


SOGI Data Collection: Promoting Best Practices for the Care of LGBTQ+ People

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1



NOTE:

In this training, we will focus on sexual orientation and gender identity and expression - these are significant parts of a person's identity, but it's important to remember that these are just some of the characteristics that come together to make up a person's complex, multifaceted identity.

In order to treat others the way they would want to be treated, we have to consider the needs of the whole person.

It is our responsibility to ensure that we treat all of our patients, customers, members, residents, and coworkers with dignity and respect and follow the Platinum Rule by treating others the way they want to be treated. In order to do that, we must acknowledge and respect people as individuals. Each person has many intersecting identities related to race, ethnicity, socioeconomic status, education level, age, and many other characteristics.

2

Our Commitment

- At UPMC we are committed to providing healthcare free from discrimination
- This includes caring for people from the LGBTQ+ Community
- Review our Non-Discrimination Policy in Patient Care Policy [here](#)
- This training is designed to help set the standards we have when caring for LGBTQ+ people at UPMC



3

Learning Objectives

This module will enable you to:

Identify verbal, nonverbal, and written practices in health care where information on Sexual Orientation and Gender Identity (SOGI) is, or should be, communicated.

Identify disparities and traumatizing healthcare experiences related to existing communication practices.

Discuss best practices in electronic (e.g., EHR) and verbal communication related to SOGI in healthcare.

Focus on hand-offs, EHR documentation, and connection between verbal communication and written documentation.

Identify strategies to mitigate misgendering and retraumatization through affirmative language, particularly in situations where legal/dead name must be used under current healthcare laws (e.g., blood transfusion).




4




You don't have to be LGBTQ+ to do this well, and don't assume LGBTQ+ people don't need training too!

5

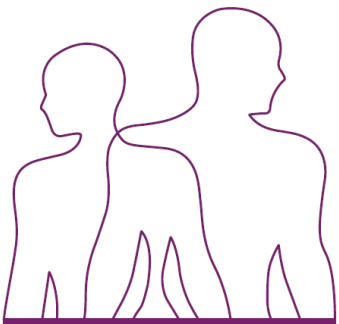
Key Concepts




Sex Assigned at Birth




Gender Expression



Understanding Gender and Sexual Orientation

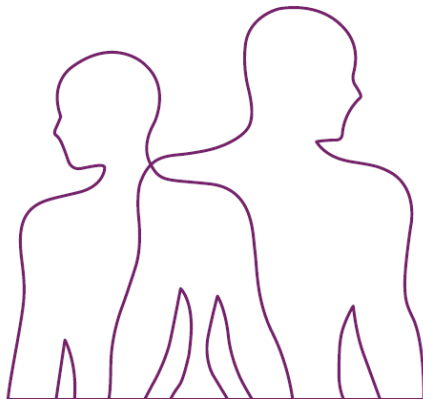


Gender Identity



Sexual Orientation

6



Understanding Gender and Sexual Orientation

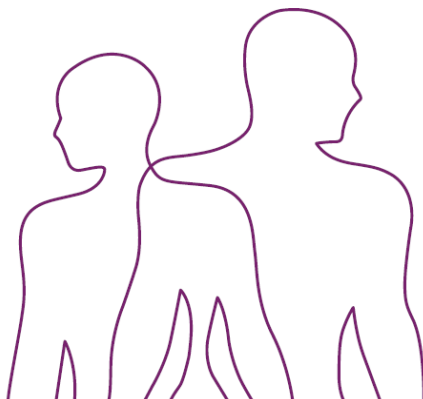
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Sex Assigned at Birth

refers to the external genitalia and reproductive organs present at birth as well as attributes like chromosomes and the hormone levels present in the body. This can also be used to refer to the physical sex characteristics that most people are born with or those that develop over time. Some people have sexual and reproductive anatomy that doesn't fit within the usual definitions of female or male, and these people are described as intersex.

7



Understanding Gender and Sexual Orientation

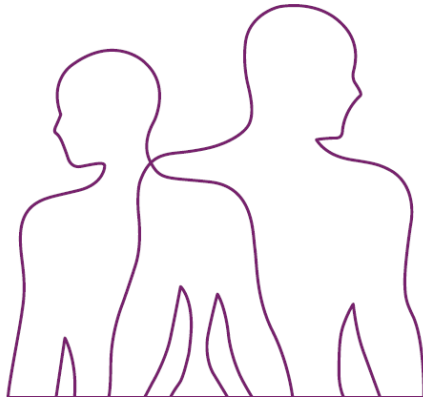
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Gender Identity

describes an individual's deepest idea of self as male, female, a blend of both, or neither. A person's gender identity can be the same as or different from the sex they were assigned at birth. When it is the same that person is described as cisgender and when it is different that person is described as transgender.

8



Understanding Gender and Sexual Orientation

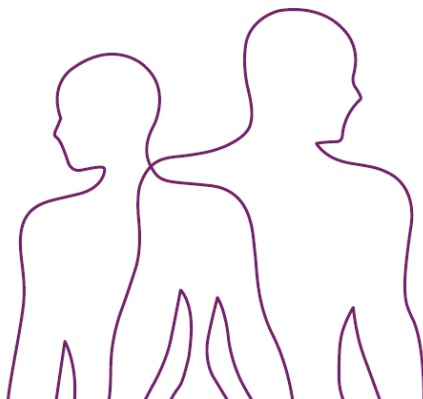
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Gender Expression

describes how a person presents their gender to the world. This can be through their actions, demeanor, or mannerisms as well as how they choose to appear through their choice of clothing, hairstyle, makeup, or other signifiers. You shouldn't make assumptions about someone's gender identity based on your perceptions of their gender expression.

