

Why Aren't Sexual Orientation and Gender Identity Being Measured and What Role Do Cancer Researchers Play?

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In recognition of the challenges specific to the sexual and gender minority (SGM) populations, the NIH identified SGM as a health disparity population. As part of its mission to promote training and information exchanges that will reduce the burden of cancer and related disparities, the American Society of Preventive Oncology (ASPO) has consistently featured research involving SGM populations at annual meetings. Most recently, at the 2019 ASPO Annual Meeting, Dr. Jennifer Griggs presented “addressing disparities in cancer care among sexual and gender minorities.” Dr. Griggs’s talk drew from the 2017 American Society for Clinical Oncology (ASCO) position statement on strategies to minimize health disparities among SGM individuals (1). The presentation offered many concrete steps to create welcoming spaces for SGM individuals and to continue thinking about work with SGM populations from a clinical perspective. Both the ASCO position statement and Dr. Griggs’s talk noted the need for research in SGM populations and routine collection of sexual orientation and gender identity (SOGI) data in clinical trials, research, and cancer registries. There have also been other national-level calls for SOGI measurement and data collection [e.g., National Academies of Medicine and Centers for Medicare & Medicaid Services (CMS)]. This attention underscores the fact that measurement is a requisite first step toward addressing cancer disparities by SOGI.

Despite repeated calls from researchers, scientific societies, and health care administration, routine collection of SOGI data is persistently lacking. A recent survey of NCI-designated comprehensive cancer centers reports that despite being leaders in cancer research and clinical practice, only three centers (14%) reported collecting sexual identity data, and only four (19%) regularly collect gender identity information (2). A lack of SOGI data as part of routine data collection within NCI comprehensive cancer centers will likely allow for persistence of cancer disparities by SOGI. As a multidisciplinary group committed to reducing cancer burden, ASPO membership is

poised to drive change in this area. Below, we describe potential challenges to routinely collecting SOGI data, progress from ongoing work to address those challenges, and a call to action for researchers, clinicians, and the broader scientific community to enhance system support to make SGM research more feasible and to set cultural norms through SOGI data collection (Table 1).

Challenge One: Not Knowing What Questions to Ask

Many researchers and clinicians do not know what questions to ask to collect SOGI data (from questionnaires, clinic forms, etc.). There are concerns and issues with measurement including: (i) sex and gender are often incorrectly used as interchangeable terms colloquially, (ii) SOGIs are distinct, requiring different questions to capture each construct, and (iii) SOGI can be dynamic, requiring multiple measurements and/or self-report questions regarding retrospective and current self-identification. Care must be taken to capture this desired information. Fortunately, standardized SOGI measures and resources exist to help researchers collect reliable and precise SOGI data. For example, the National LGBT Education Center at the Fenway Institute provides several resources including a guide to asking SOGI questions, a timeline/process for implementation of incorporating SOGI questions into electronic health records (EHR), training videos, and informational material related to SOGI and health. The NIH Sexual and Gender Minority Research office also has online resources for SOGI measurement. Cultural competency training resources are also available to educate clinicians and staff who may be asking SOGI questions. The National LGBT Cancer Network is one example of an organization with a curriculum for training staff trainers that can be adapted to multiple audiences.

Challenge Two: Perceptions that Patients Will Be Uncomfortable Answering SOGI Questions

Many researchers and clinicians fear that both non-SGM and SGM patients will experience discomfort reporting their SOGI. However, an integrative review of 21 studies suggests that both non-SGM patients and SGM patients are willing to respond to SOGI questions (3). Several of the studies showed that discomfort with answering SOGI questions was low, SOGI questions had lower nonresponse rates compared with other potentially sensitive questions (such as income), and that nonresponse rates were decreasing over time (3). Patients’ willingness to share their SOGI may be due to multiple perceived benefits from doing so. SOGI questions may be considered crucial for accurately ascertaining patients’ risk and protective factors for different medical conditions. Notably, 12 of 17 studies analyzed in the aforementioned review indicated patients felt it was important that their provider know their sexual identity to give them the best care (3). SOGI questions may also be useful with the rise of shared decision-making practices, especially the inclusion of families in care decisions. The prioritization

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Table 1. Call to action. Barriers, progress, and proposed solutions to address SOGI data collection.

