

March 2024

## 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.<sup>1</sup> 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](#).<sup>2</sup> A [recent analysis](#) from the Medicaid and Children’s Health Insurance Program (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 adults (20.7%).<sup>2</sup> Medicaid is undoubtedly an important source of coverage for populations who are lesbian, gay, bisexual, transgender, queer, intersex, or outside the gender binary (LGBTQI+).<sup>†</sup>

The inequitable treatment and outcomes that LGBTQI+ populations experience in many areas of everyday life also occur in [health and access to healthcare services](#).<sup>3</sup> 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](#).<sup>2</sup> 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](#).<sup>4</sup> This persistent health-data gap is a major barrier for understanding and [improving the health of these individuals](#).<sup>5</sup>

Although few states currently collect data about SOGI populations in Medicaid, new opportunities for collecting this data are now available. In the fall of 2023, the Centers for Medicare & Medicaid Services (CMS) announced that starting November 1, 2023, individuals applying for coverage through HealthCare.gov will be asked [new optional questions on the topic of SOGI](#).<sup>6</sup> Following this announcement, CMS also [released guidance for states](#) who want to add the same SOGI questions to their Medicaid and CHIP applications.<sup>7</sup>

The objectives of this issue brief are to summarize recent federal guidance on new opportunities to collect SOGI data and to document how information describing LGBTQI+ populations is currently collected in Medicaid. This brief also spotlights Oregon’s ongoing efforts to improve the collection of SOGI data and presents several considerations for states as they look to improve their collection of SOGI data in Medicaid.

## New Opportunities to Collect SOGI Data in Medicaid and the Marketplace

Although there is no uniform federal standard for the collection of SOGI data, various SOGI data collection practices are in place at the federal level. This includes joint CMS and [Office of the National Coordinator standards for certified electronic health record technologies \(CEHRT\)](#), [Health Resources and Services Administration \(HRSA\) standards](#) for demographics reporting through the Uniform Data System Requirements (UDS), and data collection through federal surveys.<sup>8,9</sup> (Appendix A provides an overview of various SOGI data collection practices at the federal level.)

Recently, there has been some movement toward consensus on how to best ask these questions along with activity at the federal level to improve SOGI data collection. In 2022, a panel of experts convened by the [National Academies of Sciences, Engineering, and Medicine \(NASEM\)](#) [produced a consensus report](#) with recommendations and guiding principles for collecting data on sex, gender identity, and sexual orientation based on the most recent evidence available.<sup>10</sup> (See Appendix B for additional detail on the NASEM consensus recommendations.) In June 2022, President Biden signed [Executive Order 14075: Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex](#)

† Many terms are used to describe sexual orientation and gender identity. The Human Rights Campaign has compiled a [Glossary of Terms](#) that can be helpful to understand the definitions of SOGI-related words used in this brief.

*Individuals*.<sup>11</sup> This executive order led to the release of two reports in January 2023. The first report was released by the Office of Management and Budget (OMB) and the Chief Statistician, entitled *Recommendations on the Best Practices for Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys*.<sup>12</sup> At the same time, the subcommittee on Sexual Orientation Gender Identity and Variations in Sex Characteristics Data also released its report entitled *Federal Evidence Agenda on LGBTQI+ Equity*.<sup>13</sup> (See Appendix C for additional detail on the recommendations included in these reports.)

In the fall of 2023, CMS added three new SOGI questions to the single streamlined model application, developed by the Secretary (Figure A). This “model application” is used by HealthCare.gov and all states that use the federal eligibility and enrollment platform (32 states as of November 1, 2023).<sup>6</sup>

