Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary

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Joe Alper, Monica N. Feit, and Jon Q. Sanders, Rapporteurs; Board on the Health of Select Populations; Institute of Medicine

Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records

Workshop Summary

Joe Alper, Monica N. Feit, and Jon Q. Sanders, *Rapporteurs*

Board on the Health of Select Populations

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

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Willing is not enough; we must do."
—Goethe

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PLANNING COMMITTEE ON COLLECTING SEXUAL ORIENTATION AND GENDER IDENTITY DATA IN ELECTRONIC HEALTH RECORDS[1]

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[1] Institute of Medicine planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published workshop summary rests with the workshop rapporteurs and the institution.

Reviewers

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

Leslie Calman, Mautner Project: The National Lesbian Health Organization
Kevin Johnson, Vanderbilt University Medical Center
Susan Queen, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services
David Vawdrey, Columbia University

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Hugh Tilson,** University of North Carolina at Chapel Hill. Appointed by the Institute of Medicine, he was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteurs and the institution.

Acknowledgments

Many individuals were responsible for organizing the workshop and producing this summary. The planning committee would like to thank Institute of Medicine staff members Monica Feit, Jon Sanders, Andrea Cohen, Rick Erdtmann, Hannan Braun, and Colin Fink. Joe Alper, the lead rapporteur, deserves special acknowledgment for writing the first draft of this summary. We also thank the speakers and participants of the workshop who lent their insights to the topic and contributed to the discussions throughout the day. Finally, we thank the sponsors of the workshop: The California Endowment, the California HealthCare Foundation, based in Oakland, California, and the National Institutes of Health. The workshop would not have been possible without their generous support.

Contents

APPENDIXES

Acronyms

AHA	American Hospital Association
AHRQ	Agency for Healthcare Research and Quality
CDC	Centers for Disease Control and Prevention
CHIS	California Health Information Survey
CMS	Centers for Medicare & Medicaid Services
EHR	electronic health record
FTM	female to male transgender
GI	gender identity
HEI	Healthcare Equality Index
HHS	Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HIT	Health Information Technology
HITECH	Health Information Technology for Economic and Clinical Health
HIV	human immunodeficiency virus
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine

LGBT	lesbian, gay, bisexual, and transgender
MTF	male to female transgender
NCHS	National Center for Health Statistics
NHANES	National Health and Nutrition Examination Survey
NHIS	National Health Information Survey
NSFG	National Survey of Family Growth
OIPDA	Office of Information Products and Data Analysis
ONC	Office of the National Coordinator for Health Information Technology
SAMHSA	Substance Abuse and Mental Health Services Administration
SO	sexual orientation

1

Introduction and Overview[1]

In 2011, the Institute of Medicine (IOM) released the report *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, the first comprehensive compilation of what is known about the health of each of these groups at different stages of life. This report also outlined an agenda for the research and data collection necessary to form a fuller understanding of this subject.

One of the recommendations in this report was that, provided that privacy concerns could be adequately addressed, information on patients' sexual orientation and gender identity[2] should be collected in electronic health records, just as information on race and ethnicity is routinely collected. Such data are essential because demographics provide the foundation for understanding any population's status and needs. This recommendation recognized that the possible discomfort on the part of health care workers asking questions about sexual orientation and gender identity, a lack of knowledge by providers about how to elicit this

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[1] The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the Institute of Medicine, and they should not be construed as reflecting any group consensus.

[2] In the 2011 Institute of Medicine report, sexual orientation was "conceptualized in terms of sexual attraction, behavior, identity, or some combination of these dimensions" (p. 12). Gender identity was defined using the Bockting (1999) definition as "one's basic sense of being a man, woman, or other gender (such as transgender)" (IOM, 2011, p. 318).

BOX 1-1
Statement of Task

An ad hoc committee will plan and conduct a public workshop on collecting sexual orientation and gender identity data in electronic health records. The workshop will feature invited presentations and facilitated discussions about current practices around sexual orientation and gender identity data collection, the challenges in collecting these data, and ways in which these challenges can be overcome.

Areas of focus for the workshop will include the clinical rationale behind collecting these data, standardized questions that can be used to collect these data, mechanisms for supporting providers and patients in the collection of these data, technical specifications involved in creating standards for sexual orientation and gender identity data collection and exchange, and policy considerations related to the Health Information Technology (HIT) Meaningful Use process being overseen by the Department of Health and Human Services (HHS).

The committee will develop the workshop agenda, select invited speakers and discussants, and moderate the discussions. Invited participants will include lesbian, gay, bisexual, and transgender (LGBT) health care consumer advocates, providers with experience working with LGBT populations, HIT vendors and other HIT specialists, health care administrators, and policy makers. A workshop summary will be prepared by a designated rapporteur in accordance with National Research Council policies and procedures.

information, and some hesitancy on the part of patients to disclose this information may be barriers to the collection of meaningful data on sexual orientation and gender identity.

As the next step in exploring this recommendation, an ad hoc committee was assembled to plan and conduct a public workshop on collecting sexual orientation and gender identity data in electronic health records (see Box 1-1). The workshop, held on October 12, 2012, featured invited presentations and facilitated discussions about current practices around sexual orientation and gender identity data collection, the challenges in collecting these data, and ways in which these challenges can be overcome.

ABOUT THIS SUMMARY

This document was prepared by rapporteurs Joe Alper, Monica N. Feit, and Jon Q. Sanders for the Board on the Health of Select Populations of the Institute of Medicine (IOM) as a factual summary of what occurred at the workshop Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records. The workshop speakers and presentation topics were selected to cover a range of important issues in data collection on sexual orientation and gender identity for inclusion in an electronic health record. However, it was impossible to include all potential topics during the course of a 1-day workshop, and speakers could not exhaustively cover all relevant findings and issues for each topic in their presentations. Consequently, some relevant topics could not be included in the workshop and, by extension, are not included in this workshop summary. In accordance with the policies of the IOM, the summary does not attempt to establish any conclusions or recommendations about needs and future directions, focusing instead on issues identified by the speakers and workshop participants.

Whenever possible, ideas presented at the workshop are attributed to the individual who expressed them. Any opinions, conclusions, or recommendations discussed in this workshop summary are solely those of the individual participants and should not be construed as reflecting consensus or endorsement by the workshop, the Board on the Health of Select Populations, the Institute of Medicine, or the National Academies. The workshop agenda is in Appendix A, a list of registered participants is in Appendix B, and biographical sketches of the workshop speakers are in Appendix C.

The 19 presentations at the workshop are divided into 5 chapters following this introductory chapter. (For clarity, the presentations have been somewhat reorganized from the agenda.) Chapter 2 discusses the clinical reasons to collect data on sexual orientation and gender identity, both from a population perspective and as it applies to an individual's health care. This chapter also presents some compelling personal stories illustrating the barriers and discrimination that lesbian, gay, bisexual, and transgender (LGBT) people experience in the health care system. Chapter 3 examines the role that the federal government is playing in developing methods for collecting sexual orientation and gender identity data in electronic health records and ensuring that these methods protect patient privacy and confidentiality. Chapter 4 describes the experiences of several health care systems in developing and implementing questions on sexual orientation and gender identity and incorporating the data in electronic health records. Chapter 5 examines the issues involved in developing standardized questions for collecting data on sexual orientation and gender identity and provides examples of questions that have been field-tested and deployed in actual clinical settings. Chapter 6 provides comments from participants and the workshop organizing committee chair's final observations on themes that arose during the workshop.

2

Clinical Rationale for Collecting Sexual Orientation and Gender Identity Data[1]

Key Points Raised by the Speaker

- Health disparities among LGBT people are rooted in bias, stigma, discrimination, and social determinants of health, not genetics or other molecular issues.
- Discrimination against and substandard care for LGBT people is prevalent.
- Information about sexual orientation and gender identity is critical to addressing issues of access to care and quality of care.
- Education of clinicians, health system staff, and patients is essential to improve the collection of information on sexual orientation and gender identity.

Harvey Makadon began his talk by recognizing the Surgeon General's report *Healthy People 2020*, which, for the first time, acknowledged that health disparities exist in LGBT populations. Health disparities among LGBT people are rooted in bias, stigma, discrimination, and social determinants of health, not genetics or other molecular issues, or even sexual orientation and gender identity, said Makadon. Therefore, he said, systems changes and educational changes can make a significant difference

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[1] This section is based on the presentations of Harvey Makadon, Clinical Professor of Medicine at the Harvard Medical School and Director of the National LGBT Health Education Center at The Fenway Institute; and Beverly Tillery, Director and Community Educator, Lambda Legal.

in the ability of the health care profession to provide quality, accessible care for LGBT people. "That is an important theme that we need to keep in mind," said Makadon.

At one time, hospitals were taking the lead in eliminating health care disparities among minority populations, but that role is now being shared more equally by community health centers and a variety of enabling organizations. Nonetheless, hospitals continue to be a key leader in this area, and the American Hospital Association (AHA) has issued the Health Research and Education Trust Disparities Toolkit for collecting race, ethnicity, and primary language information from patients. In issuing this toolkit, the AHA noted that disparities in health care can be addressed through a quality-of-care framework if data on race, ethnicity, and primary language are available. A 2003 report from Physicians for Human Rights, *The Right to Equal Treatment*, reiterated this message when it stated that data collection is not only central to quality assurance but also to help ensure nondiscrimination in access to care.

Makadon said that by the same token, health disparities that affect LGBT people will only be addressed if the health system collects data on sexual orientation and gender identity. The IOM, in its report *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, noted the direct benefit of collecting data on sexual orientation and gender identity for individual patients. Only by asking patients about their LGBT status and collecting data on the LGBT population will it be possible to end LGBT invisibility in health care. As Makadon put it, "I would say that unless we can do something about collecting data on LGBT people, we can't assure anyone that LGBT people are receiving quality care." He then asked the workshop audience to think about the following questions:

- Has a clinician ever asked about your sexual history, including behavior, health, and satisfaction?
- Has a clinician ever asked you about your sexual orientation?
- Has a clinician ever asked you about your gender identity?

Based on his experience, Makadon estimated that 10 to 20 percent of people would answer yes to the first question, but that close to zero would answer yes for the second and third questions. Given that there are medical issues related to sexual orientation and gender identity, it seems that it would be difficult to provide good medical care for LGBT people without that information, and it is equally challenging to assess the quality of care being provided to the LGBT population. He also remarked that the invisibility of the LGBT population results from a combination of patient reluctance to divulge information on sexual orientation or gender identity and physician discomfort or ignorance about the importance of this information.

In terms of sexual orientation, Makadon continued, it is not simply a matter of identifying someone as gay, lesbian, bisexual, or heterosexual. Rather, he said, the real question is about how people see themselves, how they actually behave, and what their desires are. Some people, for example, are attracted to others of the same sex but have never acted on that desire, yet they want to talk to their physicians about those thoughts. "Unless you can get that information and engage people in conversation, you are not going to help somebody who is thinking about whether or not they may be gay or lesbian or bisexual, but hasn't acted on it because they don't feel comfortable with it. So we have to be thinking about how we get at this information," Makadon explained.

To back up this assertion, he cited a 2006 study from the New York Department of Mental Health that found 9.4 percent of men who identified as heterosexual had had sex with a man in the previous year. These men were more likely to belong to minority racial and ethnic groups, be of lower socioeconomic status, be foreign-born, and not use a condom. In another study, between 77 and 91 percent of lesbians reported that they had at least one prior sexual experience with men, and 8 percent reported having sex with a man in the prior year. He added that while these examples might seem obvious to those attending the workshop, they are not obvious to most nurses or doctors because they do not learn about this kind of discordance between sexual identity and sexual behavior in medical school. Yet, for clinicians, it can be helpful to understand the different dimensions and manifestations of sexual orientation in order to build a better therapeutic relationship with their patients.

ACCESS TO CARE

According to the aforementioned IOM study, lesbians and bisexual women may use preventive health services less frequently than heterosexual women. From his experience as a clinician, Makadon said that he expects that reduced access to care applies to gay men and transgender people as well. What this reduced access to care translates into, he said, is that LGBT people do not receive the right preventive health screening that they need, and the only way to remedy that situation is to identify these populations.

As an illustration of the importance of identifying LGBT people, Makadon cited 2009 data from the Centers for Disease Control and Prevention (CDC) that showed that 61 percent of new cases of HIV infection were among men who have sex with men. This number, which has been climbing annually since 2006, came as a surprise given that the number of HIV cases overall remained constant, and it likely reflects the fact that prevention efforts are not reaching men who have sex with men but do not identify as gay when asked on a survey. This is particularly true among black men between the ages of 13 and 29 who have sex with men, a population in which there has been an almost 50 percent increase in the incidence of HIV cases between 2006 and 2009.

These data highlight the fact that LGBT people are not one homogeneous group, but rather that they reflect the same cultural diversity seen throughout the general population. Understanding the cultural diversity among, in this case, men who have sex with men, is going to be key to developing ways to reach underserved populations, but that lesson applies to all LGBT people, said Makadon. That understanding cannot start without data about these underserved populations.

In terms of understanding the T in LGBT, the IOM report noted that there are significant health disparities that have been documented among transgender people. It is critical that clinicians have information on a patient's gender identity, gender expression, birth sex, medical history, and current anatomy. The only way to get this information is by educating both clinicians and the transgender community about the importance of discussing these issues to ensure access to high-quality care. The clinician, said Makadon, has to be the point person in gathering this information, but the field needs to figure out ways to help clinicians so that they do not spend all of their time just gathering data and not having time to talk to their patients.

THE IMPACT ON QUALITY OF CARE

To illustrate the importance of all clinicians, not just the primary care physician, having information about a patient's gender identity, Makadon discussed two case studies. The first case involved a 50-year-old woman who developed a high fever and chills after head and neck surgery. The infection source turned out to be the patient's prostate gland, which nobody knew she had because nobody had asked about her gender identity and she had not volunteered this information. She could have received much quicker treatment for her infection had her surgeon and the hospital staff known she was a transgender woman.

The second case involved a 55-year-old man who came to his physician with pain and on X-ray appeared to have metastases from an unknown primary cancer. Evaluation ultimately showed that he had developed cancer in his residual breast tissue that remained after having "top surgery" to remove his breasts. None of his physicians were aware that he was a transgender man, so he had not been advised to have routine breast screening even though his mother and sister had also had breast cancer.

Makadon then discussed some of the new opportunities that exist for gathering patient information on sexual orientation and gender identity that take advantage of patient portals that many health care systems have now installed (Figure 2-1). These portals are designed to enable patients to input information about themselves in the privacy of their homes, which could be particularly important for LGBT people. Another approach that some health care systems are testing is to use iPads handed out at the registration desk to enable patients' to enter data in private, rather than as verbal answers to what can be embarrassing or awkward questions. That information can then become part of the electronic record that all of an individual's clinicians would have access to without the need to question the patient.

In closing, Makadon said that there are a few issues that need to be considered in preparation for collecting LGBT data in clinical settings. Clinicians, he said, need to learn about LGBT health issues and the range of expression related to identity, behavior, and desire. Health care system staff members also need to understand these concepts given that patients often report that uncomfortable questions come up at the reception desk, not in the exam room. Patients, too, need to learn about why it is important to communicate this information and to feel comfortable that it will be used appropriately. Finally, collecting data on sexual orientation and gender identity is critical and has to be done sensitively, without assumptions, and for every patient along with all other demographic data. "Our task is to improve quality and access to care for all, including LGBT people, and that starts with more data collection," said Makadon.

