

CIHI Standards 101

Creating data standards and governance to support collection, analysis and reporting

Canadian Institute for Health Information

Today's Presentation



Outline

- About CIHI
- CIHI's Data Governance Journey
- Standards Strategy and Development

Key Takeaways

- Increasing health system needs to access, link and report on data
- Proper foundation and structure is critical for implementing data governance, advancing corporate strategies and improving the management of data assets
- A corporate standards process flow has helped determine the what and who for successful standards development



About 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

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

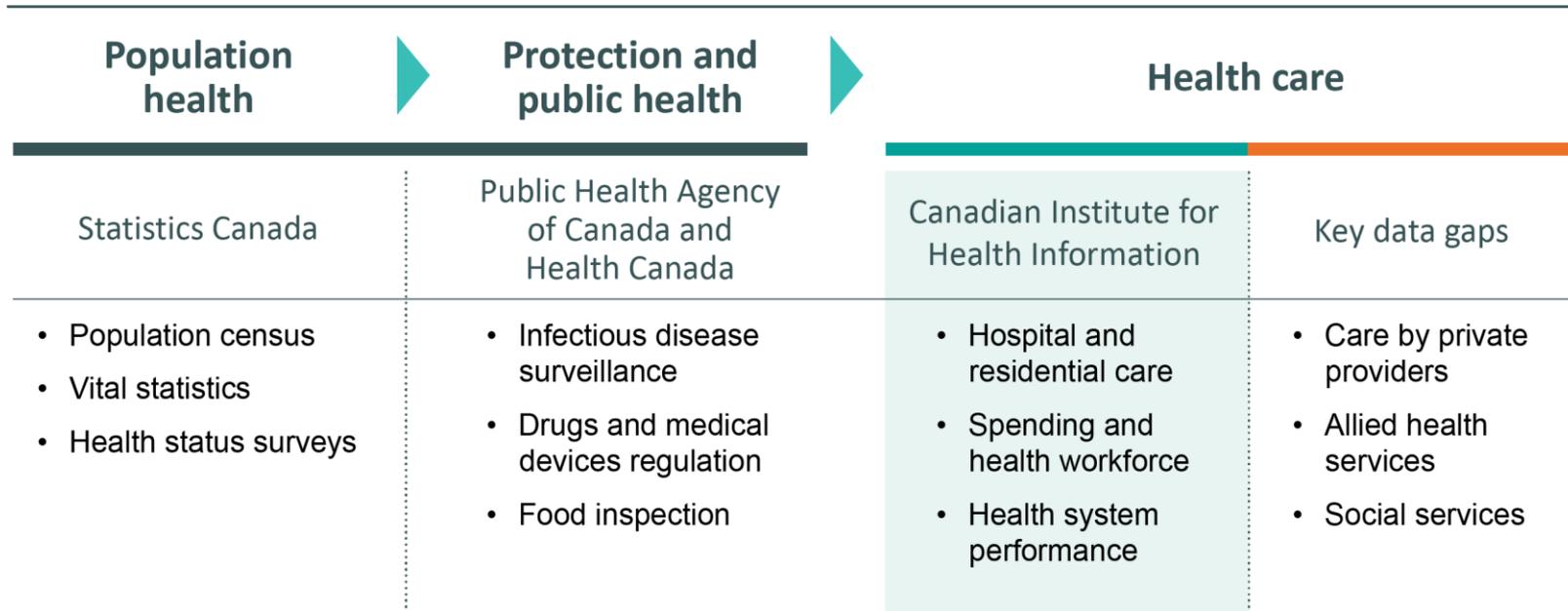
Mandate

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

Values

Respect • Integrity • Collaboration • Excellence • Innovation

Where does CIHI fit?





CIHI's Data Governance Journey

What is Data Governance?

The implementation of processes and controls to limit the risky things people can and will do with data while optimizing the value of data by using it to create insights generating impactful action.



