

Lesbians, Gays, Bisexuals, and Transgenders of Color Sampling Methodology

Strategies for Collecting Data in Small, Hidden, or
Hard-to-Reach Groups To Reduce Tobacco-Related
Health Disparities



Lesbians, Gays, Bisexuals, and Transgenders of Color Sampling Methodology

**Strategies for Collecting Data in Small, Hidden, or
Hard-to-Reach Groups To Reduce Tobacco-Related
Health Disparities**

Hide – to keep out of sight or prevent the recognition or disclosure of

We have an enormous opportunity to reduce heart disease, cancer, stroke, and respiratory disease among members of racial and ethnic minority groups, who make up the most rapidly growing segment of the U.S. population.

Surgeon General's Report, 1998



Francisco O. Buchting, Ph.D.
Director of Strategic Development
and Knowledge Transfer
ETR Associates
4 Carbonero Way
Scotts Valley, CA 95066-4200

December 2008

As a scientist and community health advocate interested in the lesbian, gay, bisexual, and transgender (LGBT) communities and in communities of color, I know the challenge of generating credible research on tobacco's impact on these populations. With evidence showing that tobacco disproportionately impacts both LGBTs and people of color, how can the best possible scientific tools fail to accurately characterize the impact on those at the intersection of these groups—LGBTs of color?

The answer lies not in any factor intrinsic to either group, but in what may be one of the biggest methodological challenges facing scientists today: the need to define what constitutes a “representative” sample of populations inadequately captured by large-scale, full probability surveys. Indeed, which tested research methods are most effective in sampling small, hidden, or hard-to-reach populations?

Momentum and increasing sophistication in research on both LGBTs and people of color make it particularly interesting to examine small population research on LGBTs of color. As we examine and call for finely tuned research tools to address the health needs of LGBTs of color, we understand the broad impact of this knowledge—enhancements to small population research are fundamental to eliminating health disparities. Indeed, the present lack of data on LGBTs of color has rendered a segment of the population invisible. As a result, initiatives and strategies to reduce health disparities have not provided the much-needed outreach and benefit these communities deserve.

Thus, it is with great pleasure that I present this report on best practices and immediate needs in sampling methodology in LGBTs of color. I was honored to work with many brilliant researchers in creating this report—the result of our collaboration at the Fall 2006 meeting, LGBTs of Color Sampling Methodology. The report is offered as a springboard for further discussion and as guidance to enhance methodological development in small population research. As with cultural competency, it is time we move beyond one-size-fits-all research and develop a range of sophisticated tools for research on exceptional populations.

Sincerely,

A handwritten signature in black ink, appearing to read "Francisco O. Buchting".

Francisco O. Buchting, Ph.D.

Table of Contents

Acknowledgements	3
Executive Summary	4
LGBTs of Color Sampling Methodology Meeting: An Overview	6
Background of Meeting	6
Purpose of Meeting	6
Outcomes of Meeting	7
Beyond the Meeting	7
Research on Tobacco Use Among LGBTs and Communities of Color	8
LGBTs and Tobacco	8
Communities of Color and Tobacco	9
Initiation of Tobacco Use	9
Smoking Prevalence	9
Health Outcomes	10
Interpretation of Data	10
Summary	10
Meeting Preparation and Format	11
Literature Review and Articles To Frame Meeting	11
Presentations and Discussions	11
Development of Recommendations	12
Meeting Presentations and Discussions	13
Presentation One	13
People of Color in Same-Sex Couples: Findings from Census 2000	13
Discussion One	13
Census	13
Experiences with Full Probability Methods	14
Issues with Identity	14
Emergent Themes	14
Presentation Two	15
Overview of Sampling Strategies for Hard-to-Reach and Hidden Populations	15
Discussion Two	16
Respondent-Driven Sampling	16
Mixed Methods	16



Funding and Methodology	16
Emergent Themes	17
Barriers	17
Promising Strategies	17
Presentation Three	18
Cultural and Social Factors in Research on LGBTs of Color Communities.....	18
Discussion Three	18
Methods	18
LGBT Data Collection on Large Surveys	19
Emergent Themes	19
Presentation Four	20
Tobacco Use Among LGBs	20
Discussion Four	20
Emergent Theme	20
Meeting Recommendations	21
Promoting Best Strategies To Achieve Adequate Sampling of LGBTs of Color	21
Understanding Tobacco Use Among LGBTs of Color.....	22
Addressing Barriers to Conducting Research on LGBTs of Color	22
Conclusion	24
References	25
Appendices	29
Appendix A. Meeting Participants	29
Appendix B. Meeting Agenda	30

Acknowledgements

The editorial team extends its gratitude to the American Legacy Foundation, the National Cancer Institute’s Division of Cancer Control and Population Sciences, the Tobacco Research Network on Disparities (TReND), and the California Tobacco-Related Disease Research Program for sponsoring this landmark meeting. We thank the meeting participants for exploring and elevating new science that will improve the health of lesbian, gay, bisexual, and transgender communities of color by reducing tobacco-related health disparities. We are grateful to Scout for leading the preparation of this report and for continuing the effort to increase diversity and inclusivity in tobacco-related research. Finally, we thank TReND for stimulating scientific thought in areas that will ultimately help reduce tobacco-related disparities.

Meeting Chair			
Francisco O. Buchting, Ph.D. ETR Associates Scotts Valley, CA			
Editorial Team			
Francisco O. Buchting, Ph.D. ETR Associates Scotts Valley, CA	Pebbles Fagan, Ph.D., M.P.H National Cancer Institute Bethesda, MD	Martha Pien, M.A. DB Consulting Group, Inc. Silver Spring, MD	Allison Rose, M.H.S. SAIC-Frederick, Inc. Bethesda, MD
Science Writer			
Scout, Ph.D. National LGBT Tobacco Control Network The Fenway Institute Boston, MA			
Planning Committee			
Francisco O. Buchting, Ph.D. ETR Associates Scotts Valley, CA	Richard R. Clayton, Ph.D. University of Kentucky Lexington, KY	Pebbles Fagan, Ph.D., M.P.H. National Cancer Institute Bethesda, MD	Gary Humfleet, Ph.D. University of California San Francisco, CA
Scout, Ph.D. National LGBT Tobacco Control Network The Fenway Institute Boston, MA	Melissa J. H. Segress, M.S. University of Kentucky Lexington, KY	Randall Sell, Sc.D Drexel University New York, NY	Donna Vallone, Ph.D., M.P.H. American Legacy Foundation Washington, DC

Executive Summary

The United States is a world leader in health research, having spent an estimated \$111 billion in this arena in 2005. This massive effort includes Healthy People 2010—a health promotion and disease prevention initiative launched in 2000 by the Department of Health and Human Services (HHS). Targeting a set of health objectives to be achieved by the Nation over the first decade of the 21st century, Healthy People 2010 serves as the benchmark for tracking health disparities in the United States. This initiative seeks “to eliminate health disparities among segments of the population, including differences that occur by gender, race or ethnicity, education, income, disability, geographic location, or sexual orientation.”¹

At the heart of Healthy People 2010, notes HHS, are its science-based, data-driven objectives that enable progress and trends to be tracked. In 2007, the *Healthy People 2010 Midcourse Review* reported information on the status of these objectives by gender, race or ethnicity, education, income, disability, and geographic location. Yet, according to the *Midcourse Review* executive summary, “Data are not available by sexual orientation for any of the Healthy People 2010 objectives.”²

The absence of such data symbolizes a significant challenge in health research today—the inability of large-scale research methods to successfully monitor the health of small, hidden, or hard-to-reach populations. This challenge is evident in the paucity of data on people who fall at the intersection of two groups with independently documented health disparities—people of color and lesbian, gay, bisexual, and transgender persons (or LGBTs).

While large data gaps exist, population-based studies of LGBTs show notably higher smoking rates in this population than in the general population.³ Among certain subgroups—lesbian and bisexual women, for example—smoking rates are almost 200 percent higher than rates in the general population. Factors such as low community awareness of higher smoking

rates and high community susceptibility to tobacco marketing efforts contribute to this disparity.

Although tobacco-related health disparities among people of color are better documented than those in LGBTs, these disparities remain complicated phenomenon for people of color. For example, Blacks/African Americans have equivalent rates of smoking as Whites, yet they die of tobacco-related diseases much sooner and at higher rates than members of other racial/ethnic groups. And while large surveys of Asian Americans/Pacific Islanders and Latinos/Hispanics show aggregate smoking rates lower than those seen in the general population, subpopulation smoking rates vary widely and can spike much higher than general population rates. For many racial/ethnic groups, large-scale surveys and reporting standards are deficient—they are not translated into the language of the target population, are not tested on the racial/ethnic group being studied, or rely on a professional’s perception of race, as exemplified by the many American Indian cancer cases reported as White cancer cases.

Data collection for both LGBTs and communities of color challenges the standard paradigm sampling methodology. To address deficiencies in sampling of LGBTs of color, four leading health and tobacco research groups—The American Legacy Foundation, the National Cancer Institute’s Division of Cancer Control and Population Sciences, the Tobacco Research Network on Disparities, and the California Tobacco-Related Disease Research Program—convened a Fall 2006 meeting of experts to address sampling methodology in LGBTs of color. Meeting participants included scientists with expertise in communities of color, sexual orientation, gender identity, and sampling methods for small, hidden, or hard-to-reach populations. The participants were charged with answering a critical question that would help us address tobacco-related disparities: What are the best current strategies and next steps for sampling LGBTs of color?

As participants discussed peer presentations and began formulating recommendations, four strategies emerged as potential solutions to the challenge of sampling LGBTs of color:

- ◆ enhance and validate research and surveillance methods for small population research
- ◆ include sexual orientation as a routine demographic marker for all research and surveillance activities
- ◆ create tangible structures (i.e., new funding mechanisms, training programs) to counter the institutional and funding barriers that challenge researchers specializing in small population research
- ◆ expand expertise on reviewer panels to reflect state-of-the-art sampling strategies for LGBTs, LGBTs of color, and other small, hidden, or hard-to-reach populations

While these strategies reflect areas of need in research on LGBTs of color, they also address fundamental institutional barriers to research on many other small, hidden, or hard-to-reach populations. Because LGBTs of color are dually or triply impacted as members of several groups challenged by health disparities, leaving them out of the measurement of health disparities is simply not acceptable.

This report details the process that led to the above strategies, the discussions among participants at the September 2006 meeting, and the recommendations participants developed to advance each strategy.

LGBTs of Color Sampling Methodology Meeting: An Overview

Background of Meeting

Research on health disparities in racial/ethnic minorities has grown steadily since the early 1990s. Progress has been made in accurately enumerating the extent of tobacco use and its devastating effects among aggregate minority racial/ethnic groups. Likewise, research on lesbian, gay, bisexual, and transgender (LGBT) health disparities has grown steadily. The study of the intersection of these two populations—LGBTs of color—promises to be a useful area of inquiry, offering new perspectives on health disparity mechanisms and pathways for LGBTs or people of color.

In 1998, the Department of Health and Human Services (HHS) published the first major report to highlight the need to address tobacco-related health disparities among racial/ethnic groups, *Tobacco Use Among U.S. Racial/Ethnic Minority Groups: A Report of the Surgeon General*.⁴ At that time, little to no data had been published on tobacco use among LGBTs of color. However, recent advances in LGBT research have since provided the momentum to identify innovative ways to reduce tobacco-related cancer, cardiovascular disease, stroke, and other diseases among LGBTs of color.

Nonetheless, researchers and practitioners interested in this area face many challenges. The relatively small size of the populations of LGBTs of color alone presents the same challenges found in studying other small, hidden, or hard-to-reach groups. Small sample sizes inhibit the ability of standard surveillance measures to accurately estimate smoking rates at local, state, and national levels and to provide insight on quitting behaviors and factors associated with quitting behaviors in these communities. Although Healthy People 2010—a health promotion and disease prevention initiative launched in 2000 by HHS—identified the need to eliminate tobacco-related health disparities among LGB populations,

baseline and target goals were left blank because baseline data were lacking.¹ This data void limits goal setting and undermines the development of appropriate interventions to reach a critical Healthy People 2010 goal—eliminating all health disparities.

In 2004, the National LGBT Communities Tobacco Action Plan⁵ called for research to examine tobacco use, including smoking rates, among LGBTs of color. In addition, several reports identified multiple gaps in the data needed to eliminate health disparities. These reports suggested the need to:

- ◆ establish new approaches for collecting and sharing data to study the relationship of tobacco use and exposure to variables such as race, ethnicity, and socioeconomic status⁶
- ◆ develop culturally and ethnically appropriate sampling methods, survey designs, and survey measures to obtain larger samples and to assess the smoking behavior of small populations at local, regional, and national levels⁷
- ◆ conduct additional research to better understand disparities in tobacco use rates among LGBT populations⁸

Purpose of Meeting

Spurred by disturbing evidence of high rates of tobacco use in the LGBT communities, tobacco-related health disparities among racial/ethnic minorities, and recommendations from key reports,^{* 5,7} several organizations collaborated in 2006 on sampling methodologies in LGBTs of color. To that end, the American Legacy Foundation, the National Cancer Institute's Division

* More than a decade of research is summarized in the next section, *Research on Tobacco Use Among LGBTs and Communities of Color*.

of Cancer Control and Population Sciences, the Tobacco Research Network on Disparities, and the California Tobacco-Related Disease Research Program convened the LGBTs of Color Sampling Methodology Meeting on September 15, 2006.

The 21 researchers attending this meeting represented some of the most experienced people in research on LGBTs of color, LGBT sampling, and tobacco-related health disparities. The aims of the meeting were to:

- ◆ identify obstacles and barriers to achieving adequate sampling of LGBTs of color in research
- ◆ summarize effective methodologies to adequately sample LGBTs of color
- ◆ generate recommendations for conducting robust research on LGBTs of color
- ◆ produce content for the meeting report and other vehicles for disseminating findings from the meeting

Outcomes of Meeting

This report reviews the problem of tobacco use among LGBTs and racial/ethnic minorities, summarizes the format and content of the Fall 2006 meeting, and makes recommendations to help eliminate tobacco-related health disparities in LGBTs of color. It distills the discussions among and lessons learned from some of the most advanced researchers in this challenging arena. This knowledge and the

recommendations of meeting participants provide invaluable resources to assist policymakers, funders, and researchers. Through this work, the larger body of knowledge on racial/ethnic health disparities, LGBT health, and small population research will be commensurately enriched.

Beyond the Meeting

Health disparities increasingly cluster in the same hidden or hard-to-reach groups, regardless of the health issue. As health care improves for the general population, groups not reached by general efforts continue to demonstrate health disparities. The need to refine our research tools to address the needs of populations not served by current surveillance instruments is increasing. Creating state-of-the-art research methods that can target LGBTs of color is relevant to discussions related to non-English speakers, multiracial individuals, American Indians, and recent immigrant subpopulations, to name a few.

Indeed, refining broad-scale research tools into tailored, narrow-scale applications is perhaps the preeminent challenge in population research today. The demand to eliminate health disparities drives the need to enhance the tested research strategies available for any hard-to-reach population, and our current methodologies are simply too crude to respond. No doubt the field of research methodologies for hard-to-reach populations will be rich and varied in coming years. The challenge is how quickly current thinking will evolve to meet this need.

Research on Tobacco Use Among LGBTs and Communities of Color

To provide context for the LGBTs of Color Sampling Methodology Meeting, this section summarizes more than a decade of research on tobacco use among LGBTs and communities of color.

LGBTs and Tobacco

Awareness has grown over the last several decades that the LGBT population experiences health disparities in several areas. Initial work on sexually transmitted diseases has grown into a vibrant field of research on almost all aspects of health and prompted the inclusion of sexual orientation as a marker for health disparities in Healthy People 2010.¹ These disparities are particularly noticeable in tobacco use.

A 2001 literature review by researchers from the Centers for Disease Control and Prevention's Office on Smoking and Health, reported that among population-based studies, LGB people smoke at rates 40 to 60 percent higher than the general population.⁹ While population-based studies that include questions of sexual orientation or gender identity are relatively rare,^{10, 11} later population-based studies¹²⁻¹⁵ support the 2001 literature review. For example, the following major California-based investigations found that:

- ◆ Gay men smoke at rates 50 percent higher than other men; lesbians smoke at rates almost 70 percent higher than other women.¹⁶
- ◆ LGBT men smoke at rates almost 50 percent higher than other men; LGBT women smoke at rates almost 200 percent higher than other women.¹⁷

Early evidence showing that LGB youth smoke at rates 68 percent higher than other youth (59 percent versus 35 percent)¹⁸ continues to be corroborated by the following more recently published analyses:

- ◆ 1999 Growing Up Today Survey: Among heterosexual adolescents, about 9 percent were

smokers, versus 42 percent of lesbian/bisexual female adolescents; 8 percent of heterosexual males versus 17 percent of “mostly heterosexual” male adolescents smoked.¹⁹

- ◆ 1994-1995 National Longitudinal Study of Adolescent Health: Among those who reported same-sex attraction or relationships, 35 percent of males and 45 percent of females smoked versus 29 percent of others.²⁰

Findings are consistent across available research, population-based studies, large cohort studies, and convenience samples: Some if not all LGBT groups demonstrate significantly higher smoking rates than are seen in the general population.^{9, 16, 21-29}

Higher smoking prevalence combines with two other factors to crystallize the need for tobacco control initiatives among LGBTs. First, LGBTs experience well-documented structural, financial, and personal barriers that limit their ability to access health care, including tobacco initiatives that target the general population.^{8, 30} For example, 37 percent of respondents in the 2003 California LGBT Tobacco Survey believe that anti-smoking campaigns ignore the LGBT community.¹⁷ Second, LGBT community members and leaders show distressingly low awareness of tobacco as a health priority for this population. For example, in the California LGBT Tobacco Survey, 7 of 10 LGBT men and 4 of 5 LGBT women thought smoking was no bigger problem for LGBTs than for anyone else—a perception that existed despite record-high smoking rates in these communities.¹⁷

University of California San Francisco researchers found that only 24 percent of 74 LGBT community leaders listed tobacco as one of the top priority issues.³¹ Failing to make this issue a priority is likely related to the early and persistent marketing efforts of the tobacco industry that targeted LGBTs—including significant sponsorship of related HIV groups—and the high brand loyalty that LGBTs give to these

vanguard corporate sponsors.³²⁻³⁴ This phenomenon is supported by evidence from focus groups conducted by University of California San Francisco researchers. When the groups were shown depictions of tobacco industry strategies to target the Black/African American and LGBT communities, Blacks/African Americans were primarily angry, while LGBTs were largely grateful that the companies had tailored materials for them.³¹⁻³⁶

LGBTs have some of the highest smoking rates of all disproportionately affected populations. This reality demonstrates the critical need for tobacco control initiatives in this population, particularly when combined with the barriers to health and the low level of community awareness of tobacco's impact that challenge LGBTs.

