



Alberta  
Innovates  
Health  
Solutions

# Secondary Use Data Project

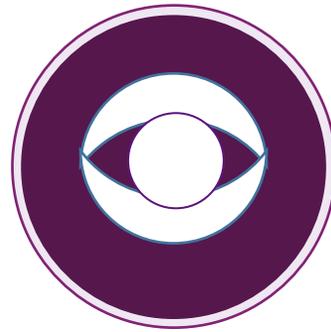
Tim Murphy  
November 30, 2015

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# Agenda



**What have we  
accomplished?**



**What are we  
trying to  
achieve?**



**How you can  
help**



*Before we start*

# Exactly what data are we talking about?

*“Health and health related clinical, socio-economic, multi-jurisdictional government, administrative and self-reported data that has been 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 to benefit Alberta and Albertans.”*



# Primary & Secondary Data Defined

**Secondary Use Data—  
using a patient’s  
information for any  
purpose not directly  
related to the care of  
an individual.**



**Primary Use Data – Patient  
health information used to  
provide health services to a  
patient**

Source: College of Physicians and Surgeons of Alberta

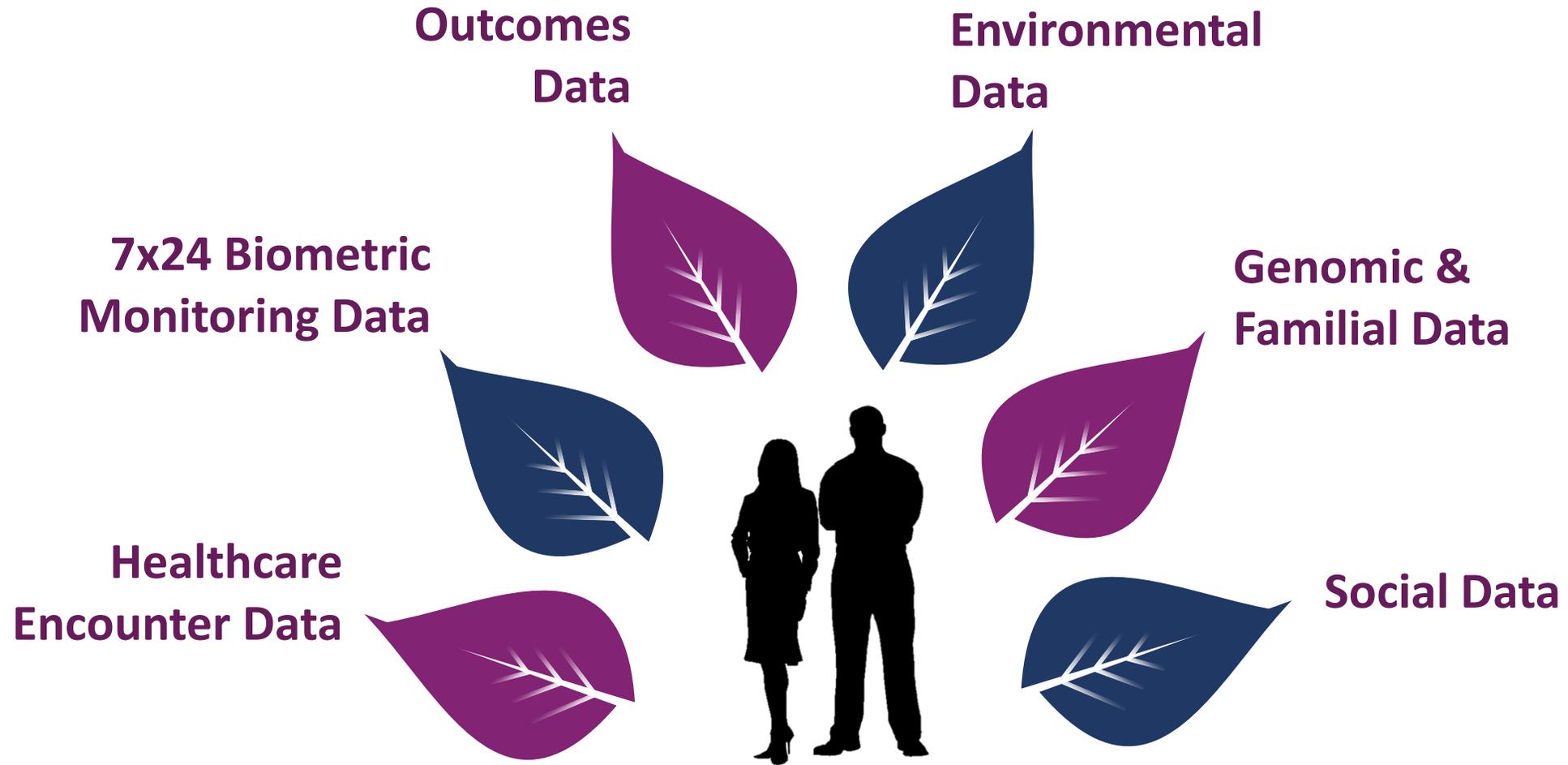
# Context



Some of the Best Secondary Use Data in the World

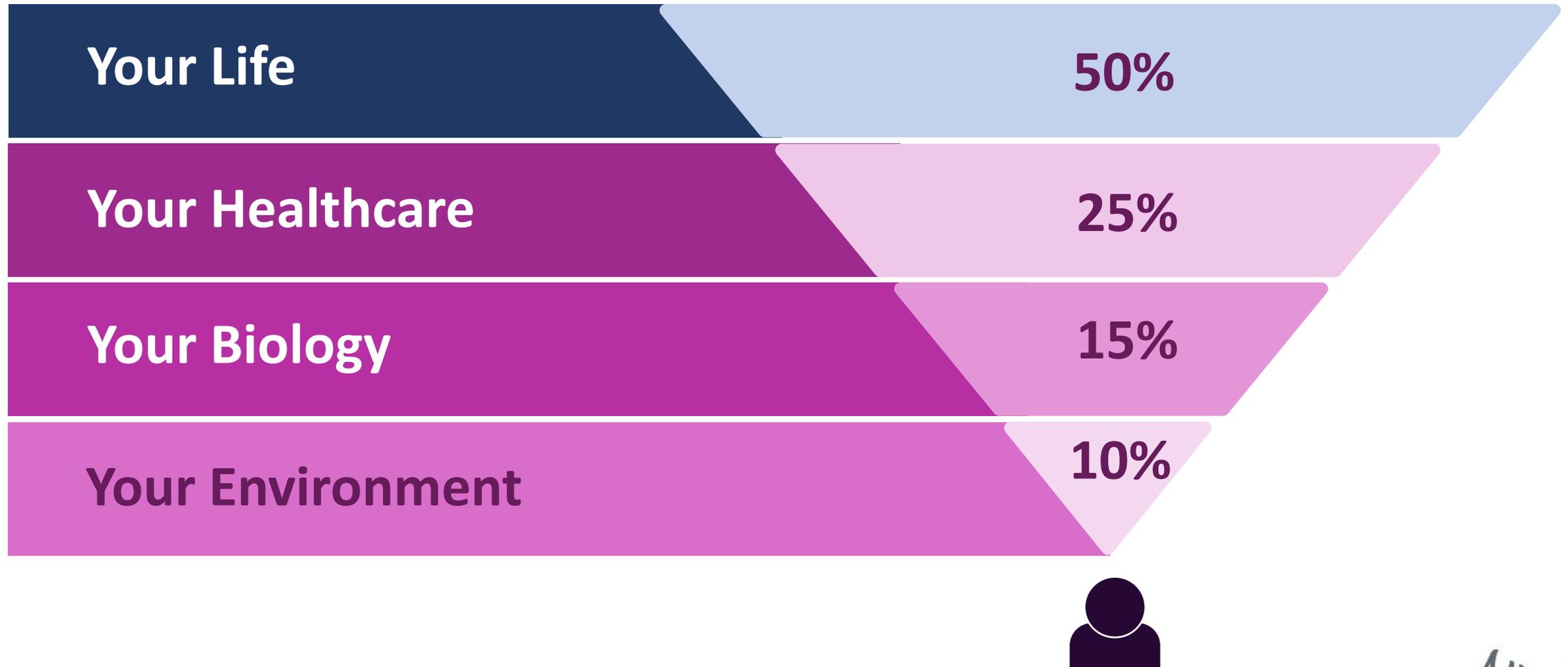
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# The Ecosystem of Human Health Data



