

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: LRS/DP-21/22-28535



YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of project

Experience of people with OCD who have undergone therapy from unqualified 'coaches'

Invitation Paragraph

I would like to invite you to participate in this research project. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Feel free to use the contact details provided below if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

The purpose of the project is to investigate the experiences and effects of receiving treatment for OCD from unqualified and unlicensed individuals who claim to be experts by experience or 'coaches'. These coaches are numerous, costly and many have a large following on social media. Thus, it is important to understand what constitutes their treatment and the effects of such are explored so that those suffering from OCD can make informed decisions about treatment with these coaches.

Why have I been invited to take part?

You are being invited to participate in this project because you are over the age of 18 and have experienced sessions with unqualified and unlicensed mental health 'coaches'. You are also not under the care of NHS psychiatric services and not currently being treated by a mental health professional.

What will happen if I take part?

If you choose to take part in the project you will be asked to attend a virtual interview with a researcher who will ask you questions about your experience with the 'coach', such as: "How did you find the coach you saw?" and "What did the help consist of?". The interviews will be recorded and transcribed for analysis with your consent. The transcription will be edited so that you will not be identifiable, and recordings will be deleted as soon as they are transcribed.

Participation will take place virtually, either over the phone, or on an internet-based call provider such as Microsoft Teams or Zoom. Interviews will last up to 1 hour. As part of participation, you will be asked to provide your age and gender so that we can gauge the representativeness of our sample. We will also request your contact details, including email address and phone number so that we can contact you to discuss the details of study participation.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you decide about taking part. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What are the possible risks of taking part?

If your experiences with such 'coaches', or incidents related to such experiences, were distressing it may be distressing for you to think about them again. You do not have to answer any questions asked and may leave at any point during the interview without having to give a reason. Resources that can be accessed for support will also be provided.

What are the possible benefits of taking part?

Sharing your experiences may help inform other's seeking help with their mental health make more informed choices about the quality of help they may receive, and whether to accept treatment from unqualified individuals.

Data handling and confidentiality

Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018). Your data will be anonymous and confidential. The audio recordings will be transcribed with all possibly identifying information being redacted and all names or locations will be changed). No one other than the researchers will have access to the recordings or the full transcriptions. After transcription the recording will be destroyed. Anonymous extracts from the transcriptions will be written up into a report which may be published. You will remain unidentifiable in this report. The recordings will be kept for no longer than a month after collection.

Your data will be securely stored on the researchers' password protected personal laptops and King's College London OneDrive, also password protected.

Data Protection Statement

If you would like more information about how your data will be processed under the terms of UK data protection laws please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

What if I change my mind about taking part?

You are free to withdraw at any point of the project by letting the researcher know using contact details below, without having to give a reason. Withdrawing from the project will not affect you in any way. You are able to withdraw your data from the project up until **4 months after your participation** after which withdrawal of your data will no longer be possible due to the

data provided being written up as a report and submitted for publishing. If you choose to withdraw from the project we will not retain the information you have given thus far.

What will happen to the results of the project?

The results of the project will be written up in a report and submitted to a scientific journal for publishing; it may be published. If you would like access to the report if it is published, contact the researcher using the email provided below and let them know. The full recordings and transcription will not be published in the report and will not be publicly available.

Who should I contact for further information?

If you have any questions or require more information about this project, please contact me using the following contact details:

Professor David Veale: david.veale@kcl.ac.uk
Tel: 0203 228 2101

What if I have further questions, or if something goes wrong?

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project you can contact King's College London using the details below for further advice and information:

The Chair, rec@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.