# Canadian Health Data Platform Summit

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# Leadership Message

Canada's health data are a uniquely valuable asset, representing comprehensive population-level information on one of the most diverse populations. Canada has a proud legacy of scientific discovery and global health innovation, but despite these contributions, we are facing a health data crisis. Our clinical and health research data remain fragmented and siloed, limiting our ability to effectively share and use our health data to realize the full value of these assets for economic and health benefits for Canadians.

The Canadian Health Data Platform Summit led by the ARCHIMEDES health data platform brought together more than 150 multidisciplinary individuals including cross-sectoral leaders, operational teams, and patient partners. Over two days, participants discussed the current landscape of health data in Canada, shared case studies and lived experiences, and co-developed strategic pathways to strengthen governance, interoperability, data standards, and public trust. Together, these discussions form the foundation for a coordinated, sovereign and interoperable health data ecosystem that will transform the way we use our health data to achieve economic value, accelerate innovation, improve care, and make informed policy decisions.

The vision is clear, and the opportunity is now. By working together to integrate Canada's varied health data assets, we can turn this vision into action and build a robust, sovereign, connected and equitable health data ecosystem that secures Canada's leadership in global health innovation.

We extend our sincere thanks to everyone who attended and contributed to this important event. We also gratefully acknowledge the support of our funding sponsors, the Brain-Heart Interconnectome (BHI) Canada First research Excellence Fund (CFREF - 2022-00007), and the Canadian Institutes of Health Research (CIHR). Your engagement, insights and shared vision are essential to advancing a connected and resilient health data ecosystem in Canada for Canadians.

Drs. Kelly Cobey, Jodi Edwards, Alan Evans and Peter Liu
ARCHIMEDES Leadership Team

# Executive Summary

On October 7 and 8th, 2025, the ARCHIMEDES health data platform team, in partnership with the Canadian Institutes of Health Research, convened diverse interest holders including health data experts and leadership from across academic institutions, health systems, federal data organizations, Indigenous data authorities, funding bodies, and patient communities to advance a vision for a robust, sovereign, interoperable, and equitable Canadian health data ecosystem (see the summit agenda). The Summit provided a timely and critical forum to identify shared priorities, align ongoing initiatives, and strengthen connections among health data platforms nationwide. The discussions reinforced a collective commitment to collaboration and highlighted the national urgency of coordinated action.

The summit opened with a blessing from Gilbert Whiteduck, a Knowledge Keeper from the Kitigan Zibi Anishinabeg First Nation community, who highlighted some of his lifelong work with vulnerable populations and the importance of engaging with and listening to the people we want our work to serve. Day 1 sessions provided an overview of the current health data landscape in Canada, discussed innovations in data governance, highlighted the capabilities of several disease specific health data platforms in Canada, offered a use case example of multi-centre registry data, and discussed considerations for multi-jurisdictional data sharing both within and beyond Canada. Dr. Jason Karmanchandani offered a masterclass keynote address on leveraging informatics to accelerate discovery in clinical biospecimen data, highlighting the ARCHIMEDES platform as a scalable multi-modal health data infrastructure for Canadian health data.

## BY THE NUMBERS

**151 ATTENDEES**

**15 SPEAKERS**

**7 PATIENT PARTNERS**
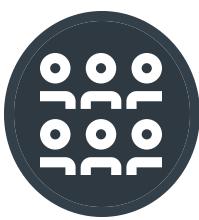
**3 WORKING SESSIONS**

# Executive Summary

Day 1 also featured an international perspective from cardiothoracic radiologist Dr. Paul Finn, from UCLA, who described how a platform like ARCHIMEDES could be applied to U.S.-led multi-site initiatives, alongside a presentation by Dr. Evans outlining the ARCHIMEDES platform's origins, how it could be readily scaled to meet today's infrastructure for accelerating Canadian health data research, and how it will enable innovation and ground-breaking research in the future. Patient partners Laurie Proulx and Mike Yeates offered insights into their lived experience and perspectives on living with chronic diseases and the importance of patient data. An engaging fireside chat with Maria Santos from the First Nations Information Governance Centre highlighted important considerations for Indigenous data sovereignty and the use of Indigenous data. Day 1 ended with a structured priority-setting exercise, with six key factors emerging as essential for coordinated action. Participants voted to identify which factors were the easiest to implement or would have the highest impact for the health data community.

