

October 2023

Introduction

Over 13 million people identify as lesbian, gay, bisexual, or transgender in the United States—a significant and growing proportion of the U.S. population.¹ It is estimated that 1.2 million lesbian, gay, bisexual, and transgender adults (ages 18 through 64 years old) are covered by Medicaid and of those, approximately 152,000 (12.7%) identify as transgender.² A recent analysis from the Medicaid and CHIP Payment and Access Commission (MACPAC) found that between 2015 and 2019 there was a higher proportion of lesbian and gay Black, non-Hispanic adults (26.9%) enrolled in Medicaid than heterosexual Black, non-Hispanic (20.7%) adults.² Medicaid is undoubtedly an important source of coverage for populations who are lesbian, gay, bisexual, transgender, queer, intersex, or outside the gender binary (LGBTQI+).

The inequitable treatment and outcomes that LGBTQI+ populations experience in many areas of everyday life also occur in health and access to healthcare services.³ For example, lesbian, gay, and bisexual adults covered by Medicaid are significantly more likely than heterosexual adults to report having a mental illness and to have not received needed treatment for their mental illness in the past 12 months.² Although there has been increasing recognition over the last decade that sexual orientation and gender identity (SOGI) are important determinants of health, health-related data about LGBTQI+ populations remains particularly scarce.⁴ This persistent health-data gap is a major barrier for understanding and improving the health of these individuals.⁵

The objectives of this issue brief are: to document how information describing LGBTQI+ populations is currently collected at the federal level and in Medicaid; summarize recent consensus recommendations for how to ask questions that measure sex, gender, and sexual orientation; and to highlight recent federal action on this topic. We also spotlight Oregon's ongoing 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.

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Sexual Orientation and Gender Identity Terms

The following represent a limited set of **SOGI terms** that are relevant for this issue brief. Many of these terms are complex constructs that are interrelated, but conceptually distinct. The Human Rights Campaign has also compiled a more comprehensive [Glossary of Terms](#).

Sex: A multidimensional construct based on anatomical and physiological traits (sex traits) that include external genitalia, secondary sex characteristics, gonads, chromosomes, and hormones. Intersex refers to people whose sex traits do not all correspond to the same sex.

Gender: A multidimensional construct that links gender identity, which is a core element of a person's individual identity; gender expression, which is how a person communicates their gender to others; and social and cultural expectations about status, characteristics, and behavior that are associated with sex traits.

Transgender: A person whose current gender identity differs from their sex assigned at birth.

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

Non-binary: An umbrella term for gender identities that lie outside the gender binary.

Sexual Orientation: A multidimensional construct encompassing emotional, romantic, and sexual attraction, identity, and behavior.

SOGI Data Collection at the Federal Level

The United States does not have federal standards for data collection specifically for LGBTQI+ populations. Therefore, few federal agencies have collected information describing these populations. While that has evolved over the years, some aspects of sexual orientation and gender identity have been more routinely measured than others. In 2010, Section 4302 of the Affordable Care Act 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. The goal was to enhance the ability of the public health and healthcare systems to identify disparities and monitor efforts to reduce them. The current HHS data standard, released in 2011, defines the category of sex only as biological sex (Figure A).⁶ Sexual orientation and gender identity were considered by HHS as separate concepts and were not addressed.

Figure A.
HHS Data Standard for Sex

“What is your sex?”

- Male
- Female

SOGI Data Collection in Federal Surveys

In 2016, the Office of Management and Budget’s (OMB) Federal Interagency Working Group on Measuring Sexual Orientation and Gender Identity released a series of seminal working papers that addressed the scarcity of data on LGBTQI+ populations.⁷ At that time, they documented only 12 federal surveys that were collecting data on sexual orientation, including identity, attraction, behavior, and gender identity. There has been some advancement, however, in the collection of this data. In 2022, the National Academies of Sciences, Engineering, and Medicine (NASEM) examined the state of data collection on SOGI and intersex status in 47 data collection instruments, including federally supported surveys and other data systems.⁸ The NASEM panel identified a total of 24 federal surveys that collect SOGI data (Appendix A), including more than a half dozen that were not included in the 2016 federal interagency report. Even so, the NASEM report concluded that, “There are many publicly and privately sponsored data collections... in which SOGI data are not yet collected.” In September 2023, the Census Bureau took the first formal steps to add SOGI questions to the American Community Survey, requesting approval to test question wording, response categories, and question placement.⁹

Figure B.
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

Other Health-Related Federal SOGI Data Collection Activities

In 2016, the Centers for Medicare & Medicaid Services and the Office of the National Coordinator added a requirement that electronic health records 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.¹⁰ While certification does not require providers to collect SOGI information from every patient, it requires that certified electronic health record technologies (CEHRT) have the ability (i.e., the data fields) to record such information in a structured way (Figure B) and is seen as a critical step in standardizing and normalizing SOGI data collection.^{10,11} In July 2021, HHS included sexual orientation and gender identity for the first time in the U.S. Core Data for Interoperability (USCDI) standards. These standards (USCDI V2 and higher) mirror the CEHRT SOGI standards.¹²

In 2016, the Health Resources and Services Administration (HRSA) began requiring SOGI data as part of standard demographics reporting through the Uniform Data System Requirements for patients ages 18 and older (Figure C).¹³

Figure C. HRSA SOGI Data Collection

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

<p>Response options are:</p> <ul style="list-style-type: none"> • Lesbian or gay • Heterosexual (or Straight) • Bisexual • Something else • Don't know • Choose not to disclose 	<p>Gender identity response options are:</p> <ul style="list-style-type: none"> • Male • Female • Transgender Man/Transgender Male/Transgender Masculine • Transgender Woman/Transgender Female/Transgender Feminine • Other • Choose not to disclose
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SOGI Data Collection in Medicaid Applications

SHADAC reviewed paper Medicaid applications for all 50 states and Washington, D.C. and online Medicaid applications for 44 states in August 2023.¹⁴ Only one state (New Hampshire) did not ask a question about either sex or gender on their paper application. There was not always consistency between whether a state used “sex” or “gender” on their online versus paper applications. We did not identify any state collecting data on intersex status.

Paper Applications

Thirty-nine states asked applicants to indicate their sex (Oregon and Washington specify “sex assigned at birth”), while eight states asked applicants to indicate their gender on their paper applications. Four states did not specify whether they were asking for sex or gender (see California example - Figure D).

Figure D. California Paper Application



The overwhelming majority of states (41) provided only binary “male” and “female” response options to either their sex or gender question. In five states (Connecticut, Maryland, Montana, Nevada, and South Dakota), applicants must write-in their sex; no pre-populated response options are given. In three states (Arkansas, Georgia, and North Carolina), applicants are offered two pre-populated check box options – “male” and “female” – and a write-in option. Only three states provided more than “male” and “female” checkboxes as responses, including Maine which provided three response options (Figure E), New York which provided six response options (Figure F), and Oregon which provided eight response options (Figure G).

Figure E. Maine Paper Application

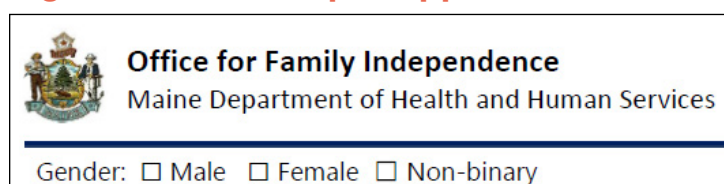


Figure F. New York Paper Application



 Department of Health	Date of Birth SEND PROOF	**Gender Identity (optional) <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Non-Binary/ Non-Conforming <input type="checkbox"/> X <input type="checkbox"/> Transgender <input type="checkbox"/> Different Identity <small>Describe your identity (optional).</small>	SEND PROOF Refer to the "Documents Needed When You Apply for Health Insurance" on pages 4-6, for a list of documents that prove Identity, Citizenship or Immigration Status. <small>*Sex: The sex you report here must be the same as what is currently on file with the Social Security Administration. The sex you report here is for our computer system's use only and will not appear on your benefit card or any other public-facing document. This is needed to process your application. If you identify differently you can add that information in the Gender Identity field provided.</small> <small>**Gender Identity: Gender identity is how you perceive yourself and what you call yourself. Your gender identity can be the same as or different from your sex assigned at birth.</small>
	*Sex --/--/--- <input type="checkbox"/> Male <input type="checkbox"/> Female		

Figure G. Oregon Paper Application

	★ 2. Birthdate: <input type="text"/> / <input type="text"/> / <input type="text"/>	For data matching purposes, what was your sex assigned at birth?: <input type="checkbox"/> Male <input type="checkbox"/> Female
	3. Gender identity: <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Trans Male (FTM) <input type="checkbox"/> Trans Female (MTF) <input type="checkbox"/> Not listed <input type="checkbox"/> Gender Non-Binary/Two Spirit <input type="checkbox"/> Decline to answer <input type="checkbox"/> Other: <input type="text"/>	

Online Applications

Compared to their paper applications, states were more likely to ask about an applicant's gender (26 states) than their sex (16 states) on their online applications. Similar to their paper applications, almost all states (42) only provided binary "male" and "female" response options on their online applications. Only California, South Carolina, and Tennessee provided additional response options. In addition to male/female responses, California provided "Transgender: Female to Male" and "Transgender: Male to Female" options (Figure H); and both South Carolina and Tennessee provided an "Unknown" response option. (Figure I).

Figure H. California Online Application


	What is Jane's sex?
	<input type="button" value="Female"/> <input type="button" value="Male"/> <input type="button" value="Transgender: Female to Male"/> <input type="button" value="Transgender: Male to Female"/>

Figure I. South Carolina Online Application

SOUTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES Healthy Connections MEDICAID
--Please Select-- --Please Select-- Female Male Unknown

No state provided an open-ended write-in response option online. Most states (39) required applicants to answer the sex/gender question and would not let an individual proceed to the next screen of the application without making a selection.

Current Evidence on Best SOGI Data Collection Approaches

Although there is no standard for the collection of SOGI data at the federal level, there has been some movement toward consensus on how to best ask these questions based on the most recent evidence available. In 2022, a panel of experts convened by the National Academies of Sciences, Engineering, and Medicine produced a consensus report with recommendations and guiding principles for collecting data on sex, gender identity, and sexual orientation.⁸

The report's key findings included the following recommendations:

- Data collection efforts should not conflate sex as a biological variable with gender or otherwise treat the respective concepts as interchangeable. In most situations, the collection of data on gender is more relevant than the collection of biological sex.
- The same measures of sex, gender identity, and sexual orientation should be used across all settings, including surveys, administrative, and clinical settings.
- With proper protections for privacy and confidentiality in place, SOGI data should be treated just like the collection of any other demographic data. Research shows that people are willing to share this information. Nonresponse rates on sexual orientation questions, for example, are lower than or comparable to other demographic or outcome variables, such as race and family income.

The NASEM consensus report recommended several specific wording constructs to collect information on sex, gender, and sexual orientation in different settings, such as surveys, clinical settings, and administrative forms (Figures J and K). The consensus report also recommended that entities seeking to identify people with intersex traits should do so by using a stand-alone measure that asks respondents to report their intersex status (not by adding intersex as a third response category to a binary measure of sex).

Figure J. NASEM Recommended Measure: Two-Part Question to Assess Sex Assigned at Birth and Gender Identity

Q1: What sex were you at birth, on your original birth certificate?

<input type="checkbox"/> Female	<input type="checkbox"/> (Don't know)
<input type="checkbox"/> Male	<input type="checkbox"/> (Prefer not to answer)

Q2: What is your current gender? [Mark only one]

<input type="checkbox"/> Female	<input type="checkbox"/> I use a different term: [free-text]
<input type="checkbox"/> Male	<input type="checkbox"/> (Don't know)
<input type="checkbox"/> Transgender	<input type="checkbox"/> (Prefer not to answer)
<input type="checkbox"/> [If respondent is AIAN:] Two-Spirit*	

Figure K. NASEM Recommended Measure: Assessing Sexual Orientation Identity

Q: Which of the following best represents how you think of yourself? [Select ONE]:

<input type="checkbox"/> Lesbian or gay	<input type="checkbox"/> I use a different term [free-text]
<input type="checkbox"/> Straight, that is, not gay or lesbian	<input type="checkbox"/> (Don't know)
<input type="checkbox"/> Bisexual	<input type="checkbox"/> (Prefer not to answer)
<input type="checkbox"/> [If respondent is AIAN:] Two-Spirit*	

*The consensus report notes that the response "two-spirit" is a term that is culturally specific to American Indian and Alaskan Native (AIAN) populations. They recommend only including "two-spirit" as a response option in automated data collection systems where racial identity is collected and respondent endorses AIAN identity first.

