

Name and address of the person subject to registration or registration centre (stamp):

**Berlin and Brandenburg Clinical Cancer Registry
Information for patients**

Dear Patient,

There are grounds for suspecting that you may have a malignant tumour (cancer), the early stages of a malignant tumour, or a benign tumour of the central nervous system, or you have already been diagnosed with this condition. Doctors and institutions are obliged to forward relevant data about you and your tumour to the Berlin and Brandenburg Clinical Cancer Registry. The Clinical Cancer Registry was set up to **improve the quality of oncological care**. It was established based on an agreement between the states of Brandenburg and Berlin.

The following describes the Clinical Cancer Registry, its tasks and how your personal data is processed there. If you have any further questions, please contact the doctor who is responsible for your treatment or the Clinical Cancer Registry of the states of Berlin and Brandenburg (see below for contact details).

We ask you to please confirm in writing on the last page of this letter that you have received and understood the following information.

Intent and purpose for patients

Information on cancer in general, the treatments used and the progression of the disease is obtained from as many patients as possible and used to review and bring about continuous improvements in the cancer treatments that are currently used. As an individual patient, you can also benefit directly from the data collected:

- The doctors who are responsible for your treatment can ask to consult information about your case in the Clinical Cancer Registry, unless you object to your data being stored in the Clinical Cancer Registry. This also applies when you change doctors, if you move house or if there is a recurrence of the disease. This is used to ensure the best course of treatment for you.
- The doctors who are responsible for your treatment can also use it to discuss the most appropriate tests for you with their medical colleagues and decide on the best possible treatment, for example, at tumour conferences.
- Medical practices and hospitals will also be assisted by summarised tumour-related evaluations of the success of all the treatments they carry out on all their cancer patients.

Benefits for the population-based (epidemiological) cancer registry

Your relevant epidemiological data (gender, month and year of birth, place of residence, tumour diagnosis and type of treatment) and identifying information, but not your insurance data, will be transferred by the Clinical Cancer Registry to the population-based (epidemiological) **Common Cancer Registry (www.berlin.de/gcc/)**.

Population-based (epidemiological) cancer registries are facilities for the collection, storage, processing, analysis and interpretation of data on the occurrence and incidence of cancer within defined catchment areas. Cancer registries provide a valuable basis for finding out more about the causes and development of cancer. In addition, they must provide mainly anonymised data for scientific research.

Benefits for research

The Clinical Cancer Registry shall, upon request and without your consent, only transfer anonymous or encrypted (pseudonymous) personal data for the purposes of processing for concrete projects in the field of **patient care research**. If a research project can only be carried out using your identifying information, because, for example, there is a need to conduct patient surveys, your prior written consent must be obtained.

The information transferred to the Clinical Cancer Registry:

Personal information used to identify you, in particular:	Important medical information about your cancer, specifically:
<ul style="list-style-type: none"> • Last name, first name, former names • Address of your main residence • Date of birth • Gender • Information about your health insurance and, where applicable, any sources of financial assistance 	<ul style="list-style-type: none"> • The type and location of the tumour • Date of diagnosis • Type of diagnosis confirmation • Type, starting time, duration and outcome of treatment, including side effects • Progression of the disease

Protecting your data

The Cancer Registry is subject to strict data protection regulations. The extent, storage, use, transfer and deletion of the data is subject to specific legal requirements and is supervised by the data protection officers of the states of Brandenburg and Berlin.

All the necessary personal information will only be stored and processed in a staffed and technically demarcated area of the specially secured Clinical Cancer registry. Only a few, expressly designated persons will have access to your personal information and they are subject to strict confidentiality obligations. All further stages of the statistical processing of the data will take place without any information that identifies your person.

Transfer of the data to cancer registries in other countries, the epidemiological Common Cancer Registry¹, or other scientific institutions is only possible under specific and verifiable conditions.

Your right of refusal in relation to the report to the Clinical Cancer Registry

You can object to the storage of your medical data from individual reports or all reports in the Clinical Cancer Registry. In this case, the data identifying you will be transferred to the Clinical Cancer Registry, but not medical information on your tumour or your insurance data. This is the only way that the Clinical Cancer Registry will know that they may not contact you again to request missing medical data because you have objected to this.

If at a later date, you object to the storage of all reports in the Clinical Cancer Registry, the medical data stored there will be deleted and your identifying information transferred to a separate data set, so that it is not included in general data traffic in the Clinical Cancer Registry.

You can register your objection with the doctor responsible for your treatment or in the service area of the Clinical Cancer Registry. The contact details of the registration centres can be found below or on the Internet at www.kkrbb.de.

¹ Common Cancer Registry of the states of Berlin, Brandenburg, Mecklenburg-Western Pomerania, Saxony-Anhalt and the Free State of Saxony and Thuringia.

If you support the objectives of cancer registration and agree to the aforementioned arrangements you need not take any further action. If you object to the storage of your medical data in the Clinical Cancer Registry, there will be no benefits for you.

