



2024 N-S EMA Ryan White Part A/MAI Consumer Needs Assessment Survey Report



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Strategic Assessment and Planning Committee:

Name	Organization
Angie Partap	
Arthur Brown	
Cathy Martens	
Cristina Witzke, MPH	Edie Windsor Healthcare Center
Colin Pearsall	
Denise Ragsdale	
Eileen Bryant	
Jacqueline Rivera	Center for Young Adult, Adolescent and Pediatric HIV (CYAAPH) at Northwell Health
James Colson	
John Van	
Joseph Pirone	
Kerry Thomas, LMSW	Thursday's Child of Long Island
Maria Mezzatesta, LCSW-R	Sun River Health
Pam Biafora	Sun River Health
Victoria Osk, Esq.	Legal Services of Long Island
Sophia Porres	Stony Brook Medicine
Stephen Sebor	Center for AIDS Education and Training, Stony Brook University

United Way of Long Island Staff:

Name	Title
Georgette Beal	Senior Vice President, Planning and Grants Management
Myra Alston	Contract Administrator, Data Manager
Nancy O'Keefe	Contract Administrator, Quality Manager
JoAnn Henn	Planning Associate
Katie Ramirez	Program Administrator
Kathy Grathwohl	Associate Director/Fiscal Manager
Marcela Van Tassel	Claims Analyst

Overview

The Nassau-Suffolk HIV Health Services Planning Council is responsible for determining HIV service needs on Long Island and establishing priorities for the allocation of funds. The Consumer Needs Assessment Survey is one of the tools the Council uses to help determine service needs and gaps for people with HIV (PWH) on Long Island and was originally developed in 2001 by the Strategic Assessment and Planning (SAP) Committee of the Council. The original survey tool was modeled after a survey in Louisiana and was designed to gather comprehensive information from consumers or their caregivers. Since 2001, the survey has been conducted periodically. The constancy of the survey assures that Ryan White priorities are responsive to the population's changing needs in the Nassau-Suffolk Eligible Metropolitan Area (EMA). This report includes the most up-to-date information concerning PWH in the Nassau-Suffolk EMA and compares survey results from 2007, 2009, 2011, 2014, 2019, and 2024.

As the HIV landscape continues to shift, the survey instrument has been updated to reflect emerging issues and needs. In 2024, new sections were introduced to address key topics such as food security, the challenges associated with aging, and the pervasive effects of stigma and discrimination. Additionally, a "status neutral" approach, which emphasizes equal care and prevention services regardless of HIV status, was considered in the instrument revisions. These updates ensure the instrument remains relevant and comprehensive, capturing the diverse experiences of PWH.

Since the inception of the survey, United Way of Long Island (UWLI) has assisted the Planning Council in implementing and administering the consumer needs assessment survey through a variety of new techniques to obtain continuous survey responses. In 2024, UWLI staff took the lead role by working with the Strategic Assessment and Planning Committee (SAP), providers, and Peers in the region to administer the survey. The survey instrument was designed with input from the SAP committee. A consultant was used for data entry, analysis, report writing, and presentation of results. To free up provider time and capture a larger audience, bilingual peers were used at three provider agencies, including Nassau Healthcare Foundation, North Shore University Hospital, and Sun River Health. In April 2024, a training was held for the peers via Zoom and facilitated by Dr. Anthony Santella, project consultant and former Chair of the Nassau-Suffolk HIV Health Services Planning Council on how to conduct needs assessments.

Provider agencies facilitated surveys onsite and promoted the survey to their clients through newsletters, mailings, phone contacts, and consumer advisory board meetings. Peers worked onsite and also during home visits. Venues utilizing bilingual peers to facilitate the survey achieved the greatest response rates. Surveys were available in both English and Spanish in paper format and online. The survey was also available by telephone (in English) with UWLI staff on Tuesdays and Thursdays from 9 AM-1 PM throughout the survey period. The survey

was confidential regardless of how the respondent completed the survey. Consumers were offered a \$25 gift card to thank them for their time and participation.

The 2024 survey initially ran from March to June and was extended to July to ensure that agencies had additional time to reach as many consumers as possible while ensuring that preliminary data would be available for use during the Council's Priority Setting and Resource Allocation Process. By extending the survey, the region was able to collect a total of 369 surveys (goal was 500) across the nine participating agencies and through United Way. However, this represented a decrease in response rate from past surveys (467 in 2019 and 500 in 2014) which were conducted over a slightly longer timeframe. Five responses were disallowed due to ineligible zip codes and duplication (completed at multiple agencies) bringing the total number of allowable surveys to 364. Some participants left varying questions blank leaving the totals for non-duplicative individual questions presented in this narrative to sometimes less than 364. ChatGPT was used to help summarize data and look at differences between groups.

When analyzing the survey results, there are certain limitations to consider. For instance, when people choose to participate in a survey, they may be different from those who do not participate. This could lead to a sample that is not truly representative of the entire population. Additionally, because the study only collects data at one specific time, it's challenging to track changes in needs over time or establish cause-and-effect relationships. Surveys administered through healthcare providers may also lead to biased results, as participants might feel pressured to respond in a way that aligns with what they think their provider expects. Furthermore, participants may have difficulty accurately recalling past needs or experiences, especially if the survey covers a long period or asks about specific medical details.

2024 Executive Summary

The Nassau-Suffolk Eligible Metropolitan Area (EMA) comprises the two suburban counties of Nassau and Suffolk on Long Island, NY and has a population of 2.9 million. The demographic makeup of the EMA is predominantly White (60%), with Hispanic (20%), Black (10%), Asian (9%), and other racial/ethnic groups making up smaller percentages. As of December 31, 2022, 5,747 persons with HIV (PWH) are in the EMA, with a racial/ethnic breakdown of 36.3% White, 34.4% Black, and 24.4% Hispanic. New HIV cases in 2022 showed significant racial disparities, particularly among Hispanics and African Americans, who had disproportionately higher rates compared to their general population share. Males accounted for 84% of new HIV cases, and the primary mode of transmission was among men who have sex with men (MSM), comprising 58% of new cases.

The EMA faces geographic challenges in providing care, with limited transportation options affecting service access. Ryan White Part A and Minority AIDS Initiative (MAI) funds support six core medical services and three support services, including medical transportation, emergency financial assistance and other professional services- *legal*. These services play a critical role in bridging gaps in the care continuum for those navigating complex health systems. By the end of 2022, the EMA achieved a high viral suppression rate of 95.1%, though disparities persist, particularly among Blacks, who make up the largest proportion of the unsuppressed population.

The 2024 survey gathered responses from PWH in Nassau County (52%) and Suffolk County (48%). Most participants are aged 55-64 (29%), followed by 45-54 (21%) and 65 and older (22%). Racially, 43% identify as Black/African American and 33% as White, with 40% identifying as Latino/a/x or Hispanic. Gender distribution shows 53% identify as male and 47% as female. Educationally, 21% have less than a high school education, 53% hold a high school diploma or GED, and 26% possess a college degree or higher. Approximately 3% have a military background. Employment status indicates that 22% work full-time, 20% are part-time, 12% are retired, and 27% are disabled and unable to work. With varying monthly incomes, 43% are at or below the federal poverty level and earn between \$0 and \$1,215. Language proficiency reveals that 72% primarily speak English and 37% primarily speak Spanish, while 66% prefer speaking in English for their medical care. Importantly, 94% report access to HIV services in their preferred language.

Most respondents were diagnosed with HIV in Nassau County (45%) and Suffolk County (27%). A little over a quarter of respondents (28%) received their diagnosis in other locations, with notable responses from Queens, El Salvador, and Manhattan. The majority (40%) were diagnosed in a hospital or emergency room, followed by health centers/community clinics (30%) and private doctor's offices (13%). Regarding sexual partners, 57% identified male partners, 25% female partners, and 1% identified both transgender male and female partners, while 24% reported being sexually inactive. The primary mode of HIV transmission was unprotected sexual intercourse with someone who has HIV (82%). Sharing needles was

reported by 8%. Other transmission modes included mother-to-child transmission (3%), blood transfusion (6%), and 6% reported different modes.

Currently, 46.1% of respondents live independently, while 16.6% reside in shelters or emergency housing, and an equal 16.6% live in group homes for people with HIV. A smaller portion live with parents (8.9%), rent a room (15.3%), or stay with roommates (8.3%). In the past, fewer respondents (6.4%) lived independently, with 19.0% living with parents, and a similar distribution across other types, including 7.3% who were homeless or in emergency housing. Food insecurity affects 29%. 43% reporting receipt of SNAP benefits in the past year and 52% indicated that they had been referred to a nutritionist.

Respondents rated their overall health with 21% considering it excellent, 37% very good, 24% average, 17% fair, and 1% poor. Health coverage is prevalent, with 36% on Medicare and 52% on Medicaid. Approximately 1% are uninsured. While 8% faced challenges enrolling in health programs, 45% understood insurance requirements.

Transportation to HIV medical services is primarily by personal car (46%), with some using public transportation (40% combined for bus and taxi) and others using friends or relatives (10%), and walking (3%). Costs for transportation are mostly covered by respondents themselves (58%), with 14% relying on Medicaid or insurance. Assistance was also reported from Ryan White Part A funded programs at Circulo de la Hispanidad (20%) and the Economic Opportunity Council of Suffolk (12%).

Respondents are accessing care from a variety of medical providers in the EMA including the Designated AIDS Centers (DACs), Federally Qualified Health Centers (FQHCs), and private providers with the highest concentrations at NUMC (n= 88) and Northwell (n= 77). Following their HIV diagnosis, 73% sought medical care within a month, with half relying on doctors and medical providers for support. While 89% had received care in the last six months (from the time of survey completion), some cited barriers like insurance loss and homelessness. Nearly all respondents (96%) had HIV labs done recently, with 98% currently on HIV medications. However, awareness of HIV genotype or phenotype testing varies, as 34% confirmed having it done, while many remain uncertain about it.

Respondents reported a range of comorbid conditions, with high blood pressure (43%) and high cholesterol (46%) as the most prevalent, alongside arthritis (35%) and vision problems (33%). Other significant health issues included diabetes (24.6%), lung problems (21%), and neurological conditions (22%). In terms of sexually transmitted infections (STIs), 42.9% reported having Trichomoniasis in the past year, with notable previous infections of genital warts (95%) and genital herpes (90%). Regarding HIV care, 86% felt their providers helped distinguish between aging symptoms, HIV symptoms, and medication side effects. 53% indicated that they received information on how HIV affects aging. Concerns about aging included managing HIV (50%) and long-term medication effects (37%), with emotional issues such as being a burden (36%) also significant. Most respondents (79%) did not report experiencing discrimination,

though 14% cited HIV stigma as a concern. In healthcare settings, 81% perceived no discrimination; however, among those who did, doctors were the most frequently identified source.

For medical services, most respondents needed and received general medical care (61%) and medical case management (57%), with high access rates also reported for dental care (53%) and eye care (52%). However, some respondents reported needing additional dental care (7.7%) or were unable to access it despite needing it (6.5%). Many respondents indicated they do not need certain services, such as OB care (77%) and nursing home care (76%). In terms of social services, case management was the most accessed (58%), followed by transportation services (35%). The majority of respondents did not require services like needle/syringe programs and pre-release services (81% each). However, a few respondents needed more support with food bank access (4%), housing assistance (3%), and copays (3%), while others identified housing support (7%) and rent or mortgage assistance (7%) as unmet needs. Some also expressed a need for rent and utility assistance but did not seek it (7% each). Overall, while some services are widely utilized, a significant portion of respondents did not report needing others, suggesting potential gaps in awareness or availability.

While 92% of respondents take their medications as prescribed and 58% reported no use of substances, the survey also reveals a notable prevalence of past or current substance use among respondents. Among those who do use, alcohol (27%) is the most common, followed by marijuana (17%) and tobacco or nicotine (12%). A small percentage (8%) reported having ever exchanged sex for anything. A significant majority (71%) do not believe they need treatment for substance issues, and 92% indicated they do not require drug or alcohol help services, though 4% needed assistance and received it. Regarding mental health, 31% reported being diagnosed with a condition and 53% expressed feelings of anxiety or depression. Additionally, incarceration experiences varied, with 25% of respondents having been jailed and 12% having been to prison, predominantly released more than three years ago.

Consumer Needs Assessment Data Trends from 2007-2024 for Select Indicators

The needs assessment surveys conducted in 2007, 2009, 2011, 2014, 2019, and 2024 provide valuable trended data that help to identify evolving patterns in service needs and gaps among PWH. These surveys capture shifts in demographics, healthcare access, and barriers to care over time. However, when interpreting this data, it is important to exercise caution. Slight differences in survey tools, question phrasing, or methodology across the years may affect direct comparisons. While the data offers useful insights into long-term trends, any conclusions should be drawn with an understanding of these variations in the survey instruments.

Table 1: Trended Data on Top 10 Services that Respondents Needed & Received (2009-2024)

SERVICES NEEDED AND RECEIVED	2024	2019	2014	2011	2009
Medications	1	1	1	1	9
Outpatient Ambulatory Medical Care	3	2	2	8	7
Dental Care	5	4	3	3	
Medical Case Management	2	5	4	5	4
Case Management		6	5	6	3
Eye Care	4	3	6	4	8
Mental Health/Emotional Counseling	6	8	7		
Transportation		7	8		
Free Condoms		9	9	8	
Support Groups			10		
Emergency Medical Care	7	10		9	10
Gynecological Care	8				
Nutritional Counseling	9				
Help Taking Medications	10				

Table 2: Trended Data on Top 10 Services that Respondents Received, but Needed More Than What Was Available (2029-2024)

RECEIVED, NEEDED MORE THAN AVAILABLE	2024	2019	2014	2011	2009
Food Bank/Vouchers		2	1	1	3
Eye Care	3	3	2		
Dental Care	1	1	3		
Money for Mortgage or Rent		6	4		
Help Finding Housing		5	5	4	4
Money for Medications			6	4	4
Money for Utilities		4	7		
Assistance with Co-payments			8		
Legal Services		7	9	4	
Case Management		10	10	3	2
Information on Available Services				2	4
Medical Case Management	4	8		4	4
Transportation		9		3	1
Client Advocacy				3	2
Nutritional Counseling	2				
Mental Health	5				
Outpatient Medical Care	5				
Hepatitis C Care	6				
Home Health	7				
Emergency Medical Care	8				
Medications	9				
Hospice	10				

Table 3: Trended Data on Top 10 Services that Respondents Needed, but Could Not Get (2009-2024)

NEEDED BUT COULD NOT GET	2024	2019	2014	2011	2009
Dental Care	3	1	1		
Eye Care	10	6	2	1	
Food Bank/Vouchers	6	4	3	3	4
Nutritional Counseling	7		4	4	
Support Group Counseling	9	8	5	4	
Help with Finding and Keeping Housing	1	5	6		
Money for Utilities	4	3	7	2	2
Money for Rent	2	2	8	2	3
Mental Health Services /Counseling		9	9		
Legal Services		10	10	7	
Complimentary Therapy		7		1	1
Assistance with co-pays	5				
Home-delivered meals	8				

Table 4: Trended Data on Top 10 Services that Respondents Needed, but Did Not Seek (2009-2024)

NEEDED BUT DID NOT SEEK	2024	2019	2014	2011	2009
Money for Utilities	2	5	1	3	2
Money for Rent	3	3	2	2	3
Assistance with Copayments	9	2	3		
Money for Medication		7	4	9	
Legal Services	8	10	6	7	
Child Care Services			7		
Support Groups		6	8		
Help Finding Housing		4	9	5	4
Food Bank/Vouchers	5	1	10	4	4
Transportation		8		7	5
Meals Delivered to My Home	6	9		6	4
Dental Care	1				
Eye Care	4				
Nutritional Counseling	7				
Gynecological Care	10				

Table 5: Trended Data on Monthly Reported Income of Survey Respondents (2007-2024)

Monthly Income	2024	2019	2014	2011	2009	2007
0-249	43.4% (0-\$1215)	12.0%	9.8%	8.6%	7.50%	0.9%
250-499		4.0%	3.8%	7.3%	10.7%	5.2%
500-749		8.0%	14.0%	15.7%	18.0%	29.6%
750-999		16.0%	20.0%	25.6%	30.5%	19.1%
1000-1499		21.0%	20.4%	18.3%	15.4%	15.7%
1500-1999	31.2% (\$1216-\$2430)	9.0%	11.0%	8.2%	10.7%	9.6%
2000-2499		8.0%	12.4%	3.1%	2.9%	5.2%
2500-2999	25.4% (\$2431+)	5.0%	1.2%	2.6%	1.5%	2.6%
3000+		16.0%	6.0%	10.6%	2.9%	12.2%

Note: Response categories changed in the 2024 survey to align with Federal Poverty Level (FPL) Income band categories. The FPL has been updated for 2024. The FPL guidelines are based on federal updates that are issued annually by the U.S. Department of Health and Human Services (HHS). For a single individual, the 2024 guideline is set at \$15,060, and for a family of four, it is \$31,200. These updates reflect the rising cost of living, adjusted through the Consumer Price Index. In NY, the Ryan White eligibility threshold was 500% as of the survey administration date.

Table 6: Trended Sources of Income by Respondent (2007-2024)

Income Source	2024	2019	2014	2011	2009	2007
SSI	23.1%	19.0%	20.1%	30.4%	42%	30%
SSDI	23.4%	22.0%	23.3%	36.4%	41%	26%
Employed	46.0%	41.0%	34.7%	30.4%	25%	25%
AFDC/TANF	2.2%	1.0%	2.0%	3.5%	1%	0%
Child Support	2.2%	0.0%	0.0%	0.9%	1%	1%
Retirement	4.2%	6.0%	2.4%	4.3%	1%	4%
Unemployed	6.4%	8.0%	8.4%	2.6%	0%	0%
Other	13.1%	7.0%	9.0%	17.1%	0%	14%

Table 7. Trended Housing Situation of Respondents (2007-2024)

HOUSING SITUATION	2024	2019	2014	2011	2009	2007
Own home, Apartment: own or rent	87.4%	56%	53%	63%	67.1%	59.8%
Parent's Home or Apartment	31.4%	13%	7%	9%	3.9%	4.2%
Rent a Room	60.7%	12%	17.2%	8.2%	15.1%	10.8%
Someone Else's Home or Apartment	60.2%	7%	9.8%	6.7%	3.9%	8.5%
Live with Roommate	28.0%	1%	2.2%	1.9%	0.7%	7.9%
Live with Partner		0%	3.8%	1.5%	5.4%	3.3%
Homeless (On Streets)	10.0%	2%	0.8%	0.6%	0.7%	0.7%
Homeless (Shelter)	18.2%	3%	1.2%	1.1%	0.4%	0.8%
Group Home, PWH	21.6%	2%	1.4%	2.8%	1.1%	0.8%
Group Home, Not PWH		0%	1.6%	0.6%	1.4%	1.6%
Drug or Alcohol Treatment	3.2%	0%	0%	0%		
Nursing Home	5.0%	0%	0%	0.6%		
Psychiatric Treatment Center	5.3%	0%	0%	0%		
Jail		0%	0.4%	0%		
Sober House	4.2%	1%	0.2%	1.1%	0.4%	
Other		2%	1%	1.9%		
Assisted Living Facility	15.8%					

Table 8. Trended Self-Reported Exposure to HIV (2007-2024)

EXPOSURE	2024	2019	2014	2011	2009	2007
Men having Sex with Men	*	36%	27%	30%	20%	28%
Injection Drug Use (sharing needles/syringes)	7.7%	7%	6%	11%	17%	17%
Heterosexual	*	44%	52%	45%	49%	38%
Transfusion	5.7%	5%	4%	6%	4%	3%
Perinatal	2.6%	3%	3%	2%	3%	6%
Other/Unknown	6.2%	3%	8%	6%	7%	8%
Unprotected Sex	81.9%					

Note: *Response categories changed in the 2024 survey which is why there is a new category for "unprotected sex".

Table 9. Trended Data on Co-morbidities of Respondents (2009-2024)

PHYSICAL CO-MORBIDITY	2024	2019	2014	2011	2009	Change from 2019 to 2024
High Cholesterol	46.4%	36%	42.0%	38.3%	30%	
High Blood Pressure	43.0%	32%	29.0%	32.7%	30%	
Gonorrhea	12.7%	14%	22.0%	13.2%		
Lung/Breathing Problems	20.6%	20%	20.2%	25.3%	14%	
Hepatitis C	12.5%	14%	17.0%	23.4%		
Problems with Thought or Memory	15.9%	20%	16.4%	20.1%	11%	
Diabetes	24.6%	11%	16.0%	13.2%	11%	
Yeast Infections (Thrush)	17.8%	18%	15.6%	17.3%		
Heart Problems	21.4%	12%	14.8%	16.2%	11%	
Neuropathy	21.8%	17%	14.8%	21.9%	24%	
Syphilis	27.8%	14%	14.4%	9.3%		
Liver problems	10.6%	13%	13.4%	13.9%	26%	
Chlamydia	19.4%	15%	13.0%	10.0%		
Hepatitis B	10.0%	8%	12.4%	10.6%		
Herpes (Genital)	9.7%	11%	12.0%	10.6%		
Cancer	12.9%	11%	10.8%	8.4%	5%	
Hepatitis A	6.6%	6%	10.0%	7.4%		
Kidney Problems	17.1%	12%	9.2%	12.9%	7%	
Human Papillomavirus	20.0%	14%	7.8%	10.2%		
Genital Warts	4.8%	11%	7.2%	11.9%		
PCP Pneumonia	12.9%	19%	6.6%	21.6%	15%	
Tuberculosis (TB)	7.5%	6%	6.6%	7.1%	6%	
Trichomoniasis	42.9%	6%	4.0%			
Other (Specified Above)		5%	15.2%	5.6%		
Arthritis	34.9%					
Asthma	21.2%					
Dermatology/Skin Problems	20.9%					
Hearing Problems/Deafness	8.5%					
Yeast Infections	16.7%					
Vision Problems/Blindness	32.5%					

Red= Increase, **Yellow**- No Change, **Green**= Decrease

Table 10. Trended data on Race/Ethnicity of respondents (2007-2024)

RACE/ETHNICITY	2024	2019	2014	2011	2009	2007
Black	43.5%	35%	38%	44%	32%	42%
White	32.7%	39%	33%	38%	34%	35%
Hispanic	40.2%	28%	31%	23%	23%	13%
Multiracial		10%	14%	5%	8%	6%
Other	25.3%	9%	15%	11%	3%	4%
Asian	2.0%					
AI/AN	3.1%					
NH/PI	0.6%					

Table 11. Trended Data on Age of Respondents (2007-2024)

AGE GROUP	2024	2019	2014	2011	2009	2007
No Response		0%	0.80%	0.10%	1%	4%
Under 20	2.8% (18-24)	0%	3.20%	0.10%	0%	4%
20-29	11.1% (25-34)	5%	13.20%	5%	5%	6%
30-39		15%	11.20%	8%	13%	16%
40-49	15.2% (35-44)	16%	20.40%	35%	33%	43%
50-59	20.5% (45-54)	33%	35.00%	34%	38%	24%
60-69	28.5% (55-64)	25%	14.80%	15%	10%	3%
70+	21.9% (65+)	4%	1.40%	2%	0%	0%

Note: Response categories changed in the 2024 survey.

Table 12. Trended Data on Medical Transportation (2007-2024)

TRANSPORT	2024	2019	2014	2011	2009	2007
Taxi	23.1%	26%	31%	10%	6%	16%
Use my own car	45.9%	37%	28%	42%	41%	37%
Take the bus	16.6%	15%	23%	19%	7%	18%
Friend gives me a ride	10.1%	9%	8%	4%	16%	10%
Managed Care Corp. supplied ride			4%			
Walk	3.7%	2.0%	2.6%	4%		2%
Gas Card	6.2%	4.0%	1.5%	1%	11%	
Able Ride	2.8%	1%	1%	1%	6%	0%
SCAT	5.1%	3.0%	0.4%	2%	3%	9%
LIRR	2.3%	2.0%	0.2%	3%	10%	7%
Other	24.2%	3.0%	0.3%	2%		

Table 13. Trended Data on Top 5 Priority Services (2007-2009)

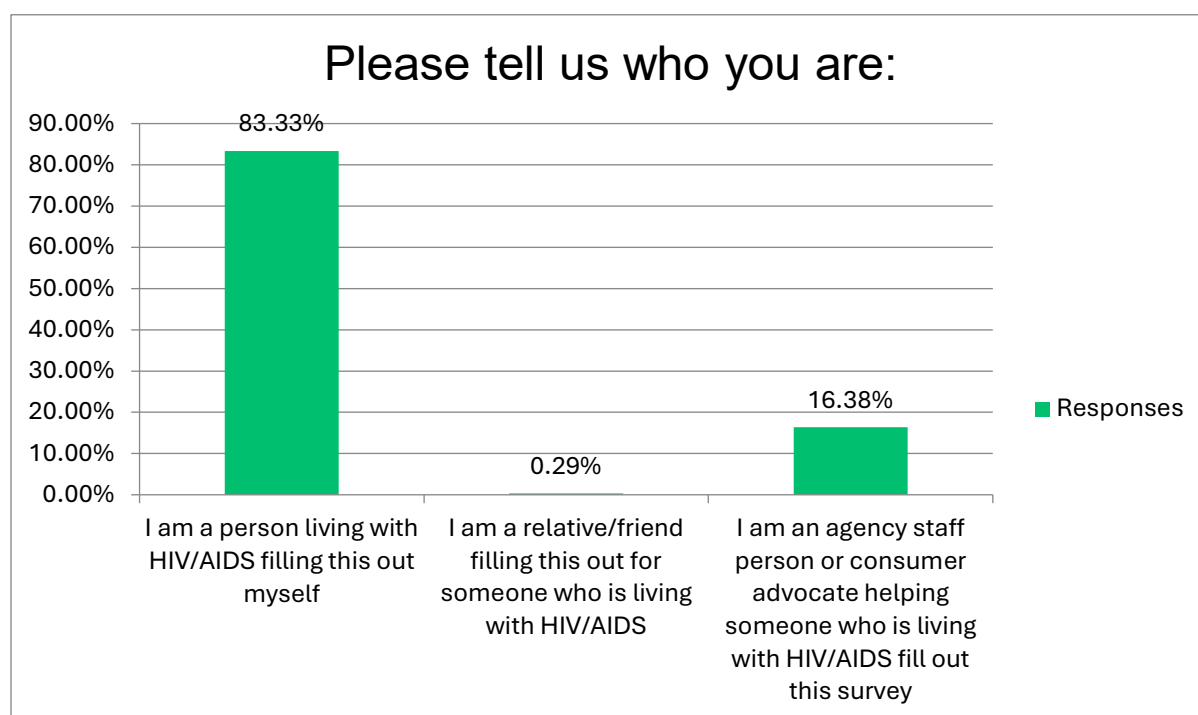
PRIORITY SERVICE	2024	2019	2014	2011	2009	2007
Medications		63.0%	57.6%	32.8%	32.9%	7.0%
Outpatient Ambulatory Health Services (medical care)	42.05%	58.0%	55.4%			
Dental	55.40%	53.0%	49.0%	44.5%	37.6%	30.0%
Medical Case Management	46.59%	50.0%	43.2%	38.5%	37.4%	27.0%
Transportation		22.0%	32.6%	36.2%	34.4%	30.0%
Health Insurance	36.08%	39.0%	27.8%	46.7%	50.5%	0.0%
Mental Health/Emotional Counseling		34.0%	27.8%			
Vision	29.83%	45.0%	24.2%			
Money for Rent		27.0%	21.2%	30.6%	30.8%	21.0%
Food Bank/ Vouchers		26.0%	21.2%	29.7%		25.0%
Legal Services		20.0%	11.4%	16.6%		25.0%



Summary of Overall Responses

Respondent Characteristics

The majority of respondents (83%) who completed the 2024 Consumer Needs Assessment Survey were individuals living with HIV who completed the survey on their own without assistance. A small fraction (0.3%) of the respondents were assisted by relatives or friends who completed the survey on their behalf. Agency staff or consumer advocates assisted approximately 16% of the respondents in completing the survey. The survey was distributed and/or shared with PWH across various service providers throughout the EMA. Nassau University Medical Center administered the most surveys in the EMA.



I am a person living with HIV/AIDS filling this out myself	83.33%	290
I am a relative/friend filling this out for someone who is living with HIV/AIDS	0.29%	1
I am an agency staff person or consumer advocate helping someone who is living with HIV/AIDS fill out this survey	16.38%	57
Answered		348
Skipped		16

Where are you completing this survey?

	%	#
Online/Internet	9.60%	34
By telephone with United Way of Long Island staff	4.24%	15
Circulo de la Hispanidad	7.63%	27
Economic Opportunity Council of Suffolk County	0.28%	1
Harmony Healthcare	0.00%	0
Hispanic Counseling Center	0.85%	3
Nassau Health Care Foundation/Nassau University Medical Center	27.97%	99
Nassau-Suffolk Law Services	2.82%	10
North Shore University Hospital	5.65%	20
Options for Community Living	4.80%	17
Research Foundation at Stony Brook/ Stony Brook Hospital	3.39%	12
Southampton Hospital/Edie Windsor Center	2.54%	9
Suffolk County Department of Health- Riverhead Health Center	0.28%	1
Thursday's Child	2.54%	9
Different location (please specify)	27.40%	97
Answered		354
Skipped		10

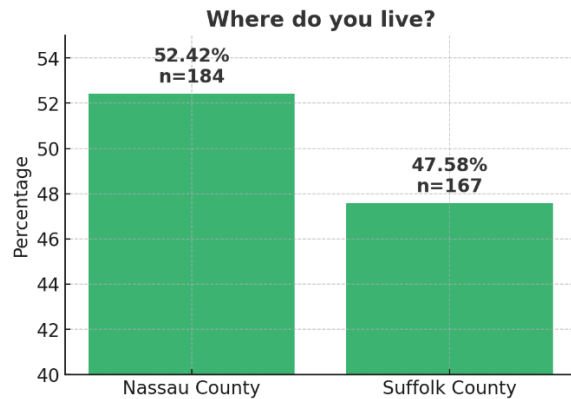
The Nassau Health Care Foundation/Nassau University Medical Center was the most utilized resource for survey completion, accounting for 28% of the responses. Additionally, 27% mentioned completing the survey at other unspecified locations. Within the Different location responses, Sun River accounted for the majority (55 out of 97). The internet is another significant source, utilized by 10% of respondents. Other noteworthy sources include Circulo de la Hispanidad (8%), North Shore University Hospital (6%), and Options for Community Living (5%). Smaller percentages reported assistance via the United Way of Long Island (4%), Thursday's Child (3%), and the Research Foundation at Stony Brook/Stony Brook Hospital (3%).

The breakdown for different location responses included:

“Other” responses:

Sun River Health (55)	NUMC (2)
United Way (11)	Centro de Salud (2)
Home (7)	Clinic (2)
Northwell Hospital (4)	Hospital Office (1)
Doctor's Office (3)	Eddie Windsor HealthCare (1)
Home visit (3)	

Residency

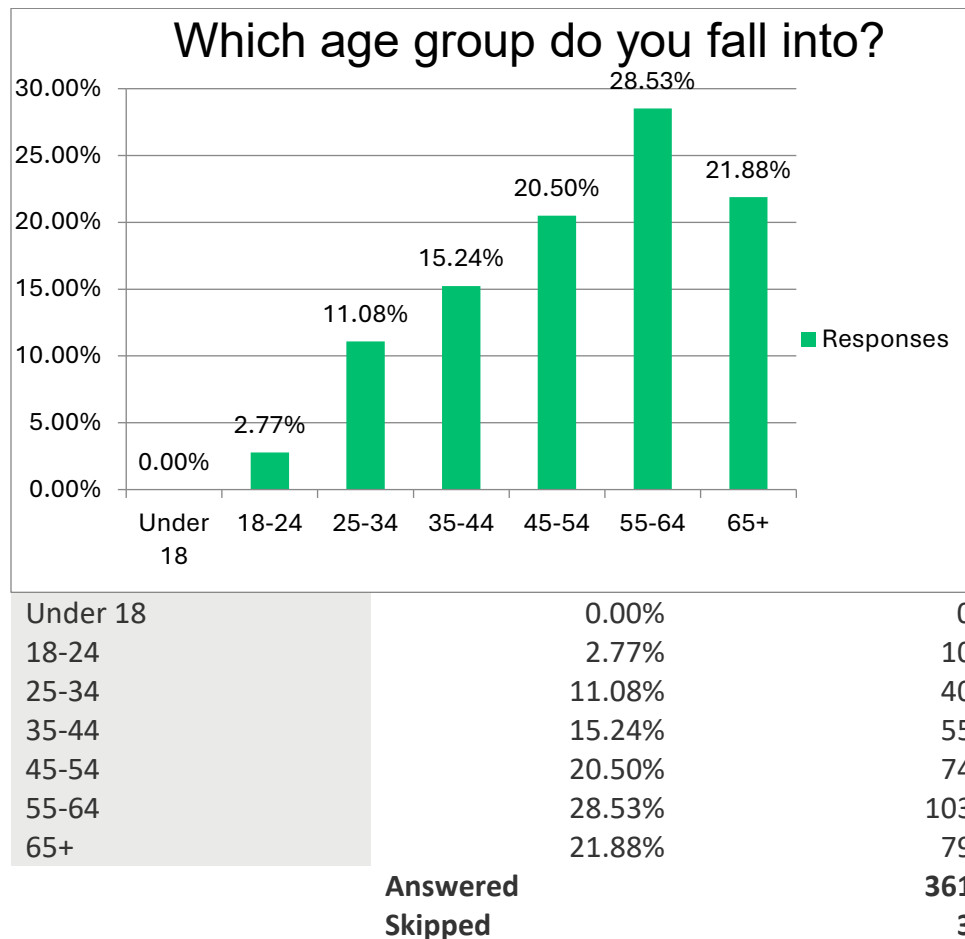


The survey responses indicate that most participants who completed the survey reside in Nassau County, accounting for 52%, while 48% reside in Suffolk County. **Note:** 351 out of 364 participants responded to this question (13 skipped this question).

Town/City	Count	Town/City	Count	Town/City	Count
Hempstead	53	Copiague	5	Holbrook	2
Central Islip	19	Deer Park	4	Shirley	2
Westbury	17	Uniondale	4	Mineola	2
Freeport	16	Centereach	4	Port Washington	2
Patchogue	15	Mastic Beach	4	Farmingville	2
Brentwood	11	Ronkonkoma	4	Inwood	2
Bay Shore	10	Oceanside	4	Roslyn Heights	2
Long Beach	9	Hauppauge	4	Medford	2
Wyandanch	8	Bethpage	4	Manhasset	2
Elmont	8	Massapequa	3	Bohemia	2
Huntington Station	8	Rockville Centre	3	Manorville	1
Riverhead	8	Mastic	3	East Hampton	1
Amityville	8	Glen Cove	3	Wainscott	1
Roosevelt	7	Sayville	3	Center Moriches	1
Hicksville	7	Lindenhurst	3	Centerport	1
Baldwin	7	Farmingdale	2	Sag Harbor	1
Valley Stream	7	Syosset	2	Mill Neck	1
Bellport	6	Hewlett	2	Merrick	1
West Babylon	6	Lynbrook	2	Lake Grove	1
Coram	6	Orient	2	N. Hempstead	1
West Hempstead	5	Port Jefferson Station	2	Garden City	1

Demographics

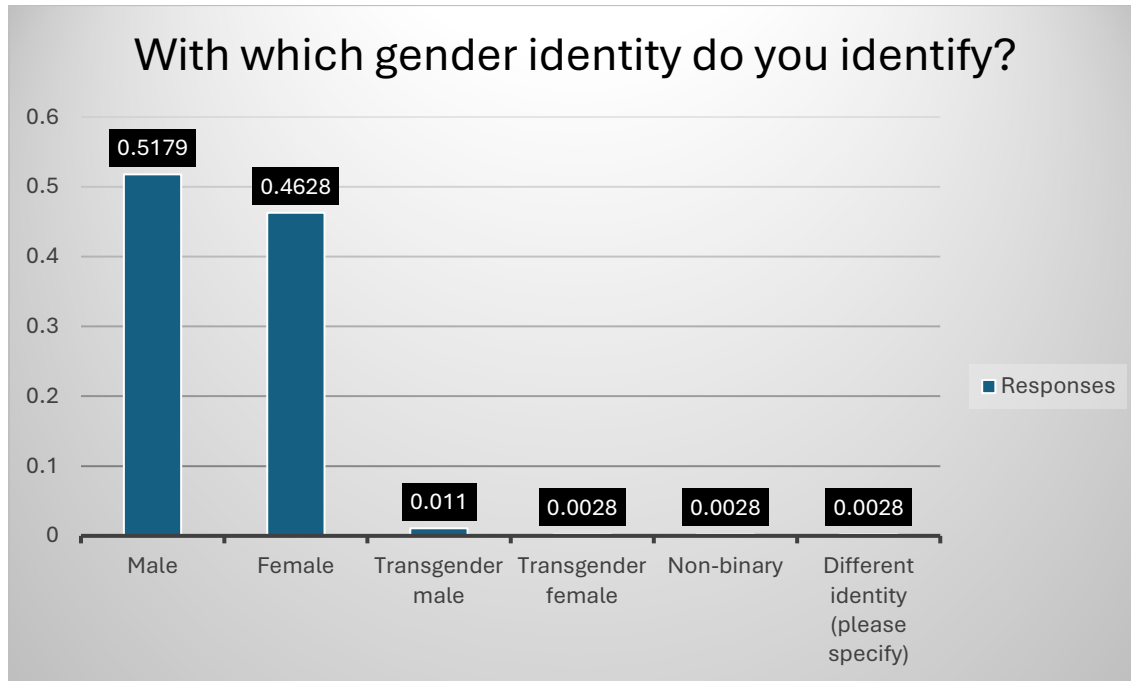
Age



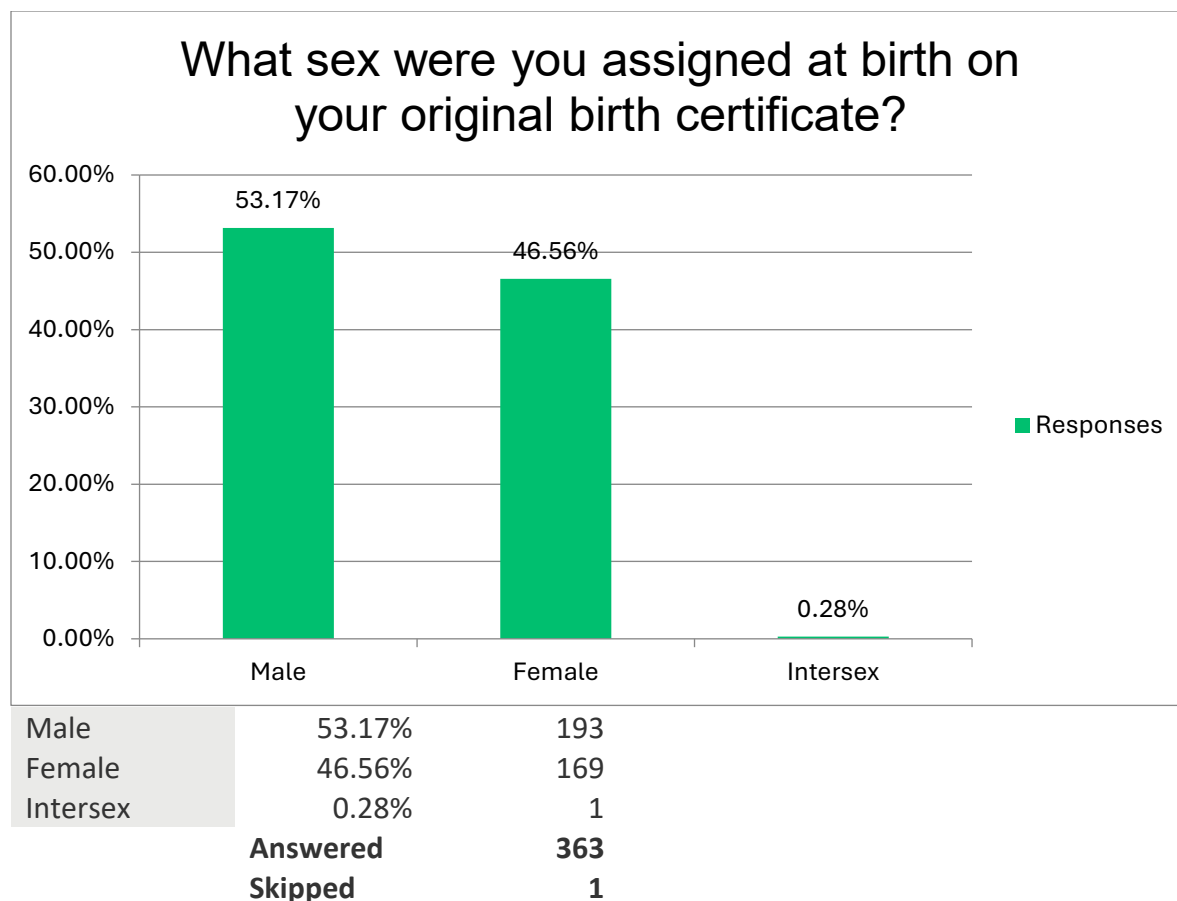
The age distribution of survey respondents shows that the largest group falls within the 55-64 age range at 29%, closely followed by those aged 65 + at 21.88% and 45-54 at 20.5%. Those aged 35-44 make up 15%. Younger age groups are represented less, with only 11% aged 25-34 and 3% aged 18-24. Notably, there are no respondents under 18.

In this sample, about 50.4% are 55+ years old and by comparison, 57.3% of PWH in New York State are age 50 and older.

Gender Identity



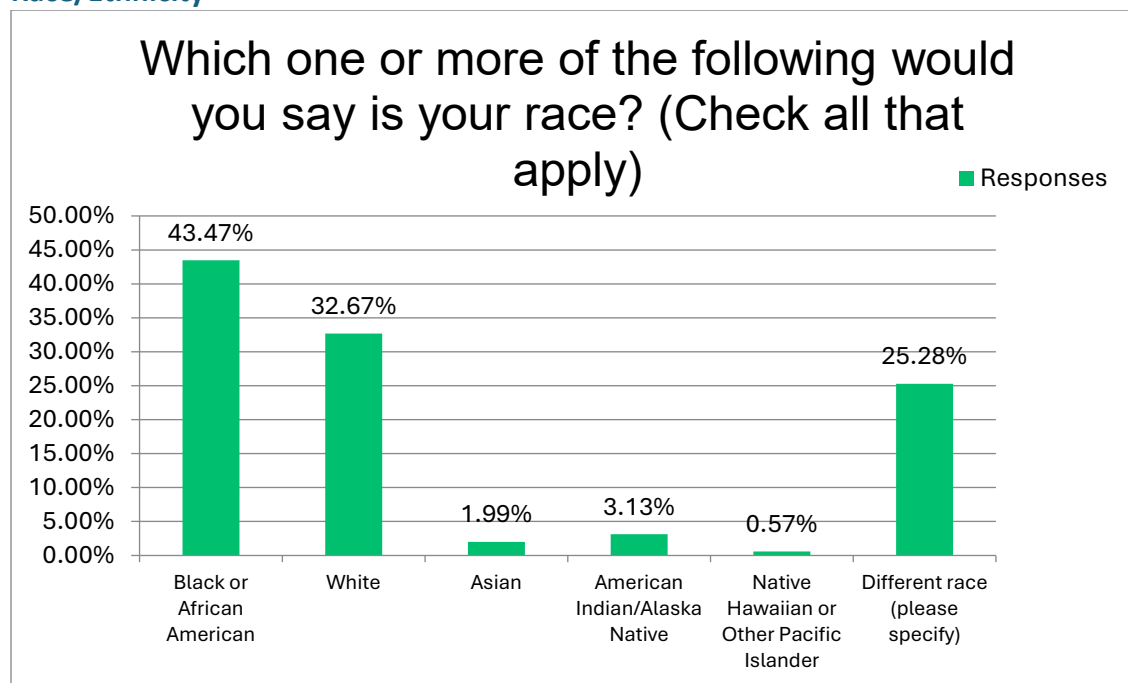
Three hundred six three (363) respondents completed this question (1 skipped). The gender distribution of survey respondents indicates that the majority identify as male ($n=188$ 52%), followed by female respondents ($n=168$ 46%). A small percentage identify as transgender male ($n=4$ 1%), with transgender female, Non-binary individuals and those identifying as a different gender accounting for 0.3% each. The one “different identity” reported being asexual.



The gender distribution of survey respondents shows that 53% identify as male, 47% as female, and a small fraction (0.3%) identify as intersex.

By comparison, 70.2% of PWH in New York State were assigned male sex at both.

Race/Ethnicity



Black or African American	43.47%	153
White	32.67%	115
Asian	1.99%	7
American Indian/Alaska Native	3.13%	11
Native Hawaiian or Other Pacific Islander	0.57%	2
Different race (please specify)	25.28%	89
Answered		352
Skipped		12

The racial demographics of respondents indicate that 43% identify as Black or African American, while 33% are White. A smaller percentage, about 2%, identify as Asian, and approximately 3% as American Indian or Alaska Native. Only 0.6% identify as Native Hawaiian or Other Pacific Islander. Additionally, around 25% reported a different racial identity, highlighting a significant diversity in the population surveyed. Among those with “different race”, Latino/a was most common (n= 57), followed by multiracial (n= 20).

The “different race” responses included:

Latino/Hispanic/Puerto Rican (54)

Multiracial (20)

Mestizos (2)

Haitian (2)

Native American (1)

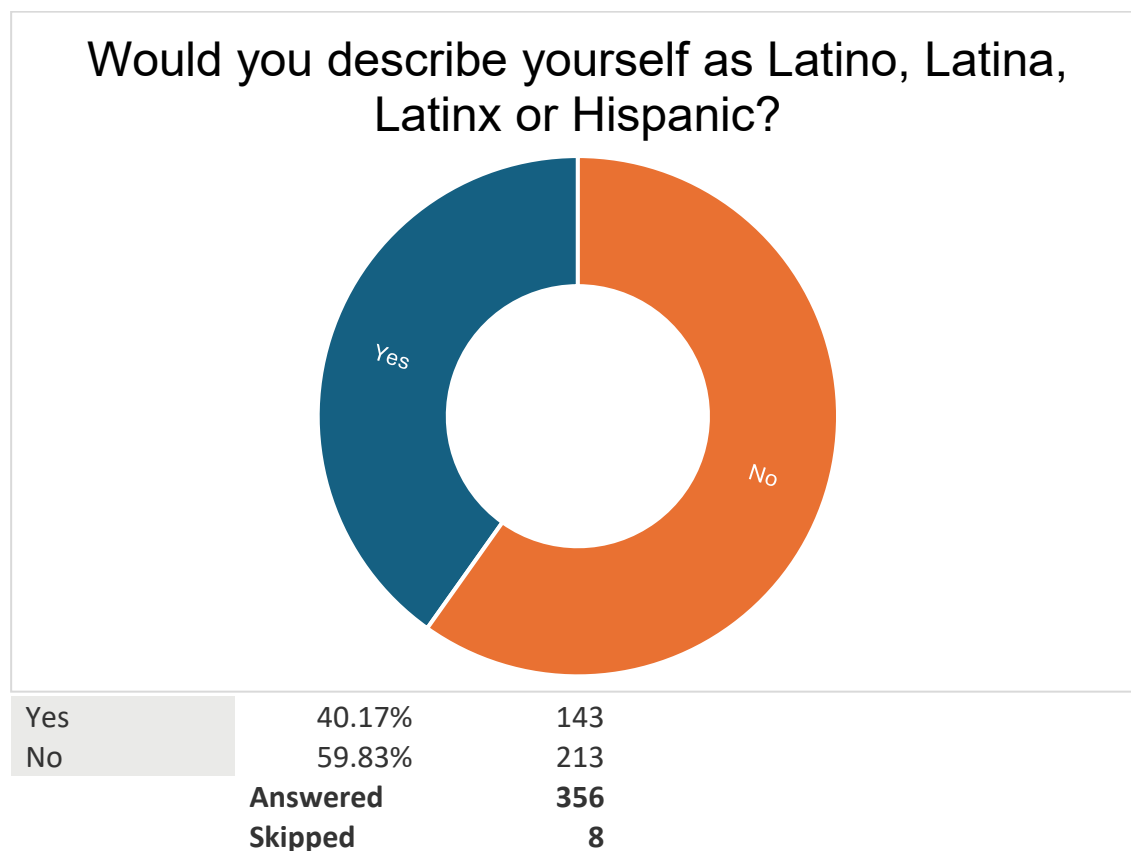
White/Hispanic (1)

Central American (1)

Indian, Latin, Black (1)

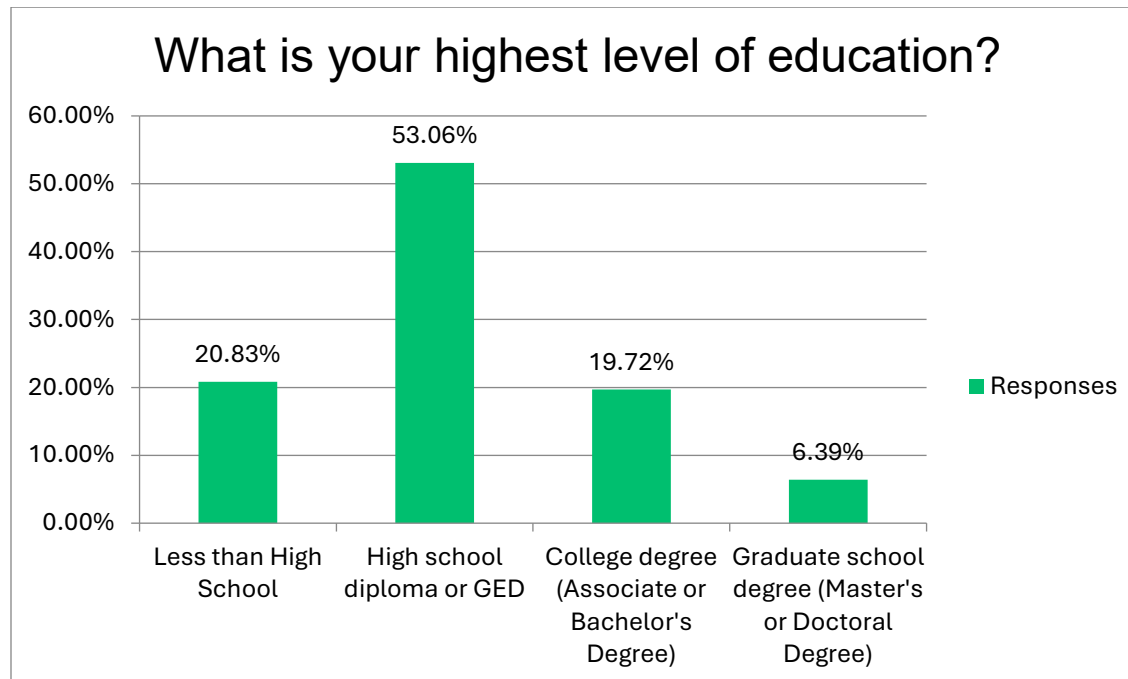
Cuban (1)
 Mexicana (1)
 NA (1)
 Caribbean (1)
 Cherokee Indian (1)
 Native Indian (Blackfoot) (1)
 Does not identify as any race (1)

By comparison, 44.5% of PWH in New York State are Black and 22.6% White. The race breakdown of all PWH in the Nassau-Suffolk EMA is 36.3% White, 34.4% Black, 24.4% Hispanic, 3.1% Asian and 1.2% Multiracial.



Approximately 40% of respondents identify as Latino/a/x or Hispanic, while about 60% do not. By comparison, 29.4% of PWH in New York State are Hispanic. In the Nassau-Suffolk EMA, 24.4% of PHW identify as Hispanic.

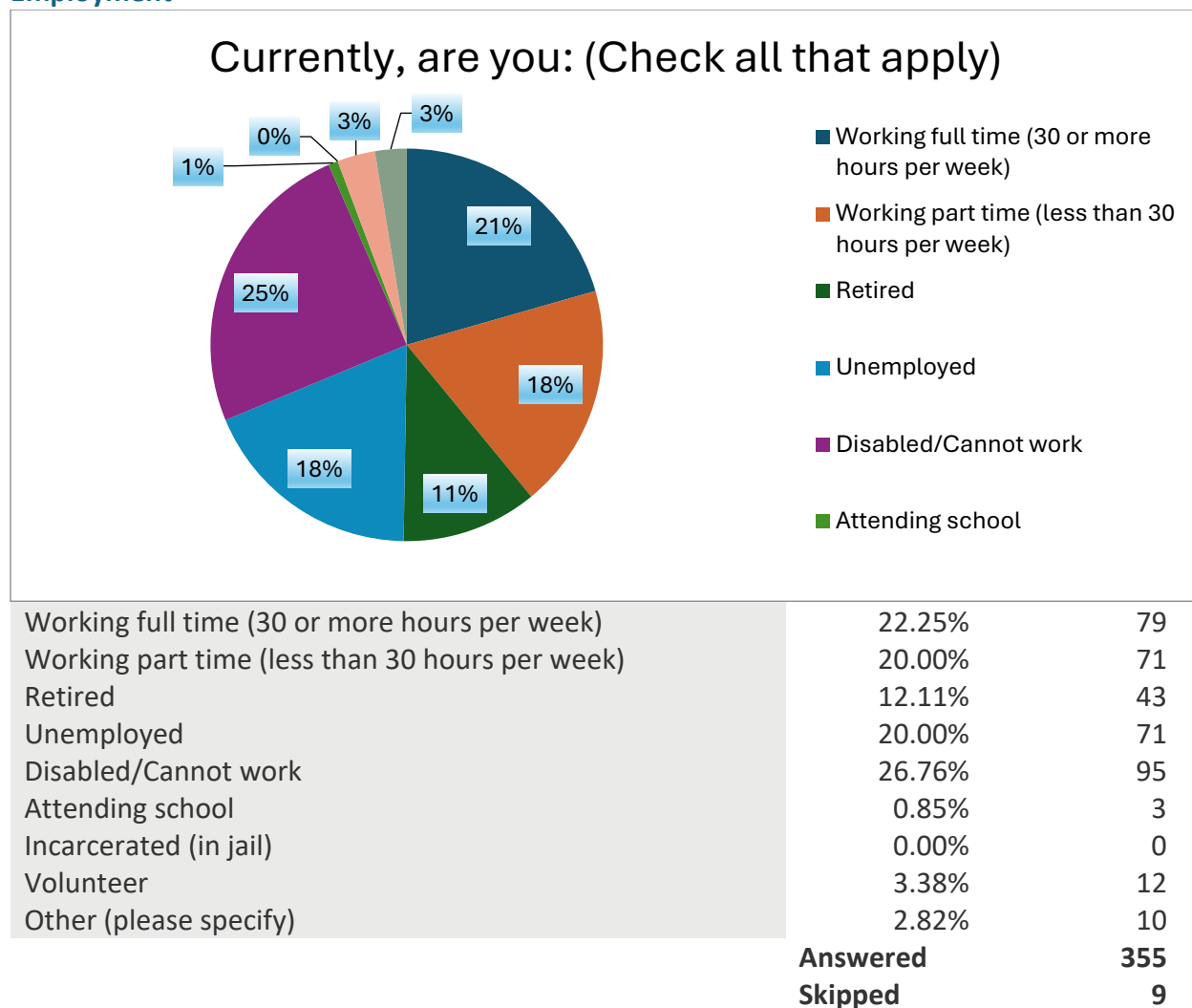
Education



Less than High School	20.83%	75
High school diploma or GED	53.06%	191
College degree (associate or bachelor's Degree)	19.72%	71
Graduate school degree (master's or doctoral Degree)	6.39%	23
Answered		360
Skipped		4

The educational background of respondents reveals that 21% have less than a high school education, while 53% hold a high school diploma or GED. Approximately 20% have completed a college degree (either an associate or bachelor's degree), and 6% have attained a graduate school degree (master's or doctoral).

Employment

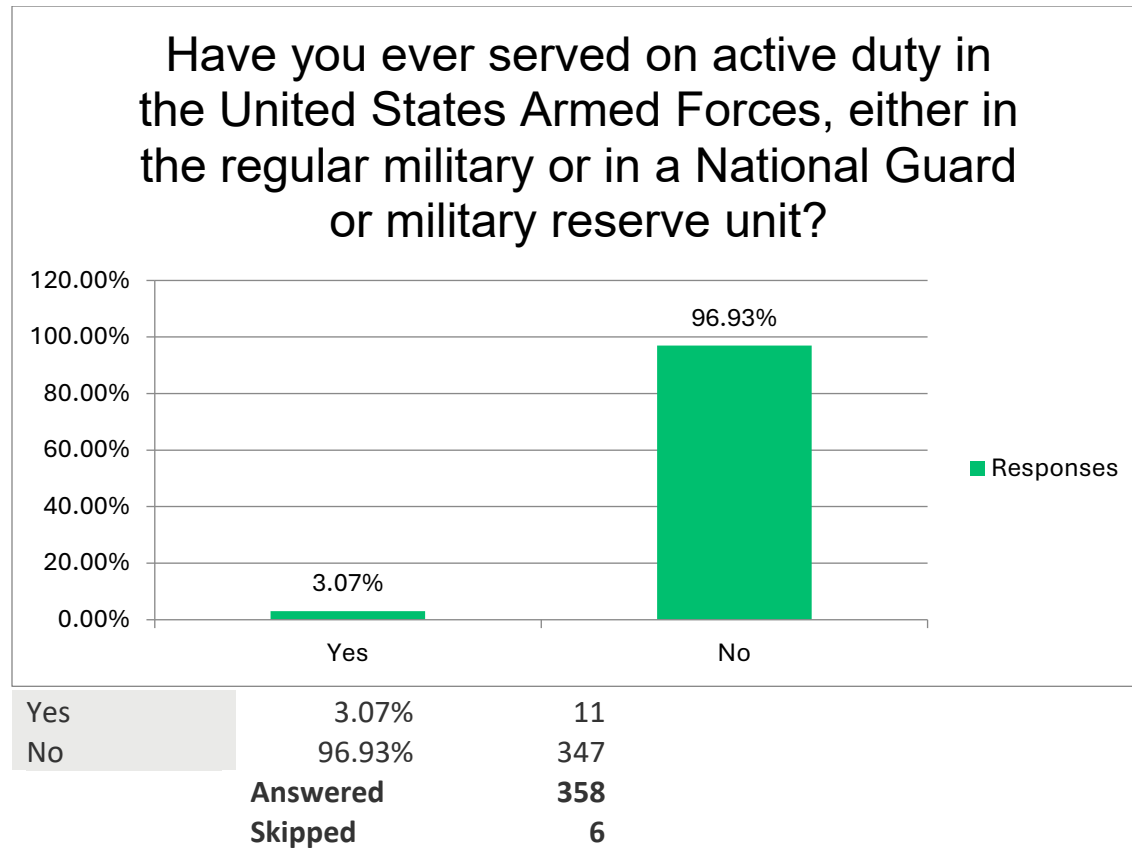


The employment status of respondents shows that 22% work full-time (30 or more hours per week), while 20% work part-time (less than 30 hours). Approximately 12% are retired. Twenty percent (20%) are unemployed. By comparison, among individuals diagnosed with HIV in New York State in 2021, 22% reported being unemployed. A significant portion, 27%, reported being disabled and unable to work. A small portion (1%) attend school, 3% are engaged in volunteer work, and 3% indicate other employment situations. None are currently incarcerated.

