

# Sexual Orientation and Gender Identity Data Collection in Oncology Practice: Findings of an ASCO Survey

Charles S. Kamen, PhD, MPH<sup>1</sup>; Mandi L. Pratt-Chapman, PhD, MA<sup>2</sup>; Stephen C. Meersman, PhD<sup>3</sup>; Gwendolyn P. Quinn, PhD<sup>4</sup>; Matthew B. Schabath, PhD<sup>5</sup>; Shail Maingi, MD<sup>6</sup>; Janette K. Merrill, MS<sup>3</sup>; Elizabeth Garrett-Mayer, PhD<sup>3</sup>; Melinda Kaltenbaugh, MBA<sup>3</sup>; Caroline Schenkel, MSc<sup>3</sup>; and Shine Chang, PhD<sup>7</sup>

**QUESTION ASKED:** What are the critical drivers of sexual orientation and gender identity (SOGI) data collection in oncology practice and research in the United States, and how do provider knowledge, attitudes, and behaviors contribute to including SOGI data collection as a component of high-quality cancer care?

**SUMMARY ANSWER:** Institutional SOGI data collection was significantly associated with a respondent's belief that knowing patient SOGI is an important component for providing high-quality care. SOGI data collection was significantly associated with both leadership support and dedicated resources (eg, cancer-specific sexual and gender minority [SGM] patient training) for SOGI data collection. Together, these individual and institutional factors could be the target of quality improvement initiatives to implement collection of SOGI data within oncology settings.

**WHAT WE DID:** Despite recommendations by national organizations and empirical evidence showing that the majority of both SGM and heterosexual/cisgender patients are willing to report SOGI data, most oncology practices do not systematically collect it. The SGM Task Force of the ASCO Health Equity Committee developed a survey that drew questions from validated questionnaires and prior instruments used in cancer settings. The task force also created an expanded set of de novo items asking about institutional policies regarding sexual orientation and gender identity data collection (assessed separately); individual respondents' knowledge, beliefs, and attitudes regarding SOGI data collection; and the importance of using SOGI data in delivering cancer care. Online survey responses were collected in Research Electronic Data Capture between October and November 2020. Current ASCO members were invited to participate via direct e-mail communications. Advertisement of the survey was also distributed via outreach to specific ASCO committee members, social media, and listservs.

## CORRESPONDING AUTHOR

Shine Chang, PhD, The University of Texas MD Anderson Cancer Center, 1155 Pressler St, Unit 1365, Houston, TX 77230; e-mail: [ShineChang@MDAnderson.org](mailto:ShineChang@MDAnderson.org).

**WHAT WE FOUND:** Factors that predict SOGI data collection are linked and self-reinforcing. The results show that the absence or insufficient provision of leadership support, lack of dedicated resources, and disagreement that knowledge of SOGI is an important component of patient-centered care were common features of institutions without efforts to collect SOGI data. These barriers hinder SOGI data collection.

**BIAS, CONFOUNDING FACTOR(S):** The current study used a convenience sampling strategy and limited sample size, although we had statistical power to detect significant associations. Because of snowball sampling, no response rate can be calculated. Furthermore, the proportion of SGM-identifying respondents was higher than national averages (9% v 5.6%), indicating a degree of selection bias. The majority (53%) of respondents reported SGM family members, and 94% reported SGM coworkers; so, this sample was likely enriched for individuals primed to care about SOGI data collection on the basis of personal factors. The proportion of non-White respondents was low, indicating the need to recruit more diverse samples to understand the perspectives of racial and ethnically diverse populations regarding SOGI data collection.

**REAL-LIFE IMPLICATIONS:** Evidence strongly suggests that SOGI data collection is acceptable to patients in health care settings. Unfortunately, the continued failure of oncology practice and research to systematically collect SOGI data perpetuates invisibility of SGM patients and fuels disparities. Multilevel interventions are needed to support systematic SOGI data collection. Such interventions must address lack of knowledge about SGM disparities, mitigate impact of implicit biases, improve workflows for SOGI documentation, and commit educational and other resources to this effort. Without such interventions, goals to advance cancer-related health equity for SGM people cannot be achieved.

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Charles S. Kamen, PhD, MPH<sup>1</sup>; Mandi L. Pratt-Chapman, PhD, MA<sup>2</sup>; Stephen C. Meersman, PhD<sup>3</sup>; Gwendolyn P. Quinn, PhD<sup>4</sup>; Matthew B. Schabath, PhD<sup>5</sup>; Shail Maingi, MD<sup>6</sup>; Janette K. Merrill, MS<sup>3</sup>; Elizabeth Garrett-Mayer, PhD<sup>3</sup>; Melinda Kaltenbaugh, MBA<sup>3</sup>; Caroline Schenkel, MSc<sup>3</sup>; and Shine Chang, PhD<sup>7</sup>

## abstract

**PURPOSE** Lack of collection of sexual orientation and gender identity (SOGI) data in oncology practices limits assessment of sexual and gender minority (SGM) cancer patients' experiences and restricts opportunities to improve health outcomes of SGM patients. Despite national calls for routine SOGI data collection, individual-level and institutional barriers hinder progress. This study aimed to identify these barriers in oncology.

**METHODS** An online survey of ASCO members and others assessed SOGI data collection in oncology practices, institutional characteristics related to SOGI data collection, respondents' attitudes about SOGI data and SGM patients, and respondent demographics. Logistic regression calculated adjusted odds ratios (ORs) and 95% CIs for factors associated with sexual orientation (SO) and gender identity (GI) data collection.

**RESULTS** Less than half of 257 respondents reported institutional SO and GI data collection (40% and 46%, respectively), whereas over a third reported no institutional data collection (34% and 32%, respectively) and the remainder were unsure (21% and 17%, respectively). Most respondents felt that knowing both SO and GI was important for quality care (77% and 85%, respectively). Collection of SO and GI was significantly associated in separate models with leadership support (ORs = 8.01 and 6.02, respectively), having resources for SOGI data collection (ORs = 10.6 and 18.7, respectively), and respondents' belief that knowing patient SO and GI is important (ORs = 4.28 and 2.76, respectively). Themes from qualitative comments mirrored the key factors identified in our quantitative analysis.

**CONCLUSION** Three self-reinforcing factors emerged as critical drivers for collecting SOGI data: leadership support, dedicated resources, and individual respondents' attitudes. Policy mandates, implementation science, and clinical reimbursement are strategies to advance meaningful data collection and use in clinical practice.

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## INTRODUCTION

Sexual and gender minority (SGM) populations (eg, lesbian, gay, bisexual, transgender, gender nonbinary, two-spirit, those who partner with others of the same gender, and those whose gender identity [GI] differs from their sex assigned at birth) experience disparities across the cancer control continuum, from risk reduction through end-of-life.<sup>1-4</sup> SGM people may experience greater cancer risk than the general population because of higher rates of smoking.<sup>5,6</sup> Sexual minority people with breast cancer are diagnosed at later stages and at younger ages than heterosexual/cisgender counterparts (H/C; ie, those who partner with others of the opposite gender and whose GI matches their sex assigned at birth).<sup>7</sup> Sexual minority people with prostate cancer report greater psychologic

distress and sexual dysfunction following treatment than H/C patients with prostate cancer.<sup>8,9</sup> Gender minority patients with cancer report that providers question their gender-affirming treatment decisions.<sup>1</sup> On the basis of these and other studies, the National Institutes of Health have declared SGM people as a health disparities population, and national organizations such as the National Academies of Science, Engineering, and Medicine, American Medical Association, and ASCO have called for increased attention to SGM patients in health care settings in general and oncology practice specifically.<sup>10</sup>

A foundational requirement to address and monitor SGM cancer disparities is collection of sexual orientation and gender identity (SOGI) data in oncology practice and research. Systematic collection of SOGI

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data by health systems would allow cancer registries to document disparities in cancer incidence and mortality affecting SGM populations; encourage clinical trialists to assess differences in treatment outcome by sexual orientation (SO) and GI; enable appropriate notation of patients' caregivers and pronouns in electronic medical records; and support providers in referring SGM patients to tailored support resources. All of these efforts are currently hindered by lack of systematic SOGI data collection.<sup>11,12</sup>

Despite recommendations by national organizations and despite empirical evidence showing that the majority of both SGM and H/C patients are willing to report SOGI data, most oncology practices do not systematically collect it.<sup>11,13,14</sup> The overall aim of this study was to assess individual and institutional factors associated with collection of SOGI data in oncology settings, including clinical practice and research. A secondary aim was to assess provider knowledge, attitudes, and behaviors about SOGI data collection, including beliefs about the value of collecting SOGI data as a component of providing high-quality cancer care.

## METHODS

### Survey Development

Researchers convened by the SGM Task Force of the ASCO Health Equity Committee developed a survey that drew questions from validated questionnaires and prior instruments used in cancer settings.<sup>15</sup> The task force also created an expanded set of de novo items asking about institutional policies regarding SO and GI data collection (assessed separately); individual respondents' knowledge, beliefs, and attitudes regarding SOGI data collection; and the importance of using SOGI data in delivering cancer care. The survey used skip logic to tailor questions for clinicians versus researchers. In total, the survey contained 54 items, including 15 for participant demographics and two for open-ended comments about barriers and facilitators to collection of SOGI data.

### Data Collection and Eligibility

The online survey was coded in Research Electronic Data Capture, a secure, web-based software platform for data collection,<sup>16</sup> and distributed between October and November 2020. Current ASCO members were invited to participate via direct e-mail communications. Advertisement of the survey was also distributed via outreach to specific ASCO committee members, social media, and listservs. Unique URLs captured the source through which respondents accessed the survey. Two reminders were sent to ASCO members. No incentives were provided.

Anyone who reported working at an institution that provided clinical care to patients with cancer or reported working in cancer research (via initial screening questions) was eligible to participate. Responses were collected anonymously, and completion of demographic characteristics was optional.

### Ethical Review

Per ASCO internal policies, this study was considered health care operations quality improvement. Thus, no institutional review board approval was sought.

### Data Analysis

**Quantitative.** Individual survey items were analyzed using descriptive statistics. Univariable and multivariable polytomous logistic regression models were used to determine factors significantly associated with the study's primary outcomes: respondents' report of SO and/or GI data collection at their institutions (yes/no/unsure). Specifically, logistic regression was used to quantify the magnitude of associations between SO and GI data collection and independent individual-level factors (eg, respondent role, level of patient contact, understanding of how to collect SOGI data, positive emotions regarding SOGI data collection, belief in the importance of knowing SOGI data for clinical practice, confidence in applying SOGI data to relevant clinical decisions, and demographics) and institutional factors (eg, leadership support for SOGI data collection, institutional resources dedicated to SOGI data collection, practice type, and practice size). Factors associated with the primary outcomes at  $P < .10$  in univariable models were included in multivariable models for SO and GI data collection separately and were then manually deleted in step-wise manner from each model until all covariates remaining in the model had  $P < .05$ . The results are presented as odds ratios (ORs) with 95% CIs and  $P$  values.

**Qualitative.** Limited qualitative data were collected as part of this survey to ASCO members, consisting of responses to two open-ended questions. Three coders (G.P.Q., M.L.P.-C., and S.M.) established a code list and coded data for the first 50 responses to each question. Coders met and obtained consensus on a codebook and then independently coded the remaining responses in Excel using content analysis and constant comparison methods. Inter-rater reliability was 0.95.

## RESULTS

### Respondent Demographics

A total of 257 respondents completed the survey. The majority of respondents (82%) had a clinical role (Table 1). More than half worked at a university hospital (54%) but almost a quarter worked at community or private hospitals (24%). The majority identified as female (56%). Most identified as heterosexual (78%), although a significant portion identified as gay (9%), lesbian (4%), or bisexual (3%), with 1% identifying as queer, 1% self-defining an SO, and 3% preferring not to answer. The majority identified as White (70%), with smaller percentages identifying as Asian (15%), Black (3%), and Hispanic (10%). Most respondents considered themselves politically liberal (69%).

Less than half of respondents reported that their institutions collected SO or GI data (40% and 46%, respectively). By contrast, over a third reported that their institutions did not collect SO or GI data (34% and 32%, respectively), and the remaining fifth were unsure (21% and 17%, respectively). Although the majority believed it was important to know patients' SO and GI (68% and 74%, respectively) to provide quality care, some respondents disagreed that it was important (17% and 12%, respectively). Respondents who identified as gay or lesbian were more likely to agree that it was important to know both patients' SO and GI than respondents of other SOs. Respondents who preferred not to identify their race and who identified as politically conservative were more likely to disagree that it was important to know patients' SO (data not shown).

