

American Society of Clinical Oncology Position Statement: Strategies for Reducing Cancer Health Disparities Among Sexual and Gender Minority Populations

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ABSTRACT

ASCO is committed to addressing the needs of sexual and gender minority (SGM) populations as a diverse group at risk for receiving disparate care and having suboptimal experiences, including discrimination, throughout the cancer care continuum. This position statement outlines five areas of recommendations to address the needs of both SGM populations affected by cancer and members of the oncology workforce who identify as SGM: (1) patient education and support; (2) workforce development and diversity; (3) quality improvement strategies; (4) policy solutions; and (5) research strategies. In making these recommendations, the Society calls for increased outreach and educational support for SGM patients; increased SGM cultural competency training for providers; improvement of quality-of-care metrics that include sexual orientation and gender information variables; and increased data collection to inform future work addressing the needs of SGM communities.

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INTRODUCTION

Sexual and gender minorities (SGMs), including individuals who are lesbian, gay, bisexual, transgender, and intersex (LGBTI), bear a disproportionate cancer burden. Such disparities in cancer-specific outcomes among SGM populations stem from the unique cancer risks, needs, and challenges faced by SGM populations, including discrimination and other psychosocial issues, as well as gaps in patient-provider communication and quality of care. For example, lesbian and bisexual women have higher rates of obesity and a greater risk of breast cancer, gay men have a greater risk of anal cancer, and people who are LGBTI are more likely to smoke cigarettes than their heterosexual cisgender counterparts.¹ In addition, SGM populations exhibit low rates of uptake of cancer screening, in part because of lower rates of insurance coverage, exclusion from traditional cancer screening campaigns, and previous experiences of discrimination when interacting with health care systems and providers.²⁻⁴ As a result, SGM patients with cancer may be more likely to present with late-stage disease.⁵ It is also likely that inadequate evidence-based knowledge and patient-provider

communication lead to suboptimal care and survivorship care planning. Because of fear of discrimination and stigmatization, SGM populations often do not disclose their sexual orientation to their health care providers, and this may create additional barriers to care.⁶ In addition, medical students and faculty who identify as SGM have reported persistent discrimination in the workforce.⁷ Finally, lack of information on sexual orientation and gender identity (SOGI) at the individual patient level and in large databases leads to gaps in the knowledge base about the disease burden, quality of care, opportunities for improvement, and research needs in SGM populations.

For this statement, ASCO has used the terminology adopted by the National Institutes of Health (NIH), “sexual and gender minorities,” to be both inclusive and consistent. As described by the NIH, the term “encompasses lesbian, gay, bisexual, and transgender (LGBTI) people, as well as those whose sexual orientation and/or gender identity varies, those who may not self-identify as LGBTI (eg, queer, questioning, two-spirit, asexual, men who have sex with men, gender-variant), or those who have a specific medical condition affecting reproductive development (eg, individuals with differences or disorders of sex development, who sometimes identify as intersex).”^{6(p1)}

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Two recent reports, one from the Institute of Medicine (IOM), which addresses the health of SGM communities and gaps in research and another from the American Association of Medical Colleges, which specifies needed curricular changes to improve care for individuals who are members of SGM communities, cite myriad examples of the health care disparities experienced by these communities.^{1,7} Increasingly, medical organizations such as the American College of Physicians are undertaking formal efforts to identify root causes of these disparities and offer solutions.⁸

In 2015, the ASCO Health Disparities Committee identified the need to develop an ASCO strategy for addressing the needs of the SGM populations as a diverse group at risk for receiving disparate care and having suboptimal experiences throughout the cancer care continuum. As a first step, the committee established a working group of ASCO members to discuss and develop a set of concrete recommendations for addressing the needs of these populations. The work group conducted an environmental scan of current initiatives and resources aimed at addressing these needs and used this information to develop a set of recommendations for addressing cancer disparities in SGM populations. These recommendations are intended to address not only the needs of patients with cancer and their loved ones, but also members of the oncology workforce who identify themselves as members of SGM communities. The work group identified five areas of need: Patient Education and Support, Workforce Development and Diversity, Quality Improvement Strategies, Policy Solutions, and Research Strategies.

The position statement was also reviewed by the Gay and Lesbian Medical Association, and their feedback was incorporated into the statement. This statement provides a summary of these recommendations and how ASCO plans to integrate them into its programs and policies. It is hoped that these recommendations can also be used to help other stakeholders in the oncology community to address the needs of SGM populations in the cancer care setting.

RECOMMENDATIONS

Patient Education and Support

In contrast to other cancer survivor populations, SGM individuals with cancer may face unique psychosocial challenges, such as estrangement from families of origin and fear of discrimination, and are often at increased risk for stress, anxiety, and depression, as well as worse cancer-specific outcomes. A recent Canadian study asserts that existing resources are described by transgender patients with cancer as inadequate.⁹ There can at times be distrust of medical institutions and of individual providers by SGM patients.¹⁰ A lack of cancer-focused SGM patient and community education outreach programs only further increases the gaps in care for these patients.¹¹

ASCO recommends that the following patient-level strategies be implemented to help provide a safe and high-quality health care environment for SGM individuals:

- **Enhance Patient Navigation and Care Coordination:** Patient navigation and care coordination should encourage safe disclosure of SGM identities, appropriate referrals to support networks, and advocacy and reassurance for SGM persons afraid of discrimination as they navigate health care systems.
- **Expand Education for SGM Patients With Cancer and Survivors:** Although an increasing number of resources are being developed for SGM communities related to health and wellness, there are few resources addressing the needs of patients with cancer and others affected by cancer. Educational resources should be developed that include information on the most common types of malignancies affecting the SGM community, as well as the effects of treatment and appropriate follow-up care plans that are tailored to the needs of SGM patients. These resources should be readily available for patients at physician practices as well as at hospital cancer resource centers so that oncology providers are able to refer their SGM patients to them when appropriate.
- **Increase Patient Access to Culturally Competent Support Services:** Improved access to support services, such as bereavement programs for SGM relatives and families of choice, are needed for SGM communities. A recently published white paper acknowledges the abundance of information related to provision of care within SGM populations related to the HIV epidemic that could be used as a model to inform future work on increased culturally competent support services.¹² Such resources could include partnering programs linking SGM patients with cancer and caregivers with cancer survivors and advocates, which can also be linked via live or virtual support groups as well as local, regional, and national support groups.¹³ ASCO recommends that greater emphasis be placed on developing and making available support services for SGM individuals and their loved ones.
- **Create Safe Spaces for SGM Patients:** Cancer providers, centers, clinics, and the health systems within which they operate should take steps to create a safe and welcoming environment for SGM patients, including but not limited to practice Web sites and patient portals, health intake forms, health literature, and in-person communications and facilities (eg, bathrooms). This is particularly important for patients with gendered cancers, such as breast cancer, who may be cared for in gender-specific facilities.
- **Increase Cancer Prevention Education for SGM Individuals:** Multiple studies have reported that SGM individuals have a greater likelihood of certain behaviors that increase the risk of cancer, including tobacco and alcohol use.¹³⁻¹⁵ Patient education efforts should also be focused on screening of SGM individuals for risk behaviors and providing counseling and support for cessation.

Workforce Development and Diversity

Several provider-level barriers exist to providing high-quality care to SGM patients. A recent Institute of Medicine report provides extensive evidence that many providers are not trained to provide care for SGM patients.¹ Providers also report a lack of knowledge and sensitivity about the health risks and health needs facing their SGM patients. Oncology providers, both those in training and those already in practice, may not be adequately informed, and their practices and the institutions in which they work may not be fully equipped to appropriately meet the needs and concerns of their SGM patients and their loved ones. Providers may not be aware of both the lived

experiences and the barriers to care, including the legal and financial barriers that exist and are not addressed for members of SGM communities.

The Joint Commission defines cultural competency as the “ability of health care providers and health care organizations to understand and respond effectively to the cultural and language needs brought by the patient to the health care encounter.”^{16(p87)} Cultural competence requires organizations and their personnel to do the following: (1) value diversity, (2) assess themselves, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge, and (5) adapt to diversity and the cultural contexts of individuals and communities served.¹⁶ Many providers lack LGBTI cultural competency and sensitivity training and may need additional training and support to acquire the skills needed to address the unique issues and concerns of members of SGM communities. For example, SGM individuals often feel isolated and uncomfortable about disclosing their SGM status and may need assistance from their providers in feeling safe to do so. Such skills include increasing patient comfort with sexual identity disclosure, understanding the definitions of and demographics for the different groups, and possible differential patterns of risk for and outcomes of cancer, as well as skills in communicating and working with members of these groups and their social support systems.^{13,17}

ASCO recommends that the following steps be taken to ensure access to culturally appropriate care for SGM individuals across the cancer continuum. These steps should be taken, where appropriate, through collaboration among existing LGBTI/SGM organizations and professional societies with expertise in prevention, education, quality of care, and palliative care, among others, whose members care for patients with cancer.

