US-PEx: Understanding how frontline staff use patient experience data

[ward and trust 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 understand how we can best use patient experience evidence to improve the experiences of those receiving care in the NHS. We are working with six medical wards across the NHS as case study sites, supporting them to design and implement frontline quality improvement projects using patient experience data, and observing what happens during the project. By 'data' we mean any information from patients about what has happened to them, such as answers to survey questions; patient stories and interviews; complaints and comments; and online feedback.

Why have I been invited?
[Name of trust] has agreed to take part in the study and proposed [name of ward] to be one of our six case study sites. As a [former patient/family member of a former patient] of the ward you are ideally placed to get involved in quality improvement work and to help us understand how to use patient experience data to improve experiences of care on the ward for patients and families. In each ward we are identifying a core multi-disciplinary team of up to 5 staff members and a patient/carer member who will lead the project, and we hope you will consent to be part of this core team.

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?
In the Spring of 2016, we will collect baseline survey and interview data from an anonymised sample of patients discharged from [name of ward] about their experiences.

We will share the findings with you. We will invite the core team from the ward where you/your family member received care (including you as a patient/carer member) to attend a 2-day learning community meeting in Oxford 12-13 July 2016, with the research team and staff from other participating wards. At the meeting, you will have a chance to learn about different approaches to using patient experience data for quality improvement; to share experiences with other participants from around the NHS; and to work with your own team to plan your local quality improvement project.

Between July 2016 and March 2017, the ward team will work with local staff and a new group of patients/family members to refine and implement your plans for quality improvement using patient experience data. Throughout that time the team will have the support of the research team and specialist quality improvement advice, but it will be up to your team to decide what activities you want to do. We will follow how you get on by using ethnographic methods. This means I will come and observe your quality improvement activities and meetings and keep in touch with you to discuss progress. I will only be observing, not taking an active part in any meetings. I will take notes of meetings and conversations, and may use audio recordings. I may ask if you would be willing to keep a diary of your involvement in the project. I will not undertake any observations of patient care on the ward.

I will ask the team to keep a record of any service improvements made during the project, and to share these and other relevant documents (such as minutes and written quality improvement plans) with me. I will also interview you and all core team members at the beginning and end of the project, to find out about your expectations and experiences, and identify lessons for other NHS staff about how to use patient experience data for improvement. 2 or 3 core team members will also be interviewed in the middle of the project. I will audiotape the discussion - which would last no longer than one hour - to make it easier for transcription.

You will be invited to two further one-day meetings of the learning community in Oxford, in December 2016 and July 2017. The study is designed to be 'formative' – that means we will use the second learning community meeting to share emerging findings from our observations and interviews with you to help you adapt what you are doing and overcome any problems you encounter. Other participating teams will also share their experiences so teams can learn from each other.

After you have completed your project, we will conduct a follow-up survey and interviews with patients discharged from [name of ward] to see if there have been any measurable changes in reported patient experience. At the third and final learning community meeting we will share these findings as well as our overall findings from the ethnographic observations and interviews. We plan to use our findings to develop an online toolkit for the NHS on using patient experience data for improvement, and at the last learning community meeting we will seek your ideas on the design and content of the toolkit.

How much time will I be asked to commit?

To be a member of the core team, you will need to commit to four days of learning community meetings in Oxford, two or three one hour interviews and occasional informal discussions with me while I am on site conducting observations, over the course of one year. We will cover travel and accommodation costs, and any respite care costs you may

need to take part. We will try to give you as much notice as possible about the date and timings of these meetings.

You will also spend time locally on your chosen quality improvement project, and it will be for you to decide with staff locally how much time you are able to commit. 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 patient experiences in the future.

What are the possible risks and benefits of taking part?
Given the nature of this study it is highly unlikely that you will suffer harm by taking part. We expect the findings to improve services in [name of ward] 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, and will contribute to an online toolkit for the NHS. We have found from past experience that patients and family members can find it rewarding to get involved in quality improvement projects that are led from the frontline and directly benefit patients.

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 care using patient experience data. The results will be published in professional journals and presented at conferences and dissemination workshops. They will also be shared with staff working elsewhere in the form of a freely available online toolkit for the NHS on using patient experience data for improvement. The toolkit is likely to include:

- a review of best evidence on using patient experience data
- methodological advice on how to collect, interpret & apply different types of data
- guidance on practical, organisational & cultural factors to consider
- good practice guidance on how best to involve patients & families in the process
- practical real-life examples building on the case studies of difficulties & barriers as well as examples of success.

You will be actively involved at the final learning community meeting in reflecting on the overall analysis and helping to shape the likely content of the toolkit. In order to share good practice, we would like the toolkit to show some real-life cases so that others can see what has worked well and what has not worked so well, and how staff have overcome challenges they encountered. The toolkit may include short videos of participating frontline staff and their patient team members talking about their experiences and the changes they have made. However, we would only include such identifiable material with the additional consent of both the individual and the organisation. Other material in the toolkit will remain anonymised to ensure participating teams can share their learning without identifying the Trust or ward concerned.

Confidentiality - what information will be held about me?
We will follow ethical and legal practice and all information about you will be handled in confidence in accordance with the UK Data Protection Act. The transcripts of the interviews and anything you say during the interviews will be confidential. I will give your interviews a unique ID number. The digital recording and the typed up record (transcript), identified only by the code number, will be kept in a secure place at the Nuffield Department of Primary Care Health Sciences at the University of Oxford. Similarly, any

recordings, handwritten or typed fieldnotes I make during my observations on site will be stored confidentially. Quotations used will not be personally identifiable. The study data may be looked at by individuals from the University of Oxford, for the purpose of audit and monitoring.

In the unlikely event that anything is disclosed that I feel is likely to result in immediate harm to you or others then it will be disclosed in accordance with the law and local safeguarding procedures.

The researcher leading the study, Prof Louise Locock at the University of Oxford, will be responsible for security and access to the data. At the end of the study the research data will be secured for five years in keeping with standard research practice and then destroyed. Any personal identifiers relating to individual participants will be held for less than three months after the end of this 27-month study.

What will happen if I don't want to carry on?
You are free to withdraw at any time without giving a reason. Any information you have provided with consent will be retained and used in the study. No further data would be collected nor any other research procedures carried out in relation to you.

Will I be reimbursed for taking part?
Yes. You will be offered an honorarium of £75 per day to attend the four days of learning community meetings and up to one further day of research-related activities such as being interviewed. You do not have to accept the honorarium if you do not wish to. If you are in receipt of welfare benefits we recommend you consult the new helpline run by Bedford Citizens' Advice Bureau for patients involved in research to check whether your benefits would be affected. Details can be obtained from benefits@invo.org.uk or phone 02380 651088.

Who is organising and funding the research?
This study is being conducted jointly by staff at the University of Oxford and researchers from the Picker Institute Europe. The Picker Institute is a leading charity in the field of person-centred care, and conducts the national patient survey programme for the Care Quality Commission. The Director of Patient Experience for NHS England is also a member of the research team. The study has the support of managers at the hospital. It has been made possible through funding received from the National Institute for Health Research Health Service & Delivery Research programme (grant reference 14/156/06).

Who has reviewed the study?
This study has been reviewed and given a favourable opinion by the North East – York Research Ethics Committee REC ref 16/NE/0071.

What if there is a problem?
The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

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 Principal investigator Louise Locock (01865289303, louise.locock@phc.ox.ac.uk) or you may contact the University of

Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224, or the head of CTRG, email ctrg@admin.ox.ac.uk.

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 ethnographic researcher], Study Researcher

[University of Oxford address email, Tel:]

CONSENT FORM

Title of Project: **US-PEx: Understanding how frontline staff use patient experience data**

NHS REC Committee and reference number:

Patient/carer Identification number for this study:

Name of Researcher: [to be confirmed]

Please initial boxes to confirm agreement:

I confirm that I have read and understand the information sheet dated 29.02.16 V2 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my (or my friend/relative's) medical care or legal rights being affected ☐

I understand I will be involved in planning and implementing quality improvement activities locally (which may include meetings, workshops and discussions between patients, family members and staff) ☐

I am willing to travel to and attend learning community events in Oxfordshire ☐

I understand a researcher from the University of Oxford will observe these activities and talk to participants about them, and will keep notes about what they observe ☐

Please turn over.

I understand that would be asked to sign an additional consent form to take part in an interview and that I do not have to agree to be interviewed ☐

I understand that parts of my comments from meetings and conversations with you may be extracted and may appear anonymously in written form. ☐

I understand that data collected during the study may be looked at by authorized individuals from the University of Oxford and [name of Trust] for monitoring and/or audit of the study to ensure compliance with regulations. ☐

I understand that if I disclose anything which in the view of the researcher is likely to result in immediate harm to me or others, then it will be disclosed in accordance with the law and local safeguarding procedures. ☐

I agree to take part in the above study. ☐

Name of Patient/ Carer	Date	Signature
Name of Person taking consent	Date	Signature

When completed, 1 for research participant; 1 for researcher site file notes