

Michael Smith Foundation for Health Research (MSFHR)
REACH Grant Knowledge Translation Topics:
Review of GSSO Settings – Primary Care
October 12th, 2021

Discussions: Introduction for two facilitators

[Facilitator 1] – This is the first part of healthcare settings special topic meetings. This one is on primary care, and tertiary and acute care will be covered in upcoming meeting in two weeks on Nov 23rd at 9am PST/12pm EST.

These meetings focus on step 5 of the action plan, which is “Integrate and tailor GSSO data collection with organizational structures, policies, use cases and workflow processes.”

The definition of primary care for this meeting is “Healthcare at a basic rather than specialized level for people making an initial approach to a doctor or nurse for treatment”. The scope of primary care for this meeting is: 1) health promotion; 2) illness and injury prevention; 3) diagnosis and treatment of illness and injury.

Providers of primary care vary, but today we are mainly focusing on family physicians, general medical practitioners, and nurse practitioners (NP). In some locations, primary care clinics might be run by nurses. Also, primary care can be delivered by some gynecologists (OBGYN).

This conversation is related to previous conversations on culturally safe policies for gender, sex, and sexual orientation (GSSO) data collection that were talked about in previous special topic meetings:

- Universal, meaning that we ask GSSO question to all patients,
- informed consent for sharing data between healthcare professionals and clinics
- updating information procedures,
- confidential processes for patients,
- training of staff to be culturally safe
- Requested GSSO information should be relevant to the clinical encounter

Potential differences in primary care compared to other types of care- lifespan issues (0 years to end of life), longitudinal care over episodic care (ideally overtime but with the shortage of general practitioners (GPs), it might be more episodic care), case management and care coordination component, for example, rheumatoid arthritis might start as primary care and then transition to specialist care.

Today, we will use a very generic workflow for primary care to ground the discussion, see Figure 1 below.

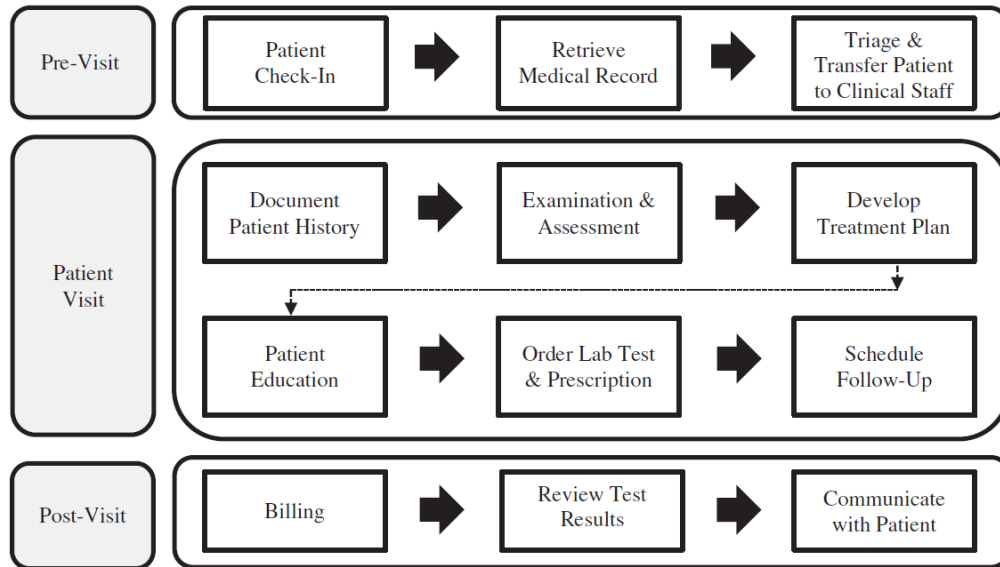


Figure 1 Typical primary care provider workflow: pre-visit, patient visit, and post-visit. Clinical Workflow Process Diagram adapted from Bowers *et al.* (2010) and Lee and Shartzter (2005: 1–2).

Three questions for this meeting are:

1. How does primary care workflow and environment affect what GSSO data is collected?
2. What would a minimum data set look like for different primary care processes?
3. What concerns need to be addressed about sharing primary care data with other levels of care (acute & tertiary)?

The Pre-Practitioner Encounter

[Facilitator 1] - Opening up first question – what is the purpose of the pre-practitioner exchange?

[1] – Since pre-practitioner encounters occurs, most often, in a public lobby and/or a waiting room, I have big concerns about privacy and confidential. One of the main reasons for pre-practitioner is identity confirmation and retrieval electronic medical records (EMRs), so if someone has updated their name socially or legally, this might not have occurred within their EMRs. So, people can get deadnamed and misidentified in the pre-practitioner encounter. Also, if their EMRs says they are male but whoever is doing the pre-practitioner encounter doesn't see them as male, this can cause problems.

[4] – I am a booking agent for a primary care practitioner (PCP), and I handle referrals and seeing what the patient are in for. Our EMR does not allow for modern GSSO data. Our gender field is only male, female, other. This literally others people. I have to ask what the patient's preferred gender is and if I can put this on the chart. If they do not know us, they might feel uncomfortable sharing information with us. It's hard to gather this data if we do not have training and trust. The purpose of pre-practitioner data

collection is to get the information to help the PCP, but if the EMR does not let us do this, it is hard from the beginning of the encounter.

[Facilitator 1] – So, you are recipient of the information from PCP?

[4] – Yes, I look for stuff like exercise and diet before we set up more specialist care appointments.

[6] – At my organization, we were involved in some training in a hospital in a large city. And one of the key things in this training was that the staff ask these questions about names and pronouns for ALL of our patients. I am not sure if gender was included at intake, but we ask these questions to all people so that patients do not feel singled out or othered.

[4] – A diversity, equity, and inclusion (DIE) committee has been set up at my organization to create more systemic training.

[2] – One of main questions is what is the purpose of the data being collected at the pre-practitioner encounter? It is mostly used for patient identification and to get the history on the patient from their records.

[Facilitator 1] – Part of the purpose of this meeting is capturing the reasons why we capture the data. As we go through these pieces, we need to consider the why of this collection and how it impacts care.

[2] – The main reason is to ensure that the PCP has the information on the patient.

[3] – While we are talking about data collection, it needs to be relevant to care being provided. For example, x-rays and setting up protective screening for certain organs the patient has. We need to protect the organs at all the time because they might be there.

[Facilitator 1] – It is important that we remind ourselves that for different types of care and setting, the GSSO data needs would differ. But patients don't usually walk into x-ray imaging themselves, they are referred most often from primary care.

[3] – The onus might be on the PCP to prepare the path for the individuals as they move into more specialized care.

[6] – On sharing of information, in going from primary care to lab, we need to be mindful that client might not be comfortable sharing their pronouns or a different name based on the trust they have with different healthcare professionals (HCP). PCPs need to be aware of this.

[Facilitator 1] – There is need to have more discussion on sharing. For example, a patient might be comfortable with sharing the recommendation shielding for x-ray but not sharing the organ inventory. Any other final thoughts on this first question.

[2] – It is about normalizing conversation on a universal level. To promote patient centered approach. We need to be able to address the patient how they like to be

addressed in a manner that in is comfortable for them. We have to normalize conversations around GSSO data within healthcare.

[Facilitator 1] – In terms of GSSO data collection, who should be collecting this info? Administrative staff, nurses, clinician providers? Are there any other folks that might collect this data?

[2] – Ideally, it would be collected using patient portals so the patient can do it themselves. Either in clinics or online.

[Facilitator 1]– So it would be self administered data?

[2] – Yes. Also, administrative staff should not be collecting clinical data like organ inventories.

