

Data Privacy, Community Trust, and HIV Criminalization

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Disclosures

NASTAD receives grant funding from Gilead and Viiv which goes towards my salary.

Data Considerations

Data in this presentation offer a limited perspective of how systemic, social, and economic factors impact health. We recognize that racism, not race, creates and perpetuates health disparities.



To Learn More:

<https://www.cdc.gov/minorityhealth/racism-disparities>

ABOUT NASTAD

- **WHO:** A leading non-partisan non-profit association that represents public health officials who administer HIV and hepatitis programs in the U.S.
- **WHERE:** All 50 U.S. states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, seven local jurisdictions receiving direct funding from the Centers for Disease Control and Prevention (CDC), and the U.S. Pacific Island jurisdictions.
- **HOW:** Interpret and influence policies, conduct trainings, offer technical assistance, and provide advocacy mobilization for U.S. health departments.

OUR MISSION AND VISION

- **MISSION:** NASTAD's mission is to advance the health and dignity of people with and impacted by HIV/AIDS, viral hepatitis, and intersecting epidemics by strengthening governmental public health and leveraging community partnerships.
- **VISION:** NASTAD's vision is a world committed to ending HIV/AIDS, viral hepatitis, and intersecting epidemics.

HIV Criminalization

- Criminal laws targeting PWH for conduct that is legal for people who have not been diagnosed with HIV (e.g. sex)
- Laws outlining increased penalties for PWH for conduct that would be a less severe offense for others (e.g. soliciting prostitution)
- Applying any criminal law in a way that makes HIV status a necessary component of the offense (e.g. when someone's saliva is considered a "deadly weapon" solely because they have HIV)

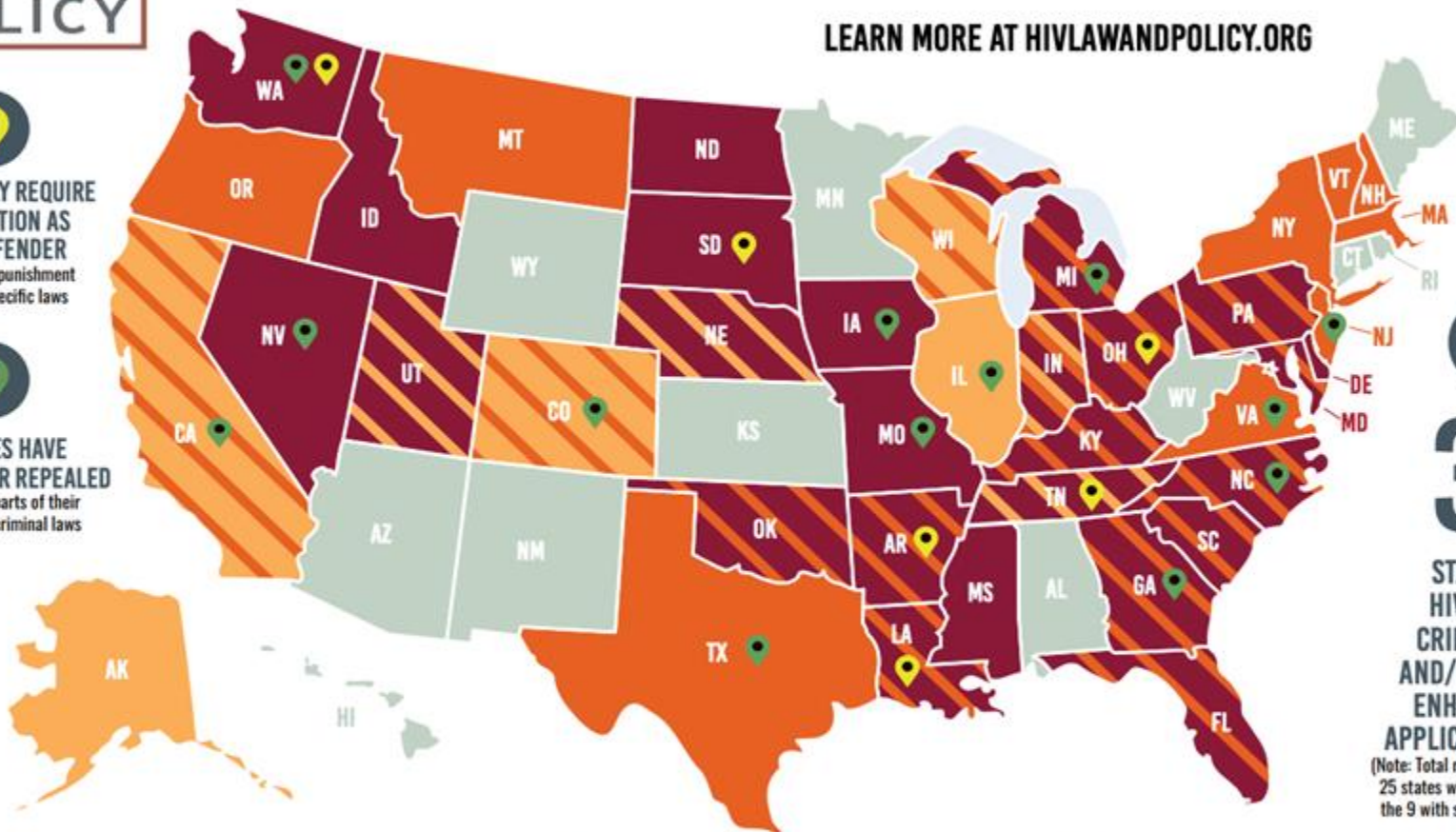
HIV CRIMINALIZATION IN THE UNITED STATES

