

Appendix A

Participant Information Sheet [version 2, 16/07/18]

Adults experiencing obsessions and compulsions



Phenomenological - Contextualist Accounts of The Experience of Obsessions and Compulsions: A Theoretical Thematic Analysis

My name is Orinayo Onabanjo and I am a trainee counselling psychologist studying at the University of Surrey. I am conducting this research study as a part of my doctoral degree in Psychotherapeutic and Counselling Psychology. I am inviting individuals who are currently experiencing obsessions and compulsions or who have had an experience of obsession and compulsions, to participate in this study. This information sheet details the purpose of the research as well as what participating will involve. Please read the following information carefully in order to help you make an informed decision as to whether or not you would be interested in participating.

The purpose of the research study

Obsessions and compulsion are experienced by many women and men and can be focused on any area of a person's life. It is often understood as the well-known disorder called OCD. However, this study does not aim to understand obsessions and compulsions from the diagnostic perspective that is commonly known as OCD; instead the focus will be on a holistic understanding of each participants' subjective experience of obsessions and compulsions in the context of their interpersonal relationships and wider environment. This in turn means that obsessions and compulsions rather than being solely symptoms of an underlying disorder, are considered to be meaningful responses to a person's unique context and relationships with other people.

I am therefore interested in learning about your personal experience of obsessions and compulsions by exploring what the experience is like in the context of your interpersonal relationships. The study will also pay particular attention to understanding your experience of obsessions and compulsions in relation to your childhood experiences.

Why have I been invited to participate in this study?

Student Number: 6086850

Invitation to participate in this study has been extended to you on the basis that you are a service user of either OCD Action, or Triumph Over Phobia UK (TOP UK), or attend an OCD support group. I would like to know about your experiences as an adult who experiences or has experienced obsessions and compulsions and what this feels like for you.

Eligibility criteria for participation in the study:

- Adult
- Any gender
- Currently experiencing obsessions and compulsions of every nature and form. There is also no restriction on how long you may have been experiencing them. All **are** welcome, subject to fulfilling the eligibility criteria.
- Feel you have enough emotional robustness to explore your experiences in detail.
- Have an interest in reflecting on your own experience of obsessions and compulsions.

6-10 participants will be recruited for the purposes of this study.

Do I have to take part in the study?

Please note that there is no obligation for you to participate in this study. If you do decide to participate, you are also free to withdraw your participation at any time without giving any reason or explanation. Non-participation **in** or withdrawal from the study will not result in any adverse consequences for you. It will also have no bearing on your legal rights or the support you receive as a service user of OCD Action, TOP UK, or the OCD support group you attend. You can request for your data to be withdrawn until (March 2019) 3 months before submission of the research report (July 2019) without giving a reason and without prejudice.

If you withdraw from the study this will mean the following for your participation and data. All identifiable and anonymised data collected would be withdrawn from the study, excluded from the data analysis and destroyed. No further data would be collected or any other research procedures would be carried out in relation to you.

What will my involvement require?

After reading the information sheet and deciding you would like to take part, you will be required to complete a consent form giving your permission for participation. You will be given a copy of both forms for your own reference. You will then be required to return your completed consent form via email directly to me. This will be backed up and stored on a secure password protected encrypted USB for the duration of the research project. The research will last 18 months but your involvement would only be for 1 to 1.5 hours depending on your unique experience.

Student Number: 6086850

During this time, you will be asked to participate in a face to face interview with me. Consent will be revisited at the interview stage at which point you can also change your mind about whether you want to participate or not.

Upon receipt of your consent form, I will make contact with you to arrange a suitable time and private location for the interviews to take place. **The interviews are likely to take place within a hired consulting room in a convenient location within London.**

What will I have to do?

The research study will involve semi-structured interviews which allow for open ended exploration of your subjective experience of obsessions and compulsions. **The questions will focus on exploring what it feels like to experience obsessions and compulsions within your family contexts and social circles and how the individuals within these contexts respond to your experience.** The questions will range from broad to specific and will generally be open-ended in nature. There are no correct or incorrect answers to any of the questions asked as the aim is to gain an understanding of your experiences and what they mean to you from your perspective. Therefore, the emphasis will be on your own thoughts and feelings. With your permission, the entire interview will be recorded and later transcribed verbatim by me.

What will happen to the data I provide?

Research data (e.g. anonymised interview transcript) are stored securely for at least 10 years following their last access and project data related to administration of the project (e.g. consent forms) for at least 6 years in line with the University of Surrey policies.

All personal data will be anonymised and made unidentifiable at the point of collection. Therefore, all data will be anonymised and unidentifiable within the analysis and the final research report. It will be held in the strictest confidence and handled in accordance with the GDPR 2018, and the University of Surrey's and Division of Counselling Psychology (2015)'s guidelines on confidentiality. All your data will be kept confidential and stored securely within an encrypted password protected USB and password protected laptop. Only myself and the study's research supervisor (Dr Ben Rumble) will have access to your data. Your personal information and data collected will not be identifiable in any reports or publications that arise out of this research study. In line with the GDPR 2018, all audio recorded data will be destroyed following transcription.

What are the possible disadvantages or risks of taking part?

This study is of a deeply personal nature as it involves in-depth exploration of your subjective experience of obsessions and compulsions. This is likely to involve recalling unpleasant

Student Number: 6086850

feelings and memories which you may find emotionally distressing. Therefore, your personal comfort and pace will be prioritised.

In the event of becoming uncomfortable during the course of the interview, you will be given the opportunity to pause or indeed terminate the process all together without the need to provide a reason or explanation. **Following the interview, we will have a debrief session during which** I will also provide you with contact information of additional sources of support such as OCD helplines and other mental health services such as **OCD Action, OCD UK**, Mind, Anxiety UK or Samaritans. **I will recommend that you seek further support from them** if you feel you would benefit from their support.

What are the possible benefits of taking part?

Some individuals find talking about their distressing experiences and telling their own unique story can have a cathartic effect. Expressing yourself can lead to increased self-awareness, feeling heard, and the consolidation of your own memories.

More so, your participation in the study could contribute to helping health care professionals gain a better understanding of other individuals that experience obsessions and compulsions. It could help inform the type of therapeutic interventions used with those affected in order to provide more effective therapeutic care.

What happens when the study stops?

Once the study has been completed, I will inform you of its completion via your preferred method of contact. If you so choose, you can contact me in order to receive a summary of the research findings.

What if there is a problem?

In the event of any complaint or concern you may have regarding any aspect of the way you have been dealt with during the course of the study; please contact me Orinayo Onabanjo, the principal researcher on o.disun-odebode@surrey.ac.uk in the first instance or the research supervisor of this study, Dr Ben Rumble on b.p.rumble@surrey.ac.uk. You may also contact Dr Cristina Harnagea on c.harnagea@surrey.ac.uk, the University of Surrey's counselling psychology course research lead.

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the

Student Number: 6086850

way you have been treated during the course of this study then you should follow the instructions given above.

Will my taking part in the study be kept confidential?

Yes. Your details will be held in confidence and we will follow ethical and legal practice in relation to all study procedures. Personal data (e.g your name, contact details, or audio recordings) will be handled in accordance with the GDPR 2018 so that unauthorised individuals will not have access to them.

Your personal data will be accessed, processed and securely destroyed by me, the principal researcher and Dr Ben Rumble, the research supervisor of this study. Both of us will have a duty of confidentiality to you as a participant and we will do our best to meet this duty.

The data you provide will be anonymised and your personal data will be stored securely and separately from those anonymised data. You will not be identified in any reports or publications resulting from this research and those reading them will not know who has contributed to it. However, with your permission we would like to use anonymised verbatim quotation in the final report.

In certain exceptional circumstances where you or others may be at significant risk of harm, I may need to report this to an appropriate authority, in accordance with the GDPR 2018. This would usually be discussed with you first.

Examples of those exceptional circumstances when confidential information may have to be disclosed are:

- I believe you are at serious risk of harm, either from yourself or others
- I suspect a child may be at risk of harm
- You pose a serious risk of harm to, or threaten or abuse others
- As a statutory requirement e.g. reporting certain infectious diseases
- Under a court order requiring the University to divulge information
- We are passed information relating to an act of terrorism

Full contact details of researcher and supervisor

Principal researcher: Orinayo Onabanjo, Trainee counselling psychologist

If you choose to participate in the study or have any questions please contact me at o.disunodebode@surrey.ac.uk, the University of Surrey.