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# Personalized, Precision Medicine



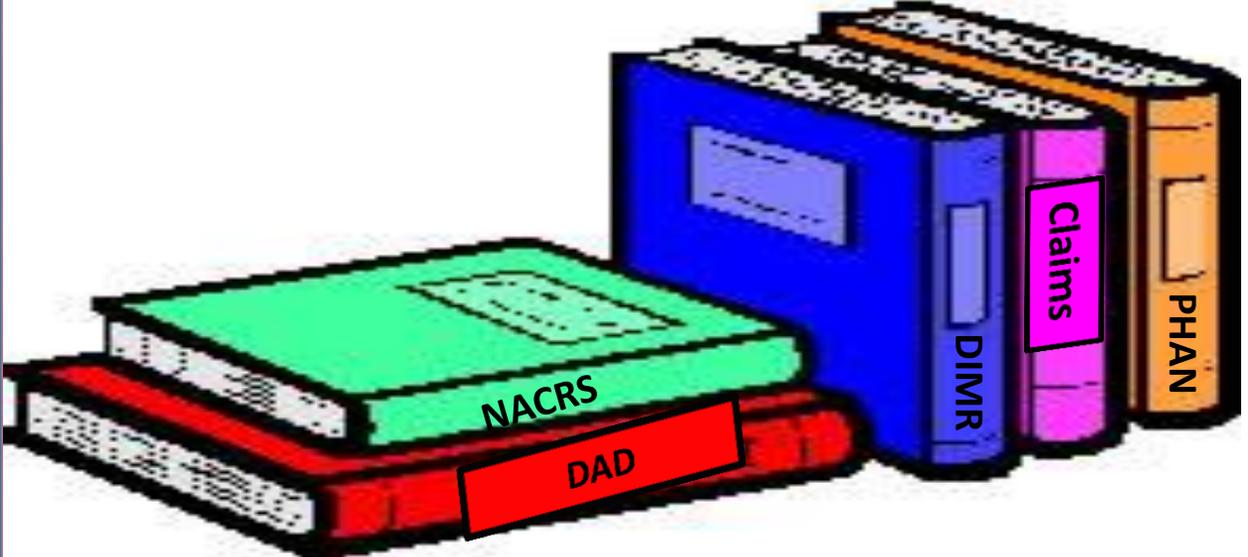
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# Building a Data Library



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# Developing a Curated Selection of Integrated Data Holdings





*What have we accomplished?*

# Working Group Objectives

## Public Engagement

- Represent **interests of Albertans** regarding use of data
- Determine strategy to receive ongoing feedback from Albertans

## Privacy & Access

- Examine **balance between access to data & individual privacy**
- Minimize risks to privacy; maximize value of data through access

## Data & Analytics

- Identify inclusive **data asset inventory** for secondary use
- Determine the access and tools required for effective use of data

## Infrastructure & Applications

- Determine **infrastructure to house, maintain, & share data**
- Support and automate features and functions required to use the data

## Enabling Legislation

- Identify **legislative opportunities** and hurdles to the concept
- Collaborate to draft regulations and amendments as appropriate

## Governance & Structure

- Develop **trusted governance** that represent interests of all stakeholders
- Determine legal structures required to create, govern, and operate HIR

# Progress to Date

Kick-off:  
March 12, 2015



- Six working groups formed
- Over 70 people from 18 different public, government, and private company organizations

July 31, 2015



- Final reports from working groups plus a summary report from the Steering Committee
- About 160 pages in total

Fall, 2015



- Findings and recommendations presented to key stakeholders
- Endorsement of Phase 2 Demonstration Projects

