

Inclusive and Affirming Care Strategies for Sexual and Gender Minority Patients

Stacey T. Stokes, MD, MPH, Matthew Lecuyer, MD, MPH

The sexual and gender minority (SGM) youth population in the United States is growing, with 150 000 self-identified gender minority adolescents¹ and 11% of youth identifying as a sexual minority.² Higher rates of negative outcomes compared with peers³⁻⁶ indicate this is a vulnerable population not having their needs met by the community. To better address these needs in health care, pediatric providers should standardize and normalize sexual orientation and gender identity (SOGI) conversations, which can be supported and uplifted through health care team education and documentation in the electronic health record (EHR).

The American Academic of Pediatrics urges pediatricians to maintain a welcoming, safe, and secure environment for all patients, especially SGM patients,^{5,7} which includes but is not limited to individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex.⁸ Documentation of SOGI information has been explicitly targeted as primary demographic information for EHRs within Meaningful Use Guidelines,^{9,10} encouraged by the Institute of Medicine,¹¹ and added to the

United States Core Data for Interoperability demographic recommendations.¹² Major EHR vendors have solutions for SOGI data capture, yet the literature on pediatric practice implementation is lacking compared with adult provider counterparts.¹³⁻¹⁶

Without comprehensive intentional changes, pediatric patient-provider relationships potentially extend a nonaffirming, noninclusive environment impacting patient wellbeing and interactions with health care professionals. SGM youth may slip through the system unrecognized, identifying them as an “invisible minority.”⁵ Safe, authentic expression of one’s gender identity has been theorized to contribute to maintaining a sense of true self.¹⁷ Not acknowledging minority status, however, exacerbates known health disparities faced by SGM patients, a concept identified as “corrosive disadvantage,” in which poor outcomes secondary to one identity are made worse because of a different minority identity.¹⁸ Failure to address SGM status in a patient with low socioeconomic status, for example, would exacerbate the known poorer health outcomes of patients with low socioeconomic status.



Children's National Hospital, Washington, District of Columbia

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Address correspondence to Stacey Stokes, MD, MPH, Department of Pediatric Hospital Medicine, Children's National Hospital, 111 Michigan Ave NW, Washington, DC 20010. E-mail: Stacey.stokes@childrensnational.org

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Because intersectional identities form an individual's lived experience of the world, one way to mitigate the minority stress of SGM patients is to openly address SOGI.

There are several reasons why patients may not disclose SOGI information. SOGIs are fluid, and although many youth identify as SGM, others will have their identity evolve with time and not disclose an SGM identity at a specific medical encounter.¹⁹ Patient-reported reasons include never being asked by a provider and feeling pressure to educate their providers on SOGI language.^{20,21} Providers have expressed discomfort discussing SOGI,²² and some physicians report feeling uncomfortable caring for SGM patients.¹⁴ Caretaker presence and concerns about confidentiality have previously been reported,²³ and although providers believe this to be a barrier, recent data suggest most patients do not have this concern.^{22,24}

Alongside health care encounter-based reasons for nondisclosure of SOGI information, SGM youth face structural barriers to disclosure. State-initiated limitations on access to SOGI-related education,^{7,25,26} bans on facility use consistent with gender identity in schools,²⁵ and state bans on gender-affirming health care services^{25,27-30} potentially impact SGM youth's

safety and privacy because of information disclosure. The American Academy of Pediatrics has joined organizations in 4 Amicus Briefs, advocating to protect gender-affirming care.^{31,32} Although advocacy and outreach are the bedrock of support it means little if the care provided at an individual level is not supportive and inclusive.

ACTION AT THE PRACTICE LEVEL

Several steps can be taken to ensure a safe, welcoming space for SGM patients at an institutional level (Table 1). Documentation of SOGI data is an integral part of that plan to guarantee patient-affirmed names and pronouns are used across encounters and appropriate health screening and guidance are given in a safe space. Only once this documentation is normalized can the health care community begin tackling patient population disparities by understanding the full scope of the population demographics.

Some of the first, most important, steps before documentation standardization include an institutional needs assessment, composed of patient and practice perspectives, leadership-led, multidisciplinary, SGM-focused, culturally effective care education, and universal open SOGI

conversations during health care encounters. The needs assessment is a critical first step to understanding the institution's initial ability to deliver culturally effective care, and specific patient population needs and concerns, including information collection and confidentiality preferences. The development of provider educational programs and documentation protocols should be driven by EHR vendor solutions, the current state of institutional knowledge, and the identified patient needs and concerns.

Staff education should be comprehensive and include culturally effective language, supportive communication techniques, navigation of patient confidentiality scenarios, and strategies for tackling difficult conversations. The Gay and Lesbian Alliance Against Defamation's media reference guide³³ provides standardized language to guide institutions. Several possibilities exist for educational opportunities: mandatory online module training, division-level meetings, clinic-based learning, and hospital resource use, including grand rounds, lunch lectures, and special calendar events to better understand institution-specific patient population needs and how best to connect with and serve them. This education should be paired with inclusive care

TABLE 1 Steps Pediatric Health Care Institutions Should Consider to Provide Sexual and Gender Affirming Care

1. Buy-in from stakeholders and leadership on the importance of targeted gender affirming education. Stakeholders should include, but are not limited to organization leadership, DEI committees, SOGI subject matter experts, clinical informaticists, and the EHR vendor. The weight of each stakeholder may depend on organizational capacity, and overall structure should rely on EHR vendor capabilities and expertise.
2. Completion of an institutional or practice needs assessment: Include understanding of how a patient experiences the health care system from check-in, chart creation, clinical care/environment, and discharge.
3. Education of all staff on gender-affirming and sexual minority language to encourage empathic SOGI conversations. Education should be congruent with EHR language that is specific to the EHR vendor used at the institution for streamlined implementation in future steps.
4. Implementation of documentation features for sexual orientation and gender identity that allow for face-up visibility within the electronic health record: Include questions to capture affirmed name, gender identity, birth or assigned sex, and preferred pronoun at minimum. Considerations around privacy should guide approaches.
5. Standardization of documentation: Allow for patient facing document completion via a patient portal or privately once on site, and standardized checkpoints within visits to make sure the data are captured and reviewed.
6. Obtain feedback from a diverse patient population and their families on whether needs are being met by the implementation of added questions and documentation. Adapt as needed.

DEI, diversity, equity, and inclusion.

policies that lay the groundwork for staff to understand the confidentiality complexity during the early years of the 21st Century Cures Act and in the context of state and federal laws. Arming staff with decision-making skills on when and where to document disclosures on the basis of patient confidentiality requests will lead to improved disclosure rates and trust in the patient-provider relationship.

EHR documentation is a critical step that allows all patients the opportunity to be heard and respectfully referred to in gender-affirmed language, when given permission by the patient, in the most complete way possible across health care interactions, leading to a more trusting and inclusive patient-provider relationship, allowing providers to treat the whole patient. A simple way an institution can affirm care through the EHR is by uplifting the universal demographics bar, highlighting SOGI content, and allowing care team members the ability to edit the information with real-time updates. EHRs may be leveraged to collect SOGI data from patients via nonverbal disclosure, which has been shown to be a preferred method of collection by adult patients.²² Collaboration with organization leadership, diversity, equity, and inclusion committees, SOGI subject matter experts, clinical informaticists, and the EHR vendor is essential to ensure inclusive language is used while efficiency is maintained. Patient-driven privacy strategies, such as EHR alerts indicating to whom SOGI data may be disclosed, and confidential content areas within pediatric patient portals should be considered to reduce potential stigma or poor response rates.

The integration of custom or standardized EHR vendor tools to capture SOGI demographics, affirmed name, and pronouns, in

addition to birth sex and assigned name, via forward-facing displays visible to all staff is one of the most effective ways to reach all involved in patient care. The refinement of functionality is expected as education is tailored, sensitive information solutions evolve, and language changes. Once a standardized practice is achieved and ongoing education is accounted for, routine monitoring of practices is essential.

A holistic approach to SGM-inclusive care is necessary in pediatrics. EHR SOGI documentation not only allows for improved affirming care, which has several patient-centered benefits, but can drive improved individual and population health outcomes, aid in SGM research, and expand information sharing for public health interventions to reduce disparities. Once this documentation gap is addressed, and SOGI conversations are normalized, further work to mitigate health disparities for this at-risk population can begin.

ABBREVIATIONS

EHR: electronic health record
SGM: sexual and gender minority
SOGI: sexual orientation and gender identity

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