



Michael Smith Foundation for Health Research (MSFHR) REACH Grant Knowledge Translation Topics:

Review of Gender, Sex and Sexual Orientation (GSSO) Policy and Practice– Part 1

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We 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 where you are located.

Agenda

1. Meeting Schedule
2. GSSO Action Plan
3. Culturally Safe GSSO Information Practices & Policies
 - Why is this information being collected?
 - What information should be collected?
 - How can information be collected?
 - Who should have access to this information?
 - How should information be displayed?
4. Next Steps

Session 1
(September 14)

Session 2
(October 12)

1. Meeting Schedule

MSFHR REACH Grant Special Topics Meetings

Second Tuesdays of the Month

- May 11
- June 8

Digital Health/EHR Functions

- July 13
- August 10

Policy & Practice

- September 14
- October 12

Settings

- November 9 - Primary Care
- November 23 – Acute & Tertiary Care

Fourth Tuesdays of the Month

Scheduled Updates to the Infoway SGWG

- May 25 – Terminology
- June 22 – Terminology
- July 27 – EHR Functions
- August 24 – EHR Functions
- September 28 – Policy & Practice
- October 26 – Policy & Practice
- December 14 – REACH project update

2. GSSO 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 *+digital health* 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

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The Why

CURRENT INEQUITABLE INFORMATION PRACTICES


PATIENT HAS A SEVERE FALL
CANNOT STAND AND IS CONCERNED THAT THEY MAY HAVE BROKEN THEIR LEG.




AMBULANCE IS CALLED
PARAMEDIC ASKS THE PATIENT WHETHER THEY ARE MALE OR FEMALE BASED ON QUESTIONS IN THE DIGITAL HEALTH SYSTEM.




REGISTRATION IN A CROWDED EMERGENCY ROOM
CLERK ASKS LOUDLY IF THERE IS ANOTHER NAME, AS THEY CANNOT FIND ANY MATCH. PATIENT PROVIDES THEIR BIRTH NAME.




TRIAGE NURSE VISIT
NURSE ASKS THE PERSON THEIR NAME AND FINDS THAT IT DOES NOT MATCH THE INTAKE FORM. THE NURSE ADDS THE PERSON'S NAME AND GENDER TO THE ENCOUNTER NOTE.




SIGNAGE IN THE EMERGENCY ROOM
WHILE WAITING THE PATIENT IS DIRECTED TO WASHROOMS WITH BINARY SIGNAGE.




EMERGENCY ROOM CARE VISIT
DOCTOR REFERS TO THE ELECTRONIC HEALTH RECORD DURING THE VISIT AND REPEATEDLY USES INCORRECT PRONOUNS.




X-RAY VISIT
A MONITOR IN THE WAITING ROOM SHOWS THE ORDER OF THE CUE, BY DISPLAYING PATIENT'S FIRST NAMES. THE PATIENT'S BIRTH NAME IS ON DISPLAY FOR OTHER PATIENTS TO SEE.




DOCTOR CONSULT
DOCTOR CONSULT IS DELAYED AS THE X-RAY RESULT HAD BEEN FLAGGED FOR REVIEW WHEN THE DIGITAL HEALTH SYSTEM IDENTIFIED A MISMATCH ON PATIENT'S GENDER.



PATIENT DISCHARGE SUMMARY NOTE
UPON DISCHARGE PATIENT IS GIVEN A FORM THAT LISTS THEIR INCORRECT NAME AND GENDER.



BILLING
THE PATIENT IS REMINDED OF THEIR HEALTHCARE ENCOUNTER WHEN AN AMBULANCE BILL ARRIVES 2 WEEKS LATER AND THEIR INCORRECT NAME AND GENDER ARE LISTED.



GENDER AFFIRMING INFORMATION PRACTICES


PATIENT HAS A SEVERE FALL
CANNOT STAND AND IS CONCERNED THAT THEY MAY HAVE BROKEN THEIR LEG.



AMBULANCE IS CALLED
PARAMEDIC ASKS THE PATIENT THEIR NAME AND GENDER AND RECORDS THE INFORMATION ON THE ELECTRONIC ADMINISTRATIVE FORM.



REGISTRATION IN A CROWDED EMERGENCY ROOM
FRONT DESK CLERK IS ABLE TO FIND THE PATIENT'S ELECTRONIC HEALTH RECORD AND GREET THE PERSON BY THEIR NAME.



