### HIV Criminalization Legal and Policy Assessment Tool

Legal, Health, and Equity Considerations Related to HIV Criminalization, Public Health Surveillance, and Data Privacy





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Content Warning: This document addresses subjects that may be upsetting such as racism, stigma, discrimination, violence, the criminal legal system (e.g., the criminalization of people with HIV and criminal offenses involving sexual assault), and violations of individual liberties — many of which have been perpetrated ostensibly for the purposes of public health. We are committed to the notion that confronting even the most disturbing parts of history is critical to correcting social injustices in the future by guaranteeing constitutional and human rights, rebuilding trust with the communities served by public health practitioners, and ensuring that health equity is centered in all of our public health activities, including HIV prevention and response.

Specific laws and policies referenced in this document are current as of June 15, 2021.

### PURPOSE AND HOW TO USE THIS ASSESSMENT TOOL

This assessment tool is designed to help individuals and organizations, including state and local health departments, to assess the extent to which a jurisdiction's laws and regulations impede HIV surveillance, facilitate privacy breaches, or criminalize HIV infection and related risk behaviors.

The tool enables an objective assessment of a jurisdiction's laws, regulations, and executive orders that control HIV surveillance and prevention.

Public health professionals, policy makers, legal counsel, and partners can use the tool to consider how HIV-related laws and policies in their jurisdiction, including HIV criminalization laws, may inhibit or advance health equity and to facilitate conversations among stakeholders. The tool can also help identify opportunities to strengthen legal and policy protections for people with HIV – protections that are also likely to benefit public health more broadly – by aligning them with evidence-based best practices.

The tool is divided into three main sections: an introduction and background section, a legal and policy assessment section, and a section containing appendices.

### Introduction and Background

The first section provides important background information about HIV and efforts to address HIV, covering the following topics:

- The Criminalization of Conduct by People with HIV
- The Role of Data: Public Health Surveillance, Privacy, and HIV Criminalization
- Structural Inequities and HIV-Related Health Disparities
- The Effects of HIV Stigma
- Legal Landscape
- State and Local Health Department Policies and Practices

#### Legal and Policy Assessment

The second section is the core of the assessment tool. This section identifies key questions and considerations for stakeholders assessing relevant laws, policies, and practices in their own jurisdiction. These questions can inform public health professionals, policy makers, and partners as they consider how HIV-related laws and policies in their jurisdiction may benefit or inhibit health and equity; facilitate conversations among stakeholders; and help identify opportunities to strengthen laws and policies by aligning them with evidence-based best practices.

The legal and policy assessment section is broken up into four subsections:

- Health Data Privacy Laws and Policies
- State Public Health Surveillance and HIV Testing Laws
- HIV Criminalization Laws
- Considerations and Resources for Implementation and Enforcement

The content within each subsection is organized to progress from assessing broader laws and policies (e.g., laws addressing confidentiality of identifiable health information generally) to assessing more narrowly applicable laws and policies (e.g., laws addressing confidentiality of HIVrelated health information specifically). In some instances, multiple laws may apply to the same issue (e.g., HIVrelated health information may be subject to confidentiality protections that apply to general heath data as well as confidentiality protections specific to HIV data). Additionally, because these subsections are modular - meaning that some

users may read and complete the assessment tool from start to finish, while others may use only individual sections of the tool – multiple subsections may include similar or overlapping content.

The legal and policy assessment subsections also include state statutory and regulatory examples. These examples are excerpts from much longer, more complex legal structures and are intended only to illustrate how different states address various legal and policy considerations. The substantive effect of the excerpted language will depend on the broader regulatory context in which it operates and the way that states implement and enforce relevant laws and policies. For these reasons, inclusion of an example does not represent an endorsement of the specific approach or language employed, nor should the examples be used to craft legislative or regulatory language for a jurisdiction. Instead, the statutory and regulatory examples should be used only to help understand key policy design considerations and inform an independent assessment of a jurisdiction's legal and policy landscape.

#### **Appendices**

The final section is a series of appendices that offer additional resources and guidance:

- Appendix I: Key Terminology and Abbreviations
- Appendix II: Additional Resources
- Appendix III: Finding the Law
- Appendix IV: Assessment Questions

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# INTRODUCTION AND BACKGROUND



Human immunodeficiency virus (HIV) is a virus that attacks the body's immune system. As of June 2021, approximately 1.2 million people have HIV in the United States (US), and the virus has claimed the lives of more than 700,000 people in the United States since 1981.

The Centers for Disease Control and Prevention (CDC)<sup>i</sup> estimates of annual HIV infections in the United States show hopeful signs of progress in recent years. CDC estimates show that new HIV infections declined 8% from 2015 to 2019, after a period of general stability.<sup>ii,4</sup> However, injection drug use has fueled recent HIV outbreaks.<sup>5</sup> Roughly 14% of people with HIV in the United States are not aware of their infection,6 and more than one-third (38%) of new HIV infections are transmitted by people who are unaware of their HIV status? Moreover, CDC reports that only 63% of people with HIV currently receive HIV-related medical care and almost half of people with HIV are not virally suppressed (having very low levels of HIV in the body),8 thereby increasing the risk of transmitting HIV to others. Substantial HIV-related health inequities also persist across racial, socioeconomic, and other demographic groups.9

The scientific understanding of and strategies to prevent, identify, and treat HIV have advanced considerably since the first case was reported in 1981, resulting in improved health outcomes for people with HIV and effective means to prevent HIV transmission.<sup>10</sup>

The introduction of effective antiretroviral therapy (ART), for example, has extended the life expectancy of people with HIV.11 A person with HIV who takes HIV medicine as prescribed and gets and stays virally suppressed or undetectable can stay healthy and has effectively no risk of sexually transmitting HIV to HIV-negative partners. Indeed, evidence shows that people who achieve and maintain viral suppression via ART cannot transmit HIV to their sexual partners.13 Pre-exposure prophylaxis (PrEP), an antiretroviral medication that when taken as prescribed can reduce the risk of HIV infection through sex by about 99% and from injection drug use by at least 74%,14 and post-exposure prophylaxis (PEP) can prevent HIV infection when taken within 72 hours of a potential exposure to HIV.15

These advancements offer an unrivaled opportunity to end new HIV infections, improve the health of people with HIV, and reduce or eliminate HIV-related health disparities. However, laws and policies that do not keep pace with these medical and scientific advancements, including those that criminalize conduct by

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OF NEW HIV INFECTIONS ARE TRANSMITTED BY PEOPLE WHO ARE UNAWARE OF THEIR HIV STATUS.

63%

OF PEOPLE WITH HIV RECEIVE HIV-RELATED MEDICAL CARE.

i CDC provides support for state, local, territorial, and tribal health officials to address and improve gaps in knowledge and medical care for people with HIV, as well as to reduce HIV-related health inequities. The National Center for HIV, Viral Hepatitis, STD, and TB Prevention's website offers additional information.

ii This report uses public health surveillance data from 2019 rather than 2020 because data from 2020 may not be reliable due to the massive disruptions in the health care system caused by the COVID-19 pandemic.

people with HIV, may provide little to no public health benefits or even actively cause harm. These potential harms include delaying or avoiding HIV testing and treatment as well as exposing individuals who have been prosecuted under HIV criminalization laws to additional health risk factors associated with the criminal legal system. Fully realizing the health and equity benefits of scientific advancements and efforts such as the Ending the HIV Epidemic in the US (EHE) initiative<sup>16</sup> requires removing barriers through the evaluation and modernization of laws and policies. 17,18

State, tribal, local, and territorial governments can take several approaches to support equitable HIV policy environments. Laws and policies frequently single out HIV for disparate treatment relative to other communicable diseases and public health issues – often to the detriment of people with HIV. Criminal laws are often used to prosecute conduct when HIV transmission does not occur – and even when HIV transmission is unlikely or impossible – and can lead to severe prison sentences. Moreover, not only does HIV disproportionately affect Black people and LGBTQ+ people, but HIV criminalization laws are often disproportionately enforced against these same populations.<sup>19,20,21</sup> Policy makers, public health officials, the legal system, and others continue to treat HIV differently than other communicable diseases, which leads to inequities and stigma. The impact of "HIV exceptionalism" is broad, making it vital for partners to work toward having a more equitable, evidencebased approach to addressing HIV and ending laws that criminalize the conduct of people with HIV.

Because the criminalization of conduct by people with HIV is often embedded across several sometimes-contradictory areas of law, comprehensive legal and policy efforts are needed to fully protect people with HIV from being unfairly and unjustly exposed to stigma, discrimination, and criminal prosecution. Therefore, it is vital that public health practitioners, policy makers, partners, and others involved in HIV prevention and response fully evaluate and understand their state's legal landscape when it comes to HIV criminalization, public health surveillance, and health data privacy. Based on this evaluation and understanding, states can consider actions to strengthen public health protections and reform or repeal laws and policies, like HIV criminalization laws, that result in harmful, unjust effects on people with HIV.iii

Fully realizing the health and equity benefits of scientific advancements requires removing barriers through the evaluation and modernization of laws and policies.

## The Criminalization of Conduct by People with HIV

HIV criminalization refers to laws that criminalize conduct or increase penalties for unlawful conduct based, at least in part, on a person's HIV status. These laws include, for example, laws criminalizing people with HIV who engage in sexual activities without disclosing their HIV status and obtaining the consent of their sexual partners or who engage in specified nonsexual conduct such as sharing

The comparative benefits and drawbacks of reforming versus fully repealing certain laws and policies depends on the specific type of law or policy at issue, the characteristics of the law or policy, and the broader legal and political landscape in the applicable jurisdiction. Due to the varied and context-specific considerations, recommendations on approaches for a particular law and jurisdiction are beyond the scope of this resource.

syringes, biting or spitting on another person, or donating blood or organs. HIV criminalization also includes laws imposing criminal penalties on the potential or actual transmission of communicable diseases (including HIV) without specific mention of HIV. And HIV criminalization includes the prosecution of people with HIV, based on the person's HIV status, under more general criminal laws such as those defining assault, battery, reckless endangerment, attempted murder, and murder, as well as the imposition of more severe penalties for criminal violations based on a person's HIV status (e.g., in laws criminalizing people who engage in sex work). These laws are opposed by a variety of public health organizations, including the National Alliance of State and Territorial AIDS Directors (NASTAD) and the Council of State and Territorial Epidemiologists.<sup>22,23</sup> (See Appendix I for additional information on the meaning of common terms referenced in these laws.)

In 1986, Florida, Tennessee, and Washington enacted the first state laws specifically designed to criminalize the conduct of people with HIV.24 As of 2021, laws that criminalize exposing another person to HIV exist in nearly three-fourths of US states (35) and territories.<sup>25</sup> The overwhelming majority of state HIV criminalization laws predate the current scientific understanding of HIV transmission risk and the widespread availability of HIV prevention measures; 22 states enacted their first HIV criminalization laws in the period from 1986 through 1990, and almost all states (29) adopted such laws before 2000.26 The uptick in the adoption of HIV criminalization laws was driven, in part, by a provision in the Ryan White Comprehensive AIDS Resources Emergency Act of 1990

that conditioned certain federal grant funding for states on the existence of state criminal laws "adequate to prosecute any HIV infected individual" for conduct such as engaging in certain sexual activity, sharing needles, or donating blood, semen, or breast milk.27 Congress repealed this requirement in 2000.28 Additionally, from 2008 through 2019, more than half of states used general criminal laws to prosecute people with HIV based on their HIV status, including laws defining assault, battery, reckless endangerment, attempted murder, and murder.29

HIV criminalization laws and the use of general criminal laws to prosecute people with HIV — which proliferated against a backdrop of widespread fear of and stigma against people with HIV — were intended to regulate and penalize the conduct of people with HIV.30 Although ostensibly a means of encouraging people with HIV to avoid conduct that risks transmitting the virus and to disclose their infection status to sexual partners, HIV criminalization laws have proven ineffective and even counterproductive to public health policies.31 Studies show that HIV criminalization laws do not reduce infection rates but, instead, further stigmatize people with HIV and may discourage people from engaging in evidence-based prevention and harm reduction practices. (See The Effects of HIV Stigma on Health, Disclosure of HIV Status, and Risk Behavior of Homeless and Unstably Housed Persons Living with HIV<sup>32</sup> for additional information on how stigma negatively affects public health and how HIV criminalization laws can reinforce stigma against people with HIV.)33,34,35

People with HIV are often unaware that HIV criminalization laws exist in their state, or they lack knowledge 22 STATES ENACTED THEIR FIRST HIV CRIMINALIZATION LAWS IN THE PERIOD FROM 1986 THROUGH 1990.

more than half

OF STATES USED GENERAL CRIMINAL LAWS TO PROSECUTE PEOPLE WITH HIV BASED ON THEIR HIV STATUS, INCLUDING LAWS DEFINING ASSAULT, BATTERY, RECKLESS ENDANGERMENT, ATTEMPTED MURDER, AND MURDER.

about the specific application and requirements of such laws.36 In one study, nearly two-thirds (63%) of survey participants did not know whether their state had an HIVspecific criminalization law, and nearly half (48%) "did not know what behaviors were prohibited without prior [disclosure of HIV status] to partners."37 Moreover, research shows that knowledge of HIV criminalization laws is not associated with outcomes such as increased condom use, HIV status disclosure, or sexual abstinence. suggesting that such laws do not advance HIV prevention efforts.38,39

HIV criminalization laws also apply only when a person knows their HIV status. Individuals aware of these criminalization laws may, as a result, avoid seeking HIV testing, receiving needed treatment services, or taking other actions that would inform the person of their HIV status, because knowing their HIV status could increase their potential exposure to criminal prosecution.40 Moreover, HIV criminalization laws often are based on misinformation and do not reflect modern science - for example, criminalizing behavior that poses little to no risk of transmission, such as biting or spitting, and failing to consider viral suppression or preventive measures that reduce or eliminate transmission risk, such as PrEP or condom use.41 Many HIV criminalization laws also criminalize conduct regardless of intent or actual transmission.42,iv

Several states have recently sought to repeal, reform, or modernize their HIV criminalization laws. The scope of these reforms varies. They include eliminating certain crimes entirely (e.g., laws criminalizing conduct with negligible transmission risk such as biting or spitting); limiting prosecution to individuals who specifically intend to transmit the virus; requiring actual transmission; and requiring consideration of factors ranging from whether an individual is virally suppressed to the use of preventive measures such as PrEP and condom use. Unfortunately, efforts to reform state HIV criminalization laws have, at times, resulted in the expansion of which activities or conduct are defined as criminal offenses, such as extending the law to apply to communicable diseases other than HIV. For example, in 2014, Iowa simultaneously repealed their HIV-specific criminalization law and adopted a new, more general contagious disease transmission law that criminalizes people with hepatitis, tuberculosis, meningococcal disease, or HIV.43,vi

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iv For additional information about intent and transmissibility, please refer to pp. 40–41.

v Specific terminology in laws and policies varies among jurisdictions and includes *communicable*, *infectious*, *contagious*, or some combination thereof. This assessment tool uses the term *communicable*, except when quoting or summarizing specific laws and policies, in which case we use the actual language of the law or policy.

vi The reformed lowa law included several important changes to reduce unjust prosecutions, such as limiting the most severe penalties to people who specifically intend to transmit a contagious or infectious disease, precluding prosecution when a person takes measures to prevent transmission, and eliminating sex offender registration. However, the extension of the law to other diseases such as hepatitis and tuberculosis highlights the need to address the criminalization of infectious diseases more generally.

#### **CASE STUDY**

#### The Inequitable Effects of HIV Criminalization

In October 2013, Missouri officials arrested Michael Johnson, ia Black man and star college athlete, for allegedly transmitting HIV to two people and exposing four other people to the virus. Although Johnson engaged only in consensual sexual conduct, Missouri nevertheless filed six charges against Johnson for violating the state criminal HIV transmission and exposure statute. As it existed at the time of Michael Johnson's prosecution, this state law made it unlawful for a person who knows they have HIV to "[a]ct in a reckless manner by exposing another person to HIV" by engaging in specified conduct, including sexual activity, without the knowledge and consent of that person to be exposed to HIV. Originally adopted in 1988, the law not only singled out HIV for disparate treatment relative to other communicable diseases but also predates modern scientific understandings of HIV, HIV transmission, and the availability of safe and effective prophylaxis and treatment options.

At his trial, the state did not produce evidence proving that Johnson intended to transmit HIV or even that he was the source of the other persons' HIV infections.<sup>47</sup> Prosecutors in the case also reportedly used homophobic and racially charged language, including through the selection of jurors with expressed prejudices against people who identify as gay.<sup>48,49</sup> Johnson was sentenced to 30 years in prison – a longer sentence than the average for second-degree murder in Missouri – after the jury convicted him on five of the six charges. A state appeals court later found that Johnson's trial was "fundamentally unfair," and in 2019, he was released on parole.<sup>50</sup> Michael Johnson's case highlights the potential use of HIV-related health information to target people with HIV. Use of HIV criminalization laws against marginalized communities can exacerbate current inequities in HIV – most notably among BIPOC communities. This case underscores the importance of safeguarding HIV-related data by ensuring that data are directed toward improving public health and reducing HIV-related harm rather than exposing individuals to additional risk factors such as stigma, trauma, and involvement in the criminal legal system.

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Michael Johnson's case is not unique. Every year across the country, numerous people with HIV face criminal prosecution because of their diagnosed HIV infection. We chose to include Michael Johnson's story because of his public advocacy of HIV prevention and the need to reform HIV criminalization laws. We respected the privacy of other individuals with similar experiences who have not chosen to publicize their stories, to prevent additional trauma for them.

# The Role of Data: Public Health Surveillance, Privacy, and HIV Criminalization

Public health surveillance is defined as "the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event."51 HIV surveillance, a specific type of public health surveillance, seeks to "collect[], analyze[], and disseminate[] information about new and existing cases of HIV,"52 as well as information related to HIV prevention and treatment such as HIV testing, PrEP, and HIV-related medical care (e.g., ART).53 Local, state, and federal surveillance efforts form the backbone of the nation's public health response to HIV.viii Data collected through such surveillance allow health officials to identify infections at early stages, detect and respond to clusters and outbreaks, refer and link individuals to treatment in a timely fashion, direct resources to where they are most needed, monitor overall trends in HIV transmission and treatment,ix and evaluate how laws and policies affect HIV-related health outcomes through legal epidemiology.x

Despite the demonstrated benefits of comprehensive HIV public health surveillance activities, the collection and use of individuals' health data can raise privacy concerns. Although federal, state, and local laws and policies regulate when, how, and by whom HIV-related public health data can be used and disclosed, the scope and applicability of such laws and policies, as well as the degree of protection they afford against the potential misuse of HIV-related data, vary considerably. The relevant privacy considerations also vary based on the level of government in question, with states and localities generally receiving identifiable public health data, while the federal government, including CDC, receives only de-identified information.

Preventing the incarceration and marginalization of people with HIV while ensuring public health officials' ability to effectively collect, use, and share HIV-related public health data requires careful consideration of the laws and policies applicable to HIV surveillance, criminalization, and data privacy. Understanding, assessing, and, where needed, modernizing these laws and policies is vital to addressing HIV.<sup>54,55</sup>

## Sources of HIV-related health information that may be used in HIV-related prosecutions (non-exhaustive)

- Health care provider records
- Other medical records (e.g., insurance, health information exchanges, all-payer claims databases)
- State, local, and territorial health departments
- Federal health agencies (de-identified data)
- Law enforcement officials (e.g., prosecutors)
- Institutional settings (e.g., criminal legal system)
- Researchers (generally de-identified data)
- School and employment records
- Service providers (e.g., syringe service programs)
- Individuals (e.g., persons who receive a partner notification)

viii For additional information about HIV surveillance, see CDC's HIV Surveillance Overview website at cdc.gov/hiv/statistics/surveillance.

ix For example, "HIV case surveillance activities allow jurisdictions to monitor HIV disease progression and utilization of care services through the ongoing collection of data on laboratory test results (viral load and CD4 cell counts), opportunistic infections and illnesses, and vital status." <a href="mailto:cdc.gov/hiv/statistics/surveillance/systems">cdc.gov/hiv/statistics/surveillance/systems</a>

x Legal epidemiology is the scientific study and deployment of law and policy as a factor in the cause, distribution, and prevention of disease and injury in a population. Legal epidemiology seeks to understand how laws (e.g., constitutions, statutes, regulations, judicial opinions) and policies (e.g., written statements of a public agency's or organization's position, decision, or course of action) are understood, implemented, and enforced.

### HIV Cluster and Outbreak Detection and Response

HIV clusters are groups of people who are experiencing rapid HIV transmission.<sup>56</sup> HIV cluster and outbreak detection and response identifies communities affected by rapid HIV transmission so that public health agencies can identify where HIV prevention and treatment services and programs are urgently needed and provide them.<sup>57</sup> One way that clusters or outbreaks are identified involves analyzing genetic sequences of the virus, known as *molecular HIV data*, that result from routine tests performed by health care providers to assess which HIV treatment regimens will be most effective for a particular individual. Molecular HIV data analysis examines the genetics of the virus, not the person with HIV, and the genetic sequences are not unique to individuals.<sup>58</sup>

Public health uses molecular HIV data to identify clusters and outbreaks and tailor and focus services for the people in the network, addressing gaps in services, helping to bring HIV prevention and care to people who need it, and preventing transmission to others. These data can also be used to examine the effects of HIV prevention strategies and track broader HIV trends at local, state, and national levels. The widespread collection of molecular HIV data and the routine use of such data to identify clusters and outbreaks are relatively new. Beginning in 2018, the collection and use of molecular HIV data became a required activity for CDC-funded HIV programs in state and local health departments.

Some stakeholders, including some people with HIV and HIV advocacy organizations, have expressed ethical and privacy concerns about the collection and use of molecular HIV data such as the potential use of HIV molecular data to criminally prosecute people with HIV.<sup>60</sup> The HIV molecular data collected by health departments alone is insufficient to prove that a person transmitted HIV to another person, and the objective of public health efforts is not to identify the direction of transmission but rather to detect networks of people who may benefit from prevention and treatment services. Nevertheless, there may be remaining concerns about the potential use of molecular HIV data as one piece of evidence in legal proceedings,<sup>61,62</sup> and these concerns could be amplified by judges and juries that may not understand the scientific limitations of public health data, including molecular HIV data.

The availability of molecular HIV data for use in HIV cluster and outbreak detection and response is vital to efforts to reduce HIV transmission and promote the effective, equitable distribution of prevention and treatment resources. CDC has already implemented robust privacy and data security protections for HIV data, including molecular HIV data, and requires state and local health departments to comply with strict data security standards as a condition of CDC HIV surveillance funding. (The section *Health Data Privacy Laws and Policies* later in this document provides additional information about the legal regime for data confidentiality, including how state laws affect confidentiality protections.) Public health professionals can help alleviate any outstanding concerns about the collection and use of molecular HIV data for public health purposes by continuing to build on these existing protections, including through the assessment and strengthening of data privacy protections at state and local levels.

#### **CASE STUDY**

### Effective Use of Public Health Data

In 2018, public health surveillance data showed a rapid increase in new HIV diagnoses among people who inject drugs in one region in North Carolina.63 Public health officials investigated this increase in HIV cases using a range of proven approaches including interviewing, contact tracing, and the use of molecular HIV data to assess the timing and scope of transmission.64 These efforts identified 177 individuals who had potentially been exposed to HIV, allowing public health officials to offer testing for HIV, hepatitis B, hepatitis C, and syphilis, as well as to refer and link individuals with newly diagnosed cases to appropriate medical care. 65,66 Moreover, molecular analysis "established that the timing of [the] outbreak was [close] to the diagnoses of [an] original seven [epidemiologically linked] cases."67 In effect, this analysis demonstrated that HIV public health surveillance efforts and subsequent interventions "detected a[n] [HIV] cluster in its early stages and prevented the small number of cases from becoming a more widespread outbreak."68 This case study demonstrates how the availability of complete, accurate, and timely HIV data, including data collected through HIV surveillance activities, is vital to effective HIV prevention and response efforts.

## Structural Inequities and HIV-Related Health Disparities

Inequities in the social, structural, and political determinants of health – income inequality, housing insecurity, lack of access to health care and educational opportunities, and structural discrimination and racism, among others – have resulted in HIV-related health disparities.<sup>69</sup>

Many communities of color are disproportionately affected by HIV, with Black and Latinx communities accounting for a disproportionate share of new HIV diagnoses relative to their population size. In 2019, Black people constituted 13% of the US population but accounted for 45% of new HIV diagnoses and 16.1% of deaths among people with HIV.70,71 Similarly, in 2019, people from the Latinx community accounted for 21.5% of new HIV diagnoses despite constituting only 18% of the US population.72,73 Substantial racial disparities also exist with respect to rates of effective treatment and viral suppression. In 2019, 71.4% of white people with HIV were virally suppressed compared to 60.8% of Black people with HIV and 64.6% of Latinx people with HIV.74,75

LGBTQ+ people and people involved with the criminal legal system are also disproportionately affected by HIV.<sup>76,77</sup> In 2019, men who have sex with men accounted for 65.4% of new HIV diagnoses.<sup>78</sup> Approximately 2%

of new HIV diagnoses represented transgender adults and adolescents, but 93% of initial diagnoses for HIV infections among transgender people were for transgender women.<sup>79</sup> Additionally, populations disproportionately affected by HIV are also among those disproportionately involved in the criminal legal system; HIV prevalence among people who are incarcerated is five to seven times greater than HIV prevalence among the general population.80 Even wider disparities exist among people with intersectional identities, such as Black transgender women, of whom 44% are estimated to have HIV.81

Many populations disproportionately affected by HIV, such as Black people and LGBTQ+ people, are also adversely affected by the inequitable implementation and enforcement of HIV criminalization laws. In some states, HIV criminalization laws may be disproportionately enforced against Black people and LGBTQ+ people, according to research conducted by the Williams Institute at UCLA School of Law.<sup>82,83,84,85</sup>

IN 2019, BLACK PEOPLE CONSTITUTED 13%

OF THE US POPULATION BUT ACCOUNTED FOR 45%

OF NEW HIV DIAGNOSES.

#### The Effects of HIV Stigma

Misinformation, fear about HIV, and implicit and explicit prejudices often fuel the stigmatization of and discrimination against people with HIV. Despite federal and state legal protections against such discrimination, HIV-related stigma and discrimination continue to harm people with HIV in almost every aspect of life, including things like denial and termination of employment;<sup>86</sup> loss of insurance;<sup>87</sup> eviction from homes;<sup>88,89</sup> disruption of social support networks;<sup>90</sup> discrimination from medical providers, including denial of medical care;<sup>91</sup> unwarranted criminal prosecution; and excessive criminal sentences;<sup>92</sup>

Moreover, people of color experience additional biases and discrimination that further exacerbate inequities and inhibit their ability to access quality care. Stigma caused by policies that criminalize HIV may serve to amplify structural discrimination and create additional obstacles to accessing the quality health care, housing, education, and economic security necessary for effective treatment.<sup>93</sup>

Laws and policies can also play an important role in creating, exacerbating, or, ideally, alleviating structural stigma. In the context of HIV, laws and policies that single out people with HIV for disparate treatment, such as HIV-specific criminalization laws, can reinforce negative perceptions of people with HIV, resulting in unfounded fears, implicit and explicit prejudice, and outright discrimination. Arkansas state law, for example, declares that people with HIV constitute "a danger to the public." In contrast, antidiscrimination protections, including those applicable to people with HIV, can help alleviate stigma.

