

KEY TO ABBREVIATIONS AND ACRONYMS

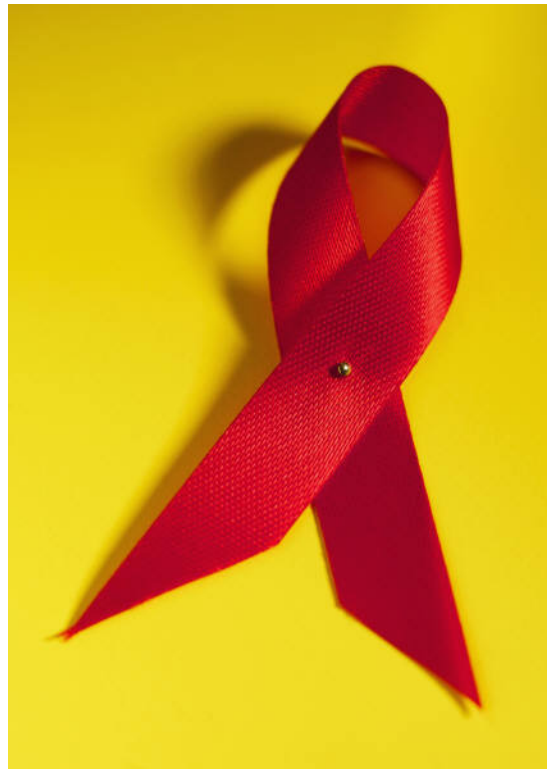
AA	African American
AAMSM	African American Men who have Sex with Men
AAMSW	African American Men who have Sex with Women
AAWSM	African American Women who have Sex with Men
AED	Academy for Educational Development
AHED	AIDS Health Educator (SC DHEC)
AIDS	Acquired Immunodeficiency Syndrome
ASO	AIDS Service Organization
ATOD	Alcohol, Tobacco, and Other Drugs
BRFSS	Behavioral Risk Factor Surveillance System
CBA	Capacity Building Assistance
CBCT	Community Based Counseling and Testing
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention
CLI	Community-Level Intervention
CPG	Community Planning Group
CTRS	Counseling, Testing, and Referral Services
DAODAS	SC Department of Alcohol and Other Drug Abuse Services
DEF	Data Entry Form
DHEC	SC Department of Health and Environmental Control
DIS	Disease Intervention Specialist (SC DHEC)
EHARS	Electronic HIV/AIDS Reporting System
EPI	Epidemiologic
GHS	Greenville Hospital System
GLI	Group-level Interventions
GMOC	Gay Men of Color
HBCU	Historically Black Colleges and Universities
HC/PI	Health Communications and Public Information
HE/RR	Health Education/Risk Reduction
HIV	Human Immunodeficiency Virus
HPC	SC HIV Planning Council
HRSA	Health Resources and Services Administration
IDU	Injection Drug User
ILI	Individual-level Intervention
IPF	Implementation Planning Form
LHD	Local Health Department

LIP	Local Implementation Plan
MCBO	Minority Community Based Organization
MIS	Management Information Systems
MUSC	Medical University of South Carolina
MSM	Men who have Sex with Men
MSM/IDU	Men who have Sex with Men/Injection Drug User
MSW	Men who have Sex with Women
NGO	Non-Governmental Organization
NIR	No Identified Risk
OUT	Outreach
PCM	Prevention Case Management
PCSI	Program Collaboration and Service Integration
PEMS	Program Evaluation Monitoring System
PLWHA	People Living with HIV/AIDS
PS	Partner Services
PSA	Public Service Announcement
SCDC	SC Department of Corrections
SCDE	SC Department of Education
SCSU	South Carolina State University
STD	Sexually Transmitted Disease (synonymous with STI)
STI	Sexually Transmitted Infection (synonymous with STD)
TA	Technical Assistance
USC	University of South Carolina
WSM	Women who have Sex with Men
YRBS	Youth Risk Behavior Survey

Appendix B

Qualitative Summary of Findings

**From Focus Groups with Consumers
Regarding HIV Care and Supportive Services in South Carolina**



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Background

South Carolina experienced a 131% increase in the number of persons living with HIV/AIDS from 1998 to 2002 and many of the newly infected were women. (*STD/HIV Program, 2005*) With the sharp increase in the number of new HIV/AIDS cases in the state, there has been a growing demand for health care, housing, support services, and prevention services for persons living with HIV/AIDS. As of December 31, 2002, there have been an estimated 12,553 cumulative cases of persons living with HIV/AIDS in the state. Approximately forty three percent (43%) of persons living with HIV are unemployed and earn less than \$10,000 annually (*STD/HIV Program, 2005*).

To specifically address the care and support service needs of HIV positive persons in South Carolina, eleven (11) Ryan White CARE Act Care Consortia service areas have been designated. The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is federal legislation that addresses the unmet health needs of persons living with HIV/AIDS (PLWHA) by funding primary health care and support services that enhance access to and retention in care. South Carolina's eleven care consortia are as follows:

Table 1: HIV Care Consortia and Counties Served

Ryan White Consortia	Counties served	Focus group conducted
AID Upstate	Anderson, Oconee, Pickens and Greenville	Greenville
Catawba Care Coalition	Chester, York and Lancaster	Rock Hill
Low Country HIV Care Consortium	Beaufort, Jasper, Hampton and Colleton	Hampton
HopeHealth	Florence, Darlington, Marlboro, Marion, Dillon and Chesterfield	Florence
HopeHealth Lower Savannah	Aiken, Barnwell and Allendale	Aiken
Midlands Care Consortium	Lexington, Richland, Newberry, Fairfield, Clarendon Sumter, Lee and Kershaw	Columbia and Sumter
Piedmont Care	Spartanburg, Union and Cherokee	Spartanburg

Ryan White Consortia	Counties served	Focus group conducted
Tri County Interagency AIDS Coalition	Orangeburg, Bamberg and Calhoun	Orangeburg
Trident HIV Care Coalition	Charleston, Dorchester and Berkeley	Charleston
Upper Savannah Care Consortium	Laurens, Abbeville, Greenwood, Saluda, McCormick and Edgefield	Greenwood
Waccamaw HIV Care Consortium	Williamsburg, Horry and Georgetown	Myrtle Beach

These care consortia are responsible for providing services to HIV positive persons and their families who have no other ability to pay for services. Services include primary medical care, medications, case management, and support services. Funding is provided for medications via the AIDS Drug Assistance Program (ADAP) and for housing via Housing Opportunities for People with AIDS (HOPWA).

The purpose of this investigation was to identify the prevention and care needs of persons living with HIV/AIDS, to identify what influences HIV positive people to seek and/or continue HIV/AIDS medical care, and the perceived quality of HIV prevention and care services in South Carolina.

Project Design

This project was designed and executed in collaboration with the SC HIV Planning Council, the SC Ryan White Care Consortia, the National Alliance of State and Territorial AIDS Directors (NASTAD), the SC Department of Health and Environmental Control’s (DHEC) STD/HIV Division, and researchers from the Arnold School of Public Health at the University of South Carolina. Each of the eleven Care Consortia were asked to recruit participants from their service area, provide a neutral site to conduct the focus groups and provide a means and incentive for consumer participation. The original plan of the study was to conduct two focus

groups in each of the eleven Care Consortium areas: one designated for HIV positive individuals currently “in care” as defined by the Health Resources and Services Administration (HRSA; having had a CD4 count, viral load test, or HIV medication within the last year) and another for persons living with HIV/AIDS who were not currently “in care.” The Consumer Advisory Workgroup for the Care Consortia indicated that persons in care would be able to recruit those not in care to participate in the focus groups. Overall, this recruiting strategy did not prove to be effective. As a result, only one focus group was held solely with persons who were “not in care.” The remaining nineteen (19) focus groups were conducted with people who were “in care,” including some people who were uncertain about their being “in care.”

The discussion guide (see Appendix 1: Focus Group Discussion Guide - Persons in Care and Appendix 2: Focus Group Discussion Guide - Persons Not Presently In Care), participant survey form (see Appendix 3: Focus Group Participant Profile), and the informed consent form (see Appendix 4: Consent to Participate in Focus Group) were developed in a collaborative effort between DHEC, NASTAD, and researchers at the Arnold School of Public Health, specifically to meet the information needs of the SC Ryan White Care Consortia. Both discussion guides addressed the following four areas as they impact (or affect) people living with AIDS: service utilization, barriers to care and unmet needs, prevention services and testing, and consumer involvement.

In general, the format of focus groups allows the participants the freedom to discuss issues and concerns about a particular topic with complete anonymity and without the fear of negative repercussions. In this case, the participants were able to fully discuss their experiences utilizing HIV care services in South Carolina, where their needs were not being met, and suggestions for improving care and support services and HIV prevention in their service area. In

addition to the participants in the focus groups, there was a trained facilitator and a note-taker for each group. The focus group facilitators and note-takers were provided with an in-service training on August 9, 2005, by NASTAD staff. Each focus group was also recorded to document the focus group and to further aid the note-taker in transcribing his/her notes for data analysis.

Data Analysis

The data analysis was comprised of two distinct sections: the quantitative (numerical) and qualitative (personal statements) sections. Quantitative data from the demographic information forms was entered into a database and analyzed utilizing SPSS to summarize the demographics of the participants. Qualitative focus group data was transcribed by the note-takers and forwarded to an independent data analyst. These data were then analyzed using NVivo 2.1, a software package for coding and analysis of textual data. Members of the research team developed a codebook, (see Appendix 5: NVivo 2.0 Node Listing for DHEC Focus Groups) derived from the questions and probes found in the discussion guides (see Appendix 1: Focus Group Discussion Guide - Persons in Care and Appendix 2: Focus Group Discussion Guide - Persons Not Presently In Care). Two members of the research team independently coded each transcript, identifying emergent and recurring themes. Emergent themes were identified from the data across all focus groups as well as from focus groups with just male participants or with just female participants. To be considered a theme, a topic had to occur across the majority of focus groups (or all female groups or all male groups) and had to be mentioned more than once in each focus group.

After all of the transcripts had been independently analyzed the researchers met and reviewed the analyzed documents to reach consensus. Having two researchers independently analyze the data ensures that each of the identified themes were correctly identified and coded

properly. The process of reaching consensus is a practice commonly done in qualitative data analysis to ensure that the data were analyzed to reduce bias. After consensus had been reached, the data were further analyzed to identify the new and recurring themes expressed during the focus groups. The quantitative and qualitative data were then assembled into a comprehensive report for the Ryan White Care Consortia and the SC HIV Planning Council.

Quantitative Summary

Twenty focus groups were conducted with a total of 113 participants across 12 sites. The largest percentages of participants were from the Rock Hill (Catawba Care Coalition) and Spartanburg (Piedmont Care) areas with 10.6% each. The smallest percentage of participants was from Hampton (Low Country Care Consortium) with 4.4%. The majority of participants were African American (75.2%). Fifty-seven (57%) percent of the participants did not identify as belonging to any one ethnicity, but 40.7% reported they were not Hispanic. The focus group participants were almost evenly divided with males and females, with 49.6% being male and 48.7% being female. The average age of participants is 44 years old. The majority of the participants reported being heterosexual (60.2%), and 31% reported being homosexual.

