



Local Investigator:

Dr Michelle Slead

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Privacy Notice for PATHWAYS

Evaluation of Parent-Infant experiences Across Time: Health, Well-being, And Support

1. Who we are

Anna Freud ('we', 'our', 'us') is a registered mental health charity. Anna Freud is the Data Controller for data processing of the PATHWAYS study.

The PATHWAYS study will look at how information and services during pregnancy and during the baby's first 2 years can have an impact, for whom, and why.

This notice informs you how we may use the personal data we collect from you when you participate in this project. If you have any questions about the content of this notice you can contact us at:

- Michelle Slead: michelle.slead@annafreud.org Anna Freud 4-8 Rodney Street, London N1 9JH.
- Contact phone number: 020 7794 2313

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

We are working with additional organisations, named here, who are data processors of your data.

University College London, Gower Street, London, WC1E 6BT

University of Oxford, University Offices, Wellington Square, Oxford, OX1 2JD

Ecorys London, 6th Floor, Queen Elizabeth House, 4 St Dunstons Hill, London, EC3R 8AD

2. Purpose of the processing and the lawful basis for the processing

We are collecting your personal data to enable us to learn more about families' needs and experiences of information and support in your local area. The information you provide will be used to gain insight into your thoughts and opinions, which we hope will lead to better services for other parents, carers and children in the future.

Our lawful bases for processing this data are:

Art 6 1(a) Consent: we process with your clear consent for specific purpose(s).

Art 6 1 (f) Legitimate interests: the processing is necessary for our legitimate interests.

We process Special Category data relying upon

Art 9(2)(a) Explicit Consent

Art 9(2)(j) Archiving, research and statistics (with a basis in law) [research purposes] and Sched 1 Part 1 (4) DPA (2018) Research

3. **How we get information**

We use information collected directly from you via application information (name, address, phone number, email address, age, ethnicity, health data, and family circumstances), email correspondence and interviews.

4. **Who we share your data with**

The personal data we process will be fully anonymised before sharing with other organisations involved in the research. They are researchers at the University of Oxford, University College London (UCL) and Ecorys. This sharing is conducted with a contract in place, governing how each recipient may use the data.

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.

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.

5. **How long we retain your data**

Your identifiable data (your name and contact details) will be held securely by Anna Freud for up to 10 years, after which it will be anonymised. After which we review it before secure disposal.

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

6. **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 Commissioners 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 <https://ico.org.uk/your-data-matters/your-right-to-get-your-data-deleted/> you have the right to ask us to erase your personal information in certain circumstances, such as where it is no longer required. <https://ico.org.uk/your-data-matters/your-right-to-get-your-data-deleted/>

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.

Rights around automated decision making and profiling

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 study has been approved by a central NHS Research Ethics Committee and as part of that approval process we are required to have your consent for your participation in this study.

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

7. 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>

8. Obligation to provide data and automated decision making

There is no legal or statutory obligation for you to provide the data, however we only ask for the minimum information we need to provide an appropriate service to you. If we don't have the full detail required, we may not be able to do this.