



pan-Canadian Health Data Strategy: Expert Advisory Group Plenary meeting: January 18, 2021



What We Heard

Overview of the Second Plenary Meeting of the Expert Advisory Group

The second plenary meeting of the Expert Advisory Group (EAG) took place on January 18, 2021. The group focused on the overall vision and direction for the pan-Canadian Health Data Strategy (pCHDS) and principles for its development based on lessons learned. They also examined a current use case for genomic data sharing, and advanced discussions on areas to be addressed in the pCHDS. This report presents a summary of the feedback received during the plenary meeting.

Vision and direction

We heard support for the provisional vision and direction as well as several suggestions for enhancements and clarifications to sharpen the focus and improve outcomes. We heard that increasing the emphasis on **future-oriented language** and on **equity** particularly towards populations with diverse needs including rural and marginalized populations. We also heard the need to clarify ‘health data’ to **bring in social factors** (notably social determinants of health) and clarify language related to **First Nations, Inuit, and Metis peoples’ data** as being ‘distinct and not separate’. We heard about opportunities to improve **data literacy** to include **capacity** in the public and health workforce; increase empowerment to include **public participation** in their own care as well as incorporate and **leverage common definitions** where possible (e.g. Quality of Care from *Institute of Medicine*).

Principles for development of the pCHDS

We heard valuable feedback on a provisional set of principles for development of the pCHDS, informed by lessons learned from prior related efforts. We heard general support for the provisional principles as well as several suggestions for refinements and improvements them. We heard the greater emphasis of **federalism** is both a challenge and an opportunity – in particular toward taking advantage of differences across jurisdictions to develop leading practices for data and opportunities to learn from each other to enable a **pan-Canadian approach**. For **data literacy**, we heard support to include the broader health workforce to improve capacity for data use. We heard recommendations to explore opportunities for **public engagement and advocacy** to support the development and implementation of the strategy.

We heard several key considerations for success of the strategy. For example, we heard that the design should to be **future-looking to respond to emerging trends** and data needs such as digital systems and demands of machine learning. We heard the importance of aligning with existing **international and domestic leading practices and standards** where possible and appropriate (such as human rights, accepted data principles, and terminology). We also heard that a strong focus on **equity and respect** for First Nations, Inuit, Metis peoples and other populations who have experienced historic health inequities (e.g. rural, marginalized) is important for the strategy. We further heard that the outcomes of the **strategy should be bold** and noticeably better than an incremental improvement to the status quo.

Use case for genomic data sharing related to variants of SARS-COV2

The EAG reviewed a case study for genomic data sharing related to analysis of variants of SARS-COV2. During the presentation we heard about barriers experienced in bringing together lab data across jurisdictions which negatively impact the ability to generate timely insight. We learned that Canada lags behind peer countries in the length of time to share data for genomics (<50 days vs. >150 days in Canada). We heard that many of the challenges experienced in this use case were consistent with the lessons learned discussed earlier in the meeting.



Following the case study, we heard that Canadian Public Health Labs should be engaged with to dig deeper into the noted challenges. We heard that legislative differences and interpretations across jurisdictions should be examined and communicated as they result in data not being shared, or being highly aggregated when shared - both of which negatively impact the ability to do needed analysis. We also heard suggestions to further explore and articulate the impact of challenges related to inconsistent standards for genomic and supplemental data across jurisdictions – related to time to collect and prepare data for analysis.

Identify areas to be addressed

During the meeting areas to be addressed in the pCHDS were discussed and agreed upon. We heard that there are four key areas to be addressed:

- 1. Data assets, standards, and literacy** (including expanding data capacity among data users)
- 2. Data collection and sharing**
- 3. Legal, ethics and privacy, and**
- 4. Technology that supports data flow, use and sovereignty**

We heard support to form working groups for each of these areas to facilitate the development of recommendations for the pCHDS.

Next steps

We will incorporate EAG recommendations into the vision, direction and principles for review by the Data Pillar ADM Committee. Significant engagement with federal, provincial and territorial partners will be undertaken to co-develop the vision, direction and principles for the pCHDS. Working groups will also be established and their respective scopes further elaborated as the groups are formed.