Day 2 of the summit convened a smaller working group of health data leaders to focus on actionable next steps towards building a robust and sovereign cross-sectoral health data ecosystem. During this intensive day of collaborative strategic planning, including break-out sessions and facilitated group discussions, participants completed a series of mapping exercises designed to take the health data community from vision to action. Facilitated exercises enabled participants to prioritize collaborative opportunities, identify priority actions and map out solutions-driven implementation plans.

The culminating outcome was a set of mission-level initiatives requiring national mobilization, including comprehensive asset mapping, establishment of a National Health Data Collective, robust public engagement, and the development of national strategies tying health data to innovation, AI, and economic growth.

# Key Themes

Legal and ethical barriers **Data principles**

**Data Standards** **Public trust**

research integrity

**Data literacy** **Artificial Intelligence**

Equity

**Data sovereignty**

**Collaboration** **Harmonization** **Privacy**

**Sustainability** **Data sharing** **Scalability**

Culture change

**public trust** **Data Management Policies**

**Patient co-development** **Incentivizing** **funding models**

**Communication**

## Summit Attendees by Area of Expertise



| Sector | Attendees |
|---|---|
| Researchers | 44 |
| Health Organization Leaders | 36 |
| Funding Bodies | 32 |
| Academic Leaders | 20 |
| Technical Infrastructure Lead | 7 |
| Patient Partners | 7 |
| Legal Experts | 6 |
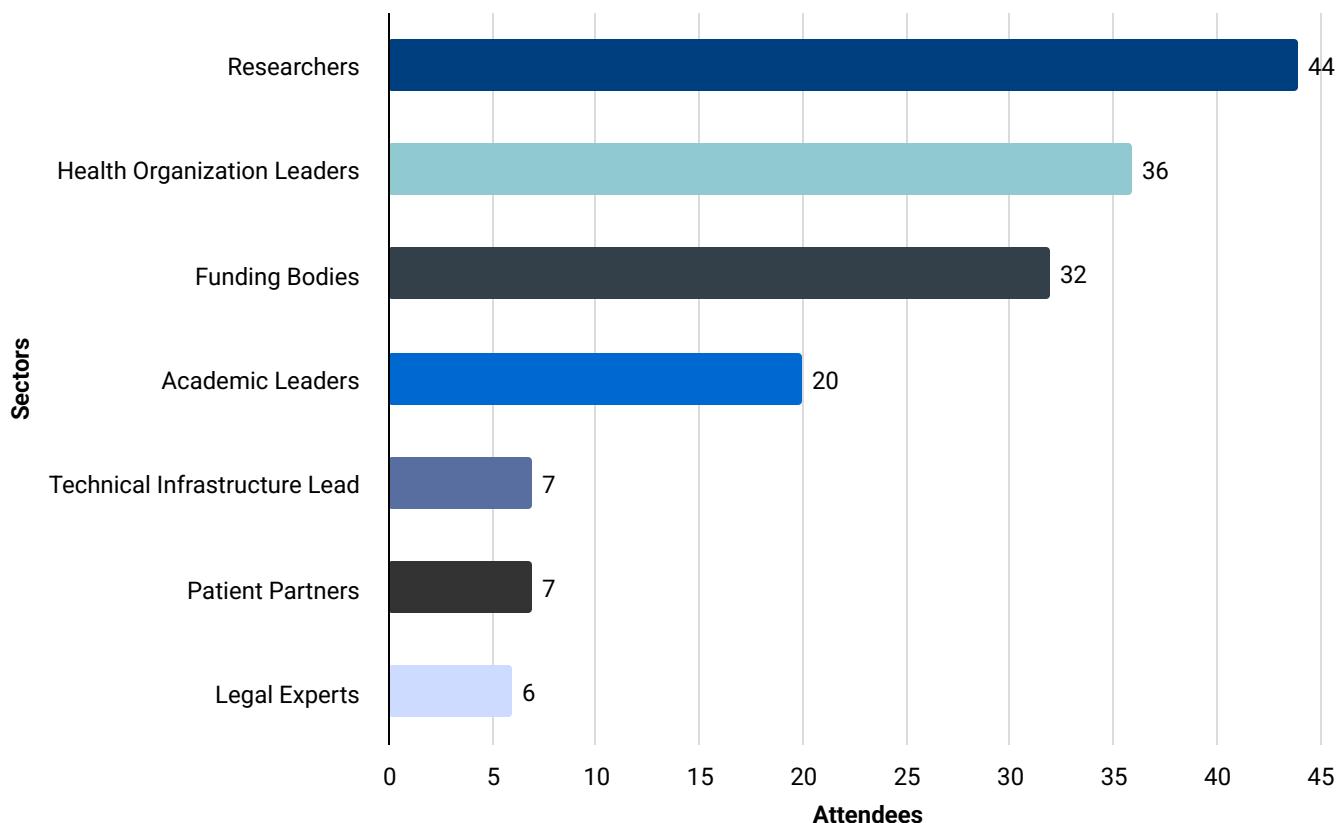
# Speakers and Panelists

