

The barriers to treatment for individuals with Obsessive compulsive disorder (OCD)

Start of Block: Information sheet and consent

Information sheet Hello!

You are being invited to take part in a research study. Before you making a decision on taking part in the study or not, it is very important that you take your time in reading and understanding the following information, where information is provided on why the research is being done and what it will involve.

Study Title: The barriers to treatment for individuals with Obsessive-compulsive disorder (OCD)

What is the purpose of the study?

Obsessive-compulsive disorder (OCD) is a mental health disorder which is mainly characterized by obsessions and/or compulsions. These obsessions and compulsions are often clustered into various groups, depending on the content and behaviours the person experiences. These obsessions and compulsions can have a big impact on an individual's day to day and life.

Different types of pharmacological and psychological treatment, such as Cognitive-behavioural therapy, are available for those with OCD. However, studies report a big delay from the first appearance of symptoms to seeking treatment (the average is of 10 years!). Various possible causes of this delay have been found; these are considered barriers to treatment. Examples of these barriers are “not knowing where to seek help”, feelings of shame and stigma, and problems with booking appointments and getting to appointments.

The present study aims to explore these barriers to treatment. Furthermore, the study will also investigate the relationship between certain types of obsessions/compulsions and barriers to treatment, alongside taking into consideration if demographic details (such as ethnicity, religion, and economic status) also impact the barriers.

Why have I been approached?

This study has been advertised on various OCD and Anxiety groups and mental health charities, with the aim of reaching individuals who are suffering from OCD to participate in the current study, where the study aims to collect data from approximately 100-200 participants. To take part in the study you need to be above the age of 18, have access to a laptop or computer, be able to read and answer questions in English, be diagnosed or believe to have OCD, and be

of any gender. Sensitive topics in relation to OCD symptoms, types of Obsessions and Compulsions, and barriers to treatments are discussed in the questionnaires. Please do not take part in the study if you believe you could find the content of the questionnaires distressing.

Do I have to take part?

Participation in the current study is completely voluntary. Following this information sheet, you will be presented with a consent form; you will only continue to take part in the study if you consent to all the items. You can exit the study at any time by closing the browser; you are also able to skip any question which you are not happy to answer. If you do wish to withdraw from the study, you are able to do so by providing your 6-digit unique code.

What will happen if I don't want to carry on with the study?

As mentioned, you have a right to change your mind and withdraw from the study at any point without giving any penalties or reasons asked. During the study you can exit the study by closing the web browser. If you wish to withdraw after completing the study, please contact the researcher with your unique participant code. If you wish to withdraw from the study, please do so before the analysis stage of the research report (before March the 14th of 2023). All data collected up to the point of withdrawal will be immediately destroyed.

What will happen to me if I take part?

If you decide to take part in the study you will be asked questions surrounding the obsessions and compulsions you experience, and the severity of these. Following this initial questionnaire, you will be asked 10 questions about your experience accessing or thinking about accessing treatment. Lastly, you will be asked an open question about your experience accessing treatment. All questionnaires will be provided online, where it is estimated that the study will take no longer than 20 minutes to complete.

What are the possible disadvantages and risks of taking part?

There are no expected disadvantages or risks of taking part in the current study, however, the questionnaires do involve questions surrounding obsessions and compulsions which some individuals may find distressing or triggering, which is something to consider before taking part in the study; if you believe completing this questionnaire could cause you distress, please do not take part. If you do decide to take part, and then find any of the items distressing, please feel free to exit the study. If you need support following the study, here is a list of good support groups/research groups and charities which could provide further support and/or resources to get support:

Orchard OCD:

- Website: Orchardocd.org
- Contact email: infor@orchardocd.org

OCD Action:

- Website: ocdaction.org.uk

- Helpline: 0300 636 5478
- Helpline email: support@ocdaction.org.uk

TOP UK

- Website: <https://www.topuk.org/>
- Email: infor@topuk.org
- Telephone: 01225 571740

International OCD foundation

- Website: <https://iocdf.org/>

What are the possible benefits of taking part?

There are no direct benefits of taking part in the study, however, participation in the study could increase your knowledge in the topic area, whilst also contributing to research to understand how the different barriers to treatment affect individuals with OCD.

What if something goes wrong?

If you are unhappy with the conduct of this study please contact my supervisor Jon Rees, or the Chair of the University of Sunderland Research Ethics Group Dr John Fulton. Contact details are included below.

