

© Health Research and Educational Trust  
DOI: 10.1111/1475-6773.12843  
RESEARCH ARTICLE

# Patient Acceptance of Sexual Orientation and Gender Identity Questions on Intake Forms in Outpatient Clinics: A Pragmatic Randomized Multisite Trial

Jordan E. Rullo , Jilian L. Foxen, Joan M. Griffin, Jennifer R. Geske, Cesar A. Gonzalez, Stephanie S. Faubion, and Michelle van Ryn

---

**Objectives.** To (1) test whether patient attitudes toward intake forms at three Midwestern outpatient clinics are significantly more negative among those who are asked to complete SOGI questions versus those who are not; and (2) gain an in-depth understanding of patient concerns about SOGI questions.

**Study Setting.** Data were collected between 6/29/2015 and 2/29/2016 from new patients ( $N = 491$ ) who presented at three outpatient clinics in a large academic medical center. This study was originally a quality improvement project, and later, institutional review board approval was obtained for secondary data analysis.

**Study Design.** Two-stage mixed-methods study. (1) Experimental: New patients at three sites were randomly assigned to complete either routine intake forms (control) or routine intake forms with SOGI questions (experimental); and (2) qualitative: interviews with patients who responded negatively to SOGI questions.

**Principal Findings.** There were no significant differences in patient attitudes between experimental and control groups ( $p > .05$ ). Of those who received SOGI questions, only 3 percent reported being distressed, upset, or offended by the SOGI questions.

**Conclusions.** Collection of SOGI data as a part of the routine clinical patient intake process is not distressing to 97 percent of patients who are heterosexual, cisgender, and older than 50 years.

**Key Words.** Ambulatory/outpatient care, gender/sex differences in health and health care, health promotion/prevention/screening, patient assessment/satisfaction

---

Sexual and gender minorities (i.e., lesbian, gay, bisexual, or transgender [LGBT] persons), compared with their heterosexual and cisgender counterparts, have higher rates of drug and alcohol use, tobacco use, mood and

anxiety disorders, and suicide attempts (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, Board on the Health of Select Populations, and Institute of Medicine of the National Academies. 2011). To understand the unique health needs of LGBT persons and to identify health care disparities in this population, the US Institute of Medicine (Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, Board on the Health of Select Populations, Institute of Medicine of the National Academies 2011), the Joint Commission, Healthy People 2020, and the US Department of Health and Human Services Affordable Care Act all recommend the collection of sexual orientation and gender identity (SOGI) data from patients. In addition, SOGI data collection is now a part of meaningful use objectives for the Medicare and Medicaid Electronic Health Record Incentive Program (Centers for Medicare and Medicaid Services, 2015; Cahill et al. 2016). Despite this, there is limited evidence regarding patient response, including potential unintended negative effects, with the addition of SOGI questions in clinical settings.

Specifically, there is great concern that asking SOGI questions to patients will be offensive. Nearly 80 percent of providers in a recent study reported that they thought patients would be offended if asked their sexual orientation in an emergency department setting (Haider et al. 2017). Providers at the University of California Davis Health System (UCDHS) also reported concern about offending patients with SOGI data collection. UCDHS was, to our knowledge, the first large health care organization to implement SOGI data collection. SOGI data collection began in June 2013 (Callahan et al. 2015), but no patient response data were collected. Providers initially reported “immediate and strong objections” to the collection of SOGI (Callahan et al. 2015), and one reason for their objections was the concern that collecting SOGI would be offensive to patients (Institute of Medicine [US] Board on the Health of Select Populations 2013; Cahill and Makadon 2014). Others have suggested that providers are concerned that identification of SOGI for LGBT

---

Address correspondence to Jordan E. Rullo, Ph.D., L.P., Department of Psychiatry and Psychology and Division of General Internal Medicine at Mayo Clinic, 200 1st Street SW, Rochester, MN 55905; e-mail: rullo.jordan@mayo.edu. Jilian L. Foxen, M.E.d., is with the Center for Regenerative Medicine at Mayo Clinic, Rochester, MN. Joan M. Griffin, Ph.D., and Michelle van Ryn, Ph.D., are with Department of Health Sciences Research at Mayo Clinic, Rochester, MN. Jennifer R. Geske, M.S., is with the Division of Biomedical Statistics and Informatics at Mayo Clinic, Rochester, MN. Cesar A. Gonzalez, Ph.D., L.P., is with the Department of Psychiatry and Psychology and Department of Family Medicine at Mayo Clinic, Rochester, MN. Stephanie S. Faubion, M.D., is with the Division of General Internal Medicine at Mayo Clinic, Rochester, MN.

patients could leave their patients susceptible to being treated differently or discriminated against by their health care provider (Institute of Medicine [US] Board on the Health of Select Populations 2013). This is particularly relevant in states where LGBT individuals do not have legal protections.

