Yorkshire Specialist Register of Cancer in Children and Young People Research Database opt out policy

As outlined in the YSRCCYP Patient Information Leaflets, this policy exists to provide further detail about the procedure when an individual or family member wishes to opt out of having their personal information stored on the Register.

**What does the law say?**

According to current data storage and retention regulations governed by General Data Protection Regulation (GDPR) and common law section 251, the Yorkshire Specialist Register of Cancer in Children and Young People (YSRCCYP) database must afford the right of opt-out to any individual it holds data about.

**What do these laws mean for my/my child’s personal data?**

The YSRCCYP database offers a right to opt out. If you choose to opt out, you/your child’s personal data will be removed from our systems. This right to opt out exists for as long as we hold data about you/your child and can be exercised at any time.

When asked to remove you/your child’s personal data we must do this within a reasonable timeframe and let you know once the process is complete.

While you/your child are opted out, no further information will be collected in the future.

**What personally identifiable data do you hold about me/my child?**

Personally identifiable data the YSRCCYP collects and stores includes:

* Name(s)
* Date of birth
* Date of death (if applicable)
* NHS number
* Address
* Hospital identifiers – such as case note number and pathology report number

**How do I start the opt out process?**

As described in the YSRCCYP Patient Information Leaflets, to start the opt out process you should discuss this with our Medical Director, Professor Adam Glaser, who is an experienced clinician who has treated children and young adults with cancer in Leeds for many years. Professor Glaser can be contacted by phone, email or by writing directly to him at the following address:

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

**What effect will this have on my care and treatment?**

Opting out will not affect your care or treatment in any way.

**How long will this process take?**

As soon as you have confirmed in writing or email to Professor Adam Glaser that you wish to opt out, we will endeavour to have your personal data removed within 25 working days of receiving the request.

**How will I be contacted once the process is complete?**

Once the process is complete either your clinician or Professor Adam Glaser will inform you directly of the outcome.

**What if I want to opt back in?**

You are able to opt back in at any time. Please let your clinician or Professor Adam Glaser know as soon as possible and we will begin collecting data again.