TRIAGE NURSE VISIT
ELECTRONIC HEALTH RECORD PROMINENTLY DISPLAYS PRONOUNS AND PATIENT'S NAME, WHICH THE TRIAGE NURSE USES IN THEIR CARE INTERACTIONS WITH THE PATIENT




SIGNAGE IN THE EMERGENCY ROOM
WHILE WAITING THE PATIENT NOTICES SIGNAGE IS GENDER NEUTRAL.



EMERGENCY ROOM CARE VISIT
ALL STAFF AND CLINICIANS ARE WEARING PRONOUN BUTTONS.



X-RAY VISIT
ALL PATIENTS ARE GIVEN A FORM THAT ASKS NAME IN USE, PRONOUNS, CURRENT LOCATION OF REPRODUCTIVE ORGANS AND PREGNANCY STATUS.



DOCTOR CONSULT
DOCTOR GREET THE PATIENT BY THEIR NAME AND PRONOUNS. TRUST HAS BEEN REAFFIRMED AS ALL CLINICIANS HAVE USE THE PATIENT'S CORRECT NAME AND PRONOUNS.



PATIENT DISCHARGE SUMMARY NOTE
UPON DISCHARGE THE PATIENT IS GIVEN A FORM THAT LISTS THEIR CORRECT NAME AND GENDER, AND GIVES APPROPRIATE RECOMMENDATIONS FOR BONE HEALTH.



BILLING
THE PATIENT IS REMINDED OF THEIR AFFIRMING CARE VISIT WHEN AN AMBULANCE BILL ARRIVES 2 WEEKS LATER AND THEIR A CORRECT NAME AND GENDER ARE INDICATED.



The How



Towards Culturally Safe GSSO Information Practices & Policies

- Why is this information being collected?
- What information should be collected?
- How can information be collected?
- Who should have access to this information?
- How should information be displayed?

Towards Culturally Safe GSSO Information Practices & Policies

- **Why is this information being collected?**
- What information should be collected?
- How and where can information be collected?
- Who should have access to this information?
- How should information be displayed?

Why is GSSO information being collected?

- Identification
- Clinically relevant
 - Treatment
 - Screening and preventive care
- Building trustful patient-provider relationships
 - Communication with care partners
- Identifying and addressing inequities
 - Hidden populations

Why is GSSO information being collected?

Imaging example

SIGE Form (Sex, Identity, Gender, Expression)

1 Name in use:

2. Pronoun: he/him she/her they/them other

Your doctor has ordered an x-ray.

We use ionizing radiation in order to obtain the images your doctor has requested. As x-ray technologists, it is our professional duty to protect patients as best as possible from any unnecessary exposure. This includes shielding reproductive tissue whenever possible.

Please complete this form to help us determine how to best protect you during your x-ray today.

If you have any questions or concerns please feel free to speak with the technologist prior to your exam.

3. Where are your reproductive organs currently?

- Internal (ovaries, uterus)
- External (testes)
- I do not have any reproductive organs
- I am unsure of the answer (please speak to the technologist prior to your exam)

*****COMPLETE BELOW IF YOU HAVE INDICATED INTERNAL REPRODUCTIVE ORGANS*****

Ionizing radiation may be harmful to a fetus. To ensure that there is no possibility of pregnancy please answer the following questions:

When was the start date of your last menstrual cycle (period)? _____

If the start date is more than 10 days ago please answer the following:

How can you be certain that you are not pregnant?



Towards Culturally Safe GSSO Information Practices & Policies

- Why is this information being collected?
- **What information should be collected?**
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Use Cases: Primary Care

Intake	A request for care is received and evaluated for eligibility by the clinical service.
Registration	A health record is created for a client.
Clinical Encounter	A client is seen by a primary care provider and the visit is documented.
Prescription	A prescription is received by the pharmacy and medication is dispensed for a patient.
Laboratory	A request for testing is received by a laboratory and a result with interpretation is received by the ordering provider.
Imaging	A request for imaging is received by a facility and a result with interpretation is received by the ordering provider.
Referral	A request for care is received by another provider and advice is received by the ordering provider.
Billing	A billing claim is created with the correct details to receive payment from the insurer.
Research	Data is used to monitor population-level healthcare experiences and outcomes.

What information should be collected across different settings?

GSSO Information	Intake	Registration	Clinical Encounter	Prescription	Laboratory	Imaging	Referral	Billing	Research
Gender Identity	Optional	Optional	Yes	Yes	Yes	Yes	PRN		Optional
Admin Gender/Sex		PRN*	PRN*		PRN*			PRN*	Optional
Admin / Legal Name		Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Name Used	Yes	Yes	Yes	Yes	Yes	Yes	Yes		
Pronouns Used	Optional	Yes	Yes	Yes	Yes	Yes	Yes		Optional
Sex Assigned at Birth		Optional							Optional
Anatomical Inventory			PRN			PRN	PRN		Optional
Hormone medication inventory			PRN		Yes		PRN		Optional
Hormone reference ranges					PRN/Yes				Optional



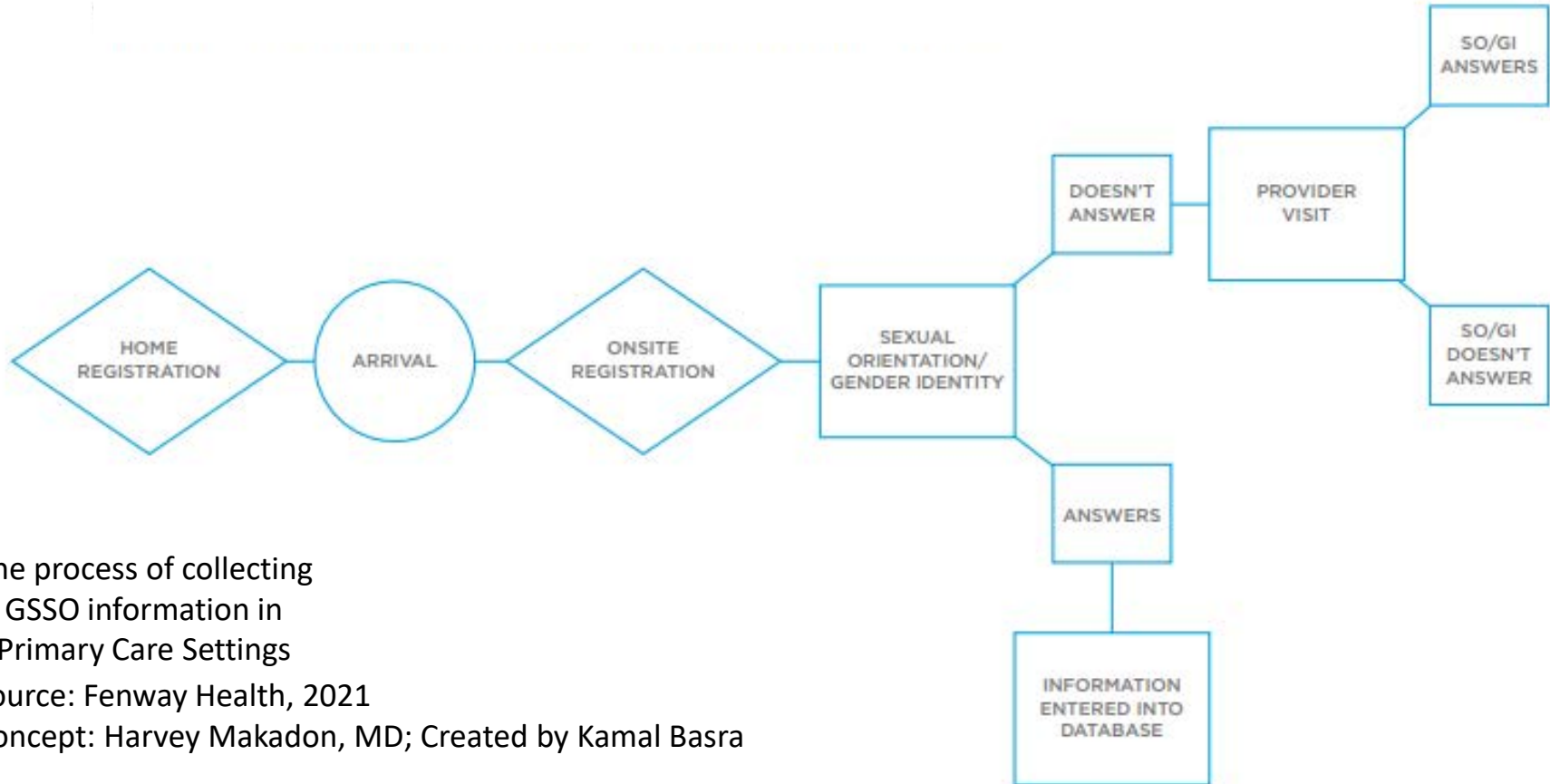
What information should be collected during intake?

