

**HIV Care in New York State, 2018:  
Linkage to Care and Viral Suppression  
Among Persons with Diagnosed HIV  
Residing in New York State**

**AIDS Institute  
New York State Department of Health**

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## **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.

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

The attached report summarizes 2018 NYS Department of Health (NYSDOH) HIV Surveillance 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.

## New York State Results

### **Major Findings**

#### *Linkage to Care*

In order to achieve ETE goals, persons newly diagnosed with HIV need to be linked to HIV medical care as quickly as possible. By the end of 2020, NYS is striving to link 90% of persons newly diagnosed with HIV to medical care within 30 days of diagnosis.

- In 2018, 82% of persons newly diagnosed with HIV in NYS showed evidence of linkage to care within 30 days of diagnosis. NYS is above the United States (U.S.) 2017 average (78%).<sup>1</sup>
- In 2018, 91% 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. 2017 average (87%).<sup>1</sup>

#### *Any HIV Care*

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

- In 2018, 84% of PLWDH in NYS showed evidence of any care during the year. Continuous care ( $\geq 2$  visits/year,  $\geq 91$  days apart) was observed for 69% of PLWDH. NYS continues to be above the U.S. average for both measures. The most recent national level estimates indicate that in 2016, 74% of PLWDH in the U.S. had any evidence of care and 58% were in continuous care.<sup>1</sup>

#### *Viral Suppression*

Persons who achieve and maintain sustained viral suppression (an undetectable viral load (VL) for an extended time) are effectively unable to sexually transmit HIV. By the end of 2020, NYS is striving for at least 85% of PLWDH in NYS to achieve viral suppression.

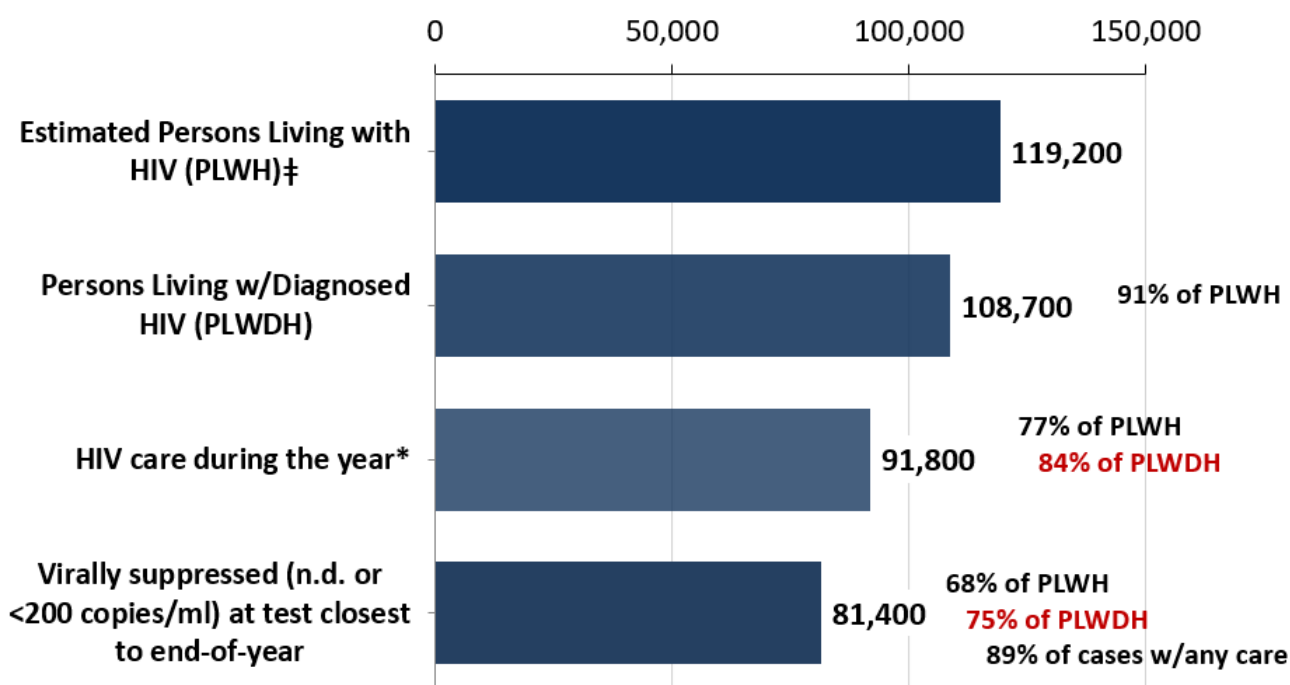
- In 2018, 75% of PLWDH in NYS were virally suppressed. This is above the last released national level estimates indicating in 2016 62% of PLWDH in the U.S. were virally suppressed.<sup>1</sup>