- Expand and Promote Cultural Competency Training:** ASCO is committed to working with other stakeholders to assess and improve the knowledge and training levels of the oncology provider community around the issues facing members of the SGM communities. SGM cultural competency curricula and other training resources that are tailored to the cancer setting should be developed and made widely available. These resources should be directed toward all levels of providers and any staff members who interact with patients and/or caregivers, such as clerical staff, technicians, patient navigators, pharmacy staff, housekeeping staff, and food service staff. Training programs should include culturally competent and trained community health workers (eg health promoters, navigators, popular opinion leaders, and SGM peer leaders) who can augment and/or deliver prevention and health promotion messages and can serve as cross-cutting subject matter experts on SGM issues for providers. In particular, patient navigators can serve a key role in coordinating services for SGM populations and should be educated about special concerns, such as the constraints placed on SGM individuals’ access to their family of choice and resulting potential for financial discrimination. In addition, these materials should recognize the intersectionality and diversity of SGM communities by considering SOGI, race, ethnicity, class, comorbidity, HIV status, disability, and other socioeconomic factors that affect cancer outcomes across the cancer care continuum.

- Incorporate SGM Training Into Training Curricula, Training Requirements, and Certification Exam Content:** Health care accreditation and standards-setting bodies should create performance standards and metrics for assessing knowledge about cancer health needs, risk factors, and prevention strategies, as well as SGM cultural competency among health care organizations and individual providers. Development of standards for sensitivity training in SGM health issues and development of standardized tools would permit SGM individuals to safely disclose their status, which would then allow for the tailoring of care, including referrals to SGM health resources.
- Foster Safe Environments for SGM Staff and Providers:** ASCO recommends that cancer centers foster a safe and open environment for SGM providers through disseminating and enforcing antidiscrimination policies as well as through additional cultural competency training in the workplace. Doing so has the potential to improve the level of cultural competence and the quality of cancer care for SGM populations.
- Integrate a Focus on SGM Physicians in Oncology Workforce Diversity Efforts:** The American Association of Medical Colleges has reported persistent discrimination among SGM students and faculty and during postgraduate training.⁷ ASCO is committed to a diverse oncology workforce, to date, with a focus on racial and ethnic diversity. Primarily through the Diversity in Oncology Initiative programs, ASCO has awarded opportunities for medical students and residents who self-identify as an underrepresented minority. ASCO is committed to promoting strategies that lead to a more inclusive workforce that welcomes SGM providers and staff, including identifying SGM individuals as a group to target for its workforce diversity efforts. Increased representation of professionals representing SGM populations on ASCO committees would increase attention and expertise regarding the needs of SGM patients and the SGM workforce. Barriers faced by SGM individuals entering the oncology workforce should be assessed and interventions developed as appropriate. Furthermore, nondiscrimination policies must be enforced in the workplace.

Quality Improvement Strategies

In 2010, the Joint Commission on Accreditation of Healthcare Organizations made several recommendations specific to SGM populations on best practices and processes that can assist hospitals in meeting the needs of SGM patients.¹³ New accreditation requirements have also been developed by the Joint Commission to assess hospital performance and discrimination related to effective communication, cultural competence, and patient- and family-centered care for all patients.¹⁸ Nonetheless, there still remains a lack of systems for continuous quality improvement for oncologists on the management of SGM patients with cancer. In response, ASCO makes the following recommendations:

- Collect and Use SGM-Relevant Data for Quality Improvement:** ASCO is committed to encouraging the collection and use of SGM-relevant data for quality improvement. This would include revision of all data forms, especially electronic medical

records, to include SOGI variables in quality-of-care metrics, professional organizations, and consumer surveys to allow SGM populations to accurately record their medical history and, in turn, receive useful and specific information on the basis of that information. Oncologists should be encouraged to routinely capture SOGI data for their clinical practice populations and use it to tailor care for their patients. Specific attention is needed to ensure that SGM patients and families are receiving high-quality cancer care, including palliative and hospice care.

