



Charting a Pathway Toward Ambition

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Longwoods, November 2021

Why Data? Why Now?

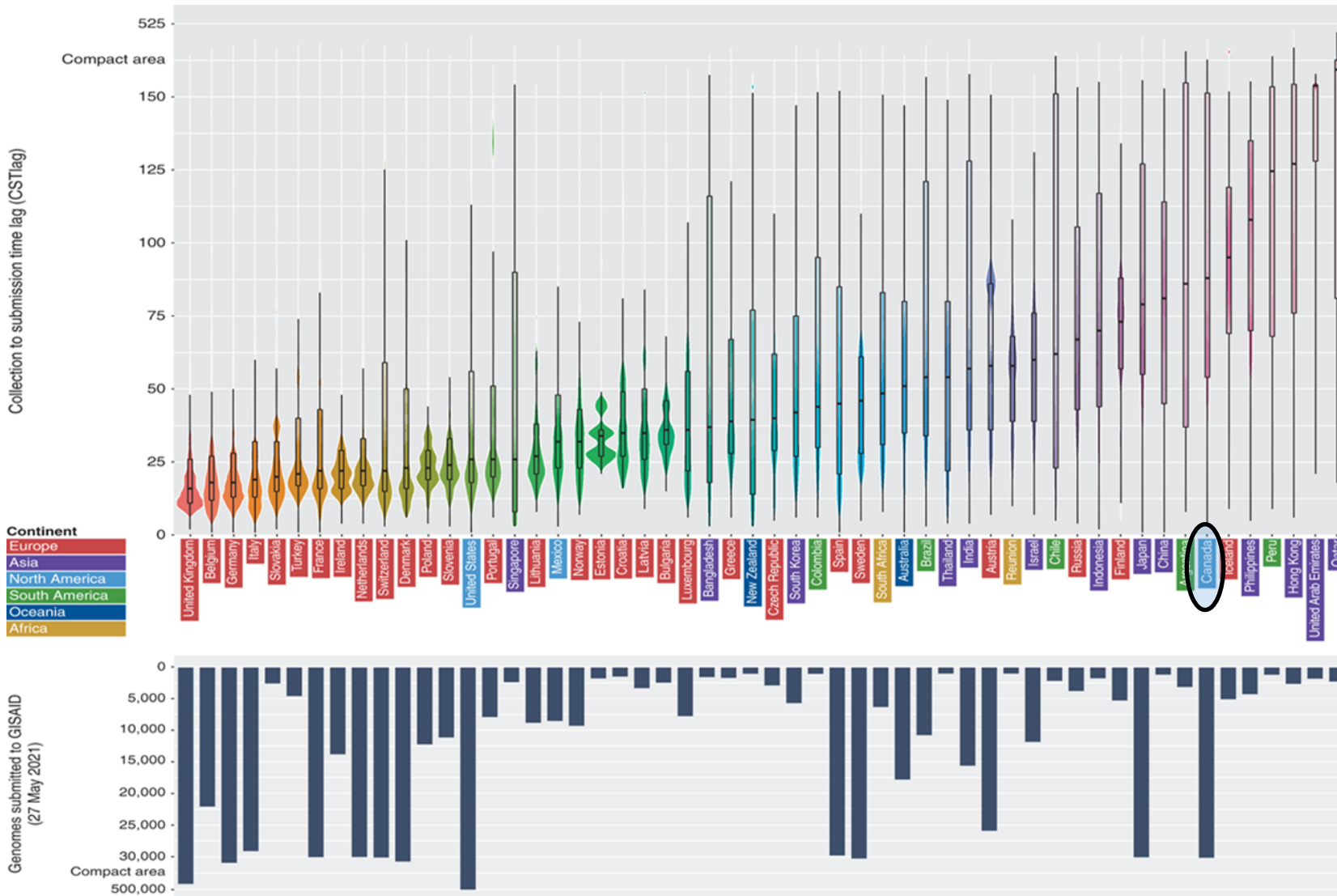
‘Critical data gaps have greatly hampered Canadian governments’ ability to face COVID-19 pandemic: report

