

Improving Data Collection for the LGBT Community

Many racial and ethnic minorities, people with disabilities, lesbian, gay, bisexual, and transgender (LGBT) communities, and other commonly underserved populations face unique health challenges, have reduced access to health care and insurance, and often pay the price with poorer health throughout their lives. Existing research suggests LGBT people and families may face significant challenges associated with health disparities in insurance coverage and access to healthcare services, including preventive care such as cancer screenings. The limited data available suggest that:

- Gay and bisexual men comprise more than half of new HIV infections in the U.S. each year, and HIV prevalence among transgender women exceeds 25 percent nationwide.
- Lesbian and bisexual women get less routine care than other women, including breast and cervical cancer screening.
- Approximately 30 percent of LGBT youth report having been physically abused by family members because of their sexual orientation or gender identity or expression.

Negative health outcomes for LGBT people may be due to a variety of factors, including reduced access to employer-provided health insurance and a lack of cultural competence in the health care system. The Institute of Medicine (IOM) in its March 2011 report, *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, emphasized the need for collection of gender identity and sexual orientation data on federally supported surveys. Due to limited data collection on sexual orientation and gender identity, the nature of these health disparities in the LGBT community are still in question.

The Affordable Care Act and LGBT Data Collection

The Affordable Care Act invests in the implementation of a new health data collection and analysis strategy. Section 4302 of the Affordable Care Act contains provisions to strengthen federal data collection efforts by requiring that all national federal data collection efforts collect information on race, ethnicity, sex, primary language, and disability status. The law also provides the Department of Health and Human Services (HHS) the opportunity to collect additional demographic data to further improve our understanding of healthcare disparities. In the past, identifying disparities and effectively monitoring efforts to reduce them has been limited by a lack of specificity, uniformity, and quality in data collection and reporting procedures. Consistent methods for collecting and reporting health data will help us better understand the nature of health problems in the LGBT community.

A Commitment to Improvement: A Timeline for LGBT Data Collection

HHS is developing a national data progression plan intended to begin the integration of sexual orientation and gender identity variables into HHS national surveys.

Sexual Orientation

The Department has collected LGBT-related data in several surveys in the past, but there are a number of challenges. The National Center for Health Statistics (NCHS) has improved comprehension and response rates over time by refining its methods. However, concern continues as missing data tend to be concentrated in certain population sub-groups. To enhance the quality of the data, the HHS Data Council, NCHS, and other relevant agencies across the federal government are testing ways to reduce bias in the estimates.

Gender Identity

HHS surveys have not collected data on transgender status. While HHS is in the beginning stages of developing data collection on gender identity, many researchers (e.g., Williams Institute at the University of California Los Angeles and the Center for Population Research in LGBT Health at the Fenway Institute) have been working on such data collection for several years. HHS will hold two roundtables with key experts in collecting data on sexual orientation and gender identity. HHS officials and the experts will review existing literature, discuss proposed questions, and develop a progression plan for gender identity data testing.

June – December 2011	Continue cognitive testing and begin field testing of sexual orientation data collection.
Summer 2011	Conduct first roundtable on gender identity data collection development. Complete initial development of sexual orientation data collection questionnaire.
Winter 2011	Conduct follow-up roundtable on gender identity data collection.
Spring 2012	Conduct and complete initial field testing of sexual orientation data collection. HHS Data Council presents a strategy to include gender identity data collection in HHS surveys.
Winter 2012	Conduct and complete large scale field test of sexual orientation data collection.
2013	If the field test is successful, implement new data collection on sexual orientation into the full NHIS data collection.

Improving the Health of LGBT Americans

The Obama Administration is committed to working with all Americans to create the brightest future for our country, including greater equality and better health for LGBT Americans. HHS continues to make significant progress toward protecting the rights and improving the health of LGBT Americans, such as implementing the Affordable Care Act, the health care law helping to improve access to care for all Americans, including individuals in the LGBT community; funding the above referenced study by the IOM to identify research gaps and opportunities related to LGBT health and outline a research agenda; issuing guidance to state Medicaid agencies on financial protections for same-sex couples; and issuing new rules requiring hospitals to protect patients' right to choose their own visitors during a hospital stay, including a visitor who is a same-sex domestic partner.