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CONSUMER KNOWLEDGE SURVEY

BALTIMORE EMA



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1. EXECUTIVE SUMMARY

This report describes a survey of consumers of HIV/AIDS-related services in the Baltimore eligible metropolitan area (EMA). The survey was designed, administered, and analyzed by InterGroup Services, Inc. (IGS) on behalf of the Greater Baltimore HIV Health Services Planning Council. The planning council is responsible for planning and prioritizing the allocation of funds received by the Baltimore EMA through the Title I program of the Ryan White CARE (Comprehensive AIDS Resource Emergency) Act. IGS is a Baltimore-based consulting and project management company that, under contract with the Baltimore City Health Department, provides support services to the planning council.

The survey described in this report, the *2005 Consumer Knowledge Survey*, was a follow up to the planning council's *2004 Consumer Survey*. That survey, which assessed the needs of people living with HIV/AIDS (PLWH/As) in the EMA, suggested that a gap in consumers' knowledge of funded services was inhibiting their ability to access care. This report describes the findings of the 2004 consumer survey that precipitated the 2005 survey, explains the process by which the 2005 survey was conducted, describes the results of the 2005 survey and, finally, presents implications for planners and community educators in the EMA.

1.1 The 2004 Consumer Survey

Among the many responsibilities of planning councils delineated in the CARE Act is assessing the unmet needs and services gaps of PLWH/As. Unmet need is the need for health care by those who have HIV but are not receiving primary medical care. A service gap is the need for a service other than primary health care by PLWH/As — both those who know their status but are not in care or those who need additional care (HRSA 2003). In order to understand and address unmet need and service gaps, planning councils must also attempt to identify the barriers that create or contribute to those gaps in care.

In 2004, the planning council, with the guidance of its Needs Assessment Committee (NAC) and the support of IGS, designed and carried out one of the largest interviewer-administered needs assessment consumer surveys in the country. Over 600 interviews were conducted with PLWH/As to determine what their health care and services needs are, as well as what barriers prevent them from receiving those services.

The most significant finding of the 2004 consumer survey was that insufficient consumer knowledge of available services is a barrier to care (IGS 2005). According to the report on the 2004 survey's results, "Lack of knowledge of available services was cited as a barrier to care more than any other barrier — 13.5 percent of those who needed but did not receive a service said it was because they did not know the service was available" (IGS 2005). The report went on to recommend additional research on consumers' knowledge of Ryan White services. The planning council agreed that the findings indicated a significant knowledge gap and that remediation might be possible through community education. As such, the council requested a follow-up survey that would 1) confirm the findings of the 2004 survey and 2) provide insight to consumers' information-seeking behaviors.

1.2 The 2005 Consumer Knowledge Survey

The 2004 consumer survey was significantly different in methodology from previous years' consumer surveys — for the first time, the survey was entirely interviewer administered. Therefore, the planning council and its NAC, again working with IGS, wanted to be sure that the findings related to consumer knowledge were reliable and were not simply an effect of the survey design. To confirm the findings of the 2004 survey, the NAC repeated that survey's protocol using a slightly modified survey instrument for the 2005 consumer knowledge survey project. Previous questions were grouped differently, a few questions were added to assess consumers' information-seeking behavior and sources of knowledge, and a new pool of interviewers was used to administer the survey.

“Across all jurisdictions, approximately 58 percent of PLWH/As needing but not receiving at least one HIV-related service said that they did not know the service was available to them.”

Over a six-week period, anonymous interviews were conducted with a convenience sample of 422 PLWH/As by 6 trained interviewers in 28 different HIV-service provider locations in 6 of the 7 jurisdictions of the EMA.

As was done with the 2004 consumer survey, by averaging the total number of individuals needing but not receiving a service in each service category, a rough estimate of overall unmet services in the EMA was obtained. Across all jurisdictions, approximately 34 percent of PLWH/As needing at least one HIV-related service did not receive that services. Likewise, by

averaging the total number of individuals who needed but did not receive a service and who cited lack of knowledge as the reason, a rough estimate of the overall knowledge gap was obtained. Across all jurisdictions, approximately 58 percent of PLWH/As needing but not receiving at least one HIV-related service said that they did not know the service was available to them.

1.3 Planning Implications of the 2005 Consumer Knowledge Survey

The 2005 consumer knowledge survey confirmed that services that consumers feel they need are not being received and that insufficient knowledge of available services plays a significant role in consumers' inability to access care. Nearly 11 percent of those interviewed had never heard of Ryan White programs, yet presumably all of those interviewed were Ryan White clients.

The Ryan White system of care is broad and robust; a lack of knowledge may be expected in clients who are new to the system and still learning to navigate it. However, the clients comprising the survey sample had been in care for, on average, over seven years. The survey also revealed an average time of 2.5 years between receipt of a positive test result and consistent participation in primary medical care; one cannot help but wonder how the gaps in consumers' care might be reduced if the gaps in their knowledge of available supportive services were reduced.

“This survey also revealed an average time of 2.5 years between receipt of a positive test result and consistent participation in primary medical care.”

While the 2005 survey confirms the existence of a problematic knowledge gap, it only begins to hint at ways to reduce that gap. Given that so much unmet service demand exists among consumers who have been in care for several years, the planning council may wish to examine the process by which consumers' emerging needs are identified not only when they first enter the care system, but throughout their time in care. Additionally, further research on the types of messages and the communication channels most likely to motivate

consumers to action seems warranted, although it is outside the purview of the planning council and its committees. Such research may, however, be conducted through the Title I administrative agency's community education program.

2. BACKGROUND

The 2005 consumer knowledge survey project is concerned with the need for, use of, and knowledge of, HIV-related medical care and supportive services by people living with HIV/AIDS (PLWH/As) in the Baltimore eligible metropolitan area (EMA), a geographical region composed of Baltimore City and six counties surrounding it. The services in question are paid for with funds provided by the federal government to the Baltimore EMA under Title I of the Ryan White CARE Act. Through the CARE Act, the federal government funds treatment of last resort for PLWH/As who would not otherwise receive care. InterGroup Services, Inc. (IGS), a Baltimore-based consulting company, designed and administered the survey project under the guidance of the Greater Baltimore HIV Health Services Planning Council. The council is responsible for prioritizing the distribution of CARE Act funds received by the EMA.

The need for the survey was indicated by the results of the planning council's 2004 Consumer Survey. The 2004 survey was conducted as part of the planning council's triennial comprehensive assessment of the needs of people living with HIV/AIDS (PLWH/As) in the EMA, as mandated by the U.S. Health Resources and Services Administration (HRSA), which oversees Ryan White Title I programs. The information gathered throughout this survey project will be used by planners to inform the design and content of future needs assessment surveys, as well as to guide additional research by the planning council or its collaborators on the apparent gap in consumers' knowledge and its effect on their access to care.

2.1 The Baltimore EMA

The city of Baltimore and the six surrounding counties — Anne Arundel, Baltimore, Carroll, Harford, Howard, and Queen Anne's — comprise the Baltimore EMA. Any assumption that the grouping of these jurisdictions or their geographic proximity to one another indicates homogeneity between them would be false. In reality, the region is diverse and the jurisdictions that comprise it are quite distinct from one another. In terms of measurable demographics, distinctions can be made in size and population density, racial composition, and income levels in each jurisdiction.

Table 1 shows key demographic characteristics of the EMA by jurisdiction — geography, poverty, and race. Of the seven jurisdictions in the EMA, Baltimore City is by far the smallest physically, yet is home to the second-largest percentage of the EMA's population; the jurisdiction with the largest percentage of the population, Baltimore County, is more than seven times larger in terms of square mileage than its neighboring city. Comparing the city to Carroll County, which is more than five times larger physically but is home to just a quarter as many people, one begins to get a sense of how diverse the EMA is.

Perhaps unsurprisingly, the urban and densely populated Baltimore City has the largest proportion of residents living in poverty, 20.2 percent. The city's poverty level is not only the highest of all of the EMA's jurisdictions, but it is vastly higher than its poorest neighbor, Baltimore County, which has poverty rate of 7.1 percent.

In terms of racial composition, Baltimore City again stands far apart from its neighbors, all of which are majority white (ranging from Carroll County, at 95.7, percent to Baltimore County at

73.0 percent). Baltimore City, on the other hand, has a majority African-American population (64.9 percent).

Table 1							
Demographic Characteristics of the Baltimore EMA by Jurisdiction							
	Anne Arundel County (n=505,620)	Baltimore City (n=628,670)	Baltimore County (n=777,184)	Carroll County (n=163,207)	Harford County (n=232,175)	Howard County (n=264,265)	Queen Anne's County (n=44,108)
Geography of the EMA							
Land area (sq. mi.)	418	80	598	452	448	251	372
Population density	1,2112.0	7,858.4	1,299.6	361.1	518.2	1,052.8	118.6
Poverty							
Percent in poverty	5.6%	20.2%	7.1%	4.5%	5.5%	3.9%	5.6%
Race							
White	82.3%	32.0%	73.0%	95.7%	87.1%	73.8%	90.5%
Af.-Am.	13.3%	64.9%	22.1%	2.4%	9.6%	14.3%	7.8%
Other	4.4%	3.1%	4.9%	1.9%	3.3%	11.9%	1.7%

Source: BC 2004a, BC 2004b, DOP 2004, MSA 2004.

Given the diversity that exists within the geographic and socio-economic characteristics of the jurisdictions of the Baltimore EMA, it is not surprising to also find differences in the HIV/AIDS epidemiological characteristics of the EMA's jurisdictions.

As table 2 shows, Baltimore City bears the greatest burden in terms of prevalent HIV/AIDS cases in the EMA; the city's caseload accounts for 80.1 percent of the total EMA prevalence. Baltimore City is not the only standout here, however. While the counties are generally more similar to one another than they are dissimilar, the percentage of prevalent HIV/AIDS cases in Baltimore County, 11.0 percent, is substantially greater than in all of its neighboring counties combined.

A final noteworthy difference between the EMA's jurisdictions involves the means by which the majority of HIV/AIDS cases are transmitted. The predominant transmission mode in Baltimore City is injection drug use (IDU) while the surrounding counties have higher reported rates of transmission by sexual contact between males.

