



## Patient Information about the

## Bremen Cancer Registry

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### **Bremer Krebsregister**

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## Brief information about the Bremen Cancer Registry

- Cancer registries collect data on cancers, including the early stages, and also on benign brain tumours. They reflect the quality of the treatment and therefore contribute to improving the care of cancer patients and also to helping to prevent and limit cancer.
- In accordance with Book V of the German Social Code (Sozialgesetzbuch V), all federal states are obliged to maintain cancer registries. The federal state of Bremen has a cancer registry. The cancer registry follows German and federal state guidelines.
- The data set is nationally standardised and contains information about the individual and the cancer.
- All doctors in the state of Bremen are obliged to report data.
- The Bremen Cancer Registry (BKR) consists of a notification centre (Bremen Association of Statutory Health Physicians), which also acts on behalf of patients, and an evaluation facility (Leibniz Institute for Preventive Research and Epidemiology - BIPS), where the data is processed anonymously.
- Evaluations are conducted at the BKR evaluation facility without any reference to names. The data is also made available (on request) for nationwide evaluations and research.
- You can withhold your consent to the storage of your name, either via your doctor or directly at the cancer registry. In that case, only data on the tumour will be stored permanently.
- There are additional requirements for participants in the breast screening programme.



## **Detailed information for cancer patients**

Dear Patient,

You have been informed by your doctor that you have a tumour. The Bremen Cancer Registry Act applies to all cancers, including the early stages, and also benign brain tumours. Advances in the early detection, diagnosis, therapy and care of cancer in recent years have increased the likelihood of a cure for most types of cancer.

To ensure good quality care and to continue improving the care of cancer patients, all German federal states are obliged by law to establish clinical cancer registries. These registries collect and evaluate data on the occurrence, treatment and development of different types of cancer. Only by collecting reliable information is it possible to obtain knowledge about cancer and its medical treatment and make further progress.

In addition to the clinical cancer registries, there are also population-based cancer registries. These cancer registries investigate the frequency and distribution of different types of cancer with the aim of preventing and isolating them.

This brochure is to inform you about the objectives and operating procedures of the Bremen Cancer Registry and explain how your data will be used.

### **The Bremen Cancer Registry**

In Bremen, the clinical cancer registry has been in existence since 2015, together with the population-based cancer registry, which has recorded the occurrence of cancer for the federal state of Bremen since 1998.

The Bremen cancer registry consists of a notification office and an evaluation facility. The data, including names and addresses, is processed at the notification office. The evaluation facility only evaluates data without a name reference. The Bremen cancer registry is based at the Leibniz Institute for Preventive Research and Epidemiology - BIPS. This also performs the functions of the evaluation facility. The Bremen Association of Statutory Health Physicians is responsible for performing the functions of the notification office. The Senator for Health, Environment and Consumer Protection oversees the Bremen cancer registry.

## **Legal Basics**

The functions of the cancer registry are nationally regulated by German federal cancer registry data law and also Book V (§ 65c) of the Social Security Statute. The specific regulations for the federal state of Bremen are set out in the cancer registry law. This law specifies that all clinics and practices in the federal state of Bremen which diagnose or treat patients with cancer should report their data to the Bremen cancer registry.

## **These data are reported**

The doctors involved in your treatment will report to the Bremen cancer registry at the following points during the progression of the disease:

Prognosis of the cancer, confirmation of the diagnosis by means of histological or cellular tests, start of treatment, termination or cancellation of treatment, any change in the status of the disease with consequences for the treatment, or the recurrence of the disease. Also, where applicable, in the event of death resulting from or while suffering from the disease.

The amount of information required is standardised throughout Germany. It includes:

### Personal details

- Name
- Address
- Date of birth
- Sex
- Health insurance
- Health insurance No.

### Medical information about the tumour

- Diagnosis, location and extent of the tumour,
- Date of diagnosis,
- Type of diagnosis
- Type, start, duration and outcome of treatment,
- Progression of the disease
- Date of death, where applicable
- Reporting institution

## **What happens to your data?**

The data should be reported to the notification office at the Bremen Cancer Registry. In order to ensure uniform evaluation, the data is checked and the information encrypted using the relevant medical classifications. In the case of patients who are not resident in the federal state of Bremen, or who were treated outside Bremen, the information will also be reported to the appropriate state cancer registry.

Details about you, your cancer diagnosis and the diagnostic data will also be forwarded to your health insurance company. This is because the work of the clinical cancer registry is sponsored by the health insurance companies.

At the request of the notification centre, the data will be made available to your doctor for the purpose of promoting interdisciplinary cooperation during treatment and also for quality assurance.

Once the work at the notification centre is complete, any identifying data, such as your name and address, will be encrypted (pseudonymised) and, together with the medical data, made permanently available for various types of scientific analysis by the evaluation facility. The type and scope of the analysis are established by the Bremen cancer registry law.

The purpose of the evaluation of data relating to your treatment and the progression of the disease is to find out more about the causes of cancer, develop more effective early detection, and improve the quality of treatment. A scientific advisory board involving patient representatives will also assess the evaluations by the cancer registry prior to publication.

In addition to these evaluations, all cancer registries in Germany are legally obliged to forward encrypted identity data and certain medical data to the following institutions:

- Centre for Cancer Registry Data at the Robert Koch Institut. Nationwide epidemiological analyses using the data from all cancer registries of the German states are performed there.
- Joint National Committee or a facility designated by the committee. Evaluations of treatment and historical data at federal level are performed there.
- Umbrella association of the statutory health and nursing care insurance funds. The GKV umbrella association is legally obliged to submit a report on the results of the nationwide clinical cancer registration every five years.

The data from the evaluation facility can also be provided to research facilities for research projects, if this is authorised by the senator for science, health and consumer protection.

## **Protection of your data**

Data processing at the Bremen cancer registry is strictly confidential and is carried out under the supervision of a medical doctor. The technical and organizational measures to protect the data comply with the current safety standards. The use of data for quality assurance and research purposes is carried out anonymously and under strict legal conditions.

If your name is required for special research projects, you will be asked to give your consent in advance. This data will only be used with your explicit consent. You naturally have the right at any time to request information about the data about you stored at the Bremen cancer registry.

## **Your right to object to data storage**

Complete registration is essential to obtain reliable evidence about the incidence of cancer and the treatment of patients. Only recording certain aspects of the progression of the disease - for example, those with a particularly good outcome - in the cancer registry should be avoided. This would present a misleading image of the treatment and be detrimental to research and the improvement of treatment options.

Any exceptions to the medical reporting obligation for the Bremen cancer registry are therefore not legally permissible. However, as a concerned party, you can raise objections to the storage of identity data either via your doctor, or directly at the cancer registry. Your data will then be pseudonymised at the reporting centre, once the invoicing and refund procedures have been performed. This means it will no longer be possible to identify you personally. Medical data relating to the cancer will continue to be stored for evaluation. If you present an objection, your data will not be available to the attending doctors and hospitals.

Further information and information can be obtained from the Bremen cancer registry.

## **Important additional information for participants in the breast screening programme**

The Bremen cancer registry is involved in the quality assurance of the breast screening programme as part of the German federal requirements. If a participant's breast cancer is not determined during the screening program, but during a visit to the doctor between two screening dates, the doctor is obliged to forward documentation of the findings to the relevant breast screening reference centre. The transfer takes place in encrypted (pseudonymised) form. You can obtain further information from your screening unit.