

A Brave New World: Understanding the Legal Frameworks That Govern HIV Data Use and Sharing

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Session Roadmap

- Connecting the dots: how navigation of privacy policy helps health departments to be more effective in their programs
- Understanding the federal and state data privacy legal landscape
 - Health Insurance Portability and Accountability Act (HIPAA)
 - State HIV confidentiality laws
 - Substance use privacy law (42 CFR Part 2)
 - Minor consent laws
- Questions/discussion

Connecting the Dots: How Navigation of Privacy Policy Helps Health Departments to use Data for Public Health Action

Use Case One: Linkage and Retention

- HIV surveillance data (sharing governed by state law)
- Prescription drug data from pharmacy networks (sharing governed by state law and HIPAA)
- Electronic Health Record (EHR) data from providers (sharing governed by state law and HIPAA)



Use Case Two: Strengthen Surveillance Data

- Match data with other jurisdictional surveillance datasets to capture individuals who have left state and are not truly out-of-care
- Use external datasets (e.g., RWHAP data) to ensure surveillance data is accurate

Use Case Three: HIV Criminalization Law Reform



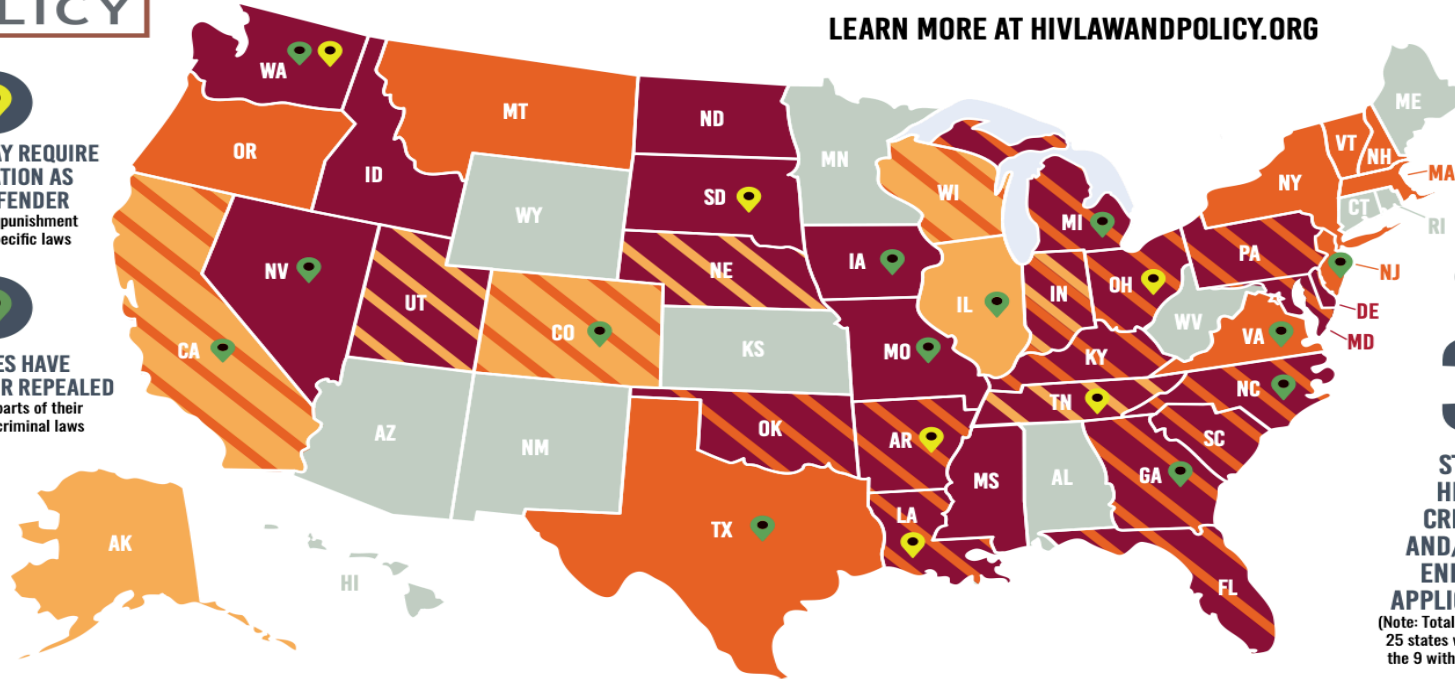
HIV CRIMINALIZATION IN THE UNITED STATES