The “others” included the following:

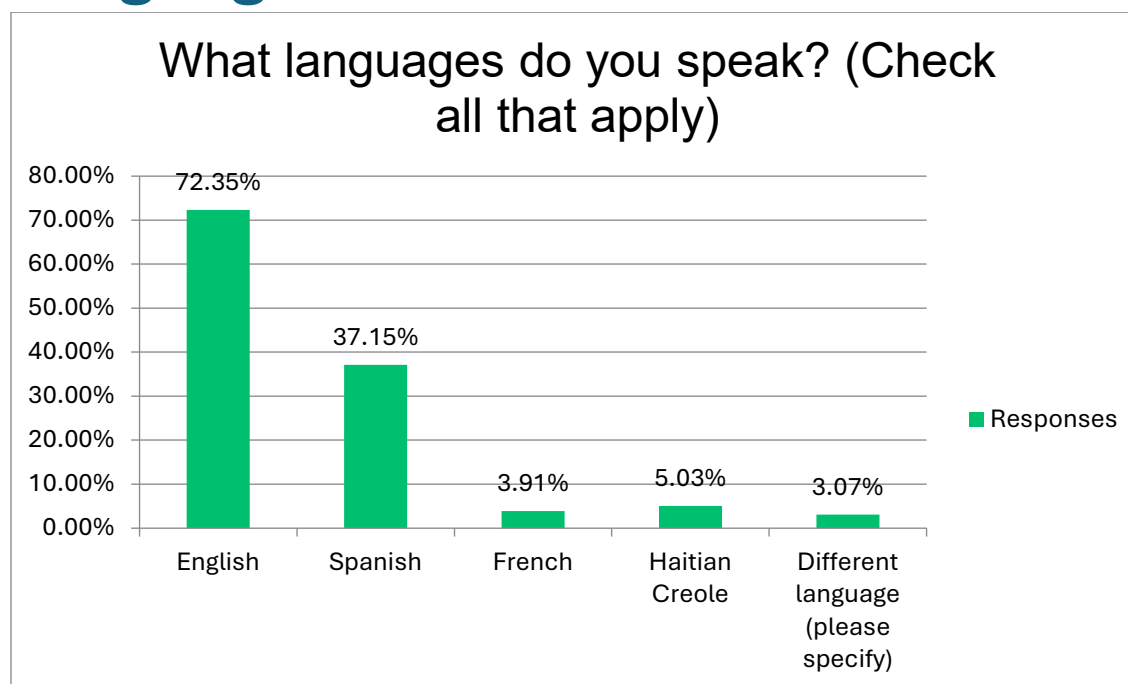
Ama de casa (1)	Never worked (1)
DSS waiting on approval (1)	Self-employed (1)
Help people (1)	Semi-Retired/Working part-time (1)
Laid off (1)	Social security income (1)
Medically Retired, Working part-time (1)	Sometimes (1)

Veteran's Status



Only about 3% of respondents have a military background, while the vast majority, approximately 97%, do not have any military experience.

Language Preference and Access

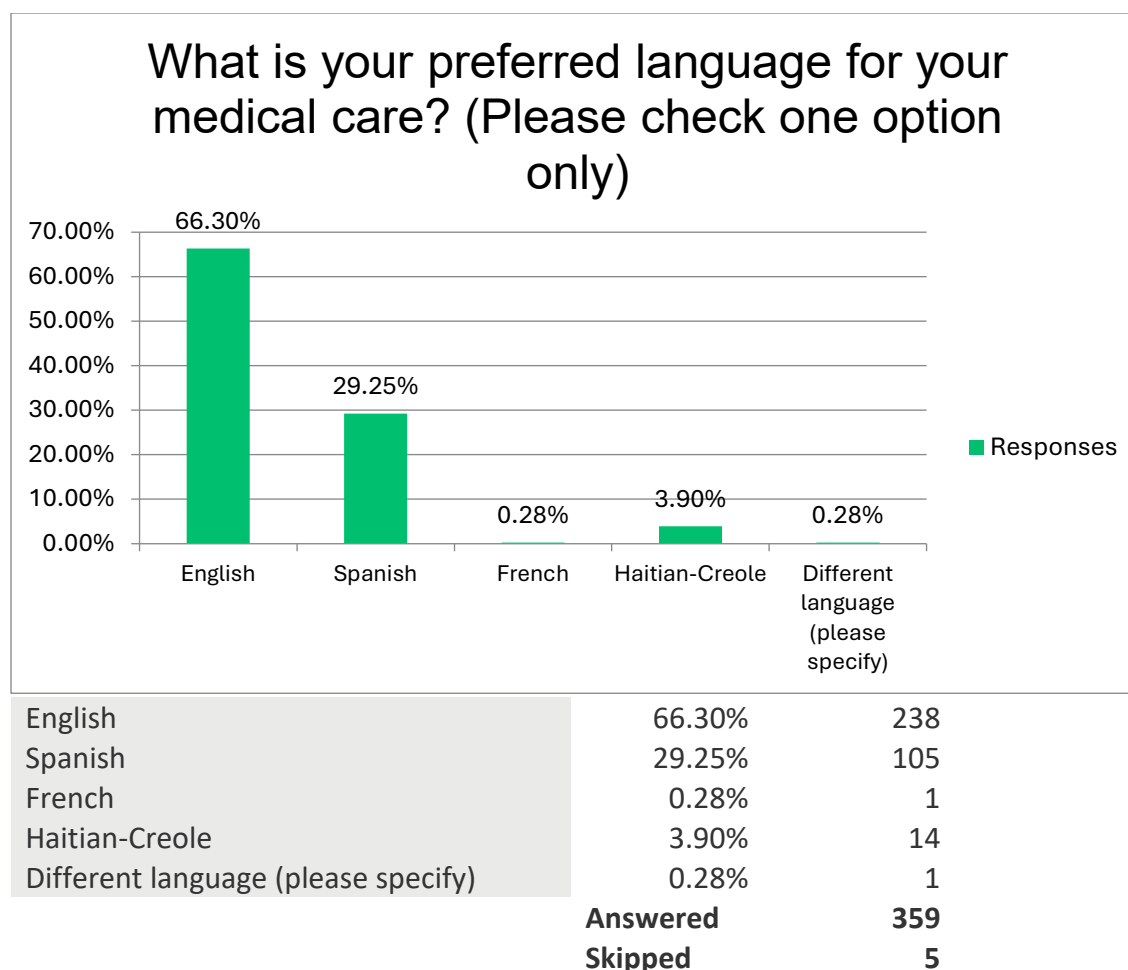


English	72.35%	259
Spanish	37.15%	133
French	3.91%	14
Haitian Creole	5.03%	18
Different language (please specify)	3.07%	11
Answered		358
Skipped		6

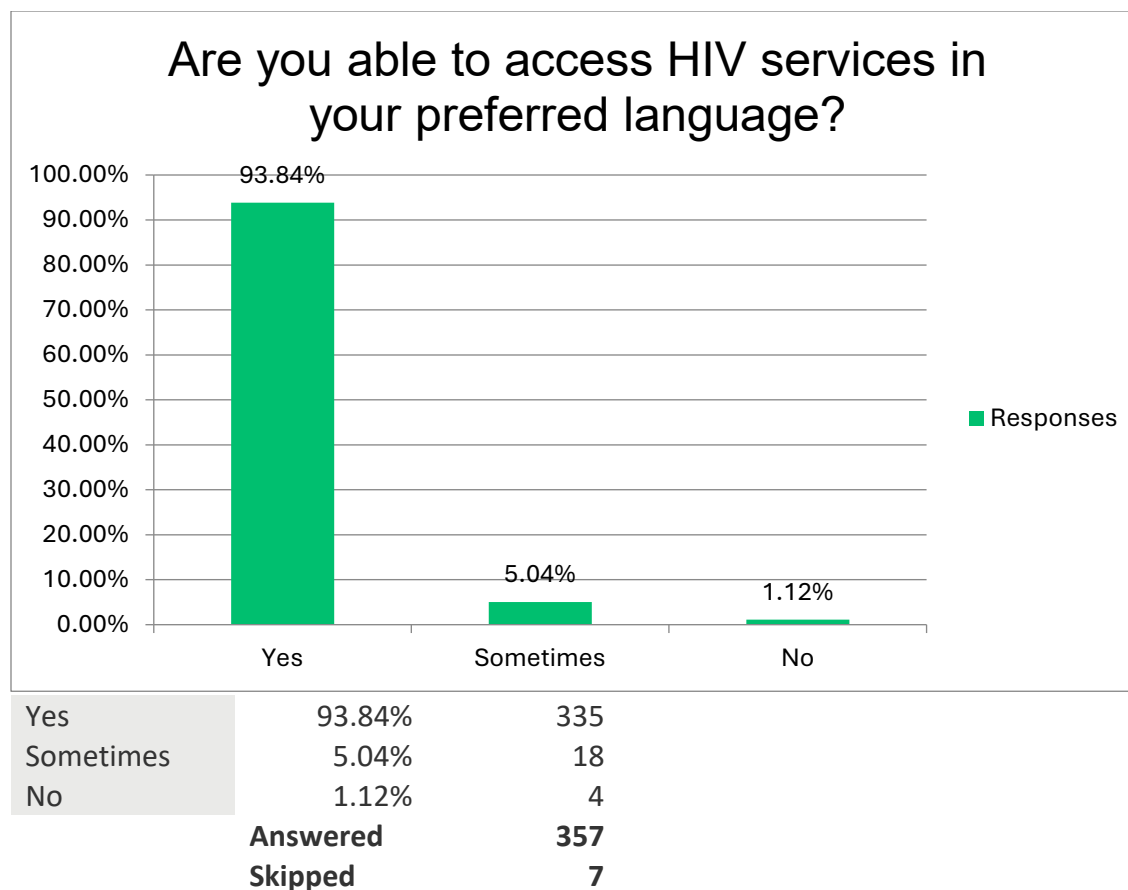
The majority of respondents speak English (72%), followed by Spanish (37%). A smaller portion speaks Haitian Creole (5%), French (4%), and other languages (3%). Other languages spoken included: French (3.9%), Haitian Creole (5.0%), and “different language” (3.1%).

The “different languages” reported included:

- Italian (4)
- Portuguese (2)
- American Sign Language (2)
- Bengali (1)
- Thai (1)
- German (1)
- Japanese (1)

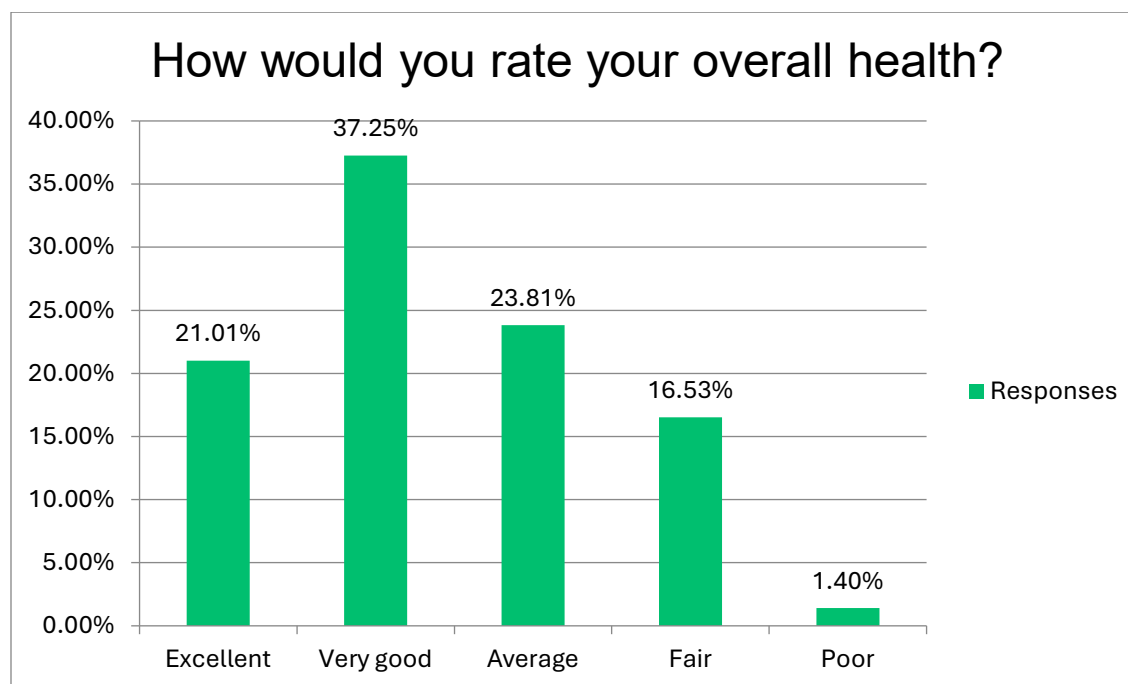


The preferred language for medical care among respondents is predominantly English (66%), followed by Spanish (29%). A small number prefer Haitian Creole (4%) and French (less than 1%). The one “different language” reported was English and Hattian-Creole (1). At least five of these Haitian Creole responses were among the newly diagnosed.



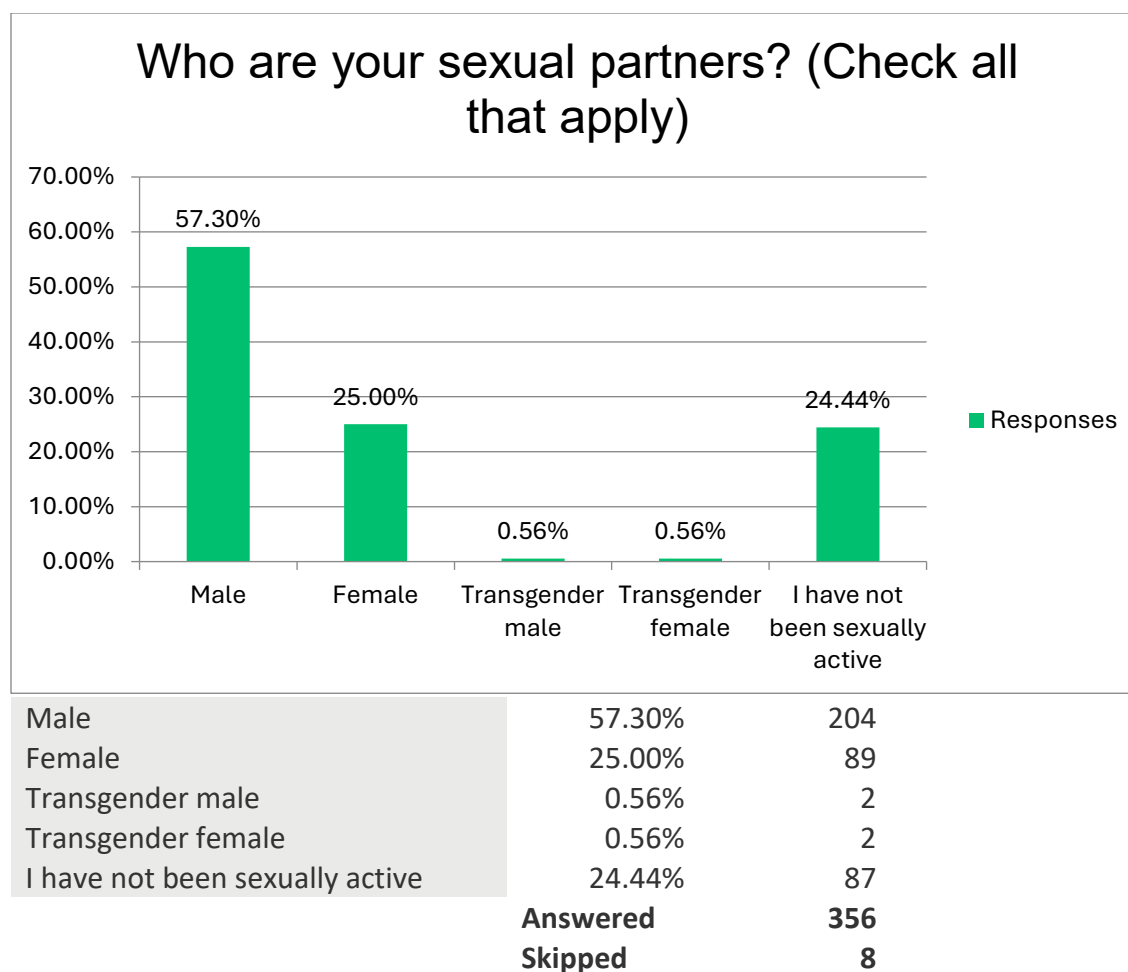
The majority of respondents (94%) reported that they can access HIV services in their preferred language, with a small percentage (5%) indicating that they sometimes can. Only 1% stated that they cannot access services in their preferred language.

Health Behaviors



Excellent	21.01%	75
Very good	37.25%	133
Average	23.81%	85
Fair	16.53%	59
Poor	1.40%	5
Answered		357
Skipped		7

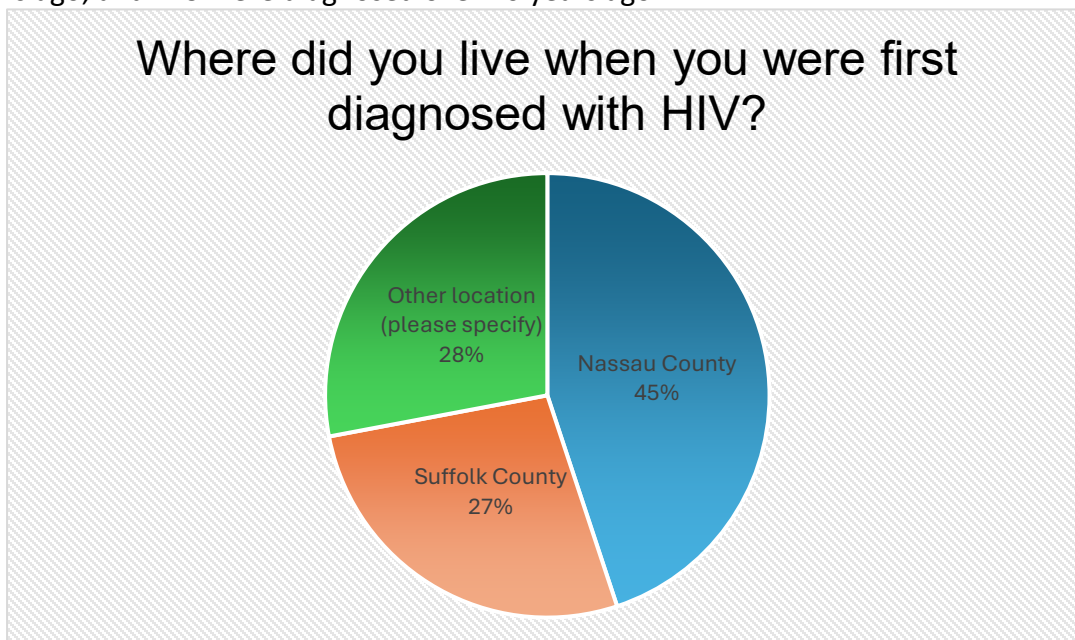
Respondents rated their overall health as follows: 21% considered it excellent, 37% rated it very good, 24% rated it as average, 17% described it as fair, and 1% reported poor health.



Among respondents regarding sexual partners, 57% identified male partners, 25% identified female partners, and both transgender male and female partners were noted at 1% each. Additionally, 24% indicated that they have not been sexually active.

HIV Diagnosis

Of 318 individuals who reported the year they were diagnosed, 20 were diagnosed in the past two years, 60 were diagnosed between 3-10 years ago, 89 were diagnosed between 11-20 years ago, and 149 were diagnosed over 20 years ago.



Three hundred fifty four (354) respondents answered this question. 10 skipped it. The majority of respondents were diagnosed with HIV in Nassau County (45%), followed by Suffolk County (27%). A notable portion (28%) reported receiving their diagnosis in other locations. Among the respondents who indicated "other locations" for their HIV diagnosis, the most common responses included Queens (13), El Salvador (7), and Manhattan (7). Other notable locations included Brooklyn (6), Florida (6), and Guatemala (4). A variety of additional locations were mentioned, including several states across the U.S. and countries such as Colombia, the Dominican Republic, and Haiti. Some respondents also cited specific correctional facilities and various international locations.

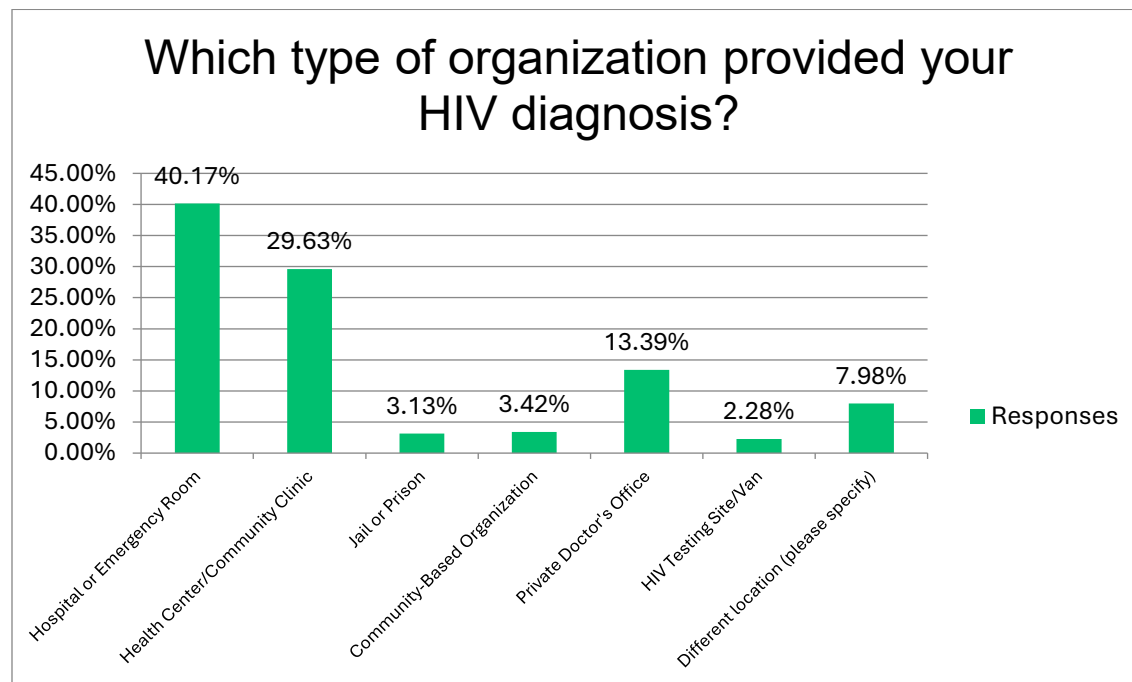
The "other locations" included:

Queens (13)	Peru (3)	Tennessee (2)
El Salvador (7)	Bronx (2)	Cameroon (1)
Manhattan (7)	California (2)	China (1)
Brooklyn (6)	Connecticut (2)	Cuenca Ecuador (1)
Florida (6)	Georgia (2)	Delaware (1)
Guatemala (4)	Honduras (2)	Grenada (1)
Colombia (3)	New Jersey (2)	Hawaii (1)
Department Of Corrections (3)	Pennsylvania (2)	Indiana (1)
Dominican Republic (3)	Puerto Rico (2)	Jamaica West Indies (1)
Haiti (3)	N/A (2)	MOA ELA (1)

Nevada (1)
Nicaragua (1)
Nigeria (1)
North Carolina (1)

Staten Island (1)
Switzerland (1)
Upstate NY (1)
Venezuela (1)

West Africa (1)
Westchester (1)



Hospital or Emergency Room	40.17%	141
Health Center/Community Clinic	29.63%	104
Jail or Prison	3.13%	11
Community-Based Organization	3.42%	12
Private Doctor's Office	13.39%	47
HIV Testing Site/Van	2.28%	8
Different location (please specify)	7.98%	28
Answered		351
Skipped		13

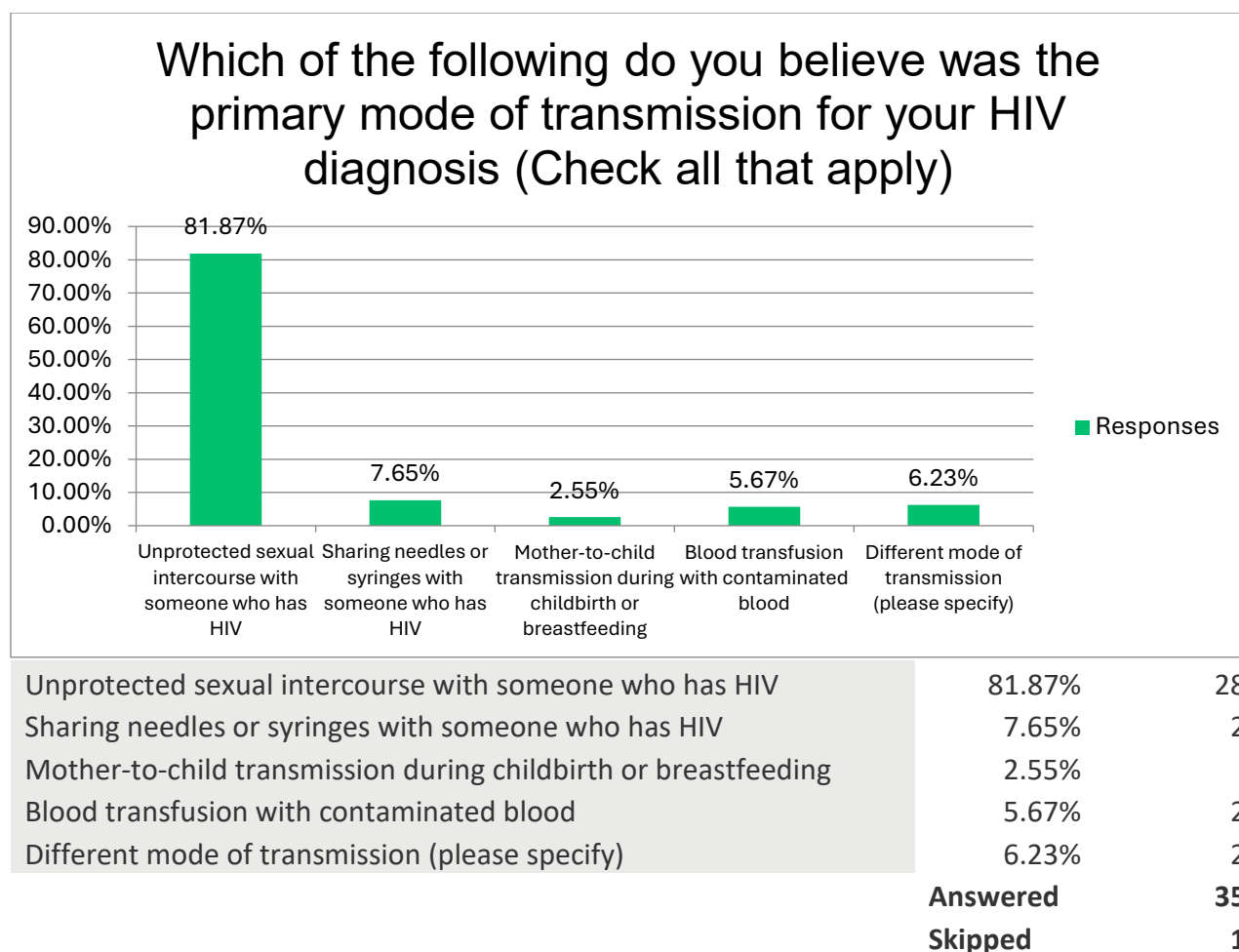
The majority of respondents reported being diagnosed with HIV in a Hospital or Emergency Room (40%), followed by Health Center/Community Clinics (30%). Private Doctor's Offices accounted for 13%, while a smaller percentage were diagnosed in Community-Based Organizations (3%), Jail or Prison (3%), and HIV Testing Sites/Vans (2%). Additionally, 8% specified different locations for their diagnosis, indicating a variety of other healthcare settings.

In addition to the primary locations, respondents specified various other places where they were diagnosed with HIV. These included Blood Banks (4), Sun River (3), and Clinic/Primary Care settings (3). Some were diagnosed at specific hospitals, such as NUMC (2) and Stony Brook (1), while others mentioned Correctional Facilities (2), Rehabilitation Centers (2), and Psychiatric

Facilities (1). Additional locations included home tests (1), a life insurance company (1), and even community resources like Planned Parenthood (1) and a Catholic Church Clinic in Nigeria (1).

The “different locations” included:

- Blood bank (4)
- Sun River (3)
- Clinic/primary care (3)
- NUMC (2)
- Correctional Facility (2)
- Rehab (2)
- Not Sure (2)
- At home test (1)
- Inpatient Rehab (1)
- Carcel Regional de P.R. (1)
- Stony Brook (1)
- Catholic Church Clinic Nigeria (1)
- EOC-Pretest (1)
- Planned Parenthood (Riverhead) Office (1)
- Psychiatric Facility (1)
- North Shore University Hospital (1)
- Life insurance company (1)



The primary mode of HIV transmission reported was unprotected sexual intercourse with someone who has HIV, accounting for 82%. Sharing needles or syringes with someone who has HIV was reported by 8%. Mother-to-child transmission during childbirth or breastfeeding was noted by 3%, and blood transfusion with contaminated blood accounted for 6%. Additionally, 6% reported a different mode of transmission.

The responses detailing "different modes of transmission" included a variety of personal experiences: two individuals indicated they didn't know the transmission method, while others mentioned sexual abuse, blood-to-blood contact injuries, and being raped. Some noted specific situations involving partners, such as not being informed of a partner's HIV status or coming into contact with blood from a person with HIV during an altercation. Additional mentions included incidents involving a needle stick from a hidden syringe, a tattoo, and a family member's drug use. A few responses were unspecified or marked as not applicable.

The “different modes of transmission” included:

I don't know (2)

I was sexually abused (1)

Blood to blood contact injury (1)

I was raped (1)

Sex with my husband (1)

Taking care of someone without any contact precaution (1)

My late husband got stuck at work with a needle and never followed up with it (1)

Did not specify (1)

Mom's husband hid needle in bathroom top sink; I reached up to get toothbrush and a needle stuck in my finger (1)

N/A (3)

Rape (1)

The HV person didn't inform me that they were positive (1)

Partner- hetero (1)

Surgery (1)

Father did needle drugs (1)

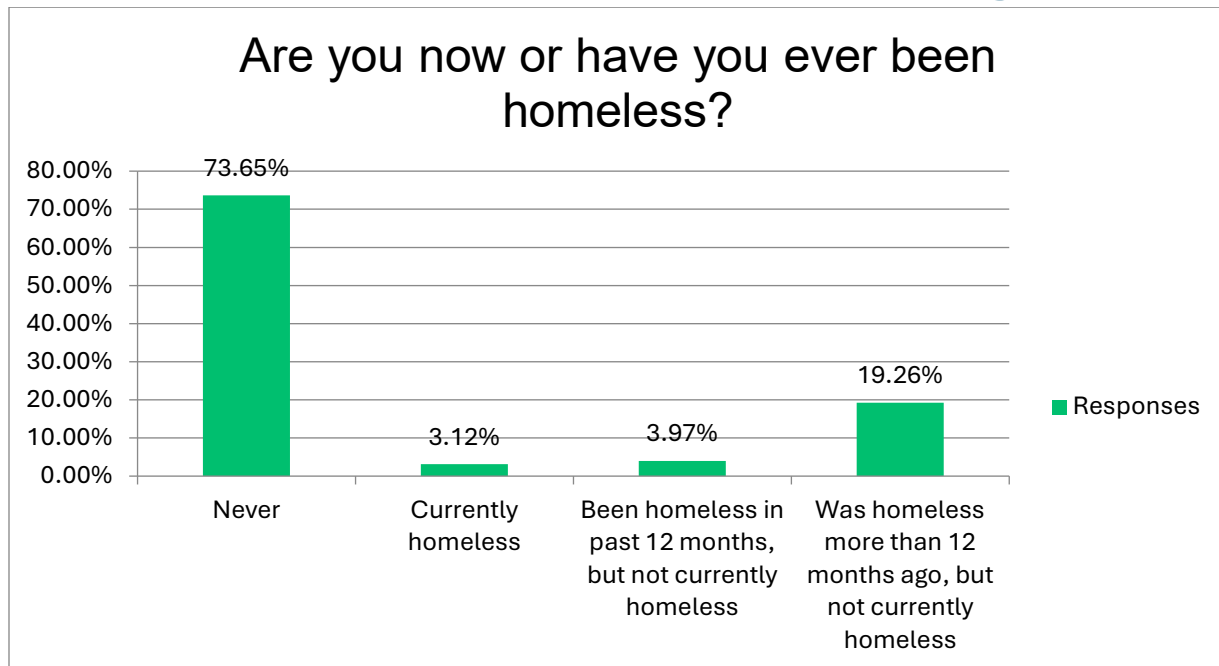
When I got a tattoo (1)

Husband (1)

Coming into contact with blood from a person with HIV who was bleeding during an altercation with someone else. (1)

By comparison, 74.4% of PWH in New York State had a sexual transmission risk (46.5% MSM and 27.9% heterosexual).

