

## Cancer Registration – what it is, the benefits of being on the register, and your options

We've made great strides in recent years in our understanding of what causes cancer and how best to diagnose and treat it. But we can only continue this progress if we have information about the people who are developing cancer. We collect this through a process called cancer registration.

Here, we explain why information about you and your cancer is recorded, how the information is used, and how, if you wish, you can see your information or have it removed from the registry.

This document accompanies a smaller leaflet and provides more detail on data confidentiality and the benefits of cancer registration.

### What is cancer registration?

If you or your child has been diagnosed with cancer, or certain conditions that can lead to cancer, the medical staff looking after your health will pass information about you on to the National Cancer Registration Service.

This will include your name, address, age, sex, and date of birth, as well as information about the type of cancer or condition you have, and your treatment.

The Registration Service has the government's permission to collect this information, and may share it with the nurses and doctors who are looking after you.

To get a complete picture we will also link this information to your other health information and to patient experience surveys such as Patient Reported Outcome Measures (PROMS) and the National Patient Cancer Experience Survey (NPCES).

Patient experience surveys can be used to compare how patients found their cancer care, both between hospitals and over time. This information can be used to identify hospitals where care is very good or where extra support might be needed. Registry data is the most accurate way to link specific information about your cancer type, diagnosis and treatment to your experience.

### Your details drive progress in cancer prevention and treatment

Cancer registration data has shown that half of people will now survive cancer for at least 10 years, without this information we would have no way to know this.

### Monitoring cancer rates

Cancer registration is the only way we can keep track of how many people are getting cancer and what types of cancer they have. It tells us how many people are diagnosed with cancer each year, how many people are living with cancer at any one time, and the survival outcomes for people with different types of cancer. We track these figures year on year, so



we can see if the number of people being diagnosed with cancer is going up or down, and if people are surviving for longer.

### Evaluating and improving cancer care

Registry information also helps us evaluate cancer services and cancer-screening programmes. For example, we look at how cancer patients are treated across the UK and how successful treatments have been for different types of cancer. Healthcare teams then use this information to improve their services.

This information is particularly important for patients with rare types of cancer. By bringing together information about these patients, the registry enables individual hospitals and doctors, who might only see one or two cases of the rare cancer themselves, to draw on the experience of other doctors when deciding how to treat their patient.

### Aiding cancer research

Cancer registration also fuels research into cancer, helping scientists investigate possible causes of cancer and improve treatments for the disease. For example, information from the registry might lead to the discovery that cancer patients who have a particular variant of a gene are more likely to respond to a certain treatment than patients who don't have that genetic variant.

### Is my information confidential?

Making sure your personal information is private and confidential is very important. Without your consent or a strict approval process, information that can be used to identify you will only be released to those providing your care, such as your hospital and doctor.

Any information collected by the National Cancer Registration Service will be kept on secure servers on the NHS network, which has a legal requirement to make sure information is stored and used correctly under the Data Protection Act (1998).

If you would like to see the information we have about you on the registry, we can give this to your doctor for them to share with you.

For more information on data confidentiality visit the United Kingdom and Ireland Association of Cancer Registries website: [www.ncr.nhs.uk/patientinfo](http://www.ncr.nhs.uk/patientinfo)

### How will it benefit me?

There is no guarantee that having your information on the cancer registry will directly benefit you. However, we know that registry information is continually leading to improvements and new information on the prevention, diagnosis and treatment of cancer and so can help future generations.

In order to give each person the best possible care, we need to know how different cancers respond to different treatments - this information is held in the registry.

If you have a family history of cancer, doctors can also use the registry to find out what treatments worked best for your relatives and tailor your care accordingly. This information may also help doctors treat any of your relatives who are diagnosed with cancer in the future.



Registry information is sometimes used to find out which patients have had a particular treatment. This helps doctors identify any patients they need to contact about the treatment should the need arise.

The registry could also make it easier for your doctor to see whether you could enrol in any clinical trials. Researchers can use registry data when planning a new trial, to see whether there will be enough eligible patients to take part. Registries can also be used to find out about patients that have already taken part in a trial, to check how well they are doing over time.

### Achievements made possible by cancer registration information:

- **Tracking cancer rates and survival**

Registry information showed that:

- Three quarters of children with cancer are now cured, compared with around a quarter in the late 1960s.
- Incidence rates of malignant melanoma (the most serious type of skin cancer) have increased more than fivefold since the mid 1970s.

- **Enabling decisions about NHS facilities**

Registry information helped the NHS decide how many proton beam therapy units (that deliver a special type of radiotherapy) to build in the UK. By 2018 there will be two proton therapy units in the UK delivering radiotherapy to up to 1,500 cancer patients a year.

- **International comparisons of cancer rates and survival**

International comparisons such as the International Cancer Benchmarking Partnership are using registry information to help us understand how we can improve cancer survival in the UK to ensure the best possible outcomes for patients.

- **Improvement of national screening programmes**

Registry information has been used to improve the breast cancer screening programme by enabling the NHS to identify and reduce the number of women diagnosed with breast cancer between screening appointments.

The decision to implement bowel scope (a method of screening for bowel cancer) as part of the bowel cancer screening programme was also made based on registry information.

- **Understanding when and where patients are being diagnosed with cancer**

Research around when and where patients are diagnosed with cancer, which showed that almost a quarter are diagnosed in an emergency and typically have poorer outcomes. This has reinforced the importance of finding ways to get more patients diagnosed early, at a time when treatments are more likely to be successful.

### What if I don't want my details on the cancer registry?

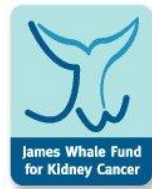
The benefits of the data collected by the cancer registry have been considerable and we are grateful that nearly everyone with cancer is prepared to share their data with the cancer registry. However, you can ask us to remove all of your details from the cancer registry at any time. These requests won't affect your treatment or care. If you wish to make such a request, you should email [optout@ncr.nhs.uk](mailto:optout@ncr.nhs.uk) or write to:

Director  
National Cancer Registration Service  
Public Health England  
Wellington House  
London  
SE1 8UG

### If you have any questions about cancer registration, you can get more information by:

- Asking your doctor.
- Visiting the Cancer Research UK website at [www.cruk.org/cancer-registration](http://www.cruk.org/cancer-registration) or the cancer registration website at [www.ncr.nhs.uk/patientinfo](http://www.ncr.nhs.uk/patientinfo).
- And for any questions on cancer, speak to one of Cancer Research UK's nurses on freephone 0808 800 4040 (9am-5pm, Monday to Friday).

Cancer registration is crucial for progress against cancer, and is supported by all the main UK cancer charities and cancer patient groups.



Beating Blood Cancers

