

**HIV Care in New York State, 2021:
Linkage to Care and Viral Suppression
Among Persons with Diagnosed HIV
Residing in New York State**

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Table of Contents

Executive Summary	3
New York State Results	4
Major Findings	4
Linkage to Care	4
Any HIV Care.....	4
Viral Suppression	4
<i>Linkage to Care after Diagnosis (Appendix Table A)</i>	6
<i>Measures of Care (Appendix Table B)</i>	7
<i>Viral Suppression (Appendix Table C)</i>	8
Technical Notes and Appendices.....	9
Changes to the 2021 Report	9
New York State Methods for Counting Persons Living with Diagnosed HIV	9
Data Sources for Calculation of HIV Care Measures	9
Calculation of NYS Cascade Measures	10
Identification of Incarcerated Individuals	10
Table A: Linkage to Care in 2021 Persons Newly Diagnosed with HIV, NYS, 2021	11
Table B: Measures of Care in 2021 Persons Living with Diagnosed HIV in Dec. 2020 and Alive in Dec. 2021, NYS	12
Table C: Viral Suppression in 2021 Persons Living with Diagnosed HIV in Dec. 2020 and Alive in Dec. 2021, NYS	13

Executive Summary

In 2014, the Governor of New York State (NYS) outlined the Ending the Epidemic (ETE) initiative, a plan to end the AIDS epidemic in NYS. As part of the three-point plan, increased efforts are being directed towards: 1) identifying persons with HIV who remain undiagnosed and linking them to care; 2) linking and retaining in healthcare persons diagnosed with HIV to maximize viral suppression; and 3) increasing access to Pre-Exposure Prophylaxis (PrEP) for persons who are at risk for acquiring HIV.

New York State was making progress to meet ETE goals by the end of 2020, but the onset of the COVID-19 pandemic and subsequent emergency response from public health officials and providers delayed progress. As a result, the ETE timeline has been revised, and New York State now pledges to reach the ETE goals by the end of 2024.

As persons retained in successful treatment who have achieved and maintained viral suppression are effectively not able to sexually transmit the virus, the provision of appropriate medical care for persons living with diagnosed HIV (PLWDH) to achieve and maintain viral suppression is a key feature of the ETE initiative. The HIV care cascade is one tool for assessing the extent and effectiveness of HIV medical care in NYS.

The attached report summarizes 2021 NYS Department of Health (NYSDOH) HIV registry data for two of the three pillars of ETE: 1) identify persons diagnosed with HIV and link them to HIV medical care and 2) link and retain persons diagnosed with HIV in care. Data are sourced from the March 2022 Data Analysis and Research Translation (DART) Statewide Analysis file which includes data combined from the New York State and New York City HIV registries.

New York State Results

Major Findings

Linkage to Care

One of the ETE goals is to link persons newly diagnosed with HIV to HIV medical care as quickly as possible. By the end of 2024, the NYS goal is to link 90% of persons newly diagnosed with HIV to medical care within 30 days of diagnosis.

- In 2021, 82% of persons newly diagnosed with HIV in NYS showed evidence of linkage to care within 30 days of diagnosis. NYS is below the preliminary United States (U.S.) 2021 average (83%).¹
- In 2021, 89% of persons newly diagnosed with HIV in NYS showed evidence of linkage to care within 91 days of diagnosis. NYS is above the U.S. 2019 average (88%).² More recent national estimates are not available.

Any HIV Care

Linking and retaining in healthcare persons diagnosed with HIV to maximize viral suppression is key to ETE.

- In 2021, 88% of PLWDH in NYS showed evidence of any care during the year. Continuous care (≥ 2 visits/year, ≥ 91 days apart) was observed for 68% of PLWDH. Both of these metrics are higher than the most recent national level estimates, which indicate that in 2020, 74% of PLWDH in the U.S. had any evidence of care and 51% were in continuous care.³

Viral Suppression

Persons who achieve and maintain sustained viral suppression (an undetectable viral load (VL) for an extended period of time) are effectively unable to sexually transmit HIV.

