
POLICY FOCUS:

**HOW TO GATHER DATA
ON SEXUAL ORIENTATION
AND GENDER IDENTITY
IN CLINICAL SETTINGS**

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How to gather data on sexual orientation and gender identity in clinical settings

Judith B. Bradford, PhD; Sean Cahill, PhD; Chris Grasso, MPH; and Harvey J. Makadon, MD

In this brief, we discuss two methods for gathering sexual orientation and gender identity from patients, by asking questions on the patient registration (intake) form, and by requiring that providers gather this information directly from patients during medical visits, recording responses in the electronic medical record.

HOW TO ASK PATIENTS ABOUT SEXUAL ORIENTATION AND GENDER IDENTITY

REGISTRATION (INTAKE) FORMS

Patients should be asked about how they self-identify as to their sexual orientation and gender identity on intake forms. Questions should be included in the demographic part of the form, alongside questions about race, sex, and date of birth. Patients should also be assured that this information will be kept confidential, and allows health care providers to provide them with the most relevant prevention information and screen them for health conditions disproportionately affecting members of their demographic group. Examples of such health conditions that correlate with race, ethnic background, sex, or sexual orientation can be given, such as sickle cell anemia, Tay Sachs's disease, or cervical cancer.

Fenway Health, a federally qualified health center in Boston, Massachusetts has been testing two versions of a sexual orientation identity question as well as a transgender identity question in 2011. The U.S. Department of Health and Human Services (HHS) will field test a sexual identity question on the National Health Interview Survey (NHIS) in early 2012. It is hoped that it will be added as a standard question to NHIS in fall 2012. HHS is also conducting research on how to measure gender identity and has committed to adding gender identity to a battery of demographic questions alongside sexual orientation, age, sex, and race/ethnicity, etc.

Fenway Health recently evaluated the best way to ask sexual orientation on its patient registration form. Two sets of questions widely used to measure sexual orientation were included in the patient registration form over a period of 7 months. Staff alternated the forms such that about half of new patients received one version of sexual orientation options and another half the second version. Sexual orientation was coded as “missing” on a total of 65 of 978 completed forms (6.6%). Fenway conducted this activity to gather patient input on the best way to ask sexual orientation identity on the registration form, required of all new patients at the main health center and other Fenway Health locations. Based on results from this evaluation, the following question has been added to the patient registration form now used at all Fenway Health locations and throughout its departments.

7 Do you think of yourself as:

Lesbian, gay, or homosexual Straight or heterosexual

Bisexual Something else Don't know

Ideally health care organizations will include sexual identity and gender identity questions on a field in the registration form. If the patient answers the questions, this is one less question the provider must ask about during patient visits, although further discussion may be desired. However, if the patient leaves these questions blank, the provider should ask them again during the visit. Providers may want to ask these questions periodically, as sexual and gender identity and sexual attraction can change over the life course.¹

It is important that staff treat all patients with respect in their interactions with patients. This will ensure a greater likelihood that patients will respond accurately and honestly to sensitive questions.

PROVIDER-PATIENT INFORMATION SHARING

BEST PRACTICES ON ASKING ABOUT SEXUAL ORIENTATION AND GENDER IDENTITY IN CLINICAL SETTINGS

When seeing a patient for the first time, providers should also ask questions about sexual orientation, behavior, and gender identity during the patient’s visit. Providers should start with an open-ended question, such as “Tell me a bit about yourself.” In talking about his or her life and family, the patient may bring up issues related to sexual orientation or gender identity.² Providers can facilitate open conversations



Providers can facilitate open conversations about being gay or transgender by sending a message that LGBT people are welcome in their medical offices.

about being lesbian, gay, bisexual, or transgender by sending a message that LGBT people are welcome in their medical offices. This can be signaled by posting a rainbow flag, the logo of the Gay and Lesbian Medical Association, and/or a social marketing campaign showing affirming images of LGBT people.³ Providers can also use inclusive or neutral language, such as “Do you have a partner?” instead of asking “Are you married?” which in most states and to most people still refers to heterosexual relationships.

Providers should ask permission to include information about a patient’s sexual orientation and gender identity in the medical record, remind the patient of its importance to quality health care, and assure him or her that the information will be kept confidential.