Table 2: SC HIV Planning Council Focus Group Demographics

Consortium	Number of Participants	Number of Focus Groups Per Site	Number of Males (%)	Number of Females (%)	Number of Transgender (%)	Number Gender not answered
HopeHealth Lower Savannah	7	2	2 (29%)	4 (57%)	0	1(14%)
Midlands Care Consortium (Sumter)	11	2	3 (27%)	8 (73%)	0	0
HopeHealth AID Upstate	10	1	4 (40%)	6 (60%)	0	0
Upper Savannah Care Consortium	6	1	3 (50%)	3 (50%)	0	0
	9	2	7 (78%)	1 (11%)	1(11%)	0

Consortium	Number of Participants	Number of Focus Groups Per Site	Number of Males (%)	Number of Females (%)	Number of Transgender (%)	Number Gender not answered
Waccamaw HIV Care Consortium	10	2	7 (70%)	3 (30%)	0	0
Tri County Interagency AIDS Coalition	9	1	1 (11%)	8 (89%)	0	0
Catawba Care Coalition	12	2	9 (75%)	3 (25%)	0	0
Piedmont Care	12	2	10 (83%)	2 (17%)	0	0
Midlands Care Consortium (Columbia)	11	2	6 (55%)	5 (45%)	0	0
Low Country HIV Care Consortium	5	1	0 (0%)	5 (100%)	0	0
Trident HIV Care Coalition	11	2	4 (36%)	7 (64%)	0	0

Socioeconomic Status

The majority of participants had some high school but didn't graduate (25.7%) or had some college but no degree (21.2%). Only 2.7% of participants reported education of 8th grade or less. A large percentage of participants were on disability (37.2%) or unemployed (25.7%) at the time of the focus groups. Almost 70% of participants reported an annual income level of \$19,999 or less (with the majority of those making less than \$5,000 per year). Most of the participants rent or own a house/apartment (63.7%), while 16.8% live with relatives or friends, or did not provide a response about their housing situation (15.9%; see Limitations page 10).

HIV Care and Prevention Services

The vast majority of participants reported they were in care (96.5%) per the Health Resources and Services Administration (HRSA) definition of "in care." Seventy-five percent

(75.2%) of participants reported having received HIV medical care or a CD4 and/or viral load test in the past year (15.9% did not respond; see Limitations page 10). Approximately 63% reported having received HIV Prevention Services (educational sessions, counseling and testing, and/or contact with an outreach worker) in the past year, while 18.6% reported not receiving HIV Prevention Services (15.9% did not respond; see Limitations page 10).

Gender

In total, 55 women participated in the focus groups. The majority of the female participants reside in Columbia (14.5%), Orangeburg (14.5%), and Charleston (12.7%). The female population was 89.1% African American, 10.9% Caucasian, and 1.8% Latina. Ninety-six percent (96.4%) of all female participants are in care. Sixty percent (60%) rent or own their home/apartment and 12.7% live with relatives or friends. Eighty-seven percent (87.3%) are heterosexual and 7.3% are homosexual. Education levels for females are as follows: 29.1% have some high school education and 20% have some college. Approximately 31% (30.9%) are unemployed and the same percentage (30.9%) is on disability, with approximately 30% working part time or full time. Thirty-six percent (36.4%) of female participants have a yearly income of less than \$5,000. Almost sixty-six percent (65.5%) have received HIV medical care, while 52.7% have received HIV prevention services.

Limitations of the Qualitative Data:

For the Sumter and Orangeburg focus groups, the participants did not receive one of the necessary demographic data forms. Although the participants did complete the NASTAD demographic form, it did not contain all of the questions on the DHEC form; therefore, some responses were not collected for those participants.

Qualitative Summary

Service Utilization

Overall, there are no definitive statements that can be made about the HIV/AIDS medical care of persons living with HIV/AIDS in South Carolina. When asked, “*How do you feel about the HIV care services you have received?*” the amount, availability and quality of the care were specific to each service area. Some reported being quite satisfied with the services offered while others reported that there was a great deal lacking in their service area.

Case Managers

The participants were further probed about their case manager. In the various consortia areas, the term “case manager” had a different and sometimes multiple meaning, according to how the Ryan White clinic was established in their specific area. Although many responded that they truly appreciate their case manager, there was frustration expressed about having multiple case managers and not knowing which one to access to solve their problems. Many participants reported that they would like to see a more centralized care system to reduce the amount of traveling and repetition required to attain health care and associated services (see Table 3: Service Utilization); however, many concerns were expressed about the stigma that would be associated with a centralized HIV service location.

Medical Care

The respondents indicated that in some areas there are good, well-trained Infectious Diseases (ID) physicians but that, over all, medical treatment in South Carolina was lacking. Some areas have only one or no Infectious Disease doctor. As a result, people living with HIV/AIDS reported receiving services from other less-qualified providers. Participants also conveyed that many emergency room doctors and other care providers such as dentists and obstetrics and gynecology (Ob/Gyn) specialists were not well trained or not willing to treat

persons living with HIV/AIDS. The participants reported that medical care providers often treated them differently after their HIV status was divulged (see Table 3: Service Utilization).

Table 3: Service Utilization

Question	Positive Perspectives	Negative Perspectives
How do you feel about the HIV care services you have received?	<ul style="list-style-type: none"> • <i>“They have been really good to me. I never have any problems. If I say I need something...they are like family.”</i> • <i>“When I first started taking meds I missed doses. But they (health center) called to remind me and encouraged me to take them. They talked to me like I was a human being; lots of respect. They came with respect, so I responded with respect.”</i> 	<ul style="list-style-type: none"> • <i>“We’ve all had bad experiences with medical care.”</i> • <i>“If you say you’re HIV positive, then you get bad care. If you don’t tell them that you’re HIV positive, then you get good care.”</i>
Probe: Case management	<ul style="list-style-type: none"> • <i>“You (the patient) have to get to know them (the case manager). You have to open up to feel welcome.”</i> • <i>“Have had no problems calling case manager if I need help.”</i> 	<ul style="list-style-type: none"> • <i>“Which one? There are so many (case managers) and they change like the wind.”</i> • <i>“I feel like the case managers take on more then they are qualified for”</i>
Probe: Medical care	<ul style="list-style-type: none"> • <i>The doctor and nurse were very considerate. Now they answer all my questions over the phone and call in ‘scripts’ for me.”</i> • <i>“I was connected with the ID doctor in [Place].... The doctor is brilliant.”</i> 	<ul style="list-style-type: none"> • <i>“Some people in the hospital find out that you have HIV and they are nasty to you. Sometimes I feel like not telling them.”</i> • <i>“I worked in the ER and avoided people with HIV and saw many doctors and nurses do it, too. The medical field still fears the disease.”</i>

Theme	Response
Lack of knowledgeable specialized medical professionals	<ul style="list-style-type: none"> ▪ <i>“My Ob/Gyn wouldn’t do a pap smear because he found out I was HIV positive.”</i> ▪ <i>“An Ear, Nose, and Throat (ENT) doctor... I have HIV related throat problems. They won’t treat you if you’re HIV positive.”</i> ▪ <i>“I got dental service once and the doctor changed all his mannerisms when he found out I was HIV positive.... I felt very ostracized.”</i>

Agency Perceptions

When asked “Have you ever felt particularly welcome, or motivated by an agency?” the participants conveyed that they rely heavily on their local HIV agencies for support and they have mostly positive perceptions of the services they receive. The participants did, however, show some concern over funding for their specific agencies, as well as discrepancies in treatment among clientele and a lack of proper training so that the agency staff could best serve them and their needs.

Table 4: Agency Perceptions

Question	Positive Perspectives	Negative Perspectives
Question: Have you ever felt particularly welcome, comfortable, or motivated by an agency?	<ul style="list-style-type: none"> • <i>“There’s lots of support. They helped me go through the services, encouraged me to go back to school, gave me clothes, and help HIV positive individuals get benefits.”</i> • <i>“I never had a bad experience. The volunteers at the clinic are like God-sent people.”</i> 	<ul style="list-style-type: none"> • <i>“Clinic not writing my reports correctly and intentionally keep you off of SSI and disability in South Carolina.”</i> • <i>“The knowledge at the agency... it seems like they are lacking knowledge in certain areas.... Resources are available but they can’t get people to them.”</i>

Reasons to be in Care

During the focus groups the facilitator asked the participants “What motivated you to get HIV care?” Overwhelmingly, the participants indicated that they were in care in order to

prolong their lives. Several other reasons were noted as reasons to be in care, including family, overcoming life-threatening illness, and the influence of a medical provider (see Table 5:

Reasons to be in Care).

Table 5: Reasons to be in Care

Question	Response
Question: What motivated you to get HIV care?	<ul style="list-style-type: none"> • <i>“I just want to live.”</i>
Probe: Primary care provider	<ul style="list-style-type: none"> • <i>“The doctor said I won’t live five years. So, I wanted to prove that he was a liar. So, I took my meds and wanted to live.”</i> • <i>“I only started meds because I got sick and the doctor said I wouldn’t survive.”</i>
Probe: Family/Friends	<ul style="list-style-type: none"> • <i>“When I found out, I wanted to give up. I let myself go down. My kids would say “Mama, what’s wrong...” You know you’ve got to be there for them.”</i> • <i>“After talking to my pastor.... and my grandkids. I wanted to live to see them grow up.”</i>
Probe: Others	<ul style="list-style-type: none"> • <i>“I went 5 years after being diagnosed. I was in denial... I got sick and felt I had to get help.”</i>

Barriers to care and unmet need

The second area explored during the focus group was barriers to care and unmet need. The greatest barriers to care among the participants in the focus groups were associated with transportation to care, the actual treatment they received while attempting to attain care, eligibility requirements, and the limiting rules and regulations around Medicare/Medicaid. The lack of public transportation in South Carolina also serves as a barrier to care. Many of the participants indicated that there was transportation offered, but often it proved to be inadequate to get them to their medical appointments in a timely manner. The participants also relayed that

they often felt mistreated by medical professionals and that not having private health insurance hinders the process for them to receive medical care in many health establishments.

The participants noted that the complex rules and regulations set forth by Medicare, Medicaid, and SC DHEC also proved to hinder care in South Carolina. Many reported that they were not able to receive adequate care for other conditions, even if the conditions were a result of having HIV.

Throughout the focus groups, it was evident that the climate surrounding HIV in South Carolina and the fear of not wanting to stigmatize their children served to be an additional barrier to receiving services. Also, because the majority of South Carolina is rural, the respondents indicated that that they perceived that there is a lack of privacy that ultimately resulted in persons living with HIV/AIDS seeking care less often.

Many of the people who participated in the focus groups indicated that depression and the additional stresses and strains associated with being HIV positive often served as an additional barrier to seeking and actively receiving care (see Table 6: Barriers to Care and Unmet Need).

Table 6: Barriers to Care and Unmet Need

Question: What services or care have you wanted or needed and couldn't get?	
Theme	Responses
Probe: Housing	<ul style="list-style-type: none"> ▪ <i>"...housing, HIV (positive people) cannot be admitted to shelters"</i> ▪ <i>"They need housing for HIV positive people"</i> ▪ <i>"I couldn't get life insurance. The seller (of the life insurance) went and told my neighbor. I had to move."</i>
Probe: Insurance	<ul style="list-style-type: none"> ▪ <i>"If you don't have insurance you can't get treatment"</i> ▪ <i>"If you have to go to ER, you have to have trauma or problems with your heart. You have to have insurance."</i>
What were the problems in getting those required services?	

Theme	Responses
Not meeting eligibility requirements and cost	<ul style="list-style-type: none"> ▪ <i>“They won’t help with meds that aren’t directly related to HIV.”</i> ▪ <i>“The doctors do what I ask but are limited in what they’re allowed to do. I can’t get my heartburn ‘script’ covered. They’re covering things directly related to HIV but not the surrounding issues.”</i>
Stigma	<ul style="list-style-type: none"> ▪ <i>“I was not welcome at my job after I told them I had it (HIV).”</i> ▪ <i>“I deal with my children. I don’t want them to be chastised for me. It’s better if I don’t go to the clinic [because of the stigma effect on my children].”</i>
Privacy	<ul style="list-style-type: none"> ▪ <i>“The problem with this being a small town is that people talk about your business. People are afraid that their families will shun them so they’re afraid to speak out.”</i>
Mental Health	<ul style="list-style-type: none"> ▪ <i>“I wish I hadn’t been diagnosed. It changed my outlook on myself. It made me feel lesser.”</i> ▪ <i>“Some days you wake up and want to go on...some days you wake up and think “Lord no!”</i>

HIV Prevention Services

The third area that was investigated during the focus groups was HIV prevention services and testing. The participants were asked, *“What prevention services do you have in your area that help people from getting HIV?”* The majority of the participants mentioned the agency that had recruited them to participate in the focus groups and the use of all types of media for HIV prevention. They also indicated that they had witnessed an increase in condom distribution in their communities but wondered if condoms were enough to address the risk among youth.

The participants were asked, *“What reasons have you heard for why people at risk for HIV have not had an HIV test?”* The reasons included fear of a positive HIV status, of stigma related to being HIV positive, and denial that they are at risk for contracting HIV.

