

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)
 - Western Canada (November)
- **Next steps for pan-Canadian GSSO data standards**



Results of provincial/territorial and vendor engagement

Provincial/territorial and vendor engagement

- **With the support of an external consultant, CIHI engaged with the provinces and territories, as well as major EMR and HIS software vendors, to better understand the sex and gender data that is currently being collected within the jurisdictions, including the flow of information between systems.**
 - Update to an environmental scan that Canada Health Infoway had completed in 2019.
- **Conducted 12 one-hour interviews with provincial and territorial stakeholders to gather input on the current state, challenges and opportunities for the collection and use of sex and gender data standards in their jurisdictions.**
- **Structured questionnaires and surveys were developed to help guide the engagement.**

What sex and gender data is being collected?


Category	Values	YK	NWT	NU	BC	AB	SK	MB	ON	QC	NB	NS	NF	PE	EPIC	CERNER	MEDITECH	TELUS	INTRA-HEALTH
SEX	Male	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
	Female	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
At Birth, Legal Sex, Administrative	Unknown	X	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X
	Undifferentiated			X	X			X	X		X					X	X		
Gender	X (mostly for MSP)	X	X			X		X		X		X			X				X
	Not Recorded on Birth Certificate					X									X				
	Other	X		X	X				X				X				X	X	
	Non-Binary			X													X		X
GENDER Gender Identity, Preferred Gender	Female				X	X		X	X				X		X	X		X	X
	Male				X	X		X	X				X		X	X		X	X
	Transgender							X										X	
	Transgender M to F				X	X			X				X		X	X			
	Transgender F to M				X	X			X				X		X	X			
	Intersex				X	X			X				X		X	X		X	X
	Questioning					X			X						X				
	Prefer Not to Answer					X			X				X		X			X	
	Two-Spirit				X	X			X				X		X	X		X	X
	Non-Binary				X	X									X	X			X
	Cis				X											X			
	Gender Creative				X											X			
	Agender				X											X			

Key findings from P/T engagement

- Overall lack of standardization of sex and gender data capture and use both *within* and *across* provinces and territories.
- Definitions for sex and gender information varied greatly as did the collection processes and use for administrative, clinical and analytical purposes.
- Some provinces captured structured gender data, but generally only in one system (e.g., HIS, EMR) or jurisdiction.
- Processes for collection of Sex at Birth / Legal Sex were similar across most of the P/Ts for vital statistics recording and registration processes for health care insurance cards.
 - However, the use of these values in downstream workflows (e.g., hospital or clinic registration, physician billing) varied greatly across P/Ts.

Common challenges

- **System limitations.**
- **Lack of standardization of concepts, names, definitions, values available across systems.**
- **No source of truth.**
- **Lack of lived experience input into the requirements for sex and gender information capture.**
- **Clinicians and front-line staff lack the training and education on how to ask potentially sensitive questions.**
- **Patient/client lack of trust in government agencies and the potential use of sensitive information.**



There are so many different standards groups with so many different standards and we're constantly struggling to keep up with who is doing what.