<sup>1</sup> Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2017. HIV Surveillance Supplemental Report 2019;24(No. 3). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published June 2019. Accessed [08/2019].

The sections that follow present estimates of linkage to care and viral suppression in NYS. These estimates are based on data from the NYS HIV Surveillance 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 (2018 NYS English and Spanish cascades can be found [here](#)). *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 Cascade of HIV Care, 2018

Persons Residing in NYS† at End of 2018



\*Based on most recent address, regardless of where diagnosed. Excludes persons with AIDS with no evidence of care for 5 years and persons with diagnosed HIV (non-AIDS) with no evidence of care for 8 years.

‡ PLWDH and persons living with undiagnosed HIV (7.2% for NYC and 14.2% Rest of State)

\*Any VL, CD4, or nucleotide sequence test during the year



## 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 91% showed evidence of linkage to care within 91 days of diagnosis.

<b>Linkage to Care within 30 days of diagnosis</b>	
<b>Variable</b>	<b>Observation</b>
<b>Region</b>	New York City (NYC) (82%) > Rest of State (ROS) (81%); Highest in the Buffalo Ryan White region (RWR) (95%); Lowest in the Syracuse RWR (67%)
<b>Sex</b>	Males (84%) > Females (77%)
<b>Race/Ethnicity*</b>	Multi Race (87%) > Asian/Pacific Islander (85%) > Hispanic (84%) > Non-Hispanic White (82%) > Non-Hispanic Black (79%)
<b>Age</b>	Highest for ages 13-19 years and 50-59 years (84%, respectively); Lowest for ages 30-39 years (81%)
<b>Transmission Risk</b>	Pediatric (100%) > History of both male-to-male sexual contact and injection drug use (MSM/IDU) (91%) > History of male-to-male sexual contact (MSM) (86%) > Heterosexual (77%) > History of injection drug use (IDU) (74%)

\* Zero new diagnosis documented among Native Americans

<b>Linkage to Care within 91 days of diagnosis</b>	
<b>Variable</b>	<b>Observation</b>
<b>Region</b>	NYC (92%) > ROS (90%); Highest in the Binghamton RWR (100%); Lowest in the Syracuse RWR (83%)
<b>Sex</b>	Males (92%) > Females (90%)
<b>Race/Ethnicity*</b>	Multi Race (94%) > Hispanic (93%) > Non-Hispanic White and Asian/Pacific Islander (91%, respectively) > Non-Hispanic Black (90%)
<b>Age</b>	Highest for ages 20-24 years, 25-29 years and 50-59 years (92%, respectively); Lowest for ages 13-19 years (88%)
<b>Transmission Risk</b>	Pediatric (100%) > MSM and MSM/IDU (94%, respectively) > Heterosexual (90%) > IDU (86%)

\* Zero new diagnoses documented among Native Americans

*Measures of Care (Appendix Table B)<sup>2</sup>*

84% of PLWDH showed evidence of any care during the year. Continuous care ( $\geq 2$  laboratory tests/year, separated by  $\geq 91$  days) was observed for 69% of PLWDH.

