



Alberta Innovates Health Solutions Secondary Use Data Project

I. Executive Summary from the Steering Committee

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I. Document Orientation

This report represents the Executive Summary from the Secondary Use Data Platform Steering Committee. The Steering Committee is comprised of the chairs and co-chairs of the following working groups:

- Privacy and Access – Mary Marshall and Lawrence Richer
- Data and Analytics – Kathryn Todd and Stafford Dean
- Infrastructure and Applications – Penny Rae and Susan Anderson
- Public Engagement – Deborah Prowse and Sharon Nettleton
- Enabling Legislation – Roger Palmer
- Governance and Structure – Dale Saunders

Additional details are available to support this Executive Summary in the report entitled “Companion Document from the Steering Committee.”

II. Terms and Definitions

The term ‘Secondary Use Data Platform’ was originally used to introduce the current project to stakeholders. The term was understood and adopted by the working groups as loosely describing the services and technologies that would support a health information repository. This interpretation was not consistent with other IT and business uses of the term ‘platform’. As a result, the Steering Committee chose to omit this term from its final reports. Instead, the overarching business and technical components that together create a ‘solution’ for improved access and use of secondary health data in Alberta are described in the final reports. The solution includes regulations, technology, privacy and security safeguards, analytics services, governance, and supporting resources.

The working group and steering committee members who contributed to this final report note that data definitions can be difficult to standardize. While much of the data used in Alberta for both primary and secondary purposes contains the same data elements, it is used for different purposes. It is prudent for the purposes of this report to include the following distinction between primary and secondary use data proposed by the College of Physicians and Surgeons of Alberta¹:

“Primary use – patient health information collected by their physician (or other healthcare provider) for the purpose of providing health services to that patient. Also includes the provider registration information used to document the provision of care. Use of a patient’s health information by another health care provider to provide a service to that patient is still considered primary use.

Secondary use – using a patient’s health information for any purpose not directly related to the care of the individual patient who is the subject of that information.”

¹ College of Physicians and Surgeons of Alberta – Data Stewardship: Secondary Use of Health Information, 2009.



A. Our Problem

Alberta currently lacks a solution to integrate the rich health and health-related data sources at its disposal - data that could optimize the precision of healthcare delivery and health improvement for Albertans. Challenges related to data sharing, data management, data standards, privacy, security, cost, regulation, and governance have contributed to a decade-long struggle to deliver an effective research and quality improvement data sharing solution. Other provinces are progressing rapidly on development of integrated health data repositories, attracting researchers and physicians away from Alberta. Among the more than 60 members of the six different working groups supporting this initiative, there is 100% agreement that the time has come to dramatically improve the integration of and access to secondary use data in Alberta.

Current secondary use data processes related to privacy and security can delay access to valuable research and quality improvement data for months or even years. As a result, opportunities for improvement and innovation are postponed or abandoned every day. Every time data access is delayed, so is the societal value of the research and quality improvement initiative that requires the data. Redundancies in technology and databases that support research efforts inflate overall provincial costs for carrying out innovative research programs; as many as a thousand standalone research databases and supporting infrastructure are maintained by multiple organizations in the province of Alberta. This represents tens of millions of dollars of cost to the system that could be reduced through collaboration, improved processes, and shared infrastructure.

Coordination of secondary data use is overdue by Albertans' standards; a culture of leadership and trust needs to be developed to support sharing and innovative use of this data.

