

National HIV Surveillance System (NHSS)

Attachment 2 (b)
60 Day Federal Register Comments

**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).
Federal Register Vol. 90, No. 187, Tuesday, September 30, 2025
Public Comments**

Name: Angie Bengtson
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 9/30/2025
Comment ID: CDC-2025-0519-0002
Full Comment:

I am writing in support of the National HIV Surveillance System (CDC-2025-0519). As a public health professional working in the field of HIV, this surveillance system is central to monitoring, responding to, and ultimately reducing the HIV epidemic in the United States. I recommend this system continue to be funded and supported by the US government in order to safeguard the health of all Americans.

Name: Anonymous
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 10/1/2025
Comment ID: CDC-2025-0519-0003
Full Comment:

Yes, CDC should continue supporting NHSS. Effective disease intervention requires timely and accurate disease reporting and analysis. Do not allow political ideology to poison public health.

Name: Jose Rodriguez
Submitter Email: jar0424@gmail.com
Submitter Address: 331 N Street Northeast, Washington, DC, USA
Date Submitted: 10/2/2025
Comment ID: CDC-2025-0519-0004
Full Comment:

As an advocate for public health, I appreciate the opportunity to provide comments on the proposed discontinuation of the HIV surveillance data collection. The National HIV Surveillance System (NHSS) plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate resources to combat this epidemic. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals living with HIV.

I have seen, firsthand, the impact of surveillance data at the Baltimore City Health Department and how it informs the department's ability to respond to and address HIV, as well as provide outreach, such as PrEP, in areas that are most needed.

I strongly urge the CDC to reconsider the decision to discontinue the collection of HIV surveillance data. The NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions, and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Kevin Sitter

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 10/3/2025

Comment ID: CDC-2025-0519-0005

Full Comment:

I am submitting these comments as a person with a Masters in Social Work and a Masters in Public Health with more than 40 years experience working in the field of HIV/AIDS and being a 65 year old cis-gender white male who has lived with HIV for the last 21 years. The CDC's national surveillance system has been vital in monitoring the HIV pandemic and guiding local prioritization of services to those most disproportionately impacted by HIV infection. It has done so with the utmost data integrity and in collaboration with the states and territories of the United States.

Now is the time to expand the surveillance system to include more factors that drive not only the HIV pandemic but most every health condition, such as elements of the social determinants of health: housing status, incarceration history, more refined racial categories, distinctions among Afro-Latinx and various immigrant communities, and continued collection of gender identity and sexual orientation data.

Including housing status, incarceration history, and income will illuminate disparities more accurately. Now is the time to improve the surveillance system and assist healthcare, social service providers, funders, and policymakers in addressing health conditions more precisely. The CDC's surveillance system is vital to promoting and supporting the health of our nation.

Organization: NMAC

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 10/16/2025

Comment ID: CDC-2025-0519-0006

Full Comment:

See attached file(s)

Attached Comment:

Comment from NMAC, formerly the National Minority AIDS Council on CDC-2025-18904: Proposed Revision of the National HIV Surveillance System (NHSS)

NMAC appreciates the opportunity to submit comments on the proposed revision of the National HIV Surveillance System (NHSS). For nearly four decades, NMAC has worked to build leadership in communities of color to end the HIV epidemic in the United States. Our mission is grounded in the principles of racial justice, health equity, and community empowerment. Surveillance data not only

measure progress, but also shape resource allocation, policy direction, and accountability. As such, the proposed revision of the NHSS has profound implications for people living with and affected by HIV, particularly those in marginalized communities. We commend the CDC for seeking to strengthen the NHSS, and we offer the following expanded comments to ensure that this revision advances equity, builds trust, and prepares the nation to meet the evolving challenges of the epidemic.

Since the earliest days of the epidemic, surveillance has been both a scientific necessity and a political tool. In the 1980s, surveillance systems were used to track the spread of HIV but often excluded marginalized populations—women, transgender individuals, immigrants, and communities of color—who bore a disproportionate burden of the epidemic. As a result, funding streams and prevention strategies failed to align with the actual demographics of HIV in America. Today, surveillance remains the cornerstone of the Federal response. The Ending the HIV Epidemic initiative, Ryan White Program funding allocations, state and local prevention grants, and broader health system planning all depend on the accuracy, inclusivity, and timeliness of NHSS data. Without robust and representative surveillance, it is impossible to design effective interventions that reach those most in need. Yet surveillance is not neutral. How we count people—what categories are used, what identities are recognized, and what determinants are measured—reflects choices that either strengthen or weaken the accuracy and reliability of data. This revision is an opportunity to ensure that the NHSS reflects the full diversity and realities of people affected by HIV.

Broad racial and ethnic categories often obscure meaningful differences. For example, “Asian” includes over 20 national origins and hundreds of languages, with HIV burden varying significantly across subgroups. Pacific Islanders are frequently grouped with Asians despite distinct histories and epidemiological profiles. Similarly, the term “Hispanic/Latino” masks differences between Afro-Latinx, Caribbean, Central and South American, and Mexican communities. NMAC strongly urges the CDC to require disaggregated data collection and reporting at the jurisdictional level. Federal recognition of these subgroups is necessary to allocate funding fairly and to develop culturally competent interventions. Transgender

women—particularly Black and Latina transgender women—experience some of the highest HIV prevalence rates in the United States, yet they remain invisible in many state surveillance systems. Nonbinary individuals are often not captured at all. The CDC must mandate standardized sexual orientation and gender identity fields across all jurisdictions and provide technical assistance for accurate implementation. This includes ensuring that staff are trained in culturally competent data collection and that systems allow for self-identification rather than forced categorization. Anything less risks perpetuating invisibility and undermining national HIV goals.

The HIV epidemic is shaped by broader social and structural factors. Individuals who lack stable housing, experience incarceration, or live without health insurance face heightened risk and poorer outcomes. Surveillance that ignores these realities paints an incomplete picture. NMAC urges the CDC to incorporate indicators of social determinants of health into the NHSS, including housing stability, incarceration history, employment and income status, access to health coverage, and food insecurity. In addition, HIV often overlaps with other public health crises. Hepatitis C, syphilis, and opioid use are tightly interlinked with HIV transmission. Surveillance must capture data on these syndemics to support integrated interventions.

By 2030, a majority of people living with HIV in the U.S. will be over the age of 50. This aging population faces unique challenges: comorbidities, polypharmacy, cognitive decline, and

increased reliance on Medicare and Medicaid. Yet current surveillance does little to account for these shifts. The CDC must ensure that the NHSS captures aging-related data, including comorbidities, mental health conditions, and payer source. This will help policymakers prepare for the health system pressures that accompany an older HIV-positive population. Without such foresight, programs risk being overwhelmed by demand and ill-prepared to provide age-appropriate care.

Surveillance is only effective if communities trust it. For populations who have historically been criminalized and stigmatized, this trust is fragile. NMAC emphasizes that data must never be shared with law enforcement or used in prosecutions related to HIV criminalization statutes, that jurisdictions adopt encryption and confidentiality protocols meeting or exceeding HIPAA standards, and that communities are informed of how their data are collected, stored, and used. This includes clear explanations in multiple languages and formats. Failure to uphold these principles risks driving people away from testing and engagement with the health system, undermining national goals.

Community involvement is not optional—it is essential. Surveillance systems that exclude the voices of people living with HIV, especially from communities of color, will lack legitimacy.

NMAC calls on the CDC to establish formal mechanisms for community advisory input into NHSS revisions, to fund community-based organizations to participate in surveillance planning and oversight, and to ensure that data dissemination is not limited to academic journals but is accessible to grassroots advocates. Surveillance must empower communities to hold governments accountable, not simply serve bureaucratic purposes. Because Federal HIV funding is tied to surveillance data, shortcomings in data collection lead directly to ineffective funding allocation. If disproportionately impacted communities are invisible in the NHSS, they will remain underfunded. The CDC must ensure that surveillance data are published regularly in disaggregated formats, that communities have access to the same datasets Federal agencies use to determine funding, and that mechanisms exist for communities to challenge or appeal funding decisions that do not align with epidemiological realities.

The revision of the National HIV Surveillance System is a defining moment for the nation's HIV response. Surveillance must evolve from a narrow focus on case counts to a holistic system that reflects the complexity of people's lives. It must disaggregate race and ethnicity, capture gender identity and sexual orientation with fidelity, integrate social determinants of health, track syndemics, and prepare for the aging of the epidemic. It must be implemented with uncompromising privacy protections and built in partnership with the very communities it seeks to serve. For too long, important populations communities have been rendered invisible by data systems designed without them. This revision is a chance to correct these gaps. NMAC urges the CDC to seize this opportunity to build a surveillance system that not only measures the epidemic but also ensures fairness, accountability, and dignity for all people living with HIV.

Name: Brian Chow

Submitter Email: brian.dw.chow@gmail.com

Submitter Address: 705 West 9th Street, Los Angeles, CA, USA

Date Submitted: 10/19/2025

Comment ID: CDC-2025-0519-0008

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Linda Kress

Submitter Email: lakress@cox.net

Submitter Address: 9785 East Golden Currant Drive, Tucson, AZ, USA

Date Submitted: 10/19/2025

Comment ID: CDC-2025-0519-0011

Full Comment:

I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Lylybell Zhou

Submitter Email: lylybell@usf.edu

Submitter Address: 215 W Beach Pl, Tampa, FL 33606, USA

Date Submitted: 10/19/2025

Comment ID: CDC-2025-0519-0009

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

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Name: Nassim Mokraoui

Submitter Email: nasmokra@gmail.com

Submitter Address: 4410 Brittany Trail Dr, Champaign, IL, 61822, US

Date Submitted: 10/19/2025

Comment ID: CDC-2025-0519-0007

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

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Name: Siri Peddineni

Submitter Email: siriped2001@yahoo.com

Submitter Address: 2337 Southwest Archer Road apt 3035, Gainesville, FL, USA

Date Submitted: 10/19/2025

Comment ID: CDC-2025-0519-0010

Full Comment:

As a future ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the

epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Chris Parsons

Submitter Email: chris.parsons@unchealth.unc.edu

Submitter Address: 302 Woodbyne Ave, Laurel Park, NC, USA

Date Submitted: 10/20/2025

Comment ID: CDC-2025-0519-0012

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

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Name: Yvonne Viteri

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 10/20/2025

Comment ID: CDC-2025-0519-0013

Full Comment:

I am a clinical pharmacist, worried about the research, patient care, and access to life saving resources due to the funding cut by the government.

Name: Aleena Zia

Submitter Email: aleenazia92@gmail.com

Submitter Address: 777 N Main St, Unit 3, West Hartford, CT, 06117, US

Date Submitted: 10/21/2025

Comment ID: CDC-2025-0519-0015

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we

maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I see firsthand how this disease ravages lives and bodies of the most vulnerable. Please. Help.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Daniel G. Garza

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 10/21/2025

Comment ID: CDC-2025-0519-0014

Full Comment:

I strongly urge the CDC to continue supporting the National HIV Surveillance System (NHSS). This system is essential for tracking HIV trends, identifying disparities, and guiding resources to communities most impacted, especially LGBTQIA+, Black, Latino, and other marginalized groups. As an advocate and survivor, I've seen firsthand how data drives life-saving outreach, early detection, and equitable care. Without NHSS, we risk losing visibility, accountability, and the ability to respond effectively. Ending the HIV epidemic requires real-time data, community trust, and targeted action. NHSS is the backbone of that response.

Name: Armando Rubio

Submitter Email: armandorubio@rubiointernationalenterprisesllc.com

Submitter Address: 1032 East Brandon Boulevard Suite PMB 7979, Brandon, FL, USA

Date Submitted: 10/27/2025

Comment ID: CDC-2025-0519-0016

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Brittany Szabo

Submitter Email: brittany.szabo@gmail.com

Submitter Address: 389 Ormond Street Southeast, Atlanta, GA, USA

Date Submitted: 10/29/2025

Comment ID: CDC-2025-0519-0017

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Ingrid Bassett

Submitter Email: ibassett@post.harvard.edu

Submitter Address: 28 Arlington Street, Cambridge, MA, USA

Date Submitted: 10/31/2025

Comment ID: CDC-2025-0519-0018

Full Comment:

As an ID/HIV health professional and researcher, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

By collecting detailed surveillance data, we are able not only to allocate resources, but to measure the effectiveness of different HIV prevention and treatment interventions. This aligns with the concept of radical transparency espoused by the current administration.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Micayla Schmitt
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/3/2025
Comment ID: CDC-2025-0519-0019

Full Comment:

As a Pediatric Nurse Practitioner (PNP) student, I support the continuation of the National HIV Surveillance System (NHSS) by the Centers for Disease Control and Prevention (CDC). The NHSS provides critical data that guide national and local strategies for HIV prevention, treatment, and resource allocation. Reliable surveillance data are essential to identify trends, monitor progress, and ensure that care reaches populations most affected by HIV. From a pediatric perspective, these data also help improve early detection, prevention education, and options for care for children and adolescents. Strengthening electronic reporting systems and integrating data on social determinants of health would further enhance the system's ability to inform appropriate interventions. Continued investment in the NHSS is vital to achieving national goals for ending the HIV epidemic and ensuring that all patients, including youth, receive evidence-based and compassionate care.

Name: Samira Zantout
Submitter Email: zantoutsamira@gmail.com
Submitter Address: 5 E 14th Pl, Chicago, IL 60605, USA
Date Submitted: 11/6/2025
Comment ID: CDC-2025-0519-0021

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Erin Bonura
Submitter Email: emurchan@gmail.com
Submitter Address: 13254 Deerfield Court, Lake Oswego, OR
Date Submitted: 11/6/2025
Comment ID: CDC-2025-0519-0020

Full Comment:

As an ID/HIV physician and fellowship Program Director, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a

crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Angel Algarin

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/7/2025

Comment ID: CDC-2025-0519-0023

Full Comment:

I strongly support the continued data collection under the National HIV Surveillance System (NHSS). As a public health researcher focused on HIV prevention and health equity, I view NHSS as an essential cornerstone of national, state, and local public health infrastructure.

The NHSS provides the only comprehensive, population-based system that monitors the incidence, prevalence, and distribution of HIV in the United States. These data are critical to identifying emerging trends in transmission, informing prevention strategies, and allocating limited resources where they are most needed. Without this ongoing surveillance, public health agencies would lack timely, accurate information to track the epidemic and measure progress toward national goals, including the Ending the HIV Epidemic in the U.S. initiative.

NHSS data are also fundamental to addressing health disparities. The inclusion of demographic, geographic, and behavioral information allows for identification of populations disproportionately affected by HIV, guiding culturally and contextually responsive interventions. The system's ability to detect and monitor clusters of recent transmission enables rapid public health action to prevent further spread, which is particularly vital in communities with limited access to HIV prevention and care services.

Furthermore, NHSS supports accountability and transparency in federally funded programs, providing reliable indicators to evaluate progress in prevention, testing, and treatment. The continuation of this data collection ensures consistency in long-term monitoring and allows for evidence-based decision-making that saves lives and resources.

For these reasons, I urge the CDC and the Office of Management and Budget to approve the continuation of the NHSS data collection without interruption. Maintaining and strengthening this system is essential to sustaining national efforts to prevent new HIV infections, improve health outcomes for people living with HIV, and achieve health equity.

Name: Anonymous
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/7/2025
Comment ID: CDC-2025-0519-0024

Full Comment:

I am writing in support of the National HIV Surveillance System (CDC-2025-0519). As a public health researcher, I see the National HIV Surveillance system is an invaluable tool for understanding and responding to the HIV epidemic in the United States. The data produced by the NHSS is critical and irreplaceable. It is imperative that the NHSS continue to operate and that funding is prioritized to ensure it continues to produce comprehensive data on HIV prevention and treatment in the United States.

