

1340 Boylston Street, 8th Fl
Boston, Massachusetts
02115

TELEPHONE 617-927-6451
FACSIMILE 617-267-0764
www.thefenwayinstitute.org

NATIONAL ADVISORY COUNCIL

American Cancer Society
American Lung Association
American Legacy Foundation
Americans for Nonsmokers Rights
Callen-Lorde Community Health Center
Campaign for Tobacco Free Kids
Chase-Brextton Health Services
CLASH
Fenway Community Health
Gay and Lesbian Medical Association
Howard Brown Health Center
LA Gay and Lesbian Center
Legacy Community Health Services
LGBT Community Center of New York
Mautner Project
National Association of LGBT
Community Centers
National Coalition for LGBT Health
National Youth Advocacy Coalition
North American Quitline Consortium
Robert Wood Johnson Foundation
Tobacco Control Network
Tobacco Technical Assistance Consortium
Whitman Walker Clinic

Moving Forward with LGBT Health: First Steps for the Federal Government

Problem statement

Studies over decades have consistently shown that LGBT people experience increased health risk factors based partially on reduced access to health care. Some of these disparities are quite pronounced: for example, smoking rates in the LGBT community range from 35% to almost 200% higher than the general population.^{1 2} Problems with concomitant access to care are also disturbingly common. For example, the National Gay and Lesbian Task Force recently released a national study showing that 25% of transgender people report being denied healthcare specifically because they are transgender.³

In 2010 the federal government expects to spend \$879 billion dollars on health.⁴ A key goal of this spending is to increase overall health and decrease health disparities. The process of addressing health disparities occurs at many levels within the federal government; each agency and department in HHS must take an active role in addressing myriad disparities before we can expect historic gaps to shift. Unfortunately for LGBT health disparities, the fact that federal systems do not routinely collect data needed to assess or monitor progress stymies this process and leaves the LGBT community with a lack of tools to assess and improve its health.

Landmark compilations of evidence

1998 Institute of Medicine Report on Lesbian Health⁵

2001 GLMA White paper⁶

2001 HP2010 LGBT Companion Document⁷

Landmark federal policy response

In the *Healthy People* documents,⁸ the federal government outlines a policy plan that sets a series of evidence-based goals each decade to improve the health of all Americans. As one of its two main goals, *Healthy People 2010* prioritized elimination of health disparities based on the following criteria: gender, race or ethnicity, education

or income, disability, geographic location, or *sexual orientation*.⁹ (Evidence of documented health disparities for transgender people was collected, but it presumably relied on too few studies to meet the standard for inclusion in Healthy People.) Inclusion of sexual orientation as a disparity marker in *Healthy People 2010* is key not only because of the federal responses initiated, but because the plan is used as a guideline by states for their health goals as well. This inclusion in Healthy People has paved the way for many subsequent federal policy pieces highlighting a range of LGBT health disparities, including NCI's *Eliminating Tobacco Disparities Summary Report*,¹⁰ SAMHSA's *A Provider's Introduction to Substance Abuse Treatment for Lesbian, Gay, Bisexual, and Transgender Individuals*,¹¹ HRSA's cultural competence¹² and bullying curricula,¹³ and CDC's Office of Minority Health and Health Disparity website.¹⁴

Federal process for eliminating health disparities

Healthy People 2010 guided the nation's federal health response through prioritizing 28 Focus Areas and, within them, 467 measurable Objectives.¹⁵ One or more lead agencies of HHS take responsibility for work in each Focus Area, and one or more major data sources are identified to track progress on each Objective. Progress is reported out routinely. *Healthy People 2020* is currently under development, the process for monitoring progress will still rely on federal data sources.

Challenge #1: Insufficient data collection

Healthy People 2010 includes 29 specific Objectives for which sexual orientation is included in the data templates. These objectives occur within nine of the 28 Focus Areas. However, for most of the 29 Objectives, "DNC" appears in the data templates: DNC means that data specific to sexual orientation are not currently collected by the data system used to track the objective.¹⁶ Thus, evidence of these disparities is not being collected by the federal government, and the federal health system is unable to track any progress in reducing these disparities.

Response #1: Add LGBT data collection to key federal surveillance instruments

There are currently 22 federal/state surveys identified as major data sources for *Healthy People 2010*.¹⁷ To achieve consistent reduction of LGBT health disparities, all of these instruments need to collect LGBT demographic data. Until that can be achieved, we recommend the following priority steps for monitoring LGBT health disparities.

