Retention in HIV Care

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

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Introduction and Definitions

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. Despite tremendous advances in HIV treatment, a significant proportion of persons with HIV do not consistently receive antiretroviral therapy, often due to poor engagement in long-term clinical care. Recent work has shown that poor retention in HIV medical care serves as a major barrier for optimal HIV care and correlates with poor outcomes and increased transmission of HIV.\[1,2,3,4\] In contrast, good retention in care correlates 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.\[10\]

Definitions

The following definitions are important to understand when evaluating and addressing issues related to retention in care.

- **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 infection status to those fully engaged in HIV care (Figure 1).\[11\] The Engagement in HIV Care model was modified and adapted by HRSA and now is prominently known as the HRSA 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 2).\[12,13\] 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 of the stages included in the HIV Care Continuum serve as key benchmark indicators in the National HIV/AIDS Strategy for the United States.

- **HIV Care Cascade**: The HIV care cascade quantitatively evaluates the HIV Care Continuum by estimating the number and proportion of individuals within each stage of the HIV care continuum; these quantitative estimates have been used to better understand weaknesses in the HIV care system. The initial model for the HIV care cascade in the United States, which was developed by Gardner and colleagues, showed significant falloffs at every step of the care cascade, with only 19%
of the persons living with HIV in the United States having an undetectable HIV RNA (Figure 3).[6]
Subsequently, the Centers for Disease Control and Prevention (CDC) performed its own analysis for
the year 2011 using similar cascade of care parameters; this analysis produced results similar to prior
analysis by Gardner and colleagues (Figure 4).[14,15] Differences in the HIV care cascade occur
among different racial/ethnic groups have been shown in earlier studies, including those from 2009
(Figure 5) and 2011 (Figure 6).[15,16]

- **Retention in HIV Medical Care (Continuous HIV Medical Care):** 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 the system. 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 either appointments missed or medical visits attended at regularly defined
intervals.[17]

- **Receipt of Any HIV Medical Care:** The CDC defines receipt of any HIV medical care as having at
least one CD4 cell count or viral load test performed during the year of evaluation.[18] This term
should not be used interchangeably with retention in HIV medical care.
Evaluation of Retention in Care

Methods and Criteria Used to Estimate Retention in HIV Medical Care

Multiple different 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 the Health Resources Services Administration (HRSA) and the Institute of Medicine (IOM) definitions focus on clinic visits.[13, 18, 19, 20]

- **Centers for Disease Control and Prevention (CDC):** For reporting purposes, the CDC defines retention in HIV medical care as documentation of at least 2 CD4 cell counts or viral load tests performed at least 3 months apart during the year of evaluation.[18] The CDC also refers to this as continuous HIV medical care.[18]
- **Health Resources and Services Administration (HRSA):** Retention in HIV medical care has been defined by HRSA as persons with diagnosed HIV who had at least 2 medical visit dates that were at least 90 days apart in the measurement year.[13] Several modifications for this definition have been made by HRSA, including changing the latest date allowed for the first visit of the year from July 1 to September 1. The most recent publication of 2017 summary data from Ryan White HIV/AIDS Program utilized this last modification and defined retention in care as persons with diagnosed 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.[19]
- **Institute of Medicine:** The Institute of Medicine (IOM) has defined retention in HIV medical care as at least 2 medical visits every 12 months, with a minimum of 90 days between visits.[20]
- **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, 18]

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.[21]

- **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 studies have reported study 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 proportion of time intervals with at least one completed visit during an observation period. This measure best accounts for loss to 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 at HRSA established revised performance measures to provide an
indication of an organization’s performance in relation to a specified process or outcome.[22] 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.[22]

- **HIV Medical Visit Frequency**: Percentage of persons with diagnosed 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.[22]

- **Gaps in Medical Visits**: Percentage of persons with diagnosed HIV, regardless of age, who did not have a medical visit in the last 6 months of the measurement year.[22]

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 patients can and should be seen at more frequent intervals as dictated by their current health status.
Estimating Retention in HIV Medical Care in the United States

Estimates of Retention in HIV Medical Care

The estimates for retention in HIV medical care vary based on the criteria of retention in HIV medical care that is used for the estimate. Cascade of care models for the United States can give particularly low estimates of retention in care if using retention in care as the numerator and all persons living with HIV as the denominator. Most contemporary estimates of retention utilize persons retained in HIV medical care as the numerator and persons with diagnosed HIV as the denominator. The following estimates are all based on the percentage of persons with diagnosed HIV who are retained in medical care. In addition, as noted above, the specific definition of retention in care used for CDC HIV surveillance data is different than the criteria used in Ryan White Clinic reporting.

