

Working in partnership with carers and promoting carer involvement.

Service User & Relative Participant Information Sheet

Study Title: Working in partnership with carers and promoting carer involvement.

We would like to invite you to take part in the above research study. Before you decide whether you would like to take part, it is important that you understand why this research is being done and what it will involve. Please take the time to read the following information carefully and discuss this with others if you wish. Please ask us if there is anything that is unclear or that you would like more information about. Take time to decide whether or not you wish to take part.

What is the research project about?

This study focuses on the triangle of care in mental health, consisting of service users, relatives, and health professionals. The study aims to explore how relatives of people with mental health problems experience the support they receive, whether they are satisfied, and how this can be improved. This will allow us to enhance our understanding of how the CNWL services meet the carers' needs for support; the carers' experience of support available within the Trust; and the potential barriers in carers accessing the support they need, with the view to inform specific interventions that aim to change the culture of carers' involvement in the management and support of service users with mental health problems in the future.

Who is organising the research?

This project is being organised by a team of researchers, service users, relatives and academics from Lancaster University in collaboration with the Central North West London NHS Foundation Trust.

Who will be taking part?

Up to 36 participants from within the Brent Borough area will take part in the study. This will consist of 10 to 12 people with a mental health diagnosis, 10 to 12 relatives, and 10 to 12 health professionals. Service users will need to be between 18 and 65 years old. Relatives and health professionals will be aged over 18, with no upper age limit.

Why have I been asked to take part?

You have been asked to take part because you are experienced with mental health either as a service user or a relative of person with a mental health problem. Sharing your experiences will help to increase our understanding of those factors which help or hold back the involvement of relatives in the mental healthcare teams. You have also been asked to take part because you live in Brent Borough. We think that you could make a valuable contribution to this research project.

Do I have to take part?

It is completely up to you to decide whether or not you would like to take part. If you do decide to take part you will be given a copy of this information sheet and asked to sign a consent form. If you do decide to take part but change your mind later you are free to withdraw up to 2 weeks after your interview and do not need to give us a reason. If you do decide not to take part, or to withdraw, this will not affect the standard of care you receive.

What will taking part involve for me?

If you do decide to take part in the study, a member of our research team will arrange a time to meet you at a CNWL premises. We will ask you some questions first about you, just to confirm that you meet the inclusion criteria for the study. Then you will be asked to talk about your experience or your views regarding relative's involvement in the care of people with mental health problems. This will include asking you to talk about what services relatives currently receive, how relatives experience these services, what are their expectations and their needs, and what can be done differently to improve the services offered.

This should take around 1 hour and will be audio taped. We will be recording it on NHS SafeBoot encrypted and password protected laptops so that the researcher can write down everything that you say afterwards (transcript) and then look at common issues at the things you have said along with other people interviewed in the study. You can have as many breaks as you like during the interviews and can stop at any time.

All the information that you give will be strictly confidential; the transcript of the interview will not be shown to anyone outside the research team. The information (data) collected will be anonymised, meaning that data will not be traceable to you. Your consent form will be kept in NHS locked filing cabinets separate from any data collected during the interview and destroyed at the end of the study. The audio recordings will be destroyed when transcription is complete and any direct quotes used in the write up of the study will be done such as not to identify individuals. Anonymised print copies of the transcripts of the interviews will be kept securely locked within CNWL premises for the duration of the study and destroyed thereafter in accordance with the CNWL Trust's policy on data storage and maintenance. Electronic copies of the anonymised transcripts will be kept on NHS SafeBoot encrypted and password protected laptops at CNWL Trust and at Lancaster University for the duration of the analysis and destroyed thereafter. It is important for us you are assured that all measures will be taken to guarantee confidentiality and anonymity of your participation. However, you may disclose information that implies that either you or someone else is at risk of harming themselves or others. If such information is disclosed, the data collection will cease, a member of the research team will discuss with you that confidentiality will be broken on this occasion, and the relevant bodies or individuals will be informed.

What are the advantages and disadvantages of taking part?

Research of this nature, does not usually have any direct benefits from taking part. Many people, however, value taking part in interview based studies because interviews provide the chance to reflect on our own experiences.

It is mostly unlikely, but it is possible that talking about your personal experiences may result in some distress. The people interviewing you will be sensitive to this. You will have the opportunity to discuss any concerns at the end of the interview. The researchers will also be able to direct you to other sources of support after the interview is over.

Will I get paid for taking part?

In return for your time and effort, you will be given a retailers' voucher worth £15. Travel expenses will also be reimbursed. We will give you separate instructions on this, but please ensure that you keep copies of the receipts.

What will happen to the results of the research?

If you would like to be informed about the results of the study, please indicate your interest in the consent form and we are happy to send you a summary of the results at the end of the study. The results will also be presented to a range of mental health professionals; carer's and service users' groups with the aim of increasing the understanding of the impact of involving relatives in mental healthcare teams. It is hoped that the findings will also help to improve services and validate the experiences of other service users, relatives and health professionals. The findings will be submitted for publication in mental health journals and other publications with the aim of reaching a range of mental health professionals, relatives and service users.

Who has reviewed this study?

This study has been reviewed and approved by the North of Scotland (1) National Research Ethics Service. On that basis it has also been reviewed by the Lancaster University's Faculty of Health and Medicine Research Ethics Committee, and approved by the Lancaster University Research Ethics Committee.

Where can I obtain further information about the study if I need it?

If you want any further information or have any questions, please contact a member of the research team on this project:

Emmi Honeybourne
Assistant Psychologist
emmi.honeybourne@nhs.net
Tel: 0203 3129842

Gerasimos Chatzidamianos
Senior Research Associate
g.chatzidamianos@lancaster.ac.uk
Tel: 07885 972 554

What do I do if something goes wrong?

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 legal action, but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, then in the first instance please contact:

Principal Investigator:

Dr Fiona Lobban, Senior Lecturer in Clinical Psychology and Co-Director of Spectrum Centre for Mental Health Research, Lancaster University, Lancaster, LA1 4YG.

Tel: 01524 593382

Email: f.lobban@lancaster.ac.uk

If you wish to speak to someone outside of the research project, you may also contact:

Professor Paul Bates, Associate Dean for Research, Faculty of Health and Medicine, Lancaster University, LA1 4YG

Tel: 01524 593718

Email: p.bates@lancaster.ac.uk

Dr John Green, Chief Psychologist, Department of Clinical Health Psychology, CNWL NHS Foundation Trust, Clarence Wing, St Mary's Hospital, London, W2 1NY.

Tel: 07986854155

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Email: donna.norstrom@nhs.net

Trust PALS Office: Stephenson House, 75 Hampstead Road, London, NW1 2PL

Tel: 020 3214 5773

Email: pals.cnwl@nhs.net

Trust Complaints Manager: Jacent Tracey, Stephenson House, 75 Hampstead Road, London, NW1 2PL

Tel: 020 3214 5784 / 020 3214 5785

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