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Establishment, Retention, and Loss to Follow-Up in Outpatient HIV Care

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Abstract

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Background—For optimal clinical benefit, HIV-infected patients should receive periodic outpatient care indefinitely. However, initially establishing HIV care and subsequent retention in care are problematic. This study examines establishment, retention, and loss to follow-up (LTFU) in a large, multi-site cohort over a 2-8 year period.

Methods—Medical record data were reviewed for 22,984 adult HIV patients receiving care at 12 clinics in the HIV Research Network between 2001-2009. Three dichotomous outcome measures were based on each patient's history of outpatient visits. Establishment reflects whether the patient made outpatient visits for longer than 6 months after initial enrollment. The retention measure reflects whether the patient had at least 2 outpatient visits separated by 90 days in each year in care. LTFU reflects whether the patient had no outpatient visits for more than 12 months without returning. Multiple logistic regression examined demographic and clinical correlates of each outcome, as well as the combined outcome of meeting all three measures.

Results—Overall, 21.7% of patients never established HIV care after an initial visit. Among established patients, 57.4% did not meet the retention criterion in all years, and 34.9% were LTFU. Only 20.4% of all patients met all three criteria. The odds of successfully meeting all three criteria were higher for women, for older patients, for Hispanics compared with whites, and for those with CD4 levels ≤50 cells/mm^3.

Conclusions—These data highlight the need to improve establishment and retention in HIV care.

Keywords

HIV; Loss to follow-up; retention in care; outpatient use

Introduction

Engagement in HIV care is associated with improved clinical status and reduced mortality. [1-12] Several authors describe a continuum of HIV care.[13,14] At one end, people are unaware of their HIV status; at the other, they consistently and regularly utilize HIV care. Intermediate points range from being aware of HIV infection but not receiving care; entering HIV care but dropping out; and moving in and out of HIV care.

Provision of HIV care is problematic at several points on this continuum. An estimated 21% of persons living with HIV (PLWH) in the United States are unaware of their infection.[15] Among those aware of their HIV infection, initial linkage to care is often delayed.[16,17] After patients have been linked with a provider and have made an initial visit, they must still remain in care, with regular visits over a long time period. This study examines these later stages in the continuum of care. “Establishment” refers to the extent to which patients form a pattern of care utilization in the first months following an initial encounter with a care provider. From 6.5% to 11% of HIV patients never make a second visit to an HIV care provider.[18,19]

Once outpatient HIV care has been established, patients must remain in care to achieve maximal benefits from antiretroviral therapy (ART). “Retention” refers to the consistency of service utilization after the initial care period. Among 2619 patients at Veterans’ Affairs clinics, only 64% had visits in each quarter in the year after starting ART.[8] Similarly, only 59% of 530 patients in one clinic had an outpatient visit in each of 4 six-month periods after their initial clinic visit.[3] A review of 12 studies of retention in HIV care, defined as ≥3 visits in an interval of 12-24 months, found that the proportion of patients retained varied from 47% to 68%.[20] Analyses of New York City HIV surveillance data found that only 45% of persons having an initial HIV clinic visit subsequently had at least one visit in every 6-

month period until the end of the study. [19] In addition, 34% of patients were lost to follow-up (LTFU), defined as having no visits for at least six months prior to the end of the observation period. Thus, prior studies suggest that substantial proportions of HIV-infected patients do not successfully integrate into the healthcare system.

Most prior research examines establishment, retention, or LTFU, but not all together. Moreover, many studies use a relatively short observation period, such as 1-2 years. Two relevant studies with relatively long observation periods used HIV-1 RNA or CD4 tests as proxies for outpatient clinic visits.[19,21] However, such tests could be administered in settings other than longitudinal HIV care, such as emergency departments or inpatient wards.[22] In contrast, the current study uses outpatient HIV clinic visit data to assess establishment, retention, and LTFU. It extends prior research by incorporating a longer observation period (from 2 to 8 years); by using a large patient sample collected from multiple, geographically diverse, HIV clinics; and by evaluating these three outcomes together and identifying their sociodemographic and clinical correlates.

Methods

Study Design & Participants

We analyzed outpatient HIV care utilization among HIV-infected adults enrolled in the HIV Research Network (HIVRN), a consortium of clinics that provide primary and subspecialty care to HIV patients.[23] Fifteen sites treat adult patients. Data from 12 sites, located in the Northeastern (6), Midwestern (1), Southern (2), and Western (3) United States, were included in this analysis. The remaining three sites discontinued participation during the study period and did not provide complete data. Nine sites have academic affiliations. Adult patients (≥18 years old) who enrolled at an HIVRN site between 2001 and 2008 and who had at least one outpatient visit in any calendar year between 2001 and 2008 were eligible for inclusion. Patients who began HIV care prior to 2001 were excluded. Patients attending HIVRN sites for limited consults and known to be receiving primary care elsewhere were excluded from the database. Patients enrolling at an HIVRN clinic could be initiating HIV care, or they could be transferring care from another provider.