Why governance is so important

- **Health systems' fastest growing asset: data**
 - Need to know what we have, where, and how to access it in order to protect and optimize value
- **International context**
 - OECD [has laid out conditions](#) to encourage greater health data availability and processing for public policy, while minimizing and managing risks to privacy and security
 - European Union's [Data Governance Act](#) to promote data availability and build an environment to facilitate its use for research and the creation of innovative new services and products
- **Governance can increase value of data exponentially because it enables sharing and linkage**

Why governance is so important at CIHI

- CIHI hosts extensive linkable, pan-Canadian data across the health care continuum
- Wide range of data holdings
 - 10 billion records
 - 3 terabytes of unique records
 - Linkable, e.g., Population Grouper links 8 databases, 3 provinces and over 23 million patients
- Increasing system needs to access, link and report on a range of data



The importance of evolving from a data-driven to a data-centric organization

Managed



Above ground

- House maintenance
- Local autonomy
- Scale to new houses

Below ground

- Community Services
- Centrally governed

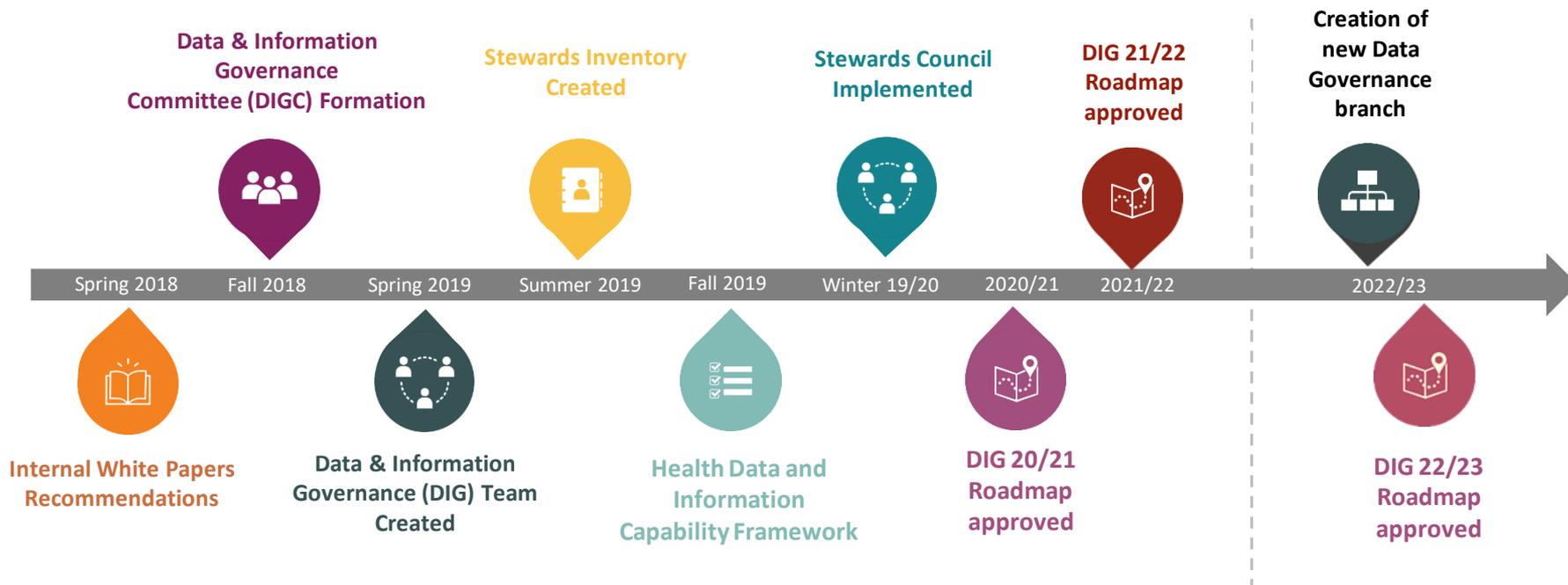
- Houses are stand-alone and deliver their value
- Maintenance must be done individually
- Difficult to connect houses
- People are experts in their house – cannot move around easily

Governed



- Houses deliver their collective value together
- Lower overall cost as maintenance is shared
- Houses are designed to connect and share
- People are experts in the community – they can move around and work together easily

