



Asking Patients Questions about Sexual Orientation and Gender Identity in Clinical Settings

A Study in Four Health Centers

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This study provides evidence that integrating sexual orientation and gender identity data collection into the Meaningful Use requirements is both acceptable to patients and feasible using existing SOGI question designs.

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Introduction

Executive Summary

The Institute of Medicine, the U.S. government's Healthy People 2020 strategy, and the Joint Commission on Accreditation of Healthcare Organizations are among many entities that have recommended asking sexual orientation and gender identity (SOGI) questions in clinical settings and including such data in Electronic Health Records (EHRs). Many health care providers are in the process of considering how to do this.¹ In order to better understand how a diverse group of people would respond when these questions are asked, several hundred patients at four health centers across the United States were surveyed about asking SOGI questions in their health center. This sample was predominantly heterosexual, racially diverse, geographically broad (South, Mid-West, Mid-Atlantic, and Northeast regions), and comes from both rural and urban health centers. There was a strong consensus among patients surveyed—heterosexual and non-transgender as well as lesbian, gay, bisexual, and transgender (LGBT)—about the importance of asking questions about sexual orientation and gender identity. Most of the LGBT respondents thought that the questions presented on the survey allowed them to accurately document their sexual orientation and gender identity. While some LGBT patients would ask the questions differently, most agreed or strongly agreed that the options presented addressed their needs.

This validation of SOGI questions in an array of clinical settings with a diverse

population of patients has important implications for public policy. The Centers for Medicare and Medicaid Services and the Office of the National Coordinator of Health Information Technology within the U.S. Department of Health and Human Services are currently considering whether to include SOGI data collection in the Stage 3 guidelines for the incentive program promoting meaningful use of electronic health records. This study provides evidence that integrating SOGI data collection into the meaningful use requirements is both acceptable to patients and feasible using existing SOGI question designs.

STUDY PURPOSE

The Institute of Medicine report *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, which was published in 2011, highlighted health disparities experienced by LGBT people and emphasized the need to routinely collect data on sexual orientation and gender identity in health care settings as one strategy to end LGBT invisibility in health care and eliminate disparities. While questions on SOGI are asked in a variety of settings, there is a need to specifically validate measures for use in EHRs and in clinical settings. The aim of this study, which surveyed diverse patient groups at four community health centers (CHCs) to assess the acceptability and feasibility of asking SOGI questions as part of registration, is to evaluate a set of standardized SOGI questions that can be incorporated into EHRs at CHCs and potentially other health care organizations. The set of standardized SOGI questions could allow for pooling of data in order to analyze the health needs of LGBT populations, evaluate the quality of care LGBT people receive, and foster opportunities for understanding, reducing, and ultimately eliminating LGBT health disparities.

STUDY OBJECTIVES

Objective 1: Collaborate with existing CHC research network infrastructures to conduct patient surveys that assess the patient experience of and satisfaction with existing SOGI questions.

Objective 2: Recommend a set of SOGI questions in clinical settings that can be tested in future research projects involving larger patient populations and greater diversity of CHCs and other health care organizations.

The Community Health Applied Research Network: A Description of Study Participants

The Community Health Applied Research Network (CHARN), funded by the Health Resources and Services Administration (HRSA) starting in 2010, seeks to build capacity to conduct meaningful and rigorous multi-site Patient Centered Outcomes Research (PCOR) that will lead to better patient care at federally-supported community health clinics with underserved patient populations. CHARN is comprised of 17 community health centers in nine states that served 519,636 individual patients in 2010. CHARN represents enormous potential for safety-net focused research that has important public health significance.

The Fenway Institute (TFI) at Fenway Health functioned as the lead site for this study. The Fenway Institute Research Node is one of four CHARN nodes funded to develop infrastructure for PCOR designed to improve the care and treatment of individuals in a network of community health centers. Participating TFI Clinical Affiliate Sites are Beaufort Jasper Hampton Comprehensive Health Services (Beaufort) in rural South Carolina; Chase Brexton Health

Center (Chase Brexton) in Baltimore and Columbia, Maryland; and Fenway Health in Boston. In addition, Howard Brown Health Center, another CHARN affiliate site located in Chicago, was also involved in the study. The Fenway CHARN investigators developed the study proposal with input from the three CHARN clinical affiliate sites and the Center for American Progress, which also contributed support for the study.

Fenway Health: The mission of Fenway Health is to enhance the wellbeing of the lesbian, gay, bisexual and transgender community and all people in our neighborhoods and beyond through access to the highest quality health care, education, research and advocacy. Fenway Health began in 1971 and grew rapidly when it became the first health care facility in New England to respond to the AIDS crisis. Today, Fenway Health is a Federally Qualified 330 Health Center (FQHC) that provides medical and behavioral health services to over 22,000 patients, 10% of whom are living with HIV/AIDS, at three different practice sites throughout Boston. Fenway Health also offers dental, optometric, pharmacy, behavioral health and substance abuse services. About half of Fenway's patients are heterosexual, and half are lesbian, gay, or bisexual; approximately 5% of the patient population is transgender.

The Fenway Institute is the research, training, and health policy division of Fenway Health. TFI has a long history of participating in and leading collaborative multi-site HIV research including the HIV Prevention Trials Network (HPTN) and the HIV Vaccines Trials Network (HVTN). Since 2008, Fenway Health has been the only community-based organization to lead an NIH-sponsored Clinical Trial Unit and is the only community-based recipient of a NICHD-funded infrastructure grant for population research.

TFI's Center for Population Research in LGBT Health develops and supports collaborative research and education programs to understand and improve the health of sexual and gender minorities. Throughout Fenway's research experience, TFI has led and managed local, national, and international multi-site trials.



Chase Brexton operates practice sites in Baltimore City, Randallstown, Columbia, and Easton.

Chase Brexton Health Services (Chase Brexton):

Founded in 1978, Chase Brexton has evolved from a small organization serving the gay and HIV-affected community into a multi-faceted health center offering a continuum of care to diverse and often medically underserved populations. These include both heterosexual/non-transgender and LGBT populations. Today, Chase Brexton is an FQHC, as defined by Section 330 of the Public Health Service Act, with a proven record of effectively identifying and addressing health care issues to meet the needs of disenfranchised, high-risk clients.

Chase Brexton operates practice sites in Baltimore City, Randallstown, Columbia, and Easton. Together these sites provide services to over 14,000 Maryland residents annually. Service

offerings vary from site to site and include primary medical care, women's health services, nutritional assessments and counseling, pediatrics, dental care, HIV medical care, walk-in HIV counseling and testing, HIV consultation services to residents of Prince George's and Somerset Counties, an STD clinic, an in-house pharmacy, medication adherence support for patients on anti-retroviral therapy, mental health services, addiction counseling, behavioral medicine, and case management, as well as sub-specialty consultations in infectious disease, podiatry, gynecology, and psychiatry. This wide range of services allows Chase Brexton patients to address multiple needs at one time within an integrated system of care.

Beaufort-Jasper-Hampton Comprehensive Health Services:

Beaufort is a Section 330 designated FQHC. Beaufort was organized in 1970 to deliver comprehensive health services to the residents of economically-deprived areas of Beaufort, Hampton, and Jasper Counties, South Carolina. Beaufort is the only provider in this area of comprehensive primary and preventive health care services, regardless of ability to pay.

Beaufort provides access to comprehensive primary and preventive care through fourteen sites. Using a family practice model, Beaufort provides residents of the three counties with prenatal care and delivery, pharmacy, dental care, environmental health, case management, home health, radiology, social work, Medicaid intake, and translation services. Over the forty years of providing health care services in the low country of South Carolina, Beaufort has gained the trust of the community and established strong relationships with community partners. Most of Beaufort's patients are heterosexual and are non-transgender.

Howard Brown Health Center (Howard Brown):

It is the mission of Howard Brown to eliminate the disparities in health care experienced by LGBT people through research, education, and the provision of health and wellness services. Howard Brown is an FQHC Look Alike. Located in Chicago, Howard Brown was founded in 1974 and is now one of the nation's largest LGBT organizations. The agency serves more than 18,000 adults and youth each year in its diverse health and social service delivery system focused around seven major programmatic divisions: primary medical care, behavioral health, research, HIV/STD prevention, youth services, elder services, and community initiatives.

The Center for American Progress (CAP): CAP

is an independent nonpartisan educational institute dedicated to improving the lives of Americans through progressive ideas and action. Alongside numerous issue areas, CAP's priorities include health, LGBT issues, and the importance of data-driven policy solutions. Founded in 2003 to provide long-term leadership and support to the progressive movement, CAP is based in Washington, D.C.

BACKGROUND

LGBT health disparities

A growing body of research has documented health disparities affecting lesbian, gay, bisexual, and transgender people.^{2,3} In Healthy People 2020, the U.S. government formally committed for the first time to eliminating health disparities affecting the LGBT population. These disparities, which are often strongly related to experiences of stigma, discrimination, bullying, and violence directed at LGBT people,⁴ include:

- Gay and bisexual men experience a high prevalence of sexually transmitted infections,

including HIV, and high rates of mental and behavioral health issues, including depression and suicidal ideation.⁵

- Lesbians and bisexual women experience cervical cancer at the same rate as heterosexual women, but are four to ten times less likely to get routine Pap tests to screen for cervical cancer.^{6,7}

- The Massachusetts Behavioral Risk Factor Surveillance Survey found poorer health among bisexual respondents compared with gay, lesbian, and heterosexual respondents, as well as higher rates of mental health issues and smoking.⁸ The Youth Risk Behavior Survey in seven states and six large cities has also found higher rates of health risk behaviors among bisexual youth compared with gay and lesbian youth.⁹

- Transgender people, particularly transgender women of color, are disproportionately likely to be victims of hate violence.¹⁰ They are also more likely to contract HIV,¹¹ to not have access to preventive screenings that can detect diseases such as cancer early,¹² and to attempt suicide.¹³ In a recent study of more than 6,400 transgender people across the United States, for example, 41% of transgender people reported attempting suicide—a rate 25 times higher than the general population.¹⁴

- There are few providers well versed in the unique health care needs of transgender patients, creating a barrier to access to quality care. For example, most transgender women have a prostate and may be candidates for the same prostate screening that is recommended for all individuals. Transgender men, even those who have had chest reconstruction surgery, may have residual breast tissue that warrants screening for breast cancer with mammography, and many transgender men have a cervix and should be screened for

cervical cancer. These screenings must be done with sensitivity to the discomfort they may evoke in transgender patients.¹⁵

In addition to societal anti-LGBT discrimination, other structural barriers driving LGBT health disparities include poverty in LGBT communities¹⁶; a lack of providers trained to address the specific health care needs of LGBT people¹⁷; low rates of health insurance coverage for same-sex couples¹⁸, LGB individuals^{19,20}, and transgender individuals, especially Black transgender people²¹; and a lack of access to culturally appropriate health care, including prevention services.²²



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Another major factor in LGBT health disparities is discriminatory treatment in health care settings. Surveys of both patients²³ and providers²⁴ indicate that LGBT people experience prejudicial treatment in clinical settings and that some providers continue to harbor anti-LGBT attitudes. As a result, many LGBT people report

culturally incompetent care, or avoid visiting health care facilities for fear of receiving sub-standard care.²⁵ The fact that many providers do not know how to discuss sexual orientation or gender identity with their patients perpetuates invisibility of LGBT patients in clinical settings and contributes to the widespread lack of LGBT-inclusive cultural competency and clinical training for providers. SOGI data collection is a key component of enhancing the ability of patients and providers to engage in meaningful dialogue in the exam room and to promote the provision of high-quality care for LGBT people.²⁶

Literature on asking questions in clinical settings and the importance of training
A provider's knowledge of a patient's sexual orientation and gender identity is essential to providing appropriate health care. In particular, these discussions facilitate a more accurate assessment of patient self-reported health and risk behaviors.²⁷ A sample of New York City men who have sex with men (MSM) from the 2004-2005 National HIV Behavioral Surveillance System, for example, found that 61% had not disclosed their same-sex orientation or behavior to their medical providers. White MSM and native-born MSM were more likely to have disclosed than Black, Latino, Asian, and immigrant MSM. Disclosure of same-sex behavior correlated with being tested for HIV, indicating how discussions of sexual orientation can lead to more effective approaches to addressing health concerns that disproportionately affect gay and bisexual men.²⁸

