



Anna Freud

Privacy Notice for the Linking Loss Study.

1. Who we are

Anna Freud ('we', 'our', 'us') is a registered mental health charity. The Linking Loss Study team is responsible for all collection and management of participant personal details (i.e., contact details), pseudonymised survey data (including special category data), and interview recordings/anonymised transcripts. Anna Freud is the data Controller for this data processing.

This notice informs you how we may use the personal data we collect about research participants ('you'). If you have any questions about the content of this notice you can contact us at:

- Hannah Hopson (Study Co-ordinator), linkingloss.study@annafreud.org, Anna Freud, 4-8 Rodney Street, London N1 9JH.
- Contact phone number: 07977948837

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

We are working with Devon NHS Partnership Trust, named here, who are the Sponsor for the study. This organisation will not control or process your data.

Devon Partnership NHS Trust
Wonford House, Dryden Road, Exeter, EX2 5AF
dpt.saferinformation@nhs.net

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

We are collecting your personal data to enable us to conduct this research study exploring the experiences of psychological support needs of different communities following pregnancy loss. The information you provide will be used to arrange and complete research activities with you (e.g., study interviews, workshops). Information provided through surveys, interviews, or workshops will be used to increase understanding of pregnancy loss before 24 weeks, and aid the adaption of a peer-led intervention to support mental health difficulties following pregnancy loss.

Our lawful bases for processing this data are:

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

We process Special Category data relying upon

Art 9(2)(a) Explicit Consent

3. How we get information

We use information collected directly from you via the research survey, interview, or workshop.

4. Who we share your data with

The data we process is shared with other organisations. This sharing is conducted with a contract in place, governing how each recipient may use the data. Interview audio files will be shared with an external service for transcription. This service is confidentiality bound and holds a contract with Anna Freud. Anonymised interview transcripts will be shared with research team members based at the University of Huddersfield for analysis procedures. Your personal data will not be shared with any other organisations.

We do not share your data 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 personal information (e.g., name, contact details) will be deleted within 12-months of the end of the study, unless you have agreed for this to be retained for future research purposes. In this event, your personal information will be stored for a maximum of 8 years after the end of the study. After which we review it before it is anonymised. Your anonymised data is held for a maximum of 10 years after the end of the study.

Providing contact information in the survey is optional. If this is not provided, the survey response will be completely anonymous. In the event that a survey participant choose to provide their contact information to receive a copy of the study results, this will be pseudonymised. All interview data will be pseudonymised. All identifiable information will be removed from interview transcripts immediately following transcription. All survey data and interview transcripts are stored under a unique identifier code, separate from contact details.

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 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.
- **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.

7. Ethics Consent

In addition to these data protection rights we also consider your ethical rights. This evaluation has been approved by the Health Research Authority Ethics Committee 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 evaluation 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.

8. 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>