Organization: Beyond Our Status
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/7/2025
Comment ID: CDC-2025-0519-0025

Full Comment:

I strongly support the continuation of the CDC's National HIV Surveillance System (NHSS). This program is vital to tracking HIV trends, guiding prevention efforts, and ensuring resources reach the communities most in need. Ending or reducing NHSS would weaken our national response, compromise data accuracy, and harm public health progress. Continued investment in NHSS is essential to achieving equity, accountability, and the goal of ending the HIV epidemic.

Organization: HIV Alliance
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/7/2025
Comment ID: CDC-2025-0519-0022

Full Comment:

We are a nonprofit focused on providing HIV care and Prevention. We do not have direct access to HIV data but we want to be sure we are using our limited funds for populations being most impacted by HIV. Access to data is critical to our ability to be effective and to efficiently use HIV funds. It is important for everyone using public dollars for HIV prevention or care to have access to data so that funds can be appropriately spent to obtain the greatest impact for specific regions.

Name: Joshua Barocas
Submitter Email: joshua.barocas@cuanschultz.edu
Submitter Address: 1520 Adams Street, Denver, CO, USA
Date Submitted: 11/8/2025
Comment ID: CDC-2025-0519-0026

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<< I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Thamicha Isaac

Submitter Email: Thamicha.Isaac@openlypositive.com

Submitter Address: 1464 Ocean Ave, Brooklyn, NY 11230

Date Submitted: 11/8/2025

Comment ID: CDC-2025-0519-0027

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

As a longtime HIV advocate, a Public Health Advisor with the New York City Department of Health, and a Black woman living with HIV for over twenty years, I know firsthand how essential accurate HIV surveillance data is to real community outcomes. HIV surveillance is not an abstract concept for me. It directly affects the quality of care people receive, how quickly they are linked to treatment, and whether prevention resources reach the communities that need them the most. The National HIV Surveillance System helps public health departments like mine identify rising trends in real time, respond to outbreaks, and ensure that care and prevention funding are distributed equitably.

Ending the HIV epidemic requires more than good intentions. It requires reliable data that reflects what is actually happening on the ground. Without NHSS, marginalized communities, especially Black and Brown women, immigrants, LGBTQ communities, and people experiencing housing instability would be left even further behind. NHSS is essential for accountability, transparency, and for guiding real solutions that actually save lives. I strongly support the continuation of this system and urge CDC to protect and strengthen it.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Ayan Mohamed

Submitter Email: xayat06@gmail.com

Submitter Address: Corso Somalia, Mogadishu, Somalia

Date Submitted: 11/9/2025

Comment ID: CDC-2025-0519-0028

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

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Name: Kirk Fetters

Submitter Email: kbffidler@gmail.com

Submitter Address: 1351 Spruce Street, Denver, CO, USA

Date Submitted: 11/9/2025

Comment ID: CDC-2025-0519-0029

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I personally have used NHSS and other similar national disease surveillance from the CDC in research and in clinical practice. There is no alternative to this important data source given the CDC's reach, influence, and statutory authority.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Douglas Krakower
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/10/2025
Comment ID: CDC-2025-0519-0034

Full Comment:

Dear HHS,

I am an infectious diseases physician and researcher who studies ways to improve HIV prevention in the US using the most impactful and cost-effective interventions. We now have access to the most potent HIV prevention tools this nation has ever seen, including long-acting injectable preexposure prophylaxis (PrEP), and we need clinical data on new HIV infections to inform an efficient and intelligent deployment of these new tools. These data can save costs and lives in the short and long term by informing how we focus our efforts to disseminate PrEP and also identify and treat people with undiagnosed HIV across the nation. The American people will benefit from a robust system of HIV surveillance to prevent a resurgence of HIV, which is a very real possibility with any dismantling of our current HIV prevention infrastructure.

Sincerely,

Douglas Krakower, MD
Cambridge, MA

Name: Ernie-Paul Barrette
Submitter Email: ernie-paulbarrette@wustl.edu
Submitter Address: 1303 Spring Snow Dr, Saint Louis, MO, 63131, US
Date Submitted: 11/10/2025
Comment ID: CDC-2025-0519-0032

Full Comment:

As an HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

While I work in St. Louis, MO rates of new HIV infections in Missouri in rural parts of the state have been historically very high. It was for this reason that the state of Missouri was added to the Ending the HIV Epidemic program during President Trump's first term. We need to know who and where new HIV infections are occurring in order to prevent new infections and treat newly infected people.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Michael T. Melia
Submitter Email: mmelia4@jh.edu
Submitter Address: 2109 Old Pine Rd, Timonium, MD, USA
Date Submitted: 11/10/2025
Comment ID: CDC-2025-0519-0033

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Miriam Barshak
Organization: NOT PROVIDED
Submitter Email: mbarshak@partners.org
Submitter Address: 25 Bellingham Dr, Chestnut Hill, MA, USA
Date Submitted: 11/10/2025
Comment ID: CDC-2025-0519-0031

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Seth Zissette
Organization: NOT PROVIDED
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/10/2025

Comment ID: CDC-2025-0519-0030

Full Comment:

I am writing in support of the National HIV Surveillance System (CDC-2025-0519). I am a public health professional who has worked in the field of HIV for over a decade and attest to the vital importance of this surveillance system in allowing medical professionals, policymakers, and researchers to understand and respond to the HIV epidemic in the United States so that we may ultimately work to end the epidemic. I wholeheartedly recommend this system continue to be funded and supported by the US government in continued support of the health of all Americans.

Name: Omar Martinez Gonzalez

Organization: AIDS Foundation Chicago

Submitter Email: Omartinezgonzalez@aidschicago.org

Submitter Address:

200 W Monroe St, Suite 1150

Chicago, IL 60606

Date Submitted: 11/12/2025

Comment ID: CDC-2025-0519-0035

Full Comment:

The HIV data collected and reported by the National HIV Surveillance System (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 epidemic if we are unable to determine what the current needs are, and we can only do this with timely, accurate, and detailed data. As such, AIDS Foundation Chicago (AFC) urges the Centers for Disease Control and Prevention (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. AFC welcomes the opportunity to comment on this important issue and lay out our argument in the attached document.

Attached Comment:

Submitted via the Federal Regulations.gov Portal

DATE: November 12, 2025

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

FROM: Omar Martinez Gonzalez

Senior Manager, Policy & Advocacy

AIDS Foundation Chicago

200 W Monroe St, Suite 1150

Chicago, IL 60606

Omartinezgonzalez@aidschicago.org

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 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 10¹⁰. 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 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,
Omar Martinez Gonzalez
Sr. Manager, Policy & Advocacy
AIDS Foundation Chicago
200 W Monroe St, Suite 1150
Chicago, IL 60606
Omartinezgonzalez@aidschicago.org

- 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/>
- 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/>

Name: Carl Latkin
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/13/2025
Comment ID: CDC-2025-0519-0036
Full Comment:

The NHBS is a critical national surveillance system for HIV prevention and care. It enables early risk detection, and the trends data are critical for planning at the national and local levels. It has also established an excellent platform for local and regional research. There is no other comparable surveillance system in the US.

Name: Michael T. Melia
Submitter Email: mmelia4@jh.edu
Submitter Address: 2109 Old Pine Rd, Timonium, MD, USA
Date Submitted: 11/13/2025
Comment ID: CDC-2025-0519-0037
Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the

importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Sherik Mossad

Submitter Email: mossads@ccf.org

Submitter Address: 9500 Euclid Ave, Cleveland, OH, 44106, US

Date Submitted: 11/13/2025

Comment ID: CDC-2025-0519-0038

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Vikas Gupta

Submitter Email: vgeputa@yahoo.com

Submitter Address: 5 Graystone Ct, Naperville, IL, USA

Date Submitted: 11/13/2025

Comment ID: CDC-2025-0519-0039

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we

maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Patrick Ching

Submitter Email: patrick.ching1@vcuhealth.org

Submitter Address: 1300 E Marshall St, Room 100, Richmond, VA, 23298, US

Date Submitted: 11/14/2025

Comment ID: CDC-2025-0519-0040

Full Comment:

As an infectious diseases/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

As an infectious diseases physician caring for people living with HIV, I am also a healthcare and clinical epidemiologist who relies on NHSS not just for clinical care but also public health interventions. NHSS is essential in planning for ways to stop the epidemic locally in Virginia and the entire United States.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Kathryn R. Love

Submitter Email: kathrynlovemd@gmail.com

Submitter Address: 9340 Sheffield Cir S, Minneapolis, MN, 55437, US

Date Submitted: 11/15/2025

Comment ID: CDC-2025-0519-0041

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we

maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Samantha Aguilar

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/16/2025

Comment ID: CDC-2025-0519-0043

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Sebastian R. Stanciu

Submitter Email: sbaschn@comcast.net

Submitter Address: 1378 Moss Creek Dr, Jacksonville, FL, 32225, US

Date Submitted: 11/16/2025

Comment ID: CDC-2025-0519-0042

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an

epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Thanks,

Sebastian R. Stanciu, M.D., FACP

Name: Paige Padgett Wermuth

Organization: NOT PROVIDED

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/18/2025

Comment ID: CDC-2025-0519-0044

Full Comment:

I strongly support CDC's proposal to continue the National HIV Surveillance System (NHSS), under OMB Control No. 0920-0573. NHSS is the foundation of our national HIV response and is essential for public health action and policy development.

Weakening or discontinuing NHSS would undermine HIV prevention and care at every level, creating dangerous blind spots in detecting threats, tracking progress, and directing resources effectively.

As a public health researcher in HIV and sexual health, I know NHSS is the only comprehensive system tracking HIV across the full disease spectrum --- from diagnosis to viral suppression to mortality. These data are vital for monitoring trends, describing geographic and demographic patterns to guide prevention strategies, and identifying people who need care, and measure progress toward Ending the HIV Epidemic (EHE).

I commend CDC for its leadership in sustaining the National HIV Surveillance System as the cornerstone of our nation's HIV response. Continued commitment to this essential infrastructure will ensure that every decision—whether at the federal, state, or local level—is informed by high-quality, timely, and actionable data.

Name: Brandi Skipalis

Submitter Email: bcskipalis@skipalisconsulting.com

Submitter Address: 85522 Phillips Rd, Yulee, FL, USA

Date Submitted: 11/19/2025

Comment ID: CDC-2025-0519-0045

Full Comment:

As a social worker with a focus on HIV prevention and education, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Understanding the socioeconomic, demographic, and geographic factors and trends in HIV transmission is crucial to engaging in prevention, testing, and treatment strategies in our communities. My community in Northeast Florida is one of the hardest hit in the United States, and it is crucial to be able to have the information and the tools to address this issue and to improve how we serve our communities in preventing and treating HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Kelly Hallowell

Submitter Email: kelly.n.hallowell@gmail.com

Submitter Address: 4129 Ewing Ave S, Minneapolis, MN, USA

Date Submitted: 11/19/2025

Comment ID: CDC-2025-0519-0047

Full Comment:

As an ID physician, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I have diagnosed multiple patients with HIV this year. In clinic, I have a dedicated hour-long appointment saved for last-minute add-ons for a new HIV diagnosis or transition of HIV care every other week - as do the majority of my colleagues. This always surprises my friends, colleagues, and other patients that in the current era there is still a need for this.

I worry about our country's ability to meet the goals of the End HIV the Epidemic initiative. I also fortunately have referrals for discussion of initiating HIV PrEP - particularly injectable options. There is currently a clinical momentum with the FDA approval of lenacapavir for injectable HIV PrEP, and patients who may not have considered every 2 month options with cabotegravir or a daily pill with Truvada/Descovy are seeing ads or hearing about lenacapavir from those in their community. We need the NHSS data to understand how we can best prioritize these medical interventions. We know that most HIV is spread by those who don't even know they are infected. Lack of understanding the burden of disease has been a large part of combating the epidemic, and we need large, national systems to help do this critical work.

I this very week am taking care of a patient in the hospital who acquired HIV at birth and has limited options to continue to treat their HIV and the associated opportunistic infections. In an age when we have effective and safe strategies to prevent tragedies like this case, we need to invest in them. The costs of surveillance - both monetary and human suffering - will pay off compared to the life-long costs of cases like this patient, who for example has been hospitalized months.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an

epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Emily Blumberg

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/21/2025

Comment ID: CDC-2025-0519-0049

Full Comment:

As an infectious diseases health care professional, I am writing to provide comments ahead of the December 2025 meeting of the Advisory Committee on Immunization Practices (ACIP).

It is critical that the Centers for Disease Control and Prevention (CDC) and ACIP once again serve as sources of credible, evidence-based information to inform vaccine coverage. Reliable information is essential to preserve vaccine access for all Americans who want and need to be vaccinated, enable clinicians to offer the highest quality care and empower individuals to make the best-informed decisions about their own health and their families' health.

Recommendations should be made by experts in the fields of vaccines and infectious diseases and based on high-quality, objective scientific data collected and analyzed by CDC scientists and not influenced by political appointees. I urge the following recommendations on planned agenda items:

Hepatitis B:

At the September 2025 ACIP meeting, there was an extensive discussion about changes to the timing of the first hepatitis B vaccine dose in newborns and the efficacy of screening mothers for hepatitis B, along with delaying the first dose of the vaccine. Vaccination prevents chronic hepatitis B, which often requires treatment for life and can lead to liver cancer. Before the universal hepatitis B infant vaccination recommendation in 1991, approximately 18,000 children in the U.S. were infected each year before they reached the age of 10. Half of these infections were the result of mother-to-child transmission during birth. Some have recommended that the vaccines should be given later in childhood because hepatitis B is transmitted sexually; however, this discounts the risk from other types of contact with people that are likely to happen at any age. I urge ACIP to maintain the recommendation for the birth dose of hepatitis B vaccine. Vaccination at birth has been shown to be effective in preventing the spread of this life-threatening disease.

Childhood and adolescent vaccine schedule:

ACIP Chair Martin Kulldorff, PhD, has called for study of the cumulative effects of the recommended childhood vaccine schedule, including interactions between different vaccines, the total number and timing of vaccines, cumulative amounts of vaccine ingredients and comparison with vaccine schedules of other nations.

I support the already ongoing monitoring of any adverse events associated with vaccines, especially those observed in infants and children. Currently, multiple systems within the federal government track vaccine safety. These systems should be supported with sufficient resources to determine any credible safety signals related to vaccines and their findings widely shared with substantive evidence and recommendations made public.

Overwhelming data indicate that routine childhood vaccinations are responsible for significant gains in human life expectancy and major declines in childhood illnesses, hospitalizations, and mortality. It is critical that we protect universal vaccine access for all, regardless of insurance status or geographic location, and that we empower all Americans with accurate information about vaccines to boost vaccine confidence, particularly in communities at greatest risk for outbreaks of vaccine-preventable diseases.

Further, if ACIP intends to compare the childhood and adolescent immunization schedule in the United States with the schedules of other countries, I ask the committee to carry out a rigorous investigation of differences between the provision of health care in the U.S. and these countries, including insurance coverage and access to health care providers. Simply examining the number of vaccines and timing of vaccine administration may overlook important aspects of public health and health care access in these countries as compared to the U.S.

As an infectious diseases health professional, I implore ACIP to take these recommendations into consideration to protect access to lifesaving vaccines for the communities I serve.

Name: Luis Del Carpio-Orantes

Submitter Email: neurona23@hotmail.com

Submitter Address: 12 de Octubre, Ricardo Flores Magón, 91900 Veracruz, Ver., Mexico

Date Submitted: 11/21/2025

Comment ID: CDC-2025-0519-0051

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Luis Del Carpio-Orantes

Submitter Email: neurona23@hotmail.com

Submitter Address: 12 de Octubre, Ricardo Flores Magón, 91900 Veracruz, Ver., Mexico

Date Submitted: 11/21/2025

Comment ID: CDC-2025-0519-0052

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our

understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Michael D. Boyd

Organization: Gilead Sciences, Inc.

