

Sexual Orientation and Gender Identity Data Collection in Clinical Settings and in Electronic Health Records: A Key to Ending LGBT Health Disparities

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Abstract

The Institute of Medicine's (IOM's) 2011 report on the health of LGBT people pointed out that there are limited health data on these populations and that we need more research. It also described what we do know about LGBT health disparities, including lower rates of cervical cancer screening among lesbians, and mental health issues related to minority stress. Patient disclosure of LGBT identity enables provider-patient conversations about risk factors and can help us reduce and better understand disparities. It is essential to the success of Healthy People 2020's goal of eliminating LGBT health disparities. This is why the IOM's report recommended data collection in clinical settings and on electronic health records (EHRs). The Center for Medicare and Medicaid Services and the Office of the National Coordinator of Health Information Technology rejected including sexual orientation and gender identity (SOGI) questions in meaningful use guidelines for EHRs in 2012 but are considering this issue again in 2013. There is overwhelming community support for the routine collection of SOGI data in clinical settings, as evidenced by comments jointly submitted by 145 leading LGBT and HIV/AIDS organizations in January 2013. Gathering SOGI data in EHRs is supported by the 2011 IOM's report on LGBT health, Healthy People 2020, the Affordable Care Act, and the Joint Commission. Data collection has long been central to the quality assurance process. Preventive health care from providers knowledgeable of their patients' SOGI can lead to improved access, quality of care, and outcomes. Medical and nursing schools should expand their attention to LGBT health issues so that all clinicians can appropriately care for LGBT patients.

Key words: clinical settings, data collection, disparities, electronic health record, meaningful use.

Introduction

THE INSTITUTE OF MEDICINE'S (IOM'S) 2011 report on the health of LGBT people pointed out that there are limited health data on these populations. It highlighted what is known about disparities that have been studied, as well as the extensive diversity among LGBT people. In response, the IOM made key recommendations for better data collection on individuals' sexual orientation and gender identity (SOGI) in research studies and electronic health records (EHRs). It is this later point that we wish to discuss, both because of the opportunity to learn about LGBT health and health disparities in health-care settings, as well as the challenges in implementing collection of these critical data.

Why LGBT Health?

The IOM report reviewed the research and highlighted health disparities among LGBT people, such as the prevalence of sexually transmitted infections and HIV (with 66% of new cases of HIV in the United States occurring in gay or bisexual men in 2010), and the high rates of behavioral health issues, including suicidal ideation and attempts, often related to stigma, discrimination, bullying, and hate crimes. Lesbians are more likely than heterosexual and bisexual women to be overweight and obese, increasing their risk for cardiovascular disease, lipid abnormalities, glucose intolerance, and morbidity related to inactivity.¹ Lesbians and bisexual women experience cervical cancer at the same rate

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as heterosexual women but are much less likely to get routine Pap tests to screen for cervical cancer.^{2,3} The Massachusetts Behavioral Risk Factor Surveillance Survey (BRFSS) found poorer health among bisexual respondents compared with gay, lesbian, and heterosexual respondents, as well as higher rates of mental health issues and smoking.⁴ There are few providers well versed in the unique health-care needs of transgender patients, creating a barrier to access of quality care. For example, most transgender women have a prostate and may be candidates for prostate screening if they are high risk (African American, family history of prostate cancer, etc.). Digital prostate exams should be performed with transgender women “as per natal males.” Transgender men, even those who have had breast reduction surgery, have residual breast tissue that warrants screening for breast cancer with mammography, and many transgender men have a cervix and should be screened for cervical cancer. These screenings should be done with sensitivity to the emotional discomfort they may evoke in transgender patients.⁵

Why the EHR?

