Perspective

Planning and implementing sexual orientation and gender identity data collection in electronic health records

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ABSTRACT

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) people experience significant health disparities across the life course and require health care that addresses their unique needs. Collecting information on the sexual orientation and gender identity (SO/GI) of patients and entering SO/GI data in electronic health records has been recommended by the Institute of Medicine, the Joint Commission, and the Health Resources and Services Administration as fundamental to improving access to and quality of care for LGBTQ people. Most healthcare organizations, however, have yet to implement a system to collect SO/GI data due to multiple barriers. This report addresses those concerns by presenting recommendations for planning and implementing high-quality SO/GI data collection in primary care and other health care practices based on current evidence and best practices developed by a federally qualified health center and leader in LGBTQ health care.

Key words: data collection, electronic health records, gay, transgender, sexual orientation, gender identity

INTRODUCTION

In 2011, the Institute of Medicine and the Joint Commission both recommended collecting and documenting patient sexual orientation and gender identity (SO/GI) information in healthcare settings as essential to providing patient-centered care for lesbian, gay, bisexual, transgender, and queer (LGBTQ) people.[1–3] As a population, LGBTQ people experience multiple health disparities, including a higher prevalence of HIV infection, other sexually transmitted infections, substance use disorders, mood disorders, and suicidality.[2–12] The invisibility of LGBTQ people in healthcare inhibits patient-provider communication and results in missed opportunities for screening and treatment.[13] Conversely, collecting SO/GI data increases the visibility of LGBTQ people in the interest of improving the quality of their care. The routine collection of SO/GI data can be used by healthcare organizations to track, monitor, and address disparities in their LGBTQ patient population.[1–3,13,14] These and other benefits of SO/GI data collection were recognized in 2016 by the Health Resources and Services Administration (HRSA) when it began requiring all federally funded health centers to submit SO/GI data to their annual Uniform Data System report.[15]

Despite recommendations to collect SO/GI dating back to 2011, most healthcare organizations have yet to implement systematic data collection due to concerns about making staff and patients uncomfortable, the inability of electronic health record (EHR) platforms to accommodate SO/GI information, and inadequate dissemination of best practices.[1] Fortunately, these concerns can

now be assuaged. Most LGBTQ and non-LGBTQ patients understand the importance of discussing SO/GI with providers and are willing to answer SO/GI questions.[16–23] Studies have found that although 78% to 80% of providers thought patients would be offended by, or refuse to answer, SO/GI questions, only 3% to 11% of patients reported such responses.[16–18] In fact, patients are more likely to answer SO/GI questions than income questions.[19] Overall, LGBTQ patients want to talk to their providers about SO/GI, although some fear negative consequences of disclosure, such as discrimination or breach of privacy.[16,19–23]

With regard to documenting SO/GI in EHRs, in 2018 the Centers for Medicare and Medicaid Services and the Office of the National Coordinator for Health Information Technology started requiring that all EHRs certified for Meaningful Use Stage 3 be able to record SO/GI.[24] Although technological shortcomings for implementation still exist, organizations have adapted with creative workarounds.

After over 2 decades of developing and testing SO/GI questions and systems in healthcare settings, best practices in SO/GI data collection have been established.[14,21,25–33] The purpose of this article is to present these recommended guidelines for planning and implementing SO/GI data collection in healthcare delivery settings. The development of the guidelines began at Fenway Health, an LGBTQ-focused federally qualified health center, where researchers, clinicians, and data managers constructed the sexual orientation questions with input from the health center's patient population and designed a way to capture SO/GI information in the EHR.[13] A 2-step gender identity question was originally developed for a survey designed by the Transgender Health Advocacy Coalition in Philadelphia,[34] then adapted for state-level transgender needs assessments[35,36] and later studied in 2012.[26,32] The Center of Excellence for Transgender Health and the World Professional Association for Transgender Health have approved these questions, as have many other experts.[25–33] Acceptability of SO/GI questions has also been tested with a diversity of populations in healthcare settings.[21]

The guidelines were further adapted by The Fenway Institute, Fenway Health's research, policy, and education division, based on lessons learned from working with organizations to implement SO/GI in EHRs. In 2016, The Fenway Institute's National LGBT Health Education Center received support through its cooperative agreement from HRSA's Bureau of Primary Health Care to deliver training and technical assistance on SO/GI implementation to federally funded health centers throughout the United States. The Fenway Institute has also disseminated the guidelines to primary care associations, hospitals, and EHR vendors through conferences, in-person trainings, webinars, and a website, www.lgbthealtheducation.org.