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/21/2025

Comment ID: CDC-2025-0519-0050

Full Comment:

Gilead Sciences, Inc. (Gilead) appreciates this opportunity to express strong support for the continued collection of data through the National HIV Surveillance System (NHSS). The NHSS is the cornerstone of our nation's HIV response, and one of the most powerful tools we have for understanding, responding to, and ultimately ending the HIV epidemic. A robust NHSS is essential to achieving President Trump's vision of ending the HIV epidemic in the United States. Continued investment in the NHSS ensures that every decision—whether at the federal, state, or local level—is informed by accurate, timely, and comprehensive data, which helps to ensure that resources are used efficiently and effectively. We strongly urge CDC to maintain and strengthen the NHSS as a national priority and have included our comment letter in the attached file.

Attached Comment:

Submitted via Regulations.gov

Docket No. CDC-2025-0519

Centers for Disease Control and Prevention (CDC)

Department of Health and Human Services

Proposed Data Collection: National HIV Surveillance System (NHSS)

November 21, 2025

Re: Comment Submission on Support for Continued Data Collection for the National HIV Surveillance System (NHSS)

To Whom it May Concern:

Gilead Sciences, Inc. (Gilead) appreciates this opportunity to express strong support for the continued collection of data through the National HIV Surveillance System (NHSS). Gilead is a research-based biopharmaceutical company that discovers, develops, and commercializes innovative medicines in areas of unmet medical need. Relevant to this submission, for over 35 years, Gilead has developed antiretroviral therapies that help people living with HIV achieve viral

suppression and maintain long-term health, as well as pre-exposure prophylaxis (PrEP) medicines that significantly reduce the risk of HIV acquisition.

The NHSS is the cornerstone of our nation’s HIV response, and one of the most powerful tools we have for understanding, responding to, and ultimately ending the HIV epidemic. Comprehensive, standardized, high-quality surveillance data provide policymakers, health departments, and communities with essential information needed to track the HIV epidemic, identify gaps in prevention and care, guide policy decisions, allocate resources, and measure progress towards goals. The collection of these data enables public health programs to efficiently focus resources where they will have the greatest impact, which not only helps to reduce the number of new HIV infections, but also lowers downstream costs to the healthcare system and society more broadly. Surveillance data also facilitates the early detection of HIV clusters—communities experiencing rapid HIV transmission—thereby enabling a rapid public health response to contain and prevent potential outbreaks before they occur.

In February 2019, President Trump launched *Ending the HIV Epidemic: A Plan for America (EHE)*, a bold initiative that aims to reduce new HIV infections in the United States by 75% in five years and by 90% by 2030. The EHE initiative utilizes the data collected by NHSS to strategically focus resources in the 57 geographic areas with the highest rates of HIV transmission nationwide, including 48 counties, Washington, D.C., and seven rural states. One of the four key strategies of Trump’s initiative is focused on HIV surveillance (“Respond quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.”) in recognition that real-time surveillance and response systems are key to ending the HIV epidemic in the United States.

NHSS data serve multiple vital functions that guide interventions that keep Americans healthy, save lives, and reduce healthcare cost, including:

- **Monitoring Trends, Disease Burden, and Care Outcomes** NHSS offers a comprehensive view of where HIV infections occur, how they affect different populations by geography, age, race/ethnicity, gender, and transmission category, and how the epidemic evolves over time. NHSS also tracks key HIV care continuum indicators such as linkage to care, retention in care, and viral suppression—critical measures for evaluating the effectiveness of HIV treatment programs. Health departments also use NHSS data to identify individuals diagnosed with HIV who are not engaged in care to facilitate their linkage or re-engagement with treatment services.
- **Detecting and Rapidly Responding to Potential HIV Outbreaks**
 - Health departments use NHSS data to identify geographic areas and communities with high rates of new HIV diagnoses or rapid transmission clusters, enabling a targeted public health response to stop further spread and prevent potential HIV outbreaks before they occur. The FY26 Congressional Justification for the new “Administration for a Healthy America” (AHA) states that over a two-year period (2022-2024), more than 400 HIV clusters were reported and addressed by 49 health departments across the country. Without early detection and quick intervention, these clusters could have grown into full scale HIV outbreaks, resulting in tens or even hundreds of preventable HIV infections and significant costs to the healthcare system.
- **Informing Policy and Program Development and Guiding Resource Allocation** Surveillance data underpin strategies such as the federal *Ending the HIV Epidemic Initiative* and the *National HIV/AIDS Strategy*, ensuring policies and programs are evidence-based and

directed to where they are most needed. NHSS data inform decisions on funding and planning for HIV prevention, treatment and care programs at all levels, including critical initiatives like the Ryan White HIV/AIDS Program, CDC's HIV Prevention grants, and the Housing Opportunities for Persons with AIDS (HOPWA) program. Data from behavioral and clinical surveillance can help to evaluate existing programs, identify best-practice interventions, and inform how to deliver services most effectively to communities.

These data have also guided decision making and resource allocation by Gilead Sciences' FOCUS program. FOCUS supports health care organizations to develop and implement best practices in routine blood-borne virus (HIV, HCV, HBV) screening, diagnosis and linkage to care and linkage to HIV comprehensive prevention services in accordance with screening guidelines promulgated by federal, state and local public health departments across various contexts, settings, and healthcare systems.

Through FOCUS partnerships, Gilead invests funds to support the scale-up and scale-out of routine screening and linkage to care infrastructure. There are more than 200 active FOCUS partners across hospital systems, FQHCs, CBOs and they have performed more than 12 million HIV tests alone. FOCUS partners have helped to expand the implementation science model to

efficiently address multiple public health epidemics, and several states have used the NHSS data to uniquely blend funding to expand and enhance the FOCUS model to address HIV, HCV, syphilis (congenital syphilis) and linkage to HIV comprehensive prevention services.

FOCUS partners have a presence in all US EHE jurisdictions and have uncovered outbreaks through implementation of routine screening in those jurisdictions. The NHSS data have been critical to prioritizing public health investment in the areas of highest unmet need and Gilead's public-private partnership through our FOCUS program exemplifies an innovative implementation science model grounded in data with improved public health outcomes. NHSS data have further driven decision-making to reach priority populations in these jurisdictions.

A robust NHSS is essential to achieving President Trump's vision of ending the HIV epidemic in the United States. Continued investment in the NHSS ensures that every decision—whether at the federal, state, or local level—is informed by accurate, timely, and comprehensive data, which helps to ensure that resources are used efficiently and effectively. We strongly urge CDC to maintain and strengthen the NHSS as a national priority.

Thank you for the opportunity to comment. Please feel free to contact us for further discussion.

Sincerely,

Michael D. Boyd
Senior Vice President, Government Affairs and Policy
Gilead Sciences, Inc.

Organization: Recovery Mobile Clinic
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/21/2025
Comment ID: CDC-2025-0519-0048
Full Comment:

See attached file(s).

Attached Comment:

As the President and Founder of the Recovery Mobile Clinic in Michigan, we are seeing a higher rate of transmission in people who use IV drugs and who share needles or people who are using substances and engaging in sexual activity to feed the addiction. The education to providers and community is still disproportionality focused on men having sex with men, which is an outdated focus and needs to focus on one of the highest growing transmission modalities, which is drug use.

The Recovery Mobile Clinic is a 501C3 nonprofit in Michigan that provides homeless shelters, transitional houses, community centers, food pantries and more. The Recovery Mobile Clinic is staffed with Nurse Practitioners, providers who are screening every client who accepts lab work for STD including HIV due to substance use, homelessness and other risk factors. This routine screening for HIV needs to be expanded to all providers. This should be a Medicare/Medicaid/private insurance covered test and even a payment bonus (HEIDIS) reimbursement to encourage providers to screen and have conversations with clients. This will improve the data collection and hopefully improve early detections. As for cluster determination, reimbursement for Genosure testing (genotype detection) needs to be paid for without approval from the providers and labs so that the clusters can be tracked better.

Improving detection through screening all high risk populations and improving provider payment for the procedure will improve compliance and a change in routine lab draws for all clients, not just those admitting to risky behaviors. This should be standard just like a HGB A1C. Payment incentives for providers to screen ALL clients on an annual routine bases to detect early exposure and track clusters by approving Genosure (genotype) tracking for improved cluster identification.

The Recovery Mobile Clinic is a viable option for screening and reaching hard to reach clients. We look forward to working with the CDC to improve screening options and tracking.

Name: Shelley Facente

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/22/2025

Comment ID: CDC-2025-0519-0053

Full Comment:

I am writing in support of the National HIV Surveillance System (CDC-2025-0519). It is imperative that this system continue to be supported by the US government, for the benefit of all Americans. I am an epidemiologist and public health consultant with over 25 years working in the field of HIV and sexual health; I know first hand how important the NHSS has been to our understanding of HIV epidemiology at both the national and local levels. Without NHSS we will be unable to systematically monitor trends and effectively allocate resources to prevent new HIV transmissions and provide appropriate care for people living with HIV. The infrastructure built over the last 30+ years to track the HIV epidemic is a model not only for the rest of the world but for other diseases in the U.S., and it's something that should make is proud. Ending funding for this work would be a tragedy and would directly contribute to further spread of HIV within our borders.

Shelley N. Facente, PhD, MPH

Name: Dr. Ray Serrano

Organization: League of United Latin American Citizens (LULAC)

Submitter Email: rserrano@lulac.org

Submitter Address: 1150 18th Street, Suite 275, Washington DC 20036

Date Submitted: 11/23/2025

Comment ID: CDC-2025-0519-0056

Full Comment:

See attached file(s)

Attached Comment:

November 21, 2025

Jeffrey M. Zirger

Information Collection Review Office

Centers for Disease Control and Prevention

1600 Clifton Road, NE, MS H21-8

Atlanta, Georgia 30329

Re: Comment on Proposed Extension of the National HIV Surveillance System (NHSS), Docket No. CDC-2025-0552

Dear Mr. Zirger:

For nearly ninety-seven years, the League of United Latin American Citizens (LULAC) has asked this country to take a clear-eyed look at the communities we serve and the systems that shape our lives. From the barrios of Los Angeles to the colonias of South Texas, our councils have insisted that dignity is not an abstract principle — it is a daily necessity. And today, that insistence requires us to look closely at the National HIV Surveillance System (NHSS).

The NHSS is the federal backbone of HIV data collection, spanning all 50 states, the District of Columbia, and six U.S. dependent areas. According to the CDC's 2024 *National HIV Surveillance System Overview*, the program is authorized under Sections 304 and 306 of the Public Health Service Act (42 U.S.C. 242b and 242k) to track incidence, prevalence, and disease progression, including AIDS. The CDC now proposes extending this system — a continued federal gaze meant to monitor diagnosis, care, and public health needs.

We support that public health goal. Surveillance data strengthens prevention programs, improves linkage to care, and guides resources toward communities with the greatest burden — a burden that, according to the Kaiser Family Foundation's 2023 *HIV Policy Report*, falls disproportionately on Hispanic/Latino individuals, who now account for 31% of new HIV diagnoses nationwide. But civil rights are not accessories to this work; they are its foundation. And for Latinos, immigrants, and other underserved communities, the stakes are especially high.

The proposed extension enlarges the volume and sensitivity of data collected but does not enlarge the safeguards necessary to ensure that this information is never misused, exposed, or transformed into an instrument of harm. Our concerns are not theoretical. They are shaped by memory. According to a 1996 *National Institutes of Health* investigation, Florida had "the weakest procedures in the nation" for safeguarding confidential HIV information when the names of 4,000 HIV-positive individuals were leaked in Pinellas County. In California, according to a 2023 Lambda Legal settlement report, 93 low-income ADAP patients had their medical records compromised

through a contractor's online enrollment system. These events did more than reveal data. They shattered trust.

Civil Rights Risks in the Proposed NHSS Extension

There is no explicit prohibition on sharing HIV surveillance data with law enforcement or immigration agencies. A 2019 *Washington Post* investigation found that Immigration and Customs Enforcement accessed personal data for 79 million Medicaid recipients. Without a firm firewall, families in El Paso, Rio Grande City, Tucson, and other border communities have reason to hesitate before seeking care. This silence in the rule effectively allows a back door that could undermine the very public health goals the system is meant to advance.

Latino communities have also been disproportionately harmed by past breaches, including documented failures in Florida and California. Expanding the amount of data collected without strengthening protections increases the likelihood of future incidents. Many Latinos already avoid seeking care due to fear of exposure, and additional data vulnerabilities could discourage entire households from testing or treatment. Language access protections are similarly inadequate. According to the Department of Justice's Limited English Proficiency Guidance, agencies must ensure meaningful access for individuals who do not speak English well, yet the NHSS proposal provides no clear multilingual notices or accessible pathways for correcting errors. Without reliable language access, data collection becomes both confusing and coercive for people who cannot fully understand how their information will be used.

The risk of re-identification is especially high in small, predominantly Latino regions. In the Rio Grande Valley, where nearly 2,000 individuals are living with HIV according to the Texas Department of State Health Services, combining ZIP code, age, and diagnosis year can reveal identities even in datasets labeled "de-identified." In many border communities, where populations are small and neighbors know one another, anonymity exists mostly on paper and not in practice. Cluster investigations also raise concerns. According to the CDC's *HIV Cluster Detection and Response Guidance* (2021), cluster data helps identify rapid transmission networks, but without civil rights safeguards these investigations can resemble patterns of over-surveillance that already burden Black and Latino communities. Past public-health interventions in minority neighborhoods have shown how easily a protective tool can be perceived as punitive when trust is already fragile.

HIV criminalization laws further intensify these risks. According to the CDC's 2022 *HIV Criminalization Fact Sheet*, more than 30 states still have HIV-specific statutes, and in places like Missouri, Alabama, and Tennessee surveillance data could be misused in ways that harm vulnerable populations. For many immigrants and mixed-status families, the possibility that medical information could enter the criminal justice system is enough to deter them from engaging in care at all. Finally, the proposal contains no civil rights or equity analysis. The Kaiser Family Foundation reported in 2023 that HIV diagnoses among Latinos have risen 24 percent since 2010, yet the rule does not examine how expanded surveillance might disproportionately impact Latino or immigrant communities. Failing to measure disparate impact all but guarantees that it will be ignored.

Data-Handling, Methodology, and De-Identification: Why Risks Remain

According to CDC's 2024 *HIV Surveillance Technical Guidance*, NHSS relies on a uniform case definition and standard report form. Case reports are sent to CDC only after direct identifiers are removed. Transmission category data is statistically adjusted using multiple imputation to account for missing information. But even after de-identification, risk remains. CDC uses several tools:

removal of direct identifiers; computer-generated patient codes; suppression of data in small-population counties; generalization of ZIP codes and ages; and perturbation — the introduction of random variation into sensitive fields. CDC further requires ZIP-code suppression when the population of a three-digit ZIP region is under 20,000 — in such cases, the ZIP code must appear as “000.”

These methods help — but they are not perfect. According to Latanya Sweeney’s 1997 re-identification study, supposedly anonymous medical data can be linked back to individuals using only a ZIP code, birth date, and sex. If a governor can be unmasked, what of the young man in Roma, Texas, or the poultry worker in Springdale, Arkansas?

What NHSS Data Is Used For — and Why That Matters

Cluster response uses NHSS data to detect rapid HIV transmission networks. According to CDC (2021), such data helps target prevention and treatment. But without civil-rights safeguards, cluster identification can become concentrated in minority neighborhoods — places already accustomed to being watched.

Data-to-Care uses surveillance data to identify people not in care, not virally suppressed, or lacking prescription renewals. According to CDC’s *Data-to-Care Overview* (2024), these programs can improve health outcomes — as our LULAC councils in Denver, Phoenix, and Orlando have seen — but without equity protections, they can also deepen disparities.