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REFORMED OR REPEALED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.



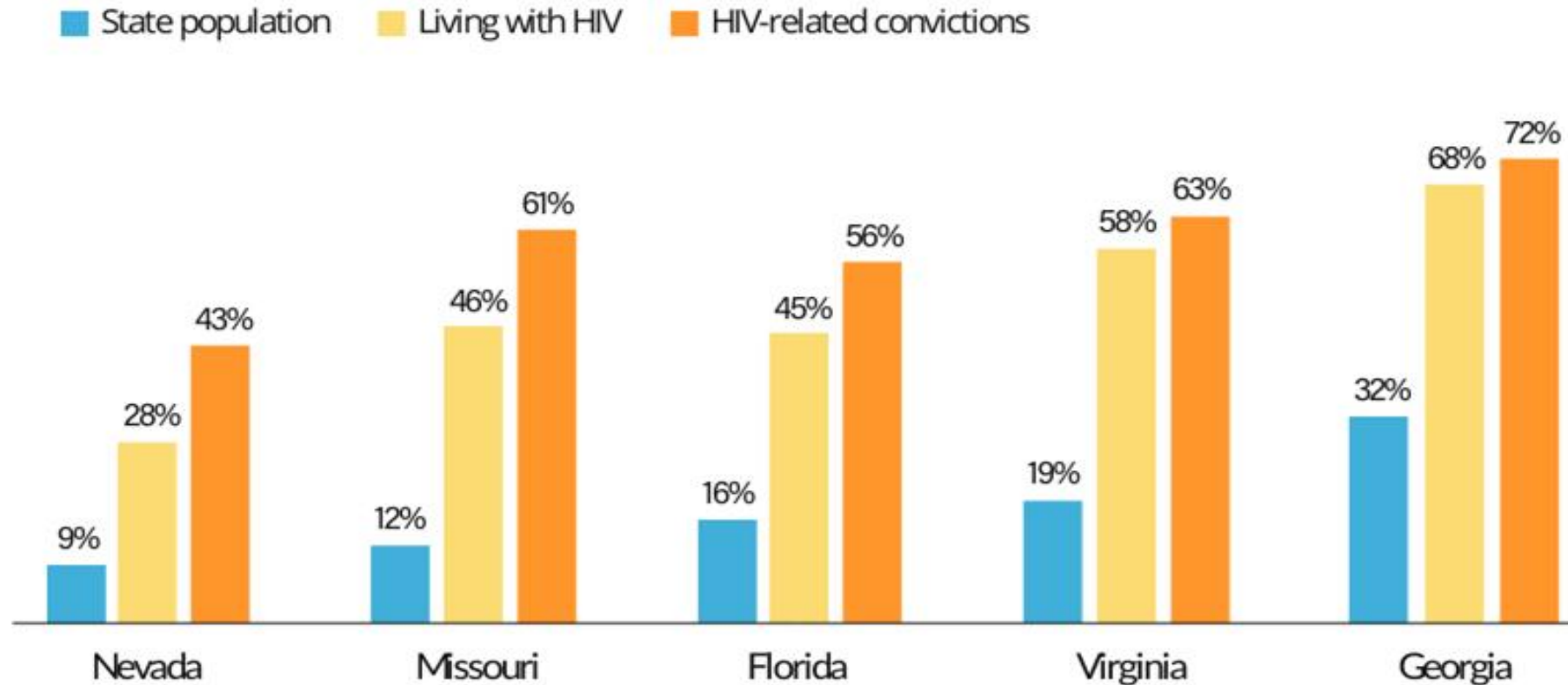
**STATES THAT HAVE PROSECUTED
PLHIV UNDER NON-HIV-SPECIFIC,
GENERAL CRIMINAL LAWS**
This number represents states with reported charges
and/or convictions for non-HIV-specific offenses,
where positive HIV status was relevant in establishing
a (non-HIV-specific) element of the offense.