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

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

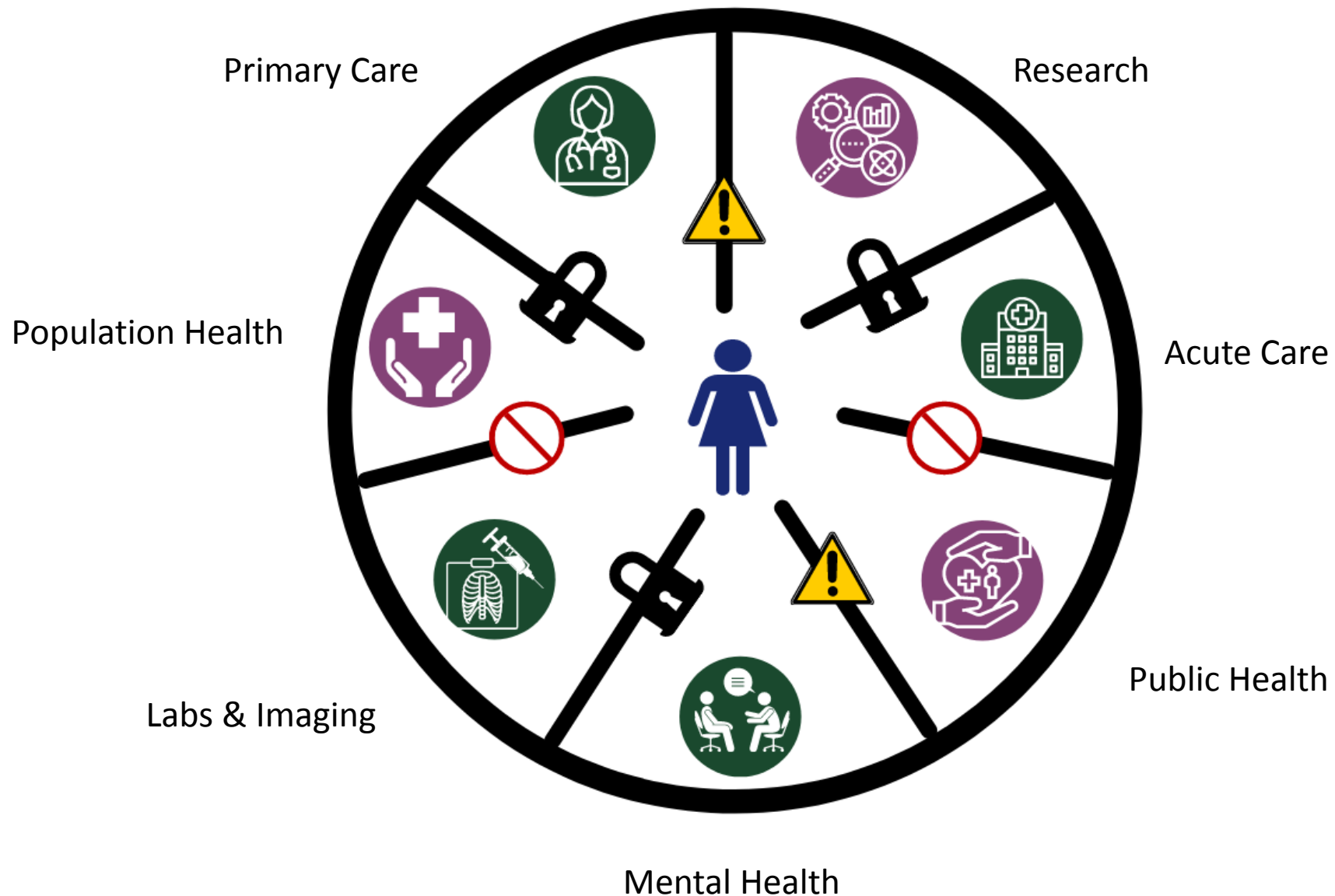
Les télécopieurs et des systèmes informatiques incompatibles provoquent lenteurs et agacement sur le terrain comme au sommet de l'État.

