



Molecular HIV Surveillance & Its Heightened Impact in the this new Trump Administration

A TRAINING FACILITATED BY LIFETIME SURVIVORS NETWORK



COMMUNITY PROMISES

01

Be respectful of other viewpoints and experiences

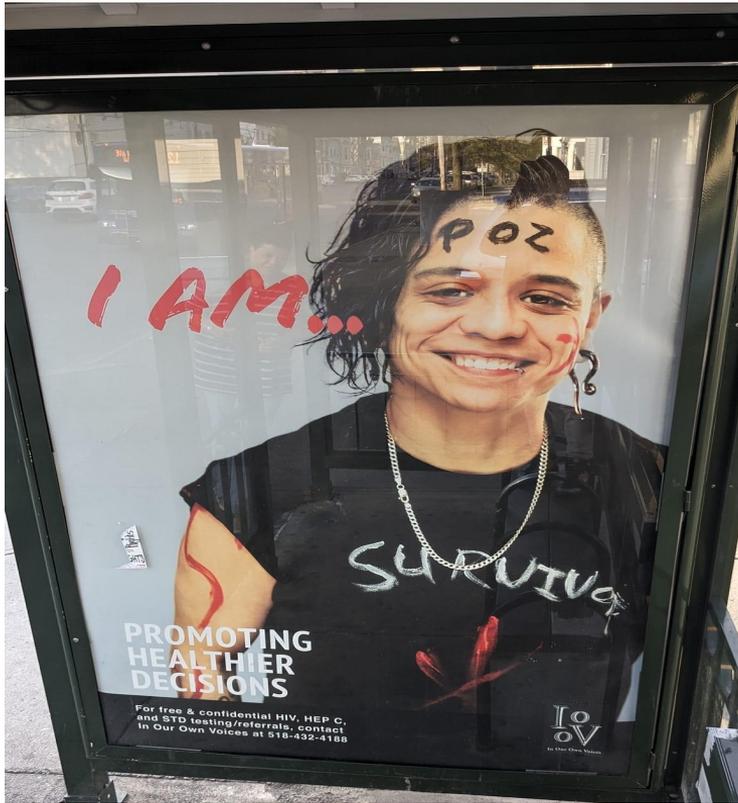
02.

Be open to learning

03.

Vegas Rule
(what happens here,
stays here)

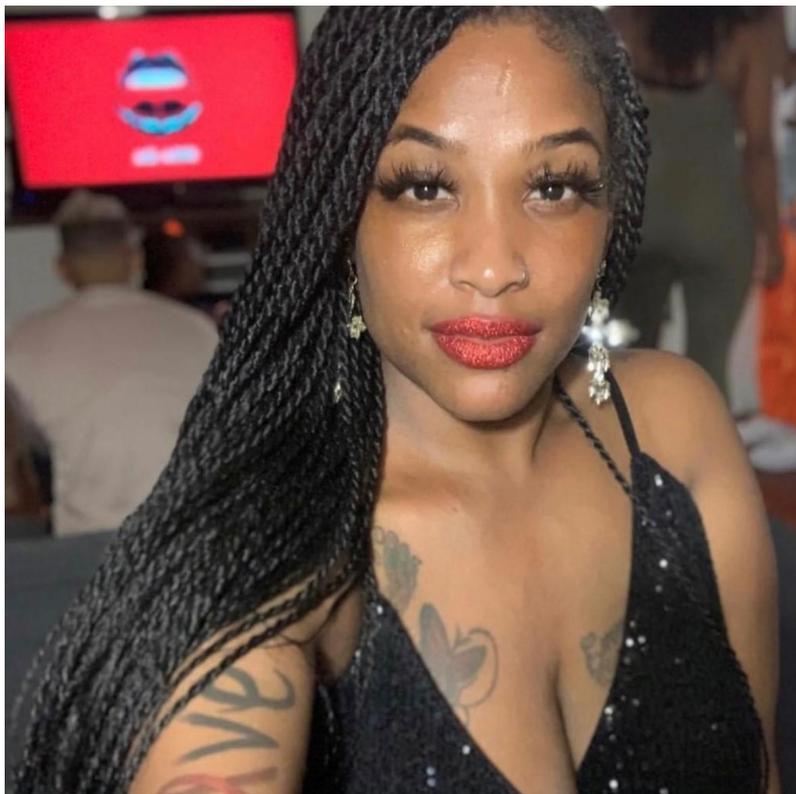




OUR **AGENDA**

- Welcome and Introductions
- Understanding MHS
- Social Factors & Rising Trends Of Surveillance.
- Relevance to Lifetime Survivor's & other communities of PLWHIV.
- Discussions and Q&A
- Closing Reflections



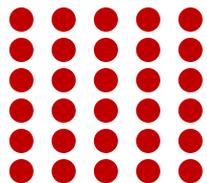


Meet the Facilitator

Porchia Dees

She, Her, Hers

CA State Lead for Positive Women's Network



TRAINING BY AND FOR LIFETIME SURVIVORS

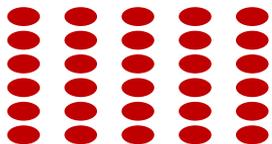
- Developed by the Lifetime Survivor's Network in collaboration with PWN.
- We are adults with careers and families, striving for more visibility and advocacy.
- Historically overlooked in HIV & Aging discussions, we are now telling our stories.



Positive Women's Network

We are the only national membership body created by and for women (trans and cis) and gender diverse people living with HIV.

Since 2008, our members have created a unified voice and built collective power for women (trans and cis) and gender diverse folks living with HIV. We believe that racial and gender justice cannot be divested from the HIV response, and ground our work in collective liberation.



Understanding MHS



WHAT IS Molecular HIV Surveillance?

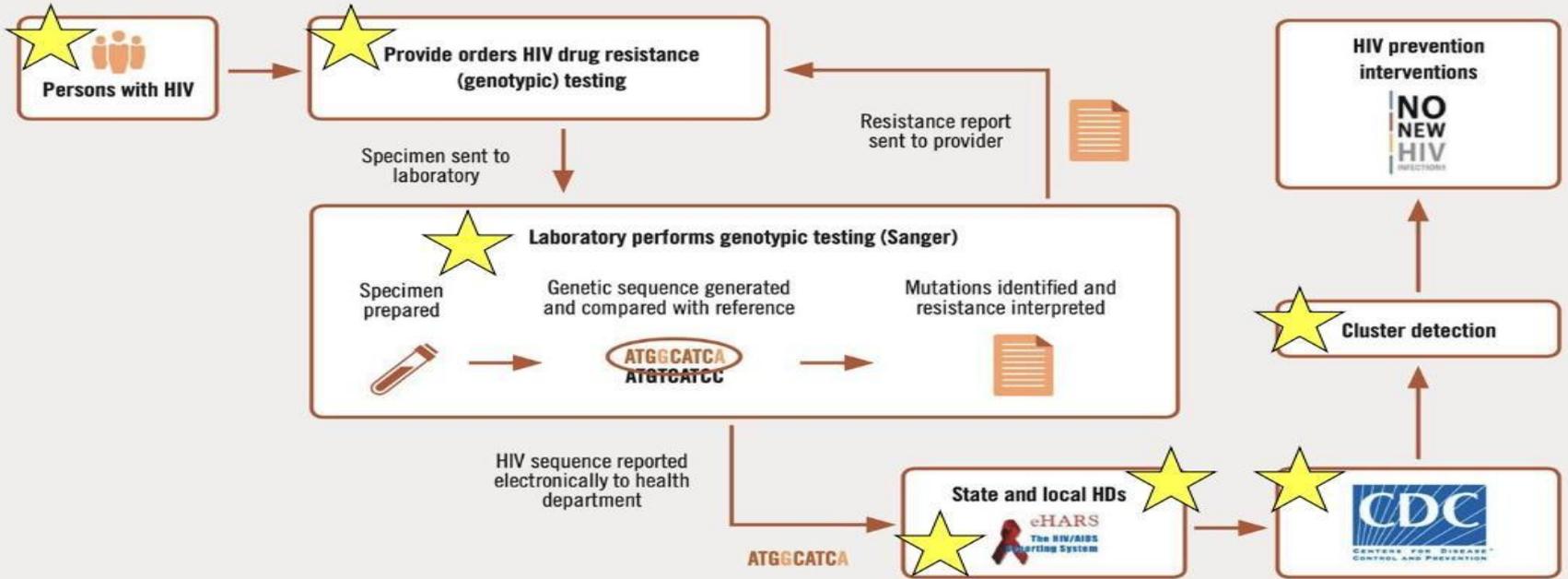
MHS is an umbrella term that describes a wide range of practices focused on the monitoring of HIV variants and the differences and similarities between them for scientific research, public health surveillance and intervention.