9



Understanding Gender and Sexual Orientation

10




Sexual Orientation


refers to the people to whom a person is drawn emotionally, romantically, or sexually. Sexual orientations include gay, lesbian, straight, bisexual, queer, pansexual, asexual, and more. Sexual orientation does not change based on your current romantic involvement.

10

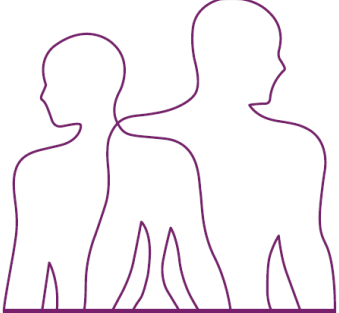
All people have these




Sex Assigned at Birth




Gender Expression





Sexual Orientation



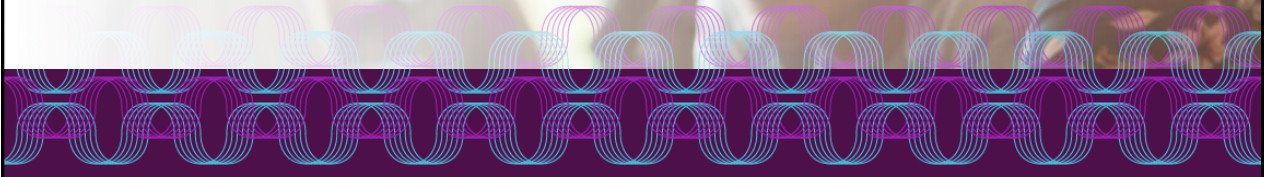
Gender Identity

**Understanding
Gender and
Sexual Orientation**

11

Why is this training important?

- Helps us to live our Value of Dignity and Respect
- Impacts the patient experience for people from the LGBTQ+ community
- A positive patient experience is tied to improved clinical outcomes
- SOGI data can impact and improve clinical decision making



12

12

Why ask SOGI questions?

- Sexual and gender minority people face significant barriers to adequate and culturally responsive health care leading to numerous health disparities.
- These health inequities can be reduced by increasing visibility through data collection in health care.
- It is critical for healthcare organizations to better understand their patients and to provide a welcoming, inclusive environment.
- SOGI data is PHI and confidentiality is essential

13


13

Why ask SOGI questions?

- A patient's gender identity, correct name, and pronouns cannot be determined based on how the patient looks or sounds.
- SOGI data are most helpful to providers when these data are in a patient's clinical chart; these data equip providers to serve their patients well.
- To facilitate discussion on preventative screenings, risk reduction, family and social support, behavioral health concerns, and other topics important for patient-centered care.


14

14

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- Staff at healthcare organizations are often reluctant to ask SOGI questions believing that patients will be offended or refuse to answer questions.
 - Studies have found that patients answer when asked.

Will patients be offended by SOGI Questions?

15

- 
- A study of 301 randomly selected patients from four racially and geographically diverse U.S. health centers found high acceptability by patients of routine SOGI data collection: most expressed believing the questions are important and reported they would answer these again in the future (Cahill, et al., 2014).
 - 78% of clinicians nationally believe patients would refuse to provide sexual orientation information, however only 10% of patients say they would refuse to provide sexual orientation (Haider et al., 2017).
 - No difference in patient attitudes toward registration forms that include SOGI questions vs. forms that do not; only 3% of patients reported being distressed, upset or offended by SOGI questions (Rullo et al., 2018).

Will patients be offended by SOGI Questions?

16

When is the right time to gather SOGI data?

There are various times and ways SOGI information can be collected and there is no single system to achieve this.



17

Gathering SOGI Data During the Process of Care

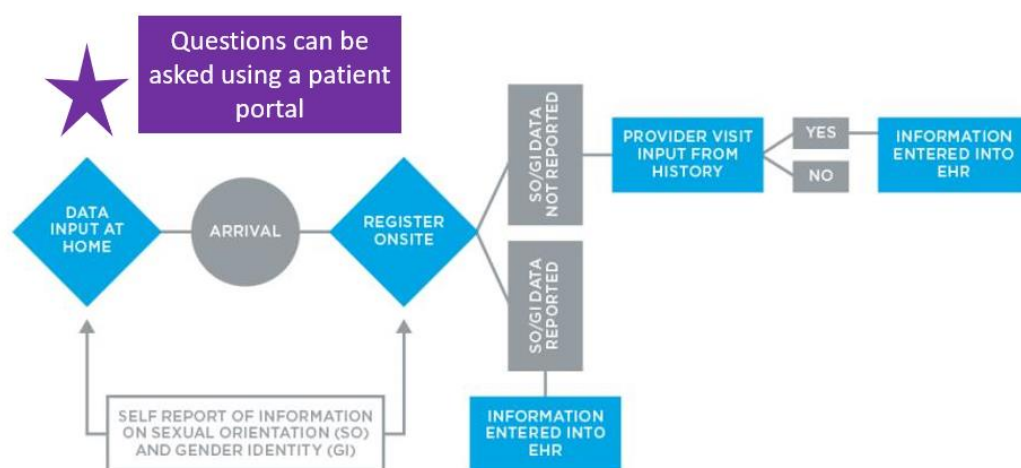


Fig. 2. Diagram from "Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health."¹³

18

Gathering SOGI Data During the Process of Care

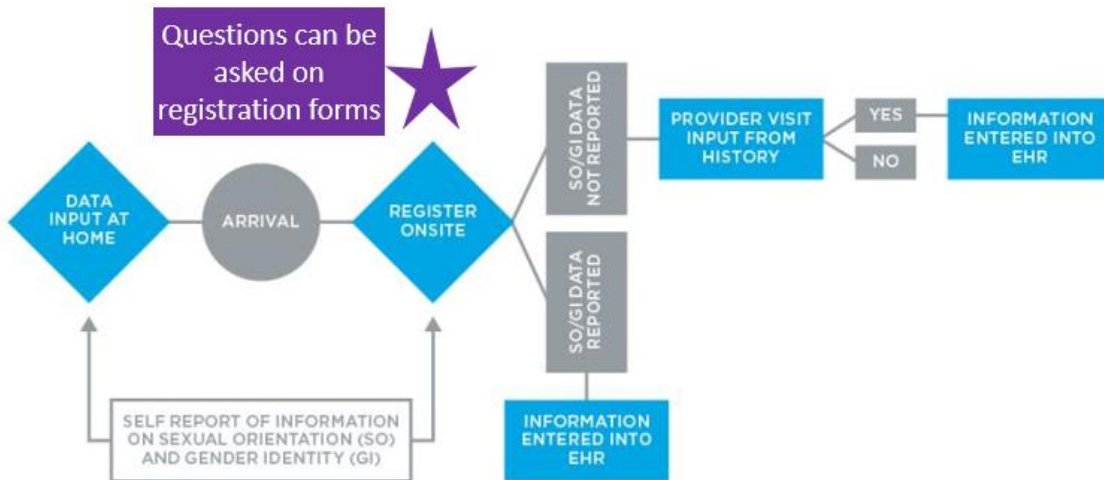


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19

Gathering SOGI Data During the Process of Care

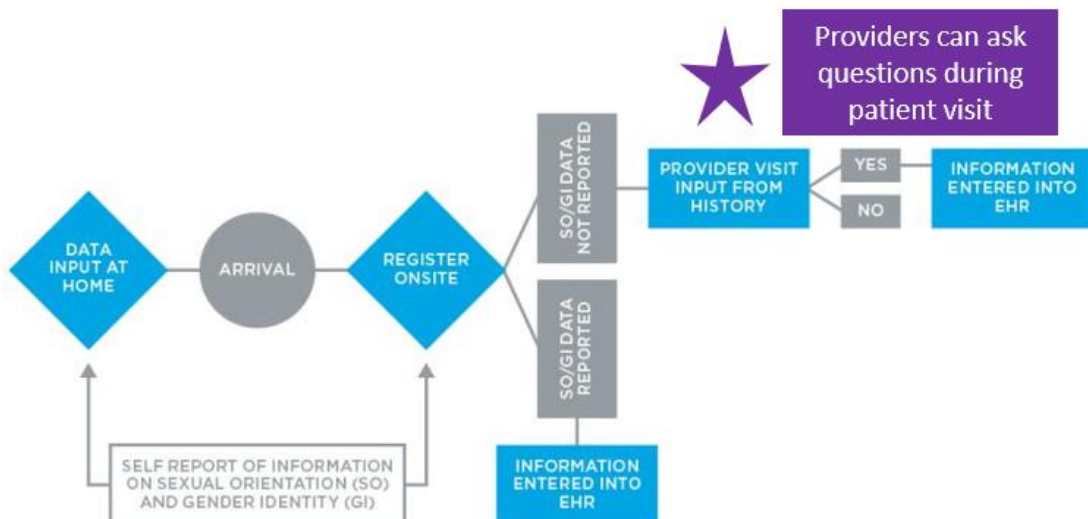


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Gathering SOGI Data During the Process of Care

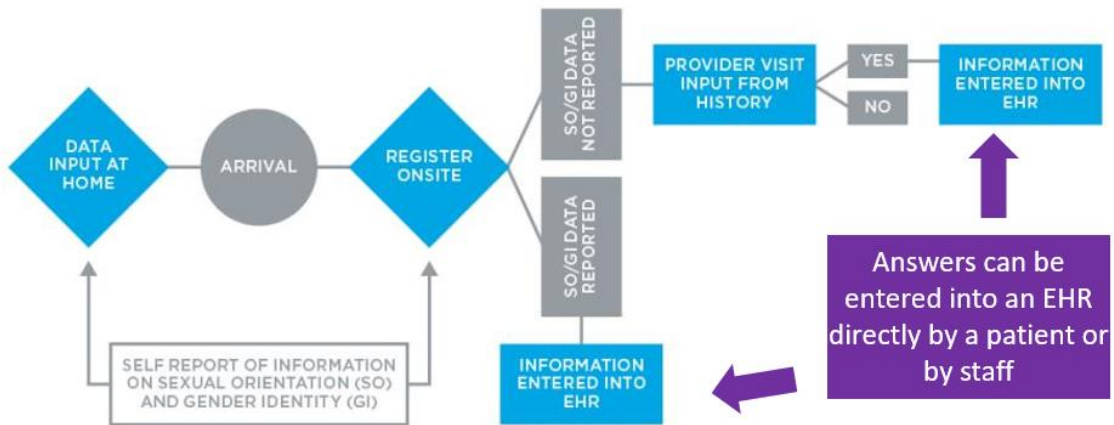


Fig. 2. Diagram from "Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health."¹³

21

The right time to gather SOGI data.

It is inevitable that we can shy away from SOGI data collection this is due to cultural experiences such as the norms that surround Don't Ask Don't Tell

The right time to ask is at least once to capture this in the EHR and subsequently when SOGI data is relevant to care

One reason we might not want to ask is because we believe incorrectly that we can tell someone is from the LGBTQ+ Community because of their gender expression. Gender expression is independent from gender identity and sexual orientation.



