

Sexual Orientation and Gender Identity (SOGI) Data Standards

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Recommended Standards for SOGI Health Data Collection in Massachusetts: Opportunities to Enhance Health Surveillance and Advance Health Equity

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Revision history

Version	Date of Revision	Name of Section/Figure	Summary of Revision
1.1	6/10/2021	 Opportunities to Enhance Health Surveillance and Eliminate Health Inequities: SOGI Data Collection SOGI Data Collection Data Standards: Recommended Standard Data Collection Survey Items 	Updated Assigned Sex at Birth data collection purposes to reflect survey weighting techniques and representation of intersex individuals.
2.0	1/31/2022 Appendix B: Glossary of Terms and References		Updated terms and references to reflect more widely accepted and clearer definitions. Combined Glossary and its References into 1 appendix and cleared unused references.
2.0	11/2023	Change all SOGIE to SOGI	We are not assessing for Gender Expression, so SOGI is more accurate.
2.0	11/2023	Recommended Standards for SOGI Health Data Collection in Massachusetts: Opportunities to Enhance Health Surveillance and	 Changing "achieve" to "advance" in the following sentence is a more accurate aim. Added that revisions were made to the document in spring/summer 2022.

		Advance Health Equity	
2.0	11/2023	Current Gender Identity and Assigned Sex at Birth Questions Current Gender Identity: Recommended DPH Two-Part Question (part 1)	Changed Male to "male; man; boy." Changed Female to "female; woman; girl." To align with the suggestions in the article Transgender data collection in the electronic health record: Current concepts and issues published in Journal of American Medical Informatics Association in January 2022 (https://pubmed.ncbi.nlm.nih.gov/34486655/) as well as the intention not to conflate sex (male/female) with gender (Man/Woman/Nonbinary).
2.0	11/2023	Current Gender Identity and Assigned Sex at Birth Questions Transgender Experience: Recommended Two-Part Question (part 2)	Add the option of "I am questioning" to "not sure" so it reads similar to the sexual orientation and gender identity questions.
2.0	11/2023	Assigned Sex at Birth: Recommended DPH Version	Added the following language so that people who were not assigned intersex at birth could still feel like selecting it was accurate" "Please select if you fall into this category since birth."
2.0	11/2023	Implementation Plan Recommendations	Removed section as it was not polished or actionable.
2.0	11/2023	Change all mentions of "non- binary" to "nonbinary"	To adhere to the GLAAD Media Guide and the Massachusetts Commission on LGBTQ Youth.

2.0	11/2023	Insert 'SOGI History and Rationale' section	Provides direct contextualization and information about how the data standard was created and the decisions made in its creation.
2.0	11/2023	Insert Reporting, Mapping, Bridging section	Provides guidance for bridging from previous data collection options to the standard, guidance for grouping response options in reporting, and overall guidance in analyzing & and reporting on SOGI data as collected.
2.0	11/2023	Insert recommendations on youth and SOGI data collection	Provides guidance on when to start asking about gender identity and sexual orientation when collecting data from people under 18 years old.
2.0	11/2023	Insert Intersex question after Sex Assigned at Birth; inserted language to separate gender identity & sex assigned at birth in the request.	Provides a method for collecting data about intersex experience. Gender questions can be asked separately of sex, intersex status, and sex assigned at birth questions.
2.0	12/2023	Reworded gender identity question.	Acknowledges limitations in gender options that may not perfectly reflect respondents' gender identity. Gender-diverse communities were consulted on this change and preferred the "best describes" language.
2.0	12/2023	Reworded the "Not exclusively male or female" gender response option.	Provides less stigmatizing framing by replacing "something else" with "something additional" and opening with an option that is more general, centering that many cultures and communities use different terms for gender identity not reflected here. Gender-diverse communities were consulted on this

			change and preferred the inclusion of many more identities in this option.
2.0	5/2024	Removed Abbreviated Gender Identity Question	Per recommendation by Commissioner Goldstein, the abbreviated question is not as effective as the 2-step question in capturing gender identity and was removed.
2.0	5/2024	Changed "Gay or lesbian" response option to "Lesbian or gay"	Per recommendation by Commissioner Goldstein, this response option now aligns with other standards.

Initially prepared by a public health consultant in 2015 and substantially edited by the SOGI Data Standards Work Group for the Massachusetts Department of Public Health (DPH), in the fall of 2019. Version 2 was revised in the fall of 2023 and finalized in May 2024.

Purpose

To provide rationale and general guidance for collecting sexual orientation and gender identity (SOGI) data in the Massachusetts health surveillance and service delivery systems.

Background

While the federal government is responsible for setting national health priorities, including to "achieve health equity, eliminate disparities, and improve the health of all groups," states play a key role in monitoring the health of the population. Healthy People 2030 extends a commitment to developing "comprehensive demographic questions to surveys can help inform effective health promotion strategies" including sexual orientation and gender, as well as race and ethnicity, disability status or special health care needs, and geographic location (rural and urban). Rates of illness and death, along with determinants of morbidity and mortality, are tracked through several sources that comprise an overarching health surveillance system. These sources include population-based health surveys such as the Youth Health Survey (YHS), disease registries, health care records and administrative data, injury surveillance systems, infectious disease reports, and vital records. Demographic information varies across these systems both in what demographic information is collected and how these data are collected. The purpose of this document is to make recommendations on both a standardized definition and approach for the inclusion of sexual orientation and gender identity data across the multiple data sources that DPH manages or in which DPH plays a role in the collection and/or dissemination.

¹ National Health Initiatives. 2021. *History of Healthy People*. August 24. https://health.gov/ourwork/national-health-initiatives/healthy-people/about-healthy-people/history-healthy-people.

² Committee on Assuring the Health of the Public in the 21st Centure. 2003. "The future of the public's health in the 21st Century." *National Academies Press.*

³ National Health Initiatives. 2021. *History of Healthy People*. August 24. https://health.gov/our-work/national-health-initiatives/healthy-people/about-healthy-people/history-healthy-people.

Sexual orientation, gender identity and expression, and sex definitions

Sexual orientation is commonly conceptualized as a multidimensional construct that has three primary components: (a) sexual or romantic attraction, (b) sexual behavior (e.g., with different and/or same-gender persons), and (c) identity (e.g., straight or heterosexual, lesbian or gay, bisexual⁴). For the purposes of the recommendations in this document, we will be focusing on sexual orientation as it relates to identity only.

The terms **gender and sex** are often used interchangeably, although they reflect different constructs and, thus, should be assessed with different questions.

Gender is a multidimensional construct that includes identity (e.g., man, woman, genderqueer, nonbinary) and expression (e.g., masculine, feminine, neither masculine nor feminine, or both masculine and feminine, or something else through appearance and behavior).⁵ For this document, we will be focusing on data collection specifically as it relates to gender identity. Understanding gender expression is an important element of understanding discrimination and inequities related to gender expression. However, questions remain around how and when gender expression should be incorporated into surveys, which instruments would be the preferred questions to use, and when it should be collected.

Sex refers to biological variation based on X and Y chromosomes and their expression (e.g., hormone levels, secondary sex characteristics, reproductive anatomy) that exist along a continuum. However, the sex assigned at birth is usually performed by medical staff based on a binary of male or female, using external genitalia as the primary cue in their determination.⁶ Current categorization that relies on a binary does not accurately reflect the full expression of biological sex or individuals who are intersex.

The need for valid measures of gender and a national data standard for sex has been acknowledged by the Institutes of Medicine,⁷ the US Department of Health and Human

⁴ GLAAD. 2023. GLAAD Media Reference Guide - 11th Edition. October 31. https://glaad.org/reference/.

⁵ Spence, JT. 2011. "Off with the old, on with the new." *Psychology Women Quarterly*, 32 ed.: 504-509.

⁶ Krieger, N. 2003. "Genders, sexes, and health: what are the connections - and why does it matter?" *International Journal of Epidemiology* 32 (4): 652-657.

⁷ IOM Institute of Medicine. 2011. "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding." Washington DC.

Services,⁸ and the Centers for Disease Control and Prevention (CDC).⁹ However, in the absence of a single standard, we have recommendations on ways to incorporate demographic variables that encompass the diverse expression of gender, sex, and identity that use intentionally inclusive language.

<u>Current SOGI data collection in Massachusetts: population-based health surveys</u>

Massachusetts has been a leader in monitoring the health of its residents along the lines of sexual orientation by adding a question about the sex of sexual partners ("sexual behavior") to the Youth Risk Behavior Survey (YRBS) in 1993 and a question about sexual orientation identity in 1995. In 2000, a question about sexual behavior was included on the adult Behavioral Risk Factor Surveillance Survey (BRFSS), and a year later, a question to assess sexual orientation that included identities of gay, lesbian, or bisexual was added. The inclusion of these survey items in the YRBS, the Youth Health Survey (YHS), and BRFSS surveillance systems has generated a tremendous amount of information about health inequities (i.e., unfair and avoidable differences in health) between those who identify as gay, lesbian, or bisexual versus those who identify as straight. Health inequities have been observed in many domains of health, such as

⁸ n.d. Improving Data Collection to Reduce Health Disparities. http://www.healthcare.gov/news/factsheets/2011/06/disparities06292011a.thml.

⁹ Beltran, VM, KM Harrison, HI Hall, and HD Dean. 2011. "Collection of Social Determinant of Health Measures in US National Surveillance Systems for HIV, Viral Hepatitis, STDs, and TB." *Public Health Reports* 126: 41-53.

¹⁰ Braveman, PA, S Kumanyika, J Fielding, T Laveist, LN Borrell, R Manderscheid, and A Troutman. 2011. "Health Disparities and Health Equity: The Issue is Justice." *Amerian Journal of Public Health* 149-155.

safety, mental health, substance use, sexual health, and health care access. 11,12,13,14,15 To date, the only sexual orientation categories collected by these surveys in Massachusetts are gay, lesbian, or bisexual.

In 2007, Massachusetts included a transgender status question to identify transgender and cisgender respondents on the adult BRFSS. ¹⁶ The inclusion of this question revealed inequities in employment, economic status, and smoking rates despite comparable levels of education between transgender and cisgender persons. ¹⁵ Analyses of the MA-BRFSS data also suggested a pattern of poorer mental health among a segment of the transgender population. They highlighted the need to include additional response options in question. ¹⁵ In 2013, the MA-BRFSS transgender status question included additional response options; CDC adopted a slightly modified version of this question for inclusion in the national BRFSS survey (optional LGBT module). ¹⁷ In 2013, similar transgender status items were added to the YRBS and the YHS ¹⁸. However, these questions have changed over the past several years and the prior questions may not have accurately captured the transgender status of survey respondents, which can make comparisons across time and populations challenging (see appendix A for questions asked across time for the YHS and BRFSS).

By collecting information around gender identity, sex (assigned at birth), and sexual orientation, these datasets provide important opportunities to monitor population health

¹¹ Corliss, HL, CS Goddenow, L Nichols, and SB Austin. 2011. "High Burden of homelessness among sexual minority adolescents: finding sfrom a representative Massachusetts High School sample." American Journal of Public Health 101 (9): 1683-1689.

¹² Faulkner, AH, and K Cranston. 1998. "Correlates of same-sex sexual behavior in a random sample of Massachusetts high school students." *American Journal of Public Health* 88 (2): 262-266.

¹³ Kann, I, EO Olsen, T McManus, S Kinchen, D Chyen, WA Harris, and H Wechsler. 2011. "Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12-youth risk behavior surveillance, selected sites, United States, 2001-2009." MMWR Surveillance Summit 60 (7): 1-133.

¹⁴ Conron, KJ, MJ Mimiaga, and SJ Landers. 2010. "A population based study of sexual orientation identity and gender differences in adult health." *American Journal of Public Health* 100 (10): 1953-1960.

¹⁵ Conron, KJ, G Scott, GS Stowell, and SJ Landers. 2012. "Transgender health in Massachusetts: Results form a household probability sample of adults." *American Journal of Public Health* 102: 118-122.

¹⁶ 2007-2009. "Behavioral Risk Factor Surveillance Surveys." www.mass.gov/dph/hsp.

¹⁷ Conron, KJ, E Lombardi, and S Reisner. 2014. "Identifying Transgender and Other Gender Minority Resondents on Population Based Surveys: Approaches." In *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys*, by J Heyman, 9-18. Los Angeles: The GenIUSS Group Williams Institute, UCLA.

¹⁸ MA Department of Public Health & Department of Elementary and Secondary Education 2013

and the specific impact of policies (e.g., marriage equality, universal health care access, anti-bullying legislation, extension of many protections against discrimination to transgender individuals) and other macro-level changes and interventions on population health and health inequities. In addition, they highlight that there have been successful efforts to collect this information at a population level through survey data for more than a decade. However, it is acknowledged that not having assigned sex at birth on these surveys¹⁹ can lead to confusion that the inclusion of this question can eliminate. This is something that is highlighted in the recommended questions described below.

SOGI data standardization rationale and history frequently asked questions

1. Why is it important/essential to collect demographic data on sexual orientation and gender identity?

Collecting these data is crucial in understanding and addressing the unique public health needs and challenges of the lesbian, gay, bisexual, transgender, queer and/or questioning, intersex, asexual, and other related (LGBTQIA+) communities, including intersections with other communities across the Commonwealth that experience health inequities. This information will help the Department inform public policy decisions, assess resource allocation, and identify health care needs grounded in evidence-based and data-driven insights.

Furthermore, for health care facilities (funded and/or operated by DPH), this information will be helpful to providers to tailor treatment on an individual level. Understanding the role sexual orientation and gender identity can play in an individual's experiences can help health care professionals provide individual and culturally responsive care.

2. Why were the Massachusetts Department of Public Health (DPH) SOGI data standards developed?

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¹⁹ Braveman, PA, S Kumanyika, J Fielding, T Laveist, LN Borrell, R Manderscheid, and A Troutman. 2011. "Health Disparities and Health Equity: The Issue is Justice." *Amerian Journal of Public Health* 149-155.

The recommendation to develop the SOGI data standards came from three places. First, DPH staff and local researchers recognized the absence of SOGI data for health conditions known to impact LGBTQIA+ individuals and families disproportionately. Second, two state commissions focused on LGBTQIA+ populations recommended that DPH develop SOGI standards: the Commission on LGBTQ Youth and the LGBT Aging Commission. Third, LGBTQIA+ communities expressed to DPH that national standards for SOGI data collection did not reflect nor describe Massachusetts communities' identities or language that was used was stigmatizing to some. This standard is developed to help DPH better reflect its population and their language.

The commitment to improve public health responses included new investments to promote the health of LGBTQIA+ populations informed by community advisory groups and investments in LGBTQIA+ health promotion and services. The formation, continuation, and collaboration with the LGBTQ Youth and Aging Commissions and the dedication of DPH staff have deepened our understanding and commitment to SOGI data collection.