### Univariable Models

In unadjusted univariable models, nine factors were significantly associated with SO data collection at  $P < .10$ : type of cancer care institution, leadership support, coworker support, resources, feeling empowered; and respondent's race, belief that knowing SO is important for providing quality care, belief that knowing GI is important for providing quality care, and receipt of cancer-specific SGM patient training. These factors were included in the full (multivariable) model for SO. In unadjusted models, 11 factors were significantly associated with GI data collection at  $P < .10$ : type of cancer care institution, leadership support, coworker support, resources and feeling empowered to collect SOGI data; respondent's SO, political views, report of SGM friends, belief that knowing SO is important for providing quality care, belief that knowing GI is important for providing quality care, and receipt of cancer-specific SGM patient training. These factors were included in the full (multivariable) model for GI (Table 2).

### Multivariable Models

In multivariable logistic regression models predicting SO and GI data collection, strong correlations between covariates reduced statistical significance of some covariates such that they were no longer statistically significant at  $P < .05$ . These covariates were removed from the models. In the final adjusted model for institutional SO data collection (Table 2), having leadership support for SOGI data collection (OR = 8.01; 95% CI, 2.45 to 26.2), having dedicated institutional resources (OR = 10.6; 95% CI, 4.05 to 27.7), and the respondent's belief in importance of knowing patients' SO (OR = 4.28; 95% CI, 1.50 to 12.2) remained significantly associated with SO data collection. Similarly, in the final adjusted model for institutional GI data collection, having leadership support (OR = 6.02; 95% CI, 2.32 to 15.6), having dedicated institutional resources (OR = 18.7; 95% CI, 5.34 to 65.3), and the respondent's belief in the importance of knowing patients' GI (OR = 2.76; 95% CI, 1.01 to 7.51) remained significantly associated with GI data collection.

**TABLE 1.** Respondent Characteristics (N = 257)

Characteristic	No. (%)
<b>Respondent's role</b>	
Clinical	210 (82)
Nonclinical	47 (18)
Missing	0 (0)
<b>Institution type</b>	
Community/private hospital	62 (24)
Private practice	22 (9)
University hospital	138 (54)
Other	32 (12)
<b>Respondent's SO</b>	
Heterosexual	201 (78)
Gay	23 (9)
Lesbian	9 (4)
Bisexual	8 (3)
Queer	3 (1)
Asexual	1 (0)
Other	3 (1)
Prefer not to answer	8 (3)
Missing	1 (0)
<b>Respondent's GI</b>	
Female	143 (56)
Male	100 (39)
Nonbinary	5 (2)
Other	2 (1)
Prefer not to answer	7 (3)
Missing	0 (0)
<b>Respondent's age, years</b>	
25-40	70 (27)
41-55	93 (36)
56+	80 (31)
Prefer not to answer	0 (0)
Missing	14 (5)
<b>Respondent's race</b>	
Asian	39 (15)
Black	8 (3)
Hawaiian/PI	2 (1)
White	181 (70)
Multiple races	3 (1)
Other	12 (5)
Prefer not to answer	12 (5)
Missing	0 (0)
<b>Respondent's ethnicity</b>	
Hispanic/Latino	24 (9)

(continued on following page)

**TABLE 1.** Respondent Characteristics (N = 257) (continued)

Characteristic	No. (%)
Not Hispanic/Latino	215 (84)
Prefer not to answer	13 (5)
Missing	5 (2)
Respondent's political leanings	
Conservative	19 (7)
Centrist/apolitical	54 (21)
Liberal	178 (69)
Prefer not to answer	5 (2)
Missing	1 (0)
LGBTQ+ family members	
Yes	135 (53)
No	117 (46)
Prefer not to answer	3 (1)
Missing	2 (1)
LGBTQ+ friends, coworkers	
Yes	234 (91)
No	18 (7)
Prefer not to answer	3 (1)
Missing	2 (1)

Abbreviations: GI, gender identity; LGBTQ+, lesbian, gay, bisexual, transgender, queer, gender nonbinary, two-spirit; PI, Pacific Islander; SO, sexual orientation.