How will my information be kept confidential?

All data will be handled in accordance with the Data Protection Act (2018). Data collected will remain completely anonymous, and no location data will be collected. Data will be stored securely in the qualtrics secure cloud based system and analysed on a password-protected laptop, which will only be shared with the project supervisor. All data will be securely disposed of two years post completion of the study.. Anonymised data or results of the current study may be shared with other researchers and/or may be used for teaching purposes. Data may also be viewed by authorised staff of the University of Sunderland for audit and quality assurance purposes.

What will happen to the results of this study?

Results of the study will form part of the project report and in an academic poster of the research report. If suitable, results may also be published in academic journals and/or presented in academic conferences.

Who is organising and funding the research?

The research is organised by Robyn Jones, who is a Psychology and Counselling student at the University of Sunderland, Faculty of Health Sciences and Wellbeing, School of Psychology. This project is not externally funded.

Who has reviewed the study?

The study has been reviewed and approved by the University of Sunderland Research Ethics Group's review system.

Further information and contact details

Robyn Jones (Researcher)

Email: bh55hv@student.sunderland.ac.uk

Jon Rees (Research Supervisor)

Email: jon.rees@sunderland.ac.uk

Phone: 0191 515 2604

Dr John Fulton (Chair of the University of Sunderland Research Ethics Group)

Email: john.fulton@sunderland.ac.uk

Phone: 0191 515 2529

Thank you for taking time to read the information sheet!

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Consent Consent form

- I confirm that I am over the age of 18 (1)
- I confirm that I have read and understood the Participant Information Sheet (2)
- I understand that data gathered in this study are completely anonymous (3)
- I understand that the data from this study may be shared with other researchers and/or used for teaching purposes (4)
- I understand that my participation is voluntary and that I am free to withdraw at any time during the study by closing my web browser (5)
- I agree to take part in this study (6)

Skip To: End of Survey If Consent form != I confirm that I am over the age of 18

Skip To: End of Survey If Consent form != I confirm that I have read and understood the Participant Information Sheet

Skip To: End of Survey If Consent form != I understand that data gathered in this study are completely anonymous

Skip To: End of Survey If Consent form != I understand that the data from this study may be shared with other researchers and/or used for teaching purposes

Skip To: End of Survey If Consent form != I understand that my participation is voluntary and that I am free to withdraw at any time during the study by closing my web browser

Skip To: End of Survey If Consent form != I agree to take part in this study

Consent *Sensitive topics in relation to OCD symptoms, types of Obsessions and Compulsions, and barriers to treatments are discussed in the questionnaires. Please do not take part in the study if you believe you could find the content of the questionnaires distressing. *

End of Block: Information sheet and consent

Start of Block: Demographic details

Participant code Please provide a unique 6-digit reference code. This should be the first three letters of your street address, the last two letters of your place of birth and the day of your birth. (For example, if your street address is Smith Avenue and you were born in London on the 2nd of May, then you would enter SMION02”

OCD yes/no Have you previously been diagnosed with OCD, or do you believe you have OCD?

Yes (1)

No (2)

Skip To: End of Survey If Have you previously been diagnosed with OCD, or do you believe you have OCD? = No

Age What is your age?

Gender What is your gender?

Female (1)

Male (2)

Prefer not to say (3)

Other (please specify): (4)

Race and ethnicity Please state what ethnicity you identify with:

- Asian or Asian British (1)
 - Black, Black British, Caribbean or African (2)
 - Mixed or multiple ethnic groups (3)
 - White (4)
 - Other ethnic group (5)
-

Religion What is your religion?

- No religion (1)
 - Christian (including Church of England, Catholic, Protestant and all other Christian denominations) (2)
 - Buddhist (3)
 - Hindu (4)
 - Jewish (5)
 - Muslim (6)
 - Sikh (7)
 - Any other religion, please specify: (8)
-

Economic status How much total combined money did all members of your household earn on average a year ?

- 0 – 9999 (1)
- 10.000-19.999 (2)
- 20.000-29.999 (3)
- 30.000-39.999 (4)
- 40.000-49.999 (5)
- 50.000-59.999 (6)
- 60.000-69.999 (7)
- 70.000-79.999 (8)
- 80.000-89.999 (9)
- 90.000-99.999 (10)
- 100.000 or more (11)

End of Block: Demographic details

Start of Block: Part 1

Explanation OBSESSIONS are unwelcomed and distressing ideas, thoughts, or impulses that repeatedly enter your mind. They may seem to occur against your will. They may be repugnant to you, you may recognize them as senseless, and they may not fit your personality.

