ISGMH statement in response to CDC plans to revoke the option for states to ask sexual orientation and gender identity questions as part of the Behavioral Risk Factor Surveillance System (BRFSS)

May 18, 2018

Evaluation, Data Integration, and Technical Assistance (EDIT) Program -

Last night, The Williams Institute broke the news that the Centers for Disease Control and Prevention (CDC) no longer intends to support the collection of sexual orientation and gender identity (SOGI) data through the Behavior Risk Factor Surveillance System (BRFSS). Since 2014, BRFSS has included an optional module to allow participants to identify their sexual orientation and gender identity. By revoking the option for states to ask these questions, the CDC is hindering the ability of researchers attempting to use data to better understand and improve the health and wellbeing of LGBT people.

The removal of LGBT questions from BRFSS is harmful to the nation’s ability to detect LGBT health disparities. BRFSS is the largest and oldest public health surveillance network in the United States. Approximately 460,000 people each year complete the survey, which includes questions about health, health behaviors, and disease prevention. BRFSS is currently the only federal health survey that includes questions to identify transgender participants. As of 2018, 30 states have adopted the use of this optional module.

In addition, leading LGBT health and think tank institutions across the country have released reports highlighting the importance of the BRFSS to identify the health disparities of LGBT populations. Not only do these reports recommend that all states should adopt the optional SOGI module, they advocate for the inclusion of these measures in the core BRFSS questionnaire, and highlight that the disparities and lessons learned from the inclusion of SOGI questions should serve as an inspiration for all state and federal surveys to follow suit.

In removing the SOGI questions from BRFSS, the federal government has chosen not only to go against the recommendations of experts in the field, but to ignore its own guidelines to improve LGBT health data surveillance. The Healthy People 2020 Recommendations state that, “Collecting SOGI data in health-related surveys and health records in order to identify LGBT health disparities,” as a critical method to improve LGBT health. Furthermore, the recommendations specifically name the BRFSS as an integral part of the government’s public health surveillance system to monitor the health of LGBT people. The detection of LGBT health
disparities, in turn, requires the U.S. government to take actions to reduce them: The 21st Century Cures Act mandates the NIH to develop programs to “carry out focused efforts to improve research related to sexual and gender minority populations” and to “understand and reduce health disparities.”

Our team at ISGMH is acutely aware of the importance of national surveillance systems like BRFSS. Postdoctoral Scholar Dr. Lauren B. Beach published a study in February 2018 using the 2014 BRFSS dataset showing that, even after adjusting for multiple known risk factors, gay and bisexual men had a higher prevalence of diabetes than heterosexual men. Similarly, EDIT Program Director Dr. Gregory Phillips II leads a study which focuses on using data from the adolescent equivalent of the BRFSS, the Youth Risk Behavior Survey (YRBS), to characterize health and HIV risk behaviors among sexual minority youth. Dr. Phillips has already published a number of studies highlighting alcohol and substance use disparities between LGBT and heterosexual adolescents, particularly among bisexual youth. Additionally, prior research by ISGMH faculty including Director of the Institute, Dr. Brian Mustanski, and Director of the CONNECT Program, Dr. Michelle Birkett, has highlighted elevated risk among LGBT youth in suicidality, victimization, and cancer diagnoses. Like BRFSS, the YRBS has a short history of including SOGI questions, yet the impact made possible by asking these questions is already apparent. Rolling back these policies hinders the ability of researchers to analyze these data to identify and report LGBT health disparities, as well as to evaluate the impact of changes in state and federal health policies on LGBT population health.

The CDC’s reported decision to phase out collection of LGBT data follows a concerning pattern of erasure of sexual and gender minority (SGM) individuals in critical national surveys. Last month, the Department of Justice’s (DOJ’s) Bureau of Justice Statistics requested a revision to the National Crime Victimization Survey to raise the minimum age from 16 to 18 at which respondents are administered questions on their sexual orientation and gender identity. In tandem, the Department of Health and Human Services’ (HHS) new Conscience and Religious Freedom Division has opened the door for health care providers to deny services to LGBT Americans on the basis of religious belief. If realized, the actions of the CDC, DOJ, and HHS will result in the health needs of LGBT Americans being ignored, erased, and unmet, in contradiction with existing federal health policy recommendations.

At the time of the DOJ’s requested revision, our Institute released a letter in response, explaining how the requested change in procedure would be detrimental to the health and safety of SGM youth. This letter also highlighted that the DOJ’s rationale that these revisions should be made due to concerns about the "potential sensitivity" of these questions for young teens were not based in evidence, and presented several publications directly refuting this point. Furthermore, response to this letter highlighted public support for the inclusion of these
types of questions, with a [MoveOn petition](https://petitions.moveon.org/sign/stand-against-the-cdcs?source=c.em&r_by=20102199) accumulating more than 1,600 signatures in less than a week and a half.

Once again we are asking the public to join ISGMH in standing firmly against the erasure of SGM identities and against federal policies, which ignore evidence-based science by signing our petition to the Director of the CDC, Robert R. Redfield:


For more information or additional comments, contact:

**Gregory Phillips II, PhD**  
Assistant Professor  
Department of Medical Social Sciences  
Department of Preventive Medicine  
Director  
Evaluation, Data Integration, and Technical Assistance (EDIT) Program  
Institute for Sexual and Gender Minority Health and Wellbeing  
Northwestern University  
625 N Michigan Ave 14-043, Chicago, IL 60611  
glp2@northwestern.edu  
312.503.3447  
Pronouns: He/Him/His