



Pan-Canadian Health Data Strategy

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

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What We Heard

Introduction

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

Dr. Yann Joly and Alexandre Bernier of McGill University presented their work on Canada's data governance framework, arguing that the health crisis is in effect a data crisis, necessitating changes in how health data are shared between data custodians and other stakeholders, particularly for health research purposes. The chair of the EAG's Data Policy and Governance Working Group, Dr. Ewan Affleck, provided an update on the latest revisions to the Data Policy Working Group Report, which incorporated the input provided by EAG members at the last Plenary.

Presentation on McGill Report on Canada's Data Governance Framework

In summer 2021, the Public Health Agency of Canada commissioned a comparative review of health data sharing to help clarify barriers and potential solutions to improve the responsible collection, sharing, and protection of health data for the public good. Dr. Yann Joly and his colleague, Alexandre Bernier, presented their research into the laws and policies on health information sharing in Canada, specifically within the context of the COVID-19 pandemic and public health institutions. They illustrated the scope of the "data crisis" through comparisons to Canada's international counterparts, and identified that the problems around sharing health data existed at several levels of the health/health care system.

The presentation centered on the key concepts of privacy law, which govern the collection, use, and disclosure of personal information, defined as *identifiable personal information (PI)* or *identifiable personal health information (PHI)*. We heard that systemic structural challenges make data sharing more cumbersome in practice than it appears to be, and that the legal barriers to sharing PHI often leads to a high administrative burden and a need for expertise that is often lacking or simply unavailable. This results in delays in data sharing that undermine the value of the data for the public good.

The other barriers identified by Dr. Joly echoed those previously identified by the EAG. Examples include the existence of complex administrative processes around data access and the fact that data sharing is typically considered low priority, compared to data generation. We heard that a major barrier is our federated health sector model, with its decentralized public health institutions and the lack of trust that exists between these stakeholders.

We heard that there are existing pathways to improved data sharing within the current legal and policy environment. These include governance measures that help limit the risk of re-identification (the process by which anonymized data is matched to its true owner), and federal and provincial public health institutions exercising their existing statutory powers to safely collect, use, and disclose health information for purposes related to activities and programs, public health surveillance, or in response to emerging crises. We also heard that legal reform



would have the benefit of clarifying and centralizing practices around data collection, sharing and use. Specifically, federal, provincial, and territorial privacy legislation should be explicitly amended for this purpose, and that Canada's governments needed to move towards a model of data stewardship, rather than the current approach based on data custodianship.

EAG members reacted positively to Dr. Joly's research. They suggested that data protection law should be amended to allow for identifiable information to be used under specific contexts, and should set in place governance structures for oversight. Members also flagged the need for the legislative landscape to address the potential harm to collective health and wellbeing caused by not sharing data. Barriers in privacy law effectively contribute to inequity in health outcomes for many of Canada's marginalized communities, including Indigenous peoples.

We also heard that a culture shift – a shared vision on the importance of data sharing to drive better health outcomes – would be critical to addressing the barriers to data sharing in Canada. This means recognizing that responsibility for these system-wide structural roadblocks is the system itself, and not the data custodians charged with enforcing the legislation. While we wait for legislative reform, we must apply existing policy levers to more effectively facilitate data sharing.

Presentation on the Data Policy Working Group Report

Dr. Ewan Affleck updated the EAG members on the revisions made to the Data Policy Working Group's report based on the input that members had provided at the last Plenary.

We heard that these revisions introduce the notion of harm – that improved data sharing contributes to the avoidance or prevention of harm to both the physical and mental well-being of the individual, and the harm resulting from an individual's lack of control over their personal health information. The shared vision of "common need and common obligation" was reiterated. We heard how the current focus on data custodianship drives fragmentation, whereas adoption of the notion of data stewardship is the desired end goal. Dr. Affleck noted that Dr. Joly's presentation validated the critical need for this shift in perspective.

EAG members reacted positively to Dr. Affleck's update. They questioned the report's implications around the scope of what data are categorized as personal health information, which could potentially undermine data sharing for the public good. Dr. Affleck clarified that the working presumption is that individuals would control their personal health information for the specific use of managing their health, and that Canadians would understand that the use of data for the greater good would not require explicit consent for each data element shared while an individual's privacy would continue to be protected. It was noted that the newly formed EAG Governance Working Group would be responsible for addressing the nuances around this issue, as well as addressing the notion of data stewardship.



Next Steps

The EAG will finalize its second report, which focuses on the broad actions needed under the Pan-Canadian Health Data Strategy (PCHDS) to support the creation of the health data foundation described in its first report. Work on Interoperability and Architecture will continue, and the newly formed Governance Working Group will begin its work.