

**South Carolina Ryan White SCSN and Comprehensive Plan Meeting
Pre-Meeting Survey Results
December 14, 2011**

Overview

A web survey was administered in November 2011 to individuals who would be attending the South Carolina Ryan White SCSN and Comprehensive Plan Meeting on December 14, 2011. The survey asked respondents to identify the needs of PLWHA who are: 1) in care, 2) not in care, and 3) unaware of their HIV status. The survey was conducted to support further discussion at the December 14th meeting about the needs of PLWHA.

Response options for survey questions about the needs of PLWHA in care and not in care were based on the needs identified in the 2009 South Carolina Ryan White SCSN and Comprehensive Plan. Because the 2009 Plan did not list needs of PLWHA unaware of their status, response options for this survey question listed a variety of hypothetical needs for this population.

The survey was created collaboratively by a planning committee, including Noreen O'Donnell, DHEC; Susan Fulmer, DHEC; Angel Harmon, MUSC Pediatrics; Johanna Haynes, Careteam, Inc; Pamela Shepherd McKnight, Lowcountry Healthcare System, Inc.; and David Napp, an independent consultant contracted by DHEC to facilitate development of the 2012 South Carolina Ryan White SCSN and Comprehensive Plan.

Respondents

The survey web-link was sent via email to 36 people. Two booster emails were subsequently sent to further encourage survey completion. A total of 32 people completed the survey for an 89% response rate. Respondent characteristics are summarized below. Multiple responses were permitted so percentages do not add to 100 percent.

Which of the following best describes you? (N=32)

Answer Option	Response Percent
Part B Ryan White provider	41%
Part C Ryan White provider	28%
HOPWA	22%
DHEC staff	19%
Part D Ryan White provider	6%
PLWHA	6%
Corrections	3%
Other	16%

Other = Community Health Center Provider, Medical provider, Prevention Coordinator, PLWHA- ex-offender, CBO Manager

Findings

Web survey findings are presented below. The percent response is listed for each answer option from most to least frequent response. Respondents were asked to select six items for each question and, since multiple responses were permitted, percentages do not add to 100 percent. Verbatim text entries are listed for those who selected "other". Although some text entries were conceptually similar to a pre-defined survey response option, these data were *not* recoded and are *not* reflected in the percentages listed below.

1. What makes it difficult for PLWHA who are in care to stay in care? (N=32)

Answer Options	Response Percent
Lack of transportation makes it difficult for clients in care to reliably get to the services they need.	88%
Societal stigma about HIV and/or risk behaviors makes it difficult for clients to stay in care because they are hesitant to access HIV-related services.	84%
Substance abuse needs makes it difficult for clients to stay in care and adhere to treatment regimes.	84%
Lack of housing makes it difficult for clients to stay in care because of the relative priority they may place on securing safe, stable housing versus seeking health care.	66%
Mental health needs make it difficult for clients to stay in care and adhere to treatment regimes.	66%
Clients have difficulty staying in care because they get fatigued with the long-term process of managing their illness, especially those who have been HIV+ for a long time.	44%
Medication side effects makes it difficult for clients to maintain adherence to treatment regimes.	28%
Clients have difficulty staying in care because they feel confused and burdened by the paperwork and eligibility process to access Ryan White services.	22%
Clients have difficulty staying in care because they feel there are not enough providers like them , such as peers or those of a similar cultural or community background.	22%
Non-English speaking clients have difficulty staying in care because they have a hard time finding language-competent providers or translation services.	13%
Clients have difficulty staying in care when they are incarcerated and do not disclose their HIV status because this disrupts their usual care routine.	13%
Other	38%

Other (PLWHA in care)

