

1 Population-based cancer registration in Germany

1.1 The aims and purposes of population-based cancer registries

Population-based (epidemiological) cancer registries are used to collect, store, process, analyse and interpret data on cancer incidence, prevalence, survival and, in some cases, care in a defined coverage area (such as a federal state). Additionally, data from these registries are indispensable as a basis for conducting detailed studies of the causes of carcinogenesis, for the evaluation of cancer screening programmes and for analysing cancer care in a particular region. Findings from population-based cancer registries include:

Almost 500,000 people are newly diagnosed with cancer in Germany every year.

Population-based cancer registries can provide information on annual cancer incidence – the frequency with which cancer occurs in a given population in a particular year. These statistics are stratified by type of cancer, a person's age and sex, and by other factors. Reliable figures on cancer incidence are essential for assessments of the extent and type of cancer burden that populations are exposed to.

For some years now, a similar incidence of lung cancer in Germany has been identified among women under the age of 45 as among men of the same age.

Reliable studies of time trends in incidence are only possible with data from population-based cancer registries. Consequently, cancer registries play a vital role in health monitoring to identify temporal changes in incidence.

The prevalence of malignant melanoma of the skin differs between regions in Europe and Germany.

Population-based cancer registries can analyse the spatial distribution of cancer and are responsible for monitoring cancers clusters. However, detailed assessments of clusters aimed at developing causal explanations usually require more targeted analytical studies.

In recent years, cancer survival estimates have almost converged in eastern and western Germany.

Population-based cancer registries analyse survival statistics for the cancer patients in their region. Survival rates derived from population-based data are important indicators of the effectiveness of cancer diagnosis, treatment and aftercare. Furthermore, registry data from Germany are also regularly

included in large international comparative studies of survival rates.

Between 2015 and 2030, new cancer cases are expected to rise by around 23 % in Germany. This rise will mainly be due to demographics.

Estimates of the future number of new cancer cases play an important role in needs-based health planning, and they can be calculated using data from cancer registries.

Research into the causes of cancer, the evaluation of cancer screening programmes, and healthcare research also rely on data from population-based cancer registries. Studies from these fields focus on answering questions such as:

- ▶ What are the causes of childhood leukaemia?
- ▶ Do women who receive hormone replacement therapy for menopausal symptoms develop cancer more frequently?
- ▶ Are lung cancer rates higher among certain occupational groups?
- ▶ Do cancers occur more frequently in the vicinity of oil and gas production facilities?
- ▶ Does skin cancer screening lead to a decline in the numbers of advanced tumours in the population?
- ▶ Do differences exist in the care provided to oncological patients according to where they live (such as differences between urban and rural areas)?
- ▶ How quickly are new or updated healthcare guidelines implemented?

Data from population-based cancer registries enable researchers to study the entire breadth of the cancer cases that have occurred within a particular population. The protection of privacy and patients' rights to informational self-determination, however, mean that robust measures are needed to protect and safeguard personal data. Moreover, legislation is needed at federal-state level to ensure that all epidemiological registries uphold these rights. For certain studies, researchers must acquire the consent of the people affected; this is often the case when additional information must be obtained to supplement the cancer registry data. Such studies that maximise participation generally can provide reliable and robust results. Population-based case-control and cohort studies, for example, use data from population-based cancer registries to investigate the causes of cancer and the risk of developing the disease.

Data from cancer registries can also be used to conduct research into more detailed and specific issues including:

- ▶ Detailed analyses of cancer survival rates
- ▶ Studies into quality of life among long-term cancer survivors
- ▶ The risk of developing subsequent tumours after surviving a primary tumour
- ▶ Evaluations of cancer screening measures, such as mammography and colonoscopy screening
- ▶ Studies of the relationship between socioeconomic position and cancer incidence/mortality
- ▶ Cooperation with cancer centres, including the assessment of their patients' long-term survival rates

In recent years, cancer survival has become a focus of research using data from population-based cancer registries and is now a key parameter in oncological care. Together with the German Cancer Research Center (DKFZ) in Heidelberg, researchers from cancer registries and the German Centre for Cancer Registry Data (ZfKD) have examined cancer survival rates extensively. The results of their research have been published internationally. For the first time, studies have also been conducted into rare tumours in Germany, with findings published on 10-year survival statistics. The researchers have published about 50 papers on this topic and have also compared survival rates in Germany with results from other countries, particularly using data from the SEER registries (Surveillance, Epidemiology, and End Results) in the US. Overall, the studies identified very good results for Germany. Nevertheless, the researchers have also found cases, such as breast cancer in women over 75, where the results for Germany were poorer than those for the US. Such differences can have various causes, and in-depth studies can be used to analyse them in more detail.

