

Linkage to HIV Care

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Module 1: [Screening and Diagnosis](#)

Lesson 5: [Linkage to HIV Care](#)

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Background and Goals

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 ([Figure 1](#))—it is a necessary precursor to antiretroviral therapy initiation and viral suppression. Antiretroviral treatment 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.[\[7\]](#) In addition, delayed linkage to care is a major barrier to “treatment as prevention” to reduce HIV transmission rates in the United States. Thus, identifying persons with HIV and successfully linking them to care plays a key role in the overall HIV epidemic, both from a treatment and a prevention standpoint ([Figure 2](#)). The 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, and the federal year 2025 goal is to have successful linkage to care in at least 95% of persons newly diagnosed with HIV.[\[8\]](#) 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 for improving 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.[\[8\]](#) The Centers for Disease Control and Prevention (CDC) monitors linkage to care after HIV diagnosis for two timeframes—within 1 month (30 days) and within 3 months (90 days).[\[9,10\]](#) The CDC surveillance data are based on documentation of an HIV RNA level (viral load) or CD4 cell count within 1 month or 3 months of HIV diagnosis as evidence for linkage to care.[\[9,10\]](#) More recently, the CDC has reported surveillance data only for linkage to care within 1 month of HIV diagnosis.[\[11\]](#) From a practical standpoint, the laboratory HIV RNA or CD4 cell count test results serve as an easily measurable surrogate marker for a clinic visit for HIV medical care. Using the standard metric for linkage to care, a first visit more than 1 month after 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. The start of antiretroviral therapy is not part of the definition of linkage to care in the United States, although this is a key part of the UNAIDS “90-90-90” goals for the HIV care continuum worldwide.

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 November 2022, 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.[\[12\]](#) One state—Idaho—and one United States territory—the United States Virgin Islands—do not require reporting of all CD4 and viral load data.[\[12\]](#) The HIV surveillance programs within state and local health departments also collect sociodemographic data and are able to 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.[\[13\]](#) HIV surveillance data has the important advantage of being population-based. Surveillance integrates data across care sites and includes more than 80% of persons with HIV in the United States.[\[14\]](#)

Current State of Linkage to Care in the United States

Estimates of Successful Linkage to Care in the United States

The United States federal benchmark for the year 2025 linkage to care goal is that at least 95% of persons with a new HIV diagnosis are linked to HIV medical care within 30 days of HIV diagnosis.^[8] Based on United States reported data from 28,422 persons newly diagnosed with HIV in 2020, the CDC reported that 82.4% of persons newly diagnosed with HIV were linked to HIV medical care within 1 month of HIV diagnosis, which is significantly below the national goal of 95%. The following summarizes additional CDC surveillance HIV linkage data (linkage to HIV care within 1 month of HIV diagnosis), including linkage to care data based on selected characteristics.^[11]

- **Trend from 2010-2021:** From 2010 through 2021, the percentage of persons linked to HIV care within 1 month increased steadily and has leveled off in the past several years ([Figure 3](#)).^[9,10,11,15,16]
- **Race-Ethnicity:** In 2021, the rates of linkage to HIV care varied among racial/ethnic groups, ranging from a low of 79.7% in Native Hawaiian other Pacific Islander individuals to a high of 87.0% in people who are Asian ([Figure 4](#)).^[16]
- **Age Group:** In 2021, rates of linkage to HIV care correlated with age, with lower rates in younger age groups ([Figure 5](#)).^[16]
- **Gender:** Rates for linkage to HIV care in 2021 were similar in males and females; rates were lower in transgender women than in transgender men ([Figure 6](#)).^[16]
- **Transmission Category:** Rates for linkage to HIV care in 2021, rates were lowest in males who acquired HIV through inject drug use and highest in females who acquired HIV through heterosexual contact ([Figure 7](#)).^[16]

