



Canada Health Infoway

Sex and Gender Working Group

Monthly (4th Tuesday) Zoom Meeting
October 22, 2024 at 9am PT / 12pm ET

Karen Courtney RN, PhD, University of Victoria
Shannon O'Connor, Manager, Data Standards, CIHI
Kelly Davison RN, CTSS, University of Victoria
Francis Lau PhD, University of Victoria (founding co-chair)

Agenda

1. Welcome and Land Acknowledgement
2. Ground rules for respectful dialogue
3. Purpose of Infoway Sex and Gender Working Group
4. Karen Courtney & Kelly Davison – Preliminary Results of the Scoping Review and Environmental Scan on Anatomical Inventories
5. Discussion
6. Schedule Review
7. Adjournment

Welcome and Acknowledgement

We respectfully acknowledge that the land on which we are hosting this meeting – the land that sustains us – includes the ancestral territories of many First Peoples. Canada Health Infoway recognizes the colonial injustices experienced by Indigenous Peoples, many of which continue today and continue to affect their health and well-being. I invite all attendees to reflect on the privilege they have of living, working and playing in the territory from which you are joining this call, and invite you to commit yourself with me to having an open heart and an open mind; to forging culturally safe spaces for and relationships with Indigenous Peoples including Two-Spirit people in Canadian healthcare; and in making a meaningful contribution to reconciliation through our shared work.

Ground Rules for Respectful Dialogue

- Express disagreement with ideas not personalities
- Share airtime
- Stay on topic - connect to what others have said
- Understand & learn from each other
- We are all equal. Leave rank at the door
- Listen respectfully especially when you disagree. Acknowledge you have heard the others
- Look for common ground
- Identify & test assumptions

Purpose

The Sex and Gender Working Group meets on the fourth Tuesday of each month at 9am PT/12pm ET. Our next meeting is November 26, 2024.

The purpose of this working group is to take action on modernizing GSSO information practices by:

- Examining the expanded definition, collection, use and sharing of sex-gender info in EHRs
- Discussing current research, practices, gaps and challenges
- Operationalizing the [Action Plan](#)

Action Plan

1. ***Vision and Goal*** – “Envisage an equity- and SGM-oriented health system that embraces diversity and aligns with other SGM-related initiatives.”
2. ***Engagement and Partnerships*** – “Engage organizations and communities across Canada to modernize GSSO information practices in EHRs that support equity-oriented health care and meet SGM needs.”
3. ***GSSO Terminology Workstream*** – “Establish a precise, inclusive, appropriate, evolving and multi-level GSSO terminology...”
4. ***Enabling EHR Systems*** – “Adopt a common set of EHR functions...”
5. ***GSSO Policy/Practice Guidance*** – “Integrate and tailor GSSO data collection...”
6. ***Education and Training*** – “Educate and train health care staff to enhance their capacity to provide culturally competent and safe care...”
7. ***Central Hub for Coordination*** – “Establish a central hub to liaise, guide, assist and monitor the progress of this action plan over time.”

Environmental Scan & Scoping Review

- Environmental Scan
 - Review of public information – Canada; English & French between November 2023 – April 2024
 - Team: Kelly Davison, Amédé Gogovor, Karen Courtney
 - Manuscript submitted for publication
- Scoping Review
 - Review of academic literature; no geographic restriction; English & French between December 2023 – August 2024
 - Team: Kelly Davison, Jess Crawford, Mikayla Hunter, Francis Lau, Karen Courtney, Janice Linton
 - Protocol available: <https://doi.org/10.17605/OSF.IO/W73UY>
 - Manuscript in progress

Environmental Scan Results

- Searched 1,679 individual websites (1,494 English; 185 French)
- Approximately 9,497 sites were screened
- 7 unique English sources located (2 standards, 1 clinical practice guideline, a forum post, 2 briefings and 1 internet article)
- No French sources located

