HEALTH INFORMATION SCIENCE SEMINAR SERIES

MODERNIZING GENDER, SEX AND SEXUAL ORIENTATION INFORMATION PRACTICES IN CANADIAN ELECTRONIC HEALTH RECORD SYSTEMS

(GSSO in EHR)

March 10, 2021

Francis Lau PhD, Professor
On behalf of CIHR Planning Project Team, Infoway Sex-Gender Working Group, and Contributing Members from Organizations and Communities
Email: fylau@uvic.ca
… acknowledge with respect the Lekwungen-speaking peoples on whose traditional territories the University of Victoria stands; the Songhees, Esquimalt and the W_SÁNEC ("w’Saanich") peoples, whose historical relationship with the land continues to this day.

… each of you will join me and acknowledge the privilege we have of coming together in the spirit of respectful dialogue from the traditional territories of indigenous peoples from across this land known as Canada.
Agenda

1. What are the issues?
2. What did we do about it?
3. What did we find?
4. What’s in the action plan?
5. What’s next?
1. What are the issues?

- “I go by Jane … but my chart still has my previous name John on it, even when I have told the clinic to update it. Then they called out John at the desk, and looked at me funny when I answered, everyone was staring … it was awful …”

- A lesbian patient went to her women’s wellness exam, and was handed an After Visit Summary with patient instructions on avoiding sexually transmitted diseases for heterosexual patients. All she could think of was “… nothing on this page relates to me …”

- Rodrigo is a 40-year-old trans man who went to the clinic with pelvic pain and spotting. A biopsy determined that he had cervical cancer “… No one told me that I still need routine cervical Pap tests …”
LGBTQIA2 communities in Canada experience numerous health inequities ... data collection [should] be improved in order to obtain a more complete picture of the health of gender and sexual minorities in Canada.” [p2]
2. What did we do about it?

- **CIHR planning project** to create a coalition of organizations and communities to develop an action plan to improve the definition, collection and use of GSSO data in EHR systems for sexual and gender minorities (SGM)

- **Rapid reviews** – examined peer-reviewed and grey literature for current landscape, emerging issues and best practices

- **Environmental scan** – examined 52 databases and 55 data standards from 12 Canadian entities and 10 standards communities

- **Mind mapping & use cases** – modeled GSSO concepts and relationships with glossary of terms, and proposed use case scenarios and workflows

- **Group discussions** – held 8 presentations by leading practices, and 8 virtual sessions with 50+ participants from communities and organizations
3. What did we find?

- **Conflated single sex/gender data field with only male and female options**
  - Inconsistency in data field names and value options
  - Limited value options making SGM invisible
  - Expanded definitions challenging to implement in existing EHR systems

- **Key themes identified on issues and needs …**
  - Inclusive, culturally competent environment with precise GSSO terminology, standardized data collection policies
  - Guidelines for identifying and matching SGM patients with unique care needs
  - Use of anatomical inventories to remove sex and gender assumptions for ALL patients
  - Standardized GSSO data to guide care, support secondary use, expand evidence base on SGM health
  - Techno-socio-organizational aspects when implementing GSSO in EHRs
4. What’s in the action plan?  

1. Envisage an equity- and SGM-oriented health system vision and goal  
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs  
3. Establish GSSO terminology for patient care, health system use and research  
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data  
5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes  
6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need  
7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step  

This plan focuses on **what** actions are needed, with details on **who, how** and **when** to be discussed and established later
4. What’s in the action plan? … *Priorities*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes
6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need
7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step

**Priorities**

1 Vision/Goal 2-4 Foundational 5-6 Strategic 7 Immediate

Scope coverage, Implementation options, Migration stages, Readiness/Needs Assessment
4. What’s in the action plan? … **Action 3**

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. **Establish GSSO terminology for patient care, health system use and research**
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes
6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need
7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step
4. What’s in the action plan? … *Action 3*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
   - Terminology mind maps and glossary of terms
   - Data elements and value sets
   - Use case scenarios and workflows
Terminology mind map for Sex

Sex recorded at birth

Anatomic inventory

Hormone inventory

Surgical inventory

Concept

Purpose

Use

Mimics

Keywords/Abbreviations

References
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Refers to the gender that a person internally feels (gender identity) and/or the gender a person expresses (gender expression) in their daily life, including at work, while shopping or accessing other services, in their housing environment, or in the broader community. A person’s current gender may differ from what is typically expected based on the sex a person was assigned at birth and may differ from what is indicated on their current legal documents. A person’s gender may change over time.</td>
<td>Goldman et al.</td>
</tr>
<tr>
<td>Legal Gender</td>
<td>Gender recorded on primary official government documents such as birth certificates and passports.</td>
<td></td>
</tr>
<tr>
<td>Administrative Gender</td>
<td>Gender recorded on primary official government documents such as birth certificates and passports or on other documents such as health care cards or drivers licenses. A term used in most existing electronic health record systems that refers to either one’s sex or gender recorded and used for administrative purposes such as billing purposes. Also known as legal gender in some systems.</td>
<td>Burgess</td>
</tr>
<tr>
<td>Male Gender</td>
<td>This category includes persons whose current gender was reported as male. This includes cisgender and transgender persons who were reported as being male.</td>
<td>StatCan</td>
</tr>
<tr>
<td>Female Gender</td>
<td>This category includes persons whose current gender was reported as female. This includes cisgender and transgender persons who were reported as being female.</td>
<td>StatCan</td>
</tr>
<tr>
<td>Gender Diverse</td>
<td>This category includes persons whose current gender was not reported exclusively as male or female. It includes persons who were reported as being unsure of their gender, persons who were reported as both male and female, or neither male nor female.</td>
<td>StatCan</td>
</tr>
<tr>
<td>Gender Expression</td>
<td>Refers to the gender a person publicly expresses in their daily life, including at work, while shopping or accessing other services, in their housing environment or in the broader community.</td>
<td>StatCan</td>
</tr>
<tr>
<td></td>
<td>How a person enacts gender in their everyday life. May include name, grooming, clothing, comportment. There are many reasons why a person may not feel that it is safe to express their gender identity in certain circumstances. Thus, a person’s gender expression may or may not be a good representation of their gender identity.</td>
<td>Goldman et al.</td>
</tr>
<tr>
<td>Data elements and value options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender identity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pronouns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex assigned at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anatomic inventory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hormone inventory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgical inventory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual orientation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data elements and value options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender identity</strong></td>
<td>Intersex, Man, Nonbinary, Two-Spirit, Unknown, Woman</td>
<td></td>
</tr>
<tr>
<td><strong>Pronouns</strong></td>
<td>He/Him/His, She/Her/Hers, They/Them/Theirs, <em>Not listed-Free text</em>, Unknown, Unreported</td>
<td></td>
</tr>
<tr>
<td><strong>Sex assigned at birth</strong></td>
<td>Female, Intersex, Male, Unknown</td>
<td></td>
</tr>
<tr>
