

Attachment 3.2 –Questionnaire: Description of each item, source, and goal for The effectiveness of donor notification, HIV counseling, and linkage of HIV positive donors to health care in Brazil

**REDS III-INTERNATIONAL
NOTIFICATION AND HIV FOLLOW UP STUDY 2014
Questions relating to survey objectives**

The purpose of the interview questions is to collect profile data to determine behaviors following notification of HIV infection among volunteer donors in Brazil, including health care seeking, behaviors that evidence risk reduction, and social consequences of HIV. The interview data on behaviors following HIV notification by the blood center will be used to; 1) understand if the former donor has successfully entered the health care system for HIV treatment, 2) if the former donor has modified his/her risk behaviors, including behaviors that could place others at risk of infection acquisition, 3) assess how the former donor is coping with his/her HIV status, and 4) inquire about ways blood centers in Brazil may be able to improve disclosure of behavioral risk factors for HIV infection before blood donation occurs, which may suggest modifications to current operational donor screening questionnaires in ways that can decrease risk and improve safety of the blood supply.

All of the content for this questionnaire, except for sections I and J come directly, or in slightly modified format to reflect the time period of interest in this study, from the previously OMB approved REDS-II Brazil HIV case-control study survey instrument (OMB Approval 0925–0597) and the REDS-III Brazil case surveillance survey instrument (OMB Approval Number: 0925–0597, Expiration Date: July 31, 2015).

Section A - Study Data

Objective: Section A will be completed by trained research staff. The following questionnaire items are related to the general profile of respondents (study subjects), and will be used for de-identified administrative record keeping, as well as for obtaining general demographic information from study subjects.

A1. Notification and HIV Follow Up Study Subject ID

A2. REDS-II or REDS-III Subject Study ID

The following questionnaire items are related to the specific details of the study, study staff and time and place for the interview.

A3. Subject Type

A4. Study Participant site

A5. Month of interview

A6. Year of interview

A7. Research assistant initials

Section B - Demographic Data

Section B will be completed by the study subject with the assistance of the trained research staff. The will allow the subject to become familiar with listening to and/or reading the questions and the use of touch screen for answering questions.

Objective: to obtain demographic data for general risk stratification based on the background of the subjects.

- B1. What is your gender?
- B2. What is your current marital status?
- B3. If you are married or living with someone, is your spouse/cohabitating partner? (male, female, transgender, don't know, refuse to answer)
- B4. What level of education do you have?
- B5. Are you presently employed?
- B6. What is your occupation?

Section C - Previous donation and HIV testing

Section C and all remaining sections will be completed by each study subject in privacy. The purpose of using a self-administered instrument is to ensure that potentially stigmatizing behaviors will be reported as honestly as possible without fear or concern that an interviewer would stand in judgment.

Objective: to obtain data related to whether a donor has tried to donate blood since he/she learned about his/her HIV status and reason for the donation attempt. In Brazil a disqualified donor registry doesn't exist (as in the US), so a person at-risk, could try to donate in many blood centers.

- C1. Since you learned of your HIV test result, have you tried to donate blood at this or another blood center?
- C2. Since you learned of your HIV test result, how many times have you tried to donate blood at this or at another blood center?
- C3. What was the reason for your attempted blood donation? Please check all the boxes for the factors that contributed to your decision to come to a blood center after you learned about your previous HIV test result. When you have selected all of your answers, please touch the "Next Question" box
- C3b. Please specify any other reason for donating blood.

Objective: to determine if the donor exhibits HIV testing behavior elsewhere, after learning of his/her HIV status through blood donation. Donor knowledge about alternative testing sites such as the HCT sites and levels of satisfaction with testing at HCT site will also be assessed.

- C4. Since you learned of your HIV test result from the blood center, have you been tested for HIV somewhere else?
- C5. Since you learned of your HIV test result from the blood center, where have you been tested for HIV?
- C5b. Please specify the other test site.

- C5c. When was the last time you were tested for HIV? Please tell us the month and year if you can remember.
- C6. Since you learned of your HIV test result from the blood center, how many times have you been tested for HIV?
- C7. Overall, how would you rate your HIV testing experience at locations other than the blood center?
- C7b. Please check all the boxes for the factors that contributed to your unsatisfactory or very unsatisfactory HIV testing experience.
- C7c. Please specify the other reason for your unsatisfactory or very unsatisfactory HIV testing experience?
- C8. Counseling and Testing Centers (CTA) are health services that provide diagnosis and prevention services for sexually transmitted diseases. At CTA's you can obtain free and confidential testing for HIV, syphilis, hepatitis B and hepatitis C among other services. Have you ever heard about Counseling and Testing Centers?
- C9. Have you ever been tested at a Counseling and Testing Center (CTA)?
- C10. When was the last time you were tested at a Counseling and Testing Centers (CTA)? Please specify the month and year.

Section D - Sexual History

Sexual lifestyle changes, after learning about HIV status, including, the number of sexual partners may impact the odds of having other sexually transmitted diseases, as well as infection spread. Learning about sexual history after the HIV status disclosure will allow us to determine the most prevalent sexual patterns for the Brazilian participants and whether these patterns may or may not be similar to known population subgroups, such as men who have sex with men, sex workers, intravenous drug users, etc. HIV spread occurs through both homosexual and heterosexual behaviors in Brazil and the rates of HIV are increasing among younger MSM. Behaviors following HIV notification related to blood donation have not previously been assessed. A better understanding of behavioral risk patterns may allow us to develop more accurate donor qualification questions.

Objective: to ascertain the respondent's self-defined sexual orientation. In many Latin American cultures, for instance, men do not consider themselves as homosexual if they only have insertive anal sex or oral sex. A transgender orientation has been included in the questionnaire as an additional response option.

D1. What do you consider yourself to be?

Objective: to ascertain the sexual history of male respondents.

D2. (Ask of Men Only) How many different women have you had sex with since you first began having sex?

D3. (Ask of Men Only) How old were you when you had sex with a woman for the first time?

D4. (Ask of Men Only) How many different men have you had sex with since you first began having sex?

D5. (Ask of Men Only) How old were you when you had sex with a man for the first time?

Objective: to ascertain sexual history in female respondents

D2. (Ask of Women Only) How many different men have you had sex with since you first began having sex?

D3. (Ask of Women Only) How old were you when you had sex with a man for the first time?

D4. (Ask of Women Only) How many different women have you had sex with since you first began having sex?

D5. (Ask of Women Only) How old were you when you had sex with a woman for the first time?

Section E - Sexual Behavior and Sexual Partners' Risks

Objective: the risk of acquiring HIV is closely linked to the nature of any sexual practices, the number of sexual partners, and the number of exposures. These questions will define sexual exposures after HIV notification.

E1. When was the last time you have had sex or intercourse with man? (Please tell us the month and year).

E2. When was the last time you have had sex or intercourse with woman? (Please tell us the month and year).

E3. Since you learned of your HIV test result, how many men have you had sex with? Please include both ongoing sexual partners and one-time encounters. (Choose one.)

E4. With regard to your ongoing sexual partners and one-time encounters with men, how often did you use condoms when you had sex? (Choose one.)

E5. Since you learned of your HIV test result, how many women have you had sex with? Please include both ongoing sexual partners and one-time encounters. (Choose one.)

E6. With regard to your ongoing sexual partners and one-time encounters with women, how often did you use condoms when you had sex? (Choose one.)

Objective: sexual and physical abuse will be assessed to determine the correlation between high risk behaviors including using drugs, having multiple sexual partners, exchange drug and money for sex, among other risks. These questions establish current (post—notification) behaviors and exposures.

E7. Have you ever been physically abused? (Please do not consider sexual abuse when answering this question).

E8. Since you learned of your HIV test result, have you been physically abused?

E9. Have you ever been sexually abused or forced to have sex without your consent?

E10. Since you have learned of your HIV test result, have you been sexually abused or forced to have sex without your consent?

E11. Since you learned of your HIV test result, have you had sex with anyone who was an intravenous drug user?

E12. Since you learned of your HIV test result, have you had sex with anyone who tested positive for hepatitis?

- E13. Since you learned of your HIV test result, have you had sex with anyone who tested positive for HIV?
- E14. Since you learned of your HIV test result, how many different HIV positive partners have you had?
- E15. To the best of your knowledge, if any of your partners were HIV positive, were they taking HIV medications?
- E16. (Ask of Women Only) Since you learned of your HIV test result, have you had sex with a man who has had sex with another man?
- E17. Since you learned of your HIV test result, have you had sex with anyone who received a blood transfusion?
- E18. Since you learned of your HIV test result, have you had sex with anyone who was a hemophiliac?
- E19. Since you learned of your HIV test result, have you had sex with anyone who has spent three or more nights in jail, prison, or a detention center?
- E20. Since you learned of your HIV test result, have you had sex with anyone who had a job that involved exposure to blood or other body fluids?
- E21. Since you learned of your HIV test result, have you exchanged (given or received) money or drugs, gifts or trips for sex?
- E22. When was the last time that you have you exchanged money or drugs, gifts or trips for sex?
- E23. Since you learned of your HIV test result, have you smoked or snorted illegal drugs? (Choose one.)
- E24. Since you learned of your HIV test result, have you used or shot up injection drugs (examples include heroin, cocaine, and amphetamines)? (Choose one.)
- E25. When was the last year you injected drugs?
- E26. Since you learned of your HIV test result, have you injected any non-prescription substances including vitamins, anabolic steroids, or hormones? (Choose one.)
- E27. When was the last time you injected non-prescription substances including drug, vitamins, anabolic steroids or hormones?
- E28. Since you learned of your HIV test result, have you shared needles or syringes with another person?
- E29. When was the last time that you shared needles?