Environmental Scan Results - Sources

Citation	Definition	Design	Use
Canadian Association of Radiologists. (2010). Performing diagnostic obstetric ultrasound examinations: CAR practice guidelines.	Yes	Yes	Yes
Alberta Medical Association. (2019). Initial assessment for gender dysphoria.	No	Yes	Yes
Rainbow Health Ontario. (2019). Brief to the Standing Committee on Health (HESA) regarding LGBTQI2S health in Canada.	No	Yes	Yes
Lau, F. (2021, March). Health information science: Supporting the health system with information management and technology [PowerPoint slides]. University of Victoria.	No	No	Yes
Canada Health Infoway Sex-Gender Working Group Forum. (2023). HL7 draft statement for anatomical inventories: Person characteristics project.	No	No	Yes
BC Ministry of Health. (2024, July). Gender, sex and sexual orientation standard and guidance (Version 3.1). Government of British Columbia.	Yes	Yes	Yes
Alberta Health Services. AHS garners award for diversity & inclusion. Alberta Health Services	No	No	Yes

9 Reference list and website list available upon request

Environmental Scan Results - Definitions

- 2 sources
 - “...presence or absence of sex-related anatomic structures [and] can be used to provide additional context via SPCU” BC GSSO Standard
 - “An ultrasound survey of fetal anatomy” CAR practice guideline

Environmental Scan – Results Design Components

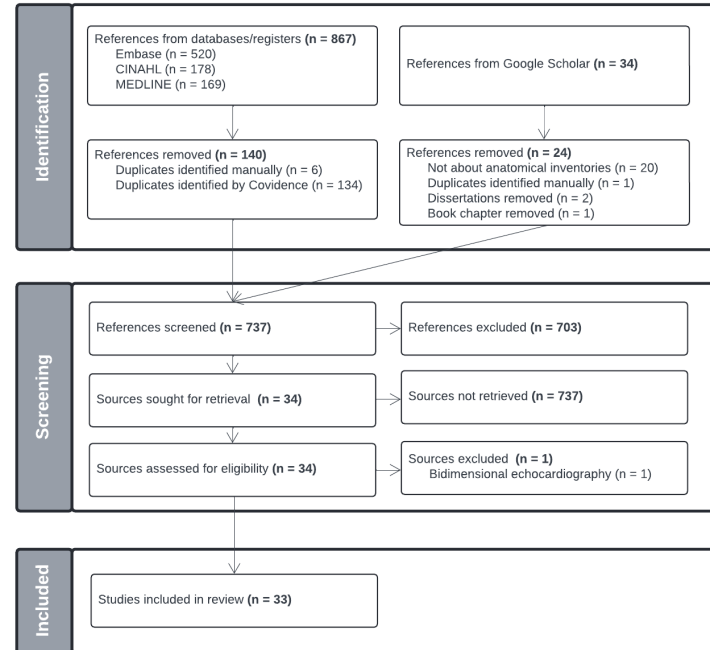
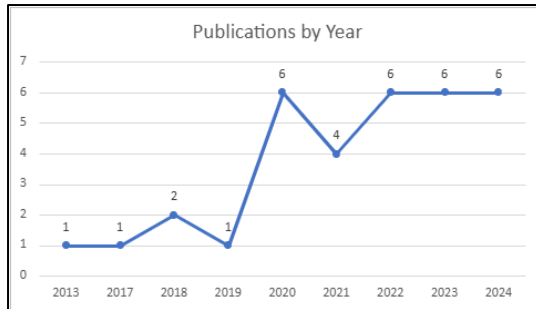
- 5 sources
 - Data fields that can reduce barriers to clinical care or screening or prevention of mis-gendering/outing - Rainbow Health Ontario
 - Anatomy specific to the type of exam and associated organs (chest: lungs, heart axis, size and position, heart four chamber view, cardiac outflow tracts) - CAR practice guideline
 - Anatomy specific to purpose of clinical encounter (presence/absence of: breast, ovaries, uterus, testes, and hair including face, scalp, and body hair as appropriate) - AMA practice guideline
 - Specific list of sex-related organs with references to controlled medical vocabulary (breast(s), uterine cervix, fallopian tube, ovary, penile structure, testes, uterus, and vagina and additional design considerations for prostheses, devices and organ laterality) - BC GSSO Standard
 - Development of anatomical inventories with HL7 FHIR – SGWG post

