

# A new approach to developing health data standards at CIHI

Sex and Gender Working Group Meeting

Canadian Institute for Health Information

# Outline

- **Purpose**
- **About the Canadian Institute for Health Information**
- **Health data standards**
  - CIHI's new approach to development
- **Sex and Gender standards**
  - Case study: Primary health care data



# Purpose

- **To share information about CIHI and our new approach to standards development.**
- **To initiate discussions about the current and future state of CIHI's sex and gender standards.**
- **To provide an update on the development of a Common Data Standard for Primary Health Care.**

# About the Canadian Institute for Health Information

# 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

# Strategic 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 linkable data across the 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

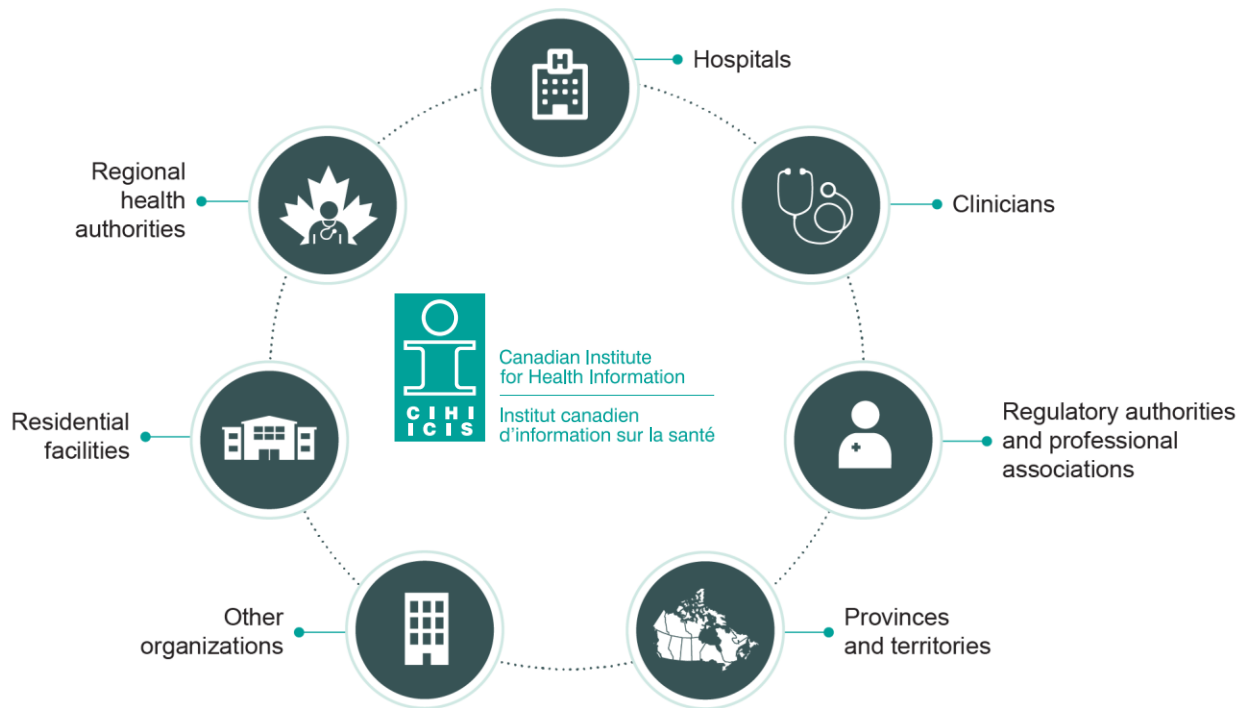
### 28 data holdings

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

#### Linkable data:

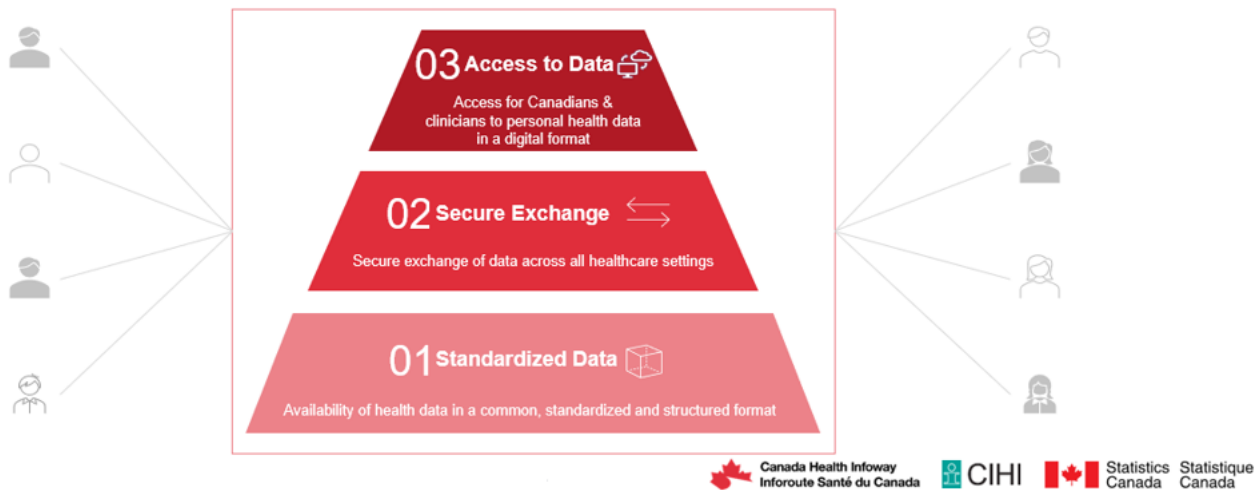
- Example: Population Grouper links 8 databases, 3 provinces, over 23 million patients

