

**WHAT WE HEARD REPORT**

# **NEXT STEPS: Pan-Canadian Health Data Strategy**

**What needs to happen following the  
Expert Advisory Group's Final Report**

**JULY 2022**



## ABOUT PPF

The Public Policy Forum builds bridges among diverse participants in the policy-making process and gives them a platform to examine issues, offer new perspectives and feed fresh ideas into policy discussions. We believe good policy makes a better Canada.

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## WITH THANKS TO OUR PARTNERS

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## KEY TAKEAWAYS

Accurate and reliable health data has become imperative, particularly in the aftermath of the COVID-19 pandemic, with a growing recognition that data saves lives. Existing challenges facing Canada's healthcare system have been exacerbated even as new ones surfaced. These present an opportunity for policy measures that result in meaningful impact particularly through leveraging the power of data.

Despite advances in technology, the needed culture shift within health care is lagging and amplified by the broader policy and governance issues throughout society. We continue to collect data in silos with minimal interaction between different systems.

This What We Heard Report highlights key outcomes and discussion threads from a roundtable of experts who discussed next steps to build a pan-Canadian Health Data Strategy, convened by the Public Policy Forum on June 20, 2022, following the release of the [\*\*third report of the Expert Advisory Group on the Pan-Canadian Health Data Strategy\*\*](#).

Along with four leading experts, more than 45 representatives from the healthcare sector convened to discuss what needs to happen now for a successful strategy. Key takeaways from the convening are:

**1. Ensuring success of a pan-Canadian Health Data Strategy is a collective action problem** – it requires cross-jurisdictional collaboration, citizen engagement and collective will.

**2. Current policy frameworks and approaches to data governance were designed in a pre-digital world and lack the ability to enable effective data and digital services.** This hinders health outcomes, as personal health information cannot be easily accessed by individuals and transferred between providers; **but also, population and public health surveillance, health systems management and research and innovation remain sub-optimal as well**, as comprehensive record level data

cannot easily be brought together to track broader health outcomes.

3. There is no easy solution that will bring Canada's health system into a technologically forward model that works for everyone. Thus, **it is necessary to develop long-term commitments across both the public and the private sectors**. This is developed through a clear vision, mutually reinforcing activities and collective action.

4. **A people-centric learning health system is necessary** and will ensure that data following the person is at the forefront of this work.

5. A “data steward” (who **protects the value of data and its confidentiality**) model as opposed to a “data custodian” (who ensures that the data are being used in a confidential manner) model is essential to ensure that a person’s data is protected, confidential and used for individual and public good, and that any trusted third party that has access to this information is using it appropriately and with oversight.

6. **There is a need to take a deep and comprehensive look at data privacy legislation** across all jurisdictions to modernize application to promote broad and responsible data sharing.

7. **Building health data literacy and renegotiating boundaries around when data are used should also be considered essential**. This is imperative for providers, clinicians and individuals alike, as well as the media and journalists. This is because it is easy to misunderstand how health data are being used and limiting the transmission of false or misleading information would allow the health data strategy to move forward smoothly.

8. **Interoperability should be among the core guiding principles** when making technology investments. This will help keep patient at the centre of their journeys.

9. **There needs to be a sustained effort in public policy and engagement with civil society** to ensure that there is a commitment to collaboration.

A people-centric learning health system is necessary and will ensure that data following the person is at the forefront of this work.



# LEVERAGING DATA TO DEVELOP A LEARNING HEALTHCARE SYSTEM

Coming out of the COVID-19 pandemic, it is important to consider what Canadians are looking for in their healthcare system and what changes can be made using data that already exists. There are several issues that serve as examples of how an effective pan-Canadian health data strategy would improve access and outcomes.



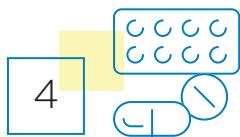
**Access to primary care** is among the most critical issues that Canadians are facing. Data can be used to better define primary care, to ensure that more Canadians are getting access to the care they need and that primary care physicians are being paid for the correct services.



