Factsheet 3: Molecular HIV surveillance concerns on criminalization

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.[1] 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, people who are low-income, and those who are unstably house or homeless.

Communities of people living with HIV have been actively fighting against HIV criminalization for years, and we still live without enough legal protections, in contexts where we are over-policed, over-surveilled, and under-protected. How might molecular HIV surveillance exacerbate existing harms?

Criminalization in the US

The US is a leading country in the world for criminalizing people living with HIV. Thirty-two states and two US territories have explicit laws that criminalize HIV in various ways. Over 1000 people [2] have been prosecuted in the US for alleged HIV non-disclosure, potential HIV exposure or alleged transmission through sex, shared needles or, in some states, exposure to "bodily fluids" that can include saliva. Depending on the state, punishments range from a small fine to incarceration of up to 30-years, such as in Arkansas. In Missouri, the HIV-specific law allows for the death penalty if HIV transmission is proven when someone did not disclose. Some states have sentence enhancements, for example, in Tennessee if someone is charged with prostitution and the person is living with HIV, they can be charged with aggravated prostitution.[3] In Washington state, it is a class A felony to "engage in activity that exposes or transmits HIV to another person with the intent to cause bodily harm". Across the US,

punishments can be extreme, including long sentences of incarceration in segregation, life-long surveillance under sex offender registration, and ongoing indefinite detention after sentenced time has been served. [4]

Many of the populations targeted by *HIV molecular surveillance* are already targets of policing and surveillance by the criminal legal system and U.S. Immigration and Customs Enforcement (ICE). This ongoing context of criminalization results in potentially greater human rights consequences for people living with HIV.

Uses of our data in HIV criminalization cases: what we know so far?
It is unknown if molecular HIV surveillance data has led to HIV criminalization yet, or other forms of criminalization, but the risks and fears are real. *Phylogenetic analysis* has been used as a forensic tool in HIV criminalization cases since the 1990s as part of the evidence in attempts to prove, or to disprove, transmission between defendant and complainant. [5]

Key term: *Phylogenetic analysis*
There are many different tools that scientists use to conduct molecular HIV surveillance, and phylogenetic analysis is one of those tools. P*hylogenetic analysis* compares the unique make-up of multiple genetic sequences of the HIV together to look for how they could be related. A genetic sequence is a bunch of long chains of RNA and DNA, but human DNA is not examined, only that of the virus itself. 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. The connectedness between sequences is illustrated like a family tree, which shows how close, or far apart, different genetic sequences are from each other.

The first documented forensic use of HIV phylogenetics is a case where an HIV-positive dentist from Florida, allegedly exposed several of his patients during routine dental treatment. In the case, use of phylogenetic analysis was used as evidence to prove or disprove a genetic relationship between the dentist's strain of HIV and the patients involved who acquired HIV. More recently, in 2010, there were two cases – in Washington state and Texas - where phylogenetic analysis was used in court. In both cases, the analysis was presented to try and establish the **direction of transmission**, where the source of the transmission was determined in the context of contact tracing.[6] In 2018, a global scientific consensus statement was issued, signed by international experts responding to HIV. The statement calls for a limited use of the criminal law and states that "phylogenetic analysis alone cannot prove beyond reasonable doubt that one person infected another".[7] While this statement is helpful, the U.S. is still a global hotspot for HIV criminalization.

The ways that *phylogenetic analysis* is used in courts as evidence is different to how it is used by Public Health authorities in molecular HIV surveillance investigations. But the use of genetic data by courts has been established, and it is now a matter of how and when it will be used again.

Key term: direction of transmission
Tools designed to undertake molecular HIV surveillance aim to determine genetic relationships between HIV sequences. Some of these tools can indicate whether viruses are related (known as **directionality of transmission**), and this information can then be used to try and work out if one individual transmitted HIV to another individual (known as **direct transmission**). The technology is not 100% effective, so relationships between viruses are only a best guess. However, over time, scientists are conducting studies to try to make the technology more effective.

For communities of people living with HIV, it is not known why this information is necessary or needed. In a context of ongoing criminalization, the concern is that such information could be used against people living with HIV and will only exacerbate existing fears and stigma.

What are the community concerns related to molecular HIV surveillance and criminalization? And what are the potential risks to our communities? Here are our 5 concerns:

1) **Racial and social justice**

There are many racial and social justice implications for molecular HIV surveillance in a context where Black, Brown, Latinx, Indigenous and other racialized people, as well as queer and trans people, and sex workers and people who use drugs are disproportionately impacted by surveillance policing, criminalization, and state violence.

On top of existing over-policing, research as outlined that HIV criminalization laws are being applied disproportionately towards marginalized people, including Black men, other people of color, women, people working in the sex trade and people living in poverty. In California, Black and Latino people accounted for 67 percent of HIV criminalization cases, despite making up only 51 percent of people living with HIV in California. [8] In that state, 95% of all HIV-specific criminal incidents impacted people engaged in sex work or individuals suspected of engaging in sex work. In Georgia, Black men have been found to be twice as likely to be convicted of the HIV-related offense as white men.[9]

These same populations are the ones being the primary targets of molecular HIV surveillance investigations. Indeed, scientists conducting molecular HIV surveillance as research have conducted many studies looking at transmission clusters between migrants to the US from African and Caribbean countries, as well as on people living in poverty who use drugs, and on trans women, many of whom are Latinx and migrants.

Existing institutional racism and lacking cultural competencies within Public Health authorities are a concern, and when combined with other forms of surveillance, policing, and criminalization, this could lead to molecular HIV surveillance being conducted in ways that continue to drive racism and stigma.

2) Data sharing across agencies: who has access?

To conduct molecular surveillance investigations, Public Health authorities compile information from several different sources including from blood tests, as well information on age, sex, gender, sexuality, race, ethnicity, location, and information on socio-economic characteristics, like if blood sample was taken from someone has informed their healthcare provider that they use drugs or are a sex worker. This demographic information might come from other sources or agencies, which is then compiled together to help enable Public Health investigations.

Federally, the CDC has not provided any assurances to communities of people living with HIV about where and how this data can be shared between federal agencies, such as the Department of Justice, Bureau of Prisons, or the Department of Homeland Security/ICE. At the state-level there is substantial variation in policies for health data privacy and sharing, such as what can be shared with law enforcement or as requested by a prosecutor in a HIV criminalization case. Although data is de-identified, meaning that personal info taken out, when it is transmitted to the CDC and state public health departments, it can be re-identified to assist in locating people.

In the current context of COVID-19, concerns about privacy and data sharing are even more present. In several jurisdictions in the U.S. COVID-19 data sharing protocols have been established with law enforcement agencies.[10] One example is Minnesota, where information on positive cases of COVID-19 is being shared with 911 emergency dispatchers without consent.

Data sharing across agencies means we are unsure how and when data is protected, what it is cross-referenced with, and who has access. This is a growing concern, when data that could support efforts to criminalize people is accessible to law enforcement and immigration authorities.

3) Invasive public health interventions

Public health 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. Public Health authorities' investigations may be aggressive, intimidating, and invasive. Public Health authorities may lack cultural competencies and may act in racist, homophobic, transphobic, and drug use stigmatizing ways. The outcome of Public Health investigations can also lead to legally mandated treatment and counselling, or even calling law enforcement. Such aggressive and coercive approaches by Public Health authorities will only exacerbate ongoing tensions and could lead to criminalization or deportation. These investigations also contribute to an environment of fear and uncertainty for many people living with HIV, where ongoing surveillance and the ever-present threat potential Public Health or police is a form of violence, in and of, itself.

4) Use of prevention science and the new viral underclass

Molecular HIV surveillance investigations can target people who may no longer be connected to care, those who might be known to be no longer connected to care, and people who are not on anti-HIV treatment, or who are not virally unsuppressed. 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.

Today, when HIV is undetectable, it's untransmittable, also known as Undetectable=Untransmittable or U=U. But this reality is only possible for those who have access to anti-HIV medications and ongoing care. In 2018, for every 100 people living with HIV in the US, only 63 initiated care treatment, 49 were retained in care, and 51 achieved viral suppression. [11] The other 49% of people living with HIV who are not virally suppressed are likely so due to ongoing forms of marginalization and may be not able to access health care m have citizenship status and may be low-income. I. While for many people living with HIV, being untransmittable is life-changing and helping to remove long-held stigma, this reality is also creating a viral underclass, where only people with privilege can access treatment.

The use of science is also being used to modernize HIV-specific laws or Public Health Department regulations. In North Carolina, Public Health regulations were updated to indicate that if someone is virally undetectable for 6 months, they do not have an obligation to disclose their HIV-positive status to sex partners. In Michigan, the HIV-specific law was revised so that people who are undetectable do not have the legal requirement to disclose. Iowa also revised theirs, including a provision that established the practical means to prevent transmission (such as compliance with an anti-HIV

treatment) as a defense to prosecution. While it is important to see laws being revised to reflect science and the realities of living with HIV, but the outcome could be that those who are already marginalized, and therefore can't access life-saving medications, will also then be subject to more intensified criminalization.

This context means that virally unsuppressed are at greater risk for heightened forms of surveillance, policing, and criminalization.

5) Increasing a context of fear and uncertainty

People's fears of criminalization are legitimate, we come from communities who are marginalized and are actively criminalized. This is specifically true for Black and Brown individuals, 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.

---

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

[2] See: https://www.hivjustice.net/publication/advancing2/

[3] See: https://www.hivjustice.net/publication/advancing2/

[4] See: https://www.hivjustice.net/publication/advancing2/

[5] See: https://journals.lww.com/aidsonline/Fulltext/2018/03130/Phylogenetic_analysis_as_a_forensic_tool_in_HIV.2.aspx

[6] See: https://journals.lww.com/aidsonline/Fulltext/2018/03130/Phylogenetic_analysis_as_a_forensic_tool_in_HIV.2.aspx

[7] See: https://pubmed.ncbi.nlm.nih.gov/30044059/

[8] See: https://williamsinstitute.law.ucla.edu/wp-content/uploads/HIV-Criminalization-CA-Dec-2015.pdf

[9] See: https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-in-georgia/

[10] See: https://www.sciencedirect.com/science/article/pii/S0168851020302700

[11] See: https://www.cdc.gov/hiv/pdf/statistics/overview/cdc-hiv-us-ataglance.pdf