The Gritty World of Granular Disparity Data

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The LGBT data story

• We only received the first national full probability LGBT smoking data 2 yrs ago.
• No national surveillance system currently collects LGBT data routinely
• The absence of our data has been the single largest factor allowing the LGBT tobacco disparity (smoking rates 50% higher) to continue unabated.
• Without data, we cannot compete with others to get research funded, we cannot get research on tailored interventions funded, thus, opportunity for behavior change is lost.
The real impact

Because lack of data has allowed many tobacco control programs to avoid tailoring work to the LGBT communities …

• The LGBT communities overwhelmingly do not understand tobacco is even an important issue for us.
Tobacco for us

- When we ask on needs assessments what people rank as the top health issue for LGBT people, they list HIV, suicide, mental health….
- Tobacco is usually 8-10\textsuperscript{th} place.
- Yet an public health analysis shows tobacco takes more years off our lives than any other single issue, by far
- CDC estimates 1 out of every 9 LGBT persons will die early from tobacco related diseases. This is 1M of us. (To put this in perspective, a few hundred thousand MSM have HIV).
- And we barely think to list tobacco on our health priorities
Data for you

• How many LGBT people in the country? Best available science estimates it at 9M. Or roughly the population of NJ.
• What percent smoke? About 35%
• How much do we spend on tobacco products every year? Est at $7.9B
• This is 65x as much money as all funders spend on all LGBT issues combined.
• How many of us will die early from tobacco related diseases? 1M
• Is the LGBT youth smoking rate dropping? Not yet.
Whenever we go to a state to train the department of health we come with a few data points that help show them what’s possible:

- The number of LGBT people in their state (usually equal to one of their major cities)
- Information on best current surveillance measures for LGBT
Do you collect LGBT data?

Best and Promising Practices:

- Include sexual orientation and gender identity as part of standard demographic questions to tailor information and resource dissemination.
We had a measure which underwent successful cognitive testing years ago. We then petitioned to get it added to the quitline MDS. We now hear over 30 states use this question on intake.

After talking with Nat Jewish Quitline reps who had administered the measure 100k times we found it worked, but it had rough spots which could go smoother.

With the help of 10 states, NAQC, and Nat Jewish, we have come up with an enhanced measure, and are fielding it starting April 1.

Drumroll please…
The Question

Do you consider yourself to be gay, lesbian, bisexual, and/or transgender? **

► If Yes: 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.

**NOTE: If respondents show concern about this question, feel free to add the following sentence: “LGBT people experience health disparities; we ask this to ensure we're serving all people equally.”
We will be reviewing the results monthly. (7k administrations per month)

Within 3 months, we expect to verify if this new question is better.

If so, it could well be the smartest measure to add to all surveillance systems.
Are you collecting EHR data?

According to the Gay and Lesbian Medical Association Guidelines for the Care of LGBT Patients...

“Filling out the intake form gives patients one of their first and most important impressions of your office. The experience sets the tone for how comfortable a patient feels being open about their sexual orientation or gender identity/expression.”
After years of helping states create new LGBT needs assessments, we convened a group and made a template.

We currently offer this template + free basic analysis + free basic report creation + TA for states to adopt.

Already conducted theirs: MI, AR

Open now: CT

Planning in future: WI, FL, PA, VT
Arkansas LGBTQ Wellness Needs Assessment

1. An LGBT Health initiative is underway to assess the health needs of the LGBTQ community in Arkansas.

The goal of this project is to collect information about the health status and health care experience of you and your community. This information will be used to determine how the Minority Initiative Sub-Recipients Grants Office, Arkansas Department of Health, community-based organizations, and other healthcare providers can better serve members of the community. Your assistance is truly valued, and we thank you in advance for your participation.

