

1 Population-based cancer registration in Germany

1.1 Objectives and tasks of population-based cancer registries

Population-based cancer registries are facilities for collecting, storing, processing, analysing and interpreting data that reflect the occurrence, course and, in some cases, the treatment of cancer in defined registration areas (e.g. a federal state). However, the data from these registries are also an indispensable basis for further studies in the search for the causes of carcinogenesis, for the assessment of early detection measures and for the care of tumour patients in a region. Findings from population-based cancer registries include:

In Germany, around 500,000 people are newly diagnosed with cancer every year.

Data from population-based cancer registries can be used to describe the incidence of cancer, i.e. the frequency with which cancers occur per year in a specific population. The incidence is calculated according to cancer type, age and gender as well as other characteristics. Reliable data on incidence is an indispensable prerequisite for describing the extent and type of cancer burden in a population.

For some years now, the incidence of lung cancer among women under 50 in Germany has been almost as high as among men of the same age.

Only with data from population-based cancer registries can the development (trend) of incidence over time be reliably observed. The registries play a central role in monitoring these trends as part of health reporting.

Regional differences in the incidence of malignant melanoma of the skin can be observed within Europe and Germany.

Population-based cancer registries can analyse the spatial distribution of cancers. They also have the task of analysing observed clusters of cancers. Further clarification of these clusters with regard to possible causes usually requires targeted analytical studies.

In recent years, the prospects of survival after cancer have largely converged in eastern and western Germany.

Population-based cancer registries carry out survival analyses on all patients suffering from cancer in their region. Population-based survival rates are an important parameter for evaluating the effectiveness of diagnosis, treatment and aftercare for cancer.

German registry data is also regularly used for large international comparative studies of survival rates, e.g. within Europe.

Between 2015 and 2030, the number of new cancer cases in Germany is expected to rise by around 23%, primarily due to demographic trends.

The forecast of the future number of new cancer cases is an important aspect of demand planning in the healthcare system, which can be determined on the basis of the registries.

The data from population-based cancer registries are also used for research into the causes of cancer, for the assessment of early cancer detection and for healthcare research. Corresponding studies investigate questions such as:

- ▶ What are the causes of childhood leukaemia?
- ▶ Are women who receive hormone replacement therapy for menopausal symptoms more likely to develop breast cancer?
- ▶ Does lung cancer occur more frequently in people in a certain occupational group?
- ▶ Is there an increased incidence of cancer in the vicinity of oil and gas production facilities?
- ▶ Does early detection of skin cancer lead to a reduction in advanced tumour stages in the population?
- ▶ Are there differences in the care of oncological patients depending on where they live (e.g. between urban and rural regions)?
- ▶ How quickly are new or updated guideline recommendations implemented in practice?

Population-based cancer registries enable all cases of cancer occurring in a defined population to be considered for research projects. The protection of the privacy of those affected and the patient's right to informational self-determination require comprehensive precautions for the protection and safeguarding of personal data, which are guaranteed in all epidemiological registries by state law. For certain studies, especially those that involve additional surveys or data collection, the consent of those affected is also a prerequisite. If participation is high, it can be largely ensured that the results of such studies are reliable and robust. Population-based case-control studies and cohort studies therefore utilise data from population-based cancer registries to research the causes and risks of cancer.

Further and more specific questions can also be analysed based on the registry data, for example:

- ▶ Detailed analyses of survival prospects after cancer
- ▶ Investigating the quality of life of long-term cancer survivors
- ▶ Occurrence of secondary tumours after treatment of the first tumour
- ▶ Evaluation of cancer screening measures, such as mammography screening or colon cancer screening, in particular early detection colonoscopy
- ▶ Studies on the relationship between socioeconomic class and cancer incidence and mortality
- ▶ Cooperation with the cancer centres, e.g. in assessing the long-term survival of patients treated there.

One focus of the analyses with data from the population-based cancer registries in recent years has been survival after cancer, one of the most important outcome parameters in oncological care. Together with the German Cancer Research Centre (DKFZ) in Heidelberg, researchers from the cancer registries and the Centre for Cancer Registry Data (ZfKD) were able to investigate survival after cancer in detail and publish their findings internationally. For the first time, rare tumours were also investigated and 10-year survival rates were published. A total of around 50 publications were produced on this topic. Survival after diagnosis of selected tumour types was also compared with international data, particularly with the US SEER (Surveillance, Epidemiology, and End Results) registries. Overall, the results for people with cancer in Germany are very good. However, there are also diagnoses, e.g. breast cancer in women over 75, where survival rates in Germany are lower than in the USA. Such differences may have various causes, which will be investigated in more detail in in-depth studies.