Any Care	
Variable	Observation
Region	NYC (86%) > ROS (79%); Highest in the Rochester RWR (84%); Lowest in the Mid-Hudson RWR (76%)
Sex	Females (86%) > Males (84%)
Race/Ethnicity	Multi Race (86%) > Hispanic (85%) > Non-Hispanic Black (84%) > Non-Hispanic White (83%) > Asian/Pacific Islander (81%) > Native American (78%)
Age	Highest for ages 13-19 years and 60+ years (88%, respectively); Lowest for ages 30-39 years (79%)
Transmission Risk	Blood Products (88%) > IDU and MSM/IDU (87%, respectively) > Heterosexual (85%) > Pediatric and MSM (84%, respectively)

Continuous Care	
Variable	Observation
Region	NYC (71%) > ROS (62%); Highest in the Rochester RWR (66%) RWR; Lowest in the Mid-Hudson RWR and Binghamton RWR (57%, respectively)
Sex	Females (71%) > Males (68%)
Race/Ethnicity	Hispanic (71%) > Multi Race (70%) > Non-Hispanic Black (69%) > Asian/Pacific Islander (68%) > Non-Hispanic White (66%) > Native American (55%)
Age	Highest for ages 13-19 years (79%); Lowest for ages 25-29 years and 30-39 years (61%, respectively)
Transmission Risk	IDU (75%) > MSM/IDU (71%) > Blood Products and Heterosexual (70%, respectively) > MSM (68%) > Pediatric (66%)

<sup>2</sup> The continuity of care and viral suppression percentages may be underestimates, since laboratory tests performed in federal facilities (e.g. Veterans Affairs hospitals, US Immigration and Customs Enforcement facilities, and in clinical trials) are not comprehensively reported to the state.

*Viral Suppression (Appendix Table C)*

75% 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.

<b>Viral Suppression</b>	
<b>Variable</b>	<b>Observation</b>
<b>Region</b>	NYC (76%) > ROS (73%); Highest in Rochester RWR (76%); Lowest in the Mid-Hudson RWR (69%)
<b>Sex</b>	Females = Males (75%, respectively)
<b>Race/Ethnicity</b>	Non-Hispanic White (79%) > Asian/Pacific Islanders (77%) > Hispanic and Multi Race (76%, respectively) > Non-Hispanic Black and Native American (72%, respectively)
<b>Age</b>	Highest among those aged 60+ years (82%); Lowest among 20-24 years and 25-29 years (66%, respectively)
<b>Transmission Risk</b>	Blood products (77%) > MSM and IDU (76%, respectively) > Heterosexual (75%) > MSM/IDU (72%) > Pediatric (61%)



## **Technical Notes and Appendices**

### **Changes to the 2018 Report**

After a systematic analysis, it was determined that the race and ethnicity variable as recorded on laboratory documents was causing a misclassification of persons into the “Hispanic” or “Multi Race” categories. Therefore, beginning in 2018, the race and ethnicity variables were no longer imported from laboratory documents. This change in methodology impacted the number of persons in the Hispanic and Multi Race categories as a portion of those got redistributed to more accurate classification of race/ethnicity.

### **New York State Methods for Counting Persons Living with Diagnosed HIV**

Residence in NYS is based on the most recent address reported to the NYS HIV Surveillance System, regardless of the residence of the individual at the time of diagnosis. Persons residing outside of NYS at the time of HIV diagnosis, but whose most recent address reported to the HIV Surveillance System is in NYS, were included in the calculations (n=9,464). Individuals diagnosed in NYS whose most recently reported address indicated residence outside NYS were excluded (n=7,865).

In addition, individuals whose last report to the surveillance system was at least 5 years before December 2018 for persons diagnosed with AIDS or 8 years before December 2018 for persons diagnosed with HIV (not AIDS) were not included in the count or estimates of care and viral suppression. These persons are presumed to be either no longer living or no longer residing in NYS (n=22,670).

