

A Discussion on Open Data

*Summary Report From A Discussion With the
Alberta Ministry of Health Held February 16th, 2016*

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TABLE OF CONTENTS

EVENT OVERVIEW	3
CONTEXT	3
OBJECTIVES	3
FORMAT	3
SUMMARY OF OPENING REMARKS	4
DR. CARL AMRHEIN, DEPUTY MINISTER OF ALBERTA HEALTH.....	4
SUMMARY OF PRESENTATIONS	4
TIM MURPHY, VP- ALBERTA SPOR SUPPORT UNIT & PROVINCIAL PLATFORMS, AIHS	4
ANNE BABINEAU, DIRECTOR - PRAIRIES, INNOVATIVE MEDICINES CANADA	6
MARTIN BARBEAU, HEAD - HEALTH ECONOMICS & OUTCOMES RESEARCH, LACAN, NOVARTIS	7
JENNIFER CHAN, VICE PRESIDENT - POLICY AND COMMUNICATIONS, MERCK CANADA	7
DISCUSSION	8
NEXT STEPS	9
APPENDIX 1: LIST OF PARTICIPANTS	11

EVENT OVERVIEW

Context

There is much work underway in Alberta to extract value, broadly defined, from secondary use data that contributes to our understanding and management of the health system. This meeting was a forum for the Alberta Ministry of Health, and several of its agencies and partners, to exchange with the innovative pharmaceutical industry to share the ongoing work in the province in this area, and to obtain a perspective from industry on how they might utilize data resources and collaborate as a key partner on initiatives that take advantage of this Alberta resource. Please see Appendix 1 for a list of participants.

Objectives

The meeting had the following objectives:

1. To describe the Alberta strategy, plans and progress to strengthen and evolve the use of secondary data to improve health system performance and patient care.
2. To share several case studies from related industry initiatives in Alberta and other jurisdictions to learn from previous experience.
3. To obtain a perspective from industry on how they might utilize data resources and collaborate as a contributing partner on initiatives that leverage this Alberta resource.

Format

The meeting took place in Edmonton and had a duration of two hours. The format was a roundtable discussion preceded by a presentation from Alberta Innovates – Health Solutions to describe a provincial initiative to establish a robust secondary use health data platform (termed the Alberta Secondary Use Data Project), as well as several industry presentations to share experiences on health data initiatives in Alberta and other jurisdictions.

SUMMARY OF OPENING REMARKS

Dr. Carl Amrhein, Deputy Minister of Alberta Health

There is much work underway in Alberta to extract value from secondary use data that contributes to our understanding and management of the health system. I am encouraged by the interest from the innovative pharmaceutical industry in supporting and contributing to this important work. The goal of any collaboration between the public and private sectors is to collectively extract more value from a joint effort than with separate efforts.

This meeting was an important first step in sharing progress to-date towards robust secondary data use capabilities in Alberta, and towards defining the areas of mutual interest and benefit where collaboration represents intriguing potential. This document summarizes the presentations and discussion at the meeting, and articulates a next step to help us further understand the perspective of industry.

Your continued interest in contributing to help us take advantage of some of the best secondary use data in the world is appreciated. I look forward to both receiving written submissions from industry that help us to define and shape the opportunity, as well as future exchanges that create some tangible projects that deliver measurable results.

