



pan-Canadian Health Data Strategy:

**Expert Advisory Group Plenary Meeting:
June 16, 2021**

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What We Heard

Overview of the Sixth Plenary Meeting of the Expert Advisory Group

The sixth plenary meeting of the Expert Advisory Group (EAG) took place on June 16, 2021. This report presents a summary of the feedback received during the plenary meeting.

The EAG discussed the publication of their first report *Charting a Path Towards Ambition*, and members were encouraged to engage with the media to raise awareness of this work.

The EAG received a presentation from Dr. David Buckeridge, a leading researcher on health data management. He discussed his current projects, which explore challenges to data sharing, remarking that his preliminary results align with the EAG's findings to date.

The EAG also had the opportunity to meet with some members of the federal Deputy Ministers' Data Pillar Committee, where the discussion centered largely on the link between the value proposition of the pan-Canadian Health Data Strategy (pCHDS), public trust and engagement, as well as the need to address the immediate challenges to data sharing.

Finally, the EAG reviewed its summer work plan, including several working groups, to build on its advice in the first report. The EAG is planning to release two reports in the fall to inform the development of recommendations for the long-term pCHDS.

The Way Forward

Dr. Vivek Goel reminded members of the planned publication of their first report on June 17, 2021. EAG members were encouraged to engage with and respond to media inquiries to raise awareness of this important work.

The pCHDS Secretariat provided the EAG with an update on the overall pCHDS engagement strategy, and the work underway. Targeted, facilitated sessions with health data stakeholders are planned, and will focus on exploring the barriers to data sharing identified by the EAG, and what practical solutions might be implemented to address them. Discussions with First Nations, Inuit and Métis (FNIM) organizational representatives have begun and will determine how these groups wish to engage in the pCHDS to align it with FNIM health data principles, strategies, and approaches. Broader, public consultations on the pCHDS are expected in fall 2021. These streams of engagement will come together as advice for a federal / provincial / territorial time-limited task group for FPT dialogue and pCHDS co-development.

Presentation: Dr. David Buckeridge

Dr. David Buckeridge, Scientific Lead on Data Management for the Canadian Immunity Task Force (CITF), presented the preliminary results of two research projects. Dr. Buckeridge's CITF work on **data challenges** focuses on two key areas: **data governance**, specifically the **legal and ethical foundation for data sharing**; and **data management**, specifically the tools to support **interoperability**. It was noted that challenges with data sharing can be categorized in two ways, **data collected for research** and **data collected for health services**; and that one of the largest concerns with data sharing is **secondary sharing** of data.

Dr. Buckeridge is also working on one of four background papers that will feed into the Canadian Public Health Officer (CPHO) report on the renewal of public health post-pandemic. He provided the EAG with a summary of his key findings, all of which align with the EAG's own findings to date. We heard that a

key theme that emerged from his research relates to a **vision for accessible public health data** through **inter-operable systems** with a **shared sense of purpose**. The **enabling components** for this vision fall under three categories, including **system structure** (shared goals, governance, and financing); **human and social components** (public engagement and trust, and trained personnel); and **IT and informatics** (single systems that are fit for purpose, with mechanisms for interoperability).

Group discussion focused largely on the **value proposition of data sharing**. We heard that there needed to be a much **clearer understanding of the benefit for individual systems' participation**. Interoperability requires that the owner of each system invest resources and enter into governance frameworks that would allow data to flow within the larger system. This in turn allows others to use that data for their own purposes. The value for taking such action must be clearly articulated. We heard that **measurement** is an underlying issue of data management, and that this can be addressed through ensuring that **systems are fit for purpose**. We also heard that the **digital transformation** needed in health systems requires **core skills/competencies** that currently do not exist widely in the health workforce, and could be incorporated into academic curriculums. We also heard that key elements to articulate and communicate the value proposition for such a transformative change are **public trust and engagement**.

Q&A with Deputy Minister Data Pillar Committee

Invited Deputy Ministers expressed their appreciation for the first report and acknowledged its importance, indicating that a number of their own initiatives intended to leverage the EAG's work to support their own. We heard that it would be important to present the EAG-identified challenges to transforming health data management to the public in a way that **communicates the real-world implications** of the current state of the health data system, and the huge potential that health data holds if it was harnessed more coherently.

The remaining discussion centered on the **value proposition** of the strategy. We heard that it would be crucial to **engage the public** and highlight the **jurisdictional complexity of data policy work**. We heard that Canadian citizens should have more information about the power of health data, to be able to engage and ask for elimination of structural barriers to data sharing. Key stakeholders need to have honest, transparent conversations about the state of data. We also heard that building public understanding and trust would require the **engagement and participation of Privacy Commissioners** across the country. We also heard some concerns about addressing the **challenges faced by the current data sharing needs** of the system, as the COVID-19 response continues.

Next steps

The EAG will next be prioritizing the work of its sub-groups, specifically the Inter-operability and Architecture Working Group, the Data Policy in the Digital Age Working Group, and the Social License, Education, and Capacity Working Group. It was noted that Governance will be treated as a cross-cutting theme and each working group will be asked to consider how accountability should be addressed.

There was some discussion around the importance of case studies, with agreement on the need to include positive examples, and at least one example on the intersection of data used for surveillance, enhanced surveillance and research, and the impact on the timeliness of public health research.