

# Medical Information Commons to Support Learning Healthcare Systems: Examples From Canada

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With appropriate governance, medical information commons (MICs) may become platforms through which to generate and utilize real-world health evidence to improve individual care and population health, and to advance the goals of a “learning health system.”<sup>1</sup> A learning health system is one that uses data to drive health system improvements. It is premised on iterative and ongoing learning, in which stakeholders participate.<sup>2</sup> MICs support a learning health system by providing “a networked environment in which diverse sources of health, medical, and genomic data on large populations become broadly available for research use and clinical applications.”<sup>3</sup>

Four principles predict the success of an MIC.<sup>4</sup> The first is a standard approach to policy and governance that enables aggregation of research and clinical data from diverse individuals. Second, MICs should be participant-centric, empowering the involvement of those who contribute data. Third, MICs must develop processes that sustain trust at both individual and institutional levels. Finally, MICs must employ practices for data-sharing that mitigate legal, regulatory, and technical barriers.

These four principles build on the seminal work of Elinor Ostrom, recipient of the Nobel Memorial Prize in Economic Sciences, on governance of knowledge commons.<sup>5</sup> Her work established an analytical framework — the Institutional Analysis and Development (IAD) framework — to inform governance that can achieve broad-based participation and sharing of data and materials for research and systems improvement.<sup>6</sup> Ostrom (2005) suggests that a successful commons requires rules and structures that create incentives for establishing and sustaining the commons, including contribution to the commons, use of the commons, and, most importantly, re-contribution of value-added

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data and materials to the commons.<sup>7</sup> Ideally, to build and sustain trust, rules need to be developed with the participation of the community,<sup>8</sup> including patients in the context of MICs.

Here, we use three illustrative case examples to explore how these four predictors of success advantaged or disadvantaged three large-scale MIC initiatives in Canada's most populous English-speaking provinces: British Columbia, Alberta, and Ontario. The first case example describes a major initiative to create an infectious diseases MIC in British Columbia. The case example from Alberta represents a single MIC initiative in support of Canada's largest health system and is representative of initiatives underway in other provincial health systems. This case example is complemented by another on precision oncology in Canada's largest cancer-specific health system (Ontario) and a major initiative to create a national infectious diseases MIC (in British Columbia).

Our examples draw on a national workshop held in October 2017 and organized by Genome Canada's Precision Medicine Policy Network. The expert workshop brought together policy and decision makers, data managers, provincial and institutional privacy officers, regulators, diagnostic laboratory leaders, industry representatives, clinicians, and researchers. Under Chatham House Rule, these stakeholders discussed the enablers and challenges for effective data use by health systems in Canada, under Chatham House Rule. Issues were brought into focus by the three case examples. Notetakers captured the discussion and their notes form the basis for our content analysis. Here, we summarize our analysis to draw lessons relevant to the four principles that knowledge commons theory predicts are important for the creation and sustainability of MICs.

### The Canadian Context

The challenge of data use across settings and regions is ubiquitous.<sup>9</sup> However, if health care is to become a "data-driven enterprise that learns from itself and drives towards the practice of precision medicine," stakeholders must take an approach that embraces both centralized and distributed functions and

authority.<sup>10</sup> Mandl and Kohane (2015) suggest that health care must "nimblely balance essential centralized functions with local participation and authority."<sup>11</sup> Canada's federated health system provides an opportunity to examine the challenges to and benefits of effective data use within a federated national health-care system.<sup>12</sup>

As a Federation of ten Provinces and three Territories, Canada has multiple public healthcare systems. Canada's constitutional framework provides for shared responsibility between the Government of Canada and Canadian Provinces.<sup>13</sup> Each Province has the constitutional responsibility to maintain and manage health care within its borders, and each Province may have multiple health authorities. These health authorities may provide either general care to a region or specialty-based care within a Province, such as cancer care.<sup>14</sup> The Government of Canada exerts its convening and policy-setting authority through its spending power; its conditional transfer payments to the Provinces fund social programs, including health-care. Receipt of funding requires provincial health systems to comply with the principles of the Canada Health Act: Public Administration.<sup>15</sup> These principles enshrine the public nature of Canadian health systems: *Comprehensiveness* in covering necessary health services, *Universality* of coverage to all insured residents, *Portability* for those re-locating within Canada, and *Accessibility* that provides insured persons with reasonable access to health care facilities.

