

## Summary Notes – REACH Special Topics Meeting, September 14, 2021

### Topic: Policy & Practice Part 1

Facilitator: Kelly Davison

Pre-session discussion on use of culturally safe vs. culturally appropriate

0904/1204 (Pacific/Eastern) Session started with territorial acknowledgement and welcome by the Facilitator.

[Facilitator] This is part 1 of a 2-part discussion. What isn't covered today, we'll address at our next session in about a month's time.

[Facilitator] Review of today's agenda:

1. Meeting Schedule
2. GSSO Action Plan
3. Culturally Safe GSSO Information Practices & Policies
  - Why is this information being collected?
  - What information should be collected?
  - How can information be collected?
  - Who should have access to this information?
  - How should information be displayed?
4. Next Steps

[Facilitator] Key questions are: why is this information being collected; what information should be collected; how can information be collected; who should have access; and how much information should be displayed. Additional questions may arise in our discussions.

[Facilitator] Reminder that the full action plan and action plan summaries (available in English and French) are available via the Infoway Central site. For an example of the consequences of information practices, please see the Infographic (also posted at Infoway Central). We will be tackling big questions during the session and so as we move forward, please feel free to interrupt me. It's your voices, your experiences that are really important to this discussion. We're here to consolidate this information, process ideas, record them for the benefit of the people who will be using these processes in the future.

[Facilitator] First roundtable question – Why is this information (GSSO) being collected?

[1] To make sure that when we provide care, we're providing care that is appropriate to the person and we understand better their history, background, potential needs and care, as well as to prevent frightening them, or inadvertently abusing them or having micro aggressions in our communications for care. So overall to support person-centered care.

[2] Something I don't agree with – being used as an identifier. Folks are often asked to present a card which has a gender or administrative sex in order to be eligible for services or to connect them to an existing record. We use other identifiers that are used in the same way, so we might use birth date to try and match within systems. Other non-healthcare systems use other biometrics, such as facial recognition, fingerprints, retinal scans and things like that. But

traditionally healthcare has gone with things like name, whatever the recorded sex is, and date of birth and possibly a health ID number.

[Facilitator] One of the things you said was to determine eligibility for services and of course as soon as you say the word eligibility you were putting up the barrier. Sometimes there are some ways of identifying people that are more or less neutral. If I can say that facial recognition will just identify data points as part of an algorithm to say that you are you and your face is your face. It's not going to look at whether or not you're male or female or your gender identity. Might associate that detail later, but like personal health number, it's neutral.

[3] From my experience, not personal experience, from conversations with others who want the information collected, that their experiences is that if the information isn't collected they're invisible and it's almost as if they don't exist authentically, as they identify themselves.

[Facilitator] To summarize, an important reason we collect this information is to address the visibility of certain populations and people. The structures we create are often just as biased as we are as people. Healthcare, sometimes, we're actually enacting ontological violence by omitting people from healthcare.

[4] The recent thing would collect this information because we do need to collect it, because we're providing a service. In order to provide a service you need the information to properly deliver the service.

[Facilitator] So information is basically collected to deliver the service but also the communication of the individual and the people that deliver the service, but also the communication between the individual and the people that deliver the service.

[5] Technological advancement and innovation. So standards to cater to the individual, you know focused service in a patient centric service, no with technology advancement we could do something better. So we have the option to come up with new standards (care?) and we can do things better.

[Facilitator] So there's a couple of threads here that I'm hearing, one is care quality. So improving technology so that we improve care quality. But it also seems like there's an element of more personalized healthcare in there.

[5] Yes, that would be accurate.

[2] So [6] in the chat box listed to provide better care. And so I'm wondering if there's a subtle difference between appropriate care and better care.

[7] I have thoughts on this because one of the things that I was going to say is that we, in part, collect this information so that we can evaluate the care that was received, and it's I mean further down the line but without the information we can't produce analytics or reports on care on health outcomes. Make sure that we are appropriately addressing the health issues of the groups that are being served by the variety of health professionals and I think that evaluation piece kind of contributes to the better care. Like here's where we are and we can benchmark and work towards achieving something higher down whatever range of outcomes we're looking for.

