

Results of CIHI's Sex and Gender Environmental Scan

Sex and Gender Working Group Meeting

Canadian Institute for Health Information

November 28, 2023

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Land acknowledgement

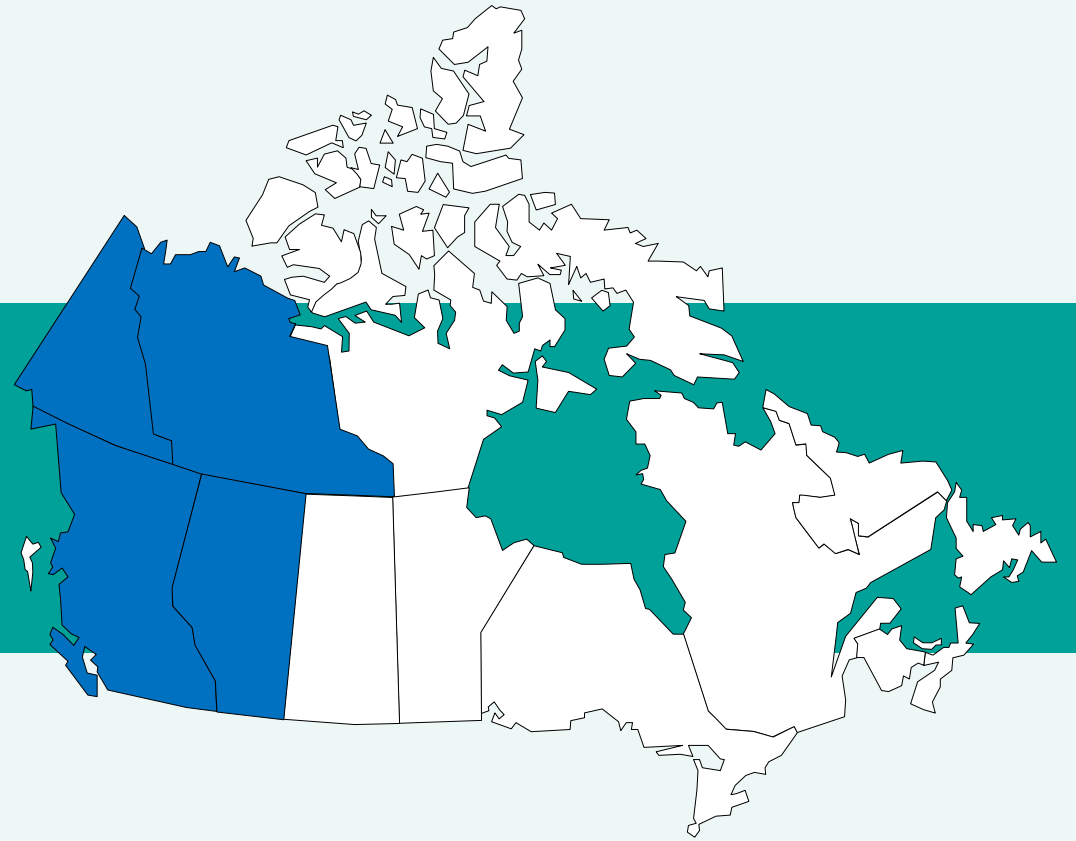
I would like to acknowledge the lands that I occupy, whether treaty or unceded. I recognize that these lands are home to many diverse First Nations, Inuit and Métis Peoples.

Outline

- **Results of provincial/territorial and vendor engagement**
- **Key findings by province and territory**
 - Eastern Canada (September)
 - Central Canada (October)
 - Western Canada (November) ← ***We are here!***
- **Next steps for pan-Canadian GSSO data standards**



Western Region



Key findings from Northwest Territories

Stakeholder(s) Engaged: Northwest Territories Health and Social Services, Government of Northwest Territories



Current State

- Collect limited sex and gender information primarily due to system limitations.
- Will be replacing both their EMR and HIS solutions with one territorial solution in the next 3 years.
 - This will give them more flexibility to address current and future requirements for the collection and use of sex and gender information.
- No integration with their Vital Statistics system and their Healthcare Insurance Registry.
 - Both capture Sex as Male and Female. Some systems also include “U” for Unknown.
 - Public Health Disease Forms include Gender Identity information, but this information is not captured electronically.