Participant from Newfoundland and Labrador

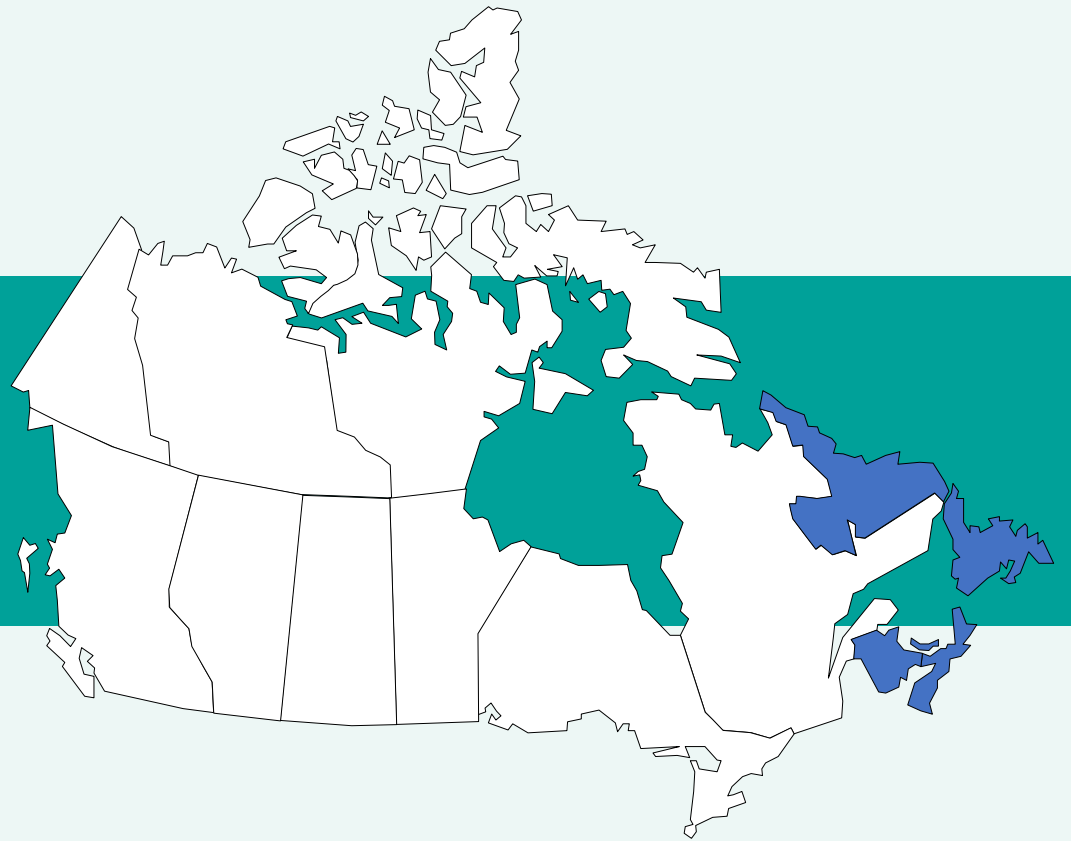
Key findings from vendor engagement

- **All vendor solutions capture some form of Sex (at Birth, Legal Sex, Administrative Gender) for administrative purposes.**
 - Male, Female and Unknown were common values. Other values varied across solutions.
- **All vendor solutions (except for one), enabled the capture of structured, coded values for Gender (Gender Identity, Preferred Gender). However, the only common values were Male, Female, Intersex and Two-Spirit. All other values varied across solution.**
- **Vendors expressed that they would be open to adopting a national standard within their databases but cautioned that local customer requirements may supersede this.**

Key Findings by Province/Territory



Eastern Region



Key findings from Newfoundland

Stakeholders Engaged: Newfoundland and Labrador Centre for Health Information & Government of Newfoundland



Current State

- Most of Newfoundland's current systems are limited to the capture of Sex as Male, Female and Unknown (sometimes X).
- In the process of procuring a new provincial EHR system that will allow for more flexibility for the capture of gender identity.
- The provincial EMR (MedAccess) captures standardized, structured data for Gender Identity (e.g., Intersex, Trans Female to Male, Trans Male to Female, Two Spirit, etc.).
- Undertook an extensive survey to capture requirements for sex and gender information across the health sector, so they have a good understanding of the requirements and concerns that need to be addressed.

Key findings from Newfoundland cont'd



Challenges

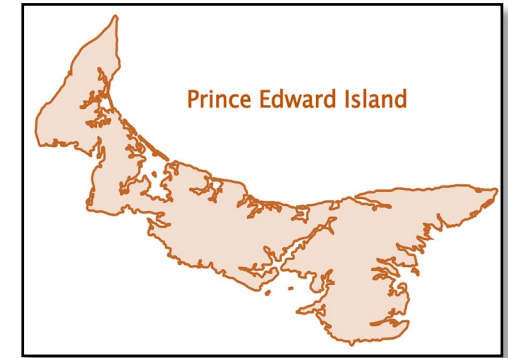
- System limitations: Want to be able to define lived gender and gender identity.
- Different requirements for clinical care vs. patient inclusion vs. research.
- Many different standards group and standards: CHI, CIHI, HL7, StatsCan, etc.
- Need for clinician input and education.

Future State

- Plans to leverage survey findings and the outcomes of the Sex and Gender Working Group to inform the requirements of their provincial EHR solution.
 - May include organ inventories rather than gender or sex for some care areas (important for medical imaging/radiation concerns), gender identity for clinical use, etc.
- NL Health Accord's 10-year plan is to change the face of health care and to expand on SDOH data to provide fair and equitable care. This will be included in the new EHR.

Key findings from Prince Edward Island

Prince Edward Island was unable to participate in the interview process, but the Environmental Scan was updated to reflect what is currently collected in their provincial HIS and EMR.



Current State

- Systems are limited to the capture of Sex as Male, Female, and Unknown.
- No comprehensive collection of gender related data.

Key findings from Nova Scotia

Stakeholders Engaged: Nova Scotia Department of Health and Wellness & Nova Scotia Health Authority



Current State

- Lack of standardized, structured, sex and gender data being collected or used:
 - Vital Statistics system allows for the capture of Sex as Male, Female, Unknown or X.
 - Medical Services Insurance (which is outsourced) does not support the value of Unknown.
 - Client Registry is integrated with many other systems for client demographics, but only contains Male or Female for Administrative Gender.
- Gender identity is not currently captured in a structured way across clinical systems (e.g. HIS, EMR).
- One Person One Record initiative is under way that will include an updated HIS solution where data collection is aligned with the current CIHI 2-step process of capturing sex at birth and gender identity information.

Key findings from Nova Scotia cont'd



Challenges

- Lack of standardized, structured sex and gender information due to system limitations.
- There is a need for clinician education regarding how to request sensitive information.

Future State

- Continued participation in the Sex and Gender Working Group. Along with the One Person, One Record initiative, this is expected to inform what is captured in the new province-wide HIS solution.
- Anticipated that the Fair Care project will also help improve sex and gender data collection, but the current focus is on providing better race-based care.

Key findings from New Brunswick

Stakeholders Engaged: New Brunswick Department of Health



Current State

- Upgrading their Medicare system to collect better sex and gender information.
- Their Client Service Delivery System (CSDS) is trying to be more responsive to patient/client needs.
- Gender (used for administrative purposes) is currently represented by Male, Female, or Unknown.

Key findings from New Brunswick cont'd



Challenges

- Lack of understanding of the differences between sex and gender for clinicians, clerks and clients. Lack of clear definitions.
- Overuse of privacy legislation to prevent the data from being collected.
- Lack of input of those with lived experience into the data standards.
- Patients can be hesitant to provide sensitive information.

Future State

- Started discussions about changing how data is collected, from a client service standpoint.
- Established a community-led diversity group with participation from 2 Regional Health Authorities and people with lived experience.
 - They initiated the request for changes to the Client Service Delivery System (CSDS).



Questions?