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Introduction

Thirteen million people identify as part of a sexual or gender minority (SGM)¹ in the United States,² and an estimated 1.17 million of those SGM adults (age 18-64 old) have Medicaid as their primary source of health insurance.³ Although there has been increasing recognition over the last decade that sexual orientation and gender identity (SOGI) are important determinants of health,⁴ the recent coronavirus (COVID-19) crisis has amplified the stark health disparities that many vulnerable populations face. Despite **gaps and inconsistencies** in state and federal reporting on COVID-19, data continues to show that **Black, Indigenous, and other people of color (BIPOC) have been disproportionately impacted by both higher risks of infection and poorer health outcomes**. However, health-related data about SGM populations is particularly scarce.

Although several states, such as California, Pennsylvania, Rhode Island, and the District of Columbia (D.C.) routinely collect SOGI data during COVID-19 testing,⁵ our review of states' reporting of COVID-19 data by demographic categories did not reveal any state that is **reporting case, death, hospitalization, testing, or vaccine administration data** by sexual orientation or gender identity. Lack of health data for SGM populations is not unique to the COVID-19 crisis. There remains a lack of data on the characteristics and well-being of these groups in general. For example, our recent analysis found that **all state Medicaid agencies collect self-reported demographic data including race, ethnicity, and language (REL) from applicants during the eligibility and enrollment process**. However, SOGI data is much less common. This persistent health-data gap is a major barrier for understanding and improving the health of SGM populations.⁶

i

Sexual Orientation and Gender Identity Terms

The following represent a limited set of SOGI terms that are relevant for this issue brief. The Human Rights Campaign has compiled a more comprehensive [Glossary of Terms which can be found here](#).

Sex: Biological characteristics that are used to categorize individuals as male, female, or intersex; labeled at birth (natal sex) based on external anatomy.

Gender: One's innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.

Sexual and Gender Minority (SGM): Populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, two-spirit, queer, and/or intersex. Individuals with same-sex or same-gender attractions or behaviors and those with a difference in sex development are also included.⁸

Transgender: A person whose gender identity differs from their sex assigned at birth. Being transgender does not imply any specific sexual orientation. Therefore, transgender people may identify as straight, gay, lesbian, bisexual, etc.

Cisgender: Someone whose gender identity matches the sex they were assigned at birth.

Non-binary: An adjective describing a person who does not identify exclusively as a man or a woman. Non-binary people may identify as being both a man and a woman, somewhere in between, or as falling completely outside these categories. While many also identify as transgender, not all gender non-conforming people do.

Sexual Orientation: The most commonly used terms to describe different sexual orientations are lesbian, gay, bisexual, heterosexual/straight. Sexual orientation has three dimensions:

- **Sexual identity:** The way a person self-identifies with a given sexual orientation.
- **Sexual attraction:** The sex or gender to which someone feels attraction (e.g., whether an individual is attracted to males/men, females/women, or both).
- **Sexual behavior:** The sex of a person's sexual partners (e.g., individuals of the same sex, different sex, or both sexes).

The objective of this brief is to document how information describing SGM populations is currently collected at the federal level and in Medicaid. We also spotlight Oregon’s recent efforts to improve the collection of SOGI data, and present several issues that states should consider as they look to improve their collection of SOGI data in Medicaid. The information presented here draws from the State Health Access Data Assistance Center’s (SHADAC) review of 50 states’ paper Medicaid applications and 33 states’ online Medicaid applications⁷ and federal research findings. While this issue brief outlines current data collection efforts and some limited research on how to collect this information, it does not make judgments on the best way to collect this data. SHADAC believes that more comprehensive and current research and guidance on this topic is needed. For example, the current ways SOGI data is collected in federal surveys does not always align with recommended best practices from advocates. Additionally, some of the research on this topic at the federal level, started under the Obama administration, is already out of date due to the fast-changing nature of social customs and evolving language around this topic. That said, we still encourage Medicaid agencies to explore SOGI data collection and highlight Oregon’s experience as an example for how to inform these efforts by engaging external stakeholders.