Data Collection

Data encompassing the period from January 1, 2001 through December 31, 2009 were abstracted from medical records at each site and sent to a data coordinating center after personal identifying information was removed. After quality control and verification, data were combined across sites to produce a uniform database. All sites endeavor to retain the same patient ID number for patients who have had a prolonged absence from the clinic. The study was approved by Institutional Review Boards at the Johns Hopkins School of Medicine and at each participating site.

Establishment and Retention Measures

Because patients entered and left care at different times, variables were based on each person's individual history of outpatient visits. For this analysis, outpatient visits refer to primary care visits to the HIV clinic in which the patient was seen by a medical provider (MD, DO, NP, PN). Each patient's outpatient history was divided into two periods: (1) “outpatient time,” defined as the period from the date of the first to the last recorded outpatient visit; and (2) “post-outpatient time,” the period from the last recorded outpatient visit to either date of death or December 31, 2009, whichever was earlier. A patient was defined as being established in care if outpatient time was more than six months, a criterion used in prior research.[18]

One measure of retention in care, endorsed by HRSA, the U.S. National HIV/AIDS Strategy, and the Institute of Medicine, and currently used as a quality-of-care indicator for providers receiving Ryan White CARE Act funding, is defined as having ≥ 2 outpatient visits separated by at least 91 days during a 12-month period.[22,24] We extended this to apply to multiple years. To calculate this "consistent retention" measure, we divided each patient's outpatient time into 360-day intervals and assessed, for each interval, whether the annual retention criterion was met. The retention measure is dichotomous, differentiating patients who met the criterion for every year (or partial year) during outpatient time from those who had one or more years in which the criterion was not satisfied.

Finally, the dichotomous loss to follow-up (LTFU) variable reflected whether post-outpatient time was ≥12 months. It was possible for a patient to be both continuously retained for several years and subsequently be LTFU.

Sociodemographic and Clinical Variables

Age in the year of clinic enrollment was categorized as 18 to 29, 30 to 39, 40 to 49, and over 50 years old. Race/ethnicity was categorized as non-Hispanic white, non-Hispanic black, Hispanic, other, or missing. HIV transmission risk factor was grouped into men who had sex with men (MSM), heterosexual transmission (HET), injection drug use (IDU) only, IDU and HET, IDU and MSM, or missing. Insurance at the time of the first outpatient visit was categorized as private, Medicaid, Medicare/dual coverage, uninsured, and other/unknown. Patients whose care was funded by Ryan White, those recorded as self-pay, and those covered by local governmental programs were considered to be uninsured. CD4 count at the time of the first outpatient visit was classified as ≤50, 51-200, 201-350, 351-500, >500 cells/mm^3, or missing. The first recorded HIV-1 RNA test in the year of enrollment was classified as suppressed (≤ 400 copies/ml), not suppressed, or missing.

Analyses

We examined overall distributions of the outcome measures: establishment, consistent retention, and LTFU. Analyses of the latter two measures were conducted only for those patients who were established in care. We derived a dichotomous measure of optimal engagement in care as the combination of being established, meeting the consistent retention criterion, and not being lost to follow-up.

Multiple logistic regression was used to examine sociodemographic and clinical factors associated with each measure. All regression models included indictors for each HIVRN site and for year of first outpatient visit. Information identifying patients who had received HIV care prior to enrolling at an HIVRN clinic was not available; we assumed that newly enrolled patients with suppressed HIV-1 RNA had previously received HIV care elsewhere. For all analyses, we used robust standard errors clustered on site. Statistical analyses were performed using Stata 11.2 (Stata Corporation, College Station, TX).

The consistent retention measure summarizes a patient's outpatient utilization over all years during outpatient time. To examine the pattern of consistent retention over time in more detail, we analyzed the proportion of patients who met the outpatient visit criterion in each separate year, stratified by the total number of years of outpatient time.

Sensitivity Analyses—Main analyses included patients regardless of their HIV-1 RNA suppression status at enrolment. To focus on the subset of patients likely to be entering HIV care for the first time, we repeated multivariate analyses using only those patients whose first HIV-1 RNA test was not suppressed. In addition, to assess the impact of relaxing the consistent retention criterion, we counted patients as being consistently retained if they had

2 outpatient visits 91 days apart either in all outpatient years or all years but one; patients with only one outpatient year, however, had to fulfill the criterion in that year.

Results

A total of 23,459 adult patients enrolled at the 12 HIVRN sites between 2001 and 2008. Of these, 6 were removed from analyses due to missing data on outpatient visit dates, 11 due to missing gender data, 156 who were transgender, and 308 because they died within six months of their first outpatient visit. The resulting analytic sample included 22,984 patients. Table 1 reports demographic and clinical characteristics of the sample.

Staggered entry and exit resulted in variation in observation periods. Overall, mean outpatient time was 33.9 months (median=25, IQR=9-54). Mean (median) outpatient time ranged from 50.6 (45) months for those who entered care in 2001 to 12.0 (13) months for those who entered care in 2008. Mean post-outpatient time was 24.5 months (median=10, IQR=1-43), ranging from 45.8 (median=39) months for those who entered care in 2001 to 6.4 (median=3) months for those who entered care in 2008.

Establishment

Overall, 4,996 patients (21.7% of the analytic sample) never established HIV outpatient care, as reflected by periods of 6 months or less between first and last outpatient visit (Table 2). Six percent had only one visit; 7.0% had multiple visits for 1-2 months, and 8.6% had multiple visits over 3-6 months. (Results not shown.)

