

Patient Information Sheet

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 registers provide important support with this. The Cancer Register of Baden-Württemberg consists of the Trust Centre, 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 Register at the German Cancer Research Centre in Heidelberg.

With your help, the Cancer Register would like to contribute towards clarifying the following questions:

- What are the causes of various cancers?
- Are early detection measures successful?

- Is the number of cases increasing over time?
- Do cancers occur more frequently in some areas than in others?
- What about the quality of the treatment and diagnostics in different hospitals and doctors' surgeries?

The Cancer Register 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 Register, you are making a significant contribution towards fighting cancer as a patient affected by the disease.

Mandatory Reporting to the Baden-Württemberg Cancer Register

The basis for the registration of cancers in Baden-Württemberg is the Law on Cancer Registration in Baden-Württemberg dated March 7, 2006.

Every doctor/dentist is legally obliged to report your disease to the Baden-Württemberg Cancer Register.

This obligation is based on a legal duty to report cancer diseases which also comprises certain pre-stages and some benign types of 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 (name, address, date of birth, etc.), but also data on the cancer (e.g. time of the disease, location of the tumour, type and size), as well as information on the treatment and the course of the disease.

How is your data processed and protected?

Your doctor initially reports this data to the Trust Centre. Personal information is encrypted separately from the medical data. The Trust Centre is only able to decrypt this personal data and checks the report to ensure that it is complete and coherent. At no time does the Trust Centre receive any insight into your medical data. Your personal data is encrypted there before it is passed on to the Clinical State Registry Office in such a way that the Registry Office is not able to identify the individuals whose illness data it has

received (pseudonymisation). The Clinical State Registry Office processes the information submitted by the Trust Centre for oncological quality assurance in cancer treatment. The epidemiological data is forwarded to the Epidemiological Cancer Register, which evaluates the data with respect to the population. Finally, epidemiological information is forwarded to the "Centre for Cancer Registers" set up at the Robert Koch Institute, which collates the data from all of the cancer registers in Germany. The data is always transmitted in encrypted form in order to protect against unauthorised access. Only the anonymised data is used for the purposes of evaluation and research.

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

You have the right to inform your doctor at any time of your objection to the report being sent to the Baden-Württemberg Cancer Register. In this case your doctor must refrain from sending the report or, if the report has already been submitted, must ensure that your data is deleted immediately. You will then be informed by your doctor in writing that the data has been deleted. You will not be disadvantaged in any way if

you object to the reporting of your data to the Cancer Register.

Patient's Right to Information

You have the right to learn whether and which entries have been stored on your person in the Cancer Register. In order to do so, please send an application to the Trust Centre, stating the name of the doctor who has reported your data to the Cancer Register and who is to provide you with the 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 information about your entries in the Baden-Württemberg Cancer Register. The information is free of charge for you.

Your trust can save lives.

How can it be determined whether a method of treatment is effective and medical facilities are good? Cancer Registers help to determine the quality of care, identify any defects that may be present and possibly eliminate them.

In order to assist with health research, it is possible for you to be contacted within the framework of epidemiological studies 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 Centre.

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

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 Register Trust Centre)

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Klinische Landesregisterstelle (Clinical State Registry Office)

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Baden-Württemberg Hospital Association
Birkenwaldstrasse 145
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Epidemiologisches Krebsregister (Epidemiological Cancer Register)

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