READY, SET, GO!

A GUIDE FOR COLLECTING DATA ON SEXUAL ORIENTATION AND GENDER IDENTITY

Updated 2020

NATIONAL LGBT HEALTH EDUCATION CENTER

A PROGRAM OF THE FENWAY INSTITUTE

INTRODUCTION

In 2016, sexual orientation and gender identity (SOGI) became required data elements to be reported yearly by Health Center Program grantees (health centers) in the Uniform Data System (UDS). Since then, health centers across the country have been integrating SOGI questions into their workflows and electronic health records (EHRs). After nearly four years of SOGI data collection in health centers, we have updated this SOGI implementation guide based on the lessons learned thus far.[1-3]

How to Use this Guide

This guide was designed to help your health center successfully collect SOGI data, **no matter where you are in the process**. For those just beginning, the guide can be used from start to finish. If you already have a system, but have encountered challenges and questions, this guide can help you address them. Even if your system is working smoothly, you will find resources and recommendations here that will help you move to the next level of data collection and analysis.

Why Collect SOGI?

Lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority (LGBTQIA+) people continue to experience significant health disparities and require care and services tailored to their unique needs.[4,5] The process of asking all patients about their SOGI empowers health centers to get to know their patients better, and to provide them with the culturally responsive, patient-centered services they need. SOGI data collection also allows health centers to learn about the populations they are serving, and to measure the quality of care provided to people of all sexual orientations and gender identities.[6,7]

1 Grasso C, McDowell MJ, Goldhammer H, Keuroghlian AS. Planning and implementing sexual orientation and gender identity data collection in electronic health records. J Am Med Inform Assoc. 2019;26(1):66-70.

2 Grasso C, Goldhammer H, Funk D, et al. Required sexual orientation and gender identity reporting by US health centers: First-year data. Am J Public Health. 2019;109(8):1111-1118.

3 Furness BW, Goldhammer H, Montalvo W, et al. Transforming primary care for lesbian, gay, bisexual, and transgender people: A collaborative quality improvement initiative. Ann Fam Med (In press.)

4 Gonzales G, Przedworski J, Henning-Smith C. Comparison of health and health risk factors between lesbian, gay, and bisexual adults and heterosexual adults in the United States: Results from the National Health Interview Survey. JAMA Intern Med. 2016;176(9):1344–1351.

5 Feldman J, Brown GR, Deutsch MB, et al. Priorities for transgender medical and healthcare research. Curr Opin Endocrinol Diabetes Obes. 2016;23(2):180–187.

6 Cahill S, Makadon H. Sexual orientation and gender identity data collection in clinical settings and in electronic health records: a key to ending LGBT health disparities. LGBT Health. 2014;1(1):34-41.

7 The Joint Commission. Advancing effective communication, cultural competence, and patient- and family-centered care for the lesbian, gay, bisexual, and transgender (LGBT) community: A field guide. Oak Brook, IL: Joint Commission; 2011.

READY!

Creating a Team

The first step in setting up a successful SOGI data collection system is to bring together a team of staff members who demonstrate commitment and enthusiasm for increasing LGBTQIA+ cultural responsiveness and engagement at the health center. Ideally, the team consists of at least one person in senior management, one staff member from the health information technology (HIT) department, and one or more clinical staff and front desk/registration staff. If any of these roles are not represented on the team, it is important for the team to set up meetings with leaders from these departments to update them on progress and needs, and to receive their input. Health center SOGI teams have reported on how important it is to have senior leadership on board throughout the process, and to have these leaders communicate their support to the entire health center and greater community. In addition, having LGBTQIA+ staff on the SOGI team is helpful, but not essential.

Implementation Timeline

Teams should meet regularly to plan the implementation of SOGI data collection across the health center. **Figure 1** provides a sample implementation timeline for SOGI teams. **Each of these steps are explained in more detail later in this publication**. Keep in mind that the length and timing of steps will vary by organization; in many cases, several of the steps can occur at the same time.

