

Update: Pan-Canadian Gender, Sex and Sexual Orientation (GSSO) Standards

Infoway Sex and Gender Working Group

Canadian Institute for Health Information

Overview

- **Quick recap**
 - Current state: CIHI's sex and gender standards
 - Establishing pan-Canadian GSSO standards
- **Engagement with individuals with lived and/or living experience**
 - What we shared and heard
 - Lessons learned and keys to success
 - Updates based on feedback
- **Next Steps**



Current state: CIHI's sex and gender standards

- **Current standards reflect a 2-step approach of collecting both Sex at Birth and Gender**
 - Align with Statistics Canada's standards used in the 2021 Census of Population
 - Allow us to identify the transgender population within our data
- **Might not be appropriate or relevant for both *clinical care* and *health system use***

Sex at Birth

F = Female

M = Male

I = Intersex

UNK = Unknown

Gender

F = Female

M = Male

X = Another Gender

UNK = Unknown

NA = Not Applicable

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
Gender	Undifferentiated			X	X			X	X		X					X	X		
	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				

Establishing pan-Canadian GSSO Data Standards

- There is a clear need for pan-Canadian gender, sex and sexual orientation (GSSO) data standards that meet a broad range of health information needs
- Implementation of these standards will lead to a more equitable health care system for all Canadians
- Ability to leverage high quality work that has been done at the P/T level rather than re-invent the wheel



Recap: Development of pan-Canadian GSSO standards

- **2023: Engagement with P/Ts and EMR/HIS vendors**
- **Establishing pan-Canadian GSSO standards based on BC's GSSO Health Information Standard and Guidance**
- **Align with Canadian and international standards**
- **Sept. 2024: Draft standards released in v1 of the pan-Canadian Health Data Content Framework and Open Review**
- **NEW: Completed engagement of individuals with lived and/or living experience**
 - Partnership with Community Based Research Centre



Engagement Process

- CIHI partnered with the Community Based Research Centre (CBRC) to host a half-day engagement session following their annual Summit in November 2024
- The goal of the session was to obtain feedback on the proposed pan-Canadian GSSO standards, as well as the collection and governance of GSSO data
- Session was co-facilitated by Dr. Murdoch Leeies, a critical care and emergency department physician and member of the 2SLGBTQ+ community
- Shared an information sheet one week ahead of time with participants with the proposed standards and background information



What we shared

- Proposed concepts and value sets
 - A use case illustrating the value of a pan-Canadian GSSO standard
- Recommendations for GSSO data collection
- Examples of data governance frameworks



What we heard

- Major theme was trust; lots of concern about data protection and privacy
- Majority of feedback related to data collection and governance
- Community-based governance is crucial
- Some conflicting feedback (e.g. Sex at Birth and Gender Identity and what a clinician “needs to know”)
- Widespread support for an anatomical inventory
- Two-Spirit should be for Indigenous individuals only



Lessons learned

- 2SLGBTQIA+ individuals have experienced trauma in healthcare systems in Canada, resulting in a lack of trust
- Don't take negative feedback personally; to many participants, CIHI is representative of a larger system that has harmed them
- Importance of trauma-informed facilitation
- Engage with community earlier in the process
- Consider more participatory approaches to engagement
- Meaningful engagement is hard but worthwhile



Keys to Success

- Partnering with an organization that has established trust with the 2SLGBTQ+ community
- Recruiting a co-facilitator with lived experience
- Allowing individuals to provide feedback in multiple ways (e.g. verbally, on written handouts, in a post-engagement survey, etc.)
- Designing plain language materials, including a use case to highlight challenges with current state
- Openness and willingness to listen

