

# Presidential Advisory Council on HIV/AIDS (PACHA)

## Molecular HIV Surveillance and Cluster Detection and Response Resolution

**DRAFT** – 10/14/2022

Molecular HIV surveillance (MHS) uses laboratory data to identify networks of people experiencing HIV transmission. HIV cluster detection and response (CDR) has allowed some public health agencies and communities affected by rapid HIV transmission to increase and more specifically target HIV prevention and treatment services and programs. After learning of concerns that all networks representing people living with HIV, some advocates and privacy experts, and some public health officials have about MHS and CDR, PACHA gathered input from researchers, public health practitioners, and community advocates who have conducted, and been affected by MHS/CDR activities. Some shared important successes as a result of these strategies, while others raised substantial human rights concerns about consent, data protections, accountable community engagement, and potentially dangerous unintended consequences should prosecutors gain access to molecular surveillance data and use this information in criminal cases against people living with HIV. Some public health officials also raised concerns about resource allocation required for implementation of MHS/CDR activities.

MHS/CDR activities are currently being implemented in multiple states across the U.S. that actively criminalize persons living with HIV for non-disclosure, exposure, or transmission—often without an understanding or incorporation of basic scientific principles-concerning HIV. Through this resolution, PACHA provides recommendations to HHS on the future implementation of MHS/CDR, recommendations that acknowledge the benefits of these activities but are also responsive to the serious concerns raised by community members.

**Whereas**, Molecular HIV Surveillance (MHS) and Cluster Detection and Response (CDR) activities are a part of the “Respond Pillar” of the Ending the HIV Epidemic in the U.S initiative and the National HIV/AIDS Strategy, and have become a ubiquitous component of public health surveillance for HIV and other diseases;

**Whereas**, MHS data has been useful in identifying new HIV outbreaks within specific communities and has allowed public health officials and community organizations to respond to these outbreaks with additional support and resources to the impacted individuals and communities<sup>1</sup>;

**Whereas**, the national rollout of MHS/CDR occurred without significant or meaningful community engagement. No organizations led by people living with HIV were involved in the planning, and few such organizations have been involved in implementation or evaluation of any efforts to educate the community at a national level<sup>2</sup>.

<sup>1</sup> Oster AM, Lyss SB, McClung RP, Watson M, Panneer N, Hernandez AL, Buchacz K, Robilotto SE, Curran KG, Hassan R, Ocfemia MC. HIV cluster and outbreak detection and response: the science and experience. *American Journal of Preventive Medicine*. 2021 Nov 1;61(5):S130-42. Tumpney M, John B, Panneer N, McClung RP, Campbell EM, Roosevelt K, DeMaria A, Buchacz K, Switzer WM, Lyss S, Cranston K. Human immunodeficiency virus (HIV) outbreak investigation among persons who inject drugs in Massachusetts enhanced by HIV sequence data. *The Journal of Infectious Diseases*. 2020 Oct 1;222(Supplement\_5):S259-67.

<sup>2</sup> Castro-Bojorquez M, French M, Lewis O, Minalga B, Ray R, Sprague, L, Sardina C, Spieldenner A, Suttle R. The Meaningful Involvement of People with HIV/ AIDS (MIPA): The Participatory Praxis Approach to Community Engagement on HIV Surveillance. *The Journal of Community Engagement and Scholarship*. 2022 Jul 27;14(2).

34 **Whereas**, CDC can and has meaningfully engaged with impacted parties when HIV surveillance  
35 technologies have changed in the past. For example, when CDC required name-based HIV reporting for  
36 funded public health departments, they engaged in a multi-year engagement of health departments and  
37 communities most impacted by HIV to obtain community buy-in.

38 **Whereas**, community members, particularly networks of people living with HIV, advocates and some  
39 health department leaders, have voiced for many years substantial concerns about the implementation  
40 of MHS. These concerns include the potential for misuse of molecular HIV surveillance data within the  
41 criminal legal system, the need for informed consent to use private health information in this manner,  
42 data security and privacy, the lack of accountable community engagement before roll-out, human rights  
43 concerns, the impact of MHS implementation of other HIV prevention activities, the lack of real-time  
44 access to data that would make MHS more useful, the concern that that in at least some instances the  
45 requirement to participate in MHS and focus on people identified as part of clusters may further  
46 exacerbate racial inequities in access to services and programs, and the cost of MHS implementation<sup>3</sup>;

47 **Whereas**, networks of people living with HIV, many other people living with HIV, and HIV advocates  
48 have demanded an immediate moratorium on all molecular HIV surveillance activities until adequate  
49 safeguards protecting the privacy and autonomy of people living with HIV are implemented;

50 **Whereas**, medical mistrust is a substantial barrier to engaging the general population of the U.S. in  
51 activities proven to enhance personal and public health, and medical mistrust is higher than average  
52 within many of the communities disproportionately impacted by HIV due to historical and current  
53 medical abuses and inequities;

54 **Whereas**, PACHA's Stigma and Disparities Subcommittee convened a Molecular HIV Surveillance and  
55 Cluster Detection and Response Workgroup on May 9-10, 2022 in Atlanta, Georgia, in response to  
56 concerns brought to PACHA by networks of people living with HIV and other HIV advocates. This  
57 convening brought together a group of community members living with HIV, advocates, academics,  
58 researchers, clinicians, public health department leaders, and federal partners, to discuss issues related  
59 to MHS/CDR and inform the development of recommendations;

60 **Whereas**, PACHA supports HIV surveillance activities as a core public health function, and the following  
61 recommendations are limited to the use of MHS data for the detection of networks of people  
62 experiencing HIV transmission and are not meant to be applicable to HIV surveillance as a whole;

63 **Be it resolved**, PACHA urges the Centers for Disease Control and Prevention (CDC) to update its  
64 guidance to state, territorial, and local health departments and other public health authorities  
65 on the implementation of CDR specific to MHS activities through its HIV-related notice of  
66 funding opportunity (NOFO) announcements and other channels used by CDC to communicate  
67 with recipients of CDC funding to include the following:

68 Guidance that directs health departments and public health authorities, in collaboration with  
69 CDC, to adapt their MHS approach and strategies through meaningful engagement with key  
70 stakeholders and people living with HIV to determine if MHS strategies should be implemented

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<sup>3</sup> Bernard EJ, McClelland A, Cardell B, Chung C, Castro-Bojorquez M, French M, Hursey D, Khanna N, Minalga MB, Spieldenner A, Strub S. We are people, not clusters!. The American Journal of Bioethics. 2020 Oct 2;20(10):1-4.

