"**This is the moment, to build a healthier today and tomorrow**"[1]
- *Justin Trudeau, Speech from the Throne, 23 Nov 2021*

A World Class Health Data System for Canada: Framework for Action
Table of Contents

Executive Summary

<u>About the Policy Modernization Group</u>
The Policy Modernization Group (PMG) is an outcomes-driven, public/private collaborative working to advocate for the modernization of health data policies in Canada. The PMG brings together the perspectives and ideas of a diverse group of approximately 45 stakeholders across the health data ecosystem. Members of the PMG are affiliated with their public, private, or not-for-profit organizations and act as interested individuals and/or as representatives of their respective organizations. The PMG is working collaboratively toward a shared vision of a health care system that is grounded in modern data policies and aligned with the principle 'as open as possible and as regulated as necessary'.

<u>Purpose</u>
Two years ago, the Public Health Agency of Canada struck an Expert Advisory Group to advise the federal, provincial, and territorial governments on how to achieve an optimized 'world class health data system' via the creation of a Pan-Canadian Health Data Strategy. The findings and recommendations from this group are sound and evidence-informed, and the members of the PMG stand behind them. As such, we have come together to author this paper in support of the recommendations of the Pan-Canadian Health Data Strategy's Expert Advisory Group. In our paper, we highlight key examples from other jurisdictions that could be starting points towards a world class health data system for Canada. Important to note is that there are many uses of health data, and the focus of this paper is regarding health data accessibility and use for clinical care and resource planning, including research that leads to better clinical care, and better and more timely resource allocation.

<u>Current State</u>
Canada has the building blocks of an innovative, data-driven, and resilient learning health system that could truly serve patients, but we're failing to fulfill our potential. We are data rich and information poor because although we collect vast volumes of data, those data are highly fragmented across provinces and territories, providers and institutions, rendering them inaccessible and underutilized. They are also often lacking in quality and comprehensiveness, something that was highlighted by the COVID-19 pandemic. Through the pandemic, we learned there is a clear need to collect more inclusive data, such as robust social determinants of health data, to generate insights that will identify gaps, and ensure that healthcare is being delivered equitably, to meet the needs of every person living in Canada.

<u>Other Jurisdictions</u>
Jurisdictions in other parts of the world are working together to build more robust health data ecosystems that will better serve patients. Many of these initiatives have been validated and have already led to improved patient outcomes and more optimal use of resources.

We have clearly demonstrated through the robust examples we have referenced that there is no need to reinvent the wheel. There is no time to waste in adopting policies and practices in place elsewhere as these best-in-class examples have been validated, and impact is being demonstrated.

Our system is in jeopardy. We must collaborate and act now to future proof the healthcare system for all.

<u>Policy Recommendations</u>
To achieve a world class health system in Canada, collaborative and cooperative action from all health system stakeholders is required on several fronts, over the short-, mid-, and long-term.

In this paper, the Policy Modernization Group has put forward several recommendations in support of the policy environment for a world class health system. The recommendations support the findings of the Pan-Canadian Expert Advisory Group and are organized by the group responsible for developing policy at the strategic level.

The stakeholders we believe must be involved and included on an ongoing basis are from the public, private and not-for-profit sectors, and must include citizens, patients, and caregivers across jurisdictions, including Inuit/First Nations/Métis peoples and people from underserved or minority communities. If we ensure broad collaboration and cooperation, we will be able to successfully prioritize issues of greatest importance to users of the system. If we can mobilize successfully, and focus on person-centred design, we will achieve the system we all strive for, and we will achieve our aligned goals more quickly. Working closely with stakeholders will help build trust along the journey, and in regard to implementation of the strategy.

<u>Conclusion</u>
This paper describes the vision towards a world class health data system - a system where timely data access, sharing, and quality are facilitated in an ethical and equitable way, while respecting and protecting privacy and human rights. In such a system, not only will we realize the power of data in informing decision-making around diagnosis, treatment, and care, but also in enabling a shift towards healthy living, risk management, and prevention that will lead to better health outcomes for all people living in Canada.

To achieve this vision, this paper highlights what is possible and achievable in some critical areas within our disparate systems. Though we have presented these key pillars as individual considerations on what is possible and what best in class can look like, it is the sum of all these components that will lead to a world class health data system in Canada. As described in the examples, Canada has fallen behind other countries; in order to harness the power of data and deliver on the healthcare system the people of Canada deserve, we must work together towards this future.

If we act on these opportunities collaboratively, with both private and public sector cooperation, we can enable and facilitate an integrated, person-centered, and data-powered healthcare system for the better health of all who live in our country. True system change cannot happen overnight. It requires individuals to come together and tackle the challenges one step at a time in order to achieve progress and realize the vision articulated in this paper.

Introduction

People who live in Canada are proud of our universal healthcare system, intended to bring equitable healthcare to everyone who resides here. Unfortunately, the pandemic helped us realize that our system is unable to provide healthcare in an equitable fashion. In the 2021 Commonwealth Fund's report comparing healthcare systems in 11 developed countries, Canada landed in 10th place.[2] A lack of data integration contributes to our ranking, and further exposes the risks associated with an unsustainable healthcare system.

Callout Box: What is Health Data?

In the simplest terms, health data is information that is produced by healthcare professionals and patients.[3] In this paper, we define health data as data that can include personal health information (PHI), which means the information (data) can identify the person. Health data can also include information that cannot be linked to a person, known as 'anonymized' data. Health data includes observations, narratives, or measurements which relate to characteristics such as the physical and/or mental health status of individuals, socio-economic and community well-being, and health system performance.

The people who live in Canada deserve a person-centred healthcare system, built with their input and for them, so that equity in care can be assured regardless of where they live, what they earn, or which culture they are from. This healthcare system should be connected, with health information (health data) moving with patients and accessible to patients - not stuck within individual systems of institutions.

Within Canada today, health data is fragmented, siloed, and not easily accessible. Our current policies have not kept pace with change, and the culture of risk aversion limits access and use of data for the greater good. To unleash the power of health data for everyone in Canada, we need purposeful steps towards an 'all of Canada' approach to tackle these challenges and seize the opportunities ahead of us.

The pandemic highlighted the ongoing pressing need for access to high quality, real-time data to understand rapid developments and changes, including changes to patterns of care, that can affect a country at a population level. Collecting data, aggregating it, and drawing conclusions or revealing trends within those data are all important areas of research that can lead to improved clinical care and improved processes, among other things. The need for timely, data-informed decision-making was imperative during the pandemic and highlighted the challenges and gaps that exist within the current health data systems in Canada. It became apparent there is no easy fix, and that working in silos will not accomplish what is needed.

To address this unmet need for real-time, integrated, holistic data, the public and private sectors must collaborate to work towards a world class health data system. A successful health data system must learn from and act on the data contained within it. A learning health system can be defined as "...a health system in which internal data and experience are systematically integrated with external evidence, and that knowledge is put into practice."[4] In addition to the work of the Expert Advisory Group, we are encouraged by the report entitled "Building a Learning Health System for Canadians" by the Canadian Institute for Advanced Research (CIFAR).[5] These two initiatives (the Pan-Canadian Health Data Strategy and the Learning Health System report) set a clear direction for a health data-powered Canada.

A world class health data system can only be achieved with a solid foundation of integrated and accessible health data. This is our opportunity to work together to build this foundation – to support the goal of improved health outcomes for all Canadians.

Callout Box: How can data enablement lead to a learning health system?

Data enablement via an optimized health data strategy would allow for a more efficient, resilient, and agile (continuously improving) learning health system able to:

- **Improve decision making** by enabling faster insights generation through robust, real-time, integrated health data
- **Improve resource allocation** by understanding where needs and gaps exist
- **Understand the true value of interventions** by considering the impacts and costs to patients, the health system, caregivers, and society, and evaluating safety and effectiveness in real-time
- **Catalyze adoption of health innovations** by demonstrating value and benefits in real-time, with data demonstrating where and when pivoting is required
- **Optimize delivery of care** by putting a spotlight on gaps in the care continuum
- **Facilitate new research and investment** by making quality real-world data generation possible, and providing timely clinical insights.

"With data, we can begin to address some of the big health and social challenges facing our country. We can better understand the nature of a problem, find its causes, and figure out how to fix it."[6]
- Kim McGrail, Scientific Director, Health Data Research Network (HDRN) Canada

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Where are we now?

Innovation, Insights, and the Use of Data for Public Good (Trust and the Impact of Not Sharing Health Data)

Robust Health Data and Insights: Canada has the building blocks of an innovative, data-driven, and resilient learning health system, but we're failing to fulfill our potential. We collect vast volumes of data, but these data are highly fragmented across provinces and territories, providers and institutions, rendering them inaccessible and underutilized. They are also often lacking in quality, something that was highlighted by the COVID-19 pandemic, which put a spotlight on existing social determinants of health and their impact on shaping different experiences. Through the pandemic, we learned there is a clear need to collect more inclusive data to generate insights that will identify gaps, and ensure that healthcare is being delivered equitably, among other things.

Innovation: Innovators can benefit from access to high-quality data which allows for novel insights to power innovation, and from high-quality, real-time data to maximize the value of innovations for patients and health systems. Looking into the future, access to high-quality data will also drive discovery of new therapies, and advance better ways of delivering effective,

efficient, and sustainable healthcare. Our current system is not connected in such a way as to facilitate true and robust innovation.

Public Good: In Canada, the general public's lack of trust in the healthcare system, and lack of understanding as to the great value data holds, leads to less information being shared overall. Layering the risk aversion within our health data custodian culture on top of this, creates major barriers to accessing information and sharing it for public good. There are negative impacts associated with this, including poorer health outcomes.

A clear example that illustrates the harms of <u>not</u> sharing data is the story of Greg Price. Greg was a healthy 31-year-old who passed away as a result of Canada's poor health data infrastructure. The lack of access to his health information caused his testicular cancer to go unnoticed, leading to a delayed diagnosis only days before his death.[7] As highlighted by Holly Longstaff, ethicist and Director, Privacy and Access, for the BC Provincial Health Services Authority, "Inaction is not value neutral. Our inability to get our researchers the data they need when they need it can lead to disastrous consequences for patients." Greg's story illustrates how maximizing data sharing in an ethical manner should be a fundamental right - when benefits outweigh potential risks - enabling individuals and communities to unleash the full potential of their data to better their health.

Data Ethics

Health data in Canada is currently under shared, due in large part to the perception that there is great risk associated with sharing health data. Our approach to sharing data is to say no, because saying no is a guarantee of no liability. What we are forgetting when we say no is that it is unethical to not share data when we know that sharing data brings the possibility of better health outcomes for people who live in Canada.

Data Governance

We have visionary plans to create a robust health data ecosystem, but our policy and regulatory environment is rooted in an antiquated understanding of privacy, risk, and rights. We have a great deal of health data in Canada, but it is stored in different places and in different ways, and cannot easily be used or combined. Patients are expected to remember the intricacies of their own health details and prescription lists, often multiple times during one doctor visit, because of barriers preventing one coordinated health record that follows each patient, like in Denmark.

In general, there are a lack of coordinated standards and procedures for data protection, sharing, and management in Canada. Although some provincial health information laws exist, they don't align with each other, and they haven't been updated in over 20 years. As technological advances continue to grow in healthcare, concerns around data exchange of personal information and personal health information also continue to grow. Despite this, Canadian legislation around data security standards is minimal, and there is a clear lack of national alignment.

Data Privacy, Protection, and Security

Stewardship Model for Health Data: Canada has a wealth of talented data scientists, policy analysts, and healthcare professionals including researchers, with the knowledge and creativity to make data work for patients and for society, but we aren't able to share data among these experts to generate and translate insights into meaningful change.

We are currently in a 'custodian' model for health data, in which data are *'as protected as possible and open as necessary'*. Canadian jurisdictions have been calling for privacy law reforms and a balanced approach for data protection that enables appropriate data sharing, so we can achieve a 'stewardship' model for health data, in which data are *'as open as possible and protected as necessary'*. However, very few provincial bodies have collaboratively tackled the need to have a common legislative approach to concepts of modern consent, privacy, or autonomous choice. This leads to continued fragmentation along the care continuum, especially for individuals that require care across jurisdictions.

Data Quality, Standards, and Interoperability (Lack of Harmonization)

The pandemic made it clear that health information in Canada cannot be used and combined quickly enough to detect health patterns in an emergency, due in part to the lack of a robust governance framework. Each province/territory manages oversight of health information with policies that lack stewardship, standardization, and harmonization across jurisdictions. Even within each jurisdiction, many healthcare providers individually collect and hold data, with limited ability to share data with patients and their circle of care. While data governance isn't the only hurdle in the way of enabling real-time health data sharing, it is a critical one.

Data Literacy, Engagement, and Social License

Contributing to the lack of national alignment is a basic lack of data literacy across our general population. For if constituents don't understand the true value of integrated health data, they won't advocate to decision makers for policy change. Data literacy is in its infancy across Canada. In general, people don't realize that they themselves produce data, and that those data are being constantly and continually leveraged by those who collect data. As a result of the pandemic, some have recognized the importance of health data for promoting health and wellbeing, for managing the spread of diseases, and for various other purposes. Alongside this recognition and in the context of emerging technologies, we need to ensure that the public fully understands how health data can be leveraged to realize individual and societal benefit.

The COVID-19 pandemic has shown us how vulnerable we are when our health data ecosystem is weak, and how, when there's political will, we can overcome policy and technology shortcomings to harness data to drive innovation, action and public health impact.

Canada is ready for transformational change.

Inuit, First Nations, and Métis considerations

Dr. Kisha Supernant, Métis archaeologist with the University of Alberta recently tweeted "Indigenous data sovereignty is more than returning our data to our control. It is about our right to determine what constitutes data, how it should be stored, organized, and analyzed, and who should care for it over the long term."[8] Indigenous peoples want to be, and should be, the stewards of and for their own data. Historically, Indigenous peoples have been pushed out of data governance roles while at the same time, their data was being leveraged by others.[9] Indigenous data sovereignty puts Indigenous peoples in control of decisions on how their data are used and leveraged. The UN Declaration on the Rights of Indigenous Peoples (UNDRIP) notes that Indigenous peoples should have "full and effective participation in all matters that concern them", including being trained and employed in the field of data collection.[10] The third Expert Report from the Pan-Canadian Health Data Strategy initiative concurs, and suggests that

as well, First Nations/Inuit/Métis (FNIM) peoples should be in decision-making roles related to data.[11]

In order to ensure this fully inclusive and equitable approach, we must uphold FNIM perspectives on data sovereignty, and a 'nothing about me, without me' philosophy is warranted. To date, FNIM peoples have been largely excluded from the conversations on data infrastructure and integration. Many believe that the assumptions made by non-Indigenous peoples have created a false sense of what is desired by Indigenous peoples.