Section F - Social Matrix

This questionnaire was designed to capture sexual information for the 5 most recent sexual partners in the 12 months before a participant completes the ACASI questionnaire. The reasons for these questions are to determine the changes in the sexual pattern of the participants (when compared to previous study responses); the nature of current sexual practices, the number of sexual partners; the number of exposures and some other sexual particularities that are relevant to identify riskier behavior for sexually transmitted disease. We believe that asking about more than 5 sexual partners will not provide any additional information.

The matrix asks the same questions of up to 5 recent sexual partners. The content for each partner is covered in its entirety before questions pertaining to the next partner are asked.

Objective: to compare current risk sexual behavior profile with the previous profile before the HIV-positive donation was given as reported in REDS-II or REDS-III case interviews.

F1. How many people did you have sex with in the last 12 months?
F2, F19, F36, F53, F70. What is Partner 1,2,3,4 and 5's gender?
F3, F20, F37, F54, F71. How old is partner 1,2,3,4 and 5?
F5, F22, F39, F56, F73. How would you describe partner 1,2,3,4 and 5's race? (Check all that apply.)

Objective: to ascertain the participant's social network and how participants may meet sexual partners. These questions are designed to evaluate whether the environment and social network have influence on sexual practices, and the potential behavior change between previous responses on REDS-II or REDS-III case interviews.

F4, F21, F38, F55, F72. What type of partner is partner 1,2,3,4, and 5?
F9, F26, F43, F60, F77. Where did you first meet partner 1,2,3,4, and 5?
F10, F27, F44, F61, F78. Please specify where you met partner 1,2,3,4, and 5?
F7, F24, F41, F58, 75. Is partner 1,2,3,4 and 5 a male who has had sex with other males?
F8, F25, F42, F59, F76. What is partner 1,2,3,4 and 5's HIV status?

Objective: to ascertain other risk factors related to HIV transmission.

F6, F23, F40, F57, F74. Is partner 1,2,3,4 and 5 an injection drug user?

Objective: to assess unprotected sexual behaviors and compare responses with the previous profile before the HIV-positive donation was given as reported in REDS-II or REDS-III case interviews.

F11, F28, F45, F62, F79. Number of times you had vaginal intercourse with partner 1,2,3,4 and 5 in past 12 months.
F12, F29, F46, F63, F80. When you had vaginal sex, how frequently did you use condoms?
F13, G30, G47, G64, G81. Number of times you had anal intercourse with partner 1 in past 12 months.
G14, G31, G48, G65, G 82. When you had anal sex, how frequently did you use condoms?
G15, G32, G49, G66, G83. Number of times you had insertive anal intercourse with partner 1 in past 12 months.
F16, F33, F50, F67, F84. When you had insertive anal sex, how frequently did you use condoms?
F17, F34, F51, F68, G85. Number of times you had receptive anal intercourse with partner 1 in past 12 months.
F18, F35, F52, F69, F86. When you had receptive anal sex, how frequently did you use condoms?

Section G - Medical History

Objective: to assess the medical procedures after the participant learned about his/her HIV status. In addition we want to determine the frequency of past and current ART therapy.

- G1. Since you learned of your HIV test result, have you received a blood transfusion? (Choose one.)
- G2. Since you learned of your HIV test result, how many transfusions have you received?
- G3. When was the last year you received a transfusion?
- G4. Since you learned of your HIV test result, have you had minor or major medical surgery, tooth extraction, or another dental procedure? (Choose one.)
- G5. Since you learned of your HIV test result, have you had endoscopy or colonoscopy? (Choose one.)
- G6. Since you learned of your HIV test result, have you taken antiretroviral therapy (ART)? (Choose one.)
- G7. If yes, what year did you start taking ART?
- G8. Are you currently taking ART?
- G9. What ART are you currently taking? A list and pictures of available therapies is provided to help you recall. (Check all that apply.)

Section H - General Activities or Exposures

Objective: to ascertain general exposures and facilitating factors for blood borne disease which the participant may have had after he/she learned about his/her HIV status.

