



School of Health Sciences
Faculty of Health and Medical Sciences
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Information Sheet

Developing an innovative healthcare system for palliative care in Ethiopia: co-design and user testing of a mobile phone based remote monitoring system

Dear Sir/Madam,

We would like to invite you to take part in a study. Your participation in the project is entirely voluntary. Before you decide you need to understand why the work is being done and what it will involve for you. Please take the time to read the following information carefully. Talk to others about the project if you wish.

This study is being undertaken by a team from the Universities of Surrey and Strathclyde, UK and Hospice Ethiopia.

What is the purpose of the study?

Palliative care in Ethiopia is in early stages of development; limited services means patients frequently experience symptoms including pain, nausea, fatigue and breathlessness that can adversely affect their ability to live well at home. Currently, there is a lack of technology to support the palliative care needs of patients, or for them to self- manage their condition and take control in the management of their symptoms. The aim is to explore views and opinions regarding the use of technology, and information requirements to support palliative care self-management and use this to inform the content of a remote delivery programme delivered via mobile phone technology.

Why have I been invited to take part in the study?

You have been chosen to take part because you are currently receiving palliative care. The information we gain from you will help us understand information requirements

and be used to inform the content of a remote delivery programme delivered via mobile phone technology.

Do I have to take part?

No, you do not have to participate. If you do participate, you are free to withdraw at any time without giving a reason. Any data collected with consent would be retained and used in the study. No further data would be collected. There will be no impact on the care you receive if you decide not to participate

What will happen to me if I take part?

If you decide to take part you will be asked for voluntary consent to take part in an interview with project workers from Hospice Ethiopia. The interview will take place at a time that is convenient to you and should last around 30-40 minutes. During the interview you will discuss your views and opinions regarding the use of technology and information requirements to support self-management for people who need palliative care. With your permission, the interview will be audio-recorded.

Will my taking part in this project be confidential?

All information collected during the course of the project will be kept strictly confidential and secured against unauthorised access according with the Data Protection Act 1998. You will not be identified within the findings of the research. Identification codes will be assigned to the data collected to maintain your anonymity. Data from the project will be retained for 10 years in accordance with University of Surrey regulations and then destroyed.

What are the advantages and disadvantages of my taking part?

There are no disadvantages other than the time it takes you to participate in the interview, which should last around one hour in total. There are unlikely to be any personal advantages to participating, however the findings will be used to inform future improvement to the care provided to people who need palliative care.

What will happen to the results of the research study?

At the end of the project the findings will be discussed with local healthcare professionals, services users and carers to review findings, and inform the content of a self-management remote delivery programme delivered via mobile phone technology. At the end of the project the findings will be published in academic journals, presented at academic conferences and be used to inform development of the remote monitoring system. We will also provide written feedback in the form of a summary of the results to

all participants, and a local conference. Although some direct quotations from interview data will be published, no identifying information about you will appear in any reports or papers emanating from the research.

Ethical Review

This study was approved using a self-certification process at the University of Surrey.

What if there is a problem?

The University has in force the relevant insurance policies which apply to this study. Any complaint or concern about any aspect of the way you have been dealt with during the course of study will be addressed; please contact either Dr Nicola Carey on the details below; or Professor Emma Ream on Tel 01483-686708 or email e.ream@surrey.ac.uk

Who is Handling My Data?

The University of Surrey, as the sponsor, will act as the 'Data Controller' for this study. We will process your personal data on behalf of the controller and are responsible for looking after your information and using it properly. This information will include your name and contact details, which is regarded as 'personal data'. We will use this information as explained above.

What will happen to my data?

As a publicly-funded organisation, we have to ensure when we use identifiable personal information from people who have agreed to take part in research, this data is processed fairly and lawfully and is done so on the basis of public interest. This means that when you agree to take part in this research study, we will use your data in the ways needed to conduct and analyse the research study.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you decide to withdraw your data from the study, we may not be able to do so. We will keep the information about you 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 your information <https://www.surrey.ac.uk/information-management/data-protection> and/or by contacting dataprotection@surrey.ac.uk

What if I want to complain about the way data is handled?

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer Mr James Newby who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) (<https://ico.org.uk/>)


For contact details of the University of Surrey's Data Protection Officer please visit: <https://www.surrey.ac.uk/information-management/data-protection>

Contact for further information

If you have any questions regarding this study please contact me using the details below.

Thank you for taking the time to read this information.

Yours Sincerely

A handwritten signature in black ink that reads "Nicola Carey". The signature is written in a cursive style with a horizontal line above the first few letters.

Nicola Carey

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