1. National Health Interview Survey (NHIS)

The federal government describes this survey as "the principal source of information on the health of the U.S. population."¹⁸ NHIS is used to monitor the greatest number of health Objectives of any instrument. The current survey asks a commonly recognized rough proxy for LGB status: whether a household is led by same-sex partners. Because of the number of Objectives tracked, adding

direct data collection for LGBT demographics to this survey would do more than any other single action to provide the missing data necessary for quantifying LGBT disparities and monitoring their reduction.

2. U.S. Census

The U.S. Census demographic section is adopted wholesale in two related surveys that play a strong role in health disparity monitoring: the Current Population Survey and the American Community Survey. These three instruments provide the most accurate quantification of the population size, key information on social determinant factors (such as employment), health information (via routine supplements), and outcome information (via linking to mortality records).¹⁹ All of these qualities make these surveys key in monitoring health disparity data. Adding LGBT demographics to this battery of surveys would expand the health knowledge base dramatically.

3. Youth Risk Behavior/Behavioral Risk Factor Surveillance Systems (YRBSS/BRFSS)

These combined instruments represent a unique opportunity for data collection. Not only do they broadly track many aspects of health, but they represent the single largest health sample collected in the United States; in 2008 alone, over 400,000 surveys were collected from all 50 states.²⁰ The addition of LGBT demographic criteria to the core data set of these surveys would allow unprecedented ability to monitor disparities according to subsets of the LGBT population, particularly LGBT people of color.

Challenge #2: Methodological challenges in collecting LGBT demographic data

Policymakers and scientists have identified several methodological challenges in collecting LGBT data.²¹ Identity conventions among LGBT people are evolving, so wording used to indicate LGBT status must be chosen with care. Perhaps more troublesome, some vocabulary used within the LGBT community is relatively unknown to outsiders, thus introducing the possibility of measurement error when non-LGBT people are confused by language they do not understand. Since best estimates show that about 5% of the population will identify as LGBT,²² the challenges of rare population data collection are also present, particularly the difficulty of attaining a sufficient sample size and heightened sensitivity to measurement errors. Concerns have also arisen about LGBT measures upsetting respondents, potentially leading to survey break-off.

Response #2: Thorough testing and strategic deployment of LGBT demographic measures

The National Center for Health Statistics includes a Question Design Research Laboratory (QDRL) that is well-versed in state of the art question development. The current head of this laboratory, Dr. Kristen Miller, is a specialist in LGBT question development. The proposed plan for adding LGBT demographic measures to NHIS includes thorough testing in this lab, followed by conversion of the main instrument to audio-CASI, a type of computer-assisted interviewing

technique that allows for greatest flexibility and confidentiality.²³ This conversion to audio-CASI will significantly enhance data collection for all complex questions, including those on race/ethnicity and insurance provision. Preliminary testing and fielding of existing questions have provided evidence countering concerns over break off, instead showing widespread acceptance of LGBT demographic questions.²⁴ This work also provides insight on best-question language and design choices for avoiding measurement error. The QDRL can take this preliminary information and create a state of the art demographic measurement, then field and test it within the flexible NHIS audio-CASI mode before expanding to other instruments.

Conclusion

Monitoring disparities is not enough to achieve health equity. Therefore, we recommend including the LGBT population in all disparity reduction efforts that are scientifically indicated by current data. In 2001 the federal government created a strategic plan to reduce LGBT health disparities.²⁵ As of 2010, most of its goals are still valid and can certainly form the basis of a strong current action plan. However, assessing the current state of federal activity shows that beginning to monitor these disparities must be a priority, and we strongly recommend inclusion of tested measures in NHIS as an immediate step, followed by measures in U.S. Census and YRBSS/BRFSS core questions as next steps.

Recommended citation

Scout. 2010. Moving Forward with LGBT Health: First Steps for the Federal Government. Joint National Coalition for LGBT Health/National LGBT Tobacco Control Network policy paper. January 11, 2010. Available at www.lgbthealth.net & www.lgbttobacco.org.

Citations:

1. Bye L, Gruskin E, Greenwood G, Albright V, Krotski K (2004). "California Lesbians, Gays, Bisexuals, Transgenders Tobacco Use Survey 2004." <http://www.dhs.ca.gov/ps/cdic/tcs/documents/eval/LGBTTobaccoStudy.pdf>. Accessed April 4, 2008.
2. Lee JG, Griffin GK, Melvin CL (2009). "Tobacco Use Among Sexual Minorities in the USA, 1987 – May 2007: A Systematic Review." *Tobacco Control* 18(4):275-82.
3. Somjen F. Personal Communication. "Findings of National Transgender Needs Assessment." *National Gay and Lesbian Task Force*. December 12, 2009.
4. "Fiscal Year 2010 Budget in Brief." U.S. Department of Health and Human Services. <http://www.hhs.gov/asrt/ob/docbudget/2010budgetinbriefa.html>. Accessed on January 11, 2010.
5. Solarz AL (1999). "Lesbian health: current assessment and directions for the future." *Institute of Medicine (U.S.): Committee on Lesbian Health Research Priorities*. Washington, D.C.: National Academy Press.
6. Dean L, Meyer IH, Robinson K, Sell RL, Sember R, Silenzio VMB, Bowen DJ, Bradford JB, Rothblum, E, Scout, White J, Dunn P, Lawrence A, Wolfe D, Xavier J. (2000). "Lesbian, Gay, Bisexual and Transgender Health: Findings and Concerns." *Journal of the Gay and Lesbian Medical Association*, Vol. 4, No. 3, 2000.
7. "Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual and Transgender (LGBT) Health." *Gay and Lesbian Medical Association, LGBT health experts*. http://glma.org/data/n_0001/resources/live/HealthyCompanionDoc3.pdf. Accessed June 12, 2010.
8. *Healthy People 2010*, 2nd ed. U.S. Department of Health and Human Services. Washington, D.C.: Government Printing Office.
9. "A Systematic Approach to Health Improvement: Healthy People 2010. 2nd ed." U.S. Department of Health and Human Services. Washington, D.C.: Government Printing Office. http://www.healthypeople.gov/Document/html/uih/uih_bw/uih_2.htm#obj. Accessed January 11, 2010.
10. "Eliminating Tobacco-Related Health Disparities: Summary Report." U.S. Department of Health and Human Services. http://cancercontrol.cancer.gov/tcrb/eliminating_tobacco_hd.pdf. Accessed December 31, 2006.
11. (2001). "A Provider's Introduction to Substance Abuse Treatment for Lesbian, Gay, Bisexual, & Transgender Individuals." SAMHSA. www.nalgap.org/PDF/Resources/ProvidersGuide-SAMSHA.pdf. Accessed January 11, 2010.
12. "Cultural Competence Resources for Healthcare Providers." HRSA. <http://www.hrsa.gov/culturalcompetence/>. Accessed January 11, 2010.
13. "Stop Bullying Now! What can adults do?" HRSA. <http://www.stopbullyingnow.hrsa.gov/adults/default.aspx>. Accessed on January 11, 2010.
14. "LGBT Health." Office of Minority Health and Health Disparities. <http://www.cdc.gov/lgbthealth/index.htm>. Accessed on January 11, 2010.
15. *Healthy People 2010*, 2nd ed. U.S. Department of Health and Human Services. Washington, D.C.: Government Printing Office.
16. "Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual and Transgender (LGBT) Health." *Gay and Lesbian Medical Association, LGBT health experts*. http://glma.org/data/n_0001/resources/live/HealthyCompanionDoc3.pdf. Accessed June 12, 2010.
17. (November 2000). "Tracking Healthy People 2010. Part C: Major Data Sources for Healthy People 2010." U.S. Department of Health and Human Services. Washington, DC: U.S. Government Printing Office.
18. (June 2007). "National Health Interview Survey." U.S. Department of Health and Human Services (CDC-NCHS). <http://www.cdc.gov/nchs/nhis.htm>. Accessed January 11, 2010.
19. Personal communication. Fagan P (NCI health disparity expert) to Scout. Topic: Role of federal data sources in health disparity monitoring. January 11, 2010.
20. "Behavioral Risk Factor Surveillance System." *Center for Disease Control*. <http://www.cdc.gov/brfss/>. Accessed January 11, 2010.
21. Scout (2008). "LGBT Surveillance and Data Collection Briefing Paper." *National LGBT Tobacco Control Network*. <http://www.lgbttobacco.org/files/Surveillance%20Briefing%20Paper%2008.pdf>. Last updated Sept 7, 2008. Assessed June 01, 2010.
22. (2002). "National Survey of Family Growth, Cycle VI." National Center for Health Statistics. *United States Department of Health and Human Services*. Ann Arbor, MI: Inter-university Consortium for Political and Social Research.
23. Miller K (Director, NCHS Question Design Research Laboratory) to Scout. Personal Communication. Topic: Strategies for successful LGBT surveillance. January 7, 2010.
24. Scout (2008). "LGBT Surveillance and Data Collection Briefing Paper." *National LGBT Tobacco Control Network*. <http://www.lgbttobacco.org/files/Surveillance%20Briefing%20Paper%2008.pdf>. Last updated Sept 7, 2008. Assessed June 01, 2010.
25. (2001). "Strategic Plan on addressing Health Disparities Related to Sexual Orientation." U.S. Department of Health and Human Services.