



## Factsheet 2: Public health myth buster

Many Public Health Departments across the US have begun re-using blood tests collected from people living with HIV for epidemiology surveillance and prevention efforts. This practice is known as *HIV molecular surveillance*, also called *cluster detection and response*.

The U.S. Department of Health and Human Services and Center for Disease Control (CDC) has made *cluster detection and response* the “fourth pillar” of the federal strategy, *Ending the HIV Epidemic: A Plan for America*.

Public health authorities say this approach aims to collect information from all U.S. residents living with HIV. However, the 57 priority “Ending the HIV Epidemic” jurisdictions are primarily Black and Brown communities.<sup>[1]</sup> Since HIV is an epidemic driven by racial injustice and social inequality, *cluster detection and response* efforts will be especially intensified towards Black, Latinx, Brown, Indigenous, migrant, and racialized people, as well as people who sell sex, people who use drugs, gay, bisexual, and queer men, women of trans experience, low-income people, and those who are unstably housed or homeless.

**Why is the CDC, along with state, and local Public Health authorities arguing for this approach? Are their arguments legitimate? We don’t think so!**

**Here we provide an overview of 7 key public health arguments, with a critical response to each one from communities of people living with HIV.**

Public Health practitioners’ justifications:	Responses from people living with HIV:

<p>1) <i>The practice is safe and ethical because the information is anonymous.</i></p>	<p>Cluster detection and response data is routinely collected by Public Health authorities <u>so that they can directly identify individuals</u>.</p> <p>The intended outcome is for Public Health authorities to get in touch with people who are identified as being part of a cluster. To do their work, information they collect is <b>not</b> anonymous, instead, it is combined with as much identifying demographic information as possible, like age, height, race, location, citizenship status, gender orientation, sexuality, information on sexual and drug taking practices. This identifying demographic information might come from other sources or agencies, including information from partner notification and contact tracing interventions, which is then compiled together to help enable Public Health investigations to directly identify people. Identifying information is not always kept confidential. In media reporting of one cluster of new transmissions among people who use drugs, first identified via contract tracing, and then verified using molecular analysis, the name of the street that people lived on was widely published.<sup>[2]</sup></p>

<p>2) <i>The public good of molecular HIV surveillance outweighs individual rights of people living with HIV.</i></p>	<p>Molecular HIV surveillance is done without any informed consent. This practice denies people living with HIV the rights to self-determination, bodily autonomy, and could lead to other human rights violations, including criminalization.</p> <p>Despite informed consent being a cornerstone of medical ethics, there is no requirement that healthcare providers let people know that resistance test results, as well as other information they collect, including gender identity, sexuality, and intimate details about their lives, including sexual practices, will be used in this way.</p> <p>And if they were informed, it is believed that many people would disagree and refuse. In one study, when people living with HIV were asked if they would consent to participate in having their blood used for molecular analysis, 50% did not consent, indicating fears and concerns related to loss of privacy and confidentiality, as well as disinterest, lack of time, or unwillingness to share their HIV status with others.</p>
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<p>3) <i>Molecular HIV surveillance findings have led to the expanded access to resources to disproportionately impacted communities.</i></p>	<p>Molecular HIV surveillance findings have not changed supports or services for communities that are disproportionately impacted by HIV. What has led to expanded access to resources for disproportionately impacted communities is years of dedicated activism and advocacy from those communities themselves.</p> <p>Instead of new technology, we know that what is needed is more housing, access to culturally sensitive healthcare, harm reduction supports, the decriminalization of sex work, criminal justice reform, reproductive health, employment, and comprehensive sexual health education.</p> <p>Political will to address inequities to access and resources is what will remove structural vulnerabilities, not more surveillance.</p> <p>The information derived from molecular HIV surveillance and cluster detection and response tells us what we already know, which is that certain communities across the U.S. who have been made to have less access to resources are services, have increased vulnerabilities for HIV. It is also not clear that this data, which comes from people who may be already in care, provides any new unique or useful prevention information that is otherwise unavailable.</p> <p>Public Health authorities have never clearly explained to community members of people living with HIV why collecting this data provides any actual new insights. All people living with HIV listed in the "cluster" have seen a healthcare provider at least once.</p> <p>Populations considered to be outside of the reach of Public Health authorities are so due to ongoing medical mistrust, lack of cultural competencies, fear</p>
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of deportation, and poor engagement on behalf of Public Health authorities. These systemic issues must be remedied, and that will not happen with an increase in invasive surveillance practices.

<p>4) <i>Public Health is for everyone's good.</i></p>	<p>Public Health authorities do not view people living with HIV as part of the “public”. Instead, people living with HIV are viewed as risks from which the “public” is to be protected. This means, Public Health authorities justify suspending our rights. The suspension of rights and any resulting harms done to people living with HIV are not seen as harms done to the public.</p> <p>But harms done to the human rights of communities of people living with HIV have wide-ranging impacts for all of society. If communities of people living with HIV are made to be precarious, under increased surveillance, they will have less capacity and ability to flourish, contribute and participate, support themselves and each other. Harms done to our health and rights are harms done to everyone's health and rights.</p>
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<p>5) <i>Your privacy is protected. We have protocols on data-sharing.</i></p>	<p>There are no consistent protections for use or sharing of sensitive health information across the U.S. Across each state, policies and laws differ widely concerning under what conditions personally identifiable data may be shared without the person's consent, including sharing HIV information with courts or law enforcement.</p> <p>While Public Health authorities often say that people's names are removed from molecular HIV surveillance information when they share it with other agencies, such as with the Center for Disease Control and Prevention, that is not the case for the same information when it is kept locally, where they connect people's names with genetic sequences so they can conduct investigations and interventions.</p> <p>The more detailed the information public health authorities collect, the more serious the concerns about the security of that sensitive information. But it is important to remember that local state Public Health authorities do not have a perfect track record when it comes to protecting sensitive health information.<sup><a href="#">[3]</a></sup></p>
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<p>6) <i>Molecular HIV surveillance does not contribute to stigma.</i></p>	<p>Using molecular HIV surveillance data to identify clusters could increase HIV-related stigma. The practice aims to identify people who are already highly marginalized, including people without access to regular healthcare, low-income including immigrants, undocumented persons, as well as people who buy and sell sex, people who buy and sell drugs, and those in past or current conflict with the criminal legal system. This is especially true in rural communities with smaller populations or smaller numbers of new diagnoses, where it can be more difficult to realize privacy protections.</p> <p>Once a cluster is detected, Public Health authorities can then publicize their findings to the public and media. This publicity identifies people from these communities as vectors of HIV transmission. Public Health authorities have also referred to clusters problematically as “risk networks”, meaning that they view people involved as “high risk” and outdated way of describing people living with HIV that drives stigma and misinformation. Such reports can lead to stigmatizing media reports, which violate privacy, and lead to discrimination towards the community highlighted as part of a cluster.</p> <p>Public Health authorities may lack cultural competencies, and consistent standards for training that protect people living with HIV from possible harm and discrimination. And the media, further lacks standards for reporting of HIV-related stories, often leading to sensationalistic coverage which drives stigma.</p>
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<p>7) <i>We have yet to see a HIV criminalization case resulting from molecular HIV surveillance, so there is nothing to worry about.</i></p>	<p>The U.S. is a leading country in the world for criminalizing people living with HIV. We do not need to wait for worst case scenarios. People living with HIV across the US already live under multiple intersecting forms of criminalization, related to HIV, drug use, migration, sex work, poverty, and race. Furthermore, thirty-two states have HIV-specific criminal laws or sentence enhancements.<sup>[4]</sup> In some states, Public Health authorities are either required by law to, or routinely do, share information with law enforcement.</p> <p>There are currently not enough protections in place, and what little we have is being taken away. In the context of COVID-19, some states began sharing people who had tested positive for the COVID-19 with police.<sup>[5]</sup></p> <p>People’s fears of criminalization are legitimate, we come from communities who are marginalized and are actively criminalized. This is specifically true on immigration, where there is a culture of fear, and people are continually traumatized by the fear and suspicion. We don’t need to wait for worst case scenarios. We need to act now to support all people living with HIV to realize our own health and well-being. More surveillance will not do that.</p>
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<sup>[1]</sup> See: <https://www.cdc.gov/endhiv/jurisdictions.html>

<sup>[2]</sup> See: <https://www.seattletimes.com/seattle-news/health/north-seattle-hiv-cluster-among-drug-users-and-homeless-people-worries-health-officials/>

<sup>[3]</sup> See: <https://www.salemreporter.com/posts/617/breaking-dhs-data-breach-exposes-health-information-could-impact-at-least-350-000-people>

<sup>[4]</sup> See:

## U.S. PLHIV Caucus Factsheets on molecular HIV surveillance

<https://www.hivlawandpolicy.org/sites/default/files/HIV%20Criminalization%20in%20the%20US%20%282020%29.pdf>

<sup>[5]</sup> See: <https://www.sciencedirect.com/science/article/pii/S0168851020302700>