



# Connecting the Dots

Expert Panel on Health Data Sharing



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**The Council of Canadian Academies**  
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This project was undertaken with the approval of the Board of Directors of the Council of Canadian Academies (CCA). The members of the expert panel responsible for this report were selected by the CCA for their special competencies and with regard for appropriate balance.

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The Council of Canadian Academies (CCA) acknowledges that our Ottawa office is located on the unceded, unsurrendered ancestral home of the Anishinaabe Algonquin Nation, who have cared for the environment of this territory for millennia. Though our offices are in a single location, our work to support evidence-informed decision-making has potentially broad impacts across Canada. We at the CCA recognize the importance of drawing on a wide range of knowledges and experiences to inform policies that will build a stronger, more equitable, and more just society.

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## Expert Panel on Health Data Sharing

Under the guidance of its Scientific Advisory Committee and Board of Directors, the CCA assembled the **Expert Panel on Health Data Sharing** to undertake this project. Each member was selected for their expertise, experience, and demonstrated leadership in fields relevant to this project.

**Chaim Bell (Chair)**, Physician-in-Chief, Sinai Health; Professor of Medicine and Health Policy, Management and Evaluation, University of Toronto (Toronto, ON)

**Lisa Austin**, Professor and Chair in Law and Technology, University of Toronto (Toronto, ON)

**Marni Brownell**, Professor, Department of Community Health Sciences, Max Rady Faculty of Health Sciences, University of Manitoba; Senior Research Scientist and Associate Director of Research, Manitoba Centre for Health Policy (Winnipeg, MB)

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**Angela Power**, Health Ethics and Law in Medicine Lecturer, Faculty of Medicine, Memorial University of Newfoundland; Senior Consultant, INQ Consulting (St. John's, NL)

**Catherine Régis**, Full professor, Faculty of Law, University of Montreal, Canada Research Chair in Health Law and Policy and Canada CIFAR AI Chair, Mila (Montréal, QC)

**Beate Sander**, Canada Research Chair in Economics of Infectious Diseases; Senior Scientist, Toronto General Hospital Research Institute; Associate Professor, University of Toronto (Toronto, ON)

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**Amol Verma**, Clinician-Scientist, Unity Health Toronto; Assistant Professor of Medicine and Health Policy Management and Evaluation and Temerty Professor of AI Research and Education in Medicine, University of Toronto (Toronto, ON)



## Message from the President and CEO

Sharing data across Canada's health systems has the potential to improve lives, make healthcare delivery more efficient and cost effective, and advance health research and innovation. While Canada's health systems already generate a wealth of data, and various initiatives across the country have demonstrated the value of data exchange, broader efforts to effectively share those data across provincial, territorial, and regional borders have been largely unsuccessful. If the capacity to share data is scaled up and facilitated nationally, the potential benefits for the health system, and everyone who connects with it, are substantial.

While enhanced health data sharing could have tangible benefits for patients, care providers, and health researchers, it is not without risks, including breaches of privacy and cybersecurity, stigmatization and bias, a widening of the digital divide, unintended secondary uses of health data, and additional burdens for health professionals. Thoughtful implementation that builds trust and prioritizes transparency can help to mitigate some of these challenges.

It's also anticipated that in the absence of greater health data sharing, negative impacts will deepen, affecting health systems management, hindering public health monitoring and interventions, exacerbating existing health inequalities, and limiting opportunities for new research and innovation. With the appropriate insight and information, Canada can modernize its current approach to health data sharing while continuing to protect the privacy of personal health information for those living in Canada.

Recognizing the potential for greater digital health innovation, the Public Health Agency of Canada asked the CCA to examine opportunities for maximizing the benefits of health data sharing.

*Connecting the Dots* was completed by an expert panel, deftly chaired by Chaim Bell, which brought a depth of health-related knowledge and expertise in clinical practice, systems management, law and policy, economics, ethics, and data science management. I extend my thanks to Chaim and his fellow panel members for their work. We appreciate the trust that PHAC placed in CCA to undertake an assessment of this importance and expect it will be of value to all who have an interest in leveraging the value of health data sharing.



**Eric M. Meslin, PhD, FRSC, FCAHS, ICD.D**  
President and CEO, Council of Canadian Academies

## Message from the Chair

Despite its contemporary salience, health data sharing is by no means a new policy issue in Canada. The COVID-19 pandemic renewed interest in and highlighted the importance, need, and ambition to enhance Canada's data sharing capacity within and across the country. Canada is recognized internationally as a leader in health data sharing for the purpose of research, having established rich and secure repositories of health data that are made increasingly accessible to researchers via networks of networks. These successes in the research community raise questions about health data sharing for other purposes, namely clinical care, system improvement and innovation, and public health.

Of course, these disciplines make use of health data in different ways and require their own governance models that are responsive to their needs. However, their overlaps must also be recognized. Health data generated in the process of delivering care are not only relevant to clinical purposes but can also be used in research to improve knowledge and understanding, in performance measurement to improve health systems, and in public health surveillance to improve population health. A comprehensive health data system integrates these uses in the governance regimes responsible for health data stewardship.

Health data sharing in Canada is now less of a technical challenge than a cultural one. Health information technologies have yet to be adequately harnessed by custodians largely because of a culture of caution fostering conservative interpretations of legislation. Governance regimes can be made less complex and more aligned if provinces and territories commit to collective leadership and collaboration with regard to national standards and policy guidance, thereby generating a culture of confidence.

*Connecting the Dots* assesses the evidence on the benefits and potential risks of enhanced health data sharing in Canada and explores the approaches taken by other jurisdictions. The report examines the legal and regulatory considerations related to health data governance, and the opportunities to effectively implement solutions that facilitate health data sharing across organizations and the country without compromising patient privacy.

It has been a pleasure to serve as Chair of this Panel. I would like to thank my fellow Panel members for their contributions and thoughtful deliberations throughout the process, and the CCA team for their support. Finally, I would like to thank the sponsor for submitting this important question and making our work possible.



**Chaim Bell**

Chair, Expert Panel on Health Data Sharing

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## Peer Review

This report was reviewed in draft form by reviewers selected by the CCA for their diverse perspectives and areas of expertise. The reviewers assessed the objectivity and quality of the report. Their confidential submissions were considered in full by the Panel, and many of their suggestions were incorporated into the report. They were not asked to endorse the conclusions, nor did they see the final draft of the report before its release. Responsibility for the final content of this report rests entirely with the authoring Panel and the CCA.

The CCA wishes to thank the following individuals for their review of this report:

**Sara Allin, PhD**, Associate Professor, Institute of Health Policy, Management and Evaluation, Dalla Lana School of Public Health, University of Toronto; Director of the North American Observatory on Health Systems and Policies (Toronto, ON)

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**Noralou P. Roos, PhD, O.C.**, Professor Emerita, Max Rady College of Medicine, University of Manitoba (Winnipeg, MB)

The peer review process was monitored on behalf of the CCA's Board of Directors and Scientific Advisory Committee by **Peter Backx, PhD, FRSC, FCAHS**, Professor, Department of Biology and Canada Research Chair in Cardiovascular Biology, York University. The role of the peer review monitor is to ensure that the Panel gives full and fair consideration to the submissions of the peer reviewers. The Board of the CCA authorizes public release of an expert panel report only after the peer review monitor confirms that the CCA's report review requirements have been satisfied. The CCA thanks Dr. Backx for his diligent contribution as peer review monitor.

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**Alex Himelfarb**, Chair (National), Steering Committee of the Canadian Centre for Policy Alternatives

**Andrew Morris**, Director, Health Data Research UK

**Tim Shaw**, Professor, Digital Health and Director, Research in Implementation Science and eHealth Group, Faculty of Medicine and Health, University of Sydney

**Lars Vilhuber**, Executive Director, Labor Dynamics Institute, Cornell University

## Summary of Main Findings

The widespread use of digital technologies in the health sector has revolutionized the way health data are created, collected, stored, used, and shared. However, Canada currently lags other jurisdictions in making effective use of digital health innovations and existing health data, which became apparent during the COVID-19 pandemic. In response to these challenges, the federal government announced its intention to develop a *Pan-Canadian Health Data Strategy* to strengthen and modernize Canada's capabilities and infrastructure in this area. The Strategy aims to develop a system for more effective coordination and sharing of health data across different organizations, networks, regions, and provinces/territories.

Within this context, the Public Health Agency of Canada (PHAC; hereafter “the Sponsor”) asked the CCA to convene an expert panel to look at the socioeconomic impacts of health data sharing in Canada, focusing on the benefits and risks associated with the increased sharing of health data; legal and regulatory considerations related to health data governance; and opportunities to implement solutions that can facilitate health data sharing across organizations, provinces/territories, and the country. To answer the Charge, the CCA assembled a multidisciplinary panel of 13 experts (the Expert Panel on Health Data Sharing, hereafter “the Panel”) with backgrounds in clinical practice, health systems management, health law and policy, health economics, ethics, and health data science management.



### **What are the opportunities for maximizing the benefits of health data sharing?**

To answer the charge, the Panel assessed evidence and looked to members' own experiences to identify ways to maximize the benefits of health data sharing. Opportunities include:

- implementing a learning health system;
- building on the experience of existing, smaller-scale health data sharing networks in Canada, as well as data-sharing initiatives in international jurisdictions;

- investing in and implementing new data-exchange and interoperability standards through a collaborative, coordinated, and incremental approach, along with the careful deployment of incentives or mandates;
- establishing an arm’s-length, independent organization mandated to coordinate data sharing across sectors, organizations, and actors; and
- relying on interpretive flexibility within existing legislative frameworks, rather than legal reform, to drive the shift toward a stewardship model of data governance.

These opportunities, as well as the benefits and risks of enhanced health data sharing, are elaborated in greater detail below.

### **When health systems are in crisis, the effective exchange of health data can improve the performance of those systems**

Although Canada has worked for decades to improve the collection and use of health data, it has largely failed to share those data efficiently across organizations, regions, and provincial/territorial borders. The barriers that prevent the establishment of robust health data sharing systems are not technical, but rather fundamentally political and cultural. Improving Canada’s health systems requires mechanisms to facilitate the dissemination of reliable and timely information on patient care, health system performance, and data concerning the social determinants of health. However, while increased data sharing is undoubtedly *necessary* for better patient care, public health, and health research and innovation in Canada, it is not *sufficient* to solve the various challenges facing Canada’s health systems. Improved health data sharing is an enabler of socioeconomic benefits but not a panacea for all of Canada’s health-related challenges.

### **By improving health data sharing, Canada can implement a learning health system**

Canada’s health systems already generate an abundance of data. By making better use of these data through sharing, Canada can build a *learning health system* that improves health outcomes for patients, boosts the efficiency and cost-effectiveness of health delivery, facilitates more and better health research, and allows for better public health programs and policy. In a learning health system, routinely collected health data (e.g., from service delivery or patient care) are shared to create iterative cycles of knowledge generation and care improvement; this is enabled by partnerships across clinical, academic, industry, and government stakeholders.

Importantly, learning health systems encompass much more than conventional health data collected in the clinical setting. They also include data about the social determinants of health (e.g., socioeconomic and demographic data, data on housing, education, the use of social services). Establishing a learning health system requires a *socio-technical architecture* based on social, scientific, technological, policy, legal, and ethical pillars. These pillars must be appropriately applied within the Canadian context — with consideration of its universal healthcare systems — and aligned with the broader societal values embedded within that context, such as equity, fairness, and solidarity.

### **Smaller-scale health data-sharing initiatives have demonstrated benefits, but wide-ranging coordination will be needed to scale up such initiatives**

Significant achievements in health data sharing have been established in various parts of Canada's health systems — most notably for research purposes — highlighting the potential value of enhancing data exchange. World-class research institutes such as the Institute for Clinical Evaluative Sciences (ICES) in Ontario and the Manitoba Centre for Health Policy (MCHP) have led the way in obtaining and making accessible a wide array of health and health-related data for researchers. Furthermore, Health Data Research Network Canada (HDRN) offers access to multi-jurisdictional data by connecting member organizations (including ICES and MCHP) in a distributed network of data managers working together to align their data holdings in ways that enable comparative analyses and make pooling data across provinces and territories more straightforward. Additionally, efforts are being made to connect and expand administrative databases and patient registries to form national networks that generate and analyze real-world data, such as the Canadian Network for Observational Drug Effect Studies (CNODES). Data-sharing initiatives such as Ontario's COVID-19 Modelling Consensus Table also played a significant role in helping Canada respond to the pandemic.

However, data networks in Canada currently have restricted mandates that limit their impact to specific populations and health issues. Moreover, their governance frameworks differ, opting to organize as either centralized or distributed networks. A fully pan-Canadian learning health system will need to coordinate the design, configuration, governance, and regulation of these initiatives to scale up and facilitate the sharing of data across networks.



### **The upfront financial costs of implementing data-sharing systems are likely to be offset by the resultant economic benefits, even in the medium term**

Evidence suggests that the economic benefits of health data sharing tend to outweigh the costs of implementation. It also suggests that larger investments in more extensive data-sharing infrastructure may generate faster and larger economic returns compared to smaller investments in less extensive data-sharing infrastructure. In addition, investments in increased data sharing in the form of interoperability are likely to cost significantly less than investments in health information technology in general. Moreover, since the value of data is much greater when it is shared than when it is held in siloed information systems, further investments in data sharing can help derive better value from investments that provinces and territories have already made in digitizing their health systems, thereby providing a better return on those investments.

### **Enhancing health data sharing in Canada would have a wide variety of benefits for patients, health practitioners, health research, and health systems**

Better health data sharing can help improve the quality of care as well as health outcomes by offering practitioners faster and more comprehensive access to a patient's medical information. When prior results are not available, doctors often simply repeat a test, leading to unnecessary duplication and deeper backlogs. Health data sharing has been shown to reduce unnecessary testing, reduce time spent manually re-entering information, improve health outcomes, and reduce hospital admissions and consultations. Since health systems across Canada face severe capacity problems, the efficiencies gained from data sharing can be critical enablers of better and more sustainable healthcare for all.

Reliable and timely data that permit comparisons and measurements across Canada's health systems are essential for good policy-making and can improve the overall performance and efficiency of those systems. For example, system-wide data sharing increases the ability to assess and compare the quality and cost-effectiveness of different treatments and care models; allows forecasting of healthcare needs in different regions so resources (human, financial, and material) can be allocated to meet those needs; and enhances the measurement and reporting of healthcare quality and costs across regions to ensure consistency and high standards. System-level data sharing is essential to improve public health programs through surveillance, reporting, and program evaluation, contributing to healthier populations and more equitable systems.

Enhanced health data sharing can also help improve health research by increasing the quantity and quality of information available to researchers and by reducing the costs of research. This creates new research opportunities that attract investment and talent, contributing to greater medical knowledge and discovery. Expanding data sharing across Canada and including broader types of data (e.g., social and economic) opens numerous new avenues for research that are already established in many other countries and in some Canadian provinces. For example, pan-Canadian data sharing permits the study of diseases that are too rare in individual jurisdictions to study properly but which, collectively, affect 5–10% of people in Canada. Multidisciplinary research about the social determinants of health can improve health and social policy and inform healthcare delivery. Importantly, applied research devoted to improving the delivery of healthcare is essential for its long-term quality and sustainability in Canada.

Enhanced health data sharing also presents a significant opportunity to improve Canada's innovation and economic productivity. The application of big data analytics and artificial intelligence to health data has the potential to drive innovations that improve both the quality of healthcare and the efficiency of health systems, while simultaneously creating economic value.

### **Potential risks and harms associated with health data sharing can be mitigated by careful implementation and building trust through public engagement**

Enhanced data sharing is associated with potential risks, such as breaches of privacy and cybersecurity, stigmatization and bias, inequity and the digital divide, unintended secondary uses of health data, and additional burdens for health professionals. Risks to privacy and data security in the health sector range from inappropriate access to sensitive health data to cyber-attacks on healthcare organizations. However, many cybersecurity risks in the health sector are not specific to data sharing, but rather inherent to the ongoing digitization of healthcare and the collection and storage of health data in general. Indeed, increased data sharing may provide an opportunity to improve privacy in healthcare, since the privacy risks linked to Canada's current outdated data-sharing systems may be even more dangerous. There has been a great deal of research into, and innovation of, methods to preserve privacy and ensure data security when sharing health data; a variety of technical, governance, and regulatory solutions are available, many of which have already been implemented in international jurisdictions.

The potential for health data sharing to exacerbate stigmatization, bias, and discrimination is perceived as a risk by the public, particularly when it comes to sharing information about substance use, sexual health, and mental health. These risks and harms can be mitigated by inclusive, participatory governance frameworks that (i) involve and engage vulnerable individuals and groups, (ii) implement both process- and technology-based mechanisms to protect privacy and ensure ethical data practices, and (iii) uphold patient control over personal data. Additionally, the increased sharing of health data could unintentionally exacerbate existing health inequities in Canada due to the country's *digital divide* — that is, the gap in opportunity between “haves” and “have-nots” with respect to accessing digital technologies and the internet. Mitigating this risk means addressing the disparities in internet access among people in rural and remote areas of Canada, as well as improving internet access and digital literacy among certain demographic groups, particularly for people who are disadvantaged, vulnerable, or marginalized.

Enhanced health data sharing could create risks of unforeseen or unintended uses of health data that can erode public trust. Mitigating these risks and harms may rely on developing clear, transparent, and ethical policies, practices, and procedures around health data that clearly communicate, in plain language, the purpose and details of these sharing arrangements (i.e., what, how, why, and by whom health data are being used).

Increased health data sharing could also present potential risks for health professionals, such as heavier administrative workloads or information overload (i.e., when health practitioners encounter a very large volume of patient data, it can become more difficult to sift through an individual's medical history). To avoid such risks, a health data system's ease of usability will be key. Designed correctly, interoperable health data-sharing systems can significantly reduce the burden on practitioners by saving them time when they are searching for information, documenting and reporting, and manually re-entering data; these systems can also reduce unnecessary patient visits and consultations.

### **The risks of not enhancing health data sharing in Canada likely outweigh the risks of enhancing it**

Importantly, the risks of *not* improving health data sharing in Canada go beyond the continuation of the status quo — which, as mentioned earlier, is in crisis. Rather, without increased health data sharing, Canada's health systems are likely to get *worse*: declining health outcomes and quality of care, poorer health system

management, less effective public health monitoring and interventions, further perpetuation of existing health inequities, less innovation, and fewer opportunities for new research. Moreover, without improved sharing of health data to rein in the increasing costs of healthcare delivery, costs will continue to rise due to factors such as Canada's growing and aging population, threatening the sustainability of its health systems.

Canada is already lagging its international peers with respect to modernizing its health-data system and capitalizing on those data for both health outcomes and innovation. As other countries continue to improve health data sharing in their own jurisdictions, failure to enhance that sharing in Canada will worsen this gap, resulting in Canada falling even further behind. Moreover, in the absence of a distinctly pan-Canadian approach to health data sharing, it is likely there will be more fragmentation of health systems as individual provinces and territories continue to move ahead on reforms to health data sharing within their jurisdictions, with little coordination across the country.

Lack of improved health data sharing will likely result in greater consolidation of personal health data in the private sector while simultaneously harming innovation. Health data in Canada are already highly concentrated in a small number of private sector companies, and public entities in Canada already lag commercial actors in reaping the benefits derived from the collection, analysis, and use of health data. At the same time, a lack of pan-Canadian data sharing inhibits competition and innovation in Canada's digital health sector, as fragmentation of privacy laws and data-governance rules makes it difficult for new digital health innovators to enter the market in multiple provinces and territories.

### **Several international jurisdictions have developed systems to share patient data across care settings, allow patients to access their health information, and provide health-related data for research, public health, health system management, and innovation**

Features that are common to some of the leading systems for health data sharing in international jurisdictions include single points of access for patients, practitioners, and researchers across a health system; federated or decentralized data infrastructure; data privacy and security features that promote public trust; unique identifiers; and institutionally agnostic governance arrangements. Many of these decentralized or federated data systems collate and make data available from a variety of sources, rather than storing them in a centralized database. These systems are designed to augment, rather than replace, existing data

repositories across a health system. There are several advantages to federated models, such as security-enhancing privacy protections, fewer requirements for policy and governance, and greater buy-in from participating organizations. In addition, federated approaches may help address challenges related to cross-jurisdictional data sharing by providing flexibility to subnational jurisdictions when implementing health data sharing infrastructure and policies as part of a national data-sharing system.

In many cases, access to data is facilitated via electronic portals that provide a single point of access for patients, health practitioners, and researchers, integrated from across a health system. Data-sharing systems in international jurisdictions also tend to make use of identifiers that are unique to each citizen to facilitate integration of patient data across their health systems. These unique identifiers are critical for interoperability, as well as ensuring patient safety and continuity of care, while also allowing patients to access eHealth services. Additionally, systems for linking health data for research purposes use anonymized encrypted versions of these identifiers to allow for the linkage of de-identified datasets at the individual level.

Some of the most successful examples of governance arrangements that facilitate health data sharing are in countries with established independent or arm's-length entities that coordinate data sharing across sectors, organizations, and actors. This approach puts the focus on the *actors* in a health-data system, rather than on the technical details around, for example, infrastructure or method of data sharing. The challenge lies in developing collaboration and coordination among various actors that can *facilitate* system-wide data sharing — rather than trying to *control* it — and the need for an institutionally agnostic entity that serves the actors, rather than supervises them.

**Successfully implementing a health data-sharing system relies on early and sustained public engagement, incremental approaches, and financial incentives or mandates to encourage participation**

Public engagement early in the process of developing and implementing a health data-sharing system is vital to building trust and to the long-term success of the initiative. Failure to engage the public and earn trust emerged as a key challenge to implementing health data sharing in international jurisdictions. To successfully build trust, it is necessary to involve a wide range of stakeholders in the early stages of development and ensure their views and concerns are considered and addressed. Moreover, ongoing public engagement in the governance of health data-sharing organizations can help maintain public trust.

Several countries have taken an incremental approach to implementing systems for health data sharing. However, such approaches can fail if they are insufficiently forward-looking, if strategies frequently change, or if they lack centralized governance arrangements. Thus, while focusing on incremental progress in the short term can be useful, lack of a long-term plan (or constantly changing plans) can make it harder to achieve longer-term goals. Incremental approaches often work by expanding the types of data that are linked or shared; generally, most countries begin with some kind of care summary or medication records, then gradually add connections.

Financial incentives and penalties are often used to encourage the adoption of data-sharing technologies and to discourage practices that inhibit data sharing. Technology vendors and health providers may be tempted to impede interoperability to gain a competitive advantage, and because health data are valuable commodities. Periodic reviews of incentives can help identify improvements to drive interoperability. In the absence of incentives, mandating data sharing via legislation may be required.

### **Shifting from a custodianship to stewardship model of health data governance may require legal reform, but there are opportunities to make this shift within the confines of existing regulatory regimes**

Restrictions on data collection, use, and disclosure in provincial/territorial privacy laws, as well as the lack of policy coordination across jurisdictions, can exacerbate risk aversion among data-holders. As a result, the dominant model for health data governance has traditionally been data *custodianship*, wherein the focus is predominantly on keeping data protected and secure from unauthorized access; this is achieved by conservatively interpreting privacy laws and policies to justify non-disclosure. However, in recent years, there has been a shift toward a data *stewardship* model of governance, in which privacy and security considerations are balanced with enabling access to data. Enhancing health data sharing in Canada will depend on a transition toward a stewardship approach to data management that emphasizes balance, trust, interoperability, and cohesion.

Making this transition will rely on national leadership to establish a standard structure that harmonizes health-data systems and facilitates cross-jurisdictional data sharing in accordance with a common framework of guiding principles. Establishing such leadership will depend on governments at all levels

approaching federalism in a collaborative way. Although legal reform is one way to address these challenges, such efforts can distract from more pragmatic solutions that are possible within the broad parameters of existing legal architectures. Interpretive flexibility within privacy laws can be used to enhance data sharing by addressing the established set of principles underpinning current legislative regimes, namely individual privacy protection and population health promotion.

### **Improving health data sharing might require reviewing existing privacy regimes in Canada**

In many cases, sharing personal health information (i.e., identifiable data) in Canada requires either the individual's consent, or de-identification or anonymization of the data. However, the most successful examples of data sharing in Canada are based on *exemptions* to consent and de-identification/anonymization, ones already provided for in existing privacy legislation. Indeed, the effectiveness of consent and de-identification when it comes to protecting privacy is questionable.

A process-based approach to minimizing risk may be a more fruitful way to advance data sharing policy than the output-based approach of de-identification and anonymization. Without abandoning de-identification, the regulatory focus can shift to mechanisms that contribute to risk minimization — namely, the spectrum of statistical disclosure limitation techniques that include direct access, dissemination-based access, and query-based access. Additionally, tiered privacy protection mechanisms that expand the traditional binary approach to data protection and exchange may also present opportunities to facilitate data sharing. For data that have been deemed less sensitive, access may be gained through a new tier called *registered access* that sits between the *open access* and *controlled/restricted access* tiers. The “Five Safes” framework similarly focuses on the trustworthiness of those requesting access to data by considering five dimensions: safe people, safe projects, safe data, safe settings, and safe outputs. Weighed jointly, these dimensions enable more thoughtful determinations about data access for research, thereby increasing access while also better protecting data. Finally, several emerging technologies may facilitate the management of privacy risks in various ways, including blockchain-based smart contracts, synthetic data, and federated learning.

## **A pan-Canadian health data strategy will need to address fundamental issues of jurisdiction to ensure governments at all levels are aligned in their approaches to health data governance**

Health data governance in Canada has been shaped by the country's federalist structure of government. Historically, health data governance has been a largely provincial/territorial undertaking, without much consideration of the national implications of policy decisions. Despite jurisdictions successfully entering data-sharing agreements, developing national data standards, and co-investing in programs, a mechanism to ensure their coordinated implementation on a national scale has not yet been developed. A successful pan-Canadian health data strategy will hinge on fundamental issues of Canadian federalism to ensure that federal and provincial/territorial governments are aligned in their approaches to health data governance. Moreover, the jurisdictional authority of Indigenous communities will need to be considered alongside issues of federal and provincial/territorial jurisdiction. When it ratified the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP), the Government of Canada formally recognized Indigenous data sovereignty and governance as essential rights. Data-sharing initiatives that respect those principles can enhance trust by heeding the voices of Indigenous peoples via collaboration.

## **To be successful, a collective, collaborative approach to health data governance is needed**

Given the years of collaborative efforts in public health surveillance, the federal government's disinclination to impose hierarchy via legislation or conditional funding, and the uncertain constitutionality of such an imposition on provinces and territories, a governance model for pan-Canadian health data sharing that does not depend solely on the federal government for leadership is needed. Instead, federal leadership might be better operationalized in terms of inter-provincial and inter-territorial collaborative and cooperative capacity. Such an approach could help foster pan-Canadian harmonization in health data sharing where responsibilities primarily fall under provincial and territorial jurisdiction.