[Facilitator] So we need to measure things we need. We need to evaluate care if we're going to improve it so we need those measurements.

[3] By way of example, I've heard many times from trans women the harm caused and the fatigue with the question "when was your last period?" And so if you collect this information, then because you asked that question, you know that there's a prostate that perhaps needs screening or with a trans masculine person you know that they are non binary, you know what organs are available or what needs screening. And so appropriate care leads to better care. Not missing really important pieces of information and not causing harm.

[Facilitator] So yes, to avoid harm and also to ensure that we provide relevant care. We know that these are two sides of the same coin: harm and appropriate care.

[7] I could be wrong, but to me, appropriate care sounds like the baseline that we should always be striving to achieve to provide and then better care is like having that baseline of appropriate care plus better experiences for the patient. There's the better and the best. A provider that goes above and beyond for their patient, but I feel like appropriate just has this tone of it should be the absolute minimum should always be appropriate.

[Facilitator] So let's take a look at what we've learned in the Sex and Gender Working Group and some of the literature about collecting this information for identification, for clinical relevance, for treatment, for screening/preventive care. One thing not up here is the avoidance of harm, but perhaps that is couched within building trusting relationships. So if we can communicate this information with care partners, we can create communities that are able to provide patient-centered care that's appropriate but is also competent and safe. And then there's the invisibility issue and structural bias and institutional bias, so identifying and addressing the inequities that are generated from that bias and from the harm that those biases create.

[3] Maybe in that list you provided, add knowledgeable care. Maybe not expert maybe just knowledgeable – that is better care.

[Facilitator] From the presentation to the Sex and Gender Working Group – Sisdal Peterson and team's form for imaging technologists. This is a paper form, which complements the digital version. Some key points that I think are important to note here are the affirming language that's used in this. And this paper form addresses cultural safety. It addresses patient safety because that avoid the harm associated with mis-gendering, mis-naming or outing. And it's used on every visit for all patients. Routine use and collection of GSSO data is one Fenway recommendation. Next question – What information should be collected?

[Facilitator] Trans Care BC in their presentation to us, provided this list of use cases and definitions for primary care settings and we can see these definitions are important because they contextualize care. [Matrix slide will be included in the summary notes with the additions from the discussion so people can reflect on this and comment further in the next session] Think about what information should be used or collected across these different settings. Don't let the existing recommendations hold you back from expressing your opinion because this may not be appropriate from a pan-Canadian perspective, but it's a place to start.

Matrix slide – group edits (additions) appear in red text as a consensus from this discussion, black text reflects the original Trans Care BC recommendations.

| GSSO Information             | Intake   | Registration | Clinical Encounter | Prescription | Laboratory | Imaging | Referral | Billing | Research |
|------------------------------|----------|--------------|--------------------|--------------|------------|---------|----------|---------|----------|
| Gender Identity              | Optional | Optional     | Yes                | Yes          | Yes        | Yes     | PRN      |         | Optional |
| Admin Gender/Sex             |          | PRN*         | PRN*               |              | PRN*       |         |          | PRN*    | Optional |
| Admin / Legal Name           |          | Yes          | Yes                | Yes          | Yes        | Yes     | Yes      | Yes     |          |
| Name Used                    | Yes      | Yes          | Yes                | Yes          | Yes        | Yes     | Yes      |         |          |
| Pronouns Used                | Optional | Yes          | Yes                | Yes          | Yes        | Yes     | Yes      |         | Optional |
| Sex Assigned at Birth        |          | Optional     |                    |              |            |         |          |         | Optional |
| Anatomical Inventory         |          |              | PRN                |              |            | PRN     | PRN      |         | Optional |
| Hormone medication inventory |          |              | PRN                |              | Yes        |         | PRN      |         | Optional |
| Hormone reference ranges     |          |              |                    |              | PRN/Yes    |         |          |         | Optional |

Notes below are specific comments made in discussion of the matrix. Respondents are not identifiable.