A best-in-class example can be seen in the Northwest Territories, where the Łı́ı́dlı̨ı̨ Kų́ę́ First Nations (LKFN) community has partnered with the Scotty Creek research facility to improve data sovereignty, and ensure research is not conducted without their review and consent[12]. The approach will be the first of its kind, and the model can be iterated as users learn and observe how the process runs. Requirements of the new approach include that the raw data will be co-owned by the LKFN and the researcher, and that researchers must describe how they have educated themselves on LKFN customs and codes of research practice.[12] This approach truly ensures a 'nothing about me, without me' philosophy.

It is important to note, understand, and appreciate that an inclusive FNIM data sovereign system would not (and should not) be one and the same with a "western" system. Instead, the FNIM data sovereign system should stand alone and be stewarded by FNIM peoples. An excellent example of this type of work is the Silent Genomes Project,[13] the goal of which is to both reduce disparities in health care and improve diagnosis for Indigenous children with genetic diseases. The leaders of the initiative are working with FNIM partners to attempt to reduce barriers to diagnosis - in the rest of Canada, many genomic tests and technologies are widely available. Unfortunately, the access to these technologies is not equitable for Indigenous peoples, which means that pediatric FNIM patients who may need life-changing interventions, might not even know that they need them. Importantly, the initiative aims to do this while also ensuring First Nations principles of OCAP®, [14] Manitoba Métis principles of OCAS[15], and/or Inuit principles of Qaujimajatuqangit[16], so that there is Indigenous-led governance over both biological samples related to health research data, and health data overall.[13]

We believe that a fulsome discussion about how a western and Indigenous data system could work together is warranted and would be a valuable undertaking in the near term. It also goes without saying that control over data is one step toward decolonizing healthcare, but it is not a panacea. Colonial health systems continue to discriminate against and harm Indigenous peoples. Solving for health data is just one step in ongoing reconciliation efforts.

Innovation, Insights, and the Use of Data for Public Good

The value of health data hinges on our ability to use data to generate healthcare insights that benefit patients, the health system, and our society. Insights can tell us what's working and what's not for patients, healthcare practitioners, and the system as a whole, and we can use these insights to drive healthcare innovation, including developing better treatments, better technologies, and better ways of delivering care. Insights and innovation informed by high-quality data are the lifeblood of a resilient learning health system that can anticipate, prepare for, and adapt to emerging healthcare needs, technological change, and public health threats.

What does best in class look like for this topic?
Guided by a commitment to equity and inclusion in the collection, use, and application of health data, all stakeholders benefit from harnessing the full potential of data to glean insights, drive innovation, and serve the public good.

- **Patients** who can access their own data are empowered to participate meaningfully in their health and wellness journey and benefit from higher-quality, more relevant, more personalized care specific to their unique biology, identity, and choices, no matter where they live or who they are.
- **Healthcare professionals** can make better clinical decisions based on more precise, predictive, complete, and up-to-date information about a patient's condition and the utility of treatment options.
- **Decision makers within health systems** are more agile and efficient, able to make equitable decisions, deploying resources and implementing policies based on robust, timely, and holistic evidence of system effectiveness, system gaps, and population needs. They also make better decisions regarding investment in and adoption of innovative health technologies, informed by a more precise understanding of the patients who will benefit from a given innovation and the circumstances needed to maximize this benefit.
- **Researchers & Innovators** (including biopharmaceutical, health technology, digital health, Artificial Intelligence/Machine Learning (AI/ML) companies working in partnership with researchers) benefit from high-quality data which allows for novel insights to power innovation, and from high-quality, real-time data to maximize the value of innovations for patients and health systems. Looking into the future, access to high-quality data will also drive discovery of new therapies, and advance better ways of delivering effective, efficient, and sustainable healthcare.
- **Indigenous Knowledge Keepers and Elders**. Indigenous Knowledge Keepers and Elders can help create a healthcare system that sees integrated understanding as the right approach, ensuring traditional knowledge is brought together with science, working together in parallel toward common goals.

Best in class examples of this action area
Many examples point the way forward. Within Canada, the Canadian Personalized Healthcare Innovation Network (CPHIN) is partnering with health systems in Canada to use aggregated health data to drive innovation and improvement in cancer care (PREDiCT).[17] The PREDiCT initiative will generate and assess high quality Real World Evidence (RWE) and will enable a Learning Health System (LHS), which may be used to help shape new sustainable reimbursement pathways for personalized cancer treatments, and to inform strategies for acting on insights.

Another example is Ontario's Institute for Clinical Evaluative Sciences (IC/ES)[18] which aims to translate data into trusted evidence that makes policy and health care better and people healthier. This example demonstrates the power of integrated administrative datasets (health, social, economic) in informing health policy.

The GEMINI initiative[19] is another leading example that has brought together multi-site clinical data to enable health research and quality improvement projects. In the UK, the National Health Service (NHS) has made data the centerpiece of health system transformation through the creation of NHS Digital, whose role and remit is to "... ensure that external organisations can access the information they need to improve outcomes, and the public are confident that their

data will be stored safely by NHS Digital. Our goal is to maximise the accessibility, quality and utility of health and care data while respecting privacy, transparency and ethics."[20]

Callout Box: How can data enablement catalyze innovation and leverage data for public good?

Consider the recent COVID-19 vaccine launch in Israel where, by the end of 2020, novel vaccines were successfully administered to more patients (proportionally) than in any other country.[6] Israel was able to provide optimized pandemic protection based on a rapid coordinated health response informed by their robust electronic health records which allow them to leverage data to help optimize treatment for patients. The country has a rich history of using patient health data to carry out research related to clinical care, epidemiology, and health policy, and was able to leverage their integrated health data system to provide (and continue to provide) valuable real-world data on the safety of the COVID-19 vaccines from the Israeli population.

"**When the SARS-CoV-2 virus was first identified at the start of 2020, its entire genetic blueprint – its genome – was shared online within days. This rapid sharing was instrumental to vaccine development, helping us to produce safe, effective vaccines within just a year**".[21]

"**Health information has become one of society's most valuable public goods. It informs policy, management, care and research, leading to better, more equitable health outcomes for all Canadians**".[22]

"**Better data. Better decisions. Healthier Canadians**".[23]
- *Canadian Institute for Health Information (CIHI) Annual Report 2021-2022*

Data Ethics

"**I think it is well understood now that *not* sharing data is unethical…I would say that we have a moral obligation to share data with those who need it to serve all patients.**"[24]

- *Holly Longstaff , PhD. Research Privacy Advisor for the Provincial Health Services Authority (PHSA), Ethicist for the BC Cancer Agency Research Ethics Board (REB), member of Schulman Institutional Review Board's Canadian panel*

Data ethics is a subfield within ethics that has emerged given the increasing importance of data in our society, and the necessity for appropriate access and use. Specifically, data ethics refers to methodologies and practices that promote the inclusion of good human values into data-driven applications, approaches, and decisions.[25][26] Emerging digital health technologies can disrupt the health system in a positive way, but can also lead to unintended consequences, such as inequities of care, undetected health outcomes based on data bias, or other risks that need to be addressed, especially if ethics are not considered. Data ethics is the key to unlocking new technologies and innovations in healthcare, while upholding human rights and promoting just health outcomes and benefits for patients.[27,28]

What does best in class look like for this topic?
Best in class data ethics goes beyond traditional concepts of privacy and aims to ensure that standards, policies, and practices maximize the benefits from health data, while minimizing the potential for harm (data are 'as open as possible and as protected as necessary'). A best-in-class data ethics approach ensures a balance of benefits and harms in relation to health data, rather than an outdated approach to protecting data at all costs (data are 'as protected as possible and open as necessary').

