

**Paterson-Passaic County/  
Bergen County  
HIV Health Services Planning Council**

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Date  
**2014**

**Comprehensive HIV Needs Assessment:  
Spanish In-Care Consumer Survey Report**



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Bergen-Passaic Transitional Grant Area

Jose "Joey" Torres, Chief Elected Official and Mayor, City of Paterson

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## **EXECUTIVE SUMMARY**

In 2011, the Paterson-Passaic County – Bergen County HIV Health Services Planning Council commissioned a comprehensive needs assessment of persons living with HIV/AIDS in the two-county Transitional Grant Area (TGA). As part of the overall assessment, a survey of persons living with HIV/AIDS (PLWHA) disease was conducted in 2012. The sample included only PLWHA engaged in HIV medical care within the past twelve months.<sup>1</sup> Due to cost considerations, the survey was available in English only. During the field work, it became apparent that potential respondents were unable to complete the survey due to English language deficiencies. Recognizing a population that might have been overlooked in the initial survey, the Planning Council considered a second survey to be administered to Spanish speakers only.

According to the United States Census Bureau, 116,528 Spanish-speaking residents of the Bergen-Passaic TGA speak English “less than very well” in the home, constituting 31% of the Spanish population.<sup>2</sup> Translating this to 1,506 Hispanic persons living with HIV/AIDS in 2013,<sup>3</sup> as many as 469 or 11% of PLWHA may have English language deficiency. With this information, the Planning Council decided to move forward with a Spanish survey to complement the existing in-care survey.

The *goal* of the Spanish in-care survey is to assess the characteristics and needs of Spanish-speaking persons living with HIV/AIDS in the Bergen-Passaic TGA in order to facilitate their continued engagement and retention in medical care.

Related *objectives* are to:

- ❑ Quantify the size and characteristics of the Spanish-speaking HIV population in the Bergen-Passaic TGA;
- ❑ Document the service needs of PLWHA in the Bergen-Passaic TGA in support of engagement and retention in medical care;
- ❑ Identify emerging issues, needs and potential solutions for reducing the number of PLWHA who are may drop out of medical care; and
- ❑ Provide recommendations to the Paterson-Passaic County – Bergen County HIV Health Services Planning Council for the development of Part A services in the Bergen-Passaic TGA.

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<sup>1</sup> For the in-care consumer survey, the HRSA definition of “in care” is used: a patient who had an HIV medical visit, CD4 test or viral load test within the past twelve months. All Ryan White recipients are required to engage in medical care as a condition of service.

<sup>2</sup> U.S. Census Bureau, 2013 American Community Survey 1-Year Estimates, “Places of Birth by Language Spoken at Home and Ability to Speak Language in the United States” Universe Population 5 years and over in the United States.

<sup>3</sup> New Jersey Department of Health, Division of HIV/AIDS, Tb and STD Services. eHARS Surveillance as of December 31, 2013.

Information gained from the Spanish In-Care Survey will be used to establish service priorities and resource allocations for persons receiving assistance from the Ryan White Part A Program; provide additional information for the 2012-2015 Comprehensive HIV Health Services Plan for the Bergen-Passaic Transitional Grant Area (TGA); and guide activities designed to support the National HIV/AIDS Strategy, Healthy People 2020 and the Patient Protection and Affordable Care Act.

The Spanish In-Care Survey design includes these components:

- ❑ Characteristics of the infected population;
- ❑ Service needs assessment with regard to engagement in medical care:
  - Need and access to medical care, other core services and support services;
  - Barriers and issues related to the ability to maintain engagement in medical care.
- ❑ Attitudes and practices of the infected and at-risk population:
  - Issues related to universal HIV testing, informing, contact elicitation, referring and engagement in medical care;
  - High risk behaviors;
  - Attitudes about and practices of risk reduction methods.

Given the special nature and size of the survey population, a stratified convenience sample was selected. Only Spanish speaking PLWHA with limited or no English reading capacity were included in the sample. The survey was administered at eleven Part A funded agencies and one Part C medical clinic. All respondents interviewed at the agencies were engaged in HIV medical care.

A unique aspect of the administration was the use of a web-based interactive system using the eCOMPAS platform. Consumers completed the survey by logging into a secure portal in the eCOMPAS website. Respondents were permitted to complete the survey during multiple sessions without the need to return to the beginning each time. Privacy was assured at each provider site to reinforce the confidentiality of each respondent, also maintained by safeguards programmed into the eCOMPAS system.

Interpretation of the present findings must take into account issues related to the survey sample. While the survey was administered throughout the two-county area to all who qualified, the sample obtained (N=33) was decidedly small. Therefore, the sample cannot be considered generalizable to the entire Spanish-speaking community. Its findings must be used only to establish a broad profile that is reflective while perhaps not representative. Second, undercounts of Bergen County Spanish speakers do not provide sufficient data to fully understand the needs of the northern county residents. Further study of Bergen County PLWH is warranted. Third, as with the 2012 consumer survey, very few respondents admitted to illicit drug use either as a transmission mode or risk factor. This does not correlate with epidemiologic data that reports over 20% with drug involvement.

With these caveats in mind, the survey helps to draw a profile of Spanish speaking PLWHA in the Bergen-Passaic TGA. Its major characteristics are summarized as follows.

### Observations and Interpretation

Essentially, the Spanish-speaking in-care population is feeling well and connected to a system of care that strives to meet its needs. For the most part, respondents indicate that they are getting the care and services they need and identify relatively few outstanding or unmet needs. Issues arise, however, with timeliness of services applied for and received.

The following summarizes the major observations resulting from the survey responses:

- ❑ The sample depicts a population that has engaged in timely medical care and is essentially taking care of its health. Access barriers are few, but some are still notable. These include help with living costs, insurance, other bureaucratic restrictions, and information about services available to them.
- ❑ Spanish-speaking PLWH tend to be younger than all Hispanic PLWH, with 42% under age 45 compared with 29% in the epidemic. This may be a cultural difference worthy of note. Sixty-five percent of respondents were diagnosed since 2000, again reflective of the younger age cohort.
- ❑ At this point in the epidemic, the most common transmission mode was clearly sexual contact, either heterosexual or homosexual. Further, transmission via syringe injection had dwindled to an all-time low, and drug abuse was rarely reported among this HIV/AIDS population. This may be evidence of effective drug treatment programs or a general decline in the use of illicit drugs among the in-care population.
- ❑ Relatively low acuity levels with HIV-only diagnoses are more common than AIDS among Spanish-speaking PLWH. This is a trend that hopefully will continue.
- ❑ Presence of co-morbid conditions was reported less often among Spanish-speaking respondents, possibly reflective of the younger cohort.
- ❑ Spanish-speaking respondents made little mention of language problems, indicating that translation services were adequate for them. With low educational attainment common among this population, however, health literacy is still a matter of concern. This survey does not address this issue and further investigation is warranted.
- ❑ Transportation remains a needed support service, both for bus or van. Case managers should investigate every mode of transportation available and work with Spanish speaking clients to assure the ability to get to medical appointments.
- ❑ Oral health care was identified as a leading unmet need, despite the availability of services in both counties. Spanish-speaking patients must be educated about the need for regular oral health exams and treatment as well as access to available care.
- ❑ Nutrition services were perceived as separate from outpatient medical care where such services are typically rendered and considered a need. Their perceptions should be noted by primary care providers.

- ❑ Spanish-speaking respondents tended not to disclose their HIV status except to their primary relationships. Further, one-quarter did not share information about HIV with friends, family or others.
- ❑ Prevention practices were mostly a matter of personal choice. Condom use was the only significant practice identified by Spanish-speaking respondents. Either educational programs are not available in Spanish, or this is a subject of low priority among this population. Further investigation is warranted.

In previous needs assessments, respondents cited a need for “information” without specifying what they needed to know. In follow-up research, we learned that their information needs spanned not only knowledge of HIV disease but, even more, knowledge about the system of care and services available to help them to obtain and remain in medical care. From the current survey, these needs are apparent for Spanish-speaking PLWH as well.

To enlighten the survey results, we compared these responses to those of Hispanic responses in the 2012 In-Care Survey. In most cases, there were few significant differences between the two. However, some comparisons are notable. The Spanish speakers tended to be more economically and educationally compromised, receiving fewer social supports such as Section 8 housing. Spanish speakers tended to be more open with their spouses/partners, and more likely to be heterosexual, indicating greater importance of the home environment. Finally, Spanish speakers entered into care later than English-speaking Hispanic PLWHA, perhaps due to lack of information in their language about available services. It is important to recognize that these results are not conclusive, given the convenience sampling and small sample sizes. However, it would appear that ability to speak English would enhance early linkage to medical care.

### Recommendations

The system of care and services offered through the Ryan White Program is working to successfully keep Spanish speaking PLWHA in care. This consumer survey, however, underscores areas that would serve to keep that system relevant in today's TGA. Based on findings of the Spanish-speaking in-care consumer survey, the following recommendations are offered:

1. Enhance patient education in multiple languages to emphasize those aspects of care that are apparently misunderstood with regard to their importance. Emphasize early engagement in medical care to non-English speaking PLWH.
2. Continue to confront the major barriers of care retention, i.e., insurance issues, necessities of daily living and transportation. Resolve transportation issues through case management. Clarify coverage for co-pays and deductibles on behalf of each Ryan White enrollee. Continue to work with Spanish speakers in their own language.
3. Implement the recommendations of the Cultural Competency Task Force, and mandate providers to offer culturally proficient services across the entire Ryan White network.

4. Further investigate health literacy among PLWH, in particular those without English proficiency.
5. Continue to outreach to Latino youth, in particular young MSM, and mobilize the outreach, education and prevention efforts toward this population.
6. Balance the findings of this survey with follow-up on Bergen County PLWHA. Determine the extent to which this county may be underserved and possible contributing factors.

**I. INTRODUCTION**

**A. OVERVIEW AND METHODOLOGY**

**Overview**

In 2011, the Paterson-Passaic County – Bergen County HIV Health Services Planning Council commissioned a comprehensive needs assessment of persons living with HIV/AIDS (PLWHA) in the two-county Transitional Grant Area (TGA). As part of the overall assessment, a survey of persons with HIV/AIDS spectrum disease was conducted in 2012. The sample included only PLWHA engaged in HIV medical care within the past twelve months.<sup>4</sup> Respondents were recruited from the Bergen-Passaic Part A Program as well as the Ryan White Part C Program in Paterson. Two hundred fifty-two (N) survey responses were completed and incorporated into the analysis.

Due to cost considerations, the survey was available in English only. During the field work, it became apparent that potential respondents were unable to complete the survey due to English language deficiencies. Recognizing a population that might have been overlooked in the initial survey, the Planning Council considered a second survey to be administered to Spanish speakers only.

According to the United States Census Bureau, 116,528 Spanish-speaking residents of the Bergen-Passaic TGA speak English “less than very well” in the home, constituting 31% of the Spanish population.<sup>5</sup> Translating this to 1,506 Hispanic persons living with HIV/AIDS in 2013,<sup>6</sup> as many as 469 or 11% of PLWHA may have English language deficiency. With this information, the Planning Council decided to move forward with a Spanish survey to complement the 2012 in-care survey.

**Goals and Objectives**

The *goal* of the Spanish in-care survey is to assess the characteristics and needs of Spanish-speaking persons living with HIV/AIDS in the Bergen-Passaic TGA in order to facilitate their continued engagement and retention in medical care.

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<sup>4</sup> For the in-care consumer survey, the HRSA definition of “in care” is used: a patient who had an HIV medical visit, CD4 test or viral load test within the past twelve months. All Ryan White recipients are required to engage in medical care as a condition of service.

<sup>5</sup> U.S. Census Bureau, 2013 American Community Survey 1-Year Estimates, “Places of Birth by Language Spoken at Home and Ability to Speak Language in the United States” Universe Population 5 years and over in the United States.

<sup>6</sup> New Jersey Department of Health, Division of HIV/AIDS, Tb and STD Services. eHARS Surveillance as of December 31, 2013.

Related objectives are to:

- ❑ Quantify the size and characteristics of the Spanish-speaking HIV population in the Bergen-Passaic TGA;
- ❑ Document the service needs of PLWHA in the Bergen-Passaic TGA in support of engagement and retention in medical care;
- ❑ Identify emerging issues, needs and potential solutions for reducing the number of PLWHA who are may drop out of medical care; and
- ❑ Provide recommendations to the Paterson-Passaic County – Bergen County HIV Health Services Planning Council for the development of Part A services in the Bergen-Passaic TGA.

Information gained from the Spanish In-Care Survey will be used to establish service priorities and resource allocations for persons receiving assistance from the Ryan White Part A Program; provide additional information for the 2012-2015 Comprehensive HIV Health Services Plan for the Bergen-Passaic Transitional Grant Area (TGA); and guide activities designed to support the National HIV/AIDS Strategy, Healthy People 2020 and the Patient Protection and Affordable Care Act.

### **Methodology**

The Spanish In-Care Survey addresses PLWHA in Bergen County and Passaic County, New Jersey who speak Spanish as their primary language and who are in care. In-care PLWHA were surveyed directly at Ryan White program sites in both counties.

The Spanish In-Care Survey design includes these components:

- ❑ Characteristics of the infected population;
- ❑ Service needs assessment with regard to engagement in medical care:
  - Need and access to medical care, other core services and support services;
  - Barriers and issues related to the ability to maintain engagement in medical care.
- ❑ Attitudes and practices of the infected and at-risk population:
  - Issues related to universal HIV testing, informing, contact elicitation, referring and engagement in medical care;
  - High risk behaviors;
  - Attitudes about and practices of risk reduction methods.

The survey utilized the 2012-2013 Consumer Survey instrument in order to maintain continuity between the original survey and the follow-up Spanish survey. The instrument was designed to obtain information for each component listed above and includes 51 questions on the following topics:

- ❑ Initial screening of PLWHA to determine whether they are in-care or out-of-care;
- ❑ Demographic characteristics;
- ❑ Experiences with diagnosis and linkage to HIV medical care;
- ❑ Barriers to receiving HIV medical care;

- ❑ Co-morbid conditions;
- ❑ Substance abuse treatment needs;
- ❑ Prevention practices;
- ❑ Use of and need for 26 distinct services included in the Bergen-Passaic Ryan White Continuum of Care.
- ❑ Suggestions for provision of care and services.

The survey was translated into Spanish by a certified translator and validated by Spanish speakers from the Ryan White Grantee office.

### **Survey Sampling Approach**

Given the special nature and size of the survey population, a stratified convenience sample was selected. Only Spanish speaking PLWHA with limited or no English reading capacity were included in the sample. The survey was administered at eleven Part A funded agencies and one Part C medical clinic. Each agency was asked to publicize the opportunity to participate in the survey. All providers were supportive in identifying dates and times that would yield the greatest number of survey respondents. All respondents interviewed at the agencies were engaged in HIV medical care.

Survey responses were entered directly by the respondent into the RDE-developed eCOMPAS database. Each respondent was assigned an eCOMPAS identification number to prevent duplicate responses. Respondents were required to answer each question before moving on to the next, thereby assuring completeness. Some questions were programmed with skip logic to assure proper sequencing when the respondent was required to move to a specific question following the answer. For example, when asked a true/false question, the respondent would be taken directly to the correct next question based on the true or false answer. The respondent did not need to follow instructions embedded in the instrument; this was done directly online. Data validity was greatly enhanced by this approach.

Statistical reports were generated by eCOMPAS. Consultants from New Solutions, Inc. worked with RDE to facilitate the calculations and graphical display. Statistical analyses included frequencies and cross tabulations. Total service need, met and unfulfilled need calculations were performed along with detailed information on barriers to care. Throughout this document, unless otherwise noted, percentages are based on number of respondents (n) who answered the specific question in the survey.

### **Survey Administration**

The sample was drawn largely from the clients of Ryan White Part A and Part C funded providers. A unique aspect of the administration was the use of a web-based interactive system using the eCOMPAS platform. Consumers completed the survey by logging into a secure portal in the eCOMPAS website and answering questions directly online. Safeguards

were incorporated into the program to assure proper sequencing of the survey questions. In addition, a unique identifier for each respondent was programmed to limit the respondents to one survey only.

Respondents were permitted to complete the survey during multiple sessions without the need to return to the beginning each time. If the respondent did not complete the survey, the record was entered into the database but labeled “incomplete.” Respondents were allowed to attempt the survey as many times as necessary to complete it. Once having done so, that respondent could no longer access the system. Only completed surveys were counted in the final sample.

Privacy was assured at each provider site to reinforce the confidentiality of each respondent. Surveys typically required 20 to 35 minutes for completion, with most requiring approximately 25 minutes. To facilitate the use of the computer for those with limited computer knowledge or experience, a survey administrator, who was not a direct service provider, was assigned at each provider site and responsible for administration of all surveys at that site. The administrator was available to assist the consumer but did not directly administer the survey, thereby allowing the consumer to select responses objectively. Survey administrators received an orientation and training prior to implementation of the survey. The survey administrators at each location assisted with initiation of the survey (logging in), answering respondents' questions about the need for the survey, providing assistance with the mechanics of using a computerized survey instrument and checking to confirm completion of the survey questions. Confidentiality and anonymity were maintained by safeguards programmed into the eCOMPAS system.

### **Limitations**

As is the case with the administration of specialized surveys, some data limitations were identified. Many of these were minimized through the eCOMPAS program as well as the presence of on-site interviewers who worked with consumers as they completed the survey. Nevertheless, potential data limitations included:

- ❑ The in-care survey was administered through Ryan White funded agencies and may not have represented the entire HIV infected population in the region.
- ❑ Inexperience with computers and online survey methods may have limited respondents' ability to complete the survey.
- ❑ Although misunderstanding or misinterpreting words or terms was minimized through survey validation with consumers and on-site facilitation by survey interviewers, some respondents may not have completely understood the questions due to low literacy levels.
- ❑ Forced selection of responses without the options of “not applicable,” “don't know” or “refused” may have skewed some responses.

- ¶ Although the possibility of selecting contradictory responses which was minimized through limitations of such questions and the eCOMPAS program, some inconsistencies were found. These responses were considered invalid and excluded from the results.

## **Data Analysis**

The eCOMPAS database was developed for data analysis. Both eCOMPAS and Microsoft Excel were used for tabulating results.

### **B. RESPONDENT OVERVIEW**

The survey sample under study consisted of 33 (N) completed responses. The sample reasonably conformed to the sampling plan and to the regional epidemic (Bergen-Passaic TGA).<sup>7</sup> Variations from the epidemic in the region suggest over- and under-sampling of some populations, namely age, PLWHA from Bergen County and injecting drug users.<sup>8</sup>

#### ***Gender***

- ¶ Males and females were proportionately represented in the sample. The survey sample included 70% male respondents and 30% female. This compared to 68% Hispanic males and 32% Hispanic females infected in the region.

