

THE NEW NATIONAL ACADEMIES REPORT & THE IMPORTANCE OF LGBTQI DATA INCLUSION

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In March 2022, the National Academies of Sciences, Engineering, and Medicine (NASEM) issued a report with formal recommendations and best practices for collecting data on sex, sexual orientation, gender identity, and variations in sex characteristics. This brief explains why data inclusion is so important for LGBTQI people, what the NASEM report recommends, and what LGBTQI community members and allies can do to advocate for data inclusion.

WHY IS INCLUSIVE DATA COLLECTION IMPORTANT FOR LGBTQI+ PEOPLE?

Data drive policy decisions. But because LGBTQI people aren't always visible in data, we're not always included in policy or funding. Very few government surveys and forms include questions that allow lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI) people to identify as such. For example, the 2020 Census didn't have sexual orientation or gender identity questions, and only allowed respondents to identify as "male" or "female."

Including questions about sex, sexual orientation, gender identity, and variations in sex characteristics on surveys and forms helps make sure that the experiences and needs of LGBTQI people are studied, considered, and responded to with good policy and meaningful funding. For example:



The **Census Bureau's Household Pulse Survey**, a special survey tracking how COVID-19 is impacting households across the country, was the first Census Bureau survey to include sexual orientation and gender identity questions. Advocates and policy makers have already used this data to understand the impact of the advanced child tax credit on LGBTQI-headed families and to advocate for extending the credit.



Since 2015, the **California Health Interview Survey** has included sexual orientation and gender identity questions, making it possible to see the scope of the challenges facing LGBTQ—and especially transgender—people. As a result, in 2020, the state passed a law creating the

Transgender Wellness and Equity Fund, dedicating more than \$13 million to provide healthcare services for transgender, nonbinary, and intersex people.¹



The Centers for Disease Control and Prevention conducts a survey of high schoolers called the **Youth Risk Behavior Surveillance System**. States can opt to include a module with sexual orientation and gender identity questions. In

Massachusetts, as a result of including this module, the Department of Elementary and Secondary Education developed more inclusive curricula and increased trainings for school staff about the experiences of LGB students.²

Because the LGBTQI population is a relatively small share of the total U.S. population, it can be hard to break out data about specific communities unless the survey has a large number of respondents. That's why it's especially important that questions about sexual orientation, gender identity, and variations in sex characteristics are included in government surveys like the U.S. Census, American Community Survey, the Behavior Risk Factor Surveillance System, the Youth Risk Behavior Surveillance System, and so much more. The large scale of those surveys means the number of respondents is large enough to examine the unique experiences of many different parts of the LGBTQI community, such as LGBTQI people of color, LGBTQI people in rural areas, or transgender youth. For example:



Data from the **2017 Youth Risk Behavior Surveillance System** showed that Asian and Pacific Islander transgender students and Latinx transgender students, in particular, were far more likely than their cisgender peers to experience sexual violence and to engage in risky behaviors such as not wearing a seat belt.³ Without this large-scale survey, analyses of these populations would be impossible.

Another way to understand the importance of inclusive data collection is through seeing what vital information we lack. For example:



Data from **COVID-NET**, the national system that collects information about COVID-related hospitalizations, found that during the first year of the pandemic, people who are Black, American Indian, Alaska Native, Hispanic, Asian, or Pacific Islander were more likely to "have a COVID-19-associated hospitalization, ICU admission, or in-hospital death compared with non-Hispanic White individuals."⁴ However, because COVID-NET does not include measures for sexual orientation, gender identity, or variations in sex characteristics, we do not have similar data to understand whether LGBTQI people are more or less likely to be hospitalized or die due to COVID-19.

These examples illustrate just how important it is for LGBTQI people to be explicitly included in data collection—as well as the harms or losses from being excluded. Being counted on a survey means we can be counted in policy.

