# Decade of HIV in Rhode Island: Demographic and Clinical Characteristics of Patients Diagnosed in 2001 and 2010

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## ABSTRACT

This article provides an overview of the current epidemiology of HIV infection in Rhode Island, summarizes disease trends over the last decade, and describes circumstances surrounding patient diagnosis.

**Methods:** We performed a retrospective chart review of patients newly diagnosed with HIV who presented to the Immunology Clinic of The Miriam Hospital in 2001 and 2010.

**Results:** From 2001 to 2010 there was an increase in patients reporting MSM (men who have sex with men) as their primary risk factor, and in diagnosis occurring at outpatient sites (p=.03). CD4 count at diagnosis was highest when diagnosed at an HIV testing site and lowest in inpatients (p=.0003). Late presenters were more likely to be tested because of illness (p=.001), as inpatients (p=.000), and heterosexuals (p=.017)).

**Conclusions:** MSM and minorities are overrepresented in the RI HIV population. Patients without traditional risk factors are more likely to present late and are poorly served by historic screening practices.


**KEYWORDS:** HIV/AIDS, CD4, MSM

## INTRODUCTION

The number of Americans living with HIV is higher than ever before. In 2006, approximately 1 million people in the United States were infected with HIV,[1] with 1 in 5 unaware of their status.[2] Despite aggressive education and prevention campaigns, the incidence rate is not slowing down. According to the most recent estimates, incidence has remained relatively stable over the past decade, accounting for 56,000 new infections per year.[3] Furthermore, immune status at presentation to care has not improved[4] despite a growing body of evidence showing that earlier diagnosis and treatment provides numerous individual health and lifestyle benefits as well as decreased transmission to sexual partners.[5,6,7]

To address these challenges, new strategies to encourage earlier HIV testing and referral into care have been implemented locally and nationally over the last decade. In 2006, the Centers for Disease Control and Prevention (CDC) published revised recommendations for HIV testing in all healthcare settings.[8] New guidelines endorse universal screening for patients in all healthcare settings with opt-out verbal consent in lieu of opt-in written consent, and eliminate counseling requirements. In 2009, Rhode Island passed legislation allowing providers to offer opt-out HIV testing with verbal consent alone.[9] In theory, these changes would facilitate universal outpatient HIV testing, leading to earlier diagnosis and care.

Despite the static nature of incidence and prevalence data over the past decade, national and regional epidemiological data have reflected a constantly changing epidemic with implications for targeted prevention and testing in certain high-risk populations.[10] This article provides an overview of the current epidemiology of HIV infection in Rhode Island, summarizes disease trends over the last decade, and describes circumstances surrounding patient diagnosis. We also describe symptoms, acute and chronic medical illnesses, and psychiatric illnesses present at the time of diagnosis. We hypothesized that more patients would present to care after testing positive at outpatient screening sites, and that this would result in improved clinical status at presentation.

## METHODS

### Setting and Population

The Samuel and Esther Chester Immunology Clinic of Miriam Hospital provides comprehensive care for approximately 1,500 HIV-positive patients from Rhode Island and surrounding states, comprising over 75% of HIV care within Rhode Island.[11] Services are provided regardless of patient insurance status or ability to pay, and include primary care, case management and counseling, opportunities to participate in research trials, hepatitis screening and coinfection care, and substance abuse education and treatment referrals.

