

# **HIV** Surveillance **Report** | Special Report

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Number 6

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## **Clinical and Behavioral Characteristics of Adults Receiving Medical Care for HIV Infection**

**Medical Monitoring Project  
2005 Pilot Data Collection Cycle**



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This report was prepared by the following staff of the Division of HIV/AIDS Prevention, CDC:

Janet M. Blair, PhD, MPH  
A.D. McNaghten, PhD, MHSA  
Linda Beer, PhD  
Jeanne Bertolli, PhD, MPH  
Emma L. Frazier, PhD, MS  
Christopher H. Johnson, MS  
Jennifer L. Fagan, MA  
Eduardo E. Valverde, MPH  
Ann Do, MD, MPH  
Jason B. Reed, MD, MPH

Division of STD Prevention, CDC  
Elaine W. Flagg, PhD, MS

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Division of HIV/AIDS Prevention, CDC  
James D. Heffelfinger, MD, MPH  
Christine L. Mattson, PhD  
Mark S. Freedman, DVM, MPH  
Alicia Edwards, MA, MSPH

Delaware Health and Social Services  
Robert Vella, MPH  
James Dowling

Houston Department of Health and Social Services  
Adebowale Awosika-Olumo, MD, MS, MPH  
Salma Khuwaja MD, MPH, DrPH

Los Angeles County Department of Public Health  
Amy Wohl, PhD  
Judy Tejero, MPH

Maryland Department of Health & Mental Hygiene

Colin Flynn, ScM

Susan Russell Walters, RN, DrPH

Michigan Department of Community Health

Eve Mokotoff, MPH

Meosia Lee-Turner

New Jersey Department of Health and Senior Services

Barbara Bolden, PhD

Kidane Meshesha, MPH

Philadelphia Department of Public Health

Kathleen A. Brady, MD

Michael G. Eberhart, MPH

South Carolina Department of Health & Environmental Control

Wayne Duffus, MD, PhD

Anand Nagarajan, MBBS, MPH

Texas Department of State Health Services

Sharon Melville, MD, MPH

Sylvia Odem, MPH

Washington State Department of Health

Maria Courogen, MPH

Elizabeth Barash, MPH

Additional assistance in the production of this report was provided by Marie Morgan (editing), Division of Creative Services, CDC, and Michael Friend (desktop publishing), Northrop Grumman contractor assigned to the Division of HIV/AIDS Prevention, CDC.

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Although the HIV/AIDS Reporting System (eHARS) is the cornerstone of surveillance of HIV disease, supplemental surveillance projects have provided additional information about care seeking, health care utilization, and behaviors. In 2005, in response to an Institute of Medicine Report [1], the Centers for Disease Control and Prevention (CDC) implemented the Medical Monitoring Project (MMP), a nationally representative, population-based surveillance system to assess clinical and behavioral outcomes among HIV-infected persons [2]. In future cycles, MMP data will be used to provide nationally representative estimates of clinical and behavioral indicators among HIV-infected persons receiving care in the United States and to describe HIV comorbidities, disease management, and quality of care. The data will also be used to identify gaps in services and allocate local HIV/AIDS services and resources for this population.

This surveillance report focuses on interview data from the pilot MMP cycle, during which information was collected on patients in care during 2005. Data were collected during January 2006–August 2007. Interviews were conducted in 10 project areas: Delaware, Houston (Texas), Los Angeles County (California), Maryland, Michigan, New Jersey, Philadelphia (Pennsylvania), South Carolina, Texas, and Washington. (See Technical Notes for more information on MMP methods.)

Of the 899 persons who participated in MMP, 72% were male, 26% were female, and 2% were transgender. Participants were of diverse racial and ethnic backgrounds and age groups. Most participants were black (47%) or white (30%). Most participants were aged 35–44 (38%) or 45–54 (37%); 40% had more than a high school education. Most participants (87%) were born in the United States. For most participants (65%), HIV infection had been diagnosed more than 5 years earlier. Of the 768 participants who reported having any type of health insurance during the past 12 months, most reported having Medicaid (47%) or Medicare (41%) (Table 1).

The benefits of treatment given early in the course of HIV infection are increased survival, reduced morbidity, improved quality of life, lower medical care costs, and reduced transmission [3, 4]. MMP respon-

dents cited structural, financial, and personal or cultural barriers to entering care. A total of 132 persons reported that they had delayed HIV care for  $\geq 4$  months and selected 1–3 reasons for the delay (Table 2). The reason mentioned by the largest percentage of respondents (37%) was “didn’t want to think about being HIV-positive.” Given the reasons provided in this report for not seeking HIV care within 4 months after diagnosis, efforts are needed to reduce barriers to obtaining care.

The following list reflects the services needed (during the past 12 months) by the largest proportions of 892 MMP respondents: HIV case management (46%), mental health counseling (30%), social services (30%; e.g., insurance assistance or financial counseling), and assistance with finding dental services (28%). The need remained unmet for 36 (9%) of those needing HIV case management, 31 (12%) of those needing mental health counseling, 31 (12%) of those needing social services, and 51 (20%) of those needing assistance with finding dental services (Table 3).