[Facilitator 1] -In pre-practitioner encounter, what information should be collected and/or updated?

[2] – Admin staff would be collecting admin data, like names, while clinical data, like organ inventory, would be collected by the physician.

[3] – The clinical vs administrative distinction makes sense to me.

[4] – For booking, we need info like what should I call you and what pronouns should I use? But what organs they have is none of my business as a booking agent. If the physician needs to know more, they should gather this during the encounter.

[Facilitator 1]– Name used, pronouns, admin/legal name and sex is all administrative data. This important for matching patients to the record. Clinician data should be gathered by PCP.

[2] – I would agree with that.

[4] – I do too.

[Facilitator 1] – Last thing on pre-practitioner encounter is what should be displayed and what information would be okay to use in the waiting room.

[5] – I work in primary care and the physical design of the clinic does not allow for private conversation, even for stuff like phone number and email. The physical set up of lobbies are not great places to have conversation. An exam room is much better for sensitive information.

[6] – What do you mean by displaying information in the waiting rooms?

[Facilitator 1] – Stuff like calling out a name to call the patient into clinics, or messaging board displaying digitally. It highly varies between clinics and can be both audio and visual display.

[6] – Thanks for that. From our perspective, less info is better for waiting rooms. Just using last name, like patient Smith. And discourage a message board. Maybe we should use numbers to avoid names all together.

[1] – I like the idea of using numbers, like when you go to a deli. This avoids names all together and avoid honorifics, like **[6]** said. No Ms. Smith or Mrs. Smith, just patient Smith. In general, the less information is better at the pre-practitioner level.

[5] – We use first name, but I like the idea of using numbers. Another thing is that we have quite a few receptionists and our waiting room isn't that big. The receptionist can go get the patient physical without needing to call out the patient's name.

[Facilitator 1] – So there seems to be many different ways of getting patients back to the clinical room.

[5] – Another thing to consider is that some clinics have symbols that show it is a safe space. But if not everyone is safe and trained in the clinic, we need to consider what words and symbols we use. And what type of expectations these sets up for patient.

[3] – Also, washrooms are always a concern and should be gender neutral ideally.

The Clinical Encounter with a Practitioner

[Facilitator 1]– Moving onto the clinical encounter, what information should be collected? What is the purpose of the exchange? Within the pre-practitioner encounter, less is more, but in the clinical encounter room, what information should be collected?

[3] – Relevance is key, but there are many different types of encounters. The first one with a PCP is a meet and greet. Then there is managing acute problems, like a pain in leg. It depends on the context.

[2] – Whatever questions are asked; they should be asked universally to all patients.

[3] – Absolutely yes.

[5] – For downstream information collection, this helps with continuing coordination of care for patients, like scheduling a pap smear or a mammogram. We are trying to avoid situations where incorrect care is suggested that this might be triggering for patients. For example, a patient that has had a hysterectomy.

[Facilitator 1] – It is on the individual level but also a system and policy level.

[1] – I think something that would be really helpful is relevance of GSSO guidelines for physician, so it's not an individual decision. I have heard from some physicians that all data is relevant, and they need it all. But I disagree with that but if I argue with them, they pull the expert card of "oh, well you are not a physician or a clinician". Which is true, but I know what I am talking. This guidance doesn't have to be very strict, more like guidelines to help the physician feel knowledgeable and the patient to feel safe.

[2] – This speaks to the minimum data sets we talked about in pervious special topic meeting.

[3] – I think that PCP would really appreciate some guidance on what is relevant.

[Facilitator 1]– A minimum data set and guidance on what is relevant would be helpful. This will need to be explored more and get more information from patient and clinicians. Circling back to the meet-greet first encounter with an PCP, what information should be gathered at this time? Should an organ inventory be gathered at this point?

[1] –Organ inventory should be collected at the beginning because it lead to less assumptions based on other points of data like sex at birth or current gender identity. Also, it will help with care moving forward, especially for stuff like screening for cancer.

