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Updated 2022

READY, SET, GO!

**A GUIDE FOR COLLECTING DATA ON SEXUAL
ORIENTATION AND GENDER IDENTITY**



**NATIONAL LGBTQIA+ HEALTH
EDUCATION CENTER**

A PROGRAM OF THE FENWAY INSTITUTE



INTRODUCTION

How to Use this Guide

This guide was designed to help health centers and other health care organizations successfully collect sexual orientation and gender identity (SOGI) data and document the data into the electronic health record (EHR). For those just beginning the process, this 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 experience health disparities and require care and services tailored to their unique needs.¹⁻⁴ 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 access to care and quality of care provided to people of all sexual orientations and gender identities.^{5,6} Health Center Program grantees and look-alikes are required to report SOGI data elements in the annual [Uniform Data System](#) (UDS).

What's New in 2022?

This Guide was updated in 2022 to reflect recent changes in SOGI policy, practice, research, and terminology.⁷⁻¹⁰ Updates include new SOGI question wording for forms, a new workflow algorithm to accommodate telehealth appointments, and new resources.

¹ 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.

² de Blok CJ, Wiepjes CM, van Velzen DM, et al. Mortality trends over five decades in adult transgender people receiving hormone treatment: a report from the Amsterdam cohort of gender dysphoria. *Lancet Diabetes Endocrinol.* 2021;9(10):663-670.

³ Branstrom R, Pachankis JE. Sexual orientation disparities in the co-occurrence of substance use and psychological distress: a national population-based study (2008-2015). *Soc Psychiatry Psychiatr Epidemiol.* 2018;53(4):403-412.

⁴ Reisner SL, Poteat T, Keatley J, et al. Global health burden and needs of transgender populations: a review. *Lancet.* 2016;388(10042):412-436.

⁵ 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.

⁶ 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:2011.

⁷ 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.

⁸ Almazan AN, King D, Grasso C, et al. Sexual orientation and gender identity data collection at US health centers: Impact of city-level structural stigma in 2018. *Am J Public Health.* 2021;111(11):2059-2063.

⁹ Cahill S, Grasso C, Keuroghlian A, Sciortino C, Mayer K. Sexual and gender minority health in the COVID-19 Pandemic: Why data collection and combatting discrimination matter now more than ever. *Am J Public Health.* 2020;110(9):1360-1361.

¹⁰ 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.

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 should include representatives of administrative and clinical departments from across your organization, including staff from senior management, health information technology (HIT), medical, and front desk/registration departments. If any of these roles are not represented on the team, it is important to set up meetings with leaders from these departments to receive their input and update them on progress and needs. Health center SOGI teams have reported on the importance of having senior leadership on board throughout the process, and to having leaders communicate their support to the entire health center and greater community. In addition, it is highly beneficial to include LGBTQIA+ staff on the team.

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:	<ul style="list-style-type: none">• 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:	<ul style="list-style-type: none">• Review SOGI questions (refine if needed)• Develop a data collection workflow and process map• Evaluate EHR functionality for collecting SOGI data. Communicate with EHR vendor to create forms and update performance, as needed• 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:	<ul style="list-style-type: none">• 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:	<ul style="list-style-type: none">• Pilot SOGI workflow in one department or site (train relevant staff)• Make refinements to the workflow and training as needed
Month 4:	<ul style="list-style-type: none">• Expand pilot and training to other departments/sites• Make refinements to the workflow and training as needed
Months 3-4:	<ul style="list-style-type: none">• Modify electronic health record systems to accommodate clinic workflow, as needed
Months 5-7:	<ul style="list-style-type: none">• Continue to expand SOGI data collection and training to other departments/sites
Months 9-10:	<ul style="list-style-type: none">• Expand to all departments/sites• Monitor progress through quarterly data feedback reports
Month 14:	<ul style="list-style-type: none">• Conduct first data summary report
Ongoing:	<ul style="list-style-type: none">• 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:	<ul style="list-style-type: none">• 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 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.	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.	glbtnearme.org
SAGEnet National Affiliates are local organizations serving LGBTQIA+ older adults.	sageusa.org
GSAnetwork and GLSEN are national LGBTQIA+ youth organizations with chapters in many communities and schools.	gsanetwork.org/national and 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.	nqapia.org

SOGI Questions

Figure 2 displays suggested SOGI questions and response options that can be used on registration forms, portals, and in EHR fields. These questions were originally developed and tested through research studies,¹¹⁻¹³ but have been updated to reflect more current terminology. SOGI questions will continue to evolve over time, and further changes are to be expected. Organizations may choose to further modify response option terms to better fit the local community's lived experiences. For example, organizations that serve a large number of American Indian/Alaska Native populations may wish to include the term Two Spirit for both sexual orientation and gender identity. Two Spirit describes American Indian/Alaska Native people who express their gender identity, spiritual identity, or social role in a traditional, non-Western way. The EHR Customization section below provides information about making modifications to accommodate additional terms.

Figure 2: Suggested SOGI Questions

Introduction: *We are asking the following information in order to understand whom we are serving and to provide you with more patient-centered health care. This information will be entered into your electronic health record.*

Sexual Orientation

Do you think of yourself as: *(Check all that apply) or (Please choose the option that best describes you. Currently our system allows only one option.)*

- Lesbian or gay
- Straight or heterosexual (that is, not gay or lesbian)
- Bisexual
- Queer
- Pansexual
- Something else: _____
- Don't know
- Prefer not to answer

What is your current gender identity? *(Check all that apply) or (Please choose the option that best describes you. Currently our system allows only one option.)*

- Female/woman/girl
- Male/man/boy
- Nonbinary, genderqueer, or not exclusively female or male
- Transgender female/woman/girl
- Transgender male/man/boy
- Another gender: _____
- Don't know
- Prefer not to answer

What sex were you assigned at birth, on your original birth certificate? *(Check one.)*

- Female
- Male
- X/Another sex: _____
- Don't know
- Prefer not to answer

Health centers may wish to provide patients with definitions of SOGI terms alongside the SOGI questions, particularly if they have patients who are unfamiliar with SOGI terminology. **Figure 3** provides sample SOGI definitions. For a more comprehensive list, see the [LGBTQIA+ Glossary of Terms for Health Care Teams](#).

¹¹ Cahill S, Singal R, Grasso C, 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.

¹² Deutsch MB, Green J, Keatley J, et al. Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group. *J Am Med Inform Assoc*. 2013;20(4):700-703.

¹³ Deutsch MB, Keatley J, Sevelius J, Shade SB. Collection of gender identity data using electronic medical records: survey of current end-user practices. *J Assoc Nurses AIDS Care*. 2014;25(6):657-663.

Figure 3: Definitions of SOGI Question Categories

Sexual Orientation: How people describe their emotional and physical attraction to others.

Lesbian describes women who are mainly emotionally and physically attracted to other women.

Gay describes men who are mainly emotionally and physically attracted to men, but can also describe women attracted to women.

Straight or heterosexual (that is, not gay or lesbian) describes women who are mainly emotionally and physically attracted to men, and men who are mainly emotionally and physically attracted to women.

Bisexual describes people who are emotionally and/or physically attracted to people of all genders.

Queer describes people who think of their sexual orientation as outside of societal norms. Some people view the term queer as more fluid and inclusive than traditional categories for sexual orientation.

Pansexual describes people who are emotionally and physically attracted to people of all gender identities, or whose attractions are not related to gender identity.

Something else is an option for people whose sexual orientation is not listed in the response options provided, including people who do not have a sexual orientation.

Don't know is an option for people who do not know their sexual orientation, are questioning their sexual orientation, or do not understand the meaning of sexual orientation.

Prefer not to answer is an option for people who do not wish to share their sexual orientation at this time.

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

Female/woman/girl describes people assigned female at birth who have a female gender identity.

Male/man/boy describes people assigned male at birth who have a male gender identity.

Nonbinary, genderqueer, or not exclusively female or male describes people whose gender identity is beyond the traditional binary of girl/woman and boy/man.

Transgender girl/woman/female describes people assigned male at birth who have a female gender identity.

Transgender boy/man/male describes people assigned female at birth who have a male gender identity.

Another gender is an option for people whose gender identity is not listed in the response options provided, including people who do not have a gender identity.

Don't know is an option for people who do not know their gender identity, are questioning their gender identity, or do not understand the meaning of gender identity.

Prefer not to answer is an option for people who do not wish to share their gender identity at this time.

Sex assigned at birth is the sex assigned to an infant and written on the original birth certificate.

Sex assigned at birth can be female, male, or X/another sex.

X/Another sex is for people born in jurisdictions that allow a third assigned sex option and whose parents assigned their sex as nonbinary or X on their birth certificate.

Don't know is an option for people who do not know assigned sex at birth or who do not understand the question.

Prefer not to answer is an option for people who do not wish to share their sex assigned at birth at this time.

Coding SOGI for the UDS

Health Center Program grantees and look-alikes are required to report SOGI data elements in the annual [Uniform Data System](#) (UDS). Although a few of the UDS SOGI data elements are not exactly the same as SOGI response options recommended in **Figure 2**, it is straightforward to recode those options for the UDS. For example, *queer* and *pansexual* may be recoded as *something else*. **Figure 4** shows how to code recommended SOGI options for the 2022 UDS.

Figure 4: SOGI response options mapped to UDS 2022 reporting elements	
SEXUAL ORIENTATION	
Recommended response options	UDS reporting elements (Tables 3A, 3B)
Lesbian or gay	→ Lesbian or gay (Line 13)
Straight or heterosexual	→ Heterosexual (or straight) (Line 14)
Bisexual	→ Bisexual (Line 15)
Queer	→ Something else (Line 16)
Pansexual	→ Something else (Line 16)
Something else: _____	→ Something else (Line 16)
Don't know	→ Don't know (Line 17)
Prefer not to answer	→ Chose not to disclose (Line 18)
GENDER IDENTITY	
Female/woman/girl	→ Female (Line 21)
Male/man/boy	→ Male (Line 20)
Nonbinary, genderqueer, or not exclusively female or male	→ Other (Line 24)
Transgender female/woman/girl	→ Transgender woman/transgender female/transgender feminine (Line 23)
Transgender male/man/boy	→ Transgender man/transgender male/transgender masculine (Line 22)
Another gender: _____	→ Other (Line 24)
Don't know	→ Other (Line 24)
Prefer not to answer	→ Chose not to disclose (Line 25)
SEX ASSIGNED AT BIRTH (SEX REPORTED ON ORIGINAL BIRTH CERTIFICATE)	
Female	→ Female
Male	→ Male
X/Another sex	→ Unknown (there is currently no equivalent in the UDS)
Don't know	→ Unknown (there is currently no equivalent in the UDS)
Prefer not to answer	→ Unknown (there is currently no equivalent in the UDS)

Translating SOGI Questions

Because SOGI terminology can vary across cultures and geography, health center teams will want to translate SOGI questions into local languages and dialects. Some health centers use professional translation services, while others may have bilingual or multi-lingual staff members who can lead the translation. It is also a good idea to ask community members to check for comprehension and cultural sensitivity of the translated wording.

Asking for Names and Pronouns

Names: Many people use a name that is different than the one on their medical insurance or government-issued identification (e.g., driver's license). This is especially the case for transgender and gender diverse people. We therefore strongly recommend asking patients for the name they want health care staff to use in personal interactions. To minimize billing issues, it is also necessary to collect the names patient use on their insurance records or government-issued identification.

Pronouns: Pronouns are the words we use to refer to someone without using that person's name. Using incorrect pronouns can be very hurtful, even when unintentional. It is therefore important to ask all patients for their pronouns and to consistently use those pronouns. Examples of pronouns are *she/her/hers*, *he/him/his*, and *they/them/theirs*. People may also use pronouns developed specifically for nonbinary gender identities, such as *ze/zir/zirs* and *co/cos/coself*. For this reason, it is recommended to include a write-in option. See **Figure 5** for a suggested way to ask about names and pronouns on forms.

Figure 5: Sample name and pronoun questions for forms

While our health center recognizes all gender identities, many insurance companies and legal entities do not. Please be aware that the name and sex listed on your insurance must be used for insurance, billing, and correspondence documents. If you do not have insurance, list what is on your government-issued ID (such as your driver's license).