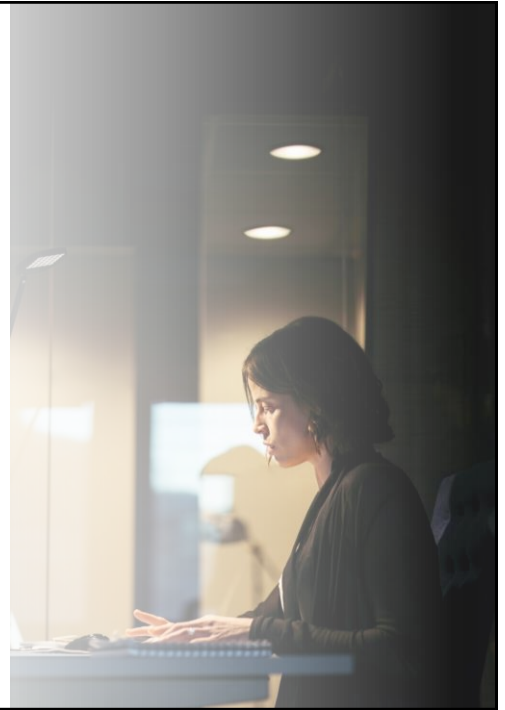
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What would you do?

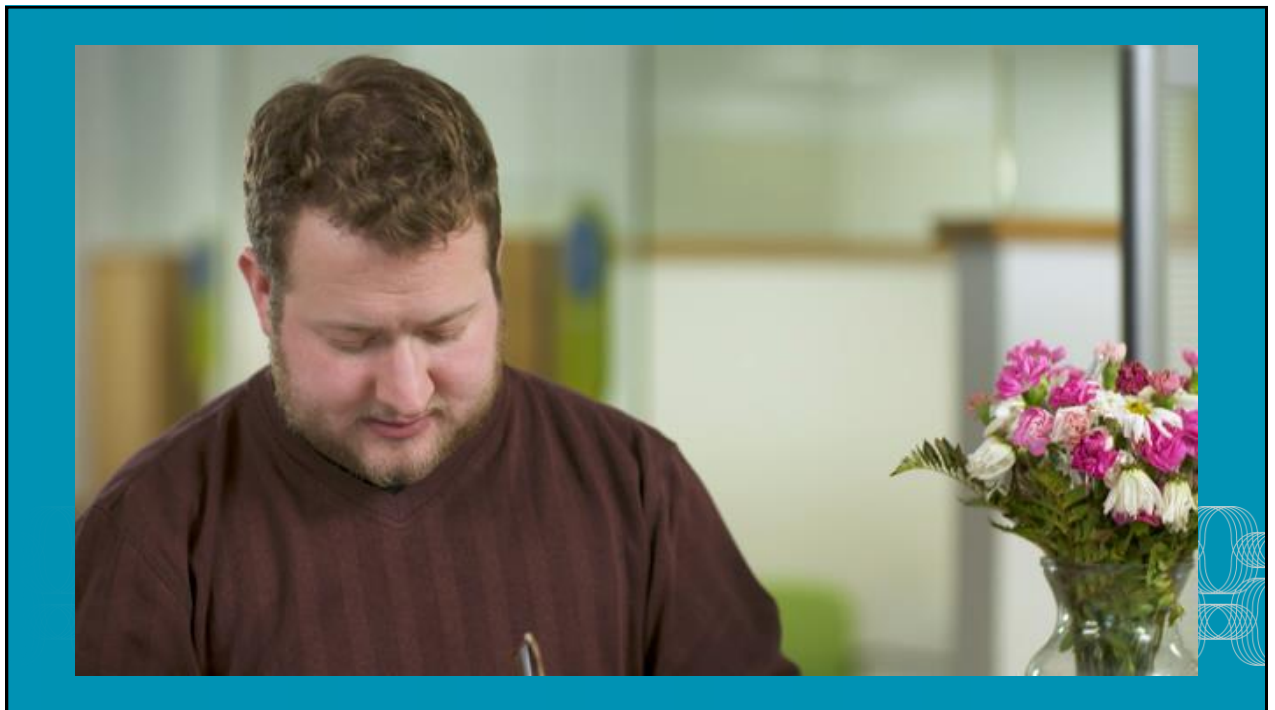
Imagine you are going to get a patient from the waiting room and on your form the person's name is Denise. You walk out and call out the name, "Denise." No one comes and you realize both people in the waiting room appear male.

What would you do?

- Walk up to the person who appears male and say "are you Denise?"
- Go back in the hallway and then come back out and call the name the person uses, "Denny."
- Say in the waiting room, "I'm sorry Denny, I got that wrong."



23



24

Gathering SOGI Data During the Process of Care

Whichever way questions are asked, they should be put into context regarding why the information is important for quality care and asked with sensitivity.