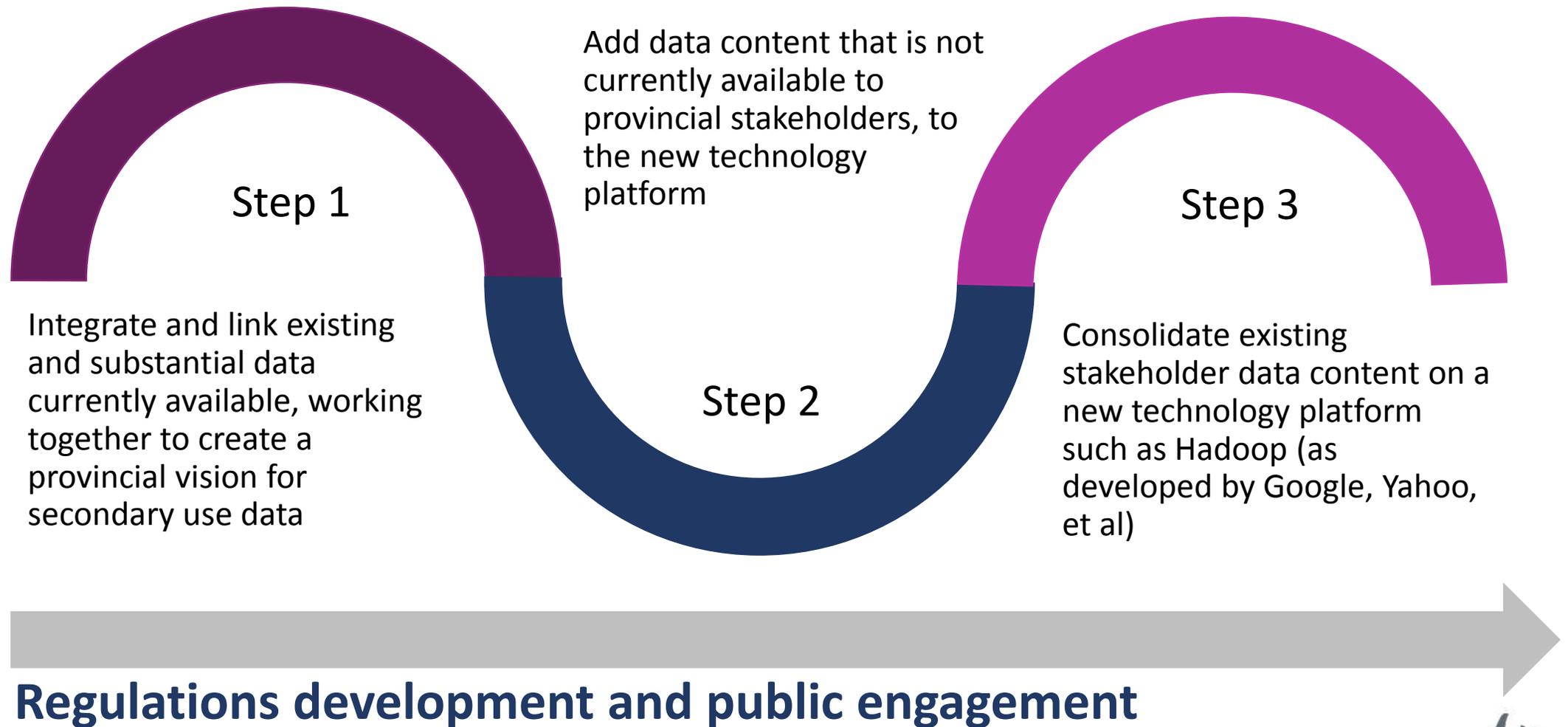
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- Present Phase 1 high level requirements gathered
- Kick off Phase 2 of project

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# General Strategy



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*What are we trying to achieve?*

Develop, enhance, and sustain Alberta's health system through the advanced use of data in research, evaluation, and improvement initiatives

*Putting our data to work for a strong, healthy province*

# Q: What is our goal?

A: Provide a single source of health and health-related data that will be used to:

1

Improve the quality of care provided to every patient, on a personal level

2

Reduce the cost of delivering high quality care

3

Improve the overall health of the community while reducing the overall economic drain of poor health on the community

