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Retention in HIV Care

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Module 2: Basic HIV Primary Care
Lesson 8: Retention in HIV Care

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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] More formal definitions and measurements have utilized required follow-up at certain intervals to define retention in care; these definitions have typically conceptualized retention in care based on appointments missed or medical visits attended at regularly defined intervals.[11]

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, spanning from persons unaware of their HIV status to those fully engaged in HIV care.[12] 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).[13,14] 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. The following summarizes current estimates for the HIV Care Continuum in 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).[15] 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.[15]

Evaluation of Retention in Care

Methods Used to Estimate Retention in HIV Medical Care

Multiple methods exist for estimating retention in HIV medical care in the United States. The CDC and the National HIV/AIDS Strategy use laboratory criteria, whereas HRSA and the Institute of Medicine definitions focus on clinic visits.[14,16,17,18]

- **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.[17] The terms retention in care and receipt of HIV medical care should not be used interchangeably.
- **Health Resources and Services Administration**: Retention in HIV medical care has been defined by HRSA as persons diagnosed with HIV who had at least 2 medical visit dates that were at least 90 days apart in the measurement year.[14,16] Several modifications have been made by HRSA to this definition, including changing the latest date allowed for the first visit of the year from July 1 to September 1.
- **Institute of Medicine**: The Institute of Medicine has defined retention in HIV medical care as at least 2 medical visits every 12 months, with a minimum of 90 days between visits.[18]
- **National HIV/AIDS Strategy**: The National HIV/AIDS strategy utilizes the same definition for retention in HIV medical care as used by the CDC—at least two CD4 cell counts or viral load tests performed at least 3 months apart during the year of evaluation.[9,17]

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.[20]

- **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.

HRSA Performance Measures Related to Retention in HIV Medical Care

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.[21] These HRSA HAB performance measures help guide, shape, and enhance the delivery and quality of care. The main HRSA performance measures related to retention in care are HIV medical visit frequency and gaps in medical visits.[21]

- **HIV Medical Visit Frequency**: Percentage of persons diagnosed with HIV, regardless of age, who had at least one medical visit in each 6-month period of the 24-month measurement period, with a minimum of 60 days between medical visits.[21]
- **Gaps in Medical Visits**: Percentage of persons diagnosed with HIV, regardless of age, who did not have a medical visit in the last 6 months of the measurement year.[21]
- **Annual Retention in Care**: In 2019, HRSA released an update defining annual retention as the "percentage of patients, regardless of age, with a diagnosis of HIV who had at least 2 encounters within the 12-month measurement year."[21] Unlike previous measures where the patient needed two encounters with a medical provider to meet the measure, HRSA has recognized that many patients with HIV may be stable enough where only one office visit with a medical provider is needed annually.[21] Therefore, as long as 90 days are between encounters, one encounter needs to be with a provider with prescribing privileges, and the second can be a viral load test.[21]

For the purpose of these performance measures, the time frame of 6 months was determined by clinical expert consensus to allow for patients who are well controlled clinically and stable on their current regimen. It is important to note that persons with HIV may need to be seen at more frequent intervals as dictated by their current health status.

Estimating Retention in HIV Medical Care in the United States

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).[15] 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).[15] Based on HIV surveillance data in the United States for the year 2022, the overall percentage of people with HIV in the United States who were retained in medical care was 53.8%; the criteria for retention in care was at least 2 CD4 cell counts or HIV RNA levels performed at least 3 months apart during the year of evaluation.[15] Since 2010, the percentage of people with HIV retained in care has remained relatively stable, ranging from 50 to 58% (Figure 4).[15,17,19,22] Retention rates were lower in people 25–44 years of age, and they varied significantly by race/ethnicity.[15] Retention rates were similar in men (53.9%) and women (53.4%).[15]

Retention in Care in Ryan White Clinics

From 2013 through 2021, retention in HIV medical care among Ryan White HIV/AIDS (non-ADAP) has consistently been in the 78 to 82% range.[16,23] For these data, retention in care is defined as 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; retention in HIV care was based on data for persons 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 (Figure 5).[16,23]

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.[17,20,24] 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.[25,26,27,28,29] These studies, as outlined below, emphasize the need for revised surveillance techniques to allow for better estimates of retention in care.[30]

- 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.[28]
- 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.[29]
- 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.[31]

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.[32] 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.[33,34,35,36,37] 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.[15]

- **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.[38] 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).[15]
- **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.[15]
- **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.[35,39,40,41] Further, these earlier studies showed that Black men have low rates of retention in HIV medical care.[39,40] 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.[15]
- **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.[42] 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.[43,44,45] 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.[36]
- **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.[44,46,47] 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.[48,49]
- **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.[34]
- **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.[50]

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.[34]
- 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.[51]
- 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.[52]
- 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.[35] 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).[35]

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.[1,7,8,53] 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.[54,55,56] 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.[57,58]

Strategies for Improving 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.[59,60,61,62] There are several 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. In a recent study, a group of investigators developed and validated a patient-centered questionnaire at several Centers for AIDS Research Network of Integrated Clinical Systems (CNIS) clinics aimed at identifying perceptions of engagement.[63] Furthermore, 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.[64,65,66] 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.[12] 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.[29,31,67] This approach is now commonly referred to as Data to Care (D2C) and has been recommended by the CDC.[68,69] 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.[70]
- **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.[64,66,71,72]
- **Walk-In, Incentivized Care Model**: In 2015, a collaborative effort between Seattle-King County Public Health and a large Ryan White 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.[73,74] 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.[73,74] 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.[73,74]
- **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.[75] 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).[75]

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.[43] 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.[20,52]
- **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%).[66] 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.[52] 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.[35]
- **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.[43]

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.
- Clinicians should identify risk factors for decreased retention in care and develop strategies to increase engagement and achieve viral suppression.
- 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.
- 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.

