

Where can I find out more?

If you would like to find out why cancer registration is important or have any questions about the work we do, you can:

- visit us online at www.ndrs.nhs.uk
- talk to a member of the NHS cancer team treating you, or
- visit www.nhs.uk/your-data-matters to find out how the NHS uses information.

Can I see the information you hold about me?

Yes, you can ask to see the information we hold about you. To do this you can write to us using the 'get in touch' link on our website www.ndrs.nhs.uk, or email FOI@phe.gov.uk.

For data-protection reasons we have to give the information to a doctor or healthcare professional who knows who you are, so they can share all the information with you.



Can I ask for my information not to be included in the cancer registry?

Yes, you have the right to opt out of cancer registration at any time. The information we hold tells us a lot about what it's like for young people with cancer in England, but having information about you and your cancer included in the registry is your choice. You have the right to ask for your information to be removed. This will not affect the personal care you receive from your healthcare team.

If you do not want your information included as part of cancer registration, you can contact us at optout@phe.gov.uk or write to:

Director
National Cancer Registry and Analysis Service
Public Health England
6th Floor, Wellington House
133-155 Waterloo Road
London SE1 8UG.



For information on your rights and privacy, visit www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy
This leaflet is reviewed regularly. If you have any comments, please email NCRASfeedback@phe.gov.uk

Version 1.0, August 2019.



Your guide to your cancer information

Why it's important and what you need to know

#datasaveslives

What is cancer registration?

If you are diagnosed with cancer or a condition that may lead to cancer, the NHS team looking after you will record information about you and the care you receive. You do not need to register. Your information is automatically sent to the National Cancer Registration and Analysis Service, which is part of Public Health England.

Why it matters

Cancer registration is the only way we can know how many people are getting cancer and the types of cancer they have.

This information helps us to:

- improve cancer services
- develop new treatments and drugs
- improve the diagnosis of cancer
- look at overall trends in cancer, and
- inform national cancer policy.



How will it benefit me?

We have the Government's permission to collect and use information about people with cancer. This is because it is in the public interest to use the information to improve the way cancer is diagnosed and treated.

Healthcare staff may use information to see if you may benefit from being part of a clinical trial.

We know some types of cancer run in families. Your doctor will tell you if this is true for your cancer. With your permission, doctors can use your information to see if other members of your family may be at risk, and find the best ways to treat them.



What information is collected?

The information we collect includes:

- your name and date of birth
- your sex and ethnic background
- your address and NHS number
- information about your diagnosis, and
- information about your treatment and how well your treatment is working.



This information may be linked to other health information that we receive about you.

Is my information secure?

Yes, all your information is kept confidential.

Cancer registration helps drive research into cancer, so we may sometimes need to share your information with researchers outside Public Health England. There are very strict rules for this. It only happens if the researchers have a lawful reason to use the information. Researchers must prove that the information will be kept safe and secure to protect your privacy.