Doi: 10.32481/djph.2025.07.11

If You Seek SOGI:

Current State and Practical Implementation Considerations for Health Care Organizations Seeking to Collect Sexual Orientation and Gender Identity (SOGI) Data Domains

Alex Waad, MA, NBC-HWC [1] & Tylisha Johnson, MSM [2]

1. Community Health Manager, Office of Community Health Impact, ChristianaCare; Department of Health Behavior & Nutrition Sciences, University of Delaware

2. Community Health Program Manager, Office of Community Health Impact, ChristianaCare

Abstract

As health care systems across the United States continue to grapple with a new health landscape changes brought from the COVID-19 pandemic, the need for robust and accurate data collection continues to be an ongoing need. While some national directives exist for health care organizations, the implementation of systematic sexual orientation and gender identity (SOGI) data domains for health care organizations is often a complex, interdisciplinary undertaking. The authors provide a current state status of national policies and best practices for SOGI data domain collection in health care environments, as well as practical considerations for health care organizations seeking to implement or expand their own collection of SOGI data domains. Due to the rapidly evolving landscape of socio and geopolitical changes around healthcare delivery in the United States, health care organizations may benefit from assessing their own current capabilities to collect and use SOGI data domains to support health equity for LGBTQIA2S+ patients and families.

Introduction

Since 1977, the United States Office of Budget and Management has outlined federal standards for collecting and reporting patient sociodemographic data, specifically race, ethnicity and language (REL).[1] The original 1977 Statistical Policy Directive No.15 was updated in 1997,[2] and again in 2024 to better reflect a growing and broader range of racial / ethnic identities within the United States.[3] Unfortunately, the same directives and systems of accountability are not available for data domains related to sexual orientation and gender identity (SOGI). SOGI data domains include their namesake components: sexual orientation and gender identity; in addition to additional domains such as name to use, pronouns, sex parameters for clinical use, as well as organ and surgical inventories.

While the United States healthcare system continues to morph and adapt to a care delivery system disruptions from the COVID-19 pandemic and subsequent aftermath, health care systems and health insurance payors alike recognize the need for robust and accurate data collection to ensure that trends and differences in population health disparities can be identified, tracked, and addressed.[4,5] Without the data infrastructure to adequately capture and leverage SOGI data domains, health care organizations and entities may not be best equipped to meet the unique health care needs of LGBTQIA+ patients and families.[6] This article explores current guidance for health care organizations seeking to collect and use SOGI data domains, as well and implementation considerations for health care organizations who currently collect, or seek to collect, SOGI data domains.

Background of Collection of SOGI Data Domains

In 2011, the National Institutes of Health published a landmark, and first of its kind, report on health considerations and disparities of LGBT(QIA2S+) individuals within the United States.[7] While the 2011 report brought new attention to disparities across LGBTQIA2S+ communities, it also tasked professional and academic communities to expand research agendas to address the growing biopsychosocial health needs of LGBTQIA2S+ individuals and families. However, it was not until 2016 that Centers for Medicare and Medicaid Services and the Office of the National Coordinator for Health Information Technology required electronic health records (EHR) programs that are certified for Meaningful Use to include sexual orientation and gender identity data domains.[8] Health care organizations were now tasked with addressing LGBT(QIA2S+) health disparities, as well as making sure their data infrastructure could manage sexual orientation and gender identity data domains.[9]

It was not until 2019 that HL7 International worked to create consistent health care terminology and system mapping for data to aid in greater consistency in accuracy in the collection and use of clinical sexual orientation and gender identity data domains.[10] With recommendations from The Fenway Institute,[11] and other LGBTQIA2S+ organizations across multiple countries, the HL7 Gender Harmony Project offered health care organizations and health insurance entities a consistent ‘playbook’ to follow in standardizing naming and data use mechanisms related to SOGI data domains.[12] Whereas the Institutes of Health 2011’s report provided a roadmap for expanding LGBTQIA2S+ health equity, CMS’s Meaningful Use requirements and HL7’s infrastructure provided health care organizations with the ‘how’ to complement the IOH’s ‘why’ for SOGI data collection.