It is important to study the most effective ways to gather sexual orientation and gender identity information in clinical settings in order to advance SOGI data collection efforts that are useful from a staff and provider perspective as well as acceptable from a patient perspective.²⁹ As many speakers at the October 2012 Institute

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of Medicine workshop on LGBT data collection in EHR systems noted, buy-in from staff, including front desk staff as well as providers, is essential to effective SOGI data collection. Furthermore, SOGI data collection should be coupled with cultural competency training in which staff can ask questions and work through any discomfort or misunderstandings they may have. Such training, which should include language defining terms such as “sexual orientation,” “gender identity,” and “transgender,” as well as information about why these questions are being asked, should occur in the context of training health professionals and administrative staff about broader issues of achieving quality care with diverse patient populations.³⁰



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12.6% of adults 18-45 reported “some same-gender sexual experience,” according to The National STD and Behavioral Measurement Experiment.
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While research on how to ask about sexual orientation and gender identity in clinical settings is still in a nascent phase, public health and demographic surveys have been gathering these data for many years. These surveys include the National Survey of Family Growth, the General Social Survey, and the National Survey of Sexual Health and Behavior.³¹ We know from these

data that LGBT people comprise a significant demographic minority group. Although only about 3.5% of adults identify as lesbian, gay, or bisexual³², a much larger percentage of the population engages in same-sex behavior and/or experiences same-sex attraction. In a national survey using Automated Computer-Assisted Self-Interview (ACASI), for instance, 12.6% of 18- to 45-year-olds reported “some same-gender sexual experience,” and 16.1% reported “some same-gender sexual attraction.”³³ The California Health Interview Survey found that 0.1% of respondents identify as transgender, while the Massachusetts Behavioral Risk Factor Surveillance Survey found that 0.5% of respondents identify as transgender.³⁴

Concerns about confidentiality and discrimination

LGBT patients may be hesitant to disclose information about their sexual orientation or gender identity due to fears about confidentiality and privacy.³⁵ Such concerns are exacerbated by the increasing computerization of health records as well as some highly publicized breaches in confidentiality.³⁶ However, with the development of proper standards for encoding medical information, along with best practices for how to manage a computer infrastructure by institutions like the National Institutes for Standards and Technology, these threats are manageable.³⁷ Sections 1411(g), 1411(c)(2), and 1414(a)(1) of the 2010 Patient Protection and Affordable Care Act (ACA) provide privacy and security protections for information used by the Health Insurance Marketplaces in each state.³⁸ A 2012 regulation further mandates “appropriate security and privacy protections” for any “personally identifiable information,” including sensitive health information that is collected and used in the provision of health care.³⁹ SOGI data are no more sensitive than other kinds of important health data that are routinely collected and stored in patient re-

cords, such as race and ethnicity, information about mental and behavioral health conditions, and information related to reproductive health matters such as birth control.

The public policy rationale

The 2011 Institute of Medicine report on LGBT health recommends the collection of sexual orientation and gender identity data in EHRs as part of the meaningful use objectives for the EHR Incentive Program run by the Office of the National Coordinator for Health Information Technology and the Centers for Medicare and Medicaid Services. The report recommends that questions be standardized to allow for the comparison and pooling of data to analyze the specific health needs of LGBT people.⁴⁰ Healthy People 2020 calls on health care providers to “appropriately inquir[e] about and be... supportive of a patient’s sexual orientation to enhance the patient-provider interaction and regular use of care.”⁴¹ Gathering LGBT data in clinical settings is consistent with efforts of the U.S. Department of Health and Human Services to gather health data on LGBT populations as authorized under Section 4302 of the ACA.⁴² Further, The Joint Commission’s 2011 report, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide*, also encourages the collection of patient data on sexual orientation and gender identity.⁴³ Moreover, longstanding rationales for gathering race and ethnicity data also apply to sexual orientation and gender identity data. The Health Research and Education Trust Disparities Toolkit, a toolkit for collecting race, ethnicity, and primary language information from patients, states that “Disparities in health care can be addressed through a quality of care framework if data on race, ethnicity, and primary language are available” (emphasis added).⁴⁴ A report

by Physicians for Human Rights on racial and ethnic disparities in medical care notes the broad range of uses of race and ethnicity data in improving quality of care and access to care:

[D]ata on race and ethnicity may be used for a variety of possible purposes beyond the detection of disparities in the quality of clinical care, such as who is accessing health services, the health status of different populations, utilization rates of services to which racial and ethnic groups do have access, the effectiveness of public health interventions among different racial and ethnic groups, and of course racial and ethnic disparities in diagnosis and treatment.⁴⁵

The Joint Commission’s 2010 report, *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*, also stresses the importance of gathering race and ethnicity data:

Hospitals must collect patient-level demographic data on race and ethnicity to identify the needs of individual patients and to eliminate disparities in the patient population. These critical data provide hospitals with information on the potential cultural needs of each patient, as well as an opportunity to monitor and analyze health disparities at the population level.⁴⁶

All of these purposes for which race/ethnicity data can be used also apply to data on sexual orientation and gender identity.

Gathering data on sexual orientation and gender identity in clinical settings via EHR systems helps clinicians, researchers, and policymakers better understand LGBT health, including disparities in insurance coverage, access to care, diagnosis, and treatment.

Storing SOGI information in the EHR promotes seamless communication among staff within health care organizations. Further, these data, coupled with race/ethnicity data, would also allow for better understandings of racial and ethnic disparities within LGBT populations.

METHODS

The specific aim of the study was to survey community health center patients to assess the acceptability, feasibility, and patient preferences on asking sexual orientation and gender identity questions to complete their electronic health record intake.

The study addressed the following questions:

1. What are the acceptable ways to ask patients about sexual orientation and gender identity in electronic health records?
2. How do patient survey responses differ based on sexual orientation, gender identity, clinical site location, and other demographic variables?