Monitoring CD4 T-lymphocyte cell counts and viral load test results are an integral part of HIV disease management. For patients who are taking antiretroviral (ARV) medication, the results of HIV viral load tests are the most important indicator of patients’ response to treatment [5]. In general, CD4 cell counts and viral load should be monitored every 3–4 months according to current guidelines [5]. CD4 cell counts and the results of viral load tests are often used as clinical markers to determine whether HIV-infected persons are receiving health care [6]. Of 690 participants who had undergone a CD4 test during the past 12 months and knew their most recent CD4 count, 115 (17%) reported a CD4 count of  $<200$  cells/mm<sup>3</sup>, and 249 (36%) reported a CD4 count of  $\geq 500$  cells/mm<sup>3</sup> (Figure 1). Of 834 participants who had at least one CD4 test during the past 12 months, 559 (67%) reported that they had been tested 3–4 times (Figure 2).

Of 646 participants who had undergone an HIV viral load test during the past 12 months and who knew their most recent viral load, 384 (59%) reported that the level had been below the level of detection (undetectable) (Figure 3). Of 818 participants who had at least one

viral load test during the past 12 months, 540 (66%) reported that they had been tested 3–4 times (Figure 4).

Of 890 participants, 827 (93%) reported ever having taken ARV medication for HIV infection; 63 (7%) reported never having taken ARV medication. Among the participants who had never taken ARV medication, the most common reasons reported for not doing so were that their CD4 cell count or viral load or both were good (54%), that they followed a doctor's advice to delay treatment (38%), and that they felt good and didn't need them (14%). A total of 80 participants who were not currently taking ARV medications reported the following as their most common reasons: followed doctor's advice to delay treatment (31%), worried about side effects (23%), and CD4 cell count or viral load was good (20%) (Table 4).

Adherence to ARV medication is associated with improved clinical outcomes [5]. Self-reported measures of adherence are associated with HIV viral load [7]. In this report, 717 participants reported currently taking any ARV medications. Of these, 241 (34%) participants had not been fully adherent to their ARV dosing schedule during the month before interview and 239 gave a reason for missing their most recent dose. Among the participants who gave a reason, the most common reasons given were forgetting (37%) and a change in daily routine (17%) (Table 5).

Data on alcohol and drug use during the past 12 months indicate that a total of 468 (52%) participants reported using alcohol or noninjection drugs (i.e., drugs not used for medical purposes). Excluding alcohol, a total of 277 participants reported use of noninjection drugs (Table 6). Of these, 200 (72%) reported using marijuana. The other most frequently reported noninjection drugs were cocaine (smoked or snorted, 24%), crack (24%), and methamphetamines (17%). A total of 31 participants reported having injected drugs (i.e., drugs not used for medical purposes) during the past 12 months. The drugs most frequently reported were methamphetamines (61%), heroin (39%), cocaine (32%), and heroin and cocaine together (32%) (Table 7).

Data on sexual behavior during the past 12 months indicate that risky sexual behaviors were common. Of 234 male participants who reported having anal sex with at least one man, 118 (50%) reported having unprotected anal sex (Figure 5). Of 130 male participants who reported having anal or vaginal sex with at least one woman, 49 (38%) reported having unpro-

tected anal or vaginal sex (Figure 5). A total of 189 (82%) men who have sex with men reported knowing the HIV status of their most recent male sex partner, and a total of 97 (77%) men who have sex with women reported knowing the HIV status of their most recent female partner (Figure 6).

Of 132 female participants who reported having had anal or vaginal sex with at least one man during the past 12 months, 62 (47%) reported having unprotected anal or vaginal sex (Figure 5). A total of 110 (87%) knew the HIV status of their most recent male partner (Figure 6).

A total of 574 (64%) participants in 9 project areas (see Technical Notes) were asked questions about HIV prevention. During the past 12 months, excluding HIV pretest and posttest counseling, 101 (18%) participants had a one-on-one conversation with an outreach worker, counselor, or prevention program worker about ways to protect themselves or their partners from HIV infection or other sexually transmitted diseases. Of these 101 participants, 83 (82%) discussed ways to talk with a partner about safer sex, and 83 (82%) discussed ways to use condoms effectively.

During the past 12 months, excluding discussions with friends, 62 (11%) had participated in at least one small-group session to discuss ways to prevent HIV infection. Of these 62 participants, 49 (79%) had discussed ways to talk with a partner about safer sex, and 48 (77%) discussed ways to effectively use condoms.

A total of 303 (53%) participants had received free condoms from various organizations during the past 12 months. Of these participants, 96 (32%) had received condoms from HIV/AIDS-focused community-based organizations, 108 (36%) from a community public health clinic, and 57 (18%) from an adult HIV/AIDS specialty clinic. Most participants (62%) stated that they had used the free condoms they received, and 167 (55%) stated that receiving these free condoms made them more likely to use condoms during sex.

