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Results of a Needs Assessment: Use of Sexual Orientation and Gender Identity Data in Health Systems in Maine

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PATIENT SAFETY AND QUALITY IMPROVEMENT EXEMPLAR

Results of a Needs Assessment: Use of Sexual Orientation and Gender Identity Data in Health Systems in Maine

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Introduction: Lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ+) patients experience significantly more health care disparities than non-LGBTQ+ patients. Although sexual orientation and gender identity data (SOGI) would help quantify and track these known disparities, there are no standardized methods for routinely and consistently including SOGI into health care management in Maine. Our needs assessment (1) evaluates the comfort of health care professionals (HCPs) in collecting SOGI and incorporating it into the medical record and (2) identifies barriers to SOGI collection.

Methods: An interprofessional team conducted a survey of Maine HCPs who identified as working directly with patients or patient records and information to assess how they manage LGBTQ+ data. We then conducted focus groups with survey participants, coded the transcripts, and identified recurrent themes through thematic analysis.

Results: We found that of 357 interprofessional respondents, 62.9% of HCPs agreed that SOGI should be collected with every patient. However, only 30.1% reported collecting SOGI for "all or most" of their patients. The primary barriers to data collection and use were identified as lack of education and comfort with LGBTQ+ topics, HCP concern for causing patient discomfort, and lack of standardization of data management and workflow.

Discussion: Most HCPs in Maine are not yet comfortable with routinely incorporating SOGI. Even if they were comfortable, patient workflows and electronic health records vary widely across systems, and this inconsistency is a substantial obstacle to standardizing SOGI collection. A multidimensional approach is needed to address these barriers moving forward.

Conclusions: HCP's discomfort with LGBTQ+ topics and non-standardized workflows are driving factors that must be overcome to fully incorporate SOGI collection as a standard best practice.

Keywords: Sexual and gender minorities, health equity, quality improvement, needs assessment, patient-centered care

In the United States, lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ+) patients experience a higher prevalence of health care disparities than non-LGBTQ+ patients.¹⁻³ LGBTQ+ patients have higher risk of mental health disorders, sexual and physical abuse, substance

misuse, homelessness, insufficient cancer screenings, and reduced preventive health care.¹⁻³ Approximately 4.9% of Maine's population identifies as LGBTQ+, meaning that nearly 1 in 20 patients may experience these disparities.⁴ Prevalence is greater in Maine youth: 13.6% currently identify as LGBTQ+, and these youth experience higher rates of violence, discrimination, substance misuse, mental health disorders, and suicidality than non-LGBTQ+ youth.³ Although demographic data (eg,

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race, age, ethnicity) are routinely collected for patients, there is no standardized method in Maine health care systems for collecting data on sexual orientation and gender identity (SOGI), limiting the ability to track and address existing disparities in LGBTQ+ health care.

We received a grant from the Maine Health Access Foundation (MeHAF) 2021 Systems Improvement and Innovation Responsive Grants Program (Award number U54GM115516). The full project, “Advancing Health Equity through Provider Education on Sexual Orientation and Gender Identity (SOGI),” required a needs assessment, for which we conducted surveys and focus groups with health care professionals (HCPs) in Maine.

Our needs assessment sought to characterize HCP comfort with eliciting and managing SOGI in Maine health care settings and identify barriers that prevent routine incorporation of SOGI in workflows. The purpose of this assessment was to inform educational and structural interventions that directly address identified barriers to more easily incorporate SOGI into standard practice. This paper presents the results of our needs assessment, identifies the most common barriers to routine use of SOGI in Maine health care systems, and advocates for the benefits of SOGI in LGBTQ+ health care when incorporated consistently into patient care.

METHODS

An interprofessional team of 1 social worker, 1 nurse, and 3 medical students associated with The Gender Clinic at Maine Medical Center designed a survey de novo. The survey contained questions that established respondent demographics, knowledge of SOGI collection and use in the electronic health record (EHR), prior education in LGBTQ+ health care, comfort incorporating SOGI into practice, and barriers to incorporating SOGI into patient care. Community organizations, including The Opportunity Alliance and EqualityMaine, provided feedback on survey development. Questions were a combination of multiple choice, 5-point Likert Scale (5 = Strongly Agree, 3 = Somewhat Agree, 1 = Strongly Disagree), and free text (Appendix I). The survey was part of a HIPAA (Health Insurance Portability and Accountability Act)-compliant REDCap database hosted at MaineHealth Institute of Research.^{5,6} The survey was distributed widely to community nonprofits (EqualityMaine, Healthy Communities of the Capital Area, OUT Maine,

Outright Lewiston-Auburn, Portland Outright, MaineTransNet) and chapters of professional health care associations in Maine (American Nursing Association, National Association of Social Workers, American Academy of Pediatrics). The Opportunity Alliance shared the survey with several major health care systems in Maine, including Central Maine Healthcare, Northern Light Health, and Federally Qualified Health Centers. Within MaineHealth, the survey was shared internally through several email distribution lists throughout the organization. The survey was available from December 2021 to January 2022. Responses were anonymous, unless participants provided contact information to be in focus groups, which made them eligible to receive a \$25 gift card. Survey and focus group data were compiled and reported with aggregate findings.