First and last name on medical insurance: _____

What name would you like our staff to use? _____

Sex/gender marker on medical insurance:

- Female
- Male

What are your pronouns?

- She/Her/Hers
- He/Him/His
- They/Them/Theirs
- Please specify: _____

Ensuring Privacy and Confidentiality

As with all patient information, SOGI data is protected similarly to any Health Insurance Portability and Accountability Act (HIPAA) information. Forms with SOGI questions can incorporate language about confidentiality, and staff can be trained to discuss these protections. Note that protections for minors vary across jurisdictions (see the Documenting SOGI of children and adolescents section below).

Developing a Workflow

When developing a standard workflow for collecting SOGI data, teams may 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.

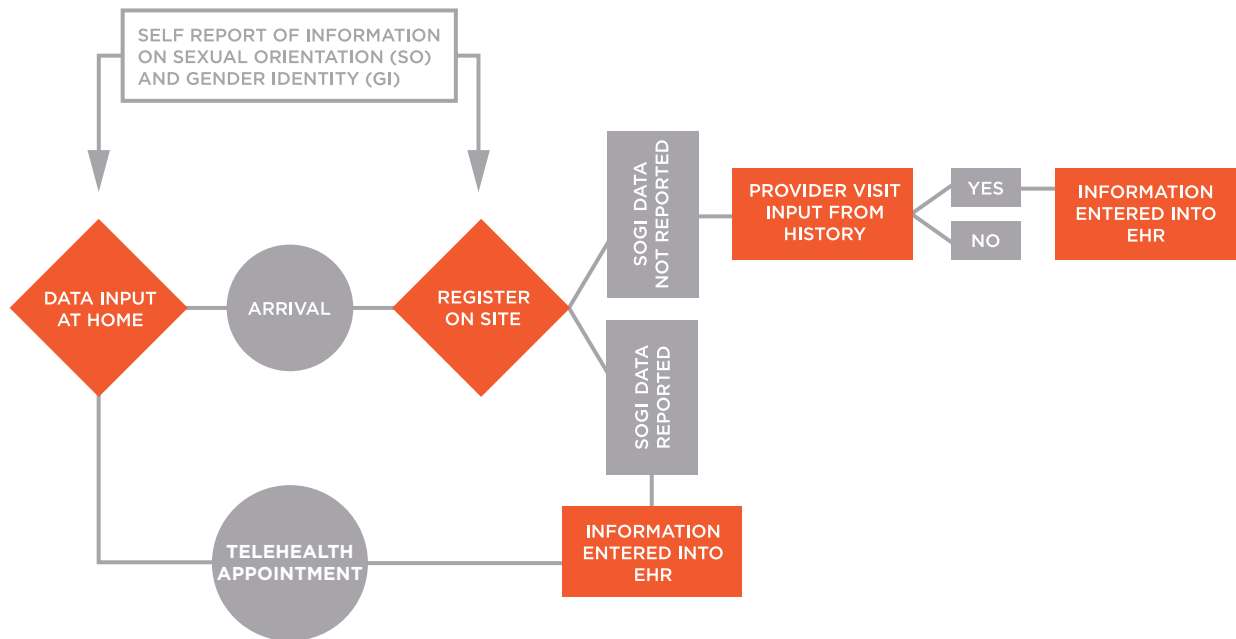
There are several ways to integrate SOGI questions into existing practices:

- 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.¹⁴

Figure 6 demonstrates a workflow for collecting SOGI data that allows for multiple points at which the data can be collected.

¹⁴ 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 health-care. *Acad Emerg Med.* 2017;24(6):655-667.

Figure 6: Sample Process of Collecting SOGI Data



Asking about SOGI during the Clinical Encounter

Below are examples of ways to ask adult 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.¹⁵

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.

¹⁵ Maragh-Bass AC, Torain M, Adler R, 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):141-152.

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
- Add more departments when ready
- Be flexible – if something is not working out, it is okay to adjust

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 minors (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. Some advantages of routinely asking children and adolescents about SOGI are:

- To provide an opportunity for patients to ask questions and discuss concerns about their identity development, relationships with peers and family, safety, and health risks
- To encourage family acceptance of their LGBTQIA+ children, which will promote their children's social and emotional health¹⁶
- To provide referrals to gender-affirming care, counseling, or social support, as needed

Providers can ask about SOGI with children and adolescents during the annual wellness visit. Questions can be broached with an opening statement that normalizes the discussion, such as: *“I am going to ask you some questions that I ask all patients your age, because it helps me provide you the best care possible.”* Providers should explain that they will not disclose the information to anyone else unless the patient gives permission to do so.

For youth ages 11 years and older, SOGI can be asked during the history that is taken without a parent/guardian in the room, which helps to protect privacy and encourage openness. Children and 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, who may not be aware of, or supportive of, their child's SOGI.

¹⁶ Westwater JJ, Riley EA, Peterson GM. What about the family in youth gender diversity? A literature review. *Int J Transgend.* 2019;20(4):351-370.

Gender identity questions

- Age to start asking: 3 to 4 years old
- What to ask:
 - o A sample question for children 3-14 years old: *“Some kids feel like a girl on the inside, some kids feel like a boy on the inside, and some kids feel like neither, both, or someone else. What about you? How do you feel on the inside? There’s no right or wrong answer.”*
 - o A sample question for children 14-17 years old: *“What is your current gender identity? Some teens feel like a girl or woman on the inside, some feel like a boy or man on the inside, and some feel like neither, both, or another gender. What about you? There’s no right or wrong answer.”*

Sexual orientation questions

- Age to start asking: 10 to 11 years old
- What to ask:
 - o A sample question for teens 10-13 years old: *“Have you ever had a crush on someone?”*
If yes: *“Was this crush on a boy, a girl, both, or someone of another gender?”*
 - o A sample question for teens 14-17 years old: *“Are you sexually attracted to boys, girls, both, neither, another gender, or are you not sure?”*

Documenting SOGI of children and adolescents

Providers should always ask the patient for consent to add SOGI information in the EHR, with a clear explanation that legal guardians are able to access to this information due to current federal policies. Disclosure of a child’s SOGI to their family or other caretakers can potentially put them at risk of physical or emotional harm, so asking for consent is critical. It is also recommended to seek legal counsel to ensure that all local and federal minor consent and privacy laws are understood and followed.

If permission is given by the child to document SOGI in the EHR, providers will need to follow-up the attractions question with an identity question about sexual orientation. Both the UDS and EHR fields require an identity label, such as gay, lesbian, or bisexual. Young people may not be ready or interested in labeling their SOGI; or they may identify with more than one option. Providers can explain the limitations of the EHR system, can ask if the patient still wants to choose an option, or prefers not to answer. The notes field can be used to add further details.



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

Online and in-person trainings that focus on basic terminology, health disparities, and effective communication strategies are available through the [National LGBTQIA+ Health Education Center](#). SOGI team members can adapt standard training materials for their health centers, or ask local community groups to run 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 LGBTQIA+ Health Education Center SOGI resources](#).

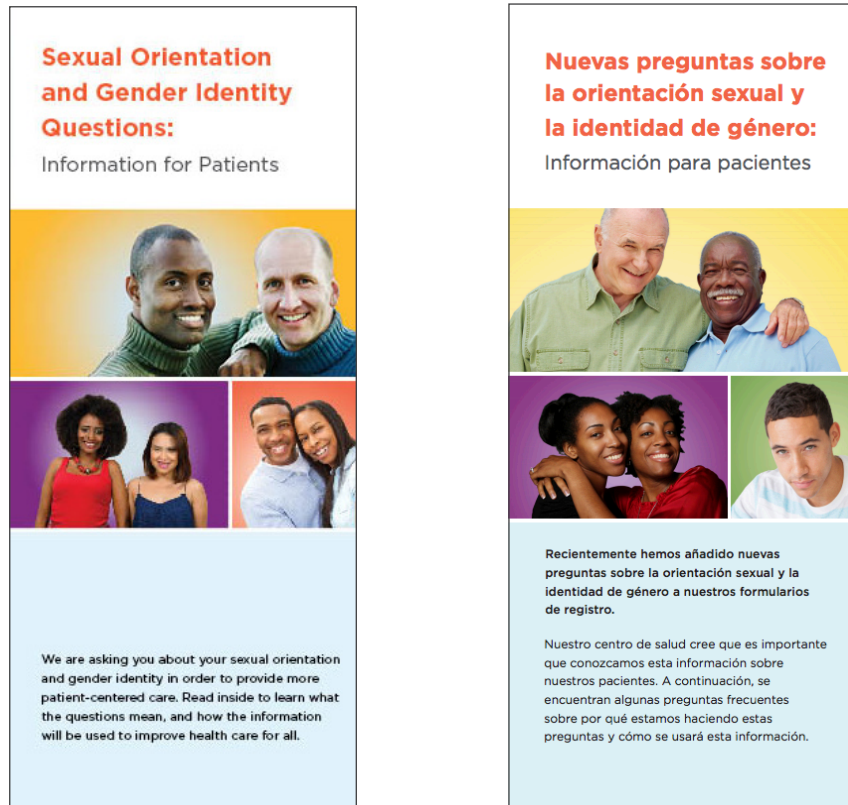
Supervisors can assess their staff's learned skills based on observed simulated interactions followed by observed interactions with real patients. Staff can then transition to unsupervised SOGI data collection with patients.

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 (see **Figure 7**).

Figure 7: SOGI Patient Education Brochures



Responding to Patient Questions and Concerns

Although health care staff often assume patients will be offended by SOGI questions, this is rarely the case.¹⁵ 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.¹⁰

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](#).

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
- Provide pronoun buttons to staff (e.g., My pronouns are: She/Her/Hers)
- 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
- Access [training materials on creating LGBTQIA+ welcoming environments](#)

EHR Customization

All EHRs certified under Office of National Coordinator of Health Information Technology (ONC) are required to have the capacity to record SOGI data. 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 changes to wording of SOGI terms). 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 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 to the EHR that can facilitate patient-centered care:

- 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 name used and pronouns
- Ensure that pronouns and names 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:

- Adjust mailing systems so that they do not automatically fill in salutations, such as Mr. and Ms.
 - 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 name used and pronouns 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; **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.

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 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	<ul style="list-style-type: none"> • Check paper registration forms against data in EHR • Provide feedback on challenges (e.g., language barriers)
Data Analyst/ Programming Staff	<ul style="list-style-type: none"> • Run regular reports • Analyze and interpret results • Identify problem areas • Look at trends over time for anything unusual
Quality Control Staff	<ul style="list-style-type: none"> • Incorporate quality control and monitoring into existing workgroups • Help develop changes in workflow to fix problem areas
HIT Staff	<ul style="list-style-type: none"> • Create checklists and confirm all components are installed after EHR upgrades • Develop forms
Clinical Staff	<ul style="list-style-type: none"> • Check for data inconsistencies within and among departments; offer training to departments with more errors and missing data
Human Resources	<ul style="list-style-type: none"> • Train relevant new staff on SOGI and LGBTQIA+ health • 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 in 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

RESOURCES

National LGBTQIA+ Health Education Center

All SOGI resources

www.lgbthealtheducation.org/resources/in/collecting-sexual-orientation-and-gender-identity-data

SOGI patient pamphlets

<https://www.lgbtqiahealtheducation.org/resources/in/collecting-sexual-orientation-and-gender-identity-data/>

SOGI training videos

<https://www.lgbtqiahealtheducation.org/courses/so-gi-data-collection-training/>

LGBTQIA+ implicit bias resources

<https://www.lgbtqiahealtheducation.org/?s=implicit+bias>

LGBTQIA+ organizational change resources

<https://www.lgbtqiahealtheducation.org/resources/in/organizational-change/>

LGBTQIA+ Glossary of Terms for Health Care Teams

<https://www.lgbtqiahealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/>

Additional Resources

Uniform Data System (UDS) Resources

<https://bphc.hrsa.gov/datareporting/reporting/index.html>

HITEQ Center

hiteqcenter.org