CDC confidentiality guidance states that personally identifiable HIV data must not be released outside public health except in the rarest circumstances, and the Assurance of Confidentiality expressly prohibits sharing with immigration agencies. But guidance is not enough. Communities whose histories include surveillance, deportation, and discrimination need protections written into regulation.

Stronger Guardrails, Clearer Responsibility

CDC needs to draw a bright, unmistakable line: NHSS data must never be used for immigration enforcement or law enforcement. The moment health data can be used to target people, people stop showing up for testing and treatment. The agency should also collect only what it truly needs and follow strict, verifiable deletion timelines — because data that isn’t stored can’t be stolen, subpoenaed, or misused. Routine equity and bias reviews are essential to catch problems early. And communities deserve multilingual notice and simple, accessible ways to correct errors; if people can’t understand what’s being collected or how to fix mistakes, the system loses its accuracy and legitimacy.

CDC must also strengthen protections for minors and perinatal cases, because mishandling their data can have lifelong consequences. Full language and disability access must be guaranteed, not treated as optional. Community oversight is non-negotiable; the people most affected by HIV deserve a seat at the table, and it’s the only way to build trust in a system that collects their data. And transparency matters: CDC should publicly report data requests, subpoenas, breaches, and system failures — because sunlight is still the best accountability tool we have.

For regions like the Rio Grande Valley — where illness, stigma, poverty, and immigration status collide — privacy is not a technical issue; it’s armor. In a country where HIV criminalization laws still exist and data-driven enforcement is expanding, that armor has to get stronger, not thinner. Public

health depends on good data, but dignity depends on trust — and trust evaporates the moment people fear their information could be used against them.

Extending the National HIV Surveillance System is a real chance to get this right. With stronger guardrails, CDC can build a system that protects people as well as their rights. Privacy and civil rights must be treated as non-negotiable, because they are the backbone of any system that claims to serve the communities hit hardest by HIV. And without that trust, public health simply doesn't work.

LULAC stands ready, as it has for nearly a century, to help the CDC build a surveillance system worthy of the communities it serves — one that strengthens public health without sacrificing civil rights, restores trust instead of eroding it, and protects people rather than placing them at risk. The path forward requires treating privacy as a public-health obligation and civil rights as the scaffolding that makes true prevention possible. When systems honor dignity, communities engage. When protections are strong, people seek care. That is the foundation of effective public health, and it is the standard our nation must uphold. Should you have any further questions, please contact our National Director of Research and Policy, Dr. Ray Serrano, at rserrano@lulac.org.

Respectfully submitted,

Roman Palomares
LULAC National President and Board Chairman

Works Cited

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10. Lambda Legal. *California ADAP Settlement Report*. 2023.
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12. National Institutes of Health. "Investigation of Confidential HIV Data Management in Florida." 1996.
13. Sweeney, Latanya. *Simple Demographics Often Identify People Uniquely*. Carnegie Mellon University, 1997.
14. Texas Department of State Health Services. *HIV Surveillance Annual Report: Rio Grande Valley Statistics*. 2024.

15. United States Congress. *Public Health Service Act*. 42 U.S.C. §§ 242b, 242k.

Name: Haley Anderson

Submitter Email: hea2109@gmail.com

Submitter Address: 35 N Cedar Lake Dr. W, Apt 201, Columbia, MO 65203

Date Submitted: 11/23/2025

Comment ID: CDC-2025-0519-0057

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals and communities.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Joel Kammeyer

Submitter Email: joelkammeyer@gmail.com

Submitter Address: 2931 Riva Ridge Road, Toledo, OH, USA

Date Submitted: 11/23/2025

Comment ID: CDC-2025-0519-0055

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

>>Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Robert Striker

Submitter Email: rtstriker@wisc.edu

Submitter Address: 2222 Kendall Ave, Madison, WI, 53726, US

Date Submitted: 11/23/2025

Comment ID: CDC-2025-0519-0054

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

>>Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Carie Harter

Organization: ViiV Healthcare

Submitter Email: carie.a.harter@ViiVhealthcare.com

Submitter Address: NOT PROVIDED

Date Submitted: 11/24/2025

Comment ID: CDC-2025-0519-0062

Full Comment:

Please find attached ViiV Healthcare's comments regarding the National HIV Surveillance System (CDC-2025-0519-0001). Thank you so much for considering our input.

Attached Comment:

November 19, 2025

VIA ELECTRONIC SUBMISSION — <https://www.regulations.gov/document/CDC-2025-0519-0001>

Centers for Disease Control and Prevention

[Docket No. CDC-2025-0519]

Robyn Neblett Fanfair, MD, MPH (CAPT, USPHS)

Director, Division of HIV Prevention (DHP)

National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

Centers for Disease Control and Prevention (CDC)

1600 Clifton Road NE

Atlanta, Georgia

RE: Proposed Data Collection Submitted for Public Comment and Recommendations

Dear Dr. Neblett Fanfair,

ViiV Healthcare supports the renewal of the National HIV Surveillance System (NHSS) as it is an essential public health tool designed to monitor, track, and respond to the ongoing HIV epidemic in the United States. The NHSS has a critical role in advancing HIV prevention, treatment, care, and policy development. It is critical for:

- **Data-Driven Decision Making:** The NHSS provides high-quality, standardized epidemiology data that empowers healthcare providers, researchers, policymakers, and public health organizations to make informed decisions. By tracking HIV diagnoses, prevalence, trends, and disparities, the system allows stakeholders to allocate resources effectively and tailor interventions to communities most in need.
- **Monitoring Progress Toward National Goals:** The NHSS plays a central role in evaluating progress toward national HIV prevention and treatment goals, including President Trump's Ending the HIV Epidemic (EHE) Initiative and state integrated HIV prevention and care plans. By measuring key indicators like new diagnoses, viral suppression rates, and linkage to care, it helps identify gaps and areas for improvement.
- **Identifying Communities of Need:** With its robust surveillance approach, the NHSS sheds light on HIV outcomes across different populations, including racial, ethnic, gender, and geographic groups. This ensures that efforts to address the epidemic focus on populations disproportionately affected by HIV, and by doing so it drives programmatic efficiency and increases the impact of taxpayer dollars.
- **Supporting Local and State Health Departments:** The NHSS provides valuable data to state and local health departments, enabling them to better understand the scope of the HIV epidemic in their communities. This information supports the design and implementation of targeted prevention programs, testing initiatives, and treatment services that address local needs.
- **Informing Research and Innovation:** The NHSS data serve as a foundation for scientific research aimed at understanding HIV transmission dynamics, evaluating interventions, and developing new treatment and prevention technologies. The system contributes to advancements in HIV care and helps prioritize areas for further study.
- **Enhancing Collaboration:** The NHSS fosters collaboration between federal, state, and local partners by providing a shared framework for surveillance and reporting. This ensures consistency in data collection and analysis, facilitating coordination and communication across agencies.
- **Improving Patient Outcomes:** By identifying trends in care engagement, viral suppression, and disease progression, the NHSS supports efforts to improve patient outcomes and reduce HIV-related morbidity and mortality.

In addition, ViiV supports the comments submitted by AIDSvu, which recommends that the NHSS:

- Prioritize data timeliness and completeness.
- Strengthen data on social and community factors affecting health.
- Enhance data accessibility and transparency.
- Improve geographic and demographic granularity.

The NHSS is a cornerstone of the nation's public health infrastructure, enabling stakeholders to track progress, identify challenges, and respond effectively to the HIV epidemic. Continued investment in this system is essential for achieving a future free of HIV/AIDS and improving the health and well-being of affected individuals and communities.

ViiV Healthcare appreciates CDC's consideration of these comments. Please feel free to contact Carie Harter at (770) 710-9620 or carie.a.harter@ViiVhealthcare.com should you have any questions.

Sincerely,

Carie Harter
Senior Director, Government Relations
ViiV Healthcare

1. AIDSVu. AIDSVu's Response to the National HIV Surveillance System Request for Public Comment. November 6, 2025. <https://aidsvu.org/news-updates/aidsvus-response-to-the-national-hiv-surveillance-system-request-for-public-comment/>. Accessed November 12, 2025.

Name: Darcy Wooten

Submitter Email: darcyw@wustl.edu

Submitter Address: 1166 N Geyer Rd, Kirkwood, MO, USA

Date Submitted: 11/24/2025

Comment ID: CDC-2025-0519-0059

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

>>Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Janet Hamilton

Organization: CSTE

Submitter Email: letters@cste.org

Submitter Address: NOT PROVIDED

Date Submitted: 11/24/2025

Comment ID: CDC-2025-0519-0061

Full Comment:

See attached file(s)

Attached Comment:

November 24, 2025

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 FR No. 2025-18904, National HIV Surveillance System (CDC-2025-0519)

Dear Mr. Zirger,

The Council of State and Territorial Epidemiologists (CSTE) supports the Centers for Disease Control and Prevention (CDC) request to continue collecting information in the National HIV Surveillance System (NHSS) using the forms described in the Federal Register Doc. 2025-18904 (CDC-2025-0519).

CSTE is a national organization representing all states and territories and over 3,300 applied public health epidemiologists. CSTE's vision is to achieve thriving and healthy people and communities everywhere and our mission is to advance the field of applied epidemiology to maximize health. CSTE champions expansion of applied epidemiology capacity and effective use of epidemiologic data to guide public health practice, implement science-based policy, and improve health. CSTE has a vested interest in promoting rules, regulations, and policies that advance health for all Americans, using robust public health surveillance and epidemiology practice. Public health action by CSTE member states has led to improvements in clinical practice, medical procedures, surveillance, detection and control of public health threats, and the ongoing development of evidence-based disease control policies and prevention successes, including multiple position statements to standardize national surveillance efforts.

CSTE strongly supports the continued collection of HIV data at the national, state, and local levels. NHSS provides critical data that are used to describe trends in HIV incidence, prevalence and characteristics of infected persons that are used widely at the federal, state, and local levels for planning, implementing, and evaluating prevention programs and healthcare services, to allocate funding for prevention and care, and to monitor progress toward achieving national prevention goals of the Ending the HIV Epidemic in the U.S. Further, information collected in NHSS is used directly by health departments to ensure people with HIV are connected to care and to identify communities most affected by HIV to tailor public health interventions to be most effective. NHSS data are necessary for the proper performance of CDC functions and have practical utility in CDC's mission to protect Americans from health and security threats. CDC has unparalleled, unique experience and expertise not available anywhere else in the federal government that is necessary to operate this system. A centralized national system that consolidates information from all levels of the U.S. public health system is critical for identifying outbreaks and emerging trends at local, state, and national levels and is necessary to improve the health, longevity and quality of life of Americans.

Data collection for NHSS and HIV prevention and response activities involves a close partnership between CDC, state Tribal, local, and territorial (STLT) health departments, healthcare, and other key organizations. CSTE appreciates the time estimates provided by CDC under "Estimated Annualized Burden Hours" related to the collection of NHSS data; these estimates likely include time to submit data but may not fully represent the necessary efforts for STLT public health professionals to investigate

illnesses and collect, clean, and organize the data. Further, continued federal resources and support for modernizing public health data systems are essential to ensure the systems can deliver optimal timely data for decision-making at each level of the public health system. STLT health departments rely on CDC for subject matter expertise and essential funding to support these activities through cooperative agreements to STLTs, which must be maintained at least at current levels to ensure the health and safety of all Americans. It is critical for the data to flow first through the STLT health departments where they are collected and acted upon, and then for a subset of relevant information to be securely provided at the national level for aggregation and reporting that will support STLT public health agencies and national partners in planning, implementing, and evaluating life-saving public health interventions within and across STLT borders. National reporting and aggregation of data also provides CDC with data critical to coordinate response and prevention activities, ultimately reducing negative health and economic impacts.

Thank you for considering these comments on behalf of our members working in STLT public health agencies. Should you like to discuss these comments further, please contact me at letters@cste.org or (770) 458-3811.

Sincerely,

Janet Hamilton, MPH
Executive Director
Council of State and Territorial Epidemiologists

Name: Rebekah Lee

Submitter Email: bekahlee1991@gmail.com

Submitter Address: Decatur, GA

Date Submitted: 11/24/2025

Comment ID: CDC-2025-0519-0060

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

HIV is a disease that, through proper surveillance, education, intervention, and management services, we can control and reduce in the United States. However, without robust surveillance, we cannot know where to allocate resources, where intervention is most needed, and which populations are most at risk.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Elaine Thomas
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/25/2025
Comment ID: CDC-2025-0519-0058
Full Comment:

HIV surveillance data is critically important to clinicians and scientists who treat and prevent this deadly disease. Data collection should be continuously ongoing to allow comparisons and analysis, and the types of data collected should be determined by those with scientific expertise, without political interference.

Name: Anonymous
Submitter Email: NOT PROVIDED
Submitter Address: NOT PROVIDED
Date Submitted: 11/26/2025
Comment ID: CDC-2025-0519-0063
Full Comment:

Comment for CDC-2025-0519-0001, National HIV Surveillance System (NHSS) 2025-18904

I am submitting this comment in strong support of the CDC's proposed information collection project titled the National HIV Surveillance System (NHSS). I am particularly interested in this notice because my work involves analyzing public health data and utilizing surveillance datasets to monitor trends, evaluate program outcomes, and research the outreach/implementation of prevention, testing, and care in HIV/STI. With years of experience working with state and county-level HIV surveillance data, I have gained direct insight into the crucial role accurate, timely, and comprehensive NHSS data play in informing HIV-related research and public health responses, aligning resources with community needs, and ultimately saving lives.

This comment specifically addresses the CDC's proposed extension of OMB Control No. 0920-0573, which is subject to the information collection for the NHSS. As outlined in the notice, the NHSS collects population-based HIV surveillance data from 59 health departments. The data collection includes laboratory results, case reports, perinatal exposures, cluster reports, deduplication activities, and annual evaluation data. The agency proposes no changes to the burden or forms, thereby maintaining the current structure that supports ongoing HIV monitoring, incidence estimation, and the detection of clusters of rapid transmission.

The continuation of NHSS data collection is essential for the CDC to fulfill its mandated public health functions under the Public Health Service Act. This system provides the only comprehensive, population-based source of information regarding HIV diagnoses, laboratory results, perinatal exposures, and clusters across all 59 reporting health departments.

These data hold critical practical utility for monitoring incidence and prevalence, guiding funding allocations, supporting data-to-care efforts, and enabling rapid responses to clusters of recent and rapid transmission. The proposed extension will maintain the current forms and data elements, and the ongoing use of standardized case definitions, electronic reporting platforms, and well-established workflows will ensure the quality, clarity, and consistency of the collected information.

However, a notable gap in the proposal is the absence of explicit information collection cost estimates. While this notice provides the total burden (in hours) as a proxy for cost estimation, it does not include actual information collection cost estimates or reference previously approved costs. Providing updated cost information in the future would enhance transparency and assist interested holders in evaluating the complete resource implications of participation.

Overall, I recommend approval of the extension (OMB Control No. 0920-0573, Exp. 2/28/2026) as proposed and suggest ongoing investments in modernization and transparency regarding system performance. These continued efforts will ensure the NHSS remains an effective, efficient, and high-value national surveillance system.