[3] – Echoing what **[1]** just did say, the organ inventory would help to gather early on to guide care moving forward.

[Facilitator 1]– Not a complete sharing in referrals, but only what is relevant to the care, such as the screening for x-ray imaging.

[3] – Yes, that is what I think about it.

[Facilitator 1] – We are within primary care, what makes this different from acute/tertiary care. How about coordination and continuity of care?

The Post Encounter

[Facilitator 1] – Moving on to post encounter care, such as results getting sent, referrals sent out, follow-ups. This can be a very large time frame of care after the clinical encounter.

[1] – For follow ups, we need to check with the patient about what names should use and how we can contract them. This especially for youths and their families. Questions that should be asked are: Can you be called at this number? Can we leave a voice mail? What name should we use on the voicemail? Or if we need to send physical mail, what address should we send to? What name should use on the envelope because this might be seen by others.

[Facilitator 1] – What I am hearing is that we need to consider what is appropriate for display, such as envelope or phone call.

[2] – A question I have is what data are they pulling this name from for this physical mail?

[3] – This is really important because individuals that are comfortable with their chosen name, do not deadname them on mail. But for people that might be out in the clinic might not be out at their homes. Asking the patient what they want to use so we avoid both problems.

[2] – Insurance and the names they use vs the names that individuals use.

[Facilitator 1] – We need to make these explicit, so we manage the information correctly. The other questions are on mini data set- based on clinical encounter or the type of assessment being done. Sharing of PC data with other levels of care (acute and tertiary). What kinds of concerns do we need to address?

[4] – For booking and billing, we often need to know legal names and preferred names and if the patient feels comfortable with what is being shared with other doctors. And how this information will be handled on the other end.

[2] – We need clear definitions for the data sets and its data elements. As our systems are so interconnected, how we mapping these in-between systems means we need to the distinct data fields.

[3] – In terms of mapping, when it comes to data, it is important on how the data is used. It is both used for caring for the individuals and keeping the health systems informed of the outcomes of care for different types of population. What kinds of care is provided to trans and non-binary people, being able to map this data onto systemic levels to assess outcomes and equity of healthcare.

[Facilitator 1] – Multiple uses for the data. Wrapping up, any last-minute concerns?

[6] – One issue we run into, if a person name is inputted into a system and then their old name gets puts back into the system. We need to look at technical solutions to this as data is shared between systems.

[Facilitator 1]– So we have to look at problems of automatic overrides of corrected information. Looking ahead to other meetings to keep this conversation going.

Post Session Feedback:

[7] – The first part of this discussion is also what we have seen in the literature – as this [pre-practitioner encounter] is the first point of contact, the significance of a welcoming environment.

[Regarding patient entered data through online portals] How do we address this for people who may not be able read or interpret the languages provided? What I haven't heard is how we address the self-administered data for people who may not read English. If are collecting this data from *all* patients than how do we reach *all* patients?

The possible use of numbers to call on people may not be the best approach either, as it may not be welcoming. I was reminded [of a quote from](#) a patient with cancer: "“You feel very vulnerable and you feel you’re only a number – I was 14-8-64 – that’s all you are at the Institute because it’s so busy.” Although a different care setting, I think it highlights the need for further research with patients. (And then I also am reminded how I would be likely to lose my number when I have been unwell and sitting in a clinic for one or two hours. What happens when they can't find their number?).

I would also add that family members may be present during some visits. Also, very significant in moving to virtual care where care visits are happening in people’s homes. There also the whole challenge of informal proxies with patient portals, where family members may get access to information in the portal. Patient portals often aren’t set up with proxy access, where patients can choose what they want to share with their proxy. The result is that there is informal proxy access, where patients share passwords. It is important to let patients know how the data that they may enter in a portal in clinic, may also link to their patient portal that family members may have access to.