Asian Journal of Current Research in Clinical Cancer
ISSN: 3062-4444
2021, Volume 1, Issue 1, Page No: 60-70

Available online at: www.galaxypub.co/page/journals

Galaxy Publication

Germany's Population-Level Cancer Registry for Clinical Data

M. Petrovic[1*], S. Jovanovic[1], A. Milosevic[1]

[1]Department of Radiation Oncology, Faculty of Medicine, University of Belgrade, Belgrade, Serbia.

***E-mail** ✉ radiation.oncology.5@gmail.com

Received: 15 January 2021; **Revised:** 29 March 2021; **Accepted:** 05 April 2021

ABSTRACT

In 2013, a federal mandate required all German states to collect additional clinical information within population-based cancer registries to actively monitor and enhance cancer care quality, improve transparency, and support health research. A decade later, we present the current state of this expanded cancer registration, including recent statistics on cancer in Germany. Cancer reporting is compulsory for physicians, with each case typically generating 5–10 reports from various healthcare providers. A standardized national dataset of approximately 130 items is utilized, and reports are generally submitted electronically. We analyzed the latest available registry data up to cases diagnosed in 2019. Incidence rates and 5-year relative survival (5YRS) for common cancers were calculated. Clinical outcomes and guideline-based quality indicator (QI) benchmarking were provided by the Cancer Registry Schleswig-Holstein (CR SH). All state cancer registries fulfilled most national eligibility requirements. In 2019, around 505,000 cancer cases were documented, with breast, prostate, colorectal, and lung cancers being the most frequent. Age-standardized incidence showed a slight decline over the past decade, and geographic variations within Germany were observed. The overall 5YRS was 67% for women and 63% for men. Therapy data for rectal cancer from 2019–2021 in CR SH illustrate that 69% of patients underwent surgery—mostly curative (84%) with tumor-free resection (91%). Radiotherapy was administered to 33% and chemotherapy to 40% of patients. Three selected QIs revealed differences across healthcare providers. The establishment of population-based clinical cancer registration in Germany can be regarded as successful. Detailed documentation of diagnosis, treatment, and disease progression, along with the use of registry data for quality assurance, benchmarking, and feedback, has been effectively implemented.

Keywords: Benchmarking, Germany, Cancer registration, Cancer, Quality assurance, Incidence

How to Cite This Article: Petrovic M, Jovanovic S, Milosevic A. Germany's Population-Level Cancer Registry for Clinical Data. Asian J Curr Res Clin Cancer. 2021;1(1):60-70. https://doi.org/10.51847/kl5vIhWrpD

Introduction

Cancer registration has a long-standing history in Germany. The first regional cancer report, published in 1902, presented cancer prevalence using maps [1]. The Hamburg Cancer Registry was established in 1927, followed by other regional registries over subsequent decades. In 1980, the German Childhood Cancer Registry (GCCR) was founded. However, it was only in 1994 that a federal law mandated all German states to create population-based cancer registries (CRs), with the primary goal: "Cancer registries shall monitor and evaluate cancer incidence and trends, provide data for epidemiological research, including causal research, and contribute to the evaluation of preventive and curative interventions" [2]. Most states implemented the law promptly [3, 4], resulting in a cancer registration system aligned with international standards [5]. In eastern Germany and Bavaria, pre-existing hospital-based registries—already collecting additional clinical and therapy-related data—formed the basis for implementation [6].

Because hospital-based registration had successfully supported quality assessment, benchmarking, and accreditation of oncological care, the 2008 German National Cancer Plan recommended expanding population-based registration to include clinical data as an active tool to monitor and improve cancer care. Consequently, in 2013, a new federal cancer registration law came into effect, obliging all states to incorporate additional clinical data collection [4]. This law's overarching aims included oncological quality assurance, transparency in cancer care, and the promotion of health services research in oncology, while also facilitating national standardization, data exchange across Germany's complex federal healthcare system, and ensuring adequate funding.

A decade later, it is timely to assess whether comprehensive clinical cancer registration has been achieved. This paper aims to describe the current status of expanded cancer registration in Germany, present recent analyses based on clinical data, and evaluate developments over the past ten years.

Materials and Methods

Objectives and functions of the new clinical cancer registration

Beyond the traditional tasks of cancer registries—such as documenting incidence, survival, and trends—the expanded clinical registration aims to monitor and improve oncological care. According to the federal law [4], this involves:

- Evaluating clinical data and providing feedback to healthcare providers;
- Promoting interdisciplinary, patient-centered cooperation in cancer treatment;
- Participating in the Joint Federal Committee's cross-institutional and cross-sectoral quality assurance initiatives;
- Collaborating with oncology centers;
- Providing essential data to enhance transparency in care and support healthcare research.

Organization of cancer registration

Germany, with a population of approximately 84 million, is divided into 16 federal states responsible for cancer registration **(Table 1)**. State populations range from 680,000 to 18 million. Each state operates its own independent registry system, reflecting historical developments, with distinct state laws, budgets, and registry structures. Exceptions include Berlin and Brandenburg, which share a joint registry, and Saxony, which maintains four regional sub-registries. Despite structural differences, state cancer registration laws are broadly aligned in content to ensure uniform and interoperable outcomes nationwide. All federal and state laws comply with the European General Data Protection Regulation (GDPR) [7].

