



# pan-Canadian Health Data Strategy: Expert Advisory Group Plenary meeting: February 19, 2021

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What We Heard

## Overview of the Third Plenary Meeting of the Expert Advisory Group

The third plenary meeting of the Expert Advisory Group (EAG) took place on February 19, 2021. The group discussed themes resulting from its four working groups' deliberations to date on initial areas of focus for the pan-Canadian Health Data Strategy (pCHDS). The EAG also examined a case study for COVID-19 vaccine surveillance data. This report presents a summary of the feedback received during the plenary meeting for each of the working group themes.

### Working Group 1: Data Assets, Standards and Literacy

We heard there is need for **shared language** that can be used across the Canadian healthcare landscape to provide clarity and consistency on terms. A **robust lexicon** would help ensure a shared understanding that would increase the timeliness and quality of data and data processes and support effective communication. The public and the health workforce should be equipped with **a strong foundation of health data literacy**.

It was also suggested that a cohesive approach to data **standards** that works **across jurisdictions and different data practices** is needed. This approach would also support alignment to international standards where appropriate.

The working group also recommended that the current state of health data infrastructure needs to be articulated, including what is working and where deficiencies are. This will help conceptualize a **future state where the system is coherent, well-aligned, and workable**, along with the high-impact steps to get there.

### Working Group 2: Data Collection, Sharing, Culture and Governance

We heard that data governance should be rooted in the fact that **data increases in value when shared**. An analogy was made to the **role of an urban planner**, whereby cities ensure that individual buildings are designed for both the building and the broader community through zoning and regulations. A similar approach for pan-Canadian data governance may be effective, with clearly defined minimum specifications for data and data processes.

Furthermore, **data cultures would need to change** across various levels of government. There has been endorsement of previous strategies at senior levels, but implementation has not necessarily followed.

Finally, it was suggested that **playbooks for data access** could be created to highlight how it should happen in different contexts. These playbooks would identify **opportunities for incentives and accountability** to create responsible value through data sharing along the health data supply chain while protecting privacy.

### Working Group 3: Legal, Ethics and Privacy

We heard that a **privacy and access toolkit** could clarify how to navigate data sharing in various jurisdictions and clearly describe the discretion held by organizations. Currently, differences across jurisdictions, combined with processes for access that are often onerous, do not incent the creation of value along the health data supply chain.

There is an opportunity to move towards a **consent driven, patient centric** approach to data management that still provides sufficient data quality and granularity for analytics, and allows for implicit

consent in some cases. The approach to consent must consider the long-term impact of consent along the health data supply chain and through changes in data standards for sustainability.

The working group also recommended that **common definitions and cohesive legislative requirements** for data custodians and consolidators would help overcome challenges performing cross-jurisdictional analysis. This would include guidance on what data is sharable, how it can be shared, and with what levels of consent would aid creation of insight.

#### **Working Group 4: IT/Interoperability, Use and Sovereignty**

We heard that the approach to (IT) vendors should be differentiated based on size. There is a need to **ensure bargaining power with larger vendors**, while providing opportunities to **smaller vendors to gain market access**.

Additionally, it was recommended that health information architecture requires a **hybrid model that combines centralization and dispersion** to serve local data needs as well as pan-Canadian functions. This would support data-informed care while also supporting data for health policy, public health, and both traditional and AI researchers. This would be aided by **minimum datasets to ensure that key data are linkable**.

Lastly, working group members felt that we need to **give prestige and value to the roles of people who are working in data management**, including data custodians, the private sector, and research ethics board members. There also needs to be consistency in how these roles are carried out.

### **Presentation on COVID-19 Vaccine Surveillance Data**

The EAG reviewed a case study for COVID-19 vaccine surveillance data. During the presentation, there was an overview of vaccine surveillance data flows and the challenges associated with the current landscape. Following the presentation, the EAG noted that the challenges associated with vaccine surveillance are the same as had been identified for the longer-term strategy. It was recommended that case studies for the strategy should note successes in dealing with these issues during the pandemic.

### **Next steps**

The next set of working groups meetings will consolidate ideas and evolve those into recommendations through March, leading to a plenary meeting in April. The draft recommendations will be provided to the Data Pillar ADM Committee and the federal-provincial-territorial governance structure.

The EAG will also provide feedback on the engagement plan, including ideas of organizations to be engaged for awareness, input, and buy-in later in the year.