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TO: Centers for Disease Control and Prevention, Department of Health and Human Services, Attention: CDC-2025-0519

FROM: Omar Martinez Gonzalez
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RE: **National HIV Surveillance System (NHSS) (OMB Control No. 0920-0573, Exp. 2/28/2026) - Extension - National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC)**

To Whom it May Concern:

AIDS Foundation Chicago appreciates the opportunity to comment on this important issue, and we are writing to express our full support for continuing to collect HIV data through the National HIV Surveillance System (NHSS).

On June 5, 1981, the Centers for Disease Control and Prevention (CDC) reported through its *Morbidity and Mortality Weekly Report* the first recorded cases of AIDS in the United States¹. This report alerted providers throughout the nation of a new public health threat that was killing otherwise young, healthy individuals from otherwise innocuous infections. AIDS had arrived in the United States, and although we wouldn't know that the Human Immunodeficiency Virus (HIV) was the cause of AIDS until 1984², this crucial data-sharing in the early years of the epidemic allowed communities to mobilize to educate the community, prevent transmission, and support individuals most impacted by HIV.

Despite the tremendous progress we have made to end the HIV epidemic, from the advent of highly active anti-retroviral therapy (HAART) in 1995³, to the development of long-acting

¹ <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5021a1.htm>

² <https://www.nejm.org/doi/full/10.1056/NEJMp038194>

³ <https://pmc.ncbi.nlm.nih.gov/articles/PMC4309625/>

injectable treatment⁴ and prevention^{5,6} modalities that promise to revolutionize the fight to end the epidemic, disparities persist in access to testing, treatment, and prevention services. This has led to a disproportionate burden of HIV among Black and Latinx same-gender-loving men, transgender people, and Black cis-gender women relative to their population size⁷. While HIV impacts all races, gender identities and sexual orientations, data allows us to see changes in trends, identify where interventions are succeeding, and where there are opportunities for improvement in our outreach efforts.

For the most contemporary example of the ability of data to demonstrate program efficacy, we can look to the Ending the HIV Epidemic (EHE) initiative established under the first Trump administration in 2020⁸. In the first two years of the EHE initiative, more than 20% of people in EHE jurisdictions who had not been diagnosed or were lost to care were linked to or reengaged in care, relative to non-EHE jurisdictions⁹. The infusion of novel, dedicated funding led to a dramatic increase in the number of people living with HIV engaged in care, and we wouldn't know this without data collection and reporting. To govern with fiscal responsibility, we must prioritize data-driven decision-making to ensure public dollars are spent efficiently and directed to the most impacted communities and jurisdictions. We cannot achieve this if HIV data collection and reporting through the NHSS stops.

Cessation of HIV data collection through the NHSS would also prevent us from identifying and quickly responding to acute HIV outbreaks. In 2015, the state of Indiana saw one of our worst modern-day HIV outbreaks in which 235 people were diagnosed with HIV in a small ¹⁰town. More recently, Penobscot County, Maine, is facing the largest outbreak of HIV in the state's history, with 28 new HIV diagnoses over the last two years, driven primarily by reductions in harm reduction programs and the targeting of the unhoused individuals¹¹. Without the monitoring systems that are in place because of the NHSS, the response to these acute outbreaks would have been slower, and more people could have acquired HIV. Additionally, the detailed demographic data collected by NHSS allows us to determine how best to prioritize interventions that may work best in rural communities that may not have the same response infrastructure as in more urban centers.

The HIV data collected and reported by NHSS is indispensable in our fight to end the HIV epidemic in the United States. It allows us to identify changing trends and needs and to respond to acute outbreaks in a timely and effective manner. We cannot end the HIV

⁴ <https://pmc.ncbi.nlm.nih.gov/articles/PMC10678064/>

⁵ <https://www.nejm.org/doi/full/10.1056/NEJMoa2411858>

⁶ <https://www.nejm.org/doi/full/10.1056/NEJMoa2407001>

⁷ <https://www.cdc.gov/hiv/data-research/facts-stats/race-ethnicity.html>

⁸ <https://www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview>

⁹ <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/hrsa-ehe-data-report.pdf>

¹⁰ <https://www.npr.org/sections/health-shots/2020/02/16/801720966/5-years-after-indianas-historic-hiv-outbreak-many-rural-places-remain-at-risk>

¹¹ <https://kffhealthnews.org/news/article/hiv-outbreak-bangor-maine-syringe-services-programs-trump-homelessness/>

epidemic if we are unable to determine what the current needs are, and we can only do this with timely, accurate, and detailed data.

Thank you for the opportunity to comment on this important issue. We urge CDC to ensure that public health remains data-driven, and that the National HIV Surveillance System continues to collect and report detailed and accurate HIV data. Please do not hesitate to contact me if we can be of further assistance.

Sincerely,

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