

iCATS-i2i Team

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iCATS-i2i

identifying Child Anxiety Through Schools-Identification to Intervention Feasibility Study

Privacy Notice for parents/carers

Ethics Reference (R71772/RE001)

What is research data?

Research data is all the information we collect during research about you, your child and your family

What is personal data?

Any research data that can identify you or your child is personal data (e.g. name, date of birth, address). Some more sensitive categories of personal data are known as **sensitive (or special category) data** (e.g. ethnicity, information concerning health).

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?

We will ask you to give us the following personal data to help us understand and describe the research findings:

- Your child's date of birth, gender and ethnicity
- Your age, relationship status, relationship to your child, gender, ethnicity, household circumstances, housing tenure
- Information about your family and your/your partner's: level of education, employment and income

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Privacy notice – Parents V1. 23.10.2020

- Information about your child's anxiety, thoughts, feelings, behaviour, health, use of services and support, and information about your health and use of services
- If you and/or your child take part in an interview or discussion group, audio-recordings of these sessions
- If you take part in the online and therapist support, audio-recordings of feedback and telephone sessions with a therapist and more detailed information about your child's anxiety, mood and general lifestyle

We will ask you to provide the following personal information to allow us to contact you about the research:

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

To help us understand and describe the research findings, we will also collect the following personal information about your child from their school records:

- Your child's gender, ethnicity, and eligibility for free school meals, whether they have English as an additional language or not, and information about any special educational needs
- Information about your child's school attendance, punctuality and academic progress

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/or on paper, and using audio-recorders
- Families who take part the online intervention 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 on the online intervention with the University of Reading, but we this will not include any information that could reveal your identify.
- Data collected on paper will be temporarily stored in locked filing cabinets, and once securely digitised will be stored on a secure server and paper copies will be destroyed.
- 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 interviews and discussion groups, 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 interviews and discussion groups – audio-recording will be stored until recordings have been transcribed, and transcriptions thoroughly checked. This means that audio files will be destroyed by the end of the project.
3. 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.
4. Families who take part in the online intervention will be given the option to have ongoing access to the website for a period of 2 years, and personal data will be stored for as long as a parent/carer retains access to the online programme. Families who are offered the online intervention will be provided with more information about how long we store your personal data, prior to agreeing to take part in the intervention.

All other personal data we hold will be permanently destroyed at the end of the project (once data collection is complete and all data and information has been carefully checked). Other research data we hold beyond the end of the project will not include any information that could 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 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

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 stud
- 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.