

**NASSAU SUFFOLK TRIENNIAL NEEDS ASSESSMENT FOR
PEOPLE LIVING WITH HIV/AIDS 2014**

**United Way
of Long Island**



**SUBMITTED BY COLLABORATIVE RESEARCH
SEPTEMBER 12, 2014**

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NASSAU-SUFFOLK EMA STAFF:

Georgette Beal, Senior Vice President, HIV/AIDS Grants Management

MEMBER	ORGANIZATION
Georgette Beal	Senior Vice President, HIV/AIDS Grants Management
Debra Ross	Contract Administrator, Quality Manager
Myra Alston	Contract Administrator, Data Manager
Vicky White	Contract Administrator

NASSAU/SUFFOLK EMA PARTNERS

Maria Mezzatesta, Chairperson, Strategic Assessment Planning Committee

MEMBER	ORGANIZATION
Maria Mezzatesta	FEGS
Ellen Higgins	SCDHS (Suffolk) Suffolk County Department Of Health Services
Teresa Maestre	Hispanic Counseling Center
Elizabeth Reyes	Circulo de Hispanidad
Vicky Osk	Nassau Suffolk Law(Bi-County)
Barbara Maertens Ana Huezo	North Shore University Hospital
Katelin Thomas	SPARC
Ramon Rivas	Economic Opportunity Council (EOC)
Allison Covino	Options for Community Living
Dan Matos Cristina Witzke	Stony Brook Research Foundation (Suffolk) Pediatric Infectious Dis.
Martine Michel-Toure Hope Sender	Nassau University Medical Center (NUMC)
Michael Collins	Southampton (Suffolk) David E. Rogers
Greg Noone	Thursday's Child
Margaret (Peg) Paastch	Suffolk County Oral Health

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INTRODUCTION

This narrative explores the results of the updated Consumer Survey issued by the Planning Council in 2014. The survey was initially commissioned by the Strategic Assessment and Planning Committee of the Nassau-Suffolk HIV Health Services Planning Council in 2001 to identify the needs of people living with HIV/AIDS (PLWHA) in the Nassau-Suffolk region. The survey tool was modeled after a survey used in Louisiana, and was designed to gather comprehensive information from consumers or their caregivers. Since 2001, this survey has been conducted every other year (biennially) but this year the survey was conducted on a triennial basis due to funding issues (three years since the prior 2011 survey). The constancy of the survey assures that Ryan White priorities are responsive to the changing needs of the population in the Nassau-Suffolk eligible metropolitan area (EMA). This report includes the most up-to-date information concerning PLWHA in the Nassau-Suffolk EMA and offers a comparison between survey results from years 2007, 2009 and 2011.

Since 2007, the United Way has used a variety of new techniques to obtain consumer survey response. An 108% increase in consumer response from 2011 is attributed to a one-month extension in the length of the survey period. The consultant, Casey Hoffman, attended Ryan White sites to facilitate surveys. Many providers facilitated surveys on-site and promoted the survey to their clients through newsletters and phone contact resulting in a significant number of phone surveys and online surveys. Venues offering a variety of modes to conduct surveys achieved the greatest response rates. Surveys were available in both English and Spanish in paper format and online. The survey was anonymous regardless of the manner in which the respondent completed the survey.

The increase of the survey period from the two-month period used in 2011 to three months ranging from April 15, 2014 to July 15, 2014 boosted the total surveys collected to 500 surveys. This sample size is a 108% increase from 2011 at 462 surveys, a 179% increase from 2009 at 279 surveys and a 410% increase from 2007 at 122 surveys. A high-level overview of other findings include: Residence in prior six months versus Current Residence, Level of Need by Zip Code, Socioeconomic Characteristics, Demographic Characteristics, Transmission Mode, Risk Behaviors, Co-Morbidities, Correlation to Comprehensive Plan, Care Status and Service Need, Barriers and Gaps. The Consumer Survey was designed with input from the Strategic Assessment and Planning committee meeting held in March 2014.

Some participants left varying questions blank, so totals for individual questions presented in this narrative are sometimes less than 500.

EXECUTIVE SUMMARY

This survey was issued by the Strategic Assessment and Planning committee in 2014 in order to track the changing needs of people living with HIV/AIDS (PLWHA) in the Nassau-Suffolk Eligible Metropolitan Area (EMA). The survey was conducted through a variety of means: onsite facilitation under the direction of Collaborative Research, via the internet and by phone. The

survey was available in both English and Spanish in paper format facilitated on-site and via the internet.

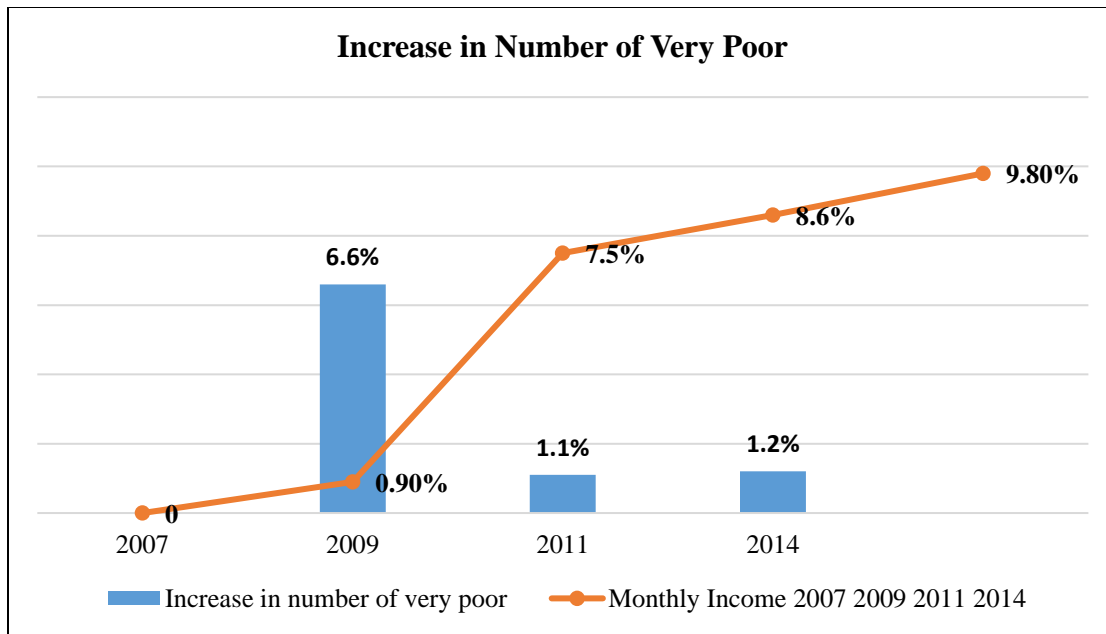
Some key findings include the impact of the implementation of the Affordable Care Act and Medicaid expansion on People Living with HIV/AIDS (PLWH/A), the continuing increase of the very poor, the need and paucity of health literacy magnified by the Affordable Care Act and Medicaid expansion, the transition of Suffolk County health care from the Suffolk County Department of Health to Hudson River HealthCare Inc., and the rise of dental care as a barrier and as a gap for periodontal and any other dental surgical need. Behavioral health issues showed promising openness from respondents to discuss mental health issues, but continued reluctance to seek treatment for substance use or even to acknowledge the need for treatment. Finally, respondents suggested that they would prefer self-directed care, with more choice on where and what services they could access. This finding is juxtaposed to the continued reduction in federal funding, limiting the choice of providers offering these services.

The Affordable Care Act enrolled approximately 10% of our survey respondents compared to 28% of the people eligible nationwide. Of these 10%; Empire Blue Shield/Blue Cross, Health First and United HealthCare enrolled 60% of the enrollees in our survey followed by Emblem Health with 17%, Affinity with 11%, Fidelis Care with 7% and North Shore Long Island Jewish with 5%. Enrollment was not concentrated with one healthcare provider.

As of December 31, 2014, 61,625 individuals were enrolled in Medicaid with single and childless adults impacted due to the increase in eligibility from 100% to 138% of the Federal Poverty Level (FPL).

The income strata of the very poor with self-reported income from 0 to \$249 monthly increased to 9.8% in 2014 from 8.6% in 2011, 7.4% in 2009 and 0.9% in 2007. This represented an increase of 6.6% from 2007 to 2009, but a 1.1% increase from 2009 to 2011 and a similar 1.2% increase in the number of very poor from 2011 to 2014. This increase places a burden on service availability and is reflected in the high ranking of subsistence services such as financial assistance, food bank vouchers/meals and home delivered meals by respondents.

Figure 1. Increase in ‘Very Poor’: Monthly Income from \$0-249, 2007-2014



The combination of new health insurance with new terminology such as co-payments, deductibles, premiums and co-insurance combined with the increase in the very poor, increases the importance of health literacy among PLWH/A. Survey respondents replied that 32% or 94 of the 293 respondents had no knowledge of basic health insurance concepts, with increased responses among those with lower incomes.

Suffolk County Department of Health Services operates eight family health centers, and is affiliated with two family health centers, strategically located throughout Suffolk County. All clinics complete transition of operations by December 31, 2014 by Hudson River HealthCare., The only remaining Suffolk County Ryan White services provided by the Suffolk County Department of Corrections will be for incarcerated PLWH/A. A total of 61 or 12.2% of all survey respondents receive care at Suffolk County Department of Health facilities.

Affected family health centers include:

- Brentwood Family Health Center
- South Brookhaven Family Health Center at Patchogue
- Riverhead Family Health Center
- Shirley Clinic
- Martin Luther King Junior Family Health Center at Wyandanch
- Maxine S. Postal Family Health Care Center at Amityville
- Dolan Family Health Center at Greenlawn
- Elsie Owens Health Center at Coram
- HRH Kraus Family Health Center at Southampton

This transition concerns many PLWH/A regarding continuity of care and about which services will continue to be covered. Coverage of dental care, currently provided by the Riverhead Family Health Center, was of great concern to both consumers and providers.

Concerns about the availability of dental care were EMA-wide with dental service reported as the highest barrier and ranked 3rd as the service needed and received, but lacking sufficient quantity. The lack of periodontics and surgical dental services was specifically mentioned by consumers.

Respondents were forthcoming about mental health issues with an average of approximately 254 or 52.9% responding that they have a mental health issue. Over half (51.4%) of respondents have been diagnosed with a mental illness, 47.7% have been referred for evaluation for a mental health issues, and 59% have felt anxious or depressed or thought that they might have a mental health issues. Respondents were not as forthcoming about substance use issues.

Survey respondents suggested that not all services are needed by all PLWHA. A “One Size Does Not Fit All”, reply, with certain target groups such as the homeless stating that their needs differ greatly from the mainstream and that more self-directed care would be more effective for their care.

HIGH-LEVEL OVERVIEW OF KEY TRENDS: 2007-2014

Need for Services, Barriers, Gaps

The following four charts indicate changes in ranked need for services that were met, barriers to needed services, gaps in access to services, and needed services that consumers did not seek. These responses are derived answers to questions 46-47. **Transportation** fell from number one among listed barriers in 2009 to number 15 in 2014, and from rank five to rank eleven as a gap from 2009 to 2014. Food bank and food vouchers ranked first as a barrier, consistent with the 2011 ranking that had raised this barrier from third in 2009. Many consumers noted the sharp decrease in SNAP¹ funding that occurred in November of 2013, with no corresponding increase in funding for food. Legal services continue to be a gap, but their priority has decreased from 2011 to 9th from 4th as a barrier and from 7th to 6th as a gap. **Subsistence services**, such as money for rent/utilities, food vouchers, and meals delivered to the home, continue to rank high as a gap in all years. The need and unavailability of dental care has increased to the highest barrier and 3rd in the services that were needed and received, but not in sufficient quantity. Noted by consumers was the unavailability of periodontics or specialty dental services (a prohibition by Ryan White Part A funding sources).

Detailed Use, Need, Barriers and Gaps are listed on pages 54 to 59

Table 1: Services that Respondents Needed & Received (2014/2011/2009)

NEED	2014	2011	2009
MEDICATIONS	1	1	9
OUTPATIENT AMBULATORY MEDICAL CARE	2	8	7
DENTAL CARE	3	3	
MEDICAL CASE MANAGEMENT	4	5	4

¹ SNAP: Supplemental Nutrition Assistance Program

CASE MANAGEMENT	5	6	3
EYE CARE	6	4	8
MENTAL HEALTH/EMOTIONAL COUNSELING	7		
TRANSPORTATION	8		
FREE CONDOMS	9	8	
SUPPORT GROUPS	10		
EMERGENCY MEDICAL CARE		9	10
HEALTH INSURANCE		2	2
INFO ON AVAILABLE SERVICES		7	5

Table 2: Services that Respondents Needed, but Needed more than what was available (2014/2011/2009)

RECEIVED, NEEDED MORE THAN AVAILABLE	2014	2011	2009
FOOD BANK/ VOUCHERS	1	1	3
EYE CARE	2		
DENTAL CARE	3		
MONEY FOR MORTGAGE OR RENT	4		
HELP FINDING HOUSING	5	4	4
MONEY FOR MEDICATIONS	6	4	4
MONEY FOR UTILITIES	7		
ASSISTANCE WITH CO-PAYMENTS	8		
LEGAL SERVICES	9	4	
CASE MANAGEMENT	10	3	2
INFO ON AVAILABLE SERVICES	13	2	4
MEDICAL CASE MANAGEMENT	14	4	4
TRANSPORTATION	15	3	1
CLIENT ADVOCACY	21	3	2
HEALTH INSURANCE		4	

Table 3: Services that Respondents Needed, but could not get (2014/2011/2009)

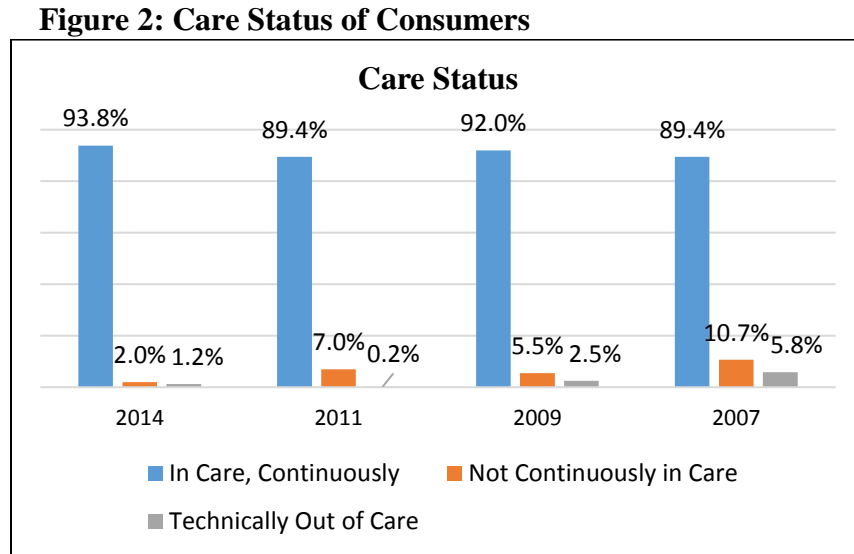
NEEDED BUT COULD NOT GET	2014	2011	2009
DENTAL CARE	1		
EYE CARE	2	1	
FOOD BACK/ VOUCHERS	3	3	4
NUTRITIONAL COUNSELING	4	4	
SUPPORT GROUPS COUNSELING	5	4	
HELP WITH FINDING AND KEEPING HOUSING	6		
MONEY FOR UTILITIES	7	2	2
MONEY FOR RENT	8	2	3
MENTAL HEALTH SERVICES/COUNSELING	9		
LEGAL SERVICES	10	7	
COMPLEMENTARY THERAPIES		1	1
NUTRITIONAL SUPPLEMENTS		2	4
MEALS DELIVERED TO MY HOME		4	

Table 4: Services that Respondents Needed, but did not seek (2014/2011/2009)

NEEDED BUT DID NOT SEEK	2014	2011	2009
MONEY FOR UTILITIES	1	3	2
MONEY FOR RENT	2	2	3
ASSISTANCE WITH COPAYMENTS	3		
MONEY FOR MEDICATION	4	9	
NUTRITIONAL SUPPLEMENTS	5	6	4
LEGAL SERVICES	6	7	
CHILD CARE SERVICES	7		
SUPPORT GROUPS	8		
HELP FINDING HOUSING	9	5	4
FOOD BANK/ VOUCHERS	10	4	4
TRANSPORTATION	11	7	5
INFO ON AVAILABLE SERVICES	14	8	6
MEALS DELIVERED TO MY HOME	15	6	4
COMPLEMENTARY THERAPIES		1	1

Care Status

There has been a general increase in the percentage of consumers in continuous care, with a 4.4% corresponding rise in consumers occurred from year 2011 to 2014.



Last Monthly Income and Income Source

Monthly income ranges of \$500-\$749 and \$750-\$999 appear in 2007, 2009, and 2011 as the mode for consumers (between 14% and 20%). Clients reporting a monthly income range of \$1,000-\$1,499 in 2014 were the most common range with a 20.4% response. Consumers who receive over \$3,000 a month decreased from 12.2% in 2007, to 2.9% in 2009, increased to 10.6% in 2011 and decreased to 6.0% in 2014. The most important shift, however, was the increase in consumers receiving from \$0-\$249 for their monthly income. In 2007, the percentage of consumers at this lower income range, in extreme poverty, was only 0.9%. In 2009 and 2011, this group increased by over 700% to 7.4% in 2009, then to 8.6% in 2011 and is currently at 9.8% in 2014. The increase in the percentage of respondents in this category corresponds with an increase in food vouchers and money for rent and utilities.

FPL: Extreme poverty—less than 50%, Below FPL—100-124%, 125-149%, 150-184% and 185-199%, Low Poverty—200-399%, Medium Income—400-499%, High Income—500% and over.