Despite the tenets of the Canada Health Act, Provinces have considerable latitude to design, manage, and deliver care. This latitude extends to the heterogeneous mix of laws and regulations that govern aspects of MICs, most prominently laws that govern the use of personal health information (Table 1). Heterogeneity exists, for example, in the definition of "identifiable" health information, custodial duties with respect to health data, criteria for data-sharing, the agreements and duties required of researchers who wish to access health data, and permission to share health data with other provinces.<sup>16</sup> Critically, while Provincial/Territorial laws allow researchers to access de-identified data, "non-identifiable data" is not defined, and practices

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differ among jurisdictions (see Table 1). Interpretation by data custodians has led to a culture of risk aversion, which leads to restrictions on data access, even if such access might be permissible within legal frameworks and might improve feedback into the health systems throughout Canada.<sup>17</sup> Further, the fragmentation of research-ethics approval processes among institutions and health systems, uncertainties about health data use for health system improvements, and a focus on transactional data use (e.g., for billing and monitoring) — rather than governance and infrastructure that

facilitate the goals of a learning health system — complicate the development of MICs within and between regions.

In 2015, the Council of Canadian Academies issued a report on timely access to health and social data for health research and health system innovation. The Council concluded, “Canadians generally support the use of their health-care encounter and related data, including evolving EHRs [electronic health records], for research.”<sup>19</sup> However, the Council identified challenges to the goals of MICs to improve individual care

Table 1

**Provincial Legislative Provisions Governing Health Information Privacy and Research Promotion.**  
(adapted from *Accessing Health and Health Related Data*)<sup>18</sup>

Legislative Provision	British Columbia (BC)	Alberta	Ontario
De-identified data can be used freely	Yes	Yes	Yes
Definition of “identifiable” health information	Used but not defined	Used but not defined	Identification is reasonably foreseeable from combination of data
Custodian duties to safeguard data	General duty to take steps to ensure confidentiality	Extensive duties to develop and follow information security protocols	Must develop information security practices
Custodian liabilities for data breaches	Investigation by Privacy Commissioner; tort liability; statutory invasion of privacy; criminal prosecution	Investigation by Privacy Commissioner; tort liability; criminal prosecution	Investigation by Privacy Commissioner; tort liability; criminal prosecution
Data may be used for approved research purposes	Yes	Yes	Yes
Approving entity	FIPPA: Privacy Commissioner must approve; PIPA: No entity designated	Designated REBs under Regulation; custodian must approve disclosure	REB not needing pre-approval but meeting statutory test
Criteria for approval decisions	Brief and generally stated	Lengthy, detailed and/or elaborate legislative standards	Lengthy, detailed and/or elaborate legislative standards
Researcher-custodian agreements required	Yes, general duty to get agreements	Yes, with extensive and detailed terms	Yes, general duty to get agreements
Duties of researchers	Researchers not bound by same duties as custodians	Researchers not “custodians”	Researchers not “custodians”
Designated research entities	None	“health information repository,” embedded in Legislation; no regulations in place	ICES, CIHI, CCO, POGO
Disclosures to another province for research	Permitted if for approved research	Permitted if custodian enters into agreement with researcher(s) that binds them to protect data confidentiality	No restrictions

**Abbreviations:** FIPPA - Freedom of Information and Protection of Privacy Act (BC); PIPA – Personal Information Protection Act (BC); REB – Research Ethics Board; ICES – Institute for Clinical Evaluative Sciences; CIHI - Canadian Institute for Health Information; CCO – Cancer Care Ontario; POGO – Pediatric Oncology Group of Ontario.

and population health. Challenges included heterogeneous data standards and formats, the “complex environment of heterogeneous entities”<sup>20</sup> that give rise to duplication or conflicting roles, and the struggle to balance timely data access and respect for privacy. The report nevertheless identified some progress in advancing best practices for data governance. We now discuss three case examples that highlight the lessons learned for the establishment of MICs in Canada.

### Case 1: Data Integration and the British Columbia Hepatitis Testers Cohort (BC-HTC)

The BC Hepatitis Testers Cohort (BC-HTC) is a dynamic cohort that integrates laboratory and provincial administrative healthcare datasets.<sup>21</sup> The goals of the BC-HTC are to monitor disease burden related

to hepatitis and other blood-borne pathogens, and to provide outcome evidence that informs policy and programming in British Columbia and Canada. Many lessons may be gleaned from the 16-year data integration odyssey that led to its creation, and it provides a proof of concept for how integrated data can be used to measure outcomes across the prevention, care, and treatment continuum.

The BC-HTC contains linked, de-identified data from 1.7 million residents of British Columbia, spanning a 30-year period. This dynamic cohort integrates datasets, including medications, hospitalizations, medical visits, cancers, and vital statistics, and enables adjustments for co-morbidities, concurrent infections, and social conditions (e.g., material and social deprivation). The cohort includes all individuals tested for hepatitis C virus (HCV), hepatitis B virus (HBV), and human immunodeficiency virus (HIV) at the British Columbia Centre for Disease Control (BCCDC) Public Health Laboratory, since 1992. It also includes confirmed cases of HCV, HBV, and HIV/AIDS since 1990.<sup>22</sup> Following a 2017/2018 cohort refresh, additional data on individuals tested for HBV or syphilis, and those diagnosed with chlamydia, gonorrhoea, and syphilis will be included, resulting in data on almost 2.4 million people.

This level of data integration has enhanced understanding of disease trends for HCV and improved program monitoring, evaluation of treatment and intervention effectiveness. It has also provided evidence to support a “syndemic approach”<sup>23</sup> to care and treatment — a biosocial approach informed by the evolving syndemics of HIV/HCV and the social/political contexts of affected populations.<sup>24</sup> The BC-HTC also demonstrates that integrated data designed to serve local evaluation needs can provide a rigorous proof of concept for international data-sharing. Data from the BC-HTC has, for example, been used with data from New South Wales, Australia and Scotland to evaluate the effect of alcohol use disorder on HCV-related liver disease and to explore public health implications of minimum unit alcohol pricing.<sup>25</sup>

Despite these successes, the BC-HTC faced numerous challenges in its development and faces ongoing challenges for its maintenance and use. Lessons learned from these experiences are summarized in Box 1. The first issue was cultural and institutional: it was difficult to achieve buy-in from the broad range of agencies and organizations required for this level of data integration. The second set of challenges related to data infrastructure deficits, which continue to limit data storage, transmission, “refresh,” and analytic tools. These deficits limit how clinical care can be researched and evaluated. For example, healthcare

#### Box 1

#### Lessons learned from the British Columbia Hepatitis Testers Cohort Experience

- *Do not under- or over-centralize:* A balance between centralized and distributed functions and authority will facilitate sharing across organizations. Enable stakeholder access to population data and analytic resources.
- *Technical infrastructure:* Resources must be directed to data infrastructure that will both accommodate transactional data and measure value, recognizing that no single system or provider will be able to fulfil all public health data needs.
- *Sharing between health surveillance and research:* Sharing between government data repositories and research is critical for a learning health system. There is a lack of inter-sectoral, multidisciplinary leadership to advance data-sharing partnerships that meet both health surveillance and research needs.
- *Learning:* Data integration is critical to measuring value, making resource decisions, and addressing health care costs. Projects and programs must incorporate capacity for system learning, with resources directed to infrastructure that will measure outcomes and guide practice.
- *People and organizational culture are key to MICs:* Strategies for data access and integration must be creative and collaborative. Big data needs diverse and broad skill sets, and organizational culture needs to affirm and foster a view of data as a shared asset.
- *Comprehensive “proof of concept” models demonstrate the value of integrated datasets to decision makers:* Decades of unused health records represent an under-utilized asset for health systems.

