

Privacy Notice (full version)

Emotion Regulation in Children (ERiC): A Randomised Clinical Trial of Mentalization Based Treatment for School-Age Children with Mixed Internalising and Externalising Difficulties

Who we are- The Anna Freud Centre, also known as the Anna Freud National Centre for Children and Families, is a registered mental health charity, and is the data Controller for the data processing in this research study (ERiC). The ERiC study aims to evaluate the clinical and cost effectiveness of Mentalization Based Treatment (MBT) in improving mental health outcomes for children aged 6-12 with mixed emotional and behavioural difficulties. This will help us to understand whether MBT is better than usual care provided in CYPMHS. MBT is an existing treatment which aims to promote emotion regulation by attending to the capacity to understand oneself and others in terms of underlying mental states. The study is a randomised controlled trial, which means that participants will be randomly allocated to either MBT or treatment as usual, in order to test whether MBT is more effective than usual treatment provided in CYPMHS. This notice informs you how we may use the personal data we collect from people who participate in this study. If you have any questions about the content of this notice you can contact us at:

- Nick Midgley: n.midgley@annafreud.org
- Write to us: Anna Freud National Centre for Children and Families, 4-8 Rodney Street, London N1 9JH.

Our Data Protection Officer is Rachel Hart, DPO@annafreud.org 020 7794 2313

We are working with three other partners in the study. Two are NHS Trusts (Barnet, Enfield and Haringey Mental Health NHS Trust and Oxford Health NHS Trust) providing CYPMHS sites, who will be the Controller of and maintain responsibility for the usual treatment and intervention delivery and data. The CYPMHS sites will share contact details of families interested in finding out more about the study with us at AFC. The other is University College London (UCL) who will store data collected during the study. Part of the ERiC research team are based at UCL.

We are collecting your personal data to enable us to conduct a research study, which evaluates the effectiveness of MBT against treatment as usual. This will help us to understand what services are helpful in CYPMHS. We collect data about you at the start, to consider if the study is appropriate for you. The information you provide during the study will be used to understand more about whether and how the intervention you receive (MBT or treatment as usual) is useful to you.

Our lawful bases for processing this data are specified in the General Data Protection Regulation:

Article 6(1)(f): Legitimate Interest. We collect your data to administrate the research study and we ensure our use does not infringe your rights and freedoms by only collecting the minimum required for the study.

Where we collect special category data, we rely on Article 9(2)(j) Research purposes and Data Protection Act (DPA) 2018 condition Schedule 1(Part 1)(4).

How we get information- We use your contact details provided by CYPMHS to us following your verbal consent to be referred to find out more about the study. We will



then collect data from you directly to see if the study is suitable for you and if so, at four timepoints during the study. This will include your responses to the questionnaires, and audio/video recordings of the research interviews.

Who we share your data with- we collect and store your data securely at UCL and the Anna Freud Centre. Information about whether you agree to take part and the treatment group you are allocated to will be shared with the CYPMHS you are attending. The identifiable data we process is only shared with the research team at your local CYPMHS site (data processor). This sharing is conducted with a contract in place governing how they must manage your data, including keeping it secure.

Anonymised and aggregate data (data that does not identify you individually) may also be used by other researchers at the Anna Freud Centre, including students, for the purposes of continued research.

We do not use third parties to process the data and we do not share it with third parties for other purposes, including direct marketing.

There are other situations when we may need to share your information; situations when:

- There is a serious risk to the health and safety of others (e.g. children and vulnerable adults)
- Information is required to be used in court
- We need to give information to the police to help detect or prevent a serious crime
- We believe there is a threat to your safety

Generally, we will ask your permission before we share your data, but in some circumstances, we are legally obliged to share information, for example under a court order. Where we do share, we satisfy ourselves that we have a lawful basis on which to share the information and document our decision making.

How long we retain your data- Your data will be held securely until the end of the research study and for up to ten years following this for analysis.

Your data rights- Under data protection law, you have rights we want to make you aware of. The rights available to you depend on our reason for processing your information and may only apply in certain circumstances. You can check the [Information Commissioner's website](#) for more detail or contact the DPO.

- Your right to be informed – this notice informs you what data we collect and how we use it.
- Your right of access – You have the right to ask us for a copy of your personal information.
- Your right to rectification - You have the right to ask us to correct information which you think is inaccurate or incomplete.
- Your right to erasure - This is known as the 'right to be forgotten' and you have the right to ask us to erase your personal information in certain circumstances, such as where it is no longer required.
- Your right to restriction of processing - You have the right to ask us to limit the processing of your information in certain circumstances.
- Your right to object to processing - You have the right to request we stop processing some or all of your data.



- Your right to data portability - This only applies to information you have given us and where we rely upon your consent to process the data but we can provide a copy of your data if desired.

You are not required to pay a charge for exercising your rights. We generally have one month within which to respond to your request.

Please contact us at DPO@annafreud.org if you wish to make a request with regard to any of your rights.

Ethics Consent

In addition to these data protection rights we also consider your ethical rights. This evaluation has been approved by the London - Bloomsbury NHS Research Ethics Committee [Project ID Number: 316392] and as part of that approval process we are required to have your consent for your participation in this evaluation.

If you, at any time, want to withdraw from the study we will respect that decision and cease to collect any further data. You can contact us using the contact details included at the top of this notice to make such a request.

Please note that, as described in the participant information sheet, we need to manage your records in specific ways for this research to be reliable. This means that we won't be able to grant all requests made about your data. We won't be able to let you see or change the data we hold about you, and if you decide to stop being part of the study, we will keep the data that we hold about you.

Making a complaint

If you feel we may not be handling your data appropriately or if you have any queries or concerns about this you can contact us, dpo@annafreud.org

You can also, at any time, make a complaint about our processing of your data to the Information Commissioner, <https://ico.org.uk/global/contact-us>

Obligation to provide data and automated decision making

You can choose to participate in the study, in which case we do require your data. We do not use profiling or automated decision making when processing your data for any purpose.

This notice was last updated on 04.10.2022