- In 2021, 78% of PLWDH in NYS were virally suppressed. This is higher than the most recent national level estimates, which indicated that 65% of PLWDH in the U.S. were virally suppressed in 2020.³

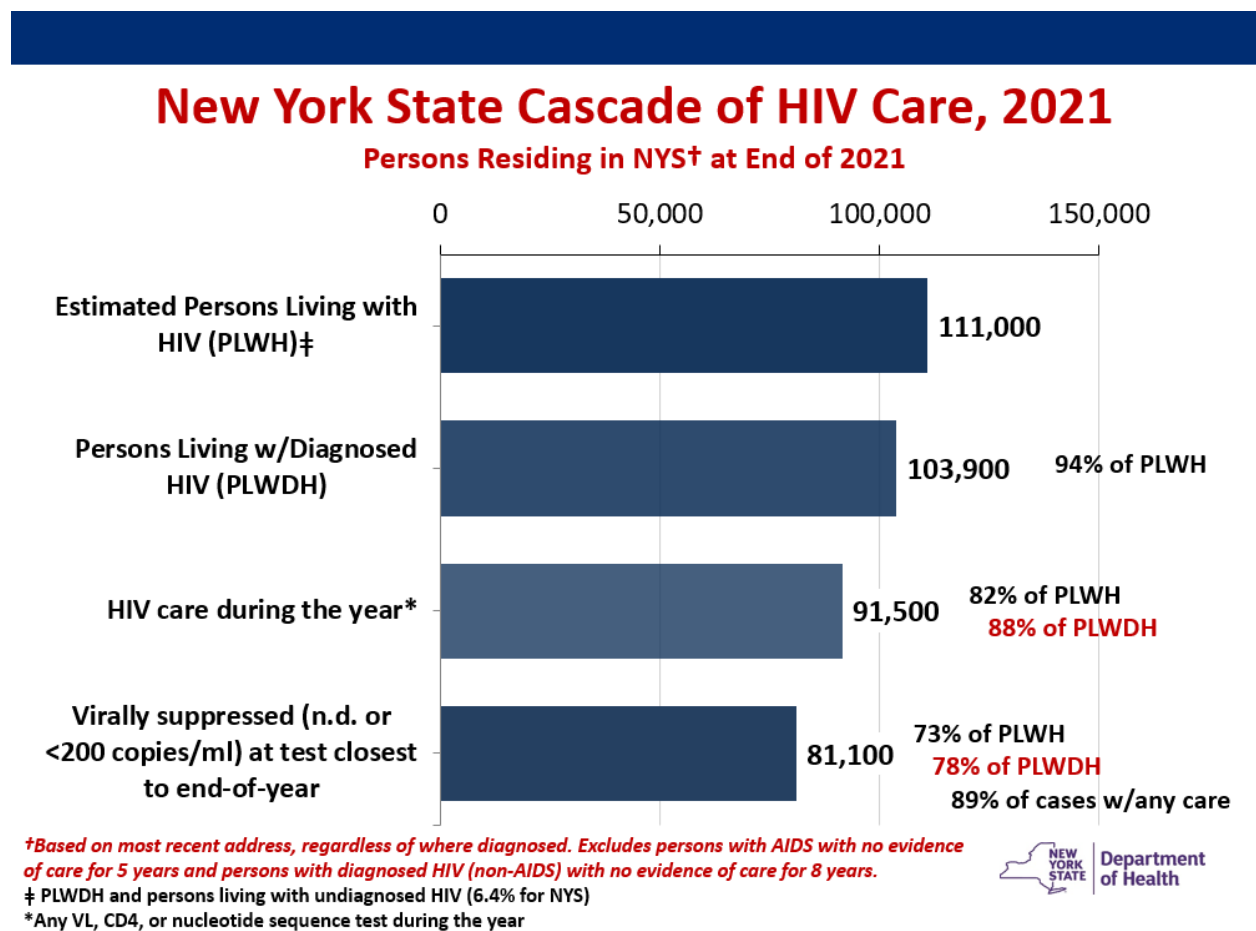
¹Centers for Disease Control and Prevention. Core indicators for monitoring the Ending the HIV Epidemic initiative (preliminary data): National HIV Surveillance System Data reported through March 2022; and preexposure prophylaxis (PrEP) data reported through December 2021. *HIV Surveillance Data Tables 2022*;3(2). Published August 2022. Accessed 08/30/2022.

²Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2019. *HIV Surveillance Supplemental Report 2021*;26(2). Published May 2021. Accessed 08/30/2022.

³Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2020. *HIV Surveillance Supplemental Report 2022*;27(3). Published May 2022. Accessed 07/11/2022.

The following sections present rates of linkage to care and viral suppression in NYS. These rates are based on data from the NYS HIV Registry System using methods defined by the Centers for Disease Control and Prevention (CDC). The **Technical Notes and Appendices** section provides detailed tables and explanations of methods and data sources. The Cascade of HIV Care presents a picture of the total HIV population in NYS at one point in time, across the continuum of care from transmission through diagnosis, participation in care, and success of care (2021 NYS English and Spanish cascades can be found at <https://www.health.ny.gov/diseases/aids/general/statistics/>).

Caution is advised in comparing cascade outcomes from different sources. Measures presented by different sources may be calculated differently or use different information even though their titles are similar. In addition, measures used in cascades from the same data source but created at different time points may use different definitions.



New York State HIV Care Outcome Measures

Linkage to Care after Diagnosis (Appendix Table A)

82% of persons newly diagnosed with HIV showed evidence of linkage to care within 30 days of diagnosis and 89% showed evidence of linkage to care within 91 days of diagnosis.

Linkage to Care within 30 days of diagnosis	
Variable	Observation
Region	Rest of State (ROS) (84%) > New York City (NYC) (81%); Highest in the Lower Hudson Ryan White Region (RWR) (93%); Lowest in the Syracuse RWR (73%)
Sex	Females (83%) > Males (82%)
Current Gender	Transgender Woman/Girl and Non-binary/non-conforming (88%, individually) > Cisgender Woman (84%) > Cisgender Man (81%) > Transgender Man/Boy (80%)
Race/Ethnicity	Native American (100%) > Asian (86%) > Non-Hispanic White (84%) > Hispanic (82%) > Non-Hispanic Black (81%) > Native Hawaiian / Pacific Islander (75%) > Multi-Race (71%)
Age	13-19 (92%) > 50-59 (84%) > 25-29 (83%) > 40-49 (82%) > 20-24 (81%) > 30-39 and 60+ (80%, individually)
Transmission Risk**	Heterosexual (85%) > history of male-to-male sexual contact (MSM) (86%) > history of both MSM and injection drug use (IDU) (MSM/IDU) (80%) > Unknown (72%) > IDU (67%)

** Zero new diagnoses with documented pediatric risk

Linkage to Care within 91 days of diagnosis	
Variable	Observation
Region	ROS (91%) > NYC (88%); Highest in the Lower Hudson RWR (96%); Lowest in the Binghamton and Syracuse RWRs (83%)
Sex	Females (94%) > Males (88%)
Current Gender	Transgender Man/Boy (100%) > Transgender Woman/Girl and Cisgender Woman (94%, individually) > Cisgender Man and non-conforming/nonbinary (88%, individually)
Race/Ethnicity	Native American and Native Hawaiian / Pacific Islander (100%, individually) > Asian (91%) > Non-Hispanic White (90%) > Hispanic (89%) > Multi-Race and Non-Hispanic Black (88%, individually)
Age	13-19 (99%) > 50-59 (91%) > 25-29 (90%) > 40-49 (89%) > 20-24 (88%) > 30-39 (87%) > 60+ (86%)
Transmission Risk	Heterosexual (94%) > MSM (92%) > MSM/IDU (91%) > Unknown (80%) > IDU (74%)

Measures of Care (Appendix Table B)

88% of PLWDH showed evidence of any care during the year. Continuous care (≥ 2 laboratory tests/year, separated by ≥ 91 days) was observed for 68% of PLWDH.

Any Care	
Variable	Observation
Region	ROS (89%) > NYC (88%); Highest in the Albany, Buffalo, and Rochester RWRs (90%); Lowest in the Lower Hudson, Mid-Hudson, and Syracuse RWRs (88%)
Sex	Females (89%) > Males (87%)
Current Gender	Cisgender Woman (89%) > Transgender Man/Boy, Transgender Woman/Girl, and Non-Binary / Non-Conforming Individuals (88%, individually) > Cisgender Man (87%)
Race/Ethnicity	Hispanic (89%) > Non-Hispanic Black and Non-Hispanic White (88%, individually) > Native Hawaiian / Pacific Islander and Multi-Race (87%, individually) > Asians, Native Americans, and Unknown (86%, individually)
Age	60+ (92%) > 50-59 (90%) > 13-19 (89%) > 20-24 and 40-49 (85%, individually) > 25-29 and 30-39 (82%, individually)
Transmission Risk	IDU and Blood Products (92%, individually) > MSM/IDU (90%) > Heterosexual (89%) > MSM and Pediatric (87%, individually) > Unknown (84%)

Continuous Care	
Variable	Observation
Region	NYC (69%) > ROS (66%) Highest in the Albany RWR (68%); Lowest in the Mid-Hudson RWR (62%)
Sex	Females (70%) > Males (68%)
Current Gender	Non-Binary / Non-Conforming Individuals (74%) > Transgender Woman/Girl (72%) > Transgender Man/Boy (71%) > Cisgender Woman (70%) > Cisgender Man (68%)
Race/Ethnicity	Hispanic (72%) > Unknown (70%) > Asian (69%) > Non-Hispanic Black (68%) > Multi-Race (67%) > Native Hawaiian / Pacific Islander (66%) > Non-Hispanic White (65%) > Native American (58%)
Age	60+ (75%) > 13-19 (74%) > 50-59 (71%) > 20-24 and 40-49 (64%) > 30-39 (60%) > 25-29 (59%)
Transmission Risk	IDU (75%) > MSM/IDU (72%) > Heterosexual (70%) > Blood Products (68%) > MSM (67%) > Pediatric and Unknown (65%, individually)

Viral Suppression (Appendix Table C)

78% of PLWDH in NYS were virally suppressed, defined as having non-detectable VL or a VL <200 copies/ml at the last test of the year.

Viral Suppression	
Variable	Observation
Region	ROS (82%) > NYC (77%); Highest in Albany and Nassau-Suffolk RWRs (84%) Lowest in Syracuse RWR (80%)
Sex	Females (79%) > Males (78%)
Current Gender	Cisgender Woman (79%) > Cisgender Man (78%) > Non-Binary / Non-Conforming Individuals (74%) > Transgender Woman/Girl (69%) > Transgender Man/Boy (61%)
Race/Ethnicity	Unknown (86%) > Non-Hispanic White and Asian (82%, individually) > Hispanic (79%) > Native Hawaiian / Pacific Islander, Native American, Multi-Race, and Non-Hispanic Black (75%, individually)
Age	60+ (85%) > 50-59 (80%) > 40-49 (75%) > 13-19 (71%) > 20-24, 25-29, and 30-39 (69%, individually)
Transmission Risk	Blood Products (84%) > Heterosexual and MSM (79%, individually) > IDU (78%) > Unknown (75%) > MSM/IDU (73%) > Pediatric (66%)

Technical Notes and Appendices

Changes to the 2021 Report

The data reported here may be affected by the COVID-19 global pandemic. Continued disruptions throughout the health care system and traditional care patterns may have impacted testing, linkage to care, routine HIV treatment, and laboratory reporting.

A revision of the race/ethnicity classification methodology was introduced in accordance with the United States Office of Management and Budget's Statistical Policy Directive No. 15, entitled "Race and Ethnic Standards for Federal Statistics and Administrative Reporting." This directive separated the "Asian and Pacific Islander" category into two distinct categories, now called "Asian" and "Native Hawaiian / Pacific Islander."

New York State Methods for Counting Persons Living with Diagnosed HIV

Residence of persons living with diagnosed HIV is assessed using the most recent address reported to the NYS HIV Registry System, regardless of the residence of the individual at the time of diagnosis. Persons residing outside of NYS at the time of HIV or Stage 3/AIDS diagnosis, but whose most recent address reported to the HIV Registry System is in NYS, were included in the calculations. Individuals diagnosed in NYS whose most recently reported address indicated residence outside NYS were excluded.

