

# Cluster and Outbreak Detection and Response & Molecular HIV Surveillance

ASTAD acknowledges the importance of implementing surveillance programs and using public health data for responding to HIV and hepatitis clusters. Quickly identifying and responding to clusters and outbreaks provides opportunities to disrupt HIV transmission and can assist in identifying and addressing gaps in prevention and treatment services.

This document is intended to serve as a resource for both NASTAD and its members for communications, community engagement, and advocacy purposes to reflect common concerns, issues, and priorities held by health departments around the implementation of HIV Cluster Detection and Response (CDR) and Molecular HIV Surveillance (MHS) strategies. The recommendations in this document are the result of feedback collected from NASTAD members and through the leadership of the Program and Policy Committee of NASTAD's Board of Directors.

While NASTAD and its members acknowledge the importance of CDR activities in Ending the HIV Epidemic (EHE) efforts, including MHS as one approach for cluster detection, we also recognize that health departments and community partners have also expressed concerns and have offered recommendations to implement CDR and MHS strategies in ways that reflect the values and priorities of NASTAD, health departments, and community members. Specific challenges and recommendations are listed below.

## **Community Engagement**

It is essential to provide meaningful opportunities for community input, education, and engagement to facilitate continued conversations around CDR and MHS implementation to ensure programs are meeting the community's needs. For community members to participate in these activities, health departments need to involve those most impacted by this work to be part of the process with partners at the local, state, and national/federal levels. Understanding and responding to the unique community concerns around MHS implementation is vital to maintaining trust between the health department and populations impacted by HIV. Additional guidance on best practices for continued engagement with community members around MHS concerns, and funding for health departments to expand their engagement approaches could benefit these relationships. Community engagement should also include physicians who treat HIV. When engaged about the uses of clinical data to guide MHS activities, physicians can be stakeholders in not only supporting patients connected to clusters but also promoting and engaging in conversations around using data to support ending the HIV epidemic.





## **Protection of Public Health Data**

NASTAD's members call for a technological and regulatory barricade between identifiable health department data and civil, criminal, or administrative proceedings. There are real concerns that new surveillance technologies may subject people living with HIV (PLWH), people engaging with health department partner elicitation and notification services (i.e., Partner Services), and people seeking HIV prevention services, to increased risk of prosecution, misuse of surveillance data in criminal or civil proceedings, or adverse actions by immigration authorities. Putting safeguards in place to protect PLWH from being penalized for participation in surveillance activities would increase engagement in HIV prevention, testing, and care services and build

trust between communities and governmental public health. Specific recommendations for the Centers for Disease Control and Prevention (CDC) to include in further implementation of CDR and MHS:

Specific recommendations for the CDC include:

- Provide jurisdictions the ability to apply for a waiver from the requirements to implement MHS if their existing HIV criminalization and/or data privacy laws allow HIV surveillance data to be used in criminal investigations or criminal, civil, or administrative proceedings.
- Engage at federal and jurisdictional levels to strengthen privacy rules around HIV surveillance data so it cannot be used in criminal investigations or criminal, civil, or administrative proceedings.
- 3. Provide additional funding to health departments and technical assistance (TA) on data privacy issues that most impact their jurisdictions.

### **Assess and Address HIV Criminalization**

As of 2022, all 50 states, the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands have valid statutes under which PLWH can be prosecuted on the basis of HIV status, which can impact MHS implementation. This is of particular concern in the <u>35 states</u> that still have laws specifically criminalizing HIV exposure; many of these states also criminalize other infectious or communicable diseases, such as viral hepatitis, under the same laws. In the <u>vast majority</u> of these jurisdictions, PLWH can be charged with felony crimes for engaging in certain activities, some of which may not be criminalized at all for people who are HIV-negative. Lifelong consequences such as felony records and sex offender registration requirements exacerbate existing disparities by making it more difficult for PLWH to obtain stable housing and employment.



However, the barriers posed by HIV criminalization are not limited to laws explicitly criminalizing exposure to HIV and other communicable diseases. Every state and territory has general criminal statutes, such as endangerment and assault statutes, that can be used to prosecute people with HIV – as of April 2022, about <u>26 states and territories</u> reported using general criminal laws to prosecute PLWH for felony crimes. In many states and territories, PLWH are also criminalized through enhanced penalties and sentences for sexual offenses or sex work and solicitation crimes.

State and local members identified HIV criminalization as a significant barrier to adequately implement MHS, and a limitation on the ability of health departments to share data with other jurisdictions that have HIV criminalization statutes. Additionally, health departments have identified HIV criminalization and concerns about misuse of HIV surveillance data for law enforcement purposes as a disincentive for PLWH to participate in HIV prevention and care services. Cluster response and molecular surveillance practices are not new, nor are they unique to HIV, but ethical considerations around the impact of these programs are unique due to HIV-related stigma and fear of potential for prosecution. A combination of additional support and TA for individual jurisdictions, along with federal funding to support local educational efforts for state and local legislatures and other law and policy making bodies, around reforming HIV criminalization laws and prosecutorial practices, is necessary to advance these efforts and end the HIV epidemic.

There is precedent for this work. Across the country, advocates are working with prosecutors to increase engagement between law enforcement and public health, promote sexual health literacy for criminal justice stakeholders, and reform prosecutorial practices related to HIV-specific criminal law. Additionally, at least 12 states have either modernized or repealed their criminalization laws to align them with current scientific evidence. In July 2021, Illinois became the second state to end criminal penalties for PLWH. <u>HB 1063</u> was implemented primarily due to work done by the Illinois HIV Action Alliance, a statewide coalition of legal, health, and policy organizations and other community advocates. Helping to support this type of advocacy can reduce the stigma associated with HIV criminalization.

## Flexible Implementation and Resources to Support Program Infrastructure

Another important consideration is the need for jurisdictional flexibility from CDC around the implementation of CDR and MHS depending on HIV prevalence, jurisdictional resources, laws, and utility of CDR approaches locally. Effectively responding to clusters involves significant staff time. Many health departments, especially those in low prevalence jurisdictions, lack adequate capacity and resources to successfully implement CDR activities. A robust CDR response requires resources across data, informatics, surveillance and field epidemiologist response, provider networks, prevention tools, and communications. The lack of unified surveillance, prevention, and care data systems across HIV, STIs, and viral hepatitis also hinders the ability to take a syndemic approach to addressing clusters. Additionally, many health departments face significant staff shortages. NASTAD members recognize that a one-size-fits-all approach to CDR and MHS implementation is not optimal. **NASTAD's membership recommends a focus on flexibility for tailored local solutions to implement CDR activities and provide additional resources to prevention and surveillance programs to support the staffing and other resources needed for CDR activities. Additional funding will ensure a sufficient HIV surveillance infrastructure, including technology and an adequate workforce to support the proposed scope of CDR and MHS activities.** 

#### **CDR Program Utility and Evaluation**

More research on the utility of CDR and MHS strategies for health departments is needed to determine the value of the implementation of CDR and MHS strategies in relation to the investment of resources required. The utility of using MHS as a tool to end the HIV epidemic must extend beyond its use as a post hoc data analysis activity. Instead, its impact depends on timely data and the ability to use these data to implement an appropriate response that slows or halts HIV transmission. As mentioned above, not all health departments have the capacity, resources, and abilities to implement CDR activities at the same level. Additionally, for many health departments, a lack of data timeliness often limits the ability of MHS strategies to detect and respond to clusters in real-time. To ensure that resources are appropriately allocated, more evidence regarding the effectiveness of CDR activities (including MHS) in populations most affected by HIV is needed to garner community support, measure the impact of CDR activities, and identify the most effective ways to implement CDR activities across different settings (rural/ urban) and priority populations (people who use drugs, MSM). NASTAD recommends CDC and other federal partners fund robust, multi-site evaluation of MHS and CDR implementation in locations where these approaches have been implemented, including a detailed assessment of benefits and harms resulting from MHS and CDR implementations.





Despite remaining questions and challenges with implementation, health departments recognize the opportunities these strategies can provide to detect new clusters and outbreaks and identify a broader range of individuals connected to known HIV clusters or outbreaks that are not identified through routine surveillance activities, field epidemiology, and partner services methods. NASTAD supports CDR strategies as one of many tools to work towards EHE goals. NASTAD encourages health departments to continue engaging with their communities, state leadership, and partners around issues related to CDR, MHS in particular. NASTAD commits to providing leadership support, advocacy, and technical assistance to members as health departments continue to navigate challenges and opportunities presented by CDR implementation.