Figure 3 : Monthly Reported Income of Survey Respondents for 2007, 2009, 2011 & 2014 for Nassau Suffolk EMA

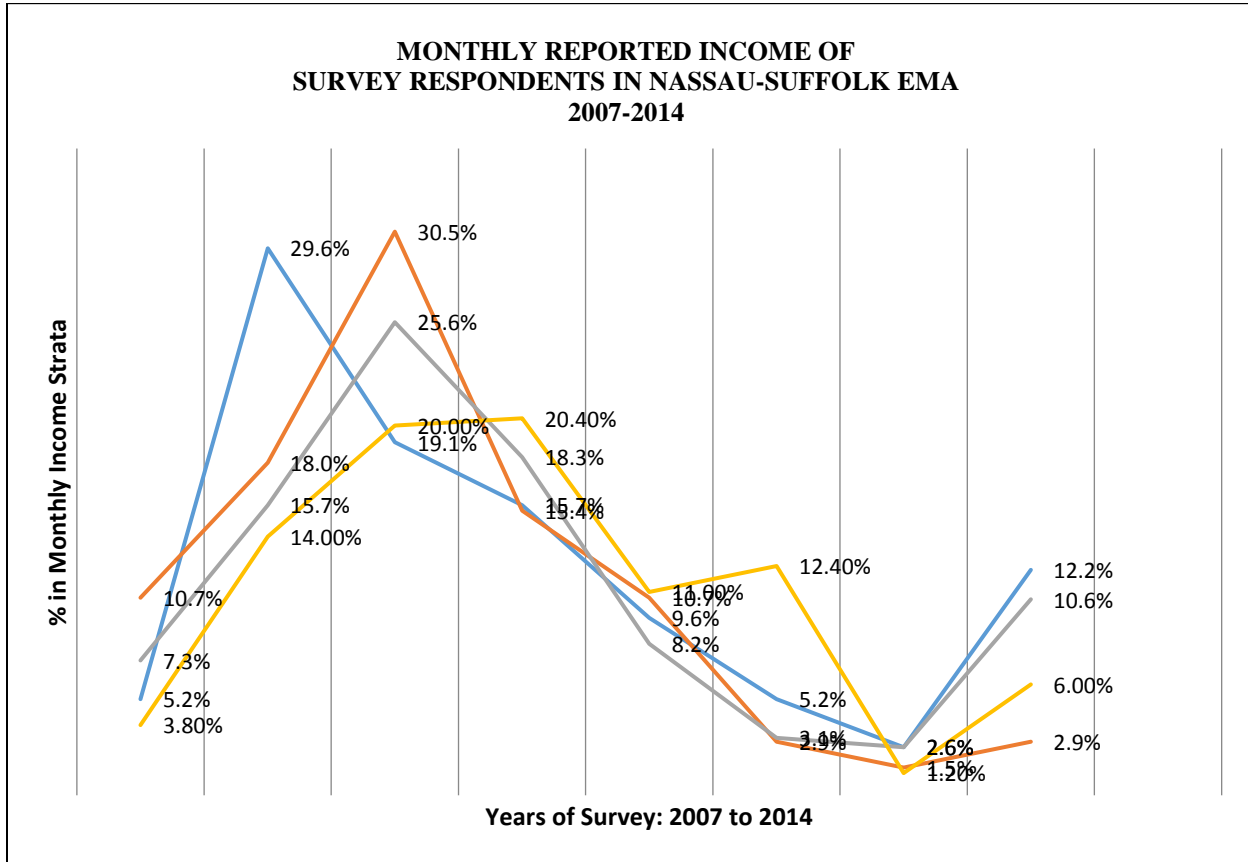


Table 5: Monthly Reported Income of Survey Respondents for 2007, 2009, 2011 & 2014 for Nassau Suffolk EMA

Monthly Income	2007	2009	2011	2014
0-249	0.90%	7.5%	8.6%	9.80%
250-499	5.2%	10.7%	7.3%	3.80%
500-749	29.6%	18.0%	15.7%	14.00%
750-999	19.1%	30.5%	25.6%	20.00%
1000-1499	15.7%	15.4%	18.3%	20.40%
1500-1999	9.6%	10.7%	8.2%	11.00%
2000-2499	5.2%	2.9%	3.1%	12.40%
2500-2999	2.6%	1.5%	2.6%	1.20%
3000+	12.2%	2.9%	10.6%	6.00%

In 2014, 34.7% of respondents worked, 8.4% were unemployed and 47.8% were disabled and cannot work. Retirees account for 2.4% of all respondents.

In 2011, 32% worked (18% full-time and 14% part-time); 19% were unemployed and 43% were disabled and can't work. Ten percent are either attending school (6%) or are retired (4%). Of the 19% unemployed, 13% are seeking work, 30% are not seeking work due to fear of losing their benefits and 56% are unable to be employed.

In 2009, 27% worked (11% full-time and 16% part-time); 17% were unemployed and 51% are disabled and can't work. Only 3% are attending school and 1% are retired.

In 2007, 30% worked (20% full-time and 10% part-time), 10% were unemployed and 53% are disabled and unable to work. The remainder (7%) were in school (6%) or retired (1%).

Figure 4: Nassau-Suffolk EMA Consumer Survey Source of Income 2007-2014

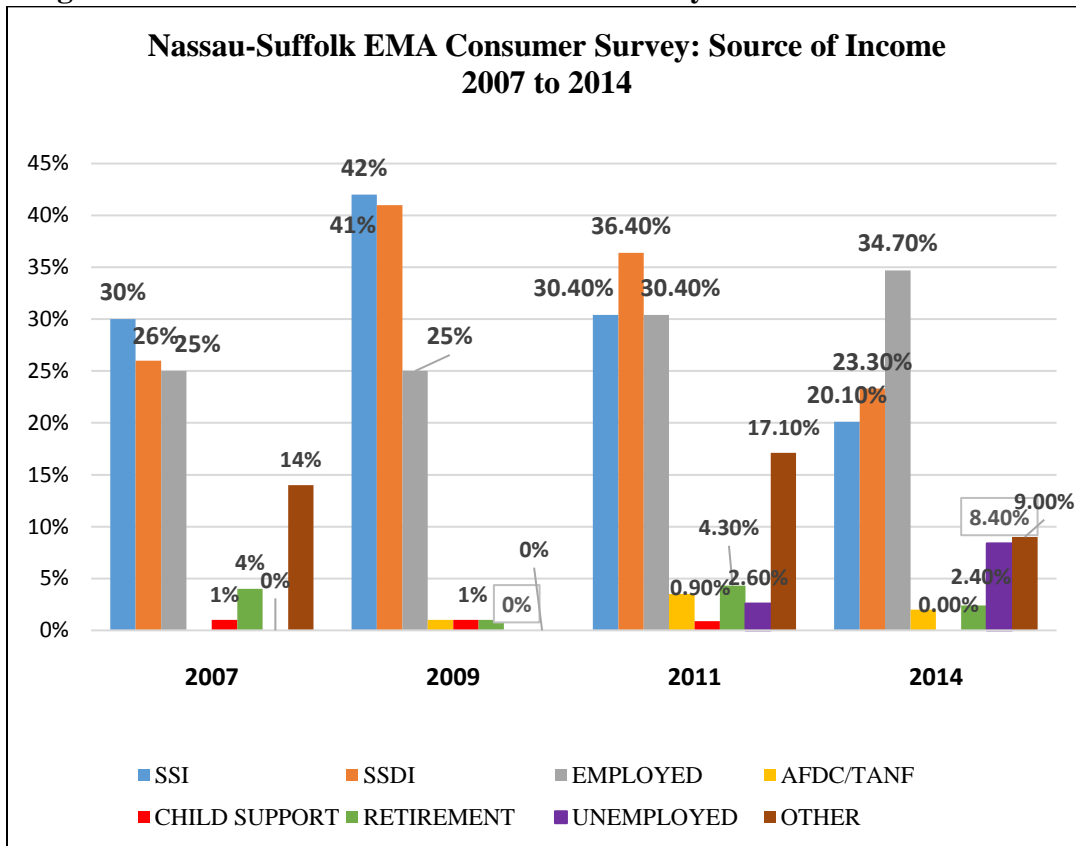


Table 6: Sources of Income by Respondent

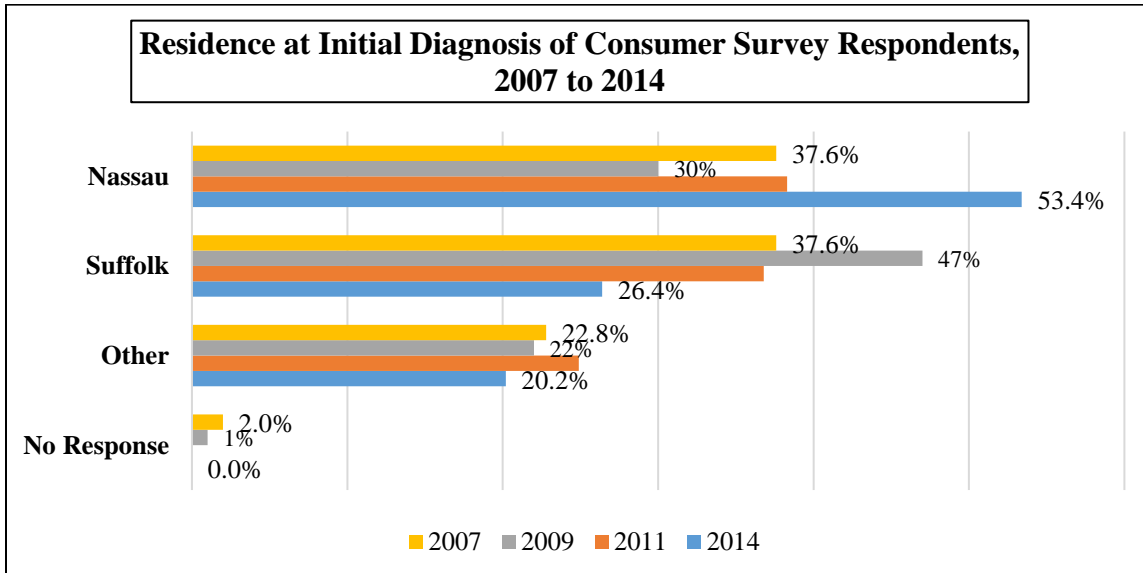
Income Source	2007	2009	2011	2014
SSI	30%	42%	30.40%	20.10%
SSDI	26%	41%	36.40%	23.30%
EMPLOYED	25%	25%	30.40%	34.70%
AFDC/TANF	0%	1%	3.50%	2.00%
CHILD SUPPORT	1%	1%	0.90%	0.00%

RETIREMENT	4%	1%	4.30%	2.40%
UNEMPLOYED	0%	0%	2.60%	8.40%
OTHER	14%	0%	17.10%	9.00%

Residence of Consumers at Diagnosis versus Current Residence

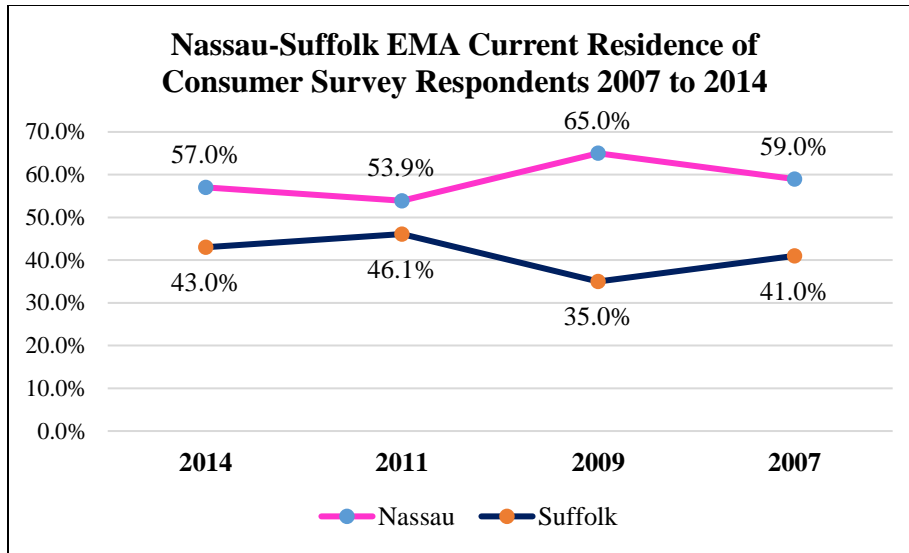
While the majority of respondents reported that they lived in either Nassau or Suffolk Counties when they were diagnosed, more respondents (53%) said they lived in Nassau County at the time of their diagnosis in 2014 versus 2011. In 2011, 38.3% of respondents reported living in Nassau County at the time of their diagnosis. All respondents answered this question in 2014 and in 2011 as compared to years earlier in which some individuals did not.

Figure 5: Residence of Respondents at Initial Diagnosis:2007 to 2014



The graph below indicates that more respondents reported living in Nassau County than (57.0%) and that respondents living in Suffolk County reduced significantly from prior years (57.0% in 2014 from 53.9% in 2011). In 2011, the number of respondents from each county was as close to 50-50 in the history of this analysis.

Figure 6: Current Residence of Respondents



Level of Need Based on Zip Code

Hempstead continues to be the area with the highest number of consumers responding to the survey over all four years. Patchogue rose from 2.9% of consumers in 2011 to 3.8% of consumers in 2014. This followed a drop from 11.8% of consumers in 2009. New towns added to the level of need table in 2014 are 11701-Amityville at 3.4%, Glen Cove at 2.8% and Baldwin at 2.6%.

A detailed response by zip code is displayed in Schedule 1 of the Appendix.

Table 7. Level of Need based on Consumer Survey Respondents in 2014

LEVEL OF NEED	COUNTY	ZIP CODE-TOWN	#	% of TOTAL
High	<i>Nassau</i>	<i>11550-Hempstead</i>	<i>84</i>	<i>16.8%</i>
High	<i>Suffolk</i>	<i>11772-Patchogue</i>	<i>19</i>	<i>3.8%</i>
High	<i>Suffolk</i>	<i>11701-Amityville</i>	<i>17</i>	<i>3.4%</i>
High	<i>Nassau</i>	<i>11520-Freeport</i>	<i>15</i>	<i>3.0%</i>
High	<i>Suffolk</i>	<i>11722-Central Islip</i>	<i>15</i>	<i>3.0%</i>
High	<i>Suffolk</i>	<i>11798-Wyandanch</i>	<i>15</i>	<i>3.0%</i>
Medium	<i>Nassau</i>	<i>11542-Glen Cove</i>	<i>14</i>	<i>2.8%</i>

<i>Medium</i>	<i>Suffolk</i>	<i>11706-Bayshore</i>	<i>14</i>	<i>2.8%</i>
<i>Moderate</i>	<i>Nassau</i>	<i>11510-Baldwin</i>	<i>13</i>	<i>2.6%</i>

Table 8 Level of Need based on Consumer Survey Respondents in 2011

LEVEL OF NEED	COUNTY	ZIP CODE-TOWN	#	% of TOTAL
<i>High</i>	<i>Nassau</i>	<i>11550- Hempstead</i>	<i>57</i>	<i>12.40%</i>
<i>High</i>	<i>Suffolk</i>	<i>11722-Central Islip</i>	<i>19</i>	<i>4%</i>
<i>High</i>	<i>Suffolk</i>	<i>11706-Bayshore</i>	<i>19</i>	<i>4%</i>
<i>High</i>	<i>Nassau</i>	<i>11520-Freeport</i>	<i>18</i>	<i>3.80%</i>
<i>High</i>	<i>Suffolk</i>	<i>11901-Riverhead</i>	<i>17</i>	<i>3.70%</i>
<i>High</i>	<i>Nassau</i>	<i>11575-Roosevelt</i>	<i>13</i>	<i>3.10%</i>
<i>Medium</i>	<i>Suffolk</i>	<i>11746-Huntington Station</i>	<i>13</i>	<i>3.10%</i>
<i>High</i>	<i>Nassau</i>	<i>11590-Westbury</i>	<i>13</i>	<i>3.10%</i>
<i>Moderate</i>	<i>Suffolk</i>	<i>11772-Patchogue</i>	<i>12</i>	<i>2.90%</i>

Table 9 Level of Need based on Consumer Survey Respondents in 2009

LEVEL OF NEED	COUNTY	ZIP CODE-TOWN	#	% of TOTAL
<i>High</i>	<i>Nassau</i>	<i>11550-Hempstead</i>	<i>36</i>	<i>12.90%</i>
<i>Moderate</i>	<i>Suffolk</i>	<i>11772-Patchogue</i>	<i>33</i>	<i>11.80%</i>
<i>High</i>	<i>Suffolk</i>	<i>11717-Brentwood</i>	<i>14</i>	<i>5.00%</i>
<i>High</i>	<i>Suffolk</i>	<i>11901-Riverhead</i>	<i>11</i>	<i>3.90%</i>
<i>High</i>	<i>Suffolk</i>	<i>11798-Wyandanch</i>	<i>10</i>	<i>3.60%</i>
<i>Moderate</i>	<i>Suffolk</i>	<i>11946-Hampton Bays</i>	<i>10</i>	<i>3.60%</i>

<i>Low</i>	<i>Suffolk</i>	<i>11752-Islip Terrace</i>	<i>10</i>	<i>3.60%</i>
<i>High</i>	<i>Nassau</i>	<i>11779-Roosevelt</i>	<i>7</i>	<i>2.50%</i>
<i>High</i>	<i>Suffolk</i>	<i>11706-Bayshore</i>	<i>6</i>	<i>2.20%</i>

Table 10 Level of Need based on Consumer Survey Respondents in 2007

LEVEL OF NEED	COUNTY	ZIP CODE-TOWN	#	% of TOTAL
<i>High</i>	<i>Nassau</i>	<i>11550-Hempstead</i>	<i>19</i>	<i>15.60%</i>
<i>Moderate</i>	<i>Suffolk</i>	<i>11772-Patchogue</i>	<i>5</i>	<i>4.10%</i>
<i>High</i>	<i>Suffolk</i>	<i>11901-Riverhead</i>	<i>4</i>	<i>3.30%</i>
<i>Low</i>	<i>Suffolk</i>	<i>11752-Islip Terrace</i>	<i>4</i>	<i>3.30%</i>
<i>High</i>	<i>Suffolk</i>	<i>11726-Copiague</i>	<i>4</i>	<i>3.30%</i>
<i>High</i>	<i>Suffolk</i>	<i>11717-Brentwood</i>	<i>3</i>	<i>2.50%</i>
<i>Moderate</i>	<i>Suffolk</i>	<i>11946- Hampton Bays</i>	<i>3</i>	<i>2.50%</i>
<i>Low</i>	<i>Nassau</i>	<i>11758- Massapequa</i>	<i>3</i>	<i>2.50%</i>
<i>High</i>	<i>Suffolk</i>	<i>11706- Bayshore</i>	<i>3</i>	<i>2.50%</i>

Housing

From 2011 to 2014, the percentage of consumers living in their own apartment dropped by 10% and those renting a room rose by 9%. A 2% decrease occurred among those living in in their parent’s home or apartment from 2009 to 2011. Rented rooms include those paid for by federal funding. In 2014, the average number of people per household was 2.65, of which 1.25 were HIV positive. In 2011, the average number of people per household was 2.59, of which 1.23 were HIV positive. In 2009, the average number of people per household remained at 2.39, of which 1.24 were HIV positive. In 2007, the majority of respondents was the only person in the household (35%) or lived with another individual (34%), with 12% living with 3 in the household. Typically, 1.0 person was HIV positive in the household.