25

Sample Registration Form

- Legal Name AND Common Use Name
- Pronouns
- Insurance/Legal Sex (with explanation)
- Gender Identity
- Sex Assigned at Birth
- Sexual Orientation
- Parent/Guardian

26

FENWAY HEALTH			<small>The information in your medical record is confidential and is protected under Massachusetts General Laws Ch. 111, Sec. 70D. Your written consent will be required for release of information except in the case of a court order.</small>		Medical Record # <small>(For office use only)</small>
Client Registration					
Legal Name* Last First Middle Initial Name used:		Legal Sex (please check one) <input type="checkbox"/> Female <input type="checkbox"/> Male			
<small>*While Fenway recognizes 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.</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	
Address 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 18, the Department of Public Health requires that you provide parent/guardian contact information.					
Parent/Guardian Name Phone Number Relationship to you					
Fenway Health 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 (MyFenway) <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: <input type="checkbox"/> Lesbian, gay, or Bisexual <input type="checkbox"/> Straight or Heterosexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Something else <input type="checkbox"/> Don't know		8.) Marital Status <input type="checkbox"/> Married <input type="checkbox"/> Partnered <input type="checkbox"/> Single <input type="checkbox"/> Divorced <input type="checkbox"/> Other	
11.) What is your gender? <input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Genderqueer or not exclusively male or female		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"/> Admitted/Media/Outreach Worker/School <input type="checkbox"/> Other	
12.) What was your sex assigned at birth? <input type="checkbox"/> Female <input type="checkbox"/> Male		13.) Do you identify as transgender or transsexual? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know		Please turn over	

26

Appropriate Screening: Rodrigo's Story

- Rodrigo is a 30-year-old trans man who came in with pelvic pain and spotting
- A biopsy determined that Rodrigo had cervical cancer
- No one had told Rodrigo that he needed routine cervical Pap tests
- Why might past clinicians never have recommended cervical cancer screening to Rodrigo?

27



27

How do we ask about SOGI?

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28

28

Preparation for Collecting Data in Clinical Settings

- **Clinicians:** Need to learn about LGBTQIA+ health and the range of experiences related to sexual orientation and gender identity.
- **Front-line staff:** Front desk and patient registration staff must also receive training on serving LGBTQIA+ people, communicating with LGBTQIA+ patients, and quality service with diverse patient populations.
- **Patients:** Deserve to learn about why it is important to communicate this information, and to feel comfortable that it will be kept confidential and used appropriately.

29

29

Sexual Orientation: What do we need to know?

- We ask about sexual orientation to improve the patient experience and inform clinical decision making
- “Do you think of yourself as...”
 - Lesbian, gay, or homosexual
 - Straight or heterosexual
 - Bisexual
 - Pansexual
 - Something else



30

Gender Identity: What do we need to know?

- What name does this person use?
- What pronouns do they use?
- What (if any) medical or surgical interventions have they had?
- What organs do they have?
 - This might be referred to as an organ inventory



31

Gender Identity: How do we ask?

“What name do you use?”

- At UPMC we call this a person's **CHOSEN** name to differentiate this from the **LEGAL** name. Some EHRs use the term 'preferred name' but this term is out-dated.
- Explain when we might need to use a person's legal name, “Thanks for letting us know Fallon. There are moments when we will need to use your legal name such as when we are going to give you medications.”



32

Gender Identity: How do we ask?

“What pronouns do you use?”

- She/Her
- He/Him
- They/Them
- Other options are also used
- Remember the culture and the language of folks in the trans community continues to evolve



33

Gender Identity:
Things to Remember

Always mirror
the language of
the patient

- If they refer to their legal name as their deadname, then we refer to their legal name as their dead name (see example)

Deadname is a union of the words “dead” and “name”. This at times can be used as a verb, “I do not like to be deadnamed!”



34

Gender Identity: Things to Remember

When you must use their legal name explain why, and always start by using their chosen name:

- “Hi Aiden. I have your morning medications. This is one of those times we need to verify your dead name. Can you tell me your dead name?”
- “Thank you, Alexis. During surgeries we utilize a safety protocol called a time out. Usually, you will be asleep during this time, and in case you can hear us please know we will use your legal name.”



35

Gender Identity: Things to Remember

This does NOT mean we ignore our need to verify positive patient identification for safety or confidentiality reasons.

- Administration of medications
- Administration of blood and blood products
- Obtaining lab specimens/point of care testing
- Distributing dietary trays
- Initiating radiological/diagnostic examinations
- Initiating all treatments and invasive procedures
- Initiating any operative procedures

This DOES mean we will have to spend a bit more time explaining the “why” for some of these activities. When we make a mistake, apologize, do better, and move on.



36

Knowledge check: Rodrigo's Story revisited

Pick the best answer: What accounts for Rodrigo not having appropriate screening?

- A. His treatment team made assumptions about his sex assigned at birth, and never discussed appropriate screenings.
- B. His doctor did not know how to talk about Rodrigo's body in a way that respects the way he thinks of himself, so they never brought it up.
- C. There was no literature in his doctor's office that helped educate Rodrigo.
- D. All of these.

37



37

Protecting SOGI Data and Medical Decision Making

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38

38

SOGI is Protected Health Information

- Sexual Orientation and Gender Identity is protected health information (PHI) and must be kept confidential
- This information is important to support the patient experience as well as improve medical decision making
- Because this information is important it is also protected by The Health Insurance Portability and Accountability Act (HIPAA)
- Ensure that patients know that SOGI data included in an EHR is available across the system



39

SOGI is Protected Health Information

- Remember all the following information about a transgender patient is protected health information
 - Diagnosis
 - Medical history
 - Sex assigned at birth
 - Anatomy
- UPMC staff should follow policy HS-EC1606: Privacy and Security Training Related to Protected Health Information



40

SOGI is Protected Health Information

- The only information relevant to the everyday care of people who identify as transgender is:
 - Chosen Name
 - Pronouns
- Do not assume the sexual orientation or gender identities of a patient, their loved ones, or their parents/caregivers. Families might include a same-sex spouse or domestic partner and/or same-sex/gender diverse parents.



41

Medical Decision Making: Including Same Sex Partners

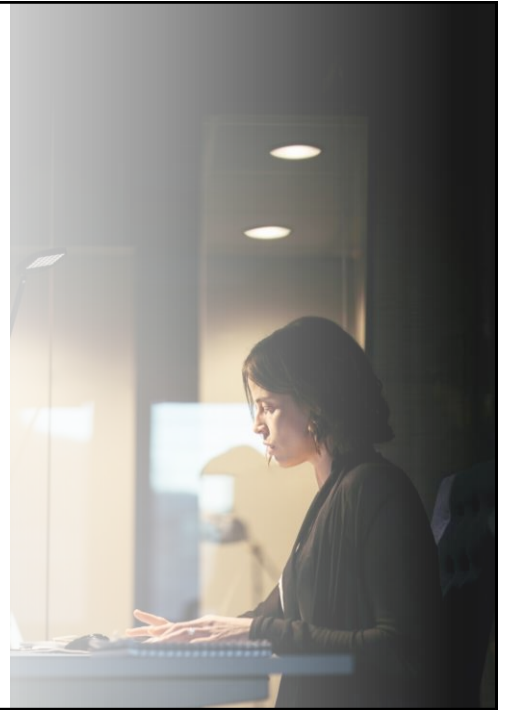
- At UPMC our patients have the right to appoint a Health Care Representative.
- This includes a person's:
 - Legal spouse (both same sex and opposite sex spouses)
 - Domestic partners (both same sex and opposite sex domestic partners)



42

What statement is not true?

- a. What statement is not true:
- b. SOGI data is protected health information.
- c. It is okay to talk about a trans person as not having transitioned meaning they have not had medication or surgery.
- d. A patient can choose anyone to be a medical decision maker even a same sex spouse or domestic partner.
- e. Communicating to colleagues about a person's name and pronouns is a way to make sure patients are treated with dignity and respect.



43

Managing Challenges & Service Recovery

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44

44

Managing Challenges and Opportunities

- How do you respond to patients who do not want to disclose SO, GI, or sex assigned at birth?
- Patients who have a primary language other than English or different cultural backgrounds may have additional barriers to disclosure.
- Important to build an affirming space to discuss, and to communicate why the information is relevant to health and treatment.
- Most important thing: respect for a patient's autonomy and agency.

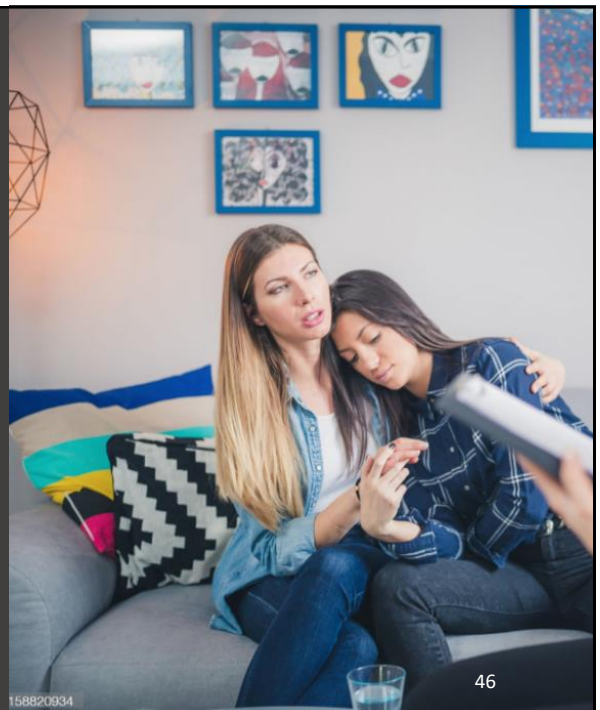


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Common Verbal Communication Mistakes

- Wrong name/pronouns called out in the waiting area
- Or in chart documentation, hearing from other staff, etc.
- Using language that doesn't align with their gender identity
- E.g., using gendered term "breasts" instead of "chest"
- Asking about birth control/pregnancy inappropriately
- Using the wrong pronouns for potential partners/spouse
- Using judgmental or biased language
- "Risky," "unsafe," "lifestyle," etc.
- Asking questions not relevant to care

