



Frequently asked questions about cancer registration

What is cancer registration?

The National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England, collects information from the NHS about the care and treatment of all patients diagnosed with cancer. This information is included in a registry for all cancers in England.

What information is collected?

NCRAS collects information about a patient's diagnosis and treatment as well as their name, date of birth, NHS number and address.

Why is the information collected?

It helps us to measure overall trends in cancer, improve the diagnosis of the disease, develop new treatments and drugs, improve the way cancer services are planned and provided and to inform national policy.

How is the information used?

So that we can identify the causes of the disease and monitor different cancer types. This in turn, helps doctors to improve cancer diagnosis, develop new drugs, improve treatments as well as plan NHS services.

Is the information shared?

Information is sometimes shared with other organisations, like NHS England and Cancer Research UK, which use it to conduct research. Information is only shared under strict conditions and only to improve patient outcomes. Information is never sold.

Why is it important for patients to know about cancer registration?

NCRAS has a legal right to collect this information from the NHS without the patient's permission, but patients need to know this happens and how important this information is for improving cancer care. Patients can choose to opt-out of cancer registration.

Why is the information collected without consent?

NCRAS has special legal permission, as part of section 251 of The NHS Act, 2006. NCRAS can do this because collecting this information to conduct research to improve cancer is so important to public health.

Who can patients contact if they have any questions or concerns?

Patients can talk to their healthcare team, visit the National Disease Registration Service (NDRS) website: www.ndrs.nhs.uk or email NCRASenquiries@phe.gov.uk

How can a patient opt-out of cancer registration?

All patients have the right to opt out of cancer registration. This will not affect the care they receive. To request an opt-out form, email optout@phe.gov.uk, or write to:
Director, National Cancer Registration and Analysis Service, Public Health England, Wellington House, 133-155 Waterloo Road, London SE1 8UG

How does the national opt-out apply to cancer registration?

A patient's national data opt-out preferences **will not apply** to the information we collect. We will apply a patient's preferences on personally identifiable information that is shared with organisations and institutions who want to use it for research and to plan health and care services.