Table 7: HIV Prevention Services

Question: What Prevention Services do you have in your area that help people from getting HIV?	
Theme	Responses
Probe: Media	<ul style="list-style-type: none"> ▪ <i>“I’ve seen some commercials. Hopefully this will open people’s eyes”</i> ▪ <i>“I’ve seen billboards and commercials and I’ve liked them.”</i> ▪ <i>“I see ads on the TV and hear them on the radio.”</i>
Question: What reasons have you heard for why people at risk for HIV have not had an HIV test?	
Theme	Responses
Theme: Fear	<ul style="list-style-type: none"> ▪ <i>“Scared to know. People say ‘knowing is beautiful’ but it is not. People are scared they might have it. ‘I’ve got a death sentence...’ People may know they have it but will not have the test.”</i> ▪ <i>“A lot don’t want to know their status. [They think] what you don’t know won’t hurt you.”</i>
Question: What reasons have you heard for why people at risk for HIV have not had an HIV test?	
Theme	Responses
Theme: Stigma	<ul style="list-style-type: none"> ▪ <i>“They’re afraid to find out. Afraid of the social stigma.”</i> ▪ <i>“There is a stigma to getting tested.”</i> ▪ <i>“...people are afraid to get tested because they are afraid they are going to be discriminated against”</i>
Theme: Denial of risk	<ul style="list-style-type: none"> ▪ <i>“They feel that it can’t happen to them.”</i> ▪ <i>“I might live longer if I don’t know it. They might not be able to handle it.”</i>

The participants were then asked, “What can care or service providers do to help people with HIV tell their sex partners about their HIV status?” The responses were not conclusive.

Many indicated that it was a personal matter that should not include professional health care providers, whereas others suggested educated personnel would help in the discussion process.

Table 8: Disclosure of HIV Status to Sex Partner

Question: What can care or service providers do to help people with HIV tell their sex partners about their HIV status?	
Theme	Response
Personal event	<ul style="list-style-type: none"> • <i>“...there is support for help in telling your partner. But I don’t think that’s for the healthcare provider. That’s personal.”</i>
Case worker assistance	<ul style="list-style-type: none"> ▪ <i>“Case workers could come with you.”</i>
Better education	<ul style="list-style-type: none"> • <i>“Give them lots of information, a real understanding. Give them literature.”</i>

Consumer Involvement

The final area of discussion solicited suggestions about improving HIV care and/or prevention services. They were asked, *“What would be the single most important change you would suggest to improve services to people living with HIV?”* The respondents from every area had a plethora of ideas and suggestions focusing on HIV education, advocacy and policy change. The respondents felt as though the greatest need for prevention was among youth. They wanted to see more education in the schools and with parents. There was also recognition that the fundamentals of HIV prevention need to start at the individual level. Many of the participants also indicated that there needed to be a change in the HIV testing policy as well as advocacy for sexual minorities in South Carolina.

Table 9: Consumer Involvement

Question: What would be the single most important change you would suggest to improve services to people living with HIV?	
Theme:	Responses
Education	<ul style="list-style-type: none"> ▪ <i>“Educate: school, community, children, and parents. Let them know HIV/AIDS is here and it is real.”</i> ▪ <i>“These kids think they are invincible. They are having sex early. I don’t understand if a person doesn’t want their kids to learn.”</i>
Individual responsibility	<ul style="list-style-type: none"> ▪ <i>“We do need more people out there spreading the word.”</i> ▪ <i>“But each individual has to take responsibility. It has to be an individual responsibility to take care of yourself. It is preventable to a certain extent.”</i>
Advocacy and policy change	<ul style="list-style-type: none"> ▪ <i>“Things are not going to change until you have mandatory testing”</i> ▪ <i>“You’d have to be able to fight homophobic politics.”</i> ▪ <i>“Ads for HIV/AIDS is very limited in this county. It’s very homophobic...more emphasis should be promoted that the disease is prevalent throughout the community.”</i>

Conclusion

At the conclusion of the focus groups the participants were asked “Is there anything else you would like us to know?” The overall sentiment expressed by the participants was that people living with HIV/AIDS are resilient and have faith that they can live long productive lives.

- *“ I have HIV, but HIV doesn’t have me.”*
- *“I strongly believe they will find a cure and I will get it.”*

Many consumers that are in care have been able to move beyond how and when they contracted the virus to focus on living.

- ***“When I found out I thought I had danced with the devil and now I’m caught.”***
- ***“I don’t think this is going to kill me as long as I take the meds.”***
- ***“It’s just about living today.”***

There are many people in South Carolina who are HIV positive and actively seeking prevention and care services. They are aware of the shortcomings of the systems in place and, when given a voice, many are willing to become advocates for change. Over the past twenty years, the face of HIV has changed drastically and SC DHEC’s STD/HIV Division and Ryan White Care programs are facing the challenge head on. HIV prevention and care services must be available for all regardless of payer source. South Carolina is a poor state and, thus, the needs of persons with HIV/AIDS burden an already overwhelmed medical system for persons with limited means.

References

STD/HIV Program. (2005). Retrieved October 21, 2005, from

<http://www.scdhec.net/health/disease/stdhiv/index.htm>

**Note: For a copy of any appendix to this document, please contact
the SC DHEC STD/HIV Division office at 803-898-0749.**

Appendix 1: Focus Group Participant Profile

Appendix 2: Consent to Participate in Focus Group

Appendix 3: Focus Group Discussion Guide - Persons in Care

Appendix 4: Focus Group Discussion Guide - Persons Not Presently In Care

Appendix 5: NVivo 2.0 Node Listing for DHEC Focus Groups



South Carolina HIV Planning Council
African American Men who have Sex
with Men (AAMSM) Workgroup

Results from the
Information and Awareness Forum
Held October 17, 2007

Prepared by
Stacy W. Smallwood, MPH

Release Date: February 7, 2008



**Greetings From The
African American MSM Workgroup
Chairperson**

The African American MSM (AAMSM) Workgroup was formed in September 2006 as an Ad Hoc Group of the South Carolina HIV Planning Council. The group was formed to provide recommendations on strategies and approaches to address barriers to HIV Testing and participation in HIV Prevention Education and activities among AAMSM.

The formation of this group was critical, as these are critical times for AAMSM in South Carolina. This population continues to be Priority Population #2, when HIV is 100% preventable. It is the belief of the workgroup that we must review the existing conditions of prevention efforts targeted toward this population, improve in areas where improvement is necessary, and create new prevention approaches in order to reach and engage AAMSM.

The information shared within was gathered during the African American MSM Forum and clearly shows “Why We Can’t Wait.” We must do more to address the HIV Prevention needs of this population. I encourage you to join us in this effort as we seek to improve the health status of African American MSM in South Carolina by decreasing the spread of HIV/AIDS.

Sincerely,

Matt Jenkins

Matt Jenkins, Chairperson
S.C. African American MSM Workgroup

Results from the AAMSM Information and Awareness Forum Held October 17, 2007

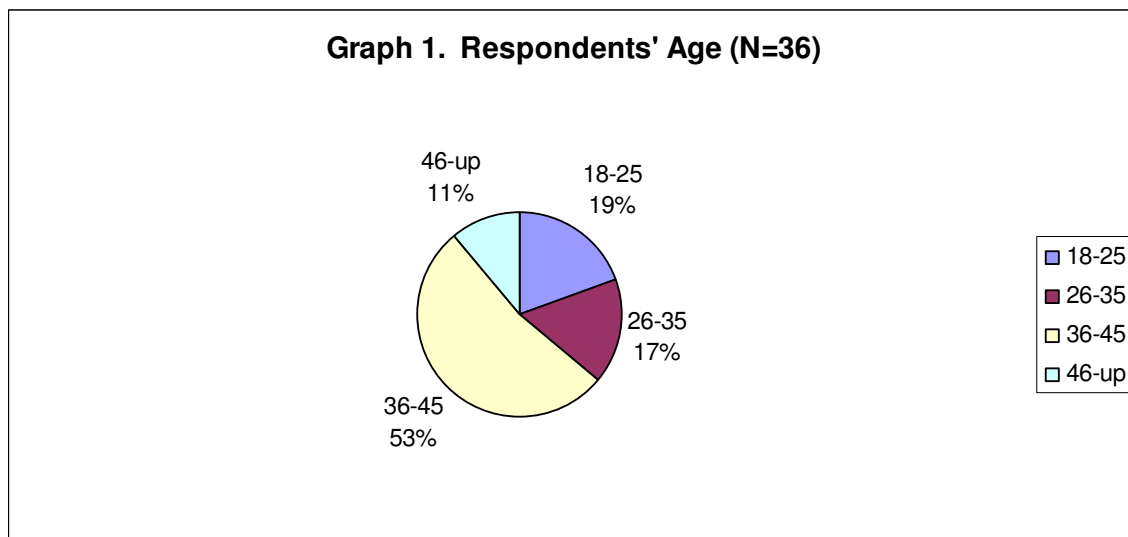
Methods

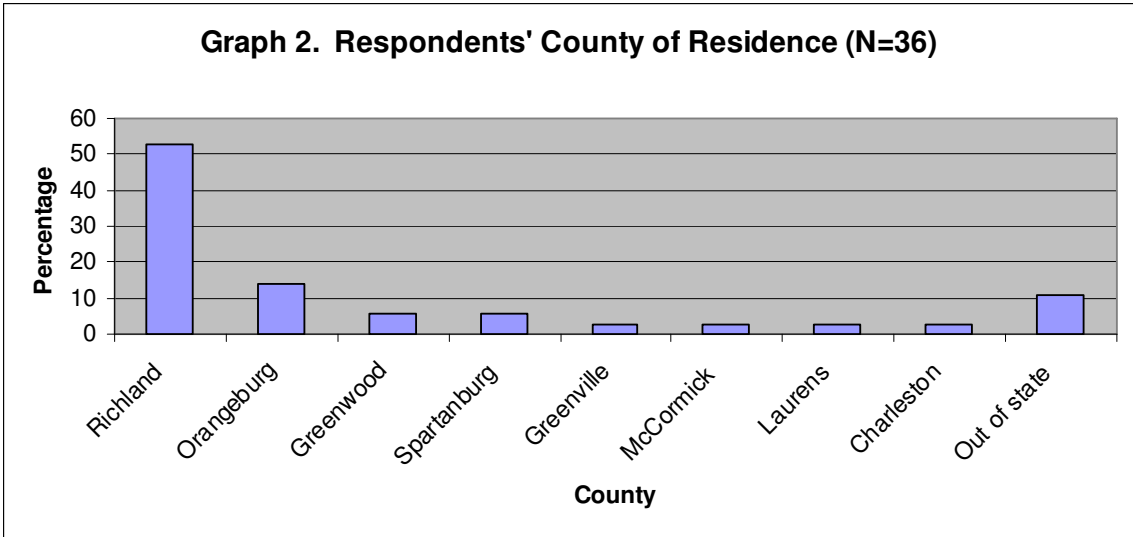
The survey instrument was a one-page, 10-item, self-administered questionnaire developed by the SC HIV Planning Council's African American Men who have Sex with Men (AAMSM) Workgroup. It included questions about demographics, HIV status and testing history, sexual identity, recognition of the "Many Men, Many Voices" HIV prevention intervention, and awareness of/participation in community HIV/AIDS services. There were also two qualitative questions about the services needed for AAMSM in respondents' respective communities, and AAMSM issues in their communities.

The survey was administered on October 17, 2007 at the AAMSM Workgroup's Information and Awareness Forum at the 2007 South Carolina HIV/STD Conference. Thirty-seven African American MSM responded to the survey. After respondents completed the survey, they participated in a moderated discussion in which they were asked additional questions about the perception of HIV in AAMSM communities, HIV/AIDS service delivery, barriers to AAMSM participation in HIV/AIDS programs, and strategies for overcoming those barriers. The discussion lasted approximately 45 minutes.

