Moving Forward on a Pan-Canadian Health Data Strategy

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Outline

Conflicts: None

- What is the issue we need to address?
- What is the Pan-Canadian Health Data Strategy and the Expert Advisory Group?
- Contents and direction of this work
- Next steps

A World-Class Health Data System?

‘Critical data gaps have greatly hampered Canadian governments’ ability to face COVID-19 pandemic: report

What's preventing Canada from creating a robust health data infrastructure?

Encore des milliers de « fax » pour lutter contre la COVID-19 au Québec

Les télécopieurs et des systèmes informatiques incompatibles provoquent lenteurs et agacement sur le terrain comme au sommet de l'État.

A World-Class Health Data System?:
Viral sequences sharing in GISAID: From collection to submission
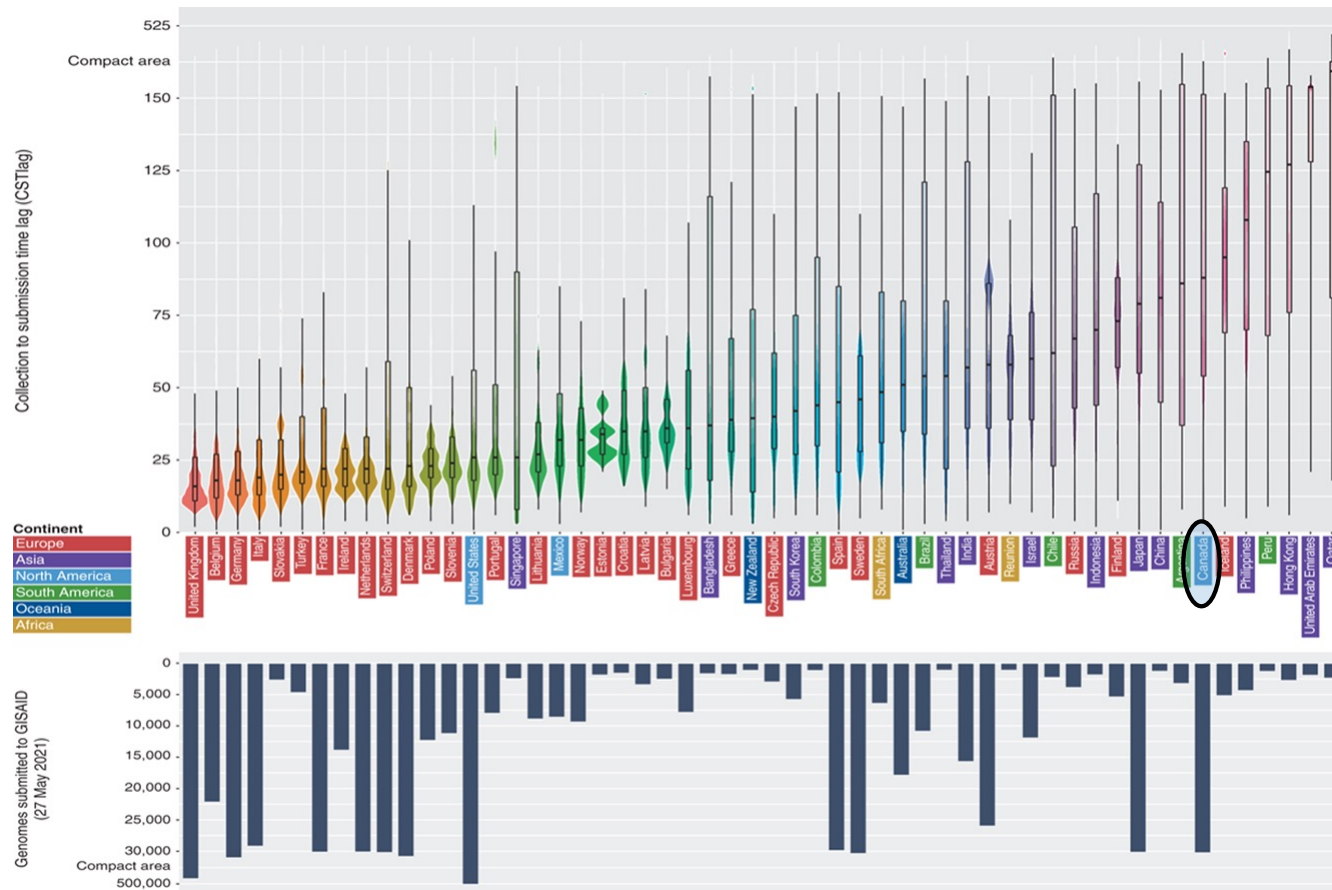
Kalia, K., Saberwal, G. & Sharma, G. The lag in SARS-CoV-2 genome submissions to GISAID. Nat Biotechnol 39, 1058–1060 (2021).

Past and Future Investments: Seeds for Change

- **Health care systems need good data to sustainably deliver care** and align health human resources with population needs.

- **Public health systems cannot effectively reduce risk without good data**: SARS and COVID-19 showed that surveillance and data linkage shortcomings led to acute, inequitable, and stark impacts during a public health emergency.

- **FPT investments in public health and health care systems** have been numerous and prolonged **without effectively addressing systemic health data shortcomings**.

- Most of these investments have only achieved **partial success in making health data work for people in Canada.**

- Future investments must be grounded in a robust pan-Canadian health data foundation wherein **privacy is protected** and **health data is accessible, to improve health outcomes**.
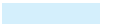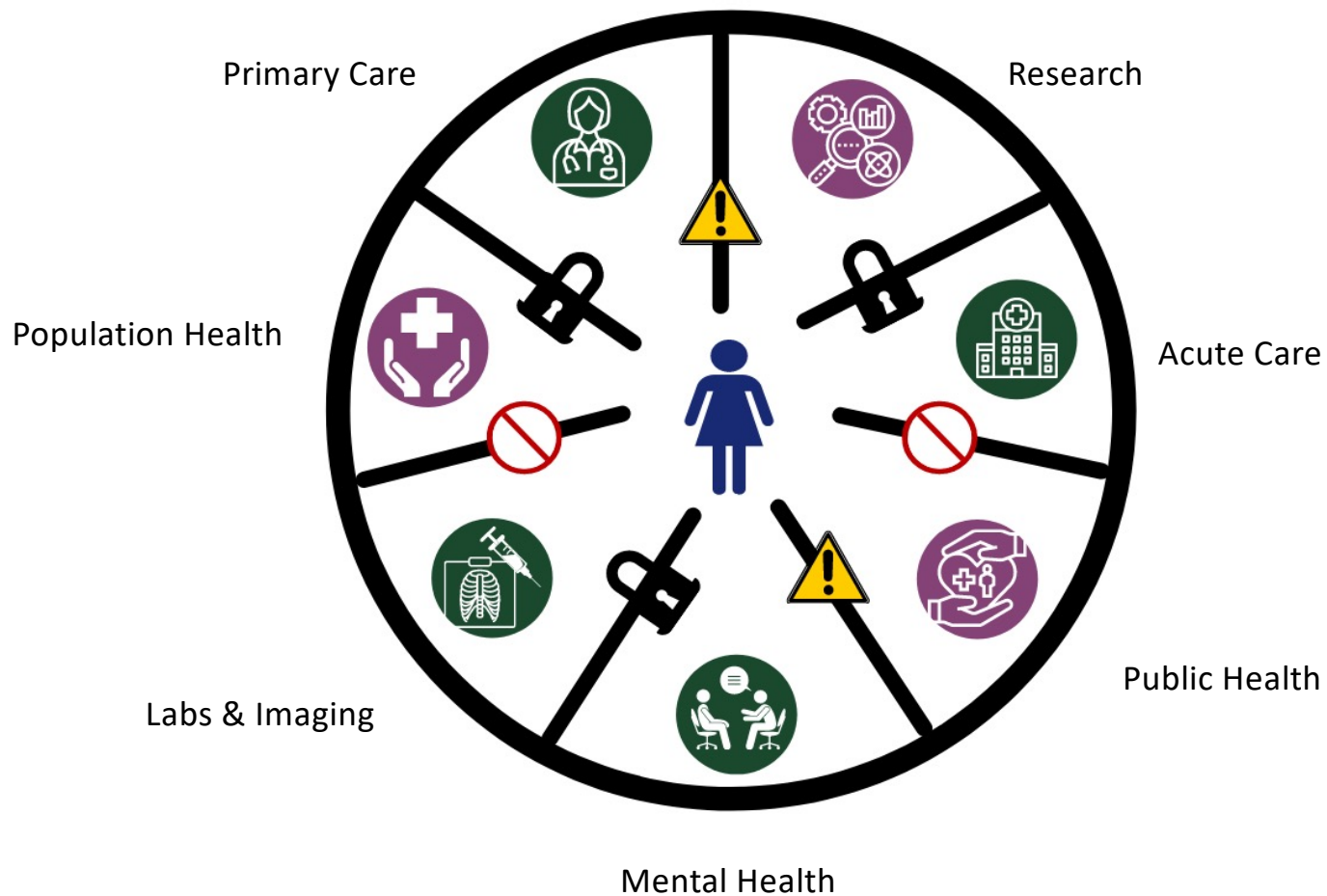
PCHDS Expert Advisory Group

- An Expert Advisory Group (EAG) was created in December 2020. The mandate of the EAG is to provide advice on the development of the Strategy.

- Membership is composed of experts from across the country with wide-ranging expertise across health system, public health, and population health data with perspectives on analytics, data management, and privacy.
  - The EAG is chaired by the PCHDS' Health Data Champion, Dr. Vivek Goel, and is provided secretariat support via the Public Health Agency of Canada.
  - EAG membership includes Dr. Janet Smylie, Director, Well Living House and Dr. Jonathan Dewar, CEO, First Nations Information Governance Centre.

- The EAG's work through spring 2021 identified systemic barriers to the improved use of health data and confirmed that there is value in the development of a Pan-Canadian approach to data

- The EAG developed vision and principles, and identified a list of potential areas for broader consultation in order to strengthen Canada's health data foundation

- The EAG has issued two reports, released in June and November 2021, respectively. The final report is planned for Spring 2022.
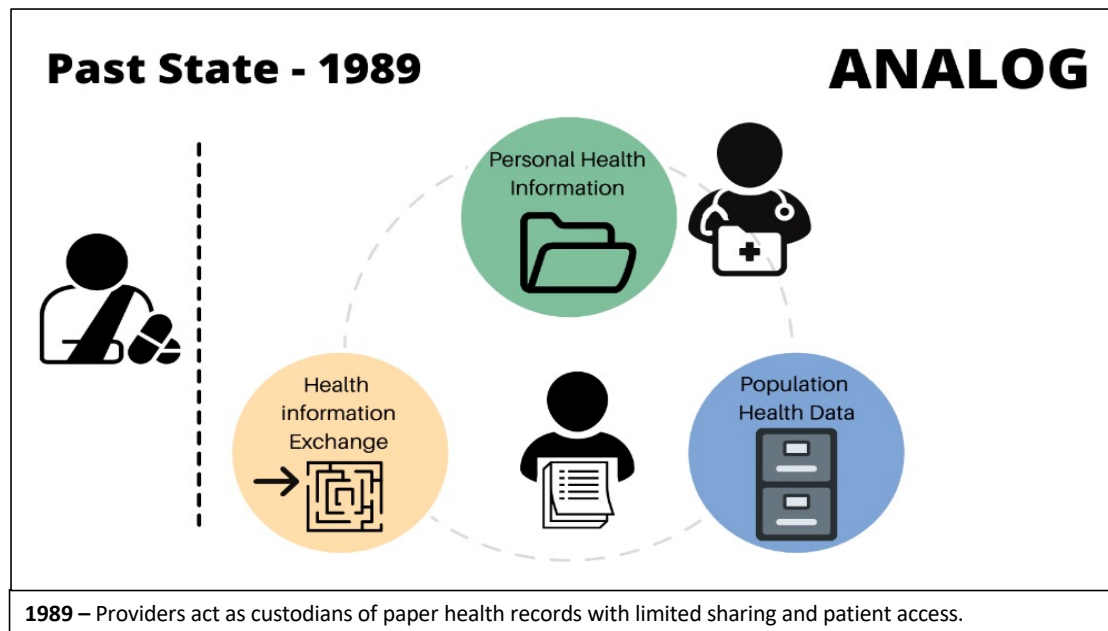
Health: moving from analog to digital

Current State: Silos connected by scaffolding

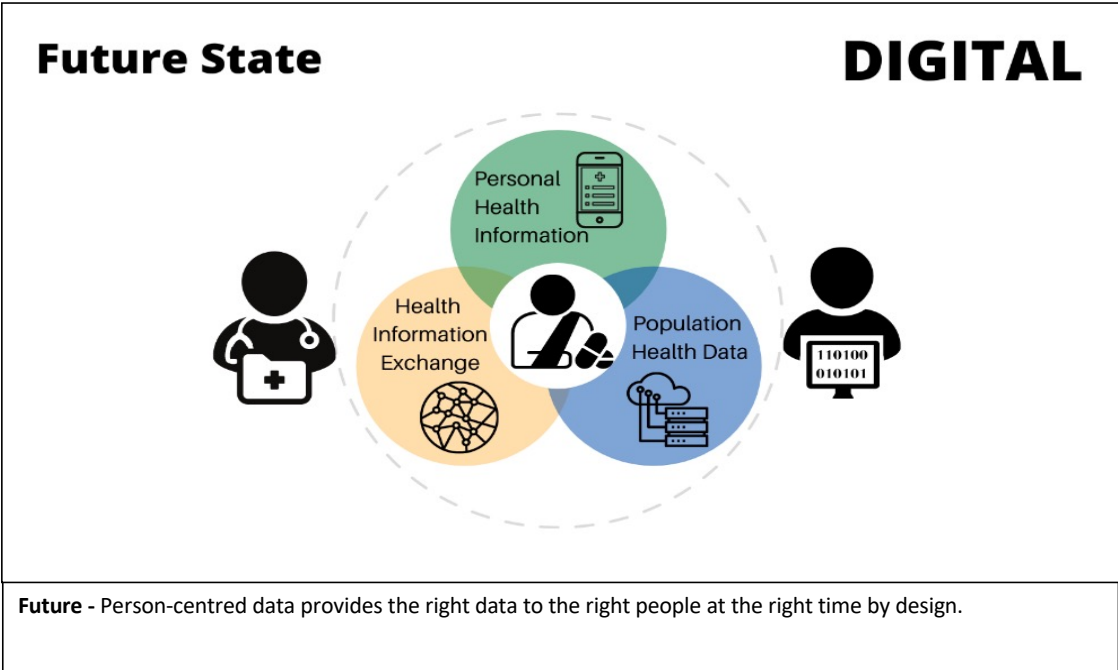# Evolution of health data management: 1989

Past State - 1989   ANALOG

Personal Health Information

Health information Exchange

Population Health Data

1989 – Providers act as custodians of paper health records with limited sharing and patient access.

Evolution of health data management: 2021

Current State - 2021   ANALOG/DIGITAL

Personal Health Information

Health information Exchange

Population Health Data

2021 - Providers act as custodians of digitized health records. Some patient access and sharing. Barriers make it difficult to share data between silos.

Evolution of health data management: Future

Future State   **DIGITAL**

Personal Health Information

Health Information Exchange

Population Health Data

Future - Person-centred data provides the right data to the right people at the right time by design.

Future State: Person-Centred by Design

1. **Put people at the centre** of health data system design

2. **Simplify data sharing** for the provision of care

3. **Streamline rules for data sharing** for research, public health, and system oversight

Outcomes:

- **Public is activated** with their own data to be able to achieve their health outcomes

- **Communities empowered** with insights to improve fair and equitable outcomes

- **Society benefits from innovation** across jurisdictions and internationally and Canada re-takes role as leader

EAG Reports to Date:
June '21: Charting a Path Towards Ambition
Nov '21: Building Canada's Health Data Foundation

Confirming the Need for Change

- The second EAG report indicates that in Canada, health data management in limited as there is:

  - **no systematic, nor systemic principle-based approach to data use** in the health sector;
  - **no clear accountability** in the health sector for its **fastest growing asset – data**;
  - **no systemic way** to understand **public and community** health data **requirements**;
  - **no strong and coherent governance model for data oversight** in the health sector;
  - **no policy that articulates the duty to share data** for the public good while **also ensuring it is secure**; and
  - **no common health data terminology** to enable effective health data literacy initiatives for health leaders, health workforce, and the public.

- The EAG advises that Canada must drive a new **person-centric approach** supported by **data stewardship** (vs data custodianship model)

Critical Success Factor: Common Vision and Principles

The **lack of a common, coherent approach** for health data within and between jurisdictions is **contributing to lagging health outcomes** for people in Canada, **escalating sector costs**, expanding **health inequities**, and **slowing innovation**. (2nd EAG report)

Vision from 1st EAG report:

By 2030,
all persons living in Canada will benefit from a
fully integrated and continuously optimized
health data ecosystem that
honours data ownership and
collective quality care through the
cooperative use of
individual and aggregate health data.

Principles for implementation:

- Person-centricity
- Equity
- Stewardship
- Increased data accessibility
- Sustainability
- Collaboration

Critical Success Factor: Overcome Barriers

Barriers as noted in the EAG's first report (June 2021)

- Lack of trust and clear accountability

- Culture of risk aversion

- Culture of avoidance

- Misaligned incentives and lack of a common vision

- Reluctance to include conditional requirements

- Antiquated data policy environment

- Failure to spread and scale

- Limited patient insight and involvement

- Significant data debt

- Fiscal pressures to contain growing costs

- Uncoordinated approach to procurement and implementation

- Lack of consensus and follow-up on pan-Canadian interoperability

- Inconsistent and insufficient investment in data capacity and capability

Critical Success Factor: Strengthen the Foundation
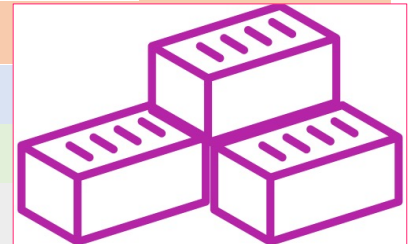

Policy and Program Solutions
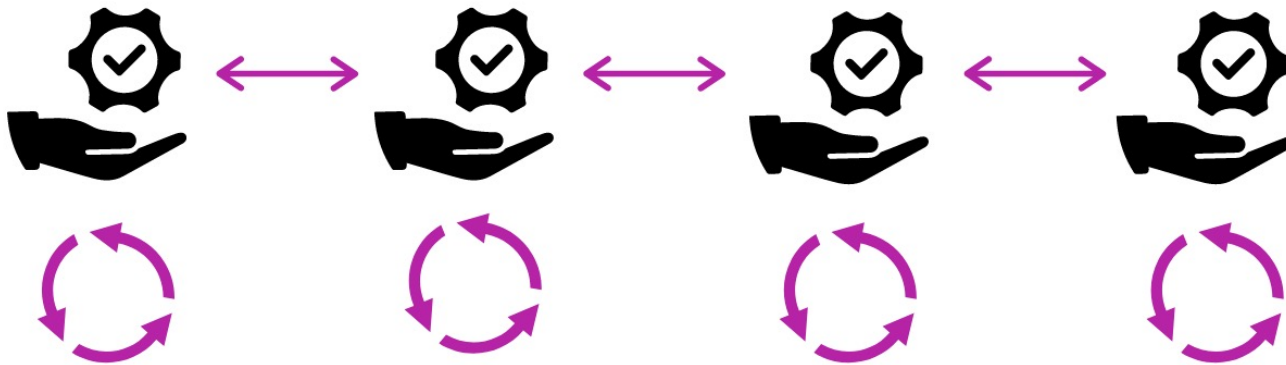
PUBLIC TRUST and **DATA LITERACY**	
EFFECTIVE and **EQUITABLE DATA POLICIES**	
CLEAR and ACCOUNTABLE DATA GOVERNANCE	
DATA INTEROPERABILITY AND ARCHITECTURE	

Critical Success Factor: Data Stewardship

- Data Stewards:

  - Assure data asset protection
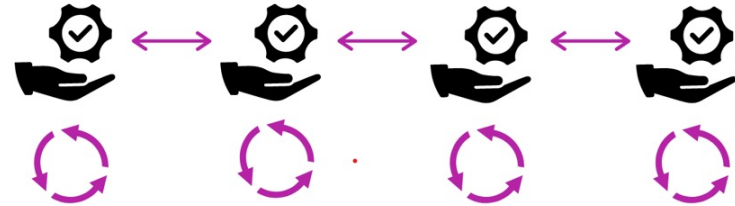
  - Encourage data asset re-use

  - Seek data assets to re-use

  - Collaborate with peers to build trust with each other and the public

  - Collaborate along the end-to-end health data supply chain to achieve the overall objective

- Data stewards are the **evolution** of privacy officers
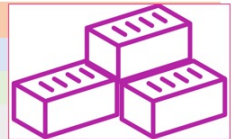
Policy and
Program
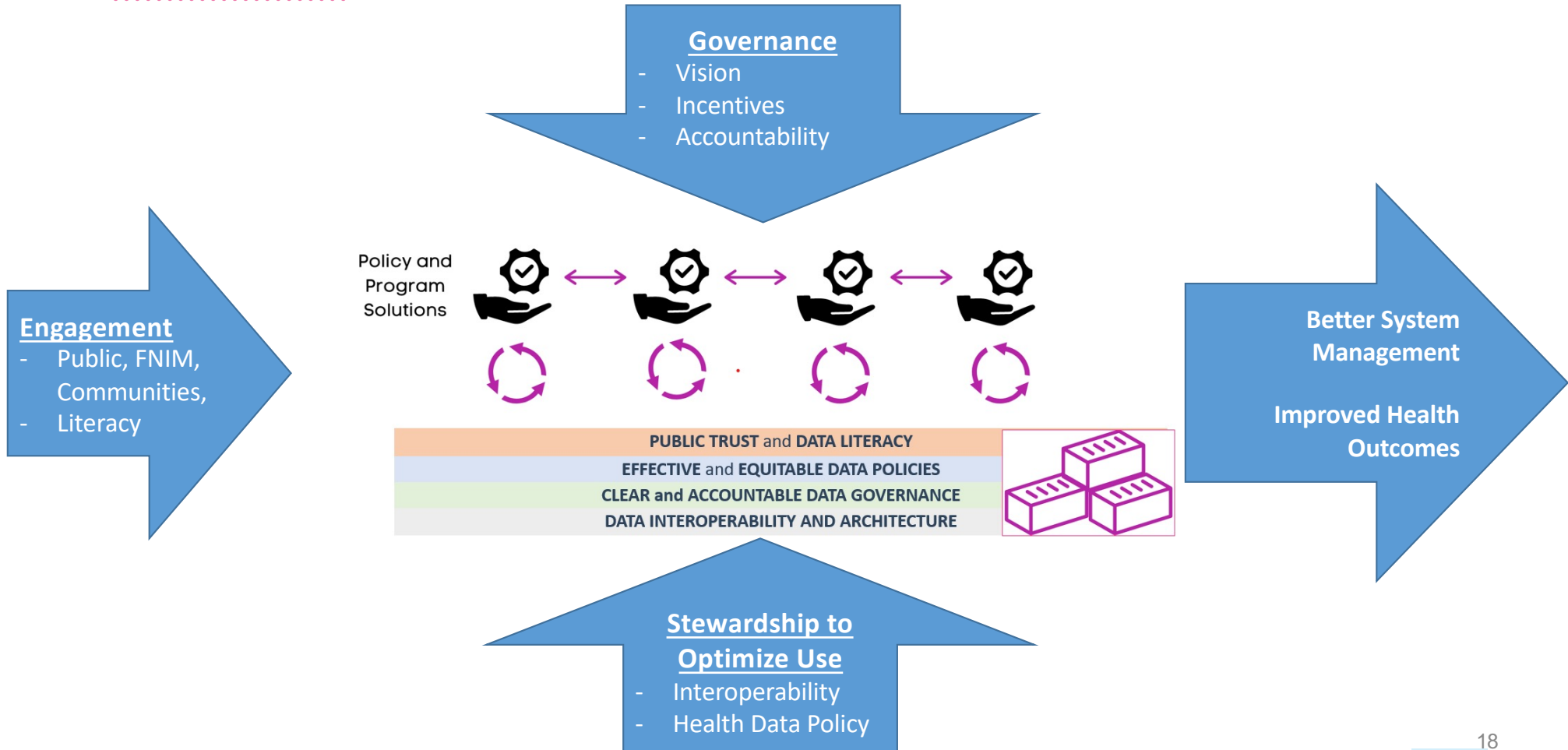Solutions

PUBLIC TRUST and DATA LITERACY
EFFECTIVE and EQUITABLE DATA POLICIES
CLEAR and ACCOUNTABLE DATA GOVERNANCE
DATA INTEROPERABILITY AND ARCHITECTURE

Vision in Action: Initial Advice

Governance
- Vision
- Incentives
- Accountability

Engagement
- Public, FNIM, Communities,
- Literacy

Policy and Program Solutions

PUBLIC TRUST and DATA LITERACY

EFFECTIVE and EQUITABLE DATA POLICIES

CLEAR and ACCOUNTABLE DATA GOVERNANCE

DATA INTEROPERABILITY AND ARCHITECTURE

Stewardship to Optimize Use
- Interoperability
- Health Data Policy

Better System Management

Improved Health Outcomes

"How governments protect and leverage their national assets in the global technology competition will increasingly determine which countries race ahead in the middle decades of the 21st century. And which ones lag behind…"

P Dawson, M-E Ouimette; Globe and Mail; September 6, 2021

Next Steps

- Working on a third (and final) report
  - Working groups for different areas (e.g. data governance, interoperability)
  - Drafting a "health data charter"
  - Funded initiative on minimum requirements for public expectations and involvement
- Operationalizing the ideas presented here
- Final report to be delivered ~ in the first half of this year