



# National L G B T tobacco control network

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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.<sup>1</sup> 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.<sup>2</sup> While population-based studies including questions of sexual orientation or gender identity are relatively rare<sup>3, 4</sup>, 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.<sup>3</sup>
- 2003 California LGBT Tobacco Survey – LGBT men smoked at rates 50% higher than other men, LGBT women almost 200% higher than other women.<sup>4</sup>
- 1997-2004 National Health Interview Survey – same sex partnered men smoked 38% higher than others, same sex partnered women smoked 54% higher than others.<sup>5</sup>

Disturbingly, early evidence showing LGB youth smoke at rates 68% higher than other youth (59% v. 35%)<sup>6</sup> 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.<sup>7</sup>
- 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.<sup>8</sup>

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.<sup>2, 3, 7, 9-17</sup>

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.<sup>18, 19</sup> For example, 37% of respondents in the 2003 California LGBT Tobacco Survey believe that anti-smoking campaigns ignore the LGBT community.<sup>4</sup> 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.<sup>4</sup> UCSF researchers found that only 24% of 75 LGBT community leaders listed tobacco as a top three LGBT health issue.<sup>20</sup> 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.<sup>22-25</sup> 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.<sup>21, 26</sup>

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.<sup>21</sup> 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.”<sup>21</sup> 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.<sup>22</sup> 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.<sup>23</sup> 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.<sup>31-33</sup> 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).<sup>22</sup> 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).<sup>24</sup> 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.”<sup>22</sup>

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.<sup>25</sup> At least thirteen Youth Risk Factor Surveillance (YRBS) surveys include SO questions.<sup>25</sup> 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.<sup>25</sup> 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).<sup>23</sup>

## ***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).<sup>26</sup>

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.<sup>27</sup> 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.<sup>25, 28</sup>

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.<sup>29</sup>

- 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 question<sup>30</sup>**

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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