Table 2

**Specific features of Alberta's MICs**

Feature	Description
Connect Care	The AHS clinical information system will consolidate the current number of 1,300 information systems to approximately 300 in the first instance, and then ultimately to one clinical information system.
Community Information Integration (CII)	The CII will capture data from electronic medical records collected in individual practices for clinical and secondary uses (e.g. research).
Central Patient Attachment Registry (CPARS)	CPARS will result in the attachment of patients to specific physician practices with the goal of improving funding models and continuity of care.
Immunization reporting	A regulation moving forward in Fall 2018 to mandate reporting of all publicly and privately funded immunization events in the province to Alberta Health. Alberta Health is additionally working with First Nations communities to establish real-time immunization reporting.
Personal Health Records	Laboratory tests, immunization records, and drugs dispensed will be displayed via a secure online tool, helping to empower individuals.

systems software is currently built for episodic, treatment-based care, rather than for cumulative longitudinal life-course management. Crisis situations, such as Canada's opioid crisis, tend to highlight the need for data-sharing and may facilitate data access. However, this response does not address fundamental deficits in the process of how data are integrated, refreshed and managed. Indeed, a focus on restrictive, purpose-built datasets — rather than retrospective data-mining to build more comprehensive datasets that enable adjustments for co-morbidities and other confounders — limits capacity for focused, efficient public health response to crises. Finally, challenges arise in sharing datasets and/or integrating data at national and global levels. Such sharing can be pragmatically accomplished by sharing ideas, processes and methods, cross-training of personnel, sharing analytic strategies between different regions, and adapting analytic strategies to the needs of each jurisdiction.

### Case 2: Evaluation of Precision Medicine Technologies in Alberta

Precision medicine aims to harness a wave of 'omics discoveries to deliver the right treatment to the right patient at the right time. Precision health initiatives rely on efficient access to, as well as integration and analysis of big data. The advent of next-generation, high-resolution DNA sequencing enables earlier and more accurate diagnosis and molecular characterization of a range of diseases to direct the most effective treatment regimen, if one is available. The certainty of a molecular diagnosis can also mitigate the diagnostic odyssey for patients with rare and/or complex diseases that manifest with heterogenous symptomology. These new diagnostic methods rely on integrated

data platforms and may drive significant costs in precision therapies, for example gene and cell therapies and other biologics. The value to the health system in terms of health outcomes for patients following these test-directed treatments will therefore need to be evaluated in real time and through a rigorous process. Sustainable learning health systems must become adept at disinvestment from as well as investment in new technologies.<sup>26</sup>

The Province of Alberta is unusual in Canada in having a single health authority. This represents an opportunity to build a provincial MIC to enable use of data for both health system improvement and to advance an innovation agenda in the development of new diagnostics and therapies. To that end, Alberta has changed its philosophy to recognize data as an asset, to use data to improve decisions from clinical to systems level, and to access data to support research that is viewed as an investment in improved health outcomes. Alberta has therefore invested in connecting data platforms from multiple partners within the province. This includes initiatives to connect Alberta Health Services (AHS) clinical information systems, to integrate data from communities and pharmacy immunization systems, to provide a portal for personal health records, to provide de-identification services, and to partner with Indigenous communities (Table 2).

The use of health data in Alberta is governed by the Health Information Act (HIA) and non-health data is governed by the Freedom of Information and Protection of Privacy Act.<sup>27</sup> The HIA enables a custodian to "use individually identifying health information [including without consent]... to promote the objectives for which the custodian is responsible," which include planning and resource allocation, health

system management, public health surveillance and health policy development (s. 27(2)). In addition, a custodian may disclose non-identifying health information for any purpose (s. 32(1)). Currently, in support of a learning health system, Alberta Health has reduced the time to access data from approximately 400 to 40 days.<sup>28</sup> This rapid access will enable health outcomes and economic evaluations of technologies and therapies in real time. Such evaluations can then inform health system investment decisions on continued adoption or disinvestment. Further, Alberta's Secondary Use Data Access (SUDA) initiative enables access to health information for academic and non-academic partners and increases capacity to aggregate, analyze, and visualize health information. The analytic infrastructure, such as the data warehouse and tools, are being strengthened, and the unit provides methodological and statistical assistance. SUDA has also partnered with the University of Alberta and is working on an agreement to provide sample data on 500,000 Albertans for exploration, testing, and teaching.

