

# Patient information on the Bremen Cancer Registry (Bremer Krebsregister)

Entity responsible for providing information to the patient  
(Clinic / practice stamp)

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## Brief information on the Bremen Cancer Registry (Bremer Krebsregister)

- All physicians resident in the Federal State of Bremen are obligated to report data on cancer cases to the Bremen Cancer Registry (Bremer Krebsregister).
- Cancer registries evaluate data pertaining to cancers, their precursors and benign brain tumours. They reflect the quality of care, thus contributing to improving the care of cancer patients and helping to prevent (and limit) the occurrence of cancer.
- According to the German Social Code (SGB, Book V), all federal states are obliged to maintain cancer registries. There is also a cancer registry in the Federal State of Bremen. Cancer registration follows state and federal legal requirements.
- The registered data set is national and includes information on the person and the respective tumour.
- All treating physicians are obligated to inform patients about registering information with the Bremen Cancer Registry (Bremer Krebsregister) in accordance with section 10 of the Bremen Cancer Registry Act (Bremer Krebsregistergesetz) and Art. 13 of the EU Basic Data Protection Regulation.
- The Bremen Cancer Registry (BKR) consists of a so-called “trust centre” (Kassenärztliche Vereinigung Bremen), which also keeps the names of patients, and an evaluation centre (Leibniz Institute for Prevention Research and Epidemiology – BIPS), which processes and evaluates data without any reference to names.
- In addition, the data is made available for nationwide evaluations and also for research (upon request).
- You can object to the storage of your name and address via your doctor or directly at the cancer registry. Only data regarding the tumour will then be permanently stored.
- Additional provisions apply to participants in early detection programmes, e.g. the mammography screening programme (see page 10).

## Detailed information for tumour patients

Dear patient,

You have been informed by your doctor that you have a tumour. According to the Bremen Cancer Registry Act, this includes all cancers, their precursors and benign brain tumours. Skin cancer is an exception, with a predominantly very favourable course of the disease. If the tumour is removed, a cure can usually be assumed. Such tumours are, therefore, not recorded in the Bremen Cancer Registry (Bremer Krebsregister). There are only a few special subgroups of skin cancer – which can also follow an unfavourable development due to the spread at the time of diagnosis or due to fine-tissue-related peculiarities – for which there is an obligation to register the information.

Advances in early detection, diagnosis, treatment and follow-up care have increased the chances of curing most cancers in recent years. In order to ensure an excellent quality of treatment, to create transparency regarding the type of care for cancer patients and to bring about further improvements, all federal states have been legally obligated to set up clinical cancer registries. These collect and evaluate data on the diagnosis, treatment and course of cancer. Only when reliable information is available can knowledge about cancer and its medical care be gained, and further progress be made.

With this brochure, we would like to explain the aims and working methods of the Bremen Cancer Registry (Bremer Krebsregister) and inform you about the use of your data.

## The Bremen Cancer Registry (Bremer Krebsregister)

In Bremen, clinical cancer registration is carried out together with the population-based cancer registration, which has been recording the occurrence of cancer cases for the Federal State of Bremen since 1998. The Bremen Cancer Registry (Bremer Krebsregister) consists of a trust centre and an evaluation centre. Data with names and addresses are processed in the trust centre. The evaluation centre only evaluates data without reference to names. The Bremen Cancer Registry (Bremer Krebsregister) is located at the Leibniz Institute for Prevention Research and Epidemiology – BIPS. This also carries out the tasks of the evaluation centre and medical management. The Association of Statutory Health Insurance Physicians in Bremen (Kassenärztliche Vereinigung Bremen) is responsible for carrying out the tasks of the trust centre. The Bremen Cancer Registry (Bremer Krebsregister) is supervised by the Senator for Health, Women and Consumer Protection.

### Legal basis

The tasks of the cancer registries are regulated nationwide in the Federal Cancer Registry Data Act (Bundeskrebsregisterdatengesetz) and in the German Social Code (SGB, Book V) (sections 25a and 65c). The state-specific regulations for the Federal State of Bremen are defined in the Bremen Cancer Registry Act (BremKRG). According to section 6 (1) Bremen Cancer Registry Act (BremKRG), all clinics and practices located in the Federal State of Bremen that diagnose or treat a patient with cancer are obliged to register data with the Bremen Cancer Registry (Bremer Krebsregister).

## This data is reported

The doctors involved in your treatment will report to the Bremen Cancer Registry (Bremer Krebsregister) at the following points in the course of the disease: Detection of a type of cancer, confirmation of the diagnosis by fine-tissue or cell-related examinations, start of treatment, termination (or even discontinuation) of treatment, change in the disease status with significance for the respective therapy, or recurrence of the disease and, if applicable, death from or with the respective cancer. Furthermore, additions to complete the data set at other times are also possible. The scope of the information to be registered is uniformly defined nationwide and includes:

### Personal details

Name	Gender
Address	Health insurance
Date of birth	Health insurance no.

### Medical information on the tumour

Diagnosis, localisation and spread of the tumour
Date of diagnosis
Type of diagnostic confirmation
Type, start, duration and result of therapy
Disease progression
If applicable Date of death
Reporting institution

## What happens to your data?

The point of acceptance for all reports from physicians is the trust centre of the Bremen Cancer Registry (Bremer Krebsregister). There, a check of the data and the coding of the information according to the valid medical classifications are carried out, in order to ensure a uniform evaluation. For patients who do not reside in the Federal State of Bremen or who were treated outside of Bremen, the information is also exchanged between the corresponding state cancer registries. Patients under the age of 18 are also transferred to the German Childhood Cancer Registry (Deutsches Kinderkrebsregister) in Mainz, provided that the person concerned or a legal representative has consented to the transfer.

Furthermore, data on your person, the tumour diagnosis and the diagnosis date are transmitted to your health insurance company for the settlement of the so-called “cancer registry flat rate” (Krebsregisterpauschale), as the health insurance companies support the operation of the clinical cancer registries.

The data will be made available to your doctor by the trust centre on request for the purpose of promoting cooperation between the different specialities involved in your treatment and improving the quality of treatment.

On completion of the work, the trust centre makes your data permanently available to the evaluation centre for various scientific analyses. Your name and exact address (street name and house number) are pseudonymised beforehand. This means that they are changed so that they are no longer recognisable.

If necessary, the trust centre may also transmit exact address data to the evaluation centre if this is required for evaluations of cancer incidence rates. After completion of the evaluation, the data is immediately deleted at the evaluation centre. When the results are published, the data are summarised in such a way that no personal reference is recognisable.

The type and scope of data evaluations are defined in the Bremen Cancer Registry Act (Bremer Krebsregistergesetz). These include, for example, the analyses of cancer incidence in the population or evaluations of the treatment of cancer patients.

A scientific advisory board, with the participation of a patient representative, also reviews the evaluations of the cancer registry before publication.

The aim of evaluating your treatment data and the course of the disease is to learn more about the causes of cancer, to develop more effective early detection measures and to improve the quality of treatment.

Summarised results are also made available to interested parties on the website of the Bremen Cancer Registry (Bremer Krebsregister) via an interactive online report ([www.krebsregister.bremen.de](http://www.krebsregister.bremen.de)).

In addition to these evaluations, all cancer registries are required by federal law to transmit pseudonymised data to the following institutions:

- Centre for Cancer Registry Data at the Robert Koch Institute. There, nationwide evaluations are carried out with the data of all cancer registries of the Federal States.
- Joint Federal Committee or a body appointed by it. Here, evaluations regarding the quality of treatment and progression data are carried out at federal level.
- Trust centre according to section 299 (2) sentence 5 of the German Social Code (SGB, Book V). Here, the data from the cancer registry is compared with data from the organised screening programmes, in order to contribute to the evaluation of the benefit of these programmes and to ensure quality.

The pseudonymised data of the evaluation centre can also be made available on request to institutions for oncological research projects or quality assurance, as well as cancer registries.



Amalgamation with other pseudonymised data (i.e. without name reference) is also possible. For the provision of data, the consent of the Senator for Health, Women and Consumer Protection and the scientific advisory board of the cancer registry must be obtained in advance, and permission must be granted by the Bremen Cancer Registry (Bremer Krebsregister).

