

Cognitive Testing of an LGBT Surveillance Question

Scout, PhD^{a, b}, Sarah E. Senseman, MPH^c

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Corresponding author:

Scout, Ph.D.

Director, National LGBT Tobacco Control Network

The Fenway Institute

7 Haviland St.

Boston, MA 02115

Email: scoutout@gmail.com

Cell: 401-263-5092

Fax: 401-633-6092

^a Fenway Institute, Fenway Community Health Center, Boston

^b Adjunct Assistant Professor, Boston University School of Public Health

^c Blue Cross and Blue Shield of Minnesota

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INTRODUCTION

Research related to tobacco use in the LGBT community has grown steadily during the past quarter century, with consistent identification of significant disparities. A 2001 review of available literature reported that LGB people smoke at rates 40-60% higher than the general populationⁱ. One California study found smoking rates almost 200% higher among LGBT versus non-LGBT womenⁱⁱ. 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^{iii iv v vi vii viii ix x xi xii xiii xiv xv xvi xvii xviii xix}.

Despite this growing evidence of LGBT health disparities in general and tobacco in particular, few population-based surveys are assessing LGBT identity, making it difficult to quantify health disparities and to measure progress toward Healthy People 2010 goals^{xx,xxi}. Further, measures of sexual orientation and gender identity vary from survey to survey, and consensus has not been reached on the best way to measure these constructs. Sexual orientation is most frequently measured by one or more of the following variables: perceived identity, behavior, and attraction/desire^{xxii xxiii xxiv}. The selection of one or more of these variables for research depends largely on the area of interest^{xxv xxvi xxvii}. For an intervention tailored to individuals who identify as LGBT, for example, a measure of self-identity alone may be appropriate^{xxviii}.

Questions related to sexual orientation are now included on an increasing number of surveys. 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)^{xxix}. Additionally, the following federal surveys include SO measures: National Health and Nutrition Examination Survey^{xxx}; National Survey of Family Growth^{xxxi}; National Epidemiologic Survey on Alcohol and Related Conditions^{xxxii}. Sexual orientation is also considered in other large surveys, including: Women Physician's Health Study^{xxxiii}; Nurses Health Study II^{xxxiv}; Women's Health Initiative^{xxxv}.

These and other efforts have demonstrated that the measurement of sexual orientation for population-based studies is feasible^{xxxvi xxxvii xxxviii xxxix xl xli}. 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^{xlii xliii xliiv}. 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^{xlv}. 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."^{xlvi} 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, and are consistent with non-response rates reported in the Women's Physicians Health Study, Nurses Health Study II, Women's Health Initiative, Dutch National Survey of General Practice, and the Washington and Oregon Behavioral Risk Factor Surveillance System surveys (BRFSS)^{xlvii xlviii xlix¹}. In the 2001 California Health Interview Survey 99% of respondents answered a sexual orientation question^{li}, and in the Washington and Oregon BRFSS surveys, non-response rates for the sexual orientation and income questions were approximately 3% and 12%, respectively^{lii}.

Efforts are needed to standardize questions that can be used in population-based surveys to assess LGBT identity. Cognitive testing is recommended to develop a measure that can accurately assess the sexual orientation of respondents^{liii liv}. 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 also allows the target population to help identify question language that is both meaningful and relevant to them^{lv}. In 2005, LGBT researchers cognitively tested an LGB question for inclusion on surveys. 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 (indicating that caution must be taken when using questions where the exact wording has not been subject to cognitive testing)^{lvi}. Another effort to cognitively test a sexual orientation measure was conducted by Clark et al.(2005). The question that evolved from this work included both sexual orientation and gender identity (transgender), and was almost identical to the question being tested here. We hoped to move that study forward by expanding the cognitive testing beyond their target population of middle-aged women.

The present study developed in response to the needs of one of Minnesota's phone-based stop-smoking programs and the statewide Adult Tobacco Survey (ATS). The phone counseling program was working to better serve the needs of Lesbian, Gay, Bisexual and Transgender (LGBT) individuals and the ATS was the primary measure for assessing tobacco disparities statewide. Advocating for the addition of a single question to these surveys was perceived to be more realistic than the addition of separate sexual orientation and gender identity items. Further, changing the sex (Male/Female) question to include a Transgender option was also perceived to be difficult to achieve, especially as it would impact comparability with years of existing data. Thus, our aim was to identify a single-item question for use in a surveillance or intervention application that could accurately classify someone as belonging to the category of LGBT.