Name: Ronald G Nahass

Organization: Infectious Diseases Society of America & HIV Medicine Association

Submitter Email: NOT PROVIDED

Submitter Address: 4040 Wilson Blvd. Suite 300. Arlington, VA 22203

Date Submitted: 11/26/2025

Comment ID: CDC-2025-0519-0064

Full Comment:

See attached file(s)

Attached Comment:

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 (AIDSVu, 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
Anna K. Person, MD, FIDSA
President, IDSA 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>
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Name: Lynne Mofenson MD

Submitter Email: mofensoL@gmail.com

Submitter Address: 2740 Camomile Drive West, Frederick, MD 21704

Date Submitted: 11/27/2025

Comment ID: CDC-2025-0519-0065

Full Comment:

As a pediatric infectious disease specialist who has spent my career in public health and conducting research in treatment and prevention of pediatric HIV infection, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System (NHSS). NHSS plays a critical role in understanding of HIV epidemiology, which enables us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I worked at NICHD/NIH for 26 years and was a medical officer who worked on the 076 clinical trial, which showed in Feb 1994 that zidovudine given during pregnancy, delivery and to the infant for a short period reduced vertical HIV transmission by nearly 70% (the first demonstration of treatment as prevention). I led the public and governmental meetings following these results to determine how to implement this in the US - interim guidelines were issued by April, with a public meeting in June and final guidelines by August. immediately followed by FDA approval. The NHSS demonstrated that with implementation of this regimen and subsequent more effective treatment for HIV reduced vertical transmission in the US by 65% between 1994 and 1997 and 97% by 2013. While vertical transmission has significantly decreased, it still occurs; surveillance is now critical to determine the reasons for continued transmission and to develop interventions to eliminate pediatric HIV infection in the United States. Without these data, we will not understand the reasons for failure of prevention.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Michael T. Melia

Submitter Email: mmelia4@jh.edu

Submitter Address: 2109 Old Pine Rd, Timonium, MD, USA

Date Submitted: 11/27/2025

Comment ID: CDC-2025-0519-0066

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Organization: AIDS Healthcare Foundation

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/28/2025

Comment ID: CDC-2025-0519-0067

Full Comment:

AIDS Healthcare Foundation (AHF) is in strong support on the National HIV Surveillance System (NHSS). AHF provides HIV/AIDS medical care and testing services in 17 U.S. states, Puerto Rico, and the District of Columbia with over 75,000 registered patients in the U.S. and over 240,000 HIV tests conducted in 2024.

Disease surveillance is key to public health as it allows for prevention and control of communicable and noncommunicable diseases. It provides insights into risk factors and the population affected as well as the spread of the disease. With this tool in hand, local leadership and health organizations can create preventive and mitigation strategies. Surveillance is especially important for HIV/AIDS intervention due to the communicable nature of the infection.

The NHSS allows providers such as AHF to make informed decisions on locating services in areas of high impact, ensuring optimal healthcare delivery and preventative intervention where it is needed most.

AHF recommends that in addition to maintaining NHSS as it is, it should also be expanded to allow access to granular data such as zip code and census tract so that local policymakers can utilize this data for changing policy and organizations can tailor interventions to their unique populations.

The NHSS is a vital tool for addressing HIV/AIDS in the United States with accuracy and timeliness. AHF strongly supports CDC's proposal to continue NHSS data collection under OMB Control No. 0920-0573.

Name: AIDSvu
Organization: AIDSvu
Submitter Email: info@AIDSvu.org
Submitter Address: NOT PROVIDED
Date Submitted: 11/29/2025
Comment ID: CDC-2025-0519-0046
Full Comment:
See attached file(s).

Attached Comment:

Submitted via Regulations.gov
Docket No. CDC-2025-0519
Centers for Disease Control and Prevention (CDC)
Proposed Data Collection: National HIV Surveillance System (NHSS)
Submitted by:
AIDSvu, Rollins School of Public Health, Emory University
Contact: info@AIDSvu.org | www.AIDSvu.org
Support for Continued NHSS Data Collection

The National HIV Surveillance System (NHSS) is one of the nation's most powerful tools for understanding, preventing, and ultimately ending the HIV epidemic. Comprehensive, standardized surveillance data allow policymakers, health departments, and community partners to direct resources where they are needed most, evaluate program outcomes, and measure progress toward national goals such as *Ending the HIV Epidemic in the U.S.* Surveillance is the backbone of public health. Accurate, timely data illuminate trends that would otherwise remain hidden—informing testing strategies, guiding prevention investments, and improving outcomes for people living with HIV. Surveillance data also helps identify HIV clusters a rapidly respond to potential outbreak. Continued investment in surveillance is not just about data collection; it is about accountability, pragmatism, and ensuring that every community benefits from scientific and programmatic advances. This pragmatism extends to lowering overall costs to the healthcare system; strategically deploying resources using data-driven decision-making reduces the number of new HIV infection overall, thus lowering overall healthcare costs. We strongly support CDC's proposal to continue NHSS data collection under OMB Control No. 0920-0573. Maintaining the NHSS ensures that public health practitioners and decision-makers have reliable information to identify geographic clusters, assess

disparities, and allocate resources effectively in order to prevent more HIV infection, reduce overall healthcare costs, and ultimately work to end the HIV epidemic in the U.S. Sustaining this national system—and the local infrastructure that feeds it—is essential for monitoring HIV incidence, prevalence, and viral suppression outcomes. Surveillance provides the factual foundation needed to evaluate progress, course-correct strategies, and strengthen response efforts across jurisdictions.

Recommendations

1. Prioritize Data Timeliness and Completeness

The National HIV Surveillance System (NHSS) remains a global model for accuracy and coordination across jurisdictions. Continued investment in systems and workforce capacity at the state and local levels is necessary to maintain this strength while improving the timeliness and completeness of reporting. These enhancements are vital for rapid response to emerging clusters and real-time monitoring of trends.

2. Strengthen Data on Social and Community Factors Affecting Health

Building on NHSS's strong data foundation, CDC should encourage integration of contextual data on social and community factors that influence health outcomes, such as HIV-related stigma, health literacy, and transit times to testing and care. Doing so will help identify the conditions that drive disparities in HIV outcomes and inform targeted, evidence-based strategies to improve public health results.

3. Enhance Data Accessibility and Transparency

NHSS has set a high standard for reliable, publicly available health data. CDC should continue expanding mechanisms that make NHSS data accessible in clear, interpretable formats for policymakers, journalists, and community advocates while preserving privacy and data integrity.

4. Improve Geographic and Demographic Granularity

The NHSS already provides invaluable insights into national and state-level trends. Expanding access to more granular data (e.g., ZIP code or census tract level) and more complete demographic detail (e.g., gender identity, ethnicity, rurality) will empower communities to design interventions that better reflect

local realities.

Conclusion

We commend CDC for its leadership in sustaining the National HIV Surveillance System as the cornerstone of our nation's HIV response. Continued commitment to this essential infrastructure will ensure that every decision—whether at the federal, state, or local level—is informed by high-quality, timely, and actionable data.

Respectfully submitted,

AIDSVu, Rollins School of Public Health, Emory University
info@AIDSVu.org | www.AIDSVu.org

Name: Anais Ovalle

Organization: NOT PROVIDED

Submitter Email: anais.ovalle@gmail.com

Submitter Address: 25 Cottage Cir, West Lebanon, NH 03784, USA

Date Submitted: 11/29/2025

Comment ID: CDC-2025-0519-0069

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Jack Miller

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 11/29/2025

Comment ID: CDC-2025-0519-0068

Full Comment:

To begin with my name is Jack R. Miller I'm a long term survivor living with AIDS since my diagnoses in 1994. I'm proud to say with advancements in treatment and care I'm a long term survivor of 31 plus years at the age of 52. I volunteered my lifetime combating and eradicating HIV/AIDS spanning over 25 plus years on Ryan White Planning Councils, Advisory Boards, attending National

and Local HIV/AIDS Conferences. I currently am a graduate of the 2025 50 + Smart and Strong Cohort for NMAC (National Minority AIDS Council) for people aging with HIV/AIDS over 50, I'm also a member of NHAAN (National HIV AGING Network). as a Co-Chair and Member of the LGBTQIA Group. First the regulation that I'm commenting on is the following: Collecting the necessary data/epidemiology data that's needed to continue government & state local funding sources. I'm in the 50 + plus aging cohort of my peers and not reporting this population would be devastating. I rely on data collected from my cohort of peers for my community based organization to receive funding for housing, food pantry and meals, mental health, dental care, and treatment in care. Today over half of the people with HIV/AIDS in the USA is now over 50 years old. A significant portion of newly diagnosed cases also occur in older adults indicating a need for better HIV prevention and testing strategies in this age group! Changes in reporting data will drastically lead to the following challenges: commodities, frailty, drug interactions, systemic gaps, lack of awareness and stigma. I read on the CDC website that in 2024 33% of people living over the age of 55 received a diagnosis in 2022 already had late stage HIV/AIDS when diagnosed. Second the key considerations for care includes ART therapy is recommended with HIV regardless of age, and older populations achieve viral suppression comparable to younger individuals. Data linking and reporting are critical for providing comprehensive support and care. Today over half the people in the USA living with AIDS is over 50 years old. In 2022 54% were aged 50 and up in addition to people aged 50 and an older accounted for approximately 16% of the 38,043 newly diagnosed in 2022.

Furthermore in my opinion I understand that the CDC wants to reduce paperwork and go green but the statistics are very alarming and having everything documented and written down is key to locating and combating high concentrations of newly diagnosed HIV/AIDS cases in America today. Many poor people of color will be drastically affected because resources are being cut especially Medicaid and state wide funding. I would suggest that you continue with reporting with emails, written documents, data collection, questionnaires and tracking services at state local medical programs.

To Conclude from my stats stated above with the over 50 population we can see that it contributes to 33% of people age 55 and over in the USA received a diagnosis in the late stages of HIV/AIDS when diagnosed. I recommend as a long term survivor living with AIDS is to continue to document and report the statistics by documenting and reporting! I feel that this administration is taking the easy way out by not reporting or dealing with the issues at hand we are going to be in a huge crisis very shortly with cutting medical and funding sources and my life will be at risk or dead because you want to be lazy and supposedly go green!

Name: Scott Fabricant

Submitter Email: scottfab@gmail.com

Submitter Address: Boston Medical Center Place, Boston, MA, USA

Date Submitted: 11/29/2025

Comment ID: CDC-2025-0519-0070

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we

maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Priya Pal

Submitter Email: Priya.pal789@gmail.com

Submitter Address: 1 Barnes Jewish Hospital Plaza, St. Louis, MO, USA

Date Submitted: 11/30/2025

Comment ID: CDC-2025-0519-0071

Full Comment:

As an ID/HIV health professional, I appreciate the opportunity to provide comments on the importance of continuing the National HIV Surveillance System. NHSS plays a crucial role in our understanding of HIV epidemiology, enabling us to monitor trends and effectively allocate and direct resources to prevent HIV transmissions in our community and state. It is imperative that we maintain a robust surveillance system to ensure that informed decisions can be made in our ongoing efforts to reduce new HIV cases and improve the health outcomes of individuals with HIV.

Insert Personalized Comments Here<<<

I urge CDC to continue the collection of HIV surveillance data. NHSS is indispensable for guiding public health strategies and ensuring that we remain vigilant in our efforts to end HIV as an epidemic. By continuing this vital data collection, we can better understand the dynamics of the epidemic, implement targeted interventions and ultimately improve the lives of those affected by HIV. Thank you for considering these important perspectives.

Name: Brandon M. Macsata

Organization: ADAP Advocacy

Submitter Email: NOT PROVIDED

Submitter Address: ADAP Advocacy P.O. Box 846 Nags Head, NC 27959

Date Submitted: 11/30/2025

Comment ID: CDC-2025-0519-0084

Full Comment:

Submitted via standard mail

Attached Comment:

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 comports 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 PL WHA. ADAP Advocacy has worked tirelessly to ensure that PL WHA 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 distinct 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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Date Submitted: 12/1/2025
Comment ID: CDC-2025-0519-0080

Full Comment:

See attached file(s)

Attached Comment:

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Professor of Pediatrics and Medicine

The Children's Hospital of Philadelphia

As Adolescent Medicine HIV Specialists, we strongly support the Centers for Disease Control and Prevention's proposal to continue the National HIV Surveillance System (NHSS) data collection under OMB Control No. 0920-0573. The NHSS is one the most comprehensive collections of public health data on HIV and AIDS in the United States. It is critical to Ending the HIV Epidemic as it serves to identify and describe trends in HIV incidence and prevalence – answering questions around which geographical locations and types of communities may benefit most from more targeted interventions.

Continued support of the NHSS is especially important to us as clinicians and researchers with expertise in adolescent and young adult (AYA) care because we see the pivotal impact that early interventions play in lifelong health outcomes every day. Current data from the NHSS demonstrate that 19% of new HIV infections occur amongst AYAs age 13 to 24 and rates are disproportionate among Black/African American and Hispanic/Latino AYAs accounting for nearly 70% of all new diagnoses (NHSS 2022). The NHSS data drives us as clinicians to ensure we are targeting AYA that need HIV prevention most – identifying, reaching, and educating youth at greatest risk for HIV and expanding pre-exposure prophylaxis (PrEP) to youth with the greatest PrEP need.

Beyond prevention, the NHSS provides the most comprehensive database for information related to AYA living with HIV and AIDS – including disparities in HIV-related care outcomes. These, too, requires surveillance and maintenance of datasets across time to develop and monitor interventions that aim to reduce HIV-disease burden, poor HIV-related health outcomes, and negative societal influences such as anti-HIV-related stigma. Providing AYA with evidencebased

HIV prevention and treatment while combatting the multitude of factors that lead to potential poor outcomes for them is at the core of our professional identities. That is how we have learned what it takes to do the job well – including data we can rely on and share. We therefore strongly support the CDC’s proposal to continue NHSS data collection as it is the most effective strategy to ensure that clinicians, researchers, and public health advocates have accurate and reliable information when developing, implementing, and maintaining interventions to end the HIV epidemic in adolescents and young adults.

National HIV Surveillance System (NHSS). Centers for Disease Control and Prevention (CDC). 2024. <https://www.cdc.gov/nhis/2019nhis.htm>

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Submitter Address: AIDS Institute, NYS Department of Health, Albany, NY 12237

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0076

Full Comment:

See attached file(s)

Attached Comment:

Docket No. CDC-2025-0519

The New York State Department of Health supports the ongoing collection of HIV surveillance data via the National HIV Surveillance System (NHSS). These data are critical for understanding the magnitude, distribution, and outcomes of HIV across geographic, demographic, and social domains. Further, comprehensive and timely surveillance information guides prevention and treatment strategies and supports a targeted and effective public health response.

HIV remains a highly stigmatized condition, more than 40 years after it was first identified as a public health concern. People living with HIV continue to experience higher levels of stigma and discrimination compared with those who are not affected. As a result, the breadth of information collected, maintained, and disseminated through the NHSS must be carefully balanced. While these data provide significant public health benefit, they also carry the potential to cause harm if improperly accessed or disclosed.

We offer the following cautions related to confidentiality risks; public trust; and scope of HIV surveillance data collection:

1. While detailed information is necessary to understand the distribution of HIV, the release of highly specific demographic categories, such as detailed race and ethnicity classifications or small area geographic data (e.g., zip code or census tract), may compromise confidentiality. In some populations, HIV diagnoses occur at very low frequencies, making

access to or dissemination of disaggregated data infeasible. Even aggregated estimates can be unreliable in these circumstances.

2. Persons living with HIV have strong and valid privacy concerns. Because surveillance data represent the granular details of persons living with HIV, any breach of confidentiality can erode public trust in the public health system's ability to safeguard sensitive information and may undermine engagement in HIV testing, prevention, and treatment services.
3. HIV surveillance systems have limited capacity to capture information related to social determinants of health. Such information, which is essential for contextualizing HIV transmissions and outcomes, should be obtained through alternative, high-quality data sources better suited to collect such information. Such alternatives can provide the necessary context without compromising surveillance integrity.

Submitted by:

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Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0077

Full Comment:

See attached file(s).