**Figure A. Sexual Orientation and Gender Identity Questions on the Model Application**

Category	Question	Responses
<b>Sex</b>	<i>Sex (existing question, required, single select)</i>	<ul style="list-style-type: none"> <li>• Male (does not trigger pregnancy question)</li> <li>• Female (triggers pregnancy question)</li> </ul>
<b>Sex Assigned at Birth</b>	What was [First Name]’s sex assigned at birth? <i>You can find this on an original birth certificate or similar document.</i> (new question, optional, single select)	<ul style="list-style-type: none"> <li>• Female</li> <li>• Male</li> <li>• A sex that’s not listed: [free text]</li> <li>• Not sure</li> <li>• Prefer not to answer</li> </ul>
<b>Gender Identity</b>	What’s [First Name]’s gender identity? <i>(new question, optional, single select)</i>	<ul style="list-style-type: none"> <li>• Female</li> <li>• Male</li> <li>• Transgender female</li> <li>• Transgender male</li> <li>• A gender identity that’s not listed: [free text]</li> <li>• Not sure</li> <li>• Prefer not to answer</li> </ul>
<b>Sexual Orientation</b>	What’s [First Name]’s sexual orientation? <i>(new question, optional, single select)</i>	<ul style="list-style-type: none"> <li>• Lesbian or gay</li> <li>• Straight</li> <li>• Bisexual</li> <li>• A sexual orientation that’s not listed: [free text]</li> <li>• Not sure</li> <li>• Prefer not to answer</li> </ul>

The existing required binary “sex” question will remain on the application. The three new optional questions will be asked for all individuals ages 12 and older and will be asked alongside existing race/ethnicity questions. At this time, CMS states that any data received from the new SOGI questions on HealthCare.gov will not be shared with downstream systems or agencies, including issuers and state Medicaid or CHIP agencies.

A subsequent *CMS Informational Bulletin* provided guidance pertaining to state Medicaid and CHIP applications.<sup>7</sup> Specifically, states are not required to add SOGI questions, but states that wish to incorporate these questions exactly as they are worded on the model application (and outlined in the guidance) will not be required to seek CMS approval. States that want to incorporate SOGI questions using alternative language are asked to work with CMS and may need to seek formal approval. In all cases, these questions must be optional for the respondent. CMS hopes to begin receiving and accepting SOGI data as part of Transformed Medicaid Statistical Information System (T-MSIS) data submissions from those states that opt to add SOGI questions to their application forms in 2025.

It is important to note that these new model application questions do not completely align with existing federal data collection standards (e.g. CEHRT or HRSA), nor do they conform to the questions proposed in the NASEM Consensus Report, OMB’s Best Practices Report, or the Federal Evidence Agenda.

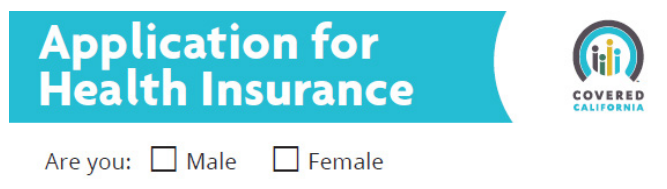
## Current SOGI Data Collection in Medicaid Applications

To understand the existing landscape of SOGI data collection in Medicaid, the State Health Access Data Assistance Center (SHADAC) reviewed paper Medicaid applications for all 50 states and Washington, D.C. along with online Medicaid applications for 44 states in August 2023.<sup>†</sup> 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. No states collecting data on intersex status were identified.

### Paper Applications

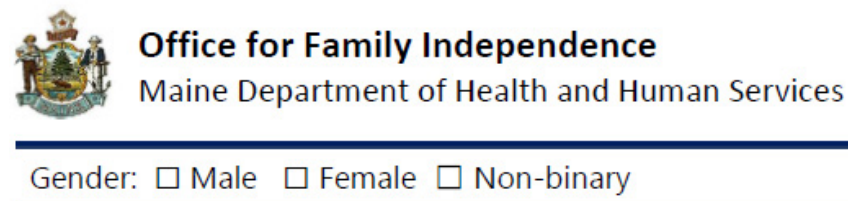
On their paper applications, 39 states asked applicants to indicate their sex (Oregon and Washington specify “sex assigned at birth”), while eight states asked applicants to indicate their gender. Four states did not specify whether they were asking for sex or gender (see the California example in Figure B).

### Figure B. 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 providing three response options (Figure C), New York providing six response options (Figure D), and Oregon providing eight response options (Figure E). See the “Spotlight on Oregon” section below for additional detail on Oregon’s efforts to improve its collection of SOGI data.