While Alberta's near real-time analytic capabilities and access to some datasets are an impressive accomplishment, numerous challenges persist. These include legal restrictions, infrastructure limitations, and training and professional development — including a need for sufficient contextual knowledge to interpret trends identified through big data analyses. Data access is necessary, but insufficient for an effective MIC to improve individual and population health. Changing risk-averse organizational culture while establishing and maintaining trust relationships to enable data access and effective use is difficult. Trust relationships also require that data users, including researchers, change their behaviour to respect reasonable restrictions on data use, to ensure adequate monitoring and to enforce any infractions.

A further challenge exists that is specific to precision medicine technologies: economic and health outcomes evaluation requires linkage among clinical outcomes and utilization data (held by the health system – AHS), cost data (held by the provincial health ministry, Alberta Health), and diagnostic data (held by Alberta Laboratory Services, which is part of AHS). Connecting utilization to cost data is relatively seamless. However, access to diagnostic data requires approval by a separate data custodian. The data custodians have significant discretion under the Health Information Act to enable or deny data access. This points to the need for cultural harmonization of risk-management within health systems. For example, researchers at the University of Alberta asked whether earlier access to a next-generation test for patients suspected of having a

## Box 2

**Lessons learned from the Alberta Experience**

- *Harmonized government policy* can enable use of health data as an asset for both health system and healthcare improvement and development of innovative health technologies.
- *A single health system can facilitate data access* to enable real-world and real-time analysis of health technologies and interventions.
- *Building a culture of trust and mitigation of risk-aversion by data custodians* will advance the goals of improving population and public health.

mitochondrial disorder would improve post-diagnosis care pathways, directing patients to appropriate specialists, and curtailing the diagnostic odyssey for these complex conditions. The lead investigator had access to the clinical data but could not use the data for health system improvement “research” purposes. The data custodian in question would not accept the University of Alberta Research Ethics Board's determination that the benefits of access to data outweighed the risks of contacting patients or their caregivers, especially when pediatric conditions proved fatal. It issued a waiver of consent to use de-identified data, linked by an AHS employee to healthcare records. This was rejected by the data custodian in this instance, necessitating a twelve-month chart review to extract the same data by hand. However, these cultural barriers to reasonable interpretation of custodial discretion are being addressed by open data initiatives within the Alberta Government, with appropriate safeguards for privacy and data security.

**Case 3: Accessing Cancer Care Ontario (CCO) Data for Research Purposes**

Cancer Care Ontario (CCO) is the advisor to the Ontario government on cancer and renal systems, and access to care for key health services. It drives “continuous improvement in disease prevention and screening, the delivery of care and the patient experience for chronic diseases.”<sup>29</sup> CCO is governed by The Cancer Act<sup>30</sup> and is accountable to the Ontario Ministry of Health and Long-Term Care (MOHLTC) in overseeing over a billion USD in funding for hospitals and other cancer and chronic kidney disease providers. It implements cancer prevention and screening programs, works with healthcare professionals and organizations to develop and implement quality improvement standards supported by electronic information and technology, plans future cancer services, and con-

ducts research into improvements and innovations in clinical practices and cancer service delivery.

In support of these evidence-based activities, CCO collects and manages one of the most comprehensive healthcare datasets in Ontario, Canada's most populous province. It gathers more than 80 datasets from health system providers and data partners from across the healthcare continuum. The data include healthcare provider information, patient reported outcomes and experience, population and demographic data, registry information (e.g., cancer registry surveillance data), and more. While ensuring that legal and privacy obligations are met, CCO supports research and health system planning by providing aggregate or de-identified, record-level data to Ontario researchers, health system planners and government organizations. However, neither data linkage nor use are permitted outside the province of Ontario.