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Figures

Figure 1 HIV Care Continuum

Source: Adapted from HRSA. HIV Care Continuum

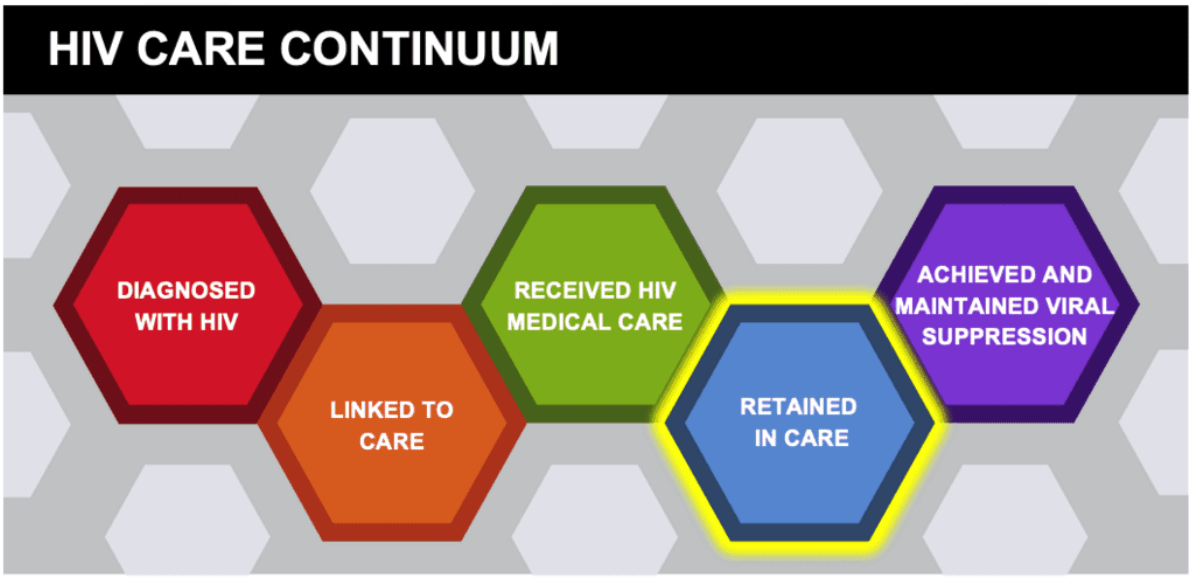


Figure 2 Prevalence-Based HIV Care Continuum, United States, 2022

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

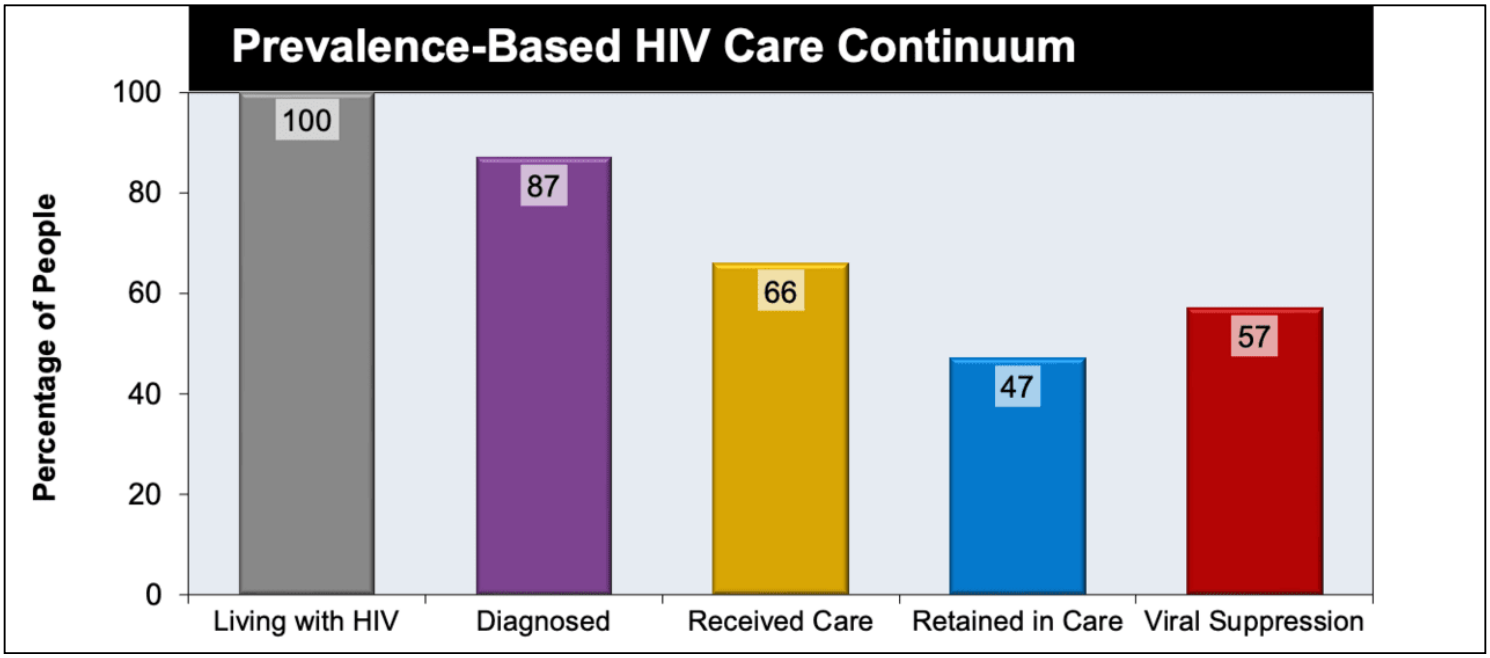


Figure 3 Retention in HIV Medical Care, United States, 2010 through 2021

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.

