

## Brief Communications

# A call to action to improve the completeness of older adult sexual and gender minority data in electronic health records

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### ABSTRACT

Sexual and gender minority (SGM) older adults experience greater health disparities compared to non-SGM older adults. The SGM older adult population is growing rapidly. To address this disparity and gain a better understanding of their unique challenges in healthcare relies on accurate data collection. We conducted a secondary data analysis of 2018–2022 electronic health record data for older adults aged  $\geq 50$  years, in 1 large academic health system to determine the source, magnitude, and correlates of missing sexual orientation and gender identity (SOGI) data among hospitalized older adults. Among 153 827 older adults discharged from the hospital, SOGI data missingness was 67.6% for sexual orientation and 63.0% for gender identity. SOGI data are underreported, leading to bias findings when studying health disparities. Without complete SOGI data, healthcare systems will not fully understand the unique needs of SGM individuals and develop tailored interventions and programs to reduce health disparities among these populations.

**Key words:** electronic health records, social determinants of health, LGBTQ+, gender minorities, sexual minorities

### INTRODUCTION

The number of older adults in the United States is estimated to more than double from 54 million in 2017 to 114 million by the year 2060.<sup>1</sup> During the same period, older adults who identify as part of a sexual and gender minority (SGM) group (lesbian, gay, bisexual, transgender, queer or questioning, intersex, nonbinary) will increase from 6% to more than 17%, or 20 million.<sup>2</sup> The SGM older adult population are a rapidly growing population, yet few studies focus on sexual orientation and gender identity (SOGI), limiting our ability to account for their specialized needs. Accurately capturing the SGM population and better understanding a patient's sexual orientation or gender identity can help clinicians to provide culturally competent care and develop population-specific health programs.

SGM older adults, relative to straight or cisgender older adults, experience greater health disparities.<sup>2,3</sup> Older SGM adults are more likely to show elevated rates of poor general health, mental distress, and higher likelihood of disability.<sup>4–6</sup> More than 80% of SGM older adults have experienced discrimination or victimization at least once because of their perceived sexual orientation or gender identity.<sup>7</sup> Experiences of discrimination and victimization are linked with difficulties in accessing healthcare and poor health outcomes.<sup>6</sup> As a result, an increased interest in improving the clinical care of SGM populations has emerged in recent years.

In response to the need to better understand this population, the Centers for Medicare and Medicaid Services (CMS) Promoting Interoperability Program in 2015 required that all electronic health record (EHR) systems develop the capacity to record SOGI data as standard practice. Theoretically, developing the capacity to collect SOGI data would inform interventions designed to address the unique needs of SGM populations within healthcare systems.<sup>8</sup> However, CMS did not require healthcare systems to collect SOGI data within their EHR.<sup>9</sup> Collecting SOGI data is necessary to allow healthcare workers to personalize care, such as through the use of patient's pronouns during communication to ensure culturally affirming, patient-centered care. Furthermore, if EHRs fail to collect these data, researchers and analysts are limited in understanding the scope of disparities to inform the design and evaluation of interventions to improve SGM older adult health. As society recognizes pervasive health inequities across all healthcare systems, payers are pushing to develop quality measures that incorporate social drivers of health.<sup>10</sup> Healthcare systems will not be able to meet these performance measure goals without standardized data collection practices.

Using discharge destination of older SGM adults ( $\geq 50$  years) as an exemplar, this study examines EHR data within 1 large academic healthcare system. Providing empirical evidence of the magnitude of the missingness of these data in EHRs serves as a call to action for healthcare systems to be more intentional in collecting these SOGI data, and for

policymakers to consider policies to standardize data collection practices to better serve this growing segment of society. Collecting SOGI data in EHRs is essential to gaining a better understanding of older SGM adults and providing high-quality, patient-centered care.

## MATERIALS AND METHODS

This study used an observational, retrospective cross-sectional design. The sample of SGM older adults (aged  $\geq 50$  years) was drawn from 1 EHR system within a large academic healthcare system located in North Carolina. The study was approved by the home institution's Institutional Review Board.

We included all adults aged 50 years and older who were admitted to the hospital system between the dates of November 1, 2018, to June 1, 2022, with a discharge disposition. Discharge disposition included home, home health, skilled nursing facility, and other (ie, expired). We included patients once in the sample. Demographic data collected (patient's age, race, ethnicity, marital status, state, zip code, location admitted from, and discharge destination) are confidential and collected as part of the EHR to ensure that providers have current information about patients. SOGI data are input during or after the clinical encounter by nonlicensed professional staff (ie, clerk) and licensed staff including clinicians, nurses, and social workers. Patients may enter demographic data by accessing their online chart (MyChart) if they have portal access. There are some environments where patients can enter their information independently (ie, clinical setting). Training on how to collect SOGI data is provided by the health system for licensed/nonlicensed staff who are in patient-facing roles. The SOGI data fields individuals could select in the EHR are presented in Table 1; there was no option for an individual to provide a custom write-in or select all that apply. That is, individuals could only select 1 option from the options listed (or not provide a selection). In this EHR for patients who did not have a specified selection for SOGI we classified those patients as "Unspecified" (for each of those categories). There were no exclusion criteria. Due to the missingness of the data and cell counts less than 10 in these categories we followed CMS recommendations<sup>11</sup> for the data table. We examined the missingness of SOGI data in the EHR with descriptive information about the population.

## RESULTS

### Missingness of data in the EHR system

A total of  $N = 153\,827$  adults aged 50 and older were discharged from the hospital system during the study period

(see Table 2). Most individuals did not have data collected on sexual orientation ( $n = 103\,975$ ; 67.6%) and are identified as "Unspecified" in Table 2. Similarly, most individuals did not have data collected on gender identity ( $n = 96,163$ ; 63%), results not shown. For those who did disclose their sexual orientation,  $n = 2805$  (6.3%) identified as a sexual minority (eg, gay, lesbian, bisexual). Individuals identifying as a sexual minority were stratified as lesbian/gay  $n = 703$  (0.5%), bisexual  $n = 292$  (0.2%), queer  $n = 28$  (0.02%), asexual  $n = 1763$  (1.2%), pansexual  $n = 19$  (0.01%), and something else  $n = 328$  (0.2%). While  $n = 44,410$  (28.9%) identified as a nonsexual minority (identified as "Straight" in Table 2). Only a total of  $n = 49$  identified as a gender minority (ie, transgender, nonbinary).

### Differences in demographics

Those who were in the unspecified category for sexual orientation were more likely to have an unspecified gender and be non-White, while less likely to be married and discharged home (Table 2). Those identifying as asexual were less likely to be of Hispanic ethnicity.

## DISCUSSION

In this research brief, we identified the high rate of missingness in the collection of SOGI data in 1 large health system in North Carolina. Results from our secondary analysis suggest among 153 827 older adults discharged from this health system, SOGI data missingness was 67.6% for sexual orientation and 63.0% for gender identity. Collecting SOGI data in EHRs are essential to gaining a better understanding of SGM older adults and providing high-quality care and yet, without accurate SOGI data, identification of disparities resulting from clinical care delivered to SGM older adults will remain lacking. Based on our results, we recommend mandating the collection of SOGI data throughout healthcare systems nationally for informing new programs designed to ensure culturally affirming, patient-centered care.

Mandating the collection and reporting of data can make a difference in care provided to patients. During the COVID-19 pandemic, the high-quality EHR was important for near real-time tracking of COVID-19 and helped guide the pandemic response.<sup>12</sup> However, missing race and ethnicity information was noted to be incomplete in public health surveillance monitoring systems rendering the pandemic response slow among vulnerable populations.<sup>13,14</sup> A similarly slow response has been found among the SGM community because of the lack of SOGI data collection.<sup>12</sup>

In our study, sexual orientation was missing 67.6% of the time followed by gender identity at 63.0%. A recently published study of 49 314 individuals who were seen in the Emergency Department or admitted through the Emergency Department indicated that 24% ( $n = 11\,943$ ) had complete gender identity fields versus 76% ( $n = 37\,371$ ) who did not.<sup>15</sup> Our study shows the number of asexual older adults as 1.2% ( $n = 1763$ ) of the population. It is not clear if older adults did not understand the term "asexual" or the data collector inferred their sexual orientation without asking or another reason. In previous studies, the rate of asexual older adults is either not reported or grouped with "other."<sup>15,16</sup> This is an area that needs further investigation. Results from this study, along with our findings, suggest that high rates of gender identity missingness in health system EHRs continue at

**Table 1.** EHR sexual orientation and gender identity fields

Sexual orientation	Gender identity
Asexual	Male
Bisexual	Female
Pansexual	Nonbinary
Gay/lesbian	Gender fluid/queer
Straight (not lesbian or gay)	Transgender female/male to female
Something else	Transgender male/female to male
Choose not to disclose	Choose not to answer
Do not know	

Abbreviation: EHR: electronic health record.

**Table 2.** Demographics stratified by sexual orientation

	Straight n = 44 410 (28.9%)	Lesbian/gay n = 703 (0.5%)	Bisexual n = 292 (0.2%)	Queer n = 28 (0.02%)	Asexual n = 1763 (1.2%)	Pansexual n = 19 (0.01%)	Something Else n = 328 (0.2%)	Unspecified n = 103 975 (67.6%)	P-value
Mean Age	64.8 (7.9)	62.9 (8.6)	69.6 (10.8)	67.2 (6.4)	69.4 (9.5)	63.7 (8.4)	68.0 (10.1)	69.2 (11.2)	<.001 <sup>^^</sup>
Gender									<.001 <sup>^^</sup>
Female	21 820 (49.1%)	260 (36.5%)	125 (42.9%)	** (**%)	752 (42.7%)	13 (68.4%)	142 (45.5%)	5131 (4.9%)	
Male	21 779 (49.0%)	369 (51.8%)	148 (51.4%)	17 (60.7%)	829 (47.0%)	** (**%)	152 (48.7%)	4354 (4.2%)	
Unspecified	765 (1.7%)	83 (11.7%)	17 (5.8%)	** (**%)	181 (10.3%)	** (**%)	18 (5.8%)	94 980 (90.8%)	
Race									<0.001 <sup>^^</sup>
Black	8796 (19.8%)	114 (16.2%)	28 (9.6%)	10 (35.7%)	324 (18.9%)	** (**%)	49 (14.9%)	38 006 (35.7%)	
White	34 089 (76.8%)	577 (82.1%)	249 (85.3%)	18 (64.3%)	1382 (78.4%)	** (**%)	259 (75.1%)	62 131 (58.3%)	
Other	1525 (3.4%)	12 (1.7%)	15 (5.1%)	0 (0.0%)	57 (2.7%)	** (**%)	20 (6.1%)	3838 (6.0%)	
Non-Hispanic	42 446 (95.6%)	687 (97.7%)	275 (94.2%)	15 (53.57%)	1669 (94.67%)	18 (94.7%)	312 (95.1%)	42 446 (95.6%)	<0.001 <sup>^^</sup>
Marital status									<0.001 <sup>^^</sup>
Married	28 025 (63.1%)	279 (39.7%)	183 (62.7%)	** (**%)	1085 (61.5%)	** (**%)	177 (54.0%)	48 791 (45.8%)	
Widowed	5392 (12.1%)	25 (3.6%)	38 (13.0%)	13 (46.4%)	214 (12.1%)	** (**%)	42 (12.8%)	21 358 (20.0%)	
Divorced	5075 (11.4%)	56 (8.0%)	32 (11.0%)	** (**%)	203 (11.5%)	** (**%)	33 (10.1%)	12 452 (11.7%)	
Single	4915 (11.1%)	246 (35.0%)	36 (12.3%)	** (**%)	225 (12.8%)	** (**%)	63 (19.2%)	19 460 (18.3%)	
Discharged									<0.001 <sup>^^</sup>
Home	30 511 (68.7%)	529 (75.3%)	188 (64.4%)	10 (35.7%)	1106 (62.7%)	** (**%)	213 (64.9%)	53 734 (51.7%)	
Home health	7900 (17.8%)	117 (16.6%)	39 (13.4%)	** (**%)	376 (21.3%)	** (**%)	61 (18.6%)	19 847 (19.1%)	
SNF	3497 (7.9%)	23 (3.3%)	37 (12.7%)	10 (35.7%)	150 (8.5%)	** (**%)	30 (9.2%)	16 002 (13.6%)	
Other	2502 (5.6%)	34 (4.8%)	28 (9.6%)	** (**%)	131 (7.4%)	** (**%)	24 (7.3%)	14 392 (13.8%)	

Abbreviation: SNF: skilled nursing facility.

\*\* Cell count is less than 10 and it is best practice to not report cell counts less than 10 to minimize inadvertent disclosure. We included \*\* in the associated percentages as well since it would be easy to determine sample sizes.

<sup>^^</sup> Significant at the 0.05 level.

alarming rates, which limits our ability to determine disparities and develop programs designed to improve care to the SGM community.

This research brief is a call to action. It is critical to improve and standardize SOGI data collection practices by strengthening oversight of completeness of SOGI data collection, enhancing staff training efforts, and developing safe and inclusive environments where SGM populations can share SOGI without stigma, prejudice, and discrimination. As such, we outline key recommendations for SOGI data collection:

### Training and infrastructure to support SOGI data collection

SOGI data may be difficult to collect because of patient fears of discrimination and beliefs that the effort required to collect data outweighs its benefits.<sup>12</sup> The lack of data collection is a symptom of a larger problem and should be considered another version of inequity in healthcare.<sup>12</sup>

SOGI data can be missing because there is no consensus about who should be responsible for collecting SOGI data and complete SOGI categories do not exist in EHR systems.<sup>17</sup> In a recent literature review,<sup>18</sup> healthcare professionals expressed that it was the responsibility of the patient to disclose their SOGI without being prompted by the healthcare worker. Healthcare professionals were concerned that they would offend patients by asking their SOGI. However, studies have repeatedly shown that when asked their SOGI information, patients support the question and will answer it, and yet, SOGI data questions are not consistently collected.<sup>19</sup>

Training is being provided in the healthcare system. However, considerations to the content and type of delivery of the training needs further discovery. Strong messaging of clinical benefits and the importance of SOGI data collection to healthcare workers may enhance the collection of SOGI data.

Healthcare workers acknowledging diversity and cultural humility adds to the health system’s culture of inclusivity. Providing a welcoming and inclusive environment that is visible to SGM patients and staff makes them feel safe.<sup>19</sup> Inclusive practices include, for example, healthcare systems adopting gender-affirming practices and use of language, having SGM-related anti-discrimination policies, gender neutral facilities, and visible cues of safe space designation.<sup>20</sup> All healthcare workers and staff attending regular mandatory trainings in SOGI data collection practices and providing inclusive care for SGM populations depicts an environment of acceptance.<sup>21</sup>

Health systems need to build or enhance their infrastructure to support the collection of SOGI data in a way that is safe and respectful to patients. For example, a private room or cubicle, or an iPad for patients to enter their own information during the registration process helps to ensure patient privacy and confidentiality.<sup>22</sup> In addition, health systems may consider providing online portals for patients and/or their caregivers to have the option to preregister before hospitalization can be a useful strategy to support the collection of SOGI data in a manner that ensures privacy to the patient when entering sensitive information.

Future iterations of SOGI data collection in the EHR should consider more detailed questioning regarding gender identity beyond the standard 2-step approach (eg, What sex were you assigned at birth, on your original birth certificate? What is your current gender identity?)<sup>23</sup>; this is important to avoid erasing the diversity of transgender or gender expansive identities.<sup>23</sup> Furthermore, surveys should consider including necessary gender identity and sexual orientation questions.<sup>17</sup> Previous studies suggested including pronoun-related information to the EHR through an automated system that prompts the user with specific sentences (ie, “What pronouns

do you use?”) and then provides a list of common pronouns for the patient to select from is another strategy that can help clinicians ask questions and provide a sense of safety to patients.<sup>24</sup>

### SOGI data standardization

The lack of standardized coding schemes for SOGI data collection practices at the federal, state, and institutional level creates challenges for exchanging information across EHR systems.<sup>17,21</sup> This can make it difficult to ensure continuity of care for patients as they transition between different health-care settings. To address this challenge, various initiatives have been developed to standardize secure information sharing across different EHR systems such as the Trusted Exchange Framework and Common Agreement.<sup>25</sup> These policies seek nationwide connectivity and facilitate electronic transfer of patients across settings and scalability.

### SGM quality measurement and payment reimbursement

Disparity-sensitive measures can be used to detect differences in quality across healthcare systems, but also differences in quality delivered to SGM populations, allowing health systems to identify areas for improvement and target interventions to reduce disparities. These measures can also be used to hold health systems accountable for the quality of care they provide to SGM populations. Tying payment reimbursement to the completeness of SOGI data and implementing disparities-sensitive measures can help incentivize health systems to collect accurate and complete SOGI data and ensure that they are providing high-quality care to SGM populations.

### Limitations

The missing data presented here are from 1 academic health system and may not be generalizable to other health systems. Additionally, this secondary analysis is not causal, and this is reflected in the data analysis. Collecting of SOGI data upon admission during an acute hospitalization may have affected the results. Future studies may examine SOGI data missingness in similar academic health systems to provide further comparison. If health systems are accurately and consistently collecting SOGI data, they may serve as an exemplar for other health systems to follow.

### CONCLUSION

SOGI data are underreported. Enhancing data collection is critical to identifying and addressing the needs of the SGM population but without complete SOGI data, health systems are limited in their ability to address health disparities and tailored interventions and provide culturally competent care. The recommendations provided in this research brief begin to share policy solutions to promote equity as well as allow healthcare systems to reduce health disparities in the SGM population and meet performance measure goals.

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### AUTHOR CONTRIBUTIONS

JTM contributed to the conceptualization, data curation, methodology, visualization, writing the original draft, review, and revisions, and funding acquisition. JM contributed by conducting formal analysis of the data, methodology, visualization, writing of the original draft, review, revisions, and editing. DN and EM contributed to conceptualization, writing—review, revisions, and editing. MPC contributed to the conceptualization, writing—review, revisions, and editing, and supervision. All authors reviewed and approved the final manuscript.

### CONFLICT OF INTEREST STATEMENT

None declared.

### DATA AVAILABILITY

The data underlying this article cannot be shared publicly due to ethical/privacy reasons.

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