

Public Health Surveillance Basics & Using Surveillance Data to Detect HIV Clusters

September 21, 2021 from 2:00 p.m. – 4:00 p.m.

Before we start...

- ✓ **Sign-in** – Please scan the QR code or click the link in the chat box to confirm your attendance.



<https://bit.ly/3j1XExh>



Project Conectate Acknowledgments

Cluster Detection and Response
Team, DSHS

HIV/STD Section, DSHS

- Surveillance
- Prevention
- Public Health Follow Up

Texas HIV Syndicate

Houston Health Department

Achieving Together

University of Texas Southwestern

Prism Health North Texas

San Antonio Metropolitan Health
District

Alamo Area Resource Center

Cluster Detection and Response information presented in this presentation comes from experience and information gathered from activities funded by PS17-1711 and PS18-1802. Cluster Detection and Response activities will be completed under PS18-182, PS20-2010, and Ending the HIV Epidemic. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.



TEXAS
Health and Human
Services

Texas Department of State
Health Services

Virtual Learning Series: HIV Cluster Response

*Public Health Surveillance Basics &
Using Surveillance Data to Detect HIV Clusters*

Elana Ross & Eve Mokotoff

September 14, 2021

Texas

Part 1



Introductions and Initial Questions

- Please rename yourself on zoom to include your role at your health department, CBO, or in the community, and your role in CDR planning (if applicable)
- Go to menti.com and enter the code on the screen
- There will be a poll and an open-ended question, all answers are anonymous

About NASTAD

- **WHO:** A non-partisan non-profit association founded in 1992 that represents public health officials who administer HIV and hepatitis programs in the U.S.
- **WHERE:** NASTAD represents all 50 U.S. states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, seven local jurisdictions receiving direct funding from the Centers for Disease Control and Prevention (CDC), and the U.S. Pacific Island jurisdictions.
- **HOW:** Interpret and influence policies, conduct trainings, offer technical assistance, and provide advocacy mobilization for health departments.

Mission and Vision

OUR MISSION

NASTAD's mission is to end the intersecting epidemics of HIV, viral hepatitis, and related conditions by strengthening domestic and global governmental public health through advocacy, capacity building, and social justice.

NASTAD's vision is a world free of HIV and viral hepatitis.

Expectations and Logistics



- Participation
 - Participants will be muted to limit background noise, but you may unmute yourself during discussion or Q&A if you want to talk
 - Will have some interactive components during the webinar
- Asking questions
 - Please submit questions in the chat box and/or can ask verbal questions during Q&A times
- Maintaining a safe space for discussion
- Webinar will be recorded for internal reference and hosted on the Texas Department of State Health Services website
- **For IT issues:** please email: aetcinfo@uthscsa.edu

Virtual Learning Series

Public Health Surveillance Basics &
Using Surveillance Data to *Detect* HIV Clusters

Part 1
Sep. 14,
2021

Health Department, Provider, and Community
Collaboration to *Respond* to HIV Clusters

Part 2
Sep. 21,
2021

Addressing Community Concerns: Data Release and HIV
Criminalization Considerations & HIV Stigma

Part 3
Sep. 28,
2021

Three-Part Webinar Series Objectives

- Understand the history and concepts behind public health surveillance including ethics, consent, and data protection for HIV surveillance data
- Explain the basic process, benefits, and drawbacks of HIV cluster response
- Effectively communicate with community members/clients/patients about common cluster response concerns

Objectives for Today

1. Understand the history, goals, and basic concepts behind public health surveillance, and specifically HIV surveillance
2. Describe the process through which HIV surveillance data are reported to the health department and to the CDC (HIV case reporting data flow) and how the data are protected from release
3. Explain how HIV surveillance data are used to guide HIV prevention work and measure progress in meeting prevention goals
4. Understand what an HIV cluster is and how health departments use public health data to detect clusters

Agenda for Today



- Public Health Disease Surveillance



- Data Protection



- Using Surveillance Data to Monitor HIV Prevention and Care Goals



- Using Surveillance Data to Detect HIV Clusters



- Visualizing HIV Clusters



- Remaining Questions and Concerns Related to Surveillance



- Q&A and Wrap Up

Public Health Disease Surveillance Overview

Disease Reporting: State and Federal Roles

- Laws and rules governing communicable disease reporting reside at the state (city/county) level
- The CDC and national organizations, like CSTE*, make recommendations not requirements
- HIV Reporting
 - The process of establishing a national HIV reporting system spanned 22 years
 - 40 HIV-related CSTE Position Statements over 34 years (1986-2020)
 - <https://www.cste.org/page/PositionStatements>

*Council of State and Territorial Epidemiologists

Public Health Surveillance: Definition

- Public health surveillance is the systematic and ongoing assessment of the health of a community, including timely
 - Collection
 - Analysis
 - Interpretation
 - Dissemination and subsequent use of the data
- Case reporting is the most common type of disease surveillance
- Population-based
 - Not research
 - Not a consent-based process

Based on:

1. Teutsch, SM and Churchill, RE. Principles and Practice of Public Health Surveillance. Oxford University Press 1994
2. Glynn KM and Backer LC . Collecting Public Health Surveillance Data, Creating a Surveillance System; Chapter 4 in Lee LM, Teutsch SM, Thacker SB and St. Louis ME. Principles and Practice of Public Health Surveillance. Oxford University Press 2010

Disease Surveillance: Consent

- Disease surveillance/case reporting do not include consent
 - Describe disease patterns in the whole population
- Examples and how the information is used
 - Food borne illness such as Salmonella
 - To stop transmission, need to identify source
 - Respiratory spread such as TB or COVID-19
 - Notify contacts for treatment or quarantine
 - Bodily fluid but non-respiratory spread such as HIV
 - Facilitate linkage to, engagement in care
 - Notify contacts and those at risk of infection, offer PrEP
 - Follow up on clusters and interrupt transmission

Non-Communicable

Examples of Using
Surveillance Data
for **Public Health
Action**

**Non-
Communicable
Illnesses**

- Foodborne outbreaks
 - Identify source and remove it
 - Identify people at risk and provide prophylaxis, if warranted
- Lead poisoning
 - Identify children with elevated blood levels, link to treatment
 - Identify locations
 - Remove source of lead

Communicable Diseases

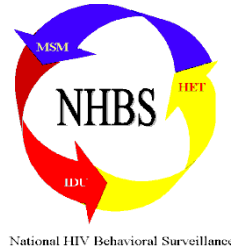
Examples of
Using
Surveillance Data
for **Public Health
Action**

**Communicable
Diseases**

- Tuberculosis
 - Link persons to care and monitor treatment (“DOT”)
 - Identify those potentially exposed and test contacts
- Syphilis
 - Provide treatment
 - Identify sexual partners of cases, test and provide treatment as warranted

Surveillance = Information for Action

1. Data Collected & Analyzed



2. Data Disseminated



5. Progress towards Strategic Plan goals

Reduce the number of new HIV infections by 25% by 2015 focusing on eliminating racial and ethnic disparities...

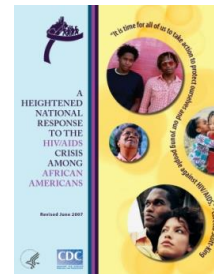


3. Public Awareness And Activism

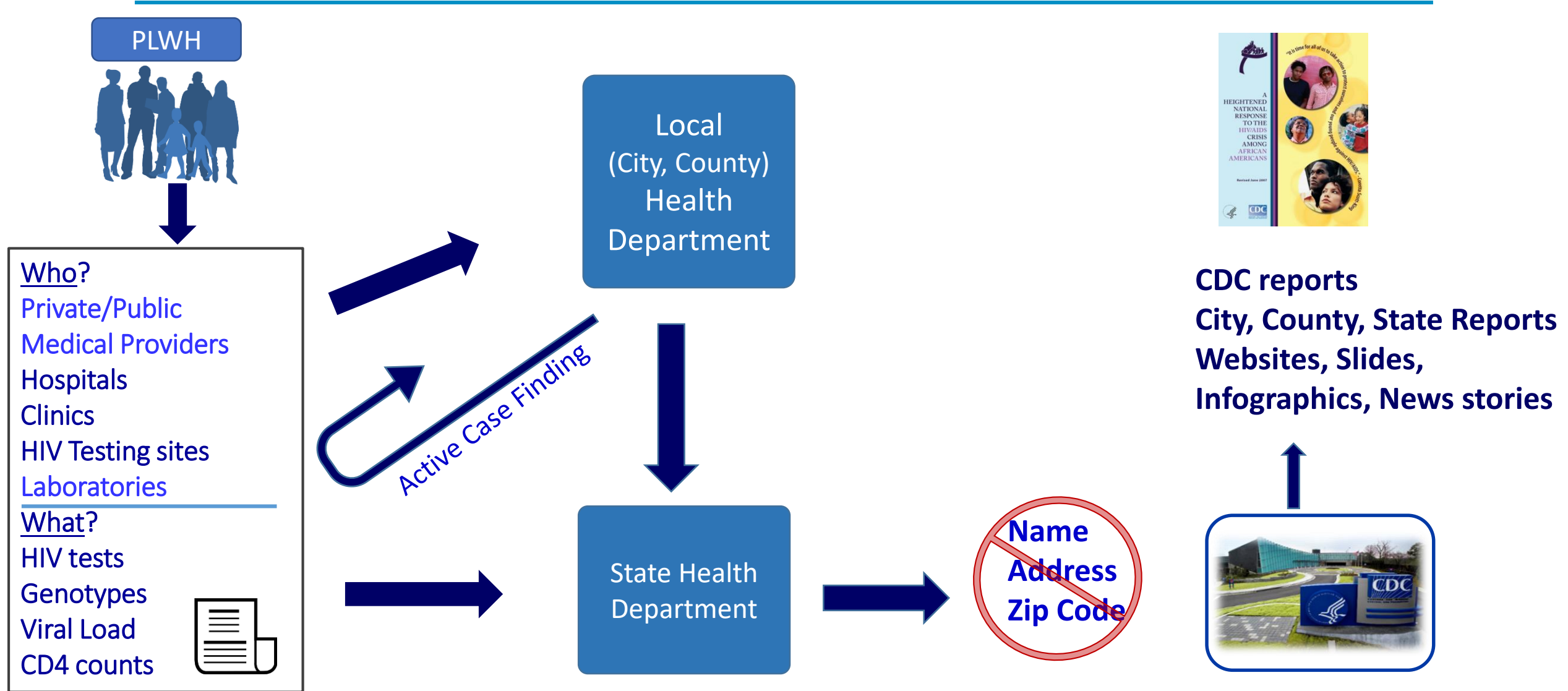


4. Public Health Response

**Many Men,
Many Voices
(3MV)**



HIV Case Reporting Data Flow



Public Health Surveillance: Ethical Considerations

- Public health surveillance data:
 - Used to protect, maintain, and improve the health of the public
 - Should be acquired and used for legitimate public health purposes
 - Must be stored securely
- Recognize:
 - Use of public health surveillance data may conflict with individual interests because of the stigmatizing and potential legal consequences
 - For highly stigmatized infections, like HIV, scrupulous attention to how the data are collected, protected and used is vital to disease control efforts
 - If used at the individual level the reason should be to improve the health of the individual (Data to Care example)

Public Health Surveillance: Implications for Persons in HIV Clusters

- Names and other identifying information are not shared outside of the health department
- Field staff who may contact partners do not disclose the identity of other persons in the cluster
 - Health departments use names to find other members of the cluster and offer help with testing, linkage to PrEP and linkage to and engagement in care

Data Protection

Public Health Surveillance: Considerations for Use

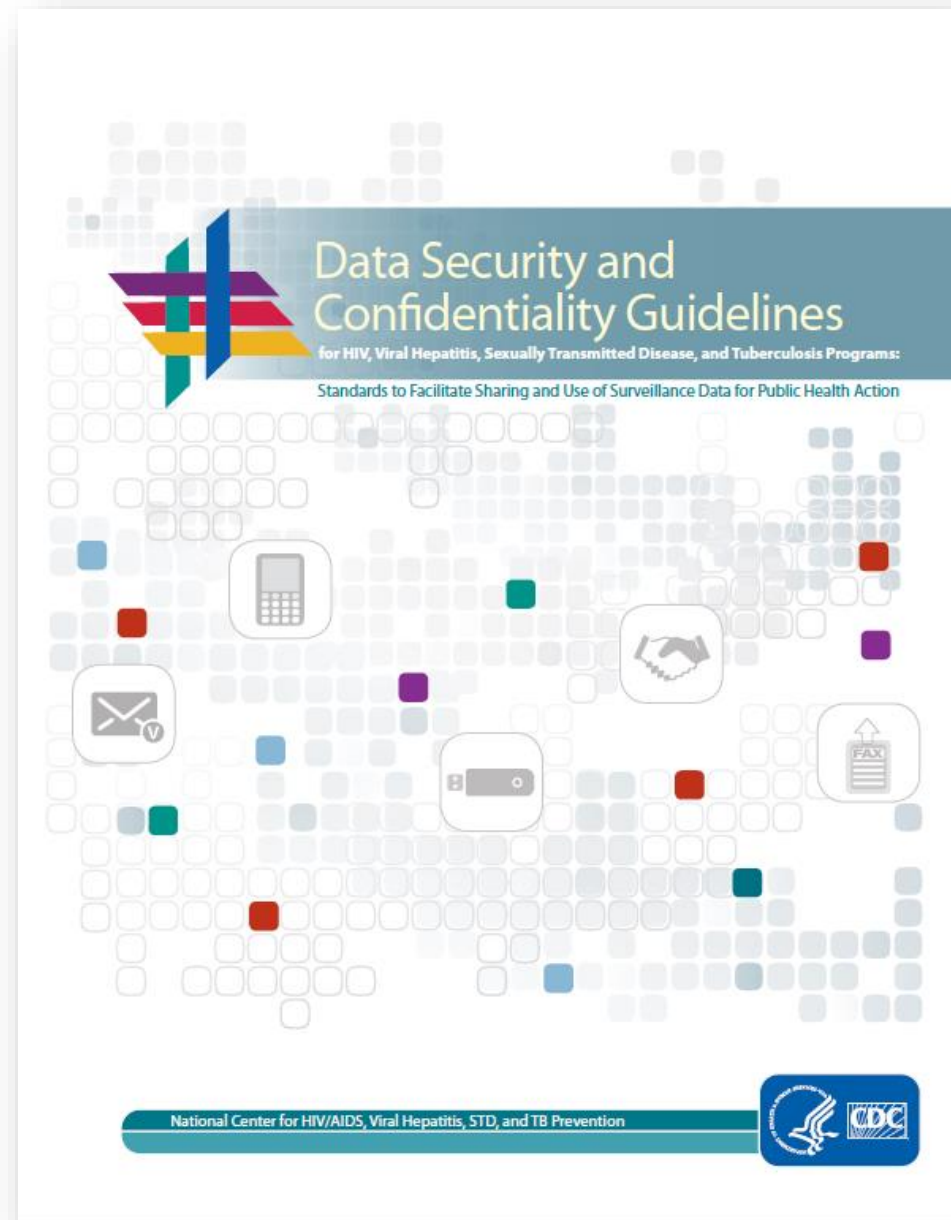
- Adequate legal and other controls for protecting privacy of health-related information and discrimination should be developed
- Use of individual-level data, including for legitimate public health purposes, should incorporate input from those directly affected by such use
 - During design of such programs
 - On an ongoing basis

