

Linkage to Care Guide

ODH Region 3 – Ryan White Part A Cleveland TGA



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INTRODUCTION

Ending the HIV epidemic cannot be achieved by one agency, rather it is a collaborative effort that will require active engagement from community-based agencies and community members. The participation of multiple health and social service agencies, as well as individual advocates, during the development of this plan indicates the community is fully engaged in this process.

Purpose

The purpose of this manual is to outline the core elements and expectations for HIV service providers to follow when conducting linkage to care activities in the Cleveland TGA/Region 3. This resource aims to promote best practices in service delivery and ensure consistent high quality care across the region so that individuals diagnosed with HIV receive the same level of care regardless of where, or by whom, their care is provided. By having a resource to refer to, we anticipate more patients with HIV will be linked and retained in care, thus improving health outcomes such as viral load suppression, increased CD4 cell levels, and decreased HIV incidence. Additionally, this manual can assist local providers from outside of the HIV service community, who may encounter patients newly diagnosed with HIV, supporting them in delivering appropriate, timely, and informed care.

Who

The linkage to care manual is recommended to any provider who diagnoses HIV in a patient and needs protocols to follow within an established network of providers to link the patient to care. This can include medical providers offering testing, as well as social service providers who have clients out of care or newly diagnosed and not linked to care. Private practice primary care physicians, nurse practitioners, and grant-funded HIV service providers can all benefit from this manual.

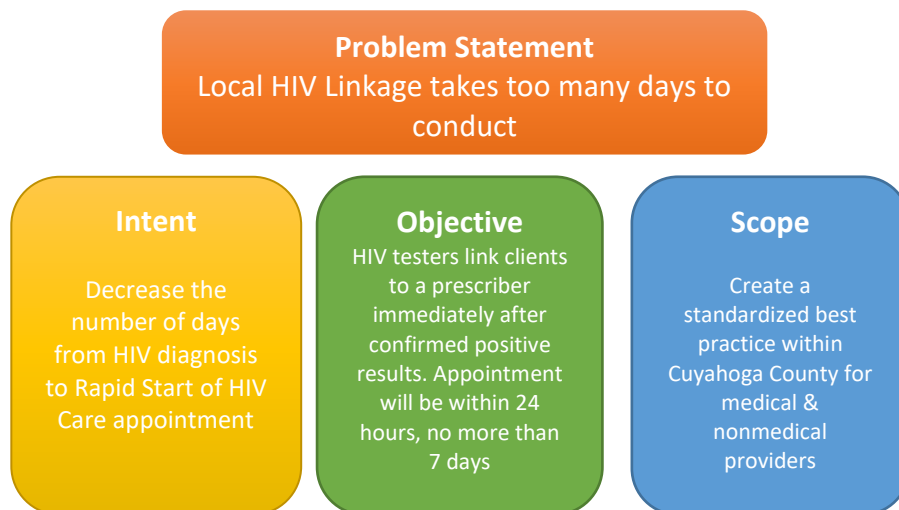


Figure 1. Cuyahoga County Linkage to Care Quality Improvement Definitions, 2025.

HIV TESTING AND DIAGNOSIS

Overview

HIV testing in Region 3 takes place in a variety of settings, including hospitals, community-based organizations, private medical practices, blood and plasma donation centers, correctional facilities, and through the use of self-test kits. While the initial point of testing may vary, the goal of rapidly linking people to care remains the same.

Because each testing setting has different resources and capacities, it is important to recognize that adherence to the CDC-recommended HIV testing algorithm, while ideal, may not always be feasible in every environment. Laboratory-based tests may not be practical for use in community-based settings or when individuals utilize self-test kits. In such cases, sites that perform point-of-care (POC) HIV testing should ensure diagnostic accuracy by using two different rapid tests from separate manufacturers (e.g., OraQuick and INSTI), which is considered an acceptable alternative for confirming an HIV diagnosis.

Testing Best Practices

It is recommended by the Centers for Disease Control and Prevention (CDC) that all individuals between the ages of 13 and 64 get tested for HIV at least once as part of their routine health care. Persons who engage in behaviors that increase the chance of HIV acquisition should be screened more frequently. An overview of some best testing practices that can be implemented across a variety of settings is provided below:

- Routine Testing
- Opt-Out Testing
- Integration with STI Testing

Delivering Test Results

Timely and compassionate delivery of HIV test results is a critical component of testing and linkage to care. All people who are tested for HIV should receive their results in a way that is confidential and responsive to their needs. Whenever possible, results should be provided in person, using plain language, by trained staff that can offer immediate counseling, education, and linkage to care.

Additional consideration should be given when providing a positive test result. Delivering a positive HIV test result requires privacy, empathy, and sufficient time to allow the individual to process the information. Staff should use clear and direct language and avoid overwhelming the individual with excessive information during the initial conversation. Whenever feasible, linkage

to care should be initiated at the time results are delivered to reduce delays and prevent the individual from being lost to care.

Risk reduction counseling has long been a cornerstone for community HIV testing, particularly for ODH Counseling, Testing, & Referral (CTR) test sites. However, counseling may look different depending on how the test is being conducted. Many who receive opt-out HIV testing may receive lab work without a risk assessment, education, or the client choosing a prevention method that would work best for them (a harm reduction strategy).

Testers are encouraged to include counseling with HIV testing, regardless of how the testing occurs. Counseling does not need to be a formalized, motivational interview. Counseling can be an informal discussion with the client about what they know, what they don't know, and what they could do to reduce the likelihood of acquisition.

Some of the best questions to ask are:

- *What brings you in today?*
- *What have you heard about HIV?*
- *What have you heard about prevention?*
- *What is the easiest way for you to prevent HIV infection?*

The answers from these questions will guide the rest of the conversation with the client, which should include education and counseling around condom/barrier use, PrEP/PEP, and other STI testing. These questions can also provide the tester with important insight to the client's circumstances in case the result is positive.

PATHWAYS AFTER NEGATIVE RESULT

Overview

When delivering a negative HIV test result, the tester should clearly explain the result using plain, nontechnical language. Individuals should understand that a negative result reflects their HIV status at the time of testing. The interaction should be supportive and nonjudgmental, avoiding assumptions about behaviors while reinforcing prevention messaging. Whenever feasible, linkage to prevention care such as PrEP should be initiated to help prevent future seroconversion.

PrEP/PEP

PrEP and PEP are important strategies to prevent new HIV infections. Many people in HIV testing services are familiar with PrEP and PEP. PrEP is an acronym for pre-exposure prophylaxis. PEP (or nPEP) stands for nonmedical post-exposure prophylaxis. These biomedical tools have a very high efficacy of preventing HIV infection when taken correctly and consistently. PrEP, PEP, and ART for HIV infection may be similar types of therapies, but are prescribed differently based on the individual's HIV status and exposure.

PrEP and PEP contain HIV medicine (but not a full HIV treatment regimen), and are prescribed to prevent HIV infection. PrEP is available as a pill (Truvada, Descovy) or a long-acting injectable (Apretude, Yeztugo). PrEP is prescribed to be taken daily, but can also be taken on demand, often called the 2-1-1 option. PrEP on demand relies on strict adherence to the schedule above and requires clear patient education.

Instructions for PrEP on demand/2-1-1:

1. Take 2 pills 2-24 hours before sex
2. Take 1 pill 24 hours after the first two-pill dose
3. Take 1 pill 48 hours after the two-pill dose
4. If someone is having sex multiple days in a row, 1 pill should be taken every 24 hours until the person has not had sex for at least 2 days

PEP is an HIV prevention option for someone who has been exposed to HIV. When antiretrovirals are prescribed as PEP, the person takes the medication in an effort to prevent HIV from making copies of itself. The exposed individual takes the medication as directed (typically up to 28 days) and gets tested afterwards to make sure the medication worked. Just like with PrEP, a person must test negative first before being prescribed PEP.

Following a negative HIV test, a tester should discuss with the client whether PrEP (or PEP) is right for them. A tester should be familiar with PrEP basics, such as the methods, frequency of testing, and why it's important to follow the prescription's dosage. A tester should also be

familiar with the costs associated with PrEP, issues related to insurance coverage, and any financial assistance options, such as Prevention Assistance Program Interventions (PAPI). The PAPI program through the Ohio Department of Health can assist with the cost of services related to PrEP (i.e. office visit, labs, etc.) based on household income, but not the cost of the prescription itself. There are additional cost saving programs that are provided by the pharmaceutical companies that can significantly reduce the out-of-pocket cost.

In Cuyahoga County, two providers offer PrEP Navigations services—The MetroHealth System and University Hospitals. Testers are encouraged to link clients to PrEP Navigators, who can provide in depth education and benefits navigation for the clients. PrEP Navigators can also counsel on barriers to PrEP adherence and help clients stay connected to their PrEP providers.

Referrals

A key theme in this guide is the difference between providing a referral and creating linkage. Both terms involve a client moving from service to service, provider to provider, department to department, or agency to agency. The difference between the terms is *how* the client moves from HIV test to care appointment.

A referral correlates to providing a client the contacts and information for additional services to which the client would connect themselves to. Linkage takes a referral a step further. Linkage involves the service provider at Point A ensuring that contact is made at Point B and services are to be carried out by the provider at Point B, who then assumes ownership of the connection at that point. This can be done several ways, including making a phone call to the provider, scheduling an appointment with the client and the new provider, or walking a client from one department to another within the same agency. Linkage also involves follow-up and confirmation between Provider A and Provider B to ensure next steps were taken. Navigating medical, behavioral health, and social service providers can be very challenging, even for the most proficient.

Common referrals & linkage opportunities following a negative HIV result include:

- PrEP/PEP services
- Community-based overdose prevention services
- STI screenings
- Mental and/or behavioral health services
- Social services and/or benefits navigation

It is a common practice to provide clients with referrals to a number of related services during an HIV test. It is best practice to curate a list of local providers accessible for the client to contact. Testers should ensure the name and contact information for the referral is up to date.

It is encouraged that testers provide linkage for additional services, rather than referrals. Linkage ensures that important client services are addressed, many of which can directly relate to future HIV exposure. Testers should consider connecting with a staff person at each service provider whom they have listed as referrals. Testers should also discuss with their employer the best practices with client privacy and confirming follow-up.

Additional Prevention Education & STI Screening Options

Clients often require additional prevention education. If a tester has provided risk reduction counseling (formally or informally) with the client, then the tester will have learned what should be reviewed with them. Common areas of education that clients often need include:

- Pathways for HIV infection (i.e. unprotected receptive anal sex, sharing drug equipment, etc.)
- PrEP efficacy
- Retesting and/or testing window period
- Condom or barrier usage
- Undetectable=Untransmissible (U=U)

If using a rapid HIV test that includes a 1-to-20-minute wait time, testers are encouraged to use that time to provide this education. It is also important to discuss the syndemics that are ongoing and correlating with HIV co-infection. These include syphilis, mpox, hepatitis C, chlamydia, and gonorrhea.

IMMEDIATE LINKAGE TO HIV CARE

Definition

Linkage to Care is the process from which a person diagnosed with HIV is successfully engaged with HIV care services. Proper linkage involves more than referral-giving; it involves several steps that ultimately gets the patient to HIV care professionals to rapidly start on HIV medication and assessed for additional wraparound/case management services.

Successful linkage to care is *crucial* for the best health outcomes for patients. We know from research and experience that patients are more likely to stay engaged in care when they start HIV medications right away. Additionally, when patients are comforted and educated by medical professionals they trust, receive support and mentoring from peers with lived experience, and receive additional wraparound services that improve health outcomes, patients will be empowered to own their healthcare experience.

A referral is not linkage. **Linkage involves hand-to-hand passing from HIV tester to HIV Care provider.** Linkage requires:

- The healthcare professional to contact providers on behalf of patient to ensure appointments are scheduled as soon as possible
- Conversations and arrangements for travel to the rapid start appointment
- Assessing barriers in the patient's life that would prevent success on antiretroviral therapy.
- Education about upcoming healthcare services
- Identifying supportive families or friends in the patient's life
- Providing options for additional services

In most cases, linkage is defined as attending first treatment appointment, receiving a prescription for ART, and conducting lab work that examines the patient's current HIV RNA viral load, CD4 levels, and/or HIV-1/HIV-2 antibody differentiation. Please note that some roles in HIV services may have differing definitions for linkage to care (such as attending appointment only).

Timelines

Cuyahoga County Board of Health (CCBH): Same-day initiation of ART, with no more than a week (7 days) from the date of diagnosis.

The National HIV Curriculum, The White House National HIV/AIDS Strategy for the United States 2022-2025, U.S. Department of Health and Human Services (HHS): Immediate initiation of ART (on the day of diagnosis).

The Center for Disease Control and Prevention (CDC): CDC defines linkage as having one or more documented CD4 or viral load tests within 30 days (1 month) of HIV diagnosis.

Ohio Department of Health (ODH): No more than 90 days after first positive test result.

Please note that while more trusted institutions are moving towards same-day initiation of ART (including CCBH), the national standard for linkage with the CDC still is no more than 30 days after diagnosis.

DIS & EIS Roles

Disease Intervention Specialists (DIS) play an important role with linkage to care. As public health professionals, DIS are tasked with being one of the initial trusted sources of information and support following their testing/diagnosis. DIS discuss the diagnosis with the patient/client, educate them about prevention methods while having an unknown HIV viral load level, encourage additional STI testing due to multiple syndemics, investigate deeper into their networks of possible exposure, and ensure that linkage either has occurred, is scheduled to occur, or needs to be conducted. This can be an overwhelming and confusing experience for the patient. DIS are trained to handle their investigations with diligence, kindness, grace, and efficiency.

DIS are introduced to new cases from the Ohio Department of Health via ODRS—a private, HIPAA-compliant database used to report on new infection investigations. DIS are expected to complete their cases within the CDC’s 30-Day standard for linkage. This means that cases must be investigated within 90 days of diagnosis (including partner interviews), with labs completed in 30 days.

DIS are critical for ending the epidemic, linking patients to care, and disabling networks through contact tracing and testing. However, as highlighted throughout this manual, linkage to care is a community-wide, multi-disciplinary approach that moves a patient/client from HIV test to labs and ART. *Linkage involves patients/clients, HIV testers, DIS, Early Intervention Services (EIS), Peer Navigators, family, friends, community members, and public health leadership.*

Early Intervention Services (EIS) and Peer Navigation at HIV Providers are equally important for linkage. EIS are tasked with welcoming patients into their healthcare treatment plans, answering questions about the diagnosis, calming any worries the patient may have, assessing case management and support services, and ensuring the patient is successfully prepared to stay engaged in their treatment. Rapid Start ART allows for immediate initiation of antiretroviral treatment, laboratory services for viral loads and CD4 levels, and education about diagnosis. Rapid Start ART is available for anyone in Cuyahoga County who tests positive for HIV, regardless of insurance coverage or their ability to pay.

FIRST MEDICAL VISIT

Rapid Start ART

Immediate initiation of HIV treatment through Rapid Start services is quickly becoming the standard providers are pursuing. Research shows that immediate initiation of ART (within 24 hours of testing) increases the likelihood of retention in care.

The rapid start of HIV treatment allows agencies to maintain capacity to ensure newly diagnosed or new-to-care clients can be given antiretroviral medication at their first appointment or interaction with the medical provider and immediately begin their path towards viral suppression.

Documentation of labs within 30 days of diagnosis is required by the CDC to be considered successfully linked to care. Typically, a physician will collect the following HIV-related baseline lab tests: (1) HIV RNA (confirming testing diagnosis and assessing HIV-1 or -2), (2) CD4 levels, and (3) other STI tests, such as syphilis and mpox. These baseline labs are also used for comparison to track whether HIV medication is reducing viral load counts to undetectable levels and to track that CD4 levels are high enough for healthy immune response.

In addition to laboratory tests, patients/clients should receive diagnostic information; education about HIV, risk reduction, U=U, HIV criminalization, HIV treatment adherence, and side effects; and referrals for additional services.

The HIV Care Team

Medical care is provided by health care professionals certified in Ohio to prescribe medications in an outpatient setting such as a clinic, medical office, or mobile unit. In addition to physicians and nurses, the HIV care team can benefit from hiring or collaborating with early intervention service associates, Peer Navigators, case managers, and social workers.

As previously mentioned, EIS staff and Peer Navigators play a crucial role in the rapid start process. These are the first professionals contacted by HIV testers and DIS when there is a new HIV positive client, as well as the first professionals to interact with the patient after successful linkage. EIS and Peer Navigators make space for a client to be seen by the provider as soon as possible. They assist with medical and nonmedical support throughout the first visit, and often schedule the client's 90-day (3 months) check-up and 180-day (6 months) follow-up appointments.

Peer Navigators serve as a liaison between health/social services and the community to facilitate access to services, and improve the quality and cultural competence of service delivery. A Peer Navigator can enhance the HIV care team by working in partnership with case

managers, nurses, doctors, social workers, and other service providers to address the medical, social, and economic needs of people with HIV. Peer Navigators can be tasked with any of the following activities: (1) assisting, education, and support people with HIV to become aware of their status, (2) linking and engaging people with HIV into medical care, (3) helping people with HIV adhere to treatment, and (4) explaining health benefits and other types of available assistance to people with HIV. As a frontline public health worker and (often) certified community health worker, Peer Navigators are often trusted members of the HIV community with a close understanding of whom they serve. As such, they play an important role of building individual and community capacity by increasing health knowledge and self-sufficiency through outreach, community education, informal counseling, social support, and advocacy.

Case management can be introduced to the client during their rapid start visit, particularly if there are concerns about retention in care. Some providers prefer to introduce case management at the 90-day appointment, due to the length and complexity of the rapid start visit. Medical and nonmedical case management can improve behavioral health and social support needs, thus reducing barriers to care and maintaining optimal outcomes.

Successful rapid start programs typically give space on the provider's schedule for same-day appointments. This allows other clients who are retained in care to keep their scheduled visit time. It also ensures clients will remain in care when they do not have to reschedule an appointment time.

