Engagement & Retention in Pre-ART HIV Care: KwaZulu-Natal South Africa

English version

Laramie R. Smith for the SA Options Team
7/17/2011

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Please answer the following questions according to the patient’s medical chart when making a referral to this study.

Staff-A. Date patient tested HIV-positive (dd/mm/yy): ____/____/____

Staff-B. Patient’s **first** CD4 count: _______ CD4 count  Date of test (dd/mm/yy): ____/____/____

Staff-C. Date patient returned to clinic to receive their **first** CD4 count results (dd/mm/yy): ____/____/____

Staff-D. Patient’s **most recent** CD4 count: _______ CD4 count  Date of test (dd/mm/yy): ____/____/____

Staff-E. How often has the patient been told to return to the clinic (e.g., for CD4 counts, Bactrim, TB or other treatments)?
- Patient was told to return every month
- Patient was told to return every 3 months
- Patient was told to return every 6 months
- There is no record in the patient’s chart indicating when the patient was told to return to clinic
- Other: ___________________________

Staff-F. Has the patient been screened for symptoms of **sexually transmitted infections** (STIs) since being diagnosed with HIV?
- Yes, screened and treatment was prescribed
- Yes, screened and no treatment was prescribed
- No, there is no record of STI screening or treatments since HIV diagnosis.

Staff-G. Has the patient been screened for symptoms of **TB** since being diagnosed with HIV?
- Yes, patient was screened and **diagnosed** TB positive, **TB treatment** was prescribed for active TB
- Yes, patient was screened and **diagnosed** TB negative, **IPT (TB prophylaxis)** was prescribed
- Yes, patient was screened and **diagnosed** TB negative, **IPT (TB prophylaxis)** was NOT prescribed
- No, there is no record of TB screening or TB treatments or IPT (TB prophylaxis) since HIV diagnosis

Staff-H. Has the patient attended any **HIV Literacy classes** at the clinic since being diagnosed with HIV?
- Yes, patient has attended **Module 1** at the clinic since being diagnosed
- Yes, patient has attended **Modules 1 and 2** at the clinic since being diagnosed
- No, patient has not attended any HIV Literacy classes at the clinic since being diagnosed
RA INSTRUCTIONS: These questions have been written for you to read them aloud to patients. Some questions will have additional instructions for you to give to the patient so that they will know what response options are available to them to choose from. Please take some time to get to know those instructions and be comfortable instructing patients how to respond to those questions.

If a patient does not want to answer any question, first check to make sure they understand the question. If they understand the question but still do not want to answer it, just respond “OK” and write down next to that question “RF” or “Refused Answer”, then proceed to the next question.

If a patient has any difficulty understanding a word or phrase, please help them by describing the question or word a bit differently. When this happens please circle the question, word/phrase, or response option the patient had trouble understanding and write out the word or phrase you used that helped the patient to understand the question. This feedback will be important to help us know how to make questions better in the future.

Thank you for your work on this project!

SECTION 1a -- Baseline Only Assessment

RA READ to Patient: “I am going to ask you some questions, starting with some questions about yourself. Please answer as honestly as possible. Your answers are strictly confidential and will not be shared with clinic staff or providers.”

A1. What is your sex?
   - Male
   - Female

A2. How old are you?
    ___________ years old

A4. What is the highest level of education you have completed?
   - No schooling
   - Class 1/Gr 1 - STD 1/Gr3/ABET1
   - STD 2/Gr 4 - STD 5/Gr 7
   - STD6/Gr 8 - STD7/Gr 9
   - STD 8/Gr 10/JC - STD 9/Gr 11/N2
   - STD 10/Matric/N3/Gr 12
   - Diploma/Occupational certificate/Technikon
   - University degree/Higher diploma
SECTION 1b – Baseline and Follow-up Assessments

1. In the past 3 months, have there been any days when you or your family have gone without eating because you did not have food to eat?
   - Yes
   - No

2. Approximately how much is the monthly income for your household? (Include income from all sources such as employment, government grants such as pension, child grants, etc.) ____________ Rand

SECTION 2 – Baseline Assessment Only

RA READ TO PATIENT: “Now I am going to ask you a few questions about your HIV diagnosis and accessing health care following your diagnosis. Please answer as honestly as possible. Your answers are strictly confidential and will not be shared with clinic staff or providers.”