Data Protection Requirements




- Adherence to specific data protection requirements are a condition of CDC funding of HIV surveillance and prevention programs:
 - *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*

<https://www.cdc.gov/nchhstp/programintegration/docs/pcsidatasecurityguidelines.pdf>

CDC Data S&C
Guidelines—
Standards to
Facilitate Sharing
and Use of
Surveillance Data
for Public Health
Action

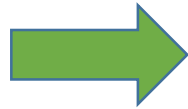


Ten Guiding Principles for Data Collection, Storage, Sharing, and Use to Ensure Security and Confidentiality

- 
1. Public health data should be acquired, used, disclosed, and stored for legitimate public health purposes.
 2. Programs should collect the minimum amount of personally identifiable information necessary to conduct public health activities.
 3. Programs should have strong policies to protect the privacy and security of personally identifiable data.
 4. Data collection and use policies should reflect respect for the rights of individuals and community groups and minimize undue burden.
 5. Programs should have policies and procedures to ensure the quality of any data they collect or use.
- 
- 

Source: CDC. Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs, 2011; Lee & Gostin. JAMA, 2009.

Ten Guiding Principles for Data Collection, Storage, Sharing, and Use to Ensure Security and Confidentiality



6.	Programs have the obligation to use and disseminate summary data to relevant stakeholders in a timely manner.
7.	Programs should share data for legitimate public health purposes and may establish data-use agreements to facilitate sharing data in a timely manner.
8.	Public health data should be maintained in a secure environment and transmitted through secure methods.
9.	Minimize the number of persons and entities granted access to identifiable data.
10.	Program officials should be active, responsible stewards of public health data.

Using Surveillance Data to Monitor HIV Prevention and Care Goals

National HIV Prevention Priorities

CDC Division of HIV/AIDS Prevention's Strategic Plan 2017-2020

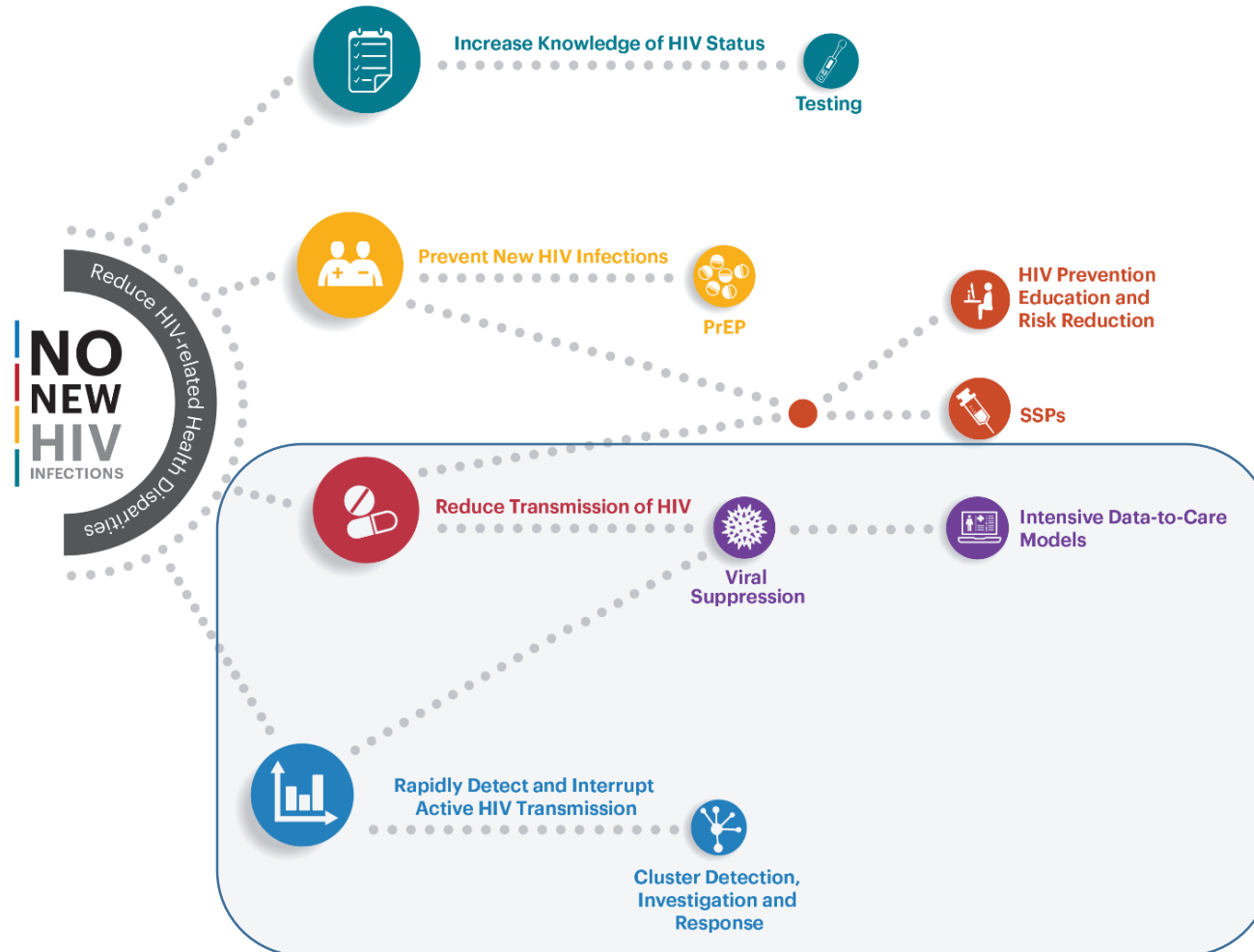


Image source:
www.cdc.gov/hiv/dhap/strategicplan/index.html

Measuring HIV Prevention Goals – Role of Surveillance

Who Reports:

Laboratories

Private/Public Medical Providers

Hospitals

Clinics

HIV Testing sites

What do they report?

HIV tests

Drug resistance/ genotypes

Viral Load

CD4 counts

- How do we know people with HIV are:
 - Diagnosed?
 - Linked to care?
 - Retained in care?
 - Virally suppressed?
- The National HIV Surveillance System is the primary source of data used to monitor the epidemic in the U.S.

