



Hessisches
Krebsregister

INFORMATION FOR PATIENTS

Information on the Hessian Cancer Registry

ENGLISH



Landesärztekammer Hessen
Körperschaft des öffentlichen Rechts

Hessisches Landesprüfungs- und
Untersuchungsamt im Gesundheitswesen





Dear Patient, Dear Relatives,

A cancer diagnosis is one of the toughest challenges a person may have to face during their lifetime. Daily life changes suddenly and you are faced with questions, situations, and decisions that you had never given any thought to before. We wish you all the best in this difficult time.

After your cancer diagnosis, you were most likely given some documentation that you were asked to read, understand, and maybe sign. You may have heard about the Hessian Cancer Registry from your doctor and are now reading about it here for the first time.

This information aims to provide you with an overview of what we do and how much we depend on your cooperation.

You can find out more about the Hessian Cancer Registry by visiting www.hessisches-krebsregister.de.

Your Hessian Cancer Registry

Why is there a Hessian Cancer Registry?

Every year, almost 500,000 people are diagnosed with cancer in Germany. Almost one-fifth of these diagnoses are related to smoking. The causes of the majority of the remaining 80% of tumour diseases remain unknown. As life-expectancy in Germany rises, an increase of newly diagnosed cancer cases of approximately 23% is to be expected. Only around half of cancer patients are able to be cured.

There is an urgent need for more causal research, cancer prevention education, screening for early cancer detection, and development of new treatment methods. In 2008, the National Cancer Plan was put into action to enable a targeted and structured approach in the fight against cancer. In 2013, the Early Cancer Detection and Registry Act (KFRG) was implemented, which complies with the recommendations of the National Cancer Plan.

Since then, the State of Hesse has been constructing a clinical-epidemiological cancer registry. The basis of the work done by the Hessian Cancer Registry is the Hessian Cancer Registry Act (HKRG), which came into force on 25/10/2014. The act states that malignant tumours diagnosed by physicians and dentists in the State of Hesse must be reported to the Hessian Cancer Registry.

Each state in Germany has a similar registry. The Hessian Cancer Registry is entrusted with recording and processing information relating to cancer cases and cancer treatment in the State of Hesse and making it available for research and quality assurance purposes.

All cancer registries in Germany send their anonymised data to the Centre for Cancer Registry Data based at the Robert Koch Institute to enable the processing of data from across Germany.

What information is registered?

1. Personal data

- Name
- Address
- Gender
- Date of birth
- Health insurance provider

2. Medical data about your cancer

- Diagnosis, localisation, and tumour spread
- Date of diagnosis
- Type of diagnosis confirmation used, e.g., tissue biopsy
- Type, beginning, duration, and results of treatment
- Course of the disease
- Vital status
- Reporting institution (physician or hospital)

How is your personal data protected?

- ✓ All data processed by the Hessian Cancer Register is strictly confidential.
- ✓ The technical and organisational data protection measures in place were coordinated with the office of the Hessian Officer for Data Protection and Freedom of Information and correspond to currently applicable standards.
- ✓ Data processing takes place in adherence to strict legal conditions and with all data being pseudonymised (without reference to a name).

Why is it important to report every case?

As many cases as possible must be recorded to obtain suitable information about the incidence of tumour diseases and their treatment. This helps us to better understand cancer and identify effective treatments. We depend on the cooperation of everyone. Please support us in the fight against cancer.

What are your rights?

You can object to your data being transferred to the cancer registry at any time, and all reports from your physicians and data stored at the Hessian Cancer Registry will be deleted. Should you wish to object to the transfer of your personal data, please speak to your physician and send us a letter stating your intent to object.

All information received about your cancer after your objection will not be recorded in the cancer registry. Likewise, reports from physicians who have not been directly informed of your objection will not be registered.

To make this possible, your personal data (name, address, and date of birth) are pseudonymised. This means that your personal data is no longer stored as readable text, but rather as control numbers. If any institution sends a report about your disease, this report will be deleted immediately after the control numbers have been compared. This enables us to continually ensure that your data is no longer registered.

Dear Patient, Dear Relatives,

Due to the information requirements stemming from the General Data Protection Regulation enacted by the European Union, we are obliged to inform you in detail about how the Hessian Cancer Registry will use your personal data. This includes informing you of your rights, e.g., your right of access and your right to object.

Please contact us or one of the offices listed below if you have any questions.