Four strengths of the Ontario initiative for advancing the goals of a learning health system are its data access processes, analytics, "patient centeredness," and fee structure. Application for data access is guided by a well-defined, web-accessible process. Its analytics are presented as integral to data use, and CCO provides access to web-based analytic tools. The dataset supports "patient centeredness" through enabling data, such as self-reported patient symptoms. Finally, data access operates on an explicit cost-recovery basis to ensure service continuity.

CCO has, however, also encountered a number of challenges. First, the ability to use CCO data for inter-provincial and international comparisons is limited due to the complexities of using CCO data for research outside the Province. As identified in the Canadian Council of the Academies report, difficulties exist in meeting the requirements of heterogeneous privacy legislation in multiple jurisdictions,<sup>31</sup> as well as the limitations set out by CCO's data partners. Second, permanent data linkage for research is not permitted under Ontario's Personal Health Information Protection Act,<sup>32</sup> despite the fact that permanent linkage is required for exploratory and longitudinal research. Nevertheless, CCO works with researchers to carefully plan the scope of their research and renew approvals that enable longitudinal analysis. Third, data is only available to support research and health system planning, with no access to the data for consultants or industry at this time. Fourth, disease reporting requirements vary. For example, while stage IV melanoma is reportable, early stage melanoma may not be reportable. Hence, data for the full scope of disease are not captured. Fifth, interpretation of privacy rules limits the ability of researchers to contact and connect with patients. Finally, guidelines for managing genetic

data are unclear. Unanswered issues include storage and ownership of genetic information, as well as the practical and ethical challenges of linking genetic data with other data.

Despite these challenges, CCO has managed to collect data from patient contact studies using a clearly defined 2-step process. First, individuals in the cohort of interest are identified and contacted by CCO for their consent to receive study information and the contact information for the researcher. And second, those who consent are contacted by the researcher for their consent to participate in the study in question. Although time- and labor-intensive, this process ensures that the correct population is identified and that those enrolled in studies are eligible and have consented. However, sample representativeness and size may be compromised because patients' understanding of their diagnosis may impact their decision to contribute their data. National patient contact studies may also be compromised by the legal and regulatory requirements that influence patient access in different regions.

## Conclusion

Three Canadian case examples of MICs each demonstrate that a standard approach to policy and governance of aggregated health information supports improvements to individual healthcare and a learning health system to improve population health. However, each case study was limited in terms of geographic scope by heterogeneous health information protection laws. Even in a country with a relatively small population, such as Canada, there are deeply entrenched legal and cultural challenges to creating an MIC that will support all uses across the country, as well as inter-provincial and international collaborations. Canada's

### Box 3

#### Lessons learned from Cancer Care Ontario Experience

- *Formal, clear processes and pathways* are critical for equitable intake and adjudication of data access, integration and use, both within and between provinces.
- *Implementation checklists* are a useful tool to ensure that researchers have the information needed to implement their projects.
- *"Real-time" and "real world" are important for data analytics:* infrastructure development is needed to facilitate collection and analysis.
- *Creative and ethical approaches* are needed to achieve consent that include data linkage options and options for follow-up contact as part of the consent process.

federated structure and multiple health systems will necessitate a networked approach to MICs.

Our exemplar MICs have employed best practices for data sharing that mitigate legal, regulatory, and technical barriers. The Ontario example demonstrates the value of a participant-centric MIC, which empowers the involvement of those who contribute data. However, all three case studies entail difficulties that MICs must overcome to develop processes that sustain trust, at both individual and institutional levels. Indeed, risk-averse data custodians continue to impede access to and use of data, even when legislatively permitted. Overcoming this risk-aversion will require reforms to institutional cultures supported by policies and practice guidelines. The implementation of these will require change-management strategies coupled with evaluation appropriate evaluative frameworks.

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