Michael Smith Foundation for Health Research (MSFHR)
REACH Grant Knowledge Translation Topics:
Review of Gender, Sex and Sexual Orientation in Digital Health Systems – Part 1
July 13, 2021

[Facilitator] Today we are focusing on step four of the action plan, which is enable electronic health records (EHR) and digital health systems (DHS) to collect, use, exchange, and reuse standardized gender, sex, and sexual orientation (GSSO) data. We will start with databases

[3]- I am a member of a group working in a large hospital to update their digital health systems. There are opportunities to make changes and these changes will impact other organizations as well. Capturing pronouns, gender identities – gender identity field has limited number of options and also included "not listed- free text" option. How this interacts with the ministry of health systems is what we are seeing now. Mismatch between self-reported gender identity and administrative gender on health/service cards. This comes down to a billing issue, how to make DHS reflect the person's identity while in hospital while still be able to bill to the ministry for their care. This creates some challenges, and we might need to get ministries more involved to overcome these challenges.

[Facilitator] - Great point, how do we link between systems, and ensure billing works for patients.

[1] - At the ministry that I work for, we are looking at internal ministry systems and external stakeholders such as the health authorities. MPI- master patient index that contents demographic information for people within province. This has a lot of downstream system implications. Need for two specific sections – one for gender and one for sex- in order to ensure that patient care needs are meant. We are starting on working differentiating between these two groups of data. In the sex field, we are moving toward using sex for clinical use (SFCU) instead of sex assigned at birth. If there is a clinical reason that sex might be clinically significant, we would use SFCU. But if not, the default is to used gender identity for all other times.

[Facilitator] - Is SFCU suppose to replace the content for sex assigned at birth/administrative gender fields? And is this tied to HL7's Gender Harmony Project (GHP)?

[1]- Yes, we would be inline with GHP and their use of SFCU

[2]- There are five primary data elements in the GHP model- one is recorded sex/gender. SFCU is context dependent and can change depending on the provider's intentions, such as getting reference ranges for lab tests. SFCU can be used to retrieve different values in a singular encounter.

[4]- We have all the same troubles in my region with mismatch between data elements.

[6]- In my organization, we have a few unique challenges as our main goal is to report on health disparities based on gender identity, but we do not have really have that data yet. We can do a top-down approach, but it will depend on the hospital's capacity to gather this information. A lot of the data we receive is from administrative sources and thus, is limited.

[Facilitator] Standardized mapping.

[6] GSSO terminology from this group has been helpful for us. We do not have a current map in place, but this is really helpful. Three categories- male, female, and an aggregated category called "another gender". This is how we roll it up, and we know current terminology is constantly updating. So, we encourage a free-text field to track the changes in terminologies and determine how our roll up methods. There is more sensitivity around aggregating gender identity data compared to other data elements.

[5] In terms of diagnosis perspective, there are ways to aggregate diagnosis and procedures.

[6] Small reporting number means we cannot report on them because this would possibly lead to identification. But we should not roll them up into an "other" category, but we do not know what to use instead of this currently.

[5] We do not use SNOMED-CT code for gender identities.

[7]- I am supportive of using SNOMED-CT if the working group determines this is the best option. Have to determine a lot of stuff first and my mind is going in a hundred different directions. Quality assurance is really important for people to contribute their expertise to this work and conversation.

[3]- People keep saying that the terminology is constantly updating and this seems to be somewhat of an excuse to not start any work. The biggest categories are pretty static, such as transgender and non-binary. And people would be grateful to have a simple starting point, we do not have to everything figured out to get started. And I think people use this an excuse to not start anything.

[2] SNOMED-CT codes will stay the same, but the context can be updated.

[1] We are moving in the direction of adopting SNOMED-CT and developing a reference model

[6] Thanks for the suggestion. Having something we can reference would be useful. We could use this to support vendors.

[5] I am thinking of implementability and creating two fields is challenging for some stakeholders.

[1] The field size is not really an issue, but it's an issue of updating the contents of the fields, such X in the gender field.

[4] We are planning on implementing SNOMED in my region. Would the SNOMED code be a front-end for patients? We see as a back-end code for professional use.

[1] Users would see the description – the fully specified name- not the SNOME-CT code.

[5] I am not sure if jurisdictions are allowed to update sex assigned at birth and gender identity.

[8] There has been a lot of confusion on our sex field in our DHS. We are having a lot of conversations within my organization on how to handle this. And this field populates other fields such an anatomical inventory. So removing this field would impact a lot of other fields in the systems. We have added ‘preferred name’ in our banner bar and did a deep dive into how this field populates prefixes and arm bands. We are planning on removing prefixes completely from our system. Services cards when swiped will automatically override the current fields in our system. We want gender identity field to replace the sex field in the banner bar and we have put in a request to do this.

[Facilitator] Should we store GSSO in demographics or in patient encounters or as observations?

[9] Privacy is a big issue here. Gender identity should be front and center. Sex for clinical use should be provided when people need this for clinical use and not provided when not necessary.

[1] Privacy is a key component of this work. I think that dividing the field into two and making the sex component be masked by default is the best approach. This is unless it is flagged as necessary for care. Patients might be asked to provide consent to unmask this field. Registration clerks should not have access to this sex information as they are not clinical people. Need training and guidance on this front.

[10] I agree with above. Sex data should be on a need-to-know basis and private. Registration areas are not set up as private places to have private conversation and registration staff does not necessarily have the training to do so. It is the patient decision to provide this information or not.

[Facilitator] next meeting will cover decision support, analytics, and IT support.

Post-session Feedback

[13]- The actors/users of Gender/Sex GSSO data?
At the core, let's summarize into two sides/groups:
The people who provide the services (Regional Health, Health Authorities, Provincial Government, Health Insurance Entities, etc), aka Providers
the people who receive the services (Recipients), aka Recipients
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What is the main interest of the "Recipients"?

Want good health care and be treated properly and equally
"Recipients" want to be treated humanely. Be called by their chosen/known name, preferred pronoun, etc. This is for face to face communication purpose, we are all happy to do that. We are glad to be of service, whether you are "A", "Adam", "Ada", "He", "Him", "She, "They", etc.
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What is the main interest of "Providers"?
Accurate identity of the "Recipients". EHR cannot function without an accurate identity management. "Gender/Sex" collected, maybe used clinically <20%, but I say >99.9% it is used for identity. Why? Mostly because of billing and record keeping.
Yes, I do agree that other GSSO data maybe all clinical(health authority may collect, ministries will not), such as "Sexual Orientation", "Anatomical Inventory".

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How do you identify an individual?
Need some kind of permanent feature or ID. For example Health Care ID, with support of name, birthday, gender/sex. For example, transient individuals usually don't have ID with them
We don't identify someone by their weight, height, hair colour, etc, because common sense say these features are not "permanent".
Now, we don't use "Gender Identity", Pronoun, "Sexual Orientation", etc, in identifying an individual. Because they are not "permanent" enough, especially when you consider the "gender fluid". The same applies to "Pronoun". But I can tell you that we do use "Sex at birth", cause it is a more permanent piece of information.
The "Recipient" may think they can use "Gender Identity" to identify themselves, doesn't mean the "Providers" will accept it as a means to identity management. There are two parties/actors here. Please don't mess up the 3 pieces of information for identity management (name, birthday, gender/sex).
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The requirements of information for "face to face communication" and "identify management" don't conflict with each other. All health information are private and secured, so label, describe and collect the data for its purpose and everyone will be happy?

[9] (A response to the above feedback)

I don't agree that we should continue to use sex assigned at birth as a primary patient identifier. The message to gender-diverse people in doing so is, "we'll patronize you by calling you by whatever name and gender you want to your face, but we know that you're really who you were assigned at birth and the rest is window dressing. Behind your back, we'll continue to think of you as your originally-assigned sex and gender." Also, I'm not satisfied with the argument that it's OK to do that because medical personnel will treat sex at birth as private information. Providers should treat patients with honesty and respect.