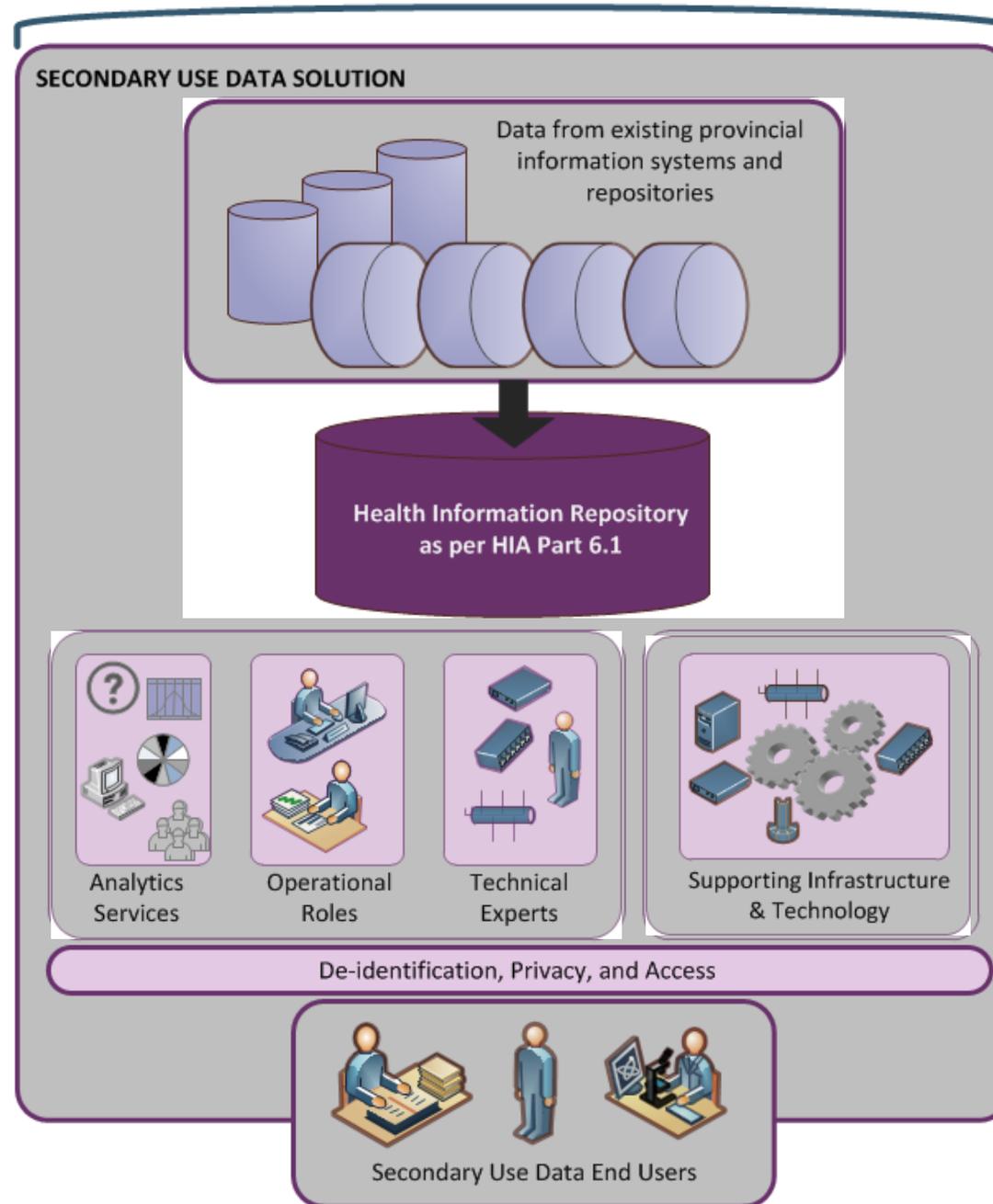
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Accelerate the pace of research

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# What will it look like?

