

**HIV Care in New York State:
Linkage, Retention and Success**

**National HIV/AIDS Strategy Measures
and the Cascade of Engagement in Care, 2012**

AIDS Institute

New York State Department of Health

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Executive Summary

The attached report presents summary measures that serve to evaluate linkage to HIV medical care, retention in care and success of care among persons living with diagnosed HIV infection (PLWDHI) in New York State (NYS).

The measures are primarily derived from the National HIV/AIDS Strategy (White House Office of National AIDS Policy, 2010) and were calculated using data from the New York State Department of Health (NYSDOH) HIV Surveillance System or from other data sources within the NYSDOH AIDS Institute (AI), where noted. Major findings:

Linkage to Care

84% of newly diagnosed cases showed evidence of entry to care within three months of diagnosis.

Continuity of Care

65% of PLWDHI showed evidence of some care during the year.

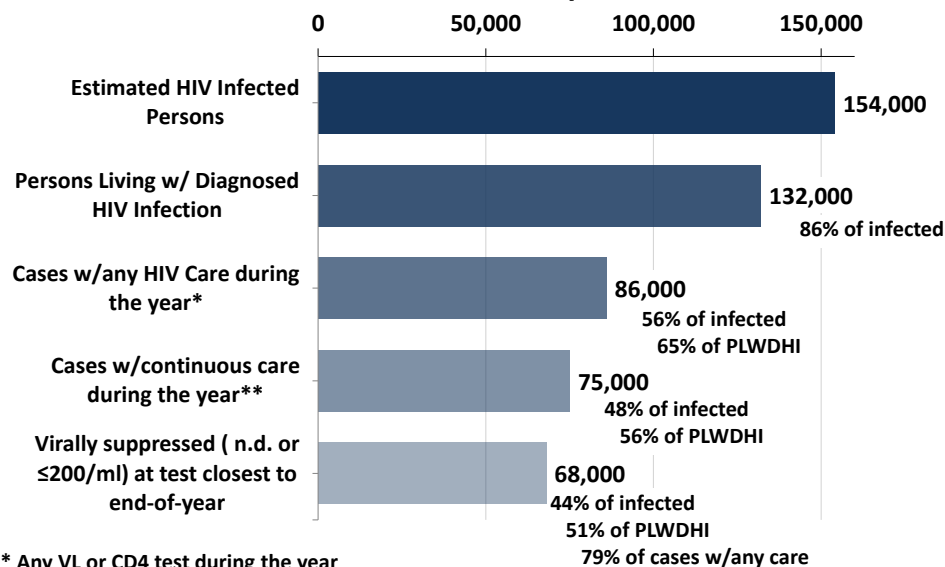
Continuous care (≥ 2 visits/year, ≥ 3 months apart) was observed for 56% of PLWDHI.

Viral Suppression

About 51% of PLWDHI in NYS appeared to be virally suppressed.

These results are combined with other surveillance data to produce the cascade of HIV Care. The cascade presents a picture of the total infected population at one point in time, across the entire spectrum of engagement in care from infection through diagnosis, participation in care and success of care.

Cascade of HIV Care New York State, 2012



Comparison of NYS NHAS-type and cascade measures with national data and targets shows:

Linkage to Care

NYS's 84% of newly diagnosed cases entering care within three months of diagnosis compares well with the NHAS 2015 target of 85%.

Continuity of Care

The percent of total infected persons who are in continuous care appears higher in New York (48%) than in the U.S. as a whole (37%), although NYS and Centers for Disease Control and Prevention (CDC) methods are not identical.

Viral Suppression

The percent of total HIV-infected persons who are virally suppressed is higher in NYS (44%) than in the U.S. (25%).

Note: Caution is advised when comparing NHAS measures and cascade-type displays from different sources. Some NHAS targets are specified only for certain population sub-groups; the related measures displayed may pertain just to those sub-groups or to the entire HIV case population. Measures used by different jurisdictions in their cascades may be calculated differently or use different data sources, even though their titles are similar or identical.