In addition to state registries, two national institutions were established in the 1980s: the GCCR, covering all cancers in individuals under 18 (methods described elsewhere [8]), and the German Centre for Cancer Registry Data at the Robert Koch Institute, which compiles data from state registries to form a national cancer database [9]. National coordination and harmonization are supported by three associations: the Association of Population-based Cancer Registries in Germany (GEKID, www.gekid.de, accessed 5 June 2023), the Working Group of Tumour Centres (ADT, www.adt-netwerk.de, accessed 5 June 2023) [8], and the expert panel "Plattform 65c" overseeing nationwide clinical cancer registration under § 65c SGB V (www.plattform65c.de, accessed 5 June 2023).

Table 1. Federal state cancer registries (CR) in Germany and national cancer registry structures.

	Population (Mio)	Founded	Clinical Data Since
CR Baden-Wurttemberg	11.1	1994	2009
CR Bavaria	13.1	1998	2017
CR Berlin and Brandenburg	6.0 (3.7/2.3)	1953	1953
CR Bremen	0.7	1998	2015
Hamburg CR	1.9	1927	2014
CR Hesse	6.3	2001	2015
CR Lower Saxony	8.0	2000	2018
CR Mecklenburg-Western Pomerania	1.6	1953	1953
CR North Rhine-Westphalia	17.9	** 1986	2016
CR Rhineland-Palatinate	4.1	1997	2016
Saarland CR	1.0	1968	2016
CR Saxony	4.1	1953	1953
CR Saxony-Anhalt	2.2	2018	1993

CR Schleswig-Holstein	2.9	1997	2017
CR Thuringia	2.1	1953	1953
German Childhood Cancer Registry	13.5	1980	-
German centre of cancer registry data at the Robert Koch-Institute *	(84.0)	1983	2023

* data provided by federal state CRs; ** administrative district of Münster within North Rhine-Westphalia; since 2005 full coverage of North Rhine-Westphalia.

Cancer reporting and data handling

In Germany, all physicians and healthcare providers involved in cancer diagnosis or treatment are legally required to report cases to the cancer registry. The law specifies five key points during a patient's disease course that trigger mandatory reporting: initial diagnosis, pathology results, specific cancer treatments, progression or routine follow-up/death, and optionally, tumour board discussions. Each tumour must include at least three critical pieces of information—diagnosis, pathology, and therapy—but in practice, multiple providers are usually involved, resulting in 5–10 reports per case.

Most submissions are made electronically, either by entering single cases into an online system or uploading batches from institutional tumour documentation software. Reporting relies on a legally mandated national oncology dataset, which is continuously updated and currently contains around 130 general items plus tumour-specific modules for colorectal, breast, prostate cancers, and melanoma.

The system also incorporates regular updates from civil registries regarding deaths and facilitates data exchange between regional registries. Patient records are linked across multiple reports using the unique health insurance number, name, address, and date of birth. When conflicting information arises from different sources, national guidelines determine which data are considered most reliable. All incoming data undergo standardized checks for consistency and plausibility, and any missing or inconsistent information can trigger follow-up queries to the reporting clinicians.

Table 2. Overview of the German Mandatory Basic Oncology Dataset and Tumour-Specific Modules. Full details available at https://basisdatensatz.de/basisdatensatz (accessed on 5 June 2023).

Dataset Component	Information Collected
Core dataset	Approximately 130 items covering all cancer types
Patient identifiers	Health insurance number, full name, address, date of birth, sex
Reporting institution identifiers	Name, address, billing details of the reporting clinic or physician
Cancer diagnosis	ICD-10 and ICD-O codes, topography, diagnosis date, diagnostic certainty, laterality
Histology	Date of report, ICD-O morphology, tumour grade, examined and affected lymph nodes; includes reporting pathologist's name and address if available
Tumour staging	TNM classification and other relevant staging systems
Genetic information	Documented genetic variants, if present
Residual tumour status	Post-surgery assessment and overall residual disease
Performance status	ECOG score at time of diagnosis
Surgical treatment	Surgery date, treatment intent, OPS codes, complications
Radiotherapy	Dates, treatment intent, relation to surgery, target region, start and end dates, total dose, boost, CTCAE-documented complications
Systemic therapy	Dates, treatment intent, relation to surgery, type of therapy (including active surveillance), protocol details, administered drugs, start and end dates
Tumour board discussion	Date and type of tumour conference
Follow-up	Dates of follow-up visits, overall tumour status, lymph nodes, metastases
Death	Date and cause of death
Organ-specific modules	Items designed for quality assurance in specific cancers
Breast cancer module	10 additional items
Prostate cancer module	10 additional items
Colorectal cancer module	12 additional items

Skin melanoma module	4 additional items

Funding of cancer registration

The introduction of the new federal law brought a major shift in the financing of population-based cancer registries. Previously, funding was primarily provided by the federal states, but under the new system, statutory health insurance funds now cover 90% of operational costs for clinical cancer registration, with the remaining 10% financed by the federal states. To qualify for this funding, registries must fulfill 43 defined eligibility criteria, which include measures of data quality such as registration completeness (target >90% of expected cases), thoroughness of reported information, timeliness, and the provision of feedback to reporting institutions.

As of 2023, the national reimbursement rate for cancer registries is approximately EUR 120 per newly documented and continuously tracked case (following IARC guidelines [5]), though this may vary between states. In addition, reporting physicians receive payments ranging from EUR 5 to 18 per notification, depending on the type of reporting event.

Data and analysis

For this study, we used the most recent dataset from all federal cancer registries, compiled by the German Centre for Cancer Registry Data (ZfKD) at the Robert Koch Institute, Berlin. Data were available up to cases diagnosed in 2019. We calculated absolute numbers, crude rates, and age-standardized incidence rates using the Segi world standard. Regional comparisons employed European Standard (1976) age-standardized rates [10] and 5-year relative survival rates determined via period analysis using the Ederer II method [11], as presented by the Cancer Atlas of the German Association of Population-based Cancer Registries (GEKID) [12], which also relies on the ZfKD dataset. Mortality statistics were obtained from the German Federal Statistical Office [13].

Quality of care was assessed using nationally defined guideline-based quality indicators (S3) [14, 15]. As an example, the Cancer Registry Schleswig-Holstein (CR SH) provided evaluations of QI adherence for three tumour entities—breast (ICD-10 C50), colorectal (ICD-10 C18-20), and prostate (ICD-10 C61)—from the 2023 regional quality conferences, displayed as anonymized bar charts comparing participating healthcare providers. Additionally, treatment information for rectal cancer (ICD-10 C20) was extracted from the CR SH interactive treatment report [16]. All data were retrieved in June 2023, and analyses were conducted using SPSS version 22 and R version 4.1.3.

Results and Discussion

Following the 2013 federal law mandating clinical cancer registration, all German states established population-based registries that have now consistently met national eligibility criteria. Consequently, complete population-level cancer registration coverage has been achieved across Germany. In 2019, the 15 federal state registries documented 505,612 new cancer cases (C00-96, excluding C44) **(Table 3)**. Women accounted for 236,218 cases (46.7%; crude incidence rate 561.2 per 100,000), and men accounted for 269,394 cases (53.3%; 657.0 per 100,000). The most common cancers in women were breast (73,279), colorectal (26,655), and lung (22,892), whereas in men, prostate (70,192), lung (34,572), and colorectal (33,440) were most frequent.

Overall 5-year relative survival (5YRS) was 67% for women and 63% for men. Highest survival rates were seen in melanoma of the skin (95%), testicular cancer (92%), prostate cancer (90%), Hodgkin lymphoma (women 89%, men 86%), breast cancer (women 87%), and thyroid cancer (92% women, 86% men). The lowest 5YRS were observed in pancreatic cancer (14% women, 12% men), lung cancer (25%, 21%), and brain cancer (28%, 24%). Age-standardized incidence rates for common cancers between 2015 and 2019 remained relatively stable.

Table 3. Most common cancer sites (ICD-10) in Germany in 2019: case numbers (N), crude rates per 100,000 (CR), age-standardised rates per 100,000 (ASR, World standard) and relative 5-year survival (5Y-RS) (period 2017–2019), percentage of all cancers (%) and ranking (place). Data source: common dataset of German cancer registries provided by the Centre for Cancer Registry Data at the Robert Koch-Institute, 2023.

	Women					**Men**				
Cancer Site	**N**	**CR**	**ASR**	**% (Place)**	**5Y-RS%**	**N**	**CR**	**ASR**	**Place-S**	**5Y-RS%**
Oral cavity, pharynx (C00–C14)	4357	10.4	4.6	1.8 (15)	61.3	9521	23.2	11.5	3.5 (9)	50.5

Oesophagus (C15)	1627	3.9	1.5	0.7 (19)	26.3	5694	13.9	6.3	2.1 (12)	26.4
Stomach (C16)	5650	13.4	4.8	2.4 (10)	39.1	9091	22.2	9.4	3.4 (10)	35.0
Colo-rectal (C18–C20)	26,655	63.3	22.1	11.3 (2)	68.2	33,440	81.6	34.3	12.4 (3)	64.8
Pancreas (C25)	9546	22.7	7.3	4.0 (7)	13.6	9614	23.4	9.6	3.6 (7)	12.4
Lung (C34)	22,892	54.4	22.5	9.7 (3)	25.0	34,572	84.3	36.0	12.8 (2)	20.6
Melanoma (C43)	11,038	26.2	14.1	4.7 (5)	95.3	12,527	30.6	14.4	4.7 (5)	94.0
Breast (C50)	73,279	174.1	86.2	31.0 (1)	86.5	721	1.8	0.8	0.3 (18)	78.8
Cervix uteri (C53)	4517	10.7	7.2	1.9 (14)	61.6	-	-	-	-	-
Corpus uteri (C54–C55)	11,221	26.7	11.6	4.8 (4)	78.4	-	-	-	-	-
Ovary (C56)	7128	16.9	7.6	3.0 (9)	41.3	-	-	-	-	-
Prostate (C61)	-	-	-	-	-	70,192	171.2	70.0	26.1 (1)	90.3
Testis (C62)	-	-	-	-	-	4113	10.0	9.3	1.5 (14)	92.4
Kidney (C64)	4912	11.7	4.6	2.1 (12)	79.2	9505	23.2	10.9	3.5 (8)	78.2
Bladder (C67)	4697	11.2	3.5	2.0 (13)	70.4	13,116	32.0	12.2	4.9 (4)	78.5
Brain (C70–C72)	3002	7.1	4.0	1.3 (18)	27.9	3909	9.5	5.5	1.5 (13)	24,3
Thyroid gland (C73)	4113	9.8	7.3	1.7 (16)	92.0	1816	4.4	3.0	0.7 (16)	86.3
Hodgkin lymphoma (C81)	1063	2.5	2.3	0.5 (20)	89.1	1386	3.4	2.7	0.5 (17)	86.0
Non-Hodgkin lym. (C82–C88)	8094	19.2	7.7	3.4 (8)	73.3	10,042	24.5	11.3	3.7 (6)	71.1
Multiple myeloma (C90)	3073	7.3	2.5	1.3 (17)	59.3	3835	9.4	3.9	1.4 (15)	57.8
Leukaemia (C91–C95)	5263	12.5	5.2	2.2 (11)	59.0	7467	18.2	8.5	2.8 (11)	60.7
All sites excluding C44	236,218	561.2	249.0	100.0	67.0	269,394	657.0	290.3	100.0	63.4

Cancer incidence varies considerably across different regions in Germany. For example, the region with the highest lung cancer rates reports nearly twice as many cases as the region with the lowest rates **(Figure 1)**. Other cancers showing pronounced geographic differences include those of the oral cavity and pharynx, liver, thyroid, as well as leukaemias and lymphomas. In contrast, cancers such as colorectal and prostate cancer display relatively uniform incidence across regions. Notably, breast cancer tends to occur less frequently in the Eastern federal states (online data [12]).