For example, the Canadian Organization for Rare Diseases (CORD) has developed principles of data ethics in their approaches to data sharing and partnerships. CORD's Consensus Framework for Ethical Collaboration aims to support ethical partnerships to ensure "proper delivery of the most appropriate care for patients worldwide."[28] Through this work, CORD has demonstrated its commitment to ethical partnerships and data ethics, which enables greater insights, sound policies, and enhancement of care for those impacted with rare diseases.

Another very useful tool is the Open Data Institute's (ODI) Data Ethics Canvas,[29] a tool "...to help you identify and manage ethical issues in your data project". The ODI reminds us that we should be thinking about data ethics at all stages of a project, from the collection and maintenance and sharing of the data (stewarding), to creating insights from those data, to ultimately deciding how to act on those data insights.

Overall, data ethics takes a proportional approach to all things data by assessing whether the rights and benefits stemming from data outweigh potential risks to privacy or other potential harms.

Best in class example of this action area.
In 2019, a Data Working Group in Canada led by patients and caregivers developed The Declaration of Personal Health Data Rights.[30] This Declaration was developed in collaboration with health data custodians, patient groups, and citizen groups. The intent was to unify principles around personal health data, in order to stimulate the health ecosystem towards the efficient and effective adoption and implementation in collaboration with industry, policymakers, and patient groups. This work resulted in the creation of 11 proposed rights, including the right to consent, benefit, object, or restrict processing of data, to list a few.[30]

Data Governance

Data governance is a term wide in scope with origins in information management, centering on best practices for data collection, storage, archiving and purging. Common elements of data governance include Collection, Privacy, Usage, Synthesis/Analysis, Control, Publication, Storage, and Archiving/Disposal.[31] In plain language, data governance reminds us of the importance of ensuring that data is secure, reliable, and available to those who should have access to it.

When speaking about health data, governance is top of mind due to the personal nature of the data being shared. Digital technologies are continuously being used to inform and improve government responses to crises such as the COVID-19 crisis, in many cases, using personal health data.

The COVID-19 pandemic helped make clear the importance of data governance. During the pandemic we quickly realized that health information in Canada cannot be used and combined

quickly enough to detect health patterns in an emergency. Canada is data rich but information poor - although we have lots of health data, we lack a robust governance framework that would enable data sharing across jurisdictions and generate insights to help transform our healthcare system into a more efficient and sustainable system. While data governance isn't the only hurdle to jump to enable real-time data sharing, it is a critical element.

The following example helps illustrate the need for real-time health data sharing: In Canada, the COVID-19 pandemic led to an average increase of approximately 3,000 additional inpatient admissions per month for respiratory conditions from March 2020 to June 2021. By April 2021, 87% of respiratory admissions to the intensive care unit (ICU) were for COVID-19, with an average cost of CAD $50,000 per ICU stay.[32]

This comprehensive Canadian data was not available in real-time, to allow healthcare workers and hospitals to adapt, resource, and plan effectively for these urgent health needs. In addition, many elective surgeries and procedures were canceled early in the pandemic while hospitals were not at capacity.[32]

Optimizing data governance and leveraging real-time health data would support the development and implementation of a robust health human resources strategy for Canada, by allowing for faster, more efficient visibility, and access into health data trends and population needs. Robust quality data available for analysis and insights generation would help us anticipate, adapt, and better prepare for future health threats in Canada, as well as potentially guiding other jurisdictions.

When considering the principles that should inform a data governance strategy, we propose using the Organisation for Economic Co-operation and Development's (OECD) work as a benchmark. The OECD's Recommendation of the Council on Health Data Governance is intended to provide guidance for users and holders of data to set "...framework conditions for enabling the availability and use of personal health information to unlock its potential."[33] Well before the pandemic, and based on the identified issues around health data, the OECD concluded that countries ought to "establish and implement a national health data governance framework to encourage the availability and use of personal health data to serve health related public interest purposes while promoting the protection of privacy, personal health data and data security".[33] Noted in the callout box below is the rationale for this conclusion.

Callout Box: Why is it important to have a strong data governance plan?

In 2016, prior to the pandemic, the Organisation for Economic Co-operation and Development (OECD) in their Recommendation of the Council on Health Data Governance[33] recognized that:

- Access to, and the processing of personal health data can serve health-related public interests and bring significant benefits to individuals and society.
- Health systems are increasingly affected by a growing volume of personal health data in electronic form that are often held in silos by organizations or government authorities.
- Public trust and confidence in the protection of personal health data must be maintained if the benefits achievable through its processing are to be realized.
- Personal health data, being sensitive in nature and subject to ethical standards and the principle of medical confidentiality, require a particularly high level of protection and that technological developments can both enable the privacy protective use of personal health data and introduce new risks to privacy and data security.
- Achieving these benefits requires the careful development and application of robust, context appropriate, privacy protective health data governance frameworks that require the identification and management of privacy and security risks.
- Considerable progress is being made to achieve coordinated health data governance frameworks, the many differences in the availability of, access to and use of personal health data both within and across national borders must be addressed.

Within the same document, and informed by the pandemic, the OECD set 12 specific principles to help countries establish a national health data governance framework.[33] Within the implementation of the Pan-Canadian Health Data Strategy, establishing and implementing the national health data governance framework provided by the OECD recommendations would support governments in assessing and reconciling the risks and benefits of using personal health data for public purposes (e.g., in the context of addressing the COVID-19 pandemic).

Important to note as well is that work towards a Canadian standard for health data governance was initiated in 2020, and that collaborative work continues through The Canadian Data Governance Standardization Collaborative. The Collaborative was launched as a response to the Digital Charter to coordinate the development and compatibility of data governance standards and complementary conformity assessment programs in Canada, contributing to the digital and the data-driven economy.[31] The development of the *Roadmap* [31] is a product of this collaborative discussion including providing recommendations to address gaps, as well as highlighting the imperative need for data governance standardization.

What does best in class look like for this topic?
Imagine if people living in Canada and their care providers could access health information in real-time to identify the risk of life altering conditions such as cardiovascular disease, cancer, or diabetes. This is possible if transparent data sharing, and governance rules are in place. In fact, countries like Israel, Finland, Denmark, and Estonia have demonstrated the effectiveness of interoperable data sharing for improving health outcomes by enabling people to access their health data in a "one person, one record" system. This system reassures people that their wishes are being respected through full transparency with respect to who has access to health data and how it is being used. This system also ensures that legal, ethical, and privacy

principles are being followed and details are fully transparent. Each of these countries follows and respects the recommendations set out by the OECD as described above.

Best in class example of this action area
The European Health Data Space (EHDS) of the European Commission's Health Union, the first common data space being established to realize the European Strategy for Data, is comprised of rules, common standards and practices, infrastructures, and a governance framework that aims at[34]

- empowering individuals through increased digital access to, and control of their electronic personal health data, at national level and EU-wide, and support to their free movement, as well as fostering a genuine single market for electronic health record systems, relevant medical devices, and high-risk AI systems (primary use of data); and,

- providing a consistent, trustworthy and efficient set-up for the use of health data for research, innovation, policy-making, and regulatory activities (secondary use of data).