**Data can provide information regarding exact waiting times for specialists.** This information is currently only collected for surgery appointments. This information would also be used to give ministries information on how to better deploy resources and to better understand how the health system is serving Canadians.



Understanding that **there is no health without mental health** is equally essential. Data are used to measure patient outcomes, to determine where training resources are needed and how to improve the mental health system for all Canadians.



**Data can be used to better plan for the purchase of drugs for rare diseases.** It is essential to see how drugs are effective in treating such diseases. Canada is currently the only country in the Western world that does not have a strategy for diagnosing rare diseases.



**Measuring health human resource capacity in a universal fashion from coast to coast to coast would better ensure that Canadian health care is cost effective in the future.** Data on this would also allow the system to better manage care providers who are working with elderly individuals in their homes and ensure career trajectories for home workers.



**Social determinants of health** are essential, especially in connection to seniors living in vertical aging facilities (mutually supportive high-rise communities) and naturally occurring retirement communities. Understanding how those communities can be integrated into the healthcare system ensures that Canadians are living where it is safe for them, and they are comfortable.



# IMPACT OF HEALTH DATA STRATEGIES IN OTHER JURISDICTIONS

When considering the future of health care across international jurisdictions, we see a shift from the idea of “care” to “health and well-being” at the centre of data strategies. Individuals residing in countries that have implemented a health data strategy at various scales have more ownership over their data. This is something that has been overwhelmingly called for during conversations that the expert advisory group had with Canadians. Other jurisdictions that have gone down this path have seen that before the development and successful implementation of a health data strategy, an individual’s experience is not measured well. It is essential to see what is driving negative patient experiences, as this can have a significant impact on health outcomes. Three key themes emerged during the discussion:

**1**

**Centrally organized interoperability**

**2**

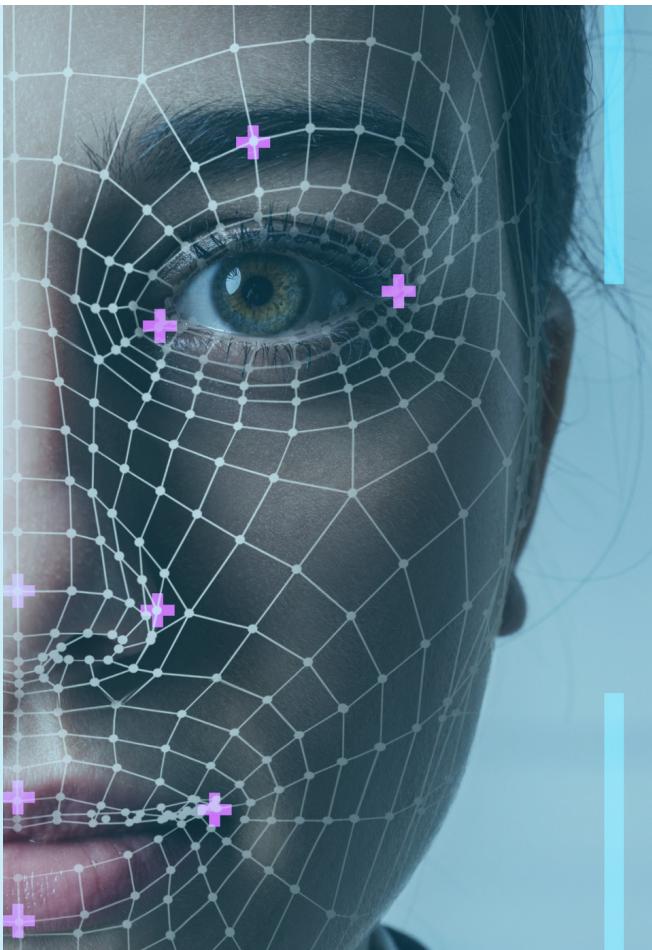
**Integration of social determinant data**

**3**

**Sharing data across providers and jurisdictions**

“

It is essential to see what is driving negative patient experiences, as this can have a significant impact on health outcomes.



