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**ImproveCare - The management of clinical uncertainty in hospital settings (Intervention)**

**REC reference: 16/LO/2010**

# PaRTICIPANT Information Sheet (RELATIVE/CLOSE FRIEND)

You are being invited to take part in a research study. Before you decide, it is very important for you to understand why the research is being done and what it will involve. Please take time to read the following very carefully. Please ask me if there is anything that is not clear or if you would like more information. Please take your time to decide whether or not you wish to take part. Here are some important questions and answers that might help you decide whether you want to join the study.

**WHAT IS THIS STUDY ABOUT?**

We are very interested to understand how we can improve the care whilst people are in hospital, particularly when their situations are clinically uncertain and they are very unwell. The AMBER Care Bundle represents a 'care package' that has been developed to provide high quality care for these patient, and their families. We know that this situation can cause many worries and concerns for patients and their families that have not been well managed by staff. It is believed the AMBER Care Bundle offers a solution. Through education and training health care professionals on this ward will be better at identifying patients like this, and then supporting them and their relatives more effectively. For example, they should be better at having conversations about a patient’s illness, their concerns about the uncertainty they may be experiencing, their preferences for current and future care, and with that planning their care. We want to see in what ways this training compares to patients (and their family members) who continue to receive usual care in other wards.

**WHAT DOES TAKING PART IN THE STUDY INVOLVE?**

Taking part in the ImproveCare study means a research nurse will ask you if you are willing to be contacted by a researcher from King’s College London who would like conduct a short interview with you. The questions she or he will ask will explore your experiences of the quality of care your relative/friend has received, your understanding of their illness, your understanding of the treatment and care they are receiving, and your views on being involved in important decisions about their care. **Your** views are very important to us and will be used by this hospital to plan future care. Thank you for your consideration.

**DO I HAVE TO TAKE PART?**

No. It will be entirely up to you to decide whether or not to take part in the study and you can withdraw from the study at any time without having to give a reason. If you decide to participate, you will be asked to sign a consent form, and you will be given a copy to keep. We would like to emphasize whatever you decide this wills not affect the care you or any of your family or close friends receive.

**WHAT ARE THE POSSIBLE BENEFITS OF YOUR INVOLVEMENT?**

We know many people find it helpful to talk in confidence about what is happening to them. We also know many people benefit from the knowledge that they share during interviews contributes to improving care in hospitals and other settings. We are very grateful for their views.

**WHAT ARE THE POSSIBLE RISKS OF TAKING PART**

Taking part in these interviews, will take some of your time. We are very grateful for this. Talking about what is happening to you and your relative can be a relief or a challenge. There is a small risk that the nature of the questionnaires might be distressing for some people. We sincerely apologise if being involved in this study is distressing for you. If that happens, please ask for the interview to be paused or stopped. The research nurse who is highly trained to talk about sensitive issues will present to talk with you. If required, she or he will refer you to a colleague who can help you more.

**WILL WHAT I SAY BE CONFIDENTIAL?**

Yes, at all times. We will follow ethical and legal practice and all information about you will be handled in strictest confidence. We will never share your name or any other identifying with anyone outside the research team.

**WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?**

We hope that the findings from the study will be used to help improve care for people like you and their relatives. We also hope that the results of this study will be made available to other health care professionals in a series of articles to be published in medical journals. No one person will be identifiable in any of these articles.

**WHO IS ORGANISING AND FUNDING THE RESEARCH**

Dr Jonathan Koffman is the Chief Investigator and the study is funded by the National Institute of Health Research. The study is organised and sponsored by King’s College London and King’s College Hospital NHS Foundation Trust.

**WHO HAS REVIEWED THIS STUDY?**

All research in the NHS is looked at 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 London Camden & King’s Cross Research Ethics Committee. It has also been approved by the Health Research Authority and each local hospital will also give confirmation that the study can go ahead.

**WHAT DO I DO IF I WISH TO MAKE A COMPLAINT ABOUT THE RESEARCH**

If you wish to complain about any aspect of the research, you should contact the Chief Investigator in the first instance, Dr Jonathan Koffman.

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints procedure by contacting your local Patient Advice Liaison Service (PALS) office.

Every care will be taken in the course of this study. However in the unlikely event that taking part injures you, compensation may be available.

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against King’s College London but you may have to pay your legal costs.

Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff or about any problems you may have experienced due to your participation in the study the normal National Health Service complaints mechanisms are available to you.

**Thank you very much for taking the time to read this sheet.**

**Local Contacts:**

**Your doctor ........................................................... Tel: ......................................................**

**Your nurse/study coordinator.............................. Tel: ........................................................**

Chief Investigator

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