



Pan-Canadian Health Data Strategy

**Expert Advisory Group Plenary Meeting
February 18, 2022**

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What We Heard #12

Introduction

The 12th plenary meeting of the Expert Advisory Group (EAG) took place on February 18, 2022. This report presents a summary of the feedback received during the plenary meeting.

EAG Chair, Dr. Vivek Goel, shared that the University of Waterloo will be hosting a health data conference in April 2022; an invitation will be sent to all members of the EAG.

The TrustSphere team gave an overview of their work to create a digital, patient-centric platform and talked about the patient engagement that was key to the successful development of the platform. The Interoperability and Architecture Working Group members presented their draft report, and that discussion was followed by Dr. Ewan Affleck who provided an update on the progress of the Data Governance Working Group.

Discussion on the TrustSphere Project

Wyeth Wasserman, Bill Tam and Tibor van Rooij presented an overview of the TrustSphere project, which takes a systems approach to solving the complex problem of the lack of trust in digital health care. They presented a model of collaborative research and development where the patient is at the centre of their own circle of care allowing them to view, share and manage their own health care data, in a trusted single access platform.

As a test use case, the TrustSphere team worked with the pediatric type 1 diabetes patient population at BC Children's Hospital. In this population, the TrustSphere team showed how data in the single access platform could include information such as: patient care plans and insulin doses; provincial data such as lab test results and Pharmanet data; and data from diabetes management devices such as insulin pumps, glucose sensors and other wearables (through partnership with medical technology companies).

The TrustSphere team stressed how patient and family engagement was key to the development of their model, and that if digital health solutions are to be successful, patients/families have to be involved throughout the entire process. Trust also relates to how data is accessed with appropriate consent and permissions for research purposes. Privacy and ethics decision makers were also involved in all parts of the development process.

The EAG was interested in the scalability of this model, in particular expanding to other jurisdictions and to other conditions. The TrustSphere team emphasized that it is not just a technology challenge to scale this model, but rather a governance challenge as well. The TrustSphere team shared that in order for this model to be successful, three things are essential: patient engagement/empowerment, a standards based approach when sharing data, and a solid governance structure to guide accountability and data stewardship in the model.

Presentation of the Interoperability and Architecture Working Group Report

Interoperability and Architecture (I&A) Working Group members, Dr. Stafford Dean and Dr. Amol Verma, shared the working group's draft report for discussion. The working group has proposed their approach to health data sharing that builds on, and strengthens, existing data repositories and seeks to standardize them toward a person-centric national health data model. The presenters gave an overview of the recommendations in their report, as well as the principles for implementing those recommendations. A proposed *Interoperable Health Data Platform* would empower health data stewards and give Canadians a voice on how their data is being used. This platform could build off of portals that are already being developed in provinces and territories (PTs). A key element of the model needed for success is meeting PTs where they are in terms of capacity and readiness to implement recommendations. Notably this model does NOT require a single physical platform, rather through modern techniques existing and new data sets can be connected through interoperable connections.

The EAG and I&A Working Group members discussed at length the implications of setting pan-Canadian standards in order to facilitate data sharing across the country, including how that would look across different settings (research, clinical care delivery, public health, technology vendors), the means of mandating and/or enforcing these standards and the costs and other factors needed for jurisdictions to have interoperable systems.

Progress Update on the Governance Working Group

Dr. Ewan Affleck presented an update on the work of the EAG's Data Governance Working Group, and noted that a pan-Canadian governance model would have to be adapted to align with the current state in each jurisdiction. He presented an overview of essential governance elements, including alignment with the proposed *Canadian Health Data Charter*, health information technology interoperability, health data oversight bodies, and health data literacy among the workforce and providers. He expanded on the oversight role, describing a *Health Information Coordination Council* as a body to oversee the implementation of the pan-Canadian Health Data Strategy and the development of standards, policies, and frameworks. The Governance working group acknowledged that a health data governance structure would need to respect First Nation, Inuit and Métis data sovereignty. Discussions wrapped up with EAG members noting that coordination across FPT governments is essential for this work to succeed, and that public participation in the oversight is needed to ensure transparency and to incorporate public perspectives and insights.

Wrap up and Next Steps

A draft of the EAG's third report will be circulated to all members in the coming weeks for review. The final meeting will be on March 25th.