Retention in HIV Care

This is a PDF version of the following document:
Module 2: Basic HIV Primary Care
Lesson 8: Retention in HIV Care

You can always find the most up-to-date version of this document at https://www.hiv.uw.edu/go/basic-primary-care/retention-care/core-concept/all.

Introduction and HIV Care Continuum

Background

For persons with HIV, the ability to remain retained in care plays a critical role in achieving good health outcomes and in preventing HIV transmission to others. In a general sense, retention in care is defined as a patient's regular engagement with medical care at a health care facility after initial entry into HIV clinical care. Despite tremendous advances in HIV treatment, a significant proportion of persons with HIV do not consistently receive antiretroviral therapy, often due to decreased engagement in long-term clinical care. Recent work has shown that lower retention rates in HIV medical care correlate with worse outcomes and increased transmission of HIV.[1,2,3,4] In contrast, higher retention rates in care correlate strongly with suppression of HIV RNA levels, improved health outcomes, and lower risk of transmitting HIV.[5,6,7,8] The National HIV/AIDS Strategy: Updated to 2020 set a goal that at least 90% of persons with diagnosed HIV in the United States are retained in HIV medical care.[9] In addition, improving screening, linkage, and retention in HIV care is clearly one of the key priorities in the bold new initiative—Ending the HIV Epidemic: A Plan for America.[10]

HRSA and HIV Care Continuum

The discussion of retention in care for people with HIV should be in the context of the overall HIV Care Continuum. The concept and foundation of the HIV Care Continuum were initially introduced by the Health Resources and Services Administration (HRSA) as the Continuum of Engagement in HIV Care—a model that described the spectrum of engagement in HIV clinical care.[11] The Engagement in HIV Care model was modified and adapted by HRSA and now is prominently known as the HIV Care Continuum, a model that outlines the sequential steps or stages of HIV medical care that persons with HIV go through, beginning with initial diagnosis to achieving consistent suppression of plasma HIV RNA levels (Figure 1).[12,13] Using this model, clinics, health officials, and policymakers can determine the proportion of individuals with HIV at each one of the stages in the HIV Care Continuum, and this process can help to identify where problems may exist in the overall care of persons with HIV. Each stage included in the HIV Care Continuum serves as a key benchmark indicators in the National HIV/AIDS Strategy for the United States.

CDC and Prevalence-Based HIV Care Continuum

The Centers for Disease Control and Prevention (CDC) provides prevalence-based HIV care continuum data based on persons living with HIV (diagnosed or undiagnosed) (Figure 2).[14] The HIV prevalence used as the starting point for this model includes an estimate of all people living with HIV in the United States during the year of reporting, irrespective of when they acquired HIV and regardless of whether or not they have received

an HIV diagnosis. These data are from 48 states and the District of Columbia.[14]

Evaluation of Retention in Care

Multiple methods exist for estimating retention in HIV medical care in the United States. The methods most relevant for clinicians are the HRSA and CDC retention measures.[13,15,16,17]

HRSA Performance Measure

In November 2013, the HIV/AIDS Bureau (HAB) at HRSA established revised performance measures to provide an indication of an organization's performance in relation to a specified process or outcome.[18] The HRSA HAB performance measures help guide, shape, and enhance the delivery and quality of care and were updated in October 2025.[18] The core HRSA performance measure related to retention in care is annual retention in care.[18]

- **Annual Retention in Care**: Defined as the percentage of patients, regardless of age, with a diagnosis of HIV who had at least 2 encounters within the measurement year.[18] The two encounters must be at least 90 days apart within the measurement year and at least one of the encounters needs to be with a medical provider who has prescribing privileges.[18]

CDC Performance Measures

The CDC provides reported data on receipt of HIV medical care and retention in care; the terms receipt of HIV medical care and retention in care should not be used interchangeably.[19]

- **Receipt of HIV Medical Care**: Defined as receipt of any HIV medical care as one or more CD4 cell count or viral load (HIV RNA) tests performed during the year of reporting.
- **Retention in Care**: Receipt of continuous HIV medical care is defined as two or more CD4 or viral load (HIV RNA) tests performed at least 3 months apart during the year of reporting.

Additional Measures Used to Evaluate Retention in HIV Medical Care

Clinicians providing HIV medical care and their clinic administrators have a challenge when considering how best to evaluate retention in HIV medical care for their specific clinic population. In addition to the commonly used methods and criteria listed above for evaluating retention in HIV medical care, several additional measures, as outlined below, may have utility in some clinical or research settings.

- **Missed Visits**: The purpose of the missed visit measure is to capture the number of missed appointments (no-shows) during an observation period. This parameter is easy to measure with a dichotomous result and is one of the most commonly used methods for evaluating retention in HIV medical care.
- **Appointment Adherence**: The measure of appointment adherence is determined by calculating the number of completed visits by the number of total scheduled visits (completed visits plus no-show visits). Alternatively, some reports have provided information on nonadherence, also referred to as the missed visit rate, by inserting the number of no-show visits in the numerator instead of the number of completed visits.
- **Visit Constancy**: The measurement for visit constancy is defined as the proportion of time intervals with at least one completed visit during an observation period. This measure best accounts for loss of follow-up and only requires capturing completed visits.
- **Gaps in Care**: The measurement for gaps in care is defined as the time interval between completed clinic visits, usually based on a predetermined threshold of 3, 4, or 6 months. A time frame of 6 months is typically used, as this threshold has been determined by clinical expert consensus to allow for patients who are well controlled clinically and stable on their current regimen.
- **Centers for Disease Control and Prevention**: For reporting purposes, the CDC defines receipt of any HIV medical care as one or more CD4 cell count or viral load (HIV RNA) tests performed during the

year of reporting. Retention in care (receipt of continuous HIV medical care) was defined as two or more CD4 or viral load (HIV RNA)tests performed at least 3 months apart during the year of reporting.[19] The CDC surveillance also provides data on receipt of HIV medical care, which is defined as having at least one CD4 cell count or viral load test performed during the year of evaluation.[16]

Estimating Retention in HIV Medical Care

The estimates for retention in HIV medical care vary based on the criteria used to define retention in HIV medical care. The percentage of persons retained in care is calculated by dividing the number of persons retained in care (numerator) by the number of persons diagnosed with HIV who are alive (denominator). For the following summaries, the percentage of people “receiving care” will be considered as the best estimate for those “retained in care.”

CDC Estimates of Retention in HIV Medical Care

The following CDC surveillance data for retention in medical care in the United States is based on laboratory studies (CD4 count and/or HIV RNA level obtained that year).[14] The CDC data, which are collected from 47 states and the District of Columbia, define retention in care as at least 2 CD4 counts and/or 2 HIV RNA tests performed that year (and performed at least 3 months apart).[14] For the year 2022, the overall percentage of people with HIV who were retained in medical care was 53.8%.[14] Since 2010, the percentage of people with HIV retained in care has remained relatively stable, ranging from 50 to 58% (Figure 4).[14,16,19,20] Retention rates were lower in people 25–44 years of age, and they varied significantly by race/ethnicity.[14] Retention rates were similar in men (53.9%) and women (53.4%).[14]

Retention in HIV Care in Ryan White Program Clinics

From 2019 through 2023, retention in HIV medical care among Ryan White Program Clinics remained stable at approximately 80% from 2019 to 2023.[21] For these data, retention in care was based on people with HIV who had at least 1 outpatient ambulatory health services visit by September 1 of the measurement year, with a second visit at least 90 days after the first visit (Figure 5).[21]

Limitations of Measuring Retention in Care

When using the above measures, one should always consider the advantages and limitations of each, especially in the context of applying the measure to a desired application, whether for clinical, administrative, reporting, or research purposes.[16,22,23] Retention in care measures should be aligned with national and international guidelines and should incorporate data sources, including state surveillance systems, clinic medical records, and administrative databases; the integration of various data sources can enhance monitoring of retention in HIV medical care efforts. Several recent studies have shown that earlier reports probably overestimated the proportion of persons out of care by not taking into account recording errors, individuals who were deceased, and the migration of individuals with HIV who were receiving ongoing medical care in a region or city outside of their prior residence.[24,25,26,27,28] These studies, as outlined below, emphasize the need for revised surveillance techniques to allow for better estimates of retention in care.[29]

- A pilot study conducted by the Massachusetts Department of Public Health found that only 25% of persons characterized as being out of care by the absence of laboratory test results were actually disengaged from care; the majority had moved or engaged in care elsewhere.[27]
- In Washington state, a clinic-based surveillance-informed re-linkage intervention found that 79% of individuals with HIV who were characterized as out of care had moved, transferred care, or were in a long-term correctional facility—and thus were not out of care.[28]
- A collaborative analysis across 6 states in the Northwestern United States reached analogous findings: 72% of patients described as out of care were not disengaged from care but rather had moved, died, or were erroneously identified as being out of care.[30]

Factors that May Impact Rates of Retention in Care

Understanding patient variables associated with lower retention rates can assist medical providers in their efforts to identify health behaviors and/or social needs that can be modified to enhance the likelihood that an individual with HIV will engage in and remain in HIV care. Critical goals for persons who are retained in care are to achieve viral suppression and obtain a high quality of life. When gaps in linkage to care and retention in care are identified and remedied, individuals maintain a better chance of remaining engaged in care. When persons with HIV are consistently retained in care, approximately 90% receive antiretroviral therapy, and 80% obtain durable viral suppression.[31] Although it is difficult to predict the likelihood of an individual being retained in HIV care, investigators have identified multiple variables associated with lower retention rates.[32,33,34,35,36] As outlined below, some factors, such as place of residence, age, and race/ethnicity, have previously been identified to correlate with highly variable rates of retention, but more recent surveillance data has not shown persistence in these disparities.[14]

- **Place of Residence**: Surveillance data from the CDC previously identified that living in a nonmetropolitan location with a population of less than 500,000 people correlated with a lower rate of HIV medical care retention, possibly due to geographical and environmental difficulties associated with accessing care.[37] More recent surveillance data for 2022 showed very similar retention in care rates (range 54 to 55%) for three different metropolitan area populations (greater than 500,000, 50,000-499,999, and less than 50,000).[14]
- **Age**: In the In 2022 CDC surveillance report, the rates of retention in HIV medical care were lower in the 25-34 and 35-44 year old age groups.[14]
- **Race/Ethnicity**: Various studies have shown an association with decreased retention in care among Black individuals and nonwhite Hispanic, Asian, and Pacific Islander people when compared to patients who are White, as measured by the number of office visits missed.[34,38,39] Further, these earlier studies showed that Black men have low rates of retention in HIV medical care.[38,39] In 2022 CDC surveillance data, the retention in care rates were relatively similar among different racial/ethnic groups, ranging from a low of 49% among Native Hawaiian/Pacific Islander individuals to a high of 55% in White, Hispanic, and Asian individuals.[14]
- **Mental Health Conditions**: Research has linked depressive symptoms to worse HIV outcomes, particularly if compounded by concomitant substance use disorders, or post-traumatic stress from physical, sexual, or emotional abuse.[41] Therefore, engaging persons with HIV in medication treatment and/or counseling for their depression or untreated mental health conditions may improve symptoms and increase engagement in care.[42,43,44] At first glance, this appears to conflict with other data indicating persons with an affective mental health disorder have higher rates of retention in care, but researchers postulate that this may be due to high rates of undiagnosed mental health disorders among persons with HIV, such that those diagnosed with a mental health disorder and receiving care have better retention outcomes relative to those with undiagnosed and unmet mental health needs.[35]
- **Substance Use Disorders**: Alcohol or illicit drug use is reported in a large portion of persons with HIV. Data on injection drug use continues to suggest that persons with HIV who have active drug use often have lower rates of retention in care.[43,45,46] For persons with alcohol or opioid use disorder, the most important factor for improving retention in care is to receive medication-assisted treatment—a process that combines behavioral therapy with medications.[47,48]
- **Uninsured or Underinsured**: Individuals with HIV who lack medical or prescription insurance, or have policies with poor coverage, are less likely to see medical providers or fill prescriptions, due to their inability to pay for services. This can lead to patients dropping out of care or not engaging in care. Helping persons with HIV explore all opportunities for assistance in paying for medical services, such as sliding fee scales, or assisting them in applying for Medicaid, Medicare, or insurance through the Affordable Care Act, can maximize their health care coverage.[33]
- **Unmet Needs**: Persons with HIV who lack certain support services such as case management, mental health counseling, and transportation assistance may also lack the ability to stay engaged in medical care.[49]

Impact of Lower Rates of Retention in Care

Impact on Clinical Outcomes

Although investigators have identified certain variables associated with decreased retention in HIV care, clinicians also need to clearly understand the overall consequences of failed retention in care. It is the responsibility of the HIV care provider to identify important risk factors that may predispose an individual to lower rates of retention in care and take appropriate measures to help reduce the negative outcomes. Until recently, little was known about the impact of low retention in HIV care on health outcomes, such as engaging in behaviors associated with increased risk of HIV transmission, time to initiation of antiretroviral therapy, and mortality rate. Several studies have measured the impact of poor retention on mortality.

- A retrospective study at the University of Alabama at Birmingham HIV/AIDS clinic for the period January 1, 2000 through December 31, 2005 demonstrated persons with HIV who missed a visit in the first year after establishing initial outpatient HIV treatment had approximately twice the long-term mortality rate when compared with those who attended all scheduled appointments.[33]
- In a Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) study, even when clients with HIV in the clinic met the overall Institute of Medicine and HRSA retention indicators, missing more than 2 clinic visits in a 2-year period was independently associated with an increased mortality risk.[50]
- In a study that involved 2,619 men with HIV seen at Veterans Affairs hospitals and clinics, investigators reported that even in a system with few financial barriers to care, a substantial percentage of clients had lower rates of retention in care, and it predicted lower survival.[51]
- In a retrospective study conducted in South Carolina, investigators analyzed data from 2,197 persons newly diagnosed with HIV from January 1, 2004 through December 31, 2009.[34] The subjects were followed over 2 years and data analyzed for 6-month intervals (total of 4 intervals); sporadic rates of retention and dropout were associated with lower rates of virologic suppression and increased mortality risk (Figure 6).[34]

Impact on HIV Transmission

In addition to increased mortality rates, persons with HIV who do not demonstrate consistent adherence with regularly scheduled appointments (and are not adequately ‘retained’ in HIV care) have an increased risk of HIV transmission when compared to individuals who are optimally engaged in HIV care. Several studies have identified that individuals with HIV who are linked to and retained in care are more likely to initiate antiretroviral therapy, achieve viral suppression, and markedly lower their risk of HIV transmission compared to individuals who had suboptimal retention in care.[1,7,8,52] These findings have important public health implications: in 2016, individuals who were diagnosed with HIV but not in care were responsible for an estimated 43% of all new HIV transmissions within the United States during that year (Figure 7).[3] Multiple studies have shown that persons with HIV who consistently have undetectable HIV RNA levels do not sexually transmit HIV to others.[53,54,55] Individuals with HIV who are not retained in care transmit HIV at an estimated rate of 6.6 transmissions per 100 person-years, compared with a rate of 0.0 transmissions per 100 person-years in those individuals engaged in care with viral suppression.[3]

Impact on Healthcare Costs

Recent cost-benefit analyses have suggested that interventions focused on improving retention in HIV care have a marked epidemiological and economic impact in the United States by reducing HIV incidence and HIV-associated morbidity and mortality.[56,57]

Strategies to Improve Retention in HIV Medical Care

Approaches to Improving Retention in HIV Medical Care

A multipronged approach targeting various aspects of the HIV Care Continuum is needed to improve retention in care. Health care systems that can facilitate rapid antiretroviral initiation for persons with HIV improve retention in care, including retention with suppressed HIV RNA levels.[58,59,60,61] There are strategies to identify individuals in HIV medical care who are at high risk of falling out of care, as well as targeted interventions and resources to avoid disengagement and improve clinical outcomes among this population. Multiple studies have demonstrated that providing comprehensive and easy-to-access services (e.g., case management, mental health support, transportation, and drug treatment programs) can enhance retention in care.[62,63,64] In addition, decreasing structural barriers in the clinic setting, utilizing interventions that assist patients in developing positive relationships with their health care professionals, providing basic HIV education, and dispelling negative health beliefs about HIV can improve patient outcomes.[11] The following summarizes several important strategies utilized to try and improve retention in HIV medical care.

- **Data to Care**: In recent years, several groups have utilized a new public health strategy that uses HIV surveillance laboratory data to identify persons diagnosed with HIV who are not in care (based on the absence of laboratory monitoring data), with a subsequent goal to link or relink these identified individuals to medical care.[28,30,65] This approach is now commonly referred to as Data to Care (D2C) and has been recommended by the CDC.[66,67] The Data to Care programs for linkage and reengagement now incorporate three models: (1) Health Department Model, (2) Health Care Provider Model, and (3) Combination Health Department/Health Care Provider Model (Figure 8).
- **Enhanced Personal Contact**: In a randomized study performed at six HIV clinics in the United States, investigators reported improved retention with enhanced personal contact with an interventionist when compared with the standard of care practices; the enhanced contact with the interventionist consisted of brief face-to-face meetings at medical appointments, reminder calls for appointments, and check-in calls for missed appointments.[68]
- **Medical Case Management**: In the Antiretroviral Treatment and Access Study (ARTAS), investigators showed that for persons newly diagnosed with HIV, as few as two case management visits significantly improved linkage to care and retention in care. Several other studies have demonstrated the benefit of medical case management on rates of retention in HIV medical care.[62,64,69,70]
- **Walk-In, Incentivized Care Model**: In 2015, a collaborative effort between Seattle-King County Public Health and a large Ryan White Program Clinic in Seattle (Madison clinic) established a high-intensity support, low-threshold care access clinic specifically for persons with HIV who have extensive barriers to HIV care.[71,72] The clinic, which provides maximum assistance and services for hard-to-reach clients with HIV, is known as the “Max Clinic”. The major goals of the clinic are to improve engagement in care, retention in care, and achieve viral suppression. As part of the clinic services, incentives are provided to clients for retention in care and viral suppression.[71,72] Access to the Max clinic has resulted in marked improvement in rates of retention in care and viral suppression among this population that has complex medical and social needs.[71,72]
- **Patient Navigation Interventions**: In a randomized trial (Project Hope) conducted from July 2012 through January 2014, investigators explored the impact of structured patient navigation interventions for engaging 801 hospitalized persons with HIV and substance use disorders in HIV medical care; the authors randomized participants to either treatment as usual, patient navigation alone, or patient navigation plus financial incentives.[73] At 6 months, the navigation plus incentive group had the highest level of viral suppression, but at 12 months, there was no statistical difference in viral suppression among the three groups (Figure 9).[73]

IPAC Guidelines

The International Association of Physicians in AIDS Care (IAPAC) has published evidence-based guidelines for improving entry into and retention in care for individuals with HIV.[42] These recommended interventions are based on randomized, controlled trials or observational studies that had at least one measured biological or behavioral end point. The recommendations are graded for overall quality and strength and consist of five major components related to entry and retention in care:

- **Systematic Monitoring of Entry into HIV Care:** These guidelines recommend that systematic monitoring of entry into HIV care should occur for all individuals diagnosed with HIV (**II A**). Within a service area, rapid HIV testing programs, public health departments, and medical clinics should coordinate the monitoring of individuals who are entering HIV care. Integrating databases, medical records, and surveillance data among service providers involved in HIV care may enhance monitoring of initial entry into HIV care. The authors also noted that improved patient survival has been observed when entry into care occurs with an HIV provider with clinical competence in prescribing antiretroviral therapy.
- **Systematic Monitoring of Retention in HIV Care:** Though monitoring retention in care is routinely recommended, specific monitoring, including retention measures and desired visit frequency, can vary among jurisdictions and should be standardized with national guidelines (**II A**). Many retention measures (e.g., visit adherence, gaps in care, visits per interval of time, etc.) and data sources (e.g., public health surveillance, medical records, administrative databases, etc.) can be applied in accordance with local resources and standards of care. Also, the integration of data sources may enhance retention in care monitoring.[22,51]
- **Strength-Based Case Management:** For individuals with a new diagnosis of HIV, a brief strength-based case management intervention should be available (**II B**). Citing data from the Antiretroviral Treatment and Access Study, utilizing multiple, strength-based case management sessions (defined as up to 5 sessions in a 3-month period) can lead to a significantly higher proportion of patients attending an HIV clinic appointment at least once in a 6-month period, as compared to patients who were passively referred to local points of care following a new HIV diagnosis (78% versus 60%).[64] In addition, case-managed individuals also attended HIV clinic appointments at least twice in a 12-month period more often than individuals not case-managed (64% versus 49%). Strength-based case management sessions entailed trained social workers identifying patient strengths and assets in order to facilitate successful linkage to and retention in care. Obviously, the effect of strength-based case management can be reduced if there is limited availability of resources in a service area.
- **Intensive Outreach for Recently Diagnosed:** For individuals with HIV who are not engaged in medical care within 6 months of a new HIV diagnosis, intensive outreach may be considered (**III C**). Maintaining individuals newly diagnosed with HIV in routine care has been shown to improve chances of achieving an undetectable viral load by 12 months of follow-up. Intensive case finding, with reenrollment into care, should focus on vulnerable populations considered at risk for receiving fewer services, including women, youth, and individuals with a history of mental conditions or substance use. A dose-response relationship has been described between increasing numbers of quarterly medical visits and decreasing patient mortality.[51] In addition, optimal care (at least four clinic visits, one per quarter, in a calendar year) is associated with increases in mean CD4 counts and decreases in mean HIV RNA levels.[34]
- **Peer or Paraprofessional Patient Navigators:** The guidelines recommend considering using peer or paraprofessional patient navigators to help facilitate interactions with health care systems and providers (**III C**). Patient navigation is based primarily on peer-based programs developed for patients with cancer. Navigators are trained to assist patients in their interactions with the complex United States health care and social service systems in order to ensure that patients get the assistance they need. The U.S. Special Projects of National Significance Outreach Initiative is one program that has demonstrated positive outcomes with the use of HIV patient navigators. This program enrolled 1,100 patients with inconsistent engagement in care and demonstrated that, after 6 months of patient navigation assistance, the proportion of patients with at least 2 visits in the previous 6 months increased from 64% at baseline to 87% at 6 months and 79% at 12 months.[42]

Summary Points

- Evaluating and discussing HIV retention in care should be done in the context of the overall HIV Care Continuum. The HIV Care Continuum outlines the sequential steps or stages of HIV medical care that persons with HIV go through, beginning with initial diagnosis to achieving consistent suppression of plasma HIV RNA levels.
- Using CDC surveillance data, the HIV Care Continuum has been evaluated with a Prevalence-Based HIV Care Continuum model and a Diagnosis-Based HIV Care Continuum model.
- In the United States, during the year 2022, approximately 54% of persons diagnosed with HIV were retained in HIV medical care, as defined by having at least 2 CD4 cell counts or HIV RNA levels obtained at least 3 months apart that year. The rates of retention in care have not improved since 2010.
- In the United States, retention in care rates are lower in persons 25–44 years of age and vary by race and ethnicity. Rates are similar among men and women and among population areas of residence.
- When persons with HIV are retained in care, they have better outcomes in terms of receiving antiretroviral therapy, achieving virologic suppression, and improving survival.
- Persons diagnosed with HIV but who are not retained in care are responsible for approximately 43% of all HIV transmissions in the United States.
- Medical providers should examine simple, low-cost ways of improving retention in care by facilitating rapid initiation of antiretroviral therapy, partnering with local/regional stakeholders, engaging with case management opportunities, and using various outreach and peer-navigation support strategies.
- Clinicians should identify factors for decreased retention in care and develop strategies to increase engagement and achieve viral suppression. Partnerships between clinics and health departments can utilize Data to Care as a tool for identifying persons not retained in care and to provide support for reengagement in care.

Citations

1. Crawford TN. Poor retention in care one-year after viral suppression: a significant predictor of viral rebound. AIDS Care. 2014;26:1393-9.
[PubMed Abstract] -

2. Horberg MA, Hurley LB, Silverberg MJ, Klein DB, Quesenberry CP, Mugavero MJ. Missed office visits and risk of mortality among HIV-infected subjects in a large healthcare system in the United States. AIDS Patient Care STDS. 2013;27:442-9.
[PubMed Abstract] -

3. Li Z, Purcell DW, Sansom SL, Hayes D, Hall HI. Vital Signs: HIV transmission along the continuum of care - United States, 2016. MMWR Morb Mortal Wkly Rep. 2019;68:267-72.
[PubMed Abstract] -

4. Zinski A, Westfall AO, Gardner LI, et al. The Contribution of Missed Clinic Visits to Disparities in HIV Viral Load Outcomes. Am J Public Health. 2015;105:2068-75.
[PubMed Abstract] -

5. Sabin CA, Howarth A, Jose S, et al. Association between engagement in-care and mortality in HIV-positive persons. AIDS. 2017;31:653-660.
[PubMed Abstract] -

6. Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clin Infect Dis. 2011;52:793-800.
[PubMed Abstract] -

7. Yehia BR, French B, Fleishman JA, et al. Retention in care is more strongly associated with viral suppression in HIV-infected patients with lower versus higher CD4 counts. J Acquir Immune Defic Syndr. 2014;65:333-9.
[PubMed Abstract] -

8. Skarbinski J, Rosenberg E, Paz-Bailey G, et al. Human immunodeficiency virus transmission at each step of the care continuum in the United States. JAMA Intern Med. 2015;175:588-96.
[PubMed Abstract] -

9. White House Office of National AIDS Policy. National HIV/AIDS Strategy for the United States: Updated to 2020. Washington, DC. July 2015.
[The White House: Washington] -

10. Fauci AS, Redfield RR, Sigounas G, Weahkee MD, Giroir BP. Ending the HIV Epidemic: A Plan for the United States. JAMA. 2019;321:844-845.
[PubMed Abstract] -

11. Cheever LW. Engaging HIV-infected patients in care: their lives depend on it. Clin Infect Dis. 2007;44:1500-2.
[PubMed Abstract] -

12. Health Resources Services Administration (HRSA). HIV Care Continuum
[HRSA] -

13. Doshi RK, Milberg J, Isenberg D, et al. High rates of retention and viral suppression in the US HIV

safety net system: HIV care continuum in the Ryan White HIV/AIDS Program, 2011. Clin Infect Dis. 2015;60:117-25.
[PubMed Abstract] -

14. 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, 2022. *HIV Surveillance Supplemental Report* 2024; 29(No. 2). Published May 21, 2024
[CDC] -

15. Health Resources and Services Administration. Ryan White HIV/AIDS Program Annual Client-Level Data Report 2018. December 2019:1-139.
[HRSA] -

16. 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, 2018 HIV Surveillance Supplemental Report. 2020;25(No. 2):1-104. Published May 2020.
[CDC] -

17. Rebeiro PF, Horberg MA, Gange SJ, et al. Strong agreement of nationally recommended retention measures from the Institute of Medicine and Department of Health and Human Services. PLoS One. 2014;9:e111772.
[PubMed Abstract] -

18. Health Resources Services Administration (HRSA). HIV/AIDS Bureau Performance Measures.
[HRSA] -

19. 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.
[CDC] -

20. Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 U.S. dependent areas, 2017. HIV Surveillance Supplemental Report. 2019;24(No. 3):1-74. Published June 2019.
[CDC] -

21. Health Resources and Services Administration. Ryan White HIV/AIDS Program: Annual Data Report. Ryan White HIV/AIDS Program Services Report 2023. December 2024:1-94.
[HRSA] -

22. Mugavero MJ, Davila JA, Nevin CR, Giordano TP. From access to engagement: measuring retention in outpatient HIV clinical care. AIDS Patient Care STDS. 2010;24:607-13.
[PubMed Abstract] -

23. Mugavero MJ, Westfall AO, Zinski A, et al. Measuring retention in HIV care: the elusive gold standard. J Acquir Immune Defic Syndr. 2012;61:574-80.
[PubMed Abstract] -

24. Buskin SE, Kent JB, Dombrowski JC, Golden MR. Migration distorts surveillance estimates of engagement in care: results of public health investigations of persons who appear to be out of HIV care. Sex Transm Dis. 2014;41:35-40.
[PubMed Abstract] -

25. Dombrowski JC, Buskin SE, Bennett A, Thiede H, Golden MR. Use of multiple data sources and

individual case investigation to refine surveillance-based estimates of the HIV care continuum. J Acquir Immune Defic Syndr. 2014;67:323-30.
[PubMed Abstract] -

26. Dombrowski JC, Kent JB, Buskin SE, Stekler JD, Golden MR. Population-based metrics for the timing of HIV diagnosis, engagement in HIV care, and virologic suppression. AIDS. 2012;26:77-86.
[PubMed Abstract] -

27. Hague JC, John B, Goldman L, et al. Using HIV Surveillance Laboratory Data to Identify Out-of-Care Patients. AIDS Behav. 2019;23:78-82.
[PubMed Abstract] -

28. Bove JM, Golden MR, Dhanireddy S, Harrington RD, Dombrowski JC. Outcomes of a Clinic-Based Surveillance-Informed Intervention to Relink Patients to HIV Care. J Acquir Immune Defic Syndr. 2015;70:262-8.
[PubMed Abstract] -

29. Risher KA, Kapoor S, Daramola AM, et al. Challenges in the Evaluation of Interventions to Improve Engagement Along the HIV Care Continuum in the United States: A Systematic Review. AIDS Behav. 2017;21:2101-2123.
[PubMed Abstract] -

30. Dombrowski JC, Bove J, Roscoe JC, et al. "Out of Care" HIV Case Investigations: A Collaborative Analysis Across 6 States in the Northwest US. J Acquir Immune Defic Syndr. 2017;74 Suppl 2:S81-S87.
[PubMed Abstract] -

31. Centers for Disease Control and Prevention (CDC). Vital signs: HIV prevention through care and treatment--United States. MMWR Morb Mortal Wkly Rep. 2011;60:1618-23.
[MMWR] -

32. Centers for Disease Control and Prevention, Health Resources and Services Administration, National Institutes of Health, American Academy of HIV Medicine, Association of Nurses in AIDS Care, International Association of Providers of AIDS Care, the National Minority AIDS Council, and Urban Coalition for HIV/AIDS Prevention Services. Recommendations for HIV Prevention with Adults and Adolescents with HIV in the United States, 2014. December 11, 2014 (amended December 30, 2016)
[CDC] -

33. Mugavero MJ, Lin HY, Willig JH, et al. Missed visits and mortality among patients establishing initial outpatient HIV treatment. Clin Infect Dis. 2009;48:248-56.
[PubMed Abstract] -

34. Tripathi A, Youmans E, Gibson JJ, Duffus WA. The impact of retention in early HIV medical care on viro-immunological parameters and survival: a statewide study. AIDS Res Hum Retroviruses. 2011;27:751-8.
[PubMed Abstract] -

35. Ulett KB, Willig JH, Lin HY, et al. The therapeutic implications of timely linkage and early retention in HIV care. AIDS Patient Care STDS. 2009;23:41-9.
[PubMed Abstract] -

36. Althoff KN, Buchacz K, Hall HI, et al. U.S. trends in antiretroviral therapy use, HIV RNA plasma viral loads, and CD4 T-lymphocyte cell counts among HIV-infected persons, 2000 to 2008. Ann Intern Med. 2012;157:325-35.
[PubMed Abstract] -

37. Nelson JA, Kinder A, Johnson AS, et al. Differences in Selected HIV Care Continuum Outcomes Among People Residing in Rural, Urban, and Metropolitan Areas-28 US Jurisdictions. J Rural Health. 2016 Sep 13.[Eub ahead of print]
[PubMed Abstract] -

38. Dailey AF, Johnson AS, Wu B. HIV Care Outcomes Among Blacks with Diagnosed HIV - United States, 2014. MMWR Morb Mortal Wkly Rep. 2017;66:97-103.
[PubMed Abstract] -

39. Dasgupta S, Oster AM, Li J, Hall HI. Disparities in Consistent Retention in HIV Care - 11 States and the District of Columbia, 2011-2013. MMWR Morb Mortal Wkly Rep. 2016;65:77-82.
[PubMed Abstract] -

40. Schranz AJ, Barrett J, Hurt CB, Malvestutto C, Miller WC. Challenges Facing a Rural Opioid Epidemic: Treatment and Prevention of HIV and Hepatitis C. Curr HIV/AIDS Rep. 2018;15:245-254.
[PubMed Abstract] -

41. Thompson MA, Mugavero MJ, Amico KR, et al. Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. Ann Intern Med. 2012;156:817-33.
[PubMed Abstract] -

42. Dombrowski JC, Simoni JM, Katz DA, Golden MR. Barriers to HIV Care and Treatment Among Participants in a Public Health HIV Care Relinkage Program. AIDS Patient Care STDS. 2015;29:279-87.
[PubMed Abstract] -

43. Coyle RP, Schneck CD, Morrow M, et al. Engagement in Mental Health Care is Associated with Higher Cumulative Drug Exposure and Adherence to Antiretroviral Therapy. AIDS Behav. 2019;23:3493-502.
[PubMed Abstract] -

44. Mugavero MJ. Improving engagement in HIV care: what can we do? Top HIV Med. 2008;16:156-61.
[PubMed Abstract] -

45. Hartzler B, Dombrowski JC, Williams JR, et al. Influence of Substance Use Disorders on 2-Year HIV Care Retention in the United States. AIDS Behav. 2018;22:742-751.
[PubMed Abstract] -

46. Altice FL, Bruce RD, Lucas GM, et al. HIV treatment outcomes among HIV-infected, opioid-dependent patients receiving buprenorphine/naloxone treatment within HIV clinical care settings: results from a multisite study. J Acquir Immune Defic Syndr. 2011;56 Suppl 1:S22-32.
[PubMed Abstract] -

47. Meyer JP, Althoff AL, Altice FL. Optimizing care for HIV-infected people who use drugs: evidence-based approaches to overcoming healthcare disparities. Clin Infect Dis. 2013;57:1309-17.
[PubMed Abstract] -

48. Rumptz MH, Tobias C, Rajabiun S, et al. Factors associated with engaging socially marginalized HIV-positive persons in primary care. AIDS Patient Care STDS. 2007;21 Suppl 1:S30-9.
[PubMed Abstract] -

49. Mugavero MJ, Westfall AO, Cole SR, et al. Beyond Core Indicators of Retention in HIV Care: Missed Clinic Visits Are Independently Associated With All-Cause Mortality. Clin Infect Dis. 2014;59:1471-9.
[PubMed Abstract] -

50. Giordano TP, Gifford AL, White AC Jr, et al. Retention in care: a challenge to survival with HIV infection. Clin Infect Dis. 2007;44:1493-9.
[PubMed Abstract] -

51. Robertson M, Laraque F, Mavronicolas H, Braunstein S, Torian L. Linkage and retention in care and the time to HIV viral suppression and viral rebound - New York City. AIDS Care. 2014;27:260-7.
[PubMed Abstract] -

52. Bavinton BR, Pinto AN, Phanuphak N, et al. Viral suppression and HIV transmission in serodiscordant male couples: an international, prospective, observational, cohort study. Lancet HIV. 2018;5:e438-e447.
[PubMed Abstract] -

53. Rodger AJ, Cambiano V, Bruun T, et al. Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study. Lancet. 2019;393:2428-38.
[PubMed Abstract] -

54. Rodger AJ, Cambiano V, Bruun T, et al. Sexual Activity Without Condoms and Risk of HIV Transmission in Serodifferent Couples When the HIV-Positive Partner Is Using Suppressive Antiretroviral Therapy. JAMA. 2016;316:171-81.
[PubMed Abstract] -

55. Maulsby C, Jain KM, Weir BW, et al. The Cost and Threshold Analysis of Retention in Care (RiC): A Multi-Site National HIV Care Program. AIDS Behav. 2017;21:643-9.
[PubMed Abstract] -

56. Shah M, Risher K, Berry SA, Dowdy DW. The Epidemiologic and Economic Impact of Improving HIV Testing, Linkage, and Retention in Care in the United States. Clin Infect Dis. 2016;62:220-9.
[PubMed Abstract] -

57. Colasanti J, Sumitani J, Mehta CC, et al. Implementation of a Rapid Entry Program Decreases Time to Viral Suppression Among Vulnerable Persons Living With HIV in the Southern United States. Open Forum Infect Dis. 2018;5:ofy104.
[PubMed Abstract] -

58. Halperin J, Conner K, Butler I, et al. A Care Continuum of Immediate ART for Newly Diagnosed Patients and Patients Presenting Later to Care at a Federally Qualified Health Center in New Orleans. Open Forum Infect Dis. 2019;6:ofz161.
[PubMed Abstract] -

59. Koenig SP, Dorvil N, Dévieux JG, et al. Same-day HIV testing with initiation of antiretroviral therapy versus standard care for persons living with HIV: A randomized unblinded trial. PLoS Med. 2017;14:e1002357.
[PubMed Abstract] -

60. Mateo-Urdiales A, Johnson S, Smith R, Nachega JB, Eshun-Wilson I. Rapid initiation of antiretroviral therapy for people living with HIV. Cochrane Database Syst Rev. 2019;6:CD012962.
[PubMed Abstract] -

61. Willis S, Castel AD, Ahmed T, Olejemeh C, Frison L, Kharfen M. Linkage, engagement, and viral suppression rates among HIV-infected persons receiving care at medical case management programs in Washington, DC. J Acquir Immune Defic Syndr. 2013;64 Suppl 1:S33-41.

[PubMed Abstract] -

62. Higa DH, Marks G, Crepaz N, Liau A, Lyles CM. Interventions to improve retention in HIV primary care: a systematic review of U.S. studies. Curr HIV/AIDS Rep. 2012;9:313-25.
[PubMed Abstract] -

63. Gardner LI, Metsch LR, Anderson-Mahoney P, et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. AIDS. 2005;19:423-31.
[PubMed Abstract] -

64. Buchacz K, Chen MJ, Parisi MK, et al. Using HIV surveillance registry data to re-link persons to care: the RSVP Project in San Francisco. PLoS One. 2015;10:e0118923.
[PubMed Abstract] -

65. Centers for Disease Control and Prevention. Data to Care.
[CDC] -

66. Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum
[CDC] -

67. Gardner LI, Giordano TP, Marks G, et al. Enhanced personal contact with HIV patients improves retention in primary care: a randomized trial in 6 US HIV clinics. Clin Infect Dis. 2014;59:725-34.
[PubMed Abstract] -

68. Harris SK, Samples CL, Keenan PM, Fox DJ, Melchiono MW, Woods ER. Outreach, mental health, and case management services: can they help to retain HIV-positive and at-risk youth and young adults in care? Matern Child Health J. 2003;7:205-18.
[PubMed Abstract] -

69. Magnus M, Schmidt N, Kirkhart K, et al. Association between ancillary services and clinical and behavioral outcomes among HIV-infected women. AIDS Patient Care STDS. 2001;15:137-45.
[PubMed Abstract] -

70. Dombrowski JC, Ramchandani M, Dhanireddy S, Harrington RD, Moore A, Golden MR. The Max Clinic: Medical Care Designed to Engage the Hardest-to-Reach Persons Living with HIV in Seattle and King County, Washington. AIDS Patient Care STDS. 2018;32:149-156.
[PubMed Abstract] -

71. Dombrowski JC, Galagan SR, Ramchandani M, et al. HIV Care for Patients With Complex Needs: A Controlled Evaluation of a Walk-In, Incentivized Care Model. Open Forum Infect Dis. 2019;6:ofz294.
[PubMed Abstract] -

72. Metsch LR, Feaster DJ, Gooden L, et al. Effect of Patient Navigation With or Without Financial Incentives on Viral Suppression Among Hospitalized Patients With HIV Infection and Substance Use: A Randomized Clinical Trial. JAMA. 2016;316:156-70.
[PubMed Abstract] -

References

- Gardner LI, Marks G, Shahani L, et al. Assessing efficacy of a retention-in-care intervention among HIV patients with depression, anxiety, heavy alcohol consumption and illicit drug use. AIDS. 2016;30:1111-9.

[PubMed Abstract] -

- Giordano TP. Retention in HIV care: what the clinician needs to know. Top Antivir Med. 2011;19:12-6. [PubMed Abstract] -
- Hall HI, Gray KM, Tang T, Li J, Shouse L, Mermin J. Retention in care of adults and adolescents living with HIV in 13 U.S. areas. J Acquir Immune Defic Syndr. 2012;60:77-82. [PubMed Abstract] -
- Halperin J, Bean MC, Richey LE. Laboratory markers slightly overestimate retention in HIV care among newly diagnosed individuals. AIDS Care. 2016;28:1188-91. [PubMed Abstract] -
- Higa DH, Crepaz N, Mullins MM, et al. Strategies to improve HIV care outcomes for people with HIV who are out of care: a meta-analysis. AIDS. 2022;36:853-62. [PubMed Abstract] -
- Horstmann E, Brown J, Islam F, Buck J, Agins BD. Retaining HIV-infected patients in care: Where are we? Where do we go from here? Clin Infect Dis. 2010;50:752-61. [PubMed Abstract] -
- Jacks A, Wainwright DA, Salazar L, et al. Neurocognitive deficits increase risk of poor retention in care among older adults with newly diagnosed HIV infection. AIDS. 2015;29:1711-4. [PubMed Abstract] -
- Jain KM, Maulsby C, Brantley M, et al. Cost and cost threshold analyses for 12 innovative US HIV linkage and retention in care programs. AIDS Care. 2016;28:1199-204. [PubMed Abstract] -
- Johnson MO, Neilands TB, Koester KA, et al. Detecting Disengagement From HIV Care Before It Is Too Late: Development and Preliminary Validation of a Novel Index of Engagement in HIV Care. J Acquir Immune Defic Syndr. 2019;81:145-152. [PubMed Abstract] -
- Kay ES, Batey DS, Mugavero MJ. The HIV treatment cascade and care continuum: updates, goals, and recommendations for the future. AIDS Res Ther. 2016;13:35. [PubMed Abstract] -
- Laurence C, Wispelwey E, Flickinger TE, et al. Development of PositiveLinks: A Mobile Phone App to Promote Linkage and Retention in Care for People With HIV. JMIR Form Res. 2019;3:e11578. [PubMed Abstract] -
- Minick SG, May SB, Amico KR, et al. Participants' perspectives on improving retention in HIV care after hospitalization: A post-study qualitative investigation of the MAPPS study. PLoS One. 2018;13:e0202917. [PubMed Abstract] -
- Monroe AK, Lau B, Mugavero MJ, et al. Heavy Alcohol Use Is Associated With Worse Retention in HIV Care. J Acquir Immune Defic Syndr. 2016;73:419-425. [PubMed Abstract] -
- Philbin MM, Feaster DJ, Gooden L, et al. The North-South Divide: Substance Use Risk, Care Engagement, and Viral Suppression Among Hospitalized Human Immunodeficiency Virus-Infected Patients in 11 US Cities. Clin Infect Dis. 2019;68:146-9.

[PubMed Abstract] -

- Rebeiro PF, Gange SJ, Horberg MA, et al. Geographic Variations in Retention in Care among HIV-Infected Adults in the United States. PLoS One. 2016;11:e0146119.
[PubMed Abstract] -

- Rotheram-Borus MJ. Strategies to improve HIV care outcomes for people with HIV who are out of care: the need for well designed health systems. AIDS. 2022;36:899-900.
[PubMed Abstract] -

- Sauceda JA, Lisha NE, Ludwig-Barron N, et al. The Brief Human Immunodeficiency Virus (HIV) Index: A Rapid 3-Item Scale to Measure Engagement in HIV Care. Clin Infect Dis. 2023;77:425-7.
[PubMed Abstract] -

- Wohl AR, Ludwig-Barron N, Dierst-Davies R, et al. Project Engage: Snowball Sampling and Direct Recruitment to Identify and Link Hard-to-Reach HIV-Infected Persons Who Are Out of Care. J Acquir Immune Defic Syndr. 2017;75:190-197.
[PubMed Abstract] -

- Zuniga JA, Yoo-Jeong M, Dai T, Guo Y, Waldrop-Valverde D. The Role of Depression in Retention in Care for Persons Living with HIV. AIDS Patient Care STDS. 2016;30:34-8.
[PubMed Abstract] -

Figures

Figure 1 HIV Care Continuum

Source: Adapted from HRSA. HIV Care Continuum

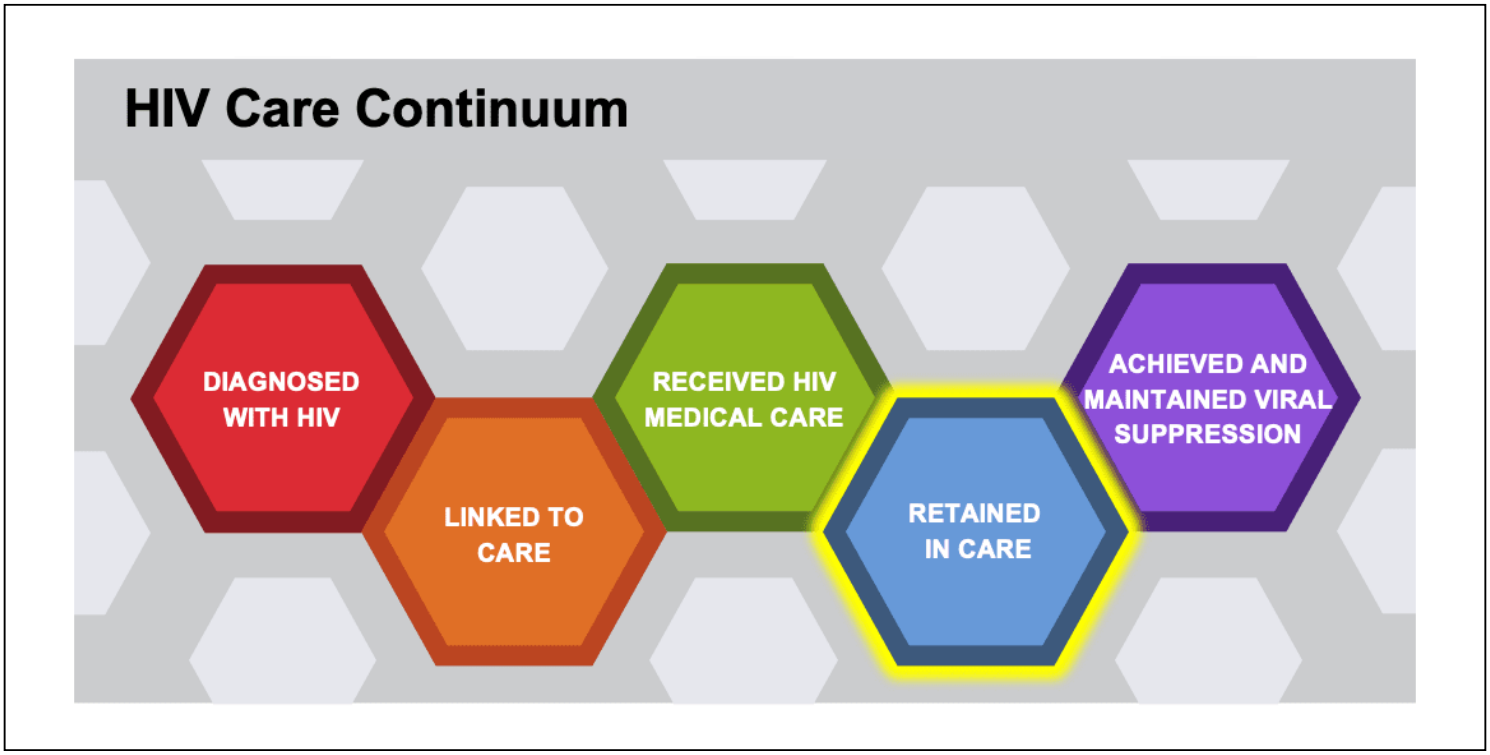

Figure 2 Prevalence-Based HIV Care Continuum, United States, 2022

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, 2022. HIV Surveillance Supplemental Report 2024; 29(No. 2). Published May 21, 2024

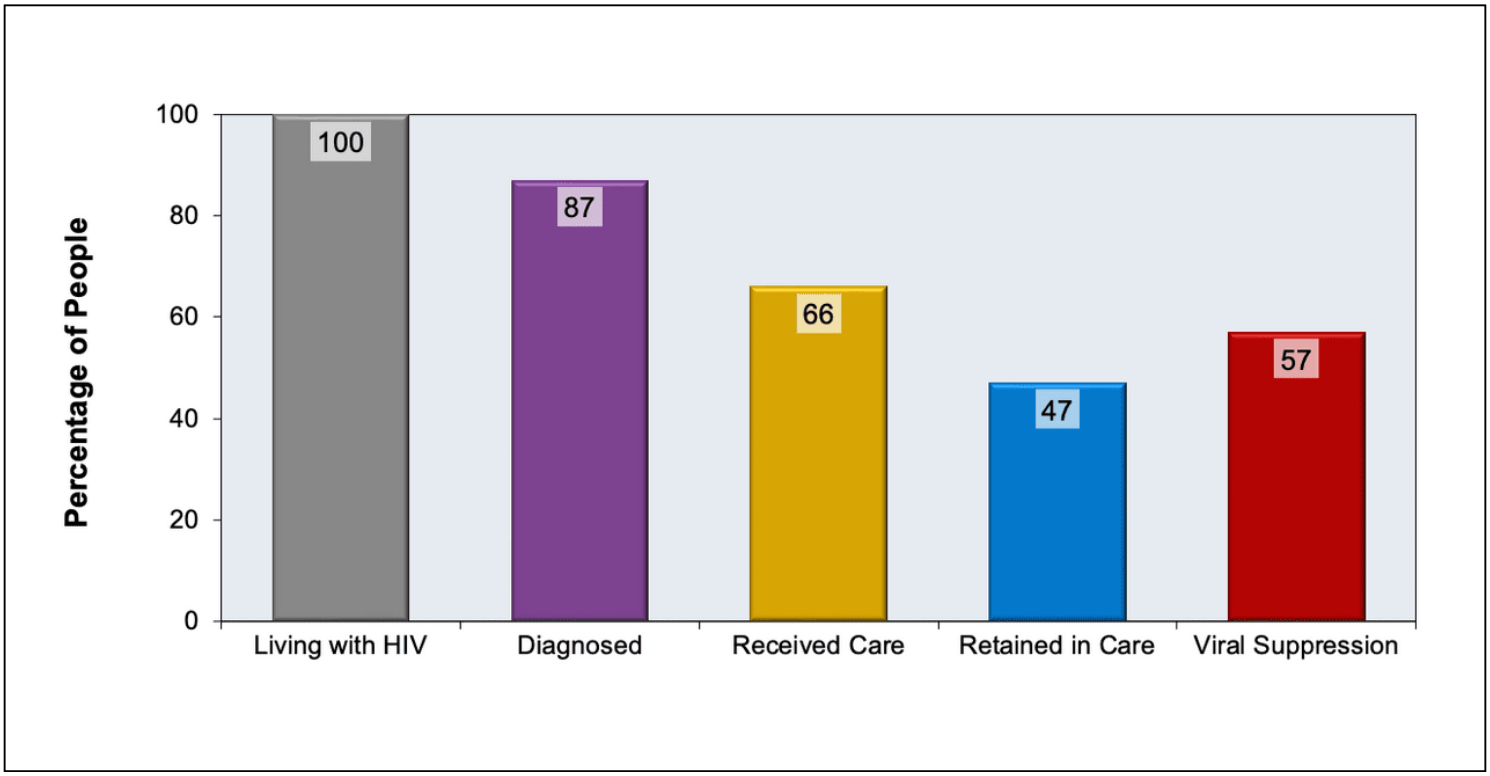

Figure 3 Retention in HIV Medical Care, United States, 2010 through 2021

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, HIV Surveillance Supplemental Reports.

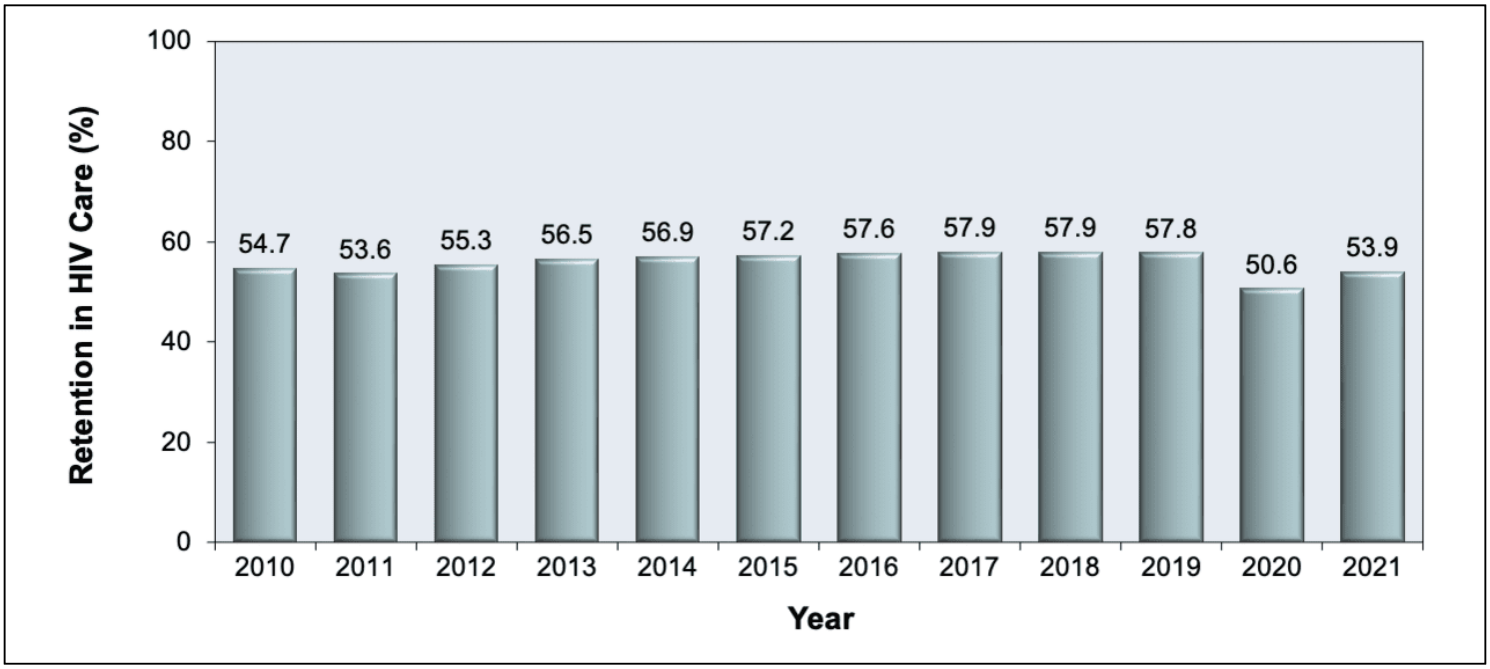

Figure 4 HIV Retention in Care

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, 2022. *HIV Surveillance Supplemental Report* 2024; 29(No. 2). Published May 21, 2024

This is a dynamic visualization. Please visit our website to experience this dynamic content.

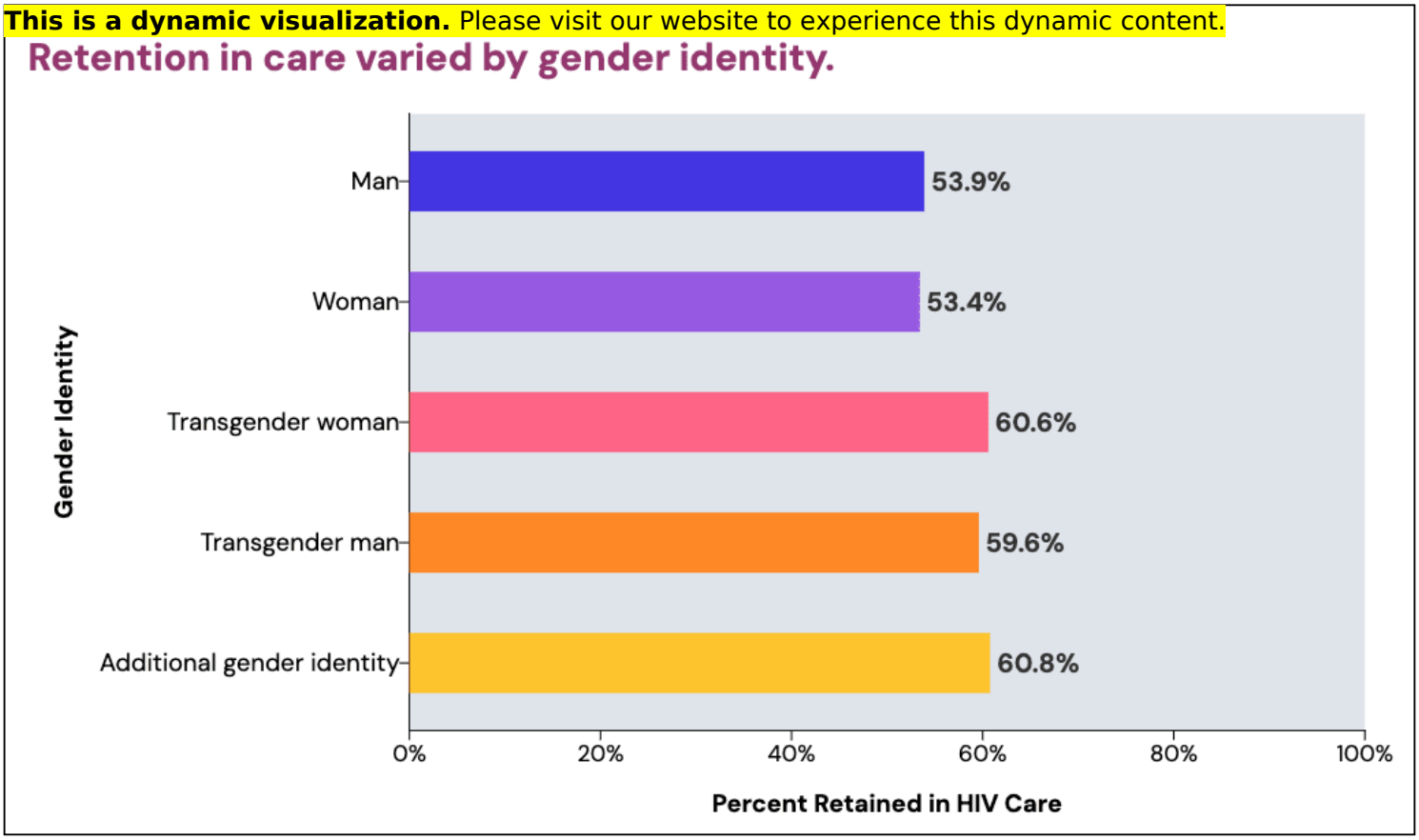

Figure 5 Retention in HIV Medical Care in Ryan White Program Clinics, 2019-2023

Source: Health Resources and Services Administration. Ryan White HIV/AIDS Program: Annual Data Report. Ryan White HIV/AIDS Program Services Report 2023. December 2024:1-94.

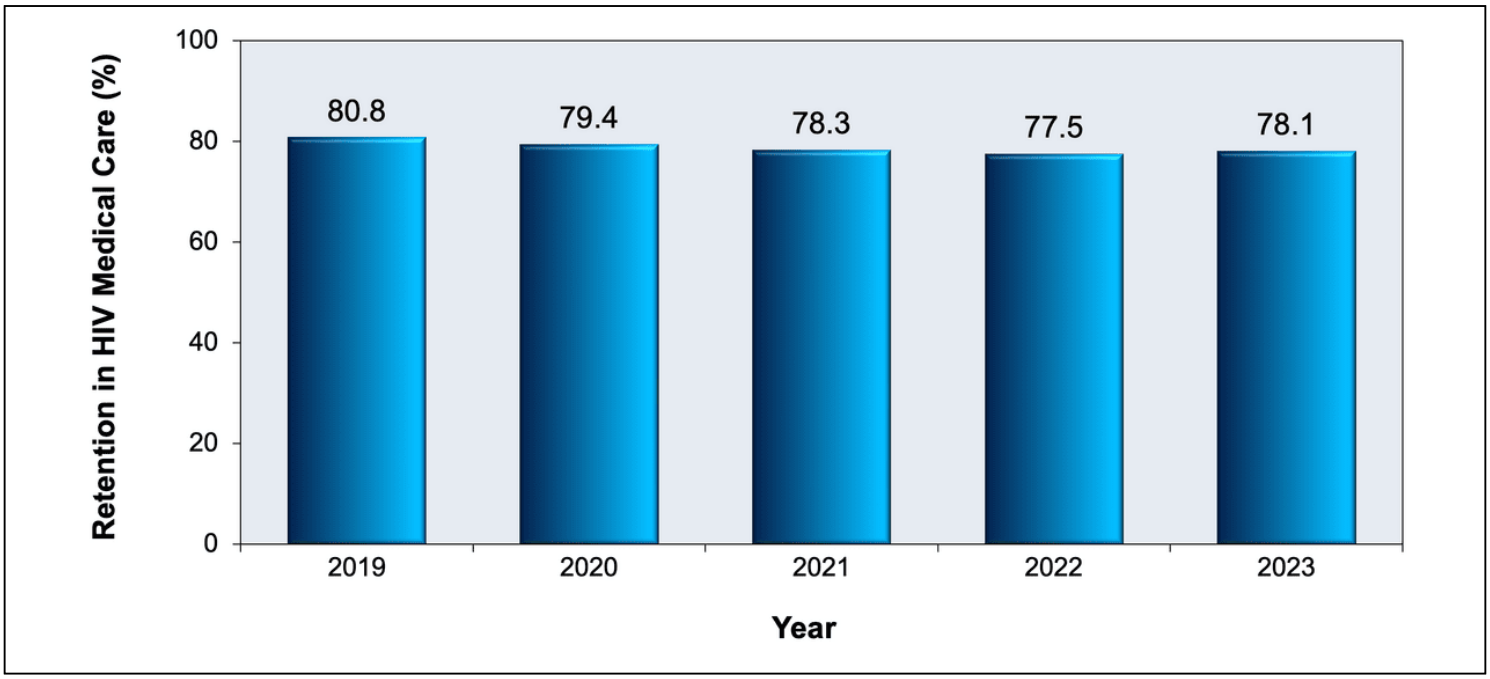

Figure 6 Correlation of Retention in HIV Care and Mortality Risk

Based on visits in 4 intervals: Optimal = 4; Suboptimal = 3; Sporadic = 1–2; Dropout = None

Source: Tripathi A, Youmans E, Gibson JJ, Duffus WA. The impact of retention in early HIV medical care on viro-immunological parameters and survival: a statewide study. AIDS Res Hum Retroviruses. 2011;27:751-8.