SOGI Data Collection at the Federal Level

Historically, few federal agencies have collected information describing SGM populations. While that has evolved over the years, some aspects of sexual orientation and gender identity have been more routinely measured than others. In 2008, Section 4302 of the Affordable Care Act (ACA) required the Secretary of the Department of Health and Human Services (HHS) to establish uniform data collection standards for race, ethnicity, sex, primary language, and disability status for use in all national population health surveys.⁹ The goal was to enhance the ability of the public health and healthcare systems to identify and track as well as reduce disparities. The current HHS data standard, released in 2011, defined the category of sex only as biological sex. Sexual orientation and gender identity were considered by HHS as separate concepts and were not addressed.

SOGI Data Collection in Federal Surveys

From 2011-2013, HHS followed a Data Progression Plan aimed at gathering information on how to best collect SOGI data and incorporated questions on those topics into federal surveys.¹⁰ HHS held roundtable meetings with researchers, experts, and interested stakeholders to discuss how to best collect and measure sexual orientation and gender identity. At the time, one participant noted that, “most of the research that was reviewed focused on sexual orientation, including how to appropriately ask the questions in Spanish.

Much less was known about how to ask about gender identity.”¹¹ After extensive cognitive and field tests,¹² the first question on sexual orientation was included in the 2013 National Health Interview Survey (NHIS). The NHIS does not ask adults about their gender identity, or whether they identify as transgender.¹³

HHS Data Standard for Sex

“What is your sex?”

- Male
- Female

National Health Interview Survey (NHIS) Sexual Orientation Question

“Which of the following best represents how you think of yourself?”

For men, the response options are:

- Gay
- Straight, that is, not gay
- Bisexual
- Something else
- I don’t know the answer

For women, the response options are:

- Lesbian or gay
- Straight, that is, not gay
- Bisexual
- Something else
- I don’t know the answer

In 2016, the Office of Management and Budget's (OMB) Federal Interagency Working Group (IWG) on Measuring Sexual Orientation and Gender Identity released three working papers to address the scarcity of data on sexual and gender minority populations:

- *Current Measures of Sexual Orientation and Gender Identity in Federal Surveys*
- *Evaluation of Sexual Orientation and Gender Identity Survey Measures: What Have We Learned?*
- *Toward a Research Agenda for Measuring Sexual Orientation and Gender Identity in Federal Surveys: Findings, Recommendations, and Next Steps*

These reports documented how 12 federal surveys were collecting data on sexual orientation, including identity, attraction, and behavior, and gender identity. (Figure 1)

Figure 1. Federal Surveys that Collect SOGI Information (2016)

Survey	Sexual Identity	Sexual Attraction	Sexual Behavior	Gender Identity
National Adult Tobacco Survey (NATS)	YES			YES
National Health and Nutrition Examination Survey (NHANES)	YES		YES	
National Health Interview Survey (NHIS)	YES			
National Inmate Survey (NIS)	YES		YES	YES
National Crime Victimization Survey (NCVS)	YES			YES
National Survey of Family Growth (NSFG)	YES	YES	YES	
Youth Risk Behavior Surveillance System (YRBSS)	YES		YES	
National Survey on Drug Use and Health (NSDUH)	YES	YES		
National Survey of Older Americans Act Participants (NSOAAP)	YES			
Behavior Risk Factor Surveillance System (BRFSS)	YES			YES
Population Assessment of Tobacco and Health (PATH)	YES	YES		YES
Health Center Patient Survey (HCPS)	YES			YES

Source: Centers for Disease Control and Prevention's (CDC) Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. (2019, August 15). *Improving Measurement of Sexual Orientation and Gender Identity in the Federal Statistical System* [Video]. YouTube. https://www.youtube.com/embed/WPeqKrAHGO4?cc_load_policy=1

The IWG's report found that sexual identity is asked in two main ways in federal surveys/studies:

Sexual Identity Questions in Federal Surveys: Two Dominant Questions

“Which of the following best represents how you think of yourself?” or “Do you think of yourself as...”

The most typical response options offered are:

- *Gay/Lesbian, Bisexual, Something else, I don't know*
- *Heterosexual or straight, Homosexual or Gay/Lesbian*
- *Other, please specify*

Six federal surveys currently feature gender identity questions. Most gender identity measures can be broken into two types: single-item and two-step measures. The one-question format asks about gender and provides a response option for transgender in the question stem as well as among response options, such as:¹⁴

Gender Identity in Federal Surveys: One-Part Question Examples

“Are you male, female, or transgender?”