**Dr. Naveed Aziz**
Genome Canada

**Dr. Jodi Edwards**
University of Ottawa Heart Institute

**Dr. Patrick Bermudez**
Canadian Open Neuroscience Platform

**Dr. Khaled El Emam**
University of Ottawa

**Dr. Kelly Cobey**
University of Ottawa Heart Institute

**Dr. Alan Evans**
McGill University

**Dr. David Castle**
University of Victoria

**Dr. Paul Finn**
University of California, Los Angeles

**Dr. Anderson Chuck**
Canadian Institute for Health Information

**Dr. Paul Hébert**
Canadian Institutes of Health Research

**Mary-Jane Dykeman**
INQ Law

**Dr. Jason Karamchandani**
McGill University

# Speakers and Panelists

**Dr. Bartha Maria Knoppers**
McGill University

**Maria Santos**
First Nations Information Governance Centre

**Dr. Peter Liu**
University of Ottawa Heart Institute

**Eric Sutherland**
Organization for Economic Co-operation and Development

**Dr. Kimberly McGrail**
Health Data Research Network Canada

**Gilbert W. Whiteduck**
Kitigan Zibi Anishinabeg First Nation community

**Laurie Proulx**
Canadian Arthritis Patient Alliance

**Dr. Jim Woodgett**
Terry Fox Research Institute

**Dr. Magda Price**
Care for Rare Canada

**Mike Yeates**
University of Ottawa Heart Institute

**Dr. Felipe Perez-Jvostov**
Digital Research Alliance of Canada

# Canadian Health Data Landscape

The summit began with a focus on understanding the state of health data in Canada, acknowledging both its strengths and its structural challenges. Canada's health data are siloed, with limited interoperability and data sharing amongst the various sources of health information. Several key influencing factors were identified that will critically shape our ability to unlock Canada's health data for broader sharing and use: technology factors, economic factors, user needs, political factors, emerging trends and uncertainties.

Lab/Biomarker Data

Wearables

Electronics Medical and Health Records

Pharmacy Data

Hospital Data

Mortality Data

Survey Data

Claims Data

Disease Registries

"Nearly 80 percent of clinical information in electronic health records (EHRs) is 'unstructured.'

