

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, treatment 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 cancer clusters. However, detailed assessments of clusters aimed at developing causal explanations usually require more targeted analytical studies.

In recent years, cancer survival estimates have largely 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, reg-

istry 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 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 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 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 skin cancer screening. Screening for colorectal and cervical cancer is currently being reorganised according to the Cancer Screening and Registry Act (KFRG). The KFRG calls for the use of cancer registry data in the evaluation of the impact of screening programmes 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 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; this is essential for research purposes.

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, new cancer cases in Germany are systematically reported in accordance with federal-state and national legislation. The 2013 Cancer Screening and Registry Act (KFRG) constituted a further milestone in the development of cancer registration in Germany. In addition to epidemiological cancer registration, the KFRG stipulates that each federal state is to establish an extended system of clinical cancer registration for quality assurance purposes. The resulting registries also record detailed data on treatment and course of the disease. Each federal state in Germany must have established a clinical cancer registry by the end of 2020. Most federal states have already integrated their epidemiological and clinical cancer registries into single institutions.

The establishment of nationwide clinical cancer registration posed major challenges for registries, clinics, practices and doctors. Greatly expanded data collection requirements, not just concerning the primary diagnosis, but also covering the course of the disease – in particular recurrence, progression and changes in treatment – represented new territory for everyone involved. The need to invoice health insurance funds, which cover 90% of the operating costs of the clinical cancer registries, posed a further hurdle. At the same time, staff had to be recruited and trained, and IT infrastructure adapted. These challenges initially caused delays in data processing in some federal states, and this is reflected in the data pool available for this report (see Chapter 2). By the end of 2019, these problems have been largely overcome. Over the next few years, clinical cancer registration is expected to improve the data available for epidemiological reporting in areas such as the completeness of information on tumour stage.

Population-based cancer registration also receives support from the federal level, as demonstrated by the enactment of the 2009 Federal Cancer Registry Data Act (BKRG) and the establishment of the German Centre for Cancer Registry Data (ZfKD) at the Robert Koch Institute. Since the end of 2011, all regional cancer registries have used a standardised format to provide the ZfKD with pseudonymised data on an annual basis. These data provide the foundation of the analyses undertaken by the ZfKD for this 12th edition of »Cancer in Germany«.

Discussions are currently taking place as to whether and how clinical data on treatment and disease progression can be pooled at the national level. The aim is to enhance health reporting capabilities at the national level as well as to facilitate and improve

access to data for research projects spanning multiple regions, such as those in the field of healthcare.

A working group has been established to further standardise cancer registration in Germany and to coordinate the various federal-state regulations. The working group, which includes representatives from all federal states, receives support from the »Platform §65c«, named after the section of federal code covering clinical cancer registration, which provides experts from the registries. Over the past few years, this platform has assisted with the practical implementation of the KFRG across federal-state borders, sought to develop common registry procedures, set 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.

In order to promote further harmonisation and standardisation, GEKID and ADT have published a cancer registration manual that provides detailed guidelines on the collection and analysis of epidemiological and clinical cancer registry data.

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 European Network of Cancer Registries (ENCR) and the Joint Research Centre (JRC) of the European Commission (see www.encre.eu). The German data can easily be compared with data from other European registries using the European Cancer Information System (ECIS).

Over the last two years, the GEKID, which counts cancer epidemiology researchers in addition to the population-based cancer registries among its members, has continued to focus intensively on improving the use of cancer registry data. Updating GEKID's Interactive Cancer Atlas to reflect current cancer incidence and mortality rates throughout the federal states is just one important result of this work. In addition to data on incidence and mortality, the atlas now provides information about regional cancer survival rates. The atlas can be accessed via GEKID's website at www.gekid.de/home, which provides an interactive map that can be used to compare data from the federal states for 27 cancer sites.

In addition to presenting cancer registry data, the population-based cancer registries and GEKID have participated in planning and implementing epidemiological cancer research projects. Information on additional projects and recent publications can be found on GEKID's website and in the appendix of this report.

These examples demonstrate that epidemiological cancer registration in Germany is currently shifting away from the mere collection of data towards the

active use of data for scientific research. This development is extremely encouraging because the knowledge gained from such painstakingly collected data would otherwise remain limited if not for their use in scientific investigations. Finally, researchers can also apply to the ZfKD to access the anonymised data compiled by the registries. The number of such applications has continued to increase in recent years. Furthermore, the numerous publications by the cancer registries and the ZfKD represent important contributions to Federal Health Reporting.

The collection of clinical cancer data represents the beginning of a completely new era. In the future, cancer registry data will contribute to comprehensive quality assurance and, increasingly, healthcare research. In turn, this will strengthen the relevance of cancer registries in oncological research and healthcare provision, thus providing further benefits to cancer patients. Overall, the current developments in cancer registration and data use in Germany are favourable and demonstrate considerable potential for the future. Moreover, nationwide clinical cancer registration has placed Germany at the forefront of this field.

1.3 Current priorities of the German Centre for Cancer Registry Data (ZfKD)

The developments in nationwide clinical cancer registration in Germany described above have also had an impact on the ZfKD: far-reaching new responsibilities and duties have led to temporary delays to data processing, which subsequently have resulted in substantially fewer case reports from registries that have otherwise provided many years of robust and reliable data. By the editorial deadline for this report, data from some federal states were only available through 2015 (see Chapter 2.1). Up to that point, the incidence estimation method was predicated on a steady improvement in cancer registration with the goal of transitioning to a pure count of cases in the future. The method was unable to compensate for the temporary underdetection of cases. Therefore, in 2018, the ZfKD postponed publication of new estimates and fundamentally revised the methodology used to estimate incidence (see Chapter 2.2). Nonetheless, the nationwide reorganisation of cancer registration means that the ZfKD's statistics will be based on an improved data pool in the years ahead.

As clinical and epidemiological cancer registration become increasingly integrated, it is important to

track the evolution of data quality systematically, thereby promoting the harmonisation of cancer registration in Germany while fostering data usability. This applies not only to the completeness of case and death notification, but also to the completeness and validity of information on diagnoses, including tumour stages and further tumour-related characteristics. In the future, this will also apply to data on the course of disease (including information about recurrence and progression). As the coordinating body for epidemiological cancer registry data, the ZfKD will increasingly undertake comparative analyses to ensure that data abnormalities are systematically reported back to the respective registry.

Over the two years since publication of the previous report, the ZfKD's scientific publication activities have strengthened its work with other institutions. One example is a joint project with the RKI's Social Determinants of Health Unit, which, for the first time, examined the correlation between regional socioeconomic characteristics and cancer incidence across Germany. Further in-depth analyses of this topic are planned for the future. In addition to well-established collaboration with researchers from cancer registries and the German Cancer Research Center (DKFZ), there is increasing demand for cooperation between the RKI and clinicians on scientific publications. These efforts have resulted in publications on rare tumours, such as cholangiocarcinoma. In addition to epidemiological short reports published regularly in the journal »Der Onkologe«, recent scientific publications have also focused on the impact of obesity and HPV infections on cancer incidence, as well as on changes in cancer survival rates since 2002.

Health reporting efforts are focused on the development of new fact sheets and website improvement (www.krebsdaten.de/english). Preparatory work has begun on the second »Report on Cancer Developments in Germany«, which is scheduled for 2021. A particular feature of this series of reports is the analysis of additional data sources and published research in the context of findings from cancer registration. Thus, in addition to epidemiological trends, a wide range of developments, including the fields of oncology care and cancer screening, are identified and discussed in more detail.

Since 2016, the ZfKD has received approximately 10 applications per year for external use of cancer registry data, almost all of which have been approved.

Over the past two years, the ZfKD has also responded to more than 200 inquiries from students, the press, experts, politicians and others from the general public.

The ZfKD's website (www.krebsdaten.de/english) provides information on current projects and activities.