In a multiple logistic regression comparing those who established care with those who did not (Table 3), establishment was more likely for women than men, for patients with MSM versus HET or IDU HIV transmission, for patients aged 40 or older versus 18-29 year olds, and for those with private coverage versus those with Medicare. Black and Hispanic patients had greater adjusted odds of establishing care than white patients. Establishment was more likely among those missing CD4 data in the year of enrollment.

Consistent Retention

Overall, 42.6% of established patients met the consistent retention criterion in all years during outpatient time. (Table 2) Only 3.6% never met the criterion in any outpatient year. For each patient who established care, we calculated the proportion of years during outpatient time in which the annual retention criterion was met; overall, the mean was 75% of eligible outpatient years (median= 0.80). (Results not shown.)

In multivariate analysis (Table 3), the likelihood of meeting the consistent retention criterion in all outpatient years was greater for more recent cohorts, who had shorter outpatient periods. Consistent with establishment results, the odds of retention were greater for older than younger patients and for MSM versus HET groups. Unlike the results for establishment, black patients were less likely than whites to meet the retention criterion; the difference between Hispanics and whites was not statistically significant. Those with IDU-related HIV transmission did not differ from MSMs. Opposite to the association for establishment, patients with Medicare coverage were more likely to be consistently retained than those with private insurance, Medicaid, or no coverage; differences between private and other insurance categories were not significant. Higher initial CD4 count and non-suppressed initial HIV-1 RNA were each inversely associated with consistent retention.

Table 4 shows the proportion meeting the retention criterion in each specific consecutive year of outpatient time, stratified by total number of outpatient years. The proportion meeting the consistent retention criterion was highest in the first year of HIV care and then

dropped in subsequent years, remaining fairly steady at 68-75% each year. A notable drop occurred in the last year a patient was actively receiving care (first diagonal entry); dropping out of care prevents reaching the retention criterion. Some patients were active for only one quarter in their last outpatient year; such patients would be unlikely to meet the retention criterion. After excluding such patients from the calculation (second diagonal entry), the proportion meeting the retention criterion in the last outpatient year rose to 67% or higher.

Loss to Follow-Up

Overall, 34.9% of established patients were subsequently LTFU (i.e., had a post-outpatient period of 12 months or longer). In multiple logistic regression, the odds of not being LTFU for ≥12 months) increased for patients aged 40 and older and for patients who entered care more recently. Groups with higher initial CD4 levels were less likely to remain in care. Patients with IDU-related HIV transmission were more likely than MSMs to be lost to follow-up, but HET+IDU and MSM+IDU did not differ significantly from MSMs. Hispanic patients were more likely than whites to remain in care, as were black patients. Unlike prior analyses, the effects of gender and insurance coverage were not significant.

It is possible that some patients' deaths were not reported to providers, and time post-death may have inappropriately been counted as LTFU. Four of the 12 HIVRN sites in this study actively perform searches of the National Death Index (NDI). Using data from these sites (n=6,302), the proportion of patients LTFU was 33.4% (versus 36.0% in other sites with passive death ascertainment). Based on these data, the absolute magnitude of inflation in LTFU rates due to patients' unreported deaths might not be substantial.

Meeting All Three Criteria

Ideally, patients would establish care, have regular visits to monitor their condition, and remain in care indefinitely. Unfortunately, only 20.4% of all patients conformed to this optimal pattern. The proportion meeting all three criteria was 24.1% in sites with active NDI searches, versus 18.2% in sites with passive death ascertainment. Results of multivariate analyses using this combined measure showed a pattern similar to that for LTFU. The odds of successfully meeting all three criteria were higher for women than men, for older patients, for Hispanics than whites (but not blacks), for MSM than for either HET or IDU patients, for patients with lower initial CD4 counts, and for patients entering care more recently. Initial insurance and HIV-1 RNA were not significantly associated with optimal care.

Sensitivity Analyses

We ascertained the extent to which the results changed when analyses were restricted to patients who did not have suppressed HIV-1 RNA at enrollment, who could be presumed to be treatment-naïve. Among this group, results were similar to those of the main analyses: 22.8% did not establish care; 43.0% met the consistent retention criterion in all years; 34.5% were LTFU, and 20.4% met all three criteria. The pattern of results of multivariate analyses was also broadly similar to those in the main analyses (Appendix Table A).

Broadening the consistent retention indicator to include patients who meet the criterion in all but one patient year, the revised proportion with consistent retention was 74.6%, and the proportion with establishment, revised retention, and no LTFU was 48%.

Discussion

Only a minority of PLWH established and consistently engaged in outpatient HIV care. Of 22,984 patients, 21.7% failed to establish long-term care, as manifested by 6 or fewer months of outpatient visits. Among those who established care, 57.4% had one or more

years in which they did not meet the retention in care criterion; 34.9% were LTFU. Only 20.4% of the entire sample successfully established care, were not lost to follow-up, and were continuously retained in outpatient HIV care. In combination with the substantial proportions of PLWH who are not linked to care, these results suggest that our health care system faces significant challenges in providing continuous, long-term care to the majority of the HIV-infected population.

