

Patient Information Sheet – ‘What Matters to Patients?’ study

We would like to invite you to take part in a research study. This research study is being carried out by health researchers from King’s College London and the Kings Fund and is looking at measuring and improving patient experience. The two organisations are separate but they are working together on this project; King’s College London is leading the work. Before you decide whether to take part you need to understand why the research is being carried out and what it would involve for you. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information; our contact details are at the end of this sheet.

What is the purpose of the project?

The project aims to explore and understand what matters to patients in terms of their experiences in the NHS. We would like to talk with patients who have one or more of the following specific conditions: depression diabetes, stroke, chronic obstructive pulmonary disease (COPD), and hip replacement surgery.

Why are you inviting me to take part?

You are being invited to take part because you have recently - or are currently - receiving care from the NHS We are very interested to hear the experiences of patients, and would like to ask you to share your experiences with us.

How will I be involved in the project?

Taking part in the research will mean you will have the opportunity to tell the story of your experience of being a patient with one or more of the conditions above. You will be able to tell your story either by means of a telephone or face-to-face interview at a location convenient to you with a member of the research team. We will come to meet with you and talk to you informally for approximately one hour. During the interview we will ask you about your experiences as a patient. The interviewer - who is not someone involved in your care but is someone experienced in interviewing patients - will be interested in those parts of your experience that you recall as being particularly positive or negative, and what matters most to you as a patient.

The interview can take place at a time that is convenient for you, either by telephone, in your home, or somewhere else that is convenient for you and that we will arrange. You are very welcome to invite a carer or friend to be at the interview with you. We will reimburse you for any travel expenses. We would like to tape-record the interview so we have an accurate record of what you tell us. The tape recording will be transcribed, and anonymised. The recording will be deleted after transcription. The data will then be analysed by the research team. With your permission, anonymised data (data which does not identify any one who has taken part) will be archived for up to five years after the end of the research, for use by other researchers for other purposes. We will ask you to sign a consent form agreeing to take part in the interview.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign forms consenting to the tape

recording of your story. If you decide to take part you will still be free to withdraw at any time and without giving a reason and any information you have provided will not be used in this study. A decision not to take part will not influence in any way the standard of care or treatment you receive.

Are there benefits in taking part?

There are no direct benefits to you as an individual. There will be benefits for other patients in the future because this study will provide evidence for better ways of measuring and improving patient experiences. We hope that this research will generate knowledge that will inform how services are provided to similar patients as yourself.

Will my taking part in this project be kept confidential?

Involvement in this project is entirely voluntary. If you agree to take part, all information collected about you and your experiences during the course of the interviews will be kept strictly confidential. Transcripts of your stories will be coded for anonymity and stored in a locked filing cabinet or on a password protected computer secured against unauthorised access. Anonymised transcripts will only be made available to the research team. No-one else will know you have taken part unless you choose to tell them. If you tell us something that indicates there is a risk of harm to yourself or someone else, then we will follow a 'disclosure protocol'. This involves seeking advice on whether we should disclose (tell a relevant agency or authority) about this risk.

What will happen to the results of the project?

Through this project we hope to learn more about patient experience, what is important to patients and how best to measure patient experience. The results of the project may be used to inform future policy, published in academic journals and presented at professional and academic conferences. Anonymised extracts from the interviews may be used in publications arising from this research. Reports or papers resulting from the research will not identify any one who has taken part. The anonymised interview transcripts, with your permission, may be made available to other researchers and students for teaching / further research

Has this study been reviewed by an ethics committee?

All research undertaken by King's College London is considered by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given approval by King's College London Psychiatry, Nursing and Midwifery Research Ethics Committee Ref: PNM/09/10-124.

Who is organising and funding the project?

The Department of Health is funding this programme of work. The project is being jointly organised and conducted by Kings College London and the King's Fund.

Further information

If you would like further information about the project, please call Vicki Tsianakas on 020 7848 3065 or email on vicki.tsianakas@kcl.ac.uk. Further details of the project and wider NNRU research programme are available at: <http://www.kcl.ac.uk/schools/nursing/nnru>. If this study has harmed you in any way you can contact King's College London using the details below for further advice and information: Vicki Tsianakas on 0207 848 3065 email: Vicki.Tsianakas@kcl.ac.uk.