

March 21, 2016

U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention  
1660 Clifton Road NE, MS-D74  
Atlanta, GA 30329

*Submitted electronically via regulations.gov*

**RE: Proposed data collection revision to the Behavioral Risk Factor Surveillance System, CDC-2016-0008**

Dear Sir/Madam:

We appreciate the invitation to provide comments in response to the notice of proposed data collection revision to the Behavioral Risk Factor Surveillance System (CDC-2016-0008). The Center for American Progress is a nonpartisan research and educational institute dedicated to promoting a strong, just, and free America that ensures opportunity for all. As a research-oriented institution, we believe that robust data collection through federally supported surveys such as the Behavioral Risk Factor Surveillance System (BRFSS) is a critical component of responsible, effective policymaking. In response to CDC's proposal to enhance BRFSS with the field testing discussed in the notice of proposed data collection revision, we would like to take this opportunity to express our strong support for BRFSS, particularly its efforts to collect demographic information on sexual orientation and gender identity (SOGI), and to make recommendations that we hope will further enhance the standing of BRFSS as one of the world's premier health surveys.

Historically, numerous states and territories have used BRFSS to measure SO and/or GI in order to assess the health and well-being of their lesbian, gay, bisexual, and transgender (LGBT) residents. In 2013, the Centers for Disease Control and Prevention (CDC) approved an optional module for BRFSS that measures sexual orientation and gender identity, and in 2015, 25 states and territories used this module,<sup>1</sup> an increase of 25 percent over 2014. Thanks to this history, BRFSS has become a leader among federally supported surveys in its efforts to promote the collection of SOGI data and assess health disparities affecting the LGBT population across the United States.

The United States is home to at least 9 million people who identify as LGBT,<sup>2</sup> and research consistently demonstrates that health and health care access disparities are a major concern for the LGBT population.<sup>3</sup> These disparities include higher rates of mental health and substance use;<sup>4</sup> a continuing HIV epidemic among transgender women and gay and bisexual men;<sup>5</sup> barriers in access to appropriate health coverage and care, especially for transgender people;<sup>6</sup> and poor treatment from health care providers who do not understand the needs of LGBT patients.<sup>7</sup> Sources such as the objectives in the Healthy People 2020 LGBT Health Topic Area recognize that adding SOGI questions to health surveys such as BRFSS is critical for advocates, researchers, policymakers, and service providers who need comprehensive and accurate data on the LGBT population in order to craft effective responses to these disparities.<sup>8</sup>

States that use the SOGI module report that it is well-received by respondents and does not negatively affect the quality of data collected. Missouri BRFSS Coordinator Janet Wilson noted, for instance, that

the state's experience using the module in 2015 did not result in any survey break-off and had very low rates of item non-response.<sup>9</sup>

The experiences of states that already have several years of LGBT population data from their BRFSS illustrate how these data help states create more effective policies and direct limited resources to where they can do the most good.

Massachusetts, for instance, began using state-designed questions on its BRFSS to collect data on sexual orientation in 2001 and gender identity in 2008 before switching to the CDC-approved module in 2015.<sup>10</sup> These data revealed that LGBT Bay Staters face higher rates of sexual assault, binge drinking, tobacco use, and anxiety and depression than non-LGBT residents.<sup>11</sup> Using these findings, the Massachusetts state government has been able to better target these issues through direct services such as suicide prevention programs, domestic violence prevention and services, homeless services, meals for LGBT elders, and LGBT youth services.<sup>12</sup>

Colorado asked BRFSS respondents about their sexual orientation with a state-added question from 2006 until the state adopted the CDC-approved SOGI module in 2015.<sup>13</sup> Analysis of the Colorado BRFSS data revealed disparities such as a greater prevalence of smoking, binge drinking, and asthma in the state's lesbian, gay, and bisexual population compared with the heterosexual population. These data allowed Colorado's statewide LGBT equality group, One Colorado, to successfully advocate for private funders to invest in an LGBT-specific state health survey in 2012. The findings from this survey, "Invisible: The State of LGBT Health in Colorado,"<sup>14</sup> have guided subsequent policy and programming advances, such as a partnership between One Colorado and the Colorado Department of Public Health and Environment on a transgender-specific statewide health survey based on BRFSS.<sup>15</sup>

These data have also aided in the development of the LGBT Health Outcomes Planning Project as part of the state's implementation efforts for Healthy People 2020, a partnership with the Colorado Medical Society on a survey of clinicians that revealed a significant need for greater LGBT cultural competency training among the state's health care workforce,<sup>16</sup> and national investment in efforts by One Colorado and other community partners to address LGBT health disparities in the state's health insurance marketplace.<sup>17</sup> Numerous other states—including Hawaii, Indiana, North Carolina, and Utah—have similarly used BRFSS data to publish reports on LGBT health.<sup>18</sup>

In order to expand on these successes, we would like to suggest the following recommendations to CDC regarding BRFSS:

- **Strongly encourage all states wishing to ask SOGI questions on their BRFSS to adopt the SOGI module:** In 2015, 11 jurisdictions used their own questions to gather sexual orientation and/or gender identity data. In order to ensure that the data collected on the LGBT population is as robust as possible, we recommend that CDC strongly encourage all states wishing to ask SOGI questions on their BRFSS to adopt the SOGI module.
- **Continue financial support for states using the SOGI module:** In order to further promote use of the module, we recommend that HHS continue financial support for states using the module beyond 2016.
- **Offer special analyses of SOGI data for states that use the module:** For the last several years, CDC has offered special analyses for jurisdictions that ask sexual orientation questions on their

Youth Risk Behavioral Surveillance System (YRBSS). An example from Broward County (FL) is attached to this comment. These analyses are extremely helpful for states as they assess the utility of the SOGI module and begin to explore the disparities affecting their LGBT residents.

- **Use the pooled national data from the module to publish a report on LGBT health disparities:** In 2011, CDC analyzed the available data from YRBSS and published a report, *Sexual Identity, Sex of Sexual Contacts, and Health-Risk Behaviors Among Students in Grades 9–12 — Youth Risk Behavior Surveillance, Selected Sites, United States, 2001–2009*, on disparities affecting sexual minority youth.<sup>19</sup>
- **Seek opportunities to educate state BRFSS coordinators about the importance of collecting SOGI data:** LGBT people live in every state, and SOGI data are critical to addressing disparities that affect this population, not least because health disparities incur significant costs to states and the U.S. overall in the form of poorer population health; greater morbidity and mortality from conditions—such as HIV, cancer, and heart disease—that are linked to discrimination, minority stress, and a lack of regular access to health care services; and policies and programs that less effectively target the root causes of poor health among disadvantaged populations.<sup>20</sup>
- **Explore the possibility of eventually adding SOGI questions to the core BRFSS demographic questions rather than as an optional module:** Sexual orientation and gender identity are not unique to LGBT individuals—every person has both a sexual orientation and a gender identity, which interact with other aspects of who they are and have important effects on fundamental issues of health and well-being such as identity development, relationship building, and mental health. Furthermore, studies increasingly indicate that more Americans are identifying outside of traditional assumptions of heterosexuality and adherence to a rigid male/female gender binary, meaning that considerations of sexual orientation and gender identity are becoming increasingly prominent for the U.S. population at large.<sup>21</sup> BRFSS should reflect the growing diversity of sexual orientations and gender identities in the U.S. today by adding these measures to its core demographics questions.

Again, we would like to express our strong support for BRFSS as an invaluable tool for helping researchers, policymakers, and advocates better understand and improve the health of our nation, particularly among populations experiencing disparities—such as the LGBT population. We thank you for your time and attention to our comments and recommendations and look forward to continuing to work in partnership with CDC and the states to build a healthier America for all. Please do not hesitate to contact me at [kbaker@americanprogress.org](mailto:kbaker@americanprogress.org) or (805) 390-2309 with any questions or concerns.

Sincerely Yours,

/s/ Kellan E. Baker, MPH, MA

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<sup>1</sup> Kellan Baker and Margaret Hughes, “Sexual Orientation and Gender Identity Data Collection in the Behavioral Risk Factor Surveillance System,” Center for American Progress (2016).

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- <sup>2</sup> Gary J. Gates, “How many people are lesbian, gay, bisexual, and transgender?” (Los Angeles: The Williams Institute, 2011), available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Gates-How-Many-People-LGBT-Apr-2011.pdf> (last accessed March 19, 2016).
- <sup>3</sup> See, e.g., National Academy of Medicine, “The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding” (2011).
- <sup>4</sup> Centers for Disease Control and Prevention, “Lesbian, Gay, Bisexual, and Transgender Health,” available at <http://www.cdc.gov/lgbthealth/about.htm> (last accessed March 19, 2016).
- <sup>5</sup> The White House, “National HIV/AIDS Strategy,” available at <https://www.whitehouse.gov/administration/eop/onap/nhas> (last accessed March 19, 2016).
- <sup>6</sup> Jaime M. Grant, Lisa A. Mottet, and Justin Tanis, “Injustice at Every Turn: A Report of the National Transgender Discrimination Survey” (Washington: National Center for Transgender Equality and National Gay and Lesbian Taskforce, 2011), available at [http://endtransdiscrimination.org/PDFs/NTDS\\_Report.pdf](http://endtransdiscrimination.org/PDFs/NTDS_Report.pdf) (last accessed March 19, 2016).
- <sup>7</sup> Lambda Legal, “When Healthcare Isn’t Caring: Lambda Legal’s Survey on Discrimination Against LGBT People and People Living with HIV” (2010).
- <sup>8</sup> U.S. Department of Health and Human Services Office for Disease Prevention and Health Promotion, “Healthy People 2020 LGBT Health Topic Area,” available at <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health> (last accessed March 19, 2016).
- <sup>9</sup> Personal communication with Janet Wilson, BRFSS coordinator, Office of Epidemiology, Missouri Department of Health and Senior Services, September 30, 2015.
- <sup>10</sup> Personal communication with Mark Paskowsky, director of health survey program, Massachusetts Department of Public Health, July 19, 2015.
- <sup>11</sup> The CDC-approved BRFSS module, particularly the gender identity question, is adapted from the Massachusetts BRFSS questions. See K.J. Conron, M.J. Mimiaga, and S.J. Landers, “A Health Profile of Massachusetts Adults by Sexual Orientation Identity: Results from the 2001-2006 Behavioral Risk Factor Surveillance System Surveys” (Boston: Massachusetts Department of Health, 2008), available at <http://www.mass.gov/eohhs/docs/dph/health-equity/sexual-orientation-disparities-report.pdf> (last accessed March 19, 2016).
- <sup>12</sup> The Fenway Institute, “Gathering Sexual Orientation Data” (2014).
- <sup>13</sup> Personal communication with Rickey Tolliver, manager of health surveys and analysis program and acting branch chief, Health Statistics and Evaluation Branch, Colorado Center for Health and Environment Data, July 2, 2015.
- <sup>14</sup> One Colorado Education Fund, “Invisible: The State of LGBT Health in Colorado” (2012).
- <sup>15</sup> One Colorado Education Fund, “Transparent: The State of Transgender Health in Colorado” (2014).
- <sup>16</sup> One Colorado Education Fund, “Becoming Visible: Working with Colorado Physicians to Improve LGBT Health” (2013).
- <sup>17</sup> U.S. Department of Health and Human Services, “Outreach and Enrollment for LGBT Individuals: Promising Practices From the Field,” available at <https://aspe.hhs.gov/basic-report/outreach-and-enrollment-lgbt-individuals-promising-practices-field> (last accessed March 2016).
- <sup>18</sup> State of Hawaii, “The Hawaii Behavioral Risk Factor Surveillance System: 2014 Results” (2014); Indiana Tobacco Prevention and Cessation Commission, “Indiana Lesbian, Gay, Bisexual, and Transgender Communities and Tobacco Use” (2015); North Carolina Department of Health and Human Services, “2014 BRFSS Survey Results: North Carolina, Sexual Orientation” (2014); Oregon Health Authority, “CD Summary: Lesbian, Gay, Bisexual and Transgender Health” (2012); Way to Quit, “Smoking by Race, Ethnicity, and Sexual Orientation” (2015).
- <sup>19</sup> Centers for Disease Control and Prevention, “Sexual Identity, Sex of Sexual Contacts, and Health-Risk Behaviors Among Students in Grades 9-12 – Youth Risk Behavior Surveillance, Selected Sites, United States, 2001-2009” (2011).
- <sup>20</sup> Centers for Disease Control and Prevention, “Health Disparities and Inequalities Report – United States, 2013,” available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/su6203a2.htm> (last accessed March 19, 2016).
- <sup>21</sup> Shepherd Laughlin, “Generation Z goes beyond gender binaries in new Innovation Group data,” available at <https://www.jwtintelligence.com/2016/03/gen-z-goes-beyond-gender-binaries-in-new-innovation-group-data> (last accessed March 19, 2016).