



Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records



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.¹ 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^{1,2} and the Joint Commission³ 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.

NEW FEDERAL DATA REQUIREMENTS

In March 2016, HRSA added SO/GI data as required elements to be reported yearly in the Uniform Data System (UDS), beginning in Calendar Year 2016. [The Program Assistance Letter \(PAL 2016-2\)](#) states that “sexual orientation and gender identity (SO/GI) can play a significant role in determining health outcomes,” and that “gaining a better understanding of populations served by health centers, including sexual orientation and gender identity, promotes culturally competent care delivery, and contributes to reducing health disparities overall.” HRSA has issued changes to Tables 3A and 3B to report data on sex at birth, current gender identity, and sexual orientation.⁴

In addition, in 2015 the Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC) issued rules requiring all electronic health record (EHR) systems certified under the Meaningful Use incentive program to have the capacity to record, change, and access structured SO/GI data. The requirement applies to vendors who are building certified EHR systems and to health institutions and practices that are using these systems as part of their participation in the Meaningful Use program. Many vendors are currently working with experts in LGBT health to develop this capacity.^{5,6}

** A Spanish translation of SO/GI questions can be found on the National LGBT Health Education Center’s website at www.lgbthealtheducation.org/topic/sogi*

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 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.⁷

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,^{8,9} we advise using the questions listed in Figure 1 as part of a patient visit.

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
- Choose not to disclose

Gender identity

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/(or Other), please specify: _____
- Choose not to disclose

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

- Male
- Female
- Choose not to disclose

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. Asking these 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 (i.e., people who do not identify as male or female).

In addition to asking about SO/GI, we strongly suggest asking patients to include their name used and their pronouns on registration forms (see Figure 2), in addition to their administrative or legal name that would appear on their insurance or other documents. This is important because many transgender patients have insurance records and identification documents that do not accurately reflect their name and gender identity. In addition, some people who have a non-binary gender identity use “they” rather than “he” or “she,” or use other gender neutral pronouns such as “ze”. Asking about name and pronouns, and training all staff to use them consistently, can greatly facilitate patient-centered communication. Health centers may also want to add questions about the name and gender that is listed on patient’s insurance or government-issued identification documents. This can be helpful in preventing mistakes and alleviating confusion.

FIGURE 2: NAME AND PRONOUNS QUESTIONS

Name Used:

Pronouns:

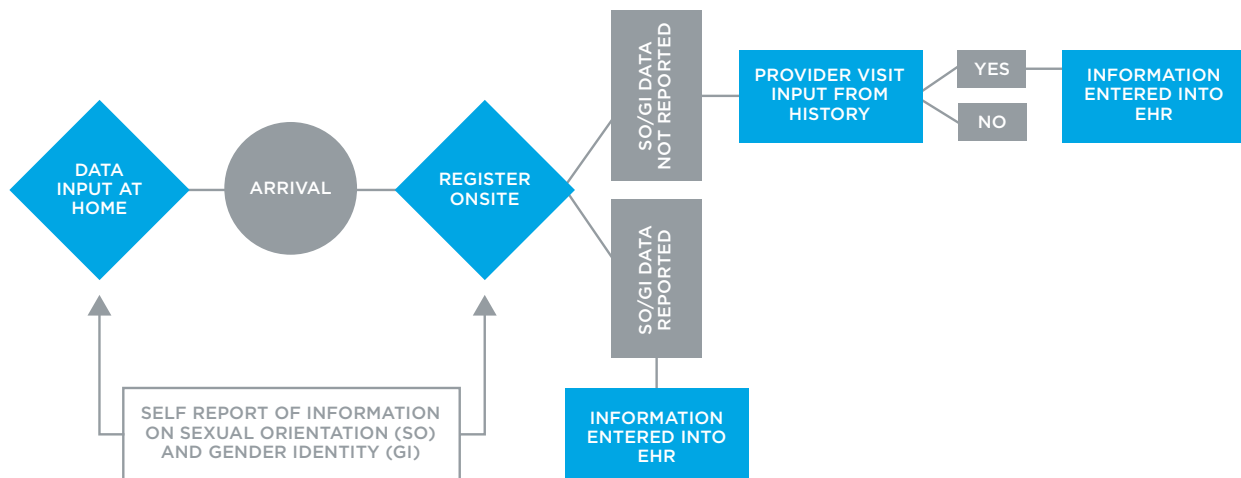
- He/Him
- She/Her
- They/Them
- Other _____

COLLECTING THE DATA

There are several ways SO/GI data can be collected. For example, questions can be included on paper 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?” If SO/GI questions are asked verbally, it is important to ask them in a private space to ensure confidentiality.

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, both clinical and non-clinical, 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.

OTHER CONSIDERATIONS

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 clinical decision support (reminder systems), coding, and communications (e.g. secure emails, letters to patients). 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.

CONCLUSION

Given the documented health disparities found in LGBT populations, it is critical for health centers to begin the standardized collection of SO/GI data in EHRs and other clinical records. Gathering this data will increase quality of care given to LGBT patients



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

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.

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
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
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
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
5. Department of Health and Human Services, Centers for Medicare and Medicaid Services: 42 CFR Parts 412 and 495 [CMS-3310-FC and CMS-3311-FC], RINs 0938-AS26 and 0938-AS58. Medicare and Medicaid Programs; Electronic Health Record Incentive Program—Stage 3 and Modifications to Meaningful Use in 2015 through 2017. Released October 6, 2015. Available at <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-25595.pdf>
6. Department of Health and Human Services, Office of the Secretary: 45 CFR Part 170, RIN 0991-AB93. 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Based Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications. Released October 6, 2015. Available at <https://s3.amazonaws.com/public-inspection.federalregister.gov/2015-25597.pdf>
7. 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 <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0107104>
8. 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.
9. 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.

RESOURCES

The National LGBT Health Education Center's website offers training, webinars, and tools for SO/GI data collection.

www.lgbthealtheducation.org/topic/sogi

A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings

www.doaskdotell.org

Center of Excellence for Transgender Health

www.transhealth.ucsf.edu

World Professional Association for Transgender Health

www.wpath.org

Healthy People 2020 LGBT Health

www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under cooperative agreement number U30CS22742, Training and Technical Assistance National Cooperative Agreements (NCAs) for \$449,985.00 with 0% of the total NCA project financed with non-federal sources. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.



**NATIONAL LGBT HEALTH
EDUCATION CENTER**

A PROGRAM OF THE FENWAY INSTITUTE

TEL 617.927.6354 **WEB** lgbthealtheducation.org **EMAIL** lgbthealtheducation@fenwayhealth.org

THE FENWAY INSTITUTE 1340 Boylston Street, Boston, MA 02215