

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

2013

2012-2013 Comprehensive HIV Needs Assessment: Final Report



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Bergen-Passaic Transitional Grant Area

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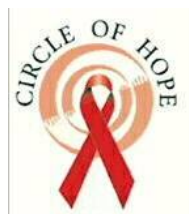
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PATERSON-PASSAIC COUNTY – BERGEN COUNTY HIV HEALTH SERVICES PLANNING COUNCIL

2012-2013 COMPREHENSIVE NEEDS ASSESSMENT

EXECUTIVE SUMMARY

A. OVERVIEW

In 2011, the Paterson-Passaic County – Bergen County HIV Health Services Planning Council, in accordance with its legislated mandate under the HIV/AIDS Treatment Extension Act of 2009, commissioned a Comprehensive HIV/AIDS Needs Assessment of persons living with HIV/AIDS (PLWHA) in the Bergen-Passaic Transitional Grant Area (TGA). This needs assessment covers a multitude of issues and circumstances that affect PLWHA and their ability to combat the deadly HIV/AIDS spectrum disease through appropriate access to medical care. Because of its importance, full access to primary medical care is the first priority of the Bergen-Passaic TGA. The 2012-2013 Comprehensive Needs Assessment investigates the current situation with regard to PLWHA who are in care, out-of-care or unaware of their HIV status.

Goal, Purpose and Objectives

The goal of the 2012-2013 Comprehensive Needs Assessment is to assess the characteristics and needs of persons living with HIV/AIDS in the Bergen-Passaic TGA in order to facilitate engagement and retention in medical care. Information gained from the Comprehensive Needs Assessment is used to:

- ✚ Establish priorities and resource allocations for persons receiving assistance from the Ryan White Part A Program;
- ✚ Inform the 2012-2015 Comprehensive HIV Health Services Plan of the Bergen-Passaic TGA;
- ✚ Guide activities designed to support the National HIV/AIDS Strategy, Healthy People 2020 and the Patient Protection and Affordable Care Acts.



The objectives of the needs assessment are to:

- ✚ Quantify the size and characteristics of the HIV population in the Bergen-Passaic TGA;
- ✚ document the service needs of PLWHA in the Bergen-Passaic TGA to support engagement and retention in medical care;
- ✚ Document the system of care and its capacity to meet the needs of PLWHA in the Bergen-Passaic TGA;
- ✚ Identify emerging issues, needs and potential solutions for reducing the number of PLWHA who are not receiving medical care; and
- ✚ Provide recommendations to the Planning Council for the development of services for PLWHA in the Bergen-Passaic TGA.

The Comprehensive Needs Assessment addresses PLWHA in Bergen County and Passaic County, New Jersey, with emphasis on three parent populations:

- ✚ PLWHA in care;
- ✚ PLWHA not-in-care, either never in care or dropped out of care; and
- ✚ Individuals with HIV/AIDS who are HIV-positive and unaware of their status or HIV-negative and at-risk for becoming HIV-positive.

Target populations are addressed by key informant interviews and further identified in the research.¹ Follow-up studies in response to the findings in this needs assessment will be conducted at a future date.

The comprehensive needs assessment consists of the following components:

- ✚ Key informant interviews;
- ✚ Consumer survey of the population in care;
- ✚ Personal interviews with the population not in care;
- ✚ Resource inventory and gaps analysis;
- ✚ Consumer survey of the general population with regard to knowledge and attitude about HIV/AIDS.

Eleven interviews with fifteen experts were conducted by New Solutions, Inc. consultants to gain insight into the opinions of recognized experts associated with HIV/AIDS in the region. Key informants were recruited from recommendations by the Planning Council as well as the City of Paterson Ryan White Part A Program. The interviews covered areas such as health status, risk factors, service utilization and community resource needs as well as gaps in services and service suggestions. Interviews also explored overarching issues, suggestions and recommendations for meeting the needs of PLWHA in the Bergen-Passaic TGA.

¹ Future follow-up target population studies are planned and intended to add detail to special populations with severe need.



The key informant results supported development of hypotheses for testing in subsequent study components as well as identifying areas of convergence of opinions, beliefs, and values. Of themselves, they provided useful insight into the status of the study population. The results also clarified questions or areas of interest for the consumer survey that was to follow.

B. HIV/AIDS POPULATION IN MEDICAL CARE

A survey of in-care PLWHA was conducted from May 4, 2012 through September 3, 2012. The sample included only PLWHA engaged in HIV medical care within the past twelve months.² 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 present report.

The survey was designed to obtain information about the in-care HIV/AIDS population. It included 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 25 distinct services included in the Bergen-Passaic Ryan White Continuum of Care.
- ✚ Suggestions for provision of care and services.

Given the special nature and size of the survey population, a stratified convenience sample was used. The sample reasonably conformed to the sampling plan and to the regional epidemic (Bergen-Passaic TGA).³ Variations from the epidemic in the region suggest over-sampling of some populations, namely residence and transmission mode.

Findings of the In-Care Survey

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

² 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.

³ Persons living with HIV/AIDS as of December 31, 2011. Source: New Jersey Department of Health, Division of HIV/AIDS, STD and TB Services (DHSTS).



- ✘ The traditionally large percentage of females continued to be notable and among the salient aspects of the Bergen-Passaic TGA.
- ✘ Black, African-Americans comprised more than half of all respondents, and Hispanics accounted for nearly one-third. One-third were foreign born, of whom 70% were Hispanic.
- ✘ The survey population was remarkably old, with nearly three-quarters over age 45 and slightly less than half over age 55.
- ✘ Seventy-one percent resided in the urban epicenters of Paterson, Passaic and Hackensack. Nine-two percent from Passaic County lived in Paterson or Passaic City while 38% from Bergen County lived in Hackensack. The smaller proportion of respondents from Hackensack indicated that residents from Bergen County were more geographically dispersed.
- ✘ Three quarters of respondents lived in permanent housing. The remainder lived in temporary or congregate facilities. Four percent lived in HIV/AIDS-defined housing, and 6% lived in shelters or on the street.
- ✘ More than half lived alone, and about 15% lived with their children.
- ✘ A small percentage (4%) had been incarcerated within the past year.
- ✘ More than 90% reported annual incomes of less than \$20,000. Nearly all would qualify below the federal poverty level.
- ✘ Respondents were 80% heterosexual, although 20% of males described themselves as gay or bisexual.

Respondents answered questions pertaining to HIV transmission, engagement, care, retention and related health conditions.

- ✘ Sexual transmission accounted for nearly all HIV infections. Heterosexual transmission was most prevalent among women and nearly half of men in this survey. Male-to-male sex accounted for one-third of PLWHA in the survey. Injecting drugs infected 18% of all respondents and 20% of males.
- ✘ Nearly half of respondents tested positive for HIV since 2000. Hispanics were more likely to be among the newly diagnosed.
- ✘ Only 21% received a diagnosis of AIDS, which was below the regional average of 54%.
- ✘ Over one-third of respondents decided to tell no one about their results when receiving a positive HIV diagnosis. Spouses/partners and other family members were told most often. By demographic category, men, Black/African-American, and older adults most frequently told no one.
- ✘ More than three-quarters (78%) entered into care within one month of diagnosis.
- ✘ Eleven percent waited six months or more. Respondents diagnosed since 2000 were more likely to enter into care within one month of diagnosis than those diagnosed prior to 2000 (89% vs 65%). Entry into care within one week improved measurably for those diagnosed since 2000 (59% vs 29%).



- ✘ For those who did not enter into care within six months, respondents most frequently cited stigma, denial and feeling well as their reasons.
- ✘ When asked about reasons for missing medical appointments, transportation, not feeling well and stigma were mentioned most often.
- ✘ Co-morbid conditions were identified by 38% of survey respondents, citing mental health problems, hepatitis c and diabetes most frequently.
- ✘ More than one-third reported some form of substance abuse, most often tobacco and alcohol; however, less than five admitted to using injecting drugs. Transportation and free drug treatment were identified as most needed by substance abusers.
- ✘ Forty percent of respondents said they were sexually active; younger respondents were more likely to have receptive sex in the last year. Of those who were sexually active, 83% said they always use protection. When asked of those who do 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.
- ✘ Nearly 60% of survey respondents have identified others who may have been exposed to the virus. The greatest percentages included women, whites, Hispanics, and older adults. When asked if they knew anyone who is HIV-positive, only 14% answered “yes.”

Respondents answered questions on use, access, need, and barriers for 25 individual services identified in the survey.

- ✘ The system of care and support services is well established with only a few gaps reported by survey respondents. Medical care and case management were well utilized. Large numbers of respondents found services easy to get.
- ✘ About 20% identified access problems for services that would make it easier to get HIV medical care, and less than 14% reported unmet need for services used in the past but unavailable today.
- ✘ Most frequent and significant access issues related to medical care centered on insurance issues. Respondents repeatedly expressed concern about meeting deductibles and co-pays.
- ✘ Transportation continued to be a notable problem among survey respondents. Need for daily supports for food and utilities ranked high in importance although most are able to find assistance. Housing, on the other hand, was highest in unmet need and perceived access barriers.
- ✘ Oral health care was among the highest in unmet need.
- ✘ Patient education may not have been sufficient in reducing barriers to care, particularly as related to Ob/Gyn and mental health treatment.
- ✘ Demand for substance abuse treatment has declined when compared to the first decades of the epidemic.



C. HIV/AIDS POPULATION OUT OF MEDICAL CARE

Conversations with key informants and experience with previous out-of-care surveys indicate that the out-of-care population is both hard to reach and unmotivated to discuss HIV. Traditionally, a survey of this population has relied on a field team and incentives to obtain a sufficient sample. While other techniques were available, there was collective skepticism regarding the ultimate success of a formal survey without utilizing a field team and incentives.

With this in mind, this needs assessment employed qualitative research based on personal interviews supplemented with a short pen and pencil survey. The results, while not statistically representative, provide insights into the study population and are worthwhile in addressing outlined goals and objectives.

Ten personal interviews were completed – nine in Passaic County and one in Bergen County. Subjects represented a cross-section of gender, age and race/ethnicity. All subjects were from minority race/ethnicities. Subjects were equally represented by gender – five male and five female. Three were under age 35; three were age 35 to 50; and four were over age 50. All were minorities --- nine Black, non-Hispanic and one Hispanic. No White, non-Hispanic subjects were available for interview.

Nine were diagnosed prior to 2010, with four diagnosed before 2000. One was diagnosed after 2010. All were out of care for six months or more, and all were re-engaged at the time of the interview. At the interview, each subject was directed to discuss only that time when he or she was out of care.

The interviews revealed a variety of personal situations and responses to positive HIV status. Two major points regarding engagement and re-engagement are notable:

- ✚ The decision to seek and remain in HIV medical care is inextricably tied to personal life situations and not to fear of the care itself. Personal situations have higher priority than medical care; and once barriers are removed, engagement can be easier for them. Most of the barriers involve a lack of support services or substance abuse.
- ✚ Re-engagement was successful across all ten interviews. Each person expressed optimism about his or her health. Outreach efforts to engage and re-engage should include positive messages about the benefits of staying in medical care.

The out-of-care interviews provided information on service use, access, needs and barriers. When asked what services were needed to get in and stay in care, subjects identified a variety of medical and support services. Medical assistance included adherence advice, specialty care, mental health treatment and nutritional advice. Support services included housing,



transportation and psychosocial support. A need for case management was implied from one interview.

When asked if their needs were changing, answers varied. Medical problems sometimes changed as did their social support needs. A common theme among the subjects centered on the benefits of receiving help, either medical or social. All spoke positively about their improving health after re-engaging in HIV medical care and, just as importantly, experiencing improvements in their daily lives. Barriers persist, however, especially with regard to food and transportation.

At the conclusion of the interview, out-of-care PLWHA were asked to identify specific service needs. Eight stated that services were needed to make it easier to get HIV medical care. When asked about specific services, six out of 25 service categories were identified by more than half of those interviewed. Nutritional counseling, food bank, and treatment adherence counseling dental care, housing assistance and transportation were identified by five or more persons interviewed.

Subjects were asked about unmet need. When asked if there are any services used in the past, still needed but no longer able to get, eight answered “yes.” When asked about specific services, only transportation was identified by more than half of those interviewed.

D. RESOURCES AND CAPACITY

A provider inventory was undertaken to assess the availability of HIV-related services in the two-county region. The inventory included listings from 133 service locations operated by 97 individual organizations across 25 categories of services. While all providers listed in this inventory extended services to persons with HIV, not all were targeted to the HIV/AIDS population. Of the 133, twenty (15%) offered HIV-targeted programs funded through the federal Ryan White Program (RWP). RWP funds were further distinguished by Parts A-F, each of which had separate grant programs.

The inventory documented a wide network of services available to persons living with HIV, with relatively few significant gaps. Service sites were comparably positioned in each county with 66 in Bergen and 67 in Passaic. RWP sites were less balanced – 14 in Passaic and 6 in Bergen – which reflects the greater portion of the epidemic in Paterson and Passaic.

There appeared to be an abundance of core services in both counties. Support services, including financial assistance, were available in both counties but to a greater degree in Bergen County.

A review of the RWP agencies provided a closer look at access to HIV-targeted services. In general, most service categories were offered by RWP agencies in both counties. More services



were offered in Passaic County than Bergen County, again representative of the greater epidemic in Paterson and Passaic. Some gaps were noted: HIV prevention in Bergen County; syringe access in Bergen County; and Faith Initiative Project in both counties.

Housing assistance was available in both counties. Housing Opportunities for Persons with HIV/AIDS (HOPWA), administered through the United States Department of Housing and Urban Development (HUD) and locally by the City of Paterson Department of Human Resources and the Housing Authorities of both counties, provided short and long term housing, housing case management, transportation, legal services and food for persons living with HIV/AIDS. Four HOPWA providers were located in the Bergen-Passaic region.

Information on hours of operation and languages spoken was available for 62 of the 133 sites listed in the inventory. A review of the 62 sites was undertaken to determine possible access problems. In general, evening and Saturday hours were noted to be in short supply, creating potential access problems for persons working full time.

Most agencies offered services in foreign languages. Seventeen (27%) reported English speaking capacity only; the others reported at least one foreign language available. Spanish speakers were available at 42 of the 62 agencies (68%). Other foreign languages spoken at one or more agencies included Russian Hindi, Polish, Korean, Arabic and French.

E. EARLY IDENTIFICATION OF INDIVIDUALS WITH HIV/AIDS

A general population survey represented the first attempt to test the level of knowledge, attitudes and HIV testing practices of those who are not HIV-positive. The assessment responded to a portion of the National AIDS Strategy that seeks to reduce new HIV infections by increasing public awareness and prevention of HIV.

The sample consisted of 256 (N) completed survey responses representing low income individuals from the two-county region. In many aspects, the sample differs from the HIV-infected population. All respondents reported to be HIV-negative. General characteristics of the respondents depict a population reflective of the minority communities in which they reside and the primary care clinics where they receive medical care.

Respondents were asked a series of questions about HIV testing and HIV/AIDS disease. Results depicted a general awareness of HIV disease and HIV testing, knowledge of its causes and risk factors, and an understanding of stigma surrounding persons with HIV/AIDS.



F. DISCUSSION AND RECOMMENDATIONS

HIV/AIDS Population in Medical Care

The in-care consumer survey probes the characteristics, health issues and care needs of PLWHA in the two counties of Bergen and Passaic, New Jersey. With a sample limited to patients receiving care under the Ryan White Program, we learn about a population that has accepted HIV/AIDS and is taking steps to secure its wellbeing. Therefore, this survey makes no attempt to describe the entire HIV/AIDS infected community, and results must be taken as a portion of the full comprehensive needs assessment.

Interpretation of the present findings must take into account issues related to the survey sample. First, despite repeated attempts to obtain additional respondents from Bergen County, the sample undercounts residents from that county and provides non-generalizable information pertaining to PLWHA from the epicenter of Hackensack. Information specific to Bergen County and Hackensack in particular must be considered as observations and not statistically representative of the population. The undersized sample may also be an indication that Bergen County PLWHA are underserved or receiving care outside of the Ryan White program, a finding that suggests further research.

Second, the survey was open only to English speakers. Although the number of Hispanic respondents was reflective of the PLWHA community, there is a population from the TGA that cannot read English and therefore does not have its needs recorded in the present survey. Additionally, the survey results indicate a substantial foreign-born population. It is a concern that the present survey does not sufficiently address the needs of the foreign residents of Bergen and Passaic counties.

Essentially, the in-care population is well 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. That stated, there are some notable observations that may be used to guide the Planning Council's decisions as it directs the priorities and allocations of Ryan White Part A funds over the next fiscal years.

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.
- ✚ At this point in the epidemic, the most common transmission mode is clearly sexual contact, either heterosexual or homosexual. Further, transmission via syringe injection has dwindled to an all-time low even though drug abuse continues to be reported among the HIV/AIDS population. This may be evidence of an effective syringe access program.



- ✂ Relatively low acuity levels with HIV-only diagnoses are more common than AIDS. This is a trend that hopefully will continue.
- ✂ The survey population is remarkably older than was expected, with 73% over age 45 and 43% over age 55. As the national epidemic focuses on newly diagnosed youth, in Bergen-Passaic, the older population dominates the in-care population, leading to speculation that newly diagnosed or at risk youth may be among those not yet in reach of the Ryan White Program.
- ✂ Hispanics (30.5% of the sample) and foreign-born (32.5% of the sample) represent a growing portion of PLWHA in the TGA. Their importance underscores the need for cultural competency across all service providers at every level of the organization.
- ✂ Presence of co-morbid conditions is reported among older respondents, a predictable consequence of aging. There are cost implications to provision of specialty care that need to be recognized.
- ✂ Respondents and key informants differ with regard to their respective attitudes toward OB/Gyn and mental health needs. This observation suggests a need for better patient education to strengthen self-empowerment and informed decision-making.
- ✂ Transportation remains a support need with apparently no clearly stated preference for bus pass or van service. Case managers should investigate every mode of transportation available and work with clients to assure the ability to get to medical appointments.
- ✂ Oral health care is identified as a leading unmet need, despite the availability of services in both counties. Patients should be educated about the need for regular oral health exams and treatment as well as access to available care.
- ✂ Continued collaboration with substance abuse treatment providers to keep substance abuse under control and minimize its risk for HIV/AIDS appears to be effective, although the need for ongoing treatment across the spectrum of treatment modalities remains high.
- ✂ Prevention practices are mostly a matter of personal choice, even though education efforts have been substantial.

After more than twenty years of HIV/AIDS in the Bergen-Passaic TGA, many of the characteristics of the infected population found earlier still persist today. They include poverty, poor living conditions, language barriers and low educational attainment. Support for daily living such as housing, food and subsidies continue to be cited as common needs.

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 obtain and remain in medical care. From the current survey, these needs continue. However, consumers indicated more concern about insurance coverage than in previous needs assessments, which is reflective of recent changes in medical and pharmaceutical coverage and predictive of future changes in Medicaid and other insurance plans affected by the Affordable Care Act.



New findings of this consumer survey relate to demographic changes in the epidemic, namely the aging of the infected population and increasing penetration into the Hispanic and foreign-born populations.

Once a deadly disease of mostly young adults, HIV/AIDS is now a chronic disease affecting older adults to a greater extent than ever before. This is reflected in the survey as the in-care population has become much older. Their characteristics are further reflected in the survey, most notably by their engagement in the system of care and reduced dependence on illicit drugs.

Hispanics now constitute approximately 28% of the infected population and is the one major demographic group with increasing infection rates. Foreign-born, of which there is extraordinary diversity in the TGA, represented fully one-third of the survey sample. This underscores the need for cultural proficiencies by all service providers at every organizational level.

It is notable that in-care survey respondents in general are in relatively good health. Lower acuity levels, willingness to engage and remain in care, understanding of the need for prevention, and reduced dependence on illicit drugs indicate successful efforts to treat PLWHA in this TGA. Co-morbid conditions, as a function of aging, remain a concern, however.

As previously stated, informational needs have long been cited in the various needs assessments, and they surface again in this survey. From the survey responses and key informant interviews, there appears to be a “disconnect” between patient and care provider with regard to certain treatments, specifically OB/Gyn, mental health therapy and oral health care. Consumers and care providers, in general, do not agree on their importance as contributors of good health. More effective patient education is indicated.

HIV/AIDS transmission is now nearly exclusively a sexually transmitted disease. Although male to male transmission is on the rise nationally, this in-care survey does not document a dramatic increase in the Bergen-Passaic TGA. Survey results suggest that the young, gay community does not routinely access the Ryan White system of care, despite indications of growing risk. It also suggests that outreach methods and prevention messages targeted to young gay men, critical to addressing the young gay male in this TGA, may need further discussion.

Injecting drug use among the in-care population is on the decline. Only one respondent admitted to currently using injecting drugs. However, 18% were originally infected from sharing needles, 37% reported said they currently use drugs and 20% identified a need for substance abuse treatment and services. These responses indicate that substance abuse treatment in general must continue to be available.



HIV/AIDS Population Out of Medical Care

Personal interviews often provide insights otherwise not available through quantitative research. In this assessment, the ten PLWHA who participated in the interview process allowed the researcher to learn about the varied circumstances affecting their refusal to receive HIV medical care. Their comments provide a glimpse into personal lives that affect engagement in HIV medical care and an opportunity to develop strategies to remove personal barriers.

As with all qualitative research, there are limitations as to how the information can be used. This sample, quite small, cannot be generalized to the entire population of out-of-care PLWHA. Further, this sample included only those who were previously out-of-care and have since re-engaged. There exists an important population that these interviews do not cover, i.e. PLWHA who are presently not engaged in HIV medical care.

Despite extensive efforts and incentives to reach those who never received care or who are presently out-of-care, not one was willing to agree to an interview. This, in itself, speaks to the barriers surrounding this hard-to-reach population. They are HIV-positive and at risk of infecting others; yet they prefer to continue their present lifestyle and remain closed to public health outreach. More must be done to educate and encourage out-of-care PLWHA to seek HIV medical care. The insights from the ten interviews may be helpful to that end.

Re-engaged PLWHA do not generally associate with other at-risk individuals, preferring instead to remain in their private circles. Thus, the ability to establish a dialogue between in-care and out-of-care PLWHA may be difficult to realize. Further, re-engaged PLWHA appear to have mixed reaction to stigma, recognizing its existence but not necessarily overwhelmed by it.

On the positive side, however, re-engaged PLWHA feel they have a breadth of wisdom that they are willing to share. They agree that openness and willingness to talk about HIV has benefit and should be encouraged. This can be accomplished through peer counseling and outreach programs.

It should be noted that the positive messages of likely improved health status could contradict prevention efforts, especially among youth who may conclude that contracting HIV/AIDS is not serious. Both prevention and engagement messages need to be clear that HIV/AIDS is serious, but, if one becomes infected, medical care is the best course of action.

Factors leading to successful re-engagement identified during the interviews point to personalized treatment and education. While mass media education should not be overlooked, a personal approach will yield success according to those interviewed. Critical areas of intervention include:



- ✚ Substance abuse treatment and mental health counseling;
- ✚ Support services such as housing, food and transportation;
- ✚ Education about HIV care;
- ✚ Personal supports, especially from family and peers.

Resources and Capacity

The Provider Inventory documented a well-developed network of care and services available to PLWHA in the Bergen-Passaic TGA. This network should be maintained at its current capacity until such time as alternatives are available. The gaps analysis further revealed few service needs of major significance, with one notable exception in Bergen County. Cultural competencies, beginning with language capacities, should be part of all service delivery, and the provider inventory indicated progress made in that regard.

Early Identification of Individuals with HIV/AIDS

A limited survey such as the General Population Survey must be interpreted carefully so as not to draw conclusions that may be inappropriate or non-reflective of an entire community. With this in mind, however, this survey does help us to understand the current status of HIV/AIDS knowledge and awareness at the epi-centers of the Bergen-Passaic TGA.

The survey provided a snapshot of minority populations, generally of low income, who had an interest in health-related matters. By targeting this population, we were able to continue the process of reducing new HIV infections through a coordinated approach that includes active collaboration with the minority communities.

The results indicated a broad knowledge of HIV as well as basic understanding of the factors affecting disease transmission and prevention. It can be reasonably stated that the respondents knew about HIV/AIDS, were sufficiently aware of how it is transmitted, and what can be done to prevent it. They linked HIV/AIDS with sexually transmitted diseases and used condoms most often as a means of protection. In these respects, the results are encouraging.

Perhaps the most heartening results pertain to HIV stigma. A large majority of respondents showed an awareness of stigma and agreement that part of the problem lies with communication. Further, many (78%) would not change their relationship with someone who is HIV positive. These responses, then, would point to a general “openness” about HIV and could validate probable beneficial effects of educational and social marketing efforts. This does not mean that stigma is no longer an issue, however, for nearly one-quarter would not continue their relationship with someone who is HIV-positive. This was the largest “negative” response in the survey. Stigma is still with HIV, and the need to change the public opinion remains.



The survey helped to identify specific populations to target for educational efforts. Results indicate:

- ✘ Hispanics were tested for HIV less than other race/ethnicities.
- ✘ Blacks and older adults appeared to be most biased about HIV stigma.
- ✘ Young adults tended to be least informed about HIV.
- ✘ Women tended to use protection for HIV and sexually transmitted diseases less than men.

Educational messages should be targeted accordingly.

RECOMMENDATIONS

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

1. Balance the findings of this survey with follow-up on Bergen County PLWH/A. Determine the extent to which this county may be underserved and possible contributing factors. Look closely at information and transportation needs in Bergen County as possible barriers to care.
2. Conduct the survey in Spanish to gain a more complete picture of foreign-born Hispanic PLWH/A.
3. Enhance patient education to emphasize those aspects of care that are apparently misunderstood with regard to their importance. OB/Gyn, mental health needs and dental care are among those clinical services that require more effective patient education.
4. 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.
5. Plan for increased costs of providing specialty care to older PLWH/A.
6. Continue to outreach to youth, in particular young MSM, and mobilize the outreach, education and prevention efforts toward this population.
7. Implement the recommendations of the Cultural Competency Task Force, and mandate providers to offer culturally proficient services across the entire Part A network.
8. Continue collaboration among outreach, HIV testing and early intervention providers to strengthen the continuum from unaware to early detection to immediate engagement in care.
9. Continue successful collaboration with the syringe access program and other substance abuse providers to maintain the downward trend of HIV transmission through injecting



drug use, and continue to support the full continuum of substance abuse treatment and services in the TGA.

HIV/AIDS Population Out-of-Medical Care

The out-of-care interviews provide valuable, albeit limited, information about the characteristics and needs of PLWHA who refuse HIV medical care. Five recommendations, offered as follows, reflect the insights gleaned from this study:

10. Continue efforts to assess the needs of out-of-care PLWHA in the Bergen-Passaic TGA, focusing on those who presently refuse HIV medical care.
11. Continue to fund outreach programs that identify, educate and engage out-of-care PLWHA. Research effective and innovative programs that combine education, peer counseling and one-on-one relationship building.
12. Continue to fund the programs that effectively remove barriers to engagement in HIV medical care. These include: substance abuse treatment, mental health counseling, housing, transportation, and case management.
13. Encourage one-on-one peer counseling and psychosocial support groups to educate and support PLWHA who previously refused HIV medical care and have recently re-engaged. Capitalize on the positive experiences of re-engaged PLWHA to convey messages of personal health improvements.
14. Support programs aimed at eliminating the stigma of HIV, both in the general population and targeted high risk populations. Encourage open dialogue across all sectors of the population, and increase knowledge about HIV disease and the need for universal testing.

Resources and Capacity

The network of HIV/AIDS care and services in Bergen and Passaic County is substantial and well documented. The following recommendations would further improve the ability to serve PLWHA:

15. Advocate for prevention programs in Bergen County.
16. Consider expansion of the syringe access program into Bergen County.
17. Update the current provider inventory at an appropriate time to fully document provider capacity, hours of operation, languages spoken, insurance policies, and other important information for PLWHA.

Early Identification of Individuals with HIV/AIDS

The key informant interviews and general population survey suggest appropriate directions for Planning Council consideration, including the following recommendations:



18. Continue the survey process to increase the value of a limited survey such as this. Consider various venues that represent other segments of the population. These include colleges, health fairs, churches, and ethnic special events. Over time, the various samples can bring a wider understanding of HIV/AIDS knowledge, attitudes and behaviors.
19. Use the results of the survey to target specific minority populations in areas where weaknesses are observed, i.e, testing among Hispanics, stigma reduction among Blacks and older adults, basic HIV/AIDS education among young people, and STD protection for women.
20. Collaborate with minority organizations, sharing the results of this survey, and establish joint interventions appropriate to the populations served.
21. Incorporate information gleaned from the survey into the TGA's Early Identification of Individuals with HIV/AIDS (EIIHA) Action Plan.



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I. INTRODUCTION

A. OVERVIEW

In 2011, the Paterson-Passaic County – Bergen County HIV Health Services Planning Council, in accordance with its legislated mandate under the HIV/AIDS Treatment Extension Act of 2009, commissioned a Comprehensive HIV/AIDS Needs Assessment of persons living with HIV/AIDS (PLWHA) in the Bergen-Passaic Transitional Grant Area (TGA). This needs assessment covers a multitude of issues and circumstances that PLWHA and their ability to combat the deadly HIV/AIDS spectrum disease through appropriate access to medical care.

Access to medical care and the needed support services that help to maintain patients in care has been at the forefront of the Ryan White Part A Program since its inception. Because of its importance, full access to primary medical care is the first priority of the Bergen-Passaic TGA. The 2012-2013 Comprehensive Needs Assessment investigates the current situation with regard to PLWHA who are in care, out-of-care or unaware of their HIV status.

Goal, Purpose and Objectives

The goal of the 2012-2013 Comprehensive Needs Assessment is to assess the characteristics and needs of persons living with HIV/AIDS in the Bergen-Passaic TGA in order to facilitate engagement and retention in medical care. Information gained from the Comprehensive Needs Assessment are used to:

- ✘ Establish priorities and resource allocations for persons receiving assistance from the Ryan White Part A Program;
- ✘ Inform the 2012-2015 Comprehensive HIV Health Services Plan of the Bergen-Passaic TGA;
- ✘ Guide activities designed to support the National HIV/AIDS Strategy, Healthy People 2020 and the Patient Protection and Affordable Care Acts.

The objectives of the needs assessment are to:

- ✘ Quantify the size and characteristics of the HIV population in the Bergen-Passaic TGA;
- ✘ document the service needs of PLWHA in the Bergen-Passaic TGA to support engagement and retention in medical care;
- ✘ Document the system of care and its capacity to meet the needs of PLWHA in the Bergen-Passaic TGA;
- ✘ Identify emerging issues, needs and potential solutions for reducing the number of PLWHA who are not receiving medical care; and
- ✘ Provide recommendations to the Planning Council for the development of services for PLWHA in the Bergen-Passaic TGA.



Project Scope

The Comprehensive Needs Assessment addresses PLWHA in Bergen County and Passaic County, New Jersey, with emphasis on three parent populations:

- ✚ PLWHA in care;
- ✚ PLWHA not-in-care, either never in care or dropped out of care;
- ✚ Individuals with HIV/AIDS who are HIV-positive and unaware of their status or HIV-negative and at-risk for becoming HIV-positive.

Target populations are addressed by key informant interviews and further identified in the research.⁴ Follow-up studies in response to the findings in this needs assessment will be conducted at a future date.

This comprehensive needs assessment includes the following components:⁵

- ✚ Profiles of persons living with HIV/AIDS (PLWHA) who are either in or out of medical care.
- ✚ Service needs assessments associated with engagement in medical care including:
 - Availability, appropriateness and accessibility of services needed to support retention in medical care; and
 - Barriers and issues related to the ability to maintain engagement in medical care.
- ✚ Resources, provider capacity and gaps in services;
- ✚ Profiles of the attitudes, HIV testing practices, knowledge of HIV and risk reduction practices by individuals who are unaware of their HIV status;
- ✚ Issues related to universal HIV testing, informing, contact elicitation, referring and engagement in medical care.

B. RESEARCH DESIGN AND METHODOLOGY

The following overarching questions provided the basis for the research design:

- ✚ What is your current medical condition?
- ✚ What is your level of understanding about HIV?
- ✚ If you are not in care, what are the circumstances that made you either stay away or drop out of medical care?
- ✚ If you are not in care, what will it take to get you into or back into medical care?
- ✚ What services do you need to stay in care? Are your needs changing?

⁴ Future follow-up target population studies are planned and intended to add detail to special populations with severe need.

⁵ The Bergen-Passaic TGA epidemiological profile, which is traditionally part of a comprehensive needs assessment, is provided to the Planning Council annually by the New Jersey Department of Health Division of HIV/AIDS, TB and STD Services.



- ✚ What helps you stay in medical care, especially when you feel like dropping out?
- ✚ Do you share HIV information with your partner, potential partner or others at risk for HIV? If yes, what is your experience with disclosing or identifying persons who may have been exposed to HIV through you?
- ✚ If you do not know your HIV status, do you know about the importance of getting tested for HIV? What prevents you or others from getting tested for HIV?
- ✚ If you do not know your HIV status, do you know where to go to get an HIV test?
- ✚ What measures do you take to prevent HIV? What is your level of knowledge about HIV prevention?

Project Components

The comprehensive needs assessment consisted of the following components:

- ✚ Key informant interviews;
- ✚ Consumer survey of the population in care;
- ✚ Personal interviews with the population not in care;
- ✚ Resource inventory and gaps analysis;
- ✚ Consumer survey of the general population with regard to knowledge and attitude about HIV/AIDS.

Key Informant Interviews

Eleven interviews with fifteen individuals were conducted by New Solutions, Inc. consultants to gain insight into the opinions of recognized experts associated with HIV/AIDS in the region. Key informants were recruited from recommendations by the Planning Council as well as the City of Paterson Ryan White Part A Program. A roster of the 15 key informants is found in Appendix A.

The interviews covered areas such as health status, risk factors, service utilization and community resource needs as well as gaps in services and service suggestions. Interviews also explored overarching issues, suggestions and recommendations for meeting the needs of PLWHA in the Bergen-Passaic TGA.

The objectives of the key informant interviews were to gain insight into:

- ✚ Characteristics of PLWHA in the Bergen-Passaic region, including those who are newly diagnosed, in care, out-of-care or unaware of their HIV status;
- ✚ Behaviors and knowledge patterns associated with risk reduction and prevention;
- ✚ Service needs of PLWHA in the Bergen-Passaic TGA in support of engagement and retention in medical care;
- ✚ The system of care and its capacity to meet the needs of PLWHA in the Bergen-Passaic TGA; and



- ⓧ Emerging issues, needs and potential solutions for reducing the number of PLWHA who are not receiving medical care.

Prior to conducting the interview, consultants developed an interview guide to include specific questions identified by the Planning & Development Committee in the initial scope of study. Consultants conducted interviews in person or via telephone with each interview lasting approximately sixty minutes. Interviews were audio recorded and transcribed to assure accuracy of the information.

Of the fifteen experts interviewed, five were directly involved in patient care or services, four were supervisors, five were from government or insurance agencies, and three (two of whom were also providers) were consumers. Areas of expertise included HIV/AIDS Care and Treatment, HIV Prevention, Ryan White Parts A, C and D Programs, public insurance programs, and HIV planning.

The key informant results supported development of hypotheses for testing in subsequent study components as well as identifying areas of convergence of opinions, beliefs, and values. Of themselves, they provided useful insight into the status of the study population. The results also clarified questions or areas of interest for the consumer survey that was to follow.

In-Care Consumer Survey

A survey PLWHA who were receiving medical care was conducted from May 4, 2012 through September 3, 2012. The sample included only PLWHA engaged in HIV medical care within the past twelve months.⁶ 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 obtained and incorporated into the present report.

The goal of the in-care survey was to assess the characteristics and needs of persons living with HIV/AIDS in the Bergen-Passaic TGA in order to facilitate their continued engagement and retention in medical care. Objectives were to:

- ⓧ Quantify the size and characteristics of the HIV population in the Bergen-Passaic TGA;
- ⓧ Document the service needs of PLWH/A 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 PLWH/A who are not receiving medical care; and

⁶ 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.



- ✚ 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.

Survey Design

The goal in designing the consumer survey was to obtain the desired information using a consumer-friendly approach. Key informant interviews (described above) were conducted prior to survey development, thus allowing expansion of questions relating to population characteristics, needs, service barriers, the care coordination system, reasons for being out-of-care and the medical care system.