AN OVERVIEW OF THE VARIETY AND PREVALENCE OF LAWS USED TO PROSECUTE AND PUNISH PEOPLE LIVING WITH HIV (PLHIV) IN THE US.

LEARN MORE AT HIVLAWANDPOLICY.ORG

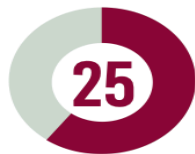
6 STATES MAY REQUIRE REGISTRATION AS A SEX OFFENDER as part of the punishment under HIV-specific laws

13 STATES HAVE REFORMED OR REPEALED one or more parts of their HIV-specific criminal laws



30

STATES HAVE HIV-SPECIFIC CRIMINAL LAWS AND/OR SENTENCE ENHANCEMENTS APPLICABLE TO PLHIV
(Note: Total reflects overlap among the 25 states with HIV-specific laws and the 9 with sentence enhancements.)



STATES WITH HIV-SPECIFIC CRIMINAL LAWS including laws targeting sex/ non-disclosure, exposure to bodily fluids, needle-sharing, sex work, and blood/ organ/semen donation



STATES WITH SENTENCING ENHANCEMENTS applicable to PLHIV who commit an underlying sexual assault crime.



STATES THAT HAVE PROSECUTED PLHIV UNDER NON-HIV-SPECIFIC, GENERAL CRIMINAL LAWS
This number represents states with reported charges and/or convictions for non-HIV-specific offenses, where positive HIV status was relevant in establishing a (non-HIV-specific) element of the offense.

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Updated: June 2022. Laws change frequently and this map is only accurate to the best of our knowledge. It is not a substitute for legal advice.

The HIPAA Privacy Rule: Overview

Key Components of HIPAA

The Health Information Portability and Accountability Act (HIPAA) governs how “covered entities” protect and secure “protected health information.”

- **HIPAA “Privacy Rule”**: Governs use and disclosure of protected health information (PHI) by covered entities
- **HIPAA “Security Rule”**: Establishes national standards (administrative, physical, and technical) for protecting PHI created, transmitted, or stored electronically

HIPAA: Key Terms

HIPAA applies to “covered entities.”

- **Covered entities:** health care providers, health plans, health care clearinghouses
- Most public health departments are *hybrid entities*

HIPAA protects “protected health information (PHI).”

- **PHI:** *Individually identifiable* health information held or transmitted by a “covered entity” or its business associate, that relates to
 - an individual's mental or physical health or condition,
 - provision of health care to the individual, OR
 - payment for the individual's health care

Health Departments as “Hybrid Entities”

Examples of HIPAA-covered health department activities:

- A health department operates a health clinic or hospital
- A health department electronically bills for testing services provided in state lab
- AIDS Drug Assistance Program (ADAP) service administration

NOT covered by HIPAA: traditional public health activities, such as surveillance

Permitted Uses and Disclosures of PHI for Public Health Purposes Under HIPAA

Use and Disclosure of PHI Under HIPAA

The HIPAA Privacy Rule generally requires a valid patient “authorization” for most uses or disclosures of PHI.

- Signed, specific, revocable at any time

A covered entity may use or disclose PHI without patient authorization only as expressly **permitted or required** under HIPAA.

