CIHI Data Standards 101

A path to interoperability

Canadian Institute for Health Information

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About the Canadian Institute for Health Information (CIHI)

What is CIHI?

- **Independent, not-for-profit organization that provides essential information on Canada's health systems.**
- **Established in 1994, we work closely with federal, provincial and territorial partners and stakeholders throughout Canada to gather, package and disseminate information to inform policy, management, care and research, leading to better and more equitable health outcomes for all Canadians.**
- **Led by a 16-person Board of Directors, with representation from across the country.**

CIHI's mandate, vision and values

About CIHI

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization that provides essential information on Canada's health systems and the health of people living in Canada.

Mandate

Deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care.

Vision

Better data.
Better decisions.
Healthier Canadians.

Values

- Inclusion
- Integrity
- Collaboration
- Excellence
- Innovation

Inclusion is an updated value broadening the intent behind our previous value of respect

Our goals for 2022 to 2027

Strategic goals

A comprehensive and integrated approach to Canada's health system data
Collaborate with partners to continuously advance the creation, validation and accessibility of health system data

An expanded offering of analytics, indicators and tools to support health system decision-making
Provide the insight needed to drive better health outcomes across Canada's health systems

Health information users who are better equipped and enabled to do their jobs
Help build users' capacity by equipping them to make the best use of data, and by convening forums where they can explore solutions together and share best practices

CIHI hosts extensive linkable, pan-Canadian data across the health care continuum…

Types of care

- Hospital and emergency
- Mental health
- Home care
- Long-term care
- Rehabilitation
- Pharmaceuticals
- Clinical registries: organ transplant/ renal, hip and knee replacements; trauma
- More

Patient-reported data

- Patient-reported outcome measures (PROMs)
- Patient-reported experience measures (PREMs)

Health spending

- Patient costing data
- Hospital and regional health authority financial accounts
- Physician billing
- System-wide health expenditures

Health workforce

- Physicians
- Nurses
- Occupational therapists
- Pharmacists
- Physiotherapists
- Allied health professionals
- More

28 data holdings

- 10 billion records
- 3 terabytes of unique records
- Pan-Canadian coverage

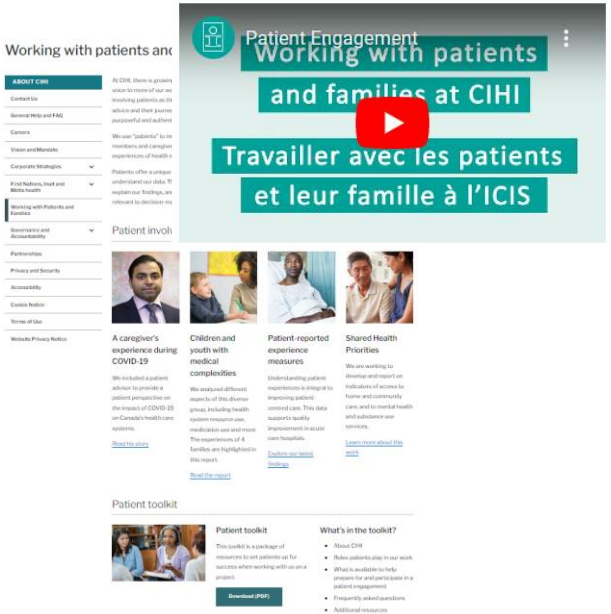
Linkable data:

- Example: Population Grouper links 8 databases, 3 provinces, over 23 million patients

…from many different sources

Evolving collaboratively

- At CIHI, we are working to raise and bring the patient voice to more of our work. We are committed to involving patients as they share their expertise, their advice and their journey in a way that's **meaningful**, **purposeful** and **authentic**
- Involving families, patients and people with lived experience in health analyses can help to identify priorities and inform analytical questions
- Patients offer a unique insight that helps us to understand our data. Their lived experiences help to explain our findings, and ensure that our work remains relevant to decision-makers at all levels of health care



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Patients engaged via…

Advisory Groups

- Representation on advisory committees to advise on product content/direction
- Sessions to inform program/project directions

Patient Groups

- Focus Groups
- Structured one-on one interviews
- Patient Stories
- Delphi groups for input on indicator selection, indicator development

Public Consultations (typically via third party vendor)

- Qualitative feedback on a particular topic area

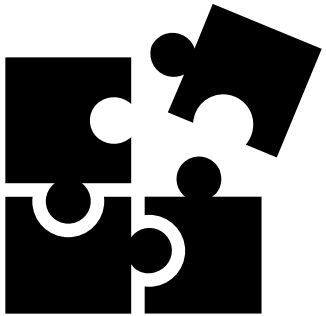
Why involve patients?