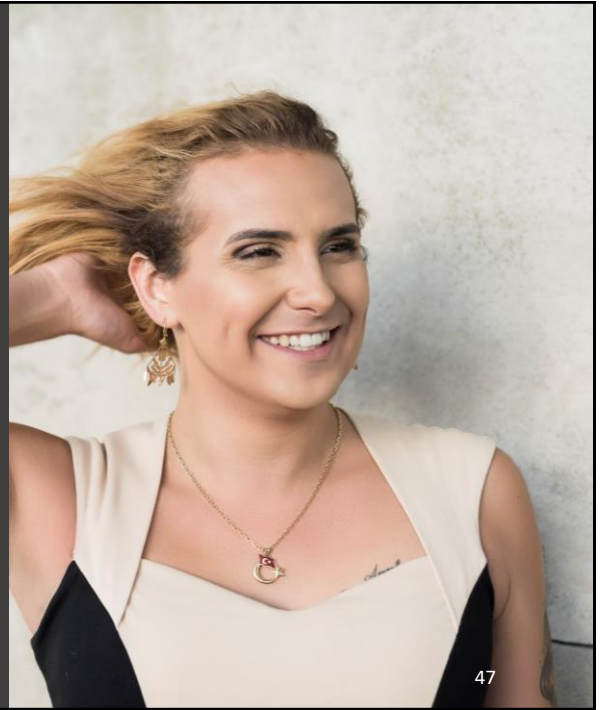


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Handling Verbal Mistakes

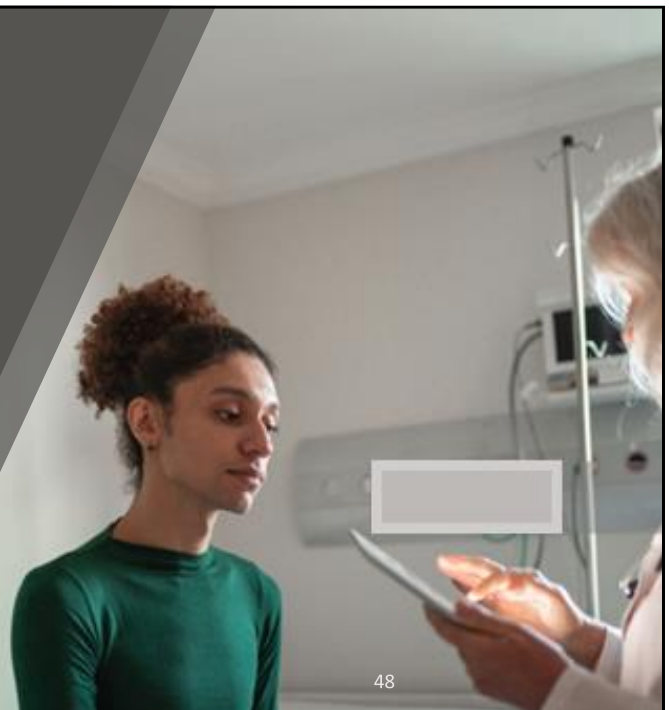
- Apologize, without centering yourself
- Not: "This is just so new to me. I never would have known."
- Instead: "I'm so sorry, let me make sure this doesn't happen again."
- Make the changes necessary to ensure it doesn't happen again
- Ask! "What language do you use to describe [your body]?"
- Build familiarity with non-gendered or gender-inclusive language
- Spouse, partner
- They/Them and additional pronouns
- Household, parents/guardians/caretakers



47

Managing Challenges

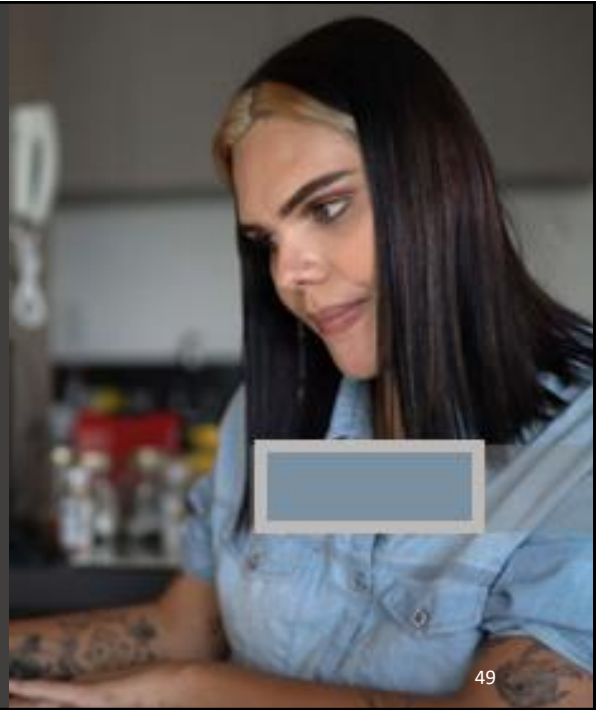
- Other potential challenges that might arise and how do you deal with them:
 - Patient's name doesn't match their insurance card
 - Provider changes name/gender in EHR and it no longer matches the insurance information
- Responses:
 - Assure patient that the name that they want to use will be used at the practice, but for insurance purposes we will need their insurance name to prevent them from getting insurance denials
 - Don't want there to be a barrier to patient care
 - Provider can flag the patient's chart to let staff know that there was a legal name/sex change
 - Searching for a patient in the EHR – asking for additional information like date of birth



48

Name/Deadname

- “Legal name” or “legal sex” is not as simple as might be assumed:
- Federally, the Constitution allows for a “common law name change,” bypassing the need for a court order
- However, some institutions may require court documentation
- Different names can be listed on a driver’s license, passport, birth certificate, etc.
- “Legal sex” is similar. A person can have a different sex marker on their license, passport, and birth certificate
- A deadname is the name given at birth that a person has changed. Not all legal names are deadnames.
- Where a legal name must be documented/used
- Transparency: tell the patient, and explain the circumstances



49

SOGI Reporting For Pediatric Patients

- At what age do you start asking these questions?
- Recommend having SOGI questions on registration forms, but not requiring that these be completed
- Recommend asking GI early, could be as young as 4 years old
- Recommend asking SO from 13+ years old
- At what age do you start reporting these data?
- Many funders require data collection and reporting starting at 18 years old; however, collection before 18 years old promotes good clinical care
- Are parents answering these questions?
- If so, look for potential bias, as responses may not reflect the identity of the youth.



50

Building Accountability

Creating an environment of accountability that values dignity and respect requires everyone to work together!

Don't be afraid to politely correct your colleagues if they make insensitive comments:

- *"I think Elliot uses they/them pronouns. We have to get more consistent about this as a team."*
- *"Bruce has two dads. We have to start getting away from saying, 'mom and dad.'"*



Inclusion begins with a core belief that everyone deserves dignity and respect.

51

51

Hear them out:

- > Take them to a private location if possible.
- > Actively listen without interruption, make eye contact, and be mindful of your body language.
- > Repeat back in summary what you heard to make sure you understood.
- > Don't jump to conclusions, make assumptions, or raise your voice.

Empathize:

- > Respond empathically with words that demonstrate compassion or acknowledgment.
- > Empathy doesn't mean that you agree, just that you can identify with how the person is feeling.
- > Don't be apathetic. Avoid language like, "This happens all the time."

