

DR. SCARLETT LIN GOMEZ (Orcid ID : 0000-0002-5143-4867)

Article type : Commentary

Surveillance of cancer among sexual and gender minority populations: where are we and where do we need to go?

Running Title: Sexual and gender minority status data

Scarlett Lin Gomez, PhD^{*1,2}, Christine Duffy, MPH¹, Jennifer J. Griggs, MD, MPH³, Esther M. John, Ph⁴

¹Department of Epidemiology and Biostatistics, University of California, San Francisco, CA

²Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco, CA

³Department of Internal Medicine, University of Michigan, Ann Arbor, MI

⁴Department of Medicine and Stanford Cancer Institute, Stanford University School of Medicine, Stanford, CA

*Corresponding Author Information:

University of California, San Francisco

Epidemiology and Biostatistics

550 16th Street

San Francisco

California

94158

United States

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1002/CNCR.32384](https://doi.org/10.1002/CNCR.32384)

This article is protected by copyright. All rights reserved

Phone: 510-608-5041

E-Mail Address: sgomez@psg.ucsf.edu

Conflicts of Interest: None

Funding: This study was funded by an Administrative Supplement to the Breast Cancer Family Registry (BCFR). The BCFR was supported by grant UM1 CA164920 from the U.S. National Cancer Institute. The content of this manuscript does not necessarily reflect the views or policies of the National Cancer Institute or any of the collaborating centers in the BCFR, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government or the BCFR.

Precis: Systematic collection of high-quality data on sexual and gender minority status is fundamental to assessing and monitoring the burden of cancer in this understudied and underserved population. The majority of hospitals do not collect these data and physicians offices do not perceive the data to be medically relevant.

Keywords: Sexual Orientation, Gender Identity, Cancer Registries, Sexual Gender Minority, Cancer Surveillance

Based on latest estimates, in the United States (U.S.), 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 (Director's message: <https://www.nimhd.nih.gov/about/directors-corner/message.html>) 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 et al. reviewed the literature on cancer care for SGM populations. This 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 (2). Using an ecological approach, a study across all registries of the Surveillance, Epidemiology, and End Results (SEER) 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 (3). Among men who have sex with men (MSM), a review showed a high burden of sexually

transmitted infections-related cancers (4), with the most frequent cancers being anal and liver cancer, and Kaposi sarcoma, related to human papillomavirus (HPV), Epstein-Barr virus, and herpes virus 8, respectively. Among women who have sex with women (WSW), Meads and Moore (5) evaluated the literature on breast cancer and found that results from five studies were inconsistent regarding whether lesbian and bisexual women had higher risks than heterosexual women, primarily due to the studies having small number of patients and being of generally 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 (4). 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 (ASCO) in 2017 recommended increased data collection on SGMs to inform future work addressing their health needs, including SGM data collection by cancer registries (6).

Data collected by diagnosing and treating hospitals and doctors' 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, it is unknown the extent to which sexual orientation and gender identity information is systematically collected by hospitals and doctors' offices. 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 are not systematically captured within most hospitals and doctors' practices in the region, an area with the highest proportion of SGM in the U.S. (7) 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 was, for the most part, 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 were made that this information was "irrelevant," "not necessary for their patient's care," "was 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 isn't. 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 healthcare systems in the region already do or are actively working on incorporating these SGM-related items into intake forms, and 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 are available from the first author upon request.

Cancer registries collect data according to rules and guidelines from the standard setters, such as NAACCR and SEER. Although the NAACCR sex variable already accommodates several categories of gender identity, they are likely under-utilized; in the Greater Bay Area Cancer Registry, from the period 1988-2014, 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 ASCO, National Cancer Institute (NCI), American College of Surgeons, etc., to develop guidelines and requirements for 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 (8-10). In a recent national survey of nearly 150 oncologists from NCI-designated cancer centers across the U.S., Schabath and colleagues measured the attitudes, knowledge, institutional practice behaviors, and interest in education on the care of LGBTQ patients with cancer (11). They found that while the majority, about two-thirds, of oncologists 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, more 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 healthcare 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 basic social determinants data such as self-reported race and ethnicity. This is especially concerning for prostate cancer and melanoma, which are increasingly diagnosed

and treated only in doctors' offices. Training as well as data collection tools are needed to encourage doctors' 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.

References

1. Gates G. How many people are lesbian, gay, bisexual, and transgender? Los Angeles, CA: The Williams Institute; 2011. Available from: <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf>.
2. Shetty G, Sanchez JA, Lancaster JM, Wilson LE, Quinn GP, Schabath MB. Oncology healthcare providers' knowledge, attitudes, and practice behaviors regarding LGBT health. *Patient education and counseling*. 2016;99(10):1676-84.
3. Boehmer U, Ozonoff A, Miao X. An ecological approach to examine lung cancer disparities due to sexual orientation. *Public health*. 2012;126(7):605-12.
4. Blondeel K, Say L, Chou D, Toskin I, Khosla R, Scolaro E, et al. Evidence and knowledge gaps on the disease burden in sexual and gender minorities: a review of systematic reviews. *International journal for equity in health*. 2016;15:16.
5. Meads C, Moore D. Breast cancer in lesbians and bisexual women: systematic review of incidence, prevalence and risk studies. *BMC public health*. 2013;13:1127.
6. Griggs J, Maingi S, Blinder V, Denduluri N, Khorana AA, Norton L, et al. American Society of Clinical Oncology Position Statement: Strategies for Reducing Cancer Health Disparities Among Sexual and Gender Minority Populations. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2017;35(19):2203-8.

7. Gates GJ. Same-sex Couples and the Gay, Lesbian, Bisexual Population: New Estimates from the American Community Survey. <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-Same-Sex-Couples-GLB-Pop-ACS-Oct-2006.pdf>. October 2018.
8. Haider AH, Schneider EB, Kodadek LM, Adler RR, Ranjit A, Torain M, et al. Emergency Department Query for Patient-Centered Approaches to Sexual Orientation and Gender Identity : The EQUALITY Study. *JAMA internal medicine*. 2017;177(6):819-28.
9. Maragh-Bass AC, Torain M, Adler R, Ranjit A, Schneider E, Shields RY, et al. Is It Okay To Ask: Transgender Patient Perspectives on Sexual Orientation and Gender Identity Collection in Healthcare. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine*. 2017;24(6):655-67.
10. Maragh-Bass AC, Torain M, Adler R, Schneider E, Ranjit A, Kodadek LM, et al. Risks, Benefits, and Importance of Collecting Sexual Orientation and Gender Identity Data in Healthcare Settings: A Multi-Method Analysis of Patient and Provider Perspectives. *LGBT health*. 2017;4(2):141-52.
11. Schabath MB, Blackburn CA, Sutter ME, Kanetsky PA, Vadaparampil ST, Simmons VN, et al. National Survey of Oncologists at National Cancer Institute-Designated Comprehensive Cancer Centers: Attitudes, Knowledge, and Practice Behaviors About LGBTQ Patients With Cancer. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. 2019;Jco1800551.