Michael Smith Foundation for Health Research (MSFHR)
REACH Grant Knowledge Translation Topics:
Review of Gender, Sex and Sexual Orientation in Digital Health Systems – Part 2

August 10, 2021

[Facilitator] thanked everyone for joining today and noted that today's session will be a knowledge translation session on "Review of Gender, Sex, and Sexual Orientation in Digital Health System – Part 2"

[Facilitator] remarked that research grant team leader is [1] and acknowledged research team. Acknowledged the land, reviewed the agenda, and recapped last meeting.

[Facilitator] noted that this session is a continuation of the discussion on the action plan and action item #4, and to identify specific implementation issues that members could implement into in their corporate digital health systems. It was also noted that in the last session they discussed databases, interfaces, outputs, and security and privacy issues.

[Facilitator] noted today's discussion will focus on decision support, analytics and IT support, reviewed item #5 of the action plan, and asked the group if they had other implementation issues that should be considered. [Facilitator] paused and solicited feedback from the group in terms of their experience with rules, evidence, and best practices that they might have come across or their organizations have used so that they all can learn from these ideas.

Discussion:

[11] responded that all of this work costs money, which is one of the biggest impediments – requiring organizations to invest money and making change. [11] was not sure if it fits in the decision support section.

[Facilitator] noted that it is important to mention it here since some of organization's cost might be related here. It could also be covered under analytics in terms of what kind of cost analysis can be done.

[11] mentioned that money is something everyone is thinking about but never talked about, instead they 'pull' out other reasons why it can't be done, but really they are talking about money. Organizations need to acknowledge and respect that money is an issue that needs to be addressed and should not be an impediment.

[Facilitator] agrees with [11] and further remarked that many times the piece on decision support rules are inevitably about making choices and these choices would lead to some differences, in terms of access to care and quality outcomes.

[Facilitator] asked if anyone at an organizational level could speak on this issue, because it still has a lot these issues around costs, as a result of some of these rules, evidence and best practices that have been done.

[14] reported that organization is currently grappling with costs and that there are two sides to this conversation. One must increase the data fields in the databases to accurately reflect all the different data elements. Organization currently has recorded sex or gender so there’s been a bit of cost associated with relabeling and redescribing, but there’s a further cost that comes in both financial and pure storage space, such as expanding databases like the clinical and administrative databases to have one or more variable. Organization has a ton of pure storage space, which takes time analytically to process data when there are more elements. There are all these kinds of things one must think about, and on top of that, the organization is hearing from the provinces and territories saying that it is going to cost them lots of money to work with vendors to get the systems to enable collection, which includes a lot of time needed in setting these standards.

[Facilitator] mentioned recently having discussion with ministry, who confirmed that changing one field in some of these existing repositories and databases can easily cost millions of dollars.

[12] noted that there are couple of things observed in terms of ‘trends: (1) there is financial costs to these changes but there is also an opportunity cost for not making these changes; (2) there is an opportunity cost to making these changes that needs to be acknowledged; and; (3) there is social cost of not making these changes that also needs to be acknowledged. The way these things can be acknowledged is through you, by literally including inclusive design as a line item in project plans, because people get so hung up on tasks and timelines in their projects that they start to drive design and care – the care paradigm is going to lose out on some of the ethics. Some of the important central ideas that we have for the Canadian Healthcare has to do with implementation, approach, and spirit. This is important because it applies to cross cutting approach

[11] agreed with another group member and recalled presenter from an earlier meeting having to describe to physicians the cost that they could be incurred for violating people’s human rights by misgendering them. [11] affirmed that ethics is huge in hospitals and health which is a point of entry that people are familiar with and understands. Everyone is embracing ethics and it is pointing people in the direction of respect for inclusion and diversity. This is important to include in final report.

[Facilitator] reflected on comments from two previous members and stated that it points to the need for evidence for this additional support. If the intention is to improve patient care or for quality improvement, both at the patient and population levels, then it is important to provide some sort of guidance in terms of how we need to tie in the evidence. For example, if it is going to improve the care, then hopefully it will result in some reduction of costs. Maybe the workgroup can provide that linkage that would help the implementers in terms of providing a stronger business case justification. There has been enough of these research projects and presentations in the past couple of months around this topic that there may be some emerging evidence that might be helpful.

[Facilitator] asked group if anyone had any specific examples of evidence or best practices that they could draw on?