Your Hessian Cancer Registry

Information obligation as per Art. 14 of the EU GDPR (European Union General Data Protection Regulation)

In the following text, the Advisory Office of the Hessian Medical Association (LÄKH) and the Accounting Office and State Evaluation Office of the Hessian State Examination Board and Medical Investigation Office for Health Care (HLPUG) would like to inform you about how your personal data will be processed.

1. Data Processing at LÄKH

Officer for EU General Data Protection Regulations

Hessian Medical Association

Hanauer Landstraße 152

60314 Frankfurt am Main

Tel: +49 (0) 69 97672-0

E-Mail: info@laekh.de

Data Protection Officer at LÄKH

Andreas Wolf

Hanauer Landstraße 152

60314 Frankfurt am Main

Telefon: 069 97672-313

E-Mail: datenschutz@laekh.de

Advisory Office

The Advisory Office is located on the premises of the Hessian Medical Association in Frankfurt. Its role is the collection and documentation of reports on tumour patients who either live or are receiving treatment in the State of Hesse.

2. Data Processing at HLPUG

Officer for EU General Data Protection Regulations

Hessian State Examination Board and Medical
Investigation Office

Lurgiallee 10

60439 Frankfurt am Main

Tel: +49 (0) 69 580013-0

Data Protection Officer HLPUG

Christoph Hucke

Lurgiallee 10

60439 Frankfurt am Main

E-Mail: dsb@hlpug.hessen.de

Medical Investigation Office for Health Care

The Medical Investigation Office for Health Care is located at the HLPUG premises in Frankfurt and Dillenburg.

State-wide epidemiological assessments of the incidence of various types of cancer and evaluation of early detection programmes (such as breast cancer screening) are already established. Also, clinical data analysis is becoming increasingly important. Those obligated to report receive the analyses of the data they provided, and these are compared to the number in Hesse.

This type of institute-specific assessment can then be used for internal quality assurance and as the foundation for certification processes. Ultimately, state-wide analyses are used to make diagnosis, treatment, course, survival rates, early cancer detection numbers, and the care of cancer patients more transparent while demonstrating development and improvement potentials. Because all data is pseudonymized by the advisory office before it is passed on to the State Evaluation Office, they receive no information which could be used to identify someone.

Accounting Department

The main part of the financing of the cancer registry comes from the statutory health insurance providers. During this process, the necessary plain text registration data required for billing is transmitted from the advisory office to the accounting department, which is also located in the premises of the HLPUG. The accounting department initiates the billing of a predetermined fee for each registered cancer case by the respective statutory health care providers. The health insurance providers also pay a fee to the reporting persons. This payment is also made by the accounting department. The process aims to ensure full registration while providing informative assessments.

The billing process is based on § 65c of the Social Security Statute Book (SGB) 5th Edition (V). The Technical Commission for the Statutory Health Care Providers in cooperation with the states have agreed a specific framework for the national electronic billing process. Information on this framework can be found at http://bit.ly/technische_anlage. All data included in the invoices is subject to an obligatory six-year storage period as per § 3 (5) and § 4 (3) of the Hessian Cancer Registry Act.

3. Categories of Personal Data

3.1. Processing of Tumour Disease Patient Data

In accordance with the Hessian Cancer Registry Act (HKRG), the Advisory Office receives personal data from all in- and outpatients via the reporting physicians. The incidence, treatment, and course of malignant neoplasms (apart from non-melanotic neoplasm), including early-stage cases, and benign tumours affecting the central nervous system are documented.

3.2. Processing of Death Certificates

In accordance with the HKRG, the Advisory Office receives the death certificates from the health authorities of those patients who died in Hesse. They are used to obtain information on the tumour disease mentioned in the death certificates and for survival rate analysis of tumour patients.

3.3. Processing of Registration Office Data

In accordance with the Registration Office Data Transmission Act (MeldDüV), the Advisory Office receives personal data from the Hessian Registration Authorities of persons who have changed their name, address, or gender. The data is used to update tumour patient data in the registry and to avoid incorrect assignment of data because of modified personal data.

3.4. Processing of Data from the Cancer Registries of Other States in accordance with the HKRG

Other states have also established state clinical cancer registries. A sharing of data between the registries is essential to ensure that patients who live in the catchment area of a cancer registry but who underwent treatment elsewhere are recorded in the correct registry.

4. Data Storage Period/Duration

In accordance with the HKRG, patient data (3.1 and 3.4) must be stored for a period of 20 years following the death of the patient, or if the patient's date of death is not known, the data should be deleted no later than 130 years after the date of birth.