METHODS – OVERALL STUDY

Cognitive interviewing represents the current highest standard for survey question development, allowing the survey designer to understand the interpretive process behind responses. The lead researcher, Dr. Scout, met with Dr. Kristen Miller of the National Center for Health Statistics (NCHS) to ensure the methods used for this project closely followed those used in developing questions for the national level health surveys. A semi-scripted, retrospective narrative and probing protocol was used for this study. With this strategy, the researcher administers the full survey in its entirety, then the participant is asked to describe their thought process during the response to the questions of interest, and the interviewer asks follow-up probe questions. The information gleaned from this process allows the researcher to identify problems in the question design and isolate if they manifest in the comprehension, retrieval, judgment, or response stages of answering.

Researchers initially planned to conduct forty cognitive interviews for this project. Ultimately, 72 were conducted due to significant question design flaws that were uncovered in the first round of testing. This paper will be presented with two findings sections to represent the two-stage process the research followed: 1. initial testing, preliminary findings, question revision; 2. second testing, and final findings.

The question of interest was intended to be used on intake for all Minnesota tobacco quitlines and on the Adult Tobacco Survey. It was felt the quitline was the more restrictive environment to test feasibility since the LGBT question was embedded in an ultra-brief demographic section. This

abbreviated demographic section included only three other questions: one on race, one on ethnicity, and one on socioeconomic status. The existing evidence of feasibility of similar questions within longer surveillance demographic batteries pushed us to test our question in what we considered a more challenging environment, quitline intake.

Sampling Frame

The question being tested was a modification of a sexual-orientation only question that had successfully undergone prior cognitive testing, and was informed by prior limited testing of a combined LGBT identity question (Clark et al. 2005). Transgender respondents were oversampled as we had less evidence of the feasibility of adding a gender-identity modification to the existing question. A breakout of the demographics of each round and the cumulative sample is presented in Table 1. Since the study simulated a tobacco quitline intake, participants were all active smokers. The researchers could not theorize any reason why restricting the sample to smokers would introduce bias to the LGBT question being tested. We further limited the sample to people 18 and older since we did not have IRB capability to address underage consent issues, and as the majority of quitline callers are eighteen and over.

We drew a purposive sample through a variety of promotional techniques. Mainstream population participants were primarily reached through direct solicitation on the street. LGBT participants were reached primarily through word of mouth, supplemented by list-serv promotion, and occasional direct solicitation at high smoking venues, such as cafes or bars. Representatives from many Minneapolis based LGBT and AIDS organizations also assisted in promoting this study. Testing was conducted during May and June of 2007 for the first and second rounds respectively. Participants were led through the informed consent process, administered the mock quitline intake interview, then led people through an in-person narrative description of their response experience, probing as appropriate. After this was completed, each participant filled out a longer demographic profile (pulled from the Adult Tobacco Survey) and was given a \$50 gift card as compensation for his/her time. The quitline intake lasted approximately 5-10 minutes; the full interview lasted between 30-60 minutes. We used standard human subjects confidentiality procedures to safeguard all data, including using locked filebags and physically separating all identity information from the data after assigning linking codes. IRB approval and oversight were handled by the standing IRB at Fenway Community Health.

Analysis

Analysis was conducted from transcribed interviews, with interviewer notes as a source of additional context. The constant comparative method was employed, using NVIVO software, to assess themes related to participants' interpretation of the question, emotional responses, and any confusion related to question meaning. Specific nodes were created for each findings category discussed in this paper.

QUESTION DESIGN -- FIRST ROUND

At the end of the quitline intake is a brief demographic battery. We present the full battery of questions in Table 2, as their context relates to the research findings to follow. Text in italics is intended to be read directly by the quitline staff.

Table 2. Initial script and question

12) Demographic Questions:

Tobacco use and quit line use may differ depending on factors such as a person’s age, race, ethnicity, education level or sexual orientation. We are collecting this kind of information to help make sure we are reaching all members with our services. Please remember that your answers are strictly confidential.