One such approach that has benefited Canada's blood system is an independent, not-for-profit body whose members (i.e., shareholders) are the participating provinces and territories. These members control the entity, avoiding jurisdictional struggles that may arise from federal mandates and leadership. While some existing organizations in Canada have been suggested as candidates whose mandates could be adapted to fill this role, there are risks in broadening



an existing entity's operational scope. Alternatively, a new, pan-Canadian Health Data Science Agency could be organized in such a way that it does not derogate from the provinces' or territories' health delivery authority. Examples of similar organizations are found in some international jurisdictions and, when given sufficient authority and influence, such bodies — which might be referred to as “Standards and Policy Entities” — have been helpful mechanisms for implementing a common framework of standards and policies for health information exchange.

## Abbreviations

CADTH	Canadian Agency for Drugs and Technologies in Health
CHA	Canada Health Act
CIHI	Canadian Institute for Health Information
CNODES	Canadian Network for Observational Drug Effect Studies
EAG	Expert Advisory Group
EHR	Electronic Health Record
EMR	Electronic Medical Record
FNIGC	First Nations Information Governance Centre (Canada)
FPT	Federal, provincial, and territorial
HDRN	Health Data Research Network (Canada)
ICES	Institute for Clinical Evaluative Sciences (Ontario)
IIS	Immunization Information Systems
Infoway	Canada Health Infoway
MCHP	Manitoba Centre for Health Policy
MCT	Modelling Consensus Table (Ontario)
OACAP <sup>®</sup>	Ownership, control, access, and possession (Canada)
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
WHO	World Health Organization

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1

# Introduction

- 1.1 The Charge
- 1.2 The Panel's Approach

The widespread use of digital technologies has revolutionized the way health data are created, collected, stored, used, and shared. Decades of research suggest that the effective use of data can significantly improve health and well-being across a population. However, the COVID-19 pandemic revealed that Canada lags other jurisdictions in making effective use of digital health innovations and its existing health data holdings. In response to the gaps and challenges that became apparent during the pandemic, the federal government announced its intention to develop a *Pan-Canadian Health Data Strategy* to strengthen and modernize Canada's health data capabilities and infrastructure.

One of the primary goals of this strategy is to more effectively coordinate and share health data across different organizations, networks, regions, and provinces/territories. However, the increased sharing of health data inevitably raises important questions about privacy, security, and the equitable distribution of benefits and costs. Canada has a long history of protecting the privacy of its residents' personal health information; the challenge lies in balancing that privacy with the benefits of sharing data to improve the quality of patient care, more effectively manage Canada's public health systems, expand Canada's health research capabilities, and encourage productivity and innovation in Canada's health sector.

This report examines the socioeconomic impacts of health data sharing in Canada. It focuses on both the benefits and risks associated with increasing that exchange, the legal and regulatory considerations related to health data governance, and the opportunities to implement solutions that facilitate health data sharing across organizations, provinces/territories, and the country while protecting patient privacy. Importantly, while increased data sharing is not sufficient to overcome the various challenges facing Canada's health systems, it is necessary for improving patient care, public health, and health research and innovation.

## 1.1 The Charge

Recognizing the opportunities, challenges, and implications of increased health data sharing, the Public Health Agency of Canada (PHAC, hereafter, “the Sponsor”) asked the CCA to convene an expert panel to provide an evidence-based and authoritative assessment that could aid in the design of a pan-Canadian health data strategy. The CCA was asked to answer the following question and sub-questions:



### **What are the opportunities for maximizing the benefits of health data sharing?**

- What are the socio-economic impacts of the current approach to health data sharing across Canada?
- What are the risks associated with both maintaining and enhancing health data sharing across Canada?

## 1.2 The Panel’s Approach

To answer the charge, the CCA assembled the Expert Panel on Health Data Sharing (“the Panel”), a multidisciplinary panel of 13 experts. Panel members brought knowledge from clinical practice, health systems management, health law and policy, health economics, ethics, and health data science management. Over the course of the assessment, the Panel met five times to review evidence and deliberate on its charge. Each member served on the Panel as an informed individual rather than as a representative of a specific discipline, organization, region, or set of values. At the beginning of the assessment process, the Panel met with the Sponsor to acquire a full understanding of the charge.

### 1.2.1 Conflict of Interest

CCA assessments are requested by a primary sponsoring organization (in this case, PHAC) with support from others that have an interest in, or are affected by, the topic. The role of the sponsor is limited to developing the initial questions, which are refined with feedback from CCA's Scientific Advisory Committee. A formal request for an assessment is forwarded to the CCA for approval by its independent Board of Directors (which occurred in December 2021 for this assessment). Once the request is approved by the CCA, the sponsor is not involved in selecting the expert panel or its ongoing work, nor does the sponsor have an opportunity to review or edit drafts of the report. The sponsor and any supporting organizations are invited to an embargoed briefing by the CCA approximately two weeks prior to the public release of the report.

CCA reports are produced by independent panels whose members are selected for their expertise, serve pro bono, and are tasked with conducting a thorough and objective assessment of the available evidence.

### 1.2.2 Evidence

The Panel's assessment was based on a review of diverse sources of evidence, including peer-reviewed publications, publicly available government information and statistics, media reports, and grey literature,<sup>1</sup> as well as interviews with key stakeholders. This report is based on a detailed analysis of sources that the Panel felt represented the best available evidence on the topics discussed. Notably, this report reflects the body of evidence available at a specific moment in time — during the COVID-19 pandemic — when interest in access to and use of health data was high.

### 1.2.3 Report Structure

The Panel developed a narrative structure to guide its examination of the opportunities for maximizing the benefits of health data sharing in Canada. **Chapter 2** provides an overview of the context, focus, and motivation for this assessment. **Chapter 3** assesses the evidence on the benefits and potential risks of enhanced health data sharing in Canada. **Chapter 4** reviews approaches to health data sharing undertaken by selected international jurisdictions. **Chapter 5** presents legislative or regulatory opportunities to strengthen health data sharing in Canada. In **Chapter 6**, the Panel provides final reflections and conclusions on the charge.

1 Grey literature refers to various types of documents produced by government, academia, industry, and other organizations that are not published commercially or formally.





# Health Data Sharing: Context, Focus, and Motivation

- 2.1 The Evolution of Health Data
- 2.2 The Need for Enhanced Health Data Sharing
- 2.3 A Vision for Health Data Sharing

## Chapter Findings

- With health systems in crisis, health data and their exchange present an opportunity to improve patient outcomes, population health, and health workforce sustainability by enabling a health system that continually improves and generates new knowledge — a *learning health system*.
- Smaller-scale health data-sharing initiatives have demonstrated the value of deploying networks to improve processes and outcomes.
- When the benefits are known and appropriate safeguards are in place, patients are generally in favour of enhanced health data sharing, but different interests, values, and concerns among patient groups will need to be addressed in an equitable manner in order to build trust.

As Canada's health systems emerge from the COVID-19 pandemic, there is no shortage of ambition to enhance the country's data-sharing capacity. Toward the beginning of the pandemic, when gaps in Canada's health data-sharing systems were identified, the federal government convened an Expert Advisory Group (EAG) to advise governments on the development and implementation of a *Pan-Canadian Health Data Strategy*. The general problem is well documented: decades of working to improve health data collection, use, and exchange have failed to establish a sound pan-Canadian health data foundation, while policies and modes of governance have not adequately evolved with the digitization of the health system (PHAC, 2021a, 2021b, 2022). As the EAG concluded, the barriers to creating a robust health data-sharing system are fundamentally political and cultural, rather than technical (PHAC, 2022).

For example, despite billions of dollars invested to increase health practitioners' uptake of electronic health records (EHRs) in Canada, the syntactic and semantic interoperability of these records — both across and within provinces and territories — has been compromised by a lack of coordination in their procurement (Webster, 2015; Persaud, 2019). In other words, although the basic capability to exchange data among systems (i.e., technical interoperability) is mostly established, the capability to process and extract meaning from exchanged data by using specified data formats and structures (i.e., syntactic interoperability) and shared conceptual meanings (i.e., semantic interoperability) has not been widely achieved (Lehne *et al.*, 2019). The promise of digitizing health systems that can enhance health data sharing has thus not been realized.

Advancing a pan-Canadian health data strategy requires stakeholders to understand the opportunities for improving the social circumstances that affect coordination and collaboration, rather than solely relying on the deployment of data-sharing technologies. Information technology is not a “magic bullet” for successfully implementing organizational change (Markus & Benjamin, 1997), let alone system-wide change. Health information exchange projects that adopt a “socio-technical approach” that recognizes the intertwined nature of non-technical and technical issues can be more successfully implemented than those that focus on the technological risk (Sicotte & Paré, 2010). The relatively weak rate of EHR adoption in Canada is partly explained by this overemphasis on building foundational infrastructure at the expense of engagement with health professionals (Zimlichman *et al.*, 2012). As described by the World Health Organization’s (WHO) Health Systems Framework, a health system’s outputs are reflected not only in its “medical products and technologies” but also in its “service delivery” (WHO, 2010). For these to be improved in ways that strengthen health systems, “both technical and political knowledge and action” are required (WHO, 2007). Thus, data-sharing technologies can *enable* significant improvement to Canada’s health systems, but they cannot *actualize* it. The latter depends on stakeholders properly deploying those technologies, which can only happen if the social and cultural conditions (i.e., the personal, professional, and organizational norms, values, and interests informing stakeholders’ decisions) underpinning their utilization promote enhanced health data sharing.

## 2.1 The Evolution of Health Data

Traditionally, *health data* has referred to data generated within health systems, such as health records, prescriptions, laboratory results, and clinical trials. With the growing use of wearable devices and software applications, health data may also include data generated within the consumer health industry. The rapid advancement of big data is further expanding the notion of health data by generating results of data analysis that are highly relevant to health (Vayena & Gasser, 2016), or what are referred to as “health-relevant data” (McGraw & Mandl, 2021). Public health surveillance efforts during the COVID-19 pandemic proved to be valuable: data on mobile device location and scheduled flights have been used by digital health firms such as BlueDot to help the federal government evaluate the risk of COVID-19 transmission from one region to another (Watts *et al.*, 2020; Au *et al.*, 2022), and wastewater-based surveillance data have been used by local governments to assess the prevalence of COVID-19 in communities (Joung *et al.*, 2022). Statistics Canada census data are increasingly linked to health data to help researchers better understand the social determinants of health. For example, research linking patient-level data from a comprehensive cystic fibrosis registry

to income quintiles derived at the neighbourhood level using postal code information found that socioeconomic status is not determinative of disparities in hospitalization rates (Stephenson *et al.*, 2011).

These types of health data can be grouped into two categories based on how they are used. *Primary uses* of health data are linked to motivating the initial exchange of health information, namely their use in the process of delivering healthcare. *Secondary uses* of health data apply to purposes beyond the direct delivery of healthcare, including research, quality and safety assessment, and public health initiatives (Safran *et al.*, 2007). More recent secondary uses of health data include “testing, validating and benchmarking artificial intelligence solutions and big data analyses across parameters and settings” (WHO, 2021a).

This twofold division in the uses of health data suggests there is a schema composed of four purposes underlying health data sharing: clinical care; health system improvement and innovation; research; and public health initiatives. Thus, *health data sharing* may be defined as the interoperable and secure exchange of health information among health care providers, health system administrators, health researchers, public health authorities, and other actors deemed appropriate (e.g., commercial health information enterprises) to enable their respective contributions to the improvement of health outcomes for people in Canada.

### Policy issues related to health data sharing pre-exist the digitization of healthcare; these need to be addressed if healthcare in Canada is to serve the population

Administrative data (e.g., those gathered from provincial/territorial health insurance plans), clinical trial data, and real-world data (e.g., those collected for health technology assessment purposes) have been accumulating for decades, creating massive data repositories. Meanwhile, the digitization of healthcare has modernized the technical infrastructure of health data, facilitating their production and, potentially, their exchange. It might be tempting to think this explosion of health data has promoted or catalyzed enhanced data sharing, but this would be wrong. Investments in digital information technology do not equate to investments in enhancing data use or exchange. For example, the General Medicine Inpatient Initiative (GEMINI) and its partner hospitals work to maintain a clinical research database that must reproduce data that have already been collected by the Province of Ontario in repositories such as the ConnectingOntario ClinicalViewer, but are not made available for secondary analysis, research, or innovation (Box 2.1). Investments to digitize Ontario healthcare have facilitated the collection of health data, but their exchange continues to lag.

The expanding definition of *health data* underscores the need to modernize the strategy for their sharing. If a health data foundation is to be sustainable, continual improvement is needed (PHAC, 2021a); this implies a need to adapt and enable the exchange and use of all forms of health data, conventional or not. The “collect once, use many times” paradigm, wherein secondary uses are facilitated by way of standardized and structured data collection (Joukes *et al.*, 2016), is increasingly necessary to inform the practice of political, administrative, and clinical decision-makers responsible for the implementation and use of health information technologies.

### Box 2.1 Innovation Within a Dated Health Data System: GEMINI’s Experience

GEMINI is a collaborative database for 30 large Ontario hospitals. Their clinical and administrative data are extracted from hospital information systems, including patient demographics, laboratory and imaging test results, vital signs, prescriptions, and clinical documentation. The data are shared by these partner hospitals with GEMINI, a research program based at Unity Health Toronto. Data are made available to researchers and analysts through a secure, cloud-based, high-performance computing centre supported by the Digital Research Alliance of Canada and Compute Ontario, under a careful data governance system that protects patient privacy.

As a rich source of health data, GEMINI’s repository has benefited a range of health system, research, and educational applications, demonstrating the value of harmonizing and using data from disparate sources. Indeed, GEMINI produced Canada’s first study characterizing hospitalization for COVID-19, which challenged the notion that the illness’s severity is comparable to seasonal influenza (Verma *et al.*, 2021). In addition, Health Quality Ontario’s General Medicine Quality Improvement Network (GeMQIN) uses GEMINI data to produce practice reports that inform physicians and hospitals about their clinical care patterns and patient outcomes. These data are also being used to develop artificial intelligence (AI) tools to improve healthcare. For instance, GEMINI’s partnership with the Vector Institute for Artificial Intelligence and the University of Toronto supports an interdisciplinary team of engineers, computer scientists, social scientists, and clinicians working to develop an AI delirium identification tool that could improve the measurement and prevention of this key cause of harm in hospitals (Wang *et al.*, 2022a, 2022b).

(Continues)

(Continued)

Much of GEMINI’s progress has occurred despite barriers in Canada’s health data systems. The process of extracting data from hospitals is labour intensive, and data are only shared in batches every 3 to 12 months, creating challenges for timely analysis. Linking data collected by GEMINI to other datasets (e.g., to capture outpatient health data) requires cumbersome modifications to data-sharing agreements and research ethics approvals. Further, given that some of these data are already collected by other repositories, a portion of GEMINI’s data collection work is redundant. Thus, although digital technologies exist to collect, use, and exchange health data — and health system partners are willing to share them — the system is configured in a way that hinders rather than facilitates data sharing.

## 2.2 The Need for Enhanced Health Data Sharing

Although they are a source of national pride, Canada’s universal healthcare systems face increased scrutiny surrounding their performance — namely, perceived inefficiencies, as indicated primarily by long wait times (Lee *et al.*, 2021). Other performance issues are raising concerns, including inequitable access to care and quality of care, as well as the health disparities experienced by Indigenous peoples (Martin *et al.*, 2018). Potential reductions in health expenditures due to economic uncertainty (CIHI, 2022a) plus labour shortages (Wyonch, 2021) threaten to push fragile health systems further into crisis after the multiple shocks caused by the COVID-19 pandemic. Cost-cutting, workforce restructuring, and other managerial strategies are inadequate in the current context; they are consistent with a trend in Canadian health policy reform to narrow the agenda to consider only health systems’ immediate shortcomings — a drive to “producing care and not producing health” (Denis *et al.*, 2023). A bolder, more innovative approach to health system governance, one that emphasizes value creation, is increasingly necessary if Canada’s health systems are to function well.

*System redesign is a priority for health care because current systems are not achieving the effectiveness and efficiency needed to improve care, spawn innovation, and accelerate research. Increasing investment or reducing costs without changing the architecture of the system is unlikely to increase value in ways that can be sustained. Efforts to reduce costs without care redesign risks making the work of providing health care services more challenging. With mounting levels of burnout, such an approach may make matters worse.*

Fjeldstad *et al.* (2020)

A networked organizational architecture aims to connect the provision of health services with the objectives of quality improvement, innovation, and research. One of the main advantages of a networked approach is that, by connecting more actors and promoting exchange, data and knowledge resources are enhanced, thereby creating opportunities for improved clinical care, system design, and knowledge production (Fjeldstad *et al.*, 2020). Consistent with the WHO's Health Systems Framework, strong health systems depend in part on health information systems that ensure “the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status” (WHO, 2007). Given the integral role of health information in governing health systems (WHO, 2007), the current state of Canadian health systems calls for the development of a well-functioning health information network that permits enhanced health data sharing.

By making better use of health data — a resource that health systems generate in abundance — Canada can build learning health systems that improve performance and, by implication, health outcomes for patients. As the EAG posits, failure to realize a learning health system “risks continued escalation of health costs, underperformance of health services and poor health outcomes including: avoidable illness and death, low levels of innovation, perpetuation of health inequities, and ineffective responses to future public health threats” (PHAC, 2022)(Section 3.3). A learning health system presents a bold and innovative policy idea that promises to deliver increased value to people in Canada.

### Learning health systems depend on data, people, and resources to fulfil their promise of delivering value-based healthcare

Broadly, the idea of a learning health system refers to “a system in which routine health practice data, from service delivery and patient care, can lead to iterative cycles of knowledge generation and improvement in healthcare, whereby the whole Learning Health System is enabled by partnership across academic, clinician, community and industry stakeholders” (Teede *et al.*, 2021). For an illustration of the scale of a national learning health system's network and its constituent health data, see Figure 2.1. Given the interdependence of stakeholders and their data when it comes to producing the knowledge necessary to improve outcomes, health data sharing is foundational to a learning health system's success. As Greene *et al.* (2022) claim, data-sharing among stakeholders is “the bedrock of a learning health system.” Ideally, stakeholders in a network continually supply and make use of the network's data for their intended



purposes. However, such activity depends on the person-centredness of the learning health system — that is, on its ability to collect and make accessible the “data that matter most” to stakeholders (i.e., patients, caregivers, providers) for improving the quality of health services (Kuluski & Guilcher, 2019).

The social determinants of health expand the range of factors that may be prioritized by stakeholders. As Kuluski and Guilcher (2019) note, “data capturing the full patient journey will require some level of integration with other providers and systems across sectors.” The integration of different data types may also contribute to enhanced health system measurement and improvement at the micro, meso, and macro levels by creating more indicators (Barbazza *et al.*, 2021), and to public health by enabling a more complete view of populations (Dolley, 2018). Statistics Canada’s Centre for Population Health Data is a leader in identifying linkages between health data and socioeconomic or environmental factors by using AI and machine learning “to estimate the prevalence of certain chronic conditions” (Drummond *et al.*, 2021). Thus, learning health systems encompass much more than conventional health data collected in the clinical setting; they also rely on data from other sectors, such as social care, education, and housing.

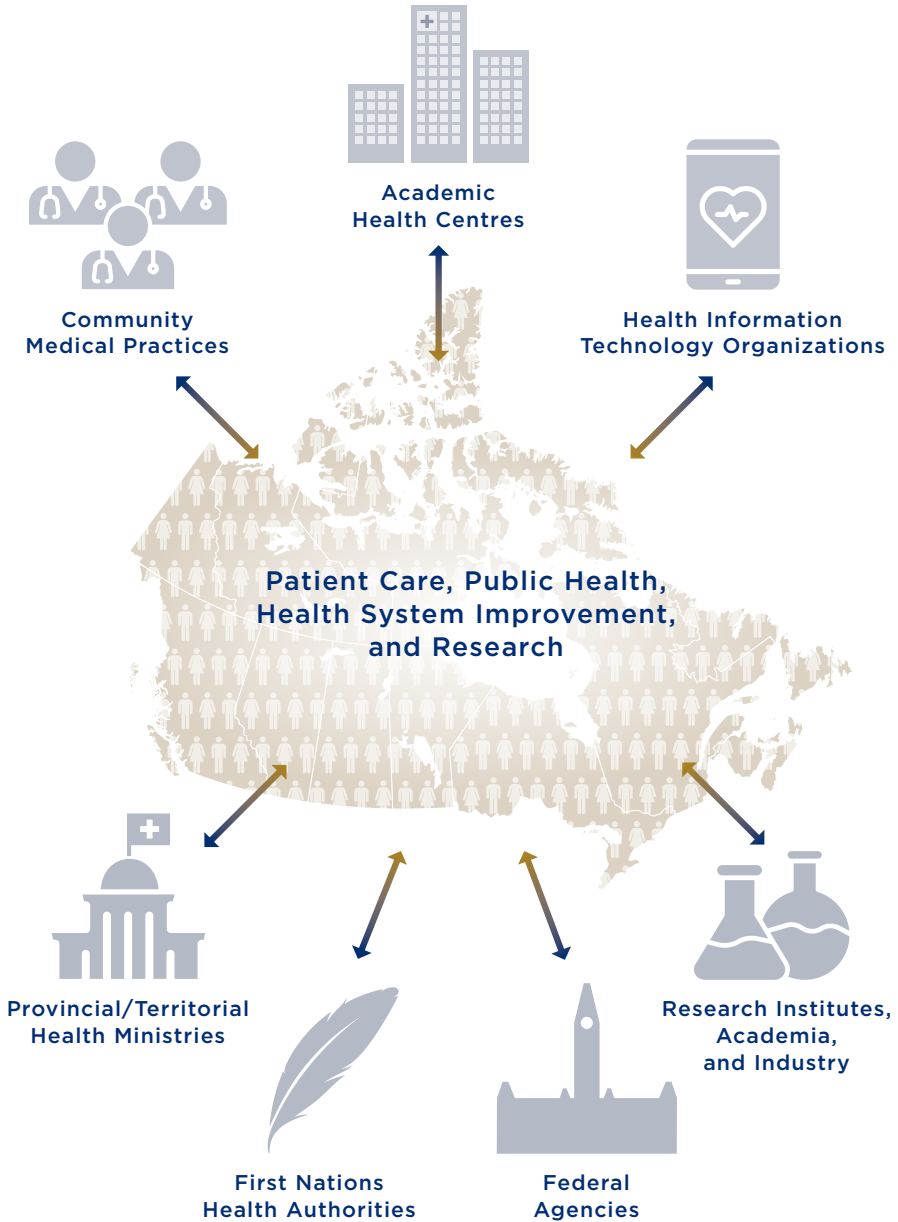
As a potential source of big data, the network underpinning a learning health system may enable new analytic methods (e.g., machine learning, AI) that can “turbocharge powers of observation in health care,” thereby increasing knowledge generation and the flow of new knowledge available to address the needs of stakeholders (Krumholz, 2014). Optimistic views hold that machine learning in medicine promises to personalize “every diagnosis, management decision, and therapy ... on the basis of all known information about a patient, in real time, incorporating lessons from a collective experience” (Rajkomar *et al.*, 2019). Big data also support “precision public health” — the use of integrated datasets from diverse sources to better measure, detect, and understand disease, predict risk, and target interventions (Dolley, 2018; Canfell *et al.*, 2022); however, the learning health system model has yet to be meaningfully connected to public health (Feng *et al.*, 2021).

In 2023, machine learning remains in a nascent stage of development, though research is increasingly demonstrating its effectiveness in healthcare settings. For example, machine-learning applications have shown improvements in predicting in-hospital mortality, re-admission, prolonged hospitalization, and discharge diagnoses (Rajkomar *et al.*, 2018). More recent studies suggest that machine-learning models may improve patient outcomes by potentially

identifying sepsis patients earlier (Adams *et al.*, 2022); decrease mortality by identifying high-risk patients who may benefit from rapid-response interventions (Escobar *et al.*, 2020); and improve the recognition of colorectal neoplasia during colonoscopy (Wallace *et al.*, 2022). There are now hundreds of AI technologies approved by the U.S. Food and Drug Administration (U.S. FDA, 2022). See Section 3.4 for a discussion of the economic value added to health data by AI.

Should the advancement of AI succeed in eliminating repetitive tasks that increasingly preoccupy physicians, health systems may offer “a less fragmented, more human experience” (Fogel & Kvedar, 2018). This promise remains unfulfilled, however, in part because “core structural changes and paradigm shifts in the health care system” are yet to be implemented, including the availability of high-quality data necessary to train machine-learning models; this may be obstructed by interpretations of privacy and regulatory requirements, intellectual property laws, and ethical issues of safety and transparency (Rajkomar *et al.*, 2019; Gerke *et al.*, 2020). Thus, enhanced health data sharing necessarily precedes effective application of AI in health services.

For example, the Epic Sepsis Model’s under-performance in the clinic setting suggests that prediction tools need training on more representative data. Developed and validated based on data from only three U.S. health systems between 2013 and 2015, Epic’s EHR sepsis prediction tool failed to detect 67% of sepsis cases when deployed in Michigan (Wong *et al.*, 2021). Such cases suggest that health systems that “support data scientists” are needed to validate and recalibrate machine-learning models in new settings before they are incorporated into care (Habib *et al.*, 2021). Moreover, the contextual specificity of machine-learning models depends on the diversity of their datasets aligning with the diversity of the communities they are meant to serve (Panch *et al.*, 2019). To the extent that sampling activity lowers the quality or availability of such data, the limitations of AI in relation to under-represented groups will require consideration.

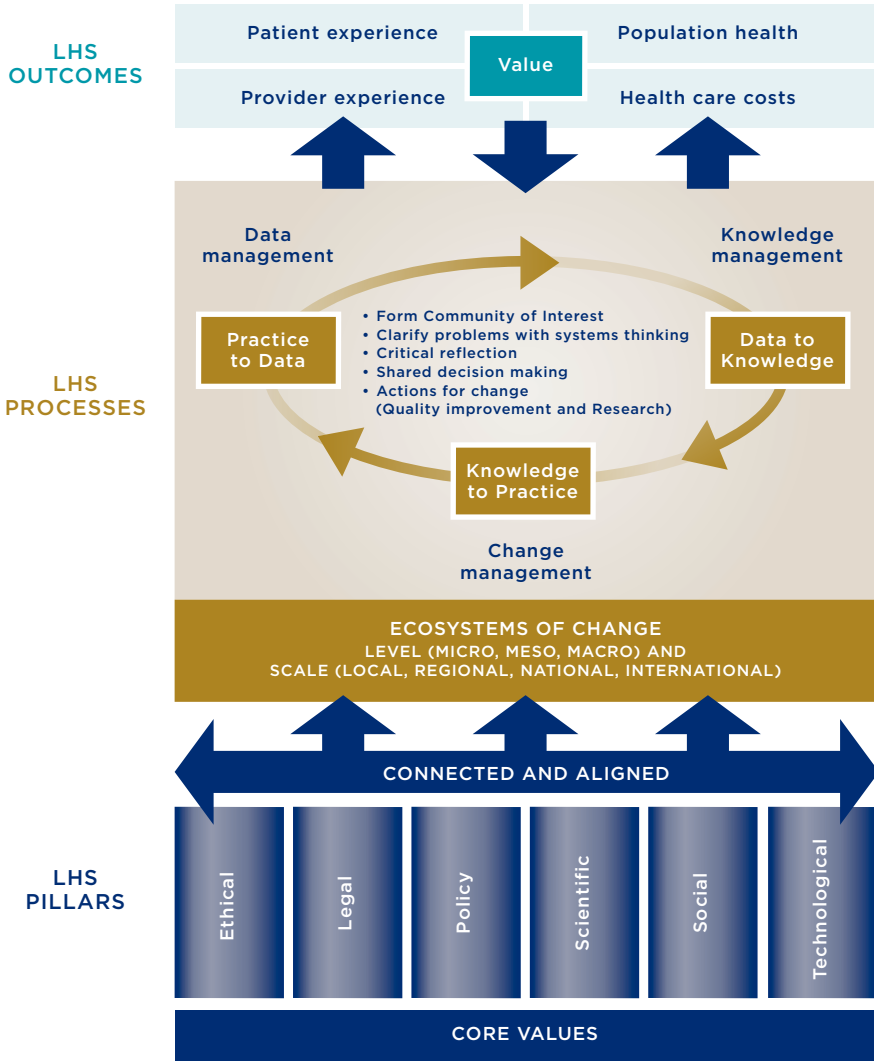


Adapted from Friedman *et al.* (2010)

**Figure 2.1 A Conceptual Map of Stakeholders in Health Data Sharing**

This illustration depicts the multiple exchange-based relationships involved in pan-Canadian health data sharing.

The formation of a learning health system requires a “socio-technical architecture” based on social, scientific, technological, policy, legal, and ethical pillars (Menear *et al.*, 2019) (Figure 2.2); these pillars reflect the health data foundation emphasized by the EAG. The challenge is in connecting and aligning the pillars in a way that enhances data sharing — something that can be difficult for a large organization to accomplish internally, let alone a national network of independent entities. Success will depend on appropriately applying the learning health system concept to the Canadian context, in particular its universal healthcare systems. Thus, not only would Canadian learning health systems be underpinned by common core values (e.g., accessibility, cooperation), they would also align with the broader societal values entrenched in the country’s universal healthcare systems, such as equity, fairness, and solidarity (Menear *et al.*, 2019). The foundational pillars of a learning health system are not configured in a strictly top-down fashion, but rather with regard to core values that are determined by meaningfully engaging with stakeholders, empowering marginalized groups to voice their concerns, and promoting a sense of collective responsibility and accountability (Menear *et al.*, 2019).



Adapted from Menear *et al.* (2019)

**Figure 2.2 A Conceptual Framework of Components and Processes in a Learning Health System (LHS)**

Given the complexity of information exchange projects, learning health system initiatives have typically been organized as concentrated networks of partners with a common concern (e.g., regional health outcomes, specific medical conditions). Importantly, smaller-scale initiatives replicating the “collaborative learning health system” or “learning network” model have demonstrated improved performance and outcomes by way of rapid learning at scale, which is achieved through collaboration (Seid *et al.*, 2021).

For example, the Cystic Fibrosis Learning Network (CFLN) generated improved health outcomes and care processes by deploying an actor-oriented network organizational architecture (Box 2.2). The advantage of a learning health system for improving quality of care and patient outcomes by “doing better with what we already know and have” has been demonstrated by improvements to preterm infants’ survival without morbidity following the implementation of a national Evidence-based Practice for Improving Quality (EPIQ) program within the Canadian Neonatal Network (Lee *et al.*, 2020).

Significant improvements can also be achieved at the provincial or territorial level. Province-wide strategic clinical networks (SCNs) in Alberta have had success in implementing, monitoring, and evaluating innovations in health service delivery; these are also beginning to emerge in British Columbia (Manns & Wasylak, 2019). Several initiatives implemented by Alberta’s Surgery SCN have “provided considerable value to the people of Alberta through improved outcomes, patient experience and access to surgical care, system-wide learning and quality improvement on a provincial scale” (Beesoon *et al.*, 2019). Furthermore, such initiatives can also provide economic value; for example, a provincially coordinated learning approach to implementing the Enhanced Recovery After Surgery guidelines for patients undergoing colorectal surgery was found to return \$3.80 of value for every \$1 invested (Thanh *et al.*, 2016).

Learning networks go beyond merely connecting resources, information, and expertise; they also emphasize the collective, aligned goal of data sharing that underpins actors’ participation. Consider the emphasis on stakeholder engagement in the development of British Columbia’s Emergency Medicine Network: three of the five key methods undertaken to inform leadership were person-centred — surveying emergency practitioners, interviewing key informants, and conducting focus groups; patients are engaged in the network’s governance, given “equal voice at the highest levels of decision-making” (Abu-Laban *et al.*, 2018, 2019). As Fjeldstad *et al.* (2020) suggest, “value in networks emerges from the types of actors that are connected and what is exchanged across the nodes.”

Given that actors within a learning network may have different intended uses for the shared health data (e.g., clinical care, research), the integration of different roles may increase the efficiency of collaboration. For example, the Post-COVID-19 Interdisciplinary Clinical Care Network is a learning health system established by clinicians, researchers, patients, and health administrators “to enhance knowledge and understanding of the long-term sequelae of COVID-19 infection” (Levin *et al.*, 2023). Within this network, care delivery in post-COVID-19 recovery clinics is organized around data capture and knowledge production by “embed[ding] research infrastructure within clinical care” (Levin *et al.*, 2023).

### Box 2.2 From Care Centre Network to Learning Health System: The Cystic Fibrosis Learning Network

As medical advancements increase life expectancy for people with cystic fibrosis (CF), health systems are adjusting their delivery of care and support in accordance with the shifting needs and priorities of those living with the chronic condition. To address this, a collaborative learning health system (i.e., a learning network) known as the Cystic Fibrosis Learning Network (or CFLN) was established to improve outcomes for patients through data-driven collaborative learning. The CFLN leverages the pre-existing care centre network accredited by the Cystic Fibrosis Foundation and its patient registry (Ong *et al.*, 2022). Implementing the CFLN in staged cohorts, including only segments of the pre-existing network, allowed for comparative analysis of the performance among care centres that benefitted from the collaborative learning network and those that did not. Participants — health professionals, and patient and family partners — perceived data-driven improvements to “health outcomes (e.g., lung function, quality of life) and care processes (e.g., shared agenda setting for clinical visits)” (Van Citters *et al.*, 2022). The CFLN also demonstrated success in implementing telehealth virtual visitation with interdisciplinary care in response to the COVID-19 pandemic, such that it has become a new CF model of care (Albon *et al.*, 2022).

## Enhancing health data sharing can broaden the benefits already observed in smaller-scale initiatives, but wide-ranging coordination will be needed

Significant advancements have been made in health data sharing and use in various parts of Canada's health systems, and these are indicative of the value of enhancing data exchange. For instance, health technology assessment has undergone rapid organizational and procedural shifts in response to the abundance of health data generated by administrative bodies, resulting in quicker and more accurate evaluations of drugs and medical devices. *Real-world data* (and the *real-world evidence* generated by their analysis) are increasingly recognized as valuable for filling gaps in evidence caused by the limitations of randomized controlled trials, such as synthetic conditions of treatment, limited follow-up time, and under-representation of diverse patient populations (CADTH, 2023).

As such, efforts are being made to connect and expand administrative databases and patient registries to form national networks that generate and analyze real-world data (Box 2.3). The Canadian Network for Observational Drug Effect Studies (CNODES) has established a distributed network of researchers and population databases in British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, and Nova Scotia, which is coordinated by federal leadership. Since September 2022, CNODES has been a member of the CoLab, an evidence-generation network established by the Post-Market Drug Evaluation (PMDE) program<sup>2</sup> at the Canadian Agency for Drugs and Technologies in Health (CADTH, 2023). Thus, CNODES is a network within a network that may be deployed to answer queries received by CADTH about drug safety. If assigned to the response team, studies are conducted at CNODES' provincial/territorial research sites with access to their respective databases, in order to generate evidence in response to the query under investigation (Platt *et al.*, 2020). By coordinating the use of administrative health data sources from multiple jurisdictions, CNODES is able to undertake more extensive assessments more rapidly and with greater clarity than was previously possible when assessment efforts were limited to provincial/territorial data, and when research teams were driven by individual interests in funding rather than collective interest in patient safety (Suissa *et al.*, 2012).

2 CADTH's PMDE program replaced the Canadian Institutes of Health Research's (CIHR) and Health Canada's Drug Safety and Effectiveness Network as the entity responsible for responding to questions and concerns about drugs approved for use in Canada raised by federal, provincial, and territorial (FPT) decision-makers.



### Box 2.3 The Value of Real-World Data for Rare Diseases: The Canadian Bleeding Disorders Registry

The transformation of Canadian data capture infrastructure for certain blood disorders exemplifies the potential value of centrally coordinated health data exchange. What was once a network of three collection resources (i.e., databases) in the early 2010s is now a centralized data network called the Canadian Bleeding Disorders Registry (CBDR) thanks to a collaborative effort among stakeholders in the rare blood disorders community between 2014 and 2016. The CBDR has generated increased value for a variety of institutional and individual stakeholders: clinicians are afforded “complementary support to the provision of optimal care;” patients benefit from “focused and individualized care and follow-up;” haemophilia treatment centres can now “query the database for centre-specific information for audit or planning purposes;” and funders (i.e., provincial/territorial governments via Canadian Blood Services and Héma-Québec) can use CBDR data to “inform product procurement processes, monitor product use patterns and variability, forecast future product volume and utilization requirements, and measure the value of treatments provided” (Iorio *et al.*, 2022).

As Mittman and Varette (2022) note, the CBDR’s successes demonstrate the value of patient registries, specifically ones for rare diseases; given that patients with rare diseases are sparsely located throughout the country, a centralized platform creates a broader population of patients by assembling and linking real-world data beyond specific regions, thereby creating richer and more useful datasets.

Despite successful cases of improved health data sharing and use, a national health data network remains “overdue” (Morin & Flegel, 2017). As the examples cited in this section illustrate, data networks in Canada currently have restricted mandates that limit their impact to specific populations and health issues. Moreover, their governance frameworks differ, opting to organize as either centralized or distributed networks. To be successful, a pan-Canadian learning health system will need to be designed in a coordinated manner, with leaders engaged in contemplating the design, configuration, governance, and regulation of that system.

## 2.3 A Vision for Health Data Sharing

The EAG's vision for Canada's health data system includes a pan-Canadian learning health system: "By 2030, all persons in Canada will benefit from a fully integrated and continually optimized health data ecosystem that honours data ownership and collective quality care through the cooperative use of individual and aggregate health data" (PHAC, 2021b). Despite progress made in digitizing health information technology and developing learning networks across the country, "the gaps from data to knowledge to impact" remain operationally and culturally reproduced (Reid & Greene, 2023). Given the foundational role of health data in knowledge production and translation, gaps in the accessibility and quality of health data are fundamental challenges that must be resolved before benefits of health data sharing — more reliable knowledge, and better-informed clinical, administrative, and political decisions — can be maximized. In the Panel's view, enhanced health data sharing that supports the EAG's broader vision for health data systems would allow key stakeholders to successfully integrate their interests and objectives to enable secure and timely exchanges of health data among actors and across disciplines (i.e., clinical care, research, health system improvement, and public health).

Canada's health data ecosystem is perhaps most advanced as it relates to data sharing for research purposes. World-class research bodies such as the Institute for Clinical Evaluative Services (ICES) in Ontario and the Manitoba Centre for Health Policy (MCHP) have led the way in obtaining and making accessible a wide array of health and health-related data to researchers. Data collected by the provinces and territories (e.g., population-based surveys, anonymous patient records, clinical and administrative databases) are made accessible to academic partners, which develop and maintain repositories that can be shared with researchers. By streamlining intra-provincial health data sharing for research in this way, pan-Canadian exchange is facilitated. For instance, Health Data Research Network Canada (HDRN) creates access to multi-jurisdictional data by connecting member organizations (including ICES and MCHP) as a distributed network of data managers working together to align their data holdings in ways that enable comparative analyses. As a national data platform that operates as a single portal through which researchers can access different datasets, HDRN makes pooling data across provinces and territories more straightforward (Guttman, 2019).

A similar distributed inter-provincial network of databases was established by CNODES, as discussed in Section 2.2. Part of CNODES' success is due to its implementation of a “common data model” as a method of organizing members' datasets (Toh *et al.*, 2020) — something HDRN recognizes will need to be considered as a possible method of diversifying and harmonizing data in its effort to develop an operationally effective and sustainable network (HDRN Canada, 2022a, 2022b). A common data model requires the network's members to commit to “a uniform data file structure and data element naming conventions and definitions” (Toh *et al.*, 2020) to ensure the syntactic and semantic interoperability discussed at the beginning of this chapter. Although such an approach may seem to indulge the “lowest common denominator” in standardizing the dataset, by no means does this necessarily reduce a distributed data network's elements to the variables common across its members' databases (Toh *et al.*, 2020). Members retain their autonomy about what data they collect and how to manage them, but they must work collaboratively with other members and researchers in mapping and standardizing their data to correspond with the common data model.

As the learning networks discussed in this chapter suggest, health data sharing in clinical care, quality improvement, research, and public health is expanding in Canada. This is a promising trend that can be harnessed to generate sustainable enhancements in Canada's health data systems, as HDRN is demonstrating in health research by linking existing networks. The benefits of health data sharing can be maximized when health datasets are as standardized, reliable, and complete as possible, enabling more rapid production of higher-quality knowledge and its application in clinical, administrative, and political decision-making.

# Benefits and Risks of Enhanced Health Data Sharing

- 3.1 Benefits of Health Data Sharing
- 3.2 Risks of Enhancing Health Data Sharing
- 3.3 Risks of Not Enhancing Health Data Sharing
- 3.4 Economic Value of Health Data

 Chapter Findings

- Health data sharing can improve health outcomes and the quality and safety of patient care through faster and more comprehensive access to patient histories, medication records, and lab results, as well as through integration with smart devices.
- Healthcare delivery can be more cost-effective with increased data sharing, which helps reduce duplication of imaging and lab tests, avoid unnecessary hospital admissions and consultations, and reduce time spent manually re-entering data; this can provide benefits to individual patients, health practitioners, and health systems overall.
- Improved health data sharing can enrich public health reporting and surveillance, allow for better assessments of public health programs at the national and local levels, create more equitable health systems, and improve public health collaboration in Canada and abroad.
- Increased data sharing can improve the quality of information available to researchers, reduce research costs, facilitate multidisciplinary research, create opportunities to pursue new research avenues, and attract funding and talent, all while increasing contributions to medical knowledge.
- While increased health data sharing brings some additional risks (e.g., privacy breaches, discrimination, an exacerbated digital divide in health, unintended secondary uses of health data, new burdens for health professionals), the risks of not increasing and improving health data sharing in Canada may be far greater, in the Panel's view.
- Health data are valuable economic assets and sharing them can increase the value of Canada's existing data holdings. Moreover, health data sharing presents a significant opportunity to improve Canada's innovation and economic productivity in this area.

There are many potential benefits to enhanced health data sharing. It can help improve health outcomes and quality of care, boost the efficiency of health systems, and slow the growth of health costs. Moreover, health data sharing can improve public health surveillance and interventions while enabling more and better health research, thereby allowing for deeper understanding of diseases and treatment effectiveness. Enhanced health data sharing also facilitates innovation in health systems. This is particularly important for Canada, which is currently lagging many international peers in both health data sharing and innovation. In the Panel's view, enhanced health data sharing presents a significant opportunity to improve Canada's performance in these areas. Importantly, while data sharing is undoubtedly *necessary* for realizing these benefits, it is not, however, *sufficient* to mitigate the challenges facing Canada's health systems. Data sharing is an enabler of social benefits but not a panacea for all of Canada's health-related challenges.

Enhanced data sharing is also associated with some potential risks, such as breaches of privacy and cybersecurity, stigmatization and bias, inequity and the digital divide, unintended secondary uses of health data, and additional burdens for health professionals. However, the benefits of health data sharing may outweigh the risks (Jones *et al.*, 2017; Kush & Nordo, 2019). Furthermore, in the Panel's view, the risks of not enhancing data sharing are also serious, perhaps even more so. Without reforms to Canada's approach to health data sharing, health systems will likely worsen, and Canada will continue to fall behind other countries in this area.

### 3.1 Benefits of Health Data Sharing

This section examines four types of health-related benefits resulting from increased health data sharing: (i) quality of care and health outcomes, (ii) health system management, (iii) population and public health, and (iv) health research. These benefits, identified through a review of the literature, are summarized in Table 3.1 and described in the subsequent sections. Importantly, these benefits are also deeply interconnected; by improving data sharing for patient care, more and better-quality data can become available for research, public health, and health system management. Similarly, data sharing for research can improve patient care by providing a better understanding of illnesses and identifying promising new treatments. Data sharing that improves the efficiency of health systems can also enhance the quality of care for patients within that health system, and so on.

**Table 3.1 Benefits of Health Data Sharing**

<b>Quality of Care and Health Outcomes</b>	<ul style="list-style-type: none"> <li>• Improved patient safety and medication safety</li> <li>• Improved ambulatory care</li> <li>• Fewer errors through integration with smart devices</li> <li>• Ability for health professionals to assess their practices</li> <li>• Faster access to patient information</li> <li>• Time savings for health professionals</li> <li>• Better-informed and more engaged patients</li> </ul>
<b>Health System Management</b>	<ul style="list-style-type: none"> <li>• Improved cost-effectiveness with: <ul style="list-style-type: none"> <li>– Fewer unnecessary or duplicated imaging and lab tests</li> <li>– Fewer unnecessary hospital admissions and re-admissions</li> <li>– Shorter patient visit times in emergency departments</li> <li>– Fewer unnecessary consultations</li> <li>– Less time spent on documentation or manually re-entering data</li> <li>– Fewer redundant prescriptions</li> </ul> </li> <li>• Improved overall efficiency of health systems</li> <li>• Reduced burden on healthcare professionals</li> </ul>
<b>Public Health</b>	<ul style="list-style-type: none"> <li>• Improved public health reporting and surveillance</li> <li>• Better assessment of public health programs</li> <li>• Improved post-market drug surveillance</li> <li>• Enhanced tracking of vaccinations and vaccine-adverse events</li> <li>• Better understanding of local or regional health issues</li> <li>• Improved quality of care for under-served patients</li> <li>• Prevention or mitigation of infectious disease spread through digital disease detection</li> <li>• Improved international collaboration in public health</li> </ul>
<b>Research</b>	<ul style="list-style-type: none"> <li>• Increased contributions to medical and scientific knowledge</li> <li>• Obtaining information not collected directly from study participants</li> <li>• Facilitation of multidisciplinary health research</li> <li>• Larger sample sizes</li> <li>• Implementation of learning health systems</li> <li>• Better access to real-world data</li> <li>• Reduced costs for health research</li> <li>• Attracting research funding and talent</li> <li>• Improved efficiency of clinical trials</li> <li>• Elimination of redundant re-entry of data</li> </ul>

### 3.1.1 Quality of Care and Health Outcomes

#### Health data sharing can help improve both the quality of care and health outcomes

A 2018 systematic review found that the use of health information exchanges can improve the quality of healthcare, with 64% of examined studies reporting positive impacts on the quality of care (Sadoughi *et al.*, 2018). Enhanced health data sharing can improve the quality of healthcare and health outcomes in the ways listed below and discussed in Box 3.1.

- **Improved patient safety:** Studies have found that a lack of EHR interoperability (i.e., the ability of an EHR system to exchange information with other health IT systems such as pharmacies, labs, radiology departments) was responsible for between 8% (Adams *et al.*, 2017) and 18% (Howe *et al.*, 2018) of patient safety events, and lack of information availability was responsible for 9% of such events (Howe *et al.*, 2018). Another study found that 20% of patient safety events in one state-wide clinical information system that provides access to integrated patient data (e.g., lab results, radiology reports, outpatient appointments) were due to problems with “information transfer,” with about half of those related to “system integration problems” (Magrabi *et al.*, 2010).
- **Improved medication safety:** A 2019 study found that Taiwan’s PharmaCloud data-sharing system — a national cloud-based service that lets healthcare providers access patients’ medical prescriptions and pharmacy claims in the previous three months — had a significant impact on patient medication safety (Liao *et al.*, 2019) (Section 4.1).
- **Improved ambulatory care:** A 2012 study found that giving primary care physicians access to clinical data such as lab results and other patient data via an electronic portal was associated with improvements in ambulatory care (an absolute improvement of 7% and a relative improvement of 12%), such as higher uptake rates of recommended screening as well as increased patient satisfaction with quality of care and communication with physicians (Kern *et al.*, 2012).
- **Fewer errors through integration with smart devices:** A 2018 study that examined the impacts of an interoperable, EHR-smart infusion pump program found that it improved the timeliness and accuracy of documentation, and reduced the number of safety alerts and staff overrides by approximately 20% (Biltoft & Finneman, 2018).



- **Ability for health professionals to assess their practices:** System-wide data sharing can help practitioners identify and reduce the use of outdated care protocols and allow them to benchmark their performance against comparable peers, in order to identify potential areas for improvement (CIHI, 2013).
- **Faster access to patient information:** A 2017 study found that when an emergency department used a health information exchange that allowed clinicians to retrieve patient information (e.g., lab and radiology results, allergies, medications) from outside organizations, it resulted in faster access to that information compared to faxing, and reduced the time patients spent in the emergency department by an average of nearly 30 minutes (Everson *et al.*, 2017).
- **Time savings for health practitioners:** Studies have found that the use of health information exchanges in emergency departments saves time for clinicians (a mean time saving of 105 to 120 minutes per patient) while also improving the quality of patient care (Carr *et al.*, 2014; Saef *et al.*, 2014).

### Box 3.1 Data Sharing to Improve Palliative Care for Cancer Patients

The Canadian Partnership Against Cancer (CPAC) has undertaken a national study to collect data on the state of palliative care for cancer patients and the timing of decisions to begin palliative care for such patients. There are limited data on palliative and end-of-life care in Canada, and a lack of comparable data from provincial/territorial and regional palliative care programs. This is due in part to the fact that palliative care is provided in a variety of different settings, including hospitals, outpatient clinics, hospice and long-term care facilities, and patients' homes, leading to challenges in data collection, standardization, and quality (CPAC, 2017; Tung *et al.*, 2019). In the view of CPAC, Canada needs to improve national data collection on how and when palliative care is provided across health systems (CPAC, 2017). Such data could shed light on when and how palliative care is initiated and used across the country and provide a better understanding of the end-of-life needs and experiences of cancer patients in Canada. They could also lead to improved quality of life for patients and reduce avoidable hospitalizations, thereby freeing up limited healthcare resources and limiting unnecessary expenditures.

## Improved health data sharing can provide significant benefits to patients, including better healthcare utilization and outcomes, as well as financial benefits

Health information exchanges — systems that allow for the transfer of health data across organizations or regions — have been used to successfully facilitate engagement, re-engagement, and retention of patients who are not up to date in specialty care, leading to the improved use of healthcare and the mitigation of disease progression (Magnus *et al.*, 2012). In addition, if health data (and research based on those data) can be shared in a way that is understandable to the public, they can provide patients with the opportunity to better assess and understand the treatment options available to them (Kush & Nordo, 2019).

For example, a systematic review found that the use of patient portals — electronic points of access through which patients can access their own health information, often integrated across a health system — is associated with better adherence to medication, improved management of chronic disease, improved disease awareness and self-care, a reduction in office visits, increased patient retention, better continuity of care, and an increase in preventative medicine (Kruse *et al.*, 2015). Subsequent studies have found improved health outcomes and increased patient satisfaction arising from patient portal use for specific conditions, such as diabetes (Alturkistani *et al.*, 2020), and for specific patient populations, such as pediatric hospital care (Kelly *et al.*, 2017). According to a survey by Canada Health Infoway (Infoway), while only 36% of people in Canada have accessed their personal health information electronically, 80% are interested in doing so (Infoway, 2023c).

Modelling by Infoway found that inefficiencies in Canada's health system (e.g., duplicate testing, ineffective inpatient and emergency department care) that could be mitigated by improved interoperability (in the form of access to shared patient summaries) contributed to over 20.7 million hours of unnecessary or redundant patient time, valued at approximately \$500 million (related to factors such as income loss, avoided travel, and dependent care expenses) (Infoway, 2023a). Increasing the range of data sharing and the breadth of interoperability further (to include, for instance, e-referral and e-consult functions) could save over 51.8 million hours of patient time, valued at over \$1.2 billion (Infoway, 2023a). Even greater benefits for patients — as well as health workers and the health system in general — could be realized if people in Canada had access to a personal, comprehensive health record, one that includes a range of information (e.g., test results, immunization and medication history, patient visit summaries, specialist consultation records). At 80% access, over 2.1 million primary care visits and

575,000 emergency department visits could be avoided, realizing over \$320 million in savings for the healthcare system and over \$361 million in patient cost savings. It could also save 5.5 million hours for patients, and 2.3 million hours for health workers (Infoway, 2023c).

### 3.1.2 Health System Management

#### Health data sharing can help improve the cost-effectiveness of healthcare delivery

Total domestic health spending has increased from less than 9% of Canada's GDP in 2000 to approximately 12.2% in 2022 (CIHI, 2022b); this is expected to continue to rise due to factors such as population aging and growth (CIHI, 2022a). Multiple empirical studies have demonstrated that data sharing can help improve the cost-effectiveness of healthcare delivery, thus providing an opportunity for governments to better manage growing health expenditures. For example, the Sadoughi *et al.* (2018) systematic review mentioned above found that the use of health information exchanges can improve the cost-effectiveness of healthcare, with 60% of studies reporting positive impacts on cost-effectiveness. Modelling by Infoway identified approximately \$950 million in inefficiencies in Canada's health systems that could be addressed by improved interoperability, in the form of increased access to shared patient summaries; increasing the range of data sharing and the breadth of interoperability even further (to include, for instance, e-referral and e-consult functions) could result in health system benefits of approximately \$2.4 billion (Infoway, 2023a). Additionally, in the Panel's view, health data sharing is likely to improve the cost-effectiveness in other areas, such as public health and health research.

As suggested above, the reduced costs that result from health data sharing are mostly due to reductions of unnecessary tests and procedures, more efficient allocation of resources, and time savings for health practitioners (Table 3.1). Some of these efficiencies are elaborated below.

- **Fewer duplicated or unnecessary medical imaging services and lab tests:** Perhaps the most widely identified efficiency benefit of health data sharing is the reduction in duplicated or unnecessary (and costly) medical imaging and lab tests (Frisse *et al.*, 2012; Bardhan *et al.*, 2014; Carr *et al.*, 2014; Lammers *et al.*, 2014; Saef *et al.*, 2014; Vest *et al.*, 2014; Jung *et al.*, 2015; Kamat *et al.*, 2015; Park *et al.*, 2015; Welk *et al.*, 2016; Everson *et al.*, 2017) (Box 3.2).

- **Fewer unnecessary hospital admissions and re-admissions:** Multiple studies have found that, when emergency department staff can access patient data via a health information exchange, costs are reduced due to fewer patients admitted to hospital from emergency departments (an estimated saving of US\$2,000–\$2,700 per patient) (Carr *et al.*, 2014; Saef *et al.*, 2014) and fewer hospital re-admissions after discharge (an estimated saving of more than US\$600,000 annually) (Vest *et al.*, 2015).
- **Shorter patient visit times in emergency departments:** A 2017 study found that patients whose data were accessed digitally via a health information exchange spent nearly 30 fewer minutes in an emergency department compared to those whose information was accessed by fax, resulting in lower average charges (Everson *et al.*, 2017).
- **Fewer unnecessary consultations:** Studies have found that the use of a health information exchange reduced unnecessary consultations in emergency departments by 15–20% (Carr *et al.*, 2014; Saef *et al.*, 2014).
- **Less time spent on documentation or manually re-entering data:** A 2018 study that examined the impacts of interoperability between EHRs and smart infusion pumps found that an estimated 5% reduction in documentation time spent by nurses could result in an annual saving of over \$2.4 million (Biltoft & Finneman, 2018). Another study found that the cost of implementing a data-sharing system for reporting transplant data was significantly less than the cost of manually transcribing data (Jones *et al.*, 2012).
- **Fewer redundant prescriptions:** Following the implementation of Taiwan’s PharmaCloud system (Section 4.1), the rate of redundant prescriptions decreased every year, saving nearly 9.35 billion in new Taiwan dollars (approximately CA\$410 million) between 2014 and 2020 (Gov. of Taiwan, 2021).

### Box 3.2 Data Sharing to Reduce Repeat Medical Imaging

A 2016 study found that nearly 13% of medical imaging tests in Ontario were repeated within 90 days; however, one region in southwestern Ontario that used a health information exchange system for diagnostic images had a 13% lower rate of repeat imaging compared with the rest of the province (Welk *et al.*, 2016). In Ontario, all hospitals are connected to one of three regional diagnostic imaging repositories (DIRs), which allow medical images to be shared among different healthcare providers. The Diagnostic Imaging Common Service (DICS) consolidates data from these DIRs and acts as a point of access to this information. The DICS is also integrated with ClinicalConnect, a web-based portal that “provides real-time access to patients’ health records, including diagnostic images and reports, generated by acute and community-based healthcare facilities across the province” (Nagels *et al.*, 2022).

### System-wide data sharing can help improve the overall efficiency of health systems

By increasing the ability to assess and compare the quality and cost-effectiveness of different treatments and care models (Jones *et al.*, 2012; CIHI, 2013), system-wide data sharing can help to improve the overall efficiency of a health system while allowing for better forecasting of future healthcare needs in different regions and more efficient allocations of human and financial resources to meet those needs (CIHI, 2013). Cross-institutional data linkage has been identified by the Organisation for Economic Co-Operation and Development (OECD) as a key mechanism for monitoring and increasing the efficiency and quality of a health system. Such linkages allow for the assessment of care coordination and outcomes across a health system, the evaluation of compliance with care guidelines, the measurement of healthcare utilization and costs, and more (OECD, 2015). These potential benefits demonstrate the power a data-sharing system could have to improve healthcare in Canada, particularly at the provincial/territorial level, where responsibility for managing the delivery of healthcare lies.

Such benefits have been realized in other jurisdictions. For example, data linkages facilitated by the Western Australia Data Linkage System have directly led to reforms in mental health legislation and health service delivery in Australia (Holman *et al.*, 2008), and linked administrative hospital data in Australia and the United Kingdom has been applied to cancer screenings, thereby improving early detection and survival (Gov. of Australia, 2017). Similarly, the MCHP used linked data to analyze Winnipeg's seasonal hospital bed crises (Menec *et al.*, 1999), leading to policy changes that expanded flu immunization programs and support for pneumonia treatments.

### Increased health data sharing could have a significant impact on health human resources

Modelling by Infoway found that improved interoperability (in the form of availability and access to shared patient summaries) in Canada could result in clinician time savings of nearly 2.3 million hours annually, valued at \$613 million. Even greater data sharing and interoperability (including, for instance, e-referral and e-consult functions) could result in clinician time savings of 5.7 million hours, worth over \$1.5 billion (Infoway, 2023a). A recent survey of clinicians in Canada found that more than half (54%) say they spend more than 30 additional minutes each day searching for patient information outside of their main record system, *over and above* the time they feel they should spend searching for such information (Infoway, 2022). Similarly, a study by the British Medical Association (BMA) found that a lack of interoperability can significantly increase physicians' workload, in the form of — for instance — chasing down missing or incomplete information (BMA, 2022). The BMA study also found that over 13.5 million working hours are lost in England due to inadequate IT systems, with a value of nearly £1 billion or the equivalent of 8,000 full-time doctors (BMA, 2022). Although not specific to health data sharing (but rather IT in health in general), this demonstrates the scale of the potential benefits.

According to a recent survey of clinicians in Canada, the vast majority (85–92%, depending on the specific question) believe that improved interoperability would help them get more accurate and timely information, improve patient experience, reduce redundant administrative tasks related to data entry, increase productivity, improve patient care and safety, and improve their ability to collaborate with healthcare providers outside of their practice (Infoway, 2022). A 2022 survey of physicians in British Columbia also found that a lack of interoperability and data-sharing functionality (e.g., e-prescribing) was cited as a burden (Doctors of BC,

2022). Of course, as noted in Chapter 2 and described in Chapter 5, the primary barriers to interoperability are not technical challenges, but rather culture- and policy-related issues; indeed, systems may be interoperable while data are not shared due to such barriers.

### 3.1.3 Public Health

#### Increased health data sharing can have a range of benefits for public health

The benefits of data sharing for public health became apparent when Canada had to address the COVID-19 pandemic (Box 3.3), as did the costs and risks associated with the gaps in health data sharing. Other benefits for public health that can arise from increased data sharing are detailed below.

- **Improved public health reporting and surveillance:** The use of health information exchanges has been found to increase the efficiency and improve the quality of public health reporting and surveillance (Goldwater *et al.*, 2014). Similarly, data linkages have been found to improve the comprehensiveness, completeness, and timeliness of data for public health surveillance (Garies *et al.*, 2020), as well as its sensitivity, specificity, and cost-effectiveness (Jutte *et al.*, 2011). In Australia, health data sharing has led to improved disease surveillance and allowed for applications that would not have been possible in the absence of a pre-existing data linkage infrastructure, such as determining risk factors for hospital inpatients who switch between private and public payment classifications (Holman *et al.*, 2008).
- **Better assessment of public health programs:** Data sharing allows for better assessment of the effectiveness of public health policies and programs, such as food supplements for children in low-income families, the comparison of vaccination against the use of health services, and publicly funded prescription drug programs (Jutte *et al.*, 2011; CIHI, 2013).
- **Improved post-market drug surveillance:** Data sharing can help enhance drug safety through post-market surveillance of health effects in all patients with prescriptions, and the identification and assessment of adverse drug reactions (CIHI, 2013). Such surveillance is particularly useful for understanding the effects and interactions of drugs in patients taking multiple drugs, or those with multiple chronic conditions (CIHI, 2013). CNODES is a good example of how networks of databases and research teams have improved the surveillance process in Canada (Section 2.2).

- **Enhanced tracking of vaccine adverse events:** Data sharing is essential for detecting and monitoring vaccine adverse events (VAEs). Because it can be difficult to detect rare VAEs in clinical trials due to limitations related to sample size, composition, and study duration (as was the case with COVID-19 vaccines), post-market surveillance is needed (Bettinger *et al.*, 2022). A review of the performance of the Vaccine Adverse Event Reporting System (VAERS) in the United States during the COVID-19 pandemic included several recommendations to improve the system, many of which related to data sharing (e.g., better data sharing among institutions and databases, improved interoperability, and better inter-regional data sharing) (Rizk *et al.*, 2021).
- **Better understanding of local or regional health issues:** Health information exchanges have been found to help local authorities better identify and focus on health issues that disproportionately affect the residents of their region (e.g., a high population of individuals with HIV) and to offer better insights into the types of treatments and strategies used to address local or regional health issues (Goldwater *et al.*, 2014).
- **Improved quality of care for under-served patients:** During the COVID-19 pandemic, combining data from different sources allowed for the identification of “hotspot” postal code regions in Ontario where high levels of racialized and immigrant populations experienced disproportionately high rates of infection and death, and who were also among the least likely to be vaccinated due to socio-demographic factors, such as language barriers or lower income (Mishra *et al.*, 2021; OAGO, 2022). These hotspots were then prioritized for COVID-19 vaccine roll-outs, with increased community outreach and access to testing (OAGO, 2022). In Manitoba, race-based data were combined with employment data in order to inform pandemic decision-making, such as providing paid leave to get vaccinated, or linking vaccination data with the Indian Register to improve vaccination rates among First Nations peoples (i.e., by offering vaccine eligibility for First Nations “set 20 years younger than the general population, based on data revealing First Nations people generally became sicker at younger age”) (Gov. of MB, 2021; May, 2022).



- **Prevention or mitigation of infectious disease spread through digital disease detection (DDD) systems:** DDD, or *digital epidemiology*, draws on widely available online data (e.g., social media posts, search engine queries, mobile device data) and makes use of tools such as AI and machine learning, natural language processing, and geolocalization to generate insights about public health trends (Vayena *et al.*, 2015; Edelstein *et al.*, 2018). DDD systems have been used to successfully detect public health emergencies, such as the 2014 Ebola outbreak in West Africa (Vayena *et al.*, 2015; Edelstein *et al.*, 2018). DDD is particularly useful in settings where public health surveillance infrastructure is lacking; greater integration of DDD with formal public health surveillance tools can help maximize its potential (Edelstein *et al.*, 2018).
- **Improved international collaboration in public health:** Enhanced health data sharing within Canada can help lay the groundwork for exchanging public health data with international jurisdictions to improve global disease detection and response. Such international data-sharing arrangements can help identify outbreaks in cases where national-level data cannot, and enable international collaboration to reduce the impact of global health crises (Edelstein *et al.*, 2018).
- **Addressing antimicrobial resistance:** A 2021 study found that, when primary care physicians were sent a “letter targeting appropriate antibiotic durations,” it “resulted in a statistically significant 4.8% relative reduction in total antibiotic use” (Schwartz *et al.*, 2021). Physicians were selected to receive the letter based on a dataset containing information about outpatient prescriptions dispensed by community pharmacies, supplemented with insurance, antibiotic sales, and geospatial data to identify the 25% of primary care physicians who prescribed the highest total number of antibiotics. With improved data sharing, automated notification systems based on similar data linkages could be established.
- **Improved immunization rates:** Multiple studies have found that immunization information systems (IISs) can help improve vaccination rates (Gianfredi *et al.*, 2019). They may also offer a more cost-effective means of reaching out to people due for vaccination (Suh *et al.*, 2012). Interoperability and data sharing are essential for effective IISs (Atkinson *et al.*, 2020), and combining data from multiple sources can help identify high-risk patients in need of vaccination (Martinelli *et al.*, 2018).

## Enhanced health data sharing at the national level could have improved Canada's response to the COVID-19 pandemic

During the pandemic, PHAC relied on the voluntary sharing of COVID-19-related data (e.g., cases, deaths, healthcare utilization) from provinces and territories, which varied in both quality and timeliness. Although some successful data-sharing initiatives occurred at the provincial/territorial level (Box 3.3), a more robust data-sharing infrastructure at the national level might have improved federal public health surveillance and helped provincial/territorial governments make more informed policy decisions by enhancing their epidemiological modelling capabilities, contact tracing and case management systems, and vaccination programs (Allin *et al.*, 2022). Indeed, lack of data sharing has been widely cited as a factor limiting the effectiveness of Canada's COVID-19 vaccination efforts (Wolfson, 2020; Marchildon, 2021; Ling, 2021) and creating challenges for case and contact management (Bhatia, 2020). A national-level data-sharing infrastructure of this kind would allow for better data sharing with international partners and better global surveillance of the pandemic (Allin *et al.*, 2022).

Patient-oriented data-sharing services might have also helped with Canada's response to the pandemic. For example, in Denmark, the sundhed.dk portal (Section 4.1) was instrumental in implementing the Danish government's response to COVID-19. It provided people in Denmark with access to test results, vaccination appointments, and personal health data through the addition of a "power of attorney" feature, as well as providing access to data for homecare nurses (Banck *et al.*, 2022). An analysis of data-sharing arrangements for COVID-19 vaccinations in international jurisdictions with federal systems similar to Canada's (specifically, Australia, Germany, Switzerland, and the United Kingdom) identified key considerations that could be applied to improve the sharing and standardization of vaccination data in this country (Farmer *et al.*, 2022). These include clearly identifying (via legislation) the respective roles of national and subnational governments; establishing national-level immunization registries, data-reporting standards, and data infrastructure requirements (including minimum datasets and data variable descriptions); addressing variations in immunization management and reporting systems that contribute to time lags and data quality problems that can impede surveillance efforts; and creating effective data-governance arrangements that also have the ability to adapt processes for data collection, reporting, and use in response to changing circumstance (Farmer *et al.*, 2022).

### Box 3.3 Data Sharing During COVID-19: Ontario's Modelling Consensus Table

One of the most effective tools used to address the COVID-19 pandemic was increased cross-sectoral health data sharing among government agencies, health professionals, and researchers. For example, Ontario's COVID-19 Modelling Consensus Table (MCT) was a partnership among the province, academic experts, and health system leaders that was created in March 2020 to provide evidence-based estimates of the impacts of COVID-19 and inform possible mitigation strategies. To inform those estimates, Ontario's Ministry of Health provided the MCT with access to an extremely broad range of health data from "epidemiological, clinical, laboratory, health system, and public health" sources, representing the largest-ever health data sharing arrangement of its type in Ontario. In addition, novel data-sharing arrangements permitted analyses of the data to be published within 24 hours, with patient-level data anonymized to ensure protection of privacy.

The MCT was started by a group of academics and public servants, and it built upon existing structures. Membership was entirely voluntary, changed over time to address different needs, and was governed by a formal Terms of Reference. Importantly, this type of data sharing was made possible largely because it occurred within a single province. Scaling up such an approach across provinces/territories or levels of government may present significant jurisdictional challenges (Chapter 5). Addressing these challenges will require building on the work and lessons learned from organizations currently facilitating pan-Canadian health data sharing (Section 2.3).

(Hillmer *et al.*, 2021)

### 3.1.4 Research

Enhanced health data sharing can help improve health research in several different ways. In 2015, the CCA published a report examining the specific challenges and benefits of increased sharing of health data for research purposes in Canada (CCA, 2015). Canada already has a significant number of intra-provincial institutions and organizations focused on facilitating data sharing for health research, such as ICES in Ontario, the MCHP in Manitoba, and HDRN (Paprica *et al.*, 2020) (Section 2.3). Ways in which enhanced health data sharing can improve health research are discussed below.

- **Increased contributions to medical and scientific knowledge:** Data linkage systems in Australia have increased the volume of published, peer-reviewed health research (Holman *et al.*, 2008; Tew *et al.*, 2017).
- **Obtaining information not collected directly from study participants:** Data linkages can help researchers track health outcomes after a study has ended and validate self-reported information from participants (Jutte *et al.*, 2011; Doiron *et al.*, 2013).
- **Facilitating multidisciplinary health research:** Linking a wide variety of socio-demographic, socioeconomic, and health information can help facilitate multidisciplinary health research and explore research questions that would not otherwise be possible (Doiron *et al.*, 2013). It can also allow researchers to examine outcomes in different areas (e.g., medical, educational, and social) among the same cohort of individuals (Jutte *et al.*, 2011).
- **Larger sample sizes:** In many cases, health outcomes for specific diseases may be poorly understood due to small sample sizes. Data sharing helps establish a more robust understanding of health outcomes for specific diseases by increasing the sample size available for analysis (Jutte *et al.*, 2011; Jones *et al.*, 2012).
- **Implementation of learning health systems:** Improved health research based on enhanced data sharing is a critical component of developing and implementing a learning health system (Section 2.2), in which knowledge generated by research is seamlessly integrated into care delivery and information is captured as an integral by-product of the care delivery experience (Kush & Nordo, 2019).

- **Better access to real-world data:** Health research benefits from enhanced data sharing by allowing for increased use of real-world data, which allows researchers to base their analyses on information from actual clinical healthcare practices. Increased use of real-world data in health research may also reduce the number of placebo patients necessary for a clinical research study, help identify potential study participants, and allow for the assessment of appropriateness and feasibility of a proposed research protocol (Kush & Nordo, 2019).
- **Reduced costs in health research:** Data linkages are generally more cost-effective than traditional health research methods, such as longitudinal studies (Holman *et al.*, 2008; Jutte *et al.*, 2011), although they are not intended to replace such studies. Moreover, population-wide administrative data linkage allows for research examining “disease-disease and procedure-disease associations” that are unlikely to be funded in randomized controlled trials (Jutte *et al.*, 2010).
- **Better understanding of social determinants of health:** Cross-sectoral data linkages (e.g., linking routinely collected health and administrative data with socio-demographic and socioeconomic datasets) can provide more robust insights into social determinants of health (Jutte *et al.*, 2011; Saunders *et al.*, 2021). For example, in Canada, mortality data have been linked to census data in order to examine differences in mortality rates among socioeconomic groups (Sanmartin *et al.*, 2016). Moreover, research linking health, socioeconomic, and education data has demonstrated that social risk factors can be better predictors than medical risk factors when it comes to both short- and long-term health and education outcomes (Jutte *et al.*, 2010; Saunders *et al.*, 2021).
- **Attracting research funding and talent:** The Western Australia Data Linkage System was found to provide Australia’s research community with a competitive advantage in attracting funding, both from within and outside western Australia, resulting in an estimated tenfold return on investment in data linkage infrastructure. Moreover, it is also believed to have helped attract and retain highly productive and sought-after researchers (Holman *et al.*, 2008).

- **Improved efficiency of clinical trials:** Providing access to information in EHRs could help improve the efficiency of clinical trials — and reduce their length and cost — by reducing the time between study design and participant enrolment; by enhancing and accelerating the identification and recruitment of suitable patients; and by reducing the resources needed for administrative and clerical tasks, such as data entry, re-entry, and verification. It could also help reduce the risk of data-entry errors, improve patient safety, and allow for more patient-centric protocols (Beresniak *et al.*, 2016). Moreover, clinical trials assessing the comparative effectiveness of approved drugs could evaluate their respective effects by looking at patients who are already taking them, rather than recruiting study participants (CCA, 2015). A cost-benefit analysis of Europe’s Electronic Health Records for Clinical Research (EHR4CR) data-sharing project found it could reduce the time and costs of certain types of clinical trials by 50% compared with existing practices.<sup>3</sup> Moreover, the analysis found that optimizing the clinical trial process in the ways described above could reduce the time of the average clinical research cycle by 20% compared with current practices, which in turn could generate hundreds of billions of dollars in commercial revenue (Beresniak *et al.*, 2016).
- **Elimination of redundant re-entry of data:** Enhanced data sharing is particularly useful when data are being used for multiple studies, as data quality can be improved through reduced transcription errors (Kush & Nordo, 2019).

### Intersectoral data linkages facilitate in-depth research that can improve care delivery and public health

As several of the above examples demonstrate, linking data sources related to social determinants of health (e.g., routinely collected administrative data) can significantly enhance health research, thereby creating even greater benefits for health systems and society more broadly. Key data sources of this type include “health services utilization, population registries, place of residence, family ties, educational outcomes, and use of social services” (Jutte *et al.*, 2011).

Several examples of this type of broad data linkage exist in Canada at the provincial/territorial level. The MCHP was established in 1991 and is responsible for the Manitoba Population Research Data Repository, a collection of de-identified person-level linkable data drawn from a wide range of government departments and agencies, including health, education, social services, and the

3 Specifically, the analysis found that it would reduce the time and costs of Phase II and Phase III oncology clinical trials.

justice system, as well as registries such as health insurance, vital statistics, immigration, and population databases (MCHP, 2023). Similarly, British Columbia's Data Innovation Program links de-identified data from a wide variety of government ministries and agencies to support approved population-level research projects. In addition to health data, the program also provides access to demographic, education, justice, social development, transportation, and work and income data (Gov. of BC, 2022). These kinds of cross-sectoral data linkages allow for research that generates social benefits that would not otherwise be possible. For example, research conducted by the MCHP has provided insights into surgical outcomes and emergency department use by specific populations; helped identify people at high risk for suicide; examined the effects of social housing on health, education, and social outcomes; evaluated and developed new intervention programs, and more (Orr *et al.*, 2016; Katz *et al.*, 2019).

Health research in Canada could be further strengthened — thereby helping to reinforce public health and the delivery of care — through interprovincial data linkages or pan-Canadian data-sharing initiatives for health data and data related to social determinants of health. Canada currently faces a variety of obstacles to conducting this kind of multi-jurisdictional, intersectoral research, due in part to legal and policy barriers, as well as to challenges related to data organization and comparability, and cultural challenges in data governance (Dahl *et al.*, 2020) (Chapters 2 and 5). However, some initiatives are working to address these issues and facilitate cross-jurisdictional, intersectoral data linkage, such as HDRN's SPOR platform for patient-oriented research in Canada (Dahl *et al.*, 2020).

### 3.1.5 Health Data Literacy

As noted in Section 3.1.1, improved health data literacy can help patients better understand and participate in their treatment. However, several studies have noted that a lack of health literacy is a barrier for patients, one that prevents them from interpreting the medical information they access through patient portals (Kruse *et al.*, 2018). In addition, there is currently very little public knowledge or understanding of data-sharing and data-linkage practices (Aitken *et al.*, 2016; Paprica *et al.*, 2019b). However, studies have found that the public is interested in opportunities for public discussion about these health sharing practices, which may increase public support and reduce concerns (Aitken *et al.*, 2016). Additional studies have found that the public is able to develop nuanced policy views on this issue (Teng *et al.*, 2019).

These discussions are, ideally, not a mere one-way provision of information; they rely on meaningful dialogue and ongoing engagement (Aitken *et al.*, 2016; PHAC, 2021a). The EAG has recommended that Canada “[e]stablish a common language for health data and support programs for health data literacy for the public, leaders and health workforces” (PHAC, 2021a). Health data literacy was also cited as a key step in implementing a pan-Canadian health data strategy by health experts and stakeholders (PPF, 2022).

## 3.2 Risks of Enhancing Health Data Sharing

### 3.2.1 Privacy and Cybersecurity

Perhaps the most widely discussed risks of increased health data sharing relate to privacy and data security, such as inappropriate access to sensitive personal health data and cyber-attacks on healthcare organizations. See Chapter 5 for an analysis of legal and regulatory issues related to privacy and security in the context of health data sharing.

#### Many cybersecurity risks in the health sector are not specific to data sharing

Healthcare organizations trail other sectors in cybersecurity protection (Kruse *et al.*, 2017). Cyber-criminals may attempt to use medical information for identity theft, medical fraud, extortion, and illegally obtaining controlled substances (Kruse *et al.*, 2017). In addition, healthcare organizations are frequently subject to ransomware attacks, in which malware is used to publish sensitive information, or block legitimate access to information unless a ransom is paid (CCCS, 2021); an example of this is the 2017 WannaCry attack on the National Health Service (NHS) in the United Kingdom (U.K. NAO, 2018). To protect against these types of cyber-threats, health organizations will need to adopt strong data-security and cybersecurity standards, procedures for handling data breaches, and cybersecurity training for health professionals (Kruse *et al.*, 2017; Sheikh *et al.*, 2021). Importantly, however, such risks are not specifically related to increased health data *sharing* but are rather inherent to the ongoing digitization of healthcare in general, and to the collection and storage of health data.

There is little comprehensive information publicly available about the frequency of privacy or security breaches in Canada’s health sector specifically related to data sharing or data linkages. Some organizations that share health information, such as ICES in Ontario, have reported several breaches in recent years (12 privacy breaches and 7 security breaches between 2016 and 2019); however, very few of



these breaches were due specifically to data sharing practices, and the risk of personal health information being compromised in these breaches was assessed as very low (ICES, 2020).

Beyond implementing stronger cybersecurity measures, some organizations and jurisdictions have turned to federated networks to mitigate potential cybersecurity risks arising from increased health data sharing (Section 4.1.2). In federated data networks, data are stored in decentralized, interconnected nodes, which can be remotely accessed by other nodes in the network without the data being transferred or shared (WEF, 2020; Hallock *et al.*, 2021). Nodes can potentially vary in their level of access control depending on the sensitivity of the data being stored (Hallock *et al.*, 2021), while the network uses common security protocols and features (WEF, 2020). Additionally, many organizations that host data repositories to share or link de-identified health data for the purposes of research and public health — including the MCHP and organizations in several international jurisdictions (Section 4.2.4) — use third parties to remove identifying information from the data before they are transferred to the repository, in such a way that none of the parties involved have full access to information that could re-identify individuals (Katz *et al.*, 2019).

### Increased data sharing may provide an opportunity to improve privacy in healthcare

As noted in Chapters 2 and 5, data custodians often cite privacy concerns as the main reason to *not* share health data. There seems to be an inherent tension between the goals of protecting privacy while at the same time expanding access to health data (McGraw & Mandl, 2021). While the potential privacy risks of sharing health data have been extensively documented elsewhere (and, as such, are not the focus of this report), two potential risks are noted here: (i) the risk of unauthorized disclosures of personal data (i.e., the possibility that wider access to health data may increase the likelihood of it being shared with individuals or organizations to which the data subject did not or would not consent) and (ii) risks related to the potential for *re-identification* (i.e., when previously anonymized or de-identified health data are combined or linked with other data sources in ways that allow for the re-identification of individuals). In other words, insofar as data sharing increases both the quantity and types of data available for analysis, so too do the risks to privacy (Dove, 2018).

Despite these risks, however, the privacy risks arising from Canada's outdated data-sharing systems may be even more dangerous. A recent joint statement by Canada's FPT privacy commissioners and ombudspersons noted that the continued use of insecure and outdated communication technologies to share

health data (e.g., fax machines) is a significant privacy risk in the health sector (OPCC, 2022). For example, in Ontario, misdirected faxes are the leading cause of unauthorized disclosure of personal health information (IPC, 2022a).

In the Panel's view, increased data sharing provides an opportunity to *improve* privacy in healthcare and move away from outdated privacy models, while also enabling the benefits of data sharing described in Section 3.1 to be realized. There has been a great deal of research and innovation into methods to preserve privacy in health data sharing, and a wide variety of technical, governance, and regulatory solutions offered (see Chapter 5). Other countries have developed privacy-preserving mechanisms for data sharing that focus on patient consent (Section 4.1.3), as well as systems for data sharing in cases where neither consent nor anonymization is feasible (Section 4.2.4 and Box 5.1).

