

# Helping Your Organization Collect Sexual Orientation and Gender Identity Data

For many healthcare facilities, the first step in beginning the process of implementing SOGI data collection protocols and practices is understanding the potential benefits and motivating factors behind systematically collecting SOGI data, and being able to convince key stakeholders that SOGI data collection is necessary and beneficial. This guide provides talking points and strategies for responding to common questions that may arise to help you make the case for implementing SOGI data collection in your healthcare organization.

## Question 1: Is there a compelling business case for collecting SOGI data?

Some may question whether there is enough of a business case or return on investment in order to undergo the process of implementing systematic SOGI data collection. Hospital administrators who have implemented SOGI data collection have noted that it can help improve patient satisfaction and increase the patient population, both of which contribute to better business and new opportunities for healthcare organizations.



### Improving patient satisfaction

In recent discussions that health researchers held with hospital administrators, several reported that SOGI data collection efforts began in response to complaints from LGBT patients. In some cases, patients even decided to leave and seek care elsewhere. Negative patient experiences have also in the past resulted in negative media attention and/or legal action. LGBT patients who feel that they are being discriminated against or not being treated in an affirmative and culturally competent manner are unlikely to be satisfied with their experience. Often, lack of knowledge from providers on how to provide competent, high-quality care to LGBT patients is perceived by patients as discrimination. Implementing SOGI data collection can improve patient satisfaction in a number of ways. First, adding inclusive SOGI data collection questions on registration forms can help LGBT patients feel more validated and affirmed. Second, implementing systematic SOGI data collection should be accompanied by cultural competency training for staff. Administrators have noted that after implementing SOGI data collection, there was better overall cultural competency among staff and fewer patient complaints, especially from transgender patients.

### Reaching more patients

One motivating factor for collecting SOGI data is to be seen as a leader in the field. There are a limited number of organizations in many service areas that are known for providing culturally competent and affirming care to LGBT patients. Some may say that they live in service areas with very few LGBT people, but according to the Gallup Poll, in many states 4% to 5% of the population identifies as LGBT. Among younger age groups, the percentage is even higher. There is an opportunity to fill this niche in the healthcare services delivery market and expand your patient population. Coupling SOGI data collection with training for staff and providers about how to be sensitive and knowledgeable when asking the questions creates a safer and more accepting healthcare environment for LGBT people.



## **Question 2:** Will patients be uncomfortable answering SOGI questions?

Another common argument you may encounter is that SOGI data are too sensitive and patients will not want to report it. Research has shown that SOGI questions are widely understood and accepted by diverse patient populations from across the country. Additionally, research has shown that providers often overestimate the number of patients who will be uncomfortable or offended by SOGI questions. For example, a survey of 1,516 patients and 429 providers found that while approximately 80% of providers thought that patients would refuse to answer SO questions, only 10% of patients said that they would refuse to answer. Lastly, other sensitive information, such as income, is already routinely asked of patients.

## **Question 3:** Since we already aim to provide all patients with the best quality of care regardless of sexual orientation or gender identity, why is collecting SOGI data important?

It is true that most, if not all, healthcare facilities aim to provide all patients with the best quality of care possible. However, because LGBT people are disproportionately burdened by various health disparities and often experience discrimination in healthcare, it is essential to collect SOGI data in order to provide the best quality of care to sexual and gender minority patients. Collecting SOGI data enables providers to deliver high quality and patient-centered care. It also allows healthcare facilities to assess any disparities that exist in access to services. SOGI data can help inform the provider of preventive screening needs, current anatomical inventory, suggested behavioral health interventions, correct name and pronouns, and other information important for providing high quality care to LGBT patients.

## Question 4: Is SOGI data medically relevant?

Some may argue that SOGI data are not medically relevant, and therefore do not need to be collected from all patients. However, there is a general consensus among researchers, healthcare organizations, professional associations, and federal and non-federal agencies that collecting SOGI data is a key strategy for reducing health disparities and improving health outcomes for sexual and gender minority populations. SOGI data may be used to track health outcomes of LGBT patients to inform the development of interventions to reduce health disparities. Collecting SOGI data can give healthcare providers the tools they need for delivering high-quality care to their LGBT patients. Furthermore, you may encounter arguments that sexual behavior data that are regularly collected in sexual histories are the data that are medically relevant. While these data are important for addressing many health disparities that affect sexual and gender minority populations, it is equally important to collect SOGI data. Much of the behavioral health burden affecting LGBT people, such as minority stress, depression, substance use, and suicidality, is related less to same-sex sexual behavior than it is to sexual orientation and gender identity itself and the accompanying social rejection, exclusion, and prejudice. As such, it is important and medically relevant to collect SOGI data in order to improve health outcomes for LGBT people.

## Question 5: Are there any professional organizations that recommend SOGI data collection?

**Yes, many professional health organizations and federal agencies have recommended the collection of SOGI data in clinical settings in order to reduce health disparities and improve quality of care. For example:**

- ◆ The [American Medical Association](#) supports inclusion of SOGI data collection in medical documentation and all related forms, including electronic health records.
- ◆ The [Institute of Medicine](#) and the [Joint Commission](#) recommend routine SOGI data collection in electronic health records.
- ◆ Hospitals & Health Networks, the journal of the American Hospital Association, has published [articles](#) encouraging the collection of SOGI data.
- ◆ The Medicaid Electronic Health Records (EHR) incentive program cites [rules](#) that require [Certified EHR Technology](#) to include data fields that allow providers to collect and enter the sexual orientation and gender identity of their patients.
- ◆ The Centers for Medicare & Medicaid Services 2015 [Equity Plan for Improving Quality in Medicare](#) encourages SOGI data collection.
- ◆ The [Health Resources and Services Administration](#), Bureau of Primary Healthcare requires health centers to report on the SOGI of their 20 million adult patients.





## **Question 6:** Where did these data come from?

Researchers from The Fenway Institute and NORC conducted key informant interviews with administrators at a variety of healthcare facilities across the US. The administrators were asked about their thoughts and experiences regarding SOGI data collection. If they were in the process of implementing SOGI data collection, they were asked about strategies, barriers, and facilitators to that process. Notes from the key informant interviews were coded and analyzed for recurring themes.

## **Conclusion**

There are many compelling motivating factors to make the case for SOGI data collection in your healthcare organization. Collecting SOGI data can present new business opportunities by improving patient satisfaction and expanding your patient population. SOGI data collection questions are also widely understood and accepted, and SOGI data collection is essential for improving health outcomes and reducing health disparities experienced by LGBT people.

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<sup>1</sup> Gallup Daily Tracking Survey. (2017 July). The Williams Institute. UCLA.

<sup>2</sup> Massachusetts Behavioral Risk Factor Surveillance System. (2016).

<sup>3</sup> Cahill S, Singal R, Grasso C et al. (2014, Sept. 8). "Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers." PLOS One. 9(9): e107104.

<sup>4</sup> Haider A, Schneider E, Kodadek L, et al. (2017 June). "Emergency Department Query for Patient-Centered Approaches to Sexual Orientation and Gender Identity: The EQUALITY Study." JAMA Intern. Med. 177(6): 819-828.

<sup>5</sup> Institute of Medicine Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities. (2011). The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Washington, DC: National Academies Press. Pages 5-16 and 5-17.

<sup>6</sup> Lambda Legal. (2010). When Healthcare Isn't Caring: Lambda Legal's Survey of Discrimination against LGBT People and People with HIV. New York: Lambda Legal.