Why now: Viral sequences sharing in GISAID: From collection to submission

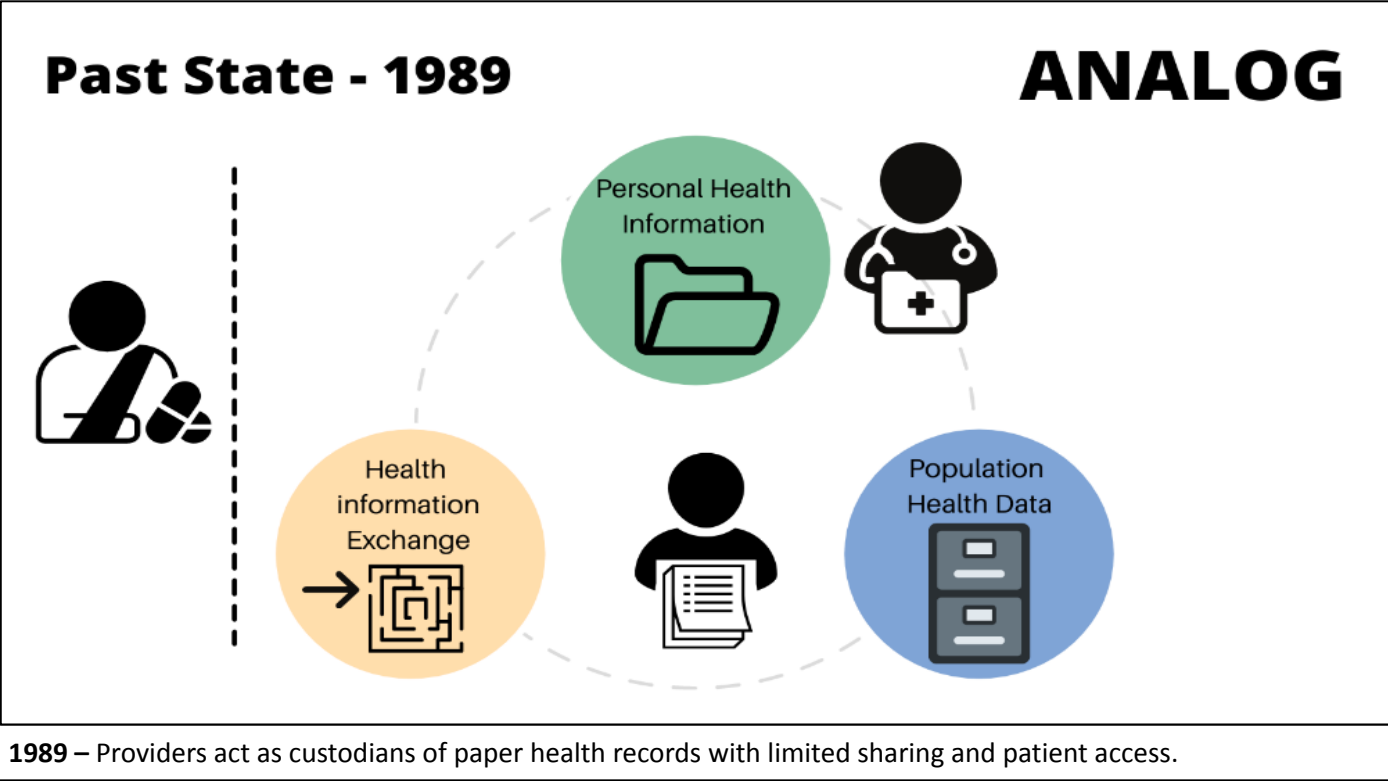


Kalia, K.,
Saberwal, G.
& Sharma,
G. The lag in
SARS-CoV-2
genome
submissions
to GISAID.
Nat
Biotechnol
39, 1058–
1060 (2021).

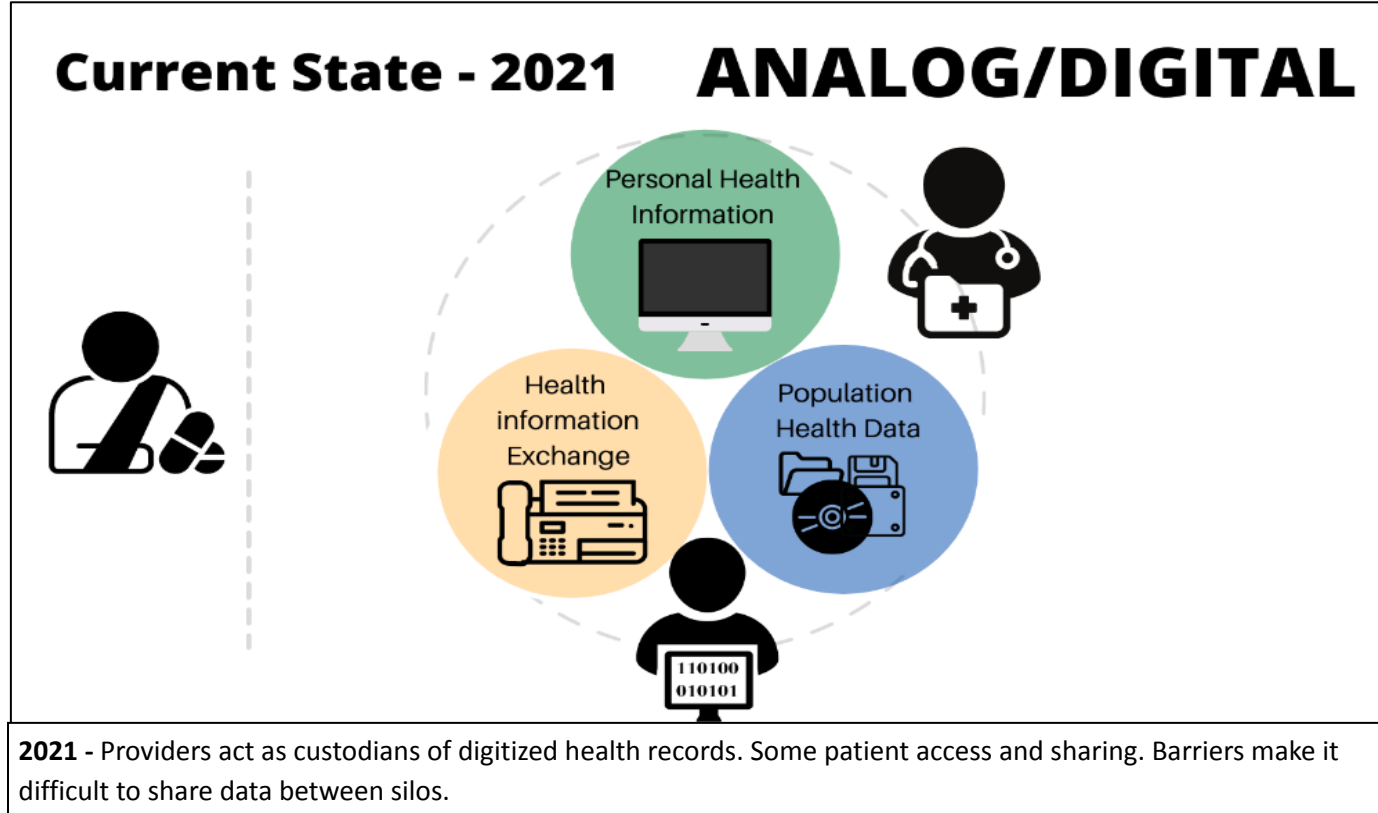
Current State: Silos connected by scaffolding



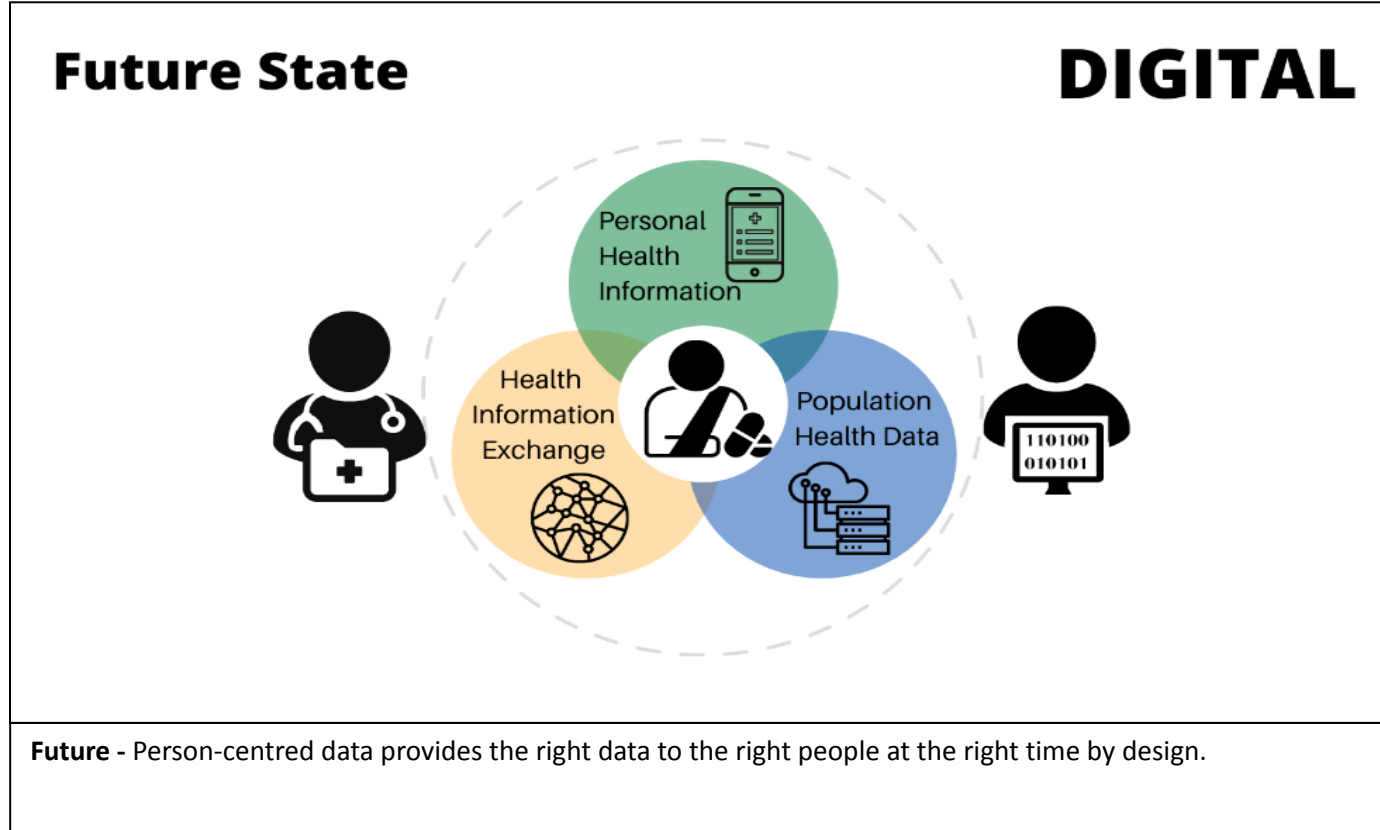
Evolution of health data management: 1989



