The Nuts and Bolts of SOGI Data Implementation:

A Troubleshooting Toolkit

Now that you've made the case for collecting sexual orientation and gender identity (SOGI) data and you've built up coalition support at your organization, you are ready to begin the process of implementation. For many organizations, implementation of SOGI data collection can seem like a daunting and overwhelming task. This guide will help facilitate the implementation process by providing troubleshooting tips and approaches that other health care organizations that have already implemented SOGI data collection have found helpful.

Incorporating SOGI data collection into the workflow

Most health care organizations already have a workflow developed for collecting demographic information, such as race/ethnicity or income, from patients. Oftentimes, this data is collected at patient registration via paper or electronic registration forms. Adding SOGI data collection questions to these registration forms alongside other demographic information can be the most efficient way to incorporate SOGI data collection into an existing workflow.

The recommended SOGI questions below have been tested and found acceptable by a diverse group of patients from four community health centers across the country:

Do you think of yourself as (check one):

☐ Lesbian, gay, or homosexual
☐ Straight or heterosexual
☐ Bisexual
☐ Something else
☐ Don't know

What is your current gender identity (check one):

☐ Male
☐ Female
☐ Female-to-Male (FTM)/Transgender Male/Trans Man
☐ Male-to-Female (MTF)/Transgender Female/Trans Woman
☐ Genderqueer, neither exclusively male nor female
☐ Additional gender category, please specify: _____
☐ Decline to answer

What sex were you assigned at birth on your original birth certificate (check one):

☐ Male
☐ Female
☐ Decline to answer

In addition to incorporating these questions into registration forms and online patient portals alongside other demographic information, SOGI data can also be collected from patients by clinicians one-on-one during the patient visit. After the SOGI data are collected, be sure that the data are entered into the EHR. SOGI data should be updated every so often as a patient's understanding of their own identity may evolve over time.

Patients should also be asked about what name and pronouns they use at registration as these may differ from their legal documents; these questions can be left open-ended for the patient to write in a response. It is very important that patients always be addressed by the proper name and pronouns as using incorrect names and pronouns can be very hurtful, even if unintentional. While this is especially helpful for transgender patients, it is applicable and useful for all patients. For example, asking what name patients would like to use would benefit any patient who happens to go by a name that is different from their legal name for any number of reasons, such as having a difficult name to pronounce or going by a middle name. Staff should always look at name and pronoun data prior to interacting with patients. If staff are unsure about name or pronouns, they can simply ask patients politely what they prefer to be called and what pronouns they use. Staff can also be trained to address patients in a gender neutral manner, such as "the patient is in the waiting room," rather than "he/she is in the waiting room."

Training staff to collect SOGI data

Once the implementation process begins, all staff should receive mandatory training on LGBT cultural competency. Training should cover topics such as LGBT terminology, LGBT health, as well as why collecting SOGI data is important to patient and population health and how to go about asking the questions in a culturally competent and affirming manner. All of this can be found in the training on the Medicare Learning Network titled, "Catching Everyone in America's Safety Net: Collecting Data on Sexual Orientation (SO) and Gender Identity (GI) in Health Care Settings."

The training should also cover how to respond to patient concerns about SOGI questions. For example, patients may have concerns related to privacy or may not understand why SOGI data are necessary. In these situations, it can be helpful to assure patients that all data collected, including SOGI data, will be kept confidential, and that they have the option of declining to answer. Staff should also inform patients that SOGI data, along with other demographic data, helps clinicians provide the best quality of care for each patient.

While patients may have concerns about answering SOGI questions, it is actually more often the case that providers and staff overestimate how uncomfortable patients will be answering these questions. A recent study found that 80% of emergency room doctors thought that patients would refuse to answer SO questions, while only 10% of patients said that they would refuse to answer. Many health care organizations that are implementing SOGI data collection noted that training was very important, not just for helping staff navigate patient discomfort, but more so to help staff navigate their own discomfort around asking the questions. It can be helpful to include case studies or role play scenarios in trainings so that staff have an opportunity to practice asking SOGI questions and responding to concerns so that they become more comfortable with the process.

Staff training should also cover topics related to creating an inclusive and affirming environment for all patients. This can include teaching staff how to avoid using gendered terms such as "sir" and "ma'am," ensuring that sexual orientation and gender identity are explicitly covered in your organization's nondiscrimination policies, and including images of LGBT people and same-sex couples in your organization's promotional and educational materials. LGBT people and same-sex couples also come from a diversity of background (e.g., race/ethnicity, age, nationality) and this diversity ought to be depicted in promotional and educational materials.

Optimizing your EHR for SOGI data collection

A lot of health care organizations struggle with optimizing and customizing their EHR systems for SOGI data collection. The following tips for EHR customization may be helpful for your organization:

◆ **All certified EHR systems under Meaningful Use Stage 3 must have the capacity to record SOGI data** as of January 1, 2018. If your EHR does not have this capability, you may first have to update your EHR to the most current system version. A version update or EHR refresh can present a good opportunity to implement SOGI data collection.

