

# **Bipolar Disorder: A qualitative study of the involvement of relatives in the mental healthcare team.**

## **Participant Information Sheet**

### **Study Title: Bipolar Disorder: A qualitative study of the involvement of relatives in the mental healthcare team.**

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 bipolar disorder, consisting of service users, relatives, and health professionals. The study aims to enhance our understanding of the barriers and facilitators to involving relatives in mental healthcare from the perspective of service users, relatives and health care professionals. It will also examine the impact that communication in mental healthcare settings may have on the course of bipolar disorder and the family's overall wellbeing.

### **Who is organising the research?**

This project is being organised by a team of researchers, service users, relatives and academics from Lancaster University.

The research study involves an interview, which will be conducted by a researcher who is employed by Lancaster University. This researcher will be asking you about your experiences in relation to relatives' involvement in the mental healthcare team.

### **Who will be taking part?**

Up to 36 participants from within the Manchester, Lancashire and Cumbria area will take part in the study. This will consist of 10 to 12 people with bipolar disorder, 10 to 12 relatives, and 10 to 12 health professionals. Participants will be aged between 18 and 65.

### **Why have I been asked to take part?**

You have been asked to take part because you are experienced with bipolar disorder either as a service user, a relative of person with bipolar disorder, or a health professional of people with bipolar disorder. 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 team of people with bipolar disorder. You have also been asked to take part because you live or work in Manchester, Lancashire or Cumbria. 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 at any time and do not need to give us a reason. If you do decide not to take part, or to withdraw at any time, 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 come and meet you, either at home or at another place where you feel comfortable. 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 the relative's involvement in the care of people with bipolar disorder. This will include asking you to talk about what relative involvement in mental healthcare means to you, whether there is any value in involving relatives, what it is that makes relative involvement difficult or easy, what support is needed if relatives were to be involved, and whether you had any experiences in which involving relatives was (or was not) beneficial.

This should take around 1 hour and will be audio taped. We will be taping it so that the researcher can write down everything that you say afterwards (transcript) and then look at common themes and issues that come up when looking 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. The tapes will be destroyed at the end of the study and any direct quotes used in the write up of the study will be done so in such a way so as not to identify individuals.

*It is important for us you are assured that all measures will be taken to guarantee the confidentiality and anonymity of your participation. However, you may disclose information that is relevant to safeguarding vulnerable individuals. 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.*

NB. Applicable only to service users: If you are under the care of a mental health NHS trust, a copy of your consent form will be copied into your usual medical notes and this copy may be reviewed by the Trust Clinical Audit Department to confirm that you have given written consent to take part. We will also ask for your permission to contact your GP and inform him that you are taking part in this project.

### **What are the advantages and disadvantages of taking part?**

The interview will give you a chance to reflect on your own experience of involving relatives in bipolar disorder. We hope that by documenting personal accounts of your perceptions that we will be able to inform the development of guidelines to facilitate the development of a collaborative intervention manual for people with bipolar disorder and their family members who are involved in their care.

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 and you are free to withdraw from the process at any point. We will check if there are any concerns you wish to raise and, if necessary, you will be able to talk to one of the clinical psychologists on the research team.

### **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:

Dr Fiona Lobban, Senior Lecturer in Clinical Psychologist and Associate Director of Spectrum Centre for Mental Health Research, Lancaster University, Lancaster, LA1 4WY.

Telephone: 01524 593752

Email: [f.lobban@lancaster.ac.uk](mailto:f.lobban@lancaster.ac.uk)

### **What will happen to the results of the research?**

If you participate in the study you will be informed of the results. The findings will also be presented to a range of mental health professionals and service users with the aim of increasing the understanding of the impact of involving relatives in the mental healthcare of people with bipolar disorder. 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.

The findings will be used to inform the development of guidelines for collaborative working in the mental healthcare across this network of people.

If you want any further information or have any questions, please contact the research assistant on this project:

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