

JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH

INFORMED CONSENT DOCUMENT

SURVEY INTERVIEW – FACE-TO-FACE & ACASI

Study Title: Collecting survey data on the survival and health of siblings

Principal Investigator: Helleringer, Stephane

What you should know about this study

- You are being asked to join a research study.
- This study is conducted jointly by the Karonga Prevention Study (KPS) and its collaborators from Johns Hopkins University in the US.
- This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- You are a volunteer. You can choose not to take part and if you join, you may quit at any time. There will be no penalty if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.

Purpose of research project

The purpose of this research is to test a new questionnaire to determine the causes of recent deaths in Malawi, and in other similar countries.

Why you are being asked to participate

You are being asked to participate in this study because you are aged 15-59 years old, and you are currently residing in the area studied by KPS.

Procedures

As part of this project, we will ask you to take part in an interview on topics related to your characteristics such as your age, your education, your marital status and your use of medical services. This interview will also ask you about your maternal siblings, that is the brothers and sisters who have the same mother as you. We will ask you to list all these siblings and to report whether they are still alive and how old they are. If they have died, we will also ask you when they died and how old they were when they died. We will ask you to describe the circumstances of their death and to report some aspects of their medical history. Finally, some questions will concern your own HIV status and the HIV status of your siblings.

I will either be asking you these questions directly, or you will hear those questions through a headset. This will be determined by chance, just as if we flipped a coin. If you

are asked to listen to the questions through a headset, you will also be asked to enter your answers yourself, by pressing touches on a keypad. This is very simple and I will show you how to do this.

Some aspects of these questions may relate to private topics. It will be entirely up to you to decide whether you want to answer these questions. If you are not comfortable answering a particular question, you can always skip it. You can also stop your participation in the study at any time.

All the information you provide will be recorded using a tablet, which is an electronic device. This is the case whether I'm asking the questions, or whether you hear the questions through a headset.

In total, we expect that this interview will last about 30 minutes.

Risks/discomforts

The risks associated with your participation in this study consist primarily of a possible breach in confidentiality. During the course of the study, some people may come to find out about the answers you have provided to some of our questions. This may occur because some people may gain access to the tablet, and may come to find out about the answers that were provided during the interview. We will put in place a number of safeguards to avoid this, but we cannot completely guarantee that this will not happen.

In addition, you may also feel discomfort and sadness while recalling a deceased relative. If that is the case, remember that you do not have to answer every question.

Benefits

There are no direct benefits for participation in this conversation. The information we will collect during the study may however help develop new ways to measure and address the burden of HIV in populations in Malawi.

Payment

You will not be paid for your participation in this interview.

Protecting data confidentiality

We will put in place every possible measure to ensure that the information you provide to us during the study remains confidential, that is only authorized study team members can see it. First, the interview will take place in a private space, where our conversation cannot be overheard. Second, we will record the information using a tablet. Tablets are electronic devices, and they are protected by a password. It will thus be very difficult for anyone to gain access to the information you reported, unless they are affiliated with the study and know the password required to access the tablet. Finally, all the data analysis will take place in limited access rooms where only members of the study team will be allowed. Despite these precautions, there remains a small risk that some of the

information you provide to us will become available to others who are not authorized to see this information.

Alternatives to procedures or treatments

The alternative to participating in the study is simply not to participate.

What happens if you leave the study early?

You can refuse to answer any question you are asked and you can choose to discontinue participation at any time. This is completely up to you. Your decision to participate in the study, or to stop participating, will not affect your capacity to access services at any health facility. It will also not affect your ability to participate in other KHDSS studies.