Environmental Scan Results - Uses

- 2 sources – specific clinical uses
 - Radiology - CAR practice guideline
 - Gender assessment - AMA practice guideline
- 5 sources – general uses
 - Documentation and exchange of clinical information – SGWG
 - Elimination of clinical assumptions, reduction in barriers to care, improvement in screening, avoidance of mis-gendering/outing – Rainbow Health Ontario & UVic presentation
 - Development of person-centred decision support systems – BC GSSO standard
 - Use with gender, affirmed name and pronouns – Alberta Health Services

Scoping Review – Preliminary Results

- 33 articles
- 17 articles provided meaningful information on anatomical inventories



Reference list available upon request

Scoping Review – Preliminary Results - Definition

- *A documented list of the organs that a person does or does not have and may also include information about when an organ is transplanted or artificially constructed, or about organs and tissues that a person has retained.*

SGWG Feedback

- *A documented list of the organs that a person does or does not have and may also include information about when an organ is transplanted or ~~artificially~~ ~~surgically~~ constructed, or about organs and tissues that a person has retained.*

Scoping Review – Preliminary Results - Attributes

- Much of the existing literature on anatomical inventories has focused on sex-related organs.
- The following sex-related organs appear in multiple articles: breasts, uterus, ovaries, cervix, vagina, penis, testes, prostate and urethra.
- Some authors have suggested anatomical inventories should be used in conjunction with surgical histories and medication or hormone inventories.
- Recommendation to de-couple procedures and diagnoses from sex at birth or administrative sex.

Scoping Review – Preliminary Results - Uses

- Many articles noted use for transgender, non-binary and gender diverse people; some articles suggested use for all people – particularly cancer screening
- Uses for both primary and acute care settings
- Accurate decision making
- Patient safety
- Healthcare quality
- Care and treatment planning
- Cultural competence
- In conjunction with surgical history, medication information and hormonal inventories
- No standard collection practices

Discussion

- Create things from other body parts / sources. Tracking of sources.
- Is it human tissue, material, etc. Explicit.
- For example, transvaginal slings, corneal implants.
- Research opportunities: menopause in gender diverse people.
- Lack of evidence can confound our efforts.

Schedule and Topics

Month	Infoway SGWG Meetings - 4 th Tuesday Each Month
Jan	Tyrone Curtis, PhD – Considering sexual orientation identity v. behaviour
Feb	Shannon O'Connor – Est. pan-Canadian GSSO Data Standards: Next steps for engagement of individuals with lived experience
Mar	Kelly Davison, Facilitator – Update on the HL7 International Anatomical Inventory and Person Characteristics Project
Apr	Mikayla Hunter and Morgan Stirling – Gender and sexual minority representation in cancer research
Apr	Nicole Blum, Licensed Genetic Counsellor – <i>Representing gender in genetic counseling practice and records</i>
May	Jessy Dame, Advisory Member, UBC Centre for Gender and Sexual Equity – Indigenous Gender Diversity (draft title)
Jun	Ellen Odai Alie, Director, Medical Imaging, The Ottawa Hospital – Ottawa Hospital's Organ Inventory work
Jul	
Aug	
Sep	Dr. Murdoch Leeies – Implementing GSSO data collection on Manitoba
Oct	Karen Courtney & Kelly Davison – Anatomical inventories environmental scan results
Nov	Kelly Davison, Facilitator – Update on the HL7 International Anatomical Inventory and Person Characteristics Project
Dec	<i>No meeting</i>



Canada Health Infoway

Thank you!

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