Establishing care is problematic. Six percent of patients had only one visit, somewhat lower than prior studies, which found that 6.5% to 11% made only one visit.[18, 19,25] Most studies define linkage to care as attending one primary HIV care visit within 3-6 months after receiving a diagnosis of HIV, but initial linkage does not imply establishment. Providers should be attentive to the high dropout rate during this period. Future studies should investigate mechanisms to facilitate establishing care during this critical period, such as using patient navigators.[26]

With the current measure of establishment, a patient who had an initial visit and then made a second visit after a gap of several years would be considered to be “established”, as the total outpatient time would exceed six months. In contrast, Giordano et al.[18] defined establishment as not having a 6-month gap in visits during the first year of care. This definition encounters problems when one considers multiple years of outpatient service use: Someone could have a 6-month gap but then have several years of consistent outpatient care; it would seem counterintuitive to classify such a person as “not established”. We believe it is conceptually clearer to define establishment in terms of a minimum span of initial service receipt; subsequent gaps in care will be reflected in measures such as consistent retention, which is strongly associated with other, direct measures of gaps in care.[27]

HRSA has been collecting data on its retention measure since 2008. Few analyses using this measure have been published. This study represents one of the first to describe this measure in a large longitudinal cohort. When analyzing multiple years in care, the issue arises whether to insist on meeting the criterion in all years, or to allow for less-than-perfect consistent retention. Should someone who meets the annual HRSA measure in 7 of 8 years be deemed less consistent than one who meets it in 2 of 2? Allowing one year in which the annual HRSA measure was not met raised the proportion of patients who established care, were consistently retained, and were not LTFU from 20% to 48%. Ideally, selecting a cut-point based on some proportion of years in which the HRSA measure was met would be based on research that relates different cut-points to specific clinical outcomes.

A substantial proportion of established patients are at risk of becoming LTFU. The 34.9% LTFU rate in our study was similar to the 34% reported in New York City surveillance data,[19] but other studies report rates between 15% and 33%.[28-30] Some studies define LTFU as an absence from care for 12 months, allowing for a subsequent return.[31] Differences in the definition of LTFU and in the observation period could contribute to differences in estimated LTFU rates.

LTFU may result from several factors, such as relocation, dissatisfaction with the provider, and logistical difficulties (transportation, convenience of appointments).[30] Future studies should focus on understanding patients’ perspectives on discontinuing care, examine clinic/health system factors influencing the risk of being LTFU, and develop interventions to prevent LTFU.[1,32]

Consistent with prior studies, older patients were more likely to establish care, remain in care, and not to be LTFU.[3,8,18,21,28,31] Younger patients may face greater socioeconomic challenges, have minimal experience in navigating the healthcare system, and/or have a

greater sense of invulnerability than older patients.[33] In addition, consistent with prior studies, patients with an IDU risk factor were less likely than MSM patients to establish care, not be LTFU, and meet all three criteria. [11,18,19,21] Patients with multiple risk factors (HET+IDU and MSM+IDU) did not differ from MSM.

In multivariate analyses, men were significantly less likely than women to establish care, but sex was not associated with retention or LTFU. Prior studies have also reported no significant adjusted sex difference in likelihood of missed visits or difficulty establishing care, [3,9,11,18] although two studies using surveillance data did show significantly more consistent care for women.[19,21]

Hispanics were significantly more likely than whites to establish care and not to be LTFU, although they did not differ in terms of retention. Other studies have also found minimal Hispanic-white differences in consistency of care or difficulty in establishing care.[8,18] As in other studies, black patients were less likely to be retained in care compared to whites;[3,8,34] however, they were more likely to establish care and not be LTFU.

Patients with an initial CD4 level < 50 cells/mm^3 were more likely than those with more advanced immune suppression to meet the retention criterion and not to be LTFU. The odds of being retained or not being LTFU dropped consistently as CD4 increased. Symptoms may increase patients' motivation to see a care provider regularly.[3,8,11,21] Although symptoms were not assessed in this study, symptoms occur more commonly at low CD4 levels. In addition, patients with no recorded CD4 test in the year of enrollment were more likely to establish care than those who were severely immunosuppressed; a priori, one would expect such patients to be less likely to establish care, similar to their being less likely to be consistently retained and not to be LTFU. We have not identified any aspect of the data that explains this anomalous finding.

This study has several limitations. First, although multi-site studies have greater generalizeability than single-site studies, the HIVRN data are not nationally representative; rates of establishment, retention, and LTFU may differ among providers with smaller HIV patient caseloads, not receiving support from the Ryan White CARE Act, or with a different mix of patients. Second, it is possible that some patients received care from non-HIVRN providers, and thus some outpatient episodes were potentially not captured in the database. Some patients may switch to a different HIV provider in the same locality, although this opportunity may be limited in areas with few HIV specialists or for patients lacking insurance. Other patients may move out of the area or may be incarcerated or institutionalized but still receive care. Studies based on patient interviews or insurance claims data are needed to track patients across multiple providers.