The consensus report cautions that there are important limitations to keep in mind with regard to these recommendations. For example, while these wording constructs are based on the best research available to-date, many of these questions have not been tested in different age groups – more research is needed, for example with youth or in different cultures or languages outside of English and Spanish.

Federal Efforts to Improve SOGI Data Collection

Executive Order

In June 2022, President Biden signed Executive Order 14075: *Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals*.¹⁵ This executive order was aimed at combating “unlawful discrimination and eliminating disparities that harm LGBTQI+ individuals and their families.” One section of the executive order focused on promoting inclusive and responsible federal data collection to help identify, understand, and address disparities experienced by LGBTQI+ people. Specifically, it required federal agencies to (discussed in more detail below):

- Identify opportunities for improved SOGI data collection.
- Identify practices to safeguard privacy and security.
- Submit SOGI Data Action Plans.
- Report best practices for the collection of SOGI data on federal statistical surveys.
- Annually evaluate the efficacy of SOGI data practices across agencies.

Best Practices for Collection of SOGI Data on Federal Surveys

In January 2023, the federal government released two new reports at the direction of the executive order. The first report was released by the OMB and the Chief Statistician, entitled *Recommendations on the Best Practices for Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys* (best practices report).¹⁶ This report provides examples and offers considerations regarding how to balance collecting SOGI data with the privacy and safety concerns of respondents. It does not mandate any particular approach or create any new requirements for agencies. Although this report does not address the collection of data in administrative forms, it does recommend consistency between data sources, while noting that more research is needed on how to collect and protect data collected as part of administrative transactions. The report notes that there is no single, best-practice set of questions for collecting information about a person’s sexual orientation or gender identity, but it does offer recommended question-wording to assess sexual orientation and gender identity using a format that is similar, although not identical to, the NASEM consensus report’s recommendation (Figures L and M).

Figure L. Best Practices Report Recommended Gender Identity Module

Q1. What sex were you assigned at birth, on your original birth certificate?

Female
 Male

Q2. How do you currently describe yourself (mark all that apply)?

Female
 Male
 Transgender
 I use a different term [free-text]

Q3. Just to confirm, you were assigned {FILL} at birth and now you describe yourself as {FILL}. Is that correct?

Yes
 No <skip back to Q1 and/or Q2>

Figure M. Best Practices Report Recommended Sexual Orientation Module

Q1. Which of the following best represents how you think of yourself?

- Gay or lesbian
- Straight, that is not gay or lesbian
- Bisexual
- I use a different term [free-text]
- I don't know

The best practices report also provides an example for a less-detailed approach to collecting gender identity and sexual orientation status, which they recommend using for situations with smaller sample sizes, or where privacy and confidentiality are of heightened concern, such as internal staff surveys. This approach adds a third response option to traditional binary measures and collects only basic information about an individual's current gender identity. Surveys that currently collect gender using only binary response options (i.e., "male" and "female") can use this approach to update to a more inclusive question (Figure N). A single question about LGBT status such as the example provided in Figure O below can provide the necessary information by asking about aspects of sexual orientation and gender identity at the same time. But the report only recommends using this type of question as a screener question or as a tool for basic equity analysis.

Figure N. Best Practices Report Less Detailed Example Gender Question

**Q1. Are you:
Mark all that apply.**

- Female
- Male
- Transgender, non-binary, or another gender

Figure O. Best Practices Report Less Detailed Example LGBT Status Question

Q1. Which of the following do you consider yourself to be? You can select as many as apply.

