



National L G B T tobacco control network

The Fenway Institute ~ 7 Haviland St. ~ Boston, MA 02115 ~ 617-927-6451

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LGBT Surveillance and Data Collection Briefing Paper

Scout, Ph.D. * September 7, 2008

Why capture LGBT smoking data?

For the last several decades, there has been growing awareness that the gay, lesbian, bisexual, and transgender (LGBT) population experiences health disparities in a number of different areas. Initial work on sexually transmitted diseases has grown into a vibrant field of research, and the inclusion of sexual orientation as a marker for health disparities in Healthy People 2010.¹ The disparities are particularly noticeable in the area of tobacco use. A 2001 review of available literature reported that LGB people smoke at rates 40-60% higher than the general population.² While population-based studies including questions of sexual orientation or gender identity are relatively rare^{3, 4}, three major investigations have since been conducted validating earlier findings:

- 2001 California Health Interview Survey data – gay men smoke at rates 50% higher than other men, lesbians smoked at rates almost 70% higher than other women.³
- 2003 California LGBT Tobacco Survey – LGBT men smoked at rates 50% higher than other men, LGBT women almost 200% higher than other women.⁴
- 1997-2004 National Health Interview Survey – same sex partnered men smoked 38% higher than others, same sex partnered women smoked 54% higher than others.⁵

Disturbingly, early evidence showing LGB youth smoke at rates 68% higher than other youth (59% v. 35%)⁶ continues to be corroborated with new studies:

- 1999 Growing Up Today Survey – 9.3 % of heterosexual v. 42.9% of lesbian/bi female adolescents: 8.2% of heterosexual v. 17.4% of “mostly heterosexual” male adolescents.⁷
- 1994/5 National Longitudinal Study of Adolescent Health – 35% of men & 45% of women reporting same sex attraction or relationships smoked versus 29% of others.⁸

Across available research, population-based studies, large cohort studies, and convenience samples, the findings stay consistent: some if not all LGBT groups demonstrate significantly higher smoking rates than the general population.^{2, 3, 7, 9-17}

This higher prevalence of smoking is combined with two other factors that 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 healthcare, including tobacco initiatives targeted at the general population.^{18, 19} For example, 37% of respondents in the 2003 California LGBT Tobacco Survey believe that anti-smoking campaigns ignore the LGBT community.⁴ Second, LGBT community members and leaders show distressingly low awareness of tobacco as a health priority for this population. For example, in the survey above, 7 out of 10 LGBT men and 4 out of 5 LGBT women thought smoking was no bigger problem for LGBTs than everyone else – this despite record high prevalence rates reported by the same group.⁴ UCSF researchers found that only 24% of 75 LGBT community leaders listed tobacco as a top three LGBT health issue.²⁰ This lack of prioritization is likely related to early and persistent tobacco industry LGBT marketing (including untold sponsorship of related HIV groups) and the high LGBT brand loyalty given to these vanguard corporate sponsors.²²⁻²⁵ When UCSF researchers conducted focus groups in the LGBT and African American communities they found that African Americans were primarily angry when shown depictions of tobacco industry targeting, while LGBTs were primarily grateful.^{21, 26}

LGBT show some of the highest smoking prevalence rates of all disproportionately affected populations. This stark reality combined with proven barriers to healthcare and a relatively low level of community awareness of the impact of tobacco demonstrate the extremely high need for tobacco control initiatives in this population. Despite availability of some full probability data, local interventions are most often driven by local data, thus adding an LGB or LGBT question to local and national tobacco surveillance surveys is the first step towards providing local interventions for this disproportionately affected population.



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Evidence for Feasibility of LGBT Data Collection

For the purpose of this paper, we will concentrate on questions that are related to LGBT identity instead of behavior. Behavior questions are best suited for surveys that have existing questions about sexual behavior, and should be embedded in that section. Survey administration in this case often has additional measures to ensure validity in the face of these “sensitive questions”. Conversely, identity questions are usually considered part of the survey demographics, and have been tested in a wide variety of survey modes with success.

Research has demonstrated that when included as a standard demographic question, the sexual orientation question is no more sensitive than other variables (and is actually less sensitive than questions about income). Response rates from a recent study of the New Mexico quitline conducted by Free & Clear indicate that only 2.5% of 3,549 callers refused to answer the sexual orientation question.²¹ Further, “callers who refused to answer one sensitive question were much more likely to refuse to answer any other questions considered personal and sensitive. This finding suggests that the refusal may be less related to the topic per se (race, sexual orientation, etc) and more associated with general unwillingness to report on any personal issue.”²¹ In the Massachusetts Behavioral Risk Factor Social Survey an average of 3.6% of people (spanning five years) refused to answer the sexual orientation identity question, compared with 5.3% refusing the income question.²² In a survey of the North American Quitline Consortium members, refusals to this question (asked at intake) ran from 1.9% to 2.9%. Again these compared very favorably with refusals for other demographic questions.²³ In three different methodological studies, researchers have shown that a sexual orientation question can be asked early in a demographic section as part of a phone or household survey with no notable adverse effect.³¹⁻³³ Strikingly, the National Epidemiological Survey on Alcohol and Related Conditions has had zero breakoffs on the sexual orientation question in over 30,000 interviews (with only 1.7% refusal rate).²² Likewise the Nurses Health Study II had zero breakoffs in 91,000 paper surveys administered with a sexual orientation identity question in 1995 (with only 0.9% refusal rate).²⁴ In short, concerns about breakoffs or agitating the respondents with this question are largely unfounded. In the words of one researcher, “Most people are happy to state that they are straight.”²²

Similarly, questions on sexual orientation are now included on an increasing number of surveys. Currently, at least eight state Behavioral Risk Factor Surveillance System surveys (BRFSS) include SO questions.²⁵ At least thirteen Youth Risk Factor Surveillance (YRBS) surveys include SO questions.²⁵ Likewise the following federal surveys include SO measures: National Health and Nutrition Examination Survey; National Survey of Family Growth; National Epidemiologic Survey on Alcohol and Related Conditions; National Household Survey on Drug Abuse; National Comorbidity Study-R.²⁵ In a North American Quitline Consortium survey, 15 states asked an LGB or LGBT question on one of their primary tobacco surveillance measures (quitline, Adult Tobacco Survey-ATS, YRBS, or BRFSS).²³

How to Capture LGBT Smoking Data

LGBT state-level data can be most easily documented through the addition of an LGBT question on the existing state surveillance surveys, particularly the BRFSS, YRBS, and ATS. LGBT tobacco intervention data is most easily captured through the addition of an LGBT question to the state tobacco quitline, and subsequent reporting on the usage rates by this subgroup. Remember, if smoking rates exceed the general population, quitline usage rates should also exceed the ratio of LGBTs in the general population. National LGBT data is best served by addition of an LGB(T) question to the surveys most commonly used for health monitoring, the surveys most commonly referenced by HP2010 are National Health Interview Survey (NHIS) and National Health and Nutrition Examination Survey (NHANES).²⁶

Localities interested in generating LGBT tobacco data before state or national measures become available are encouraged to use second tier data collection strategies, such as community-based needs assessments. Several states have used these methods, please contact the National Network for more information.



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Tested questions to add to surveys

Since the accuracy of all LGBT data collected is primarily dependent on a question that successfully excludes the non-targeted (and much larger) population – we strongly urge people to use one of the tested questions below and avoid crafting new language.

Option 1 – Sexual orientation only

In 2005, LGBT researchers cognitively tested an LGB question for inclusion on surveys. Cognitive testing is the gold standard for developing a survey question because it can uncover many problems with interpretation that go undetected in less rigorous testing methods. This testing was in part spurred by the findings that a similar question on the National Health And Nutrition Examination Survey (NHANES) was subject to significant response error among low socio-economic status and Spanish language respondents.²⁷ Thus be cautious about using any questions where the exact wording has not been subject to cognitive testing. The tested and recommended question is as follows.^{25, 28}

Do you consider yourself to be:

- Heterosexual or straight
- Gay or lesbian
- Bisexual

Interviewer note: can code DK for “Don’t know” or NA for “No answer”.

Option 2 – Gender identity

Other strategies have also been used to capture transgender status. The following question has been successfully cognitively tested with youth. The report is currently in development.²⁹

- Sex/gender
- Female
 - Male
 - Transgender male to female
 - Transgender female to male
 - Transgender do not identify as exclusively male or female
 - Not sure

Option 3 – Tested combined sexual orientation and gender identity question³⁰

In 2007, Blue Cross and Blue Shield of Minnesota commissioned the National LGBT Tobacco Control Network to use state-of-the-art methods to cognitively test a single-pass question for use on surveillance instruments that captured LGB and T identity. The question tested successfully with all population groups, including oversamples of both people of color and low-income respondents. The final successfully tested question is below. On the Minnesota quitline, only abbreviated demographics are collected, so an explanatory sentence precedes the demographic section, it is provided here as well.

[OPTIONAL QUITLINE PREFACE – “Several communities have been targeted by the tobacco industry or have higher smoking rates. We have some special materials for people in these communities. So we’d like to ask you some demographic questions, please remember your answers are completely confidential.”]

Do you consider yourself to be one or more of the following: [say the letter so that they can respond by letter]

- A) Straight
- B) Gay or Lesbian
- C) Bisexual
- D) Transgender

[IF pause or refusal/none of above, also say:

You can name a different category if that fits you better: _____]



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Suggested Citation

Scout. 2008. LGBT Surveillance and Data Collection Briefing Paper. Online publication. Downloaded from National LGBT Tobacco Control Network website at <http://www.lgbttobacco.org/files/Surveillance%20Briefing%20Paper%202004.doc>. Last updated Sept 7. 2008.

Paper Citations

1. U.S. Department of Health and Human Services. *Healthy People 2010*. 2nd ed. Washington, DC.: Government Printing Office; 2000.
2. Ryan H, Wortley PM, Easton A, Pederson L, Greenwood G. Smoking among lesbians, gays, and bisexuals: a review of the literature. *Am J Prev Med*. Aug 2001;21(2):142-149.
3. Tang H, Greenwood GL, Cowling DW, Lloyd JC, Roeseler AG, Bal DG. Cigarette smoking among lesbians, gays, and bisexuals: how serious a problem? (United States). *Cancer Causes Control*. Oct 2004;15(8):797-803.
4. Bye L, Gruskin E, Greenwood G, Albright V, Krotzki K. California Lesbians, Gays, Bisexuals, Transgenders Tobacco Use Survey 2004. <http://www.dhs.ca.gov/ps/cdic/tcs/documents/eval/LGBTTobaccoStudy.pdf>. Accessed April 4, 2008.
5. Heck JE, Jacobson JS. Asthma diagnosis among individuals in same-sex relationships. *J Asthma*. Oct 2006;43(8):579-584.
6. Garofalo R, Wolf RC, Kessel S, Palfrey SJ, DuRant RH. The association between health risk behaviors and sexual orientation among a school-based sample of adolescents. *Pediatrics*. May 1998;101(5):895-902.
7. Austin SB, Ziyadeh N, Fisher LB, Kahn JA, Colditz GA, Frazier AL. Sexual orientation and tobacco use in a cohort study of US adolescent girls and boys. *Arch Pediatr Adolesc Med*. Apr 2004;158(4):317-322.
8. Easton A, Sell R. Analysis of National Longitudinal Study of Adolescent Health. Paper presented at: Gay and Lesbian Medical Association; October 25, 2004, 2004; Palm Springs, CA.
9. Diamant AL, Wold C, Spritzer K, Gelberg L. 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*. Nov-Dec 2000;9(10):1043-1051.
10. Stall RD, Greenwood GL, Acree M, Paul J, Coates TJ. Cigarette smoking among gay and bisexual men. *Am J Public Health*. Dec 1999;89(12):1875-1878.
11. Valanis BG, Bowen DJ, Bassford T, Whitlock E, Charney P, Carter RA. Sexual orientation and health: comparisons in the women's health initiative sample. *Arch Fam Med*. Sep-Oct 2000;9(9):843-853.
12. Case P, Austin SB, Hunter DJ, et al. Sexual orientation, health risk factors, and physical functioning in the Nurses' Health Study II. *J Womens Health (Larchmt)*. Nov 2004;13(9):1033-1047.
13. McCabe SE, Boyd C, Hughes TL, d'Arcy H. Sexual identity and substance use among undergraduate students. *Subst Abus*. Jun 2003;24(2):77-91.
14. McCabe SE, Hughes TL, Boyd CJ. Substance use and misuse: are bisexual women at greater risk? *J Psychoactive Drugs*. Jun 2004;36(2):217-225.
15. Cochran SD, Mays VM, Bowen D, et al. Cancer-related risk indicators and preventive screening behaviors among lesbians and bisexual women. *Am J Public Health*. Apr 2001;91(4):591-597.
16. Gruskin EP, Hart S, Gordon N, Ackerson L. Patterns of cigarette smoking and alcohol use among lesbians and bisexual women enrolled in a large health maintenance organization. *Am J Public Health*. Jun 2001;91(6):976-979.
17. Hughes TL, Jacobson KM. Sexual orientation and women's smoking. *Curr Womens Health Rep*. Jun 2003;3(3):254-261.



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18. Gay and Lesbian Medical Association, LGBT health experts. Healthy People 2010 Companion Document for Lesbian, Gay, Bisexual and Transgender (LGBT) Health. <http://www.glma.org/policy/hp2010/>. 2001(April 12, 2001).
19. Solarz AL, Institute of Medicine (U.S.). Committee on Lesbian Health Research Priorities. *Lesbian health: current assessment and directions for the future*. Washington, D.C.: National Academy Press; 1999.
20. Offen N, Smith EA, Malone RE. Is tobacco a gay issue? Interviews with leaders of the lesbian, gay, bisexual and transgender community. *Culture, Health & Sexuality*. 2008;10(2):143 - 157.
21. Carlini BH, Bush TB, Stewart T, Zbikowski S, Padilla J, S. A. What does this have to do with quitting smoking? Push & Pull Of Asking Sensitive Questions To Callers Seeking Tobacco Treatment Through Quitlines. *NCTOH*. Washington, DC; 2006.
22. Landers S, Conron K, Sell R, R F. Developing Data for Advocacy. *National LGBTI Health Summit*. Philadelphia, PA; 2007.
23. Bailey L. Request to develop a standard optional question for MDS on sexual orientation. Personal communication to: Research and Evaluation Workgroup Members on October 14, 2005. 6. North American Quitline Consortium; 2005.
24. Case P, Austin SB, Hunter DJ, et al. Disclosure of sexual orientation and behavior in the Nurses' Health Study II: results from a pilot study. *J Homosex*. 2006;51(1):13-31.
25. Sell R. Gay Data. www.gaydata.org. Accessed March 15, 2007.
26. Glantz SA. Effect of smokefree bar law on bar revenues in California. *Tobacco Control*. Mar 2000;9(1):111-112.
27. Miller K. *Cognitive Analysis of Sexual Identity, Attraction and Behavior Questions*. Washington, DC: National Center for Health Statistics; 2002 2002.
28. Miller K. Interview on NCHS LGBT data collection & testing strategies. Personal communication to: Scout on January 11, 2007. 2007.
29. Conron K, Scout, Austin SB. "everyone has a right to, like, check their box": Findings on a Gender Identity Question from an Adolescent Cognitive Testing Study. *In progress*. 2007.
30. Scout, Senseman S. Cognitive Testing of an LGBT Surveillance Question: National LGBT Tobacco Control Network; 2008.