

Ethical and Legal Considerations for Client Consent to Share HIV Data

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Dori Molozanov

Senior Manager, Health Systems Integration
NASTAD

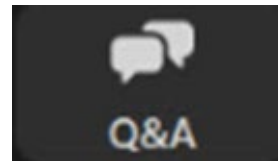
Amy Killelea

Consultant
NASTAD



Session Roadmap

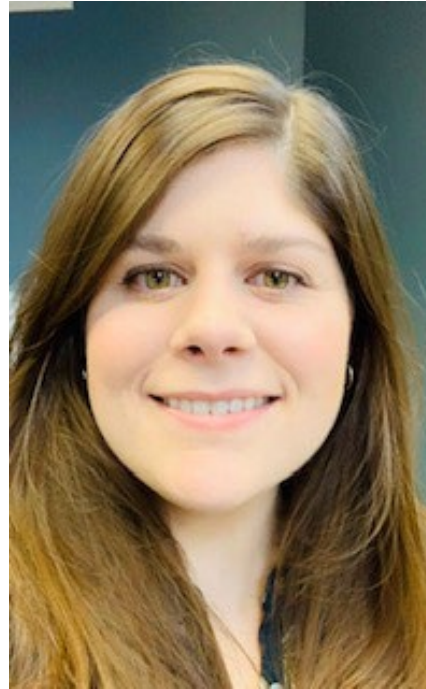
- Data sharing consent legal overview
 - HIPAA
 - 42 CFR Part 2
 - State HIV confidentiality laws
- Consent policies in action: health department and provider examples
- Discussion/questions and answer



Today's Guest Speakers



Adrian Guzman, JD, MPH (he/him)
Director, Policy and External Affairs
Bureau of Hepatitis, HIV, and STIs
NYC Health Department



Sarah Baddeley, Esq. (she/her)
Director of Compliance
Fenway Community Health Center



Katt Ross (she/her)
Associate Director of Social
Services, Ryan White Programs
Howard Brown Health