Table 2							
HIV/AIDS in the Baltimore EMA by Jurisdiction							
	Anne Arundel County	Baltimore City	Baltimore County	Carroll County	Harford County	Howard County	Queen Anne's County
	(n=505,620)	(n=628,670)	(n=777,184)	(n=163,207)	(n=232,175)	(n=264,265)	(n=44,108)
HIV/AIDS Prevalence, 2003							
Prevalent Cases	809	13,896	1,908	134	297	272	34
Percentage of EMA prev.	4.7%	80.1%	11.0%	0.8%	1.7%	1.6%	0.2%
Mode of Exposure, 2002							
MSM	21.2%	9.1%	14.9%	14.0%	18.2%	22.5%	26.5%
IDU	18.1%	32.6%	20.3%	28.7%	15.7%	9.9%	11.8%
MSM/IDU	1.5%	2.2%	3.2%	0.8%	3.2%	1.2%	5.9%
Blood products	0.8%	0.1%	0.4%	1.6%	3.6%	0%	0%
Heterosexual sex	21.3%	15.3%	16.4%	12.4%	23.9%	18.6%	23.5%
Other/Missing	37.2%	40.7%	44.8%	42.6%	35.4%	47.8%	32.4%

Source: DHMH 2003, Flynn 2004.

It is not enough that medical and supportive services are available in the EMA; the council, service providers, and community planners must work together to ensure that consumers are able to access those services. The numerous distinctions between the jurisdictions that comprise the Baltimore EMA present challenges to planners, outreach workers, and community educators who are tasked with helping current and future Title I service consumers comprehend and navigate a complex system of care. Communication channels that are effective in a densely populated area such as Baltimore City will likely be less effective, if not impossible to undertake, in rural areas of Carroll County. Just as different jurisdictions and populations demand different care and support needs, they likewise require different outreach and education messages and the use of targeted communication channels.

2.2 Needs Assessment through Consumer Surveys

The CARE Act mandates that planning councils nationwide conduct needs assessment research that determines the health care and service needs of PLWH/As that are not being met. Specifically, HRSA is seeking data about unmet need and service gaps. *Unmet need* is defined as the need for health care by those who know they have HIV but are not receiving primary medical care; a *service gap* is the need for a service other than primary health care (HRSA 2003). In addition, councils are expected to identify — and, ultimately, minimize or eliminate — the barriers that contribute to gaps in service and needs going unmet.

The planning council uses a variety of needs assessment methods to gather data that, when combined, create a complete picture of unmet need and service gaps. One of those methods is a large-scale consumer survey. The council has chosen to make a consumer survey central to its

needs assessment because survey research has been found to be one of the most effective methods for gathering data on large populations (Babbie 2001).

Since 1999, the council has conducted a comprehensive needs assessment survey every three years. The most recent of these, in 2004, was entirely interviewer administered. Prior years' surveys had been either entirely self-administered or partially interviewer administered. Despite the logistical challenges posed by an entirely interviewer-administered survey, such as the likelihood of obtaining a smaller sample, the council chose its 2004 methodology because of the higher response rates and greater validity typically associated with interviewer-administered surveys (Babbie 2001).

The triennial consumer survey collects self-reported data from consumers who assess their own needs — assessments that cannot be individually verified. For example, a consumer may indicate that he needs meals delivered at home, but does not receive that service because he does not know how to get it. While this consumer's experience may indicate a service gap, it is also possible that the consumer does not meet the medical conditions under which someone would be referred for that service; thus, no gap exists in reality, if not in the consumer's perception.

That is not to say that self-reported data have no value; again, the presence of an interviewer who can clarify definitions of terminology used on the survey increases the validity of the consumers' responses. The data gathered on these surveys are critical to understanding the barriers that consumers encounter when navigating the care system and attempting to access services. Moreover, when the consumer survey data are combined with data from other sources, such as epidemiological data from the state and utilization data from providers, the consumers' responses can be placed in context and, to a certain extent, verified. However, in recognition of the fact that the survey alone cannot provide actual unmet need and service gap data (as defined by HRSA), this report will refrain from using those terms. Instead, the terms *demand* and *unmet demand* will be used to reflect that these data are based solely on the consumers' perception of their own need.

2.3 The Consumer Knowledge Gap

As mandated by HRSA, the 2004 consumer survey sought data about not only unmet need and service gaps, but also about the obstacles that contribute to consumers' difficulties accessing medical care and support services. Among the most significant findings of the 2004 consumer survey regarding barriers was that insufficient consumer knowledge of available services is a barrier to care (IGS 2005).

According to the report on the 2004 survey's results, 13.5 percent of those who needed but did not receive a service attributed their unmet need to not knowing that the service was available to them (IGS 2005). The report went on to reveal that of those clients, "almost all (99.7 percent) were in primary medical care, nearly three quarters (70.3 percent) had a case manager, and more than a third (34.8 percent) had seen an outreach worker in the past year" (IGS 2005).

The report recommended additional research on consumers' knowledge of Ryan White services. The planning council agreed that the findings indicated a significant knowledge gap and that the gap might be narrowed through community education. However, the planners requested additional data to inform any plan designed to address consumer knowledge. The council's Needs Assessment Committee (NAC) assumed responsibility for conducting a follow-up survey that would 1) confirm the findings of the 2004 survey and 2) provide insight to consumers' information-seeking behaviors.

As explained in section 2.2 of this report, the 2004 consumer survey was significantly different in methodology from previous years' consumer surveys — for the first time, the survey was entirely interviewer administered because of the probability that that protocol would result in more reliable data. As the NAC worked with IGS on the 2005 project, they agreed that an important component of the project would be ensuring that the findings related to consumer knowledge were reliable and were not simply an effect of the survey design. To confirm the findings of the 2004 survey, the NAC and IGS decided to repeat that survey's protocol using a slightly modified survey instrument. A new pool of interviewers was used to administer the survey, previous questions were grouped differently and, most importantly, questions were added to assess consumers' knowledge level, knowledge sources, and information-seeking behavior.

Each of the data elements related to consumer knowledge plays an important role in understanding the degree to which the gap affects consumers' ability to access care as well as the possible means of closing the gap. Measuring consumers' level of knowledge of Ryan White services determines the size of the knowledge gap, while identifying the sources of their knowledge suggests communication channels that might be used to close the gap. However, simply targeting consumers' most-used sources of information with new messages is insufficient; the messages must reflect an understanding of what will motivate consumers to take action, and what prevents them from taking action, hence the reason for examining consumers' information-seeking behavior as well.

3. METHODOLOGY

The 2005 consumer knowledge survey was created to gather essential information for identifying and planning the service needs of the EMA's HIV-infected community. The survey sought to confirm findings of the previous year's consumer survey, specifically that people do not receive services because they do not know they are available; as well as seek to find out where and how people learn about available services. This section will explain the process that the planning council's Needs Assessment Committee used to gather that information.

3.1 Survey Development

The NAC began working on the survey project about six months before preliminary results were presented at the planning council's summer 2005 priority-setting data presentation meeting. The NAC began the survey project by reviewing the methodology and instrument used for the 2004 consumer survey project. It was decided that the protocol would be repeated with a slightly modified version of the instrument. Two drafts of the revised instrument were reviewed by the NAC, the final draft was approved by the full planning council, and the survey was administered by IGS in accordance with the implementation plan agreed to by the NAC.

3.2 Survey Administration

As in the 2004 survey, the NAC decided to conduct interviewer-administered surveys. While doing so would mean confronting certain logistical hurdles (e.g., managing interviewers and maintaining consumer confidentiality), the NAC believed that using trained interviewers would result in three highly desirable benefits:

- A broader array of consumers could be surveyed, including those with limited literacy levels.
- Researchers would be less likely to receive partially completed surveys.
- Interviewers could, using a standard set of prompts, help the consumer through the survey process, thus reducing any errors that might result from participant misunderstanding.

3.3 Survey Instrument

For the purposes of data comparison — and efficient IRB approval — this project used a modified version of the 2004 consumer survey instrument. The NAC had designed that instrument to facilitate data analysis by asking specific questions about each service category. The questions asked about each category were essentially the same: 1) do you need the services provided in this category and 2) have you received these services in the past year? Depending on the consumer's response to the questions, one of two additional questions was then asked: 1) if you have received the services, in what jurisdiction have you received them or 2) if you have not received the services, why not?

The instrument used for the 2005 *Consumer Knowledge Survey* followed that same pattern, but with the following changes:

- Questions about the jurisdiction in which consumers received services were removed because understanding consumers' cross-jurisdictional movement was not a goal of this project. However, questions in the demographic section of the survey about the client's jurisdiction of residence were retained.
- Questions about similar services were grouped together. Reordering questions made it easier for interviewers to explain the sometimes subtle differences between service categories like mental health services and psychosocial support services. The wording of the questions themselves did not change, only the order in which they were asked.
- A question regarding the amount of time consumers waited after being diagnosed with HIV to begin receiving care was modified significantly. This change was made in light of research showing that consumers have difficulty accurately reporting this data because they "may have a different perception of time after diagnosis than researchers do" (IGS 2004). For this project, consumers were asked two separate questions regarding the time between diagnosis and care, one regarding the time from diagnosis to acceptance, and one regarding the time from acceptance to care.
- In order to gain insight into the care-seeking behavior of those consumers who knew their status, were not in care, and who had not identified lack of knowledge of free services as a barrier to care, a question was added asking these consumers to identify and rank the factors affecting their ability to receive care.
- Three questions measuring the sources and depth of consumer knowledge of the Ryan White program were added.

As with the 2004 consumer survey, demographic data were captured for each consumer, but no identifying information was captured for any consumer.

3.4 Interviewers

Six interviewers were hired at the start of the project to work with the IGS project coordinator. The interviewers were responsible for:

- Coordinating interviews with an interview site contact.
- Gaining informed consent.
- Administering surveys.
- Distributing incentives.
- Recording the number of surveys completed and abandoned and the number of incentives distributed each day at each location.
- Temporarily storing completed consent forms and surveys.
- Returning completed consent forms and surveys to the IGS offices for verification, data entry and permanent storage.

An interviewer training program, including a survey administration guide and training session, was developed for this project. The training program covered topics such as cultural sensitivity, data integrity, participant confidentiality, and use of the survey instrument. In addition, interviewers were given a standard set of prompts to use for each question and instructions on how to address any questions the participants had. The training program helped ensure the consistent application of all aspects of the survey administration process.

3.5 Interview Sites

One of the main challenges of conducting an interviewer-administered survey was securing private space in which one-on-one interviews could be conducted. Because many members of the survey's target population have transportation difficulties, it was agreed that the most convenient place to conduct interviews would be at providers' locations when consumers were on site for services. The NAC was aware of the impact that this decision could have on consumers' confidence in the confidentiality of their responses. However, because the survey did not ask questions about specific providers or about consumers' satisfaction with providers or services, the NAC felt that consumers could be made to feel confident that their candid responses would not negatively impact their access to care or the quality of their care that they receive.

