free
Family Reported
Experiences Evaluation

Information Sheet

(Version 1.2, 11 April 2013)

Family Reported Experiences Evaluation (FREE) Study: an evaluation of families' satisfaction with adult critical care services in the NHS

Introduction

We would like to invite you to take part in a research study which aims to help improve critical care (also known as intensive care) in the National Health Service (NHS) by ensuring that the experiences of those receiving care and their family members are fed back to those organising and delivering the care. The study is being conducted in NHS intensive care units across the UK, and is being managed by the Intensive Care National Audit & Research Centre (ICNARC) in London.

For this study, a family member is anyone with a close familial, social or emotional relationship to the patient, including relatives, partners, friends, carers etc.

Before you decide whether to take part, it is important that you understand why the research is being done and what it involves. **One of our team will go through this Information Sheet with you and answer any questions you may have.** Feel free to talk to your friends and family about the study if you wish and please ask us if there is anything that is not clear or if you would like more information. Please take the time to decide whether or not you wish to take part.

What is the purpose of the study?

We want to find out how family members feel about their experience in the intensive care unit, and if this feedback can be routinely collected across the NHS, to ensure that patients and their family/loved ones have a positive experience of care.

The reason for asking family members and not patients is that patients staying in intensive care are usually severely ill and often do not remember much about their time in the unit, or sadly, some patients are too ill to survive. Feedback from family members is therefore important as they play a vital role in the support of patients.

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

You have been asked to participate as you have visited a relative/friend during their time in intensive care and have been identified as a family member, loved one or friend of the patient. We aim to identify up to four family members for those patients who spend more than 24 hours in the intensive care unit.

Why should I take part?

You will be contributing to an important study aiming to identify the best way to improve care and provide feedback to intensive care units in the NHS. We hope that feedback from family members will help towards ensuring patients and their family members have a positive experience of the NHS.

Do I have to take part?

Joining the study is entirely voluntary. You can withdraw from the study at any time, without giving a reason, and this will not affect the standard of care your relative/friend receives.

What will I have to do?

Having read this information sheet and been given the opportunity to ask questions, if you are happy to participate then you will be asked to sign a consent form. You will also be asked to provide some basic details, including your name, address and your relationship to the patient. This information will be entered onto a secure web-based data entry system. This information is taken so that we can send a questionnaire to you by post.

Three weeks after your relative/friend leaves intensive care we will post you a questionnaire with a stamped addressed envelope (for easy return, free of charge). We would ask that you complete and return the questionnaire. If we do not receive a response within four weeks of posting the questionnaire to you, a second questionnaire will be sent as a reminder. After this, no further contact will be made.

Inevitably some patients admitted to intensive care will not survive their illness. Given that all experiences of intensive care are important, we include the experiences of these families too.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. If you wish to complain about any aspect of the way you have been approached or treated during the course of this study, please contact the Principal Investigator (the person leading the study at this hospital) or the Hospital's Patient Advice & Liaison Service (PALS) – details provided below.

Will my taking part in this study be kept confidential?

Yes at all times. We will follow ethical and legal practice and all information will be handled in strict confidence. Information collected will be stored securely and in strict confidence at ICNARC and at the NHS Trust [Insert relevant NHS Trust here as appropriate]. Procedures for handling, processing, storing and destroying data are compliant with the Data Protection Act 1998.

What will happen to the results of the research study?

The results of the study will be published in professional and scientific journals and will be available from ICNARC via the website at www.icnarc.org or by telephone on 020 7269 9277. They will also be available on the ICUsteps website at www.icusteps.org. ICUsteps is the intensive care support charity for patients and their families.

It will not be possible to identify any individual who has taken part in the study in any reports or articles.

Who is funding and organising the study?

This study is being funded by the National Institute for Health Research (NIHR), Health Services and Delivery Research Programme. The study is being sponsored and managed by the Intensive Care National Audit & Research Centre (ICNARC).

Who has reviewed the study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the NRES Committee South Central – Berkshire B.

Thank you for taking the time to read this information

For more information about FREE you can contact the Principal Investigator:

[Insert name local Principal Investigator, Position]

[Contact telephone number local Principal Investigator]

If you are unhappy with any aspect of the study:

If you do not wish to speak to the research staff listed above, please contact the Patient Advisory and Liaison Service (PALS): [insert PALS contact details here]