- Straight or heterosexual
- Gay
- Lesbian
- Bisexual
- Transgender

Best Practices for Reporting SOGI Data

The best practices report also summarizes recommendations for agencies when reporting SOGI information, including pooling data from multiple time points; aggregating detailed groups where needed; and providing measures of uncertainty. Depending on sample size, the report recommends reporting out five categories for sexual orientation:

1. Gay or lesbian
2. Straight
3. Bisexual
4. A different term
5. Don't know

When using a two-step approach to measuring gender, the report recommends reporting out four categories for gender:

1. Cisgender Male: determined by Q1 “male” AND Q2 “male” OR “I use another term,” accompanied by a write-in response that codes as male.
2. Cisgender Female: determined by Q1 “female” AND Q2 “female” OR “I use another term,” accompanied by a write-in response that codes as female.
3. Gender minority: any of these combinations
 - a. Q1 female and Q2 male
 - b. Q1 male and Q2 female
 - c. Q2 transgender
 - d. Q2 “I use another term”, accompanied by a write-in response that codes the response as gender minority
4. Another gender identity: determined by Q2 “I use another term,” unless accompanied by a write-in response that codes the response into a different category.

Federal Evidence Agenda on LGBTQI+ Equity

At the same time that the report on SOGI data collection best practices was released, the subcommittee on Sexual Orientation Gender Identity and Variations in Sex Characteristics Data released its report, *Federal Evidence Agenda on LGBTQI+ Equity*.¹⁷ This report is the first time the federal government has formally summarized disparities faced by LGBTQI+ individuals and articulated how the federal government could take action. Unlike the best practices report, it includes recommendations for both federal surveys and administrative forms. Specifically, the report outlines five overarching guidelines for collecting SOGI data on administrative forms aimed at improving the collection of information while minimizing harm (Figure P).

Figure P. Guidelines for Collecting SOGI Data on Forms and in Other Administrative Contexts

1. Ensure relevant data are collected and privacy protections are properly applied.

- Like other demographic data, protect SOGI data across the data lifecycle in accordance with applicable laws, regulations, and policies. Consider where existing policies and practices are insufficient to protect LGBTQI+ people.

2. Prevent adverse adjudication.

- Absent an explicit statutory or regulatory requirement, SOGI data should not be used to inform the adjudication of decisions regarding services, benefits, or employment.

3. Make responses voluntary.

- Ensure that a respondent can make an informed decision about whether to provide this information and allow them to choose to provide a non-response.

4. Rely on self-attestation.

- No documentation should be required to provide proof of SOGI information.

5. Be consistent and intentional.

- Be open to evolving construction of SOGI questions and available response options, but be mindful of the interoperability of resulting data sets and work to facilitate effective aggregation of responses to support analyses.

SOGI Data Action Plans

Still in progress is a final requirement of the executive order which mandates federal agencies develop and implement SOGI Data Action Plans.¹⁵ Plans should “detail how the agency plans to use SOGI data to advance equity for LGBTQI+ individuals as well as the specific ways that the agency will implement the recommendations from the Federal Evidence Agenda on LGBTQI+ Equity.” These plans are not required to be published publicly. To-date only the Department of Housing and Urban Development has released one.¹⁸ Once submitted, agencies are supposed to include in their annual budget submissions any necessary funding requests to support better SOGI data inclusion.

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

In 2021, the Oregon Legislature passed House Bill 3159, which requires all coordinated care organizations [CCOs (Oregon’s Medicaid accountable care organizations)], healthcare providers, and health insurers to collect data on race, ethnicity, preferred spoken and written languages, disability status (REALD), and sexual orientation and gender identity for patients, clients, and members at least once a year.¹⁹ It also requires the Oregon Health Authority (OHA) to expand their existing REALD collection data standards to include sexual orientation and gender identity.²⁰ This legislation builds on reporting requirements put in place during the COVID-19 pandemic and was the result of efforts that began in 2018 when the OHA Office of Equity and Inclusion convened the SOGI Data Collection Workgroup to develop recommended SOGI data standards. SHADAC’s 2021 issue brief on the collection of SOGI data detailed the research and community engagement process OHA and this workgroup undertook to inform those recommendations.²¹ In September 2022, the workgroup released its draft recommended minimum standards for SOGI demographic questions (Figures Q, R and S).²²

Figure Q. Oregon’s Gender Identity Question

Q1. Please describe your gender in any way you prefer: _____

Q2. What is your gender? (check all that apply)

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

Figure R. Oregon’s Modality Question

Q1. Are you transgender?