The evaluation of the organised cancer screening programmes that have been introduced in Germany poses a particular challenge for population-based cancer registries. Data from the registries can be used to demonstrate whether and to what extent screening is leading to the intended decline in advanced-stage cancers in the population. Linking cancer registry data to data from screening programmes can also help show whether mortality is lower among screening participants. Breast cancer screening, which was introduced nationwide in Germany in 2009, is an initial focus in this area. Data from population-based cancer registries are routinely employed to evaluate breast cancer screening (<https://fragen.mammo-programm.de/en/>), and the findings are used for quality assurance purposes and programme evaluation. The registries are also responsible for identifying interval cancers (the development of breast cancer within two

years of a negative screening test result). Initial findings from some federal states have already been published and demonstrate that Germany is meeting the targets set out in the European guidelines.

Cancer registry data are being used to evaluate (opportunistic) skin cancer screening. Moreover, the usage of cancer registry data for the evaluation of the reorganised colorectal and cervical cancer screening programmes (with invitation and continuous monitoring of quality and success) according to the Cancer Screening and Registry Act (KFRG) is intended, in order to analyse the impact of both screening programmes (operating since July 2019 and January 2020) at the population level.

Population-based cancer registries also play a role in the long-term monitoring of the efficacy of the human papillomavirus (HPV) vaccination, which is currently recommended for both girls and boys between the ages of 9 and 14 years. This vaccine aims to reduce all HPV-related cancers and, in particular, is predicted to lead to a significant reduction in the number of new cases of cervical cancer and its precursors among girls.

Population-based cancer registries are also involved in the German National Cohort, a long-term, national health study with 200,000 participants. The cancer registries provide information on the incidence of new cancers among participants who have consented to such data linkage. This supports research into the causes of cancer in a substantial way.

Nationwide coverage of population-based cancer registries is crucial to fulfilling the aims and purposes of cancer registration. Since 2009, nationwide data collection has been established by federal-state law. In addition, the enactment of the 2009 Federal Cancer Registry Data Act (BKRG) and the establishment of the German Centre for Cancer Registry Data at the Robert Koch Institute (RKI) have provided greater opportunities to analyse anonymous cancer registry data at the national level.

In order to assemble data about individual cancer cases from various sources, data in the cancer registries are recorded in a manner that enables multiple reports to be linked to the same person.

Reliable studies require a high rate of registry completeness, defined as recoding at least 90% of all cancers occurring in the population. Therefore, the cooperation of all doctors involved in diagnosis, treatment and aftercare is vital to ensure the quality of data from population-based cancer registries. Patients should also be encouraged to actively participate in cancer registration and can request that their doctors report the relevant data on their illnesses to the respective cancer registry. Doing so enables patients to help improve epidemiological cancer analysis, cancer research and, thus, cancer detection, treatment and aftercare.

1.2 Current developments in cancer registration in Germany

Since 2009, all new cancer cases have been systematically recorded following federal-state and national legislation. Since the end of 2011, all federal state cancer registries have delivered their data annually in a uniform format to the German Centre for Cancer Registry Data (ZfKD) at the Robert Koch Institute (RKI). This data forms the basis for the evaluations carried out by the ZfKD, which are presented in this 13th edition of »Cancer in Germany«.

The Cancer Screening and Registry Act (KFRG) in 2013 constituted a further milestone in the development of cancer registration in Germany. With this law, all federal states were obliged to establish an extended clinical cancer registration for quality assurance purposes in addition to the epidemiological cancer registration. Detailed data on therapy and the course of the diseases are now also recorded. In the meantime, this has been established in all federal states, while in most of them the epidemiological and clinical cancer registrations have been combined into one integrated registration. The technical implementation of nationwide clinical cancer registration in clinics and practices has been largely completed, and diagnosis, treatment and also the course of the disease are comprehensively documented. This successful conversion was a great challenge not only for doctors and the documenters in practices and clinics, but also for the registries themselves. By the end of 2020, all registries were able to meet the funding criteria previously agreed with the statutory health insurance funds. This is also reflected in an improved data basis for the present report (see Chapter 2). However, it does not apply to the eastern German federal states at the moment, which is not due to insufficient registration but to a change in data flows: Last year, these federal states decided to transfer all cancer registration tasks (including epidemiological reporting at federal state level and data delivery to the ZfKD) to the federal state cancer registries, which were previously only responsible for clinical cancer registration. For this reason, the Joint Cancer Registry, which was founded in the mid-1990s as the successor institution to the epidemiological cancer registry of the GDR, will be dissolved. Since the legal basis in the affected federal states still has to be adapted for this, the ZfKD currently has only insufficiently complete data from the new federal states and Berlin: a major reason why the nationwide incidence still has to be estimated. It can be assumed that the corresponding data flows will be newly regulated and organised in two years at the latest, i.e. in time for the next edition of »Cancer in Germany«.