A particular challenge for population-based cancer registries is the evaluation of organised cancer screening programmes introduced in Germany. For example, the data from population-based registries can be used to assess whether and to what extent a reduction in advanced cancers is occurring in the target population. By linking the cancer registry data with the data of the respective early detection programme, the aim is also to show the desired reduction in mortality among participants in such a measure. An initial focus is the evaluation of the mammography screening programme, which has been introduced throughout Germany since 2009. For many years, the population-based cancer registries have routinely provided data for the evaluation reports on mammography screening (<https://fachservice.mammo-programm.de/>), which are used for quality assurance and assessments of the programme. Another complex task is the identification of interval carcinomas (occurrence of breast cancer within two years of a negative screening

examination). Some results from individual federal states have already been published and show that the targets set out in the European guidelines are being achieved there.

The cancer registry data is also used in the evaluation of (opportunistic) skin cancer screening. In addition, the use of cancer registry data for the evaluation of the screening programmes for colorectal cancer and cervical cancer, which have been redesigned on the basis of the Cancer Screening and Registry Act (KFRG), will start in 2024 – with an invitation and information system and continuous quality and success monitoring – in order to investigate the effects of the two screening programmes, which have been introduced at population level in July 2019 and January 2020, respectively.

A longer-term task of the population-based cancer registries is also to review the effectiveness of the vaccination against human papillomavirus (HPV) for girls and boys aged 9 to 14, which aims to reduce the number of HPV-related cancers. Among women in particular, a significant reduction in new cases of cervical cancer and its precursors is expected.

The population-based cancer registries are also involved in the NAKO, a national health study with 200,000 participants. Over the long-term course of the study, the cancer registries provide information on the occurrence of new cancers in the participants, provided they have agreed to a corresponding data linkage. This provides crucial support for research into the causes of cancer development.

Comprehensive, population-based cancer registries are required to fulfil the aforementioned objectives and tasks of cancer registration. This comprehensive coverage has been enshrined in law in all federal states since 2009. In addition, following the entry into force of the Federal Cancer Registry Data Act in the same year, the possibilities for the consolidation and analysis of cancer registry data at federal level were further improved by the establishment of the Centre for Cancer Registry Data (ZfKD) at the Robert Koch Institute (RKI).

In order to be able to consolidate information on a person's cancer from different sources, the data in the cancer registries is recorded in a way that enables multiple reports to be linked to the same person.

A reliable analysis of the data is only possible with a high level of coverage (at least 90% of all cancers). This is why the cooperation of all doctors and dentists involved in diagnosis, treatment or aftercare is crucial for the informative value of the data from a population-based cancer registry. Patients should also be encouraged to actively participate in cancer registration. Ask your attending physician to report the relevant data on your illness to the relevant cancer registry! In this way, you may contribute to a better assessment of the epidemiological incidence

of cancer, to cancer research and thus also to the improvement of cancer detection, treatment and follow-up care.

1.2 Current development of cancer registration in Germany

Since 2009, all new cancer cases have been systematically recorded throughout Germany on the basis of federal and state laws. Since the end of 2011, all state cancer registries have provided their data annually in a standardised format to the ZfKD at the RKI. These data form the basis for the analyses carried out by the ZfKD, which are presented in this 14th edition of *Cancer in Germany*.

A milestone in the further development of cancer registration in Germany was the passing of the Cancer Early Detection and Registry Act (KFRG) in 2013. In consequence, all federal states were obliged to establish an extended clinical cancer registration for quality assurance purposes in addition to the epidemiological cancer registration, including the collection of detailed data on therapy and the course of the diseases. This has now been established in all federal states; in most federal states, epidemiological and clinical cancer registration have been combined into one integrated registration. The technical implementation of nationwide clinical cancer registration in clinics and practices is largely complete, and diagnosis, treatment and the course of the disease are comprehensively documented. This successful changeover was a major challenge not only for doctors and the documenters in surgeries and clinics, but also for the registries themselves. At the end of 2020, all registries were able to fulfil the funding criteria previously agreed upon with the statutory health insurance funds.

This is also reflected in an improved data basis for this report (see Chapter 2). The estimated incidence for the most recent diagnosis years (2019–2020) corresponds to the recorded incidence in 13 of 16 federal states and thus for around 95% of the population. For the Eastern federal states, the ZfKD currently only has data that was transmitted by the Joint Cancer Registry shortly before its dissolution at the end of 2022. In the meantime, the respective state cancer registries are responsible for epidemiological reporting and therefore also for transmitting the data to the ZfKD themselves. However, the necessary adjustments (e.g. for the linkage with the mortality data) have not yet been established everywhere, and in some cases the relevant state laws have not yet been adapted. Although the estimated incidence for 2020 nationwide is only around 1% higher than the num-

ber of new cancer cases counted, it was nonetheless decided to postpone the final step from estimating to counting the nationwide incidence until the processing of data from all federal states has been finally established at the ZfKD.

The “Act on the Consolidation of Cancer Registry Data”, which came into force at the end of August 2021, stipulates that from the end of 2022, the main data on therapy and disease progression collected as part of clinical cancer registration will also be consolidated nationwide at the ZfKD. The primary aim of the law is to improve the possibilities for the scientific utilisation of data from German cancer registries. The extended dataset can be applied for at the ZfKD since mid-2023 – the first applications have already been received. With the newly established external scientific committee, the ZfKD has developed guidelines for the evaluation of applications, which primarily implement the assessment of the re-identification risk required by law.

In addition, the deadline for data transmission was reduced from two years to one year after the end of a calendar year. The data set delivered to the ZfKD for the first time at the beginning of 2023 should therefore already include cancers newly diagnosed in 2021. However, an analysis of the data revealed that, at the time of data delivery, not all federal states had succeeded in shortening the time periods for the reporting process and the data processing in the registries, which had become even more complex due to the clinical data. Also due to the incidence rates, which were influenced by the COVID-19 pandemic at least in 2020 and are therefore difficult to forecast for the following years (see 3.1), it was therefore decided not to extend the reporting period for this edition to 2021 and to skip the usual short-term forecast of incidence rates (through 2024) this time.

In a further step, a concept for a platform solution for the cross-regional use of high-resolution data, available in the registries but not at the ZfKD, is currently being developed by multiple stakeholders and will be available by the end of 2024. The improved dovetailing of cancer registration in the paediatric and adult sectors is the focus of another multidisciplinary working group.

In order to further standardise cancer registration in Germany and coordinate state-specific regulations, the “Platform §65c” was founded in 2015 with experts from all clinical cancer registries. In recent years, the platform has already supported the practical implementation of the KFRG across federal state borders, proposed a common approach to open questions, defined national standards and created synergies in IT implementation. The Association of Population-based Cancer Registries in Germany (GEKID) and the Association of German Tumour Centres (ADT) actively support the platform. The ZfKD is also

involved here, as the harmonisation of data is an important prerequisite for the high quality and usability of the nationwide dataset.

The data from the German cancer registries will also continue to be utilised at an international level. Together with data from other European countries, these are presented on the websites of the ENCR (European Network of Cancer Registries) and the JRC (Joint Research Centre, European Commission) (see www.encre.eu). In ECIS – the European Cancer Information System – the German data can be compared with data from other European registries.

The GEKID, which includes researchers from the field of cancer epidemiology as well as all population-based cancer registries, has continued to focus intensively on the regional presentation of cancer registry data in recent years. The GEKID's interactive cancer atlas on current cancer incidence and cancer mortality in the federal states has been completely redesigned for this purpose. In addition to incidence and mortality, the aspect of survival was analysed on a small area level at the level of districts and urban municipalities. This means that the cancer data can be viewed and compared in the overall German overview with interactive tools in regional resolution. The atlases can be accessed via the GEKID website at www.gekid.de and offer interactive comparisons in cartographic form for 26 cancers.

Beyond the mere presentation of cancer registry data, the population-based cancer registries and the GEKID have participated in the planning and implementation of cancer epidemiological research projects. Information on further research work and current publications can be found on the GEKID homepage and in the appendix to this report.

These examples illustrate that the focus of population-based cancer registration in Germany has shifted from pure data collection or case counting to active scientific utilisation of the data. This development is of essential importance, because without in-depth scientific analyses, the knowledge gained from the collected data would be limited. Finally, the anonymised data compiled from all registries can also be used by external researchers upon application to the ZfKD – a possibility that will certainly become even more important as the database expands over time. In certain cases, the new “Act on the Consolidation of Cancer Registry Data” also permits the scientific use of pseudonymised individual data. The numerous contributions of the cancer registries and the ZfKD have also become an important component of health reporting.

The collection of clinical data, which now covers not only the occurrence but also the entire course of oncological diseases, has ushered in a completely new era in Germany. The data from the cancer registries can now be used for comprehensive quality assurance and increasingly also for healthcare research. In the foreseeable future, they will also allow detailed analyses of cancer care under pandemic conditions and thus supplement the more readily available but inevitably limited analyses of health insurance or hospital data.

This will further increase the importance of cancer registration for oncological research and care and thus also the benefits for patients with cancer. Overall, the current development of cancer registration and utilisation of data on cancer incidence in Germany is positive and has considerable prospects for the future. With its comprehensive clinical cancer registration, Germany has become an international leader in this field.