Key findings from Northwest Territories (cont'd)

Challenges

- No reference data or source of truth.
- Lack of integration and synchronization between sources of sex and gender information.
- Lack of structured, electronic data; a lot of free form text.



Future State

- In the planning stages of addressing the requirements for more structured data and use of data governance practices across the territory.
- Staff have completed some training provided by Health Canada (Sex and Gender Based Analysis Plus) for the capture of better sex, gender and diversity data.

Key findings from Alberta



Stakeholders Engaged: Alberta Health Services & Alberta Health

Current State

- In the midst of implementing a provincial-wide HIS solution called Connect Care.
 - Will eventually interface with all AHS systems in the province – replacing the 40-50 legacy systems in place.
 - Enables the establishment of a well-defined, inclusive set of data for sex and gender information including **Administrative Gender** (Male, Female, X, Undetermined), **Sex at Birth** (Male, Female, Unknown, Choose not to Disclose, Not Recorded on Birth Certificate), and **Gender Identity** (Agender, Male, Female, Intersex, Non-Binary, Transgender Female, Transgender Male, Two-spirit, Not Listed, Questioning, Choose not to Disclose).
- Private providers (e.g., pharmacies) will continue to use their own systems and will continue to have data inconsistencies.

Key findings from Alberta cont'd



Challenges

- Educating front line clinicians on how to use sex and gender information as designed.
- Restrictions imposed by all interfacing systems to Connect Care.
- Patients sometimes uneasy about providing information; often dependent on how the provider presents the questions.

Future State

- Aim is to design a solution (Connect Care + workflow changes) that supports a conversation that is respectful to the patient.
 - Risk is defining the labels first and then trying to fit people in.
 - Better to understand the person and then record the data that is appropriate.
 - Tremendous opportunity to build trust in a marginalized community that has been harmed.

Key findings from Yukon

Stakeholder(s) Engaged: Yukon Government



Current State

- Their Vital Statistics system is the source of sex information for many downstream systems across the Territory including:
 - Health card Registration, Client Registry, Hospital Information System, Physician Claims, and Electronic Medical Record solutions.
 - Values are limited to Male, Female and X.
 - Some other systems also capture U for Unknown, such as the Panorama Public Health Surveillance System shared with British Columbia.
- Not aware of any structured fields for gender identity across the various systems that would capture information for clinical purposes. This information might be captured as free-text clinical notes, where appropriate.

Key findings from Yukon cont'd



Challenges

- No standardization of concepts, what they mean, and how they are to be used.
- From an analytics perspective, if gender identity was captured, it would be difficult to report on without violating privacy rules because the numbers would be so small (thus difficult to fully de-identify).
- Systems driven from the Vital Stats solution, where values are subject to legislation.
- Many health system changes are needed in many areas, but there is limited funding to address broader requirements for the capture and use of sex and gender information.

Future State

- Would like to capture both sex at birth and gender identity for clinical purposes.
- Seeking funding for gender affirming treatments and care.

Key findings from British Columbia

Stakeholders Engaged: Providence Healthcare, BC Ministry of Health, Fraser Health, Interior Health, Island Health, Northern Health & Provincial Health Services Authority



Current State

- Vital Statistics solution captures Sex at Birth as Male, Female or Other.
- For health card registration, Male, Female or X can be captured and displayed on the card.
- No direct integration between Vital Statistics solution and health card registration systems.
- There is a provincial-wide Client Roster that includes everyone registered for a health card and everyone listed in the provincial Client Registry solution. Includes Administrative Gender as Male, Female, or Undifferentiated.
- Hospital Information Solutions vary across health authorities and capture both Sex at Birth and Gender Identity. However, the values vary across systems.

Key findings from British Columbia cont'd



Challenges

- Lack of standardization across regional solutions – for HIS and EMR solutions.
- Lack of consistent naming, definitions, etc. across the province, nationally and internationally.

Future State

- Collaborating with Health Authorities to engage patient workgroups to inform standards for Gender Identity, Pronouns, and Preferred Name.
- Scope is government wide use, but health-specific standards are also envisioned.