Data sharing consent legal overview

Consent to Treatment vs. Consent to Share Data

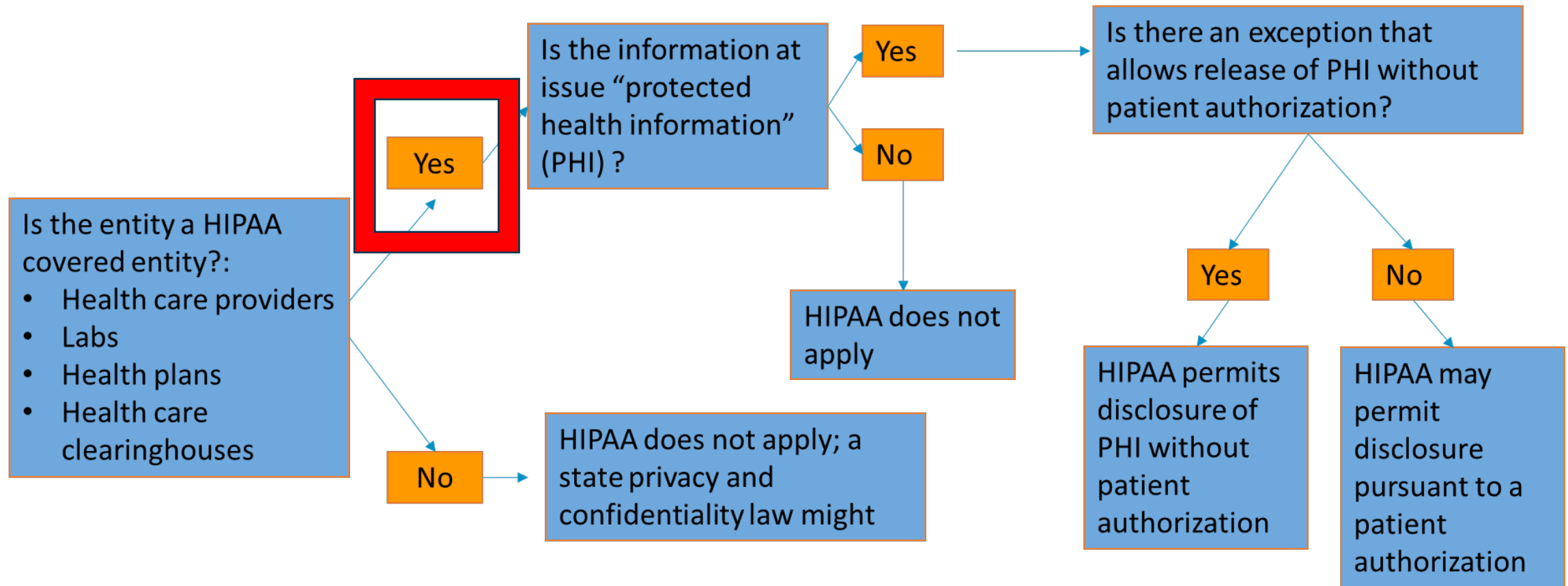
Consent to HIV testing

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

Consent to share data

- Separate from consent to undergo medical procedure
- Governed by federal and/or state law

The Intersection of HIPAA and State Public Health Laws



Poll: Determining if You Work in a HIPAA Covered Entity

- Is the HIV program you work for a “covered entity?”
 - Yes
 - No
 - I don't know

Health Departments: HIPAA Covered or Not?

- If the health department performs functions that make it a covered entity or otherwise meets the definition of a covered entity they must comply with the HIPAA Privacy Rule
 - E.g., state and local health departments that provide direct services are covered entities because they are acting as providers
 - E.g., state Medicaid programs are covered entities because they are acting as a health plan
- Many health departments are “hybrid” entities, meaning some functions are covered by HIPAA and some are not
 - E.g., an ADAP may be classified as HIPAA covered, but the state health department’s public health surveillance functions are not covered by HIPAA

HIV Care & Prevention Providers: HIPAA Covered or Not?

- If HIV care and prevention providers meet the definition of a HIPAA provider, then yes, they are covered entities
 - Under HIPAA, a covered provider is: *“a provider of medical or health services and any other person or organization who furnishes, bills, or is paid for health care in the normal course of business”*
- HIPAA often does not apply to community-based organizations offering non-clinical support services

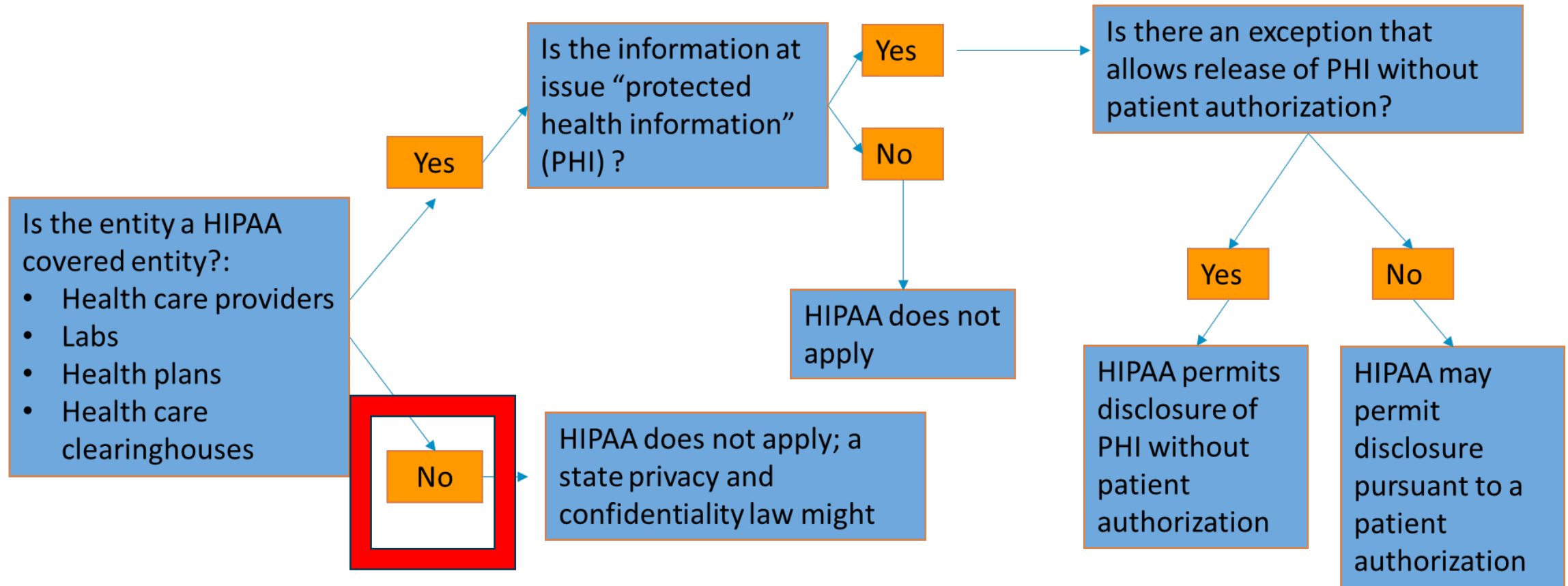
Consent to Share Data for HIPAA Covered Entities