### Figure C. Maine Paper Application




<sup>†</sup> For State-Based Marketplace (SBM) states, online applications can be either exclusive to Medicaid or integrated with the Marketplace. For the Federally Facilitated Marketplace (FFM) and states with SBMs using the federal platform (SBM-FP), we examined the online application available through the state’s Medicaid agency portal. Remote identity proofing (RIDP) processes prevented us from reviewing six states’ (AL, MA, MN, OR, RI, and VT) online Medicaid applications. RIDP requires that an applicant answer a series of personal questions (drawn from credit files and other sources) in order to verify an applicant’s identity. Some states require this information before an individual can complete an application, therefore we were not able to review these states’ online Medicaid application questions.

**Figure D. New York Paper Application**

	<b>Date of Birth</b> <b>SEND PROOF</b>	<b>**Gender Identity (optional)</b>
	<b>*Sex</b> ____/____/____ <input type="checkbox"/> Male <input type="checkbox"/> Female	<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 Describe your identity (optional).

**Figure E. Oregon Paper Application**

	★ 2. Birthdate: <input type="text"/> / <input type="text"/> / <input type="text"/>	<b>For data matching purposes, what was your sex assigned at birth?:</b> <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"/>	

★ = Required

**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. Just three states, 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 F); both South Carolina and Tennessee provided an "Unknown" response option (Figure G).

**Figure F. 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 G. South Carolina Online Application**

SOUTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES <b>Healthy Connections</b> MEDICAID
<input type="text" value="--Please Select--"/>
<input type="text" value="--Please Select--"/> <input type="text" value="Female"/> <input type="text" value="Male"/> <input type="text" value="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.

## 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 SOGI for patients, clients, and members at least once a year.<sup>14</sup> It also requires the Oregon Health Authority (OHA) to expand their existing REALD data collection standards to [include SOGI](#).<sup>15</sup> This legislation, 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, builds on reporting requirements put in place during the COVID-19 pandemic. [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.<sup>16</sup> In September 2022, the OHA Office of Equity and Inclusion SOGI Data Collection workgroup released its [draft of recommended minimum standards for SOGI demographic questions](#) (Figures H, I, and J).<sup>17</sup>

**Figure H. Oregon’s Gender Identity Question**

**Q1. Please describe your gender in any way you prefer** \_\_\_\_\_

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

<input type="checkbox"/> Girl, Woman	<input type="checkbox"/> Not listed. Please specify: _____
<input type="checkbox"/> Boy, Man	<input type="checkbox"/> Don’t know
<input type="checkbox"/> Nonbinary	<input type="checkbox"/> I don’t know what this question is asking
<input type="checkbox"/> Agender/No gender	<input type="checkbox"/> I don’t want to answer
<input type="checkbox"/> Questioning	

**Figure I. 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 J. 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)**

<input type="checkbox"/> Same-gender loving	<input type="checkbox"/> Asexual
<input type="checkbox"/> Same-sex loving	<input type="checkbox"/> Queer
<input type="checkbox"/> Lesbian	<input type="checkbox"/> Questioning
<input type="checkbox"/> Gay	<input type="checkbox"/> Don’t know
<input type="checkbox"/> Bisexual	<input type="checkbox"/> Not listed. Please specify: _____
<input type="checkbox"/> Pansexual	<input type="checkbox"/> I don’t know what this question is asking
<input type="checkbox"/> Straight [attracted mainly to or only to other gender(s) or sex(s)]	<input type="checkbox"/> I don’t want to answer

In November 2023, OHA convened 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.<sup>18</sup> 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. The building and piloting of the House Bill 3159 registry (front end) and repository (back end) is expected to be completed by 2026.

### Considerations for States Implementing the New SOGI Questions

SHADAC’s review found that very few states are currently collecting SOGI information, and no states are collecting the data in line with the new CMS recommended format. States that are interested in collecting improved SOGI data will likely be looking carefully at the CMS recommended questions. SHADAC conferred with SOGI data collection experts at the [Whitman-Walker Institute](#) and the [National Health Law Program](#) to discuss the potential implications of the changes to the single streamlined application. Together, several important considerations for states implementing CMS’ recommended SOGI questions were identified:

- **Privacy and confidentiality are paramount concerns.** States should be prepared to communicate with enrollees about why these data are being collected, how they will be used and protected, with whom and how they will be shared, and what legal protections and other safeguards are in place to protect the data from misuse. States should also emphasize that these questions are optional (per CMS guidance), they must be self-reported, and applicant responses will not affect program eligibility (per CMS guidance). To facilitate this, it will be especially important for states to provide eligibility workers, assisters, and call center staff with education on the importance of SOGI data collection. Providing them training and resources on how to ask these questions and how to respond to questions and concerns from individuals will also be pivotal.
- **The gender identity question responses *do not* align with recommended best practices.** The model application response categories of “transgender female” and “transgender male” conflict with expert recommendations on how to best ask this question. The NASEM Consensus Report (see Appendix B) specifically recommends *against* including more detailed subcategories of transgender experience or identity (e.g., transgender male/man or transgender female/woman) for data privacy reasons. The sample sizes for these responses are likely to be very small, resulting in questions that provoke confidentiality concerns among respondents and, thus, are unlikely to be reported (reported data would need to be aggregated for privacy reasons). States electing to use this question response should keep those data privacy concerns in mind. Those states should also be aware that there will be a need to improve or update the question and response design relatively soon, particularly based on [ongoing research being conducted by the Census Bureau](#) and other federal agencies.<sup>19</sup>
- **Retaining the existing sex question could be confusing for respondents.** Relying on the existing binary sex question to trigger eligibility determinations around pregnancy is likely to introduce confusion and data

quality issues. Respondents may not understand how the “sex” and “sex assigned at birth” differ from each other and may perceive that they are being asked the same question twice. States should also make it clear to consumers why they are retaining the existing binary sex question.

- **Coding protocols must be used to accurately identify transgender individuals using this question structure.** States may need help or technical assistance to understand how to code and analyze the data from these questions. Using the two-step gender identity question (asking sex assigned at birth in addition to, and followed by, gender identity) could make it especially difficult for states to code transgender individuals correctly since CMS is also retaining the existing binary sex question. This can lead to an undercount of transgender individuals. (SHADAC is available to provide technical assistance to states on this topic.)
- **The new questions don’t address pronouns.** There is no clear opportunity for people to indicate their pronouns. States should be careful to not use the existing binary sex question to drive gendered honorifics in communication with enrollees (e.g., states should avoid sending “Dear Ms. Smith” to a transgender man who would have to indicate “female” on that question in order to gain pregnancy-related coverage).
- **The new SOGI questions might not initially perform as well as other demographic questions.** Low initial response rates to the new SOGI questions do not necessarily mean the questions aren’t needed or effective. If these questions don’t immediately perform as expected, that’s not a reason to discontinue efforts to collect these data. States should reach out to CMS or data collection experts to mitigate issues (SHADAC can also provide technical assistance in this area), as well as to document and share all the data (and lessons) that can be learned from the initial cycle(s) of SOGI data collection.
- **The model single streamlined application might not align with other state data collection requirements.** States need to be aware of and be proactive in mitigating potential issues of how CMS’ single streamlined application question design might not align with other state data collection requirements. For example, [New York’s Gender Recognition Act](#) requires the state to allow for a third sex designation, “X,” for nonbinary individuals.<sup>20</sup> Or see the above section “Spotlight on Oregon’s Efforts to Develop Statewide SOGI Data Standards” for additional details on Oregon’s required standards.

## Conclusions and Looking Ahead

In general, states should take advantage of the opportunity CMS has provided to add SOGI questions to Medicaid applications. SHADAC’s review found that very few state Medicaid agencies are currently collecting this information, and there is significant opportunity to reduce this data gap by adopting these questions. States are encouraged to follow CMS’ model questions on the single streamlined application, despite the considerations described above, in order to avoid heterogeneous data collection across the nation, which can be of particular concern for smaller populations like LGBTQI+ individuals. Collecting this data is preferred over having no data at all, or having data collected in many different ways by each state Medicaid agency.

Disclosure risks and historic sensitivity around this topic should not be used as a reason to not collect these data and evidence shows people are willing to answer these questions at similar rates to other demographic questions (see Appendix B). Steps should be taken to maximize privacy and limit reidentification. States should work within their own data privacy and disclosure laws; they might also consider a risk assessment specific to the LGBTQI+ population before reporting this information.