The survey was designed to obtain information about the in-care HIV/AIDS population. It included 51 questions on the following topics:

- ✚ Initial screening of PLWH/A 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 25 distinct services included in the Bergen-Passaic Ryan White Continuum of Care.
- ✚ Suggestions for provision of care and services.

The in-care survey drew upon questions from a variety of previously validated instruments as well as additional questions specifically designed for this survey. Sources for the 2012 Consumer Survey instrument included the 2007 Consumer Survey of the Bergen-Passaic TGA and other needs assessment questionnaires from Ryan White organizations across the country.

The survey instrument was concept and face validated. Concept validity identified whether the survey fully captured and represented the concept under study. This was accomplished by a review of relevance by New Solutions, Inc. consultants and Planning & Development Committee members. Face validation used interviews with persons similar to survey respondents to ensure that the questions obtained the desired information and were clearly phrased. In this case, Part A recipients from the P&D committee provided face validity.

The survey was administered in English only. A Spanish translation may be available for future iterations of the survey.



Survey Sampling Approach

Given the special nature and size of the survey population, a stratified convenience sample was used. A general sampling plan was developed that conformed by age, gender and race/ethnicity to the regional epidemic. Throughout the field work, weekly sample profiles were produced that examined the number of respondents by gender and county of residence and evaluated for conformance to the sampling plan.

Survey Administration

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.

The sample was drawn largely from the clients of Ryan White Part A and Part C medical and service providers. A unique aspect of the administration was the use of the web-based interactive eCOMPAS platform developed by RDE Associates. 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.

Survey responses were entered directly by the respondent into the 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 report, unless otherwise noted, percentages are based on number of respondents (n) who answered the specific question in the survey.

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 personally select responses. 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 large scale surveys, some data limitations were identified. Many of these were minimized through the eCOMPAS program as well as the presence of on-site administrators 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.
- ✘ Spanish speakers were not provided with an opportunity to complete the survey, thereby compromising the sample of Hispanic respondents.
- ✘ Although misunderstanding or misinterpreting words or terms was minimized through survey validation with consumers and on-site facilitation of survey administrators, 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.

Out-Of-Care Interviews

This portion of the comprehensive needs assessment addressed persons living with HIV/AIDS in Bergen and Passaic counties who were out-of-care (i.e., refused medical care for six months or more).⁷ The goal of the research was to understand the characteristics and needs of this important population and to inform the Planning Council of needed services related to engagement and retention in medical care. The objectives were to:

- ✘ Determine general characteristics of the out-of-care HIV populations in the Bergen-Passaic TGA;
- ✘ Document the service needs of PLWHA in the Bergen-Passaic TGA who were out of care;
- ✘ Identify emerging issues, needs and potential solutions for reducing the number of individuals who are HIV-positive and not receiving medical care; and
- ✘ Provide recommendations to the Planning Council for the development of programs and/or services for out-of-care PLWHA in the Bergen-Passaic TGA.

The research was intended to answer basic questions about decisions to refuse medical care, past and present attitudes about HIV and associated medical care, risk and prevention practices, and knowledge of others who may be at risk for HIV/AIDS, such as:

- ✘ Why do you choose not to receive medical care for your HIV?
- ✘ What will change your mind about getting medical care for your HIV?
- ✘ What services do you need to get and stay in care? Are your needs changing?
- ✘ Do you routinely engage in risk reduction practices?
- ✘ Do you share HIV information with your partner, potential partner or others at risk for HIV?
- ✘ What is your experience with exposing or identifying persons who may have been exposed through you?
- ✘ What do you know about others engaging in high risk behaviors?

Approach and Methodology

Conversations with key informants and experience with previous out-of-care surveys indicate that the out-of-care population is both hard to reach and unmotivated to discuss HIV. Traditionally, a survey of this population has relied on a field team and incentives to obtain a

⁷ The HRSA definition of “out of care” is used, i.e. less than two medical visits or CD4 lab tests in a year. Thus, someone may have received health care services in the last 12 months and still be considered *out of care*.



sufficient sample. While other techniques were available, there was collective skepticism regarding the ultimate success of a formal survey without utilizing a field team and incentives.

With this in mind, this needs assessment employed qualitative research based on personal interviews supplemented with a short pen and pencil survey. The results, while not statistically representative, provide insights into the study population and are worthwhile in addressing outlined goals and objectives.

Private interviews of approximately 30 minutes each were conducted in the two-county region. Out-of-care PLWHA were recruited and scheduled by case managers and/or outreach workers with established connections with the target population. Interviews were scheduled at forty-five minute intervals at the convenience of the participants. Interviews were conducted in private settings where confidentiality was carefully maintained. Privacy was assured at each venue to reinforce confidentiality. No individual was approached in any way as to disclose identity, and every precaution was taken to assure privacy and confidentiality. Information on access to medical care was available at the interview sites.

The researcher utilized a standard interview guide, developed by the consultant and reviewed by the Planning & Development Committee prior to implementation. Questions were tailored to keep the interview to a 30-minute limit. Additionally, each subject was asked to complete a written questionnaire about service needs. Interviews were conducted in English; a Spanish translator assisted with one interview. Each subject who completed the interview received a \$25 gift card.

A New Solutions, Inc. consultant conducted all interviews. Each interview was audio taped and transcribed to assure an accurate record.

Interview Sample

Ten personal interviews were completed – nine in Passaic County and one in Bergen County. Subjects represented a cross-section of gender, age and race/ethnicity. All subjects were from minority race/ethnicities. Subjects were equally represented by gender – five male and five female. Three were under age 35; three were age 35 to 50; and four were over age 50. All were minorities – nine Black, non-Hispanic and one Hispanic. No White, non-Hispanic subjects were available for interview.

Nine were diagnosed prior to 2010, with four diagnosed before 2000. One was diagnosed after 2010. All were out of care for six months or more, and all were re-engaged at the time of the interview. At the interview, each subject was directed to discuss only that time when he or she was out of care.



General Population Survey

This survey represented the first attempt to test the level of knowledge, attitudes and HIV testing practices of those who are not HIV-positive. The assessment responded to a portion of the National AIDS Strategy that seeks to reduce new HIV infections by increasing public awareness and prevention of HIV.

HRSA has further instructed Ryan White grantees to assess and develop a plan to address the “Unaware,” i.e., persons who may or may not be HIV-positive and do not know their status. As this population is often hidden from the network of care and services for persons living with HIV/AIDS, it is important to gain a rudimentary understanding of where and how to identify them.

To that end, the Planning Council decided to implement a short general knowledge survey, canvassing those who are not HIV-positive but may be at risk for the disease. In the absence of a full, general population survey which would go beyond the scope and budget of the comprehensive needs assessment, the decision was to begin by seeking out non-infected persons from the two-county region, normally of low income and with an interest in health-related matters.

Survey Design

The goal in designing the survey was to obtain desired information using the shortest, most consumer-friendly approach. As such, a brief, objective questionnaire designed to test basic knowledge and awareness of HIV/AIDS was considered preferable.

Survey Sampling Approach

Any adult over age 13 was eligible for the survey. A random sample could not be implemented for this limited project; thus, a simple convenience sample was used. No attempt was made to have the sample reflect the population at large. Rather, the survey was administered at selected locations in Bergen and Passaic Counties targeting persons of low income who were invested in their health care and unaware of their HIV status.

Survey Instrument

The instrument consisted of 15 objective, multiple-choice questions with options for write-in elaboration. Questions were selected from the publically available validated instruments from the University of California Center for HIV, Prevention and Treatment Services (CHPTS) AIDS Knowledge, Attitude and Behavior Survey. Three questions were asked to determine whether the respondent had been tested for HIV in the last twelve months, whether the respondent was HIV-positive and, if so, whether the respondent was receiving medical care for HIV. A fourth



question screened for persons under age 13 who were considered ineligible for the survey. Five questions pertaining to beliefs about the topic of HIV/AIDs utilized a 5-point Likert scale ranging from 'agree' to 'disagree'. Four questions, answered 'yes' or 'no', probed for attitudes and risky behaviors associated with HIV. Open-ended questions were added to gain additional detail regarding behaviors. The survey was administered in English and Spanish.

Survey Administration

The survey was administered by five trained researchers employed by New Solutions, Inc. Two researchers were stationed at each site, one of whom spoke Spanish. Prior to initiating the survey, all researchers received a half-day training on recruitment and survey administration.

At the survey site, researchers approached participants by providing a description of the survey along with a sample consent form. Researchers recruited respondents, answered questions about the need for the survey, recorded responses and completed data entry into the online eCOMPAS system. Privacy was secured at each survey site to reinforce confidentiality. Following completion of the survey, information on access to HIV testing and treatment was distributed to all participants. The survey averaged nine to 12 minutes to complete.

Six federally qualified health centers (FQHC) were visited – four in Passaic County and two in Bergen County. Prior to the survey dates, permissions were obtained from the directors of each site. All but one FQHC in the region participated (Table I.1).

Table I.1
Survey Locations

County	Name	Address
Passaic	Paterson Community Health Center, Inc.	227 Broadway, Paterson
Passaic	Paterson Community Health Center, Inc.	32 Clinton Street, Paterson
Passaic	North Hudson Community Action Center @ Passaic	110 Main Ave., Passaic
Passaic	North Hudson Community Action Center @ Passaic	148 8 th Street, Passaic
Bergen	North Hudson Community Action Center @ Garfield	535 Midland Ave., Garfield
Bergen	North Hudson Community Action Center @ Hackensack	25 E. Salem Street, Hackensack



The survey was administered in English and Spanish by trained bi-lingual researchers. Field work consisted of two half days at each health center over a period of two weeks from February 11 to February 21, 2013. On average, forty surveys were completed at each site. After each survey was completed, participants were offered a directory of available HIV-related services and a brochure introducing basics of HIV/AIDS.

Limitations of the Survey

This survey did not answer questions about the population at large but rather a small segment considered to be of interest to the Planning Council. Findings were not generalizable nor representative of any specific demographic population or cohort. It is hoped that the survey process will continue over time and will ultimately include persons from various other sectors of the population. At such time, results may be used more broadly to guide our knowledge of HIV in the general public.

Provider Inventory and Capacity Analysis

This inventory was part of the comprehensive needs assessment to assess the availability of HIV-related services in the two-county region. The inventory included listings from 133 service locations operated by 97 individual organizations across 25 categories of services. While all providers listed in this inventory extended services to persons with HIV, not all were targeted to the HIV/AIDS population. Of the 133, twenty (15%) offered HIV-targeted programs funded through the federal Ryan White Program (RWP). RWP funds were further distinguished by Parts A-F, each of which had separate grant programs.

The inventory was developed solely from secondary source materials available from various directories including: the New Jersey HIV/AIDS Resource Directory (NJHARD) managed by the New Jersey HIV Prevention Community Support Initiative of Rutgers University (CPSDI),⁸ the New Jersey State Division of Mental Health and Addiction Services (DMHAS) Mental Health Directory,⁹ and MHAS Addiction Services Treatment Directory,¹⁰ and other New Jersey Department of Health websites.¹¹ To provide greater detail, additional information was obtained directly from Ryan White providers located in the two counties.

For purposes of the comprehensive needs assessment, the provider inventory served as a tool to determine gaps in access to HIV services in the two-county region. The inventory was considered limited in scope and may be expanded at a later date to include a complete listing of important information such as hours of operation, languages spoken, access procedures, etc. This information is being compiled by the NJHPCSI in accordance with the Centers for Disease

⁸ <http://hpcpsdi.rutgers.edu/dir/index.php>

⁹ <http://www.state.nj.us/humanservices/dmhs/news/publications/mhs/index.html>

¹⁰ <https://njsams.rutgers.edu/dastxdirectory/txdirmain.htm>

¹¹ <http://web.doh.state.nj.us/apps2/fhs/cphc/cphcSearch.asp>



Control National Prevention Information Network (NPIN) database and will be incorporated into this directory when available. While efforts were made to include as many service sites as possible, no claim was made as to its completeness.

Services identified for each site were listed according to information from the websites of the respective agencies and sources listed above. Only Ryan White agencies were asked to verify their service offerings.

An agency was listed as a Ryan White provider when it receives funds from a Ryan White grant program. All RWP parts are included in this inventory without specification. It is important to note that, although an agency may be identified as Ryan White, not all of its services may be funded from a Ryan White grant.

Agencies consisted of community or hospital-based organizations only. Private practices were not included in the inventory. All agencies were direct service providers with exception of the City of Paterson Department of Human Resources that administers the Ryan White Part A, Minorities AIDS Initiative and HOPWA programs and serves as an informational or referral agency only.

Service category definitions normally varied from agency to agency. Definitions used for this inventory corresponded to those of the NJHARD with some exceptions.¹² In this inventory, the category of medical care was divided into two: (1) medical treatment where a physician and nurse provide direct medical treatment on site and (2) medical support where only screenings and/or referrals are provided. Case management was divided into two categories: (1) medical and (2) non-medical. Some agencies did not differentiate between medical and non-medical case management; thus, there may have been overlap in services provided. This inventory also included recent additions to the list of service categories in NJHARD such as syringe access program and early intervention. Definitions are provided in Appendix E.

¹² <http://hpcpsdi.rutgers.edu/dir/index.php>



II. HIV/AIDS POPULATION IN MEDICAL CARE

Information pertaining to the needs of PLWHA who were engaged in medical care originated from two sources: key informant interviews and a consumer survey. Both are described in this report.

A. KEY INFORMANT INTERVIEWS

Key informants were asked about the current situation, barriers and challenges, and suggestions for retaining PLWHA in medical care. The following summarizes their remarks.

Current Situation

- ✘ Those who are in care and stay in care are usually medically stable. About 75% are compliant; the other 25% need constant reminders.
- ✘ Newly diagnosed can usually be seen within the same week, but access to medication can take longer (two to three weeks)
- ✘ Newly diagnosed patients seem to be getting younger. Outreach is finding more 18 – 30 year old infected MSM. Children of infected mothers are now coming back infected by other means.
- ✘ Patients still need to be empowered through education about HIV disease, healthy living practices, available services in the community, etc. There is no “one size fits all” approach. Many support programs, such as support groups, treat a relatively small number of PLWHA, but are effective for those who participate
- ✘ Needs remain much as before: housing, drug treatment, mental health counseling, dental care, transportation. Child care was mentioned as well.
- ✘ Complex medical conditions are more prevalent and thus increasing the cost of care.
- ✘ Dual diagnosed are among the most difficult to treat.
- ✘ Mental health can be treated in the medical clinic if a psychiatrist is on staff. This would increase access and co-location.
- ✘ Nutrition and healthy lifestyle need more emphasis in the medical clinics.
- ✘ Case management is essential to maintain engagement in care. Case managers are not always up to date with information and “uneven” in quality of services.

Barriers and Major Challenges

- ✘ Medical care from non-specialized physicians reduces quality.
- ✘ There are not enough specialists or professional staff to take care of everyone.
- ✘ Medication co-pays and access to medication are recently identified challenges that may lead to gaps in care.
- ✘ Medicaid HMOs, FQHCs are not well equipped to treat HIV/AIDS. Smaller agencies may not survive, either.



- ⌘ Long wait lists for specialty care – three to six months – are not unusual. Patients frequently miss appointments.
- ⌘ The demand for some substance abuse treatment programs outpaces availability.
- ⌘ Mental health is stigmatized, particularly in Latino cultures. Patients are slow to recognize their needs for mental health therapy. Treatment at medical clinics or using another name helps improve utilization.
- ⌘ Food and other community assistance programs are not as plentiful due to the recession.
- ⌘ Newly diagnosed have the greatest challenges. They are affected by stigma, denial, confusion, unstable living conditions, poverty, etc. Early intervention is critical.
- ⌘ Linkages to care for the incarcerated who are about to be released are weak.
- ⌘ Cultural challenges, especially with the Latino population, are major barriers. Some undocumented are compliant, but others are not due to fears and isolation.
- ⌘ Stigma and disenfranchisement continue to threaten patient stability.

Suggestions

- ⌘ Some key informants advocated no program cut, saying they're all needed.
- ⌘ Nutrition and healthy lifestyle need more emphasis in the medical clinics.
- ⌘ Increase detox and long term drug treatment programs.
- ⌘ Continue programs in Spanish.
- ⌘ Co-located services should be encouraged.

B. IN-CARE CONSUMER SURVEY

Sample Overview

A consumer survey of 252 (N) PLWHA enrolled in Part A or Part C medical care was undertaken to determine their characteristics and needs. The sample reasonably conformed to the sampling plan and to the regional epidemic (Bergen-Passaic TGA).¹³ Variations from the epidemic in the region suggest over- and under-sampling of some populations, namely residence and HIV transmission mode.¹⁴

Gender

- ⌘ Women were comparably represented in the sample. The survey sample included 63% male respondents and 36% female. This compared to 64% males and 36% females infected in the region. Differences between the sample and the regional epidemic were

¹³ Persons living with HIV/AIDS as of December 31, 2011. Source: New Jersey Department of Health, Division of HIV/AIDS, STD and TB Services (DHSTS).

¹⁴ In all tables that follow, values less than five (*) are removed to maintain confidentiality.



less than 10% and statistically considered not significant at the 99% confidence level. (Table II.1)

Table II.1
Comparison of Survey Sample with Regional Epidemic
Gender

	In-Care Sample		B-P TGA	
	Number	Percent	Number	Percent
Total Sample (N) = 252				
Gender				
Male	159	63%	2,664	64%
Female	91	36%	1,488	36%
Transgender	*	<1%	NA	NA

* Less than five.

Race/Ethnicity

- ✚ Whites comprised 41% of the regional epidemic and 46% of the survey sample while African-American/Blacks made up 56% of the epidemic and 50% of the sample.
- ✚ Hispanics comprised 31% of the epidemic and 32% of those surveyed.
- ✚ Differences between the sample and the regional epidemic were less than 10% and thus not considered statistically significant. (Table II.2)

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

	In-Care Sample		B-P TGA	
	Number	Percent	Number	Percent
Total Sample (N) = 252				
Race/Ethnicity				
White	117	46%	1,164	41%
Black/African-American	127	50%	1,591	56%
Other Race	8	3%	91	3%
Hispanic	80	32%	1,284	31%

Note: Totals may not sum to 100 due to rounding error.

Age

- ✚ The sample population was representative of the regional epidemic.
- ✚ The sample included less than 2% of PLWHA less than 25 years of age compared to 3% in the region.
- ✚ The 25 to 44 age cohort comprises 28% of the epidemic and 26% of the survey sample.
- ✚ The 45+ age cohort is 69% of the epidemic and 73% of the sample. (Table II.3)



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

	In-Care Sample		B-P TGA	
Total Sample (N) = 252	Number	Percent	Number	Percent
Age				
< 25	*	<2%	133	3%
25-44	65	26%	1,157	28%
>45	183	73%	2,842	69%

*Less than 5

Residence

- ⓧ Of the respondents who identified their residence location, 22% were from Bergen County and 71% from Passaic County. The epidemic contained 38% from Bergen County and 62% from Passaic County, suggesting that the survey sample under-represented Bergen County by 16 points. (Table II.4)

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

	In-Care Sample		B-P TGA	
Total Sample (N) = 252	Number	Percent	Number	Percent
Residence				
Bergen County	55	22%	1,578	38%
Passaic County	178	71%	2,554	62%
Other	19	7%		

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

Transmission Mode

The most frequently identified HIV transmission category included in the sample were heterosexual contact (57%), male-to-male sex (MSM) (19%), and sharing needles (18%). The New Jersey Department of Health surveillance data identify the following risk categories for PLWHA in the Bergen-Passaic TGA: heterosexual contact (40%), MSM (23%), IDU (19%), MSM/IDU (2%), and Other/Risk Not Reported (16%). (Table II.5)



- ✚ The consumer survey over-sampled transmission by heterosexual contact by 17 percentage points and under-sampled MSM transmission by 4 percentage points. The high rate of heterosexual contact and low rate of MSM transmission may be considered notable findings of the survey.

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

	In-Care Sample		B-P TGA	
Total Sample (N) = 252	Number	Percent	Number	Percent
Transmission Mode				
MSM	47	19%	964	23%
IDU	45	18%	801	19%
MSM/IDU	NA	NA	64	2%
Heterosexual Contact	144	57%	1,658	40%
Other/Unknown Risk	16	6%	645	16%

Demographic Characteristics of the In-Care Population

Summary

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

- ✚ The traditionally large percentage of females continued to be notable and among the salient aspects of the Bergen-Passaic TGA.
- ✚ Black, African-Americans comprised more than half of all respondents, and Hispanics accounted for nearly one-third. One-third were foreign born, of whom 70% were Hispanic.
- ✚ The survey population was remarkably old, with nearly three-quarters over age 45 and slightly less than half over age 55.
- ✚ Seventy-one percent resided in the urban epicenters of Paterson, Passaic and Hackensack. Nine-two percent from Passaic County lived in Paterson or Passaic City while 38% from Bergen County lived in Hackensack. The smaller proportion of respondents from Hackensack indicated that residents from Bergen County were more geographically dispersed.
- ✚ Three quarters of respondents lived in permanent housing. The remainder lived in temporary or congregate facilities. Four percent lived in HIV/AIDS-defined housing, and 6% lived in shelters or on the street.
- ✚ More than half lived alone, and about 15% lived with their children.



- ✂ A small percentage (4%) had been incarcerated within the past year.
- ✂ More than 90% reported annual incomes of less than \$20,000. Nearly all would qualify below the federal poverty level.
- ✂ Respondents were 80% heterosexual, although 20% of males described themselves as gay or bisexual.

Gender

The in-care survey sample included 36% female and 64% male respondents (Figure II.1 and Table II.6).

- ✂ On a percentage basis, few differences were found by race/ethnicity. Approximately 50% of both genders were Black/African-American, a slightly higher percentage of White/Caucasian were male and a slightly higher percentage of Hispanics were female.
- ✂ Considering participant age, males tended to be somewhat older than females, with 75% of males older than 45 vs. 68% of females and 32% of females were between the ages of 25 and 44 vs. 22% of males. All respondents under the age of 25 were male.
- ✂ A larger proportion of females resided in Passaic County, 38% compared with 31% in Bergen.

Figure II.1

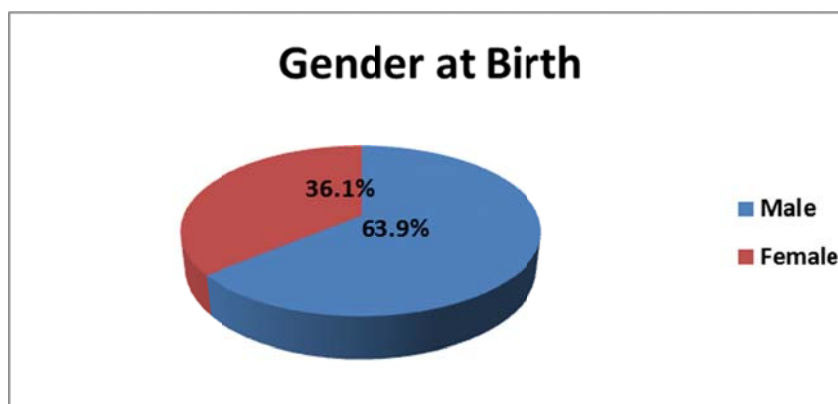




Table II.6

	Gender at birth			
	Female		Male	
N=252	Number	Percent	Number	Percent
Total Sample	91	36.1%	161	63.9%
White	41	35.0%	76	65.0%
Black/African-American	47	37.0%	80	63.0%
Other Race	*	37.5%	5	62.5%
Hispanic	31	38.8%	49	61.3%
< 25	0	0.0%	*	100.0%
25-44	29	44.6%	36	55.4%
>45	62	33.9%	121	66.1%
Bergen County	17	30.9%	38	69.1%
Passaic County	67	37.6%	111	62.4%
Other	7	36.8%	12	63.2%

* Less than five.

Race/Ethnicity and Country Of Origin

Half the survey sample was Black/African-American, 46% White and 3% Asian/Other. Among these respondents, 32% were Hispanic. (Figure II.2 and Table II.7)

- ⌘ Among Black/African-American respondents, little variation from the total sample was seen related to gender. This racial group tended to be slightly older than the total sample, and a larger percentage lived in Passaic County vs. Bergen County.
- ⌘ Whites tended to be similar in age and gender to the total sample, and more frequently lived in Bergen County.
- ⌘ Hispanics included a higher percentage of female respondents than the overall sample, had a higher percentage in the 25 – 44 age range (39%) and lived in Passaic County to a greater extent than the overall survey sample.
- ⌘ More than two-thirds of survey respondents were born in the United States. Of those born outside the U.S., nearly 70% were Hispanic.



Figure II.2

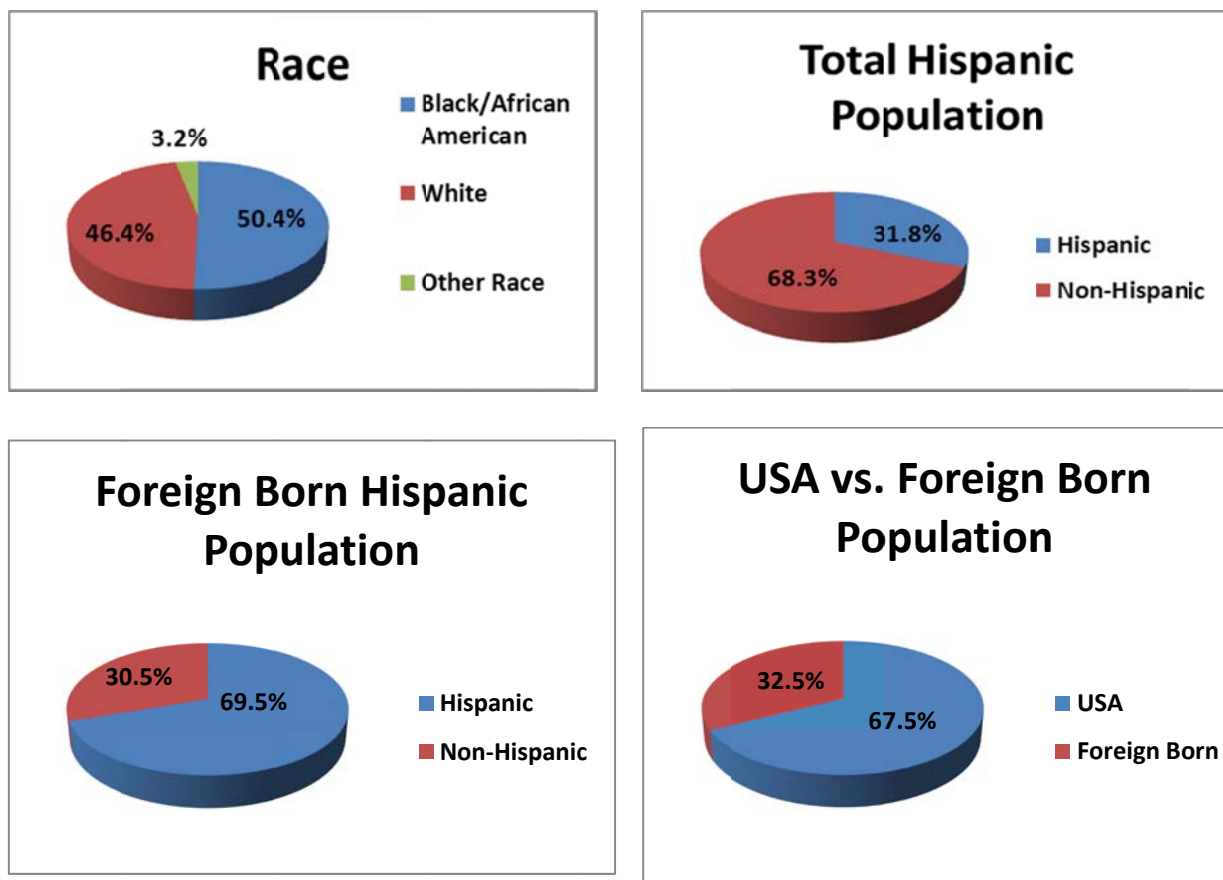




Table II.7

What is your race?							Are You Hispanic?	
	Black, African-American		White		Other		Yes	
N=252	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	127	50.4%	117	46.4%	8	3.2%	80	31.8%
Male	79	62.2%	75	64.1%	5	62.5%	48	60.0%
Female	47	37.0%	41	35.0%	*	37.5%	31	38.8%
Transgender	*	0.8%	*	0.9%	0	0.0%	1	1.3%
< 25	*	0.8%	*	2.6%	0	0.0%	69	86.3%
25-44	29	22.8%	31	26.5%	5	62.5%	6	7.5%
>45	97	76.4%	83	70.9%	*	37.5%	5	6.3%
Bergen County	19	15.0%	34	29.1%	*	25.0%	2	2.5%
Passaic County	97	76.4%	77	65.8%	4	50.0%	31	38.8%
Other	11	8.7%	6	5.1%	*	25.0%	47	58.8%

Age

Considering respondent age, survey participants were generally older adults (Figure II.3 and Table II.8).

- ✘ Nearly three-quarters were age 45 and older, and this included 43% who were 55 years of age and older.
- ✘ Among the younger respondents, less than five (1.6%) were under 25 years, and 19 (7.5%) between the ages of 25 and 34 years.
- ✘ Females tended to be in the younger age ranges when compared to males.
- ✘ White respondents were similar to the overall age distributions, with a slightly higher percentage age 45 to 54. Blacks/African-Americans had a higher percentage in the 55+ age range and lower percentages in the middle age ranges. Hispanics tended to be younger than the overall survey sample.
- ✘ Passaic County residents had a similar age distribution to the overall survey sample, while Bergen County had larger percentages in the middle age ranges, but a smaller percentage in the 55+ category.



Figure II.3

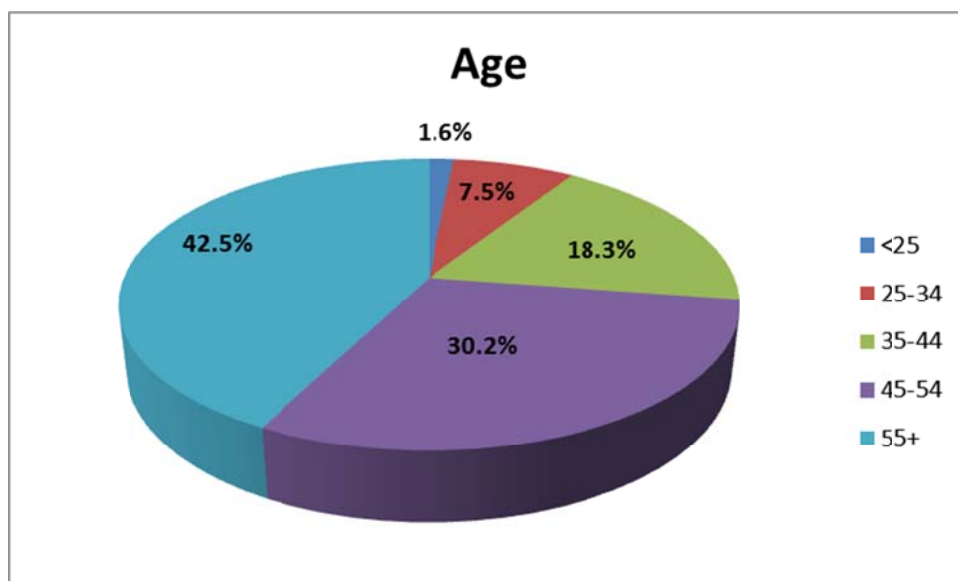


Table II.8

Age (As of Survey Date)								
	25-34		35-44		45-54		55+	
N=252	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	19	7.5%	46	18.3%	76	30.2%	107	42.5%
Male	11	7.1%	23	14.8%	45	29.0%	76	49.0%
Female	7	7.7%	22	24.2%	31	34.1%	31	34.1%
Transgender	*	50.0%	*	50.0%	0	0.00%	0	0.00%
White	9	7.9%	22	19.3%	40	35.1%	43	37.7%
Black/African-American	9	7.1%	20	15.9%	33	26.2%	64	50.8%
Other	*	12.5%	*	50.0%	*	37.5%	0	0.00%
Hispanic	8	42.1%	23	50.0%	25	32.9%	22	20.6%
Bergen County	*	5.8%	9	17.3%	20	38.5%	20	38.5%
Passaic County	15	8.5%	31	17.5%	49	27.7%	82	46.3%
Other	1	5.3%	6	31.6%	7	36.8%	5	26.3%

* Less than five.



Residence

With 70.6% of respondents from Passaic County, almost all resided either in Paterson or Passaic City. These two cities were home to 65.5% of survey respondents (Figure II.4 and Table II.9).

- ✘ Little variation existed with respect to gender and age.
- ✘ Paterson had a large percentage (78%) of Black/African-American, and Passaic City had 62% Hispanic. The small number of Hispanic respondents from Paterson (15) may have been due to sampling error.
- ✘ On the other hand, Bergen County was home to nearly 22% of in-care survey respondents, but they were more geographically dispersed with only 38% of Bergen County participants living in Hackensack. Table II.4 presents findings about this population, but a sample size of 15 provides only anecdotal information about Hackensack residents.

Figure II.4

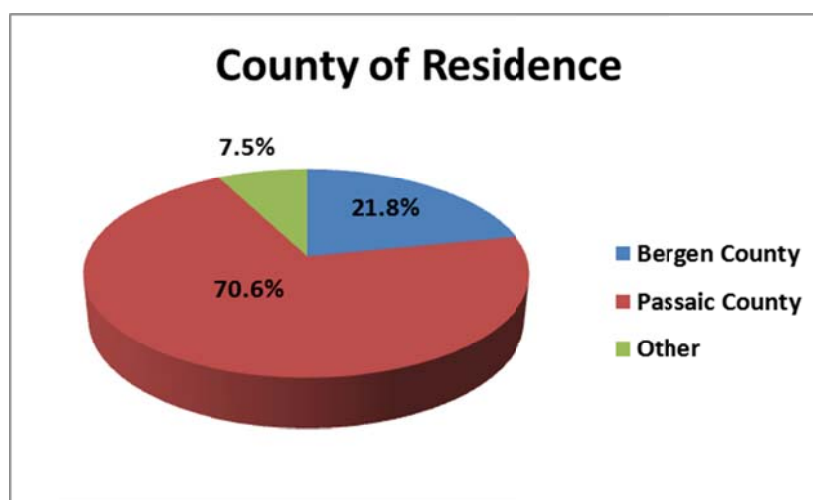


Table II.9

A. What County Do you Live in?						
	Bergen		Passaic		Other	
N=252	Number	Percent	Number	Percent	Number	Percent
Total Sample	55	21.8%	178	70.63%	19	7.5%
Male	38	69.1%	109	61.24%	12	63.2%
Female	17	30.9%	67	37.64%	7	36.8%
Transgender	0	0.0%	*	1.12%	0	0.0%
White	34	61.8%	77	43.26%	6	31.6%



A. What County Do you Live in?						
	Bergen		Passaic		Other	
N=252	Number	Percent	Number	Percent	Number	Percent
Black/African-American	19	34.5%	97	54.49%	11	57.9%
Other Race	*	3.6%	*	2.25%	*	10.5%
Hispanic	13	23.6%	65	36.52%	*	10.5%
< 25	*	5.45%	1	0.56%	0	0.0%
25-44	12	21.82%	46	25.84%	7	36.8%
>45	40	72.73%	131	73.60%	12	63.2%

* Less than five.

B. What is the ZIP code where you live?						
	Paterson		Passaic City		Hackensack	
N=252	Number	Percent	Number	Percent	Number	Percent
Total Sample	92	36.5%	73	29.0%	15	6.0%
Male	54	58.7%	45	61.6%	9	60.0%
Female	38	41.3%	26	35.6%	6	40.0%
Transgender	0	0.0%	*	2.7%	0	0.0%
White	19	20.7%	47	64.4%	*	26.7%
Black/African-American	72	78.3%	24	32.9%	11	73.3%
Hispanic	15	16.3%	45	61.6%	*	13.3%
< 25	*	1.1%	0	0.0%	*	6.7%
25-44	23	25.0%	19	26.0%	*	6.7%
>45	68	73.9%	54	74.0%	13	86.7%

* Less than five.

Housing

Three-quarters of survey respondents rented or owned their house, apartment or condo (Figures II.5 and II.6 and Tables II.9 and II.10).

