

Yorkshire Specialist Register of Cancer in Children and Young People Research Database Privacy  
Notice and Fair Processing Statement

This statement explains how we use any personal information we collect about you / the child you care for.

***What is the legal basis for you collecting this information?***

As set out under the UK General Data Protection Regulation (GDPR), our lawful basis for processing your data under Article 6(e) and special category data under Article 9(2)(j) is “Public Task”. This means the processing of your/ your child’s data is necessary for us to perform a task in the public interest. This task has a clear basis in law in terms of relating to cancer registration.

A summary of the entry for YSRCCYP is available on the register of approvals on the HRA website (YSRCCYP appears as app no. 002542 and its reference is: 20/CAG/0133).

Furthermore, ethical approval for the register has been granted by the Northern and Yorkshire Multi Centre Research Ethics Committee (YSRCCYP reference 26/NE/0002).

***What data are being collected?***

The Yorkshire Specialist Register of Cancer in Children and Young People, or YSRCCYP, aims to collect data on every child and young person aged under 40 years diagnosed with cancer within Yorkshire. Data are collected about each individual for the whole period of their care; this includes any cancer diagnoses (malignant, benign and relapses), hospital visits for physical or mental health reasons, operations, details of chemotherapy and radiotherapy treatments, any diagnosis of COVID-19 and clinical measurements relating to cardiac and metabolic syndrome appearing as long term effects of cancer treatment.

Personal identifiers include:

- Full and previous names;
- Address history;
- Date of birth;
- NHS number.

***Where does this data come from?***

The data originates from a variety of sources, including:

- Hospital case notes and electronic health record systems (from National Health Service Trust hospitals);
- National Cancer Registration and Analysis Service (from the National Disease Registration Service);
- ChemoCare (electronic chemotherapy prescribing data)
- Systemic Anti-Cancer Therapy dataset (from the National Disease Registration Service);

Additional linked data sources include:

- Hospital episode statistics (from NHS England (Digital));
- Mental health episode statistics (from NHS England (Digital));
- Primary Care (from The Phoenix Partnership and EMIS Health);
- Social outcomes (Department for Work and Pensions);

- Educational outcomes (Department for Education).

In order to receive data from these sources, YSRCCYP may need to share an appropriate identifier(s) to enable data linkage, such as NHS number, name and date of birth.

*What are the data being used for?*

The database will be used to carry out a programme of epidemiological and applied health research investigating incidence, survival, aetiology and long-term health and social outcomes of cancer occurring in children and young people. No personal information will ever be made public in any report or publication.

***Where are the data held and for how long?***

ARO Limited is our data processor providing cloud storage services. The University of Leeds instruct ARO to securely store all data in UK. ARO will not process this data outside of the UK and/or the EEA, without the explicit instruction of the University of Leeds. As an ongoing register of cancer, we keep these data permanently so we can study the impact of treatment and care on long-term outcomes for survivors.

***Automated decision making and profiling.***

YSRCCYP does not use automated decision making. YSRCCYP does not use profiling to make a decision by automated means.

***Sharing data with other organisations***

YSRCCYP may share data held on its database with researchers (in the UK and worldwide), other registers and other health or social care providers in order to help improve patient care and examine health and social outcomes. Occasionally, a very limited set of personal data may be processed by an authorised third party such as NHS England (Digital) to enable us to study health and social outcomes, but only with the appropriate regulatory permissions.

Identifiable data will not be shared outside of England and Wales.

***What rights do I have over my/my child's data?***

You have the right of access, the right of rectification, the right to restriction of processing and the right to object to processing. If you wish to enact any of these rights, please contact the YSRCCYP team using the contact details below.

You may also wish to visit the national data opt-out website for further information about removing your personal information from national datasets: <http://digital.nhs.uk/services/national-data-opt-out>

**Contact Details**

**The Yorkshire Register key contacts:**

**Prof Richard Feltbower**

**Professor of Epidemiology**

School of Medicine

Worsley Building

Clarendon Way

University of Leeds

LS2 9JT

Tel +44 (0)113 343 4841 [www.ysrcryp.org.uk](http://www.ysrcryp.org.uk)

Email: [r.g.feltbower@leeds.ac.uk](mailto:r.g.feltbower@leeds.ac.uk)

**Professor Adam Glaser**  
**Consultant Paediatric Oncologist**  
D Floor, Martin Wing  
Leeds General Infirmary  
Great George Street  
Leeds  
LS1 3EX  
TEL: 0113 3430367  
Email: [a.glaser@nhs.net](mailto:a.glaser@nhs.net)

***Who is responsible for the data and who processes it?***

The **Data Controller and Data Processor** for data collected is:

**University of Leeds**  
Woodhouse Lane  
Leeds  
LS2 9JT

**Data Protection Officer:** Rebecca Messenger-Clark

***What if I have any other concerns about the way my personal data are processed?***

If you have any concerns with regard to the way your personal data are being processed or have a query with regard to this Notice, please contact our Data Protection Officer, Rebecca Messenger-Clark via email at [dpo@leeds.ac.uk](mailto:dpo@leeds.ac.uk).

Our general postal address is University of Leeds, Woodhouse Lane, Leeds LS2 9JT, UK.  
Our data controller registration number provided by the Information Commissioner's Office is Z553814X.

If you are unhappy with the way you, or your child's data are being processed you have the right to complain to the Information Commissioner's Office (ICO). <https://ico.org.uk/>