# ... from many sources



















# Success through partnerships and engagement

CIHI is working with Canada Health Infoway and Statistics Canada to achieve three interoperability goals shared by FPT stakeholders – to standardize clinical and administrative health care data; enable secure data exchange and provide the public and clinicians with easy access to personal health information in a digital format.



## 6-Pillar Interoperability Strategy

|  |   | Lead  | Partner   |   |
|--|---|---|---|---|
|  | <p><b>1. Pan-Canadian Interoperability Governance</b></p> <p>Develop an inclusive pan-Canadian interoperability governance model that leverages existing structures and relationships, to guide and govern pan-Canadian interoperability and health data exchange</p> |  |    |  |
|  | <p><b>2. Shared Pan-Canadian Interoperability Roadmap</b></p> <p>Co-develop a shared pan-Canadian interoperability roadmap that serves the needs of all provinces and territories to achieve common goals in a systematic manner</p>                                  |  |   |   |
|  | <p><b>3. Core Data &amp; Exchange Standards and Functions</b></p> <p>Collaboratively design, select, implement, adopt and maintain pan-Canadian data standards and specifications (e.g. Patient Summary – PS-CA)</p>  |   |   |  |
|  | <p><b>4. Trusted Exchange Framework</b></p> <p>Work together to develop a common trusted exchange model to enable health information exchange, that mobilizes privacy and security resources to support interoperability efforts</p>                                  |  |   |   |
|  | <p><b>5. Vendor Activation Program</b></p> <p>Harmonize pan-Canadian efforts on vendor conformance, incentives and other mechanisms to maximize buy-in and active participation from vendors in support of digital health interoperability initiatives</p>            |  |   |   |
|  | <p><b>6. Common Procurement Requirements</b></p> <p>Develop common requirements for the procurement of health data and IT solutions including software solutions that embed interoperability standards</p>  |  |   |   |

# Health data standards

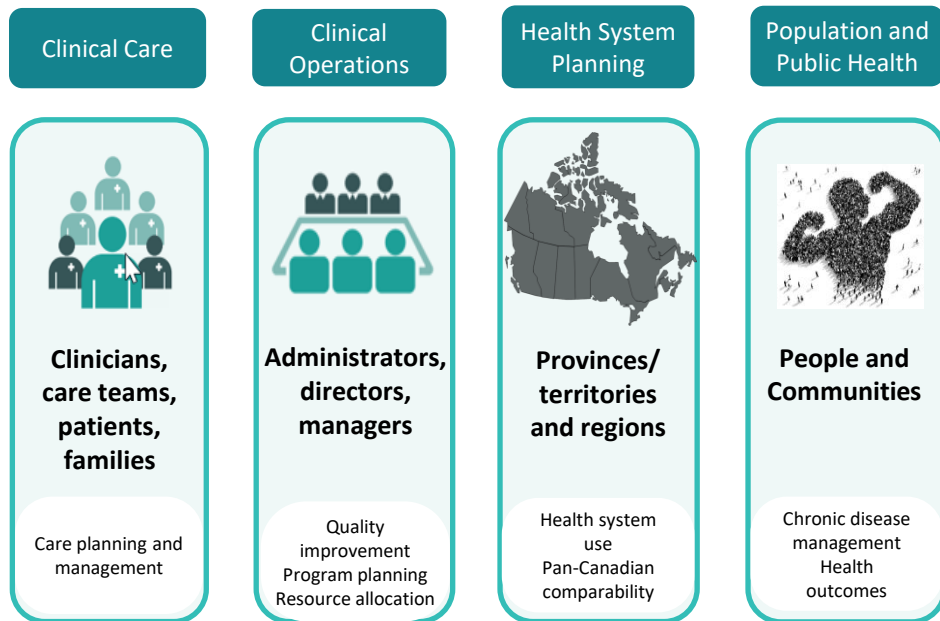
# Health data standards

Health data standards are agreed upon ways of defining and categorizing health-related concepts and patient information.

- Health data standards ensure information is captured consistently across the system.
- They also enable information to flow across computer systems and between organizations.
- This ensures providers have the right access to the right information at the right time and enables patients to have access to their own clinical information.



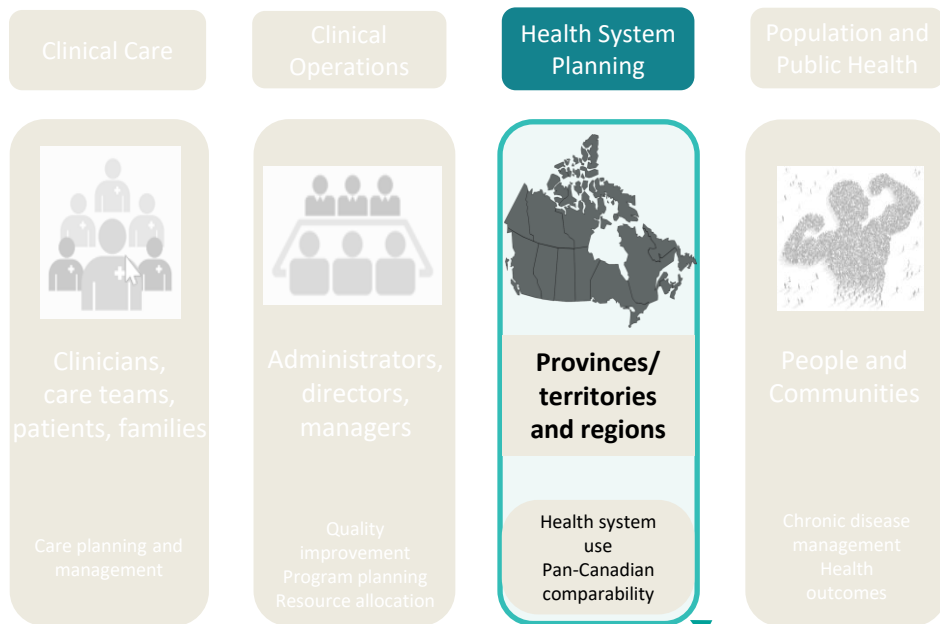
# Comprehensive standards serve many needs



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

- ✓ By patients 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

# The need for a new approach at CIHI



- **Historically, CIHI focused on standards to guide the collection and reporting of health system performance data**
  - The existing *Primary Health Care Minimum Data Set* was developed to measure health system performance and to develop pan-Canadian indicators. It was not intended to support clinical care, clinical operations, or population health.
  - The data set does not address critical issues of equity, social determinants of health, race, ethnicity, cultural safety, Indigeneity or sex and gender.

# Sex and Gender Standards

# CIHI's role in sociodemographic data standards

- **CIHI does not mandate the sociodemographic data (SDD) collected at the provincial/territorial level.**
  - Historically, we have set SDD data standards to enable the submission of this data to CIHI where it is collected. This means determining roll-up categories where more granular data may be collected by the provider or setting.
- **CIHI is moving down a new path to incorporate SDD and equity into routine reporting and create interoperable datasets which require collaboration with data collectors.**
- **Our current standards have yet to be implemented in many of our data holdings. This gives us the opportunity to adapt and improve our GSSO data standards.**

## Current status

- **CIHI's current sex and gender standards reflect a 2-step approach of using both Sex at Birth and Gender information where available.**
  - Aligns with Statistics Canada's standards used in the 2021 Census of Population.
  - Cross-tabulating Sex at Birth and Gender information allows transgender and non-binary individuals to be represented in CIHI's data.
- **We are listening! We have heard that the 2-step approach might not be appropriate or relevant where the information will be used for both *clinical care* and *health system use*.**
  - Transgender and non-binary individuals can be harmed by being asked about their assigned sex at birth and/or sex for clinical use at the point of care.
  - There might be a better way to identify the transgender population and report on the inequities they face in health care.

## Challenges to implementation

- **CIHI receives a large amount of administrative data which often comes from a health card swipe during patient registration.**
  - In April 2022, the *Gender* data element in CIHI's Discharge Abstract Database (DAD) was re-labelled *Recorded Sex or Gender* to more accurately reflect the data (which is currently a conflation of sex and gender sourced from health card).
- **Open text response options are not practical nor feasible in most healthcare databases.**
- **When data holdings are updated, there are several downstream impacts that must be considered, including the impact on established indicators and methodologies.**
- **What can help?** Concrete examples of high-quality gender data collection in Canadian healthcare settings that CIHI can leverage for modernization efforts.

# Health data standards: Primary Health Care

# Features of high-functioning primary health care systems

## Health System Level (Macro):

- Governance and accountability
- Healthy public policy
- Vertical and horizontal integration across borders and sectors
- Integrated clinical pathways
- Funding and incentives
- **Public health surveillance \***

\* **Links to public health**

## Operational Level (Meso):

- Population health
- Comprehensive (wholistic) set of services
- **Health promotion and prevention \***
- Chronic disease management
- Continuous and coordinated
- Accessible
- Team-based care
- Information technology (eHealth) systems

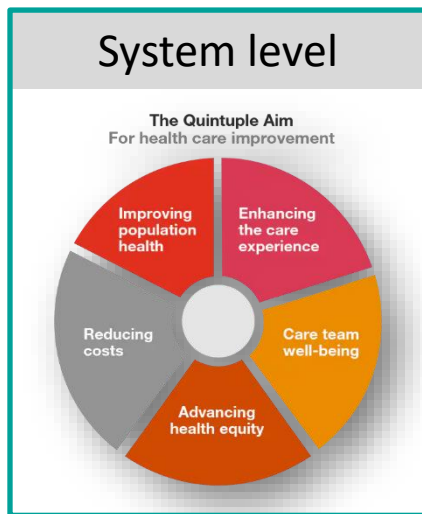
## Individual Service Level (Micro):

- Each client has a most responsible provider (enrolled/rostered)
- Person-centred
- Wholistic physical and psychosocial health assessment
- Individualized care plan (goals)
- **Education and self-management support \***
- **Immunizations \***
- Treatment(s)
- Prescribed medications
- Diagnostic imaging
- laboratory examinations
- Transitions in care

Focus on the social determinants of health, cultural safety and humility; anti-racism; equity, diversity and inclusion

Supported by interoperable information technology systems and performance measurement

# Guiding frameworks



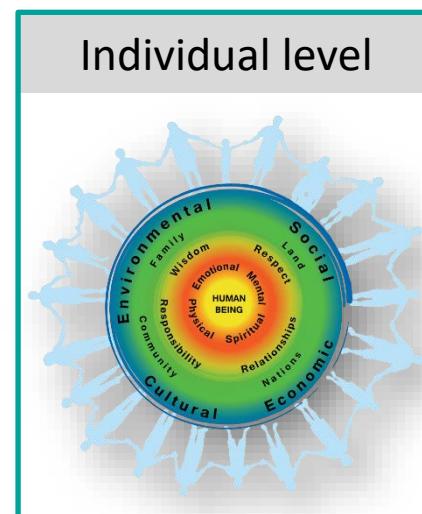
## Quintuple Aim

[The Quintuple Aim for Health Care Improvement.pdf](#)



## Model for Health and Wellbeing

[Evaluation Framework 2019 small.pdf \(allianceon.org\)](#)



## First Nations Perspective on Health and Wellness

[First Nations Perspective on Health and Wellness \(fnha.ca\)](#)

# From Minimum Data Standard to Common Data Standard

- “Plug and play” or “modular” approach based on the objectives of people and communities, providers and health systems
- A menu of data categories with associated data elements and values that reflect individual, operational and system-level data
- Reflect a whole system approach with embedded social determinants of health, health equity, cultural safety and wholistic health
- Implemented in a phased approach

## Allergies and Intolerances

Harmful or undesired physiological responses associated with exposure to a substance.

Substance (Medication)  
Substance (Drug Class)  
Reaction

## Assessment and Plan of Treatment

Health professional's conclusions and working assumptions that will guide treatment of the patient.

Assessment and Plan of Treatment  
SDOH Assessment

## Care Team Member(s)

Information on a person who participates or is expected to participate in the care of a patient.

## Health Insurance Information

Data related to an individual's insurance coverage for health care.

Coverage Status  
Coverage Type  
Relationship to Subscriber  
Member Identifier  
Subscriber Identifier  
Group Identifier  
Payer Identifier

## Health Status/Assessments

Assessments of a health-related matter of interest, importance, or worry to a patient, patient's family, or patient's healthcare provider that could identify a need, problem, or condition.

Health Concerns  
Functional Status  
Disability Status

## Patient Demographics/Information

Data used to categorize individuals for identification, records matching, and other purposes.

First Name  
Last Name  
Middle Name (including middle initial)  
Name Suffix  
Previous Name  
Date of Birth  
Date of Death  
Race  
Ethnicity  
Tribal Affiliation  
Sex  
Sexual Orientation  
Gender Identity  
Preferred Language  
Current Address  
Previous Address  
Phone Number  
Phone Number Type

United States Core Data for Interoperability (USCDI) [United States Core Data for Interoperability \(USCDI\)](#) | [Interoperability Standards Advisory \(ISA\) \(healthit.gov\)](#)



What are the mechanisms by which CIHI can get input on new GSSO standards?





Canadian Institute for Health Information

**Better data. Better decisions. Healthier Canadians.**



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