Social Drivers of Health: Housing



Never	73.65%	260
Currently homeless	3.12%	11
Been homeless in past 12 months, but not currently homeless	3.97%	14
Was homeless more than 12 months ago, but not currently homeless	19.26%	68
Answered		353
Skipped		11

In response to housing stability, the majority of respondents (74%) indicated they had never experienced homelessness. Three percent reported being currently homeless, while 4% acknowledged being homeless at some point in the past year but are not currently homeless. Additionally, 19% stated they were homeless more than a year ago but are no longer in that situation.

Among individuals diagnosed with HIV in New York State in 2021, 13% reported being homeless.

Please note that survey data may not always add up precisely, and responses may show inconsistencies across various sections of the survey. These issues are common in survey research and can result from factors such as respondent interpretation, non-response, or rounding errors. Interpret results with caution, as they reflect general trends rather than exact figures.

Current and Previous Housing Situation

Housing Situation	Currently	Previously
I live in my own house, apartment or mobile home (rent or own)	46.1%	6.4%
I live in my parent's house, apartment or mobile home (rent or own)	8.9%	19.0%
I rent a room	15.3%	9.7%
I live in someone else's house, apartment or mobile home	12.8%	8.3%
I couch surf (stay temporarily in a series of other people's homes, typically by sleeping on their sofas)	2.9%	7.3%
I live with a roommate	8.3%	7.7%
I live on the streets (homeless)	8.3%	7.3%
I live in a shelter (or emergency housing)	16.6%	7.3%
I live in a group home, specifically for people living with HIV	16.6%	5.8%
I live in a drug and alcohol treatment center	0.21%	6.0%
I live in a nursing home	0.21%	3.8%
I live in a psychiatric treatment center	0.21%	3.7%
I live in a sober home	0.21%	4.6%
I live in an assisted living facility	0.62%	3.2%
Other (please specify)		
Answered	355	
Skipped		9

Regarding the current housing situation, the majority of respondents, 46.1%, currently live independently in their own house, apartment, or mobile home, either renting or owning. A smaller proportion, 8.9%, live in their parents' residence, while 15.3% rent a room, and 8.3% live with roommates. Another 12.8% stay in someone else's home and 2.9% engage in couch surfing. Among respondents, 16.6% reside in shelters or emergency housing, with an equal 16.6% in group homes specifically for people living with HIV. Other living situations, such as on the streets (0.83%), drug or alcohol treatment centers, nursing homes, psychiatric treatment centers, sober homes, or assisted living facilities, each account for less than 1% of the sample.

Regarding the previous housing situation, 6.4% of respondents lived independently in their own home, apartment, or mobile home, either renting or owning. A larger portion, 19.0%, lived in their parents' residence, while 9.7% rented a room and 7.7% resided with roommates. Smaller segments lived in someone else's home (8.3%), couch surfed (7.3%), or were homeless (7.3%). The same percentage, 7.3%, lived in shelters or emergency housing. Other housing situations included group homes for individuals with HIV (5.8%), drug and alcohol treatment centers (6.0%), nursing homes (3.8%), psychiatric treatment centers (3.7%), sober homes (4.6%), and assisted living facilities (3.2%).

In the past, living situations varied significantly among respondents. About 13% lived in their own house, apartment, or mobile home, while a substantial 69% resided in their parent's home.

Renting a room was reported by 39%, with a similar percentage living in someone else's residence. Couch surfing was common, experienced by 72%, and nearly half (49%) lived with a roommate. A staggering 90% reported being homeless at some point, and 82% utilized shelters or emergency housing. Additionally, many lived in group homes for individuals with HIV (78%) or in drug and alcohol treatment centers (97%). High percentages also indicated residing in nursing homes (95%), psychiatric treatment centers (95%), and sober homes (96%), as well as assisted living facilities (84%).

The "other" responses regarding living situations included various arrangements: one respondent lives in someone else's home, while another is in an HIV emergency shelter following release. Some indicated they live with their parents or in their own rented apartment. Others mentioned living independently or with their son or partner. A few noted specific circumstances, such as being in a hotel or living in a house left in trust by their parents to siblings. Additionally, one response simply stated "N/A."

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The "other" included:

Both: I live in someone else's house, apartment or mobile home (1)

HIV emergency shelter/housing post release (1)

Both: I live in my parent's house, apartment or mobile home (rent or own) (1)

My own apartment, rent (1)

I live on my own (1)

SPA Housing through options (1)

Parents left house to siblings in trust (1)

With my son (1)

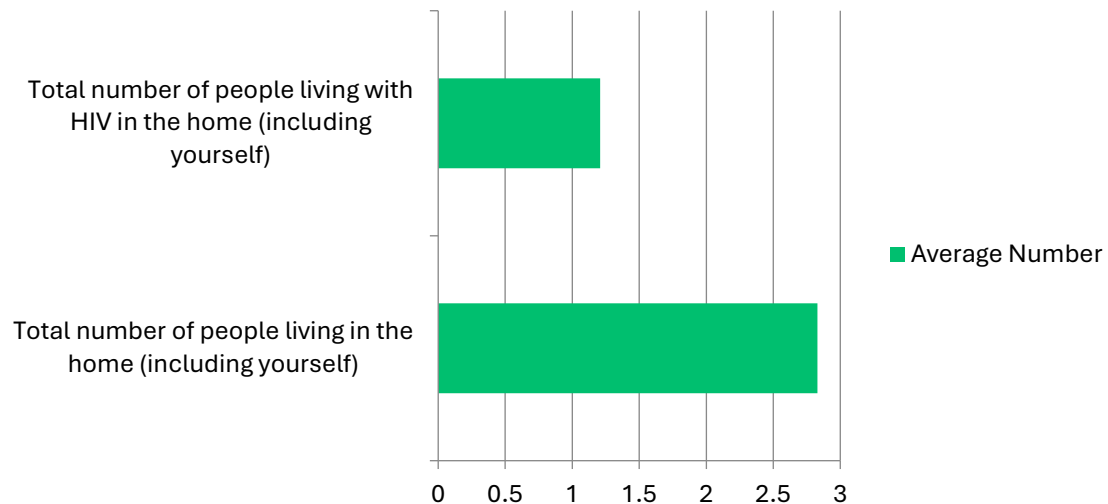
N/A (1)

Lives with daughter (1)

I live in a hotel (1)

I live with my partner (1)

If you currently have a place to live,
please list:



Total number of people living in the home (including yourself)	2.83
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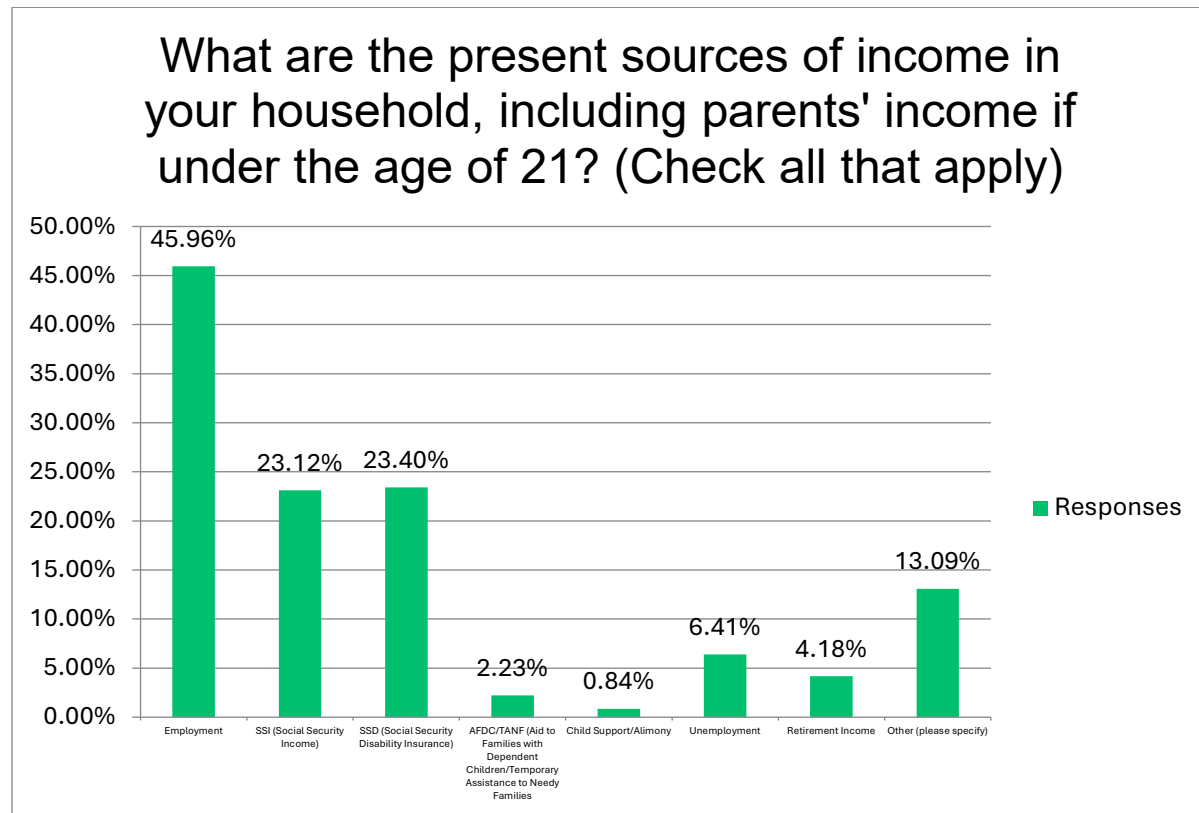
Total number of people living with HIV in the home (including yourself)	1.21
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Answered	345
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Skipped	19
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On average, participants had 2.8 people, including themselves, who were living in their homes.
On average, 1.2 people in their homes were living with HIV.

Social Drivers of Health: Income



Employment	45.96%	165
SSI (Social Security Income)	23.12%	83
SSD (Social Security Disability Insurance)	23.40%	84
AFDC/TANF (Aid to Families with Dependent Children/Temporary Assistance to Needy Families)	2.23%	8
Child Support/Alimony	0.84%	3
Unemployment	6.41%	23
Retirement Income	4.18%	15
Other (please specify)	13.09%	47
Answered		359
Skipped		5

Almost half (46.0%) of respondents were employed, while many SSI (23%) or SSD (23%). Of the 13% who reported “other” sources of income, the responses indicate several key themes regarding sources of financial support. Public assistance programs such as SNAP, WIC, and food stamps were frequently mentioned, with several individuals relying on these benefits to meet basic needs. Pension plans, including VA and widow's pensions, also emerged as a significant source of support for some respondents, while others were dependent on disability benefits or were awaiting decisions on disability claims. A few individuals reported receiving financial help from family members or partners, highlighting personal support networks. Others mentioned DSS public assistance or cash aid for disabilities. On the other hand, some respondents reported no current form of assistance or employment, with a few relying on informal work, such as collecting scrap metal, or support from friends.

The “other” reported included:

SNAP/WIC/Food Stamps (6)

Pension (5)

None (4)

DSS public assistance (3)

My husband (2)

Friend (2)

Children (1)

CASH Assistance- Disability (1)

Does not say (1)

Ayuda (1)

Supported by Partner (1)

EBT \$153 a month (1)

No recibo ningún tipo de ayuda (1)

NY State (1)

Health insurance gave debit card to help for food and HSA items (1)

IRA (1)

SSP (1)

Waiting on Disability Decision through the Court (1)

Trabajo (1)

Por el momento estoy sin empleo pero normalmente trabajo (1)

Estoy casado y mi esposo me ayuda económicamente (1)

Collect scrap metal (1)

Mother (1)

DSS Benefits (1)

Widow's benefits (1)

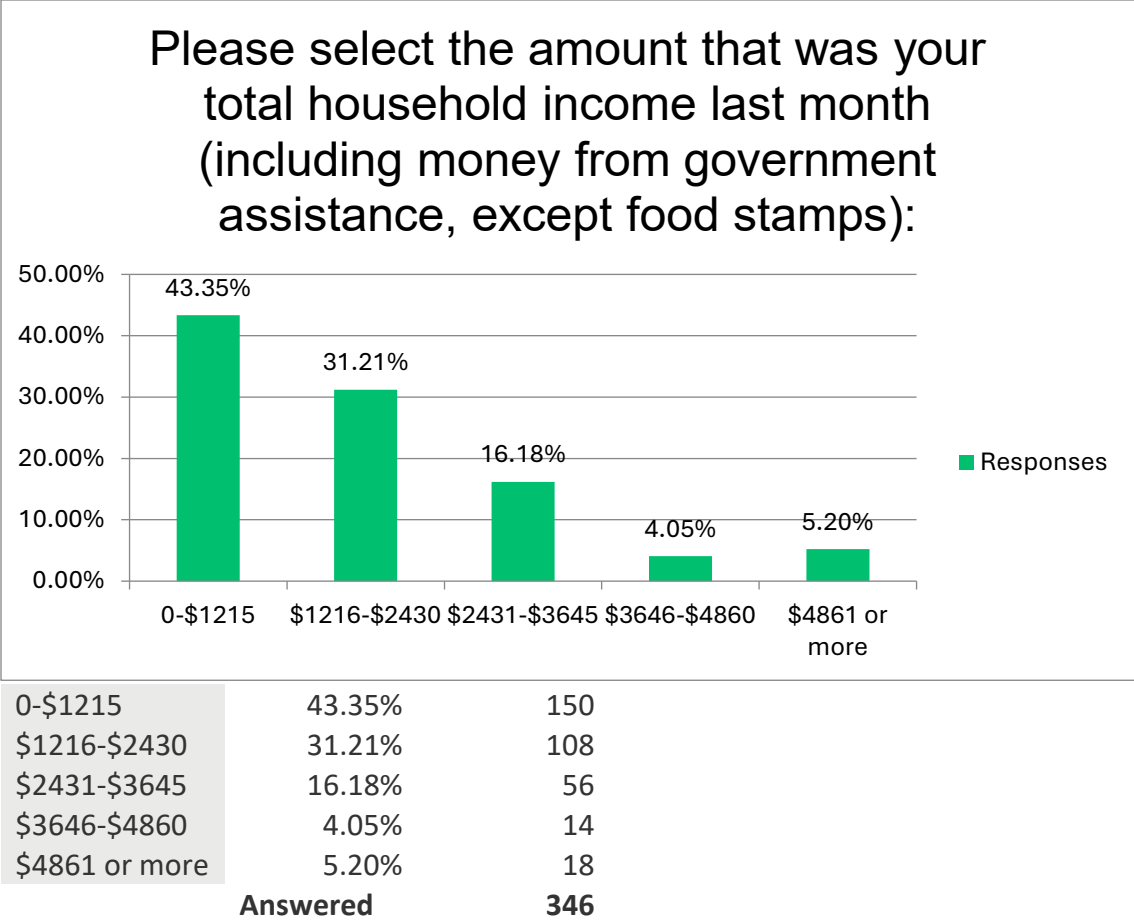
VA Pension (1)

Welfare (1)

Service benefits (1)

Compensation (1)

No source income, others in household worry (1)



In terms of monthly income, 43% of respondents reported earning between \$0 and \$1,215. Approximately 31% fall within the \$1,216 to \$2,430 range, while 16% earn between \$2,431 and \$3,645. A smaller portion, 4%, reported incomes between \$3,646 and \$4,860, and 5% indicated earnings of \$4,861 or more.

Income brackets in New York are typically analyzed about the Federal Poverty Level (FPL), a measure used to determine eligibility for various assistance programs. Households with monthly incomes of \$0-\$1,215 are often considered below the poverty line, depending on household size, and may qualify for significant government assistance such as Medicaid, SNAP, or housing subsidies. Those earning between \$1,216-\$2,430 are slightly above the FPL but still considered low-income, potentially qualifying for reduced benefits like sliding scale healthcare or partial assistance. Incomes ranging from \$2,431-\$3,645 may be considered moderate income, with eligibility for some subsidies, though access to certain programs begins to phase out. Individuals or families earning \$3,646-\$4,860 are typically above the low-income threshold but may still face challenges in affording housing and healthcare, especially in high-cost areas like Long Island. Finally, those earning over \$4,861 are generally considered higher-income and are less likely to qualify for public assistance, though they may still feel financial strain depending on their household size and location.

Social Drivers of Health: Insurance

Please choose the situation that best describes your health insurance.
(Check all that apply)

I do not have any health insurance	1.67%	6
I have Medicare	35.93%	129
I have Medicaid	52.09%	187
I have ADAP (AIDS Drug Assistance Program)	36.21%	130
I have AHIP (AIDS Health Insurance Plan)	2.51%	9
I have APIC (ADAP Plus Insurance Continuation Program)	3.90%	14
I have Veteran's Benefits	0.56%	2
I have insurance that my employer pays for	2.51%	9
I have insurance through my employer that I contribute to	3.90%	14
I have private insurance that I pay for	2.79%	10
I have insurance through a family member	1.11%	4
Other insurance (please specify)	14.76%	53
Answered		359
Skipped		5

Regarding health insurance, 1% of respondents reported having no health insurance. About 36% have Medicare, while 52% have Medicaid. Additionally, 36% are enrolled in the AIDS Drug Assistance Program (ADAP), and 3% have the AIDS Health Insurance Plan (AHIP). The ADAP Plus Insurance Continuation Program (APIC) is held by nearly 4%, and 1% have Veteran's Benefits. A small percentage (3% and 3.9%) reported insurance through their employer, either fully covered or partially contributed. Private insurance accounts for about 3%, and 1% are covered through a family member. Lastly, 15% specified having other types of insurance.

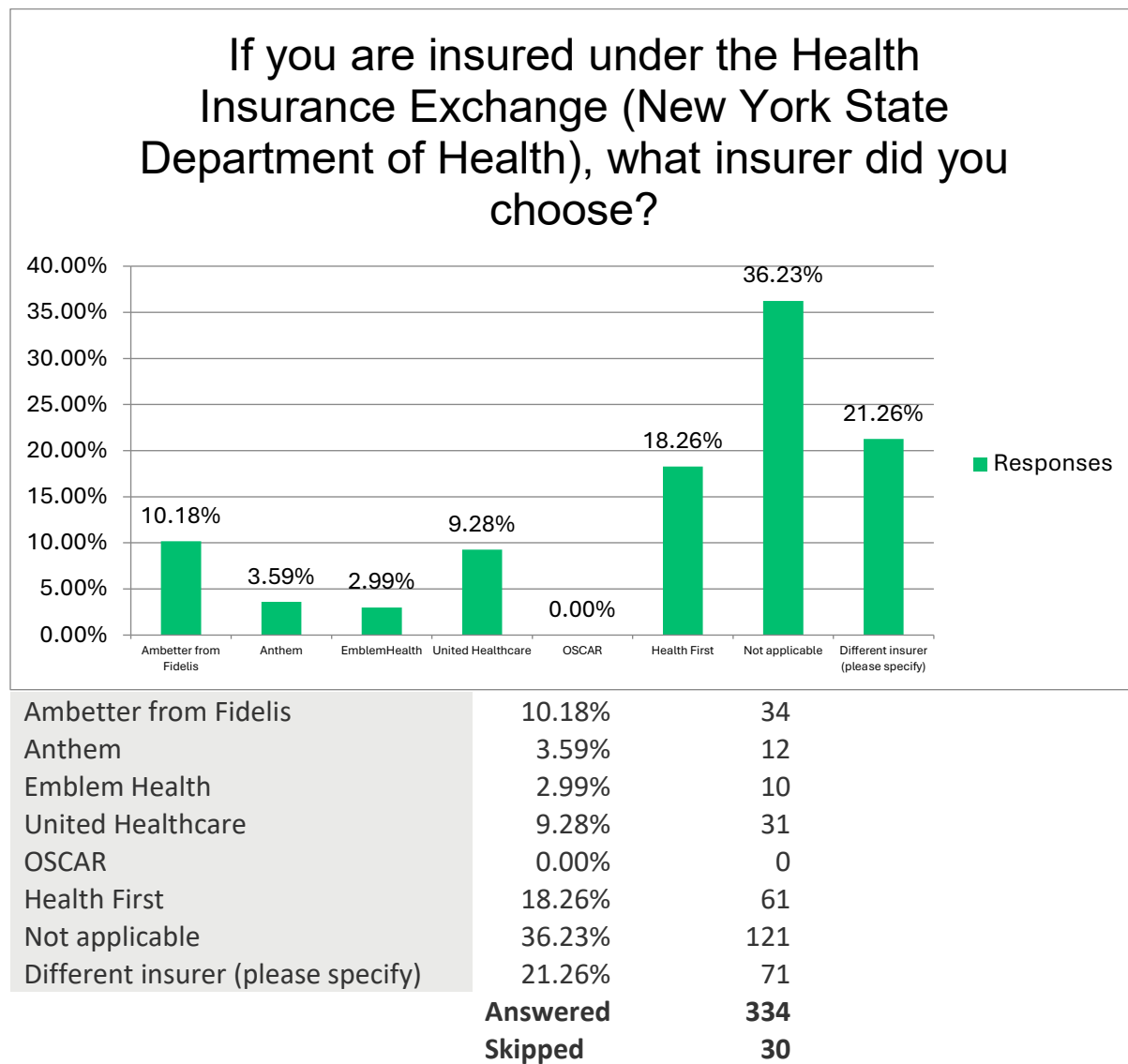
The responses regarding "other" insurance providers fall into a few key themes. Healthfirst and Fidelis Care were the most commonly mentioned providers, highlighting their significant presence in New York's healthcare landscape. Other notable insurers included Human Wellcare, United Healthcare, and Emblem, showing a range of managed care and private health plan options. A smaller number of individuals mentioned using Anthem Blue Cross/Blue Shield, Empire, and AARP supplements, indicating access to additional coverage or specialized plans. Prescription-specific coverage, such as Humana and Wellcare, and government-supported options like ADAP, were also referenced. Some individuals receive insurance through their employers, while a few do not specify their providers.

The "other insurance" included:

Health first (18)	United Healthcare (4)
Fidelis care (13)	Anthem Blue Cross, Blue Shield/Ameritas (2)
Human-wellcare (4)	

Emblem (2)
 UH AARP Supplement (1)
 Affinity (1)
 Humana- Prescriptions (1)
 Empire (1)
 New York Exchange (1)

ADAP (1)
 Wellcare for medication (1)
 Through Work
 AETNA (1)
 Did not specify (1)



In terms of specific health insurers, 10% of respondents are covered by Ambetter from Fidelis, while 9% have United Healthcare. Health First accounts for about 18% of the coverage. Anthem and Emblem Health are held by 4% and 3% of respondents, respectively. OSCAR is not represented among the responses. A significant portion, 36%, indicated "not applicable," and 21% specified "different insurers".

The “different insurers” reflect a range of insurance providers with Fidelis emerging as the most frequently mentioned, followed by Aetna, highlighting their prominence in health coverage. ADAP and Humana also appear frequently, indicating their role in providing specialized or prescription-focused coverage. Other notable providers include Wellcare, Affinity, and Blue Cross Blue Shield, showing a diversity of managed care options. Medicaid and Healthfirst were mentioned less often but still represent important coverage sources for lower-income individuals. A few respondents noted being in the application process, unsure of their coverage, or listed N/A, reflecting uncertainty or lack of insurance.

The “different insurer” included:

- Fidelis (21)
- Aetna (8)
- ADAP (7)
- Humana (6)
- Well care (5)
- N/A (5)
- Affinity (4)
- Blue Cross Blue Shield (4)
- Health First (2)
- Medicaid (3)
- Select Health VNSNY Choice (1)
- Filled out application (1)
- Medicare/not sure (1)
- Magnacare (1)

Did you have any challenges when you enrolled in Medicaid or the Health Insurance Marketplace?

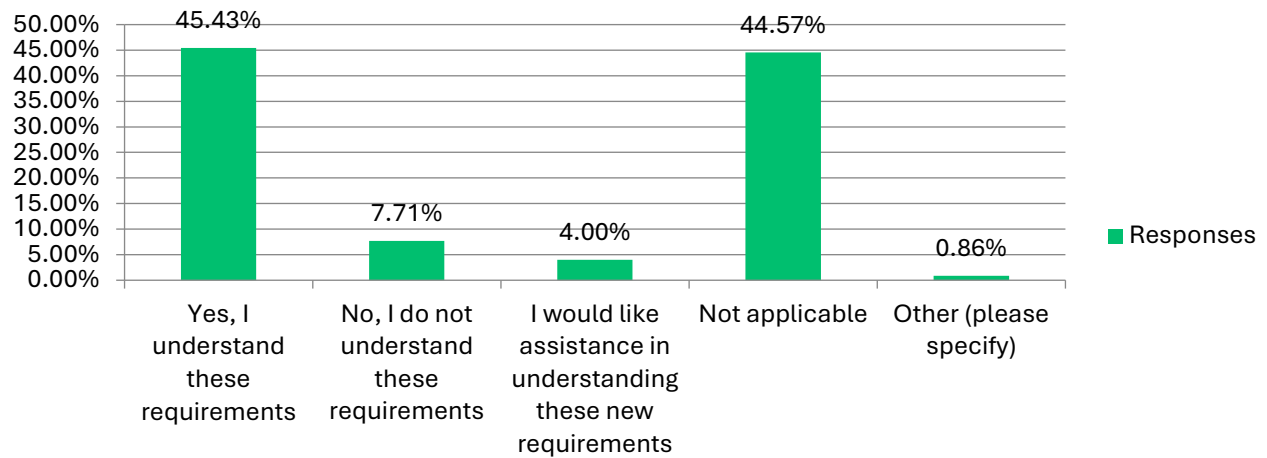


- Yes
- No, I was able to enroll in Medicaid or Health Insurance Marketplace with no challenges
- Not applicable

Yes	7.63%	27
No, I was able to enroll in Medicaid or Health Insurance Marketplace with no challenges	41.81%	148
Not applicable	50.85%	180
If "yes", please specify your top two challenges		18
Answered		354
Skipped		10

In response to challenges encountered during Medicaid or Health Insurance Marketplace enrollment, 8% of respondents reported experiencing difficulties. Conversely, 42% indicated they had no challenges enrolling in these programs. Notably, half of the respondents found the question not applicable to their situation.

**If you enrolled in Medicaid or a Health Insurance Marketplace plan, do you understand the requirements of your insurance, such as premiums, copay, deductibles, or coinsurance?
(Check all that apply)**



Yes, I understand these requirements	45.43%	159
No, I do not understand these requirements	7.71%	27
I would like assistance in understanding these new requirements	4.00%	14
Not applicable	44.57%	156
Other (please specify)	0.86%	3
Answered		350
Skipped		14

When asked about their understanding of insurance concepts, 45% of respondents indicated that they understood the requirements. In contrast, 8% stated they do not understand them, while 4% expressed a desire for assistance in grasping these new requirements. Additionally, 45% found the question not applicable to their situation.

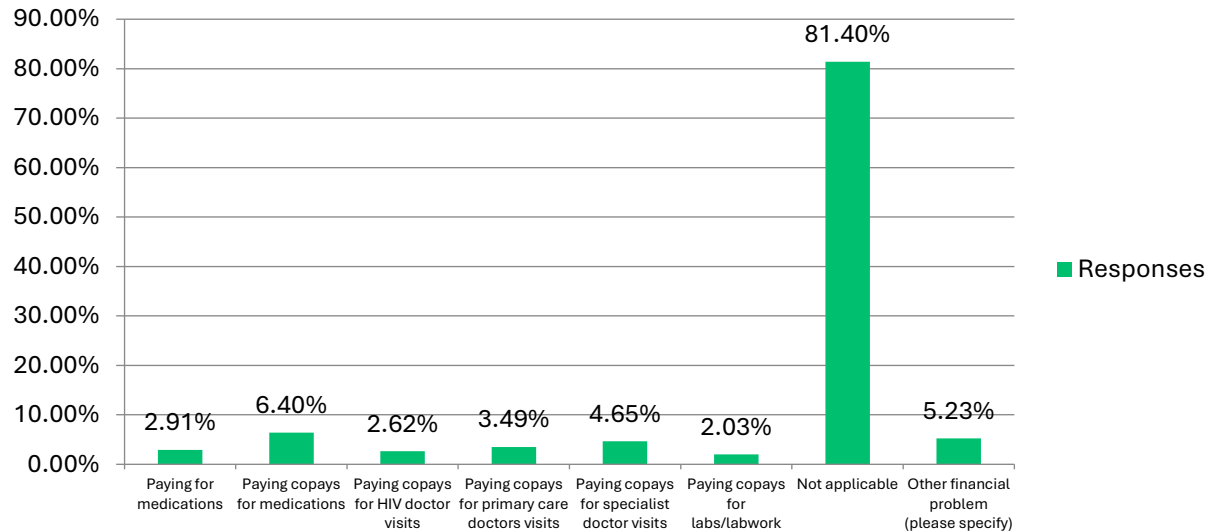
The “other” included:

I have for emergencies (1)

My daughter understands and assist me (1)

I do not get Medicaid, it's too complicated (1)

Have you had any financial problems with the Health Marketplace Insurance or Medicaid? (Check all that apply)



Paying for medications	2.91%	10
Paying copays for medications	6.40%	22
Paying copays for HIV doctor visits	2.62%	9
Paying copays for primary care doctors visits	3.49%	12
Paying copays for specialist doctor visits	4.65%	16
Paying copays for labs/labwork	2.03%	7
Not applicable	81.40%	280
Other financial problem (please specify)	5.23%	18
Answered		344
Skipped		20

In addressing financial issues related to Medicaid or the health marketplace, 3% of respondents reported difficulties paying for medications, while 6% struggled with copays for those medications. Additionally, 3% faced challenges with copays for HIV doctor visits, and 4% had similar issues with specialist visits. Copays for primary care doctor visits affected about 3.5% of respondents, and 2% reported difficulties with lab copays. Notably, 81% found the question not applicable, and 5% mentioned other unspecified financial problems.