Attached Comment:

December 1, 2025

Jeffrey M. Zirger

Information Collection Review Office

Centers for Disease Control and Prevention

1600 Clifton Road NE Atlanta, Georgia 30329

RE: Docket Number CDC-2025-0519

The Community Access National Network (CANN) is a 501(c)(3) national nonprofit organization focusing on public policy issues relating to HIV/AIDS and viral hepatitis. CANN's mission is to define, promote, and improve access to healthcare services and support for people living with HIV/AIDS and/or viral hepatitis through advocacy, education, and networking. While CANN is primarily focused on policy matters affecting access to care for people living with and affected by HIV, we stand in firm support of all people living with chronic and rare diseases and recognize the very reality of those living with multiple health conditions and the necessity of timely, personalized care for every one of those health conditions. We submit what follows in response to the RFI regarding the National HIV Surveillance System (NHSS). RFI is Timely, Necessary, and Communicates a Commitment to Collaboration The proposed collection of information is indeed necessary for the proper functioning of the CDC regarding HIV data collection. We are supportive of the efforts. The National HIV Surveillance System (NHSS) should indeed be continued and

strengthened, prioritizing areas of need in a systemic and science-driven fashion. Studies show that the United States is not on track to meet the Ending the HIV Epidemic initiative goal of a 90% reduction in new HIV infections by 2030. This is especially true in specific geographic and socioeconomic populations, such as the South, that are disproportionately affected by HIV. Recent federal funding proposals poised to drastically reduce public funding for HIV treatment and prevention efforts make surveillance, monitoring, and assessment essential for the beneficial advancement of public health. Moreover, as vulnerable populations face challenges to healthcare access due to Medicaid cuts and the affordability challenges of significantly increased insurance costs, there is strong potential for increases in transmission incidence rates.

At the state level, local health departments use their limited resources to monitor and trace HIV trends. However, continued national HIV surveillance is imperative to ensure data does not remain siloed. Centralized standardized data not only facilitates the identification of HIV clusters but also enables comparisons across demographic groups and geographic areas to identify which efforts are or are not successful and the reasons behind the outcomes. States learn from one another, and thorough surveillance analysis indicates where federal resources should be allocated. Continued surveillance will reveal data on issues such as the uptake, utilization, and success of new HIV treatments, such as long-acting injectables that are new to market. HIV monitoring and surveillance have existed since the advent of the HIV epidemic. Continued development and evolution of the NHSS are essential for holistic bolstering of public health from rural areas to large urban centers and all places in between. To improve monitoring efforts and enhance the quality, utility, and clarity of information and collection processes, we offer several recommendations. Proper Data Governance Monitoring and Protections is Paramount The NHSS Assurance of Confidentiality Statement dated October 2019 is a definitive statement of confidentiality protections for the data collected and the individuals whose protected health information informs it. Going forward, vigilance regarding confidentiality needs to be exercised. The October 2019 document states explicitly: "In particular, HIV surveillance or research information that could be used to identify any individual or institution on whom a record is maintained, either directly or indirectly, will not be disclosed for commercial purposes, nor disclosed to the public; to family members; to parties involved in civil, criminal, or administrative litigation; or to non-health agencies of the federal, state, or local governments." There has been increased scrutiny regarding the public trust of recent trends in the manner in which citizens' sensitive data has been handled. This is especially true regarding the federal utilization of A.I. in various endeavors. It is imperative that guidelines to protect citizens' HIV related health data are explicitly established, and governance remains monitored. The October 2019 document also states: "Only authorized employees of DHAP in HICSB, BCSB, the Quantitative Sciences and Data Management Branch and Laboratory Branch, their contractors, other authorized staff and other authorized agents granted access, guest researchers, fellows, visiting scientists, authorized external collaborating researchers, research interns, and graduate students who participate in activities jointly approved by CDC and the sponsoring academic institution, and the like, will have access to the information." This level of access requires dedicated oversight to prevent any unauthorized access or utilization of HIV surveillance data. Data Improvement on Social Determinants of Health HIV surveillance data collection needs greater integration of social determinants of health (SDOH). SDOH research is not propaganda or ideological discourse. It is objective, evidence-based data that provides additional context for issues that may drive transmission trends. Topics such as health literacy, health center deserts (areas with inadequate access to health services due to a lack of facilities or providers), HIV-related stigma, and more are part of the holistic reality of people living with HIV and those at high-risk of infection. The local health departments that feed data to the NHSS have the means to

obtain some of that data that may not be currently utilized. Information Should Remain Timely
Information gathered should remain timely and presented in clear formats that are easily digestible by many different stakeholders. Everyone, from legislators creating public policy to medical practitioners and lay members of the public, needs to be able to understand and act upon what is presented. Above all, the entire ecosystem of stakeholders involved in surveillance, data collection, and analysis needs to be effectively supported. On the state and local level, especially, this requires resources. Funding, policy infrastructure, educational resources, technological frameworks, and any weakness analysis need to be reinforced for effective HIV surveillance to occur.

Respectfully submitted,

Ranier Simons
Director of State Policy, PDABs
Community Access National Network (CANN)

On behalf of
Jen Laws
President & CEO
Community Access National Network

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Comment ID: CDC-2025-0519-0078
Full Comment:
See attached file(s).

Attached Comment:
December 1, 2025
Jeffrey M. Zirger
Information Collection Review Office
Centers for Disease Control and Prevention
1600 Clifton Road NE
Atlanta, Georgia 30329

Re: Docket No. CDC-2025-0519

On behalf of the HIV Prevention Action Coalition (HPAC) and undersigned organizations, we submit these comments to emphasize the crucial role of the National HIV Surveillance System (NHSS) and the necessity for sustained investment in timely, comprehensive, secure, and high-quality HIV surveillance data. The NHSS serves as a foundation of the nation's public health infrastructure and remains indispensable for monitoring trends, guiding prevention and care efforts, and evaluating progress toward ending the HIV epidemic in the United States.

We support continued investment in data modernization to ensure that the NHSS remains adaptive, efficient, and secure. Modernized data systems enhance data quality and timeliness, thereby

strengthening the ability of health departments to respond rapidly to emerging HIV outbreaks. These advancements enhance coordination across jurisdictions and increase the overall efficiency and impact of HIV prevention and care programs.

Timely HIV surveillance data are crucial for detecting and responding to outbreaks. Delayed, inconsistent, or incomplete reporting undermines the ability of health departments to identify concerning trends, deploy prevention and care resources, and communicate with partner jurisdictions. Real-time or near-real-time data enhances situational awareness and facilitates earlier intervention, thereby reducing the likelihood of broader transmission and mitigating long-term public health and financial impacts.

Health departments across the country have strengthened their surveillance workforce to meet the growing demands of modern data systems and ensure high-quality reporting. Continued investments in staffing, training, and technical support are necessary to maintain data integrity, timeliness, and completeness. However, no amount of local innovation can replace federally led, standardized, and nationally representative data collection. Health departments cannot fill gaps created by uneven or diminished national surveillance, and fragmented systems weaken national situational awareness and federal oversight. A unified federal approach is the only way to guarantee that emerging threats are detected early and that response efforts are coordinated and effective.

Community-based organizations (CBOs) and clinical providers rely on NHSS data to shape outreach strategies, tailor prevention and care programs, and identify where additional resources are needed to support people living with and affected by HIV. Accurate and timely data enables CBOs to design interventions that reflect the realities of the communities they serve and helps clinicians improve linkage to care, treatment adherence, and long-term health outcomes. Ensuring reliable, nationally representative surveillance data strengthens the entire HIV service delivery system—not only health departments but also the community partners and clinicians who depend on these data every day.

We also emphasize that investments in surveillance must be paired with strong, clear, and consistently applied data protections. Communities most affected by HIV face disproportionate criminalization, stigma, and discrimination, and the safety of their data is paramount. Federal leadership is critical to ensuring that surveillance information is protected from misuse, stored securely, shared appropriately, and used only for public health purposes. Strong data protections build trust with affected communities and strengthen the ability of health departments and community partners to engage people in prevention and care.

NHSS data informs an array of essential public health activities. Health departments and community partners rely on these data to educate communities about HIV, respond to and prevent transmission, and support tailored care and treatment programs. Federal agencies also rely on NHSS data to inform key programs, such as the Ryan White HIV/AIDS Program and the Housing Opportunities for Persons with AIDS (HOPWA) program. A robust national sample is essential to ensure equitable resource allocation and accurately assess progress toward federal HIV goals. Reliable national data also ensures that federal dollars are directed where they can have the greatest impact, allowing agencies to target gaps, scale effective interventions, and avoid wasting limited resources.

The undersigned organizations also emphasize the importance of enhancing efficiency within the NHSS to alleviate the administrative burden on health departments. Streamlining data collection processes, strengthening system interoperability, and providing clear guidance allows jurisdictions

to focus limited resources on public health action. Timely and complete data also supports faster response to new HIV transmissions and more agile program implementation.

We commend the Centers for Disease Control and Prevention for its leadership in supporting NHSS. Continued collaboration and investment in modernization, workforce capacity, data protections, timeliness, and efficiency will ensure that the NHSS remains a foundation of the nation's HIV response.

If you have any questions regarding this letter, please do not hesitate to contact the HPAC co-chairs: Kevin Herwig (kherwig@hivhep.org), Mike Weir (mweir@NASTAD.org), and Nick Armstrong (NArmstrong@taimail.org).

Endorsers

AIDS Alabama
AIDS United
AVAC
Community Access National Network
DAP Health
Five Horizons Health Services
HealthHIV
HIV+Hepatitis Policy Institute
HIV Medicine Association
NASTAD
SAGE
Southern Black Policy and Advocacy Network
The AIDS Institute

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Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0083

Full Comment:

Callen-Lorde Community Health Center in New York City, NY is submitting the attached comments in support of CDC efforts to maintain and expand the NHSS.

Attached Comment:

December 1st, 2025

Submitted electronically via Regulations.gov

Jeffrey M. Zirger, PhD

Information Collection Review Office

Centers for Disease Control and Prevention

1600 Clifton Road NE

MS H21-8

Atlanta, Georgia 30329

Re: "Proposed Data Collection Submitted for Public Comment and Recommendations: National HIV Surveillance System," Docket No. CDC-2025-0519

Dear Dr. Zirger,

Thank you for the opportunity to submit comments on the Centers for Disease Control (CDC or the Department) request for a proposed extension of the National HIV Surveillance System (NHSS), to evaluate the necessity of collecting these data, accuracy of the estimated time burden for proposed collection, ensure quality, utility and clarity of information collected, minimize the burden of collecting these data, and assess information collection costs. We strongly support the Department's continued implementation of the National HIV Surveillance System and highly encourage that the Department continues to invest in Ending the HIV Epidemic throughout the United States and associated territories.

Callen-Lorde Community Health Center (Callen-Lorde) is a federally qualified health center (FQHC) with three locations across New York City, empowered by our mission to serve lesbian, gay, bisexual, and transgender communities, people living with HIV, and anyone across our geographic service areas, regardless of ability to pay. Callen-Lorde provides primary care, dental care, behavioral health care, care coordination, case management, health insurance enrollment, and community-based health education services, all to ensure that our patients can live their healthiest and most fulfilling lives. Our health center serves over 23,000 patients annually, including over 4,000 patients living with HIV. Callen-Lorde's early adoption of HIV pre-exposure prophylaxis (PrEP) prescribing resulted in over 6,000 patients engaged in PrEP treatment and routine STI testing every 3 months. Callen-Lorde is one of the leading first responders to emerging infectious diseases across New York (i.e. Mpox, COVID-19, HIV), contributors Ending the Epidemic initiatives, and data-driven health centers for the communities we serve; Callen-Lorde is regularly recognized for our unwavering commitment to ensure timely, quality, and evidence-based care to all of the communities we serve.

As a safety net institution, Callen-Lorde relies heavily upon information gathered from HIV surveillance data to help shape our health programs and invest limited funds to resulting clinical priorities. The National HIV Surveillance System is a crucial effort that allows clinics like Callen-Lorde to effectively delegate resources to the areas of care that need it the most, such as providing present trends for our patients living with HIV (PLWH) (HIV seroconversion rates, viral load suppression, co-morbidities, and deaths associated with HIV or AIDS) and those patients considered most vulnerable to acquiring HIV. To effectively evaluate our care efficacy and quality, Callen-Lorde needs external data for comparison and technical assistance across other HIV providers.

I. NHSS Is Foundational to Ending the HIV Epidemic

Callen-Lorde emphasizes that NHSS is not simply a reporting mechanism, but acts as main informant to the United States's HIV response: NHSS is largely responsible for shaping standards of care, clinical training, and research priorities for HIV prevention, treatment, and patient education.

Cornerstone of HIV Response

NHSS provides accurate, timely, and comprehensive data that underpin national strategies such as Ending the HIV Epidemic and the National HIV/AIDS Strategy. These initiatives aim to reduce new HIV infections by 75% by 2025 and 90% by 2030. Without NHSS, programs like Ryan White and CDC

HIV Prevention grants would lack the evidence base needed for equitable funding and program design.

Evidence of Impact

CDC's 2025 update on national prevention and care objectives shows that among ~39,000 persons who received a diagnosis in 2023, 83% were linked to care within one month. Among ~1.1 million PLWH with diagnosed HIV at year-end 2023, 67% achieved viral suppression, underscoring both progress and the remaining gap to the 95% EHE goal. These NHSS-derived indicators help health systems like ours focus quality improvement on rapid linkage, retention, and viral suppression—the pillars of U=U and of epidemic control.

Rapid Outbreak Detection and Response

NHSS supports cluster detection and real-time response to prevent rapid transmission. Historic and recent outbreaks—such as Scott County, Indiana—illustrate the consequences of delayed surveillance and the value of integrating molecular and traditional epidemiology to contain spread. In Indiana, 181 diagnoses were ultimately linked to injection opioid use; over 90% were co-infected with HCV, and emergency activation of syringe service programs was a key control measure. Such lessons affirm the need for timely, complete, and granular data flows.

Accountability and Fiscal Responsibility

NHSS data are used in Ryan White allocation formulas and progress reports; they support equitable distribution of funds and enable continuous evaluation of program success. Integrated CDC/HRSA guidance depends on NHSS indicators to build epidemiologic profiles for planning, ensuring that dollars follow burden, need, and effective strategies.

Identifying Opportunities for Innovation in the HIV Field

Trends NHSS data over time have demonstrated a need for longer extended release treatments for HIV and HIV PrEP, catalyzing further research into long-acting injectable (LAI) options. Now, Callen-Lorde patients are able to access LAIs for treatment (cabotegravir + rilpivirine, lenacapavir) and PrEP (cabotegravir, lenacapavir) as a result of these innovations; with NHSS, our clinic will be better prepared to evaluate the effectiveness of these treatments and identify crucial care gaps to address. Without NHSS, HIV clinical providers may not have sufficient information to show the potential impact of LAIs and their importance to Ending the Epidemic.

II. Enhancing Equitable Access to HIV Treatment & Prevention

To ensure NHSS reflects the realities of those most impacted by HIV, Callen-Lorde supports historical changes made by CDC to ensure that trends in the HIV epidemic are better captured, and reflective of areas that require future investment. NHSS's reporting previously identified areas of significant concern, such as lower uptake of PrEP and PEP access in the southern United States, higher proportions of transgender persons seroconverting compared to the general public, and how recent prioritized efforts to engage racial minority populations yielded lower seroconversion rates in Hispanic/Latino communities but lesser so Black/African American communities.

Disaggregated Demographic Data Current broad racial and ethnic categories often obscure important differences within communities. For example, grouping all Asian populations together overlooks the unique cultural, linguistic, and health experiences of people from East Asia, South Asia, Southeast Asia, and Pacific Islander communities. Similarly, the term “Hispanic/Latino”

encompasses diverse identities, including Afro-Latinx, Caribbean, Central American, and South American populations, each with distinct social contexts and health needs. Collecting and reporting data at a more detailed level helps ensure interventions are culturally responsive, resources are allocated equitably, and programs reflect the lived experiences of all communities.