The interprofessional team conducted 4 focus groups. Survey respondents and groups were organized by topic or discipline. The number of focus groups was limited by respondents who volunteered to participate, as 112 people indicated interest in focus groups on the survey, and 38 signed up. Each group had 5 to 10 participants, lasted 1 hour, and covered the same predetermined questions (Appendix II) in a semi-structured interview format. One group included nurses, 1 group included mental health professionals, and 2 groups included interprofessional and multidisciplinary staff. Participants self-selected focus groups by discipline to increase comfort and participation. Participants were told the purpose of the focus groups and that discussions would be recorded and analyzed retroactively. Groups were conducted on videoconference and recorded. Transcriptions identifying speakers and time stamps were automatically generated for each group.

A medical student involved throughout the project led the thematic analysis.⁷ Each transcript was reviewed, and 15 codes were generated to capture the frequency and character of discussion ideas and topics. With an inductive approach to theme generation, the codes were grouped into 3 overarching themes that identify barriers to SOGI collection. Complete code saturation was not reached due to the limited number of focus groups. However, at least 11 of 15 total codes were represented in each group, and themes were consistent across all 4 groups. All codes and themes were reviewed and agreed upon by all members

of the interprofessional team at The Gender Clinic. Representative quotes were presented from focus groups.

The MaineHealth Institutional Review Board provided a letter of determination deeming this project as not research. EQUATOR Network standards for reporting qualitative research were reviewed.⁸

RESULTS

Our survey produced 357 responses from HCPs in all counties of Maine who represent a wide variety of health care backgrounds (Table 1). We found that 32.6% of respondents never received education that specifically prepared them for working with LGBTQ+ patients. Education received by 67.4% of respondents was in the form of in-person training, online training, grand rounds, and other methods. We asked HCPs to rate their comfort with eliciting different types of SOGI and using the EHR to capture the data (Figure 1). Most respondents were comfortable asking questions about sexual orientation, pronouns, and gender identity (Figures 1A-C). More variation between respondents' comfort level was seen with reproductive organs and sex assigned at birth (Figures 1D and 1E). There was wide variation in respondent comfort with using the EHR to input SOGI (Figure 1F).

Thirty-eight HCPs attended and 20 HCPs made significant verbal contributions in focus groups that discussed both the barriers to and benefits of collecting SOGI. Non-verbal participation (hand-raising, nodding) was not captured in the transcript analysis. Participants identified the biggest barriers to SOGI collection as a lack of HCP education and comfort with SOGI topics, HCP concerns for causing patient discomfort, and a lack of standardized data management and workflow. For the first barrier, two-thirds of participants reported insufficient education in LGBTQ+ topics, half of participants directly identified discomfort as they tried to elicit SOGI from patients, and one-quarter felt SOGI information was novel and unfamiliar. Referencing the ease of asking and recording SOGI questions, 1 participant said, "[some HCPs] don't have the comfort or language to actually ask [SOGI] questions. . . so I do find that information is left blank."

Table 1. Respondent Demographics

Characteristic	No. (%)
Professional role	
Mental health provider	122 (34.6)
Physician	69 (19.5)
Nurse	42 (11.9)
Other role	40 (11.3)
Nurse practitioner	32 (9.1)
Administrative staff	12 (3.4)
Case manager	11 (3.1)
Medical assistant	5 (1.4)
Pharmacist	5 (1.4)
Student/Intern/Trainee	4 (1.1)
Patient service representative	3 (0.8)
Physician assistant	2 (0.6)
Years in practice	
≤1	12 (3.4)
2-5	39 (11.0)
6-10	64 (18.1)
11-15	55 (15.6)
16-20	52 (14.7)
21≤	131 (37.1)
Primary practice setting	
Mental health provider	105 (30.1)
Primary care	66 (18.9)
Inpatient	61 (17.5)
Other practice setting	57 (16.3)
Specialty care	49 (14.0)
Emergency/Urgent care	11 (3.2)
Part of MaineHealth	
Yes	188 (55.3)
No	152 (44.7)
Identifies as part of LGBTQ+ community	
Yes	81 (23.0)
No	271 (77.0)

Abbreviation: LGBTQ+: lesbian, gay, bisexual, transgender, queer, or questioning.

