



## **Section A: The Research Project**

### **The Lived Reality of OCD in young people: Exploring the Self and Seeking Help**

My name is Charlotte, and I am an Undergraduate Sociology student at Anglia Ruskin University. This study will be part of my Sociology dissertation, which is being overlooked by my supervisor Rachel Ryder.

*Before you decide to participate, it is important that you understand why this research is being done and what your participation involves. Please take the time to read this Participant Information Form (both section A and section B) before you make your decision. You may keep this copy to refer back to.*

#### **What is the purpose of the study?**

This study hopes to explore how young people (aged 19 to 25) based in the UK with OCD live their lives whilst dealing with their diagnoses. This will involve exploration of areas such as identity and stigma. Research into this area of mental health is often overlooked and I would like to change that as research is important for educational understanding.

#### **Why have I been asked to participate?**

I am inviting you to participate because you have self-identified as a young person with OCD.

#### **How many people will be asked to participate?**

Hopefully a wider variety of people will participate as that will improve the quality of the data collected.

#### **Do I have to take part?**

You are under no contract to participate as this study is entirely voluntary. You have the right to not only refuse participation but to withdraw at any point whilst answering the questions. However, as the data collected will be anonymous, you will be unable to withdraw your data once you have completed the study.

**Has the study got ethical approval?**

This study has been given ethical approval from the Anglia Ruskin Ethics Committee.

**What will happen to the results of the study?**

This study will be presented in my undergraduate dissertation.

**Who should I contact for further information?**

If you have any questions or would like more information about this study, please email:

Me (Charlotte): [cp830@student.aru.ac.uk](mailto:cp830@student.aru.ac.uk)

Or

My supervisor Rachel Ryder: [rachel.ryder@aru.ac.uk](mailto:rachel.ryder@aru.ac.uk)

## Section B: Your Participation in the Research Project

### What will I be asked to do?

Before you start the questionnaire, you should read the entirety of this information form to ensure you understand the study before ticking the consent button. You can download and retain this form from the bottom of this page.

This entire study will be conducted via one online written questionnaire. This will allow you to take as much time as you need to answer the questions. Rough estimation of time needed overall is around 35 to 45 minutes. You will also be able to withdraw at any time before completion.

Completion does not need to occur within a block, and participants are encouraged to take a break from the questionnaire and come back if necessary. Participation is entirely anonymous. You will be given the opportunity to select 'Prefer not to say' for all multiple-choice options and can write the same saying into any text boxes. Any given information **should not** include names of individuals or locations.

Questions will be separated into multiple choice options and text boxes. You will also be shown a few images to discuss how they make you feel.

Once you have completed the questionnaire, the data will be analysed for my dissertation.

### What will happen to my data?

Your answers will be kept strictly and securely confidential until the research is finished. All data will be collected anonymously. No data will be accessed by anyone other than me and my research supervisor. If your data is individually referred to, you will be given a pseudonym of Participant No.1, Participant No. 2 etc. and a full data profile will not be presented to prevent identification. However, there is always the risk of someone you know identifying you, so it is important you understand that before answering any questions and/or participating in this study.

Data that will be collected will involve:

- Age
- Gender
- Ethnicity
- Education/Work
- Form and experience of OCD (and any other mental health issues)
- Stigma
- School, work, friends and family experiences/background
- Opinions

This data will be needed in order to provide the highest quality research analysis and to make comparisons and links. You have the option of leaving whatever you want unanswered. Before you start and finish your questionnaire you will be asked if you are happy for the data to be collected. You must consent to both of these in order for your data to be used. You will also be given the option to officially finish the questionnaire.

If you chose to withdraw before finishing the questionnaire, your already entered data will not be stored.

### **Important Data Protection Links for you**

**Data will be collected via Online Surveys (JISC). Information regarding how secure they are is available here:**

<https://www.onlinesurveys.ac.uk/help-support/online-surveys-security/>

**and here:**

<https://www.jisc.ac.uk/website/privacy-notice>

**Anglia Ruskin's general privacy notice explaining use of your personal data for research purposes is available here:**

<https://www.anglia.ac.uk/privacy-and-cookies/research-participants>

**Please visit this link for information about how long we keep your data, how we keep your data secure, how you can exercise your rights over your data, and make a complaint over our use of your data.**

### **Are there any possible disadvantages or risks to taking part?**

A primary disadvantage of taking part in the study may be that talking about your experiences of OCD and your everyday life may be emotionally and mentally triggering. However, if you feel as though reflecting or writing out certain information may have a negative impact on your wellbeing, please do not talk about them. This will be why the option of 'Prefer not to say' will be utilised for multiple choice and can be written into text boxes.

Likewise, it may be possible for individuals you know to identify you. To prevent this from happening, all possible steps have been taken. For example, your data will be automatically anonymous, no complete data profile will be shown to the public, and I will not quote any answers I believe are too specific. However, there is no guarantee, thus if you consent to this study you are consenting to that possibility.

Participants may also become bored from continuing to answer questions in one block, this is why I recommend taking rest breaks and coming back to the study at another time should you want. This recommendation is also for any participant that feels distress, please take some time away from the questionnaire either temporarily or entirely. Your health and safety are paramount and should always come first.

Your agreement to participate in this study will not affect your legal rights. You cannot get in trouble for your answers unless the police become involved.

### **What are the likely benefits of taking part?**

The data that is generated from this study is unlikely to directly benefit you. However, the knowledge that you are helping me to create an educational dissertation may be seen as a benefit.

### **Can I withdraw at any time, and how do I do this?**

You can withdraw from this study at any time you want, you do not need to give a reason. Simply leaving the page without saving will be enough to withdraw you from the questionnaire. More so you can choose not to answer any questionnaire questions you do not wish to. Options for 'Prefer not to say' will be available from multichoice questions whilst simply writing 'Prefer not to say' or leaving textbox's blank will suffice for those questions.

Any data you have already entered will be lost when you choose to withdraw before completion. Once you have completed the questionnaire it will not be possible to withdraw, however. This is because data is automatically anonymous so I will not know which belongs to you.

### **Who should I contact to complain?**

If you wish to make a complaint about this study, you can contact:

#### **Me (Charlotte)**

Email address: [cp830@student.aru.ac.uk](mailto:cp830@student.aru.ac.uk)

#### **Dissertation supervisor, Rachel Ryder**

Email address: [rachel.ryder@aru.ac.uk](mailto:rachel.ryder@aru.ac.uk)

#### **ARU Complaints Department**

Email address: [complaints@aru.ac.uk](mailto:complaints@aru.ac.uk)

Postal Address:

Office of the Secretary and Clerk,  
Anglia Ruskin University,  
Bishop Hall Lane,  
Chelmsford,  
Essex,  
CM1 1SQ.

## **Mental Health Resources**

If you would like to seek mental health advice and support at any time before, during and after the questionnaire, then please use these resources:

### **Samaritans**

Website: <https://www.samaritans.org>

Email address: [jo@samaritans.org](mailto:jo@samaritans.org)

Phone Number: 116 123

Post:

Chris  
Freepost RSRB-KKBY-CYJK  
PO Box 9090  
STIRLING FK8 2SA

### **OCD UK**

Website: <https://www.ocduk.org>

Email address: [support@ocduk.org](mailto:support@ocduk.org)

Phone Number: 03332 127890

Discussion Forums: <https://www.ocforums.org>

### **OCD Action**

Website: <http://www.ocdaction.org.uk>

Email address: [support@ocdaction.org.uk](mailto:support@ocdaction.org.uk)

Phone Number: 0845 390 6232

Discussion Forums: <http://www.ocdaction.org.uk/forum>

### **Mind**

Website: <https://www.mind.org.uk>

Email address: [info@mind.org.uk](mailto:info@mind.org.uk)

Information Phone Number: 0300 123 3393

Legal Phone Number: 0300 466 6463

Text: 86463

Post:

Mind Infoline,  
PO Box 75225,  
London,  
E15 9FS

**YoungMinds**

Website: <https://youngminds.org.uk>

Parents Helpline: 0808 802 5544

YoungMinds Crisis Messenger: If you need urgent help text YM to 85258

Thank you for reading this far and for considering participating!

Date 18 November 2020  
V1.0