In Healthy People 2020, the nation’s roadmap for improving health over the next decade, the U.S. government committed for the first time to eliminate LGBT health disparities.⁶ Health-care providers should “appropriately inquire about and be...supportive of a patient’s sexual orientation to enhance the patient-provider interaction and regular use of care.” We could take a major step toward reducing these disparities if providers both understood and discussed issues of SOGI with their patients and addressed health conditions disproportionately affecting LGBT people. When we think now of how much progress we have made with smoking cessation and the importance of simply inquiring into use of tobacco with patients, primary care providers should consider what it means to an LGBT patient to be greeted by silence on the part of their health providers, both with respect to important aspects of their identity, as well as risks they might avoid and health screenings they might receive if counseled appropriately.

The Importance of Gathering Race and Ethnicity Data

A great deal has been learned about health disparities by collecting information on race and ethnicity in hospital information systems. Mandated in Massachusetts hospitals,⁷ such data gathering has allowed organizations to identify disparities in health care that might be caused by systematic or structural discrimination, or correlate with poverty, and allow corrective action to be put in place. We know that simple reminders applied to specific populations once they are identified—such as text messages encouraging patients to come in for a cervical cancer screening/Pap test—can make a critical difference in the quality of care provided.⁸ Meaningful use guidelines for implementation of the EHR already include requirements for data collection about race and ethnicity.

The Health Research and Education Trust Disparities Toolkit, “a toolkit for collecting race, ethnicity, and primary language information from patients,” states that “Disparities in health care can be addressed through a quality of care framework if data on race, ethnicity, and primary language are available” (emphasis added).⁹ A report by Physicians for Human Rights on racial and ethnic disparities in medical care notes

the broad range of uses of race and ethnicity data in improving quality of care and access to care:

[D]ata on race and ethnicity may be used for a variety of possible purposes beyond the detection of disparities in the quality of clinical care, such as who is accessing health services, the health status of different populations, utilization rates of services to which racial and ethnic groups do have access, the effectiveness of public health interventions among different racial and ethnic groups, and of course racial and ethnic disparities in diagnosis and treatment.¹⁰

The Joint Commission’s 2010 report, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*, also 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.^{11(p11)}

All of these purposes for which race/ethnicity data can be used also apply to data on SOGI. We know that lesbians are less likely to be insured than heterosexual women² and are less likely to use preventive health services, such as mammograms.¹² Gathering data on SOGI in clinical settings and in EHRs helps us better understand LGBT health, including disparities in insurance coverage, access to care, diagnosis, and treatment. These data, coupled with race/ethnicity data, would also allow us to better understand racial disparities within LGBT health.

Asking about and gathering information on SOGI is crucial if individual providers are to provide affirmative and inclusive health care to LGBT people. Knowledge of a patient’s SOGI can be essential to understanding a patient’s history and clinical care needs. These data allow providers to compare care outcomes for LGBT patients with those of heterosexual patients and nontransgender, or cisgender, patients. They also allow providers to ensure that the care they are providing matches the standard of care for LGBT patients. As EHR data are shared through state Health Information Exchanges, these data will become a tool for health services researchers to better understand care utilization for LGBT populations.

Inclusion of SOGI in Meaningful Use Guidelines

The 2011 IOM’s report on LGBT health recommends the collection of SOGI data in EHRs as part of the meaningful use objectives for the Office of the National Coordinator for Health Information Technology (ONCHIT). The report recommends that questions be standardized to allow for the comparison and pooling of data to analyze the unique needs of LGBT people.¹³ Healthy People 2020 also calls for gathering sexual orientation data by clinicians.⁶ Gathering LGBT data in clinical settings is consistent with efforts of the U.S. Department of Health and Human Services to gather health data on LGBT populations as authorized under Section 4302 of the Affordable Care Act (ACA).¹⁴ The Joint Commission’s 2010

report, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*, also encourages the collection of patient data on SOGI.^{11(p37)}

