

# Inclusion of Lesbian, Gay, Bisexual and Transgender People in Tobacco Use-Related Surveillance and Epidemiological Research

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**ABSTRACT.** Researchers and public health advocates have long recognized the importance of demographic characteristics such as sex, race, ethnicity, age, and socioeconomic status in their efforts to understand and control the use of tobacco among population groups. Targeting prevention and cessation efforts based upon such characteristics has consistently been demonstrated to be both efficient and effective. In recent years, attention has modestly turned to how two additional demographic variables, sexual orientation and gender identity, can add to our understanding of how to reduce tobacco use. Research of tobacco industry papers has clearly documented targeted media campaigns to encourage smoking among lesbians and gays in the marketplace. The tobacco industry has long understood the role that sexual orientation can play in the uptake of smoking and the targeted marketing of brands. Those concerned with tobacco use prevention and cessation research have consequently responded to address tobacco use by lesbians and gays, and bisexuals and transgender people as well, but even more can be done. This article reviews what is known about smoking in lesbian, gay, bisexual, and transgender populations and then reviews recommendations from four panels created to examine this topic. In conclusion, we recommend that sexual orientation and gender identity be considered for inclusion as variables in all major research and epidemiological studies of tobacco use. Just as such studies, without hesitation, measure sex, race, ethnicity, age, and socioeconomic status, they need to also include questions assessing sexual orientation and gender identity. Although these new variables need not be the primary focus of these studies, at a minimum, considering their use as controlling variables should be explored. Lesbian, gay, bisexual, and transgender people can benefit from being openly included in the work researchers conduct to inform the design of tobacco control programs and policies.

**KEYWORDS.** Tobacco, gay, lesbian, transgender, data collection

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There is dangerously little scientifically obtained information about tobacco use by lesbian, gay, bisexual and transgender (LGBT) people, because these populations are rarely identified in research studies (Sell & Silenzio, in press). Although LGBT people are, for the most part not, actively excluded from research studies and investigations, their inclusion is not formally recognized by including questions that would identify their sexual orientation and/or status as transgender. This can easily be rectified by including measures of sexual orientation and gender identity in studies of tobacco use and the consequences of tobacco use. The inclusion of such variable(s) in existing surveys will reduce existing gaps in the knowledge about tobacco use in LGBT populations. Additionally, studies designed to specifically examine tobacco use in LGBT populations, rather than just identify LGBT people in existing studies, are also in great need (Sell & Becker, 2001).

A number of expert panels and forums have been held since the turn of the century to evaluate the current state of knowledge concerning LGBT tobacco use. Each of these has also made a series of general recommendations, including specific recommendations regarding data collection and research (American Legacy Foundation & Experts, 2001; Gay & Lesbian Medical Association et al., 2001; Tobacco Technical Assistance Consortium & Experts, 2004). Yet, these recommendations have not been widely distributed to the general scientific community. This article, therefore, reviews the recommendations from these sources focusing on those that discuss data collection and research, and we review progress toward the inclusion of LGBT variables in major information systems and databases used to study tobacco use. But first, we review why LGBT people have special health concerns related to tobacco use, and the current state of knowledge about tobacco use in LGBT populations. This literature review provides both context and justification for the panel recommendations. The review also provides background for individuals wanting to act upon the recommendations.

### **WHY LGBT PEOPLE HAVE SPECIAL CONCERNS RELATED TO TOBACCO USE**

There are many unique reasons why LGBT individuals may be more likely to smoke, including stresses related to homophobia and discrimination, actual and feared antigay and antitransgender violence, lack of social support; and fear of weight gain (Gay & Lesbian Medical Association et al., 2001; Hughes & Jacobson, 2003; Neisen, 1993; Rivers, 2004). Spaces where smoking has traditionally been prevalent, such as bars, have historically been important meeting places for LGBT communities (Pollack, Osmond, Paul, & Catania, 2005). Furthermore, since as far back as the 1980s, the tobacco industry began to target the lesbian and gay market through direct advertisement, sponsorship, and promotional events in LGBT dense communities and at LGBT events such as annual pride marches (Goebel, 1994).

LGBT people may also face barriers to quitting, such as limited access to culturally appropriate and sensitive tobacco cessation programs and materials and to quality health care that can address their concerns (Klitzman & Greenberg, 2002). In fact, most employers do not provide health insurance coverage to the same-sex partners of employees (Human Rights Campaign, 2006). Also, LGBT individuals may be less likely to obtain medical care in some circumstances, limiting their access to tobacco cessation education and counseling through this means. Some studies have found that lesbians may avoid seeking health care because of past negative experiences with homophobic practitioners (Cant, 2006). These experiences include patronizing treatment, intimidation, attempts to change the patient's sexual orientation, hostility toward the patient or her partner(s), breach of confidentiality; invasive and inappropriate personal questioning, neglect, denial of care, undue roughness in the physical exam, and sexual assault.

For LGBT people who also have low-incomes, have low education levels, are racial or ethnic minorities, live in nonurban areas, and/or

are young, these risk factors and access problems are exacerbated. Research suggests that LGBT and questioning youth are more likely to be depressed, lonely, isolated, to attempt suicide, discriminated against, and to have been physically or verbally victimized when compared to their heterosexual counterparts (Kitts, 2005). Most likely, all of these factors contribute to increased substance use in LGBT people, including smoking. In particular, research has suggested that smoking is more prevalent among groups who experience high levels of stress (Centers for Disease Control & Prevention, 1998; Lesbian, Gay, Bisexual Youth Sexual Orientation Measurement Group, 2003).