The Data Governance Act, launched in November of 2020, sets out a framework to ensure data sharing is enabled across sectors. The EHDS Regulation builds on this and sets forward data governance specific to health data considerations and the EHDS itself.[34]

In England, there are "Caldicott Guardians", responsible for sharing data responsibly, while making sure that people's privacy and personal information are protected. These guardians are data stewards who not only know and understand ethics and the law, but also focus on being compassionate and courageous, knowing their decisions will affect real people. Essentially, the guardians keep people's health information safe, and make sure wise decisions are made about its use.[35]

Another example is the INSIGHT initiative in the UK, which is a health data research hub that includes patients and other stakeholders in decisions around data sharing and use.[36] This example is a best in class example in governance given that it highlights the importance of patient representation in decision making to build greater trust among stakeholders and the community, encouraging more health data sharing in the future.

The Infectious Diseases Data Observatory (IDDO) has put a number of data governance processes in place to allow for sharing and secondary use of data from individual patient data from observational studies, health records and clinical trials. The data is made available for researchers, healthcare providers and public health agencies who collaboratively work toward better health outcomes.[37] Good data governance practices makes bringing data together for public good feasible.

"Understanding the evidence fuels action and provides the guidance needed to make smart choices, especially in new and unfamiliar health care terrain."[38]

- *Canada's Drug and Health Technology Agency (CADTH), 2022-2025 Strategic Plan*

Data Privacy, Protection, and Security

There is often a lack of understanding of the differences between data privacy, data protection, and data security. Each are elements of data governance, and all are necessary to ensure the appropriate and optimized use of data, in this case health data. Privacy and security go hand-in-hand: you can't exercise meaningful control over your data if the data themselves are vulnerable to uses you haven't authorized.

- Data privacy determines the access to data, and refers to an individual's ability to determine/control when, how, and to what extent their information is collected and shared, or '...controlling what others can do with information…' after it has been accessed;
- Data security and protection are directly related. Security refers to the means to achieve the goal of protection of information from unauthorized access, availability, alteration, or theft, throughout the data life cycle. Security can be achieved through the use of tools and technologies that facilitate the proper handling of data.

People who live in Canada technically "own" their data and can decide who should have access to those data. Once permission has been granted by the individual, tools and technologies are leveraged by data custodians/stewards to ensure the data are secure. Finally, those who are accessing and using the data must protect the data by handling it appropriately.

What does best in class look like for these topics?
A best-in-class system which considers privacy and protection (via security) is one where privacy laws are consistent across the country. Where individuals, if they so desire, could be in the driver's seat as active participants in decisions related to their health data - understanding how and why it's being used, shared, and accessed, and being informed about the benefits and risks associated with sharing their data. Best in class would mean that across the provinces and territories, the same focus would be given to ensuring health data are secure, through establishing consistent national protection laws that are subject to an ongoing continuous improvement process that includes evaluating and adjusting methods as appropriate. Aligned national data protection policies will ensure individuals' health data is protected, while facilitating access to data for better decision making.

Best in class examples of these action areas
In recent years, Europe's General Data Protection Regulation[39] (GDPR) has proven to be a best-in-class model for data protection given its mechanisms for privacy across borders along with its modern concepts of necessity (lawful basis for processing data) and proportionality (ensure no creeping of scope, ensure data minimization), in line with modern data uses and emerging technologies, including Artificial Intelligence. The GDPR defines seven key principles for processing and protecting personal information, including personal health information. While these principles serve as best-in-class global standards, it is important to contextualize the sensitivity of health data in relation to other personal health information and adapt a streamlined protection process accordingly.

Callout Box: The seven key principles of Europe's GDPR:[39]

1. **Lawfulness, fairness and transparency -** the data must be used in ways that are fair, clear, open and honest from the beginning.
2. **Purpose limitation -** the purposes should be documented. Data can be used for new purposes if it aligns with the original purpose, or where consent is acquired
3. **Data minimization -** only collecting, using, or disclosing the least amount of identifying information necessary for the purpose.
4. **Accuracy -** the appropriate steps should be taken to ensure the personal data being held is not incorrect or misleading and should be kept up to date.
5. **Storage limitation -** personal data should not be kept for longer than it is needed and stored data must be periodically reviewed and maintained.
6. **Integrity and confidentiality (security) -** the right security measures should be in place to protect the data that is being held.
7. **Accountability** - those who are using the data must take responsibility for what they are doing with it and be able to show that they are being compliant with all other principles.

Bill 3[40] in Quebec has also been heralded for supporting autonomy and increased access for individuals to their own health information (being able to make their own decisions related to privacy for their data). Some experts believe it provides evidence of a shift in the Canadian healthcare landscape and that similar legislation ought to be encouraged and pursued in all jurisdictions.

Fast Healthcare Interoperability Resources (FHIR),[41] published by Health Level Seven (HL7®) is a best-in-class standard for healthcare data exchange. This standard was developed using a collaborative approach and enables secure access to health information. The exchange of healthcare information, as defined by this standard, is possible even if the information is stored differently in those systems.

The First Nations principles of OCAP®,[14] a registered trademark of the First Nations Information Governance Centre (FNIGC), OCAS[15] and Qaujimajatuqangit[16] also represent best in class principles of data protection and support strong information governance. OCAP® stands for Ownership, Control, Access, and Possession for First Nations data, and is key to ensuring self-determination and data sovereignty. OCAS stands for Ownership, Control, Access, and Stewardship for Métis data, and serves a similar purpose as OCAP® principles. Some Métis communities follow the principles of OCAP® and some follow the principles of OCAS. Inuit Qaujimajatuqangit "encompasses all knowledge and many things in Inuit culture…"[16]

The Five Safes[42] is an internationally recognized framework used by Health Data Research-UK (HDR-UK), National Institute for Health Research Design Service (NIHR) and guides British Columbia's Data Innovation Program. The framework highlights five key areas (Safe Data, Safe Projects, Safe People, Safe Settings, Safe Outputs) that inform data protection and if followed, reduce the inappropriate use and access of sensitive data. The Five Safes Framework is a useful governance and data protection tool because it allows for tailoring controls based on what data are being used, who is accessing it, for what purpose, in what environment, and with what outputs.

Data Quality, Standards, and Interoperability

Our health information needs to be clear, correct, complete, timely, and meaningful, and housed in systems that access and share data with other systems – this is what data quality, standards, and interoperability are about. Imagine if we could see all our health data in one place, on a device of our choice, to help ensure and achieve the best care possible for us. Vetted clinicians and health officials could look at appropriately protected data of people grouped together, in real-time, to find trends or predict outbreaks, and inform strategies to help protect our health and the health of our children, families, and loved ones. Researchers and innovators could access health data to discover new methods to better manage chronic disease and improve health outcomes, or potentially even cure diseases altogether.

What does best in class look like for this topic?
Imagine being at a new clinic and pulling up your health information and prescriptions on your phone. After the visit, your health information is updated in real-time by your health care practitioner on a device of their choice. In an emergency, you could access all your health information so that providers could give you the best care right away, wherever you are in Canada. Doctors would have up-to-date and relevant information to provide safe and effective

care and be able to easily refer you to other services you may need. Health officials, governments, and researchers could look at real-time health data grouped together, in graphs and tables to find trends, or know the types of patients who may respond best to medicines, to make sure patients are getting the best care possible for them, especially for serious diseases like cancer and diabetes. Payers could access these data and leverage them for innovative funding agreements with drug manufacturers, moving some risk away from Payers and sharing it with manufacturers. Using and learning from our health data on an ongoing basis would help all people in Canada lead healthier and happier lives.

