Participant Information Sheet

The rapid collection and effective use of contextual information is a key aspect to saving lives during epidemics. While epidemiological data tends to be widely used, it is rarely combined with data on the local context, social relations and cultural practices, which will ultimately shape the spread of the disease and potential control strategies. Furthermore, the costs of the delivery of different types of response efforts are not taken into consideration. This project aims to improve the use of research evidence to inform response efforts in the context of epidemics in low- and middle-income countries. This is the first study to document the main problems experienced by epidemic response teams and develop a rapid research methodology that can suit their needs and provide a more holistic picture of the realities of communities affected by infectious disease.

The rapid appraisal in this project will perform an in-depth qualitative study using phone interviews with stakeholders from multiple countries. These findings will be used to design a rapid mixed-methods research methodology to generate evidence to inform response efforts in a timely manner.

The study is being carried out by an interdisciplinary team from UCL. You can contact us using the details printed at the end of this form.

The aim of this information sheet is to help you understand why we are carrying out this evaluation and what would be required of you if you decide to take part in the study.

1. Who has given ethical approval for the study?

This study was approved by the UCL Research Ethics Committee.

2. Why have I been asked to take part?

You have been asked to take part because you are currently working in the design or implementation of response efforts for infectious epidemics. We wish to capture a wide range of views from the people in charge of designing, implementing, and interacting with these response efforts. We wish to speak with you because we believe you have a valuable perspective.

3. What does taking part involve?

If you decide to take part, the researcher will ask you to sign and email a consent form. After the consent form has been received, she will liaise with you to arrange the time for an interview. The interview will take place at a time that suits you and will be conducted over the phone or via Skype. The interview will last approximately 30 minutes.

The interview will include questions on your current role, experiences responding to epidemics, the use of qualitative data to inform the design and implementation of response efforts and any problems you might have encountered in the process. The researcher would record your responses in the form of a tape recording and written notes. You can ask the researcher to stop the interview at any time.

4. Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part, we will ask you to sign a consent form before the interview commences. You can request a copy of this consent form. Whether or not you decide to take part in the interview, your employment status or relations will not be affected in any way.

5. Is what I say confidential?

Yes, we will not inform anyone outside the research team that you have participated in the study. Your personal information will not be collected. All information will be stored securely and will only be accessed by members of the research team. We will not identify you by name in any reports or publications. Your data will be archived securely for 10 years after the study's completion, before its eventual destruction.

If you disclose information that the researcher feels has implications for professional practice, we may report these concerns to the head of service or other managers. Any information passed on will be anonymised, ensuring you cannot be identified.

6. What if I change my mind?

You are free to withdraw from the study at any time. You do not have to give a reason for withdrawing. Even if you start an interview, you can stop it at any point if you want to. If you wish to withdraw, please contact us using the details at the end of this sheet.

If you withdraw, we will hold onto the information you provided before withdrawing. If you lose capacity to participate, we will withdraw you from the study automatically. In this case we will also keep the information you provided.

7. What are the risks of taking part?

Helping us with this study will take up a little of your time, but we will do our best to minimize any inconvenience to you by arranging for the interview to take place at a time convenient to you.

If you feel uncomfortable discussing any aspect of this study, you can withdraw from the interview at any time. You can also contact the study team to discuss any concerns you have before and after agreeing to take part.

The researcher who conducts the interview will abide by a professional code of conduct.

8. What are the benefits of taking part?

There may be limited personal benefits emerging from the study, but the study aims to improve the approaches used to design and implement epidemic response efforts. The findings from this study will be presented to the staff leading response efforts on an on-going basis. The final results from the study will be shared across relevant networks and will be made available on the RREAL website.

9. How will information be stored?

UCL is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL will keep the information collected for this study for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage this information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use the information collected for this study by contacting the members of the research team listed below.

10. What will happen to the results of the research study?

The findings from this study will be presented to the staff leading response efforts on an on-going basis. The final results from the study will be shared across relevant networks and will be made available on the RREAL website. We will publish our findings in scientific journals and present them at national and international scientific meetings and conferences. Your name will not be used at any time.

11. What happens if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you have met through your participation in the research, you may wish to contact the researchers (details below).

12. Where can I find out more about the research?

Further information can be found by contacting the study team.

Researchers

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THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION AND FOR CONSIDERING HELPING WITH OUR STUDY