Communities of Color and Tobacco

The 1998 Surgeon General's Report⁴ and the subsequent Healthy People 2010¹ reported unequal tobacco-related health indicators for minority racial/ethnic populations. Research into tobacco-related health disparities has expanded the understanding of disproportionate tobacco impact beyond simple prevalence—differences in tobacco use, exposure, initiation, treatment, and subsequent health outcomes all contribute to the inequalities different populations experience.³⁷ For some minority populations, differences in access to and quality of health care also may play a large role in tobacco morbidity and mortality.³⁷ Documented disparities span the initiation of tobacco use through tobacco-related disease outcomes among aggregate racial/ethnic groups.

Initiation of Tobacco Use

Smoking initiation rates among communities of color vary between and within racial/ethnic groups. Use of smokeless tobacco has been reported as early as preschool and kindergarten among Alaska Natives, and usage rates range from 18 to 60 percent among American Indian/Alaska Native youth.³⁸⁻⁴⁰ Smoking initiation for American Indians frequently has been reported in middle school.⁴¹

Initiation age for Latinos/Hispanics is predominantly later than American Indians/Alaska Natives, yet often occurs before age 18.⁴²⁻⁴⁴ Initiation age for Asian Americans/Pacific Islanders is generally later than for Latinos/Hispanics but differs by ethnicity. Data on Hawaiians and Pacific Islanders show earlier initiation⁴⁵ than among Asians. Chinese and Koreans generally initiate smoking later than Whites, and Asian Americans/Pacific Islanders are likely to start smoking after age 18.⁴²

Data on Blacks/African Americans show that this population has the latest initiation, primarily beginning to smoke regularly after age 18.^{42, 43, 46} No substantive reported differences exist among Blacks born in the Caribbean, Haiti, or the United States.⁴⁷

Smoking Prevalence

Current smoking rates among communities of color also vary between and within racial/ethnic groups. American Indian/Alaska Native youth and adults have the highest smoking rates of all racial and ethnic groups—32 percent of this population smoke.⁴⁸ The highest smoking rates are reported in Alaska, where rates range from 39 to 50 percent and tobacco use among women has been reported to be as high as 68 percent.⁴⁹ At 23 percent, Black/African American smoking rates closely track rates among Whites (22 percent).⁴⁸ Evidence shows that Blacks born in the United States smoke more than Blacks born in Haiti or other parts of the Caribbean.^{47, 50}

Smoking rates for adult Latinos/Hispanics have long been lower than the general population—15 percent.⁴⁸ An earlier study disaggregating data shows wide variation in smoking rates among the different ethnicities: 30 percent of Puerto Ricans smoke, compared with 23 percent of Mexicans, 21 percent of Central/South Americans, and 19 percent of Cubans.⁵¹

National Health Interview Survey data show that with 11 percent of adult Asian Americans/Pacific Islanders smoking, this group has the lowest rate of any racial/ethnic group.⁴⁸ However, disaggregated data show wide variation among subpopulations of Asian Americans/Pacific Islanders, with smoking rates particularly high among people of Vietnamese and Korean heritage (26.5 percent and 27.2 percent, respectively).⁵¹

Health Outcomes

Information on health outcomes among racial/ethnic groups reveals complexities in measuring tobacco's impact. Aggregate Latino/Hispanic population data show few overall cancer disparities and the lowest rates of lung cancer morbidity and mortality of all groups, despite higher smoking rates than reported for aggregate Asian populations.⁵² Asian Americans/Pacific Islanders show higher incidence of lung cancer than American Indians/Alaska Natives, despite the wide gap in smoking rates.⁵² Conversely, American Indians/Alaska Natives show higher mortality rates from lung cancer.⁵²

Perhaps most contradictory are the data for Blacks/African Americans. This group has the highest overall incidence of and death rate for all cancers, despite slightly lower smoking rates than found in the general population.⁵² As examples of the disparity in health outcomes, death rates for Black/African American men compared with White men are 38 percent higher for lung cancer, 95 percent higher for oral cancer, 124 percent higher for stomach cancer, 79 percent higher for esophageal cancer, and 138 percent higher for larynx cancer.⁵²

Interpretation of Data

Reliance on national surveys as prevalence benchmarks for racial/ethnic groups is fraught with the same liabilities that affect all small population work. The surveys excel at portraying differences in the broadest, most generalizable categories; rarely do they offer the nuanced detail to accurately describe

the fabric of subpopulations incorporated under a simple heading such as "Asian" or "Hispanic." Similarly, large surveys do not portray the differences between ceremonial and commercial tobacco use among American Indians/Alaska Natives. Additionally, cancer outcome data can be complicated by misreporting. For example, one study found that 52 percent of American Indian cancer cases in the Pacific Northwest were misclassified, with 92 percent of the cases reported as White cancer cases.⁵³

Summary

Racial/ethnic disparities in smoking and cancer are well recognized, and awareness is growing of the tobacco-related health disparities that challenge LGBT persons. Against this backdrop, it is not a stretch to hypothesize that LGBTs of color may face even greater disparities in tobacco use and its consequences than other populations. While it is prudent that we improve our understanding of health disparities that fall at the intersection of race/ethnicity and sexual orientation/gender identity, doing so is difficult in the face of enormous data gaps. Understanding these disparities requires that we collect appropriate data to develop interventions that will reduce tobacco's burden.

Hence, the question to be addressed: How do we meet the challenge of collecting data among small, hidden, or hard-to-reach populations? And of immediate relevance to this report, what are the best current strategies and next steps for sampling LGBTs of color?

Meeting Preparation and Format

The LGBTs of Color Sampling Methodology Meeting was held at the American Legacy Foundation on September 15, 2006 in Washington, DC. Twenty-one researchers representing a cross-section of disciplines, racial/ethnic groups, sexual orientations, gender identities, and geographical regions were invited to participate in a small working meeting to address the following research question: What are the best current strategies and next steps for sampling LGBTs of color?

The meeting was designed to identify barriers to sampling LGBTs of color and possible solutions. Before the meeting, participants reviewed relevant research articles. In opening presentations, four researchers summarized state-of-the-art knowledge; discussion followed each presentation. Participants broke into three workgroups for the remainder of the meeting to develop recommendations for sampling LGBTs of color.

Literature Review and Articles To Frame Meeting

The meeting planning committee reviewed the scientific literature to identify articles that address sampling issues in LGBT populations. Only a few articles addressed sampling methods in LGBT populations, and no articles were found on tobacco use among LGBTs of color.

The committee then expanded its focus to include articles on other hard-to-reach populations, such as people with HIV. It selected six articles, noted below, to serve as the foundation for meeting discussion; Dr. Buchting, Meeting Chair, asked participants to review these articles in preparation for the meeting.

- ◆ Magnani R., Sabin K., Saidel T., & Heckathorn D. (2005). Review of sampling hard-to-reach and hidden populations for HIV surveillance. *AIDS*, 19 (suppl. 2), s67-s72.
- ◆ Gates G., Holning L., & Sears R.B. (2006). Race and ethnicity of same-sex couples in California.

The Williams Project on Sexual Orientation Law and Public Policy. Los Angeles, CA: UCLA School of Law. Retrieved from http://www.law.ucla.edu/williamsinstitute/publications/Race_and_ethnicity_of_same-sex_couples_in_california.pdf.

- ◆ Zea M.C., Reisen C.A., & Diaz R.M. (2003). Methodological issues in research on sexual behavior with Latino gay and bisexual men. *American Journal of Community Psychology*, 31(3-4), 281-291.
- ◆ Ryan H., Wortley P.M., Easton A., Pederson L., & Greenwood G. (2001). Smoking among lesbians, gays and bisexuals: a review of the literature. *American Journal of Preventive Medicine*, 21(2), 142-148.
- ◆ Tang H., Greenwood G., Cowling D.W., Lloyd J.C., et al. (2004). Cigarette smoking among lesbians, gays, and bisexuals: how serious a problem? *Cancer Causes and Control*, 15, 797-803.
- ◆ Smith E.A., & Malone R.E. (2003). The outing of Phillip Morris: advertising tobacco to gay men. *American Journal of Public Health*, 93(6), 988-992.

Presentations and Discussions

The meeting began with four participants presenting state-of-the-art knowledge in topics relevant to research on tobacco-related health disparities among LGBTs of color. The purposes of the presentations were to identify barriers in sampling LGBTs of color and to summarize effective sampling methodologies for research on hard-to-reach populations. Topics included:

- ◆ demographic characteristics of LGBTs of color communities
- ◆ a review of effective models/approaches to sample hard-to-reach populations
- ◆ cultural/social/environmental factors in conducting research in LGBTs of color communities
- ◆ the state of knowledge on tobacco use in LGBT communities

A group discussion followed each presentation. In these discussions, participants shared lessons learned, challenges, and successes in each area.

