

## **SURVIVOR HOUSEHOLD TRANSMISSION STUDY**

### **PARTICIPANT INFORMATION SHEET**

**My name is XX and am I working with Save the Children. We are carrying out a study to understand how Ebola was transmitted in this community, and how survivors and their families have been affected by it.**

**You/your child(ren) are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. I will read information to you about this study. Please ask me if there is anything that is not clear or if you would like more information.**

#### **WHAT ARE WE TRYING TO LEARN WITH THIS RESEARCH STUDY?**

Many of the people who survived Ebola have continued to have symptoms and other problems. We would like to understand what problems Ebola survivors and their families are experiencing so we know how best to help them.

Also, although Ebola Virus Disease can be very severe, some people may get only very mild or no symptoms. How often this occurs is not known, but is very important for understanding how the disease spreads and therefore how to control it. By testing small samples of saliva we can see if infections are occurring without symptoms. We hope that the findings from this study will help improve our understanding of Ebola transmission.

#### **WHY ARE WE ASKING YOU TO PARTICIPATE?**

*[for survivors]* We are asking everyone who was treated at the Kerry Town ETC to take part in the study.

Or

*[for household members]* We are asking everyone who is a household member of an Ebola survivor from the Kerry Town ETC to take part in the study.

Or

*[for neighbourhood controls]* We are asking you/your child because we want to look at a group of people who did not have Ebola to compare with Ebola survivors. We chose all the houses in this neighbourhood because it is an area which has had relatively little Ebola.

#### **WHAT HAPPENS IF I DON'T WANT TO PARTICIPATE IN THE STUDY?**

You are free to refuse to participate in this study, or to withdraw your participation at any time. Refusal to participate or withdrawal will not affect you/your child in any way.

#### **WHAT WILL MY PARTICIPATION IN THIS STUDY INVOLVE?**

*for survivors and household members]*

If you choose to participate in this study, we will ask you for up to about two hours of your time. We will also ask you if you are happy for us to see you again for more in depth questions about how Ebola has affected you and your household.

[If you choose to participate in this study, we will ask about who lives in this household and you/your child will be asked a few questions. Then we will ask you about what happened in the household when Ebola came, and about contact with anyone with Ebola.

We will also help you/your child to take a sample of saliva for testing for antibodies to Ebola.

All of the samples will be analysed in Sierra Leone. It may take some time to get the results and we will not be able to make them available to you.

Or

*[for community controls]* If you choose to participate in this study, you/your child will be asked to complete a short questionnaire. We will also ask about contact with anyone with Ebola.

We will then help you/your child to take a sample of saliva for testing for antibodies to Ebola.

All of the samples will be analysed in Sierra Leone. It may take some time to get the results and we will not be able to make them available to you.

*[for survivors only]*

We would also like permission to access your/your child's medical records from when you/your child had Ebola and from the survivor's clinic so that we can see how the antibodies we measure are related to the illness.

#### **IF I/MY CHILD AM FOUND TO HAVE ANTIBODIES TO EBOLA WHAT DOES IT MEAN?**

If your sample is positive, it is possible that you have had an Ebola infection in the past. It does not mean that you have Ebola now. It does not mean that you are infectious. But, a positive test also does not mean that you are immune (protected) – you might still be able to get Ebola, so there is no benefit in knowing the result.

#### **WHAT HAPPENS TO THE BLOOD AND SALIVA SAMPLES?**

We would like to store your/your child's saliva samples for possible later testing, for example if more accurate tests become available. You can choose if you want us not to store your samples, and you can also tell us at any time in the future to have your stored samples destroyed. If we want to do further tests on the stored samples we will ask for permission first, from the Sierra Leone ethics committee.

#### **ARE THERE ANY RISKS INVOLVED WITH PARTICIPATING IN THIS STUDY?**

There are no direct risks from participating. Some of the questions we will be asking may remind you of very painful events, such as when you were sick or when you lost family members. If these questions are too difficult for you to answer, you are free to stop the interview at any time or leave the study completely.

#### **ARE THERE ANY BENEFITS INVOLVED WITH PARTICIPATING IN THIS STUDY?**

The team will be able to provide psychosocial counselling if required

#### **WILL I BE ALLOWED TO WITHDRAW FROM THE STUDY IF I CHANGE MY MIND?**

Taking part in this study is voluntary. Should you wish to withdraw from the study at any point or not to answer any of the questions you are free to do so. You can also choose to answer the questions but not to give a saliva sample. It will not affect you in any way.

#### **WHO WILL SEE THE INFORMATION THAT IS COLLECTED?**

Personal identifiers will be removed from the questionnaire before analysis, and all data will be stored in a way that only authorised people can access it. Your personal information will not be revealed in any published information.