SUPPORTING PATIENTS IN THE COLLECTION OF DATA

In 2009, Lambda Legal, together with more than 100 partner organizations, surveyed 4,916 people representing a diverse sampling of LGBT communities and people living with HIV, regardless of sexual orientation, gender identity, HIV status, race, ethnicity, age, and geography. The resulting report, *When Health Care Isn't Caring: Lambda Legal's Survey on Discrimination Against LGBT People and People Living with HIV*, was the first to document refusal of care and barriers to health care among LGBT and HIV communities on a national scale, said Beverly Tillery. She added that the findings were surprisingly high in terms of discrimination and substandard care. For example, 56 percent of lesbian, gay, or bisexual individuals and 70 percent of transgender people said that they had experienced discrimination or received substandard care. Nearly 8 percent of lesbian, gay, or bisexual people and almost 27 percent of transgender people reported being refused needed health care. More than 10 percent of lesbian, gay, or bisexual people and more than 15 percent of transgender

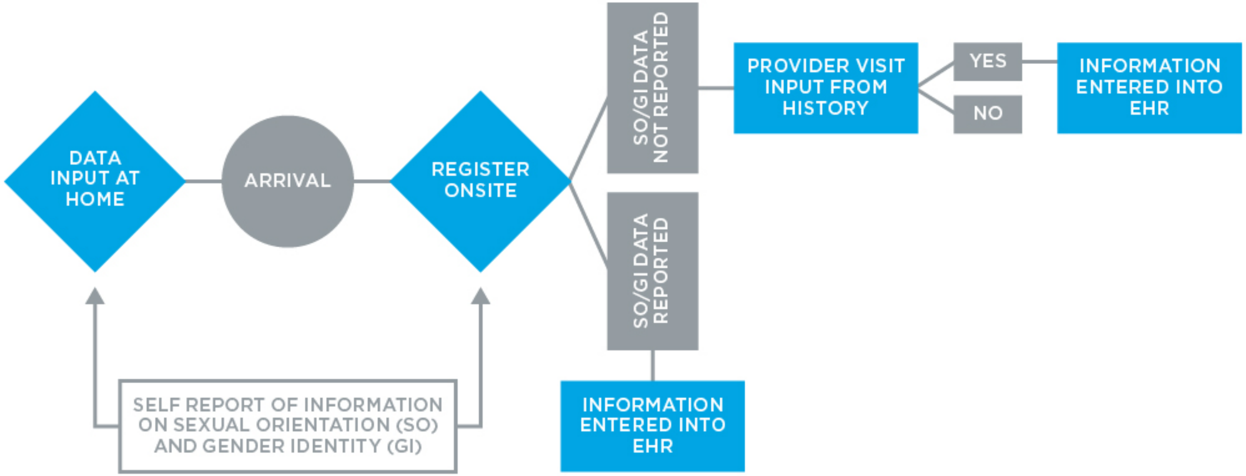

FIGURE 2-1 New opportunities for gathering LGBT data during the process of care.
NOTE: EHR = electronic health record.
SOURCE: Makadon presentation.

people reported having had the experience of a health care professional who refused to touch them or used excessive precautions before touching them. Almost 11 percent of lesbian, gay, or bisexual people and almost 21 percent of transgender people said that they had experienced a health care professional use harsh or abusive language with them and 4 percent of lesbian, gay, or bisexual people and almost 8 percent of transgender people described receiving physically rough or abusive treatment from a health care professional. In nearly every case, people of color and low-income people had higher rates of experiencing discrimination.

In terms of barriers to care, the survey found that significant percentages of LGBT individuals expressed concerns about accessing health care. Nine percent of lesbian, gay, or bisexual people and almost 52 percent of transgender people feared they would be refused medical service; more than 28 percent of lesbian, gay, or bisexual people and 73 percent of transgender people expressed concern that medical personnel would treat them differently than non-LGBT people; 49 percent of lesbian, gay, or bisexual people and almost 90 percent of transgender people said there were not enough health professionals who were adequately trained to care for them because of their sexual orientation or gender identity status; more than 24 percent lesbian, gay, or bisexual people and more than 50 percent of transgender people said there were not enough support groups; and almost 29 percent of lesbian, gay, or bisexual people and almost 59 percent of transgender people said there were not enough substance abuse programs for LGBT individuals. Again, the numbers were all higher in people of color.

As part of this project, Lambda Legal and its partners also collected 50 personal stories that provided real-life illustrations of the discrimination and substandard care LGBT people experience. Among the stories that Tillery recounted were

- **Jodi from Atlanta, who had to seek emergency room care.** "The nurse comes into the room to get my information. Among her list of questions was whether I was single or married. Well, I had a union that was not recognized in Georgia, but it would not have been accurate to answer either single or married. The nurse wanted an emergency contact and wanted to know if there was anyone with me, and if so, what was their relationship to me. I panicked for a minute.

  "I was scared to admit my life partner was in the waiting room. I was mortified to say I was single. My head was swimming trying to think of a lie about who my partner was. Should I be safe and say she was a friend? If so, she would be denied visitation if something went wrong. Should I lie and say she was my sister?

How humiliating. I was afraid that if I admitted to being gay with a partner that I might get sub-par care and even have my care and life sabotaged.

"After delaying, I felt I would take the risk and say that my relationship does not fit into one of the boxes on your form. When the nurse looked confused, I confessed that I was gay and that my life partner was in the waiting room. She looked confused again, and after a pause, said, 'Uh, oh, huh, never heard that before.' Luckily, that is the worst that happened, but no one should have to go through even that much."

- **Joe from Minneapolis.** "I was 36 years old at the time of this story and an out gay man. I was depressed over the breakup of an 8-year relationship. The doctor I went to see told me that it was not medicine I needed, but to leave my dirty lifestyle."
- **Emile in Boise.** "I'm a post-operative trans woman who began my gender transition in 2004. After talking about transitioning with my family M.D., she agreed to continue her medical relationship with me. Because she was not experienced with treating a trans person or prescribing hormone replacement therapy, she referred me to a local endocrinologist. When I called to set up an appointment, I was told by the secretary, we don't treat people like you. I called two other local endocrinologists and was told the exact same thing."
- **Tory from Portland.** "I went to visit my school's health clinic for an annual check-up. While I was filling out my health history information sheet, I was pleasantly surprised to find that the sheet indicated both male and female partners, the number of partners, and the type of birth control I used. I thought this was a great example of LGBT-friendly medical facilities. Unfortunately, when I was called into the exam room, the nurse didn't read the form and proceeded to ask me if I was sexually active and used condoms. "When I replied no and told the nurse that I was a lesbian, she was shocked. After that, the appointment was awkward, and I felt as though the nurse was not willing to touch me because I was a lesbian. The entire awkward conversation and exam could have been avoided if the nurse had only read the information sheet she was given. It just goes to show you that having an LGBT-friendly question form does not make a clinic LGBT-friendly."
- **Lee from Lock Haven, Pennsylvania.** "Fortunately, my primary care physician is awesome. She takes good care of me and has since I was 15 years old. I am able to completely be out and honest with her. Although we may not always agree on non-treatment-related topics, she is fair and non-judgmental. Unfortunately, I have been

> subjected to ignorance by specialists, female gynecological specialists, and one male plastic surgeon.
>
> "One simply refused to believe that I was not sexually active with men and refused to believe that I did have sex with women. Others struggle with my identity. I identify primarily as male, but I still have to cope with having a female body and keep it healthy. I'm blessed to be healthy these days. I have never been evasive about my person, and I have found that when I'm able to openly discuss my body and my life, I am able to make informed, rational, and essential decisions about my health."

In closing, Tillery emphasized the critical need to gather information in order to identify health care disparities in LGBT communities. It is clear from the data that Lambda Legal collected, she said, that LGBT people experience real discrimination and a significant level of it, which makes them cautious about getting the health care they need. It is also important, she added, to focus on confidentiality and privacy because privacy breaches can have repercussions that go far beyond health care. In many states, she reminded the audience, it is still legal to be fired for being LGBT. She recommended that data collection be optional with a sense of informed consent that involves educating patients about why these data are important, and how and when they will be used.

DISCUSSION

During the discussion session, Makadon was asked if the Centers for Medicare & Medicaid Services (CMS) or electronic health record system vendors were working on developing requirements and standards for the collection of this information. Robert Tagalicod, from CMS, answered that both his agency and the Office of the National Coordinator for Health Information Technology (ONC) are working closely with the vendor community to develop certification standards. Makadon said that from his understanding, the issues are not technical ones but involve defining the questions that need to be asked and structuring those questions appropriately. As an example, he said that while it is important to ask about gender identity, it is equally important to ask birth sex in order to have accurate information about a patient's anatomy.

It is also important, he added, to think about these questions in a way that works for transgender people but also for everyone else so that everyone feels comfortable that these are routine questions that are being asked because they are important for the health care of a significant number of individuals. He recounted the furor that arose when Massachusetts instituted a requirement to collect data on race and ethnicity because most people did not understand the need for this information. Now, the public understands, for example, that untreated high blood pressure is more prevalent in the African American community.

Leslie Calman, of the Mautner Project: The National Lesbian Health Organization, asked if Makadon had any insights into how to communicate these issues to her community. She noted that she regularly encounters lesbians, particularly older lesbians, who are terrified of having this information available and are particularly terrified that they will find themselves in a situation where they have an accident, go to the hospital, and receive poor care because they are lesbians. Makadon agreed that this fear is real in the LGBT community, particularly among older individuals. In a final comment, Jesse Ehrenfeld, from Vanderbilt University, noted that a prospective clinical trial that he and his colleagues recently finished showed that patients are more honest about their personal information when they provided it at home.

3

Federal Perspective on the Use of Electronic Health Records to Collect Sexual Orientation and Gender Identity Data[1]

Key Points Raised by the Individual Speakers

- The federal government has implemented a data progression plan that will ultimately integrate sexual orientation and gender identity variables into national health surveys.
- While questions about sexual orientation are now being field-tested, there are still important issues about gender identity variables that need to be resolved before those questions would be ready for field tests.
- Stage 2 meaningful use regulations for EHR adoption do not include the collection of LGBT data, as there was concern over the lack of consensus on definitions, and on the standards for structured data entry for gender identity and sexual orientation.
- EHR adoption by federally funded community health centers, which provide services to many LGBT people, exceeds the national average and can serve as a model for wider adoption by other health care systems.

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[1] This section is based on the presentations of Donald Moulds, Acting Assistant Secretary for Planning and Evaluation, Department of Health and Human Services (HHS); Robert Tagalicod, Director, Office of eHealth Standards and Services, CMS; Sylvia Fisher, Director, Office of Research and Evaluation, Health Resources and Services Administration (HRSA); Yael Harris, Director, Office of Health IT & Quality, HRSA; Sue McAndrew, Office for Civil Rights, HHS; and Deven McGraw, Director, Health Privacy Project, Center for Democracy and Technology.

Since 2009, two federal laws have raised the visibility of data collection as a tool for reducing health care disparities. The Affordable Care Act requires that all surveys sponsored by the Department of Health and Human Services (HHS) collect information on race, ethnicity, sex, primary language, and disability status. The law also allows HHS to collect additional demographic data, including data on sexual orientation and gender identity, to better understand health care disparities.

In addition, the Health Information Technology for Economic and Clinical Health (HITECH) Act, which was included as part of the American Recovery and Reinvestment Act of 2009, provides HHS with the authority to establish programs to improve health care quality, safety, and efficiency through the promotion of health information technology, including electronic health records and private and secure electronic health information exchanges. Six speakers at the workshop discussed the steps that the federal government is taking to promote the collection of sexual orientation and gender identity data as an integral part of efforts to reduce health disparities among LGBT people.

EFFORTS AT THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

In 2011, HHS released a data progression plan intended to begin the integration of sexual orientation and gender identity variables into HHS national health surveys, explained Donald Moulds. The main objective of the plan, he said, is to carry out a series of cognitive lab and field tests leading to the inclusion of sexual orientation questions on the National Health Interview Survey (NHIS), the department's flagship survey for collecting health data on the civilian population in the United States. HHS is now in the final stages of field testing the questions about sexual orientation that have been developed, and Moulds stated that testing has gone "extremely well."

The expectations are that HHS will incorporate the new questions into the core questionnaire of the National Health Information Survey in January 2013. "The inclusion of this question or these questions will be a major accomplishment and will be a complement to the current collection of sexual orientation questions in the National Health and Nutrition Examination Survey, the NHANES, and the National Survey of Family Growth," said Moulds. In addition, the Agency for Healthcare Research and Quality (AHRQ) included for the first time a focus on health care for LGBT populations in the 2011 *National Health Disparities Report*, the agency's annual publication on disparities in health care services.

For gender identity, HHS has held two roundtable meetings with researchers, experts, and interested stakeholders to discuss the health data needs and methodological issues of collecting information on transgender populations. An important finding from these meetings, Moulds said, was that there is a need for further discussions on how best to measure gender identity.

THE VIEW FROM THE CENTERS FOR MEDICARE & MEDICAID SERVICES

The "meaningful use" of electronic health records provision of HITECH is a powerful tool for getting pertinent data, including LGBT data, to better the health and well-being of all Americans, said Robert Tagalicod. CMS, he explained, oversees more than just Medicare and Medicaid; it also runs the Child Health Insurance Program, the new health insurance exchanges created by the Affordable Care Act, and the Innovation Center. Overall, CMS oversees approximately $1 trillion annually in health care transactions.

In 2012, CMS established the Office of Information Products and Data Analysis (OIPDA) to lead the agency's initiative to modernize CMS's intricate data systems and policies and help the agency to achieve the greatest improvements in health care delivery. The agency, said Tagalicod, sees this as a mission-critical initiative to use data and analytics to guide the agency's evolution from fee-for-service to value-based purchasing of health care, an approach that links reimbursement to quality and efficiency of care rather than the sheer volume of care. The data and information resources available under this initiative include

- Medicare Geographic Variation Trend Data, a unique dataset that leverages nearly 5 billion Medicare claims in an easy-to-use data format that provides key metrics at the state and hospital referral region levels.
- Medicare Enrollment Dashboard, which provides, at a single location, comprehensive statistics or summary statistics on Medicare enrollment Parts A, B, and D, and Medicare Advantage.
- *Medicare & Medicaid Research Review*, an online journal.
- CMS Data Navigator, a Web-based search tool that readily connects researchers, policy makers, and the general public to CMS data.

The idea driving the development of each of these tools, he added, is to liberate and democratize data in order to inform a wide range of programs as contemplated by the Affordable Care Act. Moreover, the goal is to make data accessible in real time in the same way that credit card charges are available to consumers within seconds of a transaction.

Tagalicod then spoke about Section 4302 of the Affordable Care Act, which allows the Secretary of HHS to develop standards for categories of data that CMS should collect. Under this authorization, CMS's Office of Minority Health is working to incorporate data standards related to LGBT health into the agency's data collection efforts. He also noted that CMS oversees the Medicare and Medicaid Electronic Health Records (EHRs) Incentives Program that provides incentives to providers for the meaningful use of EHRs. The standards for meaningful use of electronic health records are being released in stages. In August 2012, CMS issued its final regulations for the second of three states of the meaningful use incentive program.

During the public comment period for the Stage 2 meaningful use regulations, there was overall public support for including LGBT data as part of the overall demographic objective, with the majority of the comments supporting an optional versus required criteria. There was concern, Tagalicod noted, over the sensitive nature of collecting this information and over widespread collection by administrative staff. And a significant number of comments questioned the clinical benefit of collecting the information.

In the end, the final Stage 2 rule did not include the collection of LGBT data, as there was concern over the lack of consensus on definitions and on the standards for structured data entry for gender identity and sexual orientation. In addition, there was concern about the applicability to all of the various eligible professionals, eligible hospitals, and so-called Critical Access Hospitals regarding their scope of practice. Going forward, said Tagalicod, CMS needs to settle on a usable structured data definition and the terms used in that definition. It also needs to develop a way to integrate that data into a data collection system that incentivizes the use of those data and does not merely set off a wave of box checking. The goal should be better care and better health, at a lower cost, without endangering the patient or negatively impacting the quality of that care.

HEALTH RESOURCES AND SERVICES ADMINISTRATION PERSPECTIVE

The mission of the Health Resources and Services Administration (HRSA), said Sylvia Fisher, is "to improve health and achieve health equity through access to quality services, a skilled health workforce, and innovative programs." She noted that HRSA is committed to addressing the health care needs of LGBT communities. Accordingly, data collection and program policies are continuously reviewed to ensure that HRSA programs address LGBT health care disparities to the fullest extent possible. As a result of these reviews, the agency revised its funding applications to state explicitly that all LGBT populations are a service population of focus. Language was also included specifying that community health care centers can apply for HRSA funding to meet the needs of LGBT communities.

To keep health center personnel and staff well informed about the needs of LGBT populations, HRSA recently signed a cooperative agreement with Fenway Health in Boston to create a National Training and Technical Assistance Center. This center will provide technical support to all of HRSA's community health centers on the needs of LGBT persons and populations. Fisher acknowledged that this is an ongoing subject that requires continuous monitoring and intervention at its health centers. In order to assist its community health centers in meeting the needs of LGBT patients, HRSA is gathering data on sexual orientation and gender identity with respect to health care settings. These data are shared with the community health centers.

Using a set of analytics tools, HRSA is now trying to assess where its community health centers are with regard to adoption of EHRs and where they are in achieving Stage 1 and Stage 2 meaningful use adoption. Yael Harris noted that Federally Qualified Health Centers annually report data to HRSA as part of their grantee requirements. Based on data reported in December 2011, 85 percent of the community health centers had some sort of EHR and an additional 10 percent planned to purchase one in the next 12 months. Some 90 percent of the centers planned to apply for meaningful use incentive funds, and 50 percent were working with one of the 62 Regional Extension Centers funded through the American Recovery and Reinvestment Act to provide information and technical assistance to small- to medium-sized provider practices to support meaningful use of EHRs.

In a survey conducted earlier by George Washington University's Geiger Gibson Community Health Research Foundation, Harris noted that 70 percent of community health centers were using electronic records, but only 45 percent were completely electronic, using no paper in their collection of patient data. The discrepancy with the numbers reported to HRSA in December 2011 may indicate increased levels of adoption of electronic records. These numbers exceed the national rates for ambulatory care providers. In addition, 67 percent of the community health centers that serve migrant populations, 66 percent of those that provide health care for the homeless, and 73 percent of those associated with public housing units have an EHR. Additionally, of the 73 percent of the health centers that provide behavioral health services, about 50 percent use an EHR and are integrating the behavioral health components with their regular EHR. Most of the clinicians working at those facilities now have access to information on their patients' mental health as well as primary care needs. The goal, Harris added, is to have all 1,200 community health centers meet meaningful use standards and become examples for other health care providers in their communities.

Achieving adoption of EHRs by rural health clinics has been a particular challenge, Harris said. According to a recent survey by the Healthcare Information and Management Systems Society, EHR adoption in rural settings is lagging, in part because of broadband access issues but also because of workforce training issues and limited funds to install EHR systems. HRSA, said Harris, is working closely with the Office of the National Coordinator, the Department of Agriculture, and the Federal Communications Commission to address these barriers.

HRSA is also the home of the Ryan White HIV/AIDS program, which includes the 900 Ryan White clinics.[2] The agency supports a wide range of activities addressing the needs of men who have sex with men and others who have HIV and AIDS, with a particular focus on men who have sex with men and who are also persons of color. "We want to be sure that there is quality care that is provided to them that is non-judgmental, accurate, provides for their needs, and also ensures that they receive and have access to those services," Fisher explained. HRSA has also been collecting data since 2000 on transgender clients who receive services through Ryan White, though the agency found that the initial effort to collect data could have been improved. As a result, HRSA convened a meeting in 2005 of transgender clients who had HIV in order to get a better sense of how to ask the questions around gender identity. As a result of that meeting, HRSA now has two categories for transgender people: the male to female option and female to male option. She stressed that they are continuing to monitor these data collection efforts.

According to Fisher, the populations served by Ryan White clinics are those that most need electronic health records because they are populations that most need care coordination. A survey conducted in the summer of 2011 found that more than 78 percent of Ryan White clinics use an EHR. Some 97 percent are electronically capturing patient history and demographic data, 94 percent are capturing clinical notes electronically, and 84 percent view lab results electronically. Problem areas still exist in terms of electronic prescribing, ordering laboratory tests, and capturing information specific to the Ryan White program in EHRs. Fisher noted that one strength of the Ryan White information technology effort is that while confidentiality is protected, data can be analyzed to find gaps and disparities. She added that 51 percent of Ryan White clinics report quality measures directly to HRSA from their EHRs.

Fisher noted, too, that HRSA is proud to serve as a co-chair, along with the Office of Minority Health, of the LGBT Work Group that is part of the Healthy People 2020 initiative. One product of the Work Group was a

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[2] The Ryan White program is a federal program that provides services to low-income individuals with HIV/AIDS.

proposal to collect population-based data on LGBT people. This proposal was approved by HHS. In 2011, HRSA began reporting for the first time health data about women who are lesbian or bisexual through *Women's Health USA*, an annual HRSA publication. This report included data on breast cancer and other health conditions as well as domestic violence, depression, and other psychological issues. HRSA plans to continue publishing updated data annually.

On a final note, Harris spoke about the work that HRSA is doing to identify health care disparities as part of a national quality strategy that involves multiple agencies within HHS. As part of this effort, HRSA is focusing on disparity-sensitive conditions that were identified in 2010 by the National Quality Forum. She also addressed the lack of a business case for providers to adopt the EHR except for the incentive programs, a major obstacle to a more widespread adoption of EHRs outside of HRSA-funded health care settings. "Until we make it a seamless process whereby you enter your data electronically and you can have real time data to track how you are doing in quality and where you can interact and improve, we really are not helping providers," she said. "The goal is to make it seamless for providers to report to CMS, to report to HRSA, to report to other federal agencies, and also to develop the datasets they need in real time to track and identify areas of disparity so that they can improve the quality of care they provide."

CONFIDENTIALITY, PRIVACY, AND THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT

The Office for Civil Rights in HHS administers the privacy and security rules embedded in the Health Insurance Portability and Accountability Act (HIPAA). These rules, explained Sue McAndrew, protect identifiable health information that is held or obtained by most health care providers, as well as certain other parties such as health plans and, soon, business associates. The rules work by limiting how the covered entities can use and disclose identifiable health information, and they also provide certain rights for individuals with respect to their own information. Providers have an obligation as custodians of protected information to safeguard it and ensure that it is not misused or disclosed without permission of the individual.

In addition, the HIPAA security rule provides more definitive standards for safeguarding information that exists in electronic form (e.g., in an EHR). The goal of the security rule is to ensure that that electronic information remains confidential and that the integrity of the information is maintained. An important component of the security rule is that it also has provisions to ensure that the data are available to those who need them when they need them, so there is balance between security and availability that the Office for Civil Rights works to maintain in collaboration with the ONC and other offices within HHS. McAndrew also noted that the Affordable Care Act provides the Office for Civil Rights with new enforcement authority to ensure that, with regard to health programs or activities, individuals should not be excluded from participation in, discriminated against, or denied benefits based on race, color, national origins, age, disability, or sex, which includes discrimination on the basis of gender identity and sex stereotyping.

HIPAA's privacy rule has no authority in terms of data collection, explained McAndrew. That is, HIPAA does not regulate the types of data that health plans and health care providers collect, nor does it regulate what can and cannot be put into a medical record. Those matters fall under the jurisdiction of the states and professional associations. HIPAA only comes into play once data are collected, and then only when they are associated with an individual. With the exception of psychotherapy notes, HIPAA does not give preferential treatment or heightened privacy protections to any specific type of health or demographic information. However, states and individual providers can create additional protections for types of data, such as HIV status. Individuals can also ask their providers to provide additional protection for specific data, but providers are not required to agree to that request.

The HIPAA privacy rule does give entities regulatory permission to use protected health information for core purposes of providing health care to their patients. The Office for Civil Rights, however, asks that institutions consider how to limit who should have access to that information, a concept known as "minimum necessary." The regulations also allow general sharing, within this minimum necessary concept, with payers in order for the health institutions to get paid for their services. McAndrew stated that her office is committed to the electronic health record enterprise, and that it works closely with ONC and others to make sure that the privacy rule is there to underscore and to give certain foundational privacy protections to information in EHRs.

Balancing Privacy and Security Concerns with Data Flow

"We know we need to collect the data, and we know we need to use them, but what kind of assurances can we give people about who's going to have access to those data and how confidential we can keep them?" asked Deven McGraw. Answering that question, she said, is critical to ensuring that the nation gets the maximum benefit in terms of improving health care and reducing health disparities from the widespread adoption of EHRs. The goal is to enable data flows that are necessary for improving individual and population health in a way that patients trust.

While she noted that there are some additional protections for data collected in federally funded substance abuse treatment programs, those will not apply to sexual orientation and gender identity data. HIPAA provides the prevailing set of rules for these data. Something not mandated by HIPAA is who gets to see what pieces of a patient's medical record. Health care delivery organizations decide which of their employees—whether it is the front desk clerk, the billing clerk, or whomever—have access to particular types of data in the medical record.

One challenge, she noted, arises from the document-centric way in which EHRs collect, present, and share data. This document-centric approach has developed largely in response to the meaningful use provisions that require a consolidated data document be sharable among medical providers. The benefit to that approach is that it provides a relevant summary of care for a provider, but the disadvantage is that it is difficult then to segment data, particularly in the case where a patient wants to restrict sharing of certain types of data. ONC has created a data segmentation initiative to actively explore this challenge. McGraw remarked that she is encouraged by this effort and believes that a way will be found to effectively identify and separate some data from the overall EHR.

Other issues to consider are how to standardize sexual orientation and gender identity data and where exactly to place it in the EHR. These decisions will impact the solution for segmentation. Overall, McGraw stated her opinion that the technical community will come to an agreement soon on how to collect sexual orientation and gender identity data, how to standardize those data, and where specific data will be populated in EHRs so that important demographic data can be provided while privacy and confidentiality protections can be applied to certain data. She addressed the workshop participants in closing by saying, "In many respects, one could say that optimistically, and I am an optimist, that you all are right in the right place at the right time. You might feel behind, but since we don't really know how to segment the information yet and we're working on it, coming in on this phase in those discussions may actually turn out to be a little fortuitous."

DISCUSSION

In response to a question from Alex Gonzalez, medical director at Fenway Health, about how to treat mental health records that are part of a shared EHR, McAndrew said that anything incorporated into the general medical record is not shielded under the special mental health provisions. Only in cases where the records are maintained separately are they subject to additional protections, she added. In that case, they cannot be shared even for treatment purposes without the authorization of the individual.

Ignatius Bau asked McAndrew about the kind of outreach or education planned around the letter that came from the Office for Civil Rights clarifying that section 1557 under the Affordable Care Act would protect against discrimination on the basis of gender identity. He also asked how that fits into broader nondiscrimination protections. She replied that both the letter and a set of frequently asked questions are available on the Office for Civil Rights website. She said her office is continuing to work on both additional regulations and outreach materials. McAndrew noted that there is a shared interest within the department to ensure that discrimination on the basis of gender identity and sex stereotyping is not occurring.

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Existing Data Collection Practices in Clinical Settings[1]

Key Points Raised by the Individual Speakers

- Transgender people are more likely to want to self-identify as such in an EHR than are lesbian, gay, or bisexual people. It is important, then, to consider these differing sensitivities when designing and implementing questions for use in a patient portal or EHR.
- The primary concerns about collecting data on sexual orientation and gender identity among LGBT people relate to privacy and use: who is going to ask these questions, who will be able to see this information, and how will it be used to benefit the patient?
- Soliciting input from patients and clinicians, and gaining buy-in from health care system administrators, is critical to developing appropriate and useful data-collection tools for deployment across a health care system.
- Training health care system staff about working with LGBT people and the sensitivities involved in collecting data on sexual orientation and gender identity is essential for successful implementation of these tools.

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[1] This section is based on the presentations of Shane Snowdon, Director, LGBT Health & Aging Program, Human Rights Campaign Foundation, and Founding Director, Center for LGBT Health and Equity, University of California, San Francisco; John Knudsen, Chief, LGBTI Practice Task Force, Mayo Clinic; Ronald Copeland, President and Executive Medical Director, Ohio Permanente Medical Group; Alex Gonzalez, Medical Director, Fenway Health; Jesse Ehrenfeld, Assistant Professor of Biomedical Informatics, Vanderbilt University; and Robin Weinick, Associate Director, RAND Health.

Though the use of EHRs to collect data on sexual orientation and gender identity is still evolving, a number of health care systems around the nation are in the process of developing and implementing questions to gather that data. These health care systems include both single-city organizations that largely serve an LGBT population to huge, multistate providers whose treatment population includes LGBT people. This chapter relates some of these health care systems' experiences and includes lessons that they have learned and suggestions for others who want to collect data on sexual orientation and gender identity in their EHRs.

PATIENT SELF-IDENTIFICATION IN ELECTRONIC HEALTH RECORDS

Each year, hundreds of health care facilities use the online national Healthcare Equality Index (HEI) survey, managed by the Human Rights Campaign, to evaluate themselves against established criteria for LGBT patient-centered care. Shane Snowdon explained that this is the only survey in the country that invites hospitals and outpatient clinics to examine their practices and policies from an LGBT perspective, report those practices and policies, and receive education and feedback about them. In the latest survey, completed in March 2012, 122 responses were received; 12 responses came from LGBT clinics, with the remaining 110 coming from general health facilities. Most of the latter facilities are in urban locations and consider themselves progressive or on the leading edge of health care.

There are three types of LGBT patient data: same-sex partnership, transgender status, and sexual orientation. Patients, said Snowdon, have very different attitudes toward each of these types of data and about whether and when they want to volunteer or be asked about them. Same-sex partnership, she added, is often overlooked in these discussions about LGBT-relevant data, but patients consider it extremely important. "Patients with same sex partners really want to at least be offered the option to say that they have a same sex partner," said Snowdon. "They do not want to look at or hear the options single, married, widowed, divorced."

Reflecting this preference, 58 percent of the facilities that participated in the HEI survey said that they do offer a partner or significant other option, either on a paper form or an EHR, and while this question is likely aimed at different-sex partners, same-sex partner couples appreciate the option. Of the facilities included in the survey, 37 percent are in so-called registration states that offer same-sex couples the opportunity to register their relationship status and receive various health care rights and responsibilities, and some 75 percent of the facilities in a registration state offer a registered domestic partner drop-down option. Snowdon pointed out that patients often want to volunteer their same-sex partnership during the admitting process and to have their partnership recognized in the health care setting.

An increasing number of transgender people, Snowdon continued, want to self-indentify as such despite the fear and anxiety they may have about doing so. They do, however, want people to know how to communicate with them respectfully, appropriately, and accurately. They want the entire health care system—the labs running clinical assays, the pharmacies filling prescriptions, and their physicians—aware of their sex at birth because transgender people know that information is important for them to receive the best care. Having said that, the most recent HEI survey found that only three clinics—two that specifically serve an LGBT population, the other serving a general population—offer a drop-down option for transgender status on their EHR. However, 78 facilities reported that they are actively considering a drop-down option on transgender status. The one general health facility that has a drop-down option has retained "male" and "female" as the options in the existing gender field, in order to match legal identification and insurance information, but also indicates "transgender MTF [male to female]" or "transgender FTM [female to male]" in a prominent drop-down list that a patient can access at their choosing. Snowdon noted that the facility made this modification to the standard EHR without involving the vendor.

In contrast to the situation with transgender people, who increasingly want to self-identify, lesbian, gay, and bisexual people seem more reluctant to self-identify in the context of an EHR, Snowdon said. Providing information in an EHR allows providers to know more about their patients, but many lesbian, gay, and bisexual people do not necessarily want their providers to know about their sexual orientation. EHRs are also envisioned to allow information to be shared more widely, and, in Snowdon's opinion, many lesbian, gay, and bisexual patients do not want that information shared widely, if at all. While EHRs can be used to empower patients, many patients feel that being confronted with routine sexual orientation questions is disempowering.

Summarizing what she and her colleagues have learned over the years, Snowdon said that lesbian, gay, and bisexual patients have many concerns regarding volunteering information about sexual orientation in the health care setting. They are unsure whether to respond in terms of attraction, behavior, or identity. In her opinion, women in particular are unsure about whether the question refers to today, the past, or the future because they tend to view themselves as more sexually fluid. Reflecting this challenge, medical students are now taught that sexual orientation occurs on a spectrum that is not necessarily fixed over a lifetime. They are also taught to not ask about sexual orientation, but rather to ask their patients about actual behavior.

Lesbian, gay, and bisexual patients worry, often with reason she said, that they will be treated differently if their sexual orientation is known. They may even delay and avoid care because of how they feel they will be treated, not just by physicians, but by the nurses, the allied health professions, and other facility employees. "So it isn't just a question of, 'Are my data going to be held confidentially in the research phase or in the EHR?'" said Snowdon. "It is, 'I don't even want you to ask me unless I volunteer it.'" This concern is especially prevalent, she added, in the 29 states in which lesbian, gay, and bisexual people do not have legal protections.

Only 26 percent of facilities record sexual orientation in print or in an EHR, and no general health facilities record sexual orientation in an EHR using a drop-down option. Instead, the patient will note their sexual orientation on a print form or the provider will enter the patient's sexual orientation in print or electronic notes. In contrast to same sex partnership and transgender status, which patients often want to volunteer, no general health facility reported patient requests to indicate sexual orientation at admitting or registration.

On the basis of these findings, Snowdon made the following recommendations:

- Explore not only the phrasing of sexual orientation questions and confidentiality of data in research but also who will be asking those questions, what training will those asking the questions receive, in what context will they ask the questions, and to what extent will the information be available within the health care system.
- Convene diverse groups of patients to discuss their concerns because they are likely to differ substantially by gender, age, income, race and ethnicity, and health condition.
- If routine sexual orientation questioning is incentivized or otherwise encouraged, it will be essential to provide widespread patient education and empowerment activities, to require facilities to have meaningful nondiscrimination policies and staff training in place, and to teach health care providers in a systematic way how to discuss sexual orientation sensitively with patients.

Concerning this last point, Snowdon said it would be interesting to see an initiative from CMS that would require LGBT nondiscrimination policies to go hand-in-hand with incentivizing data collection. As a final note, Snowdon said that EHRs need to be modified, both by vendors and facilities, so that LGBT patients can always, if they wish, ask that information on same-sex partnership, transgender status, and sexual orientation be recorded. In doing so, however, it is essential to remember that a patient's desire to volunteer that data can vary tremendously.

THE MAYO CLINIC EXPERIENCE

The Mayo Clinic, said John Knudsen, has only recently begun an effort to gather information on sexual orientation and gender identity. He noted that the Mayo Clinic started on its path thanks to what he called a union of forces that included four reports—HHS's *Healthy People 2020* report, the IOM's 2011 report on the health of LGBT people, the Joint Commission report *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community*, and the HEI survey—as well as a receptive leadership that includes clinicians and the Mayo Clinic LGBT Employee Resource Group. This resource group, explained Knudsen, started the process by requesting that the Mayo Clinic identify a group of providers in its primary care practice who were "LGBT-friendly," and this led to an effort to collect data on some of the difficulties experienced by both LGBT patients and employees.

This data collection effort is being led by the Mayo Clinic's clinical practice committee, which heard a wealth of personal and painful stories that patients and employees shared about suboptimal care they had received from the organization. Mayo Clinic's leadership responded by creating the LGBT Practice Task Force, which was charged with studying the situation with regard to LGBT people and to develop recommendations that would facilitate and sustain an inclusive and welcoming environment for the Mayo Clinic's LGBT patients and families. This effort also included intersex people, those born with an ambiguity about their sex assignment.

One of the factors complicating efforts to collect data on LGBT and intersex people at the Mayo Clinic is that it is not just a hospital—it includes group practices and multispecialty practices based in Arizona, Florida, and Minnesota, and a regional health care system that includes 71 communities, 900 physicians, and 12,000 allied health staff spread across Iowa, Minnesota, and Wisconsin. In addition, the Mayo Clinic system uses three different EHRs. To address this last issue, the Mayo Clinic system has developed an enterprise-wide data governance and health information coordination policy that is creating uniformity and standardization across the entire system.

Another complication arises from the fact that the Mayo Clinic system uses patient portals to input information, but this information is managed separately from the EHR. Knudsen explained that there is currently no mechanism or interface for transmitting data from the patient-provided information portals into the EHR. He noted, too, that changes are likely to be slow in being enacted, giving the example of the more than 4 years it took to make a change in the collection of race and ethnicity data based on recommendations from a research team. In terms of LGBT data, a stewardship group is developing a recommended list of data elements and business rules around these data elements and codes. An external standards team will develop language and standards that will then need to be endorsed and approved by multiple stakeholders and Mayo Clinic leadership, all of which will be coordinated by the enterprise project management office at the Mayo Clinic. As a final note, Knudsen said that the goal of all of this activity is to collect data that will be able to trigger alerts for screening and preventive health services, track quality metrics, and create research opportunities.

THE KAISER PERMANENTE EXPERIENCE

Like the Mayo Clinic, Kaiser Permanente is also in the early stages of collecting data relevant to sexual orientation and gender identity. Kaiser, as the nation's largest not-for-profit health plan, has long served a diverse population that today comprises more than 230 granular ethnicities speaking more than 170 different languages, said Ronald Copeland. As a result, Kaiser has had a great deal of experience managing and optimizing diversity to improve care for its patients and enhance the performance of its workforce.

When Kaiser first introduced its EHR and began collecting data on its membership, its internal KP Pride Caucus, which consists of LGBT employees, questioned why the EHR collected data on race, ethnicity, and language, but not sexual orientation and gender identity. The answer was that the organization did not have the capacity to collect these data and it had concerns about the sensitive nature of asking questions about sexual orientation and gender identity. Instead of jumping right into what could have been a troublesome area, the leadership at Kaiser intended to phase these questions in based on internal research and in conjunction with an education and awareness campaign.

To drive this effort forward, Kaiser created two study groups, one focused on data collection and implementation, the other on referral processes to physicians who were knowledgeable about and sensitive to issues specific to LGBT populations. The data collection study group operated from the assumptions that future legislation will require and regulate the collection of LGBT data and that data will be collected in Kaiser's HealthConnect EHR. It also assumed that technical issues about data structure and definition of terms could be overcome based on Kaiser's experience with race, ethnicity, and language data and that while the final implementation may look different in each of the organization's regions, the data format would be identical. Finally, the study group assumed that individuals will have the right to refuse to answer questions about sexual orientation or gender identity. The study group recommendations are presented in Box 4-1.

BOX 4-1
Recommendations from Kaiser's Study Group for Sexual Orientation and Gender Identity Questions

The Kaiser study group recommended the collection of self-identified data at the Patient level, and recorded in Kaiser's EHR system:

1. Sexual Orientation
   - How do you identify yourself sexually?
2. Gender Identity
   - What gender (sex) do you consider yourself?
   - What gender was recorded on your original birth certificate?
3. Sexual Behavior
   - In the last 24 months, with whom have you had sex?

SOURCE: Copeland presentation.

In the second phase of Kaiser's efforts, the organization has created 11 centers of excellence that are research units within its clinical space. These units are designed to take ideas, create models, pilot the models, work out the details, and then present them for further evaluation across the entire organization. Action teams are now looking at issues involving technology and systems, operations and workflow, education and training of staff, and brand strategy. The technology and systems action team, for example, intends to develop and implement a valid and reliable system for storing, collecting, and using LGBT and intersex data by the end of the second quarter of 2013. Operating with the same deadline, the operations and workflow action team will embed in the Kaiser infrastructure a clinician referral system while the education and training action group develops education and training programs that advance different levels of core competency in caring for LGBT and intersex people. The final phase will implement the process.

THE FENWAY HEALTH EXPERIENCE

The mission of Fenway Health, an independent, federally qualified health center in Boston, is to enhance the health of the LGBT community and other people in its neighborhoods and beyond through access to the highest-quality health care, education, research, and advocacy, explained Alex Gonzalez. In 2011, Fenway Health served some 18,000 unique patients, and Gonzalez estimated that maybe half of the patients are lesbian, gay, or bisexual, and another 800 are transgender. He based these estimates on his experience taking care of patients over the past 7 years.

While Fenway Health has been using an EHR system since 1997, it has captured sexual orientation and gender identity data only in an unstructured format as part of a careful social history or behavioral health intake. That kind of data, said Gonzalez, is trackable only by doing a chart review, which is unrealistic for 18,000 patients. Beginning in December 2011, Fenway Health began collecting sexual orientation data on the registration form along with other demographic data, and it added information on gender identity in August 2012 (see Box 4-2). Text on the form indicates that the information is for demographic purposes only and will not impact patient care. The registration form also comes with a pamphlet on patient rights that includes an explanation of confidentiality and articulates a philosophy of respect for each patient as an individual with unique health needs. In addition, Fenway Health now prints out a patient profile for patients who are already registered and are returning to care in order to have the patient double-check his or her own information. The patient profile also helps capture sexual orientation and gender identify data on people who have been long-time patients.

BOX 4-2
Fenway Health Registration Form

- Do you think of yourself as…?
  - Lesbian, gay, or homosexual
  - Straight or heterosexual
  - Bisexual
  - Something else
  - Don't know
- What is your gender?
  - Female
  - Male
  - Genderqueer or not exclusively male or female
- What was your sex at birth?
  - Female
  - Male
- Do you identify as transgender or transsexual?
  - Yes
  - No
  - Don't know

SOURCE: Gonzalez presentation.

The registration form has one question designed to capture sexual orientation data in a structured format and three questions to capture data on gender identity, which are currently being pilot-tested. For sexual orientation identity, two versions—one with a write-in option and one without—were pilot-tested. For gender identity, Fenway Health convened a patient advisory committee and surveyed transgender patients on their preferences.

Gonzalez said that since implementing these questions in its information packets and patient profiles, there has been no discernible pattern of non-response to the sexual orientation and gender identity questions, nor have there been reports from front desk staff or providers of patients asking why they are being asked these questions. It is his opinion that LGBT patients seem to appreciate being asked the questions, while non-LGBT patients seem to be unaffected by the questions. For transgender patients, the data collected during the test phase suggest that there are several groups of transgender persons. There were those who identify with their affirmed gender and do not identify as being transgender as well as those who do identify as being transgender. There were also those who identify along a non-binary spectrum, or as genderqueer—neither male nor female. So far, Fenway Health has been able to capture structured data on 11-12 percent of all of its patients. Since the addition of the sexual orientation question in December 2011, roughly one-third of all patients have answered it. The questions on gender identity were only added in August, making it too soon to have acquired meaningful data.

In his final remarks, Gonzalez discussed some additional consideration for transgender patients. Third-party payment systems require that name and sex be recorded in the EHR as they are listed with the insurer. This can be an alienating experience as insurance information often does not match identity. However, transgender patients report that they feel empowered when their preferred name and pronoun are recorded in a way that is honored by all staff at Fenway Health.

THE VANDERBILT UNIVERSITY EXPERIENCE

It is important to remember, said Jesse Ehrenfeld, that the vast majority of LGBT patients across the United States receive their health care from non-LGBT affiliated medical facilities such as Vanderbilt and that facilities such as Vanderbilt also have a large number of LGBT employees, students, and patients. He estimated that at his institution, around 5 percent of the patients are LGBT and intersex people and added that in 2009, the Vanderbilt University Medical School initiated an extensive curriculum reform effort to bring LGBT health education to the forefront. Vanderbilt has revised its clinical intake forms to ensure that they are inclusive and that they provide the necessary information to maximize the value of its EHR for providing care for its patients. It also launched a new program for LGBT health and created the nation's second LGBT office in an academic medical center. (The University of California, San Francisco, had the first.)

With that institutional climate as background, Ehrenfeld discussed the work that he and his colleagues are carrying out on identifying barriers to disclosure of LGBT and intersex status by patients and how they have been using informatics tools to identify LGBT patients in their efforts to evaluate and reduce health care disparities. In a study conducted by colleague Sarah Fogel, participants recruited from gay and lesbian community centers were asked questions about their willingness to disclose their sexual orientation to a provider. The study had a diverse group of subjects in terms of race, ethnicity, age, and education level, and 84 percent of the participants had disclosed their sexual identity to a health care provider. This study identified a long list of facilitators to disclosure, such as the health care provider asking about the patient's sexual identity or making clear that this information was important for the patient's care. It also identified a long list of barriers to disclosure, such as the sexual identity information is written into the patient's medical record and that staff other than the health care provider would have access to this information.

Ehrenfeld then described some of his work using natural language processing to first identify LGBT and intersex patients from electronic health records that already exist and then determine how LGBT and intersex status affects treatment, diagnosis, and health outcomes. Natural language processing, he explained, uses advanced algorithms and the rules of the English language to analyze free-text data, such as that in unstructured text notes in medical records, for specific information through trial and error. Using this approach on its entire enterprise data warehouse, Ehrenfeld and his collaborators were able to identify several thousand unique patients using search terms such as homosexual, LGBT, gay, lesbian, receptive partner, and others. They have since refined their search technique using concepts such as negation logic, semantic search, and other natural language processing tools to reduce a 22 percent false positive rate to three percent. Additional work is under way to further reduce the false positive rate to close to zero. An initial finding from an analysis of the identified records was that it takes an average of 30 months between the time of a patient's first visit and when LGBT status appears in the medical record, and that patients had an average of 17 clinical encounters in which LGBT status was identified.

Ehrenfeld described Vanderbilt's approach to modifying its clinical intake forms and EHRs. This effort started with an extensive consensus-building process that involved Vanderbilt leadership, its patient and family council, a growing list of clinical departments, and its cultural and linguistic council. This process resulted in four recommendations that Ehrenfeld said are worth adopting at all medical centers:

1. Patients should have the opportunity to self-identify their sexual orientation and gender identity.
2. Patients should have the opportunity to define their relationship status.
3. Patients should have the opportunity to identify their family.
4. Patients should be asked about power of attorney/health care proxy and advanced health directives.

Vanderbilt has now developed a three-stage implementation plan for modifying the 210 unique clinical intake forms used by its 95 physician practices. The recommended text for use on the intake forms includes two parts. The gender identification section asks for patients' legal name; their preferred name, if different; their sex at birth; and their gender identity—male, female, transgender, and prefer not to answer. The sexual orientation section asks if the patient is heterosexual, straight, lesbian, gay, bisexual, queer, something else, or prefer not to answer. In developing these questions, the Vanderbilt team considered the same issues that the previous speakers had identified: Who is asking the questions? Where is the information recorded in the EHR? How often is the patient asked for this information? What to ask in terms of identity versus behavior?

In summary, Ehrenfeld made the following three recommendations:

1. Self-identified orientation, gender identity, and sexual behavior should be collected during routine clinical encounters in order to improve health outcomes.
2. When collecting sexual orientation and gender identity data on health care intake forms, patients should have the right to opt out.
3. Prior to collecting this information, health care institutions should develop and widely distribute educational materials, not just for staff but also for patients, that explain clearly why developing and collecting this information is important and how it remains confidential.

SUPPORTING PROVIDERS IN THE COLLECTION OF DATA

Given the importance of training providers and health care system staff prior to introducing questions about sexual orientation and gender identity, it is critical to begin thinking about how to accomplish that training early in the process, said Robin Weinick. For most health care systems, training will likely need to be done using some kind of video tool given that the people who need training are going to be dispersed, both in terms of location and time. Training methods must also take into account that three-quarters of all office visits nationally are to practices with five or fewer clinicians. And most of those practices do not have the resources to conduct extensive training programs.

Though there are important differences between collecting race and ethnicity data and sexual orientation and gender identity data, there are lessons to be learned from the experience of introducing race and ethnicity data into medical records. The first lesson is that the language provided to guide those who ask these questions must be well defined, that is, there should not be much left to the imagination of the person who is asking the question. A corollary to this lesson is that the information learned when testing questions in a research or survey context are not automatically transferrable to a clinical context, said Weinick.

A second lesson learned from collecting race and ethnicity data is that it is extremely helpful to prepare an introductory statement for the data collectors to use that explains why it is important to gather the information. That introductory statement serves the dual purpose of explaining to the patient and the staff who are going to ask these questions why the information is important to collect.

Another important lesson is that it is important to keep staff calm by identifying potential patient and staff objections in advance and build those into the training. Scripting responses so that staff can start to get comfortable with various situations is helpful, as are role-playing exercises. Another way to reassure staff is to provide them information from pilot data collection studies that show that if questions are asked in the right way, patients do not get angry. In addition, repetition is critical to making staff feel at ease. Weinick explained that the goal of training should be to drive home two points: (1) do not make assumptions about a patient based on how they look, act, or sound, and (2) patient self-identification is the only thing that matters.

Three additional factors go into successful training of the people who will be asking these questions. First, they need to understand as concretely as possible why the issue is important. Second, they need to know clearly and very specifically what they are being asked to do. And, finally, they need to have skills and scripts for addressing patient concerns.

DISCUSSION

Aaron Tax, from Services and Advocacy for GLBT Elders, asked the four speakers about their experiences in collecting sexual orientation and gender identity data for elderly persons who may be more reluctant because of personal experience to divulge this information. Ehrenfeld said that his team certainly observed a generation gap in the willingness to self-identify on intake forms. Gonzalez said that Fenway Health's approach to this problem has been to retain the ability to ask about sexual orientation and gender identity in the clinical setting rather than during registration because it is easier to put people at ease and educate them about why this information is important. Snowdon noted that this is not just a problem at the older end of the spectrum—a large longitudinal study of youth conducted by the Human Rights Campaign found a similar reluctance among youth between 16 and 24 years of age. Harvey Makadon noted, though, that in his experience, older LGBT people feel more comfortable when they talk to their physicians about their sexual orientation or gender identity because it makes them feel that their health care professional is listening to them.

George Brown of the Department of Veterans Affairs asked how intersex people are supposed to identify themselves when the sex-at-birth question offers just male or female options. Snowdon replied that these choices are dictated by insurance company systems that only accept male or female. In that respect, that field only reflects the legal identification or insurance record of the patient. Intersex status is collected in the gender identity drop-down list.

Barbara Warren, director for LGBT Health Services at Continuum Health Partners in New York, relayed her experiences in working with the New York State Office of Mental Health to add questions on sexual orientation and gender identity to the standard patient admissions form. The challenges she faced in adequately training personnel was reflected in the low rate of practices in New York State including those questions and the resulting small amount of data that was obtained. She added that they were still working to improve the training component. Weinick responded to this comment by discussing the need to approach repetitive training creatively. She used sexual harassment training as an example of training that uses role playing and vignettes to reinforce the training components.

The issue for some LGBT patients, explained Snowdon, is that just being asked these questions will make them very anxious and may make them less likely to seek care. She asked if there was an equivalent of that in race and ethnicity. Rebecca Fox, of Wellspring Advisors, pointed out that collecting ethnicity data in a community clinic in Arizona, and asking about a patient's Latino background, may make some patients very anxious. It could lead them to not seek care because they are afraid of being asked what about their racial and ethnic background and that may bring up fears around immigration status. Weinick agreed that while bias against race and ethnicity differs somewhat from bias against sexual orientation or gender identity, there is some overlap in terms of fear possibly driving patients away from health settings. Bau commented that there were similarities with language. For example, in some cases when patients are asked if they need language assistance, they refuse because they mistakenly believe it will make them vulnerable to discrimination. In fact, the right to language assistance is guaranteed and could benefit them.

In response to a question from Eva Powell, from the National Partnership for Women and Families, about whether natural language processing could be used in combination with information gathered directly from the patient as a means of improving the quality of the resulting data, Ehrenfeld said that the natural language processing methods were a research tool, not an operational tool. He does not expect natural language processing to be used in an operational setting, though it could be used in a quality improvement setting. He added that natural language processing will not provide useful information if the physician has never asked the patient about sexual orientation or gender identity or if the patient has never volunteered that information.

When asked by Susan Queen from the Office of the Assistant Secretary for Planning and Evaluation at HHS about whether information from a patient portal can be transferred directly to an EHR, Knudsen said that yes it can, and that at the Mayo Clinic, patient-provided information is incorporated into the EHR. Ehrenfeld added that at Vanderbilt, information from the patient portal is first verified by the provider before it is added to the patient's EHR.

Queen asked Copeland if the response categories for Kaiser's sexual orientation question was a set of fixed categories or did it prompt the individual to write in a response. Copeland replied that at the present time, the patient writes in the response. He added that in all of their data collection of this type Kaiser tries to have some predetermined responses, but they also want to have the patient self-identify whenever possible. They have found that, in terms of engaging patients, using the terms the patient uses is probably the most effective way to move forward with conversations between patients and clinicians and care teams. In his opinion, this approach is preferable to forcing them to make a choice and fit it into a category that has already been pre-determined.

A participant attending by phone asked about patient autonomy and whether the data collected could be used for research without patients' consent. Knudsen said that in Minnesota patients sign a form that can remove their data from any future research. This means that even if a researcher has approval from an institutional review board, certain patients can opt out of the research and they are given the opportunity to make that decision when they are seen as patients.

5

Developing and Implementing Questions for Collecting Data on Sexual Orientation and Gender Identity[1]

Key Points Raised by the Individual Speakers

- To address limitations in the way gender identity is represented in EHRs, a two-question approach may provide more accurate information while affording more respect to transgender people.
- Experience from surveys shows that it is feasible to collect accurate information about sexual identity and behavior in a diverse population.
- EHR users and vendors are working together to address issues relating to data collection on sexual orientation and gender identity in order to develop standardized questions that best serve the needs of patients.

"In a perfect world," said panel moderator Nancy Bates, of the Census Bureau, "we wish we had some tested, generally accepted, embedded set of standard questions for gender identity and sexual orientation that worked in all different settings and for all populations. We aren't there yet." However, researchers are working toward that perfect world, and

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[1] This section is based on the presentations of JoAnne Keatley, Director, Center for Excellence for Transgender Health, University of California, San Francisco; Kristen Miller, Director, Question Design Research Laboratory, National Center for Health Statistics; David Grant, Director, California Health Interview Survey; Edward Callahan, Professor of Family and Community Medicine, University of California, Davis, Health System; and Denise Rasmussen, Epic Systems Corporation.

workshop participants heard from several of those who have expertise in this area and who conveyed some of the lessons they have learned in survey settings and other settings. In this chapter, five speakers discuss efforts to design questions for collecting data on sexual orientation and gender identity.

GENDER IDENTITY DATA COLLECTION

A working definition of the word transgender, said JoAnne Keatley, is a person whose gender identity or gender expression differs from the sex assigned to them at birth. She reiterated a comment made earlier in the workshop that many transgender people do not like to self-identify as transgender, instead wanting to have their affirmed gender recognized without it being connected to their transgender history. She also pointed out the distinction between gender identity—an internal sense of self regarding gender—and sexual orientation, which is a feeling of sexual or romantic attraction to gender or gender expression of other individuals and is not necessarily linked to anatomy. This distinction can cause confusion in health surveys, an example being the case of a man who is in a relationship with a transgender woman often being categorized as a man who has sex with a man when in fact that may not be the perception of that particular individual. In fact, there is a history of the CDC capturing transgender individuals and their partners under the men who have sex with men category.

In Keatley's opinion, EHRs currently have limitations in the way they represent gender identity. If a transgender person's sex is listed in terms of anatomy and the only mention of that person's transgender status is in a provider note, other providers may not go to the notes section of the EHR and the result can be a disconnect that impacts the patient. Another limitation concerns denial of care from insurance coding that has to be gender-specific—if a transgender female is identified as female on an EHR, they may be denied prostate screening. To address these limitations, the Center of Excellence for Transgender Health recommends that transgender-inclusive data be collected using two questions. First, ask about the person's current gender identity, and then ask for the person's assigned sex at birth. Asking about current gender identity first honors the patient's gender expression by allowing the patient to self-identify in their current gender identity. It may be necessary to ask additional questions to specify current anatomy, but that can be done through drop-down menus or through provider questions.

Regarding implementation, the first step is to update the health care system's data collection forms and databases to include the two-question system. The CDC, Keatley noted, implemented the two-question system in 2011 in its adult HIV case report form and its Enhanced HIV/AIDS Reporting System. She added that CDC data collected using the two-question system registered a 64 percent increase in transgender people compared to just asking current gender identity without asking about sex assigned at birth.

The next step in implementation is to train all staff and health care professionals to ask questions about gender identity correctly and consistently. Then, it is important to educate funders, health departments, and government agencies about the need to aggregate and disseminate the collected data. Only through data aggregation and dissemination will it be possible to determine the size of the transgender population and identify specific health risks and health care needs of transgender people. The last step is to use the disseminated data to improve services and programs for transgender people.

DEVELOPING A "PERFECT" SEXUAL IDENTITY MEASURE

Developing the sexual identity question for the National Health Interview Survey (NHIS) involved multiple steps that Kristen Miller described, starting with settling on what exactly the survey needed to measure. Sexual orientation, she said, is not a measurable concept, but rather is a generic catch-all term that describes an essence of how an individual feels. Instead, sexual orientation is an amalgam of three other concepts: sexual behavior, sexual attraction, and sexual identity.

Sexual behavior looks at actual same-sex versus opposite-sex sexual behavior and is not necessarily consistent with self-conception or presentation of self. One problem in designing a question to quantify sexual behavior is that definitions of what counts as "sex" vary across subgroups. Sexual attraction refers to same sex versus opposite sex or gender desire, and it, too, is not necessarily consistent with self-conception or presentation of self. Sexual attraction is a latent and elusive phenomenon that is neither tangible nor observable. Miller said that the problem with designing a question to quantify sexual attraction is that there are different variations in what people think of as sexual attraction. Sexual identity describes an individual's conscious identification of an understanding of self, and in that respect, is similar to racial identity because it represents the individual's relationship to their social world. Sexual identity is a complex phenomenon that may fluctuate.

The key to designing questions around these three concepts is to not conflate them, Miller stated, adding that the term "sexual orientation" should be eliminated when used with scientific data because it does not reflect the realities of people's lives. This is particularly true, she added, for women, and in her mind, the use of the term "sexual orientation" does a disservice to the LGBT community. She also noted that in designing questions, it is important to consider whether the questions will be asked in a provider's office or by a field survey interviewer.

Over the past decade, the National Center for Health Statistics (NCHS) has used a number of different questions to collect data on sexual identity in a variety of surveys, and the data are inconsistent across these surveys. The result, said Miller, is a distorted picture of what is happening within the lesbian, gay, and bisexual community. In a 2002 survey that used the terms heterosexual, homosexual, and bisexual to refer to sexual orientation, lesbians were identified as the most obese group of sexual minorities. In contrast, a 2006 survey that used the terms "straight or heterosexual," "gay or lesbian or homosexual," and "bisexual" found that lesbians were the least obese group.

To develop the sexual identity questions for the NHIS, Miller and her colleagues conducted seven cognitive tests involving 377 cognitive interviews. They also conducted a number of quantitative studies and examined a variety of different surveys that used some variation of a sexual identity question. These studies showed that LGBT people answer questions from a different perspective than non–sexual minority individuals, and that this difference stems in large part from the fact that non–sexual minority people are unfamiliar with the terms used in the questions. Based on these findings, the NCHS revised the questions designed for the NHIS based on three principles. First, use labels that respondents use to refer to themselves. Second, do not use labels that respondents do not understand. Third, use follow-up questions to meaningfully categorize "something else" and "don't know" answers. Following these principles, the NCHS developed the sexual identity questions listed in Box 5-1.

She noted that though the second question includes a transgender option, this is not meant to be a transgender question. Rather, it is meant to address the complex relationship between gender and sexual identity. In closing, Miller said that this set of questions successfully categorized all but a few respondents, and that these questions will be included in the next NHIS.

ASSESSING SEXUAL IDENTITY AND BEHAVIOR IN CALIFORNIA'S DIVERSE POPULATION

The California Health Information Survey (CHIS) is an omnibus, multilingual, public health telephone survey of 42,000 to 56,000 California households conducted biannually since 2001 and continuously since 2011. CHIS has included sexual identity questions since 2001 and gender of sexual partner questions since 2003. The questionnaire development process, explained David Grant, involves multiple stakeholders organized

BOX 5-1
NCHS Sexual Identity Questions

Do you think of yourself as…?
- ☐ Lesbian or gay
- ☐ Straight, that is, not gay
- ☐ Bisexual
- ☐ Something else
- ☐ Don't know

By Something Else, do you mean that…?
- ☐ You are not straight, but identify with another label such as queer, trisexual, omnisexual, or pan-sexual
- ☐ You are transgender or transsexual
- ☐ You have not or are in the process of figuring out your sexuality
- ☐ You do not think of yourself as having a sexuality
- ☐ You personally reject all labels of yourself
- ☐ You made a mistake and did not mean to pick this answer
- ☐ You mean something else
  What do you mean by something else? ___________________________

By Don't Know, do you mean that…?
- ☐ You don't understand the words
- ☐ You understand the words, but you have not or are in the process of figuring out your sexuality
- ☐ You mean something else
  What do you mean by something else? ___________________________

SOURCE: Miller presentation.

into an advisory board, technical advisory committees, and both ad hoc and topic-specific workgroups. The general rule with CHIS is to never write new questions but to use questions from other well-established surveys. One caveat is that questions designed for data collection using registration forms or patient portals can be difficult to use in a phone survey, so questions are often adapted for that particularly medium, as well as to account for the linguistic diversity in California. Extensive testing and training and ongoing monthly monitoring of live interviews completes the process.

In the first CHIS cycle in 2001, the survey asked two sexual identity questions of adults under age 65. The first was a yes-or-no question: Are you gay, lesbian, or bisexual? The word lesbian was omitted if the respondent was male. If yes, the second question clarified the answer to the first question. There was a concern that there would be a significant hang-up rate with these questions, but, in fact, these questions posed no more of a problem than other questions in the survey. An issue that did arise was that respondents would often answer the first question by stating their sexual identity, which created problems for the interviewers and slowed down the interview process. An analysis of the 2001 survey data highlighted the need for sexual behavior questions, and these were added in 2003. Beginning in 2003, they have asked a single sexual identity question that reads, "Do you think of yourself as straight or heterosexual; as gay, lesbian, or homosexual; or bisexual?" There is also the option of opening a text box and inputting an answer verbatim. In addition, there are two questions on sexual behavior. In cycles since 2003, these questions have been only asked of adults under the age of 70 because of a high rate of misclassification concerning the word "bisexual" in adults over age 70.

Discussing data from CHIS 2009, Grant noted that about 3 percent of men reported that they had exclusively male sex partners in the preceding 12 months, and about 1.6 percent of women reported having exclusively female sex partners in the preceding 12 months. Less than 0.5 percent of both men and women reported having sex partners of both sexes. From the sexual identity questions, about 2.5 percent of men identified as gay or homosexual, and 1.1 percent of women identified as gay, lesbian, or homosexual. One percent of men and 1.7 percent of women identified as being bisexual. Non-response to these questions was low, about 2-3 percent. In contrast, 23 percent of the sample refused to answer questions on household income. Non-response, which combines "don't know" and refusals, was highest among Cantonese and Spanish speakers. Women who spoke Asian languages—Cantonese, Korean, Mandarin, and Vietnamese—were two to six times less likely to respond than men, which Grant said was unexpected.

In summarizing the lessons learned from over a decade of surveys, Grant said that it is clearly important to collect data on sexual identity in EHRs. "Electronic health records have great potential, especially for transgender populations because even in a large survey like CHIS, we're likely to pick up very few or too few to make much statistical inference about that population," he explained. He added that the CHIS results show that it is feasible to collect relatively accurate information about sexual identity and behavior in a diverse population, but that the wording of questions is important, as is the setting in which the questions are asked.

SEXUAL ORIENTATION AND GENDER IDENTITY IN THE ELECTRONIC HEALTH RECORD: A USER AND VENDOR PERSPECTIVE

The University of California, Davis (UC Davis) Health System began collecting demographic data in its EHR in 2009. At the time it was felt by the Health System's EHR task force that it could not include sexual orientation or gender identity information in the EHR. A subsequent decision to appoint a new task force on inclusion of sexual orientation and gender identity in the UC Davis Health System elicited opposition from some administrators who felt that clinicians would not be comfortable discussing this issue or that the topic was too sensitive to be discussed in the context of an EHR. And even though this resistance was eventually overcome—UC Davis was set to roll out its sexual orientation and gender identity questions in November 2012—Callahan said this experience convinced him that the only way that this information will be collected in EHRs on a widespread basis is if the federal government requires it to happen.

The taskforce saw this opposition as an opportunity to make a compelling case to both the clinical and LGBT communities for the need to collect these data. In essence, said Callahan, the task force developed a business case based on the premise that there are significant, even devastating, health disparities that LGBT people experience because of the de facto "Don't Ask, Don't Tell" attitude that pervades the medical community. "If we can desensitize our providers to be able to talk about sexual orientation and gender identity," said Callahan, "they might learn that LGBT people are part of us, not some group of 'other.'" In fact, the task force's efforts, he said, are changing attitudes and the culture at UC Davis. One tangible result of this attitude change is the development of a new medical school curriculum that incorporates LGBT health issues across the entire 4-year process.

One of the most compelling pieces of evidence for including sexual orientation and gender identity data in EHRs, said Callahan, comes from Caitlin Ryan and the Family Acceptance Project at the University of California, San Francisco. In a 2009 study, Ryan focused on young adult LGBT people and looked at their self-reports of how much acceptance and support they received from their families as they came out and the current status of their health. For those who got little support, the adverse effects were large: 8 times the amount of suicidal ideation, 8.4 times the amount of suicide attempts, almost 6 times the amount of serious depression, and significant increases in illegal drug use and unprotected sex. These data point to the value of being able to identify these young adults and provide them with necessary counseling and other health services.

For the past 3 years, Callahan and his collaborators at UC Davis have been conducting Grand Rounds about LGBT health disparities and are in the process of rolling out some written educational materials for all of the system's providers. They are also surveying these providers to identify those who are willing to be listed as LGBT friendly. The UC Davis Health System is going to use the MyChart patient portal feature of the Epic[2] EHR to provide a questionnaire that patients can answer in the privacy of their own home that includes questions about sexual orientation and gender identity. It is also working with Epic to systematize where and how questions on sexual orientation and gender identity are located in the EHR. One idea is to tie the EHR to systematic prompts in response to certain answers to these questions. For example, when someone identifies as being transgender, the prompts would alert the care provider about what organ systems need to be monitored, what kind of preventive care needs to be presented, and how best they can be a good provider for that person. Callahan noted that Epic appears willing to make these changes to its EHR system.

In fact, said Denise Rasmussen, Epic is eager to receive input from users as to how to collect information on sexual orientation and gender identity in its EHR systems. Epic already has a field to capture information on sexual partners and runs reports and triggers alerts based on the sex of that partner. She noted, too, that at least some of the 260 organizations that use Epic have extended the sex category list to capture items related to gender identity and sexual orientation.

What would be helpful to Epic as an EHR vendor, she said, is a more standardized way to document information about sexual orientation and gender identity and more direction on where each birth sex, legal gender, and identified gender should be used in terms of billing, health information exchanges, clinical decision support, and preparing materials designed for patients. Epic is also concerned about who should document this information and who should be allowed to see it. For example, while it is obvious that the primary care physician should see this information, should the patient's chiropractor?

Regarding technical issues, Rasmussen said that Epic knows that it needs to create a new field or fields to represent the sex of a patient in a way that better captures birth sex, legal gender, and identified gender and then display that information in appropriate places in the EHR. The company is also interested in making alerts more meaningful, that it is alerting the primary care physician to the issues that are appropriate to the patient in front of them: telling a physician to order a prostate exam for a female-to-male transgender patient is not helpful.

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[2] Epic is a company that makes software, including EHRs, for health providers and facilities. They are one of several large commercial vendors.

DISCUSSION

When asked by Jessica Xavier from HRSA why the NHIS includes a question about gender identity rather than behavior, Miller answered that the NHIS is a vehicle for collecting basic health data and including questions about sexual behavior would not be appropriate in the survey. She added that the National Survey of Family Growth (NSFG) and the National Health and Nutrition Examination Survey (NHANES) are more appropriate venues for asking sexual behavior questions. Clinton Anderson of the American Psychological Association asked Miller about the significance of the placement of the sexual identity and the sexual behavior questions. Miller explained that the placement of questions is important because respondents get cued in to certain topics. For example, if a question focusing on reproduction is asked after a number of behavioral questions, a respondent may be cued up to provide a sexual behavior answer. In contrast, asking the question as part of a demographic section may cue respondents to indicate sexual identity rather than behavior. Aaron Tax asked Grant if he had been able to identify questions that worked better with older adults who do not always understand terms like "bisexual" and Grant indicated that he hopes to add a question developed by Miller and her colleagues to the CHIS in 2013 that would be easier for older adults to understand. He added that moving away from the terms heterosexual and homosexual may help better identify bisexual older adults.

There was some discussion around the term "sexual orientation." While Miller asserted during her talk that the term is not a measurable concept, Harvey Makadon pointed out that the term is commonplace and any attempt to substitute "sexual identity" or another term for it would be challenging. Miller responded that "sexual orientation" is a catchall phrase and does not provide constructs around which scientific questions can be developed. Makadon, however, said that he thought of orientation and identity as the same thing and questioned the need to abandon "sexual orientation."

In response to questions from Bates and John Knudsen, Keatley discussed the two-question approach. She explained that the CDC's one-question approach provided the following response options:

- male
- female
- transgender male to female
- transgender female to male

The two-question model asks about current gender identity separate from sex assigned at birth. She further explained that for the gender identity question, the suggested drop-down options are

- male
- female
- transgender woman
- transgender man
- gender queer
- open-ended

For the open-ended option, they ask people to specify so that they capture those data. Gal Mayer, medical director at Callen-Lorde Community Health Center in New York, who was participating by phone, e-mailed that at their community health center they do ask the sex at birth and current gender identity questions, the two-step process that Keatley discussed. However, they also ask sex listed on health insurance for billing purposes and that becomes the field for that particular purpose.

Leslie Calman noted that she was struck by the ambivalence that continually is expressed about who needs to know these data. On the one hand, she explained, we know that being a self-identified lesbian or gay man creates all kinds of health issues from childhood that relates to stress and discrimination. On the other hand, it is not clear who needs to know this information. For example, does a chiropractor need to know? Perhaps it is irrelevant. But maybe the patient’s back is out of whack because she is a lesbian; not because she has sex with women, but because of the stresses of being a lesbian. She noted that it has been a thread throughout the entire day, and it presents a dilemma for patients. Rasmussen responded that there was no clear answer. She theorized that it is a generational divide, with younger people more open to sharing this information with a wider range of care givers and older people being more hesitant to make these data widely available. Callahan added that as the culture shifts, he expects this will be less of a problem. Shane Snowdon responded to this by saying that in her opinion it was not only older people who were hesitant to disclose their sexual orientation, but younger people as well. She noted that San Francisco is an LGBT-friendly city, but that her experience working in a medical center there highlights that discrimination for sexual and gender minorities exists.

In response to a question from Harvey Makadon about how Epic is working with clients to coordinate efforts to develop a common approach to collecting sexual orientation and gender identity data in EHRs, Rasmussen explained that Epic had an LGBT breakout group at its user group meeting in September 2012. This user group had 10 to 15 organizations participating and there was a good exchange of information about what each organization was doing and how Epic might approach this problem until standards are developed. This is a work in progress, she added, and this group plans to meet frequently to provide advice to Epic. "As a vendor, we hate to push something out that is then going to change. If we've pushed that out, all of the different organizations will be collecting this information, and then potentially have to collect it again," she said.

Ignatius Bau asked if sexual orientation was a field that users have customized and added to Epic products. Rasmussen said requests for adding a field on sexual orientation had come up and that it was relatively easy to do. She noted that the workflow around transgender documentation was more complicated. In response to a question about vendors working together around the issue of standards for EHRs, Rasmussen replied that while a standard that all vendors could follow would be ideal, what will likely happen is that each vendor will develop their own standards and then work together to map fields from each other's EHRs so that they can exchange data accurately. This is the approach vendors have used in the past.

6

Closing Remarks

Prior to offering his thoughts, Ignatius Bau, chair of the planning committee, opened the floor for final comments. Barbara Warren said that it was gratifying to see the people in the room working on this issue. She encouraged those who are moving ahead to pilot programs and document their experiences. It will be helpful, she added, to understand what is working and where the challenges are. This will not only help those currently in the field but will assist eventually in disseminating these lessons to others. Kellan Baker of the Center for American Progress cautioned against entering a new regime of "Don't Ask, Don't Tell" in health care. He noted that people did not have to choose between preparing patients to disclose their sexual orientation and gender identity and training providers and health staff to elicit this information, but could do both. He encouraged workshop participants to stay focused on both the training component and the data collection component, so that "we arrive at a place where providers know that they should ask and patients feel like they can tell." Finally, Kathryn Wetherby from the Substance Abuse and Mental Health Services Administration (SAMHSA) reminded everyone that SAMHSA and other federal agencies are actively working on data segmentation and standardization and she encouraged those working on this issue to let EHR vendors know which data fields would be helpful.

Bau thanked everyone for their participation and then listed the themes that struck him as important during the presentations and discussions:

1. LGBT people experience significant health care disparities and the Obama administration and HHS are committed to identifying and addressing those disparities through the use of data.
2. To address health care disparities in the LGBT population, it is important to identify and understand the barriers that these Americans face and to determine if nondiscrimination policies meant to eliminate those barriers are truly protecting LGBT individuals when they seek health care in real-world settings.
3. "If you are not counted, you do not count." The health of every individual depends on disclosing sexual orientation and gender identity, so it is important to educate LGBT people about the need for them to self-identify while at the same time creating a safe environment conducive for doing so.
4. In addition to technical issues about the questions they need to ask their patients, health care providers have their own fears and biases that will require a significant amount of education to address, both on an individual and institutional level.
5. Employee resource groups in an institution can become a powerful and important internal force of change.
6. The use of language in questions about sexual orientation or identity and gender identity is becoming more precise and that will improve the quality of the resulting data collected using these questions.
7. It is important as a matter of principle that data is always collected through a self-identification process and that there is always an opt-out option available to patients.
8. Though the questions or processes for data collection have room for improvement, data collection should start now to better understand the health care issues experienced by LGBT people.

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Appendix A

Workshop Agenda

National Academy of Sciences Building
2101 Constitution Avenue, NW, Washington, DC

Friday, October 12, 2012

8:30-8:45 **Welcome and Opening Remarks**
Ignatius Bau, Planning Committee Chair

8:45-9:25 **Federal Perspective**

Dr. Donald Moulds
Acting Assistant Secretary for Planning and Evaluation
Department of Health and Human Services

Dr. Sylvia Fisher
Director, Office of Research and Evaluation

Dr. Yael Harris
Director, Office of Health Information Technology and Quality
Health Resources and Services Administration

Mr. Robert Tagalicod
Director, Office of eHealth Standards and Services
Centers for Medicare and Medicaid Services

9:25-9:50 **Clinical Rationale for the Collection of Sexual Orientation and Gender Identity Data**

Dr. Harvey Makadon
Clinical Professor of Medicine, Harvard Medical School

9:50-10:05 **Break**

10:05-12:00 **Existing Practices**
Moderator: Harvey Makadon, Planning Committee

Ms. Shane Snowdon
Director, LGBT Health & Aging Program
Human Rights Campaign Foundation

Dr. John Knudsen
Chief, LGBTI Practice Task Force, Mayo Clinic

Dr. Ronald Copeland
President & Executive Medical Director, Ohio Permanente Medical Group

Dr. Alex Gonzalez
Medical Director, Fenway Health

Dr. Jesse Ehrenfeld
Assistant Professor, Biomedical Informatics, Vanderbilt University

Discussion

12:00-12:30 **Supporting Providers in the Collection of Data**
Dr. Robin Weinick
Associate Director, RAND Health

12:30-1:15 **Lunch Break**

1:15-2:25 **Developing Standardized Questions**
Panel moderator: Nancy Bates, Planning Committee

Ms. JoAnne Keatley
Director, Center of Excellence for Transgender Health at University of California, San Francisco

Dr. Kristen Miller
Director, Question Design Research Lab, National Center for Health Statistics

Dr. David Grant
Director, California Health Interview Survey

Discussion

2:25-3:25 **Technical Considerations**
Moderator: Ignatius Bau, Planning Committee Chair

Dr. Edward Callahan
Professor, Family and Community Medicine, University of California, Davis, Health System

Ms. Denise Rasmussen
Clinical Informatics, Epic Systems Corporation

Discussion

3:25-3:35 **Break**

3:35-4:30 **Confidentiality and Privacy Concerns**
Moderator: Dan Kasprzyk, Planning Committee

Ms. Sue McAndrew
Deputy Director, Health Information Privacy, Office for Civil Rights
Department of Health and Human Services

Ms. Deven McGraw
Director, Health Privacy Project, Center for Democracy & Technology

Discussion

4:30-5:10 **Supporting Patients in the Collection of Data**
Ms. Beverly Tillery
Director, Community Education, Lambda Legal

5:10-5:30 **Discussion and Comments**
Ignatius Bau, Planning Committee Chair

5:30 **Adjourn**

Appendix B

Registered Workshop Attendees

Clinton Anderson, American Psychological Association
Kellan Baker, Center for American Progress
Angela Bates, Department of Health and Human Services
Judith Bradford, Fenway Health
George R. Brown, Mountain Home VA Medical Center
Diane Bruessow, Gay and Lesbian Medical Association
Sean Cahill, The Fenway Institute
Leslie Calman, Mautner Project: The National Lesbian Health Organization
Erin Clark, Johns Hopkins University
Richard Clarkson, Callen-Lorde Community Health Center
Chipper Dean, Substance Abuse and Mental Health Services Administration
Emily DeCoster, Health Resources and Services Administration
Christina Dragon, Health Resources and Services Administration
Prashila Dullabh, National Opinion Research Center
Ted Eytan, DC Kaiser Permanente
Rebecca Fox, Wellspring Advisors
Bob Freeman, National Institute on Alcohol Abuse and Alcoholism
Candace Gibson, National Latina Institute for Reproductive Health
Alison Gill, The Trevor Project
William Grace, Office of AIDS Research, National Institutes of Health
Joseph Goulet, Department of Veterans Affairs
Heron Greenesmith, Family Equality Council
James Halloran, Department of Veterans Affairs
Justin Hentges, National Institutes of Health

Hutson Inniss, National Coalition for LGBT Health
Jesse Joad, Gay and Lesbian Medical Association
Enid Light, National Institutes of Health
Kali Lindsey, National Minority AIDS Council
Rachel Logan, North American Management
Natalya Maisel, VA Palo Alto Health Care System
Kristin Mattocks, VA Central Western Massachusetts Healthcare System
Alexis Matza, U.S. Veterans Administration
Gal Mayer, Callen-Lourde Community Health Center
Castilla McNamara, National Institute on Deafness and Other Communication Disorders, National Institutes of Health
Phillip Melemed, Total Health Care, Inc.
Jonathan Moore, Department of Health and Human Services
Gwendolyn Moscoe, PeaceHealth Southwest Medical Center
Susan Newcomer, National Institute of Child Health and Human Development
Katherine Nicodemus
Daniel Nugent, National Minority AIDS Council
Kathleen O'Leary, National Institutes of Health
Jennifer Park, Office of Management and Budget
Patrick Paschall, National Gay and Lesbian Task Force
A. J. Pearlman, Department of Health and Human Services
Johnette Peyton, North American Management
Eva Powell, National Partnership for Women & Families
Susan Queen, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services
Lydia Remington, North American Management
Leo Rennie, American Psychological Association
James Scanlon, Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services
Hillary Schneller, National Women's Law Center
Carl Streed, Jr., American Medical Association
Molly Sugrue, William F. Ryan Community Health Center
Cassandra Surber, Department of Health and Human Services
Nathan Tatro, American Psychological Association
Aaron Tax, Services and Advocacy for GLBT Elders
Geri Tebo, Office of Disease Prevention and Health Promotion, Department of Health and Human Services
Kate Tipping, Substance Abuse and Mental Health Services Administration
Helen Tran, Asian American Justice Center
Hector Vargas, Gay and Lesbian Medical Association
Barbara Warren, Beth Israel Medical Center
Isaiah Webster, National Association of State and Territorial AIDS Directors

Elizabeth Wehr, National Institute of Child Health and Human Development
Kathryn Wetherby, Substance Abuse and Mental Health Services Administration
Amy Wilson-Stronks, Wilson-Stronks, LLC
Gooloo Wunderlich, Committee on National Statistics, National Research Council
Jessica Xavier, Health Resources and Services Administration, HIV-AIDS Bureau
Vera Yakovchenko, Department of Health and Human Services
Nora Yates, The New York State Office of Alcoholism and Substance Abuse Services

Appendix C

Biographical Sketches of Workshop Speakers

Edward J. Callahan, Ph.D., is the Associate Dean for Academic Personnel & Professor of Family and Community Medicine, University of California, Davis, School of Medicine. Since 2009, Dr. Callahan has led the Task Force for Inclusion of Sexual Orientation and Gender Identity in the Electronic Health Record at the University of California, Davis. As a scholar, Dr. Callahan has studied physician-patient interaction and health outcomes and as an educator he developed educational efforts in Culture in Medicine and early efforts to understand and reduce health care disparities.

Ronald L. Copeland, M.D., FACS, is President and Executive Medical Director for the Ohio Permanente Medical Group. Dr. Copeland is the President and Executive Medical Director of the Ohio Permanente Medical Group, with executive responsibility for all clinical care services provided to Ohio Kaiser Permanente members. He is a Board Certified General Surgeon, a Fellow of the American College of Surgeons, and continues a limited practice. After 15 years in this role, effective January 1, 2013, Dr. Copeland will move from Cleveland, Ohio, to the California Bay area to become Senior Vice President, National Diversity Strategy and Policy and Chief Diversity Officer for Kaiser Foundation Hospitals and Kaiser Foundation Health Plan, Inc. out of the Program Office in Oakland, California. A native of Rochester, New York, Dr. Copeland earned his B.A. degree from Dartmouth College and his medical degree from the University of Cincinnati Medical College. He completed his residency in General

Surgery at the State University of New York, Upstate Medical Center in Syracuse. He joined Kaiser Permanente in 1988 after a 6-year honorable tour of duty in the U.S. Air Force Medical Corps. Dr. Copeland serves on several Kaiser Permanente national committees, including Co-Chair, Kaiser Permanente National Diversity Council, KP Institute for Culturally Competent Care. Additionally, he serves on the boards of several not-for-profit community organizations, including the Cleveland Museum of Natural History, The Cleveland Free Clinic, and the Minority Organ Tissue and Transplant Education Program (MOTTEP, Chairman). He has previously served on the Greater Cleveland and National American Heart Association Boards and currently serves as a Power to End Stroke Ambassador, as well as a member of the AHA Diversity Leadership Committee. He is a frequent lecturer on leadership development, culturally competent care, and community health issues.

Jesse M. Ehrenfeld, M.D., M.P.H., is an Assistant Professor at Vanderbilt University Medical School in the Departments of Anesthesiology and Biomedical Informatics. Dr. Ehrenfeld is a board-certified anesthesiologist with an extensive background in clinical research, advocacy, and health care policy. He serves as Director of the Center for Evidence-Based Anesthesia, Director of the Perioperative Data Systems Research Group, and Medical Director for Perioperative Quality at Vanderbilt University Medical School. He is also a co-director of the Vanderbilt Program for LGBTI Health, and a Course Director for both the School of Medicine's Continuity Clinical Experience and the immersion course titled "Sex, Sexuality, and Sexual Health." Dr. Ehrenfeld's research and policy interests include biomedical informatics and the application of information technology to increase patient safety and reduce health disparities. His research has been funded by NIH, the Anesthesia Patient Safety Foundation, and the Foundation for Anesthesia Education and Research. His work has led to the presentation of more than 100 abstracts at national/international meetings and the publication of dozens of manuscripts in high-impact journals. He has co-authored 10 clinical textbooks. For the past decade, Dr. Ehrenfeld has advocated on behalf of LGBTI patients, students, and trainees in his role as Chair of the Massachusetts Committee on LGBT Health, Chair of the Massachusetts General Hospital LGBT Employee Resource Group, a member of the Board Committee on Quality at Fenway Community Health Center, and more recently, as co-director of the Vanderbilt University Program for LGBTI Health and a member of the Association of American Medical College's LGBTI Liaison Group. Dr. Ehrenfeld holds an M.P.H. from the Harvard School of Public Health, and an M.D. from The University of Chicago. He completed residency and served as informatics fellowship director for the Department of Anesthesiology at the Massachusetts General Hospital in Boston. Dr. Ehrenfeld has received numerous teaching awards and serves on several distinguished national committees including the American Society of Anesthesiologists Standards & Practice Parameters Committee, the *New England Journal of Medicine* Publications Committee, and the American Medical Association Public Health Committee. Dr. Ehrenfeld, a Lieutenant Commander in the U.S. Navy, also serves as a medical reserve officer.

Sylvia Fisher, Ph.D., is the Director in the Office of Research and Evaluation in the Office of Planning, Analysis and Evaluation, at the Health Resources and Services Administration (HRSA). In her position, Dr. Fisher manages evaluations of diverse federal health programs about health care workforce, maternal and child health, and primary health care services. Formerly a research psychologist at the Bureau of Labor Statistics, Office of Survey Methods Research, she specialized in the application of cognitive methods to improve the quality of large government surveys. As Director of Evaluation in the Child, Adolescent and Family Branch at SAMHSA from 2004 to 2010, Sylvia was project officer for the national evaluation of the systems of care program. She has been a counselor and psychological evaluator with children and adults with diverse clinical needs; has taught graduate and undergraduate courses in measurement, evaluation, systems change, and psychological assessment at several higher education institutions; and has presented and published in numerous academic and professional venues. Her extensive efforts to improve the health and well-being of LGBT populations include serving on both the *Healthy People 2020* Committee on LGBT populations and the National Action Alliance on Suicide Prevention LGBT Task Force. While at SAMHSA, she launched and chaired a national workgroup to address the needs of youth in systems of care who are LGBT and their families. She received the Leadership Award for Outstanding Volunteer Service from the Lesbian Services Program of the Whitman-Walker Clinic in Washington, DC. Sylvia is lead editor of the recently published volume *Improving Emotional and Behavioral Outcomes for LGBT Youth: A Guide for Professionals*.

Alex Gonzalez, M.D., M.P.H., is the Medical Director at Fenway Health in Boston, Massachusetts. As Medical Director of Fenway Health, Alex oversees a staff of more than 50 physicians, physician assistants, nurse practitioners, nurses, medical assistants, and clerical staff in the delivery of medical care to Fenway's approximately 17,000 patients. Programs within the Medical Department include outpatient primary care; specialty clinics in alternative insemination, nutrition, diabetes, HIV, pulmonology, podiatry, general infectious disease, transgender health, women's health, and male and female colposcopy; complementary therapy services in massage, chiropractic, and acupuncture; nursing programs such as team-based nursing, the weekly hepatitis immunization and STD clinic, and the patient triage line; and community-based programs such as the biannual mammogram van. Alex obtained a bachelor of science degree in biology from Tulane University and a combined medical and public health degree from the University of Miami Miller School of Medicine. He completed his internship and residency training in Primary Care Internal Medicine at Beth Israel Deaconess Medical Center. He is currently an Instructor of Medicine at Harvard Medical School, and he has worked at Fenway since 2005.

David Grant, Ph.D., is the Director of the California Health Interview Survey (CHIS) at the University of California, Los Angeles, Center for Health Policy Research. Dr. Grant joined the CHIS team in 2001 and became project director in 2006. He is responsible for all aspects of CHIS, including the planning, data collection, and dissemination phases of CHIS. For 20 years, Dr. Grant has been involved in applied social research at academic and public agencies. In addition to population health and survey methodology, his research has focused on urban poverty and demography. Dr. Grant received his undergraduate degree at the University of Michigan and his master's and doctorate degrees (1998) in sociology at UCLA.

Yael Harris, Ph.D., MHS, is the Director in the Office of Health IT & Quality at the Health Resources and Services Administration (HRSA). The Office of Health IT & Quality provides technical assistance, support, and leadership across the agency to support improved care for safety net populations through the effective use of health information technology. Prior to her arrival at HRSA, Dr. Harris led the Office of Evaluation within the Office of the National Coordinator for Health Information Technology (ONC), initiating and overseeing the evaluation of ONC's grant programs to support and advance the adoption of electronic health records. She also led ONC's national measurement of EHR adoption in both ambulatory and inpatient settings. Dr. Harris currently co-chairs a cross federal Telehealth workgroup and a cross federal mobile health workgroup and represents the safety net community on the Health IT Policy Committee's Meaningful Use workgroup where she focuses on quality improvement and population health. Prior to joining the ONC, Dr. Harris worked for the Centers for Medicare & Medicaid Services where she led efforts on measurement and quality improvement in long-term and post acute care. Before joining the federal government, Dr. Harris worked for a MedPAC, a congressional advisory body, Georgetown University's Institute for Health Care Policy & Research, and served as an adviser to senior staff on the House Ways and Means Subcommittee on Health. She holds a doctorate in public policy from the University of Maryland and a master's degree in health sciences from Johns Hopkins University. Dr. Harris is an associate professor at the Erickson School of Aging where she teaches courses on technology and aging services.