## Governance



# Key Considerations

Must all be addressed as we increase our capacity to harness secondary use data

Data Storage

Data Sharing

Data Accuracy



Intellectual Property Rights



Data Collection

Data Access

Data Integration



Regulation

Privacy



Data Needs

Cost

Security

Governance

Data Standards

Analytics

# Working Groups: Key Messages

- The public expects data sharing to be happening; it's overdue
- Continued involvement and education of public is expected
- We need a culture of leadership and trust supporting this data
- Barriers are not technical; they are cultural & organizational
- Leverage existing technology, but also migrate to big data technology
- Use minimal, gated funding
- Governance - equal parts representation and competency
- Balance the value of data for health improvement with data access controls
- Create regulations to support a health information repository

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# Feedback from Lay Advisory Committee

- It was assumed that data is centrally stored
- There is surprise that data is not readily available (in a timely manner) for research and quality improvement.
- Can you guarantee people's information is non-identifiable and secure?
- Coordination with other jurisdictions
- Balance between privacy and use of data
- How co-ordinated are the electronic patient information systems?
- Will secondary use data be available for commercial use? If so, who will get the money and how will it be used?

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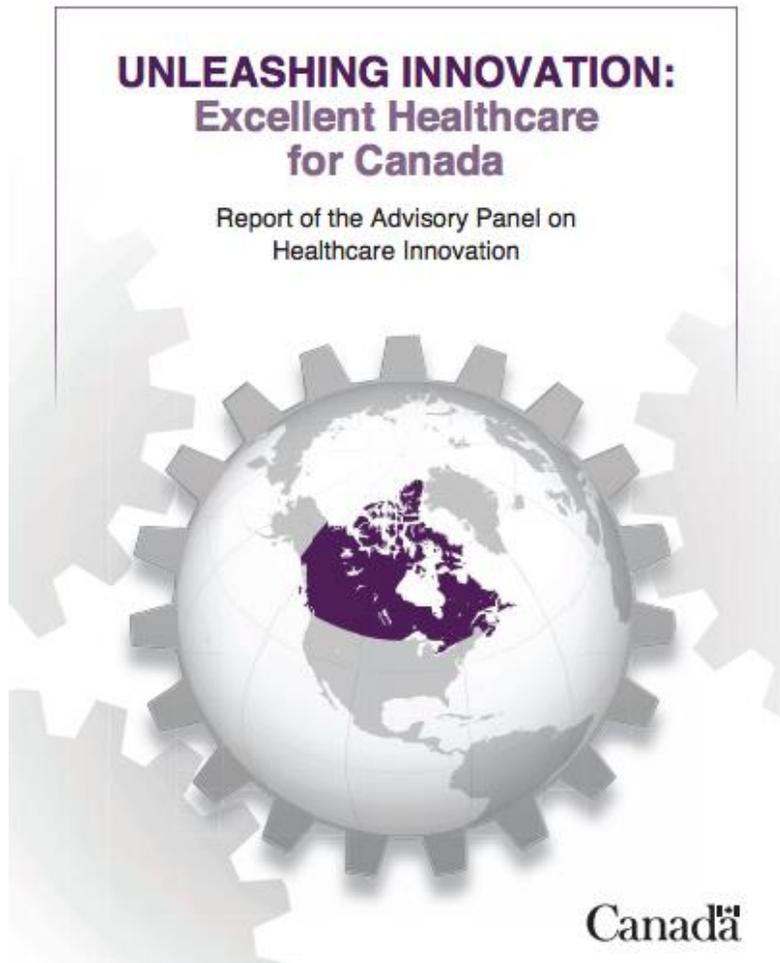


*How you can help*

# Aspirational Healthcare

Imagine if your physician could say this to you:

"I can make a health optimization recommendation to you, informed not only by the latest clinical trials, but also by our local and regional data about patients like you; the real-world health outcomes over time of every patient like you who has had your illness; and the level of your interest and ability to engage in your own care -- and in turn I can tell you within a specified range of confidence, which treatment has the greatest chance of success for a patient specifically like you and how much that treatment will cost the health system."

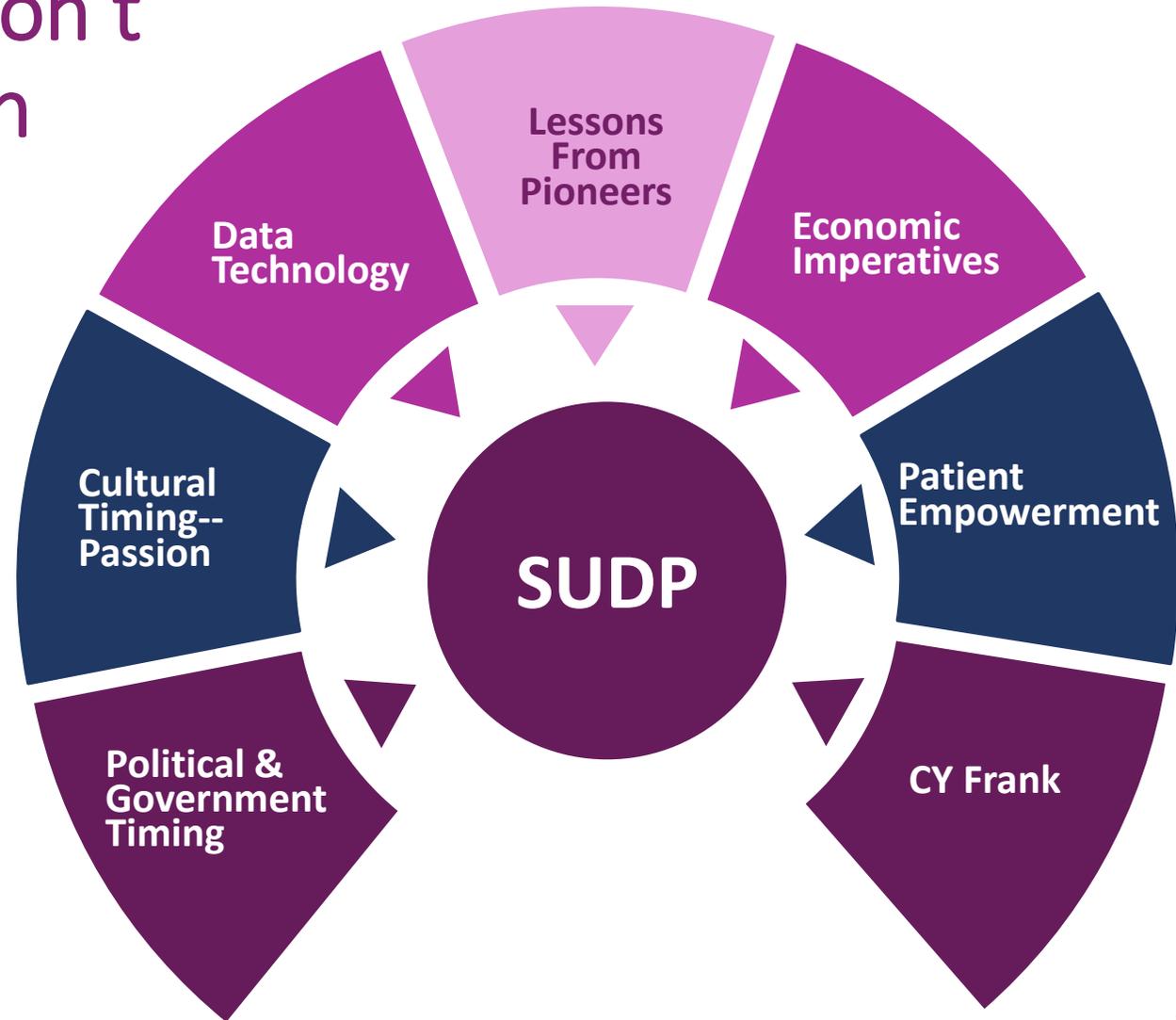


- July 2015 report to Government of Canada Health Minister
  - Chapter 7 - Channeling the Data Deluge, Mapping the Knowledge Frontier
- *“Precision medicine is an approach to medicine in which diagnostic, treatment, and prevention strategies are tailored to subpopulations of patients or even personalized at the individual level.”*
- *“We urgently need a strategy for moving precision medicine to the clinical front-lines, and for turning the sophisticated data arising from such clinical encounters back into generalizable research findings.”*
- *“Access to data and information among patients, providers, researchers, and policymakers is inconsistent. The Panel heard that data access is particularly difficult for clinicians and researchers in certain provinces who have no choice but to buy raw data or customized analyses from other jurisdictions.”*

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# These Opportunities Don't Come Along Very Often

