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Perspective

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Pediatric sexual orientation and gender identity data collection in the electronic health record

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ABSTRACT

The systematic documentation of sexual orientation and gender identity data in electronic health records can improve patient-centered care and help to identify and address health disparities affecting sexual and gender minority populations. Although there are existing guidelines for sexual orientation and gender identity data among adult patients, there are not yet standard recommendations for pediatric patients. In this article, we discuss methods that pediatric primary care organizations can use to collect and document sexual orientation and gender identity information with children and adolescents in electronic health records. These recommendations take into consideration children's developmental stages, the role of caregivers, and the need to protect the privacy of this information. We also focus on the current limitations of electronic health records in capturing the nuances of sexual and gender minority identities and make suggestions for addressing these limitations.

Key words: gender identity, electronic health records, health disparities, sexual orientation, SOGI data

INTRODUCTION

Routine and standardized documentation of patient sexual orientation and gender identity (SOGI) in the electronic health record (EHR) enables healthcare organizations to create a more patient-centered care experience, and to identify, monitor, and address health disparities of sexual and gender minority (SGM) people.[1–6] Although there are guidelines for collecting and documenting SOGI data among adult patients,[7,8] none yet exist for pediatric patients in primary care. In the United States, an estimated 9.5% of adolescents aged 13–17 years old identify as SGM,[9] and children as young as 2 or 3 years old may declare a transgender or gender diverse (TGD) identity.[10,11] Pervasive stigma and discrimination in school, family, and healthcare settings have been linked to a range of health disparities among SGM youth, including mood disorders, disordered eating, cigarette smoking, substance use disorders, suicidality, violence victimization, HIV, and sexually transmitted infections.[12–20] To promote more positive health outcomes, it is beneficial for pediatric primary care clinicians to know their patients' SOGI so they can provide space for discussing concerns, make appropriate referrals, and encourage family acceptance of SGM identities, which is critical for positive psychosocial outcomes.[21,22] Developing clinical decision tools in EHRs to prompt providers to ask about and update a pediatric patient's SOGI can further support these important conversations.[6]

While SOGI documentation in EHRs has clear advantages for pediatric primary care, it also poses potential challenges. In particular, certain healthcare policies and EHR technical factors make it difficult to prevent unwanted disclosure of SOGI information to a pediatric patient's caregivers.[23] In this article, we present strategies for pediatric primary care clinicians to elicit and document the SOGI of minors in the EHR with the goal of promoting better health outcomes while navigating privacy issues. These recommendations are based on our extensive clinical, consulting, and research experience with SOGI data in large and small primary care practices, pediatric gender clinics, and hospital adolescent clinics in urban and rural areas across all 50 US states.[1–7,24–30] We have further grounded our recommendations in research findings and guidance from the peer-reviewed literature.[8,31–42]

CREATING A SUPPORTIVE AND SAFE ENVIRONMENT

Before launching a SOGI data collection system, it is critical to first create safe and affirming clinical environments for SGM pediatric patients and their families. There are resources to support organizations in making important changes to forms, policies, and physical spaces,[43,44] as well as many options for training all staff members on culturally sensitive, nonjudgmental communication with SGM patients and families.[45] Healthcare teams should also prepare a list of SGM-supportive referrals, and clinicians should access continuing education on promoting the health and development of SGM children and adolescents, and on cultivating family acceptance. Developing a SOGI data system also requires collaboration across medical, behavioral health, information technology, and patient registration departments to set up effective workflows and confidentiality practices. See the Supplementary Appendix for resources.

WHEN AND HOW TO ASK ABOUT SOGI

Clinicians can introduce SOGI during the social history of the pediatric well-visit, with a brief explanation of the purpose of the questions (Table 1). When to ask depends on the age of the child. For adolescents aged 11–17 years, the history is typically elicited in private, without a caregiver present. For children under age 11 years, SOGI questions are likely to be asked in the presence of a caregiver. Some but not all families are aware and supportive of their child's SGM identity.[46,47] SGM children who feel unsafe disclosing SOGI information in front of their caregiver may not answer truthfully, yet it is nevertheless important to provide the opportunity. Additionally, patients should always have the option to not answer.

Gender identity questions

Gender identity refers to a person's inner sense of being a girl/woman/female, a boy/man/male, nonbinary, genderqueer, beyond girl/woman/female or boy/man/male, or having no gender.

Asking about gender identity can begin around age 3 years, the age at which most children are able to verbalize their gender identity. Some children can self-label their gender identity as young as 18 months.[10,11,48] In addition to gender identity, it is best practice to ask about and document sex assigned at birth; this practice enables EHR systems to identify TGD patients whose gender identity and sex assigned at birth are not congruent.[8,38] If a patient's sex assigned at birth is not yet documented, clinicians can ask patients or their caregivers for this information.

