

# How to Talk About MOLECULAR HIV SURVEILLANCE



## Public health is about protecting communities.



- 1.** People should be encouraged to get tested and engage in care, and the medical establishment has a responsibility to make them feel comfortable doing so.
- 2.** Informed consent, a person's ability to make educated decisions regarding their medical care, is a human right. There should be NO use of people's medical information without their informed consent.
- 3.** Policing and criminalization have no place in public health. There should be consistent safeguards required for the protection against the misuse of this data against people living with HIV, including but not limited to an absolute firewall from the law enforcement.



## What is "Molecular HIV Surveillance" and Why Are We Talking About It?

In 2018, The Centers for Disease Control and Prevention (CDC) began to require all states accepting HIV prevention funds to implement "molecular HIV surveillance." Molecular HIV surveillance (MHS) broadly refers to the practices state and local health departments and the CDC use to identify HIV transmission networks by mapping the social and sexual networks of people living with HIV (PLHIV) without requiring their knowledge or consent.

In routine HIV care, blood samples are taken from people living with HIV and an individual's HIV strain is genetically sequenced to determine whether there are mutations resistant to HIV drugs; this sequencing helps determine which treatments to offer. However, without asking patients first, this genetic information is also shared with local public health professionals who compare HIV strains to identify HIV transmission trends. Minimally stripped of "identifiable information," this patient data is then reported to the CDC where it is aggregated and available to researchers and other members of the public (subject to limitations) through research databases.

**HIV advocacy organizations, networks of PLHIV, and human rights activists have raised the alarm about MHS for years due to concerns about consent, data privacy, and potential risks for HIV criminalization.**

The [AIDS United Public Policy Council](#) and the [Presidential Advisory Council on HIV/AIDS \(PACHA\)](#) have also released recommendations for the CDC to implement and protect PLHIV.

The complicated science and public health practices of surveillance can make it difficult to discuss MHS with friends, colleagues, journalists, and people in government. Nevertheless, MHS creates more vulnerability for PLHIV, including the possibility their private, identifiable medical data may be used against them in criminal prosecutions. This risk is even higher for the communities most impacted by HIV in the United States and overpoliced: Black and Latinx people, LGBTQ+ and trans people, sex workers, low income and unstably housed folks, and people who use drugs. It's important to come together as advocates, keep talking about MHS, and demand action from your state health department and the federal government.

# Keep it Simple: Have an explanation of MHS ready

Share a brief overview of what molecular HIV surveillance (MHS) is and try your best to use clear, simple language.

Also, be mindful that your language does not stigmatize people living with HIV, whether intentionally or unintentionally.

**When explaining MHS to someone, try saying this:**

I want state and federal government agencies to work together to end the HIV epidemic—but the controversial use of molecular data to map networks of people living with HIV is dangerous. [Medical mistrust](#) has and continues to fracture relationships between our imperfect health system and the patients we most need to reach, including Black and Brown people, LGBTQ+ people affected by HIV. Molecular HIV surveillance, or MHS, is the public health use of individual genetic data to identify the sexual and social networks of people who are diagnosed with HIV. The CDC mandated all states to collect and store data that police can use against people living with HIV without safeguarding it first. Sharing this data without people's consent only deepens medical mistrust, alienates people from life-saving care, and increases their exposure to criminalization.

## Molecular HIV Surveillance

### What are the issues?

1.

They don't need your consent to share data.

2.

MHS isn't like other kinds of public health surveillance

3.

Police may use your data against you.

4.

CDC's data privacy guidelines don't protect much.

5.

Informed consent and medical mistrust.

# 1. They don't need your consent to share data.

The CDC requires all US states to collect, analyze, and report HIV genetic data gathered by medical professionals including your personal physician in order to receive HIV prevention funding. This information is used for molecular surveillance to map networks of PLHIV. However, they are only able to do molecular analysis at all because the genetic information created by HIV drug-resistance testing is used for reasons you don't explicitly consent to.

Public health efforts are only effective when they are grounded in your human dignity and respect your informed consent. Some states even have a "[patients' bill of rights](#)" stating that everyone has a right to all the relevant information about their treatment and medical diagnosis and prognosis. Federal and state health departments can and should ground public health surveillance activities affecting marginalized and stigmatized people on the principle of informed consent.

Talking with your health dept or other medical officials?

## TRY ASKING THESE QUESTIONS:

- Why are public health professionals allowed to use my genetic data, created to most effectively manage my HIV, outside of my direct care?
- Shouldn't I be able to decide when and how my medical information is shared and used?

# 2. MHS isn't like other kinds of public health surveillance.

Despite what some public health officials may say, molecular HIV surveillance should never be compared to the molecular surveillance of other health conditions. Why? Because [PLHIV are criminalized in a majority of US states and territories](#) for things that cannot transmit or are not likely to transmit HIV. Prosecutions almost never require proof that someone intended to transmit HIV to another person.

HIV criminalization is prevalent, relentless, and stigmatizing. Federal, state, and local health departments collect and store information that can be weaponized against PLHIV, so unless they require states to prohibit the release of that data, they are giving prosecutors an incentive to use it.

What's more, when HIV transmissions do occur, they are likely to happen through things that are already stereotyped, poorly understood, and stigmatized, including via sex and injection drug use. The HIV epidemic is the byproduct of generations of racism, homophobia, and transphobia in our health and public health systems, and surveillance is a symptom of bad policies that put hyper-criminalized and policed communities in harm's way. HIV isn't like food-borne illnesses in any measurable or meaningful way.

Do public health officials compare MHS to molecular surveillance of food-borne illnesses?

