

KARONGA PREVENTION STUDY



WELLCOME TRUST LEPROSIS PREVENTION AND CONTROL STUDY
PO Box 46, Chilumba

ABOUT HIV

1. WHY ME?

We are asking you to take part in a study being done by the Karonga Prevention Study ("LEPRA") to help improve the health of your community. The study is about HIV.

2. WHAT IS HIV?

HIV is a serious health problem in this district, as it is in the rest of Malawi and other countries worldwide. HIV is the virus that causes AIDS, and it lives in your body. It can live there for many years without you knowing it, but eventually it makes people very ill.

You can now get treatment for HIV/AIDS called "antiretroviral (ARV) therapy". The treatment is free through the government health services, it helps people stay healthy for longer.

3. WHAT IS KPS TRYING TO LEARN?

We are visiting all households in your area to find out several things.

Firstly, we would like to find out how many people are affected by HIV and if this number is going up or down. Secondly, we want to find out more about the behaviours that put people at risk of becoming infected, including about marriage, other types of sexual relationship (like boyfriends or girlfriends) and whether people are using methods of protection, such as condoms. Finally, we want to find out who needs treatment in this area.

This is important to help improve services for your community and plan for you and your family's future. You can choose whether you want to take part in our study, or not.

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

If you are 15 years or older we will be asking you to take part in our study. If you agree we will first ask you a few questions about marriage, other types of sexual relationship and your use of condoms. Then we will discuss HIV testing with you,

and what it means to know your result. If you agree to be tested we will take a small amount of blood (one teaspoonful) from your arm. If you prefer, we can do this with a finger-prick.

If you want to know the result we will test the blood now and immediately tell you the result. If you are HIV positive we will counsel you on how to look after yourself and how to prevent passing HIV on to other people. If you are HIV negative we will advise you on how to stay negative. We will also talk to you about support available for people with HIV/AIDS and their families, regardless of what your results show.

If your test shows us you have HIV we will refer you to the hospital so that you can find out whether you need to take treatment. Not everyone who has HIV needs treatment immediately, and they can be taught how to keep strong by living positively (eg eating a balanced diet).

5. WHAT WILL HAPPEN TO MY BLOOD?

We will take the blood sample to the laboratory so we can do further HIV-related tests at KPS. This will allow us to confirm your test result, and, if you do have HIV, tell us more about the HIV virus, for instance what type it is and if it is an old or new infection. We will also test for another infection called HSV-2, which may be important in the spread of HIV in the community.

If we understand HIV better then we can help stop the disease spreading, so even if you do not want to know the result of your HIV test we would still like a blood sample.

We would also like to store your blood for possible later testing for other diseases related to HIV or of importance in Karonga District. You can choose if you want us not to store your blood, and you can also tell us at any time in the future to have your stored blood destroyed. If we want to do further tests on the stored blood we will ask for permission first from the Malawi National Health Sciences Research Committee. We will also let people know if they could benefit from the results of these tests.

We will be asking all adults in the area to take part in our study again in three years time; in between we plan to offer testing to those age-groups where HIV is most common.

6. WHAT ARE THE BENEFITS TO BEING IN THE STUDY?

There are many advantages to knowing whether or not you have HIV (your HIV status). People who know that they do not have HIV will have more reason to take care and remain negative.

People who know that they have HIV can remain well for many years; they can get support and treatment when they need it, because they know the main cause

of their illness. For pregnant women there is also treatment to help prevent their babies from getting HIV.

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

Taking a blood sample may cause a little pain but this will soon go away. People who learn that they have HIV may suffer from anxiety and fears. Our trained counselors can help. They can tell you about services for people living with HIV. They will also advise people about the advantages and disadvantages in telling family and partners about their HIV result.

We strongly encourage everyone to be tested, since knowing the results can help them protect themselves and their partners from infection, and also help them plan for their own and their families' future. If they find out they are infected they can be seen by a clinician who will make sure they get the right treatment. Taking an HIV test is the only way to find out your HIV status.

8. WHAT IF I DO NOT WANT TO TAKE PART?

Your participation is voluntary. This means you can decide if you want us to counsel you, and have the HIV test. If you want to have an HIV test but not as part of the study you can go to a VCT centre.

9. WHO WILL SEE THE INFORMATION THAT WE COLLECT?

Information about your HIV and treatment status is confidential. Information about marriage, other types of sexual relationship and your use of condoms is also confidential. We will take steps to protect your privacy, including conducting interviews in private, not recording your name on confidential information, and keeping your records secure.

KPS will use the information to find out more about HIV; they will tell the Ministry of Health and local health services what they find but they will never let people know your name or tell people about your household; this may lead to improved services for your community,.

10. SUPPORT AVAILABLE FOR PEOPLE AFFECTED BY HIV/AIDS

Voluntary counseling and testing it is available at all major hospitals and some health centres in Malawi. In Chilumba you can also ask for an HIV test at Chilumba Rural Hospital VCT Centre, and be seen by a trained medical professional at Mwabi Clinic who will ensure you have the necessary care. Staff at the VCT centre and at Mwabi will tell you what to do next. If you prefer you can go to Karonga you can visit the MACRO clinic for testing, or the VCT centre and Buyu Clinic at Karonga District Hospital (KDH). Please ask your KPS field supervisor or the KPS team leader (named below) if you want to find out more.



HIV SEROSURVEY Consent Form KPS

Date of interview	___ / ___ / ____	Version 02, 14/11/07			
Was the subject seen?	Y N				
studyno:					
crsno:	repgp	cluster	hhlistno	memberno	visitor
ident:					
specset					

	<u>*Please delete option that is not applicable</u>	
	I have read the information or it has been read to me. I have had the opportunity to ask questions about it, and any questions I had have been answered satisfactorily. I consent voluntarily to take part in this study, I understand that the information you collect is confidential and I understand that I can withdraw from the study at any time without it affecting my right to appropriate medical care.	
1	I AGREE / DO NOT AGREE* to take part in this study.	
	I understand that, I will be asked about marriage, other types of sexual relationship and methods of protection against associated infection. KPS will record this information so they can find out more about the behaviours that put people at risk of becoming infected. The answers will be confidential.	
2	I AGREE / DO NOT AGREE* to take part in the KPS behavioural study.	
	I understand that I will have blood taken to test for HIV, HSV-2 and type of HIV infection. If I prefer, I can have blood taken by finger-prick, The results of the test will be confidential. I understand that I can choose whether I am told the result. If I am found to be HIV positive I understand that I will be helped further and will receive treatment if necessary.	
3	I AGREE / DO NOT AGREE* to have blood taken for HIV and related testing.	Rsn- blood
4	I DO/ DO NOT want to know the result	
	I understand that my blood will be stored for possible later testing for other HIV-related diseases or diseases of importance in Karonga District. Further testing will only be done if approved by the Malawi National Health Sciences Research Committee. I understand that if I let you take some of my blood I can choose at any time to have my stored blood destroyed.	
5	I AGREE/ DO NOT AGREE* to my blood being stored for later testing	

Instruction to Counsellor: If consent to give blood is refused ask the participant for the main reason for refusal or uncertainty. Indicate that they do not have to answer, but if they do answer, document the main reason as:

- | | |
|--|-------------------------------------|
| 01 no reason | 06 already tested & knows status |
| 02 family/community decision to refuse | 07 thinks knows status |
| 03 confused/incapable of consenting | 08 prefers clinics |
| 04 afraid of needles/fingerprick | 09 does not think he/she is at risk |
| 05 afraid for other reasons | 10 other |

(Signature of participant / thumbprint) (NAME).....	(Signature of counsellor) (NAME).....	Staff code		Rcdr
		Coder / checker		Codr/ chkr