Canada Health Infoway

Sex and Gender Working Group

Monthly (4th Tuesday) Zoom Meeting
May 28, 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. Consultation: Intersex data feasibility study – Statistics Canada
5. Kelly Davison and Karen Courtney – Update on progress on the Proposed Action Plan
6. Discussion
7. Schedule Review
8. Adjournment

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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.

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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

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Purpose

The Sex and Gender Working Group meets on the fourth Tuesday of each month at 9am PT/12pm ET. Our next meeting is June 25, 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

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Consultation: Intersex data feasibility study – Statistics Canada

Statistics Canada, in collaboration with Women and Gender Equality Canada, is conducting a study to examine the feasibility of collecting data specific to the intersex population. As part of a targeted consultation, we are reaching out to specific subject-matter experts, data users and other stakeholders such as yourself. The objective of the consultation is to gather feedback on possible options for survey questions, specific terminologies, data needs, as well as other issues related to collecting data about the intersex population.

This study is taking place in the context of Canada's first ever federal 2SLGBTQI+ Action Plan that seeks to strengthen data and evidence-based decision-making for 2SLGBTQI+ populations, which include the intersex population. With no national level data specific to intersex people currently collected in Canada, the launch of the Action Plan has underscored the need to examine possible approaches to data collection for this population.

If you are interested in participating in the consultation, please fill out the attached consultation guide and send it to statcan.cgdis-csgdi.statcan@statcan.gc.ca by June 5, 2024.

To broaden the reach of this consultation, feel free to share this invitation with those who are knowledgeable about this population, those with lived experience, or who are likely to have data needs specific to intersex people.

Thank you for your assistance. Your input is crucial in this consultation process and we would value your feedback.

Centre for Gender Diversity and Inclusion Statistics, Statistics Canada

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Action Plan

7. Central Hub for Coordination

1. Vision and Goal

2. Engagement and Partnerships

3. GSSO Terminology Workstream

4. Enabling EHR Systems

5. GSSO Policy/Practice Guidance

6. Education and Training

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Action Plan #7

Central Hub for Coordination – "Establish a central hub to liaise, guide, assist and monitor the progress of this action plan over time."

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Action Plan Item #1

Vision and Goal – "Envisage an equity- and SGM-oriented health system that embraces diversity and aligns with other SGM-related initiatives."

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Action Plan #1 & #7

- Federal 2SLGBTQI+ Action Plan
- Egale Rainbow Hub
- 2SLGBTQ+ Health Hub
- Digital Health Equity Group
- U of T and CAMH
- StatCan

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Action Plan Item #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."

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Action Plan #2

- **2021**
  - HL7 Gender Harmony Informative Model
  - Action Plan to Modernize GSSO Information Practices in Canadian EHRs
- **2022**
  - Gender Harmony Project – Cross-paradigm implementation work
  - StatCan – LGBTQ in Census
  - CIHI – Environmental Scan

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Action Plan #2

- **2023**
  - BC GSSO HIS Standard & Guidance - published
  - HL7 Gender Harmony Cross-Paradigm Implementation Guide – published ONC
  - ISO TC 215 - completed
- **2024**
  - CIHI pan-Canadian Health Data Content Framework & Data Model
  - HL7 International Anatomical Inventories and Person Characteristics Project

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Action Plan Item #3

GSSO Terminology Workstream –

"Establish a precise, inclusive, appropriate, evolving and multi-level GSSO terminology…"

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Action Plan #3

- Mindmapping (SGWG + Nova Scotia)
- Harmonization (Francis Lau, PhD)
- GSSO Terminology Workstream (multi-jurisdictional)
  - Concept analysis
  - Change request development
  - Requests for Change
- BC GSSO HIS Standard Subsets (July, 2024)
- CIHI pan-Canadian Health Data Content Framework (under review)

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Action Plan #3 – Gender Identity

System	Code System URI / ID	Code	Concept	Display (English)
SNOMED CT International Edition	http://snomed.info/sct	446141000124107	Identifies as female gender (finding)	Woman / girl
SNOMED CT International Edition	http://snomed.info/sct	446151000124109	Identifies as male gender (finding)	Man / boy
SNOMED CT International Edition	http://snomed.info/sct	33791000087105	Identifies as nonbinary gender (finding)	Nonbinary
SNOMED CT CA Edition	http://snomed.info/sct	33771000087106	Identifies as Indigenous gender (finding)	Indigenous gender identity
SNOMED CT CA Edition	http://snomed.info/sct	51371000087107	Identifies as cisgender woman (finding)	Cisgender woman
SNOMED CT CA Edition	http://snomed.info/sct	51411000087106	Identifies as transgender woman (finding)	Transgender woman
SNOMED CT CA Edition	http://snomed.info/sct	51361000087103	Identifies as cisgender man (finding)	Cisgender man
SNOMED CT CA Edition	http://snomed.info/sct	51401000087109	Identifies as transgender man (finding)	Transgender woman
SNOMED CT CA Edition	http://snomed.info/sct	51351000087101	Identifies as agender (finding)	Agender
SNOMED CT CA Edition	http://snomed.info/sct	51381000087109	Identifies as gender fluid (finding)	Fluid gender identity
SNOMED CT CA Edition	http://snomed.info/sct	51391000087106	Identifies as transfeminine gender (finding)	Transfeminine
SNOMED CT CA Edition	http://snomed.info/sct	51421000087103	Identifies as transmasculine gender (finding)	Transmasculine
SNOMED CT CA Edition	http://snomed.info/sct	33801000087109	Identifies as Two-Spirit gender (finding)	Two-Spirit gender identity
SNOMED CT CA Edition	http://snomed.info/sct	51341000087104	Identifies as Indigiqueer gender (finding)	Indigiqueer gender identity