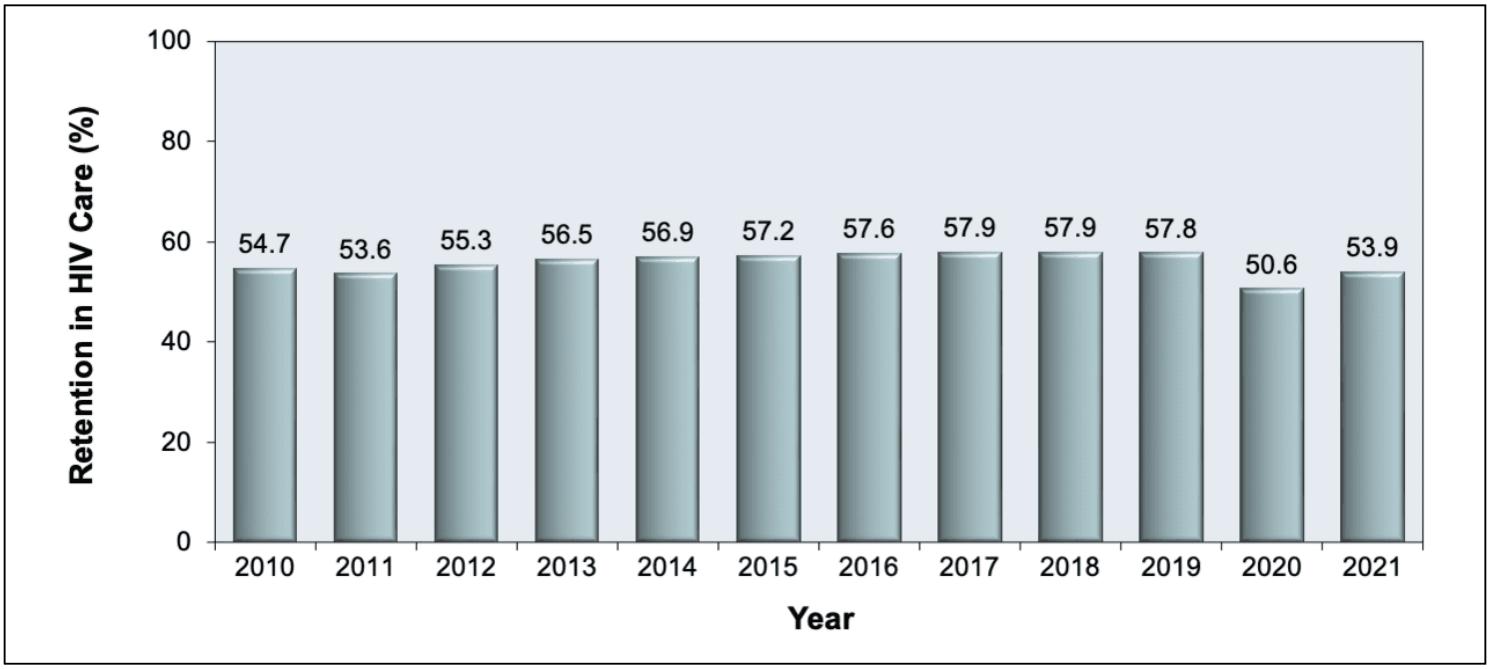


Figure 4 HIV Retention in Care

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.

