LGBT Data Collection Overview

May 10, 2016

Scout, Ph.D.
Director, LGBT HealthLink at CenterLink

Amy V. Lukowski, Psy.D.
Clinical Director
National Jewish Health
June 21, 2011 at 8:18 pm EST | by Chris Johnson

Sebelius promises to collect LGBT data in health surveys

Secretary of Health & Human Services Kathleen Sebelius (Blade file photo by Michael Kay)

Secretary of Health & Human Services Kathleen Sebelius committed on Tuesday to start the collection of LGBT data as part of federal health surveys, although she said the questions that would be used to gather the information must be market-tested before they’re made part of any questionnaire.
Design, Development and Testing of the NHIS Sexual Identity Question

Kristen Miller
J. Michael Ryan
Questionnaire Design Research Laboratory, Office of Research and Methodology,
National Center for Health Statistics
October 2011
Do you think of yourself as:

[For men:] Gay
[For men:] Straight, that is, not gay
[Bisexual]
[For women:] Lesbian or gay
[For women:] Straight, that is, not lesbian or gay

Something Else (Go to A)
Don’t Know (Go to B)
A. **[If ‘something else’ is selected]** By *something else*, do you mean that...
   You are not straight, but identify with another label such as queer, trisexual, omnisexual or pan-sexual
   You are transgender, transsexual or gender variant
   You have not figured out your sexuality or are in the process of figuring it out
   You do not think of yourself as having sexuality
   You do not use labels to identify yourself
   You made a mistake and did not mean to pick this answer
   You mean something else (Go to C)

B. **[If ‘don’t know’ is selected]** You did not enter an answer for the question. That is because you:
   You don’t understand the words
   You understand the words, but you have not figured out your sexuality or are in the process of figuring it out
   You mean something else

C. **[If ‘you mean something else’ is selected]**
   What do you mean by something else? Please type in your answer
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   You made a mistake and did not mean to pick this answer
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B. [If 'don't know' is selected] You did not enter an answer for the question. That is because you:
   You don’t understand the words
   You understand the words, but you have not figured out your sexuality or are in the process of figuring it out
   You mean something else

C. [If 'you mean something else' is selected]
   What do you mean by something else? Please type in your answer
Transgender, transsexual, or gender variant

Eliminated after 1st year
Special Report: 3.4% of U.S. Adults Identify as LGBT

by Gary J. Gates and Frank Newport

Inaugural Gallup findings based on more than 120,000 interviews
PRINCETON, NJ -- The inaugural results of a new Gallup question -- posed to more than 120,000 U.S. adults thus far -- shows that 3.4% say "yes" when asked if they identify as lesbian, gay, bisexual, or transgender.

Do you, personally, identify as lesbian, gay, bisexual, or transgender?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>DK/Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Americans</td>
<td>3.4%</td>
<td>92.2%</td>
<td>4.4%</td>
</tr>
</tbody>
</table>

Gallup Daily tracking
June 1-Sept. 30, 2012

GALLUP

Gallup chose the broad measure of personal identification as LGBT because this grouping of four statuses is commonly used in current American discourse, and as a result has important cultural and political significance. One obvious limitation of this approach is that it is not possible to separately consider differences among lesbians, gay men, bisexuals, or transgender individuals. A second limitation is that this approach measures broad self-identity, and does not measure sexual or other behavior, either past or present.
BEST PRACTICES FOR ASKING QUESTIONS TO IDENTIFY TRANSGENDER AND OTHER GENDER MINORITY RESPONDENTS ON POPULATION-BASED SURVEYS

Created by the Gender Identity in U.S. Surveillance (GenIUS) group, a multi-disciplinary and multi-institutional collaboration
2014

Option 3:
2+ measures
LGB + (1 or 2-step T)

3 recommendations for T data collection

RECOMMENDED MEASURES FOR THE "TWO-STEP" APPROACH:

ASSIGNED SEX AT BIRTH
What sex were you assigned at birth, on your original birth certificate?
- Male
- Female

CURRENT GENDER IDENTITY
How do you describe yourself? (check one)
- Male
- Female
- Transgender
- Do not identify as female, male, or transgender

RECOMMENDED MEASURE FOR SINGLE-ITEM TRANSGENDER/CISGENDER STATUS APPROACH:

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 or lives as a woman. Do you consider yourself to be transgender?

