

Towards HIV Data Justice: Activist interventions on molecular HIV surveillance practices in the United States

Symposium: Big data and AI: An ethical and human rights-based HIV response |
International AIDS Conference

Aug 2, 2022 | Montreal Canada

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Lawmaker Draws Backlash After Asking If HIV Patients Could Be 'Legally' Quarantined

Context



BY **ARIC JENKINS**  OCTOBER 21, 2017 11:26 AM EDT

A Georgia lawmaker who is married to **former U.S. health and human services secretary Tom Price** drew backlash after she inquired if HIV patients could be “legally” quarantined to stop the spread of the virus.



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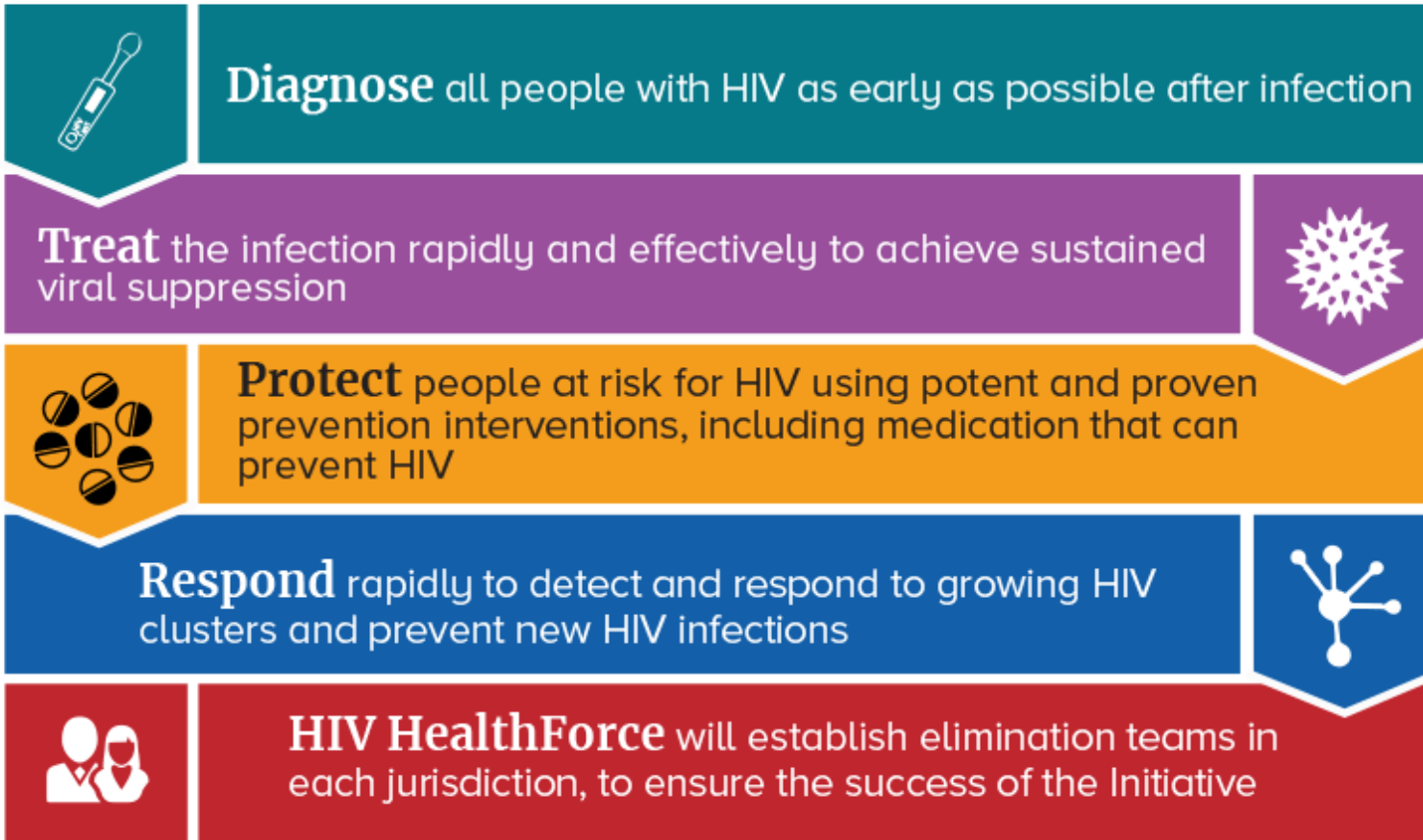
Ending
the
HIV
Epidemic

HHS Has Launched A New Initiative to End the HIV Epidemic in America

Source:
HIV.gov
June 12, 2019

GOAL:

75%
reduction
in new HIV
infections
in 5 years
and at least
90%
reduction
in 10 years.



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Summary of Activist Concerns

- **Lack of informed consent: No consent** or even knowledge from PLHIV is needed to obtain, store, and share our genomic sequences.
- **HIV Criminalization: Communities most impacted by HIV in US are also most policed**- Black and Latinx people; queer, trans communities; people who use drugs; sex workers
- **State level data protections, storage & data sharing agreements** vary widely
- **Limited federal protections**; no assurances of firewalls eg from ICE; Homeland Security
- **Stigma, disclosure and violence** concerns
- **DIS workforce** is inadequately trained and not reflective of communities where cluster investigations occur
- Despite all these risks, there was **no community involvement, engagement or consultation** PRIOR to widespread rollout and expansion



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Data Sharing & Privacy Regulations Vary Widely from State to State



HIV Data Privacy and Confidentiality

Legal & Ethical Considerations for Health Department Data Sharing

A Ten State Analysis

JUNE 2018

Report released by National Association of State and Territorial AIDS Directors (NASTAD)
June 2018

<https://www.nastad.org/resource/hiv-data-privacy-and-confidentiality>

FINDINGS

1. **Broad authority.** In general, statutes provided health departments with authority to disclose personally identifiable HIV data **without consent** for the purposes of: **(a)** Surveillance, investigation, or control of communicable disease **(b)** Treatment, payment, research, or healthcare operations **(c)** *Justifiable public health need*
2. **Data sharing activities vary** depending on jurisdiction.
3. **States vary on whether a subpoena or court order is required** for the production of HIV data from a health department.
4. **Legal authority to share data for research purposes varied** (some states required de-identified data; others allowed identifiable data but publication has to only include de-identified data; others do not address this at all)



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activist strategies



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Community education/popular education

ALL EYES ON US



What Everyone Needs to Know
about
Molecular HIV Surveillance

3/23/21
AIDSWatch 2021



Ending the Epidemic Requires Consent & Community Leadership

What is the plan?

The U.S. government has committed to ending the domestic HIV epidemic in a decade. The plan, Ending the HIV Epidemic: A Plan for America ("the ETE plan"), was announced February 2019 and promised to reduce the rate of new HIV transmissions by 75% in five years and 90% in ten.

The ETE plan will direct resources into 48 target counties, Washington, D.C., San Juan, Puerto Rico, and seven states with a high rural HIV rate. The plan rests on four basic pillars:

1. Expand testing to diagnose people with HIV as early as possible.
2. Treat HIV early and rapidly to suppress the virus (because viral suppression means people with HIV can't pass on the virus - undetectable = untransmittable).
3. Scale up prevention interventions such as PrEP and syringe exchange.
4. Use surveillance data, specifically molecular HIV surveillance, which analyzes HIV genetic sequences to determine when an "outbreak" is happening and target resources to address that outbreak.

The plan asks each jurisdiction to take the lead in creating and implementing an ETE plan that is tailored to the needs of their communities.

This sounds good. Why are advocates concerned?

Without Our
Consent

Centering People Living with HIV
in HIV Genetic Sequencing



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Open Letter to the CDC: Networks of People Living with HIV Demand a Moratorium on Molecular HIV Surveillance

**Applying
pressure on
CDC**

bit.ly/stop-mhs

People Living with HIV Need Comprehensive Education, Consent and Safeguards on Our Data




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Policy Demands



#HIVResolution #1

**END MOLECULAR
HIV SURVEILLANCE
(MHS)**


#DemandingBetter



#HIVResolution #1

Molecular HIV surveillance (MHS) is an invasive set of practices used to collect and share data from people living with HIV without our consent. Despite advocates' warnings about MHS's lack of privacy, consent, data protections, community consultation and risk for criminalization, the updated NHAS and EHE actually expands MHS efforts.