Participants. The findings from this study are based on survey responses from 251 patients at four CHARN-affiliated CHCs. By targeting CHCs with diverse patient populations, the goal was to enroll transgender (regardless of sexual orientation), LGB, and heterosexual patients to gather information on appropriate ways to ask sexual orientation and gender identity questions. The inclusion criteria included patients at each participating CHC who were 18 year of

age or older. While the participating CHCs do provide health care to patients younger than 18, this study targeted patients who completed their own registration forms and not patients whose parents or guardians fill out the forms. The exclusion criteria included non-English-speaking patients and those who refused to participate.

Human subjects protection. The Fenway Institute functioned as the lead site for this study. Beaufort and Chase Brexton, both Fenway-affiliated CHARN sites, use the Fenway Institutional Review Board (IRB) for CHARN-related study projects. All study documents were submitted and approved by the Fenway IRB. The Howard Brown Health Center IRB approved the study for that site. The IRB approved a waiver of documented informed consent due to the anonymous nature of the study and the absence of any personal identifiers attached to the survey. However, participants were provided with a “research information form” for participation in this study (included with informed consent waiver). This form was handed out with the paper survey and included all the essential elements of an informed consent. Continuing on to answer the survey questions indicated that participants voluntarily agreed to participate.

Instrument. This one-time, 5-minute survey asked respondents to answer a question about sexual orientation developed at the Fenway Institute, and to answer a two-step gender identity and birth sex question that has been endorsed by leading transgender researchers

in the U.S. and globally. The sexual orientation question was already in use at Fenway but not at Beaufort and Chase Brexton. At Howard Brown, patients are encouraged to report their sexual orientation and their gender identity at intake for inclusion in their EHR. The Centers for Disease Control and Prevention (CDC) adopted the two-step gender identity and birth sex question for use in their Adult Case Report Form and in their electronic surveillance system, the Enhanced HIV/AIDS Report System. All of the questions tested are thus already being used in some settings but have not been tested among a diverse population at CHCs.

Fenway Health in Boston recently evaluated the best way to ask about sexual orientation on its patient registration form.⁴⁷ Based on this evaluation, the following question was added to Fenway's EHR in 2011 and was included in the survey administered at the participating CHCs.

Do you think of yourself as:

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

The two-step gender identity and birth sex question was developed by the Philadelphia Transgender Health Advocacy Coalition in 1997 and endorsed by the Center of Excellence for Transgender Health at the University of California at San Francisco ten years later.⁴⁸ This question first asks about current gender identity, followed by sex assigned at birth. The World Professional Association for Transgender Health (WPATH) EMR Working Group endorsed a two-step gender identity and birth sex question in 2013.⁴⁹ Research has indicated that the two-step gender identity and birth sex question design performs

extremely well. In a recent analysis, the two-step question was found to have near-zero missing data and to result in a transgender-spectrum response rate twice that elicited by a single ques-



tion that asked respondents to select from four response options for their sex (male, female, transgender, other).⁵⁰

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While the two-step gender identity question asked at the four CHCs is slightly different from the questions promoted by the Center of Excellence, the CDC, and WPATH, there is agreement that some form of a current gender identity question should be asked, as well as a natal sex question in order to support clinical care protocols that may involve anatomy that differs from that typically associated with men or women.



In our study, we asked 251 patients at the four CHCs:

**What is your current gender identity?
(Check all that apply)**

- Male
- Female
- Female-to-Male (FTM)/Transgender Male/Trans Man
- Male-to-Female (MTF)/Transgender Female/Trans Woman
- Genderqueer, neither exclusively male nor female
- Additional Gender Category/(or Other), please specify
- Decline to Answer, please explain why

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

- Male
- Female
- Decline to Answer, please explain why

Respondents were also asked a number of clarifying questions about these sexual orientation and gender identity questions in order to gauge comprehension, acceptability, and whether they thought the question allowed them to accurately document their sexual orientation, gender identity, and, ultimately, their health needs in an electronic health record system. In addition, they were also asked whether they think it is important for their health provider to know about their sexual orientation and gender identity, and whether they would be willing to answer these questions on a registration form.

Prior to survey administration, study staff piloted the survey with eight staff from The Fenway Institute and a staff member at the

Center for American Progress, who provided comments, suggestions, and noted the time it took to complete the survey. The study team discussed these suggestions and incorporated them into the survey.

Participant recruitment and survey administration.

Each site developed its own recruitment and implementation plan to enroll participants there within a two-week period. Three of the four sites had a dedicated staff person to administer the survey. Study staff approached potential participants in the clinic waiting room or at the registration desk, asked if they were interested in completing a short survey, and provided an information sheet outlining key elements of the study. If interested, the participant completed the survey and received a \$10 gift card. If participants were called into the medical visit before completing the survey, they completed the remainder of the survey after the visit.

Fenway: Fenway Institute staff recruited from the registration desk on each of three medical floors in the Fenway Health main building at 1340 Boylston St., Boston. Only two potential respondents declined to complete the survey, citing lack of time.

Beaufort: The original implementation plan for Beaufort consisted of staff affiliates distributing the questionnaire to all patients at the time of registration and prior to the patient seeing the provider. If the waiting time was brief, the patient was permitted to take the survey into the exam room for completion. The finalized questionnaires were to be returned to the medical office assistant in order to receive the gift card; at the end of the day, the research assistant would be accountable for assembling the completed questionnaires from the registration staff. However, in an effort to get the questionnaires completed in an efficient and expeditious

manner, minor modifications were made to the implementation plan.

The surveys were implemented at two individual sites, Hardeeville Medical Center (Adult Medicine) and Port Royal Medical Center (Adult Medicine, WIC, and OB/GYN), which is one of Beaufort's busiest sites. The research associate ascertained patients' interest in participating in the survey, administered the survey while the patients were in the waiting area, and presented the gift card after completion. Only two individuals declined to participate in the survey, and their reason for non-participation was due to the fact that they did not receive their care at Beaufort.

Chase Brexton: Participants were recruited at two sites: Mount Vernon in downtown Baltimore and Columbia Center in Columbia, MD. Chase Brexton experienced challenges to study recruitment, including the loss of a research assistant and a move from one building to another for their largest clinical site. As a result, they had difficulty reaching their original recruitment goal and revised their recruitment plan. At the Columbia, Maryland site, a research assistant recruited participants while they waited for their provider visit. At the downtown Baltimore site, several providers, social workers, and a preventive health outreach worker recruited participants directly during their visits.

Howard Brown: Howard Brown Health Center (HBHC) staff first attended the agency's transgender female support group. Here information was provided and members were asked to consider completing the questionnaire. A few days later, staff spent an afternoon in the HBHC clinic waiting area, where the study was introduced, patients read the study information page, and completed the questionnaire. In both instances the participants were given the information page

and questionnaire in closed envelopes which they sealed upon completion. The sealed envelopes were returned to the HBHC Site Study Coordinator.

FINDINGS

In 2013, a sample of 251 participants was surveyed about the experience of answering sexual orientation and gender identity questions in clinical settings at both urban and rural community health centers, including Fenway Health, Howard Brown, Chase Brexton, and Beaufort. The response rate was high, with only two or three potential participants refusing to complete the surveys at each site, citing lack of interest or time limitations. Most respondents from the Beaufort Health Center network in rural South Carolina (82%) said they were straight or heterosexual, as did 45% of respondents at Chase Brexton in Baltimore, 34% of respondents at Fenway Health in Boston, and 36% of respondents at Howard Brown in Chicago. Altogether, more respondents from the four health centers reported being heterosexual (47%) than any other orientation. Twenty-nine percent from the four locations said they were gay, lesbian, or homosexual, with a range from 2% gay/lesbian/homosexual at Beaufort in South Carolina to 42% at Howard Brown in Chicago. An average of 9% self-identified as bisexual—ranging from 0% at Beaufort to 15% at Howard Brown (Table 1).⁵¹

The sample was racially diverse: 51% White, 32% Black, and 6% multiracial or other. Nine percent were Hispanic (Table 1). Thirty-three percent were age 18-29, 40% age 30-49, and 27% age 50 or older.

Nearly three in four respondents from the four CHCs said that asking about sexual orientation on registration forms is important (73% versus 25%) Table 2. An even greater majority said that asking about gender identity is important (82% versus 18%).

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We conducted the study with patients in both urban and rural areas. We were able to reach patients with different backgrounds, including racially diverse backgrounds, who may have different opinions on the importance of sexual orientation and gender identity data.

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Most lesbian, gay, and bisexual (LGB) respondents from across the four sites said that they understood the sexual orientation question and would answer it on forms if asked to do so. Ninety-five percent of lesbian, gay and bisexual respondents said that they strongly agreed or somewhat agreed that they “understood what the [sexual orientation] question was asking about me.” Most heterosexual respondents also said they understood the sexual orientation question (81% strongly or somewhat agreed that they “understood what the [sexual orientation] question was asking about me”). Most heterosexuals and LGB respondents in all age groups said they would answer the sexual orientation question.

Overall most heterosexual respondents agreed or strongly agreed that they understood the sexual orientation question, that it was easy to answer, that it accurately reflected their sexual orientation, and that they would answer it. Heterosexuals answered between an average score of 4.04 and 4.47 on a 5-point Likert scale. Lesbian, gay, and bisexual respondents were more likely to agree or strongly agree with these statements, with average responses for that group ranging from 4.58 to 4.85 on the scale.

There were some differences between gay, lesbian, or homosexual-identified respondents and bisexual respondents. Seventy-nine percent of lesbian, gay, or homosexual respondents strongly agreed that the sexual orientation question “allows me to accurately document my sexual orientation,” but only 55% of bisexual respondents strongly agreed (Table 3). When “somewhat agree” responses were combined with “strongly agree,” 93% of gay and lesbian respondents agreed that the questions accurately documented their sexuality, while 73% of bisexuals agreed.

Sixty-six percent of respondents strongly agreed that sexual orientation “information is important for my medical provider to know about me,” and another 12 percent somewhat agreed; altogether

78% agreed. Survey respondents were invited to write comments about the sexual orientation and gender identity questions. One respondent wrote, “I think my relationship with my doctor should reflect my sexual orientation because it provides better care.”

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Only 12% of those surveyed disagreed somewhat or strongly that sexual orientation information was important for their provider to know about them, while 9% were neutral (Table 2). One respondent wrote, “Orientation should not be the concern of the practitioner and should not be documented. Practitioners should be concerned over the safety of the sex that patient is having or not having, instead of whether or not they are attracted to men, women, non-gender-binary, or whomever.”



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Four out of five respondents agreed that it is important for their providers to know about their sexual orientation.
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When asked if they would make changes to the sexual orientation question, less than one in five said they would: 17% said they would ask the question differently, while 81% said that they would not make changes to the sexual orientation question tested. Among the suggested changes were adding categories like “queer” and “pansexual,” as well as having open-ended answers where respondents could fill in the blank. One respondent said, “I really like that I got to check all that apply. Too many times this type of question allows only one response.” Many transgender respondents said that their sexual orientation was something other than heterosexual, homosexual, or bisexual.

Most respondents (97%) were able to answer the two-part gender identity question.

Only 1% declined to answer the current gender identity question, while another 1% chose “other”; the other 98% chose from among the gender identity options. Three percent declined to answer the question, “What sex were you assigned on your original birth certificate?”, while 97% did answer this question.

Seventy-nine percent of all respondents strongly agreed that they understood all the choices in the gender identity question, while only 7% strongly disagreed. Heterosexual respondents were more likely than gay, lesbian, and bisexual respondents to say they did not understand all the choices of responses in the gender identity question. Eighty-five percent strongly agreed that they would answer the birth sex question, and 78% strongly agreed that they would answer the current gender identity question.

Most transgender respondents agreed that the gender identity question allowed them to accurately document their gender identity: Eighty-seven percent of transgender men and 71% of transgender women agreed or strongly agreed that the questions allowed them to accurately document their gender identity.

Nearly nine in ten of all respondents (88%) said they would not change the gender identity questions, while 8% would. More than 17% of transgender respondents would make changes to the gender identity questions, compared with 5.5% of the non-transgender respondents.

Two individuals questioned the term “gender-queer.” One said, “I’ve never heard of ‘gender-queer’ and do not know what it means.” Another raised concerns that offering this term as an option on the gender identity questions could lead to “risk of derogatory interpretation.”

Close to 84% of male and female non-transgender respondents agreed that they would answer the gender identity question on a registration form at their health center (Table 4). Among transgender men, 87% agreed, while 81% of transgender women agreed.

Several transgender respondents raised concerns about being asked their sex assigned at birth. One wrote, “Though I understand the importance of knowing birth sex when dealing with trans medical issues, it’s still a very sensitive question that most [transgender people] would probably not want to answer.” While 87% of transgender men agreed that they would answer the birth sex question, only 65% of transgender women agreed. Some 7% of transgender men and 16% of transgender women indicated that they would not answer the sex assigned at birth question. Another 7% of transgender men and 13% of transgender women neither agreed nor

disagreed with the statement, “I would answer this question on a registration form at this health center.”

Despite these concerns, overwhelming majorities of all groups—transgender and non-transgender men and women—strongly agreed that “this information is important for my provider to know about me.” Eighty percent of transgender men strongly agreed, as did 74% of transgender women. When “somewhat agree” responses were added to “strongly agree,” about 83% of transgender respondents agreed that their gender identity and birth sex are important for their providers to know about.

Some respondents said that they wanted their providers to ask them about their sexual orientation and gender identity; while they agreed that it should be in their medical record, they questioned whether it should be asked at registration. A few expressed concerns about privacy of data, and a few commented on the importance of training staff on why SOGI data are being gathered and why knowing a patient’s sexual orientation and gender identity is important for providing culturally competent and affirming care and understanding LGBT health disparities. One wrote, “I think it is important to not only know this info but to educate all staff on what it means. This would put patients at ease.”

DISCUSSION

This evaluation of questions about sexual orientation and gender identity among a diverse group of patients at four CHCs shows widespread understanding of these questions and willingness to answer them, both among LGBT respondents and among heterosexual and non-transgender respondents. Most gay, lesbian, and bisexual respondents said that the sexual orientation question accurately reflected their identities and that they would not change

the question wording. They also understood why it is important for providers to know about their sexual orientation. This indicates support among lesbian, gay, and bisexual patients for sexual orientation data collection in clinical settings. These findings also correlate with findings from a recent nationwide study of more than 860 LGBT individuals with incomes under 400% of the poverty level, in which 76% of respondents said it is important to be open with their providers about their sexual orientation and/or gender identity and 74% indicated that they are “out” to their provider about their sexual orientation and/or gender identity.⁵²

The sexual orientation question tested in these four settings could, if widely used, be acceptable to patients across the country—gay, bisexual, and straight—and allow us to ascertain important information on patients that can help us better understand health disparities affecting lesbians, gay men, and bisexuals.

.....
This evaluation shows widespread understanding of these questions and willingness to answer them.
.....

The two-step gender identity question (current gender identity and birth sex) was also widely understood by all patients surveyed. Strongly majorities believed that it was important for providers to know about their patients’ gender identity and would be willing to answer the question. Further research, including focus groups, would be helpful regarding concerns among transgender respondents with regard to answering the sex assigned at birth question. As discussed above, about 17% of transgender female respondents disagreed or strongly disagreed with the statement that they would answer the birth sex question (Table 4). An-

other 14% were neutral, while 69% agreed or strongly agreed that they would answer this question. Transgender male respondents were more likely to agree that they would answer the birth sex question: 87% said they agreed or strongly agreed, 7% were neutral, and 7% said they disagreed and would not answer the question (Table 4). It is important to note that the vast majority of transgender respondents indicated that they would answer both parts of the gender identity question—current gender identity and sex assigned at birth.

LIMITATIONS

There are limitations to consider when interpreting findings. First, we surveyed a sample of each clinic population regarding the sexual orientation and gender identity questions. If this sample differed from the actual patient population, then this may have biased our results. However, there is no reason to believe, given the high rates of participation, that the samples surveyed differed from the general patient populations of each health clinic. Second, each clinic surveyed patients using different methodologies during a two week period. Because the survey collection occurred over a brief period, not all health center patients had the opportunity to complete a survey. Third, each site only surveyed patients who arrived for appointments. Any patient who did not keep his or her appointment on a particular survey day did not have an opportunity to complete the survey. Fourth, since the surveys were administered in busy clinics, we did not want to interfere with clinic workflow, so the survey length was limited.

STRENGTHS

The primary strength of this study was the regional diversity of the patients who responded to the survey. Since we are concerned with asking SOGI questions in a clinical environment,

we conducted the study with patients in both urban and rural areas in four different community health centers in different regions of the U.S. Therefore, we were able to reach patients with different backgrounds, including racially diverse backgrounds, who may have different opinions on the importance of sexual orientation and gender identity data. An additional strength is that not all of the health centers where we tested these SOGI questions were LGBT-focused. Including a clinic that was not LGBT-focused and located in a rural community strengthened the generalizability of the results. A full range of ages and educational levels were represented among the survey respondents. Additionally, the survey provided patients with an opportunity to comment on these questions so that any new or unanticipated issues could be expressed. These results provide evidence suggesting that asking SOGI questions in clinical settings is both feasible and important for facilitating communication between patients and clinicians.

CONCLUSION

This survey of a diverse group of patients in four health centers finds that most patients understand the importance of asking about sexual orientation and gender identity and would be willing to answer a set of existing questions developed to collect SOGI data in health care settings. We believe that health care providers and regulatory bodies should move forward by taking steps to facilitate SOGI data collection in clinical settings and in EHRs. In particular, inclusion of SOGI questions in the standard demographic section of the Stage 3 meaningful use guidelines is an important step that the Centers for Medicare and Medicaid Services and the Office of the National Coordinator for Health Information Technology can take to advance SOGI data collection. This would be consistent with our findings of widespread

agreement among survey respondents regarding the acceptability of SOGI questions, as well as with the emphasis placed on SOGI data collection and LGBT health in recent years by entities such as the Institute of Medicine, The Joint Commission, and the Department of Health and Human Services itself.

This research was made possible by the research infrastructure of the Community Health Applied Research Network (CHARN). CHARN is a network of community health centers and universities established to conduct patient-centered outcome research among underserved populations. It was funded by the Health Resources Services Administration, HIV/AIDS Bureau (grant # UB2HA20233). This specific study was funded by a grant from the Center for American Progress.

