

The Epidemiological Cancer Registry of Lower Saxony (EKN)

Information for patients – reporting to the Epidemiological Cancer Registry of Lower Saxony

Dear patient,

Cancer continues to be one of the most common diseases in Germany. Its diagnosis radically changes the life of the person affected and their family. Thanks to advancements in medical technology, the prognoses for many serious illnesses have improved significantly. There are, however, still many unanswered questions which the Cancer Registry can help clarify. We sincerely thank you for sharing your details with the EKN!

Why does an epidemiological cancer registry need your details?

A population-based (epidemiological) cancer registry records all cases of malignant tumour diseases within a population group. This information is not only necessary to investigate the causes of cancer, but also serves to improve treatment strategies and measures for prevention and early detection, and to identify geographic and chronological trends within our country. In addition, it allows health facilities in Lower Saxony to better cater to cancer patients' needs.

What is registered in Lower Saxony, and how is this done?

Since 2003, all cancers nationwide have been recorded in the Epidemiological Cancer Registry of Lower Saxony (EKN) under a strict privacy policy. A modified law was introduced in 2013, stipulating that all doctors and dentists who detect and treat a cancer or benign brain tumour are obliged to report this to the EKN. Along with your personal details, the report must also contain the diagnosis date, diagnosis, histological findings, affected organ, stage of the disease, and the diagnosis method. Other information, e.g. relating to the therapy, may also be provided. The EKN's "trust centre" (Vertrauensstelle) at the Lower Saxon State Health Office assesses the incoming reports, encrypts them, and sends them to the EKN's registry office, where they are permanently stored (in encrypted form) and scientifically analysed. Some legally governed tasks, e.g. assessing diagnosis or treatment methods, may require the personal details to be decrypted at the trust centre. The Lower Saxon Ministry for Social Affairs, Women's Affairs, Health and Integration is the supervisory authority for the cancer registry.

Where can you see the results?

The cancer registry publishes an annual report. These reports and an interactive database can be viewed online (<http://www.krebsregister-niedersachsen.de>). The cancer registry can assist the relevant health authorities with analyses in the event of local or regional issues, providing data for approved scientific research products and to ensure the quality of medical care.

It works very closely with the Tumour Centre at the Hannover Medical School, the Göttingen Comprehensive Cancer Centre (G-CCC), and the Oncology division of the Lower Saxony Association of SHI Physicians. At a federal level, the EKN collaborates with the Robert Koch Institute, which, in conjunction with the Gesellschaft der

epidemiologisches Krebsregister in Deutschland e.V. (GEKID), publishes the "Krebs in Deutschland" ("Cancer in Germany") booklet.

Can you object?

Your doctor (or dentist) is obliged to report all cancers and brain tumours. Details about your illness are always saved so that the cancer registry can perform its basic tasks. By having your encrypted personal details stored, you'll be allowing the cancer registry to contact you for certain studies or in the event of regional cancer clusters. Conversely, this data will also enable you to receive information from the cancer registry about your stored details. You can, however, object to your personal details (name and address) being saved, meaning the contact and information options will no longer be available. You can lodge this objection with any doctor or with the cancer registry's trust centre.

Where can you find further information?

EKN on the Internet: www.krebsregister-niedersachsen.de

EKN trust centre:

Niedersächsisches Landesgesundheitsamt

Andreaestr. 7

30159 Hannover

Email: vertrauensstelle.ekn@nlga.niedersachsen.de

Dr Jopp, telephone 05 11 / 45 05 – 356

EKN registry office:

OFFIS CARE GmbH

Industriestr. 9

26121 Oldenburg

Email: registerstelle@krebsregister-niedersachsen.de

Mr Kieschke, telephone 04 41 / 36 10 56 – 12

(Lower Saxon Ministry for Social Affairs, Health and Women's Affairs)

Niedersächsisches Ministerium für Soziales, Gesundheit und Gleichstellung

Postfach 141

30001 Hannover

Dr Windus, telephone 05 11 / 120 – 30 43

(Centre for Cancer Registry Data at the Robert Koch Institute, Berlin)
Zentrum für Krebsregisterdaten im Robert Koch-Institut Berlin
Telephone 030 / 1 87 54-33 42
www.krebsdaten.de

German Cancer Research Centre
Cancer Information Service
Telephone 0800-420 30 40
www.krebsinformationsdienst.de

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