**Table I.1**  
**Comparison of Survey Sample with Regional Epidemic**  
**Gender**

<b>Total Sample (N = 33)</b>	<b>In-Care Sample</b>		<b>B-P TGA</b>	
	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>
<b>Gender</b>				
Hispanic Male	23	70%	997	68%
Hispanic Female	10	30%	463	32%
Hispanic Transgender	0	<1%	0	NA

#### ***Race/Ethnicity***

- ¶ All respondents were Hispanic.  
¶ Regionally, Hispanics comprised 34% of all PLWHA.

<sup>7</sup> Persons living with HIV/AIDS as of December 31, 2013. HIV/AIDS Incidence Diagnosed in 2011, 2012 and 2013 by Gender and Other Characteristics. Source: New Jersey Department of Health, Division of HIV/AIDS, STD and TB Services (NJ-DHSTS).

<sup>8</sup> In all tables that follow, values less than five are removed (\*) to maintain confidentiality.

**Table I.2**  
**Comparison of Survey Sample with Regional Epidemic**  
**Race/Ethnicity**

	In-Care Sample		B-P TGA	
Total Sample (N = 33)	Number	Percent	Number	Percent
Race/Ethnicity				
Hispanic	33	100%	1,460	34%

Note: eHARS data does not specify ethnicity by race.

### **Age**

- ❑ The sample population had three times the population under age 25 (9%) as compared to the TGA (3%).
- ❑ The 25 to 44 age cohort comprised 26% of the epidemic and 33% of the survey sample.
- ❑ The 45+ age cohort was 71% of the epidemic and 58% of the sample. (Table I.3)

**Table I.3**  
**Comparison of Survey Sample with the Regional Epidemic**  
**Age**

	In-Care Sample		B-P TGA	
Total Sample (N = 33)	Number	Percent	Number	Percent
Age				
< 25	*	9%	129	3%
25-44	11	33%	1,122	26%
>45	19	58%	3,068	71%

\*Less than 5

### **Residence**

- ❑ 94% of survey respondents identified their residence location as Passaic County and 6% as Bergen County. The epidemic had 29% from Bergen County and 71% from Passaic County, suggesting that the survey sample under-represented Bergen County by 24 points and over-represented Passaic County by 23 points. (Table I.4)

**Table I.4**  
**Comparison of Survey Sample with the Regional Epidemic**  
**County of Residence**

<b>Total Sample (N = 33)</b>	<b>In-Care Sample</b>		<b>B-P TGA</b>	
	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>
<b>Residence</b>				
Bergen County Hispanic	*	6%	424	29%
Passaic County Hispanic	31	94%	1,036	71%
Other	0	0%		

\*Less than 5

One possible reason for the under-representation of Bergen County may be that the majority of Ryan White agencies are located in Passaic County. However, it may be suggested that Bergen County consumers do not utilize Ryan White services to the extent found in Passaic County.

#### **Transmission Mode**

The most frequently identified HIV transmission categories included in the sample were heterosexual contact (49%), male-to-male sex (MSM) (30%), and Other/Unknown Risk (15%). NJ-DHSTS surveillance data identified the following risk categories for PLWHA in the Bergen-Passaic TGA: heterosexual contact (47%), MSM and MSM/ICU (24%), IDU (15%), and Other/risk not reported (15%). New diagnoses of HIV/AIDS (2011-2013) were more closely aligned to the survey sample with MSM reported at 28%. (Table I.5)

 Because the consumer survey permitted respondents to identify more than one transmission mode, comparisons with the regional epidemic cannot be determined with accuracy. It would appear, however, that the sample reasonably conformed.

**Table I.5**  
**Comparison of Survey Sample with the Regional Epidemic**  
**Transmission Mode**

<b>Total Sample (N = 33)</b>	<b>In-Care Sample</b>		<b>B-P TGA PLWHA</b>		<b>B-P TGA Newly Diagnosed 2011-2013</b>	
	<b>Number</b>	<b>Percent</b>	<b>Number</b>	<b>Percent</b>		
<b>Transmission Mode</b>						
MSM	10	30%	764	18%	111	28%
IDU	*	6%	627	15%	16	4%
MSM/IDU	NA	NA	256	6%	*	<1%
Heterosexual Contact	16	49%	2,017	47%	114	29%
Other/Unknown Risk	5	15%	655	15%	156	39%

Note: Respondents were allowed to identify more than one transmission mode.

\*Less than 5

## **II. DEMOGRAPHIC CHARACTERISTICS OF THE SURVEY POPULATION**

### **SUMMARY**

This chapter analyzes characteristics the Spanish-speaking in-care population. Significant observations comparing gender, age, and residence are summarized as follows.

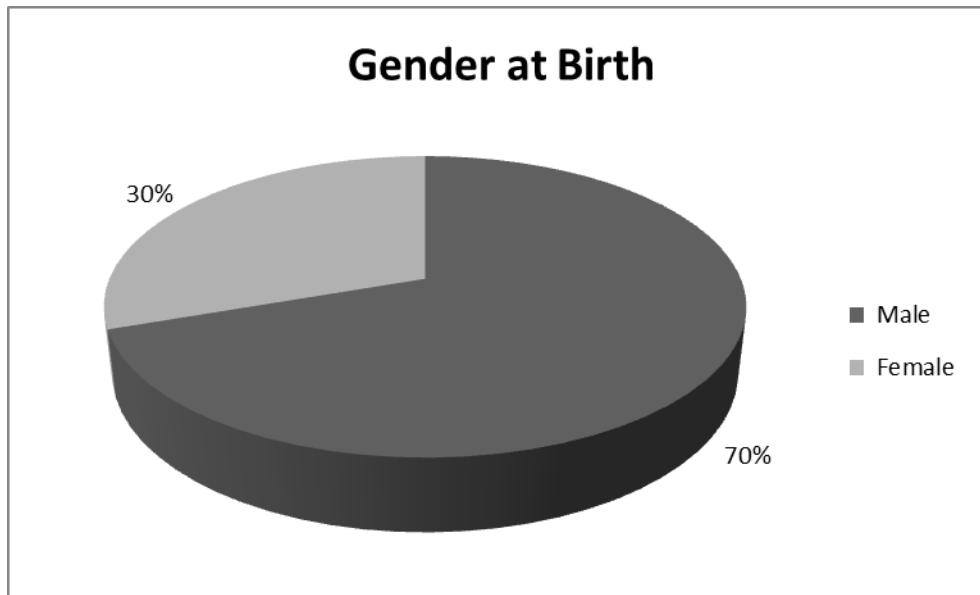
The consumer survey presents a profile of PLWHA that is predominantly male, urban, low income and poorly educated. The following summarizes some of the major characteristics:

- ❑ The traditionally large percentage of female PLWHA in the Bergen-Passaic TGA is not reflective of the Spanish-speaking in-care population.
- ❑ Three-quarters of respondents were foreign born, all from Hispanic countries.
- ❑ Spanish speaking respondents appeared to be younger than the PLWHA population at large. One-third of respondents were aged 25-44 and 56% of those surveyed were over age 45, compared to 71% in the same age cohort within the TGA.
- ❑ Fifty-eight percent reported to be heterosexual.
- ❑ Eighty-two percent resided in the urban epicenters of Paterson and Passaic. Ninety percent from Passaic County lived in Paterson or Passaic City.
- ❑ Eighty-five percent of respondents lived in permanent housing. The remainder lived with family and friends or congregate facilities. No respondents lived in shelters or on the street.
- ❑ Greater than one-third (36%) lived alone, and about 15% lived with their children.
- ❑ A small percentage (3%) had been incarcerated within the past year.
- ❑ More than 60% reported annual incomes of less than \$20,000.

**A. GENDER**

The in-care survey sample included 30% female and 70% male respondents.

**Figure II.1**



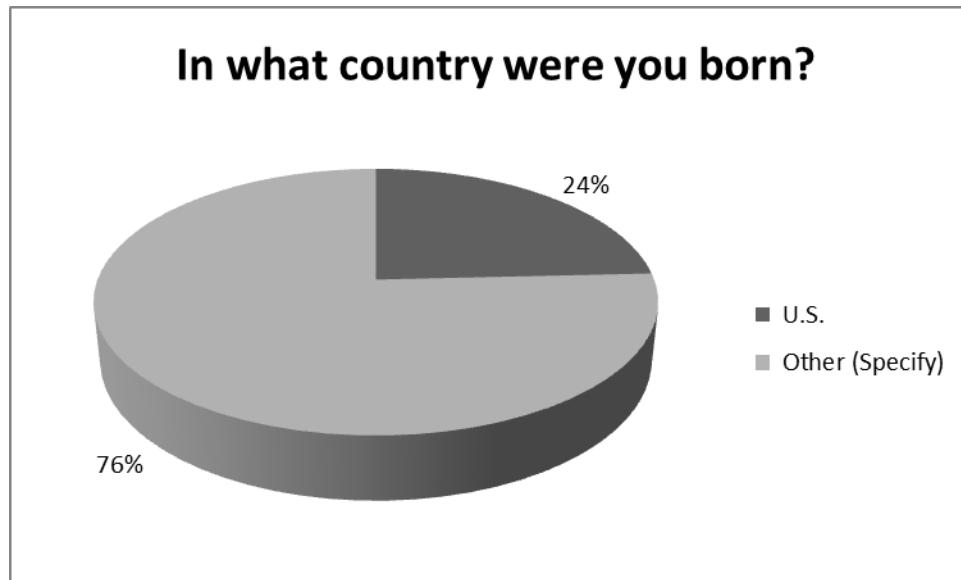
**Table II.1**

Gender at Birth		
Answer (N = 33)	#	%
Male	23	69.7%
Female	10	30.3%

**B. RACE/ETHNICITY AND COUNTRY OF ORIGIN**

All respondents were Hispanic. Three-quarters were born outside the United States. Survey respondents originated from: Mexico (6), Columbia (4), Peru (4), Puerto Rico (3), Santo Domingo (3), Argentina (1), Bolivia (1), Dominican Republic (1) and Venezuela (1).

**Figure II.2**



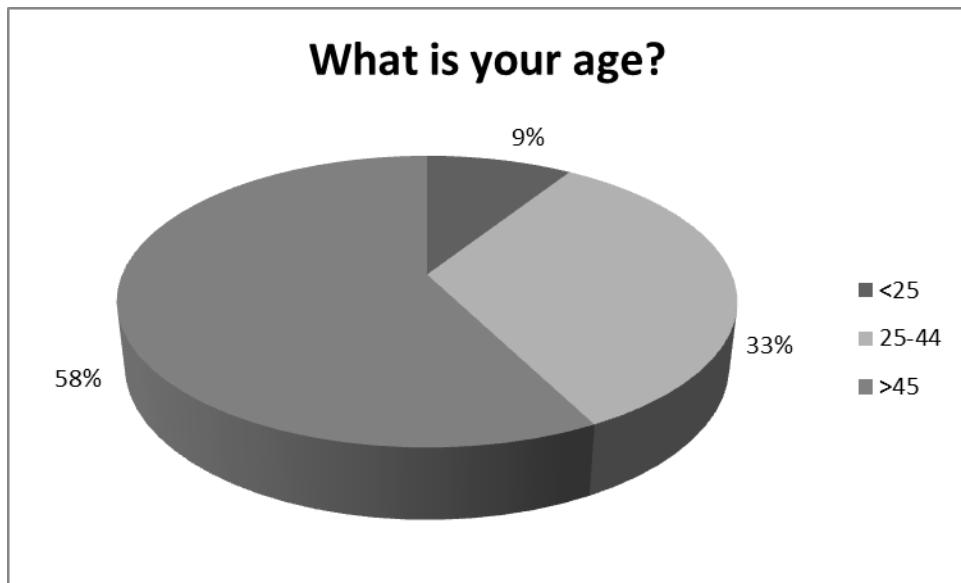
**Table II.2**

In what country were you born?		
Answer (N = 33)	#	%
U.S.	8	24.2%
Other	25	75.8%

**C. AGE**

Greater than half (58%) of survey respondents were age 45 and older. Among younger respondents, less than five (9%) were under 25 years, and 11 (33%) between the ages of 25 and 44 years.

**Figure II.3**



**Table II.3**

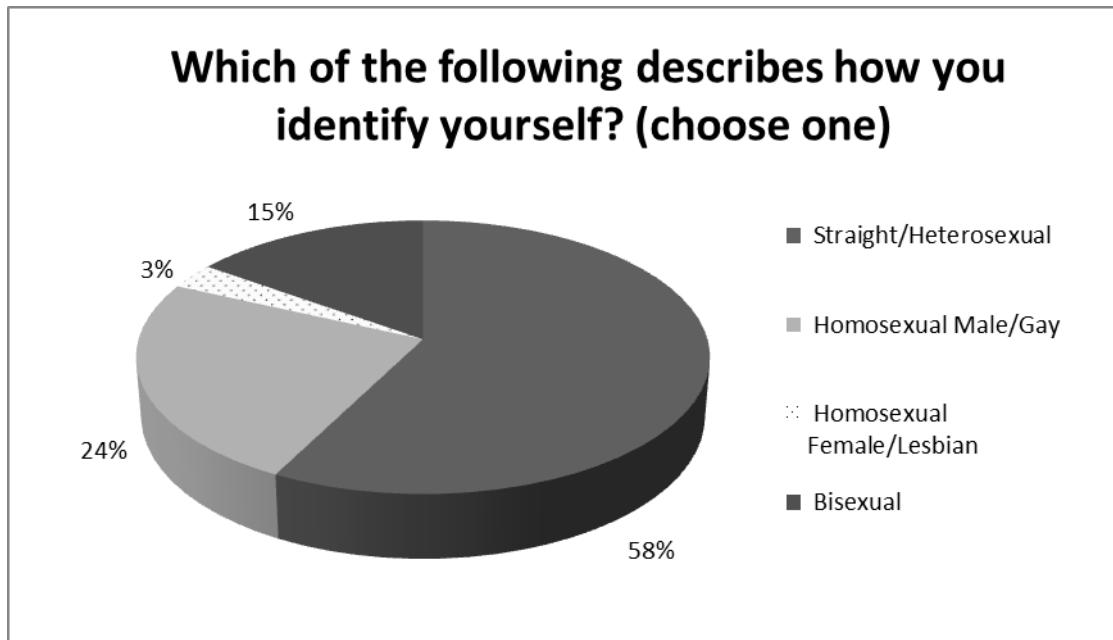
What is your age?		
Answer (N = 33)	#	%
<25	*	9.1%
25-44	11	33.3%
>45	19	57.6%

\*Less than 5

**D. SEXUAL ORIENTATION**

Fifty-eight percent of survey respondents reported their sexual orientation as straight/heterosexual. Homosexual/gay males comprised 24%. Fifteen percent were bisexual.

**Figure II.4**



**Table II.4**

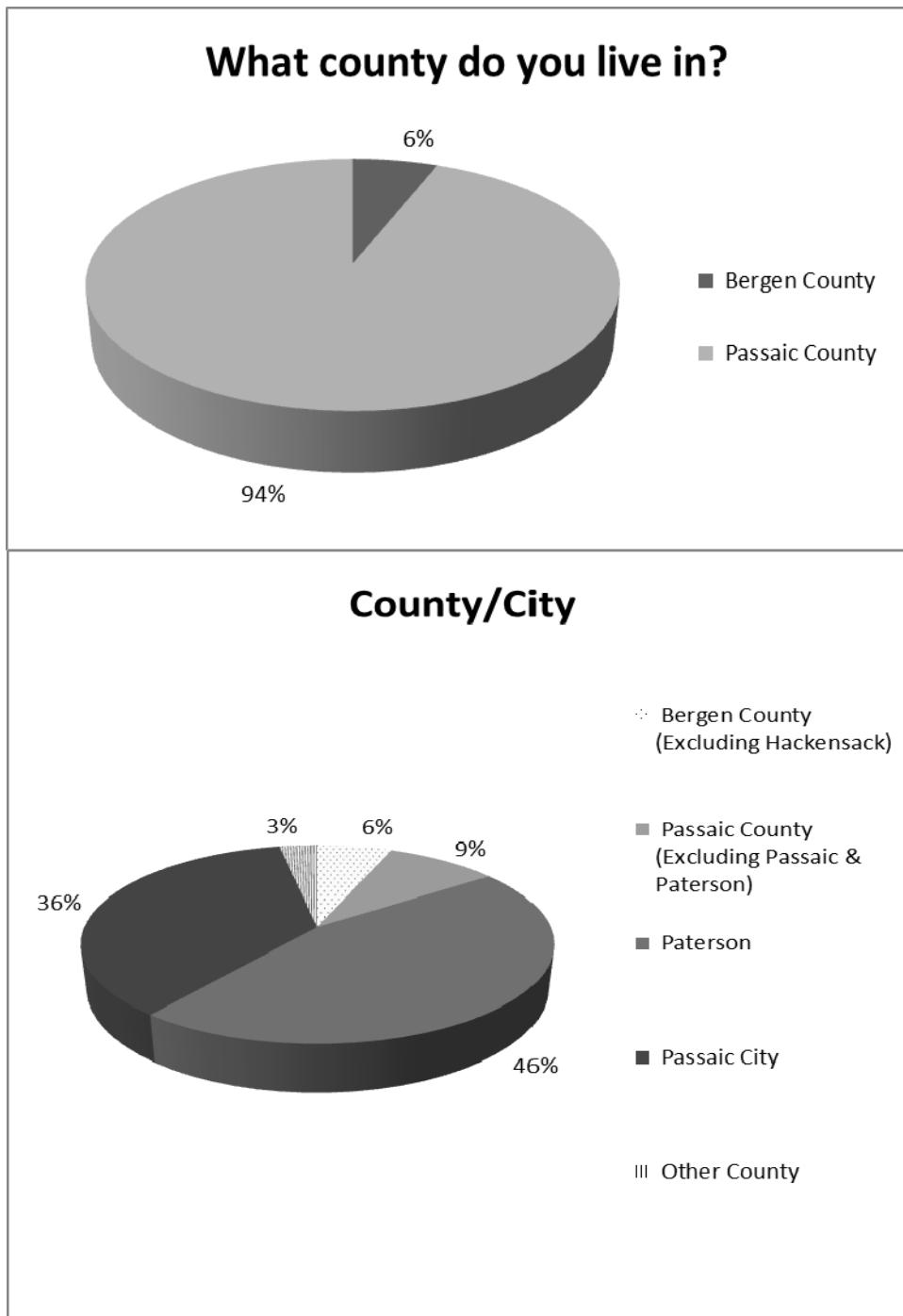
Which of the following describes how you identify yourself? (choose one)		
Answer (N = 33)	#	%
Straight/Heterosexual	19	57.6%
Homosexual Male/Gay	8	24.2%
Homosexual Female/ Lesbian	*	3.0%
Bisexual	5	15.2%

\*Less than 5

**E. RESIDENCE**

With 94% of respondents from Passaic County, almost all resided either in Paterson or Passaic City. These two cities were home to 82% of survey respondents.

**Figure II.5**



**Table II.5**

<b>What county do you live in?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
Bergen County	*	6.1%
Passaic County	31	93.9%
Other county	0	0.0%

<b>County/City</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
Bergen County (Not including Hackensack)	*	6.1%
Passaic County (Not including Passaic or Paterson)	*	9.1%
Paterson	15	45.5%
Passaic City	12	36.4%
Hackensack	0	0.0%
Other County	*	3.0%

\*Less than 5

## **F. HOUSING**

Eighty-five percent of survey respondents rented or owned their house, apartment or condo without assistance from Section 8 or Housing Opportunities for People with AIDS (HOPWA). No survey respondent indicated participation in these programs.

- ❑ Smaller percentages included:
  - 9% resided with family or friends
  - 6% lived in congregate housing for people with HIV

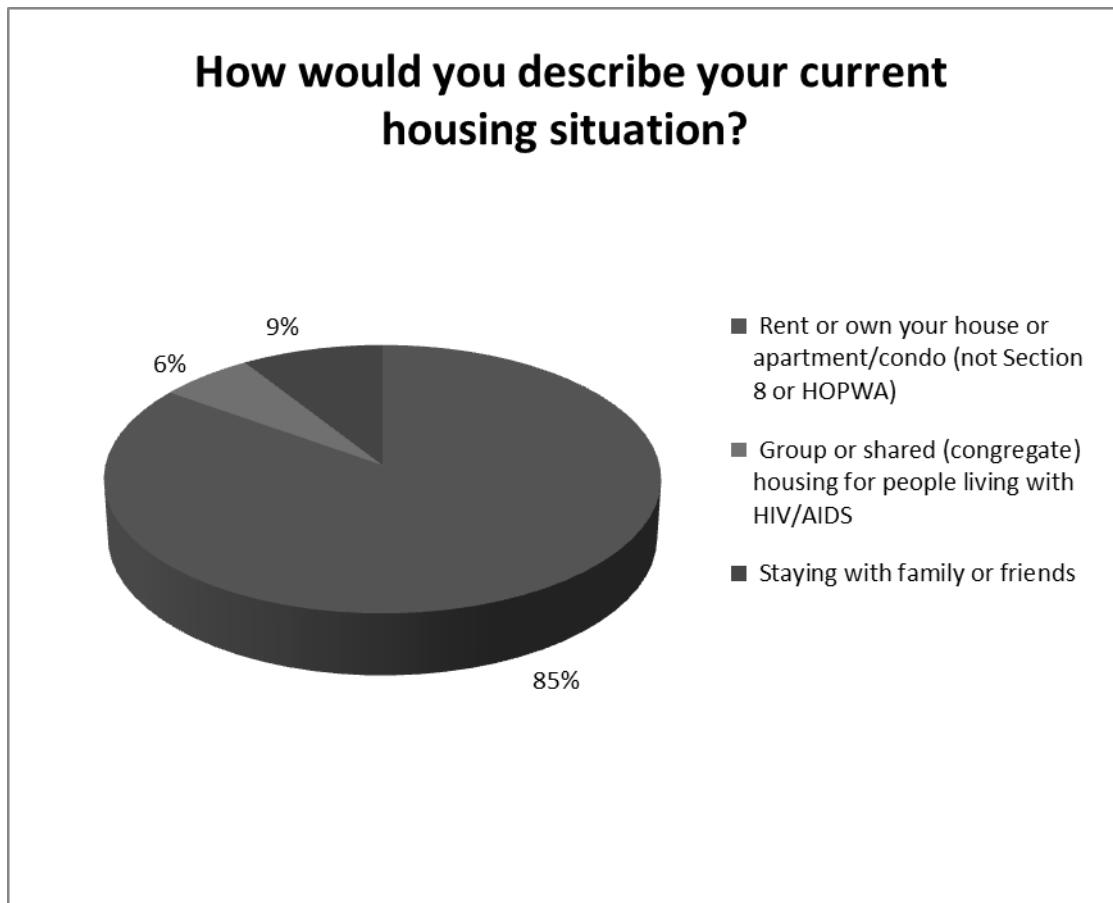
Slightly more than one-third (36.4%) of respondents lived alone.

- ❑ 33% lived with a spouse or partner.
- ❑ 18% lived with spouse/partner without children.

Eighteen percent reported living with children with either spouse/partner or with family and friends.

- ❑ 15% lived with spouse/partner with children.
- ❑ 3% lived with other family/friends with children.

**Figure II.6**

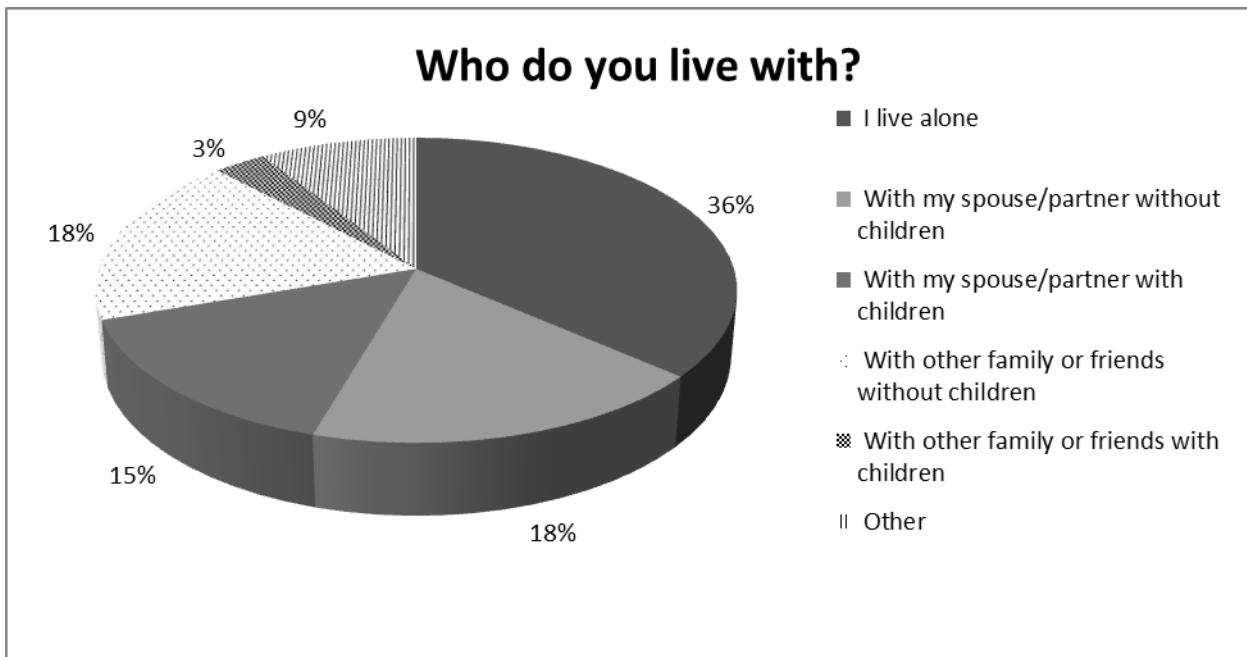


**Table II.6**

<b>How would you describe your current housing situation?</b>		
<b>Answer (n=33)</b>	<b>#</b>	<b>%</b>
Rent or own your house or apartment/condo (not Section 8 or HOPWA)	28	84.9%
Rent or own your house or apartment/condo (with Section 8 or HOPWA)	0	0.0%
Group or shared (congregate) housing for people living with HIV/AIDS	*	6.1%
Staying with family or friends	*	9.1%
Temporary/transitional housing, treatment facility or halfway house	0	0.0%
Shelter	0	0.0%
Adult foster care or hospice	0	0.0%
On the street/no home	0	0.0%
Other (Specify)	0	0.0%

\*Less than 5

**Figure II.7**



**Table II.7**

Who do you live with?		
Answer (N = 33)	#	%
I live alone	12	36.4%
With my spouse/partner without children	6	18.2%
With my spouse/partner with children	5	15.2%
With other family or friends without children	6	18.2%
With other family or friends with children	*	3.0%
Other	*	9.1%

\*Less than 5

#### **G. INCARCERATION**

Ninety-seven percent (32) of Spanish-speaking in-care survey respondents reported not being in jail or prison in the last 12 months.

**Table II.8**

<b>Have you been in jail or prison in the last 12 months?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
<b>Yes</b>	*	3.0%
<b>No</b>	32	97.0%

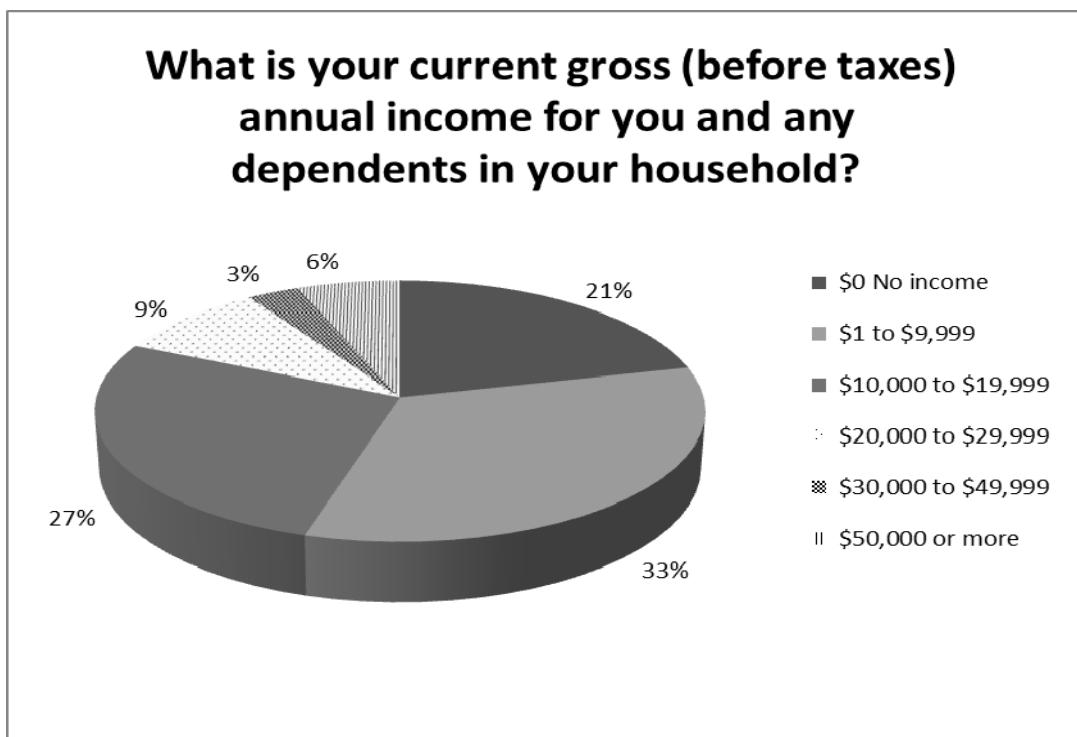
\*Less than 5

**H. INCOME**

Sixty percent of the Spanish-speaking in-care survey participants received Ryan White funding for at least one service. Therefore, it can be assumed that many of these consumers had low socioeconomic status. Responses to a question about annual household income confirmed this fact.

- ❑ One-third of Spanish-speaking in-care survey respondents reported current gross (before taxes) annual household income between \$1 and \$9,999.
- ❑ This was followed by 27% reporting incomes of \$10,000 to \$19,999.
- ❑ Over 20% reported no income.
- ❑ Eighteen percent reported incomes ranging from \$20,000 to \$50,000 or more.

**Figure II.8**



**Table II.9**

<b>What is your current gross (before taxes) annual income for you and any dependents in your household?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
\$0 No income	7	21.2%
\$1 to \$9,999	11	33.3%
\$10,000 to \$19,999	9	27.3%
\$20,000 to \$29,999	*	9.1%
\$30,000 to \$49,999	*	3.0%
\$50,000 or more	*	6.1%

\*Less than 5

#### **H. EDUCATION**

Consumers' educational background varied widely.

- ❑ Thirty-six percent of in-care survey respondents had less than a high school education. This included 15% who had not attended high school (eighth grade or less) and 21% who had attended some high school but had not graduated.
- ❑ One-third (33%) completed high school or obtained a graduate equivalency degree (GED).
- ❑ Approximately 15% had some type of college education including some college (6%), completed college (6%) and graduate school (3%).

Figure II.9

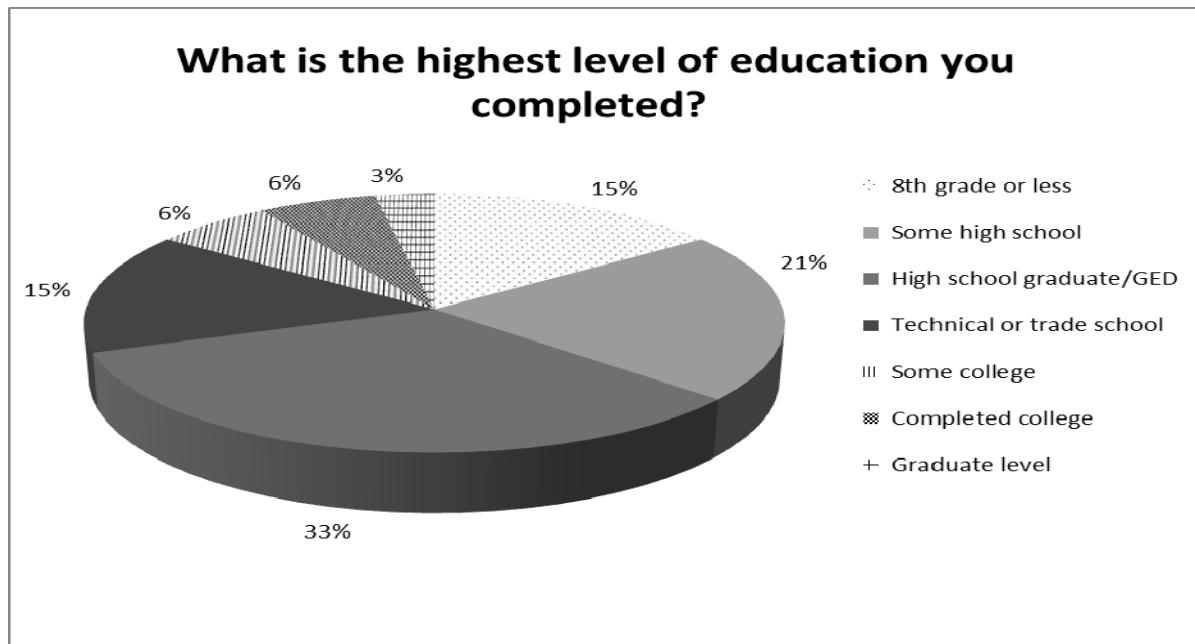


Table II.10

What is the highest level of education you completed?		
Answer (N = 33)	#	%
8th grade or less	5	15.2%
Some high school	7	21.2%
High school graduate/GED	11	33.3%
Technical or trade school	5	15.2%
Some college	*	6.1%
Completed college	*	6.1%
Graduate level	*	3.0%

\*Less than 5

### **III. HEALTH-RELATED TOPICS**

#### **SUMMARY**

This chapter reviews questions pertaining to HIV engagement, care, retention and related health conditions. Major observations are as follows:

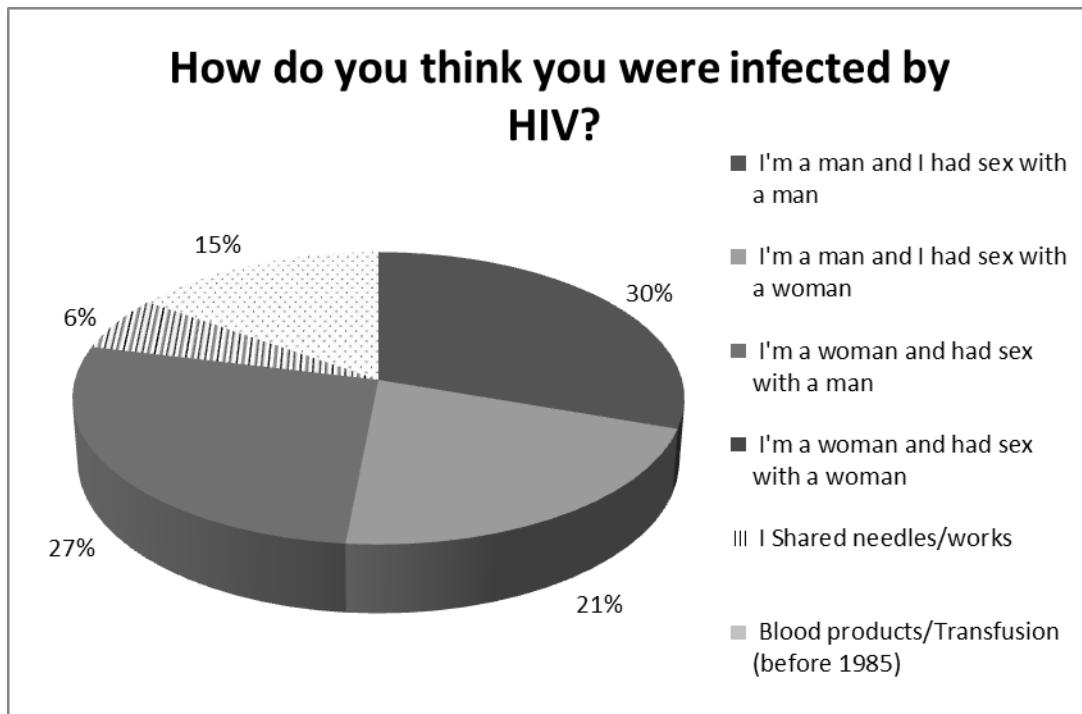
- ❑ Sexual transmission accounted for nearly all HIV infections. Heterosexual transmission was most prevalent among Spanish-speaking in-care women (90%) and 30% of men in this survey. Male-to-male sex accounted for 44% of PLWHA in the survey.
- ❑ Sixty-five percent of respondents tested positive for HIV since 2000.
- ❑ Only 15% received a diagnosis of AIDS, which was below the regional average of 54%.
- ❑ Almost 40% of respondents decided to tell their spouse/regular partner about their results when receiving a positive HIV diagnosis. Spouses/partners and other family members were told most often.
- ❑ Eighty-two percent entered into care within one month of diagnosis.
- ❑ No survey participants waited six months or more for their first medical visit. When asked about reasons for missing medical appointments, not feeling well, stigma and long wait time were mentioned most often.
- ❑ Co-morbid conditions were identified by 30% of survey respondents, citing mental health problems and hepatitis C most frequently.
- ❑ Less than 20% reported some form of substance abuse, most often tobacco. Transportation was identified as most needed by substance abusers.
- ❑ Forty-two percent of respondents said they were sexually active. Of those who were sexually active, 64% said they always use protection. When asked of those who did not use protection, personal or partner preference were mentioned most often.
- ❑ Sharing HIV information was routine for over three-quarters of survey respondents. Reasons for not discussing HIV most often related to denial and stigma. Free condoms were used most often than other prevention services.
- ❑ Forty-six percent of survey respondents have identified others who may have been exposed to the virus. When asked if they know anyone who is HIV-positive, every participant answered “no.”

