

Results of CIHI's Sex and Gender Environmental Scan

Sex and Gender Working Group Meeting

Canadian Institute for Health Information

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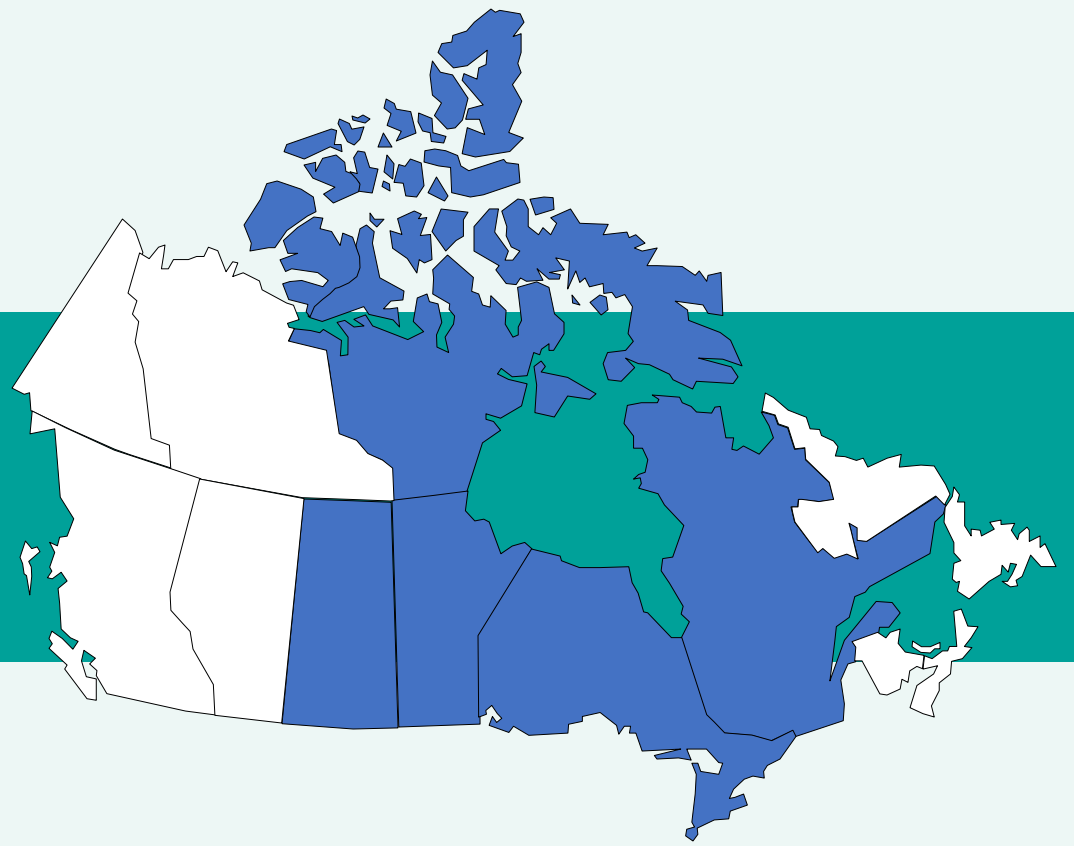


Outline

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



Central Region



Key findings from Quebec

Stakeholders Engaged: Ministère de la Santé et des Services sociaux (MSSS), Ministère de la Justice, Régie de l'assurance maladie du Québec (RAMQ)



Current State

- The collection of sex data in the Hospital Information System (HIS) is based on the Medicare number (medical insurance number).
- RAMQ currently collects Sex (male or female). Soon to also include X.
- Hundreds of HIS and Electronic Medical Record (EMR) solutions used across the province with no standardization on the capture of gender identity.
- Systems generally do not distinguish between sex at birth and gender (or legal sex).

Key findings from Quebec cont'd



Challenges

- Professional and/or physician practices and RAMQ remuneration are standardized. Some procedure codes are currently impossible to bill so physicians must go through a special justification procedure to be paid.
- Complexity of adapting systems (e.g., hundreds of outdated HIS and EMR systems, integration needs to be planned with several partners, etc.).
- Significant terminology changes will be required for some laws, regulations, standards of practice, etc.

Future State

- Ongoing work to develop Quebec guidelines on gender markers, as a follow-up to recent changes to the Civil Code. The MSSS is collaborating and has set up an internal committee to provide input into the analysis.

Key findings from Ontario

Stakeholders Engaged: Ministry of Health and Long-term Care & Ontario Health



Current State

- Ontario's Registered Persons Database (RPDB) is used for health care registration and is based on the Vital Statistics legislation.
 - Only Sex information is collected (Male, Female). This drives the provider billing process.
- The Provincial Client Registry solution is integrated with many clinical systems across the province (e.g., Lab Information System, Drug Repository, Immunization Registry, etc.).
 - Administrative Gender is collected as Male, Female, Other, Unknown.
- Some hospitals (e.g., the Centre for Addiction and Mental Health) capture gender identity information in a structured manner but this is not done consistently across all clinical systems (e.g., HIS, EMRs, etc.).