3. How were the MDPH SOGI data standards developed?

Under the initiative of the Office of Population Health (OPH) and Office of Health Equity (OHE), DPH staff representing multiple DPH program areas met to create data standards related to sexual orientation and gender identity and expression (SOGIE). See Question 10 for an explanation of the change from SOGIE to SOGI. When creating these data standards, we consulted with internal and external community groups such as the LGBTQ Youth Commission, the Transgender Health Advisory Group and Gay Men's Health Advisory Group (both of the Bureau of Infectious Disease and Laboratory Sciences (BIDLS)), as well as members on the committee having personal and professional experiences with LGBTQIA+ populations and variables. These data standards were initially approved by the Commissioner's Office under Commissioner Bharel in the summer of 2020 and affirmed by Commissioner Cooke in the Spring of 2023, when the implementation phase of these data standards started with the development of eLearning modules for DPH staff. The first version of the data standards has been used in DPH's COVID-19 Community Impact Survey (CCIS) and several smaller surveys, as well as community engagement opportunities. They are also available in the Massachusetts Virtual Epidemiologic Network (MAVEN), our statewide infectious disease surveillance system.

4. Who were the community members, leaders, and professionals engaged in developing these standards?

We recruited staff with professional and lived experience across DPH, including the Office of Health Equity, Office of Population Health, Bureau of Infectious Disease and Laboratory Sciences, Bureau of Community Health and Prevention, Bureau of Health Care Safety and Quality, Bureau of Substance Addiction Services, and the public health hospitals, as well as the Massachusetts Commission on LGBTQ Youth. The team collaboratively developed new standards with an emphasis on input from internal users of SOGI data and community members whose experiences were not reflected in the current data collection. The team prioritized the creation of standards that were inclusive, respectful, and appropriately reflected the complex nature of the social construction and personal identity of gender and sexual orientation.

We brought the standards to these groups and communities that are centered in the need for measuring SOGI health inequities, including the Massachusetts Commission on LGBTQ Youth, BIDLS's Gay Men's Health Advisory Group and BIDLS's Transgender, Nonbinary, and Gender Expansive Health Advisory Group (formerly known as the Transgender Health Advisory Group), and the Massachusetts State Epidemiology Conference²⁰ to collect feedback from collaborators, community members, and data users.

5. How have these standards impacted understanding health inequities within the LGBTQIA+ communities?

The use of the SOGI data standards within the CCIS allowed analysts to understand how COVID-19 has both inequitably impacted and exacerbated existing inequities among the LGBQ group, people of transgender experience, and/or those who identified as nonbinary. The inequities demonstrated within the data span a range of social domains — including employment, economic and housing stability, access to health care, and social inclusion — and support the importance of increasing the collection of these data in our health and social systems. Results from CCIS respondents indicated that the questions were well-understood, captured meaningful distinctions, and revealed important inequities in exposures and outcomes that would not have been visible using prior data standards.

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²⁰ Prior to original approval of the SOGI draft.

6. Why are the DPH SOGI standards different from other standards in use in Massachusetts and around the country?

When the work group started, the goal was to set a data standard representative of and responsive to Massachusetts residents rather than the entire country. The specific data standards recommendations are informed by our collaborators and reflect the best representation that we could develop for our current time. Because these data standards are designed to represent and are informed by the LGBTQIA+ population in Massachusetts, some items may be different from data standards designed by and for other communities. In the Massachusetts DPH data standard development, this meant choosing to be inclusive in ways that other standards are not so that there is representation of as many identities as current data collection can reasonably accommodate. The "bridging and grouping section" provides guidance for datasets required to submit data conforming to a different standard. If further guidance is needed, please contact DPHDataStandards@mass.gov to initiate technical assistance (TA) with the work group.

7. Why do the DPH SOGI standards have a two-question protocol to ask about transgender identity or experience?

The two-question protocol allows us to collect data about patients' transgender identity or experience without unintentionally "othering" by creating a separate category under gender (woman vs. transgender woman, for example, which implies the woman is only to be selected by cisgender women, further stigmatizing women of transgender experience for some). Asking in this way allows people to fully identify as their gender regardless of how much their gender identity includes being of transgender experience.

8. I've never seen this question before: "Are you transgender or of transgender experience?" Why do you ask this?

There are several reasons DPH recommends this question. First, the formulation of this question follows guidance received from the LGTBQ Youth Commission and BIDLS's Transgender, Nonbinary, and Gender Expansive Health Advisory Group. It allows for data collection of transgender individuals who do not identify as a transgender man or a transgender woman but a man, woman, or nonbinary individual. This also better allows nonbinary individuals to identify as transgender or of transgender experience. Of note, in our first large-scale application of the data standards in CCIS, half of the nonbinary respondents identified as transgender and of transgender experience, suggesting there is a need to

separate these identities/experiences. This method also allows us not to require asking for sex assigned at birth, which transgender community groups have requested.

9. Why does this standard avoid asking for sex assigned at birth?

This reflects what appeared to be a growing consensus in the community that asking about sex assigned at birth risked overshadowing or overwriting a person's lived experience in the minds of the data collector or analyst. Except where relevant for clinical purposes (e.g., when the presence or absence of a given organ affects health outcome), the working group decided that current gender and transgender status were more relevant metrics than the sex assigned at birth.

It is worth noting, however, that this decision has come into question as the work group attempts to capture the experience of intersex people and others for whom sex may be a critical factor in their lived experience and health outcomes.

10. Why don't these standards ask about gender expression?

Gender expression can contribute to inequities. While the work group was initially called the Sexual Orientation and Gender Identity and Expression (SOGIE) Work Group, the team ultimately recognized that without existing metrics to measure gender expression and discrimination, we could not measure gender expression. We intend to keep abreast of research in this arena and if/how gender expression can be measured and how it may inform health equity.

11. Why is self-reporting so important?

Members of the LGBTQIA+ community may or may not disclose parts of their identity to individuals in one's life, or there may be disagreement among different individuals in one's life. Third-party reports of an individual's identity cannot be assumed to be accurate. Demographic data should never be assumed through observation.

12. What if we can't implement self-reported data collection?

The current standards are intended only for self-reported responses. If your data set/system may be one of the limited scenarios where self-reporting is not possible, and you seek support for implementation of the DPH SOGI standards, please contact DPHDataStandards@mass.gov to request technical

assistance. This is also available for any program that has identified other barriers to implementation.

13. Why are we updating the SOGI data standard to include new elements?

Just as our understanding of and language for LGBTQIA+ identities evolve, these data standards occasionally need to be updated to reflect better our understanding of Massachusetts' communities and/or to provide more complete resources for DPH programs to implement these data standards.

This 2024 update includes four new sections: (1) this FAQ that reviews the development process and rationale for the standard as it currently stands; (2) a section providing guidance and recommendations for when to ask a child about sexual orientation and gender identity; (3) a section on grouping, bridging, and reporting; and (4) realizing a gap in our original work not being informed by intersex community members or organizations, we partnered with an external intersex advocacy group to develop and implement recommendations for data collection on intersex individuals (community involvement that was lacking in our first version).

14. Why not eliminate sex and gender altogether?

One of DPH's goals is to address health inequities in communities in Massachusetts. Data are critical to identifying current inequities that we know exist in the LGBTQIA+ communities. DPH cannot appropriately address these health inequities without accurate data reflecting individual identities.

15. What if I need to report data in a system that does not use these standards?

Please review the <u>bridging and grouping section</u> of the standard. If you need further guidance, please reach out to DPHDataStandards@mass.gov.

16. Why do you not include gender options such as Two-Spirit, māhū, travesti, or genderfluid?

Due to limitations of language and pressures to report data, we are unable to list all gender identities and sexual orientations that exist. This is why we frame the question as "best describes" and allow the individual to select the option that is the best fit.

Some gender and sexual orientation terms are culturally specific, and only people within the culture should be able to select these options. However, the ability to program gender or sexuality options based on someone's race or ethnicity is not feasible for most data systems. Second, when reporting data, categories with small numbers are often grouped together to protect confidentiality, and/or analysts must report to systems with fewer options, based exclusively in dominant American English terms. Because of these factors, collecting write-in answers or having more options has the potential to cause data collectors or analysts to mislabel, mis-group, and/or misreport SOGI options. For example, if the SOGI data standards included all the options listed in the appendix for gender, the sample size for many options may be too small to report; to protect confidentiality, they would need to be grouped together. Based on SOGI guidance, each grouped option would need to be stated in the label. which could be cumbersome in some reporting and/or inaccurate to group to the individuals. We intentionally ask respondents to label themselves exactly in the way the data will be reported so that they have choice over how they are grouped. Respondents may always select "I prefer not to answer" if they are not comfortable with the options or groupings listed.

The SOGI Data Standards Work Group encourages people who are working with specific cultural groups to take a community-informed approach in what terms are used within the community as reported by sexual and gender expansive populations, as well as how to map those terms to reporting standards, as a best practice. A step for DPH would be to do this community-informed work of LGBTQIA+ identities within different Massachusetts communities.

Opportunities to enhance health surveillance and eliminate health inequities: SOGI data collection

Massachusetts has abundant opportunities to improve health surveillance systems by modifying records and reporting forms within the Department's control and supplying data that feed disease registries, injury and infectious disease surveillance systems, and vital statistics. DPH can play a leadership role in providing suggested data fields for electronic health record (EHR) systems that will eventually generate records and reports for many sources within the larger health surveillance system. DPH also has an opportunity to track service and program delivery by sexual orientation, gender identity, transgender experience, and assigned sex at birth through affiliated organizations.

Addressing health inequities requires a complete understanding of the health needs of the LGBTQIA+ populations. To be effective in planning public health responses and best serve individual members of the LGBTQIA+ community requires that all DPH programs and offices explicitly ask about these important demographic factors. Data are necessary to ensure appropriate and inclusive services.

Conversely, incomplete and inconsistent collection of demographic data, including sexual orientation and gender identity, impedes statewide and local level response, service, and analysis.

Addendum: intersex data collection

Collecting demographic data on intersex status is essential for understanding possible inequities for intersex residents of Massachusetts. According to interACT, a Massachusetts-based intersex youth advocacy organization, there are over 40 intersex conditions that affect the genitals, internal organs, chromosomes, and/or hormones.²¹ Only asking if a patient or respondent is male or female ignores possible complications regarding internal sex organs, medical history, and/or discrimination facing intersex people. All of these factors could affect the public health needs of intersex individuals in Massachusetts.

In the previous iteration of the Massachusetts DPH SOGI data standards, intersex status was collected in a way that was not community-informed. For this new iteration, the SOGI Data Standards Work Group collaborated with intersex advocates at interACT

²¹ InterACT. 2022. "Intersex Variations Glossary." *Interact Advocates*. https://interactadvocates.org/wp-content/uploads/2022/10/Intersex-Variations-Glossary.pdf.

to develop a more comprehensive understanding of intersex issues and intersex community-informed data standards and guidelines.

This updated version of DPH SOGI data standards includes intersex status informed with guidance from intersex advocates for a more inclusive and comprehensive set of SOGI variables.

Many intersex experts and advocates do not recommend asking for assigned sex at birth with an intersex or "other" option, as all intersex newborns are assigned male or female at birth, even if their condition is known.²² DPH offers two data standards for intersex status: a standalone question, adapted from Gay, Lesbian, & Straight Education Network (GLSEN), a national organization focused on serving LGTBQIA+ youth, or an abbreviated Intersex/Assigned Sex at Birth question, which has been codesigned with intersex advocates to ensure cultural competency and data collection accuracy.

This version of the data standards incorporates recommendations for collecting intersex data. This question captures intersex status and has been designed by GLSEN. This question does not collect assigned sex at birth. If that question is necessary for medical treatment, please use this question in conjunction with the recommended DPH
Assigned Sex at Birth question, which is located in the "Collection of SOGI data standards" section.

The abbreviated version of the intersex question has been codesigned by this workgroup and InterACT to collect both intersex/sex variation characteristic status and assigned sex at birth. This question has specifically been designed not to conflate assigned sex at birth and intersex status and to allow intersex individuals to identify their assigned sex at birth and their intersex/sex characteristic variation status. Since some people may be unfamiliar with the term "intersex" but know they have a sex characteristic variation, both options have been included to ensure accuracy.

Addendum: age recommendations for collecting SOGI data

By collecting demographic information on youth gender identity, sex (or sex assigned at birth), and sexual orientation, important opportunities to monitor population health and implement interventions on population health and health inequities become possible. Health inequities faced by our most vulnerable youth go unseen without proper data on sexual orientation and gender identity (SOGI). Data collection using developmentally

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²² Clark, C. M. & Kosciw, J. G. 2022. "Considerations for Measuring Sexual Orientation and Gender Identity in Surveys of Secondary School Students (Research Brief)." *GLSEN*.

appropriate and culturally informed questions is vital to furthering health equity for future generations.

This section provides recommendations on developmentally appropriate and culturally informed questions to collect SOGI factors, but data teams should clearly define the rationale for collecting such SOGI demographics. Creating actionable data is a priority when asking respondents, especially youth, to answer sensitive questions, such as those about gender and sexual orientation.

When collecting SOGI data from children and youth (ages 0-17), it is essential to ensure the privacy of data for respondents. Children and young people often complete surveys and interviews under the supervision of a parent/guardian who may also have access to the child's records after data collection. This dynamic presents an increased risk of "outing" a child, revealing their sexual orientation or gender identity to people in their life before the child is ready. This forced disclosure can have detrimental impacts on the child's life. These impacts can include bullying from classmates or siblings, discrimination in the classroom, or abuse and/or neglect at home.

Due to the possible adverse outcomes at the individual level of collecting these data, if there is a possibility of exposing respondents' answers to family, peers, and/or other nonconfidential people in their lives (teachers, coaches, bystanders), it is recommended not to collect SOGI factors. Some strategies to ensure the child's confidentiality may include using privacy screen protectors on mobile devices if participants are entering data into an online form, asking the parent/caregiver to step out of the room during a verbal interview, or storing SOGI data separately from data to which the family might have access.²³

Furthermore, it is important to clearly identify why SOGI data are being collected for young children and young people (because the concern can also be present for individuals through 18 or older).

1) When safety and privacy provisions have been taken, and SOGI data collection is justified, the recommendations, modified from the Fenway Institute's recommendations²⁴ for collecting SOGI data from children are as follows:

²⁴ Goldhammer, H, Grasso C, Katz-Wise SL, Thomson K, Gordon AR, Keuroghlian AS. 2022. "Pediatric sexual orientation and gender identity data collection in the electronic health record." J Am Med Inform Assoc. 1303-1309. doi:10.1093/jamia/ocac048.

