



Pan-Canadian Health Data Strategy

**Expert Advisory Group Plenary Meeting
November 19, 2021**

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What We Heard #9

Introduction

The ninth plenary meeting of the Expert Advisory Group (EAG) took place on November 19, 2021. This report presents a summary of the feedback received during the plenary meeting.

Jocelyne Voisin and Brett Taylor presented an update on the development of Health Canada's Digital Health Strategy. Brent Diverty from the Canadian Institute for Health Information (CIHI) and Abhi Kalra from Infoway jointly presented an overview on Standards in Canada (including data standards, privacy and security standards, data exchange standards, and information standards). Finally, Jeff Nesbitt and Matthew Aubie from the Canadian Health Information Management Association (CHIMA) shared some highlights from their years long public consultations on health information in a presentation titled "People, Information and a Certified Profession."

Digital Health Strategy Presentation

Jocelyne Voisin and Brett Taylor provided update on the development of Health Canada's Digital Health Strategy, with a focus on interoperability related to technical exchange standards. EAG members were invited to give feedback on the direction of the strategy.

Standards in Canada Presentation

CIHI and Infoway began their presentation with an overview of standards definitions (content, terminology and exchange standards) and described the roles their organizations have in the "standards ecosystem" in Canada and internationally.

The presentation highlighted the foundational interconnectivity requirements (e.g., TCP/IP), structural data exchange formats (e.g., HL7 FHIR), standardized content (e.g. SNOMED), and organizational systems (e.g. governance, privacy policy). CIHI and Infoway shared their challenges to improving the health data ecosystem and provided recommendations for moving forward in five areas – aligned with the health data foundation: Governance, Trust, Policy, Interoperability, Literacy / Capacity.

Following the presentation EAG members reiterated that issues related to interoperability are largely not technical and that there is an essential need for policy and governance to come first for meaningful progress to be made.

Members also noted that the work to date seemed biomedical focussed and reminded CIHI and Infoway to take into consideration the determinants of health and broader health sector needs such as health workforce data. Members also iterated that interoperability standards must be compatible with exporting large samples / sets of aggregated patient data in addition to individual records.

Dr. Vivek Goel thanked the presenters, in particular for their thoughts on how the EAG could help the advance better collection, sharing, and use of data.

CHIMA Consultation Debrief

CHIMA presented their findings from surveys conducted over the past 2.5 years with industry, academics, professionals and the public about data for health and public health and its impact on the health information profession. Highlights from the results of the survey include:

- Technological advancements were consistently identified as the primary cause of change within the health information profession. The transition from paper records to electronic records and artificial intelligence (A.I.) were the two most common examples of “technology”.
- 81.8% of surveyed public identified “ensuring my personal health information is kept private” as the most important aspect of their health information.
- 94% of surveyed public agreed their personal health information should be used to help friends, family, and Canadians (57.6% noted the information would need to be anonymous).

CHIMA members identified a lack of awareness of the professionalization of health information workers as the primary challenge. It was noted that of all the professionals who handle health information, only a small percentage are certified health information professionals.

EAG members echoed that health professionals would have educational credentials (Masters, PhD etc) but would not likely have a professional designation in health information. This discussion tied back to insufficient data literacy for health officials with decision-making authority (e.g., hospital CEOs).

Members also touched on the privacy and anonymity of data; while individuals seem to be comfortable sharing their data if it is anonymous, there is a need to clearly explain the processes to make data “anonymous”.

Next Steps

The second report of the EAG will be published the week of November 29, during Digital Health Week. The next EAG meeting is scheduled for December 15.