90-day (3 months) and 180-day (6 months) visits are typically scheduled with the client by EIS staff. The purpose of these visits are to confirm that treatment is correctly reducing viral loads, increasing CD4 cells, and any side effects are manageable. If not, the client can discuss other options with the physician. Medical and nonmedical case management should be in coordination with the medical visits to ensure the patient is barrier-free and utilizing support systems.

Coordination of Medical & Nonmedical Support

The medical case manager is responsible for the provision of treatment adherence counseling to ensure readiness for or adherence to complex HIV/AIDS regimens. Information about the client's readiness for treatment should be shared with the prescribing physician. Treatment adherence must be incorporated into the Individual Care Plan to support the client with taking all their medications as prescribed, making, and keeping appointments; addressing barriers to care and treatment; and reducing harmful behaviors by encouraging therapeutic lifestyle changes, as necessary. The agency must have clear policies and procedures for missed appointment follow-up, especially with clients who are unstably housed, homeless, pregnant, or report no contact information.

LOCAL HEALTH DEPARTMENTS

DIS Response

Region 3 is staffed with Disease Intervention Specialists (DIS) to contact those who test positive for reportable diseases. In Cuyahoga County, DIS operate out of the Cuyahoga County Board of Health (CCBH). Cases must be investigated within 90 days of diagnosis (including partner interviews), with labs completed in 30 days. As public health professionals, DIS are tasked with being one of the initial trusted sources of information and support following their testing and diagnosis. DIS discuss the diagnosis with the patient/client, educate them about prevention methods while having an unknown HIV viral load level, encourage additional STI testing due to multiple syndemics, investigate further into their networks of possible exposure, and ensure that linkage either has occurred, is scheduled to occur, or needs to be conducted.

When engaging with clients and their partners, DIS use client-centered approaches to learn or confirm information related to their case, including sexual history, drug use history, and other behavioral circumstances that could have led to exposure. DIS use this information to gain insight about a client's barriers to care and try to relieve those barriers whenever possible. DIS use the existing network of provider and linkage partners to ensure clients have been appropriately linked to care.

Cluster Detection and Response

HIV clusters, which can be defined both by time & space analysis (i.e. a sex party, a drug party, a community event, etc.) and molecular clusters (networks identified through HIV drug resistance labs reported to the state), are typically announced by ODH and local health departments (LHDs). Because HIV clusters have such high transmission rates, detection and rapid response by state and LHDs are crucial for interrupting the spread. Due to this, LHDs may involve increased and localized investigation, partner interviewing, linkage to care, and community outreach.

The responsibility for declaring and responding to a HIV outbreak lies with each STI Prevention Region in partnership with the affected county(s). The Ohio Department of Health's (ODH) HIV, STI, & Viral Hepatitis Interventions and Treatment Section, in consultation with the STI Prevention Regions and local epidemiologists, will determine the status or extent of declared outbreaks based on available surveillance data, anecdotal information, and reports of sentinel events. State STI epidemiologists, disease intervention consultants (DICs), prevention managers, and other state resources stand ready to assist the STI prevention regions and counties with outbreak investigation and response efforts.

Once the existence of an outbreak has been confirmed, the outbreak response team is activated. The location, nature, and size of the outbreak will determine who should be included. Subject matter experts (SMEs) who can provide leadership must be involved. A team

roster, as well as roles and responsibilities, should be finalized in advance.

Those roles might include:

- Leadership, management, and oversight of outbreak activities
- Surveillance activities
- Epidemiologic activities and investigation
- Data management and security
- Contact investigation, DIS, and partner services
- Oversight of laboratory specimen collection, transport, and testing
- Risk communication and communication with media
- Control and prevention measures
- Coordination with external partners and agencies
- Provider and public education and outreach
- Support activities such as logistics and budgetary management

