

A CHLP EXPLAINER

# What is Molecular HIV Surveillance...

# and does it put me at risk?



# Public health officials are analyzing **patient HIV data** without notifying or getting consent from PLHIV.

**MOLECULAR HIV SURVEILLANCE (MHS) is a framework, technology, and set of practices public health officials are promoting to address gaps in HIV treatment and prevention.**

**THE GOAL OF MHS** is to identify where HIV transmissions are rapidly occurring so HIV services can be more effectively delivered to the people affected.<sup>1</sup> Public health surveillance isn't new, and neither is molecular analysis for public health purposes. However, many of the particular aspects of MHS are controversial and have generated concerns among people living with HIV (PLHIV) and HIV legal, policy, and advocacy organizations,<sup>2</sup> bioethics researchers,<sup>3</sup> and even some public health directors.<sup>4</sup>

**HIV CAN MUTATE** and develop resistance to medications as it multiplies. After someone is diagnosed with HIV, or if a patient needs to change their HIV treatment regimen, a medical provider will typically order a drug resistance test.<sup>5</sup> This test analyzes the genetic structure of the virus to assess whether medications will work against that strain of HIV. Testing for drug resistance is a routine part of HIV medical care, and the test results help doctors prescribe medication that will be most effective for their individual patients. However, because HIV is a mandatory reportable disease, the results are required to be shared with public health professionals without requiring the patient to know about or consent to their data being shared.

**PUBLIC HEALTH PROFESSIONALS** then compare this HIV genetic data to discover and make inferences about where rapid HIV transmissions are happening. This is MHS: the public health use of people's sensitive, private medical health information to map networks of HIV transmission. Because HIV diagnoses are most likely to occur through actions that are stereotyped, poorly understood, stigmatized, and often criminalized like sex and injection drug use, MHS creates a database that can put PLHIV at risk of further criminalization.

<sup>1</sup> Centers for Disease Control and Prevention (CDC), National Center for HIV, Viral Hepatitis, STD, and TB Prevention, "HIV CDR Guidance for Health Departments," available at <https://www.cdc.gov/hiv/programresources/guidance/hiv-cluster-detection-and-response-guidance/index.html#cluster-rapid-transition>.

<sup>2</sup> The Center for HIV Law & Policy (CHLP), U.S. People Living with HIV Caucus, Positive Women's Network-USA, Whitman Walker Institute, Sero Project et al, "PACHA MHS/CDR Resolution Anniversary sign on letter," sent October 17, 2023 to Dr. Jonathan Mermin, Director, National Center for HIV, Viral Hepatitis, STD, and TB Prevention, and Dr. Robyn Neblett Fanfair, Director, Division of HIV Prevention, CDC, available at <https://www.hivlawandpolicy.org/resources/pacha-anniversary-letter-cdc-mipa-mhs-cdr-policy-chlp-et-al-october-2023>.

<sup>3</sup> Stephen Mouldrem, Anthony K. J. Smith, and Alexander McClelland, "Predictive analytics in HIV surveillance require new approaches to data ethics, rights, and regulation in public health," *Critical Public Health* (2022), doi: 10.1080/09581596.2022.2113035.

<sup>4</sup> Sam Whitehead, Kaiser Health News, CNN, "A new tool monitoring the spread of HIV raises privacy concerns," published July 20, 2022, <https://www.cnn.com/2022/07/20/health/hiv-tool-privacy-concerns-khn/index.html>, and see CHLP, "Is HIV Molecular Surveillance Worth the Risk?" available at <https://hivlawandpolicy.org/events/hiv-molecular-surveillance-worth-risk>.

<sup>5</sup> National Institutes of Health Office of AIDS Research Advisory Council, Panel on Antiretroviral Guidelines for Adults and Adolescents, "Drug-Resistance Testing," from Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents With HIV, available at <https://clinicalinfo.hiv.gov/en/guidelines/hiv-clinical-guidelines-adult-and-adolescent-arv/drug-resistance-testing>.

# In 2018, the CDC **made MHS mandatory** for state health departments without ensuring proper safeguards for the data collected.

There are various ways besides MHS  
that public health officials can track HIV transmissions  
and improve the distribution of limited HIV-related resources to communities.

**DESPITE THE ALREADY AVAILABLE DATA** detailing the existing gaps in HIV treatment and prevention,<sup>6</sup> in 2018 the Centers for Disease Control and Prevention (CDC) made instituting MHS a mandatory requirement for states to receive HIV prevention funding.<sup>7</sup> This was a problematic decision for several reasons, including the fact that none of the PLHIV-led networks or major national HIV legal and policy organizations were engaged for feedback prior to the mandate. The meaningful involvement of PLHIV (MIPA), a longstanding principle for the HIV social justice movement, was subverted from the outset.