It can come by many different names including cluster detection and response of HIV polygenic surveillance.

Under the 1st Trump administration, when the Ending the Epidemic (EHE) plan was introduced in 2018, MHS became key, a required component of the national HIV response.



COLLECTION OF HIV MOLECULAR SEQUENCE DATA



WHAT IS Cluster Detection & Response?

CDR is the term used to describe the actions taken once a cluster is identified including efforts to link people to care and for diagnostics reasons, as well as it can also involve contacting the police.

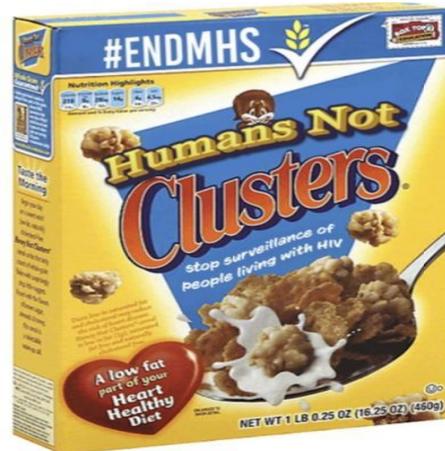
As of January 1, 2018, CDC required ALL health departments in the country to support reporting and monitoring of phylogenetic analysis results.



WHAT IS A Cluster?

First and foremost, clusters are people! In MHS a cluster is a specific and technical term used to define genetic relatedness between samples of HIV taken from different people.

Molecular surveillance proponents have said the data they study is “molecules not people.” **But molecules are connected to people & people are situated in social contexts.**



WHAT IS

Phylogenetic Analysis?

Phylogenetic analysis is the science that underlies MHS. It compares the genetics sequences of HIV by estimating their evolutionary relationship to one another. In MHS phylogenetic analysis is applied to the genetic sequences of HIV taken from PLWHIV. The viruses are compared using a phylogenetic tree, similar to a family tree, to show how close or far apart different sequences are.

This kind of mapping and science can and has led to HIV criminalization and is not well understood in law enforcement and so it is often times misused in some criminal cases.



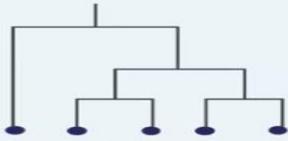
WHAT IS Phylogenetic Analysis?

Original Study: Phylodynamic Modeling of HIV Transmission

Research Question: Is there phylogenetic evidence of assortative HIV transmission by age, race, or ethnicity among men who have sex with men in King County, Washington, USA?

Inputs

1. Phylogenetic Tree of HIV Sequences collected via MHS

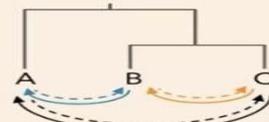


2. Linked Data

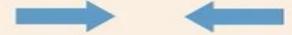
- Demographic information (**age, race, ethnicity**)
- CD4+ counts
- date of HIV sequence sampling

Outputs

1. Estimate a transmission probability weight for all pairs of HIV sequences



2. Predict population-level patterns



Social Factors & Rising Trends of Surveillance



MHS & It's Connection to HIV Criminalization

This kind of mapping and science can and has led to HIV criminalization and is not well understood in law enforcement and so it is often times misused in some criminal cases.

MHS is a weaponization of data against PLWHIV

- HIV Criminal arrests and prosecutions are not trending downwards.
- Over 30 states have variations of HIV criminalization laws, more may use general crimes against PLWHIV
- HIV confidentiality laws widely permit the release of HIV testing-related information for courts and law enforcement.

Shouldn't this have been addressed before CDC forced MHS on states?



Bodily Integrity & Bodily Autonomy

Bodily Integrity

The right not to have one's body touched or interfered with without consent; a right to be free from physical interference.

Bodily Autonomy

A principle of Western biomedical ethics; the right to make decisions for yourself, which may or may not affect your physical body.



MHS is a violation of **Informed Consent**

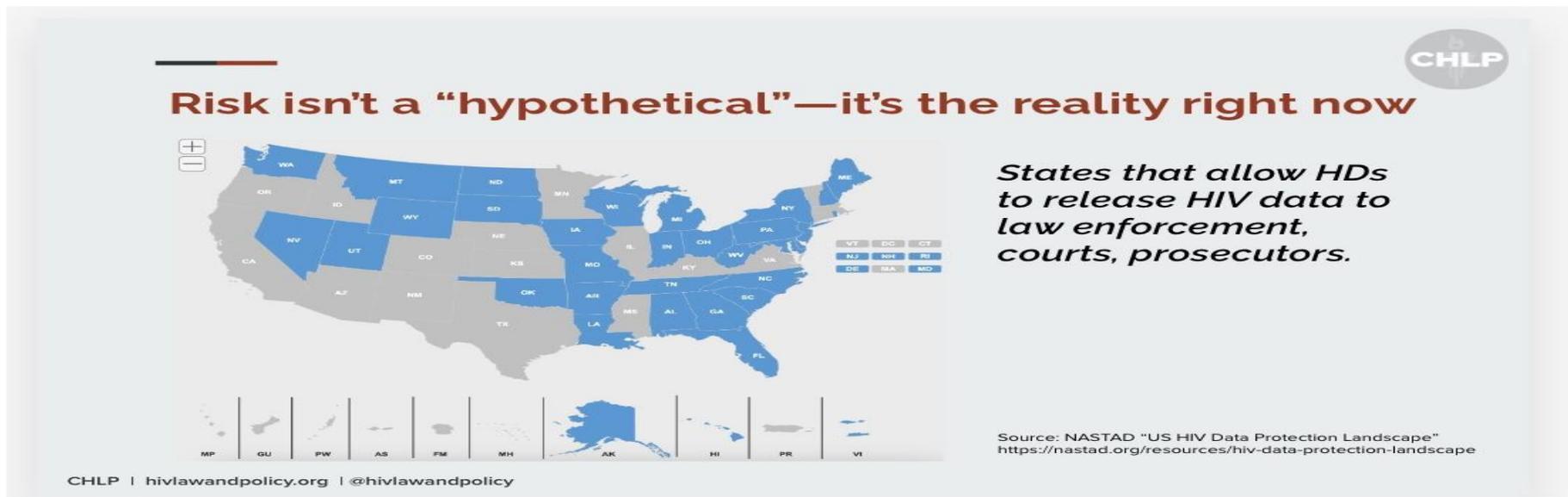
- The right to Make decisions about what medical treatment you will or will not accept.
- The duty for providers to disclose information + right to make decisions about your body.
- It puts autonomy into action and protects bodily integrity.
- It exists due to many violations after the Nuremberg Code in Europe, and massive lawsuits in North America (i.e., the Tuskegee experiments, Mk-Ultra, forced sterilization tests on prisoners and military, malnutrition experiments in residential schools, etc.)

We do not trust these systems as they are founded on these principles.



The Risk Isn't Hypothetical

THE REALITY IS NOW



The Risk Isn't Hypothetical

THE REALITY IS NOW →

The right to bodily autonomy and integrity is enshrined in medical ethics, research ethic, and laws. Depending on your country it may be in your constitution, in privacy laws, and various other legal frameworks.

Public Health is often at odds with with bodily autonomy and integrity as the ethics of public health aims to suspend the rights of some for the benefit of others.



MHS & Structural Violence



The Rise In Surveillance, Authoritarianism, & Criminalization in Public Health

- The freeze on federal and global funding of HIV programming and treatment for “review”.
- The erasure of all HIV prevention and health education information from the CDC’s website.
- The appointment of Elon Musk over DOGE and the access he has to our personal information within the department of treasury.
- The appointment of JFK Jr. over the Department of Health & Human Services.
- The refusal to acknowledge gender identities outside of male and female, as well as threat of removal of gender-affirming care for those under the age of 18.