Best in class example of this action area.
There are several best in class approaches for data quality. Some countries, like Israel, Finland, and Estonia are focusing on a 'person-centered' health data strategy, and use the "One Person, One Record" system. Denmark has been using and combining health data for many years, to better understand the health of its people, often through registries for chronic diseases.[43] Other countries like the UK, US, and the Netherlands apply a mix of legislation, technology investment, and incentives to advance data sharing.

Interoperable Europe is an initiative of the European Commission to establish a cooperative interoperability policy for public administrations across the European Union.[44] Interoperability is a key concept under the larger umbrella of data governance, and this policy is an example of a good health data governance framework that fosters coordination and the adoption of common standards for public services and data flows among jurisdictions.

In Canada, we could learn from these examples to help build a common data model and ontology to support timely sharing of quality data between systems. By bringing these validated models together with updated data access and sharing policies, we could reduce barriers to sharing data in the interest of public good. This would also allow for personal and clinical use of the data, use by governments to improve health services, and use by innovators and researchers to improve treatment of disease. We don't need to reinvent the wheel - instead we need to be comfortable stealing with pride.

Callout Box: How can Artificial Intelligence in health make managing health easier?

Artificial Intelligence (AI) is a rapidly evolving technology with the potential to transform health. AI can take varied forms. Examples include a simple digital tool that matches patients with clinical trials, based on an analysis of their diagnostic test results (health data), or an online tool that asks people to describe symptoms and then uses AI to form a likely diagnosis, such as WebMD[TM].[5]

AI is defined as "any current or future machine learning approach to predictive analytics, decision-support systems and/or automated decision-making",[5] and requires a large volume of high-quality data in order to identify meaningful patterns relevant to health. An important concept to consider in AI is the 'garbage in, garbage out' (GIGO) concept. In essence, GIGO shows us that AI outputs are only as good as the inputs - that is, if AI is trained on poor inputs, such as poor quality, incomplete, and non-representative data, then it will produce poor and invalid outputs.[45] Consider if a country like Canada was trying to make assessments on the way cancer is diagnosed across the country, to look for best practices, but the AI being used for the analysis has only been trained on data from non-Indigenous peoples. The resulting assessment would be based on incomplete data, meaning the assessment wouldn't be accurate.

Over half of all Canadians have a growing understanding of AI and appreciate the potential that AI could have for their health. They expect these transformative technologies to be adopted where they can impact prevention, diagnosis, and treatment.[46] In doing so, they also expect their health data to be handled with care, and require transparency about who is using their data, how they're using it and for what purpose.[46]

We must extend the momentum generated by our collective response to COVID-19 to do better, be better, and create stronger, more sustainable, and more resilient health systems"[38]
   - *Canada's Drug and Health Technology Agency (CADTH), 2022-2025 Strategic Plan*

Data Literacy, Engagement, and Social License

Our world is increasingly digital, and digital tools depend on data to provide value to users. In order to get greater value from digital technologies and be able to transform healthcare through leveraging of data, we need data. But what happens when people say 'no, you can't have my data'? This happens when we don't understand how our health data can and could inform decision-making, that is, if we are not 'data literate'. Lower levels of basic data literacy among people have been associated with poorer health outcomes for individuals, and also for society.[47] It's not just the general public that benefits from data literacy, but health care professionals (HCPs) as well. New developments in data technology, from analysis of data to generation of insights, happen almost every day. HCPs, including those who handle data ('custodians') have a responsibility to stay abreast of these developments, so they can understand what data-enabled support can do for them and for their patients.

We describe data literacy as being aware of how your own data is being used. This could include having some level of understanding of what health data are being collected and how, who is using those data and how, and the trade-offs between the risks and benefits of sharing data. It also includes understanding your rights and how to exercise them.

If people have a general understanding of these elements, they can make better decisions about how they want their own health data to be used, for the benefit of themselves and for society. This is why it is critically important for people to have agency over their own data. Agency allows us to make our own decisions and to be in control. It also allows us to make clear what our needs are to ensure that the ways our data are being used make sense and serve a purpose. Equally important to this basic level of understanding and agency over our data, is a basic level of trust. Having transparency around how and why one's data are being used can help build trust between those who collect and use data, and those who produce data (people).

Data literacy is a critical element of health literacy in general, and ensuring we all understand data literacy will lead to true health equity across our country.

What does best in class look like for this topic?
Some countries have higher levels of data literacy than others, particularly where a patient feels empowered to be in the driver's seat in terms of managing their own care and determining who gets access to their data. In these countries, individuals who are informed and have agency over their own information are more willing to trust and share their data, as they are better able to distinguish between trusted and untrustworthy data uses, technologies and/or partners. Layering transparency into relationships between data producers (people) and data users will increase trust even more by making clear how data are being leveraged. In turn, this enables an ecosystem that promotes meaningful consent and sharing of data so that we can all benefit from emerging technologies and data pursuits. Data knowledge is data power.

Best in class example of this action area.
The Netherlands has the highest level of health literacy in the world, according to a 2021 study.[48] Denmark follows closely behind and recent research highlights the impact of increased literacy in terms of earlier cancer diagnoses, which can change the trajectory of the disease.[48] Key elements that these countries have in common include government funding toward health literacy efforts (taking into account a public health perspective),[49] collaboration across the public and private sectors, and transparency. Henning Lanberg, director of the European Data Saves Lives initiative and professor at the University of Copenhagen has stated, "There is an enormous need to build a system as transparent as possible, so people who live in Canada and patients are informed and confident about how their data are being used and how it is protected."[5] Danish citizens were interviewed for this World Class Health Data System paper, and their perspectives on the Danish system illustrated an unwavering level of trust - trust that the data will enable better decision-making, and trust in a system that makes those decisions for the good of society.[50] When asked how this trust was earned, a specific example regarding registries was highlighted - in Denmark, chronic diseases are managed through registries (data collection and tracking), so anyone with a disease of any kind understands the value that their data offer, and the impact that making their data available can have on their own health and overall societal health.

Looking within Canada, 3,100 patients from seven clinics at Toronto General Hospital and Princess Margaret Cancer Centre were offered access to a patient portal[51] in May 2015. Over a period of 20 months, approximately half of those patients agreed to access the portal. A six-month evaluation study demonstrated that:[51]

- 65% of staff reported improved communication
- 94% felt better prepared for appointments, 98% saw improvement in their care management, 98% were better able to make decisions, and 15% were able to identify some errors in the documentation.

Data literacy is more than knowing what to do with data. People in Canada must have the agency to be active participants in their own health, and be willing to contribute toward the health of society. In order to do that, we must all be proactive and informed. Data literacy is one of the keys to unlocking data potential and establishing a social license to leverage the value of data for individual and societal benefit. Increased data literacy is needed for all stakeholders of a healthy Canada, including health care professionals, and those handling and processing data on behalf of others.

How to Get There - Policy Recommendations

To achieve a world class health system in Canada, action is required on a number of fronts. In this paper, the Policy Modernization Group has several recommendations in support of the policy environment for a world class health system.