Important changes to this 2012 report

In this 2012 report viral load suppression is based on the individual's last viral load test of the calendar year, bringing the measure into alignment with CDC's practice. Previous editions of this report used viral load at test closest to mid-year. Use of last viral load of the year tends to raise the estimated percent of persons who are virally suppressed. The 2012 percent virally suppressed PLWDHI in NYS is 51% using last test of the year and 49% using test closest to mid-year. Use of the new measure also changes NYS' 2015 NHAS viral suppression target, which was based on 2010 data, from 54% to 56%.

Individuals ever identified as inmates in New York State correctional facilities outside New York City were excluded from regional calculations. Identification may be based on reported residence at diagnosis, on information reported from the NYS Department of Corrections and Community Services to the NYS HIV surveillance program, or on receipt by NYSDOH of a laboratory report referencing a state correctional facility outside New York City. At the state level, exclusion of prisoner cases in the eight Ryan White (RW) regions outside NYC had no effect on the estimated percent of the newly diagnosed who enter care within 3 months of diagnosis but raised the percent of PLWDHI with any care during the year from 64% to 69%, the percent with continuous care from 55% to 59% and the percent virally suppressed from 51% to 56%.

Also, for this report continuity of care among RW program participants was estimated from RW Part B HIV service utilization information from the NYSDOH AIDS Institute Data Application (AIDA)¹ and from HIV surveillance data matched to AIDS Drug Assistance Program (ADAP) participants. Previous iterations of this report presented continuous care among persons living with diagnosed HIV infections in NYS, regardless of RW program participation. The RW Part B program results are presented in the “New York State and the NHAS 2015 Targets” section (See page 10).

¹ AIDA receives service information from RW Part B providers in New York State.

Introduction – Need and Measures for Assessing Engagement in Care

The provision of appropriate medical care for persons living with diagnosed HIV infection (PLWDHI) is a key feature of the fight against HIV. In addition to the immediate benefit to the infected individuals themselves, it is recognized that ‘treatment *is* prevention’, i.e. that persons retained in successful treatment for their HIV infection are less likely to transmit HIV to others. Furthermore, since a very large proportion of HIV-related care is publically funded, it is appropriate to monitor the extent and effectiveness of that care. To monitor care consistently and comparably across geographic areas and over time it is necessary to devise and use a uniform set of measures. The National HIV/AIDS Strategy (White House Office of National AIDS Policy, 2010) presented a set of goals for the nation’s fight against HIV/AIDS and defined specific targets and measures to use in assessing the fight. Several of these targets and measures relate specifically to issues of medical care for PLWDHI, namely the need for prompt entry to care after diagnosis, retention in care over time and demonstration that the care received is decreasing both morbidity and infectiousness among the population in treatment.

NHAS specifies three evaluation measures specific to linkage to care, retention in care and success of care:

1. Proportion of newly diagnosed patients **linked to care within 3 months of diagnosis**
2. Proportion of persons living with diagnosed HIV infection (PLWDHI) who are in **continuous care**, defined as ≥ 2 visits/year, separated by ≥ 3 months
3. Proportion of PLWDHI with **undetectable viral load**

NYSDOH has calculated these measures for calendar year 2012 using data from the NYS HIV surveillance system following methods specified by the CDC. For Ryan White clients, the target population specified for the NHAS goal, continuity of care was calculated using Ryan White Part B program information for 2012 from the AIDS Institute Data Application (AIDA) and from HIV surveillance laboratory data matched to AIDS Drug Assistance Program (ADAP) program participants for 2013. The results serve to monitor the state’s own progress in combating the epidemic and to place New York State’s achievements in a national context.

To present the broadest picture of the diagnostic and care status of the entire HIV-infected population, HIV surveillance data, estimates of the infected population and NHAS-type measures can be combined into a single figure, commonly referred to as a ‘cascade’, which presents the numbers of persons in the entire continuum of engagement in care at one point in time, comprising those infected, diagnosed, participating in care and virally suppressed. NYSDOH has constructed such a cascade for HIV-infected persons in NYS.

The sections that follow present the general results of the NYS linkage, retention and success of care estimations. The **Technical Notes and Appendices** provide detailed tables and explanations

of methods and data sources. *Caution is advised when comparing NHAS measures and cascades from different sources.* Some NHAS targets pertain to certain population sub-groups; but calculated measures may pertain to those groups or, as in this New York State report, to all PLWDHI. Measures used by different jurisdictions in their cascades may be calculated differently or use different data sources, even though their titles are similar.

New York State results for NHAS measures

1. Linkage to Care after Diagnosis (Appendix table A)

84% of newly diagnosed cases showed evidence of entry to care within three months of diagnosis as indicated by a viral load or CD4 test.

Linkage to Care	
Variable	Observation
Region	NYS excluding NYC (87%) > NYC (84%) Highest in the Mid-Hudson (95%*), Buffalo (89%*) Ryan White regions (RWR) Lowest in Syracuse (84%*) and Nassau/Suffolk (84%*) RWR * regional percentages exclude prisoners in state correctional facilities
Sex	Similar for females (83%) and males (84%)
Race/Ethnicity	White (89%), Asian/Pacific Islander (89%) > African American/Black (81%), Hispanic (84%)
Age	Increase from ages 20-24 (79%) to ages 50-59 (85%)
Transmission Risk	Heterosexual (84%) < MSM (87%)

2. Continuity of Care² (Appendix table B)

65% of PLWDHI showed evidence of some care during the year, as indicated by a VL or CD4 test.

Continuous care (≥2 visits/year, separated by ≥3 months) was observed for 56% of PLWDHI.

Continuous Care	
Variable	Observation
Region	Similar in NYC (57%) and NYS excluding NYC are similar (55%) Wide range across RW regions - 65%* (Rochester) to 54%* (Mid-Hudson and Lower Hudson) * regional percentages exclude prisoners in state correctional facilities
Sex	Females (60%) > males (55%)
Race/Ethnicity	Little variation across race/ethnicity groups, except for Native Americans (45%)
Age	Ages 13-19 years (71%) > older groups (54% to 59%)
Transmission Risk	Highest in pediatric risk (64%) Across the four largest defined risk groups, range from 53% (IDU risk) to 62% (heterosexual risk)

² The continuity of care and viral suppression percentages may be *underestimates*, since laboratory tests performed in federal facilities, e.g. VA hospitals, and in clinical trials are not reportable to the state.

3. Viral Suppression¹ (Appendix table C)

About 51% of PLWDHI in NYS appeared to be virally suppressed, defined as having viral load non-detectable or ≤ 200 copies/ml. This is slightly more than 3/4 of those with any evidence of care.

Viral Suppression	
Variable	Observation
Region	Similar in NYC and NYS excluding NYC (both 51%) Across RW regions, 62%* (Albany) to 53%* (Mid-Hudson and Binghamton) * regional percentages exclude prisoners in state correctional facilities
Sex	Similar for females (52%) and males (51%)
Race/Ethnicity	White, Asian/Pacific Islanders (56%) > Black (48%), Hispanic (50%)
Age	Except for youngest (13-19, 47%), percent suppressed rose steadily from younger (20-24, 41%) to older (50-59, 53%)
Transmission Risk	Highest among MSM (55%) and heterosexual (55%) Lower for female presumed heterosexual (FPHC) (50%) Lowest among IDU risk (44%) and those with pediatric risk (42%)

New York State and the NHAS 2015 Targets

1. Linkage to Care after Diagnosis

NYS's 84% compares well with the NHAS 2015 target of 85%.

2. Continuity of Care

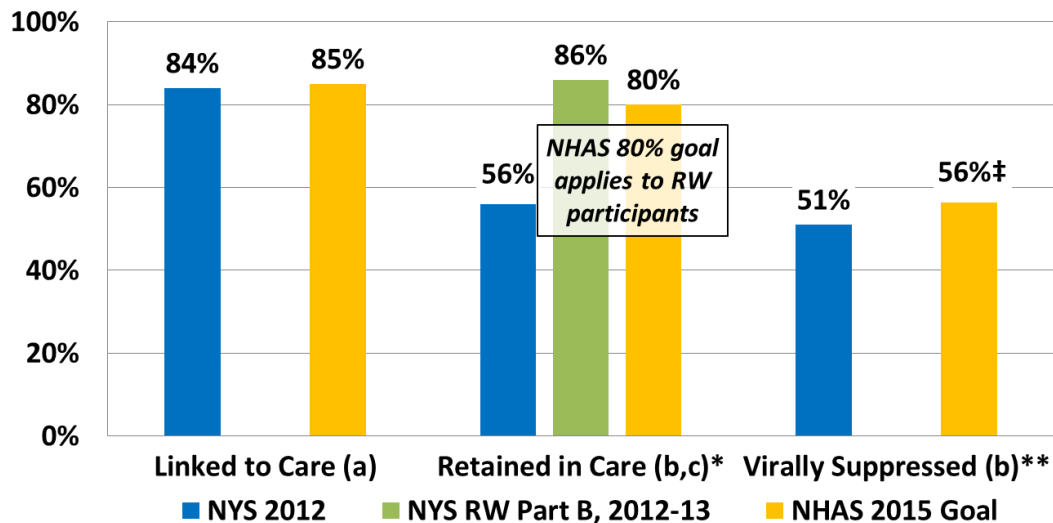
NYS's continuous care percentage of 56% applies to *all* PLWDHI and therefore cannot be compared directly to the NHAS target, which is specified only for participants in the Ryan White programs. The NYS Ryan White continuous care percentage³ of 86% exceeds the NHAS 2015 target of 80%.

3. Viral Suppression

Applying NHAS target of 20% *increase* in proportion virally suppressed to the NYS 2010 viral suppression rate of 47% yields a statewide target of 56.4%. NYS's percent virally suppressed was 51%. NHAS specifies the target only for persons of Black or Hispanic race/ethnicity and for those with MSM transmission risk. These groups, however, comprise at least 90% of PLWDHI in New York State.

NHAS Goals for 2015 and New York State Measures for 2012-13

Newly Diagnosed (a), PLWDHI (b), Ryan White Participants (c)



*NHAS specifies goal only for RW program participants; NYS all-case result is presented for reference.

**NHAS goal is 20% increase in the proportion of *MSM, Black and Hispanic* PLWDHI who are virally suppressed. *This* NYS NHAS goal is calculated as 20% increase for *all* PLWDHI.

‡ 2010 viral load baseline data calculated from test closest to the end of the year.

³ Calculated for Ryan White Part B participants only.

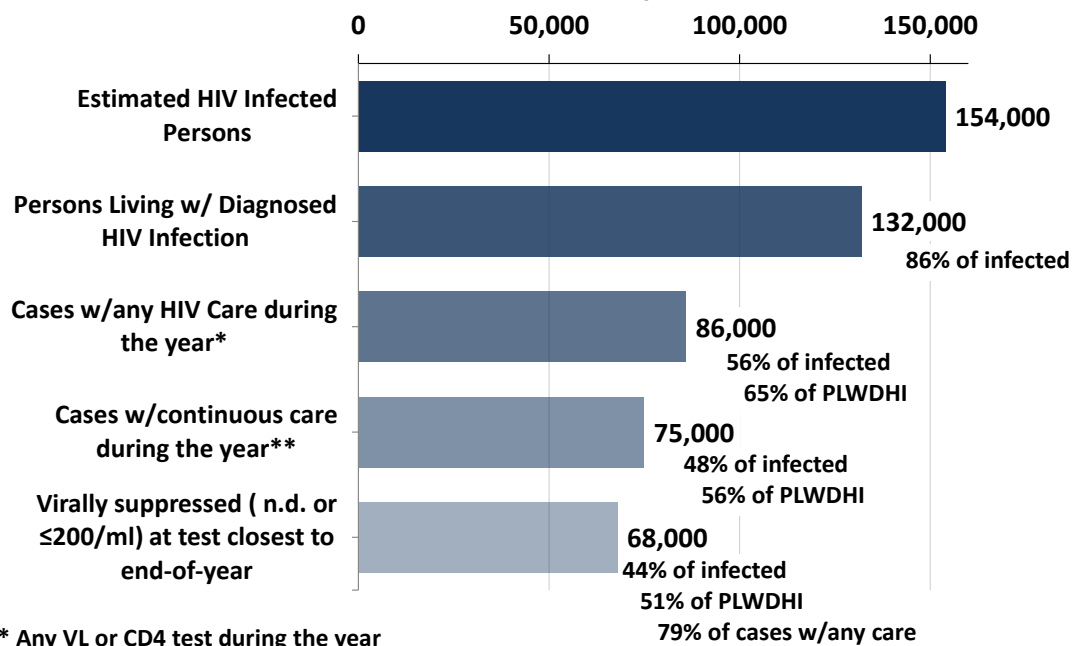
The Cascade of HIV Care

The NYS cascade combines the continuity of care and viral suppression measures above with the count of living cases (PLWDHI) and estimated total HIV-infected persons.