The responses regarding "other" financial problems highlight a few recurring themes. A significant number of individuals (8) reported having no financial issues. However, for those who experienced challenges, common issues included difficulties with rent and medical expenses such as hospital bills, copays, and medication costs. One individual mentioned a substantial debt for an operation, while another faced an issue related to insufficient financial

information and unhelpful support from a Medicaid social worker. Additionally, an immigrant reported facing financial struggles, though specific details were not provided.

The “other financial problem” included:

No problem (8)

Eye doctor (1)

Hospital bill (1)

Immigrant (1)

Does not specify (1)

Rent (2)

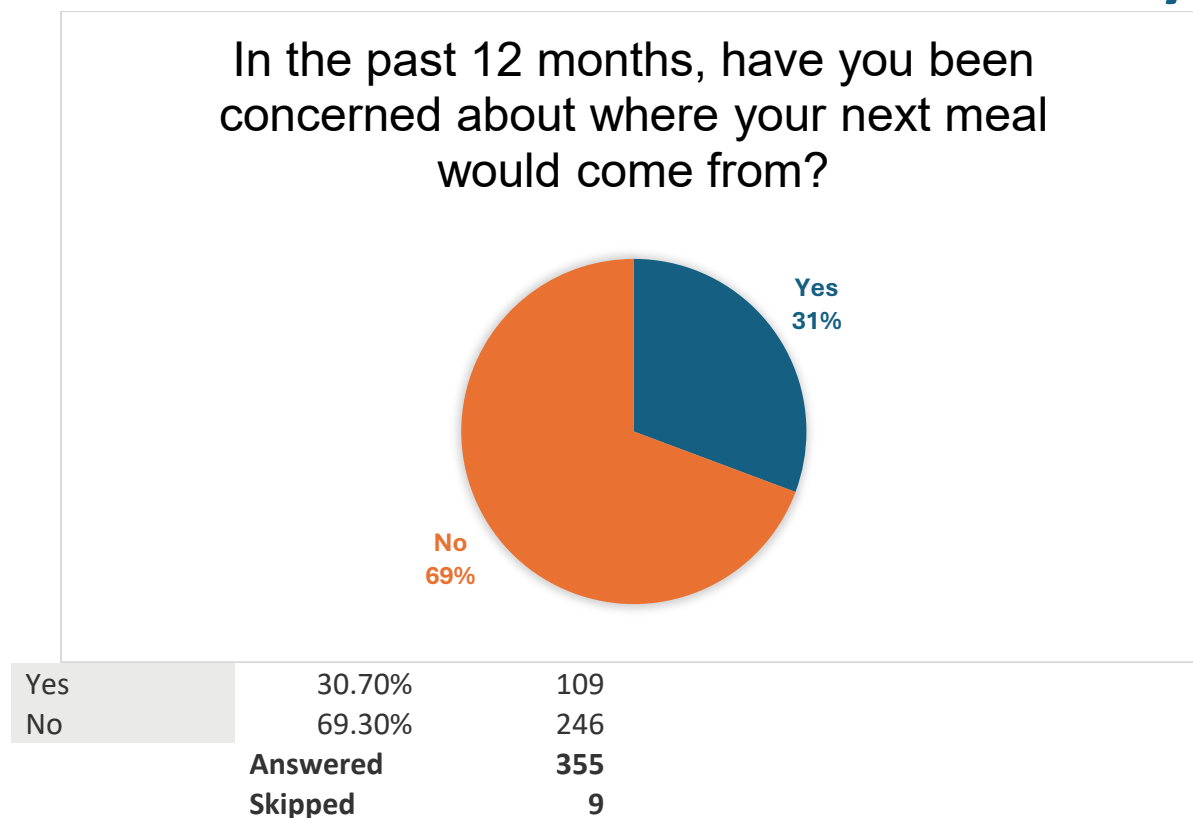
Copay (1)

When I get my meds from CVS (1)

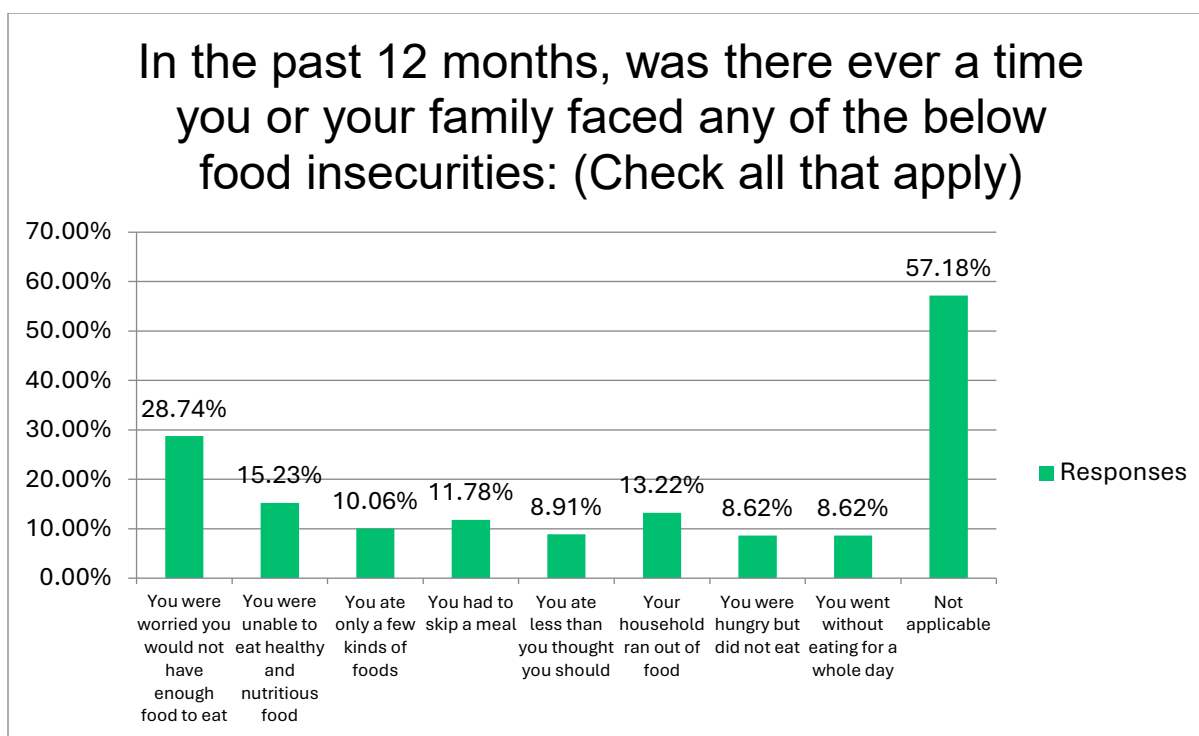
Owe \$1,960.00 for operation ADAP NY, No ADAP A2 (1)

Don't have proper financial information to understand. New Medicaid social worker has been unhelpful (1)

Social Drivers of Health: Food Security



In the past year, 31% of respondents expressed concern about their next meal.

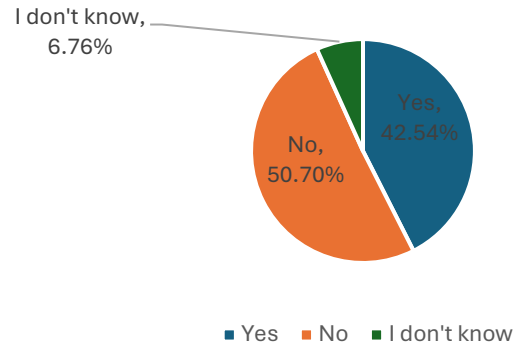


You were worried you would not have enough food to eat	28.74%	100
You were unable to eat healthy and nutritious food	15.23%	53
You ate only a few kinds of foods	10.06%	35
You had to skip a meal	11.78%	41
You ate less than you thought you should	8.91%	31
Your household ran out of food	13.22%	46
You were hungry but did not eat	8.62%	30
You went without eating for a whole day	8.62%	30
Not applicable	57.18%	199
Answered		348
Skipped		16

About 29% were worried they would not have enough food, while 15% reported being unable to eat healthy and nutritious food. Additionally, 11% had to skip meals, and 10% ate only a limited variety of foods. Some respondents (13%) indicated their household ran out of food, and 9% experienced hunger without eating. Overall, 57% found these issues not applicable to their situation.

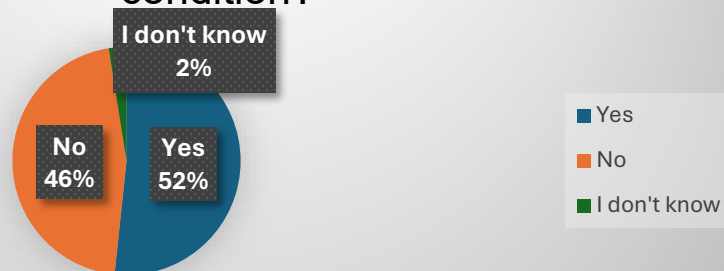
Among individuals diagnosed with HIV in New York State in 2021, 18% reported hunger/food insecure.

In the past 12 months, have you or anyone in your household received SNAP or food stamp benefits?



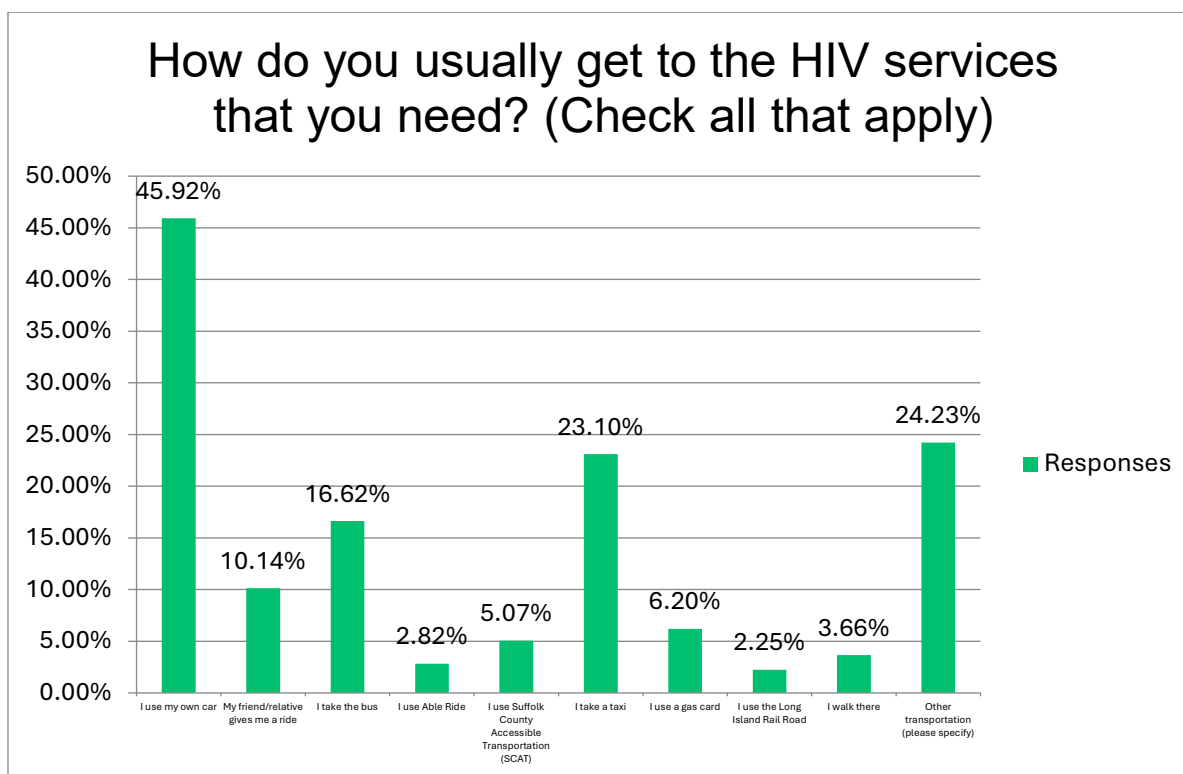
In the past year, 43% of respondents (n=151) received food stamps or SNAP benefits, while 51% (n=180) did not. Additionally, 7% (n=24) were unsure if they had received these benefits.

Have you ever been referred to or connected with a nutritionist or dietary specialist to help manage a specific medical condition?



In response to whether respondents have ever been referred to a nutritionist or dietary specialist, 52% (n=185) indicated "Yes," while 46% (n=164) answered "No." A small portion (n=9), about 3%, stated "I don't know."

HIV Health Care



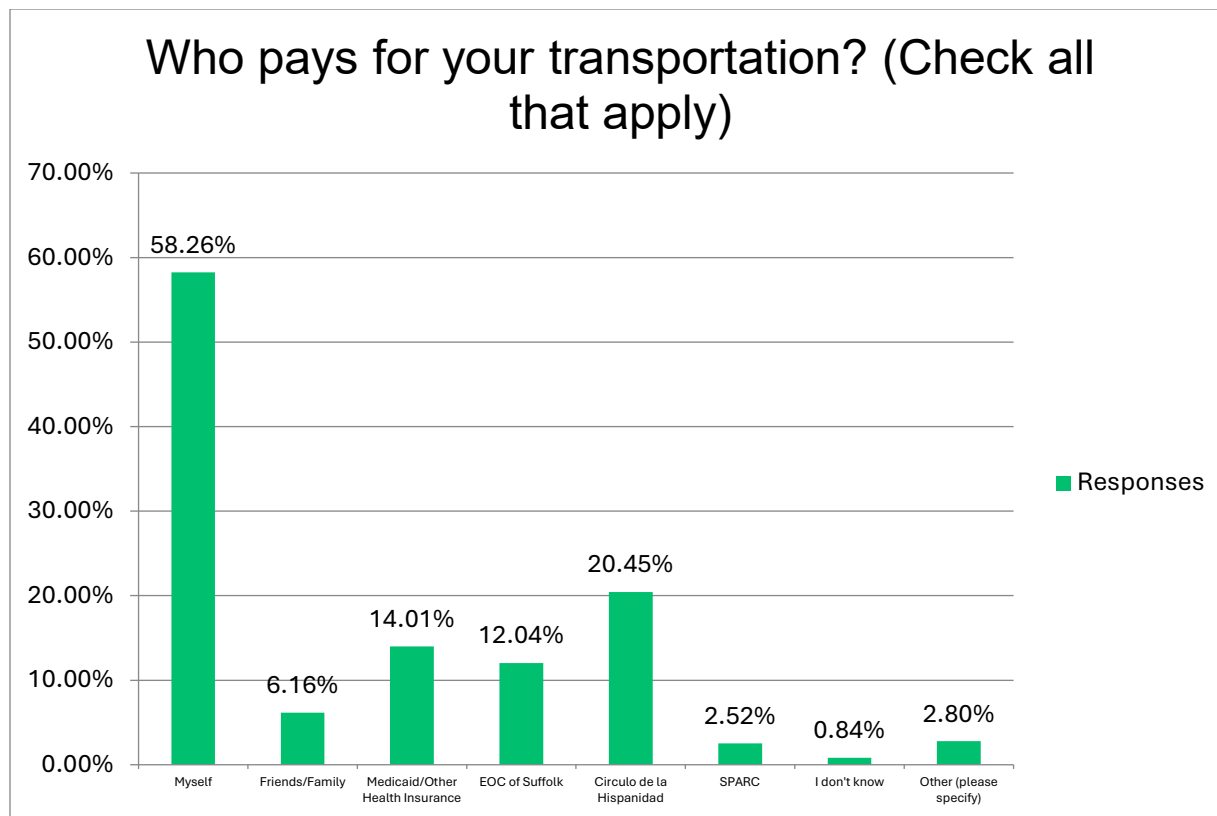
I use my own car	45.92%	163
My friend/relative gives me a ride	10.14%	36
I take the bus	16.62%	59
I use Able Ride	2.82%	10
I use Suffolk County Accessible Transportation (SCAT)	5.07%	18
I take a taxi	23.10%	82
I use a gas card	6.20%	22
I use the Long Island Rail Road	2.25%	8
I walk there	3.66%	13
Other transportation (please specify)	24.23%	86
Answered		355
Skipped		9

When it comes to transportation to HIV services, 46% of respondents use their car, while 10% rely on friends or relatives for rides. Public transportation options are also utilized, with 17% taking the bus and 23% using taxis. Additionally, 3% walk to their appointments, and 5% use Suffolk County Accessible Transportation (SCAT). Other methods, including gas cards and the Long Island Railroad, are mentioned by smaller percentages, while 24% indicated "Other transportation" options.

The “other” responses regarding transportation providers reveal a diverse range of options used by individuals. Circulo and Medicab/EOC Transport were the most frequently mentioned, followed by Medicaid transportation, which also played a significant role in providing access to healthcare. Ryan White Transportation was used by some, while others relied on more informal or flexible options such as Uber, public transport, or using their personal or work vehicles. Additional providers like Medanswering, LogistiCare, and RAP/SPARC Taxi were noted as specialized medical transport services. A few individuals mentioned receiving gas cards or support from organizations like EOC of Suffolk, while others relied on friends or taxis provided by clinics.

The “other transportation” included:

- Medicab, EOC Transport (16)
- Medicaid transportation (15)
- Circulo (22)
- Ryan White Transportation (7)
- Uber (3)
- Insurance (1)
- HCC (1)
- Public Transport (1)
- Ambulette (1)
- My work truck (1)
- Medanswering (1)
- MDC or his brother (1)
- N/A (2)
- Taxi Latino (1)
- Sometimes I get taxi from the clinic (1)
- Biking (1)
- Logistercare Medical Trans (1)
- EOC of Suffolk supplies gas cards (1)
- RAP/SPARC Taxi (1)
- Transporte de la Hispanidad (1)
- Mi amigo me presta su caro (1)
- Medical transportation (2)
- Visiting nurse services (1)
- Med Answering Service (1)
- Clinic provided transportation (1)
- MAS (1)



Myself	58.26%	208
Friends/Family	6.16%	22
Medicaid/Other Health Insurance	14.01%	50
EOC of Suffolk (<i>Part A funded</i>)	12.04%	43
Circulo de la Hispanidad (<i>Part A funded</i>)	20.45%	73
SPARC (<i>Part D funded</i>)	2.52%	9
I don't know	0.84%	3
Other (please specify)	2.80%	10
Answered		357
Skipped		7

In terms of who pays for transportation to HIV services, 58% of respondents cover the costs themselves. Friends and family contribute for 6% of individuals, while 14% rely on Medicaid or other health insurance. The Economic Opportunity Council (EOC) of Suffolk assists 12% of respondents, and Circulo de la Hispanidad supports 20%. A small percentage, 3%, receive help from SPARC, and 3% noted "Other" sources of funding. Additionally, 1% of respondents were unsure about who pays for their transportation.

The "other" included:

Northwell (2)	Federal (1)
N/a (2)	RWT (1)
Gas cards (1)	MDC or brother (1)

NUMC parking validation (1)
Nassau Suffolk Guidance (Ride Health-Prob
Medicaid) (1)

Name of Organization Where HIV Care Is Received

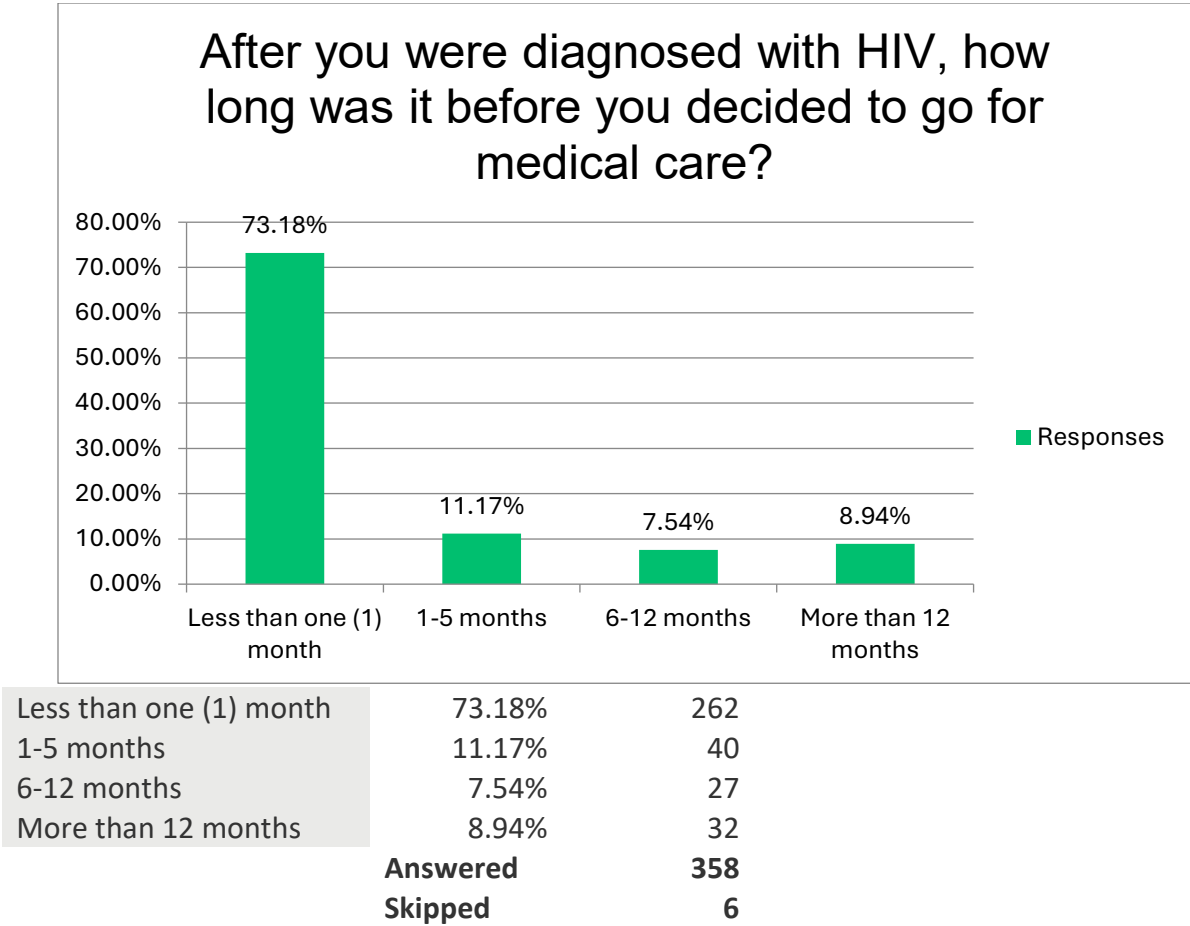
The majority of respondents receive HIV care from large healthcare institutions, with the most common being NUMC (88), Northwell (77), Sun River Health (60), and CPH and Stony Brook, each with 40 mentions. A smaller number of individuals reported receiving care from FQHCs (like Harmony Health Care), NYU, private doctors, and community organizations such as Thursday's Child and the Hispanic Counseling Center. A few respondents mentioned receiving care from less common locations such as Callen-Lorde, clinics in Ecuador and Haiti, or while incarcerated in Broward County Jail. Some also mentioned ADAP or other assistance programs, while a small number reported not having a regular care provider or not remembering where they receive care.

Individual Responses:

NUMC (88)	Elsie Owens Health Center Sunrise Health
Northwell (77)	Services (1)
Sun River Health (60)	Five Towns (1)
CPH (40)	GMHC (1)
Stony Brook (40)	Greenwich Hospital (1)
Harmony Health Care (4)	GWHC (1)
NYU (2)	Haiti (1)
Private doctor (2)	Hospitainogou (1)
Thursday's Child (2)	Hospital Vicente corral moscoso (Ecuador),
Hispanic Counseling Center (1)	Shirley (1)
ADAP (1)	IDC (2)
Broward County Jail (1)	Infectious Disease (1)
Callen-Lorde (1)	MayFair Care Center (1)
Clinica de la Positvida (1)	New York Hospital (1)
Centro Positivo (1)	New York Presbyterian (1)
Circulo de la hispanland (1)	NMC (1)
Clinica de Brentwood (1)	Gheskio (1)
CPA (1)	OPH (1)
David Weinser (1)	Total Care (1)
Options (1)	University Hospital Zurich, Switzerland (1)
Dolan health center (1)	V.A. Med Center (1)
Don't have one (1)	Winthrop Hospital (1)
Don't remember (1)	

Name of HIV Provider

The respondents mentioned a wide range of HIV care providers, with Yasmin (51), McGowan (40), Ahmed (39), and Griffin (38) being the most frequently named healthcare providers. A few respondents mentioned less commonly known providers or expressed uncertainty about their provider (e.g., "I don't know" or "Unknown").



The majority (73%) of respondents waited less than a month after their HIV diagnosis to seek medical care.

Who first helped you get into medical care after you were diagnosed with HIV? (Check all that apply)

Family Member	13.09%	47
Friend	6.13%	22
Doctor/Medical Provider	50.14%	180
HIV tester	14.21%	51
Outreach worker/Linkage to Care Coordinator/EIS Specialist	4.46%	16
Case Manager/Social Worker	17.83%	64
Nurse/Nurse Practitioner	3.34%	12
Prison/Jail staff	3.06%	11
I don't remember	3.62%	13
No one	6.41%	23
Other (please specify)	4.74%	17
Answered		359
Skipped		5

Doctor/medical provider (50%), case manager/social worker (18%), HIV tester (14%) , and family member (13%). Of the “other” responses six mentioned relying on themselves for help, suggesting a sense of personal resilience or self-advocacy. Healthcare institutions like Northwell (4) and Sun River (2) were also significant sources of support, indicating their roles in providing medical care and guidance. The “other” included: Myself (6), Northwell (4), Sun River (2), Got real sick (1), Mother (1), Public Clinic (1), DOH (1) , Already had my doctor (1)

If you did not receive medical care for your HIV during the past six (6) months, why was this the case? (Check all that apply)

Not applicable, I received medical care for my HIV within the past six (6) months	89.16%	288
I could not get an appointment	0.93%	3
I could not get transportation	1.55%	5
I could not get childcare	0.00%	0
I was concerned about confidentiality	1.24%	4
I had language problems/barriers	0.62%	2
I could not afford my copayment for these services	0.62%	2
I needed an evening or weekend appointment	0.00%	0
Other (please specify)	6.50%	21
Answered		323
Skipped		41

For most respondents (89%), this question wasn't applicable because they received HIV-related medical care within the past six months. A few individuals cited specific barriers such as loss of insurance, recent immigration to the U.S., and homelessness, which can significantly impact access to healthcare. Health issues like cancer diagnosis and recovery from knee surgery were also mentioned as reasons for not seeking HIV care. Some respondents indicated they were unsure about their need for care or had no previous problems, reflecting uncertainty or a lack of urgency. A few noted they were working or had scheduled appointments, implying that logistical challenges might affect their access. Additionally, some respondents (6) indicated "N/A," suggesting they did not have relevant concerns or reasons.

The "other" included:

Loss of insurance (1)

Estoy recibiendo (1)

Recently immigrated to USA. Fue inmigrante recién llegado a los Estados Unidos. (1)

Homeless (1)

I was diagnosed with cancer (1)

N/a (6)

Si recibí ayuda médica (1)

Had knee surgery (1)

Si obtuve (1)

I just wasn't sure (1)

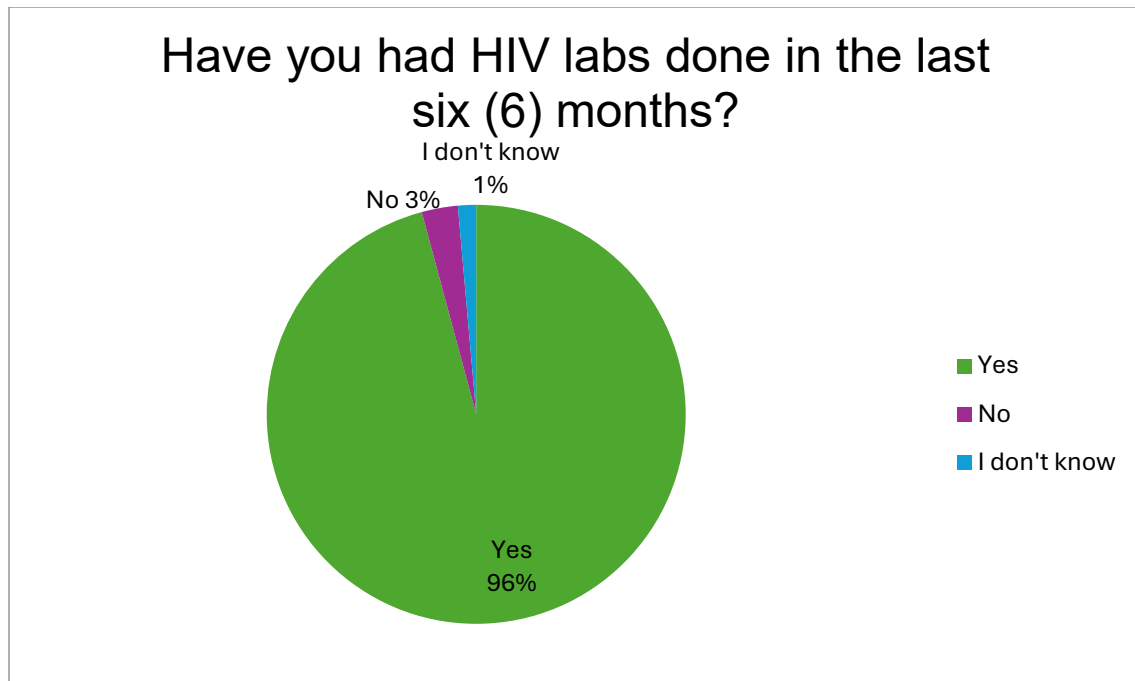
I see the doctor when my appointments are scheduled (1)

Was not unable (1)

I never had any problems (1)

Working (2)

Lives in Nigeria and stopped after 2 years (1)



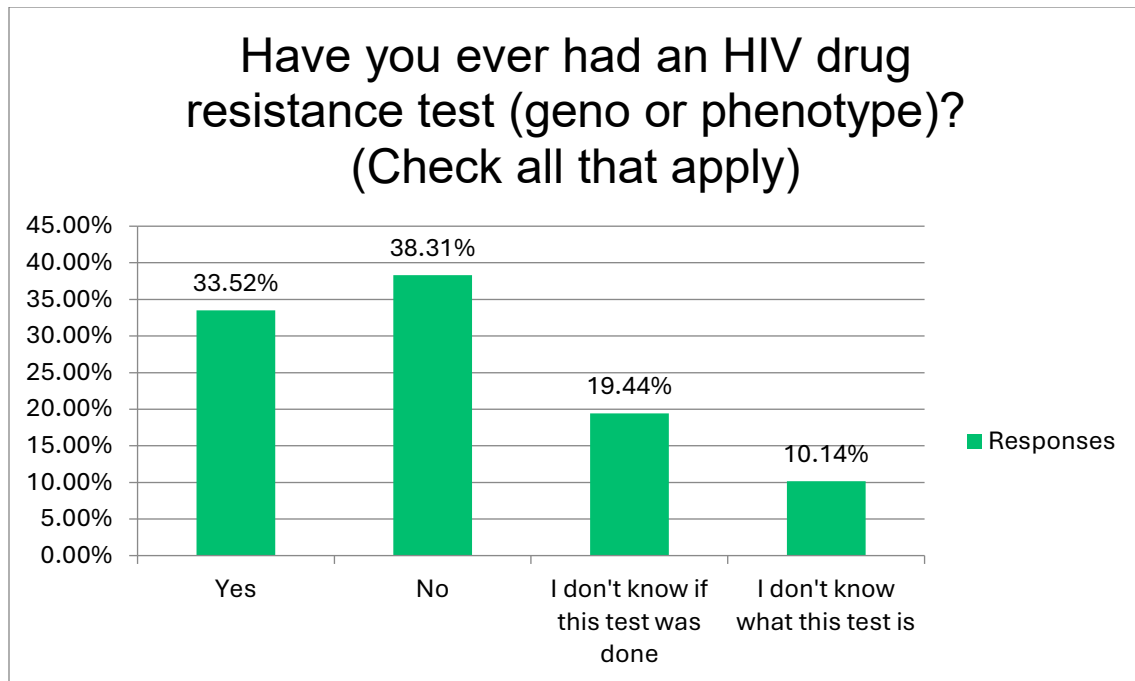
Of the 358 respondents that answered this question, nearly all (96%) HIV labs done in the last six months. Six (6) respondents skipped this question.

