




# Acquisition of Sexual Orientation and Gender Identity Data Among NCI Community Oncology Research Program Practice Groups

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**BACKGROUND:** Sexual and gender minority individuals face numerous cancer-related inequities, many of which appear to be underreported. However, to the best of the authors' knowledge, no one has assessed rates of acquisition of sexual orientation and gender identity (SOGI) data within community oncology settings. **METHODS:** Community oncology practices that were part of the NCI Community Oncology Research Program (NCORP) network were asked whether they routinely collected SOGI information and coded this information in their electronic medical records. The proportion of practice groups reporting routine collection of sexual and/or gender minority information was calculated. Potential associations between the collection of SOGI information and practice group-level and state-level characteristics (from Gallup poll data) were also provided. **RESULTS:** Twenty-four percent of the responding NCORP practice groups reported routine collection of sexual orientation information, and 10% reported collection of gender identity information. Practices located in western regions of the United States, practices in states with higher proportions of sexual and gender minority-identifying individuals, and practices with lower proportions of non-Hispanic patients were more likely to ask patients about sexual orientation and/or gender identity. **CONCLUSIONS:** US oncology practices that participate in research do not frequently collect SOGI information from patients with cancer. Educational initiatives should inform oncology staff and providers about the importance of collecting gender identity and sexual orientation information to improve existent disparities faced by sexual and gender minority patients. *Cancer* 2019;125:1313-1318. © 2018 American Cancer Society.

**KEYWORDS:** disclosure, gender identity, sexual and gender minorities, sexual orientation.

## INTRODUCTION

More than 10 million adults in the United States identify as sexual and/or gender minorities (SGMs).<sup>1</sup> As an umbrella term, *SGM* encompasses a diverse array of sexual orientations and gender identities, including lesbian, gay, bisexual, and transgender (LGBT) as well as queer/questioning, intersex, and others. These diverse SGM individuals face cancer-related health care disparities, including low rates of cancer screening, high rates of anal cancer, and high rates of cervical cancer.<sup>2-9</sup> SGM individuals also potentially face a large number of cancer-related issues that remain understudied.<sup>2</sup> Cancer outcomes may be compromised by such inequities, with one study finding that lesbian women with breast cancer have greater disease-specific mortality.<sup>10</sup>

Despite such disparities, health care providers do not routinely ask about sexual orientation and gender identity (SOGI).<sup>11</sup> Only half of primary care providers and few emergency room physicians inquire about sexual orientation.<sup>12-14</sup> With respect to cancer care, one qualitative study of 39 women with breast cancer observed that health care providers rarely or never inquired about their sexual minority status.<sup>15</sup> Health care providers may not inquire about SOGI because of concerns about offending patients.<sup>14,16</sup> Yet, although concerned about discrimination, patients appear to be willing to discuss their gender identity and/or sexual orientation.<sup>14</sup> One study of 291 LGBT individuals found that 79% self-disclosed their identity to a cancer health care provider, sometimes as a way to correct heterosexual assumptions.<sup>17</sup> In an effort to improve collection of SOGI data, a number of health care initiatives have promoted the inclusion of SOGI information within medical records, from the 2015 meaningful use stage 3 rules, which require certified electronic medical

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records (EHRs) to have SOGI fields, to the American Society of Clinical Oncology's recent recommendations for the inclusion of SGM status on tumor registries.<sup>18,19</sup>

Interestingly, no prior study has reported nationwide rates of routine collection of SOGI information from patients with cancer. Furthermore, little is known about the oncology practice characteristics associated with routine collection of SOGI information. This study was designed to determine the reported rate at which community oncology clinics and medical centers collect SOGI information and to report on the factors associated with higher rates of collecting SOGI data.

## MATERIALS AND METHODS

### Overview

Data for the current study were drawn from the 2017 NCI Community Oncology Research Program (NCORP) Cancer Care Delivery Research (CCDR) Landscape Assessment. NCORP is a National Cancer Institute (NCI)-funded research infrastructure that supports community oncology clinics in recruiting patients with cancer and survivors to clinical trials nationwide. The CCDR effort aims to facilitate research and trials that can improve cancer care delivery nationwide. The Landscape Assessment asked administrators and research staff employed at NCORP clinics about issues relevant to health care delivery and to the conduct of clinical trials. The current study focused on only a small part of that assessment, namely the part that queried research practices about whether they routinely asked patients with cancer about SOGI data. This study was deemed exempt from institutional review board review because it relied on a nonpatient database and was, therefore, not considered human subjects research.

