SUPPLEMENT ARTICLE

# Epidemiology of HIV Infection in the United States: Implications for Linkage to Care

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**The epidemiology of human immunodeficiency virus (HIV) infection in the United States has changed significantly over the past 30 years. HIV/acquired immune deficiency syndrome (HIV/AIDS) is currently a disease of greater demographic diversity, affecting all ages, sexes, and races, and involving multiple transmission risk behaviors. At least 50,000 new HIV infections will continue to be added each year; however, one-fifth of persons with new infections may not know they are infected, and a substantial proportion of those who know they are infected are not engaged in HIV care. Barriers to early engagement in care may be specific to a demographic group. In this paper, the current epidemiology of HIV/AIDS in the United States is reviewed in order to understand the challenges, successes, and best practices for removing the barriers to effective diagnosis and receipt of HIV care within specific demographic groups.**

The epidemiology of human immunodeficiency virus (HIV) infection in the United States has changed significantly from the early 1980s when it began as an epidemic predominantly in young, white, middle-class men who have sex with men (MSM) and who resided principally in a few of the larger West and East Coast cities [1, 2]. Today, HIV/acquired immune deficiency syndrome (HIV/AIDS) is a disease of far greater demographic diversity, affecting all ages, sexes, races, and income levels; involving multiple transmission risk behaviors; and having a broad geographic distribution in the United States. This epidemiologic diversity is important to understand in order to target the interventions needed to diagnose and treat this disease and to potentially slow the transmission of the virus. This paper reviews current data on the epidemiology of HIV/AIDS in the United States and sets the stage for subsequent papers in this supplement on the issues, challenges, successes, and best practices for removing the barriers to effective diagnosis and receipt of HIV care within specific demographic groups.

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## INCIDENCE AND PREVALENCE OF HIV/AIDS IN THE UNITED STATES

In August 2008, the Centers for Disease Control and Prevention (CDC) published the first national HIV incidence estimates using new methodology that more directly measures the number of new HIV infections in the United States [1, 3]. On the basis of a biological marker of recent HIV infection, the CDC used a stratified extrapolation approach to estimate the HIV incidence among persons aged ⩾13 years in 22 states in 2006. The total was extrapolated to all 50 states and the District of Columbia by applying the HIV-incidence-to-AIDS ratio in the 22 states to the number of AIDS cases in the non-incidence areas. Based on the stratified extrapolation approach, the estimated incidence of HIV in the United States for 2006 was 56,300 new infections, with a 95% confidence interval (CI) of 48,200–64,500. This number is ~40% higher than the CDC's previous estimate of 40,000 new infections per year, which was based on less precise methods.

The new estimate does not reflect an increase in HIV incidence. In fact, the annual number of new HIV infections has been roughly stable since the late 1990s (Figure 1). This analysis shows that new infections peaked in the mid-1980s at ~130,000 infections per year and reached a low of ~50,000 in the early 1990s [3]. The

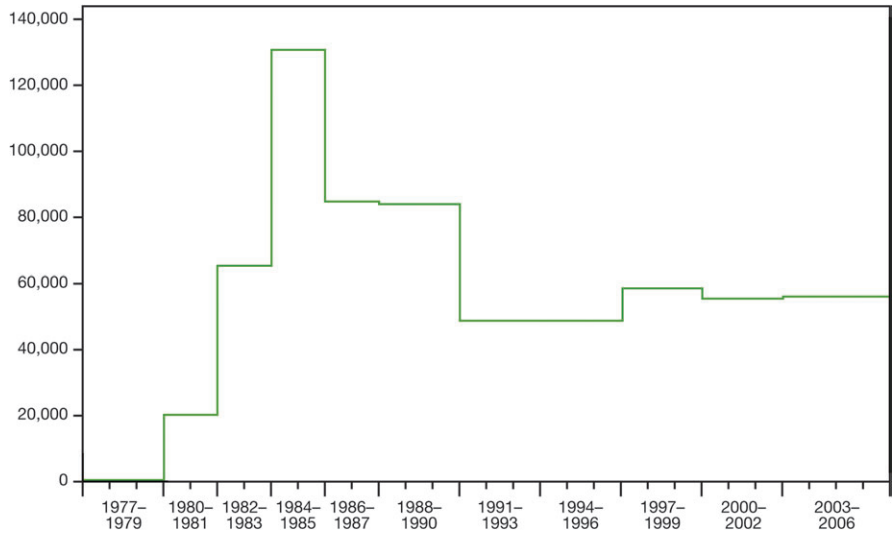


**Figure 1.** Estimated number of new human immunodeficiency virus (HIV) infections, extended back-calculation model, 1977–2006. Estimates are for 2-year intervals during 1980–1987, 3-year intervals during 1977–1979 and 1988–2002, and a 4-year interval for 2003–2006 [3].