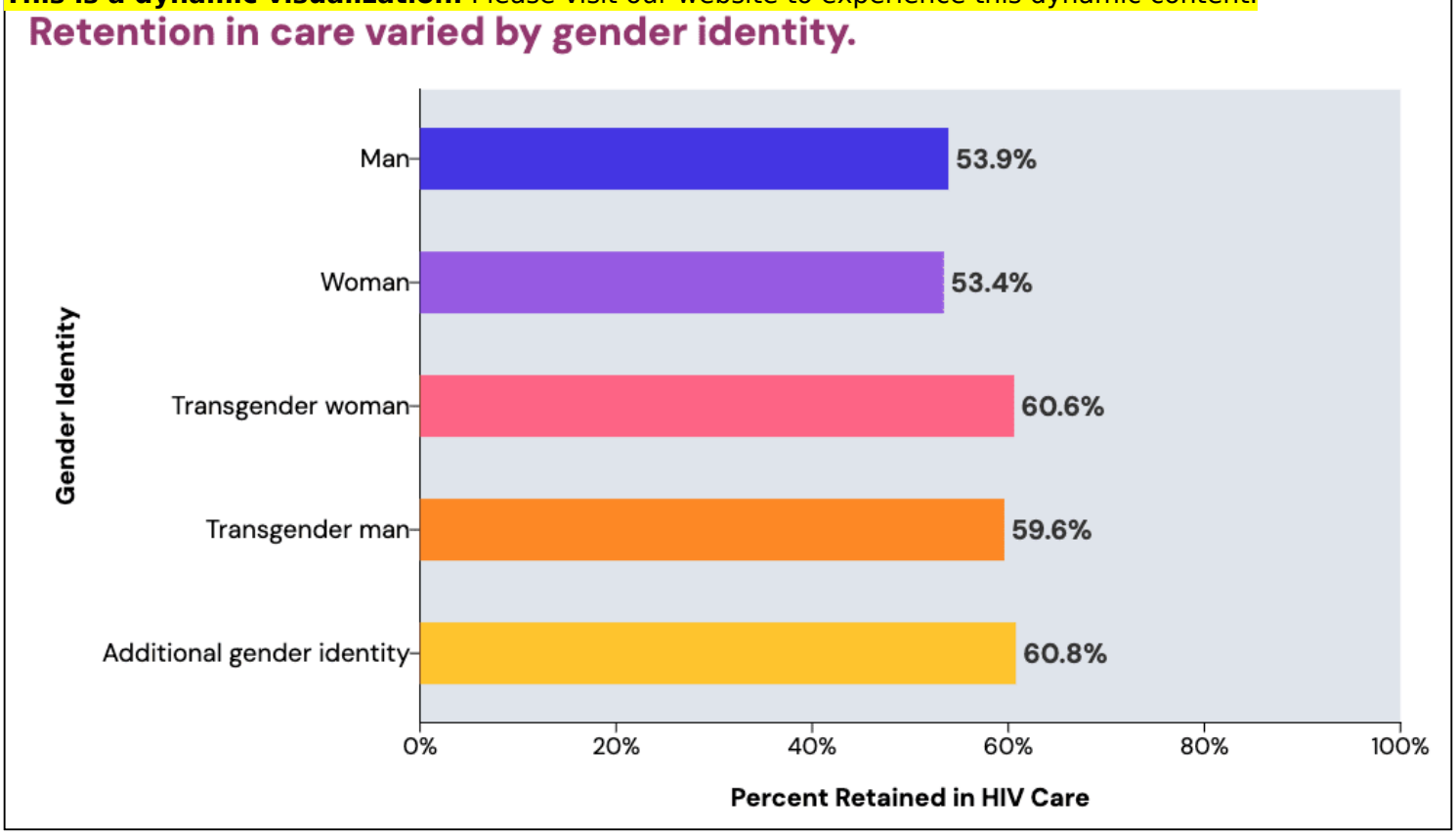


Figure 5 Retention in HIV Medical Care in Ryan White Clinics, 2013-2021

Source: Health Resources and Services Administration. Ryan White HIV/AIDS Program: Annual Client-Level Data Report. Ryan White HIV/AIDS Program Services Report 2021. December 2022:1-147.

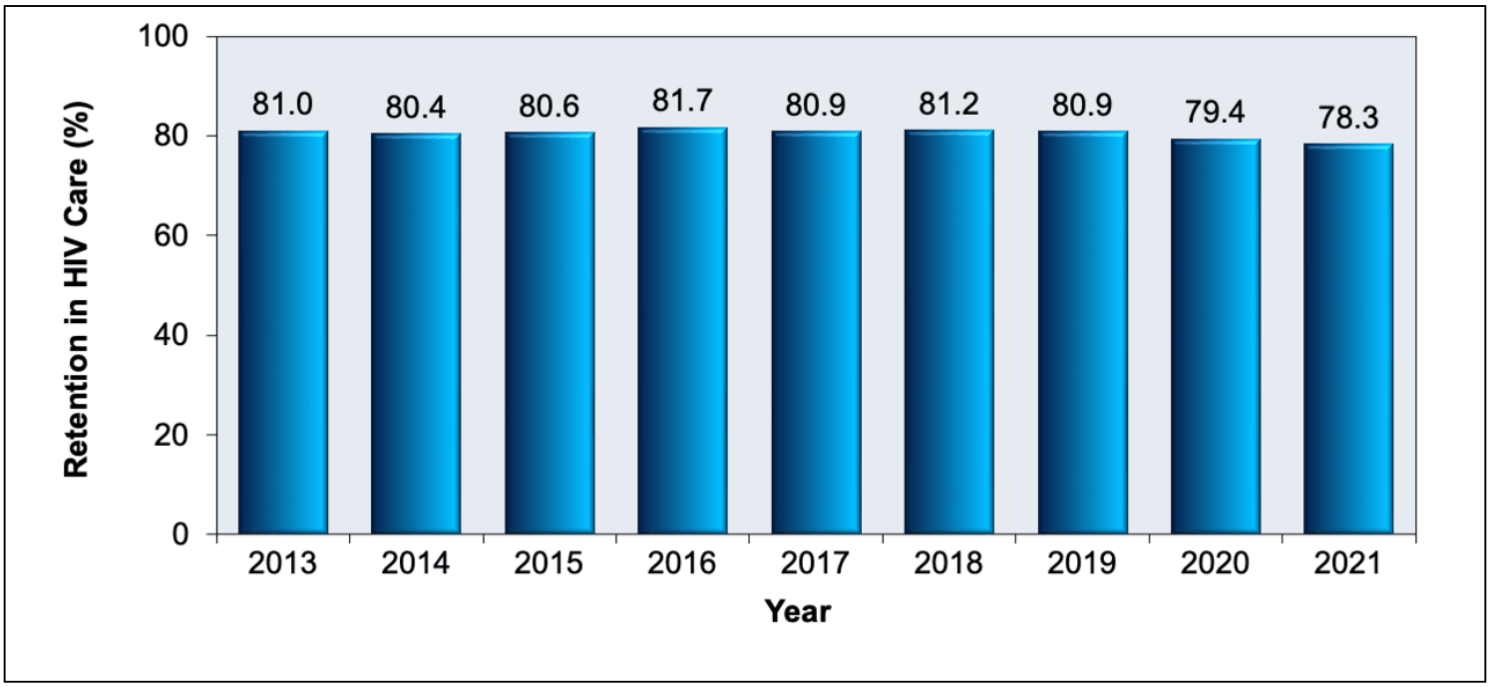


Figure 6 Correlation of Retention in HIV Care and Mortality Risk

Optimal = 4 visits in 4 intervals; Suboptimal = 3 visits in 4 intervals; Sporadic = 1-2 visits in 4 intervals; Dropout = No visits in 4 intervals

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.