To date, only one study has assessed patient response to collection of SOGI data in a clinical setting (Cahill et al. 2014). This study included data collection from four community health centers in the United States, three of which are in major cities and are known for LGBT-focused patient care; the fourth is in rural South Carolina. In that study, approximately half of the 301 participants identified as other than heterosexual (i.e., LGBT, other, don't know), 67 percent were younger than 50 years, and only 7 percent were older than 65 years. Patients were provided with self-administered SOGI questions and were subsequently asked whether (1) they understood the questions, (2) questions were easy to answer, (3) questions were accurate, (4) the information was important to ask, and (5) they would answer these questions on a patient intake form. Overall, participants reported strong support for the collection of SOGI data: 74 percent endorsed that sexual orientation data collection is important and 82 percent endorsed that gender identity data collection is important. Not surprisingly, participants who were younger (<50 years) and/or identified as LGBT had more positive responses than their older, cis-gender, heterosexual counterparts. The findings from this study suggest that the majority of patients are not offended by SOGI questions. However, this study had several limitations and its findings may not generalize to the clinical experience of other outpatient clinics.

In this study, SOGI data collection was a stand-alone questionnaire for which patients were monetarily compensated (\$10) and not a part of their standard clinical experience. Thus, patients' willingness to complete these questions and their attitudes and beliefs about SOGI data collection as part of their standard clinic intake form are still unknown. Second, by asking patients about their reactions specifically to the SOGI questions, patients were inadvertently primed to assume that something is different about these questions, thus potentially biasing their responses. Third, patients were not asked whether they were upset or offended by the questions, which is one of the primary roadblocks to health care providers asking SOGI questions (Cahill and Makadon 2014). Fourth, most participants were younger than 50 years and from LGBT-focused community health centers. Indeed, 47 percent identified as nonheterosexual. These demographics question the generalizability of this study to non-LGBT-focused health centers and those providing care to older

patients. Finally, this study did not address which beliefs drove patient responses (Cahill et al. 2014).

This study was developed to address these gaps and to provide data to help outpatient clinics take the initial steps in developing evidence-based policies and procedures for the implementation and collection of SOGI data. We tested the hypothesis that patient attitudes toward intake forms would be significantly more negative if the forms include SOGI questions versus if they do not. Additionally, given that sensitive questions are more susceptible to nonresponse (Krumpal 2013), a secondary aim was to assess the completion rate of individual SOGI questions. A SOGI question was considered “completed” if the patient provided an answer. We also qualitatively assessed the concerns of patients who responded negatively to the SOGI questions. The results of this study will add to the national discourse and help inform policies and procedures regarding routine collection of SOGI data in clinical settings.

## METHODS

This two-phase mixed-methods study included experimental and qualitative components. SOGI data were collected at three outpatient clinics between 6/29/2015 and 2/29/2016 in a large academic medical center: (1) a women’s health clinic, serving local, regional, and national patients aged 18 years and older; (2) a continuity care clinic predominantly serving regional and national patients aged 65 years and older; and (3) a primary care clinic that serves local patients and is located 20 min from the two outpatient clinics. Clinics were chosen for their diversity in patient population: (1) women, (2) advanced age, (3) rural population. This study was originally designed and implemented as a quality improvement project, and later, institutional review board approval was obtained for secondary data analysis.

### *SOGI Questions*

The SOGI questions were chosen on the basis of recommendations from published scientific literature (Tate, Ledbetter, and Youssef 2013; Cahill and Makadon 2014; Cahill et al. 2014; Thompson, Weathers, and Karnik 2016) and consensus from our institution’s Office of Health Equity and Inclusivity (OHEI). OHEI’s process for including questions has been described elsewhere (see Institute of Medicine [US] Board on the Health of Select Populations 2013). Questions included a two-step gender identity and birth sex

question, with reported high sensitivity and specificity in accurately identifying adults as transgender versus cisgender (The GeniUSS Group, 2014): (1) “What sex were you assigned at birth on your original birth certificate?” (male, female, or choose not to answer) and (2) “What is your current gender identity?” (male, female, female-to-male/transgender male/trans man, male-to-female/transgender female/trans woman, gender queer/neither exclusively male nor female, additional gender category/other [describe], or choose not to answer). Sexual orientation was assessed by a question that was pilot tested by Fenway Health (Bradford et al. 2012): “Do you think of yourself as” (lesbian/gay/homosexual, straight/heterosexual, bisexual, something else [describe], don’t know, or choose not to answer). Finally, participants were asked their preferred name and gender pronoun: “What is your preferred gender pronoun?” (he/him, she/her, something else [describe], or choose not to answer).