Results

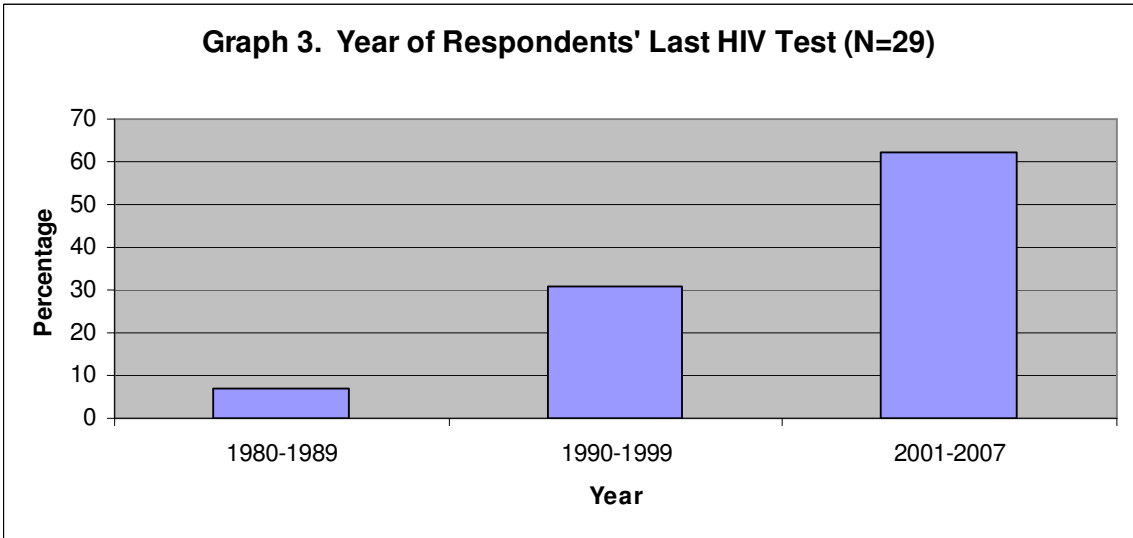
The mean age of respondents was 37.2, with a standard deviation of 9.69. Respondents' ages ranged from 18 to 57, with most respondents between the ages of 36-45. Graph 1 shows the age distribution of respondents, and Graph 2 shows the respondents' county of residence. The majority of respondents (53%) listed Richland County as their county of residence, followed by Orangeburg County. Eleven percent (11%) of respondents were from outside the state.



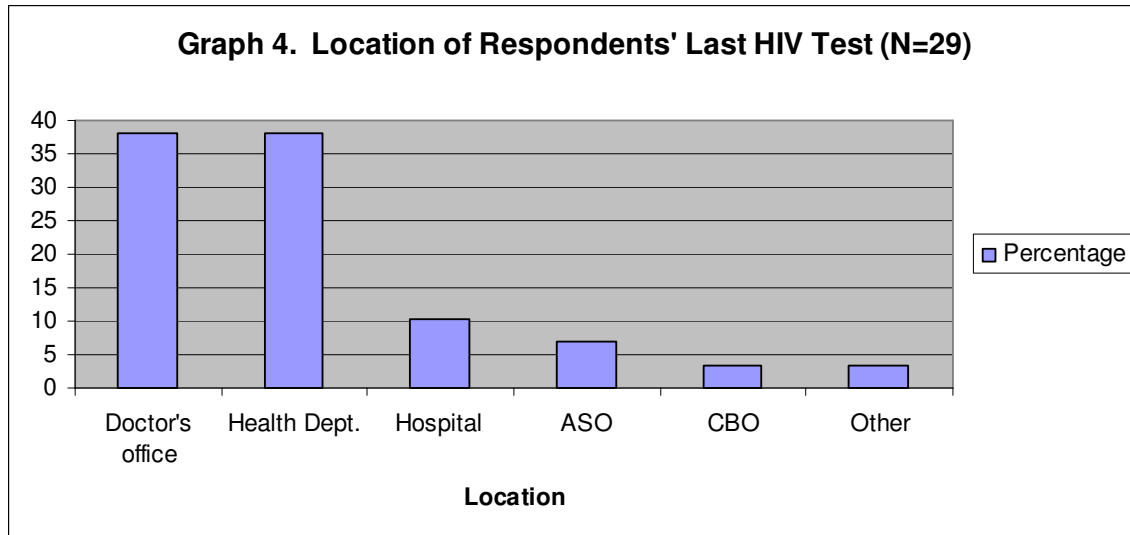


HIV Testing

One hundred percent (100%) of respondents reported having been tested for HIV. Graph 3 illustrates the year of respondents' most recent HIV test. When asked about the date of their most recent test, 24.3% had been tested in 2007, and 48.6% had been tested since 2001. Just over 24% reported their last test being in the 1990s, and 5.4% reported being tested last in the 1980s. 21.6% did not respond to this question.

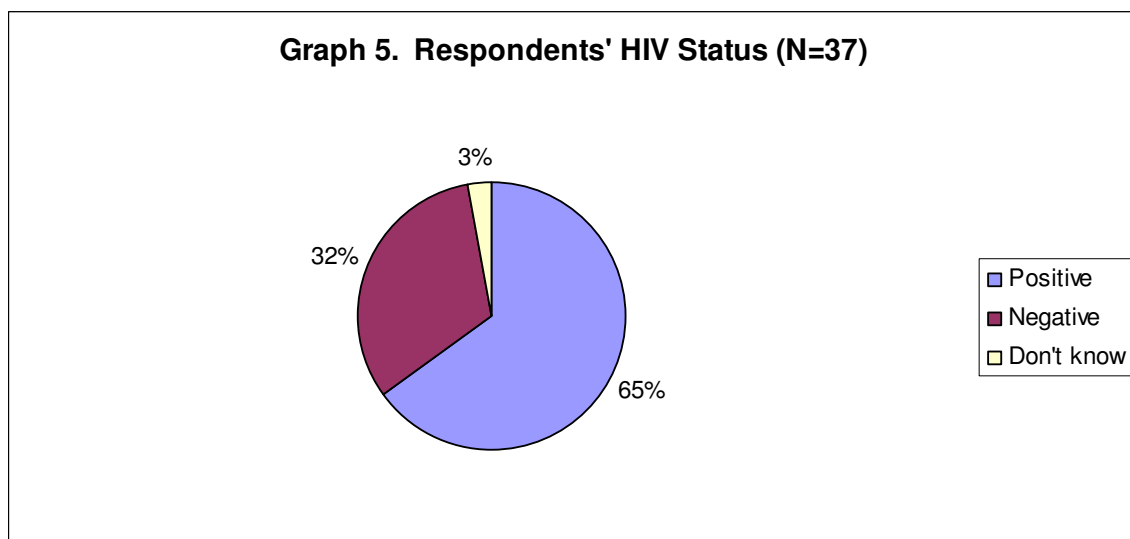


Graph 4 shows the location of respondents' most recent HIV test. Most respondents reported getting their last HIV test in a doctor's office or at the health department (37.9% each), followed by hospitals (10.3%), AIDS service organizations (6.9%), and community-based organizations (3.5%).



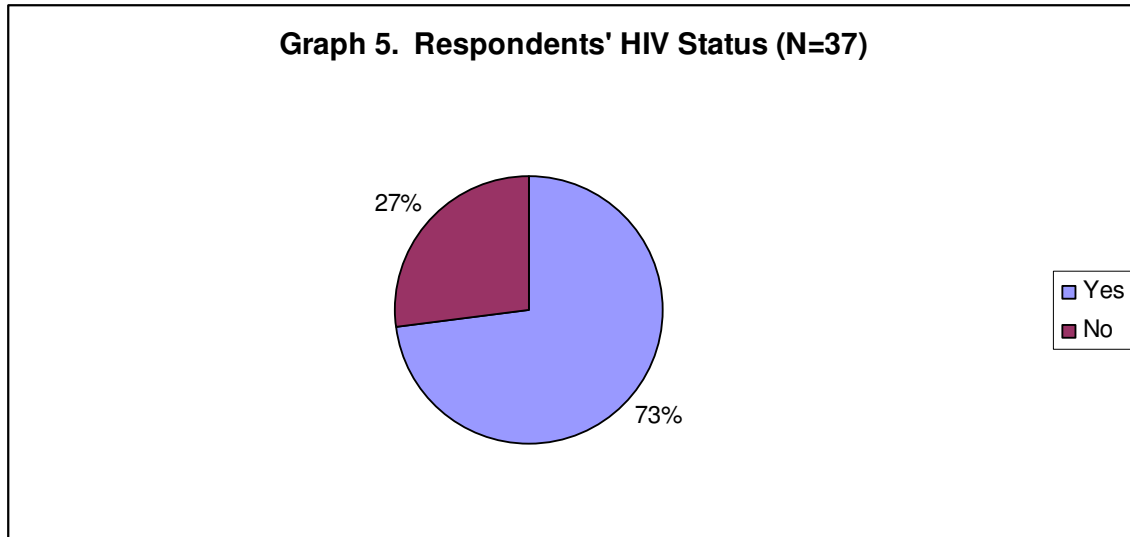
Respondents were asked to report their HIV status. Graph 5 shows the respondents' reported HIV status. Sixty-five percent (65%) of respondents reported being HIV-positive, while 32% reported testing negative, and 3% did not know their status. Of those who were HIV-negative, two-thirds reported being tested in the year 2007.

Of those who reported being HIV-positive, four percent reported not receiving care and treatment. Seventy-one percent of those who reported being HIV-positive also reported that they were receiving care and treatment.



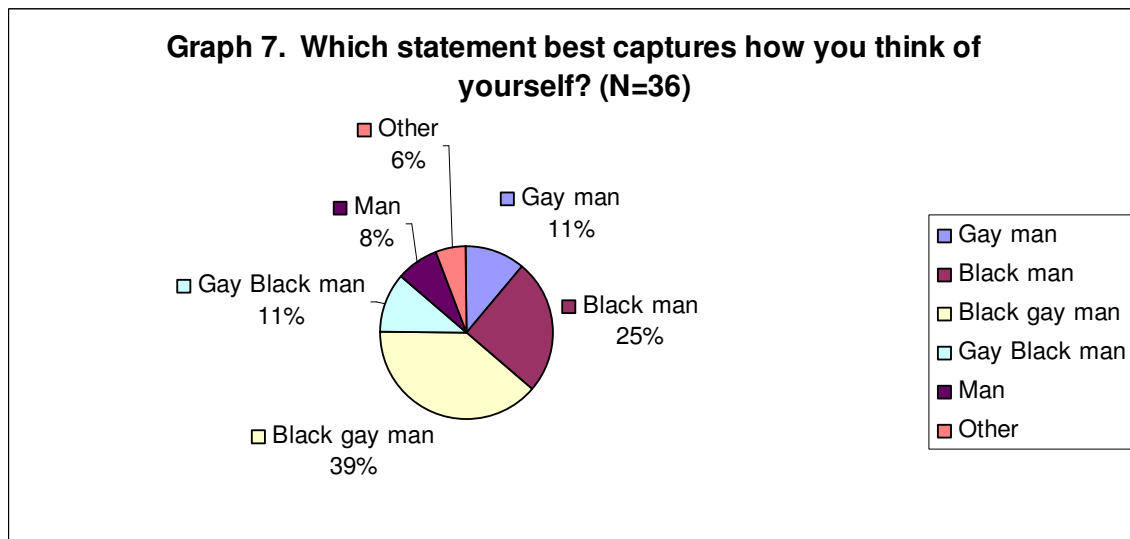
Program Recognition

Graph 6 describes respondents' familiarity with the "Many Men, Many Voices" intervention. When asked about the "Many Men, Many Voices" intervention, 73% of respondents reported that they had heard of the program, while 27% reported that they had not. Seventy percent of those who had not heard of the intervention live in Richland County.



Sexual Identity

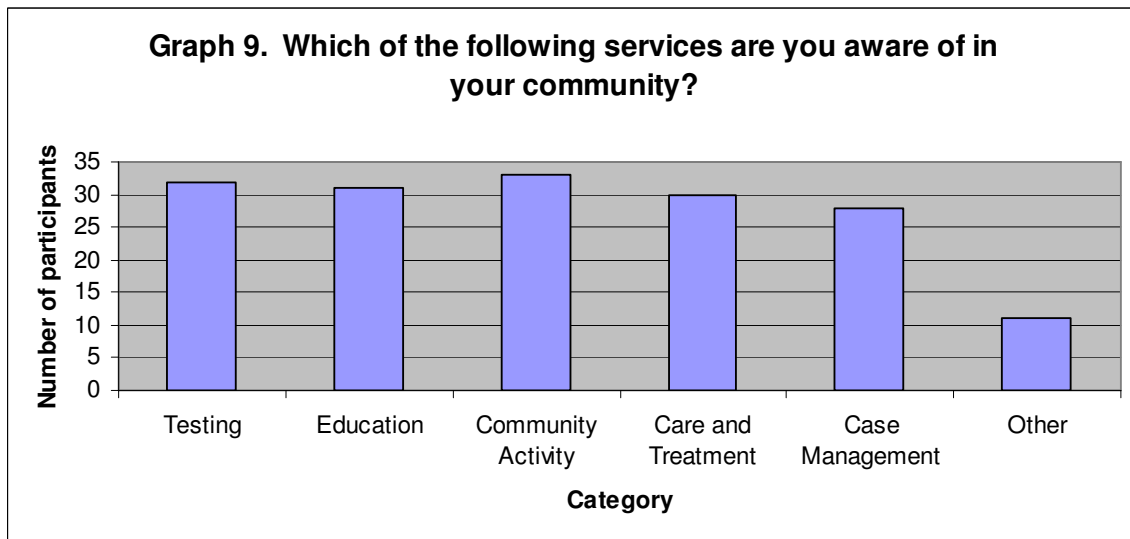
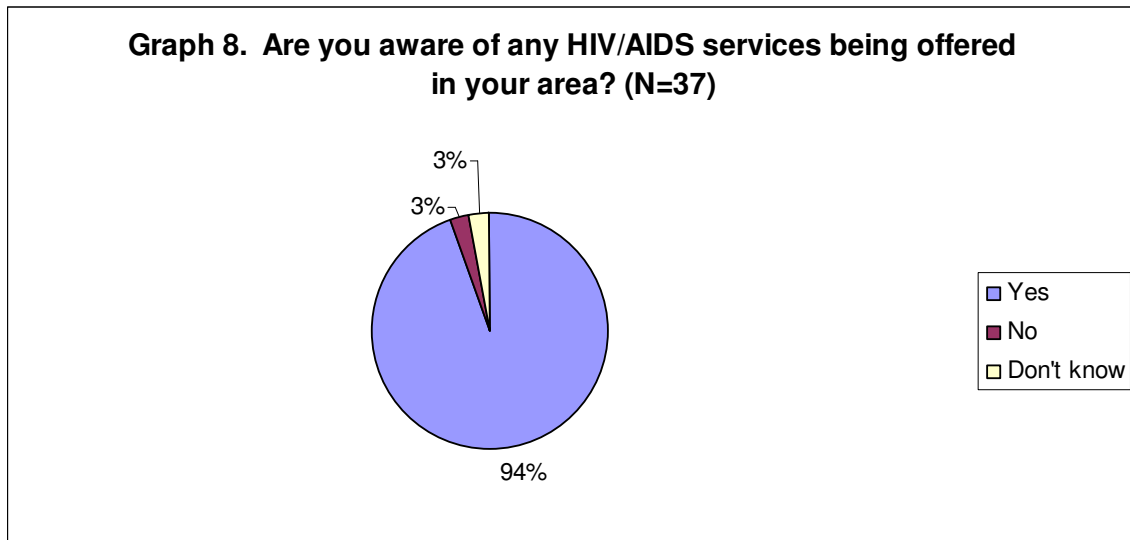
Respondents were asked to choose the statement that best described how they thought of themselves. Their responses are shown in Graph 7. More than a third (38.9%) chose the statement, “I am a Black gay man,” and 25% chose the statement, “I am a Black man.” The statements “I am a gay man” and “I am a gay Black man” were each chosen by 11.1% of respondents. Those who chose “other” identified themselves as “A man part Black and gay,” and “Same gender loving.”



HIV/AIDS Services

Graph 8 shows respondents’ awareness of HIV/AIDS services in their communities. The majority of participants reported being aware of HIV/AIDS services being offered in their area (94.6%). Graph 9 shows the services with which respondents were familiar. The services they were most aware of were: Community HIV/AIDS Activities (e.g. World AIDS Day), HIV Testing, and HIV/AIDS Education. The services they were least aware of were: Care and Treatment, and Case Management. Other services identified included

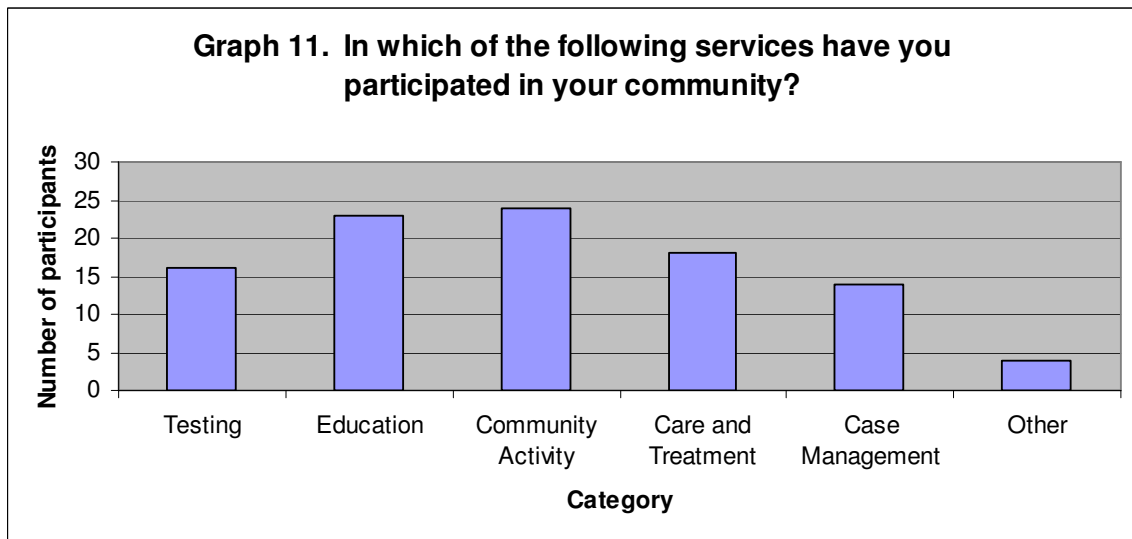
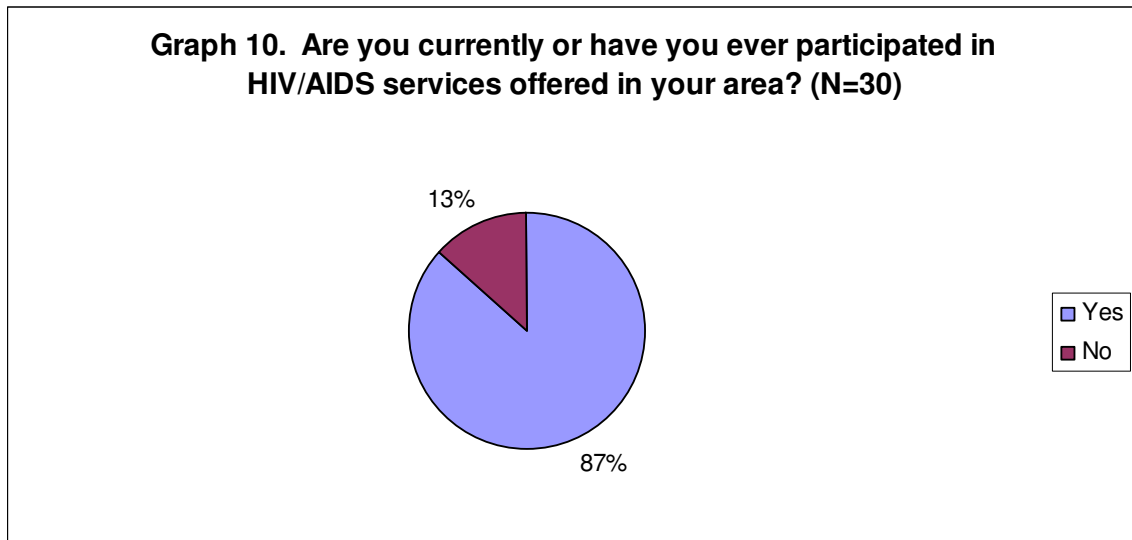
transportation, outreach, public health fairs, church HIV/AIDS ministries, interventions, and care teams.



Graph 10 shows respondents' participation in local HIV/AIDS services. Eighty-seven percent (87%) reported participating in HIV/AIDS services offered in their communities. Graph 11 illustrates the services in which respondents had participated. The services most widely participated in were: Community HIV/AIDS Activities, HIV/AIDS Education, and Care and Treatment. The services least participated in were Case Management and HIV Testing. Other activities listed included serving on the boards of AIDS Service Organizations or Community-Based Organizations; National Latino AIDS Awareness Day; Care Teams; and Housing.

Respondents who indicated no participation in HIV/AIDS services were asked to identify reasons why they were not participating. Four respondents answered this question, identifying a range of issues. These included a negative reputation of the local

HIV/AIDS community-based organization; stigma; fear of confidentiality being breached through participation; and lack of caring.



Summary of Qualitative Items

Respondents were asked about programs or services that they felt were needed for African American MSM in their communities. Nineteen respondents answered this question, and several themes emerged from their responses. A need for more education and prevention programs in general was expressed by many respondents. In particular, “Many Men, Many Voices” was mentioned as a program that needed to be promoted and implemented more frequently. Also, many responses were related to young AAMSM in their communities. There were recommendations for youth programs targeting not only HIV/AIDS awareness and education, but also life skills training through internships and experiential learning. Another theme that was discussed was the need for affirmation and acceptance on the part of AIDS service organizations.

Respondents were also asked about issues that they face as AAMSM in their respective communities. A major theme that emerged was the idea of fear and stigma. Fifteen respondents named fear and/or stigma as a major issue facing them in their communities. However, not all respondents indicated what kind of stigma they were referring to (stigma associated with being gay/bisexual, stigma associated with HIV infection). Homophobia was a theme that emerged that was closely related to fear and stigma issues. Several respondents mentioned internalized homophobia within the AAMSM community, as well as homophobia within the larger African American community. Issues of disclosure were also a major theme. Respondents were concerned about how to communicate with intimate partners about their HIV status, and the legal implications of not disclosing. Another theme that emerged was the idea of an AAMSM community identity. Three respondents identified issues around networking with other MSM and getting them to participate in AAMSM and/or HIV-related activities. Larger societal issues, such as socioeconomic status and access to services, were also mentioned.

Results of Discussion Forum

The moderated discussion following the survey reinforced themes that emerged in the survey. When asked about problems facing AAMSM in their communities, there were two main categories of responses: issues relating to sexual identity and issues relating to HIV.

Issues relating to sexual identity included fear of losing family and friends after coming out, stereotypes, lack of safe spaces for AAMSM, division and lack of infrastructure among MSM, and lack of AAMSM leaders. Many of these issues are at the community level of influence, involving community norms and culture. Issues relating to HIV were more individual in nature and included fear of getting tested, fear of confidentiality breaches, insensitivity from medical professionals, and perceived economic costs of getting tested.

When asked about the perception of HIV as a problem in our community, the idea of generational differences was raised. Younger people were perceived to be less worried about the spread of HIV than the older generation, who has witnessed many of its members die. Younger people were perceived to enjoy taking risks and not be concerned about their partners' HIV/STD status. Also, new medications are helping people to live longer and manage the disease more effectively than before, so the immediate threat is not as visible as it once was.

A major theme that emerged from a discussion about HIV services is the lack of promotion of health and wellness programs among AAMSM communities. Participants mentioned word of mouth as a primary mode of advertising, pointing out a lack of large media promotion (billboards, public service announcements, etc.). Some called for more aggressive campaigns beyond World AIDS Day and National Testing Day. There was disagreement about how community-based organizations and AIDS service organizations should market themselves; some agencies have removed any mention of HIV/AIDS or "gay" from their name and signage in an effort to draw in more people, while others

disagreed with that approach because it promotes the homophobia and stigma that is so pervasive in communities.