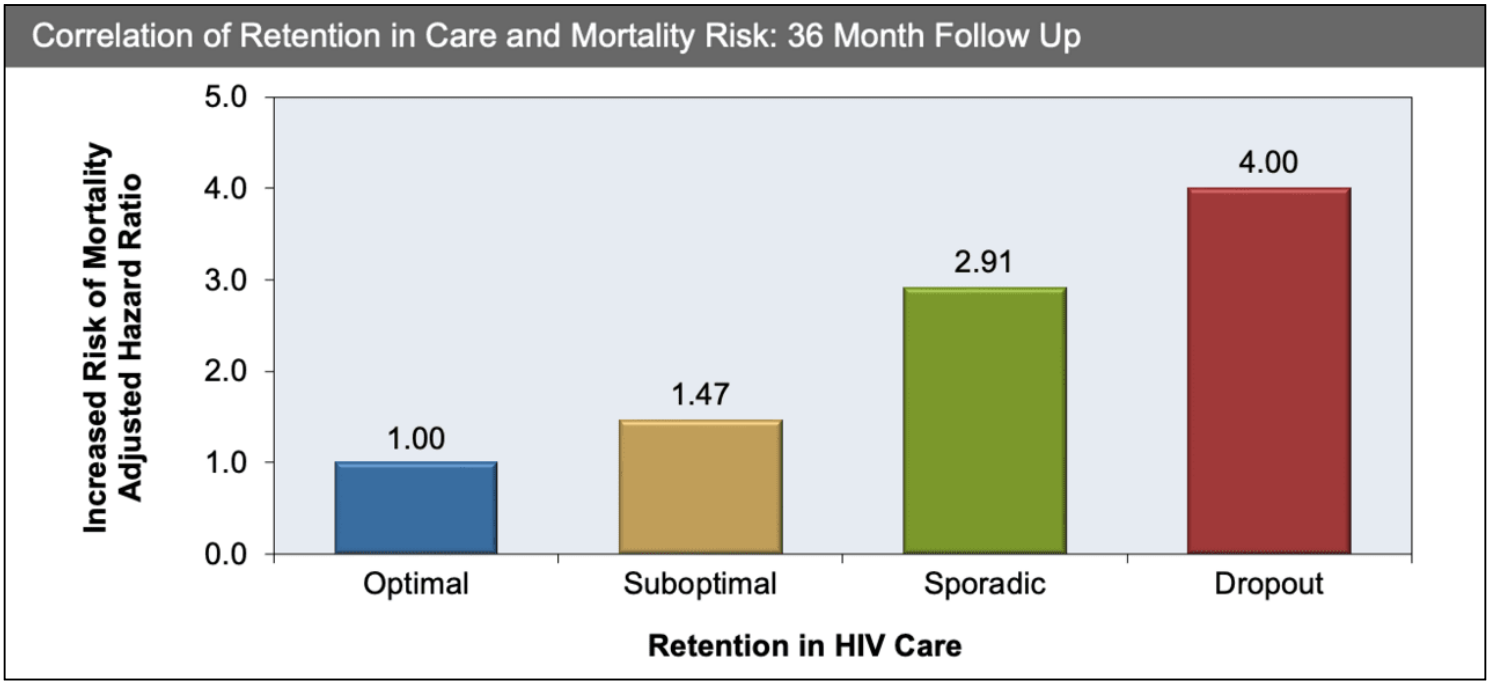


Figure 7 Estimated HIV Transmission by Awareness of Status and Stages of HIV Care Continuum, United States, 2016

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.

