

Patient information

before data transfer to the state cancer register NRW

Dear patient,

Your doctor is legally obligated* to report new cancer diagnoses and data on treatment provided to the state cancer register NRW and inform you about the report. This information for patients explains the tasks and objectives of the state cancer register NRW, how your data is handled, the use of your data, your right to appeal and your right to information.

→ What are the tasks of the state cancer register NRW?

The state cancer register NRW (LKR NRW) was established in 2016 during the course of the legal obligation for all federal states to set up a treatment-related cancer register. It has been commissioned by the North Rhine-Westphalian Ministry of Health to collect information on cancer diagnoses and treatments. This data is provided to doctors providing treatment and scientific research. The primary objective is to improve the quality of health care for cancer sufferers and better identify successful cancer therapies.

→ Why is the LKR NRW collecting data on cancer diseases?

The chance of recovery for most cancer diseases has increased in the last years. The more information is available on a disease and its treatment, the higher the chances of continually improving the therapy of cancer diseases with the information obtained. All doctors you come into contact with during the course of treatment can view your data in the LKR NRW – this is an advantage for you, for example, in case of relocation or a change of doctor.

→ Which data does the LKR NRW receive from your doctor?

1. Medical data

- Date of diagnosis
- Type of diagnosis back up
- Type, location and manifestation of the tumour
- Type, start, duration and result of therapy incl. possible side effects
- Progression of the disease

2. Personal data

- Name
- Date of birth
- Gender
- Address
- Medical insurance details
- Nationality

→ How is your data protected?

The protection of your data is crucially important to the LKR NRW. Which data is allowed to be collected and how it should be protected is legally stipulated*. This ensures that unauthorised parties cannot see the data sent by your doctor to the LKR NRW. Security is also crucial when saving your data: All data is secured against unauthorised access in multiple ways. Furthermore, medical and personal data are stored separately. Your privacy is maintained during all phases of data storage. The state representative for data protection and freedom of information for NRW has reviewed the legal regulations on data protection and found them to be appropriate.

→ What is your data used for?

Your data saved in the LKR NRW is primarily important information for all doctors who treat you during the course of your illness. Many research projects also intend to improve the medical care of cancer sufferers. Interested researchers can make an application to the LKR NRW stating that their research project is expected to make a considerable contribution towards early detection or treatment of cancer diseases. The application must also show that the research would not be possible or would at least be considerably more difficult without the LKR NRW data. The advisory council and academic committee of the LKR NRW then consult on the application. Whilst the advisory council consists of representatives from self-help organisations, medical insurance companies and the medical profession, the academic committee has high profile scientists from cancer research. For some research projects, it may be the case that information is required in addition to the LKR NRW data – if, for example, investigations should be made on how certain cancer therapies influence quality of life. In these cases, the LKR NRW will

write to you and ask if you agree to transfer of your personal and medical data. Your data will only be passed on if you explicitly agree – and exclusively to the applicant. This person will contact you directly, to send you question sheets for example.

→ What are your rights to appeal?

If you do not want your doctor to be able to view the entire course of your cancer treatment or for the LKR NRW to contact you regarding a research project, you can make use of your legal right to appeal*. In this case, the formation or storage of the so-called identity code will be waived. This means that your name, address and your insurance information will only be saved as a number by the LKR NRW after settlement with the funding agency and that the details cannot be recovered in plain text. You can either express your appeal to the doctor treating you or contact the LKR NRW directly. It is your own decision whether to lodge an appeal against the storage of the identity code at any time. Please consider that especially information from individual studies with surveys of cancer sufferers can make an important contribution towards improving care. Because it is about the primary objective of the LKR NRW, namely the further development of early detection measures and the improvement of care for cancer patients, medical and personal data will also be registered with the LKR NRW in the case of appeal. Details of your name, address and medical insurance will be required directly after registration for billing purposes. Afterwards, only numbers will be produced from your name, data of birth and other identity data, which allows the LKR NRW to assign any subsequent registrations to your case. Vice versa – deriving your name and other details from the numbers produced in this way is ruled out according to the current status of technology. Only statistical information on the occurrence of cancer as well as cancer treatment and its quality can be derived from your data. However, participation in scientific studies and especially your doctor's ability to view the course of treatment documented by the LKR NRW will no longer be possible.

→ What are your rights to information?

Of course you can find out at any time which of your information is saved in the state cancer register NRW. Please make an information application to the LKR NRW with the following information:

- Current (and any former) first and surname,
- Date and place of birth
- Current and previous addresses
- Copy of your ID card or passport
- Name of your medical insurance
- Your policy holder number
- Your signature

Further information on cancer registration in North Rhine-Westphalia can be found on the state cancer register NRW homepage: www.krebsregister.nrw.de

Landeskrebsregister NRW gGmbH
Datenannahmestelle
Gesundheitscampus 10
44801 Bochum

* The legal basis of the state cancer register NRW is the state cancer register act NRW (LKRGR NRW). You can view this on the state cancer register NRW homepage.

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E-Mail: patienten@krebsregister.nrw.de

Do you have any questions about cancer registration or suggestions? [Get in touch with us.](#)