- Male
- Female
- Transgender

“Some people describe themselves as transgender when they experience a different gender identity from their sex at birth. For example, a person born into a male body, but who feels female or lives as a woman would be transgender. Do you consider yourself to be transgender?”

- Yes
- No
- Don't Know

“Do you consider yourself to be male-to-female, female-to-male, or non-conforming?”

- Yes, Transgender, male to female
- Yes, Transgender, female to male
- Yes, Transgender, gender nonconforming
- No
- Not sure
- Don't know

The two-part gender identity question captures assigned sex at birth (i.e., natal sex) and current gender identity.

Gender Identity in Federal Surveys: Two-Part Question Examples

1. “What sex were you at birth?”

- Male
- Female

2. “What sex were you assigned at birth, on your original birth certificate?”

- Male
- Female

1. “Do you currently consider yourself to be:”

- Male
- Female

2. “Do you currently describe yourself as male, female, or transgender?”

- Male
- Female
- Transgender
- None of these

While some organizations support a two-step measure, the IWG’s research determined that more research is needed on the assessment of gender identity using a one- versus two-step measure. In addition, little is known about how question order in the two-step measure may affect response; for example, contrary to the order of most surveys, at least one peer-reviewed study has found that transgender participants preferred current gender identity be asked prior to natal sex.¹⁵

Other Health-Related Federal SOGI Data Collection Activities

In 2016, the Centers for Medicare & Medicaid Services (CMS) and the Office of the National Coordinator added a requirement that electronic health records (EHRs) certified under Stage 3 of the Meaningful Use program allow users to record data on sexual orientation and gender identity in the demographics certification criteria.¹⁶ Certification does not require providers to collect SOGI information from every patient, it only requires that certified electronic health record technologies (CEHRT) have the ability (i.e., the data fields) to record such information in a structured way.¹⁷

In 2016, the Health Resources and Services Administration (HRSA) began requiring SOGI data as part of standard demographics reporting through the Uniform Data System (UDS) Requirements for patients age 18 and older.¹⁸

CEHRT SOGI Standards

Sexual orientation must be coded as:

- *Lesbian, gay or homosexual*
- *Straight or heterosexual*
- *Bisexual*
- *Something else, please describe*
- *Don't know*
- *Choose not to disclose*

Gender identity must be coded as:

- *Male*
- *Female*
- *Female-to-Male (FTM)/Transgender Male/Trans Man*
- *Male-to-Female (MTF)/Transgender Female/Trans Woman*
- *Genderqueer, neither exclusively male nor female*
- *Additional gender category or other, please specify*
- *Choose not to disclose*

HRSA SOGI Data Collection

Providers are required to report the number of patients they see by sexual orientation

Response options are:

- *Lesbian or gay*
- *Straight*
- *Bisexual*
- *Something else*
- *Don't know*
- *Choose not to disclose*

Gender identity response options are:

- *Male*
- *Female*
- *Transgender Male/Female-to-Male*
- *Transgender Female/Male-to-Female*
- *Other*
- *Choose not to disclose*

SOGI Data Collection in Medicaid Applications

Based on our review of state Medicaid paper and online applications, nearly all states (48) asked applicants to indicate their sex/gender (these terms were used interchangeably to refer to biological sex) as either “male” or “female” on their paper and online applications. There was not always consistency between whether a state uses “sex” or “gender” on their online vs. paper applications. Only three states had a different variation of this question. Washington’s online application asks applicants to indicate their “sex assigned at birth” and provides “male” and “female” response options. Connecticut’s paper application has an open text write-in option for “gender.” Oregon asks applicants to indicate their “sex assigned at birth” and asks applicants to indicate their gender identity, (Figure 2).

Figure 2. Oregon’s Paper Application Sex and Gender Identity Question

★ 2. Birthdate: / / **For data matching purposes, what was your sex assigned at birth?:** Male Female

3. Gender identity: Male Female Trans Male (FTM) Trans Female (MTF) Not listed
 Gender Non-Binary/Two Spirit Decline to answer Other: _____

Spotlight on Oregon’s Efforts to Develop Statewide SOGI Data Standards

In 2018, the Oregon Health Authority (OHA) Office of Equity and Inclusion convened the Sexual Orientation and Gender Identity (SOGI) Data Collection Workgroup to develop a set of SOGI data standards. Oregon Department of Human Services (ODHS) joined in the work in 2019. The group consisted of stakeholders who interact with the Lesbian, Gay, Bisexual, Transgender, Queer, and other (LGBTQ+) community and health systems, many of whom also identify as LGBTQ+ themselves. The group was stratified into six subcommittees that each focused on a different level of implementation SOGI data collection in:

- Physical health in medical/clinical settings
- Clinical settings focusing primarily on behavioral health and HIV
- Eligibility, benefits, or other social services (e.g., administrative data systems such as Medicaid, SNAP)
- Clinical data received by public health and others used to identify and address disparities in health (e.g., public health surveillance such as birth certificates, cancer registries)
- General public health and community surveys (e.g., survey data that is usually anonymous and conducted to identify and address disparities in health)
- General demographics, not public health focused

The workgroup completed an inventory of existing SOGI data collection practices locally, examined SOGI standards used in certified electronic health record systems, and reviewed the research literature. From there, they developed a set of draft data collection standards. These questions included recommendations for required demographic questions (Figure 3), as well as additional questions that are not demographic but were identified as needed to ensure respectful communications for data-matching/verification issues that might occur in systems involving insurance and/or eligibility for services (Figure 4).

Figure 3. Required Demographic Questions

1. Please describe your gender in any way you prefer: _____

2. What is your gender? (check all that apply)

Woman/Girl Man/Boy Agender/No gender Questioning Don't know
 Not listed. Please specify: _____ I don't know what this question is asking†
 I don't want to answer

3. Are you transgender?

Yes No Don't know Not listed. Please specify: _____
 I don't know what this question is asking I don't want to answer

4. Please describe your sexual orientation or sexual identity in any way you want: _____

5. How do you describe your sexual orientation or sexual identity? (check all that apply)

Same-gender loving Same-sex loving Lesbian Gay Bisexual Pansexual
 Straight (attracted mainly to or only to other gender(s) or sex(s)) Asexual Queer
 Questioning Don't know Not listed. Please specify: _____
 I don't know what this question is asking I don't want to answer

† “Don’t know” means the person doesn’t know (such as a parent answering for a child); “I don’t know what this question is asking” more to capture comprehension difficulties with the question and/or response options.

Figure 4. DRAFT Required Logistical Questions When Applicable for Social Services/Eligibility Systems

Names

1. What full name do you want us to use? (Text field) _____
Is this your legal name? Yes No *If not, please list your legal name:* _____

This question format may be suitable for clinical/medical settings involving insurance and billing

1b. Are there any other names we should know about, such as on your insurance card?
 Check here if there are other names we should know about
Legal name: _____
Name on insurance card: _____
Name on billing record: _____
Name on relevant previous medical records: _____
Name on other relevant records (Please specify): _____

Pronouns and Titles

2. What pronouns do you want us to use? (select all that apply)
 They/Them She/Her He/Him No pronouns, use my name Don't know
 Not listed. Please specify: _____ I don't know what this question is asking
 I don't want to answer

Only ask the below question if the organization specifically uses titles (e.g., in correspondence)

3. What title do you want us to address you by?
 Mx. Ms. Miss Mrs. Mr. Please use my name and no titles Don't know
 Not listed. Please specify: _____ I don't want to answer

Sex- It is anticipated that if you need to ask about sex (not gender) you will probably just need to ask 1 or 2 of the questions below – depending on WHY you need this information.