In addition, individuals whose last report to the registry system was at least 5 years before December 2021 for persons diagnosed with Stage 3/AIDS or 8 years before December 2021 for persons diagnosed with HIV (not AIDS) were not included in the counts of care and viral suppression. These persons are presumed to be either no longer living or no longer residing in NYS (n=22,043).

Data Sources for Calculation of HIV Care Measures

Laboratory data used in these analyses are from the NYS HIV Registry System. NYS Public Health law requires the electronic reporting to the NYSDOH the result of any laboratory test, tests or series of tests approved for the diagnosis or periodic monitoring of HIV. 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), all HIV nucleic acid (RNA or DNA) detection test results (qualitative and quantitative; detectable and undetectable), CD4 lymphocyte counts and percentages, positive HIV detection tests (culture, antigen), and HIV genotypic nucleotide sequence from resistance testing. Exempted from this reporting requirement are tests performed in the context of clinical trials or in federal facilities (military sites, US Immigration and Customs Enforcement) though several exempted facilities do report in "the spirit of cooperation." Laboratory data are reported electronically to NYSDOH, which receives around 1 million HIV laboratory reports annually.

Counts shown in tables and the cascade may differ. The percentages for PLWDH shown in the report tables are based on persons who were diagnosed prior to the calendar year and not known to be deceased at the end of the calendar year. Data shown in the cascade are based on all persons living with diagnosed HIV at the end of the calendar year regardless of when diagnosed.

Calculation of NYS Cascade Measures

1. Estimated persons living with HIV

The percentage unaware for NYS in 2021 was 6.4% (N=~7,100).

2. Persons living with diagnosed HIV

NYS uses methodology from the CDC to calculate the cascade measures. Therefore, the total number of PLWDH (Tables B and C) in the report will be different from the number of PLWDH in the cascade picture and other NYS reports. The methodology for counting PLWDH in this report: 1) excludes those ≤ 12 years old; and 2) includes only persons diagnosed with HIV during the previous year (i.e., December 2020) or earlier, and alive at the end of the analysis year (i.e., December 2021).

3. PLWDH with any HIV care during the year

88% of PLWDH who were diagnosed and living during the entire year had at least one reported VL, CD4 or nucleotide sequence, regardless of result (Table B). This percentage was applied to the entire number of PLWDH as of December 2021 in the cascade.

4. PLWDH with continuous care during the year

68% of PLWDH who were diagnosed and alive during the entire year had at least two laboratory tests (VL, CD4 or nucleotide sequence) during the year which were separated by at least 91 days (Table B). This estimate is not shown in the HIV care cascade.

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

Of those with a VL test result, 90% had a suppressed VL (<200 copies/ml or below) at the test closest to end-of-year. 78% of all PLWDH, including those with and without a reported VL, were virally suppressed at the test closest to end-of-year. This percentage was applied to the entire number of PLWDH as of December 2021 in the cascade.

Identification of Incarcerated Individuals

Incarcerated individuals are identified as having their most recent address (as reported to the NYS HIV Registry System) indicate a residence in a NYS Department of Corrections and Community Supervision (NYSDOCCS) facility, a city jail, county jail, or federal detention facility.

Individuals identified as currently incarcerated at the end of 2021 were excluded from Ryan White regional calculations in order to avoid the artificial inflation of HIV diagnoses and prevalence among counties with relatively low HIV rates among non-incarcerated persons.