Joanne Keatley, MSW, is the Director at the Center of Excellence for Transgender Health, University of California, San Francisco (UCSF). JoAnne was born in Mexico City and became a U.S. citizen in 1986. Ms. Keatley received a master of social welfare degree from the University of California, Berkeley. Beginning at CAPS in 1999, JoAnne directed numerous NIH transgender research projects, developed and directed transgender intervention projects, and is a recognized international expert in transgender health and HIV issues. Currently she directs the Center of Excellence (CoE) for Transgender Health and is also the Minority AIDS Initiative Program Manager at the Pacific AIDS Education and Training Center (PAETC) at UCSF. JoAnne has served on the UCSF Chancellors Advisory committee on LGBT (CACLGBT) issues since 2000 and leads the CACLGBT transgender subcommittee. In addition, she has consulted on transgender health at the Centers for Disease Control and Prevention (CDC), Health Resources and Services Administration (HRSA), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In 2010, she was invited to speak on transgender issues at the White House Office of National AIDS Policy (ONAP) meeting on HIV and Aging. As Director of the CoE for Transgender Health, Ms. Keatley is responsible for overseeing all aspects of the CoE scope of work. She develops the infrastructure to support successful and sustainable transgender programs, provides day-to-day leadership of CoE staff, oversees the National Advisory Board, supervises the design and implementation of all educational and marketing materials, identifies potential funding sources, and assures the quality of all deliverables.

John Knudsen, M.D., is the Chair of the LGBTI Practice Task Force at the Mayo Clinic. The Mayo Clinic LGBTI Practice Task Force which was formed in January 2012 by the Mayo Clinic Rochester Clinical Practice leadership to research, assess, and develop recommendations that facilitate building and sustaining an inclusive and welcoming environment for LGBTI patients and their families who seek medical care from a Mayo Clinic facility. This effort is coordinated with the Mayo Clinic Office of Diversity and Inclusion to address specific strategic goals, including increasing patient diversity and identifying and eliminating health disparities while becoming a national leader in the science and promotion of health equity. The effort was initiated following a presentation from the LGBTI Mayo Clinic Employee Resource Group to clinical practice leadership identifying specific patient care related issues encountered by Mayo Clinic LGBTI employees and their families while seeking care at Mayo Clinic. Dr. Knudsen's professional background includes Assistant Professor of Radiology, Mayo Clinic College of Medicine; Staff Radiologist at Mayo Clinic for 21 years with subspecialty practice focus in Ultrasound and Abdominal Imaging; and Former Associate Chair for Clinical Practice in the Department of Radiology at Mayo Clinic Rochester, Minnesota. He has spent 12 years at Mayo Clinic in Rochester, Minnesota (2000-present), and 9 years at Mayo Clinic in Jacksonville, Florida (1991-2000). Dr. Knudsen completed his residency training at Mayo Clinic in Rochester, Minnesota (1986-1990) and Abdominal Imaging fellowship at Duke University Medical Center (1990-1991).

Harvey J. Makadon, M.D., is Clinical Professor of Medicine at Harvard Medical School and Director of the National LGBT Health Education Center at The Fenway Institute, a division of Fenway Health, Boston. He is a member of the Division of General Medicine at Beth Israel Deaconess Medical Center in Boston, where he has had a primary care practice and served as Vice President of Medical Affairs. He is currently the LGBT Advisor in Harvard Medical School's Office for Recruitment and Multicultural Affairs. Dr. Makadon is the lead editor of *The Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health*, published by the American College of Physicians in 2008. In addition to writing numerous articles and chapters related to LGBT health, he served on the Committee on LGBT Health Issues and Research Gaps and Opportunities of the Institute of Medicine of the National Academy of Sciences for *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding* in March 2011. He spoke at a White House Conference on HIV and the LGBT Community in April 2012. Dr. Makadon was the recipient of the Community Service Award (2000) and the Harold Amos Diversity Award (2008) at Harvard Medical School; an Achievement Award from the Gay and Lesbian Medical Association; and the Michael Tye Leadership Award (2004) from Fenway Health.

Sue McAndrew, J.D., is the Deputy Director for Health Information Privacy at the Office for Civil Rights (OCR) in the U.S. Department of Health and Human Services (HHS). As Deputy Director, Ms. McAndrew has responsibility for implementing and enforcing the Privacy and Security Rules issued pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA). She also has the responsibility for the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH) that sets forth a plan for promoting health information technology and electronic health information exchange to improve quality of care and establish a foundation for health care reform. Ms. McAndrew has worked primarily on the HIPAA Privacy Rule for HHS since May 2000 and is the senior adviser to the director of OCR on health information privacy and technology matters. In 2006, the Secretary of HHS delegated to OCR the responsibility for enforcement of the confidentiality protections for patient safety work product under the Patient Safety and Quality Improvement Act of 2005 (PSQIA); in May 2008, the Genetic Information Nondiscrimination Act (GINA) that prohibits most health plans from using or disclosing genetic information for underwriting purposes was added; and in July 2009, responsibility for the HIPAA Security Rule was transferred from CMS to OCR. The HIP Division leads these new enforcement efforts within OCR. Ms. McAndrew has more than 20 years of federal government experience. Ms. McAndrew received her J.D. from Georgetown University Law Center and, prior to joining HHS, practiced law in the District of Columbia, including 12 years at Wilmer, Cutler & Pickering (now WilmerHale).

Deven McGraw, J.D., is the Director of the Health Privacy Project at the Center for Democracy & Technology. Ms. McGraw is active in efforts to advance the adoption and implementation of health information technology and electronic health information exchange to improve health care. She was one of three persons appointed by Kathleen Sebelius, the Secretary of the U.S. Department of Health and Human Services (HHS), to serve on the Health Information Technology (HIT) Policy Committee, a federal advisory committee established in the American Recovery and Reinvestment Act of 2009. She co-chairs the Committee's Privacy and Security "Tiger Team" and serves as a member of its Meaningful Use, Information Exchange, and Strategic Plan Workgroups. She also served on two key workgroups of the American Health Information Community (AHIC), the federal advisory body established by HHS in the Bush administration to develop recommendations on how to facilitate use of health information technology to improve health. Specifically, she co-chaired the Confidentiality, Privacy, and Security Workgroup and was a member of the Personalized Health Care Workgroup. She also served on the Policy Steering Committee of the eHealth Initiative and now serves on its Leadership Council. She is also on the Steering Group of the Markle Foundation's Connecting for Health multi-stakeholder initiative. Ms. McGraw has a strong background in health care policy. Prior to joining CDT, Ms. McGraw was the Chief Operating Officer of the National Partnership for Women & Families, providing strategic direction and oversight for all of the organization's core program areas, including the promotion of initiatives to improve health care quality. Ms. McGraw also was an associate in the public policy group at Patton Boggs, LLP, and in the health care group at Ropes & Gray. She also served as Deputy Legal Counsel to the Governor of Massachusetts and taught in the Federal Legislation Clinic at the Georgetown University Law Center. Ms. McGraw graduated magna cum laude from the University of Maryland. She earned her J.D., magna cum laude, and her L.L.M. from Georgetown University Law Center and was Executive Editor of the *Georgetown Law Journal*. She also has a master of public health from Johns Hopkins School of Hygiene and Public Health.

Kristen Miller, Ph.D., is the Director at the Question Design Research Laboratory, National Center for Health Statistics (NCHS), at the CDC. Dr. Miller is a senior methodologist whose writings have focused on question comparability, including question design and equivalence for lower SES respondents and the improvement of evaluation methods for cross-cultural and cross-national testing studies. Through her tenure at NCHS, she has led collaborative international testing projects with collaborators including the European Social Survey, the World Bank, the World Health Organization, and the United Nations. Dr. Miller holds a Ph.D. in Sociology from the University of Delaware.

Don Moulds, Ph.D., is the Acting Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services. In August 2012, Don Moulds assumed the role of Acting Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services after serving as Principal Deputy Assistant Secretary since July 2009. Dr. Moulds is currently the Department's liaison to the U.S. Interagency Council on Homelessness and to the White House on the President's Strong Cities, Strong Communities initiative. He works closely with the Department of Housing and Urban Development on numerous initiatives affecting common target populations, including homeless individuals and families, and is overseeing multiple case studies and demonstrations aimed at identifying successful interventions for homelessness. He is currently overseeing the development of the National Strategy to End Alzheimer's Disease, and is a member of the Federal Advisory Council on Alzheimer's Research, Care, and Services. Prior to becoming Principal Deputy Assistant Secretary, Dr. Moulds served as Vice President for the California Medical Association's Center for Medical and Regulatory Policy. In that capacity, he oversaw the development of the association's health policy initiatives, guided its positions on legislation, and oversaw all of its regulatory work. From 2004 through 2007, Dr. Moulds was the director of the Senate Office of Research, the bipartisan research arm of the California State Senate. There he was responsible for developing the Senate's research agenda on everything from health care to water policy, overseeing the Senate's policy-related publications, and managing the Senate's relations with the federal government. From 1998 through 2004, Dr. Moulds served as Principal Consultant to Senate President Pro Tempore, John Burton, and was the lead staffer in the Senate on numerous issues, including insurance, health system reform, and select labor issues. Dr. Moulds has served on numerous boards and commissions, including the State Compensation Insurance Fund Board, the Advisory Board of the California Health Policy Research Council, the Advisory Board of the Sacramento Campus of the University of Southern California, the Advisory Committee of the Workers Compensation Research Institute, the Steering Committee of the University of California's Policy Research Center, and the State of California Health Insurance Portability and Accountability Act Implementation Advisory Board. He holds a B.A. degree from Bates College and M.A. and Ph.D. degrees in philosophy from the University of Illinois. He has taught philosophy and ethics courses at the University of Illinois, Harvard University, and California State University, Sacramento.

Denise Rasmussen, R.N., is a nurse on the clinical informatics team at Epic. Her nursing background is in pediatrics and her background with Epic is in implementation. She has been with Epic for 10 years and has implemented the inpatient software at a variety of organizations, including Kaiser Permanente and the Cleveland Clinic. One of her many roles is to work with the development team on driving the future of the applications.

Shane Snowdon works in on the LGBT Health & Aging Program at the Human Rights Campaign. The Human Rights Campaign, which administers the national Healthcare Equality Index for hospitals and other facilities, is the largest LGBT organization in the United States. Shane previously founded and led the Center for LGBT Health and Equity at the University of California, San Francisco, for 14 years the nation's only LGBT office in a health care or health education setting. She has provided LGBT health training and consulting for hundreds of hospitals, health professional schools, and other health organizations throughout the country. She has also written extensively on LGBT health, serving as Project Adviser for The Joint Commission's *LGBT Field Guide* (2011) and as lead author of *Recommendations for LGBT Equity & Inclusion in Health Professions Education* (2012). Shane has designed and convened numerous LGBT health meetings, including the annual LGBTQI Health Forum for Health Professional Students and the National Summit on LGBT Concerns in Medical Education for faculty and administrators. She also serves on the boards of the National LGBT Health Coalition, the Pacific AIDS

Education & Training Center, and the Alliance Health Project. Shane's groundbreaking work has received extensive recognition, including the Health Achievement Award of the Gay & Lesbian Medical Association, the Transgender Law Center Ally Award, the KQED Local Hero Award, and the University of California Award for Exceptional University Service and Award for GLBT Leadership.

Robert Tagalicod is the Director of the Office of eHealth Standards and Services, at the Centers for Medicare and Medicaid Services and its Senior Agency Official for Privacy. In this capacity, he leads and directs a multi-billion-dollar effort—the Medicare and Medicaid Electronic Health Records (EHRs) Incentive Program—to promote the adoption and meaningful use of EHRs in the United States as part of health care transformation: better care, better health, at lower cost without compromising quality. In addition, he oversees the implementation of Administrative Simplification (i.e., Operating Rules for HIPAA Transactions), including ICD-10. Previously, Rob was the Deputy Director and Acting Director of CMS's Office of Communications and also served as Special Assistant in the Office of the Administrator, assisting with oversight and reporting on key ARRA initiatives such as HITECH, Prevention, and Comparative Effectiveness Research. Rob brings his 20+ years of management practice in the areas of health policy, program operations, communications, and finance, as well as his experience in project and performance management of several health initiatives for state and county health systems in California and the University of California, San Francisco.

Beverly Tillery is the Director of Community Education and Advocacy at Lambda Legal. Lambda Legal is the oldest and largest national legal organization committed to achieving full recognition of the civil rights of lesbians, gay men, bisexuals, transgender people, and people with HIV. Tillery coordinates Lambda Legal's education and outreach work that actively engages the LGBT community and its allies in the ongoing fight for equality and justice. Through community forums, educational programs, and by building relationships with other organizations, Lambda Legal seeks to build a greater understanding of the issues it addresses through its litigation. Lambda Legal informs people about LGBT issues and rights and then gives them the tools to take individual and collective action to gain full equality of LGBT people and people with HIV in our society. Tillery has dedicated the past 15 years of her career to fighting all forms of oppression and working for social and economic justice through community-based direct action organizing, labor organizing, human rights and political advocacy, and popular education. Prior to joining the staff at Lambda Legal, she coordinated the Immigrant Worker Rights

Project at the New York Coalition for Occupational Safety and Health. Tillery also worked as the Outreach Coordinator at Amnesty International where she developed a national field organizing program, and at the Service Employees International Union where she lead organizing campaigns to help health care workers form a union. She has designed and facilitated hundreds of trainings and workshops on a variety of subjects including organizing skills. She has also served as the President of the Board of the National Organizer's Alliance, a national organization of social justice organizers.

Robin M. Weinick, Ph.D., is the Associate Director at RAND Health. Dr. Weinick's specific areas of responsibility include RAND Health's contract business line, managing policy and processes related to bid decisions, procurement, and administration of government and nonprofit contracts, with an emphasis on contracts with the Department of Health and Human Services. She also plays a key role in research staff recruitment and development, as well as business planning. As RAND Health's senior leader on the East Coast, she frequently represents the unit in discussions with key contacts in government agencies, nonprofits, and nongovernmental entities based in the National Capitol region. Dr. Weinick is also a Senior Social Scientist at RAND. Her research focuses on improving the quality of medical care in the United States, with emphasis on developing and evaluating practical tools for use in the health care system, the development and use of measures for monitoring the status of health care, and supporting their use in driving both health system improvement and public policy initiatives. Dr. Weinick brings an extensive background in a wide variety of issues related to racial/ethnic disparities, including projects designed to provide guidance to the Commonwealth of Massachusetts regarding implementing disparities provisions of its Medicaid pay-for-performance program, and studies of the impact of pay-for-performance on disparities, and of quality improvement efforts related to reducing disparities in small physician practices. A previous project resulted in lead authorship of *Creating Equity Reports: A Guide for Hospitals*, which provides tools to help hospitals assess and understand racial/ethnic disparities in their performance measures. Dr. Weinick has played a national role in advancing health care provider collection of race/ethnicity data from patients, and has conducted extensive training of hospital registrars in this area. Prior to joining RAND, Dr. Weinick was a Senior Scientist in the Institute for Health Policy at Massachusetts General Hospital and an Assistant Professor of Medicine at Harvard Medical School. She has a 10-year history of federal service in a variety of positions at the Agency for Healthcare Research and Quality, and holds a Ph.D. from the Johns Hopkins University School of Public Health.