



# Empowering Health Care Organizations to Improve Care for LGBTQ+ Populations:

HIPAA Protections for Responsible Sexual Orientation and Gender Identity Data Stewardship





## Overview

LGBTQ+ individuals, like all people, deserve comprehensive, accessible, high-quality health care delivered by practitioners and providers they can trust. Accurate and trustworthy data on patient/member sexual orientation and gender identity (SOGI)—along with other demographic data such as race, ethnicity and primary language—is the cornerstone of health care organizations' efforts to innovate and improve care delivery, identify and overcome barriers to equity, train service providers, evaluate the effectiveness of interventions and participate in research that improves both population health and individual patient outcomes. Health care organizations collecting and using any patient or member data, including SOGI data, may have questions or concerns about how to earn patient/member trust and act as responsible stewards of this information.

**This issue brief discusses long-standing protections for patient or member data provided by the Health Insurance Portability and Accountability Act (HIPAA) and a 2024 final rule from the U.S. Department of Health and Human Services (HHS) clarifying these health care and health insurance nondiscrimination protections.** Understanding these regulations helps organizations create strong internal policies and procedures for responsible data management and privacy protections. These regulations also empower health care organizations to meet the needs of LGBTQ+ people, and equitably deliver high-quality health care for all.

Pride Month, which the U.S. celebrated just a few weeks ago, celebrates the accomplishments, vibrancy and resilience of the LGBTQ+ community. It is also an opportunity for health care organizations to recommit to advancing health equity for LGBTQ+ populations. Routine, consistent collection of data on sexual orientation and gender identity (SOGI) is critical to improving delivery of appropriate health care to the LGBTQ+ community. Effectively achieving that objective requires that the health care industry challenge misconceptions that LGBTQ+ identities are too private for health care organizations to ask about, and that patients/members will be reluctant to provide the information.

It is important to note that *everyone* has a sexual orientation and a gender identity. While many people are most familiar with these concepts in the context of LGBTQ+ identities, these demographic variables are foundational elements of every person's identity. Collection of SOGI data does not solely focus on LGBTQ+ populations and patients. Rather, it seeks to understand the diversity of *all* people's experiences, and to ensure that *each person's* identity, anatomy and physiology, relationship status, and myriad other elements of personhood are fully seen and respected by service providers. It also seeks to identify where—and why—there are disparities in care, services and health outcomes between groups of patients/members who have different identities. Moreover, studies demonstrate that patients in general—both LGBTQ+ and non-LGBTQ+—are willing to provide SOGI information in health care settings when organizations are transparent about how the information will be used for their benefit.<sup>1</sup>

There is a broad movement in health care to standardize and normalize collection of patient/ member-level SOGI data as part of routine clinical care and quality improvement activities.<sup>4,5</sup> This information helps health care organizations address historic inequities, such as poorer health outcomes due to long-standing systemic, structural and institutional discrimination and stigma—and this is precisely why organizations have an obligation to collect and act on it.

### Having accurate, high-quality data on SOGI and other demographic variables enables health care organizations to:

- Evaluate the effectiveness of their programs, and pivot from ineffective approaches and elevate successful ones.
- Identify and invest in interventions that correspond to the unmet needs of all LGBTQ+ patients/members (e.g., preventive services for which they might be overlooked).
- Advance research and policies to address barriers to accessing high-quality health care (e.g., discrimination, minority stress, social drivers of health such as financial or housing insecurity).<sup>2,3</sup>

In line with the Centers for Medicare & Medicaid (CMS) National Quality Strategy, NCQA offers Health Equity Accreditation programs that require health care organizations to collect standardized SOGI data (along with race, ethnicity and language data) and to use these data to address health disparities. In 2023, CMS introduced SOGI questions on the application form used for HealthCare.gov enrollment; state Medicaid and Children’s Health Insurance Programs (CHIP) also have the option to include these questions at enrollment.<sup>6</sup>

Health care organizations navigating collection and use of SOGI data for the first time may have questions about how to be responsible stewards. Although there are valid concerns about data stewardship for many types of health care data, it is of increased importance for SOGI data, due to anti-LGBTQ+ policy initiatives in states nationwide. Recent years have seen a surge in state efforts to discriminate against LGBTQ+ populations, including adoption of bills that deprive transgender people of access to essential health care.<sup>7</sup> Some of these laws may be interpreted to empower law enforcement entities to investigate provision of health care to LGBTQ+ people, raising concerns among patients/members and health care organizations regarding the latter’s ability to act as responsible stewards of SOGI data and data about medical care sought by some transgender patients.

Federal laws already require health care organizations to be responsible data stewards, not only of SOGI data, but of all protected health information (PHI) and personally identifiable data. **HIPAA shields organizations from the obligation to comply with bad-faith legal or law enforcement demands for member/patient data, including data related to SOGI or provision of gender-affirming care**, and strictly limits the circumstances under which entities may disclose PHI. In April of this year, HHS issued the **Final Rule to Support Reproductive Health Care Privacy Under HIPAA**, which added heightened protections regarding the use or disclosure of PHI when it is sought to investigate or impose liability on individuals, health care providers or other entities who seek, obtain, provide or facilitate lawful reproductive health care.<sup>8</sup> The rubric for patient privacy outlined in this rule is similarly applicable to other types of PHI such as SOGI data and gender-affirming care. The new rule also obligates HIPAA-covered entities to modify notices of their privacy practices to reflect the clarification.

Additionally, in April 2024, HHS also **issued a final rule for Section 1557**, the primary nondiscrimination provision of the Affordable Care Act (ACA), which restored and strengthened protections for LGBTQ+ people that had been rolled back in 2020 under the Trump administration. Section 1557 prohibits health care providers, insurers, grantees and other entities that receive federal funds from discriminating based on race, color, national origin, age, disability or sex—and the final rule codified that protections for sex include LGBTQ+ patients/members. Misuse of SOGI data to perpetuate discrimination (e.g., limit services, impose liability on providers) is a violation of Section 1557 and, like HIPAA, is subject to enforcement by the HHS Office for Civil Rights. In July, multiple federal courts issued orders postponing implementation of the nondiscrimination protections included in Section 1557. Although these rulings mean HHS cannot enforce the new rule’s protections at this time, the statutory text of ACA Section 1557 protects LGBTQ+ people from discrimination in health care and health insurance coverage.

It is essential to train staff to react appropriately when they receive legal demands or disclosure requests from external authorities. HIPAA safeguards both patient data and the organizations that collect it, and a detailed review of any request for such data must be performed by legal counsel who can explain, for example, that HIPAA's provision *allowing* disclosure in response to law enforcement inquiries is not the same as *requiring* that disclosure. Organizations can also consider including, in their policies and procedures, a compliance review process for handling external requests for patient data. As responsible data stewards, organizations should carefully track legislation and other policy changes and must proactively address potential risks in their internal systems, staff training, and process documentation.

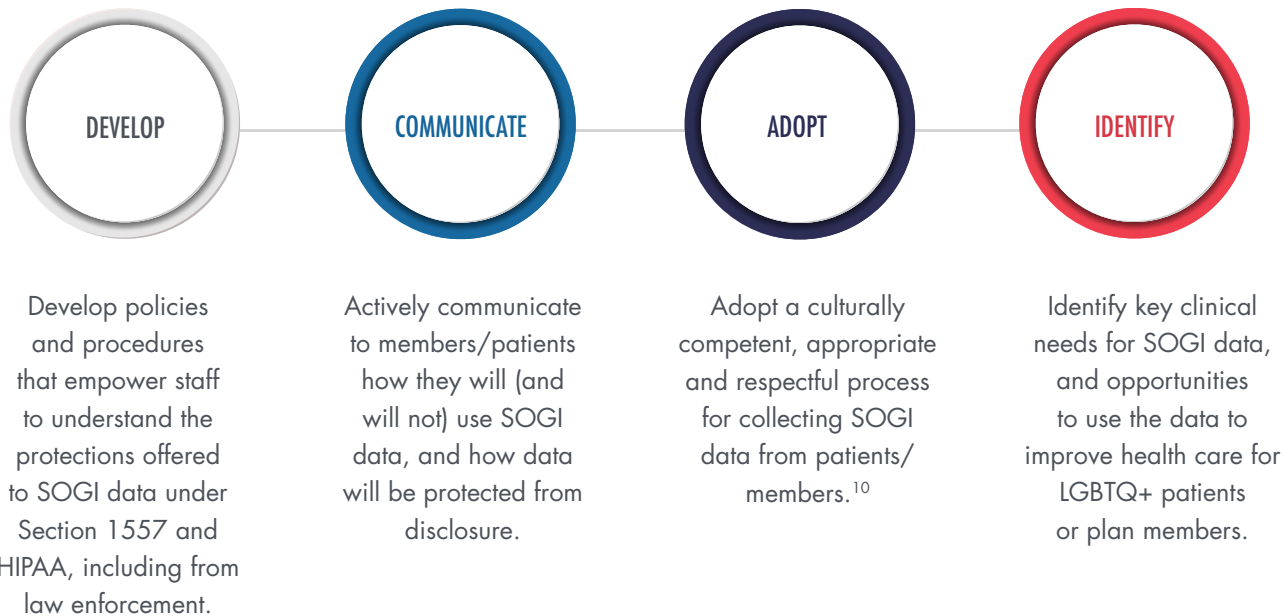
Beyond the protections afforded by HIPAA and Section 1557 of the ACA, health care organizations have other opportunities to mitigate risks associated with SOGI data stewardship; for example, they can develop robust, detailed protections for SOGI data in privacy policies and procedures. It is also critical to train staff on the actions they should take to mitigate disclosures in daily health care workflow and service delivery.

Health care organizations must also earn and build trust by communicating with patients/members about how their SOGI data will be used (and will not be used), and how that information will be protected from disclosure.

## How Health Care Organizations Can Act

There are many ways that health care organizations can better serve the LGBTQ+ community and ensure high-quality care: cultural competency training for practitioners and staff; intentional efforts to overcome institutional and individual bias; comprehensive and inclusive clinical guidelines; and increased access to key resources for behavioral health and health-related social needs.

### Organizations can also:



## Resources

Understanding and utilizing best practices for SOGI data collection and stewardship can be complex and challenging. The resources listed below detail the effects of the new rule and other relevant legislation, and can help organizations realize their responsibilities, options and potential issues.

- **National Academy of Sciences, Engineering and Medicine Paper:** [Measuring Sex, Gender Identity, and Sexual Orientation](#)<sup>10</sup>
- **Senate Finance Report:** [How State Attorneys General Target Transgender Youth and Adults by Weaponizing the Medicaid Program and their Health Oversight Authority](#)<sup>11</sup>
- **U.S. Department of Health and Human Services Office of Civil Rights:** [HHS Notice and Guidance on Gender Affirming Care, Civil Rights, and Patient Privacy](#)<sup>12</sup>
- **White House Workgroup Guidance:** [Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys](#)<sup>13</sup>
- **LGBTQ+ Education Center Resources:** [LGBTQ+ Education Center](#)<sup>14</sup>
- **Center for American Progress:** [Collecting Data About LGBTQI+ and Other Sexual and Gender-Diverse Communities](#)<sup>15</sup>
- **Center for Health Care Strategies Policy Cheat Sheet:** [New State Options for SOGI Data Collection](#)<sup>16</sup>
- **State Health & Value Strategies:** [Sexual Orientation and Gender Identity Data: New and Updated Information on Federal Guidance and Medicaid Data Collection Practices](#)<sup>17</sup>
- **Centers for Medicare & Medicaid Services:** [Resource of Health Equity-related Data Definitions, Standards & Stratification Practices](#)<sup>5</sup>



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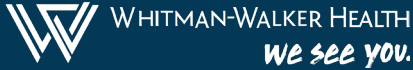
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