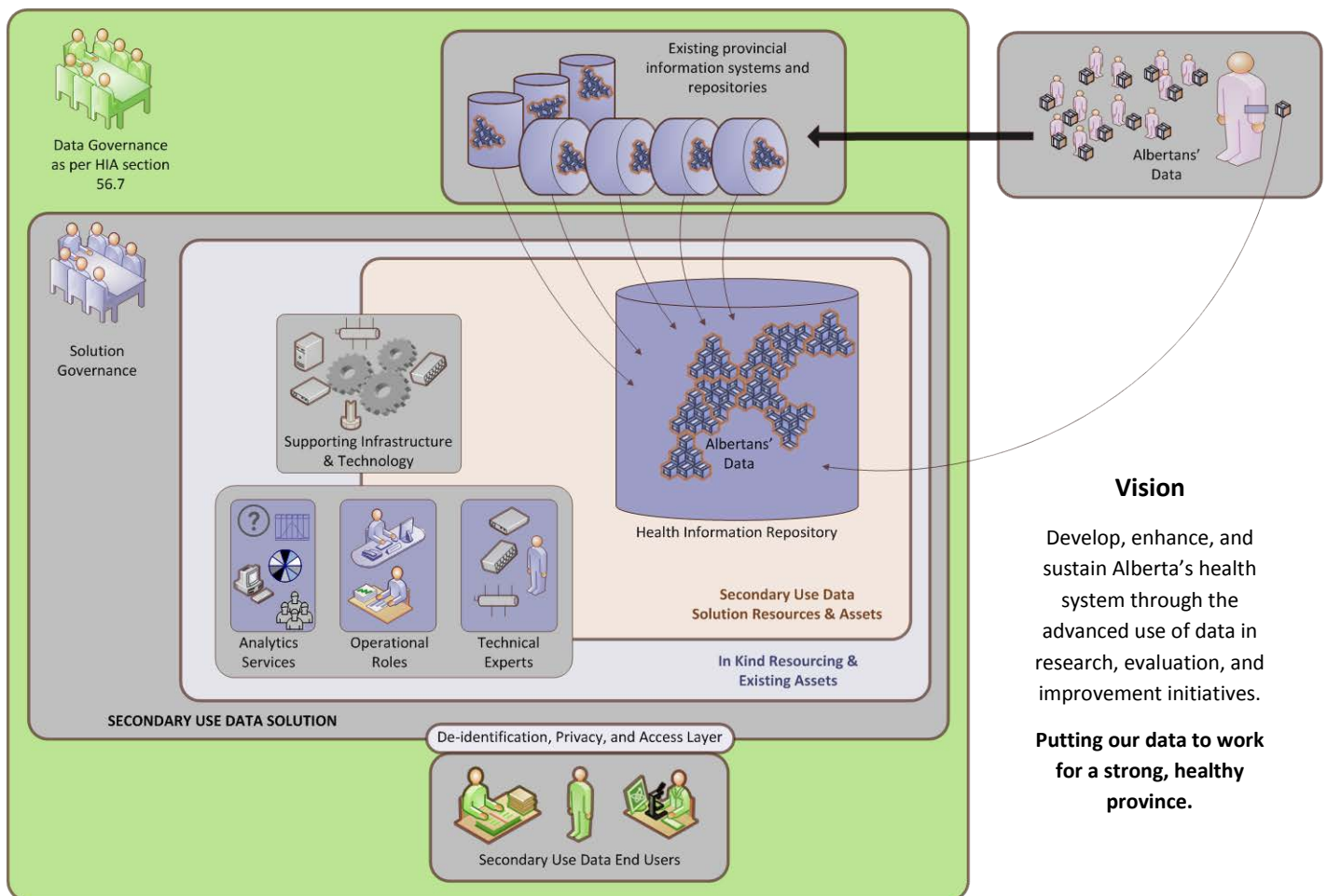
B. Our Solution

The working groups propose that Alberta develop a comprehensive solution that integrates health and health-related data for use in strategic planning, policy-making, service delivery, quality improvement, and research. The solution they recommend involves regulations, technology, privacy and security safeguards, analytics services, shared and equitable governance, and expert supporting resources.

As depicted below, the solution includes a comprehensive health information repository; supporting regulations under the Health Information Act (HIA) Part 6.1 will facilitate collection, use, integration, linkage, and maintenance of repository data from disparate health and health-related data sources. The repository will integrate health and health-related data on an unprecedented scale, bringing together data sources that are currently used in isolation or only partially integrated. In addition to the health information repository (HIR), the solution will include supporting infrastructure and technology, analytics services, operational roles, and technical experts; these resources will be a combination of net new and existing assets and resources. The solution will be governed by a steering committee that will report to the data governance entity named under HIA section 56.7.



Access to data users and privacy for Albertans will be ensured through the effective use of security and de-identification best practices and technologies.