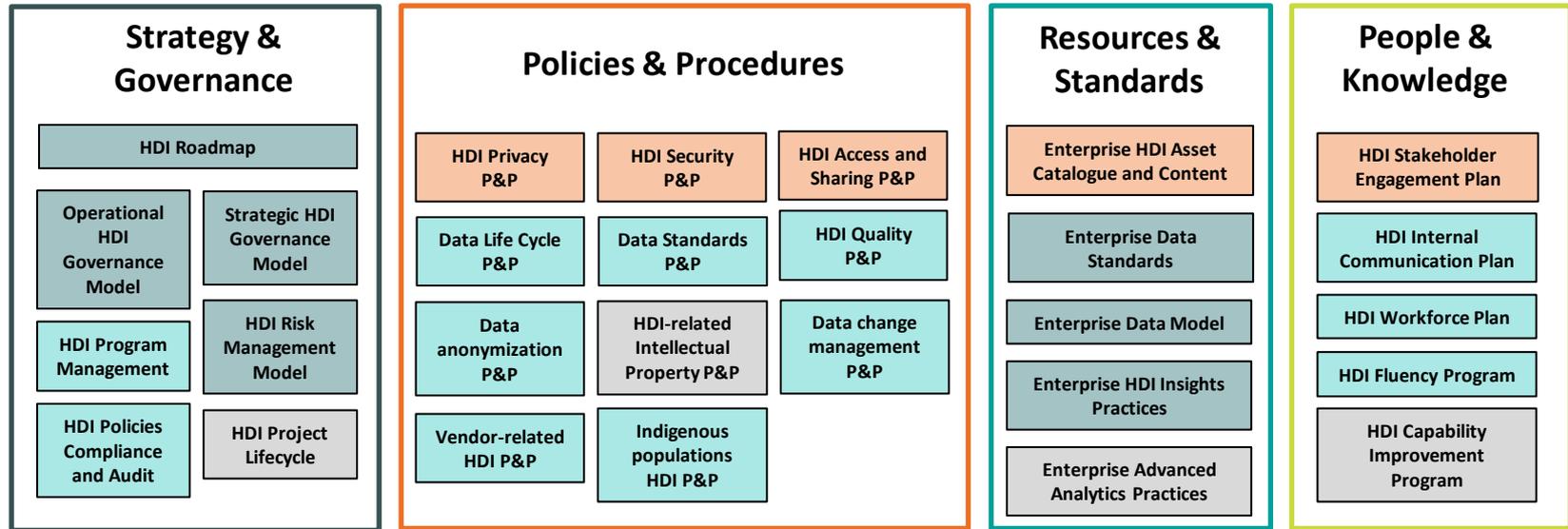
CIHI's Data Governance Journey To Date





Data Governance Framework, Governance Bodies and Roadmap

Health Data & Information Capability Framework



Governance Groups

Challenge: CIHI has a LOT of data-related activities going on and too often these activities have been happening in isolation from each other in an inconsistent way

Data and Information Governance Committee (DIGC)

- Strategic
- Ensures coordination and collaboration on data-related activities
- Develops and monitors the DIG roadmap