In conclusion, this study is one of the first to jointly evaluate 3 points along the care continuum: establishment, retention, and loss to follow-up. Only 20.4% of all patients established care, met the retention criterion in all years, and were not lost to follow-up. The three measures differed in their directions of association with some patient characteristics, suggesting that different factors may shape each measure. Increased adoption of existing interventions, and development of new, more effective interventions are urgently needed to help patients establish and remain in HIV care.

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Appendix

Table A

Multivariate Logistic Regression Analyses – Patients with HIV-1 RNA > 400 (n=15157/11707)

	Established Care	Met Retention Criterion in All Outpatient Years	No Loss to Follow-up > 12 months	Met all Three Criteria
Gender				
Female	----	----	----	----
Male	0.82 (0.69, 0.96)**	0.84 (0.73, 0.97)*	0.90 (0.77 1.05)	0.80 (0.70, 0.91)**
Race/Ethnicity				
White	----	----	----	----
Black	1.15 (1.08, 1.22)***	0.88 (0.81, 0.96)**	1.36 (1.13, 1.63)***	1.08 (0.95, 1.23)
Hispanic	1.27 (1.03, 1.57)*	1.01 (0.95, 1.08)	1.48 (1.19, 1.85)**	1.27 (1.06, 1.53)*
Other	1.01 (0.82, 1.25)	1.04 (0.81, 1.33)	1.33 (0.97, 1.82)	1.19 (0.88, 1.61)
Missing	0.47 (0.33, 0.68)***	0.84 (0.61, 1.15)	0.88 (0.42, 1.88)	0.61 (0.36, 1.06)
Risk Group				
MSM	----	----	----	----
HET	0.88 (0.79, 0.98)**	0.84 (0.73, 0.97)*	1.05 (0.95, 1.17)	0.86 (0.78, 0.95)**
IDU	0.46 (0.38, 0.57)***	0.90 (0.72, 1.13)	0.68 (0.57, 0.82)***	0.58 (0.50, 0.68)***
HET+IDU	0.90 (0.68, 1.19)	0.93 (0.73, 1.17)	0.96 (0.75, 1.23)	0.87 (0.63, 1.20)
MSM+IDU	1.09 (0.80, 1.48)	1.00 (0.86, 1.16)	1.00 (0.65, 1.54)	1.01 (0.67, 1.53)
Missing	0.26 (0.15, 0.46)***	1.19 (0.92, 1.56)	0.45 (0.24, 0.88)*	0.40 (0.21, 0.78)**
Age at Enrollment				
18-29	----	----	----	----
30-39	1.03 (0.93, 1.14)	1.15 (1.05, 1.26)**	1.07 (0.94, 1.22)	1.14 (1.04, 1.25)***
40-49	1.23 (1.01, 1.49)*	1.29 (1.16, 1.43)***	1.23 (1.11, 1.37)***	1.45 (1.33, 1.58)***
50+	1.34 (1.14, 1.57)***	1.61 (1.39, 1.87)***	1.52 (1.26, 1.84)***	1.94 (1.70, 2.20)***
Initial Insurance				
Private	----	----	----	----
Medicaid	0.83 (0.70, 0.99)*	1.04 (0.90, 1.21)	0.86 (0.70, 1.04)	0.89 (0.70, 1.12)
Medicare/Dual	0.65 (0.51, 0.82)*	1.29 (0.99, 1.67)	0.85 (0.62, 1.17)	1.00 (0.72, 1.38)
None/Ryan White	0.76 (0.57, 0.99)*	1.02 (0.93, 1.12)	0.88 (0.74, 1.04)	0.89 (0.75, 1.05)
Missing	0.74 (0.60, 0.91)**	0.96 (0.79, 1.16)	0.90 (0.71, 1.13)	0.89 (0.75, 1.05)
Initial CD4 Cell Count				
<50	----	----	----	----
51-200	1.07 (0.88, 1.30)	0.84 (0.78, 0.91)***	0.79 (0.68, 0.93)**	0.77 (0.70, 0.85)***
201-350	0.91 (0.75, 1.10)	0.84 (0.74, 0.94)**	0.76 (0.61, 0.96)*	0.71 (0.59, 0.86)***
351-500	0.96 (0.78, 1.17)	0.74 (0.65, 0.84)***	0.74 (0.61, 0.90)**	0.65 (0.57, 0.74)***
501+	0.94 (0.77, 1.15)	0.72 (0.64, 0.81)***	0.67 (0.53, 0.85)***	0.59 (0.52, 0.68)***
Missing	4.16 (1.35,12.83)***	0.55 (0.32, 0.94)*	0.79 (0.53, 1.17)	0.98 (0.56, 1.70)