Office of the Chief Statistician of the United States. 2023. "Recommendations on the best practices for collecting sexual orientation and gender identity data on federal statistical surveys." White House. https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf

a. Sexual orientation question

- i. For children 0-11 years old, do not collect for sexual orientation.
- ii. Start collecting sexual orientation for children ages 12 and up. When collecting sexual orientation for ages 12-17, provide framing around the standard question. The complete question would be as follows:
 - "Some kids have crushes on people who are another gender (heterosexual or straight) or the same gender (lesbian or gay).
 Some people have crushes on people of different genders (bisexual or pansexual), and some people do not have crushes (asexual) or aren't sure yet. Which of the following best describes your sexual orientation? There's no right or wrong answer."
- iii. Although adolescents may not know their sexual orientation identity or engage in sexual behavior, many experience romantic or sexual attractions. Asking about attractions, therefore, may increase the comprehension and accuracy of the answer. Based on cognitive interviews and field tests, an expert panel has recommended using the term crush to indicate attractions with children aged 10–13 years, and the phrase sexual attractions with adolescents aged 14–17 years."²⁵ Rationale: LGB+ children face health inequities, including mental health issues, bullying and violence, STI risk, substance use, and not yet known health inequities. Collecting this factor at this age will help measure and identify these inequities.

b. Gender identity questions

- i. For children 0-2 years old, do not collect for gender identity.
- ii. You may start collecting gender identity for children as young as three (3) years old. While gender identity may be asked as young as three (3) years old, programs should consider the appropriate age to begin asking gender identity questions, specific to program data needs based on privacy concerns (as stated above) and/or usability of data. Best practice includes identifying how gender identity data from youth will answer research question(s) and/or contribute to quality improvement and programmatic development. In alignment with the DPH Health Equity Strategy we highly recommend performing a brief literature review and/or environmental scan to understand if inequities

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²⁵ Goldhammer, H, Grasso C, Katz-Wise SL, Thomson K, Gordon AR, Keuroghlian AS. 2022. "Pediatric sexual orientation and gender identity data collection in the electronic health record." *J Am Med Inform Assoc.* 1303-1309. doi:10.1093/jamia/ocac048.

exist by gender/sex, and therefore among transgender communities, in the given field, and therefore should be collected. Programs and researchers are also encouraged to get technical assistance from the Data Standards Team. For programs that do collect gender identity data for ages 3-5 years old, please reach out to the Data Standards staff to support the continued improvement of SOGI youth data collection.

- iii. When collecting gender identity question for ages 3-17, the following framing around the gender identity question may be provided if appropriate for surveyed youth: "What is your current gender identity? Some kids feel like a girl or woman on the inside, some feel like a boy or man on the inside, and some feel like neither, both, or another gender. What about you? There's no right or wrong answer."²⁶
- iv. For all children, collect sex assigned at birth and intersex status, when otherwise necessary for medical intervention.
- v. Studies show that children's gender identity begins to stabilize and form around 3 or 4 years old, making it the developmentally appropriate time to begin asking this question.²⁷
- vi. Rationale: Children who identify as transgender and/or nonbinary face a host of health equity issues, including mental health issues, routine and culturally incompetent pediatric care, and not yet known health inequities. Collecting this factor in children this age will help measure and identify these equities.
- 2) Additional considerations may be required when collecting data from adults as well. These considerations are twofold: (1) Some adults, due to age, language, or disability, may have family members who assist with providing data and access their data, so similar precautions should be taken to ensure confidentiality. (2) For older adults, many people view the word "queer" as an offensive term for LGBTQ+ people

²⁷ Goldhammer, H, Grasso C, Katz-Wise SL, Thomson K, Gordon AR, Keuroghlian AS. 2022. "Pediatric sexual orientation and gender identity data collection in the electronic health record." *Journal of American Medical Informatics Association*. 1303-1309. doi:10.1093/jamia/ocac048

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²⁶ Goldhammer, H, Grasso C, Katz-Wise SL, Thomson K, Gordon AR, Keuroghlian AS. 2022. "Pediatric sexual orientation and gender identity data collection in the electronic health record." *Journal of American Medical Informatics Association*. 1303-1309. doi:10.1093/jamia/ocac048

and will not select that option as often as youth.^{28,29} We recommend either removing the option "queer" for older adults (ages 65+) or adding the definition (from glossary enclosed) of the term in the selection option.

Collection of SOGI data: recommended standard data collection survey items

Note: Appendix A provides a list of definitions that can be incorporated into these standards settings when and where not all key terms may be general knowledge.

Sexual orientation questions

Construct	Question	When and Where to
		Ask
Sexual Orientation Identity:	Which of the following best	When and where
Recommended DPH Version	describes your sexual	other socio-
	orientation?	demographic
	 □ Asexual □ Bisexual and/or pansexual □ Lesbian or gay □ Heterosexual (straight) 	characteristics are collected. Note: Only include the free text "Other"
	□ Queer□ Questioning/I am not	option if you will be able to utilize this
	sure of my sexuality	data.
	□ Other, specify:	
	☐ I don't understand what this question is asking☐ I prefer not to answer	
Sexual Orientation Identity:	Do you think of yourself as	When and where
Abbreviated*	(check one):	other socio-
	□ Bisexual and/or pansexual	demographic

²⁸ Committee on Measuring Sex, Gender Identity, and Sexual Orientation. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation, Consensus Study Report.* Washington DC: The National Academies Press. doi:https://doi.org/10.17226/26424.

²⁹ SAGE National Resource Center on LGBTQ+ Aging. 2023. "A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity." SAGE National Reource Center on LGBTQ+ Aging. March. https://www.lgbtagingcenter.org/resources/pdfs/SAGE%20SOGI%20Guide%20Final2.pdf.

	Lesbian or gay Straight or heterosexual	characteristics are collected.
	Something else	concotod.
	Don't know	

Current gender identity questions

Construct	Question	When and Where to
	·	Ask
Current Gender Identity:	The following two-part	When and where other
Recommended DPH Two-Part	question pertains to your	socio-demographic
Question (Part 1)	gender identity.	characteristics are
		collected.
	Please select the gender	
	identity that best	
	describes you. Check	
	one, regardless of sex	
	assigned at birth.	
	□ Male; man; boy	
	□ Female; woman; girl	
	□ Not exclusively male	
	or female, nonbinary,	
	and/or something	
	additional ³⁰	
	□ I am questioning/not	
	sure of my gender	
	identity	
	□ I don't understand	
	what this question is	
	asking	
	□ I prefer not to answer	
Transgender Experience:	Are you transgender or of	When and where other
Recommended Two-Part	transgender experience?	socio-demographic
Question (Part 2)	□ Yes	characteristics are
	□ No	collected.

^{*} Adapted from Fenway Health validated question; changes include alphabetizing, adding pansexual, and removing the term "homosexual."

³⁰ Please refer to appendix C for a more expansive list of gender identities.

DPH SOGI data standards V.1.2 (May 2024) for internal use. Data standards are continually under	
development. Check HealthNet for most recent version.	

I am questioning/not	
sure	
I don't understand	
what this question is	
asking	
I prefer not to answer	
	sure I don't understand what this question is asking

Sex, intersex status, and sex assigned at birth questions

Construct	Question	When and Where to
		Ask
Sex, Intersex Status and	What sex were you	When and where
Assigned Sex at Birth:	assigned at birth?	clinical or medical
Recommended	□ Male	information would be
Two-Step Question (Part One,	□ Female	captured for
Assigned Sex at Birth)		diagnostic, screening,
		or risk assessment
		purposes.
		Assigned sex at birth may also be collected for purposes of applying weights to survey data based on national samples.
Sex, Intersex and Assigned	Some people are born	When and where other
Sex at Birth: Recommended	with chromosomes,	socio-demographic
Two-Step Question (Part Two,	hormones, or genitalia	characteristics are
Intersex & Variations of Sex	that do not fit within typical	collected.
Characteristics ³¹⁾	notions of "male" or	NOTE: If sex assigned
	"female" sex. This is	at birth is necessary to
	known as intersex. Many	ask for medical
	learn they are intersex	treatment, use this
	from a medical diagnosis	question in conjunction
	later in life. This is	with the recommended

³¹ Clark, C. M. & Kosciw, J. G. 2022. "Considerations for Measuring Sexual Orientation and Gender Identity in Surveys of Secondary School Students (Research Brief)." GLSEN.

	different from being transgender. Are you intersex? Yes No I'm not sure I don't understand the question I prefer not to answer	option on sex assigned at birth, listed above.
Sex, Intersex Status, and Assigned at Birth Abbreviated Question	The following statements are about someone's sex, assigned sex at birth, and intersex status. Check all that may apply. I was assigned female at birth I was assigned male at birth I am intersex (If you identify as intersex, please check this box in addition to your assigned sex at birth.) I have been diagnosed with a sex characteristic variation (If you have a sex characteristic variation, please check this box in addition to your assigned sex at birth.) I don't understand what this question is asking I prefer not to answer	When and where other socio-demographic characteristics are collected. NOTE: This version is designed to be used in place of the longer form intersex question and the assigned sex at birth question listed below it when programs must abbreviate the questions.

Reporting of SOGI data

Grouping (mutual exclusivity, suppression, & aggregation)

Grouped data are data that have been bundled together into new, less specific categories than the original question options listed on the survey. When collecting SOGI data, question options should <u>not</u> be grouped; all options should be included as they are listed in the recommended standards. When reporting SOGI data, **every effort must be made to use the most specific reporting categories, whenever possible.** When possible, report on the counts for these categories "separately: "I don't understand what this question is asking," "I prefer not to answer," and "Missing."

1. Suppression and aggregation

When data suppression rules must be applied, populations with low counts may have to be suppressed or grouped to protect client privacy. Follow suppression standards when reporting small counts. See <u>Statistical & Analytic Standards</u>: <u>Cell Suppression Data Standards</u>.

If response categories cannot be shown due to the small sample size, the combined categories may be reported as an "other" category with an explicit description of the response categories this aggregated category comprises. List the names of the more granular categories included in the aggregation. The following could be used as an example if "asexual" is included in the "other" category: "Other sexual orientations (including 'asexual' and 'other')."

Please note: It is <u>not</u> recommended to create a single "LGBTQ" reporting group, combining all non-cisgender and/or non-heterosexual (straight) options into a single reporting category. This aggregation would defeat the purpose of the DPH SOGI standards, which is to provide more detailed data on sexual orientation identity, gender identity, transgender experience, and assigned sex at birth. It is okay to group LGBQ / sexual minorities ONLY if the trends are the same for all members of the LGBQ respondents. Responses from the sexual orientation and gender identity questions should not be grouped into one category.

Only aggregate groups to increase numbers if such an aggregation is meaningful. Only do so if the following are true:

- 1) It is necessary for sample size/comparable analyses.
- 2) The groups show similar patterns in outcomes/in relation to reference group.
- 3) Conceptually, the aggregation makes sense.

Please note: grouping transgender and/or nonbinary respondents <u>is permissible</u> for within group analyses. If between-group analyses with cisgender men and cisgender women, be explicit that the nonbinary and/or transgender group includes transgender men and transgender women.

Bridging: nonstandard data and external reporting requirements

Bridging refers to two techniques in the SOGI style guide:

- 1) The method to compare data collected prior to the updated DPH data standards to data collected after the implementation of the SOGI data standards
- 2) The method to map DPH SOGI data values to outside partners' data standards for reporting and grant requirements

Often, it may not make sense to bridge data collected prior to the updated DPH data standards with data collected after implementation of the SOGI data standards. See "Other Reporting Standards" for a standard footnote that can be paired with figures and tables that show both data collected prior to and after the implementation of the standards. If data are not bridged, SOGI options that were not collected prior to standard implementation will appear to emerge in graphs or tables in the year that the standards were added. It is important to remind those interpreting the data that this emergence isn't because that population was not present in years prior, but because granular data were not collected.

If bridging is necessary, recommendations will be determined on a case-by-case basis, as there are too many possible combinations to list in this document. To receive technical assistance on how to bridge your data, please reach out to DPHDataStandards@mass.gov. All cases reviewed by the SOGI Standards team will be maintained in an appendix to guide future bridging needs.

Other reporting standards

Please note: When displaying data for the recommended sexual orientation and gender identity groupings, list groups in alphabetical order, unless there are compelling reasons to do otherwise.

The SOGI Data Standards team has developed a suggested footnote for generating figures and tables with SOGI data that uses the standards, especially in instances where figures and tables may also display data from years prior to SOGI standards implementation. See below:

DPH is committed to routine data quality assurance with the goal of improving all data collection and reporting practices. The Department's goal is to ensure the collection and reporting of the most accurate and

representative data. DPH is actively working on improving its sexual orientation and gender identity (SOGI) data collection and reporting practices based on feedback from subject matter experts and Commonwealth collaborators. When reviewing DPH data reported over time, it is important to note that prior to current SOGI data standards (implemented in [20XX]), the Department's ability to capture and report SOGI data was limited and therefore may not have been representative.

Please note that this is a suggested footnote, which may need to be edited to fulfill the needs of your specific data reporting. Please include the year in which your dataset began incorporating SOGI data standards (see: "[20XX]").

Technical assistance

The above sections are recommendations for the grouping and bridging of SOGI data. If you need more assistance or guidance, please contact DPHDataStandards@mass.gov to initiate the technical assistance process.

Points of contact

- For technical assistance, DPHDataStandards@mass.gov
- Work group leads:
 - SarahEvan Colvario: SarahEvan.Colvario2@mass.gov
 - o Barry Callis: <u>Barry.Callis@mass.gov</u>
 - Sam Chanen: <u>Sam.Chanen2@mass.gov</u>

References

- Anderson, C., D'Augelli, A., Garnets, L., Herek, G., Kimmel, D., Peplau, L. A., & Rothblum, E. 1991. "Avoiding Heterosexual Bias in Language." *American Psychologist* 973-974. https://www.apa.org/pi/lgbt/resources/language.aspx.
- Arrigotti, M., Chase, K., Dinno, A. 2022. *Preliminary (Year 1) Report to OHA on Pediatric SOGI: Executive Summary. Report to Oregon Health Authority.*Portland, OR: Oregon Health Authority Office of Equity and Inclusion. https://archives.pdx.edu/ds/psu/37823.
- 2007-2009. "Behavioral Risk Factor Surveillance Surveys." www.mass.gov/dph/hsp.
- Beltran, VM, KM Harrison, HI Hall, and HD Dean. 2011. "Collection of Social Determinant of Health Measures in US National Surveillance Systems for HIV, Viral Hepatitis, STDs, and TB." *Public Health Reports* 126: 41-53.
- Braveman, PA, S Kumanyika, J Fielding, T Laveist, LN Borrell, R Manderscheid, and A Troutman. 2011. "Health Disparities and Health Equity: The Issue is Justice."

 Amerian Journal of Public Health 149-155.
- Bureau of Primary Health Care. 2018. *Uniform Data System Reporting Instructions for 2018 Health Center Data.* December 6. https://bphc.hrsa.gov/sites/default/files/bphc/data-reporting/2018-uds-reportingmanual.pdf.
- Clark, C. M. & Kosciw, J. G. 2022. "Considerations for Measuring Sexual Orientation and Gender Identity in Surveys of Secondary School Students (Research Brief)." *GLSEN*.
- Committee on Assuring the Health of the Public in the 21st Centure. 2003. "The future of the public's health in the 21st Century." *National Academies Press*.
- Committee on Measuring Sex, Gender Identity, and Sexual Orientation. 2022.

