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July 12, 2022

Jeffrey M. Zirger
Information Collection Review Office
Centers for Disease Control and Prevention
1600 Clifton Road NE, MS H21-8
Atlanta, GA 30329

SUBMITTED VIA *regulations.gov*

RE: Comment on the National HIV Behavioral Surveillance: Brief HIV Bio-behavioral Assessment (NHBS-BHBA); Docket No. CDC-2022-0064

Dear Dr. Zirger,

Thank you for this opportunity. The National LGBTQ Task Force respectfully submits this comment on the National HIV Behavioral Surveillance: Brief HIV Bio-behavioral Assessment (NHBS-BHBA) - New; Docket No. CDC-2022-0064.

We appreciate and commend the work that the CDC has done with this program in collecting data on populations at-risk for HIV and ensuring that those populations are diverse and represent all of those at risk. We ask that the CDC continue that work with this future component.

I. Task Force History

The National LGBTQ Task Force advances freedom, justice and equality for LGBTQ people. We are building a future where everyone can be free to be their entire selves in every aspect of their lives. Today, despite all the progress we have made to end discrimination, millions of LGBTQ people face barriers in every aspect of their lives: in education, housing, employment, healthcare, retirement, and basic human rights. The Task Force recognizes and appreciates the work that the CDC has put into reducing the disparate impact that HIV and other STIs have on the LGBTQ community by advancing data collection to inform HIV prevention, treatment, and diagnosis methods.

The National LGBTQ Task Force's history is deeply rooted in AIDS activism and advocacy. For over 30 years, we have fought the stigma associated with HIV/AIDS and other STIs. Recently, the Task Force has partnered with other organizations to advocate for the implementation of complete, medically accurate sex education programs. These programs work to prevent STIs and reduce their prevalence, focusing predominantly on young people from marginalized

communities. Education, medical prevention, and treatment that excludes LGBTQ identities further alienates an already at-risk community. This is why the CDC's work on studying HIV in MSM, youth MSM, transgender, and other at-risk populations to improve HIV treatment and access to prevention and treatment resources is so important. It is also why we recommend that the CDC is clear about which locations and populations will be studied in this future component of the NHBS.

II. Support for Current Approach

First, we would like to recognize that the CDC has done an exceptional job with the NHBS so far. The NHBS is a well-designed study that provides essential information to the public health community about HIV prevention, treatment, and diagnosis methods and we are glad to see the project continue.¹ The information that the study provides about the behaviors of the populations that are most at risk for HIV is essential to decreasing new HIV infections, increasing the amount of people who know their HIV status, and connecting people with treatment and prevention resources.² This is the only national study that is gathering this information.³ Findings from NHBS are used to guide local and national HIV prevention programs and to evaluate existing programs and services by assessing exposure to and use of prevention services over time, and to determine gaps in provision of, access to or use of HIV prevention services.⁴ The prevalence of HIV-related behaviors can be used to target testing, response, treatment and other prevention efforts and to evaluate uptake of current HIV testing and other prevention guidelines.⁵ The NHBS gathers data in 25 locations that have high HIV rates, which helps to inform actions that health departments in those cities can take in order to help decrease those rates and to give a comprehensive look at national trends.⁶

Multiple studies state that the data gathered by the CDC is important, reliable, and of high quality.⁷ The NHBS question formatting follows many of the suggested sexual orientation and gender identity (SOGI) data collection survey question formats from the National Academies of Sciences, Engineering, and Medicine (NASEM), including the two step gender question.⁸ Formatting questions this way has been shown to increase the accuracy and quality of the data.⁹ Multiple studies also state that the information helps improve HIV public health outcomes in cities that have higher rates of HIV than the national average.¹⁰ We commend the CDC on the collection of reliable, high quality, accurate, and important HIV behavioral data.

In addition to gathering extremely helpful information to help improve the lives of the affected communities, CDC's confidentiality procedures on these projects are comprehensive and help to ensure that patient privacy won't be violated.¹¹ This is important to continuing to gather the necessary data while protecting patients from possible backlash due to the lingering stigma around HIV in the United States. We applaud the CDC on its past work and look forward to

seeing the study continue into a new phase: the National HIV Behavioral Surveillance: Brief HIV Bio-behavioral Assessment.

III. Our Request: Release Information About Which Locations Will Provide Data and the Exact Populations That Will Be Studied

In the past, the CDC has stated that the NHBS will work with men who have sex with men, people who use injectable drugs, heterosexual people, transgender women, and female sex workers.¹ These are all populations that are at heightened risk of HIV and studying the behavior of these populations helps to further the CDC's goal of reducing new HIV infections and increasing access to treatment and prevention resources.² However, from the proposal in the federal register it is unclear which locations will provide data or the exact populations that will be studied in each location in this new component. If that data is not included, it is hard to evaluate how useful and effective the collection will be. From the model instruments and proposal, it is our understanding that the CDC is looking to collect data from traditionally underserved geographic communities, such as rural areas.³ We recommend that the CDC release information about which locations the data will be collected from and which populations will be studied for comment before starting the study so that interested organizations, such as Whitman Walker, may offer their opinions on the utility of that data collection.

IV. Summary

In summary, the National LGBTQ Task Force has a long history of advocating for quality HIV/AIDS research and medical care for the queer community. As part of our continuing advocacy work, we seek to support and improve HIV/AIDS studies, such as the CDC's work on studying HIV in MSM, youth MSM, transgender, and other at-risk populations through the NHBS-BHBS. We appreciate the work that the CDC has done with this study and recommend that the CDC release information about which locations and which populations will be studied before starting the study so interested organizations, such as Whitman Walker, may offer their opinions on the utility of that data collection. Thank you for the opportunity to comment and we hope that you will consider our request.

Thank you for the consideration of our request. For more information, please contact Clermon Acklin, Federal Regulatory Counsel, at ceacklin@thetaskforce.org or 202-604-9830.

¹ Id.

² Id.

³ Centers for Disease Control and Prevention. *60-day FRN Publication Request for Information Collection*. 2021.



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Sincerely,

A handwritten signature in black ink, appearing to read "Kierra". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Kierra Johnson
Executive Director