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APPENDIX

Data Analysis.

The survey data from each site was entered into a password-protected REDCap database. Data from all sites was exported from REDCap to SPSS for analysis. All analysis was performed and tables were created in SPSS.

In 13 cases, multiple gender identity responses were re-coded into a “primary gender identity” variable for the purposes of data analysis. The transgender categories took first precedence in the re-coding of multiple gender identity responses: Female-to-Male (FTM)/Transgender Male/ Trans Man and Male-to-Female (MTF)/Transgender Female/Trans Woman. If transgender responses were not chosen, then male or female were second, then “Genderqueer,” and “Other” was last. The answer to the birth sex question was used to confirm re-coded responses for gender identity.

TABLE 1

	Beaufort n=50 (20%)	Chase Brexton n=67 (27%)	Fenway n=101 (40%)	Howard Brown n=33 (13%)	Total
Race					
Black/ African American	35	32	3	11	81 (32%)
Asian	0	0	2	1	3 (1%)
Caucasian	10	30	74	13	127 (51%)
Multiracial	1	3	10	1	15 (6%)
Native American/Alaska Native/Inuit	0	1	0	3	4 (2%)
Pacific Islander	0	0	1	1	2 (1%)
Other	3	1	8	3	15 (6%)
Missing Answer	1	0	3	0	4 (2%)
Ethnicity					
Hispanic/Latino/Latina	6	3	11	2	22 (9%)
Not Hispanic/Latino/Latina	36	53	85	28	202 (81%)
Missing Answer	8	11	5	3	27 (11%)
Sexual Orientation					
Lesbian, Gay, or Homosexual	1	16	41	14	72 (28.7%)
Straight or Heterosexual	41	30	34	12	117 (46.6%)
Bisexual	0	6	11	5	22 (8.8%)
Something else	3	10	13	2	28 (11.2%)
Don't know	5	4	2	0	11 (4.4%)
Missing answer	0	1	0	0	1 (0.4%)

Note: Percentages may not add up to 100 due to rounding.

TABLE 2

Question 7: As part of a written registration form, do you think it is important to ask patients about sexual orientation when they register at the health center?

	Beaufort n=50 (20%)	Chase Brexton n=67 (27%)	Fenway n=101 (40%)	Howard Brown n=33 (13%)	Total
Yes	33	50	76	24	183 (73%)
No	16	16	25	7	64 (25%)
Missing Answer	1	1	0	2	4 (2%)

Question 8: As part of a written registration form, do you think it is important to ask patients about gender identity when they register at the health center?

	Beaufort n=50 (20%)	Chase Brexton n=67 (27%)	Fenway n=101 (40%)	Howard Brown n=33 (13%)	Total
Yes	39	55	83	28	205 (82%)
No	11	12	18	3	44 (17%)
Missing Answer	0	0	0	2	2 (1%)

TABLE 3

Question 10e: This question allows me to accurately document my sexual orientation.

	Lesbian, Gay, or Homosexual n=72 (28.7%)	Straight or Heterosexual n=117 (46.6%)	Bisexual n=22 (8.8%)	Something Else n=28 (11.2%)	Don't Know n=11 (4.4%)	Missing Answer n=1 (0.4%)	Total
Strongly Disagree	1	14	1	1	3	0	20 (8.0%)
Somewhat Disagree	1	3	0	2	1	0	7 (2.8%)
Neutral	3	9	4	3	2	1	22 (8.8%)
Somewhat Agree	10	9	4	5	1	0	29 (11.6%)
Strongly Agree	57	80	12	15	3	0	167 (66.5%)
Missing Answer	0	2	1	2	1	0	6 (2.4%)

TABLE 4

Question 17a: This set of questions allows me to accurately document my gender identity

	Male n=89 (35.5%)	Female n=111 (44.2%)	FTM* n=15 (6.0%)	MTF** n=31 (12.4%)	Genderqueer n=1 (0.4%)	Other n=1 (0.4%)	Decline n=3 (1.2%)	Total
Strongly Disagree	8	6	0	3	0	0	1	18 (7.2%)
Somewhat Disagree	0	1	0	2	0	0	0	3 (1.2%)
Neutral	2	6	2	3	0	0	1	14 (5.6%)
Somewhat Agree	3	3	3	4	1	1	0	15 (6.0%)
Strongly Agree	73	93	10	18	0	0	1	195 (77.7%)
Missing Answer	3	2	0	1	0	0	0	6 (2.4%)

TABLE 5

Question 15d: I would answer this question (What is your current gender identity?) on registration form at this health center

	Male n=89 (35.5%)	Female n=111 (44.2%)	FTM* n=15 (6.0%)	MTF** n=31 (12.4%)	Genderqueer n=1 (0.4%)	Other n=1 (0.4%)	Decline n=3 (1.2%)	Total
Strongly Disagree	7	9	1	2	0	0	0	19 (7.6%)
Somewhat Disagree	0	1	0	2	0	0	0	3 (1.2%)
Neutral	4	3	1	1	0	0	2	11 (4.4%)
Somewhat Agree	3	6	1	3	0	0	0	13 (5.2%)
Strongly Agree	75	91	12	22	1	1	1	203 (80.9%)
Missing Answer	0	1	0	1	0	0	0	2 (0.8%)

TABLE 6

Question 16c: I would answer this question (“What sex were you assigned at birth on your original birth certificate?”) on a registration form at this helth center.

	Male n=89 (35.5%)	Female n=111 (44.2%)	FTM* n=15 (6.0%)	MTF** n=31 (12.4%)	Genderqueer n=1 (0.4%)	Other n=1 (0.4%)	Decline n=3 (1.2%)	Total
Strongly Disagree	7	7	1	3	0	0	0	18 (7.2%)
Somewhat Disagree	0	1	0	2	0	0	0	3 (1.2%)
Neutral	1	3	1	4	0	0	2	11 (4.4%)
Somewhat Agree	3	5	1	3	0	0	0	12 (4.8%)
Strongly Agree	76	93	12	17	1	1	1	201 (80.1%)
Missing Answer	2	2	0	2	0	0	0	6 (2.4%)

TABLE 7

Question 17b: I think this information (gender identity and birth sex) is important for my provider to know about me.