- ✂ This included 54% who did so without help from Section 8 or Housing Opportunities for People with AIDS (HOPWA) and 23% who received Section 8 or HOPWA assistance. Smaller percentages included:



- 4% lived in congregate housing for people with HIV;
 - 3% lived in a shelter;
 - Less than 1% lived in temporary, transitional shelters or halfway houses;
 - Less than 1% lived on the street.
- ✚ The gender of respondents who rented or owned their house, apartment or condo, did not vary by the level of housing assistance. Males, however, were more likely to be living with family and friends than females.
- ✚ Whites were more likely to rent or own their house, apartment or condo without assistance than Blacks/African-Americans – 58% of the former and 38% of the latter. On the other hand, Blacks/African-Americans were more likely than Whites to own or rent with assistance – 63% vs. 37%.

The majority (51%) of in-care respondents lived alone, and only 14% reported living with children.

- ✚ 12% lived with family or friends without children;
- ✚ 10% lived with a spouse or partner without children;
- ✚ 10% lived with spouse or partner with children; this included 12% of females and 8% of males;
- ✚ 5% lived with family or friends with children; this included 8% of females and 3% of males.

Detailed tables by demographic category are found in on pages 33-36, Tables II.16 through II.19.



Figure II.5

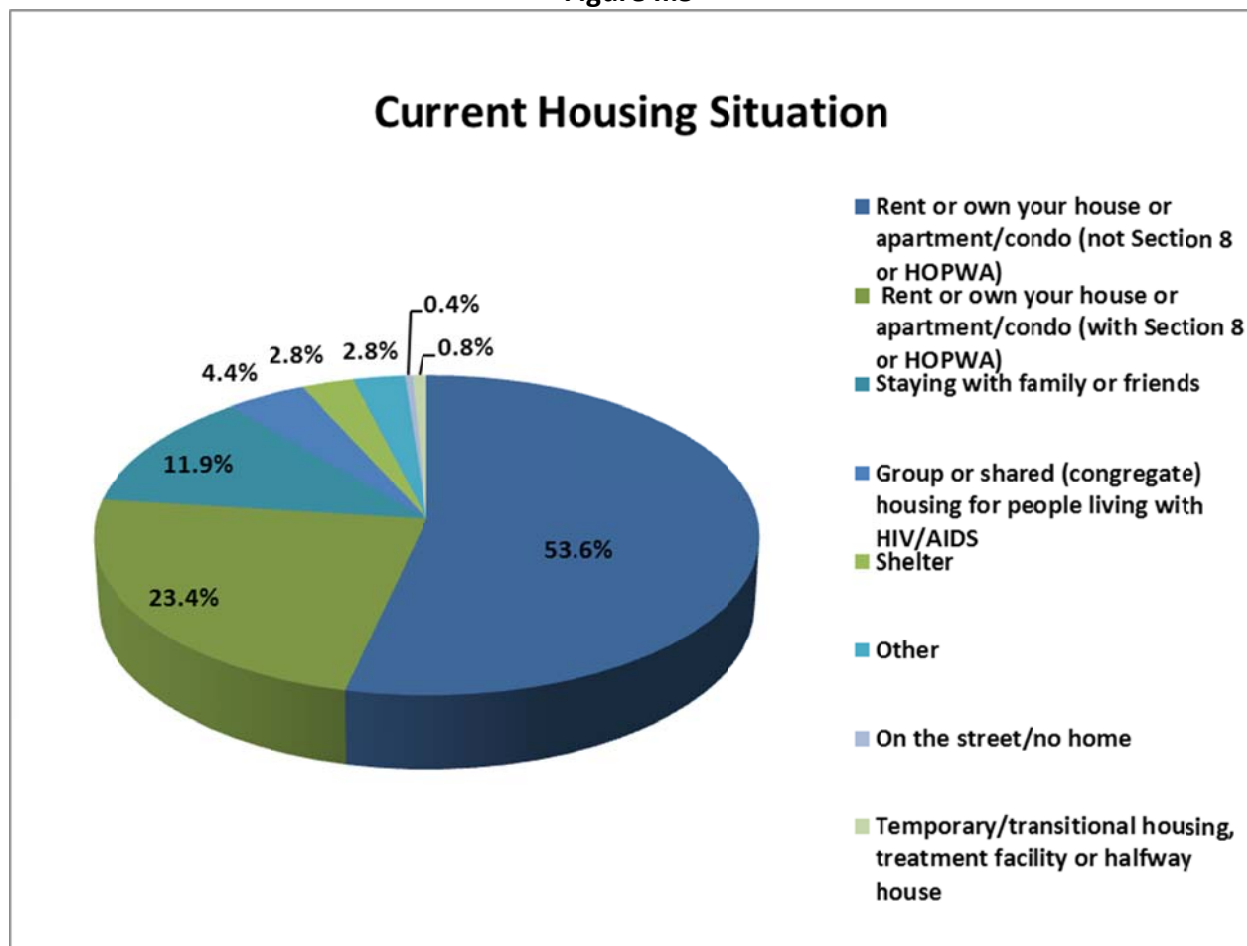


Table II.10

How would you describe your current housing situation?	Number	Percent
N= 252		
Total Sample	252	100.0%
Rent or own your house or apartment/condo (not Section 8 or HOPWA)	135	53.6%
Rent or own your house or apartment/condo (with Section 8 or HOPWA)	59	23.4%
Staying with family or friends	30	11.9%
Group or shared (congregate) housing for people living with HIV/AIDS	11	4.4%
Shelter	7	2.8%
On the street/no home	*	0.4%
Temporary/transitional housing, treatment facility or halfway house	*	0.8%
Other	7	2.8%

* Less than five.



Figure II.6

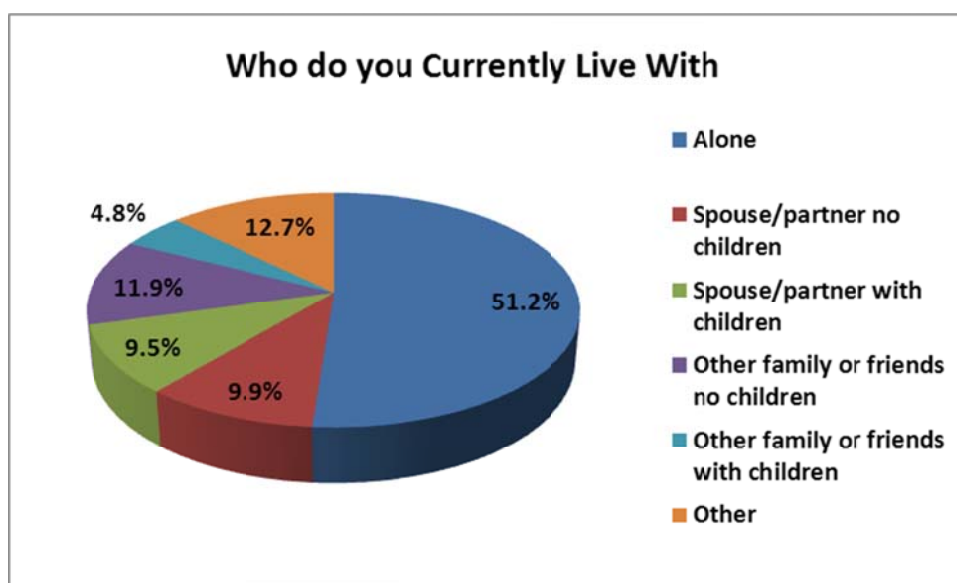


Table II.11

Who do you currently live with?		
Total Sample (N=252)	Number	Percent
Alone	129	51.2%
Spouse/partner no children	25	9.9%
Spouse/partner with children	24	9.5%
Other family or friends no children	30	11.9%
Other family or friends with children	12	4.8%
Other	32	12.7%

Incarceration

Eleven (4.4%) in-care survey respondents reported being in jail or prison in the last 12 months. (Table II.12) Those who had been incarcerated were:

- ⓧ Predominantly male (82%);
- ⓧ Majority Black/African-American (73%);
- ⓧ One-third Hispanic (36%);
- ⓧ Evenly divided by age with 55% age 25-44 and 45% age 45+;
- ⓧ Living in Passaic County (91%).



Table II.12

Have you been in jail or prison in the last 12 months?				
	Yes		No	
N= 252	Number	Percent	Number	Percent
Total Sample	11	4.37%	241	95.63%

Income

Most of the in-care survey participants received Ryan White funding for at least one service. Therefore, it could be assumed that many of these consumers had low socioeconomic status. Responses to a question about annual household income confirmed this fact (Figure II.7 and Table II.13).

- ✂ Half of in-care survey respondents reported current gross (before taxes) annual household income between \$1 and \$9,999.
- ✂ This was followed by 31% reporting incomes of \$10,000 to \$19,999.
- ✂ Over 10% reported no income.
- ✂ Seven percent reported incomes ranging from \$20,000 to \$50,000 or more.

Detailed tables by demographic category are found in on pages 33-36, Tables II.16 through II.19.

Figure II.7

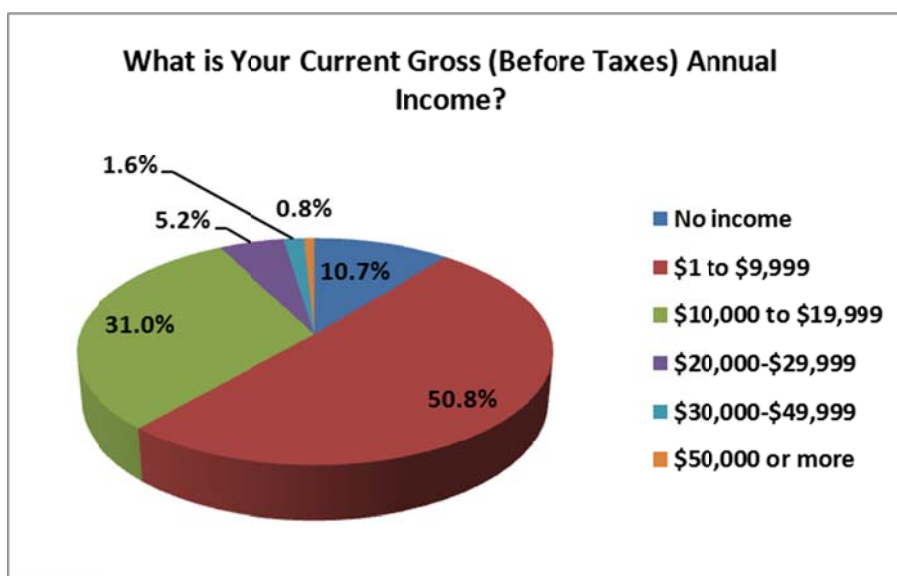




Table II.13

What is your current gross (before taxes) annual income for you and any dependents to your household?		
N= 252	Number	Percent
Total Sample	N= 252	100.0%
No income	27	10.7%
\$1 to \$9,999	128	50.8%
\$10,000 to \$19,999	78	31.0%
\$20,000 to \$29,999	13	5.2%
\$30,000 to \$49,999	*	1.6%
\$50,000 or more	*	0.8%

* Less than five.

Education

Consumers' educational background varied widely (Figure II.8 and Table II.14).

- ✂ Nearly half (49%) of in-care survey respondents had less than a high school education. This includes 18% who did not attend high school (eighth grade or less) and 31% who attended some high school but did not graduate.
- ✂ Over one-quarter (28%) completed high school or obtained a graduate equivalency degree (GED).
- ✂ Less than 20% had some type of college education including some college (12%), completed college (3%) and graduate school (2%).
- ✂ Males tended to be slightly better educated than females. One exception was that females attended trade school at a higher percentage than males.
- ✂ Considering race, higher percentages of Whites had less than an eighth grade education and are high school graduates. Blacks/African-Americans tended to have higher percentages with "some high school" and college.
- ✂ Bergen County residents were better educated than Passaic County residents with higher percentages who completed high school/GED or college. Passaic County residents had a higher percentage with an eighth grade or less education or some high school.

Detailed tables by demographic category are found in on pages 33-36, Tables II.16 through II.19.



Figure II.8

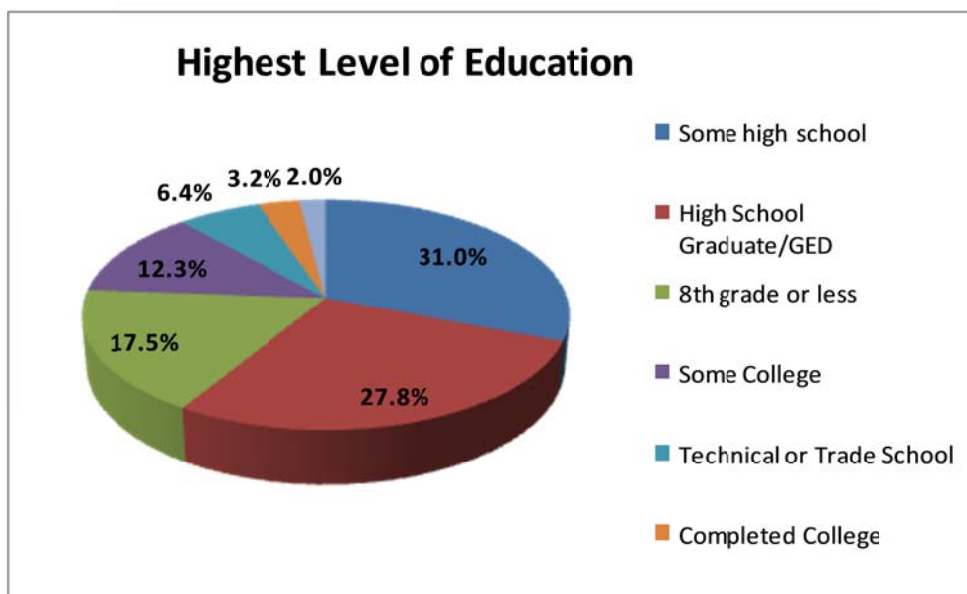


Table II.14

What is the highest level of education you completed?		
N= 252	Number	Percent
Some high school	78	31.0%
High School Graduate/GED	70	27.8%
8th grade or less	44	17.5%
Some College	31	12.3%
Technical or Trade School	16	6.3%
Completed College	8	3.2%
Graduate level	5	2.0%

Sexual Orientation

Over three-quarters (79%) of survey respondents reported their sexual orientation as straight/heterosexual (Figure II.9 and Table II.15).

- ✂ This included 95% of female respondents and 69% of male respondents.
- ✂ Considering race/ethnicity, 83% of Black/African-American respondents were heterosexual, 79% of Hispanic respondents and 75% of White respondents.
- ✂ Older respondents were more likely to report a heterosexual orientation with 84% of those 45+ identifying this.
- ✂ Over 85% of Passaic County respondents were heterosexual vs. 61% in Bergen County.



- ⓧ Fifteen percent were homosexual male/gay, and five percent were bisexual.
- ⓧ Nineteen percent of White respondents reported homosexual male/gay orientation and 6% of white were bisexual. This compared to 12% of Black/African-American respondents reporting homosexual male/gay and 5% reporting bisexual orientation.
- ⓧ One-third of Bergen County respondents were homosexual male/gay vs. 10% of those who lived in Passaic County.
- ⓧ Younger respondents were more likely to be homosexual male or bisexual than those age 45 and over.
- ⓧ Less than five respondents were homosexual female/lesbian.

Figure II.9

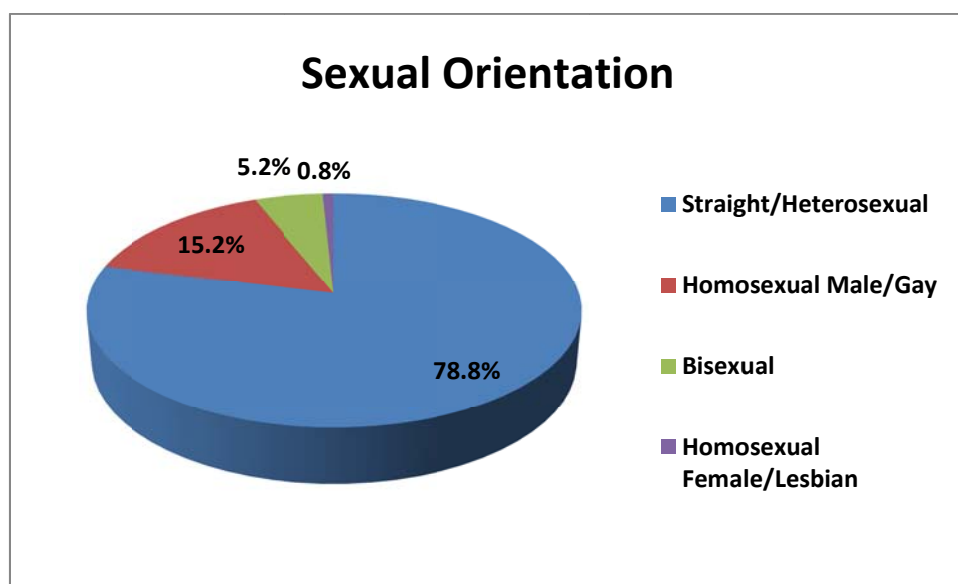


Table II.15

Which of the following describes how you identify yourself?						
	Straight/Heterosexual		Homosexual Male/Gay		Bisexual	
n= 250	Number	Percent	Number	Percent	Number	Percent
Total Sample	197	78.8%	38	15.2%	13	5.2%
Male	108	68.8%	38	24.2%	11	7.0%
Female	87	95.6%	0	0.0%	*	2.2%
Transgender	*	100.0%	0	0.0%	0	0.0%
White	88	75.2%	22	18.8%	7	6.0%



Which of the following describes how you identify yourself?						
	Straight/Heterosexual		Homosexual Male/Gay		Bisexual	
n= 250	Number	Percent	Number	Percent	Number	Percent
Total Sample	197	78.8%	38	15.2%	13	5.2%
Black/African-American	102	81.6%	15	12.0%	6	4.8%
Other Race	7	87.5%	*	12.5%	0	0.0%
Hispanic	63	78.8%	13	16.3%	*	5.0%
< 25	0	0.0%	*	75.0%	*	25.0%
25-44	47	72.3%	14	21.5%	*	6.2%
>45	151	83.9%	21	11.7%	8	4.4%
Bergen County	33	61.1%	18	33.3%	*	5.6%
Passaic County	150	85.7%	18	10.3%	7	4.0%
Other	14	73.7%	2	10.5%	*	15.8%

* Less than five.



Table II.16

Question = How would you describe your current housing situation?																
	Rent or own your house or apartment/condo (not Section 8 or HOPWA)		Rent or own your house or apartment/condo (with Section 8 or HOPWA)		Staying with family or friends		Group or shared (congregate) housing for people living with HIV/AIDS		Shelter		Other		On the street/no home		Temporary/transitional housing, treatment facility or halfway house	
N= 252	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	135	53.6%	59	23.4%	30	11.9%	11	4.4%	7	2.8%	7	2.8%	*	0.40%	*	0.8%
Male	83	61.5%	37	62.2%	22	73.3%	8	72.7%	*	42.9%	*	57.1%	0	0.00%	*	100.0%
Female	52	38.5%	22	37.3%	6	20.0%	*	27.3%	*	57.1%	*	42.9%	*	100.00%	0	0.0%
Transgender	0	0.0%	0	0.0%	*	6.7%	0	0.0%	0	0.0%	0	0.0%	0	0.00%	0	0.0%
White	79	58.5%	22	37.3%	11	36.7%	*	9.1%	0	0.0%	*	42.9%	0	0.00%	*	50.0%
Black/African-American	52	38.5%	37	62.7%	17	56.7%	9	81.8%	6	85.7%	*	57.1%	*	100.00%	*	50.0%
Other	4	3.0%	0	0.0%	*	6.7%	*	9.1%	*	14.3%	0	0.0%	0	0.00%	0	0.0%
Hispanic	50	37.0%	16	27.1%	8	26.7%	*	9.1%	*	14.3%	*	42.9%	0	0.00%	*	50.0%
< 25			0	0.0%	*	13.3%	0	0.0%	0	0.0%	0	0.0%	0	0.00%	0	0.0%
25-44	37	27.4%	6	10.2%	14	46.7%	0	0.0%	*	42.9%	*	57.1%	0	0.00%	*	50.0%
>45	98	72.6%	53	89.8%	12	40.0%	11	100.0%	*	57.1%	*	42.9%	*	100.00%	*	50.0%
Bergen County	29	21.5%	13	22.0%	10	33.3%	*	9.1%	*	14.3%	*	14.3%	0	0.00%	0	0.0%
Passaic County	98	72.6%	42	71.2%	17	56.7%	8	72.7%	5	71.4%	5	71.4%	*	100.00%	*	100.0%
Other	8	5.9%	*	6.8%	*	10.0%	*	18.2%	*	14.3%	*	14.3%	0	0.00%	0	0.0%

* Less than five.



Table II.17

Question = Who do you currently live with?												
	Alone		Spouse/partner no children		Spouse/partner with children		Other family or friends no children		Other family or friends with children		Other	
N= 252	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	129	51.2%	25	9.9%	24	9.5%	30	11.9%	12	4.8%	32	12.7%
Male	90	69.8%	14	56.0%	13	54.2%	21	70.0%	5	41.7%	16	50.0%
Female	39	30.2%	11	44.0%	11	45.8%	7	23.3%	7	58.3%	16	50.0%
Transgender	0	0.0%	0	0.0%	0	0.0%	*	6.7%	0	0.0%	0	0.0%
White	53	41.1%	17	68.0%	15	62.5%	17	56.7%	*	66.7%	11	34.4%
Black/African-American	72	55.8%	8	32.0%	8	33.3%	13	43.3%	8	33.3%	18	56.3%
Other Race	*	3.1%	0	0.0%	*	4.2%	0	0.0%	0	0.0%	*	9.4%
Hispanic	34	26.4%	12	48.0%	7	29.2%	12	40.0%	*	25.0%	12	37.5%
< 25	0	0.0%	0	0.0%	0	0.0%	*	6.7%	0	0.0%	*	6.3%
25-44	21	16.3%	*	12.0%	9	37.5%	12	40.0%	6	50.0%	14	43.8%
>45	108	83.7%	12	48.0%	15	62.5%	16	53.3%	6	50.0%	16	50.0%
Bergen County	27	20.9%	5	20.0%	7	29.2%	6	20.0%	3	25.0%	7	21.9%
Passaic County	95	73.6%	19	76.0%	16	66.7%	21	70.0%	8	66.7%	19	59.4%
Other	7	5.4%	*	4.0%	*	4.2%	*	10.0%	*	8.3%	6	18.8%

* Less than five.



Table II.18

	Some high school		High School Graduate/GED		8th grade or less		Some College		Technical or Trade School		Completed College		Graduate level	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Total Sample	78		70		44		31		16	100.0%	8	100.0%	5	100.0%
Male	51	32.1%	43	27.0%	29	18.2%	21	13.2%	*	2.5%	7	4.4%	*	2.5%
Female	26	28.6%	26	28.6%	15	16.5%	10	11.0%	12	13.2%	*	1.1%	*	1.1%
Transgender	*	1.3%	*	1.4%	0	0.0%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
White	31	26.5%	37	31.6%	27	23.1%	13	11.1%	*	3.4%	*	2.6%	*	1.7%
Black/African -American	46	36.2%	30	23.6%	16	12.6%	16	12.6%	11	8.7%	5	3.9%	*	2.4%
Other	*	1.3%	*	4.3%	*	2.3%	*	6.5%	*	6.3%	0	0.0%	0	0.0%
Hispanic	26	32.5%	18	22.5%	23	28.8%	8	10.0%	*	3.8%	*	2.5%	0	0.0%
< 25	0	0.0%	0	0.0%	*	25.0%	*	50.0%	0	0.0%	*	25.0%	0	0.0%
25-44	15	22.7%	13	19.7%	14	21.2%	11	16.7%	8	12.1%	*	4.5%	*	3.0%
>45	63	34.6%	57	31.3%	29	15.9%	18	9.9%	8	4.4%	*	2.2%	*	1.6%
Bergen County	6	10.9%	18	32.7%	5	9.1%	13	23.6%	*	7.3%	5	9.1%	8	7.3%
Passaic County	67	37.6%	45	25.3%	38	21.3%	16	9.0%	8	4.5%	*	1.7%	*	0.6%
Other	5	6.4%	7	10.0%	*	2.3%	*	6.5%	*	25.0%	0	0.0%	0	0.0%

* Less than five.



Table II.19

What is your current gross (before taxes) annual income for you and any dependents to your household?												
	No income		\$1 to \$9,999		\$10,000 to \$19,999		\$20,000-\$29,999		\$30,000-\$49,999		\$50,000 or more	
N= 252	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	27	10.7%	128	50.8%	78	31.0%	13	5.2%	*	1.6%	*	0.8%
Male	13	48.1%	80	62.5%	51	65.4%	11	84.6%	*	50.0%	*	100.0%
Female	13	48.1%	47	36.7%	27	34.6%	*	15.4%	*	50.0%	0	0.0%
Transgender	1	3.7%	1	0.8%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
White	11	40.7%	54	42.2%	43	55.1%	6	46.2%	*	50.0%	*	50.0%
Black/African-American	14	51.9%	71	55.5%	33	42.3%	7	53.9%	*	25.0%	*	50.0%
Other Race	*	7.4%	*	2.3%	*	2.6%	0	0.0%	*	25.0%	0	0.0%
Hispanic	8	29.6%	41	32.0%	24	30.8%	*	30.8%	*	50.0%	*	50.0%
< 25	*	7.4%	*	1.6%	0	0.0%	0	0.0%	0	0.0%	0	0.0%
25-44	11	40.7%	29	22.7%	18	23.1%	5	38.5%	*	100.0%	*	50.0%
>45	14	51.9%	97	75.8%	60	76.9%	8	61.5%	0	0.0%	*	50.0%
Bergen County	7	25.9%	18	14.1%	21	26.9%	7	53.9%	*	50.0%	0	0.0%
Passaic County	20	74.1%	99	77.3%	51	65.4%	5	38.6%	*	25.0%	*	100.0%
Other	0	0.0%	11	8.6%	6	7.7%	*	7.7%	*	25.0%	0	0.0%

* Less than five.



Heath-Related Topics

Summary

This section reviews questions pertaining to HIV engagement, care, retention and related health conditions. Major observations follow.

- ✘ Sexual transmission accounted for nearly all HIV infections. Heterosexual transmission was most prevalent among women and nearly half of men in this survey. Male-to-male sex accounted for one-third of PLWHA in the survey. Injecting drugs infected 18% of all respondents and 20% of males.
- ✘ Nearly half of respondents tested positive for HIV since 2000. Hispanics were more likely to be among the newly diagnosed.
- ✘ Only 21% received a diagnosis of AIDS, which was below the regional average of 54%.
- ✘ Over one-third of respondents decided to tell no one about their results when receiving a positive HIV diagnosis. Spouses/partners and other family members were told most often. By demographic category, men, Black/African-American, and older adults most frequently told no one.
- ✘ More than three-quarters (78%) entered into care within one month of diagnosis.
- ✘ Eleven percent waited six months or more. Respondents diagnosed since 2000 were more likely to enter into care within one month of diagnosis than those diagnosed prior to 2000 (89% vs 65%). Entry into care within one week improved measurably for those diagnosed since 2000 (59% vs 29%).
- ✘ For those who did not enter into care within six months, respondents most frequently cited stigma, denial and feeling well as their reasons.
- ✘ When asked about reasons for missing medical appointments, transportation, not feeling well and stigma were mentioned most often.
- ✘ Co-morbid conditions were identified by 38% of survey respondents, citing mental health problems, hepatitis c and diabetes most frequently.
- ✘ More than one-third reported some form of substance abuse, most often tobacco and alcohol; however, less than five admitted to using injecting drugs. Transportation and free drug treatment were identified as most needed by substance abusers.
- ✘ Forty percent of respondents said they were sexually active; younger respondents were more likely to have receptive sex in the last year. Of those who were sexually active, 83% said they always use protection. When asked of those who do 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.
- ✘ Nearly 60% of survey respondents have identified others who may have been exposed to the virus. The greatest percentages included women, whites, Hispanics, and older adults. When asked if they knew anyone who is HIV-positive, only 14% answered “yes.”



Diagnosis and Transmission

Transmission Mode

Heterosexual contact was the most frequent cited transmission mode for both men and women (Figure II.10 and Table II.20).

- ✚ Over three-quarters (75.8%) of women cited heterosexual transmission.
- ✚ 44% of men cited heterosexual transmission. This was followed by male homosexual transmission, 32.5%.
- ✚ Over a quarter (26.3%) of Whites identified female heterosexual transmission and 32.5% of Whites cited male heterosexual transmission. Whites highest percentage of male homosexual transmission, 22%. Among Whites, 13.2% reported injecting drug use (IDU) as their transmission mode.
- ✚ Nearly one-third (33.1%) of Black/African-American respondents reported female heterosexual transmission, and 23% reported male heterosexual transmission. Male homosexual transmission was identified by 16.5% of Black/African American respondents.
- ✚ Hispanics had high percentages of both male (35.9%) and female (33.1%) heterosexual transmission as well as 19.2% reporting male homosexual transmission. Only 6.4% of Hispanics reported IDU transmission.

Injecting drug use was the most frequently identified as the HIV/AIDS transmission among Blacks/African Americans and respondents age 45+.

Bergen County residents most frequently identified male to male sexual transmission, 37.7%. This compares to 21% of Passaic County residents identifying this transmission mode. Passaic County's most frequent transmission modes include female heterosexual (33%) and male heterosexual (29.5%).



Figure II.10

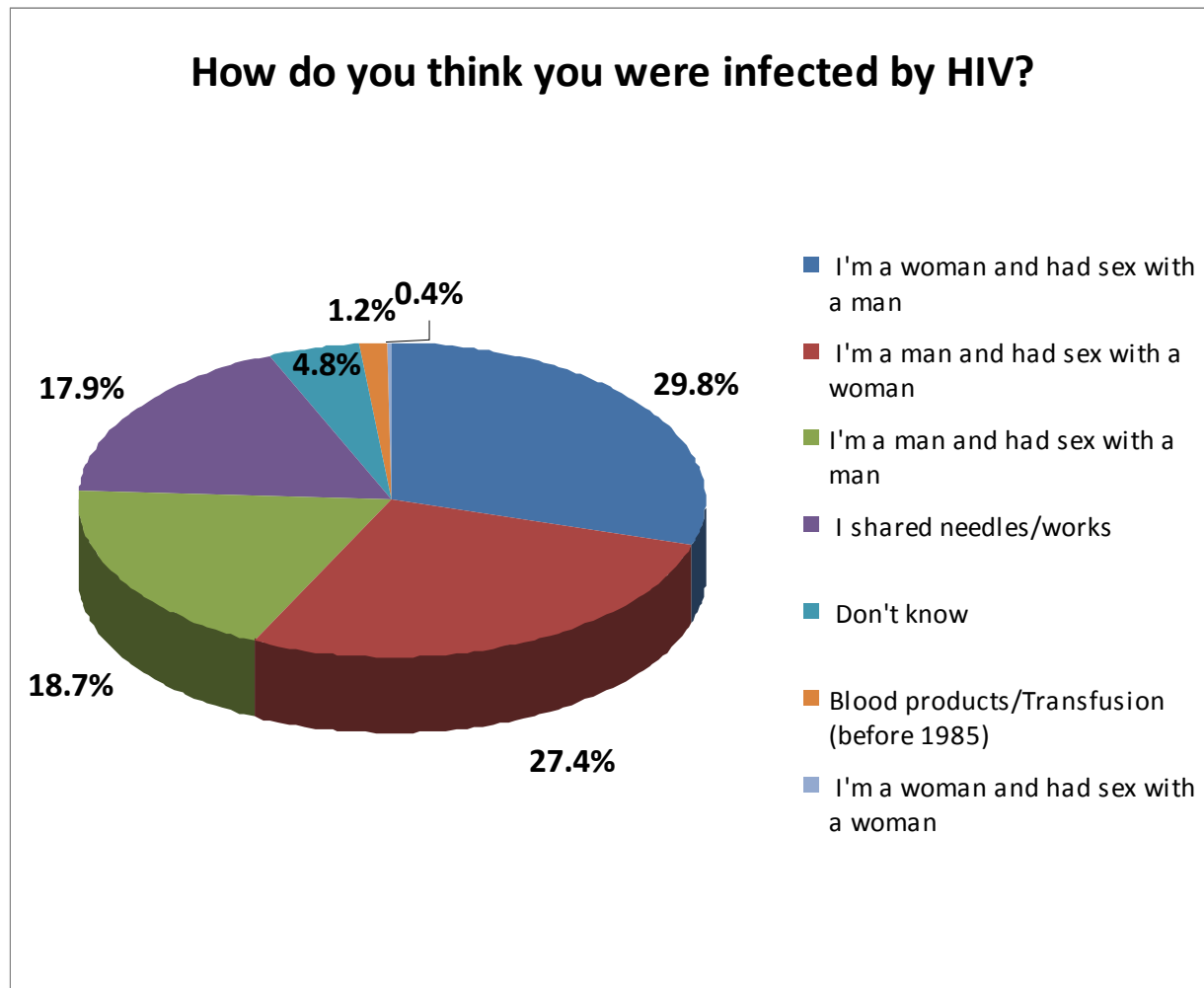




Table II.20

How do you think you were infected by HIV?										
	Female Heterosexual		Male Heterosexual		Male Homosexual		IDU		Don't know	
N= 252	#	%	#	%	#	%	#	%	#	%
Total Sample	75	29.8%	69	27.4%	47	18.7%	45	17.86%	12	4.8%
Male	0	0.0%	69	43.9%	51	32.5%	31	19.7%	6	3.8%
Female	69	75.8%	0	0.0%	2	2.2%	14	15.4%	6	6.6%
White	30	26.3%	37	32.5%	25	21.9%	15	13.2%	7	6.1%
Black/AA	42	33.1%	29	22.8%	21	16.5%	30	23.6%	5	3.9%
Hispanic	26	33.3%	28	35.9%	15	19.2%	5	6.4%	*	5.1%
< 25	0	0.0%	*	25.0%	*	75.0%	0	0.00%	0	0.0%
25-44	26	38.2%	13	19.1%	19	27.9%	*	4.4%	7	10.3%
>45	49	27.8%	55	31.3%	25	14.2%	42	23.9%	5	2.8%
Bergen County	10	18.9%	11	20.8%	20	37.7%	6	11.3%	6	11.3%
Passaic County	58	33.0%	52	29.5%	23	13.1%	37	21.0%	6	3.4%

* Less than five.

Diagnosis

- ✚ Nearly half (47.6%) of respondents first tested positive for HIV between 2000 and 2010 (Figure II.11 and Table II.21). This included 58% of females surveyed, 41% of male and transgender participants.
- ✚ Hispanics were more likely to be diagnosed between 2000 and 2012 with 71% reporting this timeframe than Whites (61%) or Blacks/African-Americans (46%).

Blacks/African-Americans and older adults represented the most long term survivors.

- ✚ Among Blacks/African-Americans, 17% were diagnosed before 1990 and 36% were diagnosed between 1990 and 1999.
- ✚ Among respondents age 45+, 17% were diagnosed before 1990 and 38% were diagnosed between 1990 and 1999.



