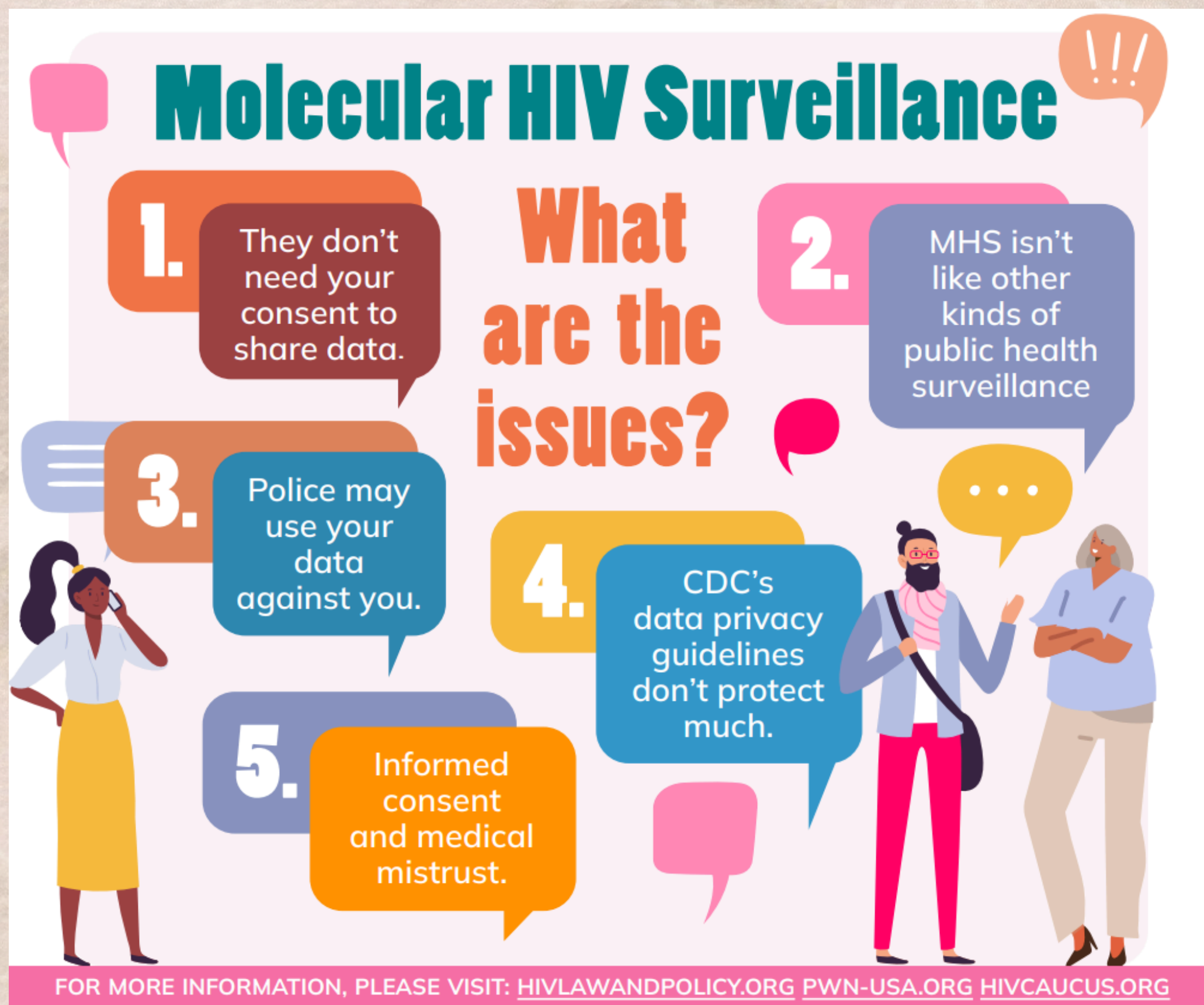


WE ARE PEOPLE, NOT CLUSTERS

By Harmony Zorio, West Virginia PWN State Lead



Molecular HIV surveillance (MHS) is a practice that involves collecting and sharing HIV genetic information to monitor HIV strains and identify transmission networks

MHS became a requirement for HIV prevention funding MHS is also known as cluster detection and response (CDR). It's part of the "Respond Pillar" of the Ending the HIV Epidemic in the U.S. (EHE) initiative.

HOW IT WORKS:



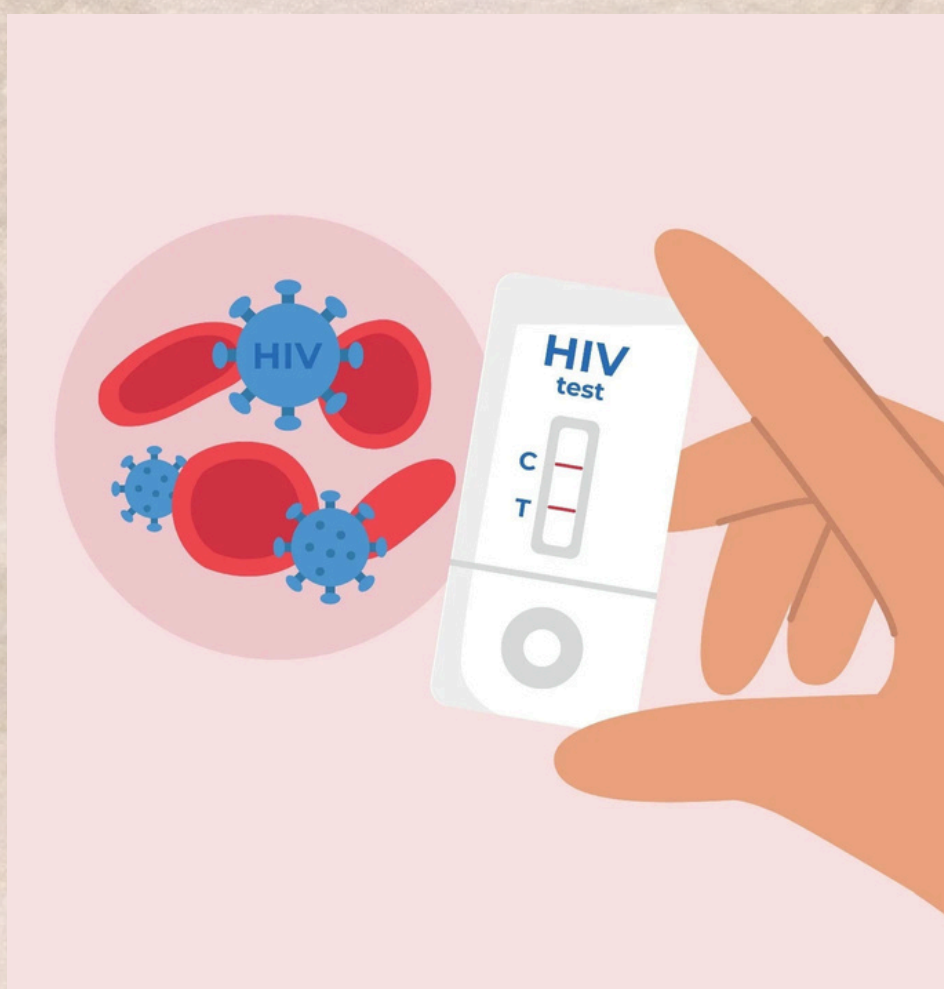
Health departments collect HIV genetic information from blood samples taken during HIV drug resistance tests. The genetic information is then shared with local public health professionals who compare the strains to identify transmission trends.

Molecular HIV Surveillance

MHS CAN HELP IDENTIFY:

1. How a person with HIV will respond to different medications
2. Rapidly growing transmission networks Populations where transmission is occurring quickly
3. New HIV outbreaks in specific communities

CONCERNS:



ADVOCATES HAVE RAISED HUMAN RIGHTS CONCERNS ABOUT MHS, INCLUDING:

1. Lack of consent and community consultation
2. Increased stigma on targeted communities
3. Privacy and data protections
4. Potential to intensify HIV criminalization

In short, this amounts to the public health departments use of individual's HIV drug resistance data to map the sexual and social networks of people living with HIV.

The CDC, state health departments then collect, store, analyze, and report HIV drug resistance data to track networks of HIV transmission.

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.

Federal and state health agencies must universally recommend concrete policies protecting all public health data from being accessed by police and immigration enforcement officials.

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.

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PUBLIC HEALTH IS ABOUT PROTECTING COMMUNITIES NOT POLICING THEM

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

DO YOU KNOW WHERE YOUR DATA IS?

Molecular HIV Surveillance: A brief explainer

WHAT IS MOLECULAR HIV SURVEILLANCE?

The CDC says that HIV Surveillance is about collecting, analyzing, and disseminating information about "new and existing cases of HIV... for the purposes of guiding prevention planning." They describe MHS as "the collection, reporting, and analysis of HIV genetic sequences generated through HIV drug resistance testing".

HOW DOES IT WORK?

MHS works by re-purposing information from "drug resistance testing". Drug resistance testing is supposed to be offered to individual patients in a clinical setting. It is supposed to help care providers tailor a person's drug regimen so that it best addresses the particular genetic makeup of their HIV.

SOUNDS OKAY, RIGHT?

Not quite. The CDC says that MHS "examines the genetics of the virus, not the person". This implies that MHS is not about individual people; it's about identifying relations—or so-called "clusters" based on an analysis of genetic similarity—between people.

This distinction—"the virus, not the person"—is misleading.

1. THAT'S NOT HOW YOUR INFO IS SUPPOSED TO BE USED

Drug resistance testing is *supposed* to be offered to individual patients in a clinical setting. It is *supposed* to help care providers tailor a person's drug regimen so that it best addresses the particular genetic makeup of their HIV. However, MHS involves a *different, secondary use of data* from drug resistance testing.

2. "CLUSTERS" ARE REAL, LIVE PEOPLE

CDC says that our genetic data is "routinely reported to the state/local HIV surveillance program and to the CDC through the National HIV Surveillance System (NHSS)."

Names and other identifying information are removed at a certain point. But don't forget: the data originally comes from **people**—real, live people just trying to meet their health care needs.

3. WE DIDN'T CONSENT

MHS is only possible because people living with HIV gave a blood sample. But too many don't know that when they go in for drug resistance testing, their genetic data is being routinely shared with, and tracked by, government programs for *another* purpose.

CONTACT:

How to Talk about MHS – CHLP Fact Sheet

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MORE INFORMATION AT
WWW.POSITIVIEWOMENSNETWORK.ORG