GUIDANCE FOR PEOPLE THINKING ABOUT TAKING PART IN RESEARCH

Taking part in research can help you learn about the latest scientific developments, and it can be rewarding to know that you are helping to improve our understanding of eating disorders. Some studies provide the opportunity to access a new type of support or treatment as part of a trial; some provide an incentive such as a small financial reward or a donation to charity.

Taking part in research is often interesting and rewarding, however in some cases people may find taking part in a particular study to be an upsetting or even harmful/ triggering experience. We have written this guidance to help you ensure that your health and wellbeing remains the top priority.

Key points

It is very important that you understand what you will be asked to do before agreeing to take part in any research.

- Always read all the information provided about a study carefully before agreeing to take part – usually this will be written in a document called an 'Information sheet' (despite the name they are usually longer than a page).
- Feel free to ask the researcher/s if you have any questions about a study, including why it is being done, whether you are eligible to take part, what you would be asked to do and whether it may be suitable for you. Most researchers will expect to receive emails containing these kinds of questions.
- If you are unsure about whether to take part in a research project, we recommend that you discuss your concerns with others close to you and if possible, a healthcare professional.
- Taking part in research can be emotionally demanding, and present risks as well as benefits
- Research can involve questions, assessments or situations that some people will find upsetting or even harmful/triggering. This can include:
- Answering questions about your experiences of an eating disorder and other difficult experiences in life. Such questions could be asked in different ways, such as within an anonymous online survey or as part of an in-depth interview.
- Being asked about your weight or Body Mass Index (BMI). In a limited number of studies participants will be weighed or have other measurements taken. For studies that do this we will include a warning within the relevant pages on our website.

- Meeting others who have or have had an eating disorder, which you may find upsetting or harmful/triggering, perhaps particularly if it leads to unhealthy comparisons. This could happen by taking part in a focus group discussion or, in some studies, when visiting a research laboratory to complete an in-person assessment or a procedure such as having a brain scan.
- Asking you to look at some images or videos and assessing your perceptions or reactions. This could include photos, computer-generated or illustrated images or videos that feature bodies or food.
- Asking you to read, listen to or watch accounts of other people's experiences of an eating disorder. For example, this may be the case with a study investigating the impacts of recovery stories or autobiographical accounts.

Please note:

- If you contact a researcher about taking part in their study, they may not respond straight away as they may have received lots of emails all at once that they are working their way through.
- Even if you contact a researcher to say that you'd like to take part and you have signed a consent form, you are free to withdraw from (stop taking part in) any study without having to give a reason why and without this affecting your rights - such as your right to access NHS treatment. If you decide to withdraw from a study, then if you can, please email the researcher to let them know.
- You do not have to answer any questions or provide any information requested if you do not feel comfortable doing so. If you choose not to answer a question or provide some information you should not be expected to explain the reason why and this will not affect your rights to access treatment or support outside of the study. Depending on the study and the specific question/information this may mean that you will need to withdraw from that study.
- If you would like to be told about the findings of a study, you should let the researcher/s know. Although you should be aware that it often takes months or in some cases years before all the data has been collected, analysed and written up.
- How does Beat decide whether to promote a research project?
- Before agreeing to promote any research on our website or social media, we ask the researchers some questions about how they will do their research, including how they will minimise any potential risks to those taking part. Researchers need to complete an application form that asks them these questions and to upload relevant documents for us to review.

We also check that the information they have written to describe the study (mainly in the 'information sheet') contains everything it should – such as appropriate warnings about anything that some people may find upsetting or harmful/triggering.

What if I have a negative experience when taking part in research?

If you have a negative experience when taking part in a study, then you should consider telling the researcher about this, if you feel comfortable doing so. Whether or not you contact the researcher you are entitled to make a complaint. The information sheet for the study will explain who you would need to contact to make this complaint. If this study has been promoted on our website or social media, please also contact us to let us know by emailing coproduction@beateatingdisorders.org.uk.

Support

If taking part in a study leads to you feeling distressed, please feel free to contact the Beat Helpline or use one of our online support services. For details of these please click here.

Positive experiences of taking part in research

Please let us know if you have enjoyed taking part in a study that we have promoted. We may ask if you would like to provide a quote (with a made-up name if you would prefer), that we could use to help encourage others to take part in eating disorder research.