The Choice Agenda presents

Wednesday
June 18
10am ET

Fight for Firewalls

HIV and Health Data Privacy in the Snowballing Surveillance State

Welcome

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

avac.org/project/choice-agenda

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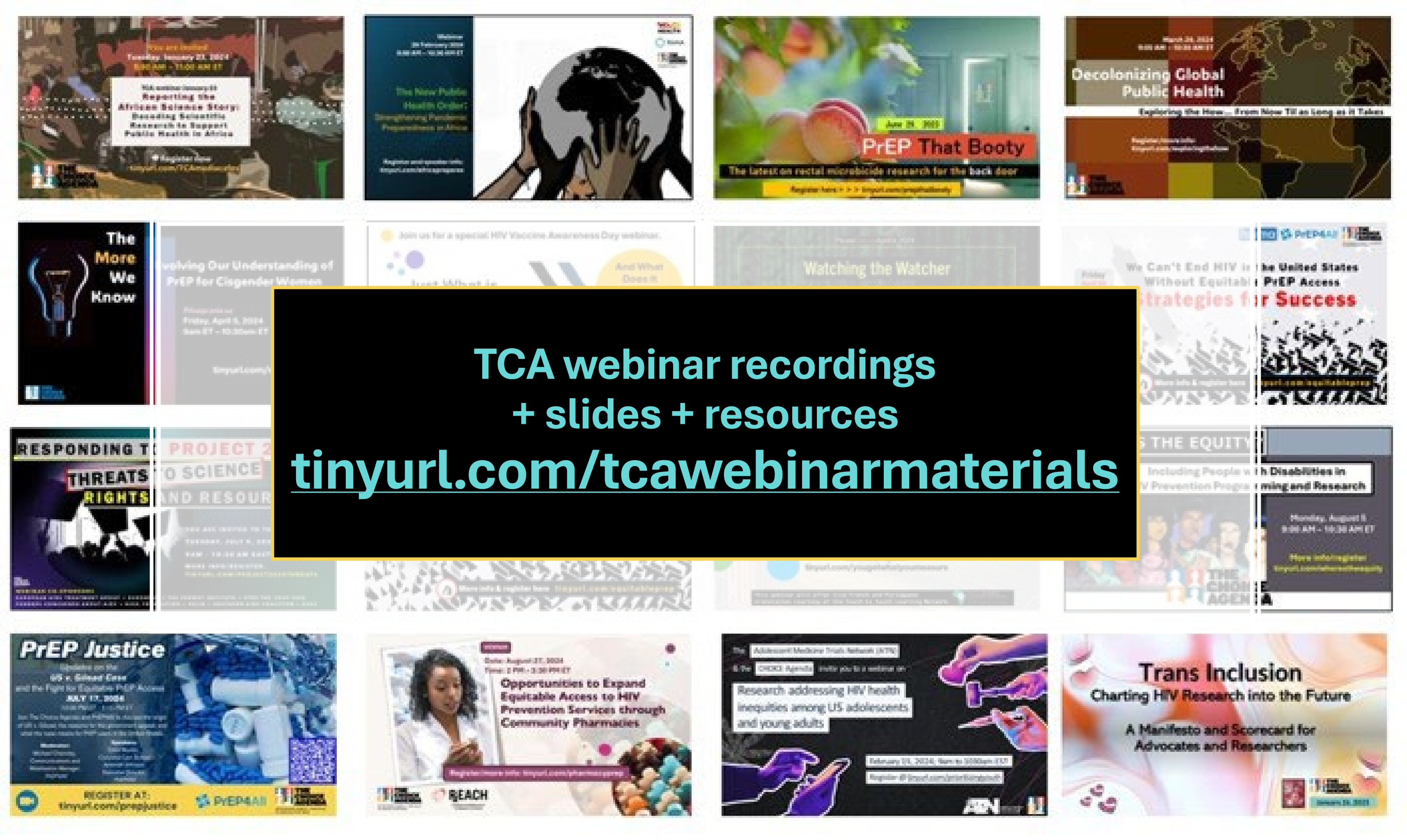

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Fight for Firewalls

HIV and Health Data Privacy in the Snowballing Surveillance State

Moderator:
Martha Cameron, International Community of Women Living with HIV , North America

Presenters:
Kendra Albert, Albert Sellars LLP
Kae Greenberg, Center for HIV Law and Policy

Fight for Firewalls: HIV and Health Data Privacy in the Snowballing Surveillance State

Kendra Albert (they/them)

Albert
Sellars

About Me

- Public interest technology and media lawyer
- Background in bodily autonomy (sex worker rights, repro) and First Amendment issues
- Board of the Tor Project, former board member of ACLU of Massachusetts

POLICY

Trump orders full access to agency data for designated officials

Under the executive order, agency heads are required to modify or rescind internal regulations that interfere with intra- or inter-agency sharing of unclassified data within 30 days.

BY CAROLINE NIHILL • MARCH 21, 2025

PRESIDENTIAL ACTIONS

Stopping Waste, Fraud, and Abuse by Eliminating Information Silos

Executive Orders | March 20, 2025

Can they do that?

The Federal Government Demands Data from SNAP—But Says Nothing About Protecting It

BY **HAYLEY TSUKAYAMA** | JUNE 3, 2025

EXCLUSIVE

USPS law enforcement assists Trump 'mass deportation' effort, sources and records show

The Postal Inspection Service recently joined a federal task force to locate undocumented immigrants using data from mail and packages, according to people familiar with the effort and records obtained by The Washington Post.

