

KARONGA PREVENTION STUDY

LONDON
SCHOOL of
HYGIENE
& TROPICAL
MEDICINE



WELLCOME TRUST LEPR
PO Box 46, Chilumba (tel: 0999 971 860/1)

Date of interview	
CRS no	
GHHID	

DEMOGRAPHIC SURVEILLANCE BY A CONTINUOUS REGISTRATION SYSTEM (CRS) INFORMATION SHEET AND CONSENT FORM

To be read out **to the head (or their spouse or other senior member) of a new household or of a household that has not already provided written consent.**

1. WHY YOUR HOUSEHOLD HAS BEEN CHOSEN

We are asking your household to (continue to) take part in a study being done by the Karonga Prevention Study ("LEPRA") to help improve the health of individuals living in your community and the country Malawi. The study is about understanding population, and you are living in the area where this study is taking place. Your household may have already been participating in this study for some years, but as part of a revision of our procedures and changes in the way that we record participation, we are requesting that you put your consent in writing.

2. WHO IS FUNDING THE STUDY AND HAS THE STUDY BEEN APPROVED ETHICALLY?

The funds for this study are being provided by the Wellcome Trust, a major UK based research charity.

The study has been approved by National Health Sciences Research Committee.

3. WHAT IS CRS?

CRS stands for Continuous Registration System. After completing the baseline house to house census between August 2002 and July 2004, we continue to keep track of the population by monitoring birth and death rates as well as the movements of people that affect population size. We are helped by members of the communities (Key informants), who tell us when births and deaths have taken place in their reporting areas. KPS interviewers then visit the households to register the birth or death. When a death has occurred we ask questions to identify why the person has died. This is followed by a

yearly house to house re-census where we update information on household membership (for example if a household member has moved out, or if someone else has joined the household). At the same time, we will ask each household member questions about their family (spouses/children), education, economic activities and some health conditions). For children aged less than 5 years we collect information on their vaccination history and for children we will also be asking to measure their height and weight.

4. WHAT IS KPS TRYING TO LEARN?

There are several things that we are trying to learn from this study. Firstly, we would like to know the estimates of the population in the CRS area in terms of size, age-structure, sex-ratio, household composition, geographic distribution and distribution by socio-economic characteristics, and how these factors might affect the health of the community. This information is crucial to inform policy in Malawi on planning of health services and other community interventions. We also are interested in why people in the community are dying and of what diseases, how many children are being successfully vaccinated and growing properly etc.

This study also helps us in screening for active TB cases who are referred for treatment. Additionally, the information gathered in this study also makes it easier to identify people who would be eligible for other KPS studies.

5. WHAT WILL IT MEAN TO TAKE PART IN THE STUDY?

If you agree for your household to take part in this study, we will visit to your household every year to ask you questions about your household membership (composition), and other health related issues, including on education, occupation, disability, vaccines, body measurements of eligible individuals, and whether you have symptoms of TB). When a child is born in your household or a member of you household dies, our interviewers will also come to ask your household questions about those events in your household.

6. WHAT WILL WE DO WITH THE INFORMATION WE COLLECT?

The information we collect is studied by scientists who analyse it to understand the health problems facing the community. This information we collect is also important for the Malawi Ministry of Health because is used to inform health policy in the country for example implementing policies to reduce under-five mortality or ways to reduce AIDS mortality or ways to reduce the spread of TB. This information is not only important to Malawi but also to other countries in the region.

Other researchers and organizations are also interested in the information we collect, as it can be used to answer many other health related questions. We have asked the Malawi Government, through the National Health Sciences Research Committee, to share the information we collect from you with other scientists to help in coming up with policies that can help make the whole world have a healthier population. These data will only be made available in an anonymised form which means that the information relating to members of your household cannot be traced back to them.

7. ARE THERE ANY BENEFITS OF BEING IN THE STUDY?

There are no immediate direct benefits to your household for participating in this study, however, the things that we will learn from this study will be used to inform Malawi Health policy which can help reduce or prevent disease and ensure appropriate treatment for people in the country. In that way your household will benefit from this study indirectly.

8. IS THERE ANY RISK TO BEING IN THE STUDY?

There is no any risk involved by participating in this study. However, we will need the members of your household to spend a small amount of your time with us to answer our questions.

9. WHAT IF I DO NOT WANT MY HOUSEHOLD TO TAKE PART?

Participation is voluntary. Your household and individual members can choose to participate or not to participate at all. Even if your household is enrolled in the study now and in-future you decide you are no longer interested to continue participating in the study you will have the freedom to withdraw. You will only need to ask the KPS interviewer visiting your household to give you a form to complete indicating that your household is no longer interested in participating in our study. If you agree to take part, then decide you do not want to take part in any particular section of the work, or answer certain questions in an interview, you can explain this to the interviewer at the time.

10. WHO WILL SEE THE INFORMATION THAT WE COLLECT?

Information we collect is confidential. We will conduct interviews in private or in the presence of other members of your family if you prefer. KPS will tell the Government, local health services and other interested stakeholders what we find – this. This information is in an anonymised format and cannot be traced back to you. We will also publish these summaries of findings as scientific papers: information which identifies you or your relatives will not be published. The information we collect from you may also be shared with other researchers but we will ensure that the information is shared in such a way that you cannot be identified (eg by withholding locations of where you live, or withholding correct birth dates etc)

11. WHO CAN I ASK IF I HAVE FURTHER QUESTIONS

If you still have questions before you sign the consent form, you can ask the KPS interviewer to explain to you where you are not clear. Alternatively, you can call the KPS office on 0888 392 753 for information or help. You can also contact the National Health Sciences Research Committee; Ministry of Health (Research Department, P O Box 30377, Lilongwe 3, Malawi, Telephone: 0 172 6422).

WE WOULD LIKE YOU TO ANSWER THE FOLLOWING TO SEE IF YOU WILL PARTICIPATE:

The information has been read to me, as a responsible adult member of my household; I have had the opportunity to ask questions, and my questions have been answered satisfactorily. I understand that the information you collect is confidential and I understand that my household can withdraw from the study at any time.	
I AGREE voluntarily that my household can take part in this study. (Yes, No)	Y N consent
I understand that, I and other members of my household will be asked about personal information for ourselves and that answers are confidential.	
I understand our personal details such as name, phone number and household will not be revealed to people outside the project.	
I understand that the information we provide may be archived by the project	
I understand that the information we provide may be used in publications, reports, web pages, and other research outputs in an anonymised form.	
I understand that other researchers may have access to this data only in a securely anonymised form.	

Name of Household Head:	Sex:	ident
Name and Signature/thumbprint of participant: Date:		
Name and signature of interviewer: Date:		rcdr <input type="checkbox"/> <input type="checkbox"/>

If consent to take part in the study is refused ask the subject the main reason for refusal and fill a refusal form