4. When you were born what biological sex was assigned to you? (Pick one)
 Male Female Unspecified Don't know Not listed. Please specify: _____
 I don't know what this question is asking I don't want to answer

5. What is your current legal sex in your state? (Pick one) (OR simply: What is your current sex?)
 Male Female Intersex Non-binary Unspecified Don't know
 Not listed. Please specify: _____ I don't know what this question is asking

If you need to verify or match based on a state-issued ID[‡]:

6. Do you have a state-issued ID?
 No Yes. If yes, please specify state associated with ID: _____
 Don't know I don't know what this question is asking I don't want to answer

6b. If Yes, what is the sex on your state-issued ID?
 M – Male F – Female X U - Unspecified Not listed. Please specify: _____
 Don't know I don't know what this question is asking I don't want to answer

If you are using sex to verify identity with the SSA and/or cannot report a response other than M/F then:

7. For federal reporting purposes if we were only given a binary option of M (Male) or F (Female), which one would you like us to use? Female Male
OR:
We respect and honor your gender. We use federal data to verify your information, like what you use for social security or on your passport.² They only offer two options – male or female. Please select the sex that matches your current federal information. (ONE-IE)
 Female Male

[‡] Note that sex is not necessarily the same across different government reporting systems. Just because SSA says “this” does not mean that Selective Service agrees. This question should be tailored to match the verification system(s) used (if applicable).

The proposed standards were vetted through an in-person and online community engagement and feedback process, and over 400 people accessed a web-based survey which asked respondents to rate the necessity of each of the proposed questions and associated answers. Most questions and response options were favored by the majority of respondents, and those respondents who indicated that they would not want to ask these questions commented they felt that way because it would create more work for them, not because they thought the questions were not in the patient's best interest.

The stakeholder discussions aligned around a dual framework for considering questions. First, considering whether questions were demographic (i.e., standard questions asked of everyone) versus logistical (i.e., questions that could be used as demographics, but are primarily asked to ensure respectful communication and for operational reasons such as data-matching and identify verification). Second, considering whether questions were essential (questions required for reporting) versus best practice (i.e., the group decided that questions needed by clinicians in order to provide appropriate and affirming medical care should be considered as best practice, but not part of the recommendations). Another guiding principle was a focus on letting the “why” (i.e., why this information is needed) inform the recommendations. As the group works on refining their recommendations, they identified several issues that need further exploration:

- **Current gender identity questions do not address gender modality.** “Gender modality” refers to how a person’s gender identity stands in relation to their gender assigned at birth. It can include being transgender and being cisgender, but it also allows for additional terms. The workgroup found it is problematic to infer gender modality based on gender identity. For example, whereas trans and cis women have a different gender modality, they share the same gender identity: woman.¹⁹
- **Current SOGI standards in certified EHR systems are problematic.** Current standards (see box on page 6) conflate gender modality and gender identity, as well as use language now considered to be outdated, inaccurate, or offensive (e.g., Male-to-Female/Transgender Female/Trans Woman).
- **Changes to Medicaid eligibility systems require special considerations.** Changing one part of the state’s integrated eligibility data system can create problems in other parts unless addressed holistically. In addition to changing SOGI data fields, changes would also have to be made to the state’s display, communications, and correspondence fields in order to align the new SOGI data with an individual’s name. For example, eligibility workers need to be able to address the person by the name they want to use and be able to search by both this name and the person’s legal name if different. Therefore, the display of both names needs to be accessible to the worker. The final recommendation of the workgroup was to avoid piecemeal updates to eligibility systems in order to collect SOGI data, as it would have too many ripple effects.
- **Need for biological sex data in Medicaid applications is unclear.** The workgroup discussed the need to understand more about the value and rationale for collecting biological sex data in Medicaid. The current question fails to account for many variations of Medicaid members and creates a seemingly unsurmountable barrier for a portion of the population to even apply. Right now, a person with something other than Male or Female listed on their birth certificate could not submit a Medicaid application without committing perjury. One common rationale provided for collecting biological sex data is to assist in the verification of identity (i.e., verify identity with the Social Security Administration [SSA] or the Department of Motor Vehicles [DMV] or for data-matching purposes.) However, individuals are able to change their sex and name with the SSA and DMV, and not every Medicaid member has information on file with SSA, so this is not necessarily a fail-proof way to verify identity. Another rationale for collecting biological sex is to prevent medical fraud. However, a sex marker on file with SSA is not a good predictor of the care a person will need. For example, trans people may have changed their sex marker with SSA and have body parts that still need care. Alternatively, cis people may have variations in sexual development, or have had surgery to alter their body parts. The best way to prevent medically unnecessary care would be an organ inventory.