To achieve several of the goals of CDC's HIV Prevention Strategic Plan through 2010 [8], information is needed about the prevalence of behavioral and clinical outcomes among HIV-infected persons. State and local jurisdictions can use MMP data to guide HIV prevention planning and allocate resources to maximize efficiencies in care and treatment [8].

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# Technical Notes

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This report presents interview data collected during the 2005 pilot cycle of the MMP. Data were collected from January 2006 through August 2007. A total of 13 project areas were funded to conduct data collection activities for this pilot cycle. Interviews were conducted in 10 of the 13 project areas: Delaware, Houston (Texas), Los Angeles County (California), Maryland, Michigan, New Jersey, Philadelphia (Pennsylvania), South Carolina, Texas, and Washington. Medical record abstractions were conducted in 6 project areas: Houston (Texas), Los Angeles County (California), Michigan, New York City (New York), Texas, and Washington. Data from the medical record abstraction component of MMP are not presented in this report.

The following are the eligibility criteria for patients in all participating project areas: diagnosis of HIV infection, age of  $\geq 18$  years, not a previous participant in the current MMP cycle, recipient of medical care during a defined 3-month period, and able to provide informed consent. Sampled participants who died before interview were considered ineligible. Eligible facilities were medical practices in which clinicians ordered tests of CD4 cell counts or HIV viral load or who prescribed ARV medications to HIV-infected patients.

In each MMP data collection cycle, behavioral information is collected by using a standardized questionnaire. The questionnaire is administered during a face-to-face interview, conducted by a trained interviewer who records information on a laptop, a handheld computer, or a paper form. The laptop and handheld devices are equipped with encryption software. CDC's Institutional Review Board determined that MMP was public health surveillance, not a research activity; however, all state and local jurisdictions were responsible for requesting review for the protection of human subjects in their respective project areas.

## MMP SAMPLING METHOD

A 3-stage sampling design was used to obtain cross-sectional probability samples of HIV-infected adults receiving care in the United States. The MMP sample is selected in the following 3 stages.

**Selection of states.** States were selected as the first of the 3 sampling stages. All 50 states, the District of

Columbia, and Puerto Rico (defined as primary sampling units) were eligible for selection. During this first stage of sampling, 20 geographic primary sampling units were selected by using probability-proportional-to-size sampling based upon AIDS prevalence at the end of 2002. Thus, the probability of selection was higher for states with higher AIDS prevalence and lower for states with lower prevalence. If a state included a city with an independent HIV/AIDS surveillance authority (e.g., Texas includes independently funded Houston), selection of the state included selection of the city (i.e., city-state pairs were selected as one unit).

**Facilities providing HIV care.** Selection of HIV care facilities was the second of the 3 sampling stages. In each participating jurisdiction, comprehensive lists of facilities providing HIV care were compiled by MMP staff. A measure of size (estimated patient load during a defined 3-month period) for each facility was determined on the basis of direct contact with the facility or from other sources. From these lists, HIV care facilities were sampled according to the likelihood of selection proportional to their estimated patient load. The probability of selection was higher for facilities with higher estimated patient loads and lower for facilities with lower estimated patient loads. Facilities that did not provide medical care, such as HIV counseling and testing sites, were excluded from the list of facilities. Other facilities that were excluded were emergency departments, facilities located outside the MMP project area's jurisdiction, federal prisons, health care facilities located on military installations, and facilities that provide HIV care exclusively to persons aged  $< 18$  years. Because the 2005 MMP activities were pilot activities, time constraints dictated that not all sample-selected facilities were recruited for participation.

**Patients receiving care.** Selection of individual patients was the third and final sampling stage. Each participating facility compiled comprehensive lists of eligible patients seen during a defined 3-month period, called the population definition period. Each project area determined its own population definition period depending upon when pilot activities began. The sample of patients was selected from the compilation of the lists of eligible patients in each jurisdiction.



Because the 2005 MMP activities were pilot activities, time constraints dictated that not all sample-selected patients were recruited.

## **PARTICIPANT RECRUITMENT**

Persons selected in the third stage of sampling were recruited through either of 2 mechanisms: contact with MMP staff or contact with a health care provider. The strategy used was dependent upon clinic needs, project area needs, and patient load. For recruitment by MMP staff, facilities provided local MMP staff with contact information for patients. For recruitment by a health care provider, patients selected to participate were initially contacted by their health care provider (or staff) in person, by telephone, or by mail. MMP project area staff would then contact the patient directly to arrange an interview.