We see other countries that have gone down a health data strategy path such as the United Kingdom, Israel and Australia look at care across systems: this is only possible when you have Electronic Medical Records (EMRs) that are explicitly designed to communicate with each other. Ensuring a centrally organized standard for tools such as records, risk assessments and administration is essential. Further, integrating data on social determinants can provide insight into systemic ways of improving effectiveness of care. A first step of sharing data across jurisdictions and providers ensures that information on what is driving the health in the population is available, which can then be used to target interventions. We also need to leverage the use of innovative technologies including machine learning and artificial intelligence (AI) to facilitate extracts and real-time standardization of data to overcome differences in underlying EMR infrastructure.



## THE ROLE OF GOVERNMENT

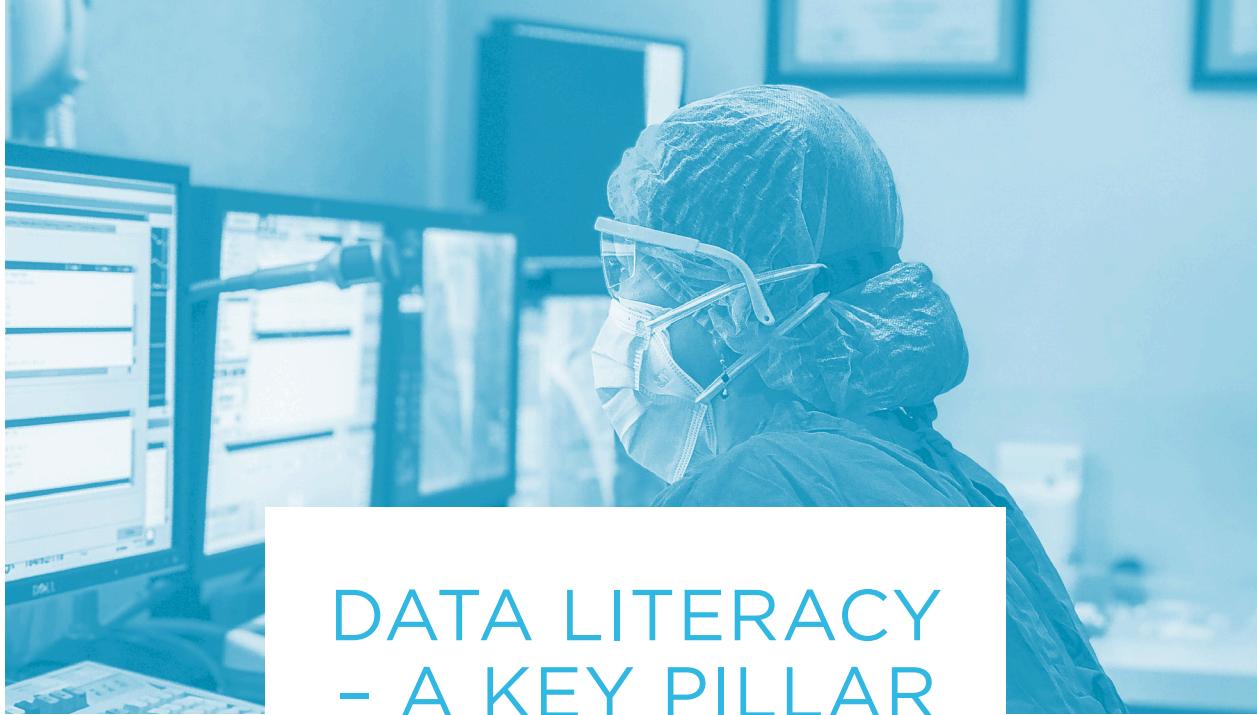
In Canada, there is recognition that the technology already exists for the implementation of an effective data strategy. There is a need to build effective data governance, including a structure that would include a data stewardship council whose chief goal is to coordinate the jurisdictions' use of data. If the private and public sector, including various jurisdictions, do not act as a collective, there will be missed opportunities to use data (especially data that can be used to track and prevent future disease outbreaks). The importance of this collaboration is to ensure that there is leadership and consistency between the

technologies that are being used. The shift from data "custodians" to data "stewards" is essential to this end. Currently, the onus is on a custodian to protect the data, but a steward would ensure that the data are used in a confidential and safe manner in order to improve health services and drive innovation. Data stewards would ensure that the pan-Canadian health data strategy is people-centric, and that individuals are the owners of their own data – this, in turn, builds trust. Overall, there are a few ways that governments can make a meaningful contribution in ensuring success of a pan-Canadian Health Data Strategy:

1. **The federal government can take on a leadership role in developing this data strategy collaboratively** to ensure that it works for all people living in Canada.
2. **Act in accordance with the Truth and Reconciliation Commission's calls to actions**, working with First Nations, Inuit and Métis people to create a system that works for them.
3. **Improve digital access** for persons and providers, encouraging health information sharing to improve individual outcomes and access for public benefit.
4. **Ensure effective governance so that health information is available to trusted secondary users** with the goal of innovation.

Data stewards would ensure that the pan-Canadian health data strategy is people-centric, and that individuals are the owners of their own data – this, in turn, builds trust.





## DATA LITERACY - A KEY PILLAR

A prime example of this is at the peak of the COVID-19 pandemic, there was a backlash over the government's use of high-level mobility data even though it was anonymized and aggregated. A new social contract is required between Canadians and their government, and a re-negotiation between parties about how their data can be used is not only essential for trust, but also to build understanding and literacy. This needs to be done with long-term considerations in mind, so that as health data policy evolves, there are existing meaningful mechanisms to engage with the public. Additionally, engaging journalists is critical given that it is through them that Canadians get their initial information on government policies and actions.

The move to an interconnected and digital system is one that might be met with resistance from healthcare providers and clinicians. This is notable because patient-provider relationships are well defined, and the shift towards online care demands a re-negotiation of boundaries and communication styles. The utilization of data demands literacy across the healthcare value chain, including providers, administrators and policymakers among others, around the need for and use of data by clinicians so that all parties involved are comfortable.

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Engaging journalists is critical given that it is through them that Canadians get their initial information on government policies and actions

# WHAT DOES A SUCCESSFUL HEALTHCARE TRANSFOR- MATION LOOK LIKE?

## The role of civil society

Given the limitations that electoral cycles impose on this long-term work; it is necessary for civil society to be involved as well. While this includes building health literacy, it also means having a discourse around principle-based systems architecture and people-centric system design. Creating a system where the health data follows an individual needs to be the chief goal for any group working towards a pan-Canadian system.

## Engagement with affected communities

To build a system that works for Canadians and their health care, it is necessary to engage both political leaders on the importance of data. Greater public engagement is also necessary to establish and gain acceptance for what is needed from the population's point of view. Critical and meaningful engagement is essential – forming groups and ensuring that their input is incorporated into a system should be a chief goal of data stewards.

## Enabling a culture shift

To implement this health data strategy, there needs to be a cultural shift towards a deeper understanding of what health data means in practice. For this to occur, a “quick win” could be helpful, an example being high-level health data being used to better anticipate wait times to see a specialist doctor.



## Ensuring First Nations, Métis and Inuit data sovereignty

A pan-Canadian health data strategy must be in line with Indigenous self-governance and data sovereignty. However, this does not mean that First Nations, Métis and Inuit communities should be left on their own to build and use technology. To this end, there should be further collaboration to ensure that everyone is included and can benefit from the use of health data.

A pan-Canadian health data strategy must be in line with Indigenous self-governance and data sovereignty.

# ROUNDTABLE

## **Final Report of the Expert Advisory Group on the Pan-Canadian Health Data Strategy: What needs to happen now?**

June 20, 2022 | 1 to 2:30 p.m. (EST)

1 – 1:05 p.m.

- Opening Remarks

1:05 – 1:45 p.m.

- Pan-Canadian Health Data Strategy: What does it call for?
- Serving patient needs through a Pan-Canadian Data Strategy
- The role of government in enabling an inclusive data strategy
- Enabling data-centric population health initiatives

1:45 – 2:25 p.m.

- Plenary Discussion

2:25 – 2:30 p.m.

- Closing remarks

