NHS Trust logo

Improving patient experience project:

[unit name – to be added]

You are being invited to take part in a research study. 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 seeks to improve the experiences of both those providing and receiving care in [name of unit]. We are using an adaptation of an approach called Experience-Based Co-Design (EBCD) which has been used previously in hospitals in the UK and Australia. The approach provides a unique opportunity for approximately 30 staff and patients to work together in redesigning cancer services in order to improve patient and staff experiences.

Why have I been chosen?

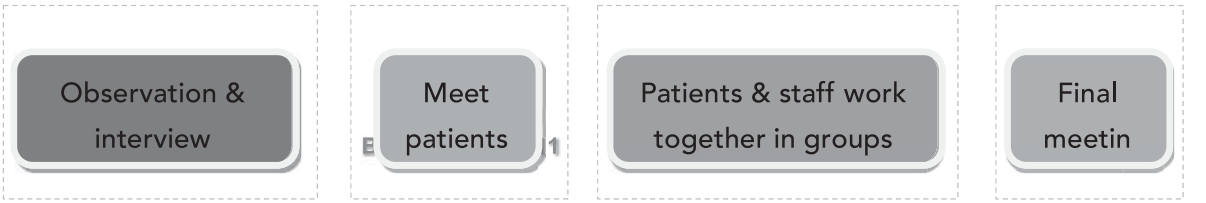
In this project, we are focussing on patients and staff who have been cared for or work in the [name of unit, name of NHS Trust]. As a staff member in the Unit you are ideally placed to tell us how to improve experiences of care here for other staff and users of this service.

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 to me if I take part?

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



During Stage A a researcher would like to unobtrusively observe routine day-to-day activities such as working in the Unit, observing multidisciplinary meetings, or perhaps observing appointments or meetings that you might have with patients. You may also be invited to discuss your experience of delivering the service to patients and your own priorities for improving the service. The interviewer will wish to audiotape the discussion - which would last no longer than one hour - to make it easier for transcription. Stage B will involve attending a feedback meeting with other members of staff and all the patients who will have previously shared their experiences of the Unit with the study team. The purpose of this meeting is for patients, families, carers and staff to begin to work together to design better patient and staff experiences. Stage C involves patients 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 Unit. Stage D involves all the patients 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 additional interview where you will be asked about what is like to take part in the project.

How much time will be taken from my work schedule?

To participate in the project, staff will need to commit to a minimum of a one hour interview (stage A) and two half-day meetings (stages B and D) over a six month period. You may also contribute by working in one of the smaller groups with patients and colleagues to improve specific aspects of the service; these groups will meet for approximately 1-2 hours on at least 3 occasions over a 3 month period (stage C). We are aware that this project will take up some of your important time and we are grateful for that. However, we hope that you understand the importance of your contribution to improving both staff and patient experiences in the future. Your managers have agreed to support your time on this project. Lunch

and other refreshments will be provided. 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 to improve services in the [name of unit] 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 staff and patients, 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 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 your managers 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: