## Attachment 5 — Survivor Questionnaire (Initial Study Visit and Follow-up) Questionnaire for the initial study visit: Pilot and Combined Module A/B

## [COMPLETE THIS PAGE AT STUDY ENROLLMENT AFTER INFORMED CONSENT]

A1. Participant's unique study ID number: \_\_\_\_\_\_

A2. Study enrollment date: \_\_\_\_\_

A3. Participant's sex (male or female): \_\_\_\_\_

A4. Participant's age at study enrollment (in years): \_\_\_\_\_\_

A5. Participant's home residency (village/district/subcounty): \_\_\_\_\_

A6. Participant's contact information (address/es):

A7. Participant's contact information (telephone/s): \_\_\_\_\_

A8. Participant's contact information (email/s): \_\_\_\_\_\_

A9. Participant's contact information (other): \_\_\_\_\_

[CONFIRM THESE DETAILS USING ETU DISCHARGE CERTIFICATE, IF POSSIBLE]

A10. Name/clinical ID of ETU where participant was treated for EVD:

A11. Date of ETU admission: \_\_\_\_\_

A12. Date of ETU discharge: \_\_\_\_\_

A13. Date of 1<sup>st</sup> blood test positive for Ebola: \_\_\_\_\_

A14. Date of 1<sup>st</sup> blood test negative for Ebola: \_\_\_\_\_

A15. Date of 2<sup>nd</sup> blood test negative for Ebola: \_\_\_\_\_

Public reporting burden of this collection of information is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).

Inquire if the participant was part of a research study. For example, did they receive an experimental drug during their illness, such as ZMapp, did they receive convalescent plasma during their illness, did they receive a vaccine to prevent Ebola infections as part of the STRIVE trial, or did they give convalescent plasma after recovering from their illness.

A16. Was the participant included in a clinical trial related to his/her illness with Ebola Virus Disease?

\_\_\_\_ No

\_\_\_\_Yes

\_\_\_\_ Don't know

A17. If yes, specify the name of the trial\_\_\_\_\_

A18. If known, specify what intervention that he/she received\_\_\_\_\_

A19. Today's date: \_\_\_\_\_

A20. Interviewer name/initials: \_\_\_\_\_

Thank you for participating in this study. I will be conducting your interview today, and it will last about 15 minutes. I ask all participants in this survey the same questions. All of your answers are confidential. I will mark a response to every question, but if you are not comfortable answering any question, you can tell me to mark "no answer." You can also ask me to go back, or repeat any questions. Are you comfortable proceeding with the interview now?

First, I would like to ask you a few questions about yourself and your family.

B1.

How many years of school have you completed? Choose one.

- \_\_\_\_ Less than six years
- \_\_\_\_ Six to eight years
- \_\_\_\_ More than eight years
- \_\_\_Other (specify) \_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

#### **B2**.

About how much money do you normally earn in a month? Fill in the blank.

Amount in Leones (SLL): <u>(will create categories)</u>

- \_\_\_ Don't know/not sure
- \_\_\_ No answer

**B3**.

Who do you live with? Mark all that apply.

\_\_\_ Alone

- \_\_\_\_ With friend/s or roommate/s
- \_\_\_\_ With spouse or partner
- \_\_\_\_ With parents or extended family member/s
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

#### B4.

## How many people live in your household, including yourself? \_\_\_\_ Number

B5.

#### What is your current relationship status? Choose one.

- \_\_\_ Single
- \_\_\_ Long-term relationship
- \_\_\_\_ Married
- \_\_\_\_ Separated, Divorced, or Widowed
- \_\_\_ Other (specify) \_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

## To be asked of women only (questions B6, B7, and B8): B6.

### How many times have you been pregnant? Choose one.

- \_\_\_ I have never been pregnant
- \_\_\_ One time
- \_\_\_ Two times
- \_\_\_ Three times
- \_\_\_ More than three times (specify) \_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

#### **B7**.

#### Is there any chance you are pregnant today? Choose one.

- \_\_\_ No chance
- \_\_\_\_Yes, I am pregnant, and my baby is due on (specify date) \_\_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

#### **B8**.

In the past 7 days, have you breastfed (provided your breast milk to any children, or allowed a child to suckle at your breast)? Choose one.

\_\_\_ No

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\_\_\_Yes

- \_\_\_Other (specify) \_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_\_ No answer / prefer not to answer

### For men and women:

#### **B9**.

Do you and your main sexual partner use any method of contraception to avoid pregnancy?

\_Yes

- \_No
- \_No answer
- \_Don't know
- \_\_Don't remember
- \_\_No sexual partner

### If answered yes to the previous question, which method/s are you using?

- \_\_\_ Condom
- \_\_\_\_ Pill/oral contraception
- \_\_\_\_ Intrauterine device
- \_\_\_ Injection/hormone shot
- \_\_\_ Other

## Now I would like to ask some questions about the time when you were sick with Ebola.

#### **C1**.

What was the month and approximate day or date when you first began to feel sick from Ebola? It is ok to guess if you are not sure of the exact date.

#### **C2**.

When you were sick with Ebola, did you have vomiting? Choose one.

- \_\_\_ No vomiting
- \_\_\_ Yes, I vomited
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

**C3**.

When you were sick with Ebola, did you have diarrhea? Choose one.

\_\_\_ No diarrhea

- \_\_\_ Yes, I had diarrhea
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

### **C4**.

When you were sick with Ebola, were you ever too sick to get up to relieve yourself in the toilet (or other usual location)? Choose one.

- \_\_\_ No
- \_\_\_Yes
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

### **C5**.

When you were sick with Ebola, were you ever too sick to drink anything for a day or more? Choose one.

\_\_\_ No

- \_\_\_Yes
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

### **C6**.

## Were you pregnant during your Ebola illness?

- \_\_\_ No / I am a man
- \_\_\_ Yes
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

#### **C7**.

## If yes, did the baby live? Choose one.

- \_\_\_ I was not pregnant during my Ebola illness / I am a man
- \_\_\_ Yes, I am still pregnant now
- \_\_\_\_Yes, the baby was born and is living now
- \_\_\_\_ No, the baby was born alive but died later
- \_\_\_\_ No, the baby was not born alive / miscarriage / stillbirth
- \_\_\_Other (specify) \_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

#### **C8**.

## Has anyone else in your family had Ebola?

- \_\_\_No
- \_\_\_Yes
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

If yes, how many of your family members had EBOLA,

\_\_\_\_\_#Please specify their relationship to you

- 1.
- 2. 3.

## Next I would like to ask about your health today.

### D1.

How is your overall health and wellbeing now, compared to before you had Ebola?

- \_\_\_\_ My overall health now is back to normal or the same as before I had Ebola
- \_\_\_\_ My overall health now is worse than before I had Ebola
- \_\_\_ My overall health now is better than before I had Ebola
- \_\_\_ Other (specify) \_\_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

#### D2.

## Since you recovered from Ebola, do you have any new health problems?

- \_\_\_\_ No, not that I know of
- \_\_\_Yes
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

#### D3.

## If answer yes to the above question, please specify

- \_\_\_ Eye/vision problems
- \_\_\_\_Muscle pains
- \_\_\_\_ Joint pains
- \_\_\_ Weight loss
- \_\_\_\_ Feeling depressed (unable to concentrate, feeling very sad, poor appetite, other)
- \_\_\_ Sexual problems (specify) \_\_\_\_\_
- \_\_\_Other (specify) \_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

# D4 Since recovering from Ebola, do you have the same level of sexual desire as before you were sick?

- \_\_\_No
- \_\_\_Yes
- \_\_\_ Don't know
- \_\_\_\_ No answer/prefer not to answer

## For men only:

# D5 Since recovering from Ebola, have you had any difficult getting or maintaining an erection, or ejaculating?'

- \_\_\_ No
- \_\_\_Yes
- \_\_\_ Don't know
- \_\_\_\_ No answer/prefer not to answer

## For men and women:

### D6.

## Do you have tuberculosis? Choose one.

- \_\_\_\_No, not that I know of
- \_\_\_ Yes, I have tuberculosis
- \_\_\_ Other (specify) \_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

### D7.

## Do you have diabetes? Choose one.

- \_\_\_ No, not that I know of
- \_\_\_ Yes, I have diabetes
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

## D8.

## Have you ever had a test for HIV? Choose one.

- \_\_\_\_ No, not that I know of
- \_\_\_\_Yes, I have been tested for HIV
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

## D9.

## Do you have HIV? Choose one.

- \_\_\_\_No, not that I know of
- \_\_\_ Yes, I have HIV
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

D10.

## If you have HIV, are you taking any HIV medications (antiretrovirals or ARVs)?

- \_\_\_\_No, they weren't offered to me
- \_\_\_\_ No, I can't afford the cost
- \_\_\_\_ No, I don't want to take them
- \_\_\_\_ Yes, I am taking HIV medications
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

## D11.

Do you now have any symptoms of a possible sexually transmitted infection, such as genital (penile, vaginal, or anal) ulcers, sores, lesions, warts, or discharge?

- \_\_\_\_ No, I do not have any of those symptoms now
- \_\_\_\_Yes, I have one or more of those symptoms now
- \_\_\_Other (specify) \_\_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

The following section E includes questions that should only be asked to men:

In addition to questions about your health we will ask you how often you have engaged in sexual activity since recovery, if at all. The reason for us asking this questions is to understand more about how any viral remains in your semen could relate to how often you have ejaculated. These questions may disturb you and you can choose not to answer them or any questions that disturb you, at any time.

