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 1st blood test positive for Ebola: _____

A14. Date of 1st blood test negative for Ebola: ______

A15. Date of 2nd blood test negative for Ebola: _____

Inquire if the participant was part of a research study. For example, did they receive

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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

___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		