THE SIGNIFICANCE OF THE 2022 NASEM REPORT ON MEASURING SEX, GENDER IDENTITY, AND SEXUAL ORIENTATION

In March 2022, the National Academies of Sciences, Engineering, and Medicine (NASEM) released a groundbreaking consensus report about measuring sex, sexual orientation, gender identity, and variations in sex characteristics. This report provides the most current review of existing research and key recommendations for how best to include these questions in a variety of settings including large surveys, clinical settings, and administrative forms.

This report's findings highlight the urgency of including these questions and provides a clear path for doing so. The report's major findings and recommendations include:

- **LGBTQI people deserve to be counted and represented in data collection**, so that they and their unique needs or experiences can then be reflected in policies, programs, and funding.
- **Surveys, research studies, administrative settings, and clinical settings should all include measures of sex, sexual orientation, and gender identity**, as necessary and in a manner that both respects respondents' identities and protects respondents' privacy.
- **In most cases, collecting data on gender is more relevant than collecting data on sex. Data collection efforts should not conflate sex with gender or use those concepts interchangeably.** Focusing on gender over sex is especially important for research on discrimination, disparities, and other life experiences.
- **Specific question wording and formats for measures of sex, sexual orientation, gender identity, and variations in sex characteristics are all included in the report—and the report calls for continued funding and further research to continually improve these recommended measures** as our understandings of LGBTQI identities continue to evolve. And, as the NASEM report focuses on measures for adult audiences, continued research will be especially important for measures for youth.⁵
- **Federal and state governments and others must start, for the first time, collecting meaningful data on intersex populations**, and this report lays out a roadmap for filling this critical gap.

In short, this report shows that these data are vitally important; these questions can be asked (including in major government surveys); and people will answer these

questions. As is the case with any type of demographic data collection, continued research is needed to ensure that the questions keep pace with our evolving understandings of sex, gender identity, and sexual orientation.

While the report calls for more funding for research, waiting any longer to start including these questions on surveys, forms, and in clinical settings is problematic and even harmful. There are clear harms caused by not including these questions; we are left unable to fully understand the experiences of LGBTQI people, to develop sound policies that include LGBTQI people, and to be able to evaluate the effectiveness of policies on addressing disparities for LGBTQI people.

The time is now to include these measures.

WHAT'S NEXT?

This NASEM report is an exciting watershed moment in terms of advancing the inclusion of measures of sex, sexual orientation and gender identity (SOGI), and variations in sex characteristics, in surveys, clinical settings, and administrative forms. It is critical that LGBTQI people are able to identify themselves on surveys about health, economics, experiences in schools, and more. To ensure that this report's recommendations are adopted, there is more work to be done. For example:

- Contact your congresspeople and ask them to push for the adoption of the NASEM recommendations across the federal government—and SOGI and variations in sex characteristics data collection in general—including in COVID-19 testing, care and vaccination.
- Participants in or coordinators of community assessment surveys can ask for those surveys to include questions about SOGI and variations in sex characteristics measures.
- Healthcare organizations can urge policymakers to quickly implement the NASEM report recommendations.
- LGBTQ advocates and allies can include data equity for LGBTQI people in conversations with policymakers, federal, state, and local agencies, and the media and emphasize the clear recommendations for the NASEM report to ensure quick action.
- State and local governments should examine the surveys they conduct and makes sure SOGI and variation in sex characteristic questions are included.

ENDNOTES ¹ [AB 2218](#) (2020). ² Human Rights Campaign Foundation. 2019. [LGBTQ-Inclusive Data Collection: A Lifesaving Imperative](#). ³ Advocates for Youth, Strength in Numbers Consulting Group, & Rhodes Perry Consulting. 2020. [On All Sides: How Race, Ethnicity & Gender Influence Health Risk for Transgender Students of Color](#). ⁴ Acosta, et al. 2021. "Racial and Ethnic Disparities in Rates of COVID-19-Associated Hospitalization, Intensive Care Unit Admission, and In-Hospital Death in the United States From March 2020 to February 2021." DOI:10.1001/jamanetworkopen.2021.30479. ⁵ E.g.: The Trevor Project. 2021. [Measuring Youth Sexual Orientation and Gender Identity](#).