3. In what month and year did you test HIV-positive?

   ____________ MM/YYYY

4. When you got tested for HIV and learned you were HIV-positive, was the main reason you decided to get tested because you were feeling sick?
   - Yes
   - No

5. Are there any other clinics you could easily go to if you wanted to switch clinics for your HIV care? (Tick only one)
   - Yes
   - No
   - Not Sure

6. Does the clinic have a current phone number they can use to contact you?
   - Yes
   - No
   - Not Sure

7. How long (in minutes or hours and minutes) do you usually have to wait at the clinic until a staff member (e.g., a nurse, counselor, or doctor) sees you?

   _______ hours _________ minutes

8. How much time does it take you to travel to this clinic?

   _______ hours _________ minutes

9. How much money does it cost you to travel to and from the clinic (return trip)?

   R__________

10. How do you get to the clinic? (Tick only one)
COMPREHENSIVE OPTIONS RETENTION IN CARE SURVEY

☐ Walking
☐ Bus
☐ Private Car
☐ Taxi
☐ OTHER: Please specify.________________________________________________________

11. How often did clinic staff say they want you to come to clinic before you start ARV medications? (Tick only one)
   ☐ I was not told how often to return
   ☐ every 6 months
   ☐ every 3 months
   ☐ every month
   ☐ Other, Please specify: ______________________________________________________
   ☐ I don’t know, Please specify: ________________________________________________

12. Are there any friends or family members that you are close to that are also HIV-positive?
   ☐ Yes
   ☐ No
   ☐ Not Sure

SECTION 3

RA instructions: Please read the following statement, “The following statements are about HIV treatment and care. I will read you each statement, then please tell me if you think the statement is correct or incorrect by replying “True”, “False” or “Not Sure” to each statement”.

RA instructions: Please have patients look at the RED Card with response options “True”, “False”, “Not Sure”. Then read the following statements to patients. Have the patients respond to each statement from the options provided on the RED Card. Please tick the patient’s response in the appropriate box to the right of the statement.

<table>
<thead>
<tr>
<th>ITEM</th>
<th>True</th>
<th>False</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. People who qualify for ARVs are healthier than those who do not qualify.</td>
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<tr>
<td>14. Regular health checks by a nurse or doctor help to keep patients with HIV more healthy.</td>
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<tr>
<td>15. If someone living with HIV waits to get healthcare until they are very sick, it can be harder to treat their HIV.</td>
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<tr>
<td>16. People who use alcohol or drugs are not eligible for ARVs.</td>
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<tr>
<td>17. People only qualify for ARVs once they are very sick.</td>
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<tr>
<td>18. People who do not qualify for ARVs can have unprotected sex without risk of infecting their partner(s).</td>
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<tr>
<td>19. CD4 counts change so slowly that people only need to have this checked once every year to year and a half.</td>
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<tr>
<td>20. HIV-positive patients do not need to meet with clinic staff regularly, until they start ARVs.</td>
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<tr>
<td>21. When HIV-positive patients who are not on ARVs see a doctor or nurse, they are only checked to see if they can start ARV medications.</td>
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</tbody>
</table>
## COMPREHENSIVE OPTIONS RETENTION IN CARE SURVEY

<table>
<thead>
<tr>
<th>ITEM</th>
<th>True</th>
<th>False</th>
<th>Not Sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. When HIV-positive patients see a doctor or nurse after finding out that they have HIV, they are checked for many conditions that may affect their health.</td>
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<tr>
<td>23. Getting treatments to protect against TB will weaken the immune system of people living with HIV.</td>
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<tr>
<td>24. If someone has both HIV and TB, taking medications to treat TB can help their body stay strong to fight HIV.</td>
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<td></td>
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<tr>
<td>25. Getting treatment for sexually transmitted infections (STIs) can help the body’s immune system have more strength to fight HIV.</td>
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</tbody>
</table>

## SECTION 4

**RA READ TO PATIENT:** “Now I am going to ask you questions about different types of feelings and beliefs you might have towards coming to clinic for your HIV-care. Please answer as honestly as possible. Your answers are strictly confidential and will not be shared with clinic staff or providers.”

**RA please read the following instructions to the patient:** “I am now going to read you some statements about how other people have said they feel about coming to the clinic. After each statement I will read you three answers that you can choose from. Please let me know which answer is closest to how you think or feel. Please know that there is no right or wrong answer; whichever response you choose is acceptable.” Then please tick the box next to their response.