If self-disclosure does not come up in response to general questions such as those proposed above, further questions can be embedded in the sexual history. Such a history should address sexual risk behavior as well as sexual health,⁴ sexual orientation (including identity, behavior, and attraction), and gender identity. A provider can start the conversation by asking,

“Do you have any concerns or questions about your sexuality, sexual orientation, or sexual desires?”⁵

It may help put the patient at ease to preface these questions with a statement that these are questions you ask all patients, and that the information is important to helping you provide the best quality care. For example, you could say:

*“I am going to ask you some questions about your sexual health and sexuality that I ask all my patients. The answers to these questions are important for me to know how to help keep you healthy. Like the rest of this visit, this information is strictly confidential.”*⁶ Most patients are forthcoming with information, particularly once they understand why they are being asked.

The provider can ask “Do you have a partner or a spouse?” or “Are you currently in a relationship?” He or she can also ask:

- Are you sexually active?
- When was the last time you had sex?
- When you have sex, do you do so with men, women, or both?
- How many sexual partners have you had during the last year?
- Do you have any desires regarding sexual intimacy that you would like to discuss?

Providers should also ask whether patients are transgender or have gender-related concerns. For example:

*“Because so many people are affected by gender issues, I ask patients if they have any relevant concerns. Anything you say will be kept confidential. If this topic isn’t relevant to you, tell me and I will move on.”*⁷

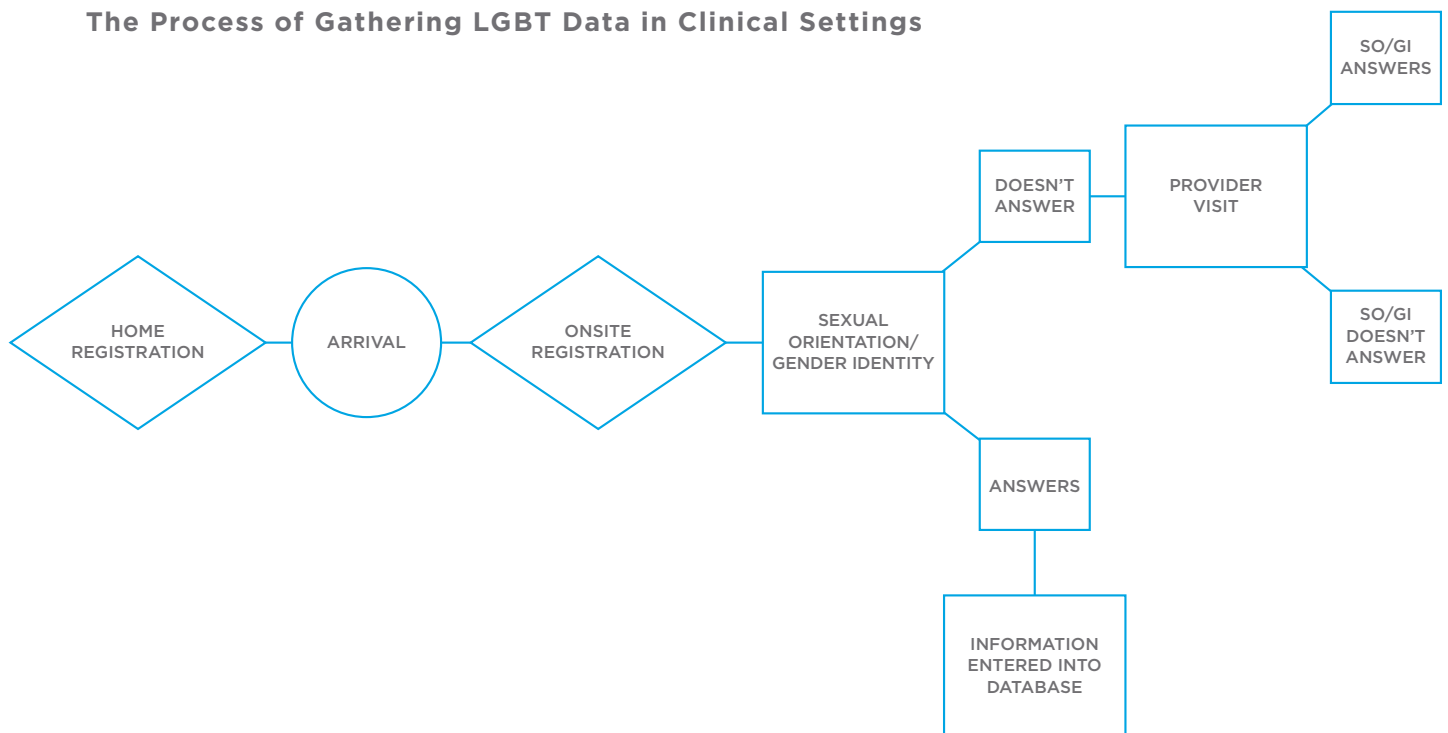
Once providers establish an open rapport with clients and they feel comfortable discussing their homosexuality, bisexuality, and/or gender identity, providers should offer care that addresses the particular health issues and disparities facing LGBT people. Guidelines for providing primary care to LGBT patients can be found in *The Fenway Guide to Lesbian, Gay, Bisexual and Transgender Health*, published by the American College of Physicians.⁸

BARRIERS TO COLLECTING DATA ON LGBT IDENTITY, INCLUDING PRIVACY CONCERNS

ON INTAKE FORMS

LGBT patients may be hesitant to disclose information about their sexual orientation or gender identity due to fears about confidentiality and privacy.⁹ These fears may have to do with the fact that one hands a filled out intake/registration form to a medical office staff person. Patients may be reluctant to provide such personal information to office staff in a waiting room, because it feels less private than answering the question of a provider in an examination room.

The Process of Gathering LGBT Data in Clinical Settings



Concept: Harvey Makadon, MD Created by: Komal Basra

Privacy and confidentiality concerns are exacerbated by the increasing computerization of health records. The U.S. government is seeking the full computerization of Americans' health records by 2014. Funded by the 2009 economic stimulus program and the 2010 health care reform legislation, the shift underway to electronic health records (EHR) and health information exchanges (HIE) could dramatically improve healthcare, increase providers' ability to determine the most effective treatments, and advance health science.¹⁰ It also poses new threats to patient data. For example, the electronic health care records of 4.9 million active and retired military members and their families may have been exposed in a major data breach reported in September 2011. Back-up tapes of these EHRs, handled by Science Applications International Corporation, were reported "lost."¹¹

However, with the development of proper standards for encoding medical information, along with the development of best practices for how to manage a computer infrastructure by institutions like the National Institutes for Standards and Technology, these threats are manageable.¹² Sections 1411(g), 1411(c)(2), and 1414(a)(1) of the 2010 Patient Protection and Affordable Care Act provide privacy and security protections for information used by HIEs.¹³ A rule proposed in July 2011 would mandate "appropriate security and privacy protections" for any "personally identifiable information," including sensitive health information, that is collected and used in the provision of health care.¹⁴ And with EHRs there is greater control over who views and copies them than with traditional paper medical records. Audit reports can be run that show who has viewed information in a patient's



Given the connection between open disclosure of same-sex behavior and health, asking about these issues is integral to providers' ability to care for their LGBT patients.

EHR. Blocks can be put in place that prevent the printing of certain document types. Such safety controls do not exist with paper records.

During provider-patient interaction there are several potential barriers to gathering this information. Providers may not be comfortable asking these questions, or lack knowledge on how to elicit this information. Some worry LGBT people will be reluctant to disclose due to anti-LGBT stigma and prejudice. This may be true, and as a result not all LGBT patients will disclose their sexual or gender identity. However, this should not prevent providers from asking such questions and trying to gather such data. As society becomes more tolerant and accepting of LGBT people, more and more LGBT patients will self-disclose. In the meantime, the data we get from those who do self-disclose allows us to better understand the unique health needs and experiences of LGBT people.

Providers may worry that they don't have the time for these discussions. High patient volume may be a barrier to comprehensive, quality data capture.¹⁵ However, given the connection between open disclosure of same-sex behavior and health, asking about these issues is integral to providers' ability to care for their LGBT patients.

USING SELF-ADMINISTERED COMPUTER-BASED QUESTIONNAIRES TO GATHER PATIENT REPORTED OUTCOMES

Research shows that respondents are 1.5 to 1.6 times more likely to report same-sex behavior and attraction on an audio computer assisted self-interviewing survey than in response to questions asked by an interviewer.¹⁶ The reporting of Patient Reported Outcomes (PROs) on computer tablets such as iPads may also garner more truthful responses to sensitive questions, not only about sexual identity and behavior but also about substance use and sexual risk behavior. Self-provided PROs may also overcome barriers to data gathering posed by high patient volume in clinical settings.¹⁷ PROs are standardized, validated patient questionnaires administered directly to patients using touch-screen computer-based administration.¹⁸

Kozak, Mugavero, Ye et al. reported higher rates of prior substance use and prior tobacco use on PROs than EHRs among a sample of 782 HIV patients at a Birmingham, Alabama clinic. However, current reported substance use and current depression were much higher on electronic health records (EHRs) than on PROs.¹⁹ The findings, in other words, are mixed on the relative value of PROs compared with EHRs in eliciting disclosure of stigmatized behavior or conditions. More research is necessary.

CONCLUSION

GATHERING LGBT DATA IN CLINICAL SETTINGS IS A CRUCIAL STEP TOWARD REDUCING HEALTH DISPARITIES AND PROMOTING HEALTH EQUITY

While the science is not yet perfect and some LGBT patients inevitably will not self-disclose, asking about sexual orientation and gender identity in clinical settings will improve health outcomes of LGBT patients, and will help advance our understanding of LGBT health. The asking of such questions both on registration forms and during patient exams will alert providers to screen patients for conditions disproportionately affecting LGBT people, and to provide preventive health education appropriate to LGBT patients.

Judith B. Bradford, PhD

Director of the Center for Population Research in LGBT Health

Co-Chair of The Fenway Institute

Sean Cahill, PhD

Director of Health Policy Research

Chris Grasso, MPH

Data Manager

Harvey J. Makadon, MD

Director of the National LGBT Health Education Center

Reviewed by:

Kenneth Mayer, MD

Medical Research Director,

Co-Chair of The Fenway Institute

Rodney VanDerwarker, MPH

Administrative Director

Graphic Design by:

John Hanawalt

Communications & Design Associate

- 1 American Psychiatric Association (May 2000). “Gay, Lesbian and Bisexual Issues”. Association of Gay and Lesbian Psychiatrists. <http://www.aglp.org/pages/cfactsheets.html#Anchor-Gay-14210>. Accessed December 22, 2011.
- 2 Makadon, 2011.
- 3 Cahill, S. & Valadez, R. (in press), Community-based approaches to HIV prevention that address anti-gay stigma. *Psychology & AIDS Exchange*.
- 4 The World Health Organization defines sexual health as “a state of physical, mental, and social well-being in relation to sexuality.” http://www.who.int/topics/sexual_health/en/. Accessed December 22, 2011
- 5 Makadon, 2011.
- 6 Ibid.
- 7 Ibid.
- 8 Makadon, H, Mayer, K, Potter, J, Goldhammer, H (eds.) *The Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health*. Philadelphia: American College of Physicians, 2008
- 9 Mayer KH, Bradford JB, Makadon HJ, Stall R, Goldhammer H, Landers S. Sexual and gender minority health: What we know and what needs to be done. *American Journal of Public Health*. 2008; 98: 989–995
- 10 Hoffman, S, Podgurski, A. Improving health care outcomes through personalized comparisons of treatment effectiveness based on electronic health records. *Journal of Law, Medicine and Ethics*. 2011; 39: 425–436.
- 11 Forsyth, J. Medical records of 4.9 million exposed in Texas data breach. Reuters. www.reuters.com/assets/print?aid=USTRE78S5JG20110929. Accessed September 29, 2011.
- 12 Gupta, A. Hackers, breaches and other threats to electronic records. *Health Data Management*. 2011; 19: 54.

- 13 Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plan. A Proposed Rule by the Health and Human Services Department on 07/15/2011. *Federal Register*. <http://www.federalregister.gov/articles/2011/07/15/2011-17610/patient-protection-and-affordable-care-act-establishment-of-exchanges-and-qualified-health-plans#p-252> Accessed September 28, 2011.
- 14 Ibid.
- 15 Kozak M, Mugavero M, Ye J, Aban I, Lawrence S, Nevin C, Raper J, McCullumsmith C, Schumacher J, Crane H, Kitahata M, Saag M, Willig J. Patient reported outcomes in routine care: Advancing data capture for HIV cohort research. *Clinical Infectious Diseases*. 1–7. Published online October 31, 2011.
- 16 Villarroel M, Turner C, Eggleston E, Al-Tayyib A, Rogers S, Roman A, Cooley P, Gordek H. Same-gender sex in the United States: Impact of T-ACASI on prevalence estimates. *Public Opinion Quarterly*. 2006; 70(2): 166–196.
- 17 Kozak M et al.
- 18 Ibid. 2.
- 19 Ibid. 4.