<td><strong>Anatomic inventory</strong>&lt;sup&gt;*&lt;/sup&gt;</td>
<td>Breast(s), Cervix, Fallopian tube(s), Ovary(ies), Penis, Prostate, Testis(es), Uterus, Vagina, Clitoris, Labia, <em>Not listed-Free text</em></td>
<td></td>
</tr>
<tr>
<td><strong>Hormone inventory</strong></td>
<td>Anti-androgen, Estrogen, Follicle stimulating hormone (FSH), Hormone replacement therapy (HRT), Progestin, Prolactin, Puberty blocker, Testosterone (TRT), <em>Not listed-Free text</em></td>
<td></td>
</tr>
<tr>
<td><strong>Surgical inventory</strong></td>
<td>Labiaplasties, Lipofilling, Liposuction, Metoidoplasty, <em>Not listed-Free text</em>, Orchiectomy, Penectomy, Penis lengthening, Phalloplasty, Salpingo-oophorectomy, Testicular implants, Urethral extension, Urethral shortening, Vaginoplasty, Vulvoplasty,</td>
<td></td>
</tr>
<tr>
<td><strong>Sexual orientation</strong></td>
<td>Sexual identity, Sexual attraction, Sexual partner, Sexual practice</td>
<td></td>
</tr>
<tr>
<td>Data elements and value options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>Gender identity</td>
<td>Intersex, Man, Nonbinary, Two-Spirit, Unknown, Woman</td>
<td></td>
</tr>
<tr>
<td>Man</td>
<td>Cisgender man, Transgender man/Trans man</td>
<td></td>
</tr>
<tr>
<td>Nonbinary</td>
<td>Agender/Genderless/Neutrois, Alternating gender, Bigender, Demiboy, Demigirl, Genderfluid, Genderqueer, Gender-nonconforming, Pangender/Polygender, Not disclosed, <em>Not listed-Free text</em>, Third gender, Transfeminine, Transmasculine</td>
<td></td>
</tr>
<tr>
<td>Woman</td>
<td>Cisgender woman, Transgender woman/Trans woman</td>
<td></td>
</tr>
<tr>
<td>Pronouns</td>
<td>He/Him/His, She/Her/Hers, They/Them/Theirs, <em>Not listed-Free text</em>, Unknown, Unreported</td>
<td></td>
</tr>
<tr>
<td>Sex assigned at birth</td>
<td>Female, Intersex, Male, Unknown</td>
<td></td>
</tr>
<tr>
<td>Anatomic inventory*</td>
<td>Breast(s), Cervix, Fallopian tube(s), Ovary(ies), Penis, Prostate, Testis(es), Uterus, Vagina, Clitoris, Labia, <em>Not listed-Free text</em></td>
<td></td>
</tr>
<tr>
<td>Hormone inventory</td>
<td>Anti-androgen, Estrogen, Follicle stimulating hormone (FSH), Hormone replacement therapy (HRT), Progestin, Prolactin, Puberty blocker, Testosterone (TRT), <em>Not listed-Free text</em></td>
<td></td>
</tr>
<tr>
<td>Surgical inventory</td>
<td>Labiaplasties, Lipofilling, Liposuction, Metoidoplasty, <em>Not listed-Free text</em>, Orchiectomy, Penectomy, Penis lengthening, Phalloplasty, Salpingo-oophorectomy, Testicular implants, Urethral extension, Urethral shortening, Vaginoplasty, Vulvoplasty,</td>
<td></td>
</tr>
<tr>
<td>Sexual orientation</td>
<td>Sexual identity, Sexual attraction, Sexual partner, Sexual practice</td>
<td></td>
</tr>
<tr>
<td>Circumstances, Data Fields and Value Sets</td>
<td>Registration</td>
<td>Scheduling</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>--------------</td>
<td>------------</td>
</tr>
<tr>
<td>Patient identification number</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chosen and legal name</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birthdate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administrative/legal gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effective date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Effective until date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pronouns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender identity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex recorded at birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organ inventory</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual orientation</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Use case scenarios and workflows

