

Acceptability and Feasibility of Collecting Sexual Orientation and Expanded Gender Identity Data in Urology and Oncology Clinics

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Abstract

Purpose: We evaluated the acceptability and feasibility of collecting sexual orientation and gender identity (SOGI) data in oncology and urology clinical settings.

Methods: We surveyed 101 urology and 104 oncology clinic patients with a standardized sexual orientation question with six response options, “lesbian, gay, or homosexual;” “straight or heterosexual;” “bisexual;” “something else;” “do not know;” and “choose not to disclose.” Next, we added the sexual orientation question and an expanded gender identity question to the electronic medical record (EMR) and analyzed data on the first 450 urology and 103 oncology patients. Acceptability and feasibility were assessed based on responses to the survey and patient intake forms.

Results: In the acceptability survey, only 3% of urology and 4% of oncology patients selected “choose not to disclose.” Over 90% of patients in both clinics assessed the sexual orientation question as understandable and easy to answer. In all, 79% of urology and 73% of oncology patients stated they would answer it in their EMR, but only 56% of urology and 54% of oncology patients described the information as important. Sexual minority patients were as likely as heterosexual patients to state they would answer the question. Only 5% of patients selected “choose not to disclose” for sexual orientation, and <1% for the expanded gender identity question.

Conclusion: Adding SOGI questions to the EMR appears to be acceptable and feasible and the sexual orientation question was understandable to a large majority of urology and oncology patients. ClinicalTrials.gov ID: NCT03343093

Keywords: data collection, gender, oncology, sexual orientation, urology

Introduction

SEXUAL AND GENDER MINORITY (SGM) populations denotes lesbian, gay, bisexual, and other nonheterosexual persons, as well as individuals whose gender identity differs from their assigned sex at birth. SGM populations experience significant cancer health disparities, including inequitable and suboptimal cancer care.^{1,2} SGM individuals represent ~4.5% of the U.S. population and are increasingly visible, particularly among young, aging, and ethnoracial minority populations.³

The American Society of Clinical Oncology has recommended that sexual orientation and gender identity (SOGI) be included as a data element in cancer registries and clinical trials to further research on the unequal burden of cancer.⁴ They also recommend that cancer care be improved for SGM populations through culturally competent patient education and support services. Neither of these recommendations can be implemented without the routine collection of SOGI in clinics where SGM populations receive oncology care.⁵

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Identifying and eliminating health disparities based on SOGI is essential to improving population health and health equity.⁶ Indeed, a national study of 429 emergency department providers and 1516 patients found that 73.8% of providers and 48.9% of patients endorsed that routine sexual orientation data collection would help providers to have a better understanding of the whole patient, versus 8.2% of providers and 13.3% of patients who disagreed with the statement.⁷ However, 79.8% of providers thought that collecting sexual orientation data would offend patients, whereas only 10.5% of patients reported that they would be offended.⁷

The lack of perceived relevance of SOGI information in oncology and urology settings may be a barrier. In a national survey of oncologists, only 39.6% agreed that knowing a patient's sexual orientation was important.⁸ This sentiment is reflected in current data collection practices. In a recent study of 21 cancer centers with a comprehensive designation from the National Cancer Institute (NCI), only 3 routinely collected sexual orientation and 4 distinguished current gender identity from sex assigned at birth.⁹ In another study of community-based oncology practices participating in the NCI Community Oncology Research Program, 24.0% and 10.0% were routinely collecting SOGI data, respectively.¹⁰

Although there is strong evidence to indicate that collecting SOGI information in primary care settings is highly acceptable and feasible to patients,^{7,11,12} the evidence for the acceptability and feasibility of collecting this information from patients seeking cancer care is lacking. Primary care providers may allocate specific time to building rapport with patients and taking their relational and sexual histories, whereas cancer specialists may not have the same opportunities. A recent study of 225 oncology patients found favorable perceptions regarding answering SOGI questions.¹³ For sexual orientation, being asked online (42%) was preferred either to being asked in person (28%) or on a form (18%).¹³ Being provided with a confidential and secure opportunity to disclose, such as through a patient-facing portal, appears to provide important benefits.¹² As Cahill et al. note, "SOGI data collection is a key component of enhancing the ability of patients and providers to engage in meaningful dialogue in the exam room."¹² This is especially important for cancers that directly impact sexual functioning and sexual health. As a participant in our Restore-1 study of prostate cancer patients said: *"I had identified myself as gay before the appointment. He knew that. At one point in the appointment, he invited my wife to leave the room. ... We talked openly and honestly at that point."* (Rosser BRS: Prostate cancer in gay and bisexual men: Selected key results from the Restore study. AUA Conference, San Francisco, CA, 2018; unpublished data).

In a recent study of 193 SGM prostate cancer survivors, 77% of participants had disclosed their sexual orientation to their primary provider, but significantly fewer were "out" to their urologist (60%), surgeon (59%), or oncologist (56%).¹⁴

The aim of this two-phase study was to evaluate the acceptability and feasibility of collecting sexual orientation data in cancer care clinical settings. Phase 1 involved assessment of the acceptability of adding a question on sexual orientation to the electronic medical record (EMR). Phase 2 was conducted after the insertion of SOGI questions in the EMR and assessed acceptability of both SOGI questions in the EMR.

Prostate cancer is the most common invasive cancer among men, including sexual minority men.² Given that urology and oncology clinics commonly coordinate the diagnosis and treatment of prostate cancer, the research questions addressed in this study included: (1) what percentage of urology and oncology patients will respond to SOGI questions on the EMR? (2) How well are sexual orientation questions understood by patients? (3) What percentage of urology and oncology patients agree that sexual orientation is important for their providers to know?

Methods

Study design

There were two phases to this research. In phase 1, the acceptability and feasibility of sexual orientation items were tested using a brief survey instrument administered to patients. In phase 2, SOGI items were implemented in a routine, previsit patient-facing portal that linked to the EMR.

Phase 1: acceptability survey

Participants. In 2018, participants were recruited from the urology and oncology clinics at a large Midwestern, university-based outpatient clinic. All consecutive patients who were 18 years or older in age and able to comprehend and read English were approached for participation. Both phases of the study were determined to be exempt from human subjects' research by the University of Minnesota Institutional Review Board [Exemption 2 of 45 CFR 46.104(d)] as both phases of the study only involved anonymous data collection from adults. Each participant provided oral consent for their participation. Given the brevity of the survey, no compensation was provided.

Measures. A paper survey was administered and took between 1 and 4 minutes to complete. Survey instructions read, "This brief survey is anonymous and will not be linked to your medical record. Our clinic is considering adding this question to our electronic medical record." Sexual orientation was assessed with the following item and response categories: Do you think of yourself as: "Lesbian, gay, or homosexual," "Straight or heterosexual," "Bisexual," "Something else, please specify," "Do not know," or "Choose not to disclose." The wording of the question and the order of the response options were taken from prior research in community primary care clinics.^{11,12,15} To assess acceptability, we made one adaptation by adding the "choose not to disclose" option. We reasoned that patients who considered this question to be unacceptable would choose this option.

Participants were then asked five questions, scored on a five-point Likert scale (1 = strongly disagree; 5 = strongly agree), to assess feasibility and acceptability of including these questions in their EMR. The first three questions assessed comprehension (i.e., understanding of the question and response options). Then, participants were asked if they would answer this question if it was on their EMR at this clinic. Next, they were asked their agreement with the statement, "I think this information is important for my provider to know about me." Four questions assessed demographics, including age, gender, race, and ethnicity that were collected on the back side of the survey. Finally, as patients with

prostate cancer are integrated into a broader clinical schedule at these clinics, participants were asked the reason for their medical visit: prostate cancer, breast cancer, other cancers, or another noncancer problem.

Procedures. Surveys were administered to patients awaiting care in waiting rooms or private patient rooms at each clinic. Patients were approached by either the research assistant or a nurse and asked to complete a short survey. While participants completed the survey, the research assistant stayed nearby to answer any questions. When in the waiting room, care was taken to ensure the patient could answer the survey confidentially and ask any questions without being overheard. If participants were called into the medical visit before completing the survey, they either completed the remainder of the survey after the visit ($n=2$) or returned the survey with what they had completed thus far ($n=4$). A small number of patients ($n=18$) were not offered the survey, including 5 who appeared preoccupied or distracted, 3 who appeared too physically impaired, and 10 who were called into the doctor or left the area before the staff reached them.

Data analyses. Demographic variables (age, gender, ethnicity, and race) and diagnosis were summarized and compared across the urology and oncology clinics using frequencies and chi-square tests for categorical variables and mean and t -tests for continuous variables.

The sexual orientation item was deemed “acceptable” if a person provided a response other than “Choose not to disclose,” or “do not know,” or skipped the question. In addition, participants who selected “something else” and wrote in responses were divided by researcher discretion. The question was considered acceptable to three participants who responded “queer,” “intersex,” or “homoflexible?” The question was considered unacceptable to two participants who responded, “we are male or female,” or “this is stupid.” It was assumed that the most likely reason to choose “do not know” was not understanding either the question or the response options. We considered the sexual orientation item to be acceptable if 80% or more of participants provided a valid response and also agreed or strongly agreed that they would answer a similar question on their EMR. Similarly, we considered the question feasible if 80% or more agreed or strongly agreed: (1) that the question was understandable, (2) that they understood the answer choices, and (3) that it was easy for them to answer. Likert scale acceptability items were dichotomized by combining the upper two categories: (“strongly agree” and “agree”) and the bottom three (“strongly disagree,” “disagree,” and “neither agree nor disagree”). The percentage of participants responding “agree” or “strongly agree” to each item was compared by clinic and sexual orientation and evaluated using chi-square tests or Fisher’s exact tests for any analysis with 10 participants in each cell. All statistical tests were two-sided and p values <0.05 were considered to be statistically significant. All statistical analyses were conducted using Stata 16.¹⁶

Phase 2: EMR implementation study

Participants. Patients visiting the urology or oncology clinics at a large university-based outpatient clinic in January 2019 were eligible to be included in this study. Data were abstracted from the EMR.

Measures. The sexual orientation question and response options were identical to the item described in Phase 1. The following two-step questions to assess sex at birth and current gender identity were also included. “Sex assigned at birth” was changed to include the following response options: “Female,” “Male,” and “Choose not to disclose.” This item was followed by “Gender identity” with the following response options: “Female,” “Male,” “Transgender Female/Male-to-Female,” “Transgender Male/Female-to-Male,” “Other,” or “Choose not to disclose.”

Procedures. SOGI items were added to the EMR and each patient attending these clinics was prompted to respond as part of an automated online “precheck” for their forthcoming appointment. Data were captured from the EMR for this phase of the study from January to March 2019 (i.e., the first 3 months of SOGI implementation).

Data analysis. Patients were excluded from the analysis if they did not respond to the EMR items on sexual orientation ($n=3439$) or gender identity ($n=3364$). The two most likely reasons for nonresponse were either not having visited the clinic during the study period or not using the online EMR to precheck in for their appointment. As in Phase 1, acceptability was operationalized as a valid response to the SOGI questions other than “choose not to disclose” or “do not know.” Overall acceptability was defined as 80% or more of patients disclosed their SOGI in the EMR. Chi-square tests were used to assess participant responses across clinics. All statistical analyses were conducted using Stata 16.¹⁶

Results

Results phase 1: acceptability survey

The final analytic dataset included 205 participants, including 101 from the urology and 104 from the oncology clinic. In the overall sample, participants ranged in age from 21 to 85 (mean = 57.4 years; standard deviation = 14.5). Forty-seven percent of participants were male, 52% were female, and 1% identified as transgender or nonbinary. The percentage of males was higher in the urology compared with the oncology clinic (60% vs. 32%, $p < 0.001$). The distribution of race and ethnicity was as follows: 89% identified as White, 7% as Black or African American, 2% as Asian American, and 3% as two or more races. Overall, 4% identified as Hispanic, Latino, or Spanish ethnicity. There were no differences in race or ethnicity between the clinics ($p > 0.05$).

Overall, 107 (56.0%) patients were being seen for cancer-related care; however, the majority of patients in the urology clinic were being seen for reasons other than cancer (68%). The other urology patients were receiving care for prostate cancer (21%) or some other type of cancer (11%). In the oncology clinic, patients were being seen for prostate (2%), breast (11%), some other type of cancer (66%), two or more cancers (1%), or a noncancer-related issue (20%).

Responses to the sexual orientation item are presented in Table 1. The acceptability of the sexual orientation item was high with 192 acceptable responses (94%). Of the 13 other responses, 2 selected “do not know,” 7 selected “choose not to disclose,” and 2 did not provide a response. No differences were observed between the two clinics with regard to responses to this item ($p = 0.16$).

TABLE 1. RESPONSES TO THE SEXUAL ORIENTATION QUESTION IN THE PHASE 1 SURVEY

N	<i>All participants</i>	<i>Urology</i>	<i>Oncology</i>	<i>p=0.16</i>
	<i>205</i>	<i>101</i>	<i>104</i>	
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	
Lesbian, gay, or homosexual	5 (2.44)	5 (4.95)	0 (0.00)	
Straight or heterosexual	179 (87.32)	84 (83.17)	95 (91.35)	
Bisexual	5 (2.44)	3 (2.97)	2 (1.92)	
Something else ^a	5 (2.44)	4 (3.96)	1 (0.96)	
Do not know	2 (0.98)	1 (0.99)	1 (0.96)	
Choose not to disclose	7 (3.41)	3 (2.97)	4 (3.85)	
Nonresponse	2 (0.98)	1 (0.99)	1 (0.96)	

^aIncludes “queer,” “intersex,” “homoflexible?,” “we are male or female!,” “This is stupid.”

Comprehension of the sexual orientation question was high (Table 2). The majority of participants indicated that they “...understood what the question was asking” (94%), “understood all of the answer choices” (95%), and that the question was “easy” to answer (93%). A smaller majority (76%) indicated that they would answer this question on their EMR. Approximately half (55%) agreed that their sexual orientation was important for their provider to know. Responses to all of these items were similar in the urology and oncology clinics ($p > 0.05$).

Sexual minority and heterosexual participants reported a higher level of agreement with each acceptability question than nonresponding participants (Table 2). Although 100% of sexual minority participants reported understanding the question and its answer choices, compared with 95% and 96% of heterosexual participants, only 85% of sexual minority participants reported that the question was easy to answer compared with 96% of heterosexual participants. Similarly, 78% of heterosexual participants, only 69% of sexual minority participants, and 54% of nonresponders replied that they would answer the item if it was added to the EMR (n.s.). Sexual minority participants

(69%) were most likely to agree that the item is important for their provider to know compared with 56% of heterosexual participants and 23% of nonresponders.

Results phase 2: EMR implementation study

For sexual orientation, 95% of participants provided a response, 1% of participants responded, “do not know,” and 5% responded “choose not to disclose.” The majority (87%) of participants identified as heterosexual, whereas 4% identified as lesbian, gay, or homosexual, and 3% as bisexual. Responses were similar for participants in the urology and oncology clinics (Table 3).

Only two participants (0.3%) chose not to disclose their gender identity (Table 4). Patients were more likely to identify as female at the oncology clinic (66%) than the urology clinic (30%), and 18 urology patients (4%) identified as transgender or other, while all responding oncology patients identified as female or male.

Discussion

The key finding in this study is that a patient-entered sexual orientation datum in the EMR is acceptable, understandable,

TABLE 2. PERCENTAGE RESPONDING “AGREE” OR “STRONGLY AGREE” TO THE ACCEPTABILITY AND FEASIBILITY QUESTIONS IN THE PHASE 1 SURVEY

N	<i>Overall</i>	<i>Urology</i>	<i>Oncology</i>	<i>p</i>	<i>Sexual minority^a</i>	<i>Straight or heterosexual</i>	<i>Nonresponse/refused^b</i>	<i>p</i>
	<i>205</i>	<i>101</i>	<i>104</i>		<i>13</i>	<i>179</i>	<i>13</i>	
I understood what the question was asking of me	94	91	96	0.16	100* [†]	95*	70 [†]	0.011
I understood all of the answer choices	95	93	96	0.37	100* [†]	96*	77 [†]	0.061
The question was easy for me to answer	93	90	96	0.10	85* [†]	96*	69 [†]	0.003
I would answer this question on my electronic medical record at this clinic	76	79	73	0.33	69*	78*	54*	0.12
I think this information is important for my provider to know about me	55	56	54	0.78	69*	56*	23	0.03

^aIncludes respondents listing lesbian, gay, or homosexual; bisexual, queer, intersex, and homoflexible.