In practice, the complete and accurate collection of SOGI data is crucial for the delivery of patient-centered care, in addition to organizational ability to bill and pay for health care services. While it is recognized that SOGI data domains are important to health care delivery, health care entities may find the implementation of standardized language and data collection mechanisms to be less than linear.[13,14] Major health care organizations across the United States, such as University of California Davis Health System,[15] the Children’s Hospital of Colorado,[16] and others, have reported on their processes in expanding SOGI data collection at their respective institutions. However, implementation of SOGI data collection is often a personal process for organizations, requiring a great deal of institutional knowledge and agility in wrangling traditionally siloed departments into collaborative working groups.

Practical Considerations for Implementation of SOGI Data Collection

Given the complexity of health care systems and the many information technology applications they employ, our team recognizes that equity in data collection is a journey, and not a destination. This is to say: there are always opportunities to make data collection more equitable, and to not let ‘perfection’ get in the way of progress. With how many programs and downstream systems that health care organizations use across the patient care continuum, it is unlikely that a ‘perfect time’ will arise begin or expand SOGI data domains. We offer three practical considerations for health care organizations seeking to expand and enhance their collection of SOGI data domains.

Inter/Intra-System Operability

Expansion of telehealth services since the onset of the COVID-19 pandemic have ushered in a new era of digital health interventions. For LGBTQIA2S+ communities in particular, digital health and telehealth services offer expanded access to affirming healthcare providers for LGBTQIA2S+ patients and families who may otherwise not be able to access affirming services due to geographic or transportation barriers.[17] Unfortunately, there is a lack of standardization across digital health applications and vendors in how SOGI data is collected and used. For example, while a healthcare system's central electronic health system may be able to collect multiple dimensions of SOGI data, downstream applications may not. In practice, this may look like a patient's affirming name appearing within the electronic health record, but that information not relaying to a downstream remote patient monitoring system and a patient seeing their non-affirming / deadname displayed. Fragmentation in care experiences such as this may contribute to known avoidance in health care engagement across LGBTQIA2S+ patients and families.[18]

In practice, organizations seeking to create data collection plans that account for system inter/interoperability, may want to engage in on-going discussions with existing and future vendors regarding their data collection capabilities around SOGI data domains. With current applications or vendors, health care organizations may want to ask about existing SOGI data domains that are supported by the platform, as well as future considerations or timelines for the implementation or expansion of SOGI data domains. This may mean existing application package upgrades or working directly with the vendor (or other clients of the vendor) to identify and implement SOGI data domain solutions.

Patient Data Safety & Privacy

As with any other sensitive, identifiable information, SOGI data domains are first and foremost protected health information (PHI). Legislative and executive orders from the 47th US Presidential administration have shifted the SOGI data collection landscape, in comparison to the significant guidance provided by the Biden administration[19] for the collection of SOGI data domains. Nonetheless, health care organizations such as the National Committee for Quality Assurance (NCQA) outline robust data privacy protection procedures as part of their Health Equity accreditation programs.[20] Data safety and privacy protection around SOGI data domains not only includes the safe, respectful and accurate collection of SOGI data domains, but also how those data are stored and shared – patient-facing and health care provider-facing.

For health care systems, a close collaboration between system legal entities and information technology entities will be vital to building safety, sustainable SOGI data collection domains. Whereas system information technology entities will have a strong understanding of data collection systems and architectures, system legal entities will have a strong understanding of data protection and privacy laws and standards. For example, a health system's information technology entities may be able to guide a SOGI data collection working group as to the available data fields to accommodate SOGI data domains – such as how many fields are pre-built by the EHR software, and if custom-built data fields and response options may be available. In practice, it is the dialogue between legal and information technology entities that will help the organization strike the balance between patient-centered methods and robust legal and privacy protections.