- Yes
- No
- Questioning
- Don’t know
- I don’t know what this question is asking
- I don’t want to answer

Figure S. Oregon’s Sexual Orientation Question

Q1. Please describe your sexual orientation or sexual identity in any way you want: _____

Q2. How do you describe your sexual orientation or sexual identity? (check all that apply)

<ul style="list-style-type: none"><input type="checkbox"/> Same-gender loving<input type="checkbox"/> Same-sex loving<input type="checkbox"/> Lesbian <input type="checkbox"/> Gay <input type="checkbox"/> Bisexual<input type="checkbox"/> Straight (attracted mainly to or only to other gender(s) or sex(s))<input type="checkbox"/> Pansexual <input type="checkbox"/> Queer	<ul style="list-style-type: none"><input type="checkbox"/> Questioning<input type="checkbox"/> Don’t know<input type="checkbox"/> Not listed. Please specify: _____<input type="checkbox"/> I don’t know what this question is asking<input type="checkbox"/> I don’t want to answer
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In November 2023, OHA will convene a Rules Advisory Committee to advise on the rule changes needed to incorporate SOGI data collection standards. During this process the draft standards detailed above will undergo in-depth review. In addition to the SOGI standards, House Bill 3159 also requires that OHA establish a data system (i.e., a registry) for collecting, storing, and reporting REALD and SOGI data. The legislation specifies that REALD and SOGI data collected in the registry must be considered confidential and can only be released publicly in the aggregate. It also stipulates that the registry must allow:

- All users to submit data at least annually (every 365 days).
- Patients/members/clients to directly submit data (e.g., rely on self-attestation).
- Providers, insurers, and CCOs to electronically submit data and query the registry to determine if data is current.

Planning for the REALD and SOGI data collection system, including design of the eventual data registry (front end) and repository (back end), is expected to occur through 2024. During this time Oregon has continued its community-engaged approach to educate anyone who is interested in learning more about SOGI data collection, analysis, and reporting. OHA has hosted monthly “SOGI Community of Practice” sessions focused on building internal capacity for using and analyzing SOGI data. OHA has also hosted two Data Analytic Institutes.²³ In April and July 2023, nearly 90 analysts attended a three-day institute to orient to the repository and learn how to work with the data given differing contexts. An institute specific to data needs of CCOs is planned for fall 2023. The building and piloting of the House Bill 3159 registry (front end) and repository (back end) is expected to be completed by 2026.

Conclusions and Looking Ahead

Despite OMB’s recent proposed updates to the federal standard for collecting race and ethnicity data, the federal government is not expected to make any official changes to the sex data standard in order to address the concepts of sexual orientation or gender identity in the near future.²⁴ Stopping short of revised federal data collection standards, the current administration has released the best practices report, Federal Evidence Agenda, and will require the submission of SOGI Data Action plans. In June 2023, several senators, led by Senator Tammy Baldwin (D-WI), introduced S. 1839 – *LGBTQI+ Data Inclusion Act*, a bill that would require the collection of voluntary, self-disclosed information on sexual orientation, gender identity, and variations in sex characteristics in certain surveys, including the decennial census.²⁵ However, the political viability of the legislation is uncertain.

There are still many unresolved methodological and conceptual issues related to collection of SOGI information. 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. While the NASEM consensus report and the best practices report are excellent starting points, there are additional issues states should consider when implementing or modifying SOGI data collection questions, including:

- **Age:** Many SOGI questions are developed for young and middle-aged 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 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,” “I use a different term,” 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 (ages 13 through 17) but not necessarily for older people.
- **Data Privacy:** While disclosure risks and historic sensitivity around this topic should not be used as a reason not to collect these data (and evidence shows people are willing to answer these questions at similar rates to other demographic questions), steps should be taken to maximize privacy and limit reidentification. States should work within their own data privacy and disclosure laws and might also consider a risk assessment specific to the LGBTQI+ population before reporting this information.

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, several states such as Colorado, Illinois, and New Mexico, have pursued legislative action to improve SOGI data collection, and ideally, those efforts will improve data collection in Medicaid.²⁶⁻²⁸ We encourage states to explore different options in this work to address current SOGI data collection gaps. Specifically, Oregon continues to serve 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.