Next steps: Establishing pan-Canadian
GSSO Data Standards

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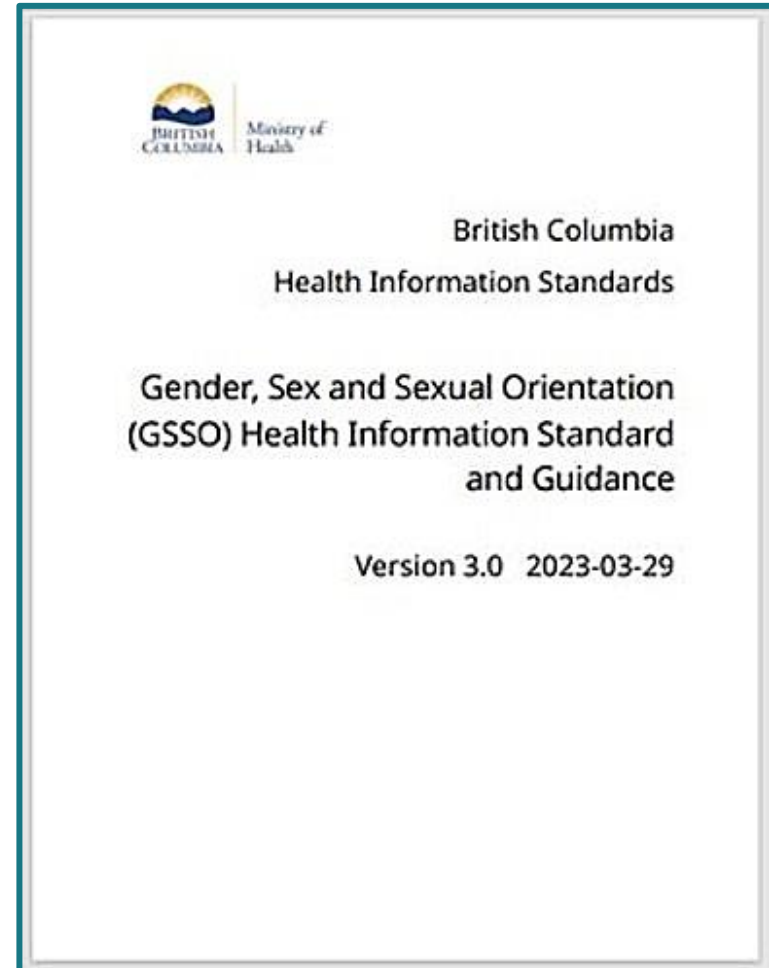
CIHI plans to establish pan-Canadian gender, sex and sexual orientation (GSSO) data standards based on British Columbia's GSSO Health Information System (HIS) standard

- Will be part of the broader pan-Canadian Health Data Content Framework (p-CHDCF)



BC's GSSO Health Information Standard

- **Based on international standards**
 - SNOMED CT, LOINC and HL7
- **Aligns with HL7 Gender Harmony model and Statistics Canada's standards for Gender and Sex of a Person**
- **Includes “common” and “expanded” options**
- **Includes implementation guidance**
- **Developed in consultation with a wide range of stakeholders, including TransCare BC and SMEs at the University of Victoria**



Alignment with HL7 Gender Harmony Model

- **Standard includes:**

- Name Used*
- Gender Identity*
- Pronouns*
- Recorded Sex or Gender*
- Sex Parameter for Clinical Use*
- Administrative Gender~
- Sex Assigned at Birth~
- Sexual Orientation

***Aligns** with HL7 Gender Harmony Model and Cross-Paradigm Implementation Guide

~Referenced in HL7 Gender Harmony Model and Cross-Paradigm IG (as a type of Recorded Sex or Gender)

Next Steps: Where do we go from here?

- **CIHI will be conducting additional engagement**
 - Provinces and Territories
 - Indigenous communities and individuals with lived experience outside of British Columbia
 - Interested in participating? Please e-mail datastandards@cihi.ca.
- **Ongoing discussions regarding governance of these standards**
- **pan-Canadian GSSO data standards to be released as part of v1 of the p-CHDCF in September 2024**