## Storage and deletion

In the trust centre, the identity data is deleted after 30 years following the patient's death, or 120 years after the birth of the data subject at the latest, and replaced by a pseudonym. The medical data is permanently stored in the trust centre and in the evaluation centre, so that long-term evaluations – such as time series – can also be created.

## Protecting your data

Data processing in the Bremen Cancer Registry (Bremer Krebsregister) is strictly confidential and subject to medical supervision. The technical and organisational measures to protect the data comply with the current security standards.

Processing of data for quality assurance and research purposes is carried out according to strict, legally prescribed conditions, and without reference to names.

Should your name be required for special research projects, you will be asked for your consent in advance. This data will only be used if you have expressly consented to it. Of course, you have the right to obtain information regarding the data stored about you from the Bremen Cancer Registry (Bremer Krebsregister) at any time

## Your right to lodge an objection to the data storage

In order to gain reliable information about the incidence of cancer and the care of patients, complete registration is essential. A situation must be avoided in which only a part of the courses of the disease – for example, only those that go particularly well – are registered with the cancer registry. This would create a false picture of treatment outcomes and be detrimental to research and improvement of treatment options.

In the Bremen Cancer Registry (Bremer Krebsregister), an exception to the medical reporting requirement is, therefore, not permitted by law. As the person concerned, however, you can object to the storage of identity data either via your doctor or directly via the cancer registry. Your data will then also be pseudonymised in the trust centre after the billing and reimbursement procedures have been carried out. This means that you, as a person, are then no longer recognisable by name and with an exact address.

However, your medical data regarding cancer will be retained for the evaluations. Lodging an objection carries with it the consequence that your data may not be made available to the institutions responsible for treatment.

If you have any questions about data collection, do not hesitate to contact your doctor – even at a later point in time. You are also welcome to contact the staff of the Bremen Cancer Registry's trust centre – they are also bound by professional secrecy! Contact details can be found on the back of the information brochure.

## Organised screening programmes

The Bremen Cancer Registry (Bremer Krebsregister) participates in the evaluation and quality assurance of organised screening programmes in accordance with national standards.

For the mammography screening programme, the trust centre receives data from the central office and the screening unit. If the occurrence of breast cancer was not detected in a screening participant during the screening programme, but during a visit to the doctor between two screening appointments, the cancer registry reports this case as a so-called “interval carcinoma” to the responsible reference centre for mammography screening.

The attending physician who diagnosed the interval carcinoma is also obligated to transmit the findings documentation to the responsible screening unit. There, the diagnostic data is merged with the screening data and pseudonymised (i.e. your name is no longer recognisable) and forwarded to the reference centre. In the case of interval carcinomas, for example, we look to see if the tumour was missed during screening, or if it is a fast-growing tumour between screening intervals. For more information, contact your screening unit.

For other organised screening programmes, e.g. colorectal cancer or cervical cancer, the Bremen Cancer Registry (Bremer Krebsregister) transmits pseudonymised identity data and medical data to the trust centre in accordance with section 299 (2) sentence 5 German Social Code (SGB, Book V). There, the data is then compared with the results from the cancer screening examinations.

## Right of appeal to a supervisory authority

If you believe that the processing of personal data concerning you is in breach of the General Data Protection Regulation (GDPR), you have the right to lodge a complaint with a supervisory authority. The competent supervisory authority for the Federal State of Bremen is:

The State Commissioner for Data Protection and  
Freedom of Information  
Arndtstraße 1  
27570 Bremerhaven  
Tel.: 0421 – 361 2010 or 0471 – 596 2010  
Fax: 0421 – 49 61 84 95  
Email: [office@datenschutz.bremen.de](mailto:office@datenschutz.bremen.de)

## Contact at the Bremen Cancer Registry (Bremer Krebsregister)

Bremer Krebsregister  
Achterstrasse 30  
D-28359 Bremen  
[www.krebsregister.bremen.de](http://www.krebsregister.bremen.de)

Trust centre:                      Britta Schubert  
Tel: 0421 – 218 56 999  
Email: [b.schubert@kvhb.de](mailto:b.schubert@kvhb.de)

Senior Medical Management:  
Dr. Sabine Luttmann  
Tel: 0421 – 218 56 961  
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