## **MMP DATA COLLECTION**

Persons who agreed to participate were interviewed in a private location—at home, in a clinic, or at another mutually agreed upon location. Interviewers obtained informed consent and conducted face-to-face interviews. Each interview lasted approximately 45 minutes and consisted of questions concerning participants' demographic characteristics, access to health care, usual source of care, adherence to ARV medications, preventive therapy, reproductive or gynecologic history (women only), vaccinations, unmet needs, (service utilization), sexual behavior, and drug and alcohol use. Two optional modules—health and well-being (not presented) and assessment of prevention activities—were used in 2005. A total of 9 areas (Delaware, Houston [Texas], Los Angeles County [California], Maryland, Michigan, New Jersey, Philadelphia [Pennsylvania], South Carolina, and Texas) implemented the optional prevention module in the 2005 pilot. Participants received \$25 in cash or a gift card in exchange for their time in taking part in the interview.

This report presents results based on interview data from the pilot cycle of MMP in the 10 participating project areas that conducted interviews. From May 2005 through December 2005, a sample of 2,390 persons was selected from 107 facilities.

A total of 900 interviews were conducted during January 2006–August 2007. For the purposes of this report, interview data were excluded for one partici-

pant for whom gender was missing. This report presents the results of a descriptive analysis (no statistical tests were performed) of data from 899 interviews.

The data presented in this report are subject to several limitations and should be interpreted with caution. First, because these data are from the pilot cycle of MMP in an initially funded subset of sampled areas and not all sampled patients were contacted or interviewed, the findings are neither nationally nor locally representative (i.e., they cannot be generalized to all U.S. states, territories, and cities). Second, the survey was administered via in-person interview, so some responses may be inaccurate: that is, participants may have underreported a socially undesirable behavior (e.g., drug use) and overreported a socially desirable behavior (e.g., adherence to ARV medication). Third, stratification by some characteristics may have produced numbers that are too small for reliable interpretation. Further analyses of MMP data from future cycles, which will include larger numbers of project areas and participants, are planned.

**Table 1. Participants, by selected characteristics—Medical Monitoring Project, 2005**

<b>Characteristic</b>	<b>No.</b>	<b>%</b>
<b>Project area</b>		
Philadelphia, PA	207	23
Delaware	184	20
Los Angeles County, CA	138	15
Washington	132	15
Texas	86	10
Houston, TX	46	5
Maryland	41	5
South Carolina	27	3
Michigan	26	3
New Jersey	12	1
<b>Gender</b>		
Male	652	72
Female	231	26
Transgender <sup>a</sup>	15	2
<b>Race/ethnicity<sup>b</sup></b>		
Black	419	47
White	272	30
Hispanic or Latino	143	16
American Indian or Alaska Native	6	1
Multiracial	21	2
Other <sup>c</sup>	38	2
<b>Age at interview (yrs)</b>		
18–24	15	2
25–34	87	10
35–44	344	38
45–54	333	37
≥55	120	13
<b>Education</b>		
<High school	248	27
High school diploma or equivalent	286	32
>High school	362	40
<b>Country or territory of birth</b>		
United States	781	87
Mexico	52	6
Puerto Rico	10	1
Other	56	6
<b>Years since HIV diagnosis</b>		
≥5	581	65
<5	186	21
<b>Homeless<sup>d</sup> at any time in the past 12 months</b>		
Yes	66	7
No	833	93

**Table 1. Participants, by selected characteristics—Medical Monitoring Project, 2005 (cont)**

<b>Characteristic</b>	<b>No.</b>	<b>%</b>
<b>Health insurance or coverage, past 12 months</b>		
Yes	768	85
No	130	14
<b>Type of health insurance or coverage, past 12 months<sup>e</sup></b>		
Medicaid	363	47
Medicare	315	41
Private/HMO	224	29
<b>Source of payments for HIV-related prescriptions, past 12 months<sup>f</sup></b>		
Health care coverage	607	67
ADAP	195	22
Not taking any prescription medicines for HIV or related illnesses	40	4
Paid for HIV medicines themselves (“out of pocket”)	33	4
Got HIV medicines at a public clinic	26	3
Medicines provided by an AIDS service organization	7	<1
<b>Source of most income or financial support, past 12 months</b>		
SSI or SSDI	449	50
Salary or wages	304	34
Public assistance	46	5
Spouse, partner, or family	39	4
No income or financial support	13	1
Pension/retirement fund	12	1
Friends	5	<1
Savings/investments	5	<1
<b>Applied for public assistance, past 12 months</b>		
Yes	190	21
No	708	79
<b>Received public assistance, past 12 months</b>		
Yes	582	65
No	316	35

Note. N = 899. Numbers may not add to total because of missing data. Values exclude cell sizes of <5, don't-know responses, and refusals to answer. HMO, health maintenance organization; ADAP, AIDS Drug Assistance Program; SSI, Supplemental Security Income; SSDI, Social Security Disability Insurance.

<sup>a</sup> Participants were classified as transgender if gender at birth and sexual identity were discordant or if the participant chose “transgender” in response to the gender question.

<sup>b</sup> Hispanics or Latinos may be of any race.

<sup>c</sup> Includes Asian and Native Hawaiian/Pacific Islander: numbers are too small to be presented separately.

