

Michael Smith Foundation for Health Research (MSFHR)
REACH Grant Knowledge Translation Topics:
Review of GSSO Policy and Practice – Part 2
October 12th, 2021

[Facilitator] – Welcome and land acknowledgement. This is the second part of the REACH Special Topic on Policy and Practice. The next meetings will focus on specific care settings, such as acute and tertiary care.

Review of the meeting schedule and the action plan, today we are focusing on step five of the action plan, which is “[gender, sex, and sexual orientation] (**GSSO**)

Policy/Practice Guidance: Integrate and tailor GSSO data collection and use including secondary uses within all organizational structures, policies, practices, governance, use cases and workflow processes in order to be responsive to specific care needs of [sex and gender minorities] (SGM.)”

The main topics for today are: Who should have access to GSSO information? And how should GSSO information be displayed?

Any input on what GSSO data should be collected for billing and insurances purposes?

[8] – I think an important distinction is: what should they need to know vs what do they currently collect? e.g. what is on the health card. Do they need it? I would say no

[Facilitator] – People have been denied coverage because their healthcare needs do not seem to be covered by their admin sex/gender category.

[2] – In my province, the ministry of health no longer connects organ inventory with gender identity and/or sex at birth. This is no longer a relationship that must exist within my province. In hospitals, the province’s human rights code states that gender identity overrides sex at birth. For example, wristbands within hospitals have gender identity on them, not sex at birth. The health card’s admin sex/gender field is what hospital requires to be billed and paid. If this needs to be part of billing, I would say no. But the system needs to be updated and changed.

[Facilitator] – I think systems conflate gender identity with admin gender/sex.

[2] – In a way, yes. In a way, no. The hospital system is trying to update itself, but it needs to communicate with other systems such as provincial level of systems. It has been updated in parts, like including pronouns, but still a lot of work needs to be done.

[3] – This chart was created before immunization/ vaccines passports came out. Would this be similar to billing or a new column?

[Facilitator] – One needs to show ID for vaccine passport. With billing in particular, people can get denied coverage. For example, people who identify as a woman and need care, but they might get denied because of the mismatch with their sex at birth.

[6] – On vaccine card, people have been deadname by their cards, but I don't think gender is on the cards. This happens because there is some linking on their cards to some system that has their deadname, though as far as they know, their name has been updated on all their documents.

[9] – Vaccine cards do not have gender on the card, but gender is on one's identification card.

[Facilitator] – What I am hearing is there is a quite a bit of work to do on the billing side.

[10] – In billing, does it encompass their individual health insurance, such as what they might get through their work. This might cover prescription and stuff not covered by provincial health insurance. Would this be under their used name or their administrative name? This might be important for billing.

[Facilitator] – Good point, people might be using their name at work, but it might be different on their insurance.

[8] – What is the purpose of these fields? For patient identification/ verification. But I don't think this needs to be case, you can use other factor of one's health information for patient identification/ verification for cross checks.

[Facilitator] – How about we use PRN, which means "as needed"?

[10] – That makes sense.

[Facilitator] – Moving on to another big question – what information should be collected during intake? There is difference across leading organizations, such as Trans Care BC and Rainbow Health Ontario. Intake is defined in slides, but it means different things to different people and organizations. In primary care and tertiary care, they do an intake interview. This is different from admission in acute care settings, such as emergency room.

[1] – Would this be in the public lobby or in a clinical room? Who would be collecting this information?

[7] – I work with agencies that work with immigrants. They require at intake racial identity, ethnicity, and language used. This is to say that for different settings and different organization, the information and the importance of the information would be different.

[Facilitator] – So it seems like we are saying it should be optional unless medically require.

[2] – Do not ask for information you don't need but whatever you do ask as your minimal set, you need to ask everyone, so you don't miss folks or other them.

[7] – This is exactly what I meant, and I totally agree with it. We need to take guidance from leading organization, but they are specialized organizations that deal with specific

sub-populations. So, their needs and recommendations might not be very applicable to non-specialized organizations or organizations that interact with different specific sub-populations.

[10] – Could we have a minimum data set and then an expanded set for speciality organizations?

[1] – Minimum data sets are a good idea and a good balance between the needs of different organizations. We have seen this from Health Level Seven's (HL7) Gender Harmony Project, as well as from our team's work on GSSO mind maps.

[Facilitator] – Do we have data models that would support a minimum data set? Canadian Institute of Health Information (CIHI) reference model or HL7's gender harmony project models? Would there be a Canadian minimum data set model?

[10] – In CIHI, I agree that minimum set would include pronouns and name used. We do not collect these at the pan-Canadian level where I work at. We are moving towards gender identity as default and included in the minimum. Having sex at birth would be good to have but gender identity should be first and if there is only one option, use gender identity.

[Facilitator] – Depending on the level that you are providing care or analyzing data the GSSO data needs are vastly different. Data elements for providing affirming care would be more important in clinical care settings and maybe not so at high level pan-Canadian levels.

[2] – Sub-populations, such sex and gender minorities, experience different healthcare than the general population.

[10] – I totally agree, it would be ideal to have all of the above data elements but in certain contexts the minimum would be good enough. Gender identity would be the preference in the minimum data set. I would be interested in seeing what other think of having sex at birth in the minimum data set.