Ending the HIV Epidemic

GOAL:

75%
reduction in new
HIV infections
by 2025
and at least
90%
reduction
by 2030.



Diagnose all people with HIV as early as possible.

Treat people with HIV rapidly and effectively to reach sustained viral suppression.



Prevent new HIV transmissions by using proven interventions, including pre-exposure prophylaxis (PrEP) and syringe services programs (SSPs).

Respond quickly to potential HIV outbreaks to get needed prevention and treatment services to people who need them.



Source: www.hiv.gov/federal-response/ending-the-hiv-epidemic/overview

5-MINUTE BREAK



Review and Up Next!

- Disease surveillance in general and HIV surveillance and case reporting more specifically
- Protecting HIV data from disclosure
- How cluster detection and response are part of CDC HIV prevention goals to move the country towards “No New Infections” and is part of the Ending the HIV Epidemic campaign
- Next, we will discuss detecting clusters in a bit more detail

Using Surveillance Data to **Detect** and Respond to HIV Clusters

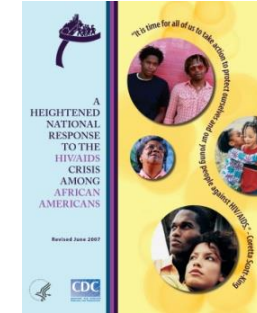
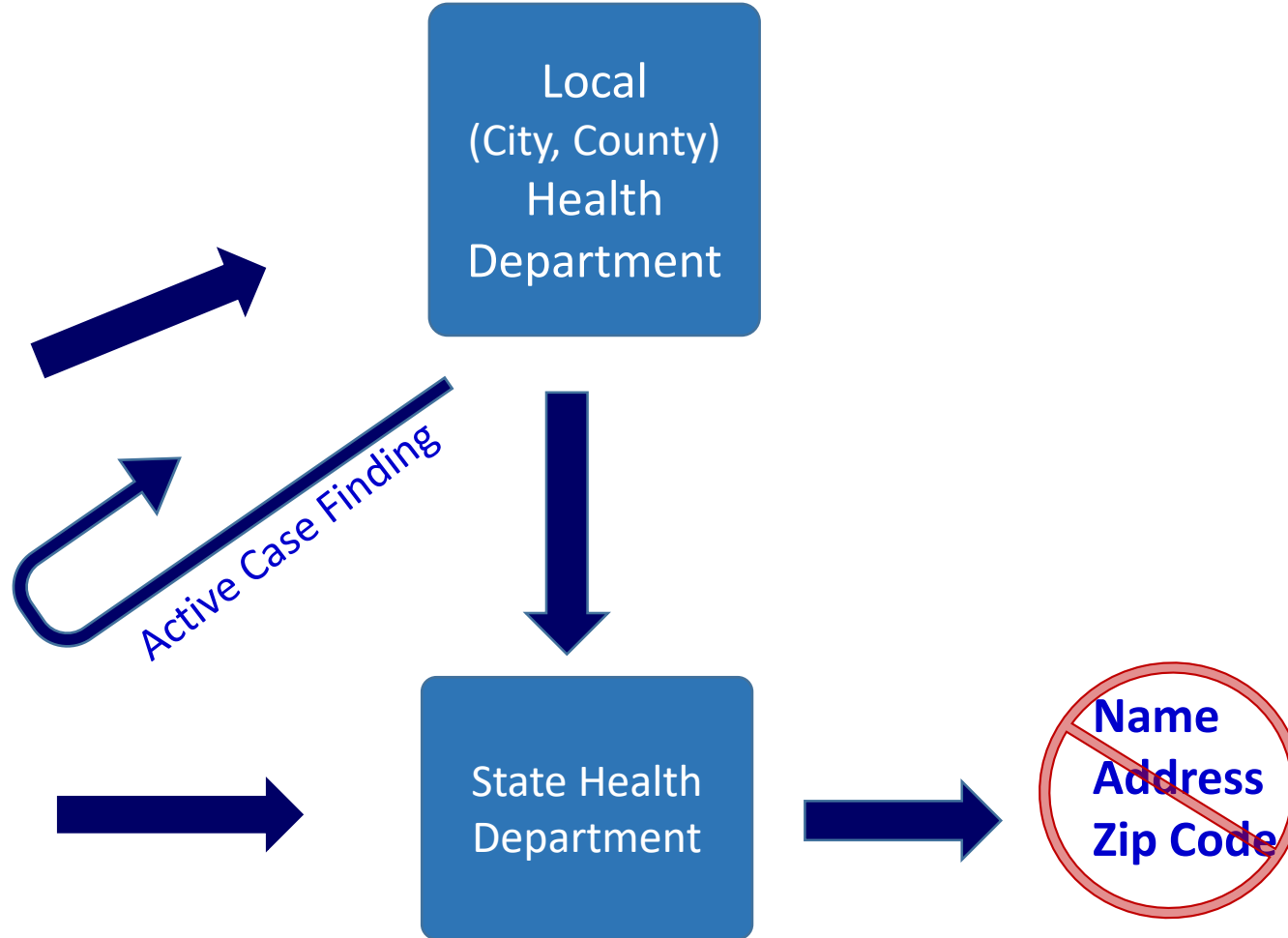
HIV Case Reporting Data Flow

PLWH



Who?
Private/Public
Medical Providers
Hospitals
Clinics
HIV Testing sites
Laboratories

What?
HIV tests
Genotypes
Viral Load
CD4 counts



CDC reports
City, County, State Reports
Websites, Slides,
Infographics, News stories



Molecular HIV Surveillance in Context

- “Traditional” HIV surveillance
 - HIV tests, Viral Load, CD4 counts
- Molecular HIV surveillance
 - Genetic sequences (genotypes) produced during resistance testing

