



# Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records Taking the Next Steps



NATIONAL LGBT HEALTH  
EDUCATION CENTER

A PROGRAM OF THE FENWAY INSTITUTE



## WHY COLLECT DATA ON SEXUAL ORIENTATION AND GENDER IDENTITY?

Lesbian, gay, bisexual, and transgender (LGBT) people are often “invisible” to their providers. Most clinicians do not discuss sexual orientation or gender identity (SO/GI) with patients routinely, and most health centers have not developed systems to collect structured SO/GI data. This invisibility masks disparities and impedes the provision of important health care services for LGBT individuals, such as appropriate preventive



**Gathering SO/GI data will increase quality of care given to LGBT patients by allowing health centers to measure and track outcomes in these populations.**

screenings, assessments of risk for sexually transmitted infections and HIV, and effective intervention for behavioral health concerns that may be related to experiences of anti-LGBT stigma.<sup>1</sup> Like all patients, LGBT people have behavioral as well as medical concerns, and want to discuss issues related to coming out, school, work, relationships, children, aging, and other issues that occur in different stages of life. An opportunity to share information about their sexual orientation and gender identity in a welcoming environment will facilitate important conversations with clinicians who are in a position to be extremely helpful.

Collecting SO/GI data in electronic health records (EHRs) is essential to providing high-quality, patient-centered care to LGBT individuals. 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 quality of care provided to LGBT people. Gathering this data is therefore an important part of identifying and addressing LGBT health disparities in health centers and other health care organizations.

## RECOMMENDED QUESTIONS

Sexual orientation and gender identity questions have been shown to be acceptable to health center patients from diverse backgrounds. In 2013, The Fenway Institute and the Center for American Progress conducted a study that asked 301 people in the waiting rooms of health centers in Chicago, Baltimore, Boston, and 3 rural South Carolina counties how they felt about answering questions about sexual orientation and gender identity. Most respondents were heterosexual and non-transgender; more than half were people of color; and 7 percent were over age 65. Across all of these variables and regardless of geography, respondents overwhelmingly supported the collection of SO/GI data in health care encounters. Most respondents agreed that “the question was easy for me to answer” and that “I would answer this question on a registration form at this health center.” In addition, most LGBT respondents said that the questions accurately reflected their SO/GI.<sup>4</sup>

Based on this and other studies of SO/GI data collection, such as research conducted by the Center for Excellence for Transgender Health at the University of California at San Francisco,<sup>5,6</sup> we advise using the questions listed in Figure 1.

### FIGURE 1: SEXUAL ORIENTATION AND GENDER IDENTITY QUESTIONS

#### Sexual Orientation

**Do you think of yourself as:**

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

## **Gender identity**

### **Do you think of yourself as:**

- Male
- Female
- Female-to-Male (FTM)/Transgender Male/Trans Man
- Male-to-Female (MTF)/Transgender Female/Trans Woman
- Genderqueer, neither exclusively male nor female
- Additional gender category/(or Other), please specify:\_\_\_\_\_
- Something else

### **What sex were you assigned at birth on your original birth certificate?**

#### **(Check one):**

- Male
- Female
- Decline to Answer

Note that the gender identity question has two parts: one on current gender identity and one on sex assigned at birth. Together, these questions replace “Sex: Male or Female?” questions on patient information forms and in EHRs. Asking two questions gives a clearer, more clinically relevant representation of the transgender patient than asking just one question. For example, asking if someone is transgender will miss some transgender people who do not identify as such (e.g., a person who was born male, but whose gender identity is female, may check “female” rather than “transgender” on a form.) The gender identity question also includes options for people who have a non-binary gender identity (people who do not identify as male or female).

In addition to asking about SO/GI, we strongly suggest asking patients to include their preferred name and pronouns on registration forms (see Figure 2). This is important because many transgender patients have insurance records and identification documents that do not accurately reflect their current name and gender identity. In addition, some people who have a non-binary gender identity want to be called “they”

rather than “he” or “she,” or prefer to use other gender neutral pronouns such as “ze” that are unfamiliar to many. Asking about preferred name and pronouns, and training all staff to use them consistently, can greatly facilitate patient-centered communication.