Given that there are still many unresolved methodological and conceptual issues related to the collection of SOGI information, states are encouraged to engage in a thoughtful community stakeholder process in order to work to improve these questions in the future. Oregon continues to serve as an excellent model for how to undertake an ongoing stakeholder process that can inform efforts to establish new data collection on a topic that is fluid, rapidly changing, and vitally important for the health of Medicaid populations.

Support for this issue brief was provided by the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.

---

#### 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.

Through our efforts, and the efforts of others, we will continue to strive toward a Culture of Health that benefits all. It is our legacy, it is our calling, and it is our honor.

For more information, visit [www.rwjf.org](http://www.rwjf.org).

---

#### ABOUT STATE HEALTH AND VALUE STRATEGIES—PRINCETON UNIVERSITY SCHOOL OF PUBLIC AND INTERNATIONAL AFFAIRS

State Health and Value Strategies (SHVS) assists states in their efforts to transform health and healthcare by providing targeted technical assistance to state officials and agencies. The program is a grantee of the Robert Wood Johnson Foundation, led by staff at Princeton University's School of Public and International Affairs. The program connects states with experts and peers to undertake healthcare transformation initiatives. By engaging state officials, the program provides lessons learned, highlights successful strategies, and brings together states with experts in the field. Learn more at [www.shvs.org](http://www.shvs.org).

---

#### ABOUT SHADAC

This issue brief was prepared by Emily Zylla and Elizabeth Lukanen. The State Health Access Data Assistance Center (SHADAC) is an independent, multidisciplinary 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.

---

#### ACKNOWLEDGMENTS

The authors thank the Oregon Health Authority for sharing the findings and experiences of Oregon's SOGI data collection efforts detailed in the "Spotlight on Oregon" section of this report. The authors also express our gratitude to Kellan Baker and Caroline Medina from the Whitman-Walker Institute, and Charly Gilfoil and Mara Youdelman at the National Health Law Program for providing expert commentary and considerations related to the new CMS recommended SOGI questions.





# Appendix A:

## Sexual Orientation and Gender Identity Data Collection at the Federal Level

The United States does not have uniform federal standards for data collection specifically for lesbian, gay, bisexual, transgender, queer, intersex, or outside the gender binary (LGBTQI+) populations. Therefore, the collected information describing these populations varies and has evolved over the years, and some aspects of sexual orientation and gender identity (SOGI) 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 K).<sup>21</sup> SOGI were considered by HHS as separate concepts and were not addressed.

In spite of a lack of overarching federal standards, there are many health-related SOGI data collection efforts happening at the federal level. 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 SOGI in the demographics certification criteria. 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 L) and is **seen as a critical step** in standardizing and normalizing SOGI data collection.<sup>8,22</sup> In July 2021, HHS included SOGI in the **U.S. Core Data for Interoperability (USCDI) standards** for the first time.<sup>23</sup> These standards (USCDI V2 and higher) mirror the CEHRT SOGI standards.

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 M).<sup>9</sup>

### Figure K. HHS Data Standard for Sex

#### **“What is your sex?”**

- *Male*
- *Female*

### Figure L. 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*

## Figure M. HRSA SOGI Data Collection

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

### Response options are:

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

### Gender identity response options are:

- Male
- Female
- Transgender Man/Transgender Male/Transgender Masculine
- Transgender Woman/Transgender Female/Transgender Feminine
- Other
- Choose not to disclose

In addition, many federal surveys (both those focused on health and those that are broader) collect information on SOGI using a variety of question structures and wording (Table A). In 2022, the National Academies of Sciences, Engineering, and Medicine [examined the state of data collection on SOGI and intersex status](#) in 47 data collection instruments, including federally supported surveys and other data systems.<sup>10</sup>

A recent [sample size analysis conducted by the State Health Access Data Assistance Center \(SHADAC\)](#) on behalf of the Medicaid and Children's Health Insurance Program (CHIP) Payment and Access Commission (MACPAC) found that of 13 federal population health surveys reviewed, only five ask about sexual orientation and two ask about gender identity.<sup>24</sup> Across these surveys, response rates for these questions were robust—above 90% (question response rates were calculated as the percentage of eligible respondents that had a valid, non-missing response to a question). The Behavioral Risk Factor Surveillance System (BRFSS), Household Pulse Survey (HPS), National Health Interview Survey (NHIS), and National Survey of Drug Use and Health (NSDUH) have sufficient sample size for analysis of people who report being lesbian, gay, or bisexual for the total population and within Medicaid. Only the BRFSS and HPS ask about gender identity and only the BRFSS has sufficient sample size to produce information for both the total population and the population within Medicaid for people who report their gender identity as transgender, gender non-conforming, or nonbinary.