- *Are you Hispanic or Latino?*
- *How do other people usually classify you in this country?
Would you say White, Black or African American, Native Hawaiian or other Pacific Islander, American Indian or Alaska Native, or some other group?*
- *What is the highest level of education you have completed?*

13) Sexual Orientation question:

The following question is personal in nature. This question relates to sexual orientation. Do you consider yourself to be:
(say the letter so that they can respond by letter)

- A) *Heterosexual or straight*
- B) *Gay or Lesbian*
- C) *Bisexual*
- D) *Transgender* **IF D, also ask** *Do you also consider yourself to be*
 - A. *heterosexual or straight*
 - B. *gay or lesbian*
 - C. *bisexual*

Notes for phone counseling staff:

If respondents need clarification on the lettered choices above, use the following definitions:

Straight or heterosexual: have sex with, or are primarily attracted to people of the opposite sex

Gay or Lesbian: have sex with, or are primarily attracted to people of the same sex

Bisexual: have sex with or are attracted to people of both sexes

Transgender: some people describe themselves as transgender when they experience a different gender identity from their sex at birth.

For example, a person born into a male body, but who feels female and lives as a woman. Some transgender people change their physical appearance so that it matches their internal gender identity. Some transgender people take hormones and some have surgery. A transgender person may be of any sexual orientation – straight, gay, lesbian, or bisexual.

FINDINGS – FIRST ROUND OF TESTING

Problems with demographic preface language

Early into the first round of testing it became clear that people were having problems understanding why a question on sexual orientation/gender identity might be in this brief demographic battery. While the concern was not enough to prompt any breakoff or non-response, 16 of 33 cases brought up some level of query about the question in their follow-up narrative:

“Ah, just wondering how that would help at all, or help me quit.” Case A01

“Why – why is that important to the survey?” Case A02

“I don’t know, it just kinda caught me off guard, ‘cause like what does your sexuality has to do with you tryin’ to quit smoking tobacco?” Case A16

As this theme emerged, we started to probe with the respondents to see why the preface language of the demographic section did not ameliorate their concerns. For some the preface language was too vague to answer their concern of inclusion:

“I, um, yeah, I get the sense that I definitely remember race and sexual orientation at some point being brought up, but it wasn’t something that... I think even there I probably had a question why – why the issue of sexual orientation, you know. And in fact, I would still have that question.” Case A07

For more the preface was not really memorable enough to stay in their brain several questions later.

“I guess I really didn’t – didn’t think about those – the opening statement because if – I guess if I had, you know, you stating that your age race, gender, and sexual orientation may differ in your ability to quit, uh, I probably would’ve stopped for a second and been like, “what do you mean, you’re telling me that if I’m gay, it’s going to be harder to quit, or that’s a possibility, or what are you saying?” Uh, if I was black, is there a chance that I need to call a different line?”
Case A08

Problems with question preface language

The second preface sentence was also problematic. Some participants became unnecessarily alarmed by the warning language. Others were confused that the question was presented as relating to sexual orientation, but then included a gender identity response option.

“I think that it’s great to include if there’s a reason, but – but just saying warning and then going right on I think puts people on edge and makes them less comfortable answering the question, but if you say – if you give a reason for the warning, like, so either include a caveat like “you can opt out,” or “here’s why we need this information, like here’s how it’s gonna benefit your care,” or just leave it out.” Case A21

“I think when it said, like, this is, whatever, personal in nature, I was like, what? I just got really, like, really? Like I didn’t understand what – like I know it’s like personal, but like it kinda like scared me kind of in a way, you know. [Interviewer: “You didn’t know what was coming next?”] “Yeah” Case A22

“I – I think that’s a totally ridiculous question. Um, because – but also the question was framed – um, I believe you said – or, you – you framed it as a sexual orientation question.” Case A21

“Well, that question, I – I had a bit of a response because I was thinking, okay, if this company has really done their research, why would they include gender identity in with sexual orientation? Um, it just felt like (pause) you know, I mean, they kind of scratched the surface, but didn’t really dig.” Case A24

Response option problems

To add to the confusion of the current question design, two respondents misunderstood the word heterosexual to mean homosexual.

“Why do you ask, do I look heterosexual?... I hope not.” [Interviewer: “You don’t want to look heterosexual?”] “No. That’s not the look I’m goin’ for.” [Interviewer: “When you said “heterosexual” – you mean you don’t wanna look homosexual, or you don’t wanna look hetero?”] “Uh, well....” [Interviewer “You wanna look straight?”] “I do look straight, yeah, yeah, yeah.” Case A15.

“It was just going through my head, I’m not heterosexual you know. I’m straight.” Case A17

Further, three of the sixteen respondents identified via LGBT community outreach had significant problems with the question wording. Two brought up the very real need for some way to indicate their identity was “queer”, while the third was unable to pick a single answer for a multidimensional question.