<sup>d</sup> Living on the street, in a shelter, a single-room-occupancy hotel, temporarily staying with friends, or living in a car.

<sup>e</sup> Participants could select more than one response. This question was asked of 768 participants who reported health insurance or coverage during the past 12 months (i.e., denominator was 768).

<sup>f</sup> Participants could select more than one response.

**Table 2. Reasons for delaying HIV care entry  $\geq 4$  months—Medical Monitoring Project, 2005**

Reason <sup>a</sup>	Delayed care entry $\geq 4$ months	
	No.	%
Didn't want to think about being HIV-positive	49	37
Didn't want to believe HIV test result	28	21
Felt good, didn't need to go	18	14
Drinking or using drugs	8	6
Didn't know where to go	5	4

Note. N = 132 participants who reported receiving care  $\geq 4$  months after HIV diagnosis (defined as delayed care) and who reported dates of HIV diagnosis and entry into care; 612 participants reported receiving care within 4 months after diagnosis, and 155 participants had missing or invalid values for dates of HIV diagnosis, entry into care, or both.

<sup>a</sup> Participants could select more than one response.

**Table 3. Met and unmet needs for ancillary services during the past 12 months—Medical Monitoring Project, 2005**

Service	Needed service		Unmet need <sup>b</sup> for service	
	No.	% <sup>a</sup>	No.	% <sup>c</sup>
HIV case management	414	46	36	9
Mental health counseling	269	30	31	12
Social services (e.g., insurance assistance or financial counseling)	267	30	31	12
Assistance finding dental services	249	28	51	20
Transportation assistance	205	23	30	15
Assistance finding meals or food	178	20	15	8
Education or information about HIV risk reduction	159	18	12	8
Assistance finding shelter or housing	146	16	52	36
Assistance finding a doctor for ongoing care	122	14	9	7
Adherence support	93	10	9	10
Home health (e.g., home nursing care or assistance)	76	9	11	14
Chore or homemaker	60	7	15	25
Child care	18	2	2	11
Other	32	4	16	50

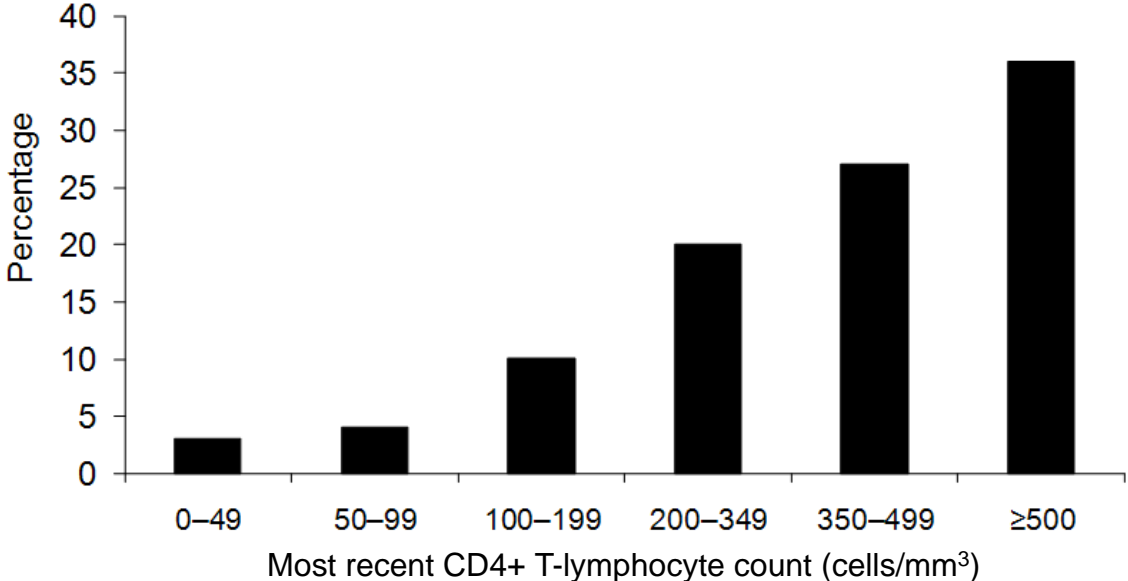
Note. N = 892 participants who were asked about needs.

<sup>a</sup> Percentage of participants who said they had needed the service during the past 12 months (denominator = 892).

<sup>b</sup> Defined as a need that the participant experienced during the past 12 months but that the participant was unable to obtain during that period.

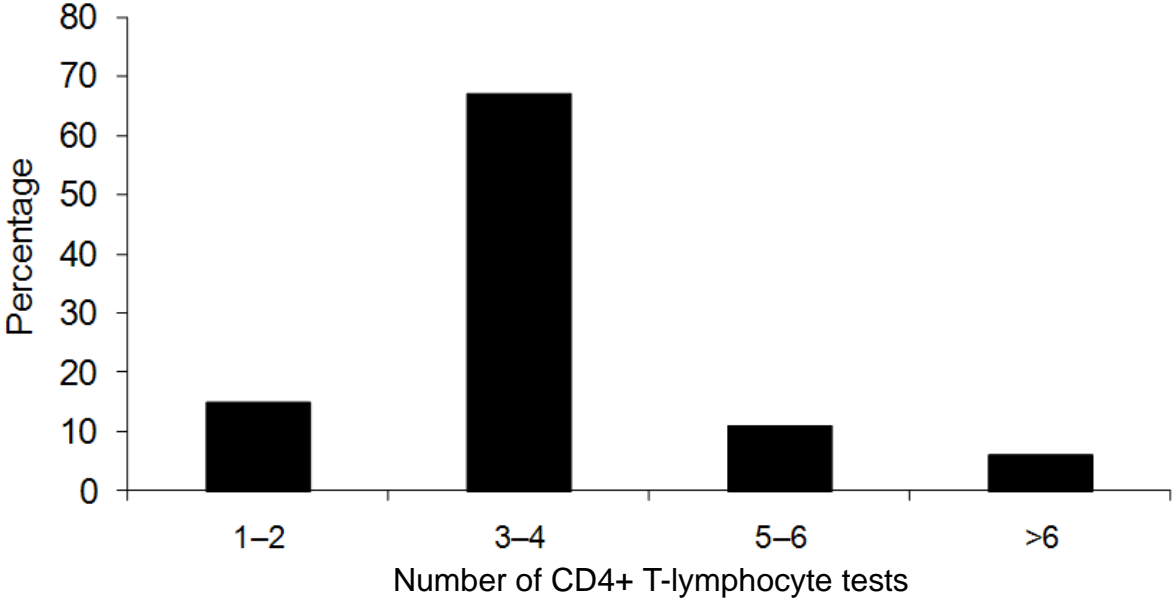
<sup>c</sup> Denominator = the number of participants who needed the specific service (e.g., for HIV case management, the denominator = 414).

**Figure 1. Most recent self-reported CD4+ T-lymphocyte count during the past 12 months—  
Medical Monitoring Project, 2005**



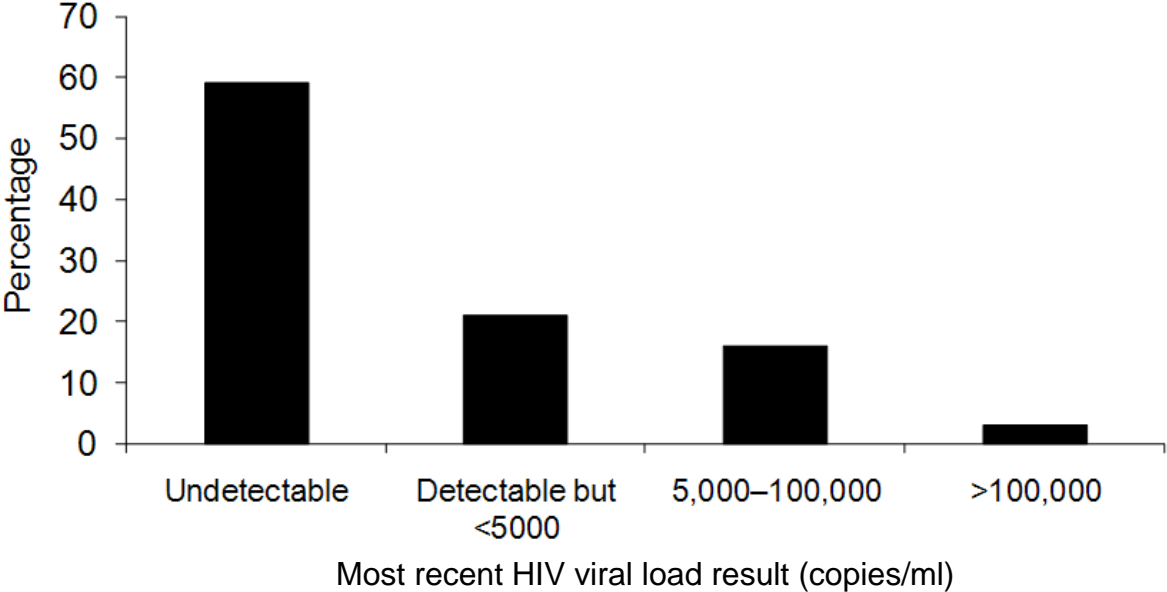
*Note.* N = 690 participants who knew the result of their most recent CD4+ T-lymphocyte test.

**Figure 2. Self-reported number of CD4+ T-lymphocyte tests during the past 12 months—  
Medical Monitoring Project, 2005**



Note. N = 834 participants who had at least one CD4+ T-lymphocyte test.