April 29, 2025

POLITICS > NATION

Trump administration gives personal data of immigrant Medicaid enrollees to deportation officials

The move could make it easier to locate people as part of President Trump's sweeping immigration crackdown.

Well, there's a lot of litigation to try and find out.

- Electronic Privacy Information Center v. U.S. Office of Personnel Management (1:25-cv-00255)(employee data)
- NATIONAL TREASURY EMPLOYEES UNION v. VOUGHT (1:25-cv-00380)(employee data)
- American Federation of Government Employees, AFL-CIO v. U.S. Office of Personnel Management (1:25-cv-01237)(employee data)
- American Federation of State, County and Municipal Employees, AFL-CIO v. Social Security Administration (1:25-cv-00596)(employee data)
- PALLEK v. ROLLINS (1:25-cv-01650)(foodstamp data)

What does this mean about personal information for PLHIV, including HIV status info and molecular surveillance?

What kind of data?

What data?

(An incomplete list, focused on HIV data specifically.)

- A universe of data
    - Electronic health records
    - State-level Medicaid claim data
    - State-level public health organization data
    - Pharmacy data
    - CDC HIV Surveillance System data
    - Molecular health surveillance data
    - Data that corporations hold that isn't health data

Identifiable
De-Identified*

- Medicaid data: names, addresses, social security number, claims data for enrollees.

- CDC diagnosis data: sex, gender, race/ethnicity, age, transmission category, location of testing (state/metropolitan statistical area)

* Whether data can be re-identified is always contextually specific, and depends on the technology and other data available. That means that “de-identified” data is often re-identifiable, especially over time.

What kind of protections?

Types of Protection

- Technical protections
- Legal protections
- Policy protections

Technical Protections

- Technical protections
    - Best technical protection is not having data in the first place - not having the data in the first place
    - Strong - encryption, a.k.a. “math says they can’t get the data”
    - Weaker - it’s technically difficult to get or use the data
- But who do technical protections protect against?
    - Often aimed at “outside adversaries” not inside data sharing.

Legal Protections

- Note- no baseline data privacy law in the United States
- Laws that prohibit sharing
- Laws that restrict data use
- Procedural hurdles for government data sharing (Privacy Act)
- Please note: HIPAA is not the answer to everything
  - Law enforcement exception
  - Only covers health data held by healthcare providers

Policy Protections

- Policy protections
    - Informal expectations and practices: “We’ve always done it this way”
    - Agency regulations and guidance
- Can be more malleable/easier to change than formal legal protections

What kinds of risk?

Types of Data Risk

- Individual identification
    - Does this person have HIV?
    - Who is the person who got this HIV diagnosis?
    - Can result in criminalization, discrimination, denial of care, etc.
- Collective identification and sorting
    - Matching datasets to each other
    - Producing a list of all Medicaid
    - recipients with HIV, for example
    - Highest risk for action against people as a class
- Other types of risk
    - Transmission patterns
    - PLHIV have other identities, can be targeted for those!

Protections in Practice: Medicaid Example

States have Medicaid records, including addresses, names, social security numbers and claims data for enrollees in those states.

Centers for Medicare and Medicaid Services (CMS) requests claim data from CA, WA, IL, NY, OR, MN, CO to determine if federal funds are providing Medicaid to non-citizens.

CA, WA, and IL provide details about non-citizens enrolled in state Medicaid programs to CMS.*

CMS gets ordered to turn data over to the Department of Homeland Security.

CMS officials explain that it violates “multiple federal statutory and regulatory authorities”, and “long-standing policy:

CMS turns the data over to Homeland Security anyway.

*I can’t tell if it was just non-citizen data that got shared, or everyone’s.

Protections in Practice: Medicaid Example

States have Medicaid records, including addresses, names, social security numbers and claims data for enrollees in those states.

States hand data over to CMS, who turns it over to DHS.

- Technical protections
  - Strong: no, not against other government actors.
  - Weak: maybe, data may be difficult to understand or combine (but AI)
- Policy protections
  - Agency regulations and guidance prohibited sharing
  - Informal expectations and practices prohibited sharing
  - Doesn't help if the people running the agency overrule
- Legal protections
  - Statutory prohibitions on sharing under the Privacy Act
  - Remedy after the fact?
  - May be able to bring legal challenge, but can be difficult to put the genie back in the bottle

Brief break for screaming into the void.

AHHHHHHHHHHHHHHHHHH!

What can we do?

What can we do?