Development of Recommendations

In the final stage of the meeting, participants broke into three workgroups to develop their recommendations on sampling methodologies. The groups were asked to address the following points in drafting recommendations:

- ◆ barriers to conducting research on LGBTs of color
- ◆ best models/approaches to achieve adequate sampling of LGBTs of color
- ◆ issues in sampling specific subgroups, especially youth and transgender LGBTs of color
- ◆ if/how sampling methods should be modified to conduct research on tobacco use

Each group reported its recommendations to fellow participants. Once all meeting participants had discussed and agreed upon a final set of recommendations, the meeting was adjourned.

Meeting Presentations and Discussions

Below are summaries of the four presentations made at the LGBTs of Color Sampling Methodology Meeting and the discussions that followed each presentation.

Presentation One

People of Color in Same-Sex Couples: Findings from Census 2000

Gary J. Gates, Ph.D., The Williams Institute, University of California Los Angeles School of Law

While the U.S. Census does not ask about sexual orientation, a householder indicating that he or she is an “unmarried partner” of another same-sex household member creates a proxy for measurement of same-sex demographics. Measurement error can be introduced through fear of disclosure, misunderstanding of the term “unmarried partner,” or choice to not label the relationship by that term; however, the methodology is robust. Three key reports have explored the census data for LGBT couples: the Williams Institute study on Asian American/Pacific Islanders,⁵⁴ the National Gay and Lesbian Task Force (NGLTF) report on Black LGBTs,⁵⁵ and the NGLTF report on Latino LGBTs.⁵⁶ These reports clarify several interesting points. For example, the number of same-sex couples is generally even across races. LG couples of color have equivalent education and income disparities as seen in their referent racial/ethnic groups. Disability rates are higher among LG couples of color, just as they are higher for the referent racial/ethnic groups. Interestingly, LG couples of color are more likely to be raising children than are White LG couples. As an example, almost 30 percent of same-sex Black/African American male couples have a child in their household, versus 8 percent of same-sex White male couples.

Dr. Gates presented geographically coded maps in his presentation to underscore the main finding of the research: Black/African American and Latino/Hispanic LGBT couples cluster in distinct geographical areas. Moreover, these populations cluster in different areas than White LGBT couples. Further, the highest density LGBT neighborhoods most closely resemble the neighborhoods where White LGBT couples cluster. Therefore, LGBTs of color will likely be under-represented in research conducted in high-density LGBT neighborhoods. Sufficient attention to the neighborhoods with higher clusters of couples who are LGBTs of color can remedy this problem.

Discussion One

Census

Participants considered encouraging the U.S. Census Bureau to modify the marital status question, as the current version is problematic. Canada already is collecting sexual orientation on its census, and the United Kingdom plans to do so in 2011. Both efforts could create a precedent for the United States to add a direct sexual orientation question. Participants noted that the American Community Survey is slated to replace the census long form.

This is an ongoing survey that could be combined to achieve neighborhood-level data. There was general acknowledgement that dependence on the proxy of household reporting is increasingly problematic for households that are less like the nuclear family. Participants posited that people of color and people in lower income strata are likely to have non-nuclear household structures (e.g., extended family or non-biologically related kin under one roof); moreover, the census forms do not capture these non-nuclear structures well, thereby increasing the chance of error in census reporting.

Experiences with Full Probability Methods

The National Longitudinal Study on Adolescent Health oversamples racial and ethnic youth and asks sexual orientation and minority identity questions. To date, studies have controlled for race/ethnicity rather than examine smoking behavior among diverse groups of youth by sexual orientation.⁵⁷ Dr. Wong did not find any substantive differences when he examined data on Asian respondents, but he noted that the inability to break out Asian subgroups creates a challenge. While the Adolescent Health Survey is generally constrained by a small sample size and suspect reporting quality, the survey research team may be amenable to enhancements to build data quality on LGBs.

Dr. Cochran described a different method. Her group obtained phone numbers for LG respondents to the California Health Interview Survey and contacted them a year later. Unfortunately, many respondents—especially youth respondents—could not be reached at follow-up, perhaps because they had switched from land lines to cell phones.

The Behavioral Risk Factor Survey tested a method that required respondents to verbally state their sexual orientation. This strategy failed; for example, not a single respondent in North Dakota acknowledged being lesbian or gay. Survey designers are now pioneering the use of a general response category.

Several participants had used random digit dialing to create an LGBT sample. This is usually achieved by

oversampling the high-density LGBT neighborhoods. However, Dr. Gates' presentation showed the weakness in this approach for sampling LGBTs of color. Population densities for LG couples from census data range from 1 to 12 percent in high-density neighborhoods. If the goal is to reach all LGBTs, a researcher might presume densities roughly double that amount (to account for single/non-cohabitating LGBTs). Random digit dialing in the neighborhoods with lower concentrations of LGBT couples of color becomes increasingly costly, as the ratio of ineligible to eligible responses increases.

Issues with Identity

Participants described many examples of complex identity formation that challenge simple categorization on large-scale surveys. The phenomenon of individuals being “straight at home, gay in the city” demonstrates this point. For many people, home life may not include disclosing that they are gay. Even if these people know of other gay people in their community, they may have little or no connection with them. Some people of color may have dual identities in their community. For instance, they may have one community identity based on sexual orientation that is bounded by gay-related geography, events, or behaviors and another community based on race/ethnicity.

Participants also noted how some LGBTs of color may actually resist concordant racial/ethnic bonds when identifying themselves as gay, because these bonds are more threatening to their non-gay identity

Emergent Themes

- ◆ Identity is a complex structure to study. The methods must be sensitive enough to capture these complexities.
- ◆ While it is perhaps not always easy to group people to study, LGBTs have commonalities, demonstrated by their higher tobacco use.
- ◆ If you want to study LGBTs of color, go to neighborhoods where people of color live.
- ◆ Do not presume people socialize in the neighborhoods where they live.
- ◆ A promising strategy might be to aggregate data from different full probability studies, but often American Indian communities are not adequately sampled in big studies. This needs to be corrected.
- ◆ Although getting quantitative data is very challenging, defensible numbers are key to many funding opportunities.

at home. While these people are likely to accrue the same pressures of social exclusion or discrimination that increase their health risk, to presume that LGBTs of color automatically create communities with other LGBTs of color may be overly simplistic. This multiple identity formation may be similar to other

common situations, such as those experienced by people of mixed race or by people who work and live in different socioeconomic strata. Estimating disease risk for people with multiple community identities is challenging, but it may provide excellent insight into the mechanisms of overall risk.

Presentation Two

Overview of Sampling Strategies for Hard-to-Reach and Hidden Populations

Gary Humfleet, Ph.D., University of California San Francisco

Dr. Humfleet discussed several strategies that hold promise for sampling hard-to-reach and hidden populations, such as LGBTs of color.

- ◆ **Snowball sampling.** The researcher identifies initial participants who act as “seeds” to identify other subgroup members; subsequent waves continue until a target sample size is reached. Weaknesses include non-random identification of original seeds and potential bias toward cooperative subjects or subjects who have larger personal networks.
- ◆ **Facility-based sampling.** Participants are recruited at community-gathering venues, such as street fairs, parties, or clinics. This method can yield a high number of respondents but is only representative of the people who attend such events.
- ◆ **Targeted sampling.** This method is an expansion of snowball sampling that builds in an initial ethnographic assessment of the community. Identified networks are then treated as sampling strata, and quota samples are obtained for each stratum. Bias is reduced with more comprehensive ethnographic assessment, but this is a high-resource endeavor.
- ◆ **Time-location sampling.** When the target population gathers at identified sites, this method can be used. An ethnographic assessment is used to make lists of gathering sites, then a probability sample is chosen and data gathered from attendees during a predefined interval. This method is useful only if all or a high percentage of the target population visits the identified sites. As is the case with targeted sampling, the effectiveness of this method depends on the thoroughness of the ethnographic assessment.
- ◆ **Respondent-driven sampling.** Seeds are identified as in snowball sampling, their networks are quantified, and the seeds are given identifying coupons to pass on to network members. If a peer in the network enrolls, the original seed receives a reimbursement and the peer becomes a new seed until saturation is reached. Prior work has demonstrated that a sample based on respondent-driven sampling is statistically equivalent to a random sample when the method is strictly followed.
- ◆ **Sampling strategies from a recent Internet-based study.** Dr. Humfleet presented the preliminary results from a methodological study embedded in his recent LGBT Internet-based smoking cessation study. Almost 800 LGBT people were enrolled in the study, which had 80-percent retention at 1-year follow-up. Demographics were diverse on many metrics, with 7 percent of the study enrollees identifying themselves as transgenders and 16 percent of the enrollees from rural areas. Nineteen percent of the enrollees were people of color, notably less than the general demographics. Dr. Humfleet suggests that due to high Internet use for social support, the Internet may be a valuable recruitment option for LGBT studies.

Discussion Two

Respondent-Driven Sampling^{58, 59}

Participants acknowledged that respondent-driven sampling is a very promising strategy for surveying hard-to-reach populations. The mathematical modeling that supports respondent-driven sampling, allowing unbiased population estimates and precision measures for those estimates, is more sophisticated than in comparable methods. The Centers for Disease Control and Prevention (CDC) has been a strong proponent of respondent-driven sampling, adopting it for its National HIV Behavioral Surveillance System and encouraging its use in other projects.

Several participants noted their concerns with respondent-driven sampling based on their experience with projects that used this sampling technique. For example, some participants said they found the methodology to be less effective than expected. In one project, respondents' hesitancy to divulge their full social network structure limited the project's reach. In another project, the geographic dispersion of the network made it a barrier to asking potential enrollees to visit a host site to enroll in the study. Similarly, respondent-driven sampling was very successful with populations that needed the incentive (i.e., homeless people) but was less successful with others not motivated by an incentive.

In all, participants had concerns about using respondent-driven sampling in populations that might not have a strong community identity or are geographically dispersed. This discussion touched on points from the earlier discussion of multiple identities. An example from an American Indian LGBT study typified the issues. While study participants might have known of other Two-Spirit people in their community, they did not form community bonds with them. Instead, they forged American Indian-based community bonds on the reservation and gay-based community bonds while away in gay neighborhoods.

Meeting participants concurred that respondent-driven sampling needs to be enhanced or modified to be successful in sampling LGBTs of color. One participant suggested that a network structure

approach may be more promising than respondent-driven sampling.

Mixed Methods

Participants expressed strong support for mixed-methods research as a strategic approach to studying LGBTs of color. They noted that qualitative work could precede quantitative work, providing the exploratory foundation to inform the instrument design. Alternately, it could follow quantitative work, further elucidating interesting findings. Likewise, several sampling methods could be used within a single project.

Funding and Methodology

Discussion was robust on the difficulty of getting funding for the innovative or emerging methodologies that hold promise in research on hard-to-reach populations. Citing respondent-driven sampling as an example, participants noted more success in getting funding for research that uses respondent-driven sampling through the CDC grant review process than through the National Institutes of Health (NIH) peer review process. Dr. Sell said that according to CRISP, the database of NIH-funded projects, NIH has funded only five respondent-driven sampling studies: three in the National Institute on Drug Abuse and two at the National Institute of Child Health and Human Development. This situation was likened to community-based participatory research, where outside validation paved a slow but successful path to adoption of the methodology in NIH peer-reviewed awards. Considering the increased competition for NIH awards, researchers are less willing to be experimental in their proposals.

Participants discussed the additional challenge of getting reviewers with competencies in the proposed research subject areas. It was generally acknowledged that too few reviewers are competent in research related to sexual orientation, gender identity, communities of color, or the newest sampling strategies for hard-to-identify populations. Participants agreed that they need to get more people with relevant backgrounds on review committees, while acknowledging that the low compensation for reviewing grants may be a bigger obstacle for

researchers in this arena than it is for the more broadly supported mainstream researchers. Also noted was that educated program officers can be a big asset in getting scientists with the right expertise on the review committees. Likewise, NIH mechanisms

such as the Funding Opportunity Announcement in the form of a Request for Application (FOA/RFA) have been successful in convening reviewers with specialty expertise.

Emergent Themes

All participants concurred on the need to increase emphasis on methodological studies. Below are the barriers and promising strategies participants identified.

Barriers

- ◆ In some cases, LGBTs of color may not form strong social communities with each other.
- ◆ Respondent-driven sampling may be weak for geographically dispersed groups.
- ◆ The most promising sampling methods have not been sufficiently tested in LGBTs of color, nor have NIH peer reviewers accepted them.
- ◆ NIH review committees often lack relevant expertise in the proposed research.
- ◆ Participating on review committees is challenging for multiple reasons.
- ◆ Younger researchers have less experience in overcoming institutional or funder barriers.

Promising Strategies

- ◆ Reinforce the value of LGBTs of color methodological inquiry for all small population research.
- ◆ Encourage NIH to use the FOA/RFA model as one route to getting appropriate expertise on study sections.
- ◆ Urge NIH to fund and test innovative sampling strategies for a variety of small, hidden, or hard-to-reach populations.
- ◆ Support testing enhancements of respondent-driven sampling to expand applicability to geographically dispersed populations.
- ◆ Encourage more LGBT and small population methodologists to join review panels.
- ◆ Mix research methods to create the strongest possible projects for grants submission.

Presentation Three

Cultural and Social Factors in Research on LGBTs of Color Communities

George Ayala, Psy.D., AIDS Project Los Angeles

A shift in research has taken place, creating a focus on cultural meanings of sex and sexuality. This shift has drawn attention to the socially constructed identities and communities structuring sexual practice within collective life. However, studies examining the cultural basis of sex and sexuality are rare.

Culture influences the articulation of sexuality, with the following factors affecting this articulation: immigration status, generation of immigration, country of origin, years in the United States, primary language, class, race, skin color, gender, gender role expectations, geography, and religion. Similarly, experiences of marginalization, such as racism, homophobia, gender violence, and economic disenfranchisement, shape the sense of self and the range of choices or resources available to individuals. Additionally, the expression of sexual identity can shift from context to context. Contexts include but are not limited to family, church, work, school, community (of origin and choice), living situation, and relationship status.

Dr. Ayala recommended that researchers abandon the *etic* or external scientific valuation and search for universality for an *emic* approach, a valuation that gives priority to local interpretations of any social phenomena by community members. In this manner, community insiders—not researchers—will define the meanings and categories. Successful strategies to achieve this goal are as follows:

- ◆ Announce you are visiting before beginning a research project.
- ◆ Begin with sufficient formative research, including inquiry into language, local meaning, social acceptability, and cultural equivalence.
- ◆ Collaborate with insiders—people from within the communities of interest—during data collection and throughout the research program.
- ◆ Engage recognized and respected leaders in discussing the goals and objectives of research.
- ◆ Respect respondent circumstances.
- ◆ Mix your methods; consider using both quantitative and qualitative approaches.
- ◆ Adopt strength-based approaches in framing the research questions.
- ◆ Link research and benefits to the community.
- ◆ Brief/debrief participants.
- ◆ Consider approaches outside of the research enterprise.

Discussion Three

Methods

Meeting participants were very supportive of the principles outlined in Dr. Ayala's presentation. They again emphasized the value of mixed-methods research and especially the use of formative research.

Several examples illustrated how traditional research loses needed sensitivity by collapsing different constructs—such as research on Latinos/Hispanics becoming research on immigrants, or research on all Asian American or Pacific Islander populations failing to disaggregate ethnic groups within this broad population.

LGBT Data Collection on Large Surveys

Participants returned to the question of how best to capture sexual orientation or gender identity on large-scale surveys in the face of such community diversity. On the large-scale surveys, the addition of every question is a long and costly process. It is usually only possible to add one or two questions to measure LGBT status. Considering the diversity of labels, identities, and strength of association, not enough research exists to easily define a single best question on sexual orientation and gender identity.

Dr. Sell noted that he hosts a website, *www.gaydata.com*, to track the questions asked on large-scale surveys. Based on this research, he recommends a single best identity question and a single best behavior question. But, Dr. Sell added, more research is needed to identify the question wording that will best minimize response error and the impact of capturing identity versus behavior.

While this methodological research is important, it should be combined with the equally important effort of expanding LGBT data collection to more large-scale surveys, especially those used as benchmarks for Federal policy documents. Recent promising studies have provided valuable information on the widespread acceptance of sexual orientation questions as part of a demographic battery, providing evidence that it need not be accorded the special treatment necessary to a “sensitive question.”^{16, 17}

The questions currently in use capture sexual orientation, not gender identity. Concern exists that a question about gender identity would provoke enough response error through use of unfamiliar terms to be of little use. Research has shown that just using the

phrase “heterosexual” on a question is unfamiliar enough to provoke problematic response error. The better sexual orientation identity questions usually use the phrase “heterosexual or straight.” The concept of gender identity does not have a similar widely used phrase that can be identified by the majority of the population. Research studies have not tested the viability of large-scale data collection that is inclusive of transgender people. One meeting participant suggested testing a slight permutation of a leading sexual orientation question.

The original question read:

Do you consider yourself to be

- a. heterosexual or straight*
- b. gay or lesbian*
- c. bisexual*

The proposed new question would read:

Do you consider yourself to be one or more of the following?

- a. straight*
- b. gay or lesbian*
- c. bisexual*
- d. transgender*

Participants acknowledged the need for more methodological research on gender identity. Currently, a large proportion of the base of knowledge on transgender people comes from community-based needs assessment surveys. These projects provide lessons on how to reach community members. Several participants opined that research on populations this rare might be better done through similar community-based methods than through population-based surveys.

Emergent Themes

- ◆ Researchers and policymakers need to continue to advocate for inclusion of LGBT questions on large-scale surveys.
- ◆ Additional methodological research is needed to develop the most successful sexual orientation question, especially among communities of color.
- ◆ Additional methodological research needs to be done on the viability of a gender identity question on large-scale surveys. Gender identity research may be better addressed through community-based methods.

