

Information leaflet on:

Cancer registration for children and young people



By your side

What is cancer registration?

Whenever a patient is told they have cancer, leukaemia, brain tumours (including benign brain tumours) or similar conditions, certain information is recorded in the medical notes by the doctor or other hospital staff. This applies to people of all ages, including children.

Some of this information is then passed to the National Cancer Registration and Analysis Service and forms the basis for national statistics. In some areas, including the West Midlands, this information is passed to local cancer registries as well. This leaflet describes the information that is collected and how it is used.

Why is registration needed?

Registration is the only way that we can find out how many people are getting cancer and what types they have.

Most countries in the world have a registration system. Registration has been running for over 60 years in the United Kingdom and, because we collect details of everyone with cancer, the information available in the UK is among the best in the world. We need to tell you that we are collecting and storing your information and using it for research.

Cancer registration information is extremely valuable for research. It tells us whether more patients are being cured and helps us to understand why people get cancer. It also shows if more people have it and whether there are groupings of particular types of cancer in particular areas.

What will they need to know?

The patient's name, address, date of birth, sex, ethnic group and NHS number as well as the type of disease they have will be recorded. They may also record other relevant information about the illness (such as genetic conditions) from hospital medical notes.

They will also need to know about the treatment the patient has had such as surgery, chemotherapy (including drugs and dosages) and radiotherapy and (with your written consent) may later write to your GP to ask about progress after treatment.

Birmingham Children's Hospital will send some of the information both to the National Cancer Registration and Analysis Service (NCRAS) and to some separate specialist registries. One of these specialist registries is based here at Birmingham Children's Hospital. It is called the West Midlands Regional Children's Tumour Registry.

What will they do with this information?

The National Cancer Registration and Analysis Service and the West Midlands Regional Children's Tumour Registry are very careful with all of the information and follow strict rules about how they look after it and who can use it. The information is stored securely on computers and in paper files in locked storage cabinets. It is all treated as strictly confidential and is only available to the staff who need to know or whose research has been approved.

The reports that are published on cancer rates and outcome of treatment will never identify any particular person.

Do I need to do anything?

You do not need to do anything – there are no forms to fill in and nothing to sign. No one from either registry will contact you.

Your doctor or hospital staff will pass the relevant information to the National Cancer Registration and Analysis Service and the West Midlands Regional Children's Tumour Registry.

Do I have a choice?

Yes, you do have the right to opt-out. However, for the registration system to work properly we need to know about everyone who has cancer.

As explained, your information will be used 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.

However, if you are still concerned about having your details registered, or about any other issues in this leaflet, please discuss this with your doctor who can answer your queries. If you prefer you can talk to the Patient Advice and Liaison Service (PALS) at Birmingham Children's Hospital. They can be contacted by phone on 0121 333 8403 or by email at bwc.pals@nhs.net. An opt-out form for can be accessed from the websites mentioned on the next page. If you still decide you do not wish to have your information registered, your request will be respected, recorded and confirmed by the registries. This will not affect the treatment you or your child receives.

Where can I get more information?

If you have any questions about cancer registration, you can:

- Ask your or your child's doctor for more information.
- Speak to the Patient Advice and Liaison Service at Birmingham Children's Hospital (0121 333 8403 / bwc.pals@nhs.net)
- Visit the West Midlands Regional Children's Tumour Registry website at <https://www.bwc.nhs.uk/tumour-registry> From here you can find out further information about the registry and access the Privacy Notice which includes further details about how your data is recorded, stored and protected.
- Visit the National Cancer Registration and Analysis Service website at <https://www.ndrs.nhs.uk/>.
- Follow us on Twitter @WMRCTR
- Visit the UK and Ireland Association of Cancer Registries' website at <http://www.ukiacr.org/>

Acknowledgments

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We have updated our Privacy Notices in line with the data protection legislation (General Data Protection Regulation (GDPR)/Data Protection Act 2018. For more information about how we use your personal data please visit our website at:

<https://bwc.nhs.uk/privacy-policy>

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