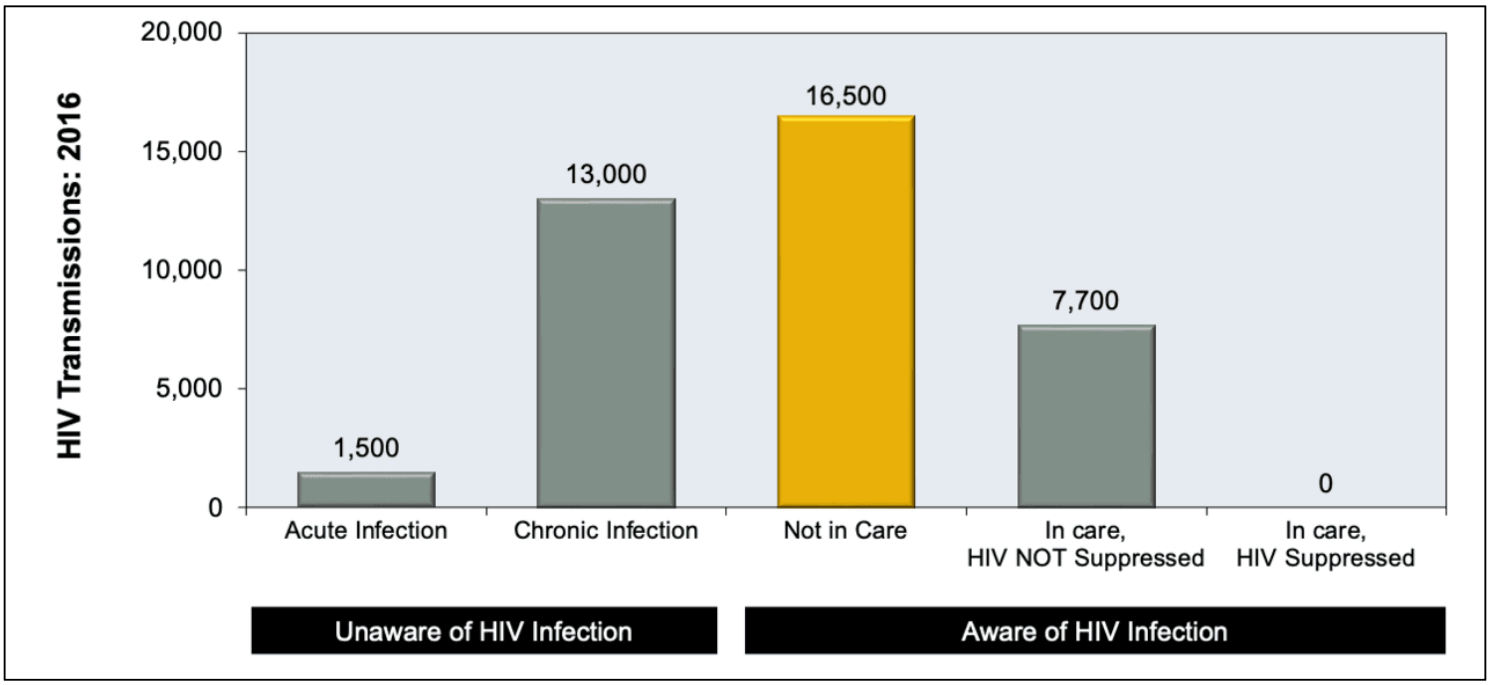


Figure 8 (Image Series) - Data to Care Models (Image Series) - Figure 8 (Image Series) - Data to Care Models
Image 8A: Health Department Model

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

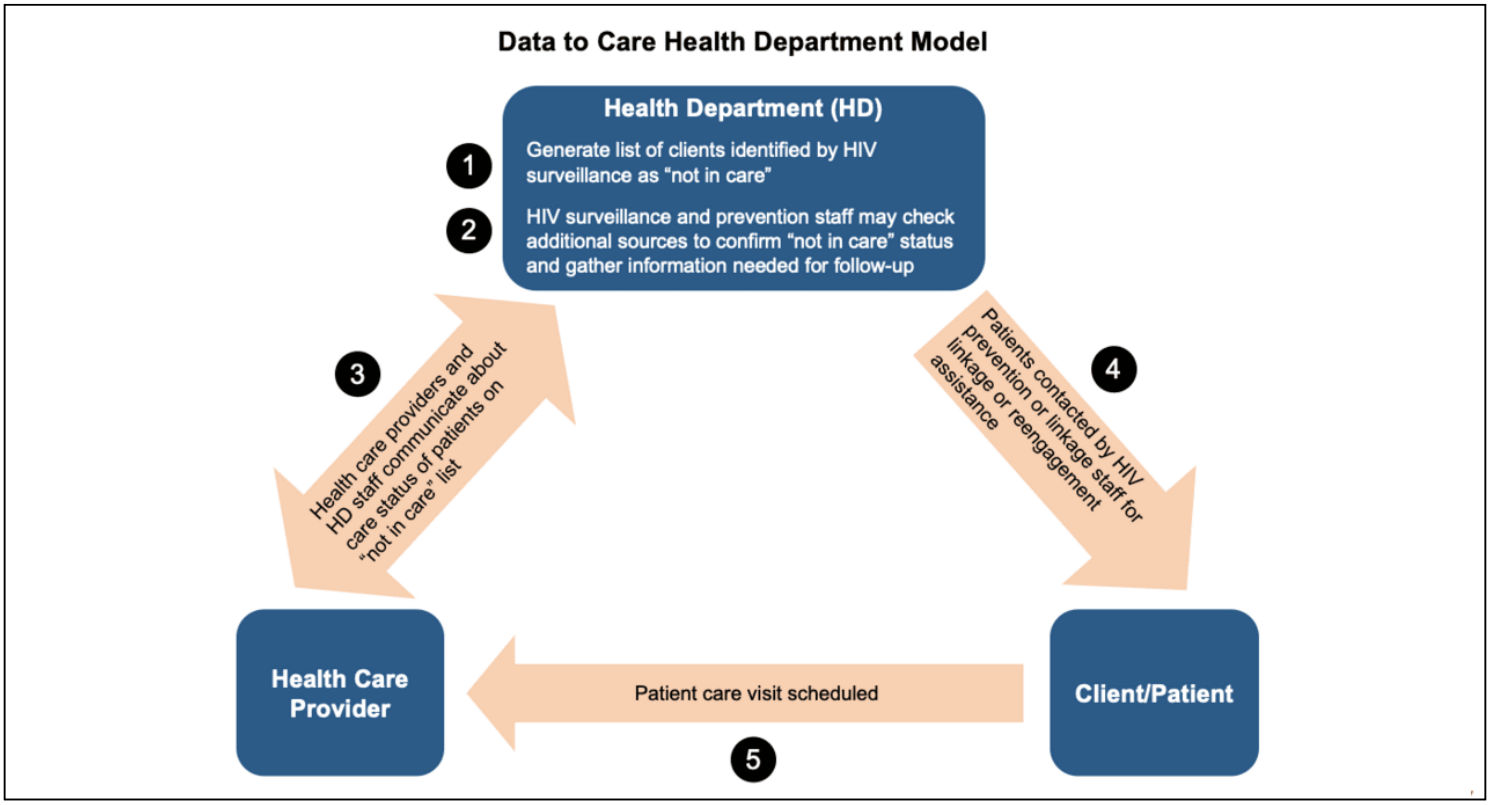


Figure 8 (Image Series) - Data to Care Models
Image 8B: Health Care Provider Model