Multi-Audience Communication Planning

There is well-documented evidence of the interpersonal challenges that may occur during collection of patient demographic data.[21] Whereas LGBTQIA+ patients may be hesitant to disclose their LGBTQIA2S+ identity within a healthcare setting, health care staff tasked with collecting SOGI data may feel uncomfortable or unprepared for collecting these data.[21,22] Subsequently, it is important to communicate to patients and healthcare team members the relevance of SOGI data to their respective care and scopes of practice. For health care staff, SOGI data may be displayed or used in a variety of clinical contexts, such as USPST preventative screening recommendations,[23] pharmacological and medication-based recommendations,[24] medical equipment settings,[25,26] and imaging procedures and precautions.[27] For patients, there may not yet be shared understanding of why SOGI data is collected, and how that information is used to inform the delivery of patient-centered care.[22]

For health care organizations, it is not simply a matter of if their EHR can collect, store, and query SOGI data domains. Organizations must also take into consideration how health care staff are trained to appropriately solicit and maintain the privacy of SOGI data domains. A robust, multimodal communication plan can equip healthcare providers, as well as patients and families with the context necessary to interact with SOGI data domains. The Fenway Institute's 2020 "Ready, Set, Go! Guidelines and Tips For Collecting Patient Data on Sexual Orientation and Gender Identity (SOGI)" guide provides patient-centered verbiage for collecting SOGI data from patients at multiple points of care (ex: face-to-face with healthcare providers versus through an asynchronous patient check-in software).[11] Focusing on specific guidance for healthcare providers around how we ask for SOGI data can help ensure patients feel heard and safe when sharing sensitive information. Standardized language can be integrated at various patient touchpoints, including registration forms, in-person contact and within the patient's EHR.

Targeting specific guidance for health care providers around soliciting SOGI data domains can ensure that patients feel safe when sharing this potentially sensitive information. Standardized guidance on language and its delivery can be included in various points, such as patient registration forms at check in, or face-to-face contact with the patient once in their clinical encounter. This includes using inclusive language and offering patient education on why this data is being collected along with training staff on how to respond appropriately to questions and concerns. Standardized methods can help an organization build trust with LGBTQIA2S+ patients and families, as well as reduce the risk of poor patient experiences.

Limitations & Future Considerations

Given the rapidly evolving landscape for LGBTQIA2S+ health equity within the United States within just the first few months of its tenure,[28] there is a great deal of uncertainty as to how the remainder of the 47th US Presidential administration may affect LGBTQIA2S+ health equity. However, this does not mean that hope and efforts around more robust and comprehensive data collection to support LGBTQIA2S+ health equity should cease, but rather that they may need to adapt.

While EHRs are used to collect and store patient information, many were not designed to collect, store, and use SOGI data domains. Organizations may need to update or adapt their systems to include expanded SOGI data domains. This may involve creating new data collection fields or modifying existing fields to collect SOGI data domains meaningfully. For some, this can be a lengthy and costly process, requiring considerable effort from information systems workforce. However, the long-term benefits include more accurate data collection, improved patient experience, and opportunities to identify and address health dipartites.

Conclusion

A wide array of health care organizations, health insurance entities, and community-based health organizations may find value in standardized collection of relevant SOGI data domains. However, determining which SOGI data domains may be organizationally necessary, and how to go about collecting those necessary data domains is often less than simple. For health care organizations with the desire to implement the collection of SOGI data domains, there are some resources and guidelines available to assist in implementation. Unfortunately, even with the assistance of the limited resources available to organizations, the standardized and systematic collection of SOGI data domains for identifying and addressing LGBTQIA2S+ health disparities is far from reality. Due to fragmentations across large health care systems and the information technology applications they use to support their operations, implementation of collection of SOGI data domains can be an onerous, but incredibly vital, undertaking. The authors provide three implementation recommendations for health care organizations seeking to begin or expand their journey in seeking SOGI data domains. As the United States health care system continues to change and adapt through turbulent socio and geopolitical times, the collection of SOGI data domains should remain a priority for those organizations seeking to support health equity for LGBTQIA2S+ communities.

Mr. Waad may be contacted at alex.waad@christianacare.org.