[14] noted that based on what was said about the need of evidence to encourage the decision making in the implementation of this type of data collection, it was something that they were grappling with and had some push back about whether this was in their mandate as a system, or whatever to collect in this registration body. They also collect information on health professional for health workforce, and the regulatory body said it was not within their mandate to ask about categories. That was pushing a boundary between the provider and registration body. This type of evidence really would help with the compensation better, especially within this space. They have a variety of their health equity domains that remains to get implemented into the system. One big one is race and indigenous identity - understanding how we look at the intersectionality; how do we specify prioritizing sex and gender over race/ethnicity, which comes back to just needing firm evidence that shows that there are big changes.

[Facilitator] remarked that they have been doing some systematic reviews and evidence review in terms of providing emerging evidence that leads to areas on gender minorities with respect to access, quality of care and health outcome. The follow-up question was posed: Do you find this type of evidence helpful, and do you think that policy and decision makers buy into this kind of evidence?

[14] said that it is hard because you want to get ahead of the curve, especially with decision about preparing the system to accept this type of data. You cannot have the evidence until it has been collected. It is a strange process, but this action plan and the review of lots of references are great start to encouraging evidence.

[11] posed the question to a group member, there is data around harm, but would this kind of evidence be acceptable?

[14] remarked that from that perspective it would be helpful and that in the absence of evidence, benefitting from evidence on harm would be helpful and welcome the sharing of resources from others in the group.

[Facilitator] posed to a group member if this could be extended to safety as well as a way of looking at harm?

[Facilitator] remarked that as researchers, we love to write papers, but decision and policy makers often want one or two pages that summarize the evidence in a very concise way into actionable type of interventions. [Facilitator] asked what - ways can researchers try to put these in a more useful way? And for people working in the health regions or ministry, and specifically asked a group member to comment on how researchers can convince the policy makers?

[8] remarked that this was an area of practical approach on how ministries look at trying to implement -and get adoption. There used be the mentality of the whole waterfall approach when you're working with vendors, with big massive amounts of funds allocated, big timelines, but the approach is now shifted to be a lot more agile. The problem with this approach has to do with when you are trying to get these monolithic CIS vendors like the Meditech, CERNER and CIS Epic to shift; it is not easy so what they have proposed on this particular standard is to partner up with the specific health authority, which they have gotten the green light with the health authority to pilot this sort of implementation on the standards within their organization. They are in the preliminary stage, but this was intentional in having both CIS partner and an agile EMR partner on both domains, especially in primary care – they can be more agile on how they adopt the data back end. Working with CIS partners is like a MVP, which is gaining more traction than going directly to the provincial governments and give them the standard to implement. Recommend to other jurisdictions to work with smaller approach with partners to work out the kinks before they go to bigger audience. This is the approach that is being endorsed than trying to "drum up" significant budget for a project.

[15] echoed a group member's point of view regarding stakeholder engagement and agreed with another member in terms of doing pilots. [15] further commented that involving patients and stakeholders right from the beginning in that process is important, which is hard to get their time. They have ready access to community, health authority partners, and other stakeholders.

[Facilitator] asked a group member to comment from other provincial perspectives.

[6] commented that the direction was not quite clear in terms of where organization was heading because some people were collecting information, while some people were not and that there were no statistics to confirm what the majority is doing.

[Facilitator] further enquire to a group member what would make this clear about how this would look in terms of statistics and whether this could come from bottom up, top down or inside out?

[6] replied that the majority of people wanted to collect HIS information but could not give by percentage. Getting this information is not easy because of the sensitive information. Organization has been trying to get these standards in place, but it has been a cascade of things, including funding; money is part of this discussion.

[Facilitator] remarked that Statistics Canada has been working in this particular space, and as part of preparing for their census and national surveys, they explore these different gender identity fields and have done some surveys as well. [Facilitator] asked for people from federal organizations to share their experience or comment on whether this is the right time to do another survey.

[14] organization has prospectively surveyed the general population through engagement with people who identify with diverse gender identities and sexual orientations. Organization has surveyed the clinical administrative database representative from different provinces and territories and have heard similar things. There is an apprehension from provincial ministries about the financial impact. They also want to see other provinces and territories do this before it does, but this is a big issue in this space, waiting to see who does it first, so the other can see how it works before implementing it.

There have been conversations with Stats Canada over the past couple years because they did extensive consultations of people with identities, and they came up with a new member data collection standard that includes nonbinary as a third group; they also provided another gender with an open text for collection, due to duplicate identification. CIHI standards are still evolving from pieces but having that open pack option for writing in a gender identity is good; they are moving towards nonbinary, but don't know when this will be implemented. It was suggested that it would be a great opportunity to have a representative from Stats Canada to present on their engagement in this space.

[Facilitator] agreed with suggestion and added that even people from this working group from health terminologies communities can be bold and come forward to present about their engagement with GSSO and open the conversation to others from other jurisdictions.

