



Pan-Canadian Health Data Strategy

**Expert Advisory Group Plenary Meeting
December 15, 2021**

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What We Heard #10

Introduction

The 10th plenary meeting of the Expert Advisory Group (EAG) took place on December 15, 2021. This report presents a summary of the feedback received during the plenary meeting.

EAG Chair, Dr. Vivek Goel, congratulated members on a year of working together and the progress that has been made. Dr. Goel highlighted Chief Public Health Officer Dr. Tam's newly released [report](#) and its references to the importance of strengthening health data linkages.

Dr. Harpreet Kochhar, President of the Public Health Agency of Canada, commended the EAG members for their work to develop clear and informed reports. He thanked members for sharing their knowledge and advice and he stated that he looks forward to reading their final report.

Dr. Sara Allin and Julie Farmer, North American Observatory, University of Toronto summarized their preliminary finding from their Governance of COVID-10 Vaccine Data in Federations report. Alexander Robert Bernier and Dr. Bartha Knoppers, Centre of Genomics and Policy, provided a synopsis and examined consequential changes stemming from draft Bill 19 (Quebec) – *An Act respecting health and social services information and amending various legislative provisions*. The chair of the EAG's Governance Working Group, Dr. Ewan Affleck, summarized the Working Group's analysis of the current state of governance in Canada, and proposed concept of a "Canadian Health Data Charter".

Finally, the EAG received a summary of lessons learned and next steps based on recent pan-Canadian Health Data Strategy (pCHDS) targeted stakeholder engagement sessions, including Indigenous engagement.

International Governance Models of COVID-19 Vaccine Data

Dr. Sara Allin and Julie Farmer, North American Observatory of Health Systems and Policies (NAO), presented an overview and summary from their *Rapid Review: Governance of COVID-19 vaccine data in federations report*. The objective of review was to draw lessons for Canada from other federation and quasi-federations on the governance of COVID-19 vaccines data. As few countries have implemented fulsome health data governance structures, the NAO chose to focus on governance of vaccine data during COVID-19 due to its immediate relevance and the ability to extrapolate from a highly visible domain to an overall model.

Four jurisdictions – Germany, Switzerland, Australia and the U.K. – were used as a comparative case study because they are high-income federated or quasi-federated states, similar to Canada. The analytic overview focused on how each country addressed the following components: (i) COVID-19 vaccine data coordinating bodies, (ii) nature of immunization data reporting/sharing systems, (iii) mention of data sharing in vaccine strategy, (iv) legislation on vaccine data sharing/reporting, (v) documented description of data flow from

subnational to national level, and (vi) identified incentives to subnational-national data sharing. The centralized/decentralized nature of data sharing as well as challenges and opportunities for each country were presented.

The key lessons from the review that could be applied to overall data governance were:

1. Legislation helps set out expectations on the roles governments and expectations concerning data sharing among governments.
2. Variation in management and reporting systems impede effective surveillance as well as the evidence needed for rapid and effective policy interventions.
3. Legislation and policies mention minimum data sets and data variable descriptions at the national level for use within subnational jurisdictions.
4. Data reporting and sharing processes can be impacted by practice changes. Governance mechanisms should build in capacity for change or adaptation to data sharing processes.

It was noted that there is no standard method of governance used in other countries. However, in jurisdictions where data sharing legislation was already in place, it generally created an enabling environment and improved timely data sharing amongst organizations and local governments.

Members asked Dr. Allin and Ms. Farmer to consider the following questions and follow up if possible:

1. Whether there are jurisdictions that have successful legislation for data sharing.
2. If yes:
 - whether that legislation works on a domain-by-domain basis (e.g. cancer).
 - whether there are specific conditions, levers or events that helped drive success stories for jurisdictions with legislation in place.

Quebec's Bill 19

Alexander Bernier and Prof. Bartha Knoppers of McGill University presented their analysis of Quebec's recently introduced *Bill 19 – An Act Respecting Health and Social Services Information and Amending Various Legislative Provision*. Mr. Bernier explained that the Bill would significantly change the existing regime for health information access and sharing. They suggested the Bill in its current form proposes several major positive changes to Quebec statute, including:

- Health institutions can share data with other institutions for purposes that are consistent with existing reasons for its use. In current legislation, information was only to be used for the specific purposes for which it was collected.
- For researchers attached to a research institution, data access requests will pass through their own institution to gain access to another institution's data. In current legislation, researchers submit requests to the custodian that holds the data.

- For unaffiliated researchers, other health bodies, and extra-provincial bodies requiring access to data, for research, quality improvement and/or planning, the access request will pass through a new central body created by the legislation.
- Close-to-broad consent is allowed for research. Researchers can now request participant consent for use of data by categories of research or types of researchers. Under current legislation, there is debate as to whether broad consent is permissible.

They also noted that the current draft of the Bill introduces several changes that could be considered neutral or negative. For example, for a Quebec-based institution to share data outside of the province, they must be able to understand and guarantee a level of privacy protection in the law and policy of the recipient institution equivalent to that of Quebec's. A large number of procedural requirements around data disclosures are also included.

Progress Update and Advancement of the Data Governance Working Group

Dr. Ewan Affleck presented the preliminary work of the EAG's Governance Working Group, which was created to articulate the contents of the "Clear Health Data Governance and Accountability" pillar of the Health Data Foundation. Dr. Affleck outlined the complex environment of current state of health data governance in Canada, including highlighting gaps, such as the lack of nation-wide standards, the emphasis on custodianship, and absence of interoperability enforcement. The group's realization that there are no agreed upon principles for how health data should be designed and used to optimize the health of individuals, communities, and Canadian society lead the group to the idea of drafting a "Canadian Health Data Charter".

The working group will focus on design principles that would be contained in their draft Charter, as well as recommendations on how to implement a new health data governance model that reflects the Charter's content. The working group will concentrate on developing of a succinct charter with a well-defined scope, using model legislation as a template.

Discussion from members included general agreement to develop the charter and the importance of finding common ground. Members suggested to co-develop with provinces and territories as much as possible and to include robust language around accountability and enforceability. Members also highlighted the impact of using language that takes into account Indigenous rights, aligns with Indigenous data principles currently in development and recommended to co-build where possible.

Stakeholder Engagement Update

A summary of the approach used during Phase I (June-November 2021) of pCHDS engagements, including summary of Indigenous engagement activities, was provided. Using the EAG's first report as a foundation, 18 two-hour facilitated meetings with targeted stakeholders (451 participants) explored the systemic barriers that have been preventing the effective collection, sharing, and use of health data in Canada. Participants shared feedback



on EAG's proposed vision, principles, and barriers as well as how to find solutions going forward. There was overall agreement that the EAG is on the right track but that more focus on the health care workforce is needed. The need to further engage the public was also highlighted, most notably to seek further clarity on patient data ownership, right to access and privacy; to promote data literacy; and to include the public as an equal partner in informing solutions. A synthesis report of engagement and outcomes will be appended to final EAG report.

Discussion highlights included an emphasis on the importance of embracing 'essential caregivers' as part of health workforce language, the need to activate the public to drive strategy forward, and the importance to co-develop with P/T's and Indigenous groups. Members also suggested that quotes from patients, health providers, researchers and industry members be used in the EAG's next report to emphasize the systemic obstacles that need to be overcome.

Next steps

The EAG will develop its third report, which will elaborate on the recommendations presented in the second report to build the Health Data Foundation. The Governance and Interoperability working groups will continue in support of the development of the third report.