### 3.2.2 Stigmatization, Bias, and Discrimination

Research on public perceptions of health data sharing in Canada and internationally has found there is concern about the potential for individuals or groups to be stigmatized or discriminated against (Aitken *et al.*, 2016; Paprica *et al.*, 2019b). Moreover, concerns about bias, discrimination, and stigma related to sharing certain types of health information (e.g., substance use, sexual health, mental health) are particularly salient for marginalized groups (Mulrine *et al.*, 2021). Patients receiving mental health treatment, as well as mental health professionals, have also noted concerns related to the potential for stigma or discrimination resulting from the sharing of health data (Ivanova *et al.*, 2020). These concerns are well founded — the sharing of personal mental health data has resulted in people from Canada being denied entry into the United States (O'Doherty *et al.*, 2016; McGraw & Mandl, 2021) (Section 3.2.4).

Another equity-related challenge is that health data are often non-representative of the broader population. For example, there is a significant lack of nationally representative health data on visible minorities in Canada, and the data that do exist are severely limited by small sample sizes of those minorities in surveys (Khan *et al.*, 2015). As a result, health policy and programs may be biased against these groups. However, it is important to note that this is primarily a challenge for data *collection*, not data sharing (although increased data sharing could potentially help remedy problems with poor data collection by providing an alternative source of data about groups that are under-represented in health datasets).

The potential for stigma, bias, or discrimination due to increased health data sharing can be mitigated through inclusive governance frameworks that involve and engage vulnerable or marginalized individuals and groups in the design, implementation, and control of data-sharing systems. Indeed, an important precondition of trust in health data systems is inclusion in its governance (Section 5.1.2). Additionally, the perceived risks of stigmatization may be partially mitigated through the implementation of mechanisms that ensure patient control over sensitive personal data. Several international jurisdictions have established such mechanisms, which have helped build public trust in data sharing (Section 4.1.3). In addition, clear and transparent policies regarding who can access what personal health data, and under what circumstances, can also help build public trust (Section 3.2.4).

### 3.2.3 Digital Divide

The increased sharing of health data could unintentionally exacerbate existing health inequities in Canada because of the country's *digital divide* — that is, the gap in opportunity between “haves” and “have-nots” with respect to digital technologies and the internet (Carter *et al.*, 2020). The digital divide in Canada is most prevalent in the rural and northern areas of the country, many of which have significant deficits in connectivity (CCA, 2021). For example, fewer than half (48%) of people in Canada living outside large population centres have high-speed internet access, compared with over three-quarters (76%) of those within such areas (StatCan, 2021a). Similarly, compared with the Canadian average (92%), lower rates of internet usage are found among Indigenous people (88%), people with a disability (85%), unemployed people (85%), and people over 75 years of age (62%) (StatCan, 2021b).

If these connectivity disparities are left unaddressed, the benefits of health data sharing will be unevenly distributed, thereby increasing health inequities. For example, the use of portals through which patients can access their personal health information and facilitate interactions with a health system has been associated with improved health outcomes. However, studies have found the use of these portals is lowest among racialized groups, elderly people, people of lower socioeconomic status, and people who live in areas without broadband internet access (Perzynski *et al.*, 2017).

The digital divide may also impact health providers and researchers, in addition to patients. Lack of access to high-speed internet and IT infrastructure in rural and remote areas can make data sharing more challenging. Additionally, medical practices in rural and remote areas are more likely to be smaller, with fewer resources to acquire and use digital health technologies and hire and retain IT

support staff; this may be hindered by these practices' lack of geographical proximity to technology vendors, funding agencies, and support organizations (Slight *et al.*, 2015; Paré *et al.*, 2018).

To mitigate the risk of exacerbating the digital divide, addressing disparities in internet access for people in rural and remote areas will be key, as will improving internet access and digital literacy for the demographic groups mentioned above. With respect to the first issue, work to improve connectivity in rural and remote communities in Canada is ongoing. However, the primary challenges in closing this gap are not technological, but rather related to policy and regulation (CCA, 2021). Technical solutions to close the connectivity gap exist, but the incremental, market-based, and private-sector-led approach to the issue has been largely unsuccessful, despite funding and support from multiple levels of government. Instead, place-based and needs-based approaches that provide flexibility to implement different policies and programs in different regions may help to successfully close the connectivity gap (CCA, 2021). On the second issue, there are ongoing efforts in Canada to improve digital literacy, such as the federal Digital Literacy Exchange Program, which provides funding and support to not-for-profit organizations that offer digital literacy skills training at no cost to people and groups that are under-represented in the digital economy (ISED, 2022).

### 3.2.4 Unintended Secondary Uses of Health Data

Secondary uses of health data (Section 2.1) can provide benefits across a health system, including optimization of services, reduction of health inequities, better allocation of resources, facilitation of personalized care, and innovation (Boyd *et al.*, 2021). However, among the risks of enhanced health data sharing are the unforeseen or unintended secondary uses of these data — that is, health data collected for one purpose (e.g., patient care) being used for other purposes for which they were not intended (e.g., personalized advertisements). Examples of unforeseen or unintended secondary uses of health data may include forensic investigations by law enforcement, civil lawsuits (such as those determining paternity), and border security and immigration (O'Doherty *et al.*, 2016). The personal health data of Canadians have already been used for border security purposes: in 2013, a Canadian woman travelling to the United States was denied entry based on having a medical history that included depression and attempted suicide. U.S. border agents were able to access that information due to longstanding data-sharing arrangements between the RCMP and the FBI (Adams & Proskow, 2014).

The public has expressed concern about secondary uses of health data, particularly by the private sector. Research has found that people have lower levels of trust in the private sector than the public sector with respect to data sharing and data linkage, and particular concerns about data being sold for profit by private sector entities (Aitken *et al.*, 2016; Paprica *et al.*, 2019b; Teng *et al.*, 2019). However, the public does not appear to oppose all forms of private sector involvement, with support being conditional upon the degree to which private sector use of health data is in the public interest and has public benefits, and when public benefits are prioritized over profits (Aitken *et al.*, 2016; Paprica *et al.*, 2019b; Teng *et al.*, 2019).

The risks of unintended secondary uses of health data can be mitigated by developing clear and transparent policies and procedures for these uses. Such policies exist in other jurisdictions. For example, the Government of Australia has developed a framework describing how data from its My Health Record (MHR) system may be used for secondary purposes; its MHR Secondary Use of Data Governance Board relies on this framework when making decisions about providing access to such data for secondary use (Gov. of Australia, 2018). Similarly, the European Union has developed a set of principles to help guide secondary uses of health data, as protected under Europe's General Data Protection Regulation (GDPR) (Boyd *et al.*, 2021).

To build public trust for health data sharing, users of health data (including clinicians, researchers, and other actors in both the public and private sectors) must be able to clearly communicate, in plain language, the purpose and details of health data sharing arrangements. Such communications should describe, at a minimum, (i) whether and how opting out is possible, and why there are cases where it is not; (ii) whether the data will be used to generate profits; (iii) who will have access to the data, and under what conditions; (iv) what privacy and security safeguards are in place; (v) what sorts of data are used, and the extent to which they contain identifiable information; (vi) the purpose of the data use, including any public or private benefits of that use; and (vii) what kind of organization is undertaking this research (e.g., commercial enterprise, not-for-profit, government department or agency, or academic institution) (Paprica *et al.*, 2019a). This could help clarify and dispel misinformation around what, how, why, and by whom health data are being used.

### 3.2.5 Risks for Health Professionals

Efforts to increase health data sharing also present potential risks for health professionals, primarily by increasing their administrative workload. For example, *meaningful use* incentives in the United States (Section 4.3.1) have increased the adoption of digital health technologies, but they have also been

criticized for increasing physician burden, reducing efficiency, and “increasing the risk of professional burnout” (Reisman, 2017). Similarly, some physicians in Prince Edward Island state the province’s new EMR systems have contributed to reduced efficiency and increased burnout (Fraser, 2022). Moreover, a recent survey of physicians in Canada found that 51% of respondents feel existing data documentation is time-consuming, and 42% feel it is challenging to integrate their practice’s information systems into their workflow (Infoway, 2022). While these examples highlight the risks related to adopting digital health technologies, it should be noted that these issues are related to the *collection* of health data, not data sharing. Nevertheless, increased data sharing does have the potential to exacerbate these challenges. For example, anecdotal concerns have also been expressed about the potential for data sharing to contribute to information overload (i.e., when health practitioners encounter a very large volume of patient data, it can become exponentially more difficult to sift through their medical history). Health professionals in rural and remote areas may also face a disproportionately greater burden in implementing and using data-sharing systems, given the lack of connectivity, resources, and IT infrastructure (Section 3.2.3).

When it comes to health data infrastructure, ease of usability can mitigate such risks for health professionals. A 2021 study assessing physicians’ attitudes toward Taiwan’s MediCloud data-sharing system (Section 4.1) found that the most important factor in determining perceived usefulness and physician satisfaction was ease of use (Chuang *et al.*, 2021). Poor usability can lead to errors when entering and sharing health information, which can, in turn, create risks for patient safety (Sheikh *et al.*, 2021) and more stress for users, contributing to low morale and burnout among health professionals (Kroth *et al.*, 2019). To ensure usability, health data infrastructure should be designed using a collaborative, iterative process involving technology vendors, health professionals, and patients (Sheikh *et al.*, 2021). Furthermore, systematic and iterative testing of usability *in situ* can be a cost-effective method of successfully detecting and mitigating many usability challenges, as well as increasing organizational efficiency and patient safety (Kushniruk *et al.*, 2019).

The American Medical Informatics Association’s “25x5” initiative, launched in 2022, seeks to reduce the documentation burden on health professionals to 25% of current levels in five years and includes actions such as improved interoperability and data sharing (AMIA, 2021, 2022, 2023). Moreover, the U.S. Surgeon General has indicated that improved interoperability, integration of data across different systems and platforms, and standards for data exchange could all help reduce burnout among health professionals (Murthy, 2022).

### 3.3 Risks of Not Enhancing Health Data Sharing

In general, lack of health data sharing can disrupt the continuity of patient care, cause delays in medical interventions when a patient's medical history cannot be verified, and result in avoidable misdiagnoses. Lack of data sharing may also create risks for health professionals, whose duty of care could be compromised by their inability to make informed decisions; it can also add unnecessary financial burdens to health systems due to wasted time and resources (Jones *et al.*, 2017). In addition, failure to share data used in health research — due to protection of intellectual property or research governance frameworks — can create risks and even harm to patients; there are many examples of health research that could have saved lives or reduced harm to patients had the results or datasets been shared (Jones *et al.*, 2017).

#### While enhancing health data sharing in Canada carries some additional risks, the risks of doing nothing are likely far greater

It is important to understand that the risks of *not* improving health data sharing in Canada go beyond simply maintaining the status quo. Without increased health data sharing, in the Panel's view, Canada's health systems are likely to get *worse*: declining health outcomes and quality of care, poorer health system management, less effective public health monitoring and interventions, perpetuation of existing health inequities, less innovation, and fewer opportunities for new research. Without improved health data sharing to rein in the increasing costs of care delivery, these costs will continue to rise due to factors such as Canada's growing and aging population, threatening the sustainability of the country's health systems.

Canada is already behind its peers when it comes to modernizing its health data systems and capitalizing on its health data holdings both for health outcomes and innovation (Ceccato & Price, 2019); Canada ranked second-to-last place for use of health data sharing in a 2019 Commonwealth Fund survey of physicians (CF, 2019).<sup>4</sup> As other countries continue to improve health data sharing in their own jurisdictions (Chapter 4), failure to enhance it in Canada will worsen this gap, resulting in Canada falling even further behind. Moreover, in the absence of a distinctly pan-Canadian approach to health data sharing, it is likely there will be more fragmentation of health systems as individual provinces and territories continue to move forward on reforms to health data sharing within their own jurisdictions, with little coordination beyond or across their borders.

4 Included in the survey were Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States.

## Lack of improved health data sharing will likely result in greater consolidation of personal health data in the private sector while simultaneously harming innovation

In the absence of reforms to the way health data are accessed and shared in Canada's public health systems, it is likely that health data (and health-related data) will be further concentrated in, and controlled by, the private sector (PHAC, 2021a). There is a great deal of interest from the private sector in health data, and public entities in Canada already lag commercial actors in reaping the benefits derived from the collection, analysis, and use of health data (Ceccato & Price, 2019; ISED, 2022).

Health data in Canada are already highly consolidated in a small number of private sector companies. For example, the majority of health providers in Canada use an EMR system owned by one of three companies (ISED, 2022), and at least some of these companies monetize their data holdings by selling them in an anonymized form without the direct consent of individuals — a practice the Information and Privacy Commissioner of Ontario has found to be legal, so long as certain conditions are met (IPC, 2022b). There are already commercial entities in Canada that sell and make use of de-identified patient data from pharmacies, drug plans, medical clinics, and governments, covering millions of patients in Canada (Spithoff *et al.*, 2022). This large-scale private monopolization of data may threaten some researchers' ability to conduct rigorous, independent, and high-quality investigations in the health field (Sadowski *et al.*, 2021). The federal government has attempted to partially address this issue through initiatives such as Health Canada's Public Release of Clinical Information (PRCI) framework, which provides public access to anonymized clinical data taken from submissions for market authorization of drugs and medical devices (HC, 2019; Egilman *et al.*, 2021).

At the same time, lack of pan-Canadian data sharing inhibits competition and innovation in the country's digital health sector. The fragmentation of privacy laws and data governance rules makes it difficult for new digital healthcare firms to enter the market in multiple provinces and territories, and to access EMR systems; this limits the ability of start-ups to compete with established players (ISED, 2022). As digital health technology becomes more important, Canada will fall further behind in the absence of reforms to enhance data sharing, or of policies and regulations related to the control of health data in the private sector.



### 3.4 Economic Value of Health Data

Health data are valuable economic assets (Harper, 2013). Furthermore, combining or linking health data can increase the value of the existing data holdings. In Australia, data linkage has increased the return on existing investments in routine administrative datasets and added value by improving the quality and accuracy of those datasets through reduction of duplication errors and technical glitches (Holman *et al.*, 2008).

Data sharing in general has been found to have significant economic impact. According to a study conducted by the OECD (2019) looking at many types of data sharing,

*data access and sharing can help generate social and economic benefits worth between 0.1% and 1.5% of gross domestic product (GDP) in the case of public-sector data, and between 1% and 2.5% of GDP (in [a] few studies up to 4% of GDP) when also including private-sector data.*

The OECD also found that health data sharing can produce economic benefits for health systems, governments, and the broader economy via increased efficiency, better research and innovation, and the elimination of redundant data collection (OECD, 2015).

#### Data sharing provides opportunities to create economic value through innovation

The application of big data analytics and AI to health data has the potential to drive innovations that improve both the quality of healthcare and the efficiency of health systems, while simultaneously creating economic value. However, increased access to data is needed to drive the development of AI-based products and services in this area, which is currently challenging for small firms in Canada (ISED, 2020) (Section 3.3).

An analysis of the value of data held by the NHS in the United Kingdom estimated that a curated, longitudinal, and patient-level dataset that combined primary, secondary, and social care data, as well as available genomic data, could be worth up to £5 billion per annum to the NHS and deliver around £4.6 billion in benefits to patients per annum (Wayman & Hunerlach, 2019). This estimate is based on the predicted operational savings for the NHS, better patient outcomes, and the creation of wider economic benefits to the United Kingdom, which would be

generated through the increased use of big data, AI, and personalized medicine that such a curated dataset would allow (Wayman & Hunerlach, 2019). These three pillars are elaborated on below.

- **Big data:** Productivity savings could be generated from the use of big-data tools that can identify best-practice care models, which would improve health system productivity and more efficiently distribute limited resources. Such a data resource could also help attract R&D investment in the life sciences sector and spur more R&D spending in the United Kingdom.
- **AI:** Applying AI to a single, curated, and patient-level NHS dataset could provide insights that improve patient outcomes, reduce errors, improve the speed and accuracy of diagnostics, reduce rates of adverse reactions to medication, and improve demand planning. Moreover, AI could be used to improve the efficiency of NHS operations, such as scheduling and capacity planning.
- **Personalized medicine:** A combined, longitudinal, and patient-level dataset containing both genomic and phenotypic data could enable greater use of personalized medicine, wherein treatments are tailored to a particular patient. By allowing for more precise diagnoses and targeted treatments, personalized medicine could reduce the waste of resources on ineffective treatments while improving morbidity and reducing mortality.

### The cost of implementing health data sharing would likely be offset by financial benefits

Studies have found that the economic benefits of health data sharing tend to outweigh the costs of implementation, and that the benefits are greater when the degree of data sharing is greater. One analysis found that full, standardized electronic data sharing in the United States would provide US\$337 billion in net value over a decade, with nearly US\$78 billion in annual value thereafter. Notably, the cost of implementing lower levels of data sharing would produce a net loss of US\$34 billion over 10 years, with an annual net benefit of nearly US\$24 million annually thereafter (Walker *et al.*, 2005). A similar analysis for Australia found that full data sharing would provide a net value of more than AU\$5.2 billion over a decade, with an annual value of more than AU\$2 billion thereafter; implementing lower levels of data sharing would produce a net loss of more than AU\$9.7 billion over 10 years, with an annual net benefit of AU\$350 million thereafter (Sprivulis *et al.*, 2007).<sup>5</sup> These results suggest that larger investments in more extensive data-sharing infrastructure may generate faster and larger economic returns compared

<sup>5</sup> According to the Bank of Canada, the exchange rate for Canadian to Australian dollars is approximately CA\$1 to AU\$1.11 as of August 2023.

with smaller investments in less extensive data-sharing infrastructure. Estimates from governments in Canada have similarly found that the cost of implementing and operating health data sharing programs is outweighed by the financial benefits. Alberta is implementing a program to share health data (Connect Care) and estimates the direct financial benefits will be more than \$2 billion in the first 10 years, compared with a total program cost of \$1.4 billion (AGA, 2020).

Investments in interoperability are likely to cost significantly less than investments in health IT in general. For example, one study found that the capital cost of implementing national-level interoperability in the United States were only about one-third of those for implementing functionalities such as EHRs and computerized physician order entry systems (Kaushal *et al.*, 2005). Moreover, since data sharing can increase the value of existing data assets, investments in data sharing can help derive better value from investments that provinces and territories have already made in digitizing their health systems, thereby providing a better return on those investments. This is not to say that the cost of implementing a health data sharing system will be negligible. In fact, underestimating such costs has contributed to the failure of data-sharing initiatives in some international jurisdictions, such as the United Kingdom.

# 4

## Health Data Sharing in International Jurisdictions

- 4.1 Common Features of Systems for Sharing and Accessing Patient Data for Care Delivery
- 4.2 Common Features of Systems for Linking Health Data for Research, Public Health, and Health System Management
- 4.3 Developing and Implementing Health Data Sharing Systems

## Chapter Findings

- Features common to successful health data sharing systems in other jurisdictions include single points of access for patients and practitioners, integrated care records, federated or decentralized data infrastructure, patient control over data, and institutionally agnostic governance arrangements.
- Public engagement early in the process of developing and implementing a health data sharing system is vital to developing trust and to the long-term success of the initiative.
- Several countries have taken an incremental approach to implementing systems for health data sharing. However, incremental approaches can fail if they are insufficiently forward-looking, if strategies frequently change, or if they lack centralized governance arrangements.
- Financial incentives and penalties are often used to encourage both adoption of data-sharing technologies and discouraging practices that inhibit data sharing. In the absence of incentives, mandating data sharing via legislation may be required.

**M**any international jurisdictions have developed health data sharing systems for a variety of purposes, such as sharing patient data across care settings to improve the quality of care and the efficiency of care delivery; allowing people to access their health information and creating a patient-centric focus to care; and providing access to health and health-related data for the purposes of research, public health, health system management, and innovation in the health sector. While these purposes involve the sharing of health data, the specific requirements of a data-sharing system differ depending on its purpose. For example, data that are shared for the purposes of research, public health, or system management can be de-identified, whereas patient data in care settings requires, of course, identifiable information.

This chapter examines several approaches to health data sharing for different purposes in select international jurisdictions. The approaches were chosen based on a review of the literature and Panel expertise, and highlight successes, failures, and lessons learned. Importantly, while the experience of implementing health data sharing systems in these countries may provide useful lessons for Canada, crucial contextual differences exist. Although all countries examined in this chapter (except for the United States) have some form of universal healthcare, differences in how that care is structured, delivered, and funded, as well as differences in the

division of responsibilities among levels of government with respect to healthcare and even geographical size will affect the feasibility of any form of data sharing. As such, it is not possible to simply replicate one country's health systems in another country. While the details of the contextual differences between Canada and the countries examined here are beyond the scope of this chapter, they will be important to keep in mind when looking to other jurisdictions as inspiration for an improved health data sharing system in Canada.

## 4.1 Common Features of Systems for Sharing and Accessing Patient Data for Care Delivery

Several world-leading systems for sharing patient data across care settings have important common features, including (i) a single point of access for patients and health professionals; (ii) integrated care records; (iii) a patient-centric focus; (iv) automatic enrolment in the system (barring opt-out); (v) federated or decentralized data infrastructure; (vi) data privacy and security features that promote public trust; and (vii) unique identifiers.

### 4.1.1 Single Point of Access

Several countries currently viewed as leaders in health data sharing for patient care have implemented eHealth portals that provide a single point of access for patients and practitioners to access personal health records that integrate data from across a health system. These include both national-level systems for integrating and sharing patient data as well as systems for integrating data across subnational jurisdictions. For instance, Australia's MHR system integrates data from across several states, which, like Canada's provinces, are responsible for the delivery of care.

Denmark's sundhed.dk eHealth portal, launched in 2003, consolidates relevant information from all parts of Denmark's health service and provides a single access point for patients and health professionals. Patients can access their clinical records and other health services (e.g., booking appointments, renewing prescriptions), while health professionals can access clinical information in their patients' EMRs (Jensen & Thorseng, 2017; Banck *et al.*, 2022). As stated in a report from the WHO:

*Sundhed.dk acts as a hub, providing easy access to relevant and personal data. The objective is to create an environment that fosters knowledge-sharing and collaboration among health professionals and serves as a resource for citizens to manage their own conditions by enabling them to navigate and empowering them to a higher degree to take an active role in the management of their chronic conditions.*

Banck *et al.* (2022)

Sundhed.dk is internationally recognized as an example of patient-oriented digital services in healthcare and has been used as a best-practice model by other countries seeking to implement similar systems (Jensen & Thorseng, 2017).

Following the implementation of sundhek.dk, Denmark developed additional tools to improve the quality and interoperability of patient-level health data. It introduced the Shared Medication Record (Fælles Medicinkort) in 2009, followed by the National Health Record (Sundhedsjournalen) in 2013. Denmark's Shared Medication Record system contains information about medication plans, prescriptions, and purchases for all Danish citizens, and provides health professionals with access to a patient's medication information from across the entire health system (Gov. of Denmark, 2018; Trifork, n.d.). Similarly, the National Health Record collates several different sources of health data, including hospital admissions, lab results, and prescription information. Patients and health personnel can access the National Health Record via the sundhed.dk portal.

Australia's MHR is a national system that provides individuals with access to their health information (McMillan, 2020) and has been cited as a world-leading example of data-sharing infrastructure for personal health records (Makeham & Ryan, 2019). MHR originally began as an opt-in system in 2012 but transitioned to an opt-out system in 2018 (McMillan, 2020). In 2019, an MHR account was created for all Australians who did not already have one, unless they chose to opt out (Makeham & Ryan, 2019). As of November 2022, over 90% of Australians had an MHR, and over 97% of those records had at least some data entered into them (MHR, 2022).

Taiwan's My Health Bank, created in 2014, allows individuals to access and download their health data stored by the National Health Insurance Administration (NHIA), which is the administrator of Taiwan's single-payer healthcare system (Huang *et al.*, 2017; Wen *et al.*, 2019). Starting in 2016, the service began updates to improve functionality and user-friendliness, such as allowing users to input their own medical data (e.g., height, weight, waist circumference, heartbeat). It also links people with specific conditions to resources for managing those conditions, with reminder notifications for those with major illness or injury (Huang *et al.*, 2017). In 2020, My Health Bank added a feature to track mask purchases in response to COVID-19 (Gov. of Taiwan, 2021). The NHIA has also begun to allow third-party vendors to design mobile applications that provide access to My Health Bank (Huang *et al.*, 2017).

In 2013, Taiwan implemented the PharmaCloud system, which provides health professionals with cloud-based access to medical prescriptions and pharmacy claims from the past three months (Yan & Lu, 2016). The purpose of PharmaCloud is to improve patient safety and reduce drug costs for the NHIA (Liao *et al.*, 2019).

In 2016, the NHIA expanded and upgraded the PharmaCloud system to include additional types of medical records beyond drug prescriptions, and renamed it MediCloud (Chuang *et al.*, 2021). By 2020, the types of records in the system included “Western medication record[s], traditional Chinese medication record[s], drug allergies, special controlled medication record[s], specific clotting factor medication record[s], test/examination records and results, dental treatment and surgical records, rehabilitation care, surgical records, discharge summaries, and Centers for Disease Control immunizations” (Gov. of Taiwan, 2021). Patients can access their MediCloud data through My Health Bank.

#### 4.1.2 Federated or Decentralized Data Infrastructure

Many of the jurisdictions that are leading in health data sharing use a decentralized or federated data system that collates and makes available data from a variety of sources, rather than storing them in a centralized database. These systems are designed to augment, rather than replace, existing data repositories across a healthcare system. There are several advantages to federated models, such as security-enhancing privacy protections (Section 3.2.1), fewer requirements for policy and governance, and addressing concerns from participating organizations about having their data stored by a third party (Tallman *et al.*, 2023). In addition, federated approaches may help address challenges related to cross-jurisdictional data sharing (Section 4.2.5).

Among the factors that have made Denmark’s sundhed.dk so successful is that it repurposes existing data sources and IT infrastructures, rather than trying to “reinvent the wheel” (Jensen & Thorseng, 2017). Sundhed.dk collates and assembles existing health data from various sources, including hospitals and general practitioners, prescription databases, and lab systems, thereby enhancing the value and usefulness of these data sources. Moreover, sundhed.dk has no data management responsibilities, leaving that to the sources to which it links. In addition, this approach allows it to build on existing local initiatives and repurpose existing data infrastructure; for example, it uses the authentication method already used for online banking and other electronic public services in Denmark (Jensen & Thorseng, 2017). Similarly, Australia’s MHR is a federated system that retrieves data from independently managed data repositories. Rather than storing data in a centralized database, it operates in parallel to other such databases and does not attempt to replace the health record systems of individual hospitals, clinics, pharmacies, general practitioners, and other health providers (McMillan, 2020).