Every day, health and healthcare organizations in Alberta create massive amounts of data, which if integrated, could increase the quality and reduce the cost of healthcare to Albertans. The proposed solution will connect this data back to the Albertans who provided it in the first place. The solution will allow us to improve the quality of care provided to every patient, on a personal and precise level. Following the lead of the Advisory Panel on Healthcare Innovation², Alberta will create a secondary use data solution that supports 'data-intensive models of

² Unleashing Innovation: Excellent Healthcare for Canada. Final Report of the Advisory Panel on Healthcare Innovation, 2015.



care and the rapid-cycle innovations that characterize precision medicine as a field'. We will reduce the cost of delivering high quality care. We will improve the overall health of the community. We will reduce the overall economic drain of poor health on the community. We will accelerate the pace of research.

C. Our Action

This is different from what we have done before. To support the new way forward, the solution will have collaborative and inclusive governance aligned with existing governance structures and analytics resources. However, it will fulfill a new mission. While attention to big data trends and related technologies will be required, many of the current barriers to the effective use of data are largely cultural and organizational. The solution's mission will be to remove these barriers and provide timely access to data as well as facilitate appropriate and innovative use of Albertans' data. It is important to note that primary and secondary use data are the same data used for different purposes; it is recommended that mandates, objectives, and goals for data use in the province of Alberta be aligned and coordinated via a provincial data governance entity under section 56.7 of the HIA.

The solution will extend what we have done to date. Alberta's HIA includes provisions for establishing a regulation to govern the designation of a health information repository; however, action to complete a regulation has not yet been taken. The working groups recommend that a Health Information Repository (HIR) regulation be drafted by Alberta Health under Part 6.1 of the HIA and moved through any required consultations and government approval processes as soon as possible, and no later than June 2016. In addition to health data, the solution will include health-related data e.g. social services data, income data, environmental toxin data. Data will be tied together using sophisticated inference engines that are built to automatically collect precise data points about specific patient groups from many sources and feed into precise registries. These precise patient registries will help reduce the variability in care delivered for similar patients, while improving the precision of care delivered to specific patients.

Stakeholders will work together in new and different ways. The solution will make use of a multi-stakeholder delivery model that builds on the expertise and analytics capacity within the province. There is currently significant overlap in data, data management, and analytics in Alberta's health system today. In particular, Alberta Health Services (AHS) and Alberta Health (AH) need to integrate and organize their analytic functions with clear role clarity aligning responsibility with skill capacity. Within this effort, the Provincial Health Analytics Network (PHAN) work will be leveraged but should not be viewed as the end point for secondary use in Alberta. By working together, Alberta can build on existing efforts to deliver not only an improved data and analytics system but also a more feasible and sustainable one. Stakeholders involved in research and quality improvement will be included in governance and operations. Through comprehensive stakeholder engagement and collaboration, the solution will break down barriers, improve data governance, improve collective processes, speed access to data, and support a new way of doing business. Key to this is a balance between the privacy of individuals and the value of secondary data to the health of Albertans; this will be supported through consistent



interpretation and behavior around privacy legislation and best practices. Special attention will be devoted to establishing gradients of non-identifying data that can be standardized and partially automated. Access to identifiable data (critically important to facilitate precise clinical care and research breakthroughs) will be facilitated by solution technical components and collaborative business processes.

D. Our Opportunity

The status quo is not an option. Our current ineffectiveness related to integrating health and health-related data prevents advancements in our understanding of the complex relationships between healthcare, health, and the social determinants of health. The technology, analytics, and reporting systems for integrating this data exist today – although new data content and technology will be required to completely fulfill the mission, technology is not the barrier. A lack of supporting HIR regulation, fractured data governance, and uncoordinated data and analytics practices prevent enhanced use of our own data. If we do not seize our current opportunity, redundant funding of uncoordinated analytics services and data management infrastructure will remain. Elevated costs, stifled research, suboptimal quality, and lost innovation will endure, and the cost to achieve the optimal health quality of Albertans will continue to suffer.

E. The Benefits

The solution will provide immediate benefits. Within 10 months, a project team will work with newly established solution governance and operational roles to develop privacy impact assessments, solution policy, analytics services, and solution infrastructure to support several solution demonstration projects. The solution project team will also work with PHAN team members to complete PHAN de-identification and portal projects, leveraging their execution, components, and results whenever possible. Early demonstration project efforts will include exposing and amplifying existing data assets to a wide audience using appropriate de-identification strategies and tools.