◆ **It is important to understand how SOGI data are displayed in your EHR, and if that view is different depending on who is looking at the EHR** (physician vs. front desk staff, for example). Ideally, the preferred name and pronouns in use for patients should be prominently displayed for all staff in the EHR to reduce misnaming and misgendering patients as much as possible. If it is not possible to get name and pronoun data fields to display prominently throughout the EHR, these data can potentially be entered into other fields, such as a comments, notes, or nickname field. You may even be able to color code your EHR depending on a patient's pronouns in use.

◆ **Some EHR systems do not allow providers to access data input at registration, including SOGI data.** If this is the case, a possible workaround could be to use an alert or banner in the EHR to inform providers of SOGI data entered at registration. Ideally, clinicians and registration staff should be able to view, enter, and modify SOGI data of patients.

◆ **It may take some work with your IT staff and your EHR vendor in order to customize your EHR** to correctly use gender identity data and sex assigned at birth data. Sex assigned at birth data may be necessary to use for billing and insurance purposes for certain procedures, and it could also be used to inform providers of potential preventive screening needs. Otherwise, gender identity data should be used when interacting with patients.

◆ **You may encounter difficulty in getting your organization to prioritize customization of the EHR for SOGI data collection,** especially since health care organizations often have a long list of other EHR-related projects and requests at any given time. It could be helpful to utilize the recommendations and requirements regarding SOGI data collection of organizations such as HRSA, CMS, and the Joint Commission in order to get your organization to prioritize SOGI-related EHR requests.

Using the data

Your organization should also have a plan in place for how you will use the SOGI data once your organization begins implementing SOGI data collection. These data can be very useful for quality improvement efforts. Many health care organizations regularly report on different quality measures, like health outcomes and service utilization, stratified by various demographic factors, such as race/ethnicity or income. Once you begin collecting SOGI data, these quality reports should also look at health outcomes and service utilization stratified by sexual orientation and gender identity in order to identify possible disparities and areas for improvement.

It is important to note that both the sexual orientation and the gender identity of each patient should be analyzed separately as each person has both a sexual orientation and a gender identity. Additionally, lesbians, gay men, bisexual men, bisexual women, and transgender people experience unique challenges and disparities. Sometimes, in order to understand disparities, populations should not be aggregated together. For example, an analysis of 2014-2015 Behavioral Risk Factor Surveillance System data from 27 states revealed important differences in health outcomes by sexual orientation. Bisexual men were significantly more likely than heterosexual men to report being in poor/fair health and having activity limitations, while there was no significant difference in these behaviors between gay men and heterosexual men. Gay men were significantly more likely than heterosexual men to be diagnosed with cancer and chronic obstructive pulmonary disease, while there were no significant differences in diagnoses of either disease between bisexual men and heterosexual men. Bisexual women were significantly more likely than heterosexual women to report having poor/fair health, poor physical health days, and being diagnosed with asthma or chronic obstructive pulmonary disease; lesbian women did not report significant differences from heterosexual women in all of those health outcomes. Aggregating these data together–for example, combining lesbians and bisexual women–would have obscured these important differences.

SOGI data can also be used to identify areas for quality improvement within your organization. For example, if there are higher levels of missing or incomplete SOGI data within a certain department in your organization, that could indicate that additional training and resources related to LGBT competency should be directed to that department. Additionally, departments that are failing to collect quality SOGI data from patients may also be failing to collect other sorts of demographic information, so this can present an opportunity to identify areas for targeted quality improvement within your organization.

Additionally, SOGI data would be useful to use in clinical decision support algorithms to remind providers to perform certain preventive screenings that they might not know to provide otherwise. For example, clinical decision support could be used to remind a provider to talk about or offer a prostate screening to a patient who is a transgender woman. Ideally, an anatomical inventory within the EHR would be developed to indicate what anatomy each patient currently has. This, alongside gender identity and sexual orientation, would provide all the information necessary to provide high quality care to all patients.

Where did these data come from?

Researchers from The Fenway Institute and NORC conducted key informant interviews with administrators at a variety of healthcare facilities across the US. The administrators were asked about their thoughts and experiences regarding SOGI data collection. If they were in the process of implementing SOGI data collection, they were asked about strategies, barriers, and facilitators to that process. Notes from the key informant interviews were coded and analyzed for recurring themes.

1 Cahill S, Singal R, Grasso C et al. (2014, Sept. 8). "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." PLOS One. 9(9): e107104.

2 Haider A, Schneider E, Kodadek L, et al. (2017 June). "Emergency Department Query for Patient-Centered Approaches to Sexual Orientation and Gender Identity: The EQUALITY Study." JAMA Intern. Med. 177(6): 819-828.

3 Gonzales G, Henning-Smith C. (2017). "Health Disparities by Sexual Orientation: Results and Implications from the Behavioral Risk Factor Surveillance System." J Community Health.

4 Ibid.

5 Ibid.