

## MY-CATS Team

**Chief Investigator:**

Professor Cathy Creswell

**Trial Manager:**

Anna Placzek

Anna Watts Building, Woodstock Road,  
Oxford OX2 6GG

**Website:** [www.osiresearch.org.uk/my-cats](http://www.osiresearch.org.uk/my-cats)

**Email:** [mycats@psych.ox.ac.uk](mailto:mycats@psych.ox.ac.uk)

**Telephone number:** 01865 618614



### MY-CATS: Minimising Young Children's Anxiety Through Schools

#### Privacy Notice for parents/carers

Central University Research Ethics Committee (CUREC) Approval Reference: R62531/RE001

#### What is research data?

Research data is all the information we collect about you during research.

#### What is personal data?

Any research data that can identify you is personal data. This includes data that directly identifies you (e.g. name, audio recordings, email address), and also research data that could potentially reveal your identity if linked to other information (e.g. questionnaire responses labelled with a unique ID, and the ID is linked to your name elsewhere). Some more sensitive categories of personal data are known as **sensitive (or special category) data** (e.g. information about health, ethnicity).

#### Why do we collect, use and store your personal data?

For the purpose of research in the public interest.

Personal and sensitive data we collect helps us to understand and describe the research findings. We will also collect some personal data to allow us to contact you about the research.

#### What personal data will we ask you to give us to use in this study?

At the **screening stage**, we will ask you to give us the following personal data to help us understand and describe the research findings:

This project is funded by Kavli Trust.  
The views expressed are those of the author(s)  
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- Your child's month and year of birth, gender, ethnicity and whether they are eligible for free school meals
- Your age, relationship to your child, gender and ethnicity
- Your relationship status, household circumstances and housing tenure
- Information about your family and your/your partner's level of education and employment
- Information about the extent to which your child experiences anxiety and shyness, and whether you experience any difficulties with anxiety

We will ask you to provide the following personal information to allow us to contact you about your eligibility for the study:

- Your child's name, your child's school name and year group
- Your name, address, telephone number, postcode and email address

If you are **eligible for the study** and happy to take part, we will also ask you to give us the following personal data to help us understand and describe the research findings:

- Any changes to your relationship status, household circumstances and housing tenure
- Information about your family and your/your partner's: employment and income
- Information about your child's fears and worries, thoughts, feelings, behaviour
- Information about yours and your child's health and use of services, and your relationship with your child and general lifestyle
- If you take part in the online and telephone support, we will ask to make audio-recordings of feedback and telephone sessions with a wellbeing practitioner. If you and/or your child take part in an interview about your experiences of taking part in this research, we will also ask to make audio-recordings of these sessions.

#### **How will we keep your personal data safe?**

- Personal data will be collected from you and your child using a secure website, with end-to-end encryption, and using audio-recorders if applicable
- Families who take part in the online and telephone support will be provided with more information about how we keep your personal data in this part of the research safe.
- We will share some information we collect from families with researchers in the wider project team at the University of Reading and University of Exeter so they can help with analysing the data, but this will not include any information that could reveal your identify. Responsible members of the University of Oxford may also need

to see the information we collect from families for data monitoring and auditing purposes.

- Audio recordings will be temporarily stored on audio-recorder devices, and once transferred to a secure server, they will be permanently deleted from audio-recorders.
- We will transcribe feedback interviews, and will not include any information that could reveal your identity in transcriptions. We will use an external transcriber who has been approved to work with the University of Oxford and has signed a confidentiality agreement.
- Your personal information will be stored under a unique ID. We will have a document that links your/your child's name and contact details to your unique ID and we will store this document separately from all other information we hold about you. All other information we collect about you and your family will be labelled with this unique ID. Files with audio-recordings will be labelled using your unique ID and will be stored separately from all other information we hold about you.
- Any data or findings from the research that is published will not identify you or your child. We may use direct quotes from interviews or discussion groups in publications, but this will not include any information that could identify you or your family.

### **How long will we store your personal data?**

We will only store your personal information for as long as it is required for research purposes and appropriate safe-guards are in place.

1. Consent forms: these will be stored for a minimum of 3 years after the end of the research project.
2. Audio-recordings of feedback interviews will be stored until recordings have been transcribed, transcriptions thoroughly checked, and detailed analysis is complete.
3. Audio-recordings of interviews about your child's anxiety and telephone sessions with the wellbeing practitioner will be stored for as long as needed to check the sessions are administered in a consistent way that is most helpful for families. This means that these audio-recordings will be safely destroyed by the end of the project.
4. If you take part in the trial, with your permission, we will retain your contact details after the end of the project so that we can invite you to take part and input on future related studies.
5. Families who take part in the online and telephone support will be granted access to the website for at least 12-months, and all personal data collected via the online support programme will be stored for as long as a parent/carer retains access to the online programme. Families who are offered the online and telephone support will be provided with more information about how long we store your personal data. The document that links yours/your child's name to other information we collect about you will be stored

until all data collection is complete, all data and information has been carefully checked and the main analysis is complete, and then permanently deleted. Beyond this point, other research data we hold, including responses to screening questionnaires, will not include any information that could directly identify you or your family.

If you withdraw from the research after data collection is complete, we may continue to use and store information that you provided for the purpose of the research. This information would not include anything that could directly identify you or your family.

### **Who is responsible for protecting your personal information?**

The University of Oxford is responsible for protecting your personal data (the 'Data Controller').

### **Who should I contact if I have concerns about data protection or my rights?**

[data.protection@admin.ox.ac.uk](mailto:data.protection@admin.ox.ac.uk)

### **What are your rights under data protection law?**

You have certain rights under data protection law which are to:

- Withdraw your consent
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, (i.e. your details to be removed from systems that we use to process your personal data)
- Restrict uses of your data
- Object to uses of your data, e.g. retention after you have withdrawn from a study

Some restrictions apply to the above rights where data is collected and used for research purposes.

You can find out more about your individual rights on the University of Oxford website at <http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/> and on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>.

You also have a right to complain the ICO if you are unhappy with how your data has been handled.