^bIncludes nonresponse and answers of “do not know,” “choose not to answer,” and other answers to “something else” (e.g., “this is stupid”).

For comparisons across sexual orientation (sexual minority vs. straight or heterosexual vs. nonresponse/refused), cells in the same row containing the same symbol (* or [†]) are not significantly different from one another.

p-Values are derived from chi-square tests across the three levels of response.

TABLE 3. RESPONSES TO THE ACTUAL ELECTRONIC MEDICAL RECORD SEXUAL ORIENTATION ITEM BY CLINIC

	<i>Overall</i>	<i>Urology</i>	<i>Oncology</i>	
	<i>553</i>	<i>450</i>	<i>103</i>	
N	n (%)	n (%)	n (%)	p = 0.12*
Lesbian, gay, or homosexual	23 (4.16)	20 (4.44)	3 (2.91)	
Straight or heterosexual	482 (87.16)	384 (85.33)	98 (95.15)	
Bisexual	15 (2.71)	13 (2.89)	2 (1.94)	
Something else	4 (0.72)	4 (0.89)	0 (0.00)	
Do not know	4 (0.72)	4 (0.89)	0 (0.00)	
Choose not to disclose	25 (4.52)	25 (5.56)	0 (0.00)	

*Chi-square test excluded 2828 urology and 611 oncology nonresponses.

and feasible for almost all urology and oncology patients. Because a small minority of patients selected the “choose not to disclose” option, we recommend that clinics include this as an option. Possible reasons for nondisclosure are varied, but may not necessarily reflect a patient’s unwillingness to discuss matters regarding their sexuality.

A surprising finding was that while only 76% predicted that they would answer the sexual orientation question when asked hypothetically, 95% actually answered it when it was placed in the EMR. It is possible that on this and other sensitive issues, patients express reluctance to address an issue until the clinic or provider asks about it directly. It may also be that some patients read the question and simply ignored it rather than answered “choose not to disclose.” This would indicate that actual acceptability lies between the hypothetical (76%) and the actual (95%).

In this study, the group that answered “choose not to disclose” or “do not know” had a much lower understanding of the sexual orientation question and response options. Lack of awareness of diverse sexual identities or the language used to describe them may explain some of these responses, especially among older populations. Limited English language proficiency and cultural differences may also limit understanding of this question. Future research about individuals who object to answering sexual orientation items in clinical settings, particularly those serving older adult populations, should explore these and other reasons (e.g., fear of discrimination) underlying nondisclosure.

A smaller percentage of nonresponders, compared with their heterosexual peers, agreed that the sexual orientation question was easy to answer. Sexual minority and heterosexual identified patients were more likely to state that this in-

formation was important for their provider to know. These results suggest that sexual orientation disclosure could be simultaneously more stressful and potentially more stigmatizing for nonresponders compared with either heterosexual or sexual minority patients. Some individuals may conceal either their uncertainty about their own orientation or their SGM status for fear of stigma and discrimination.^{17,18} Whether a provider should encourage disclosure in such cases should be guided by clinical necessity and ethics.¹⁴ Qualitative research focused on what makes a question such as this one difficult to answer among diverse populations may offer insight into ways to mitigate discomfort or related concerns.

The addition of a sexual orientation datum in the EMR simply provides an additional opportunity or option for face-to-face disclosure. However, only 55% of respondents agreed it was important for their providers to know this information. This suggests that patient education that some treatments can affect sexual health is necessary. Consistent with this, disclosure of sexual orientation was higher in this study than that reported in retrospective studies of sexual minority cancer survivors.^{19–21} Sexual minority cancer survivors may volunteer information about their sexual orientation even if not directly asked by their providers or through the intake process.^{19–21} Reasons for disclosure include the need to discuss sexual functioning, to correct assumptions about sexuality, or the desire for one’s provider to better understand the contexts of their patients’ lives.¹ The absence of sexual orientation information in the EMR places the burden of in-person disclosure directly on the patient, thus reinforcing heteronormativity and establishing a systems-level barrier to culturally relevant cancer care.⁹ Alternatively, the burden falls on the provider to ask. Directly asking about sexual