-CIO Review
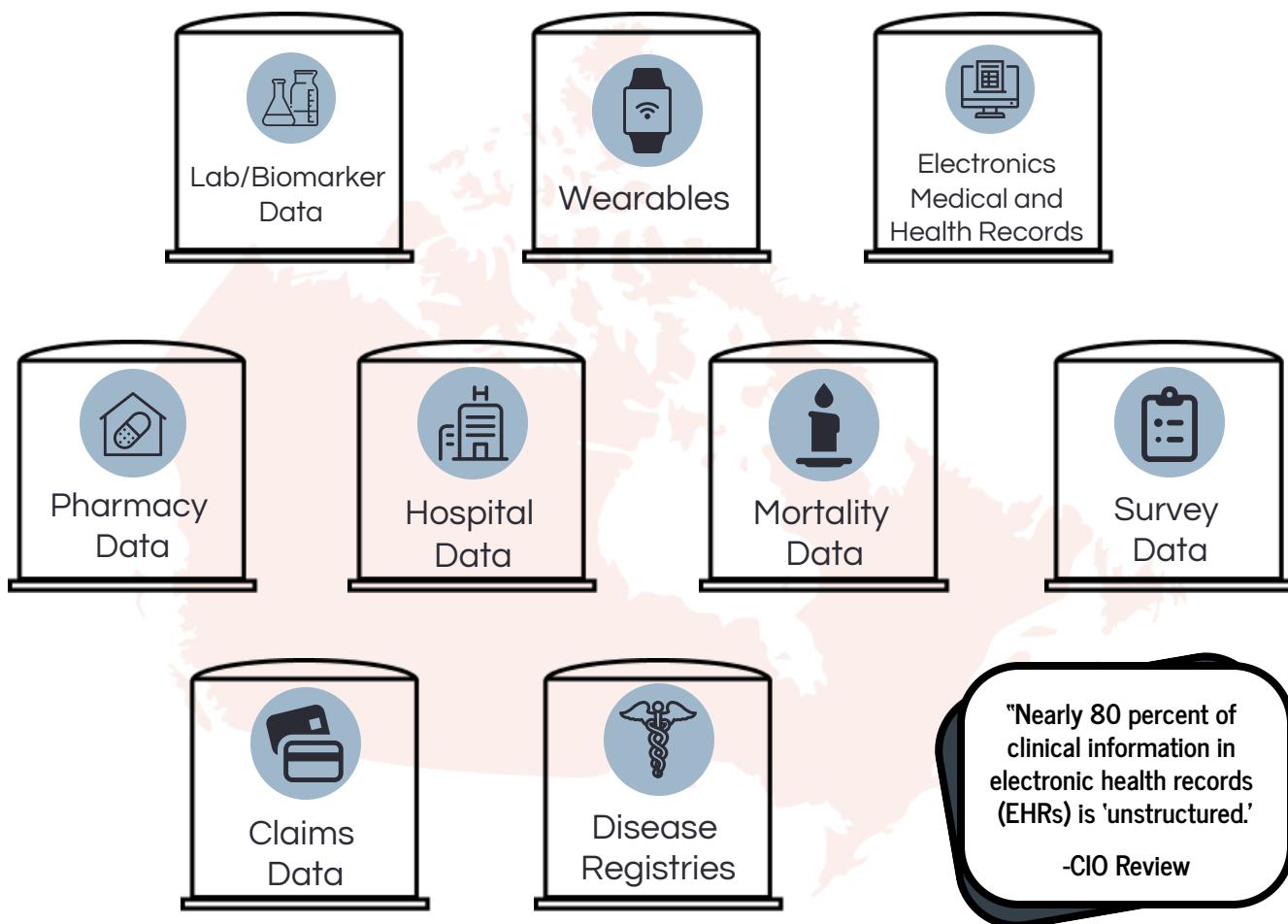
# Spotlight on the Patient Perspective

Patient Partners Laurie Proulx and Mike Yeates emphasized the essential role of trust, transparency, and lived experience in all components of national data governance.

Key messages included:
- Patients want to be co-developers, not end users, of national data initiatives.
- Trust must be earned through clear communication, demonstrable accountability, and meaningful consent processes.
- Fragmented consent policies and inconsistent explanations across institutions undermine public confidence.
- Many patients view responsible data sharing as an opportunity to improve health outcomes and system performance—provided privacy, security and equity are safeguarded.

Their input reinforced that a national health data strategy must be built with—not just for—the people whose data powers the system.

> "During my pre-surgery research, it became apparent to me that relevant data was harder to find than I thought it should be"
>
> **Mike Yeates,
> Patient Partner**

# Priority Areas for Canadian Health Data

On Day 2, a core group of interest holders developed strategic priorities and actionable steps toward a cohesive national data ecosystem.

## Highest Potential Impact

- Culture change
- Funding reform and new evaluation metrics

## Easiest to Implement

- Capacity building
- Interoperability

## Priority Areas for Action

- National urgency
- Privacy, ethics and governance alignment
- Public engagement and inclusivity
- Alignment with international best practices and standards

# Pathways to Action for Canadian Health Data



**1**

Develop a comprehensive asset map of health data resources across Canada.

**2**

Establish a National Health Data Collective representing all sectors and rights holders.

**3**

Launch ongoing communication within the collective and targeted campaigns to the public.

**4**

Support multilateral consensus building to align priorities and practices.

**5**

Develop national and economic strategies for health data, AI, and sustainable funding.