Similar to accurately capturing race and ethnicity, many CDC systems historically under-capture SOGI; a 2015–2018 assessment found only 17.7% of CDC-supported data systems collected sexual orientation and 5.9% collected gender identity, limiting analysis of disparities. In previous iterations of Health People (2020 and 2030 versions), CDC prioritized better reporting standards to capture how someone’s sexual orientation or gender identity may affect their health; with some improvements to national survey and surveillance reporting, CDC decisively found that transgender women, especially Black/African American and Hispanic/Latinx persons, were more susceptible to HIV. In recent years, FQHCs have demonstrated feasible electronic health records SOGI capture and its utility in identifying HIV screening gaps, disparities in PrEP/PEP utilization, and challenges bringing specific groups of people living with HIV into care. CDC should mandate standardized SOGI fields, provide jurisdictional technical assistance, and ensure self-identification rather than forced categorization.

Integration of Social Determinants of Health (SDOH) Housing instability, incarceration, poverty, lack of insurance, and limited access to transportation drive disparities in HIV risk, care engagement, and outcomes. CDC’s Public Health Gateway emphasizes SDOH as core drivers of health; integrating selected SDOH indicators into NHSS analytic products (or linking NHSS outputs to SDOH datasets) would improve targeting, evaluation, and equity across programs.

In New York City, the intersection of housing, mental health, and substance use with HIV requires data that go beyond case counts. Disaggregated SOGI and race/ethnicity, and SDOH linkage, help us identify hotspots for PrEP expansion, outreach, and re-engagement. Tools like AIDSvu and AHEAD already demonstrate the power of granular and contextualized data; NHSS should continue to enable ZIP code-level profiles and expand contextual overlays.

III. Privacy and Community Trust

We must protect privacy and build trust to keep people engaged in HIV care and prevention. NHSS should use the strongest confidentiality standards and clearly explain how it collects, stores, and uses data. These actions ensure surveillance supports health, not stigma or harm.

Assurance of Confidentiality and Data Security

NHSS operates under a permanent assurance of confidentiality pursuant to Section 308(d) of the Public Health Service Act; CDC’s 2011 Data Security and Confidentiality Guidelines set standards for program policies, data handling, physical and electronic security, and data release. Surveillance data forwarded to CDC exclude personal identifiers and are used only for public health purposes. Maintaining these standards (and communicating them transparently) is essential to trust and engagement.

Protect Communities from Criminalization

For populations historically stigmatized or criminalized, NHSS must not become a conduit for law enforcement action. We support explicit policies that prevent sharing surveillance data for criminal prosecution under HIV criminalization statutes, and that ensure multilingual, culturally appropriate

communication about data collection, storage, sharing, and use. These commitments reduce deterrents to testing, linkage, and care.

Operational Transparency

CDC should continue publishing technical notes, data tables, and methodological guidance (e.g., case definitions, reporting delays) so that clinics and health departments can interpret NHSS outputs consistently and communicate with communities accurately.

IV. Preparing for Emerging Needs

Callen-Lorde recognizes that CDC must adapt NHSS to keep pace with the changing realities of the HIV epidemic. As people living with HIV age and syndemics like hepatitis C, syphilis, and substance use intersect with HIV, surveillance must capture these trends and provide granular, timely data. Doing so ensures that programs anticipate future challenges and deliver care that meets evolving community needs.

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Operational Transparency CDC should continue publishing technical notes, data tables, and methodological guidance (e.g., case definitions, reporting delays) so that clinics and health departments can interpret NHSS outputs consistently and communicate with communities accurately. [cdc.gov], [cdc.gov]

V. Recommendations to Strengthen NHSS

As per CDC's request for comments, Callen-Lorde proposes the following recommendations to further strengthen the NHSS, and ensure that these data collected and most effectively inform our clinical care by:

1. *Prioritizing Timeliness and Completeness*
Continue investments in state and local surveillance workforce, laboratory reporting automation, and data exchange standards to reduce reporting delays and improve completeness in near real time, supporting cluster response and outbreak control.
2. *Standardizing and Expanding SOGI Fields*
Issue technical standards and training for accurate SOGI capture across jurisdictions; promote self-identification; and evaluate data quality routinely with public reporting of SOGI completeness.

3. *Integrating SDOH Linkages*
Develop standard approaches to link NHSS case surveillance with SDOH datasets (housing instability, insurance, transportation, incarceration) at least at county or ZIP levels to inform equity-focused interventions.
4. *Advancing Aging and Comorbidity Indicators*
Pilot the capture or linkage of aging-related measures (comorbidities, payer source) to prepare systems for the rapidly aging PLWH population.
5. *Codifying Privacy Protections and Communications*
Reaffirm NHSS Assurance of Confidentiality and data security standards; explicitly prohibit use of surveillance data for criminalization; and provide multilingual, community-facing materials on data use and rights.
6. *Publish Accessible Technical Notes and Dashboards*
Expand public technical notes, data tables, and AtlasPlus/AHEAD visualizations; support ZIP-level dashboards where feasible; and provide jurisdictional tools for cluster response and re-engagement workflows.
7. *Sustain EHE and Cross-Program Coordination*
Maintain NHSS as the backbone for tracking EHE indicators (incidence, knowledge of status, diagnoses, linkage, viral suppression, PrEP coverage) and ensure coherence across CDC, HRSA, and local health departments for planning and funding.

Conclusion

Thank you again for the opportunity to provide comments regarding the NHSS. Callen-Lorde urges CDC to maintain and enhance NHSS as a national priority. A robust, expansive, and privacy-protective surveillance system is indispensable to ending the HIV epidemic. NHSS should continue evolving to reflect the complexity of people's lives while providing granular, timely, and actionable data for communities.

If you have any questions about our comments, please contact Kimberleigh Smith at ksmith@callen-lorde.org or 212-271-7184.

Sincerely,

Kimberleigh J. Smith, MPA *Executive Vice President of Public Policy and Advocacy*
Callen-Lorde Community Health Center

Name: Marilyn Ramos

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0079

Full Comment:

See attached file(s).

Attached Comment:

Public Comment for CDC-2025-0519

Thank you for the opportunity to comment. My name is Marilyn Ramos. I am a mother, a college student, a community advocate, and a woman living with HIV. I am writing today because strong, well-supported HIV surveillance is not just a technical requirement; it is a lifeline for people like me.

The National HIV Surveillance System ensures that individuals and families affected by HIV are accurately counted and not overlooked. When surveillance is underfunded or weakened, the impact is immediate and harmful. Communities like mine, women, parents, LGBTQ individuals, people of color, and low-income families are often the first to feel the consequences. Without reliable data, our needs are easier to ignore, our services become vulnerable to cuts, and our lives are placed at greater risk.

Surveillance is what tells the truth about where support is needed and who is being left behind. It reveals gaps in care, helps identify people who are disconnected from treatment, and guides the resources that keep us healthy. When the data are strong, the public health response can be strong. When the data are weak, people suffer.

As someone who has chosen to be public about my diagnosis, I have seen how often women's experiences are overlooked or erased. Many women still do not feel safe speaking openly about HIV. Surveillance is one of the few tools that ensures our realities are acknowledged even when our voices are quieted by stigma. It protects our visibility and ensures that policymakers cannot ignore us.

I am committed to continuing my education and entering the public health field so that I can contribute to solutions and advocate for communities like mine. But right now, I am asking CDC to protect and strengthen the National HIV Surveillance System so that our progress is not reversed. Accurate data saves lives. It ensures accountability. And it ensures that people like me mothers, workers, caregivers, and students are not forgotten in national decision-making.

Please support this surveillance system with the resources and attention it deserves. Our health, our families, and our futures depend on it. Thank you for considering my comment.

Respectfully,

Marilynn Ramos

Name: Naomi Gaspard

Organization: The AIDS Institute

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0081

Full Comment:

See attached file(s).

Attached Comment:

December 1, 2025

Jeffrey M. Zinger

Information Collection Review Office

Centers for Disease Control and Prevention (CDC)

1600 Clifton Road NE, MS H21-8
Atlanta, Georgia 30329

RE: Comment on Proposed Extension of the National HIV Surveillance System (NHSS) (Docket No. CDC-2025-0519)

Dear Mr. Zinger:

The AIDS Institute is a nonpartisan, nonprofit working to ensure the millions of people living with and vulnerable to HIV, viral hepatitis and other serious chronic conditions, have access to comprehensive healthcare. We have advocated for programs and policies to bring an end to the HIV epidemic since our founding in 1985. We urge the CDC to continue its investment in the National HIV Surveillance System (NHSS), which is an essential tool to ending the HIV epidemic in the United States. The AIDS Institute strongly supports CDC's proposal to continue and maintain NHSS data collection under OMB Control No. 0920-0573.

The AIDS Institute is headquartered in Tampa, Florida. The NHSS data are crucial to help our state and community-based organizations craft appropriate outreach and prevention programs, and to target resources to communities bearing the greatest impact of HIV. Investment in this national surveillance system is critical for monitoring HIV incidence, prevalence and viral suppression outcomes – all factors related to achieving the goals outlined in the National HIV/AIDS Strategy (NHAS) and the Ending the HIV Epidemic in the U.S. Initiative (EHE). Both strategies specify the goal to end the HIV epidemic in the U.S. by 2030 with targeted and increased investments in proven prevention tools, innovative technologies and programs tailored to local needs.

We encourage CDC to prioritize improvements in data timeliness and completeness within the NHSS to support rapid and more effective real-time responses. High-quality HIV surveillance data is critical to strengthen prevention programs, improve the linkage to care process and effectively allocate resources at the federal, state and/or local level. For example, public health surveillance played a crucial role in identifying and responding to the HIV outbreak in Penobscot County, Maine – the largest HIV outbreak in the state's history.¹ It is imperative that the CDC maintain its investment in reliable, consistent, and speedy data monitoring systems to ensure that emerging threats anywhere in the country are detected as early as possible and to coordinate effective response efforts.

As the National HIV Surveillance System is extended, it is important for CDC to continue building and maintaining trust with community members by providing safeguards and protections to ensure that data is handled safely, securely and exclusively for public health. Given that more than 30 states still maintain HIV criminalization or exposure laws, it is vital that NHSS data is never used—directly or indirectly—to support punitive actions against people living with HIV.² CDC should also provide clear federal guidance to affirm the purpose of the surveillance data and its commitment to preventing misuse in order to maintain community support. Additionally, the NHSS data should be accessible to a wide range of stakeholders (i.e., policy makers, journalists, community advocates) to promote accountability and transparency.

For these reasons, The AIDS Institute urges the CDC to extend the NHSS for a robust, equitable and sustained response to the nation's HIV epidemic. We appreciate the opportunity to comment and stand ready to support CDC's efforts to strengthen the nation's HIV surveillance infrastructure.

Respectfully submitted,

Naomi Gaspard

Policy Manager

The AIDS Institute

1. *Penobscot County HIV outbreak continues to grow; providers say the rest of Maine is at risk.* Kaitlyn Budion. Maine Public. July 2025. <https://www.mainepublic.org/health/2025-07-11/penobscot-county-hiv-outbreak-continues-to-grow-providers-say-the-rest-of-maine-is-at-risk>.
 2. Center for HIV Law and Policy (CHLP). *Mapping HIV Criminalization Laws in the U.S.* February 2025. <https://www.hivlawandpolicy.org/maps>
-

Organization: Equitas Health

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0075

Full Comment:

See attached file(s).

Attached Comment:

November 25, 2025

Submitted via www.regulations.gov

Acting Director Jim O’Neill

Information Collection Review Office

Centers for Disease Control and Prevention

1600 Clifton Road NE, MS H21-8

Atlanta, GA 30329

RE: Public Feedback for National HIV Surveillance System (NHSS—Extension—National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Centers for Disease Control and Prevention (CDC), Fed. Reg. 2025-18904 (ATTN: CDC-2025-0519)

Dear Acting Director O’Neill,

Equitas Health is a federally qualified health center look-alike (FQHC look-alike) and one of the largest LGBTQ+ and HIV/AIDS serving healthcare organizations in the country. Each year, we serve tens of thousands of patients in Ohio, Texas, Kentucky, and West Virginia, and since 1984, we have been working to advance “care for all.” Our mission is to be the gateway to good health for those at risk of or affected by HIV; for the LGBTQ+ community; and for those seeking a welcoming healthcare home. In doing so, we offer primary and specialized medical care, pharmacy services, dentistry, mental health and recovery services, HIV/STI prevention and treatment services, Ryan White HIV case management, overall care navigation, and a number of community health initiatives.² We appreciate the opportunity to provide feedback related to the Centers for Disease Control and Prevention’s (CDC) continuing information collection for the National HIV Surveillance System (NHSS).

Paperwork Reduction Act

The Paperwork Reduction Act (PRA)³ was established to ensure that federal information collection is both purposeful and efficient, not to prevent valuable data gathering. Under the PRA, agencies like CDC must justify the need for each information collection, estimate the burden it will impose, and obtain approval from the Office of Management and Budgeting (OMB) before collecting the data. The law also promotes the use of information technology to improve data management and accessibility. In essence, the PRA seeks to balance the government's need for information with the public's right to be free from unnecessary administrative burden. How NHSS is Critical to Effective HIV/AIDS Treatment

In this case, the CDC's data collection under NHSS fulfills the PRA's intent by generating critical public health data that inform prevention, intervention, and policy.⁴ The information is unique, actionable, and necessary to protect health and save lives, and the modest reporting requirements are justified by the data they produce.⁵ Specifically, this system provides timely, standardized data that enable CDC and health care agencies to monitor trends, identify emerging issues, and allocate scarce resources effectively.

For community health centers like Equitas Health, NHSS plays a uniquely important role, including the following:

1. Targeting services to the communities most affected.
NHSS data helps centers identify local HIV burden, disparities, and transmission patterns. This allows organizations like Equitas Health to tailor outreach, testing, PrEP programs, and treatment services where the need is greatest.⁶
2. Strengthening integrated, whole-person care.
Because NHSS tracks engagement in care and viral suppression, it informs how clinics structure integrated services, like combining HIV care with behavioral health, addiction support, PrEP navigation, and chronic disease management. Accurate surveillance helps centers anticipate workforce needs, adjust appointment capacity, and align wraparound services with real-world demand.⁷
3. Ensuring low-barrier access and reducing disparities.
Surveillance data highlights inequities in diagnosis, linkage to care, and viral suppression among marginalized communities.⁸ Community health centers rely on these insights to design low-threshold entry points (i.e., same-day starts, telehealth options, walk-in clinics) and to secure funding for services that reduce barriers rooted in stigma, unstable housing, or lack of insurance.
4. Supporting community-based prevention and treatment innovation.
NHSS trend data allows organizations like Equitas Health to adapt quickly to emerging needs, like shifts in transmission routes or uptake of PrEP and PEP. It enables programs to remain nimble and evidence-based rather than reactive or outdated.⁹
5. Guiding resource allocation and sustaining funding.
Federal and state funding decisions for HIV care, Ryan White programs, prevention initiatives like Ending the Epidemic,¹⁰ and community health investments are all closely tied to NHSS data. Accurate surveillance ensures that health centers receive resources proportional to the community's needs, enabling them to maintain high-quality, comprehensive services.

Continuing the data collection for NHSS ensures continuity in long-term trend analysis, supports evidence-based policymaking, and strengthens coordination among public health partners at the federal, state, and local levels. Limiting or discontinuing these efforts would not only impede CDC's

ability to monitor and respond effectively to evolving public health challenges but would additionally place barriers to care for health centers like Equitas Health.