- Trans Care BC
 - Name Used
- Fenway Health
 - Gender identity and sexual orientation should be collected
- Rainbow Health Ontario (asked in the following order)
 - 1) Legal full name
 - 2) Name you go by
 - 3) Pronoun (how you want others to refer to you, such as she, he, they, etc.):
 - 4) Please tell us your gender identity, if you are comfortable disclosing (e.g. female, Non-binary, male, trans, genderqueer, etc.): [There would be a box here to write whatever people wanted with as many words as they wanted to use]
 - 5) Sex assigned at birth (circle one): Female/ Male/ Intersex/Do Not wish to disclose
 - 6) Please tell us your sexual orientation, if you are comfortable disclosing (e.g. lesbian, bisexual, heterosexual, gay, etc.) [There would be a box here to write whatever people wanted with as many words as they wanted to use]

Towards Culturally Safe GSSO Information Practices & Policies

- Why is this information being collected?
- What information should be collected?
- **How can information be collected?**
- Who should have access to this information?
- How should information be displayed?

How can information be collected?



The process of collecting
GSSO information in
Primary Care Settings

Source: Fenway Health, 2021

Concept: Harvey Makadon, MD; Created by Kamal Basra

Towards Culturally Safe GSSO Information Practices & Policies

- Why is this information being collected?
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- **Who should have access to this information?**
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Who should have access to this information?

GSSO Information	Patient (portal) *	Proxy (portal)	Medical Office Assistant / Clerical	Clinicians	Primary Care Provider
Gender Identity	Yes ¹	Optional?	Yes, all patients on EHR banner ^{1,2}	Yes, all patients on EHR banner ^{1,2}	Yes, all patients on EHR banner ^{1,2}
Name used	Yes ¹	Yes**?	Yes, all patients on EHR banner ^{1,2}	Yes, all patients on EHR banner ^{1,2}	Yes, all patients on EHR banner ^{1,2}
Pronouns Used	Yes ¹	Yes?	Yes, all patients on EHR banner ^{1,2}	Yes, all patients on EHR banner ^{1,2}	Yes, all patients on EHR banner ^{1,2}
Legal Name	Yes ¹	Optional?	Yes, all patients for identification, less visible ¹ ; only when required ²	Yes, all patients for identification, less visible ¹ ; only when required ²	Yes, all patients for identification, less visible ¹ ; only when required ²
Sex Assigned at Birth	?	Optional?	Yes, to update records (less visible section) ¹	Yes ¹ , when clinically relevant? ²	Yes, all patients ¹ Yes, when clinically relevant? ²
Inventories	?	Optional?	Yes, to update records (less visible section)	Yes ¹ , when clinically relevant? ²	Yes, all patients ¹ Yes, when clinically relevant? ²
Sexual Orientation	Yes	Optional?	?	Yes ¹ , when clinically relevant? ²	Yes, all patients ¹ Yes, when clinically relevant? ²

This is an area that requires further development.

Towards Culturally Safe GSSO Information Practices & Policies

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How should information be displayed?

