

ENHANCE Workstream 1 Privacy Notice

Where do we obtain data from?

This study aims to identify and compare different models of providing EoL care for infants, children and young people, in terms of outcomes and experiences for children and parents, resource use and costs to families. The study is comprised of three separate workstreams and this notice relates specifically to Workstream 1.

The data for this workstream is obtained from:

- surveys completed by lead clinicians in neonatal units, paediatric intensive care units, and children's and teenage and young adult principal cancer treatment centres
- interviews with the Chairs of the 13 regional palliative care networks

Who will process my personal information?

Only researchers in the ENHANCE study team will process the data collected. Data collected about children who die will not be used in the study unless parents give their consent.

The data will not be transferred internationally. It will not be used for any automated decision making.

All publications and presentations will only present aggregate level data.

What is the purpose and legal basis of the processing?

Under the General Data Protection Regulation (GDPR), the University has to identify a legal basis for processing personal data and, where appropriate, an additional legal basis for processing special category data.

In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes personal data for research purposes under Article 6 (1) (e) of the GDPR:

Processing is necessary for the performance of a task carried out in the public interest

Special category data is processed under Article 9 (2) (j):

Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes

Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data.

How will you keep my data secure?

The data controllers for this study are the University of York.

The University will put in place appropriate technical and organisational measures to protect personal data and/or special category data.

Information will be treated confidentially and shared on a need-to-know basis only. The University is committed to the principle of data protection by design and by default, and will collect the minimum amount of data necessary for the project.

How can I access my personal information?

Various rights under data protection legislation, including the right to access personal information that is held about you, are qualified or do not apply when personal information is processed solely in a research or archival context. This is because fulfilling them might adversely affect the integrity of, and the public benefits arising from the research study or project.

The full list of (qualified or inapplicable) rights is: the right to access the personal information that is held about you by the University (further details are published [here](#)); the right to ask us to correct any inaccurate personal information we hold about you; the right to delete personal information, or otherwise restrict our processing, or to object to processing (including the receipt of direct marketing) or to receive an electronic copy of the personal information you provided to us.

If you have any questions regarding your rights in this context, please use the contact details below.

How long is my information kept?

Information, including personal information will be kept for 10 years.

General information about how long different types of information are retained by the University is published [here](#)

Who can I contact?

If you have any questions about the ENHANCE study, please contact the principal investigator, Dr Lorna Fraser, on lorna.fraser@york.ac.uk.

If you have any general questions about how your personal information is used by the University, or wish to exercise any of your rights, please consult the University's [data protection webpages](#). If you need further assistance, please contact the University's Data Protection Officer at dataprotection@york.ac.uk.

How can I complain?

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Acting Data Protection Officer is Durham Burt, and you can contact him at dataprotection@york.ac.uk

For information on reporting a concern to the Information Commissioner's Office, please follow this [link](#).