**Relevance to LS & other
communities of PLWHIV.**



The Importance of Informed Consent **For Test Tube Babies**



The Many **LIFETIME** Intersectionalities **SURVIVORS**



MHS & THE GIFT ACT



GET INVOLVED

Keep this conversation going and connect with other Lifetime Survivors...



The Lifetime Survivors (LS) National NETWORK

We are a national network of PLWHIV *since birth or early childhood*. Our mission is to advocate for healthcare policy changes and make sure we are included in the development, decision-making, delivery and evaluation of the national Ending the HIV Epidemic Plan. Our vision is to increase awareness about the impact of HIV on PLWH since birth at every stage of the HIV Continuum.

Started in 2019, as an initiative that sprung from that year's USCHA, the Special Interest Group was an unincorporated project supported by NMAC originally apart of the National HIV & Aging Advocacy Network (NHAAN).



Since then, We have been strategizing and working on building out the infrastructure of our Network, creating/ adopting bylaws, and have focused in on policy priorities.

In 2024, We our announcing ourselves officially as a network and that we have our own official cohort within NMAC!

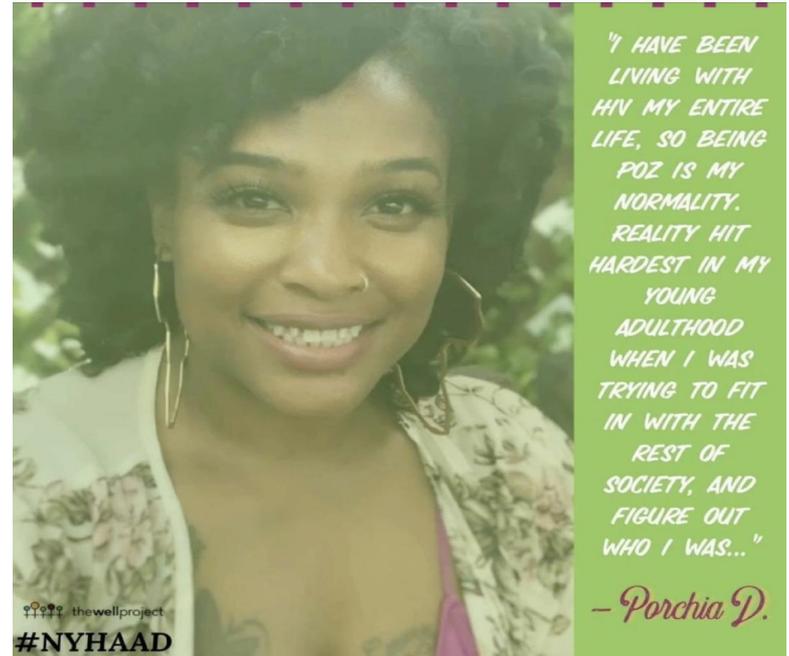


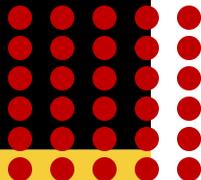
Lifetime Survivor's MEMBERSHIP

Membership is open to the following individuals:

- Persons living with HIV since birth or early childhood.

Our Network currently counts **50+ Members**, hailing from across the United States and Puerto Rico.





LIFETIME SURVIVOR NETWORK APPLICATION

**WE ARE A NATIONAL NETWORK OF
PEOPLE LIVING WITH HIV SINCE
BIRTH OR EARLY CHILDHOOD.**



JOIN US FOR:

- **A SAFE AND CONFIDENTIAL SPACE TO CONNECT WITH OTHER LIFETIME SURVIVORS**
- **BIWEEKLY SUPPORT GROUPS**
- **LEADERSHIP AND DEVELOPMENT OPPORTUNITIES**
- **AND MORE!**

✉ Lifetimesurvivorsnetwork@gmail.com

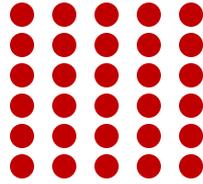
🌐 bit.ly/lifetimesurvivors

SCAN THE QR CODE, VISIT OUR WEBSITE, OR EMAIL US TO JOIN

APPLY TO JOIN

bit.ly/LifetimeSurvivors





Contact Us

LifetimeSurvivorsNetwork@gmail.com

Follow Us On
Instagram

@Lifetime_Survivors



QUESTIONS?

Questions & Comments

Q & A

