



POSITION STATEMENT ON THE USE OF MOLECULAR SURVEILLANCE TO TRACK HIV TRANSMISSION NETWORKS

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In January 2018, the Centers for Disease Control and Prevention released [PS18-1802](#) — a five-year funding cycle that includes a focus on scaling up the use of molecular surveillance technologies by health departments. These technologies marshal personal health care information for public health surveillance purposes by state, local and national public health officials. In particular, molecular surveillance of HIV uses individual treatment resistance information collected by providers to see how patients would respond to drugs that the provider might prescribe. Providers are then required to report individualized resistance information to health departments, which use the information to map networks of HIV transmission.

The widespread implementation of these technologies, and a lack of community consultation about potential risks and costs prior to use of this strategy, has fueled concern and a vigorous conversation among advocates about whether these new technologies offer benefits that are worth the potential incursions on patient privacy, the collateral legal consequences arising from HIV stigma and criminalization, and the investment of resources that might be used more efficiently to accomplish the same goals.

Molecular surveillance technologies present risks of harms in the following ways:

- 1) In criminal prosecutions for alleged HIV exposure, prosecutors may seek to introduce evidence that the defendant or alleged victim is part of a transmission cluster, and judges or juries may inappropriately give weight to that information, even though cluster detection technologies cannot determine the direction of transmission.
- 2) There is a potential in civil legal proceedings for a plaintiff or defendant to seek to use such evidence to their advantage.
- 3) While public health information is generally not available to immigration authorities, there is a justifiable concern that an immigrant identified as part of a transmission network or cluster could be targeted by ICE or subject to an adverse determination in an immigration proceeding.
- 4) Emergent and existent issues of publicly disclosing individuals living with HIV from public health information.
- 5) Public health is undermined by policies that fail to address legacies of medical mistrust and discrimination.

We propose a set of principles to support people living with HIV, advocates and policy makers in assessing how to make use of the public health benefits of these technologies (where they exist), while protecting privacy and

preventing misuse of information by the criminal justice, immigration and civil legal systems.

In formulating these principles, we prioritize the following three crucial considerations:

1. Racial, ethnic and migrant communities that experience the most significant HIV-related health disparities in the U.S. also suffer from legacies of human rights abuses and medical discrimination that continue to shape their abilities and willingness to access health care and engage with public health officials. Thus, a full analysis of the public health costs, benefits and implications of new technologies must; explicitly give weight to those considerations, consider the costs of jeopardizing civil liberties¹, and spell out steps that address racial discrimination and related barriers; and demonstrate that medical and public health systems are worthy of trust.
2. HIV-related stigma and discrimination, including stigma institutionalized in the form of laws criminalizing people living with HIV, create a context in which the consequences of sharing, misusing or misinterpreting public health and medical records has led to felony prosecution and incarceration. These potential collateral consequences should be taken seriously by policymakers. HIV criminalization can undermine the ability of public health professionals to implement evidence-based programming.² The risk that judges and juries will misunderstand the science of molecular surveillance in an HIV exposure prosecution is a real one, and our policies must address that possibility, whether or not the science of molecular surveillance would support it.
3. Black and Latinx people, immigrant communities, transgender people, people who inject drugs, and sex workers are especially likely to be harmed by overpolicing and by misuse of the criminal legal system against people living with HIV, including with the use of public health information.

In order to ensure that the use of new surveillance and research technologies does not subject people living with HIV and people who would benefit from access to safe HIV testing to an increased risk of criminal prosecution, misuse of surveillance data in civil proceedings, or adverse action against noncitizens by immigration authorities, **the CDC, state, and local health departments and jurisdictions should implement the following recommended safeguards:**

1. Federal, state and local health officials should issue public statements that identifiable information acquired through any form of public health surveillance and research cannot be used in criminal, civil or immigration proceedings.
2. Federal health officials should evaluate existing state and local laws and standards to ensure that jurisdictions prohibit sharing information with law enforcement without a court order issued by a judge or consent of the individual.
3. The CDC should require certification from state and local jurisdictions that public health officials will comply with CDC data security guidance³ and only share data with law enforcement pursuant to a valid enforceable court order issued following notice to the subject(s). Effective notice should both inform subjects that their data has been sought and provide them an opportunity to oppose disclosure in court.
 - a. Additionally, the CDC should fund initiatives to educate public health department staff and legal counsel on the legal safeguards and required processes and protections for disclosing public health information to law enforcement.
 - b. The CDC should make funding for molecular HIV surveillance and research based on molecular HIV surveillance contingent upon such certification.
4. Federal, state and local health officials should support programs to educate those working in the criminal legal system on the scientific limitations of molecular surveillance and current medical information on the routes, relative risks and treatment realities for HIV transmission.
5. Federal, state and local health departments should store information in an anonymized form that cannot be

¹ The Fair Information Practices, a framework for balancing privacy considerations when evaluating new technologies, is available at <https://www.worldprivacyforum.org/2008/01/report-a-brief-introduction-to-fair-information-practices/>.

² Galletly, C.L., Pinkerton, S. D., *Conflicting Messages: How Criminal HIV Disclosure Laws Undermine Public Health Efforts to Control the Spread of HIV*. AIDS Behav (2006) 10:451–461 DOI 10.1007/s10461-006-9117-3

³ <https://www.cdc.gov/nchhstp/programintegration/docs/PCSIDataSecurityGuidelines.pdf>

re-identified. State entities must incorporate advanced anonymizing techniques to make molecular surveillance data resistant to re-identification by algorithms or humans. At a minimum, potentially identifying demographic information attached to molecular data should be statistically randomized when dealing with samples of small sizes. Such samples are most common in rural areas where HIV disclosure from re-identification is most possible.

6. Federal, state, and local health officials should develop standardized, publically available disclosures to ensure that patients are informed of routine and potential use of their identifiable health information. Individuals shall be informed of any contemplated use of individual, identifiable treatment information, including resistance testing results, for the purposes of researching/documenting sexual networks, including their right to object to participation in such research.
 - a. The process of designing and implementing such standardized disclosures, and any surveillance program that involves the potential sharing of sensitive identifiable information, should be developed thoughtfully, and with open public consultation and input from affected communities and stakeholders, including people living with HIV networks, HIV organizations led by Black, Indigenous, and people of color (BIPOC) communities, organizations with a history of work on HIV criminalization and surveillance issues, and data privacy specialists.
7. The CDC should disclose the full cost of acquiring, implementing, and operating molecular surveillance systems and related interventions compared with existing HIV surveillance strategies and current interventions.