## TELL THEM THIS:

- Stop! That comparison is hurtful to PLHIV because it ignores the fact that PLHIV are broadly and unjustly criminalized in the United States. We're talking about people who are not only criminalized because of their health status, but because of their other identities as well. Mapping the sexual and drug-sharing networks of marginalized and stigmatized people isn't like tracking how food-borne illness outbreaks occur at all.
- If we want to reach patients alienated by legacies of state violence and racism and connect them to life-saving treatment and prevention, we have to earn their trust, respect their rights, and protect them from harm.

### 3. Police may use your data against you.

#### Thirty states have variations of laws on the books that criminalize PLHIV.

Many states allow law enforcement to subpoena surveillance data with identifying information. Some, like Arkansas, even require the health department to cooperate with police and prosecutors. State laws forbidding the release of public health information to police and prosecutors are rare, and that puts our rights and health at risk. Scientists currently claim that this genetic information can't be used to determine the chain of HIV transmission from one person to another. But a prosecution using this info wouldn't be the first based on junk science. The National Registry of Exonerations has [tracked more than 750 exonerations](#) for convictions based on bad forensic science since 1989.

#### Getting pushback on whether this is a real concern?

##### SAY THIS:

- The concern over police and district attorneys using this data against people is not unwarranted. It's not a "conspiracy theory." Laws were written by states *specifically* to permit this access and use. No state or municipality goes through the effort of passing a law for it not to be used.
- The [CDC's resources](#) and state health departments say they can protect the release of public health-related data but not where local or state laws authorize police to access data. Many states have laws allowing health data to be shared or that force health departments to cooperate in criminal prosecutions.
- If my health department wants to end the HIV epidemic, they have to take the issue of law enforcement access to my health information seriously.

### 4. CDC's data privacy guidelines don't protect much.

The CDC has issued toothless data privacy recommendations that have no enforcement mechanism. In 2011 the CDC issued the [Security and Confidentiality Guidelines](#) that give public health departments guidelines for how to protect this sensitive data. *Public health technologies have radically changed since 2011 but the guidelines haven't.*

The CDC also issued an [Assurance of Confidentiality](#), supposedly limiting the use of data collected through molecular surveillance for public health. But it only limits the use of the data held by the CDC itself in its disidentified form, not the data held by individual public health agencies. The CDC has recognized the existence of a web of state and municipal laws that cause these protections to be poked full of holes and published the [HIV Criminalization Legal and Policy Assessment Tool](#) for advocates to use to fight it.

#### Talking with your health department or lawmakers?

##### TRY TELLING THEM THIS:

- Federal and state health agencies must universally recommend concrete policies protecting all public health data from being accessed by police and immigration enforcement officials.
- Ignoring the gaps that police can exploit to access public health data and use it against PLHIV and other stigmatized people threatens public health.
- Washington, DC [passed a law](#) ending the use of public health surveillance data in criminal and civil legal proceedings. I want my health department to support passing this law in my state, and for the CDC to ask all other states to pass similar policies.



## 5. The lack of informed consent for MHS increases mistrust of the medical profession.

**Informed consent is supposed to be one of the cornerstones of medicine.** It is fundamental to informed consent and bodily autonomy that 1) people are routinely educated about procedures and tests recommended by their doctors and 2) that they have the absolute authority to say yes or no. It guarantees that ones' medical history can only be used for their medical care without their explicit consent to additional uses. Historically, however, this has not been true, especially for Black, Indigenous and People of Color (BIPOC) and disabled people in the US.

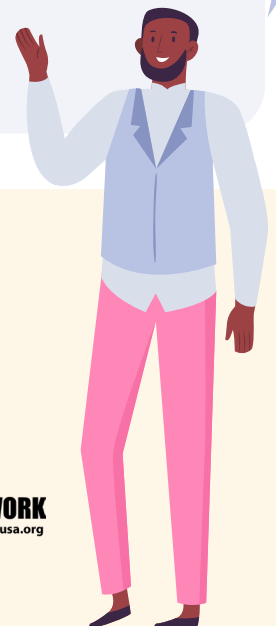
The Tuskegee Syphilis study is perhaps the most infamous example of medical tests and procedures being performed on Black people in the US without their informed consent AND with government funding – it is not, however, the first or last example of anti-Black medical violence. The harm of past and present abuses continue to impact healthcare today. Black people in the US continue to be subject to deficient medical care, which leads to results like the mortality rate for HIV/AIDS being 15.3 times higher for Black women than white women.

The use of medical information from PLHIV without their consent is explicitly authorized and encouraged by the CDC. Rather than combating the continuing mistrust of medical practitioners by mandating informed consent with the ability to opt into instead of out of MHS, the CDC instead fans the flames of mistrust. As a result, some PLHIV have chosen to delay care once aware of this practice and breach of trust.

### Talking with your health department or folks at the CDC?

#### TRY THESE QUESTIONS:

- With study after study showing that BIPOC people consistently do not engage in care due to their mistrust of the medical profession, why does the CDC insist that MHS should be done without informed consent?
- How does increasing trust and communication between patient and provider, such as properly notifying PLHIV about MHS and offering them the option to opt-out, conflict with our mission to proactively address HIV and STIs?
- Medical mistrust is a symptom of policies that dehumanize patients and reduce them to passive participants in their own health. Why can't federal- and state-level public health agencies fund patient-centered and affirming policies like expanding sexual health literacy for all medical providers?
- If I can't trust my health department to make it a priority to demand that public health data should never be accessible to police and prosecutors, why would I trust them with my health and wellbeing at all?



## Talking about these issues will protect our communities. We are people, not clusters!

