

Cancer Registry

Patient Information Sheet

Please note: the sole purpose of this translation is to facilitate the clarification of the reporting process to the Cancer Registry in Baden-Württemberg. Only the German-language form is legally binding and therefore has to be handed to the patient.

Dear Patient,

A cancer diagnosis represents a major turning point in the life of the individual concerned. Although there have been many advances in recent years in the treatment of cancer, it is still not possible to answer many questions associated with various cancers. It is therefore one of the most important tasks of modern medicine and health policy, to research into their causes and improve treatment. Cancer registries provide important support with this. The Cancer Registry of Baden-Württemberg consists of the Trust Center which has been set up at the Baden-Württemberg branch of the Deutsche Rentenversicherung (German Federal Pension Insurance), the Clinical State Registry Office, set up at the Baden-Württemberg Hospital Association and the Epidemiological Cancer Registry at the German Cancer Research Center in Heidelberg.

With your help, the Cancer Registry would like to contribute, among other things, towards clarifying the following questions:

- What are the causes of various cancers?
- Are early detection measures successful and how can they be further improved?
- How does the number of cancer cases change over the course of time?
- Do cancers occur more/less frequently in some areas than in others?
- What about the quality of the treatment and diagnostics in different medical facilities?
- How is the quality of life of cancer patients during and after the treatment of their disease?
- What is the long-term course after cancer?

The Cancer Registry can only contribute towards answering the above questions if all new cases are recorded, where possible. With the registration of only some of the cases, meaningful evaluations are not possible or not reliable. Through your willingness to make your data available to the Cancer Registry, you are making a significant contribution towards improving cancer treatment and supporting the fight against cancer as a patient affected by the disease.

Mandatory Reporting to the Baden-Württemberg Cancer Registry

The basis for the registration of cancers in Baden-Württemberg is the State Law on Cancer Registration in Baden-Württemberg.

Every doctor/dentist (hereafter referred to as a “doctor”) is legally obliged to report your disease to the Baden-Württemberg Cancer Registry. This obligation also comprises certain

pre-stages and some types of benign tumour. The latter means that you also receive this information if your tumour is not malignant.

What data is reported?

The report covers not only details about your person, such as your name, address, date of birth (so-called identity data) but data on the cancer, such as the time of the disease, location of the tumour, type and size, as well as information on the treatment and the course of the disease (so-called medical data).

How is your data processed and protected?

Your doctor reports this data in encrypted form to the Trust Center. The identity data is encrypted separately from the medical data. The Trust Center decrypts the identity data, checks that it is complete and coherent and forwards the identity data which is required for the reimbursement of the costs to the health insurance companies while complying with the provisions of data protection law. It is not possible for the Trust Center to decrypt the medical data.

The entire dataset is passed by the Trust Center to the Clinical State Registry Office. Beforehand, the identity data is encrypted again, so that the Registry Office cannot identify the individuals whose disease data it has received from. The Clinical State Registry Office can only process the medical data and uses this for oncological quality assurance in the treatment of cancer.

The medical data is also made available to the Epidemiological Cancer Registry. This describes the cancer landscape in Baden-Württemberg and uses this data for clinical-epidemiological research and for quality assurance in the early detection of cancer.

Finally, the medical data concerned is forwarded to the "Centre for Cancer Registry Data", which has been set up at the Robert Koch Institute, which collates the data from all cancer registries in Germany.

If the patient's main residence or treatment is in a different federal state, the exchange of your personal and medical data is stipulated by law. Both the exchange and the further processing of your data is performed in accordance with the legal requirements of the federal state concerned in compliance with the strictest requirements of data protection law.

What does the doctor treating the patient see?

In order to give your doctor the opportunity to learn about the treatments that have been carried out, evaluate their success and compare them with others, we offer the option of

treatment data transmission. This provides a rounded picture of the course of treatment, from his or her data and the data reported by his or her colleagues.

Patient's Right of Objection

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You have the right to inform your doctor at any time that you do not wish for your identity data to be further processed in the Baden-Württemberg Cancer Registry. In this case the doctor treating you must send your objection together with the notification to the Cancer Registry. You also have the right at any time subsequently to have your identity data deleted from the Cancer Registry. Then only your medical data on the cancer disease is retained for the evaluation and research. You are informed in writing about the deletion of the data through your doctor.

Patient's Right to Information

You have the right to learn whether and which entries have been stored on your person in the Cancer Registry. In order to do so, please send an application to the Trust Center, stating the name of a doctor whom you trust and who is to subsequently provide you with information. After receiving your application, the registry offices will inform the doctor nominated by you of the data stored concerning your person. As soon as your doctor has received this feedback from the registry offices, he or she will provide you with the letter containing the information about your entries in the Baden-Württemberg Cancer Registry after an explanation. The information is free of charge for you.

Your trust can save lives.

How can it be determined whether treatment methods are effective and medical facilities are good? This is where Cancer Registries help by determining the quality of care, identifying any defects in and pointing these out.

In order to assist with health research, it is possible for you to be contacted within the framework of studies – also in connection with your quality of life – with a request for your participation. All such requests have of course been approved by the competent Ethics Committee beforehand. The letter is sent by the Trust Center.

Please support the work of the Baden-Württemberg Cancer Registry.

For more information you are welcome to visit our website at <http://www.krebsregister-bw.de>.

We are of course also available to answer any questions that you may have directly.

**Krebsregister Baden-Württemberg Vertrauensstelle
(Baden-Württemberg Cancer Registry Trust Center)**
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**Klinische Landesregisterstelle
(Clinical State Registry Office)**

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Epidemiologisches Krebsregister

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