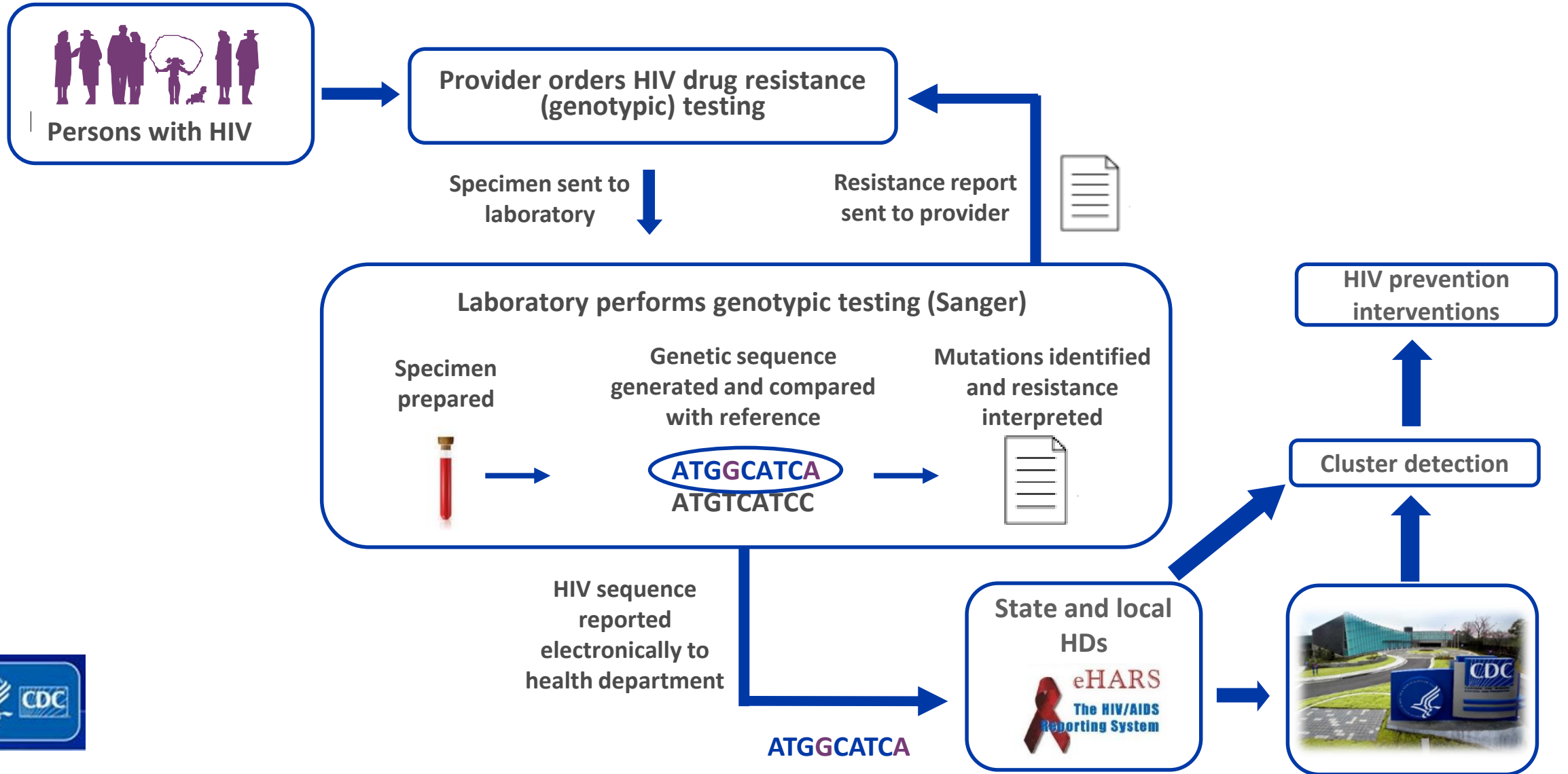
Who Reports:

Private/Public Medical Providers
Hospitals
Clinics
HIV Testing sites
Laboratories

What is Reported:

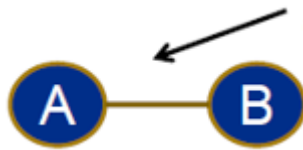
HIV tests
Viral Load
CD4 counts
Drug resistance/genotypes

Molecular Data Collection: National HIV Surveillance System



Identifying Molecular Clusters

- Compare all pairs of sequences to calculate genetic distance* between them
- Identify pairs of sequences that are very closely related
- Connect all closely related pairs to identify clusters
- Performed using the analytic tool, HIV-TRACE



*Genetic information measures the closeness of the relationship between the virus in two people

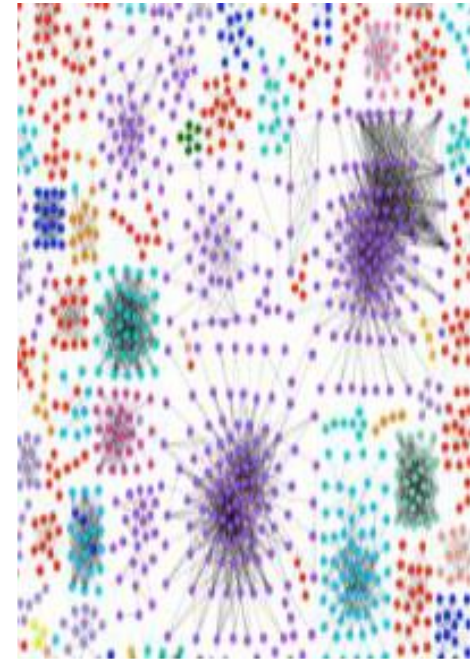


Image courtesy of Joel Wertheim

Based on information
in a slide presented
by CDC

**Reminder: These are characteristics of the virus,
not people**

Related Viral Strains – Not Directionality

- Analysis shows related viral strains showing a direct or indirect link
- Not the direction – that is, **we cannot say from these analyses which person was the source of another person's HIV infection**



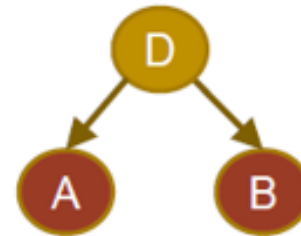
Person A transmits HIV to Person B



Person B transmits HIV to Person A



Person A transmits HIV to Person C,
who transmits to person B

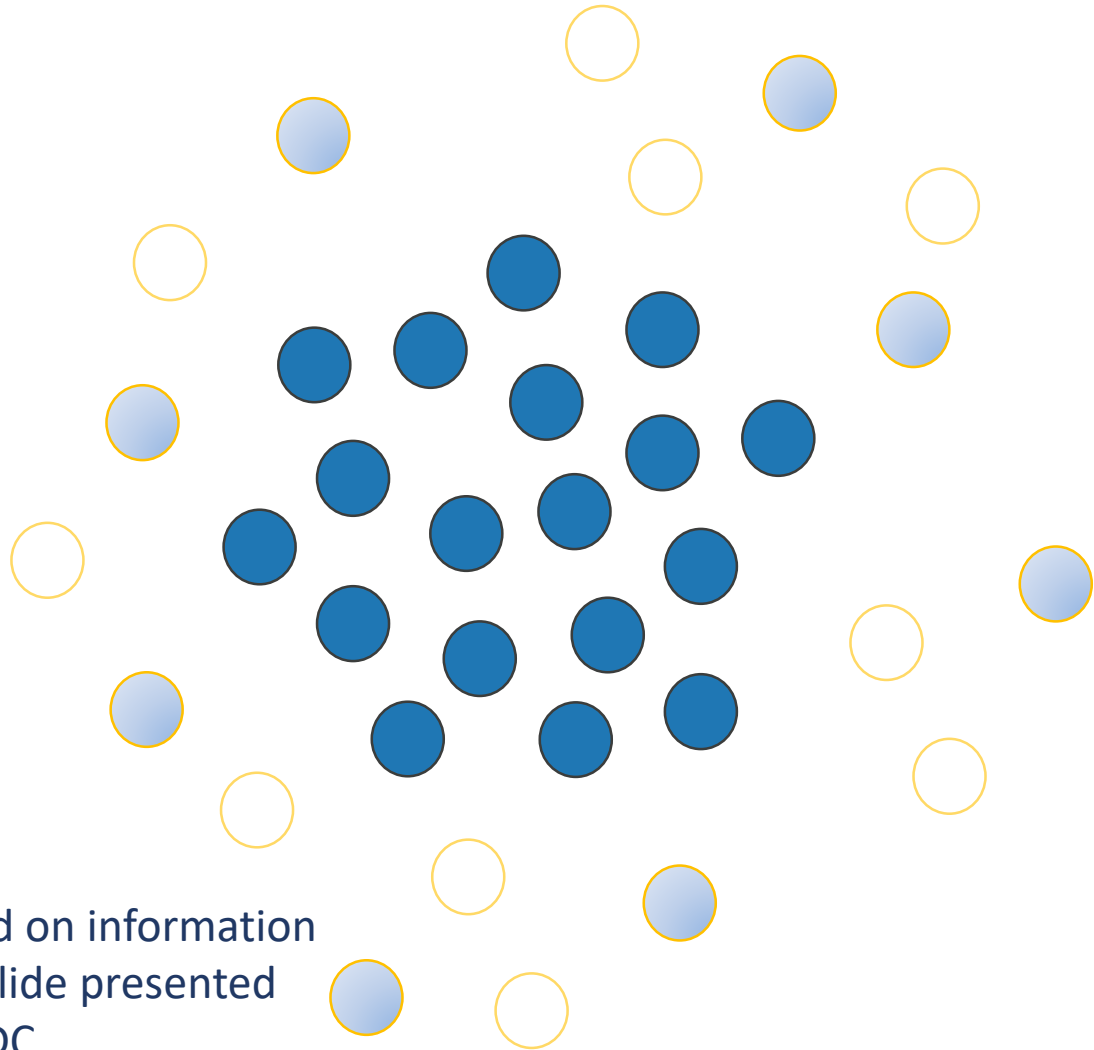


Person D transmits HIV to Persons A and B

Based on information in
a slide presented by CDC

Reminder: These are characteristics of the virus, not people

Network Where HIV is Spreading Quickly

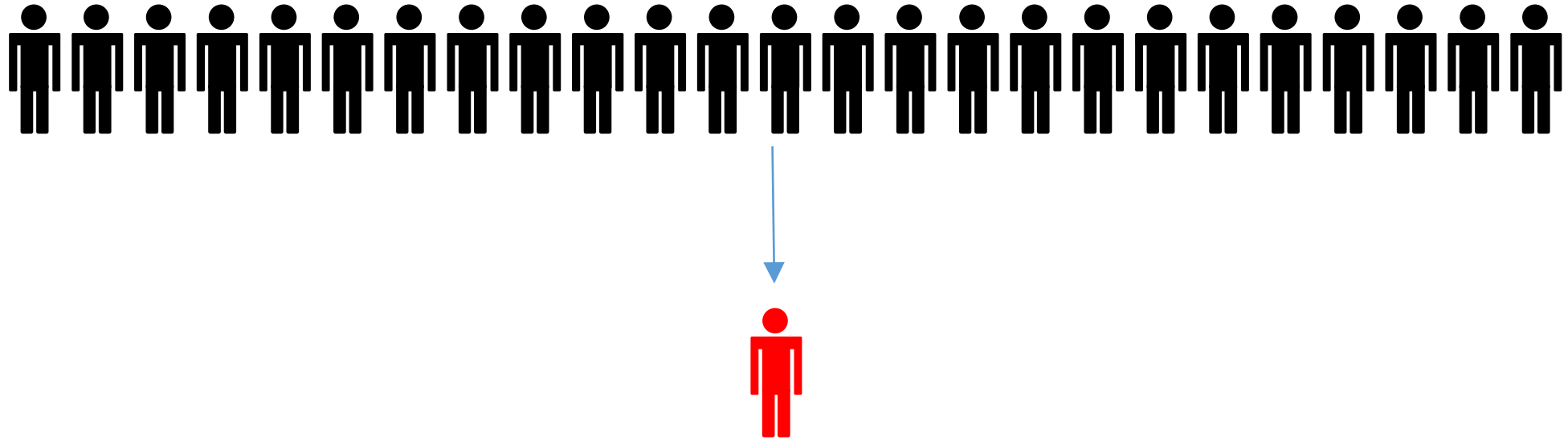


- Reach out to people in these networks
 - Provide linkage to the services they need
 - Understand barriers to care and prevention
 - Develop approaches to overcome them

Based on information
in a slide presented
by CDC

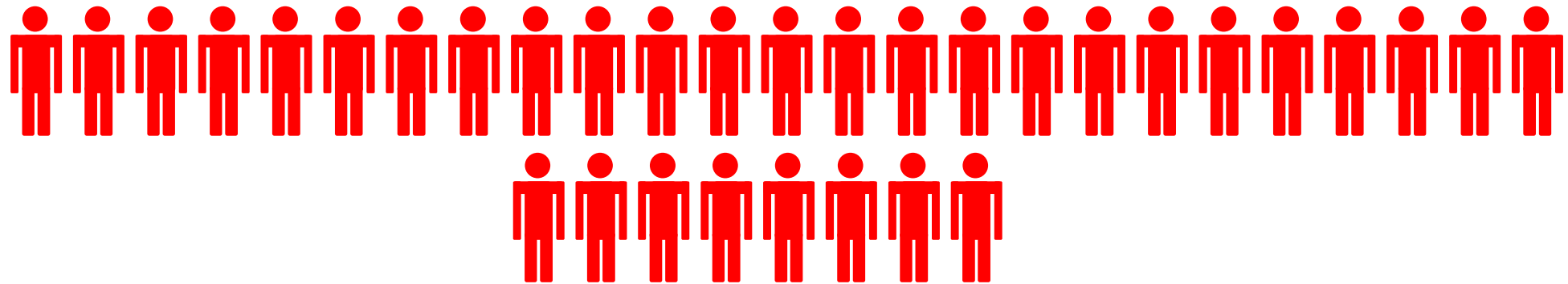
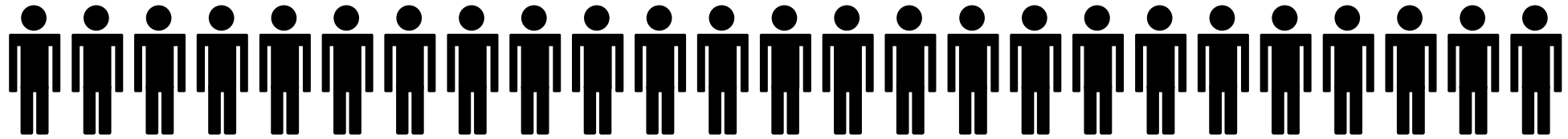
HIV transmission rate in the United States

4 transmissions per 100 people living with HIV per year



HIV transmission rate in first 60 priority clusters

21–132 transmissions per year per 100 persons living with HIV



Maximum



Detection: Field and Molecular Data

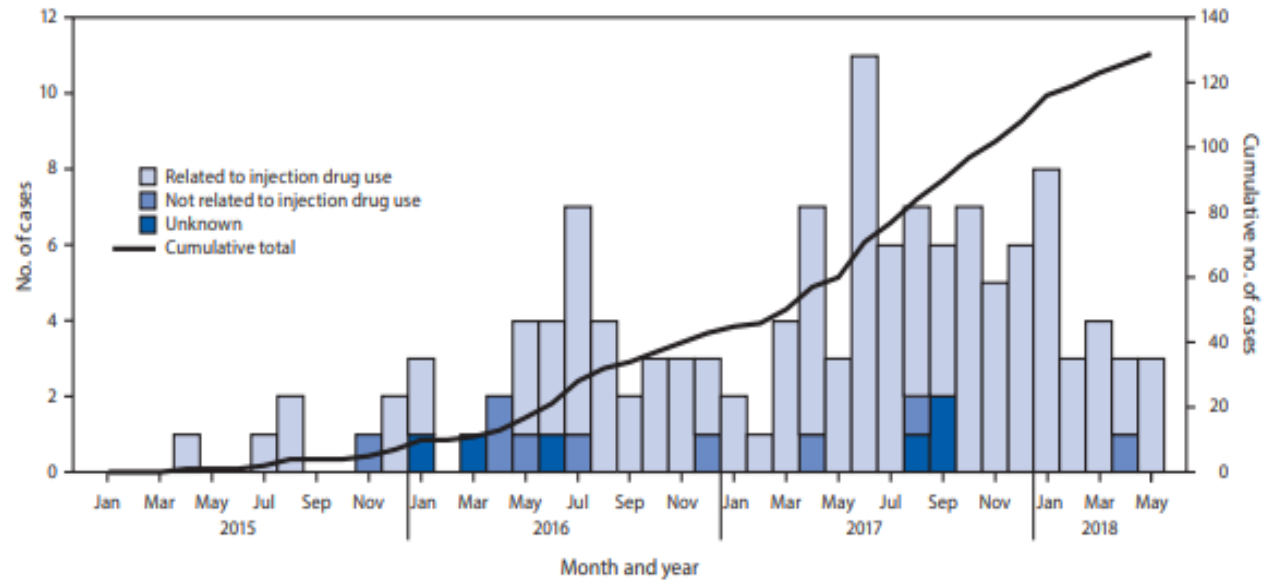
How were people in the outbreak identified?

- 22% had epidemiologic links* only
- 53% both molecular and epidemiologic links
- **25% molecular data only**

*linked to other individuals in the outbreak by behavior (e.g., injected drugs), time, and location— also called field data or time/space clusters

HIV Diagnoses Among Persons Who Inject Drugs — Northeastern Massachusetts, 2015–2018

FIGURE. Human immunodeficiency virus diagnoses linked to Lawrence and Lowell, Massachusetts, January 2015–May 2018

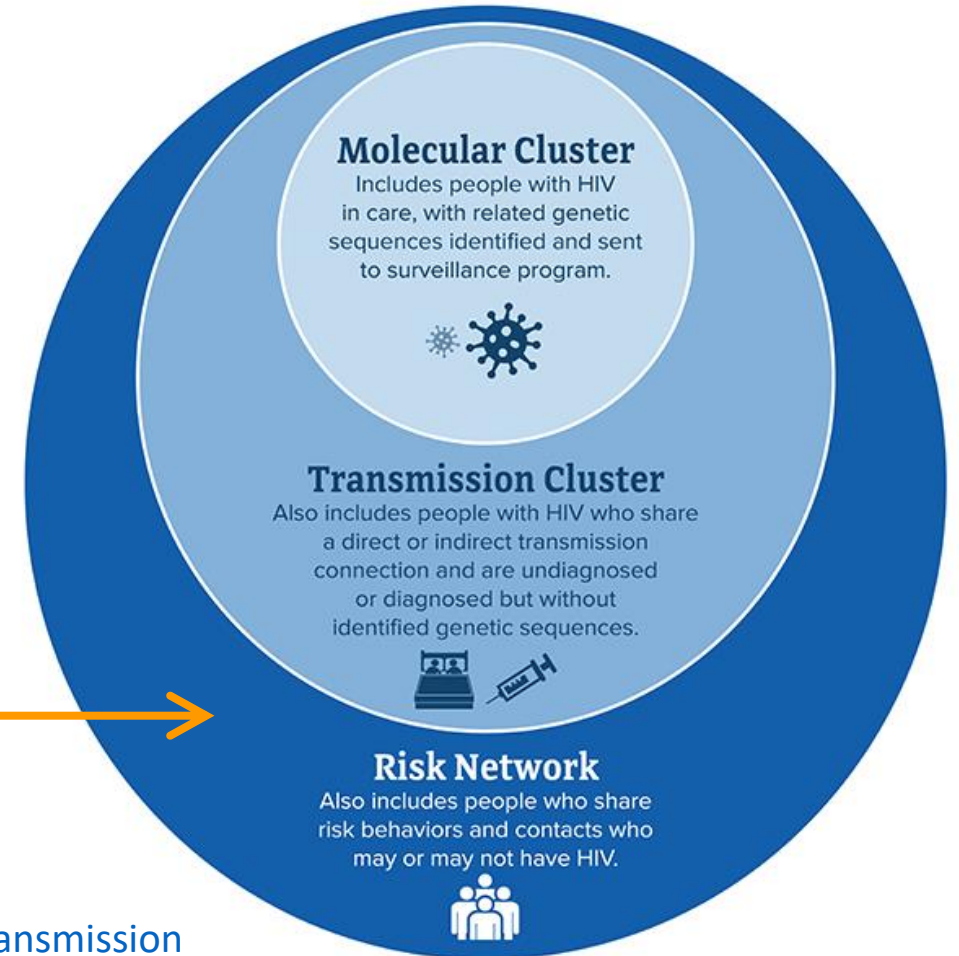


Source: <https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6810a6-H.pdf>

Visualizing HIV Clusters

HIV Clusters Visualized: Risk Network

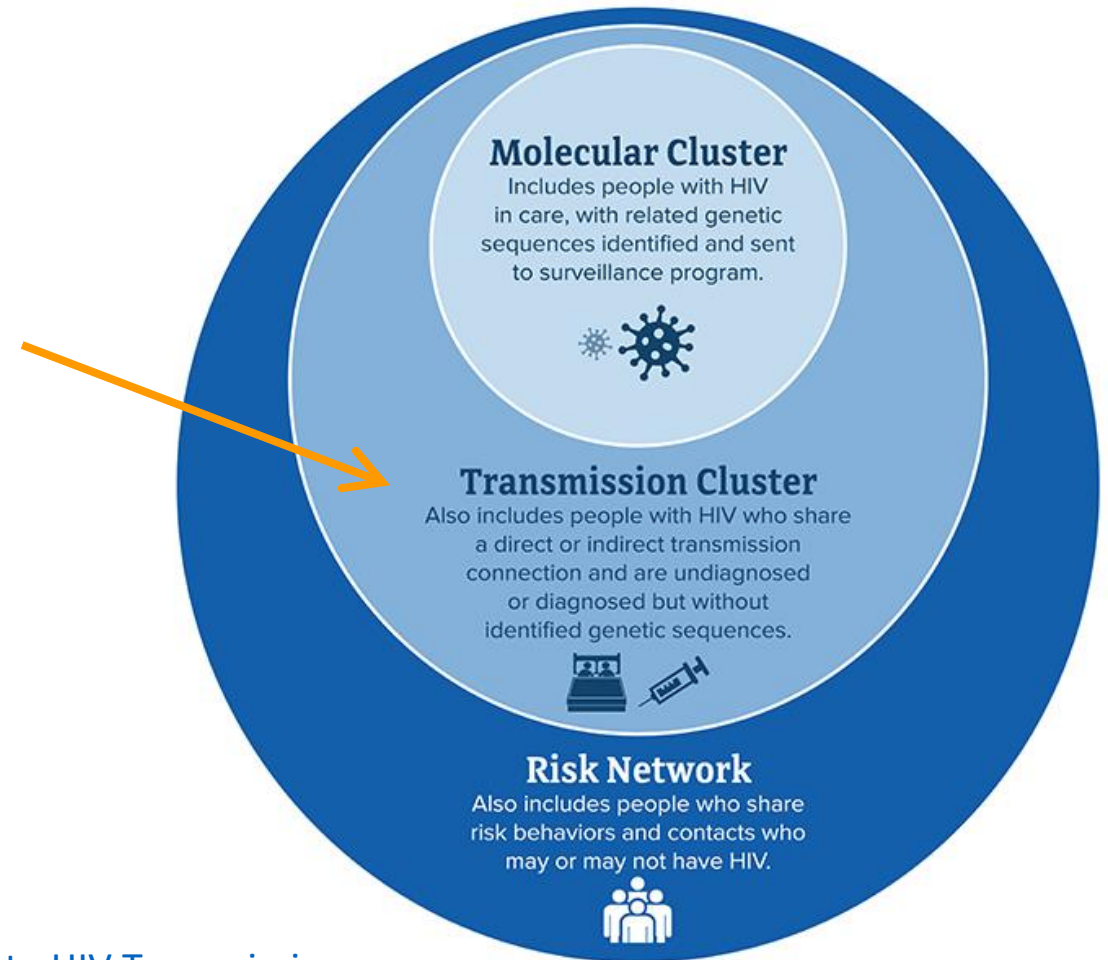
- Risk network:
 - Persons among which HIV transmission has occurred or could be ongoing
 - This network includes
 - Persons who are not HIV-positive but may be at risk for infection
 - Persons who are HIV-positive and are shown in the transmission and molecular clusters.



Centers of Disease Control and Prevention. [Detecting and Responding to HIV Transmission Clusters: A Guide for Health Departments](#); Atlanta, GA; June 2018

HIV Clusters Visualized: Transmission Cluster

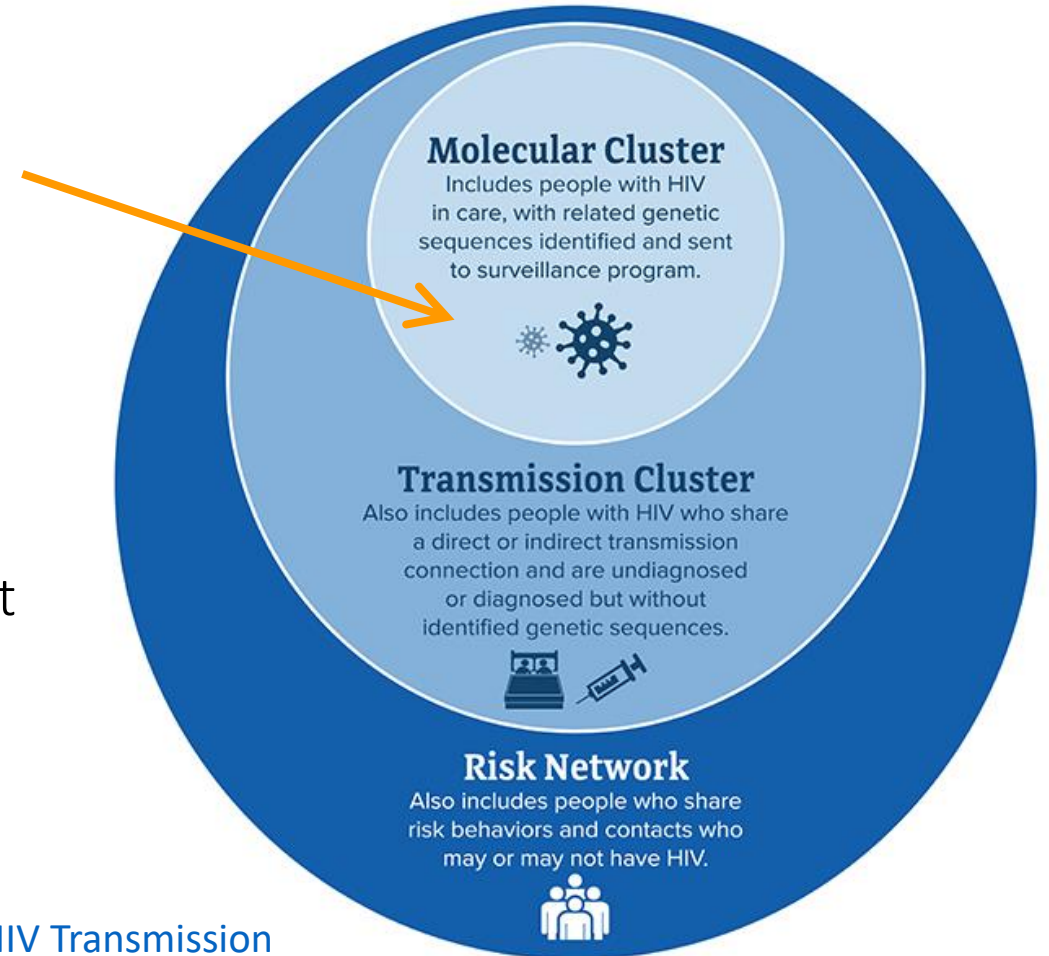
- Transmission cluster:
 - Subset of risk network
 - HIV positive
 - Diagnosed with HIV
 - Not in care
 - In care, no resistance testing
 - Resistance testing done but not reported
 - OR
 - Undiagnosed



Centers of Disease Control and Prevention. [Detecting and Responding to HIV Transmission Clusters: A Guide for Health Departments](#); Atlanta, GA; June 2018

HIV Clusters Visualized: Molecular Cluster

- Molecular cluster: contains only those people for whom molecular data (genotypes) are available and can be analyzed
 - Diagnosed
 - Were/are in care
 - Resistance testing done
 - Genotypes reported to health department
 - Genotypes analyzed to identify those persons with closely related strains



Centers of Disease Control and Prevention. [Detecting and Responding to HIV Transmission Clusters: A Guide for Health Departments](#); Atlanta, GA; June 2018

HIV Surveillance: Conclusions

- HIV surveillance data is the backbone on which effective and targeted HIV prevention and care programs are designed, planned and evaluated
- Data must be protected to prevent harm to individuals
- Cluster detection and response:
 - Allow limited resources to focus on those at highest risk in communities where HIV spread is ongoing
 - Has the potential to
 - Interrupt rapid spread of HIV
 - Identify and offer linkage to care and prevention services to individuals

Surveillance Questions Concerns

Mentimeter Activity

- Surveillance drives our response and informs prevention and care activities



“Surveillance?
Sounds like someone
is monitoring me like
Big Brother.”

Questions



Thank You

For questions contact:

Elana Ross

Associate, Prevention
NASTAD

eross@NASTAD.org

(202) 897-0032



Eve Mokotoff

NASTAD Consultant

evemokotoff@hivcounts.org

Thank You

NASTAD:

Eve Mokotoff

NASTAD Consultant

evemokotoff@hivcounts.org

Elana Ross

NASTAD Consultant

eross@nastad.org

Texas DSHS:

Texas DSHS

Cluster Detection and Response Team

HIV/STD/HCV Epidemiology and Surveillance Branch

Department of State Health Services

hivstd@dshs.texas.gov

UT Health San Antonio South Central AETC

Natalia Rodriguez, MPH

Program Manager

aetinfo@uthscsa.edu