incidence then increased in the late 1990s, but it has stabilized since that time. It was predicted that wider access to highly active antiretroviral therapy (HAART) would be associated with fewer HIV transmissions [4]. High-risk behaviors among members of different risk groups, lack of awareness of HIV serostatus, and delay in presentation for HIV care may all be barriers to further decline in the incidence of new infections.

Unlike the incidence, the overall HIV prevalence in the United States cannot be measured directly because an estimated 21% of persons infected with HIV have not been diagnosed. In addition, national HIV prevalence data are incomplete because local reporting systems for confidential, name-based HIV reporting have been fully implemented only since April 2008. Based on 80% of states reporting name-based HIV diagnoses as of January 2006, the extended back-calculation method described above was used to estimate a prevalence of 1,106,400 persons (95% CI, 1,056,400–1,156,400) in the United States living with HIV infection (prevalence rate, 447.8 per 100,000 population) [5, 6].

## RACE/ETHNICITY

While blacks/African Americans account for only 12% of the United States (US) population, they represented 46% of all people living with HIV in the United States in 2006, compared with whites (35%), Hispanic/Latino persons (18%), and others (2%) [7]. HIV prevalence among blacks (1715 per 100,000 population) was almost 8 times higher than among whites (224 per 100,000 population).

Hispanics/Latinos account for 15% of the US population and represented 18% of people living with HIV in 2006 [6]. The overall prevalence rate for Hispanics/Latinos (585 per 100,000 population) was nearly 3 times the rate for whites (224 per 100,000 population).

Although prevalence rates among whites were significantly less than those of blacks/African Americans and Hispanics, whites made up more than one-third of all people living with HIV (35% of total persons). Asians/Pacific Islanders made up ~1% of persons living with HIV, while American Indians/Alaska Natives made up <1% [6].

Black/African American males also bear the greatest burden of new HIV infection [8]. In 2006, the diagnosis rate of new HIV infection for all black males in 22 states (115.7 per 100,000 population) was 6 times that for white males (19.6 per 100,000 population), more than twice the rate for Hispanic males (43.1 per 100,000 population), and more than twice the rate for black females (55.7 per 100,000 population). The diagnosis rate for Hispanic males was ~2 times that for white males.

African American females are also severely and disproportionately affected by HIV infection [8]. In 2006, the HIV diagnosis rate for black females (55.7 per 100,000 population) was >14 times the rate for white females (3.8 per 100,000 population). The rate for Hispanic women (14.4 per 100,000 population) was ~4 times that for white females.

The breakdown of incidence by race/ethnicity using the back-calculation model is shown in Figure 2 [1, 3].

## GENDER

In 2006, men made up three-quarters of the people in the United States living with HIV (828,000 persons) and women made up

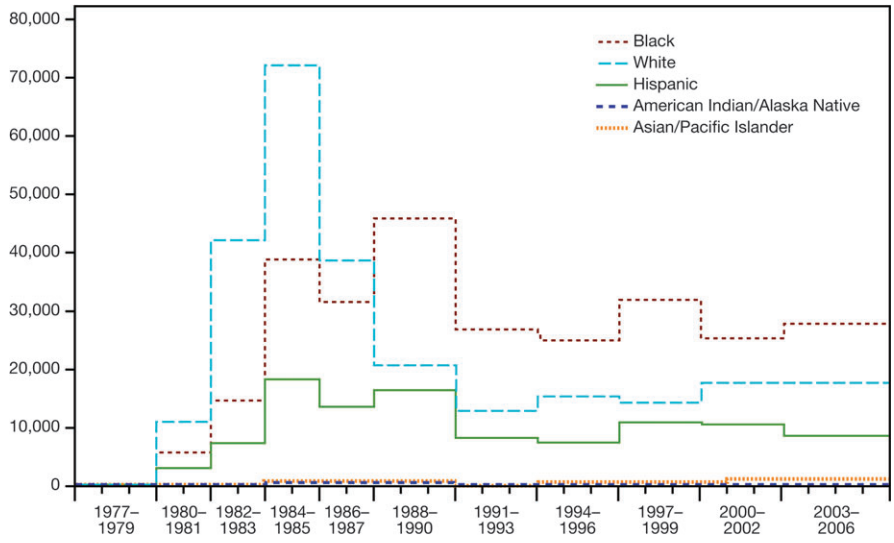


**Figure 2.** Estimated number of new human immunodeficiency virus (HIV) infections, extended back-calculation model, by race/ethnicity, 1977–2006. Estimates are for 2-year intervals during 1980–1987, 3-year intervals during 1977–1979 and 1988–2002, and a 4-year interval for 2003–2006 [3].

one-quarter (278,400 persons) [5, 6]. With regard to new infections, men also accounted for most of the estimated new HIV infections in 2006 (73%, or 41,400) [3, 8]. The historical analysis indicates that the number of infections among men has mirrored the overall trend in HIV incidence, peaking during 1984–1985 and reaching a low point in the early 1990s (Figure 3) [1, 3]. Among women, the incidence of HIV rose gradually until the late 1980s, declined during the early 1990s, and remained relatively stable after that time.

The distribution of new infections differs for males and females by race. Among males, whites had 41% of the new infections, followed by blacks/African Americans with 40% and Hispanics/Latinos with 19%. Among females, the highest proportion of new infections was in blacks/African Americans with 61%, followed by whites with 23% and Hispanics/Latinos with 16% [8].

## AGE

The estimated numbers of new HIV cases diagnosed in the 50 states and the District of Columbia in 2006 stratified by age at time of diagnosis are shown in Table 1 [7].

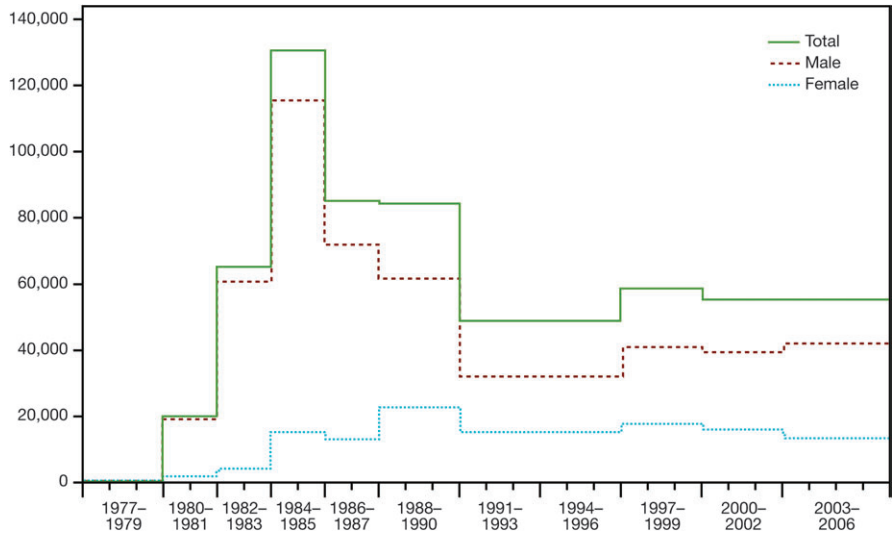


**Figure 3. Estimated number of new human immunodeficiency virus (HIV) infections, extended back-calculation model, overall and by gender, 1977–2006.** Estimates are for 2-year intervals during 1980–1987, 3-year intervals during 1977–1979 and 1988–2002, and a 4-year interval for 2003–2006 [3].

**Table 1. Estimated Number of New Human Immunodeficiency Virus (HIV) Cases in 2006**

| | Incidence | |
|---|---|---|
| Age (years) | Number | Rate per 100,000 |
| <13–29 | 19,200 | 26.8 |
| 30–39 | 17,400 | 42.6 |
| 40–49 | 13,900 | 30.7 |
| ⩾50 | 5800 | 6.5 |

Although HIV continues to be an epidemic primarily of young people, in recent years the number of persons aged ⩾50 years living with HIV/AIDS has significantly increased. Persons ⩾50 years old now account for 24% of those living with HIV/AIDS, an increase from 17% in 2001 [9]. This increase is a result of both the availability of effective antiretroviral therapy, which has reduced early mortality, and an increase in newly diagnosed infections in older individuals. As the US population continues to age, it is important to be aware of specific challenges faced by older Americans and to ensure that they receive information and services to help protect them from HIV infection.