Many factors may contribute to the vulnerability and receptiveness of LGBT communities to tobacco industry marketing. Cigarettes may provide emotional support in the face of social pressures and mental health needs of LGBT people (van Lenthe & Mackenbach, 2006). The bar culture of LGBT social life increases opportunities for the use of cigarettes as a social tool. Gay and bisexual male audiences seem to respond to ads that eroticize tobacco use, perpetuating myths such as “tobacco use equals masculinity” or “smoking will make you sexy” (Stall, Greenwood, Acree, Paul, & Coates, 1999). Other myths, such as “tobacco demonstrates independence or rebellion” and “tobacco use is just part of being gay,” may also contribute to tobacco’s appeal in LGBT communities.

Additionally, the highly prioritized problems of AIDS, antigay violence, and discrimination may lead LGBT communities to believe that tobacco use is no big deal. Finally, internalized homophobia and transphobia may play a role in LGBT audiences’ vulnerability to tobacco advertising; beliefs that “I’m not worthy of being healthy” or “I’m not entitled to live a long and happy life” can break down resistance to tobacco use messages. According to an online marketing survey, lesbian and gay smokers are more likely than the general adult population of smokers to believe that smoking shortens lives (96% vs. 88%), yet lesbian and gay people smoke at higher rates as we discuss in the following (Harris Interactive/Witeck-Combs, 2001).

## **RESEARCH KNOWLEDGE AND NEEDS**

Although this article builds a case that more research needs to be done on studying tobacco use in LGBT populations, this does not mean that a body, albeit still modest, of work investigating this topic does not already exist. However, unlike other populations, such as racial and ethnic minorities, LGBT tobacco related research can still be reasonably summarized in a few pages. Here we review some of the key findings of this research as it pertains to epidemiology, prevention, cessation, HIV/AIDS, policy, and tobacco industry marketing.

### ***Epidemiology***

Evidence demonstrates that smoking has a disproportionate impact on lesbians, gay men, and bisexuals (Ryan, Wortley, Easton, Pederson, & Greenwood, 2001). Tobacco use has been found to range from 38% to 59% among lesbian, gay, and bisexual youth; and 11% to 50% among lesbian, gay, and bisexual adults, compared to national overall smoking rates ranging from 28% to 35% for youth and approximately 28% for adults around the time these studies were conducted (Centers for Disease Control & Prevention, 1996; Sell & Becker, 2001). Although smoking prevalence data in the published literature is limited for LGBT populations, available data consistently shows that smoking rates among both gay men and lesbian and bisexual women are higher than those seen in the general population.

Some gender differences exist, suggesting that although both gay men and women exceed their heterosexual counterparts in tobacco use prevalence, lesbians and bisexual women tend to out-smoke heterosexual women by a much greater percentage than gay men out-smoke heterosexual men. Cultural differences between the gay men’s and women’s communities and other social factors may help account for this difference, but no research has addressed gender differences within the LGBT communities.

For instance, a 1997 study using random digit dialing in Los Angeles found that 37.0% of

lesbians and 50.0% of bisexual women smoke, compared to 14.0% of heterosexual women and 22.1% of women nationwide (Diamant, Wold, Spritzer, & Gelberg, 2000). In 1999, Stall and colleagues (1999) found that 41.5% of gay men smoke, compared to 28.0% of men in the general population. They also found a lower smoking rate among gay and bisexual men with higher education than the rate for other gay and bisexual men. In these examples, gay women were 160–250% more likely to smoke than heterosexual women, and gay men were approximately 50% more likely to smoke than heterosexual men.

A recent review by Ryan et al. (2001) identified eight adult studies from 1987 to 2000 that included questions on tobacco use and sexual orientation. Of these eight studies, six included lesbian and bisexual women and found smoking rates ranged from 11% to 50%. Gruskin, Hart, Gordon, and Ackerson (2001) looked at women enrolled in a large health maintenance organization and found that lesbians and bisexual women (25.4%) were significantly more likely than heterosexual women (12.6%) to be current smokers. Similarly, a study by Tang, Greenwood, Cowling, Lloyd, Roeseler, and Bal (2004) used statewide data from the California Health Interview Survey to conclude that lesbians' smoking rate (25.3%) was about 70% higher than that of heterosexual women (14.9%). An analysis of the national Women's Health Initiative data revealed that even among postmenopausal women, lesbians used cigarettes more often than heterosexual women (Valanis, Bowen, Bassford, Whitlock, Charney, & Carter, 2000). In addition, lesbians were more likely to be heavy smokers, and were less likely than heterosexual women to have never smoked (25–33% of lesbians versus almost 50% of heterosexual women; Goebel, 1994).

Smoking prevalence and related health behaviors specific to gay and bisexual men are less well documented than those for lesbians and bisexual women. Estimates of smoking prevalence for gay and bisexual men range from 31% to 48% (Greenwood et al., 2005; Sell & Becker, 2001; Tang et al., 2004; Tobacco Technical Assistance Consortium & Experts, 2004). Significant associations with smoking for gay and bisexual men included heavy

drinking, frequent gay bar attendance, greater AIDS-related losses, HIV seropositivity, lower health rating than members of same age cohort, lower educational attainment, and lower income (Tobacco Technical Assistance Consortium & Experts, 2004).