- **2006 Gardner Spectrum of Engagement in HIV Care**: Using 2006 HIV data in the United States, Gardner and colleagues estimated that 50% of persons with diagnosed HIV were retained in care; this number increased to 67% for those with HIV who were already linked to care.[6,14]
- **CDC HIV Surveillance Data**: Based on HIV surveillance data in the United States from 2010 through 2017, the retention in HIV medical care among persons with diagnosed HIV has ranged from a low of 53.6% in 2011 to a high of 57.6% in 2016, (Figure 7) which is far below the National HIV/AIDS Strategy 2020 goal of at least 90% retention in HIV medical care.[9,18] For these analyses the CDC used a definition of retention in care of at least 2 CD4 cell counts or viral load tests performed at least 3 months apart during the year of evaluation.[18]
- **Ryan White Clinics**: Using 2013 through 2017 retention in HIV medical care data from Ryan White clinics, an estimated 80 to 81% of persons with diagnosed HIV were retained in HIV medical care (defined as persons with diagnosed 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 8).[19]
- **University of Alabama at Birmingham Clinic**: In a study involving 530 participants with HIV already linked to a university-based HIV clinic in Birmingham, Alabama, 59% were identified as being consistently retained in care (defined as consistent attendance across 4 consecutive 6-month periods).[23]
- **Veterans Affairs**: In a retrospective, cohort involving 2,619 men newly identified as having HIV infection during 1997-1998 at any United States Veterans Affairs hospitals or clinics, investigators analyzed retention in HIV medical care among veterans who made an initial index visit and who survived for at least 1 year after the index visit.[24] Overall, they found only 64% of the individuals diagnosed with HIV had visits in each quarter in the year after starting antiretroviral therapy and poor retention in HIV medical care predicted poorer survival.[24]

Limitations of Measuring Retention in Care

As made clear in the performance measures, there is no gold standard for measuring retention in care.[21] 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.[18,21,25] 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 the migration of individuals with HIV infection who were receiving ongoing medical care in a region or city outside of their prior residence.[26,27,28,29,30] These studies, as outlined below, emphasize the need for revised surveillance techniques to allow for better estimates of retention in care.[31]

- 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.[29]

- 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.[30]
- 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.[32]
Risk Factors for Decreased Retention in Care

Understanding patient variables associated with poor retention in care can assist medical providers in their efforts to identify risk factors, health behaviors, or social needs that can be modified to enhance the likelihood that an individual with HIV will engage in HIV care and subsequently move in a progressive direction along the care continuum. The ultimate goal of retention in care is to reach the point of viral suppression and obtain the highest quality of life possible. When gaps in linkage and retention in care are identified and remedied, individuals maintain a better chance of remaining engaged in care. Presently, less than 50% of individuals with HIV in the United States are considered sufficiently retained in care. When persons with HIV are retained in care, approximately 90% receive antiretroviral therapy and 80% obtain complete viral suppression.[14] Although it is difficult to predict the likelihood of an individual staying engaged and retained in a system of HIV care, investigators have identified multiple variables associated with lower retention rates:[23,33,34,35,36]