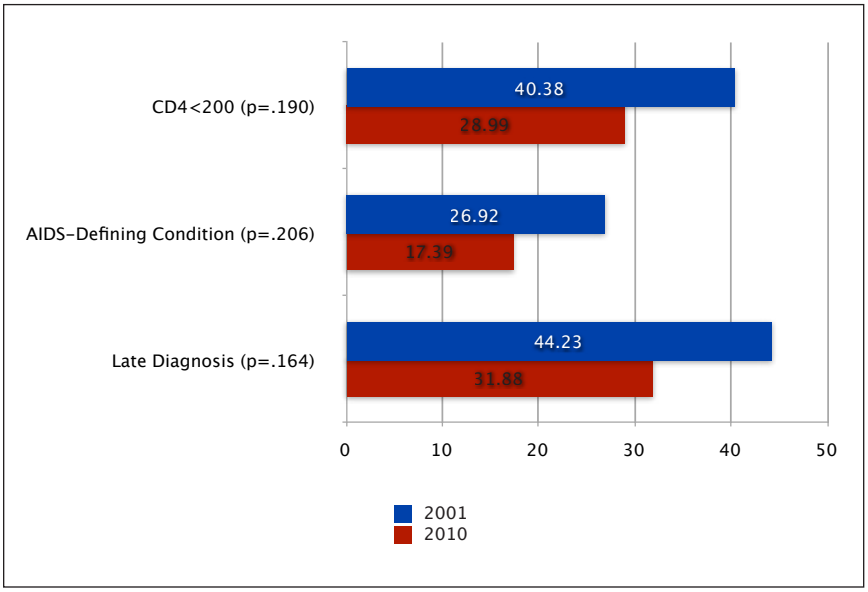
### Data Collection

We performed a retrospective chart review of patients newly diagnosed with HIV presenting to the clinic in 2001 or 2010. Exclusion criteria included an HIV-positive test result more than 12 months prior to presentation or transfer of care from another site. Data collection included demographics, details surrounding patient diagnosis, clinical presentation, and initial lab work. "Late diagnosis" was defined as CD4<200 and/or an AIDS-defining condition at diagnosis. Physician and social work notes were reviewed up to 12 months following the initial presentation and lab values were recorded up to 6

**Table 1.** Demographic and Clinical Characteristics of the Study Population, by Year of Diagnosis

| | 2001 | 2010 | p |
|---|---|---|---|
| **Demographics** | **(n= 52)** | **(n= 69)** | |
| Age, Median (IQR) | 36.7 (30,42) | 37.1 (27,45) | |
| Gender | | | |
| Male | 34 (65.4%) | 53 (76.8%) | 0.17 |
| Female | 18 (34.62%) | 16 (23.2%) | |
| Race/ethnicity | | | |
| White | 20 (38.5%) | 27 (39.2%) | 0.89 |
| Black | 17 (32.7%) | 17 (28.3%) | 0.35 |
| Hispanic | 11 (21.2%) | 18 (26.5%) | 0.50 |
| Other | 4 (7.7%) | 6 (8.8%) | 0.82 |
| Nationality | | | |
| USA | 15 (38.5%) | 40 (58.8%) | 0.04 |
| Other | 24 (61.5%) | 28 (41.2%) | |
| Sexual Identity | | | |
| Heterosexual | 30 (66.7%) | 28 (40.6%) | 0.006 |
| Gay male, lesbian, bisexual, or other | 15 (33.3%) | 41 (59.4%) | |
| HIV transmission risk group | | | |
| MSM | 16 (30.8%) | 43 (66.2%) | 0.0006 |
| IVDU | 2 (3.9%) | 2 (2.9%) | 0.77 |
| IVDU and MSM | 2 (3.9%) | 0 | 0.10 |
| Heterosexual | 30 (57.7%) | 24 (34.8%) | 0.01 |
| Other | 2 (3.9%) | 0 | 0.10 |
| **Clinical Presentation at Diagnosis** | | | |
| CD4 Count, Median (IQR) | 349.8 (102-550) | 454.4 (190-671) | 0.042 |

**Figure 1**. Immune Status at Diagnosis, by Year of Presentation




*Late diagnosis is defined as CD4 count of <200 and/or the presence of an AIDS-Defining Condition present at the time of diagnosis.

months following the initial presentation. This study was approved by the Lifespan IRB.

### Statistical Analysis

Data was aggregated for each study year, and Chi square or Fisher Exact Tests were used to compare demographics, immunological status at diagnosis, HIV risk behaviors, testing site, and testing motivation. A two-sample t-test was used to examine continuous variables. Analyses were performed using STATA10.

