Linkage to HIV Care

This is a PDF version of the following document:
Module 1: Screening and Diagnosis
Lesson 5: Linkage to HIV Care

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Background

Linkage to care is a crucial early step in successful HIV treatment and is typically defined as the completion of a first medical clinic visit after an HIV diagnosis. Linkage to care plays a key early role in the HIV care continuum, as a necessary precursor to antiretroviral therapy initiation and viral suppression (Figure 1). Antiretroviral therapy significantly reduces the risk of developing HIV-related complications and dramatically reduces HIV transmission to others.[1,2,3,4] Without timely entry into care, individuals with HIV miss an opportunity to benefit from HIV treatment at the earliest stage feasible.[5,6]

Goals for Linkage to Care

Linkage to care and rapid initiation of antiretroviral therapy after HIV diagnosis is a key pillar of the national initiative, Ending the HIV Epidemic: A Plan for America.[7,8] The Ending the HIV Epidemic has a goal for persons newly diagnosed with HIV to increase linkage to HIV medical care to 95% by the year 2025.[8,9] In addition, the Adult and Adolescent ARV Guidelines recommend rapid initiation of antiretroviral therapy for persons newly diagnosed with HIV, ideally on the same day of the HIV diagnosis.[10] Identifying persons with HIV and successfully linking them to care plays a key role in addressing the HIV epidemic, both from a treatment and a prevention standpoint (Figure 2). The following provides a review of the current state of linkage to care in the United States, examines the major barriers to linkage to care, and explores strategies to improve linkage to care.

Process for Estimating and Monitoring Linkage to Care

Metrics Used for Estimating Linkage to Care

In the United States, the established federal benchmark for successful linkage to care is the completion of a visit with an HIV medical provider within 1 month (30 days) of HIV diagnosis.[9] The Centers for Disease Control and Prevention (CDC) surveillance data for linkage to care is based on at least one HIV RNA level (viral load) or CD4 cell count within 1 month of HIV diagnosis as evidence for linkage to care.[11] From a practical standpoint, the laboratory-based HIV RNA or CD4 cell count test results serve as an easily measurable surrogate marker for a clinic visit for HIV medical care. Using this standard metric for linkage to care, a first visit more than 1 month after an HIV diagnosis is considered *failed linkage* or *delayed entry into care*. Linkage to care is considered a one-time event, whereas retention in care reflects ongoing engagement or reengagement in care.

HIV Case and Laboratory Surveillance

In areas where laboratory-based reporting of HIV RNA (viral load) and CD4 cell count results are mandated by law, state and local health departments and the CDC use this information to monitor linkage to care. As of December 2024, a total of 49 states, the District of Columbia, and Puerto Rico have enacted laws (or regulations) that require laboratory reporting of CD4 cell counts and viral load test results.[11] One state—Idaho— and the Virgin Islands do not require reporting.[11] The HIV surveillance programs within state and local health departments also collect sociodemographic data and can track differences among groups at risk for HIV acquisition and among different jurisdictions, thus providing an opportunity to develop HIV interventions that are appropriate at the local level.[12] In addition, HIV surveillance data have the important advantage of being population-based, with at least 95% of jurisdictions across 49 states, Washington D.C., and Puerto Rico reporting at least 95% of all CD4 and viral load test results to the CDC.[11]

Current State of Linkage to Care in the United States

Estimates of Successful Linkage to Care in the United States

Based on data from 38,793 persons newly diagnosed with HIV in 2023 in the United States, the CDC reported that 82.8% were linked to HIV medical care within 1 month of HIV diagnosis, which is significantly below the Ending the HIV Epidemic year goal of increasing linkage to HIV medical care to 95% by 2025.[8,9,11] Rates of linkage to care are similar in men (83.0%) and women (81.6%).[11] Linkage to care rates in 2023 are lower among the youngest age group, people who inject drugs, and Black individuals.[11] The following figure summarizes the most recent CDC surveillance HIV linkage data (linkage to HIV care within 1 month of HIV diagnosis), including data based on selected characteristics (Figure 3).[11]