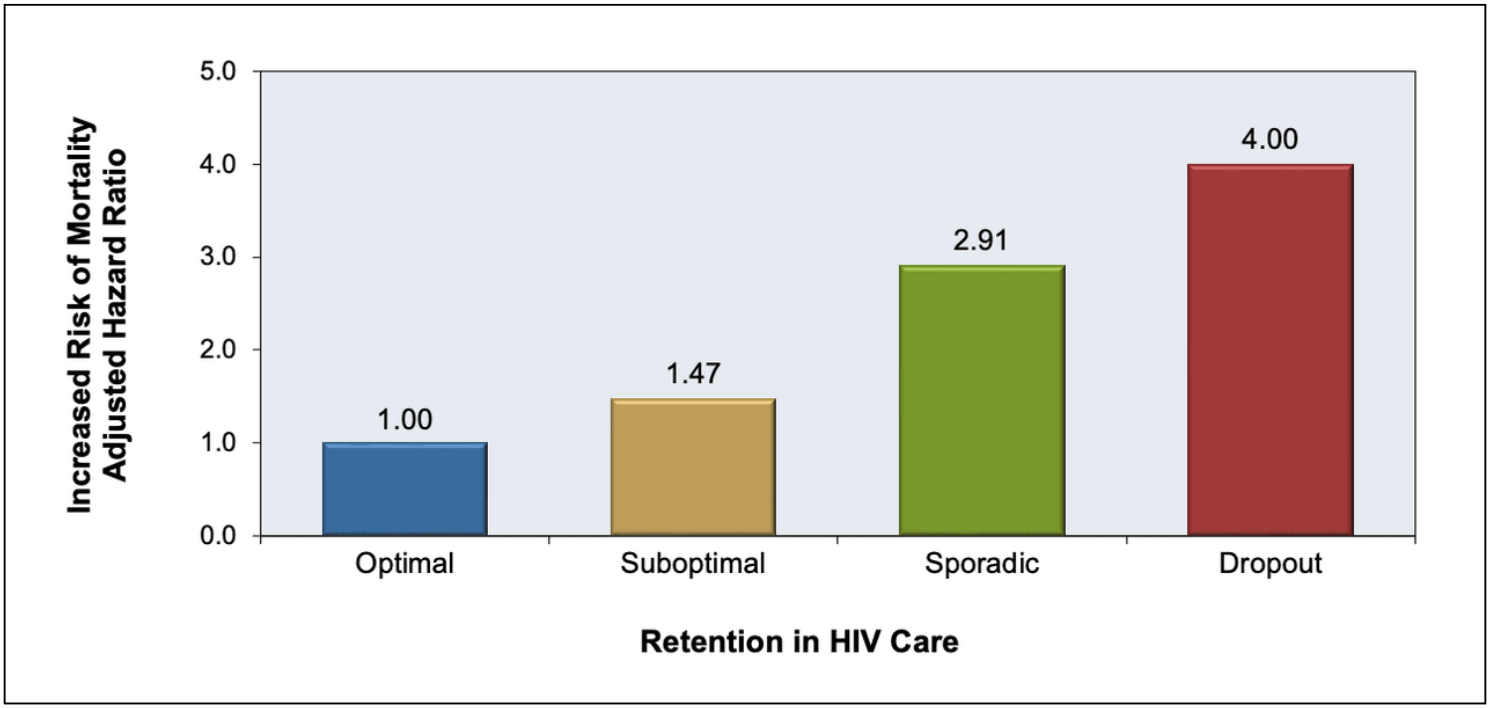

Figure 7 Estimated HIV Transmission by Awareness of Status and Stages of HIV Care Continuum, United States, 2016

The estimated number of HIV transmissions in 2016 resultant of persons with a known HIV diagnosis but who were not in care was 16,500, which was approximately 43% of all new HIV transmissions that year.

Source: Li Z, Purcell DW, Sansom SL, Hayes D, Hall HI. Vital Signs: HIV transmission along the continuum of care - United States, 2016. MMWR Morb Mortal Wkly Rep. 2019;68:267-72.

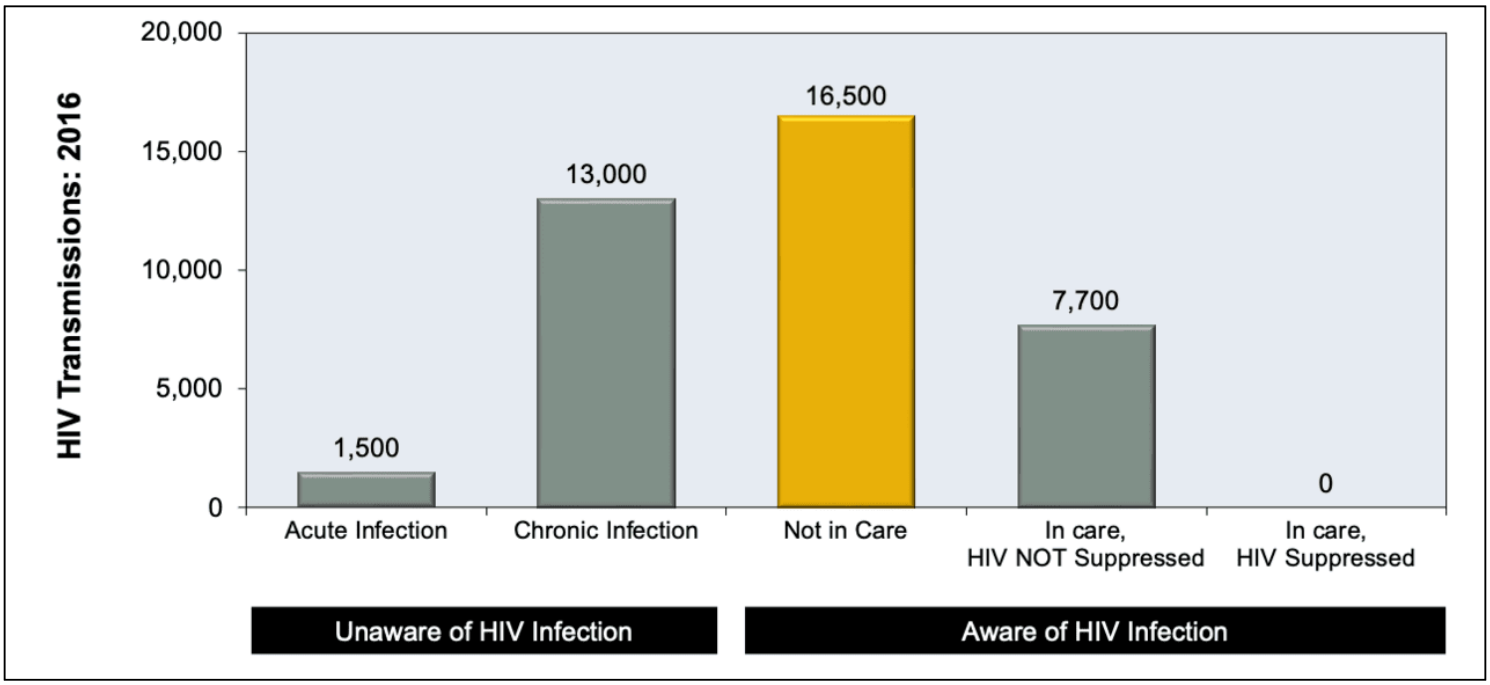

Figure 8 (Image Series) - Data to Care Models (Image Series) - Figure 8 (Image Series) - Data to Care Models
Image 8A: Health Department Model

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.

