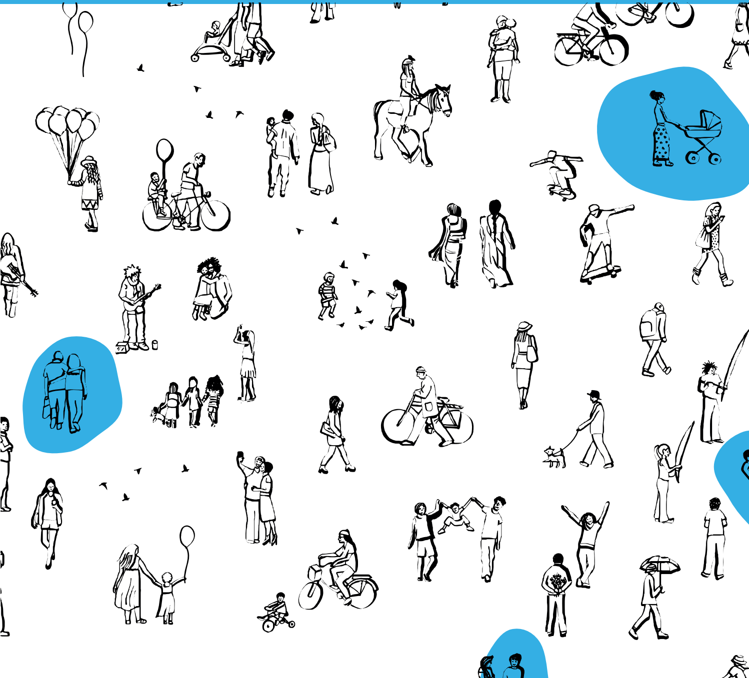
NDRS
NATIONAL DISEASE REGISTRATION SERVICE

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 NHS 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.

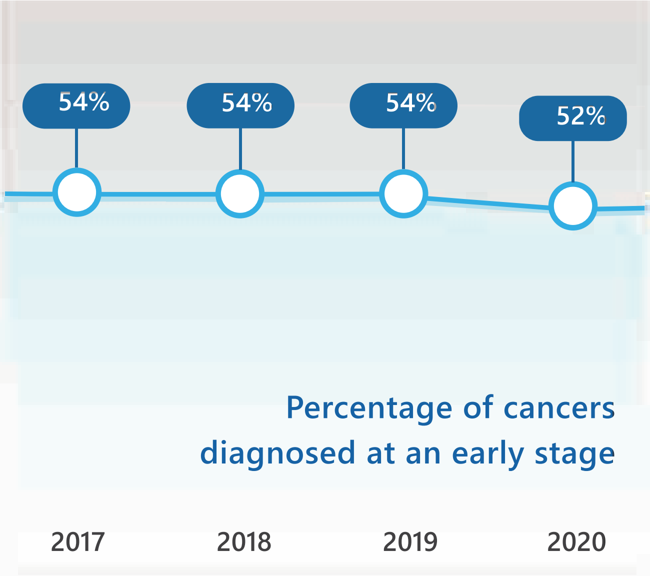
What information is collected?

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

This graph shows the percentage of cancers diagnosed at stages 1 and 2 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 NHS 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.

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 NDRSoptout@nhs.net or write to:

NDRS Data Opt-Out
5th floor
The Government Hub
23 Stephenson Street
Birmingham
B2 4BH

For information on your rights and privacy visit www.digital.nhs.uk/ndrs/patients/your-rights-and-privacy

This leaflet is available in alternative formats. Contact us at NDRSenquiries@nhs.net for more information.

This leaflet is reviewed regularly.
If you have any comments, please email

NDRSenquiries@nhs.net

Version 8, February 2023.

PN6986195

Crystal Mark
23142
Clarity approved by
Plain English Campaign

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.

NHS
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