The collection of sex assigned at birth data is evolving. As of 2022, some countries and US jurisdictions now permit a third sex option beyond female or male on a child's original birth certificate. This additional sex option is usually written as X. Although most EHRs do not yet accommodate a third sex option, organizations may be able to work with their EHR vendor to make this change. It is important to note that X sex is not equivalent to *intersex*. A person born with an intersex variation, also known as a variation in sex development, could be assigned X at birth, but most infants are assigned female or male. Intersex traits should be assessed separately from gender identity. Routine clinical or research data collection questions about intersex variations have not yet been developed, but groups of intersex health experts and advocates are working on creating and validating questions.[49]

Sexual orientation questions

Sexual orientation questions can begin between ages 10 and 13 years, depending on the clinician's judgment of the child's develop-

Table 1. Recommended sexual orientation and gender identity (SOGI) questions during the clinical encounter

Clinician introduction: "*I am going to ask you some questions that I ask all patients your age, because it helps me provide you the best care possible.*"
If patient is alone without parents/guardians and the law permits: "*I will not share this information with your parents/guardians or anyone else unless you give me permission to.*"

Gender identity questions (3–13 years)
"*Some kids feel like a girl on the inside, some kids feel like a boy on the inside, and some kids feel like neither, both, or someone else. What about you? How do you feel on the inside? There's no right or wrong answer.*"
If you do not know the patient's sex assigned at birth:
"*What sex were you (was your child) assigned at birth? Girl or boy, or another sex?*"

Gender identity questions (14–17 years)
"*What is your current gender identity? Some teens feel like a girl or woman on the inside, some feel like a boy or man on the inside, and some feel like neither, both, or another gender. What about you? There's no right or wrong answer.*"
If you do not know the patient's sex assigned at birth:
"*What sex were you assigned at birth? Female, male, or another sex?*"

Sexual orientation questions (10–13 years)
"*Have you ever had a crush on someone?*"
If yes: "*Was this crush on a boy, a girl, both, or someone of another gender?*"

Sexual orientation questions (14–17 years)
"*Are you sexually attracted to boys, girls, both, neither, another gender, or are you not sure?*"

Table 2. SOGI categories for electronic health records and patient registration forms

Introduction for forms: We are asking the following information to understand whom we are serving and to provide you with more patient-centered healthcare. This information will be entered into your electronic health record, which may be accessed by parents/guardians and by members of your healthcare team.

Parents/guardians: If you are answering these questions on behalf of your child, please answer to the best of your knowledge.

Gender identity (ages 3+ years)

What is your current gender identity? (Check all that apply) or (*Please choose the option that best describes you. Currently our system allows only one option.)*

☐ Girl/woman/female
☐ Boy/man/male
☐ Nonbinary, genderqueer, or not exclusively female or male
☐ Transgender girl/woman/female
☐ Transgender boy/man/male
☐ Another gender: _____
☐ Not sure
☐ Do not understand the question
☐ Prefer not to answer

What sex were you assigned at birth? (Check one.)

☐ Female
☐ Male
☐ X/Another sex[a] (please specify):_____
☐ Not sure
☐ Prefer not to answer

What sex is listed on your health insurance?

☐ Female
☐ Male
☐ X/Another sex[a] (please specify):_____
☐ Not sure

Sexual orientation (for ages 10+ years)

Do you think of yourself as: *(Check all that apply)* or (*Please choose the option that best describes you. Currently our system allows only one option.)*

☐ Gay or lesbian
☐ Straight or heterosexual (that is, not gay or lesbian)
☐ Bisexual
☐ Queer
☐ Pansexual
☐ Something else: _____
☐ Not sure
☐ Do not understand the question
☐ Prefer not to answer

[a]Include if a third sex option is accepted by insurance companies.

mental readiness.[50] *Sexual orientation* is a multidimensional construct that comprises sexual orientation identity, attraction, and behavior. Although adolescents may not know their sexual orientation identity or engage in sexual behavior, many experience romantic or sexual attractions. Asking about attractions, therefore, may increase the comprehension and accuracy of the answer.[51] Based on cognitive interviews and field tests, an expert panel has recommended using the term *crush* to indicate attractions with children aged 10–13 years, and the phrase *sexual attractions* with adolescents aged 14–17 years.[52]

DOCUMENTING SOGI IN THE EHR

All EHRs certified under the Office of National Coordinator of Health Information Technology (ONC) are required to have the capacity to record SOGI data. Many EHRs therefore provide built-in SOGI fields, but these fields tend to capture only identity dimensions. To capture the nuances of a patient's answers about sexual attractions and gender identity, pediatric primary care clinicians can use the EHR notes field. Clinicians can also follow-up with questions about how a patient identifies their SOGI, if they believe the child is ready. Table 2 includes recommended identity questions and terms, most of which were field tested with middle and high school students in 2016–2017,[52] and considered acceptable by adolescents for primary care settings.[29] Additional terms (ie, queer, nonbinary, and pansexual) were added by the authors to reflect current common identities among youth.[53]

