

Disclaimer

The focus of the REACT website is to provide relatives and close friends of people with psychosis or bipolar disorder with useful information. We do not warrant that information we provide will meet your health or medical requirements. It is up to you to contact a health professional if you are concerned about the health or well-being of your friend or relative.

The REACT website does not give medical advice in relation to any individual case or patient, nor does it provide medical or diagnostic services.

Responsibility for using the website usefully and appropriately lies with you, the user (we have provided Ground Rules in the Participant Information Sheet).

Legal stuff

- **Copyright for the website**

All REACT 2016 materials are copyright © Lancaster University. All rights reserved. If you wish to reproduce any part of this site in any format please contact react@lancaster.ac.uk.

- **Third party websites**

We do not monitor the content of third-party websites. Any link provided on the REACT website is solely for your convenience. We do not accept any responsibility for any third-party website.

Site Safety

Here's the technical bit....

- **What data will be collected from me?**

Data will be collected to help understand how REACT is used and how well it works. This data includes:

1. *Your online questionnaire responses*

We will ask you some questions on the website about your experiences as a relative (or close friend) of someone with psychosis or bipolar disorder. This is to help us determine how effective REACT is for reducing distress and increasing wellbeing for relatives (or close friends) of people with psychosis and bipolar disorder.

2. *Your use of the REACT site*

We are interested in finding out which bits of the site are most visited and popular with relatives. We will collect web usage data to help us understand which pages are linked to improvement in relatives' distress, to optimise the website, and to make sure the content is as useful to you as possible.

3. *Your direct messages to REACT Supporter*

The REACT Supporter is there to support your use of the site. Through the site you can send the REACT Supporter private, secure messages. We will analyse the content of these conversations so

that we can identify common queries and to make sure your questions are being answered by the REACT Supporter in a way that is most helpful to you.

4. Your online forum posts (the REACT Group)

In order to understand how relatives (or close friends) share their experiences and provide/receive support in a private, secure online forum we will explore the conversations posted in the REACT Group.

- **What will happen to the data I enter into the site?**

All responses to the study questionnaires, data on your use of the website and your forum posts will be strictly confidential i.e. we will never share your personal details with anyone outside the research team (unless clear evidence of immediate and serious risk of harm to an individual is identified).

All study data will be anonymised and pooled prior to analysis and any data used in the write up of the study will not be identifiable. The data collected for this study will be stored securely on encrypted password protected computers and only the researchers conducting this study will have access to this data during the trial.

Your anonymised data may be used in the future for secondary analysis of broader research questions related to improving outcomes for relatives of people with psychosis or bipolar disorder.

It is important for us that you are assured that all measures will be taken to guarantee the confidentiality and/or anonymity of your participation. However, if you disclose information that causes us concern for your immediate safety, or the safety of someone else during the study, we will have to break confidentiality and inform relevant authorities (police or social services) to prevent this from happening.

- **How to use the REACT site in a secure way**

Ground rules

Key things to remember when using the site:

- 1. When you register on the site you will be asked to create a username. This will be visible to the REACT Supporter if you message them, and to all other users of the site if you post on the REACT Group. If you don't want people to know your real name, then make up a username that will not identify you but that you can easily remember. The username can be anything you like.*
- 2. The site will be monitored for inappropriate use and risk indicators by the REACT Supporter during office hours*
- 3. Inappropriate or hostile language will not be tolerated*
- 4. Please respect other users, their views and experiences*
- 5. The REACT Supporter is not there in a clinical capacity (e.g. to provide therapy) but to support your use of the site*
- 6. The REACT site is not crisis service, if you feel you are struggling and need urgent help please contact the services provided at the end of the Participant Information Sheet (PIS) and provided in the Resource Directory*
- 7. Try to ask any questions without revealing personal identifiable information*

The REACT Supporter

The REACT Supporter is a trained relative who can provide additional support relevant to your personal needs. If the REACT Supporters are unavailable due to sick leave or absence, the role will be covered by a Researcher within the REACT team. The REACT Supporter will monitor the site and

during office hours. If they identify any inappropriate posts (e.g. hostile or offensive language) they will contact the participant via direct messaging and notify them that the post has been removed. In the unlikely event that participant repeatedly breaks the ground rules, their account will be suspended.

The REACT Supporter will also be available to answer your questions during office hours. Discussions with the REACT Supporters will be private and confidential. If some questions are repeatedly asked in discussions with the REACT Supporters we may post a generic version of these under Frequently Asked Questions (FAQs) to help other users who may have the same question in the future. Again, the FAQs will be completely anonymous.

The REACT Group

The REACT Group is a private, closed online discussion forum in which relatives (or close friends) can share their experiences. Conversations within the REACT Group will be visible to other relatives (or close friends) using the toolkit. Therefore, we advise that you use a 'fake' username and an optional anonymised picture when joining the study and that you do not use personal details when referring to the friend or relative you are supporting. The REACT Group will be monitored by the REACT Supporters during office hours to maintain a safe environment for everyone. In addition participants can flag inappropriate or concerning posts to the REACT Supporters via a function on the site. Depending on the nature of such posts the REACT supporter will either deal with the issue themselves via direct messaging with the participant or, where there is a clinical risk issue, report the post immediately to a clinically qualified member of our research team for guidance.

Posting Comments on the REACT Group forum

If you choose to use the Forum, postings you make shall not be treated as confidential.

You are legally responsible for the content of any material you submit for posting on the REACT Forum.

Lancaster University shall own any material posted on the REACT Forum.

We reserve the right (on behalf of ourselves and any moderator that we may appoint) to:

(a)

temporarily or permanently suspend your access to our comments facilities;

(b)

edit, not put on the website, or delete any posts you submit; or

(c)

take any other action against your registration if, in our view, you have not complied with the rules of conduct set out below.

Comments posted should relate to your personal experience or that of someone close to you. You should not name any individuals (other than yourself) or include information through which someone else could identify an individual about whom you are writing. If you want to comment on someone else's experience, (e.g. a relative or someone you care for) then you may do so if you ensure that you are not named in the posting and you state how the other person is connected to you (e.g. "my father").

Comments on services should be relevant to helping people make choices about places where they can receive medical treatment or other care. Postings should be constructive, truthful, and not abusive.

You should not use the comments facilities to make complaints about individual hospitals, GP practices or treatment centres if you wish the matter to be dealt with under [the NHS complaints procedures](#).

If you find any comments offensive or objectionable you may make a complaint to the moderator using the 'Report' link provided at the foot of each published comment.

It is important that you play your part in keeping your information safe – visit the government's [Get Safe Online](#) website for advice on how to do this.

My Tool Box

You can use this space to save any videos, articles and web links that you find interesting from the REACT site and external resources. These materials can be saved from the REACT websites by clicking on the icon. Some of the modules offer the chance to reflect on your own situation (if you want to), this can be done in your head or you can fill in the "Reflection Time" task which can be saved in My Tool Box by clicking on the icon if you wish. It is important to note that the contents of My Tool Box (including "Reflection Time") can only be accessed by you. It will not be shared with anyone else and will not be used in any part of the research .