> Patients have a **unique perspective** that none of the other players can fully represent in an unbiased way. Patients have **unique, legitimate interests** in how services are designed and delivered. **Patients have ideas and suggestions.** Patients have a lot to say. All the players in the health care system need to **hear the patient voice, not as represented by other players**, but directly. For that to happen, patients **need their own seat at the table** . . . and, from time to time, [their] own megaphone.
>
> — Michael Decter, Board Chair, Patients Canada, February 2016

Data Standards 101

Outline

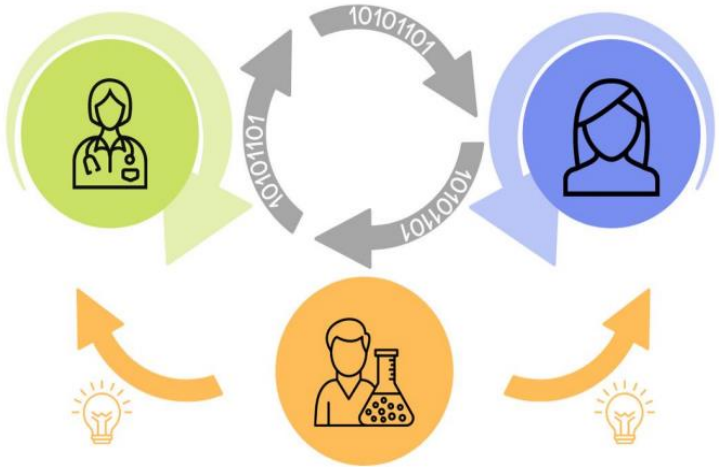
- **What are health data standards?**
- **What are the different types of health data standards?**
- **What is the development methodology lifecycle of health data standards?**
- **What is interoperability and how do health data standards relate to it?**
- **What are barriers to standardizing health data and interoperability?**
- **Summary**



What are health data standards?

Health data standards are

- Agreed upon and documented ways of defining health-related concepts and patient information
- Computable
- Understandable
- Replicable
- Reusable
- Interoperable



They contain technical specifications or other precise criteria designed to be used consistently as a rule, guideline, or definition.

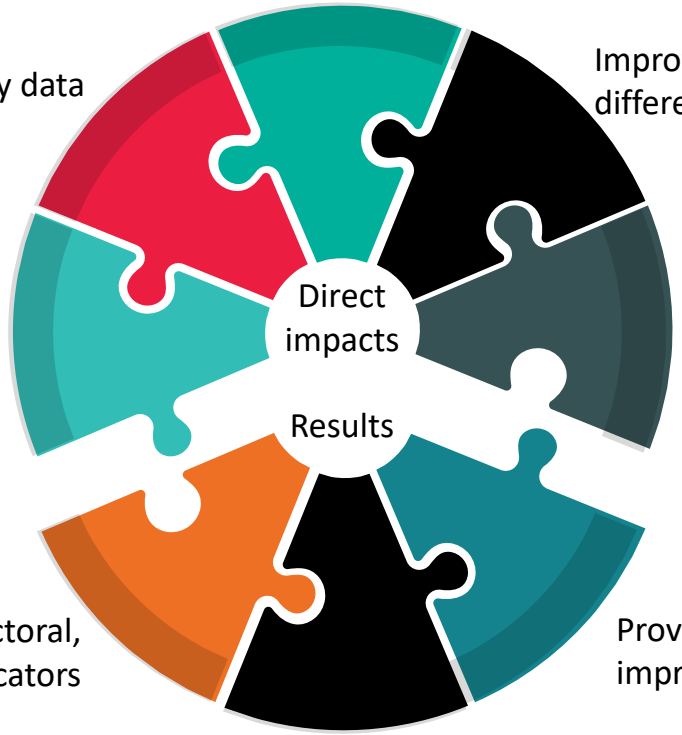
Health data standards are needed across the health system

