



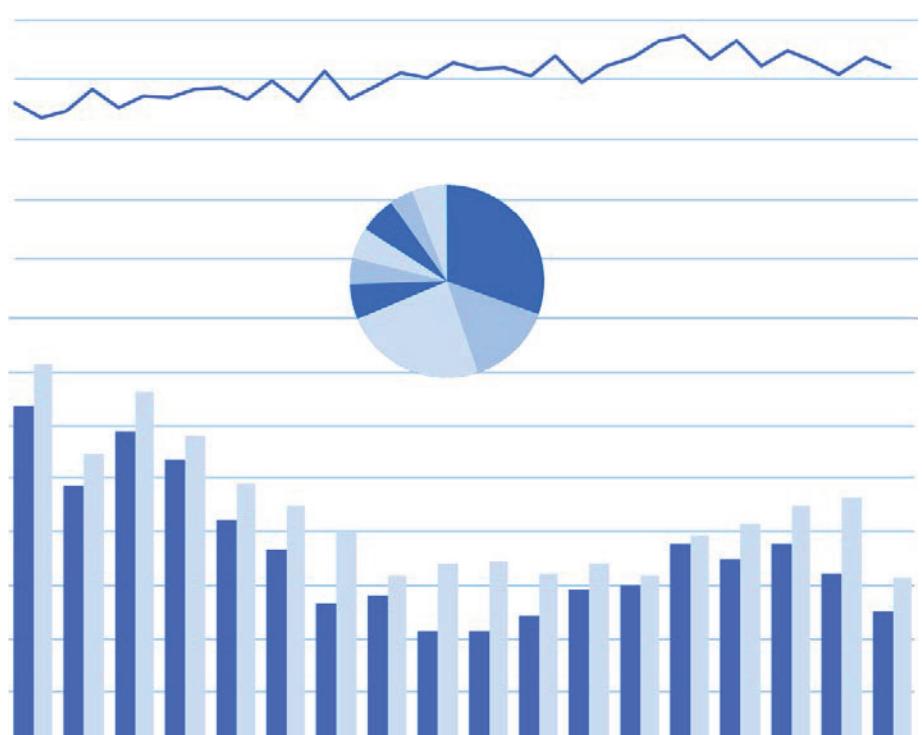
Deutsches
Kinderkrebsregister



Jahresbericht / Annual Report 2017



German Childhood Cancer Registry





Deutsches
Kinderkrebsregister

Jahresbericht Annual Report 2017

(1980-2016)

Deutsches Kinderkrebsregister DKKR
German Childhood Cancer Registry GCCR



UNIVERSITÄTSmedizin.
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Institut für Medizinische Biometrie,
Epidemiologie und Informatik

Jahresbericht / Annual Report 2017 (1980-2016)

April 2018

Deutsches Kinderkrebsregister am
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Herausgeber:

Deutsches Kinderkrebsregister
(Leitung: PD Dr. Peter Kaatsch)

Kein Druckexemplar - Nur als PDF im Internet erschienen

* zum Teil über andere Drittmittel finanziert /
partly financed by additional external funds

Zitierweise: Kaatsch P, Grabow D, Spix C. German Childhood Cancer Registry - Annual Report 2017 (1980-2016). Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI) at the University Medical Center of the Johannes Gutenberg University Mainz, 2018.

Nachdruck bzw. Vervielfältigung, auch im Auszug, nur mit Quellenangabe gestattet.

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2 Vorwort / Foreword

Das Deutsche Kinderkrebsregister legt hiermit wieder einen Jahresbericht vor, der nur über das Internet verfügbar ist. Alle Berichte, auch die, die in zweijährigem Abstand als Druckexemplare erscheinen, sind unter <http://www.kinderkrebsregister.de> abrufbar.

Wir möchten bei dieser Gelegenheit unseren herzlichen Dank den betroffenen Familien, das heißt den Eltern sowie den Patienten, aussprechen. Ohne deren Einwilligung zur Datenweitergabe an das Deutsche Kinderkrebsregister wäre die hohe Vollzähligkeit der Erfassung von Krebs im Kindes- und Jugendalter mit mittlerweile über 60.000 erfassten Neuerkrankungen nicht möglich. Auch deren Bereitschaft zur Teilnahme an Befragungen und die grundsätzliche Offenheit ehemaliger Patientinnen und Patienten, im Rahmen der Langzeitnachbeobachtung Informationen direkt an uns zu geben, ist bemerkenswert und verdient Respekt und Dankbarkeit.

Ebenso ist der lang bewährte Informationsverbund, der zwischen unserem Register, den behandelnden Kliniken und den in der deutschen pädiatrischen Onkologie und Hämatologie durchgeführten klinischen GPOH-Studien besteht, eine wesentliche Basis unserer Arbeit. Auch dafür unseren herzlichen Dank!

Die papierbasierte Archivierung der Patientenakten am Deutschen Kinderkrebsregister wurde prospektiv auf eine elektronische Archivierung umgestellt. Seit Mitte 2017 erfolgt grundsätzlich keine Archivierung mehr von papierenen Unterlagen.

Eine Ergebnis-Übersicht zu den wichtigsten Kennzahlen (Inzidenzen, Überlebenswahrscheinlichkeiten, Zweitneoplasien etc.) findet sich auf Seite 4 dieses Berichtes. Die Datenlage zu Zweitneoplasien wird immer vollständiger, damit werden auch die Risikoabschätzungen immer höher: nach derzeitigem Wissen müssen 8,4% der Patienten innerhalb von 30 Jahren mit einer erneuten Erkrankung rechnen, besonders betroffen sind Patienten mit Hodgkin-Lymphomen, Vorläuferzell-Lymphomen, Ependymomen, Medulloblastomen und PNET. Zu diesem Thema liegt eine neue Veröffentlichung vor (51).

Die Sichtbarkeit des Deutschen Kinderkrebsregisters ist nach unserer Einschätzung weiterhin national und international hoch. Beispielsweise können Vorträge genannt werden bei der Jubiläumsveranstaltung des Schweizer Kinderkrebsregisters, auf der ESLCCC-Tagung in Edinburgh (European Symposium on Late Complications after Childhood Cancer) oder vor Kinderonkologen in Paraguay.

This time the German Childhood Cancer Registry presents an Annual Report available only via the internet. All reports, including those available in print every other year, can be retrieved online under <http://www.kinderkrebsregister.de>.

We would like to take this opportunity to express our warmest thanks to the affected families, i.e. the parents and patients. Only their consent to have their data passed on to the German Childhood Cancer Registry makes it possible to have such a high completeness with almost 60,000 new cases of cancer in childhood and adolescence registered. The patients' and parents willingness to participate in surveys and the former patients' general openness to pass on information to us within the framework of the long-term follow-up is remarkable and deserves our respect and gratitude.

Similarly, the long-established information network between our registry, the treating hospitals, and the clinical trials of the German Society of Pediatric Oncology and Hematology, is crucial for our work. Our sincere thanks for this good collaboration!

The paper based archiving of patient records at the German Childhood Cancer Registry was prospectively changed to electronic archiving. Since the middle of 2017 we stopped archiving paper records.

An overview of the results with key figures (incidence, survival probability, subsequent neoplasms etc.) can be found on page 5 of this report. The data available on subsequent neoplasms is increasingly complete, which also leads to higher risk estimates: based on current knowledge patients must expect an 8.4% risk of another malignant disease within 30 years of their first diagnosis; particularly under risk are patients with Hodgkin lymphoma, precursor cell lymphoma, ependymoma, medulloblastoma and PNET. (51) presents a new publication on the topic

We consider the German Childhood Cancer Registry to be highly visible nationally and internationally, which is demonstrated by several activities. For instance, staff members gave presentations at the anniversary meeting of the Swiss Childhood Cancer Registry, at the ESLCCC-meeting in Edinburgh (European Symposium on Late Complications after Childhood Cancer), or a meeting of Paraguayan pediatric oncologists.

Auch in EU-Projekten und internationalen Datenvergleichsprojekten spielt das Deutsche Kinderkrebsregister mit dessen Mitarbeiterinnen und Mitarbeitern weiterhin eine wesentliche Rolle. So hat das Deutsche Kinderkrebsregister seine Daten zur weltweiten Sammlung aller Kinderkrebskrankungen beigetragen, die 2017 von der Internationalen Krebsforschungsagentur veröffentlicht wurde (IICC3, 47,52).

In diesem Zusammenhang erscheinen einige Publikationen unter Beteiligung des Deutschen Kinderkrebsregisters erwähnenswert: Übersichten der EUROCARE 5-Studie zu Überlebenszeitvergleichen bei Kindern und Jugendlichen mit Krebs in Europa (41,42) und die ersten Ergebnisse der Studie Pan-CareSurFup zu Spätfolgen nach Krebs im Kindesalter in Europa (39,49).

Im Rahmen der in den einzelnen Bundesländern erfolgenden Umsetzung des Krebsfrüherkennungs- und -Registergesetzes (KFRG) (19) sind wir damit beschäftigt, den seit einigen Jahren durchgeführten Datenaustausch mit den einzelnen Landeskrebsregistern nun unter Berücksichtigung der aktualisierten Gesetze zu realisieren. Wo dies noch gesetzlich möglich ist, leiten wir - unter Berücksichtigung der jeweiligen Register- und Datenschutzgesetzgebung - weiterhin die an das Deutsche Kinderkrebsregister erfolgten Meldungen grundsätzlich an die Krebsregister der Länder weiter (Tab. 10).

Wir wünschen eine informative Lektüre des Jahresberichtes und sind für Anregungen zur Optimierung unserer Berichterstattung offen.

Mainz, April 2018

Furthermore, the German Childhood Cancer Registry and its staff members play an important role in EU projects and international data collections. The German Childhood Cancer Registry contributed its data to the world wide collection of childhood cancer cases published in 2017 by the International Agency for Research on Cancer (IICC3, 47, 52)

In this context, some publications, to which the German Childhood Cancer Registry contributed, seem worth mentioning: Overviews of the EUROCARE 5-study on survival time comparisons in children and adolescents in Europe (41,42) and the first results of the PanCareSurFup study on late effects after cancer in children and adults in Europe (39,49).

The federal states are updating their federal laws on cancer registration according to the national "Krebsfrüherkennungs- und -Registergesetz" (KFRG) (19). Data exchanges have been carried out with the individual state cancer registries for several years, and we are working on adapting this exchange to the new laws. Where still possible under the law, we continue to transfer cases reported to the German Childhood Cancer Registry to the cancer registries of the federal states, taking the specific registry laws and data protection legislations into account (Table 10).

We hope you find this annual report an informative reading, and we are open for suggestions for improving our reporting.

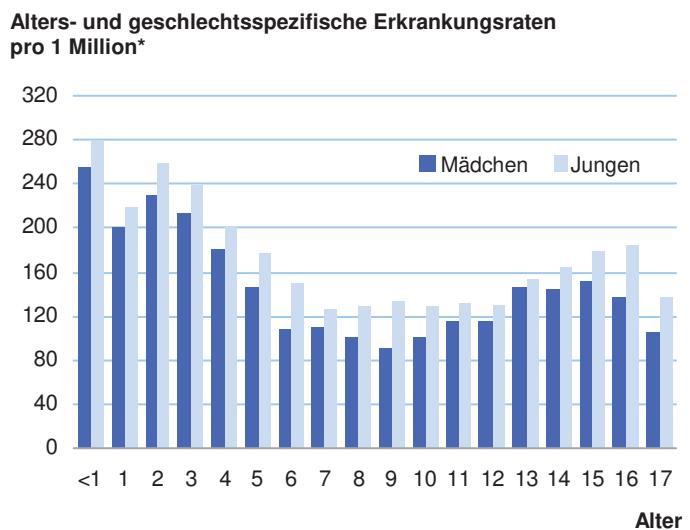
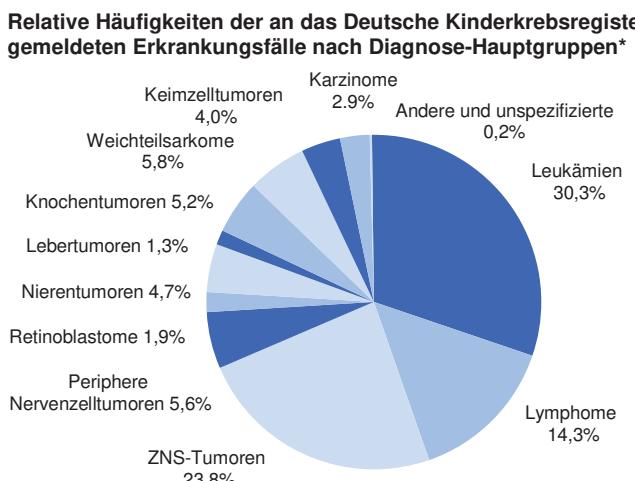
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4 Ergebnis-Übersicht / Overview of Results

Meldungen von Fällen unter 15 Jahren im Jahr 2016 (Meldungen aus 63 Kliniken) :	1741				
Meldungen von Fällen unter 18 Jahren im Jahr 2016 (Meldungen aus 63 Kliniken) :	2111				
Durchschnittliche Meldungen von Fällen unter 15 Jahren pro Jahr:	1761				
(ermittelt aus den Jahren 2007-2016)					
vor dem 15. Geburtstag erkrankt ...	eines von 409 Neugeborenen				
Jungen / Mädchen	970 / 792				
Meldungen von unter 5-Jährigen	787				
Meldungen von 5- unter 10-Jährigen	458				
Meldungen von 10- unter 15-Jährigen	517				
Lymphatische Leukämien (LL)	440				
Durchschnittliche Meldungen von Fällen im Alter von 15- unter 18 Jahren pro Jahr:	363				
(ermittelt aus den Jahren 2009-2016)					
Zahl aller Meldungen unter 15 bzw. 18 Jahren von Beginn der Erfassung im Jahr 1980 bis 2016:	61954				
in Langzeitnachbeobachtung befindlich	35270				
Bevölkerung im Alter von unter 15 / unter 18 Jahren (Million):					
in 2016	10,7 / 13,1				
im Durchschnitt (in den Jahren 2007-2016 / 2009-2016)	10,9 / 13,3				
Prognose der Fälle im Alter von unter 15 Jahren:					
82 % überleben derzeit eine Krebserkrankung mindestens 15 Jahre					
90 % überleben derzeit eine lymphatische Leukämie (LL) mindestens 15 Jahre					
Insgesamt ca. 420 Todesfälle pro Jahr innerhalb von 15 Jahren nach Diagnose					
Zweitneoplasien nach einer im Kindesalter (unter 15) aufgetretenen Ersterkrankung:					
8,4 % der Patienten erkranken innerhalb von 30 Jahren nach Diagnose erneut an Krebs					
Insgesamt sind über 1300 Patienten mit Folgeneoplasien registriert					
Durchschnittliche Meldungen von Fällen unter 15 Jahren pro Jahr nach Bundesländern:					
(ermittelt aus den Jahren 2007-2016)					
	Alle Erkrankungen	Leukämien	Alle Erkrankungen	Leukämien	
Schleswig-Holstein	64	21	Bayern	280	96
Hamburg	38	12	Saarland	18	6
Niedersachsen	172	58	Berlin	68	24
Bremen	12	4	Brandenburg	45	15
Nordrhein-Westfalen	402	126	Mecklenburg-Vorpommern	28	9
Hessen	135	46	Sachsen	87	26
Rheinland-Pfalz	89	27	Sachsen-Anhalt	43	13
Baden-Württemberg	239	76	Thüringen	39	12

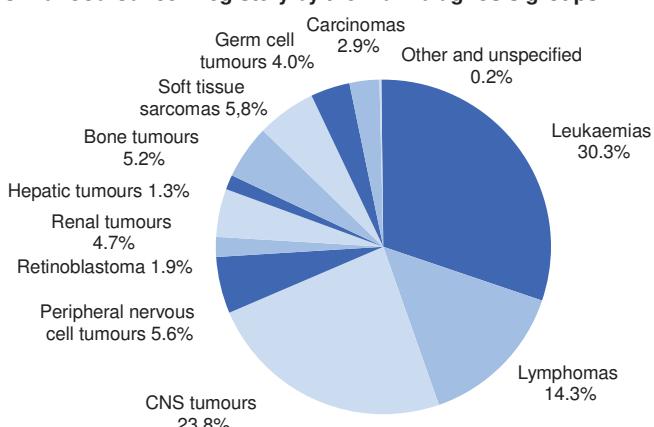


ZNS: Zentrales Nervensystem

*2009-2016, basierend auf insgesamt 16964 unter 18-jährigen Patienten

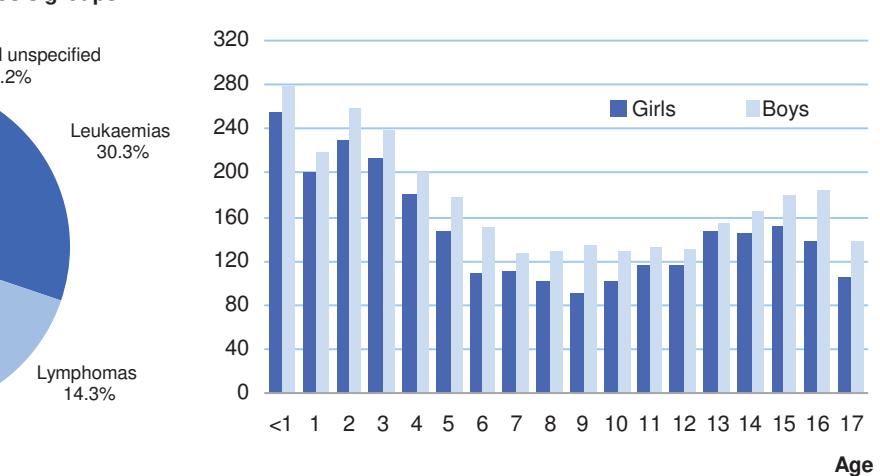
Reported cases aged under 15 years in 2016 (Reported cases from 63 hospitals) :	1741				
Reported cases aged under 18 years in 2016 (Reported cases from 63 hospitals) :	2111				
Average reported cases aged under 15 per year: (calculated from the years 2007-2016)	1761				
diagnosed before the 15 th birthday ...	one out of 409 new born children				
Boys / Girls	970 / 792				
Reported cases aged under 5	787				
Reported cases aged between 5 and under 10	458				
Reported cases aged between 10 and under 15	517				
Lymphoid leukaemias (LL)	440				
Average reported cases aged between 15 years and under 18 years per year: (calculated from the years 2009-2016)	363				
Number of all reported cases aged under 15 or under 18 years from the beginning of registration in 1980 until 2016:	61954				
in long-term surveillance (LTS)	35270				
Population aged under 15 / under 18 (per million):					
in 2016	10.7 / 13.1				
average (in the years 2007-2016 / 2009-2016)	10.9 / 13.3				
Prognosis of cases aged under 15 years:					
82 % currently survive a cancer diagnosis at least 15 years					
90 % currently survive a lymphoid leukaemia (LL) at least 15 years					
Approx. 420 deaths per year within 15 years after diagnosis					
Second neoplasms after initial cancer diagnosis in childhood (aged under 15):					
8.4 % of patients diagnosed with cancer are diagnosed again within 30 years					
More than 1300 patients registered with second neoplasms					
Average reported cases aged under 15 years per year by federal state: (calculated from the years 2007-2016)					
All diseases	Leukaemias	All diseases	Leukaemias		
Schleswig-Holstein	64	21	Bavaria	280	96
Hamburg	38	12	Saarland	18	6
Lower Saxony	172	58	Berlin	68	24
Bremen	12	4	Brandenburg	45	15
North Rhine-Westphalia	402	126	Mecklenburg-Western Pomerania	28	9
Hesse	135	46	Saxony	87	26
Rhineland-Palatinate	89	27	Saxony-Anhalt	43	13
Baden-Württemberg	239	76	Thuringia	39	12

Relative frequencies of registered cases reported to the German Childhood Cancer Registry by the main diagnosis groups*



CNS: Central nervous system

Age- and sex specific incidence rates per million*



6 Ergebnis-Übersicht / Overview of Results

15 to 17 year old adolescents

Im Jahresbericht 2013/14 wurden erstmals die Auswertungen zu den seit 2009 systematisch mit erfassten 15- bis 17-Jährigen präsentiert. Im vorliegenden Bericht sind jetzt Daten über 8 Jahre erhältlich. Erkennbar ist, dass die Meldungen der 16-Jährigen und ganz besonders der 17-Jährigen nicht vollzählig sind. Diese Fälle werden zum Teil außerhalb der Kinder- und Jugendonkologie behandelt, wo die Meldung an das Deutsche Kinderkrebsregister nicht verpflichtend ist.

Zur Präsentation zuverlässiger Zahlen zur Überlebenswahrscheinlichkeit ist die Datenlage noch nicht ausreichend.

In the annual report 2013/14 we presented analyses for cases aged 15-17, which have been registered since 2009, for the first time. The current report makes data for the last 8 years available. It is becoming clear, that the 16-year olds, and even more so the 17-year olds, are not complete. Some of these cases are treated outside of pediatric oncology units, where reporting to the GCCR is not mandatory.

There is not yet sufficient data to present survival probabilities.

I Leukaemias, myeloproliferative and myelodysplastic diseases (p. 16)

Diese hämatologischen Erkrankungen sind die häufigsten bösartigen Erkrankungen im Kindes- und Jugendalter. Betroffen ist bis unter 15 eines von 1250 Kindern, Jungen etwa 20% öfter als Mädchen. Etwa die Hälfte der Erkrankungen tritt bereits vor dem Schulalter auf. Bei Kindern und Jugendlichen überwiegen die akuten Formen, bei Erwachsenen chronische Formen, die bei Kindern sehr selten sind. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100% Vollzähligkeit der Erfassung aus.

Die häufigste Form, die lymphatische Leukämie (früher ALL), nahm Deutschland und Europa bis Mitte der 2000er langsam zu (ca. 0,7% pro Jahr), seitdem sehen wir in Deutschland keinen weiteren Anstieg. Ähnliches gilt für Europa. Fast 98% aller lymphatischen Leukämien sind Vorläuferzell-Leukämien, dies ist damit die bei Kindern und Jugendlichen häufigste Einzeldiagnose überhaupt (ca. 25% aller Krebserkrankungen unter 15 Jahren). Sie hat einen typischen Altersgipfel im Alter von 2-4. Die Prognose ist gut (90% Langzeitüberlebende, mindestens 15 Jahre).

Akute myeloische Leukämien (AML) sind deutlich seltener und haben eine schlechtere Prognose (71% Langzeitüberlebende); die seit den 1980ern erzielten Verbesserungen der Therapie sind erheblich und es werden weiter Verbesserungen erzielt.

Das myelodysplastische Syndrom (MDS) wurde erst seit Anfang des Jahrtausends (mit Veröffentlichung der ICD-O-3) als bösartig (maligne) klassifiziert. Erkrankungs- und Überlebenszahlen davor sind damit nicht repräsentativ. Ein Teil der MDS entwickelt sich zu einer AML weiter. Es gab unterschiedliche Ansätze, wie in diesem Falle mit der Zählung zu verfahren ist. Zeitliche Vergleiche und Vergleiche mit anderen Registern sind daher problematisch.

Die AML und MDS stellen zusammen gut 16% der zweiten und weiteren Krebserkrankungen (subsequent neoplasms (SN)) innerhalb von 30 Jahren nach einer Krebsdiagnose im Kindesalter.

These hematological diseases are the most frequent malignant diseases in childhood and adolescence. One child out of 1250 under 15 years is affected, boys ca. 20% more often than girls. About half of the cases are 5 years and below. Children and adolescents show mostly acute forms, whereas adults show mostly chronic forms, which are very rare in children. Based on international comparisons we assume completeness is close to 100%.

The most frequent form, lymphoid leukaemia (used to be ALL), slowly increased until the mid-2000s in Germany and Europe (ca. 0.7% p.a.), in Germany we see no further increase, similarly for Europe. Almost 98% of all lymphoid leukaemias are precursor cell leukaemias, which makes it the most frequent single diagnosis in childhood and adolescence. It shows a typical age peak at ages 2-4. The prognosis is good (90% long-term survivors for more than 15 years).

Acute myeloid leukaemias (AML) are much less frequent and have a worse prognosis (71% long-term survivors); the improvements in therapy since the 1980s are considerable and keep increasing.

The myelodysplastic syndrome (MDS) was reclassified as malignant since the 2000s (introduction of ICD-O-3). Numbers of cases and survival are not representative before this. Some MDS cases progress to an AML. There were different approaches of counting such cases; as a consequence comparisons over time or across registries are problematic.

More than 16% of the second and subsequent neoplasms (SN) within 30 years of diagnosis are AML or MDS.

II Lymphomas and reticuloendothelial neoplasms (p. 22)

Lymphome (eines von 4000 Kindern unter 15) treten im Allgemeinen im Jugend- und Erwachsenenalter und nur selten bei Kleinkindern auf.

Wir gehen von nahezu 100% Vollzähligkeit der Erfassung aus. Von Hodgkin-Lymphomen sind Jungen ca. 50% häufiger betroffen. Bei Patienten mit Hodgkin Lymphom ist die Prognose bereits seit vielen Jahrzehnten gut (derzeit 97% Langzeitüberlebende), daher sind bei dieser Erkrankung die Spätfolgen der Therapie besonders ausführlich erforscht. Hodgkin Lymphom-Patienten sind überdurchschnittlich oft von SN betroffen, fast 16% in den ersten 30 Jahren nach Diagnose.

Burkitt-Lymphome (BL) zählen zu den Non-Hodgkin-Lymphomen (NHL), werden aber für internationale Vergleichbarkeit separat dargestellt. Jungen sind von NHL mehr als doppelt so oft betroffen, von Burkitt-Lymphomen mehr als 5-mal so oft. Die Prognose ist gut (86% bzw. 92% Langzeitüberlebende). Das Risiko einer Folgeneoplasie ist nach NHL überdurchschnittlich hoch, besonders nach Vorläuferzell-Lymphomen (22% Risiko).

Unspezifizierte Lymphome werden fast nie gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Lymphomas (one child in 4000 under 15) occur mostly in adolescents and adults, while they are rare in small children.

We assume completeness is close to 100%. Hodgkin lymphomas are about 50% more frequent in boys. Patients with Hodgkin lymphoma have shown a good prognosis for decades (current long-term survival is 97%), so for this entity late effects are particularly well known. Patients with Hodgkin lymphoma are especially frequently affected by SN (almost 16% within the first 30 years).

Burkitt lymphomas (BL) are a subgroup of the Non-Hodgkin lymphomas (NHL); they are presented separately for international comparisons. Boys are affected by NHL more than twice as often as girls, five times as often by Burkitt lymphoma. The prognosis of NHL is good (NHL/BL 86%/92% long-term survivors). The SN risk after NHL is above average, especially after precursor cell lymphoma (22% risk).

Unspecified lymphomas are rarely reported, this shows the high quality of diagnosis and reports.

III CNS and miscellaneous intracranial and intraspinal neoplasms (p. 28)

Bei den Tumoren des zentralen Nervensystems (ZNS, Hirntumore), eines von 1600 Kindern unter 15 ist betroffen, handelt es sich um eine heterogene Gruppe von Krebskrankungen mit bösartigen (malignen) und nichtmalignen Formen. Internationale Vergleiche deuten auf eine gewisse Untererfassung der nichtmalignen Formen hin. Der beobachtete Anstieg der Erkrankungszahlen zeigt die stetig verbesserte Vollzähligkeit der Erfassung, besonders bei Astrozytomen und sonstigen Gliomen. Jungen sind etwa 20% häufiger betroffen als Mädchen. Die scheinbar seit 1990 schlechter werdende Prognose bei den „sonstigen Gliomen“ ist auf erhebliche Änderungen in der Zusammensetzung dieser Gruppe zurückzuführen, was durch die zunehmende Vollzähligkeit und Veränderungen in der Klassifikation bedingt ist.

Das Risiko eines SN innerhalb von 30 Jahren ist nach Astrozytomen und anderen Gliomen sowie Kranio-pharyngiomen ungewöhnlich niedrig und mit 34% nach Medulloblastomen außergewöhnlich hoch. ZNS-Tumoren stellen 23% aller SN in den ersten 30 Jahren nach einer Diagnose im Kindesalter, dabei handelt es sich mehrheitlich um Meningiome, gefolgt von den Astrozytomen.

Tumours of the central nervous system (CNS, brain tumours) affect one child in 1600 under 15. They are a heterogeneous group of neoplasms, including malignant and non-malignant forms. Based on international comparisons we assume especially the non-malignant forms to be slightly underreported. The observed increase in cases shows improvements in completeness of registration, especially regarding astrocytomas and other gliomas. Boys have an about 20% higher incidence. The seemingly worsening prognosis of “other gliomas” since 1990 is due to considerable changes in the composition of this group due to improvements in completeness and classification changes.

The risk of an SN after intracranial and intraspinal embryonal tumours is unusually low after astrocytoma, other gliomas, and craniopharyngiomas, while after Medulloblastoma it is unusually high (34%). 23% of all SN in the 30 years after primary diagnosis are CNS tumours, most of these are meningiomas, followed by astrocytomas.

8 Ergebnis-Übersicht / Overview of Results

IV Neuroblastoma and other peripheral nervous cell tumours (p. 41)

Neuroblastome gehören zu den embryonalen Tumoren, die vor allem bei Kleinkindern auftreten. Betroffen ist eines von 6000 Kindern unter 15, Jungen erkranken etwa 40% häufiger als Mädchen. Wir gehen von nahezu 100% Vollzähligkeit der Erfassung aus. Insgesamt überleben etwa 76% der Fälle langfristig, jedoch haben Patienten mit fortgeschrittenener Erkrankung (Stadium IV) nach wie vor eine relativ schlechte Prognose, auch wenn für diese Gruppe seit den 1980ern erhebliche Verbesserungen erzielt wurden.

Bei Neuroblastomen kann sich bei einem Teil der Erkrankungsfälle (insbesondere mit niedrigem Stadium bis etwa zum 2. Geburtstag) der Tumor spontan zurückbilden. Während eines Modellprojekts zur Früherkennung (1995-2000) wurden daher viele zusätzliche Fälle diagnostiziert, was zu einem erkennbaren Anstieg der Erkrankungszahlen führte. Es folgte jedoch nicht die erhoffte Mortalitätssenkung, so dass die Früh-erkennung als nicht zielführend verworfen wurde. Die erhöhte Aufmerksamkeit und die weitere Verbreitung von Ultraschalldiagnostik führten seither auch ohne Screening zu einem Anstieg der gemeldeten Erkrankungszahlen.

Folgeneoplasien sind nach Neuroblastomen selten, ihrerseits treten sie fast nie als Folgeneoplasien auf.

Neuroblastomas are embryonal tumours, which are observed mainly in small children. It affects one child in 6000 under 15, boys have an about 40% higher incidence than girls. We assume completeness is close to 100%. Overall long-term survival is 76%, but patients with advanced disease (stage IV) still have a rather bad prognosis, although it has improved considerably since the 1980ies.

A subset of neuroblastomas (especially low stages before the 2nd birthday) is capable of spontaneous regression. During the screening evaluation project 1995-2000 this led to a considerable number of additional cases, which is visible in the trend graphic. However, screening did not lead to the intended drop in mortality, so it was not introduced. The increased attention and the extended usage of ultrasound diagnostics have since led to an increase in the number of reported cases even without screening.

Subsequent neoplasms are rare after neuroblastoma, which are in turn almost never reported as SN.

V Retinoblastoma (p. 42)

Retinoblastome, unter 17.000 Kindern unter 15 tritt ein Fall auf, gehören zu den embryonalen Tumoren von denen ältere Kinder (ab ca. 10 Jahren) kaum betroffen sind. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus. Das Retinoblastom ist eine der Erkrankungen, bei denen Genetik und Vererbung eine große Rolle spielen, besonders bei beidseitig auftretenden Retinoblastomen. Grundsätzlich sollten beim Auftreten der Erkrankung Familienmitglieder mit untersucht werden.

Retinoblastome treten fast nie als Folgeneoplasien auf.

One child in 17,000 under 15 is affected with a Retinoblastoma. These are embryonal tumours which rarely affect older children (10 years or older). Based on international comparisons we assume completeness is high. Retinoblastoma has a known genetic cause and can be inherited, especially bilateral cases. When a case is diagnosed, family members should also be examined.

Retinoblastomas are very rare as SN.

VI Renal Tumours (p. 43)

Fast alle Nierentumoren im Kindesalter sind Nephroblastome (Wilmstumor). Ein Kind von 7400 bis 14 Jahre ist betroffen, Mädchen etwa 10% häufiger. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100% Vollzähligkeit der Erfassung aus. Die Prognose ist gut (93% Langzeitüberlebende). Nach einem Nephroblastom ist das Risiko einer Folgeneoplasie unterdurchschnittlich, ihrerseits treten diese nur extrem selten als Folgeneoplasie auf. Nierenkarzinome, meist im Erwachsenenalter beobachtet, treten nur selten und wenn, dann bei älteren Kindern und Jugendlichen auf, bei Jungen 40% häufiger.

Almost all renal tumours in childhood are nephroblastomas (Wilm's tumour). One child under 15 in 7400 is affected, girls about 10% more often. Based on international comparisons we assume completeness is close to 100%. The prognosis is good (93% long-term survivors).

The risk of a subsequent neoplasm is below average, nephroblastoma is hardly ever reported as an SN.

Renal carcinomas, usually observed in adults, are occasionally diagnosed in older children and adolescents; boys are affected 40% more often.

Folgeneoplasien nach Nierenkarzinomen wurden nur selten gemeldet, ihrerseits als Folgeneoplasie treten sie vereinzelt auf.

Unspezifizierte Nierentumoren wurden keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

VII Hepatic tumours (p. 46)

Fast alle Lebertumoren im Kindesalter (ein Fall unter 33.000 Kindern bis 14 Jahre) sind Hepatoblastome. Jungen sind 40% häufiger betroffen als Mädchen. Wir gehen von guter Vollzähligkeit der Erfassung aus, die seit der Gründung eines Lebertumorregisters für Kinder im Jahre 2011 erkennbar weiter verbessert wurde. Die Prognose ist moderat (79% Langzeitüberlebende) und seit den 1980ern erheblich verbessert.

Folgeneoplasien sind nach Hepatoblastomen sehr selten, ihrerseits treten sie fast nie als Folgeneoplasien auf. Leberkarzinome, meist im Erwachsenenalter beobachtet, treten nur sehr selten und wenn, dann bei älteren Kindern und Jugendlichen auf.

Folgeneoplasien nach Leberkarzinomen wurden nur selten gemeldet, ihrerseits als Folgeneoplasie treten sie vereinzelt auf.

Unspezifizierte Lebertumoren wurden keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Subsequent neoplasms after renal carcinomas are rare, renal carcinomas as subsequent neoplasms do occur occasionally.

No unspecified renal tumours were reported, this shows the high quality of diagnoses and reports.

VIII Malignant bone tumours (p. 48)

Knochensarkome (ein Kind von 9700 unter 15) sind typisch für ältere Kinder und Jugendliche. Die besonders häufigen Typen sind Osteosarkome und Ewing-sarkome. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus.

Knochentumore stellen 5% aller Folgeneoplasien innerhalb von 30 Jahren nach einer Krebsdiagnose im Kindesalter, dabei überwiegen Osteosarkome.

Unspezifizierte Knochentumoren wurden fast keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Almost all hepatic tumours in childhood (one in 33,000 children until 14 years is affected) are hepatoblastomas. Boys have a 40% higher incidence. We assume completeness is good and has visibly improved further since a hepatic tumour registry for children was funded in 2011. The prognosis is moderate (79% long-term survivors) and has been improving considerably since the 1980ies.

Subsequent neoplasms are rare; hepatoblastomas hardly ever are subsequent neoplasms.

Hepatic carcinomas, usually observed in adults, are occasionally diagnosed in older children and adolescents.

SN are rarely reported, hepatic carcinomas occasionally occur as SN.

Unspecified hepatic tumours were not reported, this shows the high quality of diagnoses and reports.

IX Soft tissue and other extraosseous sarcomas (p. 52)

Weichteilsarkome können in allen Altersklassen auftreten, betroffen ist ein Kind bis 14 Jahre von 7200. Das häufigste Weichteilsarkom im Kindesalter ist das Rhabdomyosarkom. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus. Jungen sind etwa 20% häufiger betroffen als Mädchen. Die Prognose ist unterdurchschnittlich (70% Langzeitüberlebende).

Weichteilsarkompatienten sind durchschnittlich häufig von Folgeneoplasien betroffen, etwa 6% aller Folgeneoplasien innerhalb von 30 Jahren nach einer Krebsdiagnose im Kindesalter sind ihrerseits Weichteilsarkome.

Bone sarcomas (one case in 9700 children under 15) are typical for older children and adolescents. The most frequent forms are osteosarcoma and Ewing sarcomas. Based on international comparisons we assume completeness is high.

5% of all subsequent neoplasms within 30 years of the first neoplasm are bone tumours, mostly osteosarcoma.

Unspecified bone tumours are rarely reported, this shows the high quality of diagnoses and reports.

Soft tissue sarcomas occur in all ages in childhood (one child under 15 in 7200). The most frequent type in childhood is rhabdomyosarcoma. Based on international comparisons we assume completeness is high. Boys have a 20% higher incidence than girls. The prognosis is below average (70% long-term survivors).

Soft tissue sarcoma patients have an average risk of a subsequent neoplasm; about 6% of all subsequent neoplasms within 30 years after a primary neoplasm are soft tissue sarcomas.

10 Ergebnis-Übersicht / Overview of Results

X Germ cell tumours, trophoblastic tumours and neoplasms of gonads (p. 59)

Keimzelltumoren sind eine heterogene Gruppe von Krebskrankungen (bis unter 15 ein Kind von 13.000). Einige treten häufiger mit beginnender Pubertät auf, andere sind typisch für das Kleinkindalter, so dass sie vom 4.-7. Lebensjahr eher selten sind. Wir gehen von hoher Vollzähligkeit der Erfassung aus. Mädchen sind bis 14 Jahre etwa 30% häufiger betroffen. Bei den intrakraniellen Formen (im Gehirn lokalisiert) hat es seit etwa 2000 (neue Diagnoseklassifikation ICD-O-3) Zuordnungsänderungen gegeben, so dass einige Keimzelltumoren seither der Hauptgruppe der Hirntumoren (ZNS) zugeordnet werden. Insgesamt ist die Langzeitprognose gut (93%).

Das Risiko einer Folgeneoplasie innerhalb von 30 Jahren ist durchschnittlich. Keimzelltumoren sind als Folgeneoplasien eher selten.

Germ cell tumours are a heterogeneous group of neoplasms; one child under 15 in 13,000 is affected. Some become more frequent as puberty sets in, others are typical for infants, so they are rare from the 4th to 7th year of life. We assume completeness is high. Girls under 15 have about 30% higher incidence. Some intracranial forms (localized in the brain) have been reclassified as brain tumours (CNS) since about 2000 (new diagnosis classification ICD-O-3. In general the prognosis is good (93% long-term survivors).

The risk of an SN is average. Germ cell tumours are rare as SN.

XI Other malignant epithelial neoplasms and malignant melanomas (p. 67)

Dies ist eine heterogene Gruppe von Neoplasien. Karzinome treten im Allgemeinen erst im Erwachsenenalter auf. Die häufigsten dieser seltenen Erkrankungen im Kindesalter sind Karzinome der Nebennierenrinde, der Schilddrüse (Verbesserung der Erfassung ab 1996), des Nasopharynx (Nasen-Rachenraum) und das maligne Melanom („schwarzer“ Hautkrebs). Einige Karzinome bei Kindern sind deutlich untererfasst, jedoch nicht die Nasopharynx-Karzinome und Schilddrüsenkarzinome. Seit 2011 werden Appendix-Karzinoide als maligne eingestuft, daraus erklärt sich die seitdem erheblich gestiegene Anzahl der Meldungen von Appendixkarzinomen. Bei den malignen Melanomen konnte die Erfassung im Laufe der Jahre erheblich verbessert werden, jedoch sind sie vermutlich weiterhin untererfasst. Mammakarzinome wurden primär keine gemeldet. Schilddrüsenkarzinome haben eine gute Prognose (94% Langzeitüberlebende).

Nach Karzinomen werden überdurchschnittlich häufig Folgeneoplasien gemeldet. Sie stellen ihrerseits ein Drittel aller Folgeneoplasien innerhalb von 30 Jahren nach Erstdiagnose, besonders zu nennen sind hier Schilddrüsenkarzinome, Hautkarzinome (überwiegend keine malignen Melanome), Mammakarzinome und Darmkrebs. Schon bei den unter 15-Jährigen sind gut 10% aller gemeldeten Schilddrüsentumore SN.

This is a heterogeneous group of rare cancers. Carcinomas are usually observed in adults. The most frequent among them in childhood are adrenocortical carcinoma, thyroid carcinoma (improved reporting since 1996), nasopharyngeal carcinoma, and malignant melanoma. Some carcinomas in children are clearly underreported, though not nasopharyngeal carcinomas and thyroid carcinomas. Appendix carcinoids have been reclassified as malignant in 2011, which explains the sudden considerable increase in reported appendix carcinomas since then. The reporting of malignant melanoma has improved over the years, but we assume they continue to be underreported. Breast carcinomas have not been reported as primary neoplasms. Thyroid carcinomas have a good prognosis (94% long-term survivors).

Carcinoma patients have an above average SN risk. One third of all subsequent neoplasms within 30 years are carcinomas, particularly thyroid carcinoma, skin carcinoma (mostly not malignant melanoma), breast carcinoma and colon carcinoma. Among the thyroid cancer cases under 15, more than 10% are SN.

XII Other and unspecified neoplasms (p. 76)

Dies ist eine heterogene Gruppe von sonst nicht zuordnenden, bei Kindern sehr seltenen bösartigen Krebskrankungen (ein Fall pro 250.000 Kinder unter 15). Der häufigste Einzeltumor hiervon ist das Lungenblastom.

This is a heterogeneous group of very rare neoplasms in childhood not classifiable anywhere else (one child under 15 in 250,000). The most frequent tumour among these is pulmonary blastoma.

**Systematische Darstellung epidemiologischer Kenngrößen der ICCC-3 Diagnosen /
Systematic Presentation of Descriptive Measures for ICCC-3 Diagnoses**

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12 Diagnosen / Diagnoses

Systematische Darstellung epidemiologischer Kenngrößen der ICCC-3 Diagnosen / Systematic Presentation of Descriptive Measures for ICCC-3 Diagnoses

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**Systematische Darstellung epidemiologischer Kenngrößen der ICCC-3 Diagnosen /
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14 Diagnosen / Diagnoses

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Cases in Germany aged under 15 years (1980-2016): 59048

Selected characteristics Germany 2007-2016

Relative frequency:	17613 / 17613 = 100 %			
Relative frequency of trial patients:	95.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	7915	9698	17613	
Standardized rate *:	155.9	180.5	168.5	
Cumulative incidence:	2258	2624	2446	
Sex ratio (m/f):	1.2			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	1841	6025	4575	5172
Incidence rate:	267.0	218.0	127.3	133.9
Median age at diagnosis:	5 years 9 months			
Survival probabilities (2004-2013):	5-year 85 %	10-year 83 %	15-year 82 %	

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N 4232	100.0 % 33.7	492

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

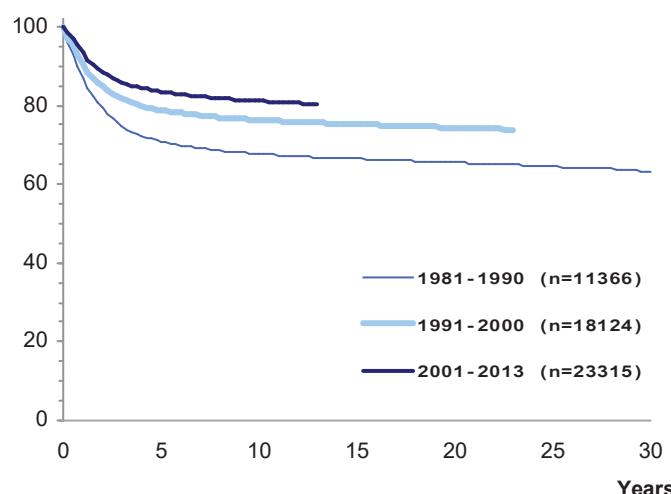
All Malignancies

SN after all malignancies

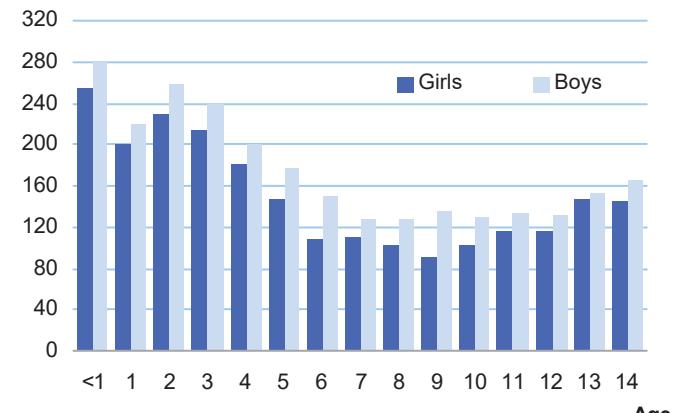
N	% of all SN	Cumulative incidence
1245	100.0 %	8.4 %

* Standard: Segi world standard population

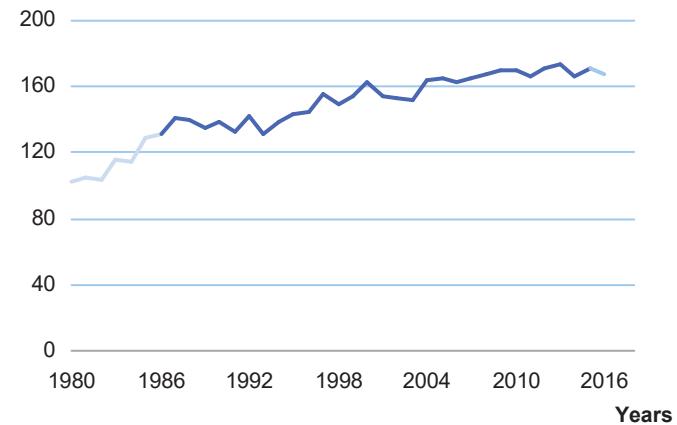
Survival probabilities by year of diagnosis Germany 1981-2013



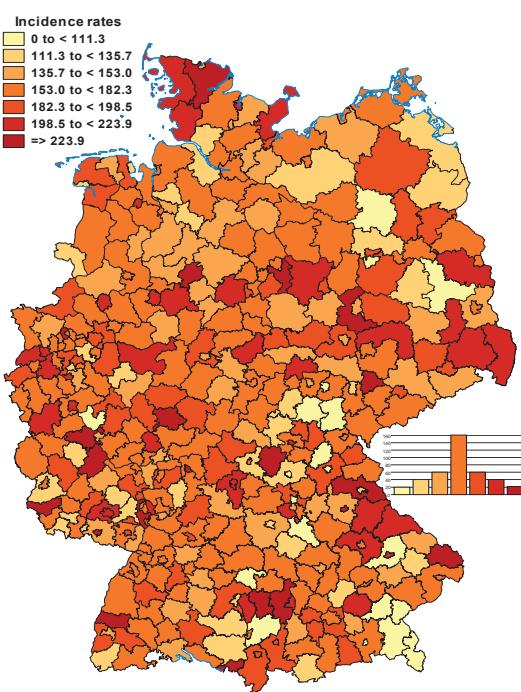
Age- and sex-specific incidence rates per million Germany 2007-2016



Standardized* annual incidence rates per million Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



16 I Leukaemias, myeloproliferative and myelodysplastic diseases

- (a) Lymphoid leukaemias
- (b) Acute myeloid leukaemias
- (c) Chronic myeloproliferative diseases

- (d) Myelodysplastic syndrome and other myeloproliferative disease
- (e) Unspecified and other specified leukaemias

Cases in Germany aged under 15 years (1980-2016): 20031

Selected characteristics Germany 2007-2016

Relative frequency:	5713 / 17613 = 32.4 %		
Relative frequency of trial patients:	99.1 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	2567	3146	5713
Standardized rate *:	52.0	59.8	56.0
Cumulative incidence:	740	858	800
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:				
<1	1-4	5-9	10-14	
Number of cases :	287	2608	1606	1212
Incidence rate:	41.6	94.4	44.7	31.4

Median age at diagnosis: 4 years 11 months

Survival probabilities		5-year	10-year	15-year
(2004-2013):		89 %	87 %	86 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths	10.6	155

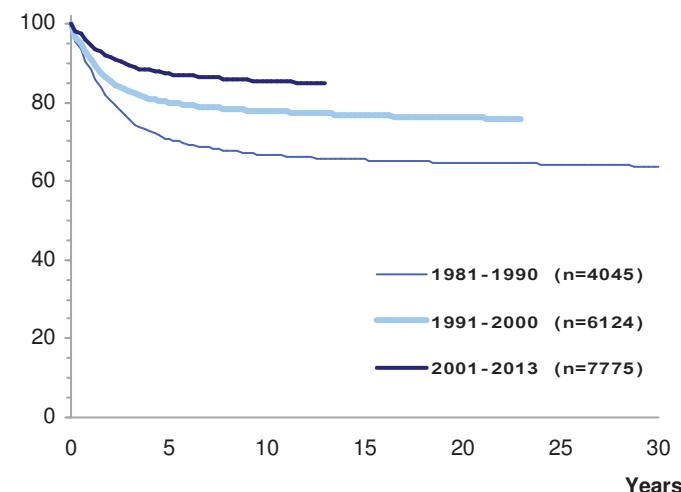
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

I Leukaemias, myeloproliferative and myelodysplastic diseases

SN after I			I as SN after any primary		
N	% of all SN	Cumulative incidence	N	% of all SN	Cumulative incidence
443	35.6 %	8.0 %	258	20.7 %	0.7 %

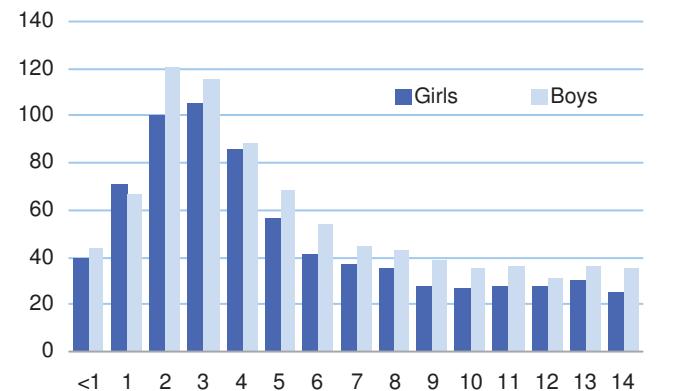
* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



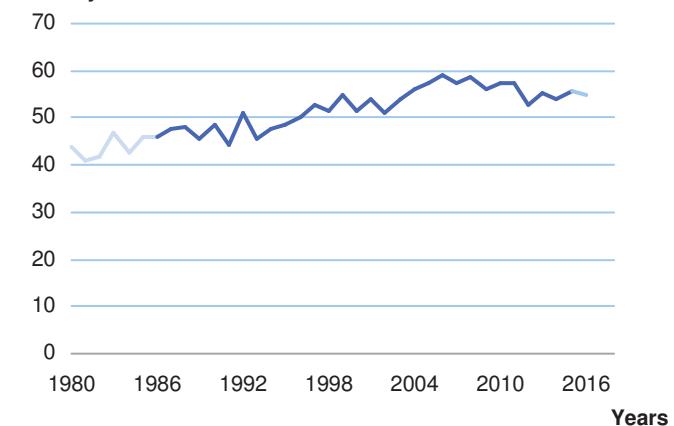
Age- and sex-specific incidence rates per million

Germany 2007-2016



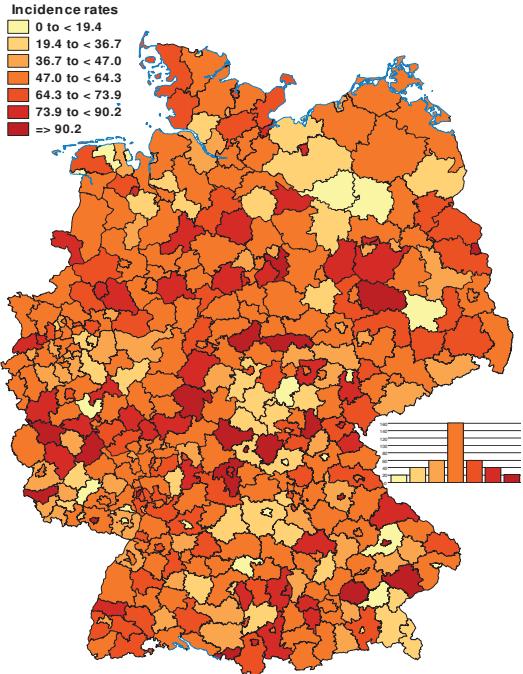
Standardized* annual incidence rates per million

Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016

Incidence rates



Cases in Germany aged under 15 years (1980-2016): 15893

Selected characteristics Germany 2007-2016

Relative frequency:	4398 / 17613 = 25 %			
Relative frequency of trial patients:	99.7 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	1963	2435	4398	
Standardized rate *:	40.2	46.5	43.4	
Cumulative incidence:	568	666	618	
Sex ratio (m/f):	1.2			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	113	2197	1289	799
Incidence rate:	16.4	79.5	35.9	20.7
Median age at diagnosis:	4 years 9 months			
Survival probabilities (2004-2013):	5-year 92 %	10-year 91 %	15-year 90 %	

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		
812	19.2 %	6.5	94

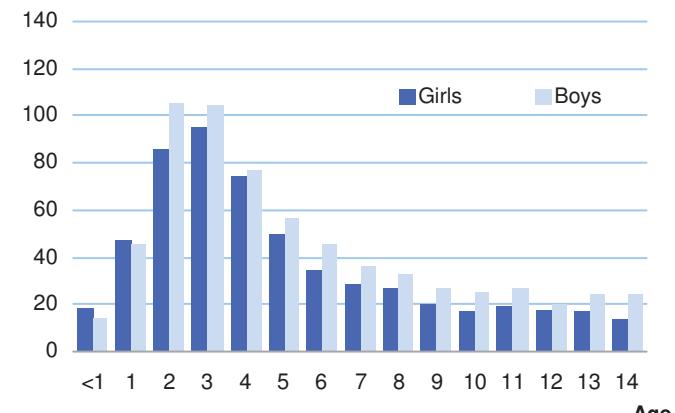
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

I (a) Lymphoid leukaemias

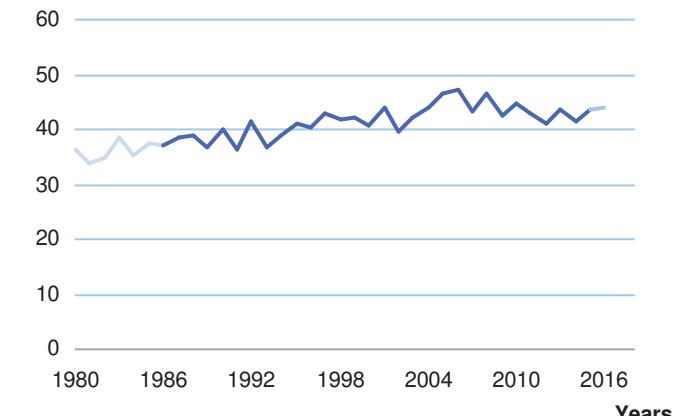
SN after I (a)			I (a) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
368	29.6 %	7.6 %	49	3.9 %	0.1 %

* Standard: Segi world standard population

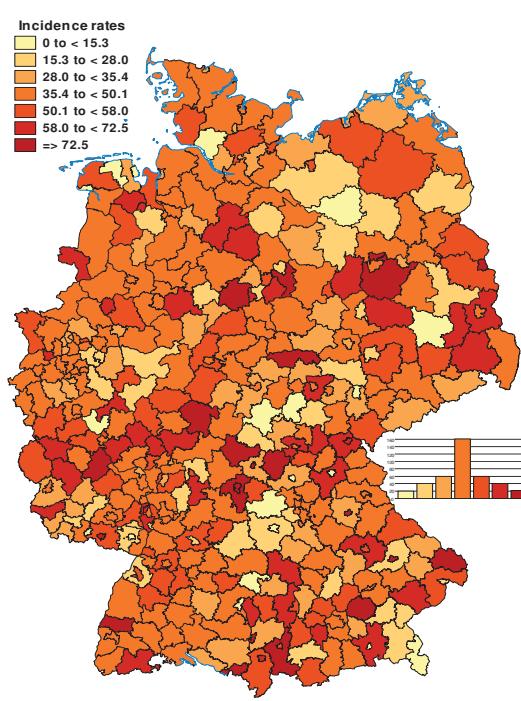
Age- and sex-specific incidence rates per million Germany 2007-2016



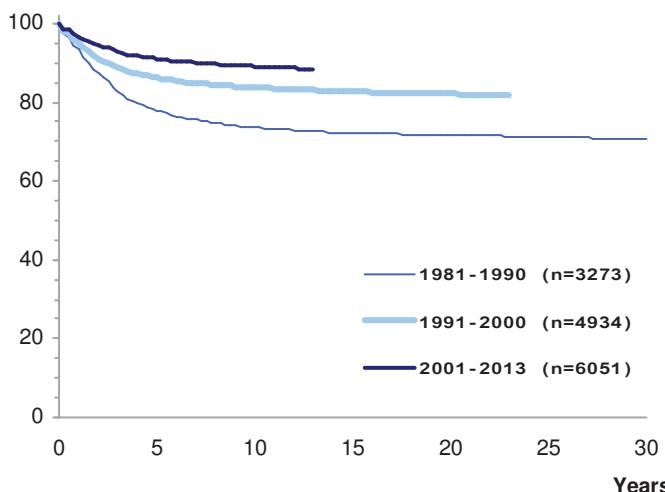
Standardized* annual incidence rates per million Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Survival probabilities by year of diagnosis Germany 1981-2013



18 I (a) Lymphoid leukaemias - Extended ICCC-3

Germany 2007-2016		N	%
Lymphoid leukaemias		4398	100.0
1 Precursor cell leukaemias		4294	97.6
2 Mature B-cell leukaemias		102	2.3
3 Mature T-cell and NK cell leukaemias		2	0.0
4 Lymphoid leukaemia, NOS		0	0.0

1 Precursor cell leukaemias

Cases in Germany aged under 15 years (1980-2016): 15507

Selected characteristics Germany 2007-2016

Relative frequency:	4294 / 17613 = 24.4 %			
Relative frequency of trial patients:	99.7 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	1939	2355	4294	
Standardized rate *:	39.7	45.1	42.5	
Cumulative incidence:	561	644	604	
Sex ratio (m/f):	1.2			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	112	2175	1236	771
Incidence rate:	16.2	78.7	34.4	20.0
Median age at diagnosis:	4 years 8 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
1 Precursor cell leukaemias				
SN after I (a) 1	I (a) 1 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence	
359 28.8 %	7.6 %	44 3.5 %	0.1 %	

* Standard: Segi world standard population

2 Mature B-cell leukaemias

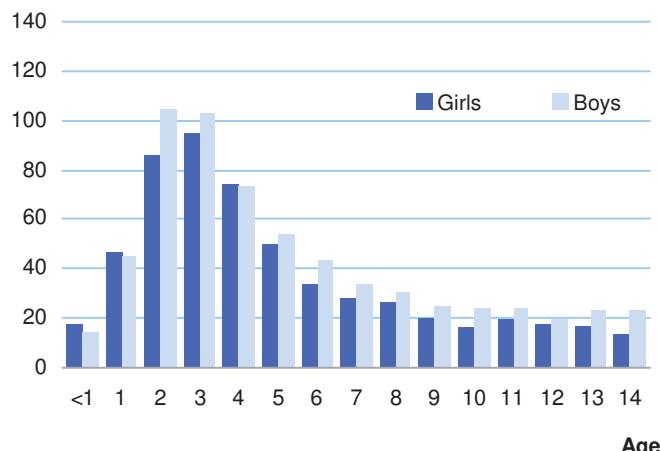
Cases in Germany aged under 15 years (1980-2016): 383

Selected characteristics Germany 2007-2016

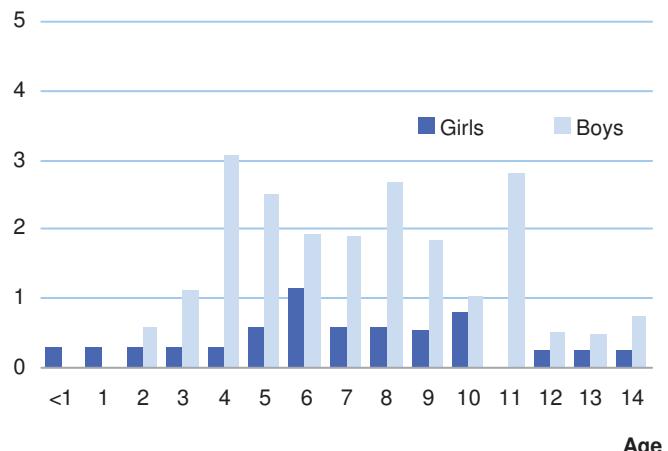
Relative frequency:	102 / 17613 = 0.6 %			
Relative frequency of trial patients:	99.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	23	79	102	
Standardized rate *:	0.4	1.4	0.9	
Cumulative incidence:	7	21	14	
Sex ratio (m/f):	3.4			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	1	21	52	28
Incidence rate:	0.1	0.8	1.4	0.7
Median age at diagnosis:	7 years 10 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
2 Mature B-cell leukaemias				
SN after I (a) 2	I (a) 2 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence	
9 0.7 %	8.6 %	5 0.4 %	0.0 %	

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Age- and sex-specific incidence rates per million Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 2790

Selected characteristics Germany 2007-2016

Relative frequency: 722 / 17613 = 4.1 %

Relative frequency of trial patients: 97.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	345	377	722
Standardized rate *:	6.9	7.2	7.1
Cumulative incidence:	98	103	101
Sex ratio (m/f):			1.1

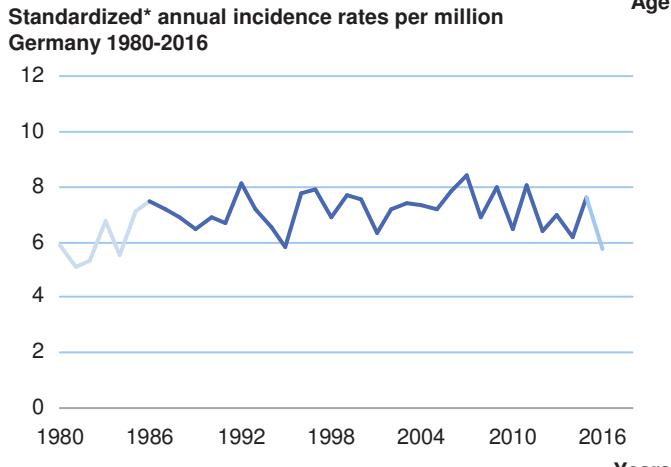
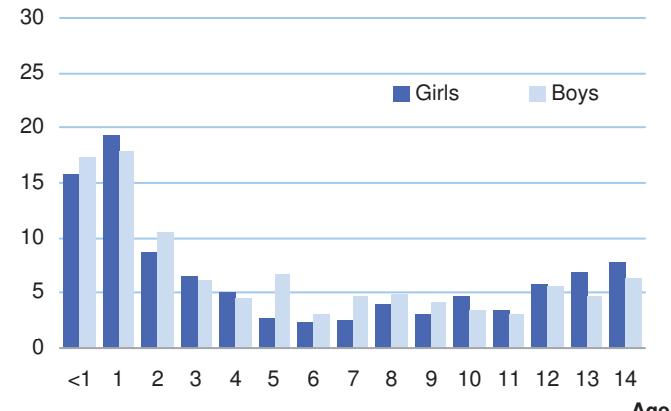
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	114	271	137	200
Incidence rate:	16.5	9.8	3.8	5.2

Median age at diagnosis: 4 years 2 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	73 %	72 %	71 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N 392	9.3 %	3.1

Age- and sex-specific incidence rates per million
Germany 2007-2016

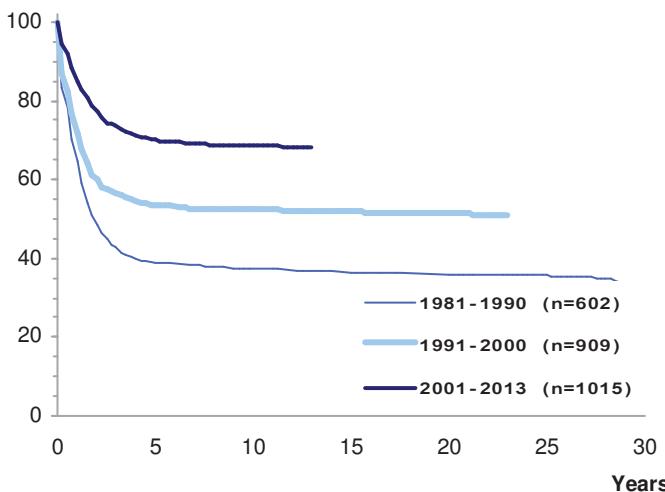
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

I (b) Acute myeloid leukaemias

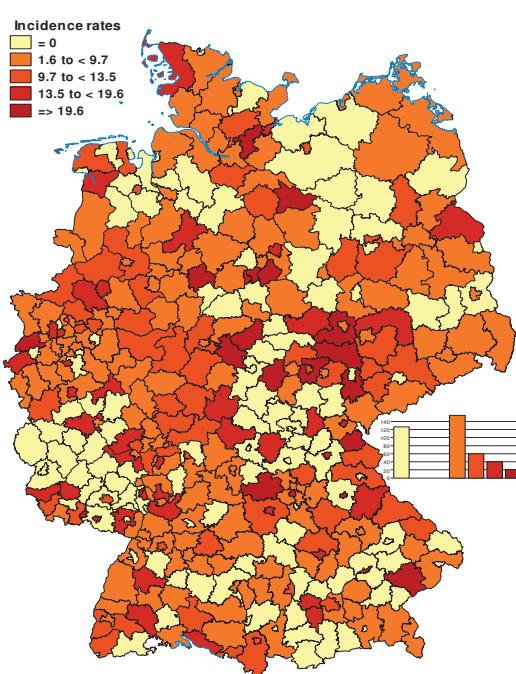
SN after I (b)			I (b) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
54	4.3 %	9.5 %	139	11.2 %	0.4 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



20 I (c) Chronic myeloproliferative diseases

Cases in Germany aged under 15 years (1980-2016): 273

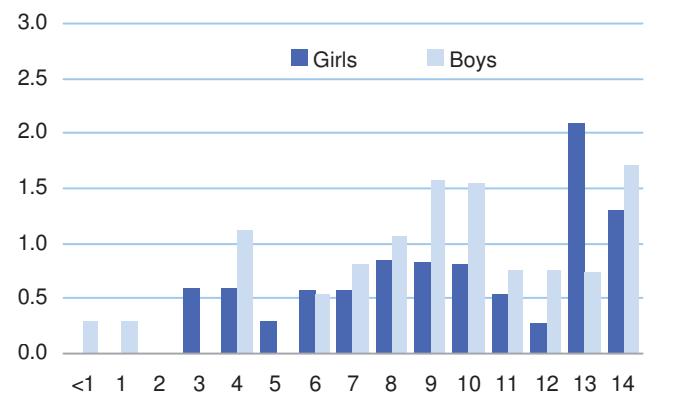
Selected characteristics Germany 2007-2016

Relative frequency:	77 / 17613 = 0.4 %			
Relative frequency of trial patients:	87.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	34	43	77	
Standardized rate *:	0.6	0.7	0.7	
Cumulative incidence:	9	11	10	
Sex ratio (m/f):	1.3			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	1	9	26	41
Incidence rate:	0.1	0.3	0.7	1.1
Median age at diagnosis:	10 years 1 month			
Survival probabilities (2004-2013):	5-year 96 %	10-year 96 %	15-year 96 %	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths N % of all 4232 deaths	33 0.8 %	Standardized* mortality rate 0.2	Cumulative mortality 4	
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
I (c) Chronic myeloproliferative diseases				
SN after I (c)				
% of all SN N 1245 SN	Cumulative incidence -	I (c) as SN after any primary		
5 0.4 %	-	N % of all 1245 SN	Cumulative incidence	
		4 0.3 %	0.0 %	

* Standard: Segi world standard population

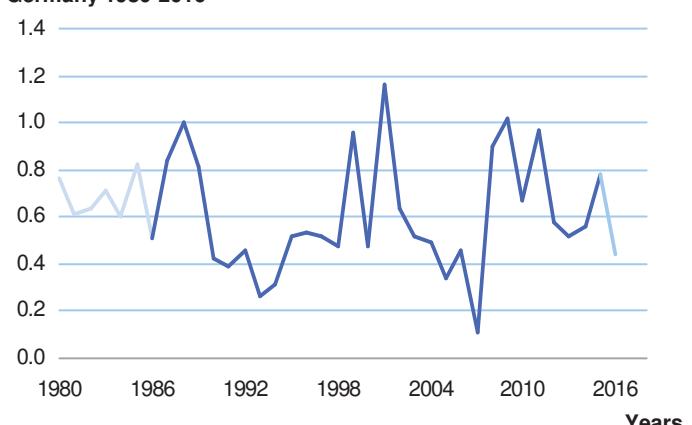
Age- and sex-specific incidence rates per million

Germany 2007-2016

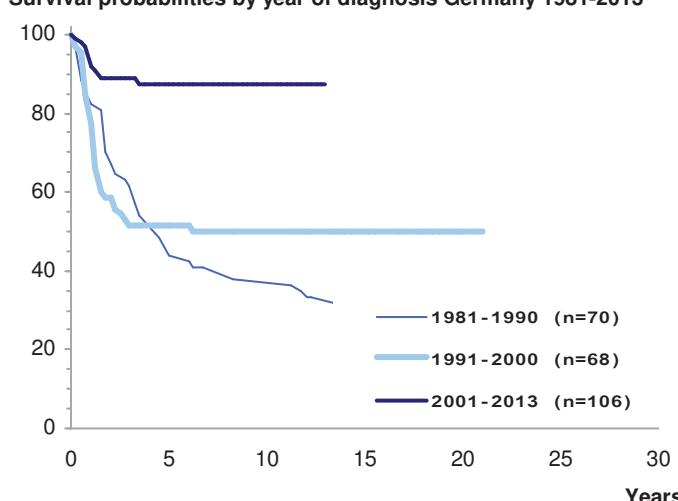


Standardized* annual incidence rates per million

Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013

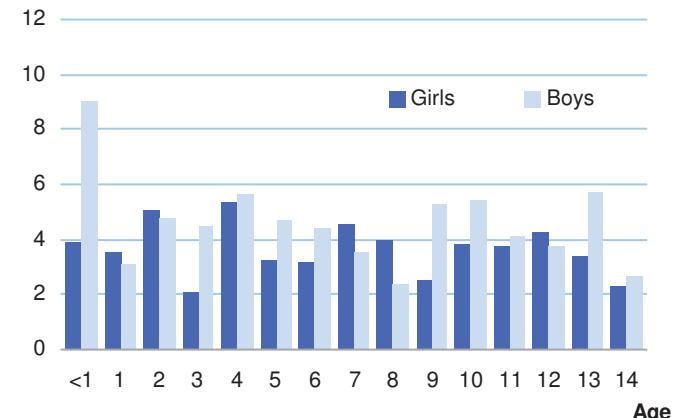


No map due to sparse data

Cases in Germany aged under 15 years (1980-2016): 881

Selected characteristics Germany 2007-2016

Relative frequency: 451 / 17613 = 2.6 %
 Relative frequency of trial patients: 99.1 %

Age- and sex-specific incidence rates per million
Germany 2007-2016

Incidence rates per million:

	Girls	Boys	Total
Number of cases:	194	257	451
Standardized rate *:	3.7	4.7	4.2
Cumulative incidence:	55	69	62
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

<1	1-4	5-9	10-14
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Number of cases :	45	118	136	152
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Incidence rate:	6.5	4.3	3.8	3.9
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Median age at diagnosis: 7 years 3 months

Survival probabilities (2004-2013): 5-year 82 % | 10-year 79 % | 15-year 76 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		
85	2.0 %	0.7	10

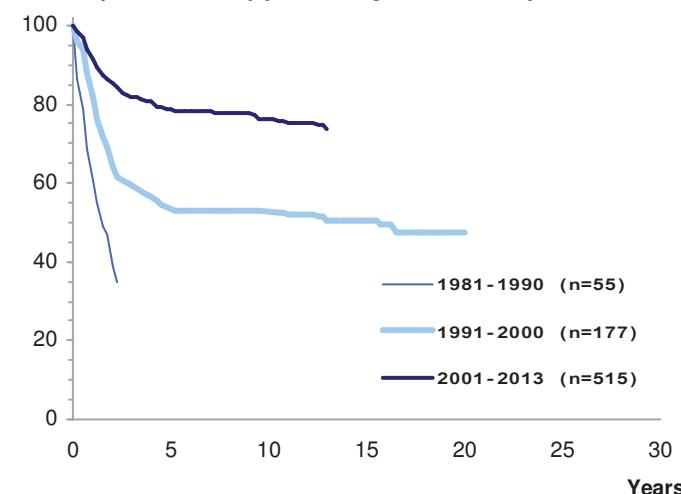
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

I (d) Myelodysplastic syndrome and other myeloproliferative diseases

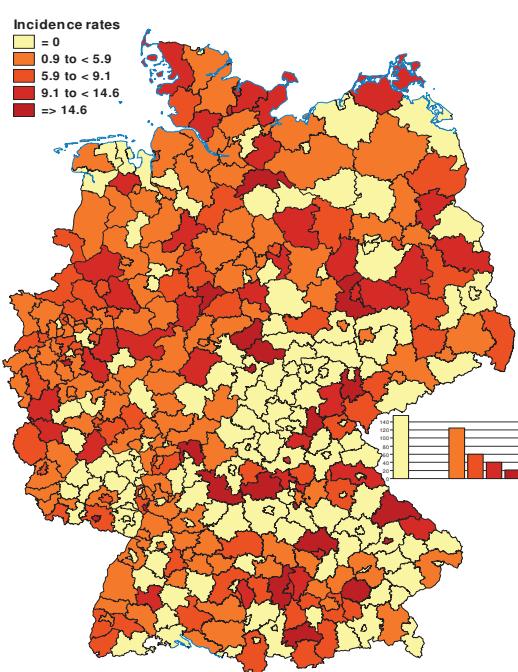
SN after I (d)			I (d) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
8	0.6 %	4.6 %	64	5.1 %	0.2 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



22 II Lymphomas and reticuloendothelial neoplasms

- (a) Hodgkin lymphomas
- (b) Non-Hodgkin lymphomas (except Burkitt lymphoma)
- (c) Burkitt lymphoma

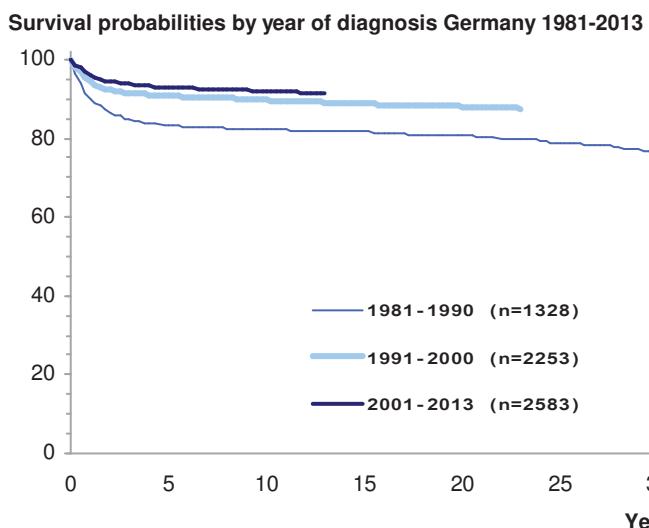
- (d) Miscellaneous lymphoreticular neoplasms
- (e) Unspecified lymphomas

Cases in Germany aged under 15 years (1980-2016): 6862

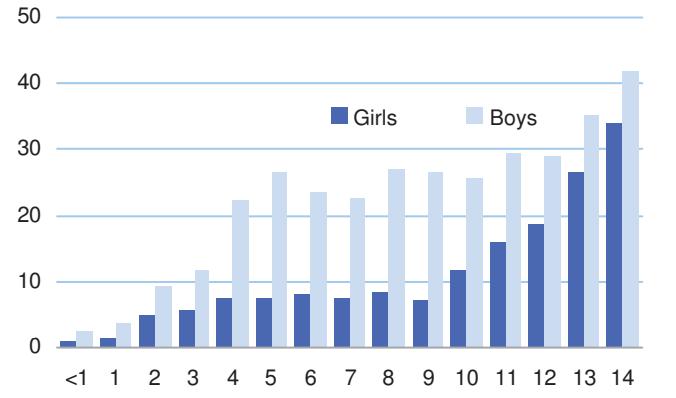
Selected characteristics Germany 2007-2016

Relative frequency:	1889 / 17613 = 10.7 %			
Relative frequency of trial patients:	97.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	608	1281	1889	
Standardized rate *:	10.3	21.3	15.9	
Cumulative incidence:	166	337	253	
Sex ratio (m/f):	2.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	11	232	601	1045
Incidence rate:	1.6	8.4	16.7	27.1
Median age at diagnosis:	10 years 8 months			
Survival probabilities (2004-2013):	5-year 94 %	10-year 93 %	15-year 92 %	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths				
N	% of all 4232 deaths	Standardized* mortality rate	Cumulative mortality	
241	5.7 %	1.8	27	
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
II Lymphomas and reticuloendothelial neoplasms				
SN after II				
% of all SN	Cumulative incidence			
N	1245 SN			
220	17.7 %	13.0 %		
II as SN after any primary				
% of all SN	Cumulative incidence			
N	1245 SN			
92	7.4 %	0.4 %		

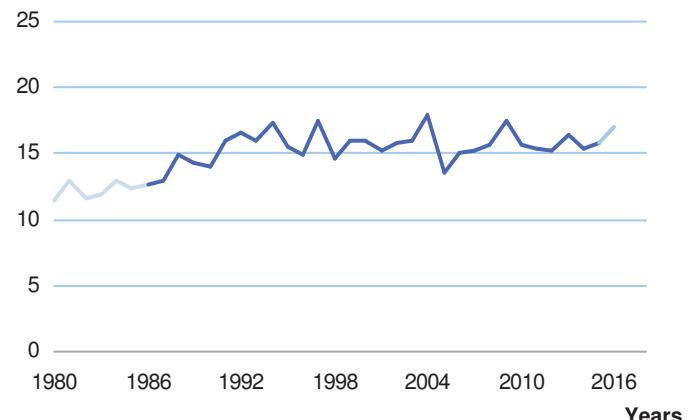
* Standard: Segi world standard population



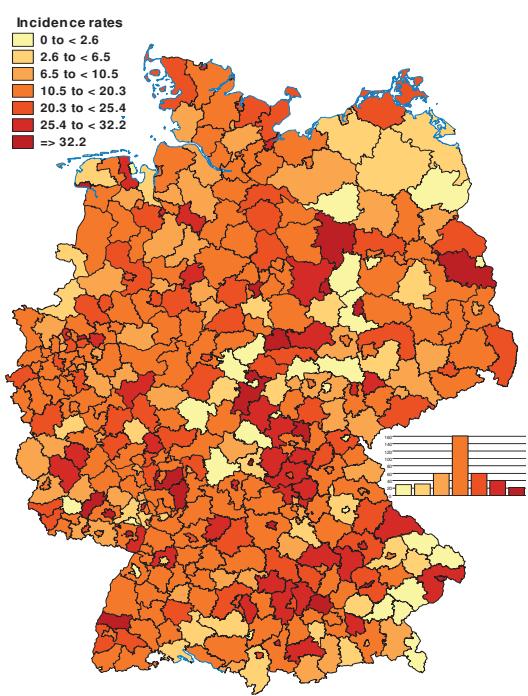
Age- and sex-specific incidence rates per million Germany 2007-2016



Standardized* annual incidence rates per million Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 2856

Selected characteristics Germany 2007-2016

Relative frequency: 820 / 17613 = 4.7 %

Relative frequency of trial patients: 97.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	327	493	820
Standardized rate *:	5.2	7.8	6.5
Cumulative incidence:	87	127	108
Sex ratio (m/f):			1.5

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	34	186	600
Incidence rate:	0.0	1.2	5.2	15.5

Median age at diagnosis: 12 years 5 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	99 %	98 %	97 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N 50	1.2 %	0.3

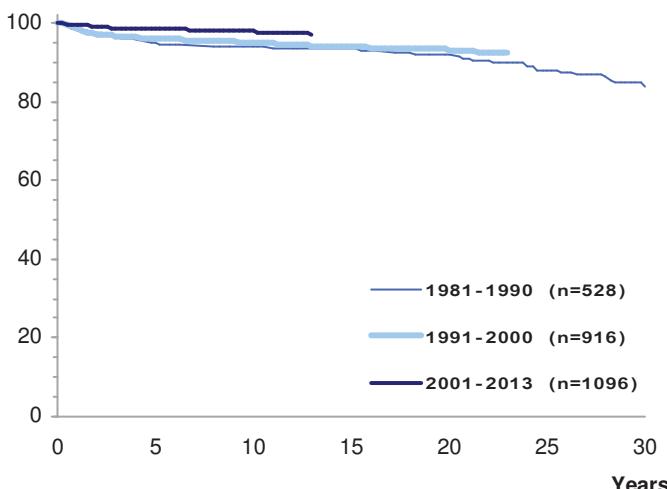
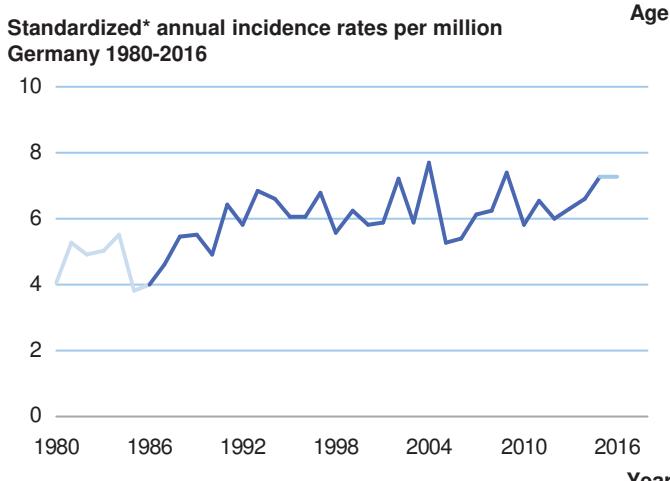
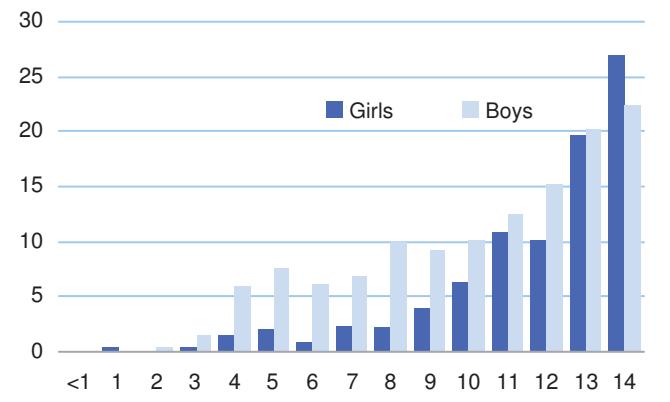
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

II (a) Hodgkin lymphomas

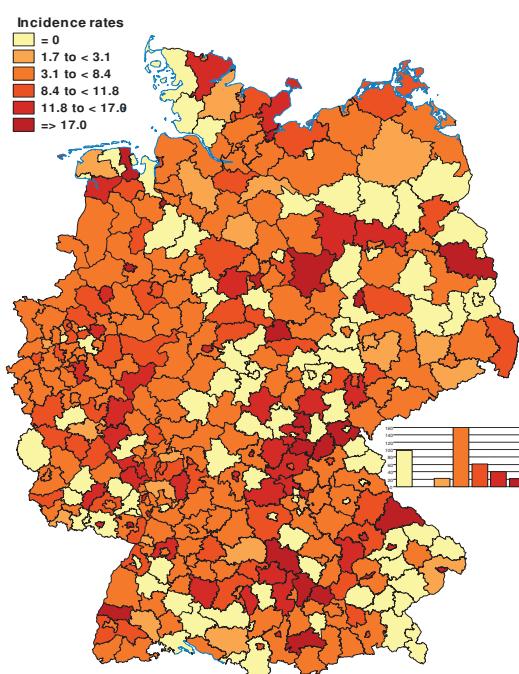
SN after II (a)		II (a) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN
116	9.3 %	15.9 %	21	1.7 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013

Age- and sex-specific incidence rates per million
Germany 2007-2016

Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



24 II (b) Non-Hodgkin lymphomas (except Burkitt lymphoma)

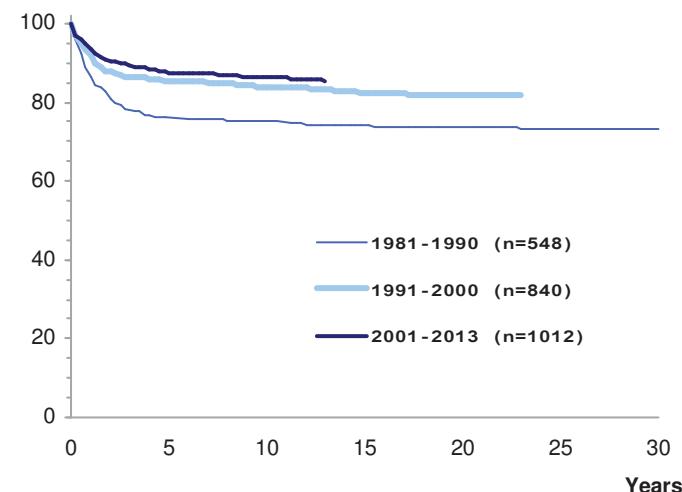
Cases in Germany aged under 15 years (1980-2016): 2678

Selected characteristics Germany 2007-2016

Relative frequency:	738 / 17613 = 4.2 %			
Relative frequency of trial patients:	96.9 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	221	517	738	
Standardized rate *:	4.0	8.7	6.4	
Cumulative incidence:	62	136	100	
Sex ratio (m/f):	2.3			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	6	126	264	342
Incidence rate:	0.9	4.6	7.3	8.9
Median age at diagnosis:	9 years 5 months			
Survival probabilities (2004-2013):	5-year 89 %	10-year 87 %	15-year 86 %	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths	Standardized* mortality rate	Cumulative mortality		
N % of all 4232 deaths	1.0	16		
140 3.3 %				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
II (b) Non-Hodgkin lymphomas (except Burkitt lymphoma)				
SN after II (b)	II (b) as SN after any primary			
% of all	Cumulative incidence	N % of all	Cumulative incidence	
N 1245 SN		N 1245 SN		
87 7.0 %	13.5 %	60 4.8 %	0.3 %	

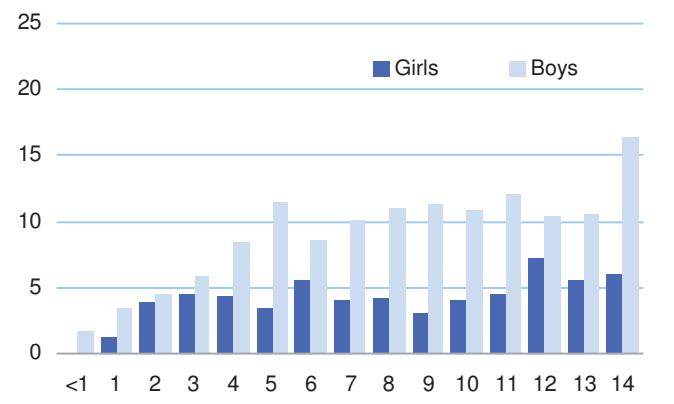
* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



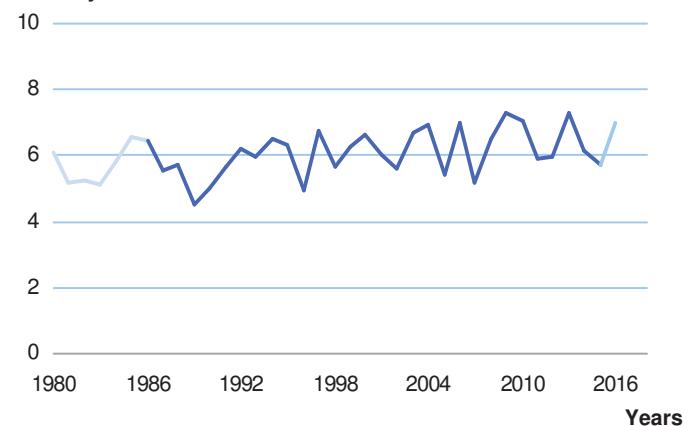
Age- and sex-specific incidence rates per million

Germany 2007-2016

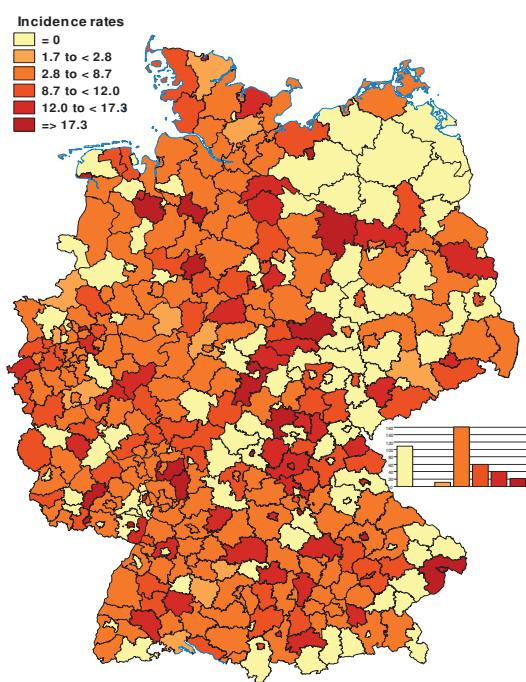


Standardized* annual incidence rates per million

Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Germany 2007-2016		N	%
Non-Hodgkin lymphomas (except Burkitt lymphoma)		738	100.0
1 Precursor cell lymphomas		261	35.4
2 Mature B-cell lymphomas (except Burkitt lymphoma)		142	19.2
3 Mature T-cell and NK-cell lymphomas		143	19.4
4 Non-Hodgkin lymphomas, NOS		192	26.0

1 Precursor cell lymphomas

Cases in Germany aged under 15 years (1980-2016): 1051

Selected characteristics Germany 2007-2016

Relative frequency:	261 / 17613 = 1.5 %			
Relative frequency of trial patients:	94.6 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	80	181	261	
Standardized rate *:	1.5	3.2	2.3	
Cumulative incidence:	23	48	36	
Sex ratio (m/f):	2.3			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	4	61	100	96
Incidence rate:	0.6	2.2	2.8	2.5
Median age at diagnosis:	8 years 0 months			

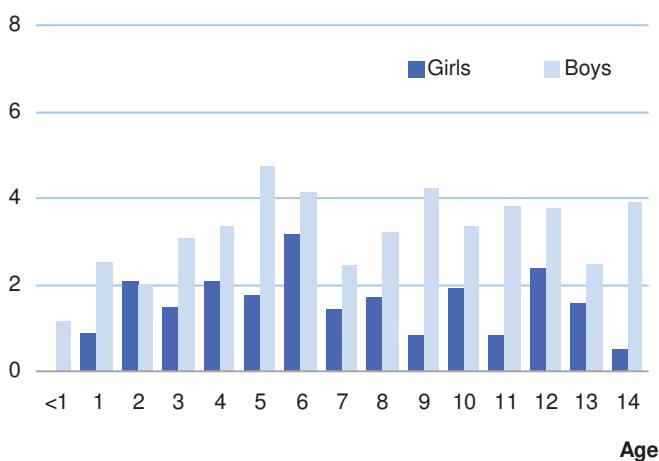
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

1 Precursor cell lymphomas

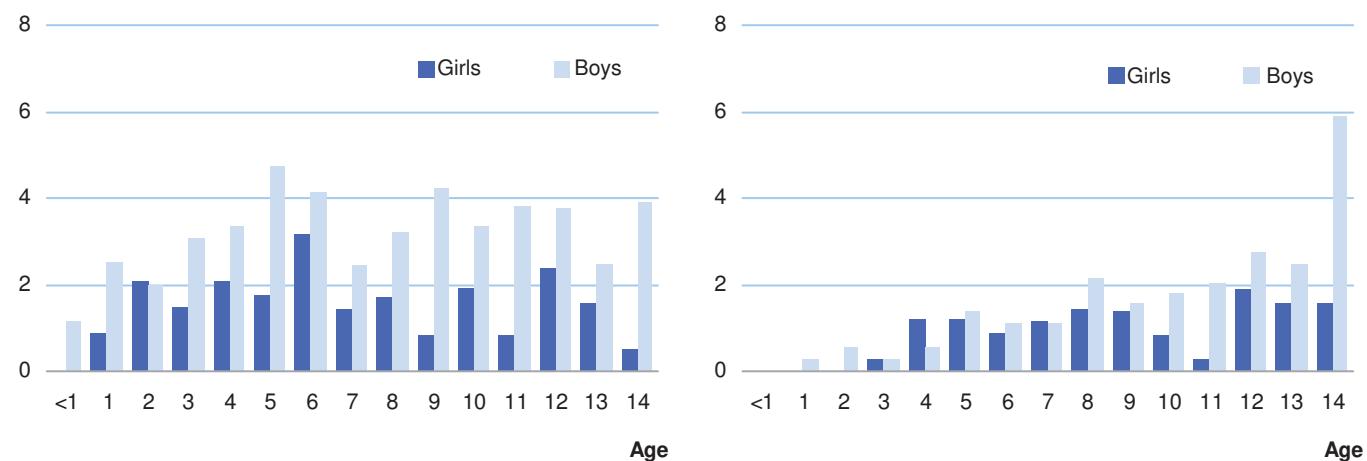
SN after II (b) 1		II (b) 1 as SN after any primary			
% of all N	Cumulative 1245 SN	% of all N	Cumulative 1245 SN		
52	4.2 %	21.8 %	17	1.4 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Age- and sex-specific incidence rates per million Germany 2007-2016



26 II (b) Non-Hodgkin lymphomas (except Burkitt lymphoma) - Extended ICCC-3

Germany 2007-2016		N	%
Non-Hodgkin lymphomas (except Burkitt lymphoma)		738	100.0
1 Precursor cell lymphomas		261	35.4
2 Mature B-cell lymphomas (except Burkitt lymphoma)		142	19.2
3 Mature T-cell and NK-cell lymphomas		143	19.4
4 Non-Hodgkin lymphomas, NOS		192	26.0

3 Mature T-cell and NK-cell lymphomas

Cases in Germany aged under 15 years (1980-2016): 487

Selected characteristics Germany 2007-2016

Relative frequency:	143 / 17613 = 0.8 %			
Relative frequency of trial patients:	98.6 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	47	96	143	
Standardized rate *:	0.8	1.6	1.2	
Cumulative incidence:	13	25	19	
Sex ratio (m/f):	2.0			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	24	38	80
Incidence rate:	0.1	0.9	1.1	2.1
Median age at diagnosis:	10 years 11 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
3 Mature T-cell and NK-cell lymphomas

SN after II (b) 3		II (b) 3 as SN after any primary			
% of all N	Cumulative 1245 SN incidence	% of all N	Cumulative 1245 SN incidence		
12	1.0 %	-	7	0.6 %	0.0 %

* Standard: Segi world standard population

4 Non-Hodgkin lymphomas, NOS

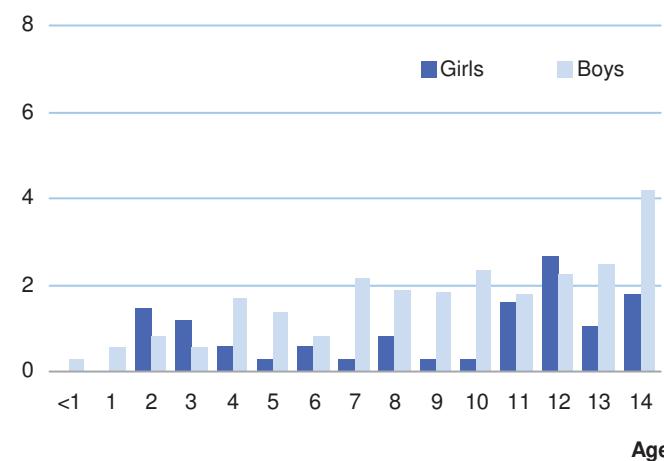
Cases in Germany aged under 15 years (1980-2016): 701

Selected characteristics Germany 2007-2016

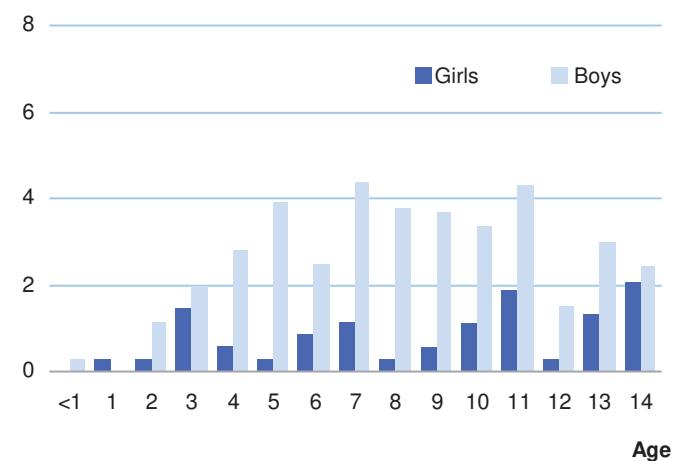
Relative frequency:	192 / 17613 = 1.1 %				
Relative frequency of trial patients:	98.4 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	45	147	192		
Standardized rate *:	0.8	2.5	1.7		
Cumulative incidence:	12	39	26		
Sex ratio (m/f):	3.3				
Age-specific incidence rates per million:	<1	1-4	5-9	10-14	
Number of cases:	1	30	78	83	
Incidence rate:	0.1	1.1	2.2	2.1	
Median age at diagnosis:	9 years 3 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):	4 Non-Hodgkin lymphomas, NOS				
SN after II (b) 4	II (b) 4 as SN after any primary				
% of all N	Cumulative 1245 SN incidence	% of all N	Cumulative 1245 SN incidence		
13	1.0 %	6.5 %	20	1.6 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016



Age- and sex-specific incidence rates per million
Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 1197
Selected characteristics Germany 2007-2016
Relative frequency: 312 / 17613 = 1.8 %

Relative frequency of trial patients: 99.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	51	261	312
Standardized rate *:	0.9	4.6	2.8
Cumulative incidence:	14	70	43
Sex ratio (m/f):			5.1

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	70	146	96
Incidence rate:	0.0	2.5	4.1	2.5

Median age at diagnosis: 7 years 7 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	93 %	92 %	92 %

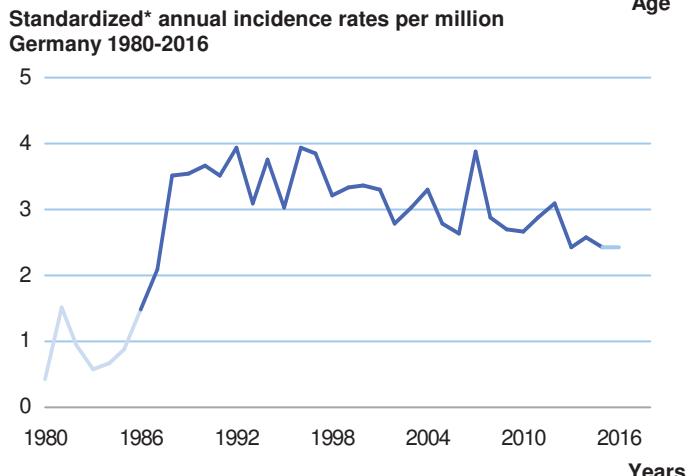
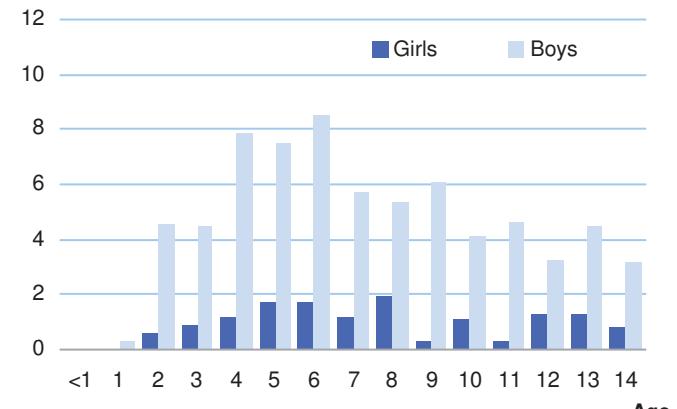
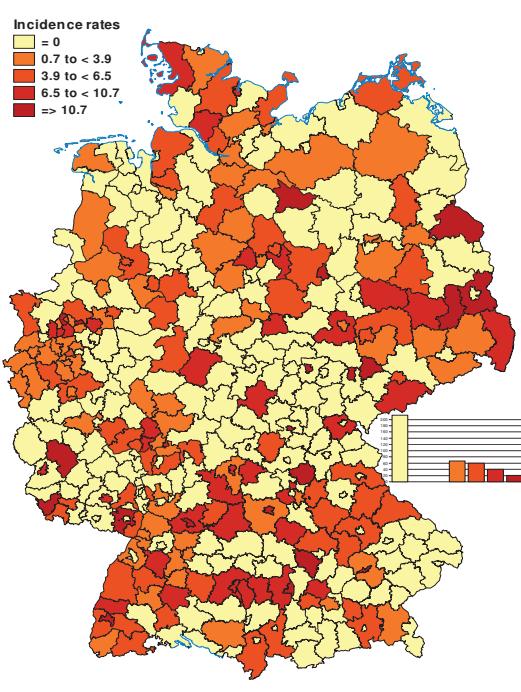
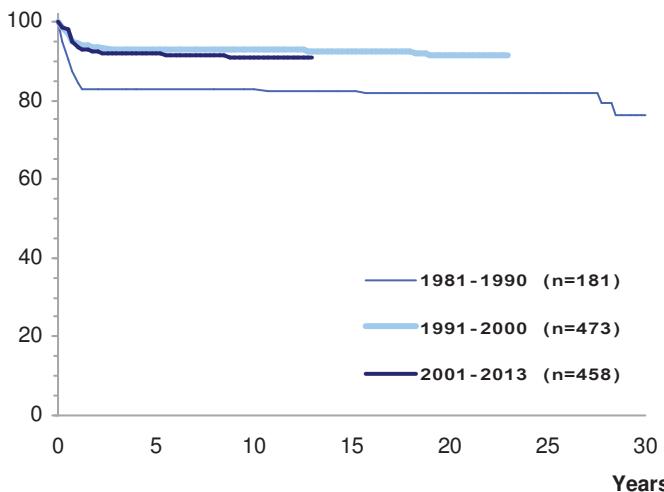
Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N 37	% of all 4232 deaths 0.9 %	0.3

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
II (c) Burkitt lymphoma

SN after II (c)			II (c) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
17	1.4 %	3.8 %	4	0.3 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016

Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016

Survival probabilities by year of diagnosis Germany 1981-2013


28 III CNS and miscellaneous intracranial and intraspinal neoplasms

- (a) Ependymomas and choroid plexus tumour
- (b) Astrocytomas
- (c) Intracranial and intraspinal embryonal tumours

- (d) Other gliomas
- (e) Other specified intracranial and intraspinal neoplasms
- (f) Unspecified intracranial and intraspinal neoplasms

Cases in Germany aged under 15 years (1980-2016): 12987

Selected characteristics Germany 2007-2016

Relative frequency: 4409 / 17613 = 25 %

Relative frequency of trial patients: 95.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	2017	2392	4409
Standardized rate *:	38.7	43.4	41.2
Cumulative incidence:	573	644	610
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:				
<1	1-4	5-9	10-14	
Number of cases :	303	1300	1420	1386
Incidence rate:	43.9	47.0	39.5	35.9

Median age at diagnosis: 6 years 11 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	77 %	74 %	71 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		
1251	29.6 %	10.0	145

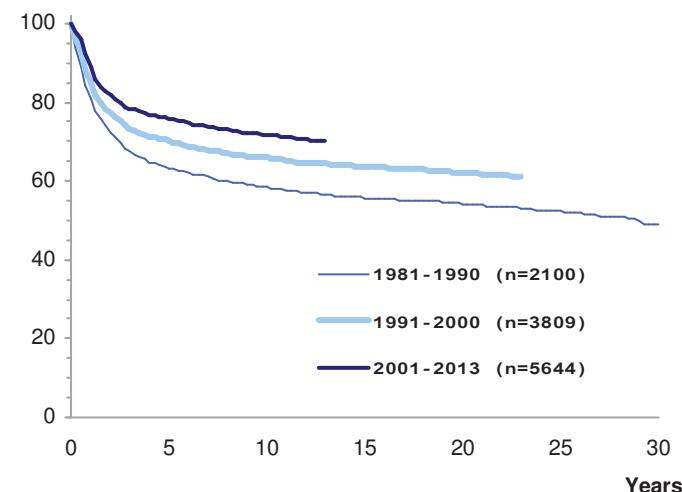
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

III CNS and miscellaneous intracranial and intraspinal neoplasms

SN after III			III as SN after any primary		
N	% of all SN	Cumulative incidence	N	% of all SN	Cumulative incidence
230	18.5 %	10.9 %	289	23.2 %	2.3 %

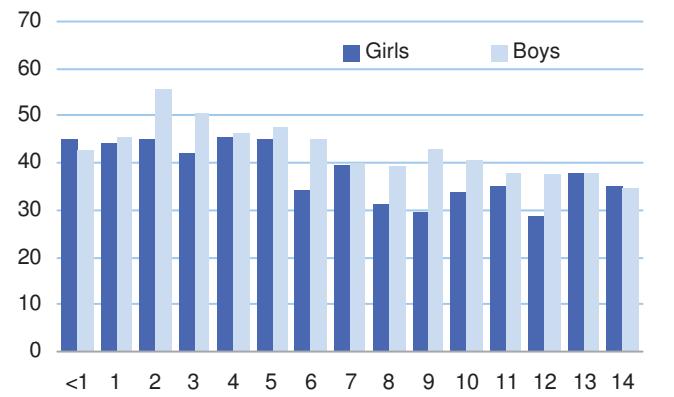
* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



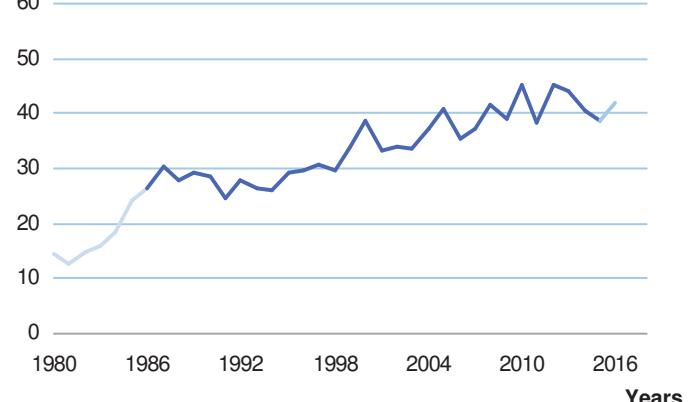
Age- and sex-specific incidence rates per million

Germany 2007-2016

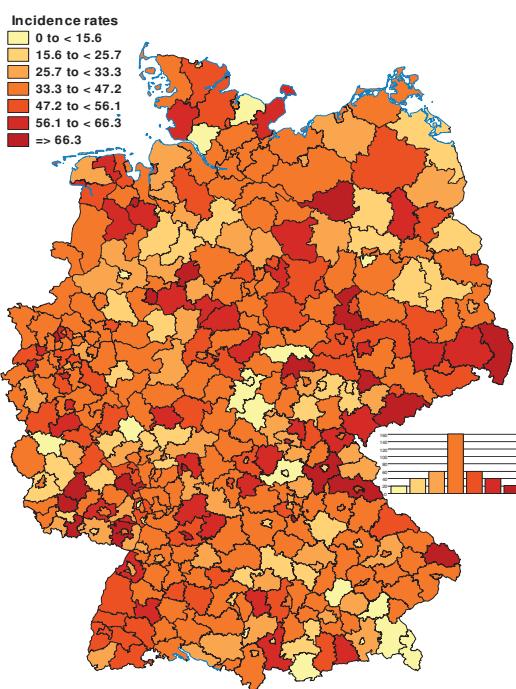


Standardized* annual incidence rates per million

Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 1304

Selected characteristics Germany 2007-2016

Relative frequency: $445 / 17613 = 2.5\%$

Relative frequency of trial patients: 96.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	192	253	445
Standardized rate *:	4.0	4.9	4.5
Cumulative incidence:	56	69	63
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	77	180	91	97
Incidence rate:	11.2	6.5	2.5	2.5

Median age at diagnosis: 3 years 9 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	81 %	75 %	70 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N % of all 4232 deaths	1.2	17