Figure II.11

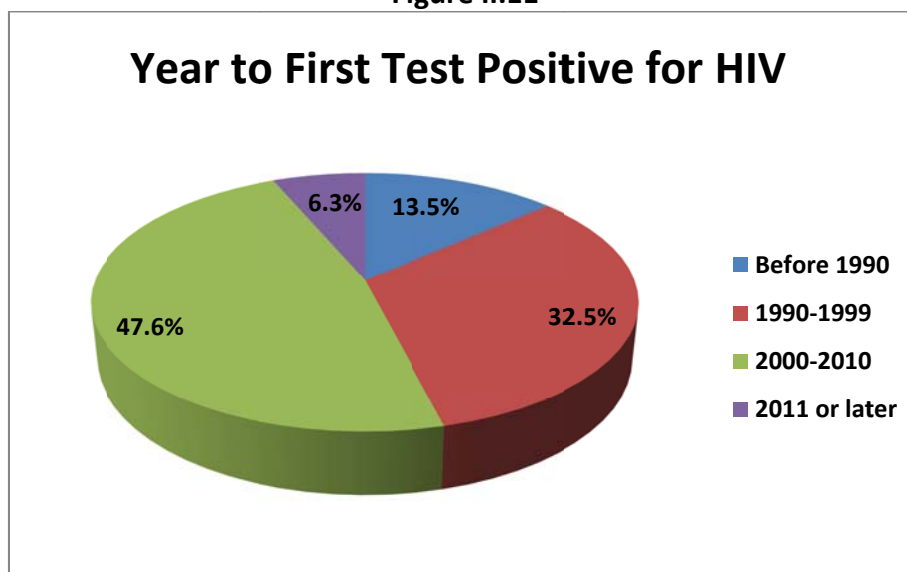


Table II.21

What year did you first test positive for HIV?								
	Before 1990		1990-1999		2000-2010		2011 or later	
N= 252	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	34	13.5%	82	32.5%	120	47.6%	16	6.3%
Male	25	15.7%	57	35.8%	65	40.9%	12	7.5%
Female	9	9.9%	25	27.5%	53	58.2%	*	4.4%
Transgender	0	0.0%	0	0.0%	*	100.0%	0	0.0%
White	11	9.4%	35	29.9%	61	52.1%	10	8.5%
Black/African-American	22	17.3%	46	36.2%	53	41.7%	6	4.7%
Hispanic	8	10.0%	15	18.8%	49	61.3%	8	10.0%
< 25	0	0.0%	0	0.0%	*	50.0%	2	50.0%
25-44	*	3.1%	12	18.5%	41	63.1%	10	15.4%
>45	32	17.5%	70	38.3%	77	42.1%	*	2.2%
Bergen County	*	7.3%	19	34.5%	25	45.5%	7	12.7%
Passaic County	26	14.6%	60	33.7%	85	47.8%	7	3.9%

* Less than five.



AIDS Diagnosis

Twenty-one percent were told by a doctor or health professional that they had AIDS. (Figure II.12 and Table II.22).

- ✚ 78% had not received an AIDS diagnosis
- ✚ 1% did not know if they have an AIDS diagnosis.

Figure II.12

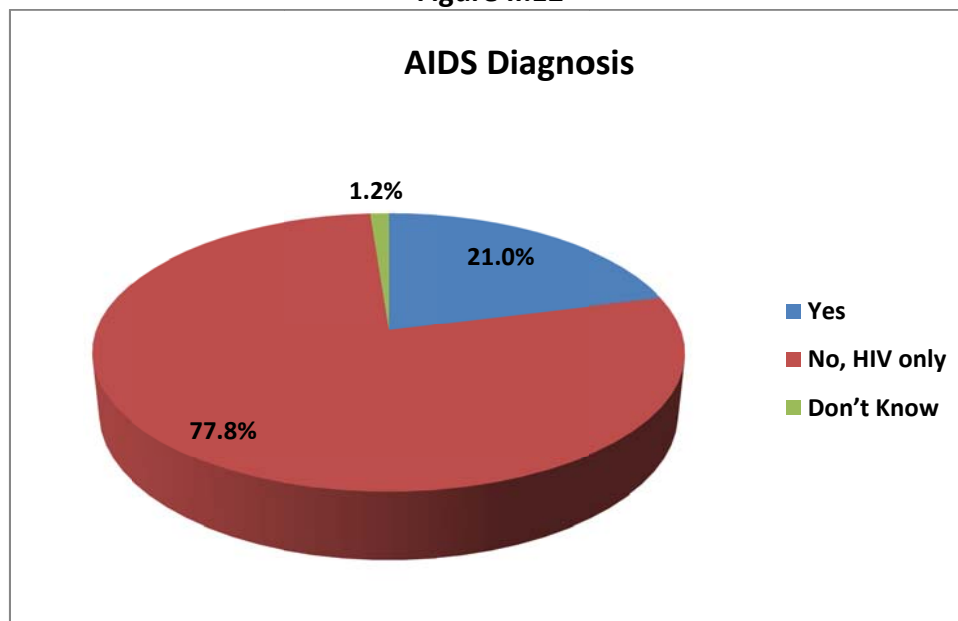


Table II.22

Has your doctor or health professional ever told you that you have AIDS?						
	Yes		No, HIV only		Don't Know	
N= 252	Number	Percent	Number	Percent	Number	Percent
Total Sample	53	21.0%	196	77.7%	*	1.2%
Male	40	75.5%	116	59.2%	*	100.0%
Female	12	22.6%	79	40.3%	0	0.0%
Transgender	*	1.9%	*	0.5%	0	0.0%
White	24	45.3%	92	46.9%	*	33.3%
Black/African-American	27	50.9%	98	50.0%	*	66.7%
Other	*	3.8%	6	3.1%	0	0.0%
Hispanic	17	32.1%	62	31.6%	*	33.3%



Has your doctor or health professional ever told you that you have AIDS?						
	Yes		No, HIV only		Don't Know	
N= 252	Number	Percent	Number	Percent	Number	Percent
Total Sample	53	21.0%	196	77.7%	*	1.2%
< 25	*	1.9%	*	1.5%	0	0.0%
25-44	9	17.0%	55	28.1%	*	33.3%
>45	43	81.1%	138	70.4%	*	66.7%
Bergen County	13	24.5%	41	20.9%	*	33.3%
Passaic County	35	66.0%	141	71.9%	*	66.7%
Other	5	9.4%	14	7.1%	0	0.0%

* Less than five.

Entry into Care and Access

Survey respondents were asked, “In the first six months after receiving your HIV diagnosis, who did you tell about your results?”¹⁵ (Figure II.13 and Table II.23).

- ✂ The most frequent answer was “No One,” cited by 33% of respondents.
- ✂ This was followed by “other family members” with 29%.
- ✂ Nearly 27% of respondents told their spouse/regular partner.
- ✂ Nearly 18% told their parents, and 17% told friend(s).

Considering specific populations:

- ✂ Men most frequently told no one (34%), other family members (31%), and spouse/regular partner (27%).
- ✂ Women most frequently told no one (32%), spouse/regular partner (29%), other family members (25%) and children (18%).
- ✂ Whites most frequently told spouse/regular partner (32%), other family members (31%), and no one (25%).
- ✂ Nearly half of Blacks/African-Americans told no one (43%), followed by other family members (26%) and spouse/regular partner (23%).
- ✂ Hispanics told no one (30%), other family members (28%) and spouse/regular partner (25%).
- ✂ Variations between age groups were seen with the 45+ age group more often telling no one (36%) and other family members (30%) than their younger counterparts. Those in the 25 to 44 age range more often told parents (31%), other family members (26%) and friends (25%) than older adults.

¹⁵ Respondents were allowed to provide multiple responses. The total number of responses for this question is 383; however, percentages are calculated on the number of respondents who answered the question (252).



- Ⓡ Respondents diagnosed since 2000 were less likely to tell no one (28% vs 34%) and more likely to tell their spouse/partner (31% vs 19%) and family members (29% vs 25%).

Figure II.13

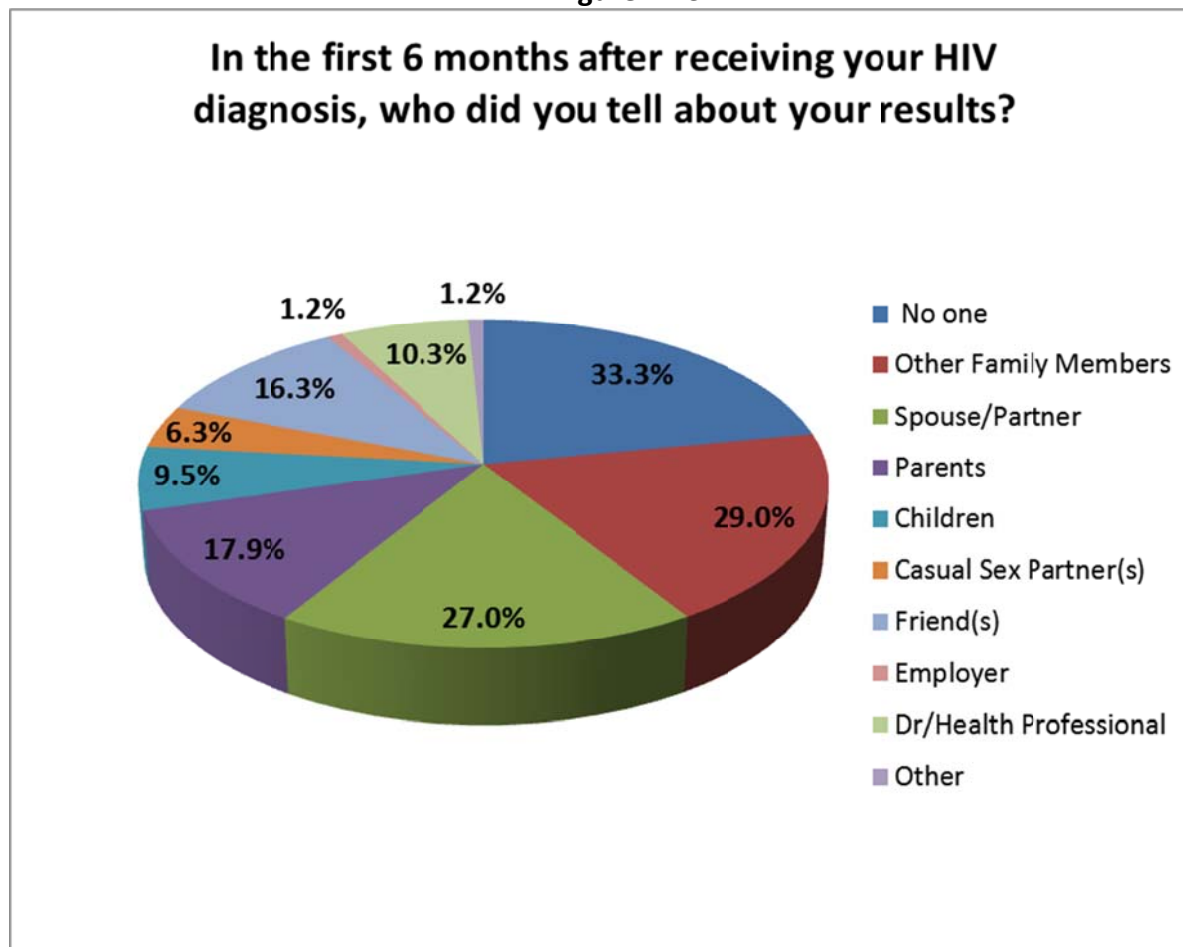




Table II.23

In the first six months after receiving your HIV diagnosis, who did you tell about your results?								
	No one		Other Family Members		Spouse/Regular Partner		Parents	
N= 252	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	84	33.3%	73	29.0%	68	27.0%	45	17.9%
Male (n=161)	54	33.5%	50	31.1%	42	26.1%	30	18.6%
Female (n=91)	29	31.9%	23	25.3%	26	28.6%	14	15.4%
Transgender (n=2)	*	50.0%	0	0.0%	0	0.0%	*	50.0%
White (n=117)	29	24.8%	36	30.8%	37	31.6%	22	18.8%
Black/African-American (n=127)	54	42.5%	33	26.0%	29	22.8%	20	15.7%
Other (n=8)	*	12.5%	*	50.0%	*	25.0%	*	37.5%
Hispanic (n=80)	24	30.0%	22	27.5%	20	25.0%	10	12.5%
< 25 (n=4)	0	0.0%	*	25.0%	*	25.0%	*	50.0%
25-44 (n=65)	19	29.2%	17	26.2%	20	30.8%	16	24.6%
>45 (n=183)	65	35.5%	55	30.1%	47	25.7%	27	14.8%
Bergen County (n=55)	12	21.8%	18	32.7%	17	30.9%	17	30.9%
Passaic County (n=178)	62	34.8%	53	29.8%	47	26.4%	26	14.6%
Other (n=19)	10	52.6%	*	10.5%	*	21.1%	*	10.53%
Dx Before 2000	46	33.8%	34	25.0%	26	19.1%	23	16.9%
Dx Since 2000	38	28.0%	39	28.7%	42	30.9%	22	16.2%

* Less than five.



Table II.23 (Continued)

In the first six months after receiving your HIV diagnosis, who did you tell about your results?								
	Children		Casual Sex Partner(s)		Friend(s)		Other	
N= 252	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	24	9.5%	16	6.3%	41	16.3%	3	1.2%
Male (n=161)	8	5.0%	12	7.5%	33	20.5%	*	1.9%
Female (n=91)	16	17.6%	*	4.4%	8	8.8%	0	0.0%
Transgender (n=2)	0	0.0%	0	0.0%	0	0.0%	0	0.0%
White (n=117)	14	12.0%	11	9.4%	24	20.5%	*	0.9%
Black/African-American (n=127)	9	7.1%	5	3.9%	0	0.0%	*	0.8%
Other (n=8)	*	12.5%	0	0.0%	0	0.0%	*	12.5%
Hispanic (n=80)	8	10.0%	5	6.3%	12	15.0%	*	1.3%
< 25 (n=4)	0	0.0%	*	50.0%	*	100.0%	0	0.0%
25-44 (n=65)	5	7.7%	*	6.2%	16	24.6%	*	1.5%
>45 (n=183)	19	10.4%	10	5.5%	21	11.5%	*	1.1%
Bergen County (n=55)	5	9.1%	8	14.5%	19	34.5%	*	1.8%
Passaic County (n=178)	19	10.7%	6	3.4%	20	11.2%	*	0.6%
Other (n=19)	0	0.0%	*	10.5%	*	10.5%	*	5.3%
Dx Before 2000	10	7.4%	5	3.7%	17	12.5	*	1.5%
Dx Since 2000	14	10.1%	11	8.1%	24	17.7%	*	0.7%

* Less than five.



First Medical Visit

Over three-quarters (78%) of survey respondents had their first medical visit within one month of diagnosis (Figure II.14 and Tables II.24 and II.25).

- ✚ This included 45% who had their first medical visit within one week and 33% within one month.
 - Hispanics and Whites represented the largest percentages receiving medical care within one month of HIV diagnosis, 90% and 86%, respectively.
 - Blacks/African-Americans were less likely to begin medical care within one month of diagnosis, with 70% responding positively.
 - Little variation existed by age or county of residence.

Over 18% waited more than six months for their first medical visit.

- ✚ This included 11% that waited seven to 11 months, and 7.5% that waited a year or more.
- ✚ Looking at recently diagnosed respondents, those diagnosed since 2000 were more likely to enter into care within one month of diagnosis than diagnosed prior to 2000 (89% vs 65%). Entry into care within one week improved measurably for those diagnosed since 2000 (59% vs 29%).
- ✚ Respondents who did not enter into medical care within six months of diagnosis were asked for their reasons. “Not feeling sick” (22%) and denial (27%) were most frequent responses. “Using drugs” accounted for 16% of responses.



Figure II.14

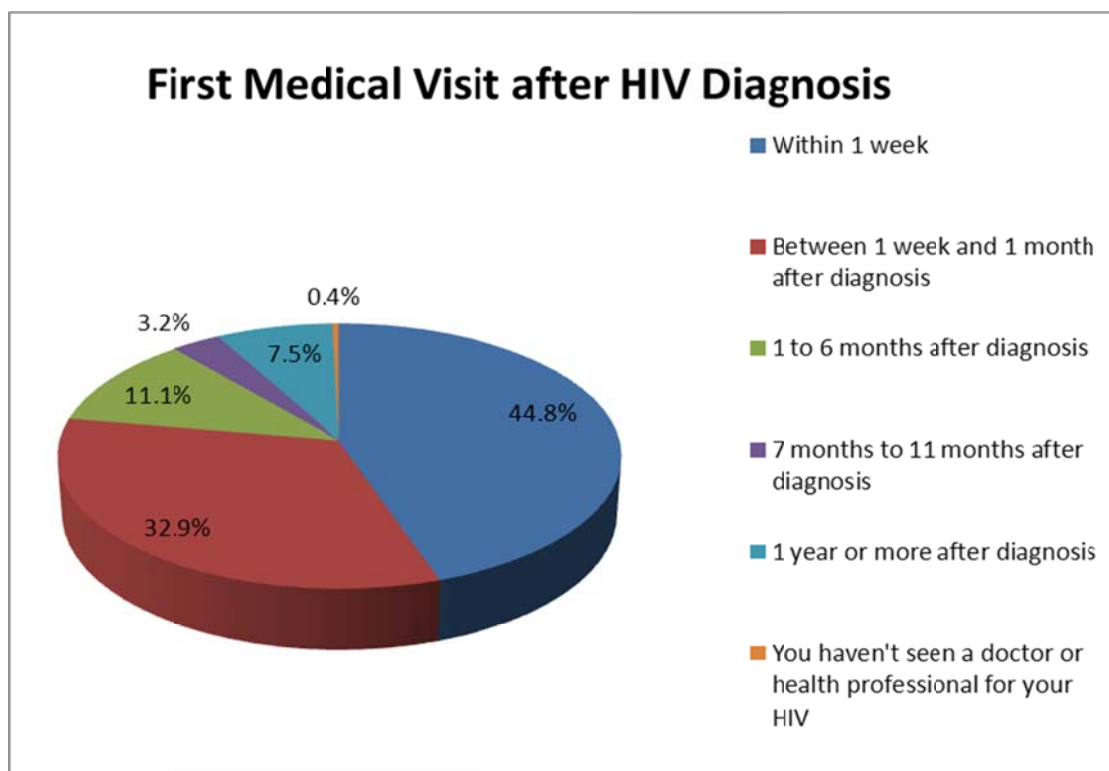




Table II.24

After receiving your HIV diagnosis, when did you have your first medical visit for your HIV/AIDS?						
	Within 1 week		Between 1 week and 1 month after diagnosis		1 to 6 months after diagnosis	
N= 252	Number	Percent	Number	Percent	Number	Percent
Total Sample	113	44.8%	83	32.9%	28	11%
Male	62	54.9%	61	73.5%	18	64.3%
Female	50	44.3%	22	26.5%	10	35.7%
Transgender	*	0.9%	0	0.0%	0	0.0%
White	62	54.9%	39	47.0%	9	32.1%
Black/African-American	47	41.6%	41	49.4%	19	67.9%
Other	*	3.5%	*	3.6%	0	0.0%
Hispanic	52	46.0%	20	24.1%	*	14.3%
< 25	*	1.8%	*	2.4%	0	0.0%
25-44	30	26.6%	23	27.7%	6	21.4%
>45	81	71.7%	58	69.9%	22	78.6%
Bergen County	21	18.6%	23	27.7%	6	21.4%
Passaic County	86	76.1%	54	65.1%	20	71.4%
Other	6	5.3%	6	7.2%	*	7.1%
Dx Before 2000	33	28.5%	42	36.2%	19	16.4%
Dx Since 2000	80	58.8%	41	30.2%	9	6.6%

* Less than five.



Table II.24 (Continued)

After receiving your HIV diagnosis, when did you have your first medical visit for your HIV/AIDS?						
	7 months to 11 months after diagnosis		1 year or more after diagnosis		You haven't seen a doctor or health professional for your HIV	
N= 252	Number	Percent	Number	Percent	Number	Percent
Total Sample	8	3.2%	19	7.5%	1	0.4%
Male	6	75.0%	11	57.9%	*	100.0%
Female	*	25.0%	7	36.8%	0	0.0%
Transgender	0	0.0%	*	5.3%	0	0.0%
White	*	25.0%	5	26.3%	0	0.0%
Black/African-American	6	75.0%	13	68.4%	*	100.0%
Other	0	0.0%	*	5.3%	0	0.0%
Hispanic	*	12.5%	*	10.5%	*	100.0%
< 25	0	0.0%	0	0.0%	0	0.0%
25-44	*	12.5%	5	26.3%	0	0.0%
>45	7	87.5%	14	73.7%	*	100.0%
Bergen County	*	37.5%	*	10.5%	0	0.0%
Passaic County	*	37.5%	14	73.7%	*	100.0%
Other	*	25.0%	*	15.8%	0	0.0%
Dx Before 2000	5	4.3%	17	14.7%	0	0.0%
Dx Since 2000	*	2.2%	*	1.5%	*	0.7%

* Less than five.



Table II.25

Why didn't you get medical care within six months of your diagnosis?		
n=45	#	%
Denial	12	26.7%
I was not sick so I did not think I needed medical care	10	22.2%
I was actively using drugs or relapsed (started using street drugs/alcohol after I got the HIV diagnosis)	7	15.6%
I did not know where to go for medical care	5	11.1%
I thought I was going to die and medical care wouldn't do any good	5	11.1%
I was worried someone might find out I am HIV positive if I went there	5	11.1%

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 (Figure II.15 and Table II.26).

- ✂ Less than 20% of respondents identified barriers to keeping medical appointments.
- ✂ Most frequently cited barriers included transportation (19%), not feeling well enough to get to the doctor (17%) and stigma (16%).

Figure II.15

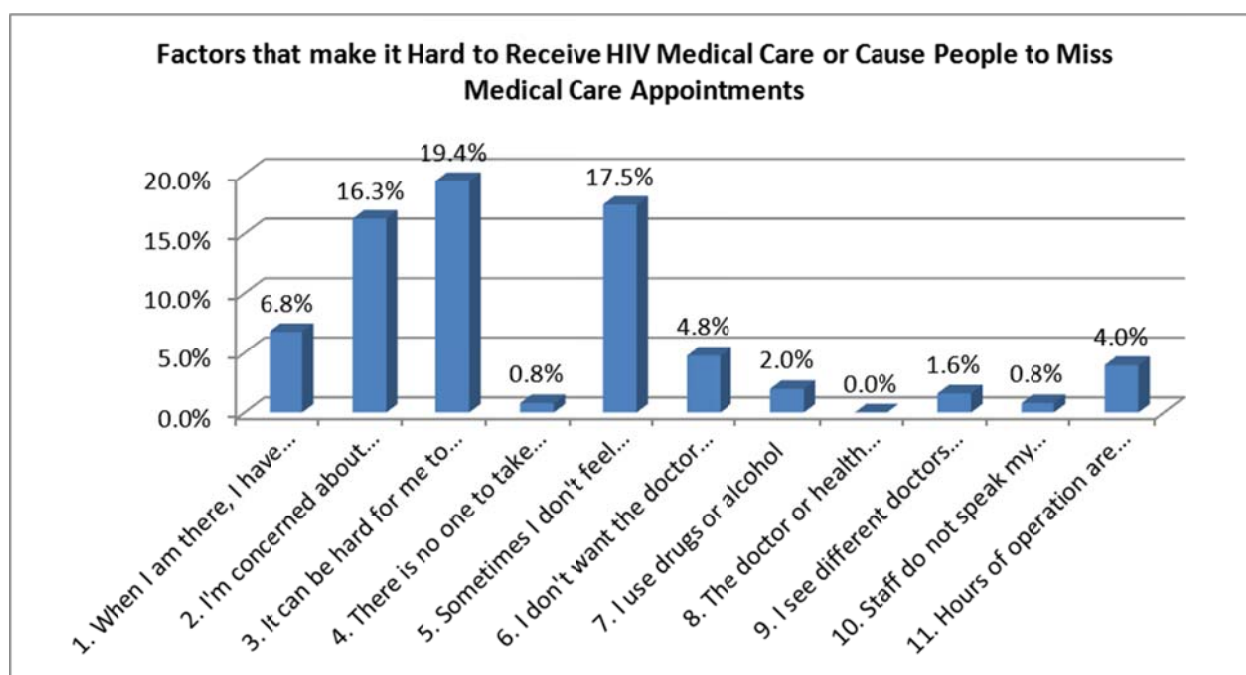




Table II.26

Do any of the following make it hard for you to get HIV medical care or cause you to miss HIV medical care appointments?		
	Other	
N=252	Number	Percent
Total Sample	252	100.00%
Answer		
1. When I am there, I have to wait too long to be seen by doctor	17	6.75%
2. I'm concerned about others finding out that I am HIV positive	41	16.27%
3. It can be hard for me to get there--transportation problems	49	19.44%
4. There is no one to take care of the children in my care	*	0.79%
5. Sometimes I don't feel well enough to go	44	17.46%
6. I don't want the doctor or health professional to know that I have not followed my HIV treatment	12	4.76%
7. I use drugs or alcohol	5	1.98%
8. The doctor or health professional I used to see is no longer there	0	0.00%
9. I see different doctors or health professionals each time I go	*	1.59%
10. Staff do not speak my language	*	0.79%
11. Hours of operation are inconvenient	10	3.97%

* Less than five.

Co-Morbidities

Ninety-six (38%) survey respondents reported treatment for a co-morbidity in the last year (Figure II.16 and Table II.27).

- ✘ The most frequent was emotional stress such as depression, anxiety or nerves cited by 19% of respondents.
- ✘ This was followed by hepatitis C and diabetes, each reported by 8% of those surveyed.
- ✘ Sexually transmitted infections (STI) and drug/alcohol treatment was reported by 5% of participants.
- ✘ Hepatitis B and tuberculosis were each treated by 4% of respondents.



Figure II.16

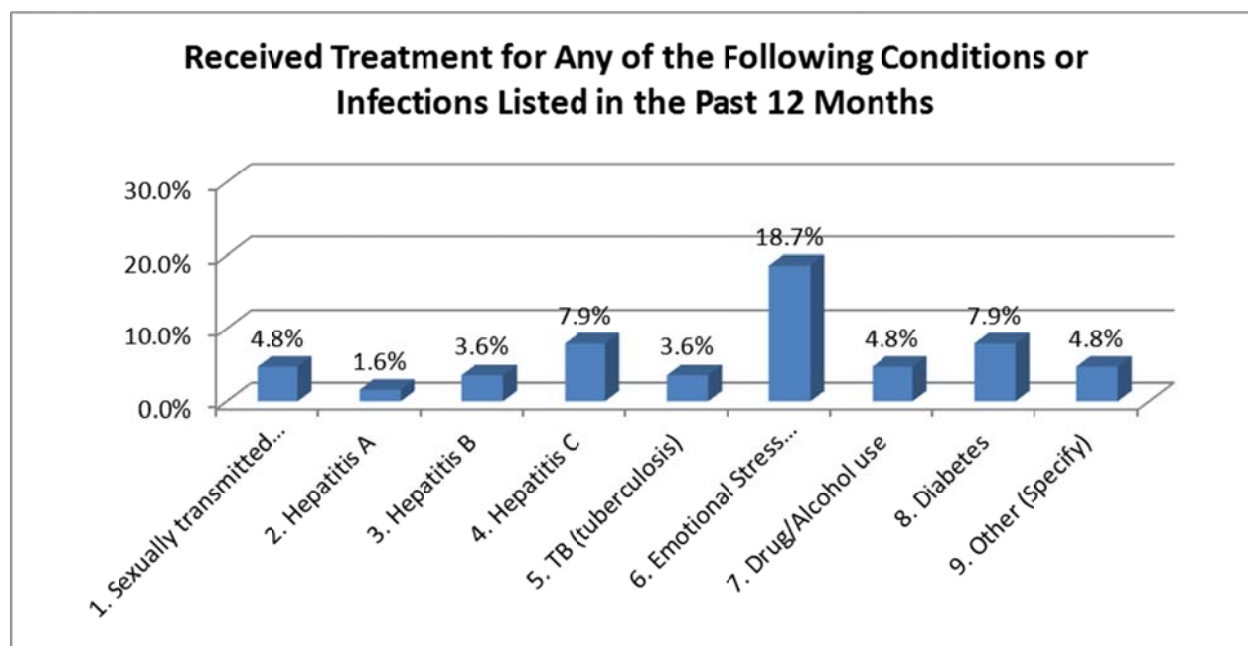


Table II.27

In the past 12 months, have you received treatment for any of the following conditions or infections?		
	Other	
N=252	Number	Percent
Sexually transmitted infections	12	4.8%
Hepatitis A	*	1.6%
Hepatitis B	9	3.6%
Hepatitis C	20	7.9%
Tuberculosis	9	3.6%
Emotional Stress (such as depression, anxiety, nerves)	47	18.7%
Drug/Alcohol use	12	4.8%
Diabetes	20	7.9%
Other (Specify)	12	4.8%
None of the above	156	61.9%

* Less than five.



Substance Use

Ninety-two respondents (36.5%) reported current substance use (Figure II.17 and Table II.28). This includes:

- ✂ 23% who used tobacco;
- ✂ Ten percent who used alcohol;
- ✂ 8% who used medications for emotional stress;
- ✂ 6% who used marijuana;
- ✂ Only one survey respondent reported injecting drugs.

Figure II.17

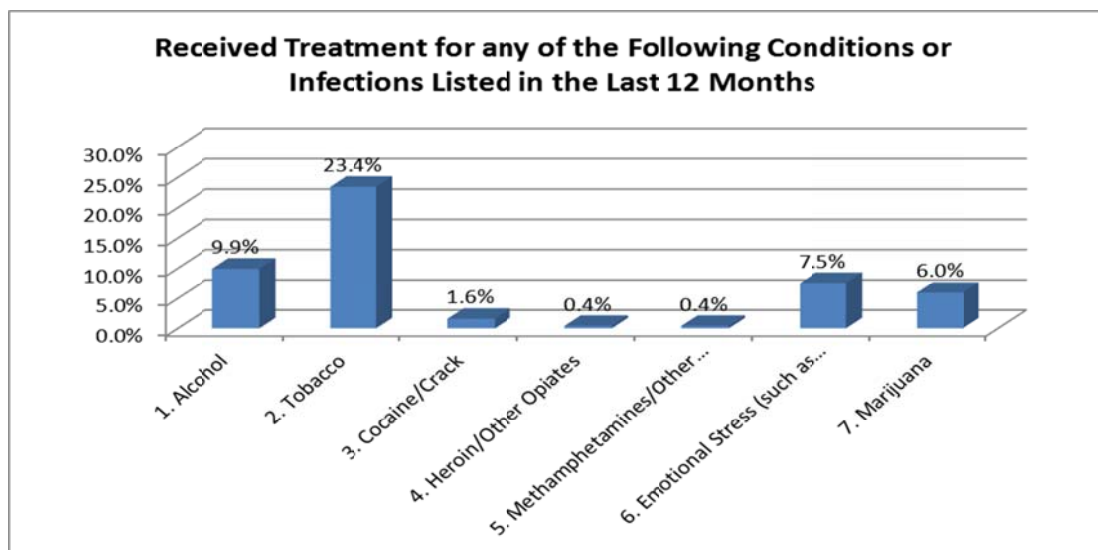


Table II.28

Current Substance Use		
	Number	Percent
Total Sample	252	100.0%
Alcohol	25	9.9%
Tobacco	59	23.4%
Cocaine/Crack	*	1.6%
Heroin/Other Opiates	*	0.4%
Methamphetamines/Other Stimulants	*	0.4%
Emotional Stress (such as depression, anxiety, nerves)	19	7.5%
Marijuana	15	6.0%
None of the above	160	63.5%

* Less than five.



Substance Abuse Treatment Needs

Fifty-one people (20% of the survey sample) identified nine needed substance abuse treatment services. The remaining 201 respondents reported not needing any services (See Figure II.18 and Table II.29).

- ✂ The most frequent service need was transportation to treatment, identified by 12% of those surveyed or 57% of those needing substance abuse treatment services.
- ✂ Free treatment for people with no insurance was identified by 9% or 43% of those needing substance abuse treatment services.
- ✂ Information about where to go for treatment was needed by nine respondents and information about available services was identified by six.
- ✂ Services needed by five respondents or less included: methadone maintenance treatment, treatment on demand, residential treatment, drug-free outpatient treatment and inpatient detox.
- ✂ One expressed a need for suboxone detox.

Figure II.18

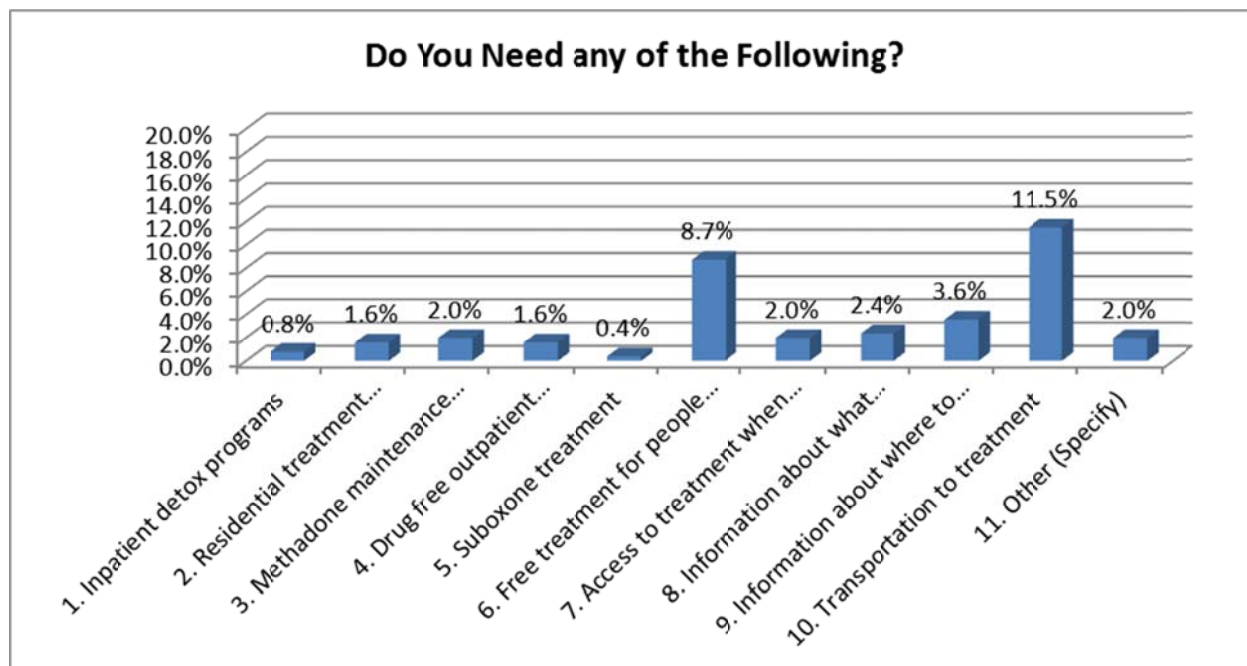




Table II.29

Substance Abuse Treatment Needs		
N=51	Number	Percent
Answer		
Inpatient detox programs	*	0.8%
Residential treatment programs	*	1.6%
Methadone maintenance treatment	5	2.0%
Drug free outpatient treatment programs	*	1.6%
Suboxone treatment	0	0.0%
Free treatment for people with no insurance	22	8.7%
Access to treatment when you're ready (Treatment on Demand)	5	2.0%
Information about what drug treatment services are available	6	2.4%
Information about where to go for treatment	9	3.6%
Transportation to treatment	29	11.5%
Other	5	2.0%

* Less than five.

Prevention Practices

Survey participants were asked about whether they had receptive anal, vaginal or oral sex in the last year. One hundred respondents (40%) responded positively. The remaining 60% had not had receptive sex or had not had sex (Figure II.19 and Table II.30).

- ✚ Women were more likely than men to report receptive sex.
- ✚ Hispanics (55%) and Whites (48%) were the racial/ethnic groups most likely to report receptive sex.
- ✚ Younger respondents were more likely than older respondents to have had receptive sex in the last year.
- ✚ There was no significant variation by county of residence.