### Survey Development and Distribution

The NCORP program developed the CCDR Landscape Assessment with an iterative process of question solicitation and review. First, the NCORP research bases and community oncology practices were invited to submit questions for inclusion in the Landscape Assessment. Then, a working group led by a coauthor (K.E.W.) and consisting of other coauthors (H.N., A.E.K., R.C., L.G., and J.M.U.) and the senior author (C.K.) reviewed the questions for their relevance to cancer care delivery research. The final set of reviewed questions was presented to NCORP research bases and community oncology practices, and staff at the practices were trained to collect survey data via a series of webinars. The survey was then distributed to NCORP practice groups electronically.

An NCORP practice group was defined with Cancer Therapy Evaluation Program (CTEP) institution codes; these codes are intended to represent discrete clinical settings in the United States that are available to participate in NCI-sponsored research and to organize clinical trial data submitted to the NCI. In some cases, several clinical locations in the same geographic region with different CTEP codes shared oncologists, patients, and services (eg, a main hospital and satellite clinics). These practices submitted Landscape data together as a practice group with multiple CTEP IDs.

### Study Goals

The primary goal of the current study was to report the percentage of NCORP community oncology practice groups that reported on collecting information on patients' SOGI. The secondary goal was to report on the characteristics of institutions that collected this information.

### Measures

The 2 survey questions relevant to SOGI information were as follows:

- "Does your component/subcomponent collect and record information about patients' sexual orientation in the EHR?"
- "Does your component/subcomponent collect and record information in the EHR about patients' gender identity? This would be distinct from the standard male-female sex field."

Within the Landscape Assessment, the term *component/subcomponent* refers to the specific NCORP community oncology practice group.

In addition to the aforementioned questions, practice group-specific information obtained from the survey and used in our analyses included the following: the geographic location of each group; the practice group ownership status; the reported proportions of patients at the research practice group with insurance coverage from Medicaid, insurance coverage from both Medicare and Medicaid, charity care, and no insurance; the total number of new cancer cases each year; the percentage of the practice group's patient population that identified as non-Hispanic; the percentage of the group's patient population that identified as white; and the dedicated outreach staff for minority outreach. To benchmark, we used Gallup poll data on rates of SGM individuals living in each state.<sup>20</sup> For the multivariate analyses in this report, only the aforementioned variables and Gallup poll data were used.

**TABLE 1.** Collection of Sexual Orientation Information

Variable	Comparison Group	Univariate <sup>a</sup>			Multivariate <sup>b</sup>		
		Collection of Sexual Orientation Information Reported to Occur	Collection of Sexual Orientation Information Reported to Not Occur	<i>P</i>	Odds Ratio	Confidence Interval	<i>P</i>
Non-Hispanic ethnicity, %	Not available	75.2 ± 36.7	91.5 ± 17.6	.02	0.78 (per 18.76% increase)	0.58-1.05	.09
State population identifying as SGMs, %	Not available	3.8 ± 0.6	3.9 ± 0.5	.14	1.36 (per 0.55% increase)	0.96-1.91	.08
Dedicated staff for minority outreach	Yes No	15 (34.9) 36 (20.5)	28 (65.1) 140 (79.5)	.04	Not included in multivariate analyses <sup>c</sup>		

Abbreviation: SGM, sexual and/or gender minority.

<sup>a</sup>For categorical variables, numbers and percentages (in parentheses) as well as chi-square *P* values are reported. For continuous variables, means and standard deviations as well as Kruskal-Wallis *P* values are reported.

<sup>b</sup>Nineteen of the 221 practice groups that responded to the sexual orientation question were excluded from multivariate analyses because of missing data.

<sup>c</sup>Removed from the model on the basis of backward elimination.

### Statistical Analyses

Initial univariate evaluations of associations between variables were conducted with chi-square and Kruskal-Wallis tests (significance at  $P < .05$ ). A logistic regression model that used backward elimination (with  $P < .2$  as the staying threshold) further evaluated potential associations between the reported collection of sexual orientation information (yes/no) and gender identity information (yes/no). The pool of variables that were used during backward selection included the following: practice group region (categorical), new cases per year, type of ownership, Medicaid insurance proportion, Medicare insurance proportion, uninsured insurance proportion, dual Medicare-Medicaid insurance proportion, charity care insurance proportion, percent non-Hispanic, percent white, and statewide percent LGBT.

## RESULTS

### Practice Group Characteristics

A total of 943 CTEP institution codes were registered as part of the NCORP network in 2017. Information for 504 of these CTEP institution codes was provided as part of the Landscape Assessment. Survey respondents clustered these 504 codes into 227 distinct practice groups. Respondents indicated that these practice groups shared providers, patients, and infrastructure and generally had a common electronic health record; thus, practice-level responses should apply to the practice group as a whole. Based on the estimate of available data for 504 of the total of 943 CTEP codes, the response rate to the survey as a whole was 53%. Of the sample of 227 practice groups that responded to any part of the survey, 221 responded to the question on the collection of sexual

orientation data, and 222 responded to the question on the collection of gender identity information.