Even less is known about smoking in transgender populations, although it is suspected that higher rates of smoking occur among transgender people. A recent study at the University of Minnesota shows that over 50% of the patients in their transgender health clinic who received hormone therapy were current or past smokers, and the rate of current smokers was almost double the rate in the general population (Feldman & Bockting, 2003).

### *Prevention*

Although people of any age can begin smoking and other tobacco use behaviors, most use begins before age 18. Prevention efforts are, therefore, most effective at the youth level. Studies investigating and informing prevention are, therefore, particularly needed for LGBT youth, and 18- to 24-year-olds (both college and noncollege; Remafedi & Carol, 2005). Only a few studies beyond those examining prevalence rates have been conducted to date on tobacco use among LGBT youth (Austin, Ziyadeh, Fisher, Kahn, Colditz, & Frazier, 2004; D'Augelli, 2004; Faulkner & Cranston, 1998; Garofalo, Wolf, Kessel, Palfrey, & DuRant, 1998; Russell, Driscoll, & Truong, 2002). Studies are needed to examine predictors of tobacco use uptake in both LGBT youth and adults, including stressors, mental health, self-acceptance, social support, victimization, discrimination, and other social and cultural determinants of health behaviors. More data are also required to identify protective factors and evaluate existing LGBT prevention programs and initiatives. And information is needed on effective prevention messages for these populations.

There are several specific steps that anti-tobacco programs and organizations have utilized to reach LGBT audiences. There is some evidence that LGBT consumers tend to respond more to marketing efforts that focus

on individuality; meet a need for association, such as creating community; highlight and celebrate life's diversity; reduce stress; and address skepticism and mistrust (Tobacco Technical Assistance Consortium & Experts, 2004). Several strategies have been used to position antitobacco use programs to appeal to LGBT populations. It is important to demonstrate sensitivity and trustworthiness to LGBT people: for example, developing and posting nondiscrimination policies within the organization that protect LGBT people, and using inclusive language in marketing communications such as "partner" and "significant other" rather than "husband" or "wife" that won't alienate LGBT people or marginalize their relationships, particularly for those that cannot legally marry (Tobacco Technical Assistance Consortium & Experts, 2004).

Another key approach has been utilizing LGBT media to establish the visibility of antitobacco programs in LGBT communities: for example, buying paid advertising space and advertising job opportunities in LGBT publications and including national and local LGBT publications on press lists. Mainstream tobacco control organizations have begun forming alliances with LGBT organizations to offer educational resources to appeal to LGBT people. Finally, antitobacco programs have focused on the ways in which LGBT people are manipulated and exploited by the tobacco industry as is discussed in the following section on Tobacco Industry Marketing.

Qualitative and anecdotal evidence indicate that these approaches and programs have been successful (American Legacy Foundation & Experts, 2001; Tobacco Technical Assistance Consortium & Experts, 2004). However, for mainstream tobacco control and public health organizations to initiate and fund such efforts, more data are needed about their effectiveness in reaching LGBT individuals and reducing smoking in LGBT communities, including LGBT youth and all racial and ethnic groups. Even more obviously, data is needed on how LGBT individuals respond to mainstream prevention efforts. Therefore, any evaluation of such interventions should make sure that they collect data on LGBT people.

## **Cessation**

Smoking-related health disparities among LGBT individuals are almost certainly exacerbated by decreased access to culturally appropriate quality health care and sensitive tobacco cessation programs and materials. These factors create barriers to quitting for LGBT smokers. LGBT individuals may be less likely to receive preventive healthcare, meaning that they may receive less frequent tobacco cessation education and counseling (Bradford & Ryan, 1988).

Although advocates and researchers agree that cessation programs that are sensitive and appropriate for LGBT populations are urgently needed to address the high smoking rates in these communities, cessation research is insufficient. According to one study, only 11% of addiction counselors considered themselves knowledgeable in LGBT-specific issues (Neisen, 1994). Nationwide, very few smoking cessation programs have been developed specifically for LGBT populations. However, in response to the high smoking rates in LGBT communities and the dearth of appropriate cessation services, LGBT health advocates have implemented a few models of treatment since the early 1990s. The first LGBT-targeted cessation program, developed by Lyon-Martin Women's Health Services in San Francisco, was a smoking cessation peer group model for LGBT and HIV-positive people called *The Last Drag* ("Free quit smoking class," <http://www.lastdrag.org/thelastdragsanfrancisco.html>).

A state-funded effort called the Queer Tobacco Intervention Project (QueerTIP) has begun to address the gaps in the cessation arena in California. Using a highly collaborative and community-driven approach, QueerTIP conducted a cessation needs assessment in 2001 to better inform the design of LGBT-focused cessation programs. Making particular efforts to include youth and transgender people among the contributors and participants, the QueerTIP study may provide the best information so far regarding the development of LGBT cessation programs. Findings include that it is especially important to LGBT youth to have an LGBT-specific cessation class (90%) and LGBT-sensitive health providers (56%; Greenwood,

Hunt, deManicor, Ralson, Ereñeta, Gordon et al., 2001). Additionally, a high percentage of youth smokers expressed interest in quitting (68%) and did not relate to current youth-targeted antismoking ads (67%). The transgender participants of the needs assessment also highly valued LGBT-specific services (84%) and LGBT-sensitive doctors (79%). Of special concern to transgender participants were the potential harmful interactions of smoking and hormone therapy and surgeries. Similar to the youth, about 67% of current transgender smokers were interested in quitting.