We believe that we must start with collaboration and cooperation, and that this will be a long journey. We must stop attempting to 'fix' the system in silos and must instead align our goals and objectives and work together for public good. Collaborators must come from the public, private and not-for-profit sectors, and must consult with and work with citizens, patients, and caregivers across jurisdictions, including Inuit/First Nations/Métis peoples and people from underserved or minority communities, in order to prioritize issues of greatest importance to users of the system. If we can mobilize successfully, and focus on person-centred design, we will achieve the system we all strive for, and we will achieve our aligned goals more quickly.

Building trust is fundamental to collaboration and cooperation and to build trust all stakeholders must acknowledge the harms of historical approaches to data collection, use and governance and the need to build meaningful and sustained relationships and partnerships. Acknowledgement is an important first step toward building trust. All stakeholders must also foster trusting relationships in communities by making specific and targeted efforts to collect and integrate representative data, and to then act on those data to benefit those communities and individuals.

We have clearly demonstrated through robust examples that there is no need to reinvent the wheel - in each section of this paper we have highlighted a best-in-class example or approach that is already being implemented in Canada or in other jurisdictions. There is no time to waste in adopting policies and practices in place elsewhere as these best-in-class examples have been validated and impact is being demonstrated and importantly, global cooperation and interoperability will be much more achievable and realistic.

In line with comments from the Public Policy Forum in their paper entitled "Next Steps: Pan-Canadian Health Data Strategy" from July 2022,[52] we highlight that most policy frameworks in Canada were created before the digital age (i.e., most of our privacy legislation in Canada was created before the iPhone was invented), and thus require a modern-day overhaul to ensure that comprehensive health data can be brought together and leveraged for public good (the value of which was clearly demonstrated by the lack of data interoperability and connection during the COVID-19 pandemic).

We have organized our summary of recommendations by the group responsible.

Federal Government

- The Federal Government must implement the recommendation of the Pan-Canadian Health Data Strategy (PCHDS) Expert Group reports, in particularly initiating the creation of an expert-led and competency-based Health Information Stewardship Council that would coordinate common efforts and steward the long-term process to creating and realize the envisioned health data foundation and implement the proposed Canadian Health Data Charter. The Council must include patient and citizen partners, as well as the provinces and territories, to ensure it is truly pan-Canadian.

  The Health Information Stewardship Council must:
    - Ensure alignment on and adoption of national data security standards for consistency across Canada
      - These standards and policies around secure movement of data should be developed with the end user as an integral part of the process to be applicable to businesses and users irrespective of their size and capabilities.
      - These standards should be transparent and include clear roles, responsibilities, and support resources, along with defined data protection processes and risk management practices.
    - Foster a culture where people trust in the system within families and communities, and across generations.
    - Foster a culture where health data are viewed as an asset, and data accessed with the notion of being 'as open as possible, and as protected as necessary'.
    - Implement a transparent governance framework so everyone understands how data is governed.
    - Ensure all levels of government are working together to align on policies for data protection, and transparent management of health data.
    - Ensure all stakeholders ask the questions essential to closing the health equity gaps.
      - Lead outreach to underserved minority communities, to increase the level of data literacy, to hold conversations about data and what we can learn from data, and to include them in conversations around a strategy for acting on the data.

Provincial and Territorial Governments

- Provincial and Territorial governments must implement the recommendation of the PCHDS[53] and "...create one or several Learning Health System Table(s) (LHS Table(s)) that would drive funding and action toward the common vision." The LHS tables must include citizen and patient partners.
- Provincial and Territorial governments must align with and execute the Pan-Canadian Health Data Strategy Expert Group's recommendations on a common vision for health data integration,[53] supported by investment, legislation, and implementation guidance to allow health data to be combined between healthcare facilities, such as family doctors' offices, specialists' offices, clinics, labs, hospitals, and pharmacies.

- Provincial and Territorial governments must implement a governance and management framework whereby data are collected once and utilized multiple times for patient care, public health decision-making, health workforce management, population research, and patient-oriented research.
- Provincial and Territorial governments must establish strategic public/private partnerships based on a foundation of trust, to bring data together to realize scale, through coalition building and converging on objectives. Existing provincial, national and international coalitions (some highlighted in the PCHDS Expert Group report) should be identified and leveraged for best practices.
- Provincial governments and the "Chief Data Steward(s)" must establish a framework for data stewardship for use by data stewards who can facilitate a partnership with healthcare stakeholders at the regional, provincial/territorial, and national levels.
  - This framework should be clear and reasonable, and should consider all our different backgrounds, communities, and cultures – a framework that people in Canada agree with – in order to create a health system that is stronger and more resilient and can protect and improve everyone's health today and into the future.

All Governments

- Establish a "Chief Data Steward" system similar to the Caldicott Guardians appointed in the National Health Service (UK). A Caldicott Guardian is a senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly. All NHS organizations and local authorities which provide social services must have a Caldicott Guardian.[54] A Chief Data Steward would optimize health data activities within their jurisdictions and collaborate with health organizations and the private sector across Canada to identify priority gaps in data sharing, incorporate international best practices, and enable appropriate data flow for the public good governed by regulation and ethics.
- Modernize privacy regulations with individuals positioned to have autonomous choice when it comes to their health data:
  - individuals are the owners of their data,
  - privacy is a fundamental right,
  - we all have responsibilities and rights to protect and share information, responsibly,
  - strike a balance between sharing and protecting data, in the context of public good.

All Stakeholders

Increased data literacy is needed for all stakeholders of a healthy Canada, including health care professionals, and those handling and processing data on behalf of others. Data literacy is more than knowing what to do with data. Data literacy is one of the keys to unlocking data potential and establishing a social license to leverage the value of data for individual and societal benefit.

- Public, private sector, health and education sectors and all stakeholders must take a national aligned approach to health data literacy.
  - Create materials for all stakeholders, including health care professionals, in plain language (grade 6)
  - Translate materials into multiple languages, including Indigenous languages

- ○ Make materials available both online and offline (hard copy)
- ○ Put materials in all healthcare institutions (doctors' offices, hospital waiting rooms, allied health professionals' offices, universities, etc.)
- ○ Work with the private (including industry associations) and non-profit sectors (including colleges and patient advocacy groups) to disseminate information
- ○ Align to common data taxonomy (common data language)
- ○ Offer transparent descriptions of the value and impact that come with sharing health data (leverage storytelling)
- ○ Leverage government funded bodies (ICES, CIHI, Vector, etc.) to help educate and reinforce the message.

Personas

The authors have developed two personas to help compare and contrast the current state of health data sharing vs a future state of health data sharing, made possible by implementation of the Pan-Canadian Health Data Strategy.

Persona 1: Senior with memory loss in the <u>current</u> environment[55]
A senior patient (Pat) with memory loss goes to a walk-in clinic with complaints of a stomachache, as well as bruises and injuries related to a fall. She is alone because her family lives in a different province. The interaction begins with a clerk requesting personal information from the patient. Pat has difficulty recalling some specifics, including her phone number. One of the questions the clinic asks is for Pat to provide the name of her regular General Practitioner.

Pat is then seen by a physician at the clinic and is asked why she is visiting today. She tells her story of a stomachache and a fall that she thinks may have been caused by the stomach ache. The physician examines her and decides to refer her for a scan to investigate her stomach pain.

The appointment is scheduled for two weeks away. Pat arrives on the date to meet with a gastroenterologist, who asks her to tell her story again. Pat becomes confused as to the details of her ailments (cannot recall how long she has had a stomachache, cannot recall how, why, or when she fell). Furthermore, Pat had previously had a colectomy and had completely forgotten about it due to her memory loss. The physicians discover the surgery during the scan.