Figure II.19

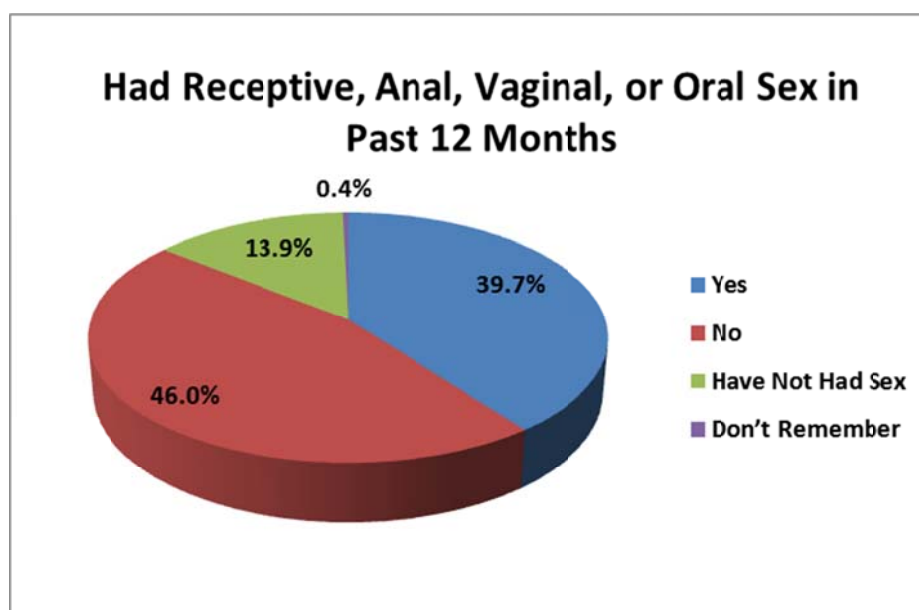


Table II.30

In the past 12 months, have you had receptive anal, vaginal, or oral sex?						
	Yes		No		Have not had sex	
N= 252	Number	Percent	Number	Percent	Number	Percent
Total Sample	100	39.7%	116	46.0%	35	13.9%
Male	61	37.9%	79	49.1%	21	13.0%
Female	39	43.3%	37	41.1%	14	15.6%
Transgender	0	0.0%	*	50.0%	*	50.0%
White	56	47.9%	48	41.0%	13	11.1%
Black/African-American	41	32.5%	64	50.8%	21	16.7%
Other	*	37.5%	*	50.0%	*	12.5%
Hispanic	44	55.0%	27	33.8%	9	11.3%
< 25	*	100.0%	0	0.0%	0	0.0%
25-44	38	58.5%	23	35.4%	*	6.2%
>45	58	31.9%	93	51.1%	31	17.0%

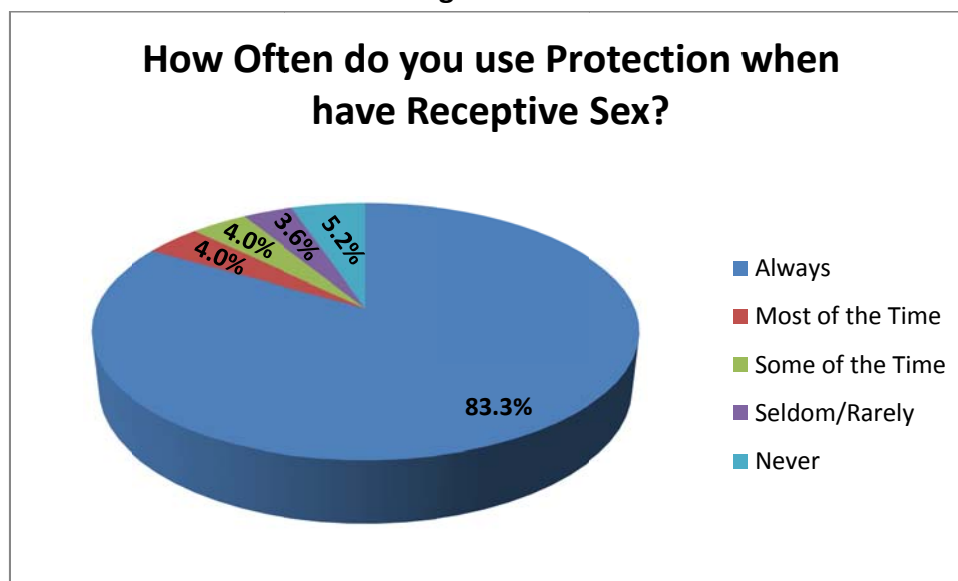
* Less than five.



Over 83% of those having receptive sex reported always using a male condom, female condom or dental dam (referred to as protection) (Figures II.20-II.21 and Table II.31).

- ✚ Four 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).
- ✚ 3.6% reported using protection seldom or rarely (one to three times out of ten).
- ✚ Over five percent (5.2%) reported never use protection when having sex.

Figure II.20

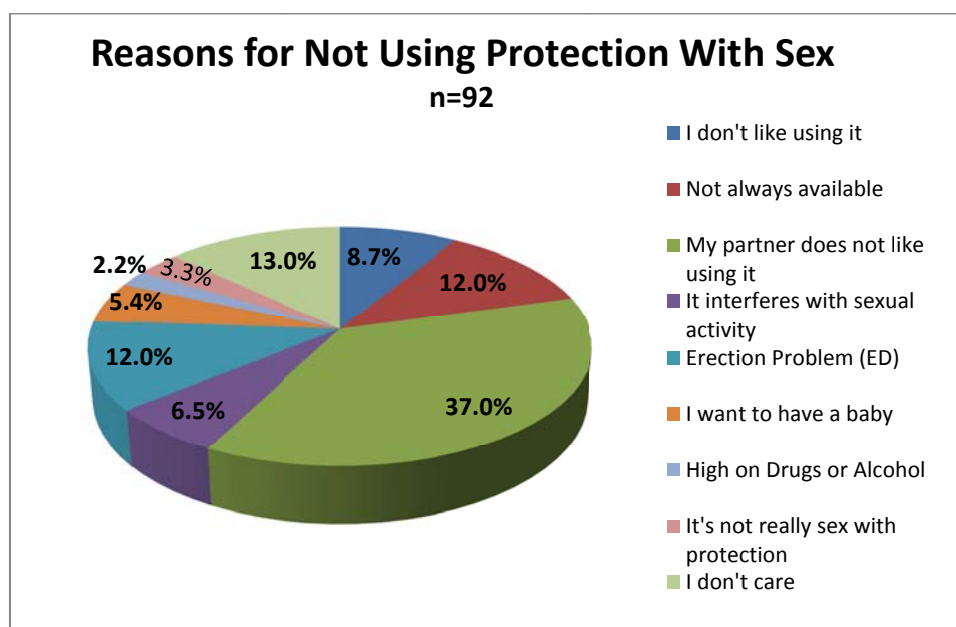


When asked the reasons for not using protection during receptive sex, 92 participants provided the following responses:

- ✚ “My partner does not like using it” was the most frequent answer, identified by 37%.
- ✚ This was followed by 13% who stated, “I don’t care.”
- ✚ “Protection is not always available” and erectile dysfunction were each cited by 12%.
- ✚ “I don’t like using it” was the reason provided by 9%, and 7% feel “protection interferes with sexual activity.”
- ✚ Over 5% reported wanting to have a baby so protection was not used.



Figure II.21



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

- ✚ Over three-quarters (78%) reported sharing HIV information, but 54 respondents (21%) do not.
- ✚ When asked why they do not share HIV information, the most frequent response was, “I am afraid of their reaction to me,” provided by 57%.
 - Men were more likely than women to provide this response.
 - Whites and Hispanics were more likely than Blacks/African-Americans to be afraid of the reaction.
 - Bergen County residents were more likely than Passaic County residents to provide this answer.
 - There was no significant variation in response by age.



Table II.31

Do you share...? If no, why not?								
	I'm afraid of their reaction to me		They don't want to talk about it (denial)		I'm afraid that someone will find out that I'm HIV-positive		Other	
n= 54	Number	Percent	Number	Percent	Number	Percent	Number	Percent
Total Sample	31	57.4%	*	5.6%	*	3.7%	17	31.5%
Male	23	60.5%	*	5.3%	*	5.3%	10	26.3%
Female	8	50.0%	*	6.3%	0	0.0%	7	43.8%
White	15	65.2%	*	4.3%	*	4.3%	6	26.1%
Black/African-American	16	53.3%	*	6.7%	*	3.3%	10	33.3%
Hispanic	10	58.8%	*	5.9%	*	5.9%	5	29.4%
Bergen County	8	72.7%	0	0.0%	0	0.0%	*	27.3%
Passaic County	21	52.5%	*	7.5%	*	5.0%	13	32.5%

* Less than five.

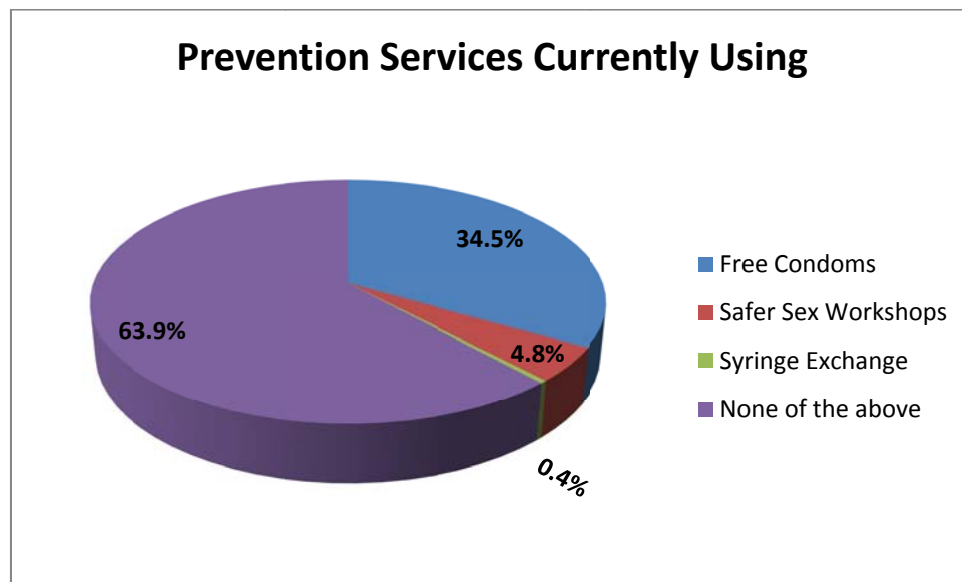
Verbatim responses:

- Do not have a partner (16)



Nearly 64% of respondents do not use any prevention services. For those that use services, the most frequent is free condoms, with 34.5% citing it (Figure II.22 and Table II.32).

Figure II.22



Nearly 60% of in-care survey respondents have identified people who they may have been exposed to the HIV virus. This included:

- ✚ Two-thirds of women and 55% of men;
- ✚ Seventy percent of Whites, 69% of Hispanics and 50% of Blacks/African-Americans;
- ✚ Nearly two-thirds of persons under 45 years.

Of those reporting exposing others to HIV, 125 (84%) 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:

- ✚ 37 reported they did not know how to identify a person;
- ✚ 18 reported sharing works or having sex with anonymous people (people they didn’t know well);
- ✚ 10 reported being too worried about themselves and 19 gave other reasons.

Of those who did not identify anyone they exposed, 19 asked for immediate help to understand how to do so.



Table II.32

Have you identified persons who may have been exposed to HIV through you?		
	Number	Percent
Total Yes	149	59.13%
Male	87	54.7%
Female	61	67.0%
Transgender	*	50.0%
White	83	70.9%
Black/African-American	63	49.6%
Other	*	37.5%
Hispanic	55	68.8%
< 25	*	100.0%
25-44	42	64.6%
>45	103	56.3%
Bergen County	37	67.3%
Passaic County	106	59.6%
Other	6	31.6%

* Less than five.

Survey participants were asked if they know anyone who is HIV positive and not receiving HIV medical care. Thirty-four (13.5%) responded positively (Table II.33).

- ✚ The majority of positive responses came from men, and Black/African-Americans.
- ✚ Little variation in response was seen based on age or county of residence.



Table II.33

Do you know anyone who is HIV-positive and not in care?		
N= 252	Number	Percent
Total Yes	34	13.5%
Male	27	16.8%
Female	7	7.7%
Transgender	*	50.0%
White	5	4.3%
Black/African-American	26	20.5%
Hispanic	7	8.8%
< 25	*	75.0%
25-44	9	13.8%
>45	22	12.0%
Bergen County	8	14.5%
Passaic County	23	12.9%

* Less than five.



III. HIV/AIDS POPULATION OUT OF MEDICAL CARE

Information pertaining to the needs of PLWHA who were out of medical care originated from two sources: key informant interviews and a consumer survey. Both are described in this report.

A. KEY INFORMANT INTERVIEWS

Key informants were asked about the current situation, barriers and challenges, and suggestions for engaging PLWHA in medical care. The following summarizes their remarks.

Current Situation

- ✘ About 20% of the in-care population drops out at some point. They return when they are not feeling well, but usually not before.
- ✘ Case managers lose track as clients migrate, change phones, live on the street, etc.
- ✘ Stigma and desire for anonymity remain prevalent.
- ✘ “Either drugged or they just don’t care.”
- ✘ Late-to-care is a problem. Newly diagnosed may stay away due to stigma, inadequate counseling, other social factors or addiction issues.
- ✘ Live in the moment; no ability to think beyond for various reasons (child care, homeless, drugs, etc.)
- ✘ They lack accurate information about HIV, the need to remain in care and where to get care.
- ✘ Economic depression creates a necessity to cope with needs of basic living.
- ✘ About 56% are black; 34% Hispanic and rest are white. Almost no other race/ethnicity has been seen in the clinics.
- ✘ Incarcerated PLWHA are outside the system. They receive the remainder of their medications upon discharge and a list of contacts. There is no follow-up.

Barriers and Major Challenges

- ✘ Drug addiction was mentioned most often
- ✘ Stigma, the need for confidentiality
- ✘ Poverty, inability to pay
- ✘ Necessities of daily living taking precedence over medical appointments
- ✘ Cultural issues, ability to communicate
- ✘ Wait time in the clinic is too long, so they don’t go
- ✘ Same challenges as in-care PLWHA, only greater



Suggestions

- ✚ Teach them about co-infection, re-infection and safety with other partners.
- ✚ Outreach on the street; don't wait until they come back when they're ill.
- ✚ Provide tangible help to stay in care; i.e., patient navigators
- ✚ Provide a safe place; peer support groups; gain trust
- ✚ Food programs can work in bringing back the out-of-care.

B. OUT-OF-CARE INTERVIEWS

Behaviors

The over-riding question asked of out-of-care PLWHA was why they chose not to receive medical care. When posing this question to the ten subjects, answers varied. Personal life situations generally guided their decisions, indicating that HIV medical care was not a priority.

Q1: Why did you choose not to receive medical care for your HIV?

- ✚ I moved to a state where I was not able to get medications.
- ✚ My housing problems made it hard for me to get there.
- ✚ I stopped caring; I was really depressed.
- ✚ Sometimes I think the medications were hurting me.
- ✚ I didn't think I needed medications yet.
- ✚ I didn't want anyone to know about my condition.
- ✚ I wanted to party instead.

Subjects were asked about whether they considered getting medical care but still refused. Of those who answered affirmatively, they were often conflicted, either not addressing their health sufficiently or preferring other means such as drugs as a way of dealing with their problems.

Q2: Were there times when you felt that you needed to see a doctor but chose not to?

- ✚ Yes, I was losing weight, and I knew it wasn't good. But I still didn't think it was serious.
- ✚ Yes, but I was in denial.
- ✚ Yes, but I went back to using drugs.

When asked, "What changed your mind?" subjects most often expressed two reasons: (1) getting sicker and needing care or (2) their "survival" instinct to live a better life made them change.

Q3: What changed your mind about getting medical care for your HIV?

- ✚ I was getting sicker (2 respondents).
- ✚ My life situation changed, and I was able to deal with my HIV (2 respondents).



- ⓧ I began to care for myself and take responsibility for my health (4 respondents).
- ⓧ Coming off drugs, I wanted to do the right thing (2 respondents).

Risk Reduction and Prevention Practices

Subjects were asked about their sexual practices, HIV prevention activities, and attitudes regarding others at risk for HIV/AIDS. All were aware of risk reduction practices, and all endorsed the need for them.

When asked if they routinely engage in risk reduction practices, answered varied. Many no longer had sex; some were monogamous and others used protection.

Q6: Do you routinely engage in risk reduction practices?

- ⓧ No longer having sex (3 respondents)
- ⓧ Will use condoms or dental dam (5 respondents)
- ⓧ Will use condoms if the situation arises, but it's only rarely.

Subjects tended to be open about their HIV status and shared information with their partner(s). However, they often chose to avoid people who were engaging in risky behaviors, preferring their own privacy instead.

Q7: Do you share HIV information with your partner, potential partner or others at risk for HIV?

- ⓧ I'm not comfortable talking about it [HIV].
- ⓧ It depends. I would have to be comfortable with the person first.
- ⓧ At first, I was scared to tell...it's hard.
- ⓧ I don't surround myself with those people.
- ⓧ I tell family and friends.

When asked about their experience with exposing or identifying persons who may have been infected with HIV, they had very little to share. They talked about how they were infected and whether they infected their partner or vice versa. Nearly all knew his or her partner and was able to divulge information freely.

Subjects were asked about others who engage in high risk behaviors. While many did not affiliate with them, they did display knowledge of widespread high risk practices.

Q8: What do you know about others engaging in high risk behaviors?

- ⓧ I don't talk with them. (3 respondents)
- ⓧ People like that need to accept and do something about it. Some have this carefree kind of living and will go as far as they can until they need help.



- ⓧ They could care less whether they give it to you or they don't.
- ⓧ Basically everybody is taking risks...everybody out there. (2 respondents).
- ⓧ Every day you see it. People don't take this virus serious. They smoke marijuana. They drink alcohol. They are fornicating in the hallways, in the back seat of cars. I can look out my window, and this stuff goes on where I live right in my yard.
- ⓧ The younger generation is having sex with prostitutes who are older women, and I never see condom wrappers on the street.

Stigma

Subjects were asked questions about discrimination and their experience with stigma. When asked about discrimination, only one openly acknowledged it.

Q9: Do you feel that there is discrimination when someone is HIV-positive?

- ⓧ Yes, I have and it broke my heart. I went to shake his hand, and he refused, saying "No, I don't touch people who have that." I felt like a fool for letting this happen to me.

Similarly, questions about stigma brought mixed responses. Two acknowledged the issue while the others denied any such experience. Those who did not acknowledge stigma had strong personal support systems in place, most often the immediate family.

Q10: Tell me about stigma. Do you experience it?

- ⓧ Yes, absolutely. Stigma is, I think, the biggest part about people not speaking openly about HIV.
- ⓧ It affects my relations with my family and other friends. They just don't treat me the same; they don't look at me the same. It's kind of like you're nothing; you're just the bottom of the bottom.
- ⓧ It hurts when people are scared to be by you or don't want to touch something that you touched, or don't want you to use their bathroom. I can tell right away if someone is prejudiced against me or has something about HIV that they don't like.

The last question was open-ended and allowed each subject an opportunity to impart words of advice. Each response is summarized here.

Q11: Do you have any suggestions to encourage people with HIV to get medical care?

- ⓧ You can do it by talking to people and letting them know that this is an illness that needs to be dealt with.
- ⓧ Get tested because the HIV life is a process. Basically I would say that they are not alone and, if everybody just comes together, we can work together and live long, happy lives.
- ⓧ I have no idea what to say.



- ⓧ Don't do it...any of it. Don't have sex unless you use a condom. Don't shoot drugs unless you go get your clean syringes; think about it before you do it. Think about your life.
- ⓧ I think people like me who have been diagnosed for a while should be able to talk to others and help them come to terms. Like, if you don't have it, you really, really have to protect yourself.
- ⓧ They need to be more compassionate with themselves and other people. If you believe in God, remember, it's wrong what you're doing. Have some faith; be the bigger person. Change.
- ⓧ If you are HIV-positive and you are like me, loving and caring, and want to make a difference in the world, you can go and take your treatment. It's true the medicine does help and it is good, because I've seen it. Just be persistent with it.
- ⓧ I would tell them have safe sex.
- ⓧ Just tell them my story. I would tell them what I went through and how I didn't even know I had it until I took the test, because I didn't have any symptoms. Mostly if they stop getting high, they'll think more because you don't think with drugs.
- ⓧ Don't do it; it's not worth it. I hate feeling like I did when I didn't take my medicine. I don't want anyone else to feel like that.



IV. SERVICE USE, ACCESS, NEED AND BARRIERS

A. IN-CARE SERVICE USE, ACCESS, NEEDS AND BARRIERS

Summary

This section presents summaries of use, access, need, and barriers for 25 individual services identified in the in-care survey.¹⁶ Questions were limited to respondents' experience within the last year. The tables reflect responses from the total sample (N=252). Respondents were asked (1) "Do you get this service?" and if yes "How easy was it to get?" For those who do 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 is presented below. Detailed tables on use, access, need and barriers are found in Appendix B. Verbatim responses to all open-ended questions are found in Appendix C.

- ✘ The system of care and support services is well established with only a few gaps reported by survey respondents. Medical care and case management were well utilized. Large numbers of respondents found services easy to get.
- ✘ About 20% identified access problems for services that would make it easier to get HIV medical care, and less than 14% reported unmet need for services used in the past but unavailable today.
- ✘ Most frequent and significant access issues related to medical care centered on insurance issues. Respondents repeatedly expressed concern about meeting deductibles and co-pays.
- ✘ Transportation continued to be a notable problem among survey respondents. Need for daily supports for food and utilities ranked high in importance although most are able to find assistance. Housing, on the other hand, was highest in unmet need and perceived access barriers.
- ✘ Oral health care was among the highest in unmet need.
- ✘ Patient education may not have been sufficient in reducing barriers to care, particularly as related to Ob/Gyn and mental health treatment.
- ✘ Demand for substance abuse treatment has declined when compared to the first decades of the epidemic.

Observations by Service Category

HIV Outpatient Medical Care

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

¹⁶ Responses for one service category "Health Insurance Continuation" were invalid and therefore not reported.



Use/Access	Need	Most Common Barriers (n=17)
<ul style="list-style-type: none"> ✚ Used by 90% of respondents ✚ Considered somewhat hard or hard to get by 5% 	<ul style="list-style-type: none"> ✚ 17% (less than five) who do not get this service say they need it. ✚ Ranked 21st in unmet need. 	<ul style="list-style-type: none"> ✚ Difficult to get an appointment (6) ✚ High co-pay for service (6) ✚ Other (6): <ul style="list-style-type: none"> ▪ Paperwork (2) ▪ Traveling ▪ No doctor ▪ Did not care ▪ Transportation

Outpatient OB/GYN Care

Female PLWHA did not identify need for or barriers to receiving OB/GYN care. Nonetheless, clinicians cite ability to obtain Pap tests as among their most difficult problems. This may indicate insufficient patient education regarding the need for routine OB/GYN exams and Pap tests.

Use/Access (n=91)	Need	Most Common Barriers (n=10)
<ul style="list-style-type: none"> ✚ Used by 92% of female respondents ✚ Less than 5 found it somewhat hard or hard to get. 	<ul style="list-style-type: none"> ✚ 43% (less than five) who did not get this service say they need it ✚ Ranked (23rd) in unmet need 	<ul style="list-style-type: none"> ✚ No barriers cited by five or more respondents

Care from a Specialist Referred by HIV Doctor

Specialty care was ranked sixth among services used by in-care respondents. Most common barriers related to scheduling, insurance and lack of perceived need.

Use/Access	Need	Most Common Barriers (n=32)
<ul style="list-style-type: none"> ✚ 66% receive care from a specialist ✚ 8% (14) found it somewhat hard or hard to get 	<ul style="list-style-type: none"> ✚ 21% (18) say they need a specialist ✚ Ranked 14th in unmet need 	<ul style="list-style-type: none"> ✚ Difficult to get appointment (11) ✚ High co-pay for service (9) ✚ Other (9) <ul style="list-style-type: none"> ▪ No Insurance (4) ▪ Never saw a need to go to a specialist ▪ My doctor does not give me the information that is needed for me to know these options are out there. ▪ To be decided as we go along ▪ My doctor didn't seem to care ▪ No doctor coverage



Help Paying for Medical Care

This was the fourth most utilized service identified in the survey and ranked 17th among 24 in unmet need. Barriers most frequently related to insurance restrictions and knowledge.

Use/Access	Need	Most Common Barriers (n=36)
<ul style="list-style-type: none"> ⚡ 81% say they get help paying for medical care ⚡ 10% found it somewhat hard or hard to get. 	<ul style="list-style-type: none"> ⚡ 27% who don't get help say they need it ⚡ Ranked 17th in unmet need 	<ul style="list-style-type: none"> ⚡ Didn't qualify (12) ⚡ Didn't know about the service (12) ⚡ High co-pay and deductible (8)

Help Paying for Prescriptions or Medications

This was the second most utilized service and 18th in insufficient access. Most common barriers related to insurance restrictions.

Use/Access	Need	Most Common Barriers (n=29)
<ul style="list-style-type: none"> ⚡ 88% get help paying for medications ⚡ 7% (18) found it somewhat hard or hard to get 	<ul style="list-style-type: none"> ⚡ 38% (11) who don't get help say they need it ⚡ Ranked 18th in unmet need 	<ul style="list-style-type: none"> ⚡ Didn't qualify (9) ⚡ High co-pay and deductible (8) ⚡ Didn't know about the service (6) ⚡ Other (8): <ul style="list-style-type: none"> ▪ Took a lot of paperwork to prove that neither of my parents were claiming me on their taxes ▪ I don't know just start the process ▪ None ▪ Don't know the reason ▪ Can't Afford it ▪ They keep sending applications ▪ Medicaid was cut ▪ Sources ran out

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 nearly 60% of survey respondents. Forty-seven (19%) identified barriers to obtaining help for co-pays and deductibles. Insurance restrictions and knowledge were among the most commonly identified barriers.

Use/Access	Need	Most Common Barriers (47)
<p>🚫 57% receive this service</p> <p>🚫 10% (15) found it somewhat hard or hard to get</p>	<p>🚫 30% of those who do not get help say they need it</p> <p>🚫 Ranked 7th in unmet needs</p>	<p>🚫 Didn't qualify (23)</p> <p>🚫 Didn't know about the service (15)</p> <p>🚫 Other (9)</p> <ul style="list-style-type: none"> ▪ Didn't qualify and high co-pay and deductible ▪ Just started the process ▪ None ▪ Reasons ▪ Uses ADDP Program ▪ Has no insurance other than charity care and ADDP ▪ I did not find help yet ▪ Have too many bills and a small income ▪ No insurance

Help Paying for Co-Pays and Deductibles for HIV Medications

Similar to help paying for medical care co-pays and deductibles, help paying for medication co-pays and deductibles were received and needed by nearly 60% of survey respondents. Thirty-five (14%) identified barriers to obtaining help for co-pays and deductibles. Insurance restrictions and knowledge were among the most commonly identified barriers.

Use/Access	Need	Most Common Barriers (n=35)
<p>🚫 59% get help paying for HIV medication co-pays and deductibles</p> <p>🚫 9% (14) found it somewhat hard or hard to get</p>	<p>🚫 20% of those who do not get help say they need it</p> <p>🚫 Ranked 12th in unmet needs</p>	<p>🚫 Didn't qualify (14)</p> <p>🚫 Didn't know about the service (13)</p> <p>🚫 Too much paperwork (5)</p>



Dental Visits

Oral health care ranked among the highest in unmet need (third) despite being easy to get. Barriers were varied.

Use/Access	Need	Most Common Barriers (n=56)
<ul style="list-style-type: none"> ⚡ 54% receive dental care ⚡ 11% (15) say it is somewhat hard or hard to get 	<ul style="list-style-type: none"> ⚡ 36% (41) who do not get dental care say they need it ⚡ Ranked 3rd in unmet needs 	<ul style="list-style-type: none"> ⚡ Limited funding (22) ⚡ Waiting list for appointment (12) ⚡ Afraid of the dentist (5) ⚡ Other (12): <ul style="list-style-type: none"> ▪ Did not know it existed (3) ▪ Buddies never got back to me about it. They said I would get all of those things taken care of and... ▪ No medical insurance (2) ▪ Expensive ▪ Need to make an appointment with a Ryan White Dentist ▪ Just did not go ▪ Have not looked into it yet ▪ My Medicaid was stopped

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 and access. Most common barriers related to knowledge about the service.

Use/Access	Need	Most Common Barriers (n=31)
<ul style="list-style-type: none"> ⚡ 86% get medical case management ⚡ Ranks #3 in service use ⚡ 4% (9) found it somewhat hard or hard to get 	<ul style="list-style-type: none"> ⚡ 61% (9) who do not get medical case management say they need it ⚡ Ranked 10th in unmet needs 	<ul style="list-style-type: none"> ⚡ Case manager not available or hard to reach (7) ⚡ Case manager's lack of information (6) ⚡ Other (14): <ul style="list-style-type: none"> ▪ Did not know (3) ▪ Did not qualify ▪ Did not need it at the time (2) ▪ My availability ▪ Just started the process ▪ Trying to qualify ▪ Limited services ▪ Lack of information ▪ Did not ask ▪ Passaic Alliance trying to help today ▪ Availability



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 knowledge about the service.

Use/Access	Need	Most Common Barriers (n=20)
<p>🚫 51% get non-medical case management</p> <p>🚫 2% (less than five) found it somewhat hard to get and none found it hard to get.</p>	<p>🚫 15% (18) who do not get non-medical case management say they need it</p> <p>🚫 Ranked 15th in unmet needs</p>	<p>🚫 Case manager not available or hard to reach (8)</p> <p>🚫 Other (5):</p> <ul style="list-style-type: none"> ▪ Did not know ▪ Appointment ▪ A lot of changes that were overwhelming at first ▪ Fairly new to NJ and don't know many of the programs out there for me. ▪ I don't know how to

Mental Health Counseling

Although generally accepted as a major priority need among service providers, consumers did not agree. They ranked use, access and unmet need for mental health counseling relatively low compared to remarks from key informant interviews. Most common barriers related to scheduling and perceptions.

Use/Access	Need	Most Common Barriers (n=28)
<p>🚫 37% get mental health counseling</p> <p>🚫 Ranked #11 in service use</p> <p>🚫 8% (8) found it somewhat hard or hard to get</p>	<p>🚫 13% (20) who do not get mental health counseling say they need it</p> <p>🚫 Ranked 13th in unmet need</p>	<p>🚫 Waiting list (12)</p> <p>🚫 Didn't know where to go (9)</p> <p>🚫 Other (5):</p> <ul style="list-style-type: none"> ▪ I was depressed at the time ▪ Waiting for an appointment ▪ I'm afraid of what the outcome might be ▪ I get sick a lot and don't want to miss the appointment ▪ Inconsistency in personnel



Nutrition Counseling

Less than 30% reported getting nutrition counseling, although clinicians claim it is routinely part of their medical care. PLWH/A did not consider this an important need, again contrary to most clinicians' opinions. Most common barriers related to knowledge about this service.

Use/Access	Need	Most Common Barriers (n=33)
<ul style="list-style-type: none"> 29% say they get nutrition counseling Access problems were identified by less than 5 respondents 	<ul style="list-style-type: none"> 17% who don't get nutrition counseling say they need it Ranked 8th in unmet need 	<ul style="list-style-type: none"> Didn't know about this service (22) Not available (8)

Outpatient Substance Abuse Treatment

Outpatient substance abuse treatment was among the least utilized services (ranked 17th out of 24 service categories), with very few identifying barriers or unmet need.

Use/Access	Need	Most Common Barriers (n=9)
<ul style="list-style-type: none"> 24% get substance abuse treatment 8% (5) found it somewhat hard to get 	<ul style="list-style-type: none"> Less than five who do not get outpatient substance abuse treatment say they need it. Ranked 22nd in unmet need 	<ul style="list-style-type: none"> No barriers reported by more than five respondents.

Adult Day Care (Activities During the Day)

Adult day care was among the least utilized services (ranked 18th out of 24 service categories), with very few identifying a need or access barriers.

Use/Access	Need	Most Common Barriers (n=12)
<ul style="list-style-type: none"> 21% are in adult day care Less than five found it hard to get 	<ul style="list-style-type: none"> 5% (9) who are not in adult day care say they need it Ranked 19th in unmet need 	<ul style="list-style-type: none"> Do not know about this service (6).



Food Bank

Food assistance was obtained by a significant percentage of survey respondents (28) although it appeared to be relatively easy to access. Identified barriers were varied though small in number.

Use/Access	Need	Most Common Barriers (n=33)
<ul style="list-style-type: none"> 🚫 28% receive food bank assistance 🚫 15% (11) found it somewhat hard or hard to get 	<ul style="list-style-type: none"> 🚫 12% (22) who do not get food bank assistance say they need it 🚫 Ranked 11th in unmet need 	<ul style="list-style-type: none"> 🚫 Location/transportation (7) 🚫 Inconsistent quality of food (5) 🚫 Inconsistent amount of food (5) 🚫 Other (16): <ul style="list-style-type: none"> ▪ Did not know about this service (3) ▪ I have transportation through ... but I had a bad experience with them and I choose not to deal ▪ Unavailable funds (4) ▪ Don't know ▪ Never introduced by case manager ▪ Don't know where they are located (3) ▪ I came across money and didn't need it, but now I do ▪ Did not qualify ▪ Didn't need it at the time

Emergency Financial Assistance for Utilities

Although accessed by relatively few respondents, nearly one quarter did not find it easy to get. Utility assistance ranked fourth in unmet need.

Use/Access	Need	Most Common Barriers (n=49)
<ul style="list-style-type: none"> 🚫 13% get this service 🚫 24%(8) found it somewhat hard or hard to get 	<ul style="list-style-type: none"> 🚫 19% (41) who do not get assistance say they need it 🚫 Ranked 4th in unmet need 	<ul style="list-style-type: none"> 🚫 Limited funding (23) 🚫 Didn't qualify (12) 🚫 Too much paperwork (5) 🚫 Other (9) <ul style="list-style-type: none"> ▪ Time ▪ Did not know this was available (3) ▪ Homeless ▪ Never offered to me ▪ Don't know how to get it ▪ Did not ask for it ▪ Did not look into yet because of work hours



Emergency Assistance for Rent, Mortgage

Responses were similar to emergency assistance for utilities. Although accessed by relatively few respondents, more than half did not find it easy to get. Housing assistance ranked fifth in unmet need. Most common barriers related to qualifications.

Use/Access	Need	Most Common Barriers (n=54)
<p>🚫 12% get emergency housing assistance</p> <p>🚫 52% (16) found it somewhat hard or hard to get. Of these, 69% found it hard to get.</p>	<p>🚫 17% (38) of those who do not get this service say they need it.</p> <p>🚫 Ranked 5th in unmet need</p>	<p>🚫 Limited funding (32)</p> <p>🚫 Didn't qualify (10)</p> <p>🚫 Too much paperwork (5)</p> <p>🚫 Other (7):</p> <ul style="list-style-type: none"> ▪ Income ▪ Did not know this option was available (2) ▪ If it's available, I could use it ▪ Waiting list ▪ Did not ask for it

Long-Term Rental Assistance

Long term rental assistance, i.e., Section 8, ranked highest in unmet need of the 24 service categories in this survey. Only 20% were able to obtain Section 8, and nearly one-third found it hard to get. Most common barriers related to restrictions pertaining to qualifications.

Use/Access	Need	Most Common Barriers (n=65)
<p>🚫 20% of respondents get long term rental assistance.</p> <p>🚫 30% found it somewhat hard or hard to get</p>	<p>🚫 25% (50) of those who do not get long term rental assistance say they need it.</p> <p>🚫 Ranked 1st in unmet need</p>	<p>🚫 Limited funding (33)</p> <p>🚫 Waiting list too long (11)</p> <p>🚫 Didn't qualify (10)</p> <p>🚫 Other (7):</p> <ul style="list-style-type: none"> ▪ Multiple hospitalizations ▪ Did not know this option was available ▪ Just started the process ▪ They said I was not qualified for TRA and there is a waiting list for housing for people in my situation ▪ Not aware of the program ▪ I was told that I would only get a 5 month approval for assistance ▪ I receive assistance that is not long-term



Facility-Based Housing (Assisted Living Facility)

A small number of PLWH/A utilized assisted living, although they did not identify access issues.

Use/Access	Need	Most Common Barriers (n=31)
<ul style="list-style-type: none"> 8% (19) live in an assisted living facility Less than five found it somewhat hard or hard to get 	<ul style="list-style-type: none"> 12% (27) who are not in assisted living say they need it Ranked 9th in unmet need 	<ul style="list-style-type: none"> Limited funding (13) Didn't qualify (7)

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

Legal services were utilized by only 38 of respondents, of whom less than one-quarter found it difficult to get. Most common barriers related to limitations of services availability and knowledge.

Use/Access	Need	Most Common Barriers (n=29)
<ul style="list-style-type: none"> 15% (38) get legal services 24% (11) found it somewhat hard or hard to get 	<ul style="list-style-type: none"> 8% (18) of those who do not get legal services say they need it Ranked 16th in unmet need 	<ul style="list-style-type: none"> Limited services (need a lawyer for other services) (16) Did not know about this service (10)

Child Care While at a Medical or Other Appointment

Child care was the least utilized and least needed service, according to survey respondents. This result was not supported by key informant interviews where child care was cited as a significant need.