## RESULTS

### Demographics

The demographic and selected clinical characteristics of the study populations for each year are shown in Table 1. Statistically significant increases have occurred in the proportion of patients who self-identify as gay males/lesbians/bisexuals/other (p=.016) and patients who list the United States as their country of origin (p=.043). Distribution of risk factors has changed significantly (p=.001), most notably with an increase in the proportion of patients who report MSM (men who have sex with men) as their primary risk factor for transmission. Statistically significant changes were not seen in terms of patient age, gender, or race/ethnicity. Mean CD4 increased from 349 to 454 (p=.042). Although the data shows a moderate decrease in the proportion of patients presenting with a CD4 count <200 and/or an AIDS-defining condition, these results do not achieve statistical significance (Figure 1).

### Test Location and Motivation for Testing

Location of diagnostic test and motivation for seeking the test are shown in Table 2 and Figure 2. A marked increase is seen in the proportion of patients who were diagnosed at HIV/STD test sites and other outpatient sites with a decrease in patients tested as inpatients (p=.03). A smaller proportion of patients were motivated to test by illness, and a larger proportion by knowledge that they or their partners were at risk.

### Risk Factors for Late Diagnosis

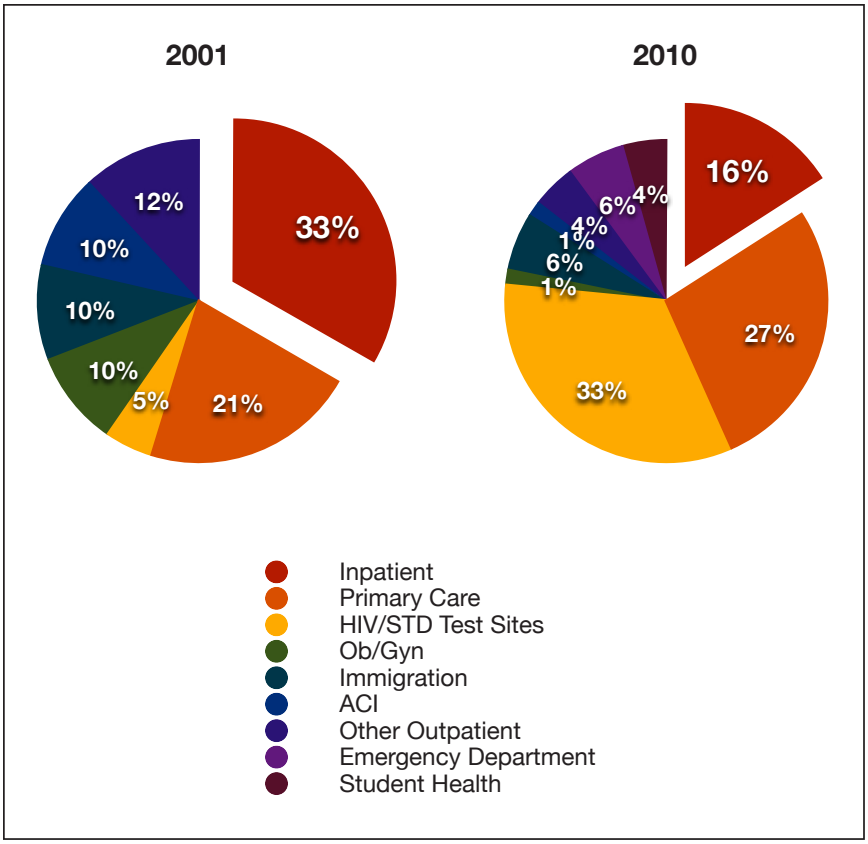
The cohorts from 2001 and 2010 were combined in order to identify groups at

