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# READY, SET, GO!

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## GUIDELINES AND TIPS FOR COLLECTING PATIENT DATA ON SEXUAL ORIENTATION AND GENDER IDENTITY

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# INTRODUCTION

## Why Collect Data on Sexual Orientation and Gender Identity?

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) people experience significant health disparities and require preventive services and treatment interventions tailored to their unique needs. Yet health care providers often do not know the sexual orientation or gender identity (SO/GI) of their patients, leading to missed screenings, less effective counseling, culturally insensitive remarks, and other missteps. The process of asking all patients about their SO/GI empowers health care organizations to get to know their patients better, and to provide them with the appropriate, patient-centered services they need.

SO/GI data collection has been recommended by both the Institute of Medicine<sup>1,2</sup> and the Joint Commission<sup>3</sup> as a way to learn about which populations are being served, and to measure the quality of care provided to LGBTQ people. In recognition of the population health benefits of collecting SO/GI data, the Bureau of Primary Health Care (BPHC), HRSA added SO/GI as required elements to be reported yearly by Health Center Program grantees (health centers) in the Uniform Data System (UDS) beginning in Calendar Year 2016.<sup>4</sup>

Although some have raised concerns that the process of identifying LGBTQ people could invite stigma or discrimination, in actual practice, SO/GI data collection has encouraged health centers to increase the cultural competence of their care delivery and environment. Patients have found that sharing SO/GI information has facilitated important health-related conversations with clinicians they trust.

In sum, the reasons to collect SO/GI data are to:

- Help clinicians provide more effective patient-centered care;
- Encourage staff to provide more culturally-sensitive services to LGBTQ patients;
- Facilitate the monitoring of quality of care to LGBTQ populations; and
- Reduce health disparities.

## How to Use This Guide

The following guide is designed to help your health center successfully collect SO/GI data, ***no matter where you are in the process***. For those just beginning, the guide can be used from start to finish. If you have already created 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.

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1 Institute of Medicine. The health of lesbian, gay, bisexual, and transgender (LGBT) people: building a foundation for better understanding. Washington, DC: National Academies Press; 2011.

2 Institute of Medicine. Sexual orientation and gender identity data collection in electronic health records: a workshop. Washington, DC: National Academies Press; 2012.

3 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.

4 Department of Health and Human Services, Health Resources and Services Administration. Program Assistance Letter (PAL 2016-02). Approved Uniform Data System Changes for Calendar Year 2016. March 22, 2016.

# READY!

## Creating a Team and a Timeline

The first step in setting up a successful SO/GI data collection system is to identify key staff who can meet regularly, be champions, and provide feedback on how the process is going. Although having LGBTQ people on the team is very helpful, it is not essential. All people can do this work effectively.

Ideally, one member of the team should be an executive (e.g., CEO, CFO) who can make sure the health center has the right resources to implement the process. Alternatively, the team can have regular meetings with senior management to update them on their progress. In addition, the team should have representatives from different departments, including clinical (e.g., medical, nursing), non-clinical (e.g., registration, patient services, billing), and health information technology (HIT) (e.g., electronic health record (EHR) building, data analysis).

Figure 1 provides a sample implementation timeline for SO/GI teams. Keep in mind that the length and timing of steps will vary by organization; in many cases, several of the steps can occur in parallel.

**Figure 1. Sample SO/GI Implementation Timeline**

<b>Months 1-3:</b>	Plan implementation
<b>Month 4:</b>	Conduct process mapping
<b>Month 4-6:</b>	Modify electronic health record (EHR) systems
<b>Month 6:</b>	Train staff; change forms, policies, and physical environment
<b>Month 7:</b>	Pilot SO/GI in one department; use Plan-Do-Study-Act (PDSA) cycle; analyze outcomes
<b>Month 8:</b>	Repeat process with another department; use PDSA cycle; analyze outcomes
<b>Month 9-10:</b>	Expand to all departments/sites; monitor progress through data feedback reports
<b>Month 14:</b>	Conduct first data summary report
<b>Ongoing:</b>	Monitor data quality



## Developing a Workflow

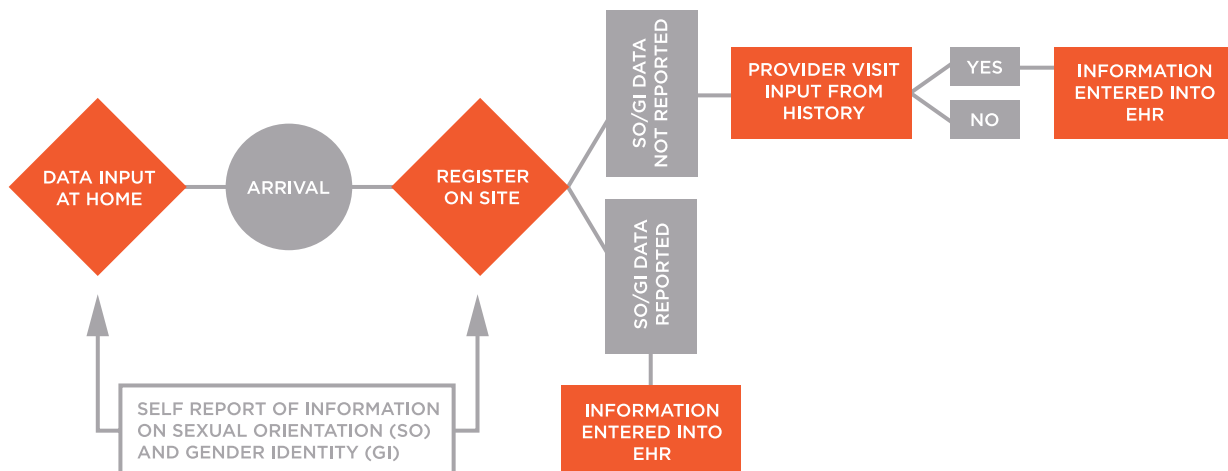
The most efficient and effective way to collect SO/GI data is during patient registration. SO/GI data can be gathered along with other demographic information, such as race, ethnicity, and employment. This normalizes the process and ensures more complete data collection. In addition, it allows health 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 SO/GI during the clinical exam.

There are various ways to integrate SO/GI into existing forms and protocols (see Figure 2):

- Patients can electronically enter SO/GI data through a patient portal at home, or onsite at a kiosk or on a tablet. Electronic methods provide the most privacy.
- Patients can complete paper or laminated registration forms. Patient services staff can then manually enter the data in the EHR.
- If SO/GI data is not reported, providers can ask about SO/GI during the social or sexual history, and can manually enter the data during or after the patient encounter.

SO/GI should be asked at the first clinical visit as well as at least annually, because this information can change over time.

**Figure 2. Sample Process of Collecting SO/GI Data**





## Adding Questions to Registration Forms

SO/GI questions can be integrated into the demographics or social history section of the registration form. The SO/GI questions in Figure 3a have been studied in different health center populations and have been found to be acceptable by most patients.<sup>5</sup> For definitions of SO/GI categories and terms, see Figure 3b on page 5. For information on how to code and report SO/GI data in the Uniform Data System (UDS), see the most up-to-date [UDS manual reporting instructions](#) from BPHC.<sup>6</sup>

**Figure 3a. Recommended SO/GI Questions**

Do you think of yourself as (Check one):

- Straight or heterosexual
- Lesbian, gay, or homosexual
- Bisexual
- Something else
- Don't know
- Choose not to disclose

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

- Male
- Female
- Transgender Male/Trans Man/ Female-to-Male (FTM)
- Transgender Female/Trans Woman/ Male-to-Female (MTF)
- Genderqueer, neither exclusively male nor female
- Additional gender category, please specify: \_\_\_\_\_
- Choose not to disclose

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

- Male
- Female
- Choose not to disclose

Important Note: the reason for asking both gender identity and sex assigned at birth is because some transgender people will identify their gender as 'male' or 'female,' and not as 'transgender' or 'gender-queer'.

<sup>5</sup> 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.

<sup>6</sup> Bureau of Primary Health Care, HRSA. 2017 UDS Manual. August 31, 2017. OMB Number: 0915-0193, Expiration Date 2/28/2018. Available at: <https://bphc.hrsa.gov/datareporting/reporting/2017udsreportingmanual.pdf>

## Translations of SO/GI Questions

[Spanish](#) and Chinese translations of SO/GI questions can be accessed from the National LGBT Health Education Center [website](#). Health centers may want to first review these translations with people in their own communities before using them; in many cultures, LGBTQ terminology may not directly translate into a single word or phrase; and in some instances, the translations can be viewed as offensive. For translation into other languages, health centers can work with their own translators, employees, and/or local LGBTQ community groups.

### Figure 3b. Definitions of SO/GI Categories

**Sexual Orientation:** describes how a person characterizes their emotional and sexual attraction to others.

**Straight or heterosexual:** describes people who are emotionally and sexually attracted to another gender (for example, women who are attracted to men; men who are attracted to women).

**Lesbian, gay, or homosexual:** describes people who are emotionally and sexually attracted to their own gender (for example, men who are attracted to men; women who are attracted to women).

**Bisexual:** describes people who are emotionally and sexually attracted to people of their own gender and people of other genders (for example, men who are attracted to men and women; women who are attracted to men and women).

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

**Don't know:** an option for people who do not know what their sexual orientation is. This option should also be used when the health center does not know the patient's sexual orientation (i.e., the data has not yet been collected by the health center).

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

**Gender Identity:** describes a person's inner sense of their gender. For example, a person may think of themselves as male, as female, as a combination of male and female, or as another gender.

**Male:** describes someone who identifies themselves as male/man.

**Female:** describes someone who identifies themselves as female/woman.

**Transgender Male/Trans Man/ Female-to-Male (FTM):** describes someone assigned female at birth who has a male gender identity.

**Transgender Female/Trans Woman/ Male-to-Female (MTF):** describes someone assigned male at birth who has a female gender identity.

**Genderqueer:** describes someone who has a gender identity that is neither male nor female, or is a combination of male and female.

**Additional gender category:** an option for people who do not identify their gender with any of the categories provided.

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

**Sex assigned at birth:** the sex (male or female) designated on a baby's birth certificate, usually based on external genitalia.

## Names and Pronouns

To facilitate patient-centered communication with LGBTQ patients, it is strongly suggested that registration forms include a field for patient pronouns as well as two name fields: one for the name of the patient on insurance records, and one for the name the patient uses. Having these fields is particularly important for transgender patients, as many have a name and gender identity that is different than what is listed on their insurance or identification documents.

A suggested way to ask is:

- What name would you like us to use? \_\_\_\_\_
- What name is on your insurance records (if applicable)? \_\_\_\_\_
- What are your pronouns? (e.g., he/him, she/her, they/them, etc.) \_\_\_\_\_

The patient's name and pronouns should then be used consistently by all health care staff. Using incorrect names and pronouns can be very hurtful, even when unintentional. Keep in mind that many genderqueer people (and other people who do not identify as male or female), use gender-neutral pronouns such as “they” or “ze” rather than “he” or “she”. For that reason, it is recommended that the pronoun question be open-ended, or include a write-in option.

Names and pronouns should be asked during the first clinical visit as well as at least annually, because this information can change over time.

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

## Considerations for Children and Adolescents

Although health centers are required to collect SO/GI data on all patients ages 18 and older, it is up to each health center to decide whether to ask about SO/GI in younger patients. HRSA's expectation is that health centers adhere to state laws and institutional policies.

### Children 12 and Under

LGBTQ health experts recommend asking parents/guardians of children 12 and under about their children's gender identity. Gender identity tends to emerge at very young ages (often at 2-3 years old). Parents/guardians generally know if their children identify with a different gender than the one traditionally associated with their birth sex. Providers who are made aware of this can help families appropriately support a child's development by providing direct care or making referrals.

For children 12 and under, the sexual orientation question can be left on the registration form as an opening for any parent/guardian or patient who wishes to start a conversation with the provider. It is likely that most parents/guardians will answer “Don't Know” or leave the question blank.



## Adolescents 13-17

Most experts recommend that sexual orientation and gender identity be asked directly of adolescents 13 and older. To protect privacy and encourage openness, providers will want to ask these questions of adolescents without the parent/guardian in the room (as they do with other history questions that may not be answered truthfully with a parent/guardian nearby). After the patient answers, the provider should then ask if the patient is comfortable having that information in their records. SO/GI questions can also be asked on registration forms, but should always be re-asked by the provider, since the information may have been filled out by the parent/guardian, or under their watch. LGBTQ adolescents face increased risk of mental health problems, suicide, and HIV/STDs; by sharing SO/GI with their providers, these adolescents can receive the support, treatment, and prevention services they need.

**Figure 4: Sample Registration Form**

Client Registration			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 # <i>(For office use only)</i>
Name on Legal Documents* Last First Middle Initial			Name you would like us to use:		
Sex on Legal Documents* <input type="checkbox"/> Female <input type="checkbox"/> Male <small>*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 name and pronouns are different from these, please let us know.</small>			What are your pronouns? <small>(e.g., he/him, she/her, they/them)</small>		
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 ( ) ( )	
Ok to leave voicemail? Yes No		Ok to leave voicemail? Yes No		Ok to leave voicemail? Yes No	
Best number to use: <input type="checkbox"/> Home <input type="checkbox"/> Cell <input type="checkbox"/> Work					
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? <input type="checkbox"/> Yes <input type="checkbox"/> 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) <input type="checkbox"/> Secure Email <input type="checkbox"/> Letter <input type="checkbox"/> Other					
This information is for demographic purposes only and will not affect your care.					
1.) What is your annual income? <input type="checkbox"/> No income		2.) Employment Status <input type="checkbox"/> Employed full time <input type="checkbox"/> Employed part time <input type="checkbox"/> Student full time <input type="checkbox"/> Student part time <input type="checkbox"/> Retired <input type="checkbox"/> Unemployed <input type="checkbox"/> Other		3.) Racial Group(s) (check all that apply) <input type="checkbox"/> African American / Black <input type="checkbox"/> Asian <input type="checkbox"/> Caucasian / White <input type="checkbox"/> Native American / Alaskan <input type="checkbox"/> Native / Inuit <input type="checkbox"/> Pacific Islander <input type="checkbox"/> Other	
1a.) How many people (including you) does your income support?		4.) Ethnicity <input type="checkbox"/> Hispanic/Latino/Latina <input type="checkbox"/> Not Hispanic/Latino/Latina		5.) Country of Birth <input type="checkbox"/> USA <input type="checkbox"/> Other	
6.) Preferred Language (choose one): <input type="checkbox"/> English <input type="checkbox"/> Español <input type="checkbox"/> Français <input type="checkbox"/> Português <input type="checkbox"/> Русский <input type="checkbox"/> Other		7.) Do you think of yourself as (Check one): <input type="checkbox"/> Lesbian, gay, or homosexual <input type="checkbox"/> Straight or heterosexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Something else <input type="checkbox"/> Don't know <input type="checkbox"/> Choose not to disclose		8.) Marital Status <input type="checkbox"/> Married <input type="checkbox"/> Partnered <input type="checkbox"/> Single <input type="checkbox"/> Divorced <input type="checkbox"/> Other	
9.) Veteran Status <input type="checkbox"/> Veteran <input type="checkbox"/> Not a Veteran		10.) Referral Source <input type="checkbox"/> Self <input type="checkbox"/> Friend or Family Member <input type="checkbox"/> Health Provider <input type="checkbox"/> Emergency Room <input type="checkbox"/> Ad/Internet/Media Outreach <input type="checkbox"/> Worker/School <input type="checkbox"/> Other		11.) What is your current gender identity? (Check one): <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender Male/Trans Man/ Female-to-Male (FTM) <input type="checkbox"/> Transgender Female/Trans Woman/ Male-to-Female (MTF) <input type="checkbox"/> Genderqueer, neither exclusively male nor female <input type="checkbox"/> Additional gender category, please specify: _____ <input type="checkbox"/> Choose not to disclose	
12.) What sex were you assigned at birth? <input type="checkbox"/> Female <input type="checkbox"/> Male					

# SET!

## Customizing the EHR

In order to effectively enter and use SO/GI data, HIT staff will need to customize their health center's EHR. All EHRs that are certified under the 2015 Edition (Meaningful Use Stage 3) have the capacity to record SO/GI data as of January 1, 2018; however, customization of the EHR will still be necessary. Health centers should talk to their EHR vendor before starting, as several vendors have been working on best practices with other customers.




The following guidelines can help minimize errors and bias when customizing EHR forms:

- Create structured and discrete data fields based on the recommended SO/GI questions.
- 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.
- Differentiate between default values and missing/unknown values.
- Carefully consider where to place the data fields based on how data will be entered and stored.
- Decide which staff will have permission to enter, modify, or view data. Ideally, the clinical staff will have access to this 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 a field for pronouns that can be viewed throughout the EHR system so that all staff are able to use correct pronouns when interacting with patients. If a field for pronouns is not available, it may be possible to use other fields, such as a comment field, to enter pronouns.
- If the patient management system does not enable clinicians or other departments to access SO/GI information from registration, it may be possible to create banners or alerts in the EHR that show a patient's gender identity, name, and pronouns.

Additional customizations may be needed in order to best serve patients and staff:

- Some health centers with large transgender populations find it helpful to use a color code to indicate pronouns on forms or EHR banners (see Figure 5).
- Systems that automatically fill in salutations, such as Mr. and Ms., for mailings can be adjusted to match pronouns and not sex. Another solution is to update letter templates to say “Dear Patient.”
- To reduce mistakes across departments, health centers may need to figure out a way to add correct names and pronouns to lab orders, prescriptions, patient instructions, chart summaries, etc.
- Additional forms, such as anatomical inventories, can be made to support clinicians in making clinical decisions based on a patient's anatomy rather than assigned sex at birth or gender identity.

**Figure 5: Sample Pronoun Color Code**

	She/Her/Hers
	He/Him/His
	They/Them/Theirs

### Training Staff

Prior to collecting SO/GI data, all health center staff (clinical and non-clinical) must be trained to communicate effectively and respectfully with patients about the reasons for collecting SO/GI data, and the ways in which the data will be used for patient care. In addition, staff should acquire foundational knowledge about LGBTQ people and their health needs, and should learn best practices in providing affirming care to LGBTQ patients. This training is especially important due to the misinformation and cultural stigma against LGBTQ identities.

Specifically, training should focus on:

- Basic LGBTQ terminology and concepts
- LGBTQ health disparities
- Communicating with cultural sensitivity, including using correct names and pronouns
- Why SO/GI data collection is important to serving all patients
- How SO/GI data will be collected and how it will be used for patient care
- Maintaining confidentiality and privacy

Additional training will be needed for staff that collect and discuss SO/GI with patients:

**Clinical staff** (e.g., primary care and behavioral health providers) should learn about:

- The range of sexual orientation and gender identity and expression
- LGBTQ health needs and how to address these needs
- How to ask and talk about SO/GI with patients and their families
- How to enter SO/GI data in the EHR

**Non-clinical staff** (e.g., front desk, patient registration, billing), should learn about:

- How to respond to patient questions and concerns about SO/GI data
- How to enter SO/GI data in the EHR
- Patient information needed for insurance claims

Training and technical assistance are available from the National LGBT Health Education Center. Visit [www.lgbthealtheducation.org/topic/sogi](http://www.lgbthealtheducation.org/topic/sogi).



## Educating Patients

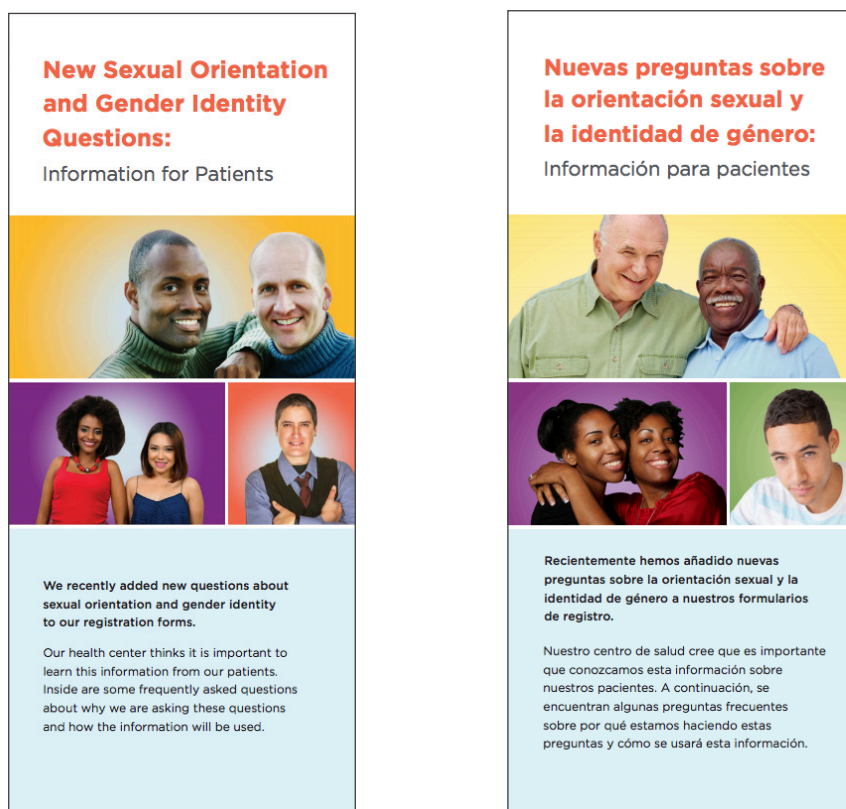
Patients need information on why it is important to disclose their SO/GI to providers, and how the health center will use that information. In addition, some patients will need help understanding the questions themselves (e.g., older patients, patients of different cultural backgrounds, foreign language speakers, and patients with limited literacy).

