

## 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 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 contact the Northern Ireland Cancer Registry by calling 028 9097 6440.

## Why We Collect Data Without Asking Everyone?

We collect this data without asking each person directly because it would be too difficult – especially during stressful times in healthcare. If people opted out, the data could be incomplete and biased, often missing those who are very ill or disadvantaged. Having full and accurate information helps us track outcomes, avoid duplication, and link with other health services. It also supports vital public health work and improving care for everyone.

There's a very small risk to your privacy and a slight loss of personal control, but the benefits of using health data are far-reaching. It helps us learn more about what causes cancer and how to prevent it, to improve treatments, and protect communities through vital research and health monitoring.

## Where can I get more information?

### Northern Ireland Cancer Registry

Telephone 028 9097 6440

Visiting the Northern Ireland Cancer Registry website at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr) which has a useful section on common questions about the cancer registration system.

### Cancer Focus Northern Ireland

Telephone 0800 783 3339 or visit [cancerfocusni.org](http://cancerfocusni.org)  
Monday, Wednesday, and Friday (9.00am – 1.00pm)

If you are a child with cancer or the parent of a child with cancer, you can get further information by visiting the Children's Cancer Unit Charity website at <https://childrenscancerunit.com/> or the Cancer Fund for Children website at <https://cancerfundforchildren.com/>



This leaflet was adapted for use in Northern Ireland from the NHS "About cancer registration" leaflet which received the awards below.

The text of this document may be reproduced without formal permission. This leaflet is also available at [www.qub.ac.uk/nicr](http://www.qub.ac.uk/nicr)

If you require further copies of this publication, please contact the Northern Ireland Cancer Registry:

Tel: 028 9097 6440

E-mail: [nicr@qub.ac.uk](mailto:nicr@qub.ac.uk)



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# About Cancer Registration

A Leaflet for Patients and Public



## What is cancer registration?

When someone is diagnosed with cancer or a condition that might lead to cancer, the doctor or hospital records the relevant details about your care and treatment. This applies to people of all ages, including children.

This information is collected by the Northern Ireland Cancer Registry 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 cancer registry including England, Wales, Scotland and the Republic of Ireland. Registration has been running in Northern Ireland since 1993.

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. Cancer registration is supported by all the main cancer charities. [\\*see adjacent list](#)

## 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 cancer related investigations such as screening tests and the treatment you are receiving or have already received as part of your progress. Other diseases for example heart disease may affect survival so we need also to know about other diseases so we can accurately account for survival differences.

We need this information to help us identify possible causes of cancer and to find out about the best treatments.

## Do I need to do anything?

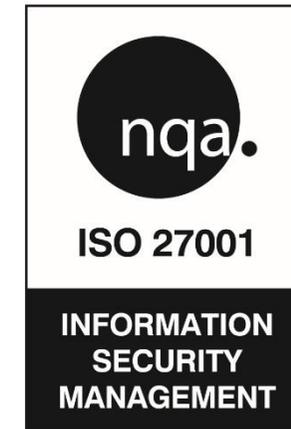
No, you do not need to do anything - there are no forms to fill in and nothing to sign. Your hospital or doctor will confidentially pass the relevant information to the Northern Ireland Cancer Registry during your care.

### Organisations that support cancer registration

- Action Cancer
- Against Breast Cancer
- Asthma + Lung UK
- Bloodwise
- Bowel Cancer UK
- Brain Tumour Research
- Brain Tumour Research Campaign
- Brainstrust
- Breast Cancer Now
- Cancer 52
- Cancer Focus NI
- Cancer Fund for Children
- Cancer Research UK
- Children's Cancer Unit
- GIST Support UK
- GUTS UK
- It's in the Bag
- Kidney Cancer UK
- Leukaemia and Lymphoma NI
- Lymphoma Action
- Macmillan Cancer Support
- Marie Curie Cancer Care
- Melanoma Focus
- Myeloma UK
- NIPANC - Pancreatic Cancer
- Oesophageal NI
- Pancreatic Cancer Action
- Rare Cancer Research Foundation
- Sarcoma UK
- Shine Cancer Support
- Skain - The Karen Clifford Skin Cancer Charity
- Skin Cancer Research Fund
- Target Ovarian Cancer
- Teenage Cancer Trust
- The Pelican Cancer Foundation
- The Pink Ribbon Foundation
- WMUK

## What will we do with this information?

We are very careful with the information and follow strict rules about how we look after it and who can use it.



The NICR have established and maintain an Information Security Management System (ISMS) which is certified to ISO27001, the highest internationally recognised information security standard.

Reports that we publish will never identify any particular person, even if they have a rare cancer.

## Will anyone contact me?

The Registry works with researchers to improve understanding of cancer. Usually this is with information that 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/hospital before this would happen.