- H1. Since you learned of your HIV test result, have you spent three or more nights in jail, prison, or a detention center? (Choose one.)
- H2. Since you learned of your HIV test result, have you had acupuncture treatments? (Choose one.)
- H3. Since you learned of your HIV test result, have you had a new tattoo or had one re-applied? (Choose one.)
- H4. Since you learned of your HIV test result, where did you get your most recent tattoo? (Choose one.)
- H5. Since you learned of your HIV test result, have you had new ear or body piercings? (Choose one.)
- H6. Since you learned of your HIV test result, where did you get your most recent piercing? (Choose one.)
- H7. Since you learned of your HIV test result, have you had a manicure or pedicure or had a shave at a barber shop? (Choose one.)
- H8. Since you learned of your HIV test result, how many times have you had manicures or pedicures or shaves at a barbershop? (Choose one.)
- H9. How many people do you personally know who do NOT have AIDS, but have HIV, the virus that causes AIDS? Please do not include yourself when answering this question (Choose one.)
- H10. How many people do you personally know who currently have AIDS? Please do not include yourself when answering this question. (Choose one.)]

Section I - Counseling and Notification

Objective: to ascertain whether participants believe blood bank counseling provides information about follow-up diagnostic evaluations and available medical, preventive, and psychosocial services, and to determine if this counseling contributes in preventing infection transmission to

others. We will assess participants perceptions related to their counseling in the blood bank setting and its correlation with HIV follow-up care.

- I1. When did you first learn about your HIV test result? Type month and year
- I2. Where did you first learn about your HIV test result? (Choose one.)
- I3. How do you rate your confidence level in the blood bank physician during your HIV counseling and notification? (Choose one.)
- I4. How do you rate the counseling skills of the blood bank physician during your HIV test result notification? (Choose one.)
- I5. How do you rate the importance of the blood bank counseling physician in your decision to seek health care? (Choose one.)
- I6. After the blood bank physician notification and counseling, did you go to seek health care somewhere else?
- I7. After the blood bank physician notification and counseling, where did you go to seek health care? (Choose one.)
- I8. Please specify other place

Objective: to determine the elapsed time between the date of the counseling and the time the blood donor has taken to obtain health care. Factors that could cause longer times to follow-up may include social circumstances that have led individuals not disclose their HIV status, we will assess HIV disclosure to others or reasons/perceptions that could contribute to non-disclosure.

- I9. After the blood bank physician notification and counseling, how long did it take for you to seek health care somewhere else? (Choose one.)
- I10. After you learned about your HIV test result, have you disclosed your result to someone else? (Choose one.)
- I11. To who have you disclosed your HIV test result? (Check all that apply.)
- I12. What are the reasons for not disclosing your HIV test result? (Check all that apply.)
 - I12b. Please specify the other reason
- I13. Have you felt discriminated against because of your HIV test result? (Choose one.)
- I14. Can you tell us more about why you feel discrimination? Did something occur that you felt was discrimination? (Check all that apply.)

Section J - Impact of Your Test Result

Objective: to determine circumstances that lead an individual to disclose or not information about his/her HIV status and whether this disclosure has influenced his/her concern about transmitting HIV to someone else.

- J1. In the place where you work are people friends with other people who have HIV?
- J2. Are you concerned you might give HIV to someone else? (Choose one.)
 - J2a. In what ways are you concerned of transmitting HIV? (Check all that apply.)
 - J2c. Could you please, specify other ways of transmission?

Objective: to determine consequences of disclosing HIV status to others and how this has affected the respondent.

- J3. Do you feel that people avoid you because of your HIV test result? (Choose one.)
J4. Has anyone forced you to move out of a place you lived because of your HIV test result?
J5. Have you been refused housing because people suspect you might have HIV?

Objective: to determine perceptions of stigma, discrimination and prejudice among health care providers in order to assess whether these perceptions are correlated with lower rates of HIV testing and lack of trust in HIV testing sites.

- J6. Has a health care provider made you feel bad because of your HIV test result?
J7. Has a health care provider refused to touch you because of your HIV test result?
J8. Have you been refused medical care or denied hospital services because of your HIV test result?

Objective: to obtain recommendations from HIV positive donors in ways to improve donor risk disclosure.

- J9. To help us to make blood safer, what would you recommend for improving the donor selection process? Any thoughts or ideas you have are good, please type as much or little as you would like to write.
J10. What could we do to get blood donors to disclose risk behaviors? Any thoughts or ideas you have are good, please type as much or little as you would like to write.
J11. Would you be more comfortable during the donation interview if the blood center staff was: (Check all that apply.)
J12. Could you please specify other ways?
J13. Would you be willing to answer more detailed and specific behavioral risk questions during the donor screening process, if the interview: (Check all that apply.)
J14. Could you please specify other ways?

Objective: to assess levels of voluntary work among individuals learning of their HIV positive results.

- J15. Since you learned of your HIV test result, have you considered volunteering or working with organizations that provide support or services to individuals living with HIV/AIDS?
J16. Do you currently do volunteer or paid work with organizations that provide support or services to individuals living with HIV/AIDS?
J17. What kind of organization are you currently doing volunteer or paid work with?
J18. Would you consider volunteering or doing paid work in the future?