#### **Internalized Stigma**

HIV-related stigma and discrimination can also result in internalized stigma, which occurs when an individual absorbs the negative messages or stereotypes associated with HIV and sees them as true of themselves. Internalized HIV stigma is strongly associated with increased levels of depression, anxiety, and hopelessness, as well as higher levels of alcohol use.<sup>97,98</sup> Internalized HIV stigma has also been linked to delayed access to care, lower

medication adherence,<sup>99,100,101</sup> greater mistrust of health care providers,<sup>102,103</sup> not reaching or maintaining viral suppression,<sup>104</sup> less HIV status disclosure to sexual partners,<sup>105</sup> and less HIV status disclosure to family members.<sup>106</sup> Avoiding testing, delaying medical care, and lower adherence to ART can not only harm the individual with HIV but also undermine HIV prevention efforts more broadly.

#### Language and Stigma

Successful efforts to reduce the transmission of HIV and ultimately end the HIV epidemic therefore require addressing and countering stigma at individual, community, and structural levels. These factors also underscore the importance of adopting a person-centered approach to HIV prevention, response, and policymaking, including lifting up the voices of people with HIV in such efforts.

Evidence on how language can contribute to stigma about people with HIV has evolved over time. Although this document aims to use non-stigmatizing, person-first language, it incorporates the language used in relevant statutes and regulations when that language affects the interpretation or application of those laws. For additional information about how language and framing can reinforce stigma and for recommendations on less-stigmatizing language, refer to the following resources:

#### Stigma Language Guide

Centers for Disease Control and Prevention

#### Stigma Scenarios: Support in Action

Centers for Disease Control and Prevention

#### HIV Language Guide

National Institute of Allergy and Infectious Diseases

#### $\underline{\text{Why Language Matters: Facing HIV Stigma in Our Own Words}}$

The Well Project

#### Legal Landscape

HIV surveillance, data privacy, and criminalization are subject to a complex, overlapping, and at times contradictory landscape of statutes, regulations, and sub-regulatory policies. These include laws and policies seeking to advance public health and well-being by improving individual and population-level health outcomes and reducing health inequities. They also include oftenharmful laws and policies that reinforce stigma against people with HIV, undermine individual privacy interests, and seek to address the HIV epidemic with punitive measures enforced through the criminal legal system. This tool focuses primarily on state laws and state and local health department policies, but stakeholders should remain cognizant of how federal, local, territorial, and tribal laws and policies related to HIV surveillance, data privacy, and criminalization may affect public health and equity.xi

At the federal level, broadly applicable laws such as the Health Insurance Portability and Accountability Act (HIPAA) and its implementing regulations, including the Privacy Rule, can influence HIV public health surveillance efforts and provide confidentiality protections for certain HIV-related data. More specific federal laws also include provisions affecting specific aspects of HIV surveillance and data privacy. As one example of

a federal law affecting HIV surveillance and data privacy, provisions within federal laws governing the Ryan White HIV/AIDS Program condition certain federal grants<sup>xii</sup> on states making "a good faith effort ... to notify a spouse of a" person who was diagnosed with HIV,<sup>107</sup> a key component of effective, evidence-based HIV prevention efforts.<sup>108,109</sup>

A more complex and varied landscape of laws relevant to HIV surveillance, data privacy, and criminalization exists at the state level. xiii Because federal laws such as HIPAA and its Privacy Rule do not apply to many state and local health departments 110,111 and the Privacy Rule explicitly exempts many health department surveillance programs, 112 these varied state laws will, in most cases, dictate the applicable protections for HIV-related data. These include xiv

- General public health laws such as those governing the establishment and operation of state and local health departments, mandated reporting of communicable disease cases, and public health surveillance more broadly.
- Confidentiality laws protecting against the disclosure and use of personally identifiable health and medical information, data collected through public health activities generally, and certain HIV-related data specifically.

HIV surveillance,
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landscape of statutes,
regulations, and subregulatory policies.

Although this assessment tool focuses primarily on state and local health departments, it is worth noting that tribal and territorial health departments have structures that are uniquely distinct from health departments in the states and the District of Columbia. The US territories – including Puerto Rico, Guam, the US Virgin Islands, American Samoa, and the Northern Mariana Islands – as well as other US-affiliated Pacific Islands and tribal health agencies often work with federal, state, and local agencies to provide public health services; however, they all have independent authority to address public health and criminal concerns in their communities. In this respect, they are similar to states. A comprehensive evaluation of territorial and tribal laws and policies related to HIV surveillance, data privacy, and criminalization is beyond the scope of this assessment tool.

xii As originally enacted, the Ryan White Comprehensive AIDS Resources Emergency Act conditioned federal grant funding for states on the existence of state criminal laws "adequate to prosecute any HIV infected individual" for specified conduct (e.g., engaging in certain sexual activity, sharing needles, or donating blood, semen, or breast milk). Congress repealed this requirement in 2000.

xiii Local laws affecting HIV surveillance, data privacy, and criminalization are less prevalent. However, some larger jurisdictions such as New York City have established independent communicable disease reporting requirements, as well as corresponding privacy protections. See New York City Health Code, Title II, Article 11.

xiv Other laws that may indirectly affect HIV surveillance, data privacy, and criminalization include those regulating health and harm reduction services (e.g., syringe services programs); sex work and sex workers; and the donation of organs, tissue, blood, and semen. A detailed analysis of such laws is beyond the scope of this assessment tool.

 Laws specific to HIV, including laws focused on HIV prevention and treatment such as those addressing partner notification and both mandatory and voluntary HIV testing (e.g., mandatory testing following a significant exposure event or upon a person's entry into the criminal legal system). This category also includes laws criminalizing certain conduct by people with HIV;xv establishing judicial procedures related to HIV (e.g., data disclosure, mandatory testing); and establishing sentencing guidelines for HIVrelated offenses. These laws may be in criminal codes, public health codes, and sub-regulatory documents. Appendix III includes additional information on how to find relevant laws and policies.

## State and Local Health Department Policies and Practices

Codified statutes and regulations generally establish the overall regulatory scheme for HIV-related surveillance and data privacy. It is important to ensure that these federal, state, and local laws are protective of and consistent with public health and health equity objectives. At the same time, the policies and procedures within state and local health departments often determine how those legal provisions are interpreted, implemented, and enforced. Indeed, strong state and local health department policies are essential to

protecting the confidentiality of public health data and governing how and when such data are released.

CDC has long required extensive data protections as a condition of HIV surveillance funding to state and local health departments, including adherence to the Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action (CDC Data Security and Confidentiality Guidelines).<sup>113</sup> These protections for HIV and related public health data include, for example,

- Maintaining data in a secure environment and only transmitting data through secure methods
- Restricting data access to authorized health department staff
- Limiting the use of such data to legitimate public health purposes<sup>xvi</sup>
- Requiring staff training in confidentiality procedures and the signing of confidentiality agreements
- Imposing strict limits on sharing any identifiable data beyond authorized health department staff

Additionally, many jurisdictions have implemented stringent procedures for reviewing data requests, which can provide important safeguards. For example, where state law authorizes (but does not mandate) the use or disclosure of HIV-related data, state and local health department policies

and procedures could prevent or limit the release of such data for purposes unrelated to public health, such as requests related to criminalization. These departmental policies and procedures can collectively help "enhanc[e] the public's health and maintain[] the public's trust," by "protecting the individual and the public from disease" while also "promoting individuals' confidentiality and right to privacy."114 Therefore, it is important that stakeholders, including state and local health departments, assess and understand both the legal and policy landscape in which they operate. Appendix III includes additional information on how to find relevant laws and policies.

xv Laws criminalizing certain conduct by people with HIV may address communicable diseases more generally rather than HIV specifically.

xvi CDC NCHHSTP guidelines define a "legitimate public health purpose" as:

<sup>&</sup>quot;[A] population-based activity or individual effort aimed primarily at the prevention of injury, disease, or premature mortality."

<sup>&</sup>quot;[T]he promotion of health in the community, including 1) assessing the health needs and status of the community through public health surveillance and epidemiologic research; 2) developing public health policy; and 3) responding to public health needs and emergencies."

<sup>&</sup>quot;[A]nalysis and evaluation of conditions of public health importance and evaluation of public health programs." www.cdc.gov/nchhstp/programintegration/data-security.htm

# ASSESSING THE LEGAL AND POLICY LANDSCAPE





This section identifies key assessment questions and considerations for stakeholders conducting assessments of relevant laws, policies, and practices in their jurisdiction. These questions and their respective answers can help public health professionals, policy makers, and partners consider how HIV-related laws and policies in their jurisdiction may benefit or inhibit health and equity; can facilitate conversations among stakeholders; and can help identify opportunities to strengthen laws and policies by aligning them with evidence-based best practices. This section also provides resources and illustrative examples to help inform the assessment. Appendix III provides additional guidance on how to locate and collect relevant laws and policies.

#### RESOURCES ON STATE HIV LAWS AND POLICIES\*VII

#### **Centers for Disease Control and Prevention**

- HIV and STD (Sexually Transmitted Disease) Criminalization Laws
- State Laws on Minors' Consent for HIV and STD Services
- State Laboratory Reporting Laws: Viral Load, CD4, and Molecular Data
- Perinatal HIV Testing Laws
- State Laws That Address High-Impact HIV Prevention Efforts

#### LawAtlas (Policy Surveillance Program)

- HIV Criminalization by State
- Public Health Departments and State Patient Confidentiality Laws
- Communicable Disease Intervention Protocol
- Syringe Service Program Laws

#### **Center for HIV Law and Policy**

- State HIV Laws
- · HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice

#### **NASTAD**

- · HIV Data Privacy and Confidentiality: Legal & Ethical Considerations for Health Department Data Sharing
- Map of Health Policies Affecting People Who Use Drugs

Appendix III provides additional guidance on how to locate and collect relevant laws and policies.

xvii Laws and policies may have changed after a listed resource was created or last updated. While information from these resources may provide a useful starting point, users of this assessment tool should verify that the information reflects currently applicable law and policy.

#### **HEALTH DATA PRIVACY LAWS AND POLICIES**

Federal, state, and local laws and policies regulate the collection, access, use, and disclosure of health information, including HIV-related information gathered through HIV testing, routine medical care for people with HIV, and public health surveillance. These laws and policies dictate when, how, by whom, and for what purposes health information may be used and disclosed – that is, these laws and policies determine what protections do or do not apply to HIV and other health-related data. Understanding and, where necessary, reforming this legal and policy landscape is vital to ensuring that complete, accurate, and timely data can inform HIV prevention and response efforts while protecting against the potential misuse of such data to stigmatize, discriminate against, criminally prosecute, or otherwise harm people with HIV.

#### Federal Landscape

At the federal level, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and its implementing regulation Standards for Privacy of Individually Identifiable Health Information (commonly referred to as the Privacy Rule) establish nationwide protections for individually identifiable health information collected, stored, used, or disclosed by certain entities and individuals (e.g., health care providers and health care plans).115 HIPAA's Privacy Rule would, for example, affect when, to whom, and for what purposes a medical provider may lawfully disclose identifiable information about their patient's HIV test results. Importantly, however, the Privacy Rule includes numerous exemptions xviii authorizing the release of such information, including for public health purposes and when state or local law mandates such disclosures. 116 For example, the Privacy Rule explicitly exempts many health department surveillance programs,117 and state and local health departments are often not subject to

HIPAA and the Privacy Rule at all.<sup>118,119</sup> Additional federal privacy laws that can affect HIV-related data include the Privacy Act of 1974, which regulates the disclosure and use of information maintained by federal agencies, including CDC, and the Family Education Rights and Privacy Act of 1974, which regulates data use and sharing by schools.<sup>120</sup>

CDC maintains an Assurance of Confidentiality (AOC), a formal confidentiality protection authorized under Section 308(d) of the Public Health Service Act. The AOC is used for projects conducted by CDC staff or contractors that involve the collection or maintenance of sensitive identifiable or potentially identifiable information. Further, CDC maintains an AOC specific to HIV surveillance and surveillance-related data. Protected information includes identifiable or potentially identifiable information on institutions or individuals who are the subjects of research or non-research studies with an approved AOC. This protection allows CDC programs to assure individuals and institutions involved in research or non-research projects that those conducting the project will protect the confidentiality of the data collected. The legislation states that no identifiable information may be used for any purpose other than the purpose for which it was supplied unless such institution or individual has consented to that disclosure.121

It is important to consider that CDC AOCs protect data only at CDC and do not extend to state departments of health. States should consider the need for similar assurances and ensuring that those assurances are inclusive of HIV surveillance and surveillance-related data.

xviii For additional information on the HIPAA Privacy Rule and exemptions most frequently applicable in the public health context, see ChangeLab Solutions' resource Leveraging Data Sharing for Overdose Prevention at www.changelabsolutions.org/product/leveraging-data-sharing-overdose-prevention.

#### State Landscape

Varying state laws may apply to HIV-related data, based on factors such as the specific type of data, how and by whom the data were obtained, and the purposes for which such data will be used or disclosed. These laws include confidentiality laws

that apply to general health information (e.g., patient information maintained by a health care professional); protections applicable to public health information generally (e.g., surveillance and disease reports made to public health officials); and specific protections that apply to HIV-related information. In some instances, local privacy laws may also apply.

#### THIS SECTION ADDRESSES THE FOLLOWING QUESTIONS:

- What is the state legal landscape regarding the confidentiality of general health information?
- What is the state legal landscape regarding the confidentiality of public health data?
- What is the state legal landscape regarding the confidentiality of HIV-related data?
- What is the landscape of state and local health department policies, practices, and procedures?

#### What is the state legal landscape regarding the confidentiality of general health information?xix

- 1. Does state law address the disclosure and use of identifiable health information?
- 2. To whom does the law apply?
- 3. What type of information does the law protect?
- 4. When, to whom, and with respect to what types of health information does the law authorize or mandate disclosure?
- 5. When state law authorizes or mandates the disclosure of health information, does the law regulate the subsequent disclosure of such information? What, if any, protections apply to disclosed data?
- 6. Does state law regulate the purposes for which identifiable health information may be used?
- 7. Does the law explicitly address when health information may be disclosed to and/or used by criminal legal system actors (e.g., law enforcement, prosecutors, courts)?

(Appendix IV is a comprehensive list of all the assessment questions.)

HIPAA and its implementing Privacy Rule establish minimum nationwide privacy standards for identifiable health information. However, these federal laws do not apply to everyone that may possess identifiable health information and include numerous exceptions that authorize or mandate the use and disclosure of such information.<sup>122</sup> Many states have enacted statutes and regulations that expressly adopt and incorporate federal health privacy standards. In

other instances, state laws build on federal laws by, for example, (1) expanding their applicability; (2) imposing additional requirements and limitations on the use and disclosure of identifiable health information; and (3) addressing how the laws apply in the context of more contemporary technologies such as health information exchanges and all-payer claims databases.

xix Laws addressing the confidentiality of general health information may use terms such as identifiable health information, personally identifiable health information, protected health information, and confidential health information, among others.

Although these state laws are not specifically designed to address HIV-related data, they nevertheless remain relevant when assessing access to health data for public health purposes and protections against the misuse of such data (e.g., stigmatization and criminalization). For example, general health confidentiality laws may address the use and disclosure of identifiable HIV-related data collected and held by individuals and entities in the health care sector such as health care systems, insurers, and individual practitioners.

Scope and applicability. State law may address general health confidentiality protections through a single, unified regulatory scheme applicable across the entire health sector. Many states, however, have established a patchwork of statutes and regulations that address the use and disclosure of identifiable health information by specific individuals or entities within the health sphere. Different state laws with varying substantive requirements and limitations may, for example, apply to general health care providers, mental health care providers, health insurers, and pharmacists. Because of the wide range of individuals and entities involved in HIV prevention and treatment efforts, including those involved in the collection and maintenance of HIV-related health data, it is important to understand how state laws and privacy protections apply to each of these actors.

**Exemptions.** State health confidentiality laws may include provisions explicitly addressing the disclosure of health information to and use by law enforcement, outlining scenarios in which such disclosures are allowed and any procedural requirements. For example, the law may authorize the disclosure of health information pursuant to a subpoena or court order. Many state laws also include a broad "catch-all" exemption authorizing the disclosure of confidential information when the disclosure is authorized or mandated by other laws. In states with a broad catchall exemption, the application and effect of state health confidentiality laws on HIV criminalization and HIV-related public health surveillance are contingent on more specific state laws addressed in the next two series of questions.

**Subsequent disclosures.** General health confidentiality laws vary as to the existence and scope of protections applicable after an initial disclosure of health information. For example, once

health information is disclosed pursuant to the federal HIPAA Privacy Rule, protections against the subsequent disclosure and use of such information apply only when the individual or entity that received the initial disclosure are themselves subject to the Privacy Rule's requirements and limitations (i.e., when health information is disclosed to an individual or entity that is not directly subject to HIPAA, such as law enforcement personnel, the HIPAA Privacy Rule does not protect against the subsequent disclosure or use of such information).<sup>123</sup> Similarly, some state general health confidentiality laws provide explicit protections against the subsequent disclosure and use of health information in specific circumstances. such as when a health care provider discloses health information to service providers (e.g., entities providing administrative, legal, financial, or actuarial services)124 or when the redisclosure is necessary to fulfill the purpose of the initial disclosure.125 Other states provide more robust protections by prohibiting any person from redisclosing health information unless the subsequent disclosure is also authorized by law.126

Case law. In addition to codified laws, understanding the general health information confidentiality landscape may require assessing applicable case law – judicial decisions that have interpreted and applied the laws in particular legal cases. Case law may indicate how broadly or narrowly courts have interpreted privacy protections and any exceptions to those privacy protections, as well as establish substantive protections that may not exist in codified laws (e.g., establishing privileged communications, such as doctor-patient confidentiality, that may limit the ability to disclose confidential information).

#### **EXAMPLES**

Adoption of federal standards. Kansas state law incorporates by reference both definitions and substantive privacy standards established by the HIPAA Privacy Rule, including the entities subject to the law and the requirements and limitations on the use and disclosure of identifiable health information.<sup>127</sup>

Hawaii state law similarly provides that the use or disclosure of identifiable health information in compliance with the HIPAA Privacy Rule is "deemed to comply with all state laws relating to the use, disclosure, or confidentiality of such information." 128

Expanded applicability. Texas' medical records privacy law largely mirrors the substantive confidentiality regulations in the HIPAA Privacy Rule but applies the regulations not only to entities directly subject to HIPAA and the HIPAA Privacy Rule but also to any person who "comes into possession of protected health information." <sup>129</sup>

#### Disclosure and use of health information (general).

The California Confidentiality of Medical Information Act requires health care providers and other health care—related entities to preserve the confidentiality of medical information and disclose such information only as expressly authorized by the Act.<sup>130</sup>

Disclosure and use of health information (criminal legal system). Maryland requires many health care providers to disclose medical information to actors within the criminal legal system (grand juries, prosecutors, and law enforcement agencies)

if (1) the disclosure is to "further an investigation or prosecution"; (2) the disclosure is made "pursuant to a subpoena, warrant, or court order for the sole purposes of investigating and prosecuting criminal activity"; and (3) "the prosecution agencies and law enforcement agencies have written procedures to protect the confidentiality of the records."<sup>131</sup>

Regulation of subsequent disclosures. Minnesota prohibits any person who receives a health record from a medical provider from further disclosing such records unless the disclosure is specifically authorized by law or the person or the person's legal representative has authorized the release.<sup>132</sup>

#### FOR ADDITIONAL INFORMATION

State Medical Records Laws FindLaw

#### What is the state legal landscape regarding the confidentiality of public health data?\*\*

- 1. Does state law address the disclosure and/or use of public health data?
- 2. Does the law define relevant terms (e.g., protected health information, public health purpose)? If so, how?
- 3. When, to whom, and with respect to what types of public health data does the law authorize or mandate disclosure?
- 4. When state law authorizes or mandates the disclosure of public health data, does the law regulate the subsequent disclosure of such information? What, if any, protections apply to disclosed data?
- 5. Does state law regulate the purposes for which public health data may be used?
- 6. Does the law explicitly address when public health data may be disclosed to and/or used by criminal legal system actors (e.g., law enforcement, prosecutors, courts)?
  - a. Does the law require health department staff to participate in legal proceedings?
- 7. What procedural protections apply to the disclosure and/or use of public health data (e.g., court orders, sealing records, notice and opportunity to contest)?
- 8. Do local health departments have access to state public health data, and if so, is the local health department required to abide by the same confidentiality laws applicable to the state?
- 9. When and under what conditions may de-identified or non-identifiable public health data be disclosed?

Public health data generally refers to data collected through public health surveillance; it may also include data from other sources such as partner notification data and Ryan White HIV/AIDS Program data. The applicability of confidentiality laws to these different forms of public health data may vary. For example, a state may have one confidentiality law applicable to all forms of public health data; different laws for public health surveillance data and other forms of public health data; or confidentiality protections only for some types of public health data.

In addition to general health privacy laws, which often focus on individuals and entities within the health care sector, state statutes and regulations may establish more specific regulations governing the collection, use, and disclosure of public health data such as communicable disease case reports sent to state and local health departments. Laws in every state regulate the release of identifiable health information held by health departments and other government entities, and the overwhelming majority of those laws also regulate how health departments and other governmental entities may use such data. 133 With HIV being a reportable disease in every state, 134 understanding and, where appropriate, strengthening the applicable privacy protections for public health data are vital to ensuring public trust and preventing the misuse of health information to harm people with HIV.

Because of the overlap among general public health confidentiality laws and more specific laws applicable to HIV-related information, this section on general public health confidentiality laws and the subsequent section on HIV-specific confidentiality laws may contain duplicative content.

Defined terms. How a law defines specific terms can substantially affect the scope and application of the law. These definitions may be codified in state statutes or in regulations issued by a state administrative agency. Locating and reviewing any applicable definitions is an important first step in assessing a public health data confidentiality law. Definitions may provide clarity on the types of information that are protected, the entities required to comply with the confidentiality requirements, and the meaning of specific words or phrases used in provisions establishing requirements, limitations, and exceptions to public health data confidentiality.

Scope of confidentiality law. State public health confidentiality laws may differ in their scope and application. For example, some states have adopted a single, unified confidentiality law for all identifiable health data collected, maintained, used, and/or disclosed by government public health officials. Other states have adopted multiple public health

confidentiality laws such as those applicable to specific diseases (e.g., HIV-specific confidentiality laws, which are addressed in the next set of questions) or categories of diseases (e.g., sexually transmitted diseases).

Authorized disclosures and uses. Substantial variation exists with respect to when and under what conditions state laws authorize the disclosure and use of public health data. State law generally authorizes the disclosure and use of otherwise confidential information if the person to whom the information applies consents to such disclosure and use. Other commonly authorized disclosures and uses, including disclosures and uses that do not require individual consent, include those for the purposes of (1) facilitating treatment; (2) research; (3) communicable disease prevention, investigation, and control; (4) partner notification; and (5) the implementation of public health laws. 135

Additionally, as with general health confidentiality laws, many public health data confidentiality laws include a catch-all exemption for disclosures and uses authorized or mandated by other laws. Where such broad exemptions exist, assessing the full scope and applicability of the confidentiality law requires comprehensive examination of state (and sometimes local and federal) law.

Certain limitations often apply even when a public health confidentiality law permits or requires a particular disclosure or use of confidential information. Public health confidentiality laws may, for example,

- Restrict disclosures to the minimum amount of information necessary to achieve the intended purpose of the disclosure;<sup>136</sup>
- Prohibit a person who lawfully receives confidential information from further disclosing the information;<sup>137</sup>
- Require the imposition of safeguards to protect against unauthorized or improper disclosures or uses:<sup>138</sup>

xxi In general, authorized disclosures and uses of public health data for research purposes are limited to de-identified data that cannot be linked to particular individuals. Some state laws may authorize the disclosure and use of identifiable public health data for research purposes but also establish additional safeguards to protect the confidentiality of these data.

Criminal legal settings. Specific provisions within public health confidentiality laws may govern whether and how information held by government health officials may be disclosed and used in criminal legal settings, such as criminal prosecutions. At one end of the spectrum, the most protective state laws include a near categorical prohibition on the disclosure to the criminal legal system of confidential information held by government public health officials, including prohibitions on the disclosure of confidential health records or the voluntary or compelled testimony of public health officials with respect to such information.<sup>139</sup> At the other end of the spectrum, the least protective state public health confidentiality laws authorize or require public health officials to disclose otherwise confidential information to actors within criminal legal settings based on, for example, a court order. 140 Between these two extremes are public health confidentiality laws that apply a general prohibition on the disclosure or use of public health data within the criminal legal system but authorize government public health officials to disclose otherwise confidential information in specific types of criminal proceedings, such as those related to sexual offenses.141

When assessing provisions in public health confidentiality laws related to disclosures to and uses by actors within the criminal legal system, it is important to determine whether the law mandates disclosure by public health officials or merely authorizes such disclosures. If the public health confidentiality law mandates disclosure, public health officials lack discretion to refuse to disclose the covered information. However, if the public health confidentiality law authorizes (but does not mandate) disclosure, opportunities may exist for the governmental public health agencies to adopt policies limiting disclosures to those that advance a legitimate public health purpose.

**Procedural requirements.** Certain procedural requirements may apply to specific disclosures or uses of information protected by public health confidentiality laws. These requirements include, for example,

- Mandating written safeguards to ensure confidentiality before disclosure;<sup>142</sup>
- Sealing records containing any disclosed confidential information;<sup>143</sup>

- Providing an opportunity for the person to whom the information applies to contest the disclosure and use of such information;<sup>144</sup>
- Requiring a court order or subpoena (court orders are more protective than subpoenas because, unlike most subpoenas, court orders must be signed by a judge);<sup>145</sup>
- Making specific findings about the need to disclose or use confidential information. State laws vary with respect to which entity is required to make such specific findings and determinations. In some instances, the court issuing the order to disclose must make such findings.<sup>146</sup> In other instances, the health officials holding the confidential information must make the determination.<sup>147</sup>

Local health department data access. The degree to which local health departments have access to state public health data varies. In some states, local health departments generally may access state public health data to the same extent as state health officials, while others allow local health departments to access such data only in more limited circumstances. When local health departments have access to state public health data, it is important to ensure that the confidentiality laws applicable to the state also apply to local officials.

De-identified or non-identifiable data. Public health confidentiality laws often include an exception allowing for the disclosure and use of either de-identified information (i.e., information stripped of any identifying information and for which no reasonable basis exists to believe that the information could be used to identify a specific person or entity) or non-identifiable information (i.e., information that is inherently incapable of identifying a specific person or entity). Although deidentified and non-identifiable data are insufficient to guide individual-level interventions, such data can provide insight into population-level trends and support research efforts. For example, public health researchers may use de-identified or non-identifiable data in legal epidemiology studies to evaluate the effects of particular legal or policy interventions on health outcomes.

#### **EXAMPLES**

#### Disclosure and use of public health data (general).

North Carolina state law requires that "information and records, whether publicly or privately maintained, that identify a person who has or may have a [reportable] disease or condition" be kept "strictly confidential" and prohibits the release of such information except in specific, enumerated circumstances.<sup>148</sup> Examples of authorized disclosures include when the person whom the information and records concern consents to disclosure<sup>149</sup> and disclosures to other "federal, State, tribal, or local public health agenc[ies] for the purpose of preventing or controlling the spread of a communicable disease or communicable condition."<sup>150</sup>

An Alaska regulation provides that "identifiable health information collected and maintained by the [Department of Health and Social Services] ... shall be safeguarded as confidential and may only be acquired, used, and stored for a public health purpose." <sup>151</sup>

Defined terms. Delaware requires that "[p]rotected health information collected by the Department of Health and Social Services or its agencies ... be used solely for legitimate public health purposes." The law defines a legitimate public health purpose as "a population-based activity or individual effort primarily aimed at the prevention of injury, disease, or premature mortality or the promotion of health in the community." Listed examples of legitimate public health purposes include "[a]ssessing the health needs of the community through public health surveillance and epidemiological research"; "[d]eveloping public health policy"; and "[r]esponding to public health needs and emergencies." 154

Disclosure and use of public health data (law enforcement). Wyoming state law generally protects the confidentiality of health information contained in communicable disease reports made to public health officials. However, regulations include an exception allowing for the disclosure of such information if the disclosure is "pursuant to a criminal prosecution for the criminal infection of or exposure to a listed reportable disease or condition." <sup>156</sup>

South Dakota state law generally prohibits the release of health information contained in communicable disease reports made to the state department of health, including a prohibition on the admission of

such information "as evidence in any action of any kind in any court or before any tribunal, board, agency, or person." However, the law includes two major exceptions related to HIV. First, the state department of health may disclose otherwise confidential information "[t]o the extent necessary to comply with a proper judicial order requiring release of [HIV] test results and related information to a prosecutor for an investigation of a violation of [the state HIV criminalization law]." Second, the secretary of the state department of health has the authority to release confidential information to the state "attorney general or an appropriate state's attorney if the secretary … has reasonable cause to suspect that a person has violated [the state HIV criminalization law]." 159

The Alaska Department of Health and Social Services or a public health agent may disclose identifiable health information in a legal proceeding (including a criminal proceeding) only if "a court orders the disclosure after having been fully advised of ... the statutes and regulations limiting disclosure; ... the public policy supporting the protection of identifiable health information; ... and the facts that support the closing of the proceeding or the sealing of the records containing identifiable health information." 160

#### Regulation of subsequent disclosures and use.

Alabama law requires that a person who receives a communicable disease report "hold such information in the strictest of confidence and privilege and ... take only those actions necessary to protect the health of the infected person or other persons where there is a foreseeable, real or probable risk of transmission of the disease."<sup>161</sup>

In Alaska, when the state's Department of Health and Social Services makes an authorized disclosure of identifiable health information, the recipient of the information "may not disclose the information to another person except for a purpose authorized in the written consent." 162

#### Public health department and criminal legal system.

Vermont state law provides that information included in disease reports to the state's Department of Health "shall be privileged and confidential." The law also specifies that the information "shall not be ... used for any purpose other than public health surveillance, and epidemiological follow-up," including an explicit prohibition on the disclosure of such information

in "any civil, criminal, administrative, or other proceeding." Additional confidentiality requirements apply to HIV-related public health data. 166

Similarly, Minnesota's criminal communicable disease exposure law explicitly prohibits law enforcement authorities or prosecutors from accessing or subpoening protected public health data without the consent of the subject of the data.<sup>167</sup>

De-identified and non-identifiable public health data. Missouri authorizes the state's Department of Health and Senior Services to receive information from medical records "for purposes of conducting

epidemiological studies to be used in promoting and safeguarding the health of the citizens of Missouri."<sup>168</sup> The department must maintain the confidentiality of such information but may release the information "in a statistical aggregate form that precludes and prevents the identification of patient, physician, or medical facility."<sup>169</sup>

#### FOR ADDITIONAL INFORMATION

Public Health Departments and State Patient
Confidentiality Laws

LawAtlas (Policy Surveillance Program)

#### What is the state legal landscape regarding the confidentiality of HIV-related data?

- 1. Does state law address the disclosure and/or use of HIV-related data?
- 2. Does the law define relevant terms (e.g., protected health information, public health purpose)? If so, how?
- 3. To whom does the law apply?
- 4. What type of information does the law protect?
- 5. When, to whom, and with respect to what types of HIV-related data does the law ...
  - a. Authorize disclosure with an individual's consent?
  - b. Authorize disclosure without an individual's consent?
  - c. Mandate disclosure with an individual's consent?
  - d. Mandate disclosure without an individual's consent?
- 6. When state law authorizes or mandates the disclosure of HIV-related data, does the law regulate the subsequent disclosure of such information?
  - a. Does the law regulate the purposeful further disclosure of HIV-related data?
  - b. Does the law regulate the inadvertent further disclosure of HIV-related data?
- 7. Does state law regulate the purposes for which HIV-related data may be used?
- 8. Does the law explicitly address when HIV-related data may be disclosed to and/or used by criminal legal system actors (e.g., law enforcement, prosecutors, courts)?
  - a. Does the law require health department staff to participate in legal proceedings?
- 9. What procedural protections apply to the disclosure and/or use of HIV-related data? Does disclosure and/or use require ...
  - a. A subpoena?
  - b. A court order?
  - c. Sealing records?
  - d. In camera review?
  - e. Notice and an opportunity to contest?
- 10. Do local health departments have access to HIV-related data held by state officials, and if so, is the local health department required to abide by the same confidentiality laws applicable to the state?
- 11. When and under what conditions may de-identified or non-identifiable HIV-related data be disclosed?

Among the myriad ways in which laws and policies single out HIV for disparate treatment relative to other communicable diseases and public health issues are state laws that specifically regulate the disclosure and use of HIV-related health information. These HIV-specific laws supplement or, in some instances, supplant more general health confidentiality laws, including those governing other data held by public health officials. Whether laws regulating the disclosure and use of HIV-specific health information advance or inhibit health and equity depends on the extent to which specific features of the law facilitate the use of such information for legitimate public health purposes while protecting against the misuse of the information to stigmatize or criminalize the conduct of people with HIV. Because of the overlap among HIV-specific confidentiality laws and more general public health confidentiality laws, this section on HIV-specific confidentiality laws and the preceding section on general public health confidentiality laws may contain duplicative content.

When assessing laws specifically regulating the disclosure and use of HIV-related health information, key components and considerations include the following:

**Definitions.** How a law defines specific terms can substantially affect the scope and application of the law. These definitions may be codified in state statutes or in regulations issued by a state administrative agency. Locating and reviewing any applicable definitions is an important first step in assessing an HIV data confidentiality law. Definitions may provide clarity on the types of information that are protected, the entities required to comply with the confidentiality requirements, and the meaning of specific words or phrases used in provisions establishing requirements, limitations, and exceptions to HIV data confidentiality. For example, if a state HIV confidentiality law authorizes certain disclosures of otherwise confidential information following a significant exposure and defines the term significant exposure, the availability and scope of permissible disclosures depends on the language of the defined term. 170 In some instances, state HIV data confidentiality laws may incorporate definitions from other sources, such as the federal HIPAA Privacy Rule.171

Scope and applicability. State HIV confidentiality laws differ in their scope and application. Some states have adopted a single, unified confidentiality law for identifiable HIV-related information collected, maintained, used, or disclosed. Other states have adopted multiple HIV confidentiality laws such as those applicable to specific entities.<sup>172</sup> For example, California has one law regulating the confidentiality of HIV-related information maintained by state and local health departments and a different confidentiality law applicable to identifiable HIV information developed or acquired during HIV-related research.<sup>173</sup>

Similarly, state HIV confidentiality laws may apply to all identifiable HIV-related information,<sup>174</sup> to certain types of HIV-related information (e.g., HIV test results),<sup>175</sup> or to specified sources of HIV-related information (e.g., information obtained while providing health care services).<sup>176</sup> In some instances, states may have a single, broadly applicable HIV confidentiality statute with different entities (e.g., health departments and private health care providers) adopting more specific regulations and sub-regulatory policies governing their respective implementation of and adherence to the state statute.<sup>177</sup>

**Authorized disclosures and uses.** Substantial variation exists with respect to when and under what conditions state laws authorize or require the disclosure and use of identifiable HIV-related information.

- Health and public health purposes. State HIV confidentiality laws commonly authorize disclosures of otherwise confidential HIV information when the disclosure will advance legitimate health and public health purposes such as the prevention, investigation, and control of HIV transmission and offering and coordinating treatment services for people with HIV.<sup>178</sup>
- Consent requirements. State HIV confidentiality laws generally authorize disclosures when the person to whom the information pertains consents to the disclosure. However, HIV confidentiality laws may impose additional and more specific consent requirements than apply to general medical and public health confidentiality laws. For example, whereas medical privacy laws such as HIPAA often allow individuals to provide blanket consent to disclosures, HIV confidentiality

laws may require the disclosure authorization to identify the individuals or entities authorized to receive the information, the specific information that may be disclosed, and the time period during which such disclosures may occur.<sup>179</sup>

- Additional commonly authorized disclosures. In addition to disclosures made for health and public health purposes and pursuant to the consent of the person to whom the information pertains, disclosures and uses commonly authorized by state HIV confidentiality laws include, for example, disclosures and uses for research purposesxxii and to (1) people who experienced a significant exposure event; (2) people who were sexually assaulted; (3) sexual partners of and people who share paraphernalia for injection drug use with a person with HIV; (4) coroners and medical examiners; and (5) individuals and entities with custody of a person with HIV such as schools, institutional care facilities, jails, and prisons. Specific requirements and limitations may apply, depending on the specific nature and recipient of the disclosure.
- Catch-all exemptions. As with general medical privacy and public health data confidentiality laws, a state HIV confidentiality law may include a catch-all exemption authorizing disclosures and uses authorized or mandated by other laws. Assessing the full scope and applicability of an HIV confidentiality law that includes a broad catch-all exemption requires a comprehensive examination of state (and sometimes local and federal) law. Importantly, catch-all exemptions in HIV confidentiality laws may include additional requirements or limitations such as the use of specific words or indications of legislative intent. For example, Georgia's HIV confidentiality law provides that confidential HIV information may be disclosed if either:
  - The disclosure is specifically authorized by the HIV confidentiality law; or
  - 2. "[W]hen that disclosure is otherwise authorized or required by any law which specifically refers to 'AIDS confidential information,' 'HIV test

results,' or any similar language indicating a legislative intent to disclose information specifically relating to AIDS or HIV."180

Ascertaining legislative intent may require referencing materials beyond the codified statutes and regulations such as legislative findings, legislative history reports, and case law.

Subsequent disclosures and uses. In contrast to laws such as the HIPAA Privacy Rule, state HIV confidentiality laws often explicitly prohibit a person who obtains confidential HIV information pursuant to a lawful disclosure from further disclosing or using such information unless the subsequent disclosure and use are also specifically authorized.<sup>181</sup> Indeed, many of these laws require that authorized or mandated disclosures be accompanied by specific notice regarding the prohibition on subsequent disclosures and use.182 The prohibition on subsequent disclosures and use may apply generally to all HIV-related information and entities or to specific types of disclosures and entities.183

State HIV confidentiality laws also may distinguish between purposeful and inadvertent disclosures. For example, Georgia state law imposes penalties only when a person "[i]ntentionally or knowingly" discloses confidential HIV information in an unauthorized manner, 184 and people who unintentionally disclose confidential HIV information are not subject to civil or criminal penalties if the individual or entity maintained "procedures ... which are reasonably adopted to avoid risk of such disclosure" and the disclosure was not "due to gross negligence or wanton and willful misconduct." 185

Mandatory disclosures. State HIV confidentiality laws generally establish the circumstances in which a person *may* disclose otherwise confidential information, providing the individual or entity the discretion to determine whether and when to ultimately make the disclosure. In some instances, however, state law may *require* particular disclosures of otherwise confidential HIV information.

xxii In general, authorized disclosures and uses of HIV-related data for research purposes are limited to de-identified data that cannot be linked to particular individuals. Some state laws may authorize the disclosure and use of identifiable HIV-related data for research purposes but also establish additional safeguards to protect the confidentiality of these data.

For example, Wisconsin mandates that health care professionals who perform HIV tests in response to a significant exposure event disclose the test results to the person potentially exposed to HIV and "the person's physician, physician assistant, or nurse." Other examples of mandated disclosures include when conducting contact tracing of a person with HIV 187 and when disclosures are otherwise authorized or required by law. 188 Individuals and entities have no discretion to refuse to disclose confidential HIV information when the law mandates such disclosures.

Criminal legal settings. Specific provisions within HIV confidentiality laws may govern whether and how identifiable HIV information may be disclosed and used in criminal legal settings, such as criminal prosecutions. At one end of the spectrum, the most protective state laws include a categorical or near categorical prohibition on the disclosure of confidential HIV information to the criminal legal system.<sup>189</sup> At the other end of the spectrum, the least protective state laws explicitly require disclosures of otherwise confidential HIV information to the criminal legal system. Between these two extremes are state laws that apply a general prohibition on the disclosure or use of confidential HIV information within the criminal legal system but authorize disclosures of such information in specific types of criminal proceedings, such as those related to sexual offenses. 190 Restrictions or prohibitions on the use of confidential HIV information in criminal legal settings may apply to any person in possession of such information or to specific entities holding such information (e.g., public health officials).

When assessing provisions in HIV confidentiality laws related to disclosures to and uses by actors within the criminal legal system, it is important to determine whether the law mandates disclosures or merely authorizes such disclosures. If the HIV confidentiality law mandates disclosure, public health officials and other individuals and entities (e.g., health care providers) lack discretion to refuse to disclose the covered information. However, if the HIV confidentiality law authorizes (but does not mandate) disclosure, opportunities may exist for government agencies (e.g., state and local health departments) and non-governmental entities (e.g., health systems)

to adopt regulations or sub-regulatory policies limiting disclosures to those that advance a legitimate public health purpose.

Minimum necessary. Most state HIV confidentiality laws require that any authorized or required disclosures of HIV information be limited to the minimum amount of information and made to the fewest number of people necessary to achieve the intended purpose of the disclosure. HIV confidentiality laws may explicitly identify specific criteria for disclosing certain types of HIV information, whereas other laws provide greater discretion to determine the minimum necessary information.<sup>191</sup>

**Procedural requirements.** Certain procedural requirements may apply to specific disclosures or uses of information protected by HIV confidentiality laws. These requirements and protections include, for example,

**Subpoenas and court orders.** HIV confidentiality laws frequently establish the circumstances and process for obtaining a subpoena or other court order compelling the disclosure of confidential HIV information. (Court orders are more protective than subpoenas because, unlike most subpoenas, court orders must be signed by a judge.) The exact scope and application varies both among individuals and entities and among types of information within a single state and across different states. For example, laws in some states grant a variety of individuals and entities (e.g., private citizens) the ability to seek an order compelling the disclosure of confidential HIV information, while others limit the availability and application of these compulsory processes to specific actors (e.g., law enforcement and public health officials),192 as well as specific means.193

HIV confidentiality laws may require courts to make specific findings – a compelling need for disclosure, 194 a clear and imminent danger to the public's health, 195 or inability to obtain the information through other means, 196 for example. Courts often must also weigh the competing interests before ordering the disclosure of confidential HIV information. 197 Additionally, state HIV confidentiality laws may require court orders to limit disclosures to the minimum information necessary and impose appropriate safeguards to protect against unlawful disclosures. 198

- HIV confidentiality laws establish specific requirements and procedures that courts must follow to protect identifiable or otherwise confidential HIV information. For example, because court records generally constitute public records by default, HIV confidentiality laws may require the use of pseudonyms in court filings, hearings conducted through *in camera* proceedings that the public is barred from observing, and sealing of court records.<sup>199</sup>
- circumstances, particularly those involving courts, state HIV confidentiality laws require that before disclosing confidential HIV information, the person to whom the confidential information pertains must be given notice of the proposed disclosure and an opportunity to contest the disclosure. This notice and opportunity is intended to protect the privacy and due process rights of the person to whom the HIV information pertains.

Local health department data access. The degree to which local health departments have access to HIV-related data held by state officials can vary. Local health departments may be allowed to access HIV-related data held by state officials to the same extent as those state officials or may be permitted to access such data only in more limited circumstances. When local health departments are permitted to access state-held HIV-related data, it is important that local officials be subject to the same confidentiality laws that apply to state officials.

De-identified or non-identifiable data. As with general public health confidentiality laws, HIV-specific confidentiality laws also frequently allow for the disclosure and use of de-identified or non-identifiable HIV data. De-identified and non-identifiable HIV data cannot be used to direct HIV prevention and treatment efforts at the individual level such as identifying and engaging people with HIV and people vulnerable to HIV who are not currently receiving HIV prevention and treatment services. However, such data can support broader evaluations of communityand population-level health outcomes, including evaluations on the effectiveness of interventions intended to reduce HIV transmission, reduce HIVrelated health inequities, and improve the health of people with HIV. These evaluations can subsequently inform the design and implementation of future interventions, including legal and policy reforms. For example, a legal epidemiology study may use de-identified or non-identifiable HIV-related health information to study how HIV criminalization laws, including specific features and variations within such laws, affect HIV-related health outcomes and inequities.

#### **EXAMPLES**

Defined terms. Georgia state law defines AIDS confidential information as information that allows identification of a person and discloses that the person has (1) "been diagnosed as having AIDS"; (2) "been or is being treated for AIDS"; (3) "been determined to be infected with HIV"; (4) "submitted to an HIV test"; (5) "had a positive or negative result from an HIV test"; (6) "sought and received counseling regarding AIDS"; or (7) "been determined to be a person at risk of being infected with AIDS."<sup>201</sup>

Disclosure and use of HIV data (general). The Illinois AIDS Confidentiality Act prohibits any person from voluntarily disclosing or being compelled to disclose HIV-related information unless the disclosure is specifically authorized by the Act.<sup>202</sup> Permissible disclosures include disclosures consented to by the person whom the information concerns and disclosures to state and specified local health officials "in accordance with rules for reporting, preventing, and controlling the spread of disease and the conduct of public health surveillance, public health investigations, and public health interventions…"<sup>203</sup>

Wisconsin state law imposes a general prohibition on disclosing the results of an HIV test without the consent of the person subject to the test but includes several exemptions authorizing disclosure, including to health care providers treating the person; pursuant to specified court orders; to state and local health officials for public health purposes; and to specified correctional officials with lawful custody of the tested individual.<sup>204</sup> Individuals who receive HIV test results pursuant to a lawful exemption may not further disclose such information unless the subsequent disclosure is specifically authorized by state law.<sup>205</sup>

Disclosure and use of HIV data (health departments).

Regulations for the District of Columbia provide
that HIV-related information received by the District

of Columbia Department of Health through disease reports may "be used for statistical, public health, epidemiological, and surveillance purposes only" and prohibit the department from disclosing the identity of a person with HIV without the person's written consent.<sup>206</sup>

When the Illinois AIDS Confidentiality Act authorizes a state agency, local health authority, or health oversight agency to disclose HIV-related information, the disclosure must be "limited to those who have a need to know the information, and no additional disclosures may be made," and the disclosed information is not "admissible as evidence nor discoverable in any action of any kind in any court or before any tribunal, board, agency, or person."

#### Disclosure and use of HIV data (law enforcement).

Ohio state law generally prohibits disclosure by a person who has obtained HIV-related information while providing health care services or while employed by a health care facility or health care provider<sup>208</sup> but includes an exemption authorizing disclosures to "law enforcement authorities pursuant to a search warrant or a subpoena issued ... in connection with a criminal investigation or prosecution."<sup>209</sup>

Disclosures and use of HIV data (non-government public health). Louisiana authorizes (but does not require) physicians to disclose otherwise confidential HIV information to contacts of a person with HIV if the physician (1) "reasonably believes the disclosure is medically appropriate and there is a significant risk of infection to the contact"; (2) "has counseled the [person with HIV] ... regarding the need to notify the contact, and the physician reasonably believes the patient will not inform the contact"; and (3) "has informed the [person with HIV] ... of [their] intent to make such a disclosure and has given the [person with HIV] the opportunity to express a preference as to whether the disclosure should be made by the physician directly or to a public health officer for the purpose of disclosure."210 The physician must honor the person's preference, and neither the physician nor the public health officer may disclose the identity of the person with HIV to the contact.211

#### Disclosure and use of HIV data (minimum necessary).

Where Michigan's state HIV confidentiality law authorizes the disclosure and use of HIV-related information, the person disclosing the information may "disclose only the minimum information necessary to accomplish the intended purpose of the disclosure." Additionally, the disclosure may not include "information that identifies the individual to whom the information pertains, unless the identifying information is determined by the person making the disclosure to be reasonably necessary to prevent a foreseeable risk of transmission of HIV, to protect the health of the individual to whom the information pertains, to prevent the further transmission of HIV, or to diagnose and care for a patient." 213

#### Regulation of subsequent disclosures and use.

Pennsylvania state law provides that when confidential HIV-related information is disclosed to a person, that person may not disclose that information to another person except as explicitly authorized by state law.<sup>214</sup>

Iowa state law provides that when a court orders the release of HIV-related information, the court must "impose appropriate safeguards against unauthorized disclosure, which shall specify the persons who may gain access to the information, the purposes for which the information shall be used, and appropriate prohibitions on future disclosure."

Ohio requires authorized disclosures of HIV-related information to be accompanied by a written statement explaining that the information is confidential and may not be further disclosed without the consent of the person to whom the information pertains or as specifically authorized by state law, including that a general authorization to release medical information is insufficient to disclose HIV-related information.<sup>216</sup>

#### Public health department and criminal legal system.

The California Acquired Immune Deficiency Syndrome (AIDS) Public Health Records Confidentiality Act provides that a confidential public health record shall not be "disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding."<sup>217</sup>

Alabama state law requires the State Health Officer to disclose HIV-related information, including whether the defendant is living with HIV, has been notified of their status, and has been provided with counseling "about appropriate methods to avoid infecting others," in response to a subpoena during grand jury and criminal trial proceedings for murder, attempted murder, or felony assault.<sup>218</sup>

Although Florida generally prohibits state health officials from being "examined in a civil, criminal, special, or other proceeding" regarding medical records related to sexually transmitted diseases, state law includes an exemption for prosecutions under the state HIV criminalization law.<sup>219</sup>

Arkansas state law allows a state prosecuting attorney to subpoena otherwise confidential HIV-related information for the purposes of enforcing the state HIV criminalization and compelled HIV testing laws, but the prosecuting attorney may disclose the subpoenaed information only to courts.<sup>220</sup>

Procedural requirements. Iowa state law requires compliance with specified procedures when a person requests and a court orders the release of HIV-related test results.<sup>221</sup> These procedures and requirements include:

- The court must find a "compelling need for the [HIV] test results which ... cannot be accommodated by other means," weighing "the need for disclosure against the privacy interest of the test subject and the public interest which may be disserved by disclosure due to its deterrent effect on future testing or due to its effect in leading to discrimination."
- The identity of the test subject must "be communicated confidentially in documents not filed with the court."<sup>223</sup>
- The court must "provide the person whose test results are in question with notice and a reasonable opportunity to participate in the proceedings if the person is not already a party."<sup>224</sup>
- Court proceedings must be "conducted in camera unless the subject of the test agrees to a hearing in open court or unless the court determines that a public hearing is necessary to the public interest and the proper administration of justice."
- The court must "impose appropriate safeguards against unauthorized disclosure, which shall specify the persons who may gain access to the information, the purposes for which the information shall be used, and appropriate prohibitions on future disclosure."<sup>226</sup>

#### De-identified and non-identifiable HIV information.

New York's state law requires that "[a]II [HIV-related] reports or information secured by" state or local health officials be kept confidential but authorizes the release of such information "when used in the aggregate, without patient specific identifying information, in programs approved by [the state health commissioner] for the improvement of the quality of medical care provided to" people with HIV.<sup>227</sup>

The Illinois AIDS Confidentiality Act allows specified entities to "create, use, and disclose de-identified information" without a person's consent, including the disclosure of "HIV-related information" to specified entities "for the purpose of de-identifying the information," so long as "the creation, use, and disclosure of such de-identified data ... comply with the requirements set forth under HIPAA."<sup>228</sup> The Act prohibits a "recipient of de-identified information" from "using any public or private data source" to re-identify such information.<sup>229</sup>

#### FOR ADDITIONAL INFORMATION

HIV Data Privacy and Confidentiality Legal & Ethical Considerations for Health Department Data Sharing NASTAD

Public Health Departments and State Patient
Confidentiality Laws
LawAtlas

#### Q What is the landscape of state and local health department policies, practices, and procedures?

- 1. Does the department have existing data sharing and confidentiality policies, practices, and procedures?
- 2. Do the department's policies, practices, and procedures comply with the standards described in the CDC NCHHSTP Data Security and Confidentiality Guidelines?\*\*\*
- 3. How have state and local government attorneys interpreted the state data privacy landscape and internal department policies, practices, and procedures?
- 4. Do department policies, practices, and procedures ...
  - a. Generally, restrict data sharing to legitimate public health purposes?
  - b. Allow the disclosure of data for purposes unrelated to public health (e.g., litigation, discovery, or court order) only to the extent such disclosures are required by law?
  - c. Restrict disclosures to the minimum amount of information needed to achieve the purpose of the disclosure?
  - d. Allow disclosures for research purposes? If so, what types of data may be disclosed and how?
  - e. Allow the department to receive data even if it may not disclose such data?
  - f. Establish procedures to review disclosure requests that fall outside established policies? Must legal counsel review disclosures unrelated to public health to determine what, if any, information must be disclosed?

In addition to codified laws (e.g., statutes and regulations) and case law, sub-regulatory measures such as internal health department policies and practices can substantially influence HIV data privacy. Laws in some states set forth a general framework regarding HIV data privacy and then explicitly direct government entities such as state and local health departments to adopt certain sub-regulatory policies to fill in the details of implementation and enforcement. In other instances, state law may grant the government entity broad authority to adopt sub-regulatory policies that are consistent with state law, but the state HIV data confidentiality law does not explicitly require the entity to adopt any specific policy. Additionally, broadly framed or ambiguous provisions in state HIV data privacy laws may afford a government entity flexibility in how they interpret and implement the law even if the law is silent on the entity's authority to adopt such sub-regulatory policies.