- **Heterosexual Orientation**: Compared with men who have sex with men (MSM), heterosexual males are more likely to have missed office visits within the first year of care; heterosexual women, however, have relatively high rates of retention in care.[35,37]
- **Mental Illness**: Research has linked depressive symptoms to poor HIV outcomes, particularly if compounded by concomitant substance use disorders, or post-traumatic stress from physical, sexual, or emotional abuse.[38] 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.[39,40,41] At first glance, this appears to conflict with 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 mental illness and receiving care have better retention outcomes relative to those with undiagnosed and unmet mental health needs.[23]
- **Nonwhite Race/Ethnicity**: Various studies have shown an association with decreased retention in care among blacks and nonwhite Hispanic, Asian, and Pacific Islander groups, when compared to patients who are white, as measured by the number of office visits missed.[35,42,43,44] Among blacks, studies have consistently shown males have lower rates of retention in HIV medical care and lower rates of virologic suppression.[42,43] In the CDC HIV surveillance supplemental report that analyzed data from 41 states for the year 2016, the HIV retention rates were similar in whites (59.3%) and Hispanics (58.6%), but both were higher than in blacks (54.9%) (Figure 9).[18]
- **Place of Residence**: Surveillance data from the CDC have identified that living in a non-metropolitan location, with population size less than 500,000 people, correlates with lower rates of HIV medical care retention, possibly due to geographical and environmental difficulties accessing care (Figure 11).[45] In addition, rates of retention in HIV medical care in the United States are lower in the West and South compared to the Northeast and Midwest.[46] A plethora of recent epidemiologic data show that Southern states are the epicenter of the HIV epidemic in the United States. Analyses of retention in HIV care among 5 southern and 6 non-southern United States cities have demonstrated worse engagement in care and HIV outcomes in the South, despite lower rates of problematic drug and alcohol use.[47]
- **Stigma and Fear**: Stigma and fear are common feelings for individuals recently diagnosed with HIV. Persons living with HIV often are vulnerable to racial, social, and economic disparities and can experience fear and stigma and therefore have difficulty remaining in care. Although the clearly described relationship between retention in care and survival is partly mediated by adherence to effective antiretroviral therapy, individuals who do not remain in care also cannot receive treatment for medical and psychiatric comorbid conditions, or benefit from the careful clinical monitoring necessary when taking antiretroviral therapy. Individuals with poor retention in care, due to stigma or fear or other factors, have been shown to have difficulty achieving a comparable CD4 cell count, plasma HIV concentration, and survival benefits to those patients who are retained in care.[24]
- **Substance Use Disorder**: 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 actively use drugs have
lower rates of retention in care, particularly among those who are younger, and are more likely to miss office visits.\cite{40,48,49} Individuals with active use of alcohol and/or injection drugs who do not have access to substance abuse treatment, or choose not to engage in treatment, tend to have a more unstable lifestyle that increases the likelihood of missed appointments and dropping out of HIV clinical care. Furthermore, the increasing rural nature of the opioid epidemic in the United States is a barrier to accessing care.\cite{38} 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.\cite{50,51} Medications with established benefit for opioid use disorder include buprenorphine, buprenorphine-naloxone, or methadone.\cite{39,52}

- **Transgender Women**: A recent study has shown that transgender women are less likely to be retained in HIV care compared to cisgender women or cisgender men.\cite{53}
- **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 inability to pay for services. This can lead to patients dropping out of, 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.\cite{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.\cite{54}
- **Young Age**: Individuals with HIV infection who are 24 years of age or younger have been shown to have lower rates of retention, receive fewer prescriptions for antiretroviral medication, and have poorer outcomes.\cite{35} Young African Americans are at particularly high risk of being lost to follow-up.\cite{55} In the CDC surveillance supplemental report for the year 2016, the rates of retention in HIV medical care was lowest in those 25 to 34 years of age and highest in those 55 years of age and older (Figure 10).\cite{18}
**Impact of Poor 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 poor retention and take appropriate measures to help reduce the negative outcomes. Until recently, little was known about the impact of poor retention in HIV care on health outcomes, such as 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 HIV clients in the clinic met the overall IOM and HRSA retention indicators, more than 2 missed clinic visits in a 2-year period was independently associated with an increased mortality risk.[56]
- A retrospective study performed in South Carolina examined data from persons newly diagnosed with HIV from January 1, 2004 through December 31, 2009 and found that sporadic rates of retention and dropout were associated with lower rates of virologic suppression and increased mortality risk (Figure 12).[35]
- 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 poor retention in care and it predicted poor survival.[24]

**Impact on HIV Transmission**

In addition to increased mortality rates, persons with HIV who do not consistently demonstrate adherence with regularly scheduled appointments (and are not adequately ‘retained’ in HIV care) consistently have 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 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.[1,7,57] 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 13).[3] Multiple studies have shown that persons with HIV who consistently have undetectable HIV RNA levels do not sexually transmit HIV to others.[58, 59, 60] 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 marked epidemiologic and economic impact in the United States by reducing HIV incidence and HIV-associated morbidity and mortality.[61, 62]
Strategies and Guidelines for Improving Retention in HIV Medical Care