CD4 counts:

- 35.6% reported a CD4 count over 500 for both their last CD4 count and their lowest.
- 49.1% reported their last CD4 count as more than 500.
- 20.0% weren't sure what their last CD4 count was.

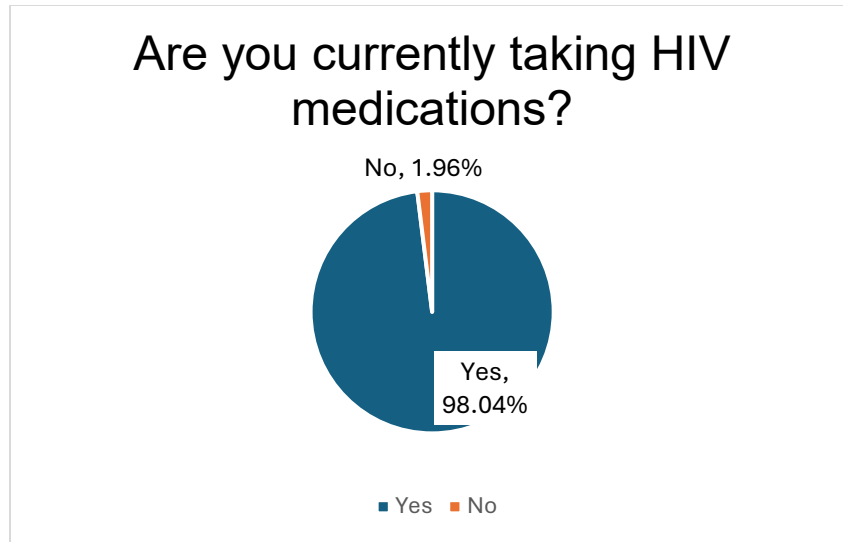
Viral loads:

- 81.7% reported their last viral load as undetectable



Yes	33.52%	119
No	38.31%	136
I don't know if this test was done	19.44%	69
I don't know what this test is	10.14%	36
Answered		355
Skipped		9

Responses regarding whether individuals have ever had HIV genotype or phenotype testing show a mixed understanding and experience with this type of testing. Approximately 33.5% confirmed they had undergone the testing, while 38.3% reported they had not. A significant portion, around 19.4%, were uncertain if the test had been conducted, and 10.1% did not know what the test entailed.



When asked, “are you currently taking HIV medications”, almost all respondents, 98% (n=350) reported that they are currently taking HIV medications. Seven respondents indicated that they are not taking medications.

If you are not currently taking HIV medications, please tell us why?
(Check all that apply)

Not applicable (I'm currently taking them)	94.92%	299
I don't know where to get them	0.00%	0
I cannot afford the cost	0.32%	1
I cannot afford the co-payment	0.32%	1
The side effects are too undesirable	0.00%	0
I am resistant to them, or they do not work for me	0.00%	0
My doctor did not prescribe them	0.32%	1
I do not want to take medication	0.32%	1
Other (please specify)	4.13%	13
Answered		315
Skipped		49

This question wasn’t applicable to most respondents (95%) because they are taking their medications. “Other” responses regarding reasons for not taking HIV medications highlight a mix of experiences and barriers. Some individuals (4) noted "N/A," suggesting they do not have relevant concerns. A few indicated they are currently taking their medications, with three confirming they are on treatment. Financial barriers were mentioned, specifically loss of insurance leading to affordability issues. One respondent referenced using a vaccine every two months instead of medication, while another identified as an Elite Controller, indicating a

unique personal health situation. Elite Controllers represent a rare group of individuals with the ability to maintain an undetectable HIV viral load overtime in the absence of previous antiretroviral therapy (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6816117/>).

The “other” included:

N/a (4)	Uso la vacuna cada dos meses (1)
estoy tomando (3)	Yes (1)
Si los tomo (2)	I am considered an Elite Controller (1)
Loss of insurance- can't afford cost (1)	

Comorbid Conditions

Arthritis	34.87%
Asthma	21.16%
Cancer (lymphoma, sarcoma etc.)	12.86%
Dermatology/Skin Problems	20.92%
Diabetes	24.58%
Heart Problems/Cardiovascular Disease	21.38%
Hearing Problems/Deafness	8.48%
Hepatitis A	6.55%
Hepatitis B	10.00%
Hepatitis C	12.50%
High Blood Pressure	43.04%
High Cholesterol	46.35%
Kidney problems	17.08%
Liver problems	10.64%
Lung or Breathing Problems	20.57%
Neurology Problems (Epilepsy, Neuropathy)	21.75%
PCP Pneumonia	12.90%
Thought or Memory Problems	15.90%
Thrush	17.79%
Tuberculosis (TB)	7.53%
Yeast Infections	16.67%
Vision Problems/Blindness	32.53%

The responses regarding current comorbid conditions among respondents indicate a diverse range of health issues. High blood pressure (43.0%) and high cholesterol (46.4%) were the most prevalent conditions, reflecting significant cardiovascular concerns. Arthritis (34.9%) and vision problems (32.5%) were also commonly reported, suggesting impacts on mobility and daily functioning. Other notable conditions included diabetes (24.6%), lung or breathing problems

(20.6%), and dermatology/skin problems (20.9%). Neurological issues, such as epilepsy and neuropathy (21.8%), and asthma (21.2%) also affected a substantial number of respondents. Various forms of hepatitis were reported, along with cancer (12.9%), kidney problems (17.1%), and thought or memory issues (15.9%).

Notable “other responses” include cataracts, colonic polyps, and eczema, indicating a range of dermatological and ophthalmological concerns. Respiratory conditions like emphysema and sleep apnea were also noted. Neurological conditions included Parkinson’s disease and epilepsy, while autoimmune disorders such as ITP were mentioned. Herpes zoster and shingles highlight viral infections that can complicate health management. Additionally, thyroid conditions were referenced, pointing to endocrine health issues.

“Other” conditions:

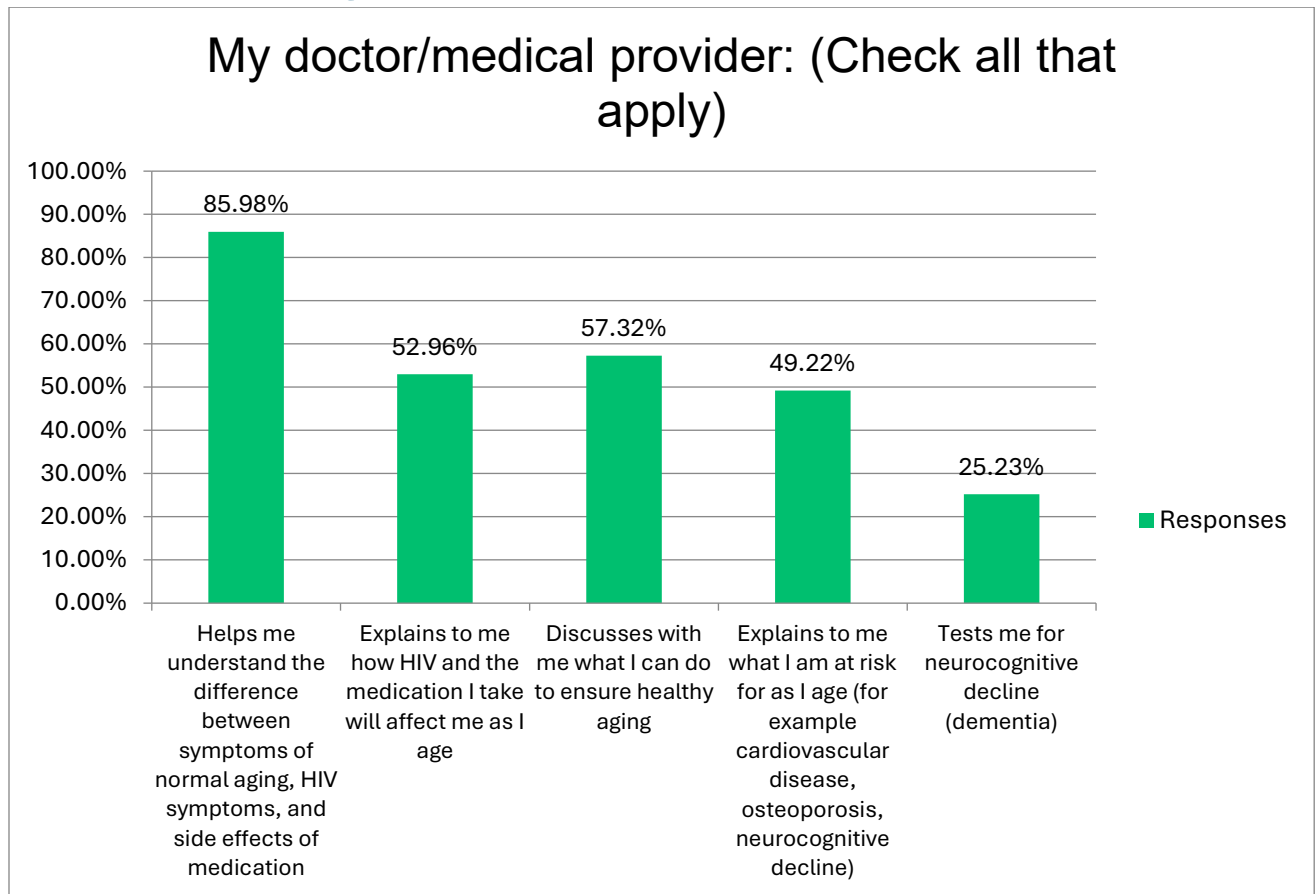
- Cataracts (1)
- Colonic Polyps (1)
- Eczema (1)
- Emphysema (1)
- Glaucoma (1)
- Hernia, Bell's Palsy (1)
- Herpes Zoster- Meningitis (2008) (1)
- HIV (1)
- ITP - auto immune blood disease (1)
- Parkinsons (1)
- Shingles (1)
- Sickle cell (1)
- Sleep apnea (1)
- Soy epileptica (1)
- Thyroid (1)
- Thyroids/huesos (1)

Sexually Transmitted Infections

	Within the last year	Previously
Chlamydia	19.35%	80.65%
Genital Herpes	9.68%	90.32%
Genital Warts	4.76%	95.24%
Gonorrhea	12.73%	87.27%
Human Papilloma Virus (HPV)	20.00%	80.00%
Syphilis	27.78%	72.22%
Trichomoniasis	42.86%	57.14%
Not applicable	92.90%	7.10%
Other (please specify)		
Answered	310	
Skipped	54	

The STI data reveals insights into the prevalence of various STIs among respondents. A significant percentage reported having Trichomoniasis within the last year (42.9%), followed by syphilis (27.8%) and HPV (20.0%). Chlamydia and gonorrhea were also reported within the past year by 19.4% and 12.7% of respondents, respectively. Genital herpes and genital warts had lower recent prevalence rates at 9.7% and 4.8%, respectively. In contrast, a majority of individuals reported previously having these infections, with the highest percentage for genital warts (95.2%) and genital herpes (90.3%). A notable 92.9% indicated that STI testing did not apply to them, suggesting a large portion of respondents may not have experienced any STIs in the last year.

Provider Dynamics



Helps me understand the difference between symptoms of normal aging, HIV symptoms, and side effects of medication	85.98%	276
Explains to me how HIV and the medication I take will affect me as I age	52.96%	170
Discusses with me what I can do to ensure healthy aging	57.32%	184
Explains to me what I am at risk for as I age (for example cardiovascular disease, osteoporosis, neurocognitive decline)	49.22%	158
Tests me for neurocognitive decline (dementia)	25.23%	81
Answered		321
Skipped		43

The data on HIV provider dynamics reveals significant aspects of patient-provider interactions related to aging and HIV care. A majority of respondents (86%) reported that their providers help them understand the differences between normal aging symptoms, HIV symptoms, and medication side effects. However, fewer individuals indicated that their providers explain how HIV and their medications might affect their health as they age (53%) or discuss strategies for healthy aging (57%). Understanding age-related risks, such as cardiovascular disease and neurocognitive decline, was conveyed to nearly half of the respondents (49%). Testing for neurocognitive decline was less common, with only 25% of respondents reporting such evaluations.

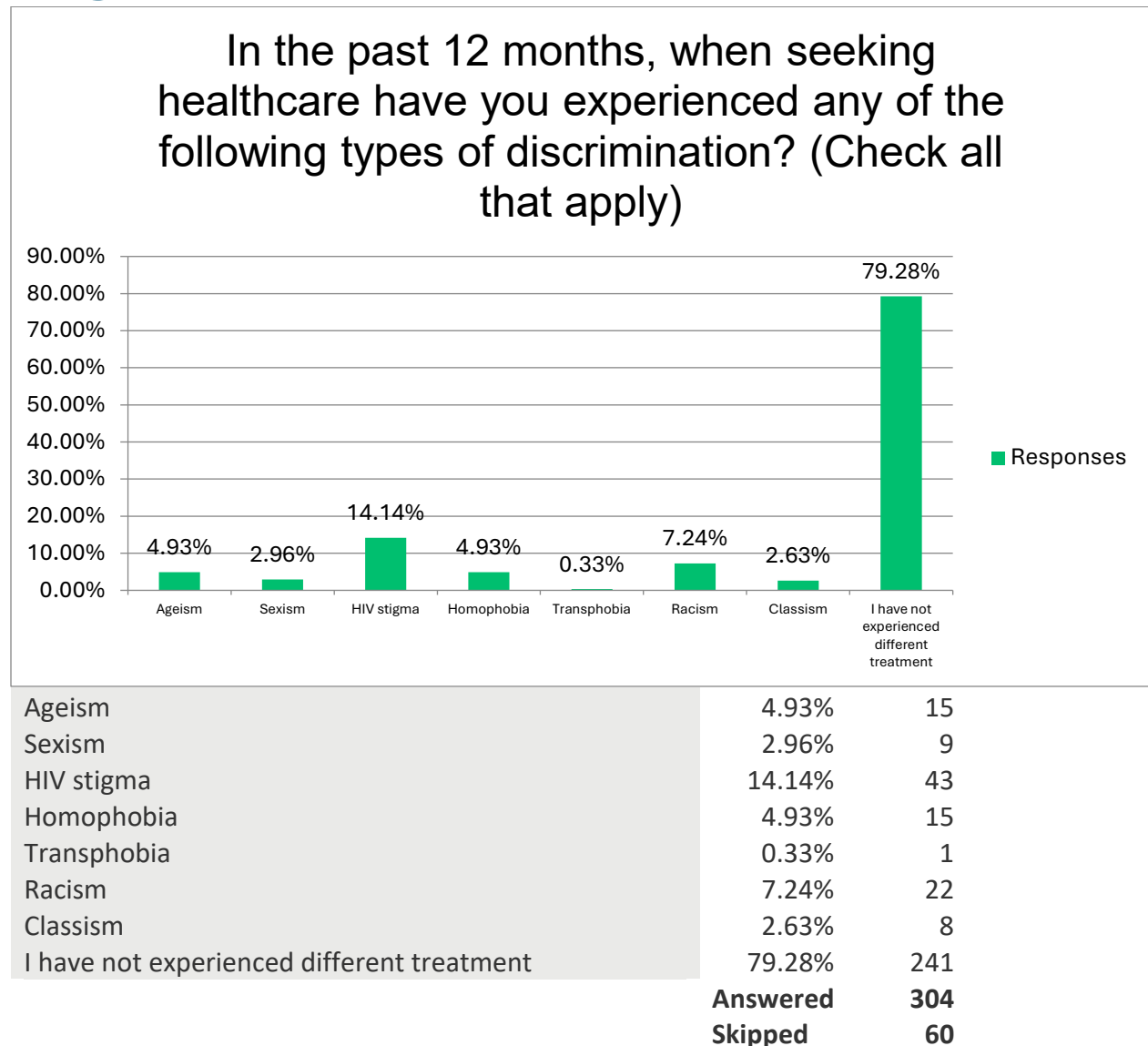
HIV and Aging

How concerned are you about the following aspects of aging?
(Check all that apply)

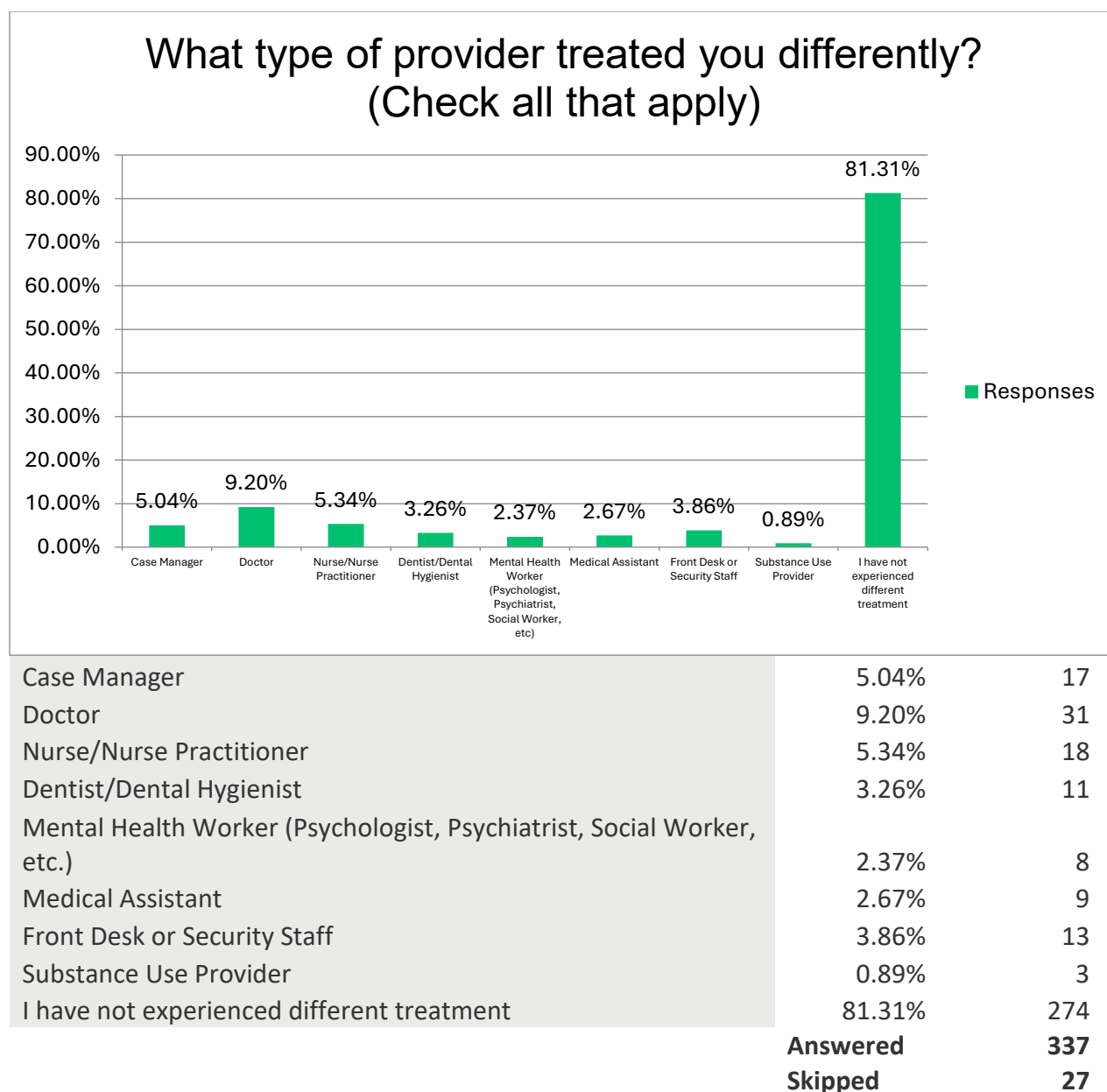
	Percentage	# of Respondents
Finding a partner or maintaining a relationship through the years	30.63%	98
Having a family	17.19%	55
Taking care of significant others	18.13%	58
Managing my HIV	50.00%	160
Long-term effects of medications	37.19%	119
Being a burden on friends and family	35.94%	115
Finding a retirement home that understands HIV	15.31%	49
Finding or having a place to live	28.44%	91
Getting or maintaining a job	19.06%	61
Having a doctor who understands how HIV will affect me as I age	24.69%	79
Multi-morbidity -- having to live with multiple chronic illnesses and take multiple daily medications	31.88%	102
	Answered	320
	Skipped	44

The responses regarding aging concerns among individuals living with HIV highlight a range of significant issues. Managing HIV itself was a primary concern for half of the respondents (50%), underscoring the ongoing challenges of living with the virus. Additionally, long-term effects of medications (37%) and multi-morbidity—dealing with multiple chronic illnesses (31%)—were notable concerns, reflecting the complexity of healthcare as individuals age. Emotional and social aspects were also significant, with many expressing worries about being a burden on friends and family (36%), finding a partner or maintaining relationships (30.6%), and securing stable housing (28%). Other concerns included the desire for family (17%), caring for significant others (18%), and finding a retirement home knowledgeable about HIV (15%). Maintaining employment (19%) and having a doctor who understands aging with HIV (24%) also emerged.

Stigma and Discrimination



The data on experiences of discrimination among respondents reveals a mixed landscape of perceived bias. The majority (79%) reported not experiencing different treatment, indicating a significant portion feels unaffected by discrimination. Among those who did report experiences, HIV stigma was the most prevalent concern (14%), highlighting ongoing societal challenges faced by individuals living with HIV. Racism (7%) and ageism (5%) were also noted, along with homophobia (5%) and sexism (3%). Transphobia was reported at a minimal rate (0.3%), while classism affected 3% of respondents.



The responses regarding sources of discrimination in healthcare settings indicate that a significant majority (81%) of respondents did not perceive different treatment, suggesting a generally positive experience. Among those who did encounter discrimination, doctors were identified as the most common source (9%), followed by nurses or nurse practitioners (5%) and case managers (5%). Other healthcare professionals, such as dental hygienists (3%) and front desk or security staff (34%), were also mentioned. Mental health workers and substance use providers were less frequently cited as sources of discrimination, with only 2.4% and 0.9% respectively.

	Needed and Received	Received this, BUT needed more than what was available	Needed this, BUT could not get it	Needed this, BUT did not seek it	Did not need this
Outpatient Ambulatory Health Services (doctor's visits)	47.7%	1.7%	0.9%	0.6%	32.1%
Dental Care	52.8%	7.7%	6.5%	9.7%	17.3%
Medical Case Management	56.8%	2.3%	1.1%	0.9%	25.0%
Emergency Medical Care	34.7%	0.9%	0.3%	0.0%	49.4%
Eye Care	52.3%	3.1%	3.1%	6.5%	22.7%
Gynecological Care	29.8%	0.6%	1.7%	3.1%	49.7%
Help with taking medications as prescribed	21.0%	0.6%	0.0%	0.6%	61.4%
Hepatitis C Services	6.0%	1.1%	0.3%	0.0%	73.8%
Home Health Services	9.1%	1.1%	2.6%	1.1%	68.5%
Hospice Services	2.0%	0.6%	0.3%	0.0%	75.3%
Medications	61.1%	0.9%	0.0%	0.6%	27.6%
Mental Health or Emotional Counseling Services	37.5%	2.0%	3.1%	1.4%	41.5%
Nursing Home Care	3.7%	0.3%	0.3%	0.3%	76.7%
Obstetrical/ Pregnancy Care	3.4%	0.3%	0.3%	0.0%	77.0%
Substance Use Services	8.0%	0.3%	0.6%	1.1%	71.9%
Nutritional (dietetic) counseling	27.0%	3.1%	1.4%	4.0%	48.0%
Answered	352				
Skipped	12				

The table outlines respondents' access to various medical services, showing a range of experiences. A majority of respondents reported needing and receiving general medical care (61%) and medical case management (57%). Dental care also showed high levels of need and receipt (53%), as did eye care (52%). Some respondents indicated that, although they received dental care, they needed more (7.7%). Additionally, dental care was the service most often needed but unavailable to respondents (6.5%). Many respondents reported not needing certain services, such as OB care (77%) and nursing home care (76%).

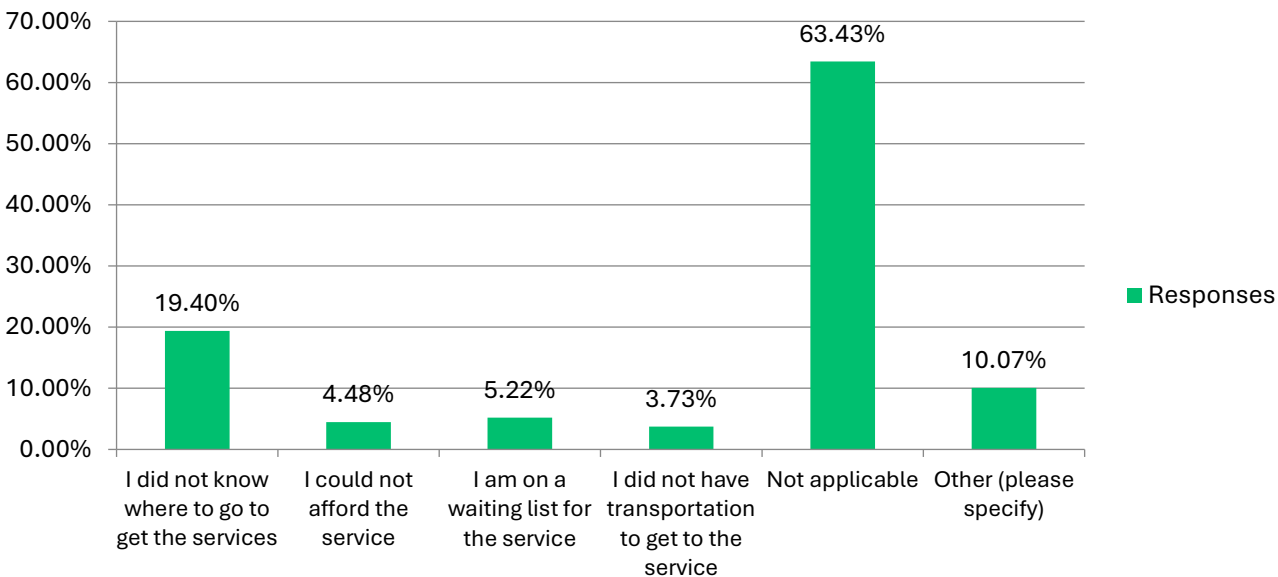
Access to Social Support Services

	Needed and Received	Received this, BUT needed more than what was available	Needed this, BUT could not get it	Needed this, BUT did not seek it	Did not need this
Peer Mentor Programs	19.9%	0.6%	1.7%	2.9%	59.7%
Assistance with copayments	13.1%	3.1%	4.9%	3.7%	61.1%
Case Management	58.3%	1.4%	2.0%	1.4%	27.7%
Childcare while I go to the doctor or another appointment	2.3%	0.9%	0.6%	0.3%	79.4%
Client Advocacy	18.6%	0.6%	1.7%	1.4%	61.1%
Dental Care	0.6%	0.0%	0.0%	0.0%	0.6%
Emergency Shelters for people living with HIV	8.3%	1.7%	1.7%	1.1%	71.4%
Food bank or food vouchers	30.6%	4.3%	4.9%	6.0%	43.4%
Free condoms	27.4%	0.6%	0.9%	1.4%	54.6%
Help with finding and keeping housing	12.9%	3.4%	7.4%	2.0%	60.3%
Information about safe sex practices	24.0%	0.9%	0.3%	1.1%	60.0%
Help with navigating HIV and social services	29.4%	1.7%	2.0%	2.6%	51.4%
Legal services	22.0%	1.7%	0.6%	4.0%	57.7%
Home delivered meals	5.1%	2.0%	3.7%	5.1%	68.9%
Money to pay for medications	7.7%	1.1%	4.0%	2.6%	68.9%
Money to pay for mortgage or rent	7.4%	2.3%	6.9%	7.4%	61.4%
Money to pay for utilities	9.1%	2.9%	5.1%	7.4%	61.4%
Needle/Syringe exchange program	2.6%	0.3%	0.9%	0.3%	80.6%
Nutritional (dietetic) counseling	0.6%	0.0%	0.0%	0.3%	0.3%
Pre-release services (before release from jail or prison)	2.6%	0.3%	0.9%	0.0%	80.6%
Respite care	1.4%	0.3%	0.3%	0.6%	80.3%
Support group/peer counseling	22.3%	1.4%	1.1%	2.9%	58.9%
Transportation to the doctor, dentist and/or other service	34.6%	2.3%	2.9%	2.9%	45.1%
Answered	350				
Skipped	14				

The table presents respondents' experiences with social services, highlighting different levels of need and access. Case management was the most accessed service, with 58% of respondents both needing and receiving it. Transportation services were also in demand, with 35% of respondents receiving assistance. In contrast, many respondents reported not needing certain services, such as needle/syringe services and pre-release services, both at 81%.

Some respondents indicated a need for more support in areas like food bank vouchers (4%), housing assistance (3%), and copay assistance (3%). However, certain services—such as housing assistance and rental/mortgage support—were needed but unavailable to 7% of respondents. Additionally, 7% of respondents needed but did not seek assistance for rent/mortgage and utility payments. Overall, while certain social services are widely utilized, many respondents did not report a need for others, suggesting a potential gap in service awareness or availability.

If you selected "Needed this, BUT could not get it" for question 57/58, or if you could not get a service that you included on question 59, then select the reasons why you could not get the service(s) that you needed.
(Check all that apply)



I did not know where to go to get the services	19.40%	52
I could not afford the service	4.48%	12
I am on a waiting list for the service	5.22%	14
I did not have transportation to get to the service	3.73%	10
Not applicable	63.43%	170
Other (please specify)	10.07%	27
Answered		268
Skipped		96

Over a third (37%) provided a reason for not getting the services they needed. The reasons respondents cited for being unable to access services primarily included a lack of knowledge about where to go for help, with 19% expressing this concern. Financial barriers were also noted, as 5% indicated they could not afford the service. Additionally, 5% reported being on a waiting list, and 4% cited transportation issues. Other specified reasons accounted for 10% of the responses, highlighting a variety of individual circumstances affecting access.

The "other" responses regarding barriers to accessing services included various personal circumstances and misunderstandings. One respondent believed services were automatically provided, while another faced physical accessibility issues due to a wheelchair. Some expressed financial concerns, such as the high cost of food and being over the income limit for assistance programs like ADAP and SNAP. Several mentioned a lack of knowledge on how to begin the process or where to find help. Others cited practical challenges like being unable to take time off work or the unavailability of services in their area. Additionally, a few responses indicated that the services did not apply to their situation or simply did not specify a reason.

"Other" responses:

I thought it was automatically done for me (1)

I'm in a wheelchair and I'm not able to get on the table at doctors office (1)

Lo mas necesario para mi son tarjetas para comida. Ya que la comida esta demasiado cara y es en lo que mas se gasta. Para tener una 75erma alimentación. (1)

No (1)

N/a (9)

100 aplica (1)

Yes (1)

I know where to get any help (1)

Did not specify (1)

I can't get out of work (1)

Service not available in central 75ermane (1)

I work – most peer/mentoring is during the day (1)

Food stamps ct, SNAP said I make to much SSD (1)

I didn't know where to start (1)

I just didn't do it (1)

Idk (1)

Need more info (1)

My salary is over the limit for ADAP (1)

Could not find (1)

Were there any other services not listed above that you needed during the last 12 months? If yes, please specify:

Responses regarding needs and services sought in the last 12 months varied widely. A significant number of respondents (17) indicated "N/A," meaning they felt no additional support was needed. Specific requests included assistance with transportation and medical care, renewing Medicaid, legal services for financial hardship, and support for housing issues. Others sought help with food stamps, clothing, dental services, eyeglasses, and mental health counseling. Some highlighted the need for financial assistance for healthy eating amid rising costs, as well as ongoing issues with obtaining services like Section 8 housing and more comprehensive support for people with HIV.

Individual responses:

transportation/ case manager atencion medica (1)

Renewing my Medicaid (1)

N/A (17)

Legal Services for non-eviction related issues. Family (siblings) withholding money and deliberately causing me financial hardship and strain, in hopes my health condition will be negatively affected and ultimately end in death (1)

No (41)

None (9)

Tarjetas para comida (1)

Help with clothes, shoes, linens, coat (1)

North Shore IPC (1)

Gas Reimbursement (1)

Social support (1)

None but housing (1)

Vivienda (1)

Learning to read (adult literacy) Decluttering services (1)

More money on food stamps (1)

Housing (2)

Help with my section 8 recertification (1)

Hearing, PT (1)

To buying a house/home (1)

Mental Health Counseling Therapist (1)

Clothing for baby (1)

Eyeglass (1)

I need dental service help (1)

I need food stamps but was refused in Suffolk Co. (1)

Contact lenses for eyes – too expensive (1)

Transportation for non-medical appointments such as support group, etc. (1)

My insurance doesn't cover contacts (1)

I need help finding permanent housing (1)

More housing for people with HIV and low income (1)

Assistant with school (1)

Help with section 8 housing (1)

Right now the biggest problem is affordability to eat healthy due to inflation. However, at some with my combined illness I most likely will need some sort of help. I have nystagmus/oscillopsia, cataract. Necrosis of the knee & hips. And eventually someone to sign me out of some of my appts that won't let me go without someone to take me home. That's for starters. (1)

Dental Vision Nutrition (1)

NEED DENTIST (1)

Dentist each month (1)

Top 5 Services

Outpatient Ambulatory Health Services (doctors visits)	42.05%
Case Management (someone to help me get the services I need)	46.59%
Childcare while I go to the doctor or another appointment	2.27%
Client advocacy (someone to help me get benefits/entitlements)	14.49%
Dental care	55.40%
Emergency medical care	11.65%
Emergency shelters for people living with HIV	5.11%
Eye care	29.83%
Food bank or food vouchers	27.27%
Free condoms	7.95%
Gynecological Care	12.22%
Health Insurance	36.08%
Help with taking medications as prescribed	3.13%
Hepatitis C services	0.57%
Home health services (an aide or nurse who visits your home)	4.26%
Hospice (services for people in the last stages of their life)	0.57%
Information about safe sex practices	1.99%
Information to help me find out what other services are available	18.18%
Legal Services	18.18%
Meals brought to my home	8.81%
Mental Health or Emotional Counseling	16.48%
Money to pay for medications	4.55%
Money to pay for rent	25.00%
Money to pay for utilities	16.48%
Needle/Syringe Exchange program	0.00%
Nursing Home Care	1.14%
Nutritional Counseling	7.95%
Obstetrical/Pregnancy Care	0.57%
Help with finding and keeping housing	11.36%
Pre-release services (someone to help me get the services I need before being released from jail or prison)	0.28%
Respite Care (to relieve the primary caregiver providing day to day care of client or client's child)	0.28%
Substance Use services/counseling	1.14%
Support group/peer counseling	9.66%
Transportation to doctor, dental and/or other service provider	21.02%
Answered	352
Skipped	12

Respondents indicated significant needs for various services, with 55% identifying dental care as the top priority, followed by 47% needing case management assistance. Additionally, 27% reported a need for food bank access or food vouchers, 25% expressed a need for financial assistance with rent, and 21% required help with transportation to medical services.

Substance Use Disorder

Alcohol	26.84%
Anabolic steroids (juice)	0.29%
Benzos/Benzodiazepines (non-medical use) (Ativan, Klonopin, Librium, Valium, Xanax etc.)	0.88%
Cocaine	3.54%
Crack/ Tina	1.77%
Crank (Crystal Methamphetamine)	0.00%
Ecstasy	0.29%
—Hash	0.29%
Heroin	0.88%
Inhalants (whippets)	0.00%
Injection drugs (non-medical use)	0.88%
K2/Spice	0.00%
Lean	0.00%
LSD (acid)	0.29%
Marijuana (Pot)	16.52%
Nicotine/JUUL	0.88%
Pain medications (non-medical use) (such as Percocet, Vicodin etc.)	2.36%
PCP (angel dust)	0.00%
Special K (Ketamine)	0.00%
Tobacco	12.09%
None of the above	58.11%
Different substance (please specify)	2.06%
Answered	339
Skipped	25

A significant majority (58%) reported no use of substances. Among those who did (n= 197), alcohol emerged as the most prevalent substance, with 27% of respondents acknowledging its use. Marijuana followed, with 17% indicating consumption. Tobacco or nicotine, including products like JUUL, was reported by 12% of participants. Other substances reported included pain medications used non-medically (2%), cocaine (4%), and a minimal presence of heroin and benzodiazepines, each at 0.9%. Various other substances were mentioned as well, but their usage rates were mostly below 1%.

The “different substances” include:

N/A (3)

Psilocybin (1)

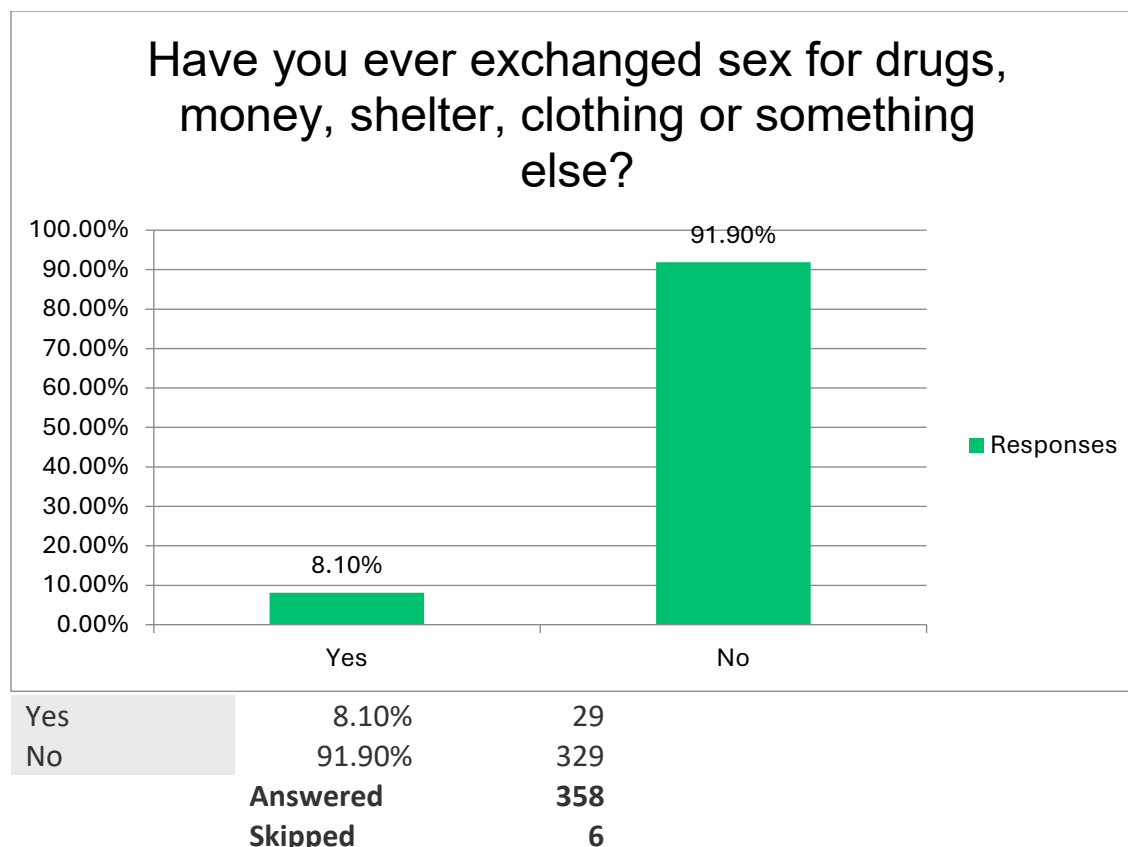
Vape (1)

Crystal meth (1)

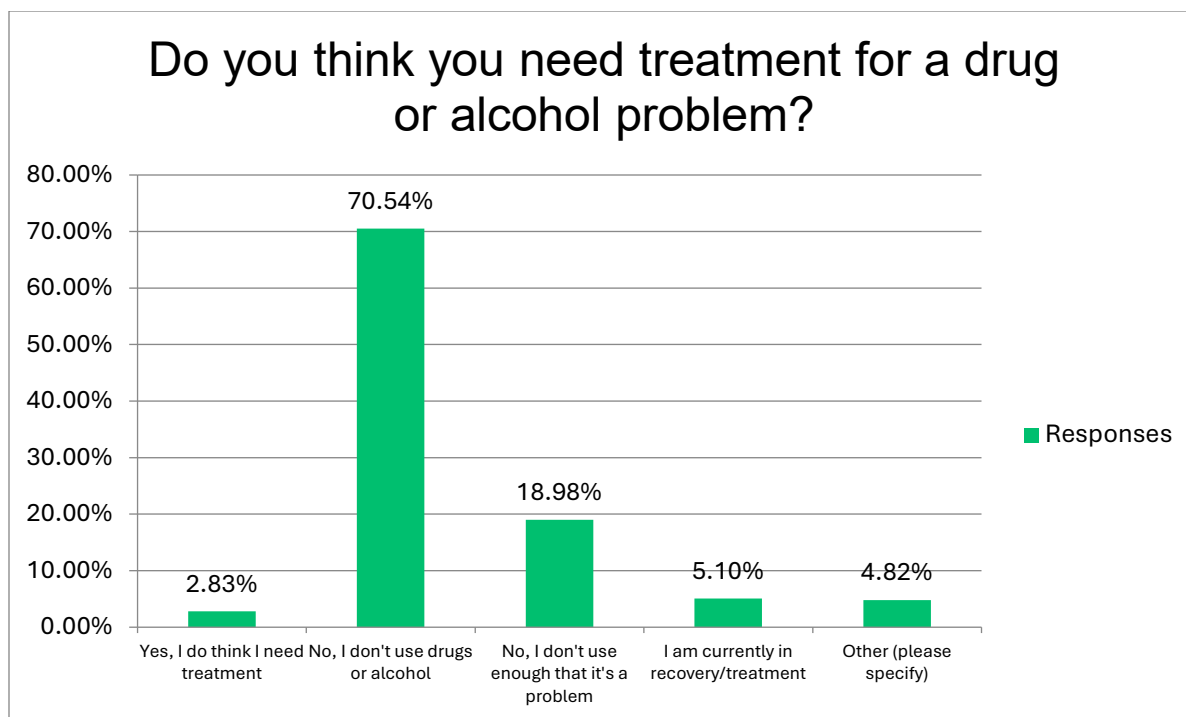
Lorazepam (1)



The majority of respondents, 92%, reported that they only take their medications as prescribed. A small percentage, 7%, indicated that they have used prescriptions above the doctor's orders, while just 1% answered "no" to this question. No respondents reported not taking any medications at all.



Very few respondents (8%) of respondents indicated they had ever exchanged sex for anything.



Yes, I do think I need treatment	2.83%	10
No, I don't use drugs or alcohol	70.54%	249
No, I don't use enough that it's a problem	18.98%	67
I am currently in recovery/treatment	5.10%	18
Other (please specify)	4.82%	17
Answered		353
Skipped		11

When asked if they think they need treatment for a drug or alcohol problem, the majority of respondents, 71%, indicated that they do not use drugs or alcohol. Additionally, 19% reported they don't use enough to consider it a problem. Only 3% believe they need treatment, while 5% are currently in recovery or treatment. The remaining 5% provided other responses, suggesting varied perspectives on their substance use and need for treatment.

The "other" include:

No (5) and N/A (5)

Perp si quiero un tramiento (1)

3 years sobriety - clean and sober (1)

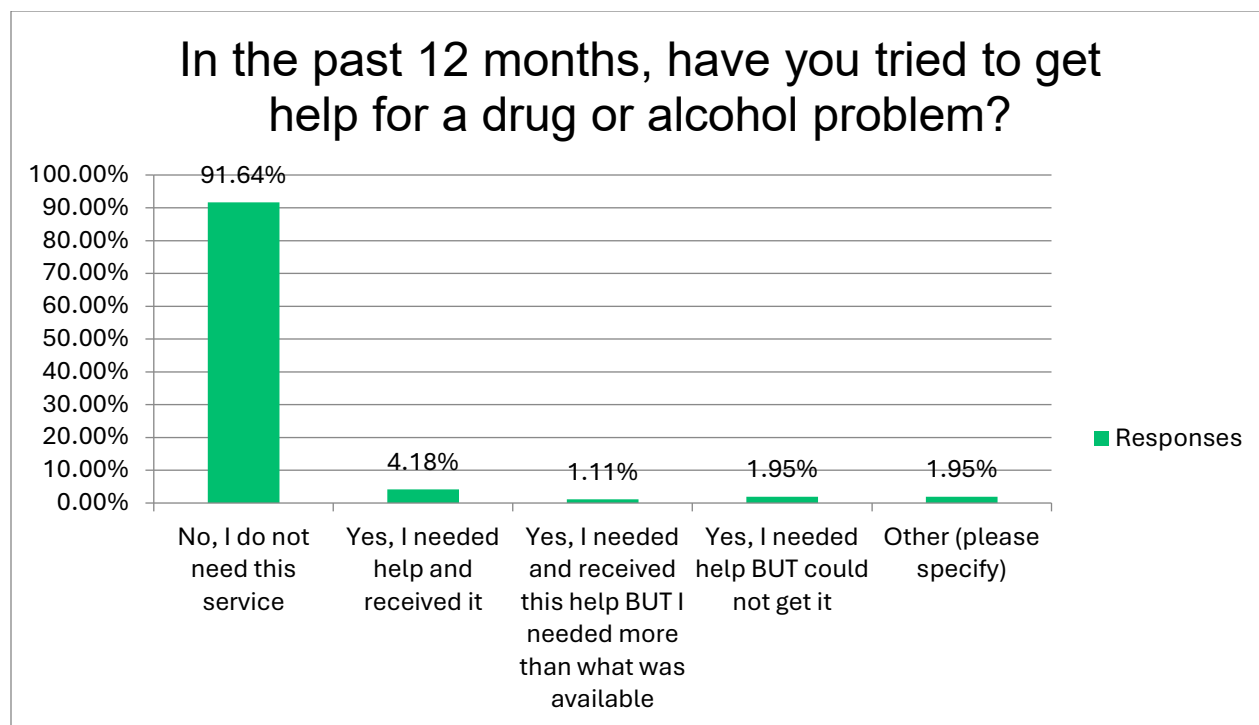
Not ready (1)

dont want to lose my apartment (1)

Uno substancia para ser social (1)

18 years (1)

Alcohol (1)



No, I do not need this service	91.64%	329
Yes, I needed help and received it	4.18%	15
Yes, I needed and received this help BUT I needed more than what was available	1.11%	4
Yes, I needed help BUT could not get it	1.95%	7
Other (please specify)	1.95%	7
Answered		359
Skipped		5

In the past year, a significant majority of respondents (92%) indicated that they do not need drug or alcohol help services. A small portion, 4%, reported that they needed help and received it, while 1% stated they needed assistance but required more than what was available. Additionally, 1.95% mentioned they needed help but could not access it, and another 2% provided other responses.

The “other” include:

Sober for 3 years (1)

I don't get high anymore (1)

I try to reduce beer (1)

Went to get help but they didn't offer the help I needed (1)

It's been a long time (1)

Sober for multiple years (1)

I have it already (1)

If you were unable to receive help for a drug or alcohol problem please tell us why:

When asked why they were unable to receive help for a drug or alcohol problem, most respondents (36) indicated "N/A," suggesting it didn't apply to them. Four respondents mentioned "none," while one noted they didn't need help. Other reasons included a lack of money and resources, having always been able to get help, needing to be actively engaged in a program, and not using drugs or alcohol at all.

Individual responses:

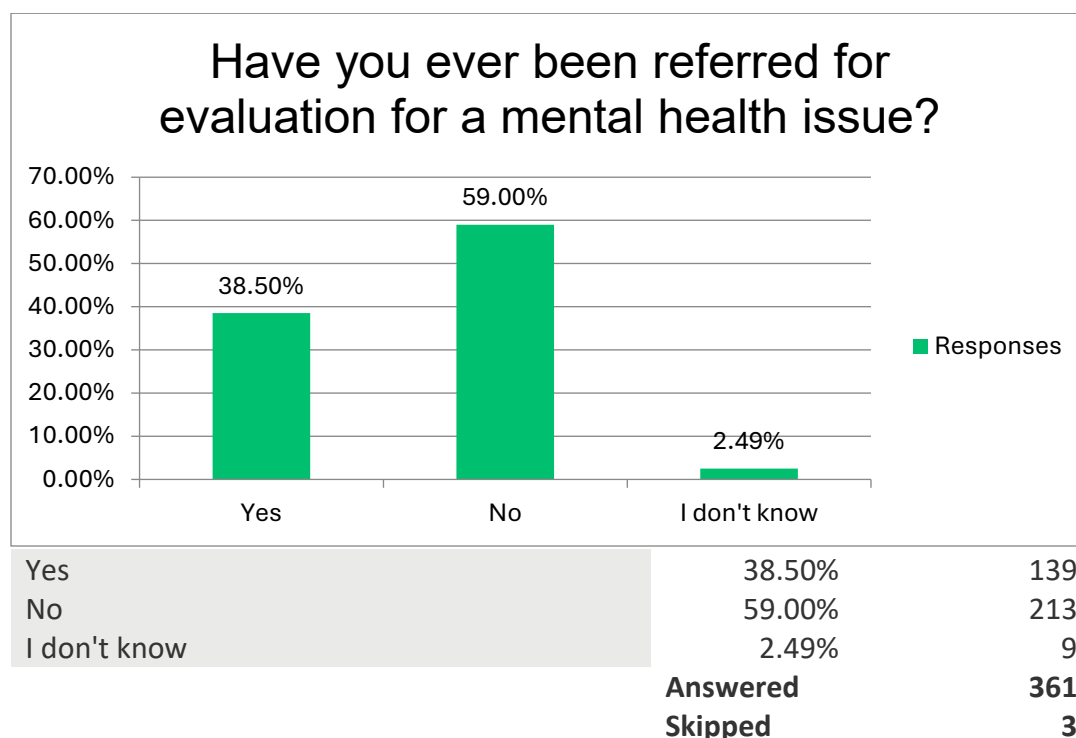
N/A (36)
 None (4)
 No lo necesite (1)
 Falta de dinero y recursos (1)
 I was always able to get help (1)
 Willpower (1)
 Drug Addiction (1) I had to be currently active in NY
 I don't use any of them (1)

If you are currently in recovery, how do you manage?

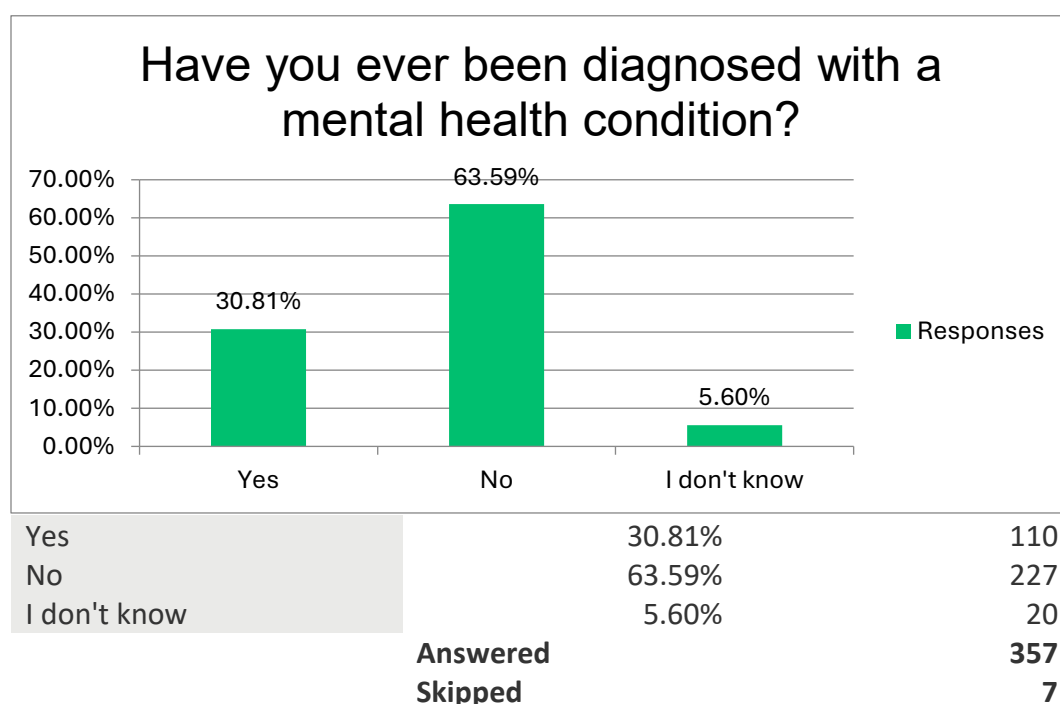
Substance Use Counseling	3.95%
Support Groups with others in recovery	3.95%
Narcotics Anonymous (NA)	2.13%
Alcoholics Anonymous (AA)	3.65%
Methadose or Dolophine (Methadone)	0.91%
Suboxone (Buprenorphine)	0.91%
Revia or Vivitrol (Naltrexone)	0.00%
Campral (Acamprosate)	0.00%
Antabuse (Disulfiram)	0.00%
Extended-release injectable Naltrexone	0.00%
Not applicable	87.84%
Other (please specify)	1.82%
Answered	329
Skipped	35

Among respondents currently in recovery, a small percentage reported various management strategies: 4% engage in substance use counseling and support groups, while 4% attend Alcoholics Anonymous (AA) meetings. Narcotics Anonymous (NA) is used by 2%, and methadone or buprenorphine treatments are mentioned by 0.91%. Notably, a significant majority (88%) indicated that these options do not apply to them, with only 2% specifying other methods. The "other" include: Church (1); Sober (1); I don't drink (1); Outreach (1) Always help (1); Therapist (1)

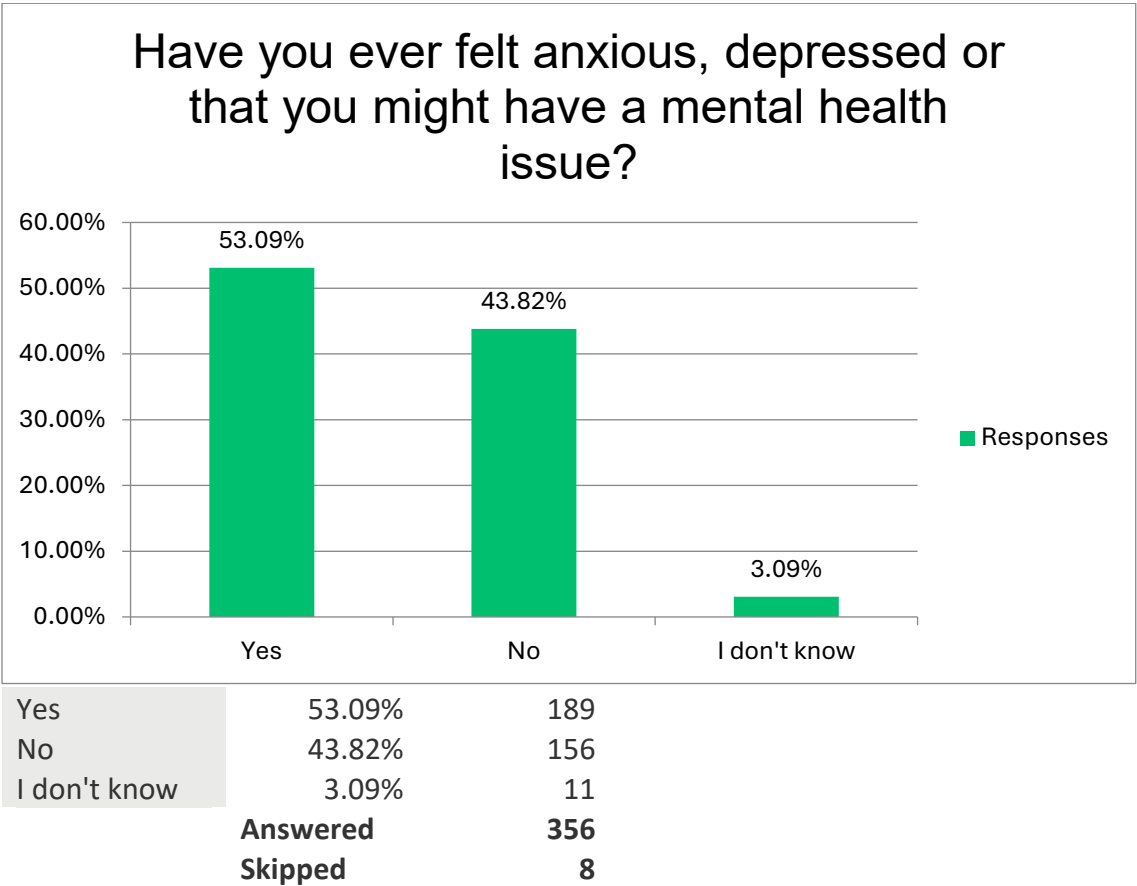
Mental Health



In response to whether they have been referred for a mental health evaluation, 39% of respondents indicated that they have received a referral, while 59% reported that they have not. A small portion, 3%, were unsure about their referral status.

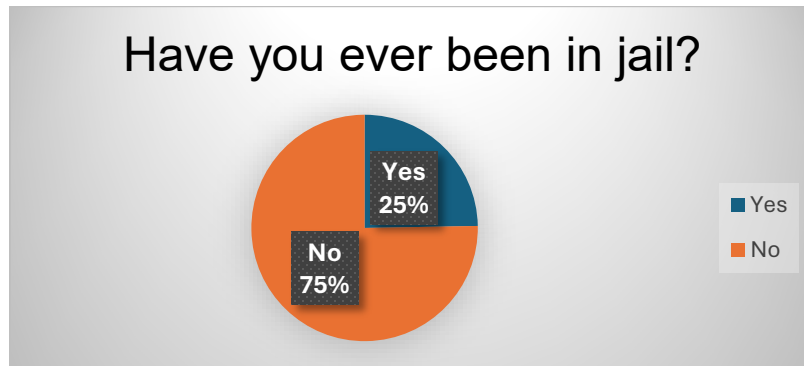


Regarding diagnoses of mental health conditions, 31% of respondents reported that they have been diagnosed with a mental health condition, while 64% indicated they have not. Additionally, 6% were unsure about their diagnosis status.