**PERHAPS ONE OF THE MOST SIGNIFICANT OVERSIGHTS** by the CDC before mandating MHS was failing to ensure adequate protections for the data collected. More than 30 states have HIV-specific criminal laws that impose heightened criminal penalties on PLHIV for conduct that is either not criminalized or not as severely criminalized for people not living with an HIV diagnosis.<sup>8</sup> The CDC didn't take precautions to ensure that states first end regulations, laws, or policies that permit HIV records, including HIV test results and MHS data, to be shared with law enforcement, or prohibit the use of this data in criminal or civil legal proceedings against PLHIV. MHS is still a mandatory state health department requirement in all 50 states, and in at least 32 states, state law explicitly permits the release of HIV records for criminal prosecutions against PLHIV.<sup>9</sup>

**WHILE PUBLIC OFFICIALS CLAIM** MHS data is “de-identified” before it's shared, data de-identification isn't a reliable protection. De-identified health records can be easily re-identified using publicly available information such as voter registration records. At least one study showed it was likely possible to re-identify health records from at least 87% of the population using limited information.<sup>10</sup>

<sup>6</sup> CDC, “Data and Trends: Impact on Racial and Ethnic Minorities,” available at <https://www.hiv.gov/hiv-basics/overview/data-and-trends/impact-on-racial-and-ethnic-minorities>.

<sup>7</sup> CDC, “Funding Opportunity Announcement (FOA) PS18-1802: Integrated Human Immunodeficiency Virus (HIV) Surveillance and Prevention Programs for Health Departments,” program announced in 2017, available at <https://www.cdc.gov/hiv/funding/announcements/ps18-1802/index.html>.

<sup>8</sup> CHLP, *HIV Criminalization in the U.S. A Sourcebook on State and Federal HIV Criminal Law and Practice* (updated January 2024), available at <https://www.hivlawandpolicy.org/sourcebook>.

<sup>9</sup> NASTAD, “U.S. HIV Data Protection Landscape,” last updated Apr 11, 2024, available at <https://nastad.org/resources/hiv-data-protection-landscape>.

<sup>10</sup> Mark A. Rothstein, “Is Deidentification Sufficient to Protect Health Privacy in Research?” *The American Journal of Bioethics*, 10(9) (2010): 3–11, doi:10.1080/15265161.2010.494215.

# MHS isn't like other forms of molecular surveillance because of rampant HIV stigma and targeted state violence.

The molecular analysis of communicable and infectious diseases to track and respond to outbreaks isn't new, but there are factors about living with HIV in the United States that make MHS fundamentally different.

## HIV DISPROPORTIONATELY IMPACTS MARGINALIZED COMMUNITIES

who experience social villainization, heightened stigma, and overpolicing. Black and brown people make up 70% of all new HIV diagnoses in the United States.<sup>11</sup> Black PLHIV are much more likely to be affected by HIV-related arrests and prosecutions, and more likely to be convicted of an HIV-related crime.<sup>12</sup>

**HIV CRIMINAL ARRESTS AND PROSECUTIONS** are also not necessarily trending downward over time, and some states continue to pass laws that increase penalties or expand criminalization targeting PLHIV.<sup>13</sup> People affected by HIV experience legacies of anti-Blackness, racism, queerphobia, transphobia, classism, and discrimination that limit their ability to access services, housing, and medical care. Living with HIV is unlike being affected by any foodborne illness or a communicable disease that isn't stigmatized and relentlessly criminalized. Lastly, contact with police<sup>14</sup> and violating patients' right to confidentiality and consent<sup>15</sup> have been shown to separately fuel medical mistrust. That means MHS may jeopardize the public health response to the HIV epidemic by eroding trust among people affected by HIV at the same time it puts those people at risk of criminalization.

<sup>11</sup> CDC, *Estimated HIV incidence and prevalence in the United States, 2018–2022: HIV Surveillance Supplemental Report*, 2024;29(No. 1), available at <https://www.cdc.gov/hiv-data/nhss/estimated-hiv-incidence-and-prevalence.html>.

<sup>12</sup> The Williams Institute, UCLA School of Law, "HIV Criminalization in the United States: Data Interactive," available at <https://williamsinstitute.law.ucla.edu/visualization/hiv-criminalization>.

<sup>13</sup> CHLP, "CHLP Denounces New Law in Tennessee that Further Criminalizes People Living with HIV," published July 2, 2024, <https://www.hivlawandpolicy.org/news/chlp-denounces-new-law-tennessee-further-criminalizes-people-living-hiv>.

<sup>14</sup> Sirry Alang, Donna D. McAlpine, and Rachel Hardeman, "Police Brutality and Mistrust in Medical Institutions," *Journal of Racial and Ethnic Health Disparities* 7(4) (2020): 760–768, doi:10.1007/s40615-020-00706-w.

<sup>15</sup> Alison Wringe, Mosa Moshabela, and Constance Nyamukapa et al, "HIV testing experiences and their implications for patient engagement with HIV care and treatment on the eve of 'test and treat': findings from a multicountry qualitative study," *Sexually Transmitted Infections* 93(3) (2017): e052969, doi:10.1136/sextrans-2016-052969.

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TO USE CHLP'S NEW MODEL POLICY

ON DATA PRIVACY.



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