Table A: Linkage to Care in 2021¹
Persons Newly Diagnosed with HIV, NYS, 2021²

	All	Linkage within 30 days of dx		Linkage within 91 days of dx	
Residence at Diagnosis					
NYC	1,578	1,281	81%	1,395	88%
ROS	542	455	84%	491	91%
NYS Total	2,120	1,736	82%	1,886	89%
Ryan White Region at Dx³					
Albany	59	50	85%	55	93%
Binghamton	18	15	83%	15	83%
Buffalo	84	72	86%	76	90%
Lower Hudson	73	68	93%	70	96%
Mid-Hudson	39	33	85%	35	90%
Nassau/Suffolk	144	114	79%	129	90%
Rochester	71	62	87%	65	92%
Syracuse	48	35	73%	40	83%
Birth Sex					
Male	1,737	1,417	82%	1,526	88%
Female	383	319	83%	360	94%
Current Gender					
Cisgender Man	1,663	1,351	81%	1,456	88%
Cisgender Woman	376	314	84%	354	94%
Transgender Man/Boy	5	4	80%	5	100%
Transgender Woman/Girl	68	60	88%	64	94%
Non-Conforming/Non-Binary	8	7	88%	7	88%
Race/Ethnicity					
Asian	100	86	86%	91	91%
Native Hawaiian / Pacific Islander	4	3	75%	4	100%
Hispanic	673	550	82%	601	89%
Multi-Race	17	12	71%	15	88%
Native American	4	4	100%	4	100%
Non-Hispanic Black	901	726	81%	791	88%
Non-Hispanic White	421	355	84%	380	90%
Age at Diagnosis					
13-19	77	71	92%	76	99%
20-24	335	271	81%	294	88%
25-29	374	311	83%	338	90%
30-39	660	526	80%	576	87%
40-49	294	242	82%	263	89%
50-59	251	212	84%	228	91%
60+	129	103	80%	111	86%
Transmission Risk					
MSM ⁴	1,105	949	86%	1,012	92%
IDU ⁵	42	28	67%	31	74%
MSM/IDU	44	35	80%	40	91%
Heterosexual	425	360	85%	401	94%
Unknown	504	364	72%	402	80%

¹ First VL, CD4 or nucleotide sequence test after diagnosis, regardless of result

² NYS HIV registry case and laboratory data as of March 2022

³ Regional figures exclude persons ever incarcerated in a city jail, a county jail, a federal detention facility or a NYSDOCCS facility

⁴ MSM-history of male-to-male sexual contact

⁵ IDU-history of injection drug use

Note – rates based on fewer than 25 individuals are not statistically reliable

Table B: Measures of Care in 2021
Persons Living with Diagnosed HIV in Dec. 2020 and Alive in Dec. 2021, NYS¹

	All	Any Care ²		≥2 tests, ≥91 days apart	
Residence³					
NYC	77,730	68,218	88%	53,765	69%
ROS	21,781	19,389	89%	14,337	66%
NYS Total	99,511	87,607	88%	68,102	68%
Ryan White Region⁴					
Albany	2,909	2,628	90%	1,988	68%
Binghamton	477	423	89%	309	65%
Buffalo	2,798	2,513	90%	1,835	66%
Lower Hudson	3,362	2,952	88%	2,251	67%
Mid-Hudson	2,098	1,852	88%	1,305	62%
Nassau/Suffolk	5,054	4,506	89%	3,383	67%
Rochester	2,697	2,419	90%	1,696	63%
Syracuse	2,110	1,851	88%	1,365	65%
Birth sex					
Male	71,515	62,569	87%	48,390	68%
Female	27,996	25,038	89%	19,712	70%
Current Gender					
Cisgender Man	69,337	60,645	87%	46,828	68%
Cisgender Woman	27,933	24,983	89%	19,666	70%
Transgender Man/Boy	49	43	88%	35	71%
Transgender Woman/Girl	2,068	1,827	88%	1,481	72%
Non-Conforming/Non-Binary	124	109	88%	92	74%
Race/Ethnicity					
Asian	2,421	2,074	86%	1,660	69%
Native Hawaiian / Pacific Islander	101	88	87%	67	66%
Hispanic	28,530	25,338	89%	20,410	72%
Multi-Race	582	507	87%	388	67%
Native American	186	160	86%	107	58%
Non-Hispanic Black	44,895	39,484	88%	30,582	68%
Non-Hispanic White	22,712	19,884	88%	14,829	65%
Unknown	84	72	86%	59	70%
Age					
13-19	206	184	89%	152	74%
20-24	1,296	1,099	85%	825	64%
25-29	4,510	3,689	82%	2,667	59%
30-39	17,578	14,433	82%	10,556	60%
40-49	17,583	15,024	85%	11,308	64%
50-59	29,010	26,162	90%	20,626	71%
60+	29,328	27,016	92%	21,968	75%
Transmission Risk					
MSM ⁵	44,746	38,999	87%	29,936	67%
IDU ⁶	9,814	9,063	92%	7,346	75%
MSM/IDU	4,344	3,929	90%	3,145	72%
Heterosexual	28,405	25,291	89%	19,765	70%
Blood Products	149	137	92%	102	68%
Pediatric Risk	1,921	1,671	87%	1,252	65%
Unknown	10,132	8,517	84%	6,556	65%