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ABOUT THE ROBERT WOOD JOHNSON FOUNDATION

The Robert Wood Johnson Foundation (RWJF) is committed to improving health and health equity in the United States. In partnership with others, we are working to develop a Culture of Health rooted in equity that provides every individual with a fair and just opportunity to thrive, no matter who they are, where they live, or how much money they have.

Health is more than an absence of disease. It is a state of physical, mental, and emotional wellbeing. It reflects what takes place in our communities, where we live and work, where our children learn and play, and where we gather to worship. That is why RWJF focuses on identifying, illuminating, and addressing the barriers to health caused by structural racism and other forms of discrimination, including sexism, ableism, and prejudice based on sexual orientation.

We lean on evidence to advance health equity. We cultivate leaders who work individually and collectively across sectors to address health equity. We promote policies, practices, and systems-change to dismantle the structural barriers to wellbeing created by racism. And we work to amplify voices to shift national conversations and attitudes about health and health equity.

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ABOUT SHADAC

This issue brief was prepared by Emily Zylla and Elizabeth Lukanen. The State Health Access Data Assistance Center (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.

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Appendix A.

Federal Surveys that Collect SOGI Information (2020)

Survey	Sponsor	Sexual Orientation	Gender Identity	Population
All of Us	NIH	X	X	All ages
American National Election Studies (ANES)	NSF	X	X	Adults (eligible voters)
Behavioral Risk Factor Surveillance System (BFRSS)	CDC	X	X	Adults
General Social Survey (GSS)	NSF	X	X	Adults
Growing Up Today Study (GUTS)	NIH	X		Young Adults (20s)
Health Center Patient Survey (HCPS)	HRSA ASPE	X		All ages
Health and Retirement Study (HRS)	NIH, SSA, DOL, ASPE, State of Florida	X		Older adults
High School Longitudinal Study of 2009 (HLS:09) – 2016 Collection 3 Years After High School Graduation	NCES	X	X	Young adults (early 20s)
National Adult Tobacco Survey (NATS)	NCHS	X	X	Adults
National Crime Victimization Survey (NCVS)	BJS	X	X	Ages 16+
National Epidemiologic Survey of Alcohol and Related Conditions (NESARC)	NIAAA	X		Adults
National Health Interview Survey (NHIS)	CDC	X		Adults
National Health and Nutrition Examination Survey (NHANES)	CDC	X		Adults
National HIV Behavioral Surveillance (NHBS)	CDC	X	X	Adults (high HIV risk)
National Inmate Survey (NIS)	BJS	X	X	Ages 16+
National Intimate Partner and Sexual Violence Survey (NISVS)	CDC, DOD, NIJ	X		Adults
National Longitudinal Study of Adolescent and Adult Health, Wave V (Add Health)	National Institute of Child Health and Human Development, with cooperative funding from 23 other federal agencies and foundations	X	X	Adults
National Outcome Measures, Center for Mental Health Services (NOM)	SAMHSA, CMHS	X	X	Adults
National Survey of Drug Use and Health (NSDUH)	SAMHSA	X		Adults
National Survey of Family Growth (NSFG)	CDC	X		Ages 15-49

National Survey of Older Americans Act Participants (NSOAAP)	AOA	X		Ages 60+
Population Assessment of Tobacco and Health Study (PATH)	NIDA, NIH, CTP, FDA	X	X	Ages 14+
Survey of Today's Adolescent Relationship and Transitions (START)	CDC	X	X	Ages 13-24
Youth Risk Behavior Surveillance System (YRBSS)	CDC	X		Grades 9-12

Source: National Academies of Sciences, Engineering, and Medicine. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.

Notes on abbreviation: NIH: National Institutes of Health, NSF: National Science Foundation, CDC: Centers for Disease Control and Prevention, HRSA ASPE: Health Resources and Services Administration Assistance Secretary for Planning and Evaluation, SSA: Social Security Administration, DOL: Department of Labor, NCES: National Center for Education Statistics, NCHS: National Center for Health Statistics, BJS: Bureau of Justice Statistics, NIAAA: National Institute on Alcohol Abuse and Alcoholism, DOD: Department of Defense, NIJ: National Institute of Justice, SAMHSA: Substance Abuse and Mental Health Services Administration, CMHS: Center for Mental Health Services, NIDA: National Institute on Drug Abuse, CTP: Center for Tobacco Products, FDA: Food and Drug Administration

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