SUMMARY OF PRESENTATIONS

Tim Murphy, VP- Alberta SPOR SUPPORT Unit & Provincial Platforms, AIHS

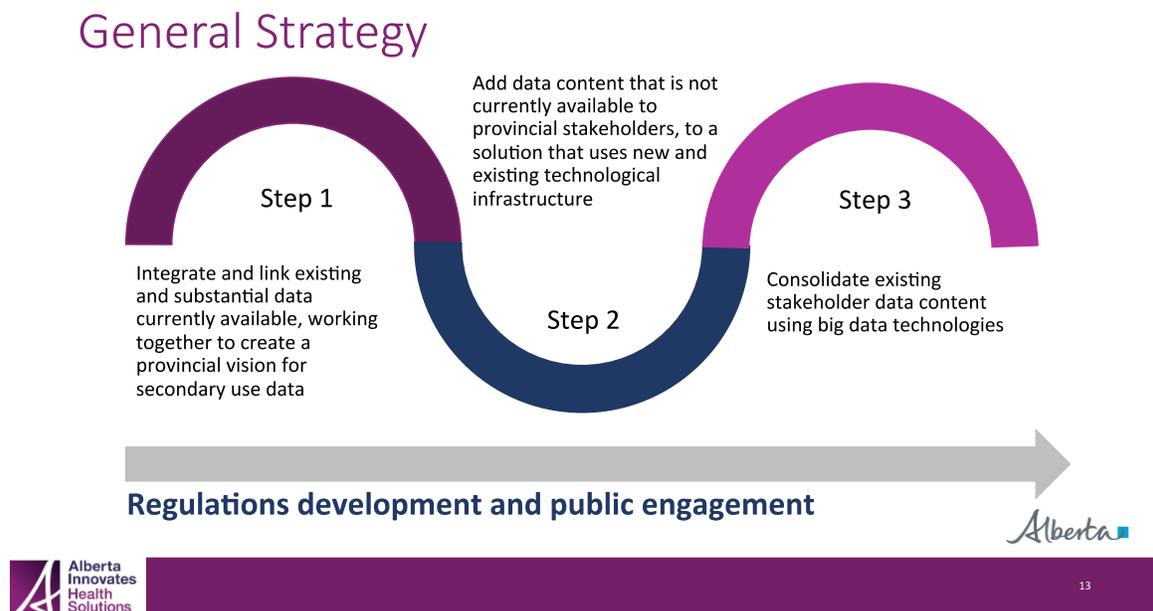
In Alberta, health data for approximately 4 million people is captured within an integrated health system and we have opportunity to take advantage of some of the best secondary use data in the world. Secondary use health data is defined as the use of a patient's information for any purpose not directly related to the care of an individual. The data referred to is health and health related clinical, socio-economic, multi-jurisdictional government, administrative and self-reported data. The ecosystem of health data includes encounter, biometric, outcomes, environmental, genomic and familial, and social data. This data can be of great benefit when aggregated, analyzed, privacy-protected and made accessible to inform decision-making in support of strategy, planning, policy-making, service delivery, care, research, and commercial efforts.

There are a number of factors that contribute to health, including lifestyle choices, health system interventions, biology, and the environment. To build a robust secondary use database we need elements of all of these captured. A useful metaphor is the concept of a library, where we have books that include health data, but also environment, education, justice and other data to permit linkage and cross-referencing in order to fully understand

population health. Integration of disparate data sets will help improve the quality of care delivered to patients, reduce costs, improve population health and reduce the overall economic drain of poor health on the community, and accelerate the pace of research and innovation.

The Alberta Secondary Use Data Project has involved 18 organizations and 70 stakeholders. There is a 3-step strategy guiding the project, with regulations development and public engagement at each step.

Figure 1 – Alberta Secondary Data Use Project Strategy



The project is structured around 6 working groups:

1. Public Engagement
2. Privacy and Access
3. Data and Analytics
4. Infrastructure and Applications
5. Enabling Legislation
6. Governance and Structure

In terms of progress to-date, the first of three phases kicked off March 2015, with reporting and presentation from the 6 working groups completed in the Fall of 2015. Phase II demonstration projects were endorsed at this time. Three core principles guide the demonstration projects; they must align with existing clinical and economic priorities, engagement must include the public, clinicians, researchers, and policy-makers, and they must leverage existing provincial assets in terms of data, technology and analytic skills.

There are five demonstration projects in Phase II that will:

1. Release four aggregate Alberta Health Services data sets to the public via a web portal;
2. Develop a Balanced COPD Quality Measurement Set;
3. Develop a Balanced Diabetes Quality Measurement Set,
4. Develop a capacity planning model to examine the needs of health system users and the capacity of health system organizations and services to respond to current and anticipated system demands;
5. Expand data assets and related data integration for researchers participating in the Child and Youth Data Lab via use of a self-serve portal.

The Phase II projects are likely to take 12-15 months, and upon completion Phase III and the building of the library will commence. Analytical support and expertise will need to be drawn from existing and new resources. Alberta will not be in a position to support all requests, and collaboration models and other partnerships for load and data sharing will need to be a topic discussed and addressed going forward.

These demonstration projects are in the process of starting and are at the project charter step. There may be opportunity for the inclusion of new partners in these streams, including the pharmaceutical industry. In terms of additional projects, the current focus is on initiating the five projects to start to realize some tangible results from the work, and following this there may be opportunity for additional suggested projects.

Anne Babineau, Director - Prairies, Innovative Medicines Canada

Innovative Medicines Canada is participating in a demonstration project in Manitoba in partnership with Manitoba Health, the Center for Health Innovation, and the Manitoba Center for Health Policy. This Innovative Medicines Canada Foundation sponsored project leverages the linked Manitoba secondary use data asset that is managed through the Manitoba Center for Health Policy.

The project has been developed with the goals of supporting innovation, demonstrating the richness of the data and the capacity of the research community, and demonstrating the benefit of partnership with industry. It will seek to understand the patterns of prescribing and real world outcomes with innovative therapies in order to enable better decision-making by physicians, help inform better decisions from both a policy and

product reimbursement perspective, and for industry to gain a better understanding of product performance outside of the clinical trial context. The partnership is intended to increase industry economic activity and investment in the province, as well as establish the foundation for future agreements between industry and the Government of Manitoba. This project aligns fully with what Alberta is seeking to do and industry will be pleased to share any learnings.

Martin Barbeau, Head - Health Economics & Outcomes Research, LACan, Novartis

Novartis Canada has experience using provincial administrative databases (note: not clear if direct or indirect access via a third party), to understand treatment patterns, burden of disease, and to assess compliance with treatment, with the objective of building a file for presentation to payers and decision-makers in order to obtain product market access. Novartis also works with community-based EMRs in private clinics to collect information about disease and treatment patterns.

Novartis is interested in additional uses of secondary data, including for the purpose of a value-based reimbursement approach in Canada, similar to what has been done in the United States. In the U.S., Novartis has executed an outcomes-based agreement with HMOs for a new agent. In this model, the company has committed to demonstrate comparable results to clinical trials in real world clinical practice. The concept is that there is an agreement to a threshold for improvement, for example in reduction in hospitalizations, and if met then a higher price is paid for the product. A similar approach is possible in Canada with access to robust secondary use data.

Jennifer Chan, Vice President - Policy and Communications, Merck Canada

An Alberta project Merck Canada is involved in, called IMPACT 5/65, is an example of an initiative where in-kind expertise and resources that supplement provincial resources is provided by a private sector partner to support a province with a major health system priority. Drawing from a global talent pool, Merck has provided these resources for this project that has the objectives to identify healthcare recipients who represent 5 percent of the population yet account for 65 percent of costs, and use secondary data to segment the populations, define care pathways, identify gaps, design interventions to improve quality of care, and measure outcomes. Segmentation has been completed and the project is at the stage of designing interventions for testing in the living lab.

In a similar approach, Merck Canada has supported provincial health systems by facilitating the sharing of experiences in other jurisdictions and by fostering connections with partners that are in a position to support particular provincial priorities and challenges. For example, Merck has global experience with data warehousing expert PHEMI and has created connections between this organization and the health system in B.C. to share capabilities and technology to support the linkage of disparate databases to answer specific research questions.

DISCUSSION

The intent of discussions with industry regarding access to secondary use data is not about use of the resource in a transactional manner to drive revenues for the province, but rather to understand the opportunity for collaboration to improve health system performance and the health of Albertans while creating mutually beneficial outcomes for partners. The goal of continued discussion with industry is to understand if collectively we can extract more value from data than with separate efforts.