- Required disclosures: 1) patient rights to an “accounting of disclosures” for their own PHI; 2) HIPAA compliance investigations
- Permitted disclosures: HIPAA permits, but does not require, use and disclosure of PHI for six enumerated purposes
 - NOTE: Disclosure may be required under other federal, state, tribal, or local laws

Permitted Use and Disclosure

- Disclosure to the individual identified in the information
- **Treatment, payment, and health care operations**
- Opportunity to agree or object (e.g., informal consent)
- Incident to an otherwise permitted use or disclosure
- **Public interest and benefit activities**
 - *Required by law*
 - *Public health activities*
 - *Disclosures to law enforcement or for judicial/administrative proceedings*
- Limited data set

Disclosure for “Public Interest and Benefit Activities”

- **Required by law:** A covered entity may disclose PHI as required by federal, state, tribal, or local law.
 - Example: Mandatory reporting of certain diseases, including HIV, to a state or local health department; partner notification
- **Public health:** A covered entity may disclose PHI to a public health authority (PHA) legally authorized to collect the information for public health purposes.
 - Example: Disclosure to PHA for the purpose of preventing or controlling disease (disease reporting, public health surveillance, investigations, interventions)
- **Law enforcement and judicial/administrative proceedings:** A covered entity may disclose PHI to law enforcement or in connection with legal proceedings under specified conditions and subject to limitations.
 - Examples: Responding to a court order or subpoena, providing basic demographic information to help locate a fugitive or missing person, reporting child abuse/neglect

“Required by Law”: Example 1

Under HIPAA, may a health care provider report a new case of HIV (including PHI) to the state health department without the patient’s permission?

“Required by Law”: Example 1

Under HIPAA, may a health care provider report a new case of HIV (including PHI) to the state health department without the patient’s permission?

Yes. Since the provider is required by state law to report HIV to the health department, HIPAA allows this disclosure without patient authorization.

Under HIPAA, a covered entity may use or disclose PHI without patient authorization if required to do so by state law. All states have laws requiring health care providers to notify public health authorities of certain reportable diseases, including HIV.

HIPAA Right to an Accounting of Disclosures

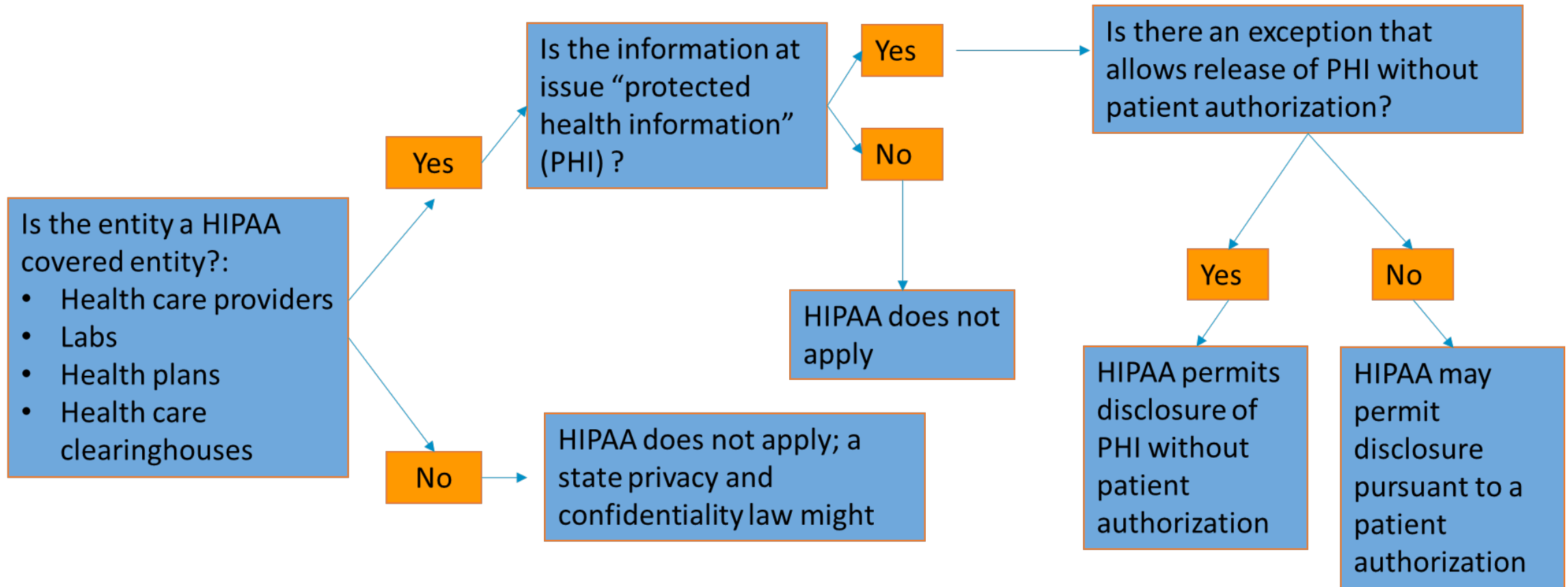
- Individuals have a right to know how their PHI is used and shared
- A covered entity must provide an “accounting” of disclosures upon patient request
 - Must explain what PHI was shared, with whom, when, and why
 - 6-year lookback period
- Accounting requirement includes PHI shared with a public health authority for public health activities (e.g., surveillance)
 - The covered entity is not required to separately document each medical record disclosed to the public health authority

New HIPAA Regulations (April 2024)

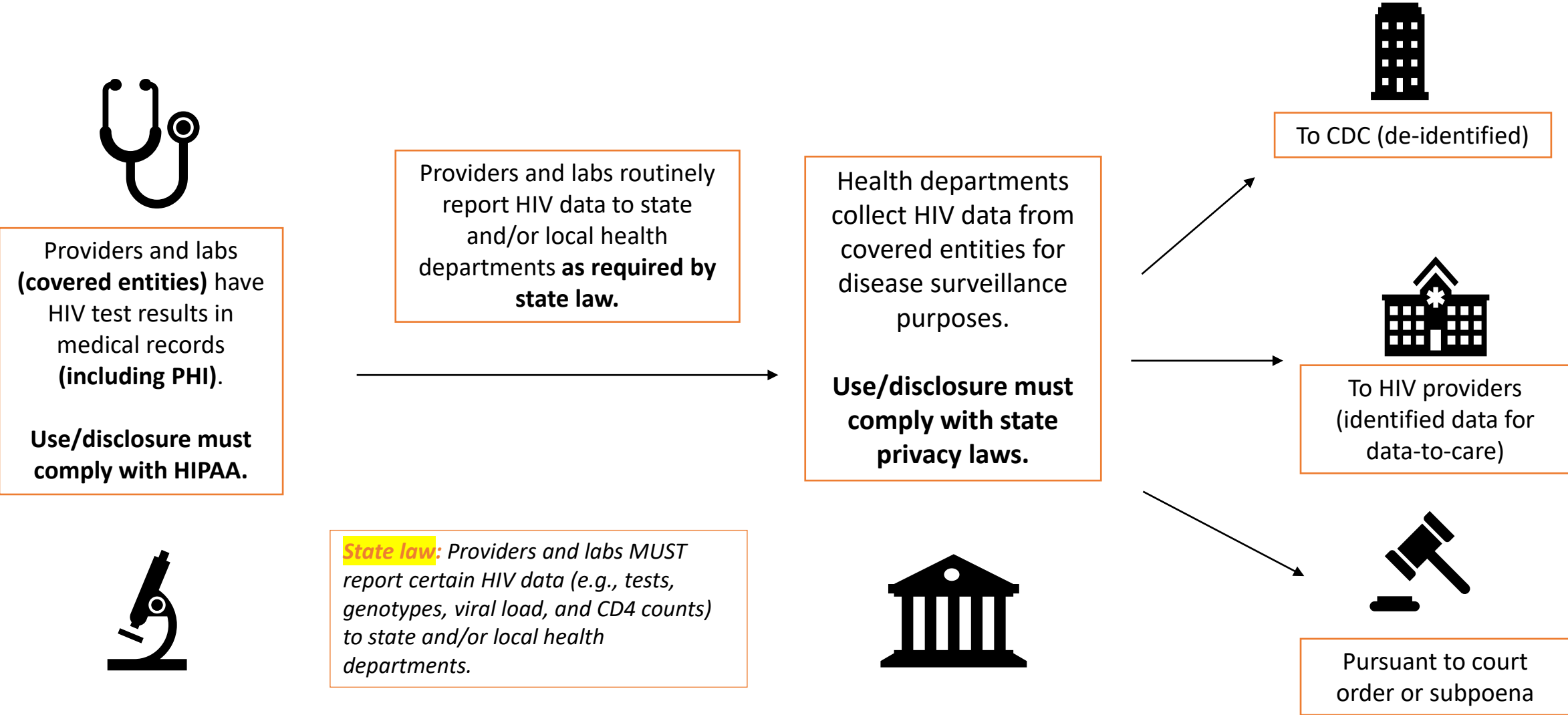
- New federal HIPAA regulations strengthen privacy and confidentiality of PHI related to reproductive health care
 - Limits circumstances in which reproductive health care data can be released in connection with criminalization of individuals for seeking legal health care services across state lines
- The new rules define “public health” for HIPAA purposes
 - Explicitly excludes “criminal, civil, or administrative investigations for seeking, obtaining, providing, or facilitating health care”
- The new protections do not extend to HIV. However, the new rules and accompanying HHS guidance...
 - recognize that privacy promotes access to care
 - recognize that public health reporting requirements should not be used as a backdoor to criminalization
 - clarify limitations on disclosures to law enforcement