QueerTIP also contributed to the cessation evaluation research by evaluating multiple existing Last Drag programs, and then piloting a new cessation model, which explicitly addresses issues unique to LGBT people. Findings include that transgender people sought traditional group-based cessation classes; 40% of participants quit by the end of the new QueerTIP class; and satisfaction was high for all participants ("A stop smoking class for lesbian, gay, bisexual and transgender communities," 2002).

Studies are also needed to investigate the use of the Internet for smoking cessation and the specific cessation needs of subgroups of the LGBT population, especially youth, racial and ethnic minorities, and transgender individuals. There is also a need to develop and evaluate cessation/treatment resources for rural LGBT individuals and others who cannot access onsite treatment (Tobacco Technical Assistance Consortium & Experts, 2004). One example of such an intervention is "iQuit," an Internet-based program for LGBT smokers ("Quit, A Quit Site for Lesbian, Gay, Bisexual and Transgender Smokers," 2004).

Finally, studies are needed comparing cessation outcomes for LGBT people using traditional versus LGBT-specific services. Smoking abstinence rates in the general population were 27% for the active nicotine patch, compared to 13% for the placebo patch at the end of 4 to 8 weeks of treatment, and 22%, compared to 9% at 6 months (Fiore, Smith, Jorenby, & Baker, 1994). However, there are no data on quit rates for LGBT individuals utilizing this most commonly advised approach to quitting.

## **HIV/AIDS**

Of further concern for LGBT communities is the relationship between HIV/AIDS and smoking. HIV positive persons are significantly more likely to smoke compared to HIV negative individuals (Burns, Kramer, Yellin, Fuchs, Wachter, DiGiola, et al., 1991; Craib, Schechter, Montaner, Le, Sestak, Willoughby, et al., 1992). There are conflicting findings on the effects cigarette smoking has on the incidence of *Pneumocystis carinii* pneumonia, Kaposi's Sarcoma, and disease progression to an AIDS diagnosis or death (Mbulaiteye, Atkinson, Whitby, Wohl, Gallant, Royal, et al., 2006). There is, however, a consistent association between smoking and bacterial pneumonia, hairy leukoplakia, oral candidiasis, and AIDS-related dementia (Boulter, Soltanpoor, Swan, Birnbaum, Johnson, Teo, et al., 1996; Conley, Bush, Buchbinder, Penley, Judson, & Holmberg, 1996; Galai, Park, Wesch, Visscher, Riddler, & Margolick, 1997; Greenspan, Barr, Sciubba, & Winkler, 1992; Hirschtick, Glassroth, Jordan, Wilcosky, Wallace, Kvale, et al., 1995; Palacio, Hilton, Canchola, & Greenspan, 1997; Reardon, Kim, Wagner, & Koziel, Kornfeld, 1996; Syrjanen, Valle, Antonen, Suni, Saxinger, Krohn, et al., 1988). Smoking among HIV positive individuals should, therefore, be a target area for prevention and cessation efforts. The special needs and concerns related to tobacco use and HIV/AIDS, however, must be addressed in these efforts and programs developed for this population must be scientifically evaluated.

## **Policy**

Public and organizational policies addressing tobacco use in LGBT communities have increased, along with rising awareness concerning the higher rates of smoking in communities and the targeting of LGBT people by the tobacco industry. These policies include regulation of advertisements in LGBT publications, acceptance or refusal of tobacco industry sponsorship of LGBT events and publications, and antismoking nights for bars. For example, in 1998, the Coalition of Lavender Americans on Smoking and Health (CLASH) produced the guidebook

“Ethical Funding for LGBT Community-Based Organizations: Practical Guidelines When Considering Tobacco, Alcohol and Pharmaceutical Funding,” which was reprinted in 1999 by Progressive Research and Training for Action, and revised and republished in 2001 (Drabble, 2001). Since 1999, with this guide, and related tools such as an ad campaign entitled “Our Pride is Not for Sale,” CLASH has led efforts to urge LGBT community organizations to adopt no-tobacco sponsorship or contribution policies.

Non-LGBT specific policies such as tax increases and antismoking laws in some cities have also impacted LGBT communities. No research has systematically examined the relationship between these policies and LGBT smoking rates, but it is known that early corporate sponsorship of LGBT events may have created loyalty to tobacco companies by LGBT people and increased smoking in this community. Research examining the impact of policies often recognizes the diverse impact they can have on populations defined by age, gender, or race–ethnicity. This research would also benefit from examining the impact on LGBT populations.

### ***Tobacco Industry Marketing***

One area where there has been a significant amount of examination is research into tobacco industry practices targeting LGBT people. Information collected from tobacco industry documents clearly shows that tobacco companies directly target LGBT people through focused advertisement, sponsorship, and promotional events to increase their tobacco consumption and encourage them to start smoking or smoke more (Goebel, 1994; Offen, Smith, & Malone, 2003; Smith & Malone, 2003; Smith, Offen, & Malone, 2005; Washington, 2002). Recognizing the powerful effects of the tobacco industry’s targeted efforts, the California Department of Health Services funded the California Lavender Smokefree Project from 1995 to 2000 to counteract tobacco industry advertising in LGBT communities through media campaigns, youth outreach, and community awareness of industry tactics. Additionally, the Web site <http://www.projectscum.org> (2006) has documented the tobacco industry’s targeting

of LGBT and other vulnerable populations, provided chat forums for public discussion of these tactics, and launched a public awareness campaign.

