

# Community Perspectives on Molecular HIV Surveillance



Ronald Johnson  
Kamaria Laffrey  
Robert Suttle

November 15, 2021  
Presidential Advisory Council on HIV/AIDS



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# Shocking Govt. Sign Posted on Indiana Freeway: "Warning HIV Outbreak"



<https://www.hivplusmag.com/stigma/2015/06/10/roadside-sign-saying-warning-hiv-outbreak-posted-busy-indiana-highway>



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# Why are we concerned?

1. No consent or even knowledge from PLHIV is needed to obtain, store, and share our genomic sequences. **We don't even know when this is happening**
2. **HIV Criminalization**
3. **Communities most impacted by HIV are also most policed:** Black and Latinx people; queer, trans communities; people who use drugs; sex workers
4. **State level data protections, storage & data sharing agreements** vary widely
5. **Limited federal protections;** no assurances of firewalls eg from ICE; Homeland Security
6. **Disclosure and violence** concerns
7. **DIS workforce** is inadequately trained and not reflective of communities where cluster investigations occur
8. Despite all these risks, there was **no community involvement, engagement or consultation** PRIOR to rollout and expansion



# HIV Criminalization

- Over 30 states still have laws that criminalize people living with HIV for a range of actions, including non-disclosure for sex, drug sharing and other activities
- While MHS does not prove directionality (yet!), science is not part of the legal argument for these policies.
- LOTS of experience shows that judges and juries don't always understand the science of HIV.
- Knowledge of HIV status is required for criminalization - these laws are barriers to get people tested and in care



# Current science cannot infer directionality



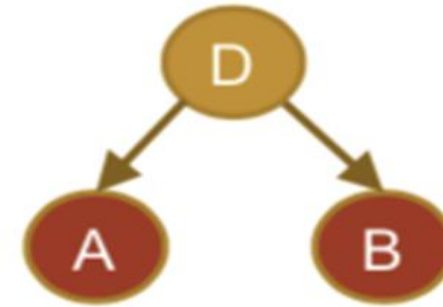
Person A infected person B



Person B infected person A



Person A infected person C, who  
infected person B



Persons D infected persons A and B

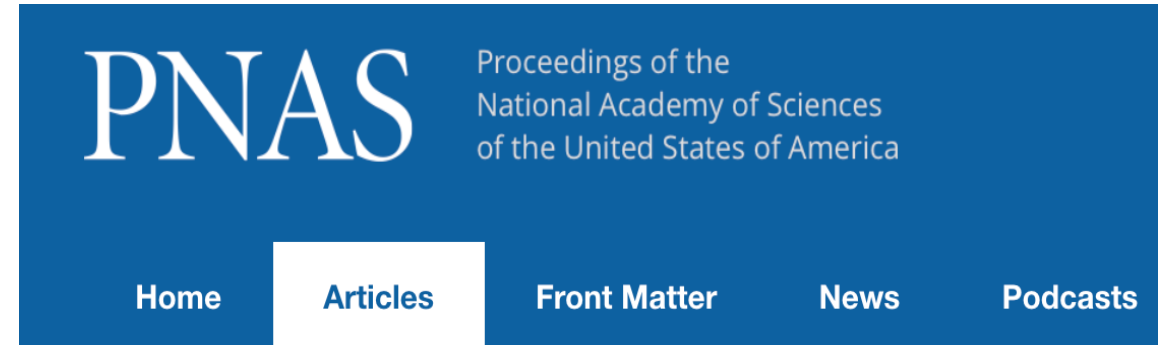


# BUT science progresses, and also...

“...with additional information, phylogenetic analyses can identify source and/or recipients. **Almost all phylogenetic analyses have access to some additional information, otherwise why would one do the phylogenetic analysis in the first place? ...**”

- Thomas Leitner, **Los Alamos Laboratory**

Also tools like **recency assays** can be used as a proxy for directionality



## RESEARCH ARTICLE

### The molecular clock of HIV-1 unveiled through analysis of a known transmission history

Thomas Leitner and Jan Albert

[+ See all authors and affiliations](#)

