



# pan-Canadian Health Data Strategy:

**Expert Advisory Group Plenary Meeting:  
April 9, 2021**

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What We Heard

## Overview of the Fourth Plenary Meeting of the Expert Advisory Group

The fourth plenary meeting of the Expert Advisory Group (EAG) took place on April 9, 2021. This report presents a summary of the feedback received during the plenary meeting. Elements of the long-term pan-Canadian Health Data Strategy (pCHDS) were further discussed and refined. The EAG also discussed the recent Auditor General's report *COVID-19 Pandemic Report 8 - Pandemic Preparedness, Surveillance, and Border Control Measures*, which recommended the creation of a pan-Canadian health data strategy, to help address both long-standing and newly identified challenges impeding public health surveillance activities in Canada. Finally, the EAG received a presentation on how improved health outcomes for Canadians could be achieved through greater access to data that is linked across health and socio-demographic domains.

## Draft Vision, Principles, Scope, and Definition of the Data Foundation

The EAG determined that **equity** should be a foundational principle for the pCHDS to ensure it helps reduce existing health system biases and contributes to improved health outcomes for all. Existing data systems are centred on improving health outcomes for the average person. An inclusive pan-Canadian health data strategy must be able to identify and better address health needs in all communities. For example, some people may not be represented in datasets due to health system access limitations and due to a perceived sense of risk associated with sharing their health information. To harness the power of data to inform health system decisions, a focus on equity and data literacy in the pCHDS would help Canadians feel confident their **data will be protected and used for their benefit**.

Securing **public trust** in governments and data holders to manage health data effectively must also be at the forefront of the pCHDS. **Canadians can enable positive change** in the collection, sharing, and use of data when they understand both the impacts of barriers to health data sharing and how a new approach can address them. The EAG believes that Canadians would be dismayed by Canada's limited capacity to use health data for individual and public good, both during and between public health events. Further, the EAG believes public engagement is essential for effective implementation of a pCHDS. A public-centred approach across all aspects of health data management is needed to drive change and meet Canadians' needs. This approach is being explored and implemented in other countries (notably in Europe), where the protection and sharing of health data for the public good is understood to be one way that communities can equitably benefit from advances in science.

The EAG also cautioned that the current model of data custodianship and consent in Canada, which was created in a time of paper-based records, has been carried forward into the digital age. It is possible now to use new digital data approaches that enable the ability to **simultaneously share and protect data**. The current system creates system-wide disincentives for the sharing and use of health data both within and between jurisdictions, as has been highlighted by challenges in data sharing during COVID-19. The EAG advises that jurisdictions must **move beyond the "custodial model" of data management** towards an approach more appropriate for the digital age. A co-developed pCHDS must move Canada into the future – not just catch up to current best practice. When successfully implemented, the pCHDS will enable jurisdictions to adopt equitable, next-generation health data management approaches that simultaneously **increase public understanding of health data and contribute to a healthier Canada**.

The EAG discussed whether the overarching goal of the pCHDS should be system reform or transformation. Given the nature of the systemic problems with Canada's health data infrastructure,

**bold transformation in data management is needed** to deliver on the promise of improved health for all Canadians through better decision-making using health data. The steps to achieve transformation must be **incremental and iterative**, learning from past attempts and proving the value of a cohesive approach.

## Auditor General's Report on PHAC's COVID-19 Response

Rhonda Kropp, Vice President of the Corporate Data and Surveillance Branch at the Public Health Agency of Canada provided an overview of the recent Auditor General's *COVID-19 Pandemic Report 8 - Pandemic Preparedness, Surveillance, and Border Control Measures*, which included a recommendation for development of the pan-Canadian Health Data Strategy. There were three main findings in the report related to data and surveillance.

1. PHAC should investigate better data infrastructure for public health surveillance data.
2. PHAC should move forward on the technical annexes for the Multi-Lateral Information Sharing Agreements.
3. There are foundational issues impacting the flow of information during the pandemic that should be addressed through a pan-Canadian Health Data Strategy.

EAG noted that a key challenge during the response was a lack of sharing data **within** some jurisdictions between health system silos and **between** jurisdictions and PHAC. When shared, data can be incomplete or not fully reliable. EAG members noted the lack of sharing may come from data being unavailable rather than unwillingness; regardless, lack of data has negatively impacted the jurisdictional responses to COVID-19. In looking forward, improved data collection, sharing, and use between the federal government and provinces and territories should be considered a key component for health system funding agreements. Furthermore, the EAG suggested that there be clear accountability measures for meeting agreed upon objectives, outcomes and targets in a timely, measurable manner.

## Presentation – “Best in Health”

Don Drummond, Stauffer-Dunning Fellow and Adjunct Professor at the School of Policy Studies at Queen's University, presented a draft paper entitled “Best in Health” to EAG members. The paper argues that Canada has the ingredients to be ‘Best in Health’ globally; however, we do not have the right balance between health promotion, prevention, and response to achieve optimal outcomes for Canadians. Greater access to data linked across health domains and socio-demographic information would help achieve a better balance.

Questions from EAG members focussed on how to generate political and public attention on the systemic challenges identified in the report and previously by the EAG as well as how engage the public on this issue.

## Next steps

The pCHDS Secretariat will develop engagement and consultation tools based on the EAG work to date for used during targeted engagements, beginning Spring, 2021.