Kevin Goebel published important findings on tobacco industry targeting of LGBT communities in 1994. In the late 1990s, Perry Stevens—on behalf of the Centers for Disease Control and Prevention (CDC)—compiled and presented one of the first workshops on the targeting of LGBT individuals by tobacco companies. Beginning with this first presentation at the International Tobacco or Health Conference in Chicago in 2000, Stevens has created many other invaluable resources for the Tobacco Technical Assistance Consortium on the history of the tobacco industry’s efforts to market their products to lesbians and gays (Stevens, Carlson, & Hinman, 2004). A National Institutes of Health grant to the University of California at San Francisco was awarded to identify references to LGBT populations in tobacco industry documents. Increased research in this area has also sparked a number of educational efforts, including the American Legacy Foundation’s Project SCUM advertising and e-mail campaign to draw attention to, and counter, the targeting of urban gays and lesbians and homeless people in an early 1990s marketing campaign (ProjectSCUM.org, 2006; Stevens et al., 2004).

### ***EXPERT MEETINGS, FORUMS, AND DOCUMENTS***

Awareness that LGBT populations were at higher risk for smoking, that cessation programs should be culturally sensitive, and that the tobacco industry had targeted LGBT people brought about a series of expert panel meetings and documents that were designed to identify research, prevention, and treatment needs for these populations. Many of the resulting recommendations overlapped or were duplicated across efforts. The authors of this article participated in four of these, of which the recommendations produced relating to tobacco use research and data collection are presented here. These recommendations should guide work in the area of LGBT tobacco use research, however the recommendations have not been widely

distributed beyond the experts that produced them. It is, therefore, useful to include them here, but also, for the first time, to examine them together as a whole.

The first of these events was the *Gay, Lesbian, Bisexual and Transgender Forum on Tobacco Control*, held in November, 2000 in Atlanta, Georgia. The forum was funded by the American Legacy Foundation and included over 50 tobacco control experts, community advocates, representatives from state and local health programs, and university-based researchers. Staff members from the American Legacy Foundation produced an executive summary of the forum, which include the recommendations presented here (American Legacy Foundation & Experts, 2001).

The second effort was the convening of experts by the Gay and Lesbian Medical Association to produce the *Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health* (2001). The experts, which numbered over 150 in total, produced this document using conference calls and e-mail through the fall of 2000 and spring 2001. The document deals with LGBT health in general, but has a chapter devoted to tobacco use (Gay & Lesbian Medical Association et al., 2001).

The third group of experts was convened by the United States CDC Office on Smoking and Health (OSH) in January 2003. The 2-day Experts Panel meeting entitled *Tobacco Surveillance among Lesbian, Gay, Bisexual, and Transgender (LGBT) Communities* included 29 participants. The mission of the meeting—cosponsored by the Gay and Lesbian Medical Association—was to make recommendations concerning how to monitor and better understand tobacco use and cessation in LGBT communities, however, the recommendations made at this meeting, and presented here, remain unpublished elsewhere. Participants at this meeting represented U.S. federal and local public health agencies, academic research institutions, community-based health and research centers, tobacco control funding organizations, national health education and advocacy organizations, national LGBT-focused organizations, and health consultants.

The fourth meeting was convened by the Tobacco Technical Assistance Consortium in October 2003, and was known as the Tobacco Action Plan Working Meeting. The meeting, which drew over 60 antitobacco and LGBT health activists from 20 states, was designed to create actionable items on the topics of prevention, cessation/treatment, and research. Results of the meeting were published in *The National LGBT Communities Tobacco Action Plan: Research, Prevention, and Cessation* (Tobacco Technical Assistance Consortium & Experts, 2004).

The research related recommendations from these four meetings of experts are presented in the following. Some of the recommendations have been edited for clarity or to make sense outside of the full documents from which they are abstracted. It should also be noted that, in some instances, multiple documents produced from the meetings contain slightly different versions of these recommendations. We try in the following to carefully preserve the intent of the recommendations as originally produced by meeting participants. It should be noted that the recommendations do not necessarily represent the opinions of the authors of this article or any of the organizations the authors represented at these meetings.

## RECOMMENDATIONS

### *Recommendations from the Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual, and Transgender Health (Gay & Lesbian Medical Association et al., 2001)*

- Sexual orientation and gender identity must be included in national and local data sets to study differences in smoking rates and treatment success.
- Data are needed on a variety of LGBT-specific tobacco-related issues so that culturally competent social marketing and public education campaigns, prevention activities, and cessation programs can be established and implemented.

***Recommendations from the American Legacy Foundation Lesbian, Gay, Bisexual, and Transgender Forum (American Legacy Foundation & Experts, 2001)***

- Local, state, and national surveillance systems should include sexual orientation and gender identity measures to monitor tobacco use among LGBT. Surveillance should also try to identify which LGBT subpopulations are disproportionately harmed by smoking (e.g., people of color, people of lower socioeconomic status, transgender people).
- A thorough evaluation—process and outcomes—of culturally specific prevention and cessation services is necessary. Similarly, researchers need to assess how LGBT people fare in cessation programs targeted at the general population and how those programs' best practices apply.
- Tobacco industry documents must be researched to learn how LGBT communities are targeted.
- LGBT tobacco researchers should work with mainstream tobacco researchers when identifying requests for proposals and when reviewing grant proposals.
- Future LGBT tobacco researchers should be supported and mentored, particularly researchers from historically disenfranchised LGBT communities.