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

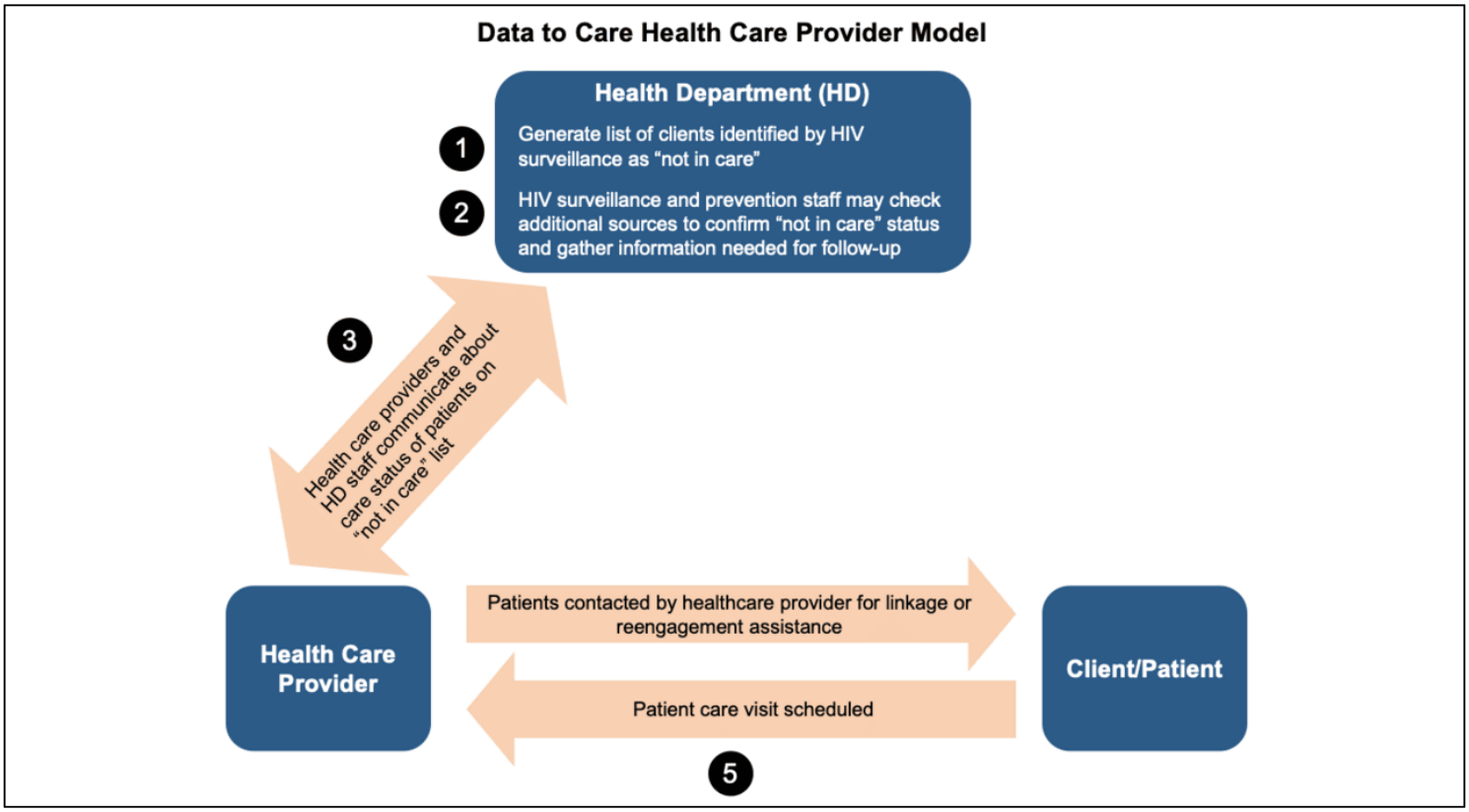


Figure 8 (Image Series) - Data to Care Models
Image 8C: Combination Health Department/Health Care Provider Model

