



RESEARCH USING FIGURES FROM THE NCR

The data from the NCR are used for scientific research and statistics relating to cancer. The research studies focus on all types of cancer. Some investigate the quality of the care provided. Others are about patients' quality of life during and after cancer treatment.

This research helps us gather more and more knowledge about cancer, so that we can recognise cancer at an earlier stage, find better ways to treat cancer, and prevent cancer more often in the future.

issued by
Netherlands Comprehensive Cancer
Organisation (IKNL)
info@iknl.nl, www.iknl.nl/en
june 2020



cancer registry

In this leaflet you can read more about the Netherlands Cancer Registry (NCR) and how it is relevant for you



information for patients



Doctors and nurses in hospital record your data in a medical file. This is required by law. Certain data from the medical files of cancer patients are included in the Netherlands Cancer Registry (NCR).



The data in the NCR are used for scientific research and statistics about cancer and cancer treatment. This helps us learn more about the disease, which in turn leads to better treatment and to better care for people with cancer – for now and in the future.

THE NETHERLANDS CANCER REGISTRY (NCR)

The NCR is a national database that contains reliable data of all cancer patients. Since 1989, the database has contained data on patients from all over the Netherlands. The Netherlands Comprehensive Cancer Organisation (IKNL) manages this database.

The data in the NCR help us understand how the care for cancer

patients can be improved. How common is cancer? What are the risk factors? How can it be treated? And what is the life expectancy? The data will be stored in the database for as long as the NCR continues to exist.

On www.iknl.nl/en/ncr you can read an extensive explanation on the registry.

● PROTECTION OF YOUR DATA ● SUPERVISORY COMMITTEE

IKNL uses your data in accordance with the General Data Protection Regulation (GDPR) and other applicable laws and regulations that set out how your data must be protected.

Your data are protected against loss, abuse, modification, distribution, destruction and theft, as well as against use or access by people who are not authorised for this. IKNL has taken various technical and organisation security measures to ensure this.

IKNL meets the requirements for information security. All employees have signed a confidentiality statement. IKNL does not use more data than is necessary, and we do not use data for any other purpose than for which the data were collected.

● YOUR PRIVACY

Only IKNL employees who are authorised for this can access a particular part of the medical file in the hospital. They then record certain data from the medical file in the NCR. Data are also combined with data from other registries.

Every hospital has given authorised employees permission to inspect your file in order to record relevant data in the NCR. These employees have a duty of confidentiality. Researchers can only view NCR data without knowing who these data relate to. This is because a code has been assigned to personal data after their registration.

Anyone who wishes to use data for research purposes must submit a request for this. An independent committee – the NCR's Supervisory Committee – then determines whether the data can be supplied. Patients are also among the members of this Committee. The data provided will be anonymous. This means that the researchers using the data will not know whose data it concerns. Sometimes it is necessary for scientific studies to combine data from the NCR with data from other registries. In this case too, the Supervisory Committee will protect your privacy.

● YOUR RIGHTS

Data from the NCR are used for scientific research that leads to increased knowledge about cancer. If you do not want your data to be included, you can object to this.

- You have the right to inspect your data and/or to have your data removed.
- You can request to amend your data in case of inaccuracies.
- You have the right to object against the inclusion of your data.

You can send any such requests to the data protection officer via fg@iknl.nl. We will respond to your request as soon as possible, but at least within one month.

For more information, you can visit www.iknl.nl/privacyverklaring. If you feel that IKNL is not handling your data properly, you can submit a complaint to the Dutch Data Protection Authority.

WHAT DATA DOES THE NCR CONTAIN?



The name of the hospital



Data about your disease

Such as the type of cancer and the stage it was in when you were diagnosed.



Information on how your cancer was diagnosed



Information on your treatment



Date of birth and your age at the time of your diagnosis



Your sex



After registration of your data, a code will be assigned to your **personal data**, like your name and address. This ensures that researchers cannot see whose data they are using.

CONTACT INFORMATION

You can contact IKNL for all questions about the use of your data in the NCR.

- Please address your letter to: Integraal Kankercentrum Nederland attn. the data protection officer, Mailbox 19079 3501 DB, Utrecht, the Netherlands
- Or send an e-mail to: fg@iknl.nl