- **Ensure Prompt Follow-Up and Continuity of Care:** Attention to addressing deficits in access to prompt follow-up after abnormal screening results, as well as timely and culturally competent coordination of transition to quality cancer care to mitigate attrition and delays, should be a high priority of the health care system. Due to high levels of mistrust, patient retention in follow-up care may be an ongoing issue, especially as patients move into the survivorship phase of their cancer journey. Quality metrics that allow us to record patient compliance and retention may be particularly helpful for SGM patient populations and provide valuable insights for future efforts to reduce disparities.

Policy Solutions

The U.S. Department of Health and Human Services Office for Civil Rights issued the final rule of Section 1557, the non-discrimination provision of the Affordable Care Act (ACA), on May 13, 2016.¹⁹ With respect to SGM populations, Section 1557 specifies that health care or health coverage cannot be denied on the basis of sex, including gender identity and sex stereotyping. Section 1557 states, "While the final rule does not resolve whether discrimination on the basis of an individual's sexual orientation status alone is a form of sex discrimination under Section 1557, the rule makes clear that the Office for Civil Rights will evaluate complaints that allege sex discrimination related to an individual's sexual orientation to determine if they involve the sorts of stereotyping that can be addressed under Section 1557. HHS [Department of Health and Human Services] supports prohibiting sexual orientation discrimination as a matter of policy and will continue to monitor legal developments on this issue."^{19a} The Joint Commission requires that all hospitals prohibit discrimination on the basis of personal characteristics, including sexual orientation and gender identity or expression. Many states and cities also prohibit discrimination on the basis of these characteristics, but far from all do.

Section 1557 of the ACA is likely to change policies at the state level. However, policies of inclusion are less far-reaching in the realm of health insurance coverage. SGM populations face unique challenges in this area. Specifically, transgender individuals experience limitations in coverage for transition-related care and cancer screening, given that a transgender individual's anatomy may not be compatible with the gender listed in his or her policy. Ultimately, it is the responsibility of policymakers and organizational leaders to encourage adoption of SGM-inclusive policies. Regardless of the future status of the ACA, policies that prohibit discrimination on the basis of sexual orientation and gender identity must be preserved.

To achieve systemic improvements in the care of SGM individuals, policy change will be needed at several levels:

- **Create and Enforce Policies Ensuring Access to Culturally Competent, Equitable Cancer Care:** Policies that encourage SGM culturally competent treatment and system-level changes in prevention and health care are needed to improve health information, communication, informed decision making, and access to health services. Examples of such policies include elimination of discrimination and arbitrary exclusion from diagnostic testing (eg, due to discordance between gender indicators and anatomy for transgender patients), provision of gender-neutral bathrooms in cancer care facilities, and implementation of policies addressing end-of-life care for SGM patients (eg, respect for patient choice of burial and death rituals).
- **Ensure Adequate Insurance Coverage to Meet the Needs of SGM Individuals Affected by Cancer:** Through state and federal advocacy efforts, ASCO has worked closely with lawmakers to ensure that patients have appropriate access to treatment and insurance coverage. ASCO will assess current coverage policies of federal, state, and private payers to ensure that they adequately cover interventions and services relevant to the care of SGM individuals with a focus on the transition and cancer care needs of transgender communities. By assessing the current insurance coverage landscape and identifying gaps, ASCO can ensure that the findings and areas for change can be integrated into ASCO's overall advocacy strategy. In particular, insurance coverage policies should be based on anatomy such that, for example, no matter what one's sex assignment is, a person who has a prostate has access to appropriate prostate cancer screening.
- **Ensure Policies Prohibiting Discrimination:** At the time of publication, 18 states have enacted laws against health care discrimination on the basis of sexual orientation and gender identity.²⁰ ASCO is committed to promoting policies that ensure zero tolerance for discrimination and hostility toward any individuals, including SGM individuals, on the basis of religious or other grounds, as such behavior has no place in the professional medical setting. Oncology care providers should affirm their SGM-affirming principles by informing patients and their partners of nondiscrimination practices regarding hospital visitation and surrogate medical decision making. Providers should encourage SGM patients and health care personnel to complete health care proxies and hospital visitation forms so that their preferences are known and respected.

Research Strategies

Limited research is being conducted to assess the needs and establish standards of care for SGM patients with cancer and cancer survivor populations. There is insufficient knowledge about the health care needs, health outcomes, lived experiences, and effective interventions to improve outcomes for SGM individuals. For example, although high rates of noncompliance with cancer screening, treatment, and surveillance have been reported, these behaviors are not widely acknowledged, documented, or addressed. Research is needed to determine whether patterns of risk (including genetic/genomic, behavioral, sociocultural, or

exposure related) and outcomes after a cancer diagnosis vary by SGM status. Concern has been expressed that the SGM community experiences a heightened perception of more cancer and worse outcomes, even if this is not always concordant with available epidemiologic data.

