PARTICIPANT INFORMATION SHEET: Understanding threat and intolerance of uncertainty in OCD

You are being invited to take part in an online research study. However, before you decide whether or not you would like to take part, it is important that you understand why the research is being carried out, and what participation will involve. Please take the time to read the following participant information sheet carefully and discuss it with others if you wish.

If you have any questions, or would like any further information, please contact the principal investigator or a member of the research team (see below). If you decide to take part in this research study, you will be presented with an electronic participant consent form to read and sign.

Who is conducting the study?

**Principal investigator:**
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<tr>
<th>Sponsoring institution</th>
<th>School of Psychology, Newcastle University</th>
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<td>Ethical approval</td>
<td>Faculty of Medical Sciences Research Ethics Committee</td>
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<td>Funding source</td>
<td>School of Psychology, Newcastle University</td>
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<td>Conflict of interest</td>
<td>There is no conflict of interest to declare</td>
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<td>How to file a complaint</td>
<td>If you have any concerns or would like to make a complaint about the conduct of the research study, please contact the principal investigator in the first instance, or another member of the research team (see above).</td>
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What is the purpose of the research?

The purpose of this research study is to investigate the role of intolerance of uncertainty (IU) in predicting levels of anxiety in OCD. IU can be thought of as how individuals interpret and react to uncertainty in their everyday lives. Currently, we know much about how threat is a key part of anxiety disorders such as OCD (e.g. the likelihood of something bad happening and how awful this might be; however, less is known about the potential role of IU in contributing to this anxiety.

It is important to note that the aim of this research study will not be to inform you whether or not you have OCD. Rather, the aim is to explore the potential contribution of IU in predicting levels of anxiety in OCD.

What is Obsessive-Compulsive Disorder?

Obsessive Compulsive Disorder (OCD) is an anxiety disorder that can include obsessions - these are unwanted thoughts or images that come into people’s minds without their control, and/or compulsions - these are repetitive behaviours (which can be both physical and/or mental) intended to reduce anxiety and get rid of the obsessional thoughts or images. Compulsions typically involve different behaviours or actions (e.g. washing, or checking), usually in response to an obsession that an individual experiences (e.g. washing hands repeatedly due to fear of contamination/germs). Both obsessions and compulsions are experienced by the majority of the general population. However, if an individual reports spending more than one hour per day preoccupied with obsessions or performing compulsions such that it causes them anxiety or distress, clinically they would be identified as having OCD.

What is Intolerance of Uncertainty?

Intolerance of Uncertainty (IU) can be thought of as how individuals interpret and react to uncertainty in their everyday lives. Recent research has shown that IU contributes to a broad range of symptoms associated with many anxiety disorders.

What is Threat Appraisal?

Threat Appraisal (TA) has been studied extensively within anxiety research and has been shown to be a key factor in the development and maintenance of anxiety. TA can be defined as the involving selective attention to threat cues in the environment, overestimation of threat, and predicting the likelihood of a negative outcome.

Why is this research important?

There has been little research which has focused on the roles of both IU and TA in OCD. This is important because IU is thought to be an independent part in predicting levels of anxiety in people with OCD. As such, if this can be demonstrated, it may help the current understanding of how IU influences the development and maintenance of OCD. This may be
particularly important for clinicians or therapists working with or supporting treatment of OCD, so that they can identify when IU might be impacting on a person’s recovery.

Has this study received ethical approval?

Yes, this research study has received full ethical approval from Newcastle University.

Why have I been asked to take part in this research study?

This research study is for individuals who would identify as having OCD (according to their own experiences). Please note that participants do not have to have a formal diagnosis of OCD from a clinician to be able to take part. OCD-UK and OCD Action have been asked to act as gatekeepers for this research study. These organisations offer important information for individuals suffering with OCD, their family members, and the general public. However, you may have also accessed information about this research study through another forum (e.g. Facebook, Twitter etc.). It may be that you are currently experiencing OCD type symptoms (e.g. obsessions and/or compulsions), and have accessed this research study for self-support.

What are the inclusion criteria?

We are looking to recruit approximately 100 participants (males and females), 18 years of age and above to take part in the study. Fluency in English (due to the language element of the tests) is a requirement for participation in this research study.

What does participation involve?

Once you have read this participant information sheet, you will then be asked to sign an online consent form to say that you have agreed to participate in this research study. You will then be asked to:

a) Complete an online demographics questionnaire (questions about your age, gender, and nationality etc.). This information is important as these may be factors which can influence some of the relationships in which we are interested (see: Why is this research important?).
b) You will then be asked to complete a questionnaire which will ask you questions related to any obsessions and/or compulsions that you may be currently experiencing. Having answered these questions, if you are eligible to participate and still wish to continue, you will be asked to complete a set of online questionnaires which will assess your current mood, levels of anxiety, and beliefs about uncertainty.
d) After this, you will be asked to identify the obsession or compulsion that is currently causing you the most anxiety or distress, and to describe a recent scenario where you have experienced this obsession or compulsion. It is important to note that for the purposes of the research study, you do not need to give large amounts of detail about your most bothersome obsession or compulsion; rather it is important that you are able to hold your chosen obsession or compulsion in mind when filling out the additional online questionnaires. Any information that you do give will be kept anonymous.
e) You will then be asked to answer a further series of online questionnaires related to your chosen scenario.
Please note that online instructions will be provided for all questionnaires. There is no limit on the amount of time to complete these, however, as a guide, most people take around 30-45 minutes to complete all of the questionnaires.

Once you have completed the questionnaires, you will then be provided with a debriefing sheet outlining further information about the research study. This will also include information on charities and national services who you can contact should you require further support or advice. Additionally, if you have any concerns about the research study specifically, you will be able to contact the principal investigator or one of the research team directly (see: Who is conducting the study?).

Do I have to take part?

No, participation in the research study is entirely voluntary. If you decide to take part and then later change your mind, either before, during, or after your participation, you can withdraw at any time without giving your reasons.

Do I have the right to withdraw my data?

You have the right to withdraw your data at any point during the research study without providing a reason for your decision. Any data collected as a result of your participation will be destroyed in the appropriate manner, or consent gained to use any data collected following your withdrawal from the research study. However, it may not be possible to withdraw data after the stage of final data analysis. As such, if you decide to withdraw, please inform the principal investigator or one of the research team at your earliest convenience.

Will my data be kept anonymous?

All data will only be used for research purposes and stored in accordance with the Data Protection Act (1998), and the policies of Newcastle University. This means that all data collected will be made anonymous by using codes instead of any personal details (e.g. name, surname, age, email address etc.), which means that nobody else will know your responses to questions. Only the principal investigator and members of the research team will have access to your email address, which will be stored separately from any data collected.

The researcher will also seek to publish the finished research study in psychological journals, or share any findings at conferences or other meetings. However, you will not be identified in any document or presentation.

Your data may also be used for future research projects with your consent. Again, all data will remain anonymous as described above.

How will the data be kept?

Your personal data will be kept confidential and anonymous through use of unique non-identifiable participation codes. Non-identifiable data will be stored and accessed via university and personal computers during the research process and dissemination of any findings. Your data will be stored securely for up to 10 years (unless you have asked to be withdrawn from the study, in which case your data will be destroyed appropriately).
Kyle Dunn – Participant information sheet - Ethics application (Understanding intolerance of uncertainty in OCD - DClinPsy, 2016-2019)

this time, only full anonymised data files will be retained. Only the named researchers associated with the study will have access to your data at this time.

What are the benefits and risks of taking part?

Benefits
As a token of thanks for your participation in this research study, you will be asked to give your email address should you want to be entered into the prize draw to win one of four £25.00 Amazon gift vouchers. Your email address may also be used to send any hard copies of documentation relating to the research study that you may have requested e.g. participant information sheet, consent form, and debrief. Generally, the research study itself will not benefit you directly, but the information obtained from your participation will be invaluable in the understanding the role of IU in OCD.

Risks
Whilst we are not assessing you for mental health problems, some of the questionnaires used in the research study measure current mood and levels of anxiety. The potential risks related to this are that when filling out questionnaires, you might come across a question or answer choice that you find unpleasant, upsetting, or offensive. For example, some of the questions may cause you to think about how upset or anxious you are feeling, particularly with regards to some of your thoughts or behaviours. You may also feel that you have performed poorly on some of the questionnaires; however, it is important to note that for all the questionnaires used in this research study, there are NO right or wrong answers. Therefore, there is no need to be concerned about your performance.

If you are experiencing anxiety or low mood, this is very common and it does not necessarily mean you are experiencing a mental health problem. However, if for any reason you feel distressed by any of your difficulties, we recommend that you speak to your GP or a health advisor from your local health service. The following resources may be helpful:
- A health advisor can be contacted using NHS 111 service available 24 hours on 111, or online at www.nhs24.com
- Other useful resources, offering information and advice about mental health and OCD can be accessed at http://www.rcpsych.ac.uk/

How do I find out more about the study?

If you would like to find out about the findings of this research study, a summary of the results can be forwarded to you when the project is completed in September 2019. If you would like to receive this, please tick the relevant box on the consent form.

If you require any additional information about this research project at this stage, please contact the principal investigator or a member of the research team.

Thank you for taking the time to read this participant information sheet, your interest in this research project is greatly appreciated.