“Um, well, the first thing that was – came to mind, or well, yesterday and today when I called, um, is that there’s no queer on the uh, on the list. Um, ‘cause I actually do identify as queer, um, but, you know, bisexual would be the, uh, other term. Uh, so that’s definitely what I noticed first.” Case A05

[Interviewer: The following question is personal in nature. This question relates to sexual orientation. Do you consider yourself to be: A heterosexual or straight, B gay or lesbian, C bisexual, D transgender?] “Um, I don’t identify as any of those. Is there an “other” option?” [Interviewer: If there was, what would you say?] “Um, queer.” Case A06

After approximately 20 interviews, the decision was made to revise the preface and question language and conduct a second round of testing. In the remaining interviews, if people showed problems in any of the above areas, we tested alternate language options that had emerged from previous interviews..

ENHANCED QUESTION DESIGN – SECOND ROUND

Our goals with the enhanced question were as follows:

1. create a memorable and explanatory preface for all demographic questions
2. eliminate the alarmist preface before the sexual orientation/gender identity question
3. create a question where the dual dimensions were acknowledged through multiple choice options
4. offer an Other category for those who use additional LGBT identity labels

In addition, we also shortened the cumbersome definition of transgender, replacing it with a version of the most common definition participants gave us for the word. The revised question text is as follows.

Table 3. Revised script and question

12) Demographic Questions:

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.

- *Are you Hispanic or Latino?*
- *How do other people usually classify you in this country?
Would you say White, Black or African American, Native Hawaiian or other Pacific Islander, American Indian or Alaska Native, or some other group?*
- *What is the highest level of education you have completed?*
- *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: _____

Notes for phone counseling staff:

If respondents need clarification on the lettered choices above, use the following definitions:

Straight: have sex with, or are primarily attracted to people of the opposite sex

Gay or Lesbian: have sex with, or are primarily attracted to people of the same sex

Bisexual: have sex with or are attracted to people of both sexes

Transgender: While many gender variant people might identify as transgender, one familiar type of transgender person is a man who has a sex change to become a woman.

FINDINGS – SECOND ROUND OF TESTING

Testing Successful

After revisions, all participants were able to respond. Very few demonstrated any noticeable hesitation after being asked the question, and on probing, this was usually attributable to the decision-making process to choose the answer. No person was misclassified between the straight and LGBT categories and LGBT people were 100% correctly classified into the categories with which they identified. Thus the main goals of the test were achieved and the question is recommended for use on similar surveillance instruments. Some notes related to issues of interest are presented below.

Demographic preface language reduced concerns

The enhanced demographic introductory language resulted in fewer concerns over the inclusion of this question among this ultra-brief demographic battery.

“No I was wondering like why that would matter, but like I said, I mean, then I remembered you saying, talking about different communities, so, it makes sense.” Case B02

Sometimes the introductory language provoked further thinking about the issue.

“Um, well, I was mostly wondering how that would factor into the demographic that is, uh like, as a targeted demographic. Although I guess, um, I did go to school for graphic design, so in my head I’m thinking well, Camel ads, Marlboro ads are very much, like, targeted towards straight people.” Case B07

Sexual Orientation and Gender Identity Overlap

While LGBT were 100% correctly classified into their identity categories, only fifty percent (4) of the second round transgender respondents designated both a sexual orientation and gender identity response. In the words of one respondent, he chose to answer based on gender identity because that is the identity label he uses most:

[Interviewer: ...why did you pick the gender identity to answer instead of the sexual orientation?] “Just ‘cause that – I mean, I think with – with the question just asking where I’m gonna identify, if I do with any of these groups, and that – that would be where I identify most of the time” Case B33.

As is not uncommon with transgender people, asking about sexual orientation is complicated and sometimes confusing. The above participant guardedly admitted that he sometimes uses “straight” or “bisexual” to represent his sexual orientation, but perhaps because it’s complicated, he most often just says that he’s “queer.” Another respondent reflects this same inability to clearly separate sexual orientation and gender identity on a personal level, being very clear *“I don’t consider myself straight, I don’t consider myself gay, I don’t consider myself bisexual, I’m just straight transgendered.” Case B23.*

For another transgender respondent, it was society’s perceived negative response that held her back from selecting the “straight” category in addition to “transgender”: *“I do consider myself straight, but sometimes society might not see it that way. You know, they’ll probably deal with me labeling myself as a transgender more than a straight woman now that I had the surgery.” Case B18.* As trainers we constantly present on how every person has a distinct sexual orientation and gender identity, while this is true, our evidence shows it is less common for people to have distinct identity labels for both metrics.