In September 2023, the Census Bureau took the first formal steps to [add SOGI questions to the American Community Survey \(ACS\)](#), requesting approval to test question wording, response categories, and question placement.<sup>19</sup> As the largest federal survey currently fielded, adding SOGI questions to the ACS would represent a major advance in the ability of researchers to identify and better understand these populations.

**Table A. Federal Surveys That Collect SOGI Information (2020)**

Survey	Sponsor	Sexual Orientation	Gender Identity	Population
<b>All of Us</b>	NIH	X	X	All ages
<b>American National Election Studies (ANES)</b>	NSF	X	X	Adults (eligible voters)
<b>Behavioral Risk Factor Surveillance System (BFRSS)</b>	CDC	X	X	Adults
<b>General Social Survey (GSS)</b>	NSF	X	X	Adults

<b>Growing Up Today Study (GUTS)</b>	NIH	X		Young Adults (20s)
<b>Health Center Patient Survey (HCPS)</b>	HRSA ASPE	X		All ages
<b>Health and Retirement Study (HRS)</b>	NIH, SSA, DOL, ASPE, State of Florida	X		Older adults
<b>High School Longitudinal Study of 2009 (HSLs:09)—2016 Collection 3 Years After High School Graduation</b>	NCES	X	X	Young adults (early 20s)
<b>Household Pulse Survey (HPS)</b>	Census	X	X	Adults
<b>National Adult Tobacco Survey (NATS)</b>	NCHS	X	X	Adults
<b>National Crime Victimization Survey (NCVS)</b>	BJS	X	X	Ages 16+
<b>National Epidemiologic Survey of Alcohol and Related Conditions (NESARC)</b>	NIAAA	X		Adults
<b>National Health Interview Survey (NHIS)</b>	CDC	X		Adults
<b>National Health and Nutrition Examination Survey (NHANES)</b>	CDC	X		Adults
<b>National HIV Behavioral Surveillance (NHBS)</b>	CDC	X	X	Adults (high HIV risk)
<b>National Inmate Survey (NIS)</b>	BJS	X	X	Ages 16+
<b>National Intimate Partner and Sexual Violence Survey (NISVS)</b>	CDC, DOD, NIJ	X		Adults
<b>National Longitudinal Study of Adolescent and Adult Health, Wave V (Add Health)</b>	National Institute of Child Health and Human Development, with cooperative funding from 23 other federal agencies and foundations	X	X	Adults

<b>National Outcome Measures, Center for Mental Health Services (NOM)</b>	SAMHSA, CMHS	X	X	Adults
<b>National Survey of Drug Use and Health (NSDUH)</b>	SAMHSA	X		Adults
<b>National Survey of Family Growth (NSFG)</b>	CDC	X		Ages 15-49
<b>National Survey of Older Americans Act Participants (NSOAAP)</b>	AOA	X		Ages 60+
<b>Population Assessment of Tobacco and Health Study (PATH)</b>	NIDA, NIH, CTP, FDA	X	X	Ages 14+
<b>Survey of Today's Adolescent Relationship and Transitions (START)</b>	CDC	X	X	Ages 13-24
<b>Youth Risk Behavior Surveillance System (YRBSS)</b>	CDC	X		Grades 9-12

**Sources:** 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>. Medicaid and CHIP Payment Access Commission (MACPAC). (September 14, 2023). *Federal Survey Sample Size Analysis: Disability, Language, and Sexual Orientation and Gender Identity*. <https://www.macpac.gov/publication/federal-survey-sample-size-analysis-disability-language-and-sexual-orientation-and-gender-identity/>