Use/Access	Need	Most Common Barriers (<5)
<ul style="list-style-type: none"> 2% use child care services 	<ul style="list-style-type: none"> Of those who do not get child care services, less than 1% say they need it Ranked 24th in unmet need 	<ul style="list-style-type: none"> None identified



Transportation to Medical Care – Bus Pass

Bus passes were identified as the second highest unmet need of the 24 services identified in this survey. Use and access, however, ranked relatively low. Most commonly identified barriers included convenience, knowledge and the feasibility of using buses.

Use/Access	Need	Most Common Barriers (n=63)
<ul style="list-style-type: none"> 🚫 34% get a bus pass to get to medical care 🚫 21% who use this service found it somewhat hard or hard to get 	<ul style="list-style-type: none"> 🚫 73% (124) of those who do not get a bus pass to medical care say they need it 🚫 Ranked 2nd in unmet need 	<ul style="list-style-type: none"> 🚫 Do not live near public transportation (18) 🚫 Must take more than one bus to the clinic (16) 🚫 Hard to take a bus if ill (14) 🚫 Other (15): <ul style="list-style-type: none"> ▪ Don't know who to ask about this ▪ No money (3) ▪ Don't know about this service (2) ▪ Don't qualify ▪ Hard to find ▪ Don't know where to get this service ▪ Have low back pain ▪ Was never offered a bus pass ▪ I have a car and did not know I may qualify for bus fares ▪ No one has passes ▪ Not always available ▪ Sometimes not enough appointments

Transportation to Medical Care – Van Service

Van service was identified as sixth highest unmet need of the 24 services identified in this survey. Approximately one-third of respondents used this service. Most commonly identified barriers included convenience and wait times.

Use/Access	Need	Most Common Barriers (n=48)
<ul style="list-style-type: none"> 🚫 33% get transportation to medical care from a van service 🚫 13% of those who use if found it somewhat hard or hard to get 	<ul style="list-style-type: none"> 🚫 22% (37) who do not use a van service say they need it 🚫 Ranked 6th in unmet need 	<ul style="list-style-type: none"> 🚫 Availability of this service (23) 🚫 Making appointments in advance (12) 🚫 Waiting time too long (9)



Translation or Interpretation

Translation services were ranked low in use, access and unmet need. However, only English speakers were able to complete the survey, making the results subject to question. A Spanish survey would likely have produced more useful results.

Use/Access	Need	Most Common Barriers (n=6)
<ul style="list-style-type: none"> ⓧ 15% use translation services ⓧ Less than five found it somewhat hard or hard to get 	<ul style="list-style-type: none"> ⓧ 2% (5) who do not get translation services say they need it ⓧ Ranked 20th in unmet need 	<ul style="list-style-type: none"> ⓧ Didn't know about the service (5)

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?

Responses are summarized in Tables IV.1 through IV.4 and Figures IV.1 through IV.4 below.

- ⓧ Fifty two (21%) identified services that would facilitate engagement and retention in medical care. These included dental care (40%), transportation to medical care (58%), mental health services (40%) and support services for daily living such as food, financial assistance and rent subsidies.
- ⓧ When asked if there are any services used in the past and still needed but no longer able to get, 34 (14%) responded "Yes." By demographic category, males, whites, older adults and Passaic County residents reported greatest unmet need.
- ⓧ Of the 34 respondents who identified services they still need but are unable to get, the most frequently identified services were dental care (50%), nutrition and food bank (41%), and housing subsidies (38%).



Figure IV.1

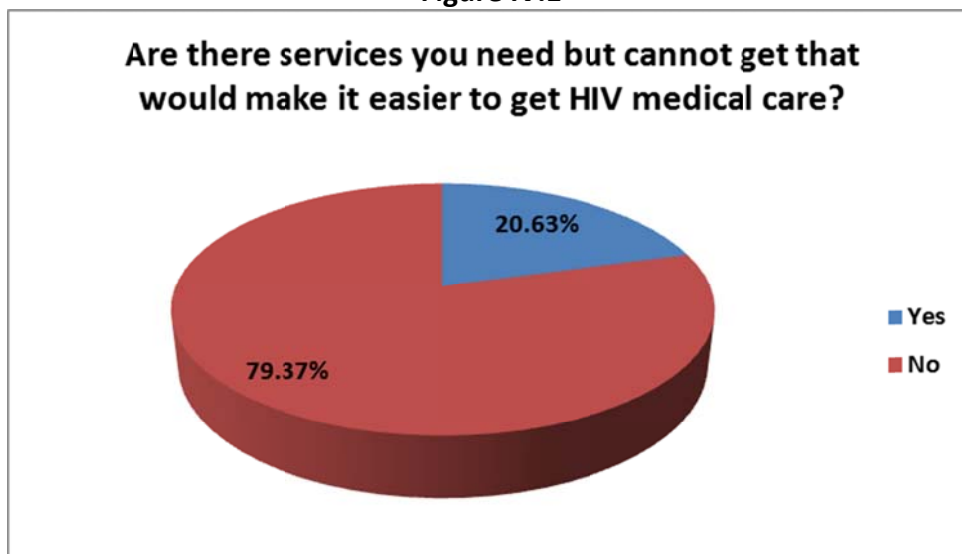


Table IV.1

Are there any services you need but cannot get that would make it easier to get HIV medical care?				
	Yes		No	
N= 252	Number	Percent	Number	Percent
Total Sample	52	20.63%	200	79.37%
Male	25	48.08%	134	67.00%
Female	26	50.00%	65	32.50%
Transgender	*	1.92%	*	0.50%
White	22	42.31%	95	47.50%
Black/African-American	29	55.77%	98	49.00%
Other	*	1.92%	7	3.50%
Hispanic	16	30.77%	64	32.00%
< 25	*	1.92%	*	1.50%
25-44	20	38.46%	45	22.50%
>45	31	59.61%	152	76.00%
Bergen County	8	15.38%	47	23.50%
Passaic County	39	75.00%	139	69.50%
Other	5	9.62%	14	7.00%

* Less than five.



Table IV.2

What services would make it easier to get HIV medical care?		
	Answer	
n= 52	Number	Percent
Total Sample (n)	52	20.6%
Dental care	33	63.5%
Transportation to medical care	30	57.7%
Mental health services	21	40.4%
Food bank	21	40.4%
Help with paying your rent or mortgage	21	40.4%
Emergency financial assistance for utilities or food	20	38.5%
Help paying for housing in an emergency	16	30.8%
Help paying for your HIV medications	14	26.9%
If you have Health Insurance, help paying or it	13	25.0%
Help paying for co-pays and deductibles	13	25.0%
Nutrition counseling	12	23.1%
Meals delivered to your home	12	23.1%
Legal services	10	19.2%
Health care services at home	9	17.3%
Education to help you follow your HIV medical treatment	9	17.3%
Case management	8	15.4%
Rehabilitation services (Physical Therapy, Occupational Therapy or Speech Therapy)	8	15.4%
Help getting HIV services after diagnosis	7	13.5%
Outpatient substance abuse treatment	7	13.5%
Education about HIV and how to reduce the risk	7	13.5%
Help with disclosing my HIV status	7	13.5%
Residential substance abuse treatment	6	11.5%
Transportation to substance abuse treatment	6	11.5%
Inpatient medical detox	5	9.6%
Child care services	5	9.6%
Translation services	5	9.6%
Medical day care for adults	*	7.7%

* Less than five.



Figure IV.2

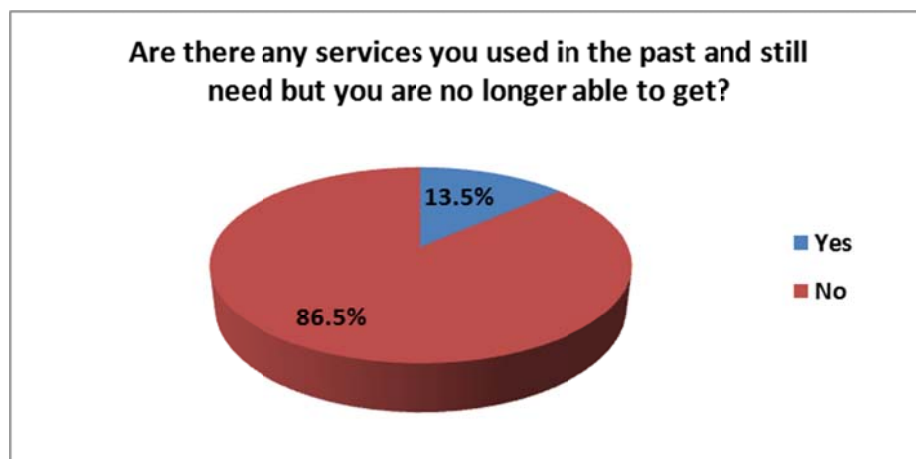


Table IV.3

Are there any services you used in the past and still need but you are no longer able to get?				
	Yes		No	
N= 252	Number	Percent	Number	Percent
Total Sample	34	13.5%	218	86.5%
Male	20	7.9%	139	55.2%
Female	14	5.6%	77	30.6%
Transgender	0	0.0%	*	0.8%
White	18	7.1%	99	39.3%
Black/African-American	16	6.3%	111	44.0%
Other	0	0.0%	8	3.2%
Hispanic	9	3.6%	71	28.2%
< 25	*	0.4%	*	1.2%
25-44	8	3.2%	57	22.6%
>45	25	9.9%	158	62.7%
Bergen County	8	3.2%	47	18.7%
Passaic County	25	9.9%	153	60.7%
Other	*	0.4%	18	7.1%

* Less than five.



Table IV.4

What services do you still need but are no longer able to get?		
	Answer	
N= 252	Number	Percent
Total Sample	34	100.0%
Dental care	17	50.0%
Nutrition counseling	14	41.2%
Food bank	14	41.2%
Help with paying your rent or mortgage	13	38.2%
Emergency financial assistance for utilities or food	11	32.4%
Transportation to medical care	10	29.4%
Meals delivered to your home	8	23.5%
Help paying for housing in an emergency	8	23.5%
Help paying for your HIV medications	8	23.5%
Mental health services	8	23.5%
If you have Health Insurance, help paying for it	6	17.7%
Case management	5	14.7%
Legal services	5	14.7%
Other transportation	5	14.7%
HIV Medical Care Visits	*	11.8%
Transportation to substance abuse treatment	*	11.8%
Medical day care for adults	*	11.8%
Outpatient substance abuse treatment	*	8.8%
Health care services at home	*	8.8%
Education to help you follow your HIV medical treatment	*	5.9%
Education about HIV and how to reduce the risk	*	5.9%
Translation services	*	5.9%
Help getting HIV services after diagnosis	*	5.9%
Residential substance abuse treatment	*	2.9%
Rehabilitation services (PT, OT or speech)	*	2.9%
Medical detox	0	0.0%
Child care services	0	0.0%

* Less than five.



Figure IV.3

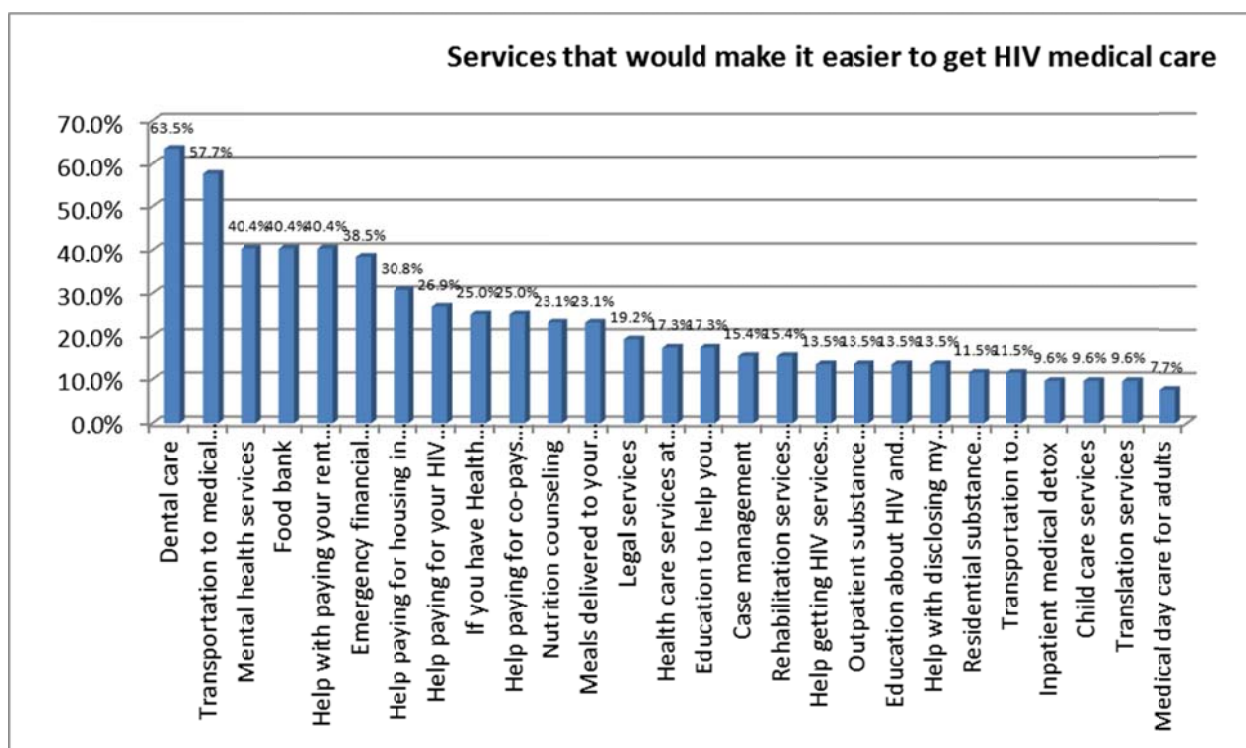
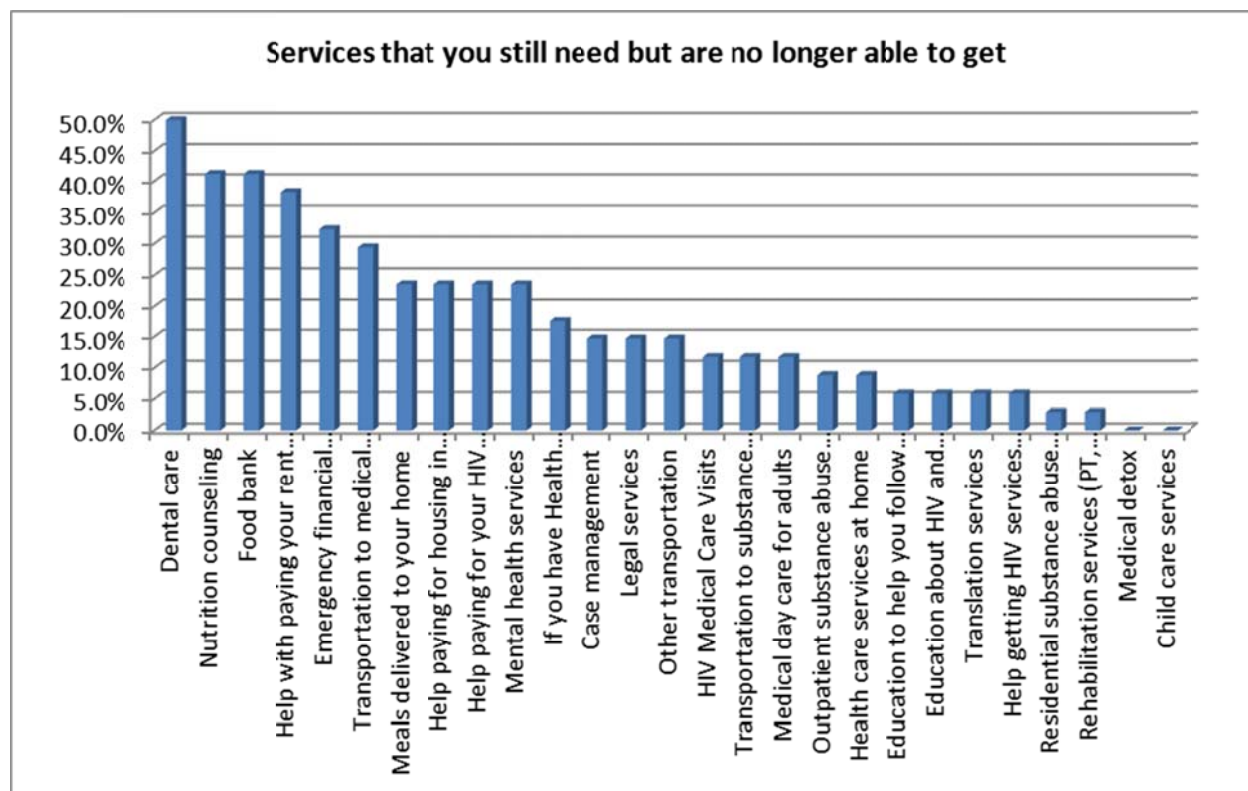




Figure IV.4





B. OUT-OF-CARE SERVICE USE, ACCESS, NEEDS AND BARRIERS

The out-of-care interviews provided information on service use, access, needs and barriers. When asked what services were needed to get in and stay in care, subjects identified a variety of medical and support services. Medical assistance included adherence advice, specialty care, mental health treatment and nutritional advice. Support services included housing, transportation and psychosocial support. A need for case management was implied from one interview.

Q4: What services did you need to get and stay in care?

- ✘ Housing (2 respondents);
- ✘ Food;
- ✘ Specialists for co-morbid conditions;
- ✘ Mental health counseling;
- ✘ Help with insurance;
- ✘ Support group or someone to talk to (2 respondents).

When asked if their needs were changing, answers varied. Medical problems sometimes changed as did their social support needs. A common theme among the subjects centered on the benefits of receiving help, either medical or social. All spoke positively about their improving health after re-engaging in HIV medical care and, just as importantly, experiencing improvements in their daily lives. Barriers persist, however, especially with regard to food and transportation.

Q5: Are your needs changing?

- ✘ My needs are becoming fulfilled, and I'm seeing all my doctors now.
- ✘ Now that I am in care, I think that everything is rolling along fine.
- ✘ I'm getting depression medicine.
- ✘ Support groups, a social worker, food, transportation...all are needed now.
- ✘ Getting nutritional supplements
- ✘ Support groups or someone to talk to (2 respondents)

At the conclusion of the interview, subjects were asked to identify specific service needs. Eight stated that services were needed to make it easier to get HIV medical care. When asked about specific services, six out of 25 service categories were identified by more than half of those interviewed. Nutritional counseling, food bank, and treatment adherence counseling were mentioned by seven respondents. Dental care and housing assistance was mentioned by six, and transportation was identified by five (Table IV.5).



Table IV.5

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

Yes	8
No	*

*Less than five.

B. What services would make it easier to get HIV medical care?

N = 10	Count
Help paying for your HIV medications	*
Dental Care	6
Help getting HIV services after diagnosis	*
If you have health insurance, help paying for it	*
Health care services at home	*
Mental health services	*
Nutritional counseling	7
Food bank	7
Meals delivered at home	*
Outpatient substance abuse treatment	*
Residential substance abuse treatment	*
Medical detox	*
Education to help you follow your HIV treatment	7
Case management	*
Childcare services	0
Emergency financial assistance for utilities, food, medications	*
Help paying your rent or mortgage	6
Help paying for housing in an emergency	*
Education about HIV and how to reduce the risk	*
Legal services	*
Translation services	*
Transportation to medical care	5
Transportation to substance abuse treatment	*
Rehabilitation services (PT, OT, or speech)	*
Medical day care for adults	*

*Less than five.



Subjects were asked about unmet need. When asked if there are any services used in the past, still needed but no longer able to get, eight answered “yes.” When asked about specific services, only transportation was identified by more than half of those interviewed. Four services – outpatient and residential substance abuse treatment, help paying for emergency housing and child care – were not identified by any of those interviewed (Table IV.6).

Table IV.6

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

Yes	8
No	*

B. What services did you use in the past and still need, but are no longer able to get?

N = 10	Count
HIV Medical Care Visits	*
Help paying for your HIV medications	*
Dental Care	*
Help getting HIV services after diagnosis	*
If you have health insurance, help paying for it	*
Health care services at home	*
Mental health services	*
Nutritional counseling	*
Food bank	*
Meals delivered at home	*
Outpatient substance abuse treatment	0
Residential substance abuse treatment	0
Medical detox	*
Education to help you follow your HIV treatment	*
Case management	*
Childcare services	0
Emergency financial assistance for utilities, food, medications	*
Help paying your rent or mortgage	0
Help paying for housing in an emergency	*
Education about HIV and how to reduce the risk	*
Legal services	*
Translation services	*
Transportation to medical care	5
Transportation to substance abuse treatment	*
Rehabilitation services (PT, OT, or speech)	*
Medical day care for adults	*

*Less than five.



V. RESOURCES AND CAPACITY

A. PROVIDER INVENTORY

A provider inventory was undertaken to assess the availability of HIV-related services in the two-county region. The inventory included listings from 133 service locations operated by 97 individual organizations across 25 categories of services. While all providers listed in the inventory extended services to persons with HIV, not all were targeted to the HIV/AIDS population. Of the 133, twenty (15%) offered HIV-targeted programs funded through the federal Ryan White Program (RWP). RWP funds were further distinguished by Parts A-F, each of which were supported by separate grant programs. The complete inventory is found in Appendix E.

The inventory was developed from secondary source materials available from various directories including: the New Jersey HIV/AIDS Resource Directory (NJHARD) managed by the New Jersey HIV Prevention Community Support Initiative of Rutgers University (CPSDI),¹⁷ the New Jersey State Division of Mental Health and Addiction Services (DMHAS) Mental Health Directory,¹⁸ and MHAS Addiction Services Treatment Directory,¹⁹ and other New Jersey Department of Health websites.²⁰ To provide greater detail, additional information was obtained directly from Ryan White providers located in the two counties.

Technical Notes

For purposes of the comprehensive needs assessment, the inventory serves as a tool to determine gaps in access to HIV services in the two-county region. The inventory is considered limited in scope and will be expanded at a later date to include a complete listing of important information such as hours of operation, languages spoken, access procedures, etc. This information is being compiled by the NJHPCSI in accordance with the Centers for Disease Control National Prevention Information Network (NPIN) database and will be incorporated into this directory when available. While efforts were made to include as many service sites as possible, no claim is made as to its completeness.

Services identified for each site are listed according to information from the websites of the respective agencies and sources listed above. Only Ryan White agencies were asked to verify their service offerings.

¹⁷ <http://hpcpsdi.rutgers.edu/dir/index.php>

¹⁸ <http://www.state.nj.us/humanservices/dmhs/news/publications/mhs/index.html>

¹⁹ <https://njsams.rutgers.edu/dastxdirectory/txdirmain.htm>

²⁰ <http://web.doh.state.nj.us/apps2/fhs/cphc/cphcSearch.asp>



An agency is listed as a Ryan White provider when it receives funds from a Ryan White grant program. All RWP parts are included in this inventory without specification. It is important to note that, although an agency may be identified as Ryan White, not all of its services may be funded from a Ryan White grant.

Agencies consist of community or hospital-based organizations only. Private practices are not included in the inventory. All agencies are direct service providers with exception of the City of Paterson Department of Human Resources that administers the Ryan White Part A, Minorities AIDS Initiative and HOPWA programs and serves as an informational or referral agency only.

Service category definitions normally vary from agency to agency. Definitions used for this inventory correspond to those of the NJHARD with some exceptions.²¹ In this inventory, the category of medical care is divided into two: (1) medical treatment where a physician and nurse provide direct medical treatment on site and (2) medical support where only screenings and/or referrals are provided. Case management is divided into two categories: (1) medical and (2) non-medical. Some agencies do not differentiate between medical and non-medical case management; thus, there may be overlap in services provided. This inventory also includes recent additions to the list of service categories in NJHARD such as syringe access program and early intervention. Definitions are provided on page 6.

B. GAPS ANALYSIS

The inventory documented a wide network of services available to persons living with HIV, with relatively few significant gaps. Service sites were comparably positioned in each county with 66 in Bergen and 67 in Passaic. RWP sites were less balanced – 14 in Passaic and 6 in Bergen – which reflects the greater portion of the epidemic in Paterson and Passaic. (Table V.1)

Table V.1
Service Sites Summary

	Bergen	Passaic	Total
Sites	66	67	133
RWP	6	14	20
Non-RWP	60	53	113

Service categories were similarly distributed across the two counties, with some exceptions (Table V.2):

- ⚡ Non-medical case management was less available in Bergen County than in Passaic County (3 sites in Bergen vs. 10 in Passaic).

²¹ <http://hpcpsdi.rutgers.edu/dir/index.php>



- ⓧ There was no documented prevention service located in Bergen County.
- ⓧ One syringe access program, located in Passaic County, served the two-county region.
- ⓧ Support groups were more numerous in Bergen County (22 in Bergen vs. 13 in Passaic).

There appears to be an abundance of core services in both counties. Thirty-one sites offer medical treatment and 37 sites claimed to offer adherence/compliance with HIV medications. Medical case management is available in both counties. The inventory counts 81 mental health sites and 37 substance abuse treatment sites in the two counties. Oral health/dental care is available at 11 sites, six in Bergen and five in Passaic. Support services, including financial assistance, are available in both counties but to a greater degree in Bergen County.

Table V.2
Service Categories by County

Service Category	Bergen	Passaic	Total
Adherence/Compliance with HIV Medications	25	12	37
Case Management – Medical	18	16	34
Case Management - Non-Medical	3	10	13
Counseling-Personal and Family	26	15	41
Early Intervention Services	3	4	7
Education	32	19	51
Faith Initiative Project	4	5	9
Financial Assistance	21	11	32
Food Services	28	15	43
HIV Testing	6	12	18
Housing Assistance	25	14	39
Legal Assistance	22	10	32
Medical Treatment ¹	17	14	31
Medical Treatment -Support	13	6	19
Mental Health	40	41	81
Oral Health/Dental Care ¹	6	5	11
Outreach: Street/Community	22	16	38
HIV Prevention	0	3	3
Substance Abuse Treatment	17	20	37
Support Group	22	13	35
Group - Peer	1	2	3
Support Group – Psycho-Social	1	1	2
Syringe Access Program	0	1	1
Translation	20	7	27
Transportation	17	12	29



A review of the RWP agencies provides a closer look at access to HIV-targeted services (Table V.3).²² In general, most service categories are offered by RWP agencies in both counties. More services are offered in Passaic County than Bergen County, again representative of the greater epidemic in Paterson and Passaic. Some gaps are noted:

- ✂ HIV prevention in Bergen County;
- ✂ Syringe access in Bergen County;
- ✂ Faith Initiative Project in both counties.

Table V.3
Service Category by County and Ryan White

Service Category	RWP-Bergen	Non-RWP Bergen	RWP-Passaic	Non-RWP Passaic
Adherence/Compliance with HIV Medications	1	24	3	9
Case Management – Medical	1	17	7	9
Case Management - Non-Medical	1	2	7	3
Counseling-Personal and Family	3	23	3	12
Early Intervention Services	3	0	4	0
Education	2	30	3	16
Faith Initiative Project	0	4	0	5
Financial Assistance	0	21	2	9
Food Services	1	27	0	15
HIV Testing	3	3	7	5
Housing Assistance	1	24	3	11
Legal Assistance	1	21	1	9
Medical Treatment ¹	1	16	2	12
Medical Treatment-Support	1	12	0	6
Mental Health	2	38	6	35
Oral Health/Dental Care ¹	2	4	2	3
Outreach: Street/Community	2	20	6	10
HIV Prevention	0	0	3	0
Substance Abuse Treatment	2	15	6	14
Support Group	1	21	2	11
Support Group - Peer	0	1	0	2
Support Group – Psycho-Social	0	1	0	1
Syringe Access Program	0	0	1	0
Translation	2	18	2	5
Transportation	2	15	1	11

¹ Excludes private practices.

²² As stated, an RWP agency may not offer every identified service through RWP funding.



Housing assistance is available in both counties. Housing Opportunities for Persons with HIV/AIDS (HOPWA), administered through the United States Department of Housing and Urban Development (HUD) and locally by the City of Paterson Department of Human Resources and the Housing Authorities of both counties, provides short and long term housing, housing case management, transportation, legal services and food for persons living with HIV/AIDS. Four HOPWA providers are located in the Bergen-Passaic region.

Information on hours of operation and languages spoken was available for 62 of the 133 sites listed in the inventory. A review of the 62 sites was undertaken to determine possible access problems. In general, evening and Saturday hours are in short supply, creating potential access problems for persons working full time. Forty-four agencies (71%) are open five days Monday through Friday; the remaining 18 do not have full-time hours. Evening hours are available at eleven sites, and five (8%) are open Saturdays. Six sites reported operating 24/7.

Most agencies offer services in foreign languages. Seventeen (27%) reported English speaking capacity only; the others reported at least one foreign language available. Spanish speakers are present at 42 of the 62 agencies (68%). Other foreign languages spoken at one or more agencies include Russian Hindi, Polish, Korean, Arabic and French.



C. CORE, SUPPORT AND PREVENTION SITES

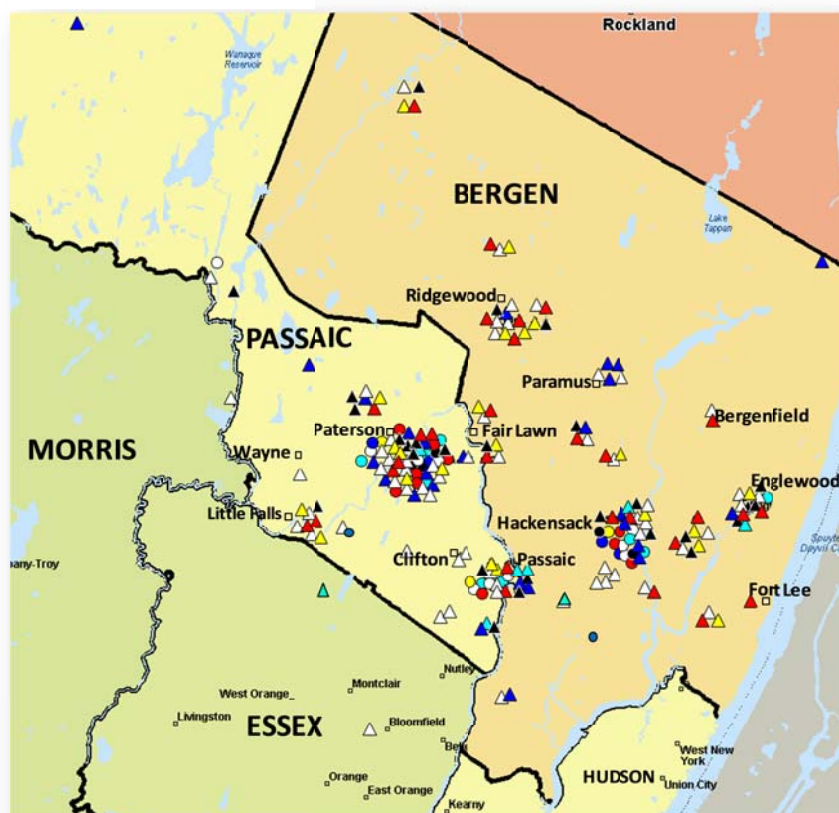
Bergen / Passaic HIV Service Providers CORE SERVICES

RYAN WHITE SERVICES

- Adherence & Compliance w/HIV Meds
- Case Mgmt: Medical
- Medical Treatment
- Mental Health
- Oral Health: Dental Care
- Substance Abuse: Treatment & Counseling

NON-RYAN WHITE SERVICES

- ▲ Medical Treatment
- ▲ Adherence/Compliance with HIV Medications
- ▲ Case Mgmt: Medical
- △ Mental Health
- ▲ Oral Health: Dental Care
- ▲ Substance Abuse: Treatment & Counseling





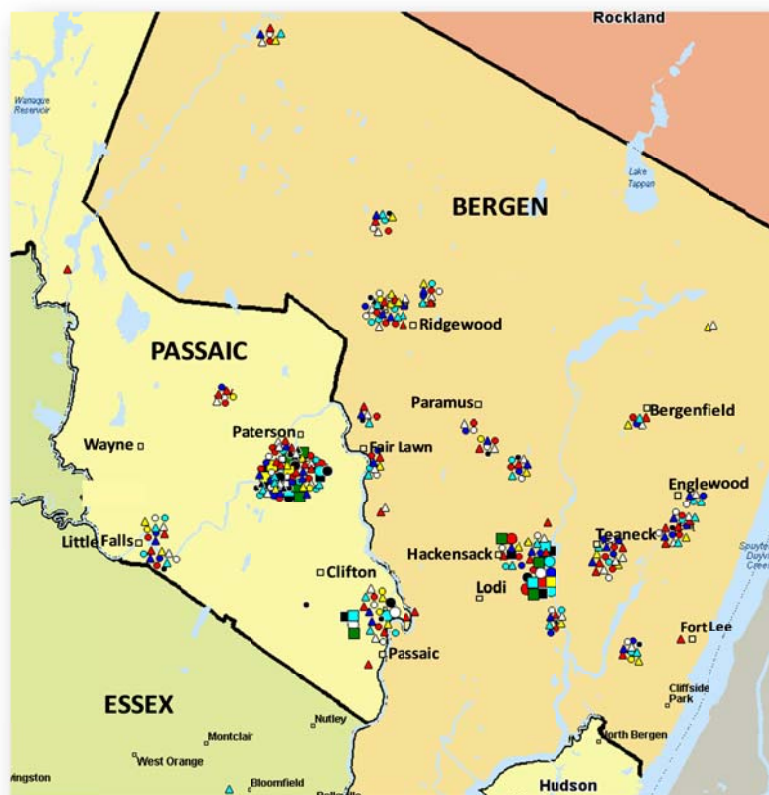
Bergen/ Passaic HIV Service Providers SUPPORT SERVICES

RYAN WHITE SERVICES

- Case Mgmt: Non Medical
- Education
- Financial Assistance
- Food Services
- Housing & Shelter
- Legal Assistance
- Counseling: Personal & Family
- Medical Support
- Support Group
- Translation
- Transportation

NON-RYAN WHITE SERVICES

- Medical Support
- Counseling: Personal/Family
- Faith Initiative Project
- Support Group
- Support Group: Peer
- Support Group: Psycho Social
- Translation
- Transportation
- ▲ Case Mgmt: Non Medical
- ▲ Education
- ▲ Financial Assistance
- ▲ Food Services
- ▲ Housing & Shelter
- ▲ Legal Assistance



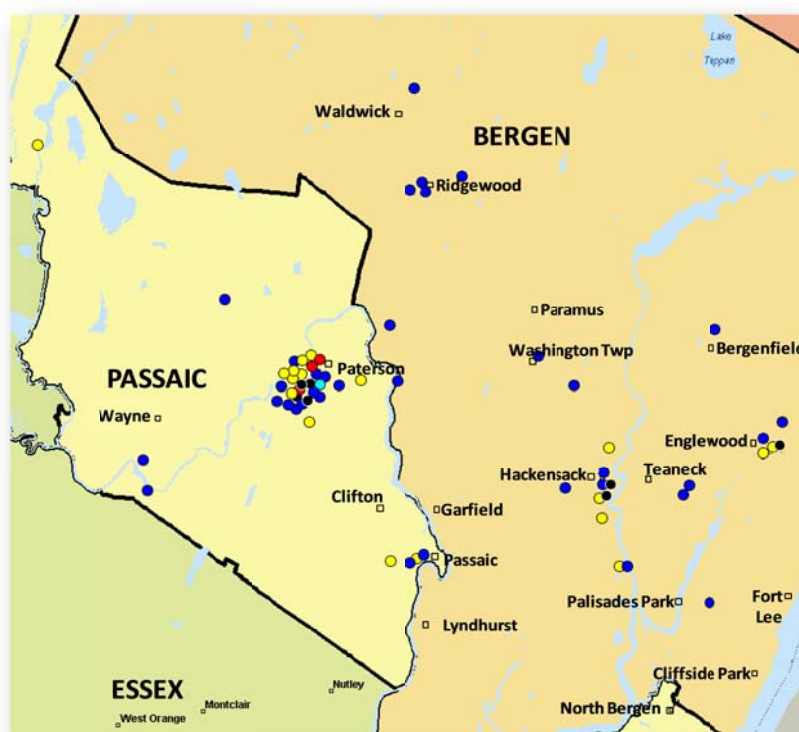


Bergen / Passaic HIV Service Providers PREVENTION SERVICES

SERVICES*

- Early Intervention Linkage To Care
- HIV Prevention
- HIV Testing
- Outreach: Street Community
- Syringe Access Program

*Includes Ryan White & Non-Ryan White Providers





VI. EARLY IDENTIFICATION OF INDIVIDUALS LIVING WITH HIV/AIDS

HRSA has instructed Ryan White grantees to assess and develop a plan to address the “Unaware,” i.e., persons who may or may not be HIV-positive and do not know their status. As this population is often hidden from the network of care and services for persons living with HIV/AIDS, it is important to gain a rudimentary understanding of where and how to identify them. To that end, key informant interviews and a general population survey were undertaken to provide profiles of the Unaware and programs to address this population.

