

## Privacy Notice

### Northern Region Young Persons' Malignant Disease Registry

#### How we collect and use your information

The Northern Region Young Persons' Malignant Disease Registry (NRYPMDR) collects personal information indirectly from hospital records such as patient medical notes, laboratory reports and letters. We use your / your child's personal information to find out how many children are getting cancers, what types they have and to learn more about the long-term outcomes for patients.

The types of personal data we collect and use include:

- Your / your child's full name
- Your / your child's address details at birth and when they were diagnosed
- Your / your child's date of birth, gender, ethnicity and NHS number
- Details of your / your child's diagnosis (including genetic conditions and hospitals attended)
- Details of your / your child's treatment and any related health issues noted during your follow-up

We have selected 'Public Task' as the legal basis for processing your information under article 6, 1(e) of the General Data Protection Regulation and Data Protection Act 2018. This means that processing your data is necessary for the performance of a task carried out in the public interest, in this case, relating to children's cancer. We are collecting and processing sensitive personal data (so called 'Special Category Data') concerning your health, ethnicity and genetic conditions. We are doing this under scientific research/statistical analysis Article 9, 2(j) of the General Data Protection Regulation.

#### How we store your information

We treat all information we hold about you as private and confidential. Your personal information is computerised and stored on secure Newcastle University servers. Some patient information may be stored on paper records until the registry works towards a paperless system. In such cases, the files are stored in locked filing cabinets in an office which requires swipe card access at the Royal Victoria Infirmary, Newcastle-upon-Tyne. Your / your child's personal information will be held by us for an indefinite period.

## Sharing your information

We share personal information with the National Cancer Registration and Analysis Service. We also release personal information to the doctors who have treated you. We have a strict data release policy for medical or university researchers who wish to access your data. We will only do so if they have gained the necessary ethical and regulatory approvals. They must provide evidence of a lawful basis on which to access your data. In most cases we will release non-identifiable information. We do not transfer personal information to countries outside of the UK. We will never contact you, unless we have your explicit consent to do so.

## Website and social media

We do not collect or store personal information when you interact with us on social media sites such as Facebook and Twitter or when you contact us by email. Our website contains links to other sites and servers. We are not responsible for the content or privacy practices of these websites.

## Your rights to the information we hold about you

The NRYPMDR is part of the Newcastle University (the data controller). Newcastle University is registered with the Information Commissioner's Office (ICO) to process personal and special categories of information under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and our registration number is Z5470161. The Data Protection Officer for Newcastle University is Maureen Wilkinson, Chief Information Security Officer. She can be contacted on [rec-man@ncl.ac.uk](mailto:rec-man@ncl.ac.uk) or by post: Data Protection Officer, Newcastle University, Blackhorse House, 91 Sandyford Road, Newcastle Upon Tyne, NE1 8HQ, United Kingdom.

You / your child have the right of access to the personal information held about you on our files and the right to have any data corrected if it is inaccurate. Inclusion in the NRYPMDR is optional. You have the right to remove your details by completing our patient opt-out form. Please send written data protection requests or any questions about our privacy policy to the address below and include your full name (and any other names you may have been known by), your date of birth and your current address.

If you are not happy with the way your information is being handled, or with the response received from us, you have the right to lodge a complaint with the Information Commissioner's Office at Wycliffe House, Water Lane, Wilmslow, SK9 5AF (<https://ico.org.uk/>).

## Contact details

Address: Northern Region Young Persons Malignant Disease Registry,  
Newcastle University, Institute of Health & Society,  
Sir James Spence Institute, Royal Victoria Infirmary,  
Queen Victoria Road, Newcastle upon Tyne,  
NE1 4LP, United Kingdom.

Tel: 0191 282 1336

Website: <https://research.ncl.ac.uk/cancerregistry/>