## HIV TRANSMISSION CATEGORY

Nearly half of all people living with HIV in the United States in 2006 (48%, or 532,000 total persons) were men who have sex with men (MSM) [5, 6]. Among men, MSM accounted for 64% of those living with HIV. People infected through high-risk heterosexual contact accounted for more than one-quarter of all people living with HIV (28%, or 305,700 persons). Thirteen percent of men (104,000 persons) and 72% of women (201,700 persons) living with HIV were infected through high-risk heterosexual contact. People infected through injection drug use (IDU) accounted for 19% of all people living with HIV (204,600 persons). Sixteen percent of men (131,500 persons) and 26% of women (73,100 persons) living with HIV were infected through IDU [6].

High-risk heterosexual contact accounted for 31% (16,800) of estimated new HIV infections in 2006, whereas IDU as a primary risk factor accounted for 12% (6600) [1, 3]. In women alone, high-risk heterosexual contact accounted for 83% of HIV transmission, with an additional 16% of HIV transmission via IDU.

Historical trend analysis indicates that new HIV infections declined dramatically in the MSM population between 1988 and 1990, but have thereafter increased (Figure 4) [3]. Male-to-male sexual contact accounted for 53% (28,700) of estimated new HIV infections in 2006 [3]. This trend is supported by other data showing increases in high-risk behavior, sexually transmitted diseases, and HIV diagnoses in this population [10].

In contrast, new HIV infections among injection drug users have continued to decline (Figure 4), indicating some level of success in interventions to reduce HIV infections among this high-risk population. As the incidence of HIV infection in women has increased, there has been a concomitant increase in HIV transmission by high-risk heterosexual contact. This route of transmission is now the second most common [3].

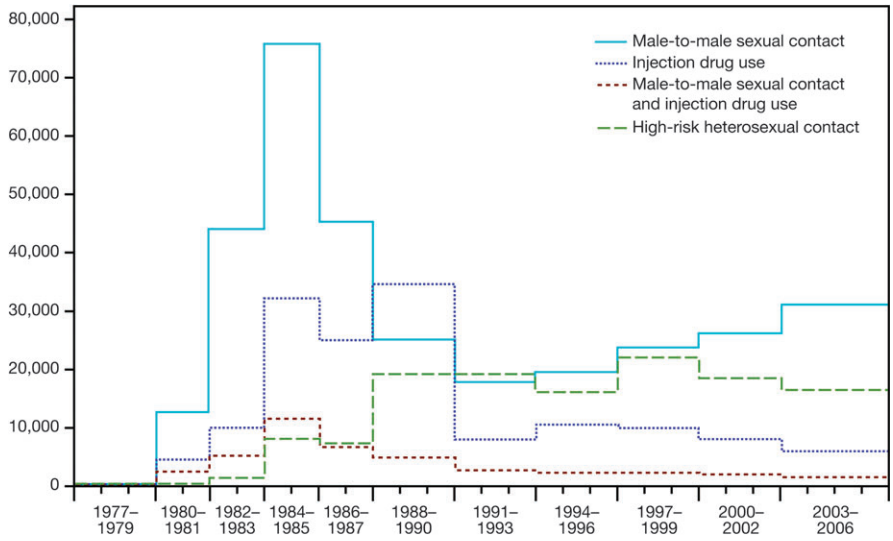


**Figure 4.** Estimated number of new human immunodeficiency virus (HIV) infections, extended back-calculation model, by transmission category, 1977–2006. Estimates are for 2-year intervals during 1980–1987, 3-year intervals during 1977–1979 and 1988–2002, and a 4-year interval for 2003–2006. High-risk heterosexual contact refers to sexual contact with a person known to have, or to be at high risk for, HIV infection [3].

The CDC also updated its estimates of the percentage of individuals infected with HIV who were unaware of their infection [11]. The number of undiagnosed HIV infections was calculated by subtracting diagnosed AIDS prevalence and diagnosed HIV prevalence from the estimated overall HIV prevalence. This new analysis indicates that ~1 in 5 people living with HIV in 2006 (21%, or 232,700 total persons) were unaware of their infection. Whites had the lowest percentage of undiagnosed infections (18.8%) compared with Hispanics/Latinos (21.6%), blacks/African Americans (22.2%), American Indians/Alaska Natives (25.8%), and Asians/Pacific Islanders (29.5%). Persons with a behavioral risk of IDU had the lowest percentage of undiagnosed infections (female, 13.7%; male, 14.5%) compared with a rate of 26.7% in men exposed through heterosexual contact and 23.5% in MSM.