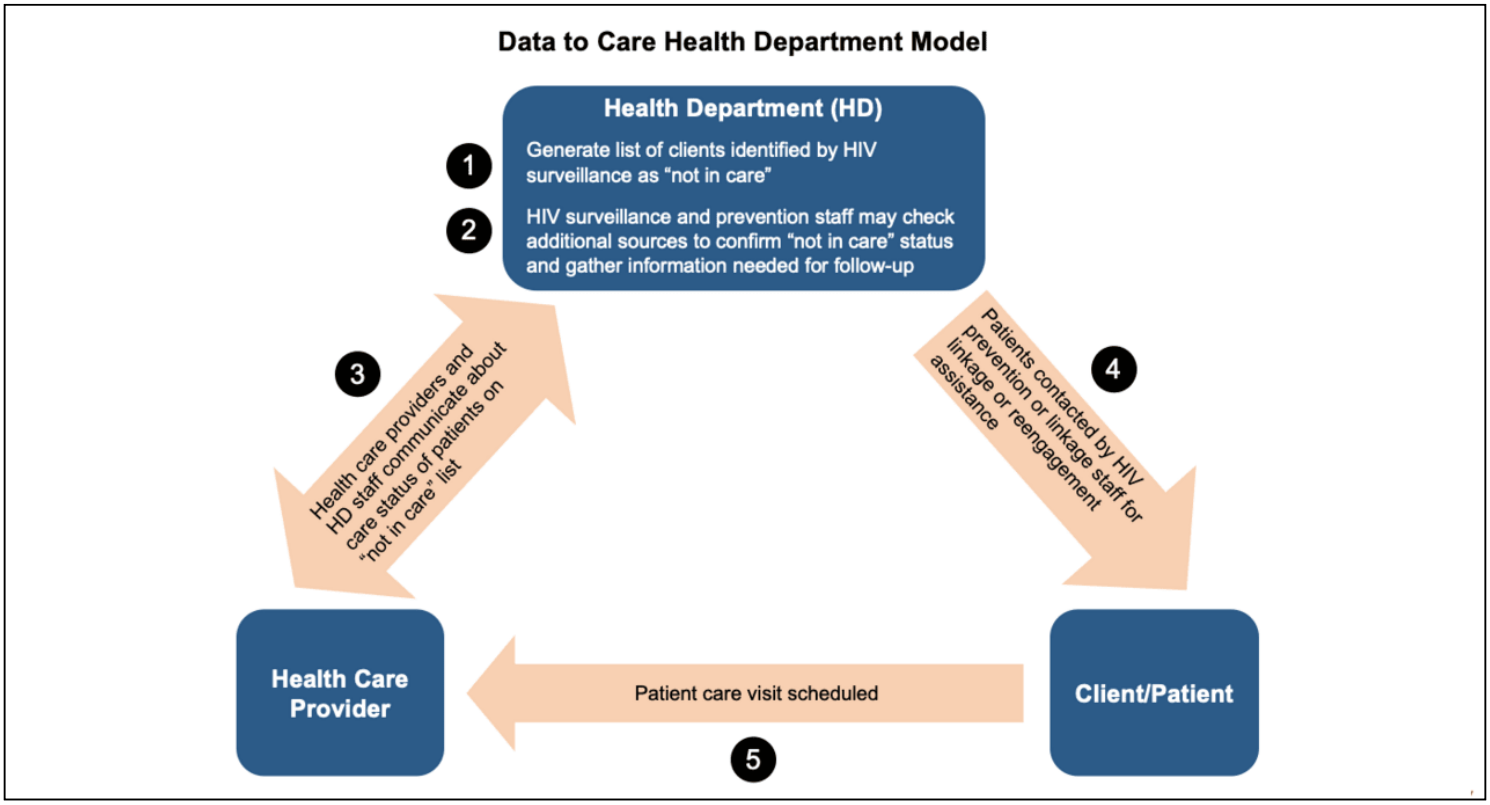

Figure 8 (Image Series) - Data to Care Models
Image 8B: Health Care Provider Model

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.

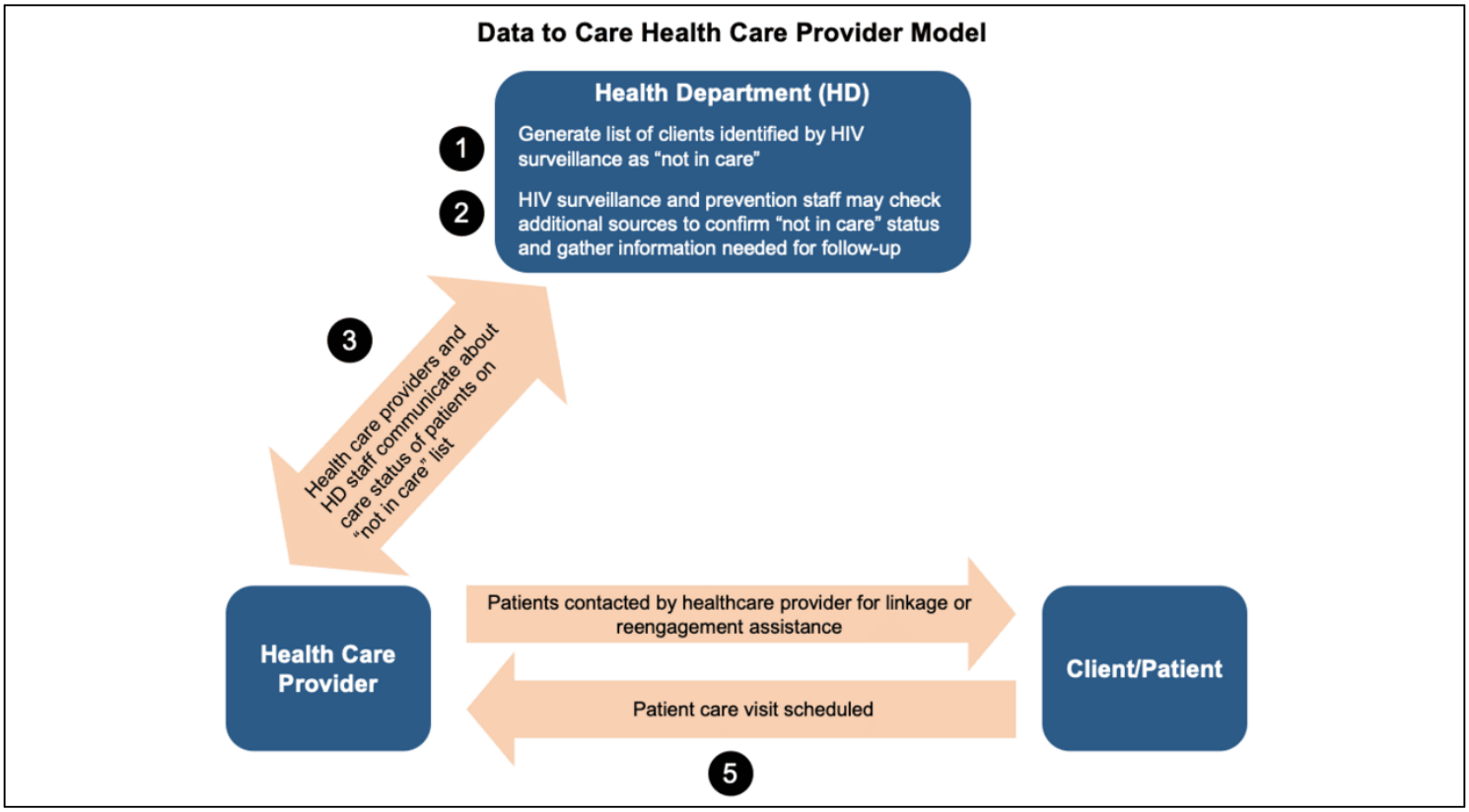

Figure 8 (Image Series) - Data to Care Models
Image 8C: Combination Health Department/Health Care Provider Model

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.

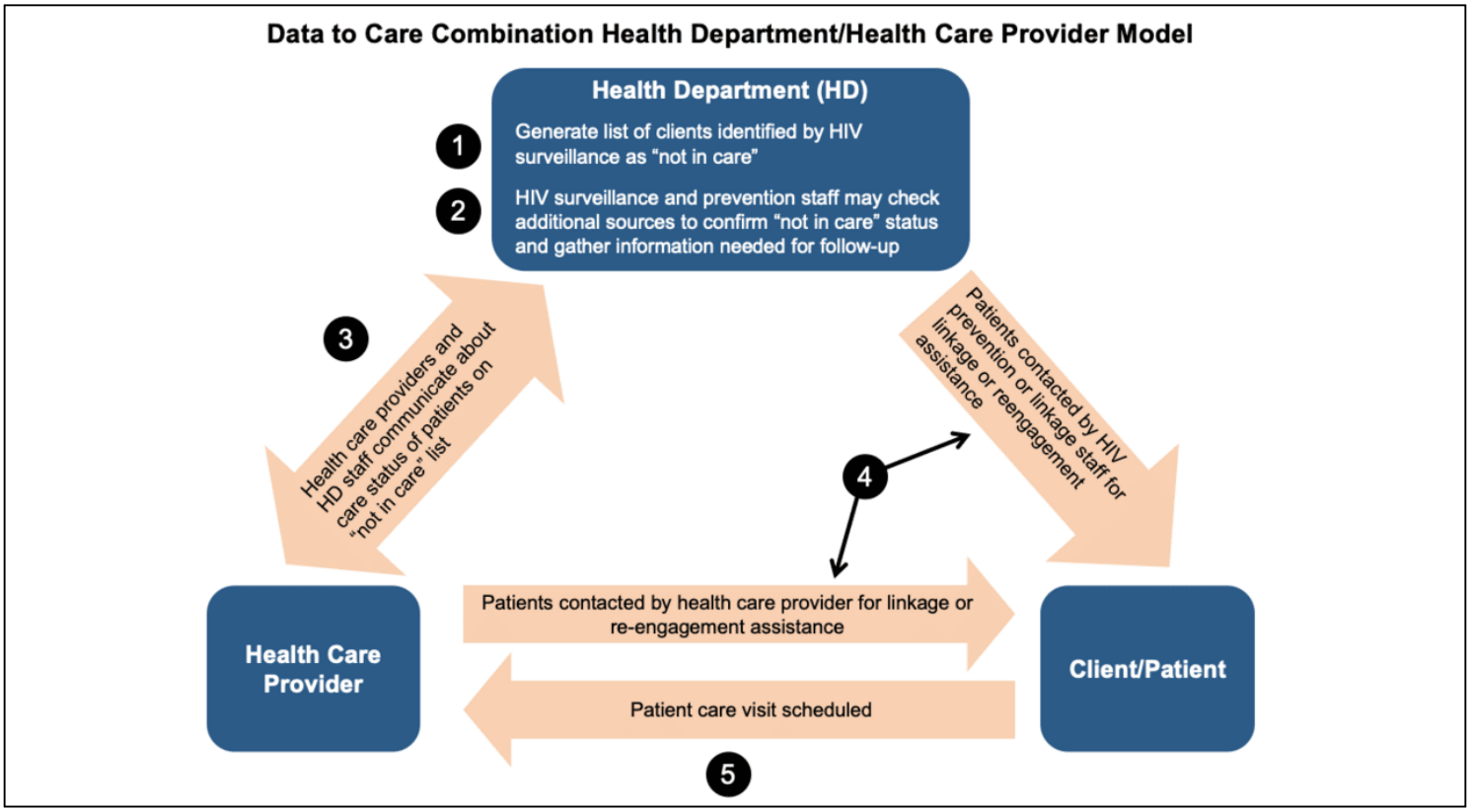

Figure 9 Project Hope: Effect of Patient Navigation with or without Financial Incentives on Viral Suppression

Source: Metsch LR, Feaster DJ, Gooden L, et al. Effect of Patient Navigation With or Without Financial Incentives on Viral Suppression Among Hospitalized Patients With HIV Infection and Substance Use: A Randomized Clinical Trial. JAMA. 2016;316:156-70.