Issues with Criminalization

- In many states the only defense to prosecution is disclosure, but proving disclosure in court is impossible
- Most states do not require HIV transmission to trigger prosecution or proof that someone acted with a specific intent to transmit HIV
- In most states, “transmission risk” is largely irrelevant
- Vast majority of arrests and prosecutions in some states target sex workers, including those by law enforcement-organized “sting” operations
- Racist bias in arrests and prosecutions clearly shows HIV criminal laws are selectively enforced overwhelmingly on Black women and men

Racial Impact of HIV Criminalization

Black Americans are more likely to be **convicted** of HIV-related crimes.



Case Study: Nevada

2019 Senate Bill (SB) 284

- This bill requires the Task Force to conduct a comprehensive examination during the 2019-2020 legislative interim of the statutes and regulations in this State related to the criminalization of exposing a person to the human immunodeficiency virus (HIV).
- Requires a report of said examinations to be provided to the Governor's Office and Legislative Counsel Bureau
- Within the legislation it requires administrative support from the Division of Public & Behavioral Health (DPBH) Office of HIV
 - There was administrative support from an Administrative Assistant, program staff, including the Health Program Manager II

2021 SB 275

- Primary Sponsor: *Senator Dallas Harris*
- Multifaceted bill that deals with several topics:
 - 1) mainly quarantine around communicable diseases,
 - 2) makes various revisions to terminology referring to the human immunodeficiency virus, and
 - 3) continues the Task Force
- With the recreation or continuation of the Advisory Task Force on HIV Modernization, the Office of HIV was again tapped with providing administrative assistance to the Task Force

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Case Study: Nevada

- Community and Health Department worked together
 - The Cupcake Girls: Provides confidential support to those involved in the sex industry, as well as trauma-informed outreach, advocacy, holistic resources, and referral services to provide prevention and aftercare to those affected by sex trafficking
 - Nevada Legal Services: Ryan White Part B funded subrecipient, provided printed materials (in-kind) that supported the various aspects of what was repealed in SB 275
 - DPBH and their work around Sexual Survivor Bill of Rights
 - Signs of HOPE and their work around the repeal of sexual assault outlined in Nevada Revised Statute 441A.320 and guidance

SB 275

- SB 275 repeals an HIV-specific criminal offense, and replaces it with a misdemeanor offense in the public health code that:
 - requires intent to transmit, conduct likely to transmit, and actual transmission;
 - applies to intentional transmission of any communicable disease (as defined in NAC 441.040 to include 78 communicable diseases);
- Other changes to Nevada's law include:
 - a statement in the public health code that "the spread of communicable diseases is best addressed through public health measures, rather than criminalization";
 - repeal of the category B felony for engaging in or soliciting prostitution after a positive HIV test;
 - repeal of a provision permitting confinement of persons with AIDS and removal of many stigmatizing references to AIDS in the public health code;
 - amendments to provisions regarding the duties of individuals with communicable diseases and public health officials' authority to order testing, treatment, isolation, or quarantine.

Understanding the Legal Framework for HIV Data Protection

Consent and HIV testing

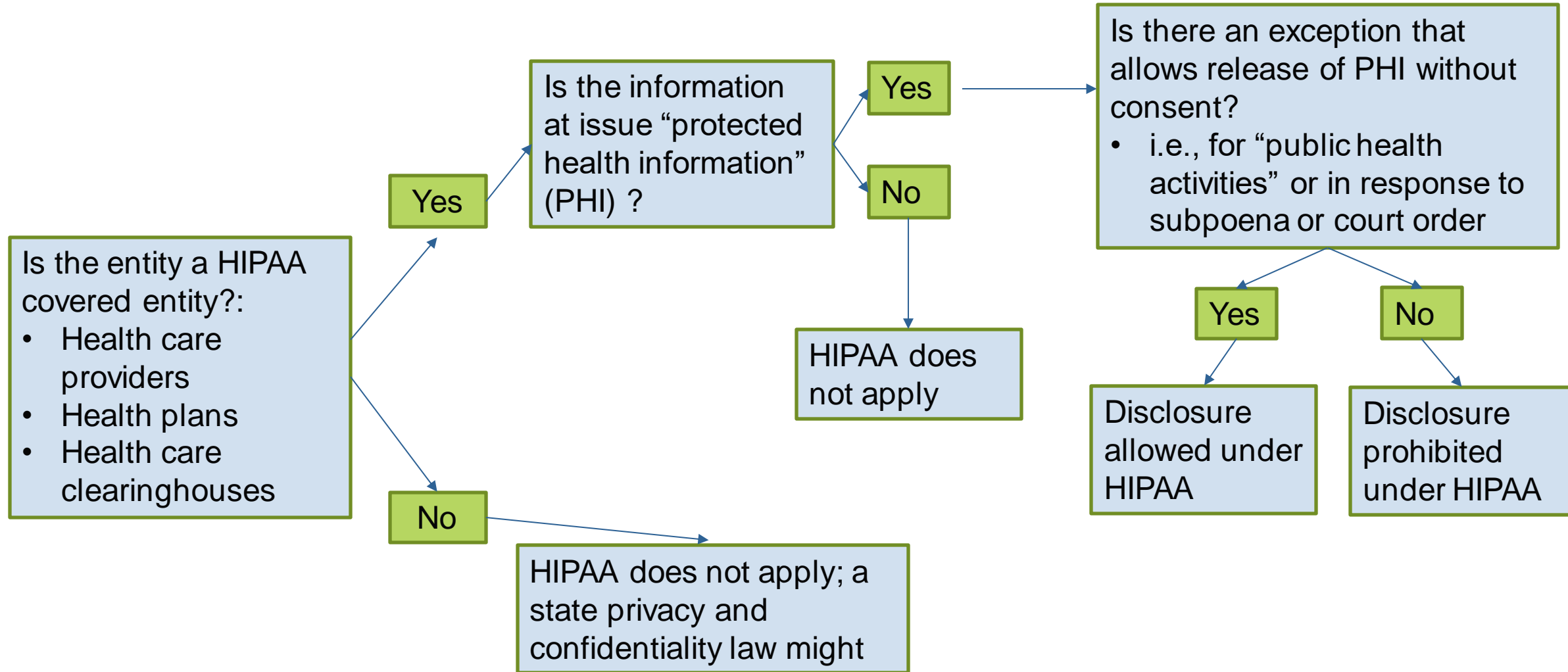
Consent to HIV testing

- Governed by laws prohibiting assault and battery
- State law may vary about opt in/opt out testing

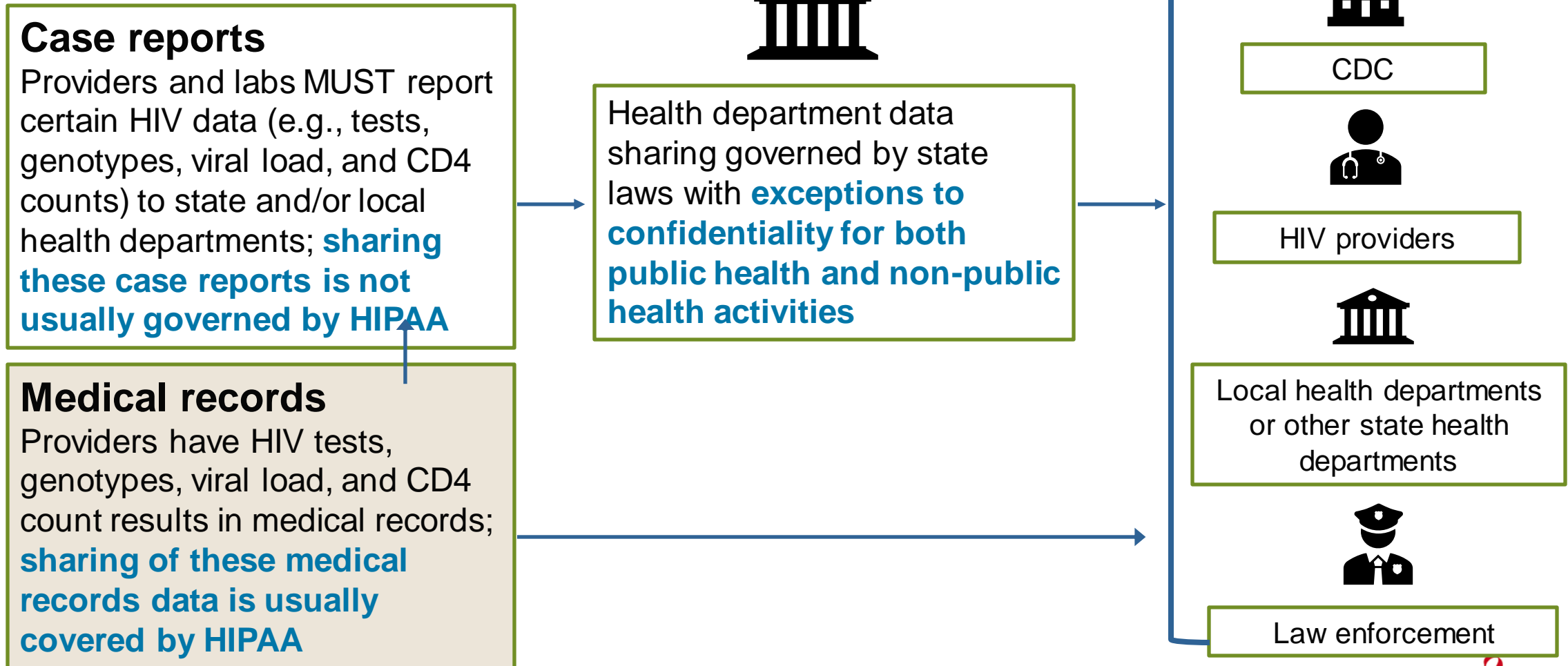
Consent to share data

- Separate from consent to undergo medical procedure
- Governed by HIPAA and/or state law
- Consent often not needed for sharing of HIV surveillance data