Person health	Care organization operations	Health system planning	People and communities
			
Clinicians, care team, clients, families	**Administrators, directors, managers**	**Provinces, territories and regions**	**Population and public health**
Clinical care planning and management	Quality improvement Program planning Resource allocation	Health system use Pan-Canadian comparability	Chronic disease management Health outcomes

Implementation of health data standards produces information that can be used:

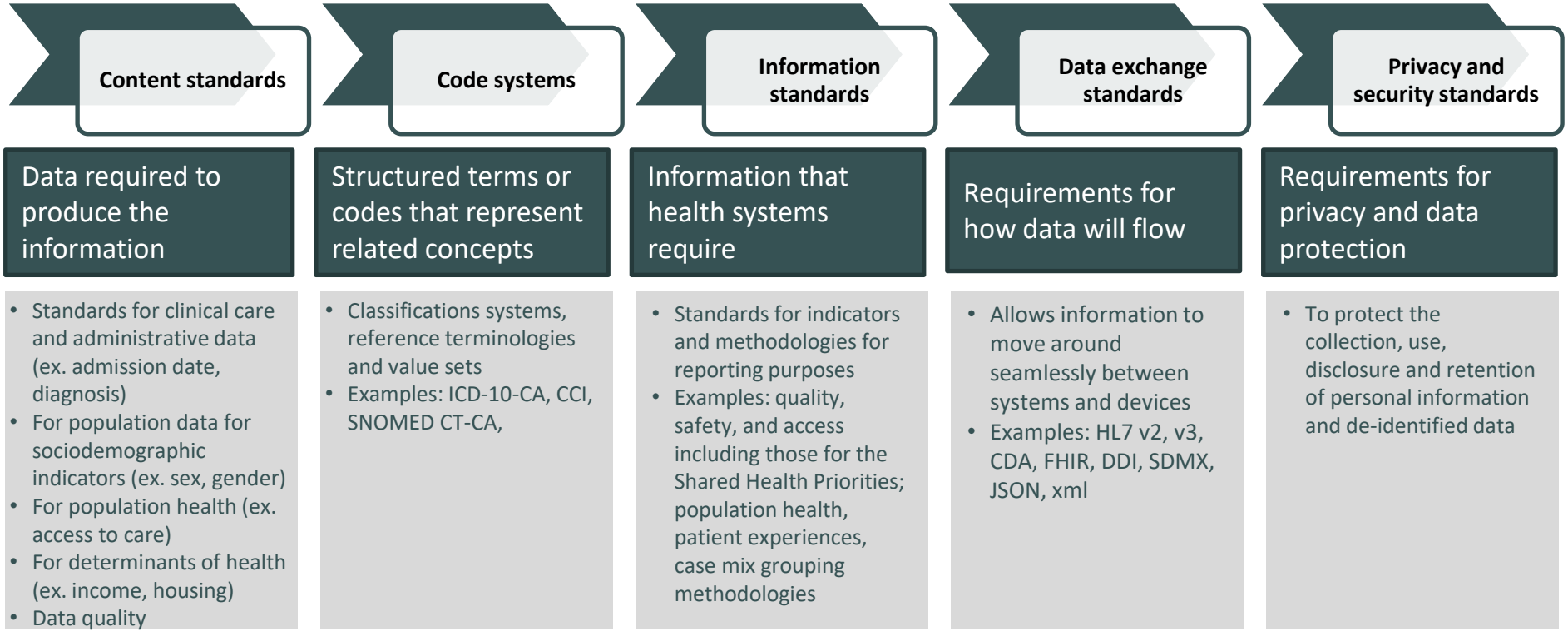
- ✓ By clients and families, to engage in care planning
- ✓ By clinicians and care teams, to inform and manage care provision
- ✓ By organizations, to inform quality initiatives and management of resources to drive continuous improvement efforts
- ✓ By the health system, to inform resource allocation, benchmarking and health outcomes by planners and policy-makers

Across these pillars, standards enable stakeholders to:



What are the different types of health data standards?