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

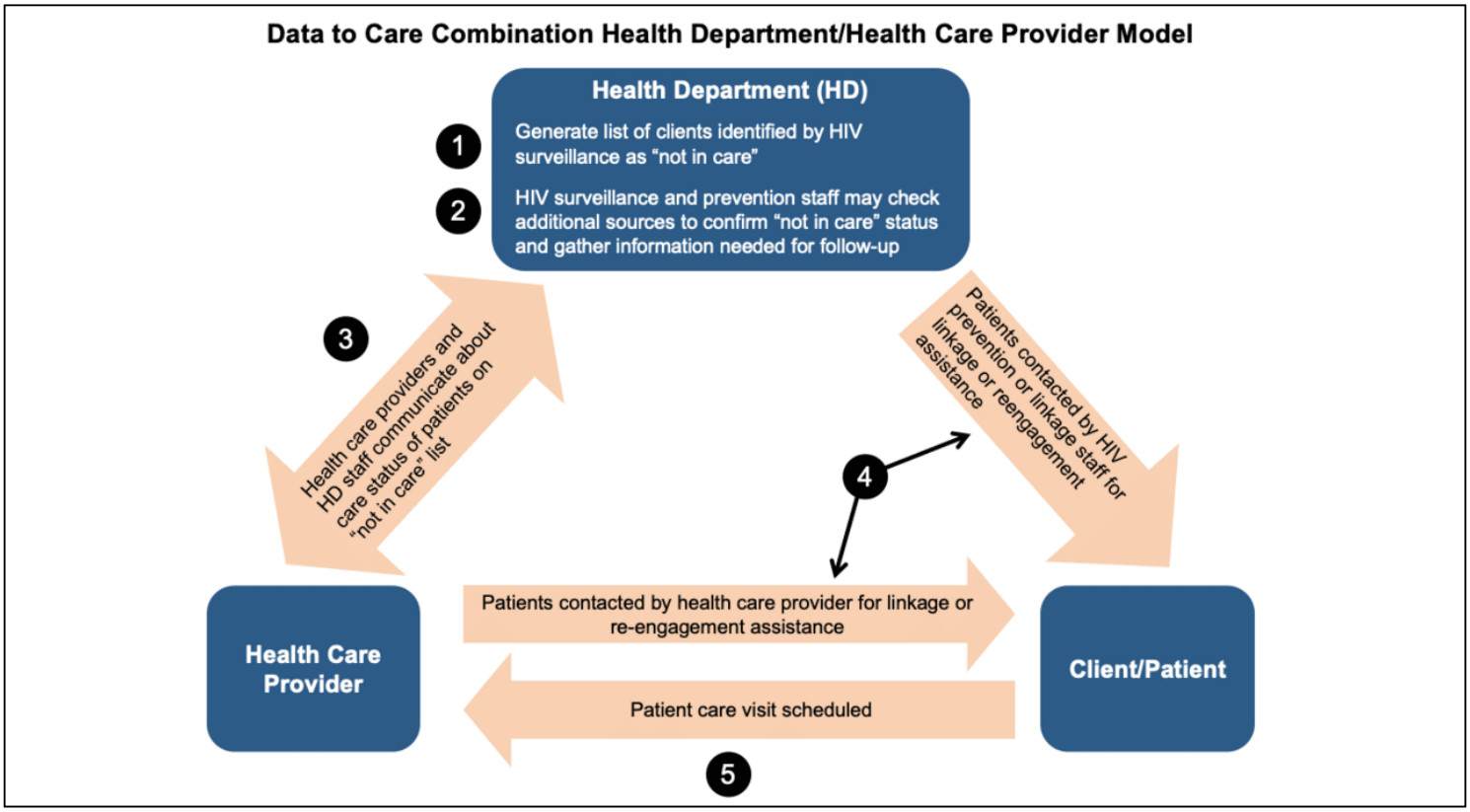
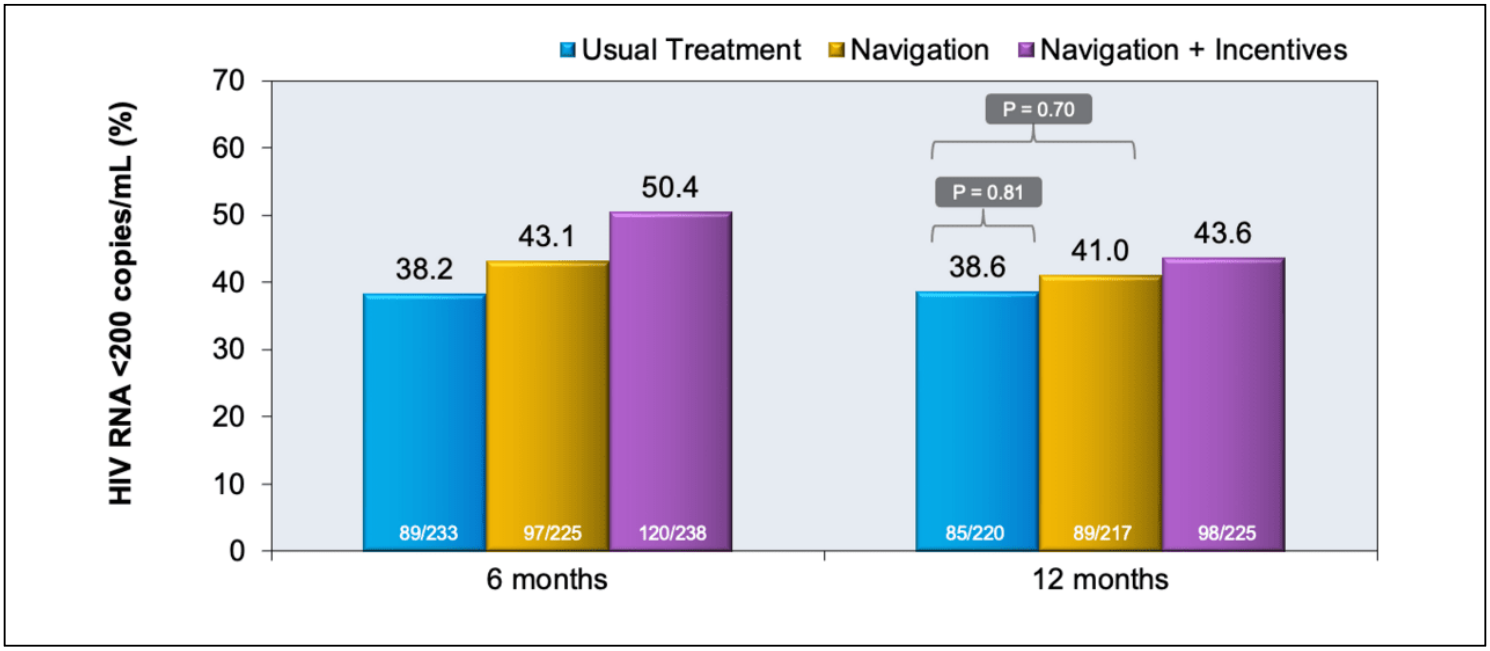


Figure 9 Project Hope: Effect of Patient Navigation with or without Financial Incentives on Viral Suppression

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.