**Table 2.** Testing Site and Motivation for Testing, by Year

| | 2001 | 2010 | p |
|---|---|---|---|
| **Test (Specific)** | n=42 | n=69 | |
| Inpatient | 14 (33.3%) | 11 (15.9%) | 0.03 |
| Emergency Department | 0 (0.0%) | 4 (5.8%) | 0.11 |
| Primary Care | 9 (21.4%) | 19 (27.5%) | 0.47 |
| HIV/STD Test Sites | 2 (4.8%) | 23 (33.3%) | 0.0004 |
| Ob/Gyn | 4 (9.5%) | 1 (1.5%) | 0.05 |
| Immigration | 4 (9.5%) | 4 (5.8%) | 0.46 |
| ACI | 4 (9.5%) | 1 (1.5%) | 0.05 |
| Student Health | 0 (0.0%) | 3 (4.4%) | 0.17 |
| Outpatient NOS | 5 (11.9%) | 3 (4.4%) | 0.14 |
| **Test Motivation** | n=42 | n=69 | |
| Illness | 18 (42.9%) | 22 (31.9%) | 0.24 |
| Self/partner at risk | 4 (9.5%) | 15 (21.7%) | 0.10 |
| Screening* | 13 (31.0%) | 25 (36.2%) | 0.57 |
| Required^ | 6 (14.3%) | 6 (8.7%) | 0.36 |
| Other | 1 (2.4%) | 1 (1.5%) | 0.72 |

* Screening: during routine medical care, outreach
^ Required: blood bank, insurance, immigration

**Figure 2.** Inpatient vs Outpatient Diagnosis by Year




Significant decrease in the percent of patients diagnosed as inpatients (p=.03).

a higher risk of late diagnosis. Patients presenting late were more likely to have been motivated to test because of illness (p=0.001), to have been tested as inpatients (p=0.0004), to self-identify as heterosexual (p=0.017), and to list heterosexual transmission as their primary infection risk (p=0.025). CD4 count at diagnosis (Figure 3) varied widely across diagnosis sites, with the highest mean CD4 reported by patients tested at HIV/STD testing sites and the lowest by patients tested as inpatients (p=.0003).

## AIDS Defining Illness and Symptoms Present at Diagnosis

Signs and symptoms were catalogued for all patients presenting with any illness prompting their diagnosis. Symptoms present varied significantly and were frequently related to AIDS defining illnesses or other conditions present at the time of diagnosis. Opportunistic infections were the most common AIDS defining illness at presentation and dropped by nearly half from 2001 to 2010. In 2010, 18% of symptomatic patients presented to the Rhode Island Hospital or The Miriam Hospital Emergency Department on one or more occasions in the six months prior to their diagnosis with no documentation of any HIV test being performed.

## Non-HIV Chronic Diseases Present at the Time of Diagnosis

Table 3 shows patients presenting with a history of or diagnosed with a chronic condition in the first 6 months of their HIV care. Laboratory data was reviewed and diagnoses of lipid disorders, diabetes, and chronic hepatitis B and C were made based on that data. Reported percentages include only patients where lab data was available. There was a significantly higher rate of reported psychiatric disease (p=0.001) and substance abuse, both active (p=0.017) and prior (p=0.0005). Overall there was no significant change in any medical illnesses reviewed, including diabetes, hypertension, or lipid disorders. Patients presenting in 2010 were significantly more likely to report one or more chronic illness (p=0.002).