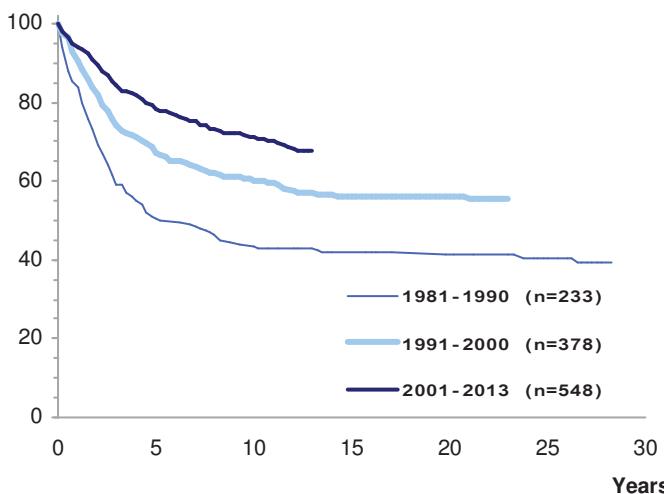
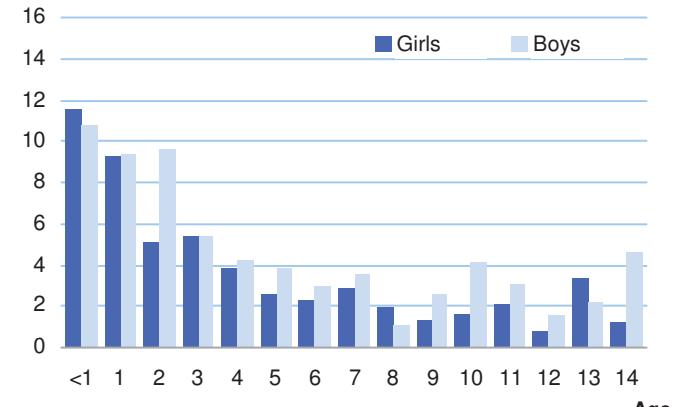
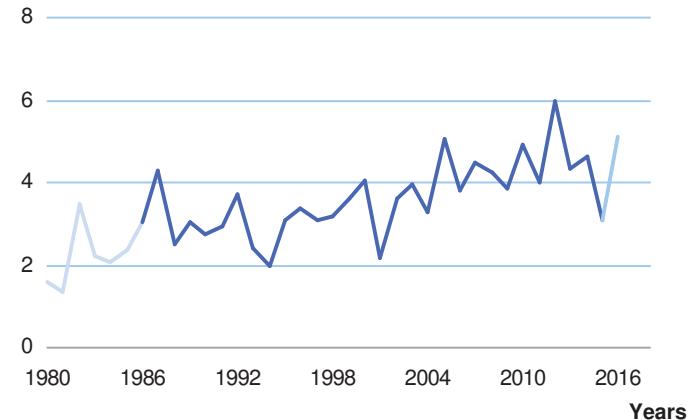
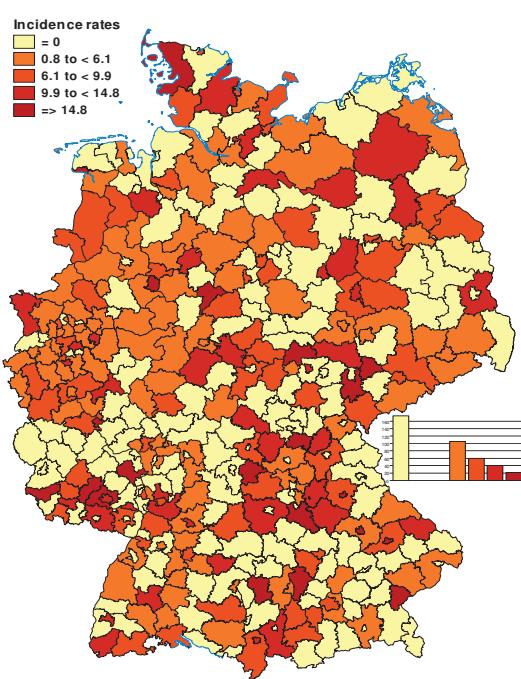
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

III (a) Ependymomas and choroid plexus tumour

SN after III (a)	III (a) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
27	2.2 %	12.1 %	10	0.8 %	0.0 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013

Age- and sex-specific incidence rates per million
Germany 2007-2016Standardized* annual incidence rates per million
Germany 1980-2016Standardized* incidence rates per million by districts
(Landkreise) Germany 2007-2016

30 III (a) Ependymomas and choroid plexus tumour - Extended ICCC-3

Germany 2007-2016		N	%
Ependymomas and choroid plexus tumour		445	100.0
1 Ependymomas		339	76.2
2 Choroid plexus tumour		106	23.8

1 Ependymomas

Cases in Germany aged under 15 years (1980-2016): 1040

Selected characteristics Germany 2007-2016

Relative frequency:	339 / 17613 = 1.9 %			
Relative frequency of trial patients:	96.8 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	141	198	339	
Standardized rate *:	2.9	3.7	3.3	
Cumulative incidence:	41	54	47	
Sex ratio (m/f):	1.4			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	30	152	72	85
Incidence rate:	4.4	5.5	2.0	2.2
Median age at diagnosis:	4 years 6 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
1 Ependymomas

SN after III (a) 1		III (a) 1 as SN after any primary			
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
22	1.8 %	14.5 %	7	0.6 %	0.0 %

* Standard: Segi world standard population

2 Choroid plexus tumour

Cases in Germany aged under 15 years (1980-2016): 264

Selected characteristics Germany 2007-2016

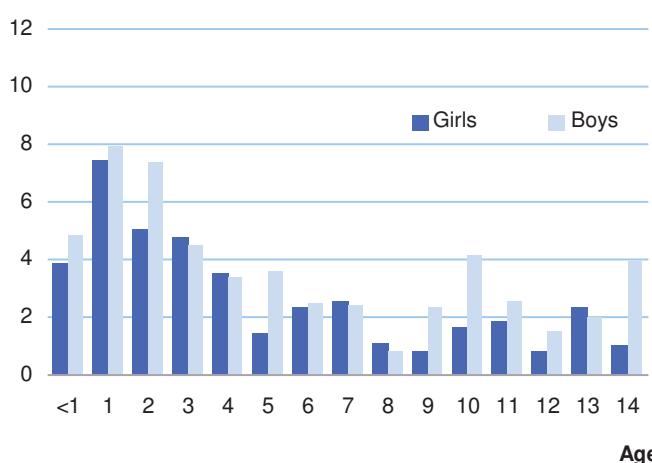
Relative frequency:	106 / 17613 = 0.6 %			
Relative frequency of trial patients:	94.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	51	55	106	
Standardized rate *:	1.1	1.1	1.1	
Cumulative incidence:	15	15	15	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	47	28	19	12
Incidence rate:	6.8	1.0	0.5	0.3
Median age at diagnosis:	1 year 6 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
2 Choroid plexus tumour

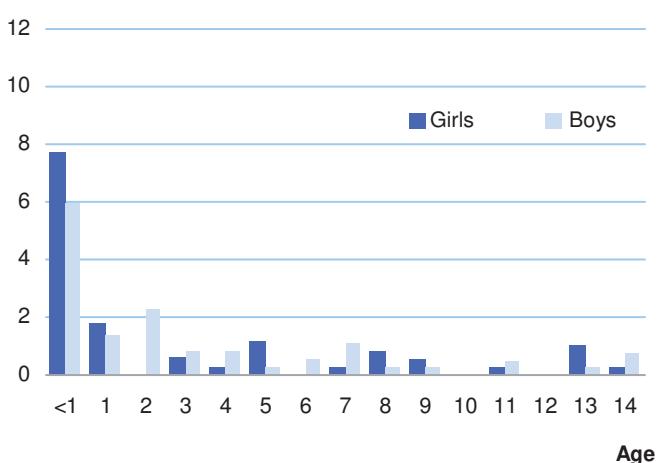
SN after III (a) 2		III (a) 2 as SN after any primary			
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
5	0.4 %	4.4 %	3	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016



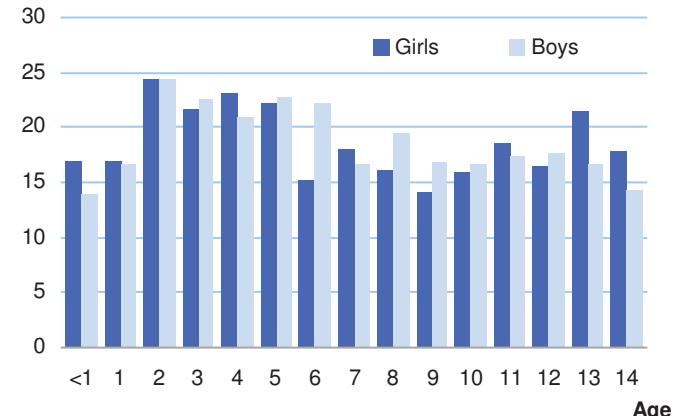
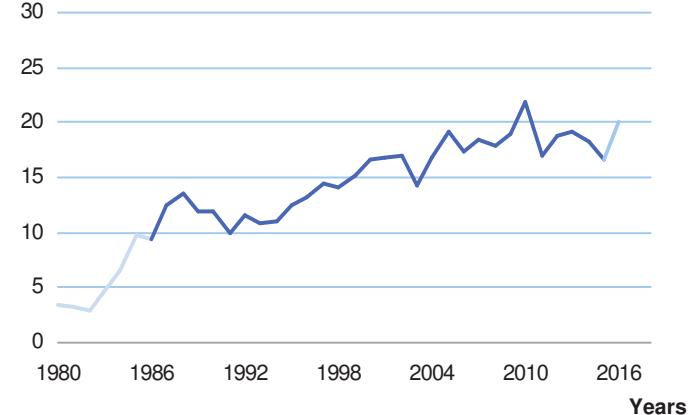
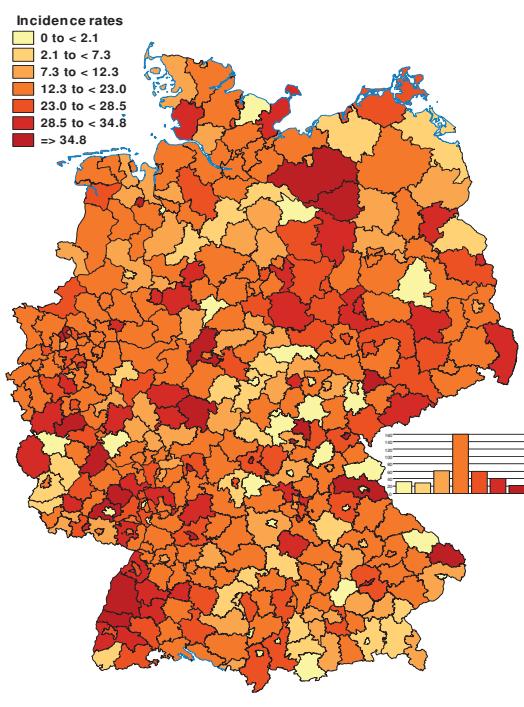
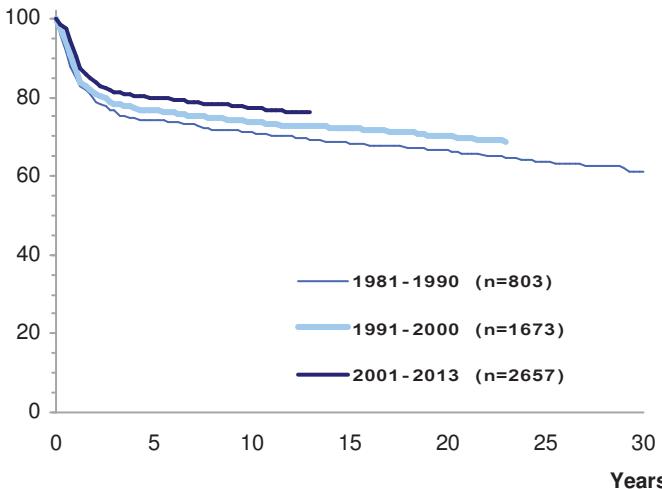
Age- and sex-specific incidence rates per million
Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 5748
Selected characteristics Germany 2007-2016

Relative frequency:	2023 / 17613 = 11.5 %			
Relative frequency of trial patients:	95.8 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	986	1037	2023	
Standardized rate *:	18.8	18.7	18.7	
Cumulative incidence:	279	279	279	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	106	590	660	667
Incidence rate:	15.4	21.3	18.4	17.3
Median age at diagnosis:	7 years 2 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
	81 %	79 %	77 %	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths	Standardized* mortality rate	Cumulative mortality		
N % of all 4232 deaths	3.2	49		
428 10.1 %				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
III (b) Astrocytomas				
SN after III (b)	III (b) as SN after any primary			
N % of all 1245 SN Cumulative incidence	N % of all 1245 SN Cumulative incidence			
43 3.5 % 2.7 %	93 7.5 % 0.3 %			

* Standard: Segi world standard population

**Age- and sex-specific incidence rates per million
Germany 2007-2016**

**Standardized* annual incidence rates per million
Germany 1980-2016**

**Standardized* incidence rates per million by districts
(Landkreise) Germany 2007-2016**

Survival probabilities by year of diagnosis Germany 1981-2013


32 III (c) Intracranial and intraspinal embryonal tumours

Cases in Germany aged under 15 years (1980-2016): 2834

Selected characteristics Germany 2007-2016

Relative frequency: 765 / 17613 = 4.3 %

Relative frequency of trial patients: 97.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	298	467	765
Standardized rate *:	6.1	8.9	7.5
Cumulative incidence:	86	128	107
Sex ratio (m/f):			1.6

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	77	294	270	124
Incidence rate:	11.2	10.6	7.5	3.2

Median age at diagnosis: 5 years 2 months

Survival probabilities (2004-2013):

	5-year	10-year	15-year
(2004-2013):	66 %	58 %	56 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths	
473	11.2 %	3.9
		56

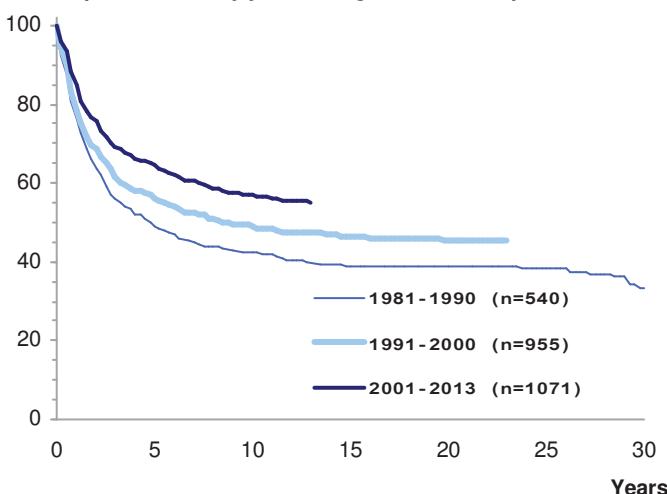
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

III (c) Intracranial and intraspinal embryonal tumours

SN after III (c)			III (c) as SN after any primary		
N	% of all SN	Cumulative incidence	N	% of all SN	Cumulative incidence
133	10.7 %	31.8 %	14	1.1 %	0.0 %

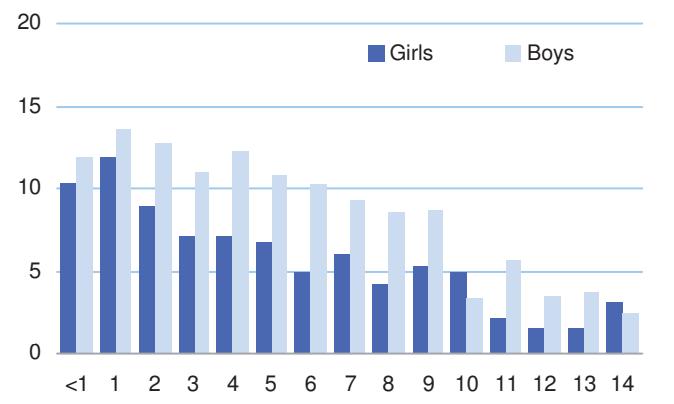
* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



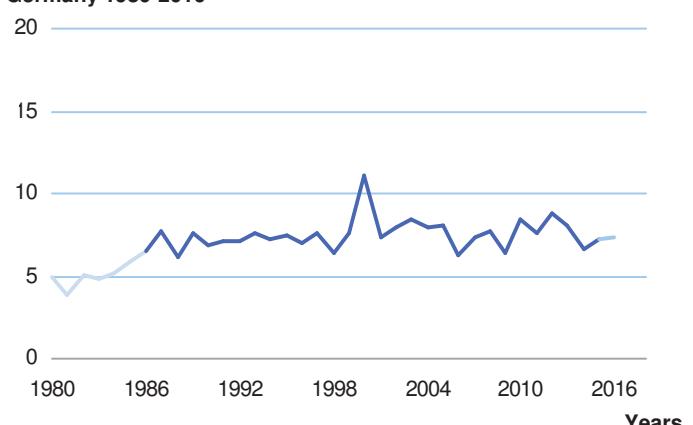
Age- and sex-specific incidence rates per million

Germany 2007-2016

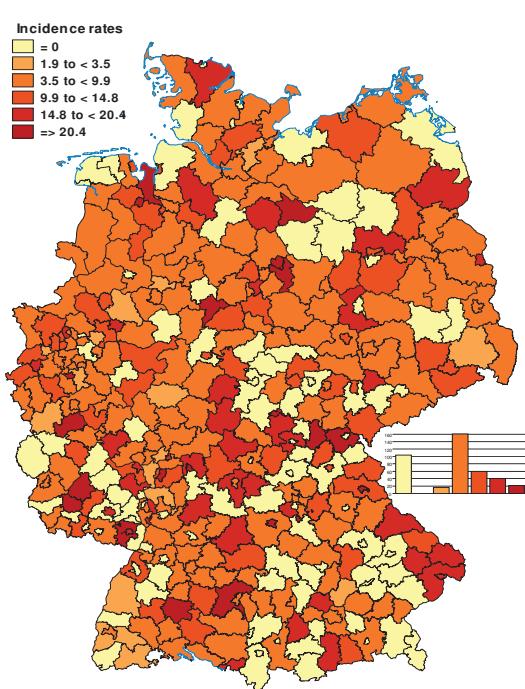


Standardized* annual incidence rates per million

Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Germany 2007-2016		N	%
Intracranial and intraspinal embryonal tumours		765	100.0
1 Medulloblastomas		544	71.1
2 Primitive neuroectodermal tumour (PNET)		63	8.2
3 Medullopithelioma		14	1.8
4 Atypical teratoid/rhabdoid tumour		144	18.8

1 Medulloblastomas

Cases in Germany aged under 15 years (1980-2016): 2148

Selected characteristics Germany 2007-2016

Relative frequency:	544 / 17613 = 3.1 %		
Relative frequency of trial patients:	98.9 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	198	346	544
Standardized rate *:	3.8	6.4	5.1
Cumulative incidence:	57	94	76
Sex ratio (m/f):	1.7		
Age-specific incidence rates per million:	<1 1-4 5-9 10-14		
Number of cases:	16	180	235
Incidence rate:	2.3	6.5	6.5
Median age at diagnosis:	6 years 7 months		

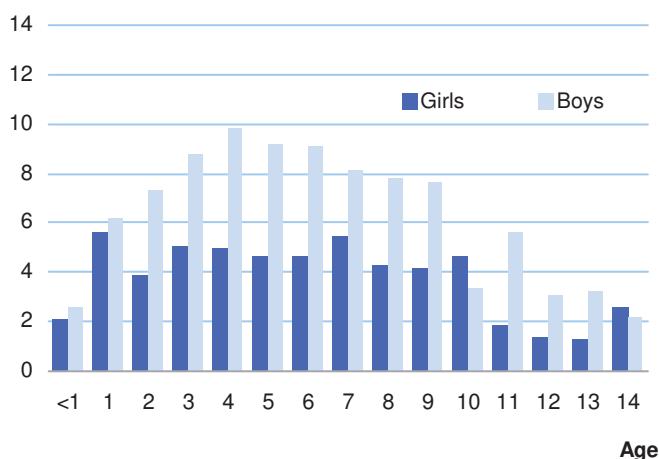
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

1 Medulloblastomas

SN after III (c) 1		III (c) 1 as SN after any primary			
% of all N	Cumulative 1245 SN	% of all N	Cumulative 1245 SN		
114	9.2 %	33.7 %	7	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



2 Primitive neuroectodermal tumour (PNET)

Cases in Germany aged under 15 years (1980-2016): 410

Selected characteristics Germany 2007-2016

Relative frequency:	63 / 17613 = 0.4 %		
Relative frequency of trial patients:	98.4 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	29	34	63
Standardized rate *:	0.6	0.7	0.6
Cumulative incidence:	8	9	9
Sex ratio (m/f):	1.2		
Age-specific incidence rates per million:	<1 1-4 5-9 10-14		
Number of cases:	5	36	13
Incidence rate:	0.7	1.3	0.4
Median age at diagnosis:	3 years 7 months		

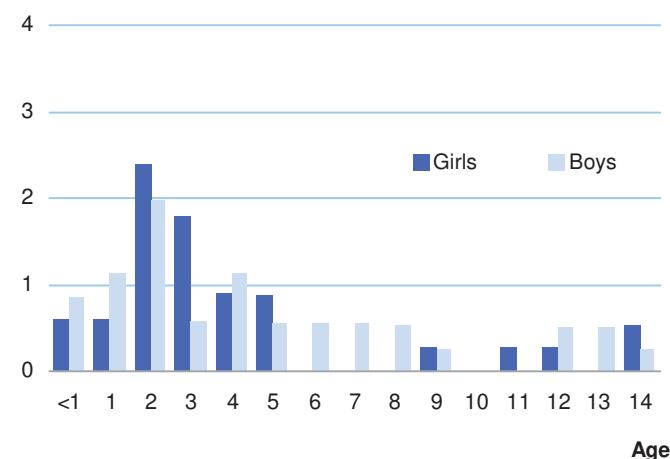
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

2 Primitive neuroectodermal tumour (PNET)

SN after III (c) 2		III (c) 2 as SN after any primary			
% of all N	Cumulative 1245 SN	% of all N	Cumulative 1245 SN		
17	1.4 %	14.6 %	7	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



34 III (c) Intracranial and intraspinal embryonal tumours - Extended ICCC-3

Germany 2007-2016	N	%
Intracranial and intraspinal embryonal tumours	765	100.0
1 Medulloblastomas	544	71.1
2 Primitive neuroectodermal tumour (PNET)	63	8.2
3 Medulloepithelioma	14	1.8
4 Atypical teratoid/rhabdoid tumour	144	18.8

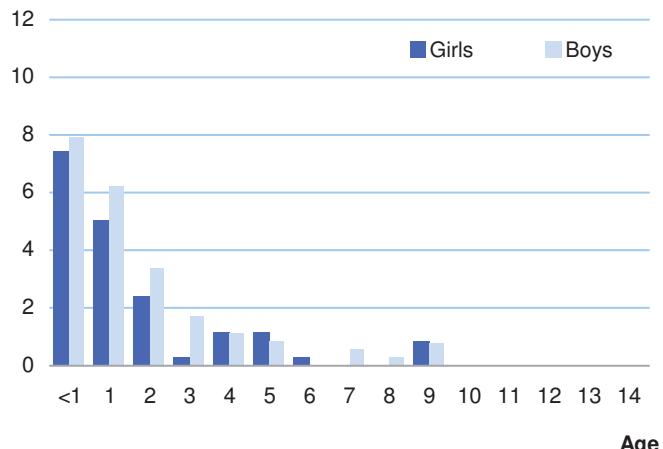
4 Atypical teratoid/rhabdoid tumour

Cases in Germany aged under 15 years (1980-2016): 247

Selected characteristics Germany 2007-2016

Relative frequency:	144 / 17613 = 0.8 %			
Relative frequency of trial patients:	89.6 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	63	81	144	
Standardized rate *:	1.4	1.8	1.6	
Cumulative incidence:	19	23	21	
Sex ratio (m/f):	1.3			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	53	74	17	0
Incidence rate:	7.7	2.7	0.5	0.0
Median age at diagnosis:	1 year 6 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
4 Atypical teratoid/rhabdoid tumour				
SN after III (c) 4	% of all N 1245 SN		III (c) 4 as SN after any primary	
	Cumulative incidence		% of all N 1245 SN	
	2.9 %		Cumulative incidence	
	0		-	
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 1034

Selected characteristics Germany 2007-2016

Relative frequency: $450 / 17613 = 2.6\%$

Relative frequency of trial patients: 94.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	221	229	450
Standardized rate *:	4.1	4.0	4.0
Cumulative incidence:	63	61	62
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	12	97	186	155
Incidence rate:	1.7	3.5	5.2	4.0

Median age at diagnosis: 7 years 9 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	46 %	44 %	43 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

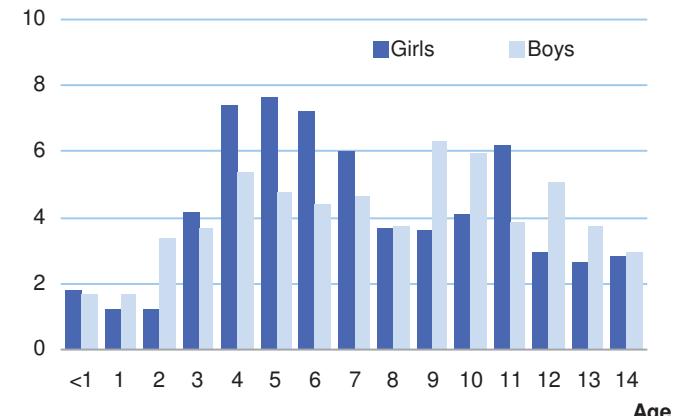
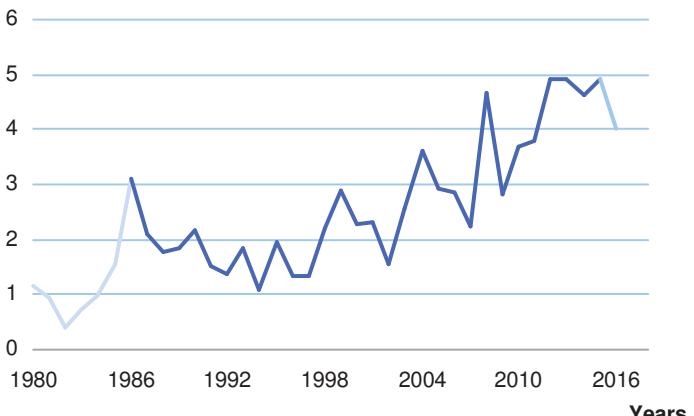
Number of deaths	Standardized* mortality rate	Cumulative mortality
N 131	1.0	15
% of all 4232 deaths 3.1 %		

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

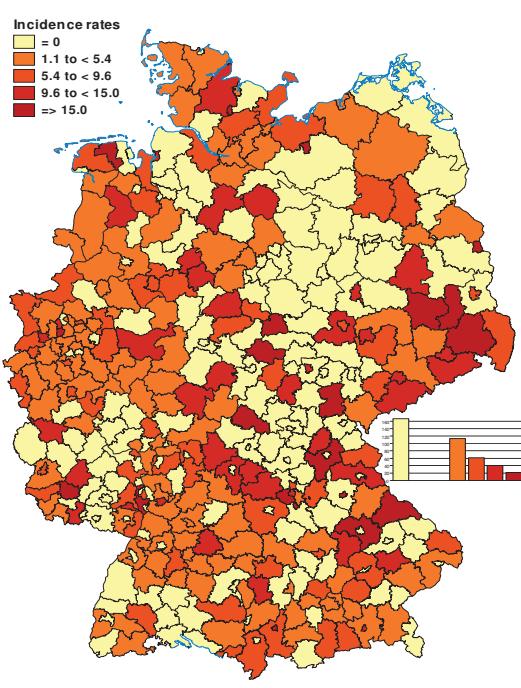
III (d) Other gliomas

SN after III (d)	III (d) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
8	0.6 %	2.7 %	23	1.8 %	0.1 %

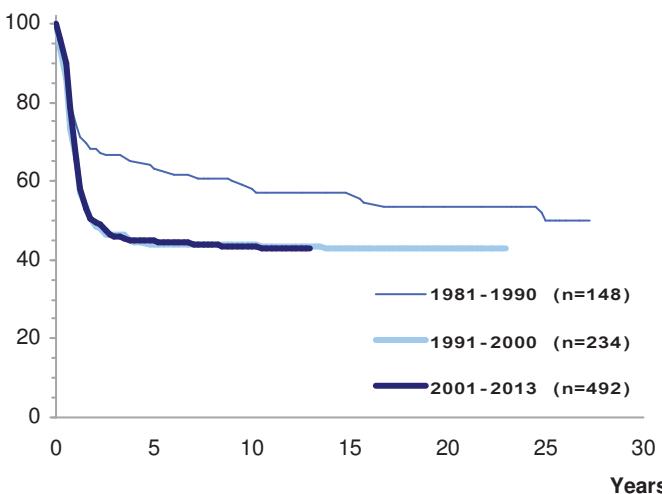
* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016Standardized* annual incidence rates per million
Germany 1980-2016

Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Survival probabilities by year of diagnosis Germany 1981-2013



36 III (d) Other gliomas - Extended ICCC-3

Germany 2007-2016		N	%
Other gliomas		450	100.0
1 Oligodendrogiomas		8	1.8
2 Mixed and unspecified gliomas		422	93.8
3 Neuroepithelial glial tumours of uncertain origin		20	4.4

1 Oligodendrogiomas

Cases in Germany aged under 15 years (1980-2016): 116

Selected characteristics Germany 2007-2016

Relative frequency:	8 / 17613 = 0.0 %			
Relative frequency of trial patients:	87.5 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	4	4	8	
Standardized rate *:	0.1	0.1	0.1	
Cumulative incidence:	1	1	1	
Sex ratio (m/f):	1.0			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	0	1	7
Incidence rate:	0.0	0.0	0.0	0.2
Median age at diagnosis:	13 years 1 month			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

1 Oligodendrogiomas

SN after III (d) 1			III (d) 1 as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
1	0.1 %	1.9 %	5	0.4 %	0.0 %

* Standard: Segi world standard population

2 Mixed and unspecified gliomas

Cases in Germany aged under 15 years (1980-2016): 882

Selected characteristics Germany 2007-2016

Relative frequency:	422 / 17613 = 2.4 %			
Relative frequency of trial patients:	94.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	206	216	422	
Standardized rate *:	3.8	3.8	3.8	
Cumulative incidence:	58	58	58	
Sex ratio (m/f):	1.0			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	11	92	182	137
Incidence rate:	1.6	3.3	5.1	3.5
Median age at diagnosis:	7 years 7 months			

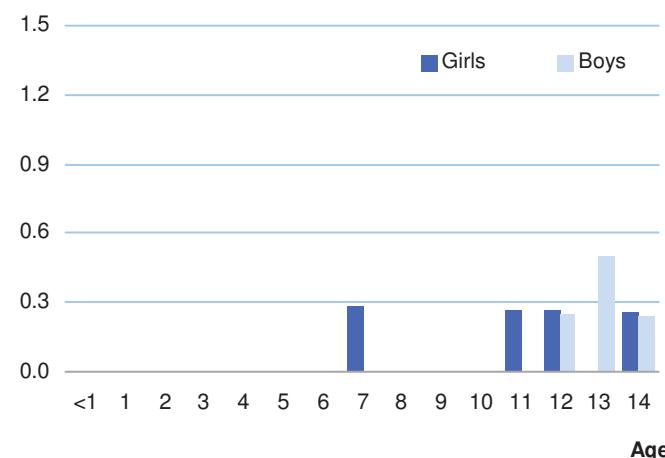
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

2 Mixed and unspecified gliomas

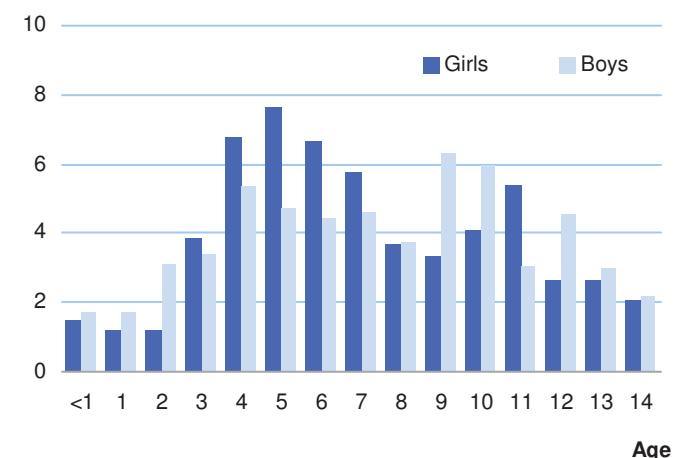
SN after III (d) 2			III (d) 2 as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
7	0.6 %	3.1 %	18	1.4 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016



Age- and sex-specific incidence rates per million
Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 1705

Selected characteristics Germany 2007-2016

Relative frequency: $660 / 17613 = 3.7\%$

Relative frequency of trial patients: 93.3 %

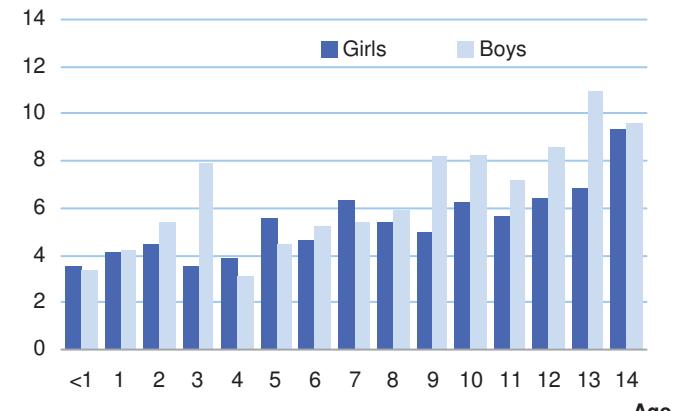
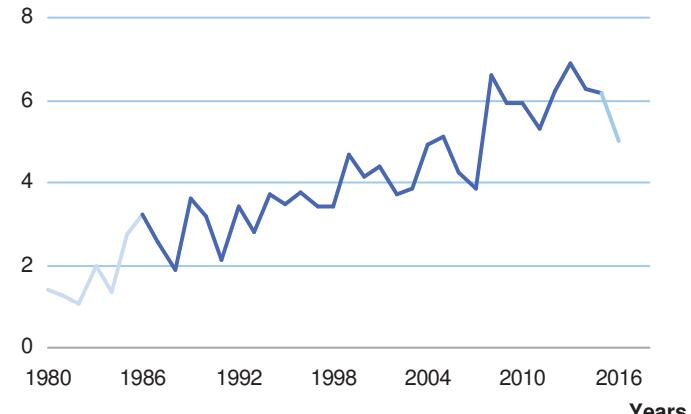
Incidence rates per million: Girls Boys Total

Number of cases: 290 370 660

Standardized rate *: 5.3 6.3 5.8

Cumulative incidence: 81 98 90

Sex ratio (m/f): 1.3

Age- and sex-specific incidence rates per million
Germany 2007-2016Standardized* annual incidence rates per million
Germany 1980-2016

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Survival probabilities (2004-2013):	5-year	10-year	15-year
	96 %	95 %	92 %
N	% of all 4232 deaths		
42	1.0 %		
		0.3	5

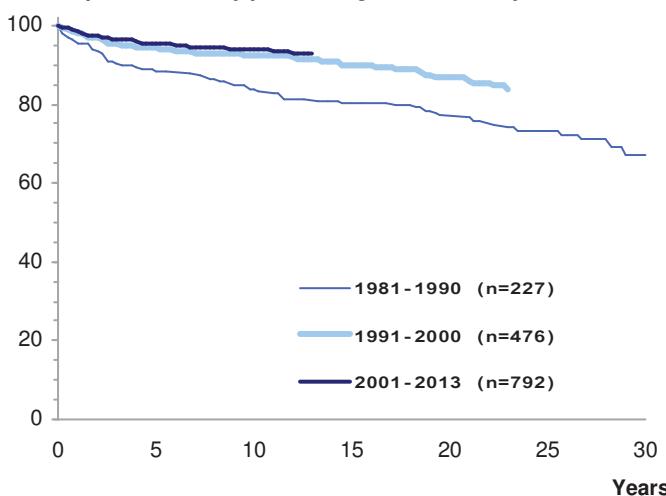
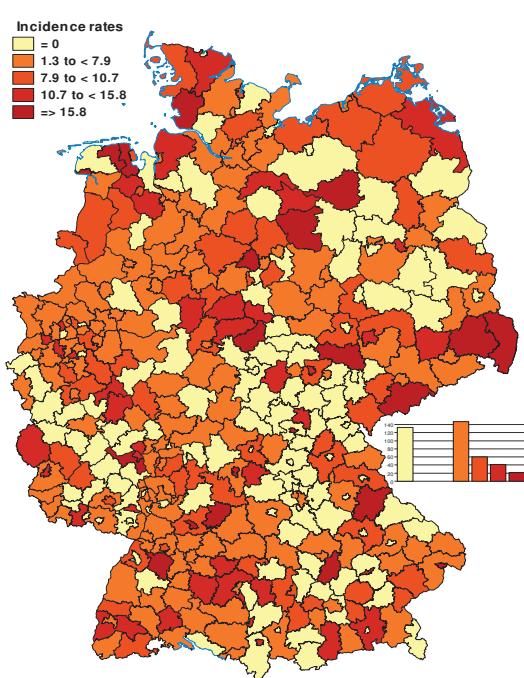
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

III (e) Other specified intracranial and intraspinal neoplasms

SN after III (e)	III (e) as SN after any primary				
	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
17	1.4 %	4.4 %	139	11.2 %	1.7 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013

Standardized* incidence rates per million by districts
(Landkreise) Germany 2007-2016

38 III (e) Other specified intracranial and intraspinal neoplasms - Extended ICCC-3

Germany 2007-2016		N	%
Other specified intracranial and intraspinal neoplasms		660	100.0
1 Pituitary adenomas and carcinomas		29	4.4
2 Tumours of the sellar region (craniopharyngiomas)		195	29.5
3 Pineal parenchymal tumours		32	4.8
4 Neuronal and mixed neuronal-glial tumours		360	54.5
5 Meningiomas		44	6.7

1 Pituitary adenomas and carcinomas

Cases in Germany aged under 15 years (1980-2016): 94

Selected characteristics Germany 2007-2016

Relative frequency:	29 / 17613 = 0.2 %			
Relative frequency of trial patients:	65.5 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	12	17	29	
Standardized rate *:	0.2	0.3	0.2	
Cumulative incidence:	3	4	4	
Sex ratio (m/f):	1.4			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	0	0	4	25
Incidence rate:	0.0	0.0	0.1	0.6
Median age at diagnosis:	12 years 8 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

1 Pituitary adenomas and carcinomas

SN after III (e) 1		III (e) 1 as SN after any primary			
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
2	0.2 %	4.8 %	6	0.5 %	0.0 %

* Standard: Segi world standard population

2 Tumours of the sellar region (craniopharyngiomas)

Cases in Germany aged under 15 years (1980-2016): 633

Selected characteristics Germany 2007-2016

Relative frequency:	195 / 17613 = 1.1 %			
Relative frequency of trial patients:	99.5 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	101	94	195	
Standardized rate *:	1.8	1.7	1.7	
Cumulative incidence:	28	25	27	
Sex ratio (m/f):	0.9			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	2	46	76	71
Incidence rate:	0.3	1.7	2.1	1.8
Median age at diagnosis:	8 years 3 months			

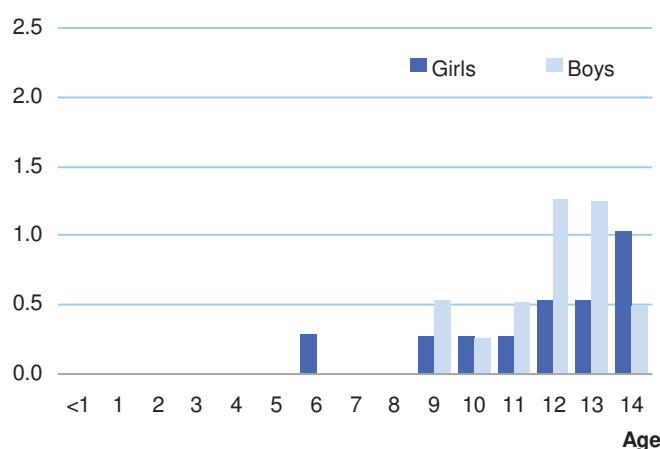
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

2 Tumours of the sellar region (craniopharyngiomas)

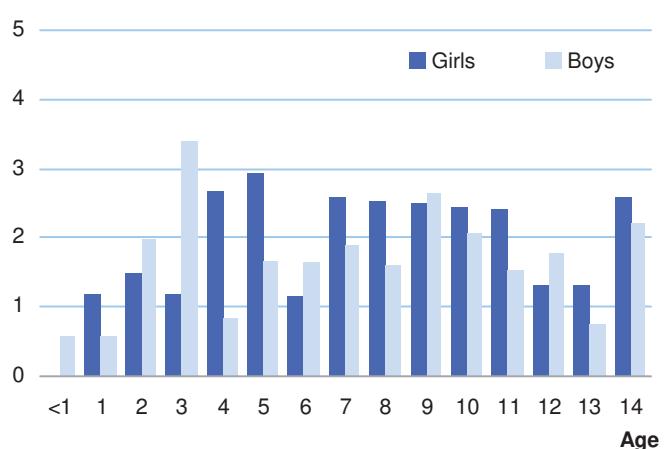
SN after III (e) 2		III (e) 2 as SN after any primary			
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
4	0.3 %	3.3 %	0	0.0 %	-

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Age- and sex-specific incidence rates per million Germany 2007-2016



Germany 2007-2016		N	%
Other specified intracranial and intraspinal neoplasms		660	100.0
1 Pituitary adenomas and carcinomas		29	4.4
2 Tumours of the sellar region (craniopharyngiomas)		195	29.5
3 Pineal parenchymal tumours		32	4.8
4 Neuronal and mixed neuronal-glial tumours		360	54.5
5 Meningiomas		44	6.7

3 Pineal parenchymal tumours

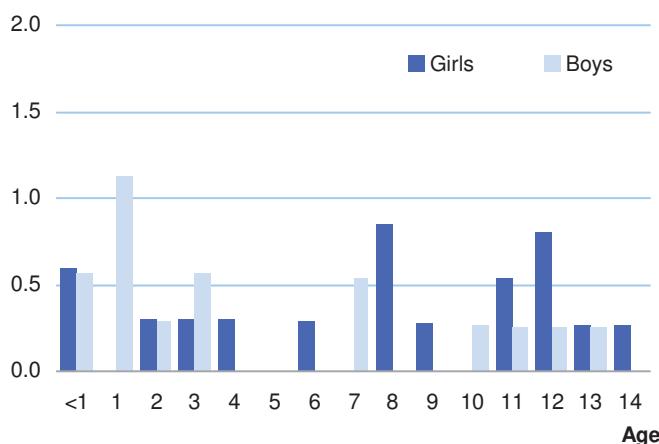
Cases in Germany aged under 15 years (1980-2016): 129

Selected characteristics Germany 2007-2016

Relative frequency:	32 / 17613 = 0.2 %			
Relative frequency of trial patients:	100.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	17	15	32	
Standardized rate *:	0.3	0.3	0.3	
Cumulative incidence:	5	4	4	
Sex ratio (m/f):	0.9			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	4	10	7	11
Incidence rate:	0.6	0.4	0.2	0.3
Median age at diagnosis:	7 years 8 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
3 Pineal parenchymal tumours				
SN after III (e) 3	III (e) 3 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence	
1 0.1 %	2.2 %	2 0.2 %	0.0 %	

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



4 Neuronal and mixed neuronal-glial tumours

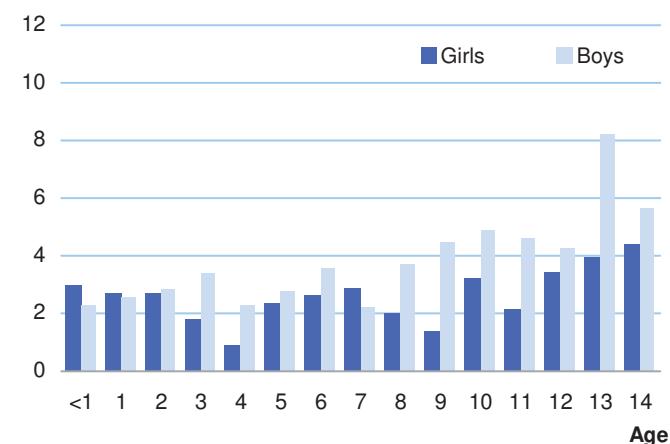
Cases in Germany aged under 15 years (1980-2016): 693

Selected characteristics Germany 2007-2016

Relative frequency:	360 / 17613 = 2.0 %			
Relative frequency of trial patients:	94.7 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	141	219	360	
Standardized rate *:	2.6	3.7	3.2	
Cumulative incidence:	39	58	49	
Sex ratio (m/f):	1.6			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	18	66	101	175
Incidence rate:	2.6	2.4	2.8	4.5
Median age at diagnosis:	9 years 8 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
4 Neuronal and mixed neuronal-glial tumours				
SN after III (e) 4	III (e) 4 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence	
2 0.2 %	1.8 %	4 0.3 %	0.0 %	

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



40 III (e) Other specified intracranial and intraspinal neoplasms - Extended ICCC-3

Germany 2007-2016		N	%
Other specified intracranial and intraspinal neoplasms		660	100.0
1 Pituitary adenomas and carcinomas		29	4.4
2 Tumours of the sellar region (craniopharyngiomas)		195	29.5
3 Pineal parenchymal tumours		32	4.8
4 Neuronal and mixed neuronal-glial tumours		360	54.5
5 Meningiomas		44	6.7

5 Meningiomas

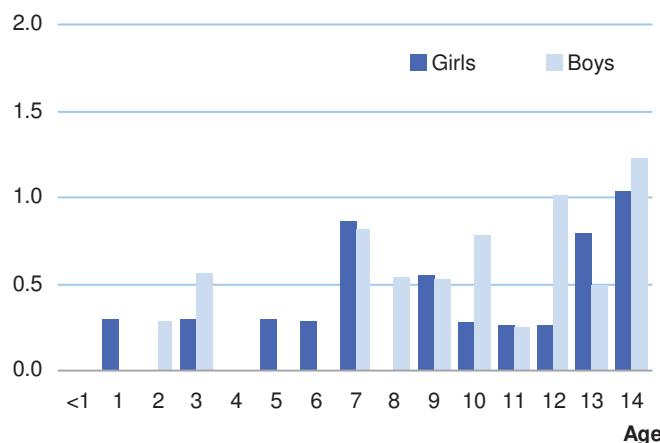
Cases in Germany aged under 15 years (1980-2016): 156

Selected characteristics Germany 2007-2016

Relative frequency:	44 / 17613 = 0.2 %			
Relative frequency of trial patients:	68.2 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	19	25	44	
Standardized rate *:	0.3	0.4	0.4	
Cumulative incidence:	5	6	6	
Sex ratio (m/f):	1.3			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	5	14	25
Incidence rate:	0.0	0.2	0.4	0.6
Median age at diagnosis:	10 years 9 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
5 Meningiomas				
SN after III (e) 5	III (e) 5 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence	
8 0.6 %	-	127 10.2 %	1.6 %	

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 4381

Selected characteristics Germany 2007-2016

Relative frequency: $1178 / 17613 = 6.7\%$

Relative frequency of trial patients: 99.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	498	680	1178
Standardized rate *:	11.4	14.8	13.1
Cumulative incidence:	147	191	170
Sex ratio (m/f):			1.4

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	540	530	82	26
Incidence rate:	78.3	19.2	2.3	0.7

Median age at diagnosis: 1 year 2 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	80 %	77 %	76 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

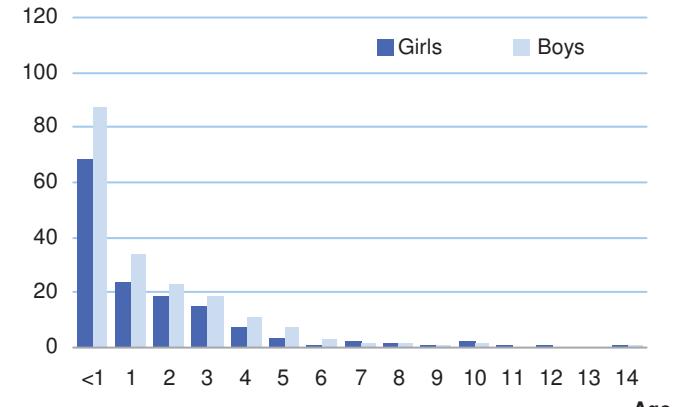
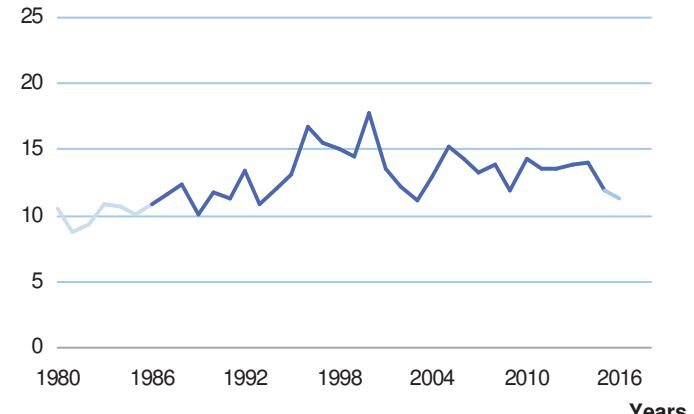
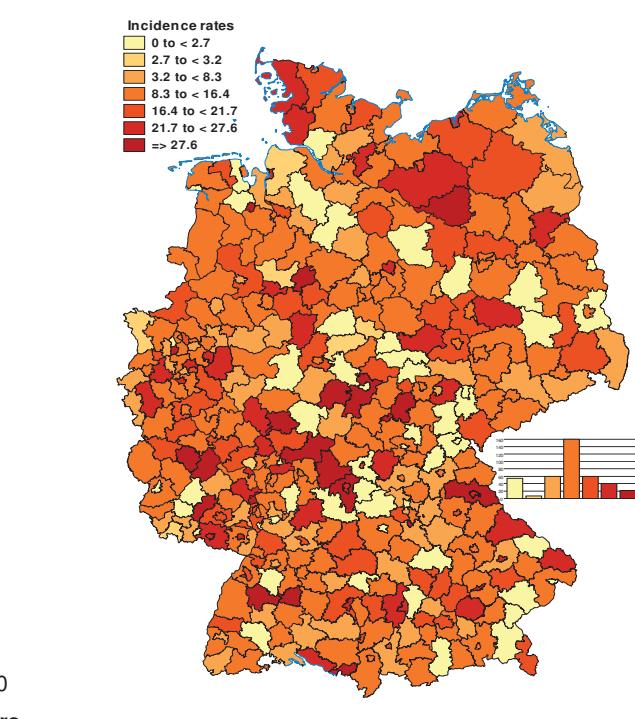
Number of deaths	Standardized* mortality rate	Cumulative mortality
N 430	10.2 % 3.9	52

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

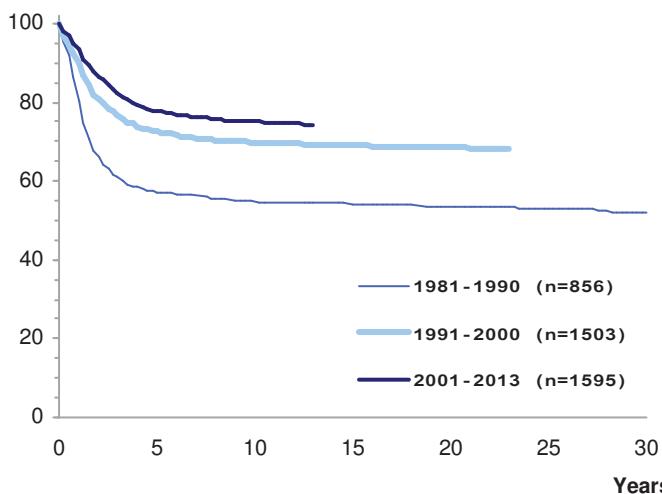
IV (a) Neuroblastoma and ganglioneuroblastoma

SN after IV (a)	IV (a) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
63	5.1 %	3.4 %	12	1.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016Standardized* annual incidence rates per million
Germany 1980-2016Standardized* incidence rates per million by districts
(Landkreise) Germany 2007-2016

Survival probabilities by year of diagnosis Germany 1981-2013



42 V Retinoblastoma

Cases in Germany aged under 15 years (1980-2016): 1412

Selected characteristics Germany 2007-2016

Relative frequency:	399 / 17613 = 2.3 %
Relative frequency of trial patients:	35.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	189	210	399
Standardized rate *:	4.4	4.6	4.5
Cumulative incidence:	56	59	58
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	181	205	10	3
Incidence rate:	26.3	7.4	0.3	0.1

Median age at diagnosis:	1 year 1 month
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Survival probabilities (2004-2013):	5-year 98 %	10-year 97 %	15-year 97 %
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Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths N	% of all 4232 deaths	Standardized* mortality rate	Cumulative mortality	
			5-year	10-year
10	0.2 %	0.1		1

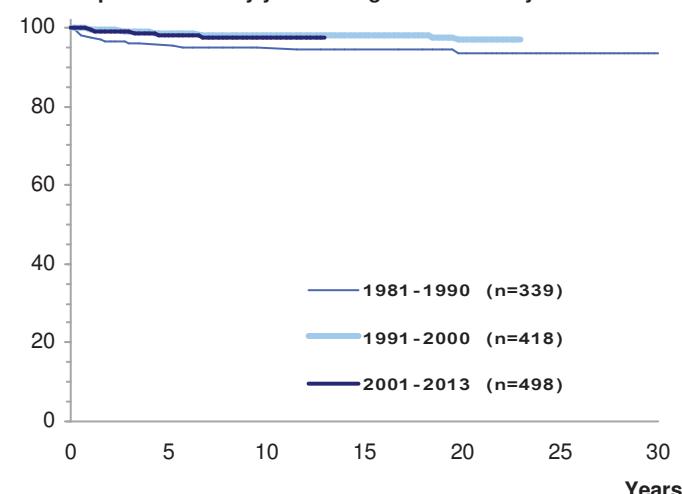
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

V Retinoblastoma

SN after V			V as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
35	2.8 %	7.0 %	3	0.2 %	0.0 %

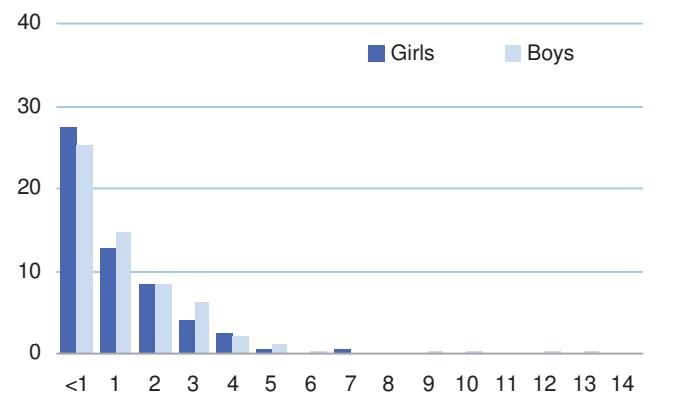
* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



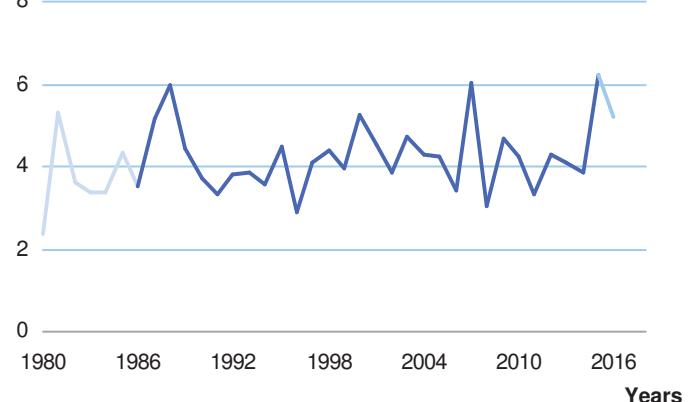
Age- and sex-specific incidence rates per million