 Measuring Sex, Gender Identity, and Sexual Orientation, Consensus Study
 Report. Washington DC: The National Academies Press.

 doi:https://doi.org/10.17226/26424.
- Conron, KJ, E Lombardi, and S Reisner. 2014. "Identifying Transgender and Other Gender Minority Resondents on Population Based Surveys: Approaches." In Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys, by J Heyman, 9-18. Los Angeles: The GenIUSS Group Williams Institute, UCLA.

- DPH SOGI data standards V.1.2 (May 2024) for internal use. Data standards are continually under development. Check HealthNet for most recent version.
- Conron, KJ, G Scott, GS Stowell, and SJ Landers. 2012. "Transgender health in Massachusetts: Results form a household probability sample of adults."

 American Journal of Public Health 102: 118-122.
- Conron, KJ, MJ Mimiaga, and SJ Landers. 2010. "A population based study of sexual orientation identity and gender differences in adult health." *American Journal of Public Health* 100 (10): 1953-1960.
- Corliss, HL, CS Goddenow, L Nichols, and SB Austin. 2011. "High Burden of homelessness among sexual minority adolescents: finding sfrom a representative Massachusetts High School sample." *American Journal of Public Health* 101 (9): 1683-1689.
- Faulkner, AH, and K Cranston. 1998. "Correlates of same-sex sexual behavior in a random sample of Massachusetts high school students." *American Journal of Public Health* 88 (2): 262-266.
- GLAAD. 2023. *GLAAD Media Reference Guide 11th Edition*. October 31. https://glaad.org/reference/.
- Goldhammer, H, Grasso C, Katz-Wise SL, Thomson K, Gordon AR, Keuroghlian AS. 2022. "Pediatric sexual orientation and gender identity data collection in the electronic health record." *Journal of American Medical Informatics Association* 1303-1309. doi:10.1093/jamia/ocac048.
- Human Rights Campaign. 2020. *Health Disparities Among Bisexual People*. https://www.hrc.org/resources/health-disparities-among-bisexual-people.
- n.d. *Improving Data Collection to Reduce Health Disparities*. http://www.healthcare.gov/news/factsheets/2011/06/disparities06292011a.thml.
- InterACT. 2022. "Intersex Variations Glossary." *Interact Advocates*. https://interactadvocates.org/wp-content/uploads/2022/10/Intersex-Variations-Glossary.pdf.
- IOM Institute of Medicine. 2011. "The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding." Washington DC.
- Kann, I, EO Olsen, T McManus, S Kinchen, D Chyen, WA Harris, and H Wechsler. 2011. "Sexual identity, sex of sexual contacts, and health-risk behaviors among students in grades 9-12-youth risk behavior surveillance, selected sites, United States, 2001-2009." MMWR Surveillance Summit 60 (7): 1-133.

- DPH SOGI data standards V.1.2 (May 2024) for internal use. Data standards are continually under development. Check HealthNet for most recent version.
- Krieger, N. 2003. "Genders, sexes, and health: what are the connections and why does it matter?" *International Journal of Epidemiology* 32 (4): 652-657.
- Lau, Josephine S, Andrea Kline-Simon, Stacy Sterling, J Carlo Hojilla, and Lauren Hartman. 2021. "Screening for Gender Identity in Adolescent Well Visits: Is It Feasible and Acceptable?" *J Adolesc Health* 1089-1095. doi:10.1016/j.jadohealth.2020.07.031.
- LGBTQIA Health Education. 2020. "LGBTQIA+ Glossary of Terms for Health Care Teams." *LGBTQIA Health Education*. August 30. https://www.lgbtqiahealtheducation.org/wp-content/uploads/2020/10/Glossary-2020.08.30.pdf.
- MA Department of Public Health and Department of Elementary and Secondary Education. 2013. *Massachusetts Youth Health Survey*. https://www.mass.gov/lists/massachusetts-youth-health-survey-myhs.
- Massachusetts Commission on LGBTQ youth. 2019. *Annual recommendations Commission on LGBTQ Youth.* https://www.mass.gov/lists/annual-recommendations-commission-on-lgbtq-youth.
- Merriam Webster Dictionary. 2020. *Definition of Agender*. May 15. https://www.merriam-webster.com/dictionary/agender.
- National Health Initiatives. 2021. *History of Healthy People*. August 24. https://health.gov/our-work/national-health-initiatives/healthy-people/about-healthy-people/history-healthy-people.
- National LGBTQIA+ Health Education Center. 2018. "Ready Set Go! Guidelines and Tips for collecting patient data on Sexual Orientation and Gender Identity." National LGBTQIA+ Health Education Center, a program of the Fenway Institute. Accessed 2018. https://www.lgbtqiahealtheducation.org/publication/ready-set-go-a-guide-for-collecting-data-on-sexual-orientation-and-gender-identity-2022-update/.
- Office of the Chief Statistician of the United States. 2023. "Recommendations on the best practices for the collection of sexual orientation and gender identity data on federal statistical surveys." *White House.* https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf.
- SAGE National Resource Center on LGBTQ+ Aging. 2023. "A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity." SAGE National Reource Center on LGBTQ+ Aging. March.

- DPH SOGI data standards V.1.2 (May 2024) for internal use. Data standards are continually under development. Check HealthNet for most recent version.
 - https://www.lgbtagingcenter.org/resources/pdfs/SAGE%20SOGI%20Guide%20Final2.pdf.
- Spence, JT. 2011. "Off with the old, on with the new." *Psychology Women Quarterly*, 32 ed.: 504-509.
- Spock, Alison, Ronna Popkin, and Christopher Barnhart. 2022. "Strategies to Improve Measurement of Sexual Orientation and Gender Identity Among Youth." *J Adolesc Health* 662-664.
- The Asexual Visibility & Education Network. 2023. *Overview of Asexuality*. https://asexuality.org/?q=overview.html.

Appendix A: Survey Reference Questions

Behavioral Risk Factor Surveillance System (BRFSS)

Year	Question	Answer choices
1986-2011	INTERVIEWER: INDICATE SEX OF RESPONDENT (ASK IF NECESSARY)	FemaleMaleMissing (coded)
2012-2018	What is your sex?	FemaleMaleRefused
2007-2012	Do you consider yourself to be transgender?	YesNoDon't knowRefused
2013-2017	Do you consider yourself to be transgender?	 Yes, transgender, male to female Yes, transgender, female to male Yes, transgender, gender (variant) non-conforming No Don't know Refused
2001-2010	Do you consider yourself to be: [Among adults ages 18- 64]	 Heterosexual or straight, Homosexual or gay/lesbian Bisexual Other Don't know Refused
2011-2017	Do you consider yourself to be: [Among all ages]	 Heterosexual or straight, Homosexual or gay/lesbian Bisexual Other Don't know Refused

Youth Health Survey (YHS)

Year	Question	Answer choices
2003, 2005	What is your sex?	FemaleMaleMissing (coded)
2007, 2009, 2011, 2013	What is your sex? (High School & Middle School)	
k (What is your sex? (HS & MS)	FemaleMaleMissing (coded)
	Which of the following best describes you? (HS only)	Heterosexual (straight)Gay or lesbianBisexualNot sure
	A transgender person is someone whose biological sex at birth does not match the way they think or feel about themselves. Are you transgender? (HS only)	 No, I am not transgender Yes, I am transgender and I think of myself as really a boy or man Yes, I am transgender and I think of myself as really a girl or woman Yes, I am transgender and I think of myself in some other way I do not know if I am transgender I do not know what this question is asking

Appendix B: Glossary of Terms

Agender (adj.): a person who has an internal sense of being neither male nor female nor some combination of male and female: of, relating to, or being a person whose gender identity is genderless or neutral.³²

Asexual (adj.): An asexual person does not experience sexual attraction — they are not drawn to people sexually and do not desire to act upon attraction to others in a sexual way. Unlike celibacy, which is a choice to abstain from sexual activity, asexuality is a sexual orientation.³³

Assigned sex at birth or sex assigned at birth (noun): The sex assigned to an infant, often based on the infant's biological and anatomical characteristics. Sometimes referred to as "birth sex," but avoid that term.³⁴

Bisexual (adj.): Describes a person who is physically, romantically, and/or emotionally attracted to more than one gender, not necessarily at the same time, in the same way, or to the same degree. The "bi" in bisexual refers to genders the same as and different from one's own gender.³⁵

Cisgender (adj.): Describes a person whose gender identity aligns with their assigned sex at birth, based on traditional expectations (e.g., a person assigned female sex at birth whose gender identity is woman/female).³⁶

Gay (adj.): Describes a person who is primarily physically, romantically, and/ or emotionally attracted to people of the same sex and/or gender as themselves. While often used to describe men who are primarily attracted to men, it can also describe women who are attracted to women. ("Homosexual" is the outdated clinical term which is sometimes considered offensive.)³⁷

³² https://www.merriam-webster.com/dictionary/agender

³³ https://www.asexuality.org/?q=overview.html

³⁴ https://health.ucdavis.edu/diversity-inclusion/LGBTQI/LGBTQ-Plus.html

³⁵ https://glaad.org/reference/terms/

 $^{^{36}\} https://health.ucdavis.edu/diversity-inclusion/LGBTQI/LGBTQ-Plus.html$

³⁷ https://glaad.org/reference/terms/

Gender (noun): A multidimensional construct that includes identity (e.g., man, woman, genderqueer, nonbinary) and expression (e.g., masculine, feminine, neither masculine nor feminine, or both masculine and feminine, or something else through appearance and behavior).

Gender identity disorder (GID) (noun): outdated, see "gender dysphoria." 38

Gender dysphoria (noun): Gender dysphoria is the feeling of discomfort or distress that might occur in people whose gender differs from their sex assigned at birth or sex-related physical characteristics based on traditional expectations. Not all transgender individuals experience dysphoria. Gender dysphoria is a diagnosis listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and was created to help people get access to necessary health care and effective treatment. Some transgender health advocates believe the inclusion of gender dysphoria in the DSM is necessary in order to advocate for health insurance that covers the medically necessary treatment recommended for transgender people. (Gender identity disorder, GID, is the outdated clinical term which is sometimes considered offensive.)³⁹

Gender euphoria (noun): Gender euphoria is the positive, comfortable feeling that occur when one's gender is affirmed through external forces. Some ways that transgender and nonbinary people achieve gender euphoria can be through being referred to with the correct name and pronouns, affirming clothing, gender affirming surgery, hormone therapy, and more. It is the opposite of gender dysphoria and is not a DMS-5 diagnosis.⁴⁰

Gender identity (noun): A person's inner sense of being a girl/woman/female, boy/man/male, something else, or of having no gender. Gender identity may or may not correspond in a traditional sense with the person's assigned sex at birth.⁴¹

Gender expression (noun):

1. The way a person communicates their gender to the world through behaviors and characteristics like clothing, mannerisms, and speech.

³⁸ https://glaad.org/reference/trans-terms

³⁹ ibid

⁴⁰ https://www.thetrevorproject.org/research-briefs/affirming-actions-and-gender-euphoria-among-transgender-and-nonbinary-young-people/#:~:text=Background-,Gender%20euphoria%20is%20defined%20as%20satisfaction%20or%20joy%20caused%20when,many%20transgender%20and%20nonbinary%20people.

⁴¹ https://www.uwmedicine.org/practitioner-resources/lgbtq/lgbtq-inclusion-glossary

2. External manifestations of gender, expressed through a person's name, pronouns, clothing, haircut, behavior, voice, and/or body characteristics. Society may identify these cues as masculine and feminine, although what is considered masculine or feminine changes over time and varies by culture.⁴²

Gender nonbinary or nonbinary (adj.): An umbrella term used by some people who experience their gender identity as falling outside the categories of man and woman. They may define their gender as falling somewhere in between man and woman, or they may define it as wholly different from these terms. The term is not a synonym for transgender. Many nonbinary people identify as transgender and many do not. ⁴³

Genderqueer or gender queer (adj.): An umbrella term that describes a person whose gender identity falls outside the traditional gender binary of male and female. Some people use the term gender expansive.⁴⁴

Heterosexual/straight (adj.): A sexual orientation that generally describes women (including transgender women) who are primarily physically, romantically, and/ or emotionally attracted to men, and men (including transgender men) who are primarily physically, romantically, and/ or emotionally attracted to women.⁴⁵

Intersex (adj.): Describes any of a group of congenital conditions in which the reproductive organs, genitals, and/or other anatomy do not develop according to traditional expectations for females and males. Intersex can also be used as an identity term for someone with one of these conditions, as an alternative to "male" or "female." The term "sex characteristic variations" is sometimes used to describe intersex conditions. Avoid the outdated and derogatory term "hermaphrodite." While some people can have an intersex condition and identify as transgender, the two are separate and should not be conflated.⁴⁶

Lesbian (adj., noun): Describes a woman who is primarily physically, romantically, and/ or emotionally attracted to other women.⁴⁷

transformation/intersex#:~:text=Describes%20a%20group%20of%20congenital,with%20one%20of%20these%20conditions.

⁴² https://glaad.org/reference/trans-terms

⁴³ ibid

⁴⁴ https://health.ucdavis.edu/diversity-inclusion/LGBTQI/LGBTQ-Plus.html

⁴⁵ https://lgbtqia.ucdavis.edu/educated/glossary#h

⁴⁶ https://www.bmc.org/glossary-culture-

⁴⁷ https://glaad.org/reference/terms

LGBTQIA+: An acronym for lesbian, gay, bisexual, transgender, queer and/or questioning, intersex, asexual, and others. May be shortened to LGBT, LGBTQ+, etc. depending on context.⁴⁸

Pansexual (adj.): Describes a person who is physically, romantically, and/ or emotionally attracted to people of all genders, or whose attractions are not related to other people's gender.⁴⁹

Person of transgender experience (noun): An umbrella term for people whose gender identity differs from the sex they were assigned at birth. People under the transgender umbrella may describe themselves using one or more of a wide variety of terms — including transgender or of transgender experience. Transgender people may be prescribed hormones by their doctors and/or undergo gender affirmation surgeries to bring their bodies into alignment with their gender identity, but not all transgender people can or will take those steps. A transgender experience or identity is not dependent upon physical appearance or medical procedures.⁵⁰

Queer (adj.): An umbrella term describing people who view their sexual orientation or gender identity as outside of societal norms. While queer has historically been used as a slur, many have reclaimed it as a term of empowerment.⁵¹

Questioning (adj.): Describes someone who is unsure about or is exploring their sexual orientation and/or gender identity.

Sex (noun): See assigned sex at birth.

