



Routine LGBT Data Collection: Impetus, Strategies, Challenges & Value.

North American Quitline
Consortium August 13, 2012



Scout, Ph.D.

Director, Network for LGBT Health Equity
at The Fenway Institute
Boston, MA



Network for LGBT Health Equity

The Network for LGBT Health Equity is a community-driven network of advocates and professionals enhancing LGBT health by countering tobacco use, and enhancing diet and exercise. We are one of six CDC-funded tobacco disparity networks and a project of The Fenway Institute in Boston. We advance these issues primarily by linking people and information to advocate for policy change. We actively monitor national and state health policymakers and urge community action when there is an opportunity to enhance LGBT wellness.



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Impetus: Federal Trends

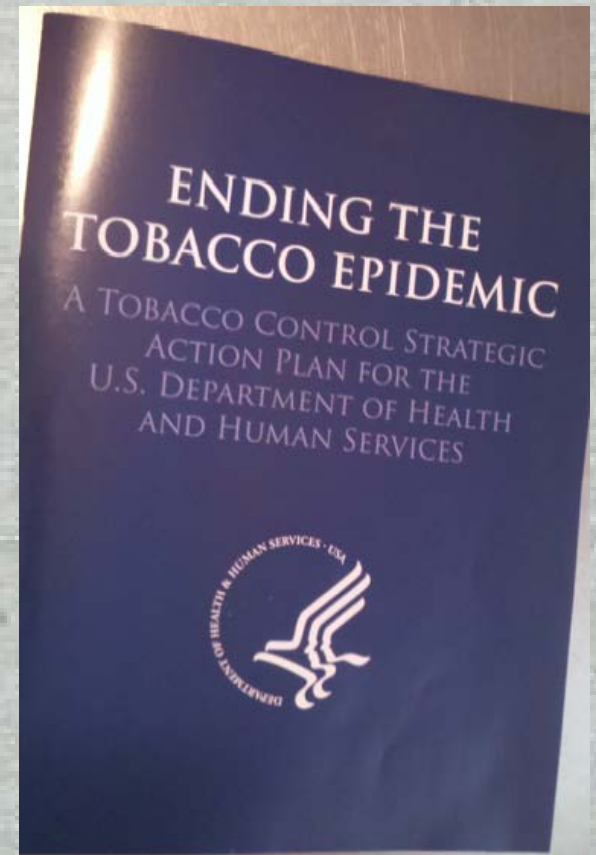
A series of recent policy documents capture the newly enhanced commitment to LGBT inclusion and data collection broadly across public health activities.



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HHS Tobacco Action Plan

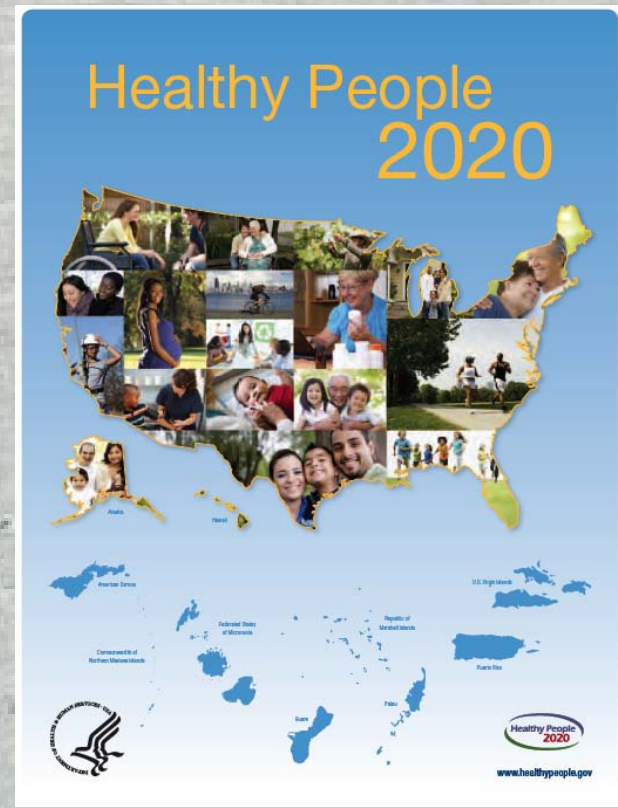
- “Available evidence also reports very high smoking rates among lesbian, gay, bisexual and transgender populations; however these populations remain underrepresented in current surveillance systems used to monitor tobacco use.”
- Read more here: [HHS Tobacco Strategic Plan Launch: Eyewitness Account & LGBT Inclusion Details](#)





Healthy People 2020

- Overarching goal: “Achieve health equity, eliminate disparities.”
- Disparities/inequity to be assessed by: Race/ethnicity, Gender, Socioeconomic status, Disability status, *Lesbian, gay, bisexual, and transgender status*, Geography
- New LGBT Topic Area
- Read more: [Healthy People 2020 Launches Today! Historic](#)





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HP2020 New LGBT Objective

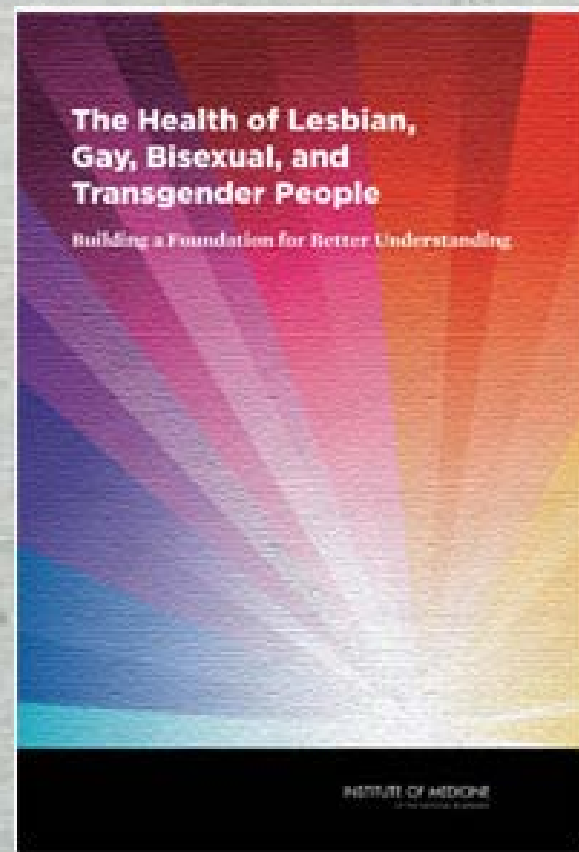
- **LGBT-1 (Developmental)** Increase the number of population-based data systems used to monitor Healthy People 2020 objectives that include in their core a standardized set of questions that identify lesbian, gay, bisexual, and transgender (LGBT) populations.
 - **LGBT 1.1 (Developmental)** Increase the number of population-based data systems used to monitor Healthy People 2020 objectives that include in their core a standardized set of questions that identify lesbian, gay, and bisexual populations.
 - **LGBT 1.2 (Developmental)** Increase the number of population-based data systems used to monitor Healthy People 2020 objectives that include in their core a standardized set of questions that identify



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IOM Report

- Historic review of LGBT health disparities
- Calls for data collection, cultural competency, & additional research.
- Read more: [Is This The Biggest 48 Hrs Ever for LGBT Health? & Why the IOM report is a healthy change for LGBTs: Op-Ed on IOM Report on LGBT Health](#)





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National Partnership for Action: Plan to Eliminate Health Disparities

- Large OMH-driven initiative
- Moved to including LGBT throughout

Read more: [2nd Action Alert Win! Nat'l Health Equity Plan adds Trans Folk & Enhances LGB Inclusion](#)



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SAMHSA Strategic Plan

1. Integrates LGBT throughout
2. Significant agency focus on trans, suicide esp.
3. They released RFA that echoed one of our asks: ask for LGBT disparity plans in the scored section of the proposals.
4. Read more: [**SAMHSA Scores A+ on Including LGBT Population in New Strategic Plan!**](#)



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CDC 1st Disparities Report

- Strong section in opening about need to add LGBT measures to surveys
- Highlights disparities for tobacco and suicide, but lists lack of data for each.
- Read more: [CDC Releases Historic Disparities Report: News on LGBT Health? No Data.](#)
- [Action Alert: Letter to CDC to Include LGBTs in Data Collection!](#)



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National Prevention Strategy

- Created from ACA
- The product of the new cross-governmental uber-health group, comprised of directors EPA, DOL, DOJ, HHS...
- First time feds have taken new health initiatives past HHS boundaries
- Read more:
- [**Together We Can Build a Healthier Nation: America's Plan for Health and Wellness**](#)



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National Prevention Strategy

- *“Pillar 4. Eliminate Health Disparities: Eliminate disparities in traditionally underserved populations to improve the quality of life for all Americans. Some groups are disproportionately affected by health risks including major disorders such as heart disease, obesity, diabetes, HIV/AIDS, or viral hepatitis; high rates of infant mortality; and high rates of violence. Disparities often occur under conditions of social, economic, and environmental disadvantage. All Americans should have access to opportunities for healthy living and be supported in their efforts to make choices that promote long, healthy, and productive lives, regardless of race or ethnicity; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; **sexual orientation or gender***



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HHS Action Plan

- Secretary Sebelius outlines range of coming LGBT health enhancements at <http://1.usa.gov/kfS5yP>.
- Read more: [Is This The Biggest 48 Hours Ever for LGBT Health? Part 2: HHS Recommendations to Improve the Health of LGBT Communities](#)

“Our goal is for all Americans to live healthier, more prosperous, and more productive lives.”

- Secretary Kathleen Sebelius



Photos by Chris Smith

U.S. Department of Health and Human Services Recommended Actions to Improve the Health and Well-Being of Lesbian, Gay, Bisexual, and Transgender Communities



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LGBT Data Collection

- Feds commit to adding LGBT measures to NHIS
- Worked with OMH & Sebelius office on community rollout.
- #1 request to date, cost est. \$5M
- **FOR IMMEDIATE RELEASE: FENWAY HEALTH STATEMENT RE: HHS LGBT DATA COLLECTION**



LGBT Data Collection

- 25+ news stories on this, many in mainstream media
- [New online factsheet](#)

The Washington Post

NATIONAL

Main federal health survey will ask about sexual orientation, gender identity

Text Size Print E-mail Reprints

By David Brown, Published: June 29

The Department of Health and Human Services will start asking questions about sexual orientation and gender identity in its flagship survey of the health of the American population.

Starting in 2013, the [National Health Interview Survey \(NHIS\)](#) will include questions about sexual orientation along with those covering health insurance, usual site of medical care, vaccination, obesity, smoking, alcohol consumption and many other topics. Sometime later, questions about gender identity — a more complicated subject — will be added.



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LGBT data collection?

- Announced it last June.
- Sexual orientation question finalized, gender identity measures held for community input, but likely facing internal hurdles.

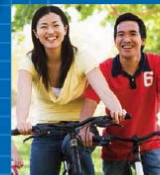


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Official disparity population?



NATIONAL HEALTHCARE DISPARITIES REPORT





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Tested Strategies

The following questions are tested and ready for quitline implementation.



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LGB Measure

Do you think of yourself as:

[For men:] Gay

[For women:] Lesbian or gay

[For men:] Straight, that is, not gay
lesbian or gay

[For women:] Straight, that is, not
lesbian or gay

Bisexual

Something Else (*Go to A*)

Don't Know (*Go to B*)



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LGB Measure part 02

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 (Go to C)

C. **[If 'you mean something else' is selected]** What do you mean by something else? Please type in your answer



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GenIUSS Workgroup

Convened by the Williams Institute to address gender identity surveillance measures. Met June 2011 to explore a consensus on the best measures to recommend.

Forthcoming in Sept: consensus statement from group

What follows is sneak preview of the likely consensus statement recommendations.



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T Measure #1: Definition

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?

- No
- Yes, transgender male to female
- Yes, transgender female to male
- Yes, transgender do not identify as male or female



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T Measure #2: Expression

What sex were you assigned at birth? Male, Female

A person's style, mannerisms, or dress may affect the way people think of them. On average, how do you think people would describe your style, mannerisms, or dress?

- Very feminine
- Mostly feminine
- Somewhat feminine
- Equally feminine and masculine
- Somewhat masculine
- Mostly masculine



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T Measure #3: 2 step

What sex were you born?

- Male
- Female

What is your gender identity? (check all that apply)

- Man
- Woman
- Transgender male to female
- Transgender female to male
- Transgender, do not identify as male or female



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LGBT Measure: Unified

Do you think of yourself as ... (please check all that apply)

- Straight
- Gay or lesbian
- Bisexual
- Transgender or transexual

If YES to Transgender, then ask this probe:

- Transgender male to female or
- Transgender female to male?



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Question placement & implementation

- Do not precede the question with unusual warnings, they create suspicion.
- Put a standard explanatory before demographics, such as "The following demographic questions are completely confidential, we simply collect them to ensure we are serving all disparity populations."
- Watch how counselors are reading the LGBT measures, do not abbreviate questions, do not skip them.



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Beyond measures

Data collection is just one part of cultural competency, these other factors are just as important:

- train counselors in cultural competency
- create tailored LGBT quitline ads to offset presumption
quitline may not be welcoming
- offer tailored resources to LGBT callers, such as our quitline
educational brochure.



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Challenges

What are the barriers quitlines encounter to adding LGBT measures?



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Internal Challenges

- Tradition
- Political obstacles
- Perception it will be offputting to non-LGBT (myth)
- Random barriers (cost too high, etc.)



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External Challenges 01

- Sample size could be the primary consideration in measure choice for some surveillance instruments, unclear re: quitlines.
- Best LGBT estimate from available data? 4-5%
- Best T estimate from available data? 0.5%
 - Is that too small yield for separate measure?
 - Possible questions that yield larger sample sizes, or allow bundling with similar measures? 2. Expression 3. Unified.



External Challenges 02

What limits community engagement? Two words: United ENDA

- 2007 largest LGBT advocacy group, HRC, supported an LGB (not T) inclusive employment nondiscrimination bill.
- This event coalesced growing LGBT support for trans inclusion, many other community groups formed a single coalition, United ENDA, opposing any bill without T inclusion.
- This marked a watershed point for LGB not T policy. Community groups now risk widespread alienation by supporting LGBT not T policies.



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External Challenges 03

- One user complains to politician, who is not educated on the reasoning, and then shuts the quitline down.



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Value



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Are you serving LGBT people?

- In a rare study in Colorado that looked at intentions of smokers to use quitlines, LGBT people who smoked and wanted to quit were 5x less likely than others to call a quitline.
- Do not underestimate the impact of the historical LGBT discrimination in health care on your service.
- Prove that LGBT people are being served, do not presume it.



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Are LGBT people the key to moving the prevalence needle?

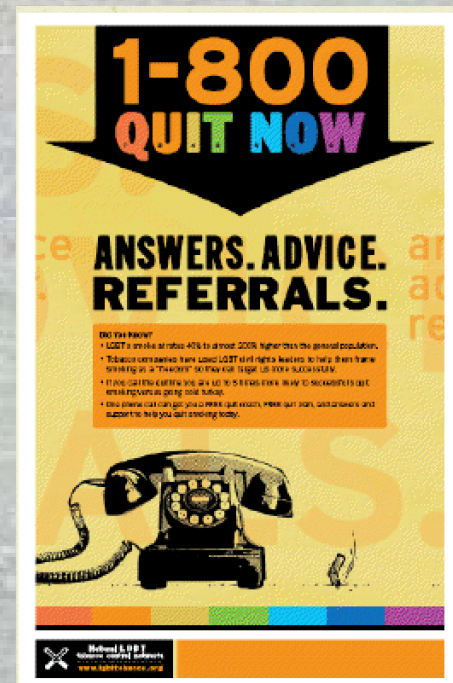
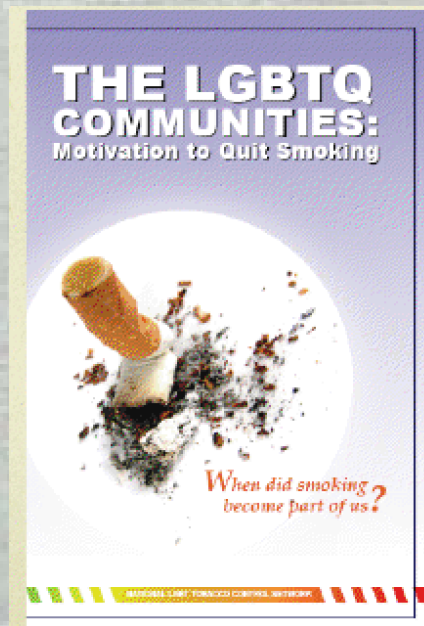
- Prevalence rates have stalled in the mainstream population.
- LGBT people smoke from 35% to almost 200% more than the mainstream population, with no discernable drop.
- Any comprehensive cessation campaign attempting to move population prevalence needs to address pockets of high use, such as LGBT people.
- Moving the needle on a high use population could be the key to eliminating the stall in the general population prevalence.



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Resources

- www.GLMA.org - for online cultural competency training





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The blog

www.lgbthealthequity.wordpress.com

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