The Evolving Landscape of Sexual Orientation and Gender Identity Data Collection in Clinical Practice

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Abstract

Lesbian, gay, bisexual, transgender, and other individuals (LGBT+) who identify as sexual and gender minorities SGM experience disparities in treatment-related side effects, early cancer screening, and overall mortality. Past research has shown that disclosure of sexual orientation and gender identity (SOGI) data in clinical settings can improve patient-provider communication. With significant advocacy along with evolving Meaningful Use Standards for Electronic Health Records that require SOGI data collection fields, the completeness of SOGI information in electronic medical records has recently been increasing. Recent policy changes, however, may alter this trend. Indeed, current policy developments seriously threaten the safety and confidentiality of LGBT+ people in research and clinical care settings. This reflection article offers observations on the current policy climate and encourages safe, confidential, and informed SOGI data disclosure in clinical practice and research. These reflections suggest that research is urgently needed to identify adaptive strategies for SOGI data disclosure based on geopolitical context.

Summary

Sexual orientation and gender identity (SOGI) data collection is vital yet inconsistently collected in clinical practice. Collection of SOGI data in research studies and clinical care is important to identify trends in morbidity, mortality, and health-related quality of life and prompt intervention to address identified disparities. With significant advocacy alongside evolving Meaningful Use Standards for Electronic Health Records (EHRs) that require SOGI data collection fields, the completeness of SOGI information in EHRs has recently increased. However, recent policy changes at institutional, state, and federal levels have stifled research efforts to advance the health of lesbian, gay, bisexual, transgender, and other individuals who identify as sexual and gender minorities (LGBT+). This threatens important confidentiality protections and trust in healthcare settings. The current political climate may have long-term implications for the collection of these data across the United States healthcare system.

Public Problem

LGBT+ individuals experience disparities in treatment-related side effects, early cancer screening, and overall mortality.1 Observational research has shown that disclosure of SOGI data in clinical settings can improve patient trust and satisfaction and improve tailored referral to fit patient needs.8,9 With significant advocacy, along with evolving Meaningful Use Standards for EHRs that require SOGI data collection fields, the completeness of SOGI information in electronic medical records has been increasing.4,5 One study by Liu et al. found that SOGI data was approximately 70-75% complete in medical records in federally qualified health centers.4 While this study does not account for private enterprises and does not apply a standard for patient self-reported data, this is still an encouraging statistic. Recent policy changes, however, may alter this trend. Indeed, current policy developments seriously threaten the safety and confidentiality of LGBT+ people in research and clinical care settings. This reflection article builds on discussions by the Sexual and Gender Minority Interest Group, which convened from April 2022 to June 2023, to examine optimal strategies for collecting SOGI data in clinical settings10 and subsequent work to ensure recommended items were acceptable and appropriate for diverse older adults.11 Here, we offer observations on the current policy climate and encourage safe, confidential, and informed SOGI data disclosure in clinical practice and research. These reflections suggest that research to identify adaptive strategies for SOGI data disclosure based on geopolitical context is urgently needed.

Trends

Funding for LGBT+-focused research initiatives is declining

Nearly all National Institutes of Health (NIH)-funded research focused on advancing the health of LGBT+ people was terminated between January and April of 2025. Grants for projects related to transgender populations and gender identity, specifically, as well as diversity, equity, and inclusion (DEI) broadly have been scrutinized, terminated, pulled from study section review, and eliminated from "agency priorities."12 Of note, while research focused on LGBT+ health outcomes and research focused on DEI overlap, these are not synonymous: DEI work broadly aims to implement practices where all people are included, diversity is valued, and people are cared for based on their level of need rather than through a one-size-fits-all approach. LGBT+-focused research is a component of DEI work but is narrower in its focus. NIH staff have been advised to place ongoing projects into categories depending on their involvement with and mention of DEI, and requested revisions to fundable projects require eliminating DEI components.13 Ironically, of course, the reduction of support for DEI research broadly and LGBT+ research specifically counters the "health for all" rhetoric that disproportionately favors those with the most access, resources, and power.

Recent federal- and state-level policies may negatively impact LGBT+ health

TThe halt of major funding sources for LGBT+-related research activities has a direct and immediate impact on LGBT+ individuals' health. For example,

researchers at Vanderbilt University who study stress and resilience among the LGBT+ population had funds terminated, leading to an end of an important longitudinal study. This study is critical because of longstanding stress, stigma, and denial of care experienced by LGBT+ people, which makes resiliency critical for higher quality of life for those experiencing disaffirming and discriminating experiences. Losing these data means a loss of valuable information about the health of a group experiencing sustained health and healthcare disparities.12 The "gender ideology extremism" Executive Order posits that there is a binary nature to sex and recognizes only "male" and "female" without regard for gender identity.7 The Presidential order effectively erases transgender, gender expansive, nonbinary, and intersex people–creating less accurate data on which to base healthcare treatment planning and decisions. According to a Fenway Health policy brief, encouragement of this sentiment may prevent efforts to collect SOGI data in public health surveillance, including at institutions that receive funding from the federal government.14 For instance, the CDC announced that it will stop collecting data on transgender identity to comply with President Trump's Executive Orders.15 Other federal datasets no longer collecting SOGI include the National Crime Victimization Survey, which added SOGI in 2016 and provides valuable information about victimization of LGBT+ people in the United States.16 Without these data, it is impossible to develop evidence-based ways of addressing the longstanding, often socially-sanctioned trauma long experienced by LGBT+ people to improve resiliency, coping, and quality of life.

Policy Considerations

Despite Executive Orders that impede SOGI data collection, there have been critical challenges to mitigate the impact and prevent further delay of research. On June 16, 2025, a federal judge ordered the NIH to restore grants terminated on the grounds that they endorsed "gender ideology" or "DEI."17 More recently, a senior NIH official instructed agency employees to cease grant terminations, including those that are in the process of being terminated.17 The Centers for Medicare & Medicaid Services Meaningful Use Stage 3 requirements of the Health Information Technology for Economic and Clinical Health (HITECH) Act, which required that Electronic Health Records have the capacity to record SOGI since 2018, continue to remain in place in 2025.2,3 On a state level, one example of a policy that encourages SOGI data collection was enacted in New Jersey: As of 2024, New Jersey required all

clinical laboratories to "electronically record the race, ethnicity, sexual orientation, and gender identity of each patient" unless the patient was not present and the laboratory only had an electronic order.18 The option to not disclose was required in addition to standardized SOGI data categories.18 A prior New Jersey policy required that if SOGI data were collected, appropriate cultural competency training must also be in place.19 New Jersey's legislation demonstrates that states can play a proactive role in protecting inclusive data practices in the setting of federal restrictions. However, when federal and state authorities are not in alignment, confusion ensues. When pressed to hand over identifiable patient data "to reconcile such records against… billing data" related to transgender care, Vanderbilt opted to comply without question.20 Yet, the HIPAA privacy rule requires that any disclosure of data satisfy a three-part test: the material requested must be "relevant and material" to a current investigation; the request must be "specific and limited" in scope; and data must be de-identified unless a clear reason for identifiable data is apparent.20 In response to a similar request by the Missouri Attorney General, the University of Washington opted to petition the request in state court to assess the Attorney General's legal authority to request patient records, with the authority resting on whether the Attorney General is deemed a health oversight agency.20 In Indiana, many healthcare settings resisted patient data disclosure, while in Texas, the Attorney General requested to obtain patient information for patients in two other states (Washington and Georgia).20 While Seattle Children's in Washington state and QueerMed in Georgia successfully settled with their respective Attorney Generals without providing identifiable patient data, these institutions were forced to stop providing healthcare to youth from Texas.21,22

Most recently, the erasure of transgender status by the President in 2025 and growing anti-LGBT+ state-level policies6,7 have created a culture of intimidation and threatens basic protections of confidentiality and safety for LGBT+ patients and research participants. We are thus left with the impossible need to collect SOGI data to advance the health of LGBT+ people in an environment where it may not be safe to do so. While HIPAA protections hold, attempts to strengthen patient privacy have so far failed.23 Furthermore, the Supreme Court has upheld state bans on transgender care for youth, potentially strengthening future Attorneys General claims to data to ensure compliance with those bans.24

Implications

The collection of data regarding LGBT+ people in institutional, state, and federal datasets can provide estimates specific to LGBT+ people and enable comparison to non-LGBT+ populations.25 The cumulative effect of the current political climate is to reduce visibility of LGBT+ patients in data and undermine data-driven quality improvement as well as provision of appropriate services. Our recent study investigating the implementation factors associated with SOGI data collection identified mandates, forced workflows, structured data fields, and leadership support as facilitators of data collection.26 Surely, if mandates are a primary force for SOGI data collection, mandates against the use of SOGI collection and data-driven clinical research for

LGBT+ patients will negatively impact the overall landscape for LGBT+ patients seeking care. So, what are we to do? First and foremost, institutions should not release SOGI patient data to government officials. Leveraging the examples of Seattle Children's in Washington State and QueerMed in Georgia, institutional leadership can and should assert and enforce unequivocal nondisclosure of patient records to comply with HIPAA. If authorities provide persuasive evidence via the three-part test, successfully arguing for the need to receive identifiable patient data to comply with a specific, limited investigation for legal compliance, institutions can petition to allow the court to decide if the request is compelling, reasonable, and within the authority of the requesting official. It is not unrealistic to assume that patients in some states where transgender care bans have been upheld by the courts may be at risk for disclosure of their data. Therefore, it may be better not to collect SOGI data in jurisdictions where the basic safety of transgender patients is at reasonable risk. Given the current landscape of extreme discrimination and the rollback of civil protections, healthcare executives should assess the risks and benefits of SOGI data documentation in their state and provide guidance to healthcare clinicians at this unique time in our nation's history: informing patients of what is and is not protected and who can see their data is critical to shared decision making regarding SOGI disclosure and documentation. To be certain, the rapidly evolving court decisions make this a challenging assessment. Healthcare clinicians should thus ask patients if they would like their SOGI data stored in their medical record or removed, given the evolving potential for data misuse and abuse. This puts researchers trying to investigate better tailored care for LGBT+ people in a significant bind: While not ideal for the research community and future data collection for evidence-based practice, adaptive strategies to encourage patient-provider communication regarding relevant behaviors and needs to tailor care for LGBT+ patients without documentation of SOGI (which may unintentionally put patients at risk) may be needed as we collectively advocate for stronger privacy regulations and an end to the discriminatory actions being taken in the current geopolitical environment.

Recommendations/Call to Action

- Federal policymakers: Reinstate and protect funding for LGBT+-focused research projects.
- Healthcare institutions: Enable confidential opt-in SOGI data collection methods and implement cultural humility training to help clinicians and staff navigate SOGI-related conversations with patients.
- Healthcare providers and researchers: Protect confidentiality of patient and research participant data. If institutional, state, and federal laws do not fully protect the confidentiality of SOGI information in EHRs, ask patients if they want their SOGI data removed until and unless such protections can be guaranteed. Advocate for the strengthening of patient and research participant data protections.
- Community stakeholders and advocates: Partner with local clinics that provide care for LGBT+ patients in the community to develop tools that capture health-related quality of life for this population. Advocate for civil rights restoration for LGBT+ people.

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