#### **A. DIAGNOSIS AND TRANSMISSION**

##### **Transmission Mode**

- ❑ 90% of women cited heterosexual transmission.
- ❑ 44% of men cited homosexual transmission. This was followed by male heterosexual transmission, 30%.

**Figure III.1**



**Table III.1**

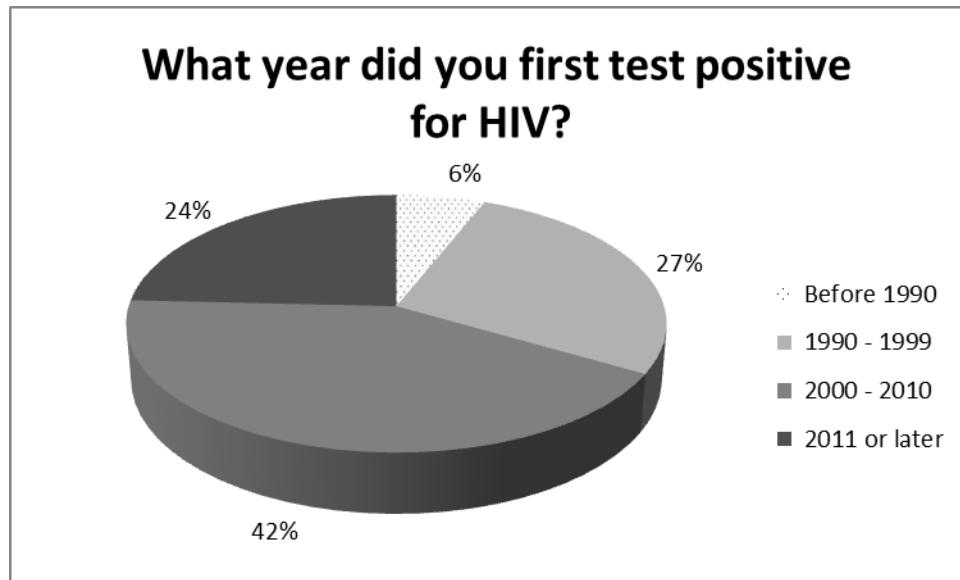
How do you think you were infected by HIV?		
Answer (N = 33)	#	%
I'm a man and I had sex with a man	10	30.3%
I'm a man and I had sex with a woman	7	21.2%
I'm a woman and had sex with a man	9	27.3%
I'm a woman and had sex with a woman	0	0.0%
I Shared needles/works	*	6.1%
Blood products/Transfusion (before 1985)	0	0.0%
I was a baby born to a mother with HIV/AIDS/Acquired at Birth	0	0.0%
Don't Know	5	15.2%

\*Less than 5

**Diagnosis**

Slightly more than 40% of respondents first tested positive for HIV between 2000 and 2010.

**Figure III.2**



**Table III.2**

What year did you first test positive for HIV?		
Answer (N = 33)	#	%
Before 1990	*	6.1%
1990 - 1999	9	27.3%
2000 - 2010	14	42.4%
2011 or later	8	24.2%

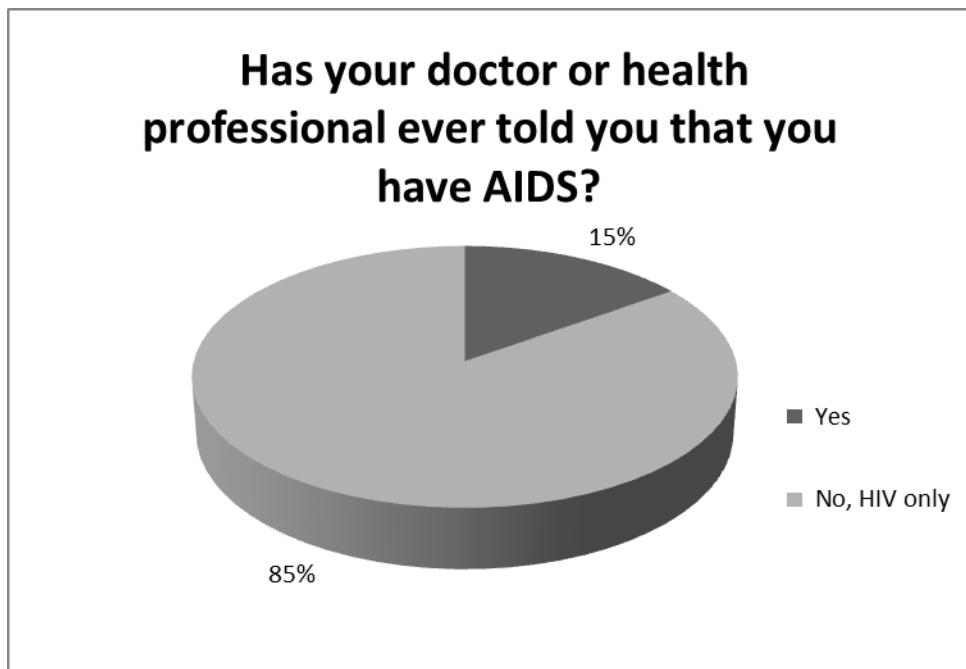
\*Less than 5

### **AIDS Diagnosis**

Fifteen percent had been told by a doctor or health professional that they have AIDS.

- ❑ 85% had not received an AIDS diagnosis

**Figure III.3**



**Table III.3**

Has your doctor or health professional ever told you that you have AIDS?		
Answer (N = 33)	#	%
Yes	5	15.2%
No, HIV only	28	84.9%
Don't know	0	0.0%

### **Disclosure**

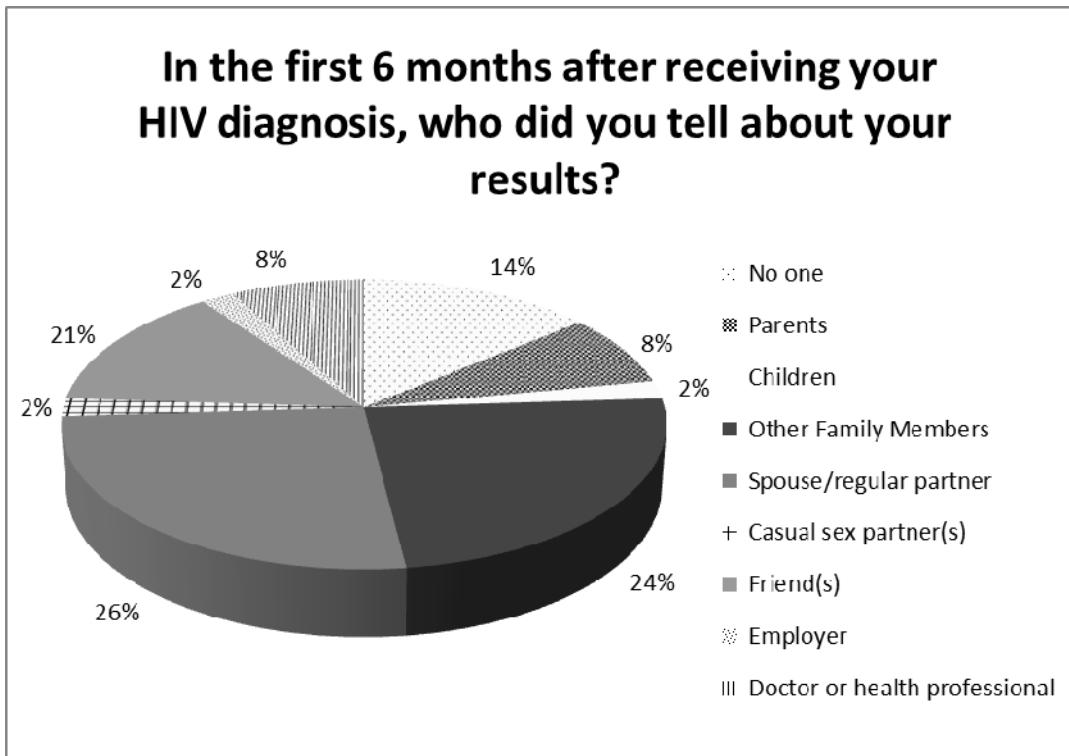
Survey respondents were asked, "In the first six months after receiving your HIV diagnosis, who did you tell about your results?"<sup>9</sup>

- ❑ The most frequent answer was "spouse/regular partner," cited by 39% of respondents.
- ❑ This was followed by "other family members" with 36%.
- ❑ 21% of respondents told their friends and an additional 21% told no one.

<sup>9</sup> Respondents were allowed to provide multiple responses. The total number of responses for this question is 50; however, percentages are calculated on the number of respondents who answered the question (33).

Red ribbon icon: Nearly 18% told their parents, and 17% told friend(s).  
 Participants who indicated they did not tell anyone of their diagnoses commonly cited “fear of rejection” as their reason for non-disclosure.

**Figure III.4**



**Table III.4**

In the first 6 months after receiving your HIV diagnosis, who did you tell about your results?		
Answer (N = 33)	#	%
No one	7	21.2%
Parents	*	12.1%
Children	*	3.0%
Other Family Members	12	36.4%
Spouse/regular partner	13	39.4%
Casual sex partner(s)	*	3.0%
Friend(s)	7	21.2%
Employer	*	3.0%
Doctor or health professional	*	12.1%
Other	0	0.0%

\*Less than 5

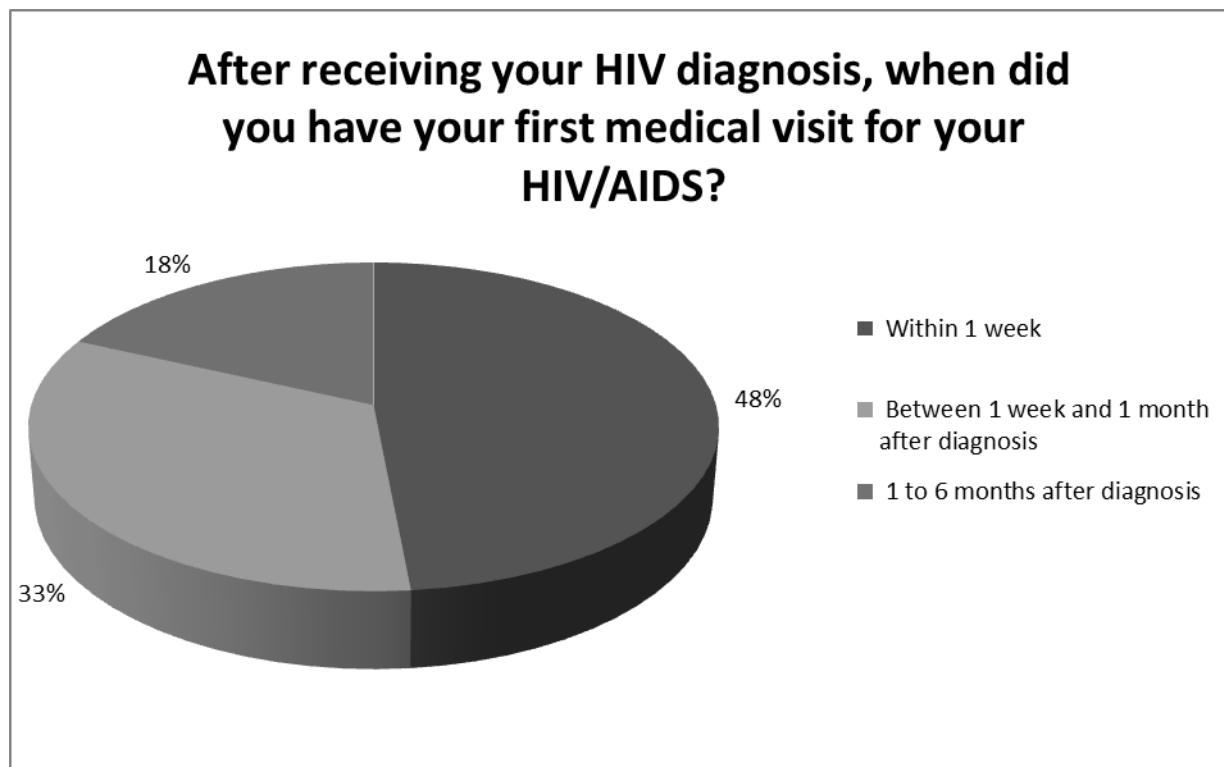
### **First Medical Visit**

Eighty-two percent of survey respondents had their first medical visit within one month of diagnosis.

Red asterisk This included 49% who had their first medical visit within one week and 33% within one month.

No respondents waited more than six months for their first medical visit.

**Figure III.5**



**Table III.5**

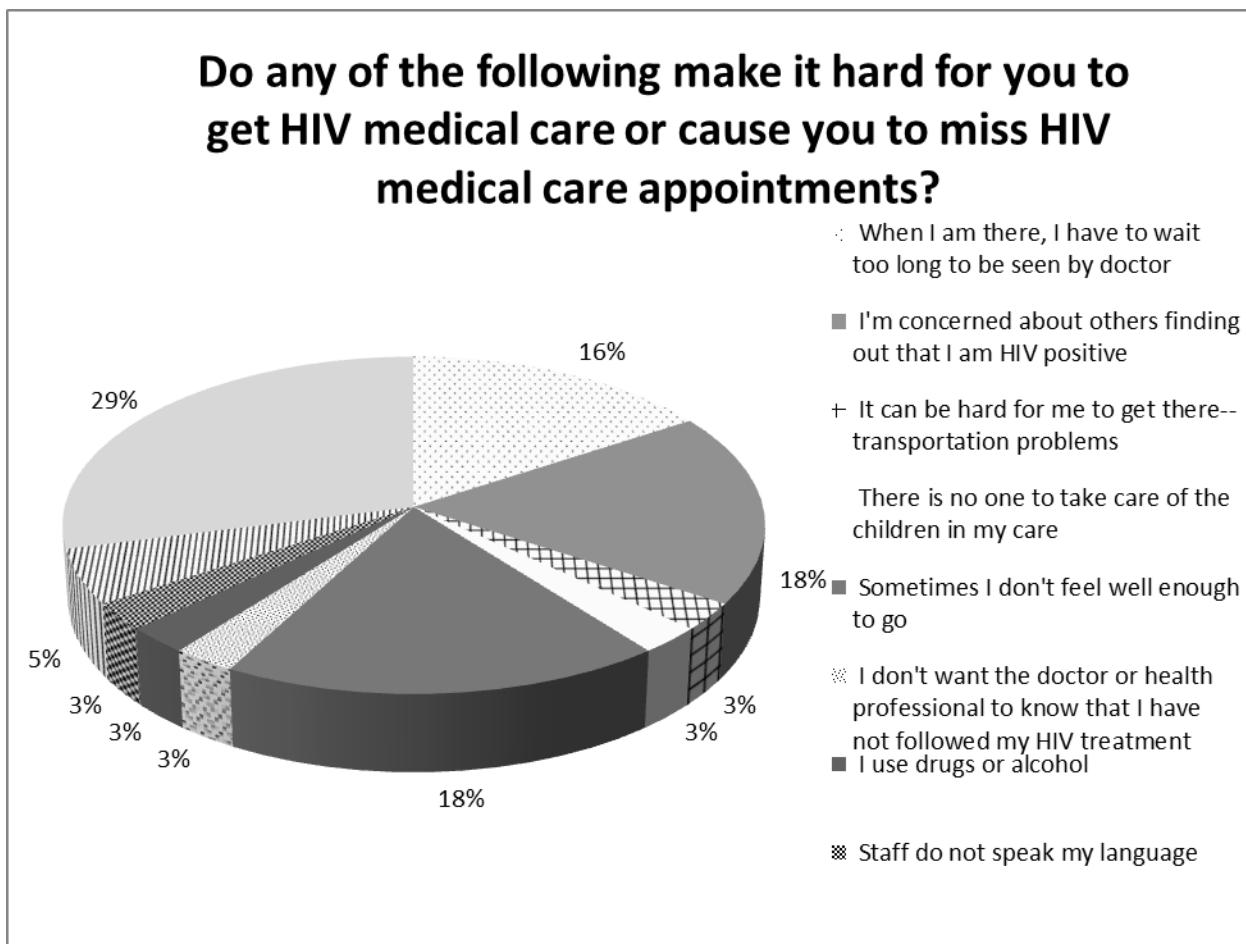
After receiving your HIV diagnosis, when did you have your first medical visit for your HIV/AIDS?		
Answer (N = 33)	#	%
Within 1 week	16	48.5%
Between 1 week and 1 month after diagnosis	11	33.3%
1 to 6 months after diagnosis	6	18.2%
7 months to 11 months after diagnosis	0	0.0%
One year or more after diagnosis	0	0.0%
You haven't seen a doctor or health professional for your HIV	0	0.0%

### **Retention in Care**

All survey respondents reported being in medical care. They were also asked about barriers that make it hard to get care or to miss appointments.

Red asterisk Most frequently cited barriers included not feeling well enough to get to the doctor (21%), stigma (21%) and wait time (18%).