- HIPAA covered entities (including HIV health department programs and providers that meet the definition of covered entity) must obtain consent (usually in writing) for sharing of personally identifiable information, unless there is an exception:
 - Disclosure to the individual identified in the information
 - **Treatment, payment, and health care operations**
 - Opportunity to agree or object (e.g., informal consent)
 - Incident to an otherwise permitted use or disclosure
 - **Public interest and benefit activities**
 - *Required by law*
 - *Public health activities*
 - *Disclosures to law enforcement or for judicial/administrative proceedings*
 - Limited data set

Authorization to Share Data under HIPAA

- An authorization to use or disclose personally identifiable data must:
 - Be written in plain language
 - Contain the specific information to be disclosed or used
 - Identify the person(s) disclosing and receiving the information
 - State the purpose for the request
 - Contain an expiration date after which the information may not be disclosed or used; and
 - Specify the individual's right to revoke the authorization in writing

The Intersection of HIPAA and State Public Health Laws



State HIV Confidentiality Laws

- State HIV confidentiality laws often apply to both HIPAA and non-HIPAA covered entities
 - For instance, some laws apply only to surveillance data held by a health department, while others might apply to all HIV test results held by providers
- State HIV confidentiality laws also generally require consent for sharing of personally identifiable data, but usually have fairly broad exceptions to allow for sharing of health department held HIV data for a range of public health purposes:
 - Surveillance case reports
 - Linkage/retention in care programs (e.g., data-to-care)
 - Public health response and/or emergency
- State HIV confidentiality laws may have more stringent protections for HIV data than HIPAA does (e.g., specific consent for sharing data)

State HIV Data Release Forms

- State laws may require providers to use a specific HIV consent form to release HIV information that is separate from a HIPAA release
 - E.g., California and New York both require written consent for a provider to disclose “HIV test result” (CA) or “HIV-related information” (NY)
 - See New York’s form below for example of how consent is obtained

COMPLETING THE FORM - Page 1:

Allows the client to specify the following:

I consent to disclosure of:

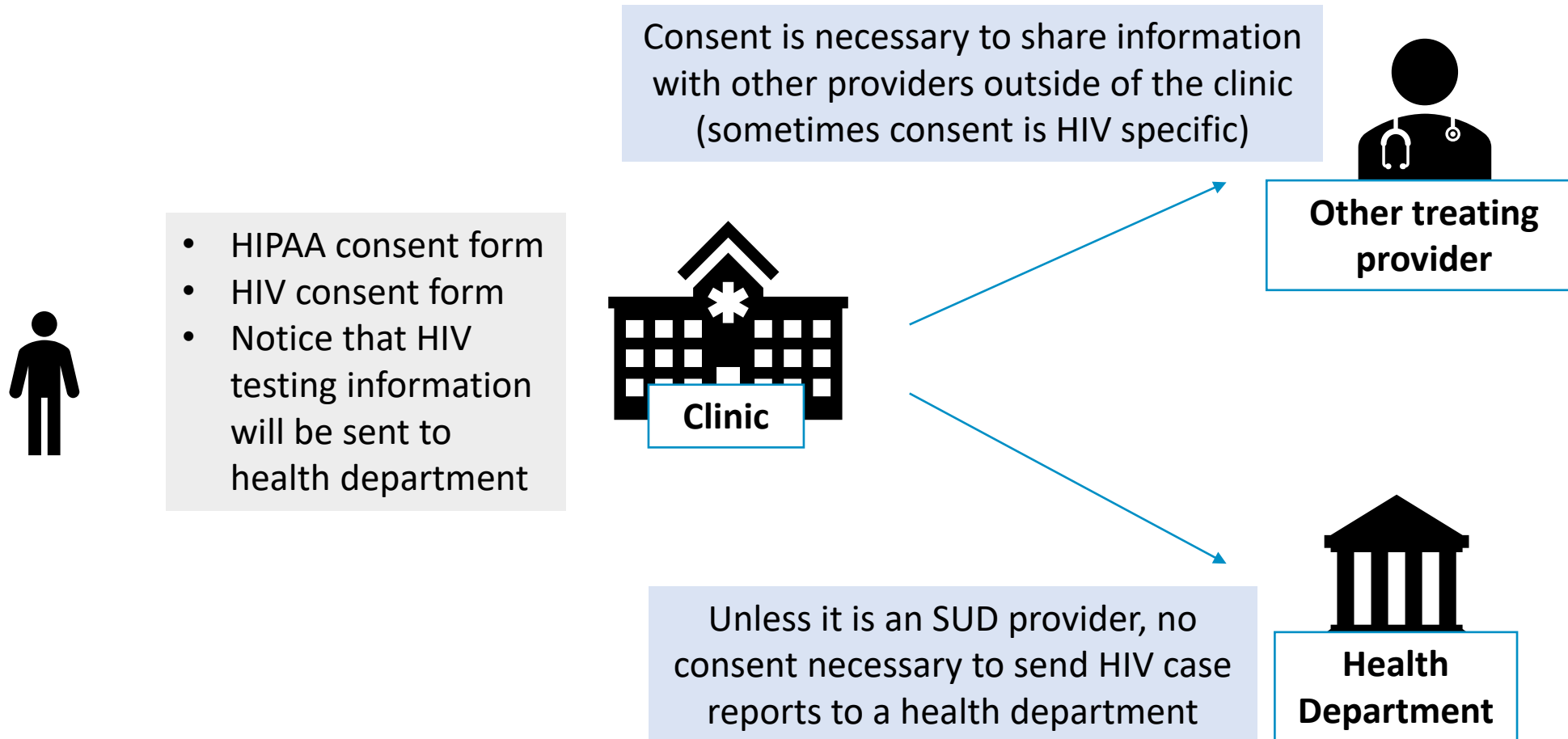
- a. My HIV-related information,*
- b. My non-HIV medical information*
- c. Both (non-HIV medical and HIV-related medical information)*

There may be circumstances in which an individual or provider only wants to release non-HIV medical information (choice “b” above). Rather than using this HIV-specific form, another approved HIPAA-compliant general medical release form may be used.

Consent Policies for Providers or Health Departments to Share HIV Data and Procedures Vary

- Consent processes may vary across the following variables even within the same jurisdiction (e.g., across RWHAP Parts):
 - The length the consent for data release is valid
 - The specific entities providers are authorized to share HIV information with (e.g., community-based organizations or other treating providers)
- Some providers include notices that HIV testing and other infectious disease testing information will be sent to a health department (these notices are typically not required by law)

Putting it Together: Consent in Action



Sharing Substance Use Data: 42 CFR Part 2

- 42 CFR Part 2 requires substance use providers to get **specific consent** for release of substance use related information, even for uses that would be exceptions under HIPAA
- Specific consent is also needed to send HIV and other infectious disease case reports to a health department

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

Consent Policies in Action

Client Consent to Share HIV-Related Information: Select Practices in New York State and New York City

NASTAD Webinar: Ethical and Legal Considerations for Client Consent to Share HIV Data
Thursday, September 19, 2024, 3-4:15pm

Adrian Guzman, JD, MPH
Director, Policy and External Affairs

Bureau of Hepatitis, HIV, and Sexually Transmitted Infections

Envisioning a New York City without transmission or illness related to viral hepatitis, HIV, and sexually transmitted infections.