As a result of memory loss, over a few weeks Pat tells a slightly different story to three different health care practitioners, resulting in uncertainty for her Care Team. If the Care Team is unable to find the source of truth, outcomes may be compromised for the patient (for example, having a stomachache for a few days vs a few weeks or a few months could mean very different things, and being aware of a prior colectomy surgery would inform diagnosis and treatment).

Persona 1: Senior with memory loss in a <u>world class</u> health data environment
A senior patient (Pat) with memory loss goes to a walk-in clinic with complaints of a stomachache, as well as bruises and injuries related to a fall. She is alone because her family lives in another province. The interaction begins with a clerk requesting personal information from the patient. Pat has difficulty recalling some specifics, including her phone number, but is able to confirm the information in her electronic medical record (EMR) because she knows she hasn't moved in years. The EMR contains the name of Pat's GP so the clerk simply confirms that information with Pat.

Pat is then seen by a physician at the clinic and is asked why she is visiting today. She tells her story of a stomachache and a fall that she thinks may have been caused by the stomach ache, and the information (data), as well as the physician's notes, get entered into her EMR by the physician in real-time. The physician is able to see in her EMR that she has had a colectomy, and is able to see the follow up from that surgical procedure. She examines Pat and decides to send her for a scan to investigate her stomach pain further with specific instructions to examine the area where a portion of her colon had been removed. The physician is concerned that Pat's severe diverticulosis has returned.

When Pat is seen by the next practitioner, she is not asked to tell her story again. Instead, the practitioner consults the patient's EMR to read the story and the notes herself. The Care Team is certain that Pat will have the best chance at achieving better outcomes, because they are able to see all the relevant information about her in one place, at one time, and the information is up to date. This enables data-driven decision-making. As well, it helps Pat feel less anxious, knowing that she won't have to keep repeating her story, and it helps Pat's family feel less anxious as they can't be with her at her appointment.

Persona 2: Patient who lives in two provinces in the <u>current</u> health data environment
Des lives in Newfoundland with his family, but he works in Fort McMurray, Alberta. Des works shifts that are three weeks on, and three weeks off, and he commutes back and forth in between.

Des took off on a flight for Edmonton, and while on the plane, began to feel unwell. By the time he arrived at his apartment in Fort McMurray, he felt feverish, had a sore throat and also a cough. Since the COVID-19 pandemic began, Des has always been cautious about wearing a mask, and when he is flying, he wears two masks, layered on top of each other. Des has serious asthma, which makes him high-risk for contracting respiratory infections.

Des has been managed by a lung specialist for many years regarding his asthma. His physicians and specialists in NL have tried different regimens for Des and after many years, have found a routine that works for him.

Des decided to go to bed for the night and reassess how he felt in the morning. When he woke up, he felt even worse. He decided to have a cup of tea to see if that might help his sore throat, and while it felt good going down, his throat still felt raw.

He immediately went to the hospital. He doesn't have a physician in Alberta because his primary residence is in Newfoundland. When he arrived at the Emergency Department, he saw how full the waiting room was and put a third mask on top of the two he was already wearing. After about an hour's wait, he was brought into the triage area and was assessed. He told the attending physician about his severe asthma but unfortunately, he was unable to describe the various asthma protocols he has tried, and the physician in Alberta couldn't access Des's medical record because the record is stored in Newfoundland, and provinces cannot share data in Canada.

As a result of not having access to Des's extensive medical record, the physicians in Alberta had to make potentially life-affecting treatment decisions for Des without fully understanding his underlying condition. Respiratory infections are life-threatening for Des due to his severe asthma, and his physicians in Alberta were forced to take their best guess at how to treat his infection in the context of severe asthma.

Persona 2: Patient who lives in two provinces in the <u>world class</u> health data environment
Des lives in Newfoundland with his family, but he works in Fort McMurray, Alberta. Des works shifts that are three weeks on, and three weeks off, and he commutes back and forth in between.

Des took off on a flight for Edmonton, and while on the plane, began to feel unwell. By the time he arrived at his apartment in Fort McMurray, he felt feverish, had a sore throat and also a cough. Since the COVID-19 pandemic began, Des has always been cautious about wearing a mask, and when he is flying, he wears two masks, layered on top of each other. Des has serious asthma, which makes him high-risk for contracting respiratory infections.

Des has been managed by a lung specialist for many years regarding his asthma. His physicians and specialists in NL have tried different regimens for Des and after many years, has found a routine that works for him.

Des decided to go to bed for the night and reassess how he felt in the morning. When he woke up, he felt even worse. He decided to have a cup of tea to see if that might help his sore throat, and while it felt good going down, his throat still felt raw.

He immediately went to the hospital. He doesn't have a physician in Alberta because his primary residence is in Newfoundland. When he arrived at the Emergency Department, he saw how full the waiting room was and put a third mask on top of the two he was already wearing. After about an hour's wait, he was brought into the triage area and was assessed. He provided his MCP number (NL health card) to the triage nurse and she was able to immediately access his electronic medical record (EMR). In the record, the nurse noticed a flag that indicated Des was high-risk for respiratory infections, and which provided a link to another part of his EMR with robust details about his underlying condition, the treatments he had tried in the past, and his current protocol.

The nurse admitted Des immediately and called in the lung specialist. Before the specialist came to Des's bed, he had already read Des's full EMR and was up to date on his current protocol and the issues that had been flagged by his physicians in NL. After seeing Des, he recorded his physician notes and all test results and follow up recommendations to Des's EMR in real time, so that Des's primary physician in NL could follow up with him upon his return.

As a result of having access to this information, the physician was confident that he would be able to provide Des with beneficial care, and Des was confident that the Alberta specialist would have all the information (data) he needed to ensure the best care possible. Des also didn't have to worry about forgetting any crucial details that might affect his choice of treatment.

Conclusion

This paper describes the vision towards a world class health data system - a system where timely data access, sharing, and quality are facilitated in an ethical and equitable way, while respecting and protecting privacy and human rights. In such a system, not only will we realize the power of data in informing decision-making around diagnosis, treatment, and care, but also in enabling a shift towards healthy living, risk management, and prevention that will lead to better health outcomes for all people living in Canada.

To achieve this vision, this paper highlights what is possible and achievable in some critical areas within our disparate systems. Though we have presented these key pillars as individual considerations on what is possible and what best in class can look like, it is the sum of all of these components that will lead to a world class health data system in Canada. As described in the examples, Canada has fallen behind other countries; in order to harness the power of data and deliver on the healthcare system the people of Canada deserve, we must work together towards this future.

If we act on these opportunities collaboratively, with both private and public sector cooperation, we can enable and facilitate an integrated, person-centered, and data-powered healthcare system for the better health of all who live in our country. True system change cannot happen overnight. It requires individuals to come together and tackle the challenges one step at a time in order to achieve progress and realize the vision articulated in this paper.

Now you might be wondering - how can I help and play a role in building this world class health data system?

The Policy Modernization Group (PMG) is a network of passionate individuals from across Canada, with various areas of expertise, working together towards modernizing and changing the health data landscape in Canada. This paper was facilitated by the individuals in this group who look forward to continued dialogue and welcome any new and interested individuals who are aligned to the need for a better data-enabled Canadian healthcare system. If you or your organization want to learn more about the PMG and ways you can contribute, please contact any of Executive Committee members listed below:

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Endorsers

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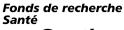
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