- Life complexities make it difficult (reference Maslow's hierarchy) e.g. caring for others such as children, managing appointments without a phone, lacking literacy, etc. Formerly incarcerated people have difficulty finding employment and housing.
- They don't realize the importance of treatment and become despondent.
- Because of denial about their HIV status; and "as long as I'm feeling well, I don't need care"
- Ex-offenders that do not have stable employment upon their release from prison.
- Employment; clients prioritize work over time off to attend medical or case management appointments.
- Low educational attainment, competing needs, lack of self-worth.
- Literacy and job skills are issues. It is hard for clients to find employment without these skills. If they do not have some income, they do not qualify for some housing programs. Individuals who have been incarcerated have a more difficult time securing employment.
- Clients have difficulty staying in care when released from prison because other concerns are first and the stigma of being segregated. First person someone meets in care does not provide cultural and sensitive care.
- Patients feel that the providers do not respect them and their time, have to wait too long for appointments, have difficulty reaching provider by phone.
- Lack of family support due to the stigma associated with HIV and therefore there is no support system in many cases outside a clinic setting.
- I believe that some patients are ashamed, embarrassed and are hesitant because of how they may be treated.
- Clients have a difficult time staying in care because they don't understand the disease and a disease that is not understood is a disease that isn't well managed. Providers have a lot of clients to see and don't have enough time to provide the education that is needed. Case managers have an overwhelming amount of tasks to complete and lots of clients to see and don't have the time to provide intensive education that is needed. Agencies don't have the funding and/or aren't thinking of other creative ways to relate to the lack of education that is received by the client.

2. What makes it difficult for PLWHA who know their HIV status and are not in care to get the care they need? (N=32)

Answer Options	Response Percent
Competing issues related to poverty (e.g., food and housing) make it difficult for clients to prioritize accessing HIV care.	97%
Clients denial or fear of disclosing their HIV status to others (e.g. family, partner) discourages them from accessing care.	84%
Substance abuse needs makes it difficult for clients to access HIV care or to recognize that they need care.	78%
Asymptomatic clients don't access care because they feel they do not need HIV care, especially in light of the shift toward thinking of HIV as a long-term chronic illness.	69%
Mental health needs make it difficult for clients to access HIV care or to recognize that they need care.	53%
Clients don't access care because they have had bad experiences with the healthcare system.	53%
Clients have a fatalistic attitude about their illness and are not motivated to access care.	31%
Clients don't access care because they don't feel comfortable engaging with a care system they feel is different from their own culture or community.	25%
Clients who have been in care and dropped out do not reenter the care system due to feelings of personal failure .	22%
Clients don't access care because they believe religion or other "therapies" will heal them.	19%
Undocumented individuals believe there will be personal consequences if they seek care, such as being deported or losing their kids.	16%
Clients don't access care because they find the administrative process to enter the Ryan White system to be burdensome or confusing.	13%
Non-English speaking clients don't access care because they can't find language-competent providers or translation services.	9%
Clients don't access care because they don't know where to go for help.	6%
Other	16%

Other (PLWHA not in care)

- Transportation concerns.
- Transportation.
- For whatever reason, possibly simple denial, clients just aren't interested in being in care.
- There is a need for more counseling services. There is also a lack of Spanish speaking counselors. Personal life issues that lead to stress, anxiety and depression often interfere with care.
- Clients of younger ages, 18-25, are not ready to engage in care and don't have a good understanding of the transition process from youth to adulthood and they don't see things that keep them from engaging in care.

3. What makes it difficult for PLWHA who don't know their HIV status to get tested and linked to care? (N=32)

Answer Options	Response Percent
People know they are at risk but fear and denial keep them from getting tested.	100%
Societal stigma about HIV and/or risk behaviors keeps people from getting tested.	97%
People don't know they are at risk for HIV and therefore do not get tested.	94%
People are tested, receive results, get referrals, but do not follow through on their first HIV care appointment.	84%
People are tested, receive results, get referrals, and try to follow through on their first HIV care appointment, but waiting times are too long .	34%
People are willing to get tested but don't know where to go for HIV testing.	28%
People are tested but do not receive their results .	22%
People are tested and receive their results, but do not get referrals to HIV care.	22%
Other	28%

Other (PLWHA don't know status)

- HIPAA violation concerns.
- Testing is not part of routine health care.
- People unable to follow through on care due to other priorities (work, child care, etc.)
- They put off testing: they'll get to it later. Misinformed about how HIV is transmitted and if their partner "looks" clean, they must be. People think it's just a disease for black people or for gay people. Misnomers.
- Fear of being tested (or of accessing health care systems) due to immigration issues.
- Lack of self-worth. Low educational attainment.
- Getting tested isn't a priority.
- People often wait until very sick and find out about HIV status at hospital.
- Don't follow thru because of behavior of those they meet at the clinic. Persons tested negative while in prison don't want to know after watching the stigma.