Table 11: Housing Situation of Respondents: 2007 to 2014

HOUSING SITUATION	2007	2009	2011	2014
Own home, apt: own or rent	59.8%	67.1%	63%	53%
Parent’s Home or Apt.	4.2%	3.9%	9%	7%

Rent a Room	10.8%	15.1%	8.2%	17.2%
Someone Else's Home or Apt.	8.5%	3.9%	6.7%	9.8%
Live with Room-Mate	7.9%	0.7%	1.9%	2.2%
Live with Partner	3.3%	5.4%	1.5%	3.8%
Homeless (On Streets)	0.7%	0.7%	0.6%	0.8%
Homeless (Shelter)	0.8%	0.4%	1.1%	1.2%
Group Home, PLWHA	0.8%	1.1%	2.8%	1.4%
Group Home, Not PLWHA	1.6%	1.4%	0.6%	1.6%
Drug or Alcohol Treatment			0.0%	0.0%
Nursing Home			0.6%	0.0%
Psychiatric Treatment Center			0.0%	0.0%
Jail			0.0%	0.4%
Sober House		0.4%	1.1%	0.2%
Other	1.6%		1.9%	1.0%

Health Insurance

In 2014, 50% have Medicaid, 30% Medicare, 33% ADAP, 10% New York State Department of Health Affordable Care Act insurance, 17% employer sponsored insurance, 4% APIC, and less than 1% have no insurance.

In 2011, 51% have Medicaid, 35% Medicare, 9% ADAP, 5% employer sponsored insurance, 1% APIC and less than 1% have no insurance.

In 2009, 45% had Medicaid, 9% ADAP, 36% Medicare, 4% employer sponsored insurance, 1% APIC, 1% private and 1% other. Only 1% reported 'NO INSURANCE'.

In 2007, 38% of respondents had Medicaid, 21% ADAP, 21% Medicare, 4% employer sponsored insurance, 3% APIC, 4% private, 2% VA, 8% 'other' and only 0.5% NONE'

Issues with the Affordable Care health insurance among the 10% or 53 respondents covered include:

1. Paying for medications (7%)
2. Paying copayments for Specialist Doctor visits (4%)
3. Paying copayments for HIV Doctor visits (3%)
4. Paying copayments for Primary Care Doctor visits (1%), and
5. Other: Invoicing (1%).

The health insurers that respondents had the greatest number of problems with were Health First (3%) and United Health Care (3%).

Transmission

The leading cause of HIV transmission self-reported by consumers in the Nassau-Suffolk EMA continues to be through heterosexual sexual encounters. Heterosexual risk was reported as 38% in 2007, 49% in 2009, 45% in 2011 and 52% in 2014. The second highest cause, decreased from 2011 by 3%, was Men have Sex with Men (MSM) at 27 % in 2014. Reported transmission from injection drug use fell from 17% in 2009 to 11% in 2011 and 6% in 2014. A concerning transmission mode appears to be the reported increase in acquiring HIV by sexual assault (3% in 2014).

Self-Reported Exposure to HIV

Table 12. Self-Reported Exposure to HIV

EXPOSURE	2007	2009	2011	2014	2013 EPI
Men having Sex with Men	28%	20%	30%	27%	37%
Injection Drug Use	17%	17%	11%	6%	13%
Heterosexual	38%	49%	45%	52%	30%
Transfusion	3%	4%	6%	4%	0.5%
Perinatal	6%	3%	2%	3%	3%
Other	8%	7%	6%	8%	16.5%

Comorbidities

The data in the chart below points to an important trend- the ongoing increase in Disease Burden carried by PLWHA from 2007, 2009, 2011 to 2014. Respondents had, on average, 5.3 co-morbidities per individual in 2014, 5.1 co-morbidities per individual in 2011, 3.95 per individual in 2009, and 2.8 per individual in 2007. In regards to Hepatitis, type C significantly decreased among consumers from prior Consumer Surveys but types A and B increased. This is conjectured to be related to increases in foreign born/immigrants in Nassau-Suffolk. Lastly the rise in sexually transmitted diseases from 2014 to 2011 is concerning. Gonorrhea increase 8.8% to 22.0% in 2014 from 13.2% in 11, Syphilis 5.1% to 14.4% in 2014 from 9.3% in 2011 and chlamydia 3% to 13.0% in 2014 from 10.0% in 2011. Other comorbidities included mental issues (10.1%), asthma (2.2%), gastroenterology issues (1.0%), fibromyalgia (1.0%), and other assorted conditions (0.9%).

Table 13. Co-morbidities of Respondents 2009 to 2014

PHYSICAL CO-MORBIDITY	2014	2011	2009
High Cholesterol	42.0% (210)	38.3% (177)	30%
High Blood Pressure	29.0% (145)	32.7% (151)	30%
Gonorrhea	22.0% (110)	13.2% (61)	
Lung/Breathing Problems	20.2% (101)	25.3% (117)	14%
Hepatitis C	17.0% (85)	23.4% (108)	
Problems with Thought or Memory	16.4% (82)	20.1% (93)	11%
Diabetes	16.0% (80)	13.2% (61)	14%
Yeast Infections (Thrush)	15.6% (78)	17.3% (80)	
Heart Problems	14.8% (74)	16.2% (75)	11%
Neuropathy	14.8% (74)	21.9% (101)	24%
Syphilis	14.4% (72)	9.3% (43)	
Liver problems	13.4% (67)	13.9% (64)	26%
Chlamydia	13.0% (65)	10.0% (46)	
Hepatitis B	12.4% (62)	10.6% (49)	
Herpes (Genital)	12.0% (60)	10.6% (49)	
Cancer	10.8% (54)	8.4% (39)	5%
Hepatitis A	10.0% (50)	7.4% (34)	
Kidney Problems	9.2% (46)	12.9% (64)	7%
Human Papillomavirus	7.8% (39)	10.2% (47)	
Genital Warts	7.2% (36)	11.9% (55)	
PCP Pneumonia	6.6% (33)	21.6% (100)	15%
Tuberculosis (TB)	6.6% (33)	7.1% (33)	6%
Trichomoniasis	4.0% (20)		
Other (Specified Above)	15.2% (76)	5.6% (26)	
<i>This data was not included in prior studies.</i>			

Demographics

The following tables display racial and age compositions from 2007-2014. The number of those who provided an “other” race in this survey increased from 2009 to 2014. Under the Age

profile, it can be seen that the 20-29, the under 20 and the 50-59 age strata increased since 2011 at 8.2%, 3.1% and 1% showing the largest increase in age among the youth with HIV.

Table 14. Race/Ethnicity of respondents

RACE/ETHNIC	2007	2009	2011	2014	2013 EPI
BLACK	42%	32%	44%	38%	32.3%
WHITE	35%	34%	38%	33%	34%
HISPANIC	13%	23%	23%	31%	24.9%
MULTIRACIAL	6%	8%	5%	14%	8%
OTHER	4%	3%	11%	15%	0.8%

Commentary: The 2011 profile of Consumer Survey Respondents is closest to the 2013 Epidemiological Profile.

Table 15. Age of Respondents 2007 to 2014

AGE GROUP	2007	2009	2011	2014	2013 EPI
No Response	4%	1%	0.1%	0.8%	0.1%
Under 20	4%	0%	0.1%	3.2%	1.3%
20-29	6%	5%	5%	13.2%	8.7%
30-39	16%	13%	8%	11.2%	13.5%
40-49	43%	33%	35%	20.4%	29.1%
50-59	24%	38%	34%	35.0%	31.8%
60-69	3%	10%	15%	14.8%	14.1%
70+	0%	0%	2%	1.4%	1.4%

Transportation

This table shows the changes in means of transportation for consumers from 2007-2014. The changes in their answers over the years correspond with a decrease in transportation as a gap and barrier for consumers. The one notable addition is a Managed Care Corporation supplied ride accessed by 2.6% of survey respondents.

Table 16. Medical Transportation 2007 to 2014

TRANSPORT	2007	2009	2011	2014
Taxi	16%	6%	10%	31%

Use my own car	37%	41%	42%	28%
Take the bus	18%	7%	19%	23%
Friend gives me a ride	10%	16%	4%	8%
Managed Care Corporation supplied ride				4%
Walk	2%		4%	2.6%
Gas Card		11%	1%	1.5%
Able Ride	0%	6%	1%	1%
SCAT	9%	3%	2%	0.4%
LIRR	7%	10%	3%	0.2%
Other			2%	0.3%

Priority Services

This chart shows the change in priority services for consumers over the past 5 years. Medication and Ambulatory Outpatient Medical Care were the new top priority services for 2014 replacing health insurance as the top priority service for 2009 and 2011. Dental was ranked 3rd decreasing from its 2nd ranking in 2011.

Table 17. Priority Services: 2007 to 2014

PRIORITY SERVICE	2007	2009	2011	2014
Medications	7.0%	32.9%	32.8%	57.6%
Ambulatory Outpatient Medical Care				55.4%
Dental	30.0%	37.6%	44.5%	49.0%
Medical Case Management	27.0%	37.4%	38.5%	43.2%
Transportation	30.0%	34.4%	36.2%	32.6%
Health Insurance	0.0%	50.5%	46.7%	27.8%
Mental Health/Emotional Counseling				27.8%
Vision				24.2%
Money for Rent	21.0%	30.8%	30.6%	21.2%
Food Bank/ Vouchers	25.0%		29.7%	21.2%
Legal Services	25.0%		16.6%	11.4%
<i>Not a top 5 priority in prior studies</i>				

RECOMMENDATIONS

There are several important steps for the Nassau-Suffolk EMA given the trends and information evident in this report. A significant item in 2014 is the transition from ADAP supplied HIV medications to obtaining medications from Affordable Care Act insurers. Often these medications are delivered through mail or private shipper (UPS or FedEx) and problems with confidentiality and receipt of correct medication were mentioned by survey respondents.

The economic downturn and rising housing costs has precipitated the rise of food and other subsistence items as barriers and gaps in Long Island. This situation has eased, but the cut in food stamps (SNAP program) in November 2013 raised the need for food bank and food vouchers in the survey responses. Some kind of food efforts need to replace the severe cuts to monthly purchasing power.

The aging process, progress of the HIV disease along with issues related to HIV medications have contributed to a significant increase in problems with high cholesterol and high blood pressure among consumers. Addressing these issues takes manifold efforts in numerous arenas. Below are goals and action steps to confront the concerns discussed in this report.

Table 18: Comprehensive Plan Link to Consumer Survey

GOAL	DESCRIPTION	QUESTION IN CONSUMER SURVEY
Goal 1	<i>INCREASE THE NUMBER OF HIV-INFECTED INDIVIDUALS WHO KNOW THEIR HIVSTATUS.</i>	Q31
Objective A	Expand testing at key points of entry into health and human service systems accessed by at-risk patients.	
Goal 2	<i>INCREASE THE NUMBER OF HIV-POSITIVE INDIVIDUALS WHO ACCESS CARE</i>	
Objective A	Ensure that programs serving as key points of entry into health and human services systems provide effective linkages to core medical care and other necessary support services for people living with HIV/AIDS.	Q31-32
Objective B	Reduce barriers to timely receipt of HIV care experienced by HIV-positive individuals.	Q45-48
Goal 3	<i>INCREASE THE PROPORTION OF PEOPLE LIVING WITH HIV/AIDS WHO ARE MAINTAINED IN QUALITY HIV CARE ONCE THEY ENTER THE SERVICE SYSTEM.</i>	
Objective A	Ensure the availability of high quality core medical and other necessary support services for people living with HIV/AIDS.	Q32 & 33

Objective B	Enhance coordination of care among providers of services to people living with HIV/AIDS.	
Objective C	Implement mechanisms to identify and re-engage people living with HIV/AIDS.	Q36
Objective D	Ensure that HIV services meet or exceed quality standards set by the quality management program.	
Goal 4	<i>ENSURE THE CONTINUUM OF HIV/AIDS SERVICES IS INTEGRATED, EFFECTIVE AND COMPREHENSIVE.</i>	Q45-48
Objective A	Ensure that the HIV/AIDS service system is integrated to the fullest extent possible.	
Objective B	Address the capacity and infrastructure barriers and gaps in the system of HIV/AIDS care.	Q48
Objective C	Evaluate the cost effectiveness and outcomes, effectiveness of services, services categories and the system of HIV/AIDS care.	

Need for Services, Barriers, Gaps

ADMINISTRATION SITE

Surveys were administered at provider sites over a three month period, and online in both English and Spanish. Phone surveys were also conducted in English. Providers promoted the survey through fliers, word-of-mouth and phone reminders to their clients. A \$10 WalMart gift incentive card was presented to all survey respondents as a thank you for their time. All providers were given a target number of responses to reach based on 15% of their Ryan White RSR reported number of clients served. Five providers: SPARC (400%), Hispanic Counseling Center (285%), FEGS (89%), Suffolk County Department of Health (52%), and Options for Community Living (20%) collected responses well in excess of their goal. Three other providers: Nassau Community Medical Center (NUMC), Southampton-David E. Rogers Center and Thursday’s Child exceeded their goal by 1 survey. Five providers: Circulo de Hispanidad (63%), Nassau Suffolk Law Services (28%), Economic Opportunity Council (19%), North Shore Long Island Jewish Hospital (7%), and Stony Brook Research Foundation (5%) did not reach their goal. A total of 502 surveys were collected with 2 surveys disallowed due to zip codes of residence outside of Nassau-Suffolk counties resulting in a final tally of 500 surveys.

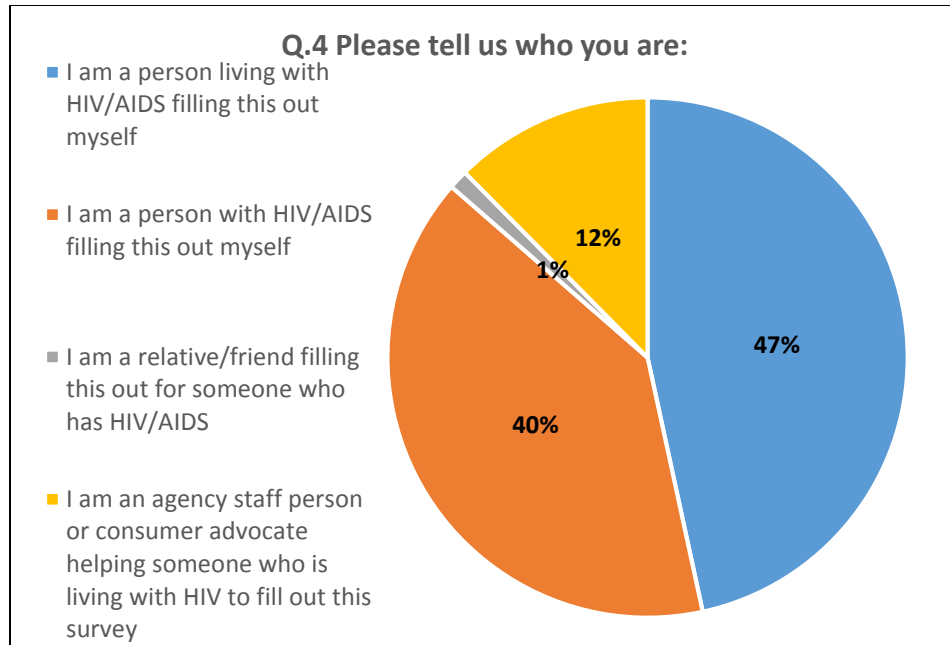
Table 19. Administration Sites

Agency	Contact Name	# HIV+ Clients	Goal @15%	Actual	Variance	Status
North Shore University Hospital	Ana Huezco/ Barbara Mertens	642	96	89	7	Completed

Agency	Contact Name	# HIV+ Clients	Goal @15%	Actual	Variance	Status
Nassau University Medical Center (NUMC)	Martine Michel-Toure / Hope Sender	464	70	71	1	Completed & Above Goal
FEGS (Suffolk)	Maria Mezzatesta	247	37	70	33	Completed & Above Goal
SCDHS (Suffolk) Suffolk County Department Of Health Services	Ellen Higgins	264	40	61	21	Completed & Above Goal
Stony Brook Research Foundation (Suffolk)	Dan Matos, Crissy Witzke, Michelle Shirokawa	389	58	55	3	Completed
Nassau Suffolk Law (Bi-County)	Vicky Osk	314	47	34	13	Completed
Hispanic Counseling Center	Teresa Maestre	45	7	27	20	Completed & Above Goal
Economic Opportunity Council	Ramon Rivas / Jennifer Jusu	205	31	25	6	Completed
Options for Community Living	Allison Covino/ Denise Rivera	133	20	24	4	Completed & Above Goal
Southampton (Suffolk) David E. Rogers	Michael Collins	152	23	24	1	Completed & Above Goal
Circulo de Hispanidad	Elizabeth Reyes	201	30	11	19	Completed
SPARC	Katelin Thomas	10	2	10	8	Completed & Above Goal
Thursday's Child	Greg Noone		0	1	1	Completed
Total		3,066	462	502	40	

RESPONDENTS

Figure 7. Identification of Person Completing Survey



DEMOGRAPHICS

Survey respondent’s demographic information collected included gender, age, ethnicity, race, transmission mode and sexual orientation. When applicable, the actual values are compared to the epidemiological profile and a variance is calculated.

Q. 8. What is your gender?

Table 20. Respondent by Gender

Gender ^a	Actual		Sample Size	Variance
	Responses	Percent	Percent	Percent
Female	235	47%	32%	15%
Male	252	50%	68%	-18%
Transgender-Female to Male	2	0.1%	0%	-1%
Transgender-Male to Female	11	2%	0%	-2%
Total	500	100%	100%	0%

^a New York State epidemiology lists gender at birth therefore no data is available for transgender respondents.

Our survey garnered more female respondents proportionately than are in the Nassau Suffolk HIV/AIDS population.

Q. 15. What is your date of birth?

Table 21. Respondents by Age

Age Strata	Actual		Sample Size	Variance
	Response	Percent	Percent	Percent
12 & under	1	0.2%	0.2%	0.0%
13-19	15	3.0%	1.1%	1.9%
20-24	21	4.2%	3.4%	0.8%
25-29	45	9.0%	5.3%	3.7%
30-39	56	11.2%	13.5%	-2.3%
40-49	102	20.4%	29.1%	-8.7%
50-59	175	35.0%	31.8%	3.2%
60+	81	16.2%	15.5%	0.7%
Unknown	4	0.8%	0.1%	0.7%
Total	500	100.0%	100.0%	0.0%

Survey respondents reported at a variance greater than 1% included age strata at a higher proportionate rate for the 13 to 19, the 25 to 29, and the 50 to 59 age groups. Reporting at a lower rate proportionately were the following age strata: 30 to 39, and 40 to 49 age groups.

Q. 10. Would you describe yourself as Latino/Latina/Hispanic?

Table 22. Respondent by Ethnicity

Ethnicity	Actual		Sample Size	Variance
	Responses	Percent	Percent	Percent
Hispanic/Latino (a)	154	31%	24.6%	6.4%
Not Hispanic or Latino	346	69%	75.4%	-6.4%
Total	500	100%	100%	0%

Q. 11. With reference to race, how would you describe yourself? (The responses did not include Hispanic/Latino).

Table 23. Respondent by Race

Race	Actual		Sample Size	Variance
	Responses	Percent	Percent	Percent
Black/African American	191	38%	34.0%	4.0%
White/Caucasian	165	33%	32.5%	0.5%
<i>Hispanic</i>	<i>154</i>	<i>31%</i>	<i>24.6%</i>	<i>6.4%</i>
Asian/Pacific Islander	3	1%	0.9%	0.1%
Native American	1	0.0%	0.0%	-
More than One Race	72	14%	8.0%	6.0%
Other	68	14%	0.1%	13.9%

A further drill down of Other or More than one race revealed these racial origins:

Drill-Down of Other and More than one race

Table 24. Respondent Drill-Down of “More than One Race”

More than one race: (72)	Other (68):
Dominican and White: 47	Central American: 40
Haitian and Black: 18	African (from Africa) 23
El Salvadoran and White: 4	Eastern European: 4
Honduran and Black: 3	German: 1

Transmission Mode

Q. 15. How do you believe you were infected with HIV?

Table 25. Respondent by Transmission Mode

Transmission Mode	Actual		Sample Size	Variance
	Responses	Percent	Percent	Percent
Heterosexual	260	52%	30.1%	21.9%
Men having sex with men	134	27%	36.4%	-9.6%
Injection drug use	29	6%	13.2%	-7.4%
Transfusion/blood products	21	4%	0.5%	3.7%
At Birth	17	3%	3.0%	0.4%
Sexual assault	15	3%		3.0%
MSM and IDU	14	3%	3.4%	-0.6%
Needle stick by accident	3	1%		0.6%
Unknown	7	1%	13.4%	-12.0%
Total	500	100.0%	100.0%	0%

The disproportionate number of respondents reporting Heterosexual as the way they were infected is consistent with the disproportionate number of female respondents (15% more than the epidemiology would suggest).

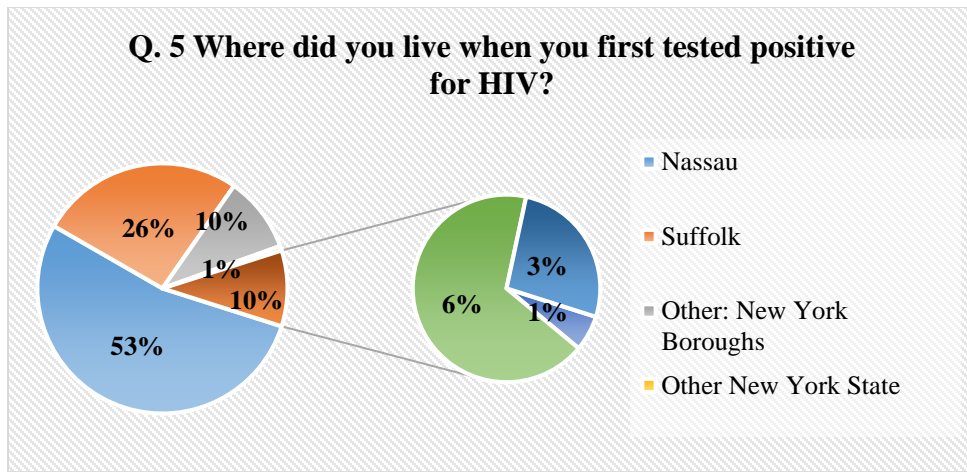
Q. 9. Do you sexual relationships with:

Table 26. Respondent by Sexual Orientation

Sexual Orientation	Number	Percent
Heterosexual	266	53%
Males Having Sex with Male	165	33%
Bisexual	23	5%
Lesbian	2	0%
Never had sex	18	4%
Prefer not to Answer	26	5%
Total	500	100%

HIV Relevant Factors

Figure 8. Residence at Initial HIV Diagnosis



Q. 5 Where did you live when you first tested HIV positive?

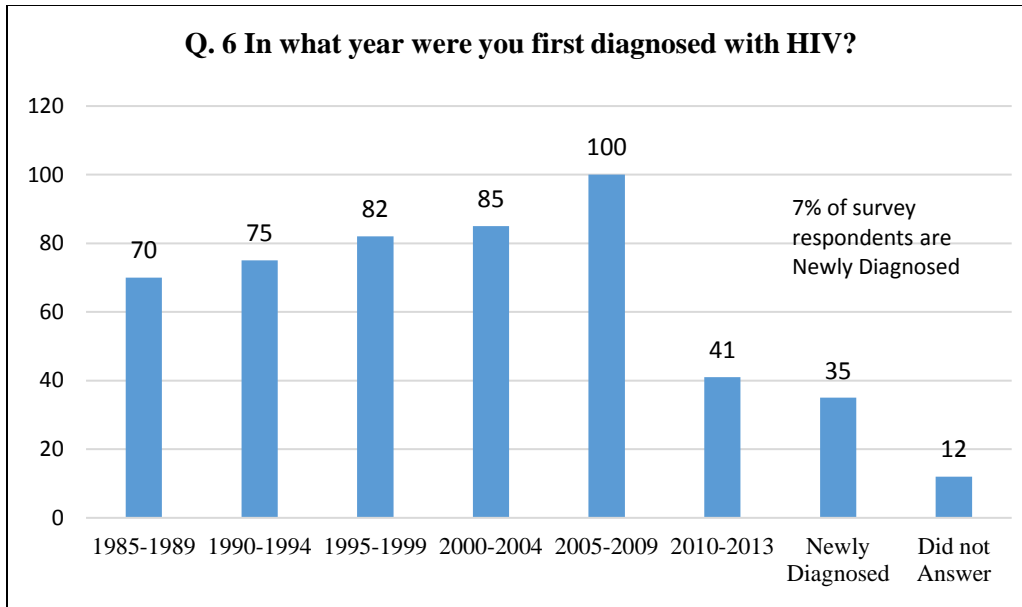
Table 27. Respondent Residence at Initial HIV Diagnosis

Residence When Tested HIV+	Frequency	Percentage
Nassau	267	53%
Suffolk	132	26%
Other: New York Boroughs	49	10%
Other New York State	3	1%
Other: NY Jails/Prison	3	1%
Other States	33	7%
Other: Not in United States	13	3%
Total	500	100%

Table 28. Drill-Down of Not in United States Residence

Other: Not In United States	Frequency	Percentage
Caribbean	7	54%
El Salvador	1	8%
Honduras	4	31%
Dominican Republic	1	8%
Total	13	100%

Figure 9. Year First Diagnosed with HIV



NEWLY DIAGNOSED PROFILE

The 35 respondents that are newly diagnosed entered care in 2013 and 2014.

Their profile regarding age and race is:

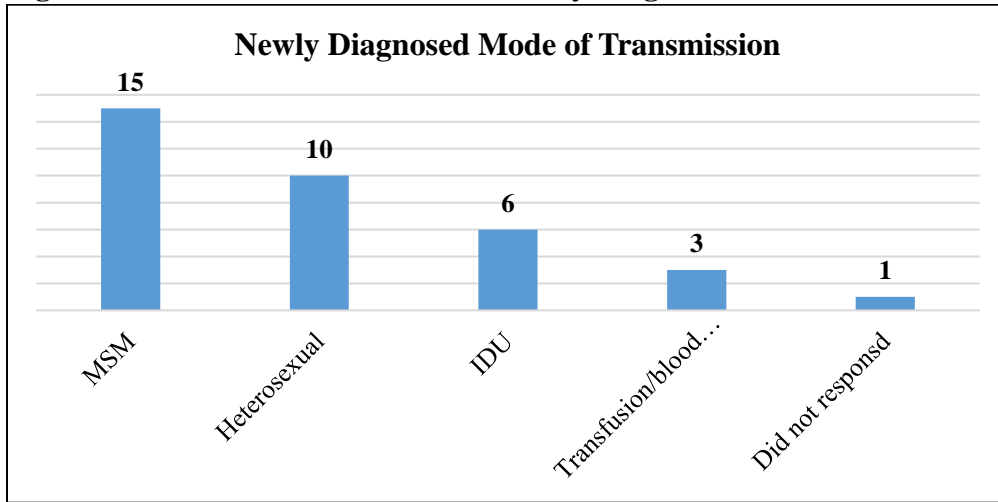
Table 29. Age and Race of Newly Diagnosed Respondents

Age Range	Black/	Other	White	Total	
16-18		1	1	2	Puerto Rican
20-24	4		1	5	
25-29	10		1	11	
30-34			1	1	
35-39	1		2	3	
40-44					
45-49		1		1	White and Honduran
50-54			1	1	
55-59			3	3	
60-64	2	5	1	8	Salvadoran (3), Dominican (2)
Total	17	7	11	35	

Additionally 19 of the newly diagnosed speak English, 13 speak Spanish and 3 are bilingual. Of the 35 newly diagnosed respondents, 28 tested HIV positive in 2014 and 7 in 2014.

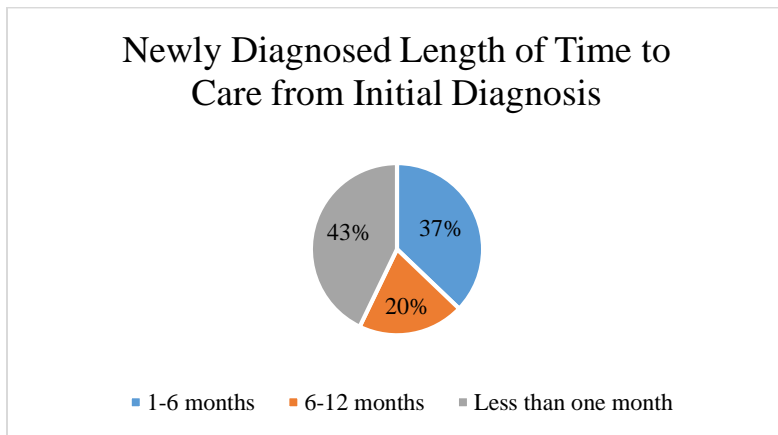
MSM's composed 43% or 15 of the newly diagnosed, Heterosexuals made up 28% or 10 of this group, Injection Drug Users totaled 17% or 6, Transfusion/blood products totaled 8% and 1 respondent did not list their mode of transmission.

Figure 10. Mode of Transmission of Newly Diagnosed



Q 32. After you were diagnosed with HIV, how long was it before you decided to go for medical care?

Figure 11. Length of Time to Care for Newly Diagnosed Respondents



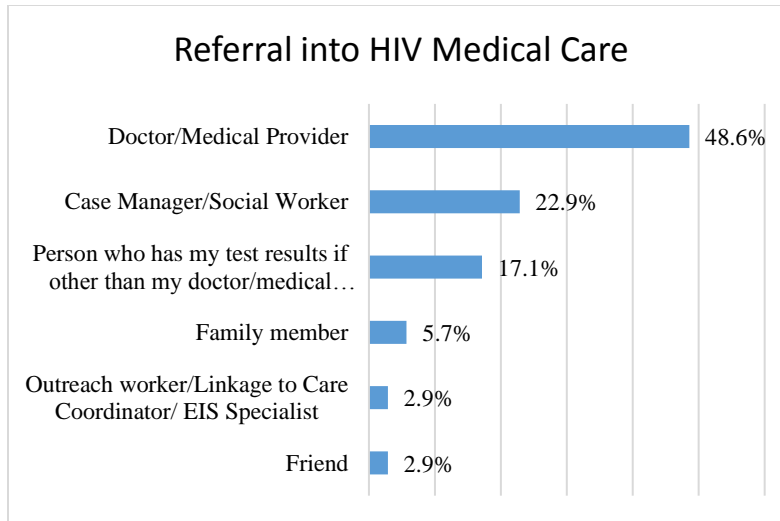
The concern is that 20% of the 35 newly diagnosed or 7 respondents took six to 12 months to enter medical care for their HIV. Of these 7 newly diagnosed late to care respondents, 5 were age 20 to 29, and 2 were age 50 to 59.

A doctor or medical provider was the top referral source (for 48.6% or 17 of the 35 newly diagnosed).

Most (85% or 6 of the 7) cited lack of transportation as the reason for not seeking medical care sooner.

Q. 33 Who first helped you get into medical care after you found out you were HIV positive?

Figure 12. Referral into HIV Medical Care for Newly Diagnosed Respondents



LANGUAGE

Q. 12. What languages do you speak?

Figure 13. Respondent by Languages Spoken

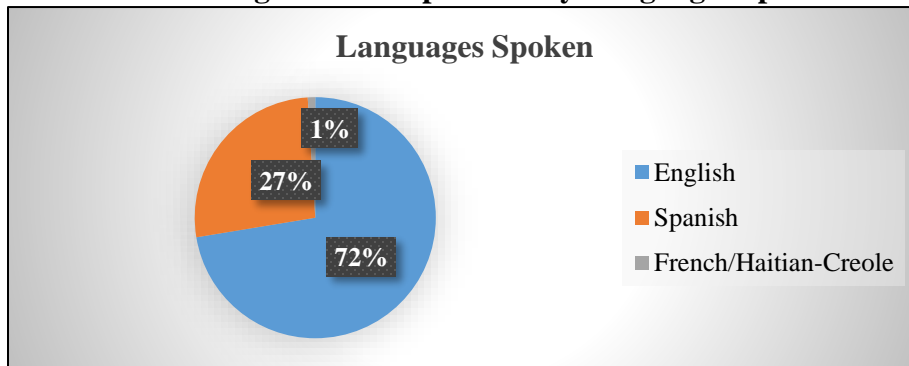


Table 30. Respondent by Languages Spoken

English	72%
Spanish	27%
French/Haitian-Creole	1%
Multi-Lingual*	10%
German	Less than 1%

*most common bilingual combination is English-Spanish fluency at 8% or 41 respondents

HIGHEST LEVEL OF EDUCATION

Q. 17. What is your highest level of education?

Table 31. Highest Level of Education Attained

Highest Level of Education Attained:	Number	Percent
Did not go to school	6	1%
Grade School	82	16%

Some high school	88	18%
High school diploma/GED	134	27%
Some college	92	19%
Technical degree	24	5%
College degree	48	10%
Some graduate school	13	3%
Graduate school degree	12	2%
Total	500	100%

Respondents completing high school or higher education composed two-thirds (66%) of respondents, but 6 or 1.2% of respondents responded that they had no schooling. These Spanish speaking respondents noted that they had no education, not even any grade school.

- (4 /27)=15% of respondents at Hispanic Counseling Center
- (2 /11)=18 % of respondents at Circulo de la Hispanidad

These relatively large numbers of completely uneducated respondents place a greater burden on these two providers to complete paperwork, to convey information about HIV services and to achieve health literacy about HIV/AIDS.

INCOME, HOUSING AND FEDERAL POVERTY LEVEL

Q. 18. Are you now or have you ever been homeless?

Table 32. Homeless Status

Homeless Status	Number	Percent
Never	361	72%
Currently homeless	21	4%
Been homeless in past 2 years, but not now	32	7%
Been homeless over 2 years ago, but not now	86	17%

Respondents stating that they have never been homeless totaled 361 or 72%. Respondents that have been homeless totaled 28%, with 4% currently homeless, 7% homeless in the past two years but not now, and 17% that had been homeless over two years ago, but not currently.

Q. 19 & 20 Please check the most appropriate box in each column to tell us about your current and previous housing situation.

Living Situation

Table 33. Current and Previous Housing Situation

Accommodation	Currently	Previously – 6 months ago	Variance

Own house or live in an apartment or mobile home (rent or own)	53.40%	53.60%	-0.20%
Parent’s house, apartment or mobile home	7.00%	7.80%	-0.80%
Rent a room	17.20%	16.00%	1.20%
Someone else’s house apartment or mobile home	9.80%	11.40%	-1.60%
With a roommate	2.20%	2.80%	-0.60%
With a partner or significant other	3.80%	3.60%	0.20%
Homeless on streets	0.80%	0.40%	0.40%
In a shelter for emergency housing	1.20%	0.60%	0.60%
In a group home specifically for people with AIDS	1.40%	1.40%	0.00%
In a group home, not specifically for people with AIDS	1.60%	0.80%	0.80%
In a drug or alcohol treatment center	0.00%	0.20%	-0.20%
In a nursing home	0.00%	0.20%	-0.20%
In a psychiatric treatment center	0.00%	0.00%	0.00%
In a jail	0.40%	0.40%	0.00%
In a sober house	0.20%	0.20%	0.00%
Other	1.00%	0.60%	0.40%

Respondents reported low mobility between their current living situation and their previous living situation with Living In Someone Else’s House Or Apartment showing the largest decrease at (1.6%) or 8, and Renting a Room showing the largest increase at 1.2% at 6.

Other

Table 34. Other Housing Options

Accommodation	Currently	Previously – 6 months ago	Variance
Motel	0.4%		0.4%
Supported housing	0.6%	0.6%	-

Q. 14. Have you ever exchanged sex for drugs, money, food, shelter or clothing?

Table 35. Ever Exchange Sex for Other Commodities

Response	All	Male	Female	TG-Female to Male	TG-Male to Female
Yes	10%	12%	8%		91%
No	88%	86%	89%	100%	9%
Did not answer	2%	2%	3%		

The number of “Yes” responses totaled 51, with a clear correlation between Injection Drug Use history and exchanging sex for some other commodity with 15 or 29% of those replying Yes to this question having an Injection Drug Use history.

Q. 21. If you presently have a place to live please list the total number of persons, and the total number of HIV infected persons living in your household.

Table 36. Number in Household & Number in Household that are HIV infected

Number	Total # of People in Household	Total # of HIV infected People in Household
1	36%	79%
2	23%	17%
3	13%	1%
4	10%	
5	5%	
6	7%	
7	2%	1%
Group Home	4%	2%

EMPLOYMENT

Q. 16. Employment

Figure 14. Respondent by Current Employment Status

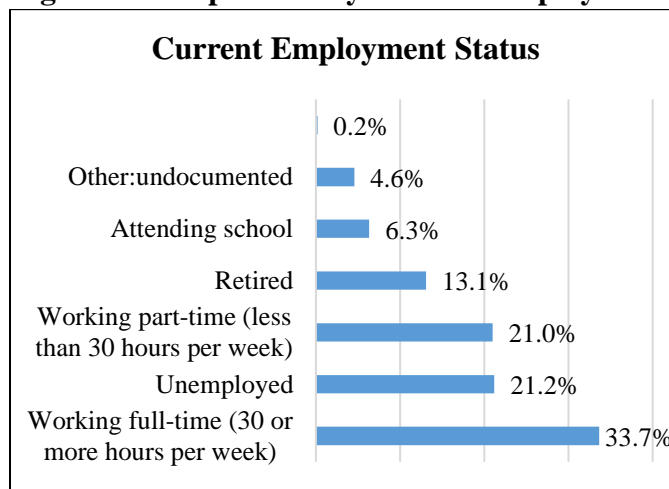


Table 37. Present Sources of Income in Household

Source of Income	#	%
Employment	173	34.6%
SSDI (Social Security Disability Insurance)	116	23.2%
SSI (Supplemental Security Income)	100	20.0%
Unemployment	42	8.4%
Retirement Income	12	2.4%

AFDC / TANF	11	2.2%
Child Support / Alimony	0	0.0%
Other: Family Support	20	4.0%
Other: Department of Social Services (DSS)	11	2.2%
Other: Spouse / Partner Income	6	1.2%
Other: Odd Jobs	4	0.8%
Did not answer	2	0.4%
Other: Private Disability	1	0.2%
Other: Workmen's Compensation	1	0.2%
None	1	0.2%
Total	500	100.0%

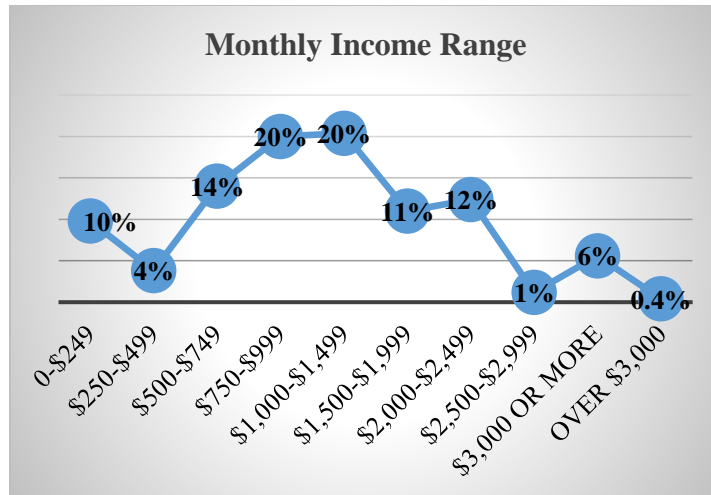
More than one-third (35.5%) of respondents reported **employment** as their source of income, but those survey respondents with **federal or state support income** totaled 56%. Respondents relying on **family or spouse/partner support** totaled 5.2%. These three sources of income composed 96.7% of the total with retirement income, private disability, workmen’s compensation, no support and no response making up the residual 3.3% of income sources.

Q. 23. Please check the box of the amount that was your total household income last month.

Table 38. Respondent by Income Strata

Monthly Income	Count per level of income	Percent
0-\$249	49	10%
\$250-\$499	19	4%
\$500-\$749	70	14%
\$750-\$999	100	20%
\$1,000-\$1,499	102	20%
\$1,500-\$1,999	55	11%
\$2,000-\$2,499	62	12%
\$2,500-\$2,999	6	1%
\$3,000 or more	28	6%
Over \$3,000	2	0%
No response	7	1%
Total	500	100%

Figure 15. Respondent’s Last month income



Percentage of Respondents under the Federal Poverty Level²-77.6% of respondents fall under the 2014 Federal Poverty Level as shown below:

Table 39. Respondents by Federal Poverty Level

Number in Household	Threshold	Number	Count per level of income
1	\$1,800	156	31%
2	2,426	130	26%
3	3,051	75	15%
4	3,677	51	10%
5	4,303	27	5%
6	4,929	37	7%
7	5,555	11	2%
8	6,181	2	Less than 1%
For each Additional Member add	626	11	2%
Total		500	100%

² 2014-2015 Federal Income Guidelines (Effective through June 30, 2015) New York State Department of Health: http://www.health.ny.gov/prevention/nutrition/wic/income_guidelines.htm.

HEALTH INSURANCE

Health Insurance Status:

Q. 24. Please choose the situation that best describes your health insurance. Check all that apply. (Totals to more than 100%)

Table 40. Respondent's Health Insurance

Health Insurance Status	% of responses
Medicaid	50%
ADAP	33%
Medicare	30%
Insurance through employer I contribute to	11%
Insurance through Health Insurance Exchange: NYS Department of Health	10%
Insurance paid by employer	6%
APIC	4%
Veteran's Benefits	1%
Private insurance paid by respondent	1%
Insurance through family member	1%
Private or Supplemental Medicare paid by State Health Insurance Continuation Program	1%
Other-through Union	1%
None	0%
AHIP	0%
Insurance through Medicaid expansion	0%

Details of New York's Health Insurance Exchange³

In 2014, the Affordable Care Act's insurance exchanges signed up 28 percent of the people eligible to use them — mainly people who don't get health benefits from their jobs or from a government program like Medicare or Medicaid — according to an analysis by the Henry J. Kaiser Family Foundation. And there was a lot of variation among the states....Using data from the Census Bureau and the Department of Health and Human Services, the Kaiser Family Foundation estimates 28.6 million U.S. residents are eligible to buy health insurance via an exchange, compared to the 8 million who did. *Results from our survey show 51 respondents or 10% signed up for coverage through the New York State Health Insurance Exchange.*

New York's Health Insurance exchange acts as an active purchaser, meaning the state selectively contracts with plans, rather than allowing any qualified insurer to participate. Ten of these companies offered coverage to New Yorkers purchasing their own insurance before the

³ Cox, Cynthia, Ma, Claxton, Gary and Levitt, Larry. "Sizing Up Exchange Market Competition" Mar 17, 2014
Accessed online at: <http://kff.org/report-section/sizing-up-exchange-market-competition-conclusion-8562/>

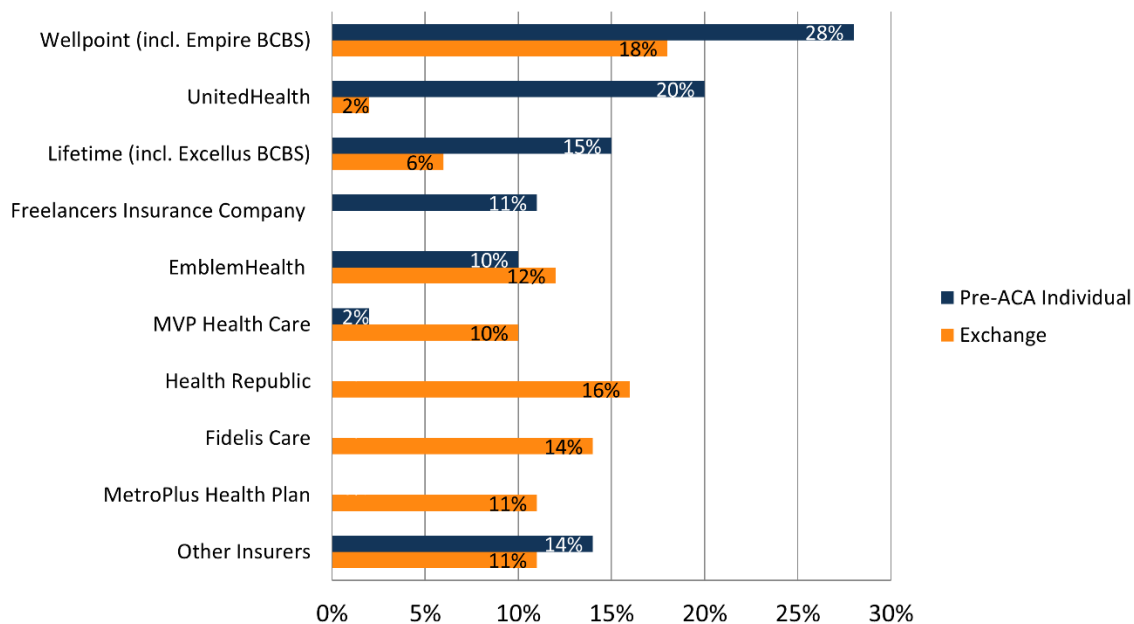
ACA. All together these ten companies enrolled 81% of the individual market in 2012, and now make up just over 54% of exchange enrollment. New York’s exchange introduced six new insurers to the individual market that combined hold 45% of the exchange market. The largest new entrant to New York’s market is Health Republic, a CO-OP plan that originally received sponsorship from Freelancers Union but is now licensed as an independent company. Other sizable new entrants are Fidelis Care and MetroPlus Health Plan, both of which served Medicaid beneficiaries before the ACA.

While New York’s largest individual market insurer, Wellpoint Inc. (which includes Empire Blue Cross Blue Shield), controlled 28% of the 2012 individual market, it now holds only 18% of the exchange market. Several smaller insurers have picked up market share. MVP Health Care, for example, held a mere 2% of the individual market in 2012, but now has about 10% of the exchange market.

UnitedHealth previously held a substantial portion (20%) of the 2012 individual market. Currently the insurer represents only 2% of the exchange market, perhaps because it priced relatively high compared to its competitors.

Figure 16.

Market Share of Insurers in New York’s Individual Market (2012) and Exchange (as of Dec. 30, 2013)

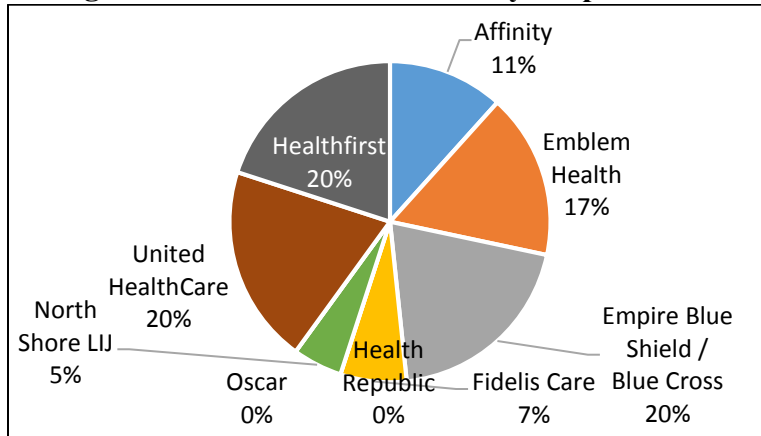


Source: Kaiser Family Foundation analysis of enrollment data released by NY State of Health, and Public Use File of Submissions of 2012 Medical Loss Ratio Annual Reporting Data available from the Center for Consumer Information & Insurance Oversight (CCIIO)



Q. 25. If you are insured under the Health Insurance Exchange, which insurer did you choose?

Figure 17. Affordable Care Act by Respondent’s Insurer



Empire Blue Shield/Blue Cross, HealthFirst and United HealthCare enrolled 60% of the enrollees in our survey followed by Emblem Health with 17%, Affinity with 11% , Fidelis Care with 7% and North Shore Long Island Jewish with 5%. Enrollment was not concentrated with one healthcare provider which bodes well for the future of the region’s health insurance.

Medicaid Expansion

As of December 31, 2014, 61,625 individuals enrolled in Medicaid through the New York State Department of Health. New York has expanded Medicaid eligibility levels to 138% of the Federal Poverty Level (FPL) for all eligible New Yorkers. This expansion affected single and childless adults whose eligibility had previously been at 100% of FPL. The new expansion population represents 20% of new Medicaid enrollees though the Marketplace.⁴

Challenges while enrolling in Medicaid or Health Insurance Exchange in past year

None-36% of respondents

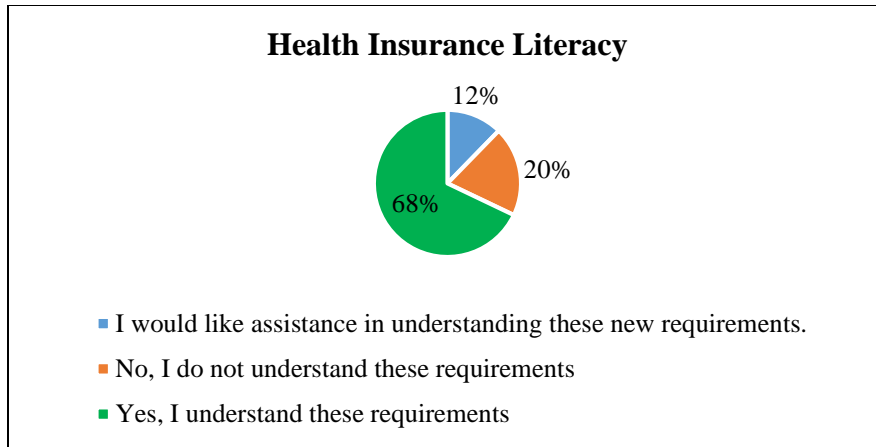
Not Applicable -64% of respondents

HEALTH INSURANCE LITERACY

Q. 27 If you enrolled in Medicaid or a Health Insurance Marketplace plan, do you understand the requirements of your new health insurance, such as premium, copays, deductibles, co-insurance?

Figure 18. Health Insurance Literacy

⁴ New York State Enrollment Report as of December 31, 2014 published January 13, 2014 and accessed online at: http://www.healthbenefitexchange.ny.gov/sites/default/files/December%202013%20Enrollment%20Report_Jan%2013%202014.pdf

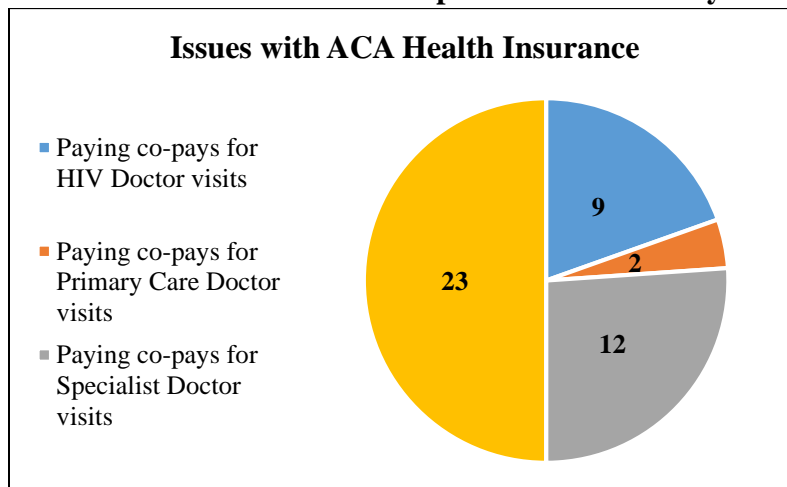


The 32% or 94 of the 293 respondents answering no or with a request for assistance about health insurance literacy are not alone in their not understanding basic health insurance concepts, and those with lower incomes were found less likely to understand health insurance.

A study of people eligible to enroll in the marketplaces showed that many were not confident in their understanding of a premium (36%), deductible (31%), copayment (28%), coinsurance (48%), maximum annual out-of-pocket spending (38%), provider network (36%), covered services (35%), annual limits on services (39%) or excluded services (40%).⁵

Q. 28 Have you had any problems with Health Insurance Marketplace or Medicaid covering any of the following services?

Figure 19. Issues with Health Insurance Marketplace or Medicaid by Service



⁵ . Blumberg, Linda J, Long, Sharon K., Kenney, Genevieve M, and Goin, Dana. “Public Understanding of Basic Health Insurance Concepts on the Eve of Health Reform.” Urban Health Institute, December, 2013. Accessed online at: http://hrms.urban.org/briefs/hrms_literacy.html.

A total of 53 or 16% of respondents reported issues with their ACA health insurance coverage. The corollary is that 284 of 84% of those responding (334) to this question reported no problems.

Problems reported and the insurer(s) with the highest incidence reported include:

Table 41. Issues with New York Health Insurance Exchange Insurers

Insurer		HealthFirst	UHC	Empire BS/BC	Emblem Health
<i>Percentage of Respondents insured with:</i>		20%	20%	20%	17%
Issue with Insurer:	%				
Paying for Medications	7%	19%	4%	20%	19%
Paying co-pays for Specialist Doctor visits	4%	3%		6%	22%
Paying co-pays for HIV Doctor visits	3%		26%	6%	
Paying co-pays for Primary Care Doctor visits	1%		4%		
Other: invoicing	1%	1%			
Total	16%	3%	3%	1%	2%

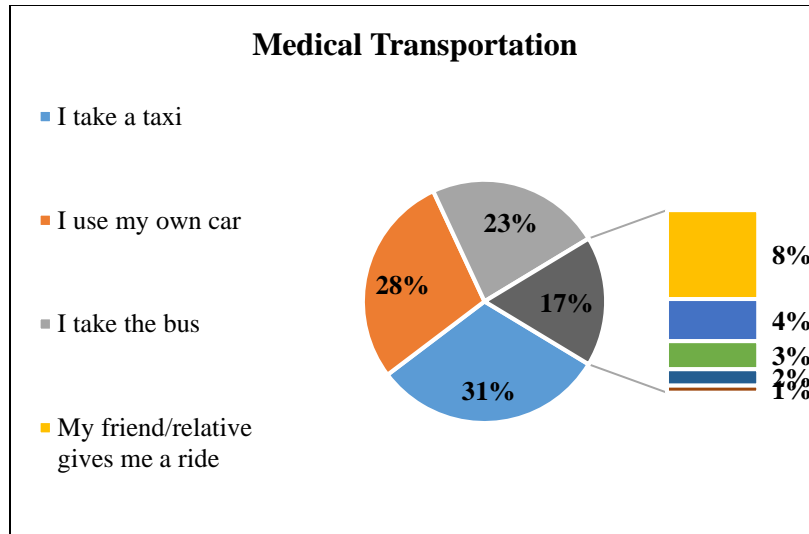
Empire Blue Shield/Blue Cross, HealthFirst and United Health Care each enrolled 20% of survey respondents, but their outcomes as reported by survey respondents having issues differs. Empire Blue Shield/Blue Cross only reports 1% of respondents having issues, compared to 3% of survey respondents having issues with HealthFirst and United Health Care (UHC).

Health First’s issues are concentrated on paying for medications (19%) and paying co-payments for Specialist Doctor visits (3%), while United Health Care’s issues are paying for medications (4%), paying co-payments for primary care doctor visits (4%) and paying co-payments for HIV Doctor visits (26%). This last statistic is most troubling as would potentially affect all respondents and occurs for more than 1 in 4 respondents. Of all insurers, only one insurer, North Shore LIJ had no problems reported by respondents.

MEDICAL TRANSPORTATION

How do you usually get to the HIV/AIDS services that you need?

Figure 20. Medical Transportation



Who pays for your transportation?

Table 42. Payer of Medical Transportation Services

Circulo de la Hispanidad	21%
EOC of Suffolk	21%
Medicaid	21%
Myself	17%
Family/Friends	4%
SPARC	4%
Don't Know / Other	13%
Other: Health First	5%
Other: Liberty	4%
Other: NUMC	2%
Other: Don't Know	2%

Notable is Health First's inclusion of medical transportation as part of their Affordable Care Act health insurance coverage.

MEDICAL CARE

Q 32. After you were diagnosed with HIV, how long was it before you decided to go for medical care?

Table 43. Time from HIV Diagnosis to Entry into HIV Medical Care

Less than 1 month	64%
1-6 months	15%
6-12 months	8%
More than 1 year	11%
I have not sought medical care	0
Other	2%

Other: Diagnosed at birth; have always had medical care	0.8%
Other: Out of Care: was in care from 1995 till 2001	0.8%

More than 75% of respondents entered care within six months of diagnosis. Of the 35 newly diagnosed respondents 66% entered medical care for their HIV within six months, with 14% entering HIV medical care within a year and 20% not responding.

Q. 33 Who helped you get into medical care after you were HIV positive?

Table 44. Referral to HIV Medical Care

Doctor/Medical Provider	47%
Family member	15%
Case Manager/Social Worker	11%
Friend	7%
Nobody	5%
Person who has my test results if other than my doctor/medical provider	3%
Outreach worker/Linkage to Care Coordinator/ EIS Specialist	3%
Peer Educator	1%
Other	9%
Other: Myself	6%
Other: Counselor at anonymous test site center	1%
Other: Gay Men's Health Coalition Hotline	1%
Other: Nursing home	1%

Q. 34 Where do you go to get care for your HIV?

Table 45. Site of HIV Medical Care

Location	# Survey Respondents	% clients at Medical Facility
NUMC	182	36.7%
NORTH SHORE HOSPITAL	123	24.8%
STONY BROOK UNIVERSITY HOSPITAL	57	11.5%
SCDOH-BRENTWOOD HEALTH CENTER	29	5.8%

Location	# Survey Respondents	% clients at Medical Facility
SCDOH-MARTIN LUTHER KING JR CENTER	21	4.2%
DAVID E. ROGERS-SOUTHAMPTON	15	3.0%
PAT DELLATO, NP	12	2.4%
SCDOH-BROOKHAVEN HEALTH CENTER	12	2.4%
SCDOH-SHIRLEY	8	1.6%
SCDOH-RIVERHEAD MEDICAL CENTER	7	1.4%
NUMC-FREEPORT CLINIC	5	1.0%
BETH ISRAEL HOSPITAL	4	0.8%
VA MEDICAL CENTER	4	0.8%
INFECTIOUS DISEASE CLINIC	3	0.6%
MY PRIMARY DOCTOR	2	0.4%
NYC	2	0.4%
QUEENS LONG ISLAND MEDICAL GROUP - NEW HYDE PARK/HEMPSTEAD	2	0.4%
DR DANIEL BROOK	1	0.2%
FENWAY HEALTH-BOSTON MA	1	0.2%
NY MEDICAL	1	0.2%
SCDOH-MAXINE POSTAL HEALTH CENTER	1	0.2%
SCDOH-ROOSEVELT/FREEPORT CLINIC	1	0.2%
ST. CATHERINE'S HOSPITAL	1	0.2%
TRI-COMMUNITY HEALTH CENTER	1	0.2%
WEST ISLIP, NY	1	0.2%
TOTAL	496	100.0%

Suffolk County Department of Health cares for a total of 79 respondents or 15.9% of all respondents at seven locations. Services formerly provided by Suffolk County Department of Health will be acquired by Hudson River Health throughout the latter part of 2014.

HIV Doctor

Table 46. HIV Doctor / Medical Provider

Doctor	# Survey Respondents	% clients being cared for by HIV Doctor
DR TABOSSUM	69	15.1%
DR LANDAU	52	11.4%
DR MCGOWAN	50	10.9%
DR ANDERSON	32	7.0%
DR FURHER	25	5.5%
DR GRIFFIN	24	5.3%

Doctor	# Survey Respondents	% clients being cared for by HIV Doctor
DR AHMED	19	4.2%
DR STEIGBIGEL	18	3.9%
DR LIN	15	3.3%
DR FERNANDO	14	3.1%
DR KELLY	12	2.6%
PAT DELLATO, NP	12	2.6%
DR HIRSCH	10	2.2%
DR DORCELY	7	1.5%
DR GOLINOWSKI	7	1.5%
DR LUKA	7	1.5%
DR SHAH	7	1.5%
DR ZAINUL	7	1.5%
DR TORKS	6	1.3%
DR AMETH	5	1.1%
DR HAGUE	5	1.1%
DR LANDELL	5	1.1%
DR BAILEY	4	0.9%
DR JIMINEZ	4	0.9%
DR LOBO	4	0.9%
DR KHANIJO	3	0.7%
DR LENEFSKY	3	0.7%
DR FIERA	2	0.4%
DR HATVE	2	0.4%
DR HAYES	2	0.4%
DR LAVANDERA	2	0.4%
DR PAVEL	2	0.4%
DR RANDEL	2	0.4%
DR VERLY	2	0.4%
SABIJA-HAKE	2	0.4%
DR DONAHUE	1	0.2%
DR GREEN	1	0.2%
DR HARIGOPTAL	1	0.2%
DR HILL	1	0.2%
DR HIRCHWORTH	1	0.2%
DR HSU	1	0.2%
DR JARVARI	1	0.2%
DR LENTNER	1	0.2%
DR NACHMAN	1	0.2%
DR ROSENTHAL	1	0.2%
DR SALOM	1	0.2%
DR ZAMULIE	1	0.2%
DR ZAWLIN	1	0.2%
DARZEE	1	0.2%
DENISE FERARRO	1	0.2%
TOTALS	457	100.0%

Q.36 If you did not receive medical care for your HIV during the past six months, why was this the case? Check all that apply.

Only 31 or 6.2% of respondents replied that they did not receive medical care for their HIV in the past six months. Their reasons included:

Table 47. Reasons for not getting medical care in past 6 months

Reason	Responses	Percent
Could not get transportation	9	29%
Could not get an appointment	6	19%
Needed an evening or weekend	5	16%
Could not afford co-payment	4	13%
Concerned about confidentiality	2	6%
Could not pay for services	1	3%
Had language problems	1	3%
Other: Always At Emergency Room	1	3%
Other: In Hospital	1	3%
Other-Nursing Home For 2/5 Years	1	3%
Total	31	100%

These responses highlight the need for medical transportation and the preference for easy appointment scheduling with evening and weekend availability.

Q. 37 Have you had your labs done in the last six months?

Most respondents (97%) have had their labs done in the last six months.

Table 48. Labs done in last six months

Response	Count	Percent
Yes	484	97%
No	10	2%
No Response	6	1%
Total	500	100%

Q. 38. Please check one box in each column which best describes your CD4/T-Cell count:

Table 49. Most Recent and Lowest CD4/T-Cell count

Range of CD4 Counts	Last CD4/T-Cell Count		Lowest CD4/T-Cell Count	
	Frequency of Response	Percent	Frequency of Response	Percent
0-49	31	6.2%	66	13.3%

100-199	14	2.8%	63	12.7%
200-500	44	8.8%	25	5.0%
200-500	75	15.0%	34	6.8%
50-99	8	1.6%	79	15.9%
Do not know	137	27.4%	208	41.9%
More than 500	191	38.2%	22	4.4%
Total	500	100.0%	497	100.0%

Q. 39. If you had a viral load measured, please check one box in each column.

Table 50. Most recent and Highest Viral Load Results

Range of CD4 Counts	Last Viral Load Test	Highest Viral Load Results		
	Frequency of Response	Percent	Frequency of Response	Percent
Undetectable	344	68.8%	48	9.9%
Less than/equal to 10,000	52	10.4%	32	6.6%
10,001 to 100,000	9	1.8%	48	9.9%
100,001 to 1,000,000	1	0.2%	57	11.8%
Greater than 1,000,00	1	0.2%	20	4.1%
Do not know	1	0.2%	280	57.7%
Total	500	100.0%	485	100.0%

HIV DRUG RESISTANCE TEST

Q. 40. Have you ever taken an HIV drug resistance test (geno or phenotype)?

Table 51. Ever had an HIV Drug Resistance Test

Response	Frequency of Response	Percent
Yes	245	49.7%
No	164	33.3%
Don't know if I've taken this test	51	10.3%
Don't know what this test is	33	6.7%
Totals	493	100.0%

Q. 40a) If not, why not?

Very few respondents answered this question, with two responses stating that their viral load was undetectable so there was no need for a drug resistance test.

HIV MEDICATIONS

Q. 41 Are you currently taking HIV medications?

Table 52. HIV Medication Status

Response	Frequency of Response	Percent
Yes	491	98.2%
No	9	1.8%
Total	500	100.0%

Q. 42. If you are not currently taking HIV medications, why not?

Most respondents are taking HIV medications (98.2%) and the nine who are not responded their reason for not taking HIV medications are:

- Can't afford the cost (1)
- Side effects are too undesirable (2)
- No reason given (6)

Co-Morbidities

Table 53. Physical Co-Morbidities

Condition	Frequency of Response	Percent
Cancer	54	10.8%
Diabetes	80	16.0%
Heart Problems	74	14.8%
Hepatitis A	50	10.0%
Hepatitis B	62	12.4%
Hepatitis C	85	17.0%
High Blood Pressure	145	29.0%
High Cholesterol	210	42.0%
Kidney Problems	46	9.2%
Liver Problems	67	13.4%
Lung/breathing Problems	101	20.2%
Neuropathy	74	14.8%
PCP Pneumonia	33	6.6%
Problems with thought or memory	82	16.4%
Tuberculosis (TB)	33	6.6%
Yeast Infections	78	15.6%
Other:	76	15.2%
Totals	500	100.0%

Other:

Table 54. Other Physical Co-Morbidities

Condition	Frequency of Response	Percent
Cancer	15	19.7%
Asthma	11	14.5%
Thrush	6	7.9%
Gastroenterology	5	6.6%
Fibromyalgia	5	6.6%
Post-Traumatic Stress Disorder	5	6.6%
Thyroid	5	6.6%
Urine Infections	4	5.3%
COPD	2	2.6%
Back Problems	2	2.6%
Cataracts	2	2.6%
C-Difficile	2	2.6%
Abnormal Pap test	1	1.3%
Arthritis	1	1.3%
Bipolar Depression	1	1.3%
Eczema	1	1.3%
Enlarged Prostate	1	1.3%
Fibroid Tumors-Cervical	1	1.3%
Gout	1	1.3%
Human Papilloma Virus	1	1.3%
Pinched Nerve	1	1.3%
Facial Atrophy	1	1.3%
Shingles	1	1.3%
Strokes	1	1.3%
Total	76	100.0%

SERVICE RESPONSE

Medically Related Services:

Table 55. Needed and Received This Service

Service	Frequency of Response	% of Responses
Medications	394	79%
Ambulatory Outpatient Medical Care	323	65%
Dental Care	288	58%

Medical Case Management	281	56%
Case Management	270	54%
Eye Care	231	46%
Mental Health/Emotional Counseling Services	228	46%
Transportation to doctor, dentist and other services	212	42%
Free condoms	205	41%
Support group/peer counseling	183	37%
Gynecological Care	149	30%
Emergency Medical Care	133	27%
Information about safe sex practices	122	24%
Legal services	122	24%
Food bank or food vouchers	121	24%

Table 56. Received this, but needed more than what was available

Service	Frequency of Response	% of Responses
Food bank or food vouchers	33	7%
Eye Care	28	6%
Dental Care	22	4%
Money to pay for mortgage or rent	16	3%
Help with finding and keeping housing	15	3%
Money to pay for medications	15	3%
Money to pay for utilities	15	3%
Assistance with copayments	13	3%
Legal services	12	2%
Case Management	11	2%
Nutritional (dietetic) counseling	11	2%
Medical Case Management	10	2%
Mental Health/Emotional Counseling Services	10	2%
Help with navigating HIV and social services	10	2%
Transportation to doctor, dentist and other services	9	2%

Table 57. Needed this, but could not get it

Service	Frequency of Response	% of Responses
Money to pay for utilities	51	10%
Money to pay for mortgage or rent	23	5%
Assistance with copayments	20	4%
Money to pay for medications	18	4%
Legal services	16	3%

Nutritional (dietetic) counseling	16	3%
Help with finding and keeping housing	12	2%
Food bank or food vouchers	11	2%
Dental Care	10	2%
Help with navigating HIV and social services	8	2%
Eye Care	7	1%
Medical Case Management	7	1%
Mental Health/Emotional Counseling Services	7	1%
Case Management	4	1%
Transportation to doctor, dentist and other services	3	1%

Most respondents were unaware of the availability of free nutritional supplements

Table 58. Needed this, but did not seek it

Service	Frequency of Response	% of Responses
Dental Care	50	10%
Eye Care	48	10%
Food bank or food vouchers	34	7%
Nutritional (dietetic) counseling	31	6%
Help with finding and keeping housing	21	4%
Money to pay for utilities	20	4%
Money to pay for mortgage or rent	15	3%
Mental Health/Emotional Counseling Services	11	2%
Legal services	10	2%
Help with navigating HIV and social services	9	2%
Assistance with copayments	8	2%
Money to pay for medications	5	1%
Transportation to doctor, dentist and other services	3	1%
Medical Case Management	1	0.2%
Case Management	1	0.2%

Table 59. Did not need this

Service	Frequency of Response	% of Responses
Money to pay for medications	88	18%
Help with navigating HIV and social services	83	17%
Money to pay for utilities	79	16%

Help with finding and keeping housing	78	16%
Nutritional (dietetic) counseling	72	14%
Assistance with copayments	69	14%
Legal services	61	12%
Food bank or food vouchers	58	12%
Transportation to doctor, dentist and other services	55	11%
Medical Case Management	54	11%
Money to pay for mortgage or rent	47	9%
Mental Health/Emotional Counseling Services	37	7%
Case Management	37	7%
Eye Care	36	7%
Dental Care	18	4%

Non-Medically Related (Supportive) Services

Table 60. Needed and Received This Service

Service	Frequency of Response	% of Responses
Medications	394	79%
Ambulatory Outpatient Medical Care	323	65%
Free condoms	205	41%
Support group/peer counseling	183	37%
Gynecological Care	149	30%
Emergency Medical Care	133	27%
Information about safe sex practices	122	24%
Client Advocacy	100	20%
Help with taking medications as prescribed	94	19%
Hepatitis C services	69	14%
Peer/Mentor programs	63	13%
Substance Abuse Services	59	12%
Home Health Services	48	10%
Obstetrical/pregnancy care	32	6%
Home Delivered Meals	30	6%
Child welfare services	19	4%
Emergency shelter for people with AIDS	18	4%
Nursing Home Care	10	2%
Respite care	8	2%
Child Care for medical visits	5	1%
Pre-release services	2	0.4%
Needle/syringe exchange programs	1	0.2%