Concepts related to gender and sexuality evolve over time, and inevitably lead to changes in SOGI terminology. Moreover, SGM adolescents may find a short list of SOGI categories to be limiting.[37] A national sample of SGM adolescents reported 26 different SOGI categories.[54] For these reasons, EHRs should maintain open text fields for SO and GI, and clinicians should never judge or doubt a patient's reported SOGI. If a SOGI term is new to a clinician, they can follow-up by asking what the term used means to the patient. Accommodating diverse SOGI identities requires balancing inclusive SOGI options with the space and technical limitations of EHR systems. The SOGI categories in Table 2 attempt to encompass a range of identities without creating an overwhelming number of fields. Nonetheless, organizations may wish to collaborate with local stakeholders to refine and add terms, and to translate terms into languages used by their patient population.

Consent, confidentiality, and the EHR

Prior to documenting the SOGI of children and adolescents in the EHR, it is critical that clinicians ask patients for consent, with a clear explanation of who can access the information. The intentional or accidental disclosure of a child's SOGI to a legal guardian can pose a grave risk to that child's safety and wellbeing, particularly in contexts where SGM people are highly stigmatized or criminalized. An organization can potentially program flags in the EHR to deter employees from accidental disclosure of SOGI when handling medical release forms. As of 2022, however, maintaining the confidentiality of a minor patient's SOGI and other health information in the EHR has its challenges. Because the 21st Century Cures Act prevents the blocking of guardians' electronic access to their children's clinical information, standard information protection methods, such as labeling SOGI or other sensitive information as *confidential*, may not sufficiently protect a pediatric patient's privacy.[23] For this reason, healthcare organizations may need to solicit legal counsel to understand if their clinical workflow and EHR systems protect minors from unwanted disclosure of SOGI. This discussion should also consider ways that the use of International Classification of Diseases (ICD) billing codes, such as those for gender incongruence, could potentially "out" children to caregivers.[41] Additionally, different jurisdictions within the United States have varying statutes with regard to the rights of minors to consent to their own healthcare services.[55] It is possible that a jurisdiction will make it illegal to even discuss SOGI without guardian consent. Again, legal counsel is advised as laws continue to change.

More sophisticated EHR protections of confidential information are being created. For example, some EHRs may allow for different visibility of clinical information on patient portals for adolescents, or have controls that enable visibility of data only to those permitted by the patient.[38] Organizations can contact their EHR vendor about their capacity to provide these services. The Protecting Privacy to Promote Interoperability (PP2PI) Workgroup is a voluntary national interest group that is developing recommendations to protect sensitive health information across systems.

SOGI ON REGISTRATION FORMS

Primary care organizations may choose to ask structured SOGI questions, similar to those in Table 2, on paper or electronic registration forms to enable routine and systematic data collection.[2,7,43] Data entered on tablets or in patient portals can flow directly into the EHR, while data from paper forms can be entered into the EHR by registration staff. Because parents and guardians often complete forms on behalf of their children, SOGI collected through forms can lead to less reliable answers. To improve privacy and data quality, minors with literacy skills can fill out SOGI questions away from the oversight of parents and guardians, if space allows.[31] Handing out youth-friendly pamphlets that define SOGI categories can help improve comprehension of the questions. Still, SGM youth may not want to disclose their identities on forms that may be accessed by their parents or guardians from the EHR. If organizations decide to ask about SOGI on forms, they should consider also checking with the patient during the clinical visit to verify the information.

DOCUMENTING PRONOUNS AND NAMES

To further provide an affirming clinical experience in which SGM patients feel safe to discuss their SOGI, it is recommended to also ask all patients at least annually for their pronouns and the name they want their healthcare providers to use.[44,53] The clinician can ask: "*I would like to be respectful. What name would you like me to call you?*" and "*What pronouns would you like me to use?*" TGD patients may not have pronouns that correspond with the sex recorded on their insurance records or government-issued identification documents; any patient, regardless of gender identity, may use a name that differs from what is on official documents. To normalize name and pronoun disclosure, clinicians can wear a pin with their pronouns or greet new patients with: "*Hello, I'm [Name]. My pronouns are [. . .].*" To protect privacy, pediatric patients should be asked which name and pronouns they want used in front of family and staff members, and whether to document the information in the EHR. Currently, EHRs do not have controls for indicating context-specific pronouns and names, but this ought to be a goal for future system upgrades.