PNAS September 14, 1999 96 (19) 10752-10757; <https://doi.org/10.1073/pnas.96.19.10752>



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# Molecular Evolution Proves Source Of HIV Infection In Criminal Cases

Posted: November 16, 2010

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Source : Baylor College of Medicine

HOUSTON -- (Nov.15, 2010) – In 2009, a Collins County, Texas, jury sentenced Philippe Padieu to 45 years in prison for aggravated assault with a deadly weapon – having sex with a series of women and not telling them he had HIV. An important part of the evidence that identified him as the source of the women's infection came from experts at Baylor College of Medicine ([www.bcm.edu](http://www.bcm.edu)) and The University of Texas at Austin ([www.utexas.edu](http://www.utexas.edu)).

"Phylogenetic analysis allows us to reconstruct the history of the infection events," said Hillis, professor at UT Austin. "We can identify the source in a cluster of infections because some isolates of HIV from the source will be related to HIV isolates in each of the recipients... **This is the first case study to establish the direction of transmission,**" said Metzker.



Canada Articles Expert witnesses Scientific tests Outcomes

## CANADA: JOHNSON AZIGA AND QUESTIONS ABOUT THE VIROLOGICAL EVIDENCE

Edwin J Bernard - April 17, 2009

**“We were able to determine that all of the complainants and Aziga had a phylogenetically distinct form of HIV and that Mr. Aziga had the virus prior to contact with any of the women,”** Sandstrom said... Aziga and the women in the Hamilton infection cluster all had Clade A, which is rare in North America but endemic in Aziga’s native Uganda.



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“A prosecution team in Canada used the **open access Los Alamos genetic database** to successfully convict a man accused of non-disclosure. While the judge noted that the court could not use the data to prove infection, it was helpful ‘circumstantial evidence’ that has been widely accepted in legal cases to identify relationships between genetic samples” (R. v Aziga, 2008, pp. 8, 9)

- Alexander McClelland, Adrian Guta & Marilou Gagnon (2019): *The rise of molecular HIV surveillance: implications on consent and criminalization*, *Critical Public Health*





**But there are laws in place  
to protect us, right???**



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# HIV Data Privacy and Confidentiality

Legal & Ethical Considerations for Health Department Data Sharing

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*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>



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# NASTAD report: sample questions studied in 10 states

“What is the extent to which state laws and regulations permit or compel health departments to share personally identifiable HIV data with various entities?

- With whom can health departments share this data (e.g., other health department programs, state agencies, providers, law enforcement, or researchers)?
- For what purposes can this data be shared?
- What are the limitations on the scope of data that can be shared?”

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



# Findings: State Level protections for MHS Data, Storage, Sharing Vary Widely

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)



FIGURE 2: Data Sharing for Law Enforcement Purposes

Sample findings

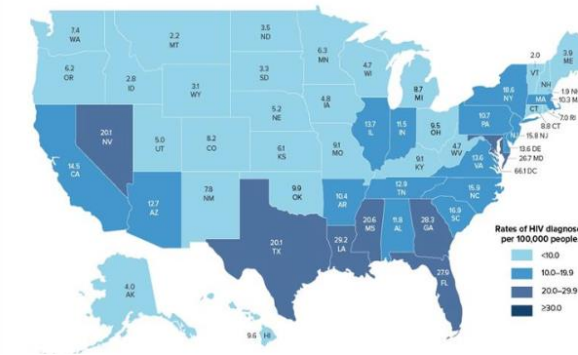
	Statute/ regulation?	Limitations on what data can be shared
IL	Yes	Pursuant to court order or subpoena, "information and records" related to HIV may be shared for prosecution under the Illinois HIV criminal transmission statute or to enforce Illinois Sexually Transmissible Disease Control Act (410 Illinois Compiled Statutes 325)
IA	Yes	Pursuant to court order, "HIV-related test"* may be shared following in camera proceedings. Pleadings must substitute a pseudonym for the test subject's true name (Iowa Code § 141A.9)
LA	Yes	Pursuant to court order, "HIV test result"† may be shared following in camera proceedings (Louisiana Revised Statutes § 40:1171.4)
MA	No	N/A
MI	Yes	Pursuant to court order or subpoena, "all reports, records, and data pertaining to testing, care, treatment, reporting, research, and [partner notification]" may be shared (Michigan Compiled Laws 333.5131)