Evolution of health data management: 2021



Evolution of health data management: Future



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

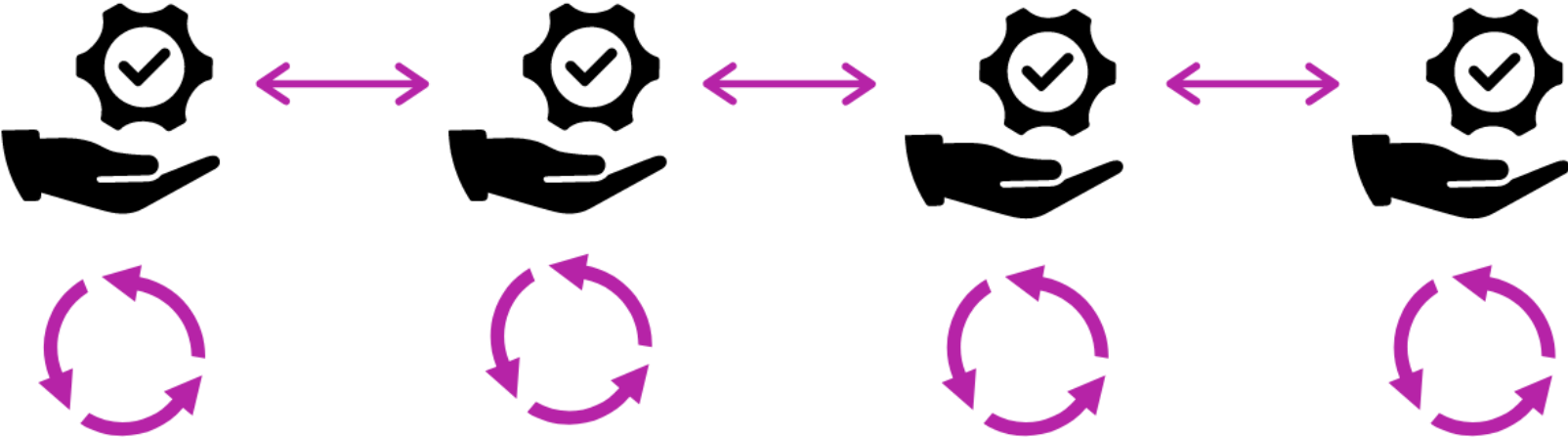
Critical Success Factor: Overcome Barriers

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

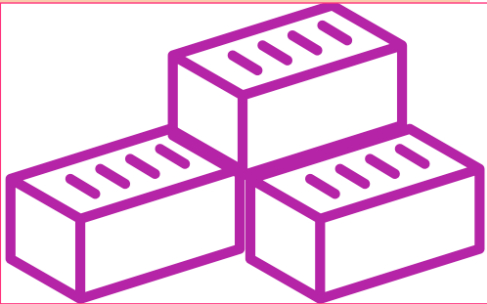
- Lack of trust and clear accountability
- Culture of risk aversion
- Culture of avoidance
- Misaligned incentives and lack of a common vision
- Reluctance to include conditional requirements
- Antiquated data policy environment
- Failure to spread and scale
- Limited patient insight and involvement
- 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

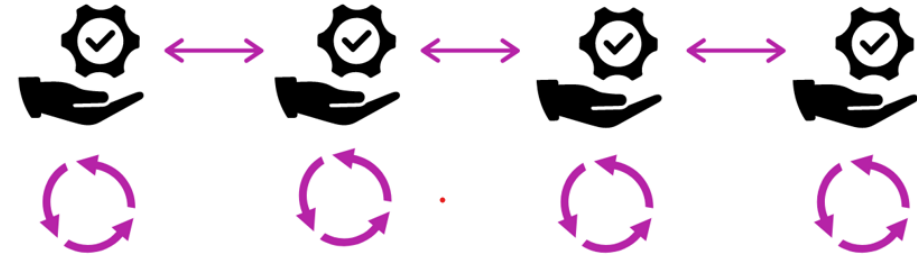
- Seek data assets to re-use

- 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

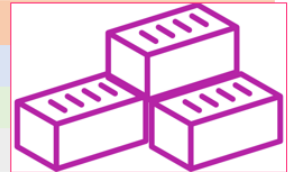


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EFFECTIVE and EQUITABLE DATA POLICIES

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Strong Stewardship: Overcoming the Privacy Chill