References

1. Office of Management and Budget. (1977). SPD 15: statistical policy directive No. 15—Race and ethnic standards for federal statistics and administrative reporting. Federal Registrar. https://www2.census.gov/about/ombraceethnicityitwg/1978-statistical-policy-handbook.pdf
2. Executive Office of the President. Office of Management and Budget (OMB), & Office of Information and Regulatory Affairs. (1997). 62 FR 58782: Revisions to the standards for the classification of federal data on race and ethnicity (62; Version 210). Federal Registrar. https://www.govinfo.gov/content/pkg/FR-1997-10-30/pdf/97-28653.pdf
3. Executive Office of the President & Office of Management and Budget. (2024). 89 FR 22182: Revisions to OMB's statistical policy directive No. 15: Standards for maintaining, collecting, and presenting federal data on race and ethnicity (2024–06469). https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and
4. Cahill, S., Grasso, C., Keuroghlian, A., Sciortino, C., & Mayer, K. (2020, September). Sexual and gender minority health in the COVID-19 pandemic: Why data collection and combatting discrimination matter now more than ever. *American Journal of Public Health*, *110*(9), 1360–1361. https://doi.org/10.2105/AJPH.2020.305829 PubMed

5. Cahill, S., & Makadon, H. (2014, March). Sexual orientation and gender identity data collection in clinical settings and in electronic health records: A key to ending LGBT health disparities. *LGBT Health*, *1*(1), 34–41. https://doi.org/10.1089/lgbt.2013.0001 PubMed
6. Deutsch, M. B., Green, J., Keatley, J., Mayer, G., Hastings, J., & Hall, A. M., & the World Professional Association for Transgender Health EMR Working Group. (2013, July-August). Electronic medical records and the transgender patient: Recommendations from the World Professional Association for Transgender Health EMR Working Group. *Journal of the American Medical Informatics Association : JAMIA*, *20*(4), 700–703. https://doi.org/10.1136/amiajnl-2012-001472 PubMed
7. Institute of Medicine. (2011). The health of lesbian, gay, bisexual, and transgender people: Building a foundation for better understanding. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding, 1–347. https://doi.org/10.17226/13128
8. Centers for Medicare & Medicaid Services (CMS) & Department of Health and Human Services. (2015). 80 FR 62762: Medicare and Medicaid programs; electronic health record incentive program-stage 3 and modifications to meaningful use in 2015 through 2017. Federal Registrar.
9. Cahill, S. R., Baker, K., Deutsch, M. B., Keatley, J., & Makadon, H. J. (2016, April). Inclusion of sexual orientation and gender identity in stage 3 meaningful use guidelines: A huge step forward for LGBT health. *LGBT Health*, *3*(2), 100–102. https://doi.org/10.1089/lgbt.2015.0136 PubMed
10. McClure, R. C., Macumber, C. L., Kronk, C., Grasso, C., Horn, R. J., Queen, R., . . . Davison, K. (2022, January 12). Gender harmony: Improved standards to support affirmative care of gender-marginalized people through inclusive gender and sex representation. *Journal of the American Medical Informatics Association : JAMIA*, *29*(2), 354–363. https://doi.org/10.1093/jamia/ocab196 PubMed
11. The Fenway Institute. (2020). 2020 update. National LGBT Health Education Center. https://www.lgbtqiahealtheducation.org/publication/ready-set-go-guidelines-tips-collecting-patient-data-sexual-orientation-gender-identity/
12. HL7 International. (2024). HL7 cross paradigm implementation guide: Gender harmony—sex and gender representation. https://www.hl7.org/implement/standards/product_brief.cfm?product_id=564
13. Kirkland, A. (2021, November). Dropdown rights: Categorizing transgender discrimination in healthcare technologies. *Social Science & Medicine*, *289*, 114348. https://doi.org/10.1016/j.socscimed.2021.114348 PubMed
14. McDowell, A., Myong, C., Tevis, D., & Fung, V. (2022, June). Sexual orientation and gender identity data reporting among U.S. health centers. *American Journal of Preventive Medicine*, *62*(6), e325–e332. https://doi.org/10.1016/j.amepre.2021.12.017 PubMed
15. Callahan, E. J., Sitkin, N., Ton, H., Eidson-Ton, W. S., Weckstein, J., & Latimore, D. (2015, February). Introducing sexual orientation and gender identity into the electronic health record: One academic health center's experience. *Academic Medicine*, *90*(2), 154–160. https://doi.org/10.1097/ACM.0000000000000467 PubMed

16. Staggs, S., Sewell, R., Buchanan, C., Claussen, L., Franklin, R., Levett, L., . . . Nokoff, N. J. (2022, October 7). Instituting sexual orientation and gender identity training and documentation to increase inclusivity at a pediatric health system. *Transgender Health*, *7*(5), 461–467. https://doi.org/10.1089/trgh.2021.0016 PubMed
17. Waad, A. (2019, June 27). Caring for our community: Telehealth interventions as a promising practice for addressing population health disparities of LGBTQ+ communities in health care settings. *Delaware Journal of Public Health*, *5*(3), 12–15. https://doi.org/10.32481/djph.2019.06.005 PubMed
18. Kuzma, E. K., Pardee, M., & Darling-Fisher, C. S. (2019, March). Lesbian, Gay, Bisexual, and Transgender health: Creating safe spaces and caring for patients with cultural humility. *Journal of the American Association of Nurse Practitioners*, *31*(3), 167–174. https://doi.org/10.1097/JXX.0000000000000131 PubMed
19. The White House & Office of Science and Technology Policy. (2023). Biden-Harris administration releases first-ever federal evidence agenda on LGBTQI+ equity (Fact Sheet). https://bidenwhitehouse.archives.gov/ostp/news-updates/2023/01/24/fact-sheet-biden-harris-administration-releases-first-ever-federal-evidence-agenda-on-lgbtqi-equity/
20. National Committee for Quality Assurance (NCQA). (2024). 2024 Health Equity and Health Equity Plus Standards and Guidelines. National Committee for Quality Assurance (NCQA). https://www.ncqa.org/
21. Mehta, S., Waad, A., Brooks, M., & Siegel, S. D. (2023, July 28). "I think there's only two fields for that": Hospital registrar attitudes and practices for collecting patient gender identity data. *Transgender Health*, *8*(4), 400–403. https://doi.org/10.1089/trgh.2021.0083 PubMed
22. Jolly, D., Boskey, E. R., Thomson, K. A., Tabaac, A. R., Burns, M. T. S., & Katz-Wise, S. L. (2021, December). Why are you asking? Sexual orientation and gender identity assessment in clinical care. *The Journal of Adolescent Health*, *69*(6), 891–893. https://doi.org/10.1016/j.jadohealth.2021.08.015 PubMed
23. Caughey, A. B., Krist, A. H., Wolff, T. A., Barry, M. J., Henderson, J. T., Owens, D. K., . . . Mangione, C. M. (2021, November 16). USPSTF approach to addressing sex and gender when making recommendations for clinical preventive services. *Journal of the American Medical Association*, *326*(19), 1953–1961. https://doi.org/10.1001/jama.2021.15731 PubMed
24. Webb, A. J., McManus, D., Rouse, G. E., Vonderheyde, R., & Topal, J. E. (2020, March 5). Implications for medication dosing for transgender patients: A review of the literature and recommendations for pharmacists. *American Journal of Health-System Pharmacy*, *77*(6), 427–433. https://doi.org/10.1093/ajhp/zxz355 PubMed
25. Foer, D., Rubins, D., Almazan, A., Wickner, P. G., Bates, D. W., & Hamnvik, O. R. (2021, March). Gender reference use in spirometry for transgender patients. *Annals of the American Thoracic Society*, *18*(3), 537–540. https://doi.org/10.1513/AnnalsATS.202002-103RL PubMed
26. Matoori, S., Donners, R., Garcia Nuñez, D., Nguyen-Duong, S., Riopel, C., Baumgartner, M., . . . Gutzeit, A. (2022, June). Transgender health and medicine - Are radiological

devices prepared? *European Journal of Radiology*, *151*, 110320. https://doi.org/10.1016/j.ejrad.2022.110320 PubMed

27. Iv Kyrazis, C. B., Stein, E. B., Carroll, E. F., Crissman, H. P., Kirkpatrick, D. L., Wasnik, A. P., . . . Maturen, K. E. (2023, February). Imaging care for transgender and gender diverse patients: Best practices and recommendations. *Radiographics*, *43*(2), e220124. https://doi.org/10.1148/rg.220124 PubMed
28. Cahill, S. R., & Makadon, H. J. (2017, June). If they don't count us, we don't count: Trump administration rolls back sexual orientation and gender identity data collection. *LGBT Health*, *4*(3), 171–173. https://doi.org/10.1089/lgbt.2017.0073 PubMed

---