Confidentiality and Disclosure of HIV-Related Information in New York State



New York State Public Health Law Article 27-F governs the confidentiality and disclosure of HIV-related information in New York State, with the regulations implementing these laws in **Part 63 of Title 10 of the New York Code of Rules and Regulations.**

Confidentiality and Disclosure of HIV-Related Information in New York State

Article 27-F protects the confidentiality of **HIV-related information** about **protected individuals** and their **contacts**.

- **“Confidential HIV-related information”** means “any information, in the possession of a person who provides one or more health or social services or who obtains the information pursuant to a release of confidential HIV related information, concerning whether an individual has been the subject of an HIV related test, or has HIV infection, HIV related illness or AIDS, or information which identifies or reasonably could identify an individual as having one or more of such conditions, including information pertaining to such individual’s contacts”
- **“Protected individual”** means “a person who is the subject of an HIV related test or who has been diagnosed as having HIV infection, AIDS or HIV related illness”
- **“Contact”** means “an identified spouse or sex partner of the protected individual, a person identified as having shared hypodermic needles or syringes with the protected individual or a person who the protected individual may have exposed to HIV under circumstances that present a risk of transmission of HIV, as determined by the commissioner”

DOH-2557: Authorization for Release of Health Information and Confidential HIV-Related Information

New York State Department of Health
AIDS Institute

Authorization for Release of Health Information and Confidential HIV-Related Information*

This form authorizes release of health information including HIV-related information. You may choose to release only your non-HIV health information, only your HIV-related information, or both. Your information may be protected from disclosure by federal privacy law and state law. Confidential HIV-related information is any information indicating that a person has had an HIV-related test, or has HIV infection, HIV-related illness or AIDS, or any information that could indicate a person has been potentially exposed to HIV.

Under New York State Law HIV-related information can only be given to people you allow to have it by signing a written release. This information may also be released to the following: health providers caring for you or your exposed child; health officials when required by law; insurers to permit payment; persons involved in foster care or adoption; official correctional, probation and parole staff; emergency or health care staff who are accidentally exposed to your blood; or by special court order. Under New York State law, anyone who illegally discloses HIV-related information may be punished by a fine of up to \$5,000 and a jail term of up to one year. However, some re-disclosures of health and/or HIV-related information are not protected under federal law. For more information about HIV confidentiality, call the New York State Department of Health HIV Confidentiality Hotline at 1-800-962-5065; for more information regarding federal privacy protection, call the Office for Civil Rights at 1-800-368-1019. You may also contact the NYS Division of Human Rights at 1-888-392-3644.

By checking the boxes below and signing this form, health information and/or HIV-related information can be given to the people listed on page two (and on additional sheets if necessary) of the form, for the reason(s) listed. Upon your request, the facility or person disclosing your health information must provide you with a copy of this form.

I consent to disclosure of (please check all that apply):

My HIV-related information
 My non-HIV health information
 Both (non-HIV health and HIV-related information)

Name and address of facility/person disclosing HIV-related information: _____

Name of person whose information will be released: _____

Name and address of person signing this form (if other than above): _____

Relationship to person whose information will be released: _____

Describe information to be released: _____

Reason for release of information: _____

Time Period During Which Release of Information is Authorized: From: _____ To: _____

Exceptions to the right to revoke consent, if any: _____

Description of the consequences, if any, of failing to consent to disclosure upon treatment, payment, enrollment, or eligibility for benefits
(Note: Federal privacy regulations may restrict some consequences): _____

Please sign below **only** if you wish to authorize all facilities/persons listed on pages 1,2 (and 3 if used) of this form to share information among and between themselves for the purpose of providing health care and services.

