

Cancer registration

Why it matters and what you need to know

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. This applies to children and adults of all ages.

This information is shared with the National Cancer Registry, which is part of Public Health England.

The National Cancer Registry has the government's permission to collect and use information about people with cancer. This is because it is in the public interest to use this information to improve the way cancer is diagnosed and treated.

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:

- look at overall trends in cancer
- improve the diagnosis of cancer
- develop new treatments and drugs

- improve cancer services, and
- inform national cancer policy.

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 may receive about you.

It is really important that cancer is diagnosed as early as possible. Cancer registration supports the work to improve earlier diagnosis.

Percentage of cancers diagnosed at an early stage

[The following information is given in the form of a diagram in the original print.]

- 2013: 47%
- 2014: 50%
- 2015: 52%
- 2016: 53%

The diagram shows there has been an increase in the percentage of cancer cases that are being diagnosed

at an early stage, when treatment is more likely to be successful.

How will it benefit me?

We know that cancer registration is leading to improvements in preventing, diagnosing and treating cancer. This benefits everyone affected by cancer.

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

Some cancers run in families. 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.

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.

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, we can give it to a doctor (GP) 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. This will not affect the personal care you receive from your healthcare team.

If you do not want your information included in the national cancer registry, you can contact us at **optout@phe.gov.uk** or write to:

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

[Logos: Public Health England: Protecting and improving the nation's health; NHS.]

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.

PHE publications gateway number: 2018747.
Version 6, January 2019.

Crystal Mark 22491: Clarity approved by Plain English Campaign.

Print produced and published by Royal National Institute of Blind People