A letter was sent to providers to notify them of the project's purpose, process and timelines, and to solicit their help with recruitment. Each of the current Ryan White providers was asked to allocate private space in which one-on-one interviews could be conducted. To ensure a broad spectrum of respondents reflective of the HIV epidemic, non-traditional HIV services sites also were asked to help with this project, either by helping to recruit participants or by providing space in which interviews could be conducted.

Interviews were conducted at 28 different provider locations in all jurisdictions of the EMA except Queen Anne's County, which has the smallest proportion of PLWH/As in the EMA. The locations included hospitals, community-based organizations, churches/faith-based organizations, city and county health departments, substance-abuse treatment centers, support groups and homeless shelters, among other places (see appendix 7.3). Just as many consumers in the EMA face limited transportation options, many of the HIV-service providers in the EMA face limited space. Interviewers met with consumers in exam rooms, in conference rooms and at the IGS offices (for those who did not wish to be interviewed at a provider location for reasons of confidentiality or convenience). An understanding of each provider's expected client volume was critical to arranging a schedule that minimized disruption of the provider, maximized the quantity of interviews conducted, and contributed to the goal of a sample that reflected the demographic composition of the HIV-infected population of the EMA.

3.6 Participant Recruitment

Most survey respondents were recruited by providers, who scheduled their clients to meet with interviewers on days when the clients were already scheduled to receive services. In addition, respondents were recruited through word of mouth, with the help of members of the planning council and its committees, and through the use of flyers, which were distributed at various service provider locations. The flyer instructed participants to contact their provider or the project recruiter to indicate their interest in participating and be scheduled for an interview session. To facilitate recruitment, participants were offered a \$20.00 gift card to one of two local grocery stores as an incentive for completing the survey.

A convenience sample of 422 people infected with HIV was recruited to participate. Of these, 0.7% received services in the EMA but did not live in any of its jurisdictions. Because the focus of the survey was consumer knowledge of services and not access to services, researchers did not seek a particular distribution of respondents across jurisdictions.

The demographic composition of the sample reflected that of the HIV-infected population of the EMA in terms of sex, race and residence in each one of the seven jurisdictions that comprise the EMA (see chapter 4 for a detailed demographic profile of the survey sample).

3.7 Data Collection Process

Interviews were conducted over a six-week period, from February 14, 2005, through March 25, 2005. During a typical interview session, the following steps occurred:

1. The interviewer read a script that described the project and its purpose to the participant.
2. The interviewer presented the consent form to the participant and read it aloud. If the participant declined to participate, the interviewer signed, dated and filed the form in an envelope and ended the session. If the participant agreed to participate, the interviewer and the participant signed and dated two copies of the consent form; one copy of the form was given to the participant, and the other was filed by the interviewer in an envelope. The interviewer then proceeded to the next step.
3. The interviewer wrote his or her name and the interview location on the front of the survey, read each question to the participant, and recorded the participant's response.
4. Once all questions were asked and answered (or skipped at the participant's request), the interviewer filed the survey in separate envelope from the one in which the completed and abandoned consent forms were stored. The surveys were filed separately from the consent forms so that the consumer's identity would be protected.
5. The interviewer asked the participant to initial an incentive receipt log, then gave the participant the incentive (grocery store gift card), and ended the session.

Some of the questions on the survey asked for personal information about sensitive subjects, such as history of drug use or sexual behavior, which could have caused minor discomfort for participants. However, participants were made aware during the introductory explanation and the consent procedure that they could skip any question that made them feel uncomfortable.

3.8 Survey Storage

Within 48 hours of survey completion, interviewers had to return completed surveys to IGS for storage in accordance with the conditions outlined in the consent form and the Baltimore City Health Department Institutional Review Board (IRB) regulations.

3.9 Survey Data Entry and Analysis

The survey responses were entered by IGS staff into a custom-designed database owned, essentially, by the planning council; this arrangement means that in addition to the analysis presented here, more detailed analysis of the data can subsequently be done by the planning council as needed.

Preliminary survey results were reviewed by an independent panel external to both the planning council and IGS. The reviewers noted some interesting trends and suggested avenues of additional analysis.

Results were presented to the full planning council at its FY 2006 priority-setting data presentation meeting on July 19, 2005.

4. DEMOGRAPHIC PROFILE OF PARTICIPANTS

Because one goal of the 2005 *Consumer Knowledge Survey* project was confirmation of the findings of the 2004 consumer survey, it may be useful to compare some key characteristics of each survey's pool of respondents. Both surveys sought samples with demographic characteristics similar to that of the PLWH/A population as a whole; therefore, it is expected that both samples will be similar in composition, if not in size.

Table 3 shows that this expectation was largely met, with only two notable exceptions: mode of exposure (MOE) and jurisdiction of residence. With regard to the first of those cases, the 2005 sample contained slightly more respondents citing heterosexual sex as their MOE; this difference can be attributed to women, 11.8 percent more of whom specified "sex with a man" instead of "unsure" as their MOE in 2005 than in 2004. With regard to the second significant difference between the 2004 and 2005 survey samples, jurisdiction of residence, the 2005 sample contained slightly fewer Baltimore County residents (8.5 percent in 2005, compared to 13.3 percent in 2004) and twice as many Howard County residents (6.6 percent in 2005, compared to 3.3 percent in 2004) than the 2004 sample. This difference is most likely attributable to last-minute changes to survey dates and locations necessitated by inclement weather.

Age, race, mode of exposure and jurisdiction of residence are not the only demographic characteristics important for understanding the pool of respondents to the 2005 survey. The amount of time a consumer has been receiving primary medical care can, when combined with other data elements, provide insight into the status of the consumer's health, and thus his or her need for services, as well as his or her expected level of knowledge about the care system. On the 2004 consumer survey, the question about time in care was multiple choice, and the only choices offered were "6 months," "1 year," and "more than one year." Interviewers observed that many respondents volunteered specific estimates of their time in care, and that for many, the duration exceeded 10 years or more. (In fact, in the final analysis, 86.2 percent of respondents EMA-wide had been in care for more than one year.) The multiple-choice question format seemed to be preventing the gathering of data that consumers were willing to offer and that might prove useful. Therefore, for the 2005 consumer knowledge survey, the question format was changed from multiple choice to open-ended. As a result of the change from one question style to another, the results from the two surveys are not directly comparable. Table 4 shows the results for respondents to the 2005 survey, sorted into categories. Clearly, changing the question format enabled more specific data to be captured; now not only can one see that 85.1 percent of the respondents have been in care for more than a year, but that 25.1 percent have been in care for 1 to 5 years, 32.1 percent for 6 to 10 years, and 29.9 percent for more than 11 years. In addition, changing the question format enabled the calculation of the survey respondents' average time in care, 7.5 years.

Another respondent characteristic of interest to planners is the length of time between when consumers test positive for HIV and when they seek medical care; this period is considered to be a crucial point of intervention. Previous surveys gathered this data by asking rather directly how long had the consumer waited before seeking care for his or her HIV. However, some research has shown that consumers have difficulty accurately reporting this data because they "may have a different perception of time after diagnosis than researchers do" (IGS 2004). Consumers may begin counting not from when they received their diagnosis, but from when they accepted it. Therefore, respondents to the 2005 survey were asked two separate questions regarding the time

between diagnosis and care, one regarding the time from diagnosis to acceptance, and one regarding the time from acceptance to care.

Table 3		
Demographic Comparison of Respondents to the 2004 and 2005 Consumer Surveys		
	2004 (n=650)	2005 (n=422)
Age		
Under 2	0%	0.0%
2 – 12	0.5%	0.7%
13 – 24	2.0%	1.7%
25 – 44	55.2%	55.2%
45 – 64	40.2%	41.9%
Over 65	1.6%	0.0%
No response	0.5%	0.5%
Sex		
Male	54.1%	52.4%
Female	44.3%	43.3%
Transgendered (male to female)	0.8%	2.4%
Unknown	0.7%	1.9%
Race/Ethnicity*		
African-American	84.6%	85.1%
White	11.0%	10.9%
Hispanic/Latino	1.8%	0.0%
Native American/Alaskan Native	0.0%	1.2%
Other **	7.2%	4.3%
Mode of Exposure		
Heterosexual sex	39.4%	44.8%
Injection drug use (IDU)	23.0%	23.9%
MSM	12.0%	12.6%
Blood products or perinatal transmission	2.6%	1.2%
Unknown‡	23.0%	17.5%
Jurisdiction of Residence		
Anne Arundel County	3.0%	4.3%
Baltimore City	73.9%	76.8%
Baltimore County	13.3%	8.5%
Carroll County	0.5%	1.2%
Harford County	2.6%	1.2%
Howard County	3.3%	6.6%
Queen Anne's County	0.3%	0.0%
Other	3.1%	1.4%
Income and Housing		
Income < Fed. Poverty Level	56.8%	65.9%
Stable Housing	62.1%	65.2%

Source: IGS client survey.

*Sum does not equal 100% as categories are not mutually exclusive.

** Includes other races, such as Hispanic, African and Asian.

‡ Includes those who specified multiple risk factors.

Table 4 Time in Primary Medical Care, 2005 (n=422)	
More than 11 years	29.9%
6 to 10 years	32.1%
1 to 5 years	23.1%
Less than one year	14.9%

Source: IGS client survey.

Table 5 Time Between Diagnosis and Care, 2004 (n=609)	
More than 1 year	17.7%
6 to 12 months	0.2%
1 to 6 months	14.4%
Less than one month	57.1%
Other/no response	10.5%

Source: IGS client survey.

aspect of the HIV/AIDS care system. The average time clients spent coming to terms with their positive test result was 1.5 years.

That same table shows the amount of time that respondents estimated it took them to seek care after coming to terms with their positive test results. During this time, clients may have started and then stopped care, they may have sought services other than primary medical care, such as substance-abuse treatment or psychosocial support. The average time clients spent before entering consistent care was 1.0 years. When the average time to accept their diagnosis is combined with the average time to seek consistent care, consumers' average time between diagnosis and care is 2.5 years — a very different result from the one month suggested by the 2004 consumer survey.

Table 6 Time Between Diagnosis and Care, 2005 (n=422)		
	<i>From Diagnosis to Acceptance</i>	<i>From Acceptance to Care</i>
More than 10 years	4.5%	3.8%
4 to 9 years	13.5%	7.3%
1 to 3 years	19.7%	10.7%
Less than one year	62.3%	78.2%

Source: IGS client survey.

Table 5 shows the estimated time between diagnosis and care for respondents to the 2004 consumer survey, when consumers were asked the more direct version of the question. A significant majority of these clients, 57.1 percent, indicated that they waited less than one month before seeking care.

Table 6, however, suggests very different post-test behavior; here one sees how respondents to the 2005 survey estimated the amount of time it took them to accept their positive test result. During this time, clients were making no changes to their behavior, were not discussing their test result with others, and were not participating in any

5. RESULTS AND ANALYSIS

As explained in section 2.2, because surveys rely on self-reported data alone, which cannot provide unmet need and service gap data (as defined by HRSA), this analysis will refrain from using those terms. Instead, the terms *demand* and *unmet demand* will be used to reflect that these data are based solely on consumers’ perception of their own need.

5.1 Consumer Knowledge of Services

Recognizing that consumers tend to think of Title I funding as a program to which they belong or a type of insurance by which they are covered, consumers were asked if they had heard of the “Ryan White programs;” table 7 shows their responses.

Table 7 Consumer Knowledge of Ryan White Services (n=422)	
Had heard of the Ryan White program	88.6%
Had not heard of the Ryan White program	10.9%
No response	0.5%

Source: IGS client survey.

Because surveys were conducted at Title I-funded provider locations and respondents were solicited with the help of providers, it is assumed that a vast majority of the survey respondents are Title I-eligible consumers receiving at least primary medical care. Based on that assumption, 10.9 percent of respondents’ saying that they had never heard of the Ryan White program is indicative of a serious problem with consumer knowledge.

Table 8 provides a closer look at consumer knowledge of specific Ryan White services. Consumers were asked which of the listed services were available through the Ryan White program.

Table 8 Consumer Knowledge of Specific Ryan White Services (n=422)			
Service	Knew About It	Service	Knew About It
Case management	65.4%	Housing assistance	52.1%
Child care	33.4%	Legal assistance	45.0%
Dental care	64.5%	Mental health counseling	58.3%
Help paying for food	44.8%	Support groups	57.8%
Help paying for medicines	71.6%	Linkages to care	58.8%
Help paying for utilities	44.3%	Medical care	75.4%
Meal delivery	45.5%	Substance-abuse treatment	56.2%
Treatment adherence	41.0%	Transportation	55.0%
Home health care	44.8%	Other services	1.4%

Source: IGS client survey.

With regard to services that were likely to be used by all consumers, such as medical care, medications and case management, the level of was fairly high: 75.4 percent knew that Ryan White funding would cover their medical care, 71.6 percent knew it would cover their medications, and 65.4 percent knew that Ryan White programs included case management. Knowledge about the remaining service categories varied, most likely due to varying demand for those categories. A consumer with no children is unlikely to be concerned with child-care issues, and will therefore have no knowledge of child-care assistance funded by Title I. For that reason, it becomes important to evaluate consumer knowledge of services in the context of demand for that service. That analysis is provided in the next section.

5.2 Unmet Service Demand

As explained in section 3.3, the survey questions were grouped by service category. For each service category, consumers were asked to first assess their need for the services funded through that category, as well as their ability to access the services within the past year.

As was done with the 2004 consumer survey, the service categories were ranked in order of the consumers' demand for them. In other words, which services did survey respondents indicate were most needed? Table 9 lists the service categories in their ranked order, from most in-demand (primary medical care, for which 96.2 percent of respondents indicated a need) to least in-demand (hospice care, for which just 0.7 percent of respondents indicated a need).

Perhaps more important than the ranking of the respondents' service needs are the rankings of the services that respondents were unable to receive. Having ranked all of those services for which any consumer identified a need by the rate of demand for the service, one can next consider how successfully consumers are able to access the services. Unmet service demand was calculated by dividing the number of respondents who said they needed but could not access a particular service by the total number of respondents who said they needed that service. Table 9 shows the percentage of consumer demand (EMA-wide) for each service that has gone unmet. For example, the service with the greatest demand, primary medical care (96.2 percent felt that they needed it), had the smallest amount of unmet demand (1.2 percent of respondents who needed it did not receive it). In contrast, legal services, for which 44.5 percent of respondents expressed a need, was not received by 69.1 percent of those respondents.

It is worth noting that a high unmet-demand figure does not necessarily mean that the service is in high demand. For example, if five people identified a need for a service, but only one person received it, the unmet demand is 80 percent (calculated by dividing the four who did not receive the service by the five who identified a need for it). An unmet demand of 80 percent sounds high, but one must remember that only five people wanted the service to start with. Therefore, when considering the chart of unmet demand, it is important to simultaneously consider the service category's ranking on the list of client priorities. That said, if the percentage of unmet demand in a given service category exceeded 15 percent, it was generally considered an indication of poor correlation between demand and use in that category warranting a closer look.

In addition to demand and unmet demand data, table 9 also shows the proportion of those who needed a service but did not receive it who indicated that they did not know that the service was available. Taking legal services as an example again, of the 69.1 percent of consumers who needed but did not receive the service, 60.0 percent did not know the service was available to them.

Service Category	2005 Consumer Knowledge Survey (n=422)			2004 Consumer Survey (n=609)	
	Needed	Not Received (as a proportion of Needed)	Didn't Know About (as a proportion of Not Received)	Needed	Not Received (as a proportion of Needed)
Primary Medical Care	96.2%	1.2%	60.0%	91.8%	2.5%
Oral Health Services	85.3%	45.8%	47.9%	82.6%	52.3%
Medication	75.4%	13.8%	40.9%	78.7%	13.8%
DEFA*	67.8%	46.9%	39.6% 61.9% 33.6%	62.9%	48.8%
Housing	67.1%	41.0%	59.5%	58.8% Perm. 58.6% Temp.	55.6% 46.2%
Transportation	67.1%	26.5%	62.7%	62.9%	15.7%
Linkages to Care*	61.6%	5.8%	66.7%	81.6% Case Mgmt. 55.2% Client Adv. 47.0% Outreach	14.3% 28.6% 38.1%
Mental Health Services	56.6%	7.5%	44.4%	47.5%	18.7%
Legal Services	44.5%	69.1%	60.0%	41.5%	75.1%
Substance-abuse Treatment	33.4%	16.3%	60.9%	29.6%	16.7%
Meal Delivery	29.9%	50.8%	60.9%	47.5%	53.3%
Treatment Adherence	27.0%	9.6%	90.9%	29.4%	2.8%
Rehabilitation Services	19.7%	49.4%	***	23.0%	57.1%
Child Care	8.1%	38.2%	84.6%	5.4% Under 6 4.9% Over 6	42.4% 63.3%
Home Health Care	5.0%	52.4%	54.5%	8.0%	75.5%
Hospice Care	0.7%	66.7%	***	2.1%	84.6%

Source: IGS client survey.

* On the 2005 survey, the need for and use of the services in this category were assessed collectively, but knowledge of them was assessed individually.

** On the 2005 survey, the need for and use of services in this category were assessed collectively; on the 2004 survey, they were assessed individually.

*** On the 2005 survey, these services were not included in the question assessing consumer knowledge of individual services.

Another category that had comparatively high rates of demand and unmet demand, as well as a sizeable knowledge gap, was oral health. In this category, 85.3 percent of all respondents expressed a need for the service, but 45.8 percent of them had not received it. One explanation for the unmet demand may be a change that occurred in two of the region's Medicaid managed care organizations' (MCOs') coverage of dental care. However, of those who did not receive the service, 47.9 percent did not know the service was available to them at all.

A third category with high rates of demand and unmet demand and a significant knowledge gap was direct emergency financial assistance (DEFA). In this category, 67.8 percent of all respondents cited a need for the service, but 46.9 percent had not received any type of emergency assistance. Although consumers’ demand for and use of the types of assistance included in this category were assessed collectively, their knowledge of the different types of assistance were assessed separately. Perhaps of greatest concern is that of all of the services included in the DEFA category, the greatest gap in knowledge was in availability of medication assistance; 61.9 percent of respondents did not know this type of service was available to them. Still within the DEFA category, 39.6 percent of those who needed but had not received help paying for groceries, and 33.6 percent of those who needed help paying for their utilities, did not know that these types of services were available.

5.2.1 Sources of Information about Ryan White-funded Services

In order to determine what communication channels might be leveraged for increasing consumers’ knowledge of Ryan White-funded services, consumers were asked how they had heard about the Ryan White program.

Table 10 Consumer Source of Knowledge of Ryan White Services (n=422)			
Source	%	Source	%
Friends/peers	14.5%	Flyer	2.6%
Family/Spouse/Partner	1.4%	Health Fair	3.6%
Case manager	36.3%	Church/minister	1.4%
Doctor or nurse	25.8%	Other	26.5%
Outreach worker	11.4%		

Source: IGS client survey.

Table 10 shows that most consumers are learning about Ryan White services from providers within the Ryan White system: 36.3 percent of respondents get information about services from their case managers, 25.8 percent from their doctor or nurse, and 11.4 percent from an outreach worker. Among sources outside of the care system, friends/peers were the greatest source of knowledge about services.

A review of the sources cited in the “Other” category yielded some interesting information. Most of these sources were also providers within the care system; however, instead of choosing a job title, like “doctor” or “case manager,” from the list of options, respondents chose to name a specific provider, such as Chase Brexton or the Health Education Resource Organization (HERO). These responses may indicate a kind of provider loyalty wherein clients will be receptive messages coming from anyone at their preferred provider.

5.2.2 Factors Influencing Consumers Care-seeking Behavior

When attempting to address the gap in consumer knowledge, it is not enough to simply target consumers’ most-used sources of information with new messages. The messages themselves must reflect an understanding of what will motivate consumers to take action, as well as what factors

prevent them from taking action. To that end, consumers were asked to evaluate a series of statements beginning with the phrase, “If I try to get medical care for my HIV,” and followed by a possible outcome. Some were outcomes that might encourage a consumer to seek care, while others were outcomes that might discourage a consumer from seeking care. Consumers were asked to rate the degree to which they agreed with the possible outcome on a scale of 1 to 5, with 1 indicating strong disagreement with the statement and 5 indicating strong agreement with the statement; table 11 shows the results.

Among the beliefs encouraging care, consumers felt strongly that they would be able to access medical care; both of these indicators (“I will be able to get an appointment” and “I will be able to get transportation to my appointment”) had an average score above 4.0. Consumers also felt strongly that they would be able to comply with a treatment regimen; both of these indicators (“I will be able to follow the doctor’s instructions” and “I will be able to take my medications the way I’m supposed to”) had an average score of 5.0. Consumers’ confidence decreased when it came to their ability to pay for their care. One of these indicators (“I will be able to get free or discounted medications”) had an average score of 3.6, and two of these indicators (“I will be able to pay for my medications” and “I will be able to pay for my care”) had an average score below 2.0.

Table 11	
If I Try To Get Medical Care For My HIV (n=422)	
<i>Perceived Outcome</i>	<i>Average Strength of Belief</i>
Beliefs encouraging care	
I will be able to follow the doctor's instructions	5.0
I will be able to take my medications the way I'm supposed to	5.0
I will be able to get an appointment	4.2
I will be able to get transportation to my appointment	4.0
I will be able to get free or discounted medications	3.6
I will have a long wait in the waiting room	3.6
I will be able to get free care	3.0
I will be able to pay for medications	1.8
I will be able to pay for my care	1.4
Beliefs discouraging care	
I will have to make lifestyle changes that I'm not ready for	4.0
My friends/family/others will find out that I have HIV	3.3
I will have a long wait for an appointment	3.0
I will get sick no matter what the doctor says or does	1.6

Source: IGS client survey.

Among beliefs that might discourage care, consumers felt strongly that entering medical care for HIV would require that they make lifestyle changes that they were not yet ready to make (average score 4.0). Stigma and inconvenience were both of moderate concern, with average scores of 3.3 and 3.0 respectively. The least influential belief, with an average score of just 1.6, was the belief

that entering care would have not preserve or extend the client's health in any way. Providers must obviously do something to disabuse consumers of this idea.

6. CONCLUSION AND PLANNING IMPLICATIONS

As was hoped for during the planning of this survey project, new light has been shed on the key barrier that was identified during the 2004 consumer needs assessment survey — insufficient consumer knowledge. In addition, this survey revealed new information about how consumers access care and the effect that a lack of awareness of available services may have on their care-seeking behavior.

6.1 Delayed Access to Care

The period between when a person tests positive for HIV and enters care is considered to be a crucial point of intervention and education. It is difficult for researchers to quantify this period because it requires consumers to accurately recall and report the amount of time they waited to seek consistent care. In fact, some research has shown that consumers have difficulty accurately reporting this data because they may define the time after diagnosis differently than researchers do. Instead of counting the delay from the time they received their positive test result, consumers may count the delay from the time they psychologically accepted their test result.

This survey project asked consumers two separate questions regarding the time between diagnosis and care, one regarding the time from diagnosis to acceptance, and one regarding the time from acceptance to care. On average, clients spent 1.5 years coming to terms with their test result, then waited an additional year before seeking consistent care. Those two figures combine to reveal an average delay of 2.5 years between receipt of a positive test result and consistent participation in primary medical care. While consumers' reasons for delaying care are surely varied, it is worth exploring how education about Ryan White services might minimize that delay.

6.2 Consumer Knowledge and Access to Care

This survey project confirmed that a gap does, indeed, exist among Title I consumers' knowledge of services available to them based on their Title I eligibility status. Slightly more than 10 percent of all respondents had never heard of the Ryan White program, despite the fact that all respondents were, presumably, recipients of Title I-funded services and despite the fact that the clients comprising the survey sample had been in care for, on average, over 7 years. Given the respondents' lack of familiarity with the overall Ryan White program, it is perhaps not surprising that a lack of knowledge of the individual Title I services was found among consumers as well. In fact, approximately 58 percent of those who needed but did not receive at least one service did not know the service was available. This nescience is of particular concern for those service categories with significant amounts of both demand and unmet demand. For example, more than two thirds (67.1 percent) of those surveyed said that they needed some type of housing assistance; of those, well over a third (41.0 percent) had not received the service. While some of those 41.0 percent may not have received housing services due to specific eligibility or availability issues, more than half of them (59.5 percent) said that they did not know that housing services might be available to them as Title I-eligible consumers.

The knowledge gap appears to be slightly greater for supportive services than for core medical services, although this is difficult to quantify because the knowledge gap for case management (a core service) and client advocacy and outreach (supportive services) were assessed collectively.

Moreover, the percentage of unmet demand is lower overall for core medical services than for supportive services. Still, the importance of a gap in knowledge of supportive services cannot be underestimated. If the knowledge gap is indeed greater for supportive services than for core medical services, there may be implications for consumers' ability to comply with their care. It is of course imperative that those who are HIV positive are brought into the care system, but it is likewise imperative that once in it, their needs are continually assessed and emerging needs are met so that they remain in the care system.

6.3 Sources of Consumer Knowledge

This study was not limited to confirming the existence of a knowledge gap. It further sought to identify sources of consumer knowledge. Most consumer knowledge of Ryan White-funded services comes from service providers; this is not surprising, as more than 99 percent of those who responded to this survey were in care. But compare the communication of information about specific, funded HIV-service options to the communication of HIV-prevention information. In the case of the latter, prevention messages can be delivered by almost anyone, almost anywhere — public service announcements, health fair exhibits, etc. Most funded service information, however, can only come from someone familiar with a specific client's needs. That being the case, consumers may need to assume more responsibility for their knowledge of the services and be willing to ask their providers if Ryan White will pay for an emerging need they believe they may have.

6.4 Consumers' Information-seeking Behaviors and Motivations

Finally, this project sought to understand consumers' information-seeking motivations and behaviors. While consumers strongly believed that if they sought care they would be able to comply with instructions and medication regimens assigned by their doctors, they were hindered from seeking care by the belief that their care would be too expensive and that they would need to make difficult lifestyle changes. Any communication campaign or community education effort attempting to minimize consumers' knowledge gap should reinforce strong beliefs that encourage consumers to seek care and attempt to both strengthen weaker beliefs that encourage care seeking and weaken strong beliefs that discourage care.

7. APPENDICES

7.1 Interviewer Script

Greater Baltimore HIV Health Services Planning Council ***2005 Consumer Knowledge Survey Script***

Interviewer: Read the instructions below to the respondent.

Thanks for helping us with this survey. First, I just want to make sure that you know that your answers will be kept confidential. That means that we will make sure that no one will know what your answers are. Next, I don't want you to worry about the size of the survey packet. While it looks big, most of it is made up of instructions for me as your interviewer. The part of the survey that you do will take about 30 minutes or perhaps less.

Before we start, I'm going to tell you a little about the survey and why we're doing it.

The Survey Purpose

This survey deals with services for people living with HIV disease and their families. Specifically, it is about services paid for by the Ryan White CARE Act. The CARE Act is a federal program. Under this program, certain places get funds to help the HIV-positive people living there get the health care and services they need.

In this area, we have a group called the Greater Baltimore HIV Health Services Planning Council. It's also just called "the planning council." This council finds out what people living with HIV disease need. Then, they give the CARE Act funds to the groups who meet those needs. The information that we get from this survey will help the council figure out how to give people living with HIV/AIDS what they need most.

This survey is really important. We want to show how much we appreciate your help by giving you a gift card from an area supermarket for \$20. It's our way of saying thank you.

Do you have any questions about the survey or why we are doing it?

Next, I'm going to tell you about the survey process.

The Survey Process

It is important for you to really understand what it means to take this survey. In a moment, I'm going to ask you to sign a consent form. The form says that you understand what the survey is for and that you agree to be a part of it. It also says how we plan to protect your privacy. For example, we will keep the form that you sign separate from your survey. That way, no one will be able to know which is the survey with *your* answers on it. It is really important for you to read the form carefully and sign it only if you agree to what it says. Because it is so important that you understand what's on the form, I will read the form along with you. The form also tells you how to contact us if you have questions later about the survey, so I will give you a copy of the form to keep.

This survey will be done like an interview. That means that I will read a question to you and wait for your answer. I'll mark your answer on the survey form, then read you the next question, and so on. For some questions — like those with a long list of answers to choose from — I will show you a list of the possible answers.

During the survey, if you have questions, stop and ask me. If I ask a question that makes you feel uncomfortable, we can skip the question or come back to it later. If you start to feel like you don't want to do this any more, we can stop the survey. No questions asked. But you must understand that the gift cards are only given for complete surveys. If you are a caregiver (such as a parent, spouse or partner) completing this survey for another person (such as a child, spouse or partner), please answer all questions only with information about the person you are helping. When we're done, I will give you the gift card. Do you have any questions now?

Interviewer: Give participant the consent form. If the participant agrees to participate, have him or her sign two copies. File one as instructed in training, give the other to the participant to keep and continue to the next section. If the participant does not sign the consent form, thank the participant for considering it, then process the consent form as instructed in training and end the session.

The Survey Structure

This survey has 2 parts:

- **Part 1: Questions about Services** — These include health care services, which deal with treatment of your physical body, and support services, which help you through your treatment or other HIV-related activities.
- **Part 2: Questions about Demographics** — This part of the survey asks you to tell us a bit about yourself and your experiences in getting care.

Interviewer: Be sure to make eye contact with the participant when reading the following paragraph.

Remember, all of your answers are completely confidential, which means that no one will know what your answers are. Do you have any questions before we start part 1?

7.2 Data Collection Instrument

<i>For IGS use only</i>		
Rec. #:	Entered by:	Date entered:

Interviewer: _____ Interview Site: _____

PART I: Health Care and Support Services

A. Primary Medical Care

Primary medical care is care given by a doctor, physician's assistant, or nurse in a doctor's office or clinic. The care might include a general medical exam, like checking your blood pressure and pulse, or it could include services like blood tests, treating infections, or prescribing medications.

A.1.	Do you think you need primary medical care for your HIV? <input type="checkbox"/> Yes <input type="checkbox"/> No
A.2.	Does your primary care physician know about your HIV status? <input type="checkbox"/> Yes <input type="checkbox"/> No
A.3.	In the past 12 months, have you received primary medical care for your HIV? <input type="checkbox"/> Yes, adult care <input type="checkbox"/> Yes, pediatric care <input type="checkbox"/> No, I am not receiving medical care for HIV/AIDS (skip to A.7.)
A.4.	How long have you been receiving medical care for HIV? <input type="text"/> <input type="text"/> years <input type="text"/> <input type="text"/> months <input type="checkbox"/> I have <i>never</i> been in care
A.5.	Has your HIV doctor performed any of these blood tests on you within the last 12 months? (Check all that apply.) <input type="checkbox"/> CD4 or T-cell <input type="checkbox"/> Viral load <input type="checkbox"/> Other (specify): _____ <input type="checkbox"/> My doctor did not perform tests <input type="checkbox"/> I do not know
A.6.	Have you been on HIV medication in the last 12 months? <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to A.8.)

A.7. If you are **not** receiving medical care for HIV, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I was not getting good care	
<input type="checkbox"/> I did not like the way I was treated by staff	
<input type="checkbox"/> I did not trust the doctor/staff	

OB/GYN care is care given specifically to women by a doctor, physician's assistant or nurse in a doctor's office or clinic. You may get this care from your primary care physician, or by someone such as an obstetrician, gynecologist, or women's clinic.

A.8. Are you receiving OB/GYN care?

Yes **(skip to A.10.)** No

Does not apply; I am male **(skip to A.10.)**

A.9. If you are **not** receiving OB/GYN care, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	

Specialty care is care given by a doctor, physician's assistant or nurse who is trained in a specific area of medicine, such as cardiology (heart care) or dermatology (skin care).

A.10. Has your doctor said that you need specialty care?

Yes No **(skip to B.1.)**

A.11. Are you receiving specialty care?

Yes **(skip to B.1.)** No

A.12. If you are **not** receiving specialty care, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	

B. Oral Health Services

Oral health services are provided by dentists, dental specialists, hygienists or dental assistants.

B.1. Do you think you need dental care?
 Yes No

B.2. In the past 12 months, have you received dental care?
 Yes **(skip to C.1.)** No

B.3. If you have **not** received dental care in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	

C. Rehabilitation Services

Rehabilitation services help you keep your quality of life and ability to take care of yourself. Services might include physical or occupational therapy (to help people get better at day-to-day activities), speech therapy (help for people who have problems talking due to illness or injury), or low-vision training (help for people who have a hard time seeing).

C.1. Do you think you need rehabilitation services?
 Yes No

C.2. In the past 12 months, have you received rehabilitation services?
 Yes **(skip to D.1.)** No

C.3. If you have **not** received rehabilitation services in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	

D. Mental Health and Psychosocial Support Services

Mental health services are for persons with a problem such as depression, anxiety, schizophrenia, or bipolar disease. Psychosocial support services are support and counseling activities like support groups, pastoral care (counseling provided by a member of the clergy), and grief counseling (counseling for those whose loved ones have died).

In addition, many people, upon learning of a positive HIV test result, feel frightened, worried, or all alone. Sometimes talking about those feelings with someone can be helpful — someone like a therapist or psychiatrist.

These questions are about those types of services.

D.1.	Do you think you need mental health services? <input type="checkbox"/> Yes <input type="checkbox"/> No
D.2.	In the past 12 months, have you been to a support group or talked to a member of the clergy about HIV? <input type="checkbox"/> Yes <input type="checkbox"/> No
D.3.	In the past 12 months, have you received individual or group therapy or treatment from a psychiatrist, social worker or psychologist? <input type="checkbox"/> Yes <input type="checkbox"/> No
D.4.	In the past 12 months, have you received any medication for a problem such as depression, anxiety, schizophrenia, or bipolar disease? <input type="checkbox"/> Yes <input type="checkbox"/> No

D.5. If you have **not** received individual or group therapy, treatment, or medication from a psychiatrist, social workers or psychologist, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I don't believe in talking about my problems with others/outside
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	
<input type="checkbox"/> I did not trust the doctor/staff	

E. Substance-abuse Treatment

Substance-abuse treatment means medical care or counseling to treat problems with alcohol or legal or illegal drugs.

E.1. Do you think you need substance-abuse treatment?
 Yes No

E.2. In the past 12 months, have you received treatment for drugs or alcohol?
 Yes (**skip to F.1.**) No

E.3. If you have **not** received substance-abuse treatment in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	

F. Treatment Adherence

Treatment adherence services include help remembering to go to your appointments or take your medication.

F.1. Do you think you need help remembering to go to your appointments or take your medication?
 Yes No

F.2. In the last 12 months, has someone reminded you of your appointments?
 Yes No

F.3. In the last 12 months, has someone reminded you to take your medication?
 Yes No

F.4. If you have **not** had someone remind you to take your medication or go to your appointments, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	
<input type="checkbox"/> I did not trust the doctor/staff	

G. Case Management/Client Advocacy/Outreach Services

Outreach workers try to reach people who are living with HIV/AIDS and help them to become aware of services available to them. Case management helps people living with HIV/AIDS to plan, coordinate and receive all needed services. Client advocacy services are focused on short-term or urgent help for a single problem; that help may come from a peer or client advocate, a case manager or a social worker.

G.1. Do you think you need help accessing services?
 Yes No

G.2. In the past 12 months, has an outreach or field worker helped you to access care or become aware of services?
 Yes No

G.3. In the past 12 months, have you received case management services?
 Yes No

G.4. In the past 12 months, did someone provide you with short-term help for a single problem?
 Yes No

G.5. If you have **not** received case management , services in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am having a problem	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	

H. Food Bank and Home Delivered Meals

This service includes the delivery of food, meals, or nutritional supplements to your home.

H.1.	Do you think you need groceries or pre-cooked meals delivered to your home? <input type="checkbox"/> Yes <input type="checkbox"/> No																					
H.2.	In the past 12 months, have you received free groceries or pre-cooked meals? <input type="checkbox"/> Yes <input type="checkbox"/> No																					
H.3.	In the past 12 months, has someone talked to you about eating right or how to make healthy meals? <input type="checkbox"/> Yes <input type="checkbox"/> No																					
H.4.	<p>If you have not received these services in the past 12 months, please tell us why not. (Check all that apply.)</p> <table border="0"> <tr> <td><input type="checkbox"/> I did not know how to get the service</td> <td><input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule</td> </tr> <tr> <td><input type="checkbox"/> I did not know the service was available</td> <td><input type="checkbox"/> The waiting list to get an appointment was too long</td> </tr> <tr> <td><input type="checkbox"/> I was not eligible</td> <td><input type="checkbox"/> When I had an appointment, they never saw me on time</td> </tr> <tr> <td><input type="checkbox"/> I couldn't afford the co-pay/fee</td> <td><input type="checkbox"/> I had no way to get there</td> </tr> <tr> <td><input type="checkbox"/> I did not need the service</td> <td><input type="checkbox"/> It was too hard to apply for</td> </tr> <tr> <td><input type="checkbox"/> I did not want the service</td> <td><input type="checkbox"/> It was too hard to get an appointment</td> </tr> <tr> <td><input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing</td> <td><input type="checkbox"/> I don't want anyone to know that I am HIV positive</td> </tr> <tr> <td><input type="checkbox"/> I was not getting good care</td> <td><input type="checkbox"/> Other (specify): _____</td> </tr> <tr> <td><input type="checkbox"/> I did not like the way I was treated by staff</td> <td></td> </tr> <tr> <td><input type="checkbox"/> I did not trust the doctor/staff</td> <td></td> </tr> </table>		<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule	<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long	<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time	<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there	<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for	<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment	<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive	<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____	<input type="checkbox"/> I did not like the way I was treated by staff		<input type="checkbox"/> I did not trust the doctor/staff	
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<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there																					
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for																					
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<input type="checkbox"/> I did not like the way I was treated by staff																						
<input type="checkbox"/> I did not trust the doctor/staff																						

I. Housing Assistance Services

Housing assistance is short-term or emergency financial help with temporary or transitional housing so that you or your family can get or keep HIV-related medical care. Housing-related services also include help finding and obtaining housing through local, state, and federal housing programs.

I.1.	Do you think you need housing assistance? <input type="checkbox"/> Yes <input type="checkbox"/> No																					
I.2.	In the past 12 months, have you received any type of housing assistance? <input type="checkbox"/> Yes <input type="checkbox"/> No (skip to L.4.)																					
I.3.	<p>What kind of short-term or emergency housing assistance did you receive? (Check all that apply.)</p> <input type="checkbox"/> Rent money <input type="checkbox"/> Transitional housing (short-term housing; may include case management services) <input type="checkbox"/> Other (specify): _____																					
I.4.	<p>If you have not received any type of housing assistance in the past 12 months, please tell us why not. (Check all that apply.)</p> <table border="0"> <tr> <td><input type="checkbox"/> I did not know how to get the service</td> <td><input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule</td> </tr> <tr> <td><input type="checkbox"/> I did not know the service was available</td> <td><input type="checkbox"/> The waiting list to get an appointment was too long</td> </tr> <tr> <td><input type="checkbox"/> I was not eligible</td> <td><input type="checkbox"/> When I had an appointment, they never saw me on time</td> </tr> <tr> <td><input type="checkbox"/> I couldn't afford the co-pay/fee</td> <td><input type="checkbox"/> I had no way to get there</td> </tr> <tr> <td><input type="checkbox"/> I did not need the service</td> <td><input type="checkbox"/> It was too hard to apply for</td> </tr> <tr> <td><input type="checkbox"/> I did not want the service</td> <td><input type="checkbox"/> It was too hard to get an appointment</td> </tr> <tr> <td><input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing</td> <td><input type="checkbox"/> I don't want anyone to know that I am HIV positive</td> </tr> <tr> <td><input type="checkbox"/> I was not getting good care</td> <td><input type="checkbox"/> Other (specify): _____</td> </tr> <tr> <td><input type="checkbox"/> I did not like the way I was treated by staff</td> <td></td> </tr> <tr> <td><input type="checkbox"/> I did not trust the doctor/staff</td> <td></td> </tr> </table>		<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule	<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long	<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time	<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there	<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for	<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment	<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive	<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____	<input type="checkbox"/> I did not like the way I was treated by staff		<input type="checkbox"/> I did not trust the doctor/staff	
<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule																					
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<input type="checkbox"/> I did not like the way I was treated by staff																						
<input type="checkbox"/> I did not trust the doctor/staff																						

J. Day and/or Respite Care (Children)

Day and respite care involves having someone temporarily care for your child. It may be full-time — several hours per day every day, or it may be part-time — a few hours so you can go to a medical or support service appointment. Day and respite care can take place in the home, out of the home, during the day only, or overnight.

J.1.	Do you think you need child care for a child of any age?
	<input type="checkbox"/> Yes <input type="checkbox"/> No
J.2.	In the past 12 months, have you had someone <i>other than</i> a friend or family member care for your child so that you could go to a medical appointment or support group?
	<input type="checkbox"/> Yes (skip to K.1.) <input type="checkbox"/> No
J.3.	If you have <i>not</i> received child care in the past 12 months, please tell us why not. (Check all that apply.)
	<input type="checkbox"/> I did not know how to get the service <input type="checkbox"/> I did not trust the doctor/staff <input type="checkbox"/> I did not know the service was available <input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule <input type="checkbox"/> I was not eligible <input type="checkbox"/> I couldn't afford the co-pay/fee <input type="checkbox"/> The waiting list to get an appointment was too long <input type="checkbox"/> I did not need the service <input type="checkbox"/> When I had an appointment, they never saw me on time <input type="checkbox"/> I did not want the service <input type="checkbox"/> I had no way to get there <input type="checkbox"/> I did not want someone else taking care of my kids (use for child care questions only) <input type="checkbox"/> It was too hard to apply for <input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing <input type="checkbox"/> It was too hard to get an appointment <input type="checkbox"/> I was not getting good care <input type="checkbox"/> I don't want anyone to know that I am HIV positive <input type="checkbox"/> I did not like the way I was treated by staff <input type="checkbox"/> Other (specify): _____

K. Day and/or Respite Care (Adult)

A regular caregiver is a person who provides, coordinates or helps you coordinate your full-time day-to-day care when you cannot provide that care for yourself. Day and/or respite care provides professional temporary relief for the caregiver. Respite care can take place in the home, out of the home, during the day only, or overnight. Home health care includes services provided in the home by a home health aide or caretaker, or by a licensed nurse or other health care professionals.

K.1.	Do you have a regular caregiver at home?
	<input type="checkbox"/> Yes <input type="checkbox"/> No (skip to K.3.)
K.2.	In the past 12 months, has your regular caregiver had time off?
	<input type="checkbox"/> Yes <input type="checkbox"/> No
K.3.	In the past 12 months, have you received adult day and/or respite care services?
	<input type="checkbox"/> Yes <input type="checkbox"/> No
K.4.	In the past 12 months, have you received home health care services?
	<input type="checkbox"/> Yes <input type="checkbox"/> No

K.5. If you have **not** received adult day and/or respite care *or* home health services in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	
<input type="checkbox"/> I did not trust the doctor/staff	

L. Transportation Services

Transportation services help people living with HIV/AIDS get to medical or social services appointments.

L.1. Do you think you need transportation services?
 Yes No

L.2. In the past 12 months, have you used transportation services?
 Yes (**skip to M.1.**) No

L.3. If you have **not** used transportation services in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I was not getting good care
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> I did not like the way I was treated by staff
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I am not in the service area	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> The transportation trip was too long	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I could not take my child with me	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> They did not pick me up on time	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I only go when I am sick	

M. Legal Services

HIV-related legal services include help preparing documents like wills, do-not-resuscitate orders, and powers of attorney. These legal services do not include help with issues like bankruptcy or criminal issues.

M.1. Do you think you need legal services?
 Yes No

M.2. In the past 12 months, have you received legal services for HIV-related problems?
 Yes (**skip to N.1.**) No

M.3. If you have **not** received legal services for HIV/AIDS related problems, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	
<input type="checkbox"/> I did not trust the doctor/staff	

N. Hospice Services

Hospice service is room, board, nursing care, counseling and physician services for patients whose doctors have referred them for those services. All of these services are available 24-hours a day in the client's home or a home-like setting.

N.1. Do you think you need hospice services?
 Yes No

N.2. In the past 12 months, has your doctor suggested that you consider hospice care?
 Yes No

N.3. In the past 12 months, have you received hospice services?
 Yes (**skip to O.1.**) No

N.4. If you have **not** received hospice services in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> I did not trust the doctor/staff
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only go when I am sick	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	

O. Emergency Financial Assistance

During a short-term, temporary crisis, emergency financial assistance helps you pay for needs such as food, utilities or medicine.

O.1. Do you think you need financial assistance?
 Yes No

O.2. In the past 12 months, have you received emergency financial assistance?
 Yes (**skip to S.1.**) No

O.3. If you have **not** received emergency financial assistance in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	
<input type="checkbox"/> I did not trust the doctor/staff	

P. Local/Consortium Drug Reimbursement Program

This program is an ongoing service to pay for medications for persons with no other payment source.

P.1. Do you think you need medications for HIV/AIDS?
 Yes No

P.2. Are you taking medication for HIV/AIDS?
 Yes (**skip to Q.1.**) No

P.3. If you have **not** received help paying for your medication in the past 12 months, please tell us why not. (Check all that apply.)

<input type="checkbox"/> I did not know how to get the service	<input type="checkbox"/> The doctor's/clinic's office hours did not fit my schedule
<input type="checkbox"/> I did not know the service was available	<input type="checkbox"/> The waiting list to get an appointment was too long
<input type="checkbox"/> I was not eligible	<input type="checkbox"/> When I had an appointment, they never saw me on time
<input type="checkbox"/> I couldn't afford the co-pay/fee	<input type="checkbox"/> I had no way to get there
<input type="checkbox"/> I did not need the service	<input type="checkbox"/> It was too hard to apply for
<input type="checkbox"/> I did not want the service	<input type="checkbox"/> It was too hard to get an appointment
<input type="checkbox"/> I only use non-traditional medical treatment, such as herbal therapy or spiritual healing	<input type="checkbox"/> I don't want anyone to know that I am HIV positive
<input type="checkbox"/> I was not getting good care	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I did not like the way I was treated by staff	
<input type="checkbox"/> I did not trust the doctor/staff	

That was the last question in Part 1. We have only a few more questions left. These last questions ask you to tell us a little bit about yourself and your experiences accessing care. Remember, all of your answers are confidential.

PART II: Demographics**Q. Participant Information**

Remember, all answers are completely confidential.

Q.1.	How old are you (in years)?
	<input type="text"/> <input type="text"/>
Q.2.	What is your sex? <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgendered (M → F) <input type="checkbox"/> Transgendered (F → M)
Q.3.	What do you consider your sexual orientation to be? (Please check only one. If you checked Transgendered in the previous question, please answer this question based on your current gender.) <input type="checkbox"/> Male, heterosexual (I am male and have sex with females only) <input type="checkbox"/> Female, heterosexual (I am female and have sex with males only) <input type="checkbox"/> Male, homosexual (I am male and have sex with males only) <input type="checkbox"/> Female, homosexual (I am female and have sex with females only) <input type="checkbox"/> Bisexual (I am male or female and sex with both males and females)
Q.4.	Which do you consider to be your ethnic background? <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Not Hispanic or Latino
Q.5.	What race do you consider yourself to be? (Please check all that apply.) <input type="checkbox"/> African-American/Black <input type="checkbox"/> Caucasian/White <input type="checkbox"/> African <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Asian <input type="checkbox"/> Haitian <input type="checkbox"/> Jamaican <input type="checkbox"/> Caribbean Islander (other) <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> Other (specify): _____
Q.6.	Where have you lived for most of the past 12 months? (For the homeless, where have you spent most of your time in the past 12 months?) <input type="checkbox"/> Anne Arundel County <input type="checkbox"/> Baltimore City <input type="checkbox"/> Baltimore County <input type="checkbox"/> Carroll County <input type="checkbox"/> Harford County <input type="checkbox"/> Howard County <input type="checkbox"/> Queen Anne's County <input type="checkbox"/> Other (specify): _____

<p>Q.7. What is the ZIP code of the residence you have had for most of the past 12 months?</p> <p style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </p> <p><input type="checkbox"/> Does not apply; I am homeless</p>		
<p>Q.8. Is the residence you had for most of the past 12 months permanent or temporary?</p> <p><input type="checkbox"/> Permanent <input type="checkbox"/> Temporary</p>		
<p>Q.9. Do you leave your jurisdiction to get HIV/AIDS services? For example, if you live in Baltimore City, do you go to a county for services? Or, if you live in a county, do you go to a different county or to Baltimore City for HIV/AIDS services?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No (skip to Q.13.)</p>		
<p>Q.10. If you leave your jurisdiction to get HIV/AIDS services, please tell us why. (Check all that apply.)</p> <p><input type="checkbox"/> I think care is better <i>elsewhere</i></p> <p><input type="checkbox"/> I feel more comfortable in a different <i>city or county</i></p> <p><input type="checkbox"/> It is easier to get all services in a different <i>city or county</i></p> <p><input type="checkbox"/> The services I need are not available in my own <i>city or county</i></p> <p><input type="checkbox"/> For confidentiality — no one knows me</p> <p><input type="checkbox"/> Other (specify): _____</p>		
<p>Q.11. Which services do you get outside of your jurisdiction? (Check all that apply.)</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%; vertical-align: top;"> <input type="checkbox"/> I do not know <input type="checkbox"/> Primary medical care (primary care physician, regular doctors) <input type="checkbox"/> Primary HIV medical care <input type="checkbox"/> HIV specialist <input type="checkbox"/> Mental health care (therapist, counselor, or group therapy) </td> <td style="width: 50%; vertical-align: top;"> <input type="checkbox"/> Dentists who treat people with HIV/AIDS <input type="checkbox"/> Child day and/or respite care <input type="checkbox"/> Transportation (bus, van, taxi) <input type="checkbox"/> Food (groceries or meals) <input type="checkbox"/> Adult day and/or respite care <input type="checkbox"/> Treatment for drug or alcohol problems <input type="checkbox"/> Other (specify): _____ </td> </tr> </table>	<input type="checkbox"/> I do not know <input type="checkbox"/> Primary medical care (primary care physician, regular doctors) <input type="checkbox"/> Primary HIV medical care <input type="checkbox"/> HIV specialist <input type="checkbox"/> Mental health care (therapist, counselor, or group therapy)	<input type="checkbox"/> Dentists who treat people with HIV/AIDS <input type="checkbox"/> Child day and/or respite care <input type="checkbox"/> Transportation (bus, van, taxi) <input type="checkbox"/> Food (groceries or meals) <input type="checkbox"/> Adult day and/or respite care <input type="checkbox"/> Treatment for drug or alcohol problems <input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> I do not know <input type="checkbox"/> Primary medical care (primary care physician, regular doctors) <input type="checkbox"/> Primary HIV medical care <input type="checkbox"/> HIV specialist <input type="checkbox"/> Mental health care (therapist, counselor, or group therapy)	<input type="checkbox"/> Dentists who treat people with HIV/AIDS <input type="checkbox"/> Child day and/or respite care <input type="checkbox"/> Transportation (bus, van, taxi) <input type="checkbox"/> Food (groceries or meals) <input type="checkbox"/> Adult day and/or respite care <input type="checkbox"/> Treatment for drug or alcohol problems <input type="checkbox"/> Other (specify): _____	
<p>Q.12. How often do you leave your jurisdiction to get HIV/AIDS services?</p> <p><input type="checkbox"/> Never</p> <p><input type="checkbox"/> Rarely — Only a few times a year</p> <p><input type="checkbox"/> Every other month or so</p> <p><input type="checkbox"/> Once a month or so</p> <p><input type="checkbox"/> Every two weeks or so</p> <p><input type="checkbox"/> Once a week or more</p> <p><input type="checkbox"/> Other (specify): _____</p>		
<p>Q.13. What was your total household income for the past year? (Include income, child support, welfare, social security, etc.)</p> <p><input type="checkbox"/> Less than \$8,980</p> <p><input type="checkbox"/> Between \$8,981 and \$17,960</p> <p><input type="checkbox"/> Between \$17,961 and \$26,940</p> <p><input type="checkbox"/> More than \$26,941</p> <p><input type="checkbox"/> I do not know</p>		
<p>Q.14. How many people live in your household? Count all of the people living there, <i>including you</i>, no matter how old they are or whether they are eligible for services.</p> <p style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> </p>		