A. KEY INFORMANT INTERVIEWS

Key informants were asked about the current situation, barriers and challenges, and suggestions with regard to persons who are unaware of their HIV status. They were also about outreach, HIV testing and early intervention services. The following summarizes their remarks.

The Unaware

General Comments

- ✚ Broad misconceptions about HIV exist in the communities.
- ✚ Most efforts continue to target the “at risk” population.
- ✚ Cultural barriers must be taken into account; Asian communities in Bergen County, Middle Eastern communities in Paterson/Passaic; Latino community is closed.
- ✚ At risk population seems to be getting younger. They play sex games.
- ✚ Those who have a suspicion will eventually get tested.
- ✚ Female partners of men in the “down-low” may be unaware of their risks.
- ✚ Economically depressed areas may be breeding grounds for HIV.
- ✚ Young and old – they all need to be educated.

Suggestions

- ✚ Social media is the cheapest, most effective method of communication (especially Twitter).
- ✚ Use Latino radio and TV channels.
- ✚ Use churches to reach the unaware population.
- ✚ Use outreach workers who can relate.
- ✚ Fight stigma by equating HIV with other chronic diseases such as cancer. To reduce stigma, HIV must be mainstreamed into generalized services.
- ✚ The millennium generation can be reached through social marketing.
- ✚ Educate the general community about the need for HIV testing, and availability of mandated insurance coverage.



Outreach, Testing and Early Intervention Services (EIS)

Current Situation

- ✘ EIS is effective as long as there is a health care system in place.
- ✘ 70% don't share their HIV status with partners or close relationships; 30% will share, even on the first date.
- ✘ Many don't want to know their status because it may interfere with their social networks,
- ✘ MSM community is the hardest to reach. They will change their identity to remain closed.
- ✘ Some think they don't need to be tested because they were negative two or three years ago.
- ✘ Cultural differences present different challenges and need different solutions.
- ✘ Individuals may test in New Jersey but access care in New York. Alternatively, people tested elsewhere may not know where to get care.
- ✘ Peer-to-Peer may help to engage in testing; however, outreach is moving away from one-on-one activity on the street and more toward social media messages. Someone "similar in age or just a little bit older" may be most effective.
- ✘ Need more prevention services, education to eliminate or reduce stigma
- ✘ There are no outreach workers under age 25 in the TGA.
- ✘ EIS should be provided by a "professional", someone with a degree and experience with mental health treatment.
- ✘ Hotlines are not used.
- ✘ Having incentives for testing in high risk settings is effective, such as concert tickets or prizes.

Program Development

- ✘ Key informants see a conflict between targeting the "at risk" and reaching the wider community – how to do both? Testing in the Emergency Department is important to support.
- ✘ Counseling, Testing and Referral (CTR) is piloting 24-hour linkage.
- ✘ A CDC strategy known as ARTAS is a new strength-based model used by case managers to encourage disclosure and testing.
- ✘ Test-to-Treat is being piloted in New Jersey; it joins the community-based testing site with a care site for 24-hour linkage in care.
- ✘ EIS needs to include counseling and testing on site.
- ✘ Provide continuity between inpatient and outpatient care to encourage engagement and retention. Also, provide confidentially friendly environments.
- ✘ "Status is Everything" in Newark has attracted attention.
- ✘ Coordination with FQHC; broadening testing in the ED; other system changes under consideration.



Suggestions

- ✚ “There can’t be too many peer/patient navigators.” They can’t work from their desk, though.
- ✚ Food is a time-honored way to reach them.
- ✚ Substance abuse treatment and housing can help if provided.
- ✚ Reach out to colleges, especially those with LGBT outreach and support services.
- ✚ Incentives are effective in getting tested.

B. GENERAL POPULATION SURVEY

Introduction

This survey represents the first attempt to test the level of knowledge, attitude and HIV testing practices of those who are not HIV-positive. The assessment responds to a portion of the National AIDS Strategy that seeks to reduce new HIV infections by increasing public awareness and prevention of HIV.

The Planning Council decided to implement a short general knowledge survey, canvassing those who are not HIV-positive but may be at risk for the disease. In the absence of a full, general population survey which would go beyond the scope and budget of the comprehensive needs assessment, the decision was to begin by seeking out non-infected persons from the two-county region, normally of low income and with an interest in health-related matters. The design and methodology are described in Chapter I. Detailed tables and verbatim responses are found in Appendix D.

Demographic Characteristics of the Survey Sample

The sample consisted of 256 (N) completed survey responses representing low income individuals from the two-county region. In many aspects, the sample differs from the HIV-infected population. All respondents reported to be HIV-negative. General characteristics of the respondents depict a population reflective of the minority communities in which they reside and the primary care clinics where they receive medical care.

Gender

- ✚ Females outnumbered males by more than two to one (70% vs. 30%) (Figure VI.1 and Table VI.1)



Figure VI.1
Survey Sample by Gender

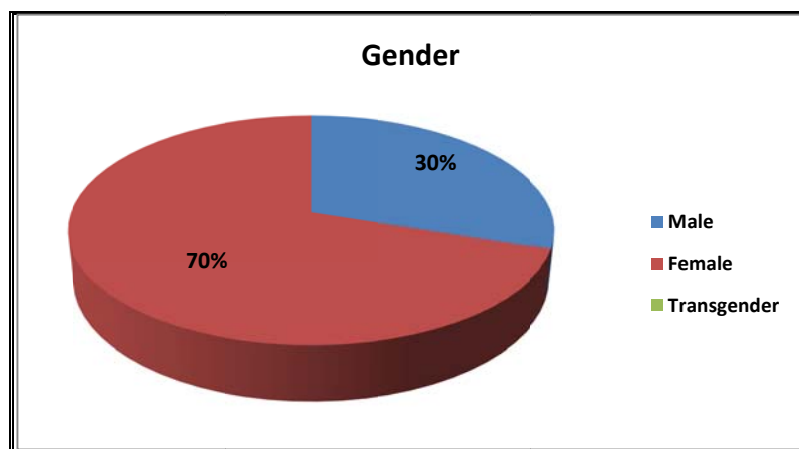


Table VI.1
Survey Sample by Gender

What is your gender?		
N=256	Count	Percent
Male	77	30%
Female	179	70%
Transgender	0	0%

Age

- ⓧ All respondents were age 13 or older.
- ⓧ More than half were between 25 and 44 years of age.
- ⓧ Women tended to be younger with 29% of females over age 45 compared to 40% of males (See Detailed Data Tables Appendix D).
- ⓧ By race, 50% of white, non-Hispanics were below age 35 compared to 40% of Black, non-Hispanics and 45% of Hispanics (See Detailed Data Tables Appendix D).
- ⓧ Twenty percent of white, non-Hispanic respondents were over age 55 compared to 15% of Hispanics and 16% of Black, non-Hispanics (Figure VI.2 and Table VI.2).



Table VI.2
Survey Sample by Age

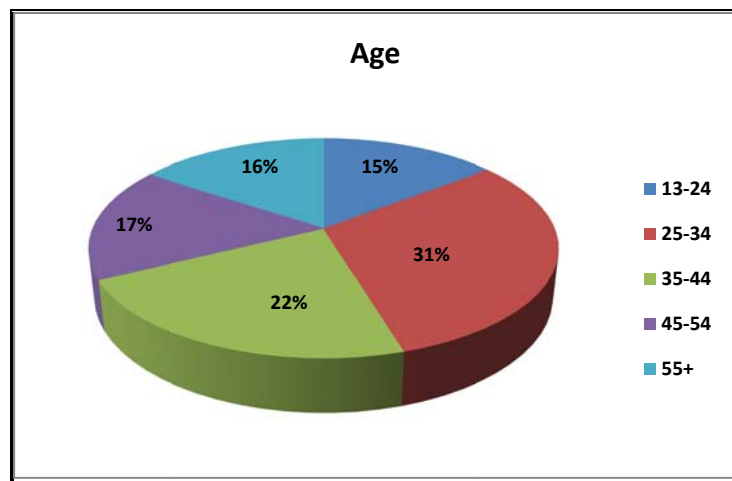


Table VI.2
Survey Sample by Age

How old are you?		
N=256	Count	Percent
13-24	15%	37
25-34	31%	79
35-44	22%	57
45-54	17%	43
55+	16%	40

Race/Ethnicity

- ✚ More than 70% of the survey sample consisted of persons of color. Whites and Blacks were represented in nearly equal proportion (27% vs. 28%).
- ✚ Hispanics comprised nearly two-thirds (64%) of all respondents (Figure VI.3 and Table VI.3).



Figure VI.3
Survey Sample by Race and Ethnicity

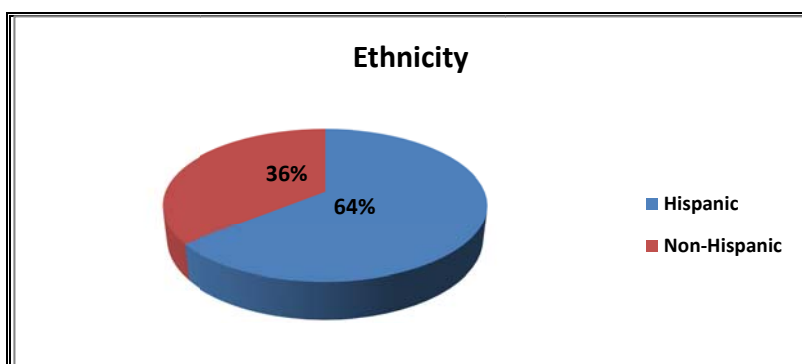
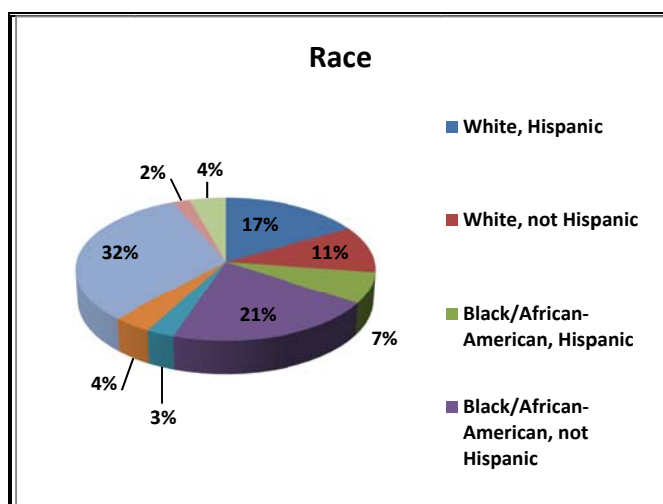


Table VI.3
Survey Sample by Race/Ethnicity

What is your race?		
N=256	Count	Percent
White, Hispanic	43	17%
White, not Hispanic	27	11%
Black/African-American, Hispanic	18	7%
Black/African-American, not Hispanic	53	21%
Asian or Pacific Islander	7	3%
More than one race	10	4%
Other, Hispanic	82	32%
Other, Not-Hispanic	5	2%
Don't know	11	4%
Are you Hispanic?		
Yes	164	64%
No	92	36%



Residence

- ✚ Two-thirds (66%) of respondents resided in Passaic County. Nearly half (48%) from Passaic County were from Paterson, and slightly less (43%) were from Passaic City, and the remainder from other parts of the county.
- ✚ Approximately one third (31%) resided in Bergen County. Hackensack accounted for 28% of Bergen County residents with the remainder from municipalities such as Garfield (6%), Lodi (4%), Elmwood Park (2%) and Lyndhurst (2%) (Figure VI.4 and Table VI.4. Detailed Data Tables are found in Appendix D.

Figure VI.4
Survey Sample by Residence

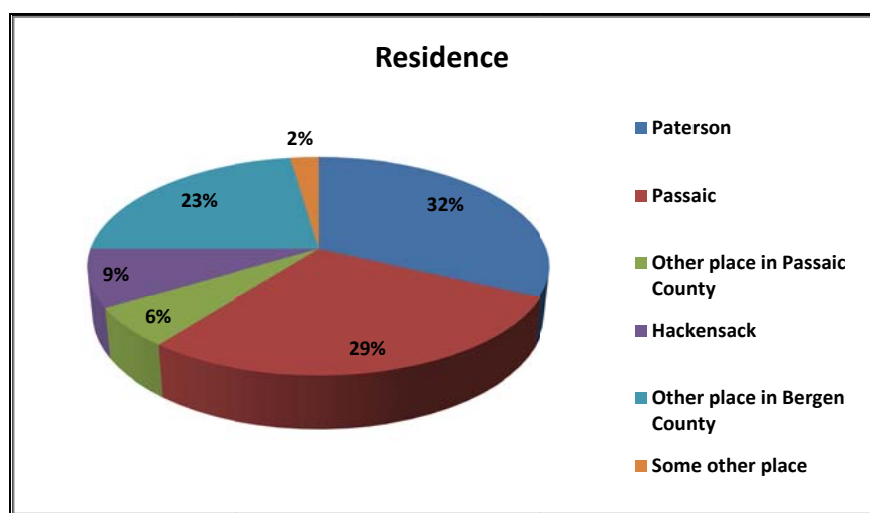


Table VI.4
Survey Sample by Residence

Where do you live?		
N=256	Count	Percent
Paterson	82	32%
Passaic	73	29%
Other place in Passaic County	15	6%
Hackensack	22	9%
Other place in Bergen County	58	23%
Some other place	6	2%



Sexual Orientation

- ✚ When asked their sexual orientation, 91% responded “heterosexual.” Gay, lesbian and bi-sexual orientation accounted for 3%. (Figure VI.5 and Table VI.5)
- ✚ No respondents were transgender.

Figure VI.5
Survey Sample by Sexual Orientation

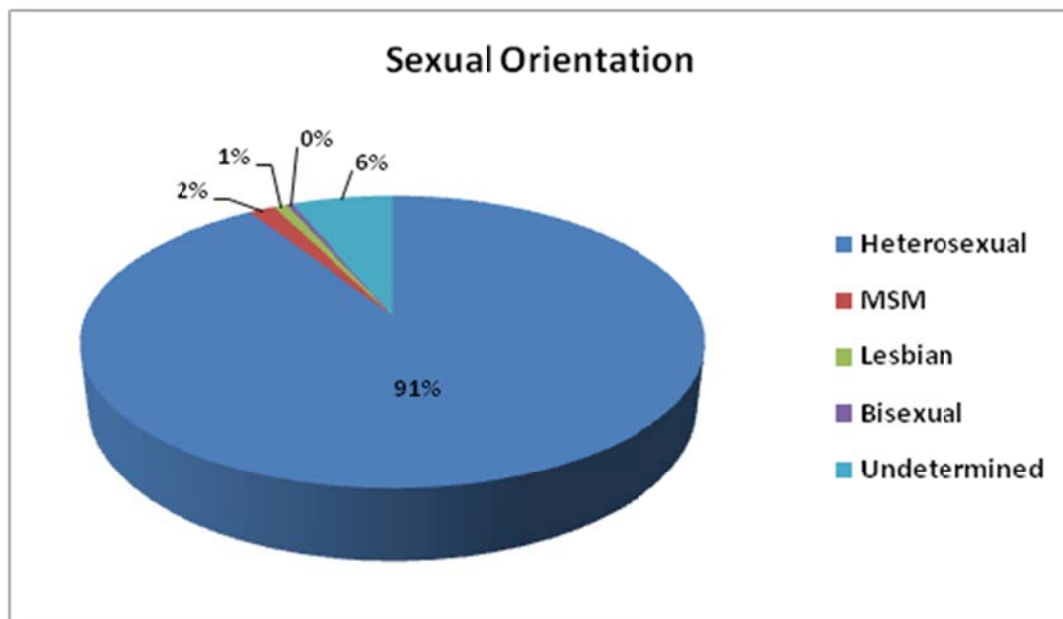


Table VI.5
Survey Sample by Sexual Orientation

N=256	Count	Percent
Heterosexual	233	91%
MSM	4	2%
Lesbian	2	1%
Bisexual	1	0%
Undetermined	16	6%



Knowledge and Attitudes about HIV/AIDS

Respondents were asked a series of questions about HIV testing and HIV/AIDS disease. Results depict a general awareness of HIV disease and HIV testing, knowledge of its causes and risk factors, and an understanding of stigma surrounding persons with HIV/AIDS.

HIV Testing

- ✚ When asked “Have you been tested for HIV in the past 12 months?”, 54% responded “Yes.” Responses differed by gender, race/ethnicity and age.
- ✚ A greater percentage of females were tested than males (58% vs. 43%).
- ✚ Hispanics (49%) and persons age 35-44 (37%) and over age 55 (40%) reported the lowest test rates.
- ✚ Highest test rates were reported by Blacks, (63%) and respondents below age 34 (68%). (Figure VI.6 and Table VI.6)

Figure VI.6
Have you been tested for HIV in the past 12 months?

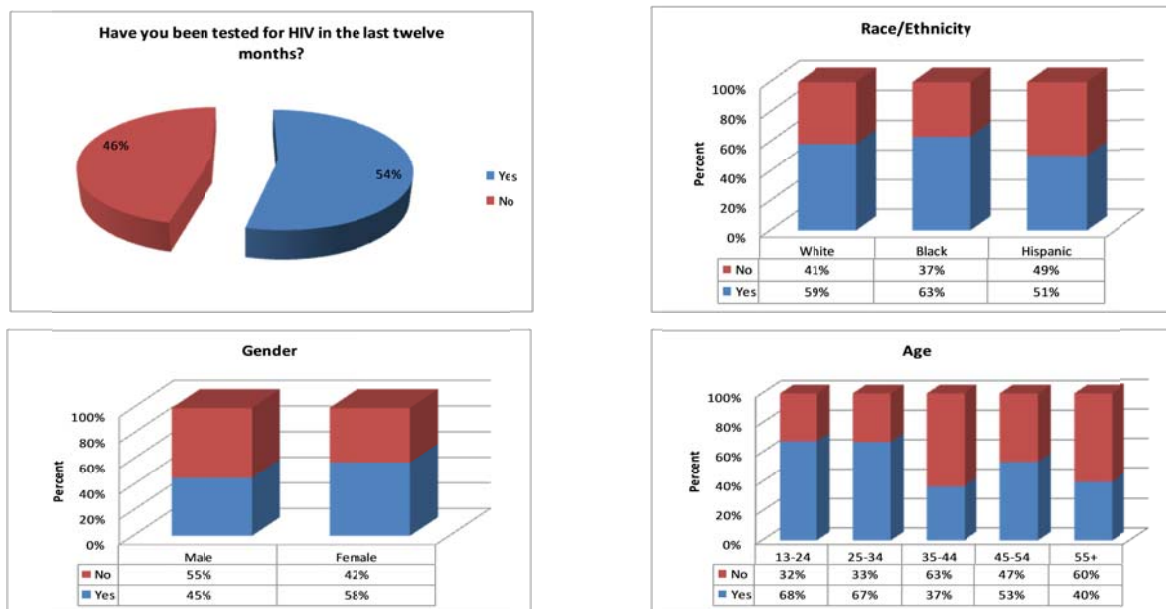




Table VI.6
Have you been tested for HIV in the last twelve months?

N=256	Total		Male		Female	
Yes	138	54%	35	45%	103	58%
No	118	46%	42	55%	76	42%

N=256	White		Black		Hispanic	
Yes	41	59%	45	63%	83	51%
No	29	41%	26	37%	81	49%

N=256	13-24		25-34		35-44		45-54		55+	
Yes	25	68%	53	67%	21	37%	23	53%	16	40%
No	12	32%	26	33%	36	63%	20	47%	24	60%

Knowledge of HIV/AIDS

- Respondents demonstrated a broad knowledge of HIV disease, its transmission via sexual contact or needle injection, and HIV testing.
- Responses did not differ significantly by gender, race/ethnicity or age (Figure VI.7-VI.9 and Table VI.7-VI.9).

Figure VI.7
You can get HIV/AIDS by having sex

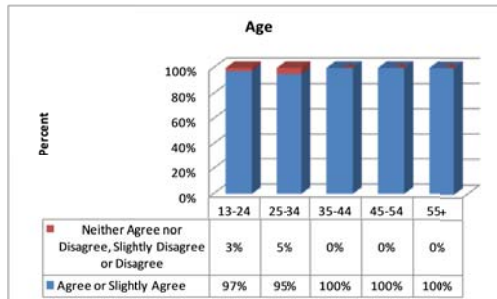
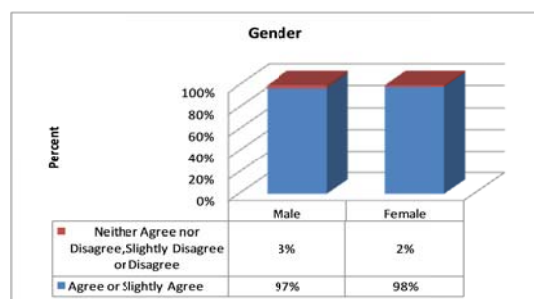
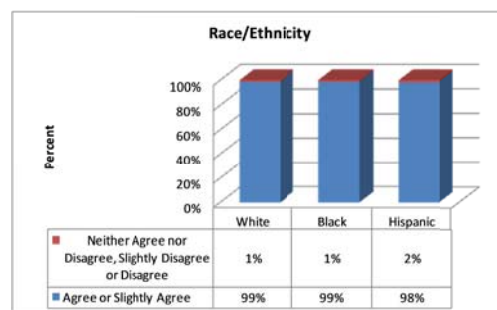
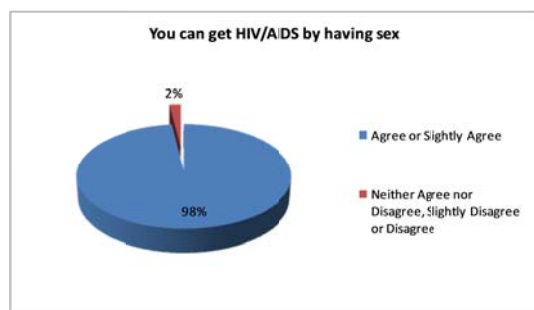




Table VI.7
You can get HIV/AIDS by having sex.

N=256	Total		Male		Female	
Agree or Slightly Agree	251	98%	75	97%	176	98%
Neither Agree nor Disagree, Slightly Disagree or Disagree	5	2%	2	3%	3	2%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	69	99%	70	99%	161	98%
Neither Agree nor Disagree, Slightly Disagree or Disagree	1	1%	1	1%	3	2%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	36	97%	75	95%	57	100%	43	100%	40	100%
Neither Agree nor Disagree, Slightly Disagree or Disagree	1	3%	4	5%	0	0%	0	0%	0	0%

Figure VI.8
You can get HIV/AIDS by using a drug-sharing needle.

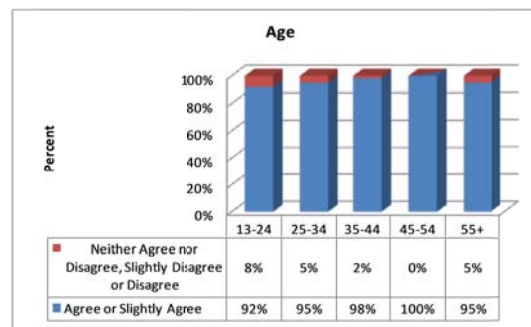
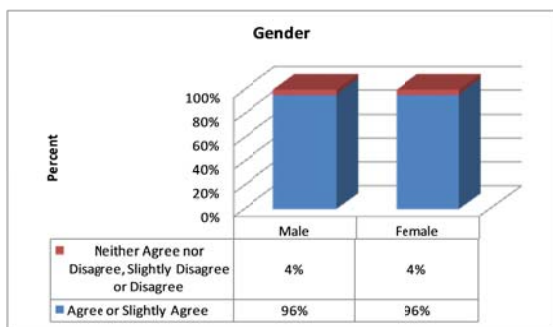
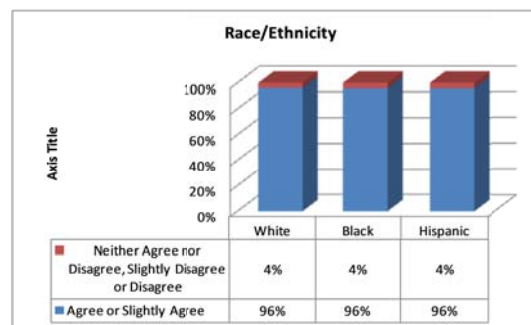
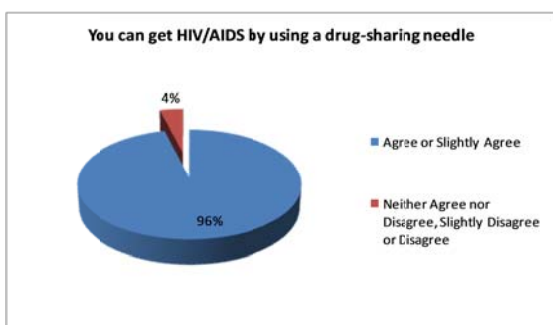




Table VI.8
You can get HIV/AIDS by using a drug-sharing needle.

N=256	Total		Male		Female	
Agree or Slightly Agree	246	96%	74	96%	172	96%
Neither Agree nor Disagree, Slightly Disagree or Disagree	10	4%	3	4%	7	4%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	74	98%	68	96%	157	96%
Neither Agree nor Disagree, Slightly Disagree or Disagree	3	4%	3	4%	7	4%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	34	92%	75	95%	56	98%	43	100%	38	95%
Neither Agree nor Disagree, Slightly Disagree or Disagree	3	8%	4	5%	1	2%	0	0%	2	5%

Figure VI.9
You can get tested for HIV.

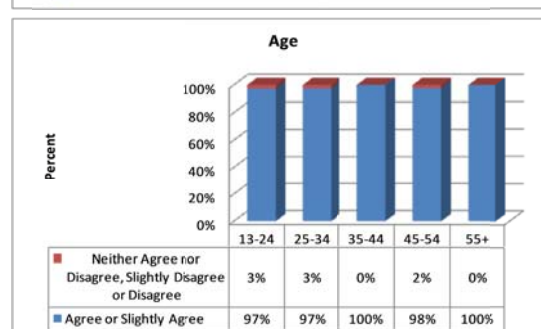
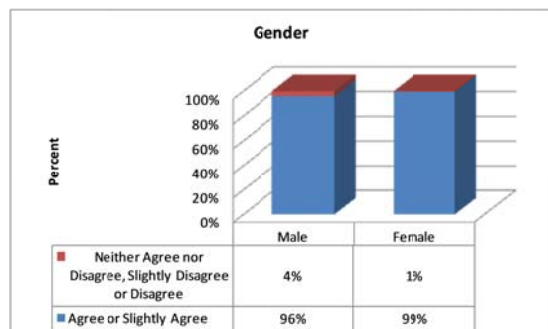
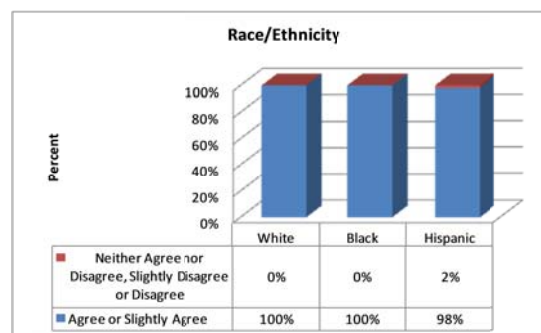
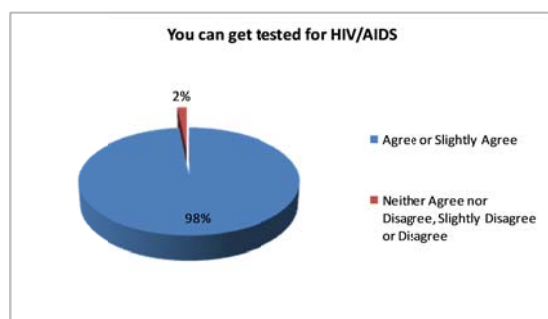




Table VI.9
You can get tested for HIV.

N=256	Total		Male		Female	
Agree or Slightly Agree	252	98%	74	96%	178	99%
Neither Agree nor Disagree, Slightly Disagree or Disagree	4	2%	3	4%	1	1%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	70	100%	71	100%	161	98%
Neither Agree nor Disagree, Slightly Disagree or Disagree	0	0%	0	0%	3	2%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	34	92%	75	95%	56	98%	43	100%	38	95%
Neither Agree nor Disagree, Slightly Disagree or Disagree	3	8%	4	5%	1	2%	0	0%	2	5%

- ✚ Most respondents (84%) believed that an HIV test is reliable (Figure VI.10 and Table VI.10).
- ✚ By gender, a greater percentage of females (87% vs. 78%) felt that HIV tests are reliable.
- ✚ By age, young respondents age 13-24 were least knowledgeable (78%) about HIV test reliability.



Figure VI.10
The medical test for HIV/AIDS will not always identify a recently-infected person.

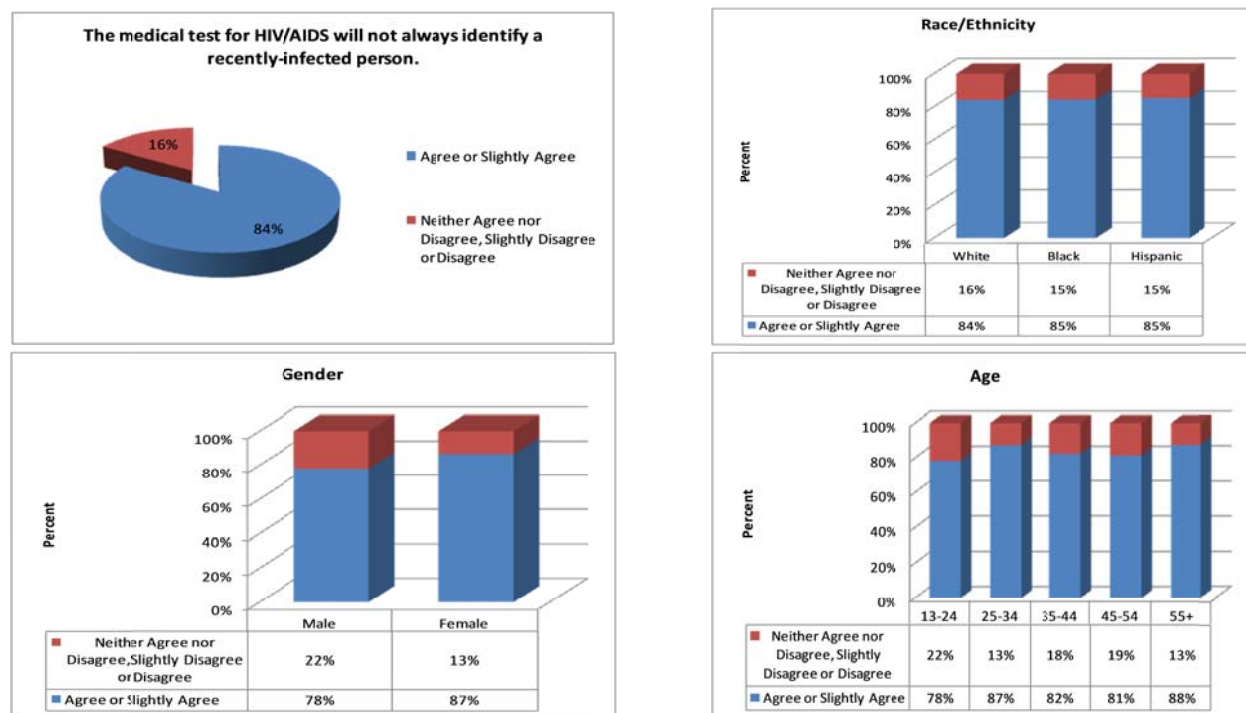


Table VI.10
The medical test for HIV/AIDS will not always identify a recently-infected person.

N=256	Total		Male		Female	
Agree or Slightly Agree	215	84%	60	78%	155	87%
Neither Agree nor Disagree, Slightly Disagree or Disagree	41	16%	17	22%	24	13%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	59	84%	60	85%	140	85%
Neither Agree nor Disagree, Slightly Disagree or Disagree	11	16%	11	16%	24	15%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	29	78%	69	87%	47	83%	35	81%	35	88%
Neither Agree nor Disagree, Slightly Disagree or Disagree	8	22%	10	13%	10	18%	8	19%	5	13%



- ✚ 81% of respondents believed that medical treatments for HIV/AIDS are effective (Figure VI.11 and Table VI.11).
- ✚ Cohorts that did not agree as uniformly about the effectiveness of HIV/AIDS medications included Hispanics (79%), respondents age 13-24 (76%) and mid-aged respondents age 45-54(79%).

Figure VI.11
There are effective medical treatments for those with HIV/AIDS.

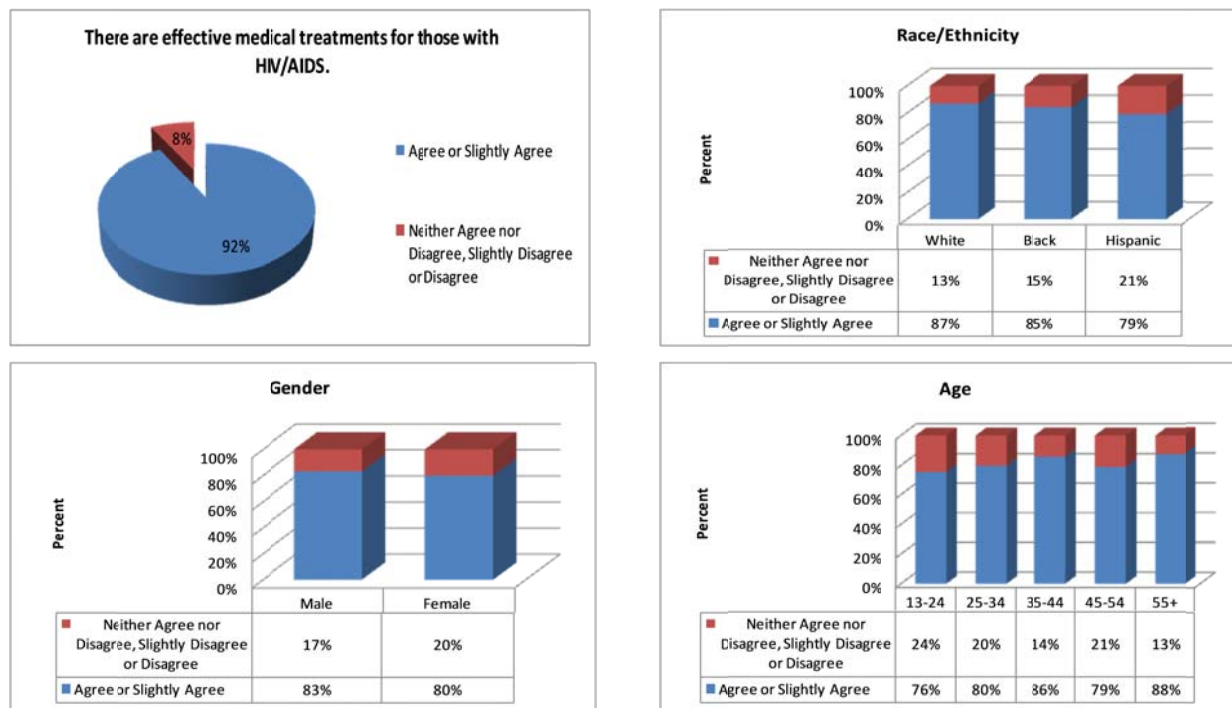




Table VI.11
There are effective medical treatments for those with HIV/AIDS.

