



Pan-Canadian Health Data Strategy

**Expert Advisory Group Plenary Meeting
September 17, 2021**

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What We Heard

Introduction

The seventh plenary meeting of the Expert Advisory Group (EAG) took place on September 17, 2021. This report presents a summary of the feedback received during the plenary meeting.

The chair of the EAG's Data Policy and Governance Working Group, Dr. Ewan Affleck, summarized the Working Group's analysis of the current state of health data policy and governance in Canada, including a vision of an optimal state and recommendations to achieve it. The Interoperability and Architecture Work Group chair, Dr. Muhammed Mamdani, presented a proposed approach to developing a pan-Canadian Interoperability Framework, currently in development.

Finally, the EAG received an update on the Social License, Education, and Capacity work being undertaken by Dr. Kim McGrail, which will include a deliberative exercise with informed public advisory communities.

Data Policy and Governance Working Group Debrief

Dr. Ewan Affleck presented the work of the Data Policy and Governance Working Group, which was created to articulate the contents of the 'Data Policy in the Digital Age' pillar of the Health Data Foundation, presented in the EAG's First Report. The Working Group's analysis of health data policy in Canada concluded that while the health sector has adopted many digital age technologies to achieve its goals, it still relies on policies that were conceived in an analogue environment. The end result is a provider-centric model of data custodianship that suppresses data exchange to avoid liability for its mishandling by others under the auspice of protecting the privacy of individuals.

For the health sector to achieve its primary purpose per the *Canada Health Act* (1985), which is "to promote and restore the physical and mental well-being of residents of Canada", the working group concluded that health data policy and governance must be reimagined to be person-centric, where data exchange is acknowledged as key to improving both individual and population health outcomes. Recommendations from the Working Group will focus on promoting ways of achieving greater alignment across provinces and territories, and with international partners – a key aspect of which is adopting a data stewardship model that exchanges data for individual and public good while protecting the privacy of individuals.

Members were very supportive of the Working Group's narrative. They suggested that clear definitions are needed when articulating the optimal, person-centred state and the recommendations to achieve it. The concept of 'stewardship' in particular needs to be clearly described to avoid confusion about what stewardship roles entail. We also heard that these roles will require common training and likely professional affiliation to minimize variation in practice and support common approaches to health data.

Interoperability and Architecture Working Group Debrief

Dr. Muhammed Mamdani presented the work of the Interoperability and Architecture Working Group to date. The goal of the Working Group is to create practical recommendations to achieve pan-Canadian interoperability, rather than guiding principles. The work is still at its inception – currently, the Working Group is gathering insights of how interoperability works in provinces and territories, as well as other countries. Once the group has gathered these insights, it will develop data standards and an interoperability framework that articulate a common target state for jurisdictions to work towards.

Members were supportive of the direction the Working Group is taking. We heard that the agreement on the technical aspects of this work is easier to obtain than the collective political will needed to implement them across jurisdictions. Members noted the need to provide both positive and negative incentives to jurisdictions to achieve interoperability. We heard that health data systems are often viewed as too complex for interoperability, often by those desiring to protect the status quo. This argument is made despite the existence of other similarly complex systems like aerospace navigation or the tax system that are currently interoperable across jurisdictions. Members agreed that perspectives need to shift to view health data in the same way – a resource that must be shared to achieve optimal outcomes and common benefit.

Social License, Education and Capacity

Dr. Kim McGrail provided an update on the work on Social Licence, Education, and Capacity. The work is in early stages, and will support moving in the direction of data sovereignty and public input into data movement, with the understanding that the public thinks their jurisdictions are able to access and use data more effectively than they actually are. There will be two components to the work. The first will be to facilitate a deliberation exercise, with people who are already involved in public advisory communities, to discuss what the health data landscape should look like from the public's perspective. The second will be a background paper that articulates that perspective, including how a citizen's assembly could be supported and what it would look like. Members looked forward to learning more about the work as it progresses.

Next Steps

The EAG will develop its second report, which will focus on the broad actions needed under the pan-Canadian Health Data Strategy (pCHDS) to support the Health Data Foundation described in first report. The Data Policy Working Group is wrapping up soon, while work on Interoperability and Architecture and Social License will continue. A new working group for governance will be created as a successor to the Data Policy Working Group.