Types of health data standards



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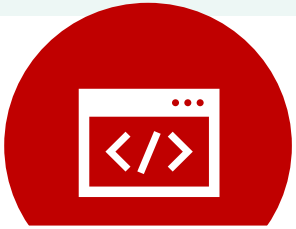
In summary:

Data standards are agreed upon and documented ways of defining and structuring health concepts and information to facilitate the consistent collection, connection and exchange of data

1. Content standards define what is collected (data structure, data elements and data types)

2. Terminology standards define values/code systems for each data element (“1”=male, “2”=female). Terminology standards are often part of content standards.



3. Data Exchange Standards leverage semantic standards and modeled relationships to facilitate data exchange between systems (system A → system B)

PRSB Professional Record Standards Body

USCDI United States Core Data for Interoperability

SNOMED CT ICD-10 LOINC

HL7® FHIR®

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Many collaborators across Canada and internationally

Canada Health Infoway

Statistics Canada / Statistique Canada
Health Canada
Public Health Agency of Canada / Agence de la santé publique du Canada

Federal Government:
StatCan, HC, PHAC, Others

Jurisdictions and Regions

WELL Health
QHR Technologies
smile DIGITAL HEALTH
ITAC health
ACTI santé
ORACLE Cerner
Epic
TELUS Health

Vendors

Canadian Institute for Health Information

IHE INTERNATIONAL Making Healthcare Interoperable
HL7 International
SNOMED International Leading healthcare terminology worldwide
WHO
DICOM Digital Imaging and Communications in Medicine
GS1
ISC
ISO HEALTH INFORMATICS TC215
interRAI

International Standards Bodies

Canadian Partnership Against Cancer / Partenariat canadien contre le cancer
HIMSS
chima
Digital Health Canada
The College of Family Physicians of Canada
CNO OIIO

Regulatory Bodies, Associations, Clinicians

Patients and Communities

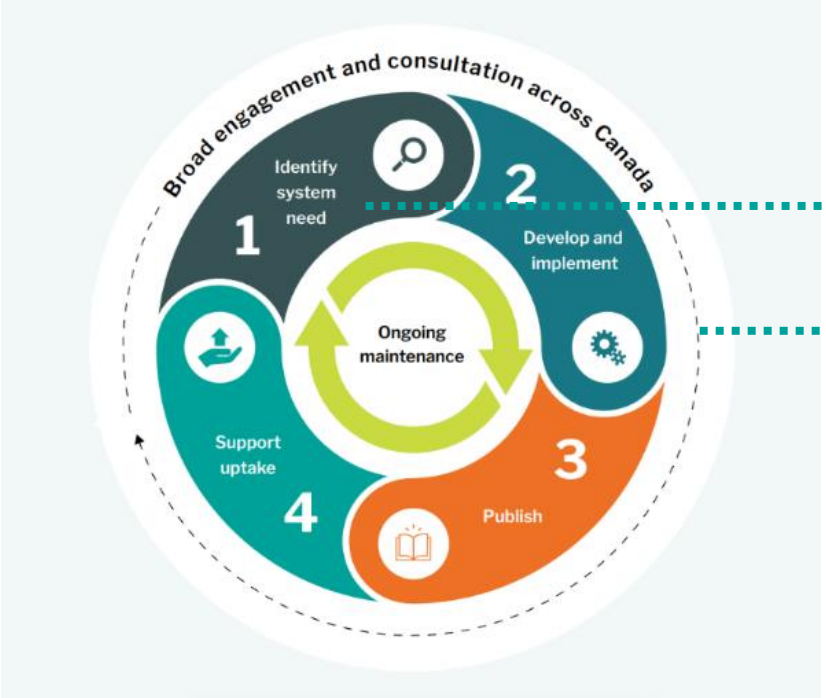
CIHR IRSC
Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

Researchers

What is the development methodology lifecycle of health data standards?

A rigorous approach is applied to develop, implement and maintain standards

Step 1: Identify system need / Periodic evaluation
Step 2: Develop and implement



1. **Identify system need / Periodic evaluation:**
   Determine new standards or modifications to existing standards that are needed to support emerging priority health system areas. Examples: equity, COVID-19.

   Periodically evaluate standards for relevance.

2. **Develop and implement**
   In collaboration with key partners and based on the input gathered through the consultations, a standard is developed and implemented with defined core data elements, value sets and code systems, which may vary based on care setting.

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Step 3: Publish
Step 4: Support uptake

3. Publish

The new or modified standard is published with supporting documentation. This may include user manuals, data dictionaries and coding resources such as training guides, specific coding directions, FAQs, infographics/data visualizations and job aids.

4. Support uptake

Provincial/territorial jurisdictions, other health-related organizations, and vendors receive ongoing support for the implementation of the standard in their systems and vendor solutions. This includes the tools to build capacity through training, including on data literacy, to troubleshoot data submissions and the support for conformance testing.

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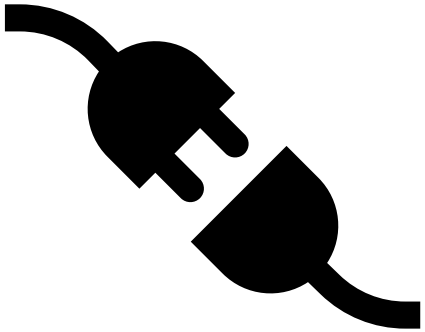
Broad engagement and consultation across Canada

Consult at pan-Canadian level:

Pan-Canadian level consultations with federal organizations, provinces and territories, clinicians, researchers, health delivery organizations, expert working groups, professional associations, patients, indigenous representatives, communities and international groups to understand information needs that inform the development of new standards or modifications to existing standards.



What is interoperability and how do health data standards relate to it?

Interoperability defined

Interoperability refers to the basic ability of systems and devices to exchange data and interpret that shared data.

For two systems to be interoperable, they must be able to exchange data and subsequently present that data so it can be understood by a user.

Patient care is a continuum

Patients see more than one provider, and often return for multiple visits.

It’s important that providers have an accurate picture of a patient’s journey across the care continuum.

This requires unambiguous communication.

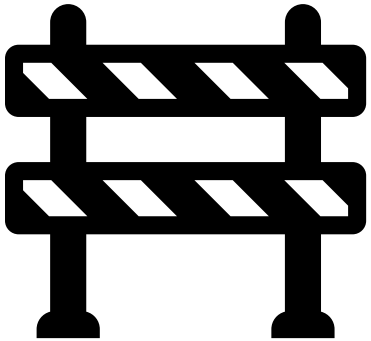
Information follows the patient. Available at the right time, at the right place and to the right people.

There is no interoperability without standards

Clinical and administrative **healthcare data standards** establish the content and technical framework that enables thousands of healthcare providers to communicate and share health information that is contextual and unambiguous in meaning.

Pan-Canadian standards support the safe and secure exchange of healthcare information across the continuum of care, clinical & operational decision support, data analytics, and population health management.

They are an important part of **interoperability**, which is the ability for information to flow seamlessly between different health systems, workflows and solutions.



What are barriers to standardizing health data and interoperability?