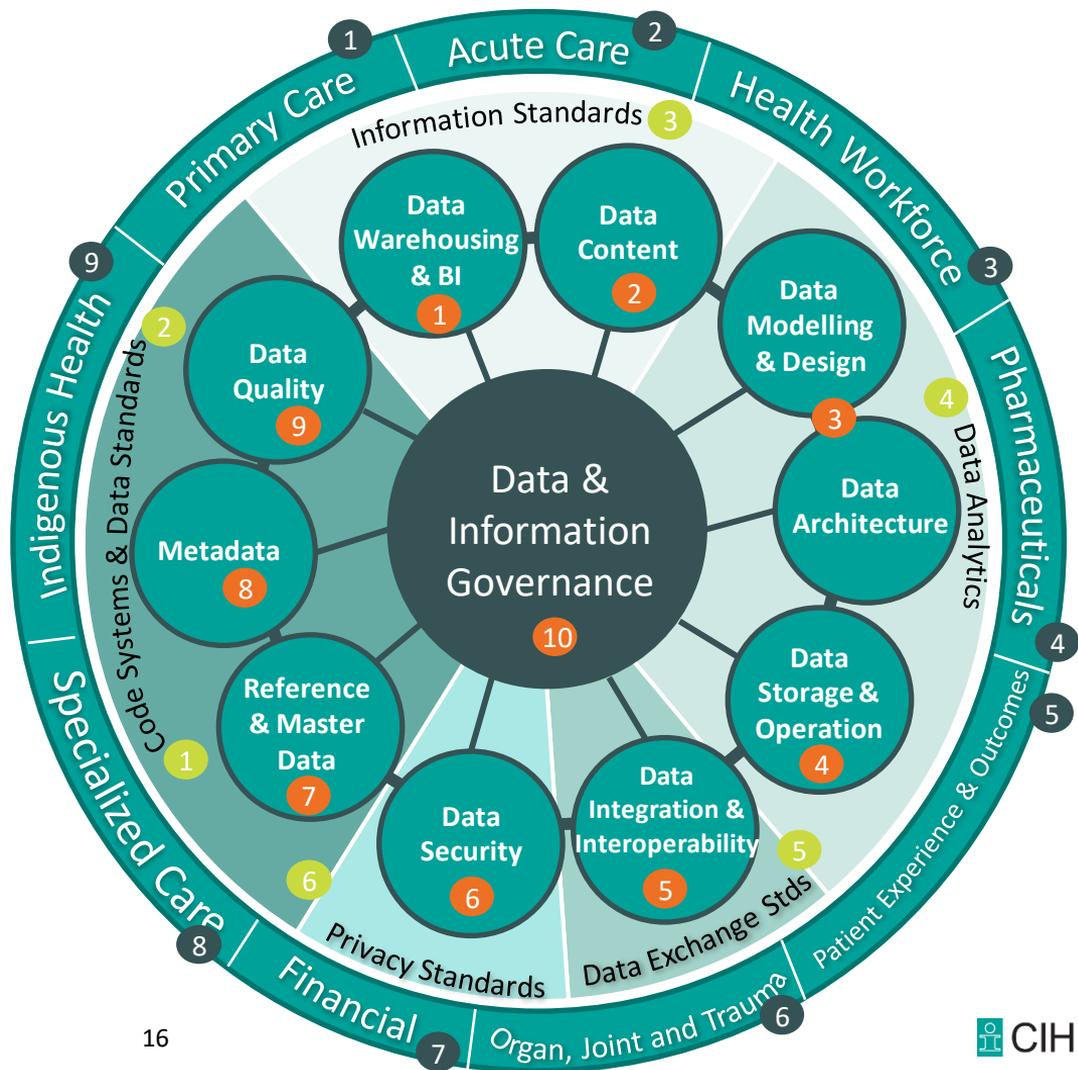
Stewardship Council

- Operational
- Identify gaps and provide input
- Promote consistent use of data and information standards

Stewardship Council Membership

- **Data Management Stewards - 10**
- **Standards Stewards - 6**
- **Enterprise Business Data Stewards - 9**

Membership total = 24



The DIG Roadmap was created to:



To more effectively govern our data assets using a coordinated enterprise-approach



To improve capability in areas of the Health Data and Information Framework that were not at the desired capacity level



To best leverage DIGC members expertise, oversight and surveillance



To provide focus on Stewardship Council operational activities



To demonstrate to Executive Committee the priority Data and Information activities for the organization

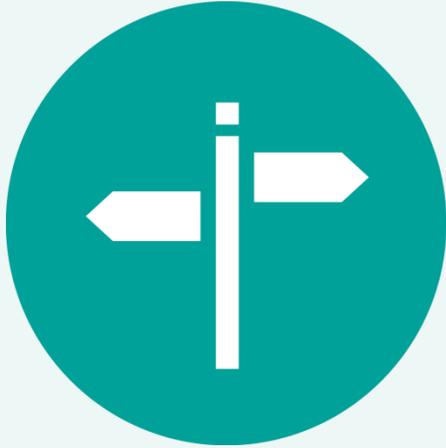
What are the activities on our DIG Roadmap?

- Defining the **role and responsibilities** including alignment with other corporate governance groups and process
- **Standards Strategy** Implementation and Expansion
- **Standards development and implementation** to support key projects (e.g. CIHI Data Hub, Organ Donation, Health Human Resources, Virtual Care)
- Advancing our **metadata work** including data catalogues, business/technical metadata and data lineage
- Developing our ability to stratify data based on **equity measures** (sex/gender, race/ethnicity, indigenous identity, etc.)
- Developing and applying an **ethics framework** for data and analytics

Governance Resources and their application

- Frameworks

- [Health Data and Information Governance and Capability Framework](#) provide a structure to help organizations self assess their data and information governance capabilities and develop an action plan to achieve target goals
- [Information Quality Framework](#) provides an overarching structure for all CIHI quality management practices related to capturing and processing data and transforming it into information products
- [Privacy and Security Framework](#) provides a comprehensive approach to privacy and security management based best practices from across the public, private and health sectors
- [Data and Analytics Ethics Framework](#) to enhance the ethical quality of the collection, analysis, sharing and use of health data at CIHI
- Indigenous Data Governance at CIHI focuses on ensuring that the release and disclosure of Indigenous identifiable data respects principles of Indigenous data sovereignty. See [A Path Forward: Toward Respectful Governance of FNIM Data](#) for more details



Standards Strategy and Development

Standards' Place in CIHI's Overall Strategy



Strategic Plan 2022-2027



Standards Strategy

Setting standards to ensure comparable data can be captured



Data Advancement Strategy

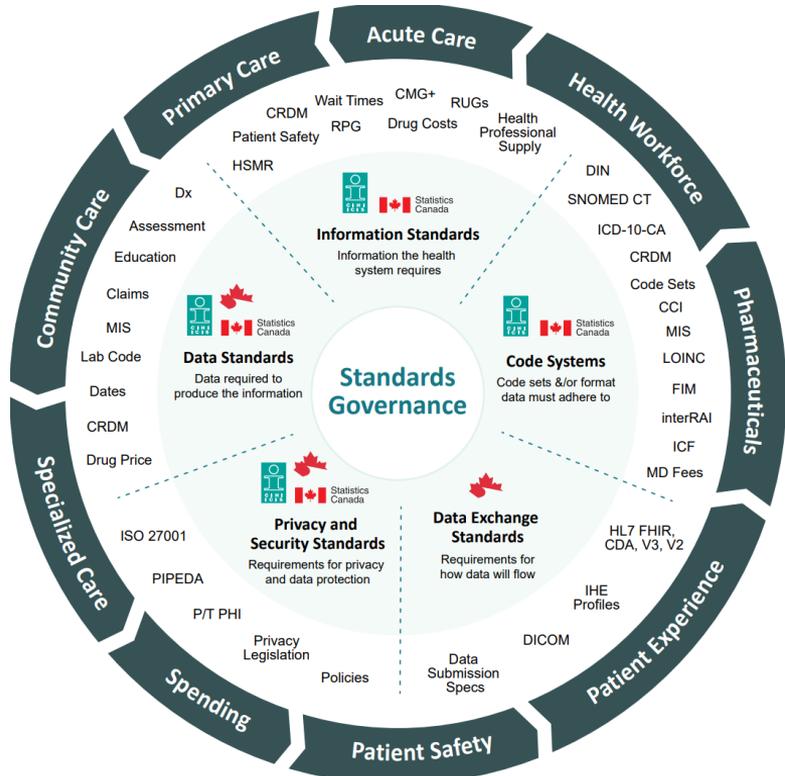
Filling gaps in data towards pan-Canadian coverage in priority areas



Analytical Plan

Using the data to inform key policy issues on priority topics

CIHI's Standards Framework



CIHI develops and supports jurisdictional implementation of standards to provide comparable and actionable data and information used to accelerate improvements in health care, health system performance and population health across Canada

Prioritization of Standards Development

CIHI's plan for tackling development of standards is informed by corporate strategic needs.