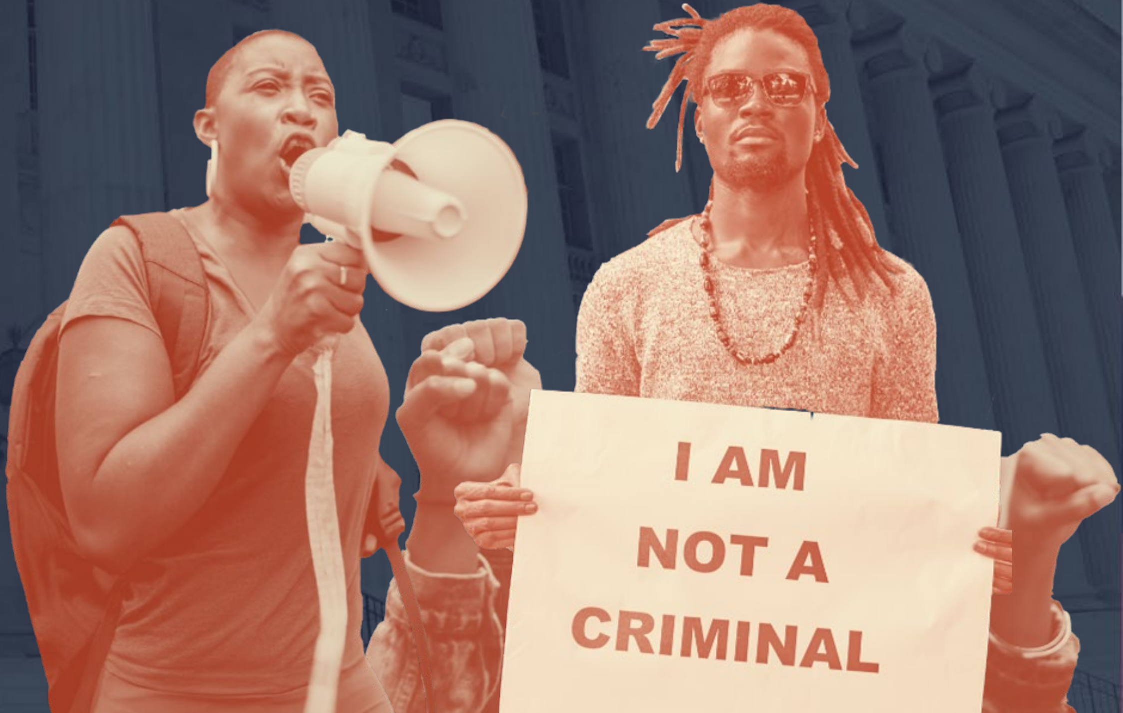
- End HIV criminalization.
- Work on a state level to minimize data collection and sharing when possible. (Difficult in the HIV context, but still worth trying.)
- Educate public health organizations about data collection risks.
    - Blue state health departments cannot bury their heads in the sand.
- Look at shield law examples.
- Build partnerships with legal organizations to prepare for challenges.

The Choice Agenda
June 18, 2025

CHLP20
CELEBRATING 20 YEARS IN 2025

Fighting for Firewalls

HIV and Data Privacy in a Snowballing Surveillance State



Kae Greenberg (he/him)
Staff Attorney, CHLP
kae@hivlawandpolicy.org

CHLP20

Making Positive Justice Possible Since 2005

The Center for HIV Law and Policy

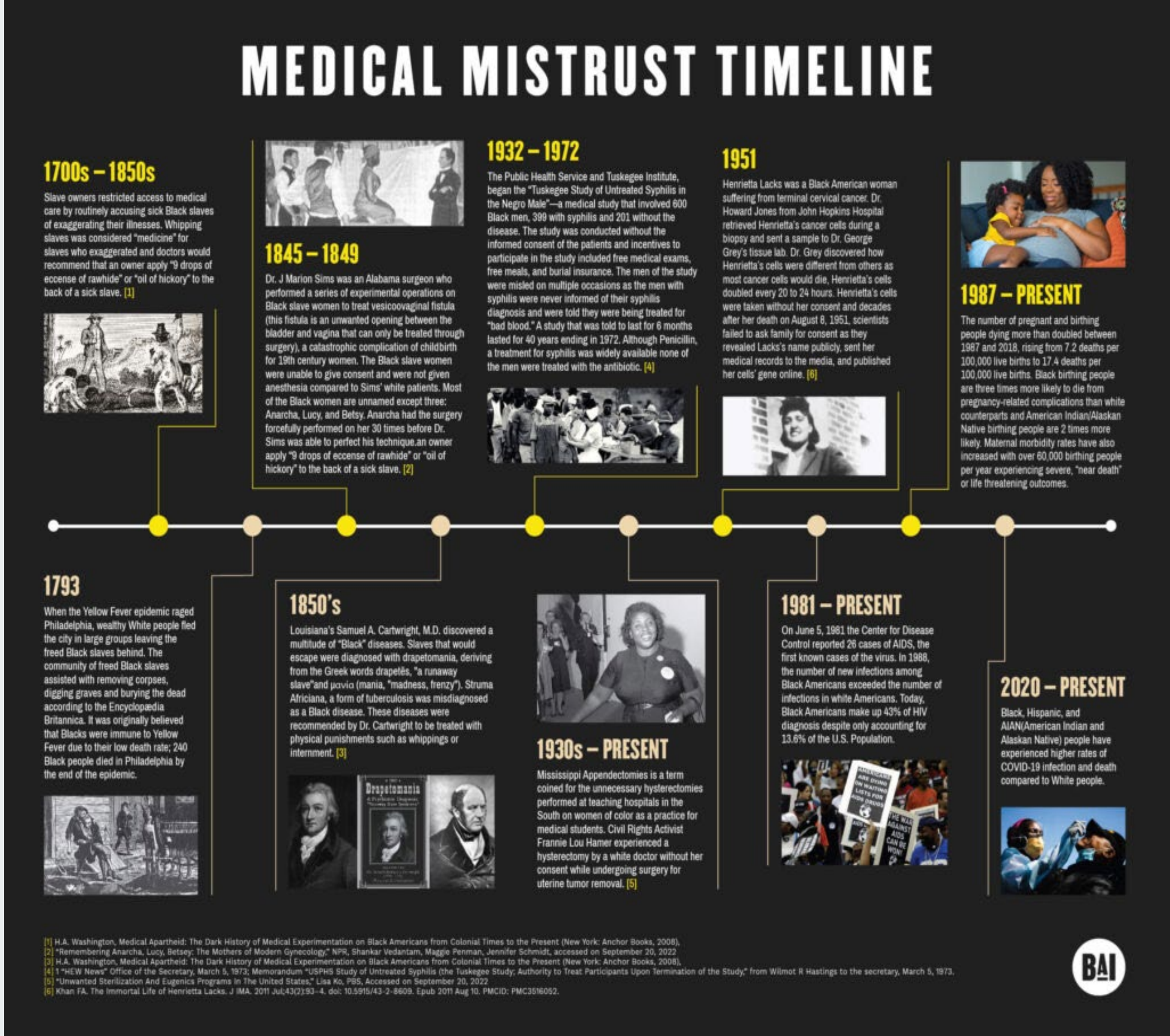
CHLP is an abolitionist legal and policy organization fighting to end stigma, discrimination, and violence at the intersection of HIV, race, health status, disability, class, sexuality and gender identity and expression, with a focus on criminal and public health systems.