Participants gave several reasons for lack of AAMSM participation in programs, including fear of getting tested, fear of being “outed,” ignorance, fear of the ramifications of a positive result, religious norms, and division within AAMSM communities. Generational gaps were once again discussed, citing that young AAMSM have not been properly engaged in the development and implementation of HIV prevention programs. Young AAMSM were also mentioned as the targets of “chicken hawks,” or older men who seek out younger men as sexual partners. This was seen as contributing to feelings of mistrust among AAMSM and lack of a cohesive community identity.

Participants offered solutions to the challenges in engaging the AAMSM community in prevention programs as well. These solutions fell into two major categories: community factors and structural factors. Community factors included an increase in affirmation and support among AAMSM, with an emphasis on learning how to foster honesty, healthy relationships, and support. Several participants discussed the importance of valuing oneself and others, and the need for respect. Structural factors included a call for an AAMSM resource center similar to the Women’s Resource Center, and the development of a strong network among AAMSM.

Conclusions and Recommendations

The results of this study provide some direction for future assessment and activities. Young AAMSM were a population of concern to many who participated in the forum. Participants expressed concern about their potential risk factors and challenges in recruiting them to participate in HIV prevention programs. This was reinforced in the fact that young AAMSM participation in the forum itself was low. Future programs should place special emphasis on determining the unique needs of young AAMSM as well as identifying young AAMSM to serve as peer health educators and recruiters for prevention programs.

Another area of focus is the concept of an AAMSM community in the state. The ability of AAMSM to form a cohesive community is linked to the concept of AAMSM identity. Participants reported a number of different identity labels, and such a diversity of labels can sometimes hinder group cohesion. Therefore, prevention programs should be cognizant of the ways in which AAMSM identify themselves and be as inclusive as possible in their program development and marketing.

In addition to addressing the specific needs of AAMSM in their respective communities, prevention programs should also endeavor to address stigma and homophobia in the larger African-American community. The majority of participants indicated that stigma, fear, and homophobia were major issues that needed to be addressed both in prevention programs and in the community. Developing initiatives to impact stigma and homophobia, coupled with the development of “safe spaces” for AAMSM, may foster more trust and validation among AAMSM and consequently increase participation in HIV prevention programs.

There were several limitations to this study. First, the small sample size (n=37) makes it difficult to generalize these results to the statewide AAMSM population. Second, the majority of participants were attending the SC HIV/STD Conference, which caters mainly to service providers; the general AAMSM population representation was not as high. Also, the majority of participants were HIV-positive, a statistic that is not representative of the state's AAMSM population. The low percentage of participants who were "young AAMSM" has also been identified as a limitation.

Further study should be conducted to determine the needs of AAMSM statewide. Because there are four sites across the state that have been identified to target AAMSM in their respective cities, these sites should also be utilized to access the target population for participation in focus groups. Participants at each site should be divided into two groups—younger AAMSM ages 18-25, and AAMSM 26 and older. The results of these focus groups can be used to inform the development of HIV prevention programs statewide, as well as unique characteristics specific to each geographic location.

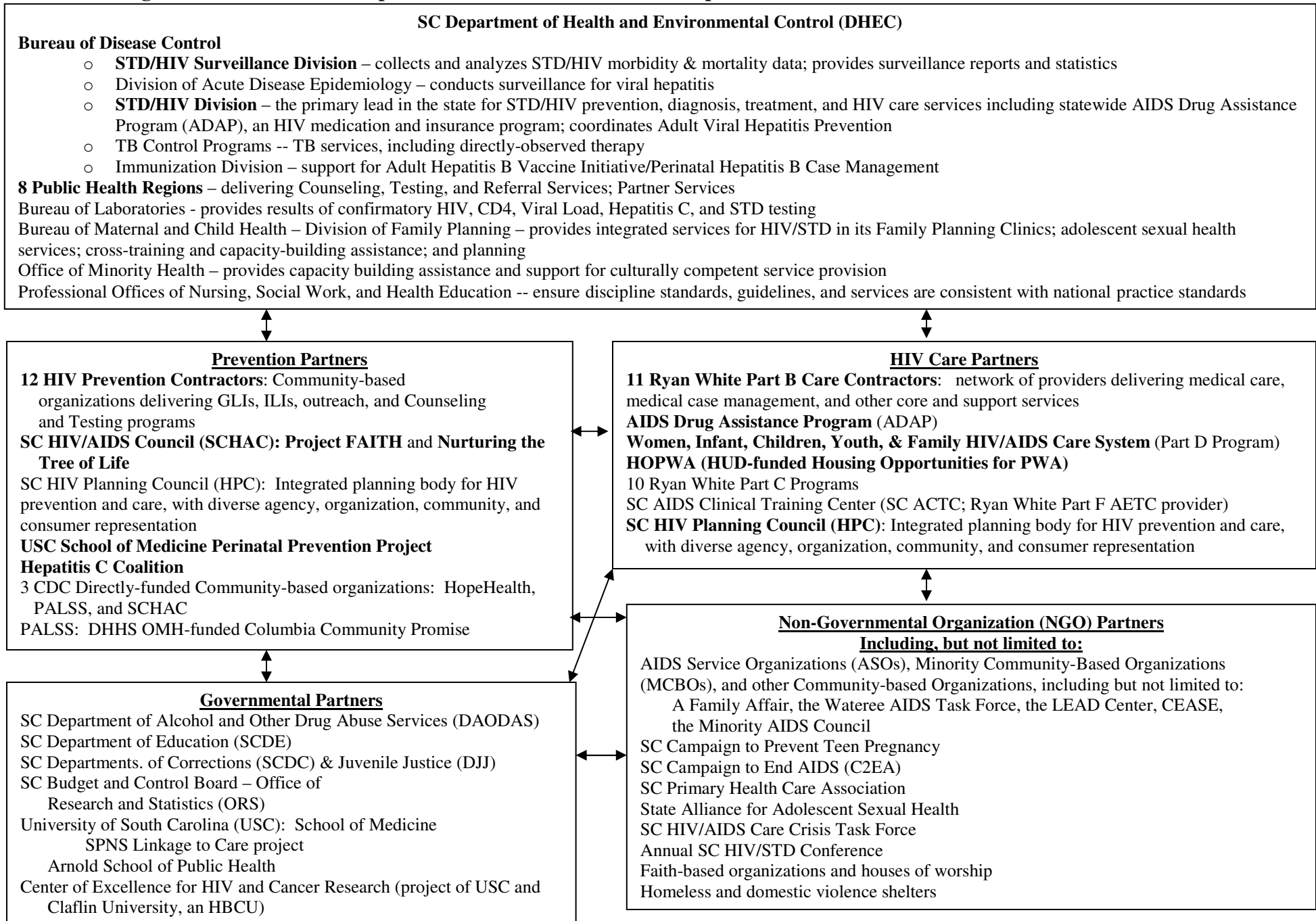
Stacy W. Smallwood, MPH
January 31, 2008

HIV/STD/Hepatitis Prevention, Care and Support, and Other Services* (as of 6/30/09)

County	Health Department Services												CDC Funded Activities 04012 (HIV Prevention)		CDC Funded Activities 07768		
	DHEC Health Region	DHEC Clinic-Based HIV Counseling, Testing and Referral (CTR) Services	DHEC Rapid HIV Testing	DHEC HIV/STD Partner Services (PS)	DHEC HIV Prevention Health Education/ Risk Reduction (HE/RR) Services	DHEC Comprehensive Risk Counseling/ Services (CRCS)	DHEC STD Screening & Treatment Services	DHEC Family Planning HIV Services (Title X funding)	DHEC Adult Viral Hepatitis Vaccination Initiative	DHEC Viral Hepatitis C Testing	DHEC TB Control Programs	Community-Based CTR	Community-Based Health Education and Risk Reduction Services	HIV Expanded Testing in Hospital Settings	HIV Expanded Testing in CBO Setting	HIV Prevention MSM Supplemental	CDC Directly Funded CBOs
Abbeville	1	X		X	A	A	X	X	X	X	A						
Aiken	5	X		X	X	A	X	X	X	X	A						
Allendale	5	X		X	A	A	X	X	X	X	A						
Anderson	1	X	X	X	X	X	X	X	X	X	A	A	A				
Bamberg	5	X		X	A	A	X	X	X	X	A		A				
Barnwell	5	X		X	A	A	X	X	X	X	A						
Beaufort	8	X		X			X	X	X	X	A	X	X				
Berkeley	7	X		X	A	A	X	X	X	X	A		A				
Calhoun	5	X		X	A	A	X	X	X	X	A		A				
Charleston	7	X	X	X	X	X	X	X	X	X	A	X	X	X	X		
Cherokee	2	X		X	A	A	X	X	X	X	A	A	A				
Chester	3	X		X			X	X	X	X	A		A				
Chesterfield	4	X		X	A		X	X	X	X	A						
Clarendon	4	X		X	A	A	X	X	X	X	A						
Colleton	8	X		X			X	X	X	X	A		A				
Darlington	4	X		X	A	A	X	X	X	X	A						
Dillon	4	X		X	A	A	X	X	X	X	A						
Dorchester	7	X		X	A	A	X	X	X	X	A		A				
Edgefield	1	X		X	A	A	X	X	X	X	A						
Fairfield	3	X		X	A	A	X	X	X	X	A		A				
Florence	4	X		X	X	X	X	X	X	X	A				X	X	
Georgetown	6	X		X			X	X	X	X	A		A				
Greenville	2	X	X	X	X	X	X	X	X	X	A	X	X	X	X		
Greenwood	1	X		X	A	A	X	X	X	X	A						
Hampton	8	X		X			X	X	X	X	A	X	X				
Horry	6	X		X			X	X	X	X	A		X				
Jasper	8	X		X			X	X	X	X	A		A				
Kershaw	4	X		X	A	A	X	X	X	X	A						
Lancaster	3	X		X			X	X	X	X	A		A				
Laurens	1	X	X	X	X	X	X	X	X	X	A						
Lee	4	X		X	A	A	X	X	X	X	A						
Lexington	3	X		X	A	A	X	X	X	X	A		A				
Marion	4	X		X	A	A	X	X	X	X	A						
Marlboro	4	X		X	A		X	X	X	X	A						
McCormick	1	X		X	A	A	X	X	X	X	A						
Newberry	3	X		X	A	A	X	X	X	X	A		A				
Oconee	1	X		X	A	A	X	X	X	X	A		A				
Orangeburg	5	X	X	X	X	X	X	X	X	X	A	X	X	X	X		
Pickens	2	X		X	A		X	X	X	X	A	A	A				
Richland	3	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X
Saluda	1	X		X	A	A	X	X	X	X	A						
Spartanburg	2	X	X	X	X	X	X	X	X	X	A	X	X				
Sumter	4	X		X	X	X	X	X	X	X	A		X				
Union	2	X		X	A	A	X	X	X	X	A	A	X				
Williamsburg	6	X		X			X	X	X	X	A		A				
York	3	X		X			X	X	X	X	A		X				

*X=counties where services are provided in that county; A=services are available to residents but provided outside the county

This figure (**Appendix E**) presents an **Overview of South Carolina’s Coordination and Linkage Partners**. **Partners/Organizations noted in bold print receive DHEC funds for HIV prevention and/or care services.**