Getting this information from an EHR may make it easier for clinicians. An important caveat is that, especially among adolescents and younger patients, it is common to change sexual identity and behavior, as well as gender identity. Some patients “come out” as gay or transgender later in life. There is no question that talking with patients about intimate issues can be difficult. An earlier IOM report stated, “ironically it may be more difficult to talk about sex than engage in it.”¹⁵ Often the best way to start a session with a patient in for a routine visit without an acute compelling concern is with a very open-ended initial question like “tell me about yourself,” with the hope that, without additional prompting, patients will include information about sexual orientation or gender identity and how it might vary from their birth gender.¹⁶ Even if you have to be more directive with subsequent questions like the commonly recommended sequence—are you sexually active, and do you have sex with men, women, or both?—entering that information into the patient’s record would be done only with the patient’s consent and ideally in a standard format. Often it is included in nonstandardized ways which precludes correlation with preventive procedures, medical or behavioral symptoms, or illnesses. Gathering the information in an EHR would both facilitate the process of gathering information and enable research to evaluate disparities. Furthermore, once SOGI data are entered into EHR as demographic data, providers do not have to address these issues each time a patient comes in to be seen.

A provider’s knowledge of a patient’s SOGI is essential to providing appropriate prevention screening and care.¹⁷ Patients who disclose their sexual orientation identity to health care providers may feel safer discussing their health and risk behaviors as well.¹⁸ A sample of New York City men who have sex with men (MSM) from the 2004–2005 National HIV Behavioral Surveillance system found that 61% had not disclosed their same-sex orientation or behavior to their medical providers. White MSM and native born MSM were more likely to have disclosed than Black, Latino, Asian, and immigrant MSM. Disclosure of same-sex behavior correlated with having tested for HIV, an example of how discussing sexual orientation can lead to addressing health concerns that disproportionately affect gay and bisexual men.¹⁹

The Challenges

In 2012, the Center for Medicare and Medicaid Services (CMS) and the ONCHIT considered including SOGI data collection in the Stage 2 meaningful use guidelines for EHR and requested public comment on this issue.* ONCHIT is an agency within the U.S. Department of Human Services that

is tasked with developing “a nationwide health information technology infrastructure that allows for the electronic use and exchange of information.”²⁰ The Health Information Technology Policy Committee makes recommendations to ONCHIT “on a policy framework for the development and adoption of a nationwide health information infrastructure, including standards for the exchange of patient medical information. The American Recovery and Reinvestment Act of 2009 provides that the Health IT Policy Committee shall at least make recommendations on the areas in which standards, implementation specifications, and certifications criteria are needed in eight specific areas.”²¹

While many leading health care and LGBT groups commented in support of collecting SOGI data in EHR,²² some opposed the collection of such data, arguing that collecting of data on SOGI by administrative staff could be considered offensive.²³ Commenters questioned the clinical significance of collecting and recording SOGI data in the demographic section of EHR, saying it would provide no additional clinical benefit. They also portrayed data collection and reporting as a burden. In deciding not to include SOGI questions in the Stage 2 meaningful use guidelines, CMS stated:

Considering the lack of consensus for the definition of the concept of gender identity and/or sexual orientation as well as for a standard measure of the concept and where it would be most appropriate to store the data within the EHR, we will await further development of a consensus for the goal and standard of measurement for gender identity and/or sexual orientation...[M]any commenters raised concerns as to whether such data collection is necessary for all EPs [Eligible Providers], eligible hospital[s], and [rural Critical Access Hospitals] regardless of specialty.²⁴

As a result, the gathering of SOGI data was not included in the core demographic section of EHR in Stage 2 meaningful use guidelines, which will be implemented in 2014.^{24,†} There is still the possibility of inclusion of SOGI questions in Stage 3 guidelines, which ONCHIT is considering in 2013. The Health Information Technology Policy Committee is reviewing recommendations for Stage 3 guidelines, and will make a recommendation to ONCHIT in fall 2013. ONCHIT and CMS will then publish draft and final regulations.[‡] These guidelines would be implemented in 2016 and beyond.

While some of the concerns expressed by commenters to CMS during Stage 2 are valid, we believe that they are not insurmountable obstacles, but rather important issues to keep in mind when implementing SOGI data collection. Clinical staff and providers can be trained in how to ask these questions in sensitive and culturally appropriate ways to guarantee privacy and confidentiality and to explain to patients that these data, like race/ethnicity and other demographic data,

*Meaningful use is a set of standards created by the CMS that providers must meet in order to receive EHR incentive payments from CMS. The goal of meaningful use guidelines is to promote the transition to EHR to improve health care in the United States. Stage 1 guidelines were rolled out in 2011 and 2012 and focused on data capture and sharing. Stage 2 guidelines focused on advanced clinical processes and will be implemented in 2014. Stage 3 guidelines, currently under development and to be implemented in 2016, focus on improved health outcomes and improving population health.

†ONCHIT decided not to require a functionality to collect data in EHR as part of meaningful use because CMS had decided not to require SOGI data collection in its Stage 2 meaningful use guidelines. It is up to CMS to require SOGI data collection. ONCHIT can require SOGI functionality in an EHR—the ability to input and track SOGI data—but not the SOGI data collection itself. Only CMS can do that.

‡CMS could say, again, that it will not require SOGI data collection in the Stage 3 guidelines. ONCHIT could still require EHRs to be able to track SOGI data in order to be certified for meaningful use.

allow health-care professionals to better understand and address health disparities. Such training should take place in the context of cultural competency training on LGBT health issues more broadly. The National LGBT Health Education Center offers such trainings to health clinics, hospitals, and providers across the United States.²⁵

As for the lack of a standard of measurement of SOGI, researchers have in fact developed measures of SOGI. At the Fenway Institute in Boston, researchers have evaluated the best way to ask about sexual orientation on its patient registration form at Fenway Health, the federally-qualified health center of which it is part. Based on this evaluation, the following question has been added:

Do you think of yourself as:

- Lesbian, gay, or homosexual
- Straight or heterosexual
- Bisexual
- Something else
- Don't know²⁶

It is important that clinical staff and providers understand what these terms mean so that they can explain them to patients who don't understand the questions or who wonder why these questions are being asked. In addition, clarifying language defining these terms can be added. Training, in which staff are allowed to ask questions and express and work through any discomfort or lack of understanding they have, is essential to achieve this. Staff buy-in is essential to effective data collection. The Center of Excellence for Transgender Health at the University of California San Francisco has developed the following questions to measure gender identity. Here is a slightly amended version of their questions:

What is your current gender identity?

- Male
- Female
- Transgender Man/Transman
- Transgender Woman/Transwoman
- Genderqueer
- Additional Category _____
- Decline to State

What sex were you assigned at birth?

- Male
- Female
- Decline to State²⁷

The Fenway Institute has also tested a gender identity question. Results have not yet been published, but two things seem clear from our experience asking these questions of patients at Fenway Health. First, despite initial concerns about collecting what many feel is intimate information, in our experience patients seem as willing to provide SOGI information as financial information. Second, allowing an option for entering information into an open field increases participation, even though it may not be as easily used for research purposes.

Finally, all information is voluntarily provided. Providers and clinical staff should stress that answering SOGI questions, like answering other questions, is voluntary. They should also stress that providing this information would be helpful to their provider in addressing their health care needs, even if individuals do not want it recorded in their paper or EHR.

While these measurements developed in community-based research centers do not yet constitute a standard, ONCHIT and the Department of Health and Human Services should lead an effort to quickly develop one. As Elina Alterman, Health IT Policy and Outreach Coordinator at the National Partnership for Women and Families, wrote recently on the Health Information Technology blog: "Some say the standards for SO/GI data don't exist. But it doesn't mean they can't. We've standardized data on quick timelines before, and the rampant health disparities experienced by LGBT individuals make a compelling case for speeding up the work already underway."²⁸

We acknowledge that there is no consensus among experts on what questions to ask or how to ask about SOGI. What we do know, however, is that there is a need to collect this information and a potential benefit to collecting it. Questions need to be tested and evaluated for their effectiveness in all populations—heterosexual, rural, Southern, etc. At several leading health-care systems across the United States—including the Mayo Clinic, UC Davis Medical Center, Kaiser Permanente, and the Beth Israel Hospital system in New York City—researchers are evaluating how to ask these questions in settings where there is less knowledge and sensitivity to LGBT health concerns. While some variation in vocabulary is inevitable, especially with identity labels, a balance must be struck with efforts to gather data that can be useful, pooled, and compared to understand trends in population health.

Ideally, patients would be asked about their sexual 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, culture, sex, or sexual orientation can be given, such as sickle cell anemia, Tay Sachs's disease, or cervical cancer.

Community-based groups and public health departments should educate LGBT patients about why it's a good thing to discuss one's sexual orientation or gender identity with a provider, and how such data will assist efforts to improve quality care and reduce disparities. Some LGBT groups encouraged cohabiting same-sex couples to self-identify on the U.S. Census in 2000. While many were concerned with giving such information to a government that had passed several antigay laws and policies, advocates argued that the benefits of being "out" outweighed the risks and stressed the confidentiality protections in place. As a result, four times as many same-sex couples self-identified in 2000 as in 1990, the first time same-sex couples could self-identify. Same-sex couples were found to live in more than 99% of U.S. counties.²⁹ This was helpful in quantifying the demographic impact of pro- and anti-gay family recognition policies, which proliferated in the mid-2000s.³⁰

Inevitably, some LGBT people will refuse to disclose their SOGI in clinical settings. This is also certainly the case with population-level surveys that ask these questions, such as the Massachusetts BRFSS. Some same-sex cohabiting couples don't disclose their relationship status to the U.S. Census. While the data gathered by BRFSS and the Census are

inevitably incomplete, they are still enormously helpful data sets that help us better understand LGBT health and demography. Providers should make sure that patients understand that they can refuse to disclose the information requested, even as they explain how a provider's knowledge of a patient's SOGI can improve quality of care. Some patients will request that their SOGI not be entered into their medical record, and providers should respect these requests.

A first challenge of entering information into an EHR will be defining a vocabulary that works for most; achieving this for all may not be realistic. Gay men are men attracted to other men; lesbians are women attracted to other women. Individuals attracted to both men and women are bisexual. Half a dozen national and state surveys that measure sexual identity indicate that there are as many self-identified bisexuals as gay men and lesbians, and that women are more likely than men to self-identify as bisexual.³¹ Technically men and women attracted to the same sex are homosexuals. However, many prefer other labels. Same-sex behavior does not always match an individual's sexual identity. For example, 9.4% of men in a 2006 New York City study identified themselves as "straight" and yet reported same-sex activity within the past year.³² Attraction, behavior, and identity are three aspects of sexual orientation that do not always correspond. We believe that questions about behavior (with whom you have sex), identity (if you identify as gay/lesbian, bisexual, or heterosexual), and attraction (to whom you are attracted) are important to ask in clinical settings. The relative importance of these three aspects of sexual orientation varies depending on context. For example, in the case of sexually transmitted infections, sexual behavior is usually paramount. Transgender people have gender identities, expressions, or behaviors not traditionally associated with their birth sex. Many transgender people identify as heterosexual, and some don't identify as transgender but simply as male or female. Both gender identity and sexual orientation can change over the life course.

Concerns About Confidentiality and Discrimination

LGBT patients may be hesitant to disclose information about their sexual orientation or gender identity due to fears about confidentiality and privacy.³³ Such concerns are exacerbated by both the increasing computerization of health records as well as some highly publicized breaches in confidentiality. 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 EHRs and national and state health information exchanges could dramatically improve health care, increase providers' ability to determine the most effective treatments, and advance health science.³⁴

Concerns about confidentiality are not without justification, given recent data breaches.³⁵ However, with the development of proper standards for encoding medical information, along with best practices for how to manage a computer infrastructure by institutions like the National Institutes for Standards and Technology, these threats are manageable.³⁶ Sections 1411(g), 1411(c) (2), and 1414(a) (1) of the 2010 Patient Protection and ACA provide privacy and security protections for information used by affordable insurance exchanges.³⁷ A 2012 HHS regulation finalized in January, 2013 mandates "appro-

prate security and privacy protections" for any "personally identifiable information," including sensitive health information that is collected and used in the provision of health care.³⁸

Another concern that some LGBT advocates have raised is whether self-disclosure may open LGBT patients up to discrimination by providers and clinical staff in states without nondiscrimination laws. Discrimination by providers violates the Hippocratic oath, but we know from surveys of both patients and providers that prejudicial treatment occurs and anti-LGBT attitudes are widespread.^{39,40} Discriminatory or insensitive treatment by clinical staff may also occur. As of early 2013, 21 states and the District of Columbia outlawed discrimination on the basis of sexual orientation, as did hundreds of municipalities. Sixteen of these states also outlaw discrimination on the basis of gender identity.⁴¹ More than half the U.S. population lives in a state or municipality with a sexual orientation nondiscrimination law, and more than a third lives in a state or municipality with a transgender nondiscrimination law. While most of these laws cover public accommodations, including health-care access, not all do. For example, New York City's gender identity nondiscrimination law protects against discrimination in access to health care and homeless shelters. Massachusetts' gender identity nondiscrimination law does not. In much of the country it is still legal to deny a person a job, promotion, housing, or access to a public accommodation, such as a health-care facility, due to real or perceived SOGI. The Joint Commission's 2010 requirement that hospitals adopt an SOGI nondiscrimination policy is an important step toward reducing anti-LGBT discrimination in healthcare.^{11(p61)} This will have to be accompanied by processes to adjudicate patient concerns.

The ACA and regulations adopted as part of its implementation include some new protections for LGBT people in health care. ACA Section 1557 prohibits discrimination on the basis of existing civil rights law by any entity taking money from the U.S. government. This would include any hospital receiving Medicaid or Medicare funding, for example. Section 1557 explicitly refers to Title IX of the Education Amendments of 1972. Title IX, often used to protect girls and women from sex discrimination in school sports, has been interpreted by the courts and the U.S. Department of Health and Human Services to also cover gender identity and, therefore, transgender people.⁴² A 2012 federal regulation outlaws SOGI discrimination by insurers whose products are offered on state health insurance marketplaces. This protects against insurance discrimination but not against discrimination in health care. Most Americans—about 55%—have insurance that is large group coverage offered by their employer. This insurance is regulated by the Employee Retirement Income Security Act, which does not prohibit SOGI discrimination. However, many of these employers do prohibit such discrimination.⁸ A federal regulation published in late 2012 calls for nondiscrimination on the basis of SOGI by qualified health plans traded on state affordable insurance exchanges.⁴³

Beyond banning discrimination, clinicians need to be trained in issues regarding the care of LGBT people and the unique disparities affecting these populations. This will enhance their ability to use the information they get electronically. While data may be pooled to better understand disparities at the

⁸Conversation with Kellan Baker, Center for American Progress, March 8, 2013.

population level, the information also provides clinicians the opportunity to use it when dealing with patients. Unfortunately, the health of LGBT Americans has been a topic that has been neglected in medical education, a fact that was recently confirmed by a study of medical school curricula published in *The Journal of the American Medical Association*, which showed that significant numbers of academic medical centers have no teaching on LGBT issues, particularly in the clinical years.⁴⁴ Perhaps related to gaps in their education, many health-care providers are uncomfortable providing care to LGBT people. Although anti-gay attitudes among providers appear to have declined significantly over the past two decades, a 2007 study found that 18% of doctors in California are “sometimes” or “often” uncomfortable caring for gay patients.⁴⁰ If clinicians are to make a difference, in addition to more data on the needs of LGBT patients, they will need to overcome their prejudices as well as obtain a greater understanding of disparities faced by LGBT patients and receive more education about how to help them reduce risk, display resilience in the face of ongoing discrimination and social marginalization, and live healthier lives. Provider training in LGBT health is essential.

The Way Forward

In summary, striking LGBT health disparities exist and overlap with racial and other disparities. LGBT people experience a shortage of primary medical care and mental health providers culturally competent to serve them. Given the outward invisibility of LGBT people and their history of invisibility in the health-care system, it is critical for clinicians to address and screen for health conditions disproportionately affecting LGBT people and have frank discussions with patients about sexual identity and behavior and gender identity. However, most clinicians don’t ask questions about these topics; many are uncomfortable discussing sex with patients. Gathering data on sexual and gender identity in EHR will improve our understanding of LGBT disparities and help improve clinicians’ conversations with patients about LGBT issues. Improved patient–provider communication about LGBT issues could be an important step toward reducing health disparities affecting this population.

As many speakers at the October 2012 IOM workshop on LGBT data collection in EHR systems noted, health professionals and administrative staff need training in LGBT cultural competence to appropriately gather this information from patients. Such training should occur in a broader context of training health professionals and administrative staff in fully incorporating the requirements of meaningful use into their daily work. Beginning the process of gathering these data as part of the implementation of meaningful use guidelines is crucial to the ability of researchers and clinicians to learn more about LGBT health needs and inform training in the future. It is important to study the most effective ways to gather SOGI information in order to optimize the data collection using ways that are most acceptable to consumers.

As this article went to press in spring 2013, ONCHIT was considering whether to include SOGI questions in the core demographic section of meaningful use guidelines. At a February 6, 2013, meeting of the Health Information Technology Policy Committee, an ONCHIT staff person noted that there was “overwhelming support” in public comment submitted for re-

quiring that providers gather SOGI data. The Fenway Institute, the Center for American Progress, the American Psychological Association, and 142 other community-based organizations submitted a community public comment to ONCHIT calling for the inclusion of SOGI in meaningful use guidelines.⁴⁵ Most of these groups were LGBT and HIV/AIDS groups. The Health Information Technology Policy Committee will make a recommendation to ONCHIT in the fall. Many health-care organizations are already moving forward with efforts to gather such data in EHR, including the Mayo Clinic in Minnesota, the University of California at Davis, Kaiser Permanente, and Beth Israel Hospital in New York City.

Primary care providers are key to better understanding, reducing and, one day, eliminating health disparities affecting LGBT patients. Structural factors exacerbating LGBT health disparities include nondisclosure of sexual and gender identity to health-care providers and a lack of providers trained to address the specific health-care needs of LGBT people.¹⁹ A provider’s knowledge of a patient’s SOGI is essential to providing appropriate prevention screening and care. Health disparities are driven in part by poor quality of care and barriers to access. Providers’ lack of training in LGBT health and widespread inability to provide culturally competent care are important factors in poor quality of care for LGBT patients. Barriers to access include lower rates of insurance coverage for LGBT people and lower rates of access to preventive care for lesbians and transgender people.^{12,46} A California study found partnered gay men were only 42% as likely as married heterosexual men to get employer-sponsored dependent coverage; partnered lesbians were only 28% as likely as married heterosexual women to have partner or spousal insurance.⁴⁷ The expansion of health coverage under the ACA is especially important for LGBT people given the repeal of public sector domestic partner health coverage for thousands of same-sex partners through anti-gay ballot measures, private insurer discrimination against LGBT people, and the high rate of HIV among gay men (a pre-existing condition that has precluded many from getting health insurance; such denial will no longer be legal starting in 2014). The importance of assessing SOGI in clinical settings should be understood in this broader context.

The advances we have seen in LGBT health policy and HIV policy under the Obama–Biden Administration have been unprecedented. However, if our government doesn’t include SOGI data collection in meaningful use guidelines, we will miss a golden opportunity to systematically gather essential data on LGBT health. It will also be very difficult to make progress toward the Healthy People 2020 goal of eliminating LGBT health disparities. While assessing and tracking SOGI in EHR is a complicated undertaking, we should not let the perfect be the enemy of the good. The benefits to patient care, medical knowledge, science, and public health that would accrue from SOGI data collection in EHR are significant.

Author Disclosure Statement

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