**FIGURE 2: PREFERRED NAME AND PRONOUNS QUESTIONS**

**Preferred name. Specify:**

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**Preferred gender pronouns:**

- He/Him
- She/Her
- They/Them
- Other \_\_\_\_\_

## COLLECTING THE DATA

There are several ways SO/GI data can be collected. For example, questions can be included on registration forms as part of the demographics section alongside information about race, sex, and date of birth; or they may be asked by providers during the patient visit. Patients may self-disclose to providers as a response to open-ended questions, such as “Tell me about yourself.” Or, providers may ask as part of the social or sexual history, with a question such as “Do you have any concerns or questions about your sexual orientation or sexual desires? Your gender identity?”

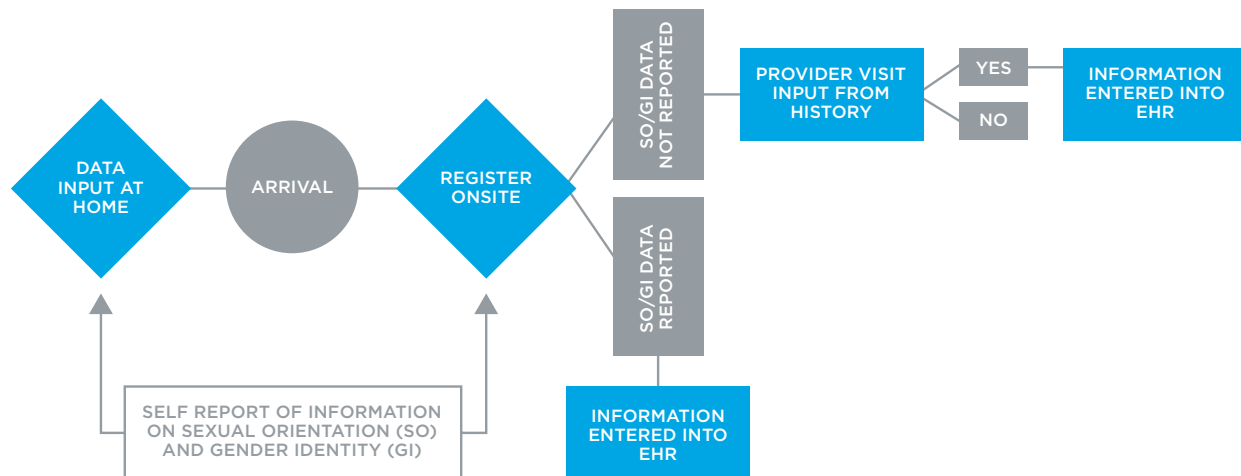


**SO/GI questions should be asked periodically, as sexual orientation and gender identity can change over time.**

SO/GI information can be entered into the EHR by appropriate staff or directly by the patient through an online portal or mobile device. Whichever way the data is collected, SO/GI questions should be asked periodically, as sexual orientation and gender identity

can change over time. Figure 3 illustrates a sample process of gathering SO/GI data in clinical settings.

**FIGURE 3: SAMPLE PROCESS FOR COLLECTING DATA FROM PATIENTS IN CLINICAL SETTINGS**



## TRAINING STAFF

Health centers that collect SO/GI data need to ensure that all staff are first trained on effective communication with LGBT people. This training should include information on LGBT people and their health needs, as well as information on how to safeguard patient privacy and confidentiality. Training is available from the National LGBT Health Education Center at [www.lgbthealtheducationcenter.org](http://www.lgbthealtheducationcenter.org).

## NEXT STEPS

There are various ways that SO/GI information can be incorporated into the EHR; there is no single system for accomplishing this. Health centers will need to work with their EHR vendors on how to structure questions as well as how to structure decision support (reminder systems) and coding. This also means it is important to educate insurers about standards of care for LGBT people so that reimbursement policies recognize the unique health needs of LGBT people.

The federal government is actively considering opportunities to support health care providers in asking SO/GI questions in clinical settings. As of spring 2015, the Office of

the National Coordinator for Health Information Technology (ONC) has proposed health IT certification requirements calling for creating an optional module to collect SO/GI data. The Centers for Medicare and Medicaid Services' proposed Meaningful Use Stage 3 rule does not include collection of SO/GI data, although many are recommending its inclusion.<sup>2,3,7</sup> To keep up to date on where these proposals stand, please refer to the Do Ask, Do Tell website at [www.doaskdotell.org](http://www.doaskdotell.org).

## **CONCLUSION**

Given the documented disparities found in LGBT populations, it is critical for health centers to begin the standardized collection of SO/GI data in EHRs. Gathering this data will increase quality of care given to LGBT patients by allowing health centers to measure and track outcomes in these populations. Asking these questions also improves patient-centered care. Providers who are informed of their patients' sexual orientation and gender identity — and are trained to care for LGBT patients — are better able to provide care that is relevant, specific, and compassionate. For further resources and information, see the Resources section below, and visit the National LGBT Health Education Center's website at [www.lgbthealtheducation.org](http://www.lgbthealtheducation.org).



## REFERENCES

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. Available at [www.nap.edu/catalog.php?record\\_id=13128](http://www.nap.edu/catalog.php?record_id=13128).
2. Institute of Medicine. Sexual orientation and gender identity data collection in electronic health records: A workshop. Washington, DC: National Academies Press; 2012. Available at [www.iom.edu/Activities/SelectPops/LGBTData.aspx](http://www.iom.edu/Activities/SelectPops/LGBTData.aspx).
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. Available at [www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf](http://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf).
4. Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, Makadon, H. 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. Available at [www.journals.plos.org/plosone/article?id=10.1371/journal.pone.0107104](http://www.journals.plos.org/plosone/article?id=10.1371/journal.pone.0107104).
5. Deutsch M, Green J, Keatley J, Mayer G, Hastings J, Hall A; the World Professional Association for Transgender Health EMR Working Group. 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):700-3.
6. Deutsch M, Buchholz D. Electronic health records and transgender patients—practical recommendations for the collection of gender identity data. *J Gen Intern Med*. 2015;30(6):843-7.
7. Public Comment on Stage 3 Meaningful Use proposed rule CMS-3310-P, published March 30, 2015. Submitted online: [www.federalregister.gov/articles/2015/03/30/2015-06685/medicare-and-medicaid-programs-electronic-health-record-incentive-program-stage-3](http://www.federalregister.gov/articles/2015/03/30/2015-06685/medicare-and-medicaid-programs-electronic-health-record-incentive-program-stage-3).

## RESOURCES

A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings - [www.doaskdotell.org](http://www.doaskdotell.org)

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)

Healthy People 2020 LGBT Health - [www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health](http://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health)

There are many publications from the National LGBT Health Education Center's website, [www.lgbthealtheducation.org/publications](http://www.lgbthealtheducation.org/publications), including:

- Do Ask, Do Tell: Talking to your provider about being LGBT
- Taking Routine Histories of Sexual Health: A System-Wide Approach for Health Centers
- Optimizing LGBT Health Under the Affordable Care Act: Strategies for Health Centers
- Ten Things: Creating Inclusive Health Care Environments for LGBT People

There are many webinars from the National LGBT Health Education Center's website, [www.lgbthealtheducation.org/training/on-demand-webinars](http://www.lgbthealtheducation.org/training/on-demand-webinars), including

- Collecting Data on Sexual Orientation and Gender Identity in the Electronic Health Record: Why and How
- How Patient-Centered Medical Homes Can Improve Health Care for Lesbian, Gay, Bisexual, and Transgender Patients and Families
- Meeting the Health Care Needs of Lesbian, Gay, Bisexual, and Transgender People: The End to LGBT Invisibility

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