Michael Smith Foundation for Health Research (MSFHR)
REACH Grant Knowledge Translation Topics:
Review of GSSO Terminology, Implementation Options and Implications – Part 2
June 8, 2021

Discussion:

[Facilitator] Continue our discussion of gender, sex, and sexual orientation (GSSO) terminology- recap of terminology options from last month's meeting, move on to implementation options and implications of these, and finally, expected outputs that would be helpful for organizations**.** We have added terminology-based feedback from last meeting and from emails, such as adding gender modality, another gender (X), and removing some terms (transamorous, polyamorous)

Gender:

[1] I question if we should use gender diverse as a term. We have heard feedback, and I tend to agree, that all genders fall under the umbrella of diversity, so we shouldn't marginalize some gender as gender diverse.

[2] Diversity means all genders and cisgender people are part of this. The question becomes 'How do we coordinate with other organizations within Canada that might use this term?'

[3] We are in a position as linguists to say what we think should use. I would like guidance on vocabulary that is used in the field and by community and how to use vocabulary

[1] Intend with gender diverse and other gender are similar but the meaning is different.

[2] This is something we have been struggling with for this whole project. What people actually say and what is a better way of saying this. What is our goal and what is our purpose? We can say something like "This is preferred but this is what you might hear in your research."

[5] Mostly just agreeing with the above point. Gender diverse includes 'mainstreams' genders such as cis. There is some duplication in the spreadsheet- is this intentional?

[Facilitator] Non-binary is a gender, and it is also an umbrella that has a bunch of different genders under it. These appear in Alberta Health Services. That is the reason for the duplication.

[5] Not all people that are gender-nonconforming would use the term non-binary gender.

[2] Gender-nonconforming is one of those terms that is in use but its not considered a preferred term. What terms do we use for which purposes and setting, and how do we align with what is used in the real world. I like the idea of having the option of another gender to capture additional genders that we do not have explicitly listed.

[5] Subclassification – another gender as the parent class and then other genders underneath, such as non-binary and genderfluid. Terms that are in used but might not be consider standard.

[Facilitator] There is overlap and synonyms of other gender- should this be recommended or what is used in real life. How do look to encode these in SNOMED-CT? And this is where parent categories and sub-categories underneath it make an effect.

[3] This reminds me of race/ethnicity conversation that happen at Statistics Canada. Race is completely social constructed and then ethnicity is where your ancestors are from. This might be similar to what happens with gender- collapsing genders into one bucket for administrative purposes. We are interested in a small number of arbitrary categories.

Sex Assigned at Birth

[Facilitator] Lets move on to sex assigned at birth and recorded sex/gender to align with Canadian Institute of Health Information (CIHI). They define it as data that is primarily sourced from health records or health card. Should be relabeled as recorded sex or gender. Inventories, we have dropped surgical inventory because this is available within the medical records. Language around breasts in organ inventory needs to be more inclusive of men with breast tissues.

[1] Health Level Seven (HL7) gender harmony project and they use recorded sex/gender. So that will align. Questions on hormone inventory, how it will interact with medication reconciliation? Not all hormone prescriptions are related to hormone replacement therapy

[5] That is good point. This is the cause in people that get hysterectomy and going on hormone to prevent early menopause.

[Facilitator] The hormone inventory was supplied by Trans Care BC. We need further guidance on this by organizations.

[1] There is an existing standard out there for medicine reconciliation. Hormones would be captured there.

[6] I think the problem we are coming up against in the organ inventory on breasts vs chest language is specificity vs inclusiveness. We need specific language to gather specific data that is important for prevention and screening healthcare. But this specificity can leave people out and make them uncomfortable and invisible.

[Facilitator] Flagging this as something we need to work and a problem we do not have a solution to currently.

Sexual Orientation

[Facilitator] Moving on sexual orientation terminology. Removed transamorous and polyamorous as sexual identities based on feedback we have received.

[4] I think if we put the write-in option, we might need to put a note on this. This is specific to certain types of information that may require mandatory reporting depending on the jurisdiction. It doesn't apply to all information that might be written there. I recommend a note be attached to the write-in option so that organizations are aware that mandatory reporting may need to be considered when making implementation and policy decisions.

[1] Echo the point above. Anything we chosen to invisibilized because it may or may not be controversial. We need to understand the implication of invisibilization in the clinical setting.

[2] Bigger issue we need to resolve is that we are putting in information that deals with many different use cases and many different settings. Free text allows to gather information outside of the listed options. People working in many different systems that might need or might not to use this information.

[3] Time frame for sexual partners. Are we asking, “In the last year who have you partner with?” or “In your lifetime who have you had you partner with?”

[1] This is something we haven’t thought about before. Once again it comes down to use cases and the setting that is used the information.

[3] There is usually a period of experimentation in people’s lives. So their life span answer would be different than in the past five years.

[Facilitator] CIHI says it should be recorded as part of observation instead of in demographic information.

[1] In the HL7’s gender harmony model, gender is dynamic and a non-fixed phenomenon

[2] I was thinking of these as a snapshot of now unless there is a reason to require a sexual history

[3] I like the idea of putting it into observation notes.

[1] We need to explore mandatory data elements that are by other organizations (e.g CIHI)

[7] just because someone is attracted to these categories doesn’t mean that they are preforming the sexual behaviour/partner.

Implementation Options

[Facilitator] Let’s more on to implementation options for different organizations and vendors. Many options with different levels of specificity.

[1] Sex for clinical use in the HL7’s gender harmony model. This will impact all of HL7 messages. It allows for the separation of clinical sex data and the administrative/legal sex/gender data. Administrative cannot be used for clinical care because it is really inaccurate. Values for sex for clinical use are male, female, unknown and specified. Specified means you can associate it with other artifacts.

[2] I liked the specified categories. Would this mean there is one sex for clinical use for one person?

[1] No, you can specific sex for clinical use for different purpose all within the same encounter if you wish.

[Facilitator] There are a lot of current electronic medical record systems only have one field. Adding options based on different definitions and these have implicated for upstream and downstream data uses.

[1] Why have male and female not man and women?

[Facilitator] It supports the most minimum changes to existing systems.

[1] Gender and sex are conflated and the value options are conflated. It is in the culture of healthcare

[Facilitator] Another option is adding new data fields such as sex assigned at birth in addition to gender, with mappable value options to harmonized GSSO values, such as mapping to StatsCan and CIHI values.

[3] We tried to report of actual gender identities in our area, and we have had a blast of negative responses from trans organizations. We did not ask for sex but asked ‘how do you describe yourself?’ and used female or male as options. Still not resolved how to roll it up and summarize the responses

[2] I have been making themselves know to Statistic Canada using male or female options instead of man or woman. I am surprised you got so much pushback using man, women. They rejected it but what did they bring as a solution?

[2] It is easy to pick out all the wrong parts, much harder to come up with what is right.

[3] What they decided is going to be different than that they want in a year.

[2] That is the name of the game we are in. we will never fully satisfy all the people involved.

[Facilitator] There are implications for privacy, data governance, French edition, multiselect, local extensions, cross maps, etc Should we use a buy-in approach? Or something like a consensus, ballot, or leading practices? What we decide, it will have upstream and downstream systems impact

[Facilitator] Some of our expected outputs are implementation guides with a chapter on terminology, Publishing value sets on Infoway Central website, harmonization examples and case studies from existing organizations, and repository of published literature on GSSO terminologies.