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**ImproveCare - The management of clinical uncertainty in hospital settings**

# REC reference: 16/LO/2010

# PaRTICIPANT Information Sheet (non-participatory observation of MDM)

You are being invited to take part in a new 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 the purpose of the study AND WHY HAVE I BEEN CHOSEN?**

Listening to health care professionals’ views on the experience of providing care in hospital is very important in order to understand what care works and why, but also to inform us on where we need to make important improvements for future patients and their families. Multi-Disciplinary Team Meetings (MDMs) are widely used across the NHS where health and social care professionals discuss patients’ situations in lots of detail. We want to find out more about what influences clinical decision-making at MDMs for patients who situations are clinically uncertain, where their condition is not reversible, and where there is a risk they will die during their current episode of care despite receiving treatment. The findings from this competent of our wider study be used to improve care for patients in this position and their families across the NHS by recommending possible improvements in the way care is offered. Your views are every important to us; we hope you are willing to share them.

**WHAT DOES THE RESEARCH INVOLVE?**

A researcher will attend and observe a number of MDMs on this ward. She/he will **not** be an active participant in these meetings, but will take notes from what is spoken about **only** from professionals who have provided written consent for their views to be included in our study. We will make a note of those individuals who have **not** provided consent and anything that they do say will not be recorded in writing by the researcher. Therefore, their comments or actions will be completely disregarded.

She/he will collect information on the structure of the meeting (including the number of patients discussed, the professional mix of members attending); processes (including the roles of each of the members); details of patients who situations are clinically uncertain, where their condition is not reversible, and where there is a risk they will die during their current episode of care despite receiving treatment, and how decisions are made in relation to their care, particularly at the end of life. You will not be required to do anything outside of, or in addition to your normal day-to-day activities.

Importantly, patients discussed at each MDM will have been given the opportunity to ‘opt out’ of having their medical information included in this study at the earliest appropriate and feasible opportunity. This will be noted and will be available at every MDM where patients eligible for inclusion in this research are discussed.

**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 given a copy to keep. We will **only** record information from those who have provided written consent for their views to be used as part of this study. A decision not to take part in this study or a decision to withdraw from the study will not affect your work in any way.

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

We know for existing evidence that the care and support of patients whose situations are clinically uncertain, where their condition is not reversible, and where there is a risk they will die during their current episode of care despite receiving treatment urgently requires improvement. We hope the findings from this study will contribute to important new knowledge to make this happen. If you take part in this focus group, your anonymised views will contribute to our findings and any resulting recommendations for change.

**WHAT ARE THE POSSIBLE DISADVANTAGES OF BEING INTERVIEWED?**

It is expected that this study does not have any disadvantages, but the interview will take between thirty and sixty minutes of your time.

**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 confidence. Any notes taken during the observation of this MDM will not contain names or any personal information. Only those members of the research team who are directly involved in analysing the information will to any notes that were written. In publications and reports, the identity of participating MDMs will not be revealed. Dr Jonathan Koffman is the Chief Investigator and he has overall responsibility for confidentiality and data security.

**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 and their relatives. We also hope that the results of this study will be made available to other health care professionals by 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.**

Chief Investigator

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