



LGBT Data Collection

Why Data Matters

Both the Institute of Medicine and the Joint Commission recommend collecting data on sexual orientation and gender identity in health care settings, especially in electronic health records/electronic medical records. These data are essential for providing high-quality, patient-centered care to LGBT individuals and for addressing LGBT health disparities. Research from 2014 shows that both LGBT and non-LGBT people strongly agree that sexual orientation and gender identity are important for their health care providers to know. Much of this data is also necessary to address the disparities faced by intersectional identities including sexual orientation, gender identity, race, ethnicity and immigration status.

But even though a significant body of research in LGBT health has developed over the last several decades, much remains to be studied about the health-related experiences, challenges, and outcomes of LGBT people. The National Institutes of Health and the Institute of Medicine have both recommended greater public and private investment in LGBT health research. Universities and health foundations in states such as South Carolina, Arkansas, Missouri, and Nebraska, as well as the national Patient-Centered Outcomes Research Institute (PCORI), are increasingly funding research projects investigating lesbian, gay, bisexual, and transgender health issues, including:

- Clinical research;
- Needs assessment surveys by community advocates;
- Large government-conducted population surveys; and
- Policy analyses of LGBT health needs in areas such as health insurance coverage, access to transition-related health care for transgender people, and specific disparities in high-priority areas such as substance use, mental health, preventive health services, and sexual health.

Where Can LGBT Data Come From

1. Population Surveys

Sexual orientation data are currently collected on a few large federal surveys, including the National Health Interview Survey, the National Survey of Family Growth, and the National Health and Nutrition Examination Survey. States have additional opportunities to add sexual orientation and gender identity questions to other surveys conducted in partnership between states and the federal government:

- **Behavioral Risk Factor Surveillance System (BRFSS):** The BRFSS is conducted separately by each state using a combination of 1) a core set of federal questions, 2) individual state-added questions, and 3) optional small question sets approved by the Centers for Disease Control and Prevention (CDC) but selected for addition by states. The CDC approved an optional question set on sexual orientation and gender identity in 2013, and in 2014 it was used by 19 states. Each state has a coordinator that oversees the BRFSS.
- **Youth Risk Behavior Survey (YRBS):** The YRBS has a similar structure to the BRFSS, and its core questionnaire includes sexual orientation and sexual behavior. The CDC has approved an optional question on gender expression.

Individual state health departments also frequently conduct other surveys that could include sexual orientation and gender identity questions, particularly surveys looking at mental health, substance use, and other areas where LGBT health disparities have already been documented.

2. Affordable Care Act Marketplace Applications

Currently, no health insurance marketplace collects voluntary sexual orientation and gender identity data on their applications, but several state marketplaces and the federal marketplace are considering adding these

questions. Recent research from the Center for American Progress indicates that asking about gender identity and sexual orientation on a marketplace application using common question designs is strongly supported by LGBT individuals: 86% of a nationally representative sample of LGBT adults with incomes under 400% of the Federal Poverty Level would answer these questions on a marketplace application. This willingness does not vary significantly at lower income levels either. Presently, more than 40 state and national partners have participated in a sign-on letter to the federal government requesting that the option to collect this data be made available to states with State Based Marketplaces. Ideally, this would influence Healthcare.gov, too.

3. *Electronic Health Records*

Major health care facilities such as Vanderbilt University, the Mayo Clinic, and Mount Sinai Health System are beginning to add sexual orientation and gender identity questions to their electronic health records systems. Consumer health advocates can begin conversations with their state's medical institutions to explore opportunities to advance data collection efforts.

4. *Research*

Several advocacy groups around the country have successfully partnered with universities' graduate programs and research centers to engage in field research about health disparities and access to care for LGBT people. For example, in South Carolina advocates from South Carolina Equality partnered with the Arnold School of Public Health at the University of South Carolina and developed a statewide needs assessment for the LGBT population. The data collected included information about health disparities as well as hate crimes, and came from more than 1,000 respondents by targeting people at events like Pride.

What Type of LGBT Data Should We Collect

The questions collecting this information typically include 1) sexual orientation, 2) current gender identity, 3) sex assigned at birth, 4) preferred name, and 5) preferred gender pronoun. The following resources offer guidance on the best questions and practices to use to gather this data.

Data Collection Resources

- Best Practices for Asking Questions about Sexual Orientation on Surveys (SMART group, 2009): <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>
- Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys (GenIUSS group, 2014): <http://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf>
- Do Ask, Do Tell: A Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings (Center for American Progress and The Fenway Institute, 2015): www.doaskdotell.org
- The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding (Institute of Medicine, 2011): www.iom.edu/lgbthealth
- Sexual Orientation and Gender Identity Data Collection in Electronic Health Records: A Workshop (Institute of Medicine, 2012): www.iom.edu/lgbtdata
- Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the LGBT Community: A Field Guide. (The Joint Commission, October 2011): http://www.jointcommission.org/assets/1/18/LGBTFieldGuide_WEB_LINKED_VER.pdf
- New York State LGBT Data Collection Initiative (2014): <https://www.governor.ny.gov/news/governor-cuomo-announces-multi-agency-state-effort-address-lgbt-disparities>
- Resources for Adding Sexuality and Gender Items to State and Local Youth Risk Behavior Surveys (All Students Count Coalition, 2014): <http://amplifyyourvoice.org/allstudentscount>
- Healthy People 2020 LGBT Health Topic Area (U.S. Department of Health and Human Services, 2010): <http://healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25>
- Improving LGBT Data Collection for the LGBT Community (U.S. Department of Health and Human Services, 2011): http://minorityhealth.hhs.gov/assets/pdf/checked/1/Fact_Sheet_LGBT.pdf