If the patient consents, name used and pronouns should appear in a high-visibility location in the EHR, such as on a banner and in bold font, or through a pop-up alert, so that all staff members can readily see and use the correct information. Care should be taken to ensure that name used and pronouns appear correctly and consistently in all parts of the EHR, including scheduling views, particularly if more than one EHR system is used. Additionally, registration forms should include fields for names and pronouns to systematically capture this information (eg, *What name do you go by? What name is listed on your health insurance? What are your pronouns? she/her/hers, he/him/his, they/them/theirs, another set of pronouns—please describe*).

ADDRESSING TECHNICAL CHALLENGES WITH THE EHR

Diverse and evolving SOGI terminology comes with questions about how to optimize interoperable health information exchange. International value sets and coding systems, such as Systematized Nomenclature of Medicine, ICD, Current Procedural Terminology, and Logical Observation Identifiers Names and Codes, will ideally be consistently updated and standardized, to the extent possible.[39] Total standardization, however, may not be feasible in the near future given the prioritization of cultural responsiveness over interoperability.

Another technical challenge relates to fixed-choice questions with only one answer option. Some children and adolescents have more than one gender identity or sexual orientation and may experience having to choose just one option as too limiting. Not all EHR systems, however, allow for selecting more than one option. In such cases, the clinician can explain the constraints of the system and then ask patients if they want to choose one option that best describes them, or if they want the clinician to check "another identity/something else" and enter these terms in the notes field.

Because a patient's SOGI can change over time, it is important for pediatric primary care clinicians to ask SOGI questions at least annually.[56] Changes in SOGI may reflect developmental processes or may indicate a fluid sexual orientation or gender identity. Organizations will need to develop EHR data entry systems that enable easy updating to responsively accommodate patient changes in SOGI and promptly alert staff members to these changes. At the same time, it is important to have safeguards for preventing staff from inadvertently making changes to SOGI fields across different EHR functions and clinical activities, for example from a primary care visit to a laboratory order.

Studies have found that clinicians do not consistently ask about SOGI[24]: one reason for this is forgetting to ask.[57] EHR systems can be programmed to prompt clinicians to ask annually about gender identity starting at age 3 years, and about sexual orientation at age 10 or 11 years. EHR systems could also provide guidance for psychosocial affirmation of SGM patients from early childhood onward. For TGD children and adolescents, EHR systems could remind clinicians to consider discussion of pubertal suppression prior to Tanner Stage 2, and of gender-affirming hormones prior to age 14 years.[6] To best inform clinical decisions and recommendations, however, it is important for future EHR systems to be set up to use SOGI data in combination with other clinical indicators. For example, clinical decisions traditionally made only based on the binary sex assigned at birth can be further informed by GI, hormone therapy levels, and an anatomical (organ) inventory that tracks surgical procedures and the presence of specific organs.[4]

SHARING INFORMATION ACROSS SYSTEMS

For primary care practices that share an EHR with an inpatient hospital system, sharing name, pronoun, and SOGI information across systems can reduce patient and clinician burden, and can support the provision of affirming care. Children and adolescents, however, may wish to use a different name and pronouns depending on the setting; therefore, patients should be asked at inpatient intake for name and pronouns, even if this information is already in the system from outpatient care, and vice versa. To promote affirming care, this information should appear along with any mandated identifiers on ID bracelets, census lists, EHR shortcuts, digital white boards and banner bars, meal orders, discharge summaries, scheduling systems, and any other documents provided to the patient.[58]

CONCLUSIONS

Asking age-appropriate SOGI questions in primary care can bring about important, life-enhancing, and affirming conversations with pediatric patients and their families that set SGM children and adolescents on a positive developmental course. Equally important is the need to implement EHR systems that protect the privacy of SGM minors who are not ready to disclose their identities to their families, or risk harm in doing so. The suggestions presented in this article will likely require adjustments based on local cultural and linguistic contexts, and jurisdictional differences in policies and practices for minors. To improve SOGI systems for the future, research is needed to assess the validity and feasibility of SOGI questions among children and adolescents, and to measure patient outcomes related to collecting SOGI data.

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ASK and CG conceived of the article, and all other authors (HG, ARG, SLK-W, KT) contributed substantially to the intellectual content of the work. HG wrote the first draft of the article; all authors critically revised and edited the work, reviewed and approved of the final version of the submission, and agreed to be accountable for all aspects of the work.

SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

CONFLICT OF INTEREST STATEMENT

Dr. Keuroghlian declares royalties from McGraw Hill as editor of a textbook on transgender and gender diverse health care. Dr. Katz-Wise is a diversity consultant for McGraw Hill and Viacom/CBS, neither of whom were involved with this article. Ms. Goldhammer, Ms. Grasso, Dr. Thomson, and Dr. Gordon have no conflicts of interest relevant to this article.

DATA AVAILABILITY

No new data were generated or analyzed in support of this research.

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