Factors Associated with Delayed Linkage to Care

Studies have identified several factors that predict delayed linkage to care, including Black race, poverty, housing insecurity, lack of insurance or access to primary care prior to HIV diagnosis, substance use disorders, and mental health conditions.^[10,17,18,19,20,21] Additional risk factors for delayed linkage to care include psychosocial, emotional, and structural barriers. A 2009 national survey revealed that health care providers more often attributed nonengagement in care to structural barriers (finances, transportation, family care, lack of time off from work, and substance use), whereas persons with HIV more often reported psychosocial issues (fear of people knowing their diagnosis, concern about medication side effects, stigma, and shame) as the most important barriers to care.^[22] Other barriers, such as inconveniently located medical services, long appointment wait times, and language barriers, also likely contribute to delayed linkage to care. 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.^[23]

Linkage Based on Site of Testing

In a study from New York City involving persons diagnosed with HIV in 2003, investigators reported that persons undergoing routine HIV testing in many nonprimary care settings, such as sexually transmitted disease clinics, correctional facilities, or community testing sites, are less likely to be linked to care than those who are diagnosed at a site that offers co-located primary medical care.^[20] Studies have shown highly variable rates of linkage to care following a diagnosis of HIV when testing is performed in an emergency department setting.^[24,25,26] In a systematic review of 31 articles, the overall rate of linkage to care after HIV testing was performed in emergency department settings was 74%, and higher linkage rates correlated with intensive linkage efforts.^[26] Although the optimal approach to testing for HIV in a busy emergency department setting remains uncertain, studies have identified strategies to improve linkage to care from the emergency department. For example, a retrospective study of rapid HIV testing in the San

Francisco General Hospital emergency department showed that more than 90% of patients were successfully linked to care by a dedicated linkage team from the hospital's associated HIV clinic.[\[27\]](#)

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 have evaluated linkage to care interventions have not used standardized outcomes, making comparisons between studies problematic.[28]

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.[29] The following summarizes key panel recommendations that are specific to improving linkage to care:[29]

- 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,
 - Use of case management to engage persons lost to follow-up
 - Provide 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, and clinics and health departments should also develop systems to maximize retention in care.

Strengths-Based Case Management

Strengths-based case management is one of the few interventions that have been tested in a controlled study. Strengths-based case management employs the technique of asking individuals to identify their internal strengths and skills in order to attain needed resources such as medical coverage, transportation to appointments, housing, mental health treatment, or addiction treatment. The ARTAS and ARTAS-II studies, taken together, showed increased rates of linkage to care with intensive strengths-based case management compared to standard procedures (78 to 79% versus 60% within 6 months); this led to the recommendation to use strengths-based case management for improving linkage to care. The primary barrier to the widespread implementation of the findings from ARTAS is that the intervention is relatively resource intensive.

- **ARTAS:** The Antiretroviral Treatment Access Study (ARTAS) was a randomized, controlled trial in 11 United States cities that examined the impact of strengths-based case management on linkage to care rates.[30] Investigators randomized individuals with recently diagnosed HIV to receive either standard of care passive referral (patients were given information about HIV and local resources) or intensive case management support with linkage to nearby HIV clinics. Intensive case management consisted of up to 5 contacts over 90 days with a case manager who emphasized strengths-based techniques. The results of the study showed 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%).
- **ARTAS-II:** In a follow-up nonrandomized study, ARTAS-II, all persons recently diagnosed with HIV

received case management (up to 5 contacts).[\[31\]](#) Of the individuals newly diagnosed with HIV, 79% received HIV clinical care within 6 months of enrolling in the study.

Intensive Outreach

The important role for early and intensive outreach efforts was demonstrated in the U.S. Special Projects of National Significance (SPNS) Outreach Initiative, a 5-year initiative to enhance service delivery strategies to engage and retain persons with HIV in primary medical care. This program consisted of nonrandomized interventions at 10 urban areas across the United States and implemented various combinations of strategies. Most interventions included components of outreach and support services in different forms, such as appointment reminders, health system navigation, health literacy training, and provision of food and transportation. Inclusion criteria and program staff training varied by site.[\[32\]](#) All sites focused on individuals considered to be underserved or marginalized by the health care system (such as women, youth, and people with a history of substance use or mental health conditions); each newly diagnosed person with HIV received an average of 19 contacts over 12 months, with an average contact time of 15 minutes per contact. Within 6 months of enrollment, 92% of newly diagnosed study participants attended medical appointments, rates of virologic suppression in the study population improved from 14% at baseline to 45% after 12 months of follow-up, and participants reported an overall reduction in structural, financial, and personal barriers to care.[\[33\]](#)

Patient Navigators

Navigators are concerned with the individual patient rather than the health care system as a whole.[\[34\]](#) Although acceptance of the patient navigator model is widespread, there is little empirical evidence related to the effectiveness of this intervention. The California Bridge Project concluded that the characteristics of the persons responsible for recruiting and linking the patient to HIV care strongly influenced the success of linkage to care efforts, with the highest success rates occurring when the staff member and client had similar social and cultural backgrounds.[\[35\]](#) Persons with HIV are often uniquely qualified to assist individuals newly diagnosed with HIV as they try and navigate the health care system; trained peers (individuals with established HIV) often have shared characteristics and circumstances as well as direct disease-relevant experience and knowledge of local community strengths, challenges, and resources.[\[36\]](#) One randomized control 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.[\[37\]](#)

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.[\[38,39,40\]](#) 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. Health departments have reported improved rates of linkage to care after implementation of public health partner services and improved linkage to care within 30 days among individuals who receive partner services.[\[38,41\]](#) 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.[\[42\]](#) 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.[\[43,44\]](#)

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. There are limited evidence-based studies that have analyzed interventions that may improve linkage to care, but several examples from HIV clinics can provide insights for improving linkage to care. In addition, the CDC maintains an online Compendium of Evidence-Based Interventions for HIV Prevention that includes information on promoting linkage to, retention in, and reengagement in care.[\[45\]](#)

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.[\[46\]](#) 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.[\[47\]](#) 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.[\[47\]](#) The initial visit no-show rate decreased from 31% at baseline to 19% after the implementation of Project CONNECT.[\[47\]](#)

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.[\[47\]](#) 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.[\[48\]](#)

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.
- The benchmark for successful linkage to HIV care is the completion of a visit with an HIV medical provider within 1 month after HIV diagnosis. The United States national goal for linkage to care is 95%.
- For the year 2020, the CDC estimates that approximately 82% of persons were linked to care within 1 month of HIV diagnosis.
- Key factors for delayed linkage include substance use, lack of medical insurance, lack of access to primary care prior to HIV diagnosis, and residence in a high-poverty area.
- Linkage to care rates are lower among persons who are Black/African American or American Indian/Alaska Native compared to other racial/ethnic groups.
- 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.
- HIV clinical programs can increase rates of linkage to care by shortening their wait times for new clinic visits, conducting outreach to persons who no-show to their first scheduled visit, and conducting 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

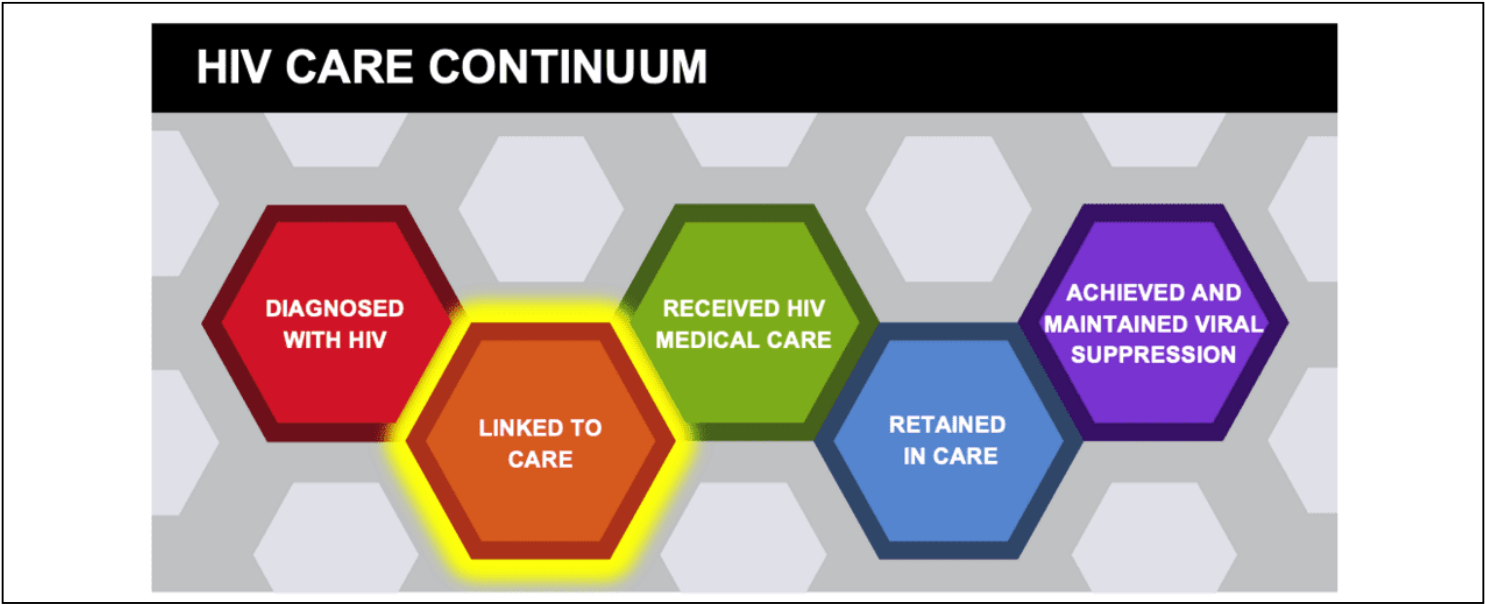


Figure 2 Linkage to HIV Care: Main Goals

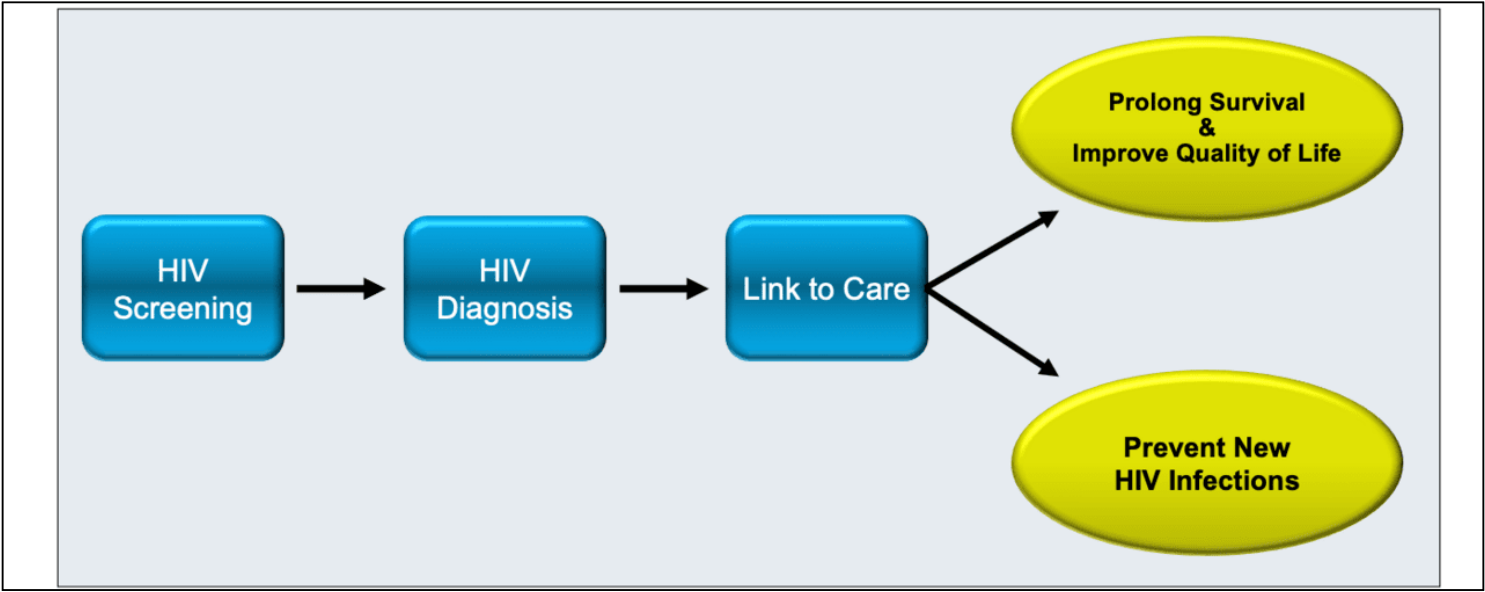


Figure 3 Linkage to Care within 1 Month of HIV Diagnosis, 2010 through 2021

The data in this figure are taken from the Centers for Disease Control and Prevention (CDC) Centers for Disease Control and Prevention. HIV Surveillance Supplemental Reports on Monitoring Selected National HIV Prevention and Care Objectives using HIV surveillance data. Note the number of states reporting data changed during this time period.

Source: Centers for Disease Control and Prevention. HIV Surveillance Supplemental Reports. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 U.S. dependent areas.

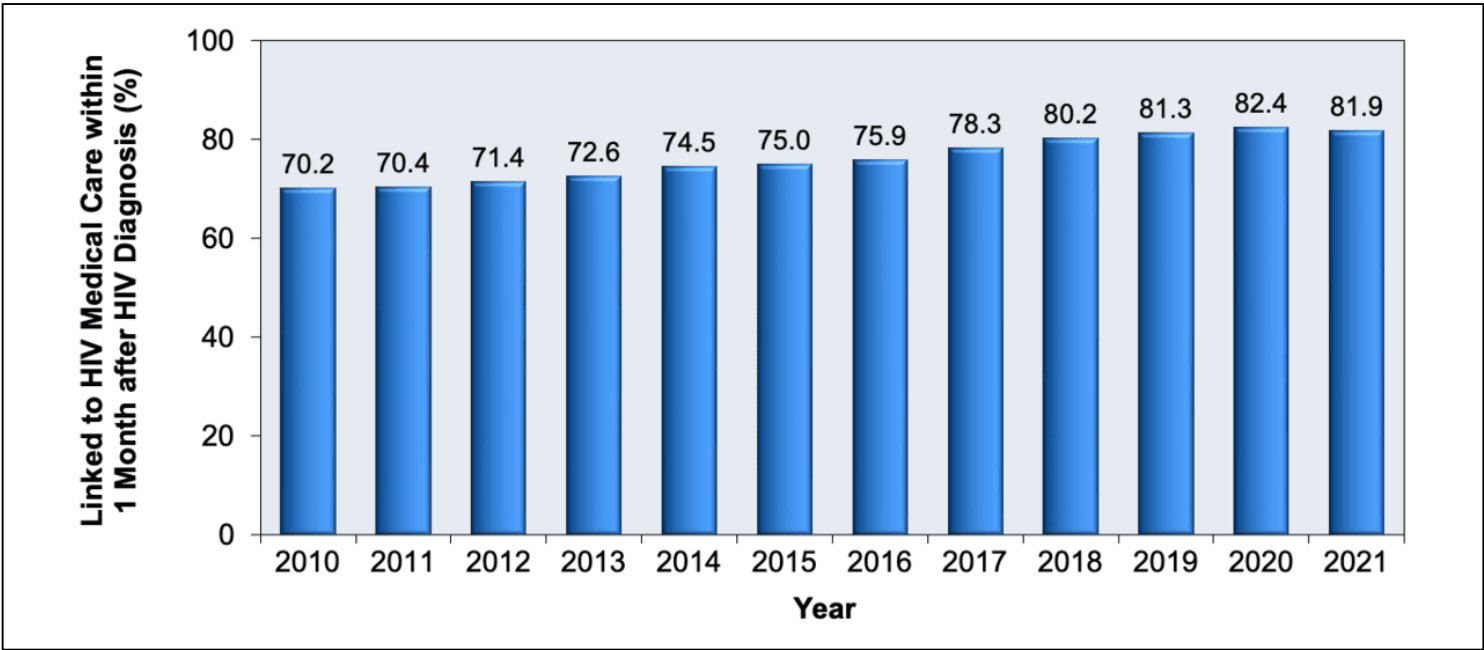


Figure 4 Linkage to Care within 1 Month after HIV Diagnosis, by Ethnicity/Race, United States, 2021

These data from the Centers for Disease Control and Prevention (CDC) are reported from 47 states and the District of Columbia.

Source: Centers for Disease Control and Prevention. Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2021. HIV Surveillance Supplemental Report. 2023;28(No. 4). Published May 2023

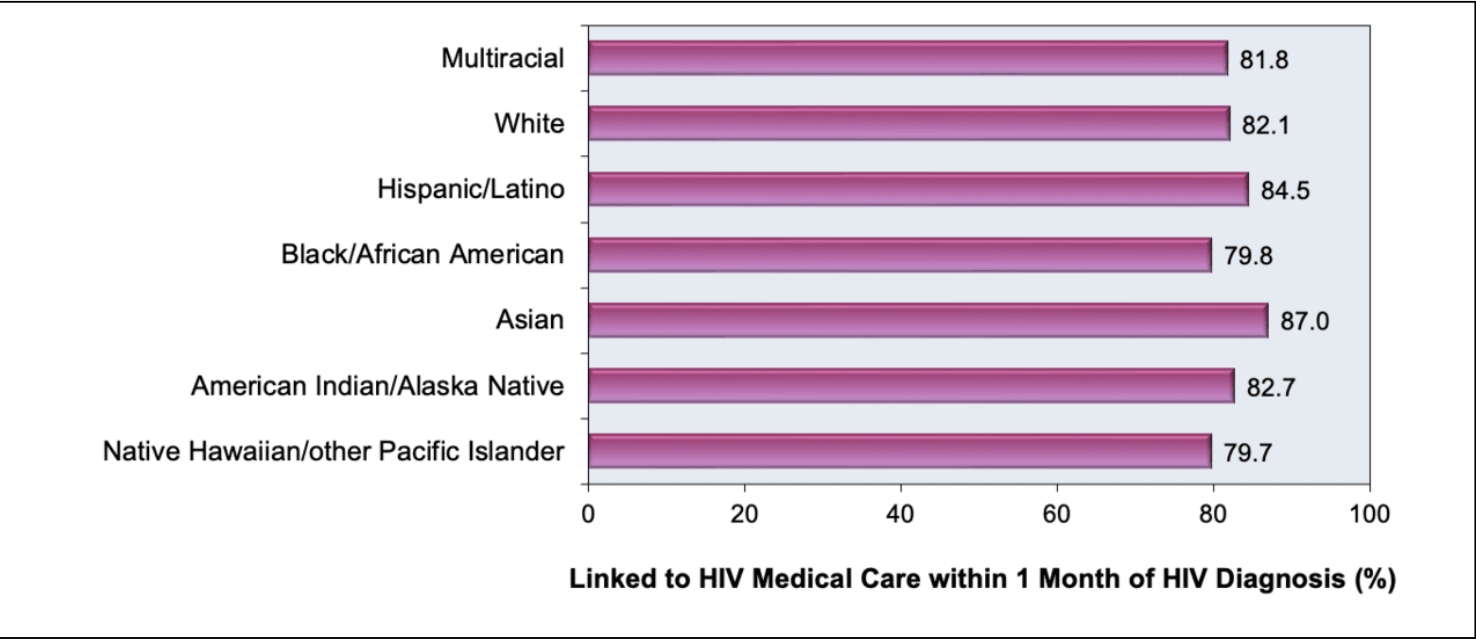


Figure 5 Linkage to Care within 1 Month of HIV Diagnosis, by Age Group, 2020

These data from the Centers for Disease Control and Prevention (CDC) are reported from 45 states and the District of Columbia.

Source: Centers for Disease Control and Prevention. Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2021. HIV Surveillance Supplemental Report. 2023;28(No. 4). Published May 2023

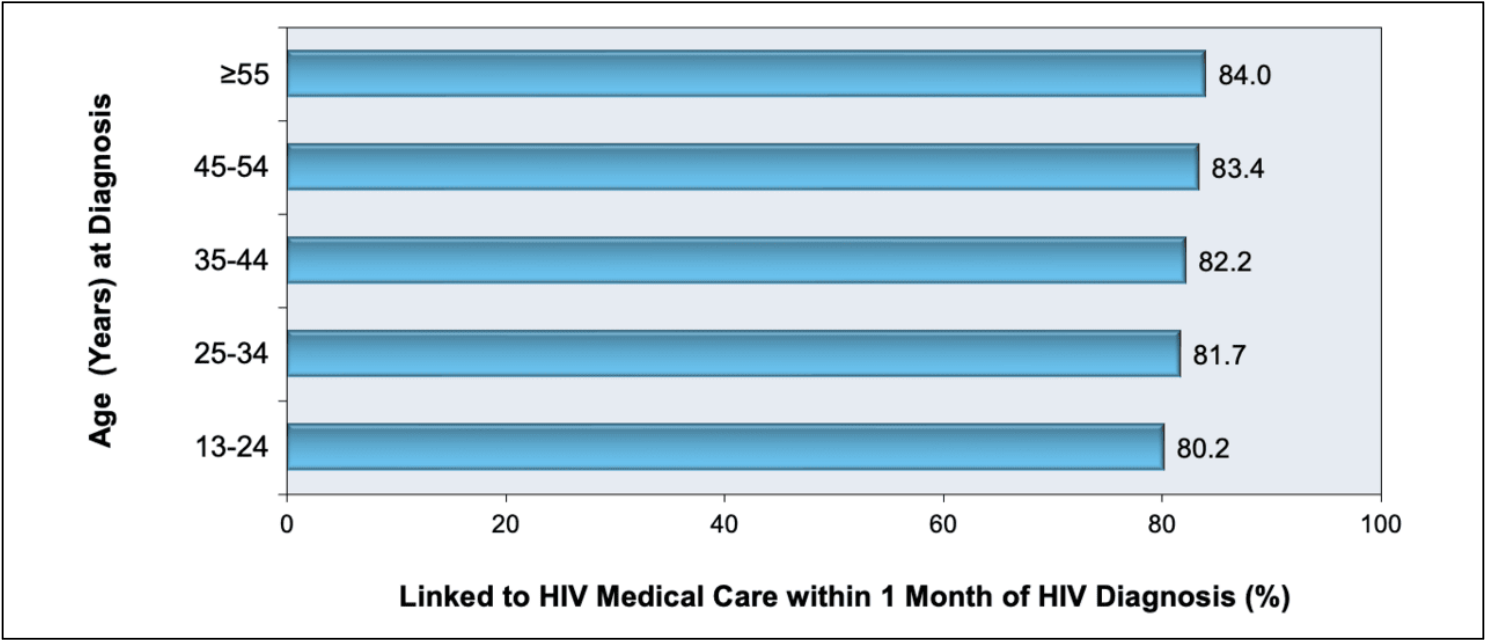


Figure 6 Linkage to Care within 1 Month of HIV Diagnosis, by Gender, 2020

These data from the Centers for Disease Control and Prevention (CDC) are reported from 45 states and the District of Columbia.

Source: Centers for Disease Control and Prevention. Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2021. HIV Surveillance Supplemental Report. 2023;28(No. 4). Published May 2023

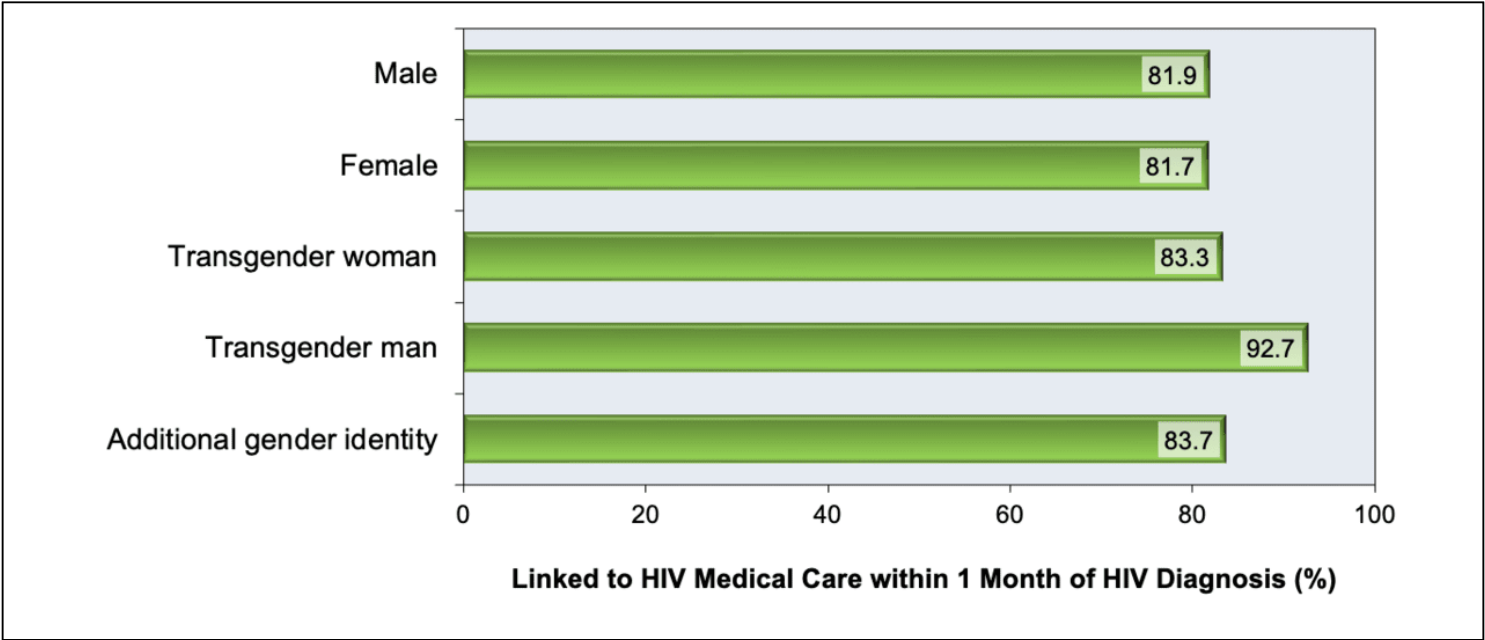


Figure 7 Linkage to Care within 1 Month of HIV Diagnosis, by Transmission Category, 2020

Source: Centers for Disease Control and Prevention. Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data—United States and 6 Dependent Areas, 2021. HIV Surveillance Supplemental Report. 2023;28(No. 4). Published May 2023