As per the information security concept of the Advisory Office of the Hessian Cancer Registry, death certificates (3.2) are to be deleted 2 years after receipt from the health authorities should no relation be found to a patient in the cancer registry.

As per the information security concept of the Advisory Office of the Hessian Cancer Registry, registration office data (3.3) must be deleted 2 years after receipt from the registration authorities should no relation be found to a patient in the cancer registry.

5. Data Recipient Categories

Generally, personal data about you that is shared with us is processed exclusively by the Hessian Cancer Registry. However, in order for us to fulfil our obligations as per § 9 HKRG, it may be necessary for us to share your personal data with natural or legal persons, governmental departments, institutes, or other bodies.

Examples of other data recipients are:

- Cancer registries in other states
- Physicians and dentists in the State of Hesse with reporting obligations.
- Data recipients involved in scientific research projects.

The transferred data can only be used by the data recipient for the purpose for which it was requested. Transmission of the data to third parties is prohibited. The data must be deleted when it has served the purpose for which it was requested. The Advisory Office must be informed of the deletion (§ 9 (5) (2) HKRG)

6. Right of Access as per § 13 HKRG

At the request of a patient, carer, guardian, or a person authorized to report, the Advisory Office must inform in writing if and what type of personal data of the patient is stored (§ 13 HKRG).

Please contact the Advisory Office if you have further questions:

Advisory Office of the Hessian Cancer Registry
Lurgiallee 10
60439 Frankfurt am Main
Tel: +49 (0) 69 5660876-0
E-Mail: info@hessisches-krebsregister.de

7. Your Rights

The EU GDPR and the HDSIG (Hessian Data Protection and Freedom of Information Act) grant you rights, in particular, those stipulated in Articles 15 to 18, and 21 of the EU GDPR:

Right of Access:

Art. 15 EU GDPR allows you to request access to your personal data that has been processed by us. Your application for access should detail your request to facilitate the compilation of the data requested. Please note that your right of access is affected by regulations stipulated in § 24 (2), § 25 (2), § 26 (2) and § 33 of the HDSIG.

Right of Rectification:

If the details relating to your person are not or are no longer correct, Art. 16 EU GDPR allows you to demand rectification. If your data is incomplete, you can request completion.

Right to Erasure:

EU GDPR Art. 17 and § 34 HDSIG grant the right to request the deletion of your personal data. Your right to erasure depends on whether data requested for deletion is still required by us to fulfil our legal obligations.

Right to Restriction of Processing:

EU GDPR Art. 18 affords you the right to request the restriction of processing of data relating to your person.

Right to Object:

EU GDPR Art. 21 grants you the right to object to the processing of data relating to your person at any time for reasons resulting from your specific situation. § 5 HKRG clarifies the right to object for patients:

“The patient [...] can object to permanent storage by the Hessian Cancer Register or to the storage of data relating to the patient’s person. In the event of objection, the person obligated to report (i.e., the physician) must cease reporting to the Hessian Cancer Registry and inform that previously report data is to be deleted and any documentation destroyed.”

You can find further information on page 6.

Right of Appeal:

If you are of the opinion that data protection laws have not been adhered to during the processing of your data, you can lodge an appeal with the Hessian Data Protection Officer.

The Hessian Officer for Data Protection and Freedom of Information

Postfach 3163

65021 Wiesbaden

Tel: +49 (0) 611 1408-0

Fax: +49 (0) 611 1408-611

Responsibilities of the Advisory Office of the Hessian Cancer Registry

- Point of contact during the registration process
- Tumour documentation
- Reporting of the vital and tumour status to the reporting physicians

Responsibilities of the State Evaluation Office of the Hessian Cancer Registry

- Nationwide and regional evaluation of the incidence and treatment of cancer
- Evaluation of cancer treatments for the reporting physicians
- Initiation of regional quality assurance conferences focusing on cancer treatment

Responsibilities of the Accounting Department of the Hessian Cancer Register

- Billing the statutory health insurance providers
- Payment of remuneration for registration to the reporting physicians

You can find more information at:
www.hessisches-krebsregister.de



Advisory Office of the Hessian Cancer Registry

Hessian Medical Association

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State Evaluation Office of the Hessian Cancer Registry

Hessian State Examination Board and
Medical Investigation Office for Healthcare

Lurgiallee 10
60439 Frankfurt/Main

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Account Department for the Hessian Cancer Registry

Hessian State Examination Board and
Medical Investigation Office for Healthcare

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