Forms / Charts / EMRs

#	Strategy (select the relevant strategies)	Relevant?	None / Poor Some / Fair Half / Good Most / Great All / Excellent	WHAT	WHO	WHEN	
				(action items)	(supports)	(target dates)	
Name Used and Legal Name				Gender Identity and Sex Marker			
1	Legal name not required and removed from forms, sign-in sheet, chart, EMR, wristband, etc	Y N	L E V E L 0 1 2 3 4	5	Sex marker not required and removed from form, application, sign-in sheet, chart, EMR, wristband, etc	Y N	L E V E L 0 1 2 3 4
2	Legal name required and there is an additional field added to write Name Used	Y N	0 1 2 3 4	6	Sex marker required and there is an additional free-text field to write Gender Identity (optimal strategy when sex marker required)	Y N	0 1 2 3 4
3	All forms, charts, EMRs, and wristbands visibly prioritize Name Used	Y N	0 1 2 3 4	6A	Gender Identity field is limited to predetermined options and can 'choose all that apply' (alternative strategy when sex marker required)	Y N	0 1 2 3 4
4	Legal names are recorded in a separate section of the form or chart, such as Notes Field	Y N	0 1 2 3 4	6B	Pre-existing boxes include: 'female', 'male', 'intersex', 'transfeminine', 'transmasculine', 'non-binary', 'decline to state', and 'unknown'	Y N	0 1 2 3 4
				Pronouns			
				7	There is a free-text field to indicate Pronouns (optimal strategy)	Y N	L E V E L 0 1 2 3 4
				7A	Pronoun field is limited to pre-existing options and can 'choose all that apply' (alternative strategy)	Y N	0 1 2 3 4
				7B	Pre-existing boxes include a minimum of: 'she', 'he', 'they', 'none', 'decline to state', and 'unknown'	Y N	0 1 2 3 4

Note: Epic ONE takes a different approach to the information that is displayed.



How should information be displayed?

- Epic ONE (US based) went live on November 7, 2020 –
 - “Preferred Name” is presented to the user in large font in the patient’s chart
 - “Legal Name” is presented in small font beneath a patient’s “Preferred Name”
 - “Gender Identity” is also presented under the “Preferred Name”
 - If there is an “i” next to the gender identity in the chart, hover your cursor over the icon to view legal sex, sex assigned at birth, and gender identity
 - “Preferred Name” appear is prominent on wristbands
 - Patient-facing documents such as letters, after-visit summaries, and lab results are defaulted to the patient’s “Preferred Name”
 - Billing information, lab specimens, and consents require “Legal Name.”
 - To prevent any potential conflicts, patients should be made aware they are sensitive to preferred names and pronouns, but there are some instances that the use of Legal Name and Legal Sex is required by law.

Culturally Safe Policies for Asking GSSO Information

- Asked for all patients
- Letting all patients know why these questions are being asked, and right to decline
- Asked annually, or when there are discrepancies
- Confidential process
 - Using standardized forms ideally through self-administered through a portal
 - Paper-based introduces considerations for who will enter this data
 - Or in a private setting when asked verbally
- Trained staff who understand how to ask information in a culturally safe way
- GSSO information that is asked should be relevant to the clinical practice
- Patients' right to choose who and what they want to disclose

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} Session 1
(September 14)

} Session 2
(October 12)

References

- SolutionHealthHQ. (2020a). Answering Your Questions about Epic ONE and Its Tools for Improving Care of LGBT Patients. <https://snhhq.org/answering-your-questions-about-epic-one-and-its-tools-for-improving-care-of-lgbt-patients/>
- SolutionHealthHQ. (2020b). Epic ONE: Tools for Improving Care of LGBT Patients <https://snhhq.org/epic-one-tools-for-improving-care-of-lgbt-patients/>
- Fenway Health. (2012) How to gather data on sexual orientation and gender identity in clinical settings. https://fenwayhealth.org/wp-content/uploads/2015/09/Policy_Brief_HowtoGather..._v3_01.09.12.pdf
- Pedersen, S. & Sanders, V. (2018). A new and inclusive intake form for diagnostic imaging departments. *Journal of Medical Imaging and Radiation Sciences*, 49, 371-5. https://7bf83b57-4eee-4107-9621-c60a37ab2437.filesusr.com/ugd/749261_b7229edd5c934f74a87bc2732eb452cf.pdf
- Rainbow Health Ontario – Sherbourne Health. (2020). Practical tips to make your electronic health records inclusive. <https://infocentral.infoway-inforoute.ca/en/resources/docs/sex-gender/sex-gender-publications/3396-how-to-make-your-ehr-inclusive-by-rainbow-health-ontario>
- Trans Care BC. (2020a). Creating Accessible Environments for Gender Diverse People . http://www.phsa.ca/transcarebc/Documents/HealthProf/Organizational_Assessment_Tool.pdf
- Trans Care BC. (2020b). Gender-affirming care for trans, Two-Spirit and gender diverse patients in BC: A primary toolkit. <http://www.phsa.ca/transcarebc/Documents/HealthProf/Primary-Care-Toolkit.pdf>
- Trans Care BC. (2020c). Update on stakeholder consultation for gender and sex data in electronic health records. Presentation by Lorraine Grieves and Lindsay MacNeil.