

## Further Information

As part of the regulations mentioned we do offer a right to opt out. More information about this can be found in the downloads section of our website:

[www.ysrcctp.org.uk/documentation](http://www.ysrcctp.org.uk/documentation)

Opting out will not affect your child or the treatment they receive in any way. You are able to opt out at any time.

If you wish to opt out or would like discuss this further please contact Professor Adam Glaser whose details are on the back of the leaflet

### What has the Yorkshire Register shown?

Our research has shown that:

- The number of children and young people diagnosed with cancer in Yorkshire is increasing.
- Survival from cancer in young people is getting better over time.
- South Asians with neuroblastoma, bone tumours and sarcomas have higher survival rates than non-south Asian individuals.
- South Asians with leukaemia and lymphoma have lower survival rates vs. non-south Asians.

### How is the Yorkshire Register funded?

Funding for the maintenance of the Yorkshire Register is supported by the Child Health Outcomes Research at Leeds programme, Leeds Hospital Charity and the Higher Education Statistics Agency.



HESA

### For further information, please contact:

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### If you would like to speak to a hospital doctor, please contact:

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Full details of the Yorkshire Register can be found on the following website:

[www.ysrcctp.org.uk](http://www.ysrcctp.org.uk)

More details on cancer registration in England can be found at the following website:

<https://digital.nhs.uk/ndrs/about/ncras>

**Yorkshire Specialist Register of  
Cancer in Children and Young People**  
(aged 0 - 39 years)

Information Leaflet for  
Parents and Guardians



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### **What is the Yorkshire Register?**

The Yorkshire Register is a collection of information on children and young people (aged 0 - 39 years), who have been diagnosed with cancer and certain benign conditions.

It lets us know how many children and young people have been diagnosed with cancer in Yorkshire. This information is shared with the National Health Service (NHS) and the National Cancer Registration and Analysis Service (NCRAS).

### **What is the National Cancer Registration and Analysis Service?**

Cancer registration lets the NHS know how many people are being diagnosed with cancer. Whenever a person is diagnosed with cancer, the registration system records their relevant details in a database.

Cancer registration has been running for over 50 years in England.

### **Why do we need cancer registration?**

Cancer Registration is the only way the NHS can identify how many new cancers there are, the type of cancer, who has been diagnosed and where.

It lets the NHS and public see how successful it is in treating people who develop cancer. NHS staff need to know this to make sure the right services and specialists are available, in the right places.

Cancer Registration information is also important for cancer research. It helps us to understand more about the cause of cancers and the best ways of treating them.

### **What is the purpose of the Yorkshire Register?**

The Yorkshire Register exists to provide answers to specific questions pertinent to the Yorkshire population, e.g. how survival differs by ethnicity which is important as Yorkshire

has a unique and diverse ethnic profile.

### **What information is held on the Register?**

The Yorkshire Register is held at the University of Leeds and has details of over 13,000 children and young people. The University will collect information about the patient for this research study from medical records. This information will include the patients name, NHS number, address and health information, which is regarded as a special category of information.

### **Will anyone be told my child has cancer?**

The Yorkshire Register and NCRAS are very careful about every person's details. There are strict rules about passing these details on to other people, agreed by the Health Research Authority Confidentiality Advisory Group. The information that registries give out or publish does not identify anyone individually, nor enable anyone to be identified. The Yorkshire Register has a data management group to make sure the details are safe and are used properly.

### **Will my child's personal data be used in any other way?**

Your child's information may be used by the registry research team to help us to retrieve additional NHS data relating directly to their diagnosis, such as, when your child first saw their GP about their cancer symptoms, subsequent hospital admissions and GP consultations. We do this by sharing a very limited dataset with NHS England (Digital), e.g. date of birth and NHS number. This will help us to understand more about the way young people present to their GP and to monitor the health and wellbeing of survivors. Patient reported outcome measures such as quality of life assessments will be collected to help understand the impact of cancer on wellbeing.

We may also seek additional chemotherapy and radiotherapy details from national datasets to help us to determine what the most successful treatments are. Information from maternity

services will help us see what the impact of cancer and treatment is on birth outcomes. In addition, we may share limited details to obtain information held in secure government databases. For example information relating to how individuals perform at school or higher education from the National Pupil Database and Higher Education Statistics Agency; and whether they have received any Employment and Support Allowance in later life. This will allow us to look at the impact of cancer on education and social outcomes, and help plan services accordingly. Findings from tests on the cancer tissue at diagnosis will help us look at whether there is anything that can help us predict response to treatment. All new data obtained is stored according to our strict secure data protocol.

### **Who is the study sponsor?**

The University of Leeds is the sponsor for this study based in the UK. We will be using information from your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you as long as the Register is funded.

### **What about your personal rights?**

You do have the right to request access to and request to rectify information held in the register as set out in the principles General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

### **What if I don't want the Yorkshire Register to know about my child's condition?**

In order to work properly, the Register needs to know about everyone with cancer. Sharing your information with us helps us to find out how best to treat cancer now and in the future.