### *Staff Training*

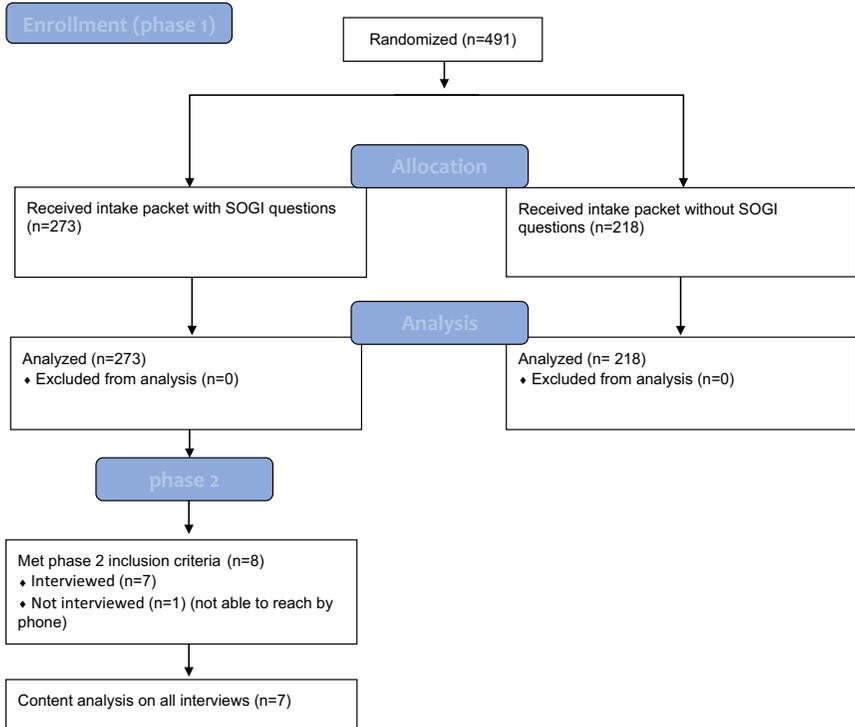
Before data collection, support staff (i.e., those who dispersed intake questionnaires to clinic patients) in each of the three clinics attended a 1-h in-person training session on SOGI data collection. The training included didactics on basic LGBT information and health disparities and in-session role-playing for answering potential patient questions about SOGI. All staff were given hand-outs on common LGBT terminology and misconceptions about SOGI data collection (French 2013). Additional online resources and a link to a recorded video of the training for future reference were also provided.

### *Study Design*

Phase 1 of the study was a pragmatic randomized trial. Patients attending any of the three clinics for the first time were randomly assigned to the control (routine intake form) or experimental groups (routine intake form including SOGI questions). For randomization, a study coordinator provided front desk staff with a stack of intake forms before the start of each clinic day. Experimental and control forms were randomly distributed within the stack using a random numbers procedure. Staff was asked to distribute the form on top of the pile when patients check in. Staff was asked not to look through the stack or the individual form they gave the patient to blind them to the experimental condition. Both experimental and control intake form packets concluded with a brief feedback form asking patients about their experience with the intake

packet as a whole so as not to prime patients for bias. Patients were asked whether filling out the form was tiring, some of the questions upset them, they did not understand some of the questions, the questions on the form are important, the questions were relevant to them, the instructions were easy to follow, and they felt comfortable answering all the questions. Response options included *strongly disagree*, *somewhat disagree*, *neither agree nor disagree*, *somewhat agree*, or *strongly agree* with the statement. Finally, patients were asked whether any questions distressed, upset, or offended them and, if so, which question(s). An optional open-ended question asked patients whether they wanted us to know anything else about their experience completing the form. If a patient expressed concern about SOGI data collection to support staff, they were given an information sheet that included the telephone number and e-mail address of the principal investigator (JER). Staff was asked to track the number of patients who refused the questionnaires. For phase 2, inclusion criteria included any patient in the experimental group who responded “yes” to the question about whether questions distressed, upset, or offended them *and* indicated their bother was specific to SOGI questions or did not identify which questions they found bothersome. Those meeting inclusion criteria were asked to participate in a 5- to 15-min recorded telephone interview to follow up and discuss their concerns about the intake questions. An interview guide was developed that focused on understanding patient feelings, beliefs, and concerns about the intake questions. Open-ended questions included, “Could you tell me which questions were upsetting?” and “Could you describe why those questions were so upsetting?” Follow-up probes were developed for two responses, irrelevant to care and SOGI questions. If patients reported questions were not relevant to care, they were then asked: Could you explain to me why you felt some questions were not relevant to your care? Could you imagine a situation of when the questions could be relevant to your care? If SOGI questions were identified as upsetting, additional questions to help guide clinical practice were asked: “Do you have concerns with information about sexual orientation or gender identity being in medical records?” and “Is there anything we can do to make you feel more comfortable with questions about sexual orientation or gender identity?” All interviews were audio recorded and transcribed verbatim with all identifiable information deleted. Transcripts were entered into NVivo 10 (QSR International) for data management. See Figure 1 for the flow of participants through this pragmatic randomized trial.

Figure 1: CONSORT Table for Pragmatic Randomized Trial to Assess Patient Acceptance of SOGI Questions [Color figure can be viewed at [wileyonlinelibrary.com](http://wileyonlinelibrary.com)]



### *Statistical Analyses*

Demographic, social, and questionnaire characteristics collected for phase 1 were compared between the experimental (SOGI) and control groups and between those who did or did not answer specific SOGI questions.  $\chi^2$  tests were conducted for comparisons across two- or three-level categorical variables; *t*-tests were used to compare participants' age. Similar comparisons were made within the SOGI group, between those who did and did not answer individual SOGI questions, to test whether patterns of nonresponse differed by participant demographics. Finally, two readers (JER and CAG) independently evaluated concordance between each patient's preferred name and their name in the electronic health record (EHR). Statistical analyses were conducted using SAS version 9.4 (SAS Institute Inc).

For phase 2, we used content analysis, a common analytical method in qualitative research (Nandy and Sarvela 1997; Hsieh and Shannon 2005) that builds on dissection of text data, to analyze the transcribed interview data. Two team members (JMG and JLF) reviewed transcripts and discussed initial, top-level codes. One of the two team members then coded transcripts. Transcribed data were read repeatedly by the analyst to reach a full understanding of the text. Next, the analyst coded the text by highlighting exact words from each interview that reflected the top-level codes. The analyst then used the codes to analyze the data and summarize common themes. The other team member (JMG) then reviewed transcripts and codes and separately summarized themes. Summaries for both team members were consistent with no discrepancies.

## RESULTS

### *Participants*

All patients attending participating clinics were provided intake and feedback forms during the study period, and a total of 491 participants completed the form (Table 1). The mean (SD) age was 52.6 (13.6) years, and most participants (87.6 percent) were identified as female in the EHR. No patients were identified as intersex. The majority of participants identified their race as white (94.7 percent) and their ethnicity as non-Hispanic/Latino (95.3 percent). Most participants (92.6 percent) lived in an urban area (population density of at least 1,000 people per square mile). Race, ethnicity, and population density of hometown did not differ significantly by experimental group (all  $p$  values  $> .4$ ).

A total of 218 participants were randomly assigned to the control (routine intake form) group (women's health clinic,  $n = 143$ ; primary care clinic,  $n = 58$ ; continuity care clinic,  $n = 17$ ), and 273 were assigned to the experimental (routine intake form including SOGI questions) group (women's health clinic,  $n = 213$ ; primary care clinic,  $n = 51$ ; continuity care clinic,  $n = 9$ ). The discrepancy in the number of those randomly assigned to the control group versus the experimental group is attributed to initial challenges in implementing the SOGI protocol in the continuity care clinic. Due to clinical staff attrition and subsequent confusion about the randomization protocol, more participants were initially given the experimental intake forms than the control forms. Participant age did not significantly differ between the two groups ( $p = .07$ ) (Table 1), but the proportion of men was higher in the control

Table 1: Participant Characteristics\*

<i>Characteristic</i>	<i>Group</i>		<i>All (N = 491)</i>
	<i>Experimental (n = 273)</i>	<i>Control (n = 218)</i>	
Mean (SD) age, year	51.6 (13.1)	53.9 (14.0)	52.6 (13.6)
Gender listed in medical record <sup>†</sup>			
Male	26 (9.5)	35 (16.1)	61 (12.4)
Female	247 (90.5)	183 (83.9)	430 (87.6)
Experimental group only			
Sex assigned at birth	(n = 254)		
Male	23 (9.1)		
Female	231 (90.9)		
Current gender identity	(n = 255)		
Male	23 (9.0)		
Female	232 (91.0)		
Preferred gender pronoun	(n = 236)		
He/him	23 (9.7)		
She/her	213 (90.3)		
Sexual identity	(n = 239)		
Homosexual	2 (0.8)		
Heterosexual	236 (98.7)		
Don't know	1 (0.4)		
Race			
White (non-Hispanic/Latino)	260 (94.0)	205 (95.4)	465 (94.7)
Nonwhite	9 (3.3)	10 (4.6)	19 (3.9)
Unknown	4 (57.1)	3 (1.4)	7 (1.4)
Ethnicity			
Non-Hispanic/Latino	257 (94.1)	211 (96.8)	468 (95.3)
Hispanic/Latino	1 (0.4)	1 (0.5)	2 (0.4)
Unknown	15 (5.5)	6 (2.8)	21 (4.3)
Site			
Women's health clinic	213 (59.8)	143 (40.2)	356 (72.5)
Continuity care clinic	9 (34.6)	17 (65.4)	26 (5.3)
Primary care clinic	51 (46.8)	58 (53.2)	109 (22.2)
Population density, persons/mi <sup>2</sup>	(n = 270)	(n = 217)	(n = 487)
<500	19 (7.0)	17 (7.8)	36 (7.4)
500–999	115 (42.6)	80 (36.9)	195 (40.0)
1,000–1,499	33 (12.2)	46 (21.2)	79 (16.2)
1,500–2,499	60 (22.2)	43 (19.8)	103 (21.1)
≥2,500	43 (15.9)	31 (14.3)	74 (15.2)

\*Values are no. of participants (%), unless otherwise stated.

<sup>†</sup>The institution's electronic health record states patient gender, not sex assigned at birth. SOGI, sexual orientation and gender identity.

group (16.1 percent vs. 9.5 percent SOGI group;  $p = .03$ ). In the experimental group, nearly all those who answered the question ( $n = 239$ ) self-identified as heterosexual (98.7 percent). All participants who answered the question

identified as cisgender, although one person gave a current gender identity as female but did not report gender assigned at birth. No patients refused to complete their intake packet. No patients directly contacted the principal investigator (JER) with acute concerns about the SOGI questions.

To further accommodate patients' identity, all patients were asked for preferred name apart from their EHR-recorded name. Twenty-five patients (5.1 percent) reported a name other than their EHR name, which may have been an abbreviated or nickname version of their EHR name.

### *Phase 1*

There were no significant differences in patient attitudes between the experimental and control groups in the proportions who answered agree, neither agree nor disagree, or disagree for any of the questions about the survey (Table 2). The proportion of respondents indicating they agreed with the question, "Was filling out this questionnaire tiring?" was higher in the experimental group (22.6 percent, vs. 15.4 percent of the control group;  $p = .03$ ) as a two-group comparison (agree vs. neither/disagree). In the experimental group, 15 participants (6.2 percent) reported being distressed, upset, or offended by questions in their intake packet; of these, only eight (3.3 percent) reported being distressed, upset, or offended by the SOGI questions specifically.

Among the experimental group, the least-answered SOGI questions were preferred gender pronoun, with 37 participants (13.6 percent) not answering this question, and sexual identity, with 31 (11.4 percent) not answering the question. Nineteen participants (7.0 percent) did not answer sex assigned at birth, and 18 participants (6.6 percent) did not answer current gender identity. Comparisons between patients who did and did not report their preferred gender pronouns, as well as sexual identity, revealed that older patients and those from the continuity care clinic were significantly less likely to answer those questions (Tables 3 and 4). In addition, those who did not answer sexual identity were significantly more likely to report that some questions in their intake packet upset them (Table 4).

### *Phase 2*

Eight participants met criteria for phase 2. Seven of eight were interviewed. The one nonparticipant did not return multiple telephone calls requesting an interview.

Table 2: Patient Attitude and Satisfaction Questions by Experimental Group

Questionnaire Item	Group*		p Value	
	Experimental (n = 273)	Control (n = 218)	Overall	2- Group†
1. Filling out this form was tiring	(n = 265)	(n = 208)	.11	.03
Agree	60 (22.6)	32 (15.4)		
Neither	87 (32.8)	69 (33.2)		
Disagree	118 (44.5)	107 (51.4)		
2. Some of the questions upset me	(n = 266)	(n = 208)	.39	.21
Agree	20 (7.5)	10 (4.8)		
Neither	62 (23.3)	43 (20.7)		
Disagree	184 (69.2)	155 (74.5)		
3. I didn't understand some of the questions	(n = 263)	(n = 207)	.20	.37
Agree	18 (6.8)	19 (9.2)		
Neither	46 (17.5)	25 (12.1)		
Disagree	199 (75.7)	163 (78.7)		
4. Many of the questions are not relevant to me	(n = 263)	(n = 209)	.40	.38
Agree	83 (31.6)	58 (27.8)		
Neither	97 (36.9)	73 (34.9)		
Disagree	83 (31.6)	78 (37.3)		
5. The instructions were easy to follow	(n = 261)	(n = 205)	.61	.66
Agree	245 (93.9)	188 (91.7)		
Neither	14 (5.4)	14 (6.8)		
Disagree	2 (0.8)	3 (1.5)		
6. I felt comfortable answering all questions	(n = 266)	(n = 207)	.22	.26
Agree	211 (79.3)	177 (85.5)		
Neither	28 (10.5)	15 (7.2)		
Disagree	27 (10.2)	15 (7.2)		

\*Values are no. of participants (%).

†Agree vs. neither/disagree for questions 1–4, agree/neither vs. disagree for questions 5 and 6.

For the seven who were interviewed, two main themes emerged from the coded data: concerns about the appropriateness of transgender questions on intake forms and concerns about sexual identity/gender identity questions. First, those interviewed found the transgender questions bothersome, stating that they were not appropriate or relevant questions for the clinical setting and, specific to one clinic, raised concern as to why transgender patients were being seen in a women's health clinic. For example, one participant stated that to be asked gender identity questions in a women's health clinic was "shocking" and reported worry that men would be treated in a women's clinic. Second, interviewees stated that they either did not understand the sexual identity/gender identity questions or they were bothered by questions about

Table 3: Comparison of Characteristics by Answering SOGI Question “Preferred Gender Pronoun”

Characteristic	Question Answered*		p Value
	No (n = 37)	Yes (n = 236)	
Mean (SD) age, y	55.5 (15.0)	51.0 (12.7)	.0495
Gender listed in medical record <sup>†</sup>			.76
Male	33 (89.2)	214 (90.7)	
Female	4 (10.8)	22 (9.3)	
Site			<.001
Women’s health clinic	23 (62.2)	190 (80.5)	
Continuity care clinic	5 (13.5)	4 (1.7)	
Primary care clinic	9 (24.3)	42 (17.8)	
Population density, persons/mi <sup>2</sup>	(n = 36)	(n = 234)	.14
<500	4 (11.1)	15 (6.4)	
500–999	19 (52.8)	96 (41.0)	
1,000–1,499	6 (16.7)	27 (11.5)	
1,500–2,499	3 (8.3)	57 (24.4)	
≥2,500	4 (11.1)	39 (16.7)	
Mean (SD) population density	1,650 (797)	2,229 (2,636)	.86
Agreed with question			
Filling out form was tiring	11/33 (33.3)	50/233 (21.5)	.13
Some questions upset me	5/33 (15.2)	15/233 (6.4)	.08
Didn’t understand some questions	2/32 (6.3)	16/232 (6.9)	>.99
Questions didn’t apply	12/30 (40.0)	71/234 (30.3)	.28
Instructions easy to follow	32/32 (100)	228/230 (99.1)	>.99
Felt comfortable answering all questions	30/33 (90.9)	210/234 (89.7)	>.99

\*Values are No. of participants (%) or No. of participants/No. available (%), unless otherwise stated.