Beyond HIPAA: Legal Protections for Health Department HIV Data

The Intersection of HIPAA and State Public Health Laws



HIPAA or State Law (or Both)?



How can health departments protect HIV surveillance data?

State public health privacy laws

- Legal framework: HIV data reported to state/local health departments is confidential and cannot be released without consent, except... [e.g., to address a public health emergency, pursuant a court order or subpoena]
- State laws can be amended to limit or prohibit disclosure for non-public health purposes (such as prosecutions under HIV criminalization statutes)

Maryland (Md. Code Ann., Health-Gen. §§ 4-102, 18-201.1; Cts. & Jud. Proc. § 10-205)

Reports of HIV/AIDS cases made by physicians to the state health department are “confidential records” that may be used and disclosed only for the purpose for which they were obtained.

They are not admissible as evidence in any legal proceeding.

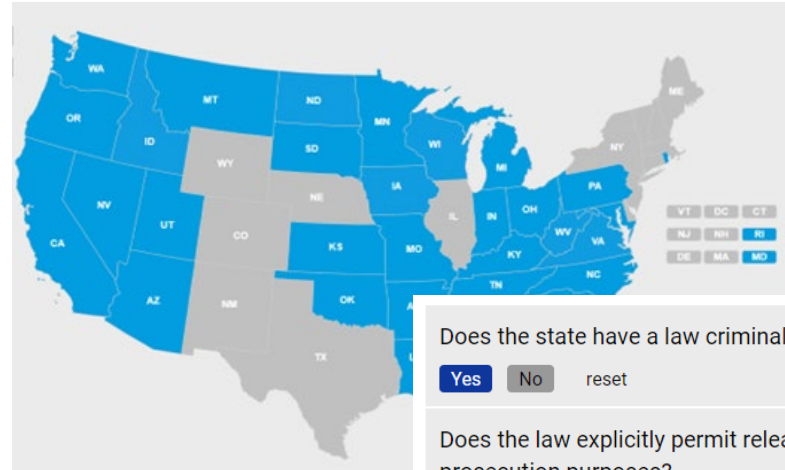
How can health departments protect HIV surveillance data?



