



**SEXUAL ORIENTATION DATA:  
INCLUSION IN INFORMATION SYSTEMS AND DATABASES  
OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES**

March 5, 2001

Randall L. Sell, ScD  
Jeffrey B. Becker

This work was supported by contract SA-00-0396 from the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services.



For additional information concerning this report contact:

Randall L. Sell, ScD  
Assistant Professor  
Columbia University  
Mailman School of Public Health  
600 West 168<sup>th</sup> Street, 7<sup>th</sup> Floor  
New York, NY 10032  
Phone: 212-305-3457  
Fax: 212-305-3702  
Email: rls39@columbia.edu

Jeffrey B. Becker  
Columbia University  
Mailman School of Public Health  
600 West 168<sup>th</sup> Street, 7<sup>th</sup> Floor  
New York, NY 10032  
Phone: 212-305-3457  
Fax: 212-305-3702  
Email: jbb38@columbia.edu



# SEXUAL ORIENTATION DATA: INCLUSION IN INFORMATION SYSTEMS AND DATABASES OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES

- Executive Summary ..... 4**
- I. Introduction ..... 6**
  - Table 1 – Data Sets Required to Monitor HP2010 Objectives Related to Sexual Orientation.....9
- II. Collecting Sexual Orientation Data: Current Practice ..... 10**
  - A. HHS Information Systems and Databases ..... 10**
    - 1. National Health and Nutrition Examination Survey .....11
    - 2. National Survey of Family Growth.....12
    - 3. Youth Risk Behavior Surveillance System .....13
    - 4. Behavioral Risk Factor Surveillance System.....15
    - 5. National Household Survey on Drug Abuse.....16
    - 6. HIV/AIDS Surveillance System .....17
    - 7. National Survey of Substance Abuse Treatment Services.....18
    - 8. National Health Interview Survey .....19
  - B. Additional Notable Information Systems and Databases ..... 20**
    - 1. National Health and Social Life Survey/General Social Survey .....20
    - 2. Project HOPE International Survey of AIDS-Risk Behaviors .....21
    - 3. National Longitudinal Survey on Adolescent Health .....22
    - 4. Women’s Health Initiative.....23
    - 5. Nurses Health Study .....23
    - 6. Gay Urban Men’s Study .....24
    - 7. National Crime Victimization Survey .....24
    - 8. Violence Against Women Survey.....25
    - 9. United States Census.....26
- III. Collecting Sexual Orientation Data: Definitions and Measures ..... 27**
  - A. Definitions of Sexual Orientation ..... 28**
  - B. Measures of Sexual Orientation ..... 34**
    - 1. Kinsey Scale.....36
    - 2. Klein Scale .....38
    - 3. Shively Scale.....40
    - 4. Sell Assessment .....42
    - 5. Friedman Measure of Adolescent Sexual Orientation .....45
  - C. Choosing a Measure of Sexual Orientation..... 45**
- IV. Future Directions..... 48**
- V. Appendixes..... 55**
  - A. Table 2 – HHS Databases That Have Assessed Sexual Orientation ..... 55**
  - B. Table 3 – Additional Databases That Have Assessed Sexual Orientation ..... 61**
  - C. Karl Ulrichs Sexual Orientation Classification Scheme ..... 64**
  - D. Kinsey Scale..... 65**
  - E. Klein Sexual Orientation Grid..... 66**
  - F. Shively Scale of Sexual Orientation..... 67**
  - G. Sell Assessment of Sexual Orientation..... 68**
  - H. Friedman Measure of Adolescent Sexual Orientation ..... 71**
  - I. Selected Bibliography ..... 77**



## Executive Summary

One of the greatest threats to the health of Lesbian, Gay and Bisexual Americans is the lack of information about their health in the form of scientifically obtained data and published reports. Without such information it is difficult to raise awareness and acquire adequate resources to address health concerns that exist or arise in these communities.

The Department of Health and Human Services (HHS), which is responsible for monitoring the health of the population, must recognize gaps in its information systems regarding sexual orientation data and take immediate steps to monitor and eliminate health disparities, particularly those delineated in Healthy People 2010 (HP2010).

HHS and other major sources of health information in the United States are only recently beginning to gain experience collecting sexual orientation data. Not surprisingly, therefore, standard definitions and measures of sexual orientation have not been developed as has recently been done for race and ethnicity.<sup>1</sup> The need for the development, testing and selection of standard definitions and measures of sexual orientations based upon sound methodological research is paramount. Standards are important to avoid future data incompatibilities across various agencies and avoid problems with interpretation. Standard measures of sexual orientation will allow HHS to make a coordinated response to major health and social service issues.

---

<sup>1</sup> Krieger, N. Counting Accountably: Implications of the New Approaches to Classifying Race/Ethnicity in the 2000 Census. *American Journal of Public Health*. 2000;90(11), 1687-1689.



To assist in the development of standard definitions and measures, this report reviews sexual orientation data collection in HHS information systems and databases as well as in other important health information systems and databases. Operational definitions and measures of sexual orientations are also reviewed. Future efforts to develop and measure sexual orientations in order to identify and eliminate health disparities must be cognizant of this groundwork. At present, as was the case with the variables of race and ethnicity not so long ago, there is little consensus on how sexual orientation should be assessed in research studies. Standardized measures of sexual orientation therefore cannot be recommended at this time by the authors of this report.

However, HHS can take a leadership role in the collection of sexual orientation data and the development of standardized measures of sexual orientation by:

- creating Data Council and National Committee on Vital and Health Statistics workgroups to examine the collection of sexual orientation data in HHS data collection and reporting activities,
- creating a set of guiding principles to govern the process of selecting standard definitions and measures of sexual orientations,
- recognizing that racial and ethnic, immigrant status, age, socioeconomic and geographic differences must be taken into account when selecting standard measures of sexual orientations, and assessing the validity and reliability of these measures,
- selecting a minimum set of standard sexual orientation measures for use in HHS databases and information systems, and
- developing a long-range strategic plan for the collection of sexual orientation data.



## I. Introduction

One of the greatest threat to the health of Lesbian, Gay and Bisexual (LGB) Americans is the lack of scientific information about their health. Service providers and researchers working with lesbian, gay and bisexual people long ago recognized important and unique health concerns within these populations; unfortunately, they also recognized the difficulty of raising awareness and acquiring adequate resources to address these concerns in the absence of evidence in the form of scientifically obtained data and published reports.<sup>2,3,4</sup> Without adequate information on the health of lesbian, gay and bisexual Americans, measurable advances in civil rights and basic health will always be extremely difficult to achieve.

The federal government, and in particular, the Department of Health and Human Services (HHS) must recognize the serious gaps in its information systems and databases regarding sexual orientation. HHS is charged with monitoring the health of the population and eliminating health disparities as they are identified. This includes disparities associated with sexual orientations.<sup>5</sup>

HHS set a goal in Healthy People 2010 (HP2010) of eliminating health disparities among different segments of the population including “differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation.”<sup>5</sup> Sexual orientation is specifically included in 29 of HP2010’s objectives spanning ten focus areas including: access to care, educational and community-based programs, family planning, HIV,

---

<sup>2</sup> Dean L., *et al.* Lesbian, Gay, Bisexual, and Transgender Health: Findings and Concerns. *J Gay and Lesbian Medical Association* 2000;4(3):101-151.

<sup>3</sup> Sell RL, Petruccio C. Sampling Homosexuals, Bisexuals, Gays and Lesbians for Public Health Research: A Review of the Literature from 1990-1992. *J Homosexuality*. 1996;30(4):31-47.

<sup>4</sup> Solarz AL (Ed). *Lesbian Health: Current Assessment and Directions for the Future*. Institute of Medicine, National Academy Press, Washington, DC, 1999.



immunization and infectious disease, injury and violence prevention, mental health and mental disorders, sexually transmitted diseases, substance abuse, and tobacco use.

The creators of Healthy People 2010 required evidence of a health disparity before sexual orientation could be included in an objective. Implicit in the 29 objectives for which sexual orientation is included, therefore, is a belief on the part of HHS that disparities exist. More importantly, however, by recognizing health disparities associated with sexual orientations in these objectives, the government is responsible for fully monitoring and achieving these objectives.

HP2010 will have a profound positive impact upon the health of all Americans, and in particular LGB Americans, if properly implemented. The biggest hurdle to realization of HP2010 objectives is successful integration of sexual orientation data collection into existing information systems and databases used to monitor HP2010 objectives. While this is a challenging task, now is the time to undertake such an effort.

The 29 objectives for which sexual orientation is included in HP2010 are listed in Table 1. The first column of this table lists the corresponding information systems and databases used to monitor these objectives. Only about half of these have any experience collecting sexual orientation data. In order to facilitate the integration of sexual orientation data collection into all of these information systems and databases, as well as other HHS information systems and databases, this paper: 1) reviews current sexual orientation data collection practice at HHS as

---

<sup>5</sup> U.S. Department of Health and Human Services. *Healthy People 2010* (Second Edition, in Two Volumes). Washington, DC: November, 2000.



well as in other notable information systems and databases, 2) reviews the history of defining and measuring sexual orientation for research studies, and 3) makes recommendations to achieve full inclusion of sexual orientation data in all relevant health information systems and databases at HHS necessary to monitor and eliminate health disparities faced by LGB Americans.

This report does not deal with the collection of gender-identity data or sexual orientation data collection at the local level. Gender-identity data collection was not examined because gender identity and transgender health issues were not addressed in HP2010, which was the impetus for this work. However, issues related to gender identity should be given equal attention. Likewise, this report focuses on data collection at the federal level to assist monitoring of HP2010 objectives at HHS. However, equal or perhaps even greater attention must be given to data collection at the state, county and city levels where sexual orientation data collection is likewise of great value.