Figure 1. Sample SOGI Implementation Timeline

Month 1:
Engage with health center leadership and community partners

Establish a process for addressing the community's comments and concerns

Plan time and space for any follow-up engagement that may be required

Month 2:
Review SOGI questions (refine if needed)

Develop a data collection workflow and process map

Establish a quality improvement process to evaluate the efficiency and effectiveness of the workflow; modify as appropriate

Translate SOGI questions as needed

Months 3-5:
Train all staff in LGBTQIA+ cultural responsiveness

Provide training and supervision of SOGI data collection to relevant staff, and assess for readiness

Begin making the clinical environment more welcoming and inclusive for people of all sexual orientations and gender identities

Month 3:
Pilot SOGI workflow in one department or site (train relevant staff)

Make refinements to the workflow and training as needed

Month 4:
Expand pilot and training to other departments/sites

Make refinements to the workflow and training as needed

Months 3-4:
Modify electronic health record systems to accommodate clinic workflow, as needed

Months 5-7:
Continue to expand SOGI data collection and training to other departments/sites

Months 9-10:
Expand to all departments/sites

Monitor progress through quarterly data feedback reports

Month 14:
Conduct first data summary report

Ongoing:
Monitor data quality; respond to patient and staff feedback; train new staff

Translate SOGI questions and resources as needed

Analyze data and report on findings

Annually:
Train all staff in LGBTQIA+ cultural responsiveness

Community Engagement

It is strongly recommended that SOGI teams begin by engaging in conversations with local LGBTQIA+ community leaders about how the health center can: decrease LGBTQIA+ stigma, ensure privacy of information, and translate SOGI terms in a way that aligns with community cultural and language norms. **Table 1** offers a list of websites with resources for finding local LGBTQIA+ organizations.

It is also valuable to reach out to non-LGBTQIA+ community members and leaders to understand how community members may respond to the addition of SOGI questions and other LGBTQIA+-inclusive changes occurring at their local health center. Addressing concerns early in the process through community education about the benefits of SOGI will go a long way towards minimizing community resistance and questions.

Table 1. LGBTQIA+ Community Engagement Organizations

CenterLink is a network of LGBTQIA+ community centers across the U.S.	www.lgbtcenters.org
PFLAG is an LGBTQIA+ family support organization with more than 400 local chapters.	pflag.org
GLBT National Help Center provides a national database of LGBTQIA+ groups and service agencies.	www.glbtnearme.org
SAGEnet National Affiliates are local organizations serving LGBTQIA+ older adults.	www.sageusa.org
GSAnetwork and **GLSEN** are national LGBTQIA+ youth organizations with chapters in many communities and schools.	gsanetwork.org/national and www.glsen.org
Center for Black Equity is a health, economic and social equity organization for Black LGBTQIA+ communities. They organize a network of Black Prides in U.S. cities.	centerforblackequity.org/black-prides/
National Queer Asian Pacific Islander Alliance is a federation of LGBTQIA+ Asian American, South Asian, Southeast Asian, and Pacific Islander organizations.	www.nqapia.org

SOGI Questions

Figure 2 displays the SOGI questions that align with the 2019 UDS SOGI reporting elements.[8] Please refer to the most recent [UDS Reporting instructions](#) for more information on how to code SOGI data. These SOGI questions were originally developed and tested through research studies, and have been modified to reflect more current terminology.[9,10] If you find that some of the SOGI terms do not fit within your community's lived experiences, you can add or exchange terms.

Figure 2. SOGI Questions

Do you think of yourself as (Check one):

☐ Straight or heterosexual

☐ Lesbian, gay, or homosexual

☐ Bisexual

☐ Something else (e.g., queer, pansexual, asexual.) Please specify: _____

☐ Don't know

☐ Choose not to disclose

What is your current gender identity? (Check one):

☐ Female

☐ Male

☐ Transgender Woman/Transgender Female

☐ Transgender Man/Transgender Male

☐ Other* (e.g., non-binary, genderqueer, gender-diverse, or gender fluid)

   Please specify: _____

☐ Choose not to disclose

What sex were you assigned at birth? (Check one):

☐ Female

☐ Male

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* You may replace the term "other" on patient-facing forms with the term that is most affirming for the communities you serve (e.g., "something else," or "additional category.")

8 Bureau of Primary Health Care, HRSA. Uniform Data System reporting instructions for 2019 health center data. May 28, 2019. OMB Number: 0915-0193, Expiration Date 03/21/2022. https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/reporting/2019-uds-manual.pdf

9 Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, et al. 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. 2014;9(9):e107104.

10 Deutsch MB, Feldman JL. Updated recommendations from the world professional association for transgender health standards of care. Am Fam Physician. 2013;87(2):89-93.

Figure 3 provides definitions of SOGI categories and terms. Health centers may wish to include these definitions with the SOGI questions if they have patients who are unfamiliar with SOGI terminology. For definitions of other terms, see the LGBTQIA+ Glossary of Terms for Health Care Teams.

Figure 3. Definitions of SOGI Terms

Sexual Orientation: how people characterize their emotional and physical attraction to others.

> **Straight or heterosexual:** describes women who are primarily emotionally and physically attracted to men, and men who are primarily emotionally and physically attracted to women.

> **Gay:** describes people who are primarily emotionally and physically attracted to the same gender as themselves. It most commonly refers to men who are primarily attracted to men.

> **Lesbian:** describes women who are primarily emotionally and physically attracted to other women.

> **Bisexual:** describes people who are emotionally and physically attracted to women/females and men/males. Some people define bisexuality as attraction to all genders.

> **Something else:** is an option for people who identify their sexual orientation as something other than the categories provided (e.g., asexual, pansexual, queer, same-gender loving).

> **Don't know:** an option for people who do not know their sexual orientation.

> **Choose not to disclose:** an option for people who choose not to share this information.

Gender Identity: a person's inner sense of being a girl/woman/female, a boy/man/male, something else, or having no gender.

> **Transgender woman/female:** describes someone assigned male at birth who has a female gender identity.

> **Transgender man/male** describes someone assigned female at birth who has a male gender identity.

> **Other (something else, additional category)** is an option for people with a gender identity that is not listed in the categories provided (e.g., non-binary, genderqueer, gender-diverse, or gender fluid).

> **Choose not to disclose:** an option for people who choose not to share this information.

Sex assigned at birth is the sex (female or male) assigned to an infant.

Translating SOGI Questions

The National LGBT Health Education Center offers SOGI questions translated into Spanish, and will provide translations into additional languages by summer 2020. Because SOGI terminology can vary across cultures and geography, health center teams will want to review these translations with people in their own communities before using them. If needed, teams can ask local translators to help with translating SOGI questions into languages spoken by their health center populations.

Asking for Names and Pronouns

Many people use a first name that is different than the one on their insurance. This is especially the case for transgender and gender-diverse people. Therefore, we strongly suggest that health centers ask patients for the name that is on their insurance records, as well as the name they use in personal interactions (this is also known as a chosen name).

One way to ask is:

- *What name would you like us to use?* _____

- *What name is on your insurance records (if applicable)?* _____

Pronouns are the words people should use when they are referring to you, but not using your name. Asking about pronouns helps staff correctly refer to patients. A growing number of people have the singular "they" pronoun, rather than "he" or "she." Others have pronouns developed specifically for non-binary gender identities, such as the pronoun "ze." It is recommended that the pronoun question be open-ended, or include a write-in option.

A suggested way to ask is:

What are your pronouns? :
- ☐ She/Her/Hers
- ☐ He/Him/His
- ☐ They/Them/Theirs
- ☐ Please specify: _____

The patient's chosen name and pronouns should be used consistently by all health care staff. Using incorrect names and pronouns can be very hurtful, even when unintentional.

Figure 4 shows an example of a registration form that incorporates SOGI, name fields, and pronoun fields, along with other pertinent demographic information.

Ensuring Privacy and Confidentiality

As with all patient information, SOGI data is protected by the Health Insurance Portability and Accountability Act (HIPAA). Forms with SOGI questions can incorporate language about confidentiality, and staff can be trained to discuss these protections.

The information in your medical record is confidential and is protected under Massachusetts General Laws Ch. 111, Sec 70. Your written consent will be required for release of information except in the case of a court order.

Medical Record #
(For office use only)

Client Registration

Name on Insurance* Last	First	Middle Initial	**What Name would you like us to use?**

Sex on Insurance* ☐ Female ☐ Male
While we recognize a number of genders / sexes, many insurance companies and legal entities unfortunately do not. Please be aware that the name and sex you have listed on your insurance must be used on documents pertaining to insurance, billing and correspondence. If your preferred name and pronouns are different from these, please let us know.

What are your pronouns?
(e.g., he/him, she/her, they/them)

Date of Birth *Month Day Year* / /	**Social Security #**	**State ID # or License #**

Your answers to the following questions will help us reach you quickly and discreetly with important information.

Home Phone ( )	**Cell Phone** ( ) -	**Work Phone** ( )	**Best number to use:** ☐ Home ☐ Cell ☐ Work
Ok to leave voicemail? Yes No -	**Ok to leave voicemail?** Yes No -	**Ok to leave voicemail?** Yes No -	

Local Address	City	State	ZIP

Billing Address (if different from above)	City	State	ZIP

Email address:

Occupation	Employer/School Name	Are you covered under school or employer's insurance? ☐ Yes ☐ No

Emergency Contact's Name	Phone Number	Relationship to you

If you are under 19, the Department of Public Health requires that you provide parent/guardian contact information.

Parent/Guardian Name	Phone Number	Relationship to you

We will send certain correspondence, such as bills, to your mailing address. **How would you prefer to receive other types of written correspondence? (check one)** ☐Secure Email (MyFenway) ☐Letter ☐Other

This information is for demographic purposes only and will not affect your care.

1.) What is your annual income? _____ ☐ No income **1a.) How many people (including you) does your income support?** _____	**2.) Employment Status** ☐ Employed full time ☐ Employed part time ☐ Student full time ☐ Student part time ☐ Retired ☐ Unemployed ☐ Other _____	**3.) Racial Group(s)** (check all that apply) ☐ African American / Black ☐ Asian ☐ Caucasian / White ☐ Native American / Alaskan Native / Inuit ☐ Pacific Islander ☐ Other _____	**4.) Ethnicity** ☐ Hispanic/Latino/Latina ☐ Not Hispanic/Latino/Latina **5) Country of Birth** ☐ USA ☐ Other _____
6.) Preferred Language (choose one:) ☐ English ☐ Español ☐ Français ☐ Português ☐ Русский Other _____	**7.) Do you think of yourself as:** ☐ Lesbian, gay, or homosexual ☐ Straight or heterosexual ☐ Bisexual ☐ Something else ☐ Don't know	**8.) Marital Status** ☐ Married ☐ Partnered ☐ Single ☐ Divorced ☐ Other _____ **9.) Veteran Status** ☐ Veteran ☐ Not a Veteran	**10.) Referral Source** ☐ Self ☐ Friend or Family Member ☐ Health Provider ☐ Emergency Room ☐ Ad/Internet/MediaOutreach WorkerSchool ☐ Other _____

11.) What is your current gender identity? (Choose one) ☐ Female ☐ Male ☐ Transgender Woman/Transgender Female ☐ Transgender Man/Transgender Male ☐ Additional gender category, please specify _____ ☐ Choose not to disclose	**12.) What sex were you assigned at birth? (Choose one)** ☐ Female ☐ Male ☐ Choose not to disclose

Developing a Workflow

When developing a standard workflow for collecting SOGI data, teams may wish to consider the following questions:

- *When and where will SOGI questions be asked?*

- *How frequently will the questions be asked?*

- *Who will respond to patient inquiries about the questions?*

Typically, the most efficient and effective way to collect SOGI data is to gather it along with other demographic or social history information (e.g., employment, race, living situation). This normalizes the process and ensures more complete data collection. In addition, it allows health centers to collect the data at the first patient visit, as well as to update the information during routine check-ins. Providers can then follow-up with patients to discuss SOGI during the clinical exam, as appropriate.

SOGI should always be self-reported by patients (or their caregivers if the patient cannot answer the questions themselves) and should be collected at least annually. Keep in mind that a person's SOGI, like other demographic variables such as race and ethnicity, can change over time.

There are several ways to integrate SOGI questions into existing practices:

- SOGI may be added to new patient registration forms, the annual UDS verification form, or other standard forms that update demographic information.
  - Patients can electronically enter SOGI data through a patient portal at home, or on a tablet or kiosk at check-in. Electronic methods generally provide the most privacy.
  - Patients can write their responses on paper forms or use dry-erase markers on laminated forms.
- Medical assistants or nurses can collect SOGI data by asking patients in a private setting and entering the answers into the EHR.
- Primary care providers can ask about SOGI during the social history, and can manually enter the data during or after the patient encounter.
- Registration staff can also ask about SOGI, but this method is the least preferred method among patients.[11]

Figure 5 demonstrates a workflow for collecting SOGI data that allows for multiple points at which the data can be collected.

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[11] Maragh-Bass AC, Torain M, Adler R, et al. Is it okay to ask: transgender patient perspectives on sexual orientation and gender identity collection in healthcare. Acad Emerg Med. 2017;24(6):655-667.

Figure 5. Sample Process of Collecting SOGI Data
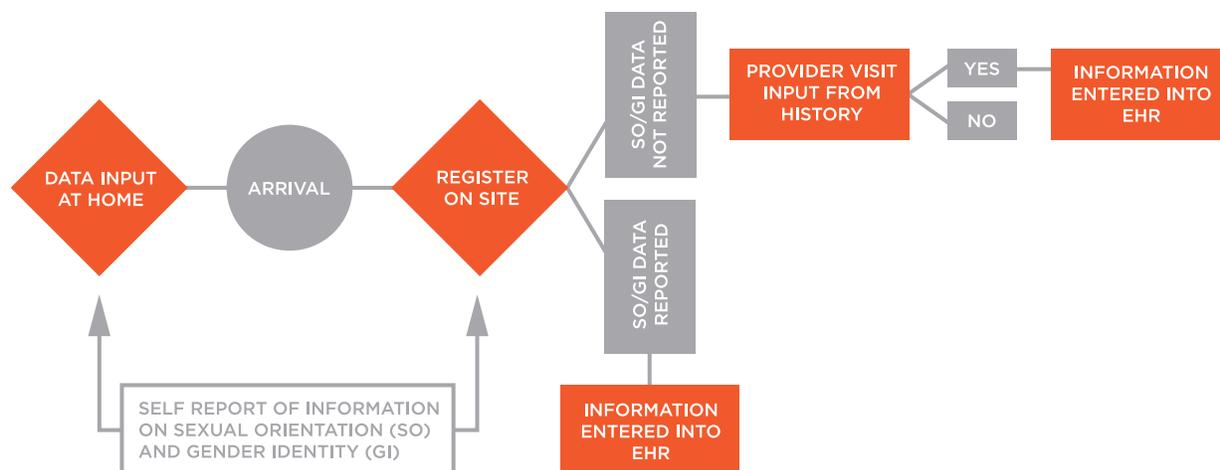
Asking about SOGI during the Clinical Encounter

Below are examples of ways to ask patients about SOGI during a clinical encounter. In these examples, the provider normalizes the conversation by explaining that all patients are asked these questions.

The more comfortable the provider is with asking about SOGI, the more comfortable the patients will be. Research has shown that most patients want to share this information with their providers, and feel it is safe to do so.[12]

In communities with higher levels of LGBTQIA+ stigma, having providers ask open-ended questions about patients' behaviors and desires can provide a better platform for patients to describe their identities and needs in their own words. If patients do not want to talk about SOGI, however, there is no reason to push them. Providers may find that these patients will open up to them at a later date.

Example 1:

Provider: We have begun asking all patients about their sexual orientation and gender identity so we can provide everyone with the best care possible. Can you tell me about yourself?

Example 2:

Provider: We have begun asking all patients about their sexual orientation so we can provide everyone with the best care possible. Do you consider yourself straight, gay, lesbian, bisexual, or something else? I can explain what these terms mean if you have questions, or you can choose not to answer.

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12 Maragh-Bass AC, Torain M, Adler R, Schneider E, Ranjit A, Kodadek LM, et al. Risks, benefits, and importance of collecting sexual orientation and gender identity data in healthcare settings: a multi-method analysis of patient and provider perspectives. LGBT Health. 2017;4(2):141-52.

Pilot Testing

Teams can slowly roll out SOGI data collection by pilot testing the workflow in one department, floor, or location. Running a pilot will help teams identify and fix problems as they arise.

- Start with one location, floor, or department
- Choose a location with staff who understand the benefits of collecting SOGI data, have been trained in the process, and are excited to try it out
- Conduct frequent check-ins with the staff who are piloting the process
- Use a continuous quality improvement method, such as Plan-Do-Study-Act (PDSA) cycles to assess what's working and what needs improvement[13]
- Add more departments when ready
- Be flexible – if something is not working out, it is okay to make adjustments

Considerations for Children and Adolescents

Health centers are required to collect SOGI data on all patients ages 18 and older. Collection of SOGI data from patients younger than 18 years of age is not mandated, but all patients regardless of age must be given the opportunity to provide this information.[5] Health center teams can discuss the pros and cons of asking SOGI of children and adolescents with regard to privacy and priorities.

Children 12 and Under

Children 12 and under and their parents/guardians are typically comfortable answering questions about gender identity. Providers made aware of a child who may be transgender or gender-diverse can help families appropriately support that child's development through direct care or referrals. In situations where the parent/guardian contradicts the gender identity of a minor, providers can refer to family systems therapy and to community organizations like a local PFLAG chapter. Clinicians can also provide psychoeducation for parents/guardians about gender identity and can model affirming communication by using the child's self-determined name and pronouns.

The sexual orientation question can also be asked as an opening for a young patient or parent/guardian who wishes to start a conversation with the provider. It is likely that most children and their parents/guardians will answer "Don't Know."

Adolescents 13–17

To protect privacy and encourage openness, providers will likely want to ask SOGI questions of adolescents without a parent/guardian in the room (as they do with other history questions, such as sexual and substance use histories, that may not be answered truthfully with a parent/guardian nearby). Providers should be clear with patients about whether the information would go into the health record and might be visible to parents/guardians.

Adolescents can also answer SOGI questions on written or electronic forms, but they should always be re-asked by the provider, since the information may have been filled out by the parent/guardian, or under their watch. LGBTQIA+ adolescents face increased risk of mental health problems, suicide, and HIV/STDs; by sharing SOGI with their providers, these adolescents can receive the support, treatment, and prevention services they need.

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13 Reed JE, Card AJ. The problem with Plan-Do-Study-Act cycles. BMJ Qual Saf. 2016;25(3):147-152.

SET!

Training All Staff on LGBTQIA+ Health

SOGI data collection works best in an environment that embraces health equity for LGBTQIA+ people. To begin, health center leaders can use all-staff meetings or similar events to communicate why SOGI and LGBTQIA+ health are priorities for the health center. Next, health center teams can train all staff on providing culturally responsive and inclusive services to LGBTQIA+ patients. Online and in-person trainings that focus on basic terminology, health disparities, and effective communication strategies are available through the National LGBT Health Education Center. Sometimes SOGI team members adapt standard training materials for their health centers, or ask local community groups to run trainings.

Training can be provided yearly and as part of onboarding training and/or compliance trainings.

Training Staff on SOGI

Relevant staff also need training on how to collect SOGI data and how to communicate effectively and respectfully with patients about SOGI data. Training videos and other resources on SOGI are also available from the National LGBT Health Education Center SOGI resources.

Supervisors can assess their staff's learned skills based on observed simulated interactions followed by observed interactions with real patients. Staff can then transition to unsupervised SOGI data collection with patients.

Patient Education

Patient education will go a long way towards improving SOGI data collection. Patients appreciate information on why it is important to disclose their SOGI to providers, how the information will be protected, and how the health center will use the information.

In addition to training staff to answer patient questions, health centers may wish to distribute the patient brochure: Sexual Orientation and Gender Identity Questions: Information for Patients, which is available in multiple languages, including Haitian Creole, Vietnamese, Arabic, Simplified Chinese, and Brazilian Portuguese (see **Figure 6**).

Sexual Orientation and Gender Identity Questions:

Information for Patients

We are asking you about your sexual orientation and gender identity in order to provide more patient-centered care. Read inside to learn what the questions mean, and how the information will be used to improve health care for all.

Nuevas preguntas sobre la orientación sexual y la identidad de género:

Información para pacientes
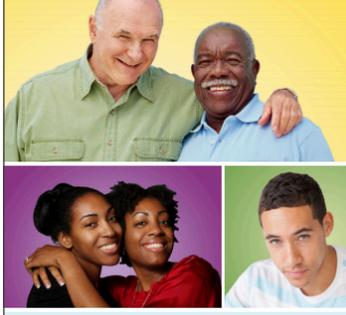
Recientemente hemos añadido nuevas preguntas sobre la orientación sexual y la identidad de género a nuestros formularios de registro.

Nuestro centro de salud cree que es importante que conozcamos esta información sobre nuestros pacientes. A continuación, se encuentran algunas preguntas frecuentes sobre por qué estamos haciendo estas preguntas y cómo se usará esta información.

Responding to Patient Questions and Concerns

Although health care staff often assume patients will be offended by SOGI questions, this is rarely the case.[12] Health centers report that very few patients have complained about or skipped SOGI questions. In fact, patients are much more likely to answer SOGI questions than they are to answer questions about income. This has been true in rural as well as urban health centers.[2]

Still, health center staff will need to be prepared to answer patient questions about SOGI in an affirming and friendly manner. Patients' basic questions can be handled by trained frontline staff who can also hand out the informational brochures described earlier. For patients with personal questions, or with strong feelings about the process, registration staff can suggest talking to their providers.

Below we provide examples of responses to patient questions regarding SOGI. These scenarios can be included in staff training workshops, and can be practiced through role-playing exercises. Staff can also view short videos demonstrating the "do's and don'ts" of responding to patient issues and concerns.

Example 1:

Patient: I don't understand why you are asking these questions. Why do you need to know my sexual orientation?

Staff: These questions are important to all of our patients' health. Here is a pamphlet with helpful information. If you have any more questions, your provider will be happy to talk to you.

Example 2:

Patient: I don't see why these questions are anyone's business.

Staff: These questions will be kept confidential. However, if you do not wish to answer, you can check the box "choose not to disclose." If you would like to discuss this more, your provider will welcome your questions. You may also wish to read this brochure for an explanation of why we're asking these questions.

Responding to Staff Concerns

Some staff members may need extra coaching and reassurance in addition to standard training. For example, one health center had a staff member who resisted asking about SOGI because she felt like it was against her religious beliefs. The supervisor coached this staff member by letting her know that this was about the health center trying to give the best care for their patients; it did not mean she had to change her own values. After this coaching, the staff member was able to start asking about SOGI. Regular observation of staff interactions with patients along with supervisory check-ins with staff members will help identify and address issues that may arise. Additionally, health centers can offer training to staff on understanding and addressing their own implicit biases.

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[12] Maragh-Bass AC, Torain M, Adler R, Schneider E, Ranjit A, Kodadek LM, et al. Risks, benefits, and importance of collecting sexual orientation and gender identity data in healthcare settings: a multi-method analysis of patient and provider perspectives. LGBT Health. 2017;4(2):141-52.

Creating a Welcoming and Inclusive Environment

To further help patients feel comfortable sharing SOGI information, health centers can make changes to the physical environment that create a more welcoming and inclusive atmosphere for LGBTQIA+ patients and their families. For example:

- Add images of same-sex couples or other LGBTQIA+ people on the website, and in educational and marketing materials
- Include sexual orientation, gender identity, and gender expression in all non-discrimination policies
- Offer restrooms that are for all genders, and have a policy that patients and staff can use restrooms that reflect their gender identity
- Ensure that patient forms include the full range of family structures and living situations, and do not make assumptions about anatomy based on gender identity or sex assigned at birth

EHR Customization

All EHRs certified under Meaningful Use are required to have the capacity to record SOGI data, and most EHRs used by health centers now have built-in SOGI fields. Nonetheless, health centers may wish to further customize their EHR to accommodate their clinic's SOGI workflow and patient population needs (such as variations in terminology). To facilitate this process, HIT team members can:

- Talk to their EHR vendor— several vendors have already helped other customers with similar needs
- Connect with other health centers/organizations that use the same EHR and may have already developed solutions
- Access the HITEQ Center, which provides national training and technical assistance to support health centers in optimizing their EHR/Health IT systems

When customizing EHR forms, the following strategies can help minimize errors and bias:

- Create structured and discrete data fields based on your SOGI questions that populate throughout the EHR
- Limit the ability to add in free text responses—it may be difficult to use free text data in logic in other parts of the EHR
- Place the data fields based on how data will be entered and stored
- For "missing" data, differentiate between the possible reasons why the data may be missing: Is it due to the data not being collected? Or is it due to a patient skipping or refusing to answer the question?

Changes that will facilitate patient-centered care include the following:

- Decide which staff will have permission to enter, modify, or view data
- Ideally, clinical staff will have access to SOGI information when meeting with patients so they can ask appropriate questions. In addition, clinicians should be able to edit the fields in case patients give them new information
- Create fields for pronouns and chosen name
- Ensure that pronouns and chosen name can be viewed throughout the EHR system so that all staff are able to use these correctly when interacting with patients. If this is not possible, consider creating banners or alerts in the EHR that show a patient's name and pronouns

Additional customizations to consider, especially in health centers with large transgender and gender-diverse populations:

- Use a color code system to indicate pronouns and chosen names on forms or EHR banners (**see Figure 7**)

- Adjust mailing systems that automatically fill in salutations, such as Mr. and Ms., to match pronouns and not sex. Another solution is to update letter templates to say "Dear Patient"

- For lab orders, prescriptions, patient instructions, and chart summaries, etc., develop a way to add pronouns and chosen names adjacent to the name on the person's insurance. This will help with staff interactions without interfering with insurance claims. For example:

  - Patient: Lawrence Jones (Name used: Lila Jones)

  - Pronouns: she/her/hers

- Create additional forms, such as anatomical inventories, to support clinical decisions based on a patient's anatomy rather than assigned sex at birth or gender identity

Figure 7: Sample Pronoun Color Coding System

She/Her/Hers

He/Him/His

They/Them/Theirs
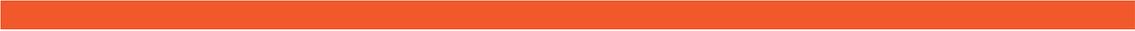
GO!

Understanding and Using SOGI Data

Collecting SOGI data is not an end in itself, but rather the first step in measuring, monitoring, and improving the health of LGBTQIA+ populations in your health center. In other words, SOGI data serve the same function as race and ethnicity data in population health management by enabling health centers to identify health disparities within a patient population. Once SOGI systems are in place, data teams can begin developing summary reports and dashboards for different populations based on SOGI. These data can be incorporated into existing population management and quality measure reports and presented to senior management and at all-staff meetings. For example, diabetes control measures can be stratified by race, age, sexual orientation, and gender identity.

Keep the following in mind when running analyses:

- Sexual orientation is not the same as gender identity. Everyone has both a sexual orientation and a gender identity; therefore, these factors should be analyzed separately.

- Health risks differ depending on sexual orientation and gender identity; for example, try to avoid grouping bisexual patients with gay or lesbian patients.

- In order to identify all of your transgender and gender-diverse patients, it is necessary to look at both gender identity and sex assigned at birth.

Monitoring Data Quality

Maintaining data quality is critical. Without putting quality checks in place, you cannot know if your data are accurate. **Figure 8** recommends ways in which staff can help ensure quality control of SOGI data.

Figure 8. Sample Staff Roles for SOGI Data Quality Control

Registration Staff	• Check paper registration forms against data in EHR • Provide feedback on challenges (e.g., language barriers)
Data Analyst/ Programming Staff	• Run quarterly reports • Analyze and interpret results • Identify problem areas • Look at trends over time for anything unusual
Quality Control Staff	• Incorporate quality control and monitoring into existing workgroups • Help develop changes in workflow to fix problem areas
HIT Staff	• Create checklists and confirm all components are installed after upgrades • Develop forms
Clinical Staff	• Provide guidance on how information is documented in the EHR
Human Resources	• Train new staff as part of orientation • Hold annual trainings for existing staff

Next Steps

Health center teams that are ready to take SOGI data analysis to the next level can access the National LGBT Health Education Center's publication: You've Built it, Now What? Applying Sexual Orientation and Gender Identity Data to Clinical Quality Improvement and Decision Support. This publication discusses how to use SOGI data to reduce health disparities among LGBTQIA+ patients in your health center.

LESSONS FROM THE FIELD

When taking on a new data collection process, it is natural for health centers to worry about added workload, patient questions, and staff resistance. Although challenges will arise, it may be helpful to know that the process is achievable.

This publication is based on lessons learned from diverse health centers across the nation. Below we highlight items that health centers reported being critical to their success in implementing SOGI data collection:

- Having passionate champions

- Having engaged leadership that demonstrate ongoing commitment

- Educating staff on LGBTQIA+ health disparities and inequities

- Bringing HIT early into the process to help design workflow and determine customization of the EHR

- Being flexible when problems arise

- Ensuring that a SOGI team member is available for staff to bring questions and challenges around data collection

- Training in small groups so staff are comfortable asking questions and discussing concerns

- Adapting standard trainings to fit the culture of one's own health center and patient population

- Having patient education brochures available in waiting and/or exam rooms

ADDITIONAL RESOURCES

National LGBT Health Education Center SOGI Resources and Training:
www.lgbthealtheducation.org/resources/in/collecting-sexual-orientation-and-gender-identity-data

Grasso C, Goldhammer H, Funk D, et al. Required sexual orientation and gender identity reporting by US health centers: First-year data. Am J Public Health. 2019;109(8):1111-1118.

Grasso C, McDowell MJ, Goldhammer H, Keuroghlian AS. Planning and implementing sexual orientation and gender identity data collection in electronic health records. J Am Med Inform Assoc. 2019;26(1):66-70.

Furness BW, Goldhammer H, Montalvo W, et al. Transforming primary care for lesbian, gay, bisexual, and transgender people: A collaborative quality improvement initiative. Ann Fam Med (in press.)

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