NHS Trust logo

Improving patient experience project:

[unit name – to be added]

You are being invited to take part in a research study that is being undertaken by the University of Oxford and King's College London. Before you decide whether or not to take part, it is important for you to understand why this study is being carried out. Please take time to read the following information carefully. Please contact the study researcher, [name of researcher], if you would like to discuss anything further. His/her contact details are provided at the end of this information sheet.

What is the purpose of this study?

The project aims to provide a unique opportunity for approximately 30 patients, family members, carers and staff to work alongside each other to improve experiences of the [name of unit and NHS Trust].

Why have I been chosen?

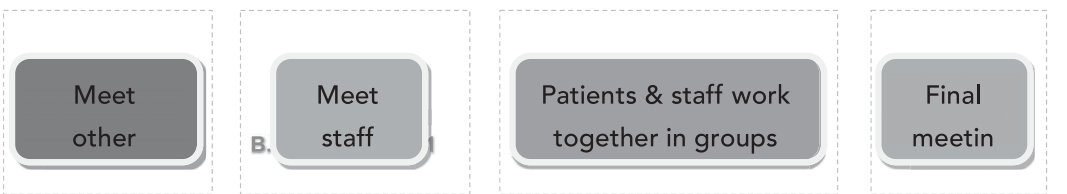
In this project, we are focussing on patients who have been cared for in the [name of unit and NHS Trust]. As a patient, carer or family member of a patient in this Unit, you are ideally placed to tell us how to improve experiences of care here for other users of this service.

Do I have to take part?

It is entirely up to you to decide whether or not to take part. Please take time to read this information sheet.

What will happen if I take part?

There are four stages in this study (see below).



Stage A will involve you being invited to attend a meeting with up to 15 other patients and carers to share and discuss your experiences with each other (this will include viewing films of patients from other parts of England talking about their experiences). If you would like a friend or carer to come with you to this meeting then that would be fine. At this event you will be invited to share your own ideas for how services for patients, their families and/or carers might be improved. Stage B involves all the patients who have shared their experiences meeting with staff at the hospital who work in the [name of unit]. The purpose of this meeting is for patients, families, carers and staff to begin to work together to design better patient and staff experiences.

The feedback meeting (stage A) with other patients/carers will take up to 6 hours to ensure that you have sufficient time to discuss anything you wish to discuss with each other and share experiences. On a different day, the first meeting with staff (stage B) will take 2-3 hours.

Stage C involves patients/carers and staff meeting in smaller groups about three times over a period of three months and for up to two hours each time to work together on a specific improvement that they would like to see made to the [name of unit]. Stage D involves all the patients/carers and staff meeting together to describe the improvements they have made and discuss the work they have completed together. All stages of the project will be observed by a researcher from King's College London who may also invite you to take part in an interview where you will be asked about what is like to take part in the project.

What are the possible disadvantages of taking part?

Participation in the project will mean you will need to think about your experiences of the [name of unit]. These questions are not intended to be upsetting, but may raise concerns for you. If you feel that outside of the meeting you would like to discuss these concerns please contact the following health professional at the hospital site where you are receiving your care: [name of health professional, NHS Trust]. Lunch and other refreshments will be provided and your travelling expenses will be paid for each of these meetings. We will try to give you as much notice as possible about the date and timings of these meetings.

What are the possible benefits of taking part?

We expect the findings of this study to improve services for patients and their families and/or carers. Although this may not benefit you personally, information you give may help influence and shape services in the future.

What information will be held about me?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you choose to take part in the meetings with other patients and staff, details of your particular experience will not be identifiable unless you choose to share this information with the group. Responsible members of the University of Oxford of the [name of Trust] may be given access to data for audit of the study to ensure we are complying with regulations and good practice.

The researcher leading the study, Dr Louise Locock at the University of Oxford, will be responsible for security and access to the data. The data collected for the study will be analysed to learn more about the needs of patients, their families and/or carers. At the end of the study the research data will be secured for five years in keeping with standard research practice. Any personal identifiers relating to individual patients will be held for less than three months after the end of this 18-month study.

What if there is a problem?

Given the nature of this study it is highly unlikely that you will suffer harm by taking part. However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research sponsor. If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Dr Louise Locock (tel: 01865 289303, email: louise.locock@dphpc.ox.ac.uk) or you may contact the University of Oxford Clinical Trials and Research Governance (CRTG) office on 01865 572224 or the head of CTRG, email heather.house@admin.ox.ac.uk

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

You are free to withdraw at any time without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care received by you now or in the future. Any information you have provided with consent would be retained and used in the study. No further data would be collected or any other research procedures carried out in relation to you.

What will happen to the results of the research study?

Through this project we hope to learn more about how patients and staff can work together to improve their experiences; we are likely to continue to use this way of working with other groups of patients as part of service improvement work. The results may be published in a professional journal or presented at a conference. They will also be shared with staff working elsewhere to help improve services elsewhere in England. If you would like a copy of the findings we will be happy to send you these.

Who is organising and funding the research?

This study is being conducted jointly by staff at [name of NHS Trust] and researchers from King's College London and the University of Oxford. It has the support of the nurses and doctors at the hospital. It has been made possible through funding received from the National Institute for Health Research Service Delivery & Organisation programme.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, well being and dignity. This study has been reviewed and given a favourable opinion by the [To be completed – name of ethics committee and reference number].

Thank you for taking the time to read this information sheet. If you need further information, [name of researcher] can be contacted as follows:

[name of researcher], Study Researcher

King's College London, Tel: