



The Northern Region Young Persons' Malignant Disease Registry

Parent/carers Information Leaflet

Hello,

We are the Northern Region Young Persons' Malignant Disease Registry (NRYPMDR) team. We are based in the Royal Victoria Infirmary hospital, Newcastle-upon-Tyne. We would like to tell you about our registry and how you and your child help us.

What is the NRYPMDR?

Our registry, the NRYPMDR, records the details of all children and young people who are diagnosed with cancer (and some specified benign conditions) when they are aged less than 25 years old and live in North East England and North Cumbria or are treated in one of the region's hospitals.

Registries help us learn more about cancer and provide better care. It allows us to see how many children and young people are being diagnosed with cancer in this area. The information may also be shared with the NHS England National Cancer Registration Service.

What is the National Cancer Registration Service?

The National Cancer Registration Service is the way the NHS can identify the number and type of cancers being diagnosed, who has been diagnosed and where.

It helps the NHS to see how well it is treating people who develop cancer. NHS staff need to know this to make sure the right treatments and people are available in the right place.

Cancer registration information is also very important for cancer research. Understanding how people get cancer can lead to better treatments.

What's different about the NRYPMR?

The NRYPMR focusses on understanding more about the causes of cancer in young people from the Northern Region. It allows more detailed research to be undertaken than could be achieved using only the National Cancer Registration Service. It also looks at the healthcare services that are available for people living in this region who develop cancer.

What details are collected?

The NRYPMR is a collection of personal and clinical information extracted from the medical records of children and young people who have been diagnosed with cancer before their 25th birthday and either live in North East England and North Cumbria or are treated in a hospital within that region. Personal details such as the patient's name, address details, date of birth and whether they are male or female are recorded. Clinical information, for example, the type of cancer and where it has occurred, also where and how the patient is being treated. The registry team also contacts your child's doctor to get updates so that monitoring of late effects of treatment and survival can continue.

What do I need to do to take part in the NRYPMDR?

To be part of the registry you and your child don't need to do anything. Your child's details will be automatically passed to the NRYPMDR and the Cancer Registration service by their doctor.

Further details are available in our privacy notice .An online copy is available at URL: <https://research.ncl.ac.uk/cancerregistry/patientinformation/privacynotice/>

Will it be possible to identify me?

The registry will never publish information in a way that identifies individuals. The registry has a Data Advisory Group that makes sure that all details are held securely and used properly in line with the General Data Protection Regulation and the Data Protection Act 2018. If identifiable data was to be release it would require separate Research Ethics Committee and Section 251 approvals.

Will anyone from the NRYPMDR contact me?

No. No one from the NRYPMDR will contact you or your family.

Do I have to take part in the NRYPMDR?

As we have explained, we will use your child's information to help improve treatment for cancer in children and young people. It will also help to increase our understanding of its causes, by contributing to the many types of research being carried out. In order for the registry to work properly we need to know about everyone diagnosed with cancer.

However, you can opt out at any time and have your child's personal information removed from the registry. You do not have to give a reason and it will not affect their treatment in any way.

Speak to a member of your child's care team or contact the NRYPMDR team (contact details are given below). They will explain what you have to do to ensure all your child's personal details are permanently removed. An anonymised version of the information will still be retained on the registry, only your personal information will be removed.

If you would like to know more about the registry please contact the NRYPMDR team:

Registry co-ordinator
Sir James Spence Institute
Royal Victoria Infirmary
Queen Victoria Road
Newcastle-upon-Tyne
Tyne & Wear
NE1 4LP



Email: tnu-tr.cancerregistry@nhs.net
Telephone: 0191 2821356

More details about the NRYPMDR can be found on our website: research.ncl.ac.uk/cancerregistry

More information about the National Cancer Registration Service can be found at the website address: <https://digital.nhs.uk/services/data-services-for-commissioners/datasets/national-cancer-registries-and-analysis-service-ncras>

Alternatively, contact your child's local care team through your doctor.

Thank you
for taking the time to read this leaflet about our
registry.