HIV Justice Worldwide and Positive Women's Network USA. Molecular HIV Surveillance: A Global Review of Human Rights Implications. (2021)

in their jurisdiction, and if implementation happens, how MHS activities can be implemented in a manner that does not pose harm to people living within that jurisdiction. This adaptation process should be responsive to local jurisdictional trends and allow for better tailoring of the process to meet the needs within a given locality. This adaptation process should include a thorough review of state and local laws and ongoing meaningful engagement and partnership with local persons and networks of people living with HIV, representatives of community-based organizations serving people living with or vulnerable to HIV, and other advocates and community members; and/or tribal consultation when American Indian/Alaska Native (AI/AN) data is involved.

CDC-funded jurisdictions must take into account local conditions, including the legal environment with respect to public health data protections, tribal data sovereignty, and the existence of HIV criminalization statutes, as well as general criminal statutes, that are used to prosecute people living with HIV for alleged non-disclosure, exposure, or transmission, which often do not require prosecutors to prove that a non-negligible risk of transmission existed or that the person living with HIV acted with any intent to harm. Acceptable local adaptations of MHS should span from full implementation of MHS strategies and activities to a jurisdiction-wide moratorium on all MHS activities until safeguards are implemented and the human rights concerns of people living with HIV are addressed. These safeguards must include concrete firewalls protecting public health research and surveillance data, including but not limited to MHS-related data, from access by law enforcement, corporations, criminal legal courts, immigration enforcement and youth detention and protective services systems.

Require jurisdictions that implement MHS activities receive federal funds to establish and maintain a Community Advisory Board specifically focused on MHS/CDR, the membership of which includes a majority of people living with HIV. This requirement could be satisfied through existing HIV-related entities including local Ryan White Planning Councils, Community Planning Groups, EHE CABs or other health department-supported HIV-related community planning groups. All ideas and feedback from the CAB should be elevated to CDC with a yearly report released for public record that includes actions taken to address implementation concerns. CDC should be responsible for providing an annual report about MHS activities across states that includes data on cost analysis.

Fund and provide technical assistance for conducting and evaluating activities that assess the efficacy and cost effectiveness of MHS activities relative to other HIV surveillance and prevention interventions and activities.

CDC, in partnership with local health departments, should create a national clearinghouse of MHS/CDR information for providers, people living with HIV, and the community at large to gather success stories, scholarship regarding MHS and CDR, documentation regarding the challenges and concerns currently being raised, and best practices around CDR and methods of addressing the challenges and concerns to inform its impact as a public health strategy to end HIV in the U.S. The national clearinghouse should include jurisdiction-level data that discusses cost-benefit analyses as compared to other HIV surveillance strategies.

Require that states provide plain language notifications to individuals living with HIV on the types of surveillance and analyses being conducted opt-out options for the use of MHS patient data for CDR activities. The types of surveillance and analyses being conducted with mandatorily reported data should be disseminated, at the local, state, and federal level. While the findings may not be published (due to confidentiality concerns), these *types* of surveillance and analyses should be public knowledge.

Fund academic detailing to providers caring for PLWH in the next NOFO, including HIV and infectious diseases providers, to explain MHS/CDR and the laboratory test results that are collected and used in these surveillance activities. Require that providers explain MHS/CDR and the laboratory test results that are collected and used in these surveillance activities to their patients. Best practices for informed consent should be included in the detailing, as well as any options (in jurisdictions where permitted by law) patients have to opt-out of data sharing for the purpose of MHS. Lastly, it should include guidance on how to protect patient confidentiality in the event of subpoena for medical records.

**Be it resolved,** PACHA urges the Centers for Disease Control and Prevention (CDC) to provide peer-reviewed evidence regarding the effectiveness of MHS in populations most affected by HIV, including but not limited to Black and Latinx cis and transgender men who have sex with men as well as Black and Latinx cis and transgender women, and people who inject drugs including an analysis of the incremental benefit of MHS in comparison to traditional surveillance tools and Geographic Information System mapping of incident cases in areas where persons newly diagnosed with HIV reside.

**Be it resolved,** PACHA urges CDC to work with states and jurisdictions, alongside community members, providers, tribes, tribal epidemiology centers, members of networks of people living with HIV, and partner agencies within HHS to create a stronger system of informed consent around the uses of molecular HIV data.

**Be it further resolved,** PACHA urges HHS, the White House Office of National AIDS Policy, CDC, HRSA, NIH, SAMHSA, and IHS to work with states and territories to educate lawmakers and prosecutors on the advances in HIV exposure risk, prevention and treatment and urge them to review their HIV criminalization laws through the lens of these advancements, as well as provide technical assistance to states, local health departments, tribes, community-based organizations, and advocates to repeal all laws that single out people living with HIV for disparate, punitive treatment under criminal and public health laws. Federal public health officials have an affirmative obligation to make it known to lawmakers that such laws are outdated, harmful, stigmatizing, and counterproductive to ending the HIV epidemic in the United States.