

Welcome

Watching the Watcher

INTERSECTIONS OF
SURVEILLANCE AND
CRIMINALIZATION IN
HIV AND REPRODUCTIVE
HEALTH CARE



Webinar
April 9, 2024
10am ET – 11:30am ET

A collaboration between The Choice Agenda, Positive Women's Network-USA, and KELIN



HIV prevention research - a new forum
for advocacy on the latest

avac.org/project/choice-agenda



Over 2300 individuals from 40+ countries are subscribed to The Choice Agenda global discussion list.



Today's playlist

DJ Jimberly

- **Watching Me**
Jill Scott
- **Big Brother**
Stevie Wonder
- **Somebody's Watching Me**
Rockwell
- **Spy Candy**
Jidenna
- **Sex Crime**
Eurythmics



Welcome

Watching the Watcher

SPEAKERS:

ALLAN MALECHE, ALEX MCCLELLAND & ARNETA ROGERS

MODERATOR:

NAINA KHANNA



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Moderator



naina khanna (they/she)
independent consultant & strategist
founding executive director, Positive Women's Network-USA



Speakers



Arnetta Rogers, Executive Director,
Center on Reproductive Rights and
Justice (CRRJ) at UC Berkeley Law



Allan Maleche, Executive Director,
Kenya Legal and Ethical Issues
Network on HIV and AIDS (KELIN)



Alex McClelland, Assistant Professor,
Institute of Criminology & Criminal
Justice (ICCI) at Carleton University

Agenda

- **Welcome and Introduction**
- **Grounding in our core concepts:**
 - Digital Innovation in HIV and Sexual and Reproductive Health Rights
 - Molecular HIV Surveillance in the context of HIV criminalization
 - Abortion criminalization
- **Discussion with Q & A**
- **Closing Reflections**



Goals and Objectives

By the time we are finished today, participants will learn:

- digital innovations and technologies come with risks
- molecular HIV surveillance can endanger human rights and health data privacy of people living with HIV.
- there are core overlapping concerns, violations and demands in the HIV and repro* movements in relation to criminalization, data security, privacy and respect for bodily autonomy.



Digital Innovation in HIV & Sexual and Reproductive Health Rights

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Molecular HIV Surveillance

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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 = Principle of Western biomedical ethics, right to make decisions for yourself, which may or may not affect your physical body



Informed Consent

- Right to make decisions about what medical treatment you will or will not accept
- Duty for providers to disclose information + right to make decisions about your body
- Puts autonomy into action and protects bodily integrity
- Exists due to many violations after the Nuremberg Code in Europe, and massive lawsuits in North America (i.e., Tuskegee, Mk-Ultra, forced sterilization, tests on prisoners and military, malnutrition experiments in residential “schools”) – we do not trust these systems as they are founded on these practices.



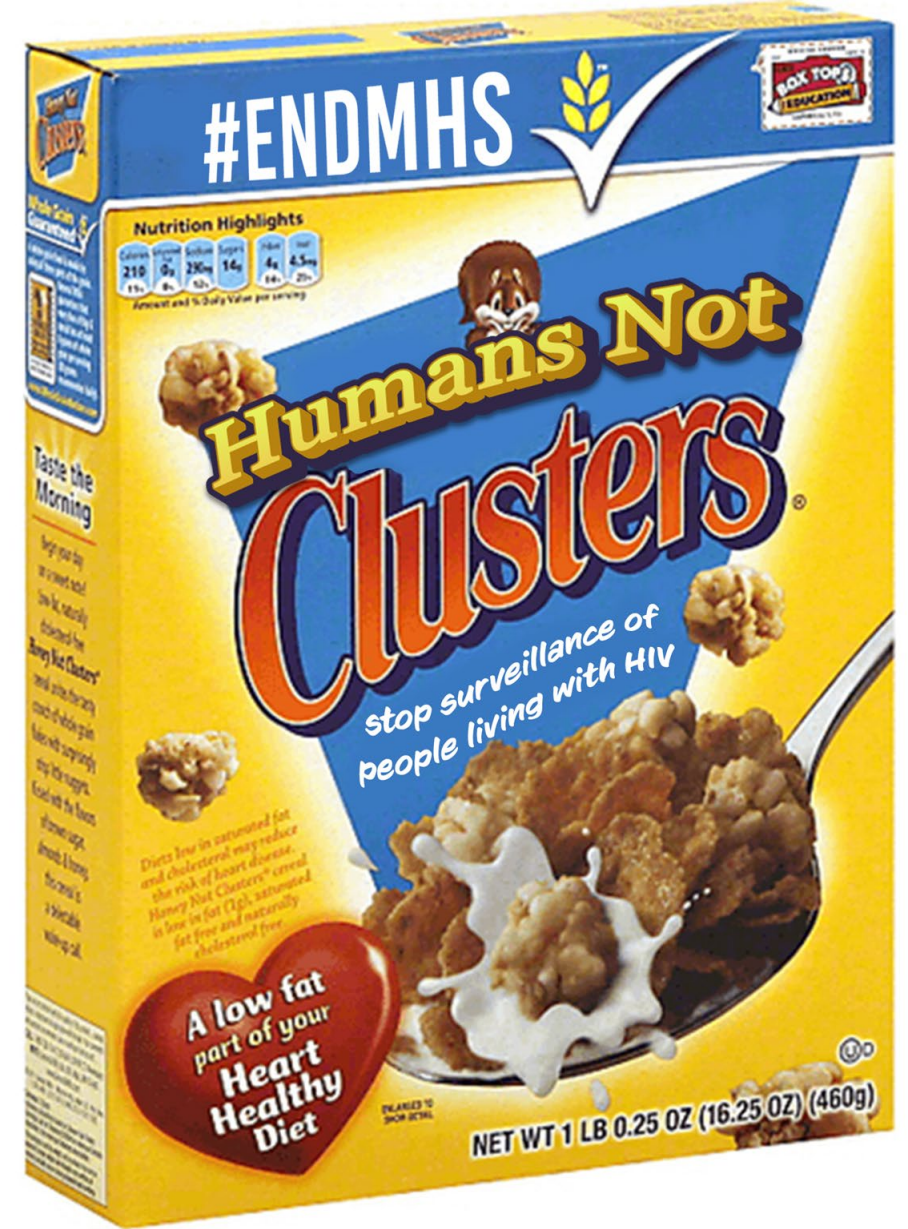


The right to bodily autonomy and integrity is enshrined in medical ethics, research ethics, and laws (depending on your country it may be in your constitution, in privacy laws, and various other legal frameworks).

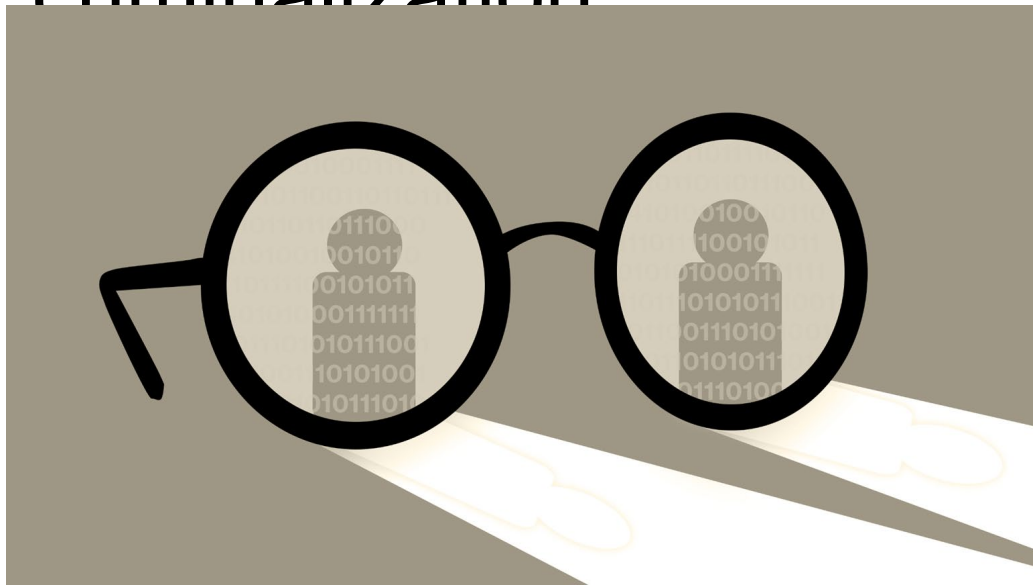
Public health is often at odds with bodily autonomy and integrity as the ethics of public health aims to suspend the rights of some for the benefit of the population.

