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

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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.[13,17,18,19]

- **Centers for Disease Control and Prevention**: 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.[17] The CDC also refers to this as continuous HIV medical care.[17]

- **Health Resources and Services Administration**: 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.[13,18] 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.[18]

- **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.[19]

- **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 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 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 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 (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 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.[21]

- **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.[21]

- **Annual Retention in Care**: In 2019, HRSA released an update defining annual retention as “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 living 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

Estimates of Retention in HIV Medical Care

The estimates for retention in HIV medical care vary based on the criteria for 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 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 2018, 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 57.9% in 2018, (Figure 5) which is far below the National HIV/AIDS Strategy 2020 goal of at least 90% retention in HIV medical care.[9, 17] 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.[17]

- **Ryan White Clinics**: From 2013 through 2018, the retention in HIV medical care in Ryan White Clinics has consistently been in the 80 to 82% range. For these data, retention in care data is 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 6).[18]

- **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).[22]

- **Veterans Affairs**: In a retrospective cohort involving 2,619 men newly diagnosed with HIV 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.[23] Overall, they found only 64% of the individuals diagnosed with HIV had visits in each quarter in the year after starting antiretroviral therapy and lower rates of retention in HIV medical care predicted poorer survival.[23]

Limitations of Measuring Retention in Care

As made clear in the performance measures, there is no gold standard for measuring retention in care.[20] 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 Associated with Lower 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 HIV care and subsequently move in a progressive direction along the care continuum. Critical goals for retention in care are to reach viral suppression and obtain the highest quality of life possible. When gaps in linkage to 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 durable viral suppression.[14] Although it is difficult to predict the likelihood of an individual staying engaged and retained in HIV care, investigators have identified multiple variables associated with lower retention rates.[22,32,33,34,35]

- **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.[34,36]
- **Mental Illness**: 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.[37] 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.[38,39,40] 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 mental illness and receiving care have better retention outcomes relative to those with undiagnosed and unmet mental health needs.[22]
- **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.[34,41,42,43] Among blacks, studies have consistently shown males have lower rates of retention in HIV medical care and lower rates of virologic suppression.[41,42] In the CDC HIV surveillance supplemental report that analyzed data from 41 states and the District of Columbia for the year 2018, the HIV retention rates were similar in whites (58.9%) and Hispanics (58.7%), but both were higher than in blacks (55.8%) ([Figure 7]).[17]
- **Place of Residence**: Surveillance data from the CDC have identified that living in a nonmetropolitan 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 associated with accessing care ([Figure 8]).[44] 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.[45] Extensive recent epidemiologic data demonstrate 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.[46]
- **Stigma and Fear**: Stigma and fear are common feelings for individuals recently diagnosed with HIV. Persons with HIV are often 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, suppressed plasma HIV RNA levels, and survival benefits to those patients who are retained in care.[23]
- **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.[39,47,48] Individuals who actively use of alcohol and/or injection drugs and who do not have access to treatment for substance use disorders (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 impact of the opioid epidemic in rural areas of the United States is a barrier to accessing care for addiction services, hepatitis C care, and HIV care.[37] 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.[49,50] Medications with established benefit for opioid use disorder include buprenorphine, buprenorphine-naloxone, or methadone.[38,51]

- **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.[52]
- **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.[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.[53]
- **Young Age**: Individuals with HIV 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.[34] Young African Americans are at particularly high risk of being lost to follow-up.[54] In the CDC surveillance supplemental report for the year 2016, the rates of retention in HIV medical care were lowest in those 25 to 34 years of age and highest in those 55 years of age and older (Figure 9).[17]
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, more than 2 missed clinic visits in a 2-year period was independently associated with an increased mortality risk.[55]
- 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 10).[34]
- 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.[23]

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 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, 56] 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 11).[3] Multiple studies have shown that persons with HIV who consistently have undetectable HIV RNA levels do not sexually transmit HIV to others.[57, 58, 59] 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.[60, 61]
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 to quantitatively 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 2018, 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 57.9%).
- When persons with HIV are retained in care, more than 90% receive antiretroviral therapy and more than 80% achieve complete viral suppression.
- At year-end 2017, among different racial/ethnic groups in the United States, the rates of retention in HIV medical care were highest in whites (58.9%) and lowest in Native Hawaiian/Pacific Islanders (52.9%). Retention rates in blacks were 55.8%.
- Persons diagnosed with HIV 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 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.
Citations


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

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

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


References


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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).

Figure 2 HIV Care Continuum Model

Source: United States Health Resources and Services Administration (HRSA)
Figure 3 Spectrum of Engagement in HIV Care, United States, 2006

This graphic represents a model generated by Gardner and colleagues. Using this cascade model, 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, 2018

This graphic represents HIV care cascade estimates from the CDC for year-end 2018.

Figure 5 Retention in HIV Medical Care, United States, 2010 through 2018

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 6 Retention in HIV Medical Care in Ryan White Clinics, 2013-2018

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 7 Retention in HIV Medical Care, by Race/Ethnicity, United States, 2018

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 2018. The data are from 41 states and the District of Columbia.

Figure 8 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 9 Retention in HIV Medical Care, by Age, United States, 2018

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 2018. The data are from 41 states and the District of Columbia.

Figure 10 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

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 12 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 Care Provider Model

**Health Department (HD)**

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.

**Health Care Provider**

Patients contacted by healthcare provider for linkage or reengagement assistance

**Client/Patient**

Patient care visit scheduled

Source: Centers for Disease Control and Prevention (CDC). Data to Care: Using HIV Surveillance Data to Support the HIV Care Continuum.
Figure 14 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.

Data to Care Combination Health Department/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.

4. Patients contacted by HIV prevention or linkage staff for assistance or re-engagement.

5. Patients contacted by health care provider for linkage or re-engagement assistance.

Patient care visit scheduled
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.