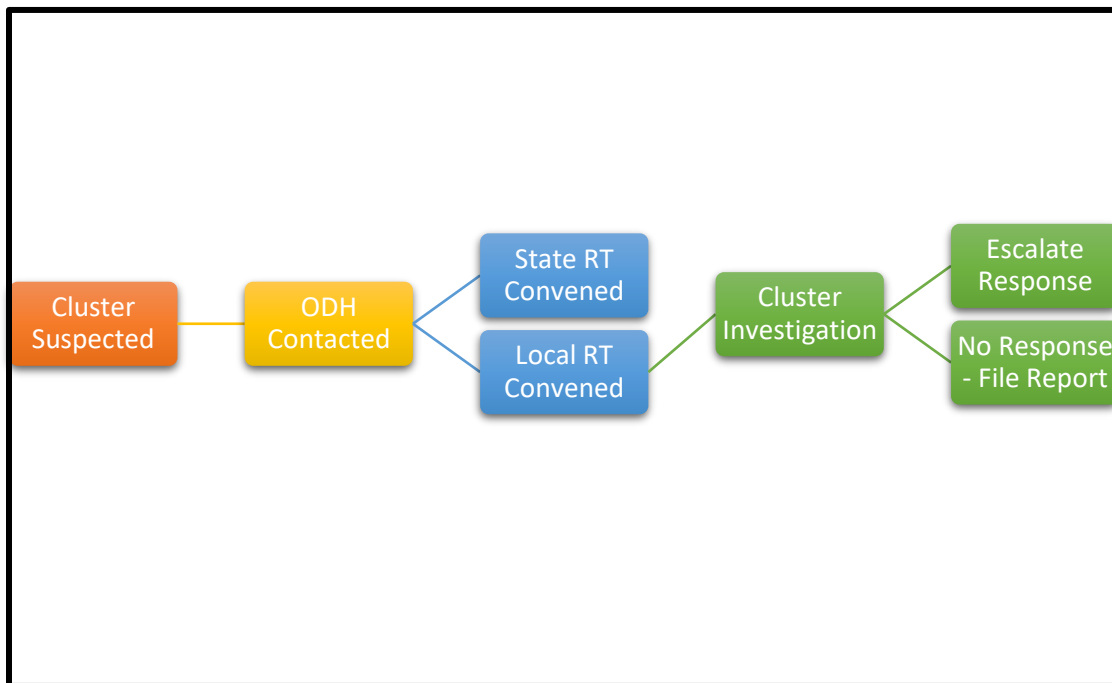


Figure 2. Flow Chart for Cluster Detection and Response Plan, 2024.

Definitions

National, state, and local health agencies look at metrics to assert that clients are linked and retained in care. These patient/client metrics for retention are:

- Undergoing at least one medical visit with lab work for HIV viral load and CD4 count within a 12-month period.
- Prescription for antiretroviral therapy for a 12-month period.

- Bloodwork that confirms the patient/client is virally suppressed with less than 200 copies of HIV RNA per milliliter and more than 500 copies of CD4 cells per milliliter.

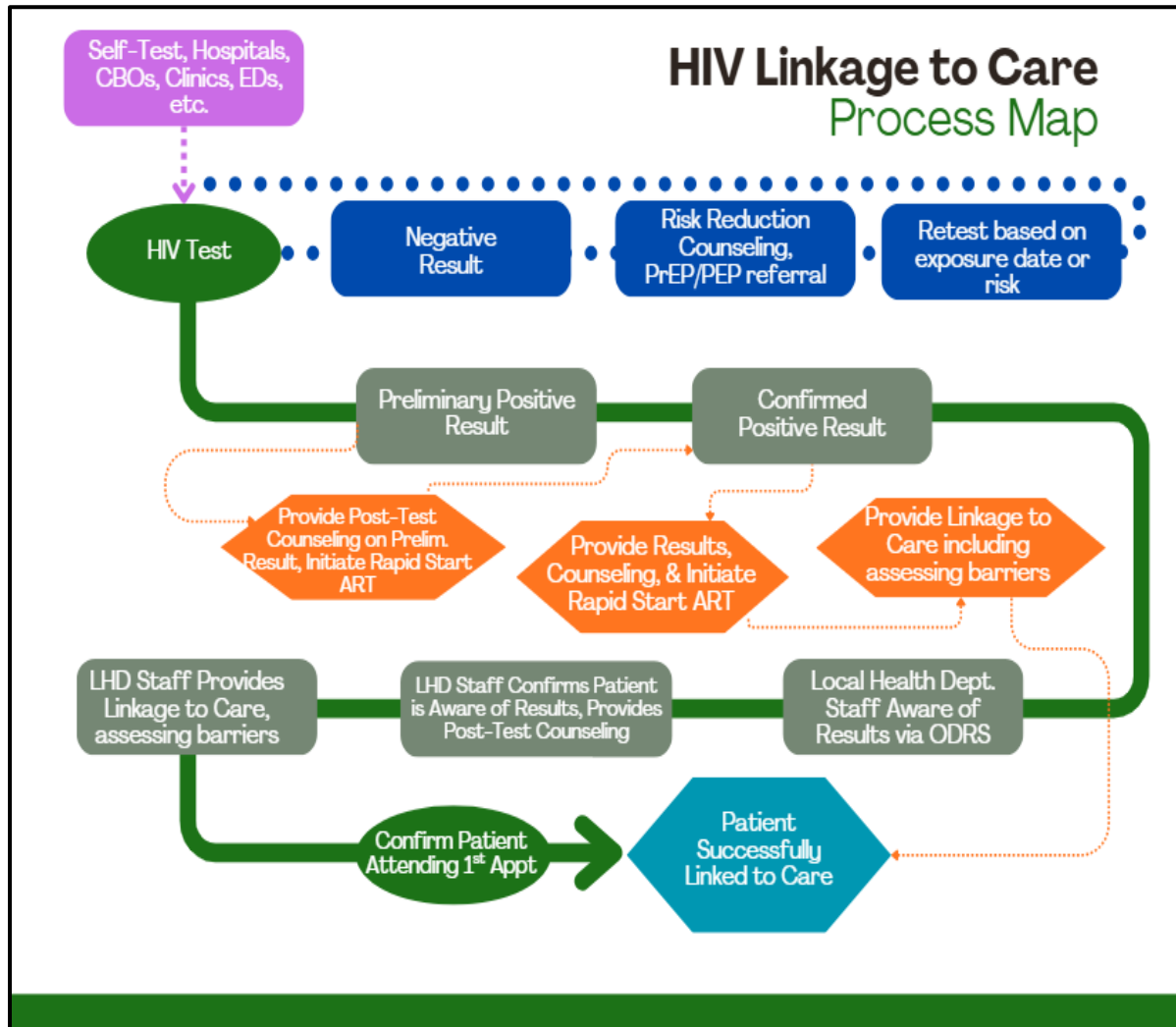


Figure 3. HIV Linkage to Care Process Map, 2025

Abbreviation Key:

CBOs: Community-based organizations
EDs: Emergency Departments
LHD: Local health departments

Additional Local Resources

Cleveland PrEP Navigators 216.957.7737

LoveLeadsHere.org

[PrEP Assistance Program Interventions \(PAPI\)](#)

[Ryan White Program](#)

Key Definitions

Antiretroviral Therapy (ART): Also known as antiretrovirals (ARVs) or highly active antiretroviral therapy (HAART); HIV medication that stops HIV replication. ARTs can reduce the number of blood supply HIVs to an undetectable level, which can completely stop sexual transmission. Typically, lower HIV viral loads correspond to higher CD4 cells, which allows the immune system to stay mostly stable.

CD4 Cells: A type of T-cell within the immune system. CD4 cells are used by HIV to replicate themselves, destroying the cell in the process. High CD4 levels correspond with continuous ART use and are a signature of a healthy immune system. Less than 200 copies per milliliter of CD4 cells is a sign of late stage HIV infection (AIDS).

Disease Intervention Specialist (DIS): These are public health professionals who interview patients regarding their diagnosis, ensure linkage to care has been carried out, and receive information about sexual and drug use partners to anonymously contact for testing.

Early Intervention Services (EIS): Under the Ryan White Part A program, these are medical professionals who provide rapid start ART medical services and follow-up during a patient's first year of diagnosis.

Harm Reduction: A client-centered approach to behavior modification in which the client is educated about all the options to reduce the harm related to their behaviors and the client chooses which is best for them. Harm reduction is typically related to the work of substance use disorders and syringe exchange programs, but it can be applied to reducing risk through sexual behaviors as well.

Linkage (to Care): The process by which a person diagnosed with HIV is successfully engaged with HIV care services. Proper linkage involves more than referral-giving; it involves several steps that ultimately gets the patient to HIV care professionals to rapidly start on antiretrovirals and assessed for additional wraparound/case management services.

Lost to Care: A PWH is said to be not in care/lost to care when they have not attended a physician appointment or not provided bloodwork for HIV viral load or CD4 levels within 12 months.

Non-occupational post-exposure prophylaxis (nPEP): A 28-day ART regimen for an HIV negative person who has been exposed to HIV given within 72 hours of the transmissible incident.

Pre-exposure prophylaxis (PrEP): A daily pill or bimonthly shot of low-dosed ART that reduces the likelihood of HIV infection by 99+% for HIV negative persons.

Re-Linkage: The process by which a person diagnosed with HIV and not retained in care is successfully re-engaged with HIV care services.

Referral: The process of providing a client the contacts and information for additional services that the client would connect themselves.

Retention: The capacity for a person with HIV to stay engaged with their HIV care service provider. This includes taking antiretrovirals as directed, achieving and maintaining viral load suppression, and updating lab work annually.

Risk-Reduction Counseling: A client-centered, harm reduction approach to HIV prevention that typically occurs during an HIV test. Components of risk reduction counseling involve HIV transmission and prevention education, self-assessment for likelihood of HIV exposure (based on the client's self-reported behaviors), motivational interviewing about the client choosing the healthiest and realistic form of HIV prevention, PrEP screening and referral, and a self-analysis of next steps if HIV test result is positive.

Seroconversion: The critical period when an HIV-negative person develops detectable antibodies to the virus, typically occurring 2–6 weeks after exposure. It marks the transition to an HIV-positive status, often causing flu-like "seroconversion illness," and is a key time for acute infection symptoms like fever, rash, and swollen glands.

Viral Load Suppression (VLS): Reducing the blood supply count of HIV microbes to an undetectable level (less than 200 copies per mL). This is done through the continuous intake of antiretrovirals as directed by a clinician.

Linkage Data

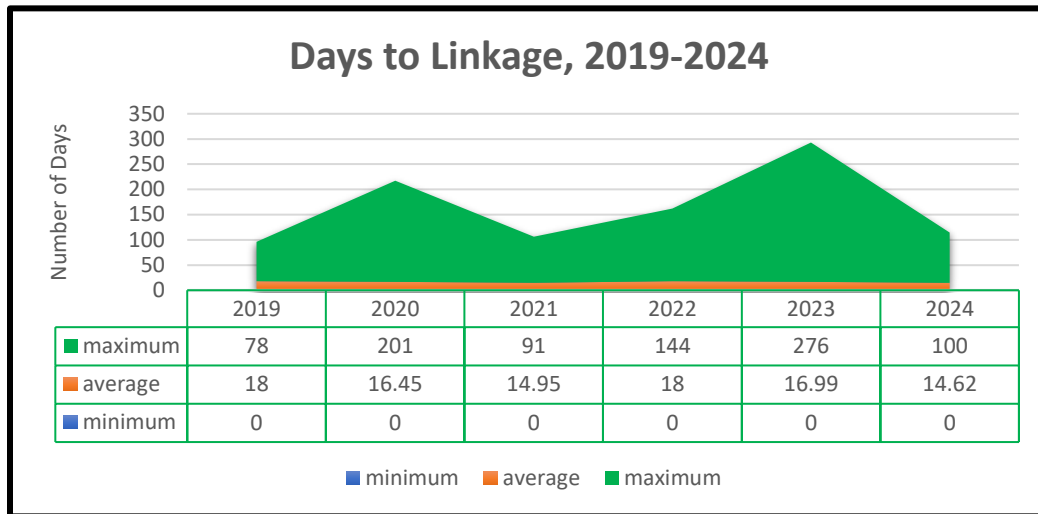


Figure 4. Number of Days to Linkage – Minimum, Average, and Maximum, 2019-2024.

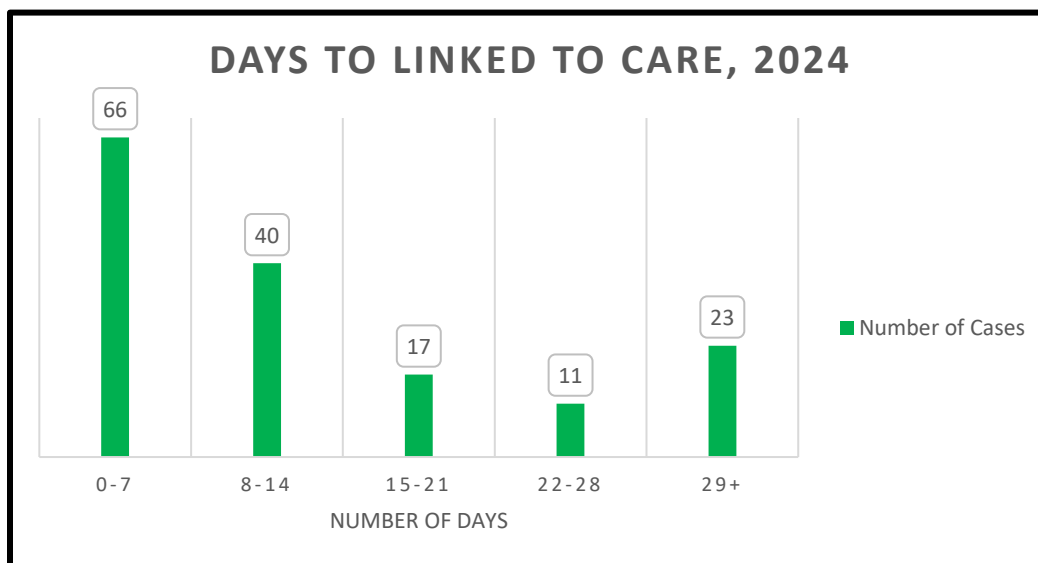


Figure 5. Number of Days Cases Are Linked to Care, 2024.