

Health Data Interoperability / Trust Standards Working Group

Terms of Reference

1. INTRODUCTION

The term *data trust* is growing in use to describe repeatable mechanisms or approaches to sharing data in an effective and efficient way across digital platforms. Health data trusts have been defined as “a set of relationships underpinned by a repeatable framework, compliant with parties’ obligations, to share health data in a fair, safe, and equitable way”.¹ Optimized virtual care is predicated on the capacity to exchange health information between two or more members of a patient’s circle of care to promote a quality health outcome. The exchange of health information requires the presence of health data interoperability, which at present is often absent in the Alberta and Canadian health sector. One means of promoting person-centric health data interoperability and fostering comprehensive virtual care is through the adoption of universal health data trust standards.

2. MANDATE

The mandate of the *Health Data Interoperability / Trust Standards Working Group* is to:

- Examine the potential value of adopting provincial health data interoperability / trust standards in Alberta.
- Clearly articulate the relationship between health data interoperability and quality of health programs and services.
- Propose:
 - An approach to setting health data interoperability / trust standards.
 - A roadmap for deployment of the health data interoperability / trust standards

¹ Hall-Presenti report. *Growing the artificial intelligence industry in the UK*. UK: Government of the United Kingdom

3. AUTHORITY

The *Health Data Interoperability / Trust Standards Working Group* functions under the authority of the cooperating organizations and individuals that comprise its membership and is supported by the Alberta Virtual Care Coordinating Body.

4. DECISION MAKING

The *Health Data Interoperability / Trust Standards Working Group* is an advisory relationship to the Alberta Virtual Care Coordinating Body.

5. SCOPE

The scope of the *Health Data Interoperability / Trust Standards Working Group* is limited to the health service of the province of Alberta. However, the Working Group will consider national and international evidence, and will promote the notions of person-centric pan-Canadian health data interoperability as a long-term goal.

6. DELIVERABLES

The *Health Data Interoperability / Trust Standards Working Group* will deliver one or more academic or grey literature papers that fulfill the mandate of the group.

7. METHOD

The *Health Data Interoperability / Trust Standards Working Group* will employ the following approach to accomplish its work:

- Systematic literature review to establish:
 - Provincial, national & international health data trust precedents / best practices
 - Impact of such standards on data interoperability and virtual care
 - Models for implementation
- Based on evidence in literature / industry best practice, propose
 - Describe impact of fragmented health data on quality health programs and services
 - An approach in Alberta to health data interoperability that is:
 - in alignment with AVCCB virtual care design principles
 - subject to iterative review with AVCCB for review and feedback
- Draft paper

- Review and consideration for ratification by AVCCB
- Format and publish with AVCCB endorsement.
 - Create 1–2-page policy brief.
 - Communication plan

8. MEMBERSHIP

The membership of the *Health Data Trust Standards Working Group* is:

- Tyler Williamson / Rob Price - Cumming School of Medicine
- Tim Murphy (Chair) / Ulrich Wolfaardt – Alberta Innovates
- Teri Price – Greg’s Wings / Imagine Citizens
- Anita Layton - University of Waterloo
- Brian Hamilton
- Stafford Dean – AHS
- Cassie Fraser – Health Canada Infoway
- Ann Chapman – Canadian Institute for Health Information
- Ewan Affleck – CPSA / secretariat
- Alberta Innovates – Research Support
- Marguerite Denman – Administrative Support (Alberta Innovates)

9. SECRETARIAT SUPPORT

Secretariate support for the *Health Data Interoperability / Trust Standards Working Group* will be provided by Alberta Innovates / CPSA. This support includes:

- Research support
- Administrative support
- Communication

10. MEETINGS

The *Health Data Interoperability / Trust Standards Working Group* will meet on a monthly basis or more frequently as required.

11. TIMELINE

The *Health Data Interoperability / Trust Standards Working Group* is expected to take about 6 months.

12. ACCOUNTABILITY AND REPORTING

The *Health Data Interoperability / Trust Standards Working Group* will report to the AVCCB and will be accountable to the virtual care Design Principles as published in the report of the Alberta Virtual Care Working Group – *Optimizing Virtual Care in Alberta*.

Reporting to the AVCCB will take the form of:

- Quarterly written progress briefs.
- As needed in-person presentations by the Working Group chair to a regular AVCCB meeting
- Submission of draft or final paper to the AVCCB for review and constructive feedback

Further the Working Group will have access to the membership of the AVCCB for the purposes of project review and feedback on an iterative basis.