Sexual Orientation and Gender Identity Data Collection: Clinical and Public Health Importance

The 2011 Institute of Medicine report on lesbian, gay, bisexual, transgender, queer, intersex, and asexual (LGBTQIA+) health and subsequent reports from other normative bodies have recommended that sexual orientation and gender identity (SOGI), as well as sexual behavior, be routinely documented for all patients accessing clinical care. Although gathering and documenting SOGI data in electronic health records (EHRs) is consistent with federal efforts to gather health data on LGBTQIA+ populations as authorized under Section 4302 of the Patient Protection and Affordable Care Act, uptake of SOGI data collection and documentation remains abysmally low.

SOGI is an important dimension of individual self-perception and behavior, and has profound effects on health, whether a patient identifies as LGBTQIA+, as cisgender (nontransgender), or as heterosexual. If clinicians do not know their patients' SOGI status and sexual behavior, important therapeutic and preventive services may be ignored, including HIV screening, appropriate referrals for behavioral health care, and support services that incorporate patients' specific needs (e.g., cancer support groups for same-gender couples).

SOGI data collection and documentation are a key component of enhancing meaningful dialogue during clinical encounters and promoting the provision of high-quality care. The collection of SOGI data are a critical step in systematically documenting and addressing health disparities affecting LGBTQIA+ persons. Patient–provider discussions about SOGI can facilitate a more accurate assessment of self-reported health and behaviors. Additionally, accurate SOGI data collection is a vital part of establishing a good patient–provider relationship and conveys competence and humility. By routinely eliciting SOGI status using a structured format, EHR systems are better equipped to notify health care providers of appropriate and targeted care and preventive services.[1] Maintaining and using SOGI information in the EHR can promote communication among staff in health care organizations, improving delivery of care and patient satisfaction. Further, SOGI data capture can be used in concert with other data collection tied to social determinants of health to support a more patient-centered and comprehensive approach to patient care at the individual and systemic levels.

The health disparities experienced by LGBTQIA+ patients are extensive and diverse. Sexual and gender minority patients frequently grow up in non-affirming environments. This may lead to internalized stigma and minority stress, which can manifest as depression, substance use, and avoiding seeking health care, with subsequently poorer health outcomes (see the box on page 992).[2–4] Low self-concept and decreased self-efficacy of LGBTQIA+ youths may lead them to engage in more risk-taking behavior than do heterosexual and cisgender peers. Cisgender lesbians and bisexual women may be less likely to undergo routine Papanicolaou testing because of potential provider stigma and a lack of LGBTQIA+ health competency, including the mistaken belief that they are not at risk for human papillomavirus–associated cervical cancer. Transgender men may also avoid cervical cancer screening because of gender dysphoria associated with sex-assigned-at-birth anatomy and lack of trained providers in gender-affirming care.

In the era of HIV preexposure prophylaxis and antiretroviral treatment as prevention, gay and bisexual men as well as other sexual and gender minority patients, such as transgender women, are at high risk for sexually transmitted infections if condoms are not routinely used. Through routine SOGI data collection, clinicians would become aware of these health disparities and more readily identify which of their patients might experience them.

In addition to improving care, the collection of structured SOGI data will facilitate information sharing for clinical care, research, and public health interventions that can reduce health care disparities in these underserved populations. Gathering SOGI structured data in clinical settings via EHRs will help clinicians, researchers, health care system administrators, and policymakers better understand LGBTQIA+ health regarding disparities in insurance coverage, access to care, diagnosis, and treatment of health conditions. It would also facilitate understanding the factors associated

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SELECTED HEALTH DISPARITIES AMONG LESBIAN, GAY, BISEXUAL, TRANSGENDER, QUEER, INTERSEX, AND ASEXUAL (LGBTQIA+) POPULATIONS

LGBTQIA+ Population	Health Disparities
Cisgender gay and bisexual men	Higher rates of HIV and other sexually transmitted infections
Transgender women	Higher rates of HIV and other sexually transmitted infections
Cisgender gay and bisexual men	Higher rates of disordered eating and unhealthy weight-and shape-control behaviors
Cisgender lesbian and bisexual women	Higher rates of disordered eating and unhealthy weight- and shape-control behaviors
Transgender people	Higher rates of disordered eating and unhealthy weight- and shape-control behaviors
Cisgender lesbian women	Lower rates of mammography and Papanicolaou test screening
Transgender men	Lower rates of mammography and Papanicolaou test screening
LGBTQIA+	Higher rates of smoking; substance use disorders and dependence; depression, anxiety, and suicidal ideation and attempts; and violence victimization

Note. LGBTQIA+ = lesbian, gay, bisexual, transgender, queer, intersex, and asexual.

with LGBTQIA+ patients' resilience in the face of systematic discrimination, lower socioeconomic status,[5] and disadvantaged social networks. SOGI data with EHRs can also inform clinical prediction tools and improve predictive accuracy (e.g., tools to identify patients who could benefit from preexposure prophylaxis).

Further, SOGI structured data, coupled with sociodemographic structured data, will allow a deeper understanding of how the intersectionality of health care disparities—particularly race and ethnicity—in LGBTQIA+ populations manifest clinically.[2] By adding SOGI data capture as another dimension of identity, clinicians, researchers, and policymakers will be able to explore the future application of newer methods of assessing how intersectionality affects the health of marginalized populations.

Despite recommendations to collect SOGI data, most EHRs do not have expanded data fields that include all aspects of SOGI, and data elements are not uniformly captured across EHR platforms. And although provider discomfort is often cited as a reason for low SOGI data collection, all patients report high levels of acceptance and satisfaction with the collection of personal SOGI data.[6] Opportunities for provider training exist through the National Center for LGBT Health Education (www.lgbthealtheducation.org) and the Human Rights Campaign (www.hrc.org); additional resources are found in collaboration with local LGBTQIA+ community organizations and professional organizations (e.g., the American Medical Association, the American College of Physicians, the American Academy of Pediatrics).

Recognizing the individual- and population-level value of SOGI data collection, the Health Resources and Services Administration's Bureau of Primary Health Care began requiring federally funded community health centers to collect and provide SOGI data in 2016 as part of their annual Uniform Data Systems report. However, a recent secondary analysis of SOGI data collection from 2016 reported by 1367 US health centers caring for nearly 26 million patients in the United States and its territories indicates disappointing uptake of SOGI data collection. More than three quarters (77.1%) of patients did not have SOGI status documented in their EHRs. Despite this concerning percentage of missing data, among those with documentation the percentages of LGBTQIA+ people were similar to national estimates, and disclosure was more than 70%: 3.7% identified as lesbian, gay, bisexual, or something else; 0.4% identified as transgender male or female; 27.5% did not disclose their sexual orientation; and 9.3% did not disclose their gender identity.[7]

Despite challenges at the system and provider levels, large health systems that have implemented SOGI data collection through EHRs will find that patients are willing to provide this information and that it will inform care and improve outcomes. Knowing that this is information that could affect health care delivery for such a sizable minority of patients should make SOGI data collection a desired goal of all health care systems. Additional federal policies that mandate, incentivize, and enforce SOGI data collection are needed to increase compliance and the use of data.

Everyone has a sexual orientation and a gender identity, and how others react to these aspects of an individual's identity and behavior has significant consequences for their health and well-being. As the medical and public health communities understand the myriad ways SOGI is associated with particular behaviors and health outcomes, the paucity of existing data limits epidemiological and clinical research and practice. This continued lack of consistent and reliable data delays the development and implementation of clinical and public health interventions with the potential to benefit everyone.

With the proliferation of EHRs and federal guidance for their implementation, the tools to routinize complete and comprehensive SOGI data collection exist; what remains is the will to adapt and improve our health care system.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

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