By saying yes to participate in this survey you are giving your permission/consent. The survey will only last around 10-15 minutes. The information that you share is completely anonymous, and will not be given to anybody else. You may stop the survey at any point, and you may refuse to answer any question at any time. By participating in this survey, you have the option to be entered to win an IPAD MINI. Your contact information, if you choose to give it to us, will be collected separately from the rest of the survey.

If you have already filled out this survey please refrain from filling it out again, as only one entry per person will be entered to win the IPAD MINI.

Do you give your consent to participate in this survey?

Yes  No

2. Do you identify as Lesbian, Gay, Bisexual, Transgender, or Queer?

Yes  No (If you continue, please mark with a box)

If you, what is your relationship to the LGBTQ community?
Findings

**Michigan LGBTQ Wellness Needs Assessment Results**

February 5, 2015

*Top health issues for the LGBTQ community*

- Suicides: 51.0%
- Mental Health: 46.6%
- STDs: 44.5%
- HIV: 45.7%
- Bullying: 23.2%
- Marriage: 19.8%
- Accessing health care: 17.7%
- Alcohol use: 11.7%
- Illicit drug use: 9.7%
- Elder care: 8.1%
- Obesity: 6.0%
- Cancer: 2.3%
Findings

Michigan LGBTQ Wellness Needs Assessment Results

February 5, 2015

Where would you most likely go for assistance to quit smoking?

- Doctor or healthcare provider: 30.3%
- An LGBTQ organization: 13.0%
- Quitline (1-800-QUITNOW): 5.5%
- Smoking cessation class or group: 12.0%
- I don’t know where to go: 16.8%
- I would not go anywhere: 41.1%
How do states use data?
How do states use data?

LESBIAN, GAY & BISEXUAL ADULTS
AND TOBACCO’S BURDEN IN COLORADO

FACT: Tobacco use is the leading preventable cause of death.

FACT: More deaths are caused each year by tobacco use than by all deaths from HIV, illegal drug use, alcohol use, motor vehicle injuries, & murders combined.

When did smoking become a part of us?
- Lesbian women: 33%
- Gay men: 34%
- Bisexual women: 37%
- Bisexual men: 28%
- Straight women: 15%
- Straight men: 20%

IN COLORADO
As a group, Lesbian, Gay and Bisexual adults smoke at about 2X the rate of heterosexual adults. The harassment, discrimination and social stress this group often faces contribute to its tobacco use.

BY DESIGN
Tobacco companies have aggressively targeted Lesbian, Gay, Bisexual & Transgender (LGBT) populations for decades, both through advertising and through philanthropic support. Tobacco companies have sought to attract LGBT smokers, garner community support, and deflect criticism from LGBT community leaders.

Fortunately:
The Colorado QuitLine coaches are trained in LGBT Cultural Competency, and research shows the services are effective. LGBT individuals can expect respect and affirmation of their identities and relationships when they call the QuitLine.

COMMUNITIES CAN TAKE ACTION

- Promote cessation services and increase the use of evidence-based and culturally tailored cessation services, cessation messaging and resource referrals.
- Expand and enforce smoke-free policies at gatherings such as pridefests, gay rodeos and gay bars to reduce second-hand smoke exposure.
- Make tobacco less affordable by increasing the unit price of tobacco through increased tobacco taxes, and banning of multipack offers & coupon redemption.

For more information visit tobaccofreeco.org or tobaccocontrolco.org
Data checklist

- BRFSS
- YRBS
- Quitline intake
- Grantee program
- Evaluation data (grantee & internal)
- Impression data on ads
- Satisfaction surveys
- Electronic Health Records
- Cancer registry/SEER
- Needs assessment
Want LGBT health stats?

We have a weekly roundup of top LGBT health/tobacco/cancer stories in Huffington Post & YouTube.
Our Resources

- Best practices for tobacco
- Countermarketing posters
- Needs assessment model
- Sample surveillance measures
- Sample nondiscrimination policies
- LGBT Welcoming Posters
- Coming soon: Cancer Action Plan
- Coming soon: Best practices for Cancer