

# Factsheet 1: Overview on molecular HIV surveillance concerns from people living with HIV

## What's the deal with molecular HIV surveillance analysis or cluster detection and response?

Many Public Health Departments across the U.S. have been re-using blood tests collected from people living with HIV for disease 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.

With molecular information on these communities, the CDC, along with state, and local Public Health authorities say their goal is to try and prevent new HIV transmissions. But communities of people living with HIV have been saying that the practice presents many major human rights and racial justice concerns.

*To better understand these concerns, it helps to understand how HIV molecular surveillance works. Let's start with the basics:*

- **Molecular HIV surveillance analysis starts with our blood tests**

There are multiple variants of HIV, and the virus is constantly mutating and changing. When seeking healthcare blood tests are given to newly diagnosed people living with HIV and for people looking to change medications. These tests are

used to help identify individual HIV variants, and if any mutations make a variant resistant to HIV medications. Out of these tests, the unique genetic make-up of an individual's HIV RNA and DNA is determined – this is known as a genetic sequence. The results of these tests are used to ensure healthcare professionals choose the most effective treatment for people living with HIV.

- **Results from our blood tests are re-used without our consent**

After resistance tests, blood is then sent – *without people's consent or knowledge* – for what is called phylogenetic analysis. This process compares many individual genetic sequences of HIV together to look for similarities and differences. A genetic sequence is a bunch of long chains of RNA and DNA. Scientists use this analysis to understand relationships between different genetic sequences of HIV to determine how closely they may, or may not, be related to each other.

- **Public Health authorities use genetic sequences to identify *clusters***

When comparing the individual genetic sequences together, scientists are looking to identify groups of very similar versions of the virus - where transmissions took place around the same time, and in the same general location. This grouping of similar genetic sequences of the virus is known as a *cluster*.

Being part of a *cluster* does not mean that the people whose blood is being examined have ever come into contact with each other, it only means that there are genetic similarities in the HIV genetic sequences among members of the cluster. Once identified as a cluster, Public Health authorities can also call this group of similar genetic sequences a “transmission network”, or “risk network”.

- **Genetic sequences are linked to other sources of information**

To further investigate a cluster, multiple other sources of information are connected together with the genetic sequences, such as age, sex, gender, sexuality, race, ethnicity, location, along with information on socio-economic characteristics, like if blood sample was taken from someone who has informed their healthcare provider that they use drugs or are a sex worker.

- **If a significant cluster is identified, public health authorities respond**

If Public Health authorities identify a cluster where HIV is being transmitted at a higher and faster rate than other places, they then try to intervene and prevent new transmissions. When authorities intervene, they can directly contact people who are part of a cluster, and if needed, authorities try to get those people connected to care or treatment. Authorities may also use other methods such as contact tracing or

partner notification to identify other people who may be connected to a cluster, and who may not have previously sought care, or had their genetic sequences collected.

### **Why are communities of people living with HIV concerned about molecular HIV surveillance analysis and cluster detection and response?**

We all want to stop new infections, but communities of people living with HIV have been increasingly concerned about how information from cluster detection and response could violate our rights to privacy, informed consent, and result in harm for communities of color that are already over-policed, surveilled, undocumented and intensify racial injustice and existing inequalities.

## **6 concerns from communities of people living with HIV**

### **1) Racial injustice: we are already over-policed, over-surveilled, and under-protected**

HIV is a racial justice issue. Black, Latinx, Brown, and Indigenous people bear the brunt of new infections across the U.S., while receiving unequal access to healthcare and other support.<sup>[2]</sup> The ongoing impact of institutional racism means government institutions enact racist beliefs into policy, where communities are framed as risks to be managed, not people to be supported. But increased surveillance does not lead to community safety or greater wellbeing, and instead, it might mean that government authorities have even more data on our bodies, which can then introduce new ways to control us, not support us.