### Patient Education Brochures

For patients who do not understand the SO/GI questions or want to know more about why the questions are being asked, staff can hand out informational brochures. The National LGBT Health Education Center has developed a patient brochure for this purpose that is currently available in [English](#), [Spanish](#), and Chinese (see Figure 6). Because terms and dialects can vary by community, health centers may want to have their own employees review and edit the translation, or work with a local LGBTQ community group that knows the language.

In addition, health centers may wish to display and distribute the patient brochure [Do Ask, Do Tell: Talking to your provider about being LGBT](#) (available from the National LGBT Health Education Center). This brochure provides additional information to patients about LGBTQ health needs and why it is important for LGBTQ patients to talk to providers about their sexual orientation and gender identity.

Figure 6: SO/GI Patient Education Brochures



## Privacy and Confidentiality

As with all patient information, SO/GI data is protected by the Health Insurance Portability and Accountability Act (HIPAA). Patients may need additional reassurance about privacy and confidentiality when providing SO/GI data or other personal information. Registration forms can incorporate language about confidentiality, and staff can be trained to reiterate and reinforce these protections.

Below is an example of language used at the top of a registration form at a Massachusetts health center:

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.

## Responding to Patient Questions and Concerns

Health center staff will need to be prepared to answer patient questions about SO/GI in an affirming and friendly manner. Patients' basic questions can be handled by trained registration 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.

Although health care staff often assume patients will be offended by SO/GI questions, this is rarely the case.<sup>7</sup> Health centers that have been collecting SO/GI data report that very few patients have complained about or skipped these questions. In fact, patients are much more likely to answer SO/GI questions than they are to answer questions about income. This has been true in rural as well as urban health centers.<sup>8,9</sup>

Below are positive and negative examples of responses to patient questions at the registration desk. 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. These are available on the National LGBT Health Education’s [website](#).

### Positive Example:

<b>Patient:</b>	I don't understand why you are asking these questions. Why do you need to know my sexual orientation?
<b>Registration Staff:</b>	These are new questions that are important to all of our patients' health. Here is a brochure with helpful information. If you would like to discuss this more, your provider will welcome your questions.
<b>Patient:</b>	Thanks. I'll talk to my nurse practitioner.

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<sup>7</sup> 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.

<sup>8</sup> 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.

<sup>9</sup> Preliminary findings from health centers, as described in the webinar “Collecting and Reporting Sexual Orientation and Gender Identity Data: Stories from the Field.” Available from: <https://www.lgbthealtheducation.org/topic/sogi/>

### Positive Example:

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

**Registration 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.

### Negative Example:

**Patient:** I don't understand these questions. What is gender identity?

**Registration Staff:** I don't understand either, but it's required, so just write down something.

In the first positive scenario, the staff member was able to help the patient by providing an informational brochure and suggesting a discussion with the doctor if the patient has more questions. In the second positive example, the staff member reassured the patient that the information was confidential and relevant to health care. She also pointed out the option to not disclose, if the patient chooses, while also leaving open the option of talking with their provider. In the negative example, the staff member dismisses the importance of the question rather than helping the patient.