Table 61. Received this, but needed more than what was available

Service	Frequency of Response	% of Responses
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Help with taking medications as prescribed	8	2%
Medications	7	1%
Emergency Medical Care	7	1%
Support group/peer counseling	6	1%
Information about safe sex practices	6	1%
Client Advocacy	6	1%
Home Delivered Meals	4	1%
Free condoms	3	1%
Hepatitis C services	3	1%
Peer/Mentor programs	3	1%
Gynecological Care	2	0.4%
Home Health Services	2	0.4%
Emergency shelter for people with AIDS	2	0.4%
Respite care	2	0.4%
Pre-release services	2	0.4%
Ambulatory Outpatient Medical Care	1	0.2%
Substance Abuse Services	1	0.2%
Nursing Home Care	1	0.2%
Child Care for medical visits	1	0.2%
Needle/syringe exchange programs	1	0.2%
Hospice Services	1	0.2%

Table 62. Needed this, but could not get it

Service	Frequency of Response	% of Responses
Child Care for medical visits	14	3%
Support group/peer counseling	12	2%
Free condoms	10	2%
Peer/Mentor programs	10	2%
Information about safe sex practices	8	2%
Emergency shelter for people with AIDS	8	2%
Emergency Medical Care	2	0.4%
Home Delivered Meals	2	0.4%
Hepatitis C services	2	0.4%
Gynecological Care	2	0.4%
Home Health Services	2	0.4%
Ambulatory Outpatient Medical Care	2	0.4%
Hospice Services	2	0.4%
Help with taking medications as prescribed	1	0.2%
Medications	1	0.2%
Client Advocacy	1	0.2%
Substance Abuse Services	1	0.2%
Needle/syringe exchange programs	1	0.2%
Obstetrical/pregnancy care	1	0.2%

Service	Frequency of Response	% of Responses
Child welfare services	1	0.2%

Table 63. Needed this, but did not seek it

Service	Frequency of Response	% of Responses
Support group/peer counseling	27	5%
Peer/Mentor programs	9	2%
Emergency shelter for people with AIDS	8	2%
Gynecological Care	8	2%
Information about safe sex practices	6	1%
Emergency Medical Care	6	1%
Client Advocacy	6	1%
Hepatitis C services	5	1%
Free condoms	4	1%
Home Delivered Meals	4	1%
Child Care for medical visits	2	0.4%
Ambulatory Outpatient Medical Care	2	0.4%
Home Health Services	1	0.2%
Help with taking medications as prescribed	1	0.2%
Substance Abuse Services	1	0.2%
Respite care	1	0.2%
Nursing Home Care	1	0.2%

Table 64. Did not need this

Service	Frequency of Response	% of Responses
Obstetrical/pregnancy care	125	25%
Hospice Services	120	24%
Nursing Home Care	118	24%
Substance Abuse Services	115	23%
Pre-release services	114	23%
Respite care	112	22%
Home Health Services	108	22%
Child Care for medical visits	106	21%
Needle/syringe exchange programs	105	21%
Child welfare services	105	21%
Home Delivered Meals	104	21%
Hepatitis C services	103	21%
Emergency shelter for people with AIDS	97	19%
Help with taking medications as prescribed	92	18%
Information about safe sex practices	88	18%

Gynecological Care	81	16%
Peer/Mentor programs	79	16%
Client Advocacy	75	15%
Ambulatory Outpatient Medical Care	61	12%
Support group/peer counseling	52	10%
Free condoms	48	10%
Medications	15	3%
Emergency Medical Care	2	0.4%

. Q. 47 Were there any other services not listed above that you needed during the past six months?

Table 65. Other Services not listed by needed in past six months

Other Responses:	Frequency of Response	Percent
Rent allowances	12	20.7%
Alternative therapies	10	17.2%
Assistance with housing	8	13.8%
Gym reimbursement	5	8.6%
Occupational therapy	5	8.6%
Help getting through affordable care net	4	6.9%
Transportation	3	5.2%
Foot care	2	3.4%
Disability	1	1.7%
Ear doctor	1	1.7%
Evening hours for therapy	1	1.7%
Food stamps	1	1.7%
Gas cards	1	1.7%
Health insurance	1	1.7%
Immigration services	1	1.7%
Needed help moving with rent & security and options provided	1	1.7%
Orthopedic care not covered by insurance	1	1.7%
Total	58	100.0%

REASONS FOR BARRIERS AND GAPS IN SERVICE ACCESS

Q. 48. If you selected “ Needed this, but could not get it for questions 45 to 46, or if you could not get a service that you included on question 47, then select the reasons why you could not get the service (s) that you needed. Check all that apply.

Table 66. Reasons respondents felt the gaps or other services not listed unobtainable

Service	Freq. Resp.	Don’t know where to obtain	Can’t Afford	On a waiting list	No Transportation	Other
Medically Related Services:						
Nutritional Supplements	39%	4	4	1		5-No Funds
Eye Care	16%	1				1-Immigration Status
Dental Care	13%	1	6		1	
Medical Case Management	6%			2		
Emergency Medical Care	3%	2				
Gynecological Care	3%	2				
Help with taking medications as prescribed	3%	2				
Hepatitis C services	3%	2	1			
Home Health Services	3%	2	1			
Hospice Services	3%	2	1			
Medications	3%	2	1			
Mental Health/Emotional Counseling Services	3%	2	1			
Non-Medically Related Services:						
Assistance with copayments	14%	10	1			3- No Funds
Money to pay for utilities	14%	16	5		1	6- Eligibility
Help with finding and keeping housing	8%	7	1			1-Immigration Status
Money to pay for mortgage or rent	8%	12				
Food bank or food vouchers	6%	2				5- No Funds
Money to pay for medications	6%	1	3		7	5-No Funds
Case Management	5%		1			2-Immigration Status
Emergency shelter for people with AIDS	5%		1			5- No Funds
Peer/Mentor programs	4%	1				4-Not provided

Service	Freq. Resp.	Don't know where to obtain	Can't Afford	On a waiting list	No Transportation	Other
Legal services	4%	6	6			5-No Funds
Support group/peer counseling	4%	2				
Transportation to doctor, dentist and other services	4%	1			1	1-No Funds
Nutritional (dietetic) counseling	3%		6			
Child Care for medical visits	1%	6	1			
Child welfare services	1%	1				
Free condoms	1%	1				
Help with navigating HIV and social services	1%				6	
Home Delivered Meals	1%	2				
Totals		90	40	3	16	43

Other reasons include No-Funds (29); Eligibility (6); Immigration Status (4); and Not Provided (4).

The ranking of gaps in obtaining services from our survey responses are:

- Respondents do not know where to obtain services (90)
- Respondents cannot afford services (40)
- Non-availability of funds (29)
- No transportation to get to services (16)
- Eligibility issues (6)
- Immigration status (4)
- Services not provided (4)
- Clients on a waiting list for services (3)

PRIORITY SERVICES

Q. 49 If you could receive only five services, which would those be?

Table 67. Priority Services

Service	Frequency of Response	Percent
Medications	288	57.6%
Ambulatory Outpatient Medical Care	277	55.4%
Dental Care	245	49.0%
Case Management	216	43.2%
Transportation to doctor, dentist and /or other services	163	32.6%
Health Insurance	144	28.8%
Mental health/emotional counseling	139	27.8%
Eye care	121	24.2%
Food Bank or Food Vouchers	106	21.2%
Money to pay for rent	106	21.2%
Emergency medical Care	70	14.0%
Money to pay for utilities	70	14.0%
Help with finding and keeping housing	63	12.6%
Legal services	57	11.4%
Support group/peer counseling	53	10.6%
Client Advocacy	52	10.4%
Free Condoms	43	8.6%
Gynecological Care	43	8.6%
Money to pay for medications	40	8.0%
Nutritional counseling	28	5.6%
Information to help me find out what other services are available	20	4.0%
Child Care while I go to the doctor or another appointment	19	3.8%
Hepatitis C services	19	3.8%
Help with taking medications as prescribed	16	3.2%
Meals brought to my home	15	3.0%
Home health services	11	2.2%
Information about safe sex practices	10	2.0%
Money to pay for mortgage	10	2.0%
Emergency shelters for people with AIDS	9	1.8%
Obstetrical/pregnancy care	5	1.0%
Substance abuse services	5	1.0%
Peer/mentor programs	4	0.8%
Child Welfare Services	2	0.4%
Hospice	2	0.4%
Nursing home care	2	0.4%

Service	Frequency of Response	Percent
Pre-release	1	0.2%
Respite care	1	0.2%
Needle / syringe exchange program	0	0.0%
Total	500	100.0%

RISK BEHAVIORS

Q. 44. Have you ever been diagnosed with or treated for sexually transmitted diseases (STD's)? Please check all that apply.

Table 68. Sexually Transmitted Diseases

STD	Frequency of Response	Percent
Gonorrhea	110	50.5%
Syphilis	72	33.0%
Chlamydia	65	29.8%
Genital Herpes	60	27.5%
Human Papilloma Virus (HPV)	39	17.9%
Genital Warts	36	16.5%
Trichomoniasis	20	9.2%
Total	218	100.0%

Q. 50. Have you used any of the following substances during the past six months?

Table 69. Use of Substances in past 6 months

Substance Used	Frequency of Response	Percent
Alcohol	301	75%
None of the above	293	73%
Tobacco	285	71%
Marijuana	259	64%
Pain medications (non-prescribed)	47	12%
Crack	21	5%
Crystal methamphetamines	19	5%
Injection drugs (non-prescribed)	16	4%
Cocaine	14	3%
Benzos /Benzodiazepines	10	2%
Heroin	9	2%
Ecstasy	6	1%
Other:	6	1%
ADD/ADHD Medications	2	0%
PCP	1	0%

Special K (ketamine)	0	0%
Total	404	100%

Q. 51 Have you ever used substance above your doctor's prescribed dosage recommendations?

Table 70. Use of substance over prescribed dosage

Response	Frequency of Response	Percent
No	441	91.3%
Yes	35	7.2%
Not taking medications	7	1.4%
Total	483	100.0%

Although 35 respondents admitted to using substances above their doctor's prescribed dosage recommendations, 47 respondents admitted to abusing non-prescribed pain medications

Q. 52 Do you think you need treatment for a drug or alcohol problem?

Table 71. Respondent need for Drug or Alcohol Treatment

Response	Frequency of Response	Percent
No, I don't use drugs or alcohol	293	60.8%
No, I don't use enough that it's a problem	154	32.0%
Yes, I do think I need treatment	35	7.3%
Total	482	100.0%

Q. 53 In the past six months, have you tried to get help for a drug and/or alcohol problem?

Table 72. Respondent Effort to get help for Drug or Alcohol Problem

Response	Frequency of Response	Percent
No, did not need this service	430	89.0%
Yes, I needed help and received it	42	8.7%
Yes, I needed help and received this help, but I needed more than what was available	2	0.4%
Yes, I needed help, but could not get it	9	1.9%
Total	483	100.0%

The 35 respondents who thought then needed treatment for a drug or alcohol problem increased to 53: 42 who needed help and received it, 2 who needed help and received it but needed more than what was available and 9 who needed help but could not get it. The need for substance

abuse counseling was also very under-reported by respondents when replying to services they need and cannot get (10 or 2%), and the top five services (5 or 1%). This is a self-reported survey and it appears that the prevalence of drug and alcohol problems is much higher than reported. A definite reluctance to admit substance abuse appears from the survey responses.

The numbers reporting alcohol, tobacco and/or marijuana use combined with the illegal drug use are for use in the past six months and do not imply a drug or alcohol problem. A range from 11.6% to 13.9% of those using substances can be inferred to have a drug or alcohol problem. (35/301=11.6%) and (42/301=13.9%).

Q. 54. If you were unable to receive help for a drug and/or alcohol problem, why?

Table 73. Barriers to receiving help for Drug or Alcohol Problem

Response	Frequency of Response	Percent
I forget things	5	1.0%
No money	1	0.2%
No services available	1	0.2%
Not eligible	1	0.2%
Not Applicable	489	98.4%
Total	497	100.0%

MENTAL HEALTH

Q. 55. Have you ever been diagnosed with a mental illness?

Table 74. Diagnosis of Mental Illness

Response	Frequency of Response	Percent
Yes	249	51.4%
No	235	48.6%
Total	484	100.0%

Q. 56. Have you ever been referred for evaluation for a mental health issue?

Table 75. History of Mental Health Evaluation

Response	Frequency of Response	Percent
Yes	228	47.7%
No	250	52.3%
Total	478	100.0%

Q. 57. Have you ever felt anxious, depressed or that you might have a mental health issue?

Table 76. Mental Health Issue Indicators

Response	Frequency of Response	Percent
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Yes	285	59.0%
No	166	34.4%
Don't Know	20	4.1%
Not Applicable	12	2.5%
Total	483	100.0%

The responses for all three questions regarding mental health are very consistent with an average of approximately 254 or 52.9% responding that they have a mental health issue. 51.4% or respondents have been diagnosed, 47.7% have been referred for evaluation and 59% have felt anxious or depressed or thought that they might have a mental health issues.

Respondents are very forthcoming about mental health issues, which is promising for healthcare providers to treat PLWH/A.

INCARCERATION

Q. 58. Have you ever been in jail?

Table 77. Ever in Jail

Response	Frequency of Response	Percent
No	343	71.0%
Yes, over 2 years ago	130	26.9%
Yes, more than a year ago but within the past 2 years	2	0.4%
Yes, more than 6 months ago, but within the past year	1	0.2%
Yes, within the past 6 months	7	1.4%
Total	483	100.0%

Q. 58. Have you ever been in prison?

Table 78. Ever in Prison

Response	Frequency of Response	Percent
No	396	83.4%
Yes, over 2 years ago	74	15.6%
Yes, more than a year ago but within the past 2 years	5	1.1%
Yes, more than 6 months ago, but within the past year	-	
Yes, within the past 6 months	-	
Total	475	100.0%

AWARENESS OF THE NASSAU SUFFOLK HIV PLANNING COUNCIL AND PUBLICATIONS

Q. 29. Are you aware of the “Medicaid Managed Care Guide” created by the Nassau Suffolk Planning Council?

Table 79. Medicaid Managed Care Guide

Response	Frequency of Response	Percent
No	199	54.4%
Yes	102	27.9%
I would like a copy	65	17.8%
Total	366	100.0%

Q. 60 Are you aware of the Nassau Suffolk HIV Planning Council?

Table 80. Aware of Nassau-Suffolk HIV Planning Council

Response	Frequency of Response	Percent
No, I am not aware	212	44.9%
Yes	188	39.8%
No, but I would like more information	72	15.3%
Total	472	100.0%

Q. 61. If you answered Yes to the previous question, are you aware of the committees of the Nassau Suffolk HIV Planning Council?

Table 81. Aware of Committees of Nassau Suffolk HIV Planning Council

Response	Frequency of Response	Percent
No	190	49%
Yes	150	37%
No, but I would like more information	56	14%
Total	404	100%

SUGGESTED CHANGES TO SERVICES

Q. 62. What would be the single most important change you would suggest to improve services to individuals with HIV/AIDS?

Table 82. Single most recommended change to improve services to PLWH/A

Response	Frequency of Response	Percent
Affordable, safe housing	60	17.2%
Shorter Wait Times for Medical Appointments, Appointments on Evenings and Weekends	52	14.9%
Self-Directed Services-“One size does not fit all”	52	14.9%

Response	Frequency of Response	Percent
Increase Awareness of available services	33	9.5%
Financial Assistance	31	8.9%
More Support Groups	22	6.3%
Transportation-better, not just for medical	17	4.9%
Mental health counseling increased	16	4.6%
Increase Funding for HIV programs	14	4.0%
More Social Events	11	3.2%
Alternative therapies and gym access	9	2.6%
Stigma, improve attitude among medical community	9	2.6%
Better Health Insurance	7	2.0%
Importance of Adherence to Medication Regimen	5	1.4%
Directory of Services updated quarterly	3	0.9%
Help with Social Services	3	0.9%
Help for undocumented	3	0.9%
24/7 phone service that could answer medical questions (HIV & non-HIV)	1	0.3%
Total	348	100.0%

APPENDICES

Schedule 1. Zip Codes of Respondents

Q. 7. What is your zip code?

11003	1	11481	2	11731	1
11040	1	11492	2	11738	4
11050	1	11501	2	11743	3
11052	1	11509	4	11746	9
11096	6	11510	13	11747	1
11099	4	11514	2	11749	3
11102	2	11515	2	11750	1
11138	1	11516	1	11752	5
11146	2	11518	1	11754	1
11149	2	11520	15	11755	1
11157	2	11531	2	11756	6
11194	2	11535	2	11757	10
11206	1	11538	2	11763	2
11223	2	11542	14	11767	1
11246	3	11543	2	11772	19
11257	2	11550	84	11777	4
11258	2	11552	8	11778	1
11260	2	11553	6	11779	3
11278	2	11555	1	11784	1
11280	2	11559	2	11788	2
11286	1	11560	1	11796	1
11289	2	11563	2	11798	15
11290	2	11570	5	11805	1
11309	2	11572	1	11901	10
11311	4	11575	12	11933	1
11319	2	11579	1	11935	3
11322	2	11580	5	11944	2
11351	2	11590	5	11949	1
11357	3	11701	17	11951	3
11360	2	11702	1	11953	6
11361	2	11703	2	11955	1
11364	2	11704	8	11961	1
11378	2	11706	14	11965	1
11406	2	11713	3	11967	4
11409	2	11717	8	11968	4
11413	2	11720	2	11969	1
11417	2	11722	15	11970	1
11419	2	11723	1	11972	1
11423	2	11481	2	11976	1
11426	2	11492	2	11978	1
11445	2	11726	3		
11473	2	11729	3		
				Nassau:286	Suffolk:214
				Total	500

Schedule 2: Consumer Survey Instrument

1. UNID*: *DOB Month, Year, Zip, 1=Male; 2=Female; 3=Transgender

2. Today's date

3. Administration Site

BASIC INFORMATION

4. Please tell us who you are:

- I am a person with HIV/AIDS filling this out myself
- I am a relative/friend filling this out for someone who has HIV/AIDS
- I am an agency staff person or consumer advocate helping someone who is living with HIV to fill out this survey.