# Pathways to Action for Canadian Health Data

Three core initiatives were mapped out with achievable timelines:

## 1. Asset Mapping & National Collective Formation

- Draft the asset map (data assets and infrastructure).

- Populate and validate the map, defining the collective's governance structure.

- Establish a steering committee and Terms of Reference.

- Communicate findings and endorse a strategic plan.
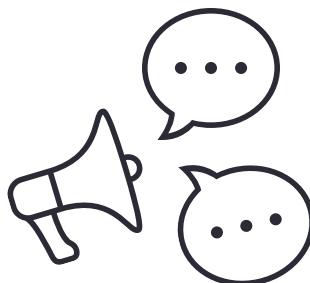
## 2. Communication & Engagement Strategy

- Define campaign vision, audiences, and key messages.

- Identify milestones and preferred channels for dissemination.

- Create educational toolkits to support literacy and public awareness.

- Engage a network of patients/public representatives to propagate value and build trust on Health Data.

## 3. Development of National Strategies

- Identify relevant ministries (ISED, Health Canada) and propose a consensus-building process modeled on the Pan-Canadian Health Data Strategy.

- Initiate consultations with provinces and territories, securing commitments.

- Analyze inputs and prepare draft budget proposals.

- Publish and launch the completed national strategy document.

# Working Groups
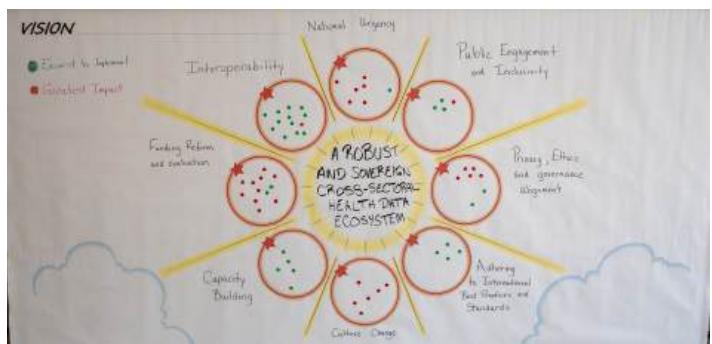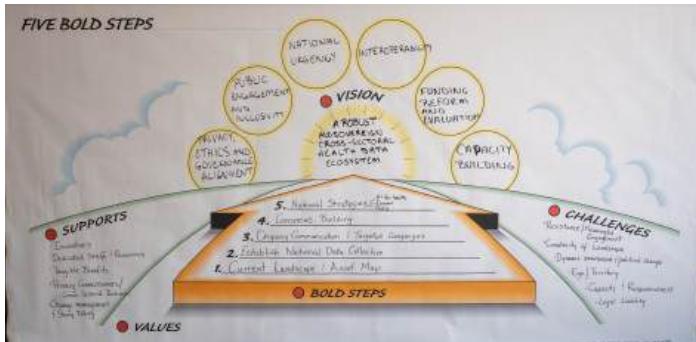
# Summary Map of Day 1

Day 1 focused on bringing together over 150 participants from diverse areas of expertise. The working map captures key insights, themes, and discussion highlights from across the day, reflecting the breadth of perspectives shared during the conference sessions.
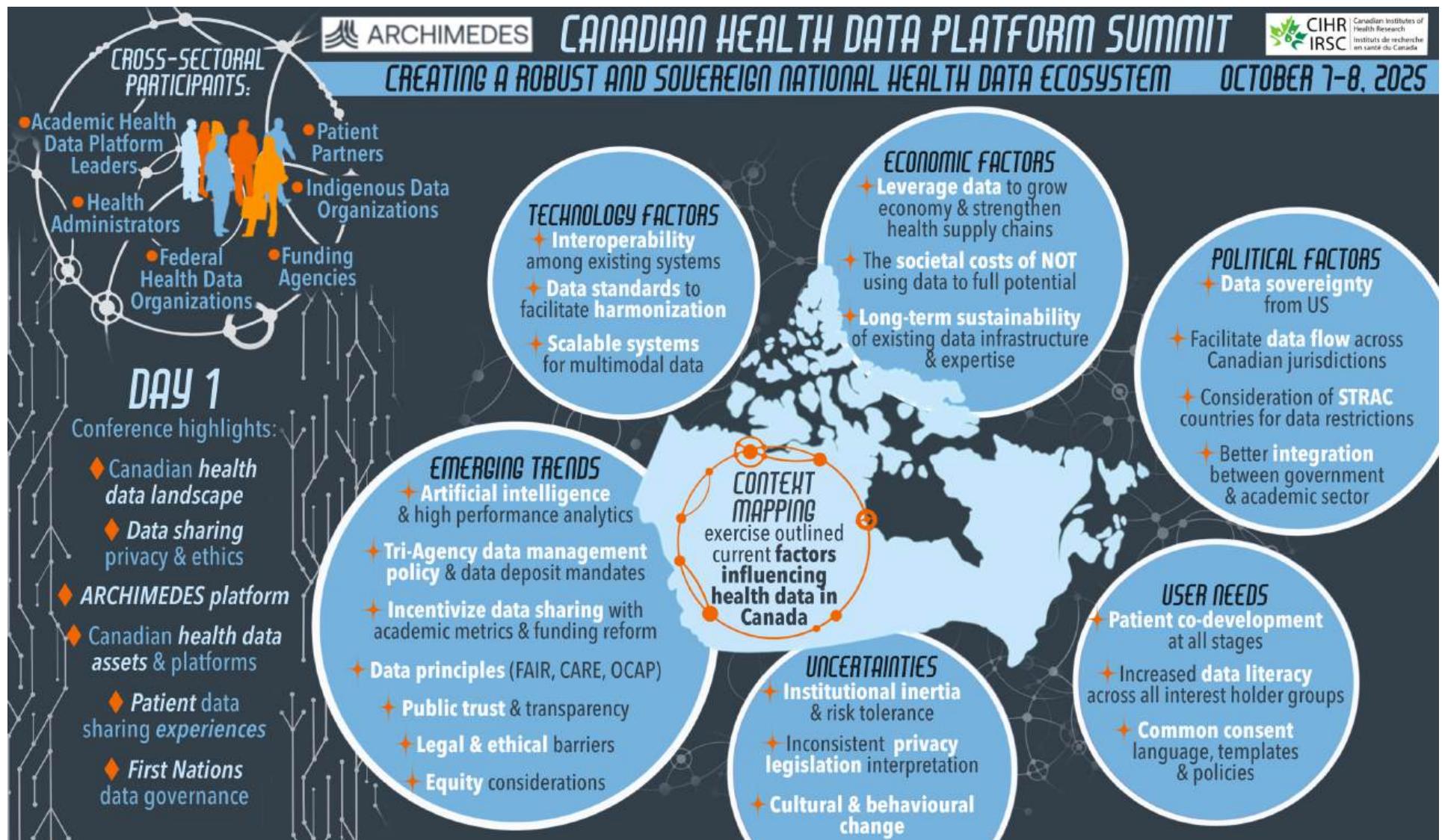
# Summary Map of Day 2

