

Cancer Registration: why it matters and what you need to know

The National Cancer Registration and Analysis Service (NCRAS), which is part of Public Health England (PHE), collects data on all cancer patients being treated by the NHS in England. Information about their disease and the treatment they are receiving helps to:

- Improve the quality of care
- Plan cancer services
- Track cancer rates and establish survival statistics

It's really important that patients know this is happening and we'd like your help to make sure they do.



Public Health
England

Three things **PATIENTS** with cancer and their carers should know:

1. Data about them and their cancer diagnosis is automatically collected and passed to PHE.
2. This data helps doctors and researchers understand more about cancer, such as how many people have the disease or who might get it in the future and ensure they get the best care possible.
3. They can opt out if they wish and it won't affect the quality of care they receive.

Three things **STAFF** should know about cancer registration:

1. Every patient diagnosed with cancer should be given our leaflet about cancer registration. Contact NCRASenquiries@phe.gov.uk for more leaflets.
2. Patients prefer to be told about cancer registration by a member of their healthcare team in a face-to-face conversation. As far as is practically possible, patients should be told at the earliest appropriate time *after* diagnosis*.
3. Patients should feel able to ask their healthcare team questions about their rights and the way the data about them and their disease is used. They should be helped to get further information if they want it.

Three things **TRUSTS** should be doing to ensure they are compliant with guidelines on cancer data:

1. Use our form to record who is responsible for the process of informing patients about cancer registration and checking that the guidelines are followed.
2. Use our form to record information about how existing and new staff are told about cancer registration so they can talk about it with patients.
3. Use our form to record the arrangements in your trust for providing information to patients. Please return this to us at NCRASfeedback@phe.gov.uk



There are a few other ways trusts can raise awareness of cancer registration:

1. Working with the Patient Advice and Liaison Service (PALS)

Patients may prefer to speak to the PALS about cancer registration. It may help to give your PALS team a copy of the FAQs sheet included with this guide.

2. Local information materials

Trusts might consider including information about cancer registration in their own patient information materials. The suggested statement below could be included in relevant leaflets, web pages and appointment letters.

3. Signposting to other sources of information

There are a number of PHE and partner led sources of information on cancer registration:

- The National Disease Registration Service (NDRS) website www.ndrs.nhs.uk
- Review of Informed Choice for Cancer Registration*
- Macmillan Cancer Support and Cancer Research UK online resources
- Local patient information centres, such as Macmillan or Maggie's
- Contact NCRAS about accessing further support or information about cancer registration. Speak to your local NCRAS Data Liaison Manager or email us at NCRASenquiries@phe.gov.uk



*www.ndrsdocs.org/icreview

Suggested statement about cancer registration to include in trust materials

When a person is diagnosed with cancer in England information about them is automatically collected by the National Cancer Registration and Analysis Service, which is part of Public Health England. This data tells us how many people are diagnosed with cancer, what treatments they are having, what drugs are effective and whether the overall picture is getting better or worse.

This information is vital to help plan cancer services and identify where further progress is needed so that we can improve the lives of all people affected by the disease.

For more information on Cancer Registration in England visit www.ndrs.nhs.uk or pick up a cancer registration leaflet in your clinic.