Taiwan has developed a system to securely exchange hospital EMR data called the National Electronic Medical Record Exchange Center (EEC). The EEC is not a data repository, but rather functions as an information index, search, and retrieval service for hospitals and clinics. Information systems in each hospital — which are not standardized and may be unique to a hospital — are indirectly connected to the EEC through what is known as an EMR gateway. Hospitals convert patients' medical records into a standardized format and save them on the EMR gateway, where they are stored for six months (Li *et al.*, 2015; Wen *et al.*, 2019). The EMR gateway registers the metadata of those records in the EEC, thereby allowing them to be indexed, searched, and retrieved (Wen *et al.*, 2019). As of 2015, there were two versions of the EMR gateway: the standard version used by hospitals that allows for mutual, two-way exchange between hospitals, and a simpler version used by clinics that only allows for one-way exchange (i.e., clinics can retrieve data from other hospitals, but its own data cannot be retrieved) (Li *et al.*, 2015).

### 4.1.3 Data Privacy and Security

In some jurisdictions, patients must personally approve of a health professional's access to their medical records; this has helped strengthen public trust in those systems (Section 4.3). For example, in Denmark's system, health professionals can only access the data of patients with whom they have an existing treatment relationship, and only after the patient approves access. Moreover, access is logged and made available to the patient (Jensen & Thorseng, 2017). These privacy and security measures have helped create a high degree of public trust in the system (Banck *et al.*, 2022).

Similarly, in order for patient data to be exchanged among hospitals in Taiwan's EEC system, patients must sign a written consent form that authorizes their physician to retrieve their medical records from another hospital (Li *et al.*, 2015; Wen *et al.*, 2019). The patient must also provide further consent in order for the physician to save their medical records at that hospital (Li *et al.*, 2015). Physicians in Taiwan can access a patient's files in the MediCloud system in two ways: they can (i) download a patient's entire medical record prior to an appointment with written consent (although records must be deleted after 24 hours), or (ii) manually query the system while a patient is present, using the physician's IC card and the patient's national health insurance card (Chiang & Chang, 2019; Chuang *et al.*, 2021).

#### 4.1.4 Unique Identifiers

Several countries use identifiers unique to each resident to facilitate integration of patient data across their health systems. In some cases, these identifiers are specifically linked to the health system; for example, in the United Kingdom, every individual registered with the NHS has a unique NHS number, which is also used in the U.K.'s Spine system (Boyd *et al.*, 2018). Patients in Australia access the MHR system using their Individual Healthcare Identifier (IHI) number, which is unique to every resident in Australia (Gov. of Australia, 2022). In Taiwan, patients use their national health insurance identification to access the My Health Bank system (Huang *et al.*, 2017), while healthcare providers use it to access a patient's MediCloud record (Chuang *et al.*, 2021). In other jurisdictions, these identifiers are not unique to a health system but are instead national ID numbers. For example, in Denmark, patients access the sundhed.dk portal using their national identifier number (NemID), which every Dane is issued at birth (Jensen & Thorseng, 2017), while patients in Israel are identified in the health system via their unique national identity numbers (Balicer & Afek, 2017).

The United Kingdom's National Audit Office (NAO) states that unique identifiers are key to achieving interoperability, ensuring patient safety and continuity of care, and allowing patients to access eHealth services (U.K. NAO, 2020). However, a similar system of unique identifiers could be difficult to replicate at the national level in Canada since health system identifiers are implemented at the provincial/territorial level.

#### 4.1.5 Independent or Arm's-Length Governance Arrangements

In the United Kingdom, some main challenges identified by the NAO in its assessment of the NHS's progress in digital transformation include complex and unclear governance arrangements, in which accountability for achieving benefits and controlling costs was shared across multiple organizations, as well as lack of national oversight for transformation occurring at the local level. The NAO recommended simplifying and strengthening governance arrangements, including "providing national bodies with the levers and monitoring capability to ensure local NHS organisations and suppliers comply with national standards for existing and new technology, and for data" (U.K. NAO, 2020).

In the Panel's view, some of the most successful examples of governance arrangements that facilitate health data sharing are in countries that have established independent, arm's-length, or institutionally agnostic entities that coordinate data sharing across sectors, organizations, and actors. This view was

echoed in an interview with Andrew Morris, Director of Health Data Research UK, who emphasized the need to focus primarily on the *actors* in a health data system, rather than on the technical details around (for instance) infrastructure or methods of data sharing. The challenge, according to Morris, is to develop collaboration and coordination among various actors that *facilitate* system-wide data sharing, rather than trying to *control* it, along with an institutionally agnostic entity that *serves* the actors, rather than *supervises* them (A. Morris, personal communication, 2022).

### Several jurisdictions have enhanced health data sharing by relying on institutionally agnostic entities

Health data sharing in Denmark is coordinated by MedCom, a publicly funded, not-for-profit organization established in 1994 that is financed and owned collectively by the Danish Ministry of Health, the five Regions of Denmark, and Local Government Denmark (which represents Denmark's municipalities). MedCom facilitates collaboration among government authorities, public organizations, and private firms in Denmark's health system (MedCom, 2016) and "is responsible for setting all of Denmark's standards related to health information. It is mandatory for each health region in Denmark to use the standards established by MedCom, and regions are regularly scrutinized to ensure that these standards are being followed" (Mu-Hsing Kuo *et al.*, 2011). Similarly, Denmark's sundhed.dk portal is governed and financed by the Danish Regions, the Municipal Organization, and the Ministry of Health. Moreover, the governing bodies of sundhed.sk are organized in a way that reflects the organization of Denmark's health system, which has been cited as a key enabling condition for success (Jensen & Thorseng, 2017).

The Indiana Health Information Exchange (IHIE) was created in 2004 to manage the Indiana Network for Patient Care (INPC), which facilitates data sharing among hospital emergency departments. The IHIE claims to be "the largest inter-organizational clinical data repository" in the United States; it contains more than 30 years' worth of data, covers the entire population of the state, and provides data-sharing services for approximately 50,000 health professionals in Indiana and neighbouring states (Siwicki, 2022). Importantly, however, the IHIE does not own any of the data. It was, rather, explicitly designed to act as a "neutral steward of the data" that is "vendor- and customer-agnostic." Moreover, the IHIE is not directly funded by the state government. It is a not-for-profit organization whose revenue is generated by offering products and services to its participants (Siwicki, 2022).

Israel's initiative to develop new interoperability standards also relies on an institutionally agnostic coordinating entity. In 2021, the country launched an initiative to implement new standards across its entire health system to improve data sharing and interoperability (WHO, 2021b). Implementation of these standards is being driven by Israel's Fast Healthcare Interoperability Resources (FHIR) community, which is managed by 8400 The Health Network (WHO, 2021b), a network of health technology leaders from a variety of different sectors (8400 The Health Network, n.d.). The FHIR community was established by 8400 The Health Network, the Israeli Ministry of Health, Israel Innovation Authority, Digital Israel, Joint ELKA, and Yad Hanadiv (FHIR Israel, n.d.).

## 4.2 Common Features of Systems for Linking Health Data for Research, Public Health, and Health System Management

Several countries have developed national-level data sharing and data linkage systems to provide access to health and health-related data for the purposes of research, public health, health policy, health system management, and health innovation. These systems differ in important ways from those described in Section 4.1, which share integrated patient data for clinical care. Perhaps most importantly, these systems do not involve sharing identifiable personal health information, but rather de-identified or anonymized population health data, which can be linked across different data sources at the individual level. This gives researchers the ability to access health data (e.g., medical records, administrative health data) and to link these data to other datasets concerning the social determinants of health (e.g., demographic information, use of social services, education, employment, and housing).

In some cases, these systems are decentralized or federated; in others, they are centralized data repositories. However, many share common features, such as a single point of access and privacy protections based on encrypted identifiers used to link data at the individual level. Additionally, some data linkage systems in specific jurisdictions have unique features, such as including the private sector in health data linkage networks in order to drive innovation in their health sectors (Section 4.2.6). Australia has experience establishing a national-level data-sharing system that addresses the challenges of cross-jurisdictional data linkage in a federated political system like Canada's. Notably, several of these examples are similar to organizations in Canada, such as CNODES, HDRN, ICES, and MCHP (Section 2.3).

### 4.2.1 Intersectoral Data Linkage

One of the most important features of leading health data sharing and linkage systems for the purposes of research, public health, and health system management is the ability to link health datasets (e.g., medical records, administrative data) to datasets containing information about the social determinants of health, at the individual level. This kind of cross-sectoral data linkage allows for research that generates social and economic benefits in the form of improved clinical care, public health insights, and policy evaluations that would not otherwise be possible (Section 3.1.4).

Australia's Population Health Research Network (PHRN) was established in 2009 to provide national-level, cross-jurisdictional linkage of health and health-related data. It allows population health and human services data about the same individual to be linked and accessed across nine jurisdictions (six states, two self-governing territories, and the Commonwealth) (Smith & Flack, 2021; Wray *et al.*, 2022). Research using PHRN data has led to changes in both government policies as well as clinical practice, and PHRN data are increasingly being used for clinical trials (Smith & Flack, 2021).

Taiwan's Health and Welfare Data Center (HWDC) is a centralized data repository that links over 70 national databases containing both health data and data on the social determinants of health, "including birth and death registries, immunization records, cancer registries, reportable infectious diseases, contraception surveys, low-income household registries and family violence/sexual assault data" (Hsieh *et al.*, 2019; Wang & Muennig, 2022). The HWDC also includes data from MediCloud (Section 4.1.1), the EEC (Section 4.1.2), and the National Health Insurance Research Database (NHIRD) (Hsieh *et al.*, 2019; Wang & Muennig, 2022). The NHIRD, established in 2002, is one of the largest population databases in the world, covering approximately 23 million people and more than 99% of Taiwan's population (Wang & Muennig, 2022). It contains individual-level claims data from across Taiwan's single-payer insurance system (Hsieh *et al.*, 2019), including data from primary outpatient departments and inpatient hospital care (Lin *et al.*, 2018). The NHIRD has been used to improve clinical care and assess the effectiveness of treatments (Lin *et al.*, 2018), as well as for public health and health system management, such as evaluating the effectiveness of pay-for-performance programs to reduce health expenditures (Wang & Muennig, 2022).

The United Kingdom's Secure Anonymised Information Linkage Databank (SAIL), established in 2007, contains de-identified information about the population of Wales that is made available for research in, and evaluation of, public services, interventions, and strategies. SAIL also contains a wide range of individual-level

data routinely collected in the delivery of healthcare and other public services, including data related to the social determinants of health (e.g., education, housing, and employment), which can all be linked at the individual level.

#### 4.2.2 Federated vs. Centralized

In contrast to the decentralized systems for health data sharing for patient care (Section 4.1.2), several of the linkage networks surveyed in this chapter use centralized data repositories to link and share health data for the purposes of research, public health, and health system management. The motivations behind this approach often include increased and simplified security, as well as considerations of IT infrastructure and its impact on data access and processing times. For example, SAIL chose to create a centralized data repository rather than a decentralized model with federated access in part to minimize the burden on public sector data providers, many of which had insufficient IT infrastructure to allow data access and processing at source. A centralized data repository also allows SAIL to monitor data quality and completeness, and to offer a privacy-protecting “separation principle,” wherein SAIL does not have access to person-identifiable data (Section 4.2.4).

Similarly, the INPC chose to employ a centralized model because of its improved data processing and access time compared with decentralized federated models, plus its additional security benefits (Zafar, 2007). However, the INPC is also federated as well as centralized, in that it stores data in federated vaults or silos residing in a centralized location. Each participating institution has its own silo in the INPC where only data from that institution are stored, which are mirrored within that institution (Zafar, n.d.). Denmark’s Secure Research Platform is a centralized database that contains a duplicate of the information in each of the 28 national health registers (Sundhedsdatastyrelsen, 2022), and Taiwan’s HWDC is also a centralized data repository that links national databases (Hsieh *et al.*, 2019; Wang & Muennig, 2022).

By contrast, Australia’s PHRN uses a decentralized model, as it operates essentially as a national network of subnational (i.e., state-level) “data linkage units” responsible for “creating the linkage maps/indexes and coordinating access to linked data” (Flack & Smith, 2019). While there is no single national data repository for the PHRN, each state and territory has its own data linkage unit, as does the Australian Institute of Health and Welfare. The PHRN also does not have standard technologies or platforms; rather, each data centre has the flexibility to choose the architecture and technology that best suits its needs (Flack & Smith, 2019).

### 4.2.3 Single Point of Access

An important feature of many leading examples of health data linkage networks is a single point of access through which researchers can apply for and gain access to a wide range of data types. In many cases, they can access these datasets remotely via a secure online portal or virtual environment. In other cases, access may be restricted to specific physical locations. For example, Australia's PHRN provides a single point of access to its datasets through the Secure Unified Research Environment (SURE) (Smith & Flack, 2021), which researchers can remotely access. They can also use the portal to submit applications to access PHRN health data via the online application system. Similarly, Israel's Kineret Data Lake allows researchers to access its data holdings through a secure, cloud-based research room (Kineret, 2022; JLM-BioCity, 2023).

By contrast, while Taiwan's HWCD also provides a single point of access to more than 70 health and health-related datasets, it is a centralized database that can only be physically accessed on-site (Hsieh *et al.*, 2019; Wang & Muennig, 2022). Although the ability to link across these databases has created significant opportunities for in-depth research, requirements for on-site access and analysis have increased the time and costs of that research (Hsieh *et al.*, 2019). Notably, the U.K.'s SAIL could only be accessed on-site when it was launched in 2007; however, the disadvantages of this model — such as increased time and costs, burdensome travel requirements, and space limitations — led to the subsequent development of the SAIL Gateway, which allows remote access (Jones *et al.*, 2014).

Other jurisdictions are currently in the process of developing a single point of access for all types of health data. While data in Denmark's National Health Service Registers (which contain detailed information about all aspects of the country's health system, including the Shared Medication Record) can be accessed from the Danish Health Data Authority's Secure Research Platform (Sundhedsdatastyrelsen, 2022), Denmark currently requires researchers to apply to different sources, depending on the type of data they are attempting to access, such as National Health Service Register data, medical records, clinical quality databases, and genomic information. However, Denmark is currently developing the National Danish Research Health Data Gateway to assist researchers in accessing health data. The gateway currently provides an overview of the types of available data as well as guidance on the application process (Gov. of Denmark, 2022; RHDG, n.d.-a, n.d.-b). In the future, however, Denmark intends to develop the gateway into a single point of access for all types of health data.

#### 4.2.4 Privacy

##### Many data linkage systems use encrypted identifiers to link de-identified data at the individual level

In order to protect individuals' privacy, data linkage networks used for research, public health, and health system management typically only provide access to de-identified or anonymized data. To preserve the ability to link datasets at the individual level, these systems often use anonymized identifiers or encrypted versions of identifiers assigned elsewhere in a health system (Section 4.1.4). For example, Denmark's Secure Research Platform encrypts both patient and practitioner identification in order to protect privacy while allowing datasets to be linked at the individual level (Sundhedsdatastyrelsen, 2022). Similarly, Taiwan's NHIRD encrypts the identifying information of patients with unique, anonymized identifiers (Hsieh *et al.*, 2019).

Some data linkage networks provide an additional layer of privacy protection by using a third party to de-identify the data and encrypt identifiers, so that no party has access to both the data and the identifying information. For example, SAIL uses encrypted versions of NHS patient numbers to identify and link datasets at the individual level. To ensure privacy and security, the encryption process is undertaken separately by the NHS Wales Informatics Service (NWIS), then re-encrypted by SAIL in such a way that ensures neither SAIL researchers nor NWIS employees can reveal the NHS numbers. Both the Western Australia Data Linkage System and the New South Wales Centre for Health Record Linkage use a similar protocol, in which identifiers are separated from health data, such that individuals with access to the data cannot access the identifiers themselves, and vice versa (Smith & Flack, 2021). A similar third-party separation process is used by the MCHP in Canada (Katz *et al.*, 2019) (Section 3.2.1).

##### Direct consent is not feasible for data sharing in research, public health, and health system management

Unlike sharing identifiable patient data for the purpose of providing clinical care (Section 4.1), consent — specifically, *narrow* consent, in which patients consent to the use of their data at a specific time and for a specific purpose — is generally not required to share data for research and public health purposes. This is because (i) the data are typically de-identified, thereby adding some level of privacy protection, (ii) it would be impractical (and potentially impossible) to obtain consent when working with population-level data, and (iii) requiring consent of this kind could “severely compromise statistical validity” when using these data for research and public health (Wellcome Trust, 2015).



However, mechanisms to acquire *broad* consent — in which patients give blanket permission for their data to be used for research purposes — may be viable options. For example, Australia provides residents with the option to opt out of allowing their MHR data to be used for any secondary purposes, such as research, public health, and health system management (Gov. of Australia, 2018; McMillan, 2020); it notably uses an *opt-out* rather than an *opt-in* mechanism to ensure a broader range of participation. In the future, Australia plans to explore the feasibility of a dynamic consent model in which patients may allow access to their data for secondary purposes on a case-by-case basis (Gov. of Australia, 2018). By contrast, there is currently no way for patients in Taiwan to opt out of having their de-identified data made available for research, which has become a controversial issue in the country and has led to several unsuccessful lawsuits challenging the practice (Lin *et al.*, 2018; Hsieh *et al.*, 2019).

#### 4.2.5 Cross-Jurisdictional Data Linkage: Australia's PHRN

A key objective of the PHRN — similar in many respects to Canada's HDRN (Smith & Flack, 2021) (Section 2.3) — is providing the capacity for national-level, cross-jurisdictional data linkage across Australia's nine jurisdictions (six states, two self-governing territories, and the Commonwealth). This is especially important for Australia, since information about a given individual may be held by a variety of state, territorial, and federal governments, and because there is a high level of cross-jurisdictional health data utilization among residents (Wray *et al.*, 2022). To achieve this, the PHRN adopted a decentralized, federated approach (Section 4.2.2) specifically designed to provide flexibility to each jurisdiction:

*Achieving participation from all jurisdictions meant supporting a high level of flexibility in how the data linkage infrastructure was developed, implemented, and operated in each jurisdiction. Strict requirements for each jurisdiction to implement and operate in specific nationally agreed ways would have delayed the participation of some jurisdictions and it is possible that a national network of any kind may not have been achieved.*

Smith & Flack (2021)

As a result, the PHRN does not have standard technologies or platforms; rather, the data linkage unit in each jurisdiction has the flexibility to choose the architecture and technology that best suits its needs (Flack & Smith, 2019). This flexibility has been key to the PHRN's success, allowing “each jurisdiction to progress at their own pace and within the limitations of their legal and policy environment” (Flack & Smith, 2019). It has also, however, created challenges for cross-jurisdictional data linkage due to a lack of standardization (in data and metadata, benchmarking and linkage methods, and approval requirements and

processes), as well as differences in legislation, regulation, policy, and culture across jurisdictions (Wray *et al.*, 2022). The PHRN is attempting to mitigate these challenges through regular engagement with participating organizations and jurisdictions (Smith & Flack, 2021). This engagement and consultation with stakeholders have been key to the success of the cross-jurisdictional data linkages created by the PHRN, resulting not only in the establishment of the PHRN itself but also the creation of mutually accepted ethics reviews for projects, along with an integrated application system that provides researchers with a single point of access to apply for data access across jurisdictions (Section 4.2.3).

#### 4.2.6 Commercial Uses and Innovation

In many cases, health data linkage systems typically only allow university researchers, health providers, and other public sector users to access data, and prohibit access for commercial uses. However, there are some examples of commercial users having access to health data for the purpose of innovation. Most notably, Israel's Ministry of Health launched the Kineret Data Lake, which provides researchers in hospitals, universities, and private firms in the health sector with cloud-based access — through a single platform — to de-identified information from government hospitals in Israel, including “procedures, diagnoses, medications, lab results, vitals, sensitivities, and more,” as well as unstructured information such as photos, videos, and audio (Kineret, 2022). This initiative is explicitly designed to promote collaboration with industry partners in Israel's health sector, such as “startups, digital health, and pharma companies” (JLM-BioCity, 2023).

Other jurisdictions provide some degree of access to private sector organizations. In Australia, MHR data cannot be used solely for commercial purposes, but private firms may apply to use them so long as they can demonstrate that the use is likely to have public health benefits or be in the public interest (Gov. of Australia, 2018). Denmark allows private companies to access health data, so long as they meet certain requirements (Sundhedsdatastyrelsen, 2023); for example, data are only made available for projects deemed to be “of significant societal importance” (RHDG, n.d.-c). Additionally, PHRN is currently exploring social licence for the use of its data by private industry (PHRN, 2019). Finally, the U.K.'s SAIL prohibits private sector researchers from directly accessing its data but allows them to collaborate with SAIL or other public sector organizations to access these data.

### 4.3 Developing and Implementing Health Data Sharing Systems

The process of developing and implementing health data sharing across an entire health system can be challenging. Policy-makers should consider the need for public engagement and trust, how to deploy incentives and mandates that encourage data sharing, and issues related to establishing system-wide interoperability. Often, an incremental approach can be helpful when implementing a data-sharing strategy; however, incrementalism can also become a barrier if the strategy is not sufficiently forward-looking.

#### Lack of public engagement early in the process can harm trust and understanding

In the United Kingdom, failure to engage the public and win its trust regarding the use of data has emerged as a key challenge in the NHS's attempts to implement data sharing (U.K. NAO, 2020). The care.data program was launched in 2013 to integrate information from general practitioners and hospitals; however, it was cancelled in 2016 due to significant concerns among both the public and healthcare providers. Specific concerns related to lack of public engagement and awareness of the program before it was announced, as well as to data security, secondary uses of data, and lack of communication around the ability to opt out of the program (U.K. NAO, 2020).

Similarly, a review of MHR in Australia found that, while there is strong support for the system among patients, researchers, government organizations, and health practitioners and organizations, there is also a commonly held perception that the benefits of MHR are not well understood by either health practitioners or patients (McMillan, 2020). An interview with Tim Shaw — Professor of Digital Health and Director of the Research in Implementation Science and eHealth (RISE) group in the Faculty of Medicine and Health at the University of Sydney — echoed this view, noting that the initial development and implementation of the MHR system failed to sufficiently involve either the general public or health providers, and did not communicate the value that data sharing through MHR would provide (T. Shaw, personal communication, 2022). By contrast, according to Jensen and Thorseng (2017), one of the reasons Denmark's sundhed.dk portal is so successful is because it engaged a wide range of stakeholders in the early stages of development, which helped legitimize the system. Indeed, the initial phase of sundhed.dk was intentionally designed to demonstrate regional collaboration and common ambition.

## Ongoing public involvement and engagement can help maintain public trust

SAIL is often cited as an example of successful, ongoing public engagement that has helped develop and maintain public trust in the portal. SAIL established a Consumer Panel in 2011 that comprises 16 members of the Welsh general public who provide input and advice on the portal and its social acceptability (SAIL, 2021). Examples of recent discussion topics for this panel include the social acceptability of using mobile phone data for health research, and the use of child-related family court records for anonymized data linkage research. In addition, three members of the Consumer Panel also sit on SAIL's Information Governance Review Panel, which reviews all proposals to use SAIL data for research (Jones *et al.*, 2020). SAIL has also solicited feedback from Consumer Panel members to improve how the organization conducts its public engagement activities.

### 4.3.1 Incrementalism, Interoperability, and Incentives

Many countries have taken an incremental approach to implementing system-wide health data sharing. In many cases, incrementalism has been successful; however, if this approach is insufficiently forward-looking, it can lead to project failures.

## Centralized governance arrangements and forward-looking plans may be helpful in facilitating the adoption of interoperable data systems

The *Health Information Technology for Economic and Clinical Health (HITECH) Act*, passed in 2009, sought to promote the adoption and use of interoperable EHRs in the United States. It did so primarily by offering financial incentives for the adoption and meaningful use of certified EHRs, coupled with penalties for non-adoption (Holmgren & Adler-Milstein, 2017). Criteria defining meaningful use were released in three stages between 2010 and 2015, with each stage increasing the requirements for the use of health data: basic data capture in Stage 1, interoperability and data sharing in Stage 2, and improved patient outcomes in Stage 3 (Holmgren & Adler-Milstein, 2017).

While EHR adoption rates have increased since the passage of the HITECH Act, the extent to which Stage 1's meaningful use incentives contributed to that adoption and related technologies is disputed and unclear (Adler-Milstein & Jha, 2017).<sup>6</sup> More importantly, however, the act and its meaningful use incentives have been widely criticized for being insufficiently forward-looking with respect to

6 For example, a 2017 study found that hospitals that were eligible for the meaningful use incentives program had significantly larger increases in EHR adoption rates (11.1%) compared with ineligible hospitals (3.3%) following the introduction of these requirements (Adler-Milstein & Jha, 2017). However, other studies have found that such incentives had little impact on EHR adoption rates among office-based physicians (Mennemeyer *et al.*, 2016).

interoperability and data sharing (Menemeyer *et al.*, 2016; Halamka & Tripathi, 2017; Reisman, 2017). Although Stage 2's requirements include criteria related to interoperability and information exchange, far fewer health professionals and hospitals have met those requirements compared to those in Stage 1. While this is likely due to a myriad of factors, key among them was a failure to consider future interoperability requirements during Stage 1 adoption; this led to the creation of hundreds of different government-certified EHR systems to meet the Stage 1 requirements, most of which are not interoperable (Halamka & Tripathi, 2017; Reisman, 2017). As Halamka and Tripathi (2017) point out:

*Meaningful use set unrealistic expectations for interoperability. Though it did not specify a nationwide patient-matching strategy, create a nationwide directory of provider electronic addresses, forge a single set of consent or privacy guidelines, or define governance for deciding who could exchange what for various purposes, it set requirements with the assumption that interoperability could somehow skip over such essentials.*

Taiwan also rolled out its health data sharing plan in stages, with an early-stage focus on EHR adoption followed by a later-stage focus on interoperability. Stage 1 developed and promoted the project; Stage 2 focused on increasing the adoption of EHRs in hospitals and clinics; and Stage 3 focused on developing interoperability and information exchange (Wen *et al.*, 2019). In addition — similar to the United States — Taiwan used financial incentives to encourage hospitals' participation, such as bonuses for hospitals that upload a sufficient amount of comprehensive, high-quality data (Chiang & Chang, 2019). Moreover, there are penalties for failure to properly use the system; for example, if the rate of unnecessarily repeated prescriptions exceed a certain threshold, or if an examination is repeated without querying the system first, the hospital will not be reimbursed for the expenses incurred (Chiang & Chang, 2019).

In contrast to the U.S. approach, Taiwan's has largely been successful; as of 2016, approximately 80% of hospitals and 54% of private clinics in Taiwan had interoperable EHRs. In the Panel's view, the differential success between these countries is due in part to the fact that, early in the process of its roll-out, Taiwan established a centralized governance body — the EMR Development Committee — to develop and implement its interoperability plan and “draft policies for promoting EMR systems, establish relevant exchange and communication standard specifications, approve annual plans and assess the results” (Li *et al.*, 2015). The 20-member committee is composed of 6 government officials, 10 representatives from the health industry (including hospitals), and

4 representatives from research institutions, and it is chaired by the Deputy Minister of Health and Welfare (Li *et al.*, 2015). Taiwan’s collaborative, multisectoral governance arrangement appears to have been sufficiently forward-looking with respect to interoperability, which avoided the problems experienced in the U.S. implementation. Israel is also taking an intersectoral, community-based approach to governance in its attempt to develop and implement new interoperability standards across its health system (Section 4.1.5).