The highest priority standards are those that are:

- ✔ Developed, supported, or used by CIHI **and**
- ✔ Have an impact across the organization

These standards are built through consensus by applicable governance bodies with an intent to be leveraged throughout the data and information lifecycle, and across CIHI data holdings, where appropriate.

Why identify priority standards?

The purpose of identifying priority standards is to:

- Ensure high quality comparable data can be captured and reported in priority areas across all CIHI data sources, where applicable
- Facilitate data integration for better analyses and reporting
- Consolidate enterprise expertise to ensure harmonized and transparent collaboration while avoiding duplication of effort and content

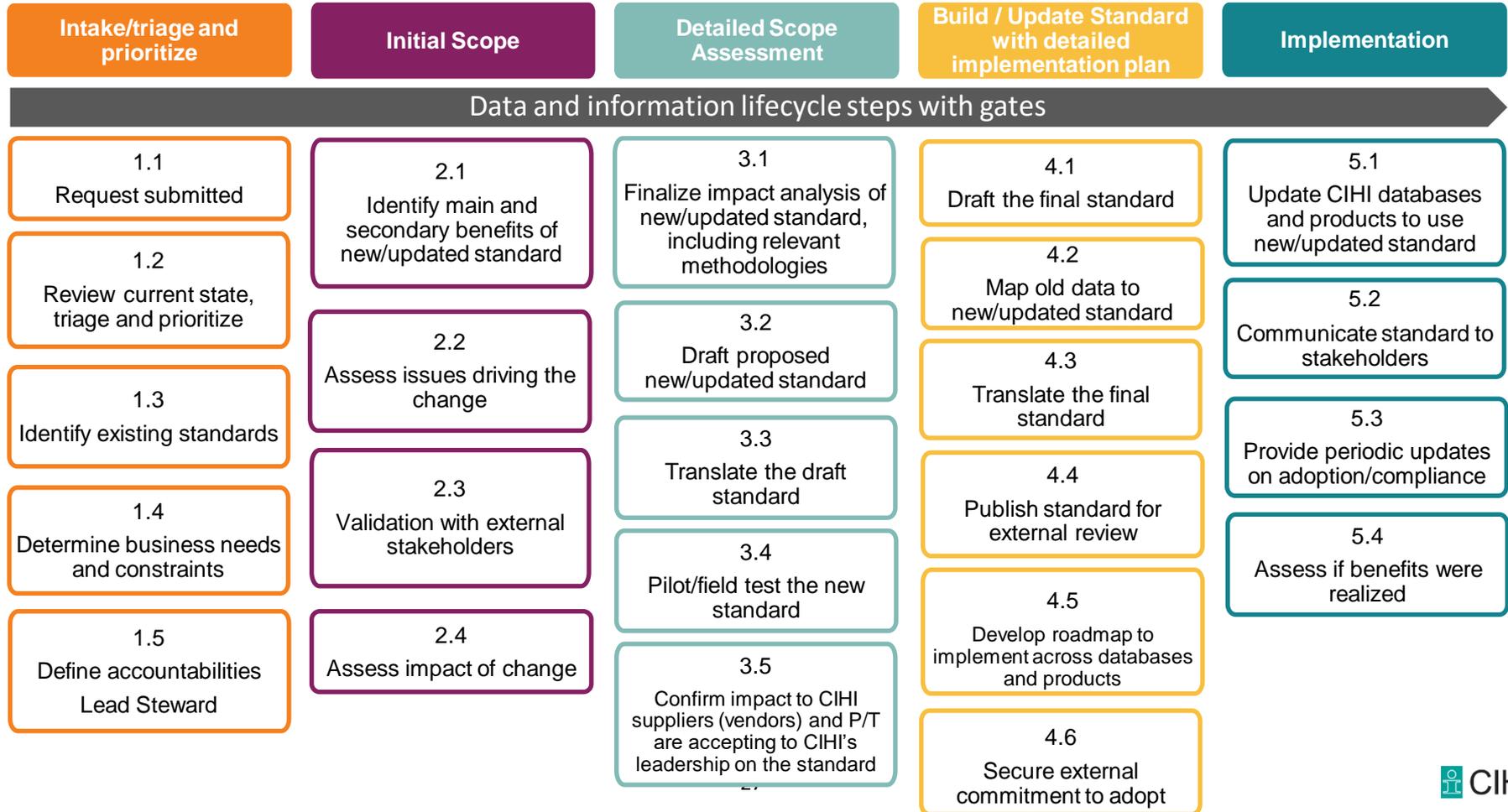
Examples of Priority Standard Concepts

- Age
- Language
- Education Level
- Ethnicity
- Gender
- Geography (e.g. urban / rural)
- Homelessness
- Indigenous Identity
- Organization
- Organization Trending
- Provider Type
- Racialized Group
- Sex at Birth
- Visit Mode

CIHI's Standards Process Flow



CIHI's Standards Process Flow



Success Story – Geography Assignment Program (GAP)

Challenge

Assigning detailed geographic information from postal codes can be complex and if done inconsistently can mean variations in indicator calculations

Solution

- Uses mastered geography data to help CIHI staff streamline the postal code conversion process necessary to assign different geographic variables
- Users select the geographic variables they want, and the program automatically assigns them using the most appropriate postal code conversion method
- This code was further built into our general use data files so that postal codes could be removed from files entirely and contribute to privacy best practices.

Benefits

- Consistent application of master data assets / better data quality
- Significant efficiency gains for analytical staff

Developing Story – Sex and Gender

Challenge: original state

Data holding	Data Element	Categories
DAD, NACRS	Gender	Male, Female, Undifferentiated for Stillbirths, Other or Unknown
PROMS	Gender	Male, Female, Unknown
NPDUIS	Patient Sex	Male, Female, Other, Unknown
HCRS	Sex	Male, Female, Blank (if unknown)
NRS	Sex	Male, Female, Other (hermaphrodite and transsexual)

Data holding	Data Element	Categories
Patient-Level Physician Billing Repository	Patient Sex (NS, ON, MB, SK, AB)	Male, Female, Unknown
CJRR	Gender	Male, Female Other
OMHRS	Sex	Male, Female, Other