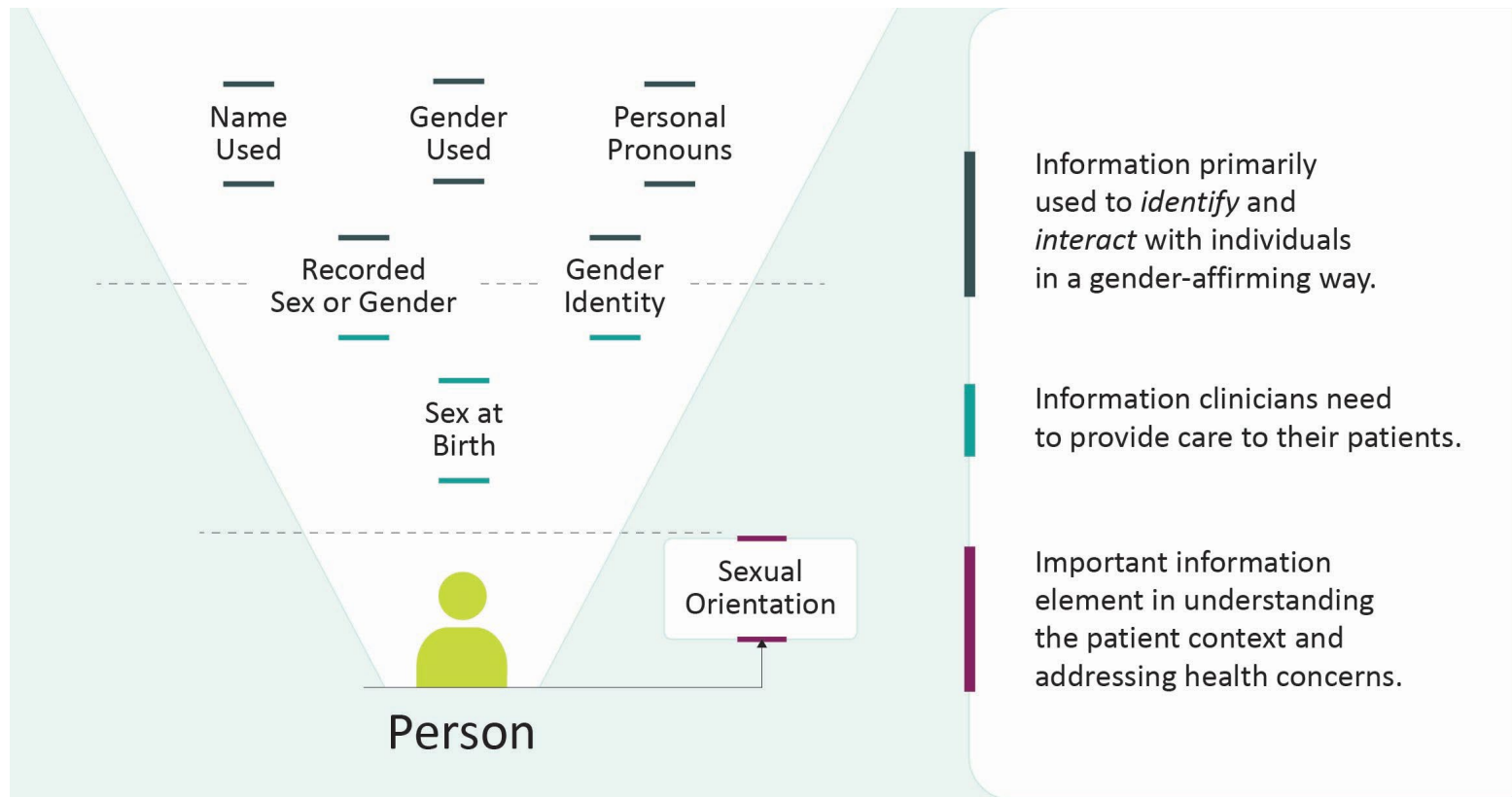


Updates based on feedback

- Removed Sex Parameter for Clinical Use from the pan-Canadian GSSO data standard pending further consultation and engagement
- Alphabetized our lists of response options within the value sets
- Added a “N/A” option for Personal Pronouns for cultures and languages that may not use pronouns
- Added “Queer” as a response option for Sexual Orientation
- Submitted RFCs to terminology standards (SNOMED CT CA, LOINC) - changing preferred terms, creating synonyms for concepts and requesting French translations



Updates based on feedback



Next Steps

- **Lots of interest in the standards from P/Ts and EMR/HIS vendors**
- **Technical specifications are available by request**
- **Updated standards to be included in September 2025 release of Pan-Canadian Health Data Content Framework**
 - Supplement will include guidance for GSSO data collection and governance
- **Ongoing engagement of individuals with lived and/or living experience**
- **Continued effort to align GSSO concepts in pan-Canadian and international standards**