Rare convergence of  
events in history



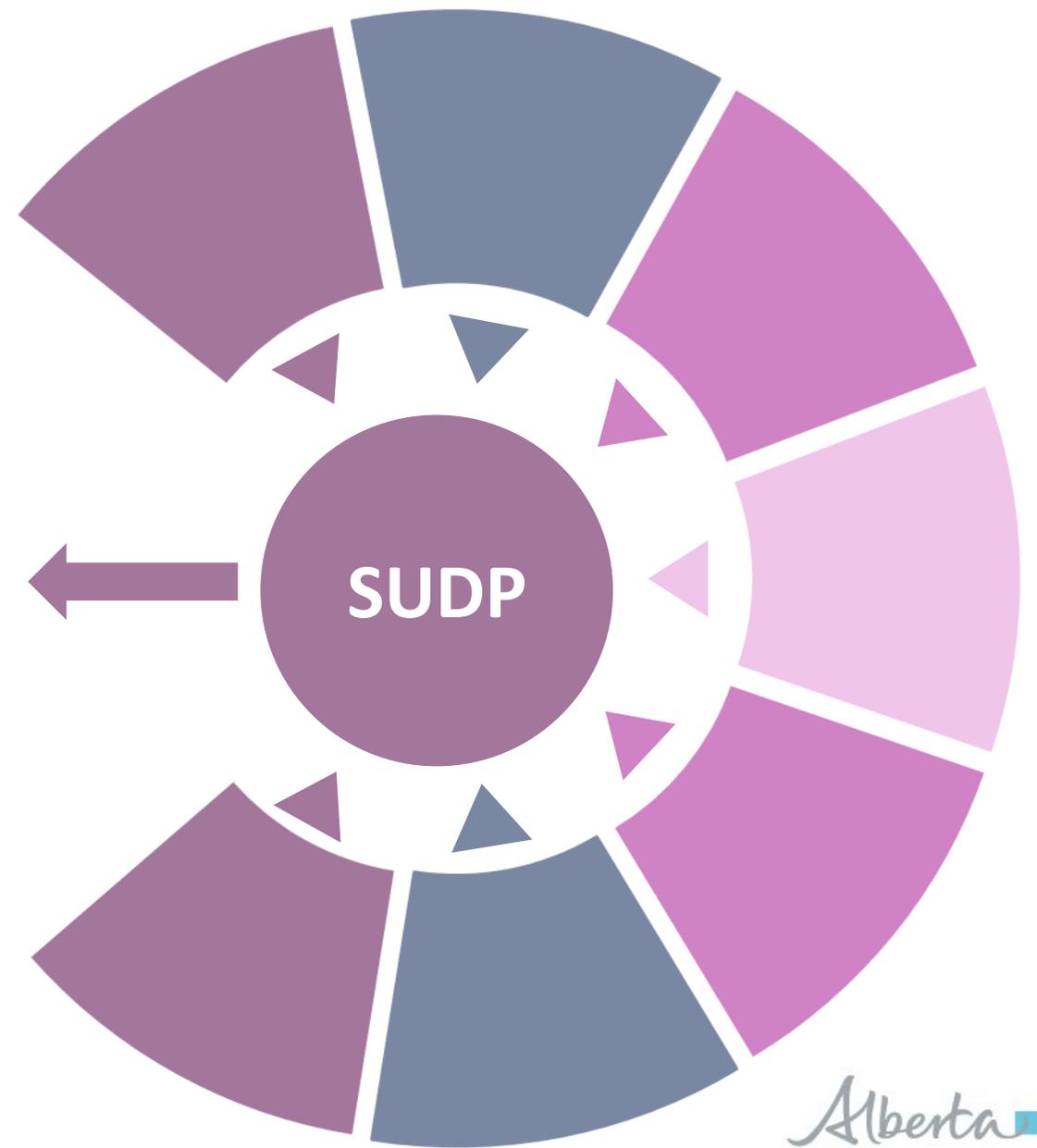
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# What will you do?

What are you willing to do contribute to this effort?

What would you do differently if you had increased access to secondary use data?

How will our health system and daily lives be improved by secondary use data?



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*Thank You*