Examples of an obsession are recurrent thought or impulses to do harm to a child even though you never would and the idea that household cleansers may lead to contamination and serious illness. Obsessions differ from worries in that worries are about possible negative things related to life problems that you are afraid might happen. For example, you may worry about failing an exam, about finances, health, or personal relationships. In contrast to obsessions, your worries don't usually seem totally senseless, repugnant, or inconsistent with your personality.

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Q3 Given the previous definitions, please read carefully the following list of types of Obsessive thoughts and indicate which of these you experience. These are grouped in to various "Obsession types". Please read the types and examples carefully; you may not experience every example given within the category.

If you experience various types of Obsessional thoughts, please indicate which is the most distressing and/or experience the most frequently. If the obsessive thoughts you experience is not listed, please select "Other", and provide an example or information about your obsessions.

- Aggressive Obsessions: These obsessions include fears of harming yourself or others, experiencing violent or horrific images in your mind, fear you will blurt out obscenities in public, fears of doing something embarrassing, fears of acting on upon unwanted impulse, fears of harming others because of not being careful enough or acting on an unwanted impulse, and fear of being responsible for something terrible. (1)
 - Contamination Obsessions: These obsessions involve fears of concern or disgust of bodily waste or secretions, concerns with dirt or germs, an excessive concern with environmental contaminants, certain household cleansers or animals, concerns of getting ill because of contamination, and concerns that you will contaminate others. (2)
 - Sexual Obsessions: This type of obsessions includes obsessions surrounding forbidden or perverse sexual thoughts, images or impulses, sexual obsessions involving children or incest, obsessions about homosexuality, and obsessions about aggressive sexual behaviour towards other people. (3)
 - Religious Obsessions: These involve obsessions where you may be concerned with sacrilege and blasphemy, and excessive concerns with morality. (4)
 - Obsessions with need for Symmetry and Exactness: Obsessions of this type include examples such as worries about papers and books being properly aligned, worries about calculations or handwriting being perfect (5)
 - Hoarding/Saving: These involve obsessions about hoarding or saving things, such as worries about throwing seemingly unimportant things that you might need in the future. (6)
 - Somatic: Obsessions concerned with illness or disease, or being excessively concerned with a part of your body or an aspect of your appearance (7)
 - Miscellaneous obsessions: Various other obsessions including feeling the need to know or remember certain things, fear of saying certain things, or fear of not saying just the right thing, fear of losing things, being bothered by intrusive (neutral) mental images, or being bothered by intrusive mental nonsense sounds, words or music, having lucky and unlucky numbers and colours, and having superstitious fears. (8)
 - Other obsessive thoughts, please give more information or an example: (9)
-

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Q4 COMPULSIONS, are behaviours or acts that you feel driven to perform although you may recognize them as senseless or excessive. Usually compulsions are performed in response to an obsession, or according to certain rules or in a stereotyped fashion. At times, you may try to resist doing them but this may prove difficult. You may experience discomfort that does not diminish until the behaviour is completed.

Examples of a compulsions are the need to repeatedly check appliances, water faucets, and the lock on the front door before you can leave the house and repeated handwashing. While most compulsions are observable behaviours, some are unobservable mental acts, such as silent checking or having to recite nonsense phrases to yourself each time you have a bad thought. Compulsions, as we define them here, are not to be confused with other kinds of compulsive behaviour such as overeating, gambling, drinking alcohol, over shopping, or other “addictive behaviours.”

Page Break

Q5 Given the previous definitions, please read carefully the following list of types of Compulsions and indicate which of these you experience. If you experience various types of Compulsive behaviours, please indicate which type you experience the most frequently. If the compulsion you experience is not listed, please select "Other" and provide an example or information about your obsessions.