F. Timing and Costs

Relative to the enormous investment in healthcare information technology projects, such as those associated with electronic health records (EHRs) and electronic medical records (EMRs), minimal investment is required for this initiative. Given that current system redundancies exist, in kind contributions will be used, in part, to fund implementation of the solution during Phase 2 of the project. The net new contributions amount up to \$3M and will be used to carry out solution development activities and demonstration projects. Policies, processes,



infrastructure, services, and governance will be produced using a combination of demonstration projects and solution development activities coordinated or carried out by the solution project team. As a result, the solution structure and functions will be available for immediate activation as soon as the regulations are put in force. As appropriate, the solution project team will liaise with Alberta Health as they work to draft regulations under Part 6.1 of the HIA; however, regulation development will be dependent on appropriate prioritization and assignment of resources by the Government of Alberta. In order to realize the intended benefits within a 10 month timeframe, work on the policy and regulations will need to begin immediately and will need to remain tightly coupled to demonstration project activities.

G. Demonstration Projects

The following demonstration projects were carefully selected by the Steering Committee to demonstrate the value of the integrated data as quickly as possible, and to test the new governance and business models under which the data content and access will be managed:

- Demonstration Project #1: Release 4 aggregate AHS reports via a web interface:
 - Total Cost and Prevalence of Disease
 - Community Level Healthcare Utilization Rates
 - Surgical Utilization Rates
 - Variations in Care Delivery.
- Demonstration Project #2: Develop a precise patient registry for Chronic Obstructive Pulmonary Disease (COPD).
- Demonstration Project #3: Develop a precise patient registry for Diabetes, including use of community and primary care data sources.
- Demonstration Project #4: Develop an acute and continuing care capacity planning model that allows us to better understand the capacity required between acute and continuing care to ensure timely transitions from hospitals and community to continuing care.
- Demonstration Project #5: Expand data assets and related data integration for researchers participating in the Child and Youth Data Lab.

H. The Future

Data management practices as well as access and use processes will be optimized through a provincial secondary use data solution; in addition, economies of scale will provide savings for infrastructure support. These efficiencies and savings will allow a larger share of provincial funds to be liberated for direct research and quality improvement activities. Researchers and quality improvement experts will be able to focus on innovation and improvement as opposed to infrastructure support and data management. Access and privacy risks will be reduced as appropriate de-identification levels, services, and automation will be consistently available to all users.



The value of the solution will grow over time. Current data and knowledge gaps make it difficult to harness the benefits of data in our everyday health system decisions; as more data becomes available, these gaps will diminish and our capacity for data use will improve. Inclusion of health-related data will make it possible to personalize medicine as well as social, educational, and justice services in ways not previously possible. Imagine being able to adjust disease courses and social outcomes in real time avoiding disability, distress, and dysfunction. Data sharing, integration, and the resulting application of expert analytics services will make this a reality for Albertans. Secondary data use will allow us to continuously improve our research and health delivery efforts. With this kind of thoughtful evaluation of our overall health system, we will continually expand our understanding and improve our processes, our care, and our health system.

The benefit to Albertans is extraordinary. By bringing this data together for use in research, quality improvement, and service delivery evaluation, we will catapult Alberta healthcare to the next level of excellence. Early examples of secondary use data sharing exist in the world today. What will separate Alberta's solution is our ability to connect secondary data use results back to programs and services that directly affect Albertans. While other secondary data use models are largely closed systems that produce research for consumption using traditional methods, our solution will directly connect the data to how we deliver care and services.

Alberta has an opportunity; one that we cannot afford to let pass us by. We have a responsibility to respect the value of the data resting at our fingertips to ensure it is used to help others. Participation from individual citizens, health care providers, government, researchers and quality improvement experts is critical to the success and value of the solution. Through meaningful participation, the solution will facilitate a data and analytics system capable of measuring, understanding, and designing interventions that create a high-performing, learning health system.

