

# The Baden-Württemberg Cancer Register

## Dear patient,

If you have been diagnosed with cancer.... Over the past years there have been great advances in the treatment of different forms of cancer. However, we are still not able to answer many of the questions that exist about the disease. This is why one of the most important goals of modern medicine and health policy is to carry out research into the causes of cancer and how it can be treated. Cancer registers are one way of helping.

Under the Regional Cancer Register Act of 13 March 2006 Baden-Württemberg created a legal framework for setting up a cancer register and introduced the requirement that all cases of cancer be reported. This means that your doctor has a legal obligation to report all cases of cancer and certain tumours, which may also be benign, to the Baden-Württemberg Cancer Register as soon as the register has been completely set up. Protection of your data is a top priority – both for your doctor and the state. The Regional Cancer Register Act therefore contains a large number of provisions to ensure that your data is protected. For example, the Baden-Württemberg Cancer Register has been divided into three parts: the "Confidentiality Office" (*Vertrauensstelle*), the "Office of Clinical Regional Registry" (*klinische Landesregisterstelle*) and the "Epidemiological Cancer Register" (*epidemiologisches Krebsregister*). Of these, only the Confidentiality Office receives all of the patient's personal data.

## The Cancer Register would like your help in finding the answer to the following questions:

- What are the causes of the different types of cancer?
- Is cancer screening effective?
- How can life expectancy be improved?
- Is the number of cancer cases increasing?
- Does cancer occur more/less frequently in certain areas?
- Do the quality of diagnosis and treatment and the time factors involved vary according to the region or clinic?

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

The cancer register can only contribute to answering the above questions if as many new cases as possible are recorded. The more patients that register their data, the more useful and reliable the resulting analyses will be.

By agreeing to make your data available to the cancer register you can make an important contribution to the fight against cancer.

## Patients' opt-out right

If you decide that you do not want your data to be saved in the **Baden-Württemberg Cancer Register** you can opt out at any time by giving written notification. Your doctor documents the fact in writing that he/she has informed you of your opt-out right. If you wish to make use of this right your doctor will not forward your data. If your data is already in the register it will all be deleted once your doctor has forwarded your decision. You will not suffer any disadvantage if you do not want your data to be included in the Baden-Württemberg Cancer Register.

If you have any other questions, please contact one of the addresses listed below. They will be pleased to help.

## **What data is recorded and passed on?**

If you have been diagnosed with a malignant form of cancer or an early stage of a malignant cancer this is to be reported by all doctors. As well as certain personal data the doctor will provide data on the cancer itself, such as date of illness, position, type and size of the tumour, and some basic information on the therapy. To begin with, the information will be forwarded to the Confidentiality Office of the Baden-Württemberg Cancer Register. There your personal data will be encrypted to ensure that no connection can be made between you as an individual and your medical history. This process is known as creating a pseudonym. The Confidentiality Office will only keep a permanent record of your personal data in an encrypted form. Only information which has been treated in this way, along with the medical data, is forwarded to the Baden-Württemberg Cancer Register's "Office of Clinical Regional Registry" for analysis.

If you have any questions on how the data is reported or if you are concerned about data privacy, please feel free to contact the Confidentiality Office (*Vertrauensstelle*) or one of the other bodies named below or the Ministry for Labour and Social Affairs. (See addresses on reverse). Once the cancer register is up and running you can find out through your doctor what information – if any – has been forwarded about you. To do this you must make an application for information to the Confidentiality Office (*Vertrauensstelle* - address below).

## **How is your data protected?**

Doctors and dentists send information on all cancer patients to the Confidentiality Office of the Baden-Württemberg Cancer Register. This information consists of personal data (name, address, date of birth) and details of the illness (date and type of diagnosis, therapy, previous tumours). The Confidentiality Office encrypts all the personal data to prevent the individual being identified and forwards the necessary data to the Office of Clinical Regional Registry (*klinische Landesregisterstelle*). This is located at the address of the Baden-Württembergische Krankenhausgesellschaft e.V.

Any encrypted data which is forwarded there will be saved permanently and analysed to monitor the quality of treatment. Unencrypted personal data is not saved permanently.

To ensure that the register is complete and can be updated if for example you move house, this data is synchronised - in its encrypted form - with the data at the Residents' Registration Office (*Einwohnermeldeamt*). The Office of Clinical Regional Registry sends the epidemiological data to the Epidemiological Cancer Register where it is also saved on a permanent basis and analysed in relation to the population as a whole. Finally epidemiological data is forwarded to the cancer documentation centre of the Robert Koch Institute where the data from all cancer registers in Germany is merged. Only data which has been rendered anonymous is used for evaluation and research.

There are plans to set up regional quality conferences based on the four tumour centres in Freiburg, Heidelberg, Tübingen and Ulm, and in Stuttgart which is a major oncology centre. These will use the results of the analyses to ensure ever-increasing standards of cancer treatment in Baden-Württemberg. This will be based on feedback received from clinics on the success of their cancer therapies. The regional quality conferences which are subject to a self-governing body will intensify collaboration between all those involved in the treatment of cancer in the region and make it possible to compare the results of treatment in various institutions.

It is intended that feedback on the results of treatment can be sent to the individual doctor concerned. All doctors who have reported a patient can apply to receive further treatment data on that patient and follow the progress of treatment. In establishing the cancer register we hope to create an instrument to assure quality in oncology which will improve the treatment of cancer patients and in the long term ensure that treatment focuses on forms of therapy which have been found to be successful.

Addresses

**Vertrauensstelle Baden-Württemberg  
("Confidentiality Office")**

Deutsche Rentenversicherung  
Baden-Württemberg  
Gartenstraße 105  
76135 Karlsruhe  
Tel.: 0721/825-79000  
Fax: 0721/825-9979099  
E-Mail: [vs@drv-bw.de](mailto:vs@drv-bw.de)

**Klinische Landesregisterstelle  
(Office of Clinical Regional Registry)**

Baden-Württembergische  
Krankenhausgesellschaft e.V.  
Postfach 10 04 28  
70003 Stuttgart  
Tel.: 0711 / 25777-70  
Fax: 0711 / 25777-79  
E-Mail: [info@klr-krbw.de](mailto:info@klr-krbw.de)

**Epidemiologisches Krebsregister  
(Epidemiological Cancer Register)**

Deutsches Krebsforschungszentrum  
Im Neuenheimer Feld 280  
69120 Heidelberg  
Tel.: 06221 42-4220  
Fax: 06221 42-2203  
E-Mail: [ekr@krebsregister-bw.de](mailto:ekr@krebsregister-bw.de)

**Ministerium für Arbeit und Soziales Baden-Württemberg  
Ministry for Labour and Social affairs in Baden-württemberg)**

Schellingstraße 15  
70174 Stuttgart  
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Fax: 0711-123-3997  
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