[12] responded that it sounded like the group was waiting on Canadian evidence related to… and (pointed to the screen), "the value…being that of the human, system or financial value" as representation of each one of these sorts of interventions. Throughout the course of the sex and gender working group, they have had presentations that have covered, in a positive way, many aspects that they were seeing right now. It was mentioned that there are more prominent ways names are used on ID and labels, for examples some recommendation about bed management, flagging special care plans and the lack of current reference ranges, and preventative care leading to worse outcomes for trans plus people than everybody else. Things like this, the group already know in general, from the evidence, but it appeared that people were waiting for some type of Canadian evidence, but there might be a couple of leaders in terms of jurisdictions implementing this or at least piloting them.

[Facilitator] agreed with a group member and stated that focusing on Canadian evidence would be one way to provide the information that is needed. Also, partnering with Canadian organizations and vendors. [Facilitator] suggested that Island Health might be interested in partnering opportunities, and they are right down the street, which is a way to look forward.

[15] mentioned that Vancouver Coastal Health and BC have a shared EMR profile and inter-health, and they have been doing some work recently. [15] is invited to another meeting at the end of August to make some adjustments to the way they capture sex

and gender in their EMR and suggested that this might a connection point for the group, and would later pass on the outcomes of this meeting.

[11] added to a previous discussion by a group member that a lot of work has been done across the country on preventable human rights codes as well as the ‘Canadian Federal Code’. [11] would not like to see a repeat of history in terms of “until tremendous harm is caused, before something is done”. This is happening with the health care system in terms of racism, which Canadians are coming to terms with slowly. The same can easily happened here because so much work has already been done with criminal codes and human rights codes have been established to protect this group of people that they are talking about today. What more needs to happen before those protections are recognized and put in place to ensure that these folks are protected, which is of concern.

[Facilitator] thanked the group member for sharing this advice.

[12] commented that the LGBTQSi Secretariat stated that most gains in LGBTQ human rights in Canada, whether it is jurisdictionally only or federally, have come through human rights and legal actions, which is an interesting point to bring up again.

[14] reflected back on the question of what kinds of evidence would be helpful. One thing they have been asked explicitly is to provide some form of evidence of what health reasons, what provinces and territories are actually making strides in this space to facilitate specifically gender identity, specific data collection that is delineated from administrative data, that isn’t recorded at the gender level. [14] further suggested that this is a possibility for this group to create a summary of health regions that have some of these activities in place and are working towards the goal of collecting this data that would be easily submitted to a place like CIHI through administrative records and care records.

[Facilitator] praised the group member for] advice and remarked that they have done pilot projects that can allow organizations to submit data directly that would be good for visual analysis. But their organization would need to do some initial analysis.

[14] remarked that just knowing where that data would come from such as health regions, provinces or specific territories don’t really help.

[Facilitator] moved to the next agenda item # 6, **“Analytics**” as referenced in the presentation slide.

Discussion:

[Facilitator] asked the group if there might be other implementation issues on analytics that need to be considered, which some might have been talked about in decision support.

[12] commented that this is something that is starting to appear in the literature as well. This is something that is of awareness; that is how systems can be enabled to label

people who would otherwise not want to be labeled, which speaks to point # **6b “derived, e.g. if sex at birth ≠ gender identity => transgender person?”**

[12] further commented that if sex at birth does not equal gender identity, are they a transgendered person? What is known for sure is that if sex at birth does not equal gender identity, then sex at birth does not equal gender identity. People have to identify as transgender because it is a gender identity, and that is not a label that systems should be enabled to apply.

[11] asked a question of [12]. Can the ‘corollary’ be true that sex at birth equals gender identity, equal system cis gender person, could that be one way of addressing the difference between cis gender and non cis gender?

[12] remarked to another member that for some people it might not.

[11] remarked that is definitely where we are at with our thinking as well but another member pointed that is not necessarily equal to transgender, which is something to consider. We have been heavily leaning on published work on the two step approach for assessing sex at birth and gender identity

[Facilitator] invited another member to make a comment on this discussion.

[4] commented that it depends and what we are trying to capture and agreed with another member in that we cannot assume anybody’s identity for them, which is what we do when we try to make these distinctions. One motivator for [4] is that if we have no idea how large the gender diverse population is, or the sexual minority population is, then we don’t have a basis for assigning resources; and if we don’t have a motivation for talking about how expensive it is to change all these systems; how do we convince anybody that it’s a good idea to change these systems, if we don’t have any idea of how many people are being affected? Therefore, agrees with [12] when stated that we do not want to assign anybody to any identity that they do not choose for themselves. We could say gender diverse, rather than transgender, but whatever we chose to try and count this population, somebody is going to object to it. We have the whole issue of our nonbinary people trans, lots of nonbinary people do not object to being called trans, so maybe transgender is not the right thing to say, but if we are going to engage any kind of quantification, we have to come up with labels, and all those labels are going to be imperfect.

[Facilitator] confirmed that instead of saying transgender, one can have gender diverse or even another gender in way to estimate quantification.

[14] stated that this may be simplistic, but there could be an edit rule that uses sex assigned at birth (SAB) with gender identity and so aggregate data would include, for example, trans male and female - SAB was male.[4] further commented that there isn’t a final answer. But the point is that there will be some kind of labels. We cannot avoid having labels if we are going to deal with data. There are plenty of labels that are not necessarily what every individual would use because we do have to aggregate at some

point. There are some people who are trying to be objective and use ‘other’; but some do not want to be called ‘other”. There are people who object to be called cisgender because they find that it is a derogatory comment. It is a minefield but, it is okay with using transgender but open to other ideas. The main point is that there will be labels.

[Facilitator] confirmed that they are talking about using analytics to generate evidence and asked for any further comments.

[11] There are many people who would not be grateful to be misgendered in the wrong category, that if they have to be aggregated understands that it a necessity for analytics, especially for data suppression for small numbers. They would be so grateful not to be misclassified in an assumed gender.

[14] stated that CIHI work in population health and they have asked others whether to include on a survey, or it is appropriate to have, ‘trans male’, ‘trans female’ or ‘male and female’. It is hard to know what the best approaches for analytics, because we understand that not all transgender individuals are going to want to identify as ‘trans male’ and female’. They are female; they selected female, but analytically in terms of the quality of data and making decisions based on both options. What can be done in terms of having an analysis, if they selected both ‘male and trans male’. [14] asked others for their input for the correct wording of what was shared.

[5] remarked that if they are thinking about linking analytics with AI, for example being part of the new strategy research and the development of the network, they are focusing on learning health system, the new direction of how and to leverage from others. One can use AI to generate sex and gender outcomes. Recently submitted proposal to look into the EMR test data on how sex and gender are being used in the natural process in the system and wondering if this idea is something that this group is considering in the implementation phase of this project.

[Facilitator] noted that there is a need in terms of understanding the extent to which second gender is being documented and incomplete so far. So, looking into these existing data sources, where they are captured somewhere shows how they may help the group figure out a bit of the baseline and go from there. [Facilitator] further noted that different techniques, including artificial intelligence/ machine learning, text mining and all of these techniques can be used, especially dealing with free text, which will be part and parcel of the analytic piece in terms of what is there.

[Facilitator] asked the group that in terms of population health, if they have some indicators or metrics that they have published or using that would reflect the health status or quality of care with sex and gender minorities. [Facilitator] asked for suggestions and if this is an emerging area?

[14] remarked that Canada is moving in the direction of having general population-based survey type information, but CIHI does not.

[Facilitator] remarked that it might be nice to gather some evidence from abroad in terms of population health, some indicators or quality metrics.

[12] commented that it appeared that this is an emerging field. Health analytics are built around the entrenched binary male, female, man, woman; thing and binary statistics are much easier than multi-variable statistics. We are getting into that discussion, so there is a lot development that needs to happen in terms analytics and how to break down these different types of aggregate categories. There is an opportunity there.

[3] Going back to the earlier point the need for intersectionality and GBA+ framework may be a good guide here.

[Facilitator] moved to the next agenda item # 7, **"IT Support**" as referenced in the presentation slide.

Discussion:

[Facilitator] opened for comments from group on implementation issues relating to IT Support.

[7] remarked that this is something that is important for organizations in trying to understand what the information is in the system, sort of like an environmental scan. What exactly is the data that is being collected within each of the different systems; how it is being collected, and what is the entity that is entering the data. Is it the system generating it; is it an individual entering it manually; is it the patient entering it on some kind of a survey and then having that transcribed back into a system. Things like this, they are trying to conceptually looking at as part of an implementation guide. The system information and how this information is leveraged and put into multiple different systems; be it data from their organization and the Ministry system or a receiving system such as a vendor EMR or an outsourced system.

[Facilitator] thanked a group member and affirmed that in the coming months the group will be moving into discussion on policy and practice, where they will talk about how the data is going to have to be captured, used, and stored, to policies and practices and all those issues. [Facilitator] wrapped up the session and confirmed the 3 topics of discussion today on Part 2 of Digital Health Systems, and the working group meeting scheduled for August 24th.