TABLE 4. RESPONSES TO THE ACTUAL ELECTRONIC MEDICAL RECORD GENDER IDENTITY ITEM BY CLINIC

	<i>Overall</i>	<i>Urology</i>	<i>Oncology</i>	
	<i>636</i>	<i>525</i>	<i>111</i>	
Total	n (%)	n (%)	n (%)	p < 0.001*
Female	231 (36.32)	158 (30.10)	73 (65.77)	
Male	385 (60.53)	348 (66.29)	37 (33.33)	
Transgender Female/Male-to-Female	9 (1.42)	9 (1.71)	0 (0.00)	
Transgender Male/Female-to-Male	6 (0.94)	6 (1.14)	0 (0.00)	
Other	3 (0.47)	3 (0.57)	0 (0.00)	
Choose not to disclose	2 (0.31)	1 (0.19)	1 (0.90)	

*Chi-square test excluded 2753 urology and 611 oncology nonresponses.

orientation in the EMR reduces the burden on the patient, provider, and clinic to find the appropriate person, time, and place to provide this information.²¹

Potential barriers to disclosing sexual orientation—such as fear of discrimination, concerns about confidentiality, or concerns about how this information will be used—did not seem to inhibit the majority of responses in this study given the high degree of acceptability for this question. This stands in contrast to prior research with university students, which found that patients' willingness to disclose SOGI information depends for some patients on the patient-provider relationship, with a preference to disclose face-to-face rather than in the EMR.²² Alternatively, it may indicate a high degree of patient acquiescence. It is unclear how the nondiscrimination policies at a given institution or in a particular state may directly or indirectly affect the acceptability of SOGI data collection. In Minnesota, both university policy and state law prohibit discrimination based on both SOGI. These associations should be explored in future research.

Limitations

There are five limitations to consider when interpreting these results. First, these data were from one large, university-based, outpatient clinic system in the Midwest, and the patients were disproportionately non-Hispanic, White. Generalizability to other populations and other areas of the country is unknown. Second, to minimize stress and participant burden in patients attending urology and oncology clinics, we kept the number of questions to a minimum. Follow-up with some patients (e.g., those who elected not to disclose) was not appropriate given the clinical setting and nature of their visits. Third, we caution that rates gathered in the first 3 months of adding this question may not be reflective of longer-term rates. Fourth, we were not able to distinguish between the patient population who were never asked or saw the question and those who might have been invited to answer the question but elected not to for whatever reason. Fifth, in combining “choose not to disclose” and “do not know” as our proxy measures of unacceptability, we have been highly conservative. Some patients may have chosen not to disclose for other reasons (e.g., feeling too anxious to fill in the datum) and some patients may have chosen “do not know” to denote genuine uncertainty about their sexual orientation.

Conclusion

This study provides evidence that adding SOGI questions for patients attending urology and oncology clinics is acceptable, feasible, and the orientation question was understandable to most participants. Adding these fields may improve patient care, for example, by reducing the risk of providers making heteronormative assumptions and by enabling providers to tailor patient conversations to the patient's circumstance. It is recommended that other clinics consider adding the standardized question to their EMR, including a “choose not to disclose” option.

Authors' Contributions

B.R.S.R. designed and ran the study and drafted the article. E.J.P., the study data analyst, drafted the tables and analysis

sections of the article. N.C., research assistant, co-designed the research forms, oversaw and conducted data collection in Phase 1 of study, and drafted the Phase 1 methods sections in the article. S.C. advised on the measures and methods on how to conduct the study to ensure comparability with other studies, and co-wrote the literature background and implications sections. C.W.W. advised on SGM cultural components of the study and drafted content for the introduction and discussion. B.R.K. and C.J.R. (directors of the urology and oncology clinics, respectively) provided access for both phases of study; addressed HIPPA and patient considerations, and contributed urological and oncological content to the article. R.H. is a urology resident who assisted in the analysis and interpretation of the data, and reviewed the article. A.K. assisted in the design of the study, co-supervised its implementation, and co-drafted the discussion section of the article. The senior author confirms that all authors contributed to, reviewed, and approved the article before its submission.

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