### **Contact Information**

Please direct inquiries about these measures to:

Bureau of HIV/AIDS Epidemiology

AIDS Institute, NYSDOH

Empire State Plaza

Albany New York 12237

518-474-4284

[BHAE@health.ny.gov](mailto:BHAE@health.ny.gov)

### **Data Sources for Calculation of HIV Care Measures**

Laboratory data used in these analyses are from the NYS HIV Surveillance 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 resistance nucleotide sequence. Exempted from this rule are tests performed in clinical trials or in Federal facilities such as military sites or by the Veterans' Administration, though several exempted facilities do report in "the spirit of cooperation." Laboratory data are reported electronically to NYSDOH, which receives around 1.3 million HIV laboratory reports annually. Counts of PLWDH were derived from the BHAЕ statewide analysis file as of June 2018.

Counts shown in tables and figures may differ. The percentages for PLWDH shown in the report tables are based on persons who were diagnosed prior to the calendar year and lived to the end of the calendar year. Data shown in the report figures 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**

CDC's national estimate (14.2%) for 2016 was applied to PLWDH residing in NYS, outside of NYC. An estimate of 7.2% was applied to PLWDH residing in NYC. Overall, the combined percentage unaware for NYS in 2018 was 8.8% (N=~10,500).

#### **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 CDC methodology for counting PLWDH: 1) excludes those  $\leq 12$  years old; and 2) includes only persons diagnosed with HIV during the previous year (i.e., December 2017) or earlier, and alive at the end of the analysis year (i.e., December 2018).

#### **3. PLWDH with any HIV care during the year**

84% 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 2018.

#### **4. PLWDH with continuous care during the year**

69% 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 percentage was applied to the entire number of PLWDH as of December 2018. This estimate is not shown in the HIV care cascade.

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

Overall, VL results were received for 84% of PLWDH who were diagnosed and alive at the end of 2018. Of those with a VL test result, 89% had a suppressed VL (<200 copies/ml

or below) at the test closest to end-of-year. 75% of all PLWDH, including those with and without a reported VL, were virally suppressed at the test closest to end-of-year.

### **Identification of Incarcerated Individuals**

Starting with the 2017 report, the definition of incarceration was expanded from PLWDH whose most recent address (as reported to the NYS HIV Surveillance System) indicated residence in a NYS Department of Corrections and Community Supervision (NYSDOCCS) facility to include residence in a city jail, county jail, or federal detention facility.

Individuals identified as currently incarcerated at the end of 2018 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 2018<sup>1</sup>**  
**Persons Newly Diagnosed with HIV, NYS, 2018<sup>2</sup>**

	All	Linkage within 30 days of dx		Linkage within 91 days of dx	
<b>Residence at Diagnosis</b>					
NYC	1,862	1,534	82%	1,705	92%
ROS	609	495	81%	550	90%
NYS Total	2,471	2,029	82%	2,255	91%
<b>Ryan White Region at Dx<sup>3</sup></b>					
Albany	68	55	81%	61	90%
Binghamton	11	10	91%	11	100%
Buffalo	58	55	95%	57	98%
Lower Hudson	101	84	83%	92	91%
Mid-Hudson	56	39	70%	49	88%
Nassau/Suffolk	178	144	81%	162	91%
Rochester	64	56	88%	58	91%
Syracuse	52	35	67%	43	83%
<b>Birth Sex</b>					
Male	1,947	1,628	84%	1,785	92%
Female	524	401	77%	470	90%
<b>Current Gender</b>					
Men	1,872	1,570	84%	1,720	92%
Transgender Men	11	10	91%	10	91%
Women	512	390	76%	459	90%
Transgender Women	70	53	76%	60	86%
Non-conforming/non-binary	6	6	100%	6	100%
<b>Race/Ethnicity</b>					
Non-Hispanic White	364	300	82%	331	91%
Non-Hispanic Black	1,016	806	79%	913	90%
Hispanic	891	751	84%	826	93%
Asian/Pac Islander	105	89	85%	96	91%
Native American	0	-	-	-	-
Multi Race	95	83	87%	89	94%
<b>Age at Diagnosis</b>					
13-19	86	72	84%	76	88%
20-24	358	293	82%	328	92%
25-29	479	398	83%	440	92%
30-39	672	544	81%	609	91%
40-49	384	313	82%	351	91%
50-59	328	275	84%	301	92%
60+	164	134	82%	150	91%
<b>Transmission Risk</b>					
MSM <sup>4</sup>	1,337	1,155	86%	1,254	94%
IDU <sup>5</sup>	57	42	74%	49	86%
MSM/IDU	65	59	91%	61	94%
Heterosexual	598	463	77%	540	90%
Pediatric	4	4	100%	4	100%
Unknown	410	306	75%	347	85%

<sup>1</sup> First VL, CD4 or nucleotide sequence test after diagnosis, regardless of result

<sup>2</sup> NYS HIV surveillance case and laboratory data as of June 2019

<sup>3</sup> Regional figures exclude persons incarcerated in a city jail, a county jail, a federal detention facility or a NYSDOCCS facility; rates based on fewer than 25 individuals are not statistically reliable

<sup>4</sup> MSM-history of male-to-male sexual contact;

<sup>5</sup> IDU-history of injection drug use

**Table B: Measures of Care in 2018**  
**Persons Living with Diagnosed HIV in Dec. 2017 and Alive in Dec. 2018, NYS<sup>1</sup>**

	All	Any Care <sup>2</sup>		≥2 tests, ≥91 days apart	
<b>Residence<sup>3</sup></b>					
NYC	82,822	71,070	86%	58,784	71%
ROS	23,326	18,544	79%	14,489	62%
NYS Total	106,148	89,614	84%	73,273	69%
<b>Ryan White Region<sup>4</sup></b>					
Albany	3,061	2,425	79%	1,906	62%
Binghamton	492	389	79%	278	57%
Buffalo	2,923	2,396	82%	1,840	63%
Lower Hudson	3,729	2,979	80%	2,341	63%
Mid-Hudson	2,172	1,643	76%	1,246	57%
Nassau/Suffolk	5,552	4,374	79%	3,415	62%
Rochester	2,877	2,417	84%	1,910	66%
Syracuse	2,288	1,817	79%	1,465	64%
<b>Birth sex<sup>5</sup></b>					
Male	75,902	63,603	84%	51,811	68%
Female	30,246	26,011	86%	21,462	71%
<b>Race/Ethnicity</b>					
Non-Hispanic White	20,760	17,242	83%	13,607	66%
Non-Hispanic Black	42,341	35,619	84%	29,079	69%
Hispanic	34,811	29,756	85%	24,883	71%
Asian/Pacific Islander	1,798	1,449	81%	1,217	68%
Native American	49	38	78%	27	55%
Multi Race	6,276	5,417	86%	4,383	70%
Unknown	113	93	82%	77	68%
<b>Age</b>					
13-19	312	276	88%	245	79%
20-24	1,889	1,589	84%	1,263	67%
25-29	6,167	4,997	81%	3,734	61%
30-39	17,577	13,965	79%	10,720	61%
40-49	20,992	17,216	82%	13,772	66%
50-59	34,060	29,490	87%	24,525	72%
60+	25,149	22,079	88%	19,013	76%
Unknown	2	2	100%	1	50%
<b>Transmission Risk</b>					
MSM <sup>6</sup>	44,949	37,890	84%	30,572	68%
IDU <sup>7</sup>	11,882	10,378	87%	8,919	75%
MSM/IDU	3,980	3,447	87%	2,840	71%
Heterosexual	30,209	25,729	85%	21,092	70%
Blood Products	174	153	88%	121	70%
Pediatric Risk	2,091	1,761	84%	1,387	66%
Unknown	12,863	10,256	80%	8,342	65%

<sup>1</sup> NYS HIV surveillance case and laboratory data as of June 2019

<sup>2</sup> At least 1 VL, CD4, or nucleotide sequence test during the year

<sup>3</sup> Residence by end of 2018

<sup>4</sup> Regional figures exclude persons incarcerated in a city jail, a county jail, a federal detention facility or a NYSDOCCS facility

<sup>5</sup> Current gender was not systematically collected by the NYS HIV surveillance system until 2013. Therefore, currently, care measures cannot be calculated by current gender for PLWDH.

