

## **What is cancer registration?**

Whenever someone is diagnosed with cancer or a condition that sometimes leads to cancer, the doctor or hospital records the relevant details. This applies to people of all ages, including children.

Hospitals and doctors are allowed by law to pass this information on to the local cancer registry, but we need to make sure that patients know this is happening.

## **Why is registration necessary?**

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

Most countries in the world have a registration system. Registration has been running for over 50 years in the United Kingdom.

By working with cancer researchers we have been able to identify the causes of some cancers. We have also been able to look at how cancer patients are treated across the UK and how successful treatments have been for different types of cancer. Registration also helps us to make sure cancer-screening programmes are working.

Registration shows whether the number of people getting cancer is going up or down so the health service can make sure the right services and staff are available in the right place.

The information registered is vital for research into cancer. Cancer registration is supported by all the main UK cancer charities.

## **What do you need to know about me?**

We need to know some details about you (such as your name, address, age and sex). We need these details to make sure we are recording the right information about the right person.

We also need to know about the type of cancer or condition you have, the treatment you are receiving or have already received and your progress. We need this information to help us to identify possible causes of cancer and to find out about the best treatments.

## **Do I need to do anything?**

You do not need to do anything - there are no forms to fill in and nothing to sign.

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

## **What will you do with this information?**

We are very careful with the information and follow strict rules about how we keep 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 kept strictly confidential and is only available to appropriate staff.

Reports that we publish will never identify any particular person.

## **Will anyone contact me?**

No one from the cancer registry will contact you.

We sometimes release information to approved cancer researchers under strict conditions. For most cancer research, patients do not need to be contacted, but in some cases they do. If a researcher needs to contact you, they will only ever do this with the approval of your own doctor.

## Do I have a choice?

Yes, you can object and this will not affect the care you receive. However, in order to work properly, the registration system needs to know about everyone with cancer.

Your details help care teams to learn how best to treat cancer, make sure they provide the best care, and help to find out the causes of cancer.

If you are concerned about your details being registered or any other issues in this leaflet, please discuss this with your doctor.

## Where can I get more information?

If you have any questions, you can get more information by:

- asking your doctor;
- contacting Cancer BACUP on 0808 800 1234; or
- visiting the cancer registration website at [www.ukacr.org](http://www.ukacr.org). The website has a useful section on common questions about the cancer registration system

If you are a child with cancer or the parent of a child with cancer, you can get further information by visiting the UK Children's Cancer Study Group's website at [www.ukccsg.org](http://www.ukccsg.org)

Prepared by the United Kingdom Association of Cancer Registries with input from patient and parent groups around England.



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