



Pan-Canadian Health Data Strategy

**Expert Advisory Group Plenary Meeting
January 14, 2022**

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What We Heard #11

Introduction

The 11th plenary meeting of the Expert Advisory Group (EAG) took place on January 14, 2022. This report presents a summary of the discussion during the plenary meeting.

During this plenary session, the Interoperability and Architecture (I&A) Working Group and the Governance Working Group both provided updates on their work, and EAG members had the opportunity to discuss the ideas presented and offer input on how to progress the work.

Additionally, the Chief Data Officer of the Public Health Agency of Canada (PHAC), Chris Allison, debriefed the group on the current news story on the Agency's purchase of location data from Telus.

Progress Update and Advancement of the Interoperability and Architecture (I&A) Working Group (WG)

Dr. Stafford Dean, co-chair of the I&A WG, along with Dr. Jason Scarlett, WG member, provided an update to the EAG on the direction of the WG's group. Dr. Dean indicated that the WG's approach was shaped by four key tenets: a focus on clinical data in real-time; the need to meet provinces at their current capacity level; the critical need for standards on interoperability, coding, reporting, etc.; and a federated data system that allows for data access on demand, but leaves the data where it is.

Dr. Dean spoke about the challenges of building a pan-Canadian interoperable health data system, and the importance of buy-in from various stakeholders. He touched on the current state, i.e., existing health data clinical information systems and common data sets that could be leveraged, and described the vast eco-system of standards that would have to be integrated into an interoperable system.

Dr. Scarlett then presented a schematic diagram of the WG's proposed system architecture which recognizes the wide variety of approaches to warehousing data, and creates a standardized layer (national data platform) that supports interoperability and allows for data sharing between jurisdictions.

EAG members asked that the presented architecture's focus on clinical systems and the health provider as the primary customer be augmented to bring personal and analytic systems and the pan-Canadian Health Data Strategy's focus on person-centricity. Key conclusions from the presentation included the need to "standardize [data] at the source" for integration into a virtualized federated data platform and that future governance discussions would need to further define data use and access priorities.

Progress Update and Advancement of the Data Governance Working Group

Dr. Ewan Affleck presented an update on the ongoing work of the Governance Working Group, and the EAG members spent the majority of the time fine-tuning the Health Data Charter, which provides ten clear principles for the implementation of the strategy. Dr. Affleck also shared an optimized governance model, divided into different health data governance elements, most of which were linked to at least one Charter principle. The WG members have divided the elements among themselves and are each working on addressing key questions, such as data use harmonization, suggested approaches to legislation, and crafting a functioning framework for the role of Data Stewardship in the model.

EAG members held a brief discussion on clarifying language used, and acknowledged that governance would be the most important piece of the pan-Canadian Health Data Strategy. It would need to be built around the health system's obligation to patients and patient outcomes.

The next steps for the WG are to validate the optimized governance model, adapt it to the current state, and craft recommendations and a roadmap for implementation.

Debrief on the Public Health Agency of Canada (PHAC) and Telus Mobile Data News Story

Mr. Christopher Allison, Chief Data Officer of the Public Health Agency of Canada, was invited to the meeting to provide the EAG members with context and an update on the news story that PHAC had purchased user location data from a cell service provider.

Chris shared that the Agency had contracted the *Telus Data for Good* program to access already collected, aggregated, de-identified operator mobility data (cell-phone tower data). The de-identified data was used to evaluate effectiveness of public lockdown measures and identify possible links between movement of populations and the spread of COVID-19 within Canada. The contract prevents PHAC from accessing any personal information data, and excludes any data or data sets that could be re-identified. The Agency is working with the Privacy Commissioner and others to demonstrate that there has been no violation of privacy laws.

EAG members acknowledged that the situation had become highly politicised, and pointed out that it also raised questions around public health literacy, knowledge of data collection opt-out options, and the role of government, if any, in ensuring an ethically responsible data economy. Members also discussed how the Data Steward role in the presented data governance model could have mitigated the negative perception of pro-active use of data to benefit Canadians.

Next steps

The EAG will continue to develop its third report, which will elaborate on the second report's recommendations to strengthen the Health Data Foundation. The Governance and Interoperability working groups will continue in support of the development of the third report.