#DemandingBetter



#HIVResolution #1

Take action:
HIV surveillance puts people living with HIV in jeopardy while ignoring our autonomy and consent. Tell the CDC to end all forms of molecular HIV surveillance (MHS) as a tactic in addressing the HIV/AIDS epidemic.

#DemandingBetter



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

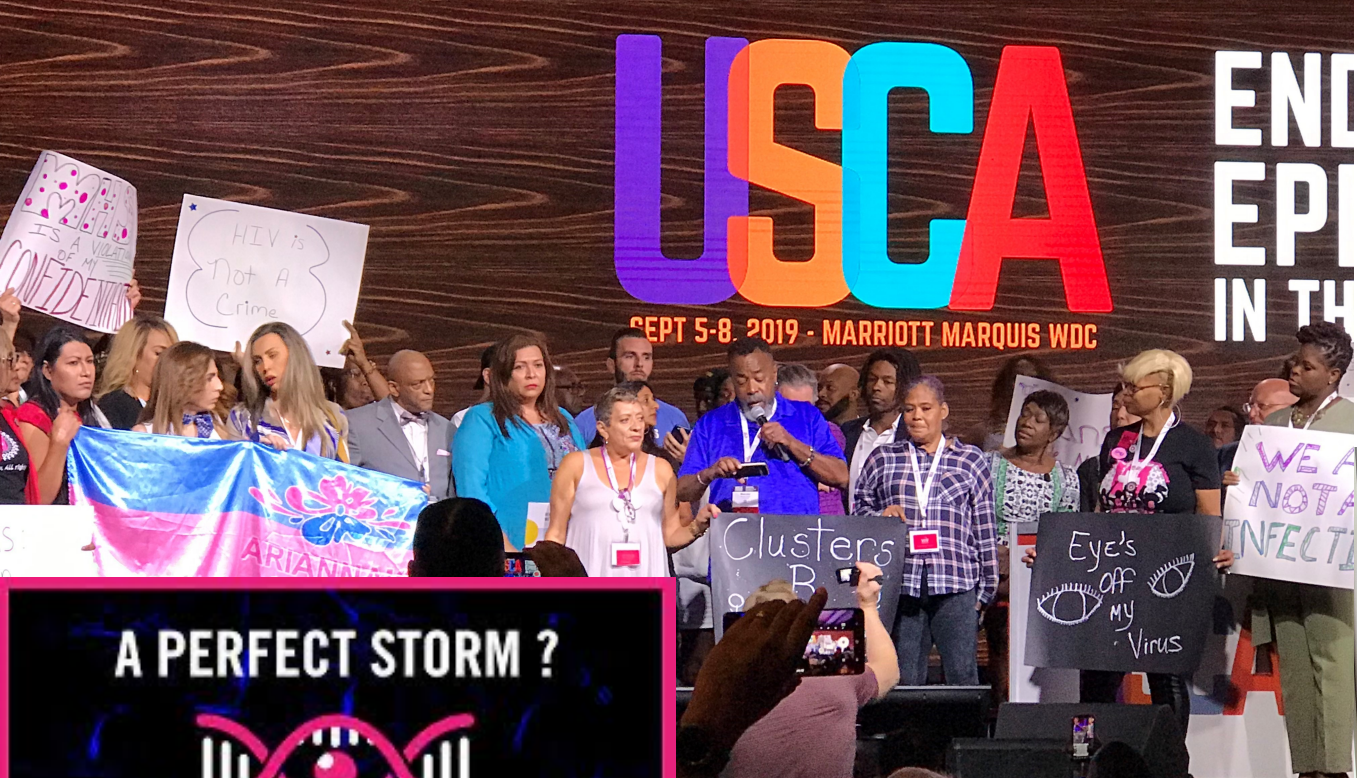
Adopted: June 16, 2020



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SEPT 5-8, 2019 - MARRIOTT MARQUIS WDC

**END
EP
IN TH**



Mark S. King
@MyFabDisease

"Molecular #HIV Surveillance is a license to hunt down marginalized people with HIV while ignoring their right to privacy or consent. It will also creep you out."
marksking.com/my-fabulous-di... #uequalsu
 @CDC_HIVAIDS @AIDS_United @HIVCaucus

A PERFECT STORM ?

**MOLECULAR HIV SURVEILLANCE
IN THE CONTEXT OF CRIMINALISATION**



The Center for HIV Law and Policy

**Is Molecular
HIV Surveillance
Worth the Risk?**



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Human rights concerns in the media

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Advocates challenge the CDC's new effort to track HIV spread

Molecular surveillance can slow outbreaks. But with states still criminalizing HIV, people with the virus see risks

By **TYNAN STEWART** PUBLISHED NOVEMBER 8, 2021 11:22AM (EST)



HIV, DISCRIMINATION, AND LAW > INTERVIEWS

Tracked and Monitored: Advocates Call for a Moratorium on Molecular HIV Surveillance



Terri Wilder, M.S.W.
Sept. 1, 2021



Critics Worry Government Surveillance of HIV May Hurt More Than It Helps

By **Sam Whitehead**
JULY 20, 2022

REPUBLISH THIS

HIV PREVENTION METHODS > TRANS

New Study Triggers Concerns Over Use of Molecular HIV Surveillance



Martha Kempner
March 3, 2019



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Contesting benefits of MHS in the literature

Editorial > Am J Bioeth. 2020 Oct;20(10):1-4. doi: 10.1080/15265161.2020.1809550.

We Are People, Not Clusters!

Edwin J Bernard ¹, Alexander McClelland ², Barb Cardell ³, Cecilia Chung ⁴, Marco Castro-Bojorquez ⁵, Martin French ⁶, Devin Hursey ⁷, Naina Khanna ⁸, Mx Brian Minalga ⁹, Andrew Spieldenner ¹⁰, Sean Strub ¹¹

Affiliations + expand

PMID: 32945744 DOI: [10.1080/15265161.2020.1809550](https://doi.org/10.1080/15265161.2020.1809550)

THE LANCET
HIV

Consent and criminalisation concerns over phylogenetic analysis of surveillance data

[Cecilia Chung](#) • [Naina Khanna](#) • [Barb Cardell](#) • [Andrew Spieldenner](#) • [Sean Strub](#) • [Alexander McClelland](#)  • et al.

[Show all authors](#)

Published: July, 2019 • DOI: [https://doi.org/10.1016/S2352-3018\(19\)30138-9](https://doi.org/10.1016/S2352-3018(19)30138-9)



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President's Advisory Council on HIV/AIDS (PACHA) tasked with addressing concerns on MHS



HIV BASICS

FEDERAL RESPONSE

EVENTS

HOME ▶ FEDERAL RESPONSE ▶ PACHA : Prior PACHA Meetings and Recommendations

■ Part 3

• View the presentation slides

○ November 15, 2021

PACHA

About PACHA

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Members & Staff

Subcommittees

- [Message from the White House, Harold Phillips, Director, ONAP \(PDF 434 KB\)](#)
- [HIV Cluster Detection and Response, Demetre Daskalakis and Alexa Oster, CDC \(PDF 2.3 MB\)](#)
- [Molecular HIV Surveillance from a Community Perspective, Ronald Johnson, Ronald Johnson, Kamaria Laffrey, and Robert Suttle, U.S. People Living with HIV Caucus \(PDF 2.2 MB\)](#)



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Next steps

- **Collaborate with other stakeholders: clinicians, public health officials**
- **Strengthen state and federal protections on HIV data collection, use, and sharing**
- **Build incentives and penalties into federal funding opportunities**
- **Potential red-yellow-green approach for jurisdictions**
- **Ensure guidance applies to future technologies**



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thank you

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