- Cleaning/Washing compulsions: These involve compulsions such as washing your hands excessively in a ritualized way, excessive or ritualized every day activities, such as bathing or grooming, compulsions involving cleaning household items and other objects, and actions preventing or removing contact with contaminants. (1)
 - Checking Compulsions: These involves behaviours such as checking you did not harm others or yourself, checking you did not make a mistake (such as leaving a household appliance on, not locking a door, etc), and checking nothing terrible has happened. (2)
 - Repeating Rituals: These involve compulsions such as rereading or rewriting things, and a need to repeat routine activities. (3)
 - Counting: This involves counting objects like ceiling or floor tiles, books in a bookcase, nails in a wall, or even grains of sand on a beach; also counting when you repeat a certain activity, like washing. (4)
 - Ordering/Arranging Compulsions: Compulsions such as straightening papers and pens on a desktop or books in a bookcase, wasting hours arranging things in your house in "order" and then becoming very upset if this order is disturbed. (5)
 - Hoarding/Collecting: Compulsions such as saving old newspapers, notes, cans, paper towels, wrappers and empty bottles for fear that if you throw them away you may need them, or findings these objects on the street or bin and keeping them. (6)
 - Miscellaneous Compulsions: Various other compulsions, such as: having mental rituals, feeling the need to tell, ask or confess, a need to take measures to prevent harm or terrible consequences to yourself or family, ritualized eating behaviours, superstitious behaviours and hair pulling. (7)
 - Other Compulsions, please give more information or an example: (8)
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Q7 Thank you for completing the first part of the questionnaire. The second part of the questionnaire consists of questions in relation to the obsessions you experience and selected in the first part of the questionnaire. Please read the following items and score these by marking the appropriate number from 0-4 under each question. If you are currently not experiencing any obsession or compulsion, please enter 0 for the questions and continue to the next question.

1 1. How much time was occupied by obsessive thoughts? How frequently did these occur?

	0 (None) (1)	1 (Less than 1 hour per day, or occasional intrusions) (2)	2 (1-3 hours per day, or frequent intrusions (most of the day are free of obsessions)) (3)	3 More than 3 hours and up to 8 hours per day, or very frequent intrusions (4)	4 (More than 8 hours per day, or near-constant intrusions) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2 2. How much did these thoughts interfere with your social or work functioning? Is there anything you didn't do because of them?

	0 (No interference) (1)	1 (Mild, slight interference with social or occupational performance, but still performance not impaired) (2)	2 (Moderate, definitive interference with social or occupational performance, but still manageable) (3)	3 (Severe interference, causes substantial impairment in social or occupational performance) (4)	4 (Extreme, incapacitating interference) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3 3. How much distress did your obsessive thoughts cause you?

	0 (None) (1)	1 (Mild, infrequent, and not too disturbing) (2)	2 (Moderate, frequent, and disturbing distress, but still manageable) (3)	3 (Severe, very frequent, and very disturbing distress) (4)	4 (Extreme, near-constant, and disabling distress) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4 4. How much effort did you make to resist the obsessive thought? How often did you try to disregard or turn your attention away from those thoughts as they entered you mind?

	0 (I made an effort to always resist (or the obsessions are so minimal that there is no need to actively resist them) (1)	1 (I tried to resist most of the time (e.g. more than half the time I tried to resist) (2)	2 (I made some effort to resist) (3)	3 (I allowed all obsessions to fill my mind without attempting to control them, but I did so with some reluctance) (4)	4 (I completely and willingly gave in to all obsessions) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5 5. How much control did you have over your obsessive thoughts? How successful were you in stopping or diverting your obsessive thinking?

	0 (Complete control) (1)	1 (Much control; usually I could stop or divert obsessions with some effort and concentration) (2)	2 (Moderate control; sometimes I could stop or divert obsessions) (3)	3 (Little control; I was rarely successful in stopping obsessions and could only divert attention with great difficulty) (4)	4 (No control; I was rarely able to even momentarily ignore the obsessions) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6 6. How much time did you spend performing compulsive behaviour? How frequently did you perform compulsions?

	0 (None) (1)	1 (Less than 1 hour per day was spent performing compulsions, or occasional performance of compulsive behaviours (no more than 8 times per day)) (2)	2 (1-3 hours per day was spent performing compulsions, or frequent performance of compulsive behaviours (most hours were free of compulsions)) (3)	3 (More than 3 hours and up to 8 hours per day were spent performing compulsions, or very frequent performance of compulsive behaviours (during most hours of the day)) (4)	4 (More than 8 hours were spent performing compulsions, or near-constant performance of compulsive behaviours (hour rarely passes without several compulsions being performed)) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7 7. How much did your compulsive behaviours interfere with your social or work functioning?

