

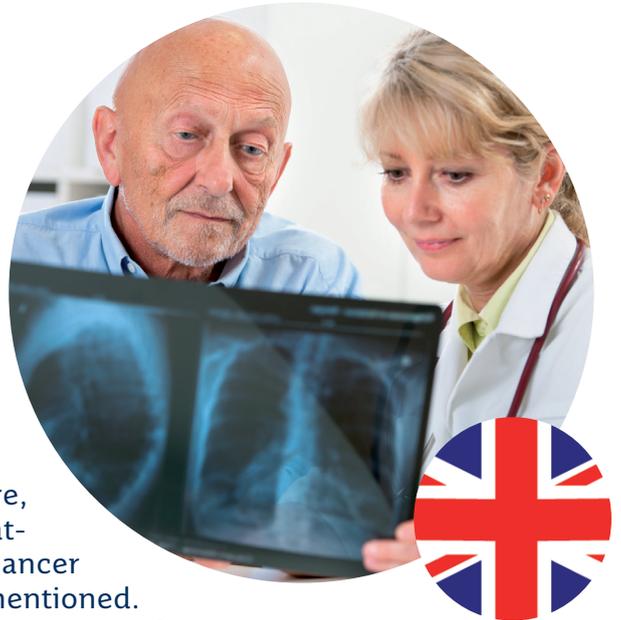


## Fast facts for patients

Dear Patient,

Steady progress in the early detection and also diagnosis, treatment and aftercare of cancerous diseases has had a positive effect on an ongoing improvement in the chances of recovery and quality of life of cancer patients.

By keeping a comprehensive and detailed record of tumour diseases, their treatment and further behaviour the Saarland Cancer Registry is making a crucial contribution to the research of causes and consequences of cancerous diseases in the population. Furthermore, the Cancer Registry can establish the efficacy of the treatment options applied, as well as the quality of care for cancer patients in Saarland and the improvements previously mentioned. As one of the first population-based cancer registries in Germany, the Saarland Cancer Registry performs these tasks with great success.



### Data collection

The following types of data and other information are collected by the Saarland Cancer Registry during the diagnosis, as well as confirmation of the cancerous diseases, after the start and completion of treatment and in the further course of cancerous diseases:

- Identity data (e.g. name, date of birth, sex, address, health insurance details)
- Epidemiological and clinical data (e.g. sociodemographic characteristics of the patient, location and morphology of the tumour, date of diagnosis, spread of the disease, specific treatment procedures undertaken)
- Follow-up data (e.g. date and location of recurrence of the tumour, vital status of the patient)
- Data of the doctor treating the patient (e.g. name, address)

The tasks of the registry and the data to be collected are determined by the Saarland Cancer Registry Act. In order for the Saarland Cancer Registry to be able to perform its statutory tasks effectively all doctors working in Saarland are under an obligation to communicate information determined by law on cancerous diseases. Objections may not be raised against registration in the cancer registry.

### Patient rights

As an affected patient, you are making a significant contribution to the fight against cancer by providing information on your tumour disease – for yourself and, especially, for people who have not developed cancer as yet.



Comprehensive organisational and technical measures have been put in place by the Saarland Cancer Registry to fulfil the stringent requirements for the protection of collected and processed data: Incoming data are checked, amongst other procedures, for consistency and completeness in the trust centre. The data on the disease, its treatment and progress are subsequently forwarded to the registry centre in pseudonymised form and evaluated. In the registry centre it is no longer possible to attribute the data to a specific person. Data acquired by the cancer registry may only be transmitted to a third party under strict and verifiable conditions (e.g. for studies and analyses on nationwide cancer incidence and research projects undertaken by the Centre for Cancer Registry Data at the Robert Koch Institute or the evaluation of the efficacy of cancer screening tests at a centre specified by the German Federal Joint Committee).

As a patient, you are entitled at any time to object to the permanent storage of identity data in plain language or to receive information regarding the data stored on your person and cancerous disease. If you so wish, please speak to the doctor treating you or to the trust centre of the cancer registry.

Detailed information for patients is available in the German language on the website of the Saarland Cancer Registry at:

<https://krebsregister.saarland.de/patientenbroschuere/>



#### Contact information

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