

“I Think There’s Only Two Fields for That”: Hospital Registrar Attitudes and Practices for Collecting Patient Gender Identity Data

Shivani Mehta,¹ Alex Waad,^{2,*} Madeline Brooks,³ and Scott D. Siegel³

¹College of Arts and Sciences, University of Delaware, Newark, Delaware, USA.

²Office of Health Equity, ChristianaCare, Newark, Delaware, USA.

³IREACH—Institute for Research on Equity and Community Health, ChristianaCare, Newark, Delaware, USA.

*Address correspondence to: Alex Waad, MA, Office of Health Equity, ChristianaCare, 4755 Ogletown-Stanton Road, Office Suite 2C76, Newark, DE 19718, USA, E-mail: alex.waad@christianacare.org

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Abstract

Purpose: This study aimed to understand the experiences of hospital registrars in collecting gender identity data.

Methods: A qualitative study that thematically analyzed key informant interviews with 37 registrars regarding their attitudes and practices in collecting gender identity data.

Results: Collection of gender identity is influenced by (1) system-level barriers, (2) discrepancies in source of truth for documentation, and (3) registrars’ underlying attitudes and behaviors.

Conclusions: Findings demonstrate that person- and system-level barriers can interfere with the accurate and respectful collection of gender identity data, which is critical for tracking and addressing lesbian, gay, bisexual, transgender, and queer health disparities.

Keywords: attitudes; electronic health record; gender identity; qualitative

Introduction

An estimated 5.6% of Americans identify as part of the lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities.¹ LGBTQ+ populations are often “invisible” in health care settings that lack systems to collect structured data on sexual orientation and gender identity (SOGI).² Although federal regulations require electronic health record (EHR) systems to have the capacity to collect, store, and retrieve structured data on SOGI,² there is a disappointing uptake of information.³

If EHRs had a structured format to collect SOGI, they would be equipped to efficiently capture this information and notify providers of appropriate targeted care and preventive services.³ In addition, the collection of SOGI data allows providers to define LGBTQ+ patient populations, address potential disparities with affirming evidence-based care, and secure funding necessary to sustain these programs.^{2,4}

Recent studies, including the EQUALITY Study funded by the Patient-Centered Outcomes Research Institute, have assessed patients’ willingness and preferred means of reporting SOGI in health care settings.^{4–6} Although many providers incorrectly assume that patients will take offense or refuse to provide SOGI, the EQUALITY study showed that most LGBTQ+ patients are willing to disclose this information if asked, with only 10% of patients declining.⁴ There are additional concerns that data collection may expose LGBTQ+ patients to discrimination; however, not collecting SOGI makes discrimination harder to address—if the experiences of these patients are not tracked, it is impossible to identify and address patterns of poor health care access and outcomes.²

According to the National LGBTQIA+ (Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual) Health Education Center, the best method for

documenting gender identity, consistent with LGBTQ+ patients' preference,⁵ is the patient nonverbally self-reporting current gender identity, sex assigned at birth, and gender identity reported to insurer as separate domains.⁷ Nevertheless, many health systems rely on registrars to verbally collect all demographic data, SOGI included.⁵ Moreover, at health systems where EHRs do not distinguish between gender identity and sex assigned at birth, registrars may rely on their own interpretation of these terms to record one but not the other. Such practices risk misgendering patients and fail to capture relevant clinical data, undermining patients' trust in the system and their willingness to receive ongoing care.

The objective of this study was to assess how the attitudes and practices of registration staff interact with system-level data collection processes to facilitate or impede the collection of gender identity data at a not-for-profit teaching health system.

Subjects and Methods

Sample

The ChristianaCare Health System includes two acute care hospitals in New Castle County, DE, which account for 88% of nonveteran, adult acute care in the county.⁸ Thirty-seven registrars from Christiana Hospital, the system's primary hospital, were recruited via convenience sampling and consented to participate in the study. They were not compensated for their time. All participants identified as women and worked in various departments with high volumes of patient registrations, including emergency, women's health, and outpatient services.

Data collection

Registrars completed key informant interviews as part of a larger study to assess their attitudes and methods for collection of race, ethnicity, language, and gender identity data. These analyses focus on gender identity. The interviewer used an unstructured guide to ask how registrars collected each data element, noting whether their practices deviated from the scripted format used for training.

Interview topics specific to gender identity covered scenarios of registering gender diverse patients, including documentation practices, the frequency of such interactions, and relevant training for registrars. Registrars were asked questions such as, "Have you ever come across a patient who would identify him or herself as a gender different from what it says on their ID or on the record?" Depending on their famil-

ilarity with the scenario, registrars were asked to describe the experience or how they would react to such a situation. All interviews were captured on a secure audio recording device. This study was deemed exempt by the ChristianaCare Institutional Review Board as participants were not identifiable.

Data analysis

The interviews were transcribed and analyzed using an open coding process. Two coders reviewed each transcript to check cohesiveness and reduce the risk of bias in coding. Transcripts were coded for two rounds to develop a parsimonious codebook, which was used for the third and final round of coding.

Results

The interviews yielded three primary themes regarding collection of patient gender identity: (1) system-level barriers, (2) discrepancies in source of truth for documentation, and (3) registrars' attitudes and behaviors.

System-level barriers cited by registrars included EHR capabilities and lack of formalized protocol or education for collecting gender identity. The EHR at this institution records gender as only male or female and does not differentiate between sex assigned at birth and gender identity, forcing registrars to record gender in a way that prioritizes either a patient's anatomy or gender identity; however, both are necessary to provide appropriate care. The first quote in Table 1 expresses that registrars would like to report gender identity in the system according to patient self-report; however, limitations within the EHR preclude capturing anything other than binary cisgender identity (i.e., only male and female options).

In addition, registrars reported a lack of formalized training with regard to gender identity and used varied methods to collect this information. Some registrars stated that they recorded patients' self-reported gender identity, others listed what was on patients' legal identification, and few reported that they would escalate the situation to a superior for guidance.

Discrepancies in source of truth for documentation of gender identity reflect how the lack of standardized protocol impacts registrars' documentation methods. Registrars often stated that they would consider one source credible for documenting gender identity but deferred to another in practice. As demonstrated by the second quote in Table 1, the registrar initially stated that she documented gender identity based on patient

Table 1. Major Themes and Exemplar Registrar Quotes

Theme	Exemplar quote from registrar
System-level barriers	"I could take the info [gender identity]—I could write down what they say if they consider, you know, but I don't, I think there's only two fields for that... So, I don't know if there's an option. I know you have to; you can't proceed without clicking that field and I believe it's just male and female, I don't believe there's another field."
Discrepancies in source of truth for documentation	"If they say they're a man, then I have to change it as a man. I'm only going by what they tell me. It's female, male or unknown." [...] "I think a lot of times we ask them for their ID and if it's not changed on their ID—we had a patient who was a man and he was here because he was going through the process of transitioning genders to female. And he was born a man, so we left him as a man. Because his ID says he's a man."
Registrars' attitudes and behaviors	"Well, I have to check with my boss because I don't know legally whether we're supposed to change from, unless they do a complete changeover. You know what I mean? See, because I can't, you know if you're physiologically still a female then you would be classified as a female. Right?" [...] "Because if somebody is looking at the thing and they say, 'Oh, this is a male,' and they go to do an exam or whatever, they're like 'Oh, that's not a male' they're going to think that they got the wrong person."

self-report, but later claimed that in practice, she documented based on legal identification. Several other registrars initially claimed to document gender identity using one information source, whether it be legal documentation or patient self-report, but in practice used a different source, often deferring to legal identification.

Registrars expressed common attitudes (both positive and negative) and behaviors regarding the collection of patient gender identity. Examples include assuming gender based on biological and/or physical attributes, the fear of saying something that negatively impacts the patient, and open-mindedness toward a standardized process for collecting gender identity respectfully and accurately.

