University of Hertfordshire

PARTICIPANT INFORMATION SHEET FOR STUDIES INVOLVING HUMAN PARTICIPANTS

Title of Research

Family, patient and staff perceptions and experiences of end of life care for those living with a non-malignant progressive respiratory condition

Introduction

You are being invited to take part in a research study. Before you decide whether to do so, it is important that you understand the research that is being done and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask about anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of this study?

The purpose of this study will be to explore and understand the care and information given to individuals who have a non-malignant progressive respiratory disease with a specific focus on issues regarding end of life. From this basis it may highlight gaps in knowledge that need to be addressed which may result in more robust education for staff and information giving for patients and their families.

Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason. A decision to withdraw at any time, or a decision not to take part at all, will not affect the rest of the treatment/care that you receive.

How will I be asked to take part?

I will arrange to attend a Practice Nurse Network meeting in order to discuss my research and to answer any questions that those considering participating might have. I will then leave written information regarding the study for those who feel they may wish to be involved or who may wish to speak to others about being involved.

If you then wish to take part you will be given a 2 week period after this meeting to consider the pros and cons for you in case you wish to change your mind. After this 2 week period I would ask you to contact me directly if you do wish to participate.

What will happen to me if I take part?

If you choose to participate I will contact you to arrange an interview with you regarding your experiences or perceptions relating to this topic. This interview will be expected to last up to 1 hour and I will arrange a time, date and venue that is suitable for you.

What are the possible disadvantages, risks or side effects of taking part?

There are no expected risks of participating in the study although it is anticipated that the discussions within the interview may be of a sensitive nature. If at any time the discussions in the interview become emotionally difficult for you it is not expected that you have to continue and I will not try to convince you to keep talking about your experiences. Additionally, after the interview, I will offer you additional time to answer any concerns you may have.

What are the possible benefits of taking part?

The benefit of participating in the study is the offer of a confidential area to voice concerns or share experiences relating to this topic area and through the discussions aim to enhance the education of staff as well as the information given to patients in the future.

How will my taking part in this study be kept confidential?

The interview will be recorded via the use of a digital voice recorder to enable me to analyse of the data. Each participants identity will be kept confidential in the write up and any experiences that are explained will be kept strictly anonymous and confidential. The final stage of transcribing the data will include checking with you that a fair representation of the individual discussions is being made.

In accordance with the Data Protection Act 1998 any of your personal information gained will be kept strictly confidential and no disclosure of that information will occur during, or following, the study.

What will happen to the results of the research study?

Once the study has been completed it is my intention that this work will be published in a peer reviewed journal and potentially be presented at conferences in order to highlight any findings of the study that relate to improving staff education and patient information.

Who has reviewed this study?

This study will be reviewed by the University of Hertfordshire Ethics Board and the National Research Ethics Service.

Who can I contact if I have a concern or complaint about this study?

If you would like to raise a concern or make a complaint about the study please contact the Patient Advice and Liaison Service (PALS). The PALS Office has a 24 hour confidential answer phone on 01234 795814. Alternatively, they can be contacted by letter at the address below:

PALS Office
Bedford Hospital NHS Trust
South Wing
Kempston Road
Bedford MK42 9DJ

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email:

Jayne Bartholomew
Room 2F319, Wright Building
Physiotherapy Department
University of Hertfordshire
College Lane,
Hatfield, AL10 9AB

Tel: 01707 286102
Email: j.e.bartholomew@herts.ac.uk

Or you can contact my research supervisor in writing or by email:

Tim Watson
Department of Alied Health Professions and Midwifery
University of Hertfordshire
College Lane
Hatfield, AL10 9AB

Email: t.watson@herts.ac.uk

Thank you very much for reading this information and giving consideration to taking part in this study.