

## **PARTICIPANT INFORMATION SHEET**

### **Qualitative interviews for the REACT study**

We would like to invite you to take part in a short interview about your use of the REACT website. Before you decide whether you would like to take part, we want to explain why this research is being done and what it will involve. Please take the time to read the following information 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. Contact details for the research team are at the end of the sheet.

#### **What is the study about and why have I been approached?**

This study is an add-on to the National Institute for Health Research Health Technology Assessment (14/49/34) funded Relatives Education and Coping Toolkit (REACT) study. The aim of this study is to explore participants' experience of the online intervention (REACT) via interviews conducted over the phone/Skype. Understanding why some people use REACT more than others; what brings people back to the REACT site; and what people like/dislike about the website is important for the development and refinement of future online interventions for relatives and will be of great value when considering the future use of REACT (and other online interventions of a similar nature).

You have been approached because we think that you could make a valuable contribution to this research study. Sharing your experiences with us will help us to develop even better online interventions in the future.

#### **Am I eligible to take part?**

We are looking for 20-25 relatives (or close friends providing regular support) of people with psychosis or bipolar who have been randomly allocated to the REACT online intervention as part of the REACT study to take part. Participants must have completed their final follow-up at 24 weeks post-randomisation to the REACT study and will have consented to be contacted about future research as part of the REACT study consent.

#### **Do I have to take part?**

No. It's completely up to you to decide whether or not you take part.

#### **What will I be asked to do if I take part?**

If you decide you would like to take part, you will be asked to provide written informed consent and a phone/Skype interview (depending on your preference) will be arranged at a time that is convenient for you. Please note that if you choose to have your interview conducted over Skype we cannot ensure a secure connection. Interviews will last up to one hour and will be recorded using an encrypted digital recorder. We will ask for verbal consent to record the interview before we start. During the interview you will be asked open questions about your experience of using the REACT online intervention. The interviewer will prompt you with specific questions about things such as how much you used the site

and why; what brought you back to site / what stopped you coming back; what you liked / disliked about the site. Following the interview you will be debriefed and given the opportunity to ask any questions you may have.

Please note, even if you have not used the REACT toolkit at all, we are keen to talk to you. In fact, you are particularly helpful to us in understanding the reasons why people do not engage with online support.

### **Will my data be Identifiable?**

The information you provide will be anonymised. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data:

- As soon as possible following the interview the recording will be downloaded to Lancaster University secure server and deleted from the audio device. If this is not possible immediately, the audio device will be locked in a cabinet in a secure office until download is possible.
- Hard copy transcripts will be kept in a locked cabinet.
- Computer files will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- As soon as interviews have been transcribed we will delete the audio file from the computer.
- At the end of the study, hard copy anonymised transcripts will be kept securely in a locked cabinet for 15 years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes the researcher think that you, or someone else, is at significant risk of harm, they will have to break confidentiality and speak to a member of the REACT team. If possible, they will tell you if I have to do this.

### **Can I change my mind and withdraw from the study?**

If you decide to take part but change your mind later you are free to withdraw at any time without giving a reason (though you will be invited to give a reason so we can learn from your experience). However, once your data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract your data, up to the point of publication.

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

If you participate in this study you will be provided with a summary of the findings at the end of the study. The findings will also be presented at appropriate academic and mental health conferences and events and will be published in mental health journals and other publications with the aim of reaching a wide audience of mental health professionals, relatives (or close friends) and service users.

**Are there any risks?**

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the REACT team and/or contact the resources provided at the end of this sheet.

**Are there any benefits to taking part?**

We hope that you will find participating interesting and feel that you have made an important contribution to research aimed at improving support for relatives (or close friends) of people with psychosis or bipolar disorder.

**Who has reviewed the study?**

This study has been extensively peer reviewed, funded by the National Institute of Health Research, and approved by an NHS Research Ethics Committee responsible for ensuring that ethical considerations and issues are addressed in the conduct of research.

**What do I do if something goes wrong?**

It is unlikely that you will be harmed by participating in this study. However, if you wish to raise concerns or make a complaint about any aspect of this study then, in the first instance, please contact the Chief Investigator:

Professor Fiona Lobban  
The Spectrum Centre for Mental Health Research  
Faculty of Health and Medicine  
(Department of Health Research)  
Lancaster University  
Lancaster  
LA1 4YG  
Tel: +44 (0)1524 59375  
Email: [f.lobban@lancaster.ac.uk](mailto:f.lobban@lancaster.ac.uk)

If you would prefer to speak to someone outside of the research team then please contact the Associate Dean for Research at Lancaster University:

Professor Roger Pickup  
Faculty of Health and Medicine  
(Division of Biomedical and Life Sciences)  
Lancaster University  
Lancaster  
LA1 4YG  
Tel: +44 (0)1524 593746  
Email: [r.pickup@lancaster.ac.uk](mailto:r.pickup@lancaster.ac.uk)

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

If you have any questions about the study, please contact the REACT team:

**REACT Team**

The Spectrum Centre for Mental Health Research  
Faculty of Health and Medicine  
(Department of Health Research)

Lancaster University  
Lancaster  
LA1 4YG  
Tel: [add interviewer email]  
Email: [add interviewer email]

**Resources for further information and support**

Should you require further information or feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

If you are already in contact with mental health services you might find it help to contact them

If you are not in contact with mental health services the following might be helpful:

Your own GP  
Your local out of hours GP or A+E (visit <http://www.nhs.uk/pages/home.aspx> if you're unsure where to find the services)

Carers UK 0808 808 7777(UK)

*NHS emergency services:*  
Call 999 (UK)

*NHS for non-emergencies:*  
Call 111 (England)  
Call 0845 46 47 (NHS Direct Wales)

Visit [www.nidirect.gov.uk](http://www.nidirect.gov.uk) for Out of Hours GP contacts in your area (Northern Ireland)

*Samaritans:* call 08457 90 90 90 (UK)

Thank you for taking the time to read this information.