Figure 5. Sample Process of Collecting SOGi Data

4. What’s in the action plan? … Action 4

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
5. Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes
6. Educate & train staff to provide culturally competent and safe care, and educate patients to understand need
7. Establish a central hub to coordinate this action plan over time and continue national conversation as next step
4. What’s in the action plan? … Action 4

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
   - Data fields and terminology
   - Interfaces for inputs/outputs
   - Security and privacy
   - Data quality
   - Decision support rules
   - IT support
   - Governance
   - Implementation options
4. What’s in the action plan? … *Action 4 Examples*

1. Envisage an equity- and SGM-oriented health system vision and goal
2. Engage and partner with organizations and communities to modernize GSSO information practices to meet SGM needs
3. Establish GSSO terminology for patient care, health system use and research
4. Enable EHRs to collect, use, exchange and reuse standardized GSSO data
   - Data fields and terminology
   - Interfaces for inputs/outputs
   - Security and privacy
   - Data quality
   - Decision support rules
   - IT support
   - Governance
   - Implementation options
   - Examples from Fenway Health …
Current practice: Registration screen

Current practice: Registration screen

# EHR Form: Organ Inventory

## BREAST
- Congenital Absence
- Chest Reconstruction
- Bilateral Mastectomy
- Unilateral Mastectomy, R
- Unilateral Mastectomy, L
- Breast Augment/Implant(s)

## CERVIX
- Congenital Absence

## OVARY
- Bilateral Salpingo-Oophorectomy
- Unilateral Salpingo-Oophorectomy, L

## PENIS
- Phalloplasty/Metoidioplasty/Penile Transplant
- Erectile Device

## PROSTATE
- Prostatectomy

## TESTIS
- Testicular Implant(s)

## URETHRA
- Urethral Lengthening

## UTERUS
- Hysterectomy - Cervix Removed
- Hysterectomy + Cervix Remains

## VAGINA
- Colpocleisis - Closure of the Vagina
- Vaginoplasty

---

Clinical Decision Support (CDS)/Health Maintenance

Current Variables:
- Sex
- Age
- Problems/Disease Conditions
  - e.g. Diabetes
- Medications
  - e.g. Coumadin
- Observations
  - e.g. Blood Pressure > 220

Recommended Additional Variables:
- Sexual Orientation
- Gender Identity
- Sex Assigned at Birth
- Anatomical Inventory

Decision Support/Health Maintenance

Sex = Male
Age = 52 yo
Sex assigned at birth = Female

Anatomical Inventory
- Cervix
- Vagina
- Uterus
- Ovaries
- Breasts

Patient Due For:
- Cervical Pap Smear
- Mammogram
- ??????????

5. What’s the next steps

CIHR planning grant knowledge translation outputs

- Lau et al. Rapid review of GSSO documentation in EHRs. *JAMIA* 2020
- Lau et al. Environmental scan of sex and gender in EHRs – Analysis of public info sources. *JMIR* 2020
- Davison et al. Culturally competent GSSO info practices in EHRs. *JMIR Medical Informatics* 2021
- Action plan infographics, summary and full reports – Infoway Sex-Gender Working Group website
  - Commentaries, abstracts, blogs, special issues, presentations, interviews …

MSFHR REACH grant by Dr. Karen Courtney => Mar 2021 …

- Share previous findings
- Develop KT tools for applying action plan in different contexts
- Develop an Implementation Strategies Guidebook
- => GSSO Terminology, EHR specifications, policies & practice, implementation settings
5. What’s the next steps …. **Terminology and EHR**
Selected References

2. Canada Health Infoway. Sex and Gender Working Group - link
3. Canada Health Infoway. GSSO Action Plan Infographic, Summary and Full Reports – link
4. Davison K, Queen R, Lau F, Antonio M. Culturally competent gender, sex, and sexual orientation information practices and electronic health records: Rapid review. JMIIR Medical Informatics 2021; 9(2). -link
5. HL7 International. HL7 Informative Document: Gender Harmony – Modeling Sex and Gender Representation, Release 1. Sponsored by HL7 Vocabulary Work Group. -link
7. Lau F, Antonio M, Davison K, Queen R, Devor A. A rapid review of gender, sex and sexual orientation documentation in EHRs. JAMIA 2020; 27(11):1174-83. -link
10. ONC Interoperability Standards Advisory. Section I: Vocabulary/Code Set//Terminology Standards. SOGI. link
11. Treasury Board of Canada Secretariat. Modernizing the Government of Canada’s Sex and Gender Information Practices: summary report, April 8, 2019. -link
Questions? Comments?
thank you