**Health Department-Based HIV Prevention Program Models By Region
CY2009**

Region w/Counties	Funded Program Models
1. Abbeville, Anderson, Edgefield, Greenwood, Laurens, McCormick, Oconee, Saluda	Counseling, Testing and Referral Services (CTRS) Partner Services (PS) Comprehensive Risk Counseling and Services (CRCS) Individual Level Intervention (ILI)
2. Cherokee, Greenville, Pickens, Spartanburg, Union	Counseling, Testing and Referral Services (CTRS) Partner Services (PS) Comprehensive Risk Counseling and Services (CRCS) Individual Level Intervention (ILI) American Red Cross (GLI) SISTA (GLI) VOICES/VOCES (GLI)
3. Chester, Fairfield, Lancaster, Lexington, Newberry, Richland, York	Counseling, Testing and Referral Services (CTRS) Partner Services (PS) Comprehensive Risk Counseling and Services (CRCS) Individual Level Intervention (ILI)
4. Chesterfield, Clarendon, Darlington, Dillon, Florence, Kershaw, Lee, Marion, Marlboro, Sumter	Counseling, Testing and Referral Services (CTRS) Partner Services (PS) Comprehensive Risk Counseling and Services (CRCS) Individual Level Intervention (ILI) American Red Cross (GLI) VOICES/VOCES (GLI) Outreach
5. Aiken, Allendale, Bamberg, Barnwell, Calhoun, Orangeburg	Counseling, Testing and Referral Services (CTRS) Partner Services (PS) Comprehensive Risk Counseling and Services (CRCS) Individual Level Intervention (ILI) American Red Cross (GLI) SISTA (GLI) VOICES/VOCES (GLI)
6. Georgetown, Horry, Williamsburg	Counseling, Testing and Referral Services (CTRS) Partner Services (PS)
7. Berkeley, Charleston, and Dorchester	Counseling, Testing and Referral Services (CTRS) Partner Services (PS) Comprehensive Risk Counseling and Services (CRCS) Individual Level Intervention (ILI) American Red Cross (GLI)
8. Beaufort, Colleton, Hampton, Jasper	Counseling, Testing and Referral Services (CTRS) Partner Services (PS)

**Funded HIV Prevention Program Models by Organization
CY2009**

Organization	Funded Program Models*
1. ACCESS Network, Inc. (Beaufort, Colleton, Hampton, Jasper)	Community-Based Counseling and Testing plus Outreach
2. Acercamiento Hispano/Hispanic Outreach (Fairfield, Lexington, Newberry, Richland, Saluda)	Community-Based Counseling and Testing plus Outreach VOICES/VOCES
3. AID Upstate, Inc. (Anderson, Greenville, Oconee, Pickens)	Community-Based Counseling and Testing plus Outreach** Healthy Relationships Individual Level Intervention Many Men, Many Voices+ Comprehensive Risk Counseling and Services (CRCS) VOICES/VOCES
4. CARETEAM, Inc. (Georgetown, Horry, Williamsburg)	Community-Based Counseling and Testing plus Outreach Individual Level Intervention
5. Catawba Care Coalition (Chester, Lancaster, York)	Community-Based Counseling and Testing plus Outreach** Individual Level Intervention (Fundamentals of Prevention Counseling Model and Project RESPECT Model) SISTA VOICES/VOCES
6. HopeHealth (Chesterfield, Darlington, Dillon, Florence, Marion, Marlboro)	Outreach for Community-Based Counseling and Testing Many Men, Many Voices (3MV)++ SISTA VOICES/VOCES
7. Lowcountry AIDS Services (Berkeley, Charleston, and Dorchester)	Community-Based Counseling and Testing plus Outreach** Many Men, Many Voices+ Mpowerment SISTA
8. LRADAC (Lexington, Richland)	VOICES/VOCES
9. OCAB CAA, Inc. (Bamberg, Calhoun, Orangeburg)	Community-Based Counseling and Testing plus Outreach VOICES/VOCES
10. PALSS (Lexington, Richland)	Community-Based Counseling and Testing plus Outreach** Healthy Relationships Partners in Prevention Female Version
11. SADAC (Cherokee, Spartanburg, Union)	Community-Based Counseling and Testing plus Outreach SISTA VOICES/VOCES
12. SCHAC	Community-Based Counseling and Testing plus Outreach+ Many Men, Many Voices+

*All Individual Level Interventions are funded to be delivered using the Fundamentals of Prevention Counseling model, except at Catawba Care Coalition, which is using this model as well as the Project RESPECT model. **Outreach includes services delivered via the Internet in addition to face-to-face interventions. +Indicates funding provided from DHEC's Expanded Testing Grant for community education targeted to African American MSM. ++Indicates funding provided from DHEC's MSM Supplemental Grant for community education targeted to African American MSM.

South Carolina HIV Services Network Provider Chart (as of 6/01/09)

SC Department of Health & Environmental Control

**Ryan White Part B Service Providers
(RW core services/specialty care*)
Target Pop: Adults/Older Youth**

**Regional HIV
Pediatric/Family providers
(RW core services*)**

**Ryan White Part C Service Providers
(RW core services/primary care*)
Target Pop: Adults/Older Youth**

- AID Upstate**** (Greenville, Oconee, Pickens & Anderson)
- ACCESS Network (Beaufort, Jasper, Colleton & Hampton)
- CARETEAM (Horry, Williamsburg & Georgetown)
- Catawba Care Coalition (York, Chester & Lancaster)
- HopeHealth (Chesterfield, Darlington, Marlboro, Dillon, Marion & Florence)
- HopeHealth Edisto (Orangeburg, Bamberg & Calhoun)
- HopeHealth Lower Savannah (Aiken, Barnwell & Allendale)
- University of South Carolina** (Richland, Lexington, Fairfield, Newberry, Kershaw, Lee, Sumter & Clarendon)
- Piedmont Care (Spartanburg, Cherokee & Union)
- MUSC Trident Care Coalition/Lowcountry AIDS** Services** (Charleston, Berkeley & Dorchester)
- Upper Savannah Care Services (Abbeville, Laurens, Greenwood, Saluda, McCormick & Edgefield)

**Regional HIV
Pediatric/Family providers
(RW core services*)**

- Greenville Hospital System – Pediatric Infectious Disease** (Greenville)
- University of South Carolina School of Medicine – Dept. Pediatrics** (Columbia)
- Medical University of South Carolina (MUSC)– Pediatric Infectious Disease Dept.** (Charleston)

- Beaufort Jasper Hampton Comprehensive Health Services, Inc. (Ridgeland)
- CareSouth Carolina (Society Hill)
- Catawba Care Coalition (Rock Hill)
- HopeHealth (Florence)
- Low Country Health Care Systems (Fairfax)
- New Horizon Family Health Services, Inc. (Greenville)
- Richland Community Health Care Association (Columbia)
- Roper Care Alliance (Charleston)
- Sandhills Medical Foundation, Inc. (Jefferson)
- Spartanburg Regional Healthcare System (Spartanburg)

***Core services: medical, medications, oral health, substance abuse, mental health, case management; **Part D Consumer Advocacy**

↔ Indicates joint family

Text in Bold Type Indicates Part D–funded Service Providers

NEEDS ASSESSMENT FOR RAPID HIV TESTING IMPLEMENTATION IN THE HEALTH DEPARTMENT

Prepared for the South Carolina Department of Health
and Environmental Control (DHEC)

November 2008

By the Center for Applied Research and Evaluation Studies
Department of Family and Preventive Medicine
Emory University School of Medicine



For more information, please contact Rebecca Culyba PhD, Director at the Center for Applied Research and Evaluation Studies, Southeast AIDS Training and Education Center, Emory University. She can be reached at 404-727-4909 or rculyba@emory.edu.

Background

This needs assessment was a collaboration between the Southeast AIDS Training and Education Center (SEATEC) and the South Carolina Department of Health and Environmental Control (DHEC). The purpose was to assess the training needs of DHEC personnel regarding the implementation of rapid HIV testing. With input from DHEC and the South Carolina HIV/AIDS Clinical Training Center, the needs assessment survey was modified from previous assessments conducted by SEATEC. The survey instrument was finalized in July 2008 and was completed by 181 DHEC personnel in eight regions across South Carolina in August 2008. Data entry and analysis was performed by SEATEC. Descriptive results of the survey are included in this report. A copy of the survey instrument is included as a reference.

Region

	Percent	Number of Respondents
1	6.6	12
2	11.6	21
3	16.6	30
4	7.7	14
5	9.9	18
6	7.2	13
7	10.5	19
8	8.3	15
Region unreported	21.5	39
Total	100%	181

1. What is your primary position as a health care worker?

	Percent	Number of Respondents
MD	0.6	1
NP	8.8	16
RN	60.9	109
LPN	1.7	3
Lab/Phlebotomist	5.7	10
Disease Investigation Specialist	12.1	23
Social Worker	4.4	8
Health Educator	3.3	6
Other*	2.5	5
Total	100%	181

*Other write-ins: APRN, CNA, human services coordinator

2a. What is your age?

	Percent	Number of Respondents
Under 25	1.2	2
25-39	27.1	46
40-54	41.8	71
55+	30.0	51
Total	100%	170

2b. What is your gender?

	Percent	Number of Respondents
Male	7.2	13
Female	92.8	167
Transgender	--	--
Total	100%	180

2c. Are you of Hispanic, Latino/a or Spanish origin?

	Percent	Number of Respondents
Yes	2.2	4
No	97.8	177
Total	100%	181

2d. What is your racial background?

	Percent	Number of Respondents
American Indian/Alaskan Native	--	--
Asian	0.6	1
Black or African-American	23.8	43
Native Hawaiian/Other Pacific Islander	0.6	1
White	72.9	132

3. How many years have you been working in STD/Family Planning?

	Percent	Number of Respondents
0-10	63.3	112
11-20	23.7	42
21-30	10.2	18
31-40	2.8	5
Total	100%	177

4. During your employment, have you received any formal training on HIV?

	Percent	Number of Respondents
Yes	82.2	143
No	17.8	31
Total	100%	174

5. Which educational methods do you find useful for receiving continuing professional educational/training in HIV/STD issues?

	Percent	Number of Respondents
Clinical case discussions	49.7	90
Clinical practicum	30.4	55
Skill- building sessions	33.7	61
Lecture –based/ didactic presentation	61.9	112
Interactive small group discussion	44.2	80
Panel discussion	20.4	37
Internet-based learning	30.4	55
Role-playing sessions	23.2	42
Self-teaching/ home study/ reading	25.4	46
Video/ audio conferencing	39.8	72
Videotapes/ CD –ROM	37	67
Other*	3.9	7

*Other write-ins: discipline specific, statewide sharing, podcast, webinar, preventive health maintenance courses

6. Please indicate which HIV/AIDS clinical management training topics would be of interest to you.

	Percent	Number of Respondents
None at this time	8.8	16
Rapid HIV testing	44.2	80
Pre-test counseling	34.8	63
Post-test counseling	43.1	78
Primary HIV infection	29.8	54
Clinical manifestations of HIV/AIDS	37.6	68
Oral manifestations of HIV/AIDS	32	58
State law and HIV	47	85
Ryan White care services (ADAP)	29.3	53
Antiretroviral treatment (ART)	26.5	48
Referral sources for HIV/AIDS patients	43.6	79
HIV/AIDS and street drug interactions	30.4	55
HIV/AIDS drug interactions	26	47
Opportunistic infections	33.1	60
Post exposure prophylaxis	29.8	54
Other*	3.3	6

*Other write-ins: explanation of lab work, how to tell someone they have HIV, pre-existing conditions that may cause false + for HIV

7. Please indicate which HIV psychosocial training topics would be of interest to you.

	Percent	Number of Respondents
None at this time	23.2	42
Cultural competency	19.9	36
Substance use/abuse	45.9	83
Other*	1.1	2
Multiple diagnoses (i.e. HIV and mental and addiction)	52.5	95
Psychiatric	38.1	69

*Other write-ins: MSM-teen populations (HIV) pre+ post test counseling

8. Which of the following factors limit your ability to participate in HIV continuing professional education/ training programs?