The NIH has proposed a strategic plan to address the research needs relevant to SGM populations, and in 2016, formally designated sexual and gender minorities as a health disparity population for NIH research.^{6,21} To expand the knowledge about the needs of SGM populations, ASCO recommends that this framework be adopted and that the following recommendations be championed to promote further research among SGM populations:

- Promote the Inclusion of SGM Status as a Required Data Element in Cancer Registries and Clinical Trials:** Although federally funded health surveys, for example, the National Health and Nutrition Examination Survey, the National Health Interview Survey, and the Behavioral Risk Factor Surveillance System, now collect data on sexual orientation and gender identity, data are not routinely collected in other clinical trials, surveys, or epidemiologic studies. For this reason, the ability to conduct studies among SGM populations is significantly hindered by limited processes for identifying and reaching out to these individuals. To address this issue, efforts should be made both to standardize capture of this information as well as to support training of staff in sensitive and respectful approaches to collecting this information. Specific efforts should include promoting the inclusion of SOGI data in cancer registries and clinical trials, advocating more broadly for inclusion of SOGI information in government-sponsored research, and supporting a modification of North American Association of Central Cancer Registries standards to include SOGI variables as part of its required core variable set.
- Promote Research Among SGM Populations:** ASCO is committed to working with stakeholders to promote increased research focus among SGM populations by the NIH and other funding organizations. Funders should be encouraged to conduct research on issues such as cancer prevention and health promotion, as well as the end-of-life/chronic illness experiences of SGM patients and their caregivers, including the development of SGM-specific psychosocial, spirituality, and existential distress measures. Research should reflect the diversity seen within SGM communities by assessing SOGI, race, comorbidities, ethnicity, class, education, disability/ability, environment, and other socioeconomic factors. ASCO encourages the NIH to conduct a portfolio analysis of funded research among these populations that should serve to inform gaps in the knowledge base and identify new areas or directions for scientific pursuit. ASCO is committed to promoting increased research on this issue through its own channels as well. The Conquer Cancer Foundation provides an opportunity for increased funding for studies designed to address SGM issues. This funding opportunity could be prominently announced and highlighted as part of ASCO's effort to address cancer disparities on the basis of SGM status. In addition, ASCO journals provide a good vehicle to highlight the findings of research on cancer-related risks and outcomes for SGM patients and survivors.

- Train the Next Generation of Researchers:** ASCO supports the development of a research training program for current and future scientists that would raise awareness of SGM health issues among these individuals. ASCO is committed to leveraging its current programs, namely, its Young Investigator and Career Development awards—both of which provide funding to investigators to encourage and promote research—to further advance these goals. Notably, the Institute of Medicine recommends that NIH create a comprehensive research training program that would raise awareness of SGM health issues among researchers. Hence, this training should be conducted in addition to, or in partnership with, NIH or other funding partners. As part of this training, participants would learn about best practices in eliciting and addressing gender and sexual orientation information from patients and research participants with whom they would expect to interact. As part of this effort, it is proposed that ASCO work with other stakeholders to create mentoring opportunities for investigators who wish to study the health of members of SGM communities. Finally, increased attention should be given to including research conducted among, and sessions describing care for, SGM populations at scientific meetings dedicated to cancer care, including the ASCO Annual Meeting. Depending on the speed of maturation of the science, a thematic symposium could be useful on research addressing cancer risk, treatment, and outcomes among SGM populations; it is expected that this work would extend to research conducted among informal cancer caregivers who themselves may self-identify as SGM individuals and play an important role in cancer-related behaviors and outcomes of their care recipient.

In conclusion, members of SGM communities are at risk for suboptimal access to cancer prevention, screening, and high-quality cancer care. To correct this, it is necessary to address barriers at many levels, including interpersonal and institutional barriers to optimal care and outcomes. Needed is a coordinated effort to enhance patient and caregiver education, to improve outreach and support, to provide training and education, to provide health care workers who are knowledgeable about and sensitive to the needs of the community, and to encourage constructive policy and legislative action. Advances in SGM health will depend on more research about the needs of SGM patients to guide actions aimed at bringing quality of care and health maintenance up to ASCO standards.

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