***Recommendations from the Experts Panel on Tobacco Surveillance Among Lesbian, Gay, Bisexual, and Transgender Communities***

- Sexual orientation and gender identity questions should be included in core questions on the following surveys: Adult Tobacco Survey (ATS), the National Health and Nutrition Examination Survey (NHANES), the Current Population Survey, the National Household Survey on Drug Abuse, the National Health Interview Survey, and the Behavioral Risk Factor Surveillance System.
- There should be a two-pronged parallel approach that includes both advocating for

inclusion of LGBT questions in national surveys and advocating for inclusion at the state level.

- It is also important to include nongovernmental/community-based organizations when creating and conducting surveys. They should be included in discussions with scientific experts to decide methodology and sampling, as well as cognitive testing of sexual orientation and gender identity questions.
- LGBT people should be oversampled in government surveys to increase power.
- The CDC, other government officials, and academic institutions should lend expertise to community-based organizations so that they can develop and implement their own research.
- The CDC should encourage the National Cancer Institute and other departments from within the CDC to include LGBT questions in surveys and research studies, and to devote resources to research in LGBT communities. They should also be urged to support organizations and researchers who have already been working with underserved populations.
- Native Americans/Alaska Natives, Hispanic/Latino, LGBT, and others working with populations with disparate smoking rates should be encouraged to continue their work.
- Sexual orientation and gender identity questions should be added to the CDC/OSH ATS, but possible questions should first be cognitively tested.
- Those applying to implement the ATS must have nondiscrimination policies that include sexual orientation and gender identity.
- Training should be provided to ensure quality control in the ATS when collecting sexual orientation and gender identity data.

***Recommendations from the Tobacco Action Plan Working Meeting (Tobacco Technical Assistance Consortium & Experts, 2004)***

- Include sexual orientation and gender identity questions in national tobacco and health surveys.

- Include tobacco use questions in LGBT health research.
- Oversample for specific LGBT groups, to obtain more precise prevalence data.
- Include LGBT investigators in mainstream tobacco research.
- Develop standard sexual orientation and gender identity questions for survey research.
- Conduct psychosocial studies (ethnographic/anthropology/history of smoking).
- Increase policy research (social norm changing in the LGBT communities, effects of tobacco industry sponsorship, uptake and cessation).
- Study comorbidities of tobacco use.
- Conduct research on tobacco use in urban versus rural LGBT individuals.
- Conduct multicity and multistate research (e.g., smoking in gay bars).
- Fund grants for pilot research studies.
- Conduct economic and marketing research studies.
- Expand prevention studies (e.g., coming out process—information is needed for developing effective prevention and cessation tools).
- Build the infrastructure/support for LGBT tobacco researchers.
- Increase research in all areas—government and private funders should issue of Request for Applications.
- Addressing LGBT and tobacco use as issues of social justice, healthy disparity, and parity, including holding funders, LGBT organizations, and non-LGBT organizations accountable for the relationship between tobacco funding and the community.
- It is necessary to determine the best way to share data already collected among LGBT tobacco programs.

### ***PROGRESS TOWARDS DATA COLLECTION AND RESEARCH***

Some limited progress has been made toward acting on the recommendations previously listed, but progress is difficult to assess. Although a number of publications on tobacco use in LGBT populations have been produced

since the recommendations were fashioned, it is hard to determine whether the research and publications were actually begun before or after the recommendations were made. However, it is clear that only modest progress has been made overall.

One of the most fundamental questions, smoking rates among LGBT individuals, an elemental epidemiological question, is still difficult to accurately quantify due to a number of barriers. Most national tobacco and health surveys still do not ask sexual orientation or gender identity questions, and there have been few federally- or state-funded studies on LGBT individuals and tobacco use. Another important obstacle is that the LGBT health studies that have been conducted to date have not generally included research on tobacco use.

Many of the findings reported in the scientific literature are, therefore, derived from research projects that have a primary focus other than tobacco, use but happen to have questions that can be used in secondary data analyses to assess this topic. Questions used in these studies to determine tobacco use and smoking status generally lack consistency, such as those regarding daily consumption and lifetime smoking. Sampling concerns and homogenous demographics of samples (e.g., gay white men) have made it difficult to adequately determine the impact of tobacco use on LGBT communities. There is also insufficient data on smoking for many groups within LGBT communities—such as persons of color and transgender individuals—due to the fact that most studies do not have large enough samples of important subpopulations to have enough power to say anything about them with confidence.

Although no nationally representative surveys focus exclusively on tobacco and LGBT persons, there are several state and national data sources that include questions about both sexual orientation and tobacco use (see Epidemiology). Researchers have analyzed these surveys to contribute to the knowledge base on tobacco use in LGBT communities, and should continue to do so. Utilizing existing datasets eliminates costly sampling and data collection efforts. The sampling in many of the large existing datasets was designed to be representative of the general population, which provides higher quality data

than the convenience samples common in most early research studies of LGBT populations. Another advantage of this research is that it raises the visibility of these datasets within the community of LGBT health researchers. This visibility can be used to increase research relevant to LGBT populations and to demonstrate to survey authors that sexual orientation and gender identity variables can be added to datasets. The limitations of analyzing existing data sources include a virtual absence of information about transgender populations, and the lack of control over the questions asked, so some inquiries related to LGBT tobacco use are impossible to ascertain based on these datasets.