- Yes, transgender, male to female
- Yes, transgender, female to male
- Yes, transgender, gender non-conforming
- No
Overview

Option 1: Single measure sexual identity

T data missing

On NHIS + spreading across HHS
Overview

Option 1: Single measure sexual identity

T data missing

On NHIS + spreading across HHS

Option 2
Single Yes/No LGBT measure

T data
No breakout options

On largest sample Gallup n=120k
Overview

Option 1
Single measure sexual identity

Option 2
Single Yes/No LGBT measure

Option 3
2+ measures: LGB + (1 or 2-step T)

T data missing

T data
No breakout options

T data
Breakout More landscape

On NHIS

On largest sample Gallup n=120k

On CDC HIV Case Reporting + MA BRFSS
### 2014 BRFSS Survey Data and Documentation

#### Description: Do you consider yourself to be:  
(We ask this question in order to better understand the health and health care needs of people with different sexual orientations.)

<table>
<thead>
<tr>
<th>Value</th>
<th>Value Label</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Weighted Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Straight</td>
<td>145,142</td>
<td>94.72</td>
<td>93.50</td>
</tr>
<tr>
<td>2</td>
<td>Lesbian or gay</td>
<td>1,987</td>
<td>1.23</td>
<td>1.45</td>
</tr>
<tr>
<td>3</td>
<td>Bisexual</td>
<td>1,978</td>
<td>1.29</td>
<td>1.81</td>
</tr>
<tr>
<td>4</td>
<td>Other</td>
<td>462</td>
<td>0.30</td>
<td>0.39</td>
</tr>
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#### Description: Do you consider yourself to be transgender?  
(If yes, ask "Do you consider yourself to be male-to-female, female-to-male, or gender non-conforming?)

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<tbody>
<tr>
<td>1</td>
<td>Yes, Transgender, male-to-female</td>
<td>363</td>
<td>0.24</td>
<td>0.27</td>
</tr>
<tr>
<td>2</td>
<td>Yes, Transgender, female to male</td>
<td>212</td>
<td>0.14</td>
<td>0.16</td>
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<tr>
<td>3</td>
<td>Yes, Transgender, gender nonconforming</td>
<td>116</td>
<td>0.08</td>
<td>0.09</td>
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<tr>
<td>4</td>
<td>No</td>
<td>150,765</td>
<td>97.86</td>
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Past testing problems raised concerns about this construct. Thus Williams Institute does not recommend it & it’s only “one to watch”.

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The mysterious case of the vanishing bisexuals on NHIS.

Health survey gives government its first large-scale data on gay, bisexual population

Less than 3 percent of the U.S. population identify themselves as gay, lesbian or bisexual, the Centers for Disease Control and Prevention reported Tuesday in the first large-scale government survey measuring Americans’ sexual orientation.

By Sandhya Somashekhar  July 15, 2014  Follow @sandhyawp
Gay-rights groups dispute federal survey’s estimate of population

By Sandhya Somashekhar August 1, 2014 Follow @sandhyawp

Gay-rights activists are distressed over the results of the first large-scale federal survey measuring sexual orientation in the United States, in which it reported in July that less than 3 percent of the population identifies as gay, lesbian or bisexual.

For example, the 2013 National Adult Tobacco Survey, a larger but less prominent CDC study, interviewed respondents exclusively over the phone. The results more resembled what gay-rights groups had expected. It found that 3.5 percent of Americans considered themselves gay, lesbian or bisexual, with 1.9 percent labeling themselves gay or lesbian and 1.6 percent identifying as bisexual.

Vanishing bisexuals found! National Adult Tobacco Survey used same measure as NHIS but conducted survey by phone v. in person. Voila! Bisexuals reappeared.
SIDEBAR 2

Current Tobacco Use Among Adults in the United States: Findings From the National Adult Tobacco Survey

Brian A. King, PhD, MPH, Shanta R. Dube, PhD, MPH, and Michael A. Tynan, BA

ABSTRACT

Objectives. We assessed the prevalence and sociodemographic correlates of tobacco use among US adults.

Methods. We used data from the 2009–2010 National Adult Tobacco Survey, a national landline and cell phone survey of adults aged 18 years and older, to estimate current use of any tobacco; cigarettes; cigars, cigarillos, or small cigars; chewing tobacco, snuff, or dip; water pipes; snus; and pipes. We stratified estimates by gender, age, race/ethnicity, education, income, sexual orientation, and US state.

