



LGL

Bavarian Cancer Registry

Information for
patients

Benefits of Cancer Registration

Dear Patients,

Science has made great progress in the treatment and cure of cancer in recent years. For you, but also for your family, the diagnosis of a cancer still means a break in your life. You are not alone with your diagnosis: your attending physicians, scientists and health politicians are working hard to further improve the care of cancer patients in Germany.




All federal states are legally obliged to establish treatment-related (clinical) cancer registries. The data of the cancer registries provide information about the frequency and distribution of cancer in the respective federal state, but also about treatments and disease progression.

In addition, the data help in research on the causes of cancer as well as in the evaluation and planning of early detection measures. They also serve to further improve established cancer therapies and to develop new ones. They also help to assess the quality of care and identify potential for improvement.

The Bavarian Health and Food Safety Authority (LGL), which manages the Bavarian Cancer Registry, would like to inform you about the advantages of registering in the Bavarian Cancer Registry and, of course, about your rights, the registration procedure and your contacts.

You will make an important contribution to the fight against cancer by consenting to the storage of your data. We therefore ask for your support.



Prof. Dr. med. Andreas Zapf

President of the Bavarian Health and Food Safety Authority

All doctors involved in my treatment can obtain complete information about my illness and then coordinate treatment.

My data are a valuable basis for the quality assurance of my treatment.

The experience gained in the treatment of all patients whose data are recorded in the course of cancer registration is available to the doctors involved in my treatment. This also benefits my treatment.

My attending physicians can consult other specialists on the basis of the available data on my illness, so that my therapy can be optimally tailored to me and monitored.



“Comprehensive cancer registration is very important for the care of cancer patients. By regularly evaluating health-related data, treating physicians and scientists can make objective statements about the current treatment situation of cancer patients and better assess early detection measures.

Cancer registration thus provides the scientific basis for further studies and contributes to improving the quality of treatment in the long term”

Prof. Dr. med. Günter Schlimok

President of the Bavarian Cancer Society (BKG)

My rights

Right to information

I have the right to be informed by the LGL whether and which data concerning me has been stored. This also includes information on whether, and if so, by whom the data was accessed in the last ten years. After ten years the record of data access is erased.

Right to object

I have the right at any time to object in writing to the permanent storage of my identity data (name, address, health insurance number), whether registered in the past or received in the future, either by contacting the trust centre of the Cancer Registry Bavaria or by informing my doctor. My identity data will then be pseudonymised as soon as it is no longer required for the purpose of mandatory quality assurance settlement or on the basis of other legal regulations. This means that I will no longer be identifiable by name. However, my cancer-related medical data which must be reported to the cancer registry, now and in the future, will permanently remain on the registry in an anonymised form for analysis purposes following my objection.

Explanations

According to the Bavarian Cancer Registry Act, doctors are obliged to register cases of cancer in the Cancer Registry Bavaria. A complete registration is vital in order to be able to make reliable statements on the occurrence of cancer and the care of patients. It is not purposeful if only a portion of the courses of diseases are registered – for instance those that progress well. This would misrepresent treatment and negatively affect the research and improvement of treatment options.

You may object to the permanent storage of your identity data, but would then be unable to benefit from the advantages. Your attending physicians cannot access your data in the Cancer Registry to share information or to consult during tumour boards. Even you will be unable to receive information concerning any medical data remaining in the registry. Staff at the Cancer Registry Bavaria cannot contact you in order to request your consent to participation in research projects (to develop new treatments, for example).

My data

The information registered is the same nationwide and includes the following data:

Information about the person (identity data)

- Surname, first name, previous names
- Address
- Health insurance number

Medical and epidemiological information

- Date of birth, sex
- Diagnosis, localisation and spread of the tumour
- Diagnosis date
- Type of diagnostic confirmation
- Type, start, duration and result of the therapy
- Progression of the disease
- Vital signs
- Registered institution

The contents of the register are sent to you upon your request.

Data Protection

Data processing at the Bavarian Cancer Registry is carried out strictly confidentially and subject to medical supervision. The work of the Bavarian Cancer Registry is monitored by the Bavarian State Commissioner for Data Protection. The technical and organisational measures for the protection of data comply with a data protection concept based on the latest security standards. This includes the regional centres separating your identity data from your medical data after data entry. Your identity data will remain within the Trust Centre of the Cancer Registry. There they are kept until 120 years after birth or 15 years after the death of the patient and then deleted. Use of the data for quality assurance and research purposes take place only in accordance with strict statutory requirements.

As a rule, only pseudonymised or anonymised data is used for evaluations. If your name is required for special research projects, you will be asked for your consent in advance. Your identity data will otherwise only be used for data maintenance, for information to your attending physicians and for billing purposes.

Legal basis

Bavarian Cancer Registry Act (BayKRegG) of 7 March 2017

Cancer Screening and Registry Act (KFRG) of 3 April 2013

My contacts

Patient rights

Bavarian Health and Food Safety Authority (LGL)

Trust Centre of the Bavarian Cancer Registry
Schweinauer Hauptstraße 80, 90441 Nuremberg, Germany
Tel. +49 (0)9131 6808-2887, Fax +49 (0)9131 6808-2906
vertrauensstelle-krebsregister@lgl.bayern.de

General questions about the Cancer Registry

Bavarian Health and Food Safety Authority (LGL)

Central Office for Cancer Screening
and Registration (ZKFR)
Schweinauer Hauptstraße 80, 90441 Nuremberg, Germany
Tel. +49 (0)9131 6808-2920, Fax +49 (0)9131 6808-2905
zkfr@lgl.bayern.de

Questions about the registration procedure

Regional centres of the Cancer Registry Bavaria

Regional offices can be found at the following locations:

Augsburg (for Swabia):

Tel. +49 (0)9131 6808-4610,
Fax +49 (0)9131 6808-4639
krebsregister-augsburg@lgl.bayern.de

Bayreuth (for Upper Franconia):

Tel. +49 (0)9131 6808-3010,
Fax +49 (0)9131 6808-3039
krebsregister-bayreuth@lgl.bayern.de

Erlangen (for Middle Franconia):

Tel. +49 (0)9131 6808-2803,
Fax +49 (0)9131 6808-2828
krebsregister-erlangen@lgl.bayern.de

Munich (for Upper Bavaria and Landshut):

Tel. +49 (0)89 4400-74752,
Fax +49 (0)89 4400-74753
tumor@ibe.med.uni-muenchen.de

Regensburg (for Upper Palatinate and Lower Bavaria –
excluding Landshut):

Tel. +49 (0)941 943-1803,
Fax +49 (0)941 943-1802
zentrum.tumor@ukr.de

Würzburg (for Lower Franconia) :

Tel. +49 (0)9131 6808-7010,
Fax +49 (0)9131 6808-7039
krebsregister-wuerzburg@lgl.bayern.de

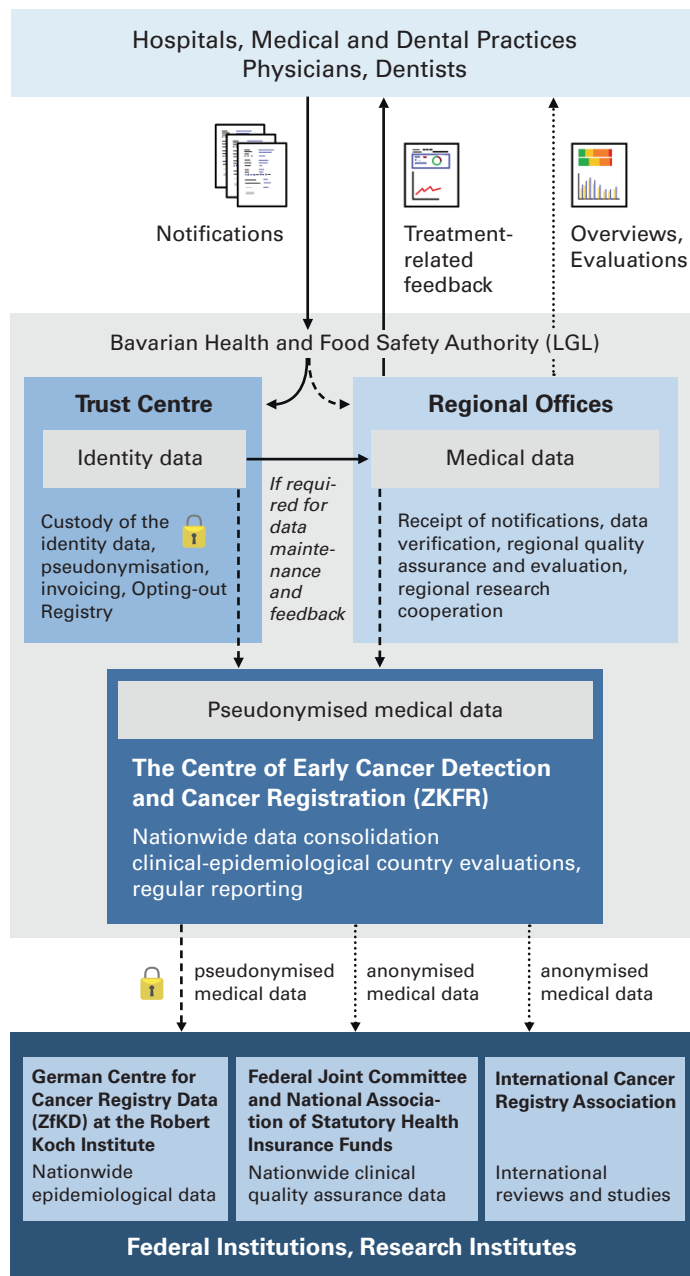
Registration procedure and reporting channel

Doctors and dentists in hospitals and practices report identity data and medical data for diagnosis, therapy and aftercare to the responsible regional office of the Cancer Registry. In addition, pathologists provide the results of tissue analysis. All malignant neoplasms including their early stages and benign cancer of the central nervous system are recorded.

The regional offices receive the notifications and check them for consistency and completeness. They separate the medical data from the identity data. The trust centre stores this identity data and pseudonymises it for analytical purposes. The employees of the regional offices only have access to the identity data if required for data maintenance, the incorporation of new messages and for treatment-related feedback to the notifying party. In the regional offices, regional evaluations of therapeutic processes and quality assurance are carried out, which are also forwarded to the notifying parties.

The Centre of Early Cancer Detection and Cancer Registration (ZKFR) is a registry entrusted with state-wide tasks, such as data consolidation, Bavaria-wide evaluations and reporting. It only receives pseudonymised medical data, which is permanently stored there for analyses and reports.

Once a year, the ZKFR supplies the pseudonymised epidemiological data to the Robert Koch Institute in Berlin for cross-national evaluation as well as exclusively anonymised clinical data and treatment data to the Federal Joint Committee (G-BA), the National Association of Statutory Health Insurance Funds, as well as to research institutions and to European and international associations of cancer registries (ENCR/IACR).



For ease of legibility, we have simplified some language and do not use the female form. Of course, the information refers to both men and women in these cases.

www.lgl.bayern.de

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