

Surveillance of Cancer Among Sexual and Gender Minority Populations: Where Are We and Where Do We Need to Go?

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On the basis of the latest estimates, in the United States, there are currently approximately 9 million lesbian, gay, bisexual, transgender, and queer (LGBTQ; also known as sexual and gender minority [SGM]) individuals.¹ The unique health needs and burden of disease, including cancer, in this population is increasingly recognized, as evidenced by designation by the National Institute of Minority Health and Health Disparities,² of SGMs as a health disparity population. There are limited data available on the burden of cancer among SGM men and women. In this issue of *Cancer*, Kent and colleagues review the literature on cancer care for SGM populations.³ Their review illustrates the severe lack of population-based studies on SGM patients, which limits the recognition of cancer and other health disparities in this underserved and understudied population.⁴ By using an ecological approach, a study across all registries of the Surveillance, Epidemiology, and End Results program showed that lung cancer incidence and mortality rates are higher in counties with a higher density of sexual minority men, whereas the reverse was found in counties with a higher density of sexual minority women.⁵ Among men who have sex with men, a review showed a high burden of sexually transmitted infection-related cancers,⁶ with the most frequent cancers being anal and liver cancers, Kaposi sarcoma related to HPV, Epstein-Barr virus, and herpes virus 8, respectively. Among women who have sex with women, Meads and Moore⁷ evaluated the literature on breast cancer and found that results from 5 studies were inconsistent regarding whether lesbian and bisexual women had higher risks than heterosexual women, primarily because the studies had small numbers of patients and generally were of limited quality. The authors emphasized the need for more research to fill the knowledge gap of the burden of cancer (and other diseases) among SGM populations.⁶ The systematic collection of high-quality data on SGM status is fundamental to assessing and monitoring the burden of cancer, including incidence, survival, and mortality rates, as well as contributing factors, in this vulnerable population. A position statement from the American Society of Clinical Oncology in 2017 recommended increased data collection on SGMs to inform future work addressing their health needs, including SGM data collection by cancer registries.⁸

Data collected by diagnosing and treating hospitals and physicians' offices are the predominant source of information on new cancers for population-based cancer registries. In the North American Association for Central Cancer Registries (NAACCR) data dictionary, the variable "sex" has several options beyond male and female, including other (intersex, disorders of sexual development); transsexual or transgender, not otherwise specified; transsexual or transgender, natal male; and transsexual or transgender, natal female. However, despite these categories, the extent to which sexual orientation and gender identity information is systematically collected by hospitals and physicians' offices remains unknown. In the San Francisco Bay Area, a feasibility assessment conducted by the Greater Bay Area Cancer Registry showed that gender identity and sexual orientation information is not systematically captured within most hospitals and physicians' practices in the region, an area with the highest proportion of SGMs in the United States.⁹ Some facilities and practices did capture "other" gender and sexual orientation categories (either as an open-ended field, or by clinician observation, or if a patient provided this information), but this information, for the most part, was not collected in a systematic way. In the feasibility assessment, based on some surveys returned by physician offices and/or verbal interactions with office staff, the level of detail regarding data collection on sexual orientation and gender identity was limited, and several comments

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were made that this information was “irrelevant,” “not necessary for their patient’s care,” “too intrusive,” or “only recorded *if* it was related to the patient’s medical condition.” Contrary to these sentiments, several comments were made by cancer registrars who abstract data from hospitals that sexual orientation and gender identity data should be routinely collected but is not. Specifically, “this needs to be collected more systematically,” “our facility just recently began...” or “will soon begin collecting these data,” or “we need questions like this added to our (patient intake/registration) form.” It was heartening to learn that several hospitals and integrated health care systems in the region already do incorporate or are actively working on incorporating these SGM-related items into intake forms and are asking patients about sexual orientation and gender identity status in a more consistent and standardized way. This feasibility survey for hospital administrators, physician offices, and certified tumor registrars is available from the first author upon request.

Cancer registries collect data according to rules and guidelines from the standard setters, such as the NAACCR and the Surveillance, Epidemiology, and End Results program. Although the NAACCR sex variable already accommodates several categories of gender identity, it is likely under-used; in the Greater Bay Area Cancer Registry, from the period 1988 through 2014, only 115 cases (0.015%) were coded as transsexual. As with any new data item, the standard setters should expand the requirements to collect gender identity and sexual orientation data from all cancer registries. However, they should first work with national accreditation organizations, such as the American Society of Clinical Oncology, the National Cancer Institute, the American College of Surgeons, etc, to develop guidelines and requirements for the collection of additional key patient sociodemographic data, including SGM status.

A national study showed that 78% of clinicians felt that their patients would refuse to disclose their SGM status, in stark contrast to only 10% of patients reporting that they would refuse to disclose their status, citing improved individualized care as a benefit to disclosure.¹⁰⁻¹² In a recent national survey of nearly 150 oncologists from National Cancer Institute-designated cancer centers across the United States, Schabath and colleagues measured the attitudes, knowledge, institutional practice behaviors, and interest in education on the care of LGBTQ patients with cancer.¹³ They found that although a majority of oncologists, approximately two-thirds, felt that it was important to know a patient’s gender identity, only about one-third felt that it

was relevant to them to know of the patient’s sexual orientation. Although there was generally limited knowledge regarding LGBTQ cancer needs, greater than 70% indicated interest in receiving education regarding the unique oncology needs for this population. Our cancer registry feasibility assessment showed that, in the San Francisco Bay Area, the leaders of large health care systems and hospitals are willing to collect SGM data and likely would do so if mandated for cancer registry reporting or for accreditation. However, independent community physician practices, which are reporting an increasing proportion of new cancer diagnoses, will need additional motivations to collect SGM data in addition to data on basic social determinants, such as self-reported race and ethnicity. This is especially concerning for prostate cancer and melanoma, which are increasingly diagnosed and treated only in physicians’ offices. Training as well as data-collection tools are needed to encourage physicians’ offices to appreciate the importance of social determinants in the context of the medical care they are providing and to facilitate data collection on social determinants of health, including SGM status. The development and implementation of tools for data collection is a process that should involve engagement of clinicians and patients. Clinicians should be reassured that the vast majority of patients nationwide welcome being asked about SGM status and related information, and the patient voice can be powerful in this regard.

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