In 2025, CHLP is celebrating 20 years of advocacy, innovation, and unwavering commitment to HIV justice.

Medical Mistrust Impacts Health Outcomes

A lack of control over one’s health data and transparency around how it will be used only increases medical mistrust.

Shukla, M.; Schilt-Solberg, M.; Gibson-Scipio, W. Medical Mistrust: A Concept Analysis. Nurs. Rep. 2025, 15, 103. https://doi.org/ 10.3390/nursrep15030103



MEDICAL MISTRUST TIMELINE

1700s – 1850s

Slave owners restricted access to medical care by routinely accusing sick Black slaves of exaggerating their illnesses. Whipping slaves was considered “medicine” for slaves who exaggerated and doctors would recommend that an owner apply “9 drops of eccense of rawhide” or “oil of hickory” to the back of a sick slave. [1]

1793

When the Yellow Fever epidemic raged Philadelphia, wealthy White people fled the city in large groups leaving the freed Black slaves behind. The community of freed Black slaves assisted with removing corpses, digging graves and burying the dead according to the Encyclopædia Britannica. It was originally believed that Blacks were immune to Yellow Fever due to their low death rate; 240 Black people died in Philadelphia by the end of the epidemic.

1845 – 1849

Dr. J Marion Sims was an Alabama surgeon who performed a series of experimental operations on Black slave women to treat vesicoovaginal fistula (this fistula is an unwanted opening between the bladder and vagina that can only be treated through surgery), a catastrophic complication of childbirth for 19th century women. The Black slave women were unable to give consent and were not given anesthesia compared to Sims’ white patients. Most of the Black women are unnamed except three: Anarcha, Lucy, and Betsy. Anarcha had the surgery forcefully performed on her 30 times before Dr. Sims was able to perfect his technique.an owner apply “9 drops of eccense of rawhide” or “oil of hickory” to the back of a sick slave. [2]

1850’s

Louisiana’s Samuel A. Cartwright, M.D. discovered a multitude of “Black” diseases. Slaves that would escape were diagnosed with drapetomania, deriving from the Greek words drapetēs, “a runaway slave”and μανία (mania, “madness, frenzy”). Struma Africiana, a form of tuberculosis was misdiagnosed as a Black disease. These diseases were recommended by Dr. Cartwright to be treated with physical punishments such as whippings or internment. [3]

1932 – 1972

The Public Health Service and Tuskegee Institute, began the “Tuskegee Study of Untreated Syphilis in the Negro Male”—a medical study that involved 600 Black men, 399 with syphilis and 201 without the disease. The study was conducted without the informed consent of the patients and incentives to participate in the study included free medical exams, free meals, and burial insurance. The men of the study were misled on multiple occasions as the men with syphilis were never informed of their syphilis diagnosis and were told they were being treated for “bad blood.” A study that was told to last for 6 months lasted for 40 years ending in 1972. Although Penicillin, a treatment for syphilis was widely available none of the men were treated with the antibiotic. [4]

1930s – PRESENT

Mississippi Appendectomies is a term coined for the unnecessary hysterectomies performed at teaching hospitals in the South on women of color as a practice for medical students. Civil Rights Activist Frannie Lou Hamer experienced a hysterectomy by a white doctor without her consent while undergoing surgery for uterine tumor removal. [5]

1951

Henrietta Lacks was a Black American woman suffering from terminal cervical cancer. Dr. Howard Jones from John Hopkins Hospital retrieved Henrietta’s cancer cells during a biopsy and sent a sample to Dr. George Grey’s tissue lab. Dr. Grey discovered how Henrietta’s cells were different from others as most cancer cells would die, Henrietta’s cells doubled every 20 to 24 hours. Henrietta’s cells were taken without her consent and decades after her death on August 8, 1951, scientists failed to ask family for consent as they revealed Lacks’s name publicly, sent her medical records to the media, and published her cells’ gene online. [6]

1981 – PRESENT

On June 5, 1981 the Center for Disease Control reported 26 cases of AIDS, the first known cases of the virus. In 1988, the number of new infections among Black Americans exceeded the number of infections in white Americans. Today, Black Americans make up 43% of HIV diagnosis despite only accounting for 13.6% of the U.S. Population.

