most, or all sectors of the health system able to contribute data to these central systems?
How timely is the data in these central systems?

Accessibility – Is data, in practice, actually accessible to end users?
Question
Is data practically accessible to patients (i.e. when surveyed, do they say they can access it)?
Is data practically available to health care providers (i.e. when surveyed, do they see they can get the data they need when they need it)?
Is data practically available to researchers? Is there a clearly articulated process and how effective is it?
Is data practically available to innovators like Roche? Is there a clearly articulated process and how effective is it?

Policy – Does the province have a robust data governance policy in place that provides clear ground-rules for the health care system on data collection, use, and sharing?
Question
Is there a policy framework in place to protect the privacy and security of health data?
Does this policy framework cover all of these areas – clinical use, health system planning use, and research use?
Is the policy generally effective in enabling data to be used across the system while also protecting patient privacy?
Are there provincial health data standards?
Are these standards implemented, imposed upon, or enforced in the sector in some way?
Are there legal mechanisms in place to require health care providers to share/contribute their data across the health system?
Are there mechanisms in place to identify and address issues in which data is not used appropriately?
Are there consistent approaches to data de-duplication/data quality?

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