



Participant Information Sheet

Parent/Guardian

Version 1.0_04.09.2024

1. Research Project title

The co-creation of a psychoeducational resource for school staff about OCD in children and young people.

1. a) What is a psychoeducational resource?

A psychoeducational resource is some kind of information or tool which aims to teach someone about the symptoms of a mental health condition.

2. Invitation

You are being invited to participate in a research project. Before you decide whether or not you would like to participate, it is important for you to understand why the research is being done, and what this will involve. Please take time to read the following information carefully, and discuss it with others if you wish. Please get in touch with Libby Colbert (contact details at the end of this document) if anything is not clear, or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

3. Who is Libby?

Libby Colbert is the researcher leading this project, and is based at the University of Sheffield. Libby herself has experience of OCD from an early age, and now volunteers for the national charity, OCD Action, running support groups for young people with OCD and parents of children with OCD. Libby is very interested in OCD, how this impacts children and young people at school, and how teachers can be helped to support children with OCD in the classroom.

4. What is this study about?

The project aims to co-create (i.e. researcher and participants working together to create something) a resource for teachers to improve their understanding and knowledge of obsessive compulsive disorder (OCD) in children and young people. For the first phase of this

project, we would like to know what you and your child believe important for school staff to know about OCD.

By asking those directly impacted by OCD, like yourself as a parent/guardian, it is hoped the resource better represents experiences of children and young people with OCD, and is therefore more likely to be successful in improving school staff's understanding of OCD. Interviews and/or focus groups will also be conducted with education and clinical professionals who work with children and young people with OCD.

5. Why have I and my child been chosen?

Because you are the parent/guardian of a child with a diagnosis of OCD, and because your child is between the ages of 7-12 years of age. Up to 8 parents and 8 children/young people will be asked to take part in this stage of the study. We will also be speaking to clinical and education professionals.

6. Do I/my child have to take part?

It is your decision whether or not you and your child take part. If you do decide to take part, you will be sent (via post or email), this information sheet to keep, a consent form through the post or via an online questionnaire, and you are also able to withdraw at any time up until a week after data collection (to allow for analysis to begin) without any negative consequences. You do not have to give a reason or justification for this. If you wish to withdraw from the study, please inform Libby Colbert (contact details at the end of this document), and she will ensure that no more information is collected from you or your child. Following a week after data has been collected, it cannot be withdrawn from the study, so please inform Libby Colbert as soon as possible after data collection if you or your child no longer wish to take part.