Signature _____ Date _____

* This Authorization for Release of Health Information and Confidential HIV-Related Information form is HIPAA compliant. If releasing only non-HIV related health information, you may use this form or another HIPAA-compliant general health release form.
DOH-2557 (2/11) Page 1 of 3

“This form authorizes release of health information including HIV-related information. You may choose to release only your non-HIV health information, only your HIV-related information, or both. Your information may be protected from disclosure by federal privacy law and state law. . . .

Under New York State Law HIV-related can only be given to people you allow to have it by signing a written release. This information may also be released to the following: health providers caring for you or your exposed child; health officials when required by law; insurers to permit payment; persons involved in foster care or adoption; official correctional, probation and parole staff; emergency or health care staff who are accidentally exposed to your blood; or by special court order. . . .”

DOH-5032: Authorization for Release of Substance Use, Mental Health, and HIV-Related Information

Authorization for Release of Health Information (Including Alcohol/Drug Treatment and Mental Health Information) and Confidential HIV/AIDS-related Information

NEW YORK STATE DEPARTMENT OF HEALTH

Patient Name	Date of Birth	Patient Identification Number
Patient Address		

1. Or my authorized representative, request that health information regarding my care and treatment be released as set forth on this form. I understand that:

1. This authorization may include disclosure of information relating to ALCOHOL and DRUG TREATMENT, MENTAL HEALTH TREATMENT, and CONFIDENTIAL HIV/AIDS-RELATED INFORMATION only if I place my initials on the appropriate line in item 8. In the event the health information described below includes any of these types of information, and I initial the line on the box in item 8, I specifically authorize release of such information to the person(s) indicated in item 6.

2. With some exceptions, health information once disclosed may be re-disclosed by the recipient. If I am authorizing the release of HIV/AIDS-related, alcohol or drug treatment, or mental health treatment information, the recipient is prohibited from re-disclosing such information or using the disclosed information for any other purpose without my authorization unless permitted to do so under federal or state law. If I experience discrimination because of the release or disclosure of HIV/AIDS-related information, I may contact the New York State Division of Human Rights at 1-888-392-3644. This agency is responsible for protecting my rights.

3. I have the right to revoke this authorization at any time by writing to the provider listed below in item 5. I understand that I may revoke this authorization except to the extent that action has already been taken based on this authorization.

4. Signing this authorization is voluntary. I understand that generally my treatment, payment, enrollment in a health plan, or eligibility for benefits will not be conditional upon my authorization of this disclosure. However, I do understand that I may be denied treatment in some circumstances if I do not sign this consent.

5. Name and Address of Provider or Entity to Release this Information:

6. Name and Address of Person(s) to Whom this Information Will Be Disclosed:

7. Purpose for Release of Information:

8. Unless previously revoked by me, the specific information below may be disclosed from: _____ until _____
INSERT START DATE INSERT EXPIRATION DATE OR EVENT

All health information (written and oral), except:

For the following to be included, indicate the specific information to be disclosed and initial below.	Information to be Disclosed	Initials
<input type="checkbox"/> Records from alcohol/drug treatment programs		
<input type="checkbox"/> Clinical records from mental health programs*		
<input type="checkbox"/> HIV/AIDS-related information		

9. If not the patient, name of person signing form: _____ 10. Authority to sign on behalf of patient: _____

All items on this form have been completed, my questions about this form have been answered and I have been provided a copy of the form.

SIGNATURE OF PATIENT OR REPRESENTATIVE AUTHORIZED BY LAW DATE

Witness Statement/Signature: I have witnessed the execution of this authorization and state that a copy of the signed authorization was provided to the patient and/or the patient's authorized representative.

WITNESS PERSON'S NAME AND TITLE SIGNATURE DATE

This form may be used in place of DOH-2557 and has been approved by the NYS Office of Mental Health and NYS Office of Alcoholism and Substance Abuse Services to permit release of health information. However, this form does not require health care providers to release health information. Alcoholism and substance abuse treatment-related information or confidential HIV-related information released through this form must be accompanied by the required statements regarding prohibition of re-disclosure.

*Note: Information from mental health clinical records may be released pursuant to this authorization to the parties identified herein who have a demonstrable need for the information, provided that the disclosure will not reasonably be expected to be detrimental to the patient or another person.