In relation to the report to the epidemiological cancer registry

Patients whose main residence is in the state of Brandenburg, independently of the right to object to the storage of medical data, also have the right to only object to the transfer of epidemiological data by the Clinical Cancer Registry to the epidemiological Common Cancer Registry.

Patients whose main residence is in the state of Berlin do not have the right to object to the transfer of epidemiological data by the Clinical Cancer Registry to the epidemiological Common Cancer Registry. This data must therefore be submitted to the Clinical Cancer Registry together with identifying information by the person subject to registration or the reporting centre.

Your right to information

You have a right to information about the data concerning you that is stored in the Clinical Cancer Registry.

To obtain this, an application should be filed in writing or by transcript - i.e., by means of a written record of your application made by an employee of the Clinical Cancer Registry which is then signed by you - at a registration centre of the Clinical Cancer Registry (see addresses below).

The application must include your last name, first name, former name(s), date of birth and the address of your main residence. You will then be asked to designate a doctor or a dentist to whom the Clinical Cancer Registry will pass written information about the stored data, so that they can provide you with a specialist explanation of the data. If you do not designate a doctor or dentist, the written information will be sent directly to you by the Clinical Cancer Registry once your identity has been verified.

Particularities regarding the settlement of private insurance and/or persons qualifying for benefits

The Clinical Cancer Registry will bill the costs (register fee and registration fees) incurred by patients with private insurance or those who qualify for benefits - contrary to normal procedure - directly to your insurance company or your appropriate benefits office. That is why the doctor who is responsible for your treatment will ask you for the necessary information (such as the relevant benefits office). For direct settlement with your private health insurance company and/or benefits office, the mutual exchange of your personal data may be necessary for billing, if you have not raised any objections to the storage of medical data in the Clinical Cancer Registry.

Further details and information

“Klinisches Krebsregister Brandenburg und Berlin gGmbH”:

Dreifertstrasse 12

03044 Cottbus,

Germany

Tel.: +49 (0)355 49493 100

Fax: +49 (0)355 78010-489

Email: kkrbb@laekb.de

www.kkrbb.de

Registration centres of the Clinical Cancer Registry

<p><u>Berlin centre:</u></p> <p>Registerstelle Berlin Potsdamer Str.182 10783 Berlin</p> <p>Telephone: +49 (0)30 21993 223 Fax: +49 (0)30 21993 208</p> <p>Email: uta.stoetzer@kkrbb.de</p>	<p><u>Cottbus centre:</u></p> <p>Registerstelle Cottbus Thiemstrasse 111 03048 Cottbus</p> <p>Telephone: +49 (0)355 49493 130 Fax: +49 (0)355 49493 139</p> <p>Email: sekr_cb@kkrbb.de</p>
<p><u>Frankfurt (Oder) centre:</u></p> <p>Registerstelle Frankfurt (Oder) Müllroser Chaussee 7 15236 Frankfurt (Oder)</p> <p>Telephone: +49 (0)355 49493 300 Fax: +49 (0)355 49493 309</p> <p>Email: birgit.kindt@kkrbb.de</p>	<p><u>Neuruppin centre:</u></p> <p>Registerstelle Neuruppin Fehrbelliner Strasse 38 16816 Neuruppin</p> <p>Telephone: +49 (0)355 49493 400 Fax: +49 (0)355 49493 409</p> <p>Email: sekr_np@kkrbb.de</p>
<p><u>Potsdam centre:</u></p> <p>Registerstelle Potsdam Charlottenstrasse 72 14467 Potsdam</p> <p>Telephone: +49 (0)355 49493 450 Fax: +49 (0)355 49493 459</p> <p>Email: doris.niepmann@kkrbb.de</p>	<p><u>Schwedt centre:</u></p> <p>Registerstelle Schwedt Auguststrasse 23 16303 Schwedt</p> <p>Telephone: +49 (0)355 49493 460 Fax: +49 (0)355 49493 469</p> <p>Email: birgit.kindt@kkrbb.de</p>

Confirmation of the information issued

Informing Doctor or
Informing Dentist (person reporting):

Last name, First name

Position

Confirmation – Patient

I hereby confirm

Last name, First name

born on

the transfer of my personal data (in particular health data) by the above Doctor or Dentist to the Clinical Cancer Registry in the States of Berlin and Brandenburg and that I have been informed both verbally and in writing of my rights in respect of this. I have understood the information and have received a copy of this information leaflet.

Date

Place

Signature of Patient or Legal Representative

Confirmation– Person reporting

(Only required if there is no written confirmation of receipt of the information by the patient.)

I hereby confirm to the Clinical Cancer Registry in the States of Berlin and Brandenburg the transfer to the above Patient of his/her personal data and that he/she has been informed both verbally and in writing of his/her rights in respect of this and has received a copy of this information leaflet.

Date

Place

Signature of the reporting doctor