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Action Plan #3 – Pronouns

System	Code System URI / ID	Code	Concept	Display (English)
LOINC	http://loinc.org	LA29518-0	he/him/his/his/himself	he/him
LOINC	http://loinc.org	LA29519-8	she/her/her/hers/herself	she/her
LOINC	http://loinc.org	LA29520-6	they/them/their/theirs/themselves	they/them
LOINC	http://loinc.org	LA29523-0	ze/zir/zir/zirs/zirself	ze/zir
LOINC	http://loinc.org	LA29521-4	xie/hir ("here")/hir/hirs/hirself	xie/hir
LOINC	http://loinc.org	LA29515-6	co/co/cos/cos/coself	co/co
LOINC	http://loinc.org	LA29516-4	en/en/ens/ens/enself	en/en
LOINC	http://loinc.org	LA29517-2	ey/em/eir/eirs/emself	ey/em
LOINC	http://loinc.org	LA29522-2	yo/yo/yos/yos/yoself	yo/yo
LOINC	http://loinc.org	LA29524-8	ve/vis/ver/ver/verself	ve/vis

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Action Plan #3 – Sexual Orientation

System	Code System URI / ID	Code	Concept	Display (English)
SNOMED CT	2.16.840.1.113883.6.96	20430005	Heterosexual	Heterosexual
SNOMED CT	2.16.840.1.113883.6.96	89217008	Female homosexual	Lesbian
SNOMED CT	2.16.840.1.113883.6.96	38628009	Homosexual	Gay
SNOMED CT	2.16.840.1.113883.6.96	42035005	Bisexual	Bisexual
SNOMED CT	2.16.840.1.113883.6.96	765288000	Sexually attracted to neither male nor female sex	Asexual
SNOMED CT	2.16.840.1.113883.6.96	51431000087101	Pansexual (finding) |	Pansexual
SNOMED CT	2.16.840.1.113883.6.96	1064711000000100	Undecided about sexual orientation	Unsure

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Action Plan #3 – Sex Parameter for Clinical Use

Code	System	Display	Definition
female-typical	http://terminology.hl7.org/CodeSystem/sex-parameter-for-clinical-use	Apply female-typical setting or reference range	Available data indicates that diagnostics, analytics, and treatments should consider best practices associated with female reference populations.
male-typical	http://terminology.hl7.org/CodeSystem/sex-parameter-for-clinical-use	Apply male-typical setting or reference range	Available data indicates that diagnostics, analytics, and treatments should consider best practices associated with male reference populations.
specified	http://terminology.hl7.org/CodeSystem/sex-parameter-for-clinical-use	Apply specified setting or reference range	Available data indicates that diagnostics, analytics, and treatment best practices may be undefined or not aligned with sex-derived reference populations. Additional information may be available in the form of comments and/or observations. The terms "Other" or "Complex" may be considered synonyms of "Specified".
unknown	http://terminology.hl7.org/CodeSystem/data-absent-reason	Unknown	The value is expected to exist but is not known.

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Action Plan Item #5

Enabling EHR Systems – "Adopt a common set of EHR functions…"

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Action Plan #5 – Improving Representation

	Demographics	Billing	History	Test Results	Commun.	Dec. Supp.	Analytics
Gender Identity	X				X	X	X
Name to Use	X				X		
Pronouns					X		
Sex Assigned at Birth	X	X		X		X	
AI&PC/ SPCU			X	X		X	X
Sexual Orientation	?				X		X

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Action Plan Item #6

GSSO Policy/Practice Guidance –

"Integrate and tailor GSSO data collection…"

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Action Plan #6

- Primary care
- Cancer care
- Acute care
- Ambulatory care
- Emergency room/triage
- Palliative and long-term care
- Mental health and substance use
- Maternity/obstetrics

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Discussion

- What are your thought on our progress?
- Where do you see opportunities for collaboration and partnership?
- What can we do to formalize a central hub?

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Schedule and Topics

Month	Infoway SGWG Meetings - 4th 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
	Kelly Davison, Facilitator – Update on the HL7 International Anatomical Inventory and Person Characteristics Project
Mar	*Mikayla Hunter and Morgan Stirling* – Gender and sexual minority representation in cancer research
Apr	*Nicole Blum, Licensed Genetic Counsellor* – Representing gender in genetic counseling practice and records
May	*Kelly Davison and Karen Courtney* – Update on progress on the Action Plan
Jun	*Ellen Odai Alie, Director, Medical Imaging, The Ottawa Hospital* – Ottawa Hospital's Organ Inventory work
Jul	
Aug	*Juniper Fedor* – Pathologist Assistant – Transgender and Gender Diverse Death Statistics
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	*No meeting*

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