



What is the True Prevalence of HIV in New York City:

Estimating the number of undiagnosed and unreported persons living with HIV and AIDS, 2003

Lucia V. Torian,¹ Yussef Bennani,¹ Thomas R. Frieden²

¹The New York City Department of Health and Mental Hygiene, HIV Epidemiology Program, ²Office of the Commissioner of Health

HIV Epidemiology Program
 NYC Department of Health and Mental Hygiene
 340 Broadway, Rooms 701-707A, CN-44
 New York, NY 10013
 Phone: (212) 442-3461
 Fax: (212) 442-3462
 Ltorian@health.nyc.gov

Abstract

Background: New York State implemented named reporting of HIV infection on June 1, 2000. Despite this mandate, the surveillance system does not capture all persons living with HIV/AIDS (PLWHA). Persons not testing for HIV may remain undiagnosed for 10+ years after seroconversion. Others are diagnosed but remain unreported. Without knowledge of the true size and characteristics of the population of PLWHA in its jurisdiction, NYC cannot accurately monitor its HIV epidemic, plan prevention and treatment services, and project the costs of antiretroviral drugs and ambulatory, hospital and terminal care. The NYCDOHMH used data from surveillance and a variety of research studies to estimate the total number of PLWHA in NYC.

Methods: As of December 31, 2003, there were 88,479 known PLWHA in NYC. An unknown number of persons was (1) not tested after June 1, 2000, and thus not diagnosed or reported, (2) diagnosed prior to June 1, 2000, but had no subsequent reportable event, (3) diagnosed after June 1, 2000, but not reported due to provider noncompliance or technical failure of the reporting system. The number of unreported PLWHA was calculated by dividing the NYC population into subpopulations by risk and demographic characteristics, estimating the untested population, and multiplying it by a high and low prevalence estimate. The total prevalence is the sum of the estimated prevalence in each of the three unknown categories added to the known (reported) HIV/AIDS cases presumed to be living.

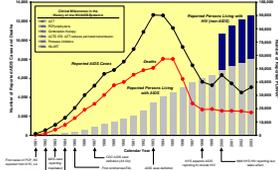
Results: An estimated 11,338-45,914 PLWHA remain undiagnosed. Between 7,968 and 14,463 may have been diagnosed and are not reportable, while between 5,151 and 8,276 are estimated to be diagnosed and not reported. Therefore at least 112,936 and as many as 157,132 persons may be living with HIV or AIDS in New York City. The lower estimate is concordant with local data on late diagnosis of HIV (concurrent HIV/AIDS) and with CDC's estimate that 25% of PLWHA in the U.S. are not diagnosed. Estimates for unreported cases were broken down by risk and demographic characteristics.

Conclusion: The prevalence of HIV in NYC is estimated to be 22-44% greater than that measured by the HIV surveillance system. This local exercise provides NYC with valuable data on the size and characteristics of its unreported population; the detailed breakdowns can be used to plan testing and early detection campaigns as well as to project the need for future services.

Background

- Accurate surveillance for HIV is key to ability to understand epidemic trajectory and to plan and provide disease control and primary care services to New Yorkers.
- In 1983, New York State mandated named reporting of AIDS diagnoses
- June 1, 2000 – Implementation of named HIV reporting

Reported AIDS Cases, PLWHA and Deaths, New York City 1981-2003



- Despite successful implementation of HIV reporting, surveillance does not account for all New Yorkers living with HIV.
- There are three gaps:
 - Persons who are infected but untested and therefore undiagnosed
 - Persons who were diagnosed prior to June 1, 2000 and have not experienced a subsequent reportable event
 - Persons who were diagnosed before or after June 1, 2000 but are not yet reported or counted, including anonymous testers
- This analysis used a combination of census, research and surveillance data to estimate the unknown populations and their test rates and establish a range for the true number of people living with HIV in NYC

Methods

Total N of PLWHA is the sum of:

- HIV+, not tested, not diagnosed
- HIV+, diagnosed < June 1, 2000, without a subsequent reportable event
 - Diagnosed cases not in care
 - Diagnosed cases in care but with no reportable event
- HIV+ diagnosed > June 1, 2000, not reported
 - Unreported HIV (non-AIDS)
 - Unreported AIDS
- Known Living Cases

Data Sources

- Population sizes
 - US Census 2000
 - Community Health Survey (CHS) 2003
 - City Health Information (CHI) 2003
 - NYC Vital Statistics (CBW and Termination of Pregnancy)
 - National Death Index
 - Holmberg S. The estimated prevalence and incidence of HIV in 86 large US metropolitan area. *Am J Publ Health* 1998; 88:524-556.
- Prevalence ranges
 - HTS 2002
 - YMS 1997-2000
 - CHS 2003
 - NY State Comprehensive Newborn Screening
 - Abortion Clinic Serosurvey 1989-1996
 - NYC DOHMH STD Clinics, 2003
 - NYCDOHMH Public Health Laboratory (PHL), 1999-2002
 - Department of Defense Mandatory Military Recruit Screening 2003
 - New York Blood Center 2002
 - National Behavior Surveys, 2004
 - DeJarlatts, DC, Perle T, Torian LV, Arasteh K, Beatrice ST, Wehlers J, Milken J, Midvan D, Yancovitz S, Friedman SR. HIV incidence among injecting drug users in New York City: use of STARHS to assess expansion of HIV prevention services, 1990-2002. *Am J Publ Health* 2004, in press.
- Persons tested for HIV in an past 12 months
 - CHS 2003
 - HIV Testing Survey (HTS) 2002
 - Young Men's Survey (YMS) 1997-2000
 - National Behavioral Surveys, 2004

Untested Populations: Source of Estimates

Population	Plan	Population size	Proportion Tested	Prevalence range low	Prevalence range high
Population 1	Plan 1	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 2	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 3	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 4	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 5	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 6	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 7	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 8	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 9	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 10	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 11	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 12	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 13	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 14	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 15	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 16	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 17	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 18	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 19	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 20	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 21	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 22	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 23	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 24	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 25	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 26	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 27	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 28	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 29	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 30	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 31	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 32	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 33	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 34	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 35	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 36	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 37	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 38	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 39	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 40	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 41	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 42	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 43	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 44	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 45	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 46	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 47	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 48	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 49	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 50	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 51	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 52	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 53	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 54	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 55	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 56	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 57	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 58	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 59	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 60	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 61	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 62	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 63	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 64	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 65	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 66	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 67	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 68	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 69	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 70	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 71	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 72	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 73	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 74	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 75	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 76	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 77	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 78	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 79	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 80	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 81	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 82	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 83	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 84	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 85	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 86	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 87	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 88	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 89	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 90	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 91	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 92	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 93	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 94	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 95	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 96	Men who have sex with men, non-gonorrheal identified	CHS (men who have sex with men, non-gonorrheal identified)	10-20% (high risk)	10-20% (high risk)
Population 1	Plan 97	Men who have sex with men, non-gonorrheal identified			