

Michael Smith Foundation for Health Research (MSFHR)
REACH Grant Knowledge Translation Topics:
Review of GSSO Terminology, Implementation Options and Implications – Part 1
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Translations and extensions

[1] Are there efforts for translation into French already happening? Are local extensions being considered for First Nations communities? With a move towards local, First Nation identities- would there be a local extension for different Nations? And French language translation?

[Facilitator] Canadian Institute of Health Informatics (CIHI) and Canada Health Infoway might be able to help with translations into French.

[2] SNOMED CT has a French edition which is managed by Infoway. But with sex and gender categories, translation is more difficult. On First Nation extensions, there is over 600 Nations and 200 languages. Each have different identities.

[1] Would local extension be available? Or would they be locked into standards?

[2] No, there will be no mandate. They will not be locked into standards.

Gender

[1] What about the multiple select for genders outside of non-binary? Is the multivalue option only available for nonbinary for gender identity?

[Facilitator] multiple select would be available for all for the gender identity elements.

[1] The overarching term I've seen used more commonly for cisgender and transgender is "gender modality"; because most binary trans people do not consider cisgender or transgender to be part of their gender identity, but rather as a modality of that identity. For reference, see https://www.florenceashley.com/uploads/1/2/4/4/124439164/florence_ashley_trans_is_my_gender_modality.pdf

Inventories

[2] "Anatomic inventory" is quite broad, is there a more explicit, precise word we can use for this? We don't want to confuse clinicians and we want to be clear what we want to discuss.

[3] For anatomic inventory, in the mind maps it is aliased as organ inventory.

[1] On anatomic inventory, we need to consider unilaterality or bilaterality. Free text needs to be available for explanations of anatomic inventory. For example, chest reconstruction surgery often leaves behind breast tissue that can be an important risk factor for cancer.

[3] For unilateral mastectomy or orchiectomy, it could be operationalized utilizing attributes for left, right, both.

[Facilitator] We are in the early stages of looking at inventories. We need to reach out to communities and surgeons to see if these are appropriate.

[4] I have only ever seen 'organ inventory'. Using the term 'breasts' can be problematic for non-binary and trans masculine people, I'm not sure why that part of the body would need to be listed here.

[1] It could be handled using "chest reconstruction surgery" or the like in surgical inventory. Many trans masculine people who report family history of breast cancer undergo genetic evaluation for risk factors beforehand to find out how a chest reconstruction should be performed.

[1] In Hormone inventory, we have hormone replacement therapy (HRT) in it, but a lot of the things listed are specific types of HRT. I am already thinking of how to operationalize these things.

[5] We need to get this into a form of specific cases that we are trying to input data into a digital health system (DHS). This will help figure out the business rules and technical requirements of DHS.

[Facilitator] Those we will handle in the upcoming meetings, such as policy and practice and DHS functions.

[1] Hormone reference ranges are different in different jurisdictions. I am interested to see how we operationalize these reference ranges.

Privacy and Security

[5] When will this all be applied? The trust of the person divulging this information in a clinic depends on where and how it is stored. If it gets in the wrong hands, it will have dire consequences. We need to ensure their trust and information is respected and kept secret.

[Facilitator] Security and privacy will be explored much more in the policy and practice session.

[7] Just to say that from the very beginning, we have discussed privacy issues and concerns. These have been flagged and will be handled farther on in the process.

Sexual Orientation

[6] It is important to note that the Sexual Orientation is just starting point and definitely has to be expanded outwards, especially in regard to sexual practices because they have different risk factors associated with them.

[7] This is a starting point and needs to be expanded out. The free text option is to expand out and catch things we might not be aware of. Free text is the most important value, in my opinion. This needs to be tested out and have more input on it.

[1] Sexology is always expanding and this list will be always be incomplete. This will be based on legal definitions. A lot of these terms will come under a lot of community fire such as transamorous and Two-Spirit in particular. I like the term sexual identity, it is clear. The problem is that most languages around the world doesn't have a sex/gender distinction, so gender identity gets translated into sexual identity. Sexual partner has a lot going on and it has to be broken out and subjected to acceptability testing.

[4] Perhaps the heading Sexual Partner could be changed to 'Sexual Partner(s)'.

[4] I have a lot of trouble seeing children listed, it is against the law. I was not thinking of this being something encompass this type of thing.

[7] The intention was to gather information that is pertinent to people's health. We are trying to describe what goes on in the world even if they are illegal and immoral.

[2] If we exclude certain things, we will be making them invisible.

[1] Typically, I would list "pedophilia" as a sexual attraction (hasn't been acted on but has been reported), "pedophilic behavior" (if a behavior has been reported), and "pedophilic disorder" (if the behavior rises to the level of disorder as considered by individual providers). Pedophilic behavior/disorder can be collected using international classification of disease (ICD) and SNOMED already, so it has been modeled elsewhere.

[1] Personally, as a trans woman, "transamorous" really makes me uncomfortable. Myself and a number of other trans women I know have been victimized by persons included under that category. I don't think we need to raise what is a fetishization of an individual to the level of a sexual identity, unless we also include "sexualizes Black women" or "sexualizes Asian women" as sexual identities.

[1] Sexual attraction in this standard seems to be a variation of the Kinsey Scale. Was this their intention?

[Facilitator] I am unsure if that was their intention.