Day 2 built on the foundational discussions from Day 1, with participants working collaboratively to clarify strategic priorities, surface actionable steps, and align efforts toward a unified national approach to health data.
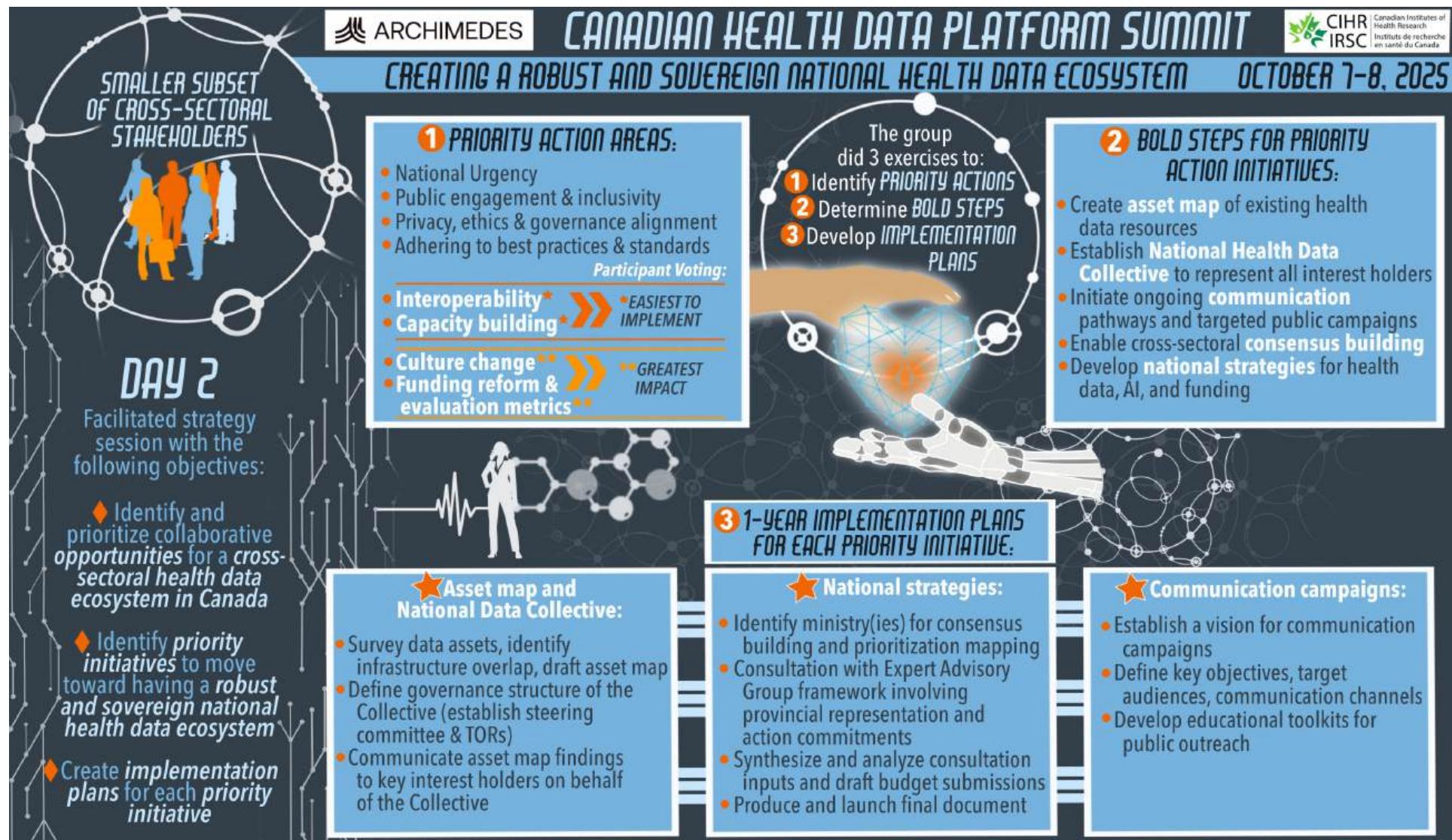
# Spotlight on ARCHIMEDES

The ARCHIMEDES health data platform was highlighted as an example of a scalable, secure, bilingual, multi-modal informatics platform for all health data regardless of disease domain.

Discussions focused on:
- Its ability to integrate multi-modal data and support high-performance analytical workflows.

- It's relevance as a model for how national platforms could enable secure data access with a robust governance structure.

- Lessons learned from ARCHIMEDES demonstrating the value of standardizing governance, creating technical interoperability, and creating cross-sectoral partnerships.

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## The Eureka Moment for Health Data

# Summary and Path Forward



Canada stands at a critical moment to transform its fragmented health data landscape into a cohesive, sovereign, and high-performing ecosystem. The identified priority areas, mission-level bold steps, and one-year implementation plans provide a solutions-focused roadmap for action.

The path forward requires all of us. Together we can create:

- A united coalition of federal, provincial, territorial, Indigenous, academic, and patient leaders.
- Commitment to national interoperability, data standards, and aligned governance.
- Sustainable funding models and evaluation metrics that reward collaboration and data stewardship.
- Public engagement strategies that build trust and reinforce transparency.
- Continued elevation of Indigenous data sovereignty and patient voices in system design.

Canada's health data are a uniquely valuable asset. Canada needs a national integrated health data ecosystem to support our research innovation, public health, clinical care, and strengthen our health and economic supply chains. Together we can build this ecosystem, while ensuring equity, sovereignty, and public trust remain uncompromised. Together we can transform health data for Canadians.

# Event Photos

# Acknowledgements

## Hosts



## Sponsors