[7] – It would be very intrusive to have sex at birth in the minimum set. Especially, if we are talking about community level care, its intrusive and unnecessary.

[5] – In a lot of cases at my organization, our hands are tied because we are working with different organizations. They all have different data they collect. This is a tension and consideration we have in our work moving forward.

[Facilitator] – From an analytics perspective, sex at birth might be important, but at a clinical/community level, it might be harmful to require this information.

[7] – A sampling approach for sex at birth would be ideal because we do not want to add burden to everyone across all of the healthcare systems.

[2] – Are talking healthcare or social services? There is a lot of overlap, but they have important differences, such as organ inventory.

[Facilitator] – This is an important point.

[7] – I work in community mental health, in the overlap between healthcare and social services. I am nervous of health terminology forcing itself into places it could cause harm. It's a scoping problem.

[8] – In my pan-Canadian organization, our goal is to identify SGM in our data with an equity lens, that is why the two-step question is important for us. But there might be different and better way to gather this data, such as “Does your sex at birth match with your gender identity?” This would be instead of asking them to identify their sex at birth.

[Facilitator] – What I am hearing is that sex at birth might not be appropriate in community care settings.

[Facilitator] – Moving on to next slide, how can information be collected? And this might be different in community care and social services settings vs healthcare settings. This slide depicts a general follow from Fenway Health on sexual orientation and gender identity data collection

[2] – In primary care, there would accomplished be filled out of forms, either paper or digital. With the provider, there would be a more in-depth analysis and interview.

[7] – Flow varies from person to person in community clinics. A lot of them are very minimal, such as paper forms or spreadsheets.

[Facilitator] – The question is to identify where in the workflow to ask these questions.

[7] – We are piloting new approaches and workflows and checking how it goes. Inserting this in the existing workflow has been a challenge. We pay these agencies a lot of money to collect this information, but it is still very difficult to get them to do it.

[Facilitator] – Are there any providers or people that do intake/registration on the call? How does this align with your workflow?

[Facilitator] – Moving on to assess to information, this area require further development. Varies by different users, such as patients, proxies, medicinal office assistants, clinicians, primary care providers. Masking data elements for proxies especially for youth and their parents who might have access to their health information.

[5] – Quick questions on proxies, would this include substitute decision markers? Those designated by the patient or those designated structures such as legal systems?

[3] – Patient gets to choose who has access to their patient portals. There is a recent paper that covers this (<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2784190>). There are differences between organizations, such as if the information is accessible for all patient versus only when clinically relevant?

[4] – We need to have an appropriate culture to prepare clinicians to ask these questions respectfully. Some of the challenges that have come up in my research for

LGBTQ immigrants. Even if there is a flag, lab technicians have referred to them by deadname. This continues discrimination and harm. Are there any organizations that do training to stop this?

[Facilitator] – Even in agencies that claim to be affirming, the professionals that work there and the organization culture might not be affirming. We need training and education to address this culture and professionals, and this is difficult to do.

[7] – My background is with deaf and hard of hearing agencies. These agencies and the professionals that work there were very homophobic. Some might have been trained but it might not have stuck. This homophobia is not going away- especially in multi-services agencies. For privacy, collecting less information rather more is best in my opinion and experience. This is to protect patients.

[1] – Having training is great but its hard to know if it sticks and changes individual's attitudes and workplace cultures. Also, what do clinicians have capacity and/or willingness to do? As well as what is the organizations' willingness and readiness to change?

[Facilitator] – Trans Care BC has an organizational readiness table. Does anyone know of any well accepted standards to monitor readiness and willingness?

[2] – I have some papers I can share for this (see bottom of notes). The more this becomes standard and consistent, the less the othering this is. By doing this, we make change. I heard in a conference recently, "Do not wait for things to be perfect to do thing", because you will never get started.

[Facilitator] – We at the end of the session, we covered pretty well everything.

[3] – Just to quickly mention that in the United States, they have very different approach and processes.

[Facilitator] – For vendors that we have imported from the US, we need to see what their workflow is and what information they collect and display.

Papers and Resources on Readiness and Willingness provided post-session:

Trans Care BC tools

- http://www.phsa.ca/transcarebc/Pages/document-search.aspx?q=* &topic=Trans%20inclusion%20basics&language=* &documentType=*
- http://www.phsa.ca/transcarebc/Documents/HealthProf/Organizational_Assessment_Tool.pdf
- http://www.phsa.ca/transcarebc/Documents/HealthProf/Service_Provider_Reflection_Tool.pdf
- http://www.phsa.ca/transcarebc/Documents/HealthProf/Gender-Affirming_Patient_Care_In_a_Hospital_Setting.pdf

EHR specific resources

- <https://academic.oup.com/jamia/advance-article-abstract/doi/10.1093/jamia/ocab136/6364772?redirectedFrom=fulltext>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6590954/>
- <https://www.hcinnovationgroup.com/clinical-it/electronic-health-record-electronic-medical-record-ehr-emr/news/21115399/ama-pushes-forward-on-fully-inclusive-ehrs-for-transgender-patients>
- <https://confluence.hl7.org/download/attachments/40743893/trans-inclusive-electronic-health-records.pdf?api=v2>
- https://assets2.hrc.org/files/assets/resources/EMR_and_Transgender_Patient.pdf