N=256	Total		Male		Female	
Agree or Slightly Agree	207	81%	64	83%	143	80%
Neither Agree nor Disagree, Slightly Disagree or Disagree	49	19%	13	17%	36	20%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	61	87%	60	85%	130	79%
Neither Agree nor Disagree, Slightly Disagree or Disagree	9	13%	11	15%	34	21%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	28	76%	63	80%	49	86%	34	79%	35	88%
Neither Agree nor Disagree, Slightly Disagree or Disagree	9	24%	16	20%	8	14%	9	21%	5	13%

- ⓧ Condoms were generally accepted as a method to reduce the risk of HIV transmission (Figure VI.12 and Table VI.12).
- ⓧ Responses did not vary significantly by gender or race/ethnicity.
- ⓧ The largest percentages of respondents who agreed on the proper use of condoms were youth age 13-24 (95%) and mid-age adults age 45-54 (95%).

Figure VI.12
Proper use of condoms can reduce the risk of catching HIV/AIDS.

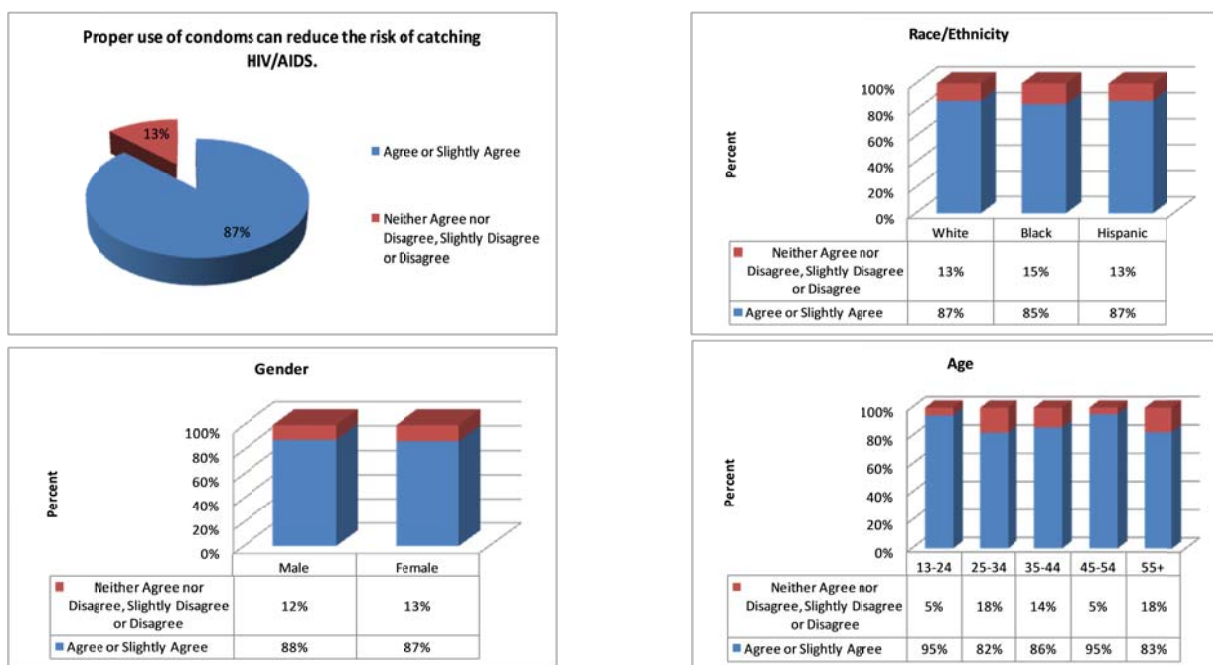




Table VI.12
Proper use of condoms can reduce the risk of catching HIV/AIDS.

N=256	Total		Male		Female	
Agree or Slightly Agree	224	88%	68	88%	156	87%
Neither Agree nor Disagree, Slightly Disagree or Disagree	32	12%	9	12%	23	13%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	61	87%	60	85%	143	87%
Neither Agree nor Disagree, Slightly Disagree or Disagree	9	13%	11	15%	21	13%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	35	95%	65	82%	49	86%	41	95%	33	83%
Neither Agree nor Disagree, Slightly Disagree or Disagree	2	5%	14	18%	8	14%	2	5%	7	18%

- ✘ Less than 10% of all respondents recognized the problems caused by lack of communication (Figure VI.13 and Table VI.13).
- ✘ Responses did not vary significantly by gender or race/ethnicity.
- ✘ By age, cohorts under age 45 agreed to a lesser extent with this statement. Mid-age adults age 35-44 agreed least (86%).



Figure VI.13
Part of the problem with HIV/AIDS is that people don't talk about it.

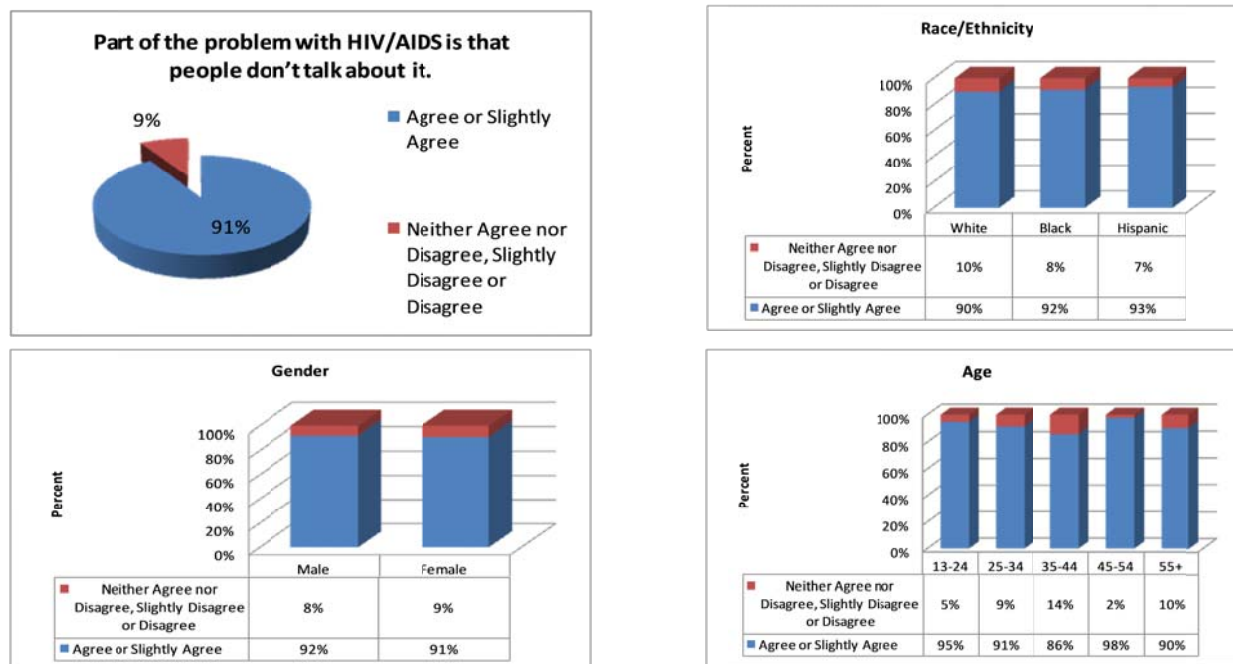


Table VI.13
Part of the problem with HIV/AIDS is that people don't talk about it.

N=256	Total		Male		Female	
Agree or Slightly Agree	234	91%	71	92%	163	91 %
Neither Agree nor Disagree, Slightly Disagree or Disagree	22	9%	6	8%	16	9%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	63	90%	65	92%	153	93%
Neither Agree nor Disagree, Slightly Disagree or Disagree	7	10%	6	8 %	11	7%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	35	95%	72	91%	49	86%	42	98%	36	90%
Neither Agree nor Disagree, Slightly Disagree or Disagree	2	5%	7	9%	8	14%	1	2%	4	10%



- ✂ When asked if it would be hard to continue a relationship with someone with HIV/AIDS, 78% of all respondents said “no” (Figure VI.14 and Table VI.14).
- ✂ The percentage of respondents who indicated difficulty with continuing a relationship (22%) was the largest such response in the survey.
- ✂ Although responses were generally similar by gender, more males expressed difficulty with continuing a relationship than females (23% vs. 21%).
- ✂ By race/ethnicity, responses were mostly similar. However, Blacks indicated greatest difficulty with continuing the relationship.
- ✂ More than one-quarter of adults age 45+ indicated having difficulty continuing a relationship.

Figure VI.14

If I knew someone with HIV/AIDS, it would be hard for me to continue that relationship.

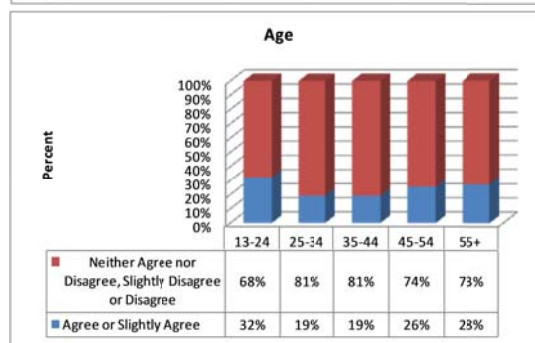
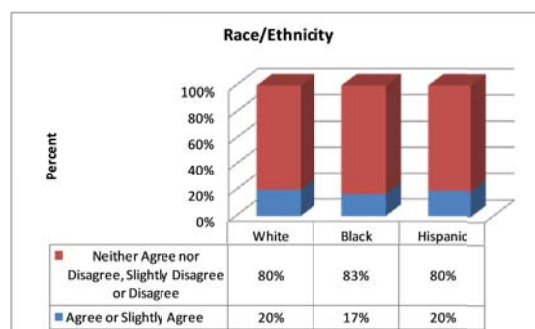
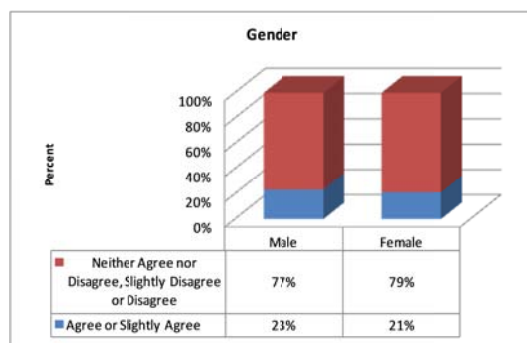
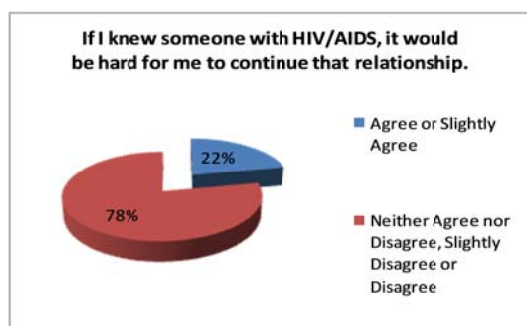




Table VI.14

If I knew someone with HIV/AIDS, it would be hard for me to continue that relationship.

N=256	Total		Male		Female	
Agree or Slightly Agree	56	22%	18	23%	38	21%
Neither Agree nor Disagree, Slightly Disagree or Disagree	200	78%	59	77%	141	79%

N=256	White		Black		Hispanic	
Agree or Slightly Agree	14	20%	12	17%	32	20%
Neither Agree nor Disagree, Slightly Disagree or Disagree	56	80%	59	83%	132	80%

N=256	13-24		25-34		35-44		45-54		55+	
Agree or Slightly Agree	12	32%	11	19%	11	19%	11	26%	11	28%
Neither Agree nor Disagree, Slightly Disagree or Disagree	25	68%	46	81%	46	81%	32	74%	29	73%

Prevention Practices

Respondents were asked a series of questions about their current practices to prevent HIV and other sexually transmitted diseases. They were asked if they talk about HIV with new sex partners, what they discuss specifically, and what they do to prevent HIV. The majority indicated they actively engage in open communication and prevention practices.

Talking about HIV/AIDS with new sexual partners

- ✚ More than half of all respondents stated that they discuss HIV before having sex with a new partner. Responses did not differ significantly between men and women (Figure VI.15 and Table VI.15).
- ✚ A greater percentage of Blacks (69%) stated that they talk about HIV before having sex with a new partner than Whites or Hispanics.
- ✚ By age, young adults age 13-24 talk about HIV more than the other age cohort, and older adults (age 55+) discuss HIV least, with 57% who replied “No.”
- ✚ Those who did not talk about HIV were asked why not. All were either monogamous or sexually inactive.



Figure VI.15
Before you have sex with a new partner, do you talk about HIV?

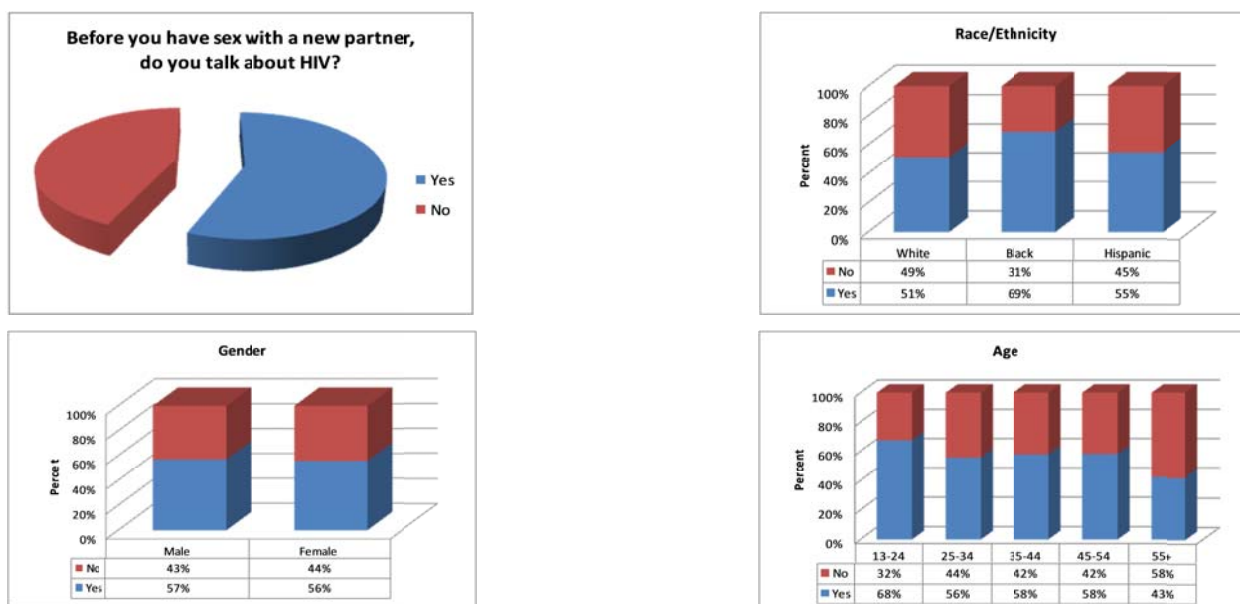


Table VI.15
Before you have sex with a new partner, do you talk about HIV?

N=256	Total		Male		Female	
Yes	144	56%	44	57%	100	56%
No	112	44%	33	43%	79	44%

N=256	White		Black		Hispanic	
Yes	144	56%	49	69%	90	55%
No	112	44%	22	31%	74	45%

N=256	13-24		25-34		35-44		45-54		55+	
Yes	25	68%	44	56%	33	58%	25	58%	17	43%
No	12	32%	35	44%	24	42%	18	42%	23	57%

Preventing HIV/AIDS

- ✂ Of those who said they talked HIV/AIDS with their new sexual partners, the great majority (97%) indicated that they actively practice prevention methods. This was true across gender, race/ethnicity and age cohorts (Figure VI.16 and Table VI.16).
- ✂ From an open follow-up question, “What do you talk about or do?” answers focused most commonly on using protection (especially condoms), getting tested, discussing experiences with previous partners and same-sex relationships, and discussing sexually transmitted diseases (See Appendix D Verbatim Responses).



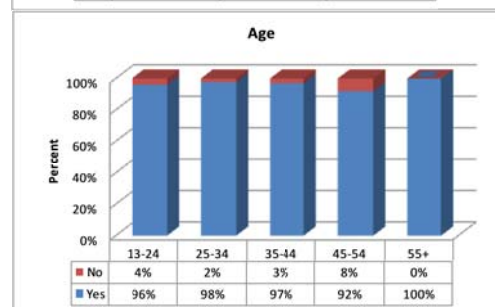
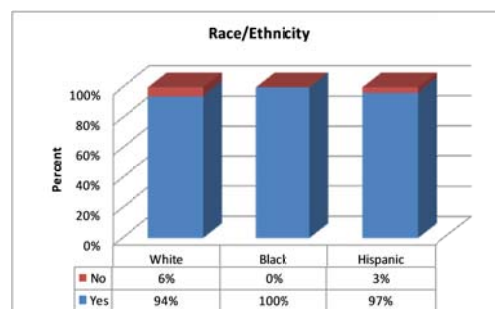
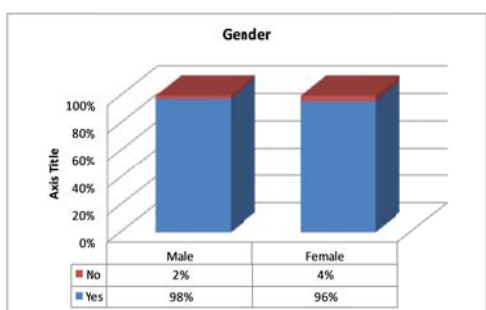
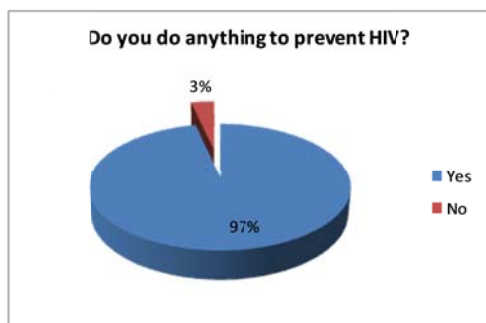
Table VI.16
Do you do anything to prevent HIV/AIDS?

N=144	Total		Male		Female	
Yes	139	97%	43	98%	96	96%
No	5	3%	*	2%	*	4%

N=144	White		Black		Hispanic	
Yes	34	94%	49	100%	87	97%
No	*	6%	0	0%	*	3%

N=144	13-24		25-34		35-44		45-54		55+	
Yes	24	96%	43	98%	32	97%	23	92%	17	100%
No	*	4%	*	2%	*	3%	*	8%	0	0%

Figure VI.16
Do you do anything to prevent HIV/AIDS?





Preventing Sexually Transmitted Diseases

- ✚ Respondents were asked if they do anything to prevent sexually transmitted diseases. Sixty-two percent replied “Yes.” This is a smaller positive response than the similar question about HIV (Figure VI.17 and Table VI.17).
- ✚ Males responded positively to a greater extent than females.
- ✚ The greatest percentages who answered affirmatively were Black (65%) and young adults age 13-24 (78%).

Figure VI.17
Do you do anything to prevent sexually transmitted diseases?

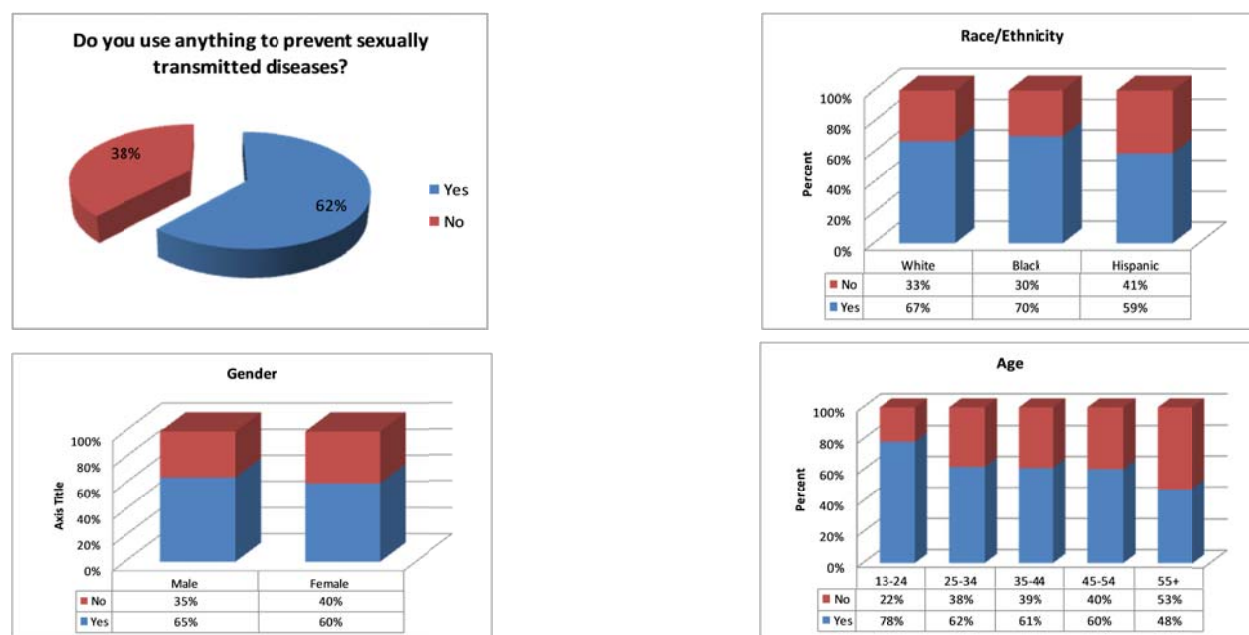


Table VI.17
Do you do anything to prevent sexually transmitted diseases?

N=256	Total		Male		Female	
Yes	158	62%	50	65%	108	60%
No	98	38%	27	35%	71	40%

N=256	White		Black		Hispanic	
Yes	36	51%	49	69%	90	55%
No	34	49%	22	31%	74	45%

N=256	13-24		25-34		35-44		45-54		55+	
Yes	29	78%	49	62%	35	61%	26	60%	19	48%
No	8	22%	30	38%	22	39%	17	40%	21	53%



- For those who answered “Yes,” respondents were asked what they did to prevent STD. Responses were similar to the questions on HIV (See Appendix D Verbatim Responses).

Those who did not do anything to prevent STD were asked why not. Most frequently, these respondents were in monogamous relationships. Occasionally, a respondent didn’t express an interest in prevention measures (See Appendix D Verbatim Responses).



VII. DISCUSSION AND RECOMMENDATIONS

A. DISCUSSION

HIV/AIDS Population in Medical Care

The in-care consumer survey probes the characteristics, health issues and care needs of PLWH/A in the two counties of Bergen and Passaic, New Jersey. With a sample limited to patients receiving care under the Ryan White Program, we learn about a population that has accepted HIV/AIDS and is taking steps to secure its wellbeing. Therefore, this survey makes no attempt to describe the entire HIV/AIDS infected community, and results must be taken as a portion of the full comprehensive needs assessment.

Interpretation of the present findings must take into account issues related to the survey sample. First, despite repeated attempts to obtain additional respondents from Bergen County, the sample undercounts residents from that county and provides non-generalizable information pertaining to PLWH/A from the epicenter of Hackensack. Information specific to Bergen County and Hackensack in particular must be considered as observations and not statistically representative of the population. The undersized sample may also be an indication that Bergen County PLWH/A are underserved or receiving care outside of the Ryan White program, a finding that suggests further research.

Second, the survey was open only to English speakers. Although the number of Hispanic respondents was reflective of the PLWH/A community, there is a population from the TGA that cannot read English and therefore does not have its needs recorded in the present survey. Additionally, the survey results indicate a substantial foreign-born population. It is a concern that the present survey does not sufficiently address the needs of the foreign residents of Bergen and Passaic counties.

Observations and Interpretation

Essentially, the in-care population is well 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. That stated, there are some notable observations that may be used to guide the Planning Council's decisions as it directs the priorities and allocations of Ryan White Part A funds over the next fiscal years.

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.
- ⓧ At this point in the epidemic, the most common transmission mode is clearly sexual contact, either heterosexual or homosexual. Further, transmission via syringe injection



has dwindled to an all-time low even though drug abuse continues to be reported among the HIV/AIDS population. This may be evidence of an effective syringe access program.

- ✘ Relatively low acuity levels with HIV-only diagnoses are more common than AIDS. This is a trend that hopefully will continue.
- ✘ The survey population is remarkably older than was expected, with 73% over age 45 and 43% over age 55. As the national epidemic focuses on newly diagnosed youth, in Bergen-Passaic, the older population dominates the in-care population, leading to speculation that newly diagnosed or at risk youth may be among those not yet in reach of the Ryan White Program.
- ✘ Hispanics (30.5% of the sample) and foreign-born (32.5% of the sample) represent a growing portion of PLWH/A in the TGA. Their importance underscores the need for cultural competency across all service providers at every level of the organization.
- ✘ Presence of co-morbid conditions is reported among older respondents, a predictable consequence of aging. There are cost implications to provision of specialty care that need to be recognized.
- ✘ Respondents and key informants differ with regard to their respective attitudes toward OB/Gyn and mental health needs. This observation suggests a need for better patient education to strengthen self-empowerment and informed decision-making.
- ✘ Transportation remains a support need with apparently no clearly stated preference for bus pass or van service. Case managers should investigate every mode of transportation available and work with clients to assure the ability to get to medical appointments.
- ✘ Oral health care is identified as a leading unmet need, despite the availability of services in both counties. Patients should be educated about the need for regular oral health exams and treatment as well as access to available care.
- ✘ Continued collaboration with substance abuse treatment providers to keep substance abuse under control and minimize its risk for HIV/AIDS appears to be effective, although the need for ongoing treatment across the spectrum of treatment modalities remains high.
- ✘ Prevention practices are mostly a matter of personal choice, even though education efforts have been substantial.

After more than twenty years of HIV/AIDS in the Bergen-Passaic TGA, many of the characteristics of the infected population found earlier still persist today. They include poverty, poor living conditions, language barriers and low educational attainment. Support for daily living such as housing, food and subsidies continue to be cited as common needs.

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 obtain and remain in medical care. From the current survey, these needs continue. However, consumers indicated more concern about insurance coverage than in previous needs assessments, which is reflective of recent changes in medical



and pharmaceutical coverage and predictive of future changes in Medicaid and other insurance plans affected by the Affordable Care Act.

New findings of this consumer survey relate to demographic changes in the epidemic, namely the aging of the infected population and increasing penetration into the Hispanic and foreign-born populations.

Once a deadly disease of mostly young adults, HIV/AIDS is now a chronic disease affecting older adults to a greater extent than ever before. This is reflected in the survey as the in-care population has become much older. Their characteristics are further reflected in the survey, most notably by their engagement in the system of care and reduced dependence on illicit drugs.

Hispanics now constitute approximately 28% of the infected population and is the one major demographic group with increasing infection rates. Foreign-born, of which there is extraordinary diversity in the TGA, represented fully one-third of the survey sample. This underscores the need for cultural proficiencies by all service providers at every organizational level.

It is notable that in-care survey respondents in general are in relatively good health. Lower acuity levels, willingness to engage and remain in care, understanding of the need for prevention, and reduced dependence on illicit drugs indicate successful efforts to treat PLWH/A in this TGA. Co-morbid conditions, as a function of aging, remain a concern, however.

As previously stated, informational needs have long been cited in the various needs assessments, and they surface again in this survey. From the survey responses and key informant interviews, there appears to be a “disconnect” between patient and care provider with regard to certain treatments, specifically OB/Gyn, mental health therapy and oral health care. Consumers and care providers, in general, do not agree on their importance as contributors of good health. More effective patient education is indicated.

HIV/AIDS transmission is now nearly exclusively a sexually transmitted disease. Although male to male transmission is on the rise nationally, this in-care survey does not document a dramatic increase in the Bergen-Passaic TGA. Survey results suggest that the young, gay community does not routinely access the Ryan White system of care, despite indications of growing risk. It also suggests that outreach methods and prevention messages targeted to young gay men, critical to addressing the young gay male in this TGA, may need further discussion.

Injecting drug use among the in-care population is on the decline. Only one respondent admitted to currently using injecting drugs. However, 18% were originally infected from sharing needles, 37% reported said they currently use drugs and 20% identified a need for substance abuse treatment and services. These responses indicate that substance abuse treatment in general must continue to be available.



HIV/AIDS Population Out of Medical Care

Personal interviews often provide insights otherwise not available through quantitative research. In this assessment, the ten PLWHA who participated in the interview process allowed the researcher to learn about the varied circumstances affecting their refusal to receive HIV medical care. Their comments provide a glimpse into personal lives that affect engagement in HIV medical care and an opportunity to develop strategies to remove personal barriers.

As with all qualitative research, there are limitations as to how the information can be used. This sample, quite small, cannot be generalized to the entire population of out-of-care PLWHA. Further, this sample included only those who were previously out-of-care and have since re-engaged. There exists an important population that these interviews do not cover, i.e. PLWHA who are presently not engaged in HIV medical care.

Despite extensive efforts and incentives to reach those who never received care or who are presently out-of-care, not one was willing to agree to an interview. This, in itself, speaks to the barriers surrounding this hard-to-reach population. They are HIV-positive and at risk of infecting others; yet they prefer to continue their present lifestyle and remain closed to public health outreach. More must be done to educate and encourage out-of-care PLWHA to seek HIV medical care. The insights from the ten interviews may be helpful to that end.

The interviews revealed a variety of personal situations and responses to positive HIV status. Two major points regarding engagement and re-engagement are notable:

- ✂ The decision to seek and remain in HIV medical care is inextricably tied to personal life situations and not to fear of the care itself. Personal situations have higher priority than medical care; and once barriers are removed, engagement can be easier for them. Most of the barriers involve a lack of support services or substance abuse.
- ✂ Re-engagement was successful across all ten interviews. Each person expressed optimism about his or her health. Outreach efforts to engage and re-engage should include positive messages about the benefits of staying in medical care.

It should be noted that the positive messages of likely improved health status could contradict prevention efforts, especially among youth who may conclude that contracting HIV/AIDS is not serious. Both prevention and engagement messages need to be clear that HIV/AIDS is serious, but, if one becomes infected, medical care is the best course of action.

Factors leading to successful re-engagement identified during the interviews point to personalized treatment and education. While mass media education should not be overlooked, a personal approach will yield success according to those interviewed. Critical areas of intervention include:



- ✚ Substance abuse treatment and mental health counseling;
- ✚ Support services such as housing, food and transportation;
- ✚ Education about HIV care;
- ✚ Personal supports, especially from family and peers.

Re-engaged PLWHA do not generally associate with other at-risk individuals, preferring instead to remain in their private circles. Thus, the ability to establish a dialogue between in-care and out-of-care PLWHA may be difficult to realize. Further, re-engaged PLWHA appear to have mixed reaction to stigma, recognizing its existence but not necessarily overwhelmed by it.

On the positive side, however, re-engaged PLWHA feel they have a breadth of wisdom that they are willing to share. They agree that openness and willingness to talk about HIV has benefit and should be encouraged. This can be accomplished through peer counseling and outreach programs.

Resources and Capacity

The Provider Inventory documents a well-developed network of care and services available to PLWHA in the Bergen-Passaic TGA. This network should be maintained at its current capacity until such time as alternatives are available. The gaps analysis further reveals few service needs of major significance, with one notable exception in Bergen County. Cultural competencies, beginning with language capacities, should be part of all service delivery, and the provider inventory indicates progress made in that regard.

Early Identification of Individuals with HIV/AIDS

A limited survey such as the General Population Survey must be interpreted carefully so as not to draw conclusions that may be inappropriate or non-reflective of an entire community. With this in mind, however, this survey does help us to understand the current status of HIV/AIDS knowledge and awareness at the epi-centers of the Bergen-Passaic TGA.

The survey provides a snapshot of minority populations, generally of low income, who have an interest in health-related matters. By targeting this population, we are able to continue the process of reducing new HIV infections through a coordinated approach that includes active collaboration with the minority communities.

The results indicate a broad knowledge of HIV as well as basic understanding of the factors affecting disease transmission and prevention. It can be reasonably stated that the respondents knew about HIV/AIDS, were sufficiently aware of how it is transmitted, and what can be done to prevent it. They linked HIV/AIDS with sexually transmitted diseases and used condoms most often as a means of protection. In these respects, the results are encouraging.



Perhaps the most heartening results pertain to HIV stigma. A large majority of respondents showed an awareness of stigma and agreement that part of the problem lies with communication. Further, many (78%) would not change their relationship with someone who is HIV positive. These responses, then, would point to a general “openness” about HIV and could validate probable beneficial effects of educational and social marketing efforts. This does not mean that stigma is no longer an issue, however, for nearly one-quarter would not continue their relationship with someone who is HIV-positive. This was the largest “negative” response in the survey. Stigma is still with HIV, and the need to change the public opinion remains.

The survey helps to identify specific populations to target for educational efforts. Results indicate:

- ✘ Hispanics were tested for HIV less than other race/ethnicities.
- ✘ Blacks and older adults appeared to be most biased about HIV stigma.
- ✘ Young adults tended to be least informed about HIV.
- ✘ Women tended to use protection for HIV and sexually transmitted diseases less than men.
- ✘ Educational messages should be targeted accordingly.

B. RECOMMENDATIONS

HIV/AIDS Population in Medical Care

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

1. Balance the findings of this survey with follow-up on Bergen County PLWH/A. Determine the extent to which this county may be underserved and possible contributing factors. Look closely at information and transportation needs in Bergen County as possible barriers to care.
2. Conduct the survey in Spanish to gain a more complete picture of foreign-born Hispanic PLWH/A.
3. Enhance patient education to emphasize those aspects of care that are apparently misunderstood with regard to their importance. OB/Gyn, mental health needs and dental care are among those clinical services that require more effective patient education.
4. 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.
5. Plan for increased costs of providing specialty care to older PLWH/A.



6. Continue to outreach to youth, in particular young MSM, and mobilize the outreach, education and prevention efforts toward this population.
7. Implement the recommendations of the Cultural Competency Task Force, and mandate providers to offer culturally proficient services across the entire Part A network.
8. Continue collaboration among outreach, HIV testing and early intervention providers to strengthen the continuum from unaware to early detection to immediate engagement in care.
9. Continue successful collaboration with the syringe access program and other substance abuse providers to maintain the downward trend of HIV transmission through injecting drug use, and continue to support the full continuum of substance abuse treatment and services in the TGA.

HIV/AIDS Population Out-of-Medical Care

The out-of-care interviews provide valuable, albeit limited, information about the characteristics and needs of PLWHA who refuse HIV medical care. Five recommendations, offered as follows, reflect the insights gleaned from this study:

10. Continue efforts to assess the needs of out-of-care PLWHA in the Bergen-Passaic TGA, focusing on those who presently refuse HIV medical care.
11. Continue to fund outreach programs that identify, educate and engage out-of-care PLWHA. Research effective and innovative programs that combine education, peer counseling and one-on-one relationship building.
12. Continue to fund the programs that effectively remove barriers to engagement in HIV medical care. These include: substance abuse treatment, mental health counseling, housing, transportation, and case management.
13. Encourage one-on-one peer counseling and psychosocial support groups to educate and support PLWHA who previously refused HIV medical care and have recently re-engaged. Capitalize on the positive experiences of re-engaged PLWHA to convey messages of personal health improvements.
14. Support programs aimed at eliminating the stigma of HIV, both in the general population and targeted high risk populations. Encourage open dialogue across all sectors of the population, and increase knowledge about HIV disease and the need for universal testing.

Resources and Capacity

The network of HIV/AIDS care and services in Bergen and Passaic County is substantial and well documented. The following recommendations would further improve the ability to serve PLWHA:

15. Advocate for prevention programs in Bergen County.
16. Consider expansion of the syringe access program into Bergen County.



17. Update the current provider inventory at an appropriate time to fully document provider capacity, hours of operation, languages spoken, insurance policies, and other important information for PLWHA.

Early Identification of Individuals with HIV/AIDS

The key informant interviews and general population survey suggest appropriate directions for Planning Council consideration, including the following recommendations:

18. Continue the survey process to increase the value of a limited survey such as this. Consider various venues that represent other segments of the population. These include colleges, health fairs, churches, and ethnic special events. Over time, the various samples can bring a wider understanding of HIV/AIDS knowledge, attitudes and behaviors.
19. Use the results of the survey to target specific minority populations in areas where weaknesses are observed, i.e, testing among Hispanics, stigma reduction among Blacks and older adults, basic HIV/AIDS education among young people, and STD protection for women.
20. Collaborate with minority organizations, sharing the results of this survey, and establish joint interventions appropriate to the populations served.
21. Incorporate information gleaned from the survey into the TGA's Early Identification of Individuals with HIV/AIDS (EIIHA) Action Plan.