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

RE: Docket No. CDC-2025-0519

Dear Mr. Zirger:

ADAP Advocacy is writing to express our support for the continuation and expansion of the National HIV Surveillance System (NHSS) project authorized under Sec. 304/306 of the Public Health Service Act (42 U.S.C. 242b and 242k).

The Office of Management and Budget (OMB) has requested information that, as currently worded in the request for public comment, implies that the Office is seeking justification for the reduction or elimination of HIV surveillance efforts in a misguided attempt to "reduce spending" by downsizing or eliminating outright projects with which the Trump Administration disagrees.

Our concerns about the wording of the information request are rooted in repeated attempts by the administration to consolidate multiple agencies within the U.S. Department of Health and Human Services (HHS), significant reductions in staffing at the Centers for Disease Control (CDC) and the Substance Abuse and Mental Health Services Administration (SAMHSA), and the administration's proposed Fiscal Year (FY) 2026 budget released by OMB in May 2025.

Of particular concern are the implications that the continuation of the NHSS project may not be "necessary for the proper performance of the functions of the agency" and that the information collected and provided by the NHSS does not have a "practical utility." Moreover, the request for public comment also implies that the methodology used to collect and report these data is overly burdensome and invalid, despite these methods largely comporting with the best scientific standards utilized around the world. Further, the request for information also implies that collecting this information is too costly—a position that fundamentally dismisses the very real fact that these data are used to identify clusters and outbreaks of HIV in the United States so that local, state, and federal governments can appropriately respond promptly to identify patients who are newly diagnosed, ensure that they have information about and access to antiretroviral (ARV) treatments to reduce transmissibility, conduct molecular surveillance to determine which cases are cluster/outbreak-related as opposed to other transmission patterns, and prevent further spread of the infectious disease,

all of which result in significantly lower long-term expenditures than if these data are unavailable.

At best, the specific wording of the information sought is poorly phrased in such a way that it appears to minimize the importance of the NHSS; at worst, this is a glaring example of a horrific political ideology standing in the way of and working to eliminate science, scientific contributions, and the importance of competent and comprehensive public health work.

ADAP Advocacy strongly opposes any reductions to or the elimination of the NHSS project.

About ADAP Advocacy

ADAP Advocacy is a national 501(c)(3) non-profit organization whose mission is to promote and enhance the AIDS Drug Assistance Program (ADAP) and improve access to care for PLWHA. ADAP Advocacy has worked tirelessly to ensure that PLWHA in the U.S. are able to access the medications they need to achieve and sustain viral suppression, undetectability, and untransmissibility.

The Vital Importance of Timely, Accurate, and Applicability of HIV Surveillance in Public Health

Since the 1980s, the CDC, HHS, and the National Institutes of Health (NIH) have played vital roles in the surveillance, reporting, and prevention of HIV transmission in the United States. In the early years of the HIV epidemic, one of the greatest challenges faced by patients living with Gay-Related Immune Deficiency (GRID)—the initial name for Acquired Immune Deficiency Syndrome (AIDS), which was changed only after disease surveillance found that the disease was not simply restricted to gay men—was the lack of timely, accurate, and unbiased information. While many other disease states prior to the discover of the HIV virus had been observed on a general population basis, this new retrovirus provided a unique opportunity to identify and track disease acquisition and progression through what were initially smaller populations, including patients with hemophilia who acquired the disease through blood transfusions, persons who injected drugs (PWID) who acquired the disease through unsafe drug consumption practices, and other smaller demographic groups.

The HIV/AIDS epidemic quick spread through these limited population groups allowed researchers and surveillance specialists to both adapt existing methodologies to be more applicable to disease- and population-specific data collection and monitoring, but to develop new methods that would soon become universally accepted as the gold standard for disease surveillance. It was through these revised and newly created surveillance methods that we began to better understand both how HIV was transmitted from person to person and how utilizing timely, accurate data could help to identify at- and high-risk population groups where outreach was necessary to prevent further spread of the disease. The information gleaned from these methods also allowed for the creation and implementation of universal precautions which helped to mitigate and reduce the risk of transmission and revolutionized healthcare, making it a safer for patients, medical staff, and the general population.

These methods also allowed us to better understand several aspects of not only HIV, but other disease states, including viral hepatitis, cirrhosis, renal disease, and other diseases, which allowed for new and better understandings of disease progression, treatment success and failure rates, the impacts of diseases on different populations, and mortality. The establishment of the NHSS has allowed for significantly better and more successful disease interventions to prevent small clusters from becoming full-blown outbreaks.

A prime example of how NHSS data were used to successfully address outbreaks occurred during and after the 2015 outbreak of HIV in Scott County, Indiana. In late-2014, an estimated 12,500 people were living with HIV/AIDS in the state of Indiana, a significant majority of whom resided in urban areas of the state. In Scott County, just 5 people had been diagnosed with HIV in the ten years prior to December 2014; by March 26th, 2015, 55 new cases had been confirmed with 13 preliminary cases under investigation (Janowicz, 2016). Alerted to this explosion of new HIV transmissions, the state of Indiana and the CDC began actively working to identify how this outbreak was occurring, which populations were being impacted worst, and which interventions would be most effective in preventing further spread. What they discovered was that this outbreak—along with a concurrent outbreak of Hepatitis C (HCV)—was largely impacting PWID. Using NHSS surveillance data allowed for development and implementation of several successful interventions and services, including community-wide surveillance, contact tracing and door-to-door HIV testing, and outreach programs targeting lower-income, transient, and high-risk populations, as well as establishing new linkages to addiction treatment and harm reduction services, including the establishment of Indiana's first sanctioned syringe service programs (SSPs) and programs to administer pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) which helped to prevent the wider spread of HIV throughout Scott County and the surrounding areas. By 2016, more than 230 individuals had contracted HIV—a number that could have been lower had political ideology not resulted in delayed action from then-Governor Mike Pence (Wright, 2025).