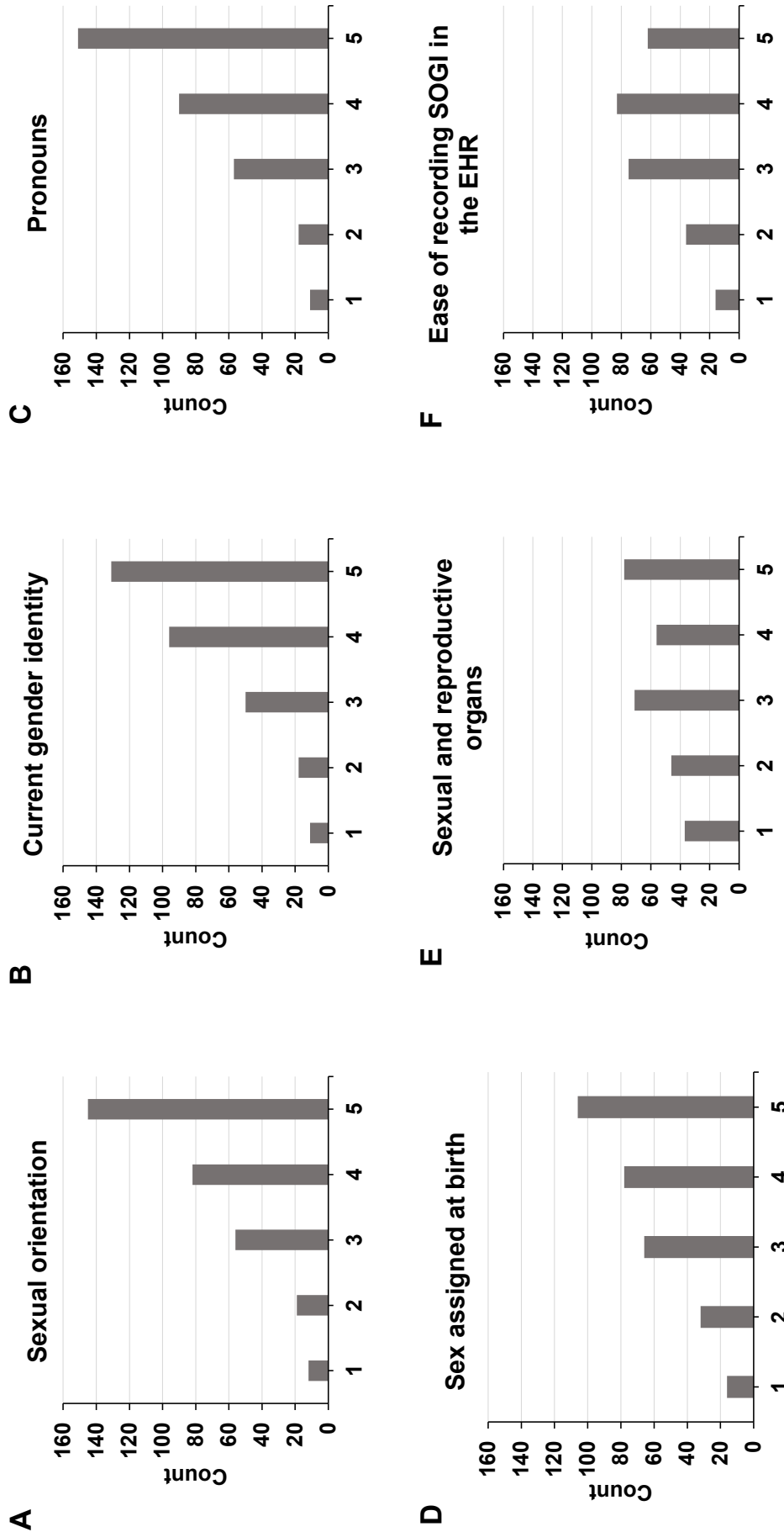


Figure 1. Health Care Professional Comfort with Collecting and Documenting Sexual Orientation and Gender Identity Data. Survey participants were asked to rate their level of comfort with eliciting SOGI data from patients and then documenting it in the EHR. A sliding 5-point Likert scale was used. Range was “not comfortable” (1), “somewhat comfortable” (3), and “very comfortable” (5), with intermediate scale options available (2 and 4).
EHR, electronic health record; SOGI, sexual orientation and gender identity.