<table>
<thead>
<tr>
<th>ITEM</th>
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<tbody>
<tr>
<td>26. How do you feel about going to this clinic regularly for HIV care?</td>
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<tr>
<td>27. How helpful do you think it is for you to go to this clinic regularly?</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>28. How important is it to you to go to this clinic regularly for HIV care?</td>
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<td></td>
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<tr>
<td>29. Do you feel like a sick or healthy person when you think about coming to this clinic every month for HIV care?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Do you feel personally ashamed or unashamed when you think about coming to this clinic every month for HIV care?</td>
<td></td>
<td></td>
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</tbody>
</table>

**RA instructions:** Please read the following statement, “The following statements reflect how some people living with HIV say they feel about coming to clinic for their HIV care. I will read you each statement, then please tell me how much you personally Agree or Disagree with that statement. Remember there are no right or wrong answers, how much you personally agree or disagree with each statement is the best answer.”

**RA instructions:** Please have patients look at the BLUE Card with response options “Strongly Agree”, “Agree”, “Not Sure”, “Disagree”, and “Strongly Disagree”. Then read the following statements to patients. Have the patients respond to each statement from the options provided on the BLUE Card. Please tick the patient’s response in the appropriate box to the right of the statement.

<table>
<thead>
<tr>
<th>ITEM</th>
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</thead>
<tbody>
<tr>
<td>31. Before going on ARVs, the other services for HIV that are available at the clinic will be enough to keep you healthy.</td>
<td></td>
<td></td>
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<tr>
<td>32. Getting treatment for other diseases (e.g., treatment for STIs, TB treatment, or TB prevention medicine) is important for my health.</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>33. Coming to the clinic on a regular basis before you start ARVs will help you stay healthy.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>34. Going to clinic for your HIV care when you are feeling sick is important.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>35. Going to clinic for your HIV care even when you are feeling healthy is important.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>36. You wish you could start ARV medications right now.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>37. Not being able to start ARV medications is frustrating.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>38. The clinic’s doctors you see for your HIV care cannot be trusted.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>39. The clinic’s nurses you see for your HIV care cannot be trusted.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>40. The clinic’s doctors that you see for your HIV care treat you with respect.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>41. The clinic’s nurses that you see for your HIV care treat you with respect.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>42. The clinic staff will gossip about you outside of clinic.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>43. Most nurses at this clinic don’t like caring for people with HIV.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>44. You worry that people in your community will gossip about you if they notice you come to the clinic often.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>45. You are comfortable talking to your family about your HIV care.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>46. You don’t like coming to the clinic because it reminds you that you have HIV.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>47. Most people from your community think that you should go to the clinic regularly to get medical care for your HIV before starting ARVs.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>48. Most people who are close to you, think that you should go to the clinic regularly to get medical care for your HIV, even before you start ARVs.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>49. Most people that you know who are HIV-positive go to the clinic regularly (on schedule) for their HIV.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
<td></td>
</tr>
<tr>
<td>50. Most people that you know who are HIV-positive are taking ARV medications.</td>
<td>□ Strongly Agree</td>
<td>□ Agree</td>
<td>□ Not Sure</td>
<td>□ Disagree</td>
<td>□ Strongly Disagree</td>
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</tr>
</tbody>
</table>
COMPREHENSIVE OPTIONS RETENTION IN CARE SURVEY

51. How much support (e.g., financial, emotional, etc.) for getting HIV care do you receive from family members who know your HIV status? (Tick only one)

☐ A lot of support
☐ A little bit of support
☐ No support
☐ I have not disclosed my HIV status to any family members

52. How much support (e.g., financial, emotional, etc.) for getting HIV care do you receive from close friends or neighbors who know your HIV status? (Tick only one)

☐ A lot of support
☐ A little bit of support
☐ No support
☐ I have not disclosed my HIV status to any close friends or neighbors

SECTION 5

RA READ TO PATIENT: “Now I am going to ask you questions about different types of things that can make it harder or easier to come to clinic for your HIV-care and get information you want about your HIV. Please answer as honestly as possible. Your answers are strictly confidential and will not be shared with anyone.”

RA instructions: Please read the following statement, “The following statements reflect how easy or hard some people living with HIV find coming to the clinic for their HIV care. I will read you each statement, then please tell me how you feel about each statement, how hard or easy you find each statement. Remember there are no wrong answers, how you feel about the each statement is the best answer.”

RA instructions: Please have patients look at Yellow Card with response options “Very hard”, “Hard”, “Not Sure”, “Easy”, and “Very easy”. Then read the following statements to patients. Have the patients respond to each statement from the options provided on the Yellow Card. Please tick the patient’s response in the appropriate box to the right of the statement.