Presentation Four

Tobacco Use Among LGBs

Elizabeth Gruskin, Dr.Ph., Kaiser Permanente Northern California

Dr. Gruskin reviewed several studies included in the Research on Tobacco Use Among LGBTs and Communities of Color section of this document and another study.³ Results were consistent in showing that LGs were more likely to smoke than referent non-LG groups. Notably, while LGB smoking rates are high, no known studies exist of transgender-specific smoking rates.

Discussion Four

Participants discussed a working hypothesis: Can we assume that LGBTs of color smoke more than their referent racial/ethnic categories? While there is significant variation within racial/ethnic categories, evidence from the larger LGBT studies would support this hypothesis. There might also be additive stress

from being both a person of color and a member of an LGBT group. Studies are needed to confirm this hypothesis and to estimate the magnitude and type of effect for different populations. Dr. Buchting noted that just as there once had been a dearth of data on the high rates of smoking among LGBTs, scientific knowledge may not have caught up with community knowledge on tobacco use among LGBTs of color.

Emergent Theme

- ◆ Working hypothesis: LGBTs of color will smoke more than their referent racial/ethnic categories.

Meeting Recommendations

Recommendations fell under one of three themes that emerged in discussions following each presentation. These themes reflect the purpose of the September 2006 meeting: to identify best practices and immediate needs in sampling methodology in LGBTs of color to help reduce tobacco-related health disparities. The themes capture needed efforts in

- ◆ promoting best strategies to achieve adequate sampling of LGBTs of color
- ◆ modifying methods for research on tobacco use among LGBTs of color
- ◆ addressing barriers to conducting research on LGBTs of color

Promoting Best Strategies To Achieve Adequate Sampling of LGBTs of Color

Participants recommended several best strategies to achieve adequate sampling of LGBTs of color.

- ◆ Promote, encourage, and fund research with innovative methodological strategies, such as:
 - ❖ mixed-methods studies, whereby the combination of methods can balance the shortcomings of individual methods
 - ❖ respondent-driven sampling, currently useful in geographically close groups with high community identity but needs to be modified for use in other groups
 - ❖ synthesis of multiple, large datasets to create a larger sample
 - ❖ formative and qualitative research—both proven strategies to provide superior knowledge about understudied populations
 - ❖ ethnographic studies to assess smoking rates
 - ❖ multidisciplinary teams
- ◆ Ask funding agencies to require investigators to provide a rationale for excluding sexual orientation questions in research, as is currently required with exclusions related to gender, race/ethnicity, and children.
- ◆ Encourage the inclusion of sexual orientation questions in standard demographic markers for all studies through efforts to
 - ❖ include sexual orientation measures in the key state and national datasets for Healthy People 2010 health disparities monitoring; for tobacco, these datasets are the National Health Interview Survey, the Tobacco Use Supplement to the Current Population Survey, the National Survey on Drug Use and Health, the Monitoring the Future Survey, the Adult Tobacco Survey, the Youth Risk Behavior Survey, and the Behavior Risk Factor Surveillance System
 - ❖ include sexual orientation measures in ethnic-specific surveys
 - ❖ ask responsible agencies to provide funding for the development and inclusion of sexual orientation questions in the National Health Interview Survey
 - ❖ test the current CDC-tested sexual orientation question with an oversample of people of color to ensure comparability
 - ❖ secure additional funding for experts to provide technical assistance on achieving this inclusion
 - ❖ create a joint position statement of experts on the need to include sexual orientation measures in standard health markers
- ◆ Promote, encourage, and fund research with the *best possible* standard of methodological strategies, such as:
 - ❖ research that examines within-group differences
 - ❖ the sampling methods delineated in this report
 - ❖ community-based studies

- ◆ Address sampling among LGBTs of color youth and transgender groups.
- ◆ Publish information on how to recruit transgenders of color for survey and intervention research using lessons learned from the transgender needs assessments conducted across the country.
- ◆ Conduct cognitive testing to develop survey questions that capture gender identity with precision; include an oversample of youth of color in all cognitive testing studies.
- ◆ Complete cognitive testing to assess whether different gender identity question designs capture comparable data (e.g., the Youth Risk Behavioral Survey in Massachusetts collects gender identity from a modified question on sex, while the New York Behavioral Risk Factor Surveillance Survey collects such data with a stand-alone question and the Minneapolis SHAPE survey includes it with a sexual orientation question).
- ◆ Encourage research on LGBT of color youth and the interaction between racial and LGBT identity formation, stressors, and the initiation of tobacco use.
- ◆ Foster research on age cohorts, especially on how age overlaps with identity formation.

Understanding Tobacco Use Among LGBTs of Color

- ◆ Research differences in tobacco uptake patterns among LGBTs of color, with special attention to how additive stressors (e.g., ageism, homophobia, and racism) impact the etiology of smoking.
- ◆ Examine identity formation in LGBTs of color and how that process interacts with tobacco use.
- ◆ Tailor tobacco control interventions for LGBTs of color and test their effectiveness in reducing tobacco use and exposure.

Addressing Barriers to Conducting Research on LGBTs of Color

- ◆ Disseminate the best available information on promising strategies for conducting research on LGBTs of color:
 - ❖ create a survey and intervention methodology training institute on LGBTs of color, which could be presented as a summer institute at the Inter-University Consortium for Political and Social Research
 - ❖ educate Institutional Review Boards on tested sampling methods, with their conferences possibly serving as one possible training venue
- ◆ Utilize and enhance existing funding structures to address the data gap on LGBTs of color:
 - ❖ use appropriate funding mechanisms to call for methodological research on sampling small, hidden, or hard-to-reach populations (e.g., NIH, CDC, and the American Cancer Society)
- ◆ Fund methodological development of statistically valid methods for small population research.
- ◆ Address workforce development issues through the following strategies:
 - ❖ research and identify systemic and institutional barriers experienced by researchers in this area; use findings to enhance plans to overcome barriers
 - ❖ promote and establish mentoring programs through new investigator awards and other structural supports to encourage the next generation of researchers
 - ❖ encourage professional development and networking opportunities, such as having an annual meeting or convening at a larger conference

-
- ❖ build reviewer pools that specialize in communities of color, small population, and LGBT research; because institutional barriers, funding challenges, and mentoring challenges may make it less feasible for these experts to suspend normal duties to review proposals, explore different incentives or structures to make this feasible
 - ❖ evaluate the success of research proposals submitted to major funders that incorporate sexual orientation or gender identity in their work
 - ❖ examine the success of research proposals incorporating non-probability methods; use the findings to highlight institutional barriers to conducting small population research

Conclusion

Since the 1964 Surgeon General’s Report on Smoking and Health, tremendous progress has been made in reducing rates of tobacco use and its life-threatening health effects among the U.S. population. Despite this progress, evidence-based literature suggests that the decline in tobacco use is not evenly distributed across all populations and that certain racial/ethnic groups suffer disproportionately from the health consequences of tobacco use.^{4, 37-52}

Newly emerging research also suggests that LGBT populations have unusually higher rates of tobacco use than are found in the general population.^{9, 16, 19, 21-29} The President’s Cancer Panel 2006-2007 Annual Report highlights the need to address tobacco use in LGBT populations, noting that “These [LGBT] individuals pay a high price for their addiction.”⁶⁰ Unfortunately, little information is available to understand the intersection of these two populations—LGBTs of color—with this community possibly at a synergistically higher level of risk of tobacco use and its devastating health effects.

Despite large-scale research efforts designed to monitor the health of our Nation and progress toward the Healthy People 2010 goal of reducing health disparities, researchers and other health professionals are limited in their ability to obtain valid and useful information to guide such efforts and to curb tobacco use and addiction among LGBTs of color. Efforts to document and eliminate health disparities among small, hidden, or hard-to-reach populations are hampered by small sample sizes that limit their ability to provide statistically valuable information and by the routine omission of valid and reliable measurement items—demographic questions of sexual identity and gender identification—to accurately identify such populations. Consequently, an urgent need exists for improved and new sampling and surveillance methods that can characterize tobacco use behaviors among hidden populations, such as LGBTs of color.

The 2006 LGBT of Color Sampling Methodology Meeting sparked dialogue that can help address the

limitations in current research methodologies. Key to this effort are strategies to enhance surveillance methods for LGBTs of color populations, such as using mixed-sampling methodologies and including sexual orientation as a routine demographic marker in all research and surveillance activities. Meeting participants called for reexamination of the deeply rooted institutional and funding barriers that challenge researchers in the field of small population research and an effort to institutionalize tangible structures and systems to overcome these barriers. As an initial step, participants recommended that the scientific field increase awareness of issues relevant to LGBTs of color and expand the expertise of review panels capable of evaluating proposed research on these issues.

By addressing the limitations in our current surveillance methods, we can obtain the indicators of tobacco-use behaviors among LGBTs of color needed to:

- ◆ identify baseline parameters and, thus, facilitate realistic, appropriate goal-setting agendas
- ◆ increase community awareness of this rarely discussed, yet life-threatening epidemic
- ◆ inform the development of effective, culturally appropriate smoking prevention and cessation programs and policies
- ◆ measure progress in reaching our goals

We recognize that public health professionals and researchers are increasingly aware that health disparities cluster among hidden or hard-to-reach populations. We hope that the ideas and recommendations in this report can be applied to other small, hard-to-reach populations and can inform other areas of health research to improve the well-being of all groups of people, regardless of gender, race or ethnicity, socioeconomic status, disability, geographic location, sexual orientation, or any combination of these characteristics.

References

1. U.S. Department of Health and Human Services. (2000). *Healthy people 2010*. 2nd ed. With understanding and improving health and objectives for improving health. 2 vols. Washington, DC: U.S. Government Printing Office.
2. U.S. Department of Health and Human Services. (2006). *Healthy people 2010 midcourse review*. Washington, DC: U.S. Government Printing Office.
3. Gruskin E.P., Greenwood G.L., Matevia M., Pollack L.M., & Bye L.L. (2007). Disparities in smoking between the lesbian, gay, and bisexual population and the general population in California. *Am J Public Health*, 97(8), 1496-1502.
4. U.S. Department of Health and Human Services. (1998). Tobacco use among U.S. racial/ethnic minority groups—African Americans, American Indians and Alaska Natives, Asian Americans and Pacific Islanders, and Hispanics: A report of the Surgeon General. Atlanta, GA: U.S. Department of Health and Human Services. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, Public Health Service.
5. National LGBT communities tobacco action plan. (2004). Retrieved December 31, 2006, from www.lgbttobacco.org/files/LGBT-TobaccoActionPlan.pdf.
6. Trans-HHS Cancer Health Disparities Progress Review Group. (2006). Making cancer health disparities history. March 2004. Retrieved December 20, 2006, from www.hhs.gov/chdprg/pdf/chdprg.pdf.
7. U.S. Department of Health and Human Services. (2005). Eliminating tobacco-related health disparities: Summary report (NIH Publication No. 05-5283). Washington, DC: National Cancer Institute.
8. Gay and Lesbian Medical Association. (2001). Healthy people 2010 companion document for lesbian, gay, bisexual, and transgender (LGBT) health. Retrieved April 12, 2001, from www.glma.org/_data/n_0001/resources/live/HealthyCompanionDoc3.pdf.
9. Ryan H, Wortley P.M., Easton A., Pederson L., & Greenwood G. (2001). Smoking among lesbians, gays, and bisexuals: A review of the literature. *Am J Prev Med*, 21(2), 142-149.
10. Sell R., & Bradford J. (2006). Elimination of health disparities based upon sexual orientation: Inclusion of sexual orientation as a demographic variable in Healthy People 2010 objectives. Retrieved January 28, 2006, from www.glma.org/_data/n_0001/resources/live/HealthyCompanionDoc3.pdf.
11. Sell R.L., & Becker J.B. (2001). Sexual orientation data collection and progress toward Healthy People 2010. *Am J Public Health*, 91(6), 876-882.
12. Burgard S.A., Cochran S.D., & Mays V.M. (2005). Alcohol and tobacco use patterns among heterosexually and homosexually experienced California women. *Drug Alcohol Depend*, 77(1), 61-70.
13. Diamant A.L., & Wold C. (2003). Sexual orientation and variation in physical and mental health status among women. *J Womens Health (Larchmt)*, 12(1), 41-49.

-
14. Greenwood G.L., Paul J.P., Pollack L.M., Binson D., Catania J.A., Chang J., et al. (2005). Tobacco use and cessation among a household-based sample of U.S. urban men who have sex with men. *Am J Public Health*, 95(1), 145-151.
 15. Stall R., Paul J.P., Greenwood G., Pollack L.M., Bein E., Crosby G.M., et al. (2001). Alcohol use, drug use and alcohol-related problems among men who have sex with men: the Urban Men's Health Study. *Addiction*, 96(11), 1589-1601.
 16. Tang H., Greenwood G.L., Cowling D.W., Lloyd J.C., Roeseler A.G., & Bal, D.G. (2004). Cigarette smoking among lesbians, gays, and bisexuals: How serious a problem? (United States). *Cancer Causes Control*, 15(8), 797-803.
 17. Bye L., Gruskin E., Greenwood G., Albright V., & Krotski K. (2005). *California lesbian, gay, bisexual, transgender (LGBT) tobacco survey—2004*. Sacramento, CA: California Department of Health Services.
 18. Garofalo R., Wolf R.C., Kessel S., Palfrey S.J., & DuRant R.H. (1998). The association between health risk behaviors and sexual orientation among a school-based sample of adolescents. *Pediatrics*, 101(5), 895-902.
 19. Austin S.B., Ziyadeh N., Fisher L.B., Kahn J.A., Colditz G.A., & Frazier A.L. (2004). Sexual orientation and tobacco use in a cohort study of U.S. adolescent girls and boys. *Arch Pediatr Adolesc Med*, 158(4), 317-322.
 20. Easton A., Sell R. (2004, October). Analysis of national longitudinal study of adolescent health. Paper presented at Gay and Lesbian Medical Association Meeting, Palm Springs, CA.
 21. Diamant A.L., Wold C., Spritzer K., & Gelberg L. (2000). Health behaviors, health status, and access to and use of health care: A population-based study of lesbian, bisexual, and heterosexual women. *Arch Fam Med*, 9(10), 1043-1051.
 22. Stall R.D., Greenwood G.L., Acree M., Paul J., & Coates T.J. (1999). Cigarette smoking among gay and bisexual men. *Am J Public Health*, 89(12), 1875-1878.
 23. Valanis B.G., Bowen D.J., Bassford T., Whitlock E., Charney P., & Carter R.A. (2000). Sexual orientation and health: Comparisons in the Women's Health Initiative sample. *Arch Fam Med*, 9(9), 843-853.
 24. Case P., Austin S.B., Hunter D.J., Manson J.E., Malspeis S., Willett W.C., et al. (2004). Sexual orientation, health risk factors, and physical functioning in the Nurses' Health Study II. *J Womens Health (Larchmt)*, 13(9), 1033-1047.
 25. McCabe S.E., Boyd C., Hughes T.L., & d'Arcy H. (2003). Sexual identity and substance use among undergraduate students. *Subst Abus*, 24(2), 77-91.
 26. McCabe S.E., Hughes T.L., & Boyd C.J. (2004). Substance use and misuse: Are bisexual women at greater risk? *J Psychoactive Drugs*, 36(2), 217-225.
 27. Cochran S.D., Mays V.M., Bowen D., Gage S., Bybee D., Roberts S.J., et al. (2001). Cancer-related risk indicators and preventive screening behaviors among lesbians and bisexual women. *Am J Public Health*, 91(4), 591-597.
 28. Gruskin E.P., Hart S., Gordon N., & Ackerson L. (2001). Patterns of cigarette smoking and alcohol use among lesbians and bisexual women enrolled in a large health maintenance organization. *Am J Public Health*, 91(6), 976-979.

-
29. Hughes T.L., & Jacobson K.M. (2003). Sexual orientation and women's smoking. *Curr Womens Health Rep*, 3(3), 254-261.
 30. Institute of Medicine, National Academy of Sciences. (1999). *Lesbian health: Current assessment and directions for the future* (A.L. Solarz, Ed.). Washington, DC: National Academy Press.
 31. Offen N., Smith E.A., & Malone R.E. (2008). Is tobacco a gay issue? Interviews with leaders of the lesbian, gay, bisexual and transgender community. *Cult Health Sex*, 10(2), 143-57.
 32. Harris Interactive. (2005). Gay and lesbian brand loyalty linked to advertising. Retrieved May 23, 2005, from www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=478.
 33. Smith E.A., Offen N., & Malone R.E. (2005). What makes an ad a cigarette ad? Commercial tobacco imagery in the lesbian, gay, and bisexual press. *J Epidemiol Community Health*, 59(12), 1086-1091.
 34. Offen N., Smith E.A., & Malone R.E. (2003). From adversary to target market: The ACT-UP boycott of Philip Morris. *Tob Control*, 12(2), 203-207.
 35. Stevens P., Carlson L.M., & Hinman J.M. (2004). An analysis of tobacco industry marketing to lesbian, gay, bisexual, and transgender (LGBT) populations: Strategies for mainstream tobacco control and prevention. *Health Promot Pract*, 5(3 Suppl):129S-134S.
 36. Yerger V.B., Daniel M.R., & Malone R.E. (2005). Taking it to the streets: Responses of African American young adults to internal tobacco industry documents. *Nicotine Tob Res*, 7(1), 163-172.
 37. Swanson G.M., Lin C.S., & Burns P.B. (1993). Diversity in the association between occupation and lung cancer among black and white men. *Cancer Epidemiol Biomarkers Prev*, 2(4), 313-320.
 38. Bruerd B. (1990). Smokeless tobacco use among Native American school children. *Public Health Rep*, 105(2), 196-201.
 39. Etzel R.A., Jones D.B., Schlife C.M., Lyke J.R., Dunaway C.E., & Middaugh J.P. (1991). Saliva cotinine concentrations in young children in rural Alaska. *Arctic Med Res*, Suppl:566-567.
 40. Centers for Disease Control and Prevention. Smokeless tobacco use in rural Alaska. (1987). *MMWR*, 36(10), 140-143.
 41. Eichner J.E., Cravatt K., Beebe L.A., Blevins K.S., Stoddart K.S., Bursac Z., et al. (2005). Tobacco use among American Indians in Oklahoma: An epidemiologic view. *Public Health Rep*, 120(2), 192-199.
 42. Trinidad D.R., Gilpin E.A., Lee L., & Pierce J.P. (2004). Do the majority of Asian-American and African-American smokers start as adults? *Am J Prev Med*, 26(2), 156-158.
 43. Griesler P.C. & Kandel D.B. (1998). Ethnic differences in correlates of adolescent cigarette smoking. *J Adolesc Health*, 23(3), 167-180.
 44. Headen S.W., Bauman K.E., Deane G.D., & Koch G.G. (1991). Are the correlates of cigarette smoking initiation different for black and white adolescents? *Am J Public Health*, 81(7), 854-858.
 45. Appleyard J., Messeri P., & Haviland M.L. (2001). Smoking among Asian American and Hawaiian/Pacific Islander youth: Data from the 2000 National Youth Tobacco Survey. *Asian Am Pac Isl J Health*, 9(1), 5-14.

-
46. Moon-Howard J. (1997). African American women and smoking: Starting later. *Am J Public Health*, 93(3), 418-420.
 47. Taylor K.L., Kerner J.F., Gold K.F., & Mandelblatt J.S. (1997). Ever vs. never smoking among an urban, multiethnic sample of Haitian-, Caribbean-, and U.S.-born blacks. *Prev Med*, 26(6), 855-865.
 48. Centers for Disease Control and Prevention. (2005). Cigarette smoking among adults—United States, 2004. *MMWR*, 54(44), 1121-1124.
 49. Kaplan S.D., Lanier A.P., Merritt R.K., & Siegel P.Z. (1997). Prevalence of tobacco use among Alaska Natives: A review. *Prev Med*, 26(4), 460-465.
 50. King G., Polednak A.P., Bendel R., & Hovey D. (1999). Cigarette smoking among native and foreign-born African Americans. *Ann Epidemiol*, 9(4), 236-244.
 51. Centers for Disease Control and Prevention. (2004). Prevalence of cigarette use among 14 racial/ethnic populations—United States, 1999-2001. *MMWR*, 53(3), 49-52.
 52. Edwards B.K., Brown M.L., Wingo P.A., Howe H.L., Ward E., Ries L.A., et al. (2005). Annual report to the nation on the status of cancer, 1975-2002, featuring population-based trends in cancer treatment. *J Natl Cancer Inst*, 97(19), 1407-1427.
 53. Becker T.M., Bettles J., Lapidus J., Campo J., Johnson C.J., Shipley D., et al. (2002). Improving cancer incidence estimates for American Indians and Alaska Natives in the Pacific Northwest. *Am J Public Health*, 92(9), 1469-1471.
 54. Gates G. & Sear, R.B. (2005). Asian/Pacific Islanders in same-sex couples in California. (2005). Data from Census 2000. Retrieved September 18, 2008, from www.law.ucla.edu/williamsinstitute/publications/API_Report.pdf
 55. Dang A. & Frazer, S. (2004). Black same sex households in the United States: A report from the 2000 Census. New York: National Gay and Lesbian Task Force Policy Institute and the National Black Justice Coalition.
 56. Cianciotto J. (2005). Hispanic and Latino same sex households in the United States: A report from the 2000 Census. New York: National Gay and Lesbian Task Force Policy Institute and the National Latino/a Coalition for Justice.
 57. Easton A., Jackson K., Mowery P., Comeau D., & Sell R. Adolescent same-sex and both-sex romantic attractions and relationships: Implications for smoking. *Am J Public Health*, 98(3), 462-467.
 58. Ramirez-Valles J., Heckathorn D.D., Vázquez R., Diaz R.M., & Campbell R.T. (2005). From networks to populations: The development and application of respondent-driven sampling among IDUs and Latino gay men. *AIDS and Behavior*, 9 (4), 387-402.
 59. Ramirez-Valles J., Heckathorn D.D., Vázquez R., Diaz R.M., & Campbell R.T. (2005). The fit between theory and data in respondent-driven sampling: Response to Heimer. *AIDS and Behavior*, 9(4), 409-414.
 60. Reuben S.H. (2007). Promoting health lifestyles: Policy, program, and personal recommendations for reducing cancer risk, 2006-2007 annual report, President's Cancer Panel. Bethesda, MD: National Cancer Institute, National Institutes of Health, U.S. Department of Health and Human Services.

Appendices

Appendix A: Meeting Participants

George Ayala, Psy.D.
AIDS Project Los Angeles
Los Angeles, CA

Lisa Bowleg, Ph.D.
Drexel University
Philadelphia, PA

Francisco O. Buchting, Ph.D.
ETR Associates
Scotts Valley, CA

Ralph Caraballo, Ph.D.
Centers for Disease Control and Prevention
Atlanta, GA

Richard R. Clayton, Ph.D.
University of Kentucky
Lexington, KY

Susan Cochran, Ph.D., M.S.
University of California Los Angeles
Los Angeles, CA

William Davis, Ph.D.
National Cancer Institute
Bethesda, MD

Pebbles Fagan, Ph.D., M.P.H.
National Cancer Institute
Bethesda, MD

Gary Gates, Ph.D.
University of California Los Angeles
Los Angeles, CA

Elisabeth Gruskin, Dr.P.H.
Kaiser Permanente Northern California
Oakland, CA

Gary Humfleet, Ph.D.
University of California San Francisco
San Francisco, CA

Natasha Jategaonkar, M.Sc.
British Columbia Centre of Excellence for
Women's Health
Vancouver, BC

Marion Kavanaugh-Lynch, M.D., M.P.H.
California Breast Cancer Research Program
Oakland, CA

Alicia Matthews, Ph.D.*
University of Illinois at Chicago
Chicago, IL

Roland Moore, Ph.D.
Pacific Institute for Research & Evaluation
Berkeley, CA

James Padilla, M.S.
New Mexico Department of Health
Albuquerque, NM

Jesus Ramirez-Valles, Ph.D., M.P.H.
University of Illinois at Chicago
Chicago, IL

Scout, Ph.D.
National LGBT Tobacco Control Network
The Fenway Institute
Boston, MA

Melissa J. H. Segress, M.S.
University of Kentucky
Lexington, KY

Randall Sell, Sc.D.
Drexel University
New York, NY

Donna Vallone, Ph.D., M.P.H.
American Legacy Foundation
Washington, DC

Karina Walters, Ph.D., M.S.W.
University of Washington
Seattle, WA

Frank Wong, Ph.D.
Georgetown University
Washington, DC

* Unable to attend meeting but participated in later report development.

Appendix B: Meeting Agenda

LGBTs of Color Sampling Methodology Meeting

September 15, 2006

American Legacy Foundation

Washington, DC

Meeting Purposes

- ◆ Identify obstacles/barriers in achieving adequate sampling of LGBT of color in research.
- ◆ Summarize effective methodologies to adequately sample LGBTs of color.
- ◆ Generate recommendations for carrying out robust research on LGBTs of color.
- ◆ Produce content for the meeting report and other deliverables.

8:00 – 8:30 AM	Continental Breakfast
8:30 – 9:00 AM	Welcome and Introduction to the Meeting <ul style="list-style-type: none">● NCI – Pebbles Fagan● Legacy – Donna Vallone● TRDRP – Francisco Buchting● TReND – Richard Clayton
9:00 – 10:00 AM	Demographic Characteristics of LGBTs of Color Communities
9:00 – 9:15 AM	Overview – Gary Gates
9:15 – 10:00 AM	Full Group Discussion
10:00 – 10:15 AM	Break
10:15 – 11:15 AM	Review Effective Models/Approaches to Sample Hard-to-Reach Populations
10:15 – 10:30 AM	Overview – Gary Humfleet
10:30 – 11:15 AM	Full Group Discussion
11:15 – 12:30 PM	Cultural/Social/Environmental Factors in Conducting Research on LGBTs of Color Communities
11:15 – 11:30 AM	Overview – George Ayala
11:30 – 12:15 PM	Full Group Discussion
12:15 – 12:30 PM	Synthesis of Morning Discussions

12:30 – 1:30 PM	Lunch (on your own)
1:30 – 2:00 PM	State of Knowledge on Tobacco Use in LGBT Communities
1:30 – 1:45 PM	Overview – Liz Gruskin
1:45 – 2:00 PM	Full Group Discussion
2:00 – 2:15 PM	Charge to Workgroups
2:15 – 4:30 PM	<p>Methodological Recommendations to the Scientific Community on Enhancing LGBTs of Color Research</p> <p><i>Participants break into three workgroups to address the following points in drafting recommendations:</i></p> <ul style="list-style-type: none"> ● barriers to conducting research on LGBTs of color ● best models/approaches to achieve adequate sampling of LGBTs of color (pros and cons for each proposed method) ● issues in sampling specific groups of color, especially LGBTs of color youth and transgenders ● if/how sampling methods should be modified to conduct research on tobacco use
4:30 – 5:15 PM	Reports from Workgroups
4:30 – 4:45 PM	Workgroup 1
4:45 – 5:00 PM	Workgroup 2
5:00 – 5:15 PM	Workgroup 3
5:15 – 5:30 PM	Next Steps
5:30 PM	Adjournment