Apologize:

- > Own the situation.
- > Use language like: "I'm so sorry to hear that," and "I'm sorry to hear you've had that experience."
- > Don't place blame on your peers or say it isn't your fault.

Resolve:

- > Take the necessary steps to fix the issue to the best of your ability. Sometimes the resolution is just listening.
- > You don't need to have all the answers. You can notify someone who can assist if needed.
- > Say things like:
 - i. "What can I do to help?"
 - ii. "I'd like to see what I can do to help, let me speak with my nurse leader"
 - iii. "We have such great teamwork here, let me call our Administrator on Duty. She is a great resource and may be able to guide us."
- > Don't pass off the responsibility.

Decide:

- > If you believe the situation is under control, thank the person for sharing their feedback.
- > If you think more action is needed after you spoke with the individual, there are a couple options:
 - i. Write a "We Heard You" card by using the template in this guide. Notes should be handwritten and hand-delivered to the patient the following day, or mailed to their home.
 - ii. If appropriate, provide a voucher for parking, cafeteria, etc. if your facility utilizes them. Then complete your department's [LJPMC Service Recovery Voucher Log](#).
- > If warranted, let your department leader and Patient Relations know about the situation.
- > If the incident requires more than a verbal apology, capture details on the [Service Recovery Tracking Form](#). A sample form is provided in this guide.

- **Remember the HEARD model**

52

52

Resources available at UPMC

LGBTQ+ Patient Care Resources

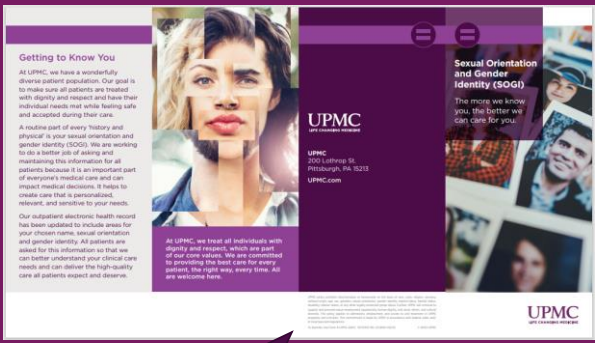
Resources for LGBTQ+ Patients and Caregivers



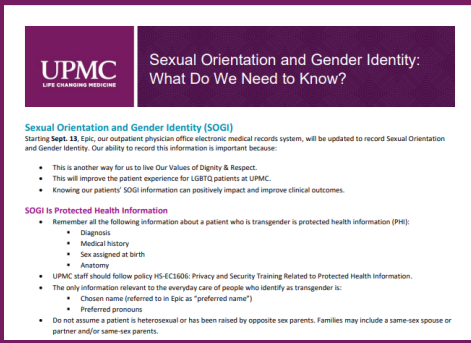
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Resources available at UPMC

SOGI Patient Brochure



SOGI: What Do We Need to Know?



To order Use Form # UPMC-2803 PATEX517161 JZ/BSW 09/20

54

Resources available at National LGBT Health Education Center

Data Collection Toolkit



Collecting SOGI Information in EHRs



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Resources available at National LGBT Health Education Center


SOGI Data Collection Demonstration Videos



SOGI Patient Pamphlets



56



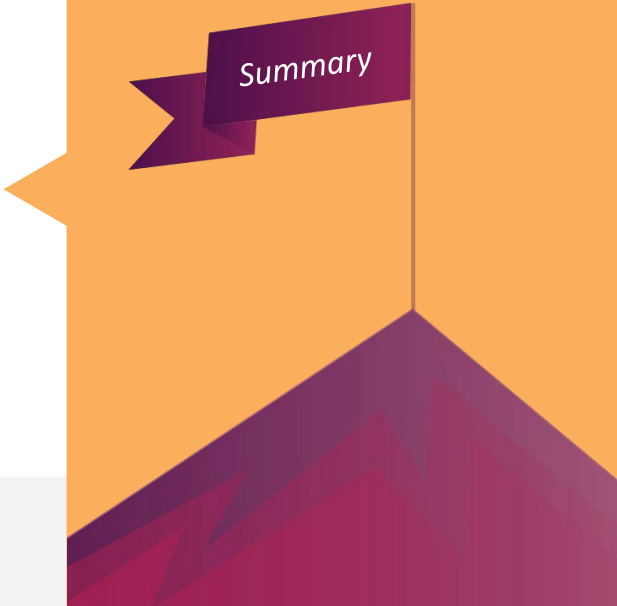
EMI NATIONAL LGBTQIA+ HEALTH EDUCATION CENTER
A PROGRAM OF THE FENWAY INSTITUTE

This training was developed in partnership with The National LGBTQIA+ Health Education Center.

The National LGBTQIA+ Health Education Center provides educational programs, resources, and consultation to health care organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority (LGBTQIA+) people.

The Education Center is part of The Fenway Institute, the research, training, and health policy division of Fenway Health, a Federally Qualified Health Center, and one of the world's largest LGBTQIA+ focused health centers.

57



If you want to learn more, please review the resources available at UPMC and at National LGBT Health Education Center.

Another module available for review is the ***LGBTQ+ Patient and Colleague Awareness Module 2020*** edition.

Summary

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58

I understand that the expectation at UPMC is patients are treated the way they want to be treated. For the LGBTQ+ community this means:

- Using the name and pronouns a person uses to describe themselves
- Including same sex parents, domestic partners, and same sex spouses as part of a patient's family and to their comfort level should be included in their care
- That I provide service recovery if I make a mistake