State and local health departments and other government entities that collect, maintain, and disclose identifiable HIV-related data can use these explicit and implied authorities to ensure that such data are used only to advance legitimate public

health purposes and to limit any disclosures to the minimum amount of information and fewest number of individuals and entities necessary to achieve those purposes or otherwise comply with applicable law. For example, if state law provides that the health department *may* disclose confidential HIV-related data – as opposed to stating that the health department *must* or *shall* disclose such information – a sub-regulatory policy could include additional restrictions specifying the circumstances in which the department will release the HIV-related data.

Government attorneys such as a health department's legal counsel are often best situated to assess the legal landscape and identify opportunities to adopt sub-regulatory policies that advance public health and equity. Further, a published reading or interpretation by legal counsel of these laws in relation to HIV or other public health data can be helpful to document decisions, retain institutional knowledge on the topics, and aid in onboarding new professional and legal staff. External resources ranging from technical assistance providers, professional organizations (e.g., NASTAD), and advocacy organizations to written guidance such as this assessment tool and the NCHHSTP Data Security

xxiii Entities receiving HIV surveillance and prevention funding from NCHHSTP are required to comply with the Data Security and Confidentiality Guidelines as a condition of the funding. Nevertheless, it remains important to assess whether departmental policies, practices, and procedures align with the guidelines to ensure compliance with any applicable funding conditions and account for health departments that do not receive such funding from NCHHSTP.

and Confidentiality Guidelines can also help inform the development, adoption, and implementation of state and local health departments' sub-regulatory policies.

The scope and application of sub-regulatory policies can vary. These policies generally apply only to the internal operations of the government entity. For example, a sub-regulatory policy adopted by a state health department may regulate the conduct of the department's employees and set forth processes and procedures the department must follow when taking certain actions. The section on implementation and enforcement later in this document addresses a government entity's authority to adopt codified regulations, which more frequently apply to non-governmental actors.

#### **EXAMPLES**

#### Mandated confidentiality policies (government).

Missouri requires "local public health agencies to establish confidentiality policies and procedures which are as stringent as Missouri Department of Health (MDOH) policies and procedures for information obtained for reporting of communicable, environmental and occupational diseases."

#### Mandated confidentiality policies (non-governmental).

Pennsylvania state law requires specified health care entities that have "access to or maintain[] individually identifying confidential HIV-related information [to] establish written procedures for confidentiality and disclosure of the records which are in accordance with [Pennsylvania state law]...."

Confidentiality agreements. Every state has to have confidentially agreements. Some states go as far as codifying data privacy and confidentially laws. California state law requires state and local health department employees and contractors to sign confidentiality agreements before accessing confidential HIV-related public health records.<sup>232</sup> These agreements must be reviewed annually.<sup>233</sup>

Compliance with CDC standards. Washington State regulations require the state's Department of Health and local health departments to "maintain HIV case reports in secure systems that ... are consistent with the 2006 Security and Confidentiality Guidelines developed by the Centers for Disease Control and Prevention."<sup>234</sup> These "[s]ecure systems must be described in written policies that are reviewed annually...."<sup>235</sup>

CDC updated the Security and Confidentiality Guidelines in 2011, and states are encouraged to update existing laws, statutes, and regulations to reflect currently available science. Washington has amended its regulations to refer to the updated 2011 guidelines, although the amended regulations do not currently take effect until January 1, 2023.<sup>236</sup>

#### FOR ADDITIONAL INFORMATION

<u>Data Security and Confidentiality Guidelines</u> NCHHSTP (CDC)

HIV Prevention Technical Assistance and Capacity-Building Programs NASTAD

### STATE PUBLIC HEALTH SURVEILLANCE AND HIV TESTING LAWS

Robust public health surveillance systems are vital to the public health response to communicable diseases, including HIV. Laws in many jurisdictions also regulate various matters related to HIV testing, including when a person must undergo HIV testing, reporting requirements for test results,

and confidentiality protections for information obtained through HIV testing. This section outlines questions, considerations, and resources to help stakeholders understand the legal, health, and equity implications of public health surveillance and HIV testing laws in their state.

#### THIS SECTION ADDRESSES THE FOLLOWING QUESTIONS:

- What is the state legal landscape with respect to HIV testing?
- What is the state legal landscape with respect to HIV-specific surveillance and reporting?
- What is the state legal landscape with respect to general disease reporting?

#### **Q** What is the state legal landscape with respect to HIV testing?

- 1. Does state law mandate that certain individuals be tested for HIV? If so, when are such tests required (e.g., following a significant exposure event, within criminal legal settings, as part of legal cases involving sexual assault)?
- 2. Does state law address routine opt-out testing during pregnancy?
- 3. With whom are test results shared?
- 4. What, if any, legal protections apply to the test results and associated information?
- 5. Do the reporting requirements apply to mandated HIV testing? Voluntary HIV testing?

State laws regulate various aspects related to testing for HIV, including when, where, how, and by whom such tests are administered; whether the testing occurs because of a request from the individual being tested or whether it is mandated by a governmental entity; and the reporting, disclosure, and use of test results, including any applicable privacy protections. Robust privacy protections, including limitations on the use and disclosure of HIV test results, as well as the availability of anonymous testing can help address concerns related to the potential misuse of HIV test results (e.g., criminal prosecution), thereby increasing a person's willingness to undergo HIV testing.<sup>237</sup> Additional requirements may address whether, when, and how a person must provide informed consent before being tested for HIV.238

Significant exposure. Laws in many states provide for mandatory HIV testing when specified individuals experience a "significant exposure" to HIV or other infectious diseases. For example, if a first responder is exposed to the blood or bodily fluids of an individual in a manner that is capable of transmitting HIV (e.g., a needlestick), that individual may be required to take an HIV test and the test results shared with the first responder. Variations among state laws include the specific definition of significant exposure, the individuals covered by the law (e.g., first responders, health professionals, correctional facility staff), and whether testing is automatically required or if the person that experienced the significant exposure must request the testing.

Criminal legal system. Specific HIV testing requirements also exist within the context of the criminal legal system. These requirements typically include mandatory, court-ordered testing when a person is charged with or convicted of specified offenses (e.g., sex-related offenses that involve the transmission of bodily fluids, people prosecuted for engaging in sex work)xxiv and testing within correctional settings such as jails and prisons. Test results are often shared with people who have been or may in the future be exposed to the individual being tested, such as survivors of sex-related offenses and correctional facility personnel.

**Public health.** State laws may authorize health officials to request or compel an individual to undergo HIV testing when necessary to protect public health. For example, Alabama authorizes HIV testing without written consent when knowledge of a person's HIV status is "necessary in order to protect health care personnel from [potential] HIV infection." The exact requirements – obtaining the individual's informed consent to the HIV testing or a court order compelling such testing – vary among states.

Routine opt-out and perinatal testing. CDC recommends the implementation of "opt-out" HIV testing for pregnant people, in which the person is tested unless they explicitly decline testing.<sup>240</sup> As of October 2018, laws in 30 states address HIV testing in pregnant people and newborns.<sup>241</sup> Laws in eight states align with CDC recommendations for HIV testing during the third trimester, labor, and delivery, as well as testing for newborns;xxv seven of these state laws also align with the recommendation to conduct HIV testing "as early as possible during each pregnancy."242 Moreover, while laws in 10 states address at least one CDC-recommended practice related to routine opt-out testing during pregnancy, only four of these states fully align with all CDC recommendations.243

Anonymous testing. All HIV testing is confidential, but some states have adopted laws authorizing or mandating the availability of anonymous HIV testing, recognizing concerns related to privacy

and stigma.<sup>244</sup> Although results from anonymous HIV testing may be reported to public health officials, such reports do not include information directly identifying the tested individual. Some states require health care professionals to provide information on the availability of anonymous HIV testing before performing an HIV test.<sup>245</sup>

**Privacy protections.** Privacy protection laws are designed to protect sensitive health information from unauthorized disclosures. Although certain exceptions to these privacy laws exist, the specific protections against the use and disclosure of HIV test results vary both among states and within a single state based on factors such as the reason for testing an individual, who administers the test, whether the test occurs through an anonymous testing program, who is seeking the test results, and the purposes for which the test results are used or disclosed. In some instances, these protections may be codified in laws specifically regulating HIV testing. In other instances, the use and disclosure of HIV test results are governed by privacy laws aimed at identifiable health information generally or HIV-related data specifically. For example, when an individual undergoes mandatory HIV testing following a significant exposure or being charged with or convicted of a crime involving the transmission of bodily fluids, state law may authorize disclosure of the test results to the person(s) potentially exposed to HIV but prohibit the subsequent use and disclosure of the test results.246

#### **EXAMPLES**

Significant exposure. Ohio state law allows a person to seek a court order "compelling another person to undergo HIV testing" if the person believes they "may have been exposed to HIV infection while rendering health or emergency care to the other person" or is a peace officer who "may have been exposed to HIV infection while dealing with the other person in the performance of official duties."

Criminal legal system. In Florida, a person who has been convicted, pled guilty, or pled *nolo contendere* (i.e., no contest) to specified offenses involving the

xxiv For additional information about the intersection between sex work and HIV criminalization, see The Center for HIV Law and Policy and National LGBTQ Task Force's The Intersection of Sex Work and HIV Criminalization: An Advocate's Toolkit.

xxv Pregnant individuals may refuse to undergo HIV testing. However, when the HIV status of the pregnant person is unknown, the newborn(s) generally may be tested for HIV regardless of parental consent or objection.

transmission of bodily fluids from one person to another must undergo HIV testing.<sup>248</sup> Similarly, Missouri state law empowers courts to require HIV testing as a condition of bond for a "person arrested for a prostitution-related offense, [and] who has been found guilty of a prior prostitution-related offense."<sup>249</sup>

### Criminal legal system (correctional settings).

Mississippi state law requires that public and private correctional facilities test "all offenders in the facility ... for tuberculosis and [HIV]" and requires such information be reported to state health officials.<sup>250</sup>

Public health. Georgia law authorizes the state's Department of Public Health "to make examinations of persons infected or suspected of being infected with HIV and to administer an HIV test with the consent of the person being tested" when "in [state health officials'] judgment [the examination and testing are] necessary to protect the public health." <sup>251</sup> If a person refuses to consent to testing, state health officials may seek a court order compelling the HIV test.

Perinatal testing. Florida state law requires that physicians and midwives "attending a pregnant woman for conditions relating to pregnancy during the period of gestation and delivery" must ensure the person is tested for sexually transmissible diseases, including HIV.<sup>253</sup> The law provides for an "opt out," meaning the person to be tested must affirmatively refuse testing.<sup>254</sup>

Disclosures of potential exposure. California state law authorizes local health officers to notify "any persons reasonably believed to be a spouse, sexual partner, or partner of shared needles of an individual who has tested positive on an HIV test about their exposure." The notice must not include identifiable information. In practice, however, certain exposure notifications are

inherently likely to result in the disclosure of a person's identity (e.g., disclosures of a person's HIV test results to their spouse).<sup>xxxi</sup>

Use and disclosure of HIV test results. In Florida, when a person convicted of certain offenses involving the transmission of bodily fluids is required to undergo HIV testing, the results of the test are disclosed to the (1) state Department of Health; (2) person convicted of the offense; (3) public health agency of both the county in which the conviction occurred and the county of residence of the person convicted; and (4) upon request, the victim of the crime.<sup>257</sup> Although the test results may not be used against the person in the criminal case that led to the mandatory testing, such information may be used to support a subsequent HIV criminal transmission prosecution.<sup>258</sup>

Anonymous testing. California state law requires that state and local public health officials "ensure continued reasonable access to anonymous HIV testing through alternative testing sites ... in consultation with HIV planning groups and affected stakeholders, including representatives of persons living with HIV and health officers." In Missouri, physicians must report HIV-positive test results to health officials but may include a unique patient identifier rather than the person's name and street address when a person is testing anonymously.<sup>260</sup>

#### FOR ADDITIONAL INFORMATION

State Laws That Address High-Impact HIV
Prevention Efforts

Centers for Disease Control and Prevention

Perinatal HIV Testing Laws

Centers for Disease Control and Prevention

xxvi Although contact tracing and partner notification are critical evidence-based practices, those engaging in such activities must balance their public health value with potential unintended consequences. For example, in the context of domestic relationships, a person with HIV may face intimate partner violence following disclosure of their HIV status. Once an initial disclosure regarding a person's HIV status occurs because of notification activities, there is also a risk that this information will be further disclosed. Additionally, public reporting about HIV outbreaks or clusters in small communities or among certain populations can lead to inadvertent disclosures about the identity of people with HIV. Public health professionals should remain cognizant of these considerations, including by engaging with people with HIV about these issues and concerns.

### **Q** What is the state legal landscape with respect to HIV-specific surveillance and reporting?

- 1. Does the state have an HIV-specific public health surveillance law?
- 2. Does the state have an HIV-specific reporting law?
- 3. Does the state HIV-specific surveillance and reporting law address reporting to ...
  - a. Local health officials?
  - b. State health officials?
  - c. Federal officials (e.g., CDC)?
  - d. Non-governmental people or entities (e.g., partner notification)?
  - e. Law enforcement?
  - f. Health care providers?
  - g. Other individuals or entities?
- 4. Who is required to report HIV-specific data?
  - a. Physicians?
  - b. Public health departments?
  - c. Emergency departments?
  - d. Laboratories?
  - e. Community-based organizations?
- 5. What types of data are included in mandatory reporting? Is reporting required for all tests or only positive tests?
  - a. CD4 cell counts?
  - b. Viral loads?
  - c. Molecular sequence data?

Many jurisdictions include HIV in their general disease reporting and public health surveillance laws. Some jurisdictions may also have laws specific to the surveillance and reporting of HIV, including notification requirements for people who have potentially been exposed to HIV (e.g., sexual partners of a person with HIV). These HIV-specific surveillance and reporting laws vary with respect to:

Mandated reporters. HIV-specific reporting requirements for new HIV diagnoses frequently apply to a variety of individuals and entities as reporters. These individuals and entities include, for example, physicians and other medical practitioners, hospitals, medical and public health laboratories, individuals and entities that perform HIV testing, and individuals and entities within the criminal legal system (e.g., jail and prison facilities).

Reporting triggers. Most commonly, HIV-specific reporting requirements apply whenever a mandated reporter obtains knowledge that a person has HIV through the results of an HIV test, an assessment of a person within the reporter's care, or the death of a person from complications related to HIV. In some

instances, however, certain reporting requirements may apply regardless of whether a person received a diagnosis of HIV (e.g., reporting requirements for court-mandated HIV testing of persons convicted of certain sex-related crimes).<sup>261</sup> Laws may require reporting within a specified amount of time.<sup>262</sup>

Report recipients. Laws and policies authorize or mandate that new HIV diagnoses be reported to both governmental and non-governmental actors. States and territories generally require that medical providers and laboratories report new HIV diagnoses to state, local, and/or territorial health departments. These jurisdictions subsequently submit such reports to CDC after removing any information that would identify the person with HIV.263 Additionally, although HIV surveillance and reporting laws generally do not require direct reports to non-governmental actors, many include requirements for subsequent disclosures by public health entities to specified individuals and entities. For example, following a new HIV diagnosis, laws may require health officials to notify people who may have been exposed to HIV, such as sexual partners or people who shared syringes with a person with HIV. Other entities that may receive

reports of HIV diagnoses include those within the criminal legal system (e.g., corrections officials taking custody of a person with HIV) and schools.<sup>264</sup>

**Required information.** The information required for reports made pursuant to HIV-specific surveillance and reporting laws varies. For example, as of 2021, 48 states, the District of Columbia, and Puerto Rico require reporting for "all CD4 and viral load data." 265 An increasing number of jurisdictions - 28 states and Puerto Rico, as of 2020 – also require reporting of HIV molecular data.<sup>266</sup> Other commonly required information includes background details (e.g., name, demographics, and contact information) and testing details (e.g., when, where, and by whom the HIV test was administered). The specific type and scope of information may vary based on the recipient and source of information. For example, although reports to state and local health departments often include individually identifiable information about the person with HIV, subsequent reports to CDC, including the National HIV Surveillance System, do not include such identifying information.<sup>267</sup> Similarly, laws may prohibit the inclusion of identifying information in reports submitted by anonymous HIV testing programs.

#### **EXAMPLES**

HIV reporting (general). California state law requires health care providers and laboratories to report cases of HIV infection to the local health officer, and the local health officer must report HIV cases to the state's Department of Public Health.<sup>268</sup>

HIV reporting (public health departments). Indiana law requires that licensed physicians, hospitals, medical laboratories, and the department of corrections report HIV cases to the state department of health<sup>269</sup> and includes an explicit waiver of physician-patient privilege for the purposes of such reports.<sup>270</sup>

HIV notification (criminal legal system). Georgia state law provides for the voluntary or compelled HIV testing of people who have been charged, convicted, or pled guilty to certain sexual offenses or other HIV-related offenses<sup>271</sup> and requires that test results finding that the person has HIV be disclosed to "[t]he officer in charge of any penal institution or other facility in which the person has been confined by order or sentence of the court for purposes of enabling that officer to confine the person separately from those not infected with HIV."<sup>272</sup>

HIV notification (people with HIV). Missouri requires people with HIV who have undergone HIV testing and are aware of their HIV status to "disclose such information to any health care professional from whom [the person with HIV] receives health care services." 273

Ohio state law requires a person with HIV who is aware of their HIV status to "disclose [their HIV status] to any other person with whom the [person with HIV] intends to make common use of a hypodermic needle or engage in sexual conduct...."274

HIV notification (non-governmental). New York State law requires a municipal health commissioner or district health officer to notify known contacts of a person with HIV when the commissioner or health officer determines that the "reported [HIV] case or, any other known case of HIV infection merits contact tracing in order to protect the public health."

CD4 cell count. Clinical laboratories in California must "report all CD4+ T-Cell test results to the local health officer ... within seven days" of completing the test regardless of the test result.<sup>276</sup> The reporting requirement explicitly notes that "CD4+ T-Cell test reports shall be considered confidential public health records" and may "not be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding."

Molecular data. Medical laboratories in Maryland are required to report HIV genotype sequence test results to the health officer for the jurisdiction in which the laboratory is located.<sup>279</sup> Similarly, Montana regulations require that laboratories performing HIV-related testing must report "all test results for assays designed to assess HIV infection subtype and resistance to antiretroviral drugs, including nucleotide sequences, in a format designated by the [state's Department of Public Health and Human Services]."<sup>280</sup>

#### FOR ADDITIONAL INFORMATION

State Laboratory Reporting Laws: Viral Load, CD4, and Molecular Data Requirements

Centers for Disease Control and Prevention

State Laws That Address High-Impact HIV
Prevention Efforts

Centers for Disease Control and Prevention

### **Q** What is the state legal landscape with respect to general disease reporting?

- 1. Does the state have a general disease reporting law?
- 2. Who is required to report communicable diseases?
- 3. To whom are communicable diseases reported?
- 4. At what level of government (federal, state, local, tribal, territorial) are diseases reported?
- 5. Which particular communicable diseases must be reported?
- 6. Does the general disease reporting statute address data confidentiality?

Laws in all states and many localities, territories, and tribes establish public health surveillance systems, including requirements to report cases of communicable diseases to relevant public health authorities. General communicable disease reporting requirements are an important source of information for public health surveillance generally and HIV surveillance specifically. Substantive variations among general disease reporting laws include the following:

Mandated reporters. Disease reporting laws specify who is *required* to report cases of communicable diseases. Mandated reporters generally include physicians and other medical professionals but may also include a broader array of individuals, including the general public. Some state laws also require local health officials and departments to forward case reports they receive to appropriate state officials.

Who receives case reports. State, local, territorial, and tribal laws also vary with respect to the individual(s) or entity that receives communicable disease case reports.<sup>281</sup> Common recipients of communicable disease case reports include local health departments, local health officers, state health departments, and state health officers. Some jurisdictions may require cases to be simultaneously reported to multiple individuals or entities such as both the local and state health departments.

#### Reportable diseases and required information.

Laws vary on which communicable diseases must be reported and the information that must be included in such reports. Some state statutes and local ordinances directly specify reportable diseases and required information. More common, however, are statutes and ordinances granting health officials the legal authority to issue regulations or sub-regulatory policies that establish more specific requirements. Some jurisdictions take a hybrid approach by including a baseline list of reportable diseases and

required information but authorize health officials to designate additional reportable conditions and information. Every state and the District of Columbia requires reporting for HIV cases.<sup>282</sup>

#### Use and disclosure of reported information.

Communicable disease reporting laws in many jurisdictions include specific privacy protections for information contained within case reports, whereas other jurisdictions rely on more general confidentiality laws to protect private health information included in communicable disease reports. These protections generally prohibit the use and disclosure of protected information contained within communicable disease reports unless the law explicitly authorizes or mandates such use or disclosure. The applicability of confidentiality protections (e.g., the individuals and entities required to abide by these protections) and the scope of any exceptions to otherwise applicable confidentiality protections, including the extent to which such data may be disclosed to and used by law enforcement and the criminal legal system, vary among jurisdictions.

### **EXAMPLES**

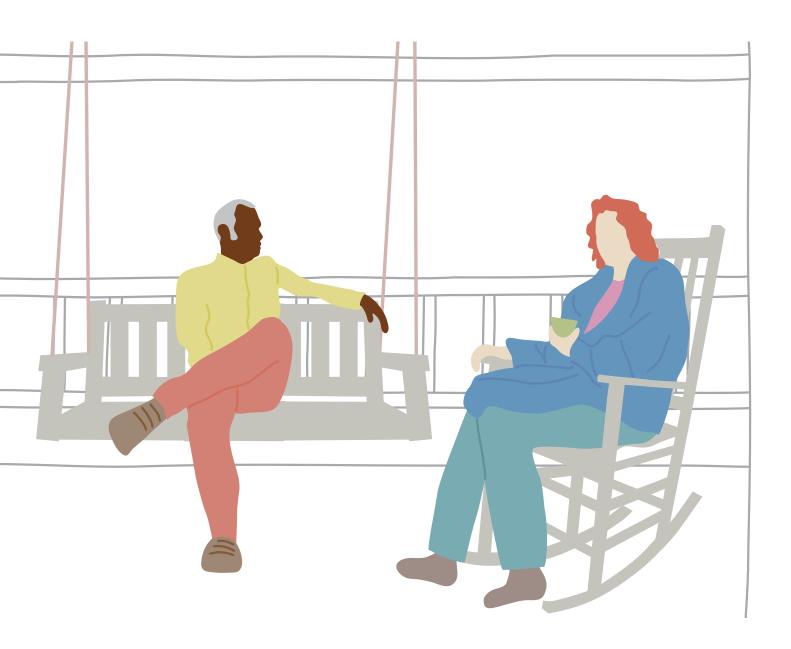
Mandatory reporting (general). The Pennsylvania Department of Health or local boards or departments of health may require individuals with "knowledge or suspicion of any communicable disease ... to make a prompt report of the disease" either to the respective local board or department of health or to the state department of health.<sup>283</sup>

Mandatory physician reporting. North Carolina requires a licensed physician "who has reason to suspect that [a patient] has a communicable disease" deemed reportable by the state's Commission for Public Health (including HIV) to report information to the applicable local health director.<sup>284</sup>

Confidentiality. North Carolina's communicable disease reporting law provides that "information and records, whether publicly or privately maintained, that identify a person who has or may have a disease or condition required to be reported ... shall be strictly confidential." <sup>285</sup> The statute prohibits the disclosure of such information except in accordance with certain enumerated exceptions. <sup>286</sup> These exceptions include certain disclosures to law enforcement if specified conditions are met. <sup>287</sup>

### FOR ADDITIONAL INFORMATION

Public Health Departments and State Patient
Confidentiality Laws
LawAtlas



### **HIV CRIMINALIZATION LAWS**

The HIV criminalization landscape varies substantially among states. These variations include both the substantive components of state laws that criminalize certain conduct by people with HIV and the implementation and enforcement of such laws.

This section outlines questions, considerations, and resources to help stakeholders understand the legal, health, and equity implications of HIV criminalization laws in their state.

### THIS SECTION ADDRESSES THE FOLLOWING QUESTIONS:

- Does the state criminalize conduct related to HIV?
- What are the characteristics of the HIV criminalization law?
- What else is known about the HIV criminalization law?

### **Q** Does the state criminalize conduct related to HIV?

- 1. Is there a specific HIV criminalization statute?
- 2. Is there a general STI (sexually transmitted infection) or communicable disease criminalization law?
- 3. Have state and/or local officials used criminal laws that are not specific to HIV, STIs, or other communicable diseases to criminalize HIV transmission or exposure (e.g., reckless endangerment)?
- 4. Does state law impose additional penalties on people with HIV who commit other crimes (e.g., upgraded charges and/or sentencing enhancements)?

Laws criminalizing conduct related to HIV can take several forms. These include the following:

- Laws that impose criminal penalties on people with HIV who are aware of their HIV status, engage in sexual activities, and do not disclose their HIV status and obtain the consent of their sexual partner(s)
- Laws imposing criminal penalties on people who transmit communicable diseases without specifically mentioning HIV or any other specific disease
- Laws criminalizing nonsexual conduct by people with HIV such as sharing syringes, biting or spitting on another person, and the donation of blood or organs

- The prosecution of people with HIV under more general criminal laws, such as laws defining assault, battery, reckless endangerment, attempted murder, and murder
- Laws and policies that impose more severe penalties on people with HIV who violate certain criminal laws (e.g., sexual offenses)

The structure and location of laws criminalizing HIV-related conduct differ among jurisdictions. States often codify these laws in their criminal or penal codes, public health codes, or in multiple locations. Therefore, assessing the HIV criminalization legal landscape in your jurisdiction may require a comprehensive review of the entire state statutory code. Provisions related to sentencing enhancements (i.e., imposing more severe penalties for criminal violations) may be codified alongside

HIV criminalization laws, in statutes or regulations governing state and/or local courts, or in uncodified, sub-regulatory policies such as judicial sentencing guidelines.

In addition to codified laws and sub-regulatory policies, understanding the HIV criminalization legal landscape may require assessing applicable case law – judicial decisions that have interpreted and applied the laws in particular legal cases involving conduct related to HIV. Reviewing case law is particularly important for assessing if, when, and how state or local governments have prosecuted people with HIV under more general criminal laws, such as laws defining assault, battery, reckless endangerment, attempted murder, and murder.

The next two series of questions address variations in the substantive characteristics of laws criminalizing HIV-related conduct.

#### **EXAMPLES**

Specific HIV criminalization law. Georgia imposes criminal penalties on people with HIV who engage in sexual acts with another person without disclosing their HIV status.<sup>288</sup>

#### Context-specific HIV criminalization law (sex work).

Oklahoma state law prohibits people with HIV who are aware of their HIV status from engaging in sex work, with violations constituting a felony punishable by up to five years in prison.<sup>289</sup> The Oklahoma HIV criminalization law for people who engage in sex work applies to conduct with low risk for transmitting HIV such as oral sex.<sup>290</sup>

#### General transmission criminalization law. lowa

imposes criminal penalties on any person who knows they are "infected with a contagious or infectious disease and exposes an uninfected person to the contagious or infectious disease" with either "the intent that" or "a reckless disregard as to whether the uninfected person contracts the contagious or infectious disease."<sup>291</sup>

General civil and criminal laws. Texas does not have a specific HIV criminalization law. However, the state has prosecuted people with HIV for aggravated assault and aggravated sexual assault, with courts finding that a person with HIV's seminal fluid can qualify as a deadly weapon.<sup>292</sup> In other instances, Texas successfully prosecuted people with HIV for attempted murder and other offenses for spitting on and/or biting another person, despite biting and spitting presenting a negligible risk of transmitting HIV.<sup>293</sup>

Sentence enhancement. Colorado establishes mandatory minimum incarceration sentences for a person convicted of certain sexual offenses when the person "had notice of the HIV infection prior to the date the offense was committed and the infectious agent of the HIV infection was in fact transmitted...."

#### FOR ADDITIONAL INFORMATION

HIV and STD Criminalization Laws

Centers for Disease Control and Prevention

HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice Center for HIV Law and Policy

HIV Criminalization by State

LawAtlas

State Laws That Address High-Impact HIV
Prevention Efforts

Centers for Disease Control and Prevention

### **Q** What are the characteristics of the HIV criminalization law?

- 1. Does the state HIV criminalization law align with current recommendations (e.g., US Department of Justice's <u>Best Practices</u> <u>Guide to Reform HIV-Specific Criminal Laws to Align with Scientifically-Supported Factors</u>)?\*\*xvii
- 2. Does the HIV criminalization law reflect current scientific information regarding HIV transmission and prevention?
  - a. Does the HIV criminalization law require specific intent to transmit the virus?
  - b. Does the HIV criminalization law require actual transmission of the virus?
  - c. Does the HIV criminalization law consider whether an individual is at reduced transmission risk, including viral suppression and/or the use of HIV prevention measures (e.g., partner PrEP and condom use)?
  - d. Does the HIV criminalization law penalize behavior with a low or negligible risk of transmitting HIV (e.g., spitting, biting)?
- 3. What are the penalties for violating the state HIV criminalization law?
  - a. Does the HIV criminalization law specify a particular length or range of lengths of incarceration for violations?
  - b. Are individuals convicted of violating state HIV criminalization laws required to register as a sex offender?

The scope, characteristics, and application of HIV criminalization laws vary substantially among jurisdictions. These variations include the extent to which such laws adhere to current evidencebased best practices such as the US Department of Justice's recommendations on aligning HIV-specific criminal laws with scientifically supported factors.<sup>295</sup> Indeed, HIV criminalization laws have more often than not failed to keep pace with the science of HIV transmission and thus continue to impose harsh penalties for conduct with little risk of transmitting HIV such as spitting, biting, engaging in sexual activities with measures to reduce transmission risk (e.g., condom and partner PrEP use), and engaging in sexual activities when the person with HIV is on ART and virally suppressed.

Common variations in HIV criminalization laws include the following:

**Legal culpability standard.** Legal culpability refers to the "state of mind" required for a person to violate a law. Culpability standards generally operate on a spectrum. On one end of the spectrum, strict liability means that a person who violates the law may be penalized for the violation regardless of whether they

intended to cause harm, commit a crime, or even had knowledge that their conduct was illegal. On the other end of the spectrum, specific intent means a person may be penalized only if they explicitly intended to commit a specified harm (e.g., intending to transmit HIV). Standards such as general intent (i.e., intending to engage in certain conduct even if not intending to cause a specific outcome), knowingly, recklessly, gross negligence, and negligence, among others, exist between strict liability and specific intent. (See Appendix I for additional information on the meaning of these terms.) Additionally, these definitions vary across states, and some states may use different terminology entirely, but the underlying principles are relatively generalizable among states.

The applicable culpability standard can substantially affect the operation of HIV criminalization laws. For example, many states impose criminal penalties only when a person with HIV has actual knowledge of their HIV status. Although a knowledge requirement ostensibly makes intuitive sense and avoids criminalizing people with HIV who are unaware of their HIV status, it can also result in unintended consequences, such as incentivizing people to avoid

xxvii The US Department of Justice's recommended best practice includes eliminating HIV-specific criminal penalties except:

xxviii Strict liability crimes are rare, with most criminal offenses requiring proof of criminal intent or, at minimum, criminal negligence. The fact that some HIV criminalization laws impose strict liability underscores the unusually harsh way in which many state laws regulate conduct by people with HIV.

<sup>1.</sup> When a person knows they have HIV and "commits a (non-HIV specific) sex crime where there is a risk of transmission (e.g., rape or other sexual assault)"; or

When a person knows they have HIV and "the evidence clearly demonstrates that individual's intent was to transmit the virus and that the behavior engaged in had a significant risk of transmission, whether or not transmission actually occurred." www.hivlawandpolicy.org/sites/default/files/DOj-HIV-Criminal-Law-Best-Practices-Guide.pdf

HIV testing or treatment because remaining ignorant of their infection status can shield them from potential criminal liability.<sup>296</sup> Similarly, some HIV criminalization laws require that a person with HIV act in a reckless manner – generally defined as being "the creation of a substantial and unjustifiable risk of harm to others [with] a conscious (and sometimes deliberate) disregard for or indifference to that risk"— in exposing another to person to HIV.<sup>297</sup>

A person's legal culpability can also influence the severity of penalties under HIV criminalization laws. Some states, for example, establish tiered violations whereby the unintentional transmission of HIV is a lesser offense (e.g., a misdemeanor) and intentional transmission is a more severe offense (e.g., a felony). Other states impose severe consequences (e.g., felony convictions) regardless of whether a person with HIV caused or intended to cause harm.

The culpability standard required to establish a violation of a particular HIV criminalization law is important to understanding the law's potential health and equity effects. For example, HIV criminalization laws that require an intent to transmit the virus generally pose fewer public health and equity concerns because the enforcement of such laws is limited to individuals who actively and purposefully seek to harm another individual. The narrower application of these HIV criminalization laws makes them less likely to deter people with HIV from seeking appropriate medical care or disclosing their HIV status. HIV criminalization laws that require only general intent (including laws requiring only that a person with HIV is aware of their HIV status). in contrast, are more worrisome from a health and equity perspective, because they can be used to prosecute people with HIV regardless of whether the person intended to cause harm, and the wideranging conduct covered by the HIV criminalization law increases the potential for inequitable application of the law based on implicit and explicit biases.

Transmission requirement. HIV criminalization laws may apply only when a person with HIV actually transmits HIV to another person, or they may penalize people with HIV for engaging in certain conduct regardless of whether their conduct resulted in the transmission of HIV to another person. In some states, HIV criminalization laws apply regardless of

transmission but establish different penalties based on whether the person with HIV *actually* transmits the virus to another person.

Consideration of preventive measures. As the effectiveness of HIV prevention and treatment interventions has improved, some states have modified their HIV criminalization laws to consider the use of specified measures to prevent the transmission of HIV (e.g., condom use and HIV treatment). These modifications can, for example, allow the use of such preventive measures to negate a finding of specific intent to transmit HIV, reduce the severity of the offense and applicable penalties, or eliminate criminal liability entirely. In contrast, many states continue to criminalize conduct related to HIV regardless of whether a person with HIV is taking preventive measures, notwithstanding scientific evidence that such precautions significantly reduce or even eliminate the risk of transmitting the virus. Laws can also specify that the failure to take measures such as HIV treatment and condom use is insufficient on its own to establish that a person acted with specific intent to transmit HIV.298 In light of substantial racial, socioeconomic, and other disparities in access to medical care and preventive measures, provisions specifying that the failure to take measures such as HIV treatment is insufficient to establish specific intent can reduce the likelihood that reformed HIV criminalization laws further compound inequities among structurally marginalized populations.

Transmission risk. HIV criminalization laws also vary in how they address conduct that poses little to no risk of transmitting HIV. Many state HIV criminalization laws were adopted before the development of current scientific evidence on transmission risk and more effective treatment options. For example, states may criminalize people with HIV who spit on or bite another person regardless of the contemporary understanding that such conduct presents a negligible transmission risk, as well as fail to account for the effectiveness of prophylactics such as pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) in reducing transmission risk. HIV criminalization laws generally do not differentiate among forms of sexual conduct despite varying transmission risk (e.g., oral sex is low-risk).<sup>299</sup> Moreover, some HIV criminalization laws expand the scope of criminalized conduct

without any corresponding increase in public health or safety. Laws criminalizing the donation of blood, tissue, semen, or breast milk by people with HIV, for instance, do not provide any additional protections against the transmission of HIV, because standard practices require that such donations be screened and tested for HIV and other diseases before their use.<sup>300</sup>

Penalties for violations. Common penalties for violations of HIV criminalization laws include fines and incarceration. The type and severity of penalties vary among states and for different types of offenses within a particular state, with potential lengths of incarceration ranging from less than one year to life imprisonment.301 The majority of states establish a maximum sentence length of between 1 and 20 years.302 Some state HIV criminalization laws do not directly establish the applicable penalties but rather classify violations as a particular type of offense, with the range of potential sanctions for that class of offense set forth in more general state criminal laws.303 In many instances, the penalties for violating HIV criminalization laws, including the length of incarceration, are disproportionately harsh relative to the severity of the offense, often exceeding penalties imposed, for example, for vehicular homicide, driving under the influence, and reckless endangerment. (These more severe penalties are imposed despite the fact that HIV criminalization laws frequently apply even to consensual activities.)304 Several states require that people convicted of violating the state HIV criminalization law register as a sex offender and comply with the requirements and restrictions that accompany such registration.305 Other states grant courts the discretion to determine whether a person convicted of violating an HIV criminalization law must register as a sex offender. These registration requirements can carry lifetime consequences, affecting where individuals can live or work and with whom they may associate, as well as further reinforce stigma against people with HIV.

#### **EXAMPLES**

No defense for reduced transmission risk. The only defenses established by Georgia's HIV criminalization law are if "a person living with HIV" discloses their HIV status before engaging in prohibited conduct (i.e., engaging in a sexual act) or the "person living with HIV ... is forced into a sexual act against [their] will." Neither a person with HIV being virally suppressed nor the use of preventive measures such as condoms are defenses to violations of the HIV criminalization law.

Defense for reduced transmission risk. Iowa does not impose criminal penalties on a person "if the person takes practical means to prevent transmission, or if the person informs the uninfected person that the person has a contagious or infectious disease and offers to take practical means to prevent transmission but that offer is rejected by the uninfected person subsequently exposed to the infectious or contagious disease." 307

Consideration of precautions to reduce transmission risk. North Carolina regulations require people with HIV to use condoms during sexual intercourse unless at least one of four conditions are met:

- "[T]he person living with HIV is" receiving HIVrelated medical care, adheres to "the treatment plan of [their] physician, and has been virally suppressed [(defined as HIV levels below 200 copies per milliliter)] for at least 6 months";
- The sexual partner is also a person with HIV;
- The sexual partner takes PrEP antiretroviral medication "to prevent HIV infection as directed by [a] physician; or"
- "[T]he sexual intercourse occur[s] in the context of a sexual assault in which the person living with HIV [is] the victim."<sup>308</sup>

Specific intent requirement. State HIV criminalization laws may require specific intent to *transmit* HIV or specific intent to *expose* another person to HIV. For example, California's infectious and communicable disease criminalization law (which includes HIV) applies when a person with HIV "acts with the specific intent to *transmit* or cause [a] ... third party [with an infectious or communicable disease] to *transmit* that [infectious or communicable] disease to another person." The "specific intent to transmit" language in California's law differs from Kansas state law, which makes it a felony for a person who knows they are "infected with a life threatening communicable disease"

to engage in sexual conduct, sell or donate bodily fluids, or share syringes with another person "with the intent to expose" others to such "life threatening communicable disease."<sup>310</sup>

Actual transmission. Michigan's HIV criminalization law makes it a felony for a person with HIV who is aware of their HIV status to engage in sexual conduct without disclosing their HIV status if they (1) specifically intend to transmit the virus; or (2) actually transmit the virus to their sexual partner, regardless of intent.<sup>311</sup>

Criminalizing conduct with low or negligible transmission risk. Idaho's HIV criminalization law applies to people with HIV who know their HIV status and "transfer[] or attempt[] to transfer any of [their] body fluid ... to another person," despite evidence that biting presents only a negligible risk of transmitting HIV.313

Tiered penalties based on intent. Iowa criminalizes people with HIV or other contagious or infectious diseases who are aware of their infection and intend to transmit the infection to another person or act with reckless disregard for whether such transmission will occur.<sup>314</sup> The statute imposes different penalties based on whether the person acted intentionally or with reckless disregard and whether the person exposed to the contagious or infectious disease contracts the disease.<sup>315</sup>

Length of incarceration. Georgia classifies violations of its HIV criminalization law as a felony and provides that a person convicted of violating the law may be imprisoned for up to five years.<sup>316</sup>

#### Requirement to register as a sex offender. South

Dakota includes "[i]ntentional exposure to HIV infection" among the crimes requiring registration as a sex offender.<sup>317</sup> A person with HIV commits the crime of intentional exposure to HIV infection if they are aware of their HIV status and "[e]ngag[e] in sexual intercourse or other intimate physical contact with another person."<sup>318</sup> In Arkansas, a court has the discretion to require that a person convicted of "[e]xposing another person to [HIV]" register as a sex offender.<sup>319</sup>

#### FOR ADDITIONAL INFORMATION

Guide to Reform HIV-Specific Criminal Laws to Align with Scientifically Supported Factors

US Department of Justice

HIV and STD Criminalization Laws

Centers for Disease Control and Prevention

HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice Center for HIV Law and Policy

HIV Criminalization by State LawAtlas

State Laws That Address High-Impact HIV
Prevention Efforts

Centers for Disease Control and Prevention

### **Q** What else is known about the HIV criminalization law?

- 1. Does the law require people with HIV to disclose their HIV status to certain people (e.g., sex partners, individuals who share syringes)?
- 2. Does the HIV criminalization law explicitly address the role of state and/or local health departments?

Mandated disclosures. HIV criminalization laws often require people with HIV to disclose their HIV status before engaging in certain conduct such as sexual activities or sharing syringes. These requirements may be direct, such as when a law directly states that a person with HIV must disclose their HIV status under specified criteria, or indirect, such as when a law prohibits specified conduct and imposes penalties on a person with HIV unless the person has disclosed their HIV status. In general, both direct and indirect disclosure mandates will have the same substantive effect.

State and local health departments. Some state HIV criminalization laws directly address the role of state and local health departments and other public health officials in identifying, investigating, and prosecuting people with HIV who are alleged to have violated the HIV criminalization law. Other state and local laws may address the role of public health officials even if the HIV criminalization law itself is silent on the issue. Laws that govern public health surveillance and the confidentiality of public health records more generally, for instance, may include provisions affecting how public health officials are authorized or required to interact with the criminal legal system with respect to enforcing the HIV criminalization law. The involvement of public health officials in the criminal legal system, especially where such participation is mandated, can undermine the general public's trust in public health and reduce their willingness to engage with prevention and surveillance activities.320 In contrast, other state laws may explicitly prohibit the use of public health data for criminal enforcement purposes, which can help alleviate privacy concerns.321

The sections of this assessment tool on health data privacy and public health surveillance address these considerations in greater detail.

#### **EXAMPLES**

#### Mandatory disclosures to criminal legal system.

Although Arkansas generally requires that "information and reports in connection with persons suffering from or suspected to be suffering from [HIV]" be kept confidential, state law provides that "any prosecuting attorney of this state may subpoena information as may be necessary to enforce [HIV criminalization laws], provided that any information acquired pursuant to the subpoena shall not be disclosed except to the courts to enforce this section."<sup>322</sup>

Mandatory disclosures outside the criminal legal system. Ohio requires people with HIV who are aware of their HIV status to inform any person with whom they intend "to make common use of a hypodermic needle or engage in sexual conduct." The Ohio law defines sexual conduct as inclusive of conduct with low risk of transmitting HIV such as oral sex. 324

### FOR ADDITIONAL INFORMATION

**HIV and STD Criminalization Laws** 

Centers for Disease Control and Prevention

HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice Center for HIV Law and Policy

HIV Data Privacy and Confidentiality: Legal & Ethical
Considerations for Health Department Data Sharing
NASTAD

**HIV Criminalization Laws Dataset** 

LawAtlas

HIV Criminalization in <u>California</u>, <u>Florida</u>, <u>Georgia</u>, and <u>Missouri</u>

Williams Institute, UCLA School of Law

State Laws That Address High-Impact HIV Prevention
Efforts

Centers for Disease Control and Prevention

# CONSIDERATIONS AND RESOURCES FOR IMPLEMENTATION AND ENFORCEMENT

The preceding sections focus primarily on the content of statutes, regulations, and sub-regulatory policies related to HIV surveillance, data privacy, and HIV criminalization. However, how these laws and policies affect public health and equity ultimately depends on how they are implemented and enforced. This

section outlines questions and considerations to help assess the implementation and enforcement of HIV surveillance, data privacy, and HIV criminalization laws, as well as understand what additional resources may be available to assist with implementation and enforcement.

#### THIS SECTION ADDRESSES THE FOLLOWING QUESTIONS:

- What is the landscape with respect to implementation and enforcement?
- What additional resources are available to support implementation and enforcement?

### **Q** What is the landscape with respect to implementation and enforcement?

- 1. Does a government entity (e.g., a state health department) have the legal authority to adopt regulations implementing state HIV surveillance and HIV confidentiality laws? If so, which government entity has such authority?
- 2. Are health department staff required to receive training on data privacy and confidentiality?
- 3. What are the penalties for disclosing confidential HIV-related information contrary to applicable law and/or department policy?
  - a. Who is responsible for enforcement?
  - b. Are the relevant authorities actively enforcing the law?
  - c. If the relevant authorities are not adequately enforcing data privacy laws, are there alternative approaches to ensure compliance (e.g., private litigation)?
- 4. Are state and local health department policies regarding disclosures to law enforcement aligned?
- 5. What types of intra- and inter-agency collaboration have been established and/or planned with respect to implementation and enforcement?
- 6. What types of collaboration among different levels of government (federal, state, tribal, local, and territorial) have been established and/or planned with respect to implementation and enforcement?
- 7. What policies, technologies, and data systems are in place to protect against security breaches (e.g., hacking)?
- 8. How have courts interpreted and applied state laws related to HIV criminalization, HIV and other public health surveillance, and data privacy? Is anyone actively tracking legal decisions on these issues?
- 9. What else is known about the implementation and enforcement of the state HIV criminalization law?

Policy agendas and policy design play an important role in shaping equitable health outcomes - including whether and how public health and data privacy laws affect people with HIV – and it is important to set priorities and draft laws and policies with equity in mind. Although they often receive less attention, policy implementation and enforcement mechanisms can be as influential as the policies themselves and merit the same level of thought, analysis, and design. Policy implementation and enforcement are particularly important considerations in the context of HIV surveillance, data privacy, and HIV criminalization laws because of the sensitive nature of HIV-related data and potential consequences should such data be misused, up to and including the criminal prosecution of people with HIV.

Rulemaking authority. When crafting legislation, it is impracticable or even entirely infeasible for lawmakers to account for every possible scenario in which the law may apply, and lawmakers may lack the technical expertise necessary to fully formulate the policy details. As a result, legislation often authorizes administrative entities, such as health departments, to adopt regulations to fill in the details of the law.

In the context of public health surveillance, state laws may delegate rulemaking authority to state and local health departments, allowing them to implement HIV reporting requirements by, for example, adopting regulations specifying when, how, and to whom such reports are made. Similarly, HIV confidentiality laws may authorize administrative rulemaking that sets forth procedures for implementation and enforcement. The Illinois AIDS Confidentiality Act, for example, authorizes the Illinois Department of Public Health to issue regulations that "include procedures for taking appropriate action with regard to health care facilities or health care providers which violate this Act."<sup>325</sup>

Understanding rulemaking authority is important to assessing the current legal landscape with respect to HIV surveillance and confidentiality. Additionally, although administrative rules cannot contravene state statutes, the rulemaking process may nevertheless provide opportunities to strengthen legal and public health protections for people with HIV.

**Training.** Because of the sensitive nature of identifiable HIV-related health information and

the complexity of laws governing the collection, maintenance, use, and disclosure of such information, it is important that all government staff involved in these efforts receive training on proper procedures, applicable law, and the importance of maintaining confidentiality. The NCHHSTP Data Security and Confidentiality Guidelines require training for all staff as well as more specific training for staff with access to identifiable health information.326 The contents of such training include (1) personal responsibilities; (2) procedures for ensuring physical security of protected information; (3) procedures for electronically storing and transferring data; (4) policies and procedures for data sharing; (5) procedures for reporting and responding to security breaches; and (6) review of relevant laws and regulations.327 It is also important that staff receive training that reflects the lived experiences of diverse communities, especially people with HIV and those with intersectional identities, in order to better understand issues such as discrimination and criminalization.

**Enforcement authority.** The entities responsible for enforcing public health and HIV-related laws vary across states and specific laws. HIV criminalization laws, for example, are typically enforced by prosecutors at the state or local level. In contrast, general public health and HIV-specific surveillance. reporting, and confidentiality laws may be enforced by a variety of actors such as state and local health officials, state attorneys general, traditional law enforcement (e.g., police), and prosecutors, among others. Multiple entities can have concurrent authority to enforce a particular law, or the designated enforcement authority may depend on the types of penalties sought for violations (e.g., health officials or professional licensing boards may enforce HIV confidentiality laws through civil and administrative penalties, while state attorneys general and prosecutors enforce the same law if the violation is charged as a criminal offense).

Some state HIV laws may not explicitly vest enforcement authority in any particular individual or entity; many states, however, have more general laws granting enforcement authority to specific actors (e.g., specifying that law enforcement and prosecutors may enforce any offense or any offense carrying certain types of penalties such as criminal

prosecution). In these instances, stakeholders must assess the types of penalties applicable to violations of the HIV-related law as well as the broader state legal landscape to understand the default enforcement entity for such penalties.

Additionally, enforcement authority may be contingent on specified conditions. In Michigan, for example, state law allows the state's Department of Health to delegate their powers to local health departments in most cases.<sup>328</sup> Other state laws grant primary enforcement authority to local health officials but allow state health officials to step in when local actors are unable or unwilling to take action.

Some health, public health, and HIV-specific confidentiality laws also grant a private right of enforcement, which enables a person harmed by a violation of a law (e.g., a person with HIV whose HIV status is unlawfully disclosed) to bring an action in court to enforce the law. Although a private right of enforcement provides a means of recourse for harmed individuals when government officials fail to take action, such private enforcement rights can also raise equity considerations, because they favor individuals who have the time, knowledge, and resources to independently litigate their case.

**Penalties.** Penalties for violations vary substantially across states and within states, depending on the specific law that was violated, the nature of the violation, and the category of people who committed the violation. For example, penalties for criminal offenses such as violations of HIV criminalization laws include incarceration, fines, and, in some instances, registration as a sex offender. Violations of other HIV-related laws, such as HIV confidentiality laws and laws that mandate reporting of HIV cases to public health authorities, may carry criminal penalties (e.g., incarceration and fines); civil penalties (e.g., fines); and administrative penalties (e.g., fines). These laws may also specify additional penalties for specific categories of individuals, such as suspending the medical license of a health care professional who unlawfully discloses confidential HIV information, and specific types of violations, such as imposing harsher penalties for intentional violations. Finally, subregulatory policies such as internal health department policies may include additional procedures and penalties to handle violations by employees.

Case law. Understanding the implementation and enforcement landscape with respect to public health surveillance, confidentiality, and HIV criminalization may require assessing applicable case law in addition to codified laws and sub-regulatory policies. Case law refers to judicial decisions that have interpreted and applied the laws in particular legal cases. Case law can, for example, illuminate how courts have interpreted the scope and applicability of confidentiality protections and exemptions to those protections. Additionally, case law both specific to public health surveillance, data confidentiality, and HIV criminalization and more generally may provide insight on government entities' legal authority to take specified actions (e.g., a state or local health department's authority to adopt regulations, adopt sub-regulatory policies, and restrict the sharing of confidential data except for legitimate public health purposes).

Alignment and collaboration. Because of the broad array of individuals and entities, both governmental and non-governmental, involved in HIV prevention and response efforts, concerted efforts are needed to ensure alignment and collaboration on the implementation and enforcement of HIVrelated public health laws. Such alignment and collaboration are particularly important in the context of confidentiality protections, where developing a shared understanding of applicable law and sub-regulatory policies and practices can prevent conflicts as to whether, when, and to what extent HIV-related health information is used and disclosed. Collaboration and alignment can also help build public trust that any confidential information collected by and shared among various entities (e.g., between local and state health departments or between government health officials and community-based service providers) will remain confidential and used only for legitimate public health purposes.

Policy versus practice. How a casual reader may interpret the written legal or policy language on the books does not always fully capture and align with how laws and policies are interpreted, implemented, and enforced in practice. Such scenarios are particularly likely when laws and policies contain ambiguous language or provide broad and unconstrained discretion for those involved with implementation and enforcement.

For example, Louisiana's HIV criminalization law prohibits a person with HIV who is aware of their HIV status from intentionally exposing another person to HIV without the person's knowledge and consent.329 This intentionality requirement could be reasonably understood as limiting application of the HIV criminalization law to scenarios in which a person acts with the explicit purpose of exposing another to HIV. However, Louisiana state courts have instead interpreted the law as requiring merely that a person with HIV intended to engage in specific conduct (e.g., sexual activity) that could result in transmitting the virus rather than a specific intent to actually transmit the virus.330 This example underscores the importance of considering not only the provisions within a law or policy but also when, how, and against whom those written provisions are acted upon.

#### **EXAMPLES**

Rulemaking authority (HIV-specific). New York state law requires the state Commissioner of Health to issue "such rules and regulations as shall be necessary and proper to effectuate the purpose of" the state HIV reporting, contact tracing, and confidentiality laws.<sup>331</sup>

Rulemaking authority (general). Michigan state law authorizes the state's Department of Health and Human Services to issue regulations "necessary or appropriate to implement and carry out the duties or functions vested by law in the department."