<table>
<thead>
<tr>
<th>Question</th>
<th>Very hard</th>
<th>Hard</th>
<th>Not Sure</th>
<th>Easy</th>
<th>Very easy</th>
</tr>
</thead>
<tbody>
<tr>
<td>53. How hard is it for you to find a clinic where the staff are kind, supportive and treat the patients with respect?</td>
<td></td>
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<tr>
<td>54. How hard is it for you to find a clinic for your HIV care that is within a reasonable travel distance?</td>
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<tr>
<td>55. How hard is it for you to pay for transportation to come to the clinic?</td>
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<tr>
<td>56. How hard is it to find the time to come into clinic for an appointment (including traveling to the clinic and waiting for your appointment)?</td>
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<tr>
<td>57. How hard is it for you to afford to come in to the clinic (including finding someone to look after my child, transportation, lost hours at work, etc.)?</td>
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<tr>
<td>58. How hard is it for you to get permission to take time off from work to come to the clinic?</td>
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</tbody>
</table>
59. How hard is it to get time away from household duties such as, cooking, laundry, caring for children or sick family members to come to the clinic?

60. How hard is it for you to come to the clinic for your HIV care because you don’t want anyone in your family to find out you have HIV?

61. How hard is it for you to come to the clinic for your HIV care because you don’t want anyone in your community to find out you have HIV?

62. How hard is it for you to find your way around the clinic (e.g., where waiting rooms, exam rooms, or specific services are located)?

63. How hard is it to find out which is the correct queue you should join when you are at clinic?

64. How hard is it to find (locate) the people you need at the clinic (e.g., counselors, staff, doctors, nurses)?

65. How hard is it to actually get to be seen by the people you need at the clinic (e.g., counselors, staff, doctors, nurses)?

66. How hard is it to get information about HIV at the clinic?

67. How hard is it to understand the information you are given at the clinic about HIV (e.g., from staff, pamphlets, or posters)?

68. How hard is it to get the support you need from clinic staff and providers at the clinic?

69. How hard is it for you to ask clinic staff or providers questions about your HIV or treatment?

70. How hard is it to wait at the clinic for long periods of time?

SECTION 6

RA READ TO PATIENT: “The next set of questions asks about sexual behaviour. Please answer as honestly as possible. Your answers are strictly confidential and will NOT be shared with anyone.”

C1. When did you last have sex?

_____ In the past week
_____ In the past 4 weeks
_____ Between 1 month and 2 months ago
_____ Between 3 months and 6 months ago
_____ More than 6 months ago (ask question C3, then skip to END OF SURVEY)
COMPREHENSIVE OPTIONS RETENTION IN CARE SURVEY

RA READ TO PATIENT: “Many people find it difficult to use condoms every time they have sex, and there are a number of reasons why people do not always use condoms. For example, sometimes the person you are having sex with does not want to use a condom. At other times, you might not have a condom with you. Also, there may be times when you just forget to use a condom.”

C3. When did you last have sex without a condom?
   ■ In the past week
   ■ In the past 4 weeks
   ■ Between 1 month and 2 months ago
   ■ Between 3 months and 6 months ago
   ■ More than 6 months ago

SECTION 7

“Now think about all the people that you may have had sex with during the past 3 months.”

X1. How many people did you have sex with during the past 3 months?
   _______ sexual partners
   ☐ I did not have sex in the past 3 months (skip to END OF SURVEY)

X2. During the past 3 months, how often were condoms used when you had sex?
   ■ Never
   ■ Seldom or rarely
   ■ Sometimes
   ■ Most of the time
   ■ Always

“Now think about all the people that you may have had sex with during the past 4 weeks.”

C4. How many people did you have sex with during the past 4 weeks?
   _______ people
   ☐ I did not have sex in the past 4 weeks (skip to END OF SURVEY)

C5. During the past 4 weeks, how often were condoms used when you had sex?
   ■ Never
   ■ Seldom or rarely
   ■ Sometimes
   ■ Most of the time
   ■ Always

C6. During the past 4 weeks, how many rounds of sex did you have?
   _______ rounds

C7. During the past 4 weeks, how many rounds of sex did you have without a condom?
   _______ rounds

RA instructions: Please read the following statement once you have completed the survey with the participant.

“Thank you for completing this survey. Your responses are very important to us and we appreciate your time.”