



Gathering Sexual Orientation and Gender Identity Data in Health IT

Better Information Can Help Close Disparities Gap

Kellan Baker February 2012

A growing body of knowledge, including the federal government's Healthy People 2020 plan for progress toward a healthier America over the next decade and two reports from the Institute of Medicine, demonstrates that the lesbian, gay, bisexual, and transgender population faces significant disparities in health status and access to health care coverage and services.¹ The Department of Health and Human Services is working to address these disparities through initiatives that include establishing a nationally representative baseline for gay² and transgender population health by improving survey research on the gay and transgender population.³

According to the Institute of Medicine, another crucial aspect of addressing gay and transgender health disparities is collecting confidential sexual orientation and gender identity data from patients, particularly via health information technology systems such as electronic health records. Sexual orientation and gender identity metrics must be included in health information technology meaningful use standards (which define the use of electronic health records and related technology within a health care organization) and other health information technology initiatives. This will facilitate the collection of data that are crucial to closing disparities and helping providers improve the health of their gay and transgender patients by delivering high-quality, patient-centered, culturally competent care.⁴

Below are examples of how this data collection will help providers and how it can be accomplished.

Collecting electronic patient data on sexual orientation and gender identity will help providers and facilities by:

- Contributing to an accurate health history for all patients and identifying the specific needs of gay and transgender patients, including recognizing patient representatives who are same-sex partners, providing the full scope of appropriate care for transgender people, and documenting comprehensive sexual and reproductive health histories

- Facilitating evaluation of the impact of LGBT-inclusive nondiscrimination protections and cultural competency standards on patient outcomes and satisfaction
- Helping improve the quality of care that all patients receive, including gay and transgender patients
- Providing a tool to track health disparities affecting gay and transgender patient populations

Sexual orientation and gender identity data collection can be accomplished by:

- Incorporating questions on relationship status, sexual orientation, sexual behavior, gender identity, and preferred name and pronoun into electronic health records and facility intake forms
- Providing staff training on asking any demographic question, whether about race, disability status, or gay and transgender identity, to promote a welcoming environment for all and diminish discomfort for both patients and staff
- Developing sufficient privacy measures to ensure the safety and confidentiality of all patient data

Examples of data collection metrics related to sexual orientation and gender identity include:⁵

Sexual orientation

Do you consider yourself to be:

- Straight
- Gay or lesbian
- Bisexual
- Something else

Sexual behavior

In the past [time], with whom have you had sex?

- Men only
- Women only
- Both men and women
- Neither

Gender identity

What is your gender identity?

- Male
- Female
- Transgender
- Transgender, female to male
- Transgender, male to female
- Other

What sex was recorded on your birth certificate?

- Male
- Female
- Don't know

As these examples show, data collection on sexual orientation and gender identity in clinical settings is possible. It is also timely. Many health care facilities around the country, including hospitals, community health centers, and managed care organizations, are already recognizing the gay and transgender individuals in their patient populations and implementing efforts to collect and safeguard important sexual orientation and gender identity data in their patient records systems.⁶

The collection of more LGBT patient data will greatly advance efforts by health care facilities, the Department of Health and Human Services, The Joint Commission, and others to understand and eliminate the disparities that undermine the health of LGBT people and their families. It is vital that health information technology initiatives help build the knowledge base regarding LGBT health and health care disparities in order to effectively promote the health of LGBT people and reduce the human and economic costs of health disparities.⁷

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Endnotes

- 1 U.S. Department of Health and Human Services, “Healthy People 2020: Lesbian, Gay, Bisexual, and Transgender Health” (2010); Institute of Medicine, “The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding” (2011); and Institute of Medicine, “Lesbian Health: Current Assessment and Directions for the Future” (2003).
- 2 We use “LGBT” and “gay and transgender” interchangeably to refer to the full range of people who identify as gay, lesbian, bisexual, and/or transgender.
- 3 U.S. Department of Health and Human Services, “Recommended Actions to Improve the Health and Well-Being of Lesbian, Gay, Bisexual, and Transgender Communities” (2011); and Office of Minority Health, “Plan for Health Data Collection on Lesbian, Gay, Bisexual and Transgender (LGBT) Populations” (2011).
- 4 J. Bradford and others, “Why gather data on sexual orientation and gender identity in clinical care settings” (Boston: The Fenway Institute, 2012).
- 5 The Joint Commission, “Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community” (2011); and J. Bradford and others, “How to gather data on sexual orientation and gender identity in clinical care settings” (Boston: The Fenway Institute, 2012).
- 6 Human Rights Campaign. “Healthcare Equality Index 2011.” (2011).
- 7 Joint Center for Political and Economic Studies, “The Economic Burden of Health Inequalities in the United States” (2009).