Factors Associated with Delayed Linkage to Care

Studies have identified several factors that predict delayed linkage to care, including poverty, housing insecurity, lack of insurance or access to primary care prior to HIV diagnosis, substance use disorders, and mental health conditions.[13,14,15,16] A 2009 national survey revealed that health care providers more often attributed delayed care to multiple factors, including financial issues, lack of transportation, family care needs, lack of time off from work, substance use, and concern about HIV diagnosis confidentiality.[17] Persons who are required to undergo HIV testing, such as for insurance, employment, or court-ordered purposes, have been found to delay linkage after receiving a diagnosis of HIV, compared with individuals who self-initiate testing or have HIV testing recommended by their medical provider.[18]

Linkage Based on Site of Testing

In a study conducted during 2019-2020, investigators evaluated linkage to care data from a total of 60 local and state health departments and 29 community-based organizations and found that persons newly diagnosed with HI within primary care or emergency department settings were more likely to receive rapid linkage to care (defined as linkage within 7 days) than those diagnosed in sexual health clinics or non-healthcare setting.[19] Other prior studies have shown highly variable rates of linkage to care following a diagnosis of HIV when testing is performed in an emergency department setting, with higher rates correlating with intensive linkage efforts.[20,21,22,23]

Interventions to Improve Linkage to Care

Although a multitude of barriers to HIV care have been identified, few randomized, controlled trials have evaluated interventions to overcome these barriers. Moreover, published studies that evaluated linkage-to-care interventions have not used standardized outcomes, making comparisons between studies problematic.[24]

Expert Panel Recommendations

In 2015, an expert panel from the International Association of Physicians in AIDS Care published evidence-based recommendations for improving the HIV care continuum.[25] The following summarizes key panel recommendations that are specific to improving linkage to care:[25]

- For persons newly diagnosed with HIV, immediately refer to HIV care
- Use case managers and patient navigators to assist in this process
- Proactively engage persons who miss their initial clinic appointments, including provision of intensive outreach for those not engaged in care within 1 month of a new HIV diagnosis, including
    - Use of case management to engage persons lost to follow-up
    - Providing transportation support for persons with HIV to attend their clinic visit

Monitoring Linkage to Care

Monitoring linkage to care provides data essential to the development, tracking, and evaluation of cost-effective linkage interventions. The responsibility to ensure successful entry into HIV care primarily falls on the medical provider (or another staff member) at the site where the diagnosis of HIV is made, although local health departments and HIV clinics would ideally also be involved in this process. It is incumbent upon each local community to define roles and accountability for the linkage-to-care process. Integrating data and surveillance systems is also important in coordinating linkage to care. It is important to recognize that linkage to care does not ensure retention in care; clinics and health departments should also develop systems to maximize retention in care.

Strengths-Based Case Management

Strengths-based case management uses the technique of asking individuals to identify their internal strengths and skills to obtain needed resources such as medical coverage, transportation to appointments, housing, mental health treatment, or addiction treatment. Strengths-based case management is one of the few interventions that have been tested in a controlled study. In the Antiretroviral Treatment Access Study (ARTAS-I), investigators randomized individuals recently diagnosed with HIV to receive either standard of care passive referral (patients were given information about HIV and local resources) or intensive case management support that emphasized strengths-based techniques.[26] The intensive management group had significantly higher rates of receiving HIV care within 6 months compared with the standard of care group (78% versus 60%).[26] In a follow-up nonrandomized study (ARTAS-II), persons recently diagnosed with HIV received case management (up to 5 contacts).[27] Of the individuals newly diagnosed with HIV, 79% received HIV clinical care within 6 months of enrolling in the study.[27] The primary barrier to the widespread implementation of the findings from ARTAS trials is the resource intensity of the intervention.

Patient Navigators

Navigators are concerned with the individual patient rather than the health care system as a whole.[28] Although acceptance of the patient navigator model is widespread, there is little empirical evidence on its effectiveness. A randomized controlled trial involving individuals with HIV released from jail in the United States compared peer navigation with standard case management and demonstrated greater linkage to care within 30 days of release with peer navigation.[29] Data from the California Bridge Project, an intervention to

locate and link patients who were out of care to HIV treatment services, concluded that the characteristics of the persons responsible for recruiting and linking the patients to HIV care strongly influenced the success of linkage to care efforts.[30] As an example, persons with HIV are often uniquely qualified to assist individuals newly diagnosed with HIV, as they often have shared characteristics and circumstances, as well as direct disease-relevant experience and knowledge of local community strengths, challenges, and resources—all of which may help others to navigate the health care system.[31] One randomized controlled trial of peer navigation, as compared to standard case management, of individuals with HIV released from jail in the United States demonstrated greater linkage to care within 30 days of release.[29]

HIV Partner Services

The term “HIV partner services” encompasses a variety of services that health departments may offer to persons newly diagnosed with HIV and to their sex and needle-sharing partners.[32,33,34] An important goal of partner services is to detect persons with previously undiagnosed HIV and prevent further HIV transmission by helping persons newly diagnosed with HIV to notify their partners and connect the partners with testing services. Partner services can also assist in linking these individuals newly diagnosed with HIV, as well as any newly diagnosed partners, to HIV medical care. Health departments across the United States vary widely in the extent to which they conduct HIV partner services, but they are increasingly using surveillance data to guide partner services and increasingly include linkage to care as a key goal. Some health departments have reported improved rates of linkage to care among individuals who receive public health partner services.[32,35] Notably, the CDC promotes the use of HIV partner services to improve linkage to care.

Financial Incentives

The use of financial incentives for linkage to care was studied as a component of HPTN-065 (“TLC-Plus”), a feasibility study evaluating an enhanced testing, linkage to care, and treatment strategy in the United States. The linkage-to-care component of the study was a randomized intervention involving 37 HIV test sites (18 in the Bronx, New York, and 19 in Washington, D.C.) to determine whether financial incentives (gift cards) improved linkage to care. Results presented in 2015 showed that financial incentives did not increase linkage to care, but did increase regular clinic attendance and viral suppression.[36] Results from the viral suppression component of the study indicated that most individuals with HIV found the use of financial incentives to be acceptable and helpful.[37,38]

Strategies for Clinics to Improve Linkage to Care

Clinics that provide HIV clinical care can also play a role in ensuring that successful linkage to care occurs, thereby improving the likelihood that patients will engage in continuous HIV care. The CDC maintains an online Compendium of Evidence-Based Interventions for HIV Prevention that includes information on promoting linkage to, retention in, and re-engagement in care.[39]

Shorten Wait Times for Initial Appointment

Very short wait times for new patient visits may increase the likelihood of appointment completion. In a study at the University of Alabama at Birmingham (UAB) 1917 Clinic, among patients who called to establish HIV care from 2004 to 2006, 31% failed to attend a clinic visit within 6 months of their initial call.[40] To address this problem, the UAB 1917 Clinic launched Project CONNECT (Client-Oriented New Patient Navigation to Encourage Connection to Treatment), which established a clinic standard of scheduling an intake and orientation appointment for all new patients within 5 days of an initial request for a new appointment.[41] The orientation visit includes an intake questionnaire, baseline laboratory testing, case manager visit, initiation of opportunistic infection prophylactic medication if needed, and referrals to services for mental health and substance-use disorders, when indicated.[41] The initial visit no-show rate decreased from 31% at baseline to 19% after Project CONNECT was implemented.[41]

Follow-up After Missed Initial Appointment

Calling or otherwise conducting outreach to follow up with patients who do not show up for their first scheduled HIV care visit should ideally be part of an HIV clinic protocol. Certain patient characteristics have been associated with higher “no-show” rates, including minority race/ethnicity (especially minority women) and having public health insurance or no health insurance.[41] Specific strategies, such as improving the initial clinic orientation process, implementing reminder phone calls, using peer navigators, and accompanying patients to medical appointments, should be implemented at the clinic level to engage populations at risk for higher no-show rates.[42]

Rapid Initiation of Antiretroviral Therapy

Current Adult and Adolescent ARV Guidelines recommend rapid initiation of antiretroviral therapy after HIV diagnosis; the strategy to rapidly initiate antiretroviral therapy after HIV diagnosis.[10] Although no randomized controlled trials have evaluated the impact of rapid initiation of antiretroviral therapy on linkage to care among United States-based cohorts, observational studies from large urban centers, including San Francisco and Atlanta, indicate that removal of institutional barriers to an initial HIV provider visit, including offering same-day or next day appointments, can improve the time to first visit and improve time to antiretroviral therapy initiation and suppression of HIV RNA levels.[5,43] For example, the San Francisco Ward 86 program, which was initiated in 2013 and 2014 as a pilot program for rapid initiation of antiretroviral therapy for individuals newly diagnosed with HIV.[5] This robust program, which involved a multidisciplinary team, offered same-day or next-day clinic appointments, multidisciplinary evaluation, insurance support, and antiretroviral therapy initiation at the first visit.[5] In a retrospective analysis of this program, the median time from HIV diagnosis to antiretroviral therapy start was 7 days among program participants, with all participants initiating antiretroviral therapy at the time of their first clinic visit.[5]

Summary Points

- Linkage to care is the first step in engaging in HIV care and is typically defined as the completion of a first medical clinic visit within 1 month after an HIV diagnosis.
- For persons newly diagnosed with HIV, ensuring rapid linkage to care and starting antiretroviral therapy, ideally within 7 days, is a key pillar of the national initiative, Ending the HIV Epidemic: A Plan for America.
- For the year 2023, the CDC estimates that approximately 83% of persons were linked to care within 1 month of HIV diagnosis, which remains significantly below the Ending the HIV Epidemic year 2025 goal of 95% of persons linked to care within 1 month of HIV diagnosis.
- Key factors for delayed linkage include younger age, substance use, lack of medical insurance, lack of access to primary care prior to HIV diagnosis, and residence in a high-poverty area.
- Ensuring linkage to care is a crucial part of any HIV testing program, and active assistance with linkage to care is more effective than a passive approach.
- The Antiretroviral Treatment Access Study (ARTAS) intervention, which includes multiple sessions of strengths-based counseling, is an evidence-based linkage-to-care model.
- Assisting persons with linkage to HIV care is a primary goal of public health HIV partner services.
- Organized programs can increase rates of linkage to care by shortening wait times for new HIV clinic visits, conducting outreach to persons who no-show at their first scheduled visit, and facilitating case management intake for new clients prior to the HIV medical provider visit.