In the third quote in Table 1, one registrar expresses a common theme regarding the assumption of gender based on anatomy and uncertainty of if (and when) it was appropriate to change a patient's gender marker within the EHR. Furthermore, she elaborates that registrars are fearful of documenting an inaccurate gender

identity resulting in another provider misgendering or making a clinical error based upon organ assumptions. This quote also expresses the common mistake of failing to differentiate gender identity and sex assigned at birth. This misperception, however, is also perpetuated by the EHR's inability to capture these distinct elements.

Throughout interviews, nearly all registrars reported interacting with gender diverse patients, or those who they perceived to be gender diverse based on physical attributes. Some registrars had prior knowledge of gender diversity and accordingly stated that they record patients' self-reported gender identity. In addition, registrars reported positive reactions from patients when respectfully asking them about their gender identity, experiencing few encounters, in which patients reacted negatively to this question.

Discussion

Many registrars were well-intentioned and/or knowledgeable about gender diversity and wanted to respectfully record gender identity as per the patient's self-reported identity; however, EHR limitations and the lack of standardized protocol posed barriers. These conditions can contribute to discrepancies between EHR-recorded and insurance-reported gender identity and therefore prevent patients from receiving evidence-based, gender-affirming care.

The National LGBTQIA + Health Education Center provides health systems and clinicians with guidelines for collecting SOGI data, from standardized language to guide registration staff in respectfully obtaining SOGI data from patients, to recommendations for EHR customizations to display SOGI data.⁹ Current best practices recommend a multiquestion approach that separately collects patients' self-reported gender identity and sex assigned at birth.^{9–12}

In addition to these recommendations, the National LGBTQIA + Health Education Center highlights the importance of clearly displaying pronouns and chosen name for use by any staff who interacts with patients.⁹ This recommendation aligns with our finding that current EHR limitations may impede respectful interactions with patients. Kronk et al. further suggest the use of a pronoun algorithm in collecting patient pronouns and honorifics, which may then automatically fill in patients' titles based on the chosen pronoun sets.¹⁰ Adequate data fields for the collection of pronouns, as well as staff training on pronouns and LGBTQ+ cultural competence, are necessary to ensure that staff provide affirming care.

Registrars described conflict in when or how to modify SOGI data within the EHR. It is important for clinicians to have the ability to edit SOGI data in the event that patients offer new or different information during their encounter.⁹ However, others advocate for allowing patients to edit their own SOGI without clinician approval.¹⁰ This practice respects the autonomy of transgender individuals to disclose their gender identity as they choose and mitigates chances of transphobic interactions or pathologizing of one's transgender status.

Limitations

This study has limited generalizability due to a small convenience sample of registrars ($N=37$) that represent only one institution. The interviews were conducted 3 years before time of analysis, in 2017, and some registrars' attitudes and behaviors may have changed since then.

Conclusion

This study highlights the importance of providing registrars with training and systems that facilitate the collection of gender identity data according to best practices. Registrar education should contain content that is inclusive of gender diverse patients, in addition to standardized protocols to provide clear expectations around accurate and gender-inclusive data collection methods. In addition, health systems should implement EHRs that capture, display, and utilize SOGI data consistently across applications.

Authors' Contributions

S.D.S. provided conceptualization, methodology, and writing contributions. M.B. and A.W. provided supervision, methodology, formal analysis, and writing contributions. S.M. provided data curation, formal analysis, and lead writing and review/editing.

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This content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Author Disclosure Statement

All of the authors have no disclosures.

Funding Information

This project was supported by the Delaware INBRE program, with a grant from the National Institute of

General Medical Sciences—NIGMS (P20 GM103446) from the National Institutes of Health and the state of Delaware.

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Abbreviations Used

EHR = electronic health record
LGBTQ+ = lesbian, gay, bisexual, transgender, and queer
SOGI = sexual orientation and gender identity