<sup>†</sup>The institution’s electronic health record states patient gender, not sex assigned at birth. SOGI, sexual orientation and gender identity.

sex assigned at birth and current gender identity. For example, one participant stated that the SOGI questions were upsetting because of their personal “belief system.” When asked if the questions could be revised to help the participant feel more comfortable, the participant stated “No,” explaining that the questions simply did not correspond with their personal beliefs.

## DISCUSSION

To our knowledge, the current study is the first to assess patients’ attitudes about collection of SOGI data on routine clinical intake forms. Patients surveyed (i.e., heterosexual and older than 50 years) were those who were previously found to be less accepting of SOGI questions when asked as a stand-

Table 4: Comparison of Characteristics by Answering SOGI Question “Sexual Identity”

<i>Characteristic</i>	<i>Question Answered*</i>		<i>p Value</i>
	<i>No (n = 31)</i>	<i>Yes (n = 242)</i>	
Mean (SD) age, y	58.9 (14.9)	50.7 (12.6)	<.001
Gender listed in medical record <sup>†</sup>			.51
Male	4 (12.9)	22 (9.1)	
Female	27 (87.1)	220 (90.9)	
Site			<.001
Women’s health clinic	16 (51.6)	197 (81.4)	
Continuity care clinic	6 (19.4)	3 (1.2)	
Primary care clinic	9 (29.0)	42 (17.4)	
Population density, persons/mi <sup>2</sup>		(n = 239)	.63
<500	3 (9.7)	16 (6.7)	
500–999	13 (41.9)	102 (42.7)	
1,000–1,499	6 (19.4)	27 (11.3)	
1,500–2,499	5 (16.1)	55 (23.0)	
≥2,500	4 (12.9)	39 (16.3)	
Mean (SD) population density	1,619 (864)	2,221 (2,609)	.42
Agreed with question			
Filling out form was tiring	10/27 (37.0)	51/239 (21.3)	.07
Some questions upset me	6/27 (22.2)	14/239 (5.9)	.002
Didn’t understand some questions	4/26 (15.4)	14/238 (5.9)	.09
Questions didn’t apply	11/25 (44.0)	72/239 (30.1)	.16
Instructions easy to follow	26/26 (100)	234/236 (99.2)	>.99
Felt comfortable answering all questions	25/27 (92.6)	215/240 (89.6)	>.99

\*Values are No. of participants (%) or No. of participants/No. available (%), unless otherwise stated.

<sup>†</sup>The institution’s electronic health record states patient gender, not sex assigned at birth. SOGI, sexual orientation and gender identity.

alone survey (Cahill and Makadon 2014). Overall, only 3 percent of patients reported being distressed, upset, or offended by SOGI questions, and 3 percent of patients reported being distressed, upset, or offended by questions *other* than SOGI. This study supports that collection of SOGI information by incorporating questions into routine clinical intake forms is acceptable to 97 percent of heterosexual and cisgender patients, many of whom are older than 50. Thus, with regard to heterosexual and cisgender individuals, the hypothesis that patient attitudes toward intake forms would be significantly more negative among those who received intake forms including SOGI questions was not supported. However, these findings do not help clarify the acceptability of SOGI for the LGBT population, as only 0.8 percent of participants in this study identified as LGBT.

Two consistent themes emerged from the seven interviews. First, participants were bothered by the gender identity questions—that is, were confused by the concept of gender identity and/or did not believe the questions to be relevant in a medical setting. Second, patients in a gender-specific clinic (i.e., women’s health clinic) were bothered and confused that transgender patients might be seen in the same clinic. Fewer patients than expected met phase 2 inclusion criteria (distressed, upset, or offended by intake questions), possibly suggesting that our eligibility criteria were biased toward only those with very strong views about the intake questions or that there was some social desirability bias in responses. Although a random sample of participants drawn from those who completed the intake form may yield different responses to qualitative questions, this phase was designed to both understand patient experiences and solicit information that would be helpful to clinic staff in the implementation of the SOGI questions.

Preferred gender pronoun and sexual identity were the least-answered SOGI questions. These data do not appear to be missing at random, because participants who did not answer these questions were significantly older. Data from Cahill and colleagues (Cahill et al. 2014) suggest that older participants may be less accepting of SOGI questions, which may account for their greater nonresponse. In the current study, 13 percent of participants did not answer the preferred gender pronoun question, yet only 7 percent did not answer sex assigned at birth and current gender identity. The greater percentage of nonresponses to the preferred gender pronoun question compared with the other gender questions suggests that the preferred gender pronoun question may have been confusing to patients. Thirteen percent of participants also did not answer the sexual identity question. Participants who did not answer this question were significantly more likely to endorse that some questions in their intake form upset them. This suggests that participants may have been upset by the sexual identity question, which led to nonresponse, and one limitation to our study is that this group was not included in the qualitative part of our study. Common reasons for nonresponse of sensitive questions include feeling as if the question is too intrusive, fear that providing a response would involve risk or consequence, and wanting to respond in a socially desirable way (Krumpal 2013). For heterosexual, cisgender individuals, feeling as if the question is too intrusive may be the most logical explanation. However, for sexual minority patients, nonresponse may be related to a reluctance to self-disclose sexual identity. Along these lines, it is surprising that the estimated population prevalence of lesbian, gay, and bisexual individuals is 3.5 percent (Gates 2011) and transgender individuals is 0.6 percent (Flores et al. 2016), yet in the