5. Where did you live when you first tested HIV positive?

- Nassau
- Suffolk
- Other (please specify)

6. In what year were you diagnosed with HIV?

7. What is your zip code?

8. What is your gender?

- Male
- Female
- Transgender: Female to Male
- Transgender: Male to Female

9. Do you have sexual relationships with:

- Only men
- Only women
- With both men and women
- I have never had sex
- Other

10. Would you describe yourself as Latino/Latina/Hispanic?

- Yes
- No

11. With reference to race, how would you describe yourself?

- Black/African American
- White/Caucasian
- Asian/Pacific Islander
- Native American
- More than one race
- Other (please specify)

12. What languages do you speak?

- English
- Spanish
- French/ Haitian-Creole
- Other (please specify)

13. How do you believe you were infected with HIV?
(Check all that apply)

- Men having sex with men
- Injection drug use
- Men having sex with men and injection drug use
- Transfusion/blood products
- Heterosexual (sex with a person of the opposite sex)
- At birth
- Other (please specify)

14. Have you ever exchanged sex for drugs, money, food, shelter or clothing?

- Yes
- No

15. What is your date of birth?
MM / DD /YYYY

16. Currently, are you:

- Working fulltime
(30 or more hours per week)
- Working part-time
(less than 30 hours per week)
- Unemployed
- Disabled/cannot work
- Retired
- Attending school
- Incarcerated (in jail)

17. What is your highest level of education?

- Grade school
- Some high school
- High school diploma/GED
- Some college
- Technical degree
- College degree
- Some graduate school
- Graduate school degree

LIVING ARRANGEMENT/HOUSEHOLD MEMBERS

Please provide information regarding your household composition. The household may include persons who are legally/financially responsible for you, such as a spouse or parent. The household may also include individuals for whom you are legally/financially responsible, such as a child under 21 years of age

18. Are you now or have you ever been homeless?

- Never
- Currently homeless
- Been homeless in past 2 years, but not now
- Been homeless over 2 years ago, but not now
- Other

19. Please check the most appropriate box in each column to tell us about your current housing situation. Please check only one response.

- I live in my own house, apartment or mobile home (rent or own)
- I live in my parent's house, apartment or mobile home (rent or own)
- I rent a room
- I live in someone else's house, apartment or mobile home
- I live with a roommate
- I live with a partner or significant other
- I live in the streets (homeless)
- I live in a shelter (or emergency housing)
- I live in a group home, specifically for people with AIDS
- I live in a group home, not specifically for people with AIDS
- I live in a drug or alcohol treatment center
- I live in a nursing home

- I live in a psychiatric treatment center
- I am in jail
- I live in a sober house
- Other

If you selected 'other' above, please describe your housing situation here.
Other

20. Please check the most appropriate box in each column to tell us about your previous housing situation. (six months ago) Please check only one.

- I live in my own house, apartment or mobile home (rent or own)
- I live in my parent's house, apartment or mobile home (rent or own)
- I rent a room
- I live in someone else's house, apartment or mobile home
- I live with a roommate
- I live with a partner or significant other
- I live in the streets (homeless)
- I live in a shelter (or emergency housing)
- I live in a group home, specifically for people with AIDS
- I live in a group home, not specifically for people with AIDS
- I live in a drug or alcohol treatment center
- I live in a nursing home
- I live in a psychiatric treatment center
- I am in jail
- I live in a sober house
- Other

If you selected 'other' above, please describe your housing situation here.
Other

21. If you presently have a place to live please list:

Including yourself total number of persons living in your household. _____
Including yourself total number of HIV infected persons living in your

household. _____

INCOME AND HEALTH INSURANCE

22. What are your present sources of income in your household? Check all that apply for you and other members of the household whose income is legally available to you. This includes spouses. Do not include income of partners and/or roommates. Only include parents' incomes if you are under age 21.

Employment

- SSI (Supplemental Security Income)
- SSDI (Social Security Disability Insurance)
- AFDC/TANF (Aid to Families with Dependent Children/Temporary Assistance to Needy Families)
- Child support/alimony
- Unemployment
- Retirement income
- Other (please specify) _____

23. Please check the box of the amount that was your total household income last month. Include all the money you received, plus the money anyone else received who lives with you and whose income is legally available to you. This includes spouses, or if you are a child under age 21, parents. Do not include income of partners and/or roommates. Include money from government assistance, with the exception of food stamps.

- \$0-\$249
- \$250-\$499
- \$500-\$749
- \$750-\$999
- \$1,000-\$1,499
- \$1,500-\$1,999
- \$2,000-\$2,499
- \$2,500-\$2,999
- \$3,000 or more

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

- I do not have any health insurance
- I have MEDICARE
- I have MEDICAID
- I have ADAP (AIDS Drug Assistance Program)
- I have AHIP (AIDS Health Insurance Plan)
- I have APIC (ADAP Plus Insurance Continuation Program)
- I have Veteran's Benefits
- I have insurance that my employer pays for
- I have insurance through my employer that I contribute to
- I have private insurance that I pay for
- I have insurance through a family member

- I have private insurance or Supplemental Medicare paid for by the State Health Insurance Continuation Program
- I have insurance through the Health Insurance Exchange *New York State Department of Health)
- I have insurance through Medicaid expansion
- Other (please specify) _____

AFFORDABLE CARE ACT / MEDICAID EXPANSION

25. If you are insured under the Health Insurance Exchange (New York State Department of Health), what insurer did you choose?

- Affinity Health Plan
- Emblem Health
- Empire Blue Shield Blue Cross
- Fidelis Care
- Health Republic (Freelancers)
- North Shore LIJ
- Oscar
- United HealthCare
- Health first

26. Did you have any challenges when you enrolled in Medicaid or Health Insurance Exchange in the past year?

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

If your answer above was "yes", please specify your top two challenges

1. _____
2. _____

27. If you enrolled in Medicaid or a Health Insurance Marketplace plan, do you understand the requirements of your new health insurance, such as premiums, copays, deductibles, coinsurance?

- Yes, I understand these requirements
- No, I do not understand these requirements
- I would like assistance in understanding these new requirements.

28. Have you had any problems with Health Marketplace Insurance or Medicaid covering any of the following services?

- Paying for Medications
- Paying copays for HIV Doctor visits
- Paying copays for Primary Care Doctor visits
- Paying copays for Specialist Doctor visits
- Not Applicable
- Other

Other (please specify) _____

29. Are you aware of the "Medicaid Managed Care Guide" created by the Nassau Suffolk Planning Council?

- Yes
- No
- I would like a copy

TRANSPORTATION

30. How do you usually get to the HIV/AIDS services that you need?

- I use my own car
- My friend/relative gives me a ride
- I take the bus
- I use Able Ride
- I use SCAT
- I take a taxi
- I use a gas card
- I use the Long Island Railroad
- I walk there
- I use a Managed Care corporation supplied ride
- Other

If you selected 'other' above, please provide a description here. _____

31. Who pays for your transportation? Check the type of transportation that you use and indicate who pays for your transportation.

- Myself
- Family/Friends
- Medicaid
- EOC of Suffolk
- Circulo de la Hispanidad
- SPARC
- Don't Know / Other

If you selected 'other' above, please provide a description here.

Other _____

PRIMARY MEDICAL CARE

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

- More than 1 year
- 6-12 months
- 1-6 months
- Less than one month
- I have not sought medical care
- Other (please specify) _____

33. Who first helped you get into medical care after you found out you were HIV positive? (Check all that apply)

- Family member
- Friend
- Doctor/Medical Provider
- Person who has my test results if other than my doctor/medical provider
- Outreach worker/Linkage to Care Coordinator/ EIS Specialist
- Case Manager/Social Worker
- Prison/Jail
- Nobody
- Don't Know
- Peer Educator
- Other (please specify) _____

34. Where do you go to get care for your HIV? _____

35. What is the name of your HIV doctor? _____

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

- Could not get an appointment
- Could not get transportation
- Could not get child care
- Could not pay for services
- Concerned about confidentiality
- Had language problems
- Could not afford copayment
- Needed an evening or weekend appointment
- Not Applicable
- I do not want to receive medical care
- Other (please specify)

37. Have you had your labs done in the last 6 months?

- Yes
- No

I do not know

38. Please check one box in each column which best describes your CD4/T-Cell count.

What was your LAST CD4/T-Cell count?

- 0-49
- 50-99
- 100-199
- 200-500
- More than 500
- Do not know

What was your LOWEST CD4/T-Cell count?

- 0-49
- 50-99
- 100-199
- 200-500
- More than 500
- Do not know

39. If you had a viral load measured, please check one box in each column.

What were the results of your last viral load test?

- Undetectable
- Less than/equal to 10,000
- 10,001-100,000
- 100,001-1,000,000
- Greater than 1,000,000
- Do not know

What was your highest viral load ever?

- Undetectable
- Less than/equal to 10,000
- 10,001-100,000
- 100,001-1,000,000
- Greater than 1,000,000
- Do not know

40. Have you ever taken an HIV drug resistance test (geno or phenotype)?

- Yes
- No
- Don't know if I've taken this test
- Don't know what this test is

If not, why not? _____

41. Are you currently taking HIV medications?

- Yes
- No
- Other (please specify) _____

42. If you are not currently taking HIV medications, why not? (Check all that apply)

- Not applicable
- Don't know where to get them
- Can't afford the cost
- Can't afford the copayment
- Side effects are too undesirable
- Resistant to them, they don't work for me
- My doctor did not prescribe them
- I do not want to take them
- Other (please specify)

43. Have you ever been diagnosed with any of the following? (Please check all that apply.)

	Yes	No	Don't Know
Cancer (lymphoma, sarcoma, etc.			
Diabetes			
Heart Problems			
Hepatitis A			
Hepatitis B			
Hepatitis C			
High Blood Pressure			
High Cholesterol			
Kidney problems			
Liver problems			
Lung/Breathing problems			
Neuropathy			
PCP Pneumonia			
Problems with thought or memory			
Tuberculosis (TB)			
Yeast Infections			
Other (please specify Below)			

Other (please specify) _____

44. Have you ever been diagnosed with or treated for sexually transmitted diseases (STDs)? Please check all that apply.

- Chlamydia
- Genital Herpes
- Genital Warts
- Gonorrhea
- Human Papilloma Virus (HPV)
- Syphilis
- Trichomoniasis
- Not applicable
- Other (please specify) _____

SERVICES

45. For the next questions, please tell us about your needs and ability to receive these medically-related services during the past six months. Check only one box for each question.

Services	Needed and received this	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
Ambulatory/outpatient medical care (Doctor's visits)					
Dental care Medical Case Management					
Nutritional supplements					
Emergency medical care					
Eye care					
Gynecological care					
Help with taking medications as prescribed					
Hepatitis C services					
Home health services					
Hospice services					
Medications					
Mental health/emotional counseling services					
Nursing Home care					
Obstetrical/pregnancy care					

Substance abuse services					
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46. For the next questions, please tell us about your needs and ability to receive these non-medical services during the past six months. Check only one box for each question.

Services	Needed and received this	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					
Assistance with copayments					
Case Management					
Child care while I go to the doctor or another appointment					
Child welfare services					
Client advocacy					
Dental care					
Emergency shelters for people with AIDS					
Food bank or food vouchers					
Free condoms					
Help with finding and keeping housing					
Information about safe sex practices					
Help with navigating HIV and social services					
Legal services					
Home Delivered meals					
Money to pay for medications					
Money to pay for mortgage or rent					
Money to pay for utilities					
Needle/syringe exchange program					
Nutritional (dietetic) counseling					
Prerelease services (before release from jail or prison)					
Respite care					
Support group/peer counseling					

Transportation to doctor, dentist and/or other services					
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47. Were there any other services not listed above that you needed during the past six months? _____

48. If you selected 'Needed this, but could not get it' for questions 45-46, or if you could not get a service that you included on question 47, 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 service
- I could not afford the service
- I am on a waiting list for the service
- I did not have transportation to get to the service
- Other (please specify) _____

49. If you could receive only five services, which would those be? Check the box of the five services below. Please read through the entire list before you make your final choices.

Ambulatory/outpatient medical care (doctor's visits)	Information to help me find out what other services are available
Case management (someone to help me get the services I need)	Legal services
Child care while I go to the doctor or another appointment	Meals brought to my home
Child welfare (services to prevent the breakup of a family and to reunite family members)	Medications
Client advocacy (someone to help me get benefits/entitlements)	Mental health/emotional counseling
Dental care	Money to pay for medications
Emergency medical care	Money to pay rent
Emergency shelters for people with AIDS	Money to pay utilities
Eye care	Needle/syringe exchange program
Food bank or food vouchers	Nursing home care
Free condoms	Nutritional counseling
Gynecological care	Obstetrical/pregnancy care
Health insurance	Peer/mentor programs
Help with finding and keeping housing	Prerelease
Help with taking medications as prescribed	(someone to help me get the services I really need when I get out of jail)
Hepatitis C services	Respite care (to relieve the primary caregiver providing day-to-day care of client or client's child)
Home health services (an aide or nurse who visits your home)	Substance abuse services/counseling
Hospice (services for people in the last stages of their life)	Support group/peer counseling

Information about safe sex practices	Transportation to doctor, dentist and/or other services
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ALCOHOL AND SUBSTANCE ABUSE

50. Have you used any of the following substances during the past six months? Check all that apply. Remember, there is no way to identify who you are, and your answers are anonymous.

- Alcohol
- ADD/ADHD medications (non-prescribed) such as Adderal, Ritalin
- Cocaine
- Crack
- Crank (crystal methamphetamine)
- Ecstasy
- Heroin
- Injection drugs (non-prescribed)
- Marijuana (pot)
- Pain medications (non-prescribed) (Such as Percocet, Vicodin, etc.)
- PCP
- Special K (Ketamine)
- Tobacco
- None of the above
- Other (please specify)

51. Have you ever used substances above your doctor's prescribed dosage recommendations?

- Yes
- No
- Not taking medications

52. Do you think you need treatment for a drug or alcohol problem?

- Yes, I do think I need treatment
- No, I don't use drugs or alcohol
- No, I don't use enough that it's a problem

53. In the past six months, have you tried to get help for a drug and/or alcohol problem?

- No, did not need this service
- Yes, I needed help and received it
- Yes, I needed help and received this help, but I needed more than what was available
- Yes, I needed help, but could not get it

54. If you were unable to receive help for a drug and/or alcohol problem, why?

MENTAL HEALTH SERVICES

55. Have you ever been diagnosed with a mental illness?

- Yes
- No

56. Have you ever been referred for evaluation for a mental health issue?

- Yes
- No

57. Have you ever felt anxious, depressed or that you might have a mental health issue?

- Yes
- No
- Don't Know
- Not Applicable

58. Have you ever been in jail?

- Yes, within the past 6 months
- Yes, more than 6 months ago, but within the past year
- Yes, more than a year ago but within the past 2 years
- Yes, over 2 years ago
- No

59. Have you ever been in prison?

- Yes, within the past 6 months
- Yes, more than 6 months ago, but within the past year
- Yes, more than a year ago but within the past 2 years
- Yes, over 2 years ago
- No

60. Are you aware of the Nassau Suffolk HIV Planning Council?

- Yes
- No
- No, but I would like more information

61. If you answered Yes to the previous question, are you aware of the committees of the Nassau Suffolk HIV Planning Council?

- Yes
- No
- No, but I would like more information

62. What would be the single most important change you would suggest to improve services to individuals with HIV/AIDS?

Thank you for completing this survey. Your input informs our decisions, guides our planning and is always appreciated and heard.

SCHEDULE 3: AIDS PREVALENCE AND HIV (NON AIDS) PREVALENCE DATA BY DEMOGRAPHIC GROUP & EXPOSURE CATEGORY

Demographic Group/ Exposure Category	2011- PREVALENCE AS OF 12/31/11		2012- PREVALENCE AS OF 12/31/12		2013- PREVALENCE AS OF 12/31/13		
	HIV	AIDS	HIV	AIDS	HIV	AIDS	TOTAL
<i>Race/Ethnicity</i>							
White, not Hispanic	818	1,108	853	1,113	891	1,145	2,036
Black, not Hispanic	714	1,111	749	1,133	786	1,162	1,948
Hispanic	546	846	569	864	602	899	1,501
Other / Unknown*	171	345	173	347	186	357	543
Total	2,249	3,410	2,344	3,457	2,465	3,563	6,028
<i>Gender</i>	HIV	AIDS	HIV	AIDS	HIV	AIDS	
Male	1,459	2,339	1,532	2,384	1,629	2,462	4,091
Female	790	1,071	812	1,073	836	1,101	1,937
Total	2,249	3,410	2,344	3,457	2,465	3,563	6,028
<i>Current Age as of 12/31/2013</i>	HIV	AIDS	HIV	AIDS	HIV	AIDS	
Unknown	2	0	2	0	2	0	2

Demographic Group/ Exposure Category	2011- PREVALENCE AS OF 12/31/11		2012- PREVALENCE AS OF 12/31/12		2013- PREVALENCE AS OF 12/31/13		
	<13 years	18	0	15	0	12	0
13 - 24 years	195	93	185	71	182	62	244
25 - 44 years	905	870	912	846	937	833	1,770
45 - 64 years	1,105	2,188	1,096	2,245	1,176	2,319	3,495
65+ years	114	259	134	295	156	349	505
Total	2,249	3,410	2,344	3,457	2,465	3,563	6,028
<i>Exposure Category</i>	HIV	AIDS	HIV	AIDS	HIV	AIDS	TOTAL
Men who have sex with men	857	1,160	913	1,199	975	1,248	2,223
Injection drug users	186	601	186	578	185	581	766
Men who have sex with men and inject drugs	60	133	61	137	67	138	205
Heterosexuals	732	973	755	986	789	1,011	1,800
Other/Unknown	414	543	429	557	449	585	1,034
Total	2,249	3,410	2,344	3,457	2,465	3,563	6,028