Comprehension of word ‘transgender’

In the two rounds of testing, 34 participants were recruited through direct street solicitations, we were particularly interested in the understanding of the terminology used in the question by these ‘mainstream’ respondents. Of these 34 participants, almost all said they had an LGBT person in their lives, either as friends, family or co-worker. All people claimed familiarity with the LGB terminology, although the two from round one were confused about the meaning of ‘heterosexual’. When asked to try to define transgender, 23 of the 34 respondents provided definitions encompassing at least some aspect of transgender. Another three gave a definition concurrent with intersex or disorders of sexual development conditions. Importantly, eight were substantively confused about the word. This is a risk that threatens the accuracy of small population data collection. If any of this group accidentally answers transgender on a population-wide survey, it is more than enough to discredit the desired transgender data with response error. But none of these

respondents did answer transgender and not one of them expressed any concern or confusion about the label they did not understand. Respondent B28 was an interesting example of this phenomenon. He identified as straight without pause, then later said the LGBT terms were clear to him, but upon probing, he admitted he had no idea what transgender meant. Yet this did not shake his confidence in his correct answer at all, he was emphatic that he had the correct response, because he heard his correct category early and then just wasn't concerned about a later word he had never heard of before.

Mainstream respondents disclosures

Presumably, some of the respondents recruited through mainstream methods might also disclose as being LGBT. Across both rounds of testing five of the 34 (15%) mainstream respondents disclosed, in each case they identified as bisexual.

Use of “Other” category

In the first round of testing, three of the 16 LGBT targeted respondents balked at responding to the fixed categories, either giving a different response, or asking for additional options. In round two of testing, the Other category was added. It did not lengthen the verbal administration of the survey, since administrator directions said only to add “You can name another category if that fits you better” upon respondent pause or refusal. Two of the 22 LGBT respondents used this option, like in round one, this choice reflected resistance to the perceived conservative associations with the chosen terminology. Case B35 typifies this thinking, they originally chose transgender, but upon being offered the other category changed to “Queer and genderqueer”. When asked to describe the process, they say... *“I’m definitely not straight. Gay and lesbian implies . . . less radical politics than I have. I’m not bisexual. And I don’t totally identify as being trans, and I don’t have any interest in starting hormones. Um, but trans would be the closest of those choices.”* When asked what difference it made to have the Other category, they say, *“That it’s actually honest... It’s something that actually fits.”* Case B35. All five of the respondents who used the Other category replied with either genderqueer or queer as their identity labels.

No concerns over confidentiality

Data confidentiality was not brought up as a concern by any of the participants. Nine times in the first round of interviews a probe question was asked on confidentiality, each time the respondents expressed no concerns on this subject.

DISCUSSION

The researchers entered into this study unsure if we could meet the goals of developing a single-pass question that could capture the dual dimensions of sexual orientation and gender identity. Since the early 1990s when the word transgender was first coined, there has been much excellent work on the distinction between those two identity categories. But this distinction can sometimes be used to create an artificial divide between overlapping populations. It is a common phenomenon in the LGBT communities for people to identify as gay, lesbian or queer at one stage in their lives and transgender in another. This may indicate that these individuals have not changed per se, but rather

that the identity labels are more fluid than absolute. The common use of a single acronym for both groups itself speaks to the intertwining of these identities. The increased usage of ‘queer’ or ‘genderqueer’ as an appellation by people who refuse the traditional further distinctions of lesbian, gay, or bisexual is another sign of the limitations of a question that artificially splits LGB and T into two identity categories. In fact, earlier researchers using cognitive testing to develop a sexual orientation question were pushed by their respondents to expand the question to one inclusive of gender identity, one almost identical to the question tested here (Clark et al. 2005). Perhaps most relevant, when we capture LGBT identity labels to help us assess health disparities, we are generally using them as a rough proxy for the discrimination or social exclusion that is the true generator of the disparities. Discrimination arises more from the perception of non-conformity due to an individual’s appearance, actions, and words, rather than the label she or he uses to identify him or herself.

Considering these thoughts, the prior evidence, and our significant experience in the LGB *and* transgender communities, we hypothesized it was potentially valuable to test a question that allowed for answers on two dimensions, sexual orientation and gender identity. Since the question is multiple response, it is actually several questions embedded in a convenient package, because multiple response questions are coded “yes/no” to each response option. To our pleasure, the question was successful for the very limited circumstances it was created to address; surveillance applications. Further, the interviews with the transgender and genderqueer respondents reinforced the difficulty of discretely separating sexual orientation and gender identity labels. Transgender people have a wealth of demonstrated health disparities. Existing sexual orientation-only questions unnecessarily bundle this part of an overlapping population into the mainstream category, which among other things dilutes the measurement of discrimination and social exclusion that is the purpose of the question. Perhaps in future work we will move beyond identity labels altogether and create a measure of perception of difference. Interestingly, the race question on the Minnesota quitline intake models this move beyond identity label to a measure of perception, asking, “How do other people usually classify you in this country? Would you say White, Black or African American, native Hawaiian or other Pacific Islander, American Indian or Alaskan Native, or some other group?”

One strength of the tested LGBT question was the ability for LGB to act as a type of firewall that stops casual respondents from accidentally checking the transgender category, *even if they do not understand the definition of transgender*. In any measurement of small populations, the greatest challenge is ensuring that the large population group is not confused, because even small response error on their part can dilute the small population data to the point of uselessness. In order to not unwittingly invite response error on a gender identity question, we have to somehow convey the opposite of transgender to the many mainstream people who may have never even heard of the word or thought about the concept. In our estimation, no easy converse phrase or words exist. The New York State Department of Health once asked if people were transgender on a surveillance instrument. However, they will not release the data because they suspect the unusually high response rate for the “transgender” category was simply response error. Thus, the bundling of LGBT together into one question has a great strength, keeping non-LGBT clear on their response category.

In discussions with transgender advocates, there has been resistance to this question for another reason, that it is not specific enough to capture the vector of transgender people (for example male-to-female versus female-to-male), or identity divisions within the population. It would certainly be an enhancement to this question to add additional categories that might capture gender vector and we heartily recommend they be tested. But it is also a reality that even with full-

population data, there is very rarely the ability to obtain statistical significance from this level of subdivision. So we recognize that this question is a blunt tool, and as such it should not be used on any community-level data collection. But for population surveys with limited flexibility to add multiple questions, this single-pass question at least offers an option that includes the range of LGBT populations.

An unprecedented number of states and quitlines are adding LGBT measurement questions to their surveillance instruments, discussions are afoot for key federal measures to follow suit. The scientific evidence for this population has provided ample justification for this effort, demonstrating that we can no longer afford to ignore LGBT people through omission. Too often, however, the questions that are added to survey instruments have not been thoroughly tested. Our experience with this project, where slight variations in wording resulted in markedly different responses, demonstrates the need to carefully consider the questions being added to surveillance instruments, and if at all possible, add a thoroughly tested question.

Table 1: Demographic summary of respondents in total and for each version of the instrument

	<u>Version 1</u> (n=33)	<u>Version 2</u> (n=39)	<u>Total (%)</u> (N=72)
<u>Age</u>			
<=24	15	9	24 (33%)
25-34	8	15	23 (32%)
35-44	5	9	14 (19%)
45-64	5	6	11 (15%)
<u>Gender</u>			
Female, non-transgender	7	14	21 (29%)
Male, non-transgender	17	15	32 (44%)
Transgender	7	8	15 (21%)
None of the above	2	2	4 (5%)
<u>Sexual Orientation</u>			
Straight	15	16	31 (43%)
Lesbian or Gay	7	12	19 (26%)
Bisexual	7	5	12 (17%)
Not specified or other	4	6	10 (14%)
<u>Race</u>			
NH-White	20	23	43 (60%)
NH-Black	12	16	28 (39%)
Asian	1	3	4 (6%)
Pacific Islander	4	2	6 (8%)
American Indian	4	6	10 (14%)
Other	3	1	4 (6%)
<u>Ethnicity</u>			
Hispanic	4	2	6 (8%)
Non-Hispanic	29	37	66 (92%)
<u>Education</u>			
HS or less	18	11	29 (40%)
More than HS	15	28	43 (60%)
<u>Income</u>			
Under 20,000	13	13	26 (36%)
20,000 & Over	20	26	46 (64%)

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