

What is molecular HIV surveillance?

Molecular HIV surveillance is a new public health use of individual treatment resistance information that doctors report to health departments. When a person living with HIV sees a doctor for treatment, they are tested to see how they would respond to drugs that the doctor might prescribe.¹ These tests improve care by increasing the chance that the medication is effective and are part of the data that doctors are required to report.

That data is reported to public health officials who store it and use it to track trends in HIV at the national and state levels.² Public health officials can now analyze that data to link together people who are part of the same sexual or needle-sharing networks by comparing their strains of HIV. While information about disease diagnosis has been collected for many years to track trends, this new use of individual treatment data is not fully developed or understood.

There is no requirement that doctors tell their patients that the results of their resistance testing, including their identity, will be used in this way. As a result, few people living with HIV know, let alone consent to, how their personal treatment information is being used for these research and surveillance purposes.

The Center for HIV Law and Policy Is Molecular HIV Surveillance Worth the Risk?



Who is doing molecular HIV surveillance?

Molecular surveillance data is collected by doctors and analyzed by state and local public health officials as well as scientists at the Centers for Disease Control and Prevention (CDC).

Expanding the use of this technology is a priority for the CDC. In 2017, the CDC announced a five-year program requiring states to collect and share molecular surveillance data in exchange for funding.³ States had no option to say no.

Not everyone is on board with this plan. In the wake of pushback, the CDC has allowed states to spend 2019 talking with the community, addressing gaps in data security, and considering possible legal consequences, including increased prosecutions under laws criminalizing HIV exposure.⁴

**Now is the moment for
community members and
advocates to communicate
concerns to public health officials.**

¹ U.S. Department of Health and Human Services, [Guidelines for the Use of Antiretroviral Agents in Adults and Adolescents with HIV](#).

² [Los Alamos National Laboratory HIV Database](#)

³ Centers for Disease Control and Prevention, [Funding Opportunity Announcement: PS18-1802](#).

⁴ Centers for Disease Control and Prevention, [Additional Implementation Guidance for PS18-1802](#).

What is the point of molecular surveillance?

The CDC and some state health departments say molecular HIV surveillance helps them identify “clusters,” or groups of people with similar strains of HIV, which the CDC says “might indicate that HIV is spreading rapidly and public health action is needed.”

While public health officials can identify “clusters” by assessing approximately how closely two or more people are linked based on their strains of HIV, the data cannot yet prove that one person transmitted HIV to another or even that they had sex or shared syringes.

Why are people concerned?

CONSENT. Using a person’s medical data for research and “network” or “cluster” mapping without letting them know, let alone giving them an opportunity to say no, is unethical and could increase medical mistrust.⁵

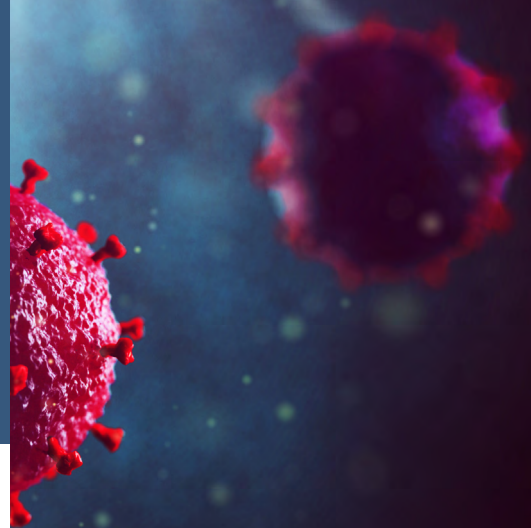
PRUDENT USE OF SCARCE RESOURCES. Public health officials have not clearly explained to community members why collecting molecular surveillance data is necessary or how it will be used. It is also not clear that this data, which comes from people already in care, provides uniquely useful prevention information that is otherwise unavailable.

CRIMINALIZATION. Thirty-four states currently have HIV-specific criminal laws or sentence enhancements.⁶ In some states, public health officials are either required by law to or routinely do share information with law enforcement officials.⁷ Even though molecular surveillance data cannot now on its own establish that one person transmitted HIV to another, it can point law enforcement to additional targets for prosecution and be used as evidence in court. While it is true that current technology cannot show the direction or the direct source of transmission, it could develop to the point that it will be able to do so.

DATA SECURITY & PRIVACY. The more detailed the information public health officials collect, the more serious the concerns about the security of that sensitive information. Unfortunately, state public health departments do not have a perfect track record when it comes to securing confidential data.^{8,9} While public health officials say they remove names from the data that they send to the CDC, the same is not the case for information kept locally. And the protections afforded to public health information vary greatly from state to state.¹⁰

STIGMA. Using science to identify a “cluster” without great care for privacy can add to the stigma of an HIV diagnosis. This is especially true in communities with smaller populations or smaller numbers of new diagnoses, where it is more difficult to protect privacy, in addition to communities disproportionately affected by HIV.

PUBLIC HEALTH. Medical mistrust is a continuing barrier to engagement in care in many communities disproportionately affected by HIV.¹¹ Expanded use of data that doctors collect for treatment purposes without notice and consent risks compounding this persistent problem.



What can you do?

ASK QUESTIONS! Public health officials should be able to explain exactly why using personal treatment data is necessary as well as how much money is being spent on surveillance technologies rather than other forms of prevention.

PUSH BACK! Demand a pause on molecular surveillance until it’s clear that it is a safe, voluntary and cost-effective way of preventing new HIV cases; and that rules are in place that prohibit sharing of this data for law enforcement or immigration purposes.

SPEAK UP! Share your concerns and unanswered questions with [your state or local HIV/AIDS policy director](#).



RESEARCH YOUR AREA’S END THE EPIDEMIC PLAN AND CONTACT ORGANIZERS: [Find out what measures are in place](#) to prevent the use of your personal data for reasons other than your health care.

⁵ CHLP, Map: [HIV Criminalization in the United States](#).
⁶ For example, Mo. REV. STAT. § 191.677(1)(2) (2018).
⁷ Alexander McClelland, Adrian Guta, and Marilou Gagnor, [The Rise of Molecular HIV Surveillance: Implications on Consent and Criminalization](#), CRITICAL PUBLIC HEALTH (2019).
⁸ Aubrey Wieber, [DHS data breach exposes health information could impact at least 350,000 people](#), SALEM REPORTER, March 3, 2019.
⁹ Marianne Kolbasuk McGee, [Victim count in Alaska health department breach soars](#), BANK INFO SECURITY, January 23, 2019.
¹⁰ NASTAD, [HIV Data Privacy and Confidentiality](#).
¹¹ Martha Hostetter and Sarah Klein, [In Focus: Reducing Racial Disparities in Health Care by Confronting Racism](#), THE COMMONWEALTH FUND, September 27, 2018. Katrina Armstrong, Karima L. Ravenell, Suzanne McMurphy, and Mary Putt, [Racial/Ethnic Differences in Physician Distrust in the United States](#), AMERICAN JOURNAL OF PUBLIC HEALTH (2007).



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