DOH-5032 (4/11)

The DOH-5032 authorization form was created to facilitate sharing of a patient's substance use, mental health, and HIV-related information – both *within* facilities where different providers handle these issues separately and *between* facilities and/or providers that care for the same patient – to allow for coordinated and comprehensive care and treatment.

The form may be used in place of DOH-2557, but is not intended to replace it.

HIV-Related Data Sharing by Health Departments in New York State

As part of efforts to advance the 2014 New York State Blueprint to End the Epidemic:



- In 2014, Governor Cuomo signed into law legislation **expanding HIV data sharing from health departments to health care providers** for the purpose of linkage to and ongoing engagement in care; and
- In 2017, the New York State Department of Health adopted regulatory amendments **expanding HIV data sharing from health departments to care coordinators*** for the purpose of linkage to and ongoing engagement in care.

Source: N.Y.S. DEP'T OF HEALTH, 2015 BLUEPRINT FOR ENDING THE EPIDEMIC (Mar. 30, 2015), available [here](#).

* "Reports and information may be used in the aggregate in programs approved by the Commissioner: . . . when used for the purposes of linkage to and retention in care, in which case the protected individual's individually identifiable health information may be shared among state health departments, local health departments, . . . and entities engaged in care coordination that have a clinical, diagnostic, or public health interest in the patient. For the purposes of this section, care coordination shall mean managing, referring to, locating, coordinating, and monitoring health care services for the individual to assure that all medically necessary health care services are made available to and are effectively used by the individual in a timely manner, consistent with patient autonomy . Care coordination shall be conducted by or with the participation of the individual's health care provider to the extent possible." 10 N.Y.C.R.R. § 63.4 (c).

Select New York City Health Department Initiatives Involving Client Consent and HIV-Related Information

- **Data 2 Suppression (D2S)** for Ryan White Part A behavioral health and housing programs
- **DISCO:** Developing Information-sharing Standards through Community



Select New York City Health Department Initiatives Involving Client Consent and HIV-Related Information

Should data sharing be an opt-out or opt-in process, or something else?

How should consumers be notified when their data are shared?

What are acceptable reasons to share Ryan White Part A consumers' HIV laboratory data?

What *types* of data and what level of details are appropriate to share?

How often should data sharing preferences be reviewed?



What are ways to make information sharing processes easier to understand for consumers?

What are consumers' own concerns and questions?

Select New York City Health Department Initiatives Involving Client Consent and HIV-Related Information

Proposed policy statements:

- Informed consent statement
- Frequency of consent
- Informed consent process
- D2S informational video
- D2S website
- Disclosure notification
- Patient portal



Contact Information

Adrian Guzman, JD, MPH

Director, Policy and External Affairs

Bureau of Hepatitis, HIV, and Sexually Transmitted Infections

New York City Department of Health and Mental Hygiene

Email: aguzman2@health.nyc.gov



Fenway Health Data Sharing and Patient Privacy

Sarah Baddeley, Esq. (she/her)
Director of Compliance, HIPAA Privacy Officer

FENWAY COMMUNITY HEALTH CENTER

- FQHC
- Public Health Division
 - HIV/AIDS outreach
 - Drug User Health
- The Fenway Institute

HOW WE KEEP PATIENTS AT THE CENTER OF OUR WORK

- Err on the side of less sharing, more consent
- Comply with State Laws and Contracts
- De-identify data

HOW WE WEIGH THE COMPETING INTERESTS

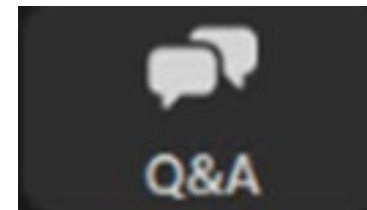
- Multi-disciplinary team for decisions
- Case specific decisions:
 - Public Safety Offices
 - Scheduling Software
- Reassess when needed

ON-GOING CONSIDERATIONS AND CHALLENGES

- Epic
 - Care Everywhere
 - HIV Diagnosis

Questions?

Drop them in the Q&A down below!



Contact Information

Dori Molozanov

NASTAD

Senior Manager, Health Systems Integration

dmolozanov@nastad.org