Current barriers to standardizing health data

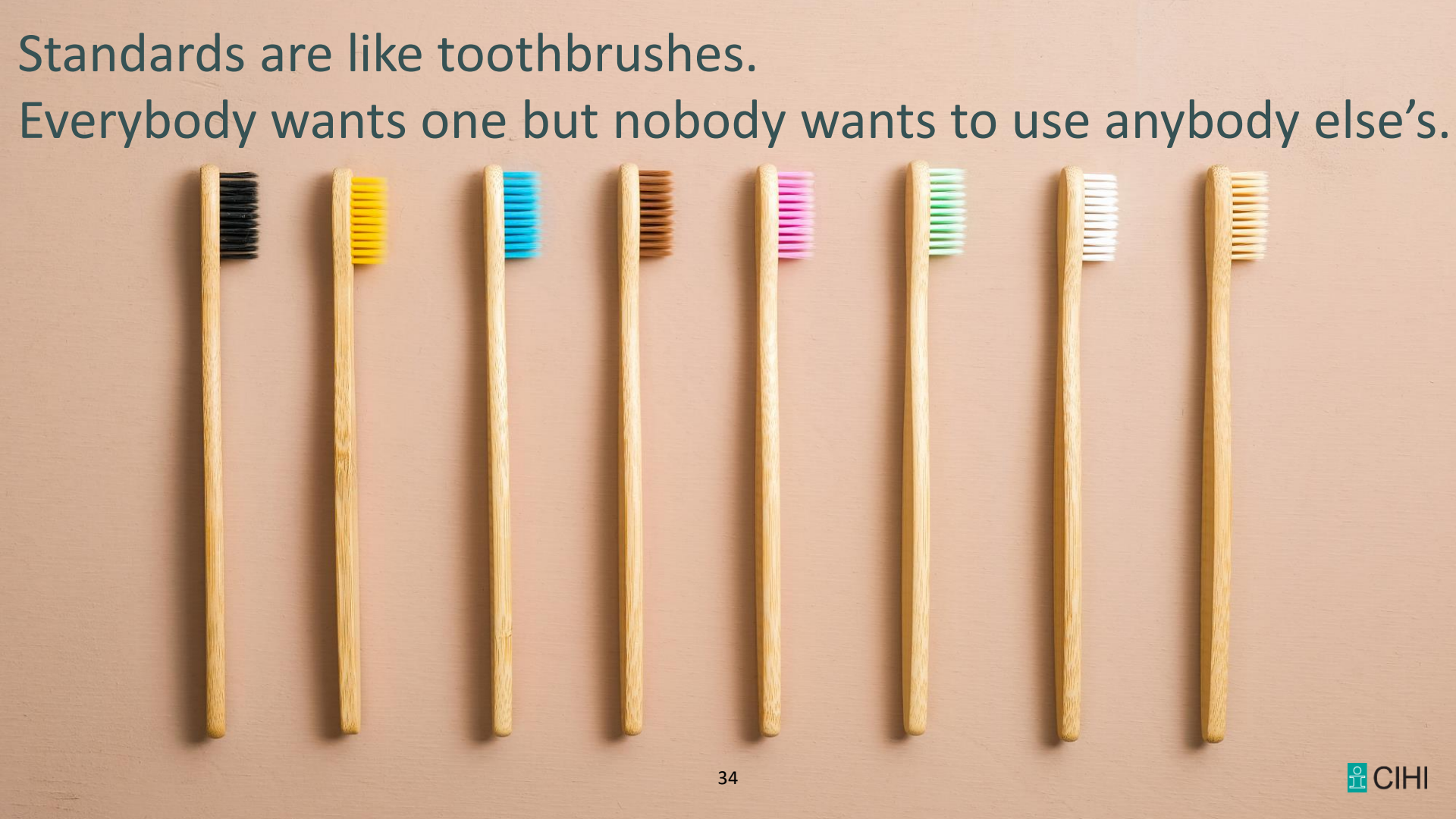
Jurisdictional readiness and funding models vary across the country: funding is not managed the same way across Canada, therefore when a new standard is released, business and clinical process changes may be required for a jurisdiction to adopt it.

Infrastructure: the digital infrastructure to collect information may not be in place; ongoing technology investments are required.

Standards have been customized over time across and within jurisdictions to meet specific information needs; similar standards might exist in Canada, but not all of Canada is on the same standard.

Lack of incentives for vendors to adopt and implement standards.

Standards are like toothbrushes.
Everybody wants one but nobody wants to use anybody else's.



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Overcoming barriers through pan-Canadian collaboration

Foundational Layer

Pan-Canadian Interoperability Roadmap

- A shared digital health vision through a jurisdictionally aligned interoperability vision.

Interoperability Governance

- Advance pan-Canadian digital health and data interoperability

Data Content and Exchange Standards

- Standardize the data and the way it is exchanged

Implementation Layer

Trusted Exchange Framework

- Build trust through privacy, security and legal frameworks

Vendor Activation Program

- Mobilize vendors through conformance and certification programs

Common Procurement Requirements

- A national procurement program for PTs

Summary

- **Standards are the foundation for high-performing patient-centric connected health systems**
- **Standards are necessary for data sharing: for clinical information to flow with the patient across settings for access by patients and care providers; and for data linkage and comparison across a wide variety of data sources to support performance evaluation, research, innovation and the delivery of better care, leading to improved health systems and better patient outcomes**
- **The ability to share health information consistently and efficiently:**
  - Improves safety and quality; improves health equity
  - Strengthens care coordination; anticipates health systems needs
  - Increases efficiency; reduces costs
  - Reduce clinician burden; improve staff experience
  - Improves population health
  - Enhances patient experience
  - Enables and supports best practices