### **2) Violations of privacy, and threats to personal safety and security of people living with HIV**

Cluster detection and response investigations have been enacted on Black and brown women of trans experience, gay, bi, queer, and same gender loving men, people who use drugs, and immigrants. In some instances, cluster detection and response has been combined with contact tracing and partner notification. Here Public Health authorities may reveal private information to someone who might not know the person they had sex with was of trans experience or also had gay, queer, or same gender partners. Transphobic and homophobic discrimination and violence is very prevalent in the U.S. For immigrants, this could contribute to an existing environment of fear and uncertainty, who are already socially marginalized due to their precarious legal standing in the U.S. Violations of privacy for all these communities could increase risks towards the safety and security, and may lead to discrimination, violence, criminal prosecution, loss of employment and deportation.

### **3) Racist legacy of Public Health**

Public health is an institution and is *not* the same as our individual or community health and well-being. Like other government institutions, such as the police, or the criminal legal system, the work of Public Health authorities is rooted in a historical legacy of colonization, racism, discrimination, and marginalization.

Throughout history the *public* in *Public Health*, has been code for white and middle-class. Anyone who did not fit into this idea of the white middle-class *public*, were not treated as people with human rights. Instead, Public Health authorities treated the bodies of Black and Indigenous people as experimental testing grounds without their knowledge or consent. The concern with molecular surveillance research is that Public Health authorities have not contended with this racist legacy, and as a result still operate in racist and othering ways towards our communities.

#### **4) Criminalization of drugs, sex work, migration, and HIV**

Most states still actively criminalize the sale and use of certain drugs, the buying and selling of sex, HIV non-disclosure, exposure and transmission, and forms of migration. Because of criminalization, there is a potential that data on communities collected for molecular HIV surveillance investigations could be shared with other authorities and used in harmful ways to support law enforcement efforts. This could exacerbate existing forms of criminalization, putting the lives of people in our communities at greater risk of harm.

#### **5) No consent to decision-making or bodily autonomy**

People living with HIV have not consented to have their blood tests reused by Public Health authorities for molecular HIV surveillance. Individuals are not informed nor asked for consent. In fact, people think they are giving their blood for their own healthcare-related tests.

To better understand this issue of consent and bodily autonomy, researchers in Philadelphia implemented a study asking 90 people living with HIV if they would consent to participate in having their blood used for molecular analysis.<sup>[3]</sup> Of those asked, 50% of the people living with HIV did not provide 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.

Not only is there no individual consent, in many places molecular HIV surveillance has been rolled-out across the US with limited community consultations, as well as a lack of community engagement in the process, denying people living with HIV the right to make autonomous and informed decisions about our bodies and health.

## **6) Lack of trust and cultural competencies in Public Health**

The goal of molecular cluster detection and response is to allow Public Health authorities to be able to contact people who are identified as being part of a cluster. This means that Public Health authorities may ultimately come knocking on people's doors. These interventions can be invasive, coercive, threatening, can violate privacy, and in some cases, police could be involved if the people which Public Health authorities are seeking in their investigations are perceived as not being cooperative or compliant. The attitudes, practices, policies of Public Health authorities have historically led to them being out of touch, harmful, and discriminatory towards our communities. This ongoing lack of cultural competencies from Public Health authorities and aggressive and invasive approaches has rightly led to a context where communities of people living with HIV have a lack of trust towards Public Health authorities.

These types of interventions are not unique to molecular HIV surveillance and have been used when people are identified as being out-of-care, not compliant with medication, and for contact tracing, and partner notification. However, with cluster detection so widespread, there is a potential for an increase in investigations. In a context where communities already lack trust, such aggressive and coercive approaches by Public Health authorities will only exacerbate ongoing tensions.

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[1] See: <https://www.cdc.gov/endhiv/jurisdictions.html>

[2] See: <https://www.hivlawandpolicy.org/issues/racial-justice>

[3] See: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7497840/>