**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

## Appendix B:

Recommendations From the 2022 National Academies of  
Sciences, Engineering, and Medicine Report:  
*Measuring Sex, Gender Identity, and Sexual Orientation*

In 2022, a panel of experts convened by the [National Academies of Sciences, Engineering, and Medicine \(NASEM\)](#) produced a [consensus report](#) with recommendations and guiding principles for collecting data on sex and SOGI based on the most recent evidence available.<sup>10</sup> The report's key findings include 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 N and O). The consensus report also recommends 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 N. 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 O. NASEM Recommended Measure: Assessing Sexual Orientation Identity


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

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

*\*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 regarding 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 and/or in different cultures or languages outside of English and Spanish.





# Appendix C:

## Federal Efforts to Improve Sexual Orientation and Gender Identity Data Collection

## Executive Order

In June 2022, President Biden signed [Executive Order 14075: Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals](#).<sup>11</sup> 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 focuses on promoting inclusive and responsible federal data collection to help identify, understand, and address disparities experienced by LGBTQI+ people. Specifically, it requires federal agencies to:

- Identify opportunities for improved sexual orientation and gender identity (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.

Further details about these requirements are discussed below.

## 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 Office of Management and Budget 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).<sup>12</sup> This report provides examples and offers considerations on how to balance the collection of 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 both 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 (Figures P and Q) using a format that is similar, although not identical, to the [National Academies of Sciences, Engineering, and Medicine consensus report’s recommendation](#).<sup>10</sup>

## Figure P. 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 Q. 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. The less-detailed approach is recommended for use in 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 R). A single question about LGBT status, such as the example provided in Figure S below, can provide the necessary information by asking about aspects of SOGI 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 R. Best Practices Report: Less Detailed Example Gender Question

**Q1. Are you:**

*Mark all that apply.*

- Female
- Male
- Transgender, nonbinary, or another gender

## Figure S. 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

While the SOGI data collection best practices report was released, the subcommittee on Sexual Orientation Gender Identity and Variations in Sex Characteristics Data simultaneously released its own report titled, *Federal Evidence Agenda on LGBTQI+ Equity*.<sup>13</sup> 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, this report 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 T).

## Figure T. 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

One final requirement from the executive order is still in progress: the mandate that federal agencies develop and implement SOGI Data Action Plans. These 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.<sup>25</sup> Once submitted, agencies are supposed to include in their annual budget submissions any necessary funding requests to support better SOGI data inclusion.

## ENDNOTES

1. The Williams Institute at UCLA School of Law. (2019, December 16). LGBT FAQs - Williams Institute. Williams Institute. <https://williamsinstitute.law.ucla.edu/quick-facts/lgbt-faqs/>
2. Medicaid and CHIP Payment Access Commission (MACPAC). (June 2022). Access in Brief: Experiences of Lesbian, Gay, Bisexual, and Transgender Medicaid Beneficiaries with Accessing Medical and Behavioral Health Care. <https://www.macpac.gov/wp-content/uploads/2022/06/Access-in-Brief-Experiences-in-Lesbian-Gay-Bisexual-and-Transgender-Medicaid-Beneficiaries-with-Accessing-Medical-and-Behavioral-Health-Care.pdf>
3. Bosworth, A., Turrini, G., Pyda, S., Strickland, K., Chappel, A., De Lew, N., Sommers, B.D.. (June 2021). Health Insurance Coverage and Access to Care for LGBTQ+ Individuals: Current Trends and Key Challenges. <https://aspe.hhs.gov/sites/default/files/2021-07/lgbt-health-ib.pdf>
4. Institute of Medicine. 2011. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. Washington, DC: The National Academies Press. <https://doi.org/10.17226/13128>
5. Mayer, K.H., Bradford, J.B., Makadon H.J., Stall, R., Goldhammer, H., Landers, L.. (2011, Oct. 10). Sexual and Gender Minority Health: What We Know and What Needs to Be Done. American Journal of Public Health, 98(6), 989-995. <https://doi.org/10.2105/AJPH.2007.127811>
6. Centers for Medicare & Medicaid Services (2023). New Sexual Orientation and Gender Identity (SOGI) Questions on the Marketplace Application. <https://www.cms.gov/files/document/sogi-questions-marketplace-application.pdf>
7. Center for Medicaid and CHIP Services (November 9, 2023). Guidance on Adding Sexual Orientation and Gender Identity Questions to State Medicaid and CHIP Applications for Health Coverage. <https://www.medicaid.gov/sites/default/files/2023-11/cib11092023.pdf>
8. U.S. Government. Department of Health and Human Services. "2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition." <https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base#p-191>
9. U.S. Department of Health and Human Services. Approved Uniform Data System Changes for Calendar Year 2016. <https://bphc.hrsa.gov/sites/default/files/bphc/data-reporting/program-assistance-letter-2016-02.pdf>
10. 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>
11. U.S. Government. Executive Office of the President. "Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals". 87 Fed Reg 37,189-37,195. (June 22, 2022) <https://www.govinfo.gov/app/details/FR-2022-06-21/2022-13391>
12. Office of the Chief Statistician of the United States. (n.d.). Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys. (Washington, D.C.) <https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf>
13. National Science and Technology Council, Subcommittee on Sexual Orientation, Gender Identity, and Variations in Sex Characteristics (SOGI) Data, Subcommittee on Equitable Data. (2023, Jan.) Federal Evidence Agenda on LGBTQI+ Equity. (Washington, D.C.) <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>
14. Oregon State Legislature, 81st Oregon Legislative Assembly – 2021 Regular Session. (2021). Enrolled House Bill 3159. (Salem, Oregon). <https://olis.oregonlegislature.gov/liz/2021R1/Downloads/MeasureDocument/HB3159>
15. McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. (Portland, Oregon) Oregon Health Authority, Equity and Inclusion Division. <https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf>
16. SHADAC. (October, 2021). Collection of Sexual Orientation and Gender Identity Data: Considerations for Medicaid and Spotlight on Oregon. <https://www.shvs.org/resource/collection-of-sexual-orientation-and-gender-identity-sogi-data-considerations-for-medicaid-and-spotlight-on-oregon/>
17. Oregon Health Authority. (September, 2022) SOGI DRAFT Data Collection Recommendations. <https://www.oregon.gov/oha/EI/REALD%20Documents/DRAFT-SOGI-Recommendations.pdf>

18. Oregon AIDS Education and Training Center. (n.d.). Sexual Orientation & Gender Identity (SOGI) Resources. <https://www.oraetc.org/sogi>
19. Submission to the Office of Management and Budget (OMB) for Review and Approval; Comment Request; American Community Survey Methods Panel: 2024 Sexual Orientation and Gender Identity Test. <https://www.federalregister.gov/documents/2023/09/19/2023-20256/agency-information-collection-activities-submission-to-the-office-of-management-and-budget-omb-for>
20. New York State Senate, Gender Recognition Act, February 4, 2021. 2021-2022 Regular Sessions. Senate Bill S4402B. Cal. No. 515. <https://legislation.nysenate.gov/pdf/bills/2021/S4402B>
21. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. (2011, Oct. 30). HHS Implementation Guidance on the Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>
22. Cahill SR, Baker K, Deutsch MB, Keatley J, Makadon HJ. Inclusion of Sexual Orientation and Gender Identity in Stage 3 Meaningful Use Guidelines: A Huge Step Forward for LGBT Health. *LGBT Health*. 2016 Apr;3(2):100-2. doi: 10.1089/lgbt.2015.0136. Epub 2015 Dec 24. PMID: 26698386.
23. The Office of the National Coordinator for Health Information Technology (ONC). (n.d.) United States Core Data for Interoperability (USCDI). <https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi>
24. Medicaid and CHIP Payment Access Commission (MACPAC). (September 14, 2023). Federal Survey Sample Size Analysis: Disability, Language, and Sexual Orientation and Gender Identity. <https://www.macpac.gov/wp-content/uploads/2023/10/Federal-Survey-Sample-Size-Analysis-Disability-Language-and-Sexual-Orientation-and-Gender-Identity.pdf>
25. U.S. Department of Housing and Urban Development. (2023, March 31). SOGI Data Action Plan for the Department of Housing and Urban Development. <https://www.huduser.gov/portal/sites/default/files/pdf/SOGI-DATA-ACTION-PLAN.pdf>