Training requirements. Kentucky requires that access to data from the state's HIV reporting system be restricted to "a minimum number of authorized ...staff who are designated by a responsible authorizing official, who have been trained in confidentiality procedures, and who are aware of penalties for unauthorized disclosure of surveillance information."333

Enforcement authority. Delaware's state HIV testing and confidentiality law authorizes enforcement by (1) a person who is harmed by a violation (e.g., a person with HIV whose HIV test result is unlawfully disclosed); or (2) the state attorney general.<sup>334</sup>

Mandatory enforcement. Kentucky state law requires "authorized surveillance staff" for the state's HIV reporting system to "[i]mmediately investigate any report of breach of reporting, surveillance, or confidentiality policy, report the breach to the CDC,

### **Equitable Enforcement**

There is a significant gap between the promise of our laws and people's lived experiences. This gap exists in part because laws designed to keep people safe and healthy often are not enforced and, when they are, are not enforced equitably in a way that promotes health and well-being for the most underserved communities. Enforcement actions taken in the name of public health can sometimes harm, discriminate against, or otherwise undermine the health of the very people whom the laws are meant to protect. In fact, enforcement that is carried out inequitably can often create, maintain, or exacerbate existing health inequities. Equitable enforcement – the process of ensuring compliance with law and policy that considers and minimizes harm to underserved communities – can hold wrongdoers accountable while protecting the health and well-being of individuals and communities. An equitable enforcement approach means considering equity at all levels of the public entity's overall enforcement strategy and individual enforcement actions, as well as considering equity at all stages of enforcement, from determining whether and when to undertake an enforcement action, and against whom, to deciding which enforcement tools to use.

Inequitable enforcement can occur due to both underenforcement and overenforcement. Underenforcement is when laws that are designed to protect individuals and communities are not consistently enforced, often in already marginalized communities. For example, the failure to adequately enforce HIV data privacy laws can undermine public health efforts, so an equitable enforcement approach would call for more frequent and forceful enforcement. Overenforcement is when laws are enforced more frequently or more strictly in certain places or against certain people in comparison with others. Overenforcement also includes the strict enforcement of laws even when it does not necessarily further a public health goal. HIV criminalization laws are grounded in stigma and fear, are often enforced disproportionately against people from underserved communities, and not only lack a legitimate public health purpose but actively discriminate against and undermine the health and well-being of people with HIV. An equitable enforcement approach would therefore avoid criminalizing conduct by people with HIV and instead focus on enforcement of laws that support evidence-based public health approaches to HIV.

ChangeLab Solutions' <u>Equitable Enforcement to Achieve Health</u> <u>Equity: An Introductory Guide for Policymakers and Practitioners</u> includes additional information on strategies for evaluating and implementing the equitable enforcement of public health laws.

develop recommendations for improvements in security measure[s], and take appropriate disciplinary action for any documented breach."<sup>335</sup>

Private right of enforcement. Arizona authorizes people who take an HIV-related test or receive a diagnosis of HIV or another communicable disease to file a legal action against a person who violates confidentiality protections.<sup>336</sup>

Penalties for violations (general). Oklahoma's public health data confidentiality law includes both civil and criminal penalties for people "who negligently, knowingly or intentionally disclose[] or fail[] to protect medical or epidemiological information classified as confidential." Criminal penalties include misdemeanor charges with a fine of at least \$1,000, up to 30 days in county jail, or both. Civil penalties include "court costs, attorney fees, exemplary damages and all actual damages, including damages for economic, bodily or psychological harm which are proximately caused by the disclosure."

Penalties for violations (tiered). The California AIDS
Public Health Records Confidentiality Act establishes
tiered penalties based on the culpability of the person
violating the law.<sup>340</sup> A person who is negligent in
unlawfully disclosing "any confidential public health
record" is "subject to a civil penalty" of up to \$5,000
"plus court costs."<sup>341</sup> In contrast, a person who unlawfully
discloses a "confidential public health record" in a
willful or malicious manner is "subject to a civil penalty"
of \$5,000 to \$25,000, "plus court costs."<sup>342</sup> The law
also establishes criminal penalties and allows a person
harmed by unlawful disclosure to recover damages.<sup>343</sup>

#### Penalties for violations (health professionals).

Illinois regulations provide that licensed, certified, or permitted "[h]ealth care facilities and health care professionals" that violate the state's AIDS confidentiality act in a "reckless, deliberate or conscious" manner may have their license, certificate, or permit suspended, revoked, or denied.<sup>344</sup>

#### Penalties for violations (government employees).

Wisconsin state law provides that an "employee of the state or a political subdivision of the state who violates [the state HIV testing and confidentiality statute] may be discharged or suspended without pay."<sup>345</sup>

#### FOR ADDITIONAL INFORMATION

<u>Data Security and Confidentiality Guidelines</u> NCHHSTP (CDC)

Public Health Law Academy <u>Administrative</u>
Law Training

Centers for Disease Control and Prevention & ChangeLab Solutions

Equitable Enforcement to Achieve Health Equity
ChangeLab Solutions

### **Q** What additional resources are available to support implementation and enforcement?

- 1. What internal legal and policy resources are available?
- 2. What external legal and policy resources are available?
- 3. Are sample data sharing agreements available?
- 4. Are training and technical assistance available with respect to interventions, organizational infrastructure, HIV testing results, policies for data security and confidentiality, data sharing across programs, and data reporting related to surveillance for providers and staff of participating health care facilities and community-based organizations or other service organizations?
- 5. What community engagement resources are available?

Assessing the legal, health, and equity landscape of HIV surveillance, data privacy, and criminalization laws may require or benefit from a variety of internal (i.e., within a state or local department or other government agency) and external (e.g., from technical assistance providers) resources.

Internal resources may include direct consultation with government legal counsel and subject matter experts; departmental memorandums, legal opinions, and guidance; and sample or model data sharing agreements.

**External resources** may include organizations that provide focused technical assistance and supports related to HIV policy, such as NASTAD; organizations that support state and local health officials more generally, such as CDC, the National Association of County and City Health Officials (NACCHO), and the Association of State and Territorial Health Officials (ASTHO); and organizations that advocate

on behalf of people with HIV such as The Center for HIV Law and Policy, Lambda Legal, and the Legal Action Center. External resources also include HIV-specific resources such as this assessment tool and NASTAD's HIV Data Privacy and Confidentiality brief, as well as resources on more foundational topics, such as the trainings available through the Public Health Law Academy.

The successful, equitable implementation and enforcement of HIV surveillance, data privacy, and HIV criminalization laws require both community support (e.g., from people with HIV and organizations that advocate on behalf of people with HIV) and efforts from other non-governmental actors (e.g., health providers). Therefore, it is equally important to assess the resources available to these individuals and entities, including trainings, technical assistance, and community engagement tools.

### CONCLUSION

State, local, and federal public health surveillance efforts, including HIV surveillance, are vital to addressing and ultimately ending the HIV epidemic. Data collected through these surveillance efforts allow health officials to identify HIV infections at early stages, detect and respond to clusters and outbreaks, refer and link individuals to treatment in a timely fashion, and evaluate how laws and policies affect HIV-related health outcomes and inequities. Nevertheless, the collection, use, and dissemination of individuals' health data can raise substantial privacy concerns – concerns that are even more acute in the HIV context because of widespread stigma and, in many instances, the criminalization of conduct by people with HIV. Concerted efforts are needed to assess and, where necessary, reform laws and policies to ensure that public health officials can effectively collect, use, and share HIV-related data for legitimate public health purposes while preventing the criminalization, incarceration, and further marginalization of people with HIV.<sup>346,347,348</sup>



# APPENDIX I: KEY TERMINOLOGY AND ABBREVIATIONS

The exact definition and meaning of terms in this glossary may vary among jurisdictions.

**AIDS** refers to acquired immunodeficiency syndrome, the most severe phase of HIV.<sup>349</sup>

**Antiretroviral therapy (ART)** refers to medications used to treat HIV.<sup>350</sup>

Case law, sometimes referred to as common law, refers to law that comes from judicial decisions rather than codified laws such as statutes, ordinances, regulations, and constitutions.

**CD4 cells** are a type of white blood cell and are a key part of the body's immune system that can be negatively affected by HIV.<sup>351</sup>

**CDC** refers to the Centers for Disease Control and Prevention, a division of the US Department of Health and Human Services.

Criminal justice system refers to the processes and institutions with which an individual interacts when investigated for or charged with a criminal offense. These include institutions and actors within law enforcement (e.g., police); the judiciary (e.g., judges and prosecutors); and corrections (e.g., jails and prisons).<sup>352</sup>

**Data sharing agreements** are contracts between two or more parties (e.g., government entities and nongovernmental organizations) to share data for a specific purpose and subject to specified conditions.

**De-identified data** refers to data that have been stripped of details so that the data cannot be attributed to any specific individual or entity.

**Department policy** refers to a type of sub-regulatory policy created and enforced by an entity (e.g., a state or local health department) with respect to the department's employees, programs, and resources.

**Discovery (legal)** refers to the process by which parties engaged in litigation (e.g., a criminal prosecution or civil lawsuit) seek information from opposing parties in the litigation.<sup>353</sup>

Ending the HIV Epidemic is "a bold plan announced in 2019 that aims to end the HIV epidemic in the United States by 2030" by leveraging "critical scientific advances in HIV prevention, diagnosis, treatment, and outbreak response by coordinating the highly successful programs, resources, and infrastructure of many [US Department of Health and Human Services] agencies and offices." 354

General intent refers to the intent of an individual to act in a certain manner even if they did not intend specific consequences to result from that action.<sup>355</sup> For example, a person with HIV may intend to engage in sexual conduct with another person (an action) without the intent to transmit HIV to their sexual partner (an outcome). General intent contrasts with specific intent.

**Gross negligence** is defined by *Black's Law Dictionary* as "the omission of even such diligence as habitually careless and inattentive people do actually exercise in avoiding danger to their own person or property." <sup>356</sup>

**HIPAA**, the Health Insurance Portability and Accountability Act of 1996, is a federal law that requires the US Department of Health and Human Services to establish regulations about the privacy of health information.<sup>357</sup>

**HIV** is an acronym for *human immunodeficiency virus*. HIV "weakens a person's immune system by destroying important cells that fight disease and infection."<sup>358</sup>

**HIV cluster detection and response** refers to leveraging "data routinely reported to health departments to identify communities where HIV may be spreading rapidly" in

order to "identify gaps in prevention and care services to ensure that services reach the populations that need them quickly." <sup>359</sup>

**HIV criminalization** refers to laws that criminalize otherwise legal conduct or increase penalties for unlawful conduct based on a person's HIV status.

HIV surveillance is one form of public health surveillance that collects, analyzes, and disseminates information about cases of HIV infection (including AIDS).<sup>360</sup>

**Identifiable health information** refers to health-related information that can be used to identify a specific individual. The meaning of the term may vary based on the jurisdiction, context, and law in question.

*In camera* review means that part of a legal proceeding occurs in private (e.g., in a judge's chambers or a closed courtroom free of spectators and jury members) to protect against the disclosure of sensitive information.

**Knowingly** means committing a specified act with knowledge that it almost certainly will result in harm.<sup>361</sup>

Law refers specifically to the codification and institutionalization of a policy by a government in the form of an ordinance, statute, or regulation. Thus, all laws are policies, but not all policies are laws.

**Legal culpability standard** refers to the specific mental state a person must have when they commit an illegal act, in order to be convicted of the crime.

Legal epidemiology is the scientific study and deployment of law and policy as a factor in the cause, distribution, and prevention of disease and injury in a population. Legal epidemiology seeks to understand how law (e.g., constitutions, statutes, regulations, judicial opinions) and policy (e.g., written statement of a public agency's or organization's position, decision, or course of action) are understood, implemented, and enforced.

Legislation is a law drafted and adopted by a legislative body, like Congress, a state legislature, or a city council. The terminology for adopted legislation differs, depending on the level of government. At the federal and state levels, legislation that has been enacted and codified is known as a statute. At the local level, legislation that has been enacted and codified is known as an ordinance.

Legitimate public health purposes, as defined by the NCHHSTP Data Security and Confidentiality Guidelines, means "a population-based activity or individual effort aimed primarily at the prevention of injury, disease, or premature mortality."<sup>362</sup> Legitimate public health purposes also include the following:<sup>363</sup>

- "[T]he promotion of health in the community"
- "[A]ssessing the health needs and status of the community through public health surveillance and epidemiologic research"
- "[D]eveloping public health policy"
- "[R]esponding to public health needs and emergencies"
- "[A]nalysis and evaluation of conditions of public health importance and evaluation of public health programs"

**Molecular HIV data** refers to genetic sequence data for an HIV virus that can be used to identify HIV clusters and outbreaks.<sup>364</sup>

National Center for HIV, Viral Hepatitis, STD, and TB Prevention (NCHHSTP) at CDC is responsible for public health surveillance; prevention research; programs to prevent and control HIV, STDs, viral hepatitis, and tuberculosis and promotion of school-based health and disease prevention among youth.<sup>365</sup>

**Negligence** is defined as the failure to act with the level of care a reasonable person would have in the same situation.

Non-identifiable data refers to data that are inherently incapable of being associated with specific people. Unlike de-identified data, which has been stripped of identifying information, non-identifiable data never included such identifying information.

Partner notification refers to the process of notifying people who may have been exposed to HIV following a diagnosed case of HIV. For example, if a person who receives a diagnosis of HIV has an active sexual partner, the person or appropriate health authorities may notify the sexual partner of their potential exposure.

**People with HIV (PWH)** is the preferred person-centered language to refer to people who have received a diagnosis of HIV.

Policy refers to a written statement of a public agency's or organization's position, decision, or course of action. Policies may be public policies (i.e., policies adopted by a government entity that apply to the general public) or private policies (i.e., policies adopted by non-governmental entities or policies adopted by a government entity that apply only to the entity and its members rather than the general public).

Post-exposure prophylaxis (PEP) refers to emergency medication taken "to prevent HIV after a possible exposure." <sup>366</sup>

**Pre-exposure prophylaxis (PrEP)** is "medicine people at risk for HIV take to prevent getting HIV from sex or injection drug use." <sup>367</sup>

The **Privacy Act of 1974** is a federal law regulating the collection, maintenance, use, and disclosure of personal information by federal agencies.<sup>368</sup> Specific regulations promulgated under the Privacy Act set forth such standards for the US Department of Health and Human Services, including CDC.<sup>369</sup>

**Privacy Rule** refers to the federal regulation ("Standards for Privacy of Individually Identifiable Health Information") that implements HIPAA requirements for health data privacy. The Privacy Rule regulates how covered entities and business associates may use and disclose individually identifiable health information.

**Private right of enforcement** refers to when a law authorizes individuals (as opposed to government officials) to bring legal action to enforce a specific law.

**Public health surveillance**, as defined by CDC, is "the ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice." <sup>370</sup>

**Recklessly**, as defined by *Black's Law Dictionary*, refers to acting in "such a manner that the [person] knew that there was a substantial and unjustifiable risk... and ignored this risk..." 371

**Regulation** is a law created by an executive or administrative agency pursuant to authority delegated to the agency by legislation. Some jurisdictions refer to regulations as **rules**; both terms mean the same thing. Importantly, a regulation is not the same as legislation, although both have the effect of law

Reportable disease is a disease or condition that when diagnosed or detected must be reported by specified people (e.g., health care providers) to specified individuals or entities (generally public health authorities).

**Ryan White HIV/AIDS Program** is a federally funded program that provides a comprehensive system of HIV primary medical care, essential support services, and medications for low-income people with HIV.<sup>372</sup>

**Sentencing enhancements** means that a person found guilty of a crime is subjected to more severe punishment because of specified factors. For example, the fines for a speeding ticket may be greater if the violation occurs within a school zone. An example in the context of HIV is when state laws impose more substantial penalties for sexual offenses when the offender is a person with HIV.

**Significant exposure** refers to a situation in which a person is exposed to HIV and there is a risk of HIV transmission.

Specific intent refers to the intent of an individual to bring about a specific outcome as the result of their conduct. For example, a person with HIV may engage in sexual conduct (an action) with the intent of transmitting HIV to their sexual partner (an outcome). Specific intent contrasts with general intent.

**Statutes** are laws enacted by a legislative body (e.g., Congress or a state legislature). At the local level, laws adopted by a legislative body are often referred to as **ordinances**.

**Strict liability** means holding a person liable (criminally or civilly) for an action and the consequences that follow, even if they did not intend to engage in such action or cause such consequences.

A **subpoena** is a legal order to produce specified materials (e.g., documents) or appear before a court or tribunal.<sup>373</sup>

Sub-regulatory policies are documents that inform employees or members of the public about an agency's interpretation of existing laws and how they will be implemented or enforced, or that set internal agency standards for day-to-day operations. These documents may take many different forms, from guidance documents to policy statements, internal agency manuals, interagency memorandums, procurement policies, and more.

**Viral suppression** is defined by CDC as "having less than 200 copies of HIV per milliliter of blood." An **undetectable viral load** occurs when HIV testing cannot detect the virus in the blood of a person with HIV.<sup>374</sup> According to CDC, "[p]eople with HIV who take HIV medicine as prescribed and get and keep an undetectable viral load (or stay virally suppressed) will not transmit HIV to their sexual partners." <sup>375</sup>

### **APPENDIX II: ADDITIONAL RESOURCES**

#### **HIV Criminalization Laws**

## Guide to Reform HIV-Specific Criminal Laws to Align with Scientifically Supported Factors

**US** Department of Justice

www.hivlawandpolicy.org/sites/default/files/DOj-HIV-Criminal-Law-Best-Practices-Guide.pdf

#### **HIV and STD Criminalization Laws**

Centers for Disease Control and Prevention www.cdc.gov/hiv/policies/law/states/exposure.html

# HIV Criminalization in the United States: A Sourcebook on State and Federal HIV Criminal Law and Practice

The Center for HIV Law and Policy www.hivlawandpolicy.org/sourcebook

### **HIV Criminalization by State**

LawAtlas (Policy Surveillance Program)
https://lawatlas.org/datasets/hiv-criminalization-statutes

### **Williams Institute Reports**

### HIV Criminalization in California: Penal Implications for People Living with HIV/AIDS

https://williamsinstitute.law.ucla.edu/publications/hivcriminalization-ca-penal

### HIV Criminalization in California: Evaluation of Transmission Risk

https://williamsinstitute.law.ucla.edu/publications/hivcrim-transmission-ca

### **HIV Criminalization and Sex Work in California**

https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-sex-work-ca

#### **HIV Criminalization Against Immigrants in California**

https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-immigrants-ca

### HIV Criminalization in Florida: Penal Implications for People Living with HIV/AIDS

https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-fl

### HIV Criminalization in Florida: Evaluation of Transmission Risk

https://williamsinstitute.law.ucla.edu/publications/hiv-crim-transmission-fl

### HIV Criminalization in Georgia: Penal Implications for People Living with HIV/AIDS

https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-in-georgia

### HIV Criminalization in Georgia: Evaluation of Transmission Risk

https://williamsinstitute.law.ucla.edu/publications/hiv-crim-transmission-ga

### The Criminalization of HIV and Hepatitis B and C in Missouri: An Analysis of Enforcement Data from 1990 to 2019

https://williamsinstitute.law.ucla.edu/publications/hiv-criminalization-mo

### **Stigma**

#### Stigma Language Guide

Centers for Disease Control and Prevention www.cdc.gov/stophivtogether/hiv-stigma/ways-to-stop. html#Stigma-Language-Guide

### Stigma Scenarios: Support in Action

Centers for Disease Control and Prevention www.cdc.gov/stophivtogether/hiv-stigma/stigma-scenarios.html

#### **HIV Language Guide**

National Institute of Allergy and Infectious Diseases (NIAID)

www.hptn.org/sites/default/files/inline-files/NIAID HIV Language Guide - March 2020.pdf

### Why Language Matters: Facing HIV Stigma in Our Own Words

The Well Project

www.thewellproject.org/hiv-information/why-language-matters-facing-hiv-stigma-our-own-words

### **Additional HIV Resources**

### **HIV Prevention Technical Assistance and Capacity- Building Programs**

**NASTAD** 

https://nastad.org/teams/hiv-prevention

### State Laws That Address High-Impact HIV Prevention Efforts

Centers for Disease Control and Prevention www.cdc.gov/hiv/policies/law/states

#### **State HIV Laws**

The Center for HIV Law and Policy www.hivlawandpolicy.org/state-HIV-laws

#### **NCHHSTP AtlasPlus**

Centers for Disease Control and Prevention www.cdc.gov/nchhstp/atlas

### State Laboratory Reporting Laws: Viral Load, CD4, and Molecular Data Requirements

Centers for Disease Control and Prevention <a href="https://www.cdc.gov/hiv/policies/law/states/reporting.html">https://www.cdc.gov/hiv/policies/law/states/reporting.html</a>

### **Perinatal HIV Testing Laws**

Centers for Disease Control and Prevention www.cdc.gov/hiv/policies/law/states/perinatal.html

### State Laws on Minors' Consent for HIV and STD Services

Centers for Disease Control and Prevention www.cdc.gov/hiv/policies/law/states/minors.html

### **Data Privacy**

### NCHHSTP Data Security and Confidentiality Guidelines

Centers for Disease Control and Prevention <a href="https://www.cdc.gov/nchhstp/programintegration/data-security.">www.cdc.gov/nchhstp/programintegration/data-security.</a> <a href="https://

# HIV Data Privacy and Confidentiality: Legal & Ethical Considerations for Health Department Data Sharing NASTAD

www.nastad.org/resource/hiv-data-privacy-and-confidentiality

### Public Health Departments and State Patient Confidentiality Laws

LawAtlas (Policy Surveillance Program)
<a href="https://lawatlas.org/datasets/public-health-departments-and-state-patient-confidentiality-laws">https://lawatlas.org/datasets/public-health-departments-and-state-patient-confidentiality-laws</a>

#### **State Medical Records Laws**

FindLaw

https://statelaws.findlaw.com/health-care-laws/medical-records.html

### Leveraging Data Sharing for Overdose Prevention

ChangeLab Solutions

www.changelabsolutions.org/product/leveraging-data-sharing-overdose-prevention

### **Additional Public Health Law Resources**

### **Equitable Enforcement to Achieve Health Equity**

ChangeLab Solutions

www.changelabsolutions.org/product/equitable-enforcement-achieve-health-equity

## A Blueprint for Changemakers: Achieving Health Equity Through Law & Policy

ChangeLab Solutions

www.changelabsolutions.org/product/blueprintchangemakers

#### **Public Health Law Academy**

Centers for Disease Control and Prevention & ChangeLab Solutions http://publichealthlawacademy.org

### Laws, Policies, & Legal Review Tools for TB, HIV, & STD Prevention Programs

Centers for Disease Control and Prevention <a href="https://www.cdc.gov/nchhstp/legal-review.html">www.cdc.gov/nchhstp/legal-review.html</a>

# Establishing a Holistic Framework to Reduce Inequities in HIV, Viral Hepatitis, STDs, and Tuberculosis in the United States

Centers for Disease Control and Prevention www.cdc.gov/nchhstp/socialdeterminants/docs/SDH-White-Paper-2010.pdf

#### **Communicable Disease Intervention Protocol**

LawAtlas (Policy Surveillance Program)
<a href="https://lawatlas.org/datasets/communicable-disease-intervention-protocol">https://lawatlas.org/datasets/communicable-disease-intervention-protocol</a>

### **Syringe Service Program Laws**

LawAtlas (Policy Surveillance Program)
<a href="http://lawatlas.org/datasets/syringe-services-programs-laws">http://lawatlas.org/datasets/syringe-services-programs-laws</a>

### Map of Health Policies Affecting People Who Use Drugs

**NASTAD** 

https://nastad.org/resources/drug-user-health-policy-map

### APPENDIX III: FINDING THE LAW

To assess HIV laws and policies in your jurisdiction, you will need to find relevant laws and record key aspects of those laws. This appendix provides a high-level introduction on how to execute these legal research steps. This content will likely be a review for individuals with legal research expertise.

# Refresher: What Are Laws and Policies?

The terms *law* and *policy* are often used interchangeably. Throughout this document, *policy* means a written statement of a public agency's or organization's position, decision, or course of action. In contrast, *law* refers specifically to the codification and institutionalization of a policy by a government in the form of an ordinance, statute, or regulation. Thus, all laws are policies, but not all policies are laws. Note that *law* can also include constitutional provisions and judicial opinions (also known as case *law*).<sup>376,377,378</sup>

# Legislation (e.g., state statutes and local ordinances)

Legislation is a law drafted and adopted by a legislative body, like Congress, a state legislature, or a city council. The terminology for adopted legislation differs according to the level of government. At the federal and state levels, legislation that has been enacted and codified is known as a statute. Federal statutes can be found in the United States Code, and state statutes can be found in state codes, which are available on legal research services and, often, on state legislatures' websites. At the local level, legislation that has been enacted and codified is known as an ordinance. Local ordinances can be found in county or municipal codes, which are available from legal research services like Municode

and, often, on city or county websites. Legislation is not static but, rather, changes over time as legislative bodies amend or repeal statutes or ordinances.

### Regulations (e.g., administrative codes)

A *regulation* is a law drafted and finalized by an administrative agency, like the federal Food and Drug Administration or a state or local health department. Regulations often fill in the details of broad-brush legislation, including rules for how a statute or ordinance will be implemented or carried out.<sup>379,380,381</sup> Accordingly, legislation and regulations often interact, and both must be researched to understand how a particular issue area is being governed.<sup>382,383,384</sup>

You may sometimes hear the term *rule* in addition to *regulation*. These terms mean the same thing and can be used interchangeably. The terminology for regulations does not differ according to the level of government; however, regulations are much less common at the local level compared with federal or state levels because local authority to adopt regulations varies widely across jurisdictions. Regulations that have been finalized are codified in federal, state, or local regulatory codes – which are often referred to as *administrative codes*. Regulatory codes can be searched via legal research services and, often, on government websites.<sup>385,386,387,388</sup>

You can learn more about the rulemaking process by reading ChangeLab Solutions' *Know the Rules: An Overview of State Agency Rulemaking*, available at www.changelabsolutions.org/product/know-rules.

#### **Case Law**

Judicial decisions also carry the force of law, and sometimes it is up to courts to figure out exactly what a law means. Once they do so, their interpretation can be binding for others. This is called case law. In some instances, different courts – federal, state, and local – may be relevant to your assessment. Broadly speaking, there are two court systems in the United States: the federal court system and the state court system. Both systems generate case law that may be relevant to your research. State court systems may encompass municipal (or city) and county courts, which tend to address matters like misdemeanors, traffic infractions, or financial disputes for smaller amounts. In some jurisdictions, identifying the applicable laws might prove challenging. In some states, it may require contacting municipal or county authorities directly or even visiting their physical offices in person. Some state and federal court decisions are accessible through legal research services or court websites.

### Sub-Regulatory Guidance Documents or Internal Agency Policies

Government agencies may issue a range of documents to inform employees or members of the public about the agency's interpretation of existing laws and how they will be implemented or enforced, or to set internal agency standards for day-to-day operations. These documents may take many different forms, from guidance documents to policy statements, internal agency manuals, interagency memorandums, procurement policies, and more. In sum, agencies may issue a host of documents to explain their interpretation of the law, set internal standards, or recommend best practices to protect the public and promote health equity. The terminology used to describe these documents can vary widely, and terms are not always used consistently within or across jurisdictions. Unlike legislation and regulations, in most cases, these types of sub-regulatory documents do not have the force and effect of law, meaning that they generally cannot be enforced against members of the

public. Nevertheless, they may be relevant for your legal assessment. Some sub-regulatory guidance documents and internal agency policies can be found on government websites, while others may need to be obtained directly from the relevant entities.

# Are Relevant Materials Accessible?

You must determine whether the laws or policies are accessible. For example, can you use one or more legal services to conduct your research, and if so, which ones (e.g., Westlaw, LexisNexis, Municode)? If you do not have access to a legal research service, can you access state statutes, state regulations, or local ordinances on the jurisdiction's website? Does your research topic require collecting policies that are not readily available from traditional legal services – for example, guidance documents, letters, or memorandums from government agencies? If so, how do you plan to access those materials?

# **Sources for Conducting Legal** and Background Research

Another important consideration is which legal research services or other research databases you will need to complete the assessment. Legal research services and other resources vary in price; ease of use and accessibility; and types of laws, policies, and secondary sources that are available. Below is an overview of various resources that can be used to find laws, policies, and secondary sources that are relevant for your assessment. 389,390,391,392

#### **Government Websites**

Various government websites provide access to laws and policies. They may include existing laws, pending legislation, administrative codes, agency guidance, and other policy documents.

- State governments often provide access to current statutes on the state legislature's website.
   For example, the Georgia General Assembly's website includes free access to the Georgia state code, information on pending legislation, and summaries of past legislative sessions.
- Local governments, such as cities and counties, may also have websites with free access to local laws and pending legislation (e.g., proposals in

front of the city council). The website for the City of Dayton, OH, includes free access to the city's municipal code, information on past and present city commission meetings, and agendas and minutes for city commission meetings that may be relevant for legislative histories.

- Some tribal governments include free online access to tribal codes, tribal constitutions, and tribal case law that may be helpful if your assessment involves tribal law. For example, the Navajo Nation Council provides access to the current law for the Navajo Nation, as well as pending legislation.
- If your assessment includes US territories such as Guam or Puerto Rico, you may be able to gain free access to relevant laws through various government websites. For example, the Library of Congress' website provides free access to Guam's laws, pending legislation, and legal guides related to Guam's laws.

Lastly, government websites at all levels may also include access to **sub-regulatory guidance documents** that may be essential in answering your research questions.

# Westlaw and LexisNexis (require subscription)

Westlaw and LexisNexis are online, subscription-based legal databases that can be used to search laws and regulations at multiple levels of government. In addition to providing access to federal and state laws, Westlaw and LexisNexis provide some access to tribal and territorial laws. The type and range of access that these databases include depends on the subscription purchased. Many subscriptions include add-on options for some materials, offering wider access. These features may be important to consider when evaluating your time, resources, and expenses. Additionally, these databases provide access to some secondary sources, such as law review articles and legal encyclopedias, that may be helpful when you are conducting your assessment.

# Municode (requires subscription for some services)

Municode is an online database of municipal codes – local laws for counties and cities. While individual

cities' or counties' municipal codes are available at no cost, a subscription allows researchers to access advanced research capabilities, such as searching more than one city's municipal code at a time, adding notes to searches, and saving searches for future reference. Note that not all municipalities use Municode to publish their municipal codes, so which legal research services you need may depend on which jurisdictions you are assessing.

#### **Court Websites**

Federal and state court websites can also provide access to current and pending court cases that may affect your research. For the federal court systems, PACER is a paid service that provides electronic access to current case files and filings. State court websites may also provide access to decisions made by the state court system as well as pending cases. For example, the Vermont Supreme Court website allows users to search Vermont Supreme Court decisions.

#### **Government Offices**

In some circumstances, the relevant materials may not be available through a government's website, and researchers may need to contact government offices or government archives. For example, some smaller, less well-resourced local governments may not have municipal codes on a website or may not make relevant documents available online. For instance, not all governments make their general plans or other planning documents accessible online. In this case, researchers will need to reach out to local government offices to request copies of relevant local laws or policies.

### **HeinOnline**

HeinOnline is a subscription-based online database of a wide variety of legal and nonlegal materials, such as journals, government materials, and international sources of legal information. If your project includes comparisons across international laws, this resource may be useful or necessary.

### Google Scholar

Google Scholar is a free service that provides access to primary and secondary research articles. In addition to accessing scientific studies, researchers

can also read law review articles and other secondary sources that may be helpful in understanding the law and gaps in research.

### **Google News**

Google News is a free service that aggregates news stories. Users can also set up Google News alerts for certain keywords, and the service will email updates whenever the keywords are mentioned together in a news article. This service might be particularly helpful for tracking potential updates or amendments to laws over time. For example, a researcher who is tracking HIV laws in New Jersey could set up a Google news alert with keywords such as *New Jersey*, *HIV*, and *state legislature* to receive updates when articles mention all of these terms.

### **Primary and Other Secondary Sources**

Primary and secondary sources such as reports, journal articles, and legal datasets might provide relevant information and help inform other research efforts such as the development of search strings. Appendix II includes resources related to HIV criminalization, public health surveillance, and data privacy. For example, the LawAtlas website includes legal datasets on HIV criminalization and public health data confidentiality laws, among others.

### **Develop a Search String**

If you're using a legal research service like Westlaw or LexisNexis, or other sources that support advanced full-text searches, a key step in finding the law is to create a search strategy. Search strategies are vital to efficiently using time and resources in the process of finding relevant laws. Typically, it is best to use multiple search strategies to conduct reliable and accurate legal research. For example, try using different search terms; searching the table of contents of the municipal, statutory, or regulatory code; and exploring multiple databases.<sup>393,394,395,396</sup>

A key component of any search strategy is the development of a solid search string. A search string contains specific terms and combinations of terms to help narrow your search. For example, if you're researching state HIV criminalization laws, you might type in the terms "HIV AND expose" or "HIV AND transmit."

Developing a solid search string saves time by finding relevant laws through one search rather than multiple searches. This method also has the following advantages:

- Minimizes errors
- Ensures that all researchers will identify relevant laws on a topic, because they are using the same search string to gather appropriate results
- Avoids a repetitive and ad hoc process by making the search process as systematic as possible.

You may encounter several common problems when developing a search string. For example, a search string may be overinclusive and turn up too many results. Using an overinclusive search string is inefficient because it will take more time and resources for researchers to assess and code all of the results. Search strings can also be underinclusive, meaning that the search terms miss relevant laws while producing too few results. Underinclusive searches could lead to problematic gaps in your research and an inaccurate picture of the status of laws across jurisdictions and/or over time. It is also important to keep in mind that search strings are rarely perfect.

Developing a search string is an iterative process. You should work to develop a search string first based on existing knowledge or a sampling of laws – for example, by using different combinations of common terms that appear in the sample laws. You can then refine the search string through trial and error, based on which search string identifies the greatest number of relevant laws.

A search string can be plugged into the search box on a legal research service, which will then pull up the laws identified with the search string. Note that on a legal research service, you can narrow your search so that you are searching only laws in a specific jurisdiction and only in relevant codes (legislative or regulatory) or code chapters or sections within those codes. If you have multiple researchers, they should use an identical search string and identical parameters – such as which code chapters or sections they are searching – to ensure that they are looking at the same results. Remember that this is an iterative process and that your search string and other parameters can be updated as you dig into your research and begin to build your dataset.

In some instances, locating relevant laws may require searching on individual websites for each jurisdiction. Additionally, you may wish to develop a search string to identify secondary sources through services such as Google and Google Scholar.

### **Reading the Law**

After finding relevant laws, it may be helpful to note and record the following key features of those laws:

- Legal citation. The legal citation is a unique identifier for locating laws and regulations. Noting citations will make it easier to revisit laws if questions arise or laws need to be recoded. For additional background information on understanding legal citations, we suggest you check out the Cornell University Law School Legal Information Institute's "Introduction to Basic Legal Citation," available at <a href="https://www.law.cornell.edu/citation">www.law.cornell.edu/citation</a>.
- Title. Legislation often has a title, such as "Confidentiality of Medical Information Act." Recording the title can help provide context for the citation, which will not provide information about the content of the law. Alternatively, if you are including case law in your assessment, you can note and record the case name (e.g., "John Doe v. Department of Health and Human Services") and the court that decided the case. (This information will also be included in the legal citation.)

- Legislative, regulatory, or case history. For certain assessments, it is important to note and record key aspects of a law's history, meaning how the law has changed over time and when. At a minimum, when researching legislation and regulations, you should note the basics like when the law was originally adopted and the dates on which the law was amended (if any). For case law, you can note when the case was decided and any subsequent history, like if there were later appeals to higher courts or remands to lower courts.
- Effective dates. The effective date is when the current version of the law became applicable or effective. When laws went into effect may correlate with changes in health outcomes, so this information may be important to keep track of.
- Content of the law. What content to note and record will depend on the goals of your assessment. Key content for legislation or regulations could include, for example, specific definitions, substantive requirements or standards, or types of penalties. If your assessment involves researching case law, key content could include the primary holding from a judicial opinion. You can use the questions posed in this assessment tool to help identify relevant content.

### **APPENDIX IV: ASSESSMENT QUESTIONS**

# Health Data Privacy Laws and Policies

# What is the state legal landscape regarding the confidentiality of general health information?

- Does state law address the disclosure and use of identifiable health information?
- 2. To whom does the law apply?
- 3. What type of information does the law protect?
- 4. When, to whom, and with respect to what types of health information does the law authorize or mandate disclosure?
- 5. When state law authorizes or mandates the disclosure of health information, does the law regulate the subsequent disclosure of such information? What, if any, protections apply to disclosed data?
- 6. Does state law regulate the purposes for which identifiable health information may be used?
- 7. Does the law explicitly address when health information may be disclosed to and/or used by criminal legal system actors (e.g., law enforcement, prosecutors, courts)?

# What is the state legal landscape regarding the confidentiality of public health data?

- Does state law address the disclosure and/or use of public health data?
- Does the law define relevant terms (e.g., protected health information, public health purpose)? If so, how?
- 3. When, to whom, and with respect to what types of public health data does the law authorize or mandate disclosure?
- 4. When state law authorizes or mandates the disclosure of public health data, does the law

- regulate the subsequent disclosure of such information? What, if any, protections apply to disclosed data?
- 5. Does state law regulate the purposes for which public health data may be used?
- 6. Does the law explicitly address when public health data may be disclosed to and/or used by criminal legal system actors (e.g., law enforcement, prosecutors, courts)?
  - a. Does the law require health department staff to participate in legal proceedings?
- 7. What procedural protections apply to the disclosure and/or use of public health data (e.g., court orders, sealing records, notice and opportunity to contest)?
- 8. Do local health departments have access to state public health data, and if so, is the local health department required to abide by the same confidentiality laws applicable to the state?
- 9. When and under what conditions may deidentified or non-identifiable public health data be disclosed?

# What is the state legal landscape regarding the confidentiality of HIV-related data?

- Does state law address the disclosure and/or use of HIV-related data?
- Does the law define relevant terms (e.g., protected health information, public health purpose)?
   If so, how?
- 3. To whom does the law apply?
- 4. What type of information does the law protect?
- 5. When, to whom, and with respect to what types of HIV-related data does the law ...
  - a. Authorize disclosure with an individual's consent?
  - b. Authorize disclosure without an individual's consent?

- c. Mandate disclosure with an individual's consent?
- d. Mandate disclosure without an individual's consent?
- 6. When state law authorizes or mandates the disclosure of HIV-related data, does the law regulate the subsequent disclosure of such information?
  - a. Does the law regulate the purposeful further disclosure of HIV-related data?
  - b. Does the law regulate the inadvertent further disclosure of HIV-related data?
- 7. Does state law regulate the purposes for which HIV-related data may be used?
- 8. Does the law explicitly address when HIV-related data may be disclosed to and/or used by criminal legal system actors (e.g., law enforcement, prosecutors, courts)?
  - a. Does the law require health department staff to participate in legal proceedings?
- 9. What procedural protections apply to the disclosure and/or use of HIV-related data? Does disclosure and/or use require...
  - a. A subpoena?
  - b. A court order?
  - c. Sealing records?
  - d. In camera review?
  - e. Notice and an opportunity to contest?
- 10. Do local health departments have access to HIVrelated data held by state health officials, and if so, is the local health department required to abide by the same confidentiality laws applicable to the state?
- 11. When and under what conditions may de-identified or non-identifiable HIV-related data be disclosed?

# What is the landscape of state and local health department policies, practices, and procedures?

- Does the department have existing data sharing and confidentiality policies, practices, and procedures?
- 2. Do the department's policies, practices, and procedures comply with the standards described in the CDC NCHHSTP Data Security and Confidentiality Guidelines?

- 3. How have state and local government attorneys interpreted the state data privacy landscape and internal department policies, practices, and procedures?
- 4. Do department policies, practices, and procedures ...
  - a. Generally, restrict data sharing to legitimate public health purposes?
  - b. Allow the disclosure of data for purposes unrelated to public health (e.g., litigation, discovery, or court order) only to the extent such disclosures are required by law?
  - c. Restrict disclosures to the minimum amount of information needed to achieve the purpose of the disclosure?
  - d. Allow disclosures for research purposes? If so, what types of data may be disclosed and how?
  - e. Allow the department to receive data even if it may not disclose such data?
  - f. Establish procedures to review disclosure requests that fall outside established policies? Must legal counsel review disclosures unrelated to public health to determine what, if any, information must be disclosed?

# **State Public Health Surveillance** and HIV Testing Laws

## What is the state legal landscape with respect to HIV testing?

- Does state law mandate that certain individuals be tested for HIV? If so, when are such tests required (e.g., following a significant exposure event, within criminal legal settings, as part of legal cases involving sexual assault)?
- 2. Does state law address routine opt-out testing during pregnancy?
- 3. With whom are test results shared?
- 4. What, if any, legal protections apply to the test results and associated information?
- 5. Do the reporting requirements apply to mandated HIV testing? Voluntary HIV testing?

# What is the state legal landscape with respect to HIV-specific surveillance and reporting?

- Does the state have an HIV-specific public health surveillance law?
- 2. Does the state have an HIV-specific reporting law?
- 3. Does the state HIV-specific surveillance and reporting law address reporting to ...
  - a. Local health officials?
  - b. State health officials?
  - c. Federal officials (e.g., CDC)?
  - d. Non-governmental people or entities (e.g., partner notification)?
  - e. Law enforcement?
  - f. Health care providers?
  - q. Other individuals or entities?
- 4. Who is required to report HIV-specific data?
  - a. Physicians?
  - b. Public health departments?
  - c. Emergency departments?
  - d. Laboratories?
  - e. Community-based organizations?
- 5. What types of data are included in mandatory reporting? Is reporting required for all tests or only positive tests?
  - a. CD4 cell counts?
  - b. Viral loads?
  - c. Molecular sequence data?

# What is the state legal landscape with respect to general disease reporting?

- Does the state have a general disease reporting law?
- 2. Who is required to report communicable diseases?
- 3. To whom are communicable diseases reported?
- 4. At what level of government (federal, state, local, tribal, territorial) are diseases reported?
- 5. Which particular communicable diseases must be reported?
- 6. Does the general disease reporting statute address data confidentiality?

### **HIV Criminalization Laws**

## Does the state criminalize conduct related to HIV?

- 1. Is there a specific HIV criminalization statute?
- 2. Is there a general STI (sexually transmitted infection) or communicable disease criminalization law?
- 3. Have state and/or local officials used criminal laws that are not specific to HIV, STIs, or other communicable diseases to criminalize HIV transmission or exposure (e.g., reckless endangerment)?
- 4. Does state law impose additional penalties on people with HIV who commit other crimes (e.g., upgraded charges and/or sentencing enhancements)?

## What are the characteristics of the HIV criminalization law?

- Does the state HIV criminalization law align with current recommendations (e.g., US Department of Justice's <u>Best Practices Guide to Reform HIV-</u> <u>Specific Criminal Laws to Align with Scientifically-</u> <u>Supported Factors</u>)?
- 2. Does the HIV criminalization law reflect current scientific information regarding HIV transmission and prevention?
  - a. Does the HIV criminalization law require specific intent to transmit the virus?
  - b. Does the HIV criminalization law require actual transmission of the virus?
  - c. Does the HIV criminalization law consider whether an individual is at reduced transmission risk, including viral suppression and/or the use of HIV prevention measures (e.g., partner PrEP and condom use)?
  - d. Does the HIV criminalization law penalize behavior with a low or negligible risk of transmitting HIV (e.g., spitting, biting)?
- 3. What are the penalties for violating the state HIV criminalization law?
  - a. Does the HIV criminalization law specify a particular length or range of lengths of incarceration for violations?
  - b. Are individuals convicted of violating state HIV criminalization laws required to register as a sex offender?

### What else is known about the HIV criminalization law?

- Does the law require people with HIV to disclose their HIV status to certain people (e.g., sex partners, individuals who share syringes)?
- 2. Does the HIV criminalization law explicitly address the role of state and/or local health departments?

### Considerations and Resources for Implementation and Enforcement

# What is the landscape with respect to implementation and enforcement?

- Does a government entity (e.g., a state health department) have the legal authority to adopt regulations implementing state HIV surveillance and HIV confidentiality laws? If so, which government entity has such authority?
- 2. Are health department staff required to receive training on data privacy and confidentiality?
- 3. What are the penalties for disclosing confidential HIV-related information contrary to applicable law and/or department policy?
  - a. Who is responsible for enforcement?
  - b. Are the relevant authorities actively enforcing the law?
  - c. If the relevant authorities are not adequately enforcing data privacy laws, are there alternative approaches to ensure compliance (e.g., private litigation)?
- 4. Are state and local health department policies regarding disclosures to law enforcement aligned?
- 5. What types of intra- and inter-agency collaboration have been established and/or planned with respect to implementation and enforcement?
- 6. What types of collaboration among different levels of government (federal, state, tribal, local, and territorial) have been established and/or planned with respect to implementation and enforcement?
- 7. What policies, technologies, and data systems are in place to protect against security breaches (e.g., hacking)?
- 8. How have courts interpreted and applied state laws related to HIV criminalization, HIV and other public health surveillance, and data privacy? Is anyone actively tracking legal decisions on these issues?
- 9. What else is known about the implementation and enforcement of the state HIV criminalization law?

# What additional resources are available to support implementation and enforcement?

- 1. What internal legal and policy resources are available?
- 2. What external legal and policy resources are available?
- 3. Are sample data sharing agreements available?
- 4. Are training and technical assistance available with respect to interventions, organizational infrastructure, HIV testing results, policies for data security and confidentiality, data sharing across programs, and data reporting to surveillance for providers and staff of participating health care facilities and community-based organizations or other service organizations?
- 5. What community engagement resources are available?

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- 124 See, e.g., WASH. REV. CODE ANN. § 70.02.270(1) (West 2014) ("No person who receives health care information for health care education, or to provide planning, quality assurance, peer review, or administrative, legal, financial, or actuarial services, or other health care operations for or on behalf of a health care provider or health care facility, may use or disclose any health care information received from the health care provider or health care facility in any manner that would violate the requirements of this chapter if performed by the health care provider or health care facility.").

- 125 See, e.g., WIS. STAT. ANN. § 146.82(5)(c) (West 2022) (providing that an entity that is not subject to HIPAA may redisclose patient health information if the "redisclosure is limited to the purpose for which the patient health care record was initially received."); GA. CODE ANN. § 24-12-12 (West 2013) (providing that "[p]ersons to whom confidential or privileged medical matter is disclosed... shall utilize such matter only in connection with the purpose or purposes of such disclosure and thereafter shall keep such matter in confidence. However, nothing in this article shall prohibit the use of such matter where otherwise authorized by law."); VA. CODE ANN. § 32.1-127.1:03(A)(3) (West 2020) (providing that, subject to limited exceptions, "[n]o person to whom health records are disclosed shall redisclose or otherwise reveal the health records of an individual, beyond the purpose for which such disclosure was made, without first obtaining the individual's specific authorization to such redisclosure.").
- 126 See, e.g., DEL. CODE ANN. tit. 16, § 1212(g) (West 2020) (providing that a "person to whom protected health information has been disclosed pursuant to [the state general health confidentiality law] shall [not] disclose the information to another person except as authorized by [the state general health confidentiality law]").
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- 136 See, e.g., LA. STAT. ANN. § 40:3.1(D) (2018) ("Any disclosure authorized ... shall include only the information necessary for the stated purpose of the requested disclosure....").
- 137 See, e.g., La. Stat. Ann. § 40:3.1(D) (2018) ("Any disclosure authorized ... [shall] not be further disclosed without written authorization of the [Louisiana Department of Health's] office of public health.").
- 138 See, e.g., N.D. CENT. CODE ANN. § 23-01.3-06(2) (West 1999) ("If a public health authority discloses protected health information under this section, that authority shall impose appropriate written safeguards to ensure the confidentiality of the information and to protect against unauthorized or improper use or disclosure."); VT. STAT. ANN. tit. 18, § 1001(a) (West 2015) ("The Department of Health shall, by rule, require that any person required to report under this section has in place a procedure that ensures confidentiality.").
- 139 See, e.g., LA. STAT. ANN. § 40:3.1(F) (2018) ("No part of the confidential data in the possession of the [Louisiana Department of Health's] office of public health or the state health officer shall be available for subpoena nor shall it be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding, nor shall such records be deemed admissible as evidence in any civil, criminal, administrative, or other tribunal or court for any reason."); VT. STAT. ANN. tit. 18, § 1001(d)(1), (3) (West 2015) (providing that a confidential public health record shall not be "disclosed or discoverable in any civil, criminal, administrative, or other proceeding" or "used for any purpose other than public health surveillance, and epidemiological follow-up").
- 140 See, e.g., OKLA. STAT. ANN. tit. 63, § 1-502.2(A)(1) (West 2021) (prohibiting the release of public health data except if the release "is made upon court order"); N.M. STAT. ANN. § 24-1-20(D) (West 1990) (creating a presumption that "[t]he files and records of [state agencies] are subject to subpoena for use in any pending cause in any administrative proceeding or in any of the courts of the state, unless otherwise provided by law").
- 141 See, e.g., FLA. STAT. ANN. § 384.29(3) (West 2001) ("No employee of the department or its authorized representatives shall be examined in a civil, criminal, special, or other proceeding as to the existence or contents of pertinent records of a person examined or treated for a sexually transmissible disease by the department or its authorized representatives, or of the existence or contents of such reports received from a private physician or private health facility, without the consent of the person examined and treated for such diseases, except in proceedings under [law on physical examination and treatment for sexually transmitted diseases] and [law on hospitalization, placement, and residential isolation for sexually transmissible diseases] or involving offenders pursuant to [HIV criminalization law].").
- 142 See, e.g., LA. STAT. ANN. § 40:3.1(C)-(D) (2018) (providing that disclosures of confidential public health information to "other local, state, or federal public health or environmental agencies, or to corroborating medical researchers, when the confidential information is necessary to carry out the duties of the agency or researcher in the investigation, control, or surveillance of disease, as determined by the [Louisiana Department of Health's] office of public health" may occur "only upon written agreement that the information will be kept confidential and will not be further disclosed without written authorization of the [Louisiana Department of Health's] office of public health"); N.D. CENT. CODE ANN. § 23-01.3-06(2) (West 1999) (providing that a public health authority that discloses protected health information to a law enforcement authority "shall impose appropriate written safeguards to ensure the confidentiality of the information and to protect against unauthorized or improper use or disclosure").
- 143 See, e.g., FLA. STAT. ANN. § 384.29(2) (West 2001) (provides that when the state department of health discloses confidential public health data related to sexually transmissable diseases pursuant to a subpoena, "the court shall seal such information from further disclosure, except as deemed necessary by the court to reach a decision, unless otherwise agreed to by all parties").
- 144 See, e.g., D.C. CODE ANN. § 7-131(b)(1) (West 2010) (generally prohibiting the disclosure (and redisclosure) of identifying information obtained or held by the health department with respect to communicable disease reports but authorizing disclosures if [1] "[a] court finds, upon clear and convincing evidence ... that disclosure (i) [i]s essential to safeguard the physical health of others; or (ii) [w]ould afford evidence probative of guilt or innocence in a criminal prosecution" and [2] the person to whom the information applies is given "an opportunity to contest the disclosure").
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- 147 See, e.g., N.D. CENT. CODE ANN. § 23-01.3-06(1) (West 1999) (providing that a public health authority "may disclose protected health information to a law enforcement authority if the state health officer determines that:...[t]he protected health information is necessary to a legitimate law enforcement inquiry that has begun or may be initiated into a particular violation of a criminal law or public health law being conducted by the authority; and ...[t]he investigative or evidentiary needs of the law enforcement authority cannot be satisfied by nonidentifiable health information or by any other information").
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- 149 N.C. GEN STAT. ANN. § 130A-143(2) (West 2020).
- 150 N.C. GEN STAT. ANN. § 130A-143(8) (West 2020).
- 151 ALASKA ADMIN. CODE tit. 7, § 27.891(a) (2020). The regulations include examples of "essential public health services and functions" such as "(1) maintaining lists and registries of immunizations and conditions of public health importance; (2) conducting epidemiological investigations; (3) providing public health nursing services; and (4) taking emergency actions and legal measures to protect individuals and the general public from adverse effects of diseases or other conditions of public health importance." ALASKA ADMIN. CODE tit. 7, § 27.892(a) (2006).
- 152 DEL. CODE ANN. tit. 16, § 1211(a) (West 2017).

- 153 DEL. CODE ANN. tit. 16, § 1210(3) (West 2018).
- 154 DEL. CODE ANN. tit. 16, § 1210(3)(a)-(c) (West 2018).
- 155 Wyo. STAT. ANN. § 35-4-132(d) (1992).
- 156 048.0046-1 WYO. CODE R. § 3(a)(vi) (2001).
- 157 S.D. CODIFIED LAWS § 34-22-12.1 (2003).
- 158 S.D. CODIFIED LAWS § 34-22-12.1(5) (2003)
- 159 S.D. CODIFIED LAWS § 34-22-12.1(6) (2003).
- 160 ALASKA ADMIN. CODE tit. 7, § 27.893(e)(2) (2013). A public health agent is "an official or employee of the [Department of Health and Social Services] who is in the division of public health or has oversight over the division responsible for carrying out the provisions of [specified state public health statutes]." ALASKA ADMIN. CODE tit. 7, § 27.990(12) (2022).
- 161 ALA. CODE § 22-11A-38(g) (1993).
- 162 ALASKA ADMIN. CODE tit. 7, § 27.894(b) (2006).
- 163 VT. STAT. ANN. tit. 18, § 1001(a) (West 2015).
- 164 VT. STAT. ANN. tit. 18, § 1001(d)(3) (West 2015).
- 165 VT. STAT. ANN. tit. 18, § 1001(d)(1) (West 2015).
- 166 VT. Stat. Ann. tit. 18, § 1001(b) (West 2015) ("Public health records developed or acquired by State or local public health agencies that relate to HIV or AIDS and that contain either personally identifying information or information that may indirectly identify a person shall be confidential and only disclosed following notice to and written authorization from the individual subject of the public health record or the individual's legal representative. Notice otherwise required pursuant to this section shall not be required for disclosures to the federal government; other departments, agencies, or programs of the State; or other states' infectious disease surveillance programs if the disclosure is for the purpose of comparing the details of potentially duplicative case reports, provided the information shall be shared using the least identifying information first so that the individual's name shall be used only as a last resort.").
- 167 MINN. STAT. ANN. § 609.2241(4) (West 1995).
- 168 Mo. Ann. Stat. § 192.067(1) (West 2019).
- 169 Mo. ANN. STAT. § 192.067(2) (West 2019) ("except that medical information may be shared with other public health authorities and coinvestigators of a health study if they abide by the same confidentiality restrictions required of the department of health and senior services...").
- 170 See, e.g., 35 PA. STAT. ANN. § 7603 (West 1990) (defining significant exposure as "[d]irect contact with blood or body fluids of a patient in a manner which, according to the most current guidelines of the Centers for Disease Control, is capable of transmitting human immunodeficiency virus, including, but not limited to, a percutaneous injury (e.g., a needle stick or cut with a sharp object), contact of mucous membranes or contact of skin (especially when the exposed skin is chapped, abraded or afflicted with dermatitis) or if the contact is prolonged or involves an extensive area"); 35 PA. STAT. ANN. § 7606(b)(4) (West 2011) (providing that certain health care providers or first responders may be notified of HIV test results following a significant exposure).
- 171 See, e.g., 410 ILL. COMP. STAT. ANN. 305/3 (West 2018) (incorporating numerous definitions from the HIPAA Privacy Rule, including definitions for de-identified information, disclosure, health care operations, health care provider, minimum necessary, and protected health information, among others).
- 172 See, e.g., ILL. ADMIN. CODE tit. 77, § 697.220(a) (2018) (prohibiting the state health department from disclosing information gathered pursuant to the state HIV/AIDS Registry Act unless the disclosure is specifically authorized in the state statute); ILL. ADMIN. CODE tit. 77, § 697.140 (2018) (prohibiting any person from disclosing or being compelled to disclose HIV-related information except as provided in the state statute); 410 ILL. COMP. STAT. ANN. 305/10 (West 2015) (prohibiting disclosures by persons who receive the results of an HIV test except as authorized in the state statute).
- 173 CAL. HEALTH & SAFETY CODE § 121035(c) (West 2006) (defining confidential public health record or records as "any paper or electronic record maintained by the department or a local health department or agency, or its agent, that includes data or information in a manner that identifies personal information, including, but not limited to, name, social security number, address, employer, or other information that may directly or indirectly lead to the identification of the individual who is the subject of the record"); CAL. HEALTH & SAFETY CODE § 121125(c) (West 2006) (defining confidential research record or records as "any data or information in a personally identifying form, including name, social security number, address, employer, or other information that could, directly or indirectly, in part or in sum, lead to the identification of the individual research subject, developed or acquired by any person in the course of conducting research or a research study relating to HIV or AIDS").
- 174 See, e.g., MICH. COMP. LAWS ANN. § 333.5131(1) (West 2019) ("A// reports, records, and data pertaining to testing, care, treatment, reporting, and research, and information pertaining to partner notification under section 5114a,1 that are associated with HIV infection and acquired immunodeficiency syndrome are confidential.") (emphasis added).
- 175 See, e.g., DEL. CODE ANN. tit. 16, § 717(a) (West 2015) (establishing confidentiality protections for "the identity of any person upon whom an HIV-related test is performed, or the results of such test in a manner which permits identification of the subject of the test").
- 176 See, e.g., 35 PA. Stat. Ann. § 7607(a) (West 1990) (prohibiting disclosure of HIV-related information when a person "obtains confidential HIV-related information in the course of providing any health or social service or pursuant to a release of confidential HIV-related information [with the individual's written consent to disclosure]").
- 177 See, e.g., 35 PA. STAT. ANN. § 7607(f) (West 1990) ("Duty to establish written procedures.--An institutional health care provider that has access to or maintains individually identifying confidential HIV-related information shall establish written procedures for confidentiality and disclosure of the records which are in accordance with the provisions of this act within 60 days of the effective date of this act.") (emphasis in original).
- 178 See, e.g., CAL. HEALTH & SAFETY CODE § 121025(a) (West 2017) (Confidential HIV information maintained by state and local health officials may be disclosed only as "provided by law for public health purposes or pursuant to a written authorization by the person who is the subject of the record or by his or her guardian or conservator"); CAL. HEALTH & SAFETY CODE § 121025(b) (West 2017) (authorizing disclosures for the "investigation, control, or surveillance of disease"); CAL. HEALTH & SAFETY CODE § 121025 (c)(1) (authorizing disclosures to CDC); CAL. HEALTH & SAFETY CODE § 121025 (c)(2)(A) (West 2017) (authorizing disclosures "for the purpose of proactively offering and coordinating care and treatment services to [a person with HIV]"); CAL. HEALTH & SAFETY CODE § 121025 (c)(3) (authorizing certain disclosures to other public health officials or health care providers for treatment purposes); D.C. Mun. Regs. tit. 22-B, § 206.5 (2013) (providing that HIV case reports made to the Department of Health "be used for statistical, public health, epidemiological and surveillance purposes only").
- 179 See, e.g., WIS. STAT. ANN. § 252.15(3m)(b) (West 2017)
- 180 GA. CODE ANN. § 24-12-21(v) (West 2016).
- 181 See, e.g., Wis. STAT. ANN. § 252.15(6) (West 2017) (prohibiting a person to whom the results of an HIV test have been lawfully disclosed from subsequently disclosing the test results unless specifically authorized).
- 182 See, e.g., 35 PA. STAT. ANN. § 7607(e) (West 1990) ("Notice to accompany disclosure.—Each disclosure made with the subject's written consent must be accompanied by the following written statement: This information has been disclosed to you from records protected by Pennsylvania law. Pennsylvania law prohibits you from making any further disclosure of this information unless further disclosure is expressly permitted by the written consent of the person to whom it pertains or is authorized by the Confidentiality of HIV-Related Information act. A general authorization for the release of medical or other information is not sufficient for this purpose.") (emphasis in original); OHIO REV. CODE ANN. § 3701.243(E) (West 2017) ("Any disclosure pursuant to this section shall be in writing and accompanied by a written statement that includes the following or substantially similar language: 'This information has been disclosed to you from confidential records protected from disclosure by state law. You shall make no further disclosure of this information without the specific, written, and informed release of the individual to whom it pertains, or as otherwise permitted by state law. A general authorization for the release of medical or other information is not sufficient for the purpose of the release of HIV test results or diagnoses.").

- 183 See, e.g., ALASKA ADMIN. CODE tit. 7, § 27.893(b)(7) (2013) (providing that the Alaska Department of Health and Social Services may disclose identifiable health information "to another state agency, a municipality, or a local government entity for the purpose of [HIV] prevention, care of persons with human immunodeficiency virus, or disease surveillance" and that "identifiable health information disclosed to another state agency, a municipality, or a local government entity under this paragraph must remain confidential, and may not be rereleased by the other state agency, the municipality, or the local government entity").
- 184 GA. CODE ANN. § 24-12-21(b)(1)(A); (b)(2)(A) (West 2016).
- 185 GA. CODE ANN. § 24-12-21(u) (West 2016).
- 186 Wis. Stat. Ann. § 252.15(3m)(e) (West 2017) ("The health care professional who performs an HIV test ... on behalf of a person who has contact with body fluids of the test subject that constitutes a significant exposure shall disclose the HIV test results to the person and the person's physician, physician assistant, or nurse.").
- 187 MICH. COMP. LAWS ANN. § 333.5131(5)(b) (West 2019) ("This subdivision imposes an affirmative duty upon a physician or local health officer to disclose information pertaining to an individual who is HIV infected or has been diagnosed as having acquired immunodeficiency syndrome to an individual who is known by the physician or local health officer to be a contact of the individual who is HIV infected or has been diagnosed as having acquired immunodeficiency syndrome.").
- 188 GA. CODE ANN. § 24-12-21(e) (West 2016) ("AIDS confidential information **shall be disclosed** to any agency or department of the federal government, this state, or any political subdivision of this state if that information is authorized or required by law to be reported to that agency or department.") (emphasis added).
- 189 CAL. HEALTH & SAFETY CODE § 121025(d) (West 2017) (providing that confidential HIV information held by state or local public health officials may "not be disclosed, discoverable, or compelled to be produced in any ... criminal ... proceeding").
- 190 See, e.g., FLA. STAT. ANN. § 384.29(3) (West 2001).
- 191 See, e.g., MICH. COMP. LAWS ANN. § 333.5131(7) (West 2019) (providing that a disclosure may not include identifiable information "unless the identifying information is determined by the person making the disclosure to be reasonably necessary to prevent a foreseeable risk of transmission of HIV, to protect the health of the individual to whom the information pertains, to prevent the further transmission of HIV, or to diagnose and care for a patient" and that any such disclosures include "only the minimum information necessary to accomplish the intended purpose of the disclosure").
- 192 See, e.g., ARK. CODE ANN. § 20-15-904(c)(2) (West 1989) (providing that "any prosecuting attorney of this state may subpoen information as may be necessary to enforce the provisions of [HIV confidentiality law] and [HIV criminalization and HIV testing laws], provided that any information acquired pursuant to the subpoena shall not be disclosed except to the courts to enforce this section"); GA. CODE ANN. § 24-12-21(t)(1) (West 2016) (authorizing state courts to order the disclosure of confidential HIV information to a prosecutor for enforcement of the state HIV criminalization law, to any party in a civil proceeding, and to a public safety agency or the Department of Public Health following a significant exposure); but see GA. CODE ANN. § 24-12-21(x) (West 2016) (providing that "[n]either the Department of Public Health nor any county board of health shall disclose AIDS confidential information contained in its records unless such disclosure is authorized or required by this Code section or any other law, except that such information in those records shall not be a public record and shall not be subject to disclosure through subpoena, court order, or other judicial process").
- 193 See, e.g., LA. ADMIN. CODE tit. 48 Pt I, § 13505(G)(5) (1992) ("No subpoena for hospital or other medical records shall be construed as a court order for disclosure of HIV-related test results unless accompanied by a copy of a court order authorizing the issue of a subpoena for such test results, after compliance with this Subsection.").
- 194 See, e.g., IOWA CODE ANN. § 141A.9(2)(g)(1) (West 2014) ("To a person allowed access to an HIV-related test result by a court order which is issued in compliance with the following provisions:... A court has found that the person seeking the test results has demonstrated a compelling need for the test results which need cannot be accommodated by other means. In assessing compelling need, the court shall weigh the need for disclosure against the privacy interest of the test subject and the public interest which may be disserved by disclosure due to its deterrent effect on future testing or due to its effect in leading to discrimination.").
- 195 See, e.g., LA. ADMIN. CODE tit. 48 Pt I, § 13505(G)(2) (1992) ("A court may grant an order for disclosure if: a. there is a compelling need for adjudication; b. there is clear and imminent danger to the individual; c. there is clear and imminent danger to the public health; d. the applicant is lawfully entitled to the disclosure.").
- 196 See, e.g., MICH. COMP. LAWS ANN. § 333.5131(3)(a)(i) (West 2019) ("A court that is petitioned for an order to disclose the information shall determine ... [t]hat other ways of obtaining the information are not available or would not be effective.").
- 197 See, e.g., LA. ADMIN. CODE tit. 48 Pt I, § 13505(G)(4) (1992) ("A court must weigh the compelling need for disclosure against the privacy interest of the protected individual and against the public interest which may not be served by disclosure which deters future testing or treatment or which may lead to discrimination.").
- 198 See, e.g., MICH. COMP. LAWS ANN. § 333.5131(3)(b) (West 2019) ("If a court issues an order for the disclosure of the information, the order must do all of the following: (i) Limit disclosure to those parts of the patient's record that are determined by the court to be essential to fulfill the objective of the order. (ii) Limit disclosure to those persons whose need for the information is the basis for the order. (iii) Include any other measures as considered necessary by the court to limit disclosure for the protection of the patient."); IOWA CODE ANN. § 141A.9(2)(g)(5) (West 2014) ("Upon the issuance of an order to disclose test results, the court shall impose appropriate safeguards against unauthorized disclosure, which shall specify the persons who may gain access to the information, the purposes for which the information shall be used, and appropriate prohibitions on future disclosure.").
- 199 See, e.g., LA. ADMIN. CODE tit. 48 Pt I, § 13505(G)(3) (1992) (providing that a "court order authorizing disclosure [of confidential HIV test results] shall direct communications to be sealed and shall direct further proceedings to be conducted in camera so as to protect the subject's confidentiality"); lowA CODE ANN. § 141A.9(2) (g)(2) (West 2014) ("Pleadings pertaining to disclosure of test results shall substitute a pseudonym for the true name of the subject of the test. The disclosure to the parties of the subject's true name shall be communicated confidentially in documents not filed with the court."); lowA CODE ANN. § 141A.9(2)(g)(4) (West 2014) ("Court proceedings as to disclosure of test results shall be conducted in camera unless the subject of the test agrees to a hearing in open court or unless the court determines that a public hearing is necessary to the public interest and the proper administration of justice.").
- 200 See, e.g., Iowa Code Ann. § 141A.9(2)(g)(3) (West 2014) ("Before granting an order, the court shall provide the person whose test results are in question with notice and a reasonable opportunity to participate in the proceedings if the person is not already a party."); LA. ADMIN. Code tit. 48 Pt I, § 13505(G)(4) (1992) ("Adequate notice shall be given to those from whom disclosure is requested to allow them to prepare a written or personal response unless there is a clear and imminent danger to an individual.").
- 201 GA. CODE ANN. § 31-22-9.1(a)(2) (West 2022).
- 202 410 ILL. COMP. STAT. ANN. 305/9(1) (West 2021).
- 203 410 ILL. COMP. STAT. ANN. 305/9(1)(a), (d) (West 2021)
- 204 Wis. STAT. ANN. § 252.15(3m)(b), (d), (d)(2), (d)(6), (d)(9), (d)(12) (West 2017).
- 205 WIS. STAT. ANN. § 252.15(6) (West 2017).
- 206 D.C. Mun. Regs. tit. 22-B, § 206.5 (2013).
- 207 410 ILL. COMP. STAT. ANN. 305/9(2) (West 2021).
- 208 Ohio Rev. Code Ann. § 3701.243(A) (West 2017) (Protected information includes "[t]he identity of any individual on whom an HIV test is performed[,] [t]he results of an HIV test in a form that identifies the individual tested[, and] [t]he identity of any individual diagnosed as having AIDS or an AIDS-related condition.").
- 209 OHIO REV. CODE ANN. § 3701.243(B)(1)(h) (West 2017).
- 210 La. Admin. Code tit. 48 Pt I, § 13505(E) (1992).
- 211 LA. ADMIN. CODE tit. 48 Pt I, § 13505(E) (1992).
- 212 MICH. COMP. LAWS ANN. § 333.5131(7) (West 2019).
- 213 MICH. COMP. LAWS ANN. § 333.5131(7) (West 2019) (These limitations do not apply to disclosures made pursuant to the consent of the person to whom the information pertains or specified purposes related to the protection of children.).
- 214 35 Pa. STAT. ANN. § 7607(b) (West 1990)
- 215 IOWA CODE ANN. § 141A.9(2)(g)(5) (West 2014).

- 216 OHIO REV. CODE ANN. § 3701.243(E) (West 2017). ("Any disclosure pursuant to this section shall be in writing and accompanied by a written statement that includes the following or substantially similar language: 'This information has been disclosed to you from confidential records protected from disclosure by state law. You shall make no further disclosure of this information without the specific, written, and informed release of the individual to whom it pertains, or as otherwise permitted by state law. A general authorization for the release of medical or other information is not sufficient for the purpose of the release of HIV test results or diagnoses.").
- 217 CAL. HEALTH & SAFETY CODE § 121025(d) (West 2017).
- 218 ALA. CODE § 22-11A-38(h) (West 1993).
- 219 FLA. STAT. ANN. § 384.29(3) (West 2001).
- 220 ARK. CODE ANN. § 20-15-904(c) (West 1989).
- 221 IOWA CODE ANN. § 141A.9(2)(g) (West 2014).
- 222 IOWA CODE ANN. § 141A.9(2)(g)(1) (West 2014).
- 223 IOWA CODE ANN. § 141A.9(2)(g)(2) (West 2014).
- 224 IOWA CODE ANN. § 141A.9(2)(g)(3) (West 2014).
- 225 IOWA CODE ANN. § 141A.9(2)(g)(4) (West 2014).
- 226 IOWA CODE ANN. § 141A.9(2)(g)(5) (West 2014).
- 227 N.Y. PUB. HEALTH LAW § 2135 (McKinney 2014).
- 228 410 ILL. COMP. STAT. ANN. 305/9.8(2) (West 2015).
- 229 410 ILL. COMP. STAT. ANN. 305/9.8(3) (West 2015).
- 230 Mo. CODE REGS. ANN. tit. 19, § 20-20.075 (2000).
- 231 35 PA. STAT. ANN. § 7607(f) (West 1990).
- 232 CAL. HEALTH & SAFETY CODE § 121022(f) (West 2015).
- 233 CAL. HEALTH & SAFETY CODE § 121022(f) (West 2015).
- 234 WASH. ADMIN. CODE §§ 246-101-520(1)(b) & 246-101-635(8) (2021).
- 235 WASH. ADMIN. CODE §§ 246-101-520(1)(b)(i) & 246-101-635(8)(a) (2021).
- 236 WASH. REG. 21-11-040 (2021) & WASH. REG. 22-01-175 (2021).
- 237 See Committee on Review Data Systems for Monitoring HIV Care; Institute of Medicine, Barriers to the collection of HIV care data, in: Ford MA, Spicer CM, Monitoring HIV Care in the United States: Indicators and Data Systems, Washington, DC: National Academies Press; 2012:237-71 ("Privacy of personal health information is a concern for many PLWHA. Fears of breaches in confidentiality and resulting HIV stigma can result in individuals not accessing or adhering to care and treatment.... When personally identifying information is disclosed, it can result in stigma, embarrassment, and discrimination. Without some assurance of privacy, people may be disinclined to provide honest and complete disclosures of sensitive information, even to their physicians...").
- 238 See, e.g., FLA. ADMIN. CODE ANN. r. 64D-2.004 (2018) (requiring compliance with notification and consent requirements before testing for HIV, specifying requirements for obtaining such consent, and establishing exceptions for when minors can be tested without parental consent).
- 239 ALA. CODE § 22-11A-52(3) (West 1991).
- 240 Valentine SS, Poulin A. Consistency of state statutes and regulations with Centers for Disease Control and Prevention's 2006 perinatal HIV testing recommendations. *Public Health Rep* 2018;133(5):601-5. doi:10.1177/0033354918792540.
- 241 Valentine SS, Caldwell J, Tailor A. Effect of CDC 2006 revised HIV testing recommendations for adults, adolescents, pregnant women, and newborns on state laws, 2018. Public Health Rep 2020;135(1 suppl):189S-196S. doi:10.1177/0033354920930146.
- 242 Valentine SS, Caldwell J, Tailor A. Effect of CDC 2006 revised HIV testing recommendations for adults, adolescents, pregnant women, and newborns on state laws, 2018. Public Health Rep 2020;135(1 suppl):189S-196S. doi:10.1177/0033354920930146.
- 243 Valentine SS, Caldwell J, Tailor A. Effect of CDC 2006 revised HIV testing recommendations for adults, adolescents, pregnant women, and newborns on state laws, 2018. Public Health Rep 2020;135(1 suppl):189S-196S. doi:10.1177/0033354920930146.
- 244 See, e.g., Ohio REV. Code Ann. § 3701.242(D) (West 2012) ("An individual shall have the right to an anonymous test. A health care facility or health care provider that does not provide anonymous testing shall refer an individual requesting an anonymous test to a site where it is available.").
- 245 See, e.g., VT. STAT. ANN. tit. 18, § 1001(g) (West 2015) ("Health care providers must, prior to performing an HIV test, inform the individual to be tested that a positive result will require reporting of the result and the individual's name to the Department [of Health], and that there are testing sites that provide anonymous testing that are not required to report positive results. The Department shall develop and make widely available a model notification form.").
- 246 See, e.g., Ohio Rev. Code Ann. § 3701.247(A)(2)(d) (West 2009) (providing that in a court action to compel an HIV test following a significant exposure, "the defendant shall be identified by a pseudonym and the defendant's name communicated to the court confidentially pursuant to a court order restricting the use of the name. Proceedings shall be conducted in chambers unless the defendant agrees to a hearing in open court."); Ohio Rev. Code Ann. § 3701.247(C) (West 2009) (providing that if the court issues an order compelling an HIV test, "the order shall guard against unauthorized disclosure of the test results by specifying the persons and governmental entities that may have access to the results and by limiting further disclosure"); see, e.g., N.D. Cent. Code Ann. § 23-07.5-06 (West 2005) (setting forth who may receive test results, prohibiting further disclosure except where specifically authorized, and requiring certain disclosures to include "the minimum amount of information needed.")
- 247 OHIO REV. CODE ANN. § 3701.247(A)(1) (West 2009).
- 248 FLA. STAT. ANN. § 775.0877(1) (West 2016).
- 249 Mo. Ann. STAT. § 567.120 (West 2017)
- 250 Miss. Code. Ann. § 41-23-1(10) (West 2000).
- 251 GA. CODE ANN. § 31-17A-2 (West 2011).
- 252 GA. CODE ANN. § 31-17A-2 (West 2011).
- 253 FLA. STAT. ANN. § 384.31 (West 2018).
- 254 FLA. STAT. ANN. § 384.31 (West 2018).
- 255 CAL. HEALTH & SAFETY CODE § 121015(d) (West 2012).
- 256 CAL. HEALTH & SAFETY CODE § 121015(d) (West 2012).
- 257 FLA. STAT. ANN. § 775.0877(2) (West 2016).
- 258 FLA. STAT. ANN. § 775.0877(1), (3) (West 2016).
- 259 CAL. HEALTH & SAFETY CODE § 121022(c) (West 2015).

- 260 Mo. Code Regs. Ann. tit. 19, § 20-26.040(4) (2012).
- 261 See, e.g., Mo. CODE REGS. ANN. tit. 19, § 20-26.070 (2000) (requiring courts to report specified information regarding court-ordered HIV testing for persons convicted of certain sex-related crimes, requiring laboratories to report the results of such tests to the state's Office of Surveillance, and requiring state health officials to convey the test results to specified parties).
- 262 See, e.g., IOWA CODE ANN. § 141A.6(2)-(6) (West 2022) (requiring reports of HIV to be made within seven days of specified triggering events).
- 263 CDC. HIV: surveillance systems. [web page]. Updated June 19, 2020 ("Using a uniform surveillance case definition and report form, all 50 states, the District of Columbia, and 6 US dependent areas (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, Republic of Palau, and the U.S. Virgin Islands) report confirmed diagnoses of HIV infection and infection classified as stage 3 (AIDS) to CDC. Case reports from these jurisdictions are sent to CDC after personal identifying information is removed.").
- 264 In Missouri, for example, if a school has "adopted a policy consistent with recommendations of the Centers for Disease Control on school children who test positive for HIV," the state "department of health and senior services [must] give prompt and confidential notice of the identity of any child reported to the department to have HIV infection and the parent or guardian of any child confirmed by the department of health and senior services standards to have HIV infection shall also give prompt and confidential notice of the identity of such child to the superintendent of the school district in which the child resides, and if the child attends a nonpublic elementary or secondary school, to the chief administrative officer of such school." Mo. ANN. STAT. § 191.689(1) (1988).
- 265 CDC. State laboratory reporting laws related to HIV. [web page]. Updated May 31, 2022 ("Two states and one U.S. territory do not meet the criteria for reporting all viral load, and CD4 count: Idaho, New Jersey, and the Virgin Islands.").
- 266 CDC. State laboratory reporting laws related to HIV. [web page]. Updated May 31, 2022.
- 267 CDC. HIV: surveillance systems. [web page]. Updated June 19, 2020 ("Using a uniform surveillance case definition and report form, all 50 states, the District of Columbia, and 6 US dependent areas (American Samoa, Guam, Northern Mariana Islands, Puerto Rico, Republic of Palau, and the U.S. Virgin Islands) report confirmed diagnoses of HIV infection and infection classified as stage 3 (AIDS) to CDC. Case reports from these jurisdictions are sent to CDC after personal identifying information is removed.").
- 268 CAL, HEALTH & SAFETY CODE § 121022(a) (West 2015).
- 269 IND. CODE ANN. § 16-41-2-3(a) (West 2001).
- 270 IND. CODE ANN. § 16-41-2-4 (West 1998)
- 271 GA. CODE ANN. § 17-10-15(b)-(c) (West 2020).
- 272 GA. CODE ANN. § 17-10-15(e)(3) (West 2020).
- 273 Mo. Ann. Stat. § 191.656(5) (West 2002).
- 274 OHIO REV. CODE ANN. § 3701.243(F) (West 2017).
- 275 N.Y. PUB. HEALTH LAW § 2133(1) (McKinney 1999).
- 276 CAL. HEALTH & SAFETY CODE § 121023(a) (West 2010).
- 277 CAL. HEALTH & SAFETY CODE § 121023(g) (West 2010).
- 278 CAL. HEALTH & SAFETY CODE § 121023(f) (West 2010).
- 279 MD. CODE REGS. 10.18.02.06(A)(1)(d) (2020).
- 280 MONT. ADMIN. R. 37.114.204(5)(d) (2020).
- 281 Hexem S. Public health departments and state patient confidentiality laws. [web page]. The Policy Surveillance Program; 2013.
- 282 Hexem S. Public health departments and state patient confidentiality laws. [web page]. The Policy Surveillance Program; 2013.
- 283 35 PENN. STAT. ANN. § 521.4(b) (West 2020).
- 284 N.C. GEN. STAT. § 130A-135 (West 1989).
- 285 N.C. GEN. STAT. § 130A-143 (West 2020).
- 286 N.C. GEN. STAT. § 130A-143 (West 2020).
- 287 N.C. GEN. STAT. ANN. § 130A-143(7a) (West 2020) ("Release is made by the Department or a local health department to a law enforcement official for any of the following purposes: (i) to prevent or lessen a serious or imminent threat to the health or safety of a person or the public, to the extent that disclosure is permitted under [the HIPAA Privacy Rule] and not otherwise permitted by [state regulations for disclosures to protect public health from communicable diseases and conditions], (ii) to enforce this Article or Article 22 of this Chapter, or (iii) to investigate a terrorist incident using nuclear, biological, or chemical agents. A law enforcement official who receives the information shall not disclose it further, except (i) when necessary to enforce this Article or Article 22 of this Chapter; or when necessary to conduct an investigation of a terrorist incident using nuclear, biological, or chemical agents; or (ii) when the Department or a local health department seeks the assistance of the law enforcement official in preventing or controlling the spread of the disease or condition and expressly authorizes the disclosure as necessary for that purpose.").
- 288 GA. CODE ANN. § 16-5-60(c) (West 2022).
- 289 OKLA. STAT. ANN. tit. 21, § 1031(B) (West 2002).
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