**Figure III.6**



**Table III.6**

<b>Do any of the following make it hard for you to get HIV medical care or cause you to miss HIV medical care appointments?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
<b>When I am there, I have to wait too long to be seen by doctor</b>	<b>6</b>	<b>18.2%</b>
<b>I'm concerned about others finding out that I am HIV positive</b>	<b>7</b>	<b>21.2%</b>
<b>It can be hard for me to get there--transportation problems</b>	<b>*</b>	<b>3.0%</b>
<b>There is no one to take care of the children in my care</b>	<b>*</b>	<b>3.0%</b>
<b>Sometimes I don't feel well enough to go</b>	<b>7</b>	<b>21.2%</b>
<b>I don't want the doctor or health professional to know that I have not followed my HIV treatment</b>	<b>*</b>	<b>3.0%</b>
<b>I use drugs or alcohol</b>	<b>*</b>	<b>3.0%</b>
<b>The doctor or health professional I used to see is no longer there</b>	<b>0</b>	<b>0.0%</b>
<b>I see different doctors or health professionals each time I go</b>	<b>0</b>	<b>0.0%</b>
<b>Staff do not speak my language</b>	<b>*</b>	<b>3.0%</b>
<b>Hours of operation are inconvenient</b>	<b>*</b>	<b>6.1%</b>
<b>Other</b>	<b>11</b>	<b>33.3%</b>

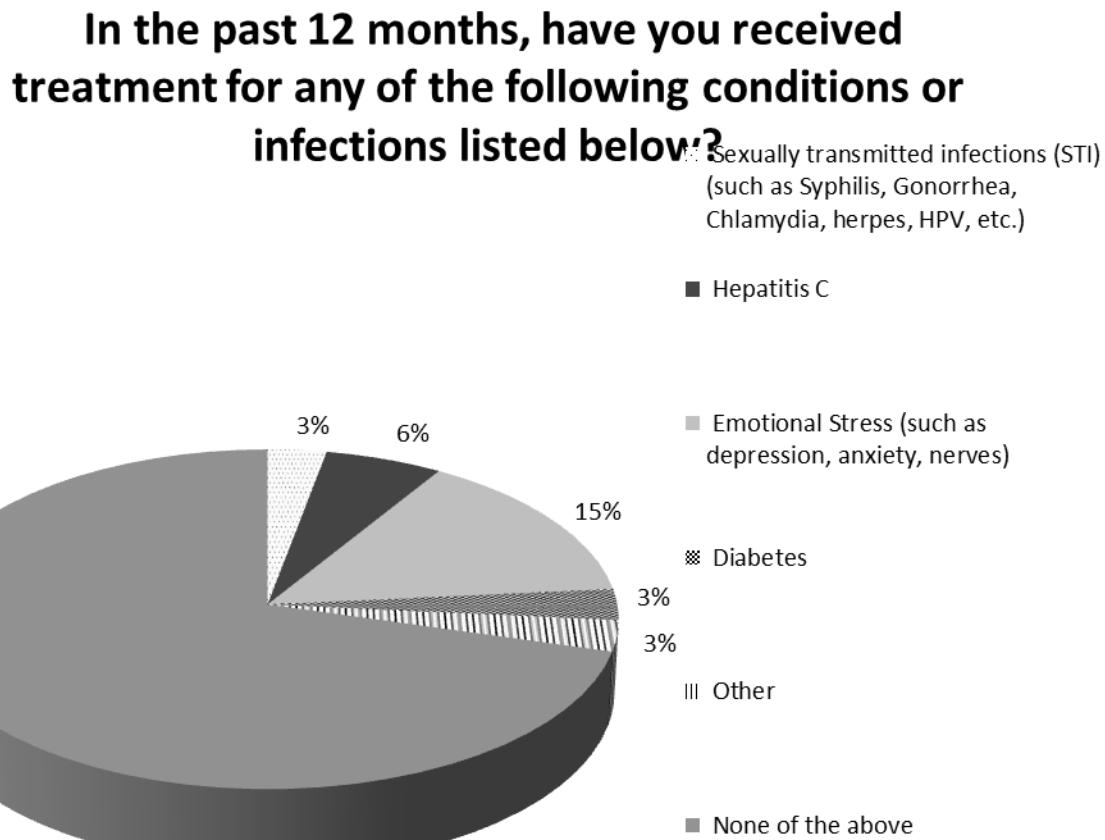
\*Less than 5

### **Co-Morbidities**

Thirty percent of survey respondents reported treatment for a co-morbidity in the last year.

- ❑ The most frequently mentioned was emotional stress such as depression, anxiety or nerves, cited by 15% of respondents.
- ❑ This was followed by hepatitis c reported by 6% of those surveyed.
- ❑ Sexually transmitted infections (STI), diabetes and other co-morbidities were each reported by one participant.
- ❑ Hepatitis a, hepatitis b, tuberculosis and drug/alcohol use were not reported.

**Figure III.7**



**Table III.7**

<b>In the past 12 months, have you received treatment for any of the following conditions or infections listed below?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
<b>Sexually transmitted infections (STI) (such as Syphilis, Gonorrhea, Chlamydia, herpes, HPV, etc.)</b>	*	3.0%
<b>Hepatitis A</b>	0	0.0%
<b>Hepatitis B</b>	0	0.0%
<b>Hepatitis C</b>	*	6.1%
<b>TB (tuberculosis)</b>	0	0.0%
<b>Emotional Stress (such as depression, anxiety, nerves)</b>	5	15.2%
<b>Drug/Alcohol use</b>	0	0.0%
<b>Diabetes</b>	*	3.0%
<b>Other</b>	*	3.0%
<b>None of the above</b>	24	72.7%

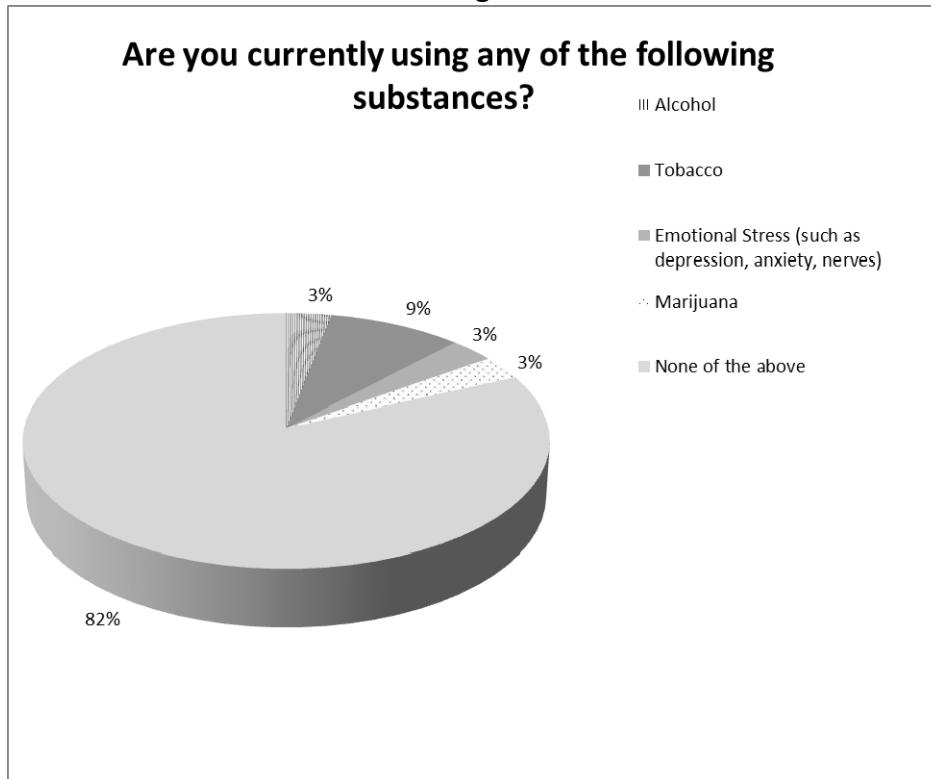
\*Less than 5. Respondents were allowed to answer more than one.

### **Substance Use**

Six (18%) reported current substance use. This included:

- ❑ 9% who used tobacco;
- ❑ 1 respondent who used alcohol;
- ❑ 1 respondent who used medications for emotional stress;
- ❑ 1 respondent who used marijuana;
- ❑ No respondent reported injecting drugs.

**Figure III.8**



**Table III.8**

Are you currently using any of the following substances?		
Answer (N = 33)	#	%
Alcohol	*	3.0%
Tobacco	*	9.1%
Cocaine/Crack	0	0.0%
Heroin/Other Opiates	0	0.0%
Methamphetamines/Other Stimulants	0	0.0%
Emotional Stress (such as depression, anxiety, nerves)	*	3.0%
Marijuana	*	3.0%
Club Drugs (X, G, Special K, etc.)	0	0.0%
LSD/Acid/Other Hallucinogens	0	0.0%
Crystal meth	0	0.0%
Ecstasy	0	0.0%
<b>None of the above</b>	<b>27</b>	<b>81.8%</b>

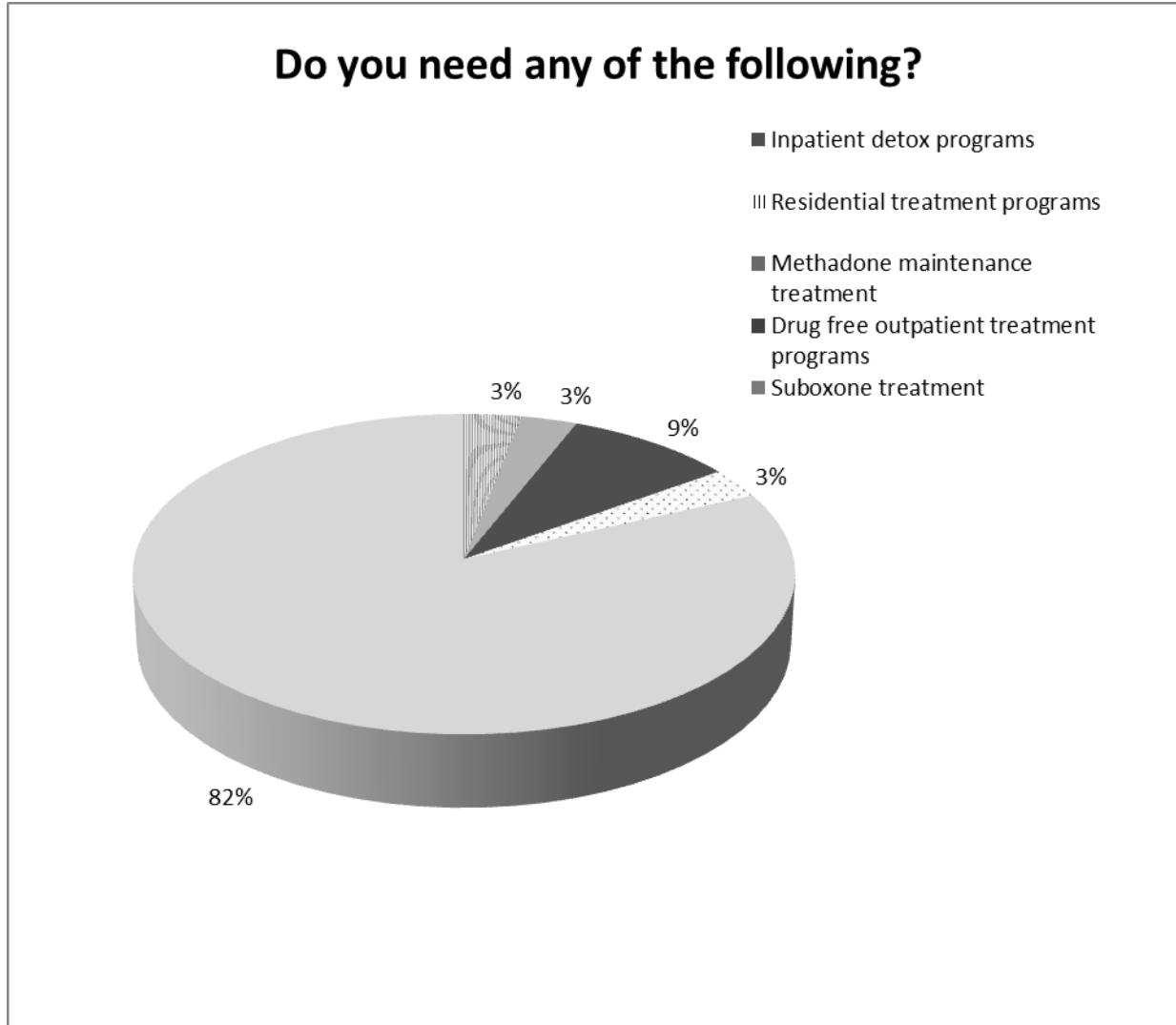
\*Less than 5. Respondents were allowed to answer more than one.

### **Substance Abuse Treatment Needs**

Six people (18% of the survey sample) said they needed substance abuse treatment services. The remaining 27 respondents reported not needing any services.

- ☒ The most frequent service need was transportation to treatment, identified by 9% of those surveyed.
- ☒ Free treatment for people with no insurance was identified by less than five respondents.

**Figure III.9**



**Table III.9**

Do you need any of the following?		
Answer (N = 33)	#	%
Inpatient detox programs	0	0.0%
Residential treatment programs	*	3.0%
Methadone maintenance treatment	0	0.0%
Drug free outpatient treatment programs	0	0.0%
Suboxone treatment	0	0.0%
Free treatment for people with no insurance	*	3.0%
Access to treatment when you're ready (Treatment on Demand)	0	0.0%
Information about what drug treatment services are available	0	0.0%
Information about where to go for treatment	0	0.0%
Transportation to treatment	*	9.1%
Other	*	3.0%
<b>None of the above</b>	<b>27</b>	<b>81.8%</b>

\*Less than 5

### **Prevention Practices**

Survey participants were asked about whether they had receptive anal, vaginal or oral sex in the last year. Fourteen respondents (42%) responded positively. The remaining 58% did not remember, had not had receptive sex or had not had sex.

**Figure III.10**



**Table III.10**

<b>In the past 12 months, have you had receptive anal, vaginal or oral sex (i.e. someone inserted their penis into your body)?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
<b>Yes</b>	14	42.4%
<b>No</b>	15	45.5%
<b>Don't remember</b>	*	6.1%
<b>None of the above, Have not had sex</b>	*	6.1%

\*Less than 5

Over 64% of those having receptive sex reported always using a male condom, female condom or dental dam (referred to as protection).

- ❑ Eighteen percent reported using protection both most of the time (seven to nine times out of ten) and some of the time (four to six times out of ten).
- ❑ Nine percent reported using protection seldom or rarely (one to three times out of ten).
- ❑ Nine percent reported never using protection when having sex.

**Figure III.11**



**Table III.11**

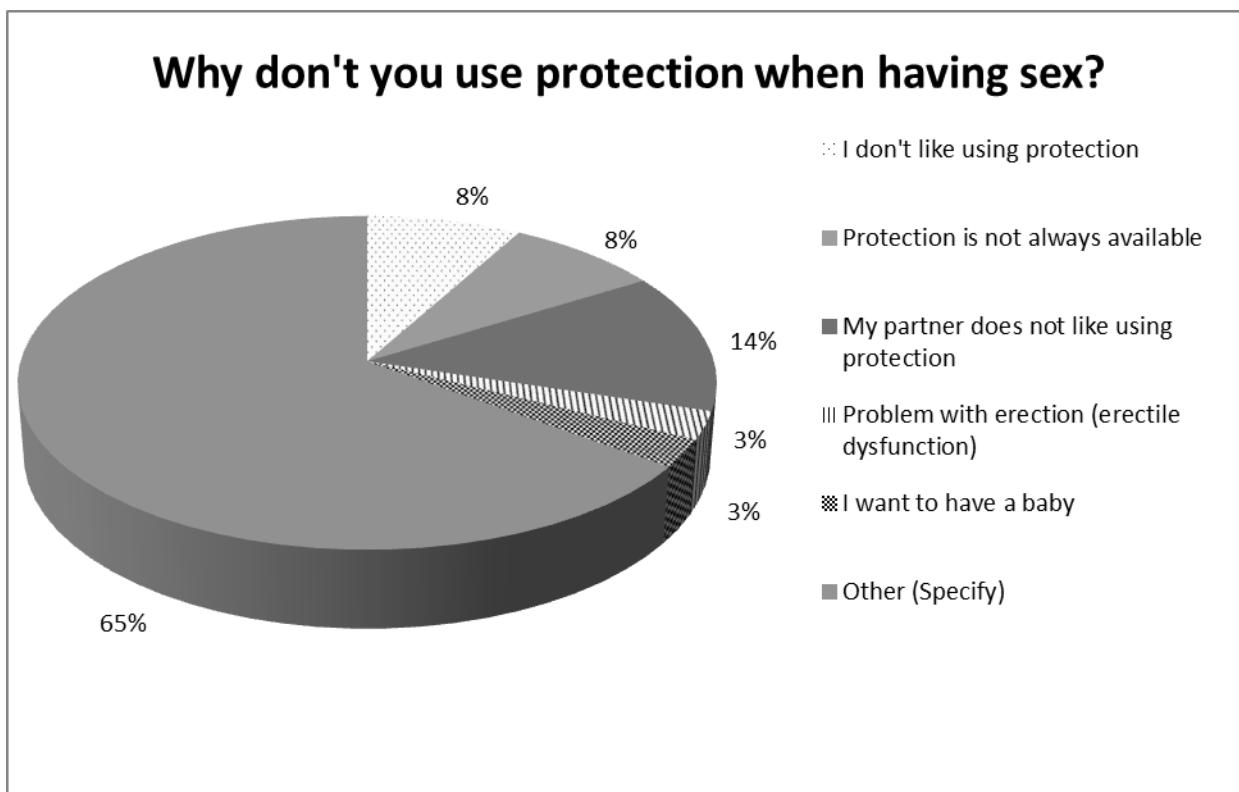
<b>When you have Oral, Anal or Vaginal sex (giving or receiving), how many times out of ten do you use a female condom, a male condom or dental dam?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
<b>Never (I use condoms 0 out of 10 times when I have sex)</b>	*	9.1%
<b>Seldom (I use condoms 1 to 3 times out of ten when I have sex)</b>	*	9.1%
<b>Some of the time(I use condoms 4 to 6 times out of ten when I have sex)</b>	*	3.0%
<b>Most of the time(I use condoms 7 to 9 times out of ten when I have sex)</b>	5	15.2%
<b>Always(I use condoms 10 out of 10 times when I have sex)</b>	21	63.6%

\*Less than 5

When asked the reasons for not using protection during receptive sex, 13 participants provided the following responses:

- ❑ “My partner does not like using it” was the most frequent answer, identified by 15%.
- ❑ This was followed by 9% each who stated, “I don’t like using it” or that protection is not always available.