For these reasons, the utility of continuing to ask a question about natal sex becomes a very poor measure of the multidimensional and bimodal group of phenomena falling under the category “reproductive biology.”

Oregon continues to finalize its draft SOGI data standard recommendations. A bill requiring OHA and the Oregon Department of Human Services to expand their [existing race, ethnicity, language and disability data collection standards](#) to include SOGI was recently passed by the state legislature and goes into effect September 25, 2021. The state plans to convene a rule-making advisory committee in January/February of 2022 to finalize SOGI standards using the work group’s draft standards as a starting point.

Conclusions and Looking Ahead

There are still many unresolved methodological and conceptual issues when it comes to collection of SOGI information. Currently, there is insufficient research to identify best practices for SOGI measurement across populations, including individuals from different race, ethnicity, language, and geographic distributions. Absent any type of federal standard, as states seek to improve the collection of information on sexual orientation and gender identity in their Medicaid applications, they may need to modify SOGI questions depending on a variety of factors including their target population for the question and the purpose of the data being collected. Some of the issues states should consider when implementing or modifying SOGI data collection questions include:

Age: Many SOGI questions are developed for young and middle age adults and those may not work as well for children or teens, or older adults. Additionally, teenagers in the midst of evolving sexual orientation may be unsure of how to answer SOGI questions.

Cultural Background: Questions and terms differ by culture; for example, some American Indian/Native American individuals may identify themselves as “two-spirit” rather than “gay” or “bisexual.” Additionally, some cultural and linguistic groups may not identify with the term “transgender.”

Language: Translation of SOGI questions can be difficult as some languages do not have terms for SOGI or only have terms that are considered offensive. For example, the term “straight” has no translation in Spanish. Research indicates that SOGI questions in surveys such as the National Health Interview Survey (NHIS) do not perform as well with non-English speakers. Published evidence and pretesting in languages other than Spanish is limited.

Response Options: Use of typical nonresponse categories (Other/ Something else /Refused) may yield unusable data. Consider alternative wording such as “I don’t know what this question is asking”, “Not sure” or “Not listed. Please specify_____.”

Evolving Terminology: Terminology used to identify gender identity can evolve over time, particularly for young people. As new terms for various gender identity subpopulations emerge, it is possible that respondents are unfamiliar with or may not fully comprehend what is meant by these newly emerging terms. For example, a recent survey found that terms like “pansexual” and “asexual” are relatively common identities among young people (age 13-17) but not necessarily for older people.

As documented above, there is a wide variation in how this data is being collected at the federal level. Different advocacy groups recommend different question wording as well. For example, the National [LGBTQIA+ Health Education Center recommends](#) questions that align with the UDS reporting instructions for Federally Qualified Health Centers (Figure 5). However, the [Human Rights Campaign recommends](#) a separate question to address transgender status.

Figure 5.

LGBTQIA+ Health Education Center recommendations	Human Rights Campaign SOGI question recommendations
<p>Do you think of yourself as (Check one):</p> <ul style="list-style-type: none"><input type="checkbox"/> Straight or heterosexual<input type="checkbox"/> Lesbian, gay, or homosexual<input type="checkbox"/> Bisexual<input type="checkbox"/> Something else (e.g., queer, pansexual, asexual.) Please specify: _____<input type="checkbox"/> Don't know<input type="checkbox"/> Choose not to disclose <p>What is your current gender identity? (Check one):</p> <ul style="list-style-type: none"><input type="checkbox"/> Female<input type="checkbox"/> Male<input type="checkbox"/> Transgender Woman/Transgender Female<input type="checkbox"/> Transgender Man/Transgender Male<input type="checkbox"/> Other* (e.g., non-binary, genderqueer, gender-diverse or genderfluid) Please specify: _____<input type="checkbox"/> Choose not to disclose <p>What sex were you assigned at birth? (Check one):</p> <ul style="list-style-type: none"><input type="checkbox"/> Male<input type="checkbox"/> Female	<p>Which of the following best represents how you think of yourself?</p> <ul style="list-style-type: none"><input type="checkbox"/> Lesbian or gay<input type="checkbox"/> Straight (that is, not gay or bisexual)<input type="checkbox"/> Bisexual<input type="checkbox"/> Something else: _____<input type="checkbox"/> Not sure about my sexual orientation<input type="checkbox"/> Not sure what this question means <p>Which of the following best describes your gender?</p> <ul style="list-style-type: none"><input type="checkbox"/> Male<input type="checkbox"/> Female<input type="checkbox"/> Another gender: _____ <p>Do you consider yourself to be transgender?</p> <ul style="list-style-type: none"><input type="checkbox"/> No, I am not transgender<input type="checkbox"/> Yes, I am a transgender woman (assigned male at birth and identify myself as a woman)<input type="checkbox"/> Yes, I am a transgender man (assigned female at birth and identify myself as a man)<input type="checkbox"/> Yes, I identify as non-binary, genderqueer, or another term<input type="checkbox"/> Not sure whether I am transgender<input type="checkbox"/> Not sure what this question means

* You may replace the term “other” on patient-facing forms with the term that is most affirming for the communities you serve (e.g., “something else,” or “additional category.”)

There are signs of increased attention to research and guidance related to SOGI data collection at the federal level. In January 2021, President Biden issued an [Executive Order to advance equity for communities that have been historically underserved](#) through federal action, which included the establishment of an Equitable Data Working Group tasked with improving data collection “to measure and advance equity.” In March 2021, President Biden signed a separate [Executive Order establishing a White House Gender Policy Council](#). The Council has been directed to work with the Equitable Data Working Group in order to “propose improvement in the collection of data related to gender and gender identity.”

In May 2021, the [National Academies of Sciences, Engineering, and Medicine convened an ad hoc panel](#) to review current measures and methodological issues related to measuring sex, gender identity, and sexual orientation. The panel is expected to produce a report with recommendations on guiding principles for collecting SOGI data and recommended measures for different settings in December 2021. Specifically the panel is expected to address SOGI data collection in surveys and research studies, administrative settings (such as grant and job applications), and in clinical settings. Most recently, the [U.S. Census Bureau began collecting and reporting SOGI data](#) for the first time in its Household Pulse Survey, a survey focused [on collecting near real-time information about the numerous impacts of the COVID-19 pandemic on people’s lives](#).

There continues to be, however, very limited research assessing the validity of SOGI data specifically collected via the Medicaid application process. In the absence of updated federal guidance, some [states are pursuing legislative action to improve SOGI data collection](#), and ideally, those efforts will improve data collection in Medicaid. We encourage states to explore different options in this work to address current SOGI data collection gaps. Specifically, Oregon serves as an excellent model for how to undertake a thoughtful community stakeholder process that can inform efforts to establish new data collection on a topic that is fluid and rapidly changing, yet vitally important for the health of Medicaid populations.

ENDNOTES

1. This Expert Perspective refers to the population of interest as SGM rather than as lesbian, gay, bisexual, and transgender (LGBT). We are following the [Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity's](#) recommendation that SGM is more inclusive than LGBT because it allows for the inclusion of persons not specifically referenced by the acronym, such as genderqueer, two-spirit, etc. We acknowledge, however, that this broader term encompasses many individuals with many individual and unique experiences and identities. In using the term "SGM" or "SGM populations," it is not our intention to diminish any of these individual experiences, and we will continue to respond to evolutions in health equity terminology and update our writing practices and language.
2. Conron, K.J. & Goldberg, S.K. (April 2020). LGBT people in the US not protected by state non-discrimination statutes. UCLA School of Law, The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-ND-Protections-Update-Apr-2020.pdf>
3. Conron, K.J. & Goldberg, S.K. (January 2018). Over half a million LGBT adults face uncertainty about health insurance coverage due to HHS guidance on Medicaid requirements. UCLA School of Law, The Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Medicaid-Coverage-US-Jan-2018.pdf>
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This issue brief was authored by Emily Zylla and Elizabeth Lukanen. SHADAC is an independent, multi-disciplinary health policy research center, housed in the School of Public Health at the University of Minnesota, with a focus on state policy. SHADAC produces rigorous, policy-driven analyses and translates its complex research findings into actionable information for states. For more information visit: www.shadac.org.

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