The Scott County outbreak was one of the largest recorded injection drug use (IDU)-related outbreaks in the history of the United States. Out of that outbreak, however, the nation began a renewed dedication to testing and prevention that might otherwise never have arisen. It clearly demonstrated the importance of timely, accurate disease surveillance in identifying disease outbreaks and developing interventions to minimize their impacts.

Unfortunately, political ideologies would soon scuttle these scientifically proven harm reduction efforts, with local, state, and federal politicians and administrators imposing "morals"-based arguments and policies that dismantled harm reduction programs and resulted in unnecessary and poorly controlled HIV outbreaks, despite evidence demonstrating their efficacy. Officials in the state of West Virginia, just three years after the Scott County, Indiana, outbreak, began working to dismantle harm reduction programs across the state, resulting in the closure of the program in Kanawha County. By late 2018, this move proved disastrous, as West Virginia entered what would become a multi-county, multi-year, and uncontrolled outbreak of HIV related to IDU.

Prior to 2018, the state of West Virginia had seen an annual average of 67 new HIV cases. In 2018, 95 new cases had been identified, of which 41 (43.2%) were IDU-related. By 2020, despite a 2/3 reduction in the administration of HIV tests due to the COVID-19 pandemic, 138 new cases were identified, of which 110 (81.5%) were IDU-related (West Virginia Office of Epidemiology & Prevention Services, 2025). The majority of new HIV cases were identified in Cabell and Kanawha Counties, the first of which just saw the closure of its harm reduction program effective December 16th, 2025 (Coyne & Kersey, 2025).

Molecular surveillance also found that the two outbreaks, while similar in transmission modality, were caused by distinc*t* strains, indicating that not one but two outbreaks were occurring simultaneously.

During these concurrent outbreaks, the state legislature worked to pass legislation designed to force harm reduction programs across the state to close unless they could comply with significantly burdensome regulatory and administrative hurdles (Senate Bill 334). Stunningly, the Kanawha County Commission and Charleston City Council chose to disbelieve then-CDC Chief of HIV Prevention Dr. Demetre Daskalakis' assertion that these outbreaks were the "most concerning in the United States," convincing then-Senator Joe Manchin to initiate a formal congressional inquiry into the matter (CBS Pittsburgh, 2021).

The fallout of these moves has been significant. Active testing for HIV in the state of West Virginia only briefly recovered after the pandemic before once again cratering due to political interference and still falls short of what is necessary to identify new cases in no small part because of state and federal funding shortages. Surveillance efforts have also been unsuccessful in reaching into the counties surrounding Cabell and Kanawha, not because the workers are unwilling, but because funding has been decreased and the harm reduction programs that once provided those services have been shuttered. This has resulted in surveillance data that are likely insufficient to combat further spread of HIV in the region.

In both Indiana and West Virginia, surveillance data from the NHSS were vital to building effective, community-based, comprehensive responses. The interventions in Indiana were successful; those in West Virginia have largely failed due to the types of political interference currently threatening the NHSS. Despite its high rate of success, Scott County's county commissioners imposed their political ideology on public health in 2021 by shuttering the harm reduction program that literally stopped an HIV outbreak (AIDS United, 2021).

Make no mistake: designating the critical work done by NHSS and the local, county, and state surveillance teams as lacking "practical utility" or being "invalid" is not only a direct threat to sound science, but a tacit implication that the acquisition of HIV is a moral failing and that the government should not be involved in engaging in public health work to prevent the spread of this potentially fatal disease.

ADAP Advocacy cannot more strenuously oppose any reductions in funding, staffing, or services provided by the NHSS project. These functions *cannot* be performed at the local level in a reasonable, accurate, or safe manner without national coordination. It cannot be done because infectious diseases do not recognize demographic, political, or "moral" borders. We know that people travel, and with them travel any infectious disease they may have acquired. Moreover, we know that no amount of moralizing will prevent the transmission of infectious diseases. We also know that robust disease surveillance provides communities and nations with their best chance of combating diseases like HIV.

Recommendations

In summary, ADAP Advocacy makes the following recommendations:

1. The Office of Management and Budget should clearly, publicly, and unequivocally recognize and assert the importance and practical utility of the National HIV Surveillance System.

2. The Office of Management and Budget should cease and desist any assertions or implications that the work of HIV surveillance is overly burdensome or costly.

3. The Office of Management and Budget should work to ensure that all Congressionally appropriated and allocated funds for HIV surveillance are disbursed to states in a timely manner without any political interference from or additional requirements imposed upon the intended recipients by any member of the Trump Administration, its appointees, or employees of the agencies, departments, offices, and/or states to which those funds have been allocated.

Thank you for allowing ADAP Advocacy the privilege of commenting on this vital health system, and we look forward to providing any additional comments or clarification should they be deemed necessary.

Respectfully submitted,

Brandon M. Macsata
CEO

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