**Figure III.12**



**Table III.12**

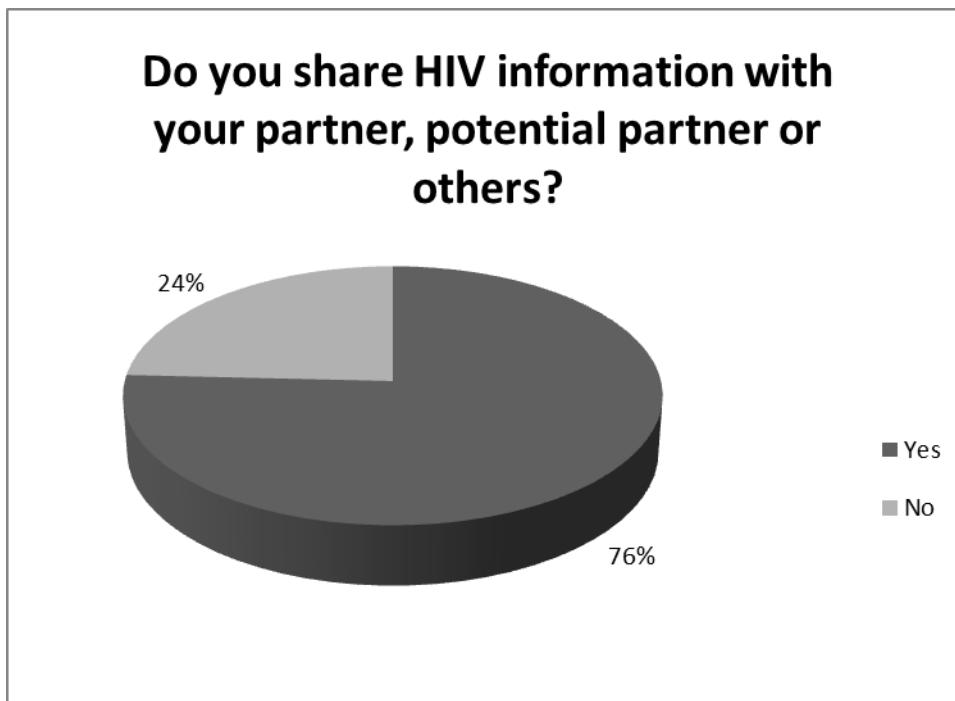
<b>Why don't you use protection when having sex?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
I don't like using protection	*	9.1%
Protection is not always available	*	9.1%
My partner does not like using protection	5	15.2%
Protection interferes with sexual activity	0	0.0%
Problem with erection (erectile dysfunction)	*	3.0%
I want to have a baby	*	3.0%
I am sometimes high or buzzed on drugs or alcohol during sex	0	0.0%
It's not really sex with protection	0	0.0%
I don't care	0	0.0%
<b>Other (Specify)</b>	<b>24</b>	<b>72.7%</b>

\*Less than 5

Participants were asked, “Do you share HIV information with your partner, potential partner or others?”

- ❑ Over three-quarters (76%) reported sharing HIV information, but 8 respondents (24%) did not.

**Table III.13**

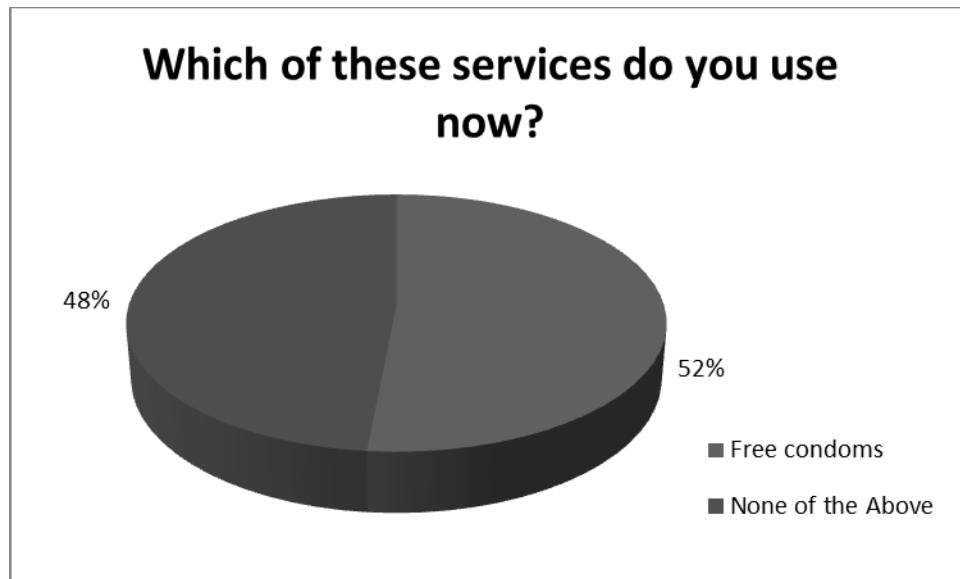


**Table III.13**

<b>Do you share HIV information with your partner, potential partner or others?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
Yes	25	75.8%
No	8	24.2%

Nearly 49% of respondents do not use any prevention services. For those that use services, all 17 participants cited free condoms.

**Figure III.14**



**Table III.14**

<b>Which of these services do you use now?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
Free condoms	17	51.5%
Syringe exchange	0	0.0%
Safer sex workshops	0	0.0%
None of the Above	16	48.5%

Forty-six percent of Spanish-speaking in-care survey respondents have identified people who they may have been exposed to the HIV virus.

Of those reporting exposing others to HIV, 93% stated the exposed partner “went to get tested” as a result.

When asked “what got in the way of identifying people you might have exposed to HIV:

- ❑ 11% reported they did not know how to identify a person, less than five respondents reported sharing works or having sex with anonymous people (people they didn't know well), being too worried about themselves or that the person who gave them HIV didn't tell them so why should they share this information.
- ❑ Less than five respondents asked for immediate help to understand how to notify people who they may have exposed.

**Table III.15**

<b>Have you identified persons who may have been exposed to HIV through you?</b>		
<b>Answer (N = 33)</b>	<b>#</b>	<b>%</b>
<b>Yes</b>	15	45.5%
<b>No</b>	18	54.6%

Survey participants were asked if they know anyone who is HIV positive and not receiving HIV medical care. No respondents responded positively.

**Table III.16**

<b>Do you know anyone who is HIV-positive and not in care?</b>		
<b>Answer (n=33)</b>	<b>#</b>	<b>%</b>
<b>Yes</b>	0	0.0%
<b>No</b>	33	100.0%

#### **IV. SERVICE USE, ACCESS, NEED, AND BARRIERS**

The following tables present summaries of use, access, need, and barriers for 25 individual services identified in the survey.<sup>10</sup> Questions were limited to respondents' experience within the last year. The tables reflect responses from the total sample (N=33). Respondents were asked (1) "Do you get this service?" and if yes "How easy was it to get?" For those who did not get this service, respondents were asked (2) "Do you need this service?" The last question (3) asked of those who found the service hard to get was "What is the main reason it is hard to get?" A summary of responses for each service category is presented below. Detailed tables on use, access, need and barriers along with results of the 2012 Hispanic in-care survey are found in the Appendix.

- ❑ Most respondents found services available and easy to get. Medical care, prescription drugs and medical and non-medical case management were among those most utilized.
- ❑ Twelve percent of respondents identified access problems for services that would make it easier to get HIV medical care, and just one respondent reported unmet need for services used in the past but unavailable today.
- ❑ Oral health care was among the highest in unmet need (3<sup>rd</sup>).
- ❑ Transportation continued to be noted among survey respondents. Need for daily supports for food and utilities ranked high in importance although most were able to find assistance. Housing, on the other hand, was highest in unmet need and perceived access barriers.
- ❑ Most frequent and significant access issues related to medical care centered on insurance. Respondents expressed concern about meeting deductibles and co-pays.
- ❑ Demand for substance abuse treatment was nearly negligible.

##### **A. OBSERVATIONS BY SERVICE CATEGORY**

###### **HIV Outpatient Medical Care**

HIV Outpatient Medical Care was the most utilized service, ranked easiest to get and lowest in unmet need. This is an expected result as the sample controlled for respondents in HIV medical care. Barriers most often related to appointment scheduling.

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<sup>10</sup> Responses for one service category "Health Insurance Continuation" were invalid and therefore not reported.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>❑ Used by 94% of respondents</li> <li>❑ Considered somewhat hard to get by 10%</li> <li>❑ No respondents considered hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ Both respondents who do not get this service said they needed it.</li> <li>❑ Ranked 19th in unmet need. (0% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Difficult to get an appointment (&lt;5)</li> <li>❑ Wanted to see a female doctor (&lt;5)</li> </ul>

### Outpatient OB/GYN Care

Female PLWHA do not identify need for or barriers to receiving OB/GYN care.

Use/Access (n=10)	Need	Most Common Barriers (n=0)
<ul style="list-style-type: none"> <li>❑ Used by 90% of female respondents</li> <li>❑ 1 Respondent found it somewhat hard or hard to get.</li> </ul>	<ul style="list-style-type: none"> <li>❑ Ranked 19th in unmet need (0% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ No barriers cited</li> </ul>

### Care from a Specialist referred by HIV Doctor

Specialty care was not considered a priority among Spanish-speaking respondents. This service was ranked 13<sup>th</sup> in use/access and nineteenth in unmet need.

Use/Access	Need	Most Common Barriers (n=0)
<ul style="list-style-type: none"> <li>❑ 33% received care from a specialist</li> <li>❑ No respondents found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ No respondents indicated they needed a specialist</li> <li>❑ Ranked 19<sup>th</sup> in unmet need (0% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ No barriers identified</li> </ul>

### Help Paying for Medical Care

This was the 6<sup>th</sup> most utilized service identified in the survey and ranked 16<sup>th</sup> among 24 in unmet need. Barriers most frequently related to enrollment restrictions and knowledge about the service.

Use/Access	Need	Most Common Barriers (n=7)
<ul style="list-style-type: none"> <li>❑ 64% said they get help paying for medical care</li> <li>❑ 29% found it somewhat hard or hard to get.</li> </ul>	<ul style="list-style-type: none"> <li>❑ 8% (&lt;5 respondents) who don't get help said they needed it</li> <li>❑ Ranked 16<sup>th</sup> in unmet need (3% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Didn't qualify (&lt;5)</li> <li>❑ Didn't know about the service (&lt;5)</li> </ul>

### Help Paying for Prescriptions or Medications

This was the 3<sup>rd</sup> most utilized service and 8<sup>th</sup> in insufficient access. Most common barriers related to knowledge about the service.

Use/Access	Need	Most Common Barriers (n=5)
<ul style="list-style-type: none"> <li>❑ 82% received help paying for medications</li> <li>❑ 7% (&lt;5) found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 50% (&lt;5) who did not get help said they needed it</li> <li>❑ Ranked 8<sup>th</sup> in unmet need (9% of respondents)</li> </ul>	Didnt know about the service (5)

### Health Insurance Continuation

This question was eliminated as results were not reliable.

### Help Paying for Co-Pays and Deductibles for HIV Medical Care Visits

From the survey responses, help paying for co-pays and deductibles for doctor visits were received and needed by 40% of survey respondents. Eleven identified barriers to obtaining help for co-pays and deductibles. Insurance restrictions (qualification) and knowledge were among the most commonly identified barriers.

Use/Access	Need	Most Common Barriers (n=11)
<ul style="list-style-type: none"> <li>❑ 40% received this service</li> <li>❑ 61% (8) found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 15% of those who did not get help say they needed it</li> <li>❑ Ranked 8<sup>th</sup> in unmet needs (9% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Didn't qualify (&lt;5)</li> <li>❑ Didn't know about the service (7)</li> <li>❑ Too much paperwork(&lt;5)</li> </ul>

### **Help Paying for Co-Pays and Deductibles for HIV Medications**

Help paying for medication co-pays and deductibles are received and needed by 64% of survey respondents. Six identified barriers to obtaining help for co-pays and deductibles. Knowledge about the service and required paperwork were most frequently identified.

Use/Access	Need	Most Common Barriers (n=6)
<ul style="list-style-type: none"> <li>❑ 64% received help paying for HIV medication co-pays and deductibles</li> <li>❑ 10% (&lt;5) found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 67% of those who did not get help say they needed it</li> <li>❑ Ranked 5<sup>th</sup> in unmet needs (12% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Didn't know about the service (&lt;5)</li> <li>❑ Too much paperwork (&lt;5)</li> </ul>

### **Dental Visits**

Oral health care ranked among the highest in unmet need (3<sup>rd</sup>) despite being easy to get. Barriers were varied.

Use/Access	Need	Most Common Barriers (n=10)
<ul style="list-style-type: none"> <li>❑ 73% received dental care</li> <li>❑ 13% (&lt;5) said it is somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 78% (7) who did not get dental care say they needed it</li> <li>❑ Ranked 3<sup>rd</sup> in unmet needs (21% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Limited funding (&lt;5)</li> <li>❑ Waiting list for appointment (&lt;5)</li> <li>❑ Afraid of the dentist (&lt;5)</li> </ul>

### **Medical Case Management, i.e. Help with Coordination of Medical Care Offered at Medical and Dental Care Locations**

Medical case management ranked among the highest in use. Most common barriers related to access and required documentation.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>❑ 82% received medical case management</li> <li>❑ Ranked #4 in service use</li> <li>❑ 4% (&lt;5) found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 33% (2) who did not get medical case management said they need it</li> <li>❑ Ranked 15<sup>th</sup> in unmet needs (6% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Case manager not available or hard to reach (&lt;5)</li> <li>❑ Too much paperwork (&lt;5)</li> </ul>

### **Non-Medical Case Management, i.e. Help Accessing Support Services**

Non-medical case management was well utilized and appeared to have few access issues. Most common barriers related to required paperwork.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>✖ 64% get non-medical case management</li> <li>✖ 5% (&lt;5) found it somewhat hard to get</li> </ul>	<ul style="list-style-type: none"> <li>✖ 25% (&lt;5) who do not get non-medical case management say they need it</li> <li>✖ Ranked 8<sup>th</sup> in unmet needs (9% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>✖ Too much paperwork (&lt;5)</li> <li>▪</li> </ul>

### **Mental Health Counseling**

Although generally accepted by service providers as a high priority need, consumers did not agree. They ranked use, access and unmet need for mental health counseling 11<sup>th</sup> out of 24.

Use/Access	Need	Most Common Barriers (n=0)
<ul style="list-style-type: none"> <li>✖ 36% received mental health counseling</li> <li>✖ Ranked #11 in service use</li> <li>✖ No respondents found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>✖ No respondents who do not get mental health counseling say they need it</li> <li>✖ Ranked 19<sup>th</sup> in unmet need (0% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>▪ None</li> </ul>

### **Nutrition Counseling**

Thirty-six percent reported getting nutrition counseling with no identified access issues. Spanish speaking PLWHA considered this an important need, ranking it 8<sup>th</sup> out of 24 services. Most common barriers related to knowledge about this service.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>✖ 36% said they get nutrition counseling</li> <li>✖ No respondents identified access problems</li> </ul>	<ul style="list-style-type: none"> <li>✖ 14% who didn't get nutrition counseling said they need it</li> <li>✖ Ranked 8<sup>th</sup> in unmet need (9% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>✖ Didn't know about this service (3)</li> </ul>

### **Outpatient Substance Abuse Treatment**

Outpatient substance abuse treatment was among the least utilized (ranked 19<sup>th</sup> out of 24 service categories), with no identifying barriers or unmet need.

Use/Access	Need	Most Common Barriers (n=0)
<ul style="list-style-type: none"> <li>❑ % (&lt;5) received substance abuse treatment</li> <li>❑ No respondents found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ No respondents who did not get outpatient substance abuse treatment said they needed it.</li> <li>❑ Ranked 19th in unmet need (0% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ No barriers reported</li> </ul>

### **Adult Day Care (Activities During the Day)**

Adult day care was among the least utilized (ranked 21st out of 24 service categories), with none identifying a need or access barriers.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>❑ &lt;5 respondents were in adult day care</li> <li>❑ Did not find it hard to get service</li> </ul>	<ul style="list-style-type: none"> <li>❑ &lt;5 respondents who were not in adult day care say he/she needed it</li> <li>❑ Ranked 16<sup>th</sup> in unmet need (3% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Did not qualify for service</li> </ul>

### **Food Bank**

Food assistance was obtained by slightly more than one-quarter of respondents and appeared to be relatively easy to access. Identified barriers were small in number.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>❑ 27% received food bank assistance</li> <li>❑ &lt;5 respondents found it somewhat hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 12% (&lt;5) who did not get food bank assistance said they needed it</li> <li>❑ Ranked 8<sup>th</sup> in unmet need (9% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Inconsistent amount of food (&lt;5)</li> <li>❑ Inconvenient hours (&lt;5)</li> </ul>

### **Emergency Financial Assistance for Utilities**

Accessed by 15% of respondents (5), one-fifth found it hard to get assistance for utility payments. Utility assistance ranked third in unmet need.

Use/Access	Need	Most Common Barriers (n=8)
<ul style="list-style-type: none"> <li>15% received this service</li> <li>20%(&lt;5) found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>25% (7) who did not get assistance said they needed it</li> <li>Ranked 3rd in unmet need (21% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>Limited funding (&lt;5)</li> <li>Didn't qualify (5)</li> <li>Too much paperwork (&lt;5)</li> </ul>

### **Emergency Assistance for Rent, Mortgage**

Accessed by relatively few respondents, housing payment assistance ranked first in unmet need. Most common barriers related to qualification requirements.

Use/Access	Need	Most Common Barriers (n=12)
<ul style="list-style-type: none"> <li>&lt;1 Respondent received emergency housing assistance</li> </ul>	<ul style="list-style-type: none"> <li>38% (12) of those who did not get this service said they needed it.</li> <li>Ranked 1st in unmet need (36% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>Limited funding (&lt;5)</li> <li>Didn't qualify (6)</li> <li>Too much paperwork (&lt;5)</li> <li>■</li> </ul>

### **Long-Term Rental Assistance**

Long term rental assistance i.e., Section 8, ranked second highest in unmet need of the 24 service categories in this survey; only 6% were able to obtain Section 8. Most common barriers related to restrictions pertaining to qualifications and long waiting lists.

Use/Access	Need	Most Common Barriers (n=12)
<ul style="list-style-type: none"> <li>6% of respondents get long term rental assistance.</li> <li>One respondent found it somewhat hard to get</li> </ul>	<ul style="list-style-type: none"> <li>36% (11) of those who do not get long term rental assistance say they need it.</li> <li>Ranked 2nd in unmet need (33% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>Limited funding &lt;5)</li> <li>Waiting list too long (&lt;5)</li> <li>Didn't qualify ((5)</li> <li>Too much paperwork (&lt;5)</li> </ul>

### **Facility-Based Housing (Assisted Living Facility)**

Very few Spanish-speaking in-care respondents utilized assisted living. None identified access issues.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>✖ 3% (&lt;5) lived in an assisted living facility</li> </ul>	<ul style="list-style-type: none"> <li>✖ 9% (&lt;5) who are not in assisted living say they need it</li> <li>✖ Ranked 8<sup>th</sup> in unmet need (9% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>✖ Limited funding (&lt;5)</li> <li>✖ Didn't qualify (&lt;5)</li> </ul>

### **Legal Services to Help Work Through a Problem Obtaining Services/Benefits, Outline Advance Directives or Establish Guardianships**

Legal services were utilized by 6 respondents, of who one-third found it somewhat difficult to get. Most common barrier related to relevancy of legal needs and knowledge of available services.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>✖ 18% (6) received legal services</li> <li>✖ 33% (&lt;5) found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>✖ 15% (4) of those who do not get legal services say they need it</li> <li>✖ Ranked 5<sup>th</sup> in unmet need (12% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>✖ Limited services (need a lawyer for other services) (&lt;5)</li> <li>✖ Did not know about this service (&lt;5)</li> </ul>

### **Child Care While at a Medical or Other Appointment**

Child care was the least utilized and least needed service, according to survey respondents.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>✖ 3% (&lt;5) used child care services</li> <li>✖ 1 respondent indicated that child care services were somewhat difficult to obtain</li> </ul>	<ul style="list-style-type: none"> <li>✖ Of those who did not get child care services, no respondents said they needed it</li> <li>✖ Ranked 19<sup>th</sup> in unmet need (0% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>✖ None.</li> </ul>

### **Transportation to Medical Care – Bus Pass**

Bus passes were identified as the 8<sup>th</sup> highest unmet need of the 24 services identified in this survey. Use and access, however, ranked relatively low (16/24). Most commonly identified barriers included proximity to home and difficulty using a bus when ill.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>❑ % (8) received a bus pass to get to medical care</li> <li>❑ 25% who used this service found it somewhat hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 12% (&lt;5) of those who did not get a bus pass to medical care said they need it</li> <li>❑ Ranked 8th in unmet need (9% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Did not live near public transportation (&lt;5)</li> <li>❑ Hard to take a bus if ill (&lt;5)</li> </ul>

### **Transportation to Medical Care – Van Service**

Van service was identified as 5<sup>th</sup> highest unmet need of the 24 services identified in this survey. Slightly more than one-quarter of respondents used this service. Most commonly identified barriers included access and wait times.

Use/Access	Need	Most Common Barriers (n=6)
<ul style="list-style-type: none"> <li>❑ 27% received transportation to medical care from a van service</li> <li>❑ 22% of those who used the van found it somewhat hard or hard to get</li> </ul>	<ul style="list-style-type: none"> <li>❑ 17% (&lt;5) who do not use a van service say they need it</li> <li>❑ Ranked 5<sup>th</sup> in unmet need (12% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Availability of this service (&lt;5)</li> <li>❑ Making appointments in advance (&lt;5)</li> <li>❑ Waiting time too long (&lt;5)</li> </ul>

### **Translation or Interpretation**

Translation services were ranked 16<sup>th</sup> in unmet needs.

Use/Access	Need	Most Common Barriers (n=<5)
<ul style="list-style-type: none"> <li>❑ 55% (18) used translation services</li> <li>❑ 95% of respondents found it easy to get this service</li> </ul>	<ul style="list-style-type: none"> <li>❑ 7% (&lt;5) who did not get translation services said they need it</li> <li>❑ Ranked 16<sup>th</sup> in unmet need (3% of respondents)</li> </ul>	<ul style="list-style-type: none"> <li>❑ Didn't know about the service (&lt;5)</li> </ul>

### **Follow-Up Questions**

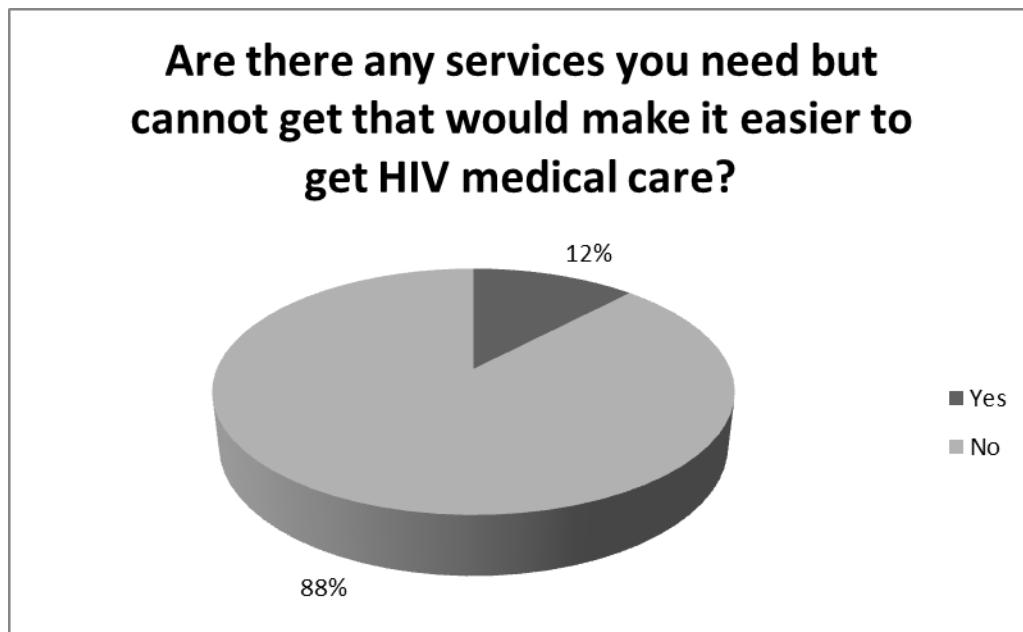
Respondents were asked additional questions to probe further into need and use. Four questions were asked:

- ❑ Are there services that would make it easier to get HIV medical care?
- ❑ What services would make it easier to get HIV medical care?
- ❑ Are there any services you used in the past and still need but are no longer able to get?
- ❑ What services do you still need but are no longer able to get?

Less than five survey participants (12%) identified services that would facilitate engagement and retention in medical care. Those identified included: help paying for co-pays and deductibles, health care services at home and nutritional counseling. When asked if there were any services used in the past and still needed but no longer able to get, 6% (<5) responded "Yes."

A small number of respondents (<5) identified assistance paying for health insurance as a service they still need but are unable to get.

**Figure IV.1**



**Table IV.1**  
**Are there any services you need but cannot get that would make it easier to get HIV medical care?**

Answer (N = 33)	Number	Percent
Yes	*	12.12%
No	29	87.88%

\*Less than 5

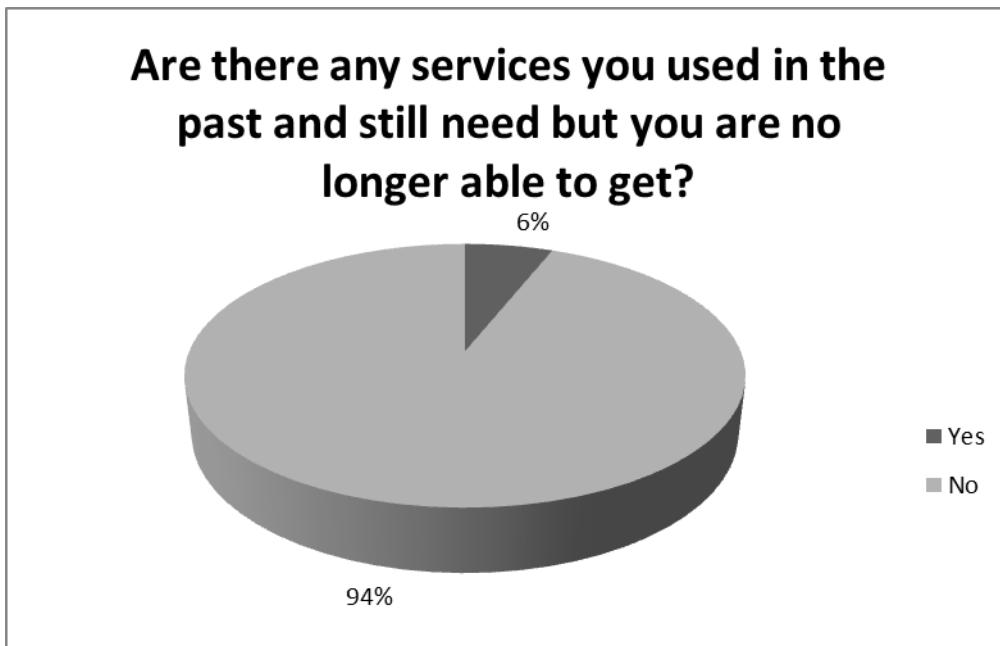
**Table IV.2**

**What services that would make it easier for you to get HIV medical care?**

Answer (n = <5)	Number	Percent
Help paying for your HIV medications	0	0.00%
Dental care	0	0.00%
Help getting HIV services after diagnosis	0	0.00%
If you have Health Insurance, help paying for it	0	0.00%
Help paying for co-pays and deductibles	*	50.00%
Health care services at home	*	25.00%
Mental health services	0	0.00%
Nutrition counseling	*	25.00%
Food bank	0	0.00%
Meals delivered to your home	0	0.00%
Outpatient substance abuse treatment	0	0.00%
Residential substance abuse treatment	0	0.00%
Inpatient medical detox	0	0.00%
Education to help you follow your HIV medical treatment	*	25.00%
Case management	*	25.00%
Child care services	0	0.00%
Emergency financial assistance for utilities or food	0	0.00%
Help with paying your rent or mortgage	*	25.00%
Help paying for housing in an emergency	0	0.00%
Education about HIV and how to reduce the risk	0	0.00%
Legal services	0	0.00%
Translation services	0	0.00%
Transportation to medical care	*	25.00%
Transportation to substance abuse treatment	0	0.00%
Rehabilitation services (Physical Therapy, Occupational Therapy or Speech Therapy)	0	0.00%
Medical day care for adults	*	25.00%
Help with disclosing my HIV status	0	0.00%

\*Less than 5

**Figure IV.2**



**Table IV.3**

**Are there any services you used in the past and still need but you are no longer able to get?**

Answer (N = 33)	Number	Percent
Yes	*	6.06%
No	31	93.94%

\*Less than 5

**Table IV.4**

**Services that you still need but are no longer able to get from the following list**

<b>Answer (n=&lt;5)</b>	<b>Count</b>	<b>Percentage</b>
HIV Medical Care Visits	0	0.00%
Help paying for your HIV medications	0	0.00%
Dental care	0	0.00%
Help getting HIV services after diagnosis	0	0.00%
If you have Health Insurance, help paying for it	*	100.00%
Health care services at home	0	0.00%
Mental health services	0	0.00%
Nutrition counseling	0	0.00%
Food bank	0	0.00%
Meals delivered to your home	0	0.00%
Outpatient substance abuse treatment	0	0.00%
Residential substance abuse treatment	0	0.00%
Medical detox	0	0.00%
Education to help you follow your HIV medical treatment	0	0.00%
Case management	0	0.00%
Child care services	0	0.00%
Emergency financial assistance for utilities or food	*	100.00%
Help with paying your rent or mortgage	*	50.00%
Help paying for housing in an emergency	*	50.00%
Education about HIV and how to reduce the risk	0	0.00%
Legal services	*	50.00%
Translation services	0	0.00%
Transportation to medical care	0	0.00%
Transportation to substance abuse treatment	0	0.00%
Other transportation	0	0.00%
Rehabilitation services (PT, OT or speech)	0	0.00%
Medical day care for adults	0	0.00%

\*Less than 5

**V. DISCUSSION AND RECOMMENDATIONS**

This consumer survey probes the special population characteristics, health issues and care needs of Spanish speaking PLWHA in the two counties of Bergen and Passaic, New Jersey. With a sample limited to patients receiving care under the Ryan White Program and whose primary language is Spanish, we learn about a population that has possibly not been heard from before. Although the sample of Spanish speaking respondents generally reflected the Hispanic PLWHA community, this is a special population that does not read English and therefore did not have its needs recorded in the 2012 in-care consumer survey that was administered exclusively in English. The Bergen-Passaic County-Bergen County HIV/AIDS Health Services Planning Council expressed concern that the 2012 survey did not sufficiently address the needs of the foreign residents of Bergen and Passaic counties, especially Latinos. This study attempts to answer its concern.

Interpretation of the present findings must take into account issues related to the survey sample. While the survey was administered throughout the two-county area to all who qualified, the sample (N=33) obtained was small, and therefore, the sample may not be considered generalizable to the entire Spanish-speaking community. Its findings must be used only to establish a broad profile that is reflective while perhaps not representative. Second, undercounts of Bergen County Spanish speakers do not provide sufficient data to fully understand the needs of the northern county residents. Further study of Bergen County PLWH is warranted. Third, as with the 2012 consumer survey, very few respondents admitted to illicit drug use either as a transmission mode or risk factor. This does not correlate with epidemiologic data that reports over 20% with drug involvement.

With these caveats in mind, the survey helps to draw a profile of Spanish speaking PLWHA in the Bergen-Passaic TGA. Its major characteristics are summarized as follows.

**Observations and Interpretation**

Essentially, the Spanish-speaking in-care population considered itself in good health and connected to a system of care that strives to meet its needs. For the most part, respondents indicated that they were getting the care and services they needed and identified relatively few outstanding or unmet needs. Issues did arise, however, with timeliness of services applied for and received.

The following summarizes the major observations resulting from the survey responses:

- ❑ The sample depicted a population that had engaged in timely medical care and was essentially taking care of its health. Access barriers were few, but some still notable. These included help with living costs, insurance, other bureaucratic restrictions, and information about services available to them.
- ❑ Spanish-speaking PLWH tended to be younger than all Hispanic PLWH, with 42% under age 45 compared with 29% overall. This may be a cultural difference worthy of note.

Sixty-five percent of respondents were diagnosed since 2000, again reflective of the younger age cohort.

- ☒ At this point in the epidemic, the most common transmission mode was clearly sexual contact, either heterosexual or homosexual. Further, transmission via syringe injection had dwindled to an all-time low, and drug abuse was rarely reported among this HIV/AIDS population. This may be evidence of effective drug treatment programs or a general decline in the use of illicit drugs among the in-care population.
- ☒ Relatively low acuity levels with HIV-only diagnoses are more common than AIDS among Spanish-speaking PLWH. This is a trend that hopefully will continue.
- ☒ Presence of co-morbid conditions was reported less often among Spanish-speaking respondents, possibly reflective of the younger cohort.
- ☒ Spanish-speaking respondents made little mention of language problems, indicating that translation services were adequate for them. With low educational attainment common among this population, however, health literacy is still a matter of concern. This survey does not address this issue and further investigation is warranted.
- ☒ Transportation remains a needed support service, both for bus or van. Case managers should investigate every mode of transportation available and work with Spanish speaking clients to assure the ability to get to medical appointments.
- ☒ Oral health care was identified as a leading unmet need, despite the availability of services in both counties. Spanish-speaking patients need to be educated about the need for regular oral health exams and treatment as well as access to available care.
- ☒ Nutrition services were perceived as separate from outpatient medical care where such services are typically rendered and considered a need. Their perceptions should be noted by primary care providers.
- ☒ Spanish-speaking respondents tended not to disclose their HIV status except to their primary relationships. Further, one-quarter did not share information about HIV with friends, family or others.
- ☒ Prevention practices were mostly a matter of personal choice. Condom use was the only significant practice identified by Spanish-speaking respondents. Either educational programs are not available in Spanish, or this is a subject of low priority among this population. Further investigation is warranted.

In previous needs assessments, respondents cited a need for “information” without specifying what they needed to know. In follow-up research, we learned that their information needs spanned not only knowledge of HIV disease but, even more, knowledge about the system of care and services available to help them to obtain and remain in medical care. From the current survey, these needs are apparent for Spanish-speaking PLWH as well.

To enlighten the survey results, we compared these responses to those of Hispanic responses in the 2012 In-Care Survey. In most cases, there were few significant differences between the two. However, some comparisons were notable. The Spanish speakers tended to be more economically and educationally compromised, receiving fewer social supports such as Section 8 housing. Spanish speakers tended to be more open with their spouses/partners, and more

likely to be heterosexual, indicating somewhat greater importance on home and/or family. Finally, Spanish speakers entered into care later than English-speaking Hispanic PLWHA, perhaps due to lack of information in their language about available services. Spanish speakers also identified translation or interpretation needs to a greater extent than English speaking Hispanic PLWH. The following documents these observations:

- ❑ The Spanish survey was heavily weighted to Passaic County residents. Ninety-four percent of Spanish-speaking in-care survey respondents resided in Passaic County as compared to 81% of English-speaking in-care Hispanics.
- ❑ Spanish speaking respondents were less likely to be MSM. Fifty-eight percent of Spanish speaking in-care survey respondents were heterosexual as compared to 79% of English-speaking in-care Hispanics. One-quarter (24%) of Spanish-speaking in-care survey respondents were MSM as compared to 16% of English-speaking in-care Hispanics.
- ❑ Spanish speakers were less likely to live in Section 8 housing. Eighty-five percent of Spanish-speaking in-care survey respondents rented/owned without Section 8 as compared to 63% of English-speaking in-care Hispanics. No Spanish-speaking in-care survey respondent rented/owned with Section 8 assistance as compared to 20% of English-speaking in-care Hispanics.
- ❑ The Spanish speakers tended to be more immersed in poverty. Twenty-one percent of Spanish-speaking in-care survey respondents reported zero income as compared to 10% of English-speaking in-care Hispanics, and 33% of Spanish-speaking in-care survey participants reported incomes between \$1 and \$9,999 as compared to 51% of English-speaking in-care Hispanics.
- ❑ The Spanish speakers were less well educated. Thirty-six percent of Spanish-speaking in-care survey participants had less than a high school education as compared to 61% of English-speaking in-care Hispanics.
- ❑ Fewer Spanish speakers were recently diagnosed. Forty-two percent of Spanish-speaking in-care survey respondents were diagnosed as HIV+ between 2000 and 2010 as compared to 61% of English-speaking in-care Hispanics.
- ❑ More Spanish speakers revealed their status to their partners. Thirty-nine percent of Spanish-speaking in-care survey participants told a spouse/partner as compared to 25% of English-speaking in-care Hispanics.
- ❑ Engagement into medical care took longer for Spanish speakers. Forty-nine percent of Spanish-speaking in-care survey participants had their first visit within one week as compared to 65% of English-speaking in-care Hispanics.
- ❑ Seven percent of Spanish speaking respondents identified an unmet need for translation or interpretation services, compared to 2% of Hispanic respondents in 2012. This may be a small difference, but it is worthy of note.