I. Recommendations

Drafting and enactment of a regulation under HIA Part 6.1 is the foundational activity that will drive establishment of a HIR to support secondary data use in Alberta. As the heart of the solution, the HIR is what will provide the impetus to take secondary data use to the next level in Alberta. The following key recommendations form the basis for policy that will inform drafting of the regulation. No statutory changes³ will be required to the HIA in order to implement the HIR:

- The interests and priorities of the citizens of Alberta will be central to the purpose and function of the solution.
- The solution will be established as a multi-stakeholder, multi-organizational collaborative.

³ While it is unlikely that statutory changes will be required to initiate the health information repository, amendments to the Health Information Act may be needed in the future.



- While primary and secondary use data are the same data, they are used for different purposes and have distinct data management needs. As such, appropriate decision-making powers are required to coordinate primary and secondary data governance and provincial initiatives. It is recommended that the mandate of the HIA legislated EHR Data Stewardship Committee be expanded in order that its role include providing guidance and input (strategic and otherwise) to the Solution Steering Committee.
- The solution will function as a shared-governance entity between data funders, users, and contributors. A Solution Steering Committee will provide the operational governance structure that facilitates achievement of solution goals and objectives.
- The initial Solution Steering Committee will be an appointed, representative/competency-based steering committee. It will be supported, as needed, by implementation working groups.
- The health information repository should be a new data entity class, 'repository', with rights, duties, powers, and responsibilities separate and distinct from a custodian or information manager.
- The health information repository will collect, use, and disclose health information for the purposes of strategy development, planning, policy making, service delivery, care, research, monitoring, and economic development to benefit Alberta and Albertans.
- The solution will include clinical, socio-economic, multi-jurisdictional government, administrative and self-reported data that is aggregated and integrated.
- Per the HIA, secondary use data will be considered as either non-identifying or individually identifying. Non-identifying means that the identity of the individual who is the subject of the information cannot be readily ascertained.
- Non-identifying data will be categorized into minimum, moderate, and maximum risk of identification or re-identification.
- The solution should be funded to include core data content, business and technical infrastructure, and applications.
- Governance will operate at arms-length from any one of the involved stakeholders. While data contributors and users will have an opportunity to actively contribute to governance of the solution and its operations, no single stakeholder will make decisions or set strategic priorities in isolation from the others.
- As the solution matures, the Solution Steering Committee will evaluate the cost and benefits of establishing an alternate solution entity and governance structure, as appropriate.

In addition to regulation drafting and enactment, a number of set-up and operational activities must be undertaken to support implementation of the solution. The following implementation recommendations are a synopsis of the comprehensive recommendations provided by six working groups during Phase 1 of the project:

- A public engagement strategy will be co-developed with members of the public. The strategy will be based on best practices and aligned with other relevant provincial health information initiatives.
- Implementation will proceed with several Phase 2 demonstration projects focused on quick delivery of data assets, with concurrent development of solution governance and initial operations structures.
- Solution funding processes will assess current analytics investments and capacity, identify opportunities to reduce duplication and waste, and redirect savings to current data and analytics gaps.
- Operational needs of the solution will be evaluated as solution development activities are carried out in Phase 2. This includes identifying the knowledge, skills, and abilities that will be required to operate the



solution. The roles and individuals required to fulfill these needs may be dedicated to the solution and/or seconded as in kind resources leveraged from existing analytics programs. Example roles may include but are not limited to Director, Chief Analytics Officer, and Chief Privacy Officer.

- Stakeholders will leverage existing technologies and infrastructure, including in-flight projects and procurements, to design and develop a big data analytics solution capable of integrating data from health and health-related source systems.
- A core set of analytics functions, tools, and resources will be designed and implemented as part of solution operations.
- The solution will ensure adequate privacy protection for individuals at the same time recognizing the benefits for the appropriate secondary use of health data for research, innovation and quality assurance. Specifically, the solution will develop and support robust de-identification practices to specify the level of risk that is acceptable given the potential benefit of any particular research.
- The initial Solution Steering Committee will be composed of nine representative stakeholders that employ formal governance practices and function as equal participants.



III. Document Abbreviations

AH	Alberta Health
AHS	Alberta Health Services
COPD	Chronic Obstructive Pulmonary Disease
EMR	Electronic Medical Record
EHR	Electronic Health Record
HIA	Health Information Act
HIR	Health Information Repository
IT	Information Technology
M	Million
PHAN	Provincial Health Analytics Network