



Cancer registration for children and young people

A GUIDE FOR PARENTS

What is cancer registration?

Whenever someone is told that they have cancer, leukaemia or certain other conditions, information is recorded 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 local cancer registry and forms the basis for national statistics. This leaflet describes the information we collect and how we use it.

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 50 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. The Data Protection Act 1998 means that we need to tell you that we are collecting and storing your information and using it for research.

We also need to tell you that we send some of the information both to the national cancer registration system and to some separate specialist registries.

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 in particular areas.

What do you need to know?

We record the patient's name, address, date of birth, sex, ethnic group, family doctor (GP), as well as the type of disease they have.

We may also record other relevant information about the illness from hospital medical notes.

We may record brief details about the patient's parents, including names, dates of birth, current jobs and family medical history, but we will not include the names of other family members.

We also need to know about the treatment the patient has had and may later write to your GP to ask about progress after treatment.

What will you do with this information?

We are very careful with all of the information and follow strict rules about how we look after it and who can use it. We store the information on computers with secure passwords 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.

As well as sending information to the national cancer registration system, we also send it to the National Register of Childhood Tumours and the North-West Cancer Information Service, which are specialist registries for cancer, leukaemia and other similar conditions affecting children and young people.

All CCLG treatment centres keep details of the patients treated there. Some centres also have a dedicated regional children's registry, which includes information on children and young people from their area who are treated in other hospitals.

The reports that we publish 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 the registry will contact you.

Your doctor or hospital staff will pass the relevant information to your local cancer registry.

Do I have a choice?

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

As we have explained, we will use your 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.

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. This will make no difference to the treatment you or your child receives. If you still decide you do not wish to have your information registered, your request will be recorded and confirmed by the Registry.

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; or visit the
- Children's Cancer and Leukaemia Group's website at www.cclg.org.uk
- visit the cancer registration page on the Department of Health's website at www.dh.gov.uk
- visit the UK Association of Cancer Registries' website at www.ukacr.org.uk



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CCLG leaflets are available to download from www.childcancer.org.uk.