<sup>6</sup> MSM-history of male-to-male sexual contact

<sup>7</sup> IDU-history of injection drug use

**Table C: Viral Suppression<sup>1</sup> in 2018**  
**Persons Living with Diagnosed HIV in Dec. 2017 and Alive in Dec. 2018, NYS<sup>2</sup>**

	All	≥1 VL test during the year		Virally suppressed at test closest to end of year		
		% of All		% of tested		% of All
<b>Residence<sup>3</sup></b>						
NYC	82,822	71,070	86%	62,542	88%	76%
ROS	23,326	18,544	79%	16,931	91%	73%
NYS Total	106,148	89,614	84%	79,473	89%	75%
<b>Ryan White Region<sup>4</sup></b>						
Albany	3,061	2,425	79%	2,228	92%	73%
Binghamton	492	389	79%	343	88%	70%
Buffalo	2,923	2,396	82%	2,120	88%	73%
Lower Hudson	3,729	2,979	80%	2,722	91%	73%
Mid-Hudson	2,172	1,643	76%	1,505	92%	69%
Nassau/Suffolk	5,552	4,374	79%	4,046	93%	73%
Rochester	2,877	2,417	84%	2,197	91%	76%
Syracuse	2,288	1,817	79%	1,676	92%	73%
<b>Birth sex<sup>5</sup></b>						
Male	75,902	63,603	84%	56,695	89%	75%
Female	30,246	26,011	86%	22,778	88%	75%
<b>Race/Ethnicity</b>						
Non-Hispanic White	20,760	17,242	83%	16,362	95%	79%
Non-Hispanic Black	42,341	35,619	84%	30,417	85%	72%
Hispanic	34,811	29,756	85%	26,404	89%	76%
Asian/Pacific Islander	1,798	1,449	81%	1,379	95%	77%
Native American	49	38	78%	35	93%	72%
Multi Race	6,276	5,417	86%	4,783	88%	76%
Unknown	113	93	82%	92	99%	81%
<b>Age</b>						
13-19	312	276	88%	217	79%	70%
20-24	1,889	1,589	84%	1,247	78%	66%
25-29	6,167	4,997	81%	4,055	81%	66%
30-39	17,577	13,965	79%	11,913	85%	68%
40-49	20,992	17,216	82%	15,100	88%	72%
50-59	34,060	29,490	87%	26,360	89%	77%
60+	25,149	22,079	88%	20,580	93%	82%
Unknown	2	2	100%	1	50%	50%
<b>Transmission Risk</b>						
MSM <sup>6</sup>	44,949	37,890	84%	34,363	91%	76%
IDU <sup>7</sup>	11,882	10,378	87%	8,977	87%	76%
MSM/IDU	3,980	3,447	87%	2,877	83%	72%
Heterosexual	30,209	25,729	85%	22,729	88%	75%
Blood Products	174	153	88%	134	88%	77%
Pediatric Risk	2,091	1,761	84%	1,272	72%	61%
Unknown	12,863	10,256	80%	9,120	89%	71%

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

<sup>2</sup> NYS HIV surveillance case and laboratory data as of June 2019

<sup>3</sup> Residence by end of 2018

<sup>4</sup> Regional figures exclude persons incarcerated in a city jail, a county jail, a federal detention facility, or a NYSDOCCS facility

<sup>5</sup> Current gender was not systematically collected by the NYS HIV surveillance system until 2013. Therefore, currently, viral suppression cannot be calculated by current gender for PLWDH.

<sup>6</sup> MSM-history of male-to-male sexual contact;

<sup>7</sup> IDU-history of injection drug use