

November 26, 2025

Jim O'Neil
Acting Director
Centers for Disease Control and Prevention
1600 Clifton Road NE
Atlanta, GA 30329

RE: Docket No. CDC–2025– 0519; Proposed Data Collection Submitted for Public Comment and Recommendations

Dear Mr. O'Neil:

The Infectious Diseases Society of America (IDSA) and the HIV Medicine Association (HIVMA) appreciate the opportunity to express our strong support for continuing data collection for the National HIV Surveillance System (NHSS) and to emphasize its vital role in public health. IDSA includes over 13,000 physicians, scientists, public health workers and other clinicians dedicated to infectious diseases (ID) prevention, care and research. Within IDSA, HIVMA represents nearly 6,000 HIV clinicians and researchers working at the forefront of the HIV epidemic. **As ID and HIV clinicians, our work depends on the essential contributions of NHSS in tracking HIV epidemiologic data to detect outbreaks, direct prevention resources and stop disease transmission.**

To achieve the ambitious elimination goals of the bipartisan Ending the HIV Epidemic initiative, enhancing surveillance through the NHSS is essential. The NHSS provides the real-time data necessary for prompt identification and response to HIV outbreaks, aligning with the EHE's goal of reducing new HIV infections in the United States by 90% by 2030. NHSS was established to collect data on HIV incidence, prevalence and demographics, providing essential insights for ID and HIV health professionals. These data empower health care professionals to make informed clinical decisions and tailor treatment protocols based on demographic trends and reported outcomes. Importantly, the utility of NHSS extends beyond ID and HIV specialists; primary care providers, emergency medicine providers and other healthcare professionals also utilize these data to enhance patient care and ensure comprehensive health responses. State and local health departments rely on NHSS data to monitor HIV trends, allocate resources effectively, and evaluate the success of prevention programs.

Surveillance data have also been foundational in shaping policies and initiatives regarding HIV and other communicable diseases. Since the publication of the first HIV surveillance report by the Centers for Disease Control and Prevention (CDC) in 1981, these data have influenced federal funding allocations, including the Ryan White Program and the Ending the HIV Epidemic initiative. Additionally, NHSS data are crucial in addressing syndemics, where HIV intersects with other communicable diseases and related conditions, such as hepatitis C, sexually transmitted infections (STI), tuberculosis (TB) and the opioid epidemic. By identifying vulnerable populations and capturing trends in coinfections, surveillance data support integrated strategies that enhance public health responses to HIV and other communicable diseases. These data are crucial for improving population health, especially in rural populations where access to health care may be limited and in the neonatal population, which is at extremely high risk in situations where the birth mother is ill with HIV, syphilis,

among others. Without NHSS, our ability to meet the EHE goals would be severely compromised, undermining efforts to ensure timely prevention, early detection and effective response to HIV.

In response to areas of specific interest to the Office of Management and Budget, we offer the following comments:

Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility.

- The proposed collection of information for NHSS is vital for CDC's and state public health functions. Continuous HIV data collection is crucial for identifying and responding to health trends. Recent outbreaks in central Nebraska—an area not traditionally associated with high HIV risk—underscore the need for ongoing surveillance (Hammel, 2022). In 2025, HIV outbreaks were reported in Maine, Indiana and West Virginia, highlighting the importance of surveillance programs to mobilize targeted public health responses to control the spread of HIV.

Evaluate the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used.

- Accurately assessing the resources required for data collection is essential to prioritize efforts to reduce duplication and increase efficiency and to ensure that public health programs have sufficient resources to support data collection. The benefits of investing in surveillance are enormous and result in long-term savings because the data allow states and communities to direct limited resources to where they are most needed.

Enhance the quality, utility, and clarity of the information to be collected.

- To improve the quality and clarity of information collected through NHSS, CDC should streamline the data collection processes. Revising forms to eliminate redundancies and investing in technology for electronic submissions can enhance accuracy and timeliness. Engaging health care providers and state and local health departments in developing these innovations will ensure that the tools meet their needs.

Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical or other technological collection techniques or other forms of information technology, e.g., permitting electronic submissions of responses.

- The current reliance on paper forms and manual data entry is outdated and counterproductive in the digital age. Modernizing and streamlining data collection makes the process more efficient and improves the timeliness of the release so that it can inform prevention strategies, better ensure that resources are deployed where they can have the greatest impact and prevent outbreaks.

Assess information collection costs.

- Assessing the costs associated with information collection is vital for understanding the overall impact of NHSS, and its impact of lowering health care costs by helping to more effectively leverage limited resources and to dramatically reduce health care costs by preventing disease transmission. While there may be initial expenses related to transitioning to electronic systems

and workforce training, these costs should be weighed against the long-term savings generated by a more efficient and accurate surveillance system. Historical data support the notion that investing in robust public health infrastructure leads to significant cost savings in health care by preventing outbreaks and facilitating timely interventions (Shrestha, 2023).

HIV surveillance saves lives and federal resources

Continuous, accurate data enable us to adapt to evolving epidemics. **Any reduction in HIV surveillance poses a grave risk, as CDC is currently the sole source of national HIV data and provides vital support for state and local health departments to conduct surveillance. Diminished surveillance will put some geographic areas, particularly rural areas, at risk of unrecognized, and therefore unaddressed, increases in HIV incidence resulting in more serious outbreaks and a rise in health care costs.**

The financial implications of a weakened surveillance system are significant. Latest trends indicate stagnation in HIV case reductions, emphasizing the urgent need for accurate data to prioritize funding and resources effectively (AIDS Vu, 2025). Proposed budget cuts threaten the integrity of vital surveillance systems, increasing the financial burden on states while hindering public health responses. Surveillance and data systems are among the most efficient uses of prevention dollars, identifying where infections are rising and targeting interventions to the communities most in need.

NHSS is indispensable in the fight against HIV syndemics, including hepatitis C, STIs, TB and infections associated with the opioid epidemic. We urge CDC to continue its commitment to robust HIV surveillance and to consider our proposed solutions to strengthen data collection. Thank you for your attention to this critical matter. We look forward to contributing to a strengthened public health response through ongoing engagement with CDC.

Sincerely,



Ronald G. Nahass, MD, MHCM, FIDSA
President, IDSA



Anna K. Person, MD, FIDSA
Chair, HIVMA

References

- AIDSvu. (2025, November 05). *Understanding the Current HIV Epidemic in the United States*. Retrieved from AIDSvu: <https://map.aidsvu.org/profiles/nation/usa/overview#0-2-Demographics>
- Hammel, P. (2022, July 20). *Nebraska Examiner*. Retrieved from Nebraska sees rise in new HIV cases, especially in rural areas, but cause unclear: <https://nebraskaexaminer.com/briefs/nebraska-sees-rise-in-new-hiv-cases-especially-in-rural-areas-but-cause-unclear/>
- Shrestha, R. K. (2023, January 26). *Costs and cost-effectiveness of a collaborative data-to-care intervention for HIV treatment and care in the United States*. Retrieved from Journal of the International AIDS Society: <https://doi.org/10.1002/jia2.26040>