HWDB (Nursing)	Sex of the registrant	Male, Female, Not stated
HWDB (Pharmacist)	Gender	Male, Female, Not collected, Unknown

We would use Gender, Sex, Patient Sex and Sex of the registrant interchangeably and would have 10 variations for categories in 10 databases

Developing Story – Sex and Gender

First steps: develop a standard

Data Element	Definition	Categories
Sex at birth	Sex as assigned and recorded at a person's birth (e.g., recorded on original birth certificate). Sex is a complex biological concept that includes anatomy, physiology, genes and hormones.	F = Female M = Male I = Intersex UNK = Unknown
Gender	Each person's internal and individual experience of gender. It is their sense of being a woman, a man, both, neither or anywhere along the gender spectrum. A person's gender may be the same as or different from their sex assigned at birth and may change over time.	F = Female M = Male X = Another gender UNK = Unknown NA = Not Applicable

We have 1 enterprise data standard

By treating key data standards as enterprise or CIHI data standards first we
build trust in our data standards

Developing Story – Sex and Gender

Next steps

- Complete work to accurately label existing fields (e.g. “Recorded sex or gender”)
- Continue to work external partners to ensure the standard is appropriate and that the data can be captured in a respectful manner
- Develop a plan to ensure all of our databases are compliant with the standard including impacts to downstream products (e.g. case mix grouper, indicators, etc.)

Standards Resources

- [CIHI Reference Data Model \(CRDM\) Toolkit](#) – data architecture standard that helps CIHI achieve common terminology, meaning and data integration throughout its national data holdings
- [Data Standards Internet Page](#) – additional information on CIHI standards that have been developed such as those for primary healthcare, acute and ambulatory care and management information systems. Also includes a list of data standards by data holding
- [Indicator Library](#) – metadata on health indicators in one convenient location for you to explore

Looking Forward...

- **Continue to work internally on the implementation process for standards**
- **Continue to build internal standards expertise**
- **Work closely with our external stakeholders and partners to develop new/update standards, share best practices and ensure adoption**





Canadian Institute for Health Information

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