Key findings from Ontario cont'd



Challenges

- Ontario Health (OH) is the result of a merger of many different organizations. Many different sources of truth for sex and gender information need to be reviewed and aligned.
 - Requires strong data governance processes.
- The Data Health Information Exchange (DHIEX) project will undertake the implementation of any changes, but it's not clear which systems will be impacted.

Future State

- Ontario Health is collaborating with CIHI and Canada Health Infoway on a common data model for interoperable health information in Canada. This will include sex and gender information.
- The Toronto Central LHIN has also been working on collecting sociodemographic data for health equity, including sex and gender information.

Key findings from Manitoba

Stakeholders Engaged: Manitoba Health, Shared Health Manitoba, Prairie Mountain Health, Winnipeg Health Authority, Southern Health & Cancer Care Manitoba



Current State

- Manitoba's iRegistration solution for health care insurance captures Administrative Sex (Male, Female, X) based on Vital Statistics legislation.
 - This information flows into the Provincial Client Registry (PCR) where X is mapped to Undifferentiated.
- The provincial HIS solution is integrated with the Provincial Client Registry.
 - Collects Administrative Gender as Male, Female and Undifferentiated.
 - If Gender Identity information is collected for clinical purposes, it would be captured as a clinical note in an unstructured form.
- Certified EMR vendors capture Sex as Male, Female or Undetermined.
- The Cancer Care and Cancer Patient Registries capture more structured values for Gender Identity.

Key findings from Manitoba cont'd



Challenges

- Do not have a standard collection process for sex and gender information.
- Difficulty determining which standards to choose; there are many national and international standards.
- Screening Programs are constrained by iRegistration data. For example, can only send out invitations for pap tests to individuals whose sex is female.

Future State

- Beginning to collaborate with various groups to engage communities (e.g., transgender clinic).
- Started to engage patients to inform requirements for self-identification of race, indigenous status and gender identity, but will need training for clinicians to be able to ask questions respectfully. The next step is to engage clinicians.

Key findings from Nunavut

Stakeholder(s) Engaged: Nunavut Department of Health



Current State

- One clinical information system is currently used across the territory.
 - Sex at Birth is captured as Male, Female or Unknown.
 - Legal Sex is captured as Male, Female, Non-Binary, Other or Undifferentiated.
- One Medical Services Plan solution is used for health care registration.
 - Sex is captured as Male or Female.
- Much data still exists on paper. Nunavut is working to migrate to digital across all communities.

Key findings from Nunavut cont'd



Challenges

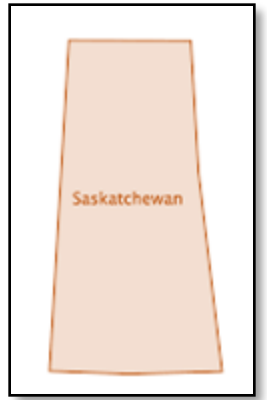
- Health care providers require more education regarding how and when to ask patients for sensitive information.
- Lack of trust between government and patients. Nunavut is working to establish new privacy legislation, with input from patients.
- Extensive patient travel to other jurisdictions to receive medical care (e.g., to Ottawa, Toronto, Winnipeg, etc.). Integrating their patient record information from outside of Nunavut is challenging.

Future State

- Nunavut is engaged with CIHI, Canada Health Infoway and others to identify new opportunities for sex and gender standards and the sharing of information.
- Once established, they intend to include these standards in their integration engine (for Client Registry, Provider Registry, etc.).
- Recognition of the need to standardize how data is used from a reporting perspective, including for public health surveillance. Data analytics will be a focus moving forward.

Key findings from Saskatchewan

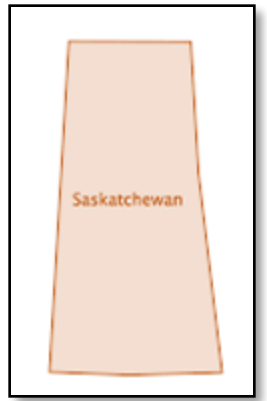
Stakeholders Engaged: Saskatchewan Ministry of Health , Saskatchewan Health Authority & eHealth Saskatchewan



Current State

- Saskatchewan has a Person Health Registration System (PHRS) Shared Client Index which populates many applications such as their HIS and WinCIS Registration System.
 - Only Sex at Birth is collected with values of Male, Female and Unknown.
- There are at least 200 different systems used across the province. It's unclear what data is collected for sex and/or gender information beyond that which comes from the PHRS system.

Key findings from Saskatchewan cont'd



Challenges

- Lack of standardized gender identity information being collected.
- Lack of systems integration. Individuals will change their sex and/or gender in one place and expect that it will change in others (e.g., pharmacies).

Future State

- No plans to improve data capture in future. Attributed to a lack of leadership and coordination.