Germany 2007-2016

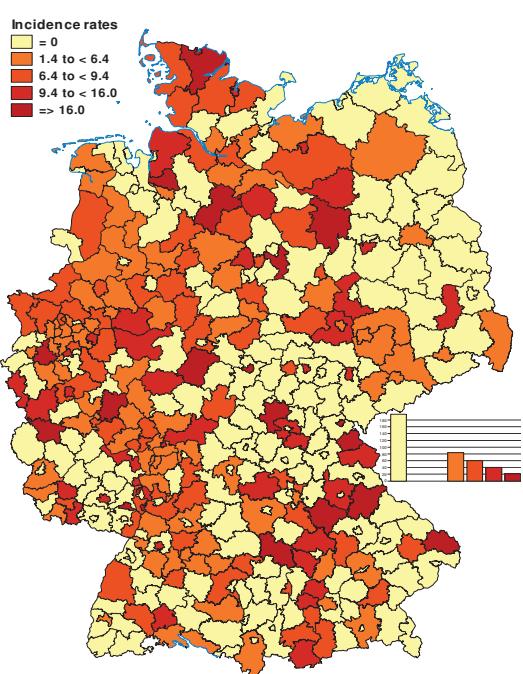


Standardized* annual incidence rates per million

Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016

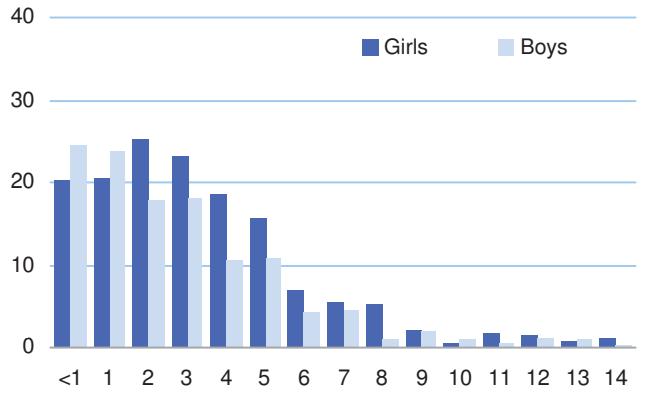


Cases in Germany aged under 15 years (1980-2016): 3373

Selected characteristics Germany 2007-2016

Relative frequency: $942 / 17613 = 5.3\%$

Relative frequency of trial patients: 99.6 %

Age- and sex-specific incidence rates per million
Germany 2007-2016

Incidence rates per million:

Girls Boys Total

Number of cases: 507 435 942

Standardized rate *: 11.0 9.1 10.0

Cumulative incidence: 149 122 135

Sex ratio (m/f): 0.9

Age-specific incidence rates per million:

<1 1-4 5-9 10-14

Number of cases : 155 544 206 37

Incidence rate: 22.5 19.7 5.7 1.0

Median age at diagnosis: 3 years 1 month

Survival probabilities
(2004-2013):

5-year 10-year 15-year
93 % 93 % 93 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		
116	2.7 %	1.0	14

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

VI (a) Nephroblastoma and other non-epithelial renal tumours

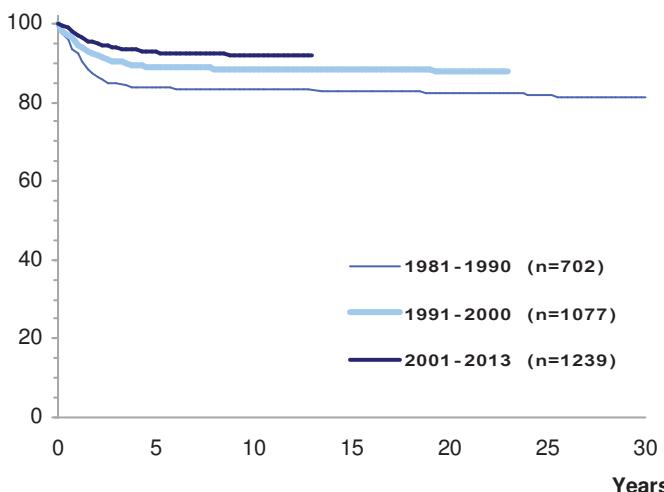
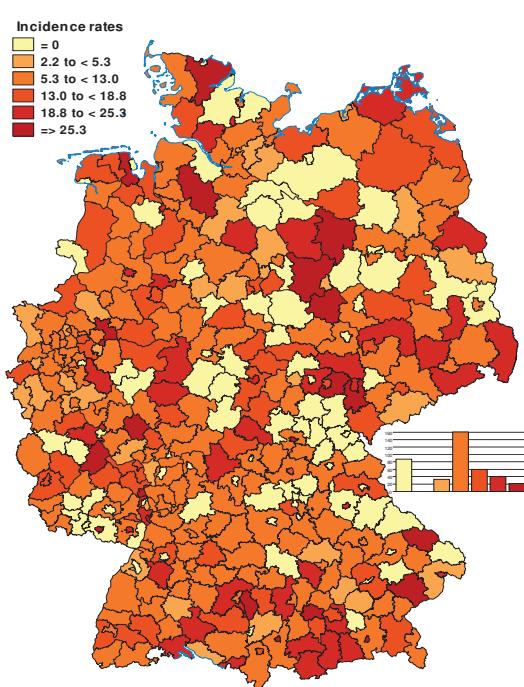
SN after VI (a)

VI (a) as SN after any primary

% of all 1245 SN		Cumulative incidence	% of all 1245 SN		Cumulative incidence
N			N		
48	3.9 %	4.8 %	10	0.8 %	0.0 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013

Standardized* incidence rates per million by districts
(Landkreise) Germany 2007-2016

44 VI (a) Nephroblastoma and other non-epithelial renal tumours - Extended ICCC-3

Germany 2007-2016		N	%
Nephroblastoma and other non-epithelial renal tumours		942	100.0
1 Nephroblastoma		919	97.6
2 Rhabdoid renal tumour		17	1.8
3 Kidney sarcomas		6	0.6
4 Peripheral neuroectodermal tumour (pPNET) of kidney		0	0.0

1 Nephroblastoma

Cases in Germany aged under 15 years (1980-2016): 3261

Selected characteristics Germany 2007-2016

Relative frequency:	919 / 17613 = 5.2 %			
Relative frequency of trial patients:	99.6 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	495	424	919	
Standardized rate *:	10.7	8.9	9.8	
Cumulative incidence:	146	119	132	
Sex ratio (m/f):	0.9			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	144	538	202	35
Incidence rate:	20.9	19.5	5.6	0.9
Median age at diagnosis:	3 years 1 month			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

1 Nephroblastoma

SN after VI (a) 1			VI (a) 1 as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
44	3.5 %	4.7 %	8	0.6 %	0.0 %

* Standard: Segi world standard population

2 Rhabdoid renal tumour

Cases in Germany aged under 15 years (1980-2016): 57

Selected characteristics Germany 2007-2016

Relative frequency:	17 / 17613 = 0.1 %			
Relative frequency of trial patients:	100.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	8	9	17	
Standardized rate *:	0.2	0.2	0.2	
Cumulative incidence:	2	2	2	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	9	6	1	1
Incidence rate:	1.3	0.2	0.0	0.0
Median age at diagnosis:	0 years 10 months			

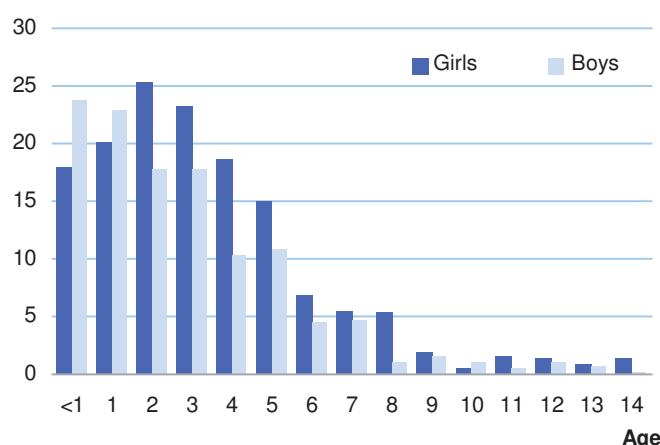
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

2 Rhabdoid renal tumour

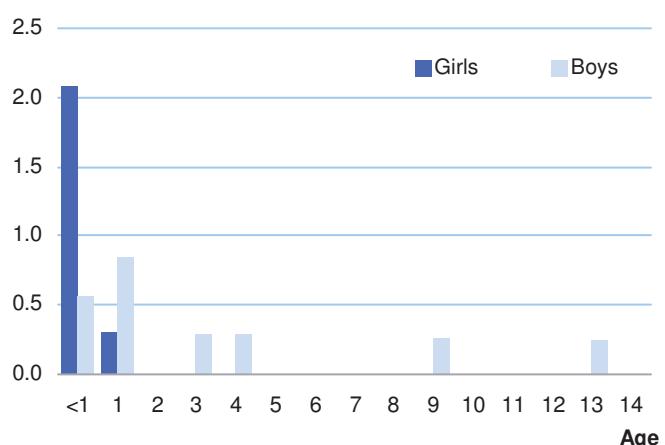
SN after VI (a) 2			VI (a) 2 as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
3	0.2 %	-	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016

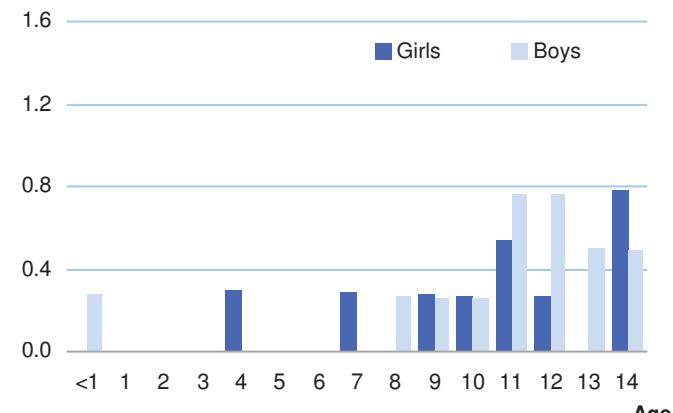


Age- and sex-specific incidence rates per million Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 70**Selected characteristics Germany 2007-2016**

Relative frequency: 24 / 17613 = 0.1 %
Relative frequency of trial patients: 95.8 %

**Age- and sex-specific incidence rates per million
Germany 2007-2016****Incidence rates per million:**

	Girls	Boys	Total
Number of cases:	10	14	24
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	3	4	3
Sex ratio (m/f):			1.4

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	1	1	4	18
Incidence rate:	0.1	0.0	0.1	0.5

Median age at diagnosis:

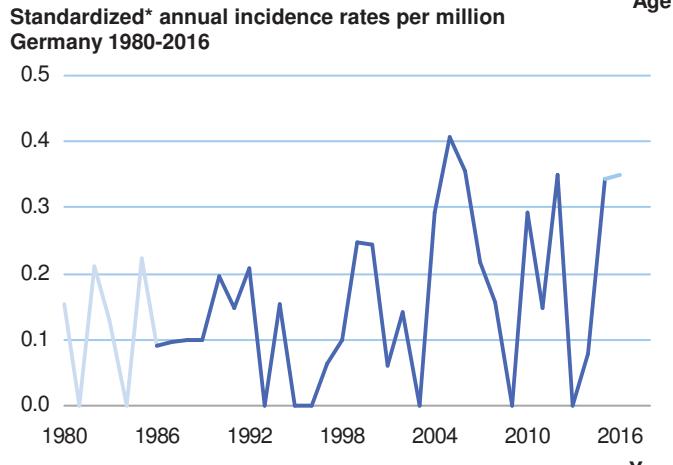
11 years 10 months

**Survival probabilities
(2004-2013):**

5-year | 10-year | 15-year

Mortality per million within 15 yrs. of diagnosis (1992-2001):

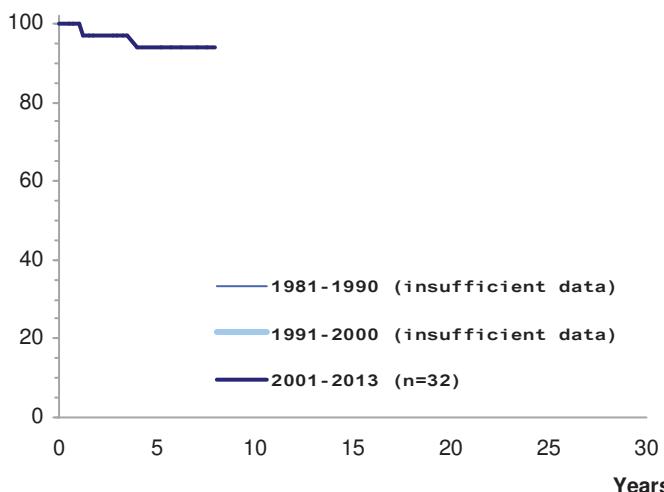
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		
3	0.1 %	0.0	0

**Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):**

VI (b) Renal carcinomas

SN after VI (b)		VI (b) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN
1	0.1 %	1.9 %	10	0.8 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013

No map due to sparse data

46 VII (a) Hepatoblastoma

Cases in Germany aged under 15 years (1980-2016): 556

Selected characteristics Germany 2007-2016

Relative frequency: 228 / 17613 = 1.3 %

Relative frequency of trial patients: 77.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	96	132	228
Standardized rate *:	2.2	2.8	2.5
Cumulative incidence:	29	37	33
Sex ratio (m/f):			1.4

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	76	131	13	8
Incidence rate:	11.0	4.7	0.4	0.2

Median age at diagnosis: 1 year 5 months

Survival probabilities (2004-2013):

	5-year	10-year	15-year
(2004-2013):	80 %	79 %	79 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths	
38	0.9 %	0.4
		5

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

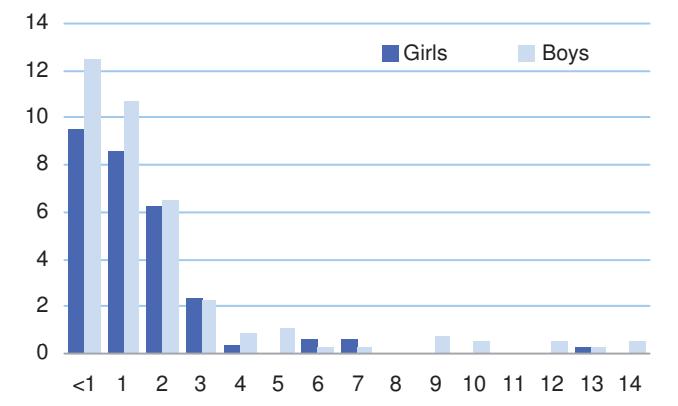
VII (a) Hepatoblastoma

SN after VII (a)			VII (a) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
3	0.2 %	1.8 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

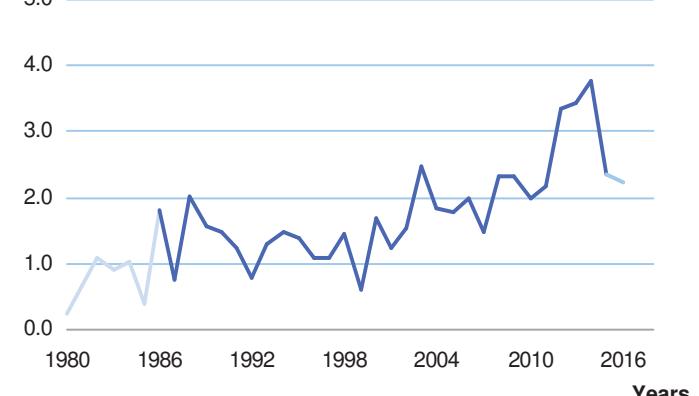
Age- and sex-specific incidence rates per million

Germany 2007-2016

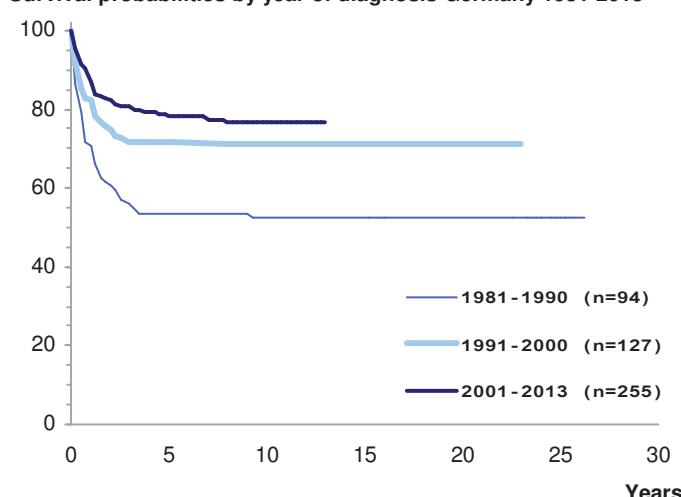


Standardized* annual incidence rates per million

Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013

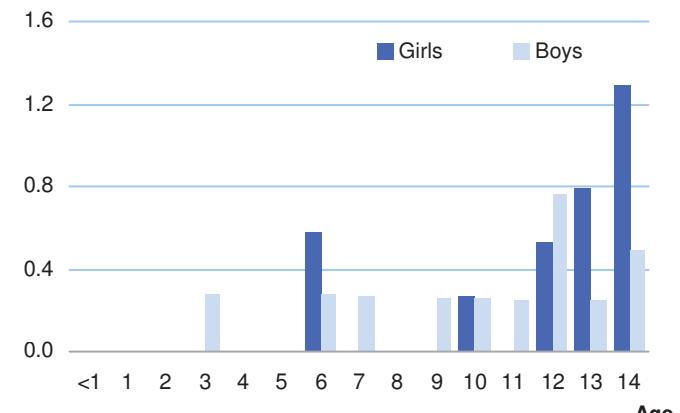
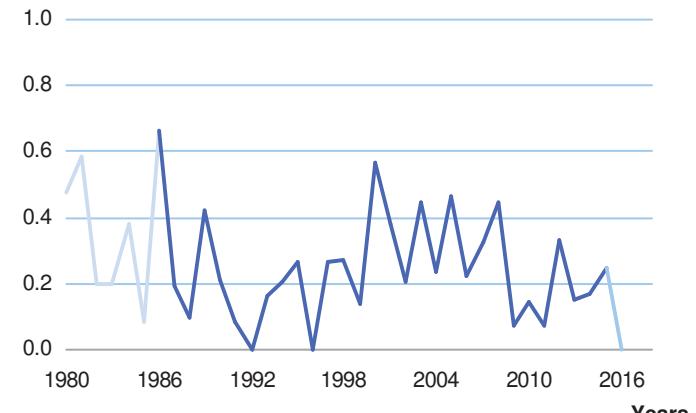
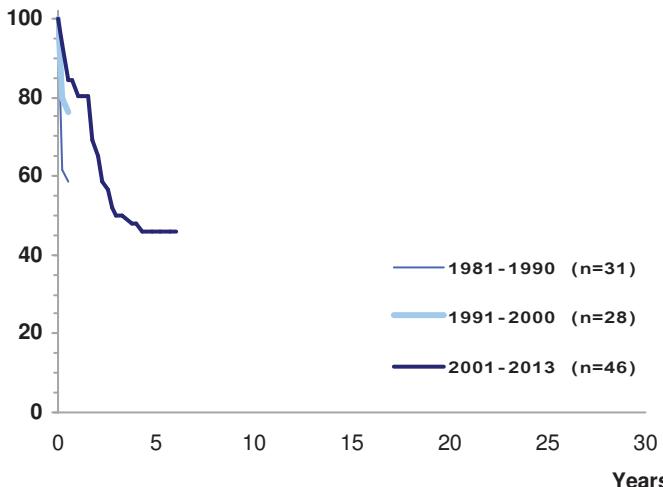


No map due to sparse data

Cases in Germany aged under 15 years (1980-2016): 115**Selected characteristics Germany 2007-2016**

Relative frequency:	25 / 17613 = 0.1 %			
Relative frequency of trial patients:	72.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	13	12	25	
Standardized rate *:	0.2	0.2	0.2	
Cumulative incidence:	3	3	3	
Sex ratio (m/f):	0.9			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	1	5	19
Incidence rate:	0.0	0.0	0.1	0.5
Median age at diagnosis:	12 years 8 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
	44 %	-	-	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths	Standardized* mortality rate	Cumulative mortality		
N % of all 4232 deaths	0.2	2		
22 0.5 %				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
VII (b) Hepatic carcinomas				
SN after VII (b)			VII (b) as SN after any primary	
	% of all 1245 SN	Cumulative incidence		
N		N		
1	0.1 %	1.8 %	4	
			0.3 %	
			0.0 %	

* Standard: Segi world standard population

**Age- and sex-specific incidence rates per million
Germany 2007-2016****Standardized* annual incidence rates per million
Germany 1980-2016****Survival probabilities by year of diagnosis Germany 1981-2013**

No map due to sparse data

48 VIII Malignant bone tumours

- (a) Osteosarcomas
- (b) Chondrosarcomas
- (c) Ewing tumour and related sarcomas of bone

- (d) Other specified malignant bone tumours
- (e) Unspecified malignant bone tumours

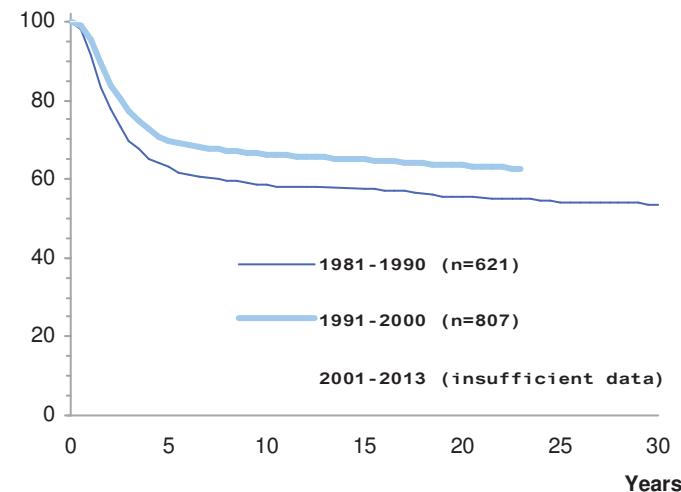
Cases in Germany aged under 15 years (1980-2016): 2755

Selected characteristics Germany 2007-2016

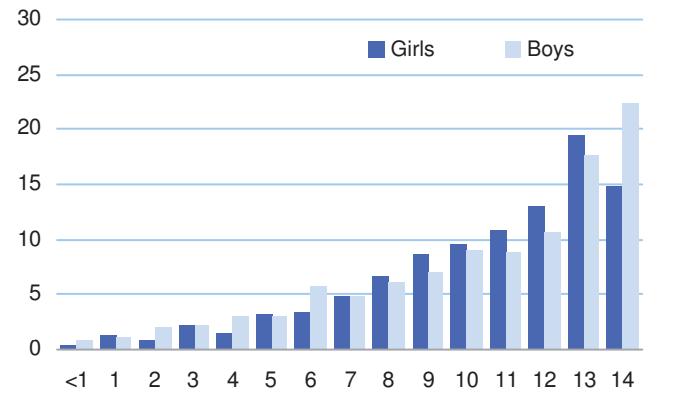
Relative frequency:	777 / 17613 = 4.4 %			
Relative frequency of trial patients:	97.6 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	370	407	777	
Standardized rate *:	6.1	6.5	6.3	
Cumulative incidence:	101	105	103	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	4	49	195	529
Incidence rate:	0.6	1.8	5.4	13.7
Median age at diagnosis:	11 years 11 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
N	-	-	-	
% of all 4232 deaths				
270	6.4 %			
		1.8	30	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths	Standardized* mortality rate	Cumulative mortality		
N				
270	1.8	30		
% of all 4232 deaths				
6.4 %				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
VIII Malignant bone tumours				
SN after VIII	VIII as SN after any primary			
N	% of all SN	Cumulative incidence		
66	5.3 %	6.5 %		
	N	% of all SN	Cumulative incidence	
	63	5.1 %	0.3 %	

* Standard: Segi world standard population

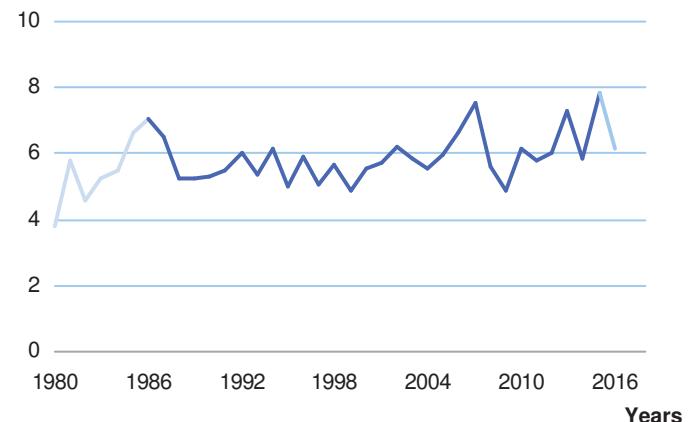
Survival probabilities by year of diagnosis Germany 1981-2013



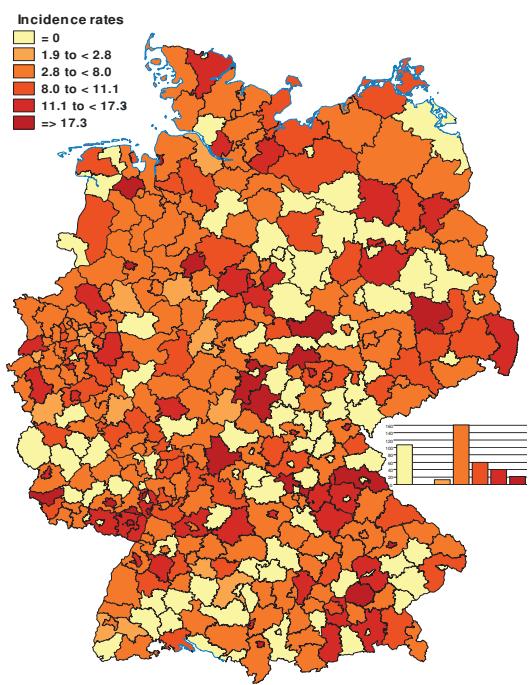
Age- and sex-specific incidence rates per million Germany 2007-2016



Standardized* annual incidence rates per million Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 1433
Selected characteristics Germany 2007-2016
Relative frequency: 388 / 17613 = 2.2 %

Relative frequency of trial patients: 98.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	193	195	388
Standardized rate *:	3.1	3.0	3.1
Cumulative incidence:	52	50	51
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	7	82	299
Incidence rate:	0.0	0.3	2.3	7.7

Median age at diagnosis: 12 years 6 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	75 %	71 %	70 %

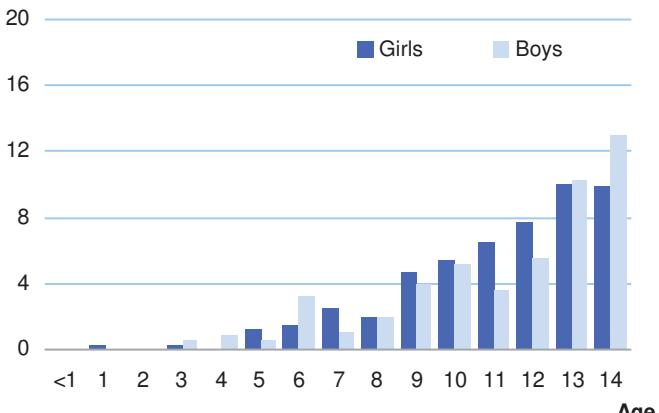
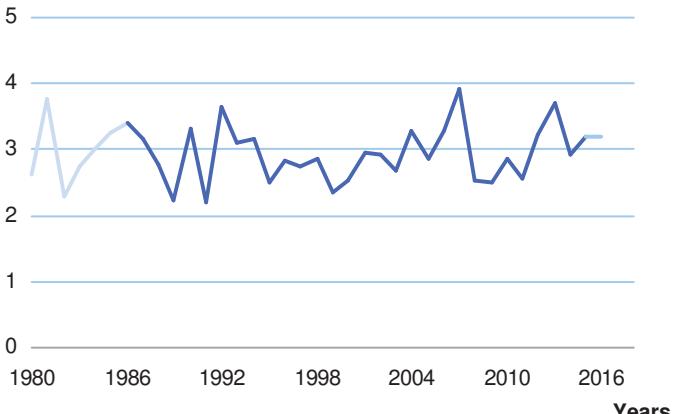
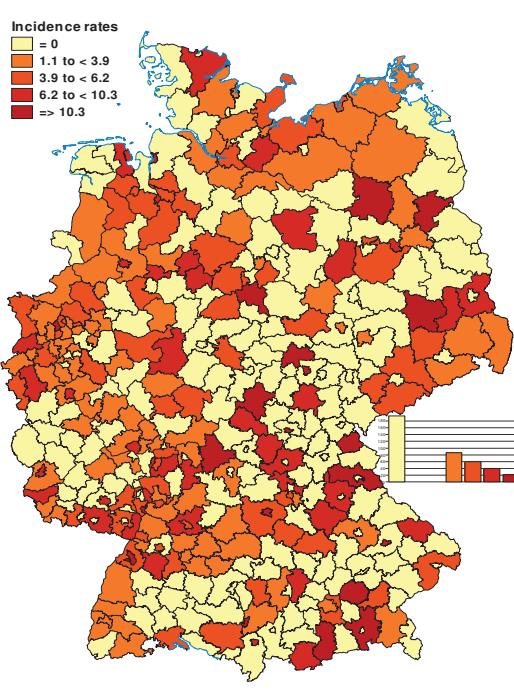
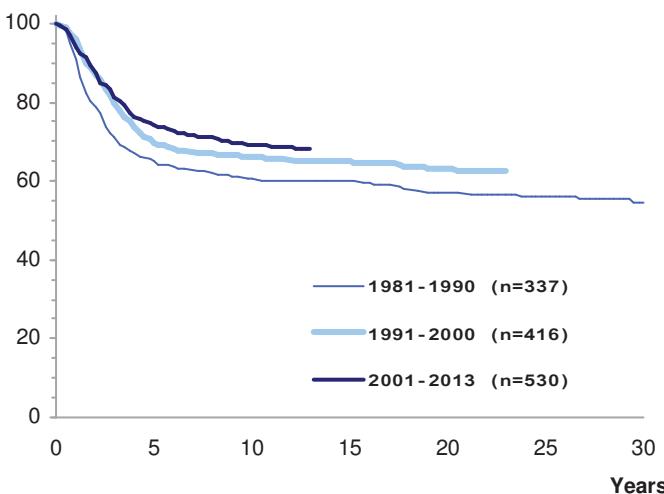
Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N 139	% of all 4232 deaths 3.3 %	0.9

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
VIII (a) Osteosarcomas

SN after VIII (a)	VIII (a) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
34	2.7 %	7.8 %	43	3.5 %	0.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016

Standardized* annual incidence rates per million
Germany 1980-2016

Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016

Survival probabilities by year of diagnosis Germany 1981-2013


50 VIII (c) Ewing tumour and related sarcomas of bone

Cases in Germany aged under 15 years (1980-2016): 1228

Selected characteristics Germany 2007-2016

Relative frequency: 357 / 17613 = 2 %

Relative frequency of trial patients: 98.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	163	194	357
Standardized rate *:	2.8	3.2	3.0
Cumulative incidence:	45	51	48
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	3	39	105	210
Incidence rate:	0.4	1.4	2.9	5.4

Median age at diagnosis: 11 years 2 months

Survival probabilities (2004-2013): 5-year | 10-year | 15-year

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths N	% of all 4232 deaths	Standardized* mortality rate	Cumulative mortality	
			5-year	10-year
122	2.9 %	0.8		14

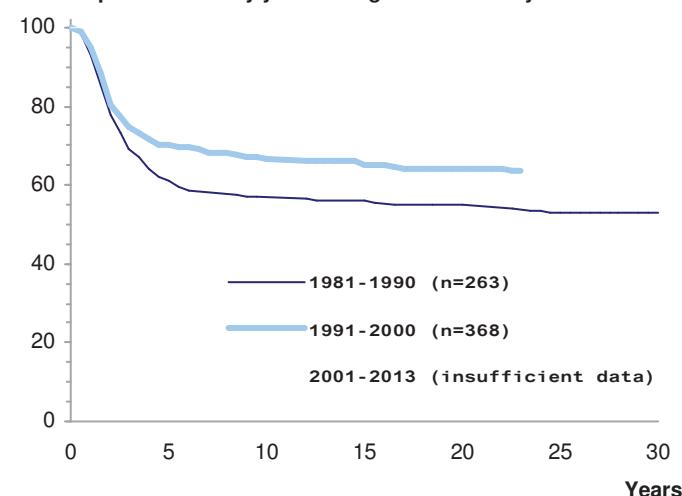
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

VIII (c) Ewing tumour and related sarcomas of bone

SN after VIII (c) N	VIII (c) as SN after any primary				
	% of all SN	Cumulative incidence	N	% of all SN	Cumulative incidence
30	2.4 %	4.8 %	16	1.3 %	0.1 %

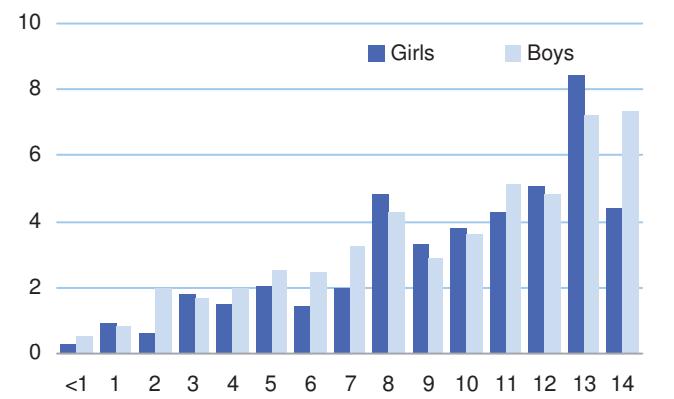
* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



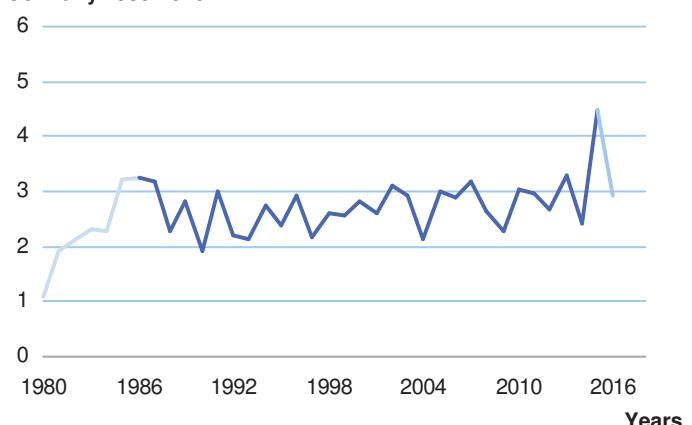
Age- and sex-specific incidence rates per million

Germany 2007-2016

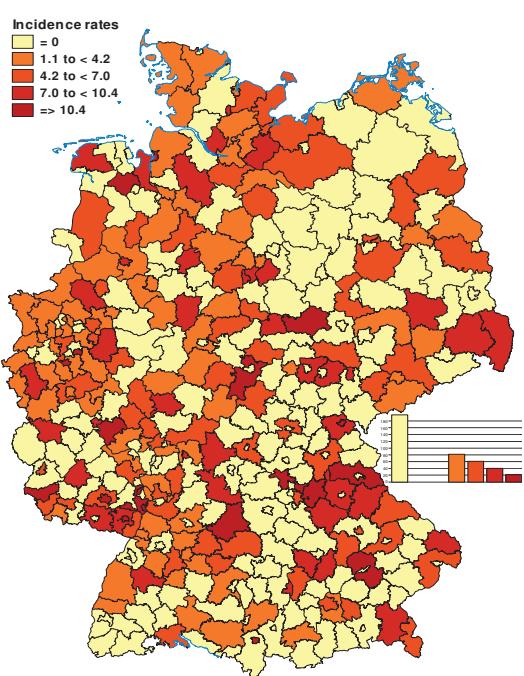


Standardized* annual incidence rates per million

Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Germany 2007-2016	N	%
Ewing tumour and related sarcomas of bone	357	100.0
1 Ewing tumour and askin tumour of bone	341	95.5
2 Peripheral neuroectodermal tumour (pPNET) of bone	16	4.5

1 Ewing tumour and askin tumour of bone

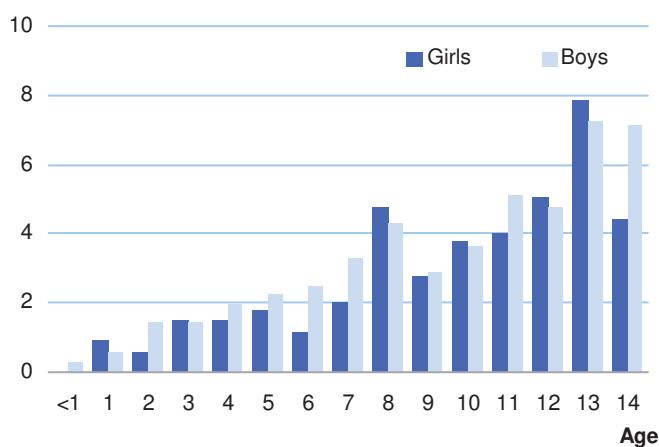
Cases in Germany aged under 15 years (1980-2016): 1060

Selected characteristics Germany 2007-2016

Relative frequency:	341 / 17613 = 1.9 %			
Relative frequency of trial patients:	98.2 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	154	187	341	
Standardized rate *:	2.6	3.0	2.8	
Cumulative incidence:	42	49	46	
Sex ratio (m/f):	1.2			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	1	34	100	206
Incidence rate:	0.1	1.2	2.8	5.3
Median age at diagnosis:	11 years 3 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
1 Ewing tumour and askin tumour of bone				
SN after VIII (c) 1	VIII (c) 1 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence	
24 1.9 %	4.6 %	11 0.9 %	0.0 %	

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



52 IX Soft tissue and other extraosseous sarcomas

- (a) Rhabdomyosarcomas
- (b) Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms
- (c) Kaposi sarcoma

- (d) Other specified soft tissue sarcomas
- (e) Unspecified soft tissue sarcomas

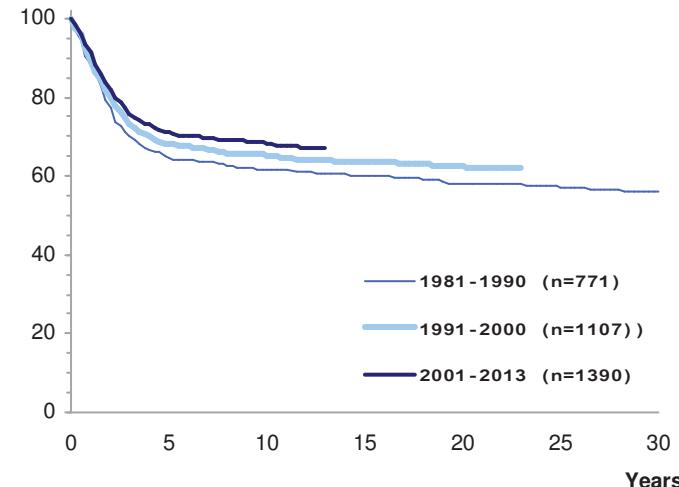
Cases in Germany aged under 15 years (1980-2016): 3598

Selected characteristics Germany 2007-2016

Relative frequency:	996 / 17613 = 5.7 %			
Relative frequency of trial patients:	98.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	458	538	996	
Standardized rate *:	8.8	10.0	9.4	
Cumulative incidence:	130	145	138	
Sex ratio (m/f):	1.2			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	129	285	257	325
Incidence rate:	18.7	10.3	7.2	8.4
Median age at diagnosis:	6 years 3 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
	73 %	71 %	69 %	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths	Standardized* mortality rate	Cumulative mortality		
N % of all 4232 deaths	3.1	46		
395 9.3 %				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
IX Soft tissue and other extraosseous sarcomas				
SN after IX	IX as SN after any primary			
% of all N SN	% of all N SN	Cumulative incidence		
1245 7.4 %	1245 5.5 %	9.9 %		
92	68	0.4 %		

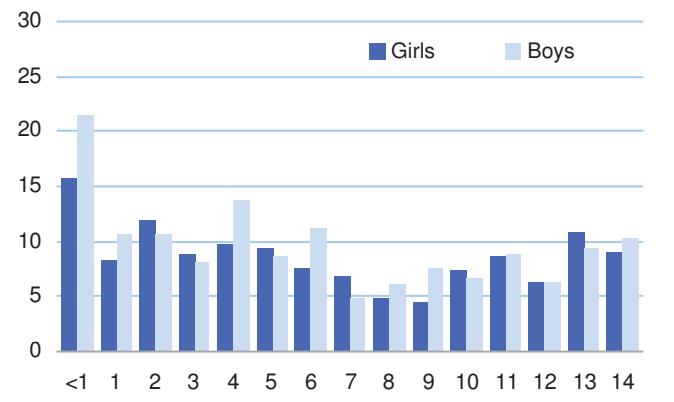
* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1981-2013



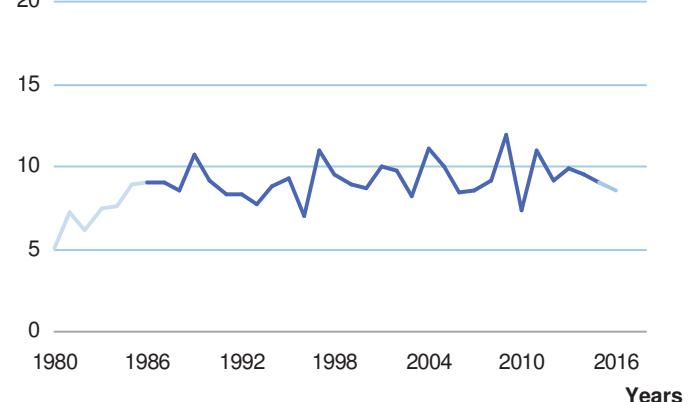
Age- and sex-specific incidence rates per million

Germany 2007-2016

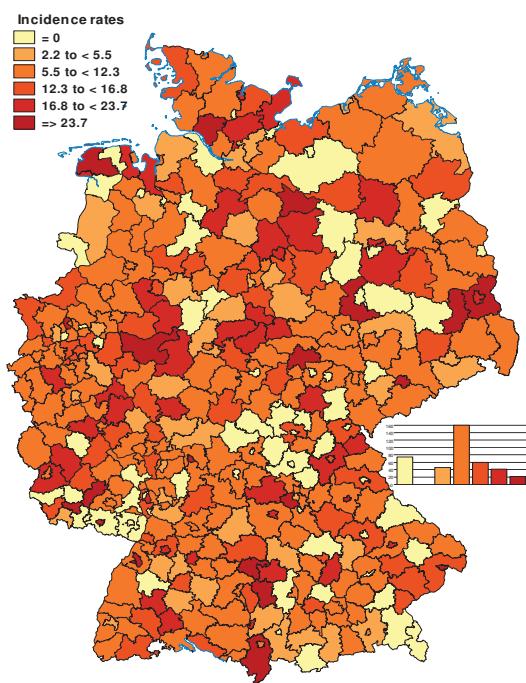


Standardized* annual incidence rates per million

Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Cases in Germany aged under 15 years (1980-2016): 2034
Selected characteristics Germany 2007-2016
Relative frequency: 511 / 17613 = 2.9 %

Relative frequency of trial patients: 99.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	229	282	511
Standardized rate *:	4.5	5.5	5.0
Cumulative incidence:	66	77	72
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	48	203	150	110
Incidence rate:	7.0	7.3	4.2	2.8

Median age at diagnosis: 5 years 1 month

Survival probabilities (2004-2013):	5-year	10-year	15-year
	73 %	71 %	70 %

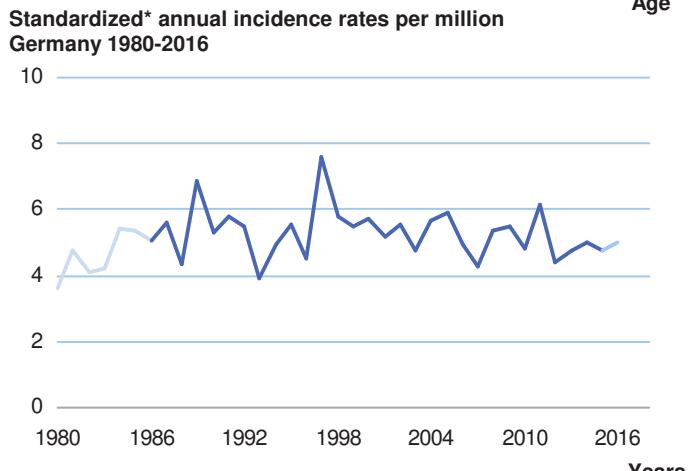
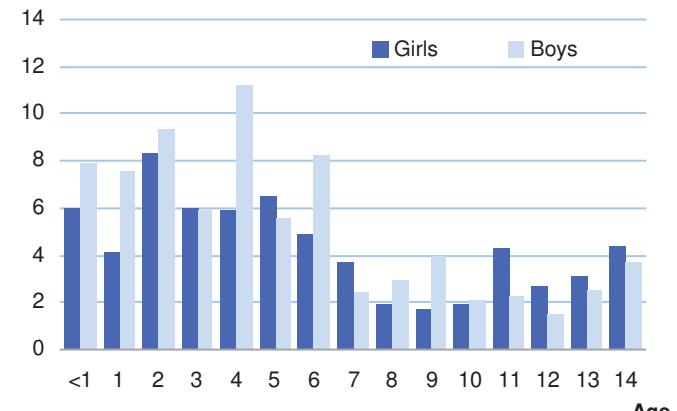
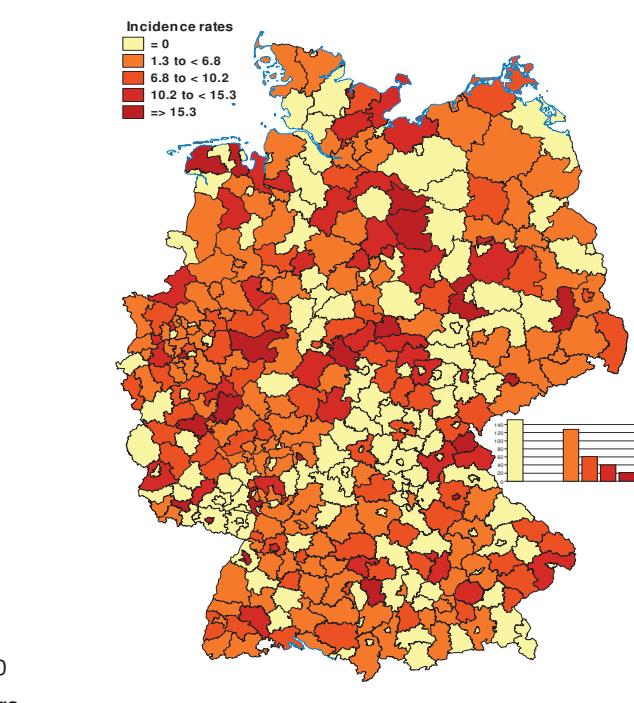
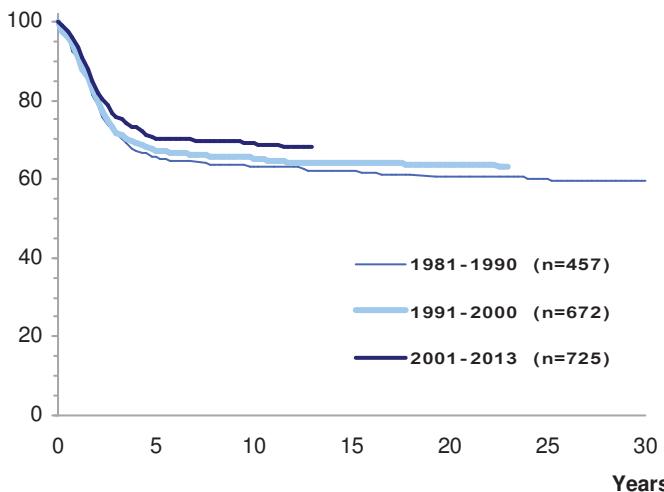
Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N 231	% of all 4232 deaths 5.5 %	1.9

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
IX (a) Rhabdomyosarcomas

SN after IX (a)	IX (a) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
64	5.1 %	10.4 %	14	1.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016

Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016

Survival probabilities by year of diagnosis Germany 1981-2013


54 IX (b) Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms

Cases in Germany aged under 15 years (1980-2016): 337

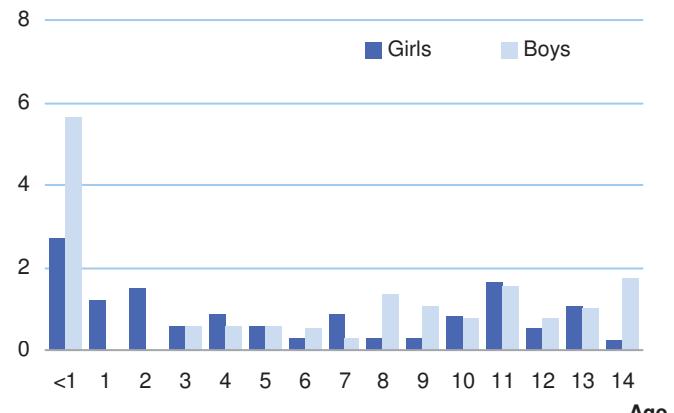
Selected characteristics Germany 2007-2016

Relative frequency:	108 / 17613 = 0.6 %			
Relative frequency of trial patients:	95.4 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	47	61	108	
Standardized rate *:	0.9	1.1	1.0	
Cumulative incidence:	13	16	15	
Sex ratio (m/f):	1.3			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	29	18	22	39
Incidence rate:	4.2	0.7	0.6	1.0
Median age at diagnosis:	7 years 0 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
	72 %	72 %	69 %	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths	Standardized* mortality rate	Cumulative mortality		
N % of all 4232 deaths	0.2	3		
30 0.7 %				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
IX (b) Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms				
SN after IX (b)	IX (b) as SN after any primary			
% of all	% of all			
N 1245 SN	N 1245 SN	Cumulative incidence		
7 0.6 %	19 1.5 %	0.1 %		

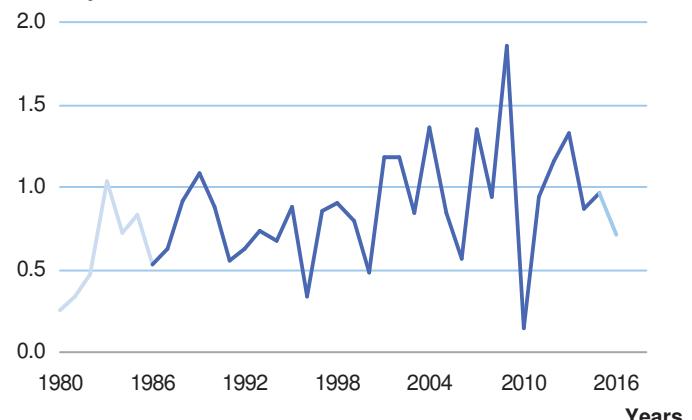
* Standard: Segi world standard population

Age- and sex-specific incidence rates per million

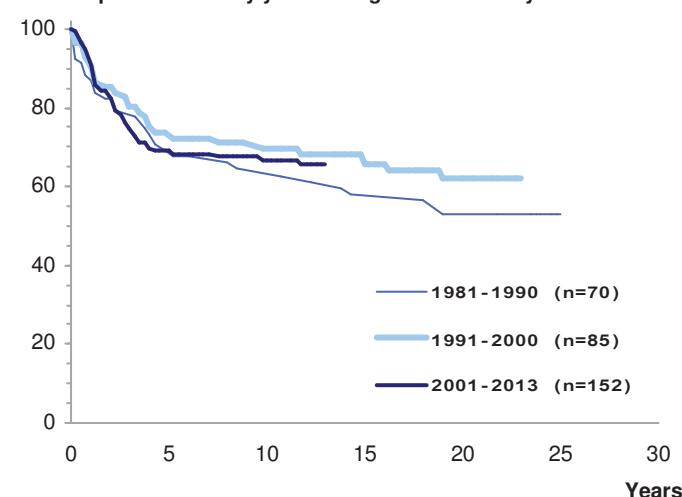
Germany 2007-2016



Standardized* annual incidence rates per million
Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013



No map due to sparse data

Germany 2007-2016		N	%
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	108	100.0	
1 Fibroblastic and myofibroblastic tumours	54	50.0	
2 Nerve sheath tumours	54	50.0	
3 Other fibrous neoplasms	0	0.0	

1 Fibroblastic and myofibroblastic tumours

Cases in Germany aged under 15 years (1980-2016): 160

Selected characteristics Germany 2007-2016

Relative frequency:	54 / 17613 = 0.3 %				
Relative frequency of trial patients:	94.4 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	24	30	54		
Standardized rate *:	0.5	0.6	0.6		
Cumulative incidence:	7	8	8		
Sex ratio (m/f):	1.3				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	22	13	8	11	
Incidence rate:	3.2	0.5	0.2	0.3	
Median age at diagnosis:	3 years 2 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
1 Fibroblastic and myofibroblastic tumours					
SN after IX (b) 1	IX (b) 1 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
4	0.3 %	8.1 %	5	0.4 %	0.0 %

* Standard: Segi world standard population

2 Nerve sheath tumours

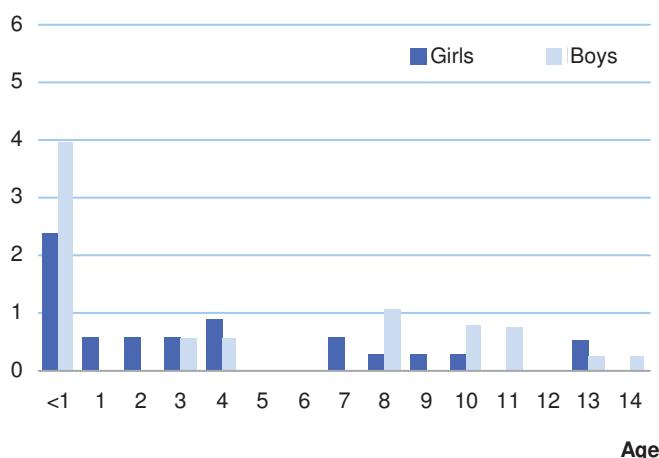
Cases in Germany aged under 15 years (1980-2016): 177

Selected characteristics Germany 2007-2016

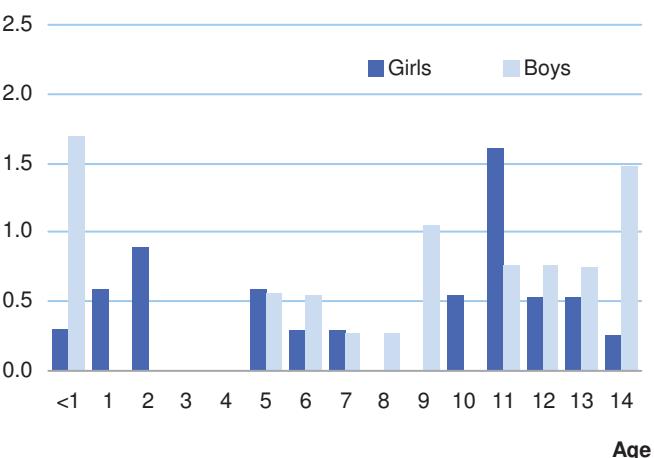
Relative frequency:	54 / 17613 = 0.3 %				
Relative frequency of trial patients:	96.3 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	23	31	54		
Standardized rate *:	0.4	0.5	0.5		
Cumulative incidence:	6	8	7		
Sex ratio (m/f):	1.3				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	7	5	14	28	
Incidence rate:	1.0	0.2	0.4	0.7	
Median age at diagnosis:	10 years 10 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
2 Nerve sheath tumours					
SN after IX (b) 2	IX (b) 2 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
3	0.2 %	3.2 %	14	1.1 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Age- and sex-specific incidence rates per million Germany 2007-2016



56 IX (d) Other specified soft tissue sarcomas

Cases in Germany aged under 15 years (1980-2016): 991

Selected characteristics Germany 2007-2016

Relative frequency: 294 / 17613 = 1.7 %

Relative frequency of trial patients: 97.6 %

Incidence rates per million:

	Girls	Boys	Total
Number of cases:	147	147	294
Standardized rate *:	2.7	2.6	2.6
Cumulative incidence:	41	39	40
Sex ratio (m/f):	1.0		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	40	45	70	139
Incidence rate:	5.8	1.6	1.9	3.6

Median age at diagnosis: 9 years 5 months

Germany 2007-2016	N	%		N	%
Other specified soft tissue sarcomas	294	100.0			
1 Ewing tumour and askin tumour of soft tissue	61	20.7	7 Synovial sarcomas	62	21.1
2 Peripheral neuroectodermal tumour (pPNET) of soft tissue	14	4.8	8 Blood vessel tumours	9	3.1
3 Extrarenal rhabdoid tumour	57	19.4	9 Osseous and chondromatous neoplasms of soft tissue	6	2.0
4 Liposarcomas	5	1.7	10 Alveolar soft parts sarcoma	12	4.1
5 Fibrohistiocytic tumours	37	12.6	11 Miscellaneous soft tissue sarcomas	31	10.5
6 Leiomyosarcomas	0	0.0			

1 Ewing tumour and askin tumour of soft tissue

Cases in Germany aged under 15 years (1980-2016): 193

Selected characteristics Germany 2007-2016

Relative frequency:	61 / 17613 = 0.3 %				
Relative frequency of trial patients:	98.4 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	34	27	61		
Standardized rate *:	0.6	0.4	0.5		
Cumulative incidence:	9	7	8		
Sex ratio (m/f):	0.8				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	1	8	20	32	
Incidence rate:	0.1	0.3	0.6	0.8	
Median age at diagnosis:	10 years 4 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
1 Ewing tumour and askin tumour of soft tissue					
SN after IX (d) 1	IX (d) 1 as SN after any primary				
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence		
8	0.6 %	-	6	0.5 %	0.0 %

* Standard: Segi world standard population

3 Extrarenal rhabdoid tumour

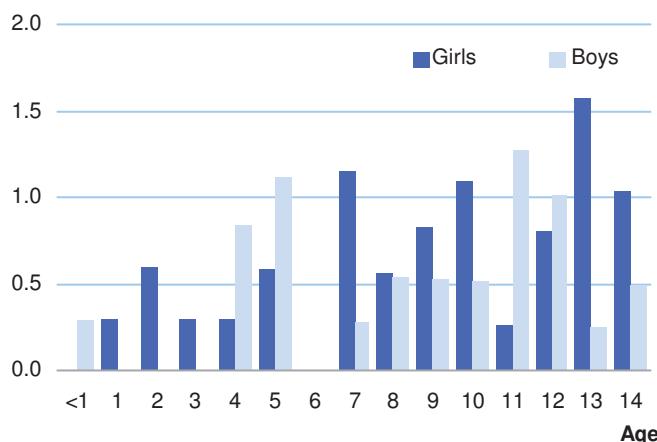
Cases in Germany aged under 15 years (1980-2016): 96

Selected characteristics Germany 2007-2016

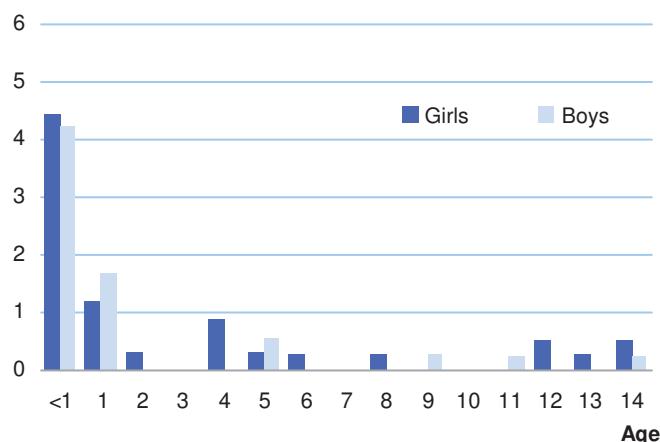
Relative frequency:	57 / 17613 = 0.3 %				
Relative frequency of trial patients:	94.7 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	31	26	57		
Standardized rate *:	0.7	0.6	0.6		
Cumulative incidence:	9	7	8		
Sex ratio (m/f):	0.8				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	30	14	6	7	
Incidence rate:	4.4	0.5	0.2	0.2	
Median age at diagnosis:	0 years 10 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
3 Extrarenal rhabdoid tumour					
SN after IX (d) 3	IX (d) 3 as SN after any primary				
% of all N 1245 SN	Cumulative incidence	% of all N 1245 SN	Cumulative incidence		
1	0.1 %	-	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Age- and sex-specific incidence rates per million Germany 2007-2016



58 IX (d) Other specified soft tissue sarcomas - Extended ICCC-3

Germany 2007-2016	N	%		N	%
Other specified soft tissue sarcomas	294	100.0			
1 Ewing tumour and askin tumour of soft tissue	61	20.7	7 Synovial sarcomas	62	21.1
2 Peripheral neuroectodermal tumour (pPNET) of soft tissue	14	4.8	8 Blood vessel tumours	9	3.1
3 Extrarenal rhabdoid tumour	57	19.4	9 Osseous and chondromatous neoplasms of soft tissue	6	2.0
4 Liposarcomas	5	1.7	10 Alveolar soft parts sarcoma	12	4.1
5 Fibrohistiocytic tumours	37	12.6	11 Miscellaneous soft tissue sarcomas	31	10.5
6 Leiomyosarcomas	0	0.0			

5 Fibrohistiocytic tumours

Cases in Germany aged under 15 years (1980-2016): 90

Selected characteristics Germany 2007-2016

Relative frequency:	37 / 17613 = 0.2 %		
Relative frequency of trial patients:	94.6 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	21	16	37
Standardized rate *:	0.4	0.3	0.3
Cumulative incidence:	6	4	5
Sex ratio (m/f):	0.8		

Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	4	9	10	14
Incidence rate:	0.6	0.3	0.3	0.4

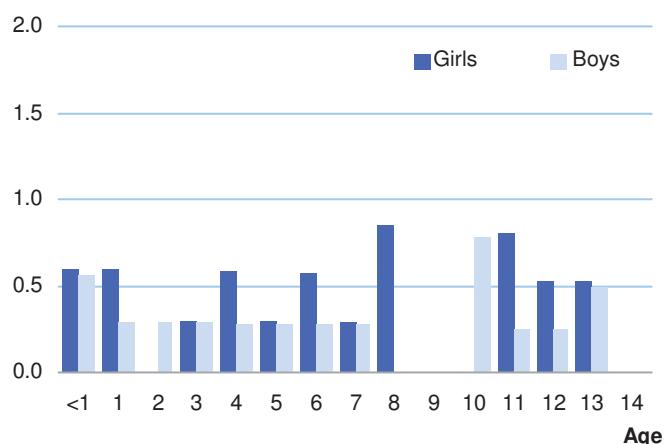
Median age at diagnosis: 7 years 9 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
5 Fibrohistiocytic tumours

SN after IX (d) 5		IX (d) 5 as SN after any primary			
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
1	0.1 %	-	6	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016



7 Synovial sarcomas

Cases in Germany aged under 15 years (1980-2016): 231

Selected characteristics Germany 2007-2016

Relative frequency:	62 / 17613 = 0.4 %		
Relative frequency of trial patients:	100.0 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	29	33	62
Standardized rate *:	0.5	0.5	0.5
Cumulative incidence:	8	9	8
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	1	3	15	43
Incidence rate:	0.1	0.1	0.4	1.1

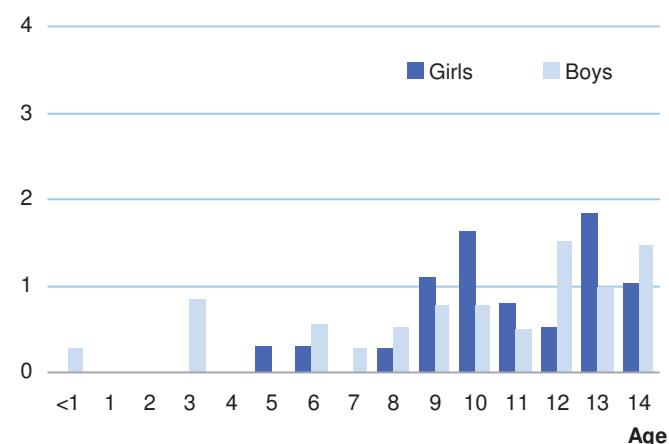
Median age at diagnosis: 11 years 7 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):
7 Synovial sarcomas

SN after IX (d) 7		IX (d) 7 as SN after any primary			
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
3	0.2 %	-	5	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016



- (a) Intracranial and intraspinal germ cell tumours
- (b) Malignant extracranial and extragonadal germ cell tumours
- (c) Malignant gonadal germ cell tumours

- (d) Gonadal carcinomas
- (e) Other and unspecified malignant gonadal tumours

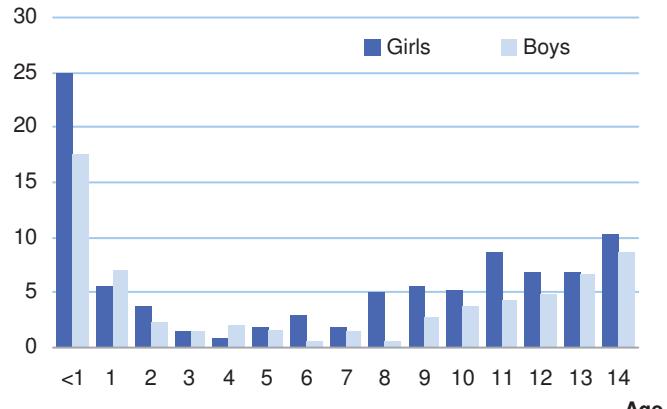
Cases in Germany aged under 15 years (1980-2016): 1896

Selected characteristics Germany 2007-2016

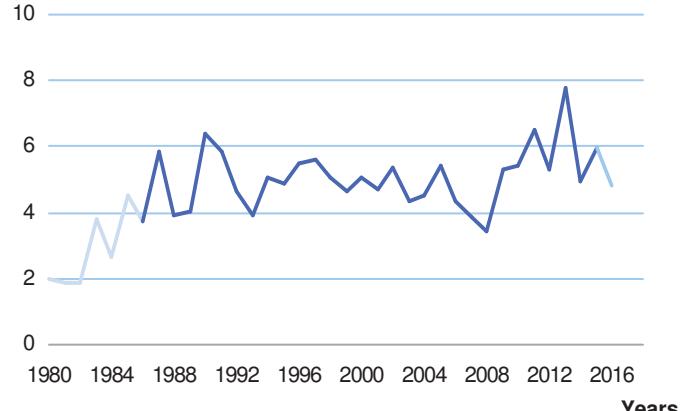
Relative frequency:	572 / 17613 = 3.2 %			
Relative frequency of trial patients:	96.5 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	327	245	572	
Standardized rate *:	6.2	4.5	5.3	
Cumulative incidence:	92	65	78	
Sex ratio (m/f):	0.7			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	146	85	85	256
Incidence rate:	21.2	3.1	2.4	6.6
Median age at diagnosis:	9 years 0 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
	94 %	93 %	93 %	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths	Standardized* mortality rate	Cumulative mortality		
N	N			
51	1.2 %	0.4	6	
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
X Germ cell tumours, trophoblastic tumours and neoplasms of gonads				
SN after X	X as SN after any primary			
N % of all 1245 SN	N % of all 1245 SN	Cumulative incidence		
30 2.4 %	13 1.0 %	7.0 %	0.1 %	

* Standard: Segi world standard population

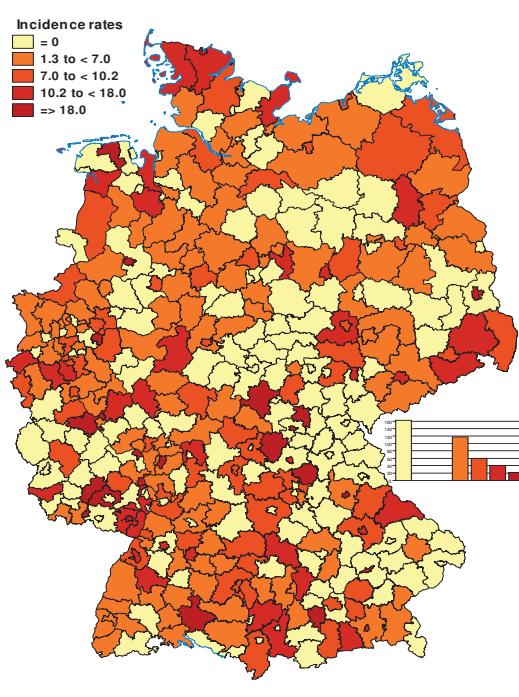
Age- and sex-specific incidence rates per million Germany 2007-2016



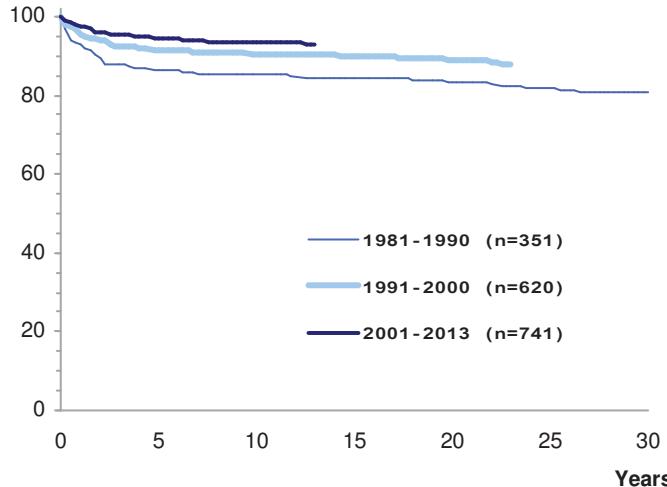
Standardized* annual incidence rates per million Germany 1980-2016



Standardized* incidence rates per million by districts (Landkreise) Germany 2007-2016



Survival probabilities by year of diagnosis Germany 1981-2013



60 X (a) Intracranial and intraspinal germ cell tumours

Cases in Germany aged under 15 years (1980-2016): 524

Selected characteristics Germany 2007-2016

Relative frequency: 172 / 17613 = 1.0 %

Relative frequency of trial patients: 95.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	58	114	172
Standardized rate *:	1.0	1.8	1.4
Cumulative incidence:	16	29	23
Sex ratio (m/f):			2.0

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	10	10	42	110
Incidence rate:	1.5	0.4	1.2	2.8

Median age at diagnosis: 11 years 1 month

Survival probabilities (2004-2013): 5-year 89 % | 10-year 86 % | 15-year 86 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality	Cumulative mortality
N	% of all 4232 deaths		
25	0.6 %	0.2	3

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

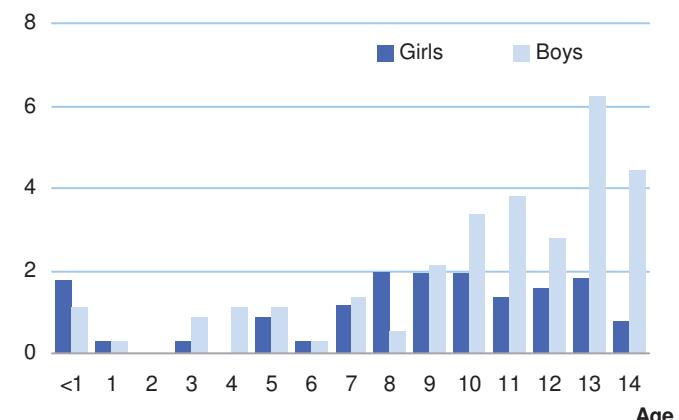
X (a) Intracranial and intraspinal germ cell tumours

SN after X (a)			X (a) as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
14	1.1 %	13.3 %	3	0.2 %	0.0 %

* Standard: Segi world standard population

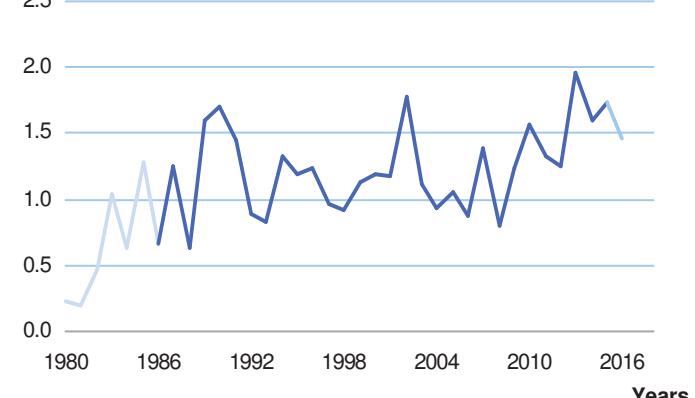
Age- and sex-specific incidence rates per million

Germany 2007-2016

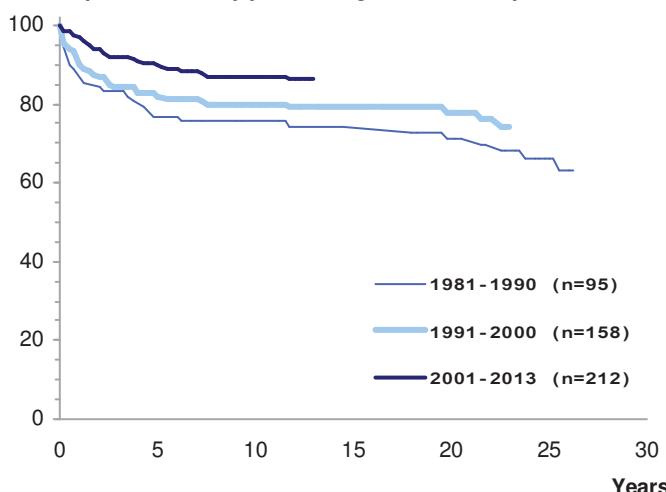


Standardized* annual incidence rates per million

Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013



No map due to sparse data

Germany 2007-2016	N	%
Intracranial and intraspinal germ cell tumours	172	100.0
1 Intracranial and intraspinal germinomas	90	52.3
2 Intracranial and intraspinal teratomas	24	14.0
3 Intracranial and intraspinal embryonal carcinomas	1	0.6
4 Intracranial and intraspinal yolk sac tumour	5	2.9
5 Intracranial and intraspinal choriocarcinoma	7	4.1
6 Intracranial and intraspinal tumours of mixed forms	45	26.2

1 Intracranial and intraspinal germinomas

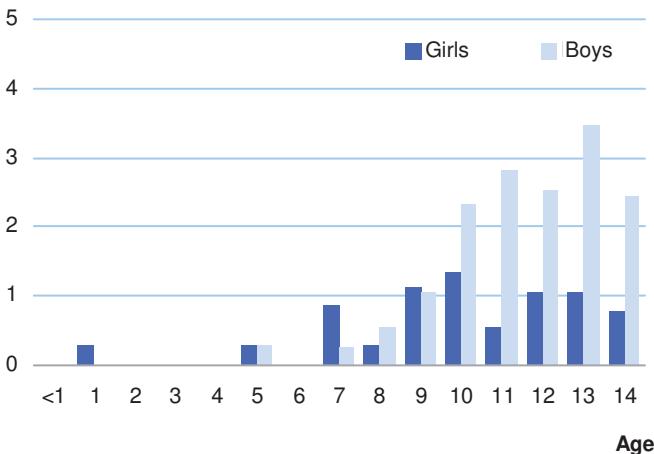
Cases in Germany aged under 15 years (1980-2016): 273

Selected characteristics Germany 2007-2016

Relative frequency:	90 / 17613 = 0.5 %				
Relative frequency of trial patients:	98.9 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	28	62	90		
Standardized rate *:	0.5	0.9	0.7		
Cumulative incidence:	8	16	12		
Sex ratio (m/f):	2.2				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	0	1	17	72	
Incidence rate:	0.0	0.0	0.5	1.9	
Median age at diagnosis:	11 years 12 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
1 Intracranial and intraspinal germinomas					
SN after X (a) 1	X (a) 1 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
7	0.6 %	-	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



2 Intracranial and intraspinal teratomas

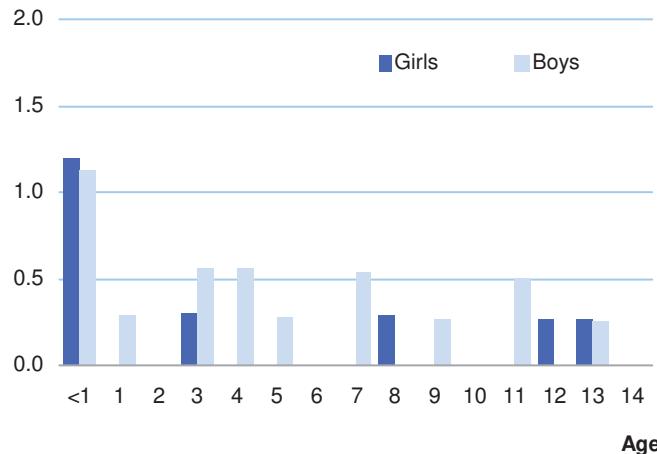
Cases in Germany aged under 15 years (1980-2016): 88

Selected characteristics Germany 2007-2016

Relative frequency:	24 / 17613 = 0.1 %				
Relative frequency of trial patients:	79.2 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	8	16	24		
Standardized rate *:	0.2	0.3	0.2		
Cumulative incidence:	2	4	3		
Sex ratio (m/f):	2.0				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	8	6	5	5	
Incidence rate:	1.2	0.2	0.1	0.1	
Median age at diagnosis:	4 years 3 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
2 Intracranial and intraspinal teratomas					
SN after X (a) 2	X (a) 2 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
1	0.1 %	1.7 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



62 X (b) Malignant extracranial and extragonadal germ cell tumours

Cases in Germany aged under 15 years (1980-2016): 565

Selected characteristics Germany 2007-2016

Relative frequency: 178 / 17613 = 1.0 %

Relative frequency of trial patients: 96.6 %

Incidence rates per million: Girls Boys Total

Number of cases:	122	56	178
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Standardized rate *:	2.8	1.2	2.0
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Cumulative incidence:	36	16	26
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Sex ratio (m/f):			0.5
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Age-specific incidence rates per million:

<1	1-4	5-9	10-14
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Number of cases :	107	52	5	14
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Incidence rate:	15.5	1.9	0.1	0.4
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Median age at diagnosis: 0 years 3 months

Survival probabilities (2004-2013): 5-year 10-year 15-year

93 %	93 %	93 %
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Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		
13	0.3 %	0.1	2

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

X (b) Malignant extracranial and extragonadal germ cell tumours

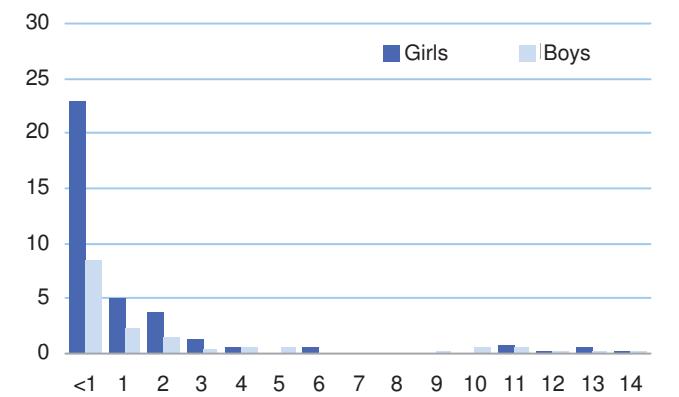
SN after X (b) X (b) as SN after any primary

% of all 1245 SN		Cumulative incidence	% of all 1245 SN		Cumulative incidence
N			N		
7	0.6 %	4.0 %	2	0.2 %	0.0 %

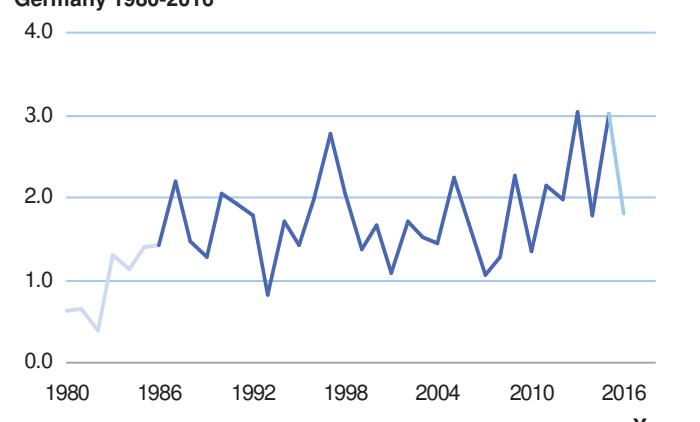
* Standard: Segi world standard population

Age- and sex-specific incidence rates per million

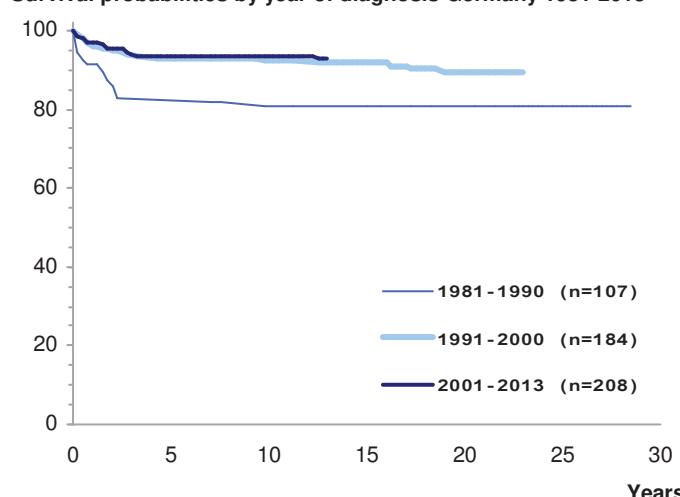
Germany 2007-2016



Standardized* annual incidence rates per million



Survival probabilities by year of diagnosis Germany 1981-2013



No map due to sparse data

Germany 2007-2016	N	%
Malignant extracranial and extragonadal germ cell tumours	178	100.0
1 Germinomas of extracranial and extragonadal sites	16	9.0
2 Malignant teratomas of extracranial and extragonadal sites	91	51.1
3 Embryonal carcinomas of extracranial and extragonadal sites	0	0.0
4 Yolk sac tumour of extracranial and extragonadal sites	45	25.3
5 Choriocarcinomas of extracranial and extragonadal sites	1	0.6
6 Other and unspecified malignant mixed germ cell tumours of extracranial an	25	14.0

2 Malignant teratomas of extracranial and extragonadal sites

Cases in Germany aged under 15 years (1980-2016): 264

Selected characteristics Germany 2007-2016

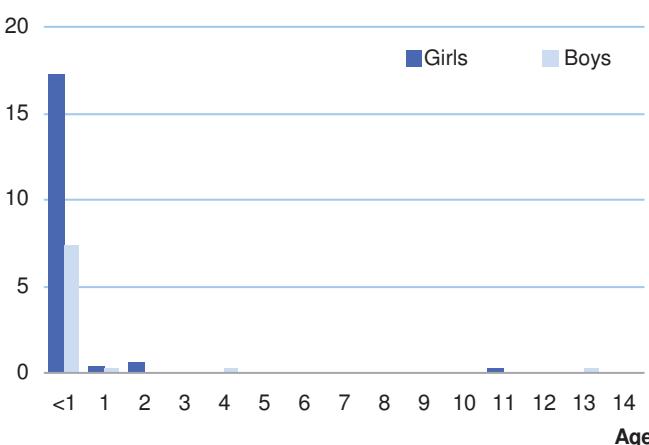
Relative frequency:	91 / 17613 = 0.5 %			
Relative frequency of trial patients:	96.7 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	62	29	91	
Standardized rate *:	1.5	0.6	1.0	
Cumulative incidence:	18	8	13	
Sex ratio (m/f):	0.5			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	84	5	0	2
Incidence rate:	12.2	0.2	0.0	0.1
Median age at diagnosis:	0 years 0 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

2 Malignant teratomas of extracranial and extragonadal sites

SN after X (b) 2	X (b) 2 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
2	0.2 %	4.4 %	0	0.0 %	-

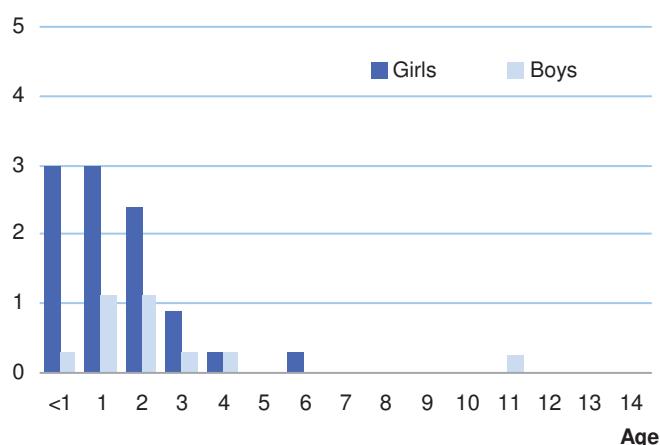
* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016**Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):****4 Yolk sac tumour of extracranial and extragonadal sites**

4 Yolk sac tumour of extracranial and extragonadal sites

SN after X (b) 4	X (b) 4 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
3	0.2 %	3.5 %	0	0.0 %	-

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2007-2016

64 X (c) Malignant gonadal germ cell tumours

Cases in Germany aged under 15 years (1980-2016): 764

Selected characteristics Germany 2007-2016

Relative frequency: 218 / 17613 = 1.2 %

Relative frequency of trial patients: 97.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	143	75	218
Standardized rate *:	2.3	1.5	1.9
Cumulative incidence:	39	20	29
Sex ratio (m/f):			0.5

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	29	23	38	128
Incidence rate:	4.2	0.8	1.1	3.3

Median age at diagnosis: 11 years 4 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	98 %	98 %	98 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths	
9	0.2 %	0.1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

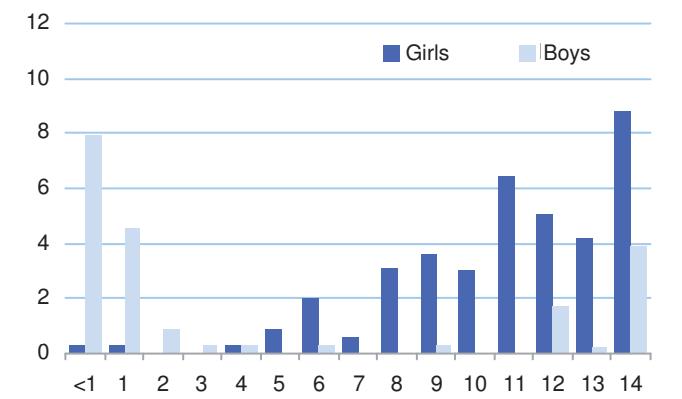
X (c) Malignant gonadal germ cell tumours

SN after X (c)	X (c) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
9	0.7 %	6.4 %	7	0.6 %	0.0 %

* Standard: Segi world standard population

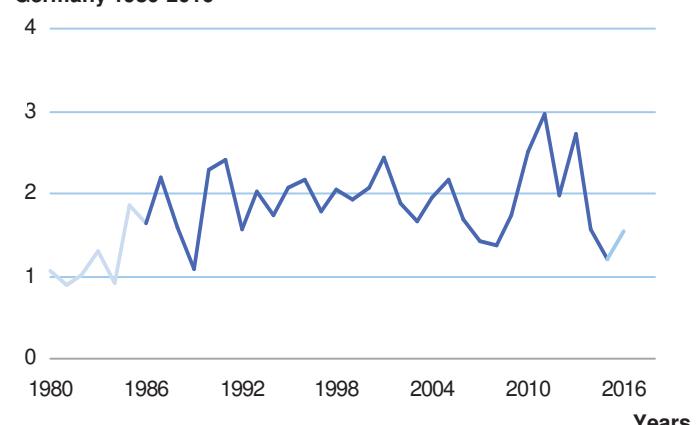
Age- and sex-specific incidence rates per million

Germany 2007-2016

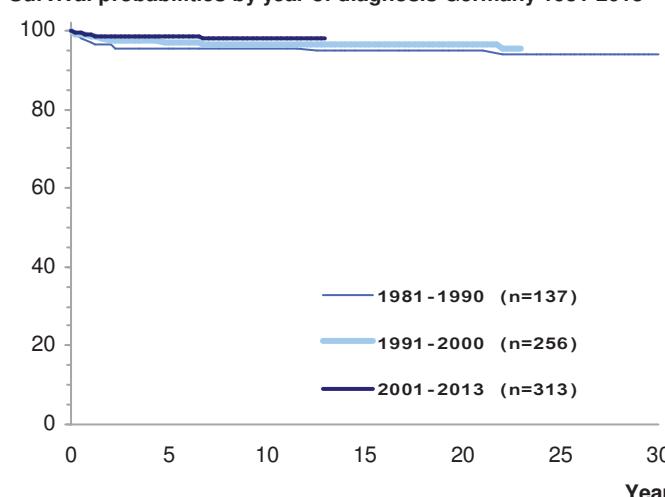


Standardized* annual incidence rates per million

Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013



No map due to sparse data

Germany 2007-2016	N	%
Malignant gonadal germ cell tumours	218	100.0
1 Malignant gonadal germinomas	41	18.8
2 Malignant gonadal teratomas	49	22.5
3 Gonadal embryonal carcinomas	1	0.5
4 Gonadal yolk sac tumour	48	22.0
5 Gonadal choriocarcinoma	6	2.8
6 Malignant gonadal tumours of mixed forms	73	33.5
7 Malignant gonadal gonadoblastoma	0	0.0

1 Malignant gonadal germinomas

Cases in Germany aged under 15 years (1980-2016): 104

Selected characteristics Germany 2007-2016

Relative frequency:	41 / 17613 = 0.2 %			
Relative frequency of trial patients:	100.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	37	4	41	
Standardized rate *:	0.6	0.1	0.3	
Cumulative incidence:	10	1	5	
Sex ratio (m/f):	0.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	2	9	30
Incidence rate:	0.0	0.1	0.3	0.8
Median age at diagnosis:	12 years 0 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
1 Malignant gonadal germinomas				
SN after X (c) 1	X (c) 1 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	N 1245 SN	% of all Cumulative incidence	
0 0.0 %	-	3 0.2 %	0.0 %	

* Standard: Segi world standard population

2 Malignant gonadal teratomas

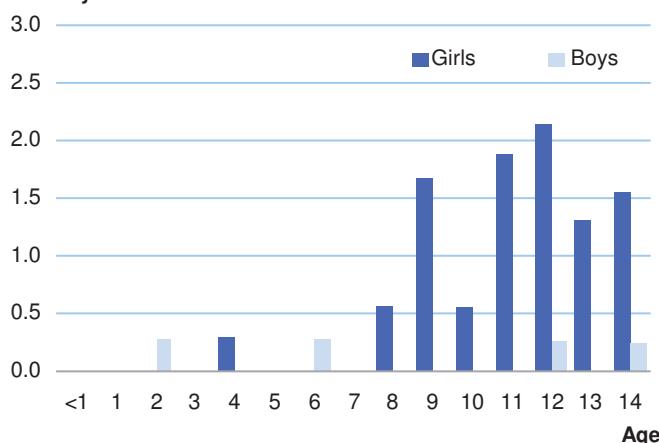
Cases in Germany aged under 15 years (1980-2016): 183

Selected characteristics Germany 2007-2016

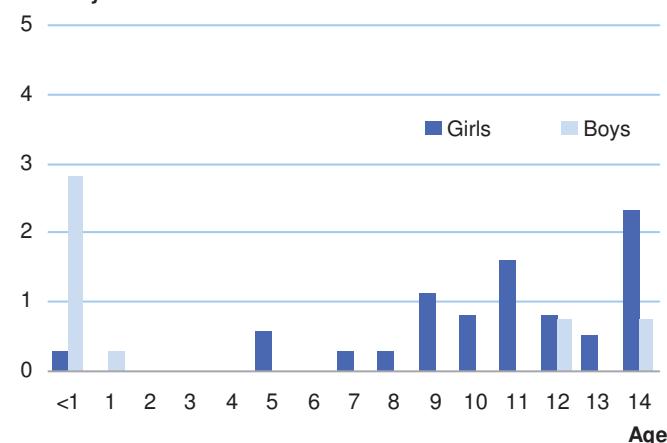
Relative frequency:	49 / 17613 = 0.3 %			
Relative frequency of trial patients:	93.9 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	32	17	49	
Standardized rate *:	0.5	0.3	0.4	
Cumulative incidence:	9	5	7	
Sex ratio (m/f):	0.5			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	11	1	8	29
Incidence rate:	1.6	0.0	0.2	0.8
Median age at diagnosis:	11 years 2 months			
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
2 Malignant gonadal teratomas				
SN after X (c) 2	X (c) 2 as SN after any primary			
% of all N 1245 SN	Cumulative incidence	N 1245 SN	% of all Cumulative incidence	
1 0.1 %	0.8 %	1 0.1 %	0.0 %	

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Age- and sex-specific incidence rates per million Germany 2007-2016



66 X (c) Malignant gonadal germ cell tumours - Extended ICCC-3

Germany 2007-2016		N	%
Malignant gonadal germ cell tumours		218	100.0
1 Malignant gonadal germinomas		41	18.8
2 Malignant gonadal teratomas		49	22.5
3 Gonadal embryonal carcinomas		1	0.5
4 Gonadal yolk sac tumour		48	22.0
5 Gonadal choriocarcinoma		6	2.8
6 Malignant gonadal tumours of mixed forms		73	33.5
7 Malignant gonadal gonadoblastoma		0	0.0

4 Gonadal yolk sac tumour

Cases in Germany aged under 15 years (1980-2016): 309

Selected characteristics Germany 2007-2016

Relative frequency:	48 / 17613 = 0.3 %			
Relative frequency of trial patients:	95.8 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	22	26	48	
Standardized rate *:	0.4	0.6	0.5	
Cumulative incidence:	6	7	7	
Sex ratio (m/f):	1.2			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	9	6	15	15
Incidence rate:	1.3	0.7	0.2	0.4
Median age at diagnosis:	1 year 11 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

4 Gonadal yolk sac tumour

SN after X (c) 4			X (c) 4 as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
6	0.5 %	-	0	0.0 %	-

* Standard: Segi world standard population

6 Malignant gonadal tumours of mixed forms

Cases in Germany aged under 15 years (1980-2016): 119

Selected characteristics Germany 2007-2016

Relative frequency:	73 / 17613 = 0.4 %			
Relative frequency of trial patients:	100.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	47	26	73	
Standardized rate *:	0.8	0.5	0.6	
Cumulative incidence:	13	7	10	
Sex ratio (m/f):	0.6			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	9	2	14	48
Incidence rate:	1.3	0.1	0.4	1.2
Median age at diagnosis:	11 years 10 months			

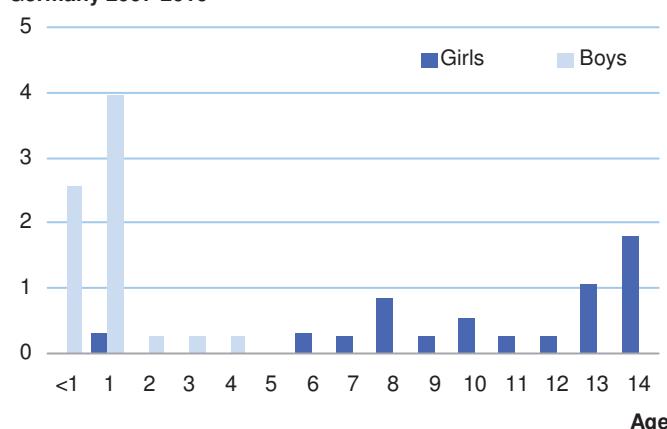
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

6 Malignant gonadal tumours of mixed forms

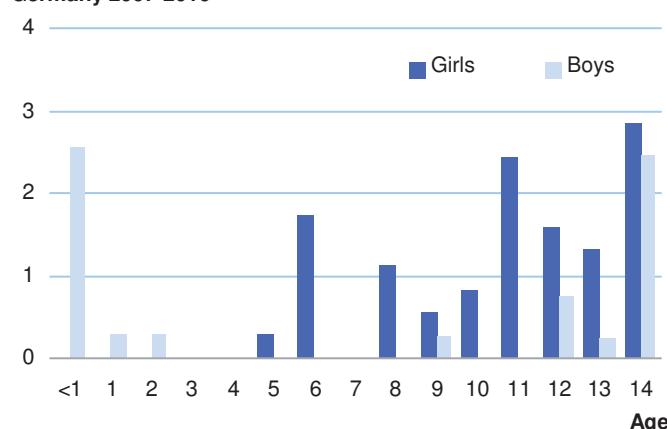
SN after X (c) 6			X (c) 6 as SN after any primary		
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
1	0.1 %	1.4 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Age- and sex-specific incidence rates per million Germany 2007-2016



- (a) Adrenocortical carcinomas
- (b) Thyroid carcinomas
- (c) Nasopharyngeal carcinomas

- (d) Malignant melanomas
- (e) Skin carcinomas
- (f) Other and unspecified carcinomas

Cases in Germany aged under 15 years (1980-2016): 907

Selected characteristics Germany 2007-2016

Relative frequency: 417 / 17613 = 2.4 %

Relative frequency of trial patients: 72.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	230	187	417
Standardized rate *:	3.8	3.0	3.4
Cumulative incidence:	62	48	55
Sex ratio (m/f):			0.8

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	4	30	87	296
Incidence rate:	0.6	1.1	2.4	7.7

Median age at diagnosis: 12 years 3 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	89 %	87 %	85 %

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N 54	1.3 % 0.4	1.3 % 6

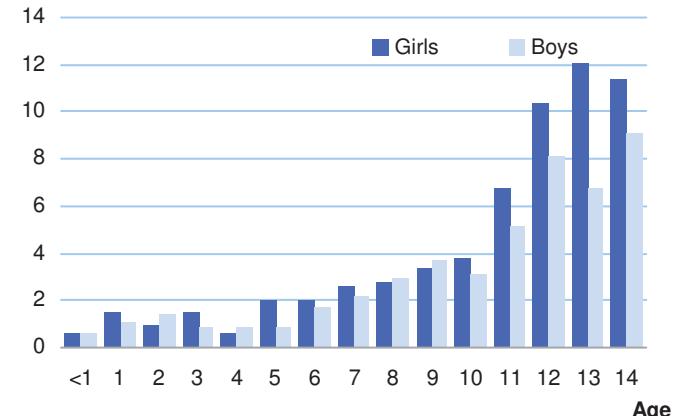
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

XI Other malignant epithelial neoplasms and malignant melanomas

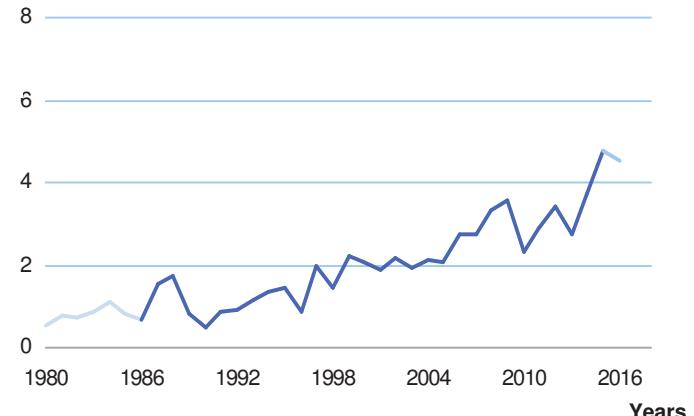
SN after XI	XI as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
11	0.9 %	-	412	33.1 %	4.3 %

* Standard: Segi world standard population

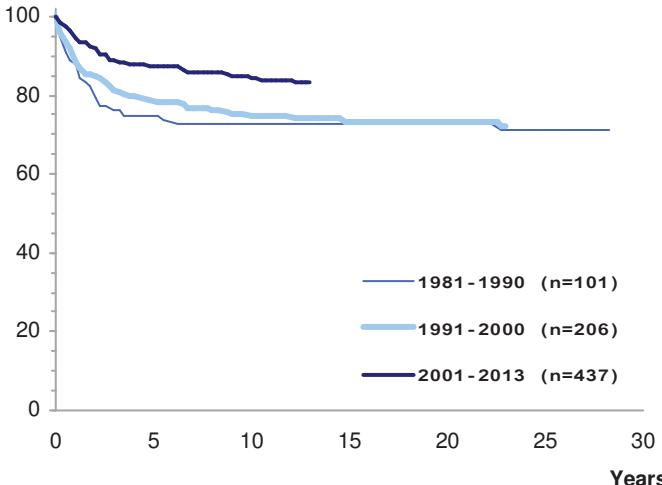
Age- and sex-specific incidence rates per million Germany 2007-2016



Standardized* annual incidence rates per million Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013



No map due to sparse data

68 XI (a) Adrenocortical carcinomas

Cases in Germany aged under 15 years (1980-2016): 75

Selected characteristics Germany 2007-2016

Relative frequency: 20 / 17613 = 0.1 %

Relative frequency of trial patients: 100.0 %

Incidence rates per million: Girls | Boys | Total

Number of cases:	12	8	20
------------------	----	---	----

Standardized rate *:	0.2	0.2	0.2
----------------------	-----	-----	-----

Cumulative incidence:	3	2	3
-----------------------	---	---	---

Sex ratio (m/f):			0.7
------------------	--	--	-----

Age-specific incidence rates per million:

<1	1-4	5-9	10-14
----	-----	-----	-------

Number of cases :	1	10	5	4
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Incidence rate:	0.1	0.4	0.1	0.1
-----------------	-----	-----	-----	-----

Median age at diagnosis: 4 years 1 month

Survival probabilities (2004-2013): 5-year | 10-year | 15-year

72 %	-	-
------	---	---

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		1
9	0.2 %	0.1	

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

XI (a) Adrenocortical carcinomas

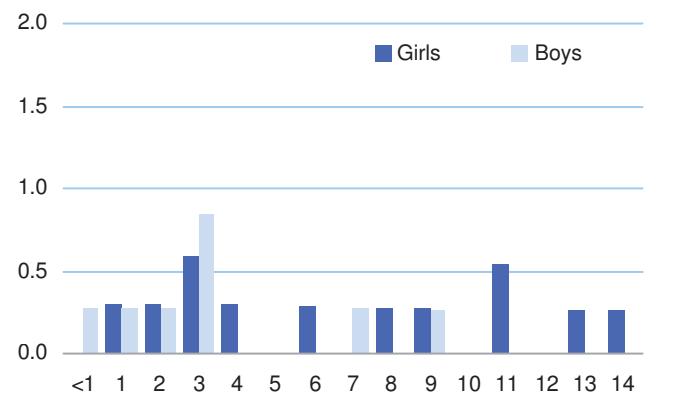
SN after XI (a) % of all Cumulative

N	1245 SN	incidence	N	1245 SN	Cumulative incidence
4	0.3 %	7.9 %	0	0.0 %	%

* Standard: Segi world standard population

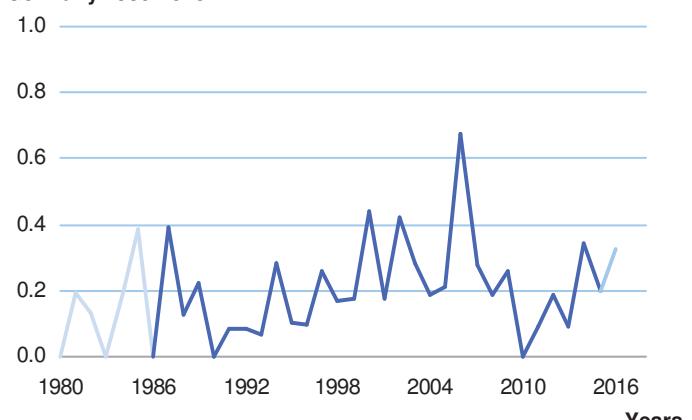
Age- and sex-specific incidence rates per million

Germany 2007-2016

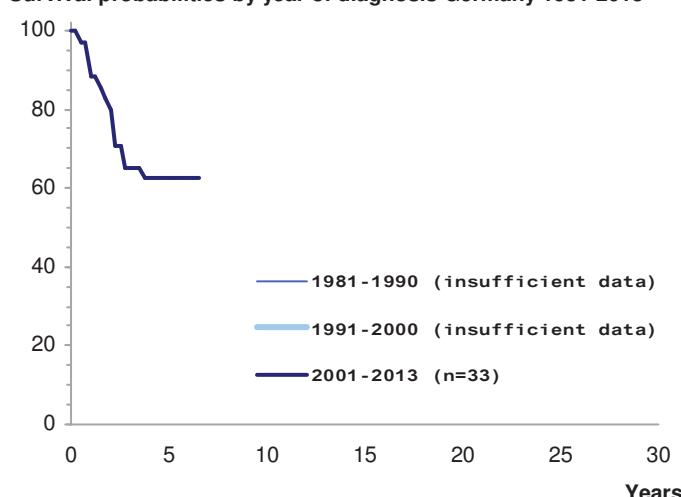


Standardized* annual incidence rates per million

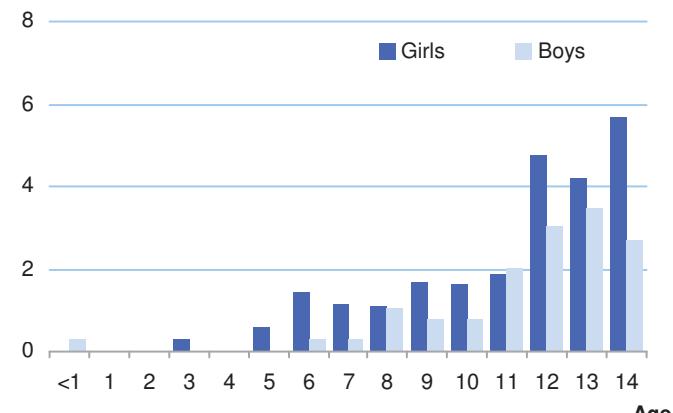
Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013



No map due to sparse data

Cases in Germany aged under 15 years (1980-2016): 359**Selected characteristics Germany 2007-2016****Relative frequency:** 149 / 17613 = 0.8 %**Relative frequency of trial patients:** 85.9 %**Age- and sex-specific incidence rates per million
Germany 2007-2016****Incidence rates per million:****Girls****Boys****Total**

Number of cases: 91 | 58 | 149

Standardized rate *: 1.5 | 0.9 | 1.2

Cumulative incidence: 24 | 15 | 19

Sex ratio (m/f): 0.6

Age-specific incidence rates per million:**<1** | **1-4** | **5-9** | **10-14**

Number of cases : 1 | 1 | 30 | 117

Incidence rate: 0.1 | 0.0 | 0.8 | 3.0

Median age at diagnosis: 12 years 8 months**Survival probabilities
(2004-2013):****5-year** | **10-year** | **15-year**

98 % | 97 % | 94 %

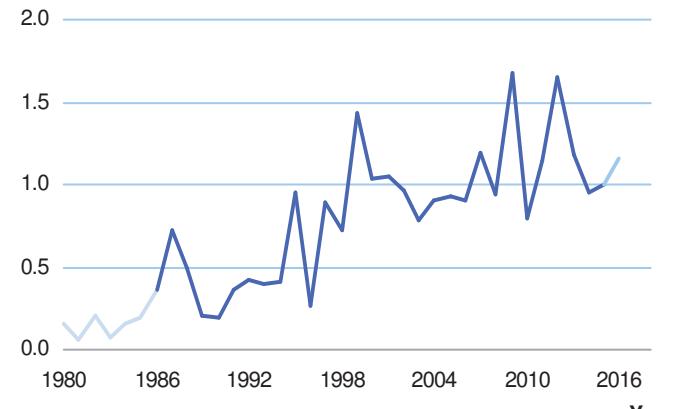
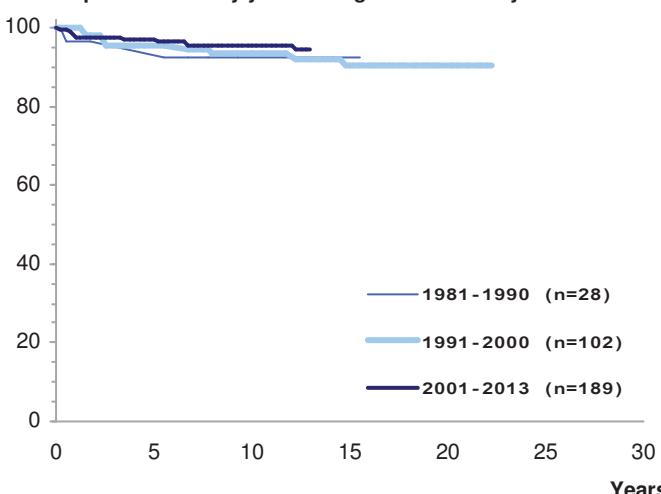
Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths		
10	0.2 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):**XI (b) Thyroid carcinomas****SN after XI (b)**

N	% of all 1245 SN	Cumulative incidence	XI (b) as SN after any primary	N	% of all 1245 SN	Cumulative incidence
2	0.2 %	2.4 %		143	11.5 %	1.1 %

* Standard: Segi world standard population

**Standardized* annual incidence rates per million
Germany 1980-2016****Survival probabilities by year of diagnosis Germany 1981-2013**

No map due to sparse data

70 XI (c) Nasopharyngeal carcinomas

Cases in Germany aged under 15 years (1980-2016): 75

Selected characteristics Germany 2007-2016

Relative frequency: 21 / 17613 = 0.1 %

Relative frequency of trial patients: 95.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	5	16	21
Standardized rate *:	0.1	0.2	0.2
Cumulative incidence:	1	4	3
Sex ratio (m/f):			3.2

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	1	0	20
Incidence rate:	0.0	0.0	0.0	0.5

Median age at diagnosis: 13 years 0 months

Survival probabilities (2004-2013):	5-year	10-year	15-year
	91 %	-	-

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths	
6	0.0	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

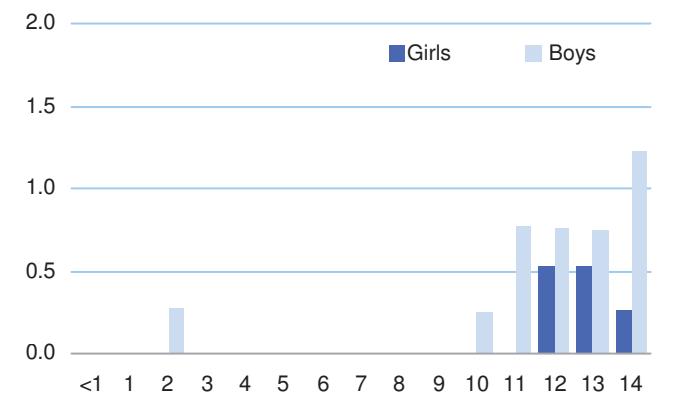
XI (c) Nasopharyngeal carcinomas

SN after XI (c)	XI (c) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
0	0.0 %	-	3	0.2 %	0.0 %

* Standard: Segi world standard population

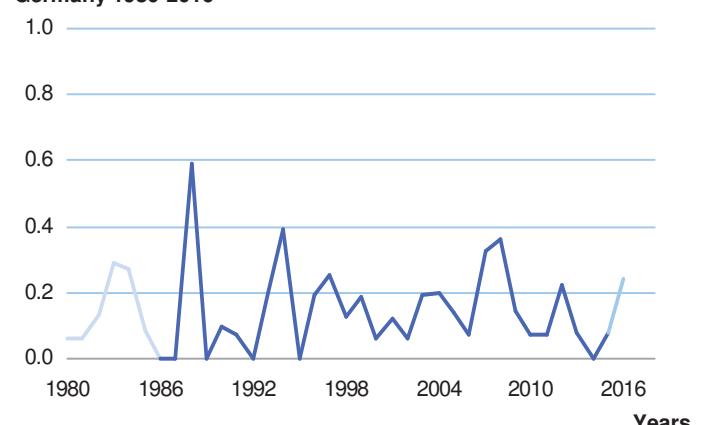
Age- and sex-specific incidence rates per million