The Role of the Health Insurance Portability and Accountability Act (HIPAA)

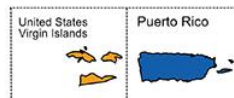
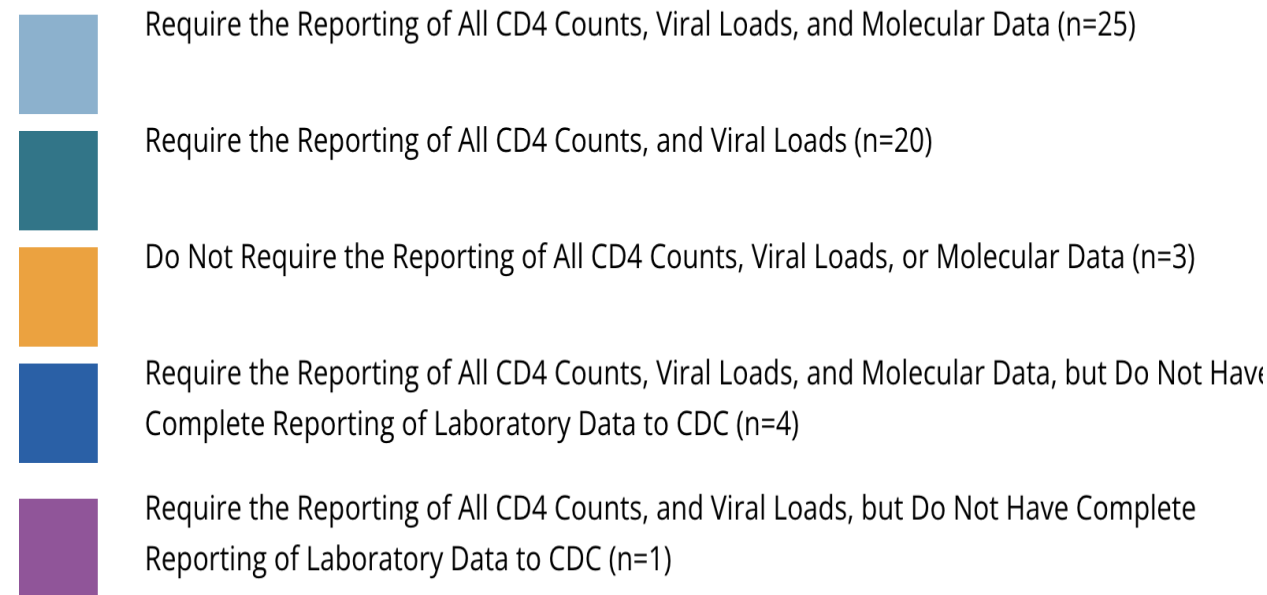
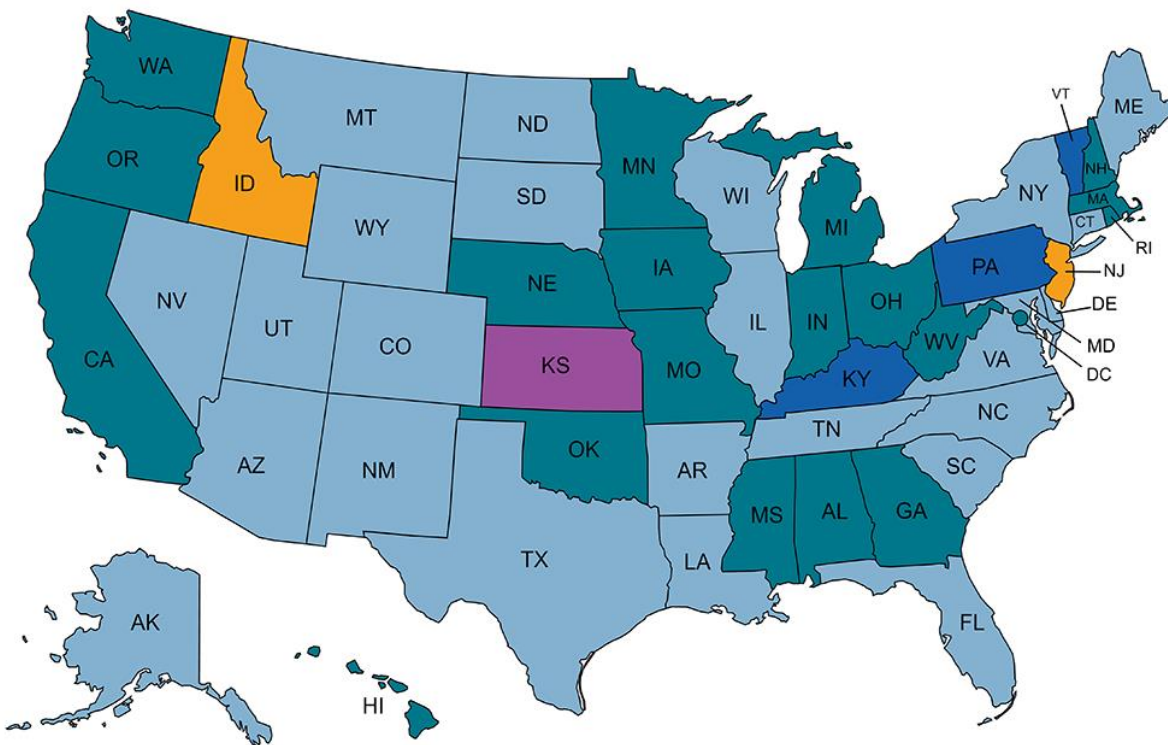