	Percent	Number of Respondents
I do not need training	2.8	5
Personal interest in topic	10	5.5
Time away from practice	46.4	84
Funds	34.3	62
Inconvenient training dates/times	22.1	40
Don't know where to get training	6.1	11
Support from administration	16	29
Support from peers	2.2	4
Inconvenient training location	30.9	56
Other*	7.7	14

*Other write-ins: heavy work load, limited clinical practice, offered to DIS/HIV staff only, plans to retire at the end of the year so part time, work hourly only, work only part time

9. At present, what kinds of HIV test are used routinely (available each day) by your health department?

	Percent	Number of Respondents
Conventional blood test (blood draw, need to return on a later date for result)	98.8	179
Conventional oral test (such as Orasure-oral fluid test, need to return on a later date for result)	1.1	2
Rapid test (such as Oraquick- get result the same day)	--	--
Other	--	--
Don't know	--	--

10. Consider current HIV testing methods available at your facility, how often do you offer HIV testing?

	Percent	Number of Respondents
I offer it to all patients	71	134
I offer it only to patients with history of STDs	15.5	28
I offer it only to patients who appear to be HIV infected	3.9	7
I offer it only if the patient request it	11	20
I don't offer it to patients	5	9
Other*	11.6	21

*Other write-ins: annual exam and pregnancy test, any patient asking STD blood work, due to time only by request, I do it when I see patients, I do not every day, I do not draw blood for the test, I offer even if they've never had an STD, I offer to most FP and all STD, I offer to patients that come for yearly check up, if patient is HIV+ I refer to Ryan White nurse, if patient ask I offer, nurses address in clinic, offer to all STD patients, offer to all TB patients, offer to all clients with high risk factors, offered to family planning/STD patients, used a screening tool in TB programs

11. If rapid HIV testing is available at your health department, how often do you offer it to patients?

	Percent	Number of Respondents
I offer it to all patients	12.2	22
I offer it only to patients with history of STDs	6.1	11
I offer it only to appear to be HIV infected	3.9	7
I offer it only if the patient request it	8.8	16
I don't offer it to patients	12.7	23
Rapid HIV testing not available at my health department	30.9	56
Other*	18.2	33

*Other write-ins: all appropriate staff put in place, always available but offered rarely, certain nurses offer it every week, clients at high risk, contact to HIV, employees exposed, FP patients during IE and AE, generally meet with patients after testing, high risk ENT from DIS, high risks, HIV contact, I would offer if wanted rapid results, limited staff, need to refer FP/STD clients to HIV nurse/HIV program, offered at local community health departments, once a week, only people able to understand same day results, only exposed employee (3), only people mentally stable enough to receive same, on Wednesdays, when nurses order it, when social workers are available.

12. Which of the following factors prevent you from offering rapid HIV testing within the health department setting?

	Percent	Number of Respondents
Time to complete test	18.8	34
Time to give results	18.8	34
Concern with follow –up	12.2	22
Do not think HIV testing is appropriate in the HD setting	2.2	4
Payment/cost for HIV testing	5.5	10
Other*	24.9	45
Testing resources not available at my facility	36.5	66
Concern with providing results to patient	17.7	32
Space availability/confidential location	6.6	12
Comfort with topic	7.2	13
Unclear referral process for persons testing positive	7.2	13

*Other write-ins: all staff available, department head, do not have rape test, handled by RN, lab director not satisfied with Ora-quick method, lab personnel do not offer the test, MSW staff may not be present if needed, no staff trained—two-day training prohibit staff attendance, not approved by lab director, not available (5), not offered to FP and STD programs, not ready for, not trained, offered at MD office, personnel, protocol- cannot test clients unless they are at high risk, provide education only, seeing patients continuously, staffing (3), strong social work team need to be put in place, these nurses have never been taught, time (2), unsure why it is not offered, we have a Ryan White nurse that handles HIV concerns, will be soon.

13. How comfortable do you feel performing the following action in a professional setting?

	Very Comfortable	Comfortable	Somewhat Comfortable	Uncomfortable	Very Uncomfortable
Offering the rapid test for HIV	27.6	9.4	19.4	11	21.5
Performing rapid test for HIV	19.3	8.3	15.5	16	29.3
Reading results of a rapid test for HIV	21.5	8.3	16.6	14.4	27.1
Giving a preliminary positive HIV test result	19.9	10.5	18.2	18.2	26
Providing medical referrals to someone with HIV/AIDS	29.3	12.7	17.7	16	17.1
Reporting HIV cases to appropriate agencies	37	13.3	16	13.3	13.3

	Very Comfortable	Comfortable	Somewhat Comfortable	Uncomfortable	Very Uncomfortable
Referring HIV patients to Partner Counseling Referral Services (PCRS)	29.9	11.6	14.4	17.1	17.7
Referring HIV patients to cases management & prevention services	31.5	13.3	16	17.1	15.5

14. Are you aware of the CDC Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health–Care Settings that were published September 2006?

	Percent	Number of Respondents
Yes	50.8	91
No	49.2	88
Total	100%	179

15. Do these new recommendations make it more likely that you will offer HIV testing to patients within the health department setting?

	Percent	Number of Respondents
Yes	77.1	64
No	22.9	19
Total	100%	83

16. Do you feel that you have adequate resources to counsel and refer HIV+ patients based on their needs?

	Percent	Number of Respondents
Yes	60.5	104
No	39.5	68
Total	100%	172

16a. Please list your top three needs to be met so you can adequately refer HIV+ patients:

Question 16a provided three blank spaces that were numbered one through three where respondents could list their top three needs in numerical order. Answers with “(2)” after the answer represent that more than one person wrote that answer. The number in between the parentheses is the number of people who wrote that answer. There were 49 respondents who filled out an answer for number one, 33 respondents for number two, and 20 respondents for number three. Below are the answers that were given by respondents

Number one needs:

- A class on telling people they are HIV positive
- Clients need more resources for transportation
- Counseling for HIV clients (2)
- Designated person to test and for counseling
- Doctors/clinics
- Don't know resources
- Experience
- Have more staff (2)
- HIV disease process
- How to deal with situational cases from patients and families
- I need basic information on the disease
- I would like practice telling people diagnostic
- Inadequate space
- In-service
- Knowledge about available resources (3)
- Lack of social work in clinical settings
- Learn more about HIV rapid test (2)
- List of referrals (2)
- Limited resources
- More training (4)
- Need course on pre and post for HIV clients
- Need more education on HIV
- Need more referral services
- Need personal information on all documents
- Practice
- RN who are able to post test counsel HIV+ patients
- Social/caseworker (2)
- Update on information
- We have DIS counseling clients
- Information on available resources (3)
- Information on adequate interpreting CD4/ viral load
- Interpretation of labs
- Lack of nursing staff
- Laws
- Learn more about post test counseling
- List of private infectious disease types
- Money, staff
- More post-test counseling and services
- Need coping education
- Need training and counseling skills
- New written materials appropriate for clients
- PCPs for high risk patients
- Protocol for follow up for HIV+ patients
- Provide education
- Retraining on rapid testing
- Sick patients don't want to be identified
- Transportation

Number three needs:

- Appropriate resources in community
- Available HIV medications (2)
- Follow up instructions
- Increase staffing
- Lack of qualified individuals
- Learn more procedures
- Need care management services
- Need courier services
- Need education on what is next after diagnosis
- Need to be trained
- Need to know how to report results
- Observe HIV+ encounter/ results being given
- Proper referral steps
- Scheduling issues-decrease staff
- Social support
- Time out of clinic to prepare results
- What other testing to do with referral

Number two needs:

- Addressing HIV issues
- Available medications
- Being able to counsel someone with a positive result
- Comfort level
- Community resources
- Designated funds
- Difficulty knowing how to test
- Don't offer rapid testing
- How to refer
- I'm only RN trained
- Increase knowledge
- Increase staffing

NEEDS ASSESSMENT FOR RAPID HIV TESTING IMPLEMENTATION IN THE HEALTH DEPARTMENT

Region _____

1. What is your primary **position** as a health care worker (Select **ONE**)?
 MD NP RN LPN Lab/Phlebotomist Disease Investigation Specialist (DIS)
 Social Worker Health Educator Other (specify) _____
2. Please provide the following demographic information: **(Items 2a-2d)**
2a) What is your **age**? _____ (years) 2b) What is your **gender**? Male Female Transgender
2c) Are you of **Hispanic, Latino/a or Spanish** origin? Yes No
2d) What is your **racial background**? **[Please select all that apply]**
 American Indian/Alaskan Native Native Hawaiian/Other Pacific Islander
 Asian White
 Black or African-American
3. How many **years** have you been working in STD/Family Planning? _____ **[Please round up to the nearest whole year]**
4. During your employment, have you received any **formal training on HIV**? Yes No
5. Which **educational methods** do you find useful for receiving continuing professional education/training on HIV/STD issues? (Select **ALL** that apply)
 Clinical case discussion Internet-based learning
 Clinical practicum Role-playing sessions
 Skill-building sessions Self-teaching/home study/reading
 Lecture-based/didactic presentation Video/audio conferencing
 Interactive small group discussion Videotapes/CD-ROM
 Panel discussion Other (specify) _____
6. Please indicate which **HIV/AIDS clinical management training topics** would be of interest to you. (Select **ALL** that apply)
 None at this time Ryan White care services (ADAP)
 Rapid HIV testing Antiretroviral treatment (ART)
 Pre-test counseling Referral sources for HIV/AIDS patients
 Post-test counseling HIV/AIDS and street drug interactions
 Primary HIV infection HIV/AIDS drug interactions
 Clinical manifestations of HIV/AIDS Opportunistic infections
 Oral manifestations of HIV/AIDS Post exposure prophylaxis
 State law and HIV Other (specify) _____
7. Please indicate which **HIV psychosocial training topics** would be of interest to you. (Select **ALL** that apply)
 None at this time Multiple diagnoses (i.e. HIV and mental illness and addiction)
 Cultural competency Psychiatric sequelae of HIV/AIDS
 Substance use/abuse
 Other (Specify) _____
8. Which of the following factors **limit your ability to participate** in HIV continuing professional education/training programs? (Select **ALL** that apply)
 I do not need training Don't know where to get training
 Personal interest in topic Support from administration
 Time away from practice Support from peers
 Funds Inconvenient training location
 Inconvenient training dates/times Other (specify) _____
9. At present, what **kinds of HIV tests** are used routinely (available each day) by your Health Department?
 Conventional blood test (blood draw, need to return on a later date for result)
 Conventional oral test (such as OraSure - oral fluid test, need to return on a later date for result)
 Rapid test (such as Oraquick – get result the same day)
 Other (Please describe) _____
 Don't know

10. Considering **current HIV testing methods available at your facility**, how often do you offer HIV testing?
(Select **ALL** that apply)
- I offer it to all patients
 - I offer it only to patients with a history of STDs
 - I offer it only to patients who appear to be HIV infected
 - I offer it only if the patient request it
 - I don't offer it to patients
 - Other (specify)_____
11. If **rapid HIV testing** is available at your Health Department, how often do you offer it to patients? (Select **ALL** that apply)
- I offer it to all patients
 - I offer it only to patients with a history of STDs
 - I offer it only to patients who appear to be HIV infected
 - I offer it only if the patient requests it
 - I do not offer it to patients
 - Rapid HIV testing not available at my Health Department
 - Other (specify)_____
12. Which of the following factors **prevent** you from offering **rapid HIV testing** within the Health Department Setting?
(Select **ALL** that apply)
- Time to complete test
 - Time to give results
 - Concern with follow-up
 - Do not think HIV testing is appropriate in the HD Setting
 - Payment/Cost for HIV test
 - Other (specify)_____
 - Testing resources not available at my facility
 - Concern with providing results to patient
 - Space availability/Confidential location
 - Comfort with topic
 - Unclear referral process for persons testing positive

13. How **comfortable** do you feel performing the following actions in a professional setting?

	Very Comfortable		Somewhat Comfortable		Very Uncomfortable
a) Offering the rapid test for HIV	1	2	3	4	5
b) Performing rapid test for HIV	1	2	3	4	5
c) Reading results of a rapid test for HIV	1	2	3	4	5
d) Giving a preliminary positive HIV test result	1	2	3	4	5
e) Providing medical referrals to someone with HIV/AIDS	1	2	3	4	5
f) Reporting HIV cases to appropriate agencies	1	2	3	4	5
g) Referring HIV patients to Partner Counseling Referral Services (PCRS)	1	2	3	4	5
h) Referring HIV patients to case management & prevention services	1	2	3	4	5

14. Are you aware of the CDC Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings that were published September 2006?

- Yes No → **Go to Question 16**

15. Do these new recommendations make it more likely that you will offer HIV testing to patients within the Health Department setting?

- Yes No

16. Do you feel that you have adequate resources to counsel and refer HIV+ patients based on their needs?

- Yes → **Go to END** No

16a. If no to Question 16 please list your top three needs to be met so you can adequately refer HIV+ patients

1. _____
2. _____
3. _____

-----END-----

**Thank you for completing this
survey.
We look forward to working with
you in the future.**