It is important to recognize that these results are not conclusive, given the convenience sampling and small sample sizes. However, it would appear that ability to speak English would enhance early linkage to medical care.

### **Recommendations**

The system of care and services offered through the Ryan White Program is working to successfully keep Spanish speaking PLWHA in care. This consumer survey, however, underscores areas that would serve to make that system even better in today's TGA. Based on findings of the Spanish-speaking in-care consumer survey, the following recommendations are offered:

1. Enhance patient education in multiple languages to emphasize those aspects of care that are apparently misunderstood with regard to their importance. Emphasize early engagement in medical care to non-English speaking PLWH.
2. Continue to confront the major barriers of care retention, i.e., insurance issues, necessities of daily living and transportation. Resolve transportation issues through case management. Clarify coverage for co-pays and deductibles on behalf of each Ryan White enrollee. Continue to work with Spanish speakers in their own language.
3. Implement the recommendations of the Cultural Competency Task Force, and mandate providers to offer culturally proficient services across the entire Ryan White network.
4. Further investigate health literacy among PLWH, in particular those without English proficiency.
5. Continue outreach to Latino youth, in particular young MSM, and mobilize the outreach, education and prevention efforts toward this population.
6. Balance the findings of this survey with follow-up on Bergen County PLWHA. Determine the extent to which this county may be underserved and possible contributing factors.

**APPENDIX**

**Service Use, Access and Need – Detail**

**2014 Spanish-Speaker In-Care Survey and 2012 Hispanic In-Care Survey Comparisons**

**2014 Spanish-Speaker In-Care Survey (Counts)**

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.a. Do you get <b>HIV Outpatient Medical Care</b> now or over the past year?	31	*		28	*	0	0	*	
48.b. Do you get (For Women) <b>Outpatient OB/Gyn Care</b> now or over the past year? (n=10)	9	*		9	0	0	0	*	
48.c. Do you get <b>Medical Care from a Specialist</b> referred by your HIV doctor (i.e., heart, skin, diabetes, orthopedic, neurology, other specialist) now or over the past year?	11	22		11	0	0	0	22	
48.d. Do you get <b>Help Paying for Medical Care</b> now or over the past year?	21	12		15	6	0	*	11	
48.e. Do you get <b>Help Paying for Prescriptions or Medications</b> now or over the past year?	27	6		25	*	0	*	*	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.f. Do you get <b>Health Insurance Continuation</b> now or over the past year?	28	5		25	*	*	*	*	
48.g. Do you get <b>Help paying for co-pays and deductibles for HIV medical care</b> visits now or over the past year?	13	20		5	*	7	*	17	
48.h. Do you get <b>Help paying for co-pays and deductibles for HIV medications</b> now or over the past year?	21	12		19	*	0	*	8	
48.i. Do you get <b>Dental Visits</b> now or over the past year?	24	9		21	*	*	7	*	
48.j. Do you get <b>Medical Case Management</b> -- that is, help with coordination of your medical care offered at medical and dental care locations now or over the past year?	26	6		26	0	*	*	*	
48.k. Do you get <b>Non-Medical Case Management</b> — that is, help accessing support services now or over the past year?	21	12		20	*	0	*	9	
48.l. Do you get <b>Mental Health Counseling</b> now or over the past year?	12	21		12	0	0	0	21	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.m. Do you get <b>Nutrition Counseling</b> now or over the past year?	12	21		12	0	0	*	18	
48.n. Do you get <b>Outpatient Substance Abuse Treatment</b> now or over the past year?	*	31		*	0	0	0	31	
48.o. Do you get <b>Adult Day Care</b> (Activities during the day) now or over the past year?	*	32		*	0	0	*	32	
48.p. Do you use <b>Food Bank</b> now or over the past year?	9	24		8	*	0	*	21	
48.q. Do you get <b>Emergency Financial Assistance for Utilities</b> now or over the past year?	5	28		*	0	*	7	21	
48.r. Do you get <b>Emergency Assistance for Rent or Mortgage</b> now or over the past year?	*	32		*	0	0	12	20	
48.s. Do you get <b>Long-Term Rental Assistance</b> now or over the past year?	*	31		*	*	0	11	20	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.t. Do you use <b>Facility Based Housing</b> (Assisted Living Facility) now or over the past year?	*	32		*	0	0	*	29	
48.u. Do you get <b>Legal Services</b> to help you work through a problem obtaining services/benefits, outline advance directives or establish guardianships now or over the past year?	6	27		*	*	0	*	23	
48.v. Do you get <b>Child Care</b> while at a medical or other appointment now or over the past year?	*	32	*	0	*	0	0	32	
48.w. Do you get <b>Transportation to Medical Care with a Bus Pass</b> now or over the past year?	8	25		6	*	0	*	22	
48.x. Do you get <b>Transportation to Medical Care with a Van Service</b> now or over the past year?	9	24		7	*	0	*	20	
48.y. Do you get <b>Translation or Interpretation Service</b> now or over the past year?	18	15		17	*	0	*	14	
NOTE: Values less than five are denoted by an asterisk (*) to assure confidentiality.									

**2014 Spanish-Speaker In-Care Survey (Percents)**

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.a. Do you get <b>HIV Outpatient Medical Care</b> now or over the past year?	93.94%	6.06%		90.32%	9.68%	0.00%	0.00%	100.00%	
48.b. Do you get (For Women) <b>Outpatient OB/Gyn Care</b> now or over the past year? (n=10)	90.00%	10.00%		100.00%	0.00%	0.00%	0.00%	100.00%	
48.c. Do you get <b>Medical Care from a Specialist</b> referred by your HIV doctor (i.e., heart, skin, diabetes, orthopedic, neurology, other specialist) now or over the past year?	33.33%	66.67%		100.00%	0.00%	0.00%	0.00%	100.00%	
48.d. Do you get <b>Help Paying for Medical Care</b> now or over the past year?	63.64%	36.36%		71.43%	28.57%	0.00%	8.33%	91.67%	
48.e. Do you get <b>Help Paying for Prescriptions or Medications</b> now or over the past year?	81.82%	18.18%		92.59%	7.41%	0.00%	50.00%	50.00%	
48.f. Do you get <b>Health Insurance Continuation</b> now or over the past year?	84.85%	15.15%		89.29%	7.14%	3.57%	40.00%	60.00%	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.g. Do you get <b>Help paying for co-pays and deductibles for HIV medical care visits now or over the past year?</b>	39.39%	60.61%		38.46%	7.69%	53.85%	15.00%	85.00%	
48.h. Do you get <b>Help paying for co-pays and deductibles for HIV medications now or over the past year?</b>	63.64%	36.36%		90.48%	9.52%	0.00%	33.33%	66.67%	
48.i. Do you get <b>Dental Visits</b> now or over the past year?	72.73%	27.27%		87.50%	8.33%	4.17%	77.78%	22.22%	
48.j. Do you get <b>Medical Case Management</b> -- that is, help with coordination of your medical care offered at medical and dental care locations now or over the past year?	78.79%	18.18%		100.00%	0.00%	3.85%	33.33%	33.33%	
48.k. Do you get <b>Non-Medical Case Management</b> — that is, help accessing support services now or over the past year?	63.64%	36.36%		95.24%	4.76%	0.00%	25.00%	75.00%	
48.l. Do you get <b>Mental Health Counseling</b> now or over the past year?	36.36%	63.64%		100.00%	0.00%	0.00%	0.00%	100.00%	
48.m. Do you get <b>Nutrition Counseling</b> now or over the past year?	36.36%	63.64%		100.00%	0.00%	0.00%	14.29%	85.71%	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.n. Do you get <b>Outpatient Substance Abuse Treatment</b> now or over the past year?	6.06%	93.94%		100.00%	0.00%	0.00%	0.00%	100.00%	
48.o. Do you get <b>Adult Day Care</b> (Activities during the day) now or over the past year?	3.03%	96.97%		100.00%	0.00%	0.00%	3.13%	100.00%	
48.p. Do you use <b>Food Bank</b> now or over the past year?	27.27%	72.73%		88.89%	11.11%	0.00%	12.50%	87.50%	
48.q. Do you get <b>Emergency Financial Assistance for Utilities</b> now or over the past year?	15.15%	84.85%		80.00%	0.00%	20.00%	25.00%	75.00%	
48.r. Do you get <b>Emergency Assistance for Rent or Mortgage</b> now or over the past year?	3.03%	96.97%		100.00%	0.00%	0.00%	37.50%	62.50%	
48.s. Do you get <b>Long-Term Rental Assistance</b> now or over the past year?	6.06%	93.94%		50.00%	50.00%	0.00%	35.48%	64.52%	
48.t. Do you use <b>Facility Based Housing</b> (Assisted Living Facility) now or over the past year?	3.03%	96.97%		100.00%	0.00%	0.00%	9.38%	90.63%	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=33	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.u. Do you get <b>Legal Services</b> to help you work through a problem obtaining services/benefits, outline advance directives or establish guardianships now or over the past year?	18.18%	81.82%		66.67%	33.33%	0.00%	14.81%	85.19%	
48.v. Do you get <b>Child Care</b> while at a medical or other appointment now or over the past year?	3.03%	96.97%		0.00%	100.00%	0.00%	0.00%	100.00%	
48.w. Do you get <b>Transportation to Medical Care with a Bus Pass</b> now or over the past year?	24.24%	75.76%		75.00%	25.00%	0.00%	12.00%	88.00%	
48.x. Do you get <b>Transportation to Medical Care with a Van Service</b> now or over the past year?	27.27%	72.73%		77.78%	22.22%	0.00%	16.67%	83.33%	
48.y. Do you get <b>Translation or Interpretation Service</b> now or over the past year?	54.55%	45.45%		94.44%	5.56%	0.00%	6.67%	93.33%	

NOTE: Values less than five are denoted by an asterisk (\*) to assure confidentiality.

**2012 Hispanic In-Care Survey(Counts)**

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.a. Do you get <b>HIV Outpatient Medical Care</b> now or over the past year?	73	7		69	*	0	*	6	
48.b. Do you get (For Women) <b>Outpatient OB/Gyn Care</b> now or over the past year? (n=31)	28	*		28	0	0	*	*	
48.c. Do you get <b>Medical Care from a Specialist</b> referred by your HIV doctor (i.e., heart, skin, diabetes, orthopedic, neurology, other specialist) now or over the past year?	53	27		51	*	0	*	24	
48.d. Do you get <b>Help Paying for Medical Care</b> now or over the past year?	66	14		62	*	*	*	10	
48.e. Do you get <b>Help Paying for Prescriptions or Medications</b> now or over the past year?	72	8		69	*	0	*	*	
48.f. Do you get <b>Health Insurance Continuation</b> now or over the past year?	63	17		59	*	0	8	9	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.g. Do you get <b>Help paying for co-pays and deductibles for HIV medical care</b> visits now or over the past year?	55	25		52	*	*	7	18	
48.h. Do you get <b>Help paying for co-pays and deductibles for HIV medications</b> now or over the past year?	57	23		54	*	0	7	16	
48.i. Do you get <b>Dental Visits</b> now or over the past year?	42	38		38	*	0	10	28	
48.j. Do you get <b>Medical Case Management</b> -- that is, help with coordination of your medical care offered at medical and dental care locations now or over the past year?	69	11		66	*	*	8	*	
48.k. Do you get <b>Non-Medical Case Management</b> — that is, help accessing support services now or over the past year?	35	45		33	*	0	7	38	
48.l. Do you get <b>Mental Health Counseling</b> now or over the past year?	20	60		17	*	0	7	53	
48.m. Do you get <b>Nutrition Counseling</b> now or over the past year?	13	67		13	0	0	9	58	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.n. Do you get <b>Outpatient Substance Abuse Treatment</b> now or over the past year?	9	71		7	*	0	0	71	
48.o. Do you get <b>Adult Day Care</b> (Activities during the day) now or over the past year?	7	73		6	*	0	*	72	
48.p. Do you use <b>Food Bank</b> now or over the past year?	9	71		5	*	0	5	66	
48.q. Do you get <b>Emergency Financial Assistance for Utilities</b> now or over the past year?	6	74		*	*	0	10	64	
48.r. Do you get <b>Emergency Assistance for Rent or Mortgage</b> now or over the past year?	6	74		*	*	*	9	65	
48.s. Do you get <b>Long-Term Rental Assistance</b> now or over the past year?	7	73		*	*	0	13	60	
48.t. Do you use <b>Facility Based Housing</b> (Assisted Living Facility) now or over the past year?	*	78		*	0	*	6	72	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.u. Do you get <b>Legal Services</b> to help you work through a problem obtaining services/benefits, outline advance directives or establish guardianships now or over the past year?	11	69		8	*	0	*	67	
48.v. Do you get <b>Child Care</b> while at a medical or other appointment now or over the past year?	2	78		*	0	0	0	78	
48.w. Do you get <b>Transportation to Medical Care with a Bus Pass</b> now or over the past year?	16	64		12	*	*	12	52	
48.x. Do you get <b>Transportation to Medical Care with a Van Service</b> now or over the past year?	15	65		13	*	0	14	51	
48.y. Do you get <b>Translation or Interpretation Service</b> now or over the past year?	26	54		26	0	0	*	53	
NOTE: Values less than five are denoted by an asterisk (*) to assure confidentiality.									

**2012 Hispanic In-Care survey (Percents)**

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.a. Do you get <b>HIV Outpatient Medical Care</b> now or over the past year?	91.25%	8.75%		94.52%	5.48%	0.00%	14.29%	85.71%	
48.b. Do you get (For Women) <b>Outpatient OB/Gyn Care</b> now or over the past year? (n=31)	35.00%	3.75%		100.00%	0.00%	0.00%	33.33%	66.67%	
48.c. Do you get <b>Medical Care from a Specialist</b> referred by your HIV doctor (i.e., heart, skin, diabetes, orthopedic, neurology, other specialist) now or over the past year?	66.25%	33.75%		96.23%	3.77%	0.00%	11.11%	88.89%	
48.d. Do you get <b>Help Paying for Medical Care</b> now or over the past year?	82.50%	17.50%		93.94%	4.55%	1.52%	28.57%	71.43%	
48.e. Do you get <b>Help Paying for Prescriptions or Medications</b> now or over the past year?	90.00%	10.00%		95.83%	4.17%	0.00%	50.00%	50.00%	
48.f. Do you get <b>Health Insurance Continuation</b> now or over the past year?	78.75%	21.25%		93.65%	6.35%	0.00%	47.06%	52.94%	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.g. Do you get <b>Help paying for co-pays and deductibles for HIV medical care</b> visits now or over the past year?	68.75%	31.25%		94.55%	3.64%	1.82%	28.00%	72.00%	
48.h. Do you get <b>Help paying for co-pays and deductibles for HIV medications</b> now or over the past year?	71.25%	28.75%		94.74%	5.26%	0.00%	30.43%	69.57%	
48.i. Do you get <b>Dental Visits</b> now or over the past year?	52.50%	47.50%		90.48%	9.52%	0.00%	26.32%	73.68%	
48.j. Do you get <b>Medical Case Management</b> -- that is, help with coordination of your medical care offered at medical and dental care locations now or over the past year?	86.25%	13.75%		95.65%	2.90%	1.45%	72.73%	27.27%	
48.k. Do you get <b>Non-Medical Case Management</b> — that is, help accessing support services now or over the past year?	43.75%	56.25%		94.29%	5.71%	0.00%	15.56%	84.44%	
48.l. Do you get <b>Mental Health Counseling</b> now or over the past year?	25.00%	75.00%		85.00%	15.00%	0.00%	11.67%	88.33%	
48.m. Do you get <b>Nutrition Counseling</b> now or over the past year?	16.25%	83.75%		100.00%	0.00%	0.00%	13.43%	86.57%	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.n. Do you get <b>Outpatient Substance Abuse Treatment</b> now or over the past year?	11.25%	88.75%		77.78%	22.22%	0.00%	0.00%	100.00%	
48.o. Do you get <b>Adult Day Care</b> (Activities during the day) now or over the past year?	8.75%	91.25%		85.71%	14.29%	0.00%	1.37%	98.63%	
48.p. Do you use <b>Food Bank</b> now or over the past year?	11.25%	88.75%		55.56%	44.44%	0.00%	7.04%	92.96%	
48.q. Do you get <b>Emergency Financial Assistance for Utilities</b> now or over the past year?	7.50%	92.50%		66.67%	33.33%	0.00%	13.51%	86.49%	
48.r. Do you get <b>Emergency Assistance for Rent or Mortgage</b> now or over the past year?	7.50%	92.50%		50.00%	33.33%	16.67%	12.16%	87.84%	
48.s. Do you get <b>Long-Term Rental Assistance</b> now or over the past year?	8.75%	91.25%		57.14%	42.86%	0.00%	17.81%	82.19%	
48.t. Do you use <b>Facility Based Housing</b> (Assisted Living Facility) now or over the past year?	2.50%	97.50%		50.00%	0.00%	50.00%	7.69%	92.31%	

	A			B			C		
	During the past 12 months, did you get:			If YES, how easy was it for you to get this service?			If NO during the past 12 months, did you need?		
n=80	Yes	No	Don't Know	Easy	Somewhat Hard	Hard	Yes	No	Don't Know
48.u. Do you get <b>Legal Services</b> to help you work through a problem obtaining services/benefits, outline advance directives or establish guardianships now or over the past year?	13.75%	86.25%		72.73%	27.27%	0.00%	2.90%	97.10%	
48.v. Do you get <b>Child Care</b> while at a medical or other appointment now or over the past year?	2.50%	97.50%		100.00%	0.00%	0.00%	0.00%	100.00%	
48.w. Do you get <b>Transportation to Medical Care with a Bus Pass</b> now or over the past year?	20.00%	80.00%		75.00%	18.75%	6.25%	18.75%	81.25%	
48.x. Do you get <b>Transportation to Medical Care with a Van Service</b> now or over the past year?	18.75%	81.25%		86.67%	13.33%	0.00%	21.54%	78.46%	
48.y. Do you get <b>Translation or Interpretation Service</b> now or over the past year?	32.50%	67.50%		100.00%	0.00%	0.00%	1.85%	98.15%	
NOTE: Values less than five are denoted by an asterisk (*) to assure confidentiality.									