current sample only 0.8 percent of patients identified as lesbian, gay, and bisexual, and no participants identified as transgender. This may result from the homogeneity of the sample collected or a reluctance to disclose. Recent research suggests the former, as only about 6 percent of LGBT patients in a nationally representative sample stated that they would refuse to disclose their sexual identity in an emergency department setting. Most LGBT individuals expressed the importance of disclosing SOGI for normalization and recognition and felt that it was a relevant part of their health care encounter (Haider et al. 2017). Indeed, recognition is important as providers at UCDHS indicated that SOGI questions were irrelevant because few if any of their patients (to their knowledge) were lesbian, gay, bisexual, or transgender (LGBT) (Callahan et al. 2015).

Ultimately, extensive pilot testing of the SOGI questions, including their specific wording, placement, skip patterns, and mode of data collection, is needed to determine effective implementation of these questions. Recent research on SOGI data collection suggests that patients and providers are more comfortable with SOGI data collection when there is an assurance of confidentiality, privacy to complete the questions, and collection is documented the same as all other demographics (Haider et al. 2017). Additionally, the Williams Institute has outlined current best practices regarding these issues (The GeniUSS Group and Herman 2014). The findings from the present study indicate that a simple explanation of why SOGI data are being collected, in conjunction with brief explanations of questions more likely to be confusing (e.g., preferred pronoun), will enhance disclosure. Five percent of patients reported a preferred name other than their EHR name. Preferred name is especially relevant for transgender persons, whose name assigned at birth may differ. However, in the present study of exclusively cisgender individuals, preferred name was found to also be a meaningful demographic. Furthermore, this study highlighted that patients are being asked their “gender” in the EHR, with response options of male or female. Unfortunately, it is unclear whether this question is capturing sex assigned at birth or gender identity, or perhaps both depending on the patient’s interpretation. These questions are important for organizations in the process of revising their EHR demographics.

As implemented in the present study, SOGI data collection must involve a training program for frontline staff (Cahill et al. 2016; Thompson, Weathers, and Karnik 2016). In fact, providers at UCDHS reported that they should not be required to ask SOGI questions because they had no relevant training (Callahan et al. 2015). The University of California, San Francisco,

Center of Excellence for Transgender Health, for example, suggests that patients who report confusion or ambivalence about answering SOGI questions be told that “We ask these questions to make sure all our patients are comfortable telling us their full identity and medical history” (Center of Excellence for Transgender Health University of California, San Francisco 2017). The Fenway Institute has developed a free training module available at <http://www.lgbthealtheducation.org/webinar/training-frontline-staff/>. Institution-wide implementation of SOGI data collection requires institutional support and dedicated time for staff training. Future research is needed to develop an empirically supported curriculum for staff and faculty.

The current study is limited in that it only addresses frontline SOGI data collection in an almost exclusively white, heterosexual patient population. Future SOGI data collection would benefit from cognitive interviewing to learn how patients understand the questions being asked of them. Additionally, future research is needed to understand the appropriate follow-up to SOGI data collection during clinical encounters, as well as the potential implications for health care interventions in diverse populations (Thompson, Weathers, and Karnik 2016). Furthermore, it is unclear how SOGI data collection will affect those who identify as LGBT. Data from Cahill and colleagues (Cahill et al. 2014) suggest that LGBT persons respond more positively to SOGI data collection than do those who identify as heterosexual. However, although there was previously a gender identity and sex stereotype nondiscrimination rule enacted by the Office of Civil Rights and the US Department of Health and Human Services (Department of Health and Human Services 2016a), there is currently an injunction in place that prohibits protection on the basis of gender identity (Department of Health and Human Services 2016b). This leaves transgender patients who disclose their gender identity at risk of discrimination, including denial of health care access and benefits (Thompson, Weathers, and Karnik 2016). Patients may benefit from being reminded on intake forms about their health care institution’s nondiscrimination and confidentiality policies. Recently, the National Institutes of Health designated sexual and gender minorities as a health disparity population for research, which hopefully will advance research efforts involving this population (National Institutes of Health, Director’s message 2016).

Our study suggests that collection of SOGI information using routine clinical intake forms is not likely to be distressing to heterosexual, cisgender, white, and older adult populations. These data provide strong support for the feasibility and acceptability of the implementation of routine collection of SOGI data in outpatient clinical settings.

## ACKNOWLEDGMENTS

*Joint Acknowledgment/Disclosure Statement:* We would like to acknowledge the following funders: The Division of General Internal Medicine at Mayo Clinic, the Office of Health Disparities Research at Mayo Clinic, the Care Experience Program in the Kern Center for the Science of Healthcare Delivery, and the Department of Psychology and Psychiatry. We would also like to acknowledge Sean Phelan, PhD, for his conception and design contributions and Sharyn L. French for her administrative support.

*Disclosures:* None.

*Disclaimer:* None.

