Thinking Ahead: Exploring and Understanding Experiences and Decisions in End of Life Care

Workshop Information Leaflet

Study Title
Thinking Ahead: Exploring and Understanding Experiences and Decisions in End of Life Care

Invitation
We are a team of researchers at LOROS Hospice in Leicester and we would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. Please feel free to talk to others about the study and please ask us about anything that is unclear.

Why are we doing this study?
We want to find out about the experiences of people from diverse ethnic backgrounds who are living with serious illness. We have spoken to patients, family or friends who care for them and the health care professionals who support them. The things that we find out will help us improve the training that healthcare professionals receive and the care they provide for patients and their families.

In the first phase of the study we compiled patient case studies including patients, family and friend care givers and health care professionals and in the second phase we interviewed bereaved family or friend care givers.
In this, the third and final phase of the study, we are seeking the views of stakeholders on our findings. We would like to hear your thoughts on how these findings can be most usefully translated for training for doctors, nurses and allied health professionals.
This may involve coming to a 3hr workshop or joining a webinar or responding via email to our findings.

Why have I been invited?

You have been invited to take part in this study because you are either a:

- Patient with a serious illness
- Close friend or a family carer of someone with or who has died from a serious illness
- Member of a group for people of diverse ethnic communities and faiths
- Member of a health care user group
- Health care professional who supports people with advanced illness
- Managers of services for patients with advanced illness
- Local NHS decision-maker

- Professional who provides or commissions education or training for health care professionals

Do I have to take part?
No, it is up to you to decide whether or not to take part. If you do decide to take part, you are free to withdraw from the study at any time and without giving a reason.

What happens if I take part?
If after reading this information sheet you decide to take part you will be invited to take part in either a workshop lasting up to 3 hours at LOROS Hospice in Leicester or Nottingham University, a webinar or to respond via email to our findings. You will be asked to sign a consent form. Parts or all of the discussions in the workshop and webinar may be audio recorded.

We will present you with fictionalised scenarios developed from the data collected in phases 1 and 2 and ask you to undertake a number of tasks to help to identify best practice and training for doctors, nurses and for service delivery.

Photographs may be taken during the workshops for the purpose of dissemination of findings. Please let the researchers know before the workshop if you would prefer not to be photographed.

The findings will help us to develop an e-learning session available for all health care staff and accompanying resources together with recommendations for training doctors and nurses.

What are the possible benefits of taking part?

The study is not intended to help you directly but the findings we share with you from phases 1 and 2 may provide you with new insights and knowledge which might inform and influence your practice if you are a professional participant. The information we collect from stakeholders will shape the way that the study findings will be used to help health professionals to understand the experiences of minority ethnic patients and their families. This should help to improve the care and support provided to patients in the future.

What are the possible disadvantages of taking part?
We understand that talking about issues relating to your involvement in the care of a patient with a serious illness is sensitive and might be difficult and upsetting. We ask you to consider this carefully. Please remember that you will never be under any pressure to answer any questions or talk about any topics that you prefer not to discuss. You can leave the workshop or webinar at any time or withdraw from the study at any time by letting the researcher know that this is your wish.

Expenses and payments
You will be given a £20 voucher after the workshop as a "Thank You" for your time. If you incur any travel expenses as a result of your participation these may be reimbursed on production of a receipt for public transport or as a claim for mileage which would be reimbursed at the LOROS standard rate up to £20.

Will my information be kept confidential?
Yes, this is very important to us. The study will be conducted in accordance with current data protection regulations.

All information which is collected will be kept strictly confidential and will be stored in a locked cabinet within a locked office at LOROS Hospice. All information that is stored on a computer will be kept in password protected files with restricted access.

The workshop tapes will be sent securely to a qualified professional (transcriber) who will listen to them and turn them into a written document (transcript). Your name and identifying details will be removed from interview transcripts and replaced with a study identification number so that you cannot be recognised (anonymised). All recordings will be deleted after having been transferred to the secure LOROS computers.

The study data will only be accessed by authorised members of the research team but may also be looked at by authorised representatives of the Sponsor, Regulatory Authorities or Host NHS organisations for the purpose of monitoring and audit.

The only circumstances under which confidentiality may be broken would be if the researchers were made aware of actions or situations resulting in serious risk or harm to yourself or others. In this case the researchers would discuss this with you and consider the need to raise the matter with managers of the service involved.

All study data will be stored securely for the duration of the study and will be kept for seven years before being disposed of securely.

Data Protection and General Data Protection Regulations

The University Hospitals of Leicester NHS Trust (UHL) is the Sponsor for this study based in the UK. LOROS and UHL will be using information from you in order to undertake this study and UHL will act as the data controller for the study. This means that we are responsible for looking after your information and using it properly.

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 withdraw from the study, 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.

The Legal Basis for collecting your data for the purposes of this research is specific consent.

The data we will be collecting, processing and storing about you for this research is listed below:

- Your name and personal contact details
- The workshop transcripts
- Webinar related data such as, responses to online questions and completed webinar workbooks
- Completed questionnaires

For further information about the way the University Hospitals of Leicester NHS Trust use data for research please see the Privacy Statement at the Trust's public website:
http://www.leicestershospitals.nhs.uk/aboutus/about-this-website/fair-processing-notice/
More information from the Health Research Authority can be found here: https://www.hra.nhs.uk/information-about-patients

What will happen if I don't want to carry on with the study?
Your participation in the study is voluntary and you are free to withdraw at any time, without giving a reason, by contacting the research team using the contact details at the end of this leaflet. If you decide to withdraw, the anonymised information collected up to the point of withdrawal will still be used.

What if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researchers in the first instance who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Jo Kavanagh, Director of Care Services at LOROS, Tel. (0116) 231 8403 or email JoKavanagh@loros.co.uk

If you remain unhappy and wish to complain formally, you can do this by contacting the **Patient Information and Liaison Service (PILS) Free phone line:** 08081 788337. Or Alternatively
Write to: Patient Information and Liaison Service, The Firs, C/O Glenfield Hospital, Groby Road, Leicester, LE3 9QP. Email: **pils@uhl-tr.nhs.uk**

What will happen to the results of the study?
The results of the study will be used to help health care professionals and services improve the care and support they provide to patients and families during serious illness. The researchers will prepare a report for the NHS, who has funded the study. The results of the research will be made widely available through talking to the public and professionals, publications and conference presentations. We may include direct quotes from the workshops, but these will not contain any personal details and you will not be able to be recognised from them. You will not be identified in any report of publication arising from the research.
If you would like us to, we will send you a summary of the findings and recommendations at the end of the study.

Who is organising and funding the research?
The research is being organised by the research team at LOROS Hospice and the University Hospitals of Leicester NHS Trust are the study Sponsor. The research is funded by the NHS National Institute of Health Research.

Who has reviewed the study?
This study has been reviewed by the Sponsor and the Health Research Authority which includes review by a Research Ethics Committee.

What should I do now?
If you are interested in taking part or receiving further information please contact the research team using the contact details below by phone, e-mail or post. A freepost envelope is provided for you to return the reply slip if your preference is to reply by post.
The research team will then contact you to discuss the study further and answer any questions you may have.

If you don't want to take part, you don't need to do anything, and we thank you for your time and consideration of this.

Further information and contact details
If you have any further questions or would like some more information, please feel free to contact **the LOROS research team on 0116 231 8498 or by email; research@loros.co.uk**
Our team will be happy to discuss any concerns and to answer your questions.