### Under-developed implementation plans and frequently changing strategies can create barriers to adopting interoperable data-sharing systems

As the U.S. and Taiwanese examples demonstrate, achieving system-wide interoperability can be difficult if it is not built into plans from the beginning. In other words, while incremental progress in the short term can be useful, the lack of a long-term plan (or constantly changing plans) can make it harder to achieve longer-term goals. This was the experience in the United Kingdom, where an audit by the NAO found that the NHS’s failure to develop and implement a concrete plan to achieve interoperability in the short or medium terms made it much more difficult to achieve that interoperability in the longer term (U.K. NAO, 2020).

Specifically, the NAO assessment found that achieving interoperability of data and IT systems across the NHS was difficult because of previous failed attempts to implement interoperability standards, which resulted in “the use of multiple standards or different versions of the same standard” (U.K. NAO, 2020). Moreover, those attempts failed because there was no clear, fully developed plan for achieving interoperability, including a lack of clear schedules or timeframes, a lack of standards development, and potential tensions between interoperability goals and the NHS’s plan to increase the number of different health technology vendors. To address these challenges, the NAO recommended (i) developing a detailed plan for the implementation of interoperability standards (with specific objectives and measurable actions), one that is realistic about the time and investment required, with clearly identified responsibilities of local NHS organizations and the support available to them; and (ii) having a clearer conception of the total cost of digital transformation, including the development and implementation of interoperability and data standards (U.K. NAO, 2020).

## Incentives and penalties are often necessary to encourage the adoption of data-sharing technologies and discourage practices that inhibit data sharing

As noted above, financial incentives and penalties can encourage health professionals and organizations to adopt health data sharing systems and infrastructure.<sup>7</sup> Such incentives are often necessary because, as Taiwan found when implementing interoperability, it was more difficult to convince hospitals to participate in the EMR exchange than it was to implement their own EMR systems “because sharing medical records with other hospitals or clinics does not produce a financial incentive” (Li *et al.*, 2015); this necessitated the need for financial bonuses and penalties.

In addition to offering financial incentives to encourage interoperability, the United States also uses financial penalties for practices that discourage interoperability, such as “designing products with limited interoperability or by charging high fees for providing HIE [health information exchange] capabilities” (Reisman, 2017). A report by the Office of the National Coordinator for Health Information Technology found “there is little doubt that information blocking is occurring and that it is interfering with the exchange of electronic health information” (ONC, 2015). EHR vendors and health organizations may be tempted to block interoperability because “data have become more of a commodity and competitive advantage than a basis for coordinated care” (Reisman, 2017). To address these challenges, the United States passed the *21st Century Cures Act* in 2016, which included financial penalties of up to US\$1 million for technology developers, vendors, networks, and providers engaging in any action “that may inhibit the appropriate exchange, access, and use of electronic health information” (Reisman, 2017). Notably, the Competition Bureau of Canada recommended implementing similar anti-blocking rules for bodies that discourage interoperability across Canada’s health systems (ISED, 2022).

7 In Canada, Infoway has attempted to incentivize the adoption of national standards via funding mechanisms (Section 5.2).

### Periodic reviews of incentives can help identify improvements to drive adoption

The Government of Australia has encouraged health providers to use MHR through the Practice Incentives Program eHealth (ePIP) initiative, which offers incentive payments to general practices for adopting digital health technologies, including uploading shared health summaries to MHR (Services Australia, 2016). While participation in the MHR system is automatic for residents unless they opt out, participation by health professionals and organizations is voluntary and based on an opt-in system (McMillan, 2020). However, despite the voluntary nature of MHR for health professionals and organizations, there is a high degree of participation; as of November 2022, 99% of general practitioners, 99% of pharmacies, and 97% of public hospitals were registered and using the system. However, only 30% of specialists were registered in the system, and only 13% had actually used it (MHR, 2022).

A review of the legislation that created the MHR system found that common criticisms were related to the outdated and patchy information in many records, its uneven use among some categories of health providers, and a lack of integration and interoperability across multiple health information systems (McMillan, 2020). To address these challenges, the review recommended that the government examine the ePIP initiative to determine whether it is helping achieve MHR objectives, or whether incentive payments should be tied to different general practice activities to better support and strengthen MHR. In particular, the review also suggested considering additional incentives to increase citizen participation, core clinical content, and adoption among health professionals (McMillan, 2020).

### While incentives can drive the adoption of data-sharing technologies, it is unclear whether they increase the quality of patient care

Although the adoption of a health data exchange system has been largely successful in Taiwan, a 2019 report found that the ratio of uploads to downloads of EMR data on the EEC was about 81:1 — meaning that, for every 81 EMRs uploaded by hospitals, only 1 was downloaded by health professionals for medical purposes (Wen *et al.*, 2019). In addition, though the volume of health data sharing has increased in Taiwan due to the EMR exchange system, the extent to which the EEC has contributed to increasing the quality of patient care “is still unclear and worthy of further study” (Wen *et al.*, 2019).



## Mandating data sharing among health organizations is an alternative to incentives

While Australia, Taiwan, and the United States have all offered financial incentives (and penalties) to encourage health providers to adopt data-sharing technologies, other jurisdictions have attempted to drive progress on data sharing through legislative mandates. In 2022, for example, the United Kingdom enacted the *Health and Care Act 2022*, which imposes a duty to share information on health organizations for the purpose of providing care (Gov. of U.K., 2022a). The act also contains several provisions related to mandating or requiring data sharing or access, as well as the adoption of data-sharing standards by private health providers. These include:

- allowing the Secretary of State for Health and Social Care to require health and adult social care organizations to provide information about themselves, their activities, the services they offer, and the individuals to whom they provide those services, for the purposes of system planning and oversight;
- allowing health and adult social care public bodies to require the provision of anonymized information from other such bodies, as well as private bodies commissioned to provide these services;
- altering NHS Digital’s legal framework, including clarifying its ability to access data for any purposes “connected with the provision of health care or adult social care services” and the promotion of health;
- allowing NHS Digital to compel private health organizations to provide data for the purpose of complying with an information-collecting directive from the Secretary of State for Health and Social Care;
- allowing the Secretary of State for Health and Social Care to mandate data standards for public and private bodies that provide health and adult social care; and
- allowing for the introduction of regulations that impose financial penalties on private health or social care providers that fail to implement a mandated data standard or provide information (or who provide false or misleading information) (Gov. of U.K., 2022a).

Moreover, the U.K. government has indicated that it plans to make legislative amendments to the *Health Services (Control of Patient Information) Regulations 2002* to “facilitate timely and proportionate sharing of data — including, where necessary and appropriate, personal information — for the purposes of supporting the health and care system” (Gov. of U.K., 2022b).

### Incremental approaches often work by expanding the types of data that are linked or shared

Frequently, countries will slowly expand the types of data that are linked or shared when they undertake health data sharing initiatives. Generally, most countries begin with some kind of care summary or medication records, then gradually add more connections. For example, Denmark's National Health Record includes information related to hospital admissions, lab results, and prescription information. Health records from general practitioners, municipalities, and private healthcare providers were not included, and Denmark committed to address this in its 2018 digital health strategy (Gov. of Denmark, 2018). Taiwan's MediCloud and My Health Bank systems originally included only a limited variety of medical records when it was launched in 2014 (Huang *et al.*, 2017); however, the number of record types available has since expanded (Gov. of Taiwan, 2021). Similarly, Taiwan's EEC was initially developed to allow hospitals and clinics to exchange information, but the Ministry of Health and Welfare has advocated for extending that connection to administrative record systems in other government agencies, including "the Bureau of Labor Insurance (Ministry of Labor), MOHW's Centers for Disease Control, National Aeromedical Approval Center and MOHW's Department of Mental and Oral Health" (Gov. of Taiwan, 2021).

#### 4.3.2 Lessons Learned from Health Data Sharing in the United Kingdom

The NHS first identified the importance of health data sharing and the need for national data sharing standards in 1998 (U.K. NAO, 2020). In the subsequent 25 years, the United Kingdom made several attempts to improve health data sharing, with mixed success. In 2020, a report by the NAO found that "the track record for digital transformation in the NHS has been poor, with the previous major national programme [National Programme for IT] being closed early without achieving its objectives" (U.K. NAO, 2020). However, the United Kingdom has also learned from its previous attempts and devoted significant time and resources to diagnosing and understanding the reasons these plans failed.

The National Programme for IT was launched in 2002 with the goal of making a patient's care record available to health professionals caring for that patient. The program was cancelled in 2011 and, in 2016, a review was commissioned to identify the reasons for its failures (U.K. NAO, 2020). The resulting Wachter report, released in 2016, identified six key problems: (i) a lack of engagement with clinical staff, combined with an overemphasis on technological change and not enough attention to service changes and workforce adaptation; (ii) a centralized,

top-down approach to implementing IT systems with insufficient support for local organizations and professionals; (iii) a rushed deployment of the program with unrealistic expectations, which was felt to be politically driven; (iv) a lack of central support for NHS trusts;<sup>8</sup> (v) problems with procurement and contracting arrangements; and (vi) frequent changes in leadership and a lack of skilled personnel (Wachter, 2016; U.K. NAO, 2020; Keith *et al.*, 2022).

In 2019, the NAO assessed progress made by NHS national bodies in mitigating the issues identified in the Wachter report. It found that, while some progress was made, challenges and risks remain in all the identified areas (U.K. NAO, 2020). The audit also identified several additional challenges with the United Kingdom's digital transformation, including:

- insufficient financial investments from the government to achieve the goals it set, and uncertainty about whether currently planned future investments would be sufficient;
- frequently changing national strategies that contributed to a fragmented digital environment and a proliferation of “legacy” IT systems (i.e., systems that are currently in operation, but which have been superseded by other technologies or changed business needs); and
- a lack of specialist skills in the health workforce, and a lack of plans to improve digital skills development.

<sup>8</sup> NHS trusts are public sector bodies that provide health services in the NHS and typically serve a particular region or function, such as a hospital, a community, or mental healthcare (NHSP, 2015).

# 5

## **Legal and Regulatory Opportunities to Strengthen Canada's Health Data Sharing Approach**

- 5.1 Toward Data Stewardship: Data Management Approaches to Protect Data and Promote Their Exchange
- 5.2 Harmonizing Health Data Governance Under Canadian Federalism

## Chapter Findings

- A shift from a custodianship model to a stewardship model of health data management and governance may require legal reformation, but there are opportunities to make this shift within the confines of current regulatory regimes.
- The realization and sustainability of data stewardship requires a governance model that is participant-centric, which demands the engagement of data subjects and other stakeholders in establishing data-sharing rules.
- Given the “culture of caution” among data custodians, clear and coordinated guidance under current privacy regimes could increase flexibility and improve responsible data sharing.
- Organizational opportunities are available for FPT governments to exercise their leadership roles in enhancing health data sharing in Canada.

By imposing restrictions on data collection, use, and disclosure, Canadian privacy law creates compliance challenges for data custodians. Although legislation can mitigate risk by making liability more manageable, Canada's privacy regimes have generally not had this effect. The relative complexity of privacy laws — which may vary by province and territory — and the lack of clear policy guidance can exacerbate risk aversion among stakeholders (Infoway, 2023c). One intuitive course of action that is often considered is privacy law reform.<sup>9</sup> The legal reform needed to enhance health data sharing is a complex issue that questions whether, and to what extent, the data management and governance options that appeal to stakeholders conflict with the existing legal rules. There is conditional public support for health data sharing, but that support is compromised by data breaches and cyber-attacks on datasets governed by varying degrees of transparency (Ghafur *et al.*, 2020; Cumyn *et al.*, 2023). Privacy law reform at FPT levels that give the impression of liberalizing data custodianship is therefore extremely difficult. In the Panel's view, the effort to enhance health data sharing cannot solely rely on legal reform; rather, the *approach* to privacy law as it is currently formulated requires rethinking.

9 In their report to PHAC, Bernier *et al.* (2021) provided an extensive review of the laws governing data protection in each Canadian jurisdiction, with particular attention to laws enabling data use and disclosure for public health and research purposes. Besides encouraging public health institutions to exercise their existing legal powers to share data to their full extent, the authors provided legal reform recommendations that would improve data flow. In this chapter, the Panel is careful not to duplicate the work already done by Bernier *et al.* (2021).

The risk aversion conditioned by complexity, variation, and unclear guidance in privacy law has generated a “culture of caution” that impels data custodians to approach data management more conservatively than may be necessary by law (Sethi & Laurie, 2013). Indeed, legal reform efforts can distract from more pragmatic solutions that are possible within the broad parameters of current legal architectures; addressing this cultural problem necessitates “a deeper understanding of how to operate *within* those parameters.” Interpreting privacy laws more flexibly can enhance data sharing by addressing the established set of principles that underpin legislative regimes — namely, individual privacy protection and population health promotion. As expressions of “the values and norms to be considered *in addition* to the legislative demands upon different actors,” principles can guide stakeholders’ activities and judgments in sharing health data (Sethi & Laurie, 2013).

Ultimately, the way in which these principles are articulated shapes how risk of non-compliance with privacy law is perceived — whether it is to be avoided at all costs (as in a custodianship model of governance, or a culture of caution) or shared by stakeholders (as in a stewardship model, or a possible culture of collaboration and coordination). There is opportunity in the latter, but it would rely on national leadership to establish a standard structure that harmonizes health data systems in accordance with a common framework of guiding principles. A national body authorized to set technical and privacy-related standards can increase transparency in data sharing. Establishing such leadership would depend on governments at all levels approaching federalism in a more collaborative way.

## 5.1 Toward Data Stewardship: Data Management Approaches to Protect Data and Promote Their Exchange

The dominant model for health data governance — the process by which data management methods are conceptualized and put into effect (Rosenbaum, 2010) — has traditionally been the *data custodianship* model, in which the focus is on keeping data protected and secure from unauthorized access. However, there has been a shift toward a *data stewardship* model of governance, in which privacy and security considerations are balanced, and where access to data is made a much higher priority (CCA, 2015). This shift has been driven by both the increase of digital health technologies and greater acknowledgement that the custodianship model may create unnecessary barriers to data sharing. It has been argued that the data custodianship model is “the systemic problem that underlies issues with data interoperability and access to health records in Canada” (Mehta, 2019). Enhanced

data sharing demands a transition toward a stewardship approach to data management, one that emphasizes balance, trust, interoperability, and cohesion (PHAC, 2021a, 2021b).

New sharing initiatives and technologies are emerging to help data stewards meet their dual responsibilities of protecting data and promoting their exchange. Ultimately, the successful dissemination of these initiatives and technologies depends on broad acceptance — by governments, custodians, and the public — of a risk spectrum that permits nuance in data management decision-making, and perhaps reduced control over data by custodians. Data stewardship models have been found to have advantages over data custodianship models for health research in Canada by reducing the time and cost of the research, as well as by providing researchers with greater flexibility in their investigations (Katz *et al.*, 2018).

### 5.1.1 Protecting Privacy Interests

Privacy laws and the data security efforts they compel — or are thought to compel — in data sharing for secondary uses have established a custodianship model of data management that combines risk aversion and discretion in information sharing. Absent any rules mandating disclosure, data sharing under this model is approached as an avoidable risk by relying on data categorizations and consent, or on data de-identification.<sup>10</sup> Without addressing how these mechanisms impact data management strategies, expecting custodians to change their posture toward data sharing is unrealistic. The risk environment of health data sharing needs to be addressed.

Privacy laws tend to create “nebulous categories of data” that are bound by definitions and their corresponding rules; this is particularly true of genomic data in Europe, where privacy law now distinguishes between “genetic data” and “data concerning health” (Dove, 2018). With the introduction of “the results of a genetic test” as a legal category in the enactment of the *Genetic Non-Discrimination Act*, Canadian law implicitly makes this distinction, albeit narrowly applying it to the provision of services. The utility of such categorization is uncertain; it could cause further confusion about what is captured by different categories, or disregard data subjects’ expectations about their valued data objects (Dove, 2018). For instance, although “genetic data” and “data concerning health” are both considered sensitive, the distinction “fuels concerns of persistent genetic exceptionalism in regulation” (Dove, 2018). Thus, the distinction introduces categories that may not resonate with data subjects’ concerns about their privacy while increasing ambiguity for data custodians.

<sup>10</sup> Although the terms de-identification and anonymization may refer to distinct processes (depending on the author or jurisdiction), unless otherwise indicated, this chapter uses de-identification to refer to either.

Aside from the recent categorization of genetic data mentioned above, Canadian privacy regimes have resisted the inclination to categorize data by type, only going so far as to distinguish “personal information” and “personal health information.” Yet even with such a broad category, the binary approach of determining whether data can be shared on the basis of “identifiability” presents problems for custodians by largely eliminating the spectrum of risk from consideration and, therefore, flexibility from data management. Importantly, there are mechanisms within privacy legislation that offer custodians flexibility by exempting disclosure from consent requirements.

In Ontario, for example, custodians are permitted to disclose personal health information without consent in various prescribed circumstances, including but not limited to approved research purposes, exchange with prescribed entities, and exchange with a person maintaining a registry of personal health information (Cavoukian, 2004). In the case of the Canadian Institute for Health Information (CIHI), for instance, its status as “a secondary data collector of health information, specifically for the planning and management of the health system” facilitates its collection of health data shared by custodians across the country because provincial and territorial privacy legislation authorizes the disclosure of personal health information without consent for purposes consistent with CIHI’s uses (CIHI, 2019). Exemptions are important legal mechanisms that can be harnessed to help maximize the benefits of health data sharing by permitting discretion.

Where a specified exemption in federal or provincial/territorial privacy law does not apply, sharing personal health information (i.e., identifiable data) requires either the patient’s consent or the de-identification of the data (see Bernier *et al.* (2021) for a legislative review).<sup>11</sup> Although consent and de-identification create circumstances in which health information may be shared, their effectiveness has been challenged as imaginary mechanisms of privacy protection that mislead stakeholders. On one hand, by “superimposing ... consent for choice,” the “Consent Myth” gives the appearance that individual autonomy has been advanced and, by implication, that privacy has been protected (Tschider, 2019).<sup>12</sup> In reality, consent may be less of a reflection of an individual’s choice than one might assume, especially where privacy policies come in the form of “contracts of adhesion” and assume the consumer has fully read and understood the terms and risks after being notified of data collection and use (Tschider, 2019). On the other hand, data de-identification may be a manifestation of the “sanitization pipe dream” that datasets of useful but sensitive information can be de-identified and also yield accurate answers (Dwork & Pottenger, 2013; Rubinstein & Hartzog, 2016).

11 For example, Ontario’s *Personal Health Information Protection Act* (PHIPA) provides that “once de-identified, in a manner such that it falls outside the scope of PHIPA, the information may then be used and disclosed for secondary purposes, without the consent of the individual” (IPC, 2011).

12 On the implications of big data for informed consent, see Froomkin (2019).



Some have argued that cases of data re-identification demonstrate the failure of de-identification, claiming that “time and again, both in the real world and in the scientific literature, sanitization fails to protect privacy” (Dwork & Pottenger, 2013; see also Ohm, 2010). However, this view is misleading insofar as it is based on re-identification cyber-attacks of datasets that were merely pseudonymized or not sanitized in accordance with existing standards, as revealed by a systematic review of the evidence (El Emam *et al.*, 2011). Importantly, a more conservative estimation of the respect afforded to individual autonomy via consent and data sanitization is consistent with patients’ perspectives (Box 5.1).

### Box 5.1 The Public’s Nuanced View of Anonymization and Consent

Although the public considers the anonymization of health data to be important, it also considers the process to be both insufficient to fully protect privacy (Aitken *et al.*, 2016; Paprica *et al.*, 2019b) and a potential barrier to research (Aitken *et al.*, 2016). While some studies have found mixed views on the need for consent even when data are anonymized (Paprica *et al.*, 2019b), other studies have found that the issue of consent “may not be a fundamental requirement for public acceptability” (Aitken *et al.*, 2016) and that, when participants can discuss and reflect on consent, their views tend to shift away from an initial preference for an opt-in model, toward a more flexible opt-out or varied consent model. These findings may suggest that, “rather than focusing on which consent mechanisms are most favoured by members of the public, it may be more valuable to focus on how relationships of trust are built up (and conversely eroded) and how trust can be facilitated within research and data-sharing or data-linkage processes including through public/patient engagement or involvement” (Aitken *et al.*, 2016).

One alternative to direct consent is *authorization* — currently used in the United Kingdom and elsewhere — wherein a body of experts provides advice and guidance on data access requests when neither consent nor anonymization is feasible (Aitken *et al.*, 2016). However, there is little public awareness of, or literature engaging with, authorization as a data governance mechanism. In practice, notice of privacy practices can amount to an alternative to direct consent by bundling terms and conditions in an agreement before service provision (see Tschider (2019), discussed in this section).

Technologies are emerging that may facilitate the management of privacy risks. Blockchain-based smart contracts may improve transparency by empowering patients to view and update the accessibility of their data, perhaps introducing increased autonomy in consent (Mann *et al.*, 2021). Synthetic data — “data that has been generated from real data and that has the same statistical properties as the real data” — have proven useful to solving challenges in accessing personal health information caused by privacy regulations (El Emam *et al.*, 2020). Federated learning (i.e., the collaborative training of a machine-learning model without a collaborator’s data leaving their control) may enable AI applications in healthcare without compromising privacy (Sheller *et al.*, 2020).

There are opportunities to improve privacy regimes by expanding beyond de-identification as a primary strategy. As Rubinstein and Hartzog (2016) suggest, a “process-based approach to minimize risk” — rather than an “output regime,” in which data security efforts are sanctioned “so long as the information is made anonymous” or protected, such that the risk of re-identification is minimal — is a fruitful way to advance data-sharing policy. Without abandoning de-identification, the regulatory focus might shift to the data controls contributing to the process of risk minimization, namely the spectrum of statistical disclosure limitation techniques: direct access, dissemination-based access, and query-based access (Rubinstein & Hartzog, 2016). In this way, de-identification is supplemented, not replaced. Yet given the risk of legal non-compliance caused by the indeterminacy of identifiability (Bernier & Knoppers, 2021), a process-based regime would depend on concretizing the notion of “identifiability.” The inherent ambiguity of data identifiability as a qualitative determination can be resolved by privacy regulators introducing guidance that assigns quantifiable re-identification risk scores to the standard of identifiability (Bernier & Knoppers, 2021). Reducing the ambiguity of the meaning of identifiability can increase the predictability of laws and a regulated entity’s compliance.

**Introducing new *tiers* to data protection and access would help data custodians better manage risk; however, discretion would have to be clearly authorized in privacy laws and policies**

Where opportunities for discretion in data sharing exist under applicable privacy laws, its exercise by custodians could be promoted by facilitating risk assessment for varying levels of *sensitivity*. A risk management approach to data protection and access implies that significant weight is given to the sensitivity of the data at issue. Levels of data sensitivity may be determined by using a “data sharing privacy test” that assesses “privacy impact” according to (i) the data’s sensitivity; (ii) the potential harm resulting from re-identification; and (iii) the subject’s expectations concerning their data (Dyke *et al.*, 2016b).

In this approach, heightened protection does not necessarily apply to any data categorized as “sensitive.” As a tiered mechanism, levels of protection may range from minimal to stringent (Dyke *et al.*, 2016b). The analysis considers points based on socioeconomic and cultural factors, which will vary depending on context. For example, ethnicity data about small or vulnerable groups should receive higher protection because of the higher potential for stigmatization or discrimination; however, determining a group's size or vulnerability requires analysis of the local political and social context (Dyke *et al.*, 2016b). Although consent would still enter into the third stage of the test, data-sharing decisions would be more flexible, given that they are contextually informed.

By considering the sensitivity of data, other opportunities to make data sharing more efficient become possible — for instance, by using a tiered protection mechanism. Where data are deemed less sensitive, their accessibility may be eased through a new data access tier: “registered access” (Dyke *et al.*, 2016a, 2018). By introducing a novel tier between the “open access” and “controlled/restricted access” tiers, the traditional binary approach to data protection and sharing is expanded (Dyke *et al.*, 2016a). Moreover, registered access simplifies the review procedure mandated by controlled access systems. Data access compliance offices (DACOs) — bodies within health information organizations responsible for receiving and reviewing requests for access to their data holdings — may rely on the qualifications of applicants for access to data, rather than having to review the merits supporting requests, as required for controlled access datasets (Dyke *et al.*, 2016a).

A “layered” registration system can create two procedures for researchers or clinicians to demonstrate their status, either directly or by way of a voucher from another registered user (thereby making registered access possible for those without publications or institutional employment) (Dyke *et al.*, 2018). The review for registered access focuses on the data user's trustworthiness (a determination of whether they are *bona fide*), allowing DACOs to impute the safety of the project, security infrastructure, and output (Dyke *et al.*, 2016a). On this basis, unilateral contractual commitments may be entered by data users via clickwrap-type online agreements, thereby expediting the process to execute agreements among data-sharing parties compared with traditional data transfer or access agreements (Dyke *et al.*, 2016a).

The “Five Safes” framework similarly emphasizes the trustworthiness of requests for access to data using one of five dimensions: safe people, safe projects, safe data, safe settings, and safe outputs. Considered jointly, these dimensions enable more thoughtful determinations about data access for research, thereby increasing access while also better protecting data (Desai *et al.*, n.d.). Access to data through the Data Innovation Program, which links and de-identifies data from ministries and organizations in British Columbia, is based on the Five Safes framework.

### 5.1.2 Promoting Trust and Other Public Interests Through Data Governance

Without public trust in the data-sharing foundation, advanced information technologies for collecting, using, and sharing health data are likely to meet resistance. For instance, without some form of public consultation, digital technologies deployed in epidemiological interventions (e.g., contact tracing apps on smartphones) may be viewed by end-users as unacceptably invasive (Parker *et al.*, 2020). To prevent mistrust in health data systems, it is “crucial to promote open dialogue with stakeholders, codesign of technologies, careful assessment of the enabling context, and meaningful involvement with vulnerable individuals and marginalized groups” (Ferretti & Vayena, 2022). The implementation of machine-learning models in clinical settings, discussed below, may be facilitated with similar end-user engagement to develop trust (Verma *et al.*, 2021).

#### A sustainable data-sharing ecosystem is built on trust and the accommodation of multiple interests in data — not on competing rights claims to data

Akin to a fiduciary role, the data steward is expected to be loyal to data subjects’ interests (Rosenbaum, 2010). This requires them to know those interests, which in turn demands their engagement. The sustainability of data sharing is contingent upon the governing model’s participant-centricity, reflected by data-sharing rules that are established with reference to the system’s orientation around its subjects and its own trustworthiness (Deverka *et al.*, 2017; McGuire *et al.*, 2019). There is reason to suggest that improvement in this regard is necessary.

Regardless of whether they are legally valid, claims to data rights suggest that competing interests occupy Canada’s health data ecosystem. Data ownership is a powerful metaphor, one that indicates stakeholders’ understanding of their relationship to data and potentially suggests the presence of “competing narratives towards and around data sharing” (Sorbie *et al.*, 2021). Indicative of this is the “commercialization of patient data in Canada,” whereby de-identified patient data are disclosed by pharmacies, private drug plans, and EHRs, and used by commercial data brokers — all without consent (Spithoff *et al.*, 2022). Such circumstances create the perception that personal data ownership is a means by which patients can protect themselves from data harms, as reflected by academic advocacy for the data ownership model (Kish & Topol, 2015; Cohen, 2021).

This view may be particularly appealing where commercial entities — with which the public is generally less keen to share personal health information (Paprica *et al.*, 2019a) — could be entitled to ownership-like rights for *proprietary data* (see Scassa, 2022). In this way, federal and provincial/territorial laws may foster division and competition among stakeholders, rather than trust and cooperation. However, federal privacy legislation currently under consideration could restrict commercial entities from sharing de-identified personal health information without consent, with the exception of disclosure “for a socially beneficial purpose” (House of Commons of Canada, 2022). Despite their enthusiasm for this restriction on health data exchange, Spithoff *et al.* (2022) suggest the bill does not do enough to restrict commercial entities’ use of these data. As such, trust may remain an issue for health data sharing with the private sector.

### Governments may face similar issues of trust, particularly among marginalized populations

Race and ethnicity are important factors to account for to ensure that Canada’s health data system performs equitably and effectively. For instance, because privacy preferences may differ by race, consent policies (i.e., opt-in or opt-out) can exclude certain groups from participating in data-sharing initiatives, thereby determining who benefits from improved health services (Turvey *et al.*, 2020).<sup>13</sup> As observed during the COVID-19 pandemic, contact tracing efforts were hindered by the distrust of government among some minority populations, a sentiment rooted in centuries of racism within governments and the medical research community (Landau, 2021). Some people’s willingness to use a contact tracing application was largely determined by their perception of how likely data would be shared with certain government agencies (Landau, 2021).

An important precondition of trust in health data systems is inclusion in its governance. As Rowe *et al.* (2021) observe, “Indigenous health information is often produced and perpetuated by non-Indigenous Peoples for non-Indigenous health policy makers, which results in fragmentation and a continued need for Indigenous activism.” Data-sharing initiatives that respect Indigenous<sup>14</sup> data sovereignty can enhance trust by increasing the voices of Indigenous peoples via collaboration. For example, integration of the First Nations OCAP<sup>®15</sup> principles (ownership, control, access, and possession) and other guidance in the

13 On the importance of incorporating diversity into datasets, see Hindorff *et al.* (2018).

14 *Indigenous* refers to the first inhabitants of what is now Canada (i.e., First Nations, Métis, and Inuit). It is important to note that these groups are culturally distinct; therefore, data sovereignty must be conceived with nuance.

15 OCAP<sup>®</sup> is a registered trademark of the First Nations Information Governance Centre (FNIGC). To fully understand these principles, see their website at <https://fnigc.ca/ocap-training/>.

development of the First Nations Health Authority (FNHA)<sup>16</sup> overdose surveillance system — established in response to British Columbia’s public health emergency, beginning in 2016 — was the result of a collaborative partnership among the FNHA, the British Columbia Centre for Disease Control, and the Ministry of Health (Sabeti *et al.*, 2021). As the data steward of First Nations whose leaderships give it direction, the FNHA enables self-determination, which in turn builds trust.

The research community also faces trust issues, especially in relation to Indigenous peoples. Compared to the general public, which tends to support data sharing for research purposes (Section 2.3), Indigenous individuals, communities, and organizations are less willing to participate in studies due to the history of exploitation of Indigenous health data by researchers (James *et al.*, 2014). Many Indigenous groups hold that genomic data are collectively owned (Garrison *et al.*, 2019), which complicates data-sharing relations further. Building trust, enhancing accountability, and improving equity are efforts that will need to be made by research institutions and researchers themselves, in order to respond to Indigenous rights and interests in genomic data (Hudson *et al.*, 2020). When it ratified the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP),<sup>17</sup> the federal government formally recognized Indigenous data sovereignty and governance as essential rights, adding legislative force to previously established principles intended to guide research with Indigenous peoples as provided in guidelines (e.g., Tri-Council Policy Statement 2) and OCAP.<sup>®</sup> Indigenous groups have been leading efforts in the governance of Indigenous data (Walker *et al.*, 2005), which may provide models for implementing UNDRIP. Following UNDRIP principles, the First Nations Information Governance Centre developed a promising data governance strategy (PHAC, 2022) (Box 5.2).

16 British Columbia’s FNHA is the first province-wide health authority in Canada, responsible since 2013 for programs and services formerly delivered by Health Canada.

17 On June 21, 2021, the *United Nations Declaration on the Rights of Indigenous Peoples Act* (UNDRIP) received Royal Assent, creating a legislative framework to implement UNDRIP in Canada.

## Box 5.2 A First Nations Data Governance Strategy: The Path to Data Sovereignty

Indigenous data sovereignty is key to dismantling state policies on Indigenous data that emphasize Indigenous difference and perpetuate the narrative of Indigenous peoples “as a deficit and problematic sub-population” (Walter & Carroll, 2020). Indigenous governance operationalizes Indigenous data sovereignty, incorporating Indigenous rights and interests in decision-making about Indigenous data (Walter & Carroll, 2020). The First Nations Information Governance Centre (FNIGC) has put forward the *First Nations Data Governance Strategy*, which enables First Nations to “harness their information and leverage meaningful and reliable data, from all sources” (FNIGC, 2020). This relies on establishing a national network of regional, First Nations-led data hubs using a bottom-up (as opposed to top-down) approach to implementation in order to meet local needs and priorities.

Importantly, Indigenous data sovereignty has a role to play in improving health outcomes. According to the FNIGC, a first step toward addressing health and socioeconomic disparities between Indigenous and non-Indigenous people in Canada is to “clos[e] the gaps in data and information.” As the FNIGC suggests, “it is essential for First Nation governments to be in a position of authority and have control over their data and all research that pertains to their people as a distinct Indigenous society” (FNIGC, 2020). By giving effect to a distinctly First Nations approach to the stewardship of data about First Nations people, the *First Nations Data Governance Strategy* makes possible self-determination in relation to health.

## Legal and policy reform aimed at enhancing data sharing in Canada may be guided by a right to science

A *right to science* can be understood as the idea that everyone has the right to “share in scientific advancement and its benefits” (Knoppers & Thorogood, 2017). As an obligation — one deriving from international law that Canada agreed to implement when it joined the United Nations’ *International Covenant on Economic, Social and Cultural Rights* — “the content of this human right has universal force and its ‘actionability’ can reach beyond the moral appeals of bioethics” (Knoppers & Thorogood, 2017; see also Petitgand *et al.*, 2019). Given big data’s promise to improve health outcomes, along with advancements in data security, failure to equitably enhance data sharing in Canada may be considered both an ethical issue as well as a compliance issue.

Although international in scope, the Global Alliance for Genomics and Health (GA4GH) has centred the right to benefit from science in its approach to developing a platform for sharing health data (GA4GH, 2023). Taking this right seriously “ensures a universal approach to balancing the benefits and potential risks” of data sharing with regulatory compliance issues in mind (Rehm *et al.*, 2021). By establishing standards and building tools that enable broad access to genomic and health-related data around the world, GA4GH exemplifies the importance of a leadership group dedicated to maintaining a cooperative data-sharing community — something intrinsic to any national data-sharing system.

## 5.2 Harmonizing Health Data Governance Under Canadian Federalism

The shift from a custodianship model to a stewardship model of data governance has been occurring on an organizational basis (CCA, 2015). However, as suggested by the EAG, this culture shift needs to expand in the form of “pan-Canadian health data policies” in order to generate a harmonized, national data-sharing system (PHAC, 2021a). Many health information organizations in Canada have begun to acknowledge that existing data governance structures are inadequate for facilitating the efficient sharing of health data. To help address these shortcomings, CIHI released its *Health Data and Information Governance and Capability Framework* in 2020, which is intended to assist health information organizations assess and improve their current data governance and capabilities, including their ability to effectively share data (CIHI, 2020). A pan-Canadian health data strategy requires a national health data governance framework that can facilitate cross-jurisdictional data sharing. In 2017, the OECD’s Council on Health Data Governance, in collaboration with health ministers in OECD countries, released a recommendation on developing such a health data governance system (Box 5.3).



### Box 5.3 OECD Principles for Health Data Governance

The OECD Council on Health Data Governance has recommended that countries develop a national health data governance framework based on 12 high-level principles:

1. Engagement and participation ... with a wide range of stakeholders
2. Co-ordination within government and promotion of cooperation among organisations processing personal health data, whether in the public or private sectors
3. Review of the capacity of public sector health data systems used to process personal health data to serve and protect the public interest
4. Clear provision of information to individuals
5. Informed consent and appropriate alternatives
6. Review and approval procedures, as appropriate, for the use of personal health data for research and other health-related public interest purposes
7. Transparency, through public information mechanisms which do not compromise health data privacy and security protections or organisations' commercial or other legitimate interests
8. Maximising the potential and promoting the development of technology
9. Monitoring and evaluation mechanisms
10. Establishment of appropriate training and skills development in privacy and security measures for those processing personal health data
11. Implementation of controls and safeguards
12. Require organisations processing personal health data to demonstrate that they meet national expectations for health data governance.

OECD (2022)

Although conceptual frameworks can help guide organizational and political decision-making, a successful pan-Canadian health data strategy will hinge on fundamental issues of Canadian federalism to ensure that federal and provincial/territorial governments are aligned in their approaches to health data governance. For an illustration of the different approaches to federalism and the opportunities they present for health data sharing, see Figure 5.1. For the data management opportunities discussed in this section to have systemic significance, the structural conditions of health data sharing — the accountability framework, and the policies, processes, standards, and architecture that underlie institutional decision-making about data collection, access, use, and storage — will need to be collaboratively addressed. In so doing, successful data governance — having “the right information, of the right quality ... available to the right person, for the right purpose, at the right time” (KPMG, 2018) — is made possible.

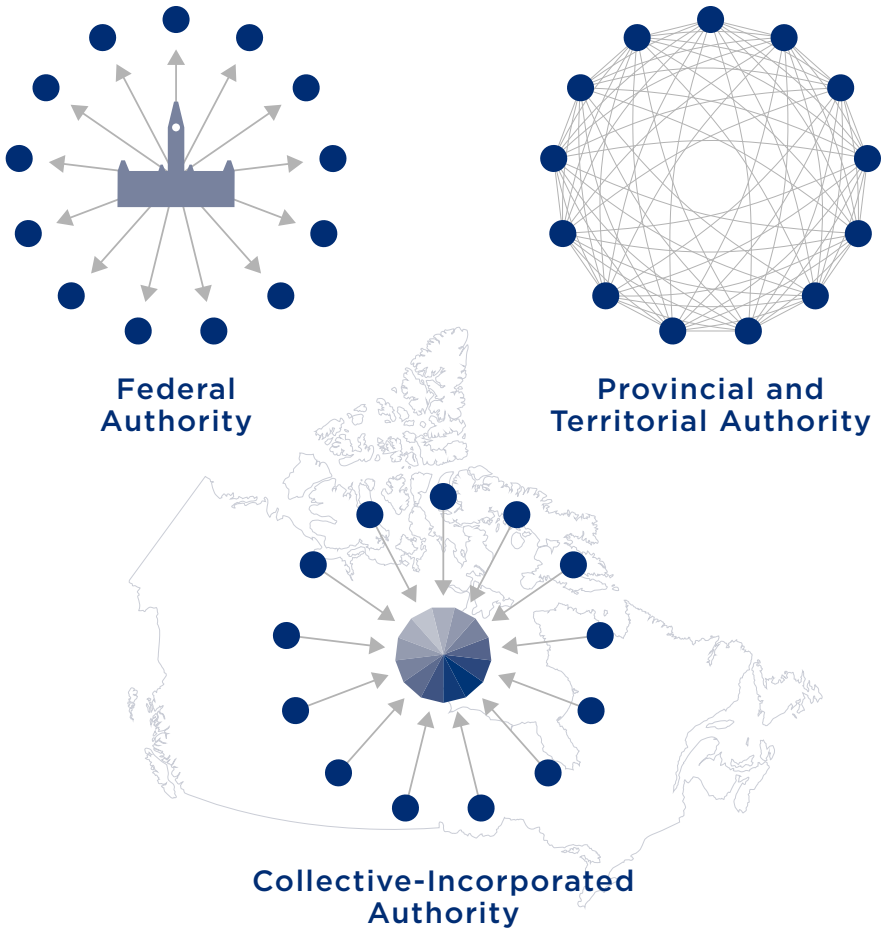
### A coordinated health data sharing system relies on a collective approach to data governance

Health data governance in Canada has been shaped by the country’s federalist structure. The fragmentation of health system governance under Canadian federalism has rendered FPT relations in healthcare a “troubled romance,” in which the federal government’s role is portrayed as residual (Flood *et al.*, 2017). Of course, the division of powers related to healthcare derive from Canada’s *Constitution Act, 1867*, which has been interpreted as providing the provinces and territories with primary jurisdiction over the delivery of healthcare. With respect to financing, jurisdiction is more divided, though a federal “spending power” has been recognized by provincial Courts of Appeal and the Supreme Court of Canada, providing the constitutional basis for the *Canada Health Act* (Flood *et al.*, 2017). As such, health data governance has been largely a provincial/territorial undertaking, without much consideration of the national implications of policy decisions.

Despite jurisdictions successfully entering into data-sharing agreements, developing national data standards, and co-investing in programs, a mechanism to ensure their coordinated implementation on a national scale has not yet been developed. Public health surveillance currently depends on FPT cooperation based on voluntary health data sharing. Likewise, health and equity surveillance efforts have been largely limited to clinical and administrative data-sharing networks among regional actors participating voluntarily.

An important exception to this is the governance model developed by CIHI, which connects health system databases across the country, in order to centralize and standardize clinical and administrative data via agreements between CIHI and the provinces and territories. These agreements stipulate “the purpose, use,

disclosure, retention and disposal requirements of personal health information provided to CIHI, as well as any subsequent disclosures that may be permitted” (CIHI, 2019). Although issues of data quality (e.g., accuracy, comprehensiveness, consistency) affect CIHI’s datasets (Lucyk *et al.*, 2017; Boulanger *et al.*, 2022), in the view of the Panel, it is a promising model to follow or expand upon. Gaps in data and analytic scope might be addressed by forming partnerships with health organizations, governments (FPT, municipal), and health professionals (Drummond *et al.*, 2021). For a discussion of other jurisdictions’ approaches to federalism, see Chapter 4.



**Figure 5.1 Three approaches to health data federalism, where a different authority is responsible for leading the governance of health data sharing**

A lack of inter-jurisdictional coordination in health systems may be expected in federalist governance structures, as observed during the COVID-19 pandemic (Poirier & Michelin, 2021; Farmer *et al.*, 2022). Coordination is a principal normative pressure that favours “the placing of decision-making authority over health care as far as possible up the decision-making ladder” (Weinstock, 2021). This pressure is not only political but also economic; as Kelley *et al.* (2021) suggest, market forces compel national-scale coordination of data infrastructure. By making vendors establish “unique integrations and data-sharing agreements with each institution” with whom they contract, the current approach to clinical health data sharing limits the scalability and transferability of firms’ integration work (Kelley *et al.*, 2021). While it may be an improvement on the current approach, standardizing data management practices at the provincial/territorial level would divide the relatively small Canadian marketplace into even smaller markets that are less appealing to digital health innovators. Given the commercial interests at stake, Kelley *et al.* (2021) claim that the coordination, standardization, and interoperability of health data technologies may be viewed as “matters of national commerce and trade more than they are matters of health care,” rendering them within federal jurisdiction.

However, lessons from prior health subsystem reforms support a hybrid approach that deploys collaborative and hierarchical efforts at different stages of policy-making. As Wilson *et al.* (2004) observe in their comparison of blood system and health surveillance reforms in Canada, collaborative approaches appear to successfully *design* reform plans that are widely supported, though they are susceptible to “slow, incremental change;” therefore, a hierarchical approach may be more effective at the *implementation* stage.

### To be successful, a collective approach to health data governance is necessarily collaborative

Given years’ worth of collaborative efforts in public health surveillance (McDougall *et al.*, 2014) and the federal government’s disinclination to impose hierarchy via legislation or conditional funding — along with the uncertain constitutionality of such an imposition on provinces and territories (Poirier & Michelin, 2021) — it may be unproductive to sustain the call for federal leadership. In the Panel’s view, a pan-Canadian approach that does not depend solely on the federal government for leadership may be a better option; indeed, leadership might be better operationalized as a collaborative and cooperative capacity.

Wilson *et al.* (2021) note that “formal interprovincial and interterritorial collaboration” is an approach to federalism that has found success in Canada’s blood system, and may work for public health surveillance. As an independent, not-for-profit corporation responsible for delivering transfusion and transplantation products and services to its participating provinces and territories, the Canadian Blood Services is a model for coordinating immunization systems and potentially other health surveillance systems. As shareholders, participating provinces and territories control the entity, avoiding jurisdictional struggles that may arise from federal mandates and leadership. As Wilson *et al.* (2021) suggest, this approach “would likely work best for activities for which responsibilities primarily fall under provincial and territorial jurisdiction, but there is a need for pan-Canadian harmonization.” With its similar governance model, some have proposed that CIHI could be adapted to fill this role in relation to public health data, though there are risks in broadening an existing entity’s operational scope (Buckeridge, 2022). Alternatively, a “new truly effective pan-Canadian ‘Health Data Science Agency’” could be organized in a way that does not detract from the provinces’ and territories’ healthcare delivery authorities (Wolfson, 2021). Figure 5.1 illustrates where such an entity would fit within the division of powers under Canadian federalism.

If given sufficient authority and influence, this type of organization — which could be referred to as a “standards and policy entity” — has been recognized as a necessary mechanism for implementing a common framework for health information exchange (Halamka *et al.*, 2005). Examples of similar organizations exist in some international jurisdictions, such as Denmark’s MedCom and Health Data Authority (Section 4.1.5). In the United Kingdom, the British Academy and the Royal Society (2017) have stressed the importance of a “stewardship body” to “steward the evolution of the governance landscape as a whole.” The following characteristics are important for such a body: independence; having diverse connections; inter- and transdisciplinarity; having formal or informal authority in decision-making; sustainability; and having a national focus with global relevance (The British Academy, 2017).

The importance of the entity’s authority within a federation may be illustrated by the outcome of Infoway’s work in developing national standards for health information technologies, particularly EHRs. As an independent not-for-profit corporation adopting shared governance and co-investment models of leadership among the FPT governments, Infoway’s organizational structure is consistent with the collectively governed entity contemplated above. Yet interprovincial variability of health information technology systems persists, in part because

there is no mechanism to ensure data standardization across sectors and provinces or territories (Kelley *et al.*, 2021). As demonstrated by its strategy to implement a national system of interoperable EHRs (Rozenblum *et al.*, 2011), Infoway has a limited approach to digitizing health systems; its contribution to building infrastructure is through establishing national standards and incentivizing their adoption via funding mechanisms. Although arguably providing an essential foundation for data sharing, leaving the implementation of such applications and infrastructure to the provinces and territories falls short of a coordinated national policy for health information technology (Rozenblum *et al.*, 2011).

It is important to note that, while exploring opportunities for collective leadership in health data governance, the Panel was mindful of fiscal measures taken by the federal government to promote enhanced health data sharing. Exercising its constitutional spending power by negotiating the conditions of the Canada Health Transfer provided for by the *Canada Health Act* (CHA) (Flood *et al.*, 2017), the federal government stipulated that up to \$46.2 billion in new funding will be payable to the provinces and territories if they commit to improving their health data systems (Duong, 2023). The powers to make regulations that “prescribe the information to be provided by provinces and territories” and issue policy interpretation letters may also be useful mechanisms for the federal government, if it wishes to push for certain changes (Forest & Stoltz, 2022). Because the CHA is based on federal spending power and allows the federal government to pass regulations, there may be “safer alternatives” than “opening” the CHA up for amendment (Forest & Stoltz, 2022). However, given “the fundamentally consensual nature of the CHA,” these powers imply consultation with the provinces and territories (Forest & Stoltz, 2022). Redirecting this consensual orientation to the politics of jurisdiction over health toward interprovincial cooperation and collaboration in developing a sustainable pan-Canadian data ecosystem is an opportunity worth considering.

6

# Panel Reflections

Health data sharing is not a new policy issue in Canada. For decades, health institutions have been collecting and storing personal health information, creating rich but fragmented repositories of data. Significant investments have been made with the ultimate objective of connecting these repositories and facilitating data exchange. Canada's health information technology infrastructure is now well established. The challenge is that infrastructure is not effectively harnessed in order to generate the expected benefits at scale. Learning networks to enhance clinical care, health system improvement and innovation, public health, and research remain too scattered to constitute a comprehensive, pan-Canadian health data sharing system. However, the success of some of these initiatives may indicate that the social, political, and cultural conditions that inhibit health data sharing unnecessarily support systemic under-performance. These circumstances are increasingly intolerable in health systems approaching crisis levels with respect to accessibility, quality, and equity.

No approach to health data governance and management can maximize the benefits of health data sharing in Canada without first maximizing the opportunities for exchange. This relies on leadership and coordination focused on standardizing the structures in which stakeholders operate; interoperability and legal compliance are promoted by structures that are transparent, coherent, and unambiguous. Coordination among jurisdictions, regions, sectors, and individual actors is the critical first step toward enhancing pan-Canadian health data sharing. Ideally, stakeholders will begin to see themselves as allies working towards the same goals, which implies that trust is a central pillar in a robust health data system. A reasonable first step for leaders at all levels of decision-making is to include patients, health professionals, researchers, and other stakeholders in those processes. Trust in health data systems would do much to prevent antagonism from developing among parties, since all interests can be seriously considered and accounted for in designing, implementing, and sustaining data governance.

A data ethics approach is key to balancing and weighing benefits and harms, and to ensuring these are thoughtfully considered in the governance and operationalization of Canada's data-sharing partnerships and FPT discussions. This approach acknowledges that all harms that could arise from data sharing are not yet known, and that not all data sharing will provide equal benefits to people in Canada. Therefore, embedding ethics while moving forward may provide the necessary foundation to evaluate processes and ensure that data sharing is established to maximize public good and provide equitable and better health outcomes for people in Canada.

The fragmented nature of leadership under federalism can cause challenges in building trust and collaboration, as was observed in FPT negotiations regarding the Canada Health Transfer; there, the federal government pushed for a commitment



from provinces and territories to modernize health systems by adopting standardized information and digital tools (Picard, 2023). Whether negotiating the Canada Health Transfer is an effective leadership strategy to enhance health data sharing cannot be determined when the provinces and territories reluctantly accept federally imposed conditions; nothing in this approach compels interprovincial cooperation. However, with the provinces and territories set to seek opportunities to invest in their health data systems in accordance with the federal government's conditions for top-up funding, now is the time to push for collaboration in health data governance. As allies, provinces and territories can more successfully pursue improved health for everyone in Canada.

With world-class health data organizations such as ICES and MCHP, and an innovative governance model developed by HDRN to enable comparative analysis of multiple jurisdictions by connecting these and other actors, Canada is a recognized leader in health data sharing for the purpose of research. There is no reason it cannot also lead in health data sharing for clinical care, health system improvement and innovation, and public health purposes. It is unwise to ignore the distinct uses that different organizations have for health data (or the need for governance models that are responsive to these differences), but overlaps should also be kept in mind to improve efficiencies. Health data generated in the process of delivering care (e.g., patient and billing data) are not only relevant to clinical purposes but can also be used in research to improve knowledge, in performance measurement to improve health systems, and in public health surveillance to improve population health. The same is true for data generated in the other disciplines. A comprehensive health data system integrates these uses in the governance regimes responsible for health data stewardship.

Sustaining the trend toward data standardization is important for enhancing health data sharing. Minimum data standards can align all actors without necessarily proscribing what data can be collected. Developing standards is one thing; implementing them at the national level in a sustainable way is another. National standards without provincial/territorial endorsement do not support a pan-Canadian health data system, as indicated by the current variation in health data systems across the country. In a similar vein, the complexity of privacy laws across jurisdictions calls for authoritative guidance that stakeholders can rely on in managing their data holdings. In this way, the culture of caution that prevents health data exchange by legitimizing conservative interpretations of privacy rules can be replaced by a culture of confidence. A stewardship body responsible for data standardization and policy surveillance, governed collectively by the provinces and territories, is a promising strategy. However, given the urgent need to act sooner than later, the federal government's constitutional and legislative powers may be leveraged to expedite a collaborative effort.

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## Connecting the Dots

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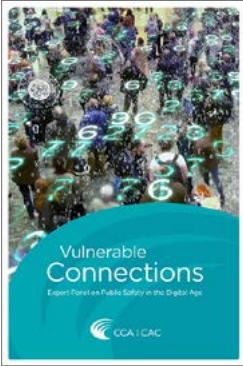
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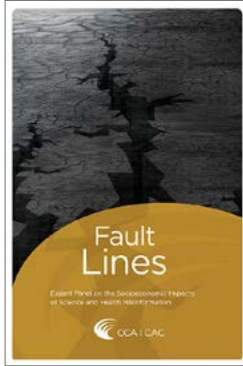
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# CCA Reports of Interest

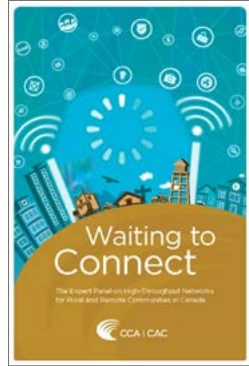
The assessment reports listed below are available on the CCA's website ([www.cca-reports.ca](http://www.cca-reports.ca)):



Vulnerable Connections (2023)



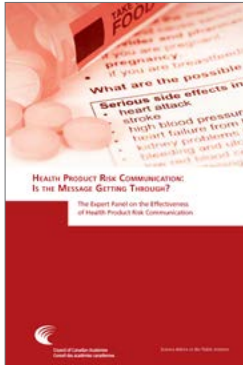
Fault Lines (2023)



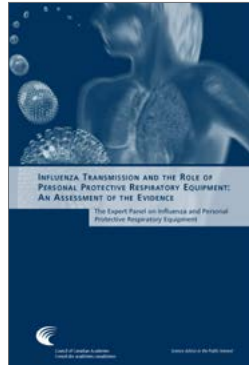
Waiting to Connect (2021)



Accessing Health and Health-Related Data in Canada (2015)



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