1987 – PRESENT

The number of pregnant and birthing people dying more than doubled between 1987 and 2018, rising from 7.2 deaths per 100,000 live births to 17.4 deaths per 100,000 live births. Black birthing people are three times more likely to die from pregnancy-related complications than white counterparts and American Indian/Alaskan Native birthing people are 2 times more likely. Maternal morbidity rates have also increased with over 60,000 birthing people per year experiencing severe, “near death” or life threatening outcomes.

2020 – PRESENT

Black, Hispanic, and AIAN(American Indian and Alaskan Native) people have experienced higher rates of COVID-19 infection and death compared to White people.

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[1] H.A. Washington, Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present (New York: Anchor Books, 2008),
[2] “Remembering Anarcha, Lucy, Betsey: The Mothers of Modern Gynecology,” NPR, Shankar Vedantam, Maggie Penman, Jennifer Schmidt, accessed on September 20, 2022
[3] H.A. Washington, Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present (New York: Anchor Books, 2008),
[4] 1 “HEW News” Office of the Secretary, March 5, 1973; Memorandum “USPHS Study of Untreated Syphilis (the Tuskegee Study; Authority to Treat Participants Upon Termination of the Study,” from Wilmot R Hastings to the secretary, March 5, 1973.
[5] “Unwanted Sterilization And Eugenics Programs In The United States,” Lisa Ko, PBS, Accessed on September 20, 2022
[6] Khan FA. The Immortal Life of Henrietta Lacks. J IMA. 2011 Jul;43(2):93–4. doi: 10.5915/43-2-8609. Epub 2011 Aug 10. PMCID: PMC3516052.

Transparency → More Trust → Better Health Outcomes

“The majority of respondents expressed willingness to undergo ARVRT even with disclosure of public health uses of these data, but willingness markedly decreased when learning about these uses after the fact, highlighting the importance of transparency in MHS programs. Accordingly, in line with the ethical principle of respect for autonomy and the likelihood that the potential public health benefits of MHS programs will not be compromised, consideration should be given to encouraging clinicians to disclose public health uses of ARVRT at the time ARVRT is recommended.”

Sugarman J, Bollinger J, Agostini J, Weinfurt K, Geller G, Jose S, Hannah M, Edwards OW, Henry LM, Sanchez The Impact of Disclosing to Patients the Use of Antiretroviral Resistance Testing Results for Molecular HIV Surveillance: A Randomized Experiment in 2 National Surveys JMIR Public Health Surveill 2025;11:e64663 URL: https://publichealth.jmir.org/2025/1/e64663 doi: 10.2196/64663

Increased Weaponization of Health Data

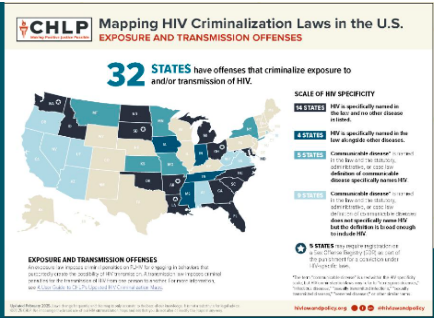
Symone D. Sanders Townsend @SymoneDSanders

Remember when folks said some of us were being dramatic? We weren't. This is terrifying.

Jesse Lehrich @JesseLehrich · Aug 9, 2022
Facebook is already turning over users' private data to aid abortion prosecutions. this is a huge deal.
forbes.com/sites/emilybak...

INNOVATION
Nebraska Cops Subpoenaed A Teen's Facebook DMs So They Could Prosecute Her For Having An Abortion

1:03 PM · Aug 9, 2022



CHLP Making Positive Justice Possible

Mapping HIV Criminalization Laws in the U.S.
EXPOSURE AND TRANSMISSION OFFENSES

32 STATES have offenses that criminalize exposure to and/or transmission of HIV.

SCALE OF HIV SPECIFICITY

- **14 STATES** HIV is specifically named in the law and no other disease is listed.
- **4 STATES** HIV is specifically named in the law alongside other diseases.
- **5 STATES** Communicable disease* is named in the law and the statutory, administrative, or case law definition of communicable disease specifically names HIV.
- **9 STATES** Communicable disease* is named in the law and the statutory, administrative, or case law definition of communicable diseases does not specifically name HIV but the definition is broad enough to include HIV.
- **5 STATES** may require registration on a Sex Offense Registry (SOR) as part of the punishment for a conviction under HIV-specific laws.

EXPOSURE AND TRANSMISSION OFFENSES

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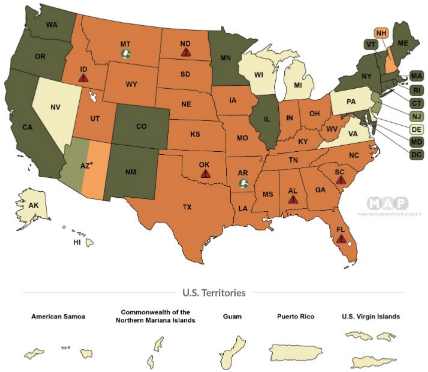


- 🟫 State has "shield" law protecting access to transgender health care (see this map for more information) *(14 states + D.C.)*
- 🟩 State has "shield" executive order protecting access to transgender health care (see this map for more information) *(2 states)*
- 🟨 State neither bans nor has "shield" law for best practice medical care for transgender youth *(8 states, 5 territories)*
- 🟧 State bans best practice surgical care for transgender youth *(2 states)*
- 🟫 State bans best practice medication and surgical care for transgender youth, though ban may not be in effect (see note) *(25 states)*
- ⚠ State ban makes it a felony crime to provide certain forms of best practice medical care for transgender youth *(6 states)*
- ● Court ruling is currently blocking enforcement of state's healthcare ban *(2 states)*

ABORTION

Will HIPAA Protections Continue for Abortion Care? Courts to Soon Decide.