### Survey Results

Of the 221 practice groups that responded to both SOGI questions, 14 practice groups (6.3%) collected both gender identity and sexual orientation information. Thirty-nine practice groups (17.6%) collected only sexual orientation information. Nine practice groups (4.1%) collected only gender identity information. One hundred fifty-nine practice groups (71.9%) collected neither gender identity nor sexual orientation information.

Fifty-three community oncology practice groups (24% of those that completed the survey) reported that they routinely collected information on sexual orientation. Table 1 shows statistically significant associations between the collection of sexual orientation information and practice group characteristics. Notably, although initial univariate analyses showed an association between dedicated staff for minority outreach and routine collection of sexual orientation information (Kruskal-Wallis  $P = .04$ ), this association was not observed in the multivariate model.

Twenty-three practice groups (10%) reported that they routinely collected information on patient gender identity. Table 2 and Figure 1 show statistically significant associations between the collection of gender identity information and practice group characteristics. On the basis of the multivariate logistic regression analyses, we observed that sites in the western region of the United States were more likely to collect gender identity information than sites in the southern ( $P = .0092$ ) and midwestern regions ( $P = .0092$ ). Practice groups that identified as a hospital, clinic, or physician practice owned by a

**TABLE 2.** Collection of Gender Identity Information

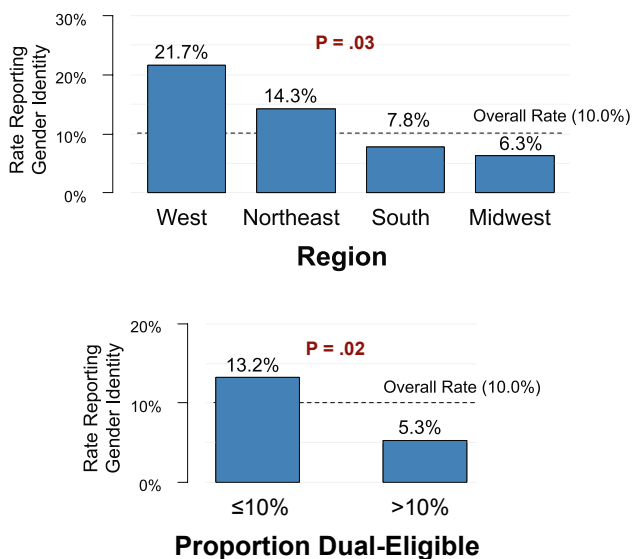
Variable	Comparison Group	Univariate <sup>a</sup>			Multivariate <sup>b</sup>		
		Collection of Gender Identity Information Reported to Occur	Collection of Gender Identity Information Reported to Not Occur	<i>P</i>	Odds Ratio	Confidence Interval	<i>P</i>
Practice group region	Midwestern	7 (6.3)	104 (93.7)	.03	1	Reference	.02
	Western	10 (21.7)	36 (78.3)		3.01	1.31-6.88	
	Northeastern	2 (14.3)	12 (85.7)		1.23	0.34-4.49	
	Southern	4 (7.8)	47 (92.2)		0.44	0.16-1.23	
Practice ownership type	Independently owned	9 (11.4)	70 (88.6)	.07	1	Reference	.08
	Hospital, clinic, or physician practice owned by a large regional/multistate health system	9 (7.5)	111 (92.5)		0.45	0.22-0.91	
	Other	5 (23.8)	16 (76.2)		1.90	0.83-4.35	
Non-Hispanic ethnicity, %	Not available	80.3 ± 23.9	88.5 ± 24.5	.05	0.69 (per 24.84% increase)	0.44-1.07	.09
Proportion of dual Medicare-Medicaid cases	≤10%	20 (13.2)	131 (86.8)	.10	1	Reference	.02
	>10%	3 (5.3)	54 (94.7)		0.43	0.21-0.89	
State population identifying as SGMs, %	Not available	4.1 ± 0.6	3.8 ± 0.5	.03	Not included in multivariate analyses <sup>c</sup>		

Abbreviation: SGM, sexual and/or gender minority.

<sup>a</sup>For categorical variables, numbers and percentages (in parentheses) as well as chi-square *P* values are reported. For continuous variables, means and standard deviations as well as Kruskal-Wallis *P* values are reported.

<sup>b</sup>Twenty-two of the 222 practice groups that responded to the gender identity question were excluded from multivariate analyses because of missing data.

<sup>c</sup>Removed from the model on the basis of backward elimination.



**Figure 1.** Practice group characteristics statistically significantly associated with reporting gender identity.

large regional/multistate health system were less likely to report collecting gender identity information than both independently owned sites (*P* = .0260) and practice

groups within another category of ownership (*P* = .0379) according to the multivariate model. Likewise, groups for which more than 10% of the patients had both Medicare and Medicaid were less likely to routinely collect gender identity information according to the multivariate model (*P* = .0187). Conversely, although the initial univariate analyses showed an association between the percentage of the state population identifying as SGM and the routine collection of gender identity information (Kruskal-Wallis *P* = .0295), this association was not observed in multivariate analyses.

## DISCUSSION

Only approximately 1 in 5 responding NCORP community oncology practice groups reported routinely collecting SOGI data, and site characteristics, including the location of the practice group, whether the group served a lower proportion of non-Hispanic patients, and whether the group served a higher proportions of LGBT-identifying individuals, were all directly associated with a greater likelihood of querying patients about such information. In keeping with the growing literature on underreporting,<sup>11-15</sup> this study shows that even in a large NCI-funded research network, health care providers and

health care personnel remain reluctant to ask for SOGI information. Because data collection on SOGI status does not occur at the majority of cancer institutions, SGM patients cannot be identified and may be underserved when they are cared for at cancer clinics. Physicians who are unaware that they are treating SGM patients may be less responsive to these patients' needs, and this may contribute to a lack of patient-centered care.

Not surprisingly, states in the United States with a higher proportion of SGM patients and with nondiscrimination legislation appear to have higher rates of asking about gender identity information. For instance, California, Oregon, and Washington have statewide employment, antibullying, and public accommodation legislation, have higher percentages of SGM individuals, and are more likely to collect SOGI information.<sup>21</sup> Although the association was not evaluated directly in this study, we surmise that SGM individuals who live in regions that harbor SGM-friendly attitudes might explain this favorable association because such states likely have higher numbers of SGM-friendly staff and thereby provide an SGM-welcoming environment.<sup>22</sup> Educating oncology staff on cultural sensitivity toward SGM individuals and hiring staff of all sexual orientations and gender identities may enhance collection of SOGI information.

Interestingly, this study also showed that community oncology practice groups with more ethnic diversity (measured by proportions of non-Hispanic patients) were more likely to ask about sexual orientation. Although it is not clear why this relation was observed, SGM individuals are more likely to lack adequate insurance and to report unmet medical needs, and this sometimes makes them recipients of care in underserved areas.<sup>23</sup> Potentially, the health care providers who work in these underserved clinics are more adept at managing a variety of issues among various minority groups and are hence willing to ask about SOGI information. This may also be a result of the higher proportion of Hispanic patients seen in the Western United States.

This study has both strengths and weaknesses. A strength is that this work was undertaken nationwide within research settings embedded in community-based oncology settings. Although previous studies on this topic have focused on clinical practice settings, this research perspective is of great importance.<sup>13,17</sup> Understanding that SGM issues are not addressed in a research setting undercuts our ability to learn how to better screen or detect cancer in potentially high-risk SGM individuals and to learn whether malignancies within SGM individuals

behave differently and, therefore, require a modified treatment approach. Thus, at a broad public health level, these findings point to a need for further education among health care providers and clinical research personnel in an effort to collect these data routinely and systematically. In terms of weaknesses, this study did not use a validated questionnaire to assess SOGI data. The fact that our survey was rooted in a quality initiative and the fact that our queries and goals are somewhat unique explain why our project needed to be built from the ground level. In addition, response rates were low, and this increased the risk for a nonresponse bias. For this reason as well, the power to detect true associations may have been limited. Similarly, we are unable to report on data from practice groups that did not provide a response because no comparable data are available for these groups. Despite such limitations, this study provides important information that should prompt efforts to better serve this understudied minority population.

In summary, this study provides an important starting point for investigating the integration of SOGI information into cancer clinical trial research. Such efforts will be of value in moving forward research initiatives and better patient care in this group of patients with cancer.

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#### CONFLICT OF INTEREST DISCLOSURES

The authors made no disclosures.

#### AUTHOR CONTRIBUTIONS

**Elizabeth J. Cathcart-Rake:** Conceptualization–supporting, writing–original draft, and visualization. **Tyler Zemla:** Formal analysis and validation. **Aminah Jatoi:** Conceptualization–supporting, funding acquisition–supporting, writing–review and editing. **Kathryn E. Weaver:** Conceptualization–supporting and review and editing–supporting. **Heather Neuman:** Conceptualization–supporting and review and editing–supporting. **Anne E. Kazak:** Conceptualization–supporting and review and editing–supporting. **Ruth Carlos:** Conceptualization–supporting and review and editing–supporting. **Lucy Gansauer:** Conceptualization–supporting and review and editing–supporting. **Joseph M. Unger:** Conceptualization–supporting and review and editing–supporting. **Nicholas M. Pajewski:** Conceptualization–supporting and review and editing–supporting. **Charles Kamen:** Conceptualization–lead, data curation, funding acquisition–lead, writing–review and editing, and resources.



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