U.S. HIV Data Protection Landscape

Health department policies and practices

- Working with public health legal counsel to ensure a protective interpretation of a broad or vague data privacy law
- Engaging communities in dialogue about HIV data protections, existing safeguards on surveillance data, and concerns about data misuse



Does the state have a law criminalizing transmission of or exposure to HIV?

Yes No [reset](#)

Does the law explicitly permit release of health department HIV data for law enforcement and/or prosecution purposes?

Yes No [reset](#)

Does state law explicitly require a court order for release of health department HIV data in response to requests from courts, law enforcement, or prosecutors in all circumstances?

Yes No [reset](#)

Does state law limit the type of HIV data the health department may release to courts, law enforcement, or prosecutors?

Yes No [reset](#)

Does state law explicitly require that a defendant be charged with a crime before health department HIV data may be released in connection with criminal matters?

Yes No [reset](#)

Access this NASTAD resource and accompanying webinar [here](#).

How can health departments protect HIV surveillance data?

Prosecutorial and law enforcement practices

- Informing prosecutorial discretion grounded in current medical knowledge
- Engaging criminal justice stakeholders in HIV criminalization and data privacy reform



White House Office of National AIDS Policy Hosts Historic Prosecutor Roundtable on HIV Criminal Laws

Nearly 50 state prosecutors, attorneys general, federal officials and national infectious disease experts convened to consider concrete ways to modernize state criminal laws and the criminal justice response to HIV-specific criminal laws



State of New Jersey
OFFICE OF THE ATTORNEY GENERAL
DEPARTMENT OF LAW AND PUBLIC SAFETY
DIVISION OF CRIMINAL JUSTICE
PO Box 085

DATE: October 6, 2021

SUBJECT: Guidance Regarding N.J.S.A. 2C:34-5(b) in Light of Advancements in Treatment for HIV/AIDS



New York City Council Resolution 1584-2021: "The City will formalize the Task Force on Health and Safety Needs of Sex Workers to expand supportive community-based services for sex workers."

The Task Force includes representatives from the NYPD and the NYC Dept. Of Health.

Limiting Principles of Health Department Data Release

Statutory protections

- Limits on types of data that can be disclosed and under what circumstances
- Procedural protections (e.g., in camera review)

Legal relevance

- Health departments are not the only, or best, source of HIV data that may be of interest to law enforcement

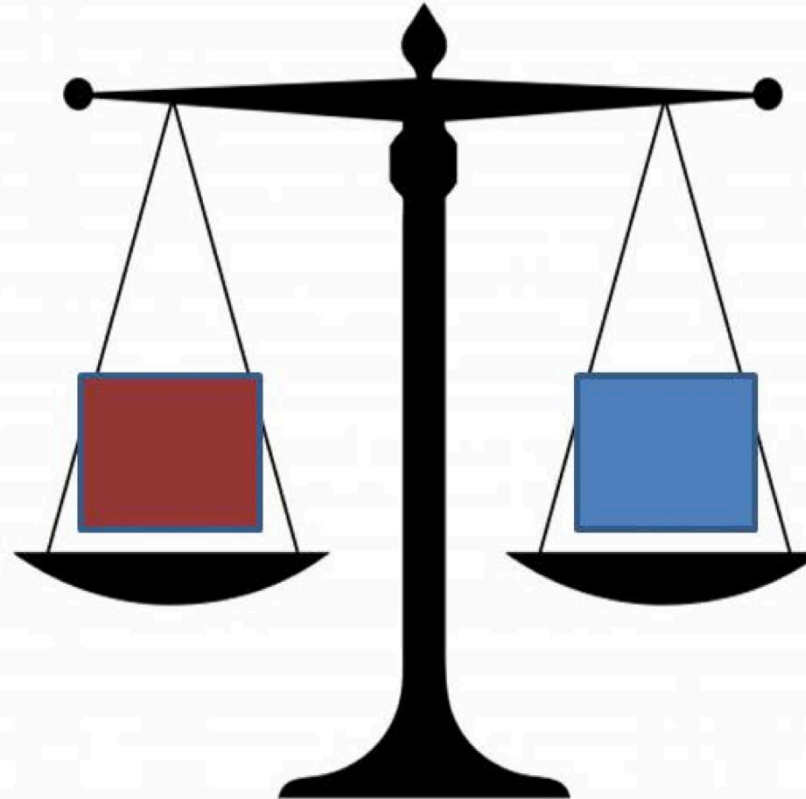
Health department policy and procedure

- Data release can and should be structured in a limited way

Understanding the Federal and State Data Privacy Legal Landscape

A Balancing Act

Patient
Confidentiality

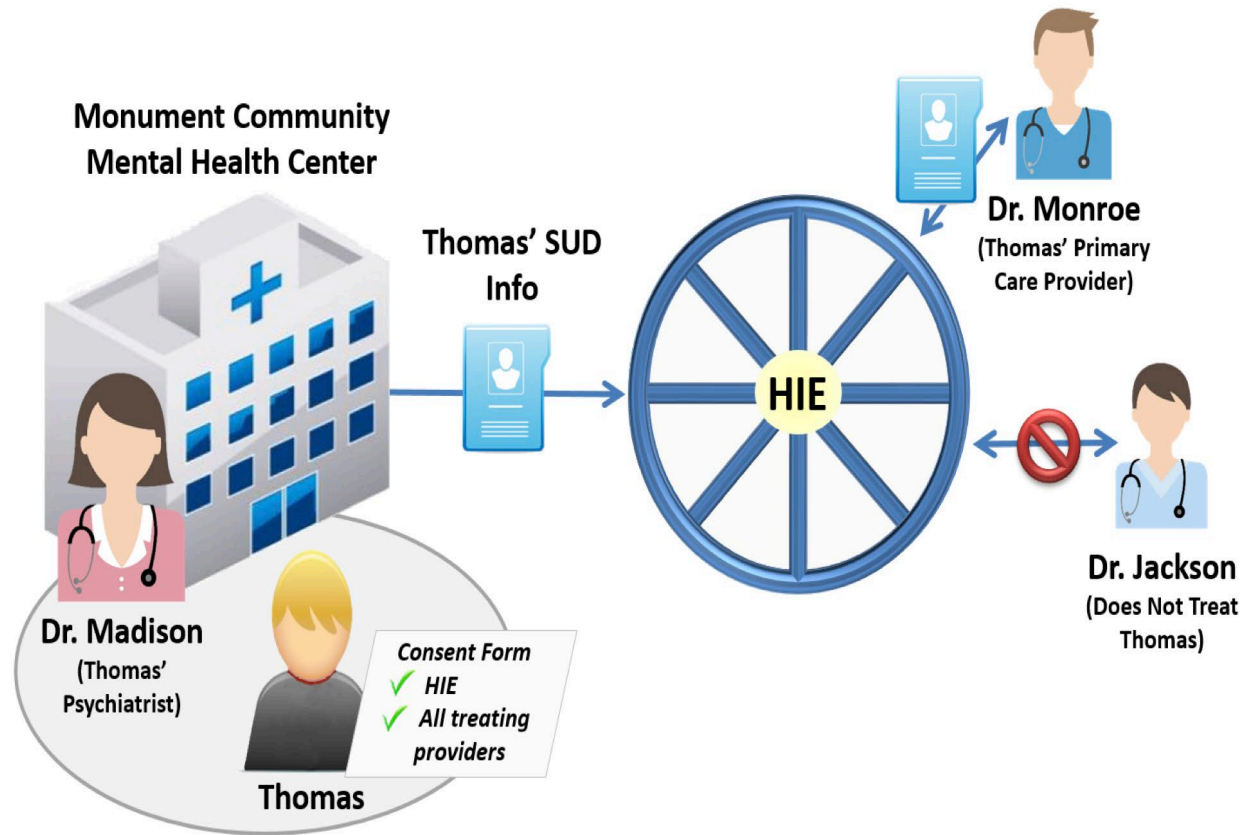


Information Sharing
among Providers

42 CFR Part 2

- Federal regulation that protects substance use disorder (SUD) health information
- Protects information held by substance use programs receiving federal assistance ("an individual or entity must be federally assisted and hold itself out as providing, and provide, alcohol or drug abuse diagnosis, treatment, or referral for treatment")
- More stringent than HIPAA, requiring specific consent for covered entities to release SUD data

42 CFR Part 2 Protections in Action



Source: SAMHSA, <https://www.samhsa.gov/sites/default/files/how-do-i-exchange-part2.pdf>

Differences between HIPAA and 42 CFR Part 2

- HIPAA allows disclosure without consent to other health care providers for certain purposes (e.g., treatment), whereas 42 CFR Part 2 requires specific consent
- HIPAA's exception for release of information for law enforcement purposes is broader than 42 CFR Part 2
- The consent requirements are more specific under 42 CFR Part 2 (e.g., designation of a specific receiving party)

42 CFR Part 2 and Surveillance

- There is no public health exception in 42 CFR Part 2 that allows for the reporting of HIV and hepatitis cases to state and local health departments **without consent**
- Only deidentified may be shared for public health purposes (patient name and identifying information redacted)

Minor Consent Laws

Allowing minors to consent to HIV treatment and prevention

Protecting confidentiality of minors' health care information

Suppressing sensitive information in payer explanation of benefits (EOBs)

Minor Consent to HIV Treatment and Prevention



HIV

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HIV Legal Landscape -

State Laws that Enable a Minor to Provide Informed Consent to Receive HIV and STD Services

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A minor is a person who is under the legal age of full legal rights and responsibilities. CDC assessed the statutes and regulations (laws) addressing a minor's legal right to provide informed consent to receive STD and/or HIV services without the consent, knowledge, or involvement of a parent or guardian, in each of the 50 states and the District of Columbia (jurisdictions). Jurisdictions have different types of laws, and the age at which the minor has the legal right to provide informed consent to receive STD or HIV services varies by jurisdiction. **State laws can:**

- **Explicitly allow a minor to give informed consent to receive STD diagnosis and treatment, and/or prevention**
- **Explicitly allow a minor to give informed consent to HIV testing, treatment, and/or prophylaxis, including pre-exposure prophylaxis (PrEP), or**
- Allow a minor to give informed consent to general health care, services, or procedures

CDC, [State Law Chart](#)

Minor Confidentiality Laws

- HIPAA generally allows a parent to have access to the medical records about his or her minor child because the parent is the child's "personal representative" (with some exceptions)
- In states that allow minors to consent to HIV treatment and prevention, the parent is no longer the child's personal representative under HIPAA and is not automatically entitled to access the record
- However, a state law mandating a parent have access to the minor's record even if the state allows a minor to consent to the service would prevail
 - For instance, some states explicitly allow or require a minor's medical record to be shared with the minor's parent or guardian without the minor's consent

Payer EOB Suppression

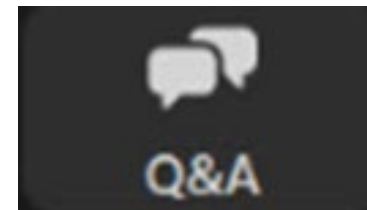
TABLE 3— State-Level Laws Protecting Minors’ Health Care Payor Information From Disclosure to Guardians: United States, 1900–2021

State	Years	Explanation of Benefits	Other Communications From Health Care Payor
Colorado	2018–2021	Y	N
Delaware	2012–2021	N	Y
Florida	1986–2021	Y	Y
New York	2016–2021	Y	Y
Washington	2001–2021	Y	Y

Source: Nelson, Kimberly M et al. “Minor Consent Laws for Sexually Transmitted Infection and Human Immunodeficiency Virus Services in the United States: A Comprehensive, Longitudinal Survey of US State Laws.” American journal of public health (1971) 113.4 (2023): 397–407. Web.

Questions?

Drop them in the Q&A down below!



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