[Facilitator] Starting with gender identity and intake

- If you're going in for a specific clinical service that may have very clinical relevance, intake means sort of different things depending on where you are in the care continuum. From a tertiary care program, intake is a comprehensive assessment. For primary care, it's creating a file with a clerk up at the desk.

[Facilitator] It's different processes and so it would be more meaningful if we said what else must be collected during intake because it's not clear, so we can either get rid of it because it's not adequately defined or you can say intake is the process in which these functions happen.

- We're doing this with a bunch of programs right now, social service programs. What's the difference between intake, first contact, registration and initial assessment because different people call them different things.
- But if we say that intake is the minimum information that you need to identify them in the data system, then some people say date of birth must be collected, other people say no, it just has to be whatever name they want to use, plus an email or phone number where we can contact them again.
- I don't think we can define intake because intake is so broad, but I think what you can do, is say this is how we define intake for the purposes of GSSO, where it is essential that as soon as you have their name you collect the gender or is all you need their email address

[Facilitator] So the focus of this is on just the GSSO data elements that are being collected so other demographic information, although it may be relevant to intake processes is outside of this discussion.

- I think we really want to know what the important information is to have on intake, whatever that may look like on a personal level. I would tend to agree that if all you have is other contact information and demographic information, that name used is probably the most important one.

[3] I would add pronouns, because if you're going to potentially speak about the individual to someone else in the healthcare setting, you want to be speaking correctly about them.

[Facilitator] In the first column here, in your experience who is responsible? Is it a tech and what is the nature of their role? I'm asking because we have got people from a number of different programs here. Anybody from primary care network or clinic that knows about their intake process? Now how about the emergency department?

- My experience in Ottawa is non-technical people

[Facilitator] So for non-clinical people, what do we mean for a registration clerk? Probably someone with experience in health information management. HIM folks. These people are generally unregulated, do they abide by a code of ethics, are they registered?

- I mean in ON, I don't think so but I'm speaking as a nurse so I could be wrong, but they would abide by the ethics of the privacy confidentiality etc. of their hospital. I believe they might belong to a college but I could be wrong.
- Regulation is questionable but bound by privacy confidentiality by their hospital, their employer, let's say right about for tertiary care. So when I say tertiary care I mean specialized programs that usually require a referral to get into.
- I'm going to comment since I'm with the cancer agency and for me I tend to conflate intake and registration because it tends to be the same thing. When you do an intake, you have to do a full registration and get a fair amount of background information so that you can start to act. The act of intake requires that you register somebody, and actually start entering information into their chart and into that particular encounter
- I don't think this is meaningful if people use intake in two different ways so rename it or get rid of it or put optional under gender identity and pronouns used and then move on until the process has been defined more rigorously. I think ? has some documentation around different processes.
- A comment on the intake side of things, it's only really been sort of my personal experience being referred places, that just the basic information from my family doctor's system would go for the referral but I would imagine depending on where you're going they would have to do a basic registration. But it always seems like when I go for the appointment I have to give much more information but I'm wondering if there was more information provided on intake whether it would allow them to better interact with me when they're setting up that first appointment. Maybe appropriate tests may be ordered if they have more information and that sort of thing.
- So potentially, might be important to have that better defined because in my own experience, it's always registration where I provide additional information

[Facilitator] So that means intake and registration sort of look the same, other than administrative sex and gender and sex assigned at birth. Is there anything else that registration, that you think should be collected?

- What's not listed is what I would consider clinical content.

[Facilitator] Can you define what you mean by clinical content?

- In my mind is a fairly clear separation of the administrative from the clinical content. I don't know why registration clerks or intake person will need to know anything about an anatomical or hormone inventory or medications because it's outside of scope for them and not relevant for administrative matters, unless that person is doing analytics.
- This is where different environments, you can run into different things, so even then the purpose and the meaning of registration becomes very specific. Where I've worked, registration is used to start to prepare for all clinical encounters and so the question becomes how and when does that get collected? Our registration is done by nurses and so they are actually starting interventions at the time of registration. So clinical nurses are doing the registration and the intake and they're looking through the information and starting to care plan as much as nurses do.
- Is this the person who works at a cancer clinic, right? So maybe, it's in part because the person's arrival already indicates they're there for a particular treatment or concern. So that's a different situation than a lot of others.
- So this goes back to what is the exact meaning of registration for example. We conflate intake and registration because it's already been determined why they're coming in.
- In terms of GSSO, one thing that's not here and I know this comes from Trans Care BC, is sexual orientation and where that information gets collected.

[Facilitator] Do you have any ideas on where that information should be collected?

- Again for our processes, that would be part of registration so that we can ensure throughout the rest of the processes, people are aware of it and are able to act and support the patient accordingly.
- The screen has to link closely with why we are collecting this data and go back to the purpose of why you're collecting the information so if it's for billing purposes that these are the fields we record or should be collected if it's for communicating with a patient to book an appointment.
- It may be up to the people to decide. At what point in their processes, do they do these things? Because there may be a bunch of stuff that happens during registration if it's a clinical nurse doing it.

[Facilitator] There's a couple of things that I've heard so far: One is that we don't really have consistent definitions of what these terms mean: intake, registration, clinical encounters; and we also don't have a standard way, standard operating procedures, in regards to who is doing that task. In some cases, might be non-regulated medical assistant, might be HR professional, administrative professional or someone the doctor has hired with little training. It might also be a nurse who is initiating a comprehensive assessment and care planning process through registration. Now in terms of clinical encounters, patient-provider interactions. My definition of provider means clinical staff and clinicians. So social workers, nurses, PTs, doctors, physicians and people who would be regulated and unregulated. Who should be taking anatomic inventories or hormone, or medication inventories?

- It should be someone with some clinical knowledge. I know that has to specify whether it's a doctor or a nurse or pharmacist or some other clinicians.

[Facilitator] One question on my mind for a while with hormone inventories and actually hormone medication inventory is in BC, we have a standard medication reconciliation process as many provinces do. Should hormone medication and medication that's used to support

transition and affirmative care be separated in a different medication inventory or should that be part of a medication reconciliation standard?

- I guess it depends on the goal of the reconciliation. If it's to ensure the person receives the correct medications while they're in the hospital, would be different than ambulatory care for an appointment.
- When it comes to prescriptions, this includes the prescription and the information that we're sending, collecting over the wire, should that information include anything listed here? Administrative legal name?
- That's usually the case the name that's used to confirm ID name is used – the pharmacist can interact with the patient when they come to pick up their prescriptions appropriately – pronouns for the same reason
- Is there any more information that will be relevant for the pharmacist? Are you only asking for the pharmacist or asking for the physician like a prescriber and nurse practitioner? Would anybody in the loop know this information?
- If you were in the place of a physician or NP or anybody who can put orders in an EHR or EMR, just doing an order. That order gets sent off automatically and the data that is sent with it needs to be specified and it may not be specified on the front end or may or may not be specified by the provider. If somebody's sending an order over the wire, what information should be going along with that order?

Hand notes regarding laboratory and imaging

- Laboratory
  - Gender ID, hormone inventory, hormone reference ranges may be necessary.
  - Hormone reference ranges need display of information that is appropriate to patient rather than blind linking to M/F
  - Match hormone inventory and reference ranges
- Imaging
  - Gender ID is needed
  - Anatomy inventory is needed
  - Recommendation for universal protection

[8] In chat window, "I just wanted to remind about some of the two step admin standards (like CIHI's current one) that include both gender identity and sex at birth and where that fits (for future conversations)"

Next session will pick up with Referrals