	Male n=89 (35.5%)	Female n=111 (44.2%)	FTM* n=15 (6.0%)	MTF** n=31 (12.4%)	Genderqueer n=1 (0.4%)	Other n=1 (0.4%)	Decline n=3 (1.2%)	Total
Strongly Disagree	7	8	1	2	0	0	0	18 (7.2%)
Somewhat Disagree	2	3	0	1	0	0	0	6 (2.4%)
Neutral	3	4	1	2	0	0	1	11 (4.4%)
Somewhat Agree	6	9	1	2	0	0	0	18 (7.2%)
Strongly Agree	68	84	12	23	1	0	2	190 (75.7%)
Missing Answer	3	3	0	1	0	1	0	8 (3.2%)

*FTM = Female-to-Male/Transgender Male/Trans Man

*MTF = Male-to-Female/Transgender Female/Trans Woman

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Fenway Health Patient Survey on Asking Sexual Orientation and Gender Identity Questions

We are asking you to help us to find out more about the health of lesbian, gay, bisexual, and transgender (LGBT) people. Collecting this information in electronic health records (EHRs) can help to improve health care for LGBT people.

The goal of this survey is to help us learn how to ask questions about sexual orientation and gender identity. This survey will ask you to complete some questions and then ask for your input. We encourage you to write comments in the space provided.

Sexual orientation is defined as to which gender(s) a person is physically attracted: to the opposite gender (heterosexual), to the same gender (homosexual), or to both genders (bisexual).

Gender identity is defined as a person's identification as male or female, which may or may not correspond to the person's body or their sex at birth (meaning what sex was originally listed on a person's birth certificate).

1. What is today's date? _____ / _____ / _____ (Month/ Day/Year)

2. What is your age?

- 18-29 years old
- 30-49 years old
- 50-64 years old
- 65 or older

3. What is your race?

- Black/African American
- Asian
- Caucasian
- Multiracial
- Native American/Alaskan Native/Inuit
- Pacific Islander
- Other _____

4. What is your ethnicity?

- Hispanic/Latino/Latina
- Not Hispanic/Latino/Latina

CONCLUDING STATEMENT

Thank you for participating in this survey. Your responses will help us better understand how to ask about sexual orientation and gender identity in electronic health records.

If you have any questions or concerns regarding this survey, you may contact the Investigators, Robbie Singal, DrPH (rsingal@fenwayhealth.org) or Harvey Makadon (hmakadon@fenwayhealth.org) of Fenway Health, or the Fenway Coordinator of Research Compliance by calling or writing the following:

The Fenway Institute
Fenway Community Health
1340 Boylston St
Boston MA 02115
(617) 927-6400

Thank you!

The Study Team

5. What is the highest degree or level of school you have completed?

- Less than high school
- High school/GED
- Some college
- 2-year college (Associates)
- 4-year college (BA, BS)
- Master's degree
- Doctoral degree
- Professional degree (JD, MD)
- Other _____

6. Is English your first language?

- Yes
- No

6a. If not, what is your first language? _____

FOR QUESTIONS 7 & 8,

7. As part of a written registration form, do you think it is important to ask patients about sexual orientation when they register at the health center?

- Yes
- No

8. As part of a written registration form, do you think it is important to ask patients about gender identity when they register at the health center?

- Yes
- No

Below are some ways we could ask about sexual orientation and gender identity. Please answer the questions and then let us know what you think about these questions (such as wording, importance of asking the question).

SEXUAL ORIENTATION

9. Which of the following do you identify most closely with?

- Lesbian, gay or homosexual
- Straight or heterosexual
- Bisexual
- Something else, Please describe _____
- Don't know

10. In answering the question above about sexual orientation, please tell us whether you agree or disagree:

(CIRCLE YOUR ANSWER ON EACH LINE)	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
10a. I understood what the question was asking about me	1	2	3	4	5
10b. I understood all of the answer choices	1	2	3	4	5
10c. The question was easy for me to answer	1	2	3	4	5
10d. I would answer this question on a registration form at this health center.	1	2	3	4	5
10e. This question allows me to accurately document my sexual orientation	1	2	3	4	5
10f. I think this information is important for my medical provider to know about me	1	2	3	4	5

11. Would you make any changes to this question?

- Yes
- No

11a. If yes, what changes would you make?

12. Please include any comments about the sexual orientation question:

GENDER IDENTITY

13. What is your current gender identity?

(Check all that apply)

- Male
- Female
- Female-to-Male (FTM)/Transgender Male/ Trans Man
- Male-to-Female (MTF)/Transgender Female/Trans Woman
- Genderqueer, neither exclusively male nor female
- Additional Gender Category/(or Other), please specify _____
- Decline to Answer, please explain why _____

14. What sex were you assigned at birth on your original birth certificate?

(Check one)

- Male
- Female
- Decline to Answer, please explain why _____

15. In answering Question 13 (“What is your current gender identity?”), please let us know whether you agree or disagree:

(CHOOSE ONE ANSWER ON EACH LINE)	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
15a. I understood what the question was asking about me	1	2	3	4	5
15b. I understood all of the answer choices	1	2	3	4	5
15c. The question was easy for me to answer	1	2	3	4	5
15d. I would answer this question on a registration form at this health center.	1	2	3	4	5

16. In answering Question 14 (“what sex were you assigned at birth on your original birth certificate?”), please let us know whether you agree or disagree:

(CHOOSE ONE ANSWER ON EACH LINE)	Strongly Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Strongly Agree
16a. I understood what the question was asking about me	1	2	3	4	5
16b. The question was easy for me to answer	1	2	3	4	5
16c. I would answer this question on a registration form at this health center.	1	2	3	4	5

17. In answering the gender identity questions (which includes questions 13 and 14), please let us know whether you agree or disagree:

17a. This set of questions allows me to accurately document my gender identity	1	2	3	4	5
17b. I think this information is important for my provider to know about me	1	2	3	4	5

18. Would you make any changes to this question?

Yes

No

18a. If yes, what changes would you make?

19. Please include any comments you have about the gender identity questions:

 THE FENWAY INSTITUTE

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