national lgbt cancer network

TOBACCO RELATED CANCER PROJECT

JUSTIFICATION SHEET

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ADVANCING SEXUAL AND GENDER MINORITY MEASURES IN THE BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

Lesbian, gay, bisexual, and transgender (LGBT) Americans are a growing sexual and gender minority (SGM) population in the United States (US). According to the 2018 Gallup and Pew Research Center report [1,2], at least 11 million US adults identify as LGBT (4.5% of the US adult population). This represents a modest but substantial increase from the 8 million US adults (3.5% of US adult population) who identified as LGBT in 2012 [2]. This growth may be in part due to progress in societal acceptance and legislative protections (e.g., the 2015 US Supreme Court ruling on same-sex marriage [3]). As the number of Americans who identify as members of the LGBT population increase, the role of surveillance systems like the Behavior Risk Factor Surveillance System (BRFSS) [4], a vital nationwide longitudinal surveillance system that informs the nation about environmental and behavioral risk factors for various health disparities, has become even more critical in informing health recommendations and ensuring that the health disparities of LGBT populations are measured and analyzed.

Understanding health disparities faced by LGBT Americans begins with SGM measures in population-level surveillance systems like the BRFSS. A critical first step in assessing the existence of and trends related to the health disparities many SGM populations face is to ensure that LGBT-specific demographic measure such as the BRFSS' SGM's optional module, also known as sexual orientation and gender identity (SOGI) module5 is adopted. The SGM module is a standardized surveillance measurement for capturing respondents' sexual orientation and gender identity. It is a 2-item, 2-step question that specifically asks how respondents think of themselves in terms of their sexual orientation as well as if they consider themselves to be transgender (Figure 1 [5]). This module has been utilized as primary SGM-related population-based health dataset to monitor the progress of Healthy People 2020 objective specifically on increasing "the number of states, territories and the District of Columbia that use the provided module on sexual orientation and gender identity" [6]. It continues to serve as a primary source of health data for the incoming Healthy People 2030, the federal blueprint for America's health [7].

Approved BRFSS Sexual Orientation and Gender Identity Module

The next two questions are about sexual orientation and gender identity.

1) **Which of the following best represents how you think of yourself?**
   - ○ Gay/Lesbian
   - ○ Straight
   - ○ Bisexual
   - ○ Something else
   - ○ I don't know the answer
   - ○ Refused

2) **Do you consider yourself to be transgender?**
   - ○ Yes, Transgender, male-to-female
   - ○ Yes, Transgender, female-to-male
   - ○ Yes, Transgender, gender nonconforming
   - ○ No

Figure 1: Approved BRFSS Sexual and Gender Minority (SGM) Module

However, not all states have adopted the BRFSS SGM module, leading to an incomplete assessment of the nation's LGBT health. Currently, SGM measures are not part of the BRFSS standardized demographic core questionnaire that every state uses each year, making national-level inferences from the dataset challenging. This leaves an incomplete picture of the health needs of LGBT populations in the US and impedes numerous states and territories' programs to reduce health disparities effectively [8]. Like race, sex, age, income, and disability status, having the SGM questions as part of the demographic data would enhance the ability of BRFSS and state programs to provide important information on the condition and progress of LGBT health in the US. Incorporating SGM module into the core questionnaire to ensure that it is being collected annually by all states and territories would further enhance the consistency and overall quality of the information being collected.

ADVANCING SEXUAL AND GENDER MINORITY MEASURES IN THE BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM

This year, the Center for Disease Control and Prevention (CDC) is proposing the addition of SGM module into the into the BRFSS' core questionnaire to advance "high-quality representative data in addressing the health issues and needs of [LGBT] individuals" [9]. **As such, to ensure that SGM measures are being consistently collected for assessment, it is critical for states and territories to adopt the SGM module (or to continue implementing it if already adopted), and consider including it as part of the demographic core questionnaire for the following reasons:**

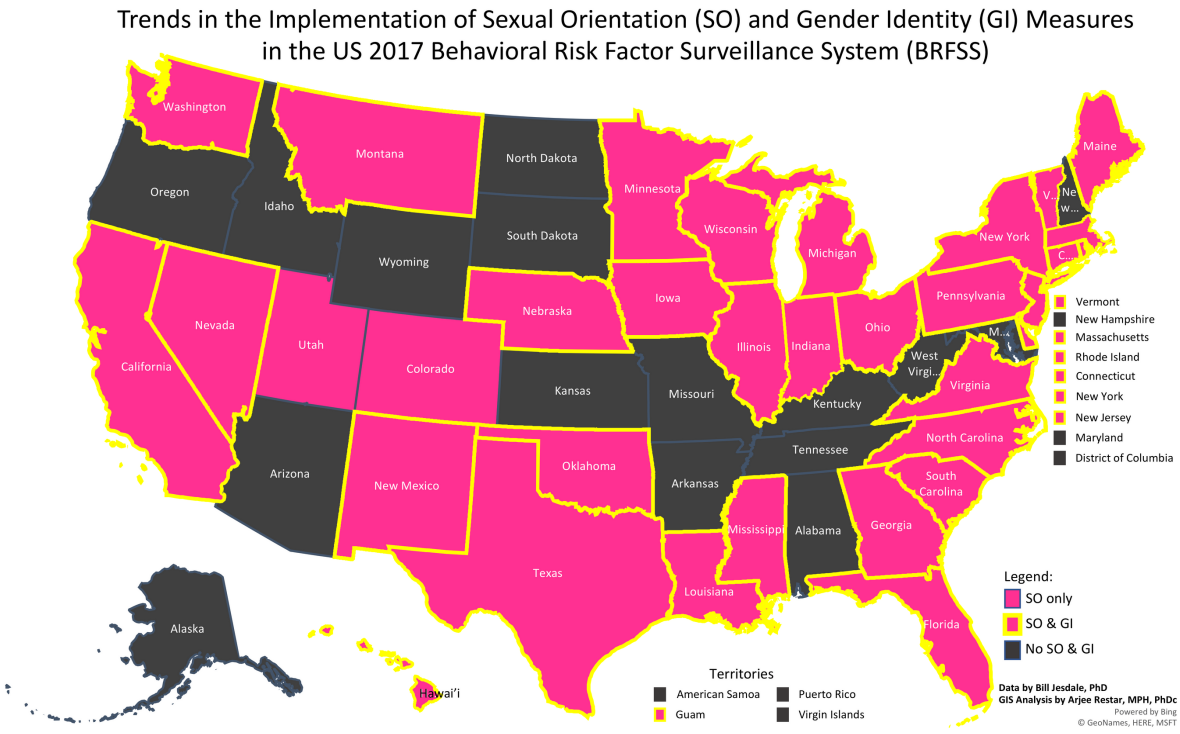

Figure 2a: Trends in the Implementation of BRFSS 2017 SGM Measures [8]

1) Use of the approved optional BRFSS' SGM module is becoming a norm for many states, providing vital knowledge about LGBT health in the US. In recent years, there has been a rapid increase in the number of states and territories who adopted the SGM module. Since 2014, when the first standardized optional SOGI module was first approved for use, 35 states have now adopted and assessed sexual orientation and gender identity in each year, with 34 states implementing the module in 2017 (see Figure 2a ad 2b [10]). Given the BRFSS' large sample size, sophisticated probability sampling approach, and public accessibility, it has generated numerous empirical peer-reviewed publications that have informed and filled in the critical gaps in the health and well-being of LGBT populations. The module has resulted in the production of more than 50 empirical studies that specifically address a myriad of health behaviors and outcomes among US LGBT adults; this includes more than two dozen studies in the last three years that analyzed the health and well-being of US transgender adults (see examples [11,12]), as well as specific communities within LGBT populations including veterans [13], cancer survivors [14], and rural residents [15]. Health areas and issues covered by these empirical studies have broadly explored health insurance coverage, health policy, mental health, violence, as well as socioeconomic (e.g., education, employment, income) and behavioral determinants of health such as smoking, drinking, diet, activity, and screening (e.g., HIV, colorectal, and pap testing).

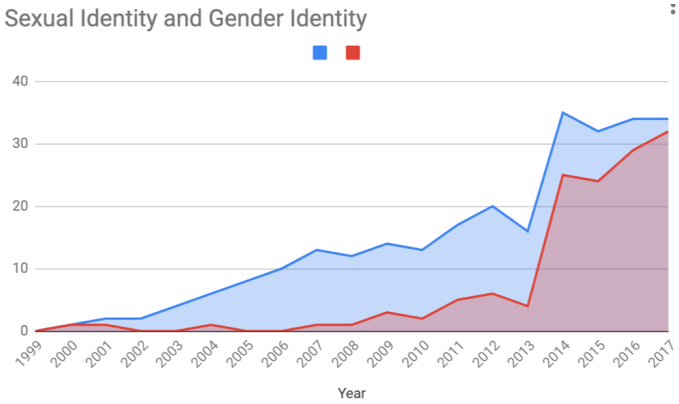

Figure 2b: Trends in State Implementation of the BRFSS SGM Module Across Years 1999-2017 [8]

2) States that have adopted the SOGI module are successfully able to understand health disparities faced by SGM populations living in those states and consequently tailor and target health programs and legislatures. To reduce health disparities, it is important to understand how negative health outcomes and behaviors of populations impacted, including LGBT populations. For states that have collected SGM measures like Arizona, New Mexico, Colorado, Massachusetts, and Hawaii, data suggests LGBT people are disproportionately impacted various health outcomes and behaviors. For example:

- In Arizona [16,17], 4.5% of adults identify as LGBT; through BRFSS' data, its state health department found that the prevalence of current smoking behavior among Arizona lesbians is 31%, a rate that is twice that of its state female population, which prompted Tobacco Free Arizona to partner with the state health department to target lesbians for tobacco cessation interventions.
- Similarly, informed by its own state's BRFSS, New Mexico [16] launched numerous prevention and cessation programs to reduce health disparities aimed its LGBT populations, including a series of cultural competency training for health care providers and staff who interact with LGBT patients.
- In Colorado [16,18], state BRFSS data showed higher rates of smoking, binge drinking, driving while intoxicated, and asthma among sexual minorities compared to heterosexual people, leading One Colorado, an LGBT advocacy group, to outline legislative goals alongside state policymakers regarding health systems and healthcare providers servicing LGBT members.
- Massachusetts [16,19] provided a range of services to take multiple health issues found from its state's BRFSS, including prevention of suicide, domestic violence, and social isolation, as well as community-centered programs like homeless services, congregate meals for LGBT elders, and youth services for teens and young adults.
- Hawaii has adopted and continually implemented SOGI module each year since 2005. In its recent state BRFSS report [20], numerous health disparities were made visible including those that had been scantly researched such as smoking, obesity, and cancer. Specifically, they found that among SGM adults (a) 2 out of 4 currently smoke cigarettes, 1 in 3 currently use of electronic vaping products, about 1 in 2 are at increased risk for alcohol dependency; (b) 1 in 5 are obese; and (c) and about 1 in 10 have been diagnosed with cancer, 1 in 3 do not meet national colorectal cancer screening recommendations, and 1 in 4 lesbian or bisexual women of adult age have not had mammograms in the past 2 years.

As such, the adoption of the SOGI module has led various states to identify a myriad of health issues among LGBT communities in their states. In turn, it has provided state health departments and organizations vital data to inform their strategic and concerted efforts to reduce such health disparities.

3) Accurate SGM data are necessary to write competitive proposals and justify new programming. Collecting SGM measures is warranted in making various health issues visible and in providing justification for the need to specifically tailor and target services specific to LGBT populations. Researchers writing proposals without state and national level full probability data are at an extreme disadvantage as compared to researchers able to cite such data. SGM data are also critical for justifying need for new preventative and treatment programming for the population. Having those data is also critical for monitoring, evaluation, and reporting purposes to ensure that such programs receive continued funding. While states can and have used national data as a proxy for state data but that is an inaccurate and limited proxy.

4) SGM measures do not negatively impact response rates and accuracy of the data. Research indicates that sexual orientation and gender identity questions do not negatively impact response rates and can be administered feasibly and successfully in population surveillance systems [21]; indeed, federal surveys have found that respondents often do not encounter any issues in willingly and accurately disclosing information about their LGBT status [21]. Federal surveys that include SGM measures like SOGI items as part of the demographic questionnaire show that they do not lead to survey breakoff [21,22]. Additionally, the Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys specifically states that "[m]ost surveys incorporating SOGI items have not found higher nonresponse rates than other 'sensitive' questions, such as personal or household income" [21,23]. While SGM measures could pose as sensitive for some respondents, the Federal Interagency Working Group asserts that it is not more than sensitive than other demographic information such as income, employment, or disability status; The provision of voluntary responses (e.g., "something else", "don't know," and "refused") also contributes to accuracy of the data as it alleviates respondents from being forced to answer a question, particularly those who may be uncomfortable or uneasy about disclosing their LGBT status [24,25]. As such, federal surveys have shown that implementing SGM items does not introduce high nonresponse rates or survey break-offs.

5) Incorporating the SGM module at the national level will improve data validity. Currently, the SGM module is fielded on a state by state basis, and almost always at the end of the survey, resulting in high rates of missing data due to respondent fatigue and break-off. Several states have incorporated the SGM module within the core interview in the demographics section without increasing break-off rates, and also getting much more complete (and thus less biased) data on SGM status in BRFSS. Furthermore, the state-by-state adoption process means that BRFSS SGM data cannot be interpreted as nationally representative. Adoption of a standard SGM module at the national level would thus improve data validity in several ways: truly national coverage, much lower missing data rates, and allowing respondents to feel "heard" and "included" early in the interview process.

CONCLUSION

The CDC's BRFSS is a " powerful tool for targeting and building health promotion activities"[4] across all US residents, including LGBT Americans. Collecting SGM measures does not impact response rates and accuracy of the data, and is a norm for most US states. If implemented by all states, it would provide vital information and an accurate complete picture of LGBT peoples' health needs that can support state and local programs to: (a) reduce health disparities effectively through specific programming activities, (2) develop specific and tailored legislatures that supports LGBT health, (c) support for planning, developing, monitoring, evaluation, and reporting of current and new preventative and treatment programs as well as new programming. **To ensure health disparities of all LGBT Americans are addressed, it is vital for all states and territories to adopt and continue to implement SGM measures in their state BRFSS, and highly consider it as part of the core demographic questionnaire.**

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