### Qualitative Themes

A total of 152 people provided qualitative responses to two open-ended questions in the survey about barriers and facilitators to SOGI data collection (Table 3). Barriers included *institutional culture*, with respondents stating SOGI data collection was not part of the culture/not required and that there was no messaging from the health system that patient-specific SOGI answers matter (ie, have any impact on clinical care or outcomes, or are even important to delivering person-centered care). Respondents also described *provider beliefs and discomfort* as a barrier, citing “lack of individual understanding of SOGI nomenclature (ie, what’s gender queer v gender diverse, etc) that may factor in to (providers’) comfort level asking questions of a patient on their SOGI” and “lack of understanding on the true impact of SOGI on clinical outcomes.” *Patient discomfort* was also cited, with respondents voicing “concerns of patients regarding possible prejudices” if they disclosed SOGI. Practical barriers included the *electronic medical record*, with respondents saying there was “no innate field for data” in their practices’ systems, as well as *lack of training, resources, and time*, with respondents saying they had no time for the discussion or training on how to approach patients about their SOGI.

Facilitators included *robust protocols*, with automatic processes, standardized fields, and a process where this (SOGI

data collection) occurs up front for all patients regardless of preference. Several respondents commented on the need for *culture change*, “with more representation of queer/trans people among staff and safe spaces to be who we are.” Respondents noted the importance of *training* on how to collect and what to do with SOGI data, as well as *improving community trust*, particularly in conservative regions of the country. Of note, three respondents made negatively biased comments about SGM patients. For example, one provider noted, “Sexual deviants should receive treatment for their condition.”

### DISCUSSION

In this study, we used an online survey disseminated to ASCO members and others recruited via social media to identify individual-level and institutional barriers and facilitators to SOGI data collection in oncology. A key finding was that institutional SOGI data collection was significantly associated with a respondent’s belief that knowing patient SOGI is an important component for providing high-quality care. We found that SO and GI data collection was significantly associated with both leadership support and dedicated resources for SOGI data collection. Together, these individual and institutional factors could be the target of quality improvement initiatives to implement collection of SOGI data within oncology settings.

Themes from qualitative comments mirrored the key factors identified in our quantitative analysis. Respondents commented on their own perceptions of the importance of SOGI data collection, workplace culture including leadership support, and the presence/absence of resources that affected the success of SOGI data collection. Respondents also provided additional details about types of resources that could facilitate SOGI data collection in oncology, including detailed protocols for data collection, designated space in electronic health records (EHRs) to document SOGI, and training to increase provider and staff cultural competence. Notably, in 2015, the Centers for Medicare and Medicaid Services and the Office of the National Coordinator for Health Information Technology mandated SOGI documentation capability in EHRs for stage 3 of Meaningful Use. Yet, most institutions and providers are not systematically using these capabilities.<sup>17</sup> This suggests that institutional leadership must play a role in incentivizing and/or requiring collection of these data in practice.

The need for additional training about SGM patients’ cancer disparities and experiences of discrimination is underscored by our finding that some respondents did not see value in collecting SOGI data as a way to improve cancer care. Although providers’ demographic characteristics may predict such beliefs,<sup>18</sup> SGM-specific training<sup>19</sup> and exposure to SGM persons<sup>19</sup> also predicted increased SGM-specific health care knowledge, better attitudes of providers toward SGM patients, and lower expressed transphobia and homophobia.<sup>20</sup> With 7.1% of Americans identifying as SGM in a recent national poll,<sup>21</sup> and growing numbers of young adults disclosing their SGM identities, the mandate for all oncology

**TABLE 2.** Univariate Linear Regression for the Association Between Institutional and Individual Factors of SO and GI Data Collection