Germany 2007-2016

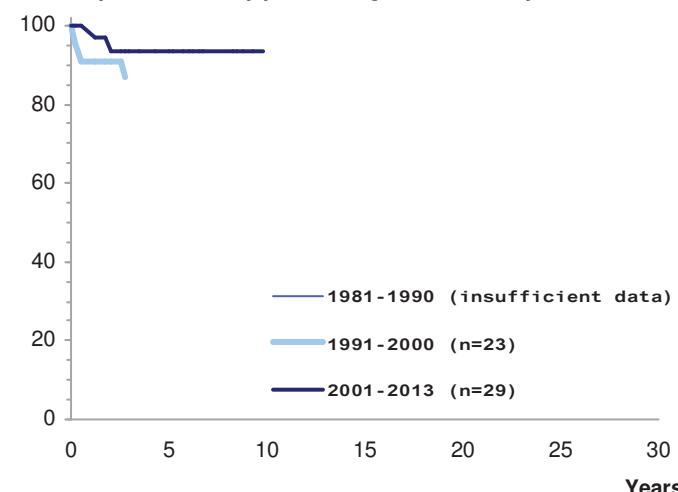


Standardized* annual incidence rates per million

Germany 1980-2016



Survival probabilities by year of diagnosis Germany 1981-2013

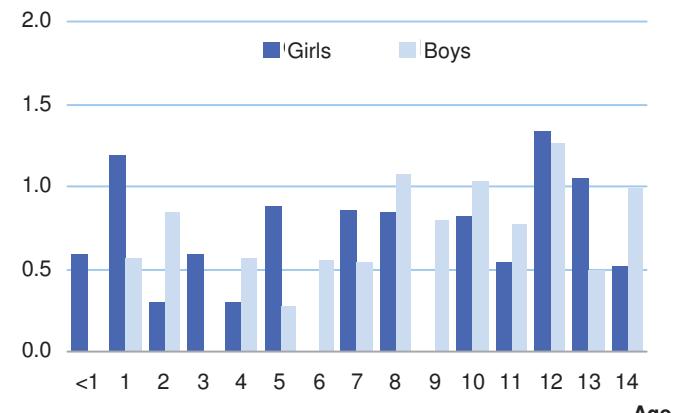
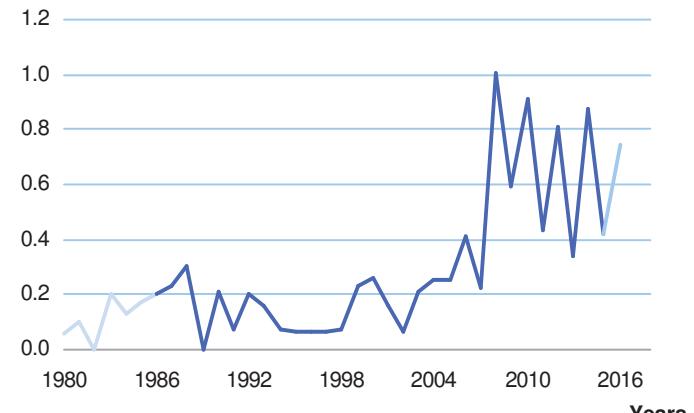
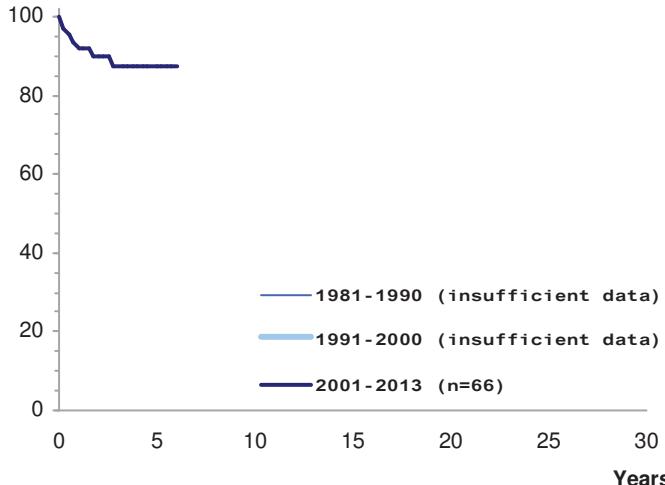


No map due to sparse data

Cases in Germany aged under 15 years (1980-2016): 122**Selected characteristics Germany 2007-2016**

Relative frequency:	72 / 17613 = 0.4 %			
Relative frequency of trial patients:	33.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	35	37	72	
Standardized rate *:	0.6	0.6	0.6	
Cumulative incidence:	10	10	10	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	2	15	21	34
Incidence rate:	0.3	0.5	0.6	0.9
Median age at diagnosis:	9 years 4 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
	87 %	-	-	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths		Standardized* mortality rate	Cumulative mortality	
N	% of all 4232 deaths			
11	0.3 %	0.1	1	
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
XI (d) Malignant melanomas				
SN after XI (d)		XI (d) as SN after any primary		
% of all 1245 SN	Cumulative incidence	N 1245 SN	% of all 1245 SN	
N	-	30	Cumulative incidence	
0	0.0 %	2.4 %	0.3 %	

* Standard: Segi world standard population

**Age- and sex-specific incidence rates per million
Germany 2007-2016****Standardized* annual incidence rates per million
Germany 1980-2016****Survival probabilities by year of diagnosis Germany 1981-2013**

No map due to sparse data

72 XI (e) Skin carcinomas

Cases in Germany aged under 15 years (1980-2016): 20

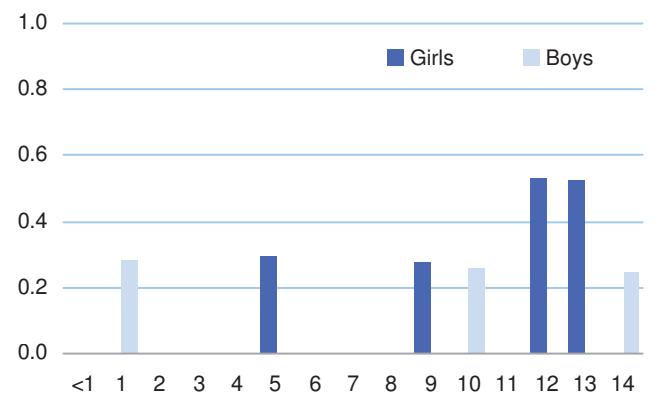
Selected characteristics Germany 2007-2016

Relative frequency:	9 / 17613 = 0.1 %			
Relative frequency of trial patients:	44.4 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	6	3	9	
Standardized rate *:	0.1	0.1	0.1	
Cumulative incidence:	2	1	1	
Sex ratio (m/f):	0.5			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	1	2	6
Incidence rate:	0.0	0.0	0.1	0.2
Median age at diagnosis:	12 years 2 months			
Survival probabilities (2004-2013):	5-year	10-year	15-year	
	-	-	-	
Mortality per million within 15 yrs. of diagnosis (1992-2001):				
Number of deaths				
N	% of all 4232 deaths	Standardized* mortality rate	Cumulative mortality	
2	0.0 %	0.0	0	
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):				
XI (e) Skin carcinomas				
SN after XI (e)				
% of all	Cumulative incidence			
N	1245 SN			
0	0.0 %	-		
XI (e) as SN after any primary				
% of all	Cumulative incidence			
N	1245 SN			
104	8.4 %	1.4 %		

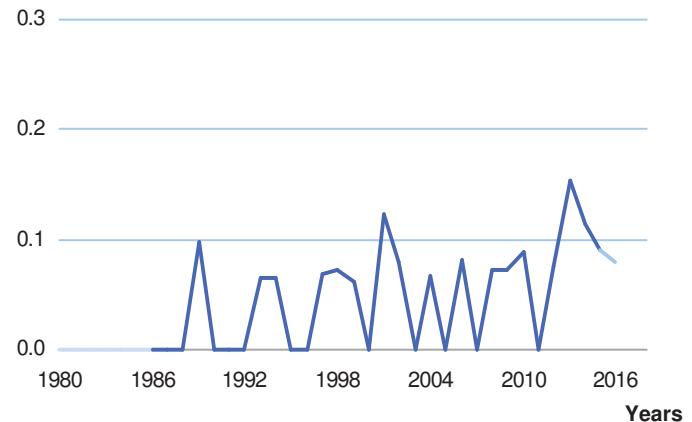
* Standard: Segi world standard population

Age- and sex-specific incidence rates per million

Germany 2007-2016



Standardized* annual incidence rates per million
Germany 1980-2016



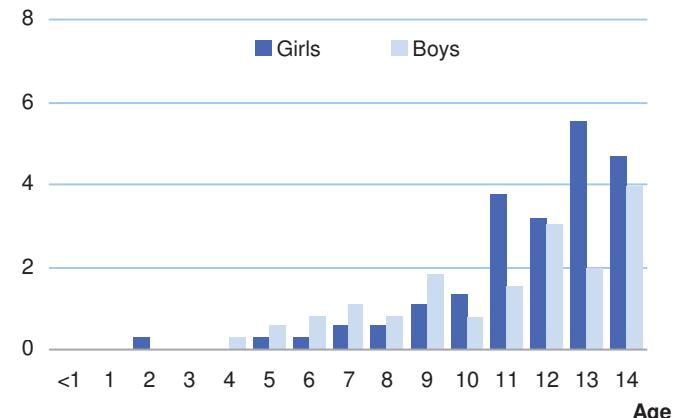
No map due to sparse data

No survival curves due to sparse data

Cases in Germany aged under 15 years (1980-2016): 256**Selected characteristics Germany 2007-2016**

Relative frequency: 146 / 17613 = 0.8 %

Relative frequency of trial patients: 72.6 %

**Age- and sex-specific incidence rates per million
Germany 2007-2016****Incidence rates per million:**

Girls

Boys

Total

Number of cases: 81 65 146

Standardized rate *: 1.3 1.0 1.1

Cumulative incidence: 22 17 19

Sex ratio (m/f): 0.8

Age-specific incidence rates per million:

<1 **1-4** **5-9** **10-14**

Number of cases : 0 2 29 115

Incidence rate: 0.0 0.1 0.8 3.0

Median age at diagnosis: 12 years 7 months

Survival probabilities

(2004-2013): 5-year 78 % | 10-year 74 % | 15-year -

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths		5-year	10-year	15-year
N	% of all 4232 deaths	78 %	74 %	-
16	0.4 %			

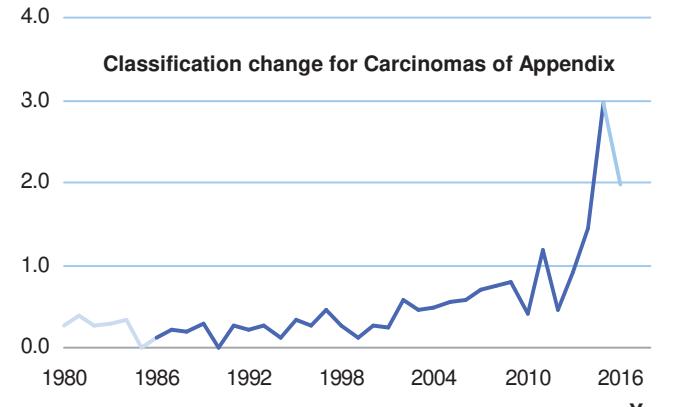
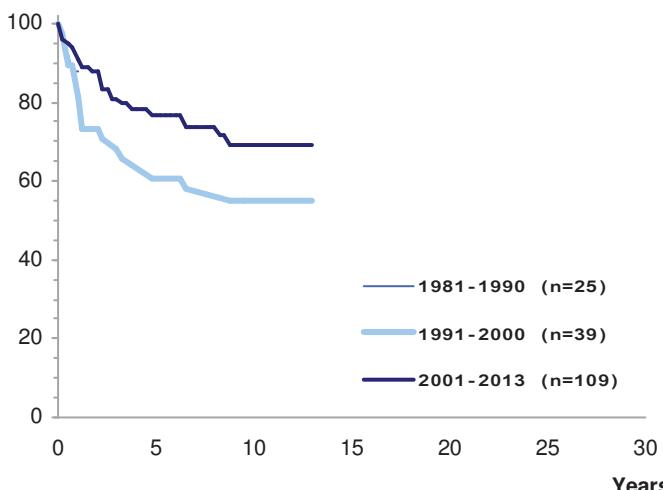
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

XI (f) Other and unspecified carcinomas

SN after XI (f)

% of all 1245 SN		Cumulative incidence	XI (f) as SN after any primary	
N	1245 SN		N	% of all 1245 SN
5	0.4 %	-	132	10.6 %

* Standard: Segi world standard population

**Standardized* annual incidence rates per million
Germany 1980-2016****Survival probabilities by year of diagnosis Germany 1981-2013**

No map due to sparse data



74 XI (f) Other and unspecified carcinomas - Extended ICCC-3

Germany 2007-2016	N	%		N	%
Other and unspecified carcinomas	146	100.0			
1 Carcinomas of salivary glands	22	15.1	7 Carcinomas of cervix uteri	1	0.7
2 Carcinomas of colon and rectum	11	7.5	8 Carcinomas of bladder	0	0.0
3 Carcinomas of appendix	73	50.0	9 Carcinomas of eye	2	1.4
4 Carcinomas of lung	7	4.8	10 Carcinomas of other specified sites	25	17.1
5 Carcinomas of thymus	0	0.0	11 Carcinomas of unspecified site	5	3.4
6 Carcinomas of breast	0	0.0			

1 Carcinomas of salivary glands

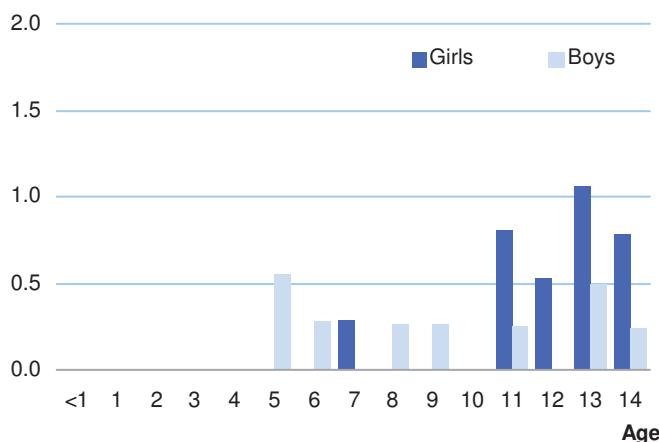
Cases in Germany aged under 15 years (1980-2016): 38

Selected characteristics Germany 2007-2016

Relative frequency:	22 / 17613 = 0.1 %				
Relative frequency of trial patients:	22.7 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	13	9	22		
Standardized rate *:	0.2	0.1	0.2		
Cumulative incidence:	3	2	3		
Sex ratio (m/f):	0.7				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	0	0	6	16	
Incidence rate:	0.0	0.0	0.2	0.4	
Median age at diagnosis:	12 years 7 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
1 Carcinomas of salivary glands					
SN after XI (f) 1	XI (f) 1 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
1	0.1 %	-	11	0.9 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



2 Carcinomas of colon and rectum

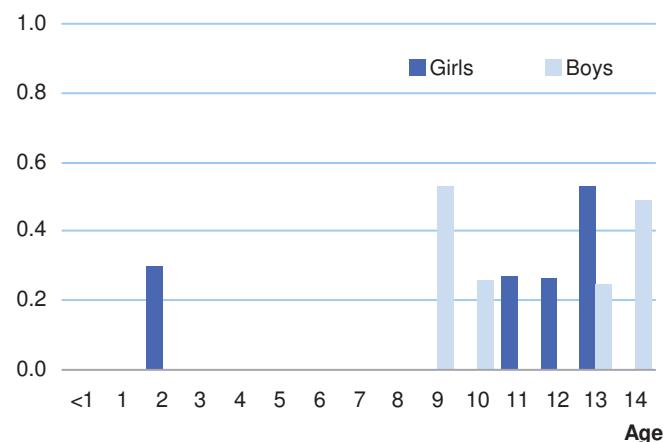
Cases in Germany aged under 15 years (1980-2016): 33

Selected characteristics Germany 2007-2016

Relative frequency:	11 / 17613 = 0.1 %				
Relative frequency of trial patients:	45.5 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	5	6	11		
Standardized rate *:	0.1	0.1	0.1		
Cumulative incidence:	1	2	1		
Sex ratio (m/f):	1.2				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	0	1	2	8	
Incidence rate:	0.0	0.0	0.1	0.2	
Median age at diagnosis:	12 years 5 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
2 Carcinomas of colon and rectum					
SN after XI (f) 2	XI (f) 2 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
1	0.1 %	-	22	1.8 %	0.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



Germany 2007-2016	N	%		N	%
Other and unspecified carcinomas	146	100.0			
1 Carcinomas of salivary glands	22	15.1	7 Carcinomas of cervix uteri	1	0.7
2 Carcinomas of colon and rectum	11	7.5	8 Carcinomas of bladder	0	0.0
3 Carcinomas of appendix	73	50.0	9 Carcinomas of eye	2	1.4
4 Carcinomas of lung	7	4.8	10 Carcinomas of other specified sites	25	17.1
5 Carcinomas of thymus	0	0.0	11 Carcinomas of unspecified site	5	3.4
6 Carcinomas of breast	0	0.0			

3 Carcinomas of appendix

Cases in Germany aged under 15 years (1980-2016): 74

Selected characteristics Germany 2007-2016

Relative frequency:	73 / 17613 = 0.4 %				
Relative frequency of trial patients:	97.3 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	46	27	73		
Standardized rate *:	0.7	0.4	0.6		
Cumulative incidence:	12	7	9		
Sex ratio (m/f):	0.6				
Age-specific incidence rates per million:	<1	1-4	5-9	10-14	
Number of cases:	0	0	10	63	
Incidence rate:	0.0	0.0	0.3	1.6	
Median age at diagnosis:	12 years 11 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
3 Carcinomas of appendix					
SN after XI (f) 3	XI (f) 3 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
0	0.0 %	-	1	0.1 %	0.0 %

* Standard: Segi world standard population

6 Carcinomas of breast

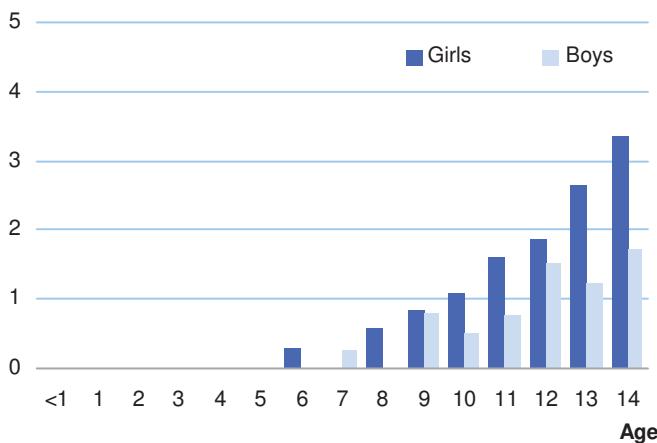
Cases in Germany aged under 15 years (1980-2016): 0

Selected characteristics Germany 2007-2016

Relative frequency:	0 / 17613 = 0.0 %				
Relative frequency of trial patients:	-				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	0	0	0		
Standardized rate *:	0.0	0.0	0.0		
Cumulative incidence:	0	0	0		
Sex ratio (m/f):					
Age-specific incidence rates per million:	<1	1-4	5-9	10-14	
Number of cases:	0	0	0	0	
Incidence rate:	0.0	0.0	0.0	0.0	
Median age at diagnosis:	years months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):					
6 Carcinomas of breast					
SN after XI (f) 6	XI (f) 6 as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
0	0.0 %	-	58	4.7 %	0.8 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2007-2016



No incidence rates due to sparse data

76 XII (a) Other specified malignant tumours

Cases in Germany aged under 15 years (1980-2016): 54

Selected characteristics Germany 2007-2016

Relative frequency: $25 / 17613 = 0.1\%$

Relative frequency of trial patients: 84.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	13	12	25
Standardized rate *:	0.3	0.3	0.3
Cumulative incidence:	4	3	4
Sex ratio (m/f):			0.9

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	1	18	3	3
Incidence rate:	0.1	0.7	0.1	0.1

Median age at diagnosis: 3 years 2 months

Survival probabilities (2004-2013):

	5-year	10-year	15-year
N	-	-	-

Mortality per million within 15 yrs. of diagnosis (1992-2001):

Number of deaths	Standardized* mortality rate	Cumulative mortality
N	% of all 4232 deaths	
7	0.2 %	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013):

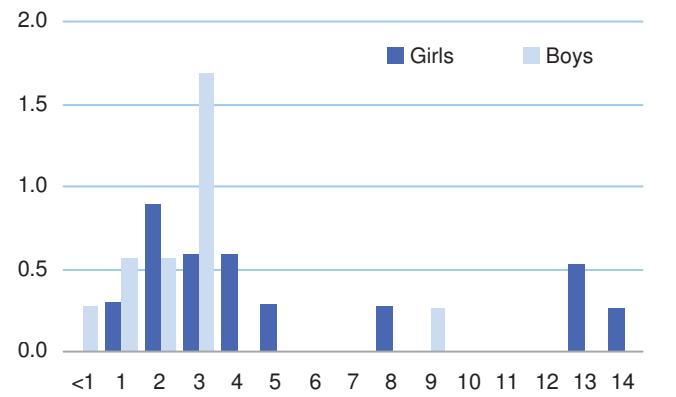
XII (a) Other specified malignant tumours

SN after XII (a)	XII (a) as SN after any primary				
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
2	0.2 %	-	1	0.1 %	0.0 %

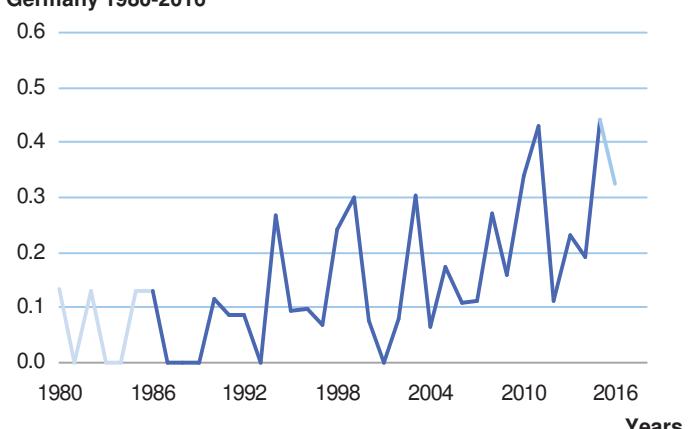
* Standard: Segi world standard population

Age- and sex-specific incidence rates per million

Germany 2007-2016



Standardized* annual incidence rates per million



No map due to sparse data

No survival curves due to sparse data

Tabelle 1 / Table 1

79

Anzahl der gemeldeten Fälle und Inzidenzraten unter 15 Jahren nach Diagnose, Alter und Geschlecht /
Number of cases and incidence rates under 15 years by diagnosis, age, and sex

Abbildung 1 / Figure 1

92

Meldungen an das DKKR (Registerpopulation) je Klinik, Patienten unter 15 / 18 Jahren /
Reported cases to the GCCR (registry population) per hospital, patients under 15 / 18 years

Tabelle 2 / Table 2

92

Anzahl der Fälle unter 15 Jahren, altersstandardisierte Inzidenzenrate und kumulative Inzidenz (pro Million) nach ICCC-3-Diagnosegruppen /
Number of cases aged under 15, age-standardized incidence rate and cumulative incidence (per million) by ICCC-3 diagnosis groups

Abbildung 2 / Figure 2

93

Relative Häufigkeit der Fälle nach den häufigsten ICCC-3-Diagnose-Hauptgruppen und Alter /
Relative frequencies of cases by the main ICCC-3 diagnosis groups and age

Tabelle 3 / Table 3

94

Anzahl der Fälle unter 15 Jahren, 15 bis unter 18 Jahren und unter 18 Jahren, altersstandardisierte Inzidenzrate und Wohnbevölkerungsbezug nach Jahren /
Number of cases aged under 15, 15 to under 18 years and under 18 years, age-standardized incidence rate and population base by year

Tabelle 4 / Table 4

95

Verteilung aller Fälle ohne Altersbeschränkung sowie zusätzlich erfassste Diagnosen /
Distribution of all cases without age restriction and additional diagnoses

78 Tabellen und Abbildungen / Tables and Figures

Tabelle 5 / Table 5

95

Nicht in der ICCC-3 definierte, systematisch registrierte Diagnosen, Fälle unter 15 Jahren /
Systematically registered diagnoses not defined in ICCC-3, cases under the age of 15

Tabelle 6 / Table 6

96

Altersstandardisierte Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR)
regional gegliedert für Fälle unter 15 Jahre /
Age-standardized incidence rates (per million), standardized incidence ratios (SIR) for cases
under 15 by region

Tabelle 7 / Table 7

97

Anzahl der verstorbenen Patienten innerhalb von 5, 10 bzw. 15 Jahren nach Diagnose unter 15
Jahren und kumulative Mortalität nach Diagnosejahr /
Annual number of deaths 5, 10 or 15 years from diagnosis of patients aged under 15 and
cumulative mortality by year of diagnosis

Tabelle 8 / Table 8

98

Anzahl der in der Langzeitnachbeobachtung (LTS) befindlichen Patienten /
Number of patients in Long-Term-Surveillance (LTS)

Tabelle 9 / Table 9

99

Anzahl der gemeldeten Fälle und Inzidenzraten unter 18 nach Diagnose, Alter und Geschlecht /
Number of cases and incidence rates under 18 years by diagnosis, age and sex

Tabelle 10 / Table 10

112

Zahl der vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister
weitergeleiteten Meldungen /
Number of forwarded reports from the German Childhood Cancer Registry to the state cancer
registries

Tabelle 1:
Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Kinder unter 15 Jahren aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2007-2016). *ICCC-3 extended Subklassifikation kursiv dargestellt.*
Number of cases and incidence rates per million children under the age of 15 years in Germany by diagnosis classified according to ICCC-3, age and sex (2007-2016).
ICCC-3 extended subclassification in italics.

Diagnoses	Sex ratio		N		Relative Group		Number of cases		Age groups		Incidence rates per million		Trial participants		Survival probabilities(%)			
	m / f	0 - 14	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World *	0 - 14	%	5- yrs	10- yrs	15- yrs	
All malignancies																		
girls	7915	100	100	854	2770	1939	2352	254	206	111	125	2258	95.1	85	84	82		
boys	9698	100	100	987	3255	2636	2820	279	229	143	142	2624	95.5	85	82	81		
total	1.2	17613	100	1841	6025	4575	5172	267	218	127	134	169	2446	95.3	85	83	82	
Leukaemias, myeloproliferative and myelodysplastic diseases																		
girls	2567	32	100	133	1220	693	521	40	91	40	28	52	740	99.2	89	87	87	
boys	3146	32	100	154	1388	913	691	44	98	50	35	60	858	99.1	89	87	86	
total	1.2	5713	32	100	287	2608	1606	1212	42	94	45	31	56	800	99.1	89	87	86
Lymphoid leukaemias																		
girls	1963	25	76	61	1022	561	319	18	76	32	17	40	568	99.5	93	91	90	
boys	2435	25	77	52	1175	728	480	15	83	39	24	47	666	99.8	92	90	90	
total	1.2	4398	25	77	113	2197	1289	799	16	79	36	21	43	618	99.7	92	91	90
Precursor cell leukaemias																		
girls	1939	24	76	60	1017	549	313	18	76	31	17	40	561	99.6	93	91	90	
boys	2355	24	75	52	1158	687	458	15	82	37	23	45	644	99.7	92	90	90	
total	1.2	4294	24	75	112	2175	1236	771	16	79	34	20	42	604	99.7	93	91	90
Mature B-cell leukaemias																		
girls	23	0	1	1	4	12	6	0	0	1	0	0	7	95.7	-	-	-	
boys	79	1	3	0	17	40	22	0	1	2	1	1	21	100.0	87	87	85	
total	3.4	102	1	2	1	21	52	28	0	1	1	1	14	99.0	88	88	87	
Mature T-cell and NK cell leukaemias																		
girls	1	0	0	0	1	0	0	0	0	0	0	0	0	0	100.0	-	-	
boys	1	0	0	0	0	1	0	0	0	0	0	0	0	0	100.0	-	-	
total	1.0	2	0	0	0	1	1	0	0	0	0	0	0	0	100.0	-	-	
Lymphoid leukaemia, NOS																		
girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	
boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	
total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	
Acute myeloid leukaemias																		
girls	345	4	13	53	133	51	108	16	10	3	6	7	98	98.6	73	72	72	
boys	377	4	12	61	138	86	92	17	10	5	5	7	103	96.0	72	71	70	
total	1.1	722	4	13	114	271	137	200	17	10	4	5	7	101	97.2	73	72	71
Chronic myeloproliferative diseases																		
girls	34	0	1	0	4	11	19	0	0	1	1	1	9	88.2	92	92	-	
boys	43	0	1	1	5	15	22	0	0	1	1	1	11	86.0	100	-	-	
total	1.3	77	0	1	1	9	26	41	0	1	1	1	10	87.0	96	96	96	
Myelodysplastic syndrome and other myeloproliferative diseases																		
girls	194	2	8	13	54	61	66	4	4	3	4	4	55	98.5	81	78	73	
boys	257	3	8	32	64	75	86	9	5	4	4	5	69	99.6	82	80	79	
total	1.3	451	3	8	45	118	136	152	7	4	4	4	62	99.1	82	79	76	

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	m / f	0 - 14	%	0	1 - 4	5 - 9	10 - 14	Number of cases			Incidence rates per million			Trial participants	% 5- yrs 10- yrs 15- yrs	Survival probabilities(%)		
									N	Relative Group	Age groups	Age-specific	Age-stand.	Cum.	World *				
Unspecified and other specified leukaemias	girls	31	0	1	6	7	9	9	2	1	1	0	1	1	9	100.0	-	-	
	boys	34	0	1	8	6	9	11	2	0	0	0	1	1	9	97.1	68	-	
	total	1.1	65	0	1	14	13	18	20	2	0	1	1	1	9	98.5	70	-	
Lymphomas and reticuloendothelial neoplasms	girls	608	8	100	3	65	136	404	1	5	8	21	10	166	97.5	92	91	91	
	boys	1281	13	100	8	167	465	641	2	12	25	32	21	337	97.2	94	93	92	
	total	2.1	1889	11	100	11	232	601	1045	2	8	17	27	16	253	97.3	94	93	92
Hodgkin lymphomas	girls	327	4	54	0	7	40	280	0	1	2	15	5	87	99.1	98	97	97	
	boys	493	5	38	0	27	146	320	0	2	8	16	8	127	96.6	99	98	98	
	total	1.5	820	5	43	0	34	186	600	0	1	5	16	7	108	97.6	99	98	97
Non-Hodgkin lymphomas	girls	221	3	36	0	47	71	103	0	3	4	5	4	62	96.4	84	83	82	
	boys	517	5	40	6	79	193	239	2	6	10	12	9	136	97.1	91	89	87	
	total	2.3	738	4	39	6	126	264	342	1	5	7	9	6	100	96.9	89	87	86
Precursor cell lymphomas	girls	80	1	13	0	22	31	27	0	2	2	1	1	1	23	93.8	82	82	79
	boys	181	2	14	4	39	69	69	1	3	4	3	3	3	48	95.0	89	87	86
	total	2.3	261	1	14	4	61	100	96	1	2	3	2	2	36	94.6	87	86	84
Mature B-cell lymphomas (except Burkitt lymphoma)	girls	49	1	8	0	5	21	23	0	0	1	1	1	1	14	98.0	84	83	81
	boys	93	1	7	0	6	27	60	0	0	0	1	3	1	24	96.8	96	94	94
	total	1.9	142	1	8	0	11	48	83	0	0	1	2	1	19	97.2	93	90	90
Mature T-cell and NK-cell lymphomas	girls	47	1	8	0	11	8	28	0	1	0	1	1	1	13	95.7	84	84	84
	boys	96	1	7	1	13	30	52	0	1	2	3	2	2	25	100.0	89	88	84
	total	2.0	143	1	8	1	24	38	80	0	1	2	1	1	19	98.6	87	87	84
Non-Hodgkin lymphomas, NOS	girls	45	1	7	0	9	11	25	0	1	1	1	1	1	12	100.0	83	-	-
	boys	147	2	11	1	21	67	58	0	1	4	3	2	3	39	98.0	91	89	87
	total	3.3	192	1	10	1	30	78	83	0	1	2	2	2	26	98.4	89	88	86
Burkitt lymphoma	girls	51	1	8	0	9	24	18	0	1	1	1	1	1	14	98.0	93	92	92
	boys	261	3	20	0	61	122	78	0	4	7	4	5	70	99.2	93	92	92	
	total	5.1	312	2	17	0	70	146	96	0	3	4	2	3	43	99.0	93	92	92
Miscellaneous lymphoreticular neoplasms	girls	5	0	1	3	0	1	1	1	0	0	0	0	1	80.0	-	-	-	-
	boys	4	0	0	2	0	1	1	1	0	0	0	0	1	50.0	-	-	-	-
	total	0.8	9	0	0	5	0	2	1	0	0	0	0	1	66.7	-	-	-	-
Unspecified lymphomas	girls	4	0	1	0	2	0	2	0	0	0	0	0	1	50.0	-	-	-	-
	boys	6	0	0	0	0	0	3	0	0	0	0	0	2	100.0	-	-	-	-
	total	1.5	10	0	1	0	2	3	5	0	0	0	0	1	80.0	-	-	-	-

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	N	Number of cases				Incidence rates per million				Trial participants	% 5-yr 10-yr 15-yr Survival probabilities(%)									
				m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World*						
CNS and miscellaneous intracranial and intraspinal neoplasms				girls	2017	25	100	152	597	627	641	45	44	36	34	39	573	95.0	79	76	74	
	boys	2392	25	100	151	703	793	745	43	50	43	38	43	644	95.5	76	72	69				
total	1.2	4409	25	100	303	1300	1420	1386	44	47	40	36	41	610	95.3	77	74	71				
Ependymomas and choroid plexus tumour				girls	192	2	10	39	79	39	35	12	6	2	4	56	96.9	86	83	79		
	boys	253	3	11	38	101	52	62	11	7	3	3	5	69	95.7	78	70	64				
total	1.3	445	3	10	77	180	91	97	11	7	3	3	4	63	96.2	81	75	70				
Ependymomas				girls	141	2	7	13	70	29	29	4	5	2	2	3	41	97.2	85	81	76	
	boys	198	2	8	17	82	43	56	5	6	2	3	4	54	96.5	76	67	60				
total	1.4	339	2	8	30	152	72	85	4	5	2	2	3	47	96.8	79	72	67				
Choroid plexus tumour				girls	51	1	3	26	9	10	6	8	1	1	0	1	15	96.1	92	-	-	
	boys	55	1	2	21	19	9	6	6	1	0	0	1	15	92.7	88	82	-				
total	1.1	106	1	2	47	28	19	12	7	1	0	1	15	94.3	90	87	85					
Astrocytomas				girls	986	12	49	57	290	299	340	17	22	17	18	19	279	95.8	82	80	78	
	boys	1037	11	43	49	300	361	327	14	21	20	16	19	279	95.9	80	78	76				
total	1.1	2023	11	46	106	590	660	667	15	21	18	17	19	279	95.8	81	79	77				
Intracranial and intraspinal embryonal tumours				girls	298	4	15	35	118	95	50	10	9	5	3	6	86	96.0	65	61	58	
	boys	467	5	20	42	176	175	74	12	12	9	4	9	128	97.6	66	56	54				
total	1.6	765	4	17	77	294	270	124	11	11	8	3	8	107	97.0	66	58	56				
Medulloblastomas				girls	198	3	10	7	66	81	44	2	5	5	2	4	57	98.5	76	70	67	
	boys	346	4	14	9	114	154	69	3	8	8	3	6	94	99.1	74	63	60				
total	1.7	544	3	12	16	180	235	113	2	7	7	3	5	76	98.9	75	66	63				
Primitive neuroectodermal tumour (PNET)				girls	29	0	1	2	19	4	4	1	1	0	1	8	96.6	66	-	-	-	
	boys	34	0	1	3	17	9	5	1	1	0	0	0	1	9	100.0	54	49	-	-		
total	1.2	63	0	1	5	36	13	9	1	1	0	0	0	2	2	87.5	-	-	-	-		
Medulloepithelioma				girls	8	0	0	1	3	2	2	0	0	0	0	2	2	87.5	-	-	-	-
	boys	6	0	0	2	1	3	0	1	0	0	0	0	2	2	100.0	-	-	-	-		
total	0.8	14	0	0	3	4	5	2	0	0	0	0	0	2	2	92.9	-	-	-	-		
Atypical teratoid/rhabdoid tumour				girls	63	1	3	25	30	8	0	7	2	0	0	1	19	88.9	-	-	-	-
	boys	81	1	3	28	44	9	0	8	3	0	0	0	2	23	90.1	30	-	-	-		
total	1.3	144	1	3	53	74	17	0	8	3	0	0	0	2	21	89.6	26	-	-	-		
Other gliomas				girls	221	3	11	6	47	98	70	2	3	6	4	4	63	93.2	43	41	41	
	boys	229	2	10	6	50	88	85	2	4	5	4	4	61	95.6	48	46	44				
total	1.0	450	3	10	12	97	186	155	2	4	5	4	4	62	94.4	46	44	43				

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex ratio m / f	0 - 14 %	N	Relative Group	Number of cases Age groups					Incidence rates per million Age-specific					Trial participants % 0 - 14	Survival probabilities(%) 5- yrs 10- yrs 15- yrs				
					0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World*	Age-stand. Cum.						
Oligodendrogliomas					girls	4	0	0	0	1	3	0	0	0	0	1	75.0			
					boys	4	0	0	0	0	4	0	0	0	0	1	100.0			
total	1.0	8			total	1.0	8	0	0	1	7	0	0	0	1	87.5	-			
Mixed and unspecified gliomas					girls	206	3	10	5	44	94	63	1	3	5	3	58	93.2		
					boys	216	2	9	6	48	88	74	2	3	5	4	58	95.4		
total	1.0	422			total	1.0	422	2	10	11	92	182	137	2	3	5	58	94.3		
Neuroepithelial glial tumours of uncertain origin					girls	11	0	1	1	3	3	4	0	0	0	0	3	100.0		
					boys	9	0	0	0	2	0	7	0	0	0	0	2	100.0		
total	0.8	20			total	1.3	660	4	15	24	127	202	307	3	5	6	6	90	93.3	
Other specified intracranial and intraspinal neoplasms					girls	290	4	14	12	54	94	130	4	4	5	7	5	81	93.8	
					boys	370	4	15	12	73	108	177	3	5	6	9	6	98	93.0	
total	1.4	29			total	0.9	195	1	0	0	4	25	0	0	1	0	4	65.5		
Pituitary adenomas and carcinomas					girls	101	1	5	0	22	41	38	0	2	2	2	2	28	100.0	
					boys	94	1	4	2	24	35	33	1	2	2	2	2	25	98.9	
total	0.9	195			total	0.9	32	0	1	4	2	46	76	71	0	2	2	27	99.5	
Tumours of the sellar region (craniopharyngiomas)					girls	101	0	1	2	3	5	7	1	0	0	0	5	100.0		
					boys	94	1	4	2	24	35	33	1	2	2	2	2	25	98.9	
total	0.9	195			total	0.9	32	0	1	4	2	46	76	71	0	2	2	27	99.5	
Pineal parenchymal tumours					girls	17	0	1	2	3	5	7	1	0	0	0	5	100.0		
					boys	15	0	1	2	7	2	4	1	0	0	0	4	100.0		
total	1.6	360			total	1.3	44	0	1	4	10	66	101	175	3	2	3	3	39	92.9
Neuronal and mixed neuronal/gliat tumours					girls	141	2	7	10	27	39	65	3	2	2	3	3	39	92.9	
					boys	219	2	9	8	39	62	110	2	3	3	6	4	58	95.9	
total	1.6	360			total	1.3	44	0	1	4	10	66	101	175	3	2	3	3	49	94.7
Meningiomas					girls	19	0	1	0	2	7	10	0	0	0	1	0	5	73.7	
					boys	25	0	1	0	3	7	15	0	0	0	1	0	6	64.0	
total	1.2	66			total	1.2	66	0	1	7	12	11	36	1	0	1	1	9	78.8	
Unspecified intracranial and intraspinal neoplasms					girls	30	0	1	3	9	2	16	1	1	0	1	1	8	73.3	
					boys	36	0	2	4	3	9	20	1	0	0	1	1	10	83.3	
total	1.4	1189			total	1.4	1189	7	100	540	535	83	31	78	19	2	1	13	172	98.8
Neuroblastoma and other peripheral nervous cell tumours					girls	504	6	100	231	226	31	69	17	2	1	12	149	98.2		
					boys	685	7	100	309	309	52	87	22	3	1	15	193	99.3		
total	1.4	1189			total	1.4	1189	7	100	540	535	83	31	78	19	2	1	13	172	98.8

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	N	Number of cases					Incidence rates per million					Trial participants	% 5-yr 10-yr 15-yr		
				m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	Age-specific	Age-stand.	Cum.			
Neuroblastoma and ganglioneuroblastoma	girls	498	6	99	231	222	31	14	69	16	2	1	11	147	99.0	80 78 77	
	boys	680	7	99	309	308	51	12	87	22	3	1	15	191	99.4	80 77 76	
	total	1.4	1178	7	99	540	530	82	26	78	19	2	1	13	170	99.2	80 77 76
Other peripheral nervous cell tumours	girls	6	0	1	0	4	0	2	0	0	0	0	0	0	2	33.3	- - -
	boys	5	0	1	0	1	1	3	0	0	0	0	0	0	1	80.0	- - -
	total	0.8	11	0	1	0	5	1	5	0	0	0	0	0	2	54.5	- - -
Retinoblastoma	girls	189	2	100	92	93	4	0	27	7	0	0	4	56	37.6	98 98 98	
	boys	210	2	100	89	112	6	3	25	8	0	0	5	59	33.8	98 97 97	
	total	1.1	399	2	100	181	205	10	3	26	7	0	0	5	58	35.6	98 97 97
Renal tumours	girls	517	7	100	68	296	125	28	20	22	7	1	11	152	99.6	94 93 93	
	boys	449	5	100	88	249	85	27	25	18	5	1	9	125	99.3	93 92 92	
	total	0.9	966	5	100	156	545	210	55	23	20	6	1	10	138	99.5	93 93 93
Nephroblastoma and other non-epithelial renal tumours	girls	507	6	98	68	295	123	21	20	22	7	1	11	149	99.8	94 93 93	
	boys	435	4	97	87	249	83	16	25	18	5	1	9	122	99.3	93 92 92	
	total	0.9	942	5	98	155	544	206	37	22	20	6	1	10	135	99.6	93 93 93
Nephroblastoma	girls	495	6	96	60	294	120	21	18	22	7	1	11	146	99.8	95 94 94	
	boys	424	4	94	84	244	82	14	24	17	4	1	9	119	99.3	94 93 93	
	total	0.9	919	5	95	144	538	202	35	21	19	6	1	10	132	99.6	94 94 94
Rhabdoid renal tumour	girls	8	0	2	7	1	0	0	2	0	0	0	0	0	2	100.0	- - -
	boys	9	0	2	2	5	1	1	0	0	0	0	0	0	2	100.0	- - -
	total	1.1	17	0	2	9	6	1	1	0	0	0	0	0	2	100.0	- - -
Kidney sarcomas	girls	4	0	1	1	0	3	0	0	0	0	0	0	0	1	100.0	- - -
	boys	2	0	0	1	0	0	1	0	0	0	0	0	0	1	100.0	- - -
	total	0.5	6	0	1	2	0	3	1	0	0	0	0	0	1	100.0	- - -
Peripheral neuroectodermal tumour (pPNET) of kidney	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	- - -	
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	- - -	
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	- - -	
Renal carcinomas	girls	10	0	2	0	1	2	0	7	0	0	0	0	0	3	90.0	- - -
	boys	14	0	3	1	0	2	11	0	0	0	1	0	4	100.0	- - -	
	total	1.4	24	0	2	1	4	18	0	0	0	0	0	3	95.8	- - -	
Unspecified malignant renal tumours	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	-	- - -	
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	-	- - -	
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	-	- - -	

* Standard: Segi world standard population

- insufficient data

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Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	m / f	0 - 14	%	0	1 - 4	5 - 9	10 - 14	Incidence rates per million			Trial participants	% 5- yrs 10- yrs 15- yrs					
									Age-specific	Age-stand.	Cum.							
Hepatic tumours	girls	109	1	100	32	59	6	12	10	4	0	1	32	75.2	75	75		
	boys	144	1	100	44	73	12	15	12	5	1	1	3	40	77.8	74	72	
total	1.3	253	1	100	76	132	18	27	11	5	1	1	3	36	76.7	74	73	
Hepatoblastoma	girls	96	1	88	32	59	4	1	10	4	0	0	2	29	76.0	79	79	
	boys	132	1	92	44	72	9	7	12	5	0	0	3	37	78.0	81	79	
total	1.4	228	1	90	76	131	13	8	11	5	0	0	3	33	77.2	80	79	
Hepatic carcinomas	girls	13	0	12	0	0	2	11	0	0	0	0	1	0	3	69.2	-	-
	boys	12	0	8	0	1	3	8	0	0	0	0	0	0	3	75.0	-	-
total	0.9	25	0	10	0	1	5	19	0	0	0	0	0	3	72.0	-	-	
Unspecified malignant hepatic tumours	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
Malignant bone tumours	girls	370	5	100	1	19	95	255	0	1	5	14	6	101	97.0	-	-	-
	boys	407	4	100	3	30	100	274	1	2	5	14	6	105	98.0	-	-	-
total	1.1	777	4	100	4	49	195	529	1	2	5	14	6	103	97.6	-	-	-
Osteosarcomas	girls	193	2	52	0	2	42	149	0	0	2	8	3	52	99.0	79	75	73
	boys	195	2	48	0	5	40	150	0	0	2	8	3	50	98.5	72	67	67
total	1.0	388	2	50	0	7	82	299	0	0	2	8	3	51	98.7	75	71	70
Chondrosarcomas	girls	4	0	1	0	0	2	2	0	0	0	0	0	1	75.0	-	-	-
	boys	8	0	2	1	0	1	6	0	0	0	0	0	2	100.0	-	-	-
total	2.0	12	0	2	1	0	3	8	0	0	0	0	0	2	91.7	-	-	-
Ewing tumour and related sarcomas of bone	girls	1633	2	44	1	16	48	98	0	1	3	5	3	45	96.3	-	-	-
	boys	194	2	48	2	23	57	112	1	2	3	6	3	51	99.5	-	-	-
total	1.2	357	2	46	3	39	105	210	0	1	3	5	3	48	98.0	-	-	-
Ewing tumour and askin tumour of bone	girls	154	2	42	0	15	44	95	0	1	3	5	3	42	96.8	-	-	-
	boys	187	2	46	1	19	56	111	0	1	0	0	0	49	99.5	-	-	-
total	1.2	341	2	44	1	34	100	206	0	1	3	5	3	46	98.2	-	-	-
Peripheral neuroectodermal tumour (pPNET) of bone	girls	9	0	2	1	1	4	3	0	0	0	0	0	3	88.9	-	-	-
	boys	7	0	2	1	4	1	1	0	0	0	0	0	2	100.0	-	-	-
total	0.8	16	0	2	2	5	5	4	0	0	0	0	0	2	93.8	-	-	-
Other specified malignant bone tumours	girls	8	0	2	0	1	3	4	0	0	0	0	0	2	87.5	-	-	-
	boys	7	0	2	0	2	2	3	0	0	0	0	0	2	71.4	-	-	-
total	0.9	15	0	2	0	3	5	7	0	0	0	0	0	2	80.0	-	-	-

Tabelle 1 Forts. Table 1 cont.

Diagnoses	Sex	Number of cases										Incidence rates per million Age-specific	Age-stand.	Cum.	Trial participants	% 5-yrs 10-yrs 15-yrs	
		m / f	0 - 14	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9						
<i>Malignant fibrous neoplasms of bone</i>	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	
	boys	1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	
total	-	1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	
<i>Malignant chordomas</i>	girls	6	0	2	0	1	3	2	0	0	0	0	0	2	100.0	-	
	boys	5	0	1	0	1	2	2	0	0	0	0	0	1	60.0	-	
total	0.8	11	0	1	0	2	5	4	0	0	0	0	0	2	81.8	-	
<i>Odontogenic malignant tumours</i>	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	100.0	-
	boys	1	0	0	0	1	0	0	0	0	0	0	0	0	0	100.0	-
total	-	1	0	0	0	1	0	0	0	0	0	0	0	0	0	100.0	-
<i>Miscellaneous malignant bone tumours</i>	girls	2	0	1	0	0	0	2	0	0	0	0	0	1	50.0	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-
total	-	2	0	1	0	0	0	2	0	0	0	0	0	0	0	50.0	-
<i>Unspecified malignant bone tumours</i>	girls	2	0	1	0	0	0	2	0	0	0	0	0	1	50.0	-	-
	boys	3	0	1	0	0	0	3	0	0	0	0	0	1	33.3	-	-
total	1.5	5	0	1	0	0	0	5	0	0	0	0	0	1	40.0	-	-
<i>Soft tissue and other extraosseous sarcomas</i>	girls	458	6	100	53	131	115	159	16	10	7	8	9	130	98.7	75	71
	boys	538	6	100	76	154	142	166	22	11	8	8	10	145	98.0	72	70
total	1.2	996	6	100	129	285	257	325	19	10	7	8	9	138	98.3	73	71
<i>Rhabdomyosarcomas</i>	girls	229	3	50	20	82	65	62	6	6	4	3	5	66	100.0	71	69
	boys	282	3	52	28	121	85	48	8	9	5	2	5	77	99.6	74	73
total	1.2	511	3	51	48	203	150	110	7	7	4	3	5	72	99.8	73	71
<i>Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms</i>	girls	47	1	10	9	14	8	16	3	1	0	1	1	13	91.5	67	67
	boys	61	1	11	20	4	14	23	6	0	1	1	1	16	98.4	75	70
total	1.3	108	1	11	29	18	22	39	4	1	1	1	1	15	95.4	72	72
<i>Fibroblastic and myofibroblastic tumours</i>	girls	24	0	5	8	9	4	3	2	1	0	0	1	7	91.7	-	-
	boys	30	0	6	14	4	4	8	4	0	0	0	1	8	96.7	88	-
total	1.3	54	0	5	22	13	8	11	3	0	0	0	1	8	94.4	89	89
<i>Nerve sheath tumours</i>	girls	23	0	5	1	5	4	13	0	0	1	0	1	6	91.3	-	-
	boys	31	0	6	6	0	10	15	2	0	1	1	1	8	100.0	-	-
total	1.3	54	0	5	7	5	14	28	1	0	0	1	0	7	96.3	51	51
<i>Other fibrous neoplasms</i>	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-

* Standard: Segi world standard population

- insufficient data

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Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	m / f	0 - 14	%	0	1 - 4	5 - 9	10 - 14	Incidence rates per million			Trial participants	% 5- yrs 10- yrs 15- yrs
									Age-specific	Age-stand.	Cum.		
Kaposi sarcoma	girls	1	0	0	0	1	0	0	0	0	0	0	100.0
	boys	1	0	0	0	0	0	1	0	0	0	0	-
	total	1.0	2	0	0	0	1	0	0	0	0	0	50.0
Other specified soft tissue sarcomas	girls	147	2	32	19	24	35	69	6	2	4	3	41
	boys	147	2	27	21	35	70	6	1	2	4	3	39
	total	1.0	294	2	30	40	45	70	139	6	2	4	3
<i>Ewing tumour and askin tumour of soft tissue</i>	girls	34	0	7	0	5	11	18	0	0	1	1	9
	boys	27	0	5	1	3	9	14	0	0	1	0	7
	total	0.8	61	0	6	1	8	20	32	0	0	1	8
<i>Peripheral neuroectodermal tumour (pPNET) of soft tissue</i>	girls	4	0	1	0	1	2	1	0	0	0	0	1
	boys	10	0	2	0	3	2	5	0	0	0	0	3
	total	2.5	14	0	1	0	4	6	0	0	0	0	2
<i>Extrarenal rhabdoid tumour</i>	girls	31	0	7	15	8	3	5	4	1	0	0	1
	boys	26	0	5	15	6	3	2	4	0	0	0	7
	total	0.8	57	0	6	30	14	6	7	4	1	0	8
<i>Liposarcomas</i>	girls	2	0	0	0	0	0	2	0	0	0	0	1
	boys	3	0	1	0	0	1	2	0	0	0	0	1
	total	1.5	5	0	1	0	1	4	0	0	0	0	1
<i>Fibrohistiocytic tumours</i>	girls	21	0	5	2	5	7	7	1	0	0	0	6
	boys	16	0	3	2	4	3	7	1	0	0	0	4
	total	0.8	37	0	4	9	10	14	1	0	0	0	5
<i>Leiomyosarcomas</i>	girls	0	0	0	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0	0	-
<i>Synovial sarcomas</i>	girls	29	0	6	0	7	22	0	0	1	0	1	8
	boys	33	0	6	1	3	8	21	0	0	1	1	9
	total	1.1	62	0	6	1	3	15	43	0	0	1	8
<i>Blood vessel tumours</i>	girls	4	0	1	0	2	2	0	0	0	0	0	1
	boys	5	0	1	0	0	1	4	0	0	0	0	1
	total	1.3	9	0	1	0	2	3	4	0	0	0	1
<i>Osseous and chondromatous neoplasms of soft tissue</i>	girls	4	0	1	0	0	1	3	0	0	0	0	1
	boys	2	0	0	0	0	1	1	0	0	0	0	1
	total	0.5	6	0	1	0	0	2	4	0	0	0	1

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	N	Number of cases					Incidence rates per million					Trial participants	% 5-yr 10-yr 15-yr	Survival probabilities(%)	
				m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14		
<i>Alveolar soft parts sarcoma</i>			girls	8	0	2	0	0	1	7	0	0	0	0	0	2	100.0
			boys	4	0	1	0	0	1	3	0	0	0	0	0	1	100.0
	total	0.5	12	0	1	0	0	2	10	0	0	0	0	0	2	100.0	-
<i>Miscellaneous soft tissue sarcomas</i>			girls	10	0	2	2	3	1	4	1	0	0	0	0	3	100.0
			boys	21	0	4	2	2	6	11	1	0	0	1	0	6	100.0
	total	2.1	31	0	3	4	5	7	15	1	0	0	0	0	4	100.0	-
<i>Unspecified soft tissue sarcomas</i>			girls	34	0	7	5	10	7	12	1	0	1	1	1	10	100.0
			boys	47	0	9	7	8	8	24	2	1	0	1	1	12	93.6
	total	1.4	81	0	8	12	18	15	36	2	1	0	1	1	11	96.3	73
<i>Germ cell tumours, trophoblastic tumours and neoplasms of gonads</i>			girls	327	4	100	84	40	60	143	25	3	3	8	6	92	96.9
			boys	245	3	100	62	45	25	113	18	3	1	6	4	65	95.9
	total	0.7	572	3	100	146	85	85	256	21	3	2	7	5	78	96.5	94
<i>Intracranial and intraspinal germ cell tumours</i>			girls	58	1	18	6	2	22	28	2	0	1	1	1	16	96.6
			boys	114	1	47	4	8	20	82	1	1	4	2	29	94.7	
	total	2.0	172	1	30	10	10	42	110	1	0	1	3	1	23	95.3	89
<i>Intracranial and intraspinal germinoma</i>			girls	28	0	9	0	1	9	18	0	0	1	1	0	8	100.0
			boys	62	1	25	0	0	8	54	0	0	0	0	3	16	98.4
	total	2.2	90	1	16	0	1	17	72	0	0	2	1	12	98.9	95	
<i>Intracranial and intraspinal teratomas</i>			girls	8	0	2	4	1	1	2	1	0	0	0	0	3	79.2
			boys	16	0	7	4	5	4	3	1	0	0	0	4	75.0	
	total	2.0	24	0	4	8	6	5	5	1	0	0	0	0	3	79.2	-
<i>Intracranial and intraspinal embryonal carcinomas</i>			girls	0	0	0	0	0	0	0	0	0	0	0	0	0	100.0
			boys	1	0	0	0	0	1	0	0	0	0	0	0	0	100.0
	total	-	1	0	0	0	0	1	0	0	0	0	0	0	0	100.0	-
<i>Intracranial and intraspinal yolk sac tumour</i>			girls	1	0	0	0	0	1	0	0	0	0	0	0	0	100.0
			boys	4	0	2	0	0	0	4	0	0	0	0	0	1	100.0
	total	4.0	5	0	1	0	0	1	4	0	0	0	0	0	1	100.0	-
<i>Intracranial and intraspinal choriocarcinoma</i>			girls	5	0	2	0	0	3	2	0	0	0	0	0	1	100.0
			boys	2	0	1	0	1	0	1	0	0	0	0	0	1	100.0
	total	0.4	7	0	1	0	0	1	3	3	0	0	0	0	1	100.0	-
<i>Intracranial and intraspinal mixed form</i>			girls	16	0	5	2	0	8	6	1	0	0	0	4	93.8	
			boys	29	0	12	0	2	7	20	0	0	1	0	7	96.6	
	total	1.8	45	0	8	2	2	15	26	0	0	1	0	6	95.6	82	-

* Standard: Segi world standard population

- insufficient data

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Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	ratio	N	Relative Group	Number of cases					Incidence rates per million					Trial participants	% 0 - 14	% 5- yrs 10- yrs 15- yrs	Survival probabilities(%)
					m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	World *	Age-specific				
Malignant extracranial and extragonadal germ cell tumours	girls	122	2	37	77	36	2	7	23	3	0	0	3	36	96.7	95	95	95
	boys	56	1	23	30	16	3	7	8	1	0	0	1	16	96.4	90	90	88
	total	0.5	178	1	31	107	52	5	14	16	2	0	2	26	96.6	93	93	93
<i>Germinalomas of extracranial and extragonadal sites</i>	girls	9	0	3	0	5	0	4	0	0	0	0	0	3	77.8	-	-	-
	boys	7	0	3	0	3	0	4	0	0	0	0	0	2	100.0	-	-	-
	total	0.8	16	0	3	0	8	0	8	0	0	0	0	2	87.5	-	-	-
<i>Malignant teratomas of extracranial and extragonadal sites</i>	girls	62	1	19	58	3	0	1	17	0	0	0	1	18	98.4	95	95	95
	boys	29	0	12	26	2	0	1	7	0	0	0	1	8	93.1	-	-	-
	total	0.5	91	1	16	84	5	0	2	12	0	0	1	13	96.7	93	93	93
<i>Embryonal carcinomas of extracranial and extragonadal sites</i>	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
<i>Yolk sac tumour of extracranial and extragonadal sites</i>	girls	33	0	10	10	22	1	0	3	2	0	0	1	10	97.0	95	95	95
	boys	12	0	5	1	10	0	1	0	0	0	0	0	3	100.0	-	-	-
	total	0.4	45	0	8	11	32	1	1	2	1	0	1	7	97.8	95	95	95
<i>Choriocarcinomas of extracranial and extragonadal sites</i>	girls	1	0	0	0	0	0	1	0	0	0	0	0	0	0	100.0	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	-	1	0	0	0	0	1	0	0	0	0	0	0	0	-	-	-
<i>Other and unspecified malignant mixed germ cell tumours of extracranial and extragonadal sites</i>	girls	17	0	5	9	6	1	1	3	0	0	0	0	5	100.0	-	-	-
	boys	8	0	3	3	1	3	1	1	0	0	0	0	2	100.0	-	-	-
	total	0.5	25	0	4	12	7	4	2	0	0	0	0	4	100.0	-	-	-
<i>Malignant gonadal germ cell tumours</i>	girls	143	2	44	1	2	36	104	0	0	2	6	2	39	97.9	99	99	99
	boys	75	1	31	28	21	2	24	8	1	0	1	1	20	97.3	97	97	97
	total	0.5	218	1	38	29	23	38	128	4	1	3	2	29	97.7	98	98	98
<i>Malignant gonadal germimomas</i>	girls	37	0	11	0	1	8	28	0	0	0	1	1	10	100.0	100	-	-
	boys	4	0	2	0	1	1	2	0	0	0	0	1	1	100.0	-	-	-
	total	0.1	41	0	7	0	2	9	30	0	0	1	0	5	100.0	100	-	-
<i>Malignant gonadal teratomas</i>	girls	32	0	10	1	0	8	23	0	0	0	1	1	9	93.8	100	100	100
	boys	17	0	7	10	1	0	6	3	0	0	0	0	5	94.1	-	-	-
	total	0.5	49	0	9	11	1	8	29	2	0	1	0	7	93.9	100	100	100
<i>Malignant gonadal embryonal carcinomas</i>	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys	1	0	0	0	0	0	0	1	0	0	0	0	0	100.0	-	-	-
	total	-	1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses	Sex	Number of cases										Incidence rates per million					Survival probabilities(%)	
		m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	Age-specific	Age-stand.	Cum.	0 - 14	5 - 9	10 - 14	World*		
<i>Malignant gonadal yolk sac tumour</i>	girls	22	0	7	0	1	6	15	0	0	0	1	0	0	6	95.5	97	
	boys	26	0	11	9	17	0	0	3	1	0	0	1	7	7	96.2	100	
total	1.2	48	0	8	9	18	6	15	1	0	0	0	0	7	95.8	99	99	
<i>Malignant gonadal choriocarcinoma</i>	girls	5	0	2	0	0	1	4	0	0	0	0	0	1	100.0	-	-	
	boys	1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-	
total	0.2	6	0	1	0	0	1	5	0	0	0	0	0	1	100.0	-	-	
<i>Malignant gonadal tumours of mixed forms</i>	girls	47	1	14	0	0	13	34	0	0	1	2	1	13	100.0	100	-	
	boys	26	0	11	9	2	14	48	1	0	0	1	1	10	100.0	100	-	
total	0.6	73	0	13	9	2	14	48	1	0	0	1	1	10	100.0	100	-	
<i>Malignant gonadal gonadoblastoma</i>	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
<i>Gonadal carcinomas</i>	girls	3	0	1	0	0	0	3	0	0	0	0	0	1	66.7	-	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
total	-	3	0	1	0	0	0	3	0	0	0	0	0	0	66.7	-	-	-
Other and unspecified malignant gonadal tumours	girls	1	0	0	0	0	0	1	0	0	0	0	0	0	0	100.0	-	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
total	-	1	0	0	0	0	0	1	0	0	0	0	0	0	0	100.0	-	-
<i>Other malignant epithelial neoplasms and malignant melanomas</i>	girls	230	3	100	2	15	45	168	1	1	3	9	4	62	72.2	93	92	91
	boys	187	2	100	2	15	42	128	1	1	2	6	3	48	72.7	84	82	78
total	0.8	417	2	100	4	30	87	296	1	1	2	8	3	55	72.4	89	87	85
<i>Adrenocortical carcinomas</i>	girls	12	0	5	0	5	3	4	0	0	0	0	0	3	100.0	-	-	-
	boys	8	0	4	1	5	2	0	0	0	0	0	0	2	100.0	-	-	-
total	0.7	20	0	5	1	10	5	4	0	0	0	0	0	3	100.0	-	-	-
<i>Thyroid carcinomas</i>	girls	91	1	40	0	1	21	69	0	0	1	4	1	24	84.6	99	98	98
	boys	58	1	31	1	0	9	48	0	0	0	2	1	15	87.9	96	96	-
total	0.6	149	1	36	1	30	117	0	0	1	3	1	19	85.9	98	97	94	
<i>Nasopharyngeal carcinomas</i>	girls	5	0	2	0	0	0	5	0	0	0	0	0	1	100.0	-	-	-
	boys	16	0	9	0	1	0	15	0	0	0	1	0	4	93.8	-	-	-
total	3.2	21	0	5	0	1	0	20	0	0	1	0	1	3	95.2	-	-	-
<i>Malignant melanomas</i>	girls	35	0	15	2	8	9	16	1	1	1	1	1	10	31.4	-	-	-
	boys	37	0	20	0	7	12	18	0	1	1	1	1	10	35.1	-	-	-
total	1.1	72	0	17	2	15	21	34	0	1	1	1	1	10	33.3	87	-	-

* Standard: Segi world standard population

- insufficient data

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Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	m / f	0 - 14	%	0	1 - 4	5 - 9	10 - 14	Incidence rates per million			Trial participants	% 5- yrs	Survival probabilities(%)
									Age-specific	Age-stand.	Cum.			
Skin carcinomas	girls	6	0	3	0	0	2	4	0	0	0	2	33.3	-
	boys	3	0	2	0	1	0	2	0	0	0	1	66.7	-
	total	0.5	9	0	2	0	1	2	6	0	0	1	44.4	-
Other and unspecified carcinomas	girls	81	1	35	0	1	10	70	0	0	1	4	1	22
	boys	65	1	35	0	1	19	45	0	0	1	2	1	17
	total	0.8	146	1	35	0	2	29	115	0	0	3	19	72.6
Carcinomas of salivary glands	girls	13	0	6	0	0	1	12	0	0	0	1	0	3
	boys	9	0	5	0	0	5	4	0	0	0	0	0	2
	total	0.7	22	0	5	0	0	6	16	0	0	0	3	22.7
Carcinomas of colon and rectum	girls	5	0	2	0	1	0	4	0	0	0	0	1	40.0
	boys	6	0	3	0	0	2	4	0	0	0	0	2	50.0
	total	1.2	11	0	3	0	1	2	8	0	0	0	1	45.5
Carcinomas of appendix	girls	46	1	20	0	0	6	40	0	0	0	2	1	12
	boys	27	0	14	0	0	4	23	0	0	0	1	0	7
	total	0.6	73	0	18	0	0	10	63	0	0	2	1	9
Carcinomas of lung	girls	1	0	0	0	0	0	1	0	0	0	0	0	100.0
	boys	6	0	3	0	0	2	4	0	0	0	0	2	66.7
	total	6.0	7	0	2	0	0	2	5	0	0	0	1	71.4
Carcinomas of thymus	girls	0	0	0	0	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0	0	0	-
Carcinomas of breast	girls	0	0	0	0	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0	0	0	-
Carcinomas of cervix uteri	girls	1	0	0	0	0	0	1	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	-
	total	-	1	0	0	0	0	0	1	0	0	0	0	-
Carcinomas of bladder	girls	0	0	0	0	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0	0	0	-
Carcinomas of eye	girls	0	0	0	0	0	0	0	0	0	0	0	0	-
	boys	2	0	1	0	0	0	0	0	0	0	2	0	-
	total	-	2	0	0	0	0	0	0	0	0	2	0	-

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio m / f	0 - 14 %	N	Relative Group	Number of cases Age groups	Incidence rates per million						Trial participants	Survival probabilities(%)	
							0 - 14	5 - 9	10 - 14	0 - 14	5 - 9	10 - 14	World*		
Carcinomas of other specified sites															
girls	14	0	6	0	0	3	11	0	0	1	0	0	4	64.3	-
boys	11	0	6	0	0	5	6	0	0	0	0	0	3	72.7	-
total	0.8	25	0	6	0	8	17	0	0	0	0	0	3	68.0	-
Carcinomas of unspecified site															
girls	1	0	0	0	0	1	0	0	0	0	0	0	0	-	-
boys	4	0	2	0	1	1	2	0	0	0	0	0	1	75.0	-
total	4.0	5	0	1	0	1	3	0	0	0	0	0	1	60.0	-
Others and unspecified malignant neoplasms															
girls	19	0	100	3	9	2	5	1	1	0	0	0	5	68.4	-
boys	14	0	100	1	10	1	2	0	1	0	0	0	4	85.7	-
total	0.7	33	0	100	4	19	3	7	1	0	0	0	5	75.8	-
Other specified malignant tumours															
girls	13	0	68	0	8	2	3	0	1	0	0	0	4	76.9	-
boys	12	0	86	1	10	1	0	1	0	0	0	0	3	91.7	-
total	0.9	25	0	76	1	18	3	3	0	1	0	0	4	84.0	-
Gastrointestinal stromal tumour															
girls	1	0	5	0	0	0	1	0	0	0	0	0	0	100.0	-
boys	1	0	7	0	0	1	0	0	0	0	0	0	0	100.0	-
total	1.0	2	0	6	0	1	1	0	0	0	0	0	0	100.0	-
Pancreatoblastoma															
girls	4	0	21	0	1	2	1	0	0	0	0	0	1	50.0	-
boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-
total	-	4	0	12	0	1	2	1	0	0	0	0	1	50.0	-
Pulmonary blastoma and pleuropulmonary blastoma															
girls	7	0	37	0	7	0	0	1	0	0	0	0	2	100.0	-
boys	11	0	79	1	10	0	0	1	0	0	0	0	3	90.9	-
total	1.6	18	0	55	1	17	0	0	1	0	0	0	3	94.4	-
Other complex mixed and stromal neoplasms															
girls	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-
boys	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-
total	-	1	0	3	0	0	0	1	0	0	0	0	0	-	-
Mesothelioma															
girls	1	0	5	0	0	0	1	0	0	0	0	0	0	-	-
boys	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-
total	-	0	0	0	0	0	0	1	0	0	0	0	0	-	-
Other specified malignant tumours															
girls	0	0	0	0	0	0	0	0	0	0	0	0	0	2	50.0
boys	2	0	14	0	0	0	2	1	0	0	0	0	1	50.0	-
total	0.3	8	0	24	3	1	0	4	0	0	0	0	1	50.0	-

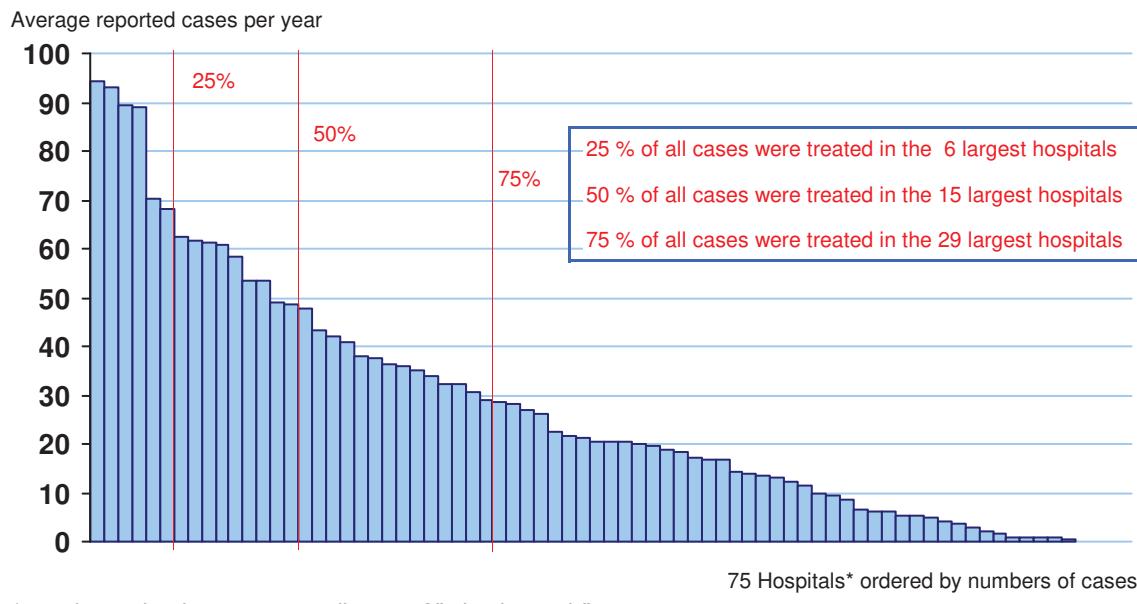
* Standard: Segi world standard population

- insufficient data

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Abbildung 1:

Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2007-2016, Patienten unter 15 / 18 Jahren (unter 15 Jahren bis 2008)
 Reported cases to the GCCR (registry population) per hospital, period 2007-2016, patients under 15 / 18 years (under 15 years until 2008)



* One hospital with 6 cases is a collection of "other hospitals"

Tabelle 2:

Anzahl der gemeldeten Fälle unter 15 Jahren aus der deutschen Wohnbevölkerung, alters-standardisierte Inzidenzrate und kumulative Inzidenz (pro Million) nach ICCC-3-Diagnosegruppen.

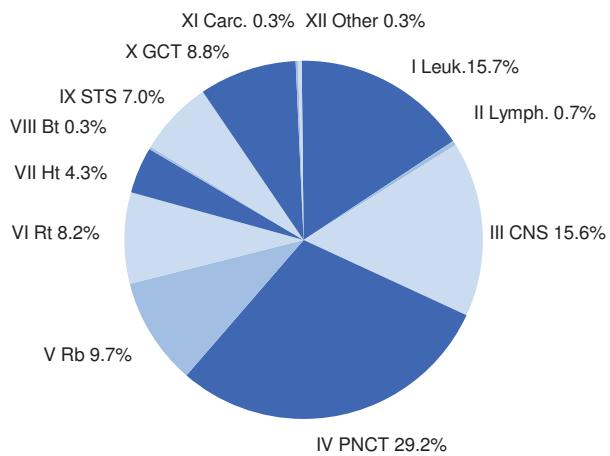
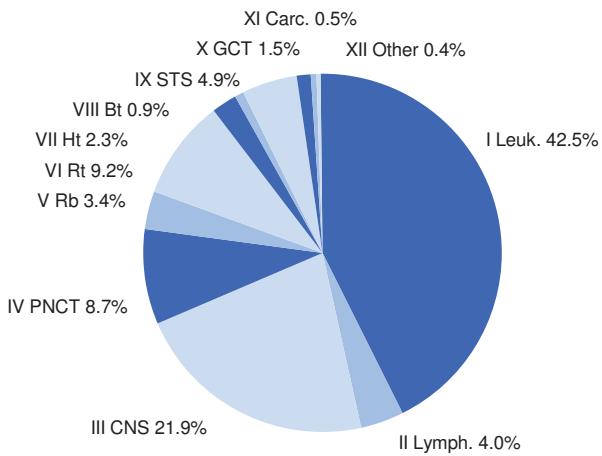
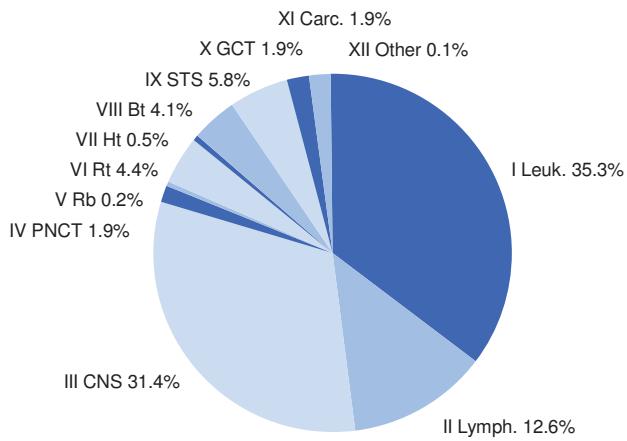
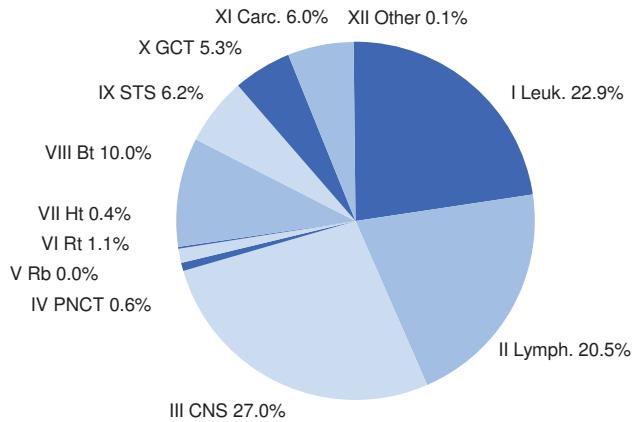
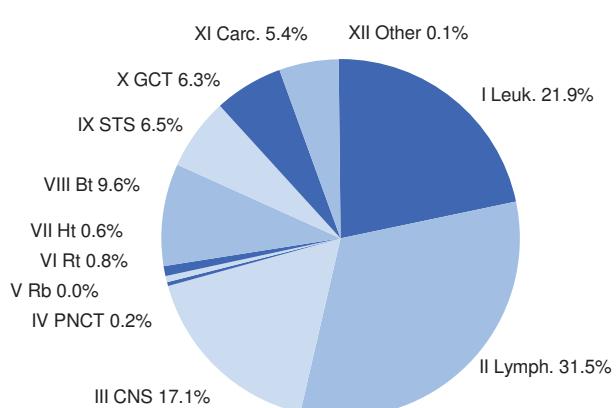
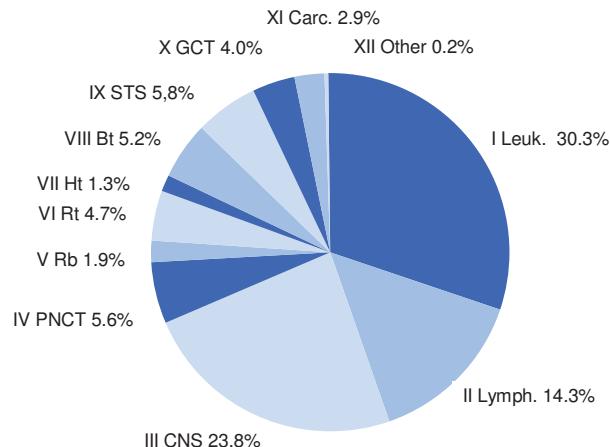
Number of registered cases in Germany aged under 15, age-standardized incidence rate and cumulative incidence (per million) by ICCC-3 diagnosis groups.

Diagnosis groups	Number of cases 1980-2016		Number of cases 2007-2016		Incidence rates 2007-2016	
	Absolute	Relative (%)	Absolute	Relative (%)	Age-standard.*	Cumulative
I Leukaemias	20031	33.9	5713	32.4	56	800
II Lymphomas	6862	11.6	1889	10.7	16	253
III CNS tumours	12987	22.0	4409	25.0	41	610
IV Peripheral nervous cell tumours	4410	7.5	1189	6.8	13	172
V Retinoblastoma	1412	2.4	399	2.3	5	58
VI Renal tumours	3445	5.8	966	5.5	10	138
VII Hepatic tumours	672	1.1	253	1.4	3	36
VIII Bone tumours	2755	4.7	777	4.4	6	103
IX Soft tissue sarcomas	3598	6.1	996	5.7	9	138
X Germ cell tumours	1896	3.2	572	3.2	5	78
XI Carcinomas	907	1.5	417	2.4	3	55
XII Others and unspecified	73	0.1	33	0.2	0	5
All malignancies	59048	100.0	17613	100.0	169	2446

* Standard: Segi world standard population

Abbildung 2:

Relative Häufigkeit der gemeldeten Fälle aus der deutschen Wohnbevölkerung nach den häufigsten ICCC-3 Diagnose-Hauptgruppen und Alter (ausführliche ICCC-3 Kategoriebezeichnungen siehe Seite 131)
Relative frequencies of the registered cases in Germany by the main ICCC-3 diagnosis groups and age (for the detailed ICCC-3 category legends see page 131)

Age 0, 2009-2016 (n=1481)

Age 1-4, 2009-2016 (n=4812)

Age 5-9, 2009-2016 (n=3613)

Age 10-14, 2009-2016 (n=4152)

Age 15-17, 2009-2016 (n=2906)

Age 0-17, 2009-2016 (n=16964)


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Tabelle 3:

Anzahl der gemeldeten Fälle unter 15 Jahren, 15 bis unter 18 Jahren und unter 18 Jahren auf Basis des ICCC-3, altersstandardisierte Inzidenzrate und Wohnbevölkerungsbezug nach Jahren für Deutschland

Annual number of registered cases aged under 15, 15 to under 18 years and under 18 years based on ICCC-3, age-standardized incidence rate and resident population base by calendar year for Germany

Years	Number of cases			Incidence rates per million *		Population base (in million)	
	< 15	15 to < 18	< 18	<15	< 18	<15	< 18
1980	1017			102		11.187	
1981	1048			105		10.803	
1982	974			103		10.392	
1983	1074			116		9.957	
1984	1032			114		9.539	
1985	1140			129		9.232	
1986	1144			132		9.070	
1987	1216			141		8.903	
1988	1216			140		9.019	
1989	1222			135		9.260	
1990	1300			139		9.621	
1991 #	1669			132		13.013	
1992	1812			143		13.166	
1993	1684			132		13.279	
1994	1768			139		13.298	
1995	1802			143		13.264	
1996	1803			145		13.209	
1997	1908			155		13.139	
1998	1821			149		13.035	
1999	1880			154		12.936	
2000	1977			163		12.836	
2001	1854			155		12.698	
2002	1826			154		12.517	
2003	1774			152		12.288	
2004	1872			164		12.042	
2005	1834			165		11.787	
2006	1768			162		11.544	
2007	1777			165		11.361	
2008	1778			167		11.212	
2009	1793	353	2146	170	165	11.078	13.579
2010	1766	314	2080	169	163	10.979	13.408
2011	1734	358	2092	166	164	10.884	13.277
2012	1765	358	2123	170	167	10.782	13.187
2013	1774	339	2113	174	169	10.628	13.050
2014	1707	397	2104	166	166	10.628	13.062
2015	1778	417	2195	171	171	10.784	13.219
2016	1741	370	2111	167	166	10.744	13.121
Total	59048	2906	61954				

* Standard: Segi world standard population

Erweiterung um neue Bundesländer / inclusion of East Germany

Tabelle 4:

Verteilung aller gemeldeten Fälle aus der deutschen Wohnbevölkerung nach Altersgruppen ohne Altersbeschränkung # sowie zusätzlich erfasste Diagnosen (2007-2016)

Distribution of all reported cases in Germany by age groups without age restriction # and additional diagnoses (2007-2016)

Age groups (years)	Diagnoses according to ICCC-3		Additional diagnoses (see Table 5)	
	N	%	N	%
0	1841	8.6	455	26.9
1-4	6025	28.1	334	19.8
5-9	4575	21.4	335	19.8
10-14	5172	24.2	425	25.1
0-14	17613	82.3	1549	91.6
15-17	2906	13.6	107	6.3
0-17	20519	95.8	1656	97.9
18-19	273	1.3	8	0.5
20-24	235	1.1	10	0.6
≥25	384	1.8	17	1.0
≥15	3798	17.7	142	8.4
≥18	892	4.2	35	2.1
reported cases	21411	100.0	1691	100.0

Altersgrenze bis 2008 unter 15, ab 2009 unter 18. Junge Erwachsene ab 18 Jahren werden nur unvollständig erfasst.

The age limit was under 15 until 2008 and under 18 from 2009. Young adults 18 or older are incompletely registered.

Tabelle 5:

Nicht in der ICCC-3 definierte, systematisch registrierte Diagnosen, Fälle unter 15 Jahren (2007-2016)

Systematically registered diagnoses not defined in ICCC-3, cases under the age of 15 (2007-2016)

Diagnoses	Sex	Number of cases						Incidence rates per million					Trial participants	
		ratio	N	Age groups				Age groups				Age-stand.		
				m / f	0-14	0	1-4	5-9	10-14	0	1-4	5-9	10-14	
Non-malignant	girls		286	77	84	74	51	23	6	4	3	6	83	85.3
Langerhans cell	boys		401	90	116	93	102	25	8	5	5	8	109	86.3
histiocytosis	total	1.4	687	167	200	167	153	24	7	5	4	7	96	85.9
Benign/mature teratoma	girls		510	131	60	108	211	39	4	6	11	10	144	96.3
	boys		146	86	29	18	13	24	2	1	1	3	41	94.5
	total	0.3	656	217	89	126	224	31	3	4	6	6	91	95.9
Severe aplastic anaemia	girls		43	2	7	18	16	1	1	1	1	1	12	93.0
	boys		52	2	16	15	19	1	1	1	1	1	14	92.3
	total	1.2	95	4	23	33	35	1	1	1	1	1	13	92.6
Mesoblastic nephroma	girls		18	18	0	0	0	5	0	0	0	0	5	88.9
	boys		23	21	1	0	1	6	0	0	0	1	6	95.7
	total	1.3	41	39	1	0	1	6	0	0	0	0	6	92.7
Other diseases	girls		29	15	6	4	4	4	0	0	0	1	8	55.2
of blood and	boys		38	13	15	4	6	4	1	0	0	1	11	55.3
haemopoietic system	total	1.3	67	28	21	8	10	4	1	0	0	1	10	55.2

* Standard: Segi world standard population

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Tabelle 6:

Altersstandardisierte* Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert nach Patientenwohnsitz für Fälle unter 15 Jahre (2007-2016)

Age-standardized* incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for cases under 15 by patients residence region (2007-2016)

Bundesländer und Regierungsbezirke States and counties	All malignancies				Leukaemias			
	No. of cases	Incidence rate *	SIR	95%-CI	No. of cases	Incidence rate *	SIR	95%-CI
Schleswig-Holstein	645	174	1.04	0.96-1.12	213	58	1.06	0.93-1.22
Hamburg	375	165	0.98	0.88-1.09	124	56	0.99	0.83-1.18
Niedersachsen	1723	165	0.98	0.93-1.03	578	56	1.02	0.94-1.11
Bremen	125	157	0.93	0.77-1.10	40	51	0.91	0.65-1.24
Nordrhein-Westfalen	4024	172	1.02	0.99-1.05	1256	55	0.99	0.93-1.04
Düsseldorf	1144	173	1.03	0.97-1.09	361	57	1.00	0.90-1.11
Köln	1008	170	1.02	0.96-1.09	291	50	0.91	0.81-1.02
Münster	599	170	1.01	0.93-1.09	216	63	1.13	0.98-1.29
Detmold	491	174	1.01	0.93-1.11	156	56	1.00	0.85-1.17
Arnsberg	782	170	1.00	0.93-1.07	232	51	0.92	0.81-1.05
Hessen	1350	170	1.00	0.95-1.06	464	59	1.07	0.97-1.17
Darmstadt	852	165	0.98	0.92-1.05	294	58	1.04	0.93-1.17
Gießen	246	194	1.11	0.97-1.26	85	68	1.19	0.95-1.47
Kassel	252	166	0.98	0.87-1.11	85	58	1.03	0.82-1.28
Rheinland-Pfalz	893	176	1.03	0.97-1.10	269	54	0.97	0.86-1.09
Baden-Württemberg	2391	165	0.98	0.94-1.02	760	54	0.96	0.90-1.04
Stuttgart	897	164	0.97	0.91-1.04	285	53	0.95	0.85-1.07
Karlsruhe	621	173	1.04	0.96-1.13	202	59	1.05	0.91-1.20
Freiburg	506	166	1.00	0.91-1.09	168	58	1.03	0.88-1.20
Tübingen	367	150	0.87	0.78-0.96	105	44	0.77	0.63-0.93
Bayern	2805	169	1.00	0.96-1.04	955	59	1.05	0.99-1.12
Oberbayern	958	159	0.94	0.88-1.00	336	56	1.01	0.91-1.12
Niederbayern	255	161	0.96	0.85-1.09	81	55	0.95	0.75-1.18
Oberpfalz	271	195	1.14	1.01-1.29	90	67	1.18	0.95-1.45
Oberfranken	202	151	0.92	0.80-1.05	69	55	0.98	0.76-1.23
Mittelfranken	338	151	0.90	0.81-1.00	103	47	0.85	0.69-1.03
Unterfranken	310	188	1.11	0.99-1.24	108	68	1.20	0.99-1.45
Schwaben	471	193	1.14	1.04-1.25	168	71	1.26	1.08-1.47
Saarland	181	154	0.94	0.81-1.09	59	51	0.95	0.73-1.23
Berlin	681	159	0.94	0.87-1.01	235	55	0.99	0.87-1.12
Brandenburg	449	159	0.95	0.86-1.04	152	55	0.98	0.83-1.15
Mecklenburg-Vorpommern	282	154	0.92	0.81-1.03	86	48	0.85	0.68-1.05
Sachsen	866	183	1.09	1.02-1.17	265	56	1.01	0.89-1.14
Sachsen-Anhalt	434	177	1.05	0.96-1.16	134	55	0.99	0.83-1.17
Thüringen	389	160	0.95	0.86-1.05	123	51	0.91	0.76-1.09

* Standard: Segi world standard population

Tabelle 7:

Anzahl der verstorbenen Patienten innerhalb von 5, 10 bzw. 15 Jahren nach Diagnose auf Basis des ICCC-3 unter den gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung und kumulative Mortalität nach Diagnosejahr, 1980-2011 (inklusive neue Länder seit 1991)

Annual number of deaths 5, 10 or 15 years from diagnosis based on ICCC-3 from the group of registered patients aged under 15 in Germany and cumulative mortality by year of diagnosis 1980-2011 (including East Germany since 1991)

Year of diagnosis	Deaths within 5 years after diagnosis		Deaths within 10 years after diagnosis		Deaths within 15 years after diagnosis	
	No. of cases	Cum. mortality per million	No. of cases	Cum. mortality per million	No. of cases	Cum. mortality per million
1980	342	490	370	533	382	550
1981	341	484	377	534	393	558
1982	313	472	347	521	357	537
1983	319	493	359	557	372	577
1984	325	514	354	560	364	577
1985	322	523	362	586	379	615
1986	319	531	354	588	364	605
1987	327	550	352	592	366	615
1988	316	522	347	573	357	590
1989	291	466	325	522	338	542
1990	326	498	354	541	370	565
1991 #	400	457	445	509	460	526
1992 #	435	494	471	535	491	558
1993 #	382	434	427	484	444	504
1994 #	374	425	409	465	421	479
1995 #	338	389	385	443	407	468
1996 #	349	404	386	447	402	465
1997 #	372	432	417	484	439	510
1998 #	350	410	391	458	405	475
1999 #	360	422	399	467	414	484
2000 #	394	468	428	508	450	534
2001 #	302	363	340	408	359	431
2002 #	320	387	359	435		
2003 #	322	400	362	448		
2004 #	293	372	342	433		
2005 #	298	385	325	419		
2006 #	295	389	330	435		
2007 #	271	363				
2008 #	289	390				
2009 #	261	356				
2010 #	247	341				
2011 #	224	310				

Including East Germany since 1991

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Tabelle 8:

Anzahl der am Deutschen Kinderkrebsregister in der Langzeitnachbeobachtung (LTS) befindlichen Patienten mit Erstdiagnose im Alter von unter 15 / 18 (Stand 2016)

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged under 15 / 18 (as of 2016)

Year of diagnosis	1980 - 1989 *	1990 - 1999 *	2000 - 2009 **	2010 - 2016 ***	1980 - 2016 **
	N (%)	N (%)	N (%)	N (%)	N (%)
Patients registered	10997	17244	18329	14583	61153 #
deceased	3894 (35.4 %)	4243 (24.6 %)	3396 (18.5 %)	1328 (9.1 %)	12861 (21.0 %)
surviving	7103 (64.6 %)	13001 (75.4 %)	14933 (81.5 %)	13255 (90.9 %)	48292 (79.0 %)
anonymous ⁺	994 (14.0 %)	1111 (8.5 %)	439 (2.9 %)	125 (0.9 %)	2669 (5.5 %)
identifiable	6109 (86.0 %)	11890 (91.5 %)	14494 (97.1 %)	13130 (99.1 %)	45623 (94.5 %)
< 5 years since diagnosis	-	-	-	8311 (63.3 %)	8311 (18.2 %)
>= 5 years since diagnosis	6109 (100 %)	11890 (100 %)	14494 (100 %)	4819 (36.7 %)	37312 (81.8 %)
lost-to-follow-up	728 (11.9 %)	900 (7.6 %)	369 (2.5 %)	45 (0.9 %)	2042 (5.5 %)
in LTS	5381 (88.1 %)	10990 (92.4 %)	14125 (97.5 %)	4774 (99.1 %)	35270 (94.5 %)

61153 patients correspond to 61954 cases diagnosed under 15 / 18 years resident in Germany at the date of diagnosis 1980-2016 and diagnosed with a disease included in ICCC-3.

- Not applicable

+ Consent not available, refused or withdrawn later.

* First diagnosis under 15.

** First diagnosis under 15 until 2008, under 18 from 2009 onwards.

*** First diagnosis under 18.

Tabelle 9:
Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Kinder und Jugendliche unter 18 aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2009-2016). ICCC-3 extended Subklassifikation kursiv dargestellt.
Number of cases and incidence rates per million children and adolescents aged under 18 years in Germany by diagnosis classified according to ICCC-3, age and sex (2009-2016).
ICCC-3 extended subclassification in italics.

Diagnoses	Sex ratio		N		Relative Group		Number of cases Age group			Incidence rates per million Age stand. *			Trial participants			
	m / f	0-17	%	%	0 - 14	15 - 17	0 - 14	15 - 17	Cum.	0 - 17	0 - 17	0 - 17	%			
All malignancies																
girls	7506	100	100	6266	1240		155	132	152	2644			95.6			
boys	9458	100	100	7792	1666		182	167	180	3155			96.0			
total	1.3	16964	100	100	14058	2906	169	150	166	2906			95.8			
Leukaemias, myeloproliferative and myelodysplastic diseases																
girls	2253	30	100	2006	247		51	26	47	806			99.4			
boys	2885	31	100	2497	388		60	39	56	975			99.0			
total	1.3	5138	30	100	4503	635	56	33	52	892			99.2			
Lymphoid leukaemias																
girls	1658	22	74	1532	126		39	13	35	598			99.6			
boys	2190	23	76	1934	256		47	26	43	743			99.7			
total	1.3	3848	23	75	3466	382	43	20	39	672			99.7			
Precursor cell leukaemias																
girls	1636	22	73	1512	124		39	13	35	590			99.6			
boys	2118	22	73	1869	249		45	25	42	719			99.7			
total	1.3	3754	22	73	3381	373	42	19	38	656			99.7			
Mature B-cell/leukaemias																
girls	21	0	1	19	2		0	0	0	7			100.0			
boys	71	1	2	64	7		1	1	1	24			100.0			
total	3.4	92	1	2	83	9	1	0	1	16			100.0			
Mature T-cell/NK cell/leukaemias																
girls	1	0	0	1	0		0	0	0	0			100.0			
boys	1	0	0	1	0		0	0	0	0			100.0			
total	1.0	2	0	2	0		0	0	0	0			100.0			
Lymphoid leukaemia, NOS																
girls	0	0	0	0	0		0	0	0	0			-			
boys	0	0	0	0	0		0	0	0	0			-			
total	-	0	0	0	0		0	0	0	0			-			
Acute myeloid leukaemias																
girls	333	4	15	271	62		7	7	7	117			99.4			
boys	354	4	12	292	62		7	6	7	119			96.9			
total	1.1	687	4	13	563	124	7	6	7	118			98.1			
Chronic myeloproliferative diseases																
girls	40	1	2	28	12		1	1	1	13			95.0			
boys	63	1	2	37	26		1	3	1	20			79.4			
total	1.6	103	1	2	65	38	1	2	1	17			85.4			
Myelodysplastic syndrome and other myeloproliferative diseases																
girls	195	3	9	152	43		4	5	4	68			99.0			
boys	250	3	9	209	41		5	4	5	83			100.0			
total	1.3	445	3	9	361	84	4	4	4	76			99.6			

- insufficient data

* Standard: Seidi world standard population

Tabelle 9 Forts.

100 Tabellen und Abbildungen / Tables and Figures

Diagnoses	Sex	ratio m / f	N	Relative Group	Number of cases			Incidence rates per million Age stand. *			Trial par- ticipants		
					0-17	%	0-14	15-17	0-14	15-17	Cum.	0-17	%
Unspecified and other specified leukaemias	girls	27	0	1	23	4			1	0	1	9	100.0
	boys	28	0	1	25	3			1	0	1	9	100.0
	total	1.0	55	0	48	7			1	0	1	9	100.0
Lymphomas and reticuloendothelial neoplasms	girls	867	12	100	474	393	10	42	15	288	288	97.6	
	boys	1556	16	100	1033	523	22	52	26	500	500	97.2	
	total	1.8	2423	14	100	1507	916	16	47	21	397	397	97.4
Hodgkin lymphomas	girls	587	8	68	262	325	5	34	10	192	192	97.8	
	boys	708	7	46	398	310	8	31	11	223	223	97.0	
	total	1.2	1295	8	53	660	635	7	33	11	208	208	97.4
Non-Hodgkin lymphomas	girls	235	3	27	169	66	4	7	4	81	81	97.4	
	boys	604	6	39	428	176	9	18	10	196	196	97.2	
	total	2.6	839	5	35	597	242	7	12	7	140	140	97.3
Precursor cell lymphomas	girls	66	1	8	59	7			1	1	1	23	95.5
	boys	184	2	12	146	38			3	4	3	61	95.1
	total	2.8	250	1	10	205	45	2	2	2	42	42	95.2
Mature B-cell lymphomas (except Burkitt lymphoma)	girls	53	1	6	34	19	1	2	1	18	18	98.1	
	boys	133	1	9	76	57	2	6	2	42	42	97.0	
	total	2.5	186	1	8	110	76	1	4	2	30	30	97.3
Mature T-cell and NK-cell lymphomas	girls	57	1	7	40	17	1	2	1	19	19	96.5	
	boys	107	1	7	81	26	2	3	2	35	35	100.0	
	total	1.9	164	1	7	121	43	1	2	1	27	27	98.8
Non-Hodgkin lymphomas, NOS	girls	59	1	7	36	23	1	2	1	20	20	100.0	
	boys	180	2	12	125	55	3	6	3	59	59	97.8	
	total	3.1	239	1	10	161	78	2	4	2	40	40	98.3
Burkitt lymphoma	girls	37	0	4	35	2	1	0	1	13	13	100.0	
	boys	231	2	15	198	33	4	3	4	77	77	98.7	
	total	6.2	268	2	11	233	35	3	2	3	46	46	98.9
Miscellaneous lymphoreticular neoplasms	girls	5	0	1	5	0	0	0	0	2	2	80.0	
	boys	7	0	0	3	4	0	0	0	2	2	71.4	
	total	1.4	12	0	0	8	4	0	0	0	2	2	75.0
Unspecified lymphomas	girls	3	0	0	3	0	0	0	0	1	1	66.7	
	boys	6	0	0	6	0	0	0	0	2	2	100.0	
	total	2.0	9	0	0	9	0	0	0	0	2	2	88.9

Table 9 cont.

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio m / f	0-17 %	N	Relative Group	Number of cases Age group	Incidence rates per million Age stand.*				Trial par- ticipants %
						0 - 14	15 - 17	0 - 17	Cum.	
CNS and miscellaneous intracranial and intraspinal neoplasms										
girls	1848	25	100	1616	232	39	25	37	652	95.5
boys	2192	23	100	1926	266	44	27	41	734	96.2
total	1.2	4040	24	100	3542	498	42	26	39	95.8
Ependymomas and choroid plexus tumour										
girls	168	2	9	152	16	4	2	4	60	96.4
boys	219	2	10	203	16	5	2	4	74	97.3
total	1.3	387	2	10	355	32	4	2	68	96.9
Ependymomas										
girls	131	2	7	117	14	3	1	3	47	96.9
boys	171	2	8	158	13	4	1	3	58	97.1
total	1.3	302	2	7	275	27	3	1	53	97.0
Choroid plexus tumour										
girls	37	0	2	35	2	1	0	1	13	94.6
boys	48	1	2	45	3	1	0	1	17	97.9
total	1.3	85	1	2	80	5	1	0	15	96.5
Astrocytomas										
girls	885	12	48	786	99	19	11	18	312	96.4
boys	954	10	44	829	125	19	13	18	319	96.1
total	1.1	1839	11	46	1615	224	19	12	18	316
Intracranial and intraspinal embryonal tumours										
girls	251	3	14	233	18	6	2	5	90	96.8
boys	412	4	19	378	34	9	3	8	141	98.5
total	1.6	663	4	16	611	52	8	3	7	97.9
Medulloblastomas										
girls	169	2	9	153	16	4	2	3	60	98.2
boys	310	3	14	278	32	6	3	6	105	99.4
total	1.8	479	3	12	431	48	5	2	5	99.0
Primitive neuroectodermal tumour (PNET)										
girls	23	0	1	22	1	1	0	1	8	95.7
boys	29	0	1	28	1	1	0	1	10	100.0
total	1.3	52	0	1	50	2	1	0	9	98.1
Medulloepithelioma										
girls	8	0	0	7	1	0	0	0	3	87.5
boys	6	0	0	6	0	0	0	0	2	100.0
total	0.8	14	0	0	13	1	0	0	2	92.9
Atypical teratoid/rhabdoid tumour										
girls	51	1	3	51	0	1	0	1	19	94.1
boys	67	1	3	66	1	2	0	2	24	94.0
total	1.3	118	1	3	117	1	2	0	21	94.1
Other gliomas										
girls	202	3	11	178	24	4	3	4	71	94.6
boys	216	2	10	193	23	4	2	4	72	98.1
total	1.1	418	2	10	371	47	4	2	4	96.4

* Standard: Sedl world standard population

insufficient data

Tabelle 9 Forts.

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Diagnoses	Sex	N	Relative Group	Number of cases			Incidence rates per million			Trial participants			
				m / f	0-17	%	0 - 14	15 - 17	Age stand. *	0 - 14	15 - 17	0 - 17	
Oligodendrogliomas	girls	4	0	0	1	3	0	0	0	0	0	1	100.0
	boys	5	0	0	4	1	0	0	0	0	0	2	100.0
	total	1.3	9	0	0	5	4	0	0	0	0	1	100.0
Mixed and unspecified gliomas	girls	188	3	10	167	21	4	2	4	67	67	94.1	
	boys	201	2	9	181	20	4	2	4	67	67	98.0	
	total	1.1	389	2	10	348	41	4	2	4	67	96.1	
Neuroepithelial glial tumours of uncertain origin	girls	10	0	1	10	0	0	0	0	0	0	4	100.0
	boys	10	0	0	8	2	0	0	0	0	0	3	100.0
	total	1.0	20	0	0	18	2	0	0	0	0	3	100.0
Other specified intracranial and intraspinal neoplasms	girls	311	4	17	241	70	5	7	6	107	107	93.2	
	boys	363	4	17	297	66	6	7	6	119	119	92.6	
	total	1.2	674	4	17	538	136	6	7	6	113	92.9	
Pituitary adenomas and carcinomas	girls	34	0	2	12	22	0	2	1	11	11	82.4	
	boys	18	0	1	11	7	0	1	0	6	6	72.2	
	total	0.5	52	0	1	23	29	0	1	0	8	78.8	
Tumours of the sellar region (cranioopharyngiomas)	girls	91	1	5	81	10	2	1	2	32	32	100.0	
	boys	86	1	4	72	14	2	1	2	29	29	98.8	
	total	0.9	177	1	4	153	24	2	1	2	30	99.4	
Pineal parenchymal tumours	girls	22	0	1	17	5	0	1	0	8	8	100.0	
	boys	14	0	1	12	2	0	0	0	5	5	100.0	
	total	0.6	36	0	1	29	7	0	0	6	6	100.0	
Neuronal and mixed neuronal-glia tumours	girls	142	2	8	114	28	3	3	3	49	49	94.4	
	boys	214	2	10	182	32	4	3	4	70	70	94.9	
	total	1.5	356	2	9	296	60	3	3	60	60	94.7	
Meningiomas	girls	22	0	1	17	5	0	1	0	8	8	68.2	
	boys	31	0	1	20	11	0	1	1	10	10	67.7	
	total	1.4	53	0	1	37	16	0	1	9	9	67.9	
Unspecified intracranial and intraspinal neoplasms	girls	31	0	2	26	5	1	1	1	11	11	80.6	
	boys	28	0	1	26	2	1	0	0	9	9	85.7	
	total	0.9	59	0	1	52	7	1	0	10	10	83.1	
Neuroblastoma and other peripheral nervous cell tumours	girls	395	5	100	391	4	11	0	10	146	146	98.2	
	boys	554	6	100	551	3	15	0	13	195	195	99.6	
	total	1.4	949	6	100	942	7	13	0	11	171	99.1	

Table 9 cont.

Tabelle 9 Forts.

Table 9 cont.

Diagnoses		Sex ratio			Number of cases			Incidence rates per million			Trial participants
		m / f	0-17	%	0 - 14	15 - 17	Age group	Age stand.*	Cum.	0 - 17	
Neuroblastoma and ganglioneuroblastoma		girls	391	5	99	387	4	11	0	10	98.7
		boys	551	6	99	548	3	15	0	13	99.6
	total	1.4	942	6	99	935	7	13	0	11	99.3
Other peripheral nervous cell tumours		girls	4	0	1	4	0	0	0	1	50.0
		boys	3	0	1	3	0	0	0	1	100.0
	total	0.8	7	0	1	7	0	0	0	1	71.4
Retinoblastoma		girls	157	2	100	157	0	5	0	4	58
		boys	162	2	100	162	0	4	0	4	57
	total	1.0	319	2	100	319	0	5	0	4	58
Renal tumours		girls	425	6	100	412	13	11	1	10	156
		boys	365	4	100	356	9	9	1	8	127
	total	0.9	790	5	100	768	22	10	1	9	141
Nephroblastoma and other non-epithelial renal tumours		girls	413	6	97	404	9	11	1	9	152
		boys	347	4	95	345	2	9	0	8	122
	total	0.8	760	4	96	749	11	10	1	9	136
Nephroblastoma		girls	401	5	94	394	7	11	1	9	148
		boys	336	4	92	334	2	9	0	7	118
	total	0.8	737	4	93	728	9	10	0	8	132
Rhabdoid renal tumour		girls	8	0	2	7	1	0	0	0	3
		boys	9	0	2	9	0	0	0	0	3
	total	1.1	17	0	2	16	1	0	0	3	100.0
Kidney sarcomas		girls	4	0	1	3	1	0	0	0	1
		boys	2	0	1	2	0	0	0	0	1
	total	0.5	6	0	1	5	1	0	0	1	100.0
Peripheral neuroectodermal tumour (pPNET) of kidney		girls	0	0	0	0	0	0	0	0	-
		boys	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	-
Renal carcinomas		girls	12	0	3	8	4	0	0	4	83.3
		boys	18	0	5	11	7	0	1	0	6
	total	1.5	30	0	4	19	11	0	1	0	86.7
Unspecified malignant renal tumours		girls	0	0	0	0	0	0	0	0	-
		boys	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	-

* Standard: Secri world standard population

- insufficient data

Tabelle 9 Forts.

Table 9 cont.

Diagnoses	Sex	ratio m / f	N	Relative Group	Number of cases			Incidence rates per million			Trial par- ticipants	
					0-17	%	0-14	15-17	Age stand.*	Cum.	0-14	15-17
Hepatic tumours												
girls	103	1	100	94	9		3	1	2	37	71.8	
boys	124	1	100	115	9		3	1	3	43	72.6	
total	1.2	227	1	100	209	18	3	1	3	40	72.2	
Hepatoblastoma												
girls	85	1	83	85	0		2	0	2	32	74.1	
boys	111	1	90	109	2		3	0	3	39	73.0	
total	1.3	196	1	86	194	2	3	0	2	35	73.5	
Hepatic carcinomas												
girls	18	0	17	9	9		0	1	0	6	61.1	
boys	13	0	10	6	7		0	1	0	4	69.2	
total	0.7	31	0	14	15	16	0	1	0	5	64.5	
Unspecified malignant hepatic tumours												
girls	0	0	0	0	0		0	0	0	0	-	
boys	0	0	0	0	0		0	0	0	0	-	
total	-	0	0	0	0	0	0	0	0	0	-	
Malignant bone tumours												
girls	383	5	100	277	106		6	11	7	129	98.4	
boys	504	5	100	330	174		7	17	8	160	98.0	
total	1.3	887	5	100	607	280	6	14	7	145	98.2	
Osteosarcomas												
girls	195	3	51	143	52		3	6	3	65	99.5	
boys	266	3	53	159	107		3	11	4	83	98.1	
total	1.4	461	3	52	302	159	3	8	4	75	98.7	
Chondrosarcomas												
girls	3	0	1	2	1		0	0	0	1	100.0	
boys	8	0	2	8	0		0	0	0	3	100.0	
total	2.7	11	0	1	10	1	0	0	0	2	100.0	
Ewing tumour and related sarcomas of bone												
girls	175	2	46	126	49		3	5	3	59	98.3	
boys	223	2	44	158	65		3	7	4	72	98.7	
total	1.3	398	2	45	284	114	3	6	3	66	98.5	
Ewing tumour and skin tumour of bone												
girls	166	2	43	120	46		3	5	3	56	98.8	
boys	216	2	43	153	63		3	6	4	69	98.6	
total	1.3	382	2	43	273	109	3	6	3	63	98.7	
Peripheral neuroectodermal tumour (pNET) of bone												
girls	9	0	2	6	3		0	0	0	3	88.9	
boys	7	0	1	5	2		0	0	0	2	100.0	
total	0.8	16	0	2	11	5	0	0	0	3	93.8	
Other specified malignant bone tumours												
girls	9	0	2	5	4		0	0	0	3	77.8	
boys	5	0	1	4	1		0	0	0	2	80.0	
total	0.6	14	0	2	9	5	0	0	0	2	78.6	

Tabelle 9 Forts.

Table 9 cont.

Diagnoses	Sex	N	Number of cases			Incidence rates per million				Trial participants
			m / f	0-17	%	0 - 14	15 - 17	0 - 17	Cum.	
<i>Malignant fibrous neoplasms of bone</i>	girls	0	0	0	0	0	0	0	0	-
	boys	2	0	0	0	1	1	0	0	100.0
	total	-	2	0	0	1	1	0	0	100.0
<i>Malignant chordomas</i>	girls	8	0	2	4	4	0	0	3	87.5
	boys	3	0	1	3	0	0	0	1	66.7
	total	0.4	11	0	1	7	4	0	0	81.8
<i>Odontogenic malignant tumours</i>	girls	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	-
<i>Miscellaneous malignant bone tumours</i>	girls	1	0	0	1	0	0	0	0	0.0
	boys	0	0	0	0	0	0	0	0	-
	total	-	1	0	0	1	0	0	0	0.0
<i>Unspecified malignant bone tumours</i>	girls	1	0	0	1	0	0	0	0	100.0
	boys	2	0	0	0	1	1	0	0	50.0
	total	2.0	3	0	0	2	1	0	0	66.7
<i>Soft tissue and other extraosseous sarcomas</i>	girls	439	6	100	360	79	9	9	154	98.9
	boys	553	6	100	443	110	10	11	10	98.0
	total	1.3	992	6	100	803	189	10	10	98.4
<i>Rhabdomyosarcomas</i>	girls	201	3	46	177	24	4	3	71	100.0
	boys	282	3	51	233	49	6	5	95	99.6
	total	1.4	483	3	49	410	73	5	84	99.8
<i>Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms</i>	girls	52	1	12	40	12	1	1	18	92.3
	boys	55	1	10	44	11	1	1	1	98.2
	total	1.1	107	1	11	84	23	1	1	95.3
<i>Fibroblastic and myofibroblastic tumours</i>	girls	25	0	6	20	5	1	1	9	92.0
	boys	22	0	4	20	2	0	0	7	95.5
	total	0.9	47	0	5	40	7	1	8	93.6
<i>Nerve sheath tumours</i>	girls	27	0	6	20	7	0	1	9	92.6
	boys	33	0	6	24	9	1	1	11	100.0
	total	1.2	60	0	6	44	16	0	10	96.7
<i>Other fibrous neoplasms</i>	girls	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	-

* Standard: Sedi world standard population

- insufficient data

Tabelle 9 Forts.

Table 9 cont.

Diagnoses	Sex	ratio	N	Relative Group	Number of cases			Incidence rates per million			Trial participants	
					m / f	0-17	%	0 - 14	15 - 17	Age stand. *	Cum.	0 - 17
Kaposi sarcoma	girls	1	0	0	1	0		0	0	0	0	100.0
	boys	1	0	0	1	0		0	0	0	0	0.0
	total	1.0	2	0	0	2	0	0	0	0	0	50.0
Other specified soft tissue sarcomas	girls	151	2	34	113	38		3	4	3	52	99.3
	boys	167	2	30	128	39		3	4	3	55	97.0
	total	1.1	318	2	32	241	77	3	4	3	53	98.1
Ewing tumour and askin tumour of soft tissue	girls	33	0	8	24	9		1	1	1	11	97.0
	boys	28	0	5	21	7		0	1	0	9	100.0
	total	0.8	61	0	6	45	16	0	1	1	10	98.4
Peripheral neuroectodermal tumour (pPNET) of soft tissue	girls	3	0	1	2	1		0	0	0	1	100.0
	boys	10	0	2	9	1		0	0	0	3	100.0
	total	3.3	13	0	1	11	2	0	0	0	2	100.0
Extrarenal rhabdoid tumour	girls	28	0	6	27	1		1	0	1	10	100.0
	boys	26	0	5	24	2		1	0	1	9	92.3
	total	0.9	54	0	5	51	3	1	0	1	10	96.3
Liposarcomas	girls	5	0	1	2	3		0	0	0	2	100.0
	boys	6	0	1	2	4		0	0	0	2	100.0
	total	1.2	11	0	1	4	7	0	0	0	2	100.0
Fibrohistiocytic tumours	girls	18	0	4	16	2		0	0	0	6	100.0
	boys	20	0	4	16	4		0	0	0	7	95.0
	total	1.1	38	0	4	32	6	0	0	0	6	97.4
Leiomysarcomas	girls	1	0	0	0	1		0	0	0	0	100.0
	boys	1	0	0	0	1		0	0	0	0	100.0
	total	1.0	2	0	0	2	0	0	0	0	0	100.0
Synovial sarcomas	girls	34	0	8	23	11		0	1	1	11	100.0
	boys	39	0	7	28	11		1	1	1	12	97.4
	total	1.1	73	0	7	51	22	1	1	1	12	98.6
Blood vessel tumours	girls	5	0	1	4	1		0	0	0	2	100.0
	boys	5	0	1	4	1		0	0	0	2	80.0
	total	1.0	10	0	1	8	2	0	0	0	2	90.0
Osseous and chondromatous neoplasms of soft tissue	girls	3	0	1	2	1		0	0	0	1	100.0
	boys	3	0	1	2	1		0	0	0	1	100.0
	total	1.0	6	0	1	4	2	0	0	0	1	100.0

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex	N	Number of cases			Incidence rates per million				Trial participants
			m / f	0-17	%	0 - 14	15 - 17	0 - 17	Cum.	
<i>Alveolar soft parts sarcoma</i>	girls	10	0	2	6	4	0	0	3	100.0
	boys	7	0	1	4	3	0	0	2	100.0
	total	0.7	17	0	2	10	7	0	3	100.0
<i>Miscellaneous soft tissue sarcomas</i>	girls	11	0	3	7	4	0	0	4	100.0
	boys	22	0	4	18	4	0	0	7	100.0
	total	2.0	33	0	3	25	8	0	6	100.0
<i>Unspecified soft tissue sarcomas</i>	girls	34	0	8	29	5	1	1	12	100.0
	boys	48	1	9	37	11	1	1	16	93.8
	total	1.4	82	0	8	66	16	1	14	96.3
Germ cell tumours, trophoblastic tumours and neoplasms of gonads	girls	345	5	100	278	67	7	7	120	96.5
	boys	327	3	100	212	115	5	12	6	106
	total	0.9	672	4	100	490	182	6	9	97.3
<i>Intracranial and intraspinal germ cell tumours</i>	girls	55	1	16	46	9	1	1	19	96.4
	boys	132	1	40	99	33	2	3	42	96.2
	total	2.4	187	1	28	145	42	2	2	96.3
<i>Intracranial and intraspinal germinoma</i>	girls	28	0	8	21	7	0	1	0	9
	boys	84	1	26	57	27	1	3	1	26
	total	3.0	112	1	17	78	34	1	18	100.0
<i>Intracranial and intraspinal teratomas</i>	girls	9	0	3	7	2	0	0	3	88.9
	boys	13	0	4	13	0	0	0	5	69.2
	total	1.4	22	0	3	20	2	0	4	77.3
<i>Intracranial and intraspinal embryonal carcinoma</i>	girls	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	-
<i>Intracranial and intraspinal yolk sac tumour</i>	girls	1	0	0	1	0	0	0	0	100.0
	boys	5	0	2	4	1	0	0	2	100.0
	total	5.0	6	0	1	5	1	0	1	100.0
<i>Intracranial and intraspinal choriocarcinoma</i>	girls	4	0	1	4	0	0	0	1	100.0
	boys	0	0	0	0	0	0	0	0	-
	total	-	4	0	1	4	0	0	1	100.0
<i>Intracranial and intraspinal tumours of mixed for</i>	girls	13	0	4	13	0	0	0	5	92.3
	boys	30	0	9	25	5	0	1	10	96.7
	total	2.3	43	0	6	38	5	0	7	95.3

* Standard: Sedi world standard population

- insufficient data

Tabelle 9 Forts.

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Table 9 cont.

Diagnoses	Sex	Sex ratio m / f	N	Relative Group	Number of cases			Incidence rates per million				Trial participants %
					0-17	%	Age group	0 - 14	15 - 17	0 - 17	Cum.	
Malignant extracranial and extragonadal germ cell tumours	girls	107	1	31	105	2		3	0	3	39	99.1
	boys	67	1	20	51	16		1	2	1	23	98.5
	total	0.6	174	1	26	156	18	2	1	2	31	98.9
Germinomas of extracranial and extragonadal sites	girls	7	0	2	7	0		0	0	0	3	100.0
	boys	12	0	4	6	6		0	1	0	4	100.0
	total	1.7	19	0	3	13	6	0	0	0	3	100.0
Malignant teratomas of extracranial and extragonadal sites	girls	53	1	15	53	0		2	0	1	20	100.0
	boys	28	0	9	28	0		1	0	1	10	96.4
	total	0.5	81	0	12	81	0	1	0	1	15	98.8
Embryonal carcinomas of extracranial and extragonadal sites	girls	0	0	0	0	0		0	0	0	0	-
	boys	0	0	0	0	0		0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0	-
Yolk sac tumour of extracranial and extragonadal sites	girls	29	0	8	28	1		1	0	1	11	96.6
	boys	13	0	4	9	4		0	0	0	4	100.0
	total	0.4	42	0	6	37	5	1	0	0	7	97.6
Choriocarcinomas of extracranial and extragonadal sites	girls	0	0	0	0	0		0	0	0	0	-
	boys	0	0	0	0	0		0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0	-
Other and unspecified malignant mixe gem cell tumours of extracranial and extragonadal sites	girls	18	0	5	17	1		0	0	0	7	100.0
	boys	14	0	4	8	6		0	1	0	5	100.0
	total	0.8	32	0	5	25	7	0	0	0	6	100.0
Malignant gonadal germ cell tumours	girls	171	2	50	123	48		3	5	3	57	98.2
	boys	128	1	39	62	66		2	7	2	41	100.0
	total	0.7	299	2	44	185	114	2	6	3	49	99.0
Malignant gonadal germinomas	girls	48	1	14	32	16		1	2	1	16	100.0
	boys	14	0	4	4	10		0	1	0	4	100.0
	total	0.3	62	0	9	36	26	0	1	1	10	100.0
Malignant gonadal teratomas	girls	33	0	10	29	4		1	0	1	11	93.9
	boys	15	0	5	13	2		0	0	0	5	100.0
	total	0.5	48	0	7	42	6	0	0	0	8	95.8
Malignant gonadal embryonal carcinomas	girls	0	0	0	0	0		0	0	0	0	-
	boys	8	0	2	0	8		0	1	0	2	100.0
	total	-	8	0	1	0	8	0	0	0	1	100.0

- insufficient data

Tabelle 9 Forts.

Table 9 cont.

Diagnoses	Sex	N	Relative Group	Number of cases			Incidence rates per million			Trial participants
				m / f	0-17	%	0 - 14	15 - 17	0 - 17	
<i>Malignant gonadal tumour</i>										
girls	22	0	6	17	5	0	0	1	7	95.5
boys	23	0	7	21	2	1	0	1	8	100.0
total	1.0	45	0	38	7	0	0	0	8	97.8
<i>Malignant gonadal choriocarcinoma</i>										
girls	5	0	1	4	1	0	0	0	2	100.0
boys	0	0	0	0	0	0	0	0	0	-
total	-	5	0	1	4	1	0	0	1	100.0
<i>Malignant gonadal tumours of mixed forms</i>										
girls	63	1	18	41	22	1	2	1	21	100.0
boys	68	1	21	24	44	1	4	1	21	100.0
total	1.1	131	1	19	65	66	1	3	1	21
<i>Malignant gonadal gonadoblastoma</i>										
girls	0	0	0	0	0	0	0	0	0	-
boys	0	0	0	0	0	0	0	0	0	-
total	-	0	0	0	0	0	0	0	0	-
<i>Gonadal carcinomas</i>										
girls	10	0	3	3	7	0	1	0	3	40.0
boys	0	0	0	0	0	0	0	0	0	-
total	-	10	0	1	3	7	0	0	2	40.0
<i>Other and unspecified malignant gonadal tumours</i>										
girls	2	0	1	1	1	0	0	0	1	100.0
boys	0	0	0	0	0	0	0	0	0	-
total	-	2	0	0	1	1	0	0	0	100.0
<i>Other malignant epithelial neoplasms and malignant melanomas</i>										
girls	275	4	100	186	89	4	9	5	92	76.7
boys	222	2	100	155	67	3	7	4	71	73.0
total	0.8	497	3	100	341	156	3	8	81	75.1
<i>Adrenocortical carcinomas</i>										
girls	9	0	3	7	2	0	0	0	3	88.9
boys	8	0	4	8	0	0	0	0	3	100.0
total	0.9	17	0	3	15	2	0	0	3	94.1
<i>Thyroid carcinomas</i>										
girls	108	1	39	75	33	2	4	2	36	84.3
boys	61	1	27	46	15	1	2	1	19	88.5
total	0.6	169	1	34	121	48	1	2	1	27
<i>Nasopharyngeal carcinomas</i>										
girls	3	0	1	1	2	0	0	0	1	100.0
boys	22	0	10	11	11	0	1	0	7	86.4
total	7.3	25	0	5	12	13	0	1	4	88.0
<i>Malignant melanomas</i>										
girls	33	0	12	27	6	1	1	1	11	45.5
boys	40	0	18	31	9	1	1	1	13	40.0
total	1.2	73	0	15	58	15	1	1	12	42.5

* Standard: Sedi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Table 9 cont.

Diagnoses	Sex		Number of cases		Incidence rates per million		Trial par-		
	Sex ratio m / f	N	Relative Group 0-17	%	Age group 0-14	15-17	Age stand. *	Cum.	participants %
Skin carcinomas									
girls	5	0	2	5	0	0	0	2	40.0
boys	5	0	2	3	2	0	0	2	40.0
total	1.0	10	0	2	8	2	0	2	40.0
Other and unspecified carcinomas									
girls	117	2	43	71	46	1	5	2	78.6
boys	86	1	39	56	30	1	3	1	73.3
total	0.7	203	1	41	127	76	1	4	33
Carcinomas of salivary glands									
girls	9	0	3	8	1	0	0	3	33.3
boys	9	0	4	8	1	0	0	3	33.3
total	1.0	18	0	4	16	2	0	0	3
Carcinomas of colon and rectum									
girls	5	0	2	4	1	0	0	2	60.0
boys	13	0	6	5	8	0	1	0	46.2
total	2.6	18	0	4	9	9	0	0	50.0
Carcinomas of appendix									
girls	66	1	24	44	22	1	2	1	97.0
boys	32	0	14	26	6	0	1	1	100.0
total	0.5	98	1	20	70	28	1	1	98.0
Carcinomas of lung									
girls	8	0	3	1	7	0	1	0	75.0
boys	10	0	5	5	5	0	1	0	70.0
total	1.3	18	0	4	6	12	0	1	72.2
Carcinomas of thymus									
girls	2	0	1	0	2	0	0	1	0.0
boys	0	0	0	0	0	0	0	0	-
total	-	2	0	0	2	0	0	0	0.0
Carcinomas of breast									
girls	1	0	0	0	1	0	0	0	0.0
boys	0	0	0	0	0	0	0	0	-
total	-	1	0	0	1	0	0	0	0.0
Carcinomas of cervix uteri									
girls	1	0	0	1	0	0	0	0	0.0
boys	0	0	0	0	0	0	0	0	-
total	-	1	0	1	0	0	0	0	0.0
Carcinomas of bladder									
girls	2	0	1	0	2	0	0	1	50.0
boys	1	0	0	0	1	0	0	0	100.0
total	0.5	3	0	1	0	3	0	0	66.7
Carcinomas of eye									
girls	0	0	0	0	0	0	0	0	0.0
boys	1	0	0	1	0	0	0	0	0.0
total	-	1	0	1	0	0	0	0	0.0

Tabelle 9 Forts.

Table 9 cont.

Diagnoses	Sex	N	Relative Group	Number of cases			Incidence rates per million				Trial participants
				m / f	0-17	%	0 - 14	15 - 17	0 - 17	Cum.	
Carcinomas of other specified sites	girls	20	0	7	12	8	0	1	0	7	65.0
	boys	13	0	6	7	6	0	1	0	4	69.2
	total	0.7	33	0	7	19	14	0	1	5	66.7
Carcinomas of unspecified site	girls	3	0	1	1	2	0	0	0	1	66.7
	boys	7	0	3	4	3	0	0	0	2	71.4
	total	2.3	10	0	2	5	5	0	0	2	70.0
Others and unspecified malignant neoplasms	girls	16	0	100	15	1	0	0	0	6	75.0
	boys	14	0	100	12	2	0	0	0	5	85.7
	total	0.9	30	0	100	27	3	0	0	5	80.0
Other specified malignant tumours	girls	11	0	69	10	1	0	0	0	4	81.8
	boys	12	0	86	11	1	0	0	0	4	83.3
	total	1.1	23	0	77	21	2	0	0	4	82.6
Gastrointestinal stromal tumour	girls	1	0	6	1	0	0	0	0	0	100.0
	boys	1	0	7	1	0	0	0	0	0	100.0
	total	1.0	2	0	7	2	0	0	0	0	100.0
Pancreatoblastoma	girls	3	0	19	3	0	0	0	0	1	66.7
	boys	1	0	7	0	1	0	0	0	0	0.0
	total	0.3	4	0	13	3	1	0	0	1	50.0
Pulmonary blastoma and pleuropulmonary blastoma	girls	6	0	38	6	0	0	0	0	2	100.0
	boys	10	0	71	10	0	0	0	0	4	90.0
	total	1.7	16	0	53	16	0	0	0	3	93.8
Other complex mixed and stromal neoplasms	girls	0	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0.0
Mesothelioma	girls	1	0	6	0	1	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	-
	total	-	1	0	3	0	1	0	0	0	0.0
Other specified malignant tumours	girls	0	0	0	0	0	0	0	0	0	-
	boys	0	0	0	0	0	0	0	0	0	-
	total	-	0	0	0	0	0	0	0	0	0.0
Other unspecified malignant tumours	girls	5	0	31	5	0	0	0	0	2	60.0
	boys	2	0	14	1	1	0	0	0	1	100.0
	total	0.4	7	0	23	6	1	0	0	1	71.4

* Standard: Seeti world standard population

- insufficient data

112 Tabellen und Abbildungen / Tables and Figures

Tabelle 10:

Zahl der vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister (LKR) bis einschließlich 2016 weitergeleiteten Meldungen

Number of forwarded reports from the German Childhood Cancer Registry to the state cancer registries (LKR) up to and including 2016

State cancer registry	Diagnosis period		Cases
	from	to	
Krebsregister Schleswig-Holstein	01.01.2010	15.07.2015	469
Hamburgisches Krebsregister	01.01.2011	15.01.2016	231
Epidemiologisches Krebsregister Niedersachsen	01.01.2011	15.07.2016	1125
Bremer Krebsregister	01.01.2010	15.07.2015	77
Epidemiologisches Krebsregister NRW	01.01.2010	15.07.2015	2640
Hessisches Krebsregister	01.01.2010	15.07.2015	899
Krebsregister Rheinland-Pfalz	01.01.2010	15.07.2015	573
Bevölkerungsbezogenes Krebsregister Bayern	01.01.2011	15.07.2016	1792
Epidemiologisches Krebsregister Saarland	01.01.2010	15.07.2015	134
Gemeinsames Krebsregister GKR *	01.01.2011	15.07.2016	1970
Gesamt			9910

* der Länder Berlin, Brandenburg, Mecklenburg-Vorpommern, Sachsen-Anhalt und der Freistaaten Sachsen und Thüringen / the states Berlin, Mecklenburg-Western Pomerania, Saxony-Anhalt, the Free States of Saxony and Thuringia

Anmerkung>Note:

Die gesetzlichen Regelungen zur epidemiologischen Krebsregistrierung im gemeinsamen Krebsregister (GKR) und im epidemiologischen Krebsregister Niedersachsen unverändert, in allen übrigen Ländern sind seit 2014 zunehmend veränderte Gesetze in Kraft getreten.

Neues zu Forschungsprojekten / News on Research Projects **114**

Tabelle 11 / Table 11 **120**

Forschungsprojekte und internationale Kooperationsprojekte seit 2014

Tabelle 12 / Table 12 **123**

Research projects and international cooperations since 2014

ACCIS: Automated Childhood Cancer Information System

In ACCIS, einem europäischen Projekt, wurden bis 1997 die Daten sämtlicher bevölkerungsbezogener Krebsregister zu Kindern und Jugendlichen in Europa in Bezug auf Inzidenz und Überlebenswahrscheinlichkeiten zusammengeführt (34). Derzeit werden die Daten bis 2009 und zum Teil bis 2012 für eine aktualisierte Fassung bei der IARC (International Agency for Research on Cancer) ausgewertet.

Das Deutsche Kinderkrebsregister hat seine Daten zu dem Projekt beigetragen.

EUROCARE: EUROpean CAncer REgistry Based Study on Survival and Care of Cancer Patients

Das EUROCARE-Projekt ist ein von der EU finanziertes Projekt, das Ende der achtziger Jahre begann und in dem Überlebenswahrscheinlichkeiten bei Krebspatienten im internationalen Vergleich und unter Berücksichtigung zeitlicher Trends systematisch und umfassend analysiert werden. Zuletzt wurden die Daten der EUROCARE-5-Studie, die die Jahre bis 2007 abdeckt, publiziert (29, 41, 42). Das Deutsche Kinderkrebsregister hat seine Daten für die aktuelle EUROCARE-6-Studie eingereicht und Publikationen sind in Vorbereitung.

PanCare: Forschungsprojekte im Rahmen des PanCare-Netzwerkes

Das Netzwerk PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) ist ein Zusammenschluss von Experten (z.B. Medizinern, Epidemiologen) und Betroffenen (Eltern und Langzeitüberlebende). Ziel ist es, Häufigkeit, Schwere und Auswirkungen von Spätfolgen der Therapie bei Kindern und Jugendlichen mit einer Krebserkrankung zu reduzieren. Das langfristige strategische Ziel ist es sicherzustellen, dass jeder europäische ehemalige Patient eine optimale Langzeitnachsorge erhält (32).

Zwei EU-finanzierte Projekte wurden aus dem PanCare Netzwerk initiiert:

PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies

PanCareSurFup (www.pancaresurfup.eu) startete im Februar 2011 und ging Ende Januar 2017 zu Ende. Das Projekt umfasst 16 Partner. Im Rahmen dieser Verbund-Forschung wurden Richtlinien entwickelt, um die Nachsorge ehemaliger Patienten zu optimieren und eine Grundlage für forschungsbezogene Informationen bereitzustellen, die alle Spätfolgen der Krebstherapie betreffen. Eine große europäische Kohorte von über 100.000 ehemaligen Patienten mit einer Krebserkrankung

ACCIS: Automated Childhood Cancer Information System

The European project ACCIS collected data from all European population based registries with data on children and adolescents with respect to incidence and survival probabilities. They published data available until 1997 (34). Currently data up to 2009 and partially up to 2012 is being analyzed at IARC (International Agency for Research on Cancer) for an updated version.

The German Childhood Cancer Registry has contributed its data to the project.

EUROCARE: EUROpean CAncer REgistry Based Study on Survival and Care of Cancer Patients

EUROCARE is an EU funded project, founded in the late 1980ies, which aims at comparing and analyzing international survival data on cancer patients. Regarding children, the latest published data in EUROCARE-5 covers the years until 2007 (29, 41, 42). Survival probabilities for childhood cancers have greatly improved, but differences among countries persist. The German Childhood Cancer Registry contributed its data to the current EUROCARE-6 study and publications are being prepared.

PanCare: Research in the Framework of the PanCare Network

PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) is a multidisciplinary pan-European network of professionals (such as clinicians and epidemiologists), survivors, and their families that aims to reduce the frequency, severity, and impact of late side-effects of the treatment of children and adolescents with cancer. The long-term strategic aim of PanCare is to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care (32).

The PanCare network has so far started two EU-funded projects:

PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies

PanCareSurFup (www.pancaresurfup.eu) started in February 2011 and ended in January 2017. It included 16 partners. The joint research aimed to provide a basis for establishing guidelines for follow-up in Europe, as well as a basis for research generating information on late effects of cancer therapies. The project has collated a large European cohort of more than 100,000 former patients with cancer in childhood or adolescence, their follow-up, and potential late

kung im Kindes- und Jugendalter wurde aufgebaut, nachbeobachtet und mögliche Spätfolgen wurden speziell untersucht. Dazu zählt das Auftreten von Zweittumoren, Herzschädigungen und das Versterben der Patienten mehr als fünf Jahre nach der Erkrankung (late mortality). Erste Publikationen sind erschienen (35, 39, 49).

PanCareLIFE: PanCare Studien zu Fertilität, Ototoxizität und Lebensqualität nach Krebs im Kindes- und Jugendalter

An dem im November 2013 begonnenen EU-finanzierten Forschungsprojekt PanCareLIFE (www.pancare-life.eu) sind Wissenschaftler aus acht europäischen Nationen beteiligt. Fertilität, Ototoxizität und gesundheitsbezogene Lebensqualität stehen im Fokus dieses Projektes. Insgesamt fließen die Daten von rund 32.000 Betroffenen in das Vorhaben ein. Anhand dieser Daten wollen die beteiligten Forscher Risikofaktoren identifizieren, die möglicherweise im Zusammenhang mit Infertilität und Ototoxizität stehen. Dazu wird DNA untersucht um festzustellen, welche genetischen Varianten potentiell mit diesen Spätfolgen assoziiert sind. Auch Leitlinien zur Fertilitätserhaltung werden erarbeitet. PanCareLIFE wird an der Universitätsmedizin Mainz koordiniert und endet Ende 2018 (22,32,35).

KiKme: Krebserkrankungen im Kindesalter und molekulare Epidemiologie

Die Studie „Krebserkrankungen im Kindesalter und molekulare Epidemiologie“ – KiKme konzentriert sich auf die Erforschung von angeborenen Risikofaktoren bei der Entstehung von Krebserkrankungen im Kindesalter. Für ehemalige und aktuell betroffene Kinder hat diese Grundlagenforschung keinen direkten Nutzen, wird jedoch langfristig und im Zusammenhang mit anderen Forschungsvorhaben einen praktischen Nutzen in der Medizin erlangen.

Der Schwerpunkt liegt auf der Untersuchung des Zusammenspiels zwischen Erbanlagen und Strahlung bei der Entstehung von Krebserkrankungen. Dabei sollen spezifische Wege der Krebsentstehung erforscht werden, um den Einfluss von angeborenen Veranlagungen und von molekularen Markern der Strahlenempfindlichkeit auf die Reparatur unserer Erbinformationen zu untersuchen. Dies erfolgt durch einen Vergleich von Bestrahlungsversuchen an Hautproben von Studienteilnehmern. Die Gewebeproben aus der Haut werden dann zur Bestimmung von Laborwerten und für die Bestimmung von Erbinformationen und ihrer Botenstoffe (genetische Untersuchungen) herangezogen. Es sollen drei Gruppen miteinander verglichen werden: Studienteilnehmer mit einer erneuten Krebserkrankung nach einer früheren Krebserkrankung im Kindesalter, Studienteilnehmer mit nur einer Krebserkrankung im Kindesalter und Studienteilnehmer ohne Krebserkrankung. Die Krebspatienten wurden über das Deutsche

effects. These include cardiac disease, second cancers and late mortality (more than 5 years after diagnosis). First publications have been published (35,39,49).

PanCareLIFE: PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood

Scientists from 8 European nations contribute to the EU-funded research project PanCareLIFE (www.pancarelife.eu). The main issues of this project are fertility, ototoxicity, and quality of life. Data from 32,000 former patients are included in the project. The researchers will identify risk factors for ototoxicity and infertility. This includes an examination of DNA, which may modify the risk for these late effects. The project includes a work package which develops guidelines for fertility preservation. PanCareLIFE is coordinated at the University Medical Centre in Mainz and ends at the end of 2018 (22,32,35).

KiKme: Cancer in childhood and molecular epidemiology

The focus of the study „Cancer in childhood and molecular epidemiology“ – KiKme – is to explore genetic risk factors for the development of cancer during childhood. This basic research is of no direct benefit to formerly or currently affected children; however, it will be of practical use in the medical field in the long run and in connection with other research projects.

The main focus is to research the interaction of genetic factors and radiation in the development of cancer. Specific pathways of the development of cancer will be researched in order to explore the influence of congenital predispositions and of molecular markers for radiation sensitivity on the repair mechanisms of our genetic information. This is being done by comparing study participants' skin samples, which were irradiated. The tissue samples from the skin are used to measure laboratory values and to identify genetic information and their messenger substances (genetic examination). Three groups will be compared with one another: patients with a second neoplasm after childhood cancer, patients with only one primary neoplasm in childhood, and control patients without cancer. The cancer patients were identified by the German Childhood Cancer Registry. The project was funded by the German Federal Ministry of Education and Research (BMBF) and is part of the research consortium ISIBELa.

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Kinderkrebsregister bestimmt. Die Studie wird vom Bundesministerium für Bildung und Forschung (BMBF) finanziert und ist Teil des ISIBELa Forschungsverbundes.

VIVE: Basiserhebung zu Lebenssituation, Gesundheitszustand und Lebensqualität nach onkologischer Erkrankung im Kindes- und Jugendalter

Die Heilungschancen nach Krebs im Kindesalter liegen mittlerweile je nach Erkrankungsart bei 70 - 95 Prozent. Die notwendigen Therapien (u.a. Chemo- und Strahlentherapie) können Spätfolgen verursachen; diese werden im Rahmen des Projekts VIVE näher erfasst. Dazu werden die ehemaligen, jetzt erwachsenen Patienten (mindestens 25 Jahre alt) mittels Fragebogen in einer umfassenden Basiserhebung nach (psycho-) somatischen Spätfolgen, ihrem jetzigen Gesundheitszustand und ihrer Lebensqualität befragt.

Die Gesamtkoordination und zusammenfassende Auswertung erfolgt durch die Projektleitung in Bonn (Universitätsklinikum Bonn, Zentrum für Kinderheilkunde, Abt. Pädiatrische Hämatologie und Onkologie). Das Deutsche Kinderkrebsregister in Mainz führt die eigentliche Befragung (mittels Fragebogen) durch und wertet zudem die Angaben zu den Zweitmalignomen aus. Eine Arbeitsgruppe in Hannover ordnet die Patientendaten den ehemaligen Therapieoptimierungsstudien mit Hilfe einer Therapiedatenbank zu (20).

Die Befragung der etwa 10000 ehemaligen Patienten begann im Jahre 2014 und endete 2015.

CVSS: Kardiale und vaskuläre Spätfolgen bei Langzeitüberlebenden nach Krebserkrankungen im Kindesalter

Das Projekt „Kardiale und vaskuläre Spätfolgen von Langzeit-Überlebenden nach Krebs im Kindes- und Jugendalter“ (**C**ardiac and **v**ascular **s**equelae in **l**ong-term **s**urvivors of **c**hildhood **c**ancer, CVSS) wird von der Deutschen Forschungsgemeinschaft (DFG) gefördert und startete im Juli 2013. Es wird an der Universitätsmedizin Mainz als interdisziplinäres, kooperatives Projekt des Deutschen Kinderkrebsregisters am IMBEI, der Pädiatrischen Hämatologie/Onkologie/Hämostaseologie des Zentrums für Kinder- und Jugendmedizin und der Präventiven Kardiologie und Medizinische Prävention an der der II. Medizinischen Klinik und Poliklinik durchgeführt.

Ziel der CVSS-Studie ist es, die Zusammenhänge zwischen der Behandlung von Krebserkrankungen im Kindesalter und den Spätfolgen für das Herz-Kreislauf-System zu erforschen, um frühzeitig Risikogruppen für das Auftreten von Therapiespätfolgen zu identifizieren und schließlich Empfehlungen für Vorsorgeuntersuchungen ableiten zu können sowie eine zielgerichtete Nachsorge zu ermöglichen.

Insgesamt wurden über das Deutsche Kinderkrebsre-

VIVE: Baseline Survey on Life Situation, Health, and Quality of Life after an Oncological Disease in Childhood or Adolescence

The chances of survival after cancer in childhood are between 70 and 90% nowadays, depending on the disease entity. The therapies necessary for this (such as chemo- and radiotherapy) can potentially cause late effects; these are the research topic of VIVE. For this, all former patients who are adults now (at least 25 years of age) are invited to participate in a baseline survey of their current situation: (psycho-) somatic late effects, current health status, and quality of life.

The coordination and concluding analysis and evaluation lie with the principal investigators in Bonn (Universitätsklinikum Bonn, Zentrum für Kinderheilkunde, Abt. Pädiatrische Hämatologie und Onkologie). The German Childhood Cancer Registry in Mainz conducts the technical side of the survey (with a questionnaire) and analyses the second neoplasm information. A working group in Hannover retrospectively assigns the therapy data with the help of a therapy data base (20).

The survey, including about 10,000 former patients, started in 2014 and ended in 2015.

CVSS: Cardiac and vascular late sequelae in long-term survivors of childhood cancer - a multidisciplinary clinical, epidemiological and genetic approach

The project “Cardiac and vascular late sequelae in long-term survivors of childhood cancer” (CVSS-study) is funded by the Deutsche Forschungsgemeinschaft (DFG) and was launched in July 2013. It is conducted jointly at the University Medical Center Mainz by the German Childhood Cancer Registry at the IMBEI, the Pediatric Hematology/Oncology/Hemostaseology at the Center for Childhood and Adolescent Medicine, and the Preventive Cardiology and Medical Prevention at the 2nd Medical Clinic and Polyclinic.

The aim of the CVSS-study is to investigate the correlation between childhood cancer treatment and cardio-vascular late-sequelae to identify risk groups for the occurrence of therapy-associated late sequelae early on and to eventually infer recommendations for medical screening and to make targeted follow-up care possible.

Altogether 2,657 former patients have been invited by

gister 2.657 ehemalige Patienten eingeladen, an der CVSS-Studie teilzunehmen, rund 1000 wurden in dem standardisierten kardiovaskulären Untersuchungsprogramm im Mainzer Studienzentrum der „Gutenberg-Gesundheitsstudie“ untersucht. Ein besonderes Augenmerk liegt auf subklinischen Veränderungen. Die unmittelbar erhobenen und medizinisch relevanten Untersuchungsergebnisse werden den Teilnehmern in einem umfassenden Bericht zur Besprechung mit dem Haus- oder Facharzt ausgehändigt (21,26,46,48). Weitere Informationen zur CVSS-Studie finden sich unter www.CVSS-Studie.de.

Strukturoptimierung für krebskranke Kinder nach Anthrazyklintherapie - Eine Studie zur Ursache und Früherkennung der Anthrazyklin-induzierten Kardiomyopathie nach Behandlung eines Nephro- und Neuroblastoms

Die häufigsten soliden Tumore im Kleinkindalter sind Nephro- und Neuroblastome. Die Heilungschance für diese Tumore liegen – abgesehen von Neuroblastom Stadium IV – bei über 80%. Diese erfolgreiche Therapie kann aber auch eine Schädigung am kindlichen Herzmuskel verursachen. Bekannte Risikofaktoren sind das junge Alter der Patienten, die Anthrazyklindosis und eine Strahlentherapie mit Streustrahlung auf den Herzmuskel.

Ziel der Studie ist die Anbindung dieser Patienten an die Kardiologen des Kompetenznetzes „Angeborene Herzfehler“ und die Erfassung von kardiologischen Spätfolgen bei Kindern und Jugendlichen nach einer Nephroblastom- bzw. Neuroblastombehandlung in den Jahren 1990-2012. Hierbei werden vorhandene Strukturen des Deutschen Kinderkrebsregisters, des Nachsorgenetzwerkes LESS (Late Effects Surveillance System), der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) und des Kompetenznetzes „Angeborene Herzfehler“ (KN-AHF) genutzt. Eine Untersuchung der ehemals krebskranken Kinder und Jugendliche durch Ärzte des KN-AHF bietet den Vorteil, dass Kinderkardiologen und internistische Kardiologen mit einer spezifischen Weiterbildung die Versorgung der ehemals krebskranken Kinder und Jugendlichen, aber auch der mittlerweile Erwachsenen übernehmen. Im Rahmen dieser Versorgungsforschung sollen eine neue standardisierte kardiologische Untersuchung durchgeführt, sowie die Lebensqualität und Lebenssituation der ehemaligen Patienten analysiert und mit den kardiologischen Befunden korreliert werden. Zur Überarbeitung der klinischen Risikoprofile ist die Entnahme und Asservierung einer Blutprobe vorgesehen. Die Erstellung von individuellen Risikoprofilen ermöglicht in zukünftigen Therapieoptimierungsstudien eine dem einzelnen Patienten angepasste Therapie. Das Auftreten der Anthrazyklin-induzierten Kardiotoxizität in Zukunft vermindert und damit die Langzeitprognose dieser Patienten verbessert werden.

the GCCR to participate in the CVSS-study. More than 1000 former patients have already been examined with a standardized cardiovascular examination program at the study center of the “Gutenberg Health Study” in Mainz. Subclinical diseases are particularly looked at. The patients are provided with the immediately available and medically relevant results of their examinations in a comprehensive report for their general practitioner or medical specialist (21,26,46,48).

More information is available at www.CVSS-Studie.de.

Structural Optimization for Childhood Cancer Survivors after Anthracycline Therapy – A Study on Causes and Early Detection of Anthracycline-induced Cardiomyopathy after the Therapy of a Nephro- or Neuroblastoma

Nephro- and Neuroblastomas are the most frequent solid tumours in small children. The survival probability is 80% or more (except for advanced stage neuroblastoma). These successful therapies may however also damage a child's myocardial muscle. Known risk factors are very young age, the anthracycline dose and radiotherapy with myocardial involvement.

The goal of this study is to connect these patients to the cardiologists of the Competence Network for Congenital Heart Defects and to record cardiological late effects in children and adolescents after treatment of a Nephro- or Neuroblastoma in the years 1990-2012. The project uses existing structures of the German Childhood Cancer Registry, the network LESS (Late Effects Surveillance System), the Society for Pediatric Oncology and Hematology (GPOH) and the Competence Network for Congenital Heart Defects (KN-AHF). Having the former childhood cancer patients examined by physicians in the KN-AHF has the advantage that pediatric cardiologists with specific qualifications provide the care for the children, adolescents and young adults. This research includes a standardized cardiologic examination and an assessment of Quality of Life and correlates the findings. In order to improve future risk profiling also blood samples are drawn and stored. In the long run, individual risk profiles will permit to adapt treatment in future therapy optimization studies and are expected to reduce anthracycline-induced cardio-toxicity and contribute to an improved long-term prognosis.

STATT-SCAR-Studie (Second Tumour After Tumour Therapy - Second Cancer After Radiotherapy)

Folgeneoplasien, also ein weiterer Krebs, sind eine Spätfolge, an der etwa 8% der Langzeitüberlebenden nach Krebs im Kindesalter in Deutschland innerhalb von 35 Jahren nach ihrer Erstneoplasie erkranken (51). Wichtige Risikofaktoren für Folgeneoplasien sind die Therapien zur Behandlung des Primärtumors.

Basierend auf der Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters wird eine Fall-Kontroll-Studie bestehend aus 1244 Fällen mit einer Folgeneoplasie und gematchten Kontrollen durchgeführt. Die Therapiedaten werden entweder basierend auf den Angaben der jeweiligen Therapieoptimierungsstudien aus der GPOH-Therapieprotokoll Datenbank erhoben oder durch Evaluation der Patientenakten aus den Kliniken für pädiatrische Onkologie und Radiotherapiezentren. Es sollen Unterschiede in der Behandlung zwischen Fällen und Kontrollen ermittelt werden. Primäres Ziel der Studie ist es, das Risiko von Folgenoplasien durch die medikamentöse Krebstherapie und durch die Radiotherapie zu quantifizieren. Dies kann mithelfen, eine Grundlage dafür zu schaffen, zukünftige Therapieprotokolle so zu gestalten, dass bei einem optimalen Therapieerfolg das Risiko für Folgenoplasien möglichst gering gehalten wird. Des Weiteren werden Risikogruppen für die Entwicklung einer Folgenoplasie identifiziert (nach Krebsart, Alter bei Erstdiagnose, Latenzzeit etc.). Diese Informationen können weiterhin einen Beitrag bei der Entwicklung von Nachsorgeleitlinien leisten. Die STATT-Studie wird von der Deutschen Krebshilfe finanziert. Die SCAR-Studie wird vom Bundesministerium für Bildung und Forschung (BMBF) finanziert und ist Teil des ISIBELa Forschungsverbundes.

Info-Onko: Evaluation der psychosozialen Situation von Langzeitüberlebenden einer Krebserkrankung im Kindes- oder Jugendalter

Über die Bedürfnisse und alltäglichen Herausforderungen von ehemaligen Patienten nach ihrer Krebserkrankung im Kindes- oder Jugendalter ist bislang wenig bekannt; ehemals Betroffene bemängeln aber, dass in ihrem Alltag Schwierigkeiten auftreten, die sie selbst auf ihre Erkrankung oder Therapie zurückführen, Fachleute jedoch nicht als solche anerkennen und sich bestehende Hilfsangebote lediglich auf evidenzbasierte medizinische Problematiken beziehen.

Das Projekt Info-Onko hat zum Ziel, die psychosoziale Situation Langzeitüberlebender zukünftig besser zu verstehen und ihre Wünsche und Bedürfnisse in Bezug auf die Langzeitnachsorge zu erfassen. Durch qualitative Interviews ehemaliger Betroffener wurde erhoben, in welchen Bereichen Herausforderungen bestehen und ein Fragebogen auf Basis der so identifizierten Oberthemen entwickelt. Mithilfe dieses Fragebogens werden deutschlandweit ehemals erkrankte Patienten, die sich in der Langzeitnachbeobachtung des Deutschen KinderkrebsRegisters befinden, befragt, um be-

STATT-SCAR-Study (Second Tumour After Tumour Therapy - Second Cancer After Radiotherapy)

Second neoplasms, i.e. subsequent cancers, are a late effect, which occurs in about 8% of long-term survivors after cancer in childhood in Germany within 35 years after the first neoplasm (51). Important risk factors for second neoplasms are the therapies for the treatment of the first neoplasm.

Based on the long-term follow-up cohort of the German Childhood Cancer registry, the STATT-SCAR study carries out a case-control study which consists of 1244 cases with a second neoplasm and matched controls. Data is obtained either from the GPOH therapy protocol database based on information from the therapy optimization studies or through the examination of patient files in the paediatric oncology centres or radiotherapy centres. Differences in the treatment between cases and controls shall be identified.

The primary aim of the study is to quantify the risk for second neoplasms from chemotherapy and radiotherapy of the first neoplasm. This may help to establish a basis for modifying future therapy protocols in a way that minimizes the risk for second neoplasms while holding up a maximum of therapeutic success. Furthermore, the study will identify risk groups for developing second neoplasms (concerning cancer entity, age at first diagnosis, latency time etc.). This information may contribute to the development of follow-up care guidelines. The STATT-study is funded by the Deutsche Krebshilfe. The SCAR-study is funded by the German Federal Ministry of Education and Research (BMBF) and is part of the research consortium ISIBELa.

Info-Onko: Evaluation of the psychosocial situation of long-term survivors after cancer in childhood or adolescence

Little is known about the needs and daily challenges of long-term survivors after cancer in childhood or adolescence; however, the former patients criticise that they face difficulties in their daily lives which they ascribe to their cancer or its therapy, but which specialists do not recognise as such, and that existing assistance applies only to evidence-based medical problems.

The aim of the project Info-Onko is to better understand the psychosocial situation of survivors and to gather their requests and needs with respect to long-term care. Qualitative interviews of former patients were used to identify areas which present a challenge, and a questionnaire was developed based on these areas. This questionnaire is used to carry out a nationwide survey of long-term survivors, who are in the long-term follow-up of the German Childhood Cancer Registry, with the aim of obtaining reliable evidence on the challenges of the disease. The results are the basis for developing needs-oriented possibilities to support long-term survivors and to strengthen their self-determined

lastbare Aussagen über bestehende Herausforderungen durch die Erkrankung zu erhalten. Die Ergebnisse bilden die Basis für eine bedarfsorientierte Entwicklung von Unterstützungsmöglichkeiten für ehemalige Patienten und Ihre Stärkung bei der selbstbestimmten Lebens- und Alltagsgestaltung. Sie dienen auch als Voraussetzung für Verhandlungen zur Finanzierung von zielgerichteten Hilfen durch Kostenträger.

E-SURV: Entwicklung innovativer Strategien zu Datenerhebung, Datenaustausch und Follow-up nach Krebs im Kindesalter und Verknüpfung epidemiologischer und klinischer Daten

Die Datenerhebung in der VIVE-Studie umfasste eine papierbasierte Befragung von 10.000 Langzeitüberlebenden nach Krebs im Kindesalter. Die Antwortraten waren moderat und mit den Antwortraten von ähnlichen Studien im internationalen Kontext vergleichbar, sind aber dennoch ausbaufähig.

Das erste Ziel von E-SURV ist es, eine internetbasierte Erhebungsmethode mit der konventionellen papierbasierten Erhebungsmethode innerhalb einer Stichprobe des Deutschen Kinderkrebsregisters (DKKR) von 2000 Langzeitüberlebenden im Alter zwischen 20 und 25 Jahren zu vergleichen. In dieser Altersgruppe ist die Nutzung von Internet und Smartphones weit verbreitet. Falls sich der internetbasierte Ansatz tatsächlich als überlegen herausstellt, wäre dies auch eine optimale Methodologie um einen kontinuierlichen Kontakt zu den Langzeitüberlebenden zu etablieren und zukünftige Forschung zu verbessern.

Das zweite Ziel von E-SURV umfasst die Entwicklung eines Beispiels für eine zusammengeführte Datenplattform, die Informationen bündelt aus

- GPOH Studiengruppen und Therapieoptimierungsstudien, die klinische Daten mit dem Fokus auf Spätfolgen beiträgt
- dem DKKR, das Registerdaten zu Verfügung stellt
- dem „Late effects surveillance system“ (LESS), das (Spätfolgen-)informationen zu Organtoxizitäten sammelt
- der „Quality of Life“-Arbeitsgruppe (**QoL**), die Informationen zur Lebensqualität und dem psychosozialen Status der Patienten erhebt.

Für eine Gruppe von 100 Sarkom-Patienten, deren Daten in den verschiedenen Datenbanken gesammelt wurden, soll ein Beispiel entwickelt werden, wie Daten verschiedener Datenbanken technisch optimal, sicher und unter Wahrung des Datenschutzes und ethischer Grundsätze zusammengeführt werden können.

Beide Ansätze sollen zu einer Weiterentwicklung des Langzeit-Follow-up nach Krebs im Kindesalter beitragen und die Entwicklung innovativer Strategien zu Datenerhebung und –austausch fördern. Dieser sollte im Idealfall in Zukunft an die einzelnen Betroffenen, ihre Wünsche und ihre jeweiligen Risiko-/Spätfolgenprofile angepasst sein.

Beschreibungen der anderen Projekte finden Sie in den vorangegangenen Jahresberichten.

way of living and daily routine. They are also a prerequisite for negotiating the financing of targeted support by the funding agencies.

E-SURV: Development of comprehensive strategies for assessment, data-sharing and follow-up in childhood cancer survivors linking epidemiological and clinical data

The data collection of the VIVE study included a paper based assessment of 10,000 long-term childhood cancer survivors. The response rates were moderate and comparable to international studies implementing the same assessment method, yet are improvable.

The first aim of E-SURV is to compare an internet-based assessment versus conventional paper-pencil assessment among a sample of 2000 long-term survivors registered at the GCCR (German Childhood Cancer Registry) and aged 20 to 25 years, an age group commonly using internet and smartphones. If the response rate of the internet-based approach proves superior, it will be an optimal methodology for continuous contact to survivors and future research.

The second aim of E-SURV is to develop an example for an aggregated data base, sharing information of

- GPOH study groups and treatment optimization studies, which contribute clinical data with focus on long-term effects,
- the GCCR, which provides registry data,
- the “Late effects surveillance system” (LESS), which collects (follow-up) information on organ toxicities, and
- the “Quality of Life” working group (**QoL**), which collects information on quality of life and psychosocial status of patients.

A group of about 100 sarcoma patients, whose data was collected by the different data sources, will be used to test the feasibility of such a joint data base in terms of technical issues, data safety, data privacy and ethical principles.

Both aims may lead to an advanced and comprehensive long-term follow-up of childhood cancer survivors, which is capable to be designed according to well-defined risk groups and adapted to the individual survivor and their needs.

For descriptions of the other projects, please see previous annual reports.

120 Forschungsprojekte / Research Projects

Tabelle 11:

Forschungsprojekte und internationale Kooperationsprojekte seit 2014 (see Table 12 for the English version)

Projektbezeichnung	Studententyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
ACCIIS: Automated Childhood Cancer Information System	Internationale Datenbank	34	IARC, Lyon, Frankreich	nein	J.
EUROCARE: Survival of cancer patients in Europe	Follow-up Studie	29, 41, 42	Istituto Nazionale dei Tumori, Mailand, Italien	nein	J.
Befragungsprojekte ehemaliger Kinderkrebspatienten in Zusammenarbeit zwischen externen Kooperationspartnern und dem DKKR	Registerbasierte Umfragen	24, 44	DKKR; Uni.-Klinik Ulm; Otto-Heubner-Zentrum für Kinder- und Jugendmedizin Berlin; Zentrum für Kinder- und Jugendmedizin Giessen; Uni. Erlangen; BIOGUM, Uni. Hamburg	vom externen Kooperationspartner mitfinanziert	Deutsche Kinderkrebsstiftung, Deutsche Krebshilfe, Eigenmittel der ext. Kooperationspartner, 6. EU-FRP "ACGT-Advancing Clinico-Genomic Clinical Trials on Cancer"
PanCareSurFUp: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	Internationale Kohorten- und Fall-Kontroll-Studie	32, 35, 39, 49	Gesamtleitung: Lund University Hospital, Schweden; Leitung Workpackage 1 (Data Collection and Harmonization); DKKR	ja	Europäische Kommission EU FP7
KiKMe: Krebskrankungen im Kindesalter und molekulare Epidemiologie	Fall-Kontroll-Studie		Studieneleitung: Leibniz-Institut für Präventionsforschung und Epidemiologie - BiPS, Bremen, Verbundleitung: IMBEI	ja	Bundesministerium für Bildung und Forschung
KiCT: Kinderkrebsrisiko nach Exposition durch computertomographische Untersuchungen im Kindesalter	Kohortenstudie	18, 40, 43	IMBEI	ja	Bundesministerium für Bildung und Forschung

Tabelle 11 Forts. **Table 11 cont.**

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
VIVE: Basiserhebung zu Lebenssituation, Gesundheitszustand und Lebensqualität nach onkologischer Erkrankung im Kindes- und Jugendalter	Kohortenstudie	20	Projektkoordination: Universitätsklinikum Bonn, Zentrum für Kinderheilkunde, Abt. Pädiatrische Hämatologie und Onkologie	ja	Deutsche Krebshilfe
PanCareLife: PanCare Studies in Fertility and Ootoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	Internationale Kohorten- und Fall-Kontroll-Studie	22, 32, 35	DKKR	ja	Europäische Kommission EU FP7
CVSS: Kardiale und vaskuläre Spätfolgen bei Langzeitüberlebenden nach Krebserkrankungen im Kindesalter	Kohortenstudie	21, 26, 46, 48,	Universitätsmedizin Mainz; DKKR, Pädiatrische Hämatologie und Onkologie, II. Medizinische Klinik	ja	Deutsche Forschungsgemeinschaft
RASopathien und Krebs im Kindesalter	Kohortenstudie	33, 45	Abt. päd. Hämatologie und Onkologie Hannover, Institut für Humangenetik Magdeburg, Deutsches Kinderkrebsregister	ja	National Institute of Health
Strukturoptimierung für krebskranke Kinder nach Anthrazyklithерапie	Querschnittsstudie		Klinik für Kinder- und Jugendmedizin, Universitätsklinikum Schleswig-Holstein	ja	Madeleine Schickendantz Kinderkrebsstiftung
STATT-SCAR-Studie (Second Tumour After Tumour Therapy - Second Cancer After Radiotherapy)	Fall-Kontroll-Studie	51	DKKR/IMBEI	ja	Deutsche Krebshilfe und Bundesministerium für Bildung und Forschung (BMBF)
ikidS-OEVA: Onkologische Erkrankung im Vorschulalter und der Übergang in die Schule	Querschnittsstudie	50	IMBEI	ja	Bundesministerium für Bildung und Forschung (BMBF)

IMBEI: Institut für Medizinische Biometrie, Epidemiologie und Informatik IARC: International Agency for Research on Cancer, Lyon, Frankreich

DKKR: Deutsches Kinderkrebsregister

Research projects

Tabelle 11 Forts. **Table 11 cont.**

Projektbezeichnung	Studententyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
Info-Onko. Evaluation der psychosozialen Situation von Langzeitüberlebenden einer Krebskrankung im Kindes- oder Jugendalter	Querschnittsstudie		Netzwerk für die Versorgung schwerkranker Kinder und Jugendlicher e.V.	ja	Deutsche Kinderkrebsstiftung
E-SURV: Entwicklung innovativer Strategien zu Datenerhebung, Datenaustausch und Follow-Up nach Krebs im Kindesalter und Verknüpfung epidemiologischer und klinischer Daten	Querschnittsstudie		Projektkoordination: Pädiatrische Hämatologie und Onkologie des Universitätsklinikums Bonn	ja	Deutsche Krebshilfe
IICC: International Incidence of Childhood Cancer	Internationale Datenbank	47, 52	IARC, Lyon, Frankreich	nein	-

IMBEI: Institut für Medizinische Biometrie, Epidemiologie und Informatik IARC: International Agency for Research on Cancer, Lyon, Frankreich

DKKR: Deutsches Kinderkrebsregister

DKKR: Deutsches Kinderkrebsregister

Tabelle 12:
Research projects and international cooperations since 2014 (see table 11 for the German version)

Name of the project	Type of study	References
ACClS: Automated Childhood Cancer Information System	International Data Base on Childhood Cancer	34
EUROCARE: Survival of cancer patients in Europe	Follow-up Study	29, 41, 42
Survey-projects on former childhood cancer patients in cooperation between external cooperation partners and the German Childhood Cancer Registry	Registry-based Study	24, 44
PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	International Cohort and Case-Control Study	32, 35, 39, 49
KiKme: Cancer in childhood and molecular epidemiology	Case-Control Study	
KiCT: Risk of childhood cancer after computed tomography in childhood	Cohort Study	18, 40, 43
VIVE: Basic Survey on Life Situation, State of Health, and Quality of Life of Childhood Cancer Survivors in Germany	Cohort Study	20
PanCareLife: PanCare Studies in Fertility and Otoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	International Cohort and Case-Control Study	22, 32, 35
CVSS: Cardiac and vascular late sequelae in long-term survivors of childhood cancer - a multidisciplinary clinical, epidemiological and genetic approach	Cohort Study	21, 26, 46, 48,
RASopathies and cancer in childhood	Cohort Study	33, 45
Structural Optimization for Childhood Cancer Survivors after Anthracycline Therapy	Cross Sectional Study	
		Research projects

124 Forschungsprojekte / Research Projects

Tabelle 12 Forts. **Table 12 cont.**

Name of the project	Type of study	References
STATT-SCAR-Study (Second Tumour After Tumour Therapy - Second Cancer After Radiotherapy)	Case-Control Study	51
ikidS-OEVA: Oncological disease in preschool age and the transition to school	Cross-sectional Study	50
Info-Onko: Evaluation of the psychosocial situation of long-term survivors after cancer in childhood or adolescence	Cross-sectional Study	
E-SURV: Development of comprehensive strategies for assessment, data-sharing and follow-up in childhood cancer survivors linking epidemiological and clinical data	Cross-sectional Study	
IICC: International Incidence of Childhood Cancer	International Data Base on Childhood Cancer	47, 52

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<i>Grundlagen der Registrierung und Arbeitsweise zum Nachlesen / Further Information on the Basis of Registration and Procedures</i>	129
<i>Maßzahlen und deren Berechnung Inzidenz und allgemeine Kennzahlen / Descriptive Measures Incidence and general measures</i>	129
<i>Daten für Überlebenswahrscheinlichkeit, Mortalität und Folgeneoplasien / Data for Survival probability, mortality and subsequent neoplasms</i>	131
<i>Berechnung von Überlebenswahrscheinlichkeit und Mortalität / Estimating survival probability and mortality</i>	132
<i>Zweit-/Folgeneoplasien / Second/Subsequent neoplasms</i>	132
<i>Räumliche Verteilung / Spatial distribution</i>	133
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Datengrundlage, Methoden und Ergebnisdarstellung

Rechtliche Grundlagen und Finanzierung des Registers

Das Deutsche Kinderkrebsregister (DKKR) wird auf der Basis der geltenden Datenschutzgesetze ohne eigene gesetzliche Grundlage geführt. Das bedeutet, dass von den betroffenen Patienten oder deren Sorgeberechtigten eine spezielle Einwilligung gegeben werden muss. Aufgrund des großen Engagements der Familien liegt der Anteil der nicht gegebenen Einwilligungen bei unter 1%, weitere unter 1% der Einwilligungen fehlen aus anderen Gründen. Im Falle einer fehlenden Einwilligung erfolgt eine anonymisierte Minimal-Erfassung, um diese Fälle zumindest mit ihrer Verdachtsdiagnose bei den allgemeinen Inzidenzberechnungen mitzählen zu können. Spätere Datenprüfungen, Ergänzungen, Nachbeobachtung und direktes Ansprechen der Betroffenen sind dann nicht möglich.

Die behandelnden Ärzte melden unentgeltlich und grundsätzlich freiwillig. Aufgrund dieser Voraussetzungen war durch das Inkrafttreten des Krebsregistergesetzes des Bundes (1.1.1995) und der diversen Landeskrebsregistergesetze eine Änderung in der Verfahrensweise zur systematischen Erfassung der Erkrankungsfälle nicht erforderlich. Seit dem 1.1.2007 schreibt die „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämatologisch-onkologischen Krankheiten gemäß § 137 Abs. 1 Satz 1 Nr. 2 SGB V für