A recent analysis of data from the North American AIDS Cohort Collaboration on Research and Design examined the CD4 cell level at first presentation for HIV care at >60 HIV/AIDS clinical care sites in the United States and Canada [12]. This analysis showed that the median CD4 cell count at first presentation for care was only 235 cells/μL (interquartile range [IQR], 175–426 cells/μL) in 1996, with a relatively modest increase to 327 cells/μL (IQR, 142–528 cells/μL) by 2007. There was remarkable homogeneity geographically across the United States and Canada in the percentage of HIV-infected patients presenting late into care. In one of the participating cohorts where the data were available, the diagnosis of HIV infection itself occurred at a median of <200 days prior to the patients' first presentation for care, suggesting that the actual diagnosis of HIV infection occurs almost as late as their initial presentation for care [13].

In an attempt to diagnose and treat HIV infection earlier than is currently the case, the CDC has recommended universal testing for HIV during routine medical care to identify individuals with HIV/AIDS and link them to HIV-specific medical services [14]. The recommendations specify routine testing for all Americans aged 13–64 years (persons aged ⩾64 years should be counseled to receive HIV testing if they have risk factors for HIV infection). Routine testing is intended not only to identify persons who are unaware that they are HIV infected but also to remove the stigma of being tested.

Unfortunately, many persons who already know they are HIV positive are not sufficiently engaged in care or treatment. Research conducted in 2003 suggested that only slightly more than half of all people living with HIV/AIDS in the United States who were eligible for antiretroviral treatment were receiving it [15]. A study of 16 sites funded through the Ryan White CARE Act to locate "hard-to-reach" people living with HIV/AIDS found that 42% of those individuals were not receiving antiretroviral treatment [16]. This study also found that marginalized groups (including racial/ethnic minorities, nonprescription drug users, and those who are poor, uninsured, and/or homeless) were less likely to be receiving HIV care than the general population of people living with HIV/AIDS if they had low CD4 cell counts. In a recent study combining national prescription data with CDC HIV prevalence estimates, it was estimated that as many as 314,000 individuals who have been diagnosed as being HIV infected are not receiving HIV care [17]. If correct, this number exceeds the number of individuals estimated by the CDC to be infected with HIV but unaware of their infection.

In summary, the HIV epidemic in the United States has not abated. Contemporary antiretroviral therapy does prolong life, and the prevalence of HIV-infected individuals in the United States is higher than ever before. The data indicate that at least 50,000 new HIV infections will continue to be added each year, one-fifth of persons with new infections may not know they are infected, and a substantial proportion of those who know they are infected may not engage in HIV care. The demography of HIV infection has changed over time, with the poor, minority racial/ethnic groups, and women accounting for a greater proportion of infections than ever before. MSM remains an important risk factor for transmission, and heterosexual contact is responsible for an increasing proportion of new infections. Although HIV infection remains predominantly an infection of young people, there are a growing number of men and women aged ⩾50 years who are infected. This number will grow as the HIV-infected population ages on effective antiretroviral therapy.

The challenges of early diagnosis of HIV infection and early engagement in HIV care are multiple, and a number of barriers must be overcome. Systemic barriers can affect anyone and include resource constraints to conduct testing [18], lack of primary care provider training in HIV testing and counseling [19–21], linking newly diagnosed persons to HIV care [22–24], and state legal barriers [25, 26].

Some barriers may be specific to a demographic group. Among blacks/African Americans in the United States, lack of medical insurance and limited access to health care, poverty, and drug use are particular barriers [27]. In women, competing subsistence needs (ie, going without care because money is needed for food, clothing, or housing or postponing care because of lack of transportation) and unmet needs for basic necessities such as child care are particular barriers [28]. In some women, HIV infection may be a less immediate and pressing problem than other problems attendant to depression, drug use, sex trading, and a lack of adequate familial or social support [29].

Fear of stigma associated with a diagnosis of HIV infection also puts many African American communities at a high risk of HIV infection and prevents infected individuals from identifying and seeking HIV care [27, 30]. Many at risk for HIV infection have a fear of the stigma that is greater than their desire to know

their status, choosing instead to hide their high-risk behavior rather than seek counseling and testing. Therefore, they continue to be at risk and may infect others [30]. Many of the same barriers that affect blacks/African Americans also affect Latinos in the United States. In addition, some Latinos face additional unique challenges, including language barriers, cultural values that may impede acknowledgment of risk behaviors (eg, machismo), and migration among those born outside the United States [31].

These challenges and the best practices to link HIV-infected individuals to care are explored in the remaining papers in this supplement.

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