Sexual orientation (noun): The way a person characterizes their physical, romantic, and/ or emotional attraction to others. Avoid the offensive term "sexual preference," which is used to suggest that being gay, lesbian, or bisexual is voluntary and therefore "curable." People need not have had specific sexual experiences to know their own sexual orientation; in fact, they need not have had any sexual experience at all.⁵²

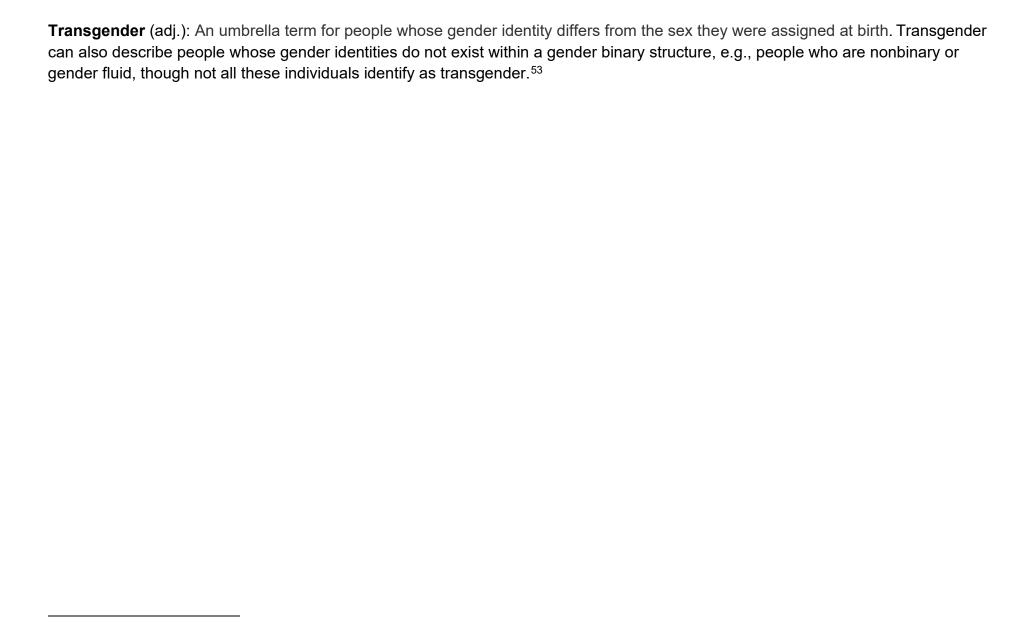
⁴⁸ ibid

⁴⁹ ibid

⁵⁰ https://www.hrc.org/resources/sexual-orientation-and-gender-identity-terminology-and-definitions

⁵¹ https://glaad.org/reference/terms

⁵² ibid



⁵³ https://glaad.org/reference/trans-terms

Appendix C: List of Gender Identities

The following list of comes from the National Center for Transgender Equality (NCTE) 2015 US Transgender Survey.⁵⁴ The results and full questions for the 2022 US Transgender Survey are forthcoming.

Which of these terms do you identify with? (Mark all that apply.)

- 1. A.G. or aggressive
- 2. Agender
- 3. Androgynous
- 4. Bi-gender
- 5. Butch
- 6. Bulldagger
- 7. Cross dresser
- 8. Drag performer (king/queen)
- 9. Fa'afafine
- 10. Gender non-conforming or gender variant
- 11. Genderqueer
- 12. Gender fluid/fluid
- 13. Intersex
- 14. Māhū
- 15. Multi-gender
- 16. Nonbinary
- 17. Third gender
- 18. Stud
- 19. Transgender

⁵⁴ <u>https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf</u>

- 20. Trans
- 21. Trans man (FTM, female to male)
- 22. Transsexual
- 23. Trans woman (MTF, male to female)
- 24. Travesti
- 25. Two-spirit
- 26. A gender not listed above (please specify)_____

Additionally, there is a listing of genders and definitions across the world listed at pbs.org/independentlens/content/two-spirits maphtml.

Appendix D: Health Equity Style Guide: Sexual Orientation

Health Equity Style Guide: Sexual Orientation

Topic Overview:

Sexual orientation refers to how a person describes their emotional and/or sexual attraction towards others.¹ It is often conceptualized as a multidimensional construct with three principal components: sexual or romantic attraction, sexual behavior (i.e., with different and/or same-gender persons) and identity (the way a person self-identifies with a sexual orientation). Sexual orientations include straight, gay, lesbian, bisexual, queer, pansexual, and asexual.² Same-sex or same-gender sexual behavior does not always coincide with a lesbian, gay, or bisexual identity. Both identification and behavior can be fluid and change over time. Labels used to describe one's sexual orientation also vary in meaning and use among ethnic, racial, cultural, socioeconomic, and age groups.

Sexual orientation/gender identity (SOGI) data collection has increased with greater recognition of the inequities in health and health care that sexual minority individuals experience. These inequities are often a result of stigma, discrimination, denial of rights, and lack of provider awareness.³ They may also be more pronounced for people of color, or as a result of factors such as income, geographic location, and immigration status.⁴ Inequities also often differ within the LGBTQ community; for example, studies suggest that bisexual women report lower levels of mental and emotional well-being than both lesbian and heterosexual women.⁵ To address health and health care inequities for LGBTQ individuals and families, the Massachusetts Department of Public Health has established SOGI data collection standards for publicly funded services to characterize and inform responses to address them.

General Recommendations:

Below are some recommendations for how to talk about this topic in your work.

- Ask the individual or group for their preferred terminology regarding sexual orientation (including how they refer to their relationships or partners).
- Because health risks and concerns can differ depending on sexual orientation, avoid grouping people of different sexual orientations together (e.g., grouping bisexual, lesbian, and gay participants together into one "LGB" group).
- Avoid conflating sexual orientation with gender identity. Though the commonly used umbrella acronym "LGBTQ" (lesbian, gay, bisexual, transgender, queer or questioning) refers to both sexual orientation and gender identity, these concepts are distinct and not correlated.

- Avoid language and sentence structure that perpetuate stigma (e.g., in the sentence, "Program staff work with special populations such as gay men, drug abusers, and the currently incarcerated," the parallel grammatical structure suggests equivalence between being gay, using drugs, and committing a crime).
- Reduce heterosexual bias (sometimes known as heterosexism) in writing:
 - When referring to activities that are usually only associated with heterosexual people (e.g., parenting), use examples with people of other sexual orientations, such as lesbians, gay men, or bisexual people.
 - Only include reference to a person's marital status or sexual orientation if relevant.
 - Refer to sexual and romantic partners with multiple gender terms or without reference to gender (e.g., "Women taking the survey were asked whether they had ever been insulted on social media by a date, partner, or spouse" rather than "by a date, boyfriend, or husband").
 - o Use sexual terminology that is relevant to people of all sexual orientations ("sexual activity" rather than "sexual intercourse").

Top Terms

Below are terms to use and terms not to use when talking about this topic. Make sure to consult experts in the field if you are unsure about the use of a word.

Description	Terms to Use	Terms NOT to Use
LGBTQ (lesbian, gay, bisexual, transgender, queer or questioning) describes the community in broad terms. It is not explicitly inclusive of all genders or sexual orientations (e.g., intersex or asexual individuals, or those who don't identify with a labeled identity). The acronyms "LGB" or "LGBQ" are also used to talk about groups or data defined by sexual orientation, rather than gender; therefore these groups may or may not include transgender or gender-nonconforming individuals. ⁷	LGBTQIA, LGBTTQ+, LGBTQ, GLBT, LBG, LGBQ, LGBQQTIA2-S (lesbian, gay, bisexual, queer, questioning, transgender, intersex, asexual, two-spirit), LGBQ	

These terms focus on the person and their identification. The terms not to use have been associated with pathology in the past and may perpetuate negative stereotypes. ⁶ Note: "Queer" is an umbrella term that describes people who identify as outside of the societal norms in regards to sexual orientation, sexual/romantic behaviors, and gender identity. The term was formerly considered derogatory and is still considered as such by certain communities, particularly among older generations. Some people, especially youth, view its use and reclamation as a political act that challenges gender and sexual binaries. ⁷ Queer can be appropriate to use when referring to a broader community (e.g., queer people), but avoid the use of "queer" in reference to an individual unless they have said that that is how they identify.	Gay, gay male, gay person/people, lesbian, bisexual, heterosexual, gray-a, sexual orientation, bisexual persons, bisexual women and men, pansexual, queer, questioning, sexual minority, sexual minority youth	Sexual preference, lifestyle choice, gay lifestyle, non-straight Lesbianism, heterosexuality, homosexuality, bisexuality Homosexual
Words like "openly" or "out" describe someone who has self-identified as lesbian, gay, or bisexual in their public, professional, and/or personal lives. These terms are often used as shorthand, even though in reality there are many complexities to how, when, and to whom a person may be "out." The terms "admitted" or "avowed" imply the disclosure of a secret or of something shameful. ⁸	Openly lesbian, openly gay, openly bisexual, out	Admitted homosexual, avowed homosexual
These terms are used to describe sexual behavior, regardless of self-identified sexual orientation.	Male-male sexual behavior, same-gender sexual behavior, female-female sexual behavior, male- female sexual behavior	Opposite-sex behavior
These terms are common in scientific literature and are used to describe people and their sexual behaviors. The terms are imprecise and may neither reflect nor honor people's identities (e.g., sometimes "MSM" includes transgender women and excludes transgender men).		Men who have sex with men (MSM), Women who have sex with women (WSW) ⁶

Data Definitions

The sources listed below include data regarding sexual orientation. Sources differ in the number of sexual orientation components collected, and thus differ in sexual orientation definition. Survey questions regarding multiple components of sexual orientation (i.e., identity, attraction, and behavior) measure separate constructs. Responses that appear to lack correspondence may not necessarily indicate a data quality issue.

NOTE: Some of these sources use questions that ask about the respondent's attraction and/or sexual activity with males and females in order to categorize the respondent's sexual orientation. In doing so, these sources both perpetuate the gender binary and limit one's ability to accurately identify their sexual orientation.

Data Source	Definition	Population
Massachusetts High School Youth Health Survey	Identity: 2007 – present Which of the following best describes you? Heterosexual; Gay or Lesbian; Bisexual; Not Sure Behavior: Topic added: 2011; Current question added: 2013 During your life, with whom have you had sexual contact? I have never had sexual contact; Females; Males, Females and males	MA public HS students
Massachusetts Comprehensive Rape Crisis Centers Incident Reports	Identity: Self-identified sexual orientation at time of assault: Heterosexual; Lesbian; Gay; Bisexual; Questioning/ Undecided; Not Yet Identifying Due to Age; Other Sexual Orientation; Unknown/Undisclosed Sexual Orientation	Survivors of sexual assault who reported the incident to a MA rape crisis center
Youth Risk Behavior Survey (YRBS)	Which of the following best describes you? Heterosexual (straight); Gay or lesbian; Bisexual; Not sure Behavior: Added 2015 (Q67) During your life, with whom have you had sexual contact? I have never had sexual contact; Females; Males; Females and males	MA public high school students

Behavior Risk Factor Surveillance Survey (BRFSS)	Identity: Which of the following best represents how you think of yourself? Lesbian or Gay (if R male, Gay); Straight, that is, not gay; Bisexual; Something Else; I don't know the answer; Refused	U.S. adult civilian, noninstitutionalized population aged 18+
MA Violent Death Reporting System (MAVDRS)	Identity: Added August, 2013 This variable is used to report sexual orientation. Response options include heterosexual, gay, lesbian, bisexual, or unknown and are coded based on interviews of friends, family or acquaintances. This variable is only coded if the information is reported in the LE or CME report. Sexual orientation is not inferred from marital status, and if not explicitly reported, is recorded as 'unknown'. This information is not collected systematically, and definitive information on sexual orientation may not be available.	MA victims of violent death (homicides, suicides, unintentional firearm deaths, legal intervention deaths, and deaths of undetermined intent)
National Survey of Family Growth (NSFG)	Identity: 2006-2013 (ORIENT) Do you think of yourself as Heterosexual or straight; Homosexual or Gay [If R is female then Lesbian]; Bisexual; Something else; (Don't Know); (Refused) Sexual Attraction: 2002, 2006-2010, 2011- 2013 (ATTRACT) People are different in their sexual attraction to other people. Which best describes your feelings? Are you [If R is male] Only attracted to females; Mostly attracted to females; Equally attracted to females and males; Mostly attracted to males; Only attracted to males; Not sure [If R is female] Only attracted to males; Mostly attracted to males; Equally attracted to males and females; Mostly attracted to females; Only attracted to females; Not sure Sexual Behavior: 2002, 2006-2010, 2011- 2013 NSFG includes questions on a wider range of sexual activities—including oral and anal sex with opposite-sex partners and sexual contact with same-sex partners (See report for sexual behavior questions: http://www.cdc.gov/nchs/data/nhsr/nhsr036.pdf).	U.S. adult civilian, noninstitutionalized population aged 15- 44
National Crime Victimization Survey (NCVS)	Identity: July 2016*- present Which of the following best represents how you think of yourself? [If R is female then Lesbian or] Gay; Straight, that is, not [If R is female then Lesbian or] Gay; Bisexual; Something else; I don't know the answer;(Refused) *Earlier versions of the survey (2001-2015) collected respondent sexual orientation only for respondents who indicated their belief that they were targeted by the offender because of their sexual orientation.	U.S. adult civilian, noninstitutionalized population aged 16 and older

American Community Survey (ACS)	The ACS does not ask SOGI questions. It includes questions regarding the relationship and sex (Male or Female) of each household member to the respondent, as well as the respondent's sex. This allows for the determination of whether the respondent has a same-sex or different-sex partner within their household.	U.S. residents (includes institutional and non-institutional group quarters residents)
National Health	Identity: Topic added: 2013; Current question added: 2015	U.S. adult civilian,
Interview Survey	(ACISIM/F) Which of the following best represents how you think of yourself?	noninstitutionalized
(NHIS)	[If R is female then Lesbian or] Gay; Straight, that is, not [If R is female then Lesbian or] Gay; Bisexual; Something else; I don't know the answer; (Refused)	population aged 18- 59
National Survey of	Identity: Added 2015	U.S. adult civilian,
Drug Use and	(QD63) Which one of the following do you consider yourself to be?	noninstitutionalized
Health (NSDUH)	Heterosexual, that is, straight; [If R is female then Lesbian or] Gay; Bisexual; (Don't Know); (Refused) Attraction: Added 2015	population aged 18 and older
	(QD62) People are different in their sexual attraction to other people. Which best describes your feelings? [If R is male]	
	I am only attracted to females; I am mostly attracted to females; I am equally attracted to females and males; I am mostly attracted to males; I am not sure (Don't Know); (Refused) [If R is female]	
	I am only attracted to males; I am mostly attracted to males; I am equally attracted to males and females; I am mostly attracted to females; I am not sure (Don't know); (Refused)	
Population	Identity: Topic added:2013; Current question added: 2014	U.S. civilian,
Assessment of	(R02_AM0063/R03_AM0063) Do you consider yourself to be	noninstitutionalized
Tobacco and Health (PATH)	Straight; Lesbian or Gay; Bisexual; Something else; Don't know; Refused	population aged 14 and older
5,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	Attraction: Topic added 2013; Current question added: 2015	
DHHS/ NIH and DHHS/FDA	(R01_AM0021) The next question asks about your level of sexual attraction to BOTH males and females. Please consider the response choices carefully, as it is important that you understand them and are as honest as you can be in your answer.	
	To whom have you felt sexually attracted, even if you did not take any action based on feeling attracted?	
	Only to females, never to males; Mostly to females, and at least once to a male; About equally often to females and	
	to males; Mostly to males, and at least once to a female; Only to males, never to females; I have never felt sexually attracted to anyone at all; Don't Know; Refused	