	Established Care	Met Retention Criterion in All Outpatient Years	No Loss to Follow-up > 12 months	Met all Three Criteria
Year of First Visit				
2001	----	----	----	----
2002	1.28 (0.90, 1.81)	1.08 (0.97, 1.20)	1.13 (0.95, 1.33)	1.35 (1.02, 1.80)**
2003	1.22 (0.83, 1.80)	1.22 (1.00, 1.49)*	1.26 (1.07, 1.48)**	1.65 (1.25, 2.17)***
2004	1.01 (0.72, 1.41)	1.33 (1.16, 1.53)***	1.37 (1.14, 1.66)***	1.64 (1.22, 2.20)***
2005	0.84 (0.54, 1.29)	1.48 (1.31, 1.67)***	1.73 (1.35, 2.23)***	2.01 (1.53, 2.64)***
2006	0.96 (0.64, 1.45)	1.70 (1.38, 2.08)***	2.40 (1.93, 2.98)***	2.85 (2.30, 3.53)***
2007	0.88 (0.65, 1.20)	1.95 (1.58, 2.42)***	4.08 (3.18, 5.25)***	3.50 (2.62, 4.68)***
2008	0.73 (0.55, 0.99)*	3.15 (2.62, 3.78)***	22.14 (16.13, 30.37)**	6.63 (4.84, 9.08)***

Note: Entries are adjusted odds-ratios (95% CIs). MSM – Men who have sex with men; IDU – injection drug use; HET – heterosexual transmission. All models included indicators for treatment site.

* p<0.05

** p<0.01

*** p< 0.001

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Table 1

Demographic and Clinical Characteristics of Study Sample

Variable	N (%)	Outpatient Time (months) [median, iqr]	Ratio of Actual Outpatient Time to Possible Outpatient Time [median, iqr]
Overall	22,984 (100%)	25 (9,54)	0.60 (0.17, 0.97)
Gender			
Female	6,357 (27.7)	27 (10,58)	0.82 (0.20, 0.98)
Male	16,627 (72.3)	25 (8,53)	0.73 (0.17, 0.97)
Race/Ethnicity			
White	6,157 (26.8)	23 (8,52)	0.64 (0.15, 0.96)
Black	11,040 (48.0)	27 (10,57)	0.82 (0.21, 0.97)
Hispanic	4,931 (21.4)	26 (9,56)	0.81 (0.16, 0.98
Other	451 (2.0)	22 (7,47)	0.58 (0.13, 0.96)
Missing	405 (1.8)	11 (3,26)	0.29 (0.06, 0.82)
Risk Group			
MSM	8,601 (37.4)	26 (10,54)	0.76 (0.20, 0.97)
HET	8,857 (38.5)	29 (11,59)	0.85 (0.23, 0.98)
IDU	1,904 (8.3)	20 (5,44)	0.58 (0.09, 0.96)
HET+IDU	1,247 (5.4)	33 (12,65)	0.83 (0.29, 0.98)
MSM+IDU	694 (3.0)	30.5 (10,60)	0.72 (0.19, 0.96)
Missing	1,681 (7.3)	10 (2,26)	0.19 (0.03, 0.85)
Age at Enrollment			
18-29	4,035 (17.6)	23 (8,52)	0.71 (0.16, 0.96)
30-39	7,593 (33.0)	26 (8,59)	0.69 (0.15, 0.97)
40-49	7,876 (34.3)	26 (9,53)	0.79 (0.19, 0.98)
50+	3,480 (15.1)	49 (27,77)	0.88 (0.24, 0.98)
Initial Insurance			
Private	2,731 (11.9)	24 (10,49)	0.80 (0.20, 0.97)
Medicaid	7,361 (32.0)	24 (8,51)	0.77 (0.16, 0.98)
Medicare/Dual	1,802 (7.8)	21 (7,44)	0.78 (0.17, 0.97)
None/Ryan White	8,063 (35.1)	26 (9,56)	0.76 (0.17, 0.97)
Missing	3,027 (13.2)	36 (11,66)	0.70 (0.19, 0.97)
Initial CD4			
<50	3,008 (13.1)	25 (8,55)	0.82 (0.20, 0.97)
51-200	4,231 (18.4)	24 (9,53)	0.78 (0.18, 0.97)
201-350	4,679 (20.4)	25 (8,53)	0.75 (0.16, 0.97)
351-500	4,061 (17.7)	25 (8,53)	0.73 (0.16, 0.97)
501+	5,863 (25.5)	24 (7,53)	0.69 (0.14, 0.97)
Missing	1,142 (5.0)	40 (20,72)	0.87 (0.45, 0.97)

Variable	N (%)	Outpatient Time (months) [median, iqr]	Ratio of Actual Outpatient Time to Possible Outpatient Time [median, iqr]
Year of first visit			
2001	3,135 (13.6)	45 (9,96)	0.57 (0.09, 0.97)
2002	2,702 (11.8)	51 (14,86)	0.74 (0.18, 0.98)
2003	3,186 (13.9)	49 (14,75)	0.74 (0.20, 0.98)
2004	2,887 (12.6)	40 (9,62)	0.68 (0.14, 0.97)
2005	2,495 (l0.9)	33 (7,51)	0.68 (0.14, 0.96)
2006	2,565 (11.2)	34 (8,41)	0.84 (0.20, 0.98)
2007	2,860 (12.4)	24 (7,29)	0.84 (0.23, 0.97)
2008	3,154 (13.7)	13 (6, 18)	0.83 (0.32, 0.95)
First HIV-1 RNA			
Not suppressed	15,157 (66.0)	24 (8, 53)	0.74 (0.16, 0.97)
Suppressed	5,696 (24.8)	24 (8, 51)	0.78 (0.17, 0.97)
Missing	2,131 (9.2)	38 (14,70)	0.76 (0.17, 0.97)

Note: MSM – Men who have sex with men; IDU – injection drug use; HET – heterosexual transmission; iqr – inter-quartile range.

Table 2

Unadjusted Associations of Retention Measures with Sociodemographic and Clinical Variables

	Established Care	Met Retention Criterion in All Outpatient Years	No Loss to Follow-up > 12 months	Met all Three Criteria
N	22,984	17,988	17,988	22,984
Overall	78.3%	42.6%	65.1%	20.4%
Gender *¶				
Female	79.9	42.2	67.6	21.4
Male	77.7	42.7	64.1	20.1
Race/Ethnicity *‡¶†				
White	76.8	43.7	60.0	18.9
Black	79.9	40.1	67.6	20.6
Hispanic	78.1	46.6	66.6	22.8
Other	75.8	45.6	59.4	19.7
Missing	59.3	42.1	56.3	11.1
Risk Group *¶‡				
MSM	80.2	43.3	64.0	21.2
HET	81.0	40.8	68.8	21.7
IDU	71.7	45.8	62.4	19.1
HET+IDU	84.0	39.9	64.2	20.1
MSM+IDU	80.8	39.8	57.8	16.6
Missing	56.3	50.6	54.1	13.3
Age at Enrollment ‡¶†				
18-29	77.0	36.8	63.0	16.5
30-39	77.8	39.4	61.3	17.1
40-49	78.8	45.0	66.6	22.4
50+	79.5	50.5	72.0	27.9
Initial Insurance *‡¶†				
Private	79.9	44.3	67.6	22.5
Medicaid	77.3	46.0	67.1	22.3
Medicare/Dual	76.6	52.7	69.0	27.1
None/Ryan White	77.9	39.8	65.4	18.9
Missing	81.2	34.6	55.3	14.3
Initial CD4 Cell Count *‡¶†				
<50	77.6	45.8	70.4	24.0
51-200	78.9	44.4	66.1	21.6
201-350	77.0	44.4	65.7	21.0

	Established Care	Met Retention Criterion in All Outpatient Years	No Loss to Follow-up > 12 months	Met all Three Criteria
351-500	77.2	42.5	64.5	20.0
501+	76.5	42.6	62.9	18.9
Missing	96.0	24.3	59.1	13.1
Year of First Visit *‡¶†				
2001	77.9	34.0	50.2	10.2
2002	83.9	33.7	54.1	13.1
2003	84.2	36.6	55.0	15.0
2004	78.7	39.6	56.1	14.5
2005	75.3	41.8	61.9	17.0
2006	77.4	46.1	71.5	24.1
2007	75.5	50.3	80.3	27.9
2008	73.0	60.7	95.1	40.7
First HIV-1 RNA *‡¶†				
Not suppressed	77.2	43.0	65.5	20.4
Suppressed	78.1	46.7	66.5	22.9
Missing	86.0	30.2	59.1	14.4

Note: MSM – Men who have sex with men; IDU – injection drug use; HET – heterosexual transmission.

* p< 0.01 for association with establishing care.

‡ p<0.01 for association with continuous retention.

¶ p<0.01 for association with loss to follow-up.

† p<0.01 for association with meeting all three criteria.

Table 3

Multivariate Logistic Regression Analyses

	Established Care	Met Retention Criterion in All Outpatient Years	No Loss to Follow-up > 12 months	Met all Three Criteria
Gender				
Female	----	----	----	----
Male	0.81 (0.71, 0.93)**	0.90 (0.80, 1.01)	0.87 (0.75 1.01)	0.82 (0.72, 0.93)**
Race/Ethnicity				
White	----	----	----	----
Black	1.16 (1.08, 1.24)***	0.88 (0.82, 0.95)***	1.32 (1.12, 1.56)***	1.07 (0.98, 1.16)
Hispanic	1.26 (1.05, 1.50)*	1.03 (0.97, 1.09)	1.37 (1.12, 1.68)**	1.24 (1.07, 1.44)**
Other	1.05 (0.81, 1.37)	1.01 (0.82, 1.24)	1.01 (0.77, 1.33)	1.05 (0.90, 1.22)
Missing	0.46 (0.37, 0.58)***	0.91 (0.64, 1.28)	0.74 (0.44, 1.25)	0.56 (0.37, 0.86)**
Risk Group				
MSM	----	----	----	----
HET	0.87 (0.80, 0.94)**	0.85 (0.76, 0.96)**	1.04 (0.93, 1.16)	0.83 (0.74, 0.94)**
IDU	0.51 (0.44, 0.59)***	0.86 (0.70, 1.06)	0.66 (0.57, 0.77)***	0.58 (0.49, 0.68)***
HET+IDU	0.96 (0.70, 1.32)	0.86 (0.70, 1.04)	0.89 (0.75, 1.07)	0.79 (0.59, 1.06)
MSM+IDU	1.07 (0.78, 1.46)	0.91 (0.79, 1.05)	0.93 (0.70, 1.22)	0.85 (0.61, 1.17)
Missing	0.27 (0.15, 0.48)***	1.14 (0.95, 1.38)	0.47 (0.26, 0.88)*	0.40 (0.21, 0.77)**
Age at Enrollment				
18-29	----	----	----	----
30-39	1.04 (0.96, 1.12)	1.14 (1.07, 1.20)***	1.08 (0.94, 1.24)	1.16 (1.04, 1.28)***
40-49	1.19 (1.04, 1.37)**	1.31 (1.22, 1.40)***	1.25 (1.11, 1.42)***	1.48 (1.34, 1.64)***
50+	1.36 (1.24, 1.49)***	1.54 (1.37, 1.72)***	1.57 (1.35, 1.84)***	1.92 (1.67, 2.21)***
Initial Insurance				
Private	----	----	----	----
Medicaid	0.85 (0.72, 1.01)	1.03 (0.87, 1.23)	0.94 (0.75, 1.17)	0.93 (0.74, 1.18)
Medicare/Dual	0.76 (0.61, 0.95)*	1.30 (1.12, 1.51)**	0.94 (0.72, 1.24)	1.11 (0.89, 1.38)
None/Ryan White	0.77 (0.57, 1.03)	1.01 (0.91, 1.12)	0.96 (0.83, 1.12)	0.93 (0.78, 1.06)
Missing	0.93 (0.79, 1.10)	0.86 (0.64, 1.16)	0.99 (0.80, 1.24)	0.93 (0.69, 1.24)
Initial CD4 Cell Count				
<50	----	----	----	----
51-200	1.08 (0.91, 1.28)	0.86 (0.81, 0.91)***	0.77 (0.67, 0.90)***	0.77 (0.70, 0.86)***
201-350	0.95 (0.78, 1.15)	0.86 (0.76, 0.96)*	0.74 (0.61, 0.90)**	0.73 (0.62, 0.85)**

	Established Care	Met Retention Criterion in All Outpatient Years	No Loss to Follow-up > 12 months	Met all Three Criteria
351-500	0.97 (0.78, 1.19)	0.79 (0.71, 0.88)***	0.71 (0.59, 0.86)***	0.69 (0.60, 0.79)***
501+	0.91 (0.76, 1.08)	0.78 (0.70, 0.86)***	0.65 (0.53, 0.81)***	0.62 (0.57, 0.68)***
Missing	6.57 (4.15,10.40)***	0.47 (0.36, 0.61)***	0.71 (0.55, 0.93)**	0.58 (0.40, 0.82)***
Year of First Visit				
2001	----	----	----	----
2002	1.44 (0.97, 2.13)	1.10 (1.01, 1.21)*	1.16 (0.99, 1.34)	1.50 (1.08, 2.07)**
2003	1.59 (0.96, 2.63)	1.27 (1.06, 1.52)*	1.27 (1.08, 1.49)***	1.83 (1.27, 2.63)***
2004	1.10 (0.77, 1.59)	1.42 (1.22, 1.64)***	1.35 (1.12, 1.64)***	1.77 (1.24, 2.54)***
2005	0.97 (0.61, 1.55)	1.48 (1.32, 1.67)***	1.74 (1.38, 2.20)***	2.17 (1.50, 3.16)***
2006	1.04 (0.69, 1.59)	1.72 (1.43, 2.07)***	2.62 (2.09, 3.30)***	3.17 (2.36, 4.25)***
2007	0.98 (0.67, 1.43)	1.99 (1.53, 2.58)***	4.45 (3.54, 5.61)***	3.88 (2.62, 5.72)***
2008	0.84 (0.60, 1.18)	2.97 (2.45, 3.60)***	20.92 (16.34, 26.77)**	6.89 (4.62, 10.02)***
First HIV-1 RNA				
Not suppressed	----	----	----	----
Suppressed	1.13 (0.98, 1.31)	1.06 (1.01, 1.10)*	1.04 (0.93, 1.16)	1.11 (0.99, 1.24)
Missing	0.92 (0.66, 1.30)	0.91 (0.71, 1.16)	1.08 (0.92, 1.26)	0.91 (0.68, 1.21)

Note: Entries are adjusted odds-ratios (95% CIs). MSM – Men who have sex with men; IDU – injection drug use; HET – heterosexual transmission. All models included indicators for treatment site.

* p<0.05

** p<0.01

*** p< 0.001

Table 4

Proportion Meeting the Consistent Retention Criterion in Each Outpatient Year, among Established Patients

Total Number of Outpatient Years	Outpatient Year 1	2	3	4	5	6	7	8	9
1	1.00								
2	0.91	0.49/0.68							
3	0.90	0.76	0.48/0.67						
4	0.88	0.72	0.74	0.50/0.67					
5	0.88	0.72	0.72	0.74	0.50/0.67				
6	0.86	0.71	0.70	0.71	0.75	0.51/0.69			
7	0.85	0.72	0.71	0.70	0.73	0.77	0.55/0.72		
8	0.85	0.73	0.72	0.69	0.71	0.72	0.77	0.51/0.70	
9	0.91	0.79	0.77	0.74	0.75	0.76	0.77	0.82	0.48/0.69
Total	0.90	0.67	0.66	0.66	0.68	0.68	0.67	0.64	0.48

Note: Entries are proportions meeting the consistent retention criterion in each year of outpatient time. Second diagonal entries are proportions calculated after removing patients with ≤90 days in their last outpatient year.

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