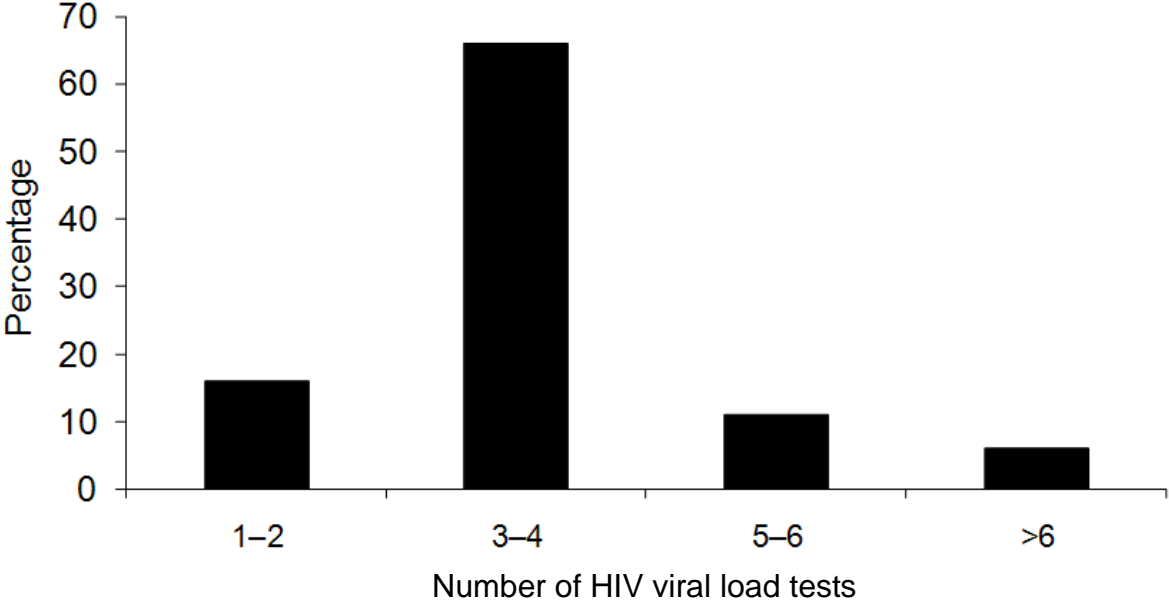
**Figure 3. Most recent self-reported HIV viral load result during the past 12 months—Medical Monitoring Project, 2005**



Note. N = 646 participants who knew the result of their most recent HIV viral load test.



**Figure 4. Self-reported number of HIV viral load tests during the past 12 months—Medical Monitoring Project, 2005**



Note. N = 818 participants who had at least one HIV viral load test.

**Table 4. Most common reasons for not currently taking antiretroviral medications—Medical Monitoring Project, 2005**

<b>Reason<sup>a</sup></b>	<b>No.</b>	<b>%</b>
Doctor advised to delay treatment	25	31
Worried about side effects	18	23
CD4 count or viral load or both are good	16	20
Feel good, so don't need them	13	16

*Note.* N = 80 participants who were not currently taking antiretroviral medications.

<sup>a</sup> Participants could report more than one reason.

**Table 5. Most common reasons for not taking most recent antiretroviral dose—Medical Monitoring Project, 2005**

<b>Reason<sup>a</sup></b>	<b>No.</b>	<b>%<sup>b</sup></b>
Forgot to take them	89	37
Had a change in daily routine	40	17
Was busy with other things	27	11
Wanted to avoid side effects	20	8
Felt depressed or overwhelmed	11	5
Had problems taking pills at specified times (e.g., with meals, on an empty stomach)	6	3

*Note.* N = 239 participants who were currently taking antiretroviral medications and who reported at least one reason for not taking their most recent ARV dose.

<sup>a</sup> Participants could report more than one reason.

<sup>b</sup> Percentage of participants who had missed a dose during the past month.

**Table 6. Noninjection drug use during the past 12 months, by type of drug—Medical Monitoring Project, 2005**

Type of drug	No.	%
Marijuana	200	72
Cocaine (smoked or snorted)	68	24
Crack	68	24
Methamphetamines	48	17
Poppers (amyl nitrate)	43	16
Painkillers (e.g., Oxycontin, Vicodin, Percocet)	30	11
Downers (e.g., Valium, Ativan, Xanax)	29	10
X, or Ecstasy	12	4
Heroin or opium (smoked or snorted)	11	4
GHB	9	3
Special k (ketamine)	6	2
Hallucinogens	5	2

*Note.* N = 277. Drugs used by <5 persons are not reported in this list.