**Figure 3.** Variation in Mean CD4 Count, by Diagnosis Site

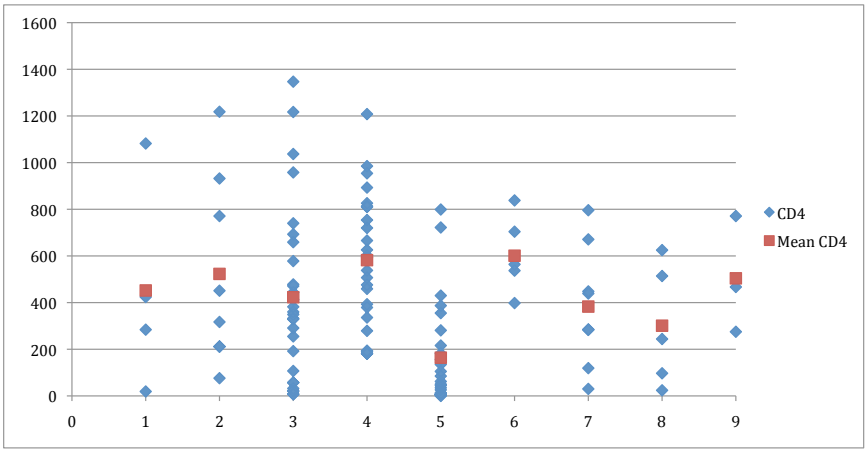



Figure 3 shows the range and mean of CD4 count by diagnosis site. The highest mean CD4 reported by patients tested at HIV/STD testing sites and the lowest by patients tested as inpatients (p=.0003).
1=Emergency Department 2=Outpatient NOS 3=Primary Care 4=HIV/STD Testing Site
5=Inpatient 6=Ob/Gyn 7=Immigration 8=ACI 9=Student Health

**Table 3.** Chronic Diseases Present at the Time of Diagnosis

| | 2001 | 2010 | p |
|---|---|---|---|
| **PCP identified** | 18 (35%) | 35 (51%) | 0.08 |
| | | | |
| **Psychiatric** | 1 (1.9%) | 15 (19%) | 0.001 |
| **Substance Use** | | | |
| Substance abuse- active | 4 (10%) | 21 (30%) | 0.02 |
| Substance abuse- prior | 9 (23%) | 40 (58%) | 0.0005 |
| Smoking History | 9 (22%) | 26 (38%) | 0.87 |
| **Endocrine** | | | |
| Diabetes history | 3 (6%) | 6 (9%) | 0.54 |
| New Diabetes Diagnosis | 2 (4%) | 5 (8%) | 0.38 |
| Total Diabetes | 5 (10%) | 11 (16%) | 0.31 |
| Thyroid disorder | 0 | 4 (6%) | 0.08 |
| **Cardiovascular** | | | |
| Hypertension History | 6 (12%) | 10 (15%) | 0.63 |
| Lipid Disorder- History | 1 (4%) | 4 (6%) | 0.29 |
| Lipid Disorder- New | 2 (18%) | 10 (25%) | 0.64 |
| Lipid Disorder- Total | 3 (27%) | 14 (20%) | 0.60 |
| Low HDL | 4 ( 36%) | 29 (73%) | 0.03 |
| **Co-infections** | | | |
| Hepatitis C | 5 (10%) | 6 (10%) | 0.95 |
| Hepatitis B | 3 (6%) | 2 (3.7%) | 0.62 |
| **Asthma/COPD** | 6 (12%) | 10 (15%) | 0.63 |
| **Seizure Disorder** | 0 | 4 (6%) | 0.08 |
| **Other Illness** | 13 (25%) | 15 (22%) | 0.67 |
| | | | |
| **Total Number of Chronic Illnesses** | | | |
| 0 | 24 (46%) | 14 (20%) | 0.002 |
| 1 | 11(21%) | 23 (33%) | 0.14 |
| 2 | 4 (8%) | 14 (20%) | 0.05 |
| 3-4 | 11 (21%) | 13 (19%) | 0.75 |
| 5+ | 2 (4%) | 6 (8%) | 0.29 |

## LIMITATIONS

Our study was limited by a relatively small sample size. We captured two single "snapshots" in time, which may not accurately reflect epidemic trends or which may represent outlying patient populations. Our study was observational, and thus any changes in demographics, clinical presentation, or diagnostic methodology cannot definitively be attributed to modifications in CDC guidelines or RI legislation. Finally, data for the 2010 cohort was collected shortly after the 2009 RI legislative changes, and so the full impact of that reform may not yet be evident.

