

# WHAT RIGHTS DO YOU HAVE?

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A **complete registration** is essential in order to make reliable statements about the occurrence of cancer and the care of patients. It is not constructive if only part of the progressions of the disease – for example those that go particularly well – are reported. This would give a false picture of the treatment and have a negative impact on the research and improvement of treatment options.

The state's cancer registry law for the Rhineland-Palatinate therefore provides for no exception to the obligation to report cancerous diseases. As an afflicted person, however, you can object at any time to the permanent storage of identity data (name, address, health insurance information). Your data will then be made anonymous after performing the processing. This means that you as a person are then no longer recognisable by name. However, your medical information about cancerous diseases is retained for evaluation.

Objecting to the permanent storage has the consequence that your data cannot be provided to the attending physicians and hospitals. Moreover, we cannot contact you for you to give your consent to participate in research projects (such as for the development of new treatments).

You always have the right to apply to the **Cancer Registry of the RLP** through a physician named by you in order to be informed in writing about whether and possibly what data is stored about you and whether and by whom this data is accessed.



**Krebsregister**  
Rheinland-Pfalz



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Rheinland-Pfalz

## EVALUATE DATA

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## SUPPORT RESEARCH

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## FIGHT CANCER

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## CONTACT US

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## INFORMATION FOR PATIENTS



# DEAR PATIENT

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The diagnosis of your cancer means a turning point in your life so far. While a great deal of progress has been made in the treatment and curing of cancer to date, it is important to learn even more about the development and treatment of this disease.

For more than 20 years, there has been a population-based (epidemiological) cancer registry in the Rhineland-Palatinate.

After the early cancer diagnosis and registration law came into effect at the federal level, a population and treatment-based cancer registry was set up, which since then has been called the **Cancer Registry of the Rhineland-Palatinate GmbH**. The Cancer Registry of the RLP observes the occurrence of all cancers and their early forms, evaluates this data and thus provides a basis for research and quality assurance. The benefits of a cancer

registry for all patients depends mainly on the completeness and quality of the data collected. The information about your illness that your health care professional has to report to the Cancer Registry of the Rhineland-Palatinate based on the state's cancer registry law thus makes an important contribution to the research and treatment of cancer.

## We ask for your support!

## WHAT ARE THE DATA USED FOR?

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The Cancer Registry of the Rhineland-Palatinate records all of the information about the diagnosis, treatment and follow-up of a patient that is important for the doctor. A compilation of the information stored about your cancer can thus be accessed by your attending physician according to legally prescribed requirements.

The Cancer Registry of the RLP is therefore a valuable tool for the quality assurance of treatment and is of great importance for the direct support of the attending physician. Similar facilities exist in all German states.

## WHAT DATA IS REPORTED?

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The scope of information to be reported was determined uniformly nationwide and includes:

### 1 PERSONAL INFORMATION

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

### 2 MEDICAL INFORMATION ABOUT THE TUMOUR

- Diagnosis, localisation and spread of the tumour
- Date of diagnosis
- Type of diagnosis
- Type, start, duration and outcome of treatment
- Disease progression
- Vital status
- Reporting institution

## HOW IS YOUR INFORMATION PROTECTED?

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- 1 The data processing in the Cancer Registry of the Rhineland-Palatinate is strictly confidential and subject to medical supervision.
- 2 The technical and organisational measures to protect the data conform to the latest safety standards.
- 3 The work of the Cancer Registry of the Rhineland-Palatinate is accompanied by the State Commissioner for Data Protection and Freedom of Information of the Rhineland-Palatinate.
- 4 Any use of the data for quality assurance and for research purposes is done according to strict, legally prescribed requirements and without a name relation (encrypted / pseudonym).
- 5 If your name is required for specific research projects, you will be notified in advance for your consent. This information will only be used if you have expressly consented to its usage.