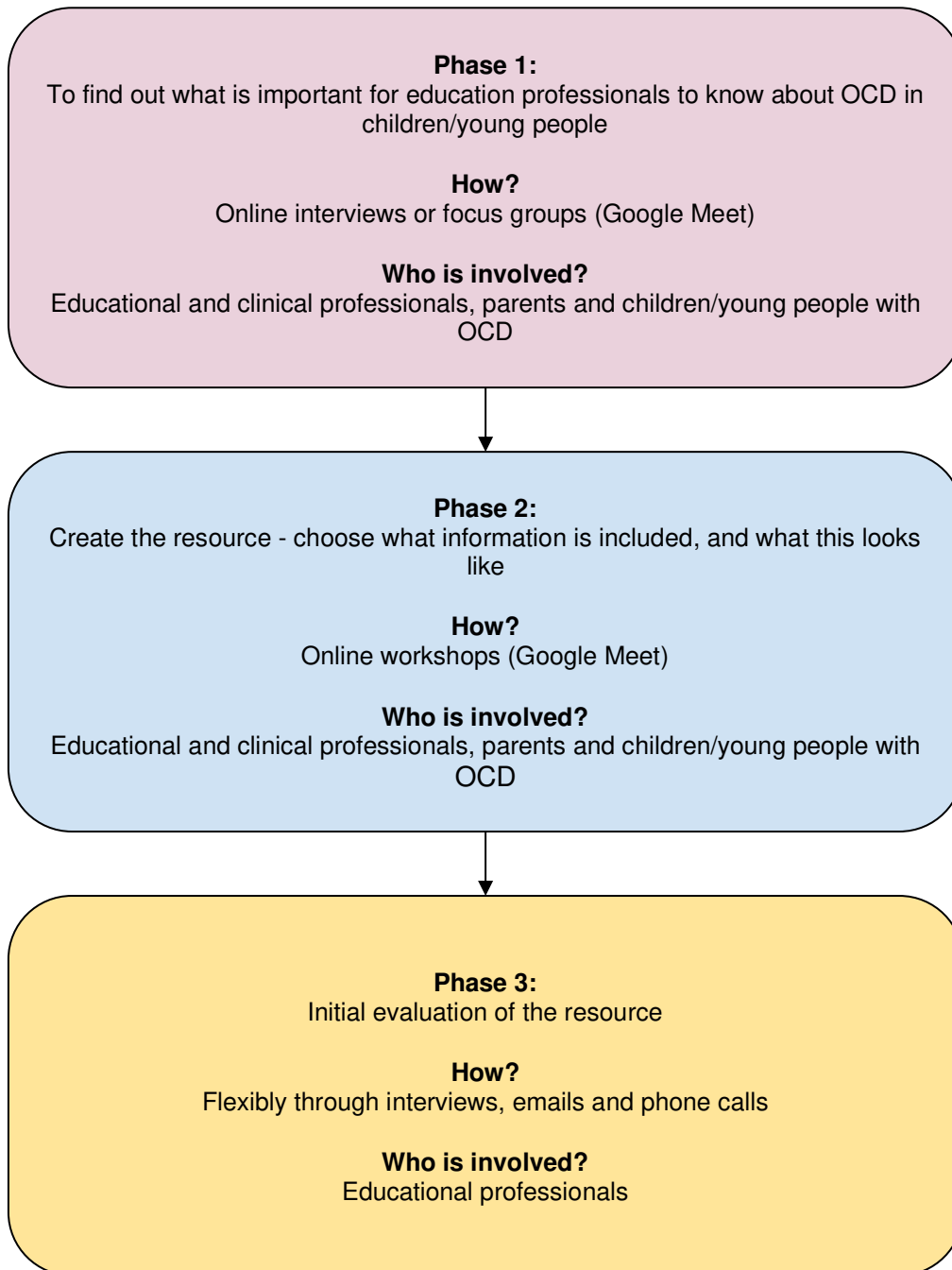
7. What will happen if myself and my child take part?

The following page contains a phase-by-phase diagram of the project.

If preferred or more convenient, you can choose to take part in person. Interviews/focus groups will last no longer than an hour.

If you and your child do decide to take part, you will be asked to give informed consent (either via an online questionnaire or a form sent in the post, to your convenience) on your child's behalf. Your child will also be asked to do the same so that they understand what is involved. You will be asked to provide informed consent for yourself to take part in the same way. You and/or your child can still withdraw from the study at any time (up until a week after data collection) without providing a reason.

One week prior to the interview, Libby will send a list of questions/topics which may be covered in the interview. Do inform Libby if you would like any questions/topics on this list to be avoided.



You and your child will be invited to participate in the next phase of the project, however you are under no obligation to do so. This information sheet corresponds to the first phase of the project only.

8. Will I/my child be recorded, and how will recorded media be used?

The video and audio recordings of the interview made during this research will be used only for analysis. No other use will be made of you/them without your written permission, and no one outside the project will be allowed access to the original recordings. If you choose for the interview to take place online, it is preferable that your camera is turned on, however you can

choose to turn this off at your discretion. The recording will be transcribed and anonymised, then the original recording will be deleted. The anonymised data will be used for reports and publications of this project.

9. How do I give permission for my child to take part in the study?

You will be asked to give informed consent (via an online questionnaire or form sent via post) on your child's behalf, and your child will be asked to do the same so that they understand what is involved. We require consent from you and your child in order for them to take part. You will also provide informed consent for yourself, in the same way. You are welcome to take part without your child if this is preferred.

10. What are the possible risks and benefits of taking part?

There are no risks anticipated with taking part in this study. While it is believed there will be no immediate benefits to those participating in the project, it is hoped that this work will support the production of a resource to improve school staff's knowledge of OCD in children and young people.

11. What if something goes wrong and I wish to complain about the research?

If you have any cause to complain about how you have been approached or treated during this project, you can contact the project supervisor Dr Lauren Powell at the University of Sheffield (email: l.a.powell@sheffield.ac.uk). You are also able to contact the School of Education's Head of Department if you have a complaint you wish to express to somebody outside of the research team (Professor Rebecca Lawthom, email: r.lawthom@sheffield.ac.uk). If you are unhappy with how your personal data has been handled, information on how to raise a complaint can be found in the University's Privacy Notice (<https://www.sheffield.ac.uk/govern/data-protection/privacy/general>).

12. Will mine and my child's taking part in this project be kept confidential?

All of the information and data we collect about you and your child during the course of the research will be kept strictly confidential, and will only be accessible to members of the research team (Libby Colbert, Dr Lauren Powell, Dr Anna Weighall and Dr Jilly Gibson-Miller). You will not be able to be identified in any reports or publications. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly request this. All information we collect from you will be stored in a folder that is only accessible to members or the research team.

13. Who is the Data Controller?

The University of Sheffield will be using information from you in order to undertake this study and will act as the data controller of this study. This means that we (the research team) are responsible for looking after your information and using it properly. The University of Sheffield will keep identifiable information about you for two years after the study has finished (i.e. until October 2028).

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study up until a week after data collection, we will remove and dispose of your information/data. Following this time, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

14. What is the legal basis for processing my personal data?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>

In other words, we need your name and phone number (or email address if you prefer) in order to contact you to take part in this study. Without this information the study could not go ahead. This is why we ask for this information. This type of information comes under the category of "personal data".

15. Safeguarding

The University has developed a policy for safeguarding to aim to prevent harm in research and innovation and there is recognition that research activities can have an impact in the wider community and/or other individuals. The policy is designed not only to consider wider impacts of research, but also to ensure that there are clear procedures in place for reporting and escalation, placing those who have been potentially affected in a key role in guiding how incidents or concerns are resolved. This policy is available at: <https://www.sheffield.ac.uk/rs/ethicsandintegrity/safeguarding>

The Designated Safeguarding Contact is: Dr Lauren Powell.

If the concern or incident relates to the Designated Safeguarding Contact, or if you feel a report you have made to this Contact has not been handled in a satisfactory way, please contact the Head of the School of Education, Professor Rebecca Lawthom (r.lawthom@sheffield.ac.uk) and/or the University's Research Ethics & Integrity Manager, Lindsay Unwin (l.v.unwin@sheffield.ac.uk).

16. What will happen to the data collected, and the results of the research project?

Only the research team at the University of Sheffield will have access to your data and personal information. We will also use the data from this phase to inform future phases of the

research project. For example, we hope to conduct workshops which will begin to design how the resource will look, and what information it will include. This cumulative data will then inform the creation of the prototype resource, which will then be shared with educational professionals to gauge their feedback on the resource. Further research may need to be conducted, such as the further development and refinement of the resource to make it the best it can be.

Also, due to the nature of this research it is very likely that other researchers may find the data collected to be useful in answering future research questions. We will ask for your explicit consent for your data to be shared in this way. The information you provide us with will be stored for up to four years and then destroyed (i.e. no later than October 2028).

A study summary will be made available to you if you indicate you would like one. An age appropriate summary will also be made if you or your child indicate you would like one. This is optional, and you can indicate that you would like to receive this in the consent form.

The findings of this project will aim to be published in an academic paper that will be available to the public. You will not be named or identified in publication(s). We hope that the study findings will be available within 18 months of data collection.

17. Who is organising and funding the research?

This study is part of a PhD project based at the University of Sheffield, funded by the Economic and Social Research Council.

18. Who has ethically reviewed the project?

This project has been ethically approved via the University of Sheffield's Ethics Review Procedure, as administered by The School of Education.

19. Who can I contact for further information and support?

You can contact the research team using any of the methods below:

Libby (Elizabeth) Colbert, email: ejcolbert1@sheffield.ac.uk

Dr Lauren Powell, email: l.a.powell@sheffield.ac.uk

Dr Anna Weighall, email: anna.weighall@sheffield.ac.uk

Dr Jilly Gibson-Miller, email: jilly.gibson@sheffield.ac.uk

University of Sheffield
School of Education
The Wave
2 Whitham Road
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OCD specific support is also available from the following organisations:

OCD Action: <https://ocdaction.org.uk/i-need-support/>

OCD UK: <https://www.ocduk.org/support-groups/online/>

No Panic: <https://nopanic.org.uk/>

This information is for you to keep as well as a copy of your signed consent form. Thank you for your time and help.