PLANNING AND IMPLEMENTATION

Getting started

The first step for implementing SO/GI data collection involves identifying a dedicated team of staff "champions" who can meet regularly and lead the change process throughout the organization. Internal change champions are often effective agents for supporting and sustaining system-level improvements.[37] Champion teams ought to consist of an administrator (eg, Chief Medical Officer, Executive Director) and representatives from clinical, non-clinical (eg, registration, patient services), and health information technology (HIT) departments. Team members will need to devise a realistic timeline for implementing the SO/GI process, hold each other accountable

for meeting deadlines, and use a continuous quality improvement method to regularly evaluate the effectiveness and efficiency of the change process.[38] Table 1 provides a sample timeline that can be adjusted to fit the unique features of individual healthcare organizations.

Data collection methods

SO/GI categories have been developed and tested in different populations and have been found to be acceptable and understandable for a majority of patients.[21,29,31] Standardized questions are available online.[33] The recommended method for collecting SO/GI data involves integrating SO/GI questions into registration forms alongside other demographic information, such as race/ethnicity and employment, as this helps normalize the questions. The information can be captured by electronic means, such as patient portals or tablets that transmit data automatically into EHRs, or on paper forms handed over to registration staff who manually enter the data. Ideally, providers can easily access SO/GI data from the EHR during the clinical visit.

Another option is for providers to ask patients about SO/GI during a social or sexual history, and then enter the data into the EHR. Some organizations collect SO/GI at both registration and during the provider visit in order to validate the data. In other organizations, providers ask about SO/GI only if the patient has skipped questions on the registration form. As with other demographic data, SO/GI questions ought to be asked annually, as this information may change over time.

Collecting SO/GI during registration makes the process more systematic, less vulnerable to provider bias, and less burdensome to clinical staff. Because every healthcare organization is unique, teams will need to consider their site's patient population, work culture, workflow, and the limitations of their EHRs before deciding which method to use. As with all patient information, SO/GI data are protected by the Health Insurance Portability and Accountability Act. Therefore, forms should include language about confidentiality and privacy, and staff should be trained to explain and reinforce these protections with patients.

EHR customization

Until very recently, most EHR systems lacked the flexibility to accommodate SO/GI data fields. Even with the Meaningful Use Stage 3 requirement, customization of EHRs is often necessary. Organizations can discuss options with their EHR vendor prior to starting the implementation process to see if the vendor has created SO/GI customizations before. In some cases, a vendor may have an updated version that includes SO/GI data fields.

To minimize errors when customizing EHR forms, it is important to create structured and discrete data fields for SO/GI questions, as well as limit the ability to add free-text responses. Additionally, forms should default to fields for "unknown" or "missing," rather than "don't know" or "choose not to disclose." To increase usability, HIT staff should consult with clinicians and registration staff to understand how they wish to enter and access SO/GI data. It is also important, especially for transgender patients, to create fields for correct pronouns and name (if different from the name on insurance or legal documents) that can be viewed by all staff accessing the system.[27,28] If such fields are not available, teams may consider using a comment field. If the patient management system does not enable other departments to access this information from registration, it

Table 1. Sample timeline for implementing sexual orientation and gender identity (SO/GI) data collection in healthcare settings

Months 1 to 3	Identify a team of internal change champions
	Collect and read resources on SO/GI
	Engage leadership
	Plan implementation timeline
	Begin continuous quality improvement process
Months 4 to 6	Determine data collection systems
	Modify electronic health record
Months 6 to 8	Train staff
	Make changes to policies and physical environment
Month 7	Pilot SO/GI in 1 department/provider panel
Months 8 to 11	Expand to more departments and monitor progress through data feedback reports
Month 12	Conduct first data summary report
Ongoing	Monitor data quality
	Train new staff and re-train existing staff
	Gather feedback from staff and make changes as needed

Table 2. Staff roles for quality assurance and control of sexual orientation and gender identity (SO/GI) data

Staff	Role in Data Quality Assurance and Control
Registration	Cross-check paper registration forms with electronic health records
	Provide feedback on challenges (eg, language barriers)
Data Analysis/Programming	Run monthly reports of SO/GI data to identify problem areas, such as missing data and misclassification errors
	Look at trends over time (eg, every 6 months) to identify unexpected patterns and statistical outliers
Quality Improvement	Incorporate SO/GI quality control and monitoring into existing workgroups
	Help develop changes in workflow to fix problem areas
Health Information Technology	Create checklists and confirm all components are installed after upgrades
Clinical Care	Provide feedback on challenges in accessing SO/GI data from the EHR

may be possible to create custom banners or alerts in the EHR that show a patient's name and pronouns.

Systems that automatically fill in salutations (ie, Mr and Ms) must be adjusted to match pronouns; alternatively, all letter templates can use a standard greeting such as "Dear Patient." To reduce mistakes across departments, organizations can add correct names and pronouns to lab orders, prescriptions, patient instructions, and chart summaries. Additional forms, such as anatomical inventories, can be built into EHRs to support care teams in making clinical decisions based on a patient's anatomy rather than on sex assigned at birth or gender identity.

Staff training

Prior to collecting data, all staff who interface with patients will need to learn to communicate effectively and respectfully with patients about SO/GI data collection, and will also require training in providing affirming care and services for LGBTQ patients, including consistently using patients' correct names and pronouns. Because mistakes do occur, staff will need to learn to feel comfortable apologizing, and to work together to maintain a culture of accountability.

Staff training programs can be incorporated into orientation for new staff and repeated annually. Resistant staff, such as those with personal objections, may need extra coaching and reassurance beyond the standard training. To address staff concerns, supervisors may find it helpful to share positive feedback from patients about the program, and/or show data demonstrating LGBTQ disparities in health services and outcomes.[30,39]

Patient education

Although health care staff often assume patients will be confused or offended by SO/GI questions, this is rarely the case.[16,17] Nonetheless, staff must be prepared to respond effectively to patient concerns about SO/GI questions, including why the questions are being asked, who will see the data, and how the data will be protected. In addition, some patients (eg, older patients, patients of different cultural backgrounds, and patients best served in a language other than English) may need help in understanding SO/GI terms. Organizations can stock their waiting and exam rooms with brochures that answer

frequently asked SO/GI questions; staff can be trained to hand out the brochures or answer the questions themselves.[33]

Creating a welcoming space

In order for patients to feel comfortable sharing SO/GI information, organizations must create an atmosphere that is intentionally inclusive and respectful of LGBTQ patients and their families. Changes to the physical environment can consist of offering restrooms for all genders, and ensuring that all forms, policies, and educational/promotional materials reflect LGBTQ people and families (eg, by using images of same-gender couples or other LGBTQ people, avoiding gendered terms such as "husband/wife," and adding SO/GI in nondiscrimination policies).

Piloting data collection

Ideally, organizations can conduct a pilot of the data collection process in one provider's panel (eg, the provider on the SO/GI team) or department to test the system and make improvements on a smaller scale. Teams can use a quality improvement methodology such as the PDSA (Plan-Do-Study-Act) cycle to implement and continuously evaluate and improve the new process.[40] Once the pilot is deemed successful, the SO/GI team can begin to expand the process to 1 or 2 other locations within the organization, while continuing to monitor and assess the process at all locations. Eventually, SO/GI data collection can be added to all provider panels and clinical departments.

Applying SO/GI data

Once data collection systems are in place, teams can begin developing summary reports to identify and address disparities in access, screening, and health outcomes based on SO/GI. These data can be incorporated into existing population management and quality measure reports and presented to senior management and at staff meetings. Throughout the process, maintaining data integrity is critical to achieving valid results. Therefore, teams can assign staff to different roles to help ensure data accuracy, as seen in Table 2.

CONCLUSIONS

SO/GI data collection, despite its challenges, is achievable within every healthcare organization. Federally funded health centers across the United States began systematically collecting and entering SO/GI data in EHRs in 2016; since then, several health centers have started analyzing data to improve patient health. According to health center leaders, factors that have facilitated data collection success include: identifying champions who are passionate about LGBTQ health, having leadership engaged in the process, incorporating HIT staff from the beginning, and handing out patient education brochures about SO/GI. The National LGBT Health Education Center website offers free online training, patient brochures, and other resources on SO/GI data collection and LGBTQ-affirming care (www.lgbthealth-education.org). Next steps for SO/GI data collection include conducting more research to examine how organizations are experiencing the process of SO/GI data collection, and how they are using SO/GI data to monitor and achieve reductions in LGBTQ health disparities.

CONTRIBUTORSHIP STATEMENT

CG is an original developer of systems for sexual orientation and gender identity data collection and entry into electronic health records. MJM wrote the text. HG developed the outline, tables, and edited the text. ASK consulted on all aspects of the article, and contributed original ideas to the sections on training, education, and creating a welcoming space. All authors reviewed the final manuscript.

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