Equitas Health would like to thank you for this opportunity to present comments and concerns on the proposed changes to the Center for Disease Control and Prevention's (CDC) continuing information collection for the National HIV Surveillance System (NHSS). Should you have any questions about our comments, please feel free to contact Candace Janidlo (she/her), Legislative Affairs Manager at Equitas Health.

1. Document prepared by Candace Janidlo (she/her), Legislative Affairs Manager of Equitas Health, with assistance from Dr. Rhea Debussy (she/her), Director of External Affairs. Document reviewed by Tim Wilson, Esq. (he/him), Associate General Counsel.
2. <https://equitashealth.com/about-us/>
3. <https://pra.digital.gov/>
4. <https://www.cdc.gov/data-modernization/php/policy-standards/index.html>
5. <https://www.waldenu.edu/programs/health/resource/how-does-the-centers-for-disease-control-and-prevention-track-public-health-trends>
6. <https://pmc.ncbi.nlm.nih.gov/articles/PMC10605962/>
7. <https://pmc.ncbi.nlm.nih.gov/articles/PMC11528829/>
8. <https://odphp.health.gov/healthypeople/objectives-and-data/data-sources-and-methods/data-sources/national-hiv-surveillance-system-nhss>
9. <https://www.cdc.gov/hiv-data/nhss/national-hiv-prevention-and-care-objectives-2025.html>
10. <https://www.cdc.gov/ehe/index.html>

Organization: Human Rights Campaign

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0082

Full Comment:

See attached file(s).

Attached Comment:

December 1, 2025

Jeffrey M. Zirger

Information Collection Review Office

Centers for Disease Control and Prevention

1600 Clifton Road NE

Atlanta, Georgia 30329

Re: Docket No. CDC-2025-0519

On behalf of the Human Rights Campaign (HRC)—the nation's largest civil rights organization working to achieve equality for LGBTQ+ people we are committed to ending the HIV epidemic, we submit these comments to underscore the critical importance of the National HIV Surveillance

System (NHSS) and to offer strategic recommendations to ensure that surveillance is modernized, people-centered, equitable, and community-protective.

The NHSS is foundational to the integrity and accountability of multiple federal programs authorized under federal law, including but not limited to:

- The Ryan White HIV/AIDS Program (Title XXVI of the Public Health Service Act, 42 U.S.C. § 300ff-11 et seq.);
- Housing Opportunities for Persons with AIDS (HOPWA) under the AIDS Housing Opportunity Act, 42 U.S.C. § 12901;
- The Affordable Care Act, which expanded access to HIV treatment and prevention including PrEP, under 42 U.S.C. § 18001;
- The CARES Act and Public Health Service Act (42 U.S.C. § 247d), which recognizes surveillance as essential to national preparedness and emergency response.

Surveillance data plays a determinative role in federal resource allocation, civil rights enforcement, and monitoring of legal responsibilities under Title VI of the Civil Rights Act of 1964 (42 U.S.C. § 2000d), Section 504 of the Rehabilitation Act (29 U.S.C. § 794), the Americans with Disabilities Act (42 U.S.C. § 12101), and Section 1557 of the ACA prohibiting discrimination in federally funded health programs (42 U.S.C. § 18116). We emphasize that accurate, representative, standardized, and protected surveillance data is necessary to uphold the government's legal obligations for equity, nondiscrimination, fiscal accountability, and informed public health action.

Timeliness and national uniformity of HIV surveillance is not discretionary; it is the statutory responsibility of federal public health authorities under 42 U.S.C. § 242b, which mandates the collection, analysis, and dissemination of health data as part of the nation's public health surveillance infrastructure. Furthermore, federal leadership is crucial to ensuring trust, transparency, and consistent protections across states, as required under federal privacy and confidentiality provisions in 42 U.S.C. § 1320d (HIPAA).

We recommend that CDC:

1. Modernize NHSS data systems to ensure real-time interoperability, consistent with the purposes laid out in the Public Health Service Act (42 U.S.C. § 252 and § 247d), which emphasize coordination for disease control.
2. Align HIV surveillance with broader public health infrastructure mandates, including national preparedness under the Pandemic and All-Hazards Preparedness Act (42 U.S.C. § 300hh).
3. Protect HIV surveillance data from criminalization and misuse, consistent with federal protections for sensitive personal health information under HIPAA and Section 1557 of the Affordable Care Act (42 U.S.C. § 18116).
4. Standardize collection of sexual orientation and gender identity (SOGI) data in accordance with federal agency mandates under Executive Order 13985 (Advancing Racial Equity and Support for Underserved Communities) and Executive Order 14075 (Advancing Equality for LGBTQI+ Individuals).

Surveillance is essential not only for public health—but also for civil rights, privacy, and equity. CDC cannot fulfill its mandate under the End the HIV Epidemic Initiative, the National HIV/AIDS Strategy, or federal nondiscrimination laws without an accurate, ethical, legally protected, and community-supported surveillance system. We commend CDC for its leadership and urge continued

investment in modernization, workforce capacity, system interoperability, community trust, and civil rights compliance to ensure that NHSS remains a vital instrument for justice, equity, accountability, and health.

Thank you for the opportunity to comment. Please contact the Human Rights Campaign team with any questions or requests for additional information.

Organization: SIECUS: Sex Ed for Social Change

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0073

Full Comment:

Comment from SIECUS: Sex Ed for Social Change in Support of Continued HIV Data Collection to Strengthen Comprehensive Sex Education and Youth Health Outcomes.

Attached Comment:

Submitted to the Centers for Disease Control and Prevention (CDC), Department of Health and Human Services (HHS)

SIECUS submits the following organizational comment on the 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).

SIECUS: Sex Ed for Social Change is a national organization leading policy and advocacy for comprehensive sex education. Comprehensive sex education (CSE) is instruction that is medically accurate, evidence-based, age-appropriate, culturally responsive, and inclusive of LGBTQIA+ identities. CSE empowers young people to make informed, safe, positive choices about their sexuality and sexual health while building healthy relationships and developing a shame-free view of sexuality. This education includes instruction on the prevention of sexually transmitted infection, including HIV, through correct condom use, regular testing, and appropriate pre- and post-exposure prophylaxis in addition to where and how to access sexual and reproductive health services. s.

Young people ages 13 to 24 accounted for 21% of all new HIV infections in the US and youth between 15 and 25 accounted for 50% of all new STI infections. In 2022, the CDC found that out of the 37,981 people who received HIV diagnoses, gay and bisexual men ages 13 to 34 comprise almost 45% of these new HIV cases. Despite these high rates of new infections, youth are least likely to be linked to care one year after a positive HIV diagnosis, are the population group with the lowest level of viral suppression, and only 9 - 15% have ever been tested for HIV. Studies have shown that CSE in both school and community-based education settings has meaningful impacts on HIV-related behaviors, student grades, and risk-reducing actions such as delayed sexual intercourse and condom use. Comprehensive HIV/AIDS education has also been associated with young people's reduced sexual partners, reduced likelihood of non-consensual sex, injection drug use, and reduced alcohol or drug use before sex. Health outcomes and retention in care can also be improved via CSE; students who are at a higher risk for HIV compared to their peers seek out resources at higher rates when they receive CSE in conjunction with supportive services.

Continuing robust HIV data collection through the National HIV Surveillance System is essential to sustaining and strengthening this work. Surveillance data allow public health agencies, educators, and youth-serving organizations like SIECUS to understand where new infections are occurring, which populations are most affected, and how risk patterns are shifting over time. These insights directly inform the development and refinement of CSE curricula, ensuring that instruction is aligned with real-world trends and responsive to the needs of the youth most impacted by HIV and STIs. High quality data enable educators to incorporate accurate information about HIV prevention methods, emerging disparities, and local transmission dynamics which ultimately equipping young people with the knowledge and skills they need to protect their health. By integrating timely, detailed HIV data into sex education programs, schools and communities can better target interventions, allocate resources, and implement evidence-based strategies that reduce infections, close care gaps, and improve long-term outcomes for young people nationwide.

1. Necessity and Practical Utility of the Information Collection

The National HIV Surveillance System plays a critical and irreplaceable role in monitoring HIV incidence, prevalence, drug resistance, and geographic and demographic trends. For organizations like ours that develop strategy and disseminate CSE data and toolkits, accurate surveillance data are imperative to our work. This data helps ensure curricula are responsive to the real world public health landscape, particularly as young people continue to face barriers to accessing inclusive, medically accurate information. Surveillance data directly inform our ability to inform members of Congress and bring awareness to HIV prevention strategies that reflect current transmission trends, emerging drug resistance, and disparities affecting youth, especially LGBTQ+ youth, youth of color, and youth in underserved communities. Without robust surveillance data, federal, state, and local partners cannot adequately protect young people or allocate resources to meet their needs.

2. Enhancing Quality, Utility, and Clarity of the Information Collected

We encourage CDC to continue expanding the clarity of demographic data, particularly data assessed by age, race/ethnicity, gender identity, sexual orientation, and geographic location. For sex education providers, such detailed information significantly enhances the ability to tailor curricula to the specific needs of communities and to address disparities among youth populations most disproportionately affected by HIV. Continued clarity around definitions, reporting standards, and timelines will further improve the utility of the National HIV Surveillance System dataset for prevention partners.

Sincerely,

SIECUS: Sex Ed for Social Change

Organization: PrEP in Black America (PIBA)

Submitter Email: NOT PROVIDED

Submitter Address: NOT PROVIDED

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0074

Full Comment:

See attached file(s).

Attached Comment:

Jeffrey M. Zirger,
Lead, Information Collection Review Office,
Office of Public Health Ethics and Regulations, Office of Science
Centers for Disease Control and Prevention

Re: PrEP in Black America (PIBA) Comments on 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).

1. **Necessity and Practical Utility** NHSS remains a critical national asset. The proposed information collection is necessary to ensure accurate, population-based monitoring of HIV in the United States. NHSS data are essential for understanding systemic differences in HIV incidence, prevalence, and care outcomes—particularly among people born with HIV or those HIV exposed at a young age, Black women, Black sexual and gender minority communities, and individuals experiencing co-occurring structural vulnerabilities such as poverty, trauma, and violence. The NHSS is essential for monitoring HIV trends, clusters, drug resistance, and care-continuum outcomes. Without these data, it would be significantly more difficult to evaluate implementation of local and national HIV initiatives, including Ending the HIV Epidemic strategies.
2. **Accuracy of Burden Estimates**
We encourage the CDC to verify that the burden estimates fully account for variations in state and local reporting capacity, particularly in jurisdictions with limited public health staffing or older surveillance systems. Underestimation of time or personnel burden could affect the completeness and timeliness of data.
3. **Enhancing Quality, Utility, and Clarity**
The utility of NHSS would be improved by expanding race, gender, and risk-category variables to better capture intersectional identities (e.g., Black transgender women, Black women with experiences of interpersonal violence). Enhancing variables related to social determinants of health (housing status, economic instability, trauma) would further strengthen the value of the system for public health planning as well as highlight gaps in programming and research.
4. **Assessing Information Collection Costs**
Clearer descriptions of cost impacts by jurisdiction—especially those with limited infrastructure—would help partner agencies better anticipate and prepare for resource needs related to compliance and data submission.
5. **Minimizing Burden**
Prioritizing the use of automated laboratory reporting and streamlined digital tools would improve efficiency. CDC may consider supporting states with technical assistance to ensure equitable implementation of these technologies.
6. **Costs**
Costs may be disproportionately high for small or resource-limited health departments. Additional support for modernization efforts could reduce inequities in data completeness and quality. The CDC should consider whether and how continued federal financial and technical support is adequate to meet the goals of surveillance modernization across all jurisdictions, not only those with advanced infrastructure.
7. **Research**

The NHSS is essential for population-level HIV research in the United States. It enables monitoring of trends, incidence, prevalence, and care-continuum outcomes and is often the only source of standardized, longitudinal data across jurisdictions. For researchers focused on disproportionately impacted populations—such as Black communities, women, and people with intersecting structural vulnerabilities—NHSS data are critical for identifying inequities, tracking progress, and informing evidence-based interventions. We recommend expanding and standardizing variables that better capture intersectional identities and social determinants of health. This could include:

- More granular race/ethnicity and gender identity categories (e.g., Black transgender women, nonbinary people).
- Indicators related to housing instability, incarceration history, intimate partner violence, substance use, and behavioral health.
- More robust measures of prevention engagement (e.g., PrEP use and discontinuation) and care engagement (e.g., missed visits, retention patterns). These additions would significantly strengthen the ability of researchers to examine structural drivers of HIV and evaluate interventions that seek to reduce disparities.

Name: Stephen Lee

Organization: NASTAD

Submitter Email: NOT PROVIDED

Submitter Address: 444 North Capitol Street NW, Suite 339, Washington, DC 20001

Date Submitted: 12/1/2025

Comment ID: CDC-2025-0519-0072

Full Comment:

See attached file(s).

Attached Comment:

December 1, 2025

Jeffrey M. Zirger

Information Collection Review Office

Centers for Disease Control and Prevention

1600 Clifton Road NE

Atlanta, Georgia 30329

Re: Docket No. CDC-2025-0519

On behalf of NASTAD, a nonpartisan, nonprofit association that represents governmental public health officials who administer HIV and hepatitis programs in the U.S., I am writing to submit comments on the critical importance of the National HIV Surveillance System (NHSS) and the need for sustained investment in timely, complete, and high-quality HIV surveillance data. The NHSS is a critical component of the nation's public health infrastructure and remains essential for monitoring trends, guiding prevention and care efforts, and evaluating progress toward ending the HIV epidemic in the United States.

NASTAD supports continued investment in data modernization to ensure that the NHSS remains adaptive, efficient, and secure. Modern data systems improve data quality and timeliness while strengthening the ability of health departments to respond rapidly to emerging infection clusters

and trends. These advancements enable more effective coordination across jurisdictions and enhance the overall impact of HIV prevention and care programs.

Timely HIV surveillance data is indispensable for outbreak detection and response. Delayed, incomplete, or inconsistent reporting can significantly hinder the ability of health departments to identify emerging clusters, deploy prevention and care interventions, and coordinate with partner jurisdictions. Real-time or near-real-time data strengthens situational awareness and allows health departments to intervene earlier, reducing the likelihood of broader transmission and mitigating long-term public health and financial impacts.

Health departments across the nation have enhanced their workforce to ensure high-quality, timely, and complete surveillance data reporting. Continued investments in training, staffing, and technical support are necessary to meet the ongoing demands of modern surveillance while maintaining data integrity and consistency. However, no amount of local innovation or staffing can substitute for federal data collection that is standardized, complete, and nationally representative. Health departments cannot fill gaps caused by diminished or uneven data collection at the national level, and fragmented data systems undermine national situational awareness and federal oversight.

The data gathered through NHSS is utilized by health departments and their partners in creating a comprehensive, jurisdiction-wide set of programs and services to educate communities about HIV, respond to and prevent HIV transmission, and provide tailored care and treatment programs. Additionally, the federal government relies on NHSS data for a variety of critical programs such as the Ryan White HIV/AIDS Program and the Housing Opportunities for Persons with AIDS (HOPWA) assistance program. A robust national sample is essential to ensure equity in resource allocation and to accurately assess progress toward national goals.

NASTAD emphasizes the importance of increasing efficiency in the NHSS to reduce administrative burden on health departments. Streamlining data collection and reporting processes, improving system interoperability, and providing clearer guidance will allow jurisdictions to focus limited resources on public health action rather than administrative tasks. Timely and complete data also allows for reduced response time in responding to new HIV transmissions and pivoting program response and implementation.

NASTAD commends the Centers for Disease Control and Prevention for its continued leadership in supporting NHSS. Continued collaboration and investment in modernization, workforce, timeliness, and efficiency will ensure that the NHSS remains a cornerstone of the nation's HIV response.

Sincerely,

Stephen Lee, MD, MBA, DHSM
Executive Director
NASTAD