<p>Q.15. How many children 17 years old or younger usually live in your household? Include all children, not only your biological or dependent children.</p> <p><input type="checkbox"/> None <input type="checkbox"/> 1 <input type="checkbox"/> 2 or more</p>
<p>Q.16. How many people 18 years old or older usually live in your household, <i>including you</i>?</p> <p><input type="checkbox"/> None <input type="checkbox"/> 1 <input type="checkbox"/> 2 or more</p>
<p>Q.17. What health insurance did you use this past year? (Check all that apply.)</p> <p><input type="checkbox"/> I have no health insurance</p> <p><input type="checkbox"/> Private health insurance</p> <p><input type="checkbox"/> Veterans benefits (VA)</p> <p><input type="checkbox"/> Pharmacy assistance</p> <p><input type="checkbox"/> Medicare</p> <p><input type="checkbox"/> Medicaid (Medical Assistance)</p> <p><input type="checkbox"/> I do not know</p> <p><input type="checkbox"/> Other (specify): _____</p>
<p>Q.18. How do you think you may have been infected with HIV? (Check only one)</p> <p><input type="checkbox"/> Having sex with a man</p> <p><input type="checkbox"/> Having sex with a woman</p> <p><input type="checkbox"/> Sharing needles or works</p> <p><input type="checkbox"/> Blood products/transfusion (not for hemophilia treatment)</p> <p><input type="checkbox"/> Hemophilia treatment products/transfusion</p> <p><input type="checkbox"/> I do not know</p> <p><input type="checkbox"/> Other (specify): _____</p>
<p>Q.19. After you were told that you were HIV positive, how long was it before you <i>came to terms</i> with your diagnosis? (INTERVIEWER: If the respondent asks what this means, explain that it means “accepting your diagnosis, feeling ready to seek medical care.”)</p> <p style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> years <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> months </p> <p><input type="checkbox"/> I came to terms with my diagnosis right away</p> <p><input type="checkbox"/> I am still coming to terms with my diagnosis</p>
<p>Q.20. After <i>coming to terms</i> with your diagnosis, how long was it before you first sought care from a doctor or nurse?</p> <p style="text-align: center;"> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> years <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> <input style="width: 30px; height: 30px; border: 1px solid black;" type="text"/> months </p> <p><input type="checkbox"/> I sought care as soon as I was diagnosed</p> <p><input type="checkbox"/> Does not apply; I have never been in care</p> <p><input type="checkbox"/> Other (specify): _____</p>
<p>Q.21. If you are not currently getting medical care for your HIV, please rate how strongly you agree or disagree with each of the following statements</p>

If I try to get medical care for my HIV...

- I will be able to pay for my care
- I will be able to get free care
- I will be able to pay for medications
- I will be able to get free or discounted medications
- I will have a long wait for an appointment
- I will be able to get an appointment
- I will be able to get transportation to my appointment
- I will have a long wait in the waiting room
- I will be able to follow the doctor's instructions
- I will be able to take my medications the way I'm supposed to
- I will get sick no matter what the doctor says or does
- I will have to make lifestyle changes that I'm not ready for
- My friends / family / others will find out that I have HIV

- 1 = Strongly disagree
- 2 = Disagree a little
- 3 = Don't agree or disagree; don't even think about this
- 4 = Agree a little
- 5 = Strongly agree

Q.22. What was your last T-cell (CD4) count?

- I don't know what this means
- It's never been tested
- I don't remember
- I don't know
- 0 – 50
- 51 – 200
- 200 – 500
- More than 500

Q.23. What was your last viral load (VL)?

- I don't know what this means
- It's never been tested
- I don't remember
- I don't know
- Undetectable
- Less than 5,000
- 5,000 – 20,000
- 20,000 – 100,000
- More than 100,000

Q.24. In the past 12 months, how many times did you stay in the hospital because of HIV/AIDS?

- None
- 1 – 2 times
- 2 – 5 times
- More than 5 times

Q.25. Have you heard of the combination or cocktail therapies used to treat HIV infection?

- Yes No

Q.26. Have you ever had a problem with drugs or alcohol?

- Yes No

Q.27. Have you ever injected drugs?

- Yes No

<p>Q.28. Have you used any of the following drugs? (Please check all that apply.)</p> <p><input type="checkbox"/> Speedball</p> <p><input type="checkbox"/> Cocaine</p> <p><input type="checkbox"/> Crack</p> <p><input type="checkbox"/> Alcohol (beer, wine, liquor)</p> <p><input type="checkbox"/> Heroin</p> <p><input type="checkbox"/> Marijuana</p>	<p><input type="checkbox"/> Poppers</p> <p><input type="checkbox"/> Meth (methamphetamine, ice, crystal)</p> <p><input type="checkbox"/> Club drugs (ecstasy, hallucinogens)</p> <p><input type="checkbox"/> Oxycontin</p> <p><input type="checkbox"/> Does not apply; I have never used drugs</p> <p><input type="checkbox"/> Other (specify): _____</p>	
<p>Q.29. Have you heard of the Ryan White program?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>		
<p>Q.30. What is the Ryan White program?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>		
<p>Q.31. Which of these services does the Ryan White program offer? (Check all that apply.)</p> <p><input type="checkbox"/> Case management</p> <p><input type="checkbox"/> Child care</p> <p><input type="checkbox"/> Dental care</p> <p><input type="checkbox"/> Help paying for food</p> <p><input type="checkbox"/> Help paying for medicines</p> <p><input type="checkbox"/> Help paying for utilities, like heat or electricity</p> <p><input type="checkbox"/> Meal delivery when you don't feel well enough to make your own meals</p> <p><input type="checkbox"/> Help remembering to go to our appointments or take your medications</p>		<p><input type="checkbox"/> Home health care</p> <p><input type="checkbox"/> Help finding housing</p> <p><input type="checkbox"/> Legal help</p> <p><input type="checkbox"/> Mental health counseling</p> <p><input type="checkbox"/> Support groups</p> <p><input type="checkbox"/> Help getting connected to services or medical care</p> <p><input type="checkbox"/> Medical care for your HIV</p> <p><input type="checkbox"/> Substance-abuse treatment</p> <p><input type="checkbox"/> Transportation to my appointments</p> <p><input type="checkbox"/> Other (specify): _____</p>
<p>Q.32. How did you hear about the Ryan White program? (Check all that apply.)</p> <p><input type="checkbox"/> From friends</p> <p><input type="checkbox"/> From family/spouse/partner</p> <p><input type="checkbox"/> From my case manager</p> <p><input type="checkbox"/> From my doctor or nurse</p> <p><input type="checkbox"/> From an outreach worker</p>		<p><input type="checkbox"/> Saw a flyer about it</p> <p><input type="checkbox"/> Booth or table at a health fair</p> <p><input type="checkbox"/> At church/from my minister</p> <p><input type="checkbox"/> Other (specify): _____</p>
<p>Q.33. Where else do you get information about HIV services? (Check all that apply.)</p> <p><input type="checkbox"/> From friends</p> <p><input type="checkbox"/> From family/spouse/partner</p> <p><input type="checkbox"/> From my case manager</p> <p><input type="checkbox"/> From my doctor or nurse</p> <p><input type="checkbox"/> From an outreach worker</p>		<p><input type="checkbox"/> Saw a flyer about it</p> <p><input type="checkbox"/> Booth or table at a health fair</p> <p><input type="checkbox"/> At church/from my minister</p> <p><input type="checkbox"/> Other (specify): _____</p>
<p>Q.34. You know about free services, yet you are not in care. What has stopped you from getting care? (Check all that apply.)</p> <p><input type="checkbox"/> I use drugs or alcohol</p> <p><input type="checkbox"/> It is hard to get there</p> <p><input type="checkbox"/> I forget to go</p> <p><input type="checkbox"/> I do not have time to go</p> <p><input type="checkbox"/> I need help with childcare or family care</p>		<p><input type="checkbox"/> I feel ashamed, guilty or embarrassed</p> <p><input type="checkbox"/> I do not want anybody to find out</p> <p><input type="checkbox"/> Does not apply; it is <i>not</i> hard to get care</p> <p><input type="checkbox"/> Other (specify): _____</p>

That's the end of the survey. Thank you again for your help. Do you have any questions about the survey?

7.3 Participating Providers

- Anne Arundel County Health Department (Glen Burnie)
- AIDS Interfaith Resource Services (AIRS)
- Baltimore County Health Department (Liberty)
- Baltimore County Health Department (Towson)
- Baltimore Pediatric HIV Program
- Carroll County Health Department
- Chase Brexton
- Evelyn Jordan
- Family & Children Services
- Grateful, Inc.
- Harford County Health Department
- Haven
- HERO
- Howard County Health Department
- The Imani Center
- Manna House
- Park West Medical Center
- Peoples Community Health Care
- Project PLASE
- Sacred Zion
- South Baltimore Family Health
- Sisters Together and Reaching (STAR)
- Star Track
- Total Health Care
- Tuerk House
- University of Maryland Plus Clinic
- Women Accepting Responsibility

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