JUN 11, 2025, 9:02AM | KELCIE MOSELEY-MORRIS, NEWS FROM THE STATES

A decision is imminent in three of the four cases that will determine whether individual health information for legal reproductive care remains protected by a 2024 federal rule.

Law Enforcement Can Access Your Data

HIPAA: Some exceptions are:

- Law enforcement requests (often without a court order)
- Compliance investigations
- Certain emergency situations
- State-mandated public health activities

Lane Crossing:
Public health & law enforcement

Public Health (city and state health departments)

- State laws that require testimony concerning health records, counseling
- Health department officials who offer services as "experts" testifying against PLHIV
- Perceived "duty to warn"

Law Enforcement

- Called on to enforce quarantine, masking orders
- Arrests, enforcement/ prosecution of HIV/VH exposure laws and policies occur in a vacuum of information or pushback from public health professionals

Good Intentions —> Problematic Outcomes

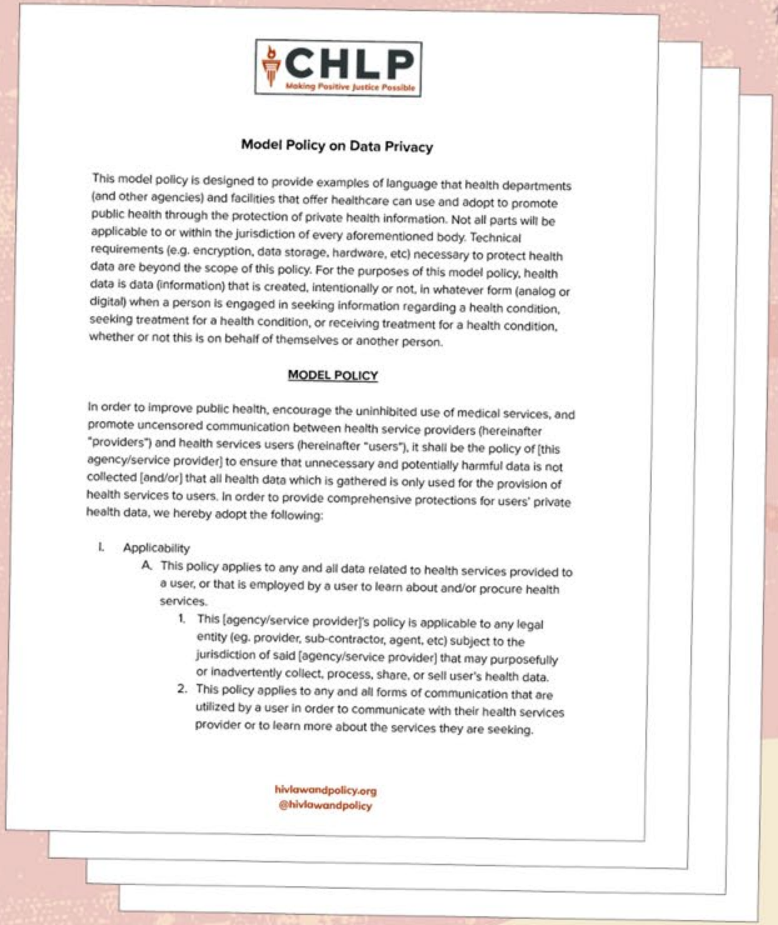

WHEN ALL
YOU HAVE
IS A HAMMER
EVERYTHING
LOOKS
LIKE A NAIL

Why Create a Model Policy?

1. People should have control over their private health information
2. Increased weaponization of health data
3. Limit loopholes that increase access to health data by law enforcement

Data privacy → Better Health Outcomes

Model Policy on Data Privacy



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Making Positive Justice Possible

Model Policy on Data Privacy

This model policy is designed to provide examples of language that health departments (and other agencies) and facilities that offer healthcare can use and adopt to promote public health through the protection of private health information. Not all parts will be applicable to or within the jurisdiction of every aforementioned body. Technical requirements (e.g. encryption, data storage, hardware, etc) necessary to protect health data are beyond the scope of this policy. For the purposes of this model policy, health data is data (information) that is created, intentionally or not, in whatever form (analog or digital) when a person is engaged in seeking information regarding a health condition, seeking treatment for a health condition, or receiving treatment for a health condition, whether or not this is on behalf of themselves or another person.

MODEL POLICY

In order to improve public health, encourage the uninhibited use of medical services, and promote uncensored communication between health service providers (hereinafter "providers") and health services users (hereinafter "users"), it shall be the policy of [this agency/service provider] to ensure that unnecessary and potentially harmful data is not collected [and/or] that all health data which is gathered is only used for the provision of health services to users. In order to provide comprehensive protections for users' private health data, we hereby adopt the following:

I. Applicability
    A. This policy applies to any and all data related to health services provided to a user, or that is employed by a user to learn about and/or procure health services.
        1. This [agency/service provider]'s policy is applicable to any legal entity (eg. provider, sub-contractor, agent, etc) subject to the jurisdiction of said [agency/service provider] that may purposefully or inadvertently collect, process, share, or sell user's health data.
        2. This policy applies to any and all forms of communication that are utilized by a user in order to communicate with their health services provider or to learn more about the services they are seeking.