Covariate	Categories	SO Data Collection (yes v no)			GI Data Collection (yes v no)		
		OR	95% CI	P <sup>a</sup>	OR	95% CI	P <sup>a</sup>
Respondent institution	Community/private hospital	Ref			Ref		
	Other	3.94	1.14 to 13.60	.03	3.29	0.96 to 11.20	.06
	Private practice	1.41	0.48 to 4.14	.54	0.66	0.22 to 1.94	.46
	University hospital	1.29	0.66 to 2.54	.46	1.17	0.60 to 2.28	.65
Institution support for SOGI data collection	Disagree	Ref			Ref		
	Agree	22.41	8.36 to 60.1	< .01	44.00	14.8 to 130.3	< .01
	No opinion	1.70	0.54 to 5.34	.36	2.77	0.88 to 8.67	.08
Coworker support	Disagree	Ref			Ref		
	Agree	5.70	2.39 to 13.6	< .01	16.00	5.63 to 45.4	< .01
	No opinion	0.76	0.26 to 2.23	.62	3.08	0.98 to 9.66	.05
Resources support	Disagree	Ref			Ref		
	Agree	13.83	6.48 to 29.5	< .01	15.12	7.02 to 32.6	< .01
	No opinion	2.38	0.94 to 6.01	.07	2.25	0.95 to 5.35	.07
Empowered support	Disagree	Ref			Ref		
	Agree	10.25	4.62 to 22.8	< .01	12.02	5.60 to 25.8	< .01
	No opinion	3.15	1.04 to 9.52	.04	2.22	0.83 to 5.97	.11
Role type	Nonclinical	Ref			Ref		
	Clinical	0.91	0.43 to 1.92	.80	1.28	0.63 to 2.59	.49
Respondent SO	Heterosexual	Ref			Ref		
	Not heterosexual	0.74	0.36 to 1.52	.41	0.56	0.28 to 1.12	.10
Respondent GI	Female	Ref			Ref		
	Male	0.90	0.50 to 1.65	.74	0.74	0.41 to 1.33	.31
Age, years	25-40	Ref			Ref		
	41-55	0.69	0.33 to 1.46	.33	0.82	0.40 to 1.68	.59
	> 55	0.80	0.38 to 1.69	.56	0.63	0.30 to 1.31	.21
Race	White	Ref			Ref		
	Not White	1.75	0.92 to 3.33	.09	1.06	0.57 to 1.97	.86
Ethnicity	Not Hispanic/Latino	Ref			Ref		
	Hispanic/Latino	1.28	0.46 to 3.52	.64	0.73	0.29 to 1.81	.50
Political views	Liberal	Ref			Ref		
	Centrist/apolitical	0.67	0.24 to 1.90	.45	0.38	0.13 to 1.08	.07
	Conservative	1.35	0.64 to 2.87	.43	1.24	0.61 to 2.55	.55
SGM family members	No	Ref			Ref		
	Yes	0.72	0.40 to 1.30	.28	0.66	0.37 to 1.18	.16
SGM friends	No	Ref			Ref		
	Yes	0.74	0.23 to 2.36	.62	0.34	0.09 to 1.25	.10
Respondent's belief of importance of SO collection	Disagree	Ref			Ref		
	Agree	4.70	2.04 to 10.8	< .01	3.65	1.71 to 7.82	< .01
Respondent's belief of importance of GI collection	Disagree	Ref			Ref		
	Agree	3.10	1.27 to 7.59	.01	3.03	1.26 to 7.29	.01
Receipt of cancer-specific SGM patient training	No	Ref			Ref		
	Yes	3.28	1.45 to 7.42	< .01	4.44	1.86 to 10.6	< .01

NOTE. ORs represent the ratio of odds for collecting data (yes) versus not collecting data (no), 95% CI for OR. Fitted model had a trinary-dependent variable with categories of yes versus no versus not sure.

Abbreviations: GI, gender identity; OR, odds ratio; Ref, reference; SGM, sexual and gender minority; SO, sexual orientation; SOGI, sexual orientation and gender identity.

<sup>a</sup>P value, comparing category to reference category.

**TABLE 3.** Multivariable Logistic Regression for the Association Between Institutional and Individual Factors and SOGI Collection

Covariate	Categories	SO Data Collection (yes v no)		GI Data Collection (yes v no)	
		OR	95% CI	OR	95% CI
Institution support for SOGI data collection	Disagree	Ref		Ref	
	Agree	8.01	2.45 to 26.2	6.02	2.32 to 15.6
	No opinion	1.00	0.23 to 4.40	2.86	0.84 to 9.73
Institutional resources	Disagree	Ref		Ref	
	Agree	10.6	4.05 to 27.7	18.7	5.34 to 65.3
	No opinion	6.79	1.82 to 25.3	2.19	0.52 to 9.19
Importance of knowing patient SO	Disagree	Ref			
	Agree	4.28	1.50 to 12.2	—	—
Importance of knowing patient GI	Disagree			Ref	
	Agree	—	—	2.76	1.01 to 7.51

NOTE. ORs from logistic regression models including these three predictors as covariates comparing respondents who reported SO or GI collection (yes v no) as the dependent variables. Fitted models had a trinary-dependent variable with categories of yes versus no versus not sure.

Abbreviations: GI, gender identity; OR, odds ratio; SO, sexual orientation; SOGI, sexual orientation and gender identity.

providers and staff to receive training in the care of SGM patients is urgent. This training should incorporate evidence-based tools to reduce implicit bias toward SGM patients and their families, up-to-date information on cancer-related disparities experienced by SGM patients, and best practices for supporting SGM people facing cancer.<sup>22,23</sup> Such training should also inform professionals about barriers and facilitators to SOGI data collection and provide practical guidance to collect these data effectively. Importantly, the National Academies of Science, Engineering, and Medicine recently released guidance on how to collect SOGI data on the basis of evidence to date.<sup>24</sup> Given the distinct needs reported by transgender and gender diverse patients, and the unknown risks of hormonal therapy on oncology management decisions, trainings would also benefit from an explicit focus on GI, and more research is needed in general on the optimal management for gender diverse patients on hormonal therapies with cancer.<sup>25</sup>

In addition to perceived lack of value in collecting SOGI, more than 30% of respondents believed that their patients would be uncomfortable if asked about their SOGI. However, this belief is refuted by a growing body of research. One study reported the majority of both SGM and H/C patients would agree to disclose SO (95%) and GI (99%) in emergency medicine settings,<sup>26</sup> and another study of oncology patients found that the majority of patients across multiple demographic groups had favorable perceptions of being asked SOGI questions.<sup>26,27</sup> Importantly, preliminary evidence suggests that disclosure of SOGI to cancer care providers improves self-reported health among SGM cancer patients.<sup>28</sup> Furthermore, although some patients may feel uncomfortable being asked about SOGI, asking will help to normalize collecting these data to reduce discomfort for H/C individuals in the long term. In short, the risk of alienating a minority of patients by asking about SOGI must be evaluated against the

benefits of improving care for SGM patients, documenting SGM disparities, and reducing these disparities through research-driven and SGM-specific interventions.

It is important to note that some SGM patients may have experienced lived or community-level discrimination in health care settings, leading to mistrust of health care systems and reticence to disclose SOGI to health care providers.<sup>5</sup> By not systematically collecting SOGI data on all patients, we may reinforce mistrust, place the onus of disclosure on SGM patients, and exacerbate stigma. Furthermore, growing numbers of studies have shown that nondisclosure of SOGI status is associated with delays in seeking care<sup>29</sup> and poorer mental health among SGM patients.<sup>30</sup> These sequelae may contribute to SGM disparities in areas of the country that are historically conservative, and where institutional efforts to collect SOGI data are less common. Given the lack of nationwide protections for SGM people from job and housing loss at the time of writing this article, and the recent surge in legislation limiting access to medical care for transgender patients, SGM patients' hesitation to voluntarily disclose SOGI in the absence of institutional efforts to collect, protect, and act on these data is understandable. It is important to note that SOGI data disclosure is a proxy for patient comfort with their health care team and ability to show up as a whole person for cancer care. Ultimately, social interventions to normalize sexual and gender diversity are needed to advance health equity among SGM persons.

Our study shows that factors that predict SOGI data collection are linked and self-reinforcing, regardless of the geographic context. The results show that the absence or insufficient provision of leadership support, lack of dedicated resources, and disagreement that knowledge of SOGI is an important component of patient-centered care were common features of institutions without efforts

to collect SOGI data. These barriers hinder SOGI data collection. Our qualitative data suggest that systematic collection of SOGI data may also be constrained by difficulty implementing, locating, and consistently using SOGI data collection fields in EHRs, lack of institutional procedures and assigned personnel for collecting SOGI data, as well as individual barriers, such as bias or uncertainty about how best to discuss SOGI on the part of providers. Thus, in addition to training, mandates from leadership to collect SOGI data are a necessary first step in conveying institutional commitment to this process. Broader system-level policies tying reimbursement and accreditation to completeness of SOGI data collection would lend further weight to such mandates, particularly if endorsed by payors such as the Center for Medicare and Medicaid Studies. Finally, implementation science studies are needed to determine the best way to integrate SOGI data into oncology clinic workflows to ensure that data are collected and used effectively.

Limitations of the current study include a convenience sampling strategy and limited sample size, although the sample had statistical power to detect significant associations. Because of snowball sampling, no response rate can be calculated for our study. In our study, the proportion of SGM-identifying respondents was higher than national averages (9% v 5.6%), indicating a degree of selection bias. The majority (53%) of respondents reported SGM family members, and 94% reported SGM coworkers, further underscoring that this sample was likely enriched for individuals primed to care about SOGI data collection on the basis of their personal identities or relationships. The proportion of non-White respondents was low, indicating the need to recruit more diverse samples to understand the perspectives of racial and ethnically diverse

populations regarding SOGI data collection. In addition to identifying factors associated with institutional SOGI data collection, a strength of the study was the insight derived from responses to open-ended questions about barriers and facilitators to SOGI data collection. These data reinforced quantitative findings and encourage future inquiry. However, the qualitative data collected in this study were limited to two open-ended survey questions; more in-depth qualitative research into this topic is needed.

In conclusion, many national organizations have responded to growing awareness of health disparities affecting minoritized populations by strengthening their commitment to eliminating structural barriers to health equity. Failure to collect SOGI data is one such structural barrier. Evidence strongly suggests that SOGI data collection is acceptable to patients in health care settings.<sup>13,14,26</sup> Unfortunately, the continued failure of many oncology practices and research studies to systematically collect SOGI data perpetuates invisibility of SGM patients and, potentially, fuels disparities.<sup>4</sup>

We identified several factors independently associated with both SO and GI data collection: leadership support and dedicated resources for SOGI data collection, and individual respondents' belief that SOGI data are important for patient care in oncology. These factors suggest that multilevel interventions are needed to support systematic SOGI data collection. Such interventions, on the basis of our qualitative data, must address lack of knowledge SGM disparities, mitigate the impact of implicit biases on SOGI data collection, improve workflows for SOGI documentation, and commit educational and other resources to this effort. Without such interventions, goals to advance cancer-related health equity for SGM people cannot be achieved.

## AFFILIATIONS

<sup>1</sup>University of Rochester Medical Center, Rochester, NY

<sup>2</sup>Department of Medicine, GW Cancer Center, The George Washington University School of Medicine and Health Sciences, Washington, DC

<sup>3</sup>American Society of Clinical Oncology, Alexandria, VA

<sup>4</sup>Departments of OB-GYN, Population Health, Perlmutter Cancer Center, Grossman School of Medicine, New York University, New York City, NY

<sup>5</sup>Department of Cancer Epidemiology, H. Lee Moffitt Cancer Center and Research Institute, Tampa, FL

<sup>6</sup>Dana-Farber/Brigham and Women's Cancer Center at South Shore Hospital, South Weymouth, MA

<sup>7</sup>Division of Cancer Prevention and Population Sciences, Department of Epidemiology, The University of Texas MD Anderson Cancer Center, Houston, TX

## CORRESPONDING AUTHOR

Shine Chang, PhD, The University of Texas MD Anderson Cancer Center, 1155 Pressler St, Unit 1365, Houston, TX 77230; e-mail: ShineChang@MDAnderson.org.

## EQUAL CONTRIBUTION

C.S.K. and M.L.P.-C. equally contributed as first authors to this work.

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## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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## AUTHOR CONTRIBUTIONS

**Conception and design:** Charles S. Kamen, Mandi L. Pratt-Chapman, Stephen C. Meersman, Gwendolyn P. Quinn, Matthew B. Schabath, Shail Maingi, Janette K. Merrill, Shine Chang

**Administrative support:** Stephen C. Meersman, Janette K. Merrill

**Collection and assembly of data:** Charles S. Kamen, Mandi L. Pratt-Chapman, Stephen C. Meersman, Gwendolyn P. Quinn, Janette K. Merrill, Shine Chang

**Data analysis and interpretation:** Charles S. Kamen, Mandi L. Pratt-Chapman, Gwendolyn P. Quinn, Matthew B. Schabath, Shail Maingi,



Elizabeth Garrett-Mayer, Melinda Kaltenbaugh, Caroline Schenkel, Shine Chang

**Manuscript writing:** All authors

**Final approval of manuscript:** All authors

**Accountable for all aspects of the work:** All authors

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**AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST**

**Sexual Orientation and Gender Identity Data Collection in Oncology Practice: Findings of an ASCO Survey**

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**Shine Chang**

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