



## Modernizing Programs to Collect Sexual Orientation and Gender Identity Data

### Overview

Through the support of the MAC AIDS Fund, the following issue brief provides governmental public health programs with information on current sexual orientation and gender identity (SOGI) data collection efforts occurring throughout the Federal and state governments. This brief will highlight opportunities to expand SOGI data collection and the importance of these data to implement meaningful programming for the lesbian, gay, bisexual, and transgender (LGBT) community. Please contact [Blake Rowley](#) or [Mike Weir](#) if you have questions.

### Modernizing Programs to Collect Sexual Orientation and Gender Identity Data

Over nine million individuals who identify as LGBT live in the United States.<sup>1</sup> LGBT individuals encompass all races, ethnicities, religions, ages, geographic locations, and social classes – identities and social factors that affect their health outcomes and needs. Stigma, discrimination, and misunderstanding at the individual, community, and institutional levels, coupled with a public health system that is often not equipped to serve LGBT individuals, pave the way for an increasing disease burden that is challenging to address. Data that better captures the needs and experiences of this population could help to address persistent health disparities; but unfortunately, the SOGI questions that are needed to identify LGBT individuals are rarely asked or included in data metrics and systems, making it difficult to access the health needs and barriers to care for LGBT individuals.

LGBT individuals face health disparities that can be exacerbated by the added stress of a minority sexual orientation and/or gender identity, internal and external homophobia, and limited family and peer support. Institutionalized homophobia within schools, workplaces, and healthcare settings results in high levels of violence toward LGBT individuals, as well as disproportionate rates of substance use, mental health concerns, suicidal ideation, school drop-out, sexual risk taking, certain cancers, HIV, and sexually transmitted infections (STIs). Additionally, compared to the general population, LGBT individuals have lower rates of health insurance coverage.<sup>2</sup> This coverage gap can lead to poorer health outcomes and worsen many of the disparities mentioned above.

Appropriate data collection has long been fundamental to ensure patients receive quality and culturally appropriate care. Effective SOGI data collection is needed to assess, track, and improve health disparities in LGBT populations. Both the [Institute of Medicine](#) and the [Joint Commission on Accreditation of Healthcare Organizations](#) support asking SOGI data in clinical settings and including such data in Electronic Health Records (EHRs). Providers who are knowledgeable about their patients' SOGI are better equipped to deliver appropriate, quality healthcare.

This brief will explore opportunities for more nuanced SOGI data collection through:

- Health systems data collection activities, including federal surveys, public and private insurance applications, Meaningful Use program, and Medicaid and Medicare
- Health department data collection activities, including infectious disease, prevention, care, and surveillance programs

### Health Systems Data Collection Activities

Given that LGBT individuals are less likely to have health insurance when compared to the non-LGBT community,<sup>2</sup> the Affordable Care Act (ACA) and other state and federal initiatives to expand access to insurance coverage are important opportunities to ensure that marginalized populations can access comprehensive and equitable healthcare. Emerging

SOGI data collection efforts through surveys, health records, and public and private insurance have the potential to reduce health disparities among vulnerable populations, including LGBT individuals.

### *Electronic Health Records and Meaningful Use*

EHRs play an integral role in collecting important patient demographic data that helps health care providers and programs serve key populations. The Centers for Medicare and Medicaid Services (CMS) Meaningful Use program, which went into effect in 2011, incentivizes providers and healthcare systems to modernize data collection efforts through EHRs.

As mentioned earlier, an abundance of evidence indicates that specific populations are disproportionately impacted by the HIV epidemic; primarily, Black gay men, other men who have sex with men (MSM), and Black transgender women.<sup>3,4</sup> Because of the Meaningful Use program, a growing number of providers and healthcare systems are beginning to recognize the utility SOGI data can provide in addressing these and other health inequities.

Better data collection through EHRs allows health departments, working with providers, to evaluate opportunities to implement interventions based on various demographic and geographic considerations. For example, information from EHRs allow health departments and providers to

efficiently attain timely data about key populations to design and implement care coordination models and interventions that are informed by the specified individuals and communities.<sup>5</sup>

In October 2015, CMS and the Office of the National Coordinator for Health Information Technology (ONC) released a [final rule](#) on SOGI data collection under Stage 3 of the Meaningful Use program. Specifically, the final requirements, which take effect in 2018, require all EHR systems and software certified under Stage 3 of Meaningful Use to allow users to record, modify, and access structured SOGI data. CMS and ONC [noted](#) that this rule will “help those within the patient’s care team to have more information on the patient that can aid in identifying interventions and treatments most helpful to the particular patient.”

The new requirements apply to developers and vendors who are building certified EHR systems and health institutions and practices that are using these systems as part of their participation in the Meaningful Use program. The ONC [notes](#) that the final requirements do not necessitate that providers collect SOGI information or data. Even though the rule does not require providers to collect SOGI data, this is a critical step in making SOGI data collection standard in clinical data and highlights the important role this data can play in providing quality care to patients.<sup>6</sup> While SOGI data collection is not required, a growing number of providers who utilize

#### **Important Terms:<sup>6</sup>**

**Sex:** Either of the two categories—male and female—into which people are commonly divided based on characteristics such as anatomy. “Sex” can also refer to sexual activity or intercourse.

**Assigned Sex at Birth:** At birth, infants are assigned a sex (male or female), usually based on the appearance of their external anatomy

**Gender:** Attitudes, feelings, behaviors, and expectations that a culture associates with either males or females.

**Gender Identity:** A person’s internal sense of being male, female, both, or another gender.

**Sexual Orientation:** How people identify their physical and emotional attraction to others. Common terms for sexual orientation include “gay/lesbian,” “bisexual,” “straight/heterosexual,” and “queer.” Some people use other terms to identify their sexual orientation.

EHRs are beginning to recognize the value of the information.

## Medicaid and Medicare

Medicaid and Medicare provide lifesaving health care to millions of Americans, including many LGBT individuals. But, like many other Federal programs, they have lagged in SOGI data collection, with neither Medicaid or Medicare requiring SOGI data collection.<sup>6</sup>

Specifically, Medicaid is a lifeline for many LGBT people living in the U.S. – a number that is growing with the implementation of the Medicaid expansion in many states. Because of Medicaid expansion, many LGBT individuals are now eligible for the program, and people living with HIV no longer must wait for their health to deteriorate to the point they receive a disability diagnosis before they can qualify. A recent study found that approximately 386,500 uninsured LGBT individuals could qualify for Medicaid in states that plan to expand Medicaid.<sup>7</sup> This is significant since Medicaid previously excluded healthy childless adults from enrolling.

**The following two-step question is recommended to ask about gender identity in a clinical setting:<sup>6</sup>**

### **Gender Identity**

What is your current gender identity?

- a. Male
- b. Female
- c. Female-to-male (FTM)/Transgender Male/Trans Man
- d. Male-to-Female (MTF)/Transgender Female/Trans Woman
- e. Genderqueer, neither exclusively male nor female
- f. Additional Gender Category/(or Other), please specify: \_\_\_\_\_
- g. Decline to answer

What sex were you assigned at birth on your original birth certificate? (Check one)

- a. Male
- b. Female
- c. Decline to answer

With the growing number of Medicaid LGBT enrollees, HHS must ensure that applications are streamlined and include SOGI questions and encourage Medicaid providers to collect SOGI data. These changes will provide improved data on LGBT Medicaid beneficiaries and the disparities they may be experiencing.

There are an estimated 1.5 million LGBT adults who are 65 and older, with the number expected to double by 2030.<sup>1</sup> Like Medicaid, Medicare is not equipped to collect SOGI data on its beneficiaries, preventing targeted activities to address the significant health disparities this population experiences.

In September 2015, the CMS Office of Minority Health released [The CMS Equity Plan for Improving Quality in Medicare](#). The CMS Equity Plan notes that, within the Medicare population, the LGBT population continues to “experience disparities that include disproportionately high burdens of disease, poorer quality of care, and barriers to accessing quality care.” To address these disparities, the CMS Equity Plan calls for stakeholders to collect more robust, standardized SOGI data. The collection of comprehensive SOGI data is “required to plan for quality improvements, and to address changes among the target population over time.”

These data will better equip Medicare providers and the Federal government to address the health disparities that occur among this growing LGBT population.

## Federal Surveys

Federally coordinated surveys provide crucial data about the U.S. population; however, until recently, most of these major surveys were missing opportunities to collect SOGI data.

As of August 2016, there are 11 federal surveys and one federal study that collect sexual orientation data, including identity, attraction, behavior, and gender identity; these surveys include: [National Health Interview Survey](#) (NHIS), [Behavioral Risk Factor Surveillance System](#) (BRFSS), and the [Youth Risk Behavior Surveillance System](#) (YRBS).<sup>8</sup>

To further SOGI data collection, [The LGBT Data Inclusion Act](#) was introduced during the 114<sup>th</sup> Congress. The proposed legislation would require that federal surveys include SOGI data collection “to strengthen the LGBT community's access to resources.” The legislation’s sponsors specifically [call](#) for the U.S. Census Bureau to collect SOGI data because of the significant role the data can play in “directly influenc[ing] policy” and the “allocation of federal funds.”

**The following question is recommended to ask about sexual orientation in a clinical setting:<sup>6</sup>**

**Sexual Orientation**

Do you think of yourself as:

- a. Lesbian, gay or homosexual
- b. Straight or heterosexual
- c. Bisexual
- d. Something else (please specify): \_\_\_\_\_
- e. Don't know

### *Health Insurance and Medicaid Applications*

The ACA, through federally subsidized health insurance Marketplaces, extends health insurance coverage to an estimated 1.12 million uninsured LGBT individuals with incomes between 100% and 400% of the federal poverty limit (FPL).<sup>7</sup> Currently, the federally facilitated and state-based Marketplaces are not required and do not ask SOGI questions on their Marketplace applications. This exclusion is a missed opportunity for health officials who are working to address health disparities among LGBT populations.

While SOGI data are not currently being collected on the Marketplaces, research activities are being conducted to address this gap. The [Center for Consumer Information and Insurance Oversight](#) (CCIIO) convened a working group to develop strategies for SOGI data collection on Marketplace applications. The convening group sought to offer guidance to “state Marketplaces seeking to add SOGI questions to their applications, provide clarity regarding the existing sex question on the federal Marketplace application, and explore the feasibility of adding SOGI questions to the federal Marketplace application.”<sup>8</sup>

As more Americans gain access to health insurance through federal and state health reform initiatives, these activities and more are required to gather the influx of data for newly insured LGBT individuals. With the addition of SOGI questions, state and federal insurance regulators will be better equipped to conduct outreach, ensure nondiscrimination requirements are met, and evaluate customer satisfaction. To a greater degree, regulators and policy makers will have data to understand and address health disparities that LGBT individuals experience -- disparities that affect health status, access to healthcare and insurance, and healthcare outcomes.

While efforts at the federal level to include SOGI data in health insurance applications will likely not continue under the new Administration, states are continuing to explore opportunities to collect this data through the insurance application process.

### *Health Department Collected Data*

Health Departments have a long history of collecting data through several systems. Prevention, surveillance, ADAP and Ryan White Part B, are all data sources that the Health Department uses to garner information on populations and make decisions. However, many of the systems do not uniformly collect the same information, particularly as it is related to SOGI data collection, as data collection and reporting requirements vary. Additionally, provider pushback may play a role in not asking key questions related to sexual orientations due to stigma from both the provider and the patient.

### *Prevention*

In prevention programs, health departments collect information on gender identity and risk behavior from clients receiving targeted HIV testing and/or behavioral interventions through a standardized form (created by the health department) that health department employees and funded agencies/testers are required to complete with all clients, regardless of testing result. The information collected has typically focused on behaviors and risk of transmission, rather than identities, but some programs are starting to expand the questions

asked on these forms to better capture populations. For instance, several health departments have begun to standardize the inclusion of questions aimed at transgender identity, generally, through the use of two questions: “What was your ‘gender at birth?’” and “How do you identify your ‘current gender?’” Since these data are collected at the health department level, health departments have some latitude on what questions they can include as they modernize prevention program data collection.

In addition to more nuanced questions about gender identity, some prevention programs have tried to better address sexual orientation by adding questions to elicit whether young men ages 13 to 19 years old are “sexually attracted to males” in addition to asking whether they have “ever had oral sex with a male.” These two questions were added to target behavioral prevention services to young gay and bisexual men who may not have engaged in anal sex. Given the sharp increase in new HIV infections in this population, it is critical that health departments include these questions. By identifying priority populations early on, health departments may plan and emphasize programs for education and risk/harm reduction.

### *[Ryan White Part B and ADAP](#)*

The [Ryan White HIV/AIDS Program](#) is administered through the [Health Resources and Services Administration HIV/AIDS Bureau](#) and is a federal program that provides services to low income individuals living with HIV/AIDS. State health departments – as the grantee for Ryan White Program Part B and AIDS Drug Assistance Programs (ADAPs) – play a unique role in SOGI data collection for individuals enrolled in ADAP or receiving Part B services.

Serving many patients already living with HIV, data collected through the Ryan White Program on sexual orientation and gender identity helps federal, state, and local governments to more robustly address the health inequities of LGBT individuals. Since 2000, the Ryan White Program has been monitoring data collected on transgender patients, and in 2014 revised the [Ryan White HIV/AIDS Program Services Report](#), requiring funded agencies

to collect new data, which includes clients’ sex assigned at birth. According to the [2016 ADAP Data Reporting Instruction Manual](#), as part of client demographic information collected in ADAP, gender and transgender status are required data reporting elements by using a variation of the aforementioned “two-step question.”

While these advances in the data collection and monitoring of transgender persons will ideally help shift the services landscape, robust SOGI data collection efforts have not been consistent and thus may not accurately reflect a patient’s sexual orientation or gender identity. The Ryan White Program collects data on mode of HIV transmission and therefore assumes sexual orientation. By imputing sexual orientation on clients, Ryan White Programs are not able to infer an accurate picture of the number of gay/bisexual persons in a jurisdiction and may miss opportunities for more comprehensive outreach and programming.

Unlike gender identity, data on sexual orientation, however, are not mandatory to collect or report. Specific orientation information may be collected via other surveys, e.g., BRFSS; however, generally, orientation is imputed on to clients based on transmission method. Currently, there is no uniform methodology to collect this information, however, some states include risk questions in their joint ADAP/Ryan White application, which are then included in CAREware for Ryan White Programs and ADAPs to use for reporting.

By standardizing data collection efforts in all Ryan White health care settings as well as ADAP applications to include questions on both sexual orientation and gender identity, grantees will be able to better facilitate relevant service provision for LGBT persons.<sup>9</sup> Although SOGI data collection may not be enough to enable comprehensive analysis, the initiation of these data collection efforts across SOGI is critical to establishing a baseline<sup>10</sup> and identifying future areas for program improvement and expansion.



## Surveillance

HIV surveillance data provide the foundation for understanding the burden of disease and is used to focus public health action at the federal, state, and local level.<sup>11</sup> These data are critical for ensuring that people are receiving the HIV care services that they need to be healthy and reduce transmission. Surveillance data also helps to inform health departments about persons who may not be receiving care and generate ways to help them reengage in care. The primary data collected in this system are demographic data (i.e., sex, race/ethnicity, age, and location of diagnosis), mode of exposure, viral load and CD4 count, and immune status.

On the Centers for Disease Control and Prevention (CDC) [adult confidential HIV Case report form](#), which health departments may use, but are not required to use, patients are asked a variation of the two-step question above, which asks about sex assigned at birth as well as current gender identity. Similar to other data sources discussed, data on sexual orientation is not explicitly collected. It is rather imputed and assumed based on transmission category. Considering the primary purpose of surveillance data collection is to monitor disease burden and implement appropriate public health actions (e.g., Data to Care), the collection of sexual orientation data specifically may not be as relevant. Nevertheless, this data could be useful for better understanding where subpopulations (e.g., transwomen, young gay men, etc.) are falling out of care.

## Conclusion and Action Steps

As data collection activities become more sophisticated, there are opportunities both within broader health systems and payers, and within public health programs to gather more nuanced demographic information in a consistent way across all systems. As states are beginning to modernize and streamline their data collection efforts, the inclusion of risk, sexual orientation, and gender identity will be critical for maximizing programs and targeting resources.

There are limitations in both surveillance and prevention data collection efforts. Historically, systems have focused their attention on the collection risk behaviors to inform public health programing; however, this may not accurately reflect patient identities, thus inadvertently establishing barriers to initiation, care, or retention in care services. Additionally, some providers and clients may not be comfortable discussing risk or sexual orientation.

As states seek to modernize their data collection efforts, they have looked to create SOGI data collection standards for consideration in public health programs, inclusive of a rationale for how these data will inform and address health disparities and contextualize population health needs. The creation of uniform guidelines across systems, that collect risk, gender identity, and accurate sexual orientation data, is imperative for strengthening programs and providing services.

## Recommendations

- State health departments should work with their networks to initiate and expand SOGI data collection, including working with contractors to ensure SOGI data collection occurs in all EHRs.
- All states and territories should adopt CDC-approved SOGI questions for surveys and questionnaires administered via the health department, including but not limited to: BRFSS/YRBS, DIS collected information, surveillance, etc.
- In an effort to contextualize and fully understand population dynamics and needs, SOGI data measures should be considered core demographic questions.
- Collaborate with Medicaid and Marketplace directors to initiate and expand SOGI data collection on their respective applications.
- Ensure staff are appropriately trained to facilitate SOGI data collection.

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