

Will anyone contact me?

The National Cancer Registry works with researchers to improve understanding of cancer. Usually this is with information which would not identify a person.

Occasionally for some studies a researcher may need to contact patients. This is done only under strict conditions and your consent would be sought through your doctor before this would happen.

Do I have a choice?

Yes, you do have the right to opt-out 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 or write to us at the National Cancer Registry in Wales:

Email: WCISU.enquires@Wales.nhs.uk

Post to:

Director, Welsh Cancer Intelligence &
Surveillance Unit
Public Health Wales
Number 2 Capital Quarter
Tyndall Street
Cardiff
CF10 4BZ

Where can I get more information about cancer registration?

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

- Asking your Doctor
- Visiting the national cancer registry for Wales website at www.WCISU.Wales.nhs.uk

Further copies of this leaflet can be downloaded from the Welsh Cancer Intelligence & Surveillance Unit website. www.WCISU.Wales.nhs.uk



About Cancer Registration
A leaflet for patients

What is cancer registration?

When someone who lives in Wales is diagnosed with cancer or a condition that might lead to cancer, the doctor or hospital records the relevant details. This applies to people of all ages, including children.

This information is collected by the National Cancer Registry for Wales and we would like 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 including England, Scotland, Northern Ireland and the Republic of Ireland. Cancer registration in Wales began back in 1972.

By working with cancer researchers, cancer registries have been able to identify the causes of some cancers. It also allows us to look at how cancer patients are treated 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 services and staff are available in the right place.

The information registered is vital for research

into cancer. Here are a few examples of health intelligence made possible by using cancer registration information in Wales:

- Survival from all types of cancers combined has steadily improved in Wales
- Breast, prostate, lung and bowel cancers remain the most common cancers in Wales
- Melanoma skin cancer, showed the largest increase in numbers over the past ten years
- In Wales, the number of deaths from lung cancer is more than bowel and breast cancer combined

We would not know any of these facts without cancer registration.

Cancer Registration is crucial for progress against cancer, and is supported by the Wales Cancer Alliance, other UK cancer charities and cancer patient groups.

What do you need to know about me?

In order to register your case of cancer we need to know some details about you (such as your name, address, age and sex) as well as information about the type of cancer or condition you have, and your treatments.

To get a complete picture we will also look at

other conditions you may have, such as heart disease, which may affect cancer survival.

We use this information to produce cancer statistics, reports and for research. It can help us to identify possible causes of cancer and to find out about the best treatments, for example.

Do I need to do anything?

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

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

What will we do with this information?

How we use your information is controlled by law and we are governed by strict rules about how we look after it and who can use it.

We store the information on computers in a safe place with secure passwords. It is all kept strictly confidential and is only available to appropriate staff.

Reports or data that we use for analysis or publish is anonymous and will never identify any particular person, even if they have a rare cancer.