	0 (No interference) (1)	1 (Mild, slight interference with social or occupational activities, but overall performance not impaired) (2)	2 (Moderate, definite interference with social or occupational performance, but still manageable) (3)	3 (Severe interference, substantial impairment in social or occupational performance) (4)	4 (Extreme, incapacitation interference) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8 8. How would you have felt if prevented from performing your compulsion(s)? How anxious would you have become?

	0 (Not at all anxious) (1)	1 (Only slightly anxious if compulsions prevented) (2)	2 (Anxiety would mount but remain manageable if compulsions prevented) (3)	3 (Prominent and very disturbing increase in anxiety if compulsions interrupted) (4)	4 (Extreme, incapacitating anxiety from any intervention aimed at reducing the compulsions) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9 9. How much effort did you make to resist the compulsions? Or how often did you try to stop the compulsions?

	0 (I made effort to always resist (or the symptoms were so minimal that there was no need to actively resist them)) (1)	1 (I tried to resist most of the time (e.g. more than half the time)) (2)	2 (I made some effort to resist) (3)	3 (I yielded to almost all compulsions without attempting to control them, but I did so with some reluctance) (4)	4 (I completely and willingly yielded to all compulsions) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10 10. How much control did you have over the compulsive behaviour? How successful were you in stopping the ritual(s)?

	0 (I had complete control) (1)	1 (Usually I could stop compulsions or rituals with some effort and willpower) (2)	2 (Sometimes I could stop compulsive behaviour but only with difficulty) (3)	3 (I could only delay the compulsive behaviour, but eventually it had to be carried out to completion) (4)	4 (I was rarely able to even momentarily delay performing the compulsive behaviour) (5)
(1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Part 1

Start of Block: Part 2

Explanation part 2 Thank you for completing the first part of the study! The last part of the study involves answering questions about your experience accessing treatment, or if you have not accessed treatment your experiences on considering and/or thinking about accessing treatment.

Q19 Please read the following questions and indicate on a scale from 0 to 5 how much you perceive each barrier to have been a barrier to treatment.

	0 (Not at all) (1)	1 (2)	2 (3)	3 (4)	4 (5)	5 (Extremely) (6)
1. I was worried about how much it would cost (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I was unsure about who to see or where to go (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I thought it would be too inconvenient or take too much time (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I had problems with transportation or scheduling (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I could not get an appointment (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I felt ashamed of needing help for my problem (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I wanted to handle it on my own (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I felt ashamed of my problems (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I worried about what people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

would think if they knew I was in treatment (9)

10. I was afraid of being criticized by my family if I sought psychiatric help (10)

11. I was not comfortable discussing my problems with a health professional (11)

12. I was scared about being put into a hospital against my will (12)

13. I didn't think treatment would work (13)

14. I received treatment before and it didn't work (14)

15. I was not satisfied with the services that were available (15)

16. Would be treated unfairly because of race or ethnicity (16)

17.
Communication
concerns
because of
language
barriers (17)



End of Block: Part 2

Start of Block: Open question - Qualitative

Q27 Could you please tell us a bit more about your experience seeking, or thinking about seeking, treatment for OCD. Is there a main factor which acted as a barrier? Are there any factors we haven't mentioned previously which are meaningful to you?

End of Block: Open question - Qualitative

Start of Block: Debrief:

End of survey debrief Thank you for completing the questionnaire!

If you would like any further information about the study or have any further questions, please use the contact details below. If you wish to withdraw at the study from any point, please contact the researcher with your 6-digit participant code.

Contact details:

Robyn Jones (Researcher)

Email: bh55hv@student.sunderland.ac.uk

Jon Rees (Research Supervisor)

Email: jon.rees@sunderland.ac.uk

Phone: 0191 515 2604

Dr John Fulton (Chair of the University of Sunderland Research Ethics Group)

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If you need support following the study, here is a list of good support groups/research groups, and charities which could provide further support and/or resources to get support:

Orchard OCD:

- Website: Orchardocd.org
- Contact email: infor@orchardocd.org

OCD Action:

- Website: ocdaction.org.uk
- Helpline: 0300 636 5478
- Helpline email: support@ocdaction.org.uk

TOP UK

- Website: <https://www.topuk.org/>
- Email: infor@topuk.org
- Telephone: 01225 571740

International OCD foundation

- Website: <https://iocdf.org/>

End of Block: Debfief:
