

# Agenda

- Introduction and welcome
- How are genotypes used for public health?
- Role plays – health care provider and consumer
- Q & A

# Panelists



Caressa Harding  
Data to Action Program Manager  
NC DPH



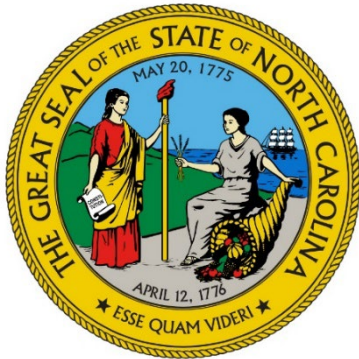
Erika Samoff  
HIV/STI/Hepatitis B and C  
Epidemiology Manager  
NC DPH



Chelsea Gulden  
President and CEO  
RAIN



Esther Ross  
Vulnerable Populations Coordinator  
NC DPH



NC Department of Health and Human Services

# Using HIV Genetic Information for Public Health Response

**Erika Samoff, MPH, Ph.D.**

**HIV/STD/Hepatitis Lead Epidemiologist**

**April 12, 2023**

# Goals of this Conversation

- Describe how genetic information is used for public health
- Share what we are doing – always transparency
- Learn from your thoughts and suggestions
- Provide you language and understanding to help communicate with clients, friends, and community members about this work

We are socialized to see what is wrong, missing, off, to tear down the ideas of others and uplift our own. To a certain degree, our entire future may depend on learning to listen, listen without assumptions or defenses.

- Adrienne Maree Brown, Emergent Strategy

# Goals of this Conversation

- HIV genotype information can be an overwhelming topic
- This topic was new in 2019, and there was not a lot of discussion of it in 2020-2022 due to the pandemic
- Feelings of anger and vulnerability are real and important

We are socialized to see what is wrong, missing, off, to tear down the ideas of others and uplift our own. To a certain degree, our entire future may depend on learning to listen, listen without assumptions or defenses.

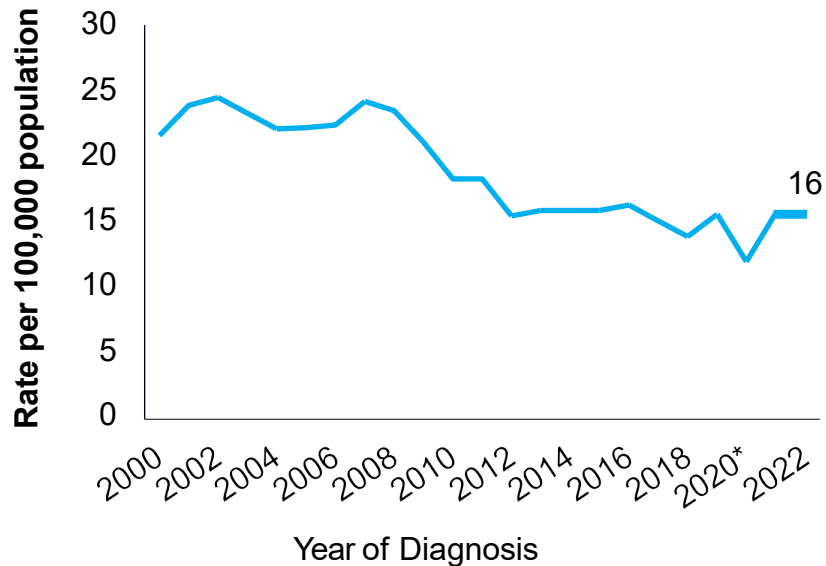
- Adrienne Maree Brown, Emergent Strategy

# HIV: Where are we now?



# North Carolina HIV Rate by Year of Diagnosis, 2000-2022

(preliminary)



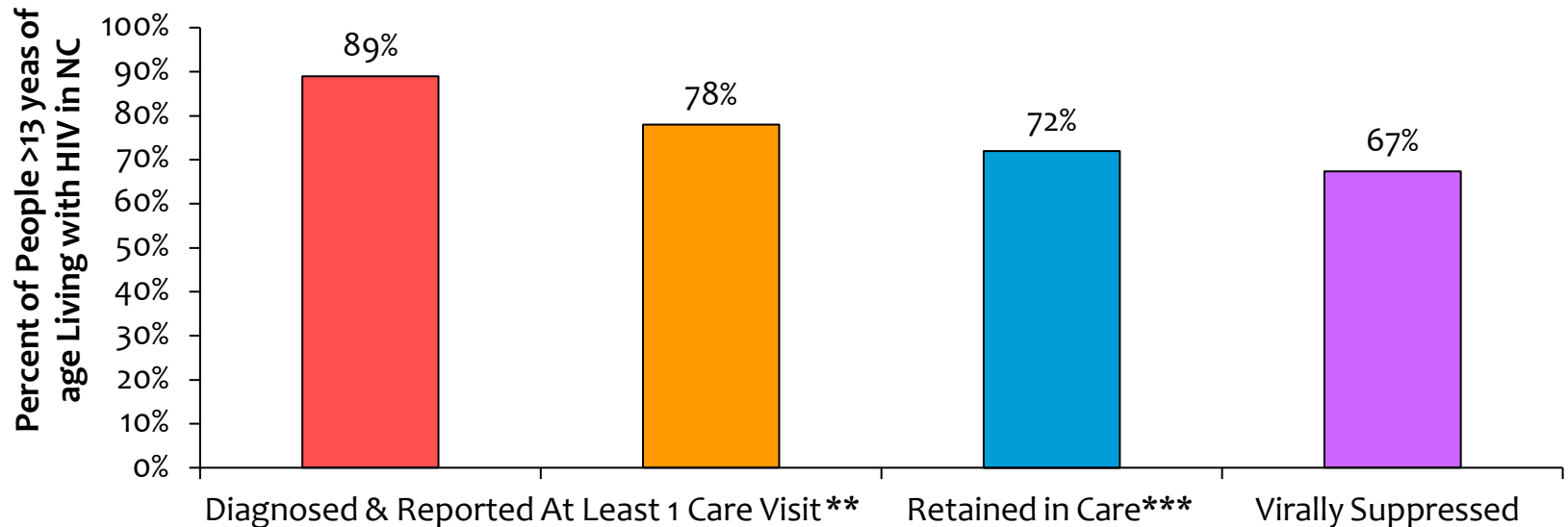
<sup>^</sup>Note: 2020 data should be treated with caution due to reduced availability of testing caused by the COVID-19 pandemic.

<sup>\*</sup>Based on most recent address in enhanced HIV/AIDS Reporting System (eHARS) as of December 31 of the given year.

<sup>\*\*</sup>New cases are only among adults and adolescents (13 years and older).

Data Source: eHARS (data as of September 2022) and North Carolina Vital Statistics, Volume 2: Leading Causes of Death 2000-2019.

# North Carolina HIV Continuum of Care 2021



Note: Data are preliminary (do not include vital records or national death matches).

\*\*At least 1 care marker (CD4 or VL test, HMAP dispense, or Medicaid claim) in the given calendar year.

\*\*\*Virally suppressed within 12 months or having 2 or more care markers (CD4 or VL test, HMAP dispense, or Medicaid claim) at least 90 days apart in the given calendar year.

^Last viral load during the given calendar year <200 copies/ml.

Data Sources: enhanced HIV/AIDS Reporting System (eHARS) (June 2022) and NC ECHO (July 2022).

# What is a genotype and how is it used?





# What Is a Genotype?

- Every organism has genetic material (DNA and RNA)
- The DNA and RNA sequences (genotypes) can be used
  - to see whether an organism has drug resistance or other characteristics; and
  - to see how related two organisms are

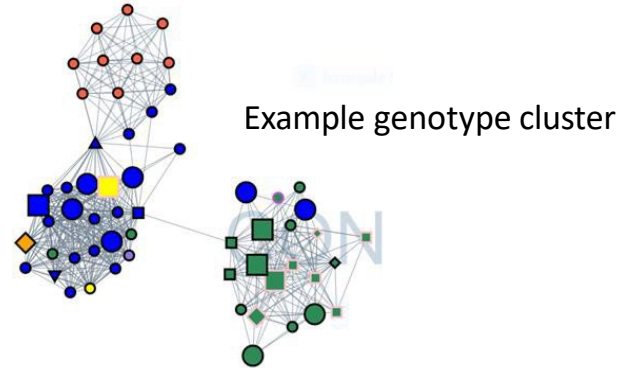


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NOT HUMAN GENOTYPE –  
HIV GENOTYPE

# How Are Genotypes Used for Public Health?

- Organism genotypes are compared to understand how they group
- Public health agencies may respond by
  - Reaching out to people with the disease e.g. HIV, food-borne outbreaks
  - Changing the environment to control disease spread e.g. food-borne outbreaks
  - Providing information about the outbreak to the public (always general, non-identifiable information) e.g. COVID-19 variants
- Genotypes are used for many organisms and genotype-based follow-up is part of the public health process.



**How do we get genotype information (for any disease) and how does it touch consumers and providers?**



# What Does Public Health Genotype Use Mean for people affected by disease?

In most cases, public health genetic sequencing does not affect patient care



- In most cases, clinicians do not need this information to treat people.
- Public health agencies use this information to understand the overall population of disease-causing organisms.
- Some material used for genetic sequencing (meaning, cells of the disease-causing organism) is obtained from specimens submitted to public health agencies
  - as directed by public health law
  - separate from normal patient care.

For some diseases, genetic sequences are used for patient care; public health may also use this information

- Sequencing that identifies resistance to treatment drugs in the disease-causing organism (like for HIV) can also be used for public health
- If genetic sequencing indicates that a consumer has a drug resistant infection, a healthcare provider will work with the consumer to determine the best treatment for their disease
- If required by public health law, the laboratory may also report that sequence to a public health agency

If an outbreak is identified by genetic sequences sent to public health



Public health agencies may respond by

- Reaching out to people with the disease
- [NC DHHS Contact Tracing – What is it?](#)
- Changing the environment to control disease spread
  - Providing information about the outbreak to the public (always general, non-identifiable information)

# What Does Public Health Genotype Use Mean for the Provider?

How does the sample go for sequencing?



- Provider sends a sample to their normal lab for sequencing as part of patient care
  - Example: HIV
- Provider or laboratory sends a sample to the State Lab for Public Health or other lab for public health sequencing when:
  - Required by public health law – example: tuberculosis, some gut organisms
  - Requested for an outbreak investigation
- Provider has no action: remnant specimen will be sequenced and reported to a public health agency as part of laboratory processing
  - Example: COVID-19

What does the provider need to know to help the consumer understand?



- Help patients understand that some diseases are reported to public health and that public health outreach is normal and not punitive

[Public health reporting and outreach explainer](#)

- Be able to explain how genetic sequencing is used for public health

[NC HIV genotype for public health Fact Sheet](#)

[CDC Molecular Detection one page](#)

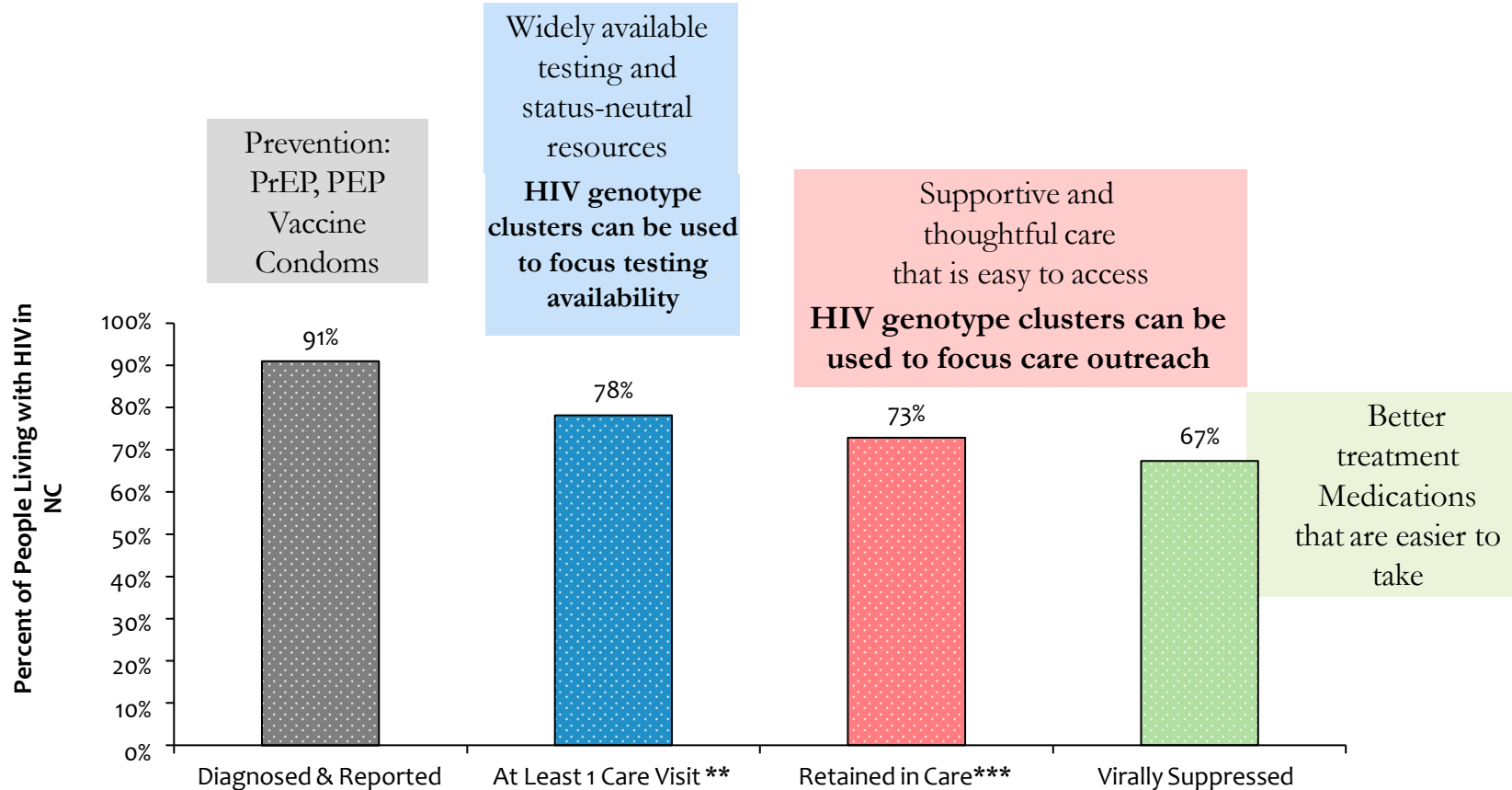
[CDC Molecular Detection website](#)

- Be able to explain that public health sequences the organisms and not the consumer's DNA

# How does it work for HIV specifically?



# To End HIV, We Need Innovation. Where Do HIV Genotypes Fit in?



# Using Genotypes as Part of the Public Health Process

- Currently, NC and CDC identify growing genotype clusters
  - Required by CDC
  - NC DPH has name and genotype information and performs individual outreach
  - CDC has only an identifier number and genotype
- NC DPH can offer testing, linkage, and other supportive resources to people who are out of care or not suppressed and in growing clusters
  - Clusters become part of prioritizing testing and linkage to care outreach
- Outbreak definition – a work in progress
  - Especially rapid cluster growth or increase in cases in a geographic area will result in outreach to local public health staff with additional linkage to care work, general information to providers and CBOs, and additional linkage to care outreach

How NC DPH prioritizes HIV linkage to care outreach

People who are not virally suppressed

AND who are

- ❖ In demographic groups with the highest HIV rates
- ❖ Women of reproductive age
- ❖ People in a growing cluster



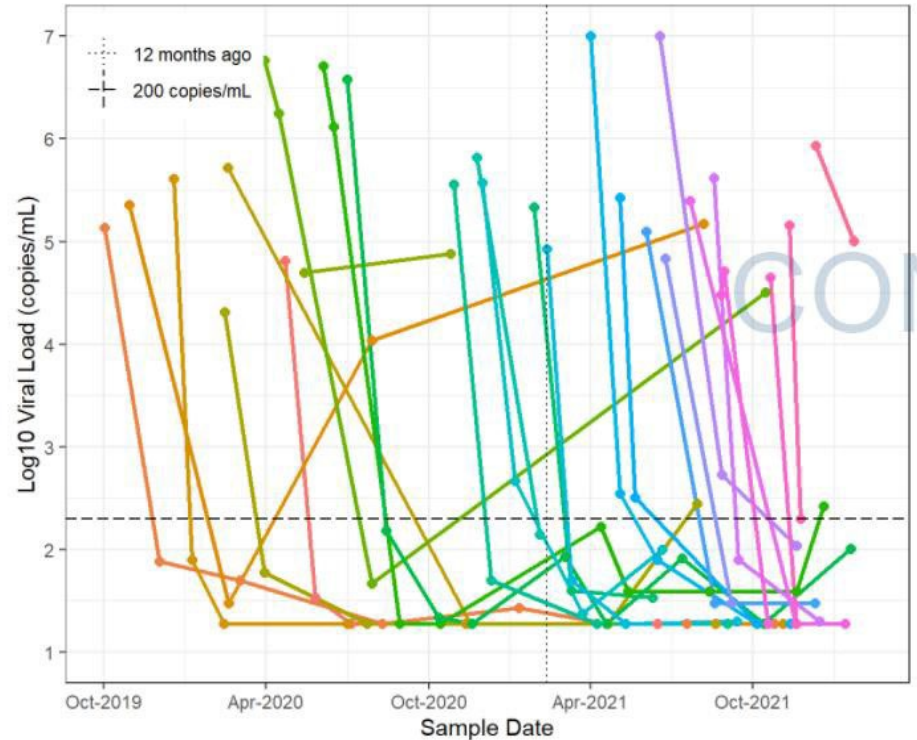
# What Happens When Linkage to Care Outreach Is Offered to People in a Cluster?

When a rapidly growing HIV cluster is identified, they are assigned to regional linkage counselor

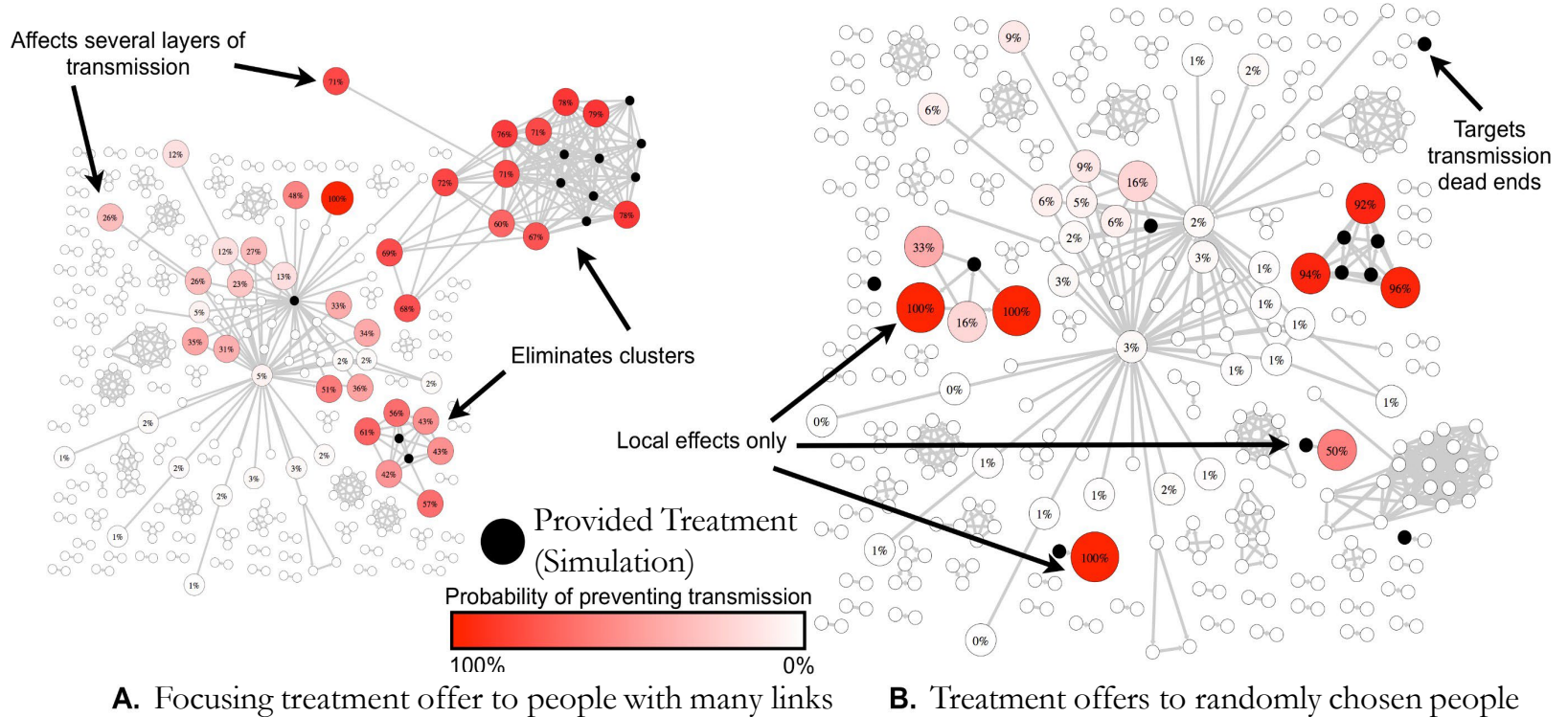
The linkage counselor reviews care history, including HIV viral load

- Suppressed – do nothing
- Not suppressed or no VL in last 12 months
  - Outreach to determine care status, identify and assist with barriers
  - Ask people if there is anyone in their social/sexual network who would benefit from an HIV test or linkage to prevention services

All Cluster Member's Viral Loads over Time



# Cluster-based Outreach Can Be More Effective Than Random Outreach



SOURCE: Little et al. Using HIV Networks to Inform Real Time Prevention Interventions

# Two Key Things

**While a public health agency will have information about the person and about the disease-causing organism, it will only have the genetic sequence of the organism.**

So, we can't:

Plant a person's genetic information anywhere

Link a person to a crime scene

... because we don't have the person's genetic sequence

**The public health agency will never have perfect information – there is always missing information**

So, we can't

Know exactly who transmitted an organism to someone else

... because there may always be unknown people (people who don't know they have HIV or whose sequence is not in our records) in any genotype cluster

We learn enough to help prioritize our outreach

# How We're NOT Using Genotype Information

- Genotype information does not ...
  - Indicate transmission between two people
    - Just that their infecting organisms are genetically similar
  - Show who is transmitting to whom
    - Information is always incomplete
  - Get linked to identity at the national level
    - Since no identifying information is reported to CDC
  - Get released publicly
    - NC DPH maintains data confidentiality
- HIV is not the only disease where we are using genotypes – they are also used for covid (variants), E. coli and salmonella (outbreaks), tuberculosis, and many other diseases

## **Role-play: How does this sound in conversation?**



# Questions and discussion



# Are We Doing Everything We Can to Support the Community and Decrease HIV?

What we currently do

- Prioritize people for bridge counselor outreach, including offers of support for partners
- Respond to outbreaks

What we are starting on

- Equipping providers and community members to talk about the use of genotypes for public health
- Making ourselves available for communication

What else?

# Contact Information

## [CDC HIV genotype resources](#)

### HIV Cluster and Outbreak Detection and Response

[Print](#)

HIV cluster detection and response (CDR) identifies communities affected by rapid HIV transmission. CDR helps public health agencies and communities identify where to boost HIV prevention and treatment services and programs. These services may include linking people to HIV testing, medical care, pre-exposure prophylaxis (PrEP), and syringe services programs. Real-time CDR is key to stopping HIV transmission and is a pillar of the federal [Ending the HIV Epidemic in the U.S. Initiative](#).

Stories from the Field

Evidence for Effectiveness  
of HIV CDR

Frequently Asked  
Questions

#### The Benefits of HIV Cluster Detection and Response

Many communities have successfully used CDR strategies to

- Improve HIV care and viral suppression outcomes.
- Increase HIV testing and use of prevention services, and
- Reduce HIV transmission.

CDR can reveal gaps in HIV prevention and treatment services. State and local health departments, medical and social service providers, community-based organizations, and others then work together to address these gaps.

An HIV cluster or outbreak signifies increased HIV transmission among a group of people in an area or in a sexual or social network. This can indicate gaps in HIV prevention or care for that group of people. Tailoring services to the people in the network helps bring HIV prevention and care to people who need it and helps prevent transmission.



[erika.samoff@dhhs.nc.gov](mailto:erika.samoff@dhhs.nc.gov)

Data requests:

[Taylor.swankie@dhhs.nc.gov](mailto:Taylor.swankie@dhhs.nc.gov)