Currently, there are a number of datasets, many of them publicly available, with excellent potential for yielding information about tobacco use in LGB populations (note here that only one of these may be used to study the “T” population, therefore the surveys listed here have measures of sexual orientation and not gender identity). The following list is not comprehensive, but lists those that are the most current or those with larger sample sizes (GayData.org, 2006):

- Over 10 states have now added sexual orientation questions to their CDC-sponsored Youth Risk Behavioral Surveys (YRBS). However, there is tremendous variability in how sexual orientation is asked across states, making the combination of datasets and between state comparisons difficult.
- Eight states have added sexual orientation questions to their CDC-sponsored Behavioral Risk Factor Surveys (BRFS). Although like with the YRBS, sexual orientation questions added to the BRFS differ from state to state.
- The NHANES sponsored by the CDC’s National Center for Health Statistics.
- The National Survey of Family Growth sponsored by the CDC’s National Center for Health Statistics.
- The Women’s Health Initiative study, sponsored by the National Heart, Lung, and Blood Institute.
- The National Longitudinal Study of Adolescent Health, sponsored by the National Institute of Child Health and Human Development.

- The Growing Up Today Study, conducted out of Harvard Medical School.
- The California Health Interview Survey, sponsored by the UCLA Center for Health Policy Research, California Department of Health Services, and The Public Health Institute.
- The Nurses Health Study II, conducted out of Harvard Medical School.
- The Urban Men’s Health Study, conducted out of the University of California San Francisco.

Surveys that may also be of interest include:

- Two states (Illinois and New York) have added sexual orientation questions to their ATS, which are sponsored by the individual states with technical assistance provided by the CDC’s Office on Smoking and Health. It is not known if the sample sizes are large enough to analyze the lesbian, gay, and bisexual samples in these surveys. Also, the New York ATS is one of the few population-based surveys to ever ask questions to identify people who are transgender. As with the sexual orientation data, it is not known if there are enough transgender people in this sample for it to be analyzed.
- The National Epidemiologic Survey on Alcohol and Related Conditions, sponsored by the National Institute on Alcohol Abuse and Alcoholism, has longitudinal data on over 35,000 people, but data is not expected to be released until mid-2007.

More information on these and other surveys including data on LGBT indicators, along with links to datasets, can be found at [www.gaydata.org](http://www.gaydata.org) (2006).

### ***MEASUREMENT OF SEXUAL ORIENTATION AND GENDER IDENTITY ON SURVEYS AND IN RESEARCH***

There are a number of reasons why researchers studying tobacco use should consider including questions of sexual orientation and

gender identity on surveys. First, adding these questions will help identify and monitor progress toward reducing tobacco use disparities (Sell & Becker, 2001). For example, adding a sexual orientation variable to surveys on tobacco use such as the ATS would allow researchers to examine inequalities in the use of tobacco products across sexual orientations. Second, adding sexual orientation and gender identity questions allows investigators to account for possibly important confounding variables that may explain other results. Just as race, ethnicity, and age can confound results and must be controlled for, sexual orientation and gender identity should be collected, as well. Third, sexual orientation and gender identity may be used to identify effect measure modification in analytic studies. That is, they may show relative risks vary by sexual orientation in studies of fear of weight-gain on smoking. And fourth, perhaps most important, collecting sexual orientation and gender identity data can inform the development of policies and programs that positively impact the lives and health of LGBT people.

Although the surveys described in the previous section measure sexual orientation, they do so in a variety of ways with only a few using the same question, and only one attempting to identify transgender subjects. This variability in sexual orientation measures and lack of questions about transgender status is problematic. Further, the validity and reliability of the questions that have been used to assess sexual orientation and gender identity (in these surveys and elsewhere) have not been investigated in any coordinated fashion (Sell, in press; Sell & Bradford, 2000). It is imperative that researchers identify, develop, test, and standardize valid and reliable sexual orientation and gender identity questions for surveys, because the lack of such well-designed and tested questions is impeding the collection of high-quality data (Sell, 1997).

Cognitive testing of questions as they are developed and placed into surveys is strongly recommended, and time, funds, and other resources should be allocated to make sure testing is factored into survey development. In addition, interviewer instructions concerning sexual orientation and gender identity questions should be specific so that measurement is done accurately

and consistently. In particular, the method of administration needs to be evaluated (for example, telephone vs. self-administered). There is particular concern that, regardless of which questions are used to assess these constructs, the questions may not work as well in nonacculturated and low socioeconomic status populations, as well as youth (Friedman et al., 2004). Similar problems occur with most other major demographic questions so this problem should not discourage the collection of this data. Questions, however, need to be tested in diverse populations to better understand when and where they work, and delineate their limitations.

The OSH's Experts Panel, Tobacco Surveillance Among Lesbian, Gay, Bisexual, and Transgender (LGBT) Communities, recommended specific survey questions to measure sexual orientation, gender identity, and transgender/transsexual status. The Experts Panel recommended the following question to assess sexual orientation identity:

- Do you consider yourself to be
- a. Heterosexual or straight;
  - b. Gay or Lesbian;
  - c. Bisexual.

This question fared well in cognitive testing conducted at the National Center for Health Statistics, the findings of which have not yet been published. It should be noted that this is an identity question. The panel recognized and discussed the fact that sexual orientation could also be measured using sexual behavior questions or sexual attraction questions. The panel concluded that most surveys would only be able to ask a single question and that identity would probably be the measure most closely associated with tobacco use. That is, it is during the development of an identity as lesbian, gay, or bisexual that individuals are exposed to tobacco use-risks.

Any questions assessing gender identity or transgender/transsexual status must also be cognitive tested. As with sexual orientation questions, the method of administering the questions would also need to be evaluated. The Experts Panel felt that questions used to assess transgender/transsexual status could be particularly confusing to many people, thus causing

problems with validity. For example, many people might not understand the difference between the words transgender and transsexual, or know what either of these terms means. Because of potentially small sample sizes, there could be major limitations to interpreting survey results if even a few nontransgender people misidentifying themselves as transgender on a survey.

At present, most surveys are particularly bad at assessing gender. For example, most major telephone surveys ask the interviewer to code the gender of the respondent based upon the sound of their voice. The Experts Panel felt that instead, a question to assess gender should be provided and the interviewer trained to ask it of everyone. A sample question that was offered:

Can you please tell me if you are a man or a woman? We need to ask everyone this question in order to be sure we accurately identify people's gender.

- a. man;
- b. woman;
- c. Other—specify.

The Experts Panel made several recommendations regarding questions related to transgender status. It advised creating a series of questions, including topics such as sex assignment at birth, gender identity, social presentation, and legal document identity (such as driver's license, birth certificate, passport, etc.). However, if only one question related to gender identity is feasible due to limited time and space, then an ideal question would be:

Currently, or in the past, have you identified as transgender or transsexual?

Finally, the Expert Panel concluded that researchers, despite any uncertainty about the validity and reliability of questions, should continue to collect sexual orientation and gender identity data. Lessons learned during the process of collecting data should be used to improve future data collection. Further, ideal questions may never exist, and like race and ethnicity, they may be changed relatively frequently as society shifts its conceptions of these constructs. However, the questions, when asked in surveys, have already

demonstrated their value in providing insights into important health concerns and the development of more informed tobacco use prevention and cessation efforts.

## CONCLUSIONS

Lesbian, gay, bisexual, and transgender people are not routinely included in scientific studies of tobacco use, nor are they included in major epidemiological studies used to monitor tobacco use. This is not to say that they are not allowed to participate in such studies, but rather that these studies do not collect the data necessary, sexual orientation and gender identity, to identify who in these studies is LGBT. We argue that important opportunities to prevent and decrease the use of tobacco are consequently being lost.

Further, enough evidence now exists to show that valid and reliable sexual orientation data can, and should, be collected. First, studies show that people will answer sexual orientation questions (with refusal rates generally below 1%, much lower than refusal rates for income which on major U.S. surveys now often exceeds 25%), second, that respondents will not be offended by being asked their sexual orientation and drop out of the research study (the National Epidemiologic Survey on Alcohol and Related Conditions reported 0 dropouts on a sexual orientation question that was asked of over 35,000 respondents). And third, although there is variability in how sexual orientation has been assessed, there is now evidence with some questions that the measures are valid and reliable. Finally, as we have reviewed in this article, studies are consistently showing that disparities in tobacco use exist based upon sexual orientation. These disparities clearly indicate that efforts to prevent tobacco use as well as cessation efforts can benefit from being tailored to people based upon such characteristics as their sexual orientation. So not only can this data be collected, but there is good reason to collect it.

However, we do concede that more work needs to be conducted on the collection of gender identity data. Questions to assess transgender status have only rarely appeared in research studies, and the questions that have been used

are not well understood. This is not to say that such questions should not immediately be added to research studies, but that researchers should investigate how well the question is performing in the context of their study. Further, when such questions are asked, researchers should report not just the results of the study, but also report on their experience with asking such questions. Rarely is such methodological work reported or published, but it is greatly needed concerning the measurement and collection of data to assess gender identity and transgender status.

Finally, we note that the research reported on and presented in this article focuses on studies conducted in the United States. This is because tobacco use in the United States has been the focus of the work of the authors of this article. How sexual orientation and gender identity are being incorporated into research in other countries deserves to be reviewed as well, but is beyond our expertise. We recognize that, because sexual orientation and gender identity are social constructs, much can be learned from how this process is playing out in locations outside of the United States.

### WHAT THIS ARTICLE ADDS

During the last 5 years, there has been a sudden and promising explosion of interest by researchers and research funders in tobacco use by LGBT people. We argue that this interest came about because of the inclusion of sexual orientation variables in a few surveys and research studies beginning in the late 1990s, which allowed for the study of tobacco use in these populations and the discovery of disparities for the first time. We also argue that this work is at a critical stage in development. Although much progress has been made, as is evidenced in the review of knowledge included in this article, there is much more work to be done. For example, researchers still do not generally include tested questions of sexual orientation and gender identity or transgender status in their work, nor do the most important surveys of tobacco use include such questions (e.g. the National Health Interview Survey). This article encourages researchers to take such actions and reminds them of the impor-

tant recommendations many dedicated experts have made in order to guide and encourage such investigations.

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