HIPAA or State Law (or Both!)?



State Public Health Privacy Laws

- States have laws on the books requiring certain conditions to be “reported” to state and/or local health departments (note: many states that do not explicitly require sequence data to reported interpret broader reporting laws to include this data)



Legal Framework for HIV Surveillance Data

- HIV data reported to state and local health departments is CONFIDENTIAL and cannot be released without consent,

EXCEPT...

- To address a public health crisis or emergency
- For HIV treatment purposes
- If specifically authorized in state or federal law

Over time, the purpose and use of HIV surveillance data has changed, with uses expanding beyond monitoring the epidemic to implementing prevention interventions and responding to outbreaks

What New Data Privacy Issues Does Cluster Detection and Response (CDR) Present?

HIV Criminalization Laws and CDR

- The concern surrounding CDR data centers on potential use of sensitive data for non-public health purposes (i.e., to aid in prosecutions under state HIV criminalization laws)

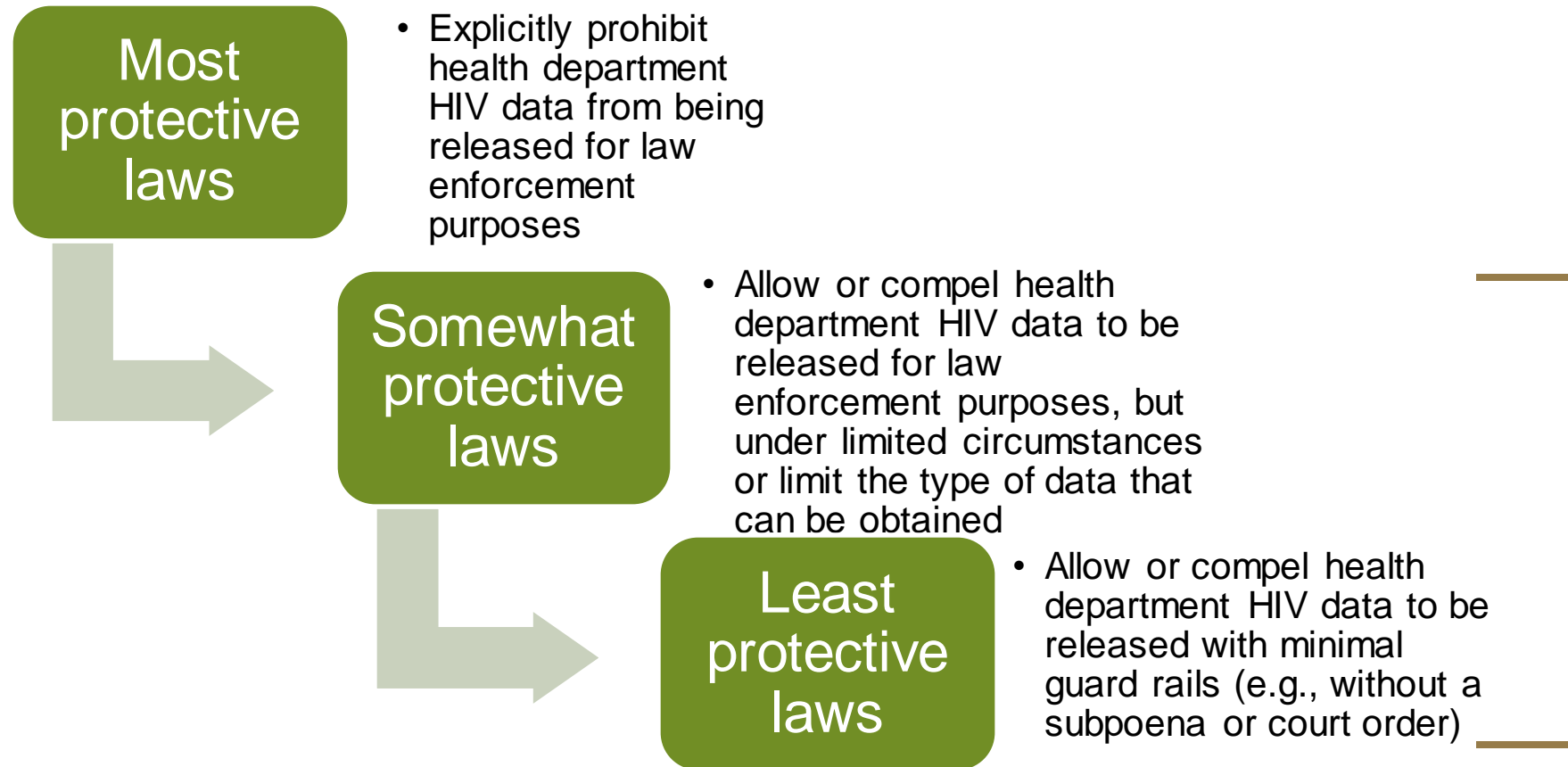
Excerpt from 2022 PACHA Resolution on Molecular HIV Surveillance (MHS)

“These safeguards must include concrete firewalls protecting public health research and surveillance data, including but not limited to MHS-related data, from access by law enforcement, corporations, criminal legal courts, immigration enforcement, and youth detention and protective services systems.”

Considerations for Health Department HIV Data Release for Law Enforcement Purposes

- 1) Do statutes and regulations protect health department HIV data from being released?
- 2) Are public health legal counsel willing and able to interpret broad or vague statutes in ways that are most protective of health department HIV data?
- 3) Is health department HIV data relevant to prosecutions under HIV criminalization statutes?

State Laws Vary in How Protective They Are of Health Department HIV Data



Ways That Health Departments Can Protect HIV Surveillance Data (Including CDR Data)

- State laws and regulations can be amended to limit or prohibit health department sharing of HIV data for non-public health purposes (e.g., prosecution of HIV criminalization statutes)
- Health departments can work with public health legal counsel to ensure a protective approach to interpretation of broad or vague statutory language
- Health departments can discuss the data privacy and confidentiality concerns of the communities they serve and provide information on safeguards that are already in place for HIV surveillance data

Acknowledgment

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