With the new amendment to the Act on Cancer Registry Data, which came into force at the end of August 2021, it was stipulated that from the end of

2022 essential data on therapy and disease progression collected within the framework of clinical cancer registration will also be merged nationwide at the ZfKD. Thereby, the data basis for reporting at the federal level will be considerably expanded and, by bringing forward the data delivery by one year, will also be significantly more up-to-date. The law is primarily intended to improve the possibilities for the scientific use of data from German cancer registries. The expanded data set can be applied for at the ZfKD from 2023. In a further step, a concept for a platform solution for the cross-regional use of high-resolution cancer data, which is available in the registries but not at the ZfKD, will be developed by the end of 2024 to allow project-specific merging of data. Also, by the end of 2024, a concept is to be developed for an improved coordination of cancer registration in the paediatric and adult sectors.

By mid-2022, the registries and the ZfKD will determine the final data set for the annual data delivery. The content framework for this is already specified in the law. Particularly for variables in which the cancer registries frequently combine information from several reports (so-called »best of procedures«), specifications must still be made to ensure the greatest possible comparability of the data from different registries.

In order to further standardise cancer registration in Germany and to coordinate state-specific regulations, the »Plattform §65c« was founded in 2015 with experts from all clinical cancer registries. In recent years, this platform has already accompanied the practical implementation of the KFRG across state borders, proposed a joint approach where possible in the case of outstanding issues, defined national standards and created synergies in IT implementation. The Association of Epidemiological Cancer Registries in Germany e.V. (GEKID) and the Association of German Tumour Centres (ADT) actively support the platform. Meanwhile, the ZfKD is also involved here, because the harmonisation of data is an important prerequisite for high quality and usability of the nationwide data set.

Data from the German cancer registries continue to be used at the international level. These data are presented together with those from other European countries on the websites of the ENCR (European Network of Cancer Registries) and the JRC (Joint Research Centre, European Commission) (see www.enccr.eu). In ECIS – the European Cancer Information System – the German data can be compared with data from other European registries.

The GEKID, which includes all population-based cancer registries as well as researchers from the field of cancer epidemiology, has worked intensively on the

small-scale presentation of cancer registry data over the past two years. The GEKID's Interactive Cancer Atlas on current cancer incidence and cancer mortality in the federal states has been expanded by another atlas on cancer incidence at the level of districts and urban municipalities. For the first time, cancer data can be viewed and compared in the all-German synopsis with an interactive tool in fine regional resolution. The atlases can be accessed via the GEKID website at www.gekid.de/home and offer interactive comparisons for 26 cancer localisations in cartographic form.

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

These examples illustrate that the focus of population-based cancer registration in Germany has shifted from pure data collection to the active scientific use of data. This development is of essential importance, because without in-depth scientific analyses, the knowledge gained from such painstakingly collected data would be limited. Finally, the anonymised data sets compiled from all registers can also be used by external scientists upon application to the ZfKD – an option that will certainly gain in importance with the expansion of the database. In certain cases, the renewed legal framework also allows scientific use of pseudonymised individual data. Numerous contributions of the cancer registries and the ZfKD have also become an important component in health reporting.

By collecting comprehensive clinical data, which now covers not only the occurrence but the entire course of oncological diseases, a completely new era has been introduced in Germany. Data from the cancer registries can now be used for comprehensive quality assurance and increasingly also for health services research. In recent years, these data will also allow, among other things, detailed analyses of cancer care under pandemic conditions, thus complementing the more readily available but inevitably limited data of statutory health insurances or hospitals.

The importance of cancer registration for oncological research and care, and hence the benefit for patients with cancer, will continue to increase. Overall, the current development of cancer registration and the use of data on cancer incidence in Germany can be assessed positively and has considerable prospects for the future. With nationwide clinical cancer registration, Germany has risen to the top countries in this field.