Strategies for Improving Retention in HIV Medical Care

A multipronged approach targeting various aspects of the HIV care continuum is needed to improve retention in care. Healthcare systems that can facilitate rapid antiretroviral initiation for persons with HIV improve retention in care, including retention with suppressed HIV RNA levels. 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 have developed and validated a patient-centered questionnaire at several United States-based Centers for AIDS Research Network of Integrated Clinical Systems (CNIS) clinics aimed at identifying perceptions of engagement. Furthermore, multiple studies have demonstrated that providing comprehensive and easy-to-access services (e.g. case management, mental health support, transportation, drug treatment programs) can enhance retention in care. 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. 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 infection who are not in care (based on absence of laboratory monitoring data), with a subsequent goal to link or relink these identified individuals to medical care. This approach is now commonly referred to as Data to Care (D2C) and has been recommended by the CDC. 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.

- **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 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.

- **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 and retention in care. Several other studies have demonstrated the benefit of medical case-management on rates of retention in HIV medical care.

- **Patient Navigation Interventions**: In a randomized trial (Project Hope), investigators explored the impact of structured patient navigation interventions for engaging 801 hospitalized persons with HIV and substance use into HIV medical care; the authors randomized participants to either treatment as usual, patient navigation alone, or patient navigation plus financial incentives. 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.

- **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. 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. 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.
International Association of Physicians in AIDS Care Guidelines

The International Association of Physicians in AIDS Care (IAPAC) has published evidenced-based guidelines for improving entry into and retention in care for individuals with HIV infection. 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. As well, the integration of data sources may enhance monitoring of retention in care.

- **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%). 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 illness or substance use. A dose-response relationship has been described between increasing numbers of quarterly medical visits and decreasing patient mortality. 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.

- **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 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. Furthermore, the proportion of participants receiving patient navigation assistance who had undetectable HIV RNA levels increased 40% after 12 months in care, as compared to baseline.[39]
Summary Points

- 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.
- The HIV Care Cascade helps providers to understand how larger groups or populations are engaged at each step of this cascade in order to identify, monitor, and ensure that more patients are tested, linked, retained, placed on antiretroviral therapy, and virologically suppressed.
- In the United States, during the year 2016, approximately 58% of persons with diagnosed HIV were retained in HIV medical care, defined as having at least 2 CD4 cell counts or HIV RNA levels obtained that year. The rates of retention in care have increased only marginally since 2010 (from 54.7% to 57.6%).
- When persons with HIV are retained in care, more than 90% receive antiretroviral therapy and more than 80% achieve complete viral suppression.
- In 2016 in the United States, older persons, particularly those 55 years of age and older had the higher rates of retention in HIV medical care and the lower rates were seen in the 13 to 24 and 25 to 34 year-old age groups.
- Among different racial/ethnic groups in the United States, the rates of retention in HIV medical care were highest in whites (59.3%) and lowest in Native Hawaiian/Pacific Islanders (51.0%). Retention rates in blacks were 54.3%.
- Persons diagnosed with HIV infection but who are not retained in care are responsible for approximately 43% of all HIV transmissions in the United States.
- It should be a goal of all HIV clinicians to 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.
- 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 Continuum of Engagement in HIV Care Model

This graphic represents the continuum of engagement in HIV care, as represented by the Health Resources and Services Administration (HRSA).


<table>
<thead>
<tr>
<th>Not in Care</th>
<th>Fully Engaged</th>
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</thead>
<tbody>
<tr>
<td>Unaware of HIV infection</td>
<td></td>
</tr>
<tr>
<td>Aware of HIV infection (not in care)</td>
<td></td>
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<tr>
<td>Receiving some medical care but not HIV care</td>
<td></td>
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<tr>
<td>Entered HIV care but lost to follow-up</td>
<td></td>
</tr>
<tr>
<td>Cyclical or intermittent user of HIV care</td>
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<tr>
<td>Fully engaged in HIV medical care</td>
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Figure 2: HIV Care Continuum Model

Source: United States Health Resources and Services Administration (HRSA)

The series of steps a person with HIV takes from initial diagnosis through their successful treatment with HIV medication.
Figure 3 Spectrum of Engagement in HIV Care, United States, 2006

This graphic represents a model generated by Gardner and colleagues. With this cascade only 19% of persons living with HIV in the United States in 2006 had undetectable HIV RNA levels. Among persons with diagnosed HIV, 24% had undetectable HIV RNA levels. Abbreviations: ART = antiretroviral therapy

Figure 4 Estimated Numbers of Persons Living with HIV Infection Along the HIV Care Continuum — United States, 2011

This graphic represents HIV care cascade estimates from the CDC for 2011; the CDC used data from the National HIV Surveillance System and the Medical Monitoring Project for these estimates.

Figure 5 HIV Care Cascade, by Race, 2009

This graph shows the percentages for individuals in the United States engaged in HIV medical care, as estimated by the Centers for Disease Control and Prevention for selected stages of the HIV cascade during 2009. Abbreviations: ART= antiretroviral therapy

**Figure 6 HIV Care Cascade, by Race, 2011**

This graph shows the percentages for individuals in the United States engaged in HIV medical care, as estimated by the Centers for Disease Control and Prevention for selected stages of the HIV cascade during 2011.

Figure 7 Retention in HIV Medical Care, United States, 2010 through 2016

This report utilized the following criteria for retention in care: at least 2 CD4 cell counts or HIV RNA levels performed at least 3 months apart (for each year analyzed).

Figure 8 Retention in HIV Medical Care in Ryan White Clinics

For these data, retention in HIV care was based on data for persons with diagnosed 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 9 Retention in HIV Medical Care, by Race/Ethnicity, United States, 2016

This report utilized the following criteria for retention in care: at least 2 CD4 cell counts or HIV RNA levels performed at least 3 months apart during the year 2016. The data are from 41 states and the District of Columbia.

Figure 10 Retention in HIV Medical Care, by Age, United States, 2016

This report utilized the following criteria for retention in care: at least 2 CD4 cell counts or HIV RNA levels performed at least 3 months apart during the year 2016. The data are from 41 states and the District of Columbia.

Figure 11 Retention in HIV Medical Care and Viral Suppression, by Population Category of Residence at Diagnosis

Data shown are for persons 13 years of age and older with diagnosed HIV by year-end 2011 and alive at year-end 2012.

**Figure 12 Correlation of Retention in HIV Care and Mortality Risk**

This retrospective study analyzed data from 2,197 persons in South Carolina newly diagnosed with HIV infection from January 1, 2004 through December 31, 2009. The subjects were followed over 2 years and data analyzed for 6-month intervals (total of 4 intervals). 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

Figure 13 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.

Figure 14 Data to Care Health Department Model for Linkage and Reengagement

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

Data to Care Health Department Model

1. **Health Department (HD)** Generate list of clients identified by HIV surveillance as “not in care”
2. HIV surveillance and prevention staff may check additional sources to confirm “not in care” status and gather information needed for follow-up.
3. Health care providers and HD staff communicate about care status of patients on “not in care” list
4. Patients contacted by HIV prevention or linkage staff for linkage or reengagement assistance
5. Patient care visit scheduled
Figure 15 Data to Care Health Care Provider Model for Linkage and Reengagement

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

Data to Care Health Care Provider Model

1. Generate list of clients identified by HIV surveillance as “not in care”

2. HIV surveillance and prevention staff may check additional sources to confirm “not in care” status and gather information needed for follow-up.

3. Health care providers and HD staff communicate about care status of patients on “not in care” list.

Patients contacted by healthcare provider for linkage or reengagement assistance

Patient care visit scheduled

Client/Patient
Figure 16 Data to Care Combination of Health Department and Health Care Provider Models for Linkage and Reengagement

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.
Figure 17 Project Hope: Effect of Patient Navigation with or without Financial Incentives on Viral Suppression

This study was conducted from July 2012 through January 2014 and investigators enrolled 814 patients with HIV infection and substance use who were hospitalized to determine the impact of different strategies on subsequent engagement in HIV care and treatment. Patients were randomized to one of three groups: patient navigation alone, patient navigation plus financial incentives, or treatment as usual. At 12 months, there was not a statistical difference in the three groups.


![Bar chart showing the effect of patient navigation with or without financial incentives on viral suppression among hospitalized patients with HIV infection and substance use. The chart compares usual treatment, navigation, and navigation plus incentives at 6 and 12 months. At 6 months, 50.4% of patients in the navigation group had viral suppression compared to 43.1% in the navigation plus incentives group and 38.2% in the usual treatment group. At 12 months, 43.6% of patients in the navigation plus incentives group had viral suppression compared to 41.0% in the navigation group and 38.6% in the usual treatment group. No statistical difference was found between the groups.](chart.jpg)