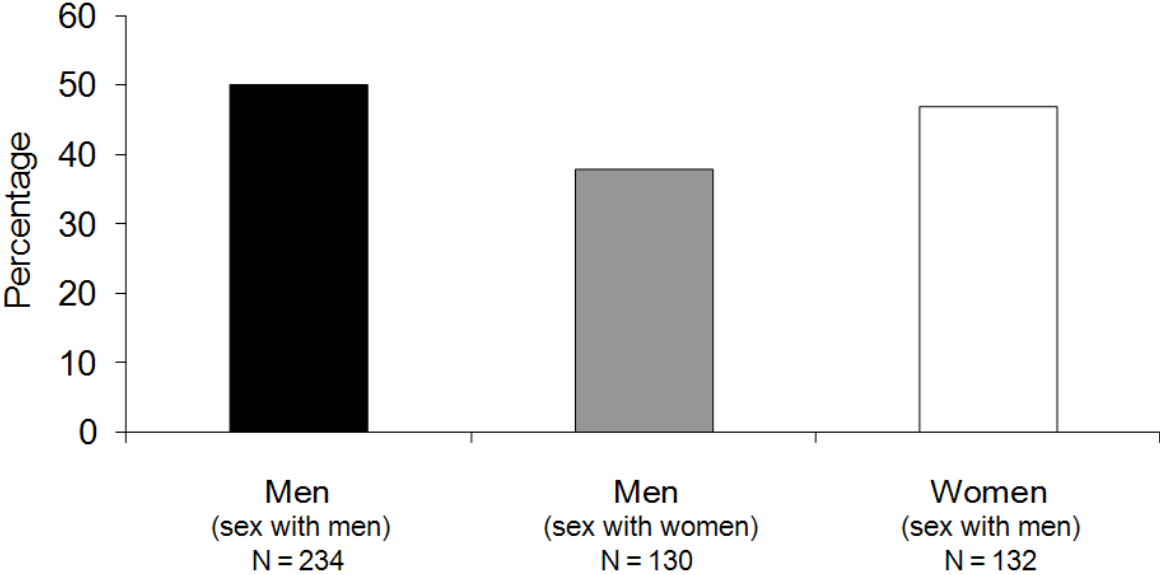
GHB, gamma hydroxybutyrate.

**Table 7. Injection drug use during the past 12 months, by type of drug—Medical Monitoring Project, 2005**

Type of drug	No.	%
Methamphetamines	19	61
Heroin	12	39
Cocaine	10	32
Heroin and cocaine	10	32
Crack	6	19

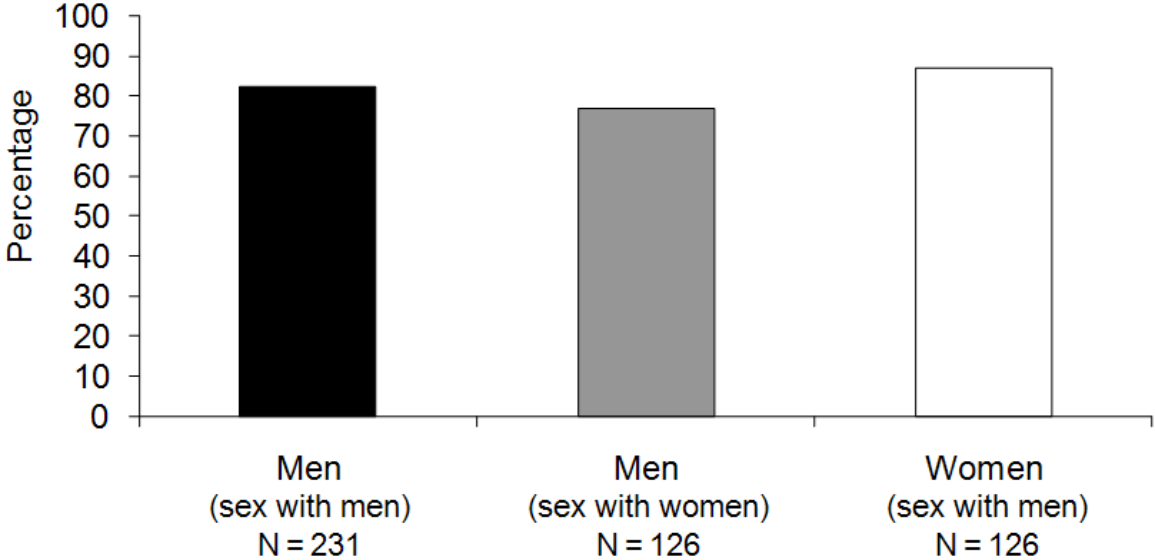
*Note.* N = 31. Drugs used by <5 persons are not reported in this list.

**Figure 5. Unprotected anal and/or vaginal sex with at least one partner during the past 12 months, by gender of patient and sex partner—Medical Monitoring Project, 2005**



*Note.* N = 496. The following categories are not mutually exclusive: “men who have sex with men” and “men who have sex with women.” Data for transgender respondents not reported because of small numbers.

**Figure 6. Knowledge of HIV status of most recent sex partner during the past 12 months, by gender of patient and sex partner—Medical Monitoring Project, 2005**



Note. N = 483. The following categories are not mutually exclusive: “men who have sex with men” and “men who have sex with women.” Data for transgender respondents not reported because of small numbers.