Collaboration and a partnership approach to solve complex challenges, similar to the 5/65 project, with shared resources as the foundation of a mutually beneficial relationship, likely represents an important path forward. Supporting information that would be valuable to inform efforts to architect similar shared initiatives include an understanding of similar projects and how they are structured, the resources industry has available to contribute that are complementary to those in Alberta, and the key areas of industry research interest related to secondary use data.

There is interest in understanding how greater access to robust secondary use health data can lead to new previously inaccessible opportunities. For example, for performance-based product listing agreements that are informed by real world evidence, or to provide clear evidence of savings harvested outside of the pharmaceutical budget sufficient to stimulate budget shifting. Additionally, collaboration on data-driven health initiatives may provide an economic impact in the province, and there is interest in further understanding the potential opportunity in this area.

There are many conversations currently taking place regarding how we can invest our resources to extract greater value, and extending the conversation to include the innovative pharmaceutical industry is attractive to government. To support this dialogue and exchange there is interest in understanding the best process to engage industry and include their perspective alongside those of other stakeholders.

NEXT STEPS

Industry comment and input on a number of areas highlighted in the discussion will help establish a framework for collaboration and partnership moving forward. Specifically, we are interested in understanding the following:

Collaboration

- Research questions of interest to industry that can be answered with secondary use data, along with the data requirements to support this work.
- The type of database resources that industry can contribute to joint initiatives that are complementary or supplemental to data that is currently available or anticipated to be available in Alberta.
- The type of in-kind expertise, relationships, or other resources that industry can provide on joint initiatives that are complementary or supplemental to those within the public sector.
- Insight into any potential barriers to collaboration and data access that should be proactively addressed in the discussions.

Experience & Case Studies

- Examples of mutually beneficial projects where industry has collaborated with public sector partners on data initiatives intended to improve patient care and corporate and health system performance.

New Opportunities With Access to Data

- Anticipated applications that follow from access to robust secondary use data (e.g., performance-based product reimbursement).
- If and how greater access to secondary use data and or related joint initiatives may lead to greater economic investment in Alberta, as well as the order of magnitude.

Engagement Process

- Recommendations for the best process for industry and the Government of Alberta, and its health agencies and partners, to convene to discuss these issues.

Written responses, following the categories and addressing the points above, would be most appreciated to shape the engagement process. Those that wish to provide this information can do so through BioAlberta, who will provide a summary of the feedback without attribution to individual companies.

Responses are requested by March 31, 2016, and can be sent to admin@bioalberta.ca. Please also address any questions or comments to this address. BioAlberta will provide respondents with a summary of the feedback at the same time as other stakeholders. Based upon the input an engagement process will be jointly developed with industry as a contributing partner in establishing a path forward.

APPENDIX 1: LIST OF PARTICIPANTS

Name	Organization
Anne Babineau	Innovative Medicines Canada
Beth Kidd	AstraZeneca Canada
Brent Korte	Impact Consulting
Brian Hamilton	OIPC
Carl Amrhein	Alberta Health
Carole Bradley-Kennedy	Boehringer Ingleheim Canada
Christie Schmidt	Alberta Health
Dan Labbe	Boehringer Ingleheim Canada
Dan Palfrey	Institute of Health Economics
Daria Horbay	Pfizer Canada
David Zygun	Alberta Health Services
Deb Koweski	Alberta Health
Cathryn Landreth (representative)	Open Government
Hubert Eng	Economic Development and Trade
Janey Shin	Janssen Canada
Jennifer Chan	Merck Canada
Kathleen Addison	Alberta Health Services
Kim Wieringa	Alberta Health
Larry Svenson	Alberta Health
Lorne Koscielnuk	Servier Canada
Martin Barbeau	Novartis Canada
Mel Wong	BioAlberta
Michael Duong	Roche Canada
Michele Evans	Alberta Health
Peter Brenders	Sanofi Genzyme Canada
Reg Joseph	Alberta Innovates - Health Solutions
Rob Lee	Takeda Canada
Shanleigh Lount	Shire Canada
Steven Urquhart	Roche Canada
Thu Parmar	Roche Canada
Tim Murphy	Alberta Innovates - Health Solutions
Xaxier Nouvelot	bioMérieux Canada