But who is the “public” in public health?

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.**



This is an issue about violations of ethics, evolving conceptions of ethics, & the rights to privacy, bodily autonomy, & consent of people living with HIV in contexts of criminalization



Data is not benign. We must be wary of how data can be weaponized.

Molecular HIV surveillance analysis starts with our blood tests. The unique genetic make-up of the virus in our blood is translated into digital form and shared inter-institutionally (for clinical purposes and public health purposes).

Results from our clinical blood tests are re-used by public health authorities without our knowledge or consent for surveillance purposes.

Public health authorities use genetic sequences to identify clusters (i.e., transmission networks happening at higher rates than normal).



To be meaningful analytically, genetic sequences are linked to other sources of demographic information (e.g., age, race, sex assigned at birth, gender, migration/citizenship status, drug use history, sex work history, sexual practices – and whatever else people share in clinical encounters).



- Being used widely around the world
- Know your HIV surveillance system!
- Often tied to USAID funding, such as in Nigeria
- Targets the most socially marginalized, including migrants, people who use drugs, trans people, people who sell sex. The same populations who are targets of criminalization.



Concerns

- **Lack of informed consent**
- **Intensified stigmatization** (MSM case in Kenya and drug users in US)
- **Criminalization**
- **Engagement with people living with HIV**
- **No demonstrated impact**
- **Privacy**
- **Sharing of information** across sectors for purposes beyond care
- **Violations of research ethics**



Viral load information has been shared with police to contribute towards police investigations targeting people living with HIV.

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Vancouver police search for subject of unprecedented HIV-medication order



[redacted] ordered by court to take medication and report to doctors



Jason Proctor · CBC News · Posted: Jun 06, 2019 5:44 PM PT | Last Updated: June 6, 2019

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Edmonton man facing aggravated sexual assault charge; police believe there may be additional complainants

For Immediate Release: 28-Nov-2018 @ 2:26 PM

MRU #: SA18R003

The Edmonton Police Service has charged a 28-year-old male with aggravated sexual assault following encounters that occurred approximately two years ago.

On Tuesday, May 22, 2018, it was reported to police that a 57-year-old male had engaged in consensual sex with [redacted] on two occasions in late 2016 and had contracted HIV as a result. It was reported that [redacted] did not disclose his HIV status to the complainant.

[redacted] was charged with *aggravated sexual assault* on Thursday, Nov. 22, 2018.

Due to [redacted] work in the sex trade and high-risk lifestyle, detectives from the Edmonton Police Service's Sexual Assault Section believe there could be additional complainants who may have engaged in sexual relations with the accused, without being informed by [redacted] of his medical history. [redacted] is considered to have a high HIV viral load and has not sought treatment in a number of years.

MOLECULAR HIV SURVEILLANCE: A GLOBAL REVIEW OF HUMAN RIGHTS IMPLICATIONS



HIV JUSTICE
WORLDWIDE



RECOMMENDATIONS

Based on our global scoping review of MHS research and intervention literature, we have produced a number of recommendations for a wide range of stakeholders which can be found at the end of the document. The most important of these are:

1. Take seriously and act upon community concerns about MHS.
2. Respect the bodily autonomy and integrity of people living with HIV in all our diversity.
3. MHS implementers must demonstrate a clear public health benefit that outweighs the potential harms of MHS, including by ensuring protections (i.e., data privacy, legal protections, social harms prevention, etc). These demonstrated benefits of MHS must measurably include people living with HIV.
4. Providers ordering HIV sequencing must inform people living with HIV about how their blood and data are being used for MHS purposes and be allowed to withdraw consent if they so wish, without fear of negative consequences to their HIV treatment and care.
5. Implementers of MHS should publicly advocate against punitive or coercive laws and policies aimed at people living with HIV and ensure that MHS is never used in criminal, civil, or immigration investigations or prosecutions.

<https://www.hivjusticeworldwide.org/en/mhs/>

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

MORATORIUM

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

HIV surveillance is widely recognized as a public good. Public health leaders often say that they count on surveillance data to guide their interventions. However, for people and communities affected by HIV, surveillance may act as a double-edged sword, especially when it participates in stigmatizing and even criminalizing them.

The Criminalization of Pregnancy

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Reproductive Justice

The human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities

- SisterSong

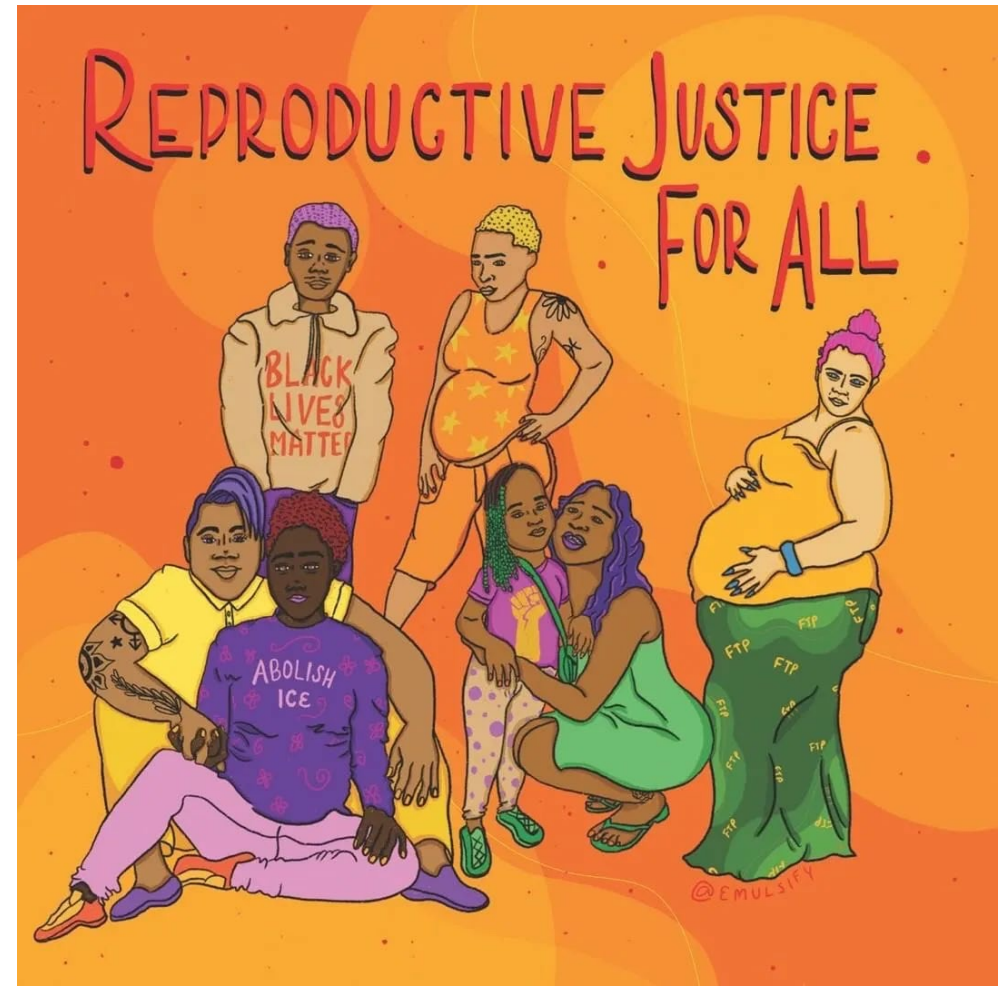
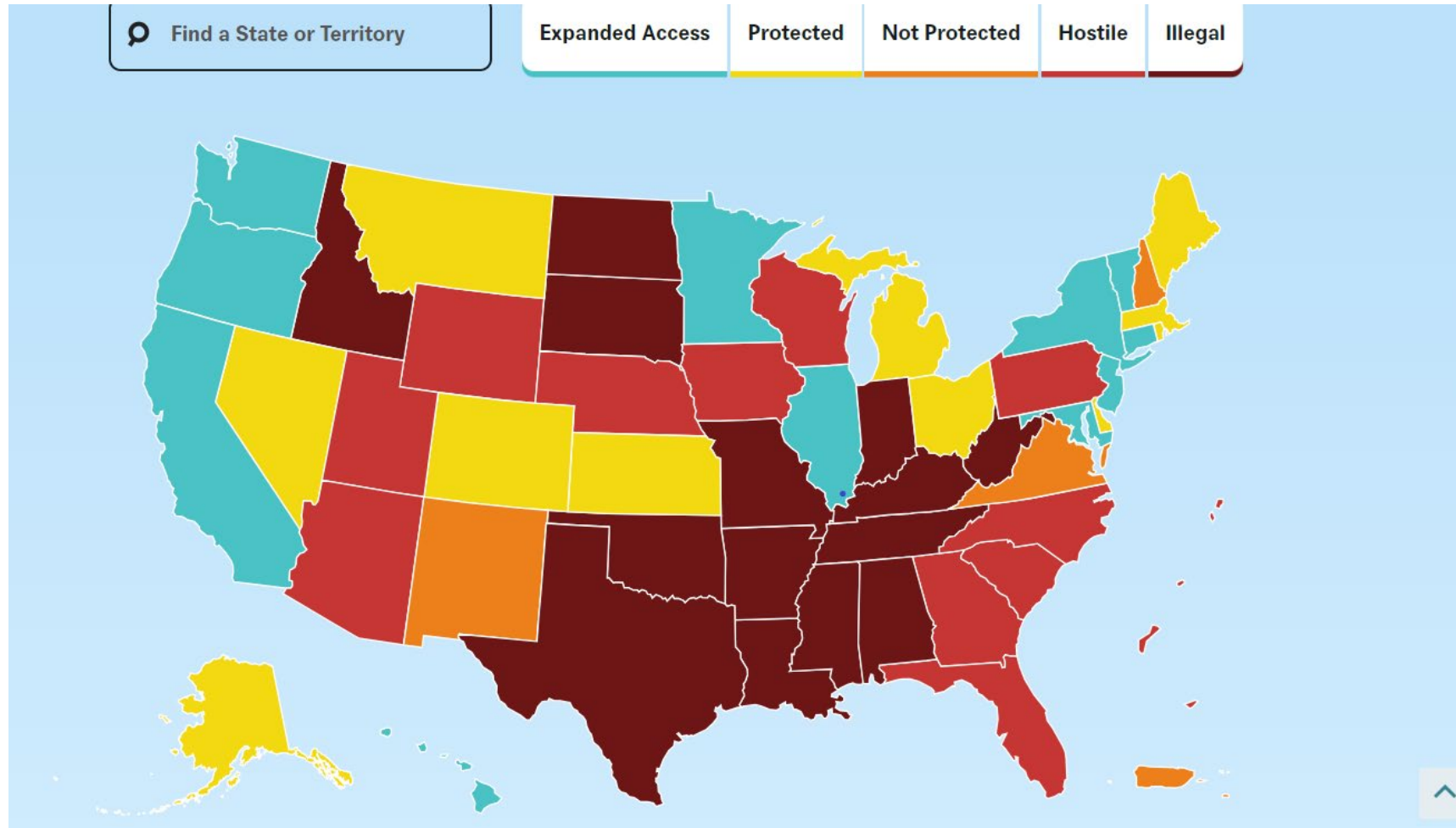


Image by @em_mulsify



Post-*Dobbs* Abortion Landscape



Source: Center on Reproductive Rights: After *Roe* Fell Abortion Laws by State



Criminalization of Pregnancy

- Someone arrested for reasons related to their pregnancy, or where the terms of their bail, sentencing, or probation are heightened because they became pregnant after being charged with an unrelated crime. - Pregnancy Justice
- People who use drugs, BIPOC, and low-income people



Micah Bazant for Forward Together

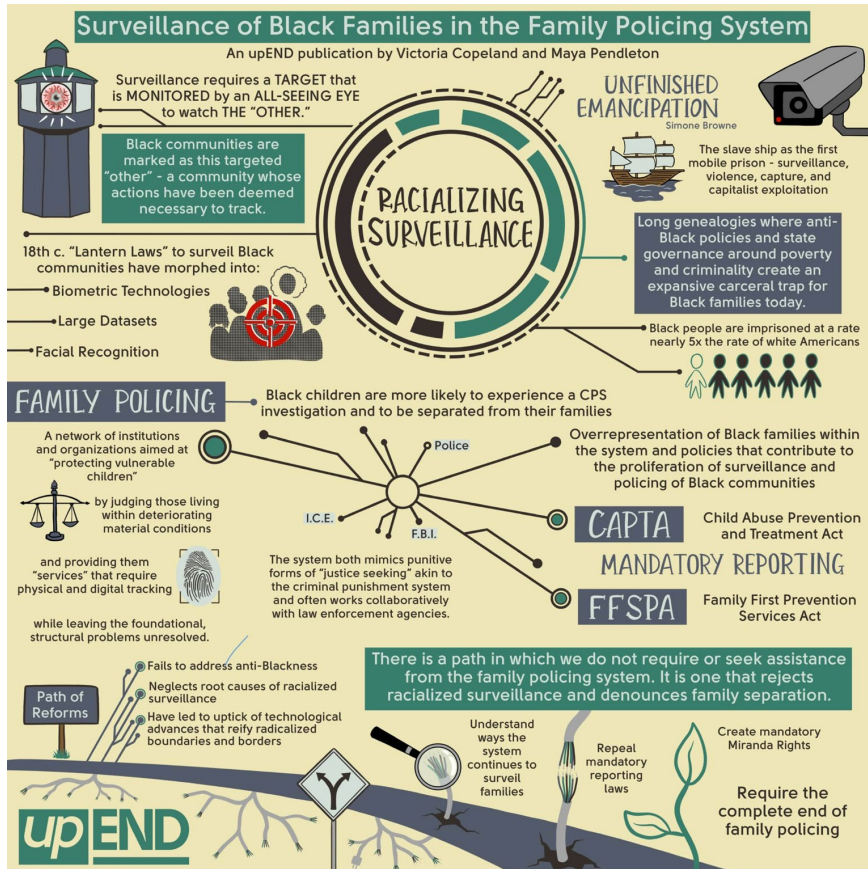
Fetal Personhood Movement

- Legal rights attached to fetuses, embryos
- Fringe idea entered mainstream in collision with “war on drugs”
- Right to bodily autonomy for people with capacity for pregnancy diminished



Ebin Lee for Forward Together

Surveillance, Criminalization, and Bodily Autonomy



- Fetal personhood movement paves way for more surveillance
- Drug testing pregnant people without informed consent
- Providers facilitate criminal and civil consequences for pregnant people



Resisting Criminalization and Surveillance

- Educating and organizing providers to break up with the police
- Digital privacy education for abortion seekers, helpers, providers - without fear mongering!
- Policy - “shield laws”
- Abortion funds as reproductive justice hubs



Discussion

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**Questions, Comments,
Reactions, Feedback?**

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Sign the Open Letter to the CDC: bit.ly/MHSopenletter

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



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

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Resources/References

- **Molecular HIV Surveillance: A Global Review of Human Rights Implications – HIV Justice Worldwide:** www.hivjusticeworldwide.org/en/mhs/
- **How to Talk About Molecular HIV Surveillance:** bit.ly/talkaboutMHS
- **Canadian Coalition to Reform HIV Criminalization (CCRHC):** www.hivcriminalization.ca/
- **Center on Reproductive Rights and Justice at UC Berkeley School of Law:** www.law.berkeley.edu/research/center-on-reproductive-rights-and-justice/
- **Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN):** www.kelinkenya.org/
- **Positive Women’s Network – USA:** www.pwn-usa.org/



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