

# New State Options for Sexual Orientation and Gender Identity Data Collection

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n a <u>November 2023 informational bulletin</u>, the Centers for Medicare & Medicaid Services (CMS) introduced three optional sexual orientation and gender identity (SOGI) questions in its model application that state Medicaid and CHIP agencies may add to their state-specific enrollment application. By collecting this data, CMS hopes that states and the federal government will be able to better understand health disparities faced by people who identify as lesbian, gay, bisexual, transgender, queer, or additional sexual and gender identities (LGBTQ+) and improve their health care experience by allowing applicants to self-identify in ways that affirm their identities. CMS' addition of SOGI questions reflects a growing movement at the federal, state, and local levels to better understand and meet the health needs of LGBTQ+ communities.

## Why SOGI Data Matters

LGBTQ+ people experience <u>unique health disparities when compared to non-LGBTQ+ people</u>, including higher rates of chronic conditions and disabilities, greater needs for mental health care, and disparities in access to and type of health care. LGBTQ+ people are <u>more likely</u> to be enrolled in public health insurance, increasing the impact Medicaid policies and programs have on their health and health care experience. Collecting SOGI data will allow states to better understand and monitor disparities and outcomes among LGBTQ+ communities.

CMS' decision to add three questions to the model application reflects <u>growing interest</u> in <u>Medicaid SOGI</u> <u>data</u> and mirrors similar decisions from other federal agencies, such as the <u>U.S. Census Bureau</u> and <u>Indian Health Services</u>. The move also follows several <u>executive orders</u> related to LGBTQ+ health equity. On the provider side, many health systems have also begun collecting SOGI data, including those seeking the National Committee for Quality Assurance's <u>health equity accreditation</u>.

## **State Options for SOGI Data**

In the bulletin, CMS outlines the three new questions covering sex assigned at birth, gender identity, and sexual orientation. The questions are optional for all applicants age 12 and older and do not apply to applicants under 12 years. The existing, mandatory "sex" question – with binary male and female options – remains required and unchanged, and any applicant who selects female will be asked a follow-up question about pregnancy status.

As states review the new SOGI questions, they have three options. States may:

**1. Not include the new SOGI questions:** Continue using current applications without the addition of SOGI questions. *This option does not require CMS approval.* 

2. Add in the new SOGI questions as is: Incorporate the new SOGI questions using the language outlined by CMS in the model application without any changes to wording. (See Table 1)

Table 1: Sexual Orientation and Gender Identity Questions on the Model Application

| QUESTION   | RESPONSES  |
|--|--|
| Sex (existing question, required, single select)   | <ul><li>Male (does not trigger pregnancy question)</li><li>Female (triggers pregnancy question)</li></ul>  |
| What was [First Name]'s sex assigned at birth? You can find this on an original birth certificate or similar document. (new question, optional, single select) | <ul> <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>   |
| What's [First Name]'s gender identity? (new question, optional, single select)   | <ul> <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> |
| What's [First Name]'s sexual orientation? (new question, optional, single select)  | <ul> <li>Lesbian or gay</li> <li>Straight</li> <li>Bisexual</li> <li>A sexual orientation that is not listed: [free text]</li> <li>Not sure</li> <li>Prefer not to answer</li> </ul>                     |

**Source**: Centers for Medicare and Medicaid Services. "CMCS Informational Bulletin: Guidance on Adding Sexual Orientation and Gender Identity Questions to State Medicaid and CHIP Applications for Health Coverage." November 2023. Available at: <a href="https://www.medicaid.gov/sites/default/files/2023-11/cib11092023.pdf">https://www.medicaid.gov/sites/default/files/2023-11/cib11092023.pdf</a>.

States may change the order of questions, as long as applicant age is asked before SOGI questions. States may also choose when to present the questions to members. The questions can appear directly in the application, after the applicant signs and submits the application, or after the applicant is determined eligible for Medicaid by the state. *This option does not require CMS approval.* 

**3. Modify the CMS SOGI questions**: Incorporate SOGI questions using modified wording, add, or remove application questions from the CMS model questions. *This option requires that states work with CMS to determine whether submission of a state plan amendment is required.* 

Some states are working directly with LGBTQ+ community members to draft SOGI questions that reflect their community's unique needs. In Oregon, <u>the proposed questions</u> differ significantly from the SOGI questions written by CMS. As states begin to collect SOGI data using language that diverges from CMS' proposed

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questions, state policymakers, advocates, providers, researchers, and other stakeholders should look for emerging best practices.

As states consider which option is right for them, they must also determine if they are able to meet requirements related to data submission and confidentiality outlined in the CMS bulletin. CMS anticipates updates to T-MSIS (its data collection system) in 2025 which will allow the agency to accept SOGI data from states that opt to collect it. As with all applicant data, states must <u>safeguard the use or disclosure</u> of SOGI data and ensure that data are only used for the administration of the Medicaid or CHIP state plan. CMS notes that answers (or the absence of answers) must in no way affect an applicant's eligibility. CMS also explicitly states that SOGI data cannot be shared with other state agencies or be used to "enable child welfare investigations or to pursue criminal charges or civil penalties that are not directly related to the administration of the state plan." States must also obtain permission from applicants before disclosing data to an outside source. This is especially important as the rise in homophobia and transphobia make collecting SOGI data more sensitive and may increase applicants' privacy concerns.

### What's the bottom line?

CMS' inclusion of SOGI questions in the model application is a step toward making Medicaid and health care services more responsive and equitable for LGBTQ+ communities. Collecting SOGI data may allow states to better monitor and address health disparities and allow for LGBTQ+ individuals to better self-identify.

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