Results. National prevalence of current use was 25.2% for any tobacco; 19.5% for cigarettes; 6.6% for cigars, cigarillos, or small cigars; 3.4% for chewing tobacco, snuff, or dip; 1.4% for water pipes; 1.4% for snus; and 1.1% for pipes. Tobacco use was highest among respondents who were male, younger, of non-Hispanic “other” race/ethnicity, less educated, less wealthy, and lesbian, gay, bisexual, or transgender. Prevalence ranged from 14.1% (Utah) to 37.4% (Kentucky).

Conclusions. Tobacco use varies by geography and sociodemographic factors, but remains prevalent among US adults. Evidence-based prevention strategies are needed to decrease tobacco use and the health and economic burden of tobacco-related diseases.

The mysterious case of the vanishing transgender people on NATS

2012

LGBT tobacco use reported. 50% higher smoking rates.
Research Article
Tobacco Product Use Among Sexual Minority Adults: Findings From the 2012–2013 National Adult Tobacco Survey

Sarah E. Johnson, PhD¹, Enver Holder-Hayes, MPH¹, Greta K. Tessman, MA¹, Brian A. King, PhD, MPH², Tesfa Alexander, PhD³, Xiaquan Zhao, PhD³,⁴

Methods
Data from the 2012–2013 National Adult Tobacco Survey, a random-digit dialed landline and cellular telephone survey of U.S. adults aged ≥18 years, were analyzed in 2014. A sexual minority category was created by combining gay, lesbian, and bisexual responses, along with those who selected an option for other non-heterosexual identities.

2015
Vanishing transgender people stay lost!
LGB only tobacco use reported. 50% higher smoking rates.
Or...

Option 4
LGBT Identity + probe

T data
Breakout
Less landscape

In use by 15 state quit lines
Field tested 33k times
Cognitive Testing of an LGBT Surveillance Question

Scout, PhD a, b, Sarah E. Senseman, MPH

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Email: scoutout@gmail.com
Cell: 401-263-5092
Fax: 401-633-6092

LGBT measure

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

- Straight
- Gay or lesbian
- Bisexual
- Transgender

[If pause or refusal you can add the following]
You can name a different category if that fits you better: ___________________________

2008

Testing commissioned by Blue Cross Blue Shield of Minnesota, for use in two applications: state tobacco quitline and state surveillance instruments.
• 4 days training all tobacco quitline counselors
• They had administered the existing LGBT measure 100k times
• Feedback about how the current measure was cumbersome – especially for people who were upset by being asked
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• Feedback about how the current measure was cumbersome – especially for people who were upset by being asked

National Jewish offered free field testing for an enhanced LGBT measure.

Option 4: LGBT Identity + probe
• Webinar presenting the enhanced measure
• Solicited feedback from participants
• Allowed feedback from others over next 3 weeks
• Solicited additional feedback from gender identity survey experts
• Modified measure as a result
Enhanced LGBT Measure As Tested

Across your lifetime, do you consider yourself to be gay, lesbian, bisexual, and/or transgender?
- No
- Yes

[If No continue. If Yes, probe with the following question.]
[If callers show concern about this question, feel free to add the following sentence:] "LGBT people smoke at higher rates than others; we ask this to ensure we're serving all people equally."

Thanks, indicate all of the following which apply to you:
- Bisexual,
- Gay or
- [for a woman] Lesbian,
- Queer,
- Transgender or gender variant and assigned male at birth,
- Transgender or gender variant and assigned female at birth.

*All square brackets indicate instructions to survey administrators, this is not information that is to be read aloud.
Testing results
• 33k administrations
• 5% yield
• The measure was gauged to be easier to administer by 79% of intake staff
• Easier to answer for LGBT respondents by 74% of intake staff, and
• Less disruptive to people uncomfortable with the topic by 74% of intake staff
2016

Testing results
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## Overview

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</tr>
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<td>T data</td>
<td>T data</td>
<td>T data</td>
</tr>
<tr>
<td>No breakout options</td>
<td>Breakout</td>
<td>Breakout</td>
<td>Breakout</td>
</tr>
<tr>
<td>More landscape</td>
<td>Less landscape</td>
<td></td>
<td></td>
</tr>
<tr>
<td>On NHIS</td>
<td>On largest sample Gallup n=120k</td>
<td>On CDC HIV Case Reporting + MA BRFSS</td>
<td>Used by 11 state quitlines Field tested 33k times</td>
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