

INFORMATION FOR PARTICIPANTS

Questionnaire Study (Phase 5)

Study Title:	The importance of measuring illness representations among children and young people with anxiety and/or depression: modification and validation of the Revised Illness Perceptions Questionnaire
Department:	University College London (UCL), Clinical Educational and Health Psychology
Researchers:	Holly Bear, Lead Researcher, Holly.Bear.16@ucl.ac.uk Professor Miranda Wolpert, Principal Investigator, Miranda.Wolpert@annafreud.org
UCL Research Ethics Number:	9777/003

Invitation to participate

We would like to invite you to take part in our research study. Before you decide whether you want to take part, we would like to tell you a bit more about this study. Please take your time to read this information sheet and discuss it with others if you like. Please ask us if anything is not clear or if you would like more information.

Why are we doing this study and what is it about?

The current project aims to better understand how children and young people understand, feel and think about anxiety and/ or depression and the associated treatments. We are also interested in your views, insights and experiences in relation to treatment endings when recovery, cure or improvement are unlikely or where treatment ending has been particularly challenging. It is hoped this research will help us modify and develop a questionnaire which will be used to prioritise an individual's understanding and emotions in response to their anxiety and/ or depression above other factors such as the clinician's understanding and the objective symptom severity.

Why have I been invited to participate in this study?

We are recruiting children and young people aged 14 to 24 who may or may not have past or current experience with anxiety and/ or depression. We would like you to participate as we are interested in your understanding and feelings.

What do we mean by anxiety and depression?

Definition of *Anxiety*: While most of us feel anxious at times, anxiety is considered a mental health problem if it affects your ability to live your life as fully as you want to. For example, if your feelings of anxiety are very strong or last for a long time, you avoid situations that might cause you to feel anxious, your worries feel very distressing or are hard to control, you find it hard to go about your everyday life or do things you enjoy.

Definition of *Depression*: While we all have times when our mood is low and we are feeling sad or miserable about life, these feelings usually pass in due course. Depression is when these feelings of sadness or distress and accompanying experiences such as not being able to sleep or sleeping too much do not go away after two weeks and impact on your daily life.

What does this involve?

Taking part in this research will involve completing a questionnaire, which should take no longer than 20 minutes. You will be asked if you want to be entered into a prize draw by entering your email address at the start of the questionnaire to win one of two £50 Amazon vouchers.

Do I have to take part?

It is completely up to you to decide whether you wish to take part. If you agree to take part, we will then ask you to sign a consent form. Even if you start to take part and then change your mind, you can stop at any time.

What are the benefits of taking part?

There is no guaranteed benefit in taking part. However, taking part in this research may help to build our knowledge and understanding about what challenges are faced by young people, families and professionals, and how we can improve this in the future. This may benefit staff, young people, and communities in the future. Some people find that making this contribution can be rewarding and interesting.

What are the possible risks of taking part?

There are no known risks to taking part. If you are unhappy with how you have been treated during the study, please contact the Principal Researcher on this project, Professor Miranda Wolpert (Miranda.wolpert@ucl.ac.uk). If you feel that your complaint has not been handled appropriately, please contact the Chair of the University College London (UCL) Research Ethics Committee (ethics@ucl.ac.uk).

What happens if I change my mind?

If you do participate you are free to stop at any time.

What will happen to the results of the study?

The anonymous results will be published in project reports, scientific journals, presented at conferences and published as part of Holly Bear's PhD thesis. If you would like a copy of the results, please inform the researcher, who will ask to keep your contact details on file, so we can send you a summary of the results.

Who is organising and funding the research?

This research is being carried out by researchers at Anna Freud National Centre for Children and Families and University College London. This research is being funded through a PhD Impact Studentship that has been awarded to Holly Bear by University College London and the Anna Freud National Centre for Children and Families (AFNCCF).

Who has reviewed the study?

The University College London (UCL) Research Ethics Committee has reviewed this project and has raised no objections. We will need to make your records in this research to people from UCL, who will check that the research has been done properly and that your interests were protected.

Data Protection Privacy Notice

Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR).

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice.

The legal basis that would be used to process your personal data will be your consent and performance of a task in the public interest.

The legal basis used to process special category personal data will be for scientific and historical research or statistical purposes/explicit consent.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

What happens next?

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information. You can keep this information sheet to look at whenever you need to. If you decide that you are happy to take part, you must sign a consent form.

If you have any questions about this research, your rights as a participant, or you would like to report any problem or complaint arising from this research, please contact any of the following researchers:

Lead Researcher: Holly Bear, Holly.Bear.16@ucl.ac.uk, 020 3108 9888

Principal Investigator: Professor Miranda Wolpert, Miranda.Wolpert@annafreud.org, 020 7443 2225

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.