## Discussing SO/GI during the Clinical Encounter

When patients leave SO/GI questions unanswered on registration forms, health care providers should be trained to re-ask these questions during the clinical encounter. This can be done as part of the social or sexual history, or while filling in blanks left at registration. The questions may have been left unanswered because the patient didn't understand them, didn't notice them, or was uncomfortable answering them.

Below are two positive and one negative example of what a provider might say to a patient who did not answer the SO/GI questions during registration.

### Positive Examples:

**Provider:** We have begun asking all patients about their sexual orientation and gender identity so we can provide everyone with the best care possible. I see you left these questions about sexual orientation and gender identity blank. I was wondering if you had questions about this, and whether we might talk about how you think about yourself in this regard.

**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? Do you consider yourself straight or heterosexual, gay/lesbian/homosexual, bisexual, or something else? I can explain what these terms mean if you have questions. Or, you can say 'don't know' or you can choose not to answer.



## Negative Example:

**Provider:** I see you left these questions about sexual orientation and gender identity blank. I'm sorry to have to ask you about this, because I know you're not gay or transgender. Can I just write down female and heterosexual?"

The providers in the positive examples normalize the conversation and avoid assumptions. The provider in the negative example apologizes for asking the questions and makes assumptions about the patient. The more comfortable the provider is with asking about SO/GI, the more comfortable the patients will be. Remember, most patients want to share this information with their providers, and feel it is safe to do so. If patients do not want to talk about SO/GI, there is no reason to push them. The information is voluntary and there is an option to not disclose. Providers may find that these patients will open up to them at a later date.

## 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 SO/GI 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 SO/GI. Regular check-ins with staff members will help identify and address their concerns.<sup>10</sup>

## Creating a Welcoming and Inclusive Health Center

Health centers will need to create an atmosphere that is intentionally inclusive and respectful of LGBTQ patients and their families in order for patients to feel comfortable sharing information about their sexual orientation and gender identity. Even just a few changes to the physical environment will create a more culturally sensitive environment. These include:

- Reviewing all forms and policies to see that they are inclusive of LGBTQ individuals and families
- Adding images of same-sex couples or other LGBTQ people in educational and marketing materials
- Offering restrooms that are for all genders, and having a policy that patients and staff can use restrooms that reflect their gender identity

Promoting culturally sensitive communication among staff is also of critical importance. Often the most important, but challenging, communication strategy is to have staff consistently use correct names and pronouns with patients. Because mistakes do occur, staff should learn to feel comfortable apologizing, and should work together to maintain a culture of accountability. LGBTQ champions can also make themselves available to answer questions or handle complaints.

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<sup>10</sup> As reported by Andrew Cronyn, MD, El Rio Community Health Center in the webinar "Collecting and Reporting Sexual Orientation and Gender Identity Data: Stories from the Field." Available from: <https://www.lgbthealtheducation.org/topic/sogi/>

## **LGBTQ Cultural Competency Resources**

Resources to help train staff to create more welcoming and affirming environments, such as online/in-person training, publications, videos, and technical assistance are available from the National LGBT Health Education Center, [www.lgbthealtheducation.org](http://www.lgbthealtheducation.org).

The following publications focus on training frontline staff to communicate effectively with LGBTQ people:

- [Providing Inclusive Services and Care for LGBT People: A Guide for Health Care Staff](#)
- [Affirmative Care for Transgender and Gender Non-Conforming People: Best Practices for Front-line Health Care Staff](#)
- [Providing Affirmative Care for Patients with Non-binary Gender Identities](#)

The following publications cover strategies for making system and policy changes that are inclusive of LGBTQ people and their families:

- [Focus on Forms and Policy: Creating an Inclusive Environment for LGBT Patients](#)
- [Ten Things: Creating Inclusive Health Care Environments for LGBT People](#)
- [Building Patient-Centered Medical Homes for Lesbian, Gay, Bisexual, and Transgender Patients and Families](#)



# GO!

## Piloting the Process

Once the forms, processes, and trainings are completed, the next recommended step is to pilot the data collection process on a small scale. Running a pilot of SO/GI data collection for a few months will help you identify and fix problems as they arise. For the pilot:

- Start with one location, floor, or department
- Choose a location with staff who understand the benefits of collecting SO/GI 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
- Consider using the Plan-Do-Study-Act (PDSA) cycle as a quality improvement process. Learn more at: [www.ihl.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx](http://www.ihl.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx)
- Add more departments when ready

## Analyzing and Applying SO/GI Data

Collecting SO/GI data is not an end in itself, but rather the first step in measuring, monitoring, and improving the health of LGBTQ populations in your health center. Once systems are in place, data teams can begin developing summary reports and dashboards for different LGBTQ populations. This data can be incorporated into existing population management and quality measure reports and presented to senior management and at all-staff meetings. For example, if you are already checking levels of A1c by race and age, you can also stratify by sexual orientation.

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; therefore, it is important not to group bisexual patients with gay or lesbian patients for every measure.
- In order to identify all of your transgender (and genderqueer/non-binary) patients, it is necessary to look at both gender identity and sex assigned at birth.



## Monitoring Data Quality

Maintaining data integrity is critical. Without quality checks, you cannot know if your data is accurate. Figure 7 recommends ways in which staff can help ensure quality control of SO/GI data.

**Figure 7. Sample Staff Roles for Quality Control of SO/GI Data**

<b>Registration Staff</b>	<ul style="list-style-type: none"><li>• Check paper registration forms against data in EHR</li><li>• Provide feedback on challenges (e.g., language barriers)</li></ul>
<b>Data Analyst/ Programming Staff</b>	<ul style="list-style-type: none"><li>• Run regular reports</li><li>• Analyze and interpret results</li><li>• Identify problem areas</li><li>• Look at trends over time for anything unusual</li></ul>
<b>Quality Control Staff</b>	<ul style="list-style-type: none"><li>• Incorporate quality control and monitoring into existing workgroups</li><li>• Help develop changes in workflow to fix problem areas</li></ul>
<b>HIT Staff</b>	<ul style="list-style-type: none"><li>• Create checklists and confirm all components are installed after upgrades</li><li>• Develop forms</li></ul>
<b>Clinical Staff</b>	<ul style="list-style-type: none"><li>• Provide guidance on how information is documented in the EHR</li></ul>
<b>Human Resources</b>	<ul style="list-style-type: none"><li>• Train new staff as part of orientation</li><li>• Hold annual trainings for existing staff</li></ul>

# LESSONS FROM THE FIELD

When taking on a new data collection process, it is natural for health centers to worry about added work load, patient questions, and staff resistance. But, although challenges will arise, it may be helpful to know that the process is achievable. Just one year after beginning implementation, many health centers are now successfully collecting SO/GI data. Some have even begun analyzing their data to improve patient health. Below we highlight lessons learned from two health centers that are now collecting SO/GI data across all of their sites and departments: El Rio Community Health Center in Tucson, AZ, and Crescent Care, in New Orleans, LA.

El Rio and Crescent Care<sup>11</sup> found that the following were critical to their success in implementing SO/GI data collection:

- Having passionate LGBTQ champions
- Having engaged leadership that demonstrate ongoing commitment
- Bringing HIT early into the process to help design work flow and determine customization of the EHR
- Being flexible when problems arise. New systems and forms often need to be developed for each department or site
- Training in small groups so staff are comfortable asking questions and discussing concerns
- Having champions adapt standard trainings to fit the culture of their own health center
- Having patient education brochures about SO/GI available in waiting and/or exam rooms

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<sup>11</sup> As reported in the webinar “Collecting and Reporting Sexual Orientation and Gender Identity Data: Stories from the Field.” Available from: <https://www.lgbthealtheducation.org/topic/sogi/>

# ADDITIONAL RESOURCES

Online SO/GI training from the National LGBT Health Education Center:  
<https://www.lgbthealtheducation.org/topic/sogi/>

Health Equality Index from the Human Rights Campaign  
<https://www.hrc.org/hei>

Center of Excellence for Transgender Health  
[www.transhealth.ucsf.edu](http://www.transhealth.ucsf.edu)

World Professional Association for Transgender Health  
[www.wpath.org](http://www.wpath.org)

HRSA Health Center Data and Reporting  
<https://bphc.hrsa.gov/datareporting/>

The Fenway Guide to LGBT Health, 2nd Edition.  
<https://store.acponline.org/ebizatpro/Default.aspx?TabID=251&ProductId=21572>

Do Ask, Do Tell - The Fenway Institute and Center for American Progress  
<http://doaskdotell.org/>