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@hivlawandpolicy

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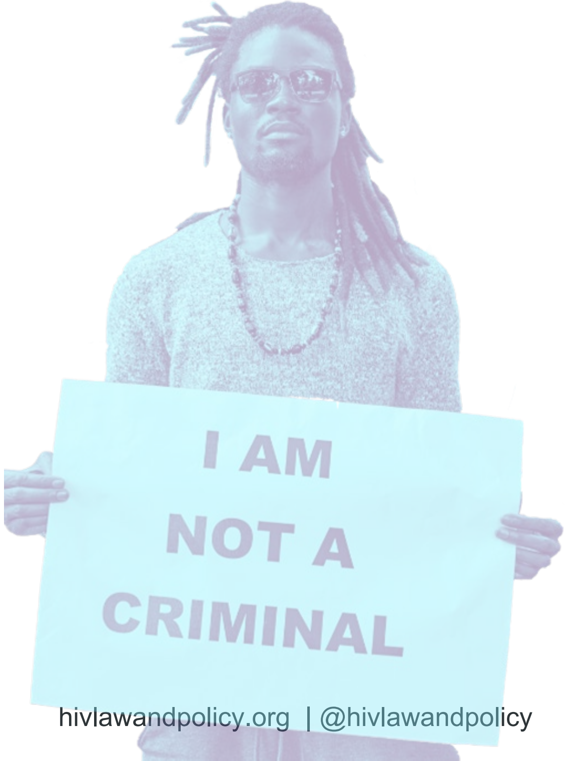
Making Positive Justice Possible Since 2005

Model Policy on Data Privacy

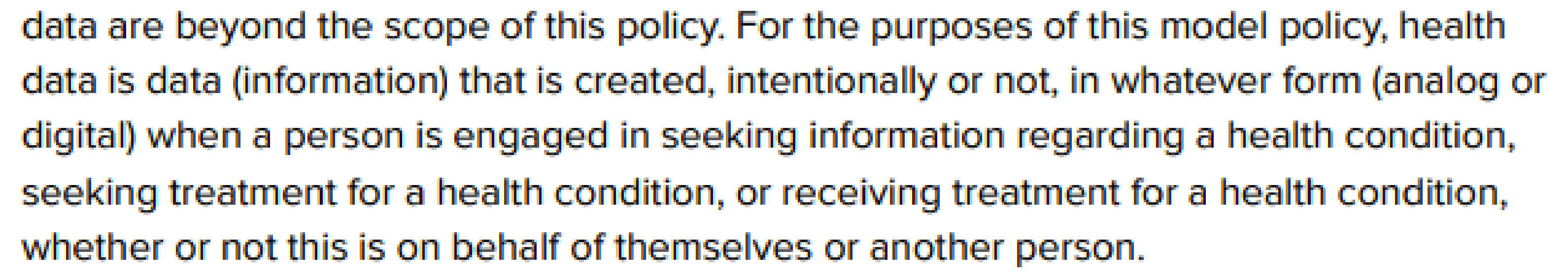
Audience: Health Departments, Clinics, CBOs, Doctors, etc.

- This is policy, not sample legislation
- Does not include “technical” protections
- “Choose your own adventure” style
- Designed to be used in self advocacy by individuals as well as by larger groups of advocates/NGOs



Model Policy: Highlights

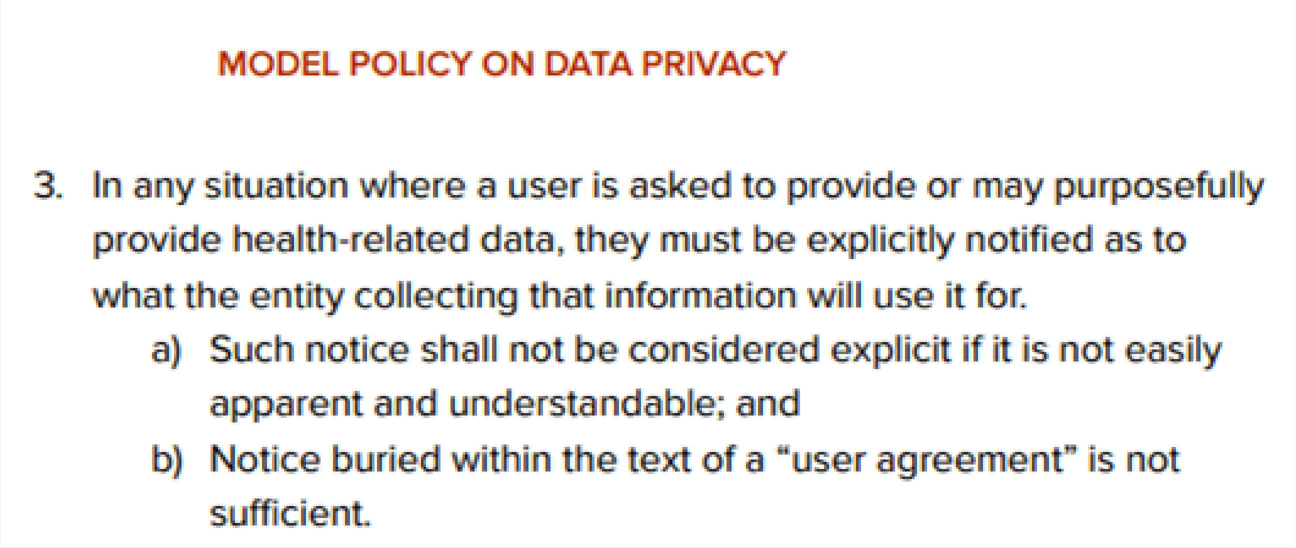
1. Broad definition of health data to capture beyond "just" medical records



data are beyond the scope of this policy. For the purposes of this model policy, health data is data (information) that is created, intentionally or not, in whatever form (analog or digital) when a person is engaged in seeking information regarding a health condition, seeking treatment for a health condition, or receiving treatment for a health condition, whether or not this is on behalf of themselves or another person.

Model Policy: Highlights

2. Requires unambiguous consent

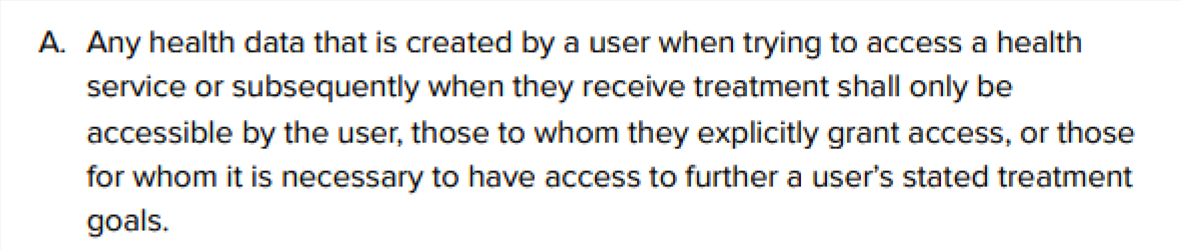


MODEL POLICY ON DATA PRIVACY

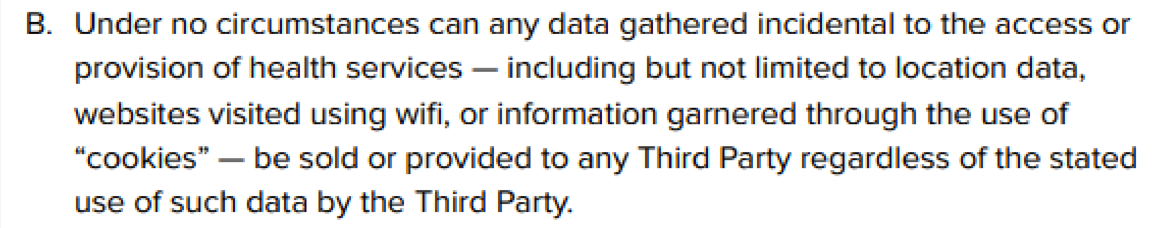
3. In any situation where a user is asked to provide or may purposefully provide health-related data, they must be explicitly notified as to what the entity collecting that information will use it for.
    a) Such notice shall not be considered explicit if it is not easily apparent and understandable; and
    b) Notice buried within the text of a "user agreement" is not sufficient.

Model Policy: Highlights

3. Affirmatively agree not to use for reason beyond healthcare or sell data to third parties



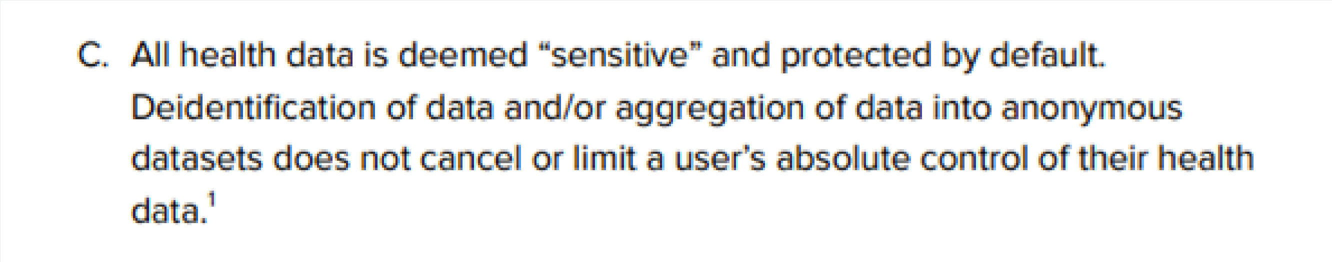
A. Any health data that is created by a user when trying to access a health service or subsequently when they receive treatment shall only be accessible by the user, those to whom they explicitly grant access, or those for whom it is necessary to have access to further a user's stated treatment goals.



B. Under no circumstances can any data gathered incidental to the access or provision of health services — including but not limited to location data, websites visited using wifi, or information garnered through the use of "cookies" — be sold or provided to any Third Party regardless of the stated use of such data by the Third Party.

Model Policy: Highlights

4. Aggregation/”de-identification” does not eliminate need to get consent



C. All health data is deemed “sensitive” and protected by default. Deidentification of data and/or aggregation of data into anonymous datasets does not cancel or limit a user's absolute control of their health data.[1]

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PositiveJusticeProject

Scan the QR to sign up for the PJP email list. For more info about our HIV decriminalization work, email us at pjp@hivlawandpolicy.org