London School of Hygiene & Tropical Medicine

(University of London)

[redacted]

Switchboard: [redacted] Telex [redacted]

Department of Public Health & Policy

Telephone: [redacted]

Fax: [redacted]

E-Mail: [redacted]

SERVICE USER INFORMATION SHEET

Commissioning for Long Term Conditions

You are being invited to take part in this research study.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part.

- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

Part 1:

What is the purpose of the study?

The purpose of the research is to examine how Primary Care Trusts (PCT) takes into account the views of people who have a long term condition and to identify what impact this has on the commissioning process and pattern of services.

Commissioning is the process through which a PCT decides what NHS services are needed and should be provided, who should provide the services and how they should be paid for. The main aim of this study is to find out how service users are involved in the commissioning process.

Why have I been invited?

We are inviting you because you are a service user, or care for someone with a long term condition, or represent service users with long term conditions within one of three PCT case study sites around England.

Do I have to take part?

Absolutely not. It is up to you to decide whether or not to take part.

If you decide to take part you are still free to withdraw at ***any time*** and 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 you receive.

What will happen to me if I take part?

If you agree to take part in the study one of the researchers will contact you. They will arrange a convenient time for you to come to a focus group which will be made up of 6-8 people with or representing people with a long term condition. With your permission the discussion will be recorded, but only the research team will have access to the recordings and they will be deleted at the end of the study. The focus group will take about 90 minutes and will seek your views on how service users are involved in deciding which and how long term condition services are provided. If you do have to travel for the focus group please give us your receipts and you will be reimbursed for your travel expenses.

At the end of the group we will ask you to complete a quick rating scale about service user involvement. We would also like you to fill in the rating scale twice more over the next year so that we can see if there are any changes in how service users are involved in commissioning.

What do I have to do?

If you agree to take part in the focus group, simply sign the response form and return to us in the pre-paid envelope. We will then contact you to arrange a time and place for the focus group. Before the focus group starts the researcher will answer any questions you have. You will be asked to sign a consent form giving us permission to conduct the focus group. You can leave the focus group at any time.

What are the possible disadvantages and risks of taking part?

There are no disadvantages except the time element required from you.

You can withdraw from the study at ***any time***.

What are the possible benefits of taking part?

There is unlikely to be any personal benefit from taking part. However, your participation may help PCT’s to involve service users more effectively in the commissioning process.

What happens when the research study finishes?

The findings will be available to you on the project website. A report will be sent to the funders of the research and each PCT involved in the study.

What if there is a problem?

It is unlikely that something may go wrong during the focus group, however if this does happen it will be dealt with immediately. The detailed information on this is given in Part 2

Will my taking part in this study be kept confidential?

Yes. All the information about your participation in this study will be kept confidential. The details are included in Part 2.

For more information about this study please contact:

[redacted]

Telephone: [redacted]

Email: [redacted]

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

As this is a focus group, it is very unlikely that anything could go wrong. However if you have a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. Please contact Lorraine Williams on 020 7927 2671.

If you are harmed by taking part in this research project there are no special compensation arrangements. If you are harmed due to someone's negligence then you may have grounds for a legal action for compensation against the London School of Hygiene and Tropical Medicine and the University of Hertfordshire but you may have to pay for it. The normal NHS complaints mechanism is available to you if you wish to complain about any aspect of the way you are approached or treated during the course of this study. Formal complaints should be addressed to:

(Removed for confidentiality)

Should you require independent advice about making a complaint or seeking compensation you may wish to contact the:

(Removed for confidentiality)

Will my taking part in this study be kept confidential?

All information collected in this project will only be accessible by the relevant research staff. The information we collect will be kept on secure university computers only accessible to the research team with password protection. All the information you provide will be treated confidentially. Your comments may be used as quotations within the study findings but will be anonymous and you will not be identified. You will also not be identified in any report or publication arising from this project.

Who is organising & funding the study?

The study is being organised by a team of researchers at the London School of Hygiene and Tropical Medicine and the University of Hertfordshire. They are being funded to do the study by the National Institute of Health Research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study was given a favourable ethical opinion for conduct by the Great Ormond Street Hospital/Institute of Child Health Research Ethics Committee.

THANK YOU FOR READING THIS INFORMATION SHEET.

YOU MAY KEEP THIS INFORMATION SHEET.

Service user

Focus Group Response Form

Yes, I am interested in taking part in a focus group and am happy for the researchers to contact me.

Name (please print) ______________________________

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Address (please print) ______________________________

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Telephone number

Email

Signed____