Sexual Orientation and Gender Identity Data Collection Update: U.S. Government Takes Steps to Promote Sexual Orientation and Gender Identity Data Collection Through Meaningful Use Guidelines

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Abstract

Collecting data on sexual orientation and gender identity (SO/GI) in healthcare settings and in electronic health records (EHRs) is essential to understanding, addressing, and reducing LGBT health disparities. The federal government took two key steps in early 2014 in support of asking SO/GI questions in clinical settings as part of the meaningful use of EHRs. First, the Office of the National Coordinator for Health Information Technology issued proposed 2015 Edition Certified EHR Technology (CEHRT) Criteria, which suggest Systematized Nomenclature of Medicine (SNOMED) code sets for SO/GI data collection in 2017. To facilitate the effective and accurate collection of SO/GI data, 153 LGBT and HIV groups recommended that the national coordinator request that the National Library of Medicine develop new codes to reflect SO/GI data. Second, the Health Information Technology Policy Committee submitted recommendations to the national coordinator, including the recommendation that ''CEHRT [certified EHR technology] provides the functionality to capture ... sexual orientation, gender identity.'' If the national coordinator accepts this recommendation, it will be put up for public comment in fall 2014 along with other Stage 3 proposed rules. Also, the 2017 Edition CEHRT Notice of Proposed Rule Making Criteria will be up for comment in fall 2014. Final Stage 3 Meaningful Use Guidelines will be published in summer 2015, and other key steps will take place into 2017. A critical parallel step is the training of clinical staff on LGBT health disparities and how to use SO/GI data and manage them in ways that meet the clinical needs of LGBT patients and protect confidentiality and privacy. We must also educate LGBT community members about why offering this information is important for their health and how collecting SO/GI data in EHRs is an important step to understanding LGBT health, reducing disparities, and improving outcomes.

Key words: data collection, electronic health records, gender identity, health disparities, health information technology, meaningful use, sexual orientation.

Introduction

COLLECTING DATA ON SEXUAL ORIENTATION and gender identity (SO/GI) in healthcare settings and in electronic health records (EHRs) is essential to understanding, addressing, and reducing LGBT health disparities.[1] Without this information, it is not possible to assure that the quality of care provided to LGBT patients is appropriate and approaches standards for the general population. Lesbian and bisexual women are 4–10 times less likely to have a Pap test, and are also less likely to have a mammogram.[2,3] However, without knowing who identifies as a lesbian or bisexual woman, it is impossible to assess quality and whether we are addressing this disparity in preventive care. Knowledge of a patient's gender identity is essential to understanding a patient's history and clinical care needs. For example, many transgender men have a cervix and should be offered a Pap test. Transgender women should be offered a prostate exam to screen for prostate cancer.[4] While such examinations have to be approached and done with sensitivity to each patient, they are critical to quality care.

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Meaningful Use of EHRs

The federal government is currently considering steps that would support healthcare providers' asking SO/GI questions in clinical settings. One opportunity is provided by the nation's shift from paper to EHR. ''Meaningful use'' of EHRs involves using certified EHR technology to ensure that appropriate demographic and clinical elements are included in EHRs that will allow measurement of quality and reduce disparities. It is hoped that meaningful use of EHRs will result in improved clinical outcomes, improved population health, and better research on health systems.[5] Meaningful use of EHRs has been shown to improve diabetes care and outcomes.[6]

Meaningful use guidelines for the implementation of EHRs already require race and ethnicity data collection. The Joint Commission stresses the importance of gathering race and ethnicity data:

> Hospitals must collect patient-level demographic data on race and ethnicity to identify the needs of individual patients and to eliminate disparities in the patient population. These critical data provide hospitals with information on the potential cultural needs of each patient, as well as an opportunity to monitor and analyze health disparities at the population level.[7]

Recent Developments

The federal government took two key steps in early 2014 in support of asking SO/GI questions in clinical settings as part of the meaningful use of EHRs: (1) proposing 2015 EHR Certification Criteria, which suggest Systematized Nomenclature of Medicine (SNOMED)[*] code sets for SO/GI data collection in 2017, and (2) recommending that ''CEHRT [certified EHR technology] provides the functionality to capture … sexual orientation, gender identity.''

Code Sets for SO/GI

In late February 2014, the Office of the National Coordinator for Health Information Technology issued proposed 2015 Edition Certified EHR Technology Criteria, which suggest SNOMED code sets for SO/GI. The proposed SNOMED code sets were:

- Sexual orientation: asexual; bisexual; gay; heterosexual; lesbian; questioning (a person who is questioning his/her sexual orientation); decline to answer; and not applicable (ages 0–17)
- Gender identity: gender variant; man; intersex; questioning (a person who is questioning his or her sexual orientation)[†]; transgender; woman; decline to answer; and not applicable (ages 0–17)[8]

LGBT Community Comment on the Proposed Rules

The Fenway Institute and the Center for American Progress organized a community public comment, submitted

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[*]Systematized Nomenclature of Medicine is an international, multilingual clinical healthcare terminology maintained by the International Health Terminology Standards Development Organization. www.ihtsdo.org/snomed-ct/ (accessed June 2, 2014).

[†]This is apparently a mistake and should read ''(a person who is questioning his or her *gender identity*).''

April 28, 2014, which included a total of 153 institutional signers, including the Mayo Clinic and UC Davis Medical School. Fifty-seven individuals also signed the comment.[9] The comment commended Dr. Karen DeSalvo, the national coordinator for health information technology, for utilizing the proposed Voluntary 2015 Edition Electronic Health Record Certification Criteria to signal their intent to include SO/GI in the 2017 Edition CEHRT. The comment noted that a growing body of research and policy analysis indicates that collecting these data is an important aspect of providing optimal care for diverse populations, particularly with regard to advancing patient-centered care for the LGBT population.[1,9]

Because we believed that the proposed SNOMED code sets are inappropriate in their use of terminology and concepts that do not accurately reflect the realities of patients' lives and identities, we proposed alternative questions. Fenway and the Center for American Progress shared these questions with the Office of Health Information Technology's Standards Committee and Health Information Technology Policy Committee in December 2013 and recommended their adoption in their public comment submitted April 28, 2014.

We encouraged the national coordinator of health information technology to move forward with including the following SO/GI data concepts in the 2017 edition, as well as in future CEHRT editions:

Sexual orientation

Do you think of yourself as:
- Lesbian, gay, or homosexual
- Straight or heterosexual
- Bisexual
- Something else, please describe: _____
- Don't know

Gender identity

We recommended that gender identity data collection involve both of the following concepts:

What is your current gender identity? (Check all that apply)
- 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: _____
- Decline to answer

What sex were you assigned at birth on your original birth certificate? (Check one)
- Male
- Female
- Decline to answer

With regard to gender identity, it is important to note that many transgender people do not identify as transgender. For example, a person who was born male, but whose current gender identity is female, may choose ''female'' rather than ''transgender.'' By asking about sex assigned at birth as well as current gender identity, we will get better, more clinically relevant data, and have a clearer picture of the patient's identity and clinical needs. For example, without asking about

sex assigned at birth, it would not be clear whether someone who identifies as ''female'' is a cisgender (nontransgender) natal female, or a transgender natal male with a female identity. The two-step gender identity and birth sex question was developed by the Philadelphia Transgender Health Advocacy Coalition in 1997[10] and endorsed by the Center of Excellence for Transgender Health at University of California–San Francisco 10 years later.[11] A two-step approach to gender identity measurement is used by the Centers for Disease Control and Prevention,[12] and the World Professional Association for Transgender Health endorsed a two-step gender identity and sex assigned at birth question in 2013.[13]

To facilitate the effective and accurate collection of SO/GI data, we recommended that the Office of Health Information Technology request that the National Library of Medicine develop new codes that reflect SO/GI data as captured in these questions.

In addition to a sexual orientation question, a current gender identity question, and a question about assigned sex at birth, we also suggested that two additional questions be added:

Preferred gender pronoun
- He/him
- She/her
- Something else (Specify: _____)

Preferred name (Specify: _____)

Preferred name and gender pronoun information have been shown to greatly facilitate patient-centered communication in clinical settings when coupled with appropriate staff training.

Technology to Capture SO/GI Data

A second major development occurred in March 2014. The Health Information Technology Policy Committee submitted recommendations to the national coordinator of health information technology, including the recommendation that ''CEHRT [certified EHR technology] provides the functionality to capture … sexual orientation, gender identity.'' If the national coordinator accepts this recommendation, it will be put up for public comment in fall 2014 rules. Also, the 2017 Edition CEHRT will be up for comment in fall 2014. Final Stage 3 Meaningful Use Guidelines will be published in summer 2015, along with the 2017 Edition CEHRT. The national coordinator of health information technology will publish 2018 EHR Certification Criteria in February 2016 and solicit comment then. Stage 3 Meaningful Use Guidelines will be implemented in October 2016 for hospitals and in January 2017 for providers.

Protecting Privacy and Minimizing the Risk of Discrimination

The Notice of Proposed Rule Making elicited the public comment from 153 organizations and noted that ''concerns have been raised about the need to balance privacy and security with data flow needs.'' Given the stigma and discrimination that many LGBT people experience, these are important concerns. The public comment acknowledged the potential sensitivity of these data and the need to train staff in how to gather these data in a culturally appropriate way, while safeguarding patient privacy and confidentiality. However, as institutions such as the National Institutes for Standards and Technology continue to develop standards for encoding medical information, along with best practices for how to manage a computer infrastructure, the potential risks to privacy and security posed by SO/GI data collection are manageable and no greater than those posed by the collection of any other personal information, particularly in the intimacy of healthcare settings.[14] Further, a 2012 federal regulation mandates ''appropriate security and privacy protections'' for any ''personally identifiable information,'' including sensitive health information that is collected and used in the provision of healthcare.[15] It is important to note that EHRs provide a stronger system than paper medical records for tracking who is accessing patients' medical records. Inappropriate disclosure of sensitive information in EHRs can be traced back to the perpetrator.

Another concern is whether self-disclosure may expose LGBT patients to discrimination by providers and clinical staff in states without nondiscrimination laws. While 29 states lack sexual orientation nondiscrimination laws and 33 lack gender identity nondiscrimination laws,[16] the sex nondiscrimination provision in Section 1557 of the Affordable Care Act prohibits discrimination on the basis of gender identity and sex stereotyping by any provider, facility, or program receiving federal funds,[17] and current jurisprudence is moving in the direction of explicitly recognizing sexual orientation as a protected category as well.[‡] The Joint Commission's 2011 *Comprehensive Accreditation Manual for Hospitals* requirement that hospitals adopt SO/GI nondiscrimination policies is another important step toward reducing anti-LGBT discrimination in healthcare.[7]

Finally, it is important to note that disclosing SO/GI information—like any demographic data—is voluntary for all patients. While we acknowledged the concerns raised in the proposed rule about privacy and security, we argued that these can be addressed and that the benefits of gathering SO/GI data to improve patient care and improve understanding of LGBT health disparities substantially outweigh these risks.

The Importance of Provider and Staff Training and Community Education

While these steps are still in process and the outcome is uncertain, there are hopeful signs that the federal government will take concrete steps to promote SO/GI data collection in EHRs. A critical parallel step is the training of providers and clinical staff on LGBT health disparities, why collecting SO/GI data is so important, and how to use SO/GI data and manage them in ways that meet the clinical needs of LGBT patients and protect confidentiality and privacy. We must also educate LGBT community members about why offering this information is important for their health and how collecting SO/GI data in EHRs is an important step to understanding LGBT health, reducing

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[‡]*Terveer v. Billington* (2014) found that discrimination on the basis of sexual orientation is prohibited under the sex nondiscrimination protections in Title VII of the Civil Rights Act of 1964, which are analogous to the sex nondiscrimination protections in Section 1557 of the Affordable Care Act.

disparities, and improving outcomes for both individuals and the LGBT community.

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