Two measures in the New York and the July 2012 CDC cascades can be compared meaningfully:

- The percent of total infected persons who are in continuous care appears higher in New York (48%) than in the U.S. as a whole (37%), although NYS and CDC methods are not identical.
- The percent of total infected persons who are virally suppressed is higher in NYS (44%) than in the U.S. (25%).

Cascade of HIV Care New York State, 2012



* Any VL or CD4 test during the year

** At least 2 tests, at least 3 months apart

Technical Notes and Appendices

Contact Information

Please direct inquiries about these measures of HIV health care in NYS to:

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Empire State Plaza

Albany New York 12237

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Data sources for calculation of NHAS measures

Laboratory data used in these analyses come from the NYS HIV Surveillance System. NYS Public Health law requires the electronic reporting to the NYSDOH any laboratory test, tests or series of tests approved for the diagnosis or periodic monitoring of HIV infection. This includes reactive initial HIV immunoassay results, all results (e.g. positive, negative, indeterminate) from supplemental HIV immunoassays (HIV-1/2 antibody differentiation assay, HIV-1 Western blot, HIV-2 Western blot or HIV-1 Immunofluorescent assay), HIV nucleic acid (RNA or DNA) detection tests (qualitative and quantitative), CD4 lymphocyte counts and percentages, positive HIV detection tests (culture, antigen), and HIV genotypic resistance testing. Excepted from this rule are tests done for insurance purposes or in clinical trials or in Federal facilities such as military sites or by the Veterans' Administration. Laboratory data are reported electronically to NYSDOH, which receives around 1.3 million HIV laboratory reports annually.

Counts of PLWDHI were derived from the NYSDOH Bureau of HIV/AIDS Epidemiology (BHAЕ) statewide analysis file of January, 2014.

The NYS Ryan White continuous care measure pertains to Ryan White Part B participants, and is a composite of information from two sources. First, client and HIV medical care visit information for 2012 was derived from the AIDS Institute Data Application (AIDA), which holds AIDS Institute Reporting System (AIRS) data, submitted monthly by funded providers throughout NYS. HIV medical care visits may be service visits provided by a particular program or HIV medical care visits administered by other service providers and entered into AIDA. Ryan White Part B direct services program client data were identified by selecting only clients of AI-Part B funded programs; clients of non-AI funded programs were excluded from analyses, as were clients of service programs that are not required to collect retention information. Second, AIDS Drug Assistance Program (ADAP) participants in 2013 were matched to HIV surveillance data for 2013, and participants with continuous care were identified using the same criteria as those used for the statewide calculation. The composite RW continuity of care measure is thus a blend of 2012 and 2013 data.

Calculation of NYS Cascade measures

1. Estimated HIV Infected Persons

NYC's estimate of infected and unaware as percent of total (14%) was applied to PLWDHI residing in NYC as of December 2012. CDC's national estimate (15.8%) was applied to PLWDHI residing in NYS excluding NYC.

2. Persons living with diagnosed HIV infection

PLWDHI as of December 2012, from BHAЕ statewide analysis file, January, 2014.

3. Cases with any HIV care during the year

65% of living cases who were diagnosed and living during the entire year had at least one reported viral load or CD4 test, regardless of result (Table B). This percentage was applied to the entire number of PLWDHI as of December 2012.

4. Cases with continuous care during the year

56% of living cases who were diagnosed and alive during the entire year had at least two laboratory tests (VL or CD4) during the year which were separated by at least 3 months (Table B). This percentage was applied to the entire number of PLWDHI as of December 2012.

86% of persons in Ryan White (Part B) programs for an entire year had evidence of at least two HIV medical care visits separated by at least 3 months.

5. Virally suppressed at test closest to end-of-year

Viral load results were received for 64% of PLWDHI who were diagnosed and alive over the whole year (Table C). Of these, 79% had a viral load ≤ 200 copies/ml or below quantifiable detection limit at the test closest to end-of-year. Thus, 51% (79% of 64%) of living cases were virally suppressed. This percentage was applied to the entire number of PLWDHI as of December 2012.

Identification of Prisoner Cases

In counties with relatively low HIV rates among unincarcerated persons, inclusion of diagnosis and prevalence data from individuals in state correctional facilities may produce a substantial overestimate of HIV diagnoses and prevalence. To address this problem, individuals ever identified as inmates in New York State correctional facilities outside New York City are excluded from Ryan White regional calculations. Identification may be based on reported residence at diagnosis, on information reported from the NYS Department of Corrections and Community Services to the NYS HIV surveillance program, or on receipt by NYSDOH of a laboratory report referencing a state correctional facility outside New York City. It is important to note that because both the timing and location of incarceration may be uncertain, surveillance data on individuals identified as prisoners cannot yield a reliable description of the number and characteristics of persons with HIV who are actually incarcerated in state facilities in a given year.

**Table A: Linkage to Care: Entry to Care within Three Months of Diagnosis¹
Persons Newly Diagnosed with HIV, NYS, 2012²**

	All	Entry within 3 months of dx	
Residence at Diagnosis			
NYC	2,552	2,138	84%
N Y S, excluding NYC	719	624	87%
NYS Total	3,298	2,772	84%
Ryan White Reg. at Dx^{3,4}			
Albany	72	62	86%
Binghamton	13	11	85%
Buffalo	105	93	89%
Lower Hudson	116	102	88%
Mid-Hudson	40	38	95%
Nassau Suffolk	178	150	84%
Rochester	85	74	87%
Syracuse	81	68	84%
Birth sex			
Male	2,561	2,158	84%
Female	737	614	83%
Race/Ethnicity⁵			
White	668	596	89%
Black	1,399	1,136	81%
Hispanic	1,008	844	84%
Asian/Pac Isl	83	74	89%
Native Am.	4	3	75%
Multirace	136	119	88%
Age at Dx.			
13-19	136	120	88%
20-24	543	429	79%
25-29	549	463	84%
30-39	806	690	86%
40-49	686	583	85%
50-59	407	346	85%
60+	171	141	82%
Transmission Risk			
MSM	1,723	1,491	87%
IDU	112	89	79%
MSM/IDU	58	50	86%
Heterosexual	437	367	84%
Female Presumed Hetero Contact	419	349	83%
Pediatric Risk	2	1	50%
Unknown	547	425	78%

¹First Viral Load or CD4 test after diagnosis, regardless of result

²NYS HIV surveillance case and laboratory data as of January 2014

³Rates based on fewer than 25 cases are not statistically reliable

⁴Regional figures exclude prisoners in state correctional facilities

⁵High proportion entering care among multi-race is not reliable and is likely an artifact of CDC's algorithm for inferring multi-race status.

Table B: Continuity of Care in 2012
Persons Living with Diagnosed HIV Infection Dec. 2011 and Alive Dec. 2012, NYS¹

	All	Any Care ²		≥2 tests, ≥3 mos apart	
Residence³					
NYC	100,457	65,525	65%	57,130	57%
NYS, excluding NYC	26,420	16,834	64%	14,505	55%
NYS Total	126,877	82,359	65%	71,635	56%
Ryan White Reg.⁴					
Albany	2,367	1,709	72%	1,504	64%
Binghamton	420	287	68%	239	57%
Buffalo	2,323	1,712	74%	1,486	64%
Lower Hudson	3,910	2,474	63%	2,116	54%
Mid-Hudson	2,026	1,297	64%	1,084	54%
Nassau Suffolk	5,509	3,697	67%	3,042	55%
Rochester	2,541	1,867	73%	1,655	65%
Syracuse	1,745	1,258	72%	1,103	63%
Birth sex					
Male	88,987	56,225	63%	48,789	55%
Female	37,890	26,134	69%	22,846	60%
Race/Ethnicity⁵					
White	26,615	17,024	64%	14,365	54%
Black	53,365	34,803	65%	30,132	56%
Hispanic	40,546	25,752	64%	22,996	57%
Asian/Pac Isl	1,642	1,041	63%	894	54%
Native Am.	100	54	54%	38	38%
Multirace	4,247	3,547	84%	3,083	73%
Age					
13-19	1,054	821	78%	746	71%
20-24	3,015	2,189	73%	1,788	59%
25-29	5,464	3,779	69%	3,100	57%
30-39	17,185	11,107	65%	9,297	54%
40-49	39,072	25,510	65%	22,017	56%
50-59	40,895	26,633	65%	23,590	58%
60+	20,171	12,310	61%	11,089	55%
Transmission Risk					
MSM	42,428	28,486	67%	24,460	58%
IDU	21,913	12,875	59%	11,556	53%
MSM/IDU	3,527	2,466	70%	2,200	62%
Heterosexual	22,222	15,883	71%	13,852	62%
Female Presumed Hetero Contact	14,008	9,252	66%	8,024	57%
Blood Products	274	189	69%	166	61%
Pediatric Risk	2,419	1,781	74%	1,552	64%
Unknown	20,086	11,427	57%	9,825	49%

¹ NYS HIV surveillance case and laboratory data as of January 2014

² At least 1 VL or CD4 test during the year

³ Residence at AIDS dx for AIDS cases; residence at HIV dx for all others

⁴ Regional figures exclude prisoners in state correctional facilities

⁵ High proportion of persons with care among multi-race persons is likely an artifact of CDC's algorithm for inferring multi-race status.

Table C: Viral Suppression¹ in 2012
Persons Living with Diagnosed HIV Infection Dec. 2011 and Alive Dec. 2012, NYS²

	All	≥1 VL Test during the year		Virally suppressed at test closest to end of year		
			% of All	% of tested	% of All	
Residence³						
NYC	100,457	64,881	65%	50,927	78%	51%
NYS, excluding NYC	26,420	16,613	63%	13,563	82%	51%
NYS Total	126,877	81,494	64%	64,490	79%	51%
Ryan White Reg. ⁴						
Albany	2,367	1,700	72%	1,463	86%	62%
Binghamton	420	276	66%	221	80%	53%
Buffalo	2,323	1,700	73%	1,409	83%	61%
Lower Hudson	3,910	2,446	63%	1,992	81%	51%
Mid-Hudson	2,026	1,281	63%	1,072	84%	53%
Nassau Suffolk	5,509	3,658	66%	2,981	81%	54%
Rochester	2,541	1,801	71%	1,495	83%	59%
Syracuse	1,745	1,246	71%	1,059	85%	61%
Birth sex						
Male	88,987	55,665	63%	44,942	81%	51%
Female	37,890	25,829	68%	19,548	76%	52%
Race/Ethnicity⁵						
White	26,615	16,834	63%	14,851	88%	56%
Black	53,365	34,381	64%	25,696	75%	48%
Hispanic	40,546	25,557	63%	20,133	79%	50%
Asian/Pac Isl	1,642	1034	63%	926	90%	56%
Native Am.	100	53	53%	43	81%	43%
Multirace	4,247	3,497	82%	2,716	78%	64%
Age						
13-19	1,054	816	77%	497	61%	47%
20-24	3,015	2,169	72%	1,227	57%	41%
25-29	5,464	3,729	68%	2,520	68%	46%
30-39	17,185	11,018	64%	8,150	74%	47%
40-49	39,072	25,260	65%	19,857	79%	51%
50-59	40,895	26,350	64%	21,673	82%	53%
60+	20,171	12,142	60%	10,559	87%	52%
Transmission Risk						
MSM	42,428	28,245	67%	23,493	83%	55%
IDU	21,913	12,741	58%	9,666	76%	44%
MSM/IDU	3,527	2,433	69%	1,814	75%	51%
Heterosexual	22,222	15,718	71%	12,306	78%	55%
Fem. Pres. Het. Cont.	14,008	9,129	65%	6,981	76%	50%
Blood Products.	274	185	68%	151	82%	55%
Pediatric Risk	2,419	1,772	73%	1,005	57%	42%
Unknown	20,086	11,271	56%	9,074	81%	45%

¹ Virally suppressed defined as viral load non-detectable or ≤ 200 copies/ml

² NYS HIV surveillance case and laboratory data as of January 2014

³ Residence at AIDS diagnosis for AIDS cases; residence at HIV diagnosis for all others

⁴ Regional figures exclude prisoners in state correctional facilities

⁵ High proportion of persons with viral load test and virally suppressed is likely an artifact of CDC's algorithm for inferring multi-race status.