## REFERENCES

- Bradford, J., S. Cahill, C. Grasso, and H. Makadon. 2012. *How to Ask About Sexual Orientation and Gender Identity in Clinical Settings*. Boston, MA: The Fenway Institute.
- Cahill, S., and H. Makadon. 2014. "Sexual Orientation and Gender Identity Data Collection in Clinical Settings and in Electronic Health Records: A Key to Ending LGBT Health Disparities." *LGBT Health* 1 (1): 34–41.
- Cahill, S., R. Singal, C. Grasso, D. King, K. Mayer, K. Baker, and H. Makadon. 2014. "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." *PLoS ONE* 8 (9): e107104.
- Cahill, S. R., K. Baker, M. B. Deutsch, J. Keatley, and H. J. Makadon. 2016. "Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health." *LGBT Health* 3 (2): 100–2.
- Callahan, E. J., N. Sitkin, H. Ton, W. S. Eidson-Ton, J. Weckstein, and D. Latimore. 2015. "Introducing Sexual Orientation and Gender Identity into the Electronic Health Record: One Academic Health Center's Experience." *Academic Medicine* 90 (2): 154–60.
- Center of Excellence for Transgender Health University of California, San Francisco. 2017. "Acknowledging Gender and Sex" [accessed on March 28, 2017]. Available at <http://transhealth.ucsf.edu/video/story.html>
- Centers for Medicare and Medicaid Services. 2015. "Medicare and Medicaid programs; Electronic Health Record Incentive Program – Stage 3 and Modifications to Meaningful Use in 2015 Through 2017. 45 CFR 412" [accessed on July 20, 2017]. Available at <https://www.federalregister.gov/documents/2015/10/16/2015-25595/medicare-and-medicare-programs-electronic-health-record-incentive-program-stage-3-and-modifications>
- Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities, Board on the Health of Select Populations, Institute of Medicine of the National Academies. 2011. *The Health of Lesbian, Gay, Bisexual,*

- and *Transgender People: Building a Foundation for Better Understanding*. Washington, DC: National Academies Press.
- Department of Health and Human Services. 2016a. "Nondiscrimination in Health Programs and Activities." Final rule. Fed Regist. 2016 May 18:31375-31473 [accessed on March 28, 2017]. Available at <https://www.federalregister.gov/documents/2016/05/18/2016-11458/nondiscrimination-in-health-programs-and-activities>
- Department of Health and Human Services. 2016b. Nondiscrimination Under the Patient Protection Act and Affordable Care Act. 45 CFR 92" [accessed on July 20, 2017]. Available at <https://www.hhs.gov/civil-rights/for-individuals/section-1557>
- Flores, A. R., J. L. Herman, G. J. Gates, and T. N. Brown. 2016. "How Many Adults Identify as Transgender in the United States?" [accessed on December 20, 2016]. Available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf>
- French, S. 2013. "Inclusive Questions for Older Adults: A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity." [accessed on December 20, 2016]. Available at <http://www.sageusa.org/resources/publications.cfm?ID=161>
- Gates, G. 2011. "How Many People are Lesbian, Gay, Bisexual, and Transgender?" [accessed on December 20, 2016]. Available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf>
- The GeniUSS Group; Herman, J. L., editor. 2014. "Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys" [accessed on December 20, 2016]. Available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>
- Haider, A. H., E. B. Schneider, L. M. Kodadek, R. R. Adler, A. Ranjit, M. Torain, R. Y. Shields, C. Snyder, J. D. Schuur, L. Vail, D. German, S. Peterson, and B. D. Lau. 2017. "Emergency Department Query for Patient-Centered Approaches to Sexual Orientation and Gender Identity: The EQUALITY Study." *JAMA Internal Medicine* 177 (6): 819–28.
- Hsieh, H. F., and S. E. Shannon. 2005. "Three Approaches to Qualitative Content Analysis." *Qualitative Health Research* 15 (9): 1277–88.
- Institute of Medicine (US) Board on the Health of Select Populations. 2013. *Collecting Sexual Orientation and Gender Identity Data in Electronic Health Records: Workshop Summary*. Washington, DC: National Academies Press.
- Krumpal, I. 2013. "Determinants of Social Desirability Bias in Sensitive Surveys: A Literature Review." *Quality and Quantity* 47 (4): 2025–47.
- Nandy, B., and P. Sarvela. 1997. "Content Analysis Reexamined: A Relevant Research Method for Health Education." *American Journal of Health Behavior* 21 (3): 222–34.
- National Institutes of Health, Director's message. 2016. "Sexual and Gender Minorities Formally Designated as a Health Disparity Population for Research Purposes" [accessed on January 3, 2017]. Available at <https://www.nimhd.nih.gov/about/directors-corner/message.html>

- Tate, C. C., J. N. Ledbetter, and C. P. Youssef. 2013. "A Two-Question Method for Assessing Gender Categories in the Social and Medical Sciences." *Journal of Sex Research* 50 (8): 767–76.
- Thompson, H. M., A. L. Weathers, and N. S. Karnik. 2016. "Re: Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health." *LGBT Health* 3 (4): 319–21.

## SUPPORTING INFORMATION

Additional supporting information may be found online in the supporting information tab for this article:

Appendix SA1: Author Matrix.