Student Number: 6086850

Research supervisor: Dr Ben Rumble, Counselling Psychologist

This research study is being supervised by Dr Ben Rumble at the University of Surrey. You are also free to contact her via email at b.p.rumble@surrey.ac.uk if you have any concerns or questions.

Who is organising the research?

This research is organized by the University of Surrey with the support of OCD Action and TOP UK.

Who has reviewed this project?

This research has been looked at by an independent group of people, called an Ethics Committee, to protect your interests. This study has been reviewed by and received a favorable ethical opinion from the Faculty of Health and Medical Sciences at the University of Surrey.

Thank you for taking the time to read this information sheet.

Appendix B

Consent Form [version 1, 16/07/18]

Adults experiencing obsessions and compulsions



Phenomenological - Contextualist Accounts of The Experience of Obsessions and Compulsions: A Theoretical Thematic Analysis Study

- I have read and understood the Information Sheet provided (version 1, 06/12/17). I have been given a full explanation by the researcher of the nature, purpose, location and likely duration of the study, and of what I will be expected to do.
- I agree to take part in this study about understanding the subjective experiences of individuals experiencing obsessions and compulsions in the context of their wider environment and interpersonal relationships.
- I agree that I meet the eligibility criteria for participation in the study as outlined in the information sheet.
- I have been advised about any distress which may result due to my participation. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.
- I understand that if I become uncomfortable, distressed or experience significant deterioration in my wellbeing, I have the right to pause, reschedule or terminate the interview altogether. No reason or explanation has to be given.
- I understand that the researcher may also pause or terminate the interview temporarily if they feel that I am experiencing marked levels of distress.
- I agree to comply with the requirements of the study as outlined to me to the best of my abilities. I shall inform the researcher immediately if I have any concerns or suffer any deterioration of any kind in my health or well-being.
- I agree not to restrict the researchers use of my data within the parameters of use previously outlined and explained within the information sheet.
- I agree for my anonymised data to be used for this study that will have received all relevant legal, professional and ethical approvals.
- I give consent for the interview to be audio recorded.
- I give consent to anonymous verbatim quotation being used in the final research report.

Student Number: 6086850

- I understand that all project data will be held for at least 6 years and all research data for at least 10 years in accordance with University policy
- I understand that my personal data is held and processed in the strictest confidence, and in accordance with the GDPR (2018).
- I agree for the researchers to contact me to provide me with a study results summary.
- I agree for my data to be shared with Dr Ben Rumble, the research supervisor of this project.
- I understand that I am free to withdraw from the study at any time without needing to justify my decision, without prejudice and without my legal rights and care being affected.
- I understand that I can request for my data to be withdrawn up until (March 2019) 3 months before the submission of the research report in July 2019 and that following my request all data already collected from me will be destroyed.
- I understand that I reserve the right to request a copy of any data, provided by me, at any time during or after the submission of the research report.
- I understand that the researcher will offer me a debrief session, following the interview, where I can discuss any questions or concerns that may have arisen. I understand that I will also be given the contact details of other mental health support services whom I can contact and seek extra support from if I so wish.
- I agree to inform the researcher if I become unwell and I am no longer able to attend the scheduled time and location of the interview.
- I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation.

Name of participant (BLOCK CAPITALS):

Signed:

Date:

Name of researcher taking consent (BLOCK CAPITALS):

Signed

Date

Student Number: 6086850

Participant details form



- I can confirm that I am over 18 years old.
- I can confirm that I currently experience obsessions and compulsions
- I can confirm that in my opinion I am emotionally prepared to participate in this research

Please circle below the organisation or medium through which you were recruited

OCD Action TOP UK OCD support group Social Media

Please circle below your preferred method of contact regarding the research

Post Email Telephone

Please provide your postal/email address/telephone number below

Please complete your details below

NAME (Please use BLOCK CAPITALS):

AGE:

SIGNATURE:

DATE: