

The Impact of the Liverpool Care Pathway on Care at the End of Life INFORMATION ABOUT THE RESEARCH FOR STAFF (POINT 2 INTERVIEWS)

Introduction

We would like to invite you to consider taking part in our research study by undertaking an interview with the researcher about the care of the patients in the last days and hours of life in your organisation. In order for you to do this, it is important that we provide you with information to help you to understand why the research is being done and what it would involve. Please feel free to talk to anyone you feel comfortable with about the research before making your decision.

What is the purpose of the study?

The government's National End of Life Care Strategy (2008) emphasizes the importance of care at the end of life by promoting the use of the Liverpool Care Pathway for the Dying Patient (LCP) to support the delivery of quality care. The LCP is a 'good practice' template, underpinned by education and training, that staff caring for patients in the last hours or days of life can use to help them to deliver appropriate care. This study has been designed to understand whether the tool makes a difference to the quality of care provided. We have chosen to undertake this study in Intensive Care and Nursing Homes because these are two settings in which care should take into account the end of life.

We plan to collect information from a variety of sources (policy documents, patient notes, by observing care as it is delivered to patients, interviewing staff and interviewing bereaved relatives) to help us to understand what care looks like in Intensive Care and Nursing Home settings that use the LCP to support care and those that do not. By comparing the care delivered with and without the support of the LCP we will be able to identify the impact of the LCP.

Why have I been approached?

An important part of this research study involves interviewing one member of staff who provided care during the period of observation. We have approached you to take part in this element of the project because we feel that your experience of providing care to the observed patient will provide valuable insights.

Do I have to take part?

No. We will describe the study and go through this information sheet with you. It is up to you to decide whether or not you wish to take part. If you agree to take part, we will then ask you to sign a consent form. If at any time you change your mind about taking part, you can withdraw from the study without giving a reason or an explanation. The choice that you make will have no bearing on your job or on any work-related evaluations or reports.

What will happen if I take part?

We would like to gain an understanding of how dying people are cared for within your organization in general terms and from your point of view. If you decide to take part in this research, you will be asked to participate in one interview that will last for between one and one and a half hours and which will take place in a venue that is convenient to you. The interview will be guided by the researcher, and will begin

after further explanation about the research. The entire discussion will be audio-recorded (with your permission), but you will not be identified by name on the recording. The audio-recording will then be transcribed and analysed.

What will happen if I don't want the study to carry on?

If at any time you change your mind about taking part, you can withdraw from the study without giving a reason or an explanation and without this decision having any bearing on your job or on any work-related evaluations or reports.

Expenses and Payments

We will provide travel expenses if you are asked to attend a venue outside of your normal place of work or outside of your normal working hours.

What are the possible disadvantages and risks of taking part?

We do not think that there are any major risks involved in taking part in this study. Please remember you do not have to take part in the discussion if you feel the questions are too personal or if talking about them makes you uncomfortable and you are free to withdraw at any time without giving a reason or an explanation.

What are the possible benefits of taking part?

There is unlikely to be any direct benefit to you but your participation in this study will help us find out more about the impact that the LCP has on care at the very end of life.

Will my taking part in the research be kept confidential?

Yes. We will follow current ethical and legal practice and all information about you will be handled in confidence. However, we may need to breach confidentiality for any issues that may arise where we have a statutory duty to disclose. For example, if during the course of the interview issues of malpractice, sub-optimal care or abuse are identified, the researcher will report the 'incident' in line with risk and governance arrangements operating within the organization. The entire discussion will be audio-recorded with your permission, but you will not be identified by name on the recording. The information recorded is confidential. Only the project team and the person transcribing the recording (who has signed a confidentiality agreement and has 10 years experience of undertaking such transcriptions without incident) will have access to the data.

These recordings will be stored in two ways: as an audio file and, as a transcript. The audio recordings will be stored on a password protected data stick which will be kept in a safe in the University of Liverpool for a period of 3 years after publication of the results of the study, after which, they will be securely destroyed. The transcripts of the interviews will be analysed by the researcher and other members of the project team. No-one will be identified by name in the transcripts – only numeric identifiers will be used. The transcripts and the analysed materials will be kept in a locked filing cabinet in the University of Liverpool for 3 years after the publication of the results of the study, after which they will be securely destroyed.

What will happen to the results of this study?

All of the information that we collect from the various elements of the project will be brought together to help us to understand the impact of the LCP on care at the very end of life. The findings of this study will be useful in highlighting where services and the delivery of care can be improved in the future. The results will be written up as a final report for the funding body and will include recommendations for future practice. We also intend to publish the findings in peer reviewed journals and make presentations

to national and international research conferences in order to make sure that the messages from this study are shared widely and appropriately.

Who is organizing and funding the research?

The Principal Investigator for the study is Professor John Ellershaw, Director, Marie Curie Palliative Care Institute Liverpool, University of Liverpool. The study is sponsored by the University of Liverpool and funded by the National Institute for Health Research, Service Delivery and Organisation Programme.

Who has reviewed the study?

This proposal has been reviewed and approved by “North West Wales Research Ethics Committee”, which is a committee whose task it is to make sure that research participants are protected from harm. You can find out more about the work of Research Ethics Committees by visiting the National Research Ethics Service website at <http://www.nres.npsa.nhs.uk>.

Please note

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (see contact information below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure (or Private Institution). Details can be obtained from the hospital/nursing home.

Further Information

If you would like any further information about this study please contact:

Sheila Harper
Research Fellow
XXXX

Alternatively, if you would like to speak to the Principal Investigator, please contact:

Jacqueline Jones
PA to Professor John Ellershaw
Director, Marie Curie Palliative Care Institute, Liverpool
XXXX

Study number: REC Ref:

Centre number:

Participant identification number for this study:

CONSENT FORM

The Impact of the Liverpool Care Pathway on Care at the End of Life

Name of Researcher: Professor John Ellershaw

Please initial box

I confirm that I have read and understand the information sheet dated August 2010 (Version 2) for the above study.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I agree to any interview being recorded and transcribed.	
I understand that I am free to withdraw my consent at any time without giving any reason and that this will have no bearing on my job or any work-related evaluations or reports.	
I agree to take part in the above study.	

Name of staff member :

Date:

Signature

Name of person taking consent:

Date:

Signature

When completed: 1 copy for participant; 1 copy for researcher