Participant ID

INFORMATION SHEET AND INFORMED CONSENT FORM: Focus Group Discussions

TITLE OF THE STUDY: The role of social network approaches in delivering integrated Public Health interventions: Application to HIV and schistosomiasis services

[The following text must be read to the participant, who must have their own copy to take home]

Introduction

Hello. My name is ……, and I am working with the Kamuzu University of Health Sciences on behalf of Dr. Madalo Mukoka and colleagues. I would like to invite you to consider participating in a research study, titled "The role of social network approaches in delivering integrated Public Health interventions: Application to HIV and schistosomiasis services." Before you agree to take part in this research study, please take time to read this information sheet carefully as it contains important information to help you decide whether you want to participate or not.

What is the purpose of the study?

You are being invited to participate in a research study that aims to explore the role of social network approaches in optimizing the delivery of integrated public health interventions targeting HIV and schistosomiasis services. HIV and Schistosomiasis are major public health threats in Mangochi fishing communities. This is so despite other parts of the country seeing a decline in the incidence of these conditions and effective treatment being available. The challenge that exists is that the services for these conditions are not readily available in the communities. The FISH trial (a 3-arm cluster randomized trial) was conducted between Jan 2020 to January 2023 and it created demand for HIV and Schistosomiasis services using network-based approaches for some of its arms with varying performance. It created demand for the services through distribution of information leaflets, coupons or HIV self-testing kits through a peer leader depending on the study arm. In this study, we would like to understand

why the FISH interventions worked in some clusters but not others, the role of social relationships in taking up health services and use this understanding as well as prospective social network data to propose a hypothetical delivery approach.

What is a social network approach?

A social network approach involves collecting information about relationships between people in a social context and drawing a map of how they are all connected. This helps us see how people share information, who has a lot of connections, and how groups form. This approach can be used to identify people that are potentially influential and can help in disseminating information about health services or sharing the services in the community. In this study, we would like to collect social network information to help inform an approach that could be used to deliver information and services related to HIV and schistosomiasis.

What will be involved if I accept to participate in the study?

You have been considered to participate in this study because you reside in a cluster that recruited participants into the FISH trial (which was providing HIV and schistosomiasis services to Fishermen but using different approaches). If you are willing to participate, a member of the study team will invite you to a group discussion where you (along with other participants) will discuss the role social relationships play in health behaviour/intervention adoption and barriers and facilitators to HIV testing and schistosomiasis treatment uptake for men. There will be a further discussion on how acceptable social network data collection would be in your community.

It is expected that the discussion will take between one hour to one hour 30 minutes. During the discussion we will write down the information that you give us. However, it is very important that we capture all the valuable information that you give so that your views are not misrepresented. As it is often difficult to keep pace with writing down what is said in a discussion, we request your permission to record the conversation using a voice recorder. Your voice record will only be identified by a study identity number and not by your name. Your participation in the study will end on the same day on which we do the interview.

We don't anticipate that you will face any risks or discomforts associated with the procedures. However, should you feel uncomfortable with some of the questions that I will ask or some of the issues that will be discussed, you are perfectly entitled to refuse to discuss issues that you do not want to. Your participation is voluntary, and you may withdraw at any time without penalty or loss of benefits.

Will there be any benefits in this study?

There are no direct benefits to you in your taking part in this study. However, what we learn from this study would help the Ministry of Health to make important decisions regarding how to deliver services in communities through social networks.

Will the findings in the study be confidential?

All personal information collected in this study will be kept strictly confidential. I will not share the information you provide with anyone who is not part of this research. But it may be shared with fellow researchers and may also be published through meetings or journals in a manner that does not reveal your identity. Before sharing in this manner, the information from you will be combined with that from other research participants. Information which could identify you or anyone related to you will never be released. However, it may be necessary to include direct quotes in some of the research outputs. These quotes will be anonymized. This means that names of study participants, including your own will not be included when sharing or publishing the data. We expect you not to share anything that will be discussed in this discussion with anyone. While the research team will maintain confidentiality regarding what is discussed, we cannot ensure that all participants will adhere to the request not to disclose this information to others. Data collection equipment and the data collected will be kept with identifiers, locked, and only accessible to people that have authorized access.

Can I withdraw from the study anytime and will this affect my treatment?

You are free to choose whether or not to participate in this study. There will be no penalty or loss of benefits to which you are otherwise entitled if you choose not to participate.

Compensation

You will not receive payment for participating in the study. However, since participating in this study will take you away from your home and work, we will offer you MWK4,000 as a token of our appreciation for your having taken the time to take part in this study.

Contact details

This research has been approved by the Kamuzu University of Health Sciences Research Ethics Committee (KUREC) and London School of Hygiene and Tropical Medicine Ethics Committee. If you have any questions regarding your rights as a research participant or concerns on how you have been treated in the study, please feel free to contact the number below:

Phone

Dr. Madalo Mukoka on +265 (0) 888 518 464

Or by mail to:

Helse Nord Tuberculosis Initiative
Kamuzu University of Health Sciences
Private Bag 360
Blantyre 3, Malawi

Or you can inform KUREC on the following contact:

Name:	KUREC Secretariat (Administrative officer)
Phone:	01 877 245 or 1871911 ext 334
Address:	Kamuzu University of Health Sciences P/Bag 360 Chichiri Blantyre 3

Participant consent

	Participant Initials / thumb print
I have received and read or had read to me the information sheet provided by the Researcher that explains in detail the reasons for the study	
I have understood the purpose of the research.	
I have asked all the questions that I have about the purpose of the research and feel that I have enough information about it	
I understand what I will be required to do if I participate in the study	
I understand and agree to be audio-recorded	
I understand and agree to the use of directly anonymized quotes in research outputs	
I know that I have the right to leave the study at any time or to refuse to answer any questions. I understand that I will not be penalized for doing so by the researcher nor by any medical service providers in the future	
I voluntarily agree to take part in this study	

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Participant name Date Signature or thumb print

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Name of Witness Date Signature or thumb print

I attest that I have explained the study information accurately in _____ to and was understood to the best of my knowledge by the participant and that he/she has freely given their consent to participate* in the presence of the above named impartial witness (where applicable).

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Study staff	Date	Signature