Common challenges	Responses and solutions
Not knowing what questions to ask	Solutions have been developed: multiple standardized SOGI measures exist and are readily available for use
Perceptions that patients will be uncomfortable answering SOGI questions	Solutions in progress: numerous studies on patient discomfort suggest response rates are better than those for income questions and discomfort is low
Many clinicians are unfamiliar with and uncomfortable talking about SOGI	Solutions in progress: limited, but growing research on provider attitudes suggests while many are unfamiliar, many providers are interested in SGM training
Institutional policies, guidelines, and practices to collect SOGI data are lacking due to logistic challenges	Solutions that need to commence: <ul style="list-style-type: none"> • funders' and payers' mandates for SOGI data collection • cultural norms regarding SOGI data reporting and incorporation in models

of these needs may consequently “override” anticipated negative reactions and discomfort for many patients.

Challenge Three: Clinicians Are Unfamiliar with and Uncomfortable Talking about SOGI

Many clinicians lack familiarity with SGM populations and how a patient's SOGI can impact various aspects of clinical care (4). In a survey of NCI-designated comprehensive cancer center physicians, only 40% considered it important to know sexual orientation to provide the best care (4). Overall, these physicians reported a lack of confidence in their knowledge about the unique health needs of sexual minority patients (53% of physicians felt confident) and transgender patients (37% of physicians felt confident; ref. 4). Yet, within the same NCI physician survey, 70% indicated high interest in receiving education on the unique health needs of SGM patients and 44% indicated that the education should be mandatory (4). These survey results suggest that although providers believe that knowing their patients' SOGI does not affect their clinical practices, they recognize opportunities for additional education and demonstrate interest in expanding their knowledge about the needs of SGM populations.

Challenge Four: Institutional Policies, Guidelines, and Practices to Collect SOGI Data Are Lacking Due to Logistic Challenges

The lack of institutional policies, guidelines, and practices regarding routine SOGI measurement was recently documented by the majority of NCI-designated comprehensive cancer centers responding to a survey on cultural competence for SGM patients (2). Despite the identified importance of routine collection of SOGI data in clinical settings, widespread adoption of this recommendation has lagged. To date, CMS mandates the ability to collect SOGI data within the EHRs, but does not mandate data collection and reporting. Simultaneously, hospitals have received relatively little external pressure from researchers, funders, and payers to collect SOGI data. Characterizing and addressing the systemic capacity and cultural norms within hospital and academic settings (i.e., norms in administering SOGI measures) remain major, persistent gaps impeding widespread SOGI data collection. Given their role in training future oncology clinicians, educating the public, and engagement with the community, NCI-designated comprehensive cancer centers are particularly good places for bridging this gap (2).

Overall, there has been progress in efforts to promote widespread SOGI data collection. Nonetheless, this effort has been concentrated in

the development of SOGI data collection tools, as well as the examination of patient and provider attitudes regarding SOGI data collection. This is a call to action to complement these important advances by enhancing system supports and cultural norms within the academy and in oncology settings to collect capacity, as well as implement policies and procedures to systematically and routinely collect SOGI data.

In the context of systems, the NIH have made significant strides toward the inclusion of diverse populations in health research. Several mandates have emerged to ensure inclusion of marginalized groups by biological sex, age, and race/ethnicity in NIH-funded projects. These requirements have shifted with advances in science and shifts in academic norms. For example, the NIH recently expanded their policy on the inclusion of children in clinical research to better capture children's health across the lifespan with policy for inclusion across the lifespan. Similarly, despite progress including SGM as health disparity populations, there is still room for increasing system supports to make SGM research feasible. For example, expanding policy on the inclusion of women in clinical research and policy on sex as a biological variable to incorporate SGM communities may be one reasonable step toward increasing high-quality SOGI data collection.

There is a need for researchers to systematically collect (like other demographic variables) and report SOGI data in research manuscripts. Indeed, SOGI is as important a demographic characteristic as other routinely reported factors (e.g., age and education). In addition to examining potential disparities by SOGI, researchers should also investigate the role of SOGI in statistical model building (e.g., confounding and effect modification).

Although SGM populations are exposed to more cancer risk factors, have more difficulty accessing health care, and experience differences in social support compared with other patient populations, we lack data to consistently quantify and intervene to improve these issues. Asking SOGI questions is a critical first step toward understanding and better meeting the needs of these populations, and signaling that they are not invisible to clinicians and cancer researchers. As an organization, ASPO is working to foster these changes. The ASPO Health Disparities Special Interest Group Leadership Council has actively sought SOGI research for feature in our newsletters and other content. In addition, at the 44th annual ASPO conference in March 2020, online registration specifically requested preferred gender pronouns in an effort to dismantle stigma, recognize unique health issues, and create awareness of the health needs of SGM populations, both within and outside ASPO. Cumulatively, small changes such as these will continue moving the needle on addressing cancer disparities by SOGI.

Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

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