**Media  
coverage of  
"clusters" has  
been  
troubling**

## Cluster Of HIV Cases Involves Hispanic Men In San Antonio

By WENDY RIGBY • JUL 27, 2017

Share Tweet Email



## Transgender women in Los Angeles are more likely to be in high HIV incidence clusters than any other group

More likely to connect to each other and straight men than to gay men



Manon Ragonnet-Cronin at  
CROI 2018. Photo by Liz  
Highleyman.

Gus Cairns

Published: 07 March 2018

## North Seattle HIV cluster among drug users and homeless people worries health officials

April 19, 2019 at 5:07 pm | Updated April 19, 2019 at 10:07 pm



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



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.



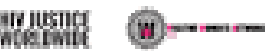
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# Concerns about MHS have been widespread and global

**MOLECULAR HIV SURVEILLANCE:**  
A GLOBAL REVIEW  
OF HUMAN RIGHTS  
IMPLICATIONS





**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...](https://marksking.com/my-fabulous-di...) [#uequalsu](#)  
[@CDC\\_HIVAIDS](#) [@AIDS\\_United](#) [@HIVCaucus](#)

### Watch Activists Storm The Stage at USCA, Protesting Neglect From CDC



Protestors from across the nation have a message for Dr. Robert Redfield:

## 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?





## Episode 1: Whose Blood is it Anyway?

Questioning the rollout of molecular HIV surveillance

With Alexander McClelland, Naina Khanna, Joe Amon and Dr Larissa Mulka



Hosted by Edwin J Bernard (HIV Justice Network)

54:07

# 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)

Rese

HIV PREVENTION METHODS > TRANS

## New Study Triggers Concerns Over Molecular HIV Surveillance



Martha Kempner

March 3, 2019



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

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# in the literature

Critical Public Health The rise of molecular HIV surveillance: implications on consent and criminalization

February 2019 · [Critical Public Health](#) 30(1)

DOI:[10.1080/09581596.2019.1582755](#)

Authors:



Alexander McClelland  
Carleton University



Adrian Guta  
University of Windsor



Marilou Gagnon  
University of Victoria

THE LANCET  
HIV

Editorial

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

## We Are People, Not Clusters!

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

Affiliations + expand

PMID: 32945744 DOI: [10.1080/15265161.2020.1809550](#)

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

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



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# Recommendations for PACHA

1. Meaningfully engage networks of people living with HIV in the domestic HIV response so that consent, privacy, and PLHIV rights are built into the forefront of any new developments.
  - a. PACHA, CHAC and OARAC should be rechartered with two seats for the US PLHIV Caucus, to be filled by representatives of our own choosing
2. Call for CDC, HRSA, and NIH to partner with the US PLHIV Caucus to develop:
  - a. Guidance on HIV data collection, sharing, and use;
  - b. Informed consent standards and practices;
  - c. Community engagement standards for the development of future HIV-related data collection, use, sharing and storage.
3. Demand the creation and implementation of national standards for HIV data protection, including prohibiting law enforcement and immigration enforcement from accessing data, prohibiting data from being used for criminalization purposes, firewalls to protect data from other agencies, and limitations on the length of time data may be stored.



# Recommendations for PACHA

4. Funded EHE jurisdictions should be required, as a condition for funding, to incorporate efforts to create an affirming human rights environment for people living with HIV, such as:

- a commitment to end laws and practices that criminalize people living with HIV.
- adopting state statutes to appropriately limit HIV data storage, sharing and use
- integrate data privacy into EHE plans
- require that jurisdictions certify in writing that surveillance data will not be used for other purposes before they receive surveillance funding





# Thank you



For more info: US People Living with HIV Caucus  
[hivcaucus.org](http://hivcaucus.org)



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