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Figures

Figure 1 HIV Care Continuum

Source: Adapted from HRSA. HIV Care Continuum

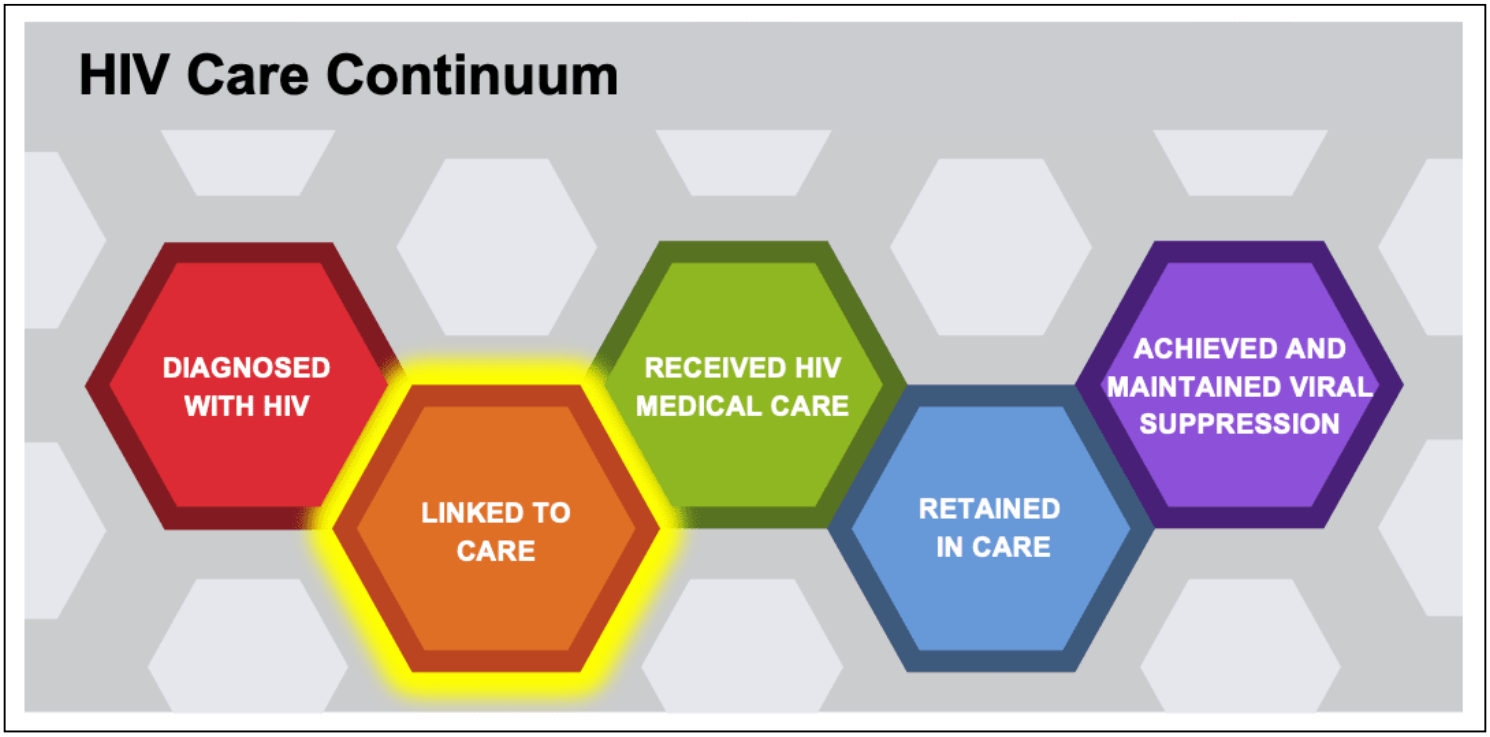

Figure 2 Linkage to HIV Care: Main Goals

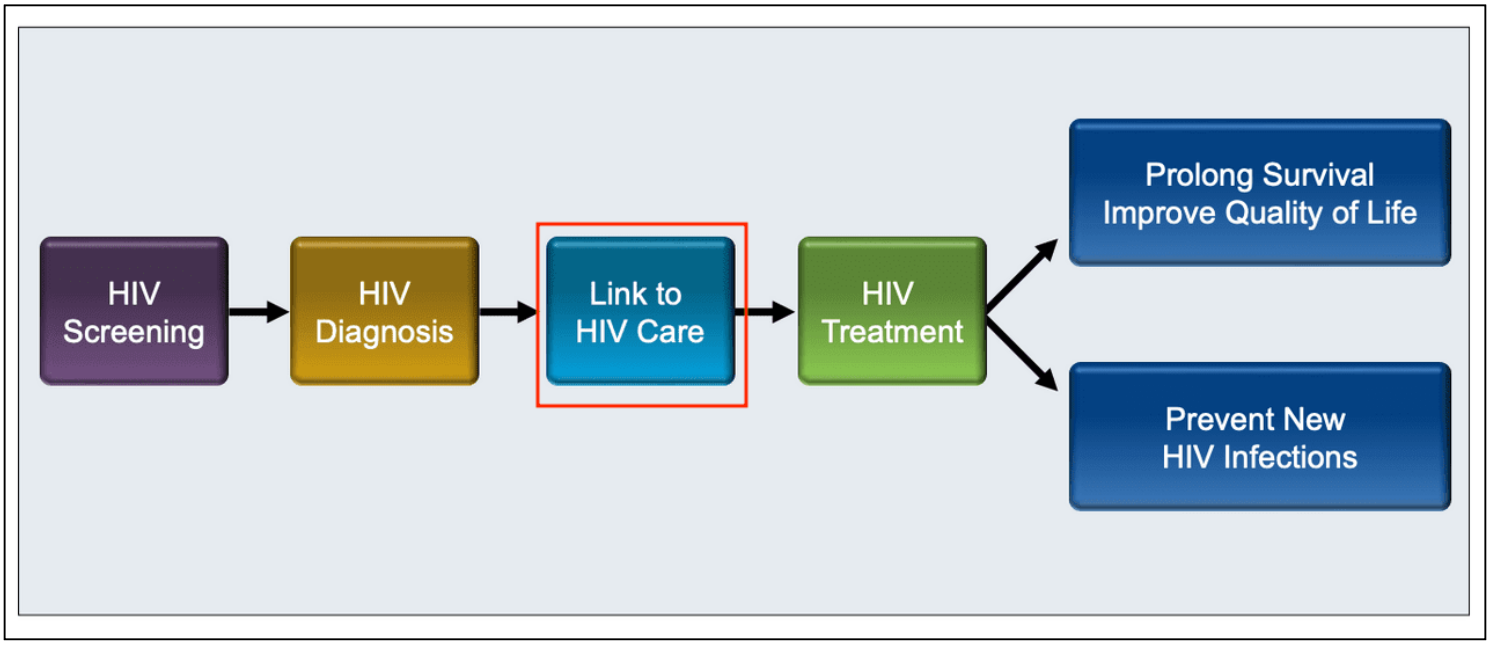

Figure 3 Linkage to HIV Medical care

Source: Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 territories and freely associated states, 2023. Published April 29, 2025.

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