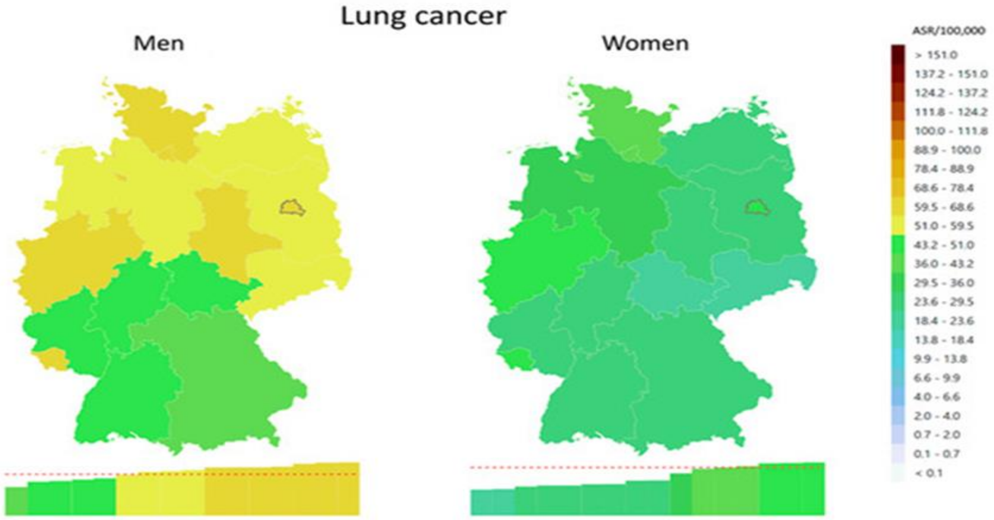
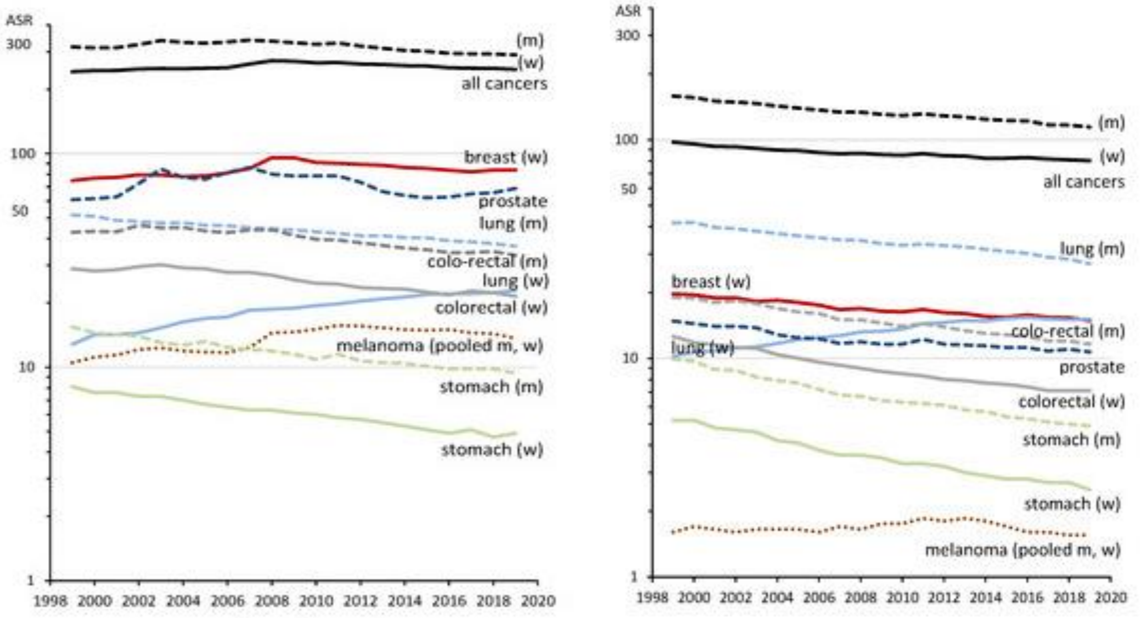


Figure 1. Distribution of lung cancer incidence (ICD-10: C33–C34) across German federal states in 2019, expressed as age-standardized rates per 100,000 population (ASR, European Standard 1976). Data source: GEKID Cancer Atlas [12].

Analysis of long-term trends in age-standardized cancer incidence reveals that rates were stable in men or showed a modest increase for most cancer sites between 1999 and roughly 2008 **(Figure 2a)**. In the past decade, a gradual decline has been observed, with incidence decreasing from 272.6 to 248.3 per 100,000 among women (−9%) and from 336.7 to 290.4 per 100,000 among men (−14%) between 2008 and 2019. This downward trend is largely attributable to reductions in colorectal cancer (−23%), stomach cancer (−22%), and male lung cancer (−17%), whereas female lung cancer incidence increased by 22%. Prostate cancer incidence has recently risen after peaking in 2007, following a subsequent decline until 2015 (−23%).

Cancer mortality rates **(Figure 2b)** have generally decreased over several decades, with the notable exception of lung cancer among women. Overall, total cancer mortality in 2019 was 18% lower in women and 28% lower in men compared with 1999.



a) b)

Figure 2. Trends in cancer incidence (a) and mortality (b) from 1999 to 2019 for common malignancies and all cancers excluding C44, presented as age-standardized rates per 100,000 population (ASR, World), with a logarithmic y-axis. Data source: Centre for Cancer Registry Data, Robert Koch Institute [9].

For evaluating the quality of oncological care, comprehensive treatment data are systematically recorded. **Table 4** provides an example for rectal cancer (C20) from Schleswig-Holstein, broken down by tumour stage. In this analysis, any missing or unreported data are conservatively treated as an indication that the corresponding treatment was not administered.

Surgery was performed in 69% of patients, with the majority (84%) intended to be curative. Complete tumour removal (R0) was achieved in 91% overall, though rates dropped to 79% in patients with stage III–IV disease, compared with 86% in stages I–II. Radiotherapy was delivered to 33% of patients, and 4% of these cases ended treatment early due to patient refusal (n = 4), adverse effects (n = 12), progression (n = 1), or other causes (n = 8). Chemotherapy was administered to 40% of patients, with 44% receiving it prior to surgery (neoadjuvant). Among these, 22% discontinued treatment, mostly due to patient refusal (n = 9), toxicity (n = 45), disease progression (n = 34), or other factors (n = 73). The most commonly used drugs were antimetabolites—such as 5-FU, capecitabine, gemcitabine, and cytarabine (96%)—followed by platinum-based agents (48%) and topoisomerase inhibitors (16%). Immune or antibody therapies were administered in 12% of cases.

Table 4. Treatment of rectal cancer (ICD-10 C20) patients, treated in 2019–2021 in Schleswig-Holstein, stratified by tumour stage. Data source: interactive cancer report CR Schleswig-Holstein [16].

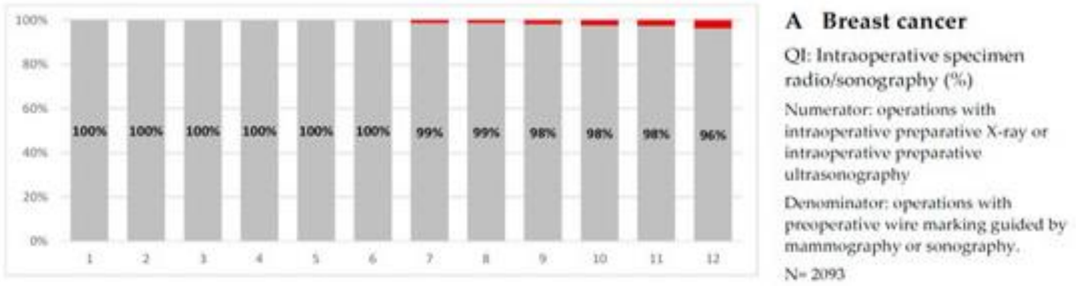
	Patients Total N = 1734	**UICC Stages I–II N = 554**	**UICC Stages III–IV N = 792**	**UICC Stage Unknown N = 388**
Surgery	1200 (69%)	432 (78%)	591 (75%)	177 (46%)
Curative intention	1003 (84%)	372 (86%)	465 (79%)	166 (94%)

Resection R0 *	1047 (91%)	394 (95%)	496 (87%)	157 (92%)
Operation within 14 days after diagnosis	285 (24%)	128 (30%)	145 (25%)	12 (7%)
Radiation	850 (33%)	92 (17%)	286 (36%)	202 (52%)
Curative intention	552 (95%)	90 (98%)	268 (94%)	194 (96%)
Premature termination	25 (4%)	5 (5%)	11 (4%)	9 (4%)
Neoadjuvant	452 (78%)	67 (73%)	215 (75%)	170 (84%)
Chemotherapy	698 (40%)	87 (16%)	428 (54%)	183 (47%)
Curative intention	458 (69%)	68 (72%)	280 (69%)	110 (65%)
Premature termination	152 (22%)	10 (11%)	1127 (26%)	30 (16%)
Neoadjuvant	310 (44%)	41 (47%)	175 (41%)	94 (51%)
Immune/Antibody-therapy	99 (14%)	2 (2%)	79 (18%)	18 (10%)
cytostatic agents used:				
Antimetabolic	672 (96%)	85 (98%)	410 (96%)	177 (97%)
Platin-based	333 (48%)	29 (33%)	217 (51%)	110 (60%)
Topoisomerase inhibitors	115 (16%)	2 (2%)	90 (21%)	23 (13%)

* R0, no residual tumour/in sano, R-classification.

Beyond documenting treatments, cancer registries are responsible for organizing regular regional quality conferences where healthcare providers review the care delivered to patients. To evaluate performance, quality indicators (QIs) derived from evidence-based S3 guidelines are employed. Currently, approximately half of these indicators (94 out of 188) have been fully operationalized using cancer registry data, with standardized definitions for both numerators and denominators.

Figure 3 illustrates selected QIs for three cancer types, showing how each indicator is applied. Each bar represents a healthcare provider, typically a hospital or large outpatient clinic. In breast cancer care **(Figure 3a)**, intraoperative radiography or ultrasound is recommended whenever feasible, and all providers met this standard in at least 96% of cases. For prostate cancer surgeries **(Figure 3b)**, reports documenting lymph node involvement must be provided, yet four of ten providers fell short of the 90% threshold. In colorectal cancer surgery **(Figure 3c)**, optimal quality of total mesorectal excision (TME) is expected; only six out of twelve providers achieved rates above 90%.



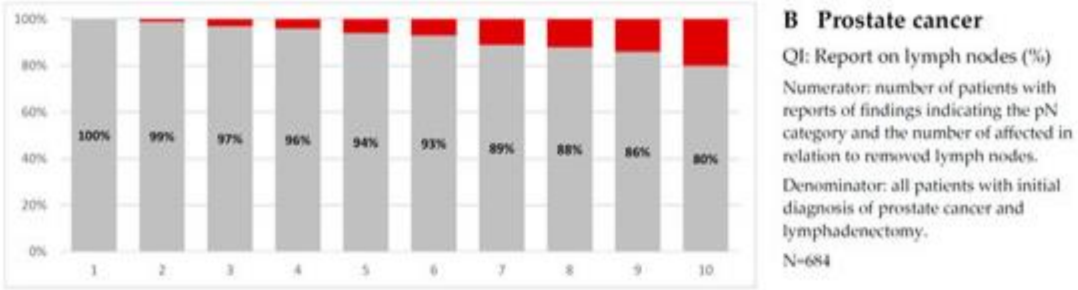
QI: Intraoperative specimen radio/sonography (%)

Numerator: operations with intraoperative preparative X-ray or intraoperative preparative ultrasonography

Denominator: operations with preoperative wire marking guided by mammography or sonography.

N= 2093

a)



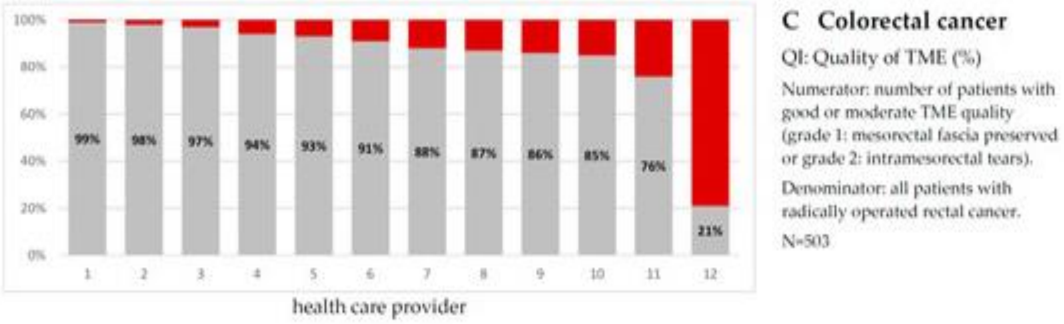
QI: Report on lymph nodes (%)

Numerator: number of patients with reports of findings indicating the pN category and the number of affected in relation to removed lymph nodes.

Denominator: all patients with initial diagnosis of prostate cancer and lymphadenectomy.

N=684

b)



d)

Figure 3. Examples of selected quality indicators (QIs) based on the German S3 therapy guidelines for patients treated in 2020–2021. Each bar represents a healthcare provider managing more than 40 cases per year. Data source: Cancer Registry Schleswig-Holstein (www.cancer-sh.de, accessed 5 June 2023).

The implementation of population-based clinical cancer registration in Germany, driven by the 2013 federal law, can be regarded as a success. Over the past decade, all major legal requirements have been fulfilled. Despite managing cancer registration for a population of 84 million through 15 independent registries, the decentralized system has proven feasible, achieving a high degree of standardization. Key achievements include not only a uniform, legally mandated dataset but also efficient data sharing between registries, standardized evaluation procedures, and national accessibility of data for research and health monitoring. In this sense, Germany’s cancer registration system now operates at a level comparable to large international programs, such as SEER [17].

The transition from a limited, partially paper-based dataset to a fully electronic, comprehensive system could have introduced disruptions in epidemiological indicators; however, no gaps or breaks in data quality or completeness have occurred. Time trends in incidence and other epidemiological measures remain consistent, and national completeness of cancer registration has improved. In the past, national incidence estimates were required due to regional gaps [18], but now actual case counts can be directly reported. Comparisons with neighboring countries, such as the Scandinavian nations, show similar incidence rates and trends [19]. In 2019, age-standardized incidence (world standard) in Scandinavia was 288 per 100,000 women and 311 per 100,000 men, closely matching Germany’s 249 and 290 per 100,000, respectively. Comparable figures are seen in the Netherlands, with 2019 incidence of 293/303 per 100,000 women/men [20], and European Cancer Observatory estimates for Germany (ECIS: 267/307 per 100,000 women/men) [21] align with these findings.

Overall, the German population-based cancer registry provides reliable national-level data. Survival outcomes are also consistent with European estimates reported by ECIS. Importantly, registry data, some dating back to 1967, are readily available for research and have been extensively utilized. These data also support routine health reporting, with interactive databases allowing analyses of incidence, mortality, and survival at federal, state, and even municipal levels [22].

A major milestone in German cancer registration has been the use of registry data to support quality assurance and management of oncological care. Information on treatment, disease progression, and survival is now analyzed not only at the population level but also at the level of individual healthcare providers (HCPs). This allows feedback to each provider regarding the quality of their processes and outcomes, as well as benchmarking between providers. Currently, these comparisons are primarily discussed confidentially with HCPs, but some countries have begun publicly reporting quality indicators along with the names of institutions [23], marking a significant step toward transparency. Over time, such measures may enable patients to make informed choices based on care quality.

Importantly, cancer registries assess quality across the entire spectrum of care, not just in selected hospitals. This is particularly relevant in Germany, where healthcare is highly segmented between inpatient and outpatient sectors. While cancer centers certified by the German Cancer Society have well-documented care standards [24], they treat only about half of all cancer patients (own calculation based on [24]), leaving the quality of care for the remaining population largely unknown. Population-based registries, which capture care across both hospital and outpatient settings, offer a comprehensive view of cancer treatment.

European data show that roughly 50% of registries collect clinical information, but many record only basic treatment details, such as whether surgery or chemotherapy was performed [25, 26]. Hospital-based studies on quality indicators exist—for example, for breast [27] or renal cancer [28]—but these are not based on routine, population-level registration. Recent developments indicate that using cancer registry data for quality assessment at the provider level is still emerging. In the Netherlands, comparisons of hospitals based on quality indicators have already been reported for gynecological [29–31], lung [32], and rectal cancers [33]. These studies, like ours, demonstrate that provider-level cancer care can be quantified and benchmarked fairly, though whether such monitoring ultimately improves patient outcomes remains to be seen. Key questions include whether providers with well-documented quality achieve better survival, lower recurrence, or improved quality of life compared with those with lower documented quality—issues that future registry analyses may clarify.

These efforts require substantial financial investment. In Germany, the cost per registered case is approximately EUR 160 (EUR 120 for the registry plus EUR 40 covering five notifications from physicians), with higher costs if relapses or additional treatments are recorded. This is considerably above the European average of around EUR 50 per case [34]. With roughly 500,000 new cancer cases per year and five notifications each, the total annual cost reaches about EUR 80 million, 90% of which is funded directly by statutory health insurance. The 2013 law integrating cancer registration into public healthcare has enabled the use of registry data for quality monitoring without requiring institutional consent [35]. As a return on this investment, the healthcare system gains a detailed, evidence-based overview of oncological care, allowing targeted improvements at the provider level when needed.

Despite substantial progress over the past decade, challenges remain. While incident cancers are likely now fully captured, treatment data remain incomplete. Limitations arise from Germany's sectoral healthcare structure, patients' unrestricted choice of providers, and ongoing development of technical solutions for complex registry reporting. These obstacles are expected to diminish in the coming years through continued digitization and improved interoperability across systems.

The national dataset maintained at the ZfKD for research purposes is set to be expanded to include essential clinical variables on treatment and disease progression, in line with the 2021 federal law on data consolidation [36]. This legislation facilitates improved access to cancer registry data for research, enables linkage with other health datasets, supports identification of comparable disease cases ("digital twins"), and allows investigation of long-term cancer outcomes. Furthermore, discussions are ongoing regarding the integration of patient-reported outcomes and experience measures into the registries, allowing patients to participate directly in the registration process. Early results in the near future are expected to demonstrate whether these enhancements in clinical cancer registration improve not only the quality of care processes but also patient-relevant clinical outcomes.

Conclusion

The introduction of population-based clinical cancer registration in Germany has been largely successful. Over the past decade, key elements—including comprehensive documentation of diagnoses, treatments, and disease progression, as well as the use of registry data for quality assurance, benchmarking, and feedback—have been established. Nevertheless, substantial work remains to achieve a fully comprehensive and transparent evaluation of oncological care across the country.

Acknowledgments: None

Conflict of Interest: None

Financial Support: None

Ethics Statement: None

References

1. Leyden E, Kirchner M, Wutzdorf E, Hansemann D, Meyer G, editors. Report on the Collection Research Surveyed by the Committee on Cancer Research on October 15, 1900. Jena, Germany: Gustav Fischer;1902.
2. Gesetz Über Krebsregister (KRG) 04.11.1994. Bundesgesetzblatt. Available from: http://www.bgbl.de/xaver/bgbl/start.xav?startbk=Bundesanzeiger_BGBl&jumpTo=bgbl194s3351.pdf (accessed 5 June 2023).
3. Hundsdörfer G. Epidemiological cancer registries in Germany: history from a legal point of view. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2014;57(1):7–12.

4. Holleczek B, Katalinic A. Toward a comprehensive cancer registration in Germany. Eur J Cancer Prev. 2017;26(S-1):S132–8.
5. Jensen O, Parkin D, MacLennan R, Muir C, Skeet R. Cancer Registration: Principles and Methods. Lyon, France: IARC Scientific Publications; 1991.
6. Klinkhammer-Schalke M, Gerken M, Barlag H, Tillack A. Quality management in oncology supported by clinical cancer registries. Z Evid Fortbild Qual Gesundhwes. 2015;109(6):452–8.
7. European Commission. General Data Protection Regulation (GDPR). Available from: https://commission.europa.eu/law/law-topic/data-protection/data-protection-eu_en (accessed 20 July 2023).
8. Spix C, Erdmann F, Grabow D, Ronckers C. Childhood and adolescent cancer in Germany — an overview. J Health Monit. 2023;8(1):79–94.
9. Robert Koch-Institut, German Centre for Cancer Registry Data. Database Query Tool. Berlin, Germany. Available from: https://www.krebsdaten.de/Krebs/EN/Database/databasequery_step1_node.html (accessed 5 June 2023).
10. Waterhouse J, Muir C, Correa P, Powell J. Cancer Incidence in Five Continents Vol. III. Lyon, France: IARC; 1976.
11. Holleczek B, Gondos A, Brenner H. PeriodR — an R package to calculate long-term cancer survival estimates using period analysis. Methods Inf Med. 2009;48(2):123–8.
12. Association of Population-Based Cancer Registries in Germany (GEKID). Cancer Atlas of the Association of Population-Based Cancer Registries in Germany. Available from: https://www.gekid.de/gekid-atlas/ (accessed 5 June 2023).
13. Federal Statistical Office of Germany. Mortality by age, sex, year and ICD-10. Available from: https://www-genesis.destatis.de/genesis/online (accessed 5 June 2023).
14. Leitlinienprogramm Onkologie. Guideline-Based Oncological Quality Indicators, v5.0. Berlin, Germany; 2021.
15. Plattform65. Operationalization of S3 cancer guideline indicators. Available from: https://confluence.basisdatensatz.de/pages/viewpage.action?pageId=2818461 (accessed 5 June 2023).
16. Krebsregister Schleswig-Holstein. Interactive therapy-related report. Available from: https://www.krebsregister-sh.de/iBOB (accessed 5 June 2023).
17. National Cancer Institute, Surveillance, Epidemiology, and End Results (SEER) Program. About SEER. Available from: https://seer.cancer.gov/about/ (accessed 5 June 2023).
18. Robert Koch-Institut; Gesellschaft der epidemiologischen Krebsregister in Deutschland e.V., editors. Cancer in Germany. Berlin, Germany: Robert Koch-Institute; 2021. ISBN: 978-3-89606-309-0.
19. Association of the Nordic Cancer Registries. Cancer Registry of Norway (NORDCAN): Cancer incidence, mortality, prevalence and survival in the Nordic countries, version 9.2 (23.06.2022). Available from: https://nordcan.iarc.fr/ (accessed 5 June 2023).
20. Netherlands Cancer Registry (NCR). NCR data. Available from: https://nkr-cijfers.iknl.nl (accessed 5 June 2023).
21. European Commission. ECIS – European Cancer Information System. Available from: https://ecis.jrc.ec.europa.eu (accessed 5 June 2023).
22. Pritzkuleit R, Eisemann N, Katalinic A. The cartographic depiction of regional variation in morbidity: data analysis options using the example of the small-scale cancer atlas for Schleswig-Holstein. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2017;60(12):1319–27.
23. Krebsregister Hamburg. Interactive therapy-based cancer report 2021 — comparison of health care providers. Available from: https://ijbbehandlungsort.krebsregister-hamburg.de/ (accessed 5 June 2023).
24. OnkoZert. Certification system for the verification of organ cancer centres and oncology centres. Available from: https://www.onkozert.de/en/ (accessed 5 June 2023).
25. Giusti F, Martos C, Trama A, Bettio M, Sanvisens A, Audisio R, et al. Cancer treatment data available in European cancer registries: where are we and where are we going? Front Oncol. 2023;13:1109978.
26. Siesling S, Louwman WJ, Kwast A, van den Hurk C, O'Callaghan M, Rosso S, et al. Uses of cancer registries for public health and clinical research in Europe: results of the European Network of Cancer Registries survey among 161 population-based cancer registries during 2010–2012. Eur J Cancer. 2015;51(8):1039–49.
27. van Dam PA, Tomatis M, Marotti L, Heil J, Mansel RE, Rosselli Del Turco M, et al. Time trends (2006–2015) of quality indicators in EUSOMA-certified breast centres. Eur J Cancer. 2017;85:15–22.

28. Lawson KA, Saarela O, Abouassaly R, Kim SP, Breau RH, Finelli A. The impact of quality variations on patients undergoing surgery for renal cell carcinoma: a National Cancer Database study. Eur Urol. 2017;72(3):379–86.
29. Algera MD, Slangen BFM, van Driel WJ, Wouters MWJM, Kruitwagen RFPM. Textbook outcome as a composite outcome measure to compare hospital performances regarding cytoreductive surgery for ovarian cancer: a nationwide population-based study. Gynecol Oncol. 2023;174:89–97.
30. Algera MD, Baldewpersad Tewarie NMS, van Driel WJ, van Ham MAPC, Slangen BFM, Kruitwagen RFPM, et al. Case-mix adjustment to compare hospital performances regarding complications after cytoreductive surgery for ovarian cancer: a nationwide population-based study. Int J Gynecol Cancer. 2023;33(3):534–42.
31. Vos EL, Lingsma HF, Jager A, Schreuder K, Spronk P, Vrancken Peeters MJTFD, et al. Effect of case-mix and random variation on breast cancer care quality indicators and their rankability. Value Health. 2020;23(9):1191–9.
32. Ten Berge MG, Beck N, Steup WH, Verhagen AFTM, van Brakel TJ, Schreurs WH, et al. Textbook outcome as a composite outcome measure in non-small-cell lung cancer surgery. Eur J Cardio-Thorac Surg. 2021;59(1):92–9.
33. Warps AK, Detering R, Tollenaar R AEM, Tanis PJ, Dekker JWT. Textbook outcome after rectal cancer surgery as a composite measure for quality of care: a population-based study. Eur J Surg Oncol. 2021;47(11):2821–9.
34. Zanetti R, Sacchetto L, Calvia M, Bordoni A, Hakulinen T, Znaor A, et al. Economic evaluation of cancer registration in Europe. J Regist Manag. 2014;41(1):31–7.
35. Sozialgesetzbuch (SGB) V – Statutory Health Insurance – § 65c Clinical Cancer Registries. Available from: https://www.gesetze-im-internet.de/sgb_5/__65c.html (accessed 5 June 2023).
36. Gesetz zur Zusammenführung von Krebsregisterdaten. Available from: https://www.buzer.de/gesetz/14935/index.htm (accessed 5 June 2023).