## DISCUSSION

### Demographic changes

Many of the demographic trends suggested by these two data points mirror statewide and national trends over the past decade. In Rhode Island, analysis between 2003 and 2007 showed a greater than 30% increase in the proportion of MSM patients, coinciding with a decrease in the proportion of patients infected via IVDU.[11] Nationwide, the proportion of new infections attributable to male-to-male sexual contact has increased rapidly over the past decade, accounting for over half of new infections in 2006.[12] Concurrently, surveys of sexual risk behavior in the MSM population have described increases in high-risk behaviors and other STDs.[13]

In Rhode Island, black and Hispanic patients accounted for roughly 50% of the new infections in Rhode Island over the time period studied, despite making up only 14% of the state's population.[11] In 2006, the nationwide incidence among blacks was 7 times the rate among whites, and the incidence among Latinos was 3 times the rate among whites.[14] Ongoing research highlighting the specific factors that put MSM and ethnic minority populations at heightened risk for HIV infection is essential for targeted prevention, testing, and treatment campaigns.

### Clinical changes

Immunological status at presentation in our cohort (as indicated by mean CD4 count at diagnosis as well as proportion of patients meeting criteria for "late"

diagnosis) appears to have marginally improved over the past decade, although many of the changes in our data set do not achieve statistical significance. Although we are in the midst of a national effort to bring about earlier diagnosis for people with HIV exemplified by the 2006 CDC guidelines as well as the 2009 RI legislation, our data cannot definitively demonstrate a beneficial result. This failure to make gains in the arena of earlier diagnosis has been well documented at other clinical sites. For example, Keruly et al in their report of the Johns Hopkins Clinical Cohort from 1990 through 2006 show a marked decrease in the median presenting CD4+ cell count, from 371 cells/mm3 during 1990–1994 to 276 cells/mm3 during 2003–2006 ($P < .01$).[4]

We were able to identify demographic groups particularly vulnerable to delayed diagnosis. Compared with those patients diagnosed early, patients who presented to care late were more likely to self-identify as heterosexual with no additional HIV infection risk factor. In contrast, neither race, non-US origin, nor gender was significantly associated with early or late diagnosis. These data are consistent with a multi-site study in the United States from 2000-2003, which also found heterosexual contact to predict late diagnosis.[15] Theoretically, a full transition from targeted HIV testing to adoption of the 2006 CDC recommendations for routine screening of all patient populations would minimize this disparity. Until then, it is important for providers to be aware that absence of "traditional" risk factors for HIV infection may actually place patients at a higher risk of late diagnosis.

### Diagnosis site/reason

To our knowledge, motivation for HIV test and HIV testing site have not previously been described in the Rhode Island population, and so we are unable to compare our data points to larger trends. Our data suggests that not only is the proportion of outpatient tests growing, but that patients diagnosed at outpatient sites are generally diagnosed at higher CD4 counts. Additionally, patients who are motivated by illness to test themselves for HIV generally have a lower CD4 count at diagnosis than those motivated by other reasons. This data, while limited, indicates that policies supporting outpatient testing as well as routine screening might improve rates of early diagnosis and entry into care.

### Chronic Disease

Our data shows a striking increase in the presence of chronic disease, specifically psychiatric illness and substance abuse present at the time of HIV diagnosis. The potential explanations for this were not further explored; however in 2010 patients were asked to provide a more extensive psychosocial history during the initial visit to the Immunology Center. With 30% of new patients reporting active substance abuse, and 19% with psychiatric illness, it is of utmost importance that we are prepared to treat these illnesses alongside the HIV and other medial illnesses present in this population.

## CONCLUSIONS

More Americans are living with HIV than ever before, and a large portion remains unaware of their infection. Groups in Rhode Island that are overrepresented in terms of new infections include men who have sex with men as well as patients of African-American or Hispanic ethnicity. Groups overrepresented in terms of late diagnosis of new infection include heterosexual patients without "traditional" risk factors. Historic screening practices based on risk factors or HIV-associated illnesses are poorly suited to identify patients at early stages of infection. Widespread adoption of the new CDC guidelines regarding universal screening is likely to result in an increase in outpatient diagnoses as well as diagnoses at earlier stages of infection. These trends are suggested by this data but further analysis of larger cohorts over time is necessary to confirm these outcomes.

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