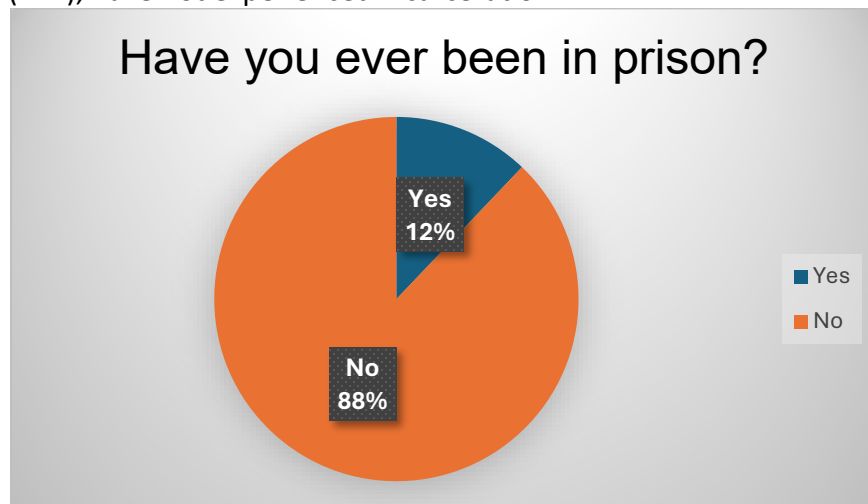


More than half of respondents (53%) reported feeling anxious or depressed and believe they may have a mental health condition. In contrast, 4% indicated they do not feel this way, while a small portion (3%) is unsure.

Incarceration

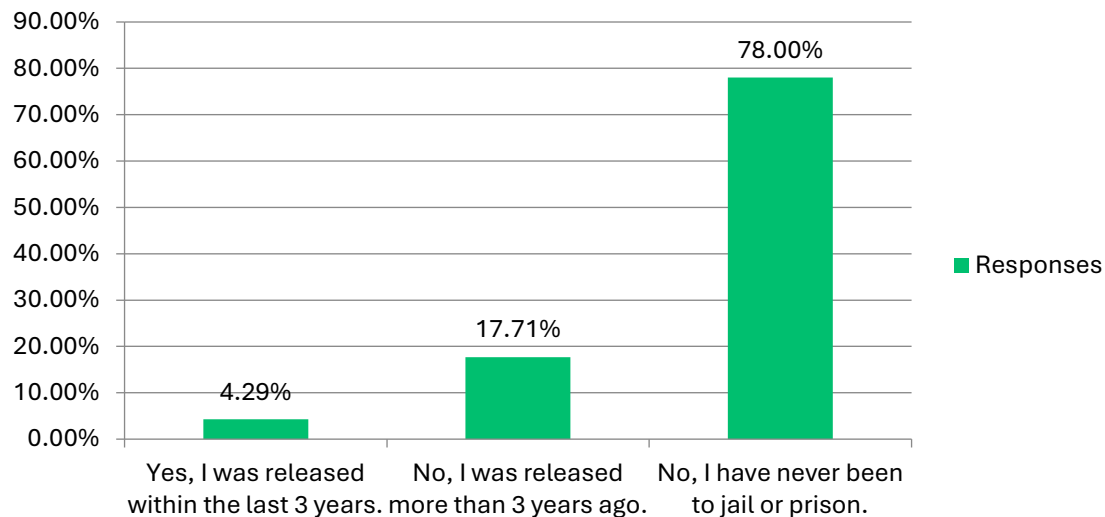


A quarter (25%) of respondents (n=89) have reported having been in jail, while a significant majority, 75% (271), have not experienced incarceration.



Approximately 12% (n=43) of respondents have been to prison, whereas 88% (n=312) have not had this experience.

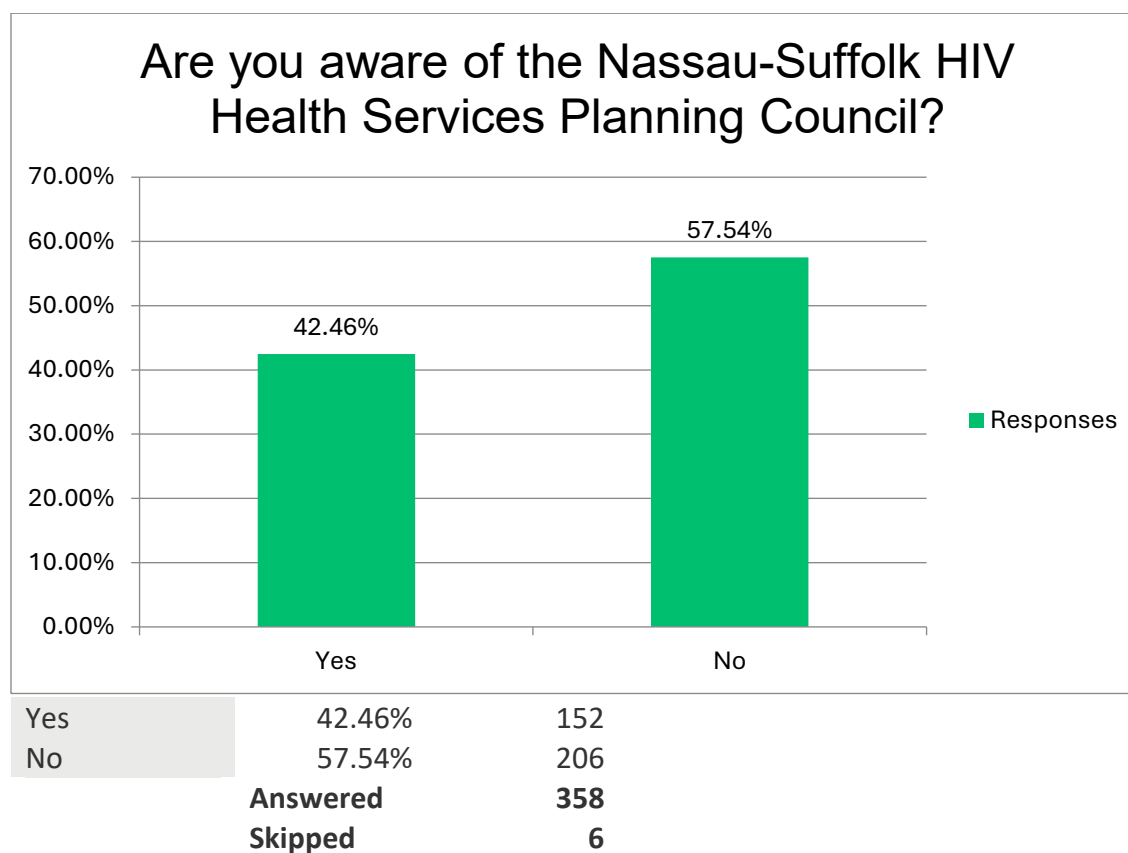
Have you been released from jail or prison in the last 3 years?



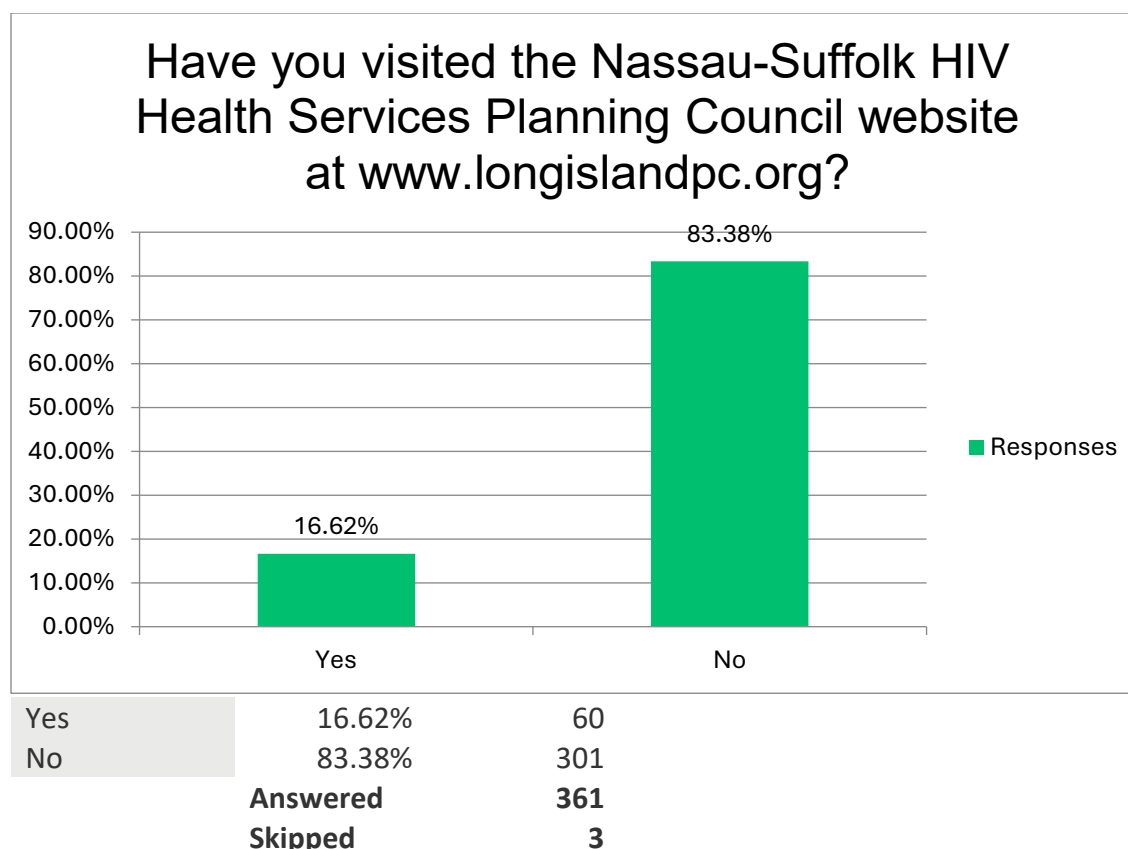
Yes, I was released within the last 3 years.	4.29%	15
No, I was released more than 3 years ago.	17.71%	62
No, I have never been to jail or prison.	78.00%	273
Answered	350	
Skipped	14	

Among those who have been incarcerated, 4% were released within the last three years, while 18% were released more than three years ago. The majority (78%) have never been to jail or prison.

Nassau-Suffolk EMA Planning Council



Approximately 42% of respondents are aware of the Planning Council, while 58% are not.



Only 17% of respondents have visited the Planning Council website, whereas a significant 84% have not.

What is the single most important change you would suggest to improve services for people with HIV on Long Island?

The feedback gathered reveals several prominent themes. Housing was the most frequently mentioned issue, with many individuals advocating for more affordable housing opportunities, rental assistance, and stable living conditions. Additionally, there was a strong call for increased access to medical care, particularly mental health services, dental care, and transportation to healthcare facilities. Many also expressed the need for better support groups, especially to combat isolation, while others emphasized the importance of reducing the stigma surrounding HIV.

Another key concern was the need for better communication and transparency, both in service provision and within healthcare teams. Some respondents suggested improving appointment flexibility and accessibility to services, particularly for aging individuals and PWH. Financial assistance, legal services, and employment support were also common requests. Finally, many expressed gratitude for the services they were receiving, indicating overall satisfaction but highlighting areas for improvement, such as more outreach, education, and awareness efforts.

Individual Responses

La Cura! (1)
Viviendo segura (1)
Go to the doctor (1)
Acceptance (1)
Better Doctors that help listen to their patients (1)
A cure (3)
HIV Awareness- lessen the stigma (1)
Stigma Reduction (1)
Housing/Transportation (1)
Keep having good support groups (1)
Ambulance Service besides Medical (1)
Housing (14)
More care centers (1)
More events for education (1)
I think they should have group meetings with the people to help each other (1)
Know your rights (1)
Appointment times (1)
More support groups (1)
Offer more help (1)
Communication Barrier (1)
Emergency financial assistance. Legal Services Dental services (1)
No, estoy muy agradecida (1)
HIV + Aging (1)
Movefaster (1)
Great (1)
Ninguna (1)
Todo esta bien (1)
Nada (3)
No comment (1)
More doctors (1)
Call everyday and check in. (1)
The stigma of HIV (1)
Affordable Housing (1)
To keep getting check for HIV (1)
That we could be cured. (1)
More money and people to inform others what is available (1)
Understanding the different needs of individuals (1)
Educating the public of services available. (1)
More gift cards (1)
Vivienda/Dinero/Empleo (1)
MSeguro medico en general (1)
Ninguno (1)

Help with housing (1)
 None. Everything is excellent (1)
 N/A (4)
 No lo se (1)
 Financial Assistant (1)
 Housing - Jobs (1)
 Help with rent (1)
 Doctors- not your PA's Housing
 None (3)
 Fund events that help people living with HIVore Housing (1)
 Everyone should have a good care team, like mine. (1)
 Continue to outreach so there is visibility (1)
 Access to stable housing (1)
 More resources/consolidation of information especially on the East End (1)
 I believe that every person going to the ER should automatically be tested. (1)
 Transportation across counties (1)
 A treatment (1)
 More housing opportunities (1)
 Counseling- mental (1)
 More funding for services most needed (1)
 More resources for medication (1)
 Communication through existing service (1)
 More services for personal hygiene (1)
 Educational Groups (1)
 Developing more social groups, gatherings (1)
 Not Sure (4)
 Me (1)
 Nothing (1)
 Take your medication (1)
 OBGYN care at HIV Clinic (1)
 More social activities and networking (1)
 Everything is good. (1)
 More housing (affordable) holistic or alternative therapies. (1)
 Encuesta mas fácil (1)
 Ningno (2)
 Llamar a las personas por números y no por nombre. (Call people by numbers and not names)
 (1)
 Evaluar, educar el equipo que se relaciona con las personas y brindar atención personalizada
 (Evaluate, Educate the team that interacts with people, and provide personalized attention) (1)
 No se (1)
 Nada todo bien. (1)
 Mas informacion (1)
 Excelente services (1)
 All is well (1)

More cultural programs in Spanish having a spanish (1)
 Mas ayuda y transparencia (1)
 Ayuda con alimentos o renta. (1)
 Estoy muy agradecia con toda la ayuda (1)
 En io personal, todo esta bien, agradecido (1)
 Mejorar los horarios de las citas medicas/ horarios mas flexibles por el trabajo (1)
 Yo pienso que todo esta bien (1)
 Que responda un poco rápido a nuestras peticiones gracias (1)
 Todo esta bien (1)
 No aplica, todo esta bien (1)
 Gracias por todo (1)
 Everything is good, thankful always. (1)
 Todo esta bien, agradecida con los servicios que se nos proveen (1)
 Nia (1)
 Everything has been good (1)
 Is to have some place where we can get together and talk because loneliness can cause development of mental health problems (1)
 Better accessibility to medical care with transportation and local pharmacy pickup/delivery (1)
 No, todo esta bien (2)
 El tema de la vivienda es algo importante que en un futuro se deberia implementar (1)
 Todo esta bien, agradecida con los servicios que nos proveen. (1)
 Maintaining our health care services (1)
 Waiting times for doctor (1)
 Don't be scared. Be true to the game (1)
 More help with getting resources (1)
 Don't know (2)
 Mental health counseling in Creole speaking population. Living with HIV (1)
 Support groups. This doesn't mean CAB meetings (1)
 More available walk in private locations in Nassau - Suffolk group settings (1)
 Outreach Suffolk/Nassau (1)
 Privacy practices and confidentiality (1)
 Let everyone aware (1)
 Keep doing what you are doing! (1)
 I don't know (2)
 Housing assistance (1)
 Housing living comfortable (1)
 Pantry Assistance (1)
 Housing rent too high (1)
 Make services available to people who need it (1)
 Dentures/oral surgery (1)
 More workers (1)
 Having s voice and knowing someone is listening. Having a positive impact in this disease (1)
 Come to meetings (1)
 Having more housing for them (1)

Services for the aging population. Thank you! (1)
Everything is good (1)
Faster service, it take longer time (1)
More services (1)
Just focus on your medications (1)
Community building (1)
Keep providing HIV medications and mental health services (1)
Housing/food stamps (1)
The younger demographic getting involved (1)
Dental services (1)
EAC Program (1)
Employment (1)
Food/Utilities/Housing (1)
More understanding (1)
More awareness about HIV programs (1)
Getting all services (1)
More mental health counseling "talk therapy" (1)
After Hours Consumer Involvement (1)
Take your medicine every day, don't forget! Take care of yourself and body (1)
To have more awareness (1)
Help them (1)
More funds for social/peer/mentoring (1)
More SSD (1)
Transportation (1)
Help to pay my bills (1)
Keep moving forward (1)
Dental & Nutrition (1)
Suffolk Housing and Food Stamps (1)
More funding (1)
More information in programs, more outreach in the community (1)
More availability to services on Long Island (1)
Focus on aging community and how it effects out bodies (1)
Life insurance (1)
Getting more information out to consumers (1)
Transportation (1)
To keep up with the most recent medication for HIV and support services. (1)
I want to know what services and programs are available. (1)
Continue funding agencies that provide services to people living with HIV. (1)
Not at the moment (3)
Permanent housing help. And food stamps (1)
More for living situations (1)
More housing for low income (1)
Housing and food (1)
Improving point of access and availability of services (1)

Medication assistance (1)

More affordable housing opportunities, when I escort my members, sometimes workers at the reception area have often seem desensitized and not interested in dealing with any of the clients. I think we should all have a refresher on the impact we have while seeing/working with each other. (1)

Support groups. Combat loneliness (1)

My opinion, create more services for long term senior survivors. (1)

Helping people understand benefits they qualify for and expanding those benefits (1)

Information about services (1)

Easier to navigate the systems (1)

mentally and emotionally support services for gay males (1)

Find a cure as the elders are very frustrated with stigma & we are being forgotten as prep has the nation going crazy sexually while we are dying a slow lonely death & still being rejected because of being positive. (1)

Better dental care (1)

More help in food cards. More help in housing for undocumented More services in dental (1)

Allow services for all income levels and advertise (1)

Approach to the nearest doctor to make a test (1)

More financial help for rent and bills (1)

More participation from consumers (1)

Help dealing with mental health issues (1)

Improve Dental Services (1)

More mental health help (1)

Aging becomes an issue with affordable rent, provider not talking about aging process and possible complications (1)



Comparisons of Overall Sample And Priority Populations by Select Indicators

Comparisons of Overall Sample and Priority Populations by Select Indicators

In the EMA, HIV disproportionately affects African American and Hispanic subpopulations, particularly among men who have sex with men (MSM). These groups experience higher rates of new diagnoses, are more likely to be out of care and face significant unmet needs in terms of treatment and support. Social drivers of health such as poverty, limited access to healthcare, stigma, discrimination, and systemic racism contribute to the barriers these communities face in both prevention and care. For example, African Americans represent a smaller portion of the overall population but account for a larger percentage of new HIV cases, highlighting persistent health inequities.

Hispanic communities, particularly Latinx MSM, are similarly impacted. Language barriers, immigration status, and cultural factors further complicate access to HIV testing, treatment, and prevention services. The stigma around both HIV and sexual orientation within some Latinx and African American communities exacerbates the issue, often resulting in delayed diagnosis and care. Addressing these disparities requires targeted outreach and culturally competent healthcare interventions that focus on improving access, retention in care, and overall health outcomes for these subpopulations.

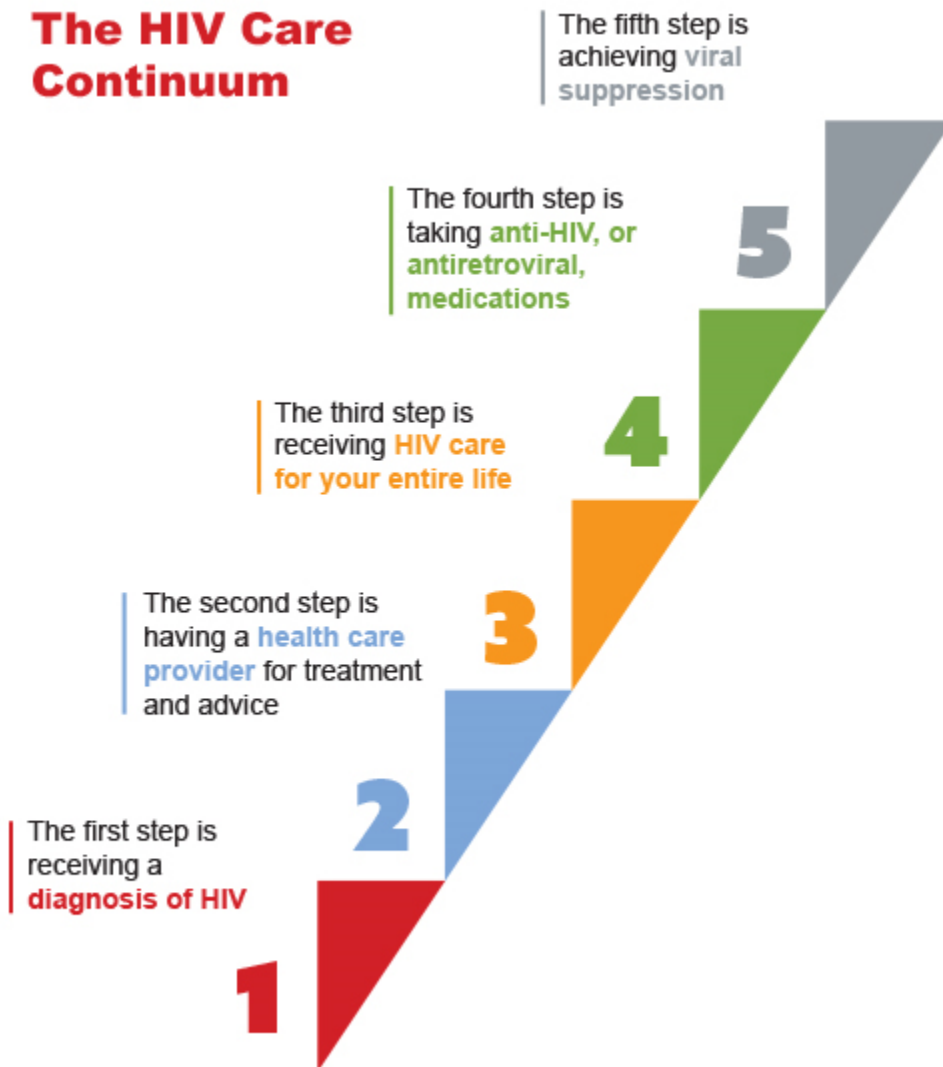
The health needs of MSM are complex, involving challenges like reducing stigma, eliminating homophobia, and addressing discrimination, alongside barriers related to cultural norms, non-disclosure, and bisexual transmission. This population is also impacted by factors such as education, income, immigration status, and limited social support, as well as substance use, homelessness, incarceration, and mental health issues. Many MSM individuals are also Black/African American or Hispanic/Latino, carrying additional needs specific to these groups. Black/African Americans face issues like racism, housing instability, extreme poverty, lack of transportation, low HIV knowledge, and unequal healthcare access and treatment. For Hispanic/Latino MSM, unique barriers include linguistic and cultural challenges, lack of translation services, health literacy issues, fear of disclosure, immigration status, work constraints on medical access, and high uninsured rates. Together, these intersecting factors create far-reaching health needs across these communities.

Table 14. Comparison of Results for Overall Sample to Priority Populations

	Overall Sample	Hispanic Respondents	African American Respondents	MSM Respondents
Total Respondents	364	143	146	84
Rate overall health as “Excellent” or “Very Good”	58%	76%	53%	69%
Concerned with where next meal would come from	31%	39%	25%	29%
Using own car to get to HIV services	46%	49%	41%	48%
Top 3 Comorbidities	1. High Cholesterol (46%) 2. High BP (43%) 3. Arthritis (35%)	1. High BP (33%) 2. High Cholesterol (27%) 3. Diabetes (21%)	1. High BP (55%) 2. High Cholesterol (48%) 3. Vision (38%)	1. High Cholesterol (42%) 2. High BP (28%) 3. Dermatology & Vision Problems (21%)
Currently taking HIV medications	98%	99%	98%	98%
Experiences HIV stigma	14%	14%	12%	25%
Top 5 Services: <i>Dental care</i>	55%	54%	55%	57%
History of homelessness	26%	18%	34%	23%
Ever exchanged sex for money, clothing or anything else	8%	4%	12%	12%
Diagnosed with a mental health issue	31%	25%	31%	42%
Ever been in jail	25%	18%	35%	14%
Aware of the Nassau Suffolk Planning Council	43%	30%	51%	40%

The Newly Diagnosed

The HIV Care Continuum



Characteristics of Newly Diagnosed Respondents

Between 2020 and 2022, new HIV diagnoses rose from 120 to 169 cases per year, averaging 145 annually, while new AIDS cases averaged 66 annually. Concurrent HIV/AIDS diagnoses—where individuals progress to AIDS within 12 months of an HIV diagnosis—signal missed opportunities for early detection. In 2022, 24.9% of new HIV cases in the EMA were concurrent diagnoses, although concurrency rates have decreased from 27.5% in 2020, reflecting progress in early HIV identification. Hispanics/Latinos had the highest percentage of new HIV cases (43.8%), followed by Blacks/African Americans (27.2%), showing a persistent disparity in new diagnoses that mirrors broader population representation. HIV cases among Hispanic individuals have increased 25% since 2013, while new AIDS diagnoses in 2022 were most common among Whites (39%), followed by Hispanics (33.8%) and Blacks (26%). Women accounted for fewer new HIV cases than men (27 vs. 142), with 70% of these cases among women of color, predominantly Black (44.4%) and Hispanic/Latino (22.7%). New HIV and AIDS cases predominantly affected males (84% and 76.6%, respectively) and were concentrated among those aged 25–39, with nearly a third of new HIV cases over age 40. MSM remain the primary group for new HIV and AIDS diagnoses, representing 58% of new HIV cases, with 72.4% of these in communities of color (50% Hispanic and 22.4% Black). Despite a 16% decline since 2013, MSM still comprise the most impacted subpopulation, underscoring ongoing disparities in HIV prevention and diagnosis access.

The data below represent select characteristics of the **20 survey respondents who reported being newly diagnosed**. A participant was considered newly diagnosed if their self-reported year of diagnosis was 2022, 2023, or 2024. Not all responses add up to 20 because of missing data.

Where do you live?

Nassau County (9)

Suffolk County (11)

What is your current zip code?

11798 (2) - Wyandanch

11704 (2) - West Babylon

11520 (2) - Freeport

11590 (1) - Westbury

11550 (1) - Hempstead

11717 (1) - Brentwood

11768 (1) - Northport

11949 (1) - Manorville

11901 (1) - Riverhead

11801 (1) - Hicksville

11554 (1) - East Meadow

11580 (1) - Valley Stream

11722 (1) - Central Islip

11803 (1) - Plainview

11950 (1) - Mastic

11746 (1) - Huntington Station

With which gender identity do you identify?

Male (16)

Female (4)

Which age group do you fall into?

18-24 (7, 35%)

25-34 (6, 30%)

35-44 (4, 20%)

45-54 (2, 10%)

55-64 (1, 5%)

Note: The age breakdown for all newly diagnosed PWH in the N-S EMA from 2022, are as follows: 13-19 (4.7%), 20-24 (13.6%), 25-29 (24.3%), 30-39 (24.9%), 40-49 (14.8%), 50-59 (13.0%), 60+ (4.7%)

Which one or more of the following would you say is your race? (Check all that apply)

Hispanic/Latino (5, 25%)

Black or African American (9, 45%)

White (3, 15%)

Multiracial (1, 7.5%)

American Indian/Alaska Native (1, 7.5%)

Note: The demographic breakdown for highest number of new cases among all newly diagnosed PWH in the N-S EMA from 2022, include: Hispanic (43.8%), Non-Hispanic Black (27.2%), Non-Hispanic White (26.0%)

What is your highest level of education?

Less than High School (6)

High school diploma or GED (10)

College degree (Associate or Bachelor's Degree) (4)

What languages do you speak? (Check all that apply)

Spanish (13)

English (7)

Italian (1)

Portuguese (1)

French (2)

Haitian Creole (5)

What is your preferred language for your medical care? (Please check one option only)

Spanish (12)

English (4)

Haitian-Creole (4)

How would you rate your overall health?

Excellent (6)
Very good (7)
Average (4)
Fair (3)

In what year were you first diagnosed with HIV?

2022 (5)
2023 (10)
2024 (5)

Which type of organization provided your HIV diagnosis?

Hospital or Emergency Room (6)
Health Center/Community Clinic (5)
Private Doctor's Office (4)
Inpatient Rehab (1)
Sun River (3)

Which of the following do you believe was the primary mode of transmission for your HIV diagnosis (Check all that apply)

Unprotected sexual intercourse with someone who has HIV (17)
I don't know (1)
Blood transfusion with contaminated blood (1)

What are the present sources of income in your household, including parents' income if you are under the age of 21? (Check all that apply)

Employment (15)
Child Support/Alimony (1)
Unemployment (5)

Please select the amount that was your total household income last month (including money from government assistance, except food stamps):

0-\$1215 (12)
\$1216-\$2430 (4)
\$2431-\$3645 (3)
\$4861 or more (1)

Please choose the situation that best describes your health insurance. (Check all that apply)

I have ADAP (AIDS Drug Assistance Program) (9)
I have insurance through my employer that I contribute to (1)
I have Medicare (5)
I have insurance through a family member (1)
I have private insurance that I pay for (1)
Fidelis Care (1)

Healthfirst (1)
I have Veteran's Benefits (1)

In the past 12 months, have you been concerned about where your next meal would come from?

No (10)
Yes (9)

Who pays for your transportation? (Check all that apply)

Circulo de la Hispanidad (7)
EOC of Suffolk (1)
Myself (13)

After you were diagnosed with HIV, how long was it before you decided to go for medical care?

Less than one month (17)
1-5 months (3)

What is the name of the organization where you get your HIV medical care?

NUMC (6)
Sun River (5)
CPH (2)
Northwell (2)
Circulo de la Hispanland (1)
N/A (1)

Have you had HIV labs done in the last six (6) months?

Yes (20)

Are you currently taking HIV medications?

Yes (20)

In the past 12 months, when seeking healthcare have you experienced any of the following types of discrimination? (Check all that apply)

Homophobia (2)
HIV stigma (2)
Racism (1)
I have not experienced different treatment (12)

Have you ever used substances above your doctor's prescribed dosing recommendations?

Yes (3)
I only take my medications as prescribed. (17)