To be asked to men only:

## E1

Since recovering from Ebola, have you resumed sexual activity?

\_\_No (stop here, go to section **F** below)

\_Yes (continue to the next question E2)

## If yes:

#### **E2** What was the date/ month you resumed sexual activities? It is okay to guess. Fill in the blank.

Date:

\_\_\_ Don't know/not sure

\_\_\_\_ No answer/prefer not to answer

## E3

# How often have you engaged in sexual activities with a partner since recovery from Ebola?

- \_every day
- \_> 3 times a week
- \_3 times weekly
- \_< 3 times weekly</pre>
- \_once every week
- \_once/one-off meeting
- \_\_Never
- \_No answer/prefer not to answer

To finish the interview we would like to understand what kind of information and advise you received when you left the ETU, and how you have related to that information on sexual activity and also breast-feeding. It is important to us to understand if the information is clear and easy to understand and follow, or if it is sometimes not provided, forgotten easily or difficult to understand or follow.

## For men and women:

F1.

Before today, did you receive information from anyone about when it is safe for someone who had Ebola to have sex? Mark all that apply.

- \_\_\_ No
- \_\_\_\_ Yes, from friends or family members
- \_\_\_\_Yes, from leaders in my community
- \_\_\_ Yes, from staff at the clinic where I was treated / other doctors or medical professionals
- \_\_\_\_ Yes, from public health or government officials
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

#### F2.

What advice did you hear about when it is safe for someone who had Ebola to have sex? Mark all that apply.

- \_\_\_ Don't remember hearing any advice
- \_\_\_\_ Abstain from sex for \_\_\_\_ days or months
- \_\_\_\_ Use condoms for \_\_\_\_ days or months
- \_\_\_\_ Abstain or use condoms for \_\_\_\_ days or months
- \_\_\_\_ Safe to have unprotected sexual intercourse immediately
- \_\_\_Other (specify)
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

#### F3.

## Before today, did you receive information from anyone about when it is safe for someone who has had Ebola to breastfeed? Mark all that apply.

\_\_\_No

- \_\_\_\_ Yes, from friends or family members
- \_\_\_\_Yes, from leaders in my community
- \_\_\_ Yes, from staff at the clinic where I was treated / other doctors or medical professionals
- \_\_\_\_ Yes, from public health or government officials
- \_\_\_ Other (specify) \_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer
- F4 Did you engage in sexual activity following three first months after recovering from Ebola Ebola recovery

Yes (continue)

- \_ No (Go to G1 or finish the interview)
  - \_\_\_\_ Don't know/not sure (Go to G1 or finish the interview)
  - \_\_\_\_ No answer/prefer not to answer (Go to G1 or finish the interview)

### If yes:

## During the three first months after recovering from Ebola, how often did you use a condom during sex? Choose one.

- \_\_\_ Never
- \_\_\_ Some of the time
- \_\_\_ Every time
- \_\_\_ Other (specify) \_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_\_ No answer/prefer not to answer
- **F5** Where did you get the condoms you used? Mark all that apply.

- \_\_\_ I did not use any condoms
- \_\_\_ I got them at the ETU where I was treated
- \_\_\_\_ Free donation from another organization
- \_\_\_\_ I bought them from a shop/market/pharmacy
- \_\_\_\_ Gift from a friend/family member/loved one
- \_\_\_ I already had them before I got sick
- \_\_\_ Other (specify) \_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

### The following question (G2+3) will be asked of lactating women only:

#### G1.

What advice did you hear about when it is safe for someone who has had Ebola to breastfeed? Mark all that apply.

- \_\_\_\_ Don't remember hearing any advice
- \_\_\_ Resume/continue breastfeeding as soon as possible
- \_\_\_ Do not breastfeed for 2 months
- \_\_\_ Give the child formula instead of breast milk
- \_\_\_ Give the child animal milk instead of breast milk
- \_\_\_ Give the child water instead of breast milk
- \_\_\_ Other (specify) \_\_
- \_\_\_\_ Don't know/not sure
- \_\_\_ No answer

#### G2.

# Did you receive any ready-to-use infant formula (RUIF) when you were discharged from the ETU? Choose one.

- \_\_\_ No
- \_\_\_ Yes
- \_\_\_ Other (please specify) \_\_\_\_\_
- \_\_\_ Don't know/not sure
- \_\_\_ No answer

Thank you very much for participating in the survey today. Do you have any other comments or concerns you would like to share about these topics?

Specify \_\_\_\_\_

For staff use only		
	Date	Staff initials
Questionnaire administered		
Questionnaire checked for completeness		
Data entered		
Data entry checked for completeness		