



HOW WE WILL KEEP YOUR INFORMATION SAFE

The University of Reading is the sponsor for this study based in England. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University will keep identifiable information about you **5 years** after the study has finished.

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, 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. You can find out more about how we use your information by contacting a member of the research team or if you have concerns about the use of your data, the University Data Protection Officer at imps@reading.ac.uk

To protect your information, you will be assigned a unique participant number for the duration of the study.

The information you give us (including audio recordings) will be **stored on a secure University system.**

No information will be taken outside of the offices where we do the research, and it will not be stored on personal computers.

The computer drive we store the information on is password controlled, and only members of the research team will have access to these passwords.

For parents identified through Berkshire Healthcare Foundation Trust (BHFT) the following information will also apply:

Berkshire Healthcare Foundation Trust (BHFT) will collect information from you for this research study in accordance with our instructions. BHFT will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. BHFT will pass these details to the University along with the information collected from you. The only people in the University who will have access to information that identifies you will be people who need to contact you to conduct the research or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. BHFT will keep identifiable information about you from this study for 5 years after the study has finished.

PARENTS' EXPERIENCES OF PARENTING A CHILD WITH OBSESSIVE COMPULSIVE SYMPTOMS/DISORDER

PARENT/GUARDIAN INFORMATION SHEET
Version 4.0, 02/05/2019, IRAS ID 260035

If you have any questions or concerns about any aspect of this research, please contact the research team.



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OVERVIEW: WHAT IS THIS ALL ABOUT?

We are carrying out a research project to find out about parents' experiences of parenting a child with OCD, and their views/preferences towards parent involvement in Cognitive Behaviour Therapy (CBT) for children with OCD.

We would like to invite you to take part.

Here, you will find information which we hope will help you to decide whether to take part in this research.

What you can find in this leaflet:

- Page 2 An overview of the study
- Page 3 Advantages of taking part in this study
- Page 4 Disadvantages of taking part in this study
- Page 5 What you will be asked to do
- Page 6 Important points about this study
- Page 7 How your information is stored and kept safe

IMPORTANT POINTS

You **do not have to take part** in this study, and you have the right to withdraw from the study at any time.

Taking part, or deciding not to take part, will **not affect your son/daughter's current or future treatment**.

All information and research data will be kept **confidential and secure**

Please see page 7 for more information about how we keep your information safe

The only time we share information without agreement, is if we believe someone is at risk of harm. In this case, we would speak to you first.

Interviews will be **audio recorded** so we can carry out a detailed analysis of what parents tell us.

When we write up our research, we will include some **quotes from the interviews** so people know the important things that were said. **We will not use any real names**, so people will not be able to identify who said what.

WHAT WE WILL BE ASKING YOU TO DO

We will ask you to complete some **short questionnaires** to confirm you are eligible for the study.

If you are **eligible** to take part in the study, you may be asked to take part in an **interview**

If you are **not eligible** to take part, you will be informed that you do not need to take part in an interview

The **interview** will be with a member of the research team, at a convenient time for you

You can choose whether the interview is held at the University of Reading, Berkshire Healthcare NHS Foundation Trust, your home, telephone or Skype

What happens now

- **If you would like to take part:** if you have provided permission for a member of the research team to contact you, you will be contacted by the research team and you can let them know you wish to take part.
- **If you do not want to take part:** you do not need to do anything.

AN OVERVIEW OF THE STUDY

We want to understand **parents' experiences** of parenting a child with Obsessive Compulsive Disorder (OCD), and **their views/preferences** towards parent involvement in Cognitive Behaviour Therapy (CBT) for children with OCD.

This study is relevant to you if your son/daughter:

- Is aged 7 to 12 years old and is suspected to have OCD, or has a current diagnosis of OCD, or is aged 7 to 14 years old and has previously been diagnosed with OCD (when aged between 7 and 12 years old).
- If you are yet to seek professional support for your child's OCD; if your child is on the waitlist or receiving any form of treatment for OCD, or if your child has previously received any form of treatment for OCD (when aged between 7 and 12 years old).

By hearing parents' experiences and views, we hope to develop treatments that families want and need.

We will ask you to complete **short questionnaires** to confirm you are eligible to take part in the study. These questionnaires will ask about your child's OCD, any treatment they have received, and general questions about your family. It is expected this will take approximately **10 to 25 minutes**.

If you are eligible to take part, **we may then ask you to attend an interview**. Before the interview, we will give you information on what CBT for OCD is, and how parents can be involved. During the interview, we will ask you about your experiences of parenting your child, and your views/preferences towards parent involvement in treatment.

We expect the interview will take approximately **45 minutes**

ADVANTAGES OF TAKING PART

By taking part in this research, you will be helping us to understand **how we can best support parents** whose children suffer from OCD, and **help us to design treatments** which are suited to families' experiences and needs.

During the interview, you will have the opportunity to **share your experiences** of parenting a child with OCD, and **share your views** about whether parents should be involved in treatment.

If you wish, we can send you a summary of the study and the findings once the research is completed.

You will be given a **£10 voucher** to thank you for taking part in the interview.

THE DISADVANTAGES OF TAKING PART

This interview may involve discussing sensitive topics

However, you will be **able to decide what you want to talk about**, and we will not ask you to discuss anything you do not wish to.

You can take breaks during the interview, and stop at any time. If you become upset, we will always ask if you want to continue the interview or not.

We **do not expect any harm to come to you** from taking part in this study. This study has been reviewed and given a **favourable ethical opinion** for conduct by the NHS Research Ethics Committee, and the University of Reading Ethics Committee.

If the topics discussed in the interview raise any concerns, there are **people you can talk to for support and advice**:

- National Organisations such as Young Minds (www.youngminds.org.uk; parent helpline 08088025544) or OCD-UK (<https://www.ocduk.org/>; advice helpline 03332127890)
- The Chief Investigator (Professor Cathy Creswell) can also provide additional contacts.

If you take part, and wish to make a complain at any time, please contact:

- Professor Carmel Houston-Price or Dr Graham Schafer, Joint Heads of School of Psychology and Clinical Language Sciences at the University of Reading at: School of Psychology and Clinical Language Sciences, University of Reading, Harry Pitt Building, Early Gate, Reading, RG6 7BE (Telephone: 0118 978 8523; Email: c.houston-price@reading.ac.uk or g.w.schafer@reading.ac.uk)
- The NHS Patient Advice and Liaison service (PALs) on the NHS Choices website, by asking your GP, a member of the research team or calling NHS 111.