For the second barrier, more than half of participants worried that asking SOGI questions would make their patients uncomfortable or disengaged; one-quarter thought SOGI questions may offend patients, particularly in older generations; one-quarter were concerned that patients may feel offended if they found SOGI questions irrelevant to them; and a few were concerned about patient privacy. For the third barrier, more than half of participants cited difficulty collecting SOGI due to an unclear workflow in which there was no specific person or role assigned to collecting the data. More than half of participants also expressed logistical difficulties in including SOGI in the EHR. More than one-quarter of participants cited difficulties in incorporating SOGI because of competing priorities that required more time in the existing workflow. A few participants were concerned about the legal and billing implications of incorporating SOGI into the EHR. Regarding workflow standardization, 1 participant said, "I will just say matter of fact, that we do not across our system do a great job with the [SOGI] collection. It does get buried, depending on the individual practitioners' style and interview and documentation preferences and therefore it's very hard to correlate or do anything meaningful with the data."

More than half of participants expressed that patients benefit when providers understand LGBTQ+ identities because patients are more willing to express specific health needs and can receive more appropriate treatment. One participant stated, "[SOGI] gets a bigger picture of who someone is or how they identify which . . . lets you build trust more quickly . . . especially just being able to use the name that they want to hear and the pronouns that they want use." A few participants noted that SOGI is important for discharge planning to safe housing, helps when applying for grants for continued research, aids in developing educational and support programs, and informs hiring practices so that HCPs can reflect and support the communities they serve.

More than three-quarters of participants wanted these barriers addressed by prioritizing continued education in LGBTQ+ topics for HCPs and standardizing the SOGI collection process. However, more than one-quarter noted that finding dedicated education time is difficult with competing priorities. Standardization is complicated by many

independent health care systems having their own data processes and EHRs.

DISCUSSION

Despite evidence of LGBTQ+ health disparities in the United States and the increasing number of community members identifying as LGBTQ+, Maine health care systems are not yet prepared to address these disparities and provide equitable care to LGBTQ+ patients. With no standardized way to collect and use SOGI, disparities are not quantified, making quality improvement initiatives hard to implement without a way to track outcomes. Standardizing SOGI collection for all patients would allow health care systems to create targeted, effective approaches to addressing LGBTQ+ specific health care, likely improving health outcomes across the state.⁹

Our survey and focus groups identified lack of HCP comfort and education, fear of causing patient discomfort, and unstandardized workflow as barriers to SOGI collection. Even if education and discomfort were addressed, our survey results (Figure 1F) identified wide variation in HCP's ability to input SOGI into the EHR, suggesting implementation is logistically difficult across systems.

Addressing these barriers is a multistep process. Education in LGBTQ+ topics is available in different platforms. However, health systems must decide how to standardize incorporation, whether during hiring and onboarding; require it as continuing medical education; or include it in current EHR training protocols. Mandatory education requirements would require designated time for HCPs to complete it among other priorities. Also, health systems must standardize collection of SOGI. Evolving recommendations suggest current best practices prioritize methods in which the patient can input the data themselves into the EHR, such as with an iPad or in the patient portal.⁹ Although having many health care systems that independently operate in Maine makes a universal solution challenging, prioritizing the standardization of SOGI collection workflows within each system could still support Maine LGBTQ+ health through the statewide Health Information Exchange, HealthInfoNet.¹⁰ Regardless of how SOGI is collected, HCPs must understand its clinical relevance and be able to incorporate it consistently into patient encounters.

Limited research is available on SOGI education for HCPs and best practices for SOGI collection. Further research could analyze how health systems that routinely use SOGI design their workflows, identify effective methods for collecting SOGI, or investigate strategies for using SOGI to track LGBTQ+ disparities. It would be beneficial to explore barriers to SOGI collection with non-clinical health care staff so that both clinical and administrative perspectives are incorporated into interventional strategies. Consistent SOGI collection supports identifying specific goals in improving LGBTQ+ health care in Maine and creating targeted quality improvement strategies.

This project has some limitations. First, although our respondents came from a wide variety of backgrounds all over Maine, certain professional roles were overrepresented, and strictly administrative staff were not included. Also, 23% of survey respondents identified as LGBTQ+, which is significantly greater than the Maine average (4.9% LGBTQ+). Given that survey participants self-selected to participate and self-reported their experiences within their health care systems, there is likely some degree of general response bias. Survey and focus group participants indicated substantial comfort with SOGI, but noted that they had coworkers who were less comfortable. It is likely that HCPs who were more comfortable with SOGI potentially skewed the results to show greater HCP comfort with SOGI than that of all Maine HCPs.

CONCLUSIONS

Most HCPs in Maine health care systems are not consistently collecting SOGI for their patients, despite evidence that LGBTQ+ patients experience health disparities that could be better assessed with access to SOGI information. Lack of comfort with LGBTQ+ topics, concern for causing patient discomfort, and lack of standardized workflows are barriers that must be addressed for SOGI to become routine best practice.

Conflicts of Interest: None

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