Health Center Patient Survey (HCPS) DHHS/HRSA/ BPHC	Identity: Added 2014 (DMO8a] Do you think of yourself as straight or heterosexual, as gay, lesbian or homosexual, or as bisexual? Straight or heterosexual; Gay, Lesbian, homosexual; Bisexual; Not sexual/celibate/none; Other, please specify	All federally funded health center patients, ages 15 and older. Surveys were available in English, Spanish, Chinese, Korean, and Vietnamese.
National Adult	Identity: 2012-2014	U.S. adult civilian,
Tobacco Survey (NATS)	(SEXUALORIENT1) Do you think of yourself as? [If R is female then Lesbian or] Gay; Straight, that is, not [If R is female then Lesbian or] Gay; Bisexual;	noninstitutionalized population aged 18
,	Something else; (Don't Know); (Refused)	and older
DHHS/CDC	[If R selects "Something else" in SEXUALORIENT1] (SEXUALORIENT2) By something else, do you mean that	
	You are not straight, but identify with another label such as queer; trisexual, omnisexual or pansexual; You are transgender, transsexual or gender variant; You have not figured out your sexuality or are in the process of figuring it out; You do not think of yourself as having sexuality; You do not use labels to identify yourself; You made a mistake and did not mean to pick this answer; You mean something else; (Don't Know); (Refused) [If R selects "You mean something else" in SEXUALORIENT2] (SEXUALORIENT3)You gave "Don't know" as an answer. Is that because	
	You don't understand the words; You understand the words, but you have not figured out your sexuality or you are in the process of figuring it out; You mean something else; (Don't Know); (Refused) [If R selects "You mean something else" in SEXUALORIENT3] Please tell me what you mean by "something else"? Open ended	
National Inmate Survey (NIS)	Identity: Years asked: 2007, 2008- 2009, 2011- 2012 (D5) Do you consider yourself to be heterosexual or 'straight', bisexual, or homosexual or gay?	U.S. prison and jail inmates, age 18 and
DOJ/BJS	'Straight,' which is also called Heterosexual; Bi-sexual; [If R is male] Homosexual or Gay; [If R is female, DK, Refused] Homosexual, Gay, or Lesbian; Other; (Don't Know)	older (except in 2011-12, which included inmates
	Sexual Behavior: 2007, 2008-2009, 2011- 2012 [IF D3 "number of partners" NE 1 (no partners)] (D4) Before you entered this facility, had you had sex with men only, women only, or both men and women? Men only; Women only; Both men and women	age 16 or older)

National Survey of	Identity: 2014-Present	Administration on
Older Americans	(ACISIM/F) Which of the following best represents how you think of yourself?	Aging Title III service
Act Participants	[If R is female then Lesbian or] Gay; Straight, that is, not [If R is female then Lesbian or] Gay; Bisexual	participants. Most
(NSOAAP)	Something else; Refused; Don't Know	respondents are
	If R answers "Something else" to ACISM/F: (ACISMELS/FELS) What do you mean by something else?	aged 60 and older.
DHHS/ACL	You are not straight, but identify with another label such as queer, trisexual, omnisexual or pansexual;	Respondents
	You are transgender, transsexual or gender variant; You have not figured out or are in the process of	answering questions
	figuring out your sexuality; You do not think of yourself as having sexuality; You do not use labels to identify	under the Caregiver
	yourself; You mean something else; Refused; Don't Know	module are adults
	If R answers "Don't know" to ACISMELS/FELS: (ACISIMDK/FDK) What do you mean by don't know?	age 18 and over.
	You don't understand the words; You understand the words, but you have not figured out or are in the process of	
	figuring out your sexuality; You mean something else; Refused; Don't know	
	If R answers "Something else" to ACISIMDK/FDK: (ACIMSESP/FSESP) What do you mean by something else?	
	Open ended	

Additional resources for datasets containing data on sexual minority populations in the United States include:

1) Gaydata, Program for Lesbian, Gay, Bisexual and Transgender Health at Drexel University, http://www.lgbtdata.org/

DPH SOGI Contacts

- Barry Callis, Director, Behavioral Health and Infectious Disease Barry.Callis@MassMail.State.MA.US
- SarahEvan Colvario, Workforce Development and Training Coordinator Bureau of Substance Addiction Services sarahevan.colvario2@mass.gov
- Sam Chanen, LGBTQ+ Health Equity Strategist Office of Health Equity <u>sam.chanen2@mass.gov</u>
- Data Standards Project Email: <u>DPHDataStandards@mass.gov</u>

Resources

- 1. "Avoiding Heterosexual Bias in Language" (1991), http://www.apa.org/pi/lgbt/resources/language.aspx
- 2. National LGBT Health Education Center, Glossary of LGBT Terms for Health Care Teams, https://www.lgbtqiahealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/
- 3. Human Rights Campaign, Glossary of Terms, http://www.hrc.org/resources/glossary-of-terms/#/html/body/div[1]/main/section/div[1]/section/div[1]/div/ul[2]/li[4]/

- 4. Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity, https://www.lgbtqiahealtheducation.org/publication/ready-set-go-a-guide-for-collecting-data-on-sexual-orientation-and-gender-identity-2022-update/
- 5. Best Practices for Asking About Sexual Orientation on Surveys, Williams Institute (2009), https://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf
- 6. How Many People Are Lesbian, Gay, Bisexual and Transgender is about quantifying LGBT people in the United States, https://williamsinstitute.law.ucla.edu/publications/adult-lgbt-pop-us/
- 7. Estimating Populations of Men Who Have Sex with Men in the Southern United States, Williams Institute, UCLA School of Law (2009), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2791823/
- 8. Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-based Surveys, https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf
- 9. Lesbians, Gays, Bisexuals, and Transgenders of Color Sampling Methodology: Strategies for Collecting Data in Small, Hidden, or Hard-to-Reach Groups to Reduce Tobacco-Related Health Disparities, https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-POC-Sample-Method-Dec-2009.pdf
- 10. National LGBT Health Education Center, Resources and Suggested Readings, https://www.lgbtgiahealtheducation.org/resources/

References

- United States, Bureau of Primary Health Care, Department of Health & Human Services. (2018, November 6). Uniform Data System: Reporting Instructions for the 2018 Health Center Data. Retrieved December 6, 2018, from https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/reporting/2018-uds-reporting-manual.pdf
- Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity (Rep.). (2018, January).
 Retrieved December 6, 2018, from National LGBT Health Education Center website:
 https://www.lgbtqiahealtheducation.org/publication/ready-set-go-guidelines-tips-collecting-patient-data-sexual-orientation-gender-identity/
- 3. United States, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (n.d.). LGBT. Retrieved April 2, 2-24 from https://health.gov/healthypeople/objectives-and-data/browse-objectives/lgbt.
- 4. The Joint Commission: Advancing Effective Communication, Cultural Competence, and Patient- and FamilyCentered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide. Oak Brook, IL, Oct. 2011. LGBTFieldGuide.pdf.

- Retrieved December 6, 2018, from https://www.jointcommission.org/assets/1/18/LGBTFieldGuide.pdf. [Accessed prior to archive of page]
- 5. Campaign, H. R. (n.d.). Health Disparities Among Bisexual People. Human Rights Campaign. Retrieved January 30, 2020, from https://www.hrc.org/resources/health-disparities-among-bisexual-people/
- 6. Anderson, C., D'Augelli, A., Garnets, L., Herek, G., Kimmel, D., Peplau, L. A., & Rothblum, E. (1991). Avoiding Heterosexual Bias in Language. American Psychologist, 46(9), 973-974. Retrieved December 6, 2018, from https://www.apa.org/pi/lgbt/resources/language.aspx.
- 7. Massachusetts Commission on Lesbian, Gay, Bisexual, Transgender, Queer, and Questioning Youth. (2018). Massachusetts Commission on LGBTQ Youth: 2019 Fiscal Year Recommendations. Retrieved December 6, 2018, from https://www.mass.gov/annual-recommendations
- 8. GLAAD Media Reference Guide Terms To Avoid. (2016, October 25). Retrieved January 14, 2019, from https://www.glaad.org/reference/offensive [Accessed prior to removal of page]
- 9. White House, Recommendations on the Best Practices for the collection of Sexual Orientation and Gender Identity Data on Federal Statistical Survey. 2023. https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf
- 10. Goldhammer H, Grasso C, Katz-Wise SL, Thomson K, Gordon AR, Keuroghlian AS. Pediatric sexual orientation and gender identity data collection in the electronic health record. J Am Med Inform Assoc. 2022 Jun 14;29(7):1303-1309. doi: 10.1093/jamia/ocac048. PMID: 35396995; PMCID: PMC9196694. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9196694/
- 11. National Academies of Sciences, Engineering, and Medicine. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press. https://ht
- 12. SAGE Advocacy & Services for LGBTQ+ Elders. (2023, March). Inclusive Questions for Older People. Retrieved from National Resource Center on LGBT Aging: https://lgbtagingcenter.org/resources/resource.cfm?r=601
- 13. Lau JS, Kline-Simon A, Sterling S, Hojilla JC, Hartman L. Screening for Gender Identity in Adolescent Well Visits: Is It Feasible and Acceptable? J Adolesc Health. 2021 Jun;68(6):1089-1095. doi: 10.1016/j.jadohealth.2020.07.031. Epub 2020 Sep 15. PMID: 32948402; PMCID: PMC9005214.
- 14. Spock A, Popkin R, Barnhart C. Strategies to Improve Measurement of Sexual Orientation and Gender Identity Among Youth. J Adolesc Health. 2022 Dec;71(6):662-664. doi: 10.1016/j.jadohealth.2022.09.009. Epub 2022 Oct 10. PMID: 36229396.
- 15. Arrigotti, M., Chase, K., Dinno, A. (2022). Preliminary (Year 1) Report to OHA on Pediatric SOGI: Executive Summary. Report to the Oregon Health Authority, Office of Equity and Inclusion

Appendix E: Health Equity Style Guide: Sex, Gender Identity and Gender Expression

Health Equity Style Guide: Sex, Gender Identity and Gender Expression

Topic Overview:

This style guide addresses the concepts of sex and gender, which also encompasses gender identity and gender expression. There will also be a sexism style guide which will address health inequities by sex. Please note: Words in bold italics are defined below (in the "Expanded Definitions" section) and mostly adapted from GLAAD's Media Reference Guide, Glossary of Terms, available at glaad.org/reference/transgender.

In 2015, the National Center for Transgender Equality conducted a nationwide survey to quantify the experiences of **transgender** people. The survey had 27,715 total respondents from all across the United States, American Samoa, Guam, Puerto Rico, and U.S. military bases overseas. It provides insight into some of the challenges transgender people face in the different spheres of life (education, employment, family life, health, housing, and interactions with police and prisons), but its findings cannot be generalized to all transgender people as the respondents were not randomly selected. The report underscored some of the health disparities experienced by this group. Transgender populations face health disparities that are often exacerbated by the intersection of other factors/identities, such as age, race, income, geographic location, and immigration status. For example, HIV rates are disproportionately higher among transgender women of color than **cisgender** individuals. Providers are not always well informed about transgender health concerns or overly attribute health problems to their transgender identity, which can act as a barrier to care. About one fifth of respondents reported that they avoided seeking health care they needed in the past year due to fear of being mistreated. Without the establishment of trust and a safe environment, transgender people may have a harder time disclosing things about their health and fear of judgement and discrimination results in poorer health outcomes.

Allostatic load refers to the "wear and tear' of chronic stress in synergy with unhealthy behaviors." This framework implies that systematic and interpersonal discrimination can and do manifest physiologically in response to the environment. Sexual minorities living in stigmatizing environments contributes to "later health disparities." Within the LGBTQIA+ community, transgender individuals are at greater risk for developing psychological, physical, and behavioral health problems." There is a tremendous void in the literature

pertaining to people who are **intersex**. The majority of what is published focuses on the need for supporting parents of intersex children and advising against medical intervention. Many intersex individuals experience psychological stress and emotional distress as a result of "corrective surgeries" or parents withholding information about their conditions.ⁱⁱⁱ

Sex and **gender** are two distinct terms. Because of the health inequities that transgender, gender nonbinary, and intersex people experience, it is important that data captures these populations.

Sex is often described as "**sex assigned at birth,**" meaning how an individual was classified when born. Most states only have options for male and female, not capturing individuals who are **intersex** or are born with **differences in sexual development**. Individuals who are transgender or gender nonbinary may or may not align their listed sex on birth certificate, license, or other official documents to match their gender identity, and each state has different laws regulating these changes. Sex assigned at birth is often asked in medical settings with the rationale of different lab values for those who were classified male or female, or for ensuring proper cancer screenings (e.g., cervical vs. prostate) are done, when applicable.

Gender encompasses social and cultural codes used to distinguish what a society considers "masculine" and "feminine" conduct and/or characteristics. Gender is also an identity and refers to a person's internal, deeply felt sense of being female, male, both, or something other than female or male. It does not necessarily correspond to the sex assigned or presumed at birth. Because gender identity and pronouns may not match an individual's sex assigned at birth, best practice is to ask the person their gender identity, chosen name, and pronouns when appropriate. This avoids assumptions based on cultural gender norms.

Gender identity is a person's internal, deeply held sense of their gender. Most people have an internal sense of gender identity that matches their sex assigned at birth (e.g., male or female), and are considered **cisgender**. Conversely, **transgender** and gender nonbinary people have an internal gender identity that does not match the sex they were assigned at birth.

For some people, their gender identity does not fit neatly into one of those two choices and they may identify as **genderqueer**, **gender nonconforming**, **gender nonbinary**, **gender fluid**, or **agender**. Unlike **gender expression**, gender identity is not visible to others. Everyone — **transgender** or not — has a gender identity (unless they identify as having no gender at all) and all identities are valid,

⁵⁵ Oregon, California, Washington and New Jersey offer a third gender category "X" on birth certificates.

⁵⁶ In June 2018, the Massachusetts Senate passed a bill that would allow someone to check "X" instead of male or female on their driver's license and other state identity cards.

regardless of appearance or "transition" (the process of changing one's appearance, documentation, etc.). An estimated 1.4 million, or 0.6% of the U.S. adult population, identify as transgender.

Note:

- Transgender people may not always identify openly as transgender and may not routinely disclose their sex assigned at birth.
- Transsexual is an older definition and is now often considered offensive. It should not be used unless an individual uses this term for themselves. Similarly, "male-to-female" (MTF) and "female-to-male" (FTM) are used less commonly, compared to "transgender woman" and "transgender man."
- "Trans" or "trans*" is often used as shorthand for transgender and gender nonconforming identities.
- Transgender people may choose to outwardly transition to match their gender identity through one or more possibilities (e.g., social, medical, and surgical transition), but some transgender people may not outwardly transition for any reason, including restrictions due to cost or insurance coverage these people are still transgender due to their identity. Using terms like "completed transition" or "pre-op" assume outward transition is compulsory, which it is not.

Gender expression is the external manifestation of gender, expressed through a person's name, pronouns, clothing, haircut, behavior, voice, and/or body characteristics. Society identifies these cues as masculine and feminine, although what is considered masculine or feminine changes over time and varies by culture or sub-population.

Though conceptually distinct from gender identity, providers of survey instruments may wish to include the collection of gender expression and gender identity to broaden the sample. Gender nonconforming behavior or presentation may give rise to assumptions about a person's gender identity (or even their sexual orientation) that single them out for violence or discrimination regardless of whether these assumptions are accurate. A gender expression measure may thus capture a greater number of respondents, increasing the sample size and allowing for more robust analyses.^{vi}

Clarifications:vii

- What's the difference between sexual orientation and gender identity? **Gender identity** and **sexual orientation** are two different things. Gender identity refers to one's internal knowledge of their own gender — for example, one's knowledge that they're a man, a woman, another gender, or agender. Sexual orientation has to do with to whom an individual is attracted. Like **cisgender** people, **transgender** people can have any sexual orientation. For example, a transgender man (someone who lives as a man) may be primarily attracted to other men and identify as a gay man,

- or he may be primarily attracted to women and identify as a straight man. He could also identify as queer or have any other sexual orientation. Sexual orientation can also change over the course of one's lifetime.
- What's the difference between being *transgender* and being *intersex*?

 People sometimes confuse being transgender and being intersex. Intersex people have reproductive anatomy or genes that don't fit typical definitions of male or female, which is often discovered at birth or when puberty does not follow the expected course. Being transgender, meanwhile, has to do with your internal knowledge of your gender identity. A transgender person is usually born with a body and genes that match a typical male or female, but they know their gender identity to be different.

Expanded Definitions:

Intersex: An umbrella term that refers to a range of traits and conditions that cause individuals to be born with chromosomes, gonads, and/or genitals that vary from what is considered typical for female or male bodies. A former medical term, "intersex" has been reclaimed by some as a personal and political identity. Intersex is not the same as transgender, which describes individuals whose gender differs from the sex they were assigned or presumed at birth.

Differences of Sex Development (DSD): A medical term used to refer to conditions that cause intersex traits, "DSD" is often used by medical practitioners (sometimes styled as "Disorders of Sex Development," which many find stigmatizing). It became a key term in the 2006 Consensus Statement process, during which some intersex community groups agreed to use it because it was an effective way to communicate with medical providers.

Cisgender: A term used by some to describe people who are not transgender. "Cis-" is a Latin prefix meaning "on the same side as," and is therefore an antonym of "trans-."

Transgender (adj.): An umbrella term for people whose gender identity and/or gender expression differs from what is typically associated with the sex they were assigned at birth. People under the transgender umbrella may describe themselves using one or more of a wide variety of terms — including transgender. Some of those terms are defined below. Use the descriptive term preferred by the person. Many transgender people are prescribed hormones by their doctors to bring their bodies into alignment with their gender identity. Some undergo surgery as well. But not all transgender people can or will take those steps, and a transgender identity is not dependent upon "transitioning" — changing one's physical appearance or undergoing medical treatment and/or procedures. Transgender people are people whose gender identity is different from the gender they were thought to be at birth. "Trans" is often used as shorthand for transgender.

Gender Nonconforming: A term used to describe some people whose gender expression is different from conventional expectations of masculinity and femininity. Please note that not all gender nonconforming people identify as transgender. Many transgender men and women have gender expressions that are conventionally masculine or feminine, and do not also identify as gender nonconforming. Many people have gender expressions that are not entirely conventional — that fact alone does not make them transgender or gender nonconforming. The term should only be used if someone self-identifies as gender nonconforming.

Nonbinary: This term is used by some people who experience their gender identity and/or gender expression as falling outside the categories of man and woman. They may define their gender as falling somewhere in between man and woman, or they may define it as outside a binary view of male/female. The term is not a synonym for transgender or transsexual and should only be used if someone self-identifies as nonbinary and/or genderqueer.

Two-Spirit: Two-spirit does not refer to a Native American/Alaskan native that is gay, however it does refer to a third or fourth gender distinction, depending on what tribe an individual belongs to. "Two-spirit people were male, female, and sometimes intersexed [sic.] individuals who combined activities of both men and women with traits unique to their status as two spirit people." viii

Note: There are many ways people choose to identify their gender and gender expression (e.g., AG, Stud, genderqueer, agender, androgynous, etc.). Please see the following resources for a more expansive list of terms and definitions:

- https://gscc.msu.edu/education/glossary.html
- https://itgetsbetter.org/glossary
- https://lgbtqia.ucdavis.edu/educated/glossary
- https://lgbtq.multicultural.ufl.edu/programs/speakersbureau/lgbtq-terms-definitions/
- https://www.refinery29.com/en-us/gender-identity-terms

General Recommendations:

The Massachusetts Department of Public Health convened a Sexual Orientation and Gender Identity/Expression (SOGI) Work Group, headed by the Office of Health Equity, to make recommendations on how these data points should be captured.

Current Gender Identity Questions

Construct Question When and Where to As

Current Gender Identity:	Please select the gender identity	When and where other
Recommended DPH Two-Part Question	that best describes you. Check	socio-demographic
(Part 1)	only <u>one</u> regardless of sex	characteristics are collected.
	assigned at birth.	
	□ Male; man; boy	
	□ Female; woman; girl	
	□ Not exclusively male or	
	female, nonbinary, and/or	
	something additional ⁵⁷	
	□ I am questioning/not sure of	
	my gender identity	
	□ I don't understand what this	
	question is asking	
	□ I prefer not to answer	
Transgender Experience: Recommended	Are you transgender or of	When and where other
Two-Part Question (Part 2)	transgender experience?	socio-demographic
	□ Yes	characteristics are collected.
	□ No	
	☐ I'm not sure	
	□ I don't understand what this	
	question is asking	
	□ I prefer not to answer	

 $^{^{\}rm 57}$ For more information, please review appendix C.

Current Assigned Sex at Birth and Intersex Status Questions

Construct	Question	When and Where to Ask
Sex, Intersex Status and	What sex were you assigned at birth?	When and where clinical or
Assigned Sex at Birth:	□ Male	medical information would be
Two-Step Question (Part One,	□ Female	captured for diagnostic,
Assigned Sex at Birth)		screening, or risk
		assessment purposes.
		Assigned sex at birth may also be collected for purposes of applying weights to survey data based on national samples
Sex, Intersex and Assigned Sex at	Some people are born with	When and where other
Birth: Two-Step Question (Part Two, Intersex & Variations of	chromosomes, hormones, or genitalia	socio-demographic
Sex Characteristics ⁵⁸⁾	that do not fit within typical notions of	characteristics are collected.
Out official control of	"male" or "female" sex. This is known as	NOTE: If sex assigned at
	intersex. Many learn they are intersex	birth is necessary to ask for
	from a medical diagnosis later in life. This	medical treatment, use this
	is different from being transgender. Are	question in conjunction with
	you intersex?	the recommended option on
	□ Yes	sex assigned at birth, listed
	□ No	above.
	☐ I'm not sure	
	□ I don't understand the question	

⁵⁸ Clark, C. M. & Kosciw, J. G. 2022. "Considerations for Measuring Sexual Orientation and Gender Identity in Surveys of Secondary School Students (Research Brief)." GLSEN.

	□ I prefer not to answer	
Sex, Intersex Status, and Assigned at Birth Abbreviated	The following statements are about someone's sex, assigned sex at birth, and intersex status. Check all that may apply. I was assigned female at birth I was assigned male at birth I am intersex (If you identify as intersex, please check this box in addition to your assigned sex at birth.) I have been diagnosed with a sex characteristic variation (If you have a sex characteristic variation, please check this box in addition to your assigned sex at birth.) I don't understand what this question is asking I prefer not to answer	When and where other socio-demographic characteristics are collected. NOTE: This version is designed to be used in place of the longer form intersex question and the assigned sex at birth question listed below when programs must abbreviate the questions.

Best Practices Recommendations for Implementation:

1) Sexual orientation, current gender identity, transgender experience, and assigned sex at birth should <u>always</u> be self-reported and not assumed by providers or others. The collection of data in contexts where self-report is not possible (e.g., death certificates) should reflect the affirmed name and gender of the decedent. <u>Under no circumstances</u> should a data collector fill in responses based on their own assessment of a respondent's voice, appearance, mannerisms, behavior, known partners, etc.

- 2) When possible, sexual orientation, current gender identity, and assigned sex at birth should be collected privately on a self-administered form rather than verbally, to enhance respondent comfort with answering.
- 3) When data are to be collected by others (e.g., providers), data collectors should be trained to respectfully ask questions about sexual orientation, current gender identity, transgender experience and assigned sex at birth. Training should cover the purpose of data collection, cultural awareness, data security procedures and uniform definition for terms.
- 4) Sexual orientation, current gender identity, transgender experience, and assigned sex at birth should <u>only</u> be collected by individuals and organizations committed to data security and privacy that have established mechanisms to maintain security and privacy at all stages of data collection, storage, and reporting. Collecting these data as part of the electronic health record may facilitate data security and ensure privacy.
 In contrast, providers should <u>never</u> verbally collect sexual orientation, current gender identity, transgender experience, and assigned sex at birth in a group setting. If clients receive services in a group setting, it is advisable to have clients privately complete a self-report socio-demographic form.
- 5) Recommended sexual orientation, current gender identity, transgender experience, and assigned sex at birth questions should be translated to, and validated in, the languages of intended respondents. See the DPH CLAS guidance for more information to support these efforts.
- 6) The presence of sexual orientation, current gender identity, transgender experience, and assigned sex at birth questions on data collection forms may be perceived by clients as an indication of global LGBT inclusivity. Therefore, direct service organizations are responsible for ensuring this inclusivity through institutional trainings, educational materials, policies, and practices. Appropriate technical assistance should be part of budget and operational planning.
- 7) Cultural tailoring includes collecting additional information, such as the client's name (which may differ from the legal name), gender pronouns (he, she, they, specify: ____), and/or sexual behaviors if relevant to treatment planning. DPH has not included recommended questions for pronouns because they do not represent data constructs. However, collecting this information in any direct service setting is a best practice.

NOTE: Pronouns should always be asked, and not assumed based on responses to sexual orientation, current gender identity, transgender experience, and assigned sex at birth questions.

NOTE: The sex or gender identity listed may be different than the one on record with the health insurer.

- 8) The use of the assigned sex at birth question should only be used when there is a legitimate need for biologically based information that relates directly to clinical or medical information necessary for diagnostic, screening, or risk assessment purposes. This may necessitate use of an anatomical survey to assess for specific relevant screenings. For example, a man with a uterus may be at risk for pregnancy or may be considering becoming pregnant, which would be relevant to his care. This information, however, would not be relevant for purely administrative purposes, and in that case should not be captured.
- 9) Gender expression is an important conceptual domain for research and understanding of inequities based on presentation of gender; however, this requires a larger discussion to determine where and how they should best be collected and used.
- 10)Sexual behavior information is conceptually independent of the demographic information being described here, so is not included within these recommendations.

Top Terms

Below are terms to use and terms not to use when talking about this topic. Make sure to consult experts in the field if you are unsure about the use of a word.

Use (terms and examples)	Explanation	Avoid
 All people Everyone All genders People of all genders Siblings Parents Children Spouse 	Not all individuals fit into a gender binary. These recommendations recognize that there are more than two genders and is inclusive of people who do not identify within the gender binary. Use singular they in a generic sense and avoid the language of gender opposites.ix	 Male or Female Man or Woman The opposite sex Both genders Brothers and Sisters Moms and Dads Boys and Girls Ladies and Gentlemen

Use (terms and examples)	Explanation	Avoid
PartnerFolksAttendees		
 Pregnant people Menstruating people People with uteruses Birthing parent Nursing parent 	For greater precision, separate references to biological function from gender categories. Some people who give birth are not women; many women do not have uteruses or experience menstruation. When identifying a group of people who (for example) are at risk for childbirth-associated mortality, or who might benefit from distribution of menstrual hygiene supplies, using gender as a shorthand reduces the accuracy of your message.	 Pregnant women, expectant mothers Women (when referring to a group that is only known to share biological traits) Mother
TheyThis person	When you do not know someone's pronouns, do not make assumptions based on appearance. It is appropriate to use the terms in the avoid column if you have asked someone their gender identity and/or how they would like to be referred.	 Mr., he, sir, this man Ms./Mrs./Miss, she, ma'am, this woman He or she (as a generic term for an unknown individual)
 Use chosen name OK to ask for legal name if necessary, but don't refer to someone this way if chosen name is supplied 	Some individuals have a name they identify with and, while not legal, should be the name used in conversation. There are many reasons an individual may not identify with or want to be called by their legal name, with gender concordance being one of those reasons. When filling out legal or medical documentation, check your organization's protocol to ensure that the person is	 Use someone's legal name if they have provided you with a chosen or preferred name "Given name" "Preferred name"

Use (terms and examples)	Explanation	Avoid
	correctly identified and matched with their record and that the name they should be called is clear for all staff. Many people cannot afford or navigate the processes in most systems (legal, medical, etc.) that it takes to change one's name; because of this, you should use a person's chosen name.	
 Individual who is transgender A transgender person Transgender history or identity Person of transgender experience 	Transgender is an adjective, not (usually) a gender and not always an identity. V Transgender does not refer only to binary-identified trans women and men. Many trans people (35%) are nonbinary. V	 Transgenders Transgendered Transgenderism Man, woman, or transgender (pick one)
 Individual who is intersex Individual born with a difference in sexual development (DSD) 	Use the term that the individual uses to describe their sex assigned at birth and do not use outdated and offensive terms.	Hermaphrodite
 Transgender woman, trans woman, transgender man, trans man 	The space between <i>trans</i> and <i>man/woman</i> is important to include.	Transman, transwoman
Jamie is [a man, a woman, nonbinary, etc.]	There is not universal consensus on this point, but there is a growing sense in the trans community that saying someone "identifies as" their gender implies that their gender is not real or is merely a matter of personal choice.	Jamie identifies as [a man, a woman, nonbinary, etc.]

Use (terms and examples)	Explanation	Avoid
	It is appropriate to ask, "How do you identify?" Once known, that person is [a man, a woman, nonbinary, etc.].	
Gender nonconformingNonbinary	The terms gender nonconforming and nonbinary are not synonyms. Use the term each individual uses.	Conflating gender nonconforming and nonbinary
 Chris socially transitioned in her late 20s, and began medically transitioning at age 32 The transition process 	Transition is the correct word for the social and/or medical process of publicly living into one's true gender. Medical transition may involve a number of different treatments or procedures; referring to it as "the surgery" or "a sex change" (or the "op" implied by "postop") is reductive and inaccurate.	 Chris is transgendering Chris had a sex change Chris had "the surgery" Chris became a woman Pre-op Post-op
 Assigned female at birth (AFAB) Assigned male at birth (AMAB) 	Avoid language that reduces people to their birth-assigned sex or their (assumed) biology. While not ideal, the suggestions to the left are preferred if someone's sex assignment at birth should be discussed.	 Born a woman Born a man Biologically female Biologically male Genetically female Genetically male Pre-op Post-op
Monique is transgenderBeing transgender is not a crime	Avoid treating transgender people as though they have "a condition."	Monique has transgenderism

Use (terms and examples)	Explanation	Avoid
Gender dysphoria	Aligned with what is stated above, using a diagnosis such as gender dysphoria may be offensive to some. However, for medical coverage, often this diagnosis of gender dysphoria is often used and needed for access to medical transition. Not all transgender or nonbinary people experience dysphoria, and the terms should not be used interchangeably. Pathologizing language that refers to trans or nonbinary people as "disordered" or "confused" should be avoided in all circumstances.	 Gender disordered Gender confused Gender identity disorder (outdated)
 Openly transgender Not openly transgender **Don't sensationalize or nonconsensually disclose a trans person's gender history. Remember that transgender people may be openly transgender to some individuals but not to others.** 	Avoid language that puts more value on being or appearing cisgender (not trans), or that carries judgments or biases around how public a person is about being trans. Never use language that paints trans people as deceptive for living as our authentic selves.	 Passes/passable Stealth Her secret was discovered You'd never be able to tell He disguised himself as a woman She fooled everyone No one knew the truth The lie was exposed Transgenderism
 Bridget knew from the age of 3 that she was a girl. 	Using a trans person's birth name or former pronouns without permission is not acceptable.	 At the age of 3, Bob announced that he was a girl. After transitioning, Bob — now Bridget — threw out her old clothes.
 Pronouns Personal pronouns	Pronouns are simply pronouns. They aren't "preferred," and they aren't inherently tied to gender identity or biology.	Preferred pronounsMasculine pronouns

Use (terms and examples)	Explanation	Avoid
 Gender pronouns She/her/hers He/him/his They/them/theirs Ze/zir/zirs Sam (use name instead of pronouns) And any other pronoun or combination 	When introducing yourself you can introduce your name and your pronouns. If someone omits their pronouns, you can ask, "What pronouns should I use for you?"	 Feminine pronouns Male pronouns Female pronouns
 Elizabeth loves their cat They are a big cat lover They did something nice for themselves yesterday 	Respect singular they as a personal pronoun and use it appropriately. Many dictionaries have addressed and/or endorsed this use already, including Merriam-Webster, the Oxford English Dictionary, and the American Heritage Dictionary; the American Dialect Society voted singular they 2015 Word of the Year; and in March 2017 AP style got on board as well. When using singular they, verb conjugations follow the same rules as those for singular you: they did, they are, themself (you did, you are, yourself).	Don't focus on what has been historically the grammar norms and accept that even the dictionary includes the singular they.
 When referring to trans people, if you are someone (like a medical provider) who needs to refer to anatomy, find out what language an 	Practice sensitivity around bodies and anatomy. For more information refer to NATIONAL STANDARDS OF CARE FOR TGIQ HEALTH at	Female-bodiedMale-bodied

Use (terms and examples)	Explanation	Avoid
individual uses and/or use generic and broad terminology (e.g., genitals, reproductive organs, and chest) instead of genderassociated words (e.g., vagina, penis, and breasts).	https://transreads.org/wp-content/uploads/2021/06/2021-06-04_60baaadf4ab90_rad-remedy-standards-of-careaug2017.pdf	
 All women, including trans women Cis and trans men Cisgender people Maria, a woman from Nogales Nonbinary students Zed is an agender young adult 	Affirm that trans women are women, trans men are men, and nonbinary people are nonbinary.	 Women and trans women Normal people Real men Biological women Nogales resident Maria, who identifies as a woman Students who consider themselves "nonbinary" Zed identifies as agender
 LGBTQ people versus non-LGBTQ people LGB versus straight; transgender versus cisgender "The Transgender Day of Remembrance, which commemorates victims of anti-trans violence" 	When using the acronym "LGBTQ" or its many variants (LGBT, LGBTQIA+, etc.), ensure that you actually mean to refer to all of the identities you're grouping together. "LGBTQ" is not a synonym for "gay" or "transgender," and it is extremely rare that any one person can be "LGBTQ" all by themselves.	 LGBTQ people versus straight people "The Transgender Day of Remembrance, which commemorates victims of anti-LGBT violence" An LGBTQ person (when referring to an individual who does not share all of these identities)

Use (terms and examples)	Explanation	Avoid
 A transgender person, a bisexual person, a gay person, etc. 		

Data Definitions

Below are common data sources that are available that use the topic along with how it is defined and some common terms to use.

Data Source	Question	Answers	Data Limitation(s)
Massachusetts High School Youth Health Survey	What is your sex?	 Female Male Missing (coded) 	 Omits Intersex or other sex Does not clarify if it is sex assigned at birth or current sex No gender question
	A transgender person is someone whose biological sex at birth does not match the way they think or feel about themselves. Are you transgender?	 No, I am not transgender Yes, I am transgender and I think of myself as really a boy or man Yes, I am transgender and I think of myself as really a girl or woman Yes, I am transgender and I think of myself in some other way 	

		5. I do not know if I am transgender6. I do not know what this question is asking	
Massachusetts Middle School Youth Health Survey	What is your sex? (all years)	 Male Female Missing 	Omits Intersex or other sexNo gender questionNo transgender experience question
Massachusetts Comprehensive Rape Crisis Centers Incident Reports	Self-identified gender at time of assault:	 Female Male Transgender, MTF/Trans Female/Trans Woman Transgender, FTM/Trans Male/Trans Man Transgender, Undisclosed Gender-Non-Conforming/Gender Queer Not Yet Identifying Due to Age Other (not already listed) Gender Identity Undisclosed/Unknown Gender 	
Youth Risk Behavior Survey (YRBS)	What is your sex? (all years) Some people describe themselves as transgender when their sex at birth does	 Male Female Missing No, I am not transgender Yes, I am transgender I am not sure if I am transgender 	
	not match the way they think or feel about their gender. Are you transgender? (2017)	4. I do not know what this question is asking9. Missing	

Behavior Risk Factor Surveillance Survey (BRFSS)	What is your sex?	 Female Male Refused 	No gender question
	Do you consider yourself to be transgender? (2013-2017)	 Yes, transgender, male to female Yes, transgender, female to male Yes, transgender, gender (variant) non-conforming No Don't know Ref 	
MA Violent Death Reporting System (MAVDRS)			ICD Codes – not sure exactly what would be used, we would have to talk with someone who works with MAVDRS
National Crime Victimization Survey (NCVS) DOJ/BJS	What sex were you assigned at birth, on your original birth certificate?	 Male Female Refused Don't know 	
	Do you currently describe yourself as male, female or transgender?	 Male Female Transgender None of these 	
American Community Survey (ACS)	What is person's sex?	 Male Female 	No gender question
National Health Interview Survey (NHIS)			Not sure what the questions are for this one

National Survey of Drug Use and Health (NSDUH)	Interviewer: Record respondent's gender.	 Male Female 	No gender question
Population Assessment of Tobacco and Health (PATH) DHHS/ NIH and DHHS/FDA			Not sure what the questions are for this one
Health Center Patient Survey (HCPS) DHHS/HRSA/ BPHC	What is your sex?	 Male Female Don't know Refused 	No gender question
National Adult Tobacco Survey (NATS) DHHS/CDC	What sex were you at birth?	 Male Female Don't know / Not sure Refused Not ascertained 	
	Do you currently consider yourself to be:	 Male Female Don't know / Not sure Refused Not ascertained 	
National Inmate Survey (NIS) DOJ/BJS	Are you male, female, or transgender?	 Male Female Transgender DK/REF 	Unless this question allows "check all that apply," this question does not follow recommendations of acknowledging an individual's sex assigned at birth, gender

National Survey of Older Americans Act Participants (NSOAAP) DHHS/ACL			identity and transgender experience appropriately. Need to get questions
2015 U.S. Transgender Survey	1.10 Do you think of yourself as transgender? 1.11 Do you identify as more than one gender or as no gender (such as	 No Yes No Yes 	
	genderqueer or nonbinary)? 1.12 Do you currently live full-time in a gender that is different from the one assigned to you at birth?	1. No 2. Yes	
	2.1 What sex were you assigned at birth, on your original birth certificate?	 Female Male 	
	2.2 Which of these terms do you identify with? (Mark all that apply.)	 A.G. or aggressive Agender Androgynous Bi-gender Butch Bulldagger Cross dresser Drag performer (king/queen) Fa'afafine 	

2.3 If you had to choose only one of the following terms, which best describes your current gender identity? (Please choose only one answer.) 2.5 What gender pronouns	10. Gender non-conforming or gender variant 11. Genderqueer 12. Gender fluid/fluid 13. Intersex 14. Māhū 15. Multi-gender 16. Nonbinary 17. Third gender 18. Stud 19. Transgender 20. Trans 21. Trans man (FTM, female to male) 22. Transsexual 23. Trans woman (MTF, male to female) 24. Travesti 25. Two-spirit 26. A gender not listed above (please specify) 1. Cross-dresser 2. Woman 3. Man 4. Trans woman (MTF) 5. Trans man (FTM) 6. Nonbinary/Genderqueer	Related to Pronoun
2.5 What gender pronouns do you ask people to use to refer to you? [Respondents	 He, his She, hers They, their Ze, hir 	Related to Pronoun

could mark all answers that applied.]	 5. No pronouns. I ask people only to use my name. 6. I don't ask people to use specific pronouns. 7. Pronouns not listed above (please specify) 			
2.7 People can tell I am trans even if I don't tell them.	 Always Most of the time Sometimes Rarely Never 			Related to Gender Expression (SOGI Data WG interest)
12.5 Was there a time in the past 12 months when you needed to see a doctor but did not because you thought you would be disrespected or mistreated as a trans person?	1. No 2. Yes			Related to accessing healthcare because of TG status (SOGI Data WG interest)
12.7 In the past year, did you have any of these things happen to you, as a trans	In the past year My doctor knew I was trans and treated me with respect.	No O	Yes O	Related to TG's experiences in healthcare (SOGI Data WG interest)
person, when you went to see a doctor or health care provider? (Please provide an answer in each row.)	I had to teach my doctor or other health care provider about trans people so that I could get appropriate care.	0	Ο	
	A doctor or other health care provider refused to give me trans-related care.	0	Ο	
	A doctor or other health care provider refused to give me	0	0	

other health care (such as for like physicals, flu, diabetes). My doctor asked me unnecessary/invasive questions about my trans status that were not related to the reason for my visit. A doctor or other health care 0 provider used harsh or abusive language when treating me. A doctor or other health care 0 0 provider was physically rough or abusive when treating me. I was verbally harassed in a 0 0 health care setting (such as a hospital, office, clinic). I was physically attacked by 0 someone during my visit in a health care setting (such as a hospital, office, clinic). I experienced unwanted sexual 0 contact (such as fondling, sexual assault, or rape) in a health care setting (such as a hospital, office, clinic).

Resources:

- Massachusetts Commission on LGBTQ Youth, https://www.mass.gov/orgs/massachusetts-commission-on-lgbtq-youth
- National Center for Transgender Equality
 - Frequently Asked Questions, https://transequality.org/issues/resources/frequently-asked-questions-about-transgender-people

- Understanding Nonbinary People: How to Be Respectful and Supportive,
 https://transequality.org/issues/resources/understanding-nonbinary-people-how-to-be-respectful-and-supportive
- o 2015 U.S. Transgender Survey, http://www.ustranssurvey.org/
 - Report: https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf, James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.
 - Appendix B has survey questions
- GLAAD Media Reference Guide, Glossary of Terms, https://www.glaad.org/reference/transgender
- <u>"I Want to be Like Nature Made Me: Medically Unnecessary Surgeries on Intersex Children in the US."</u> Human Rights Watch. June 25, 2017. ISBN 978-1-6231-35027.
- InterACT Advocates for Intersex Youth, http://interactadvocates.org/fag/
- The Gender Neutral Pronoun Blog, https://genderneutralpronoun.wordpress.com/
- THE RADICAL COPYEDITOR'S STYLE GUIDE FOR WRITING ABOUT TRANSGENDER PEOPLE, <u>https://radicalcopyeditor.com/2017/08/31/transgender-style-guide/</u>

Endnotes:

DPH Contacts

- Barry Callis, Director, Behavioral Health and Infectious Disease, Office of HIV/AIDS, <u>Barry.Callis@MassMail.State.MA.US</u>
- SarahEvan Colvario, Workforce Development and Training Coordinator, Bureau of Substance Addiction Services, sarahevan.colvario2@mass.gov
- Sam Chanen, LGBTQ+ Health Equity Strategist, Office of Health Equity, sam.chanen2@mass.gov
- Data Standards Project: <u>DPHDataStandards@mass.gov</u>

¹ James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The Report of the 2015 U.S. Transgender Survey. Washington, DC: National Center for Transgender Equality.: https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf

- ii Juster, R.-P. (2019). Sex × Gender and Sexual Orientation in Relation to Stress Hormones and Allostatic Load. Gender and the Genome. https://doi.org/10.1177/2470289719862555
- Esther Morris Leidolf BA, Megan Curran MD, Scout PhD & Judith Bradford PhD (2008) Intersex Mental Health and Social Support Options in Pediatric Endocrinology Training Programs, Journal of Homosexuality, 54:3, 233-242, DOI: 10.1080/00918360801982074
- ^{IV} CHANGING BIRTH CERTIFICATE SEX DESIGNATIONS: STATE-BY-STATE GUIDELINES https://www.lambdalegal.org/know-your-rights/article/trans-changing-birth-certificate-sex-designations
- v http://williamsinstitute.law.ucla.edu/wp-content/uploads/How-Many-Adults-Identify-as-Transgender-in-the-United-States.pdf
- vi The GenIUSS Group. (2014). Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. J.L. Herman (Ed.). Los Angeles, CA: The Williams Institute.
- vii National Center for Transgender Equality Frequently Asked Questions https://transequality.org/issues/resources/frequently-asked-questions-about-transgender-people
- viii https://www.ihs.gov/lgbt/health/twospirit/
- ix https://radicalcopyeditor.com/2017/08/31/transgender-style-guide/