¹ NYS HIV registry case and laboratory data as of March 2022

² At least 1 VL, CD4, or nucleotide sequence test during the year

³ Residence by end of 2021

⁴ Regional figures exclude persons who were incarcerated in a city jail, a county jail, a federal detention facility or a NYSDOCCS facility as of their last known address in 2021

⁵ MSM-history of male-to-male sexual contact

⁶ IDU-history of injection drug use

Note – rates based on fewer than 25 individuals are not statistically reliable

Table C: Viral Suppression¹ in 2021
Persons Living with Diagnosed HIV in Dec. 2020 and Alive in Dec. 2021, 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	77,730	67,294	87%	59,694	89%	77%
ROS	21,781	19,194	88%	17,948	94%	82%
NYS Total	99,511	86,488	87%	77,642	90%	78%
Ryan White Region⁴						
Albany	2,909	2,606	90%	2,458	94%	84%
Binghamton	477	419	88%	384	92%	81%
Buffalo	2,798	2,493	89%	2,304	92%	82%
Lower Hudson	3,362	2,908	86%	2,709	93%	81%
Mid-Hudson	2,098	1,828	87%	1,700	93%	81%
Nassau/Suffolk	5,054	4,464	88%	4,266	96%	84%
Rochester	2,697	2,398	89%	2,228	93%	83%
Syracuse	2,110	1,836	87%	1,692	92%	80%
Birth sex						
Male	71,515	61,791	86%	55,557	90%	78%
Female	27,996	24,697	88%	22,085	89%	79%
Current Gender						
Cisgender Man	69,337	59,884	86%	54,045	90%	78%
Cisgender Woman	27,933	24,645	88%	22,045	89%	79%
Transgender Man/Boy	49	41	84%	30	73%	61%
Transgender Woman/Girl	2,068	1,812	88%	1,430	79%	69%
Non-Conforming/Non-Binary	124	106	85%	92	87%	74%
Race/Ethnicity						
Asian	2,421	2,050	85%	1,984	97%	82%
Native Hawaiian / Pacific Islander	101	85	84%	76	89%	75%
Hispanic	28,530	25,019	88%	22,468	90%	79%
Multi-Race	582	502	86%	434	86%	75%
Native American	186	157	84%	139	89%	75%
Non-Hispanic Black	44,895	38,948	87%	33,740	87%	75%
Non-Hispanic White	22,712	19,655	87%	18,729	95%	82%
Unknown	84	72	86%	72	100%	86%
Age						
13-19	206	180	87%	146	81%	71%
20-24	1,296	1,080	83%	889	82%	69%
25-29	4,510	3,642	81%	3,108	85%	69%
30-39	17,578	14,216	81%	12,156	86%	69%
40-49	17,583	14,837	84%	13,138	89%	75%
50-59	29,010	25,893	89%	23,319	90%	80%
60+	29,328	26,640	91%	24,886	93%	85%
Transmission Risk						
MSM ⁵	44,746	38,562	86%	35,259	91%	79%
IDU ⁶	9,814	8,921	91%	7,672	86%	78%
MSM/IDU	4,344	3,883	89%	3,176	82%	73%
Heterosexual	28,405	24,947	88%	22,512	90%	79%
Blood Products	149	137	92%	125	91%	84%
Pediatric Risk	1,921	1,645	86%	1,270	77%	66%
Unknown	10,132	8,393	83%	7,628	91%	75%

¹ Virally suppressed defined as VL non-detectable or <200 copies/ml

² NYS HIV registry case and laboratory data as of March 2022

³ Residence by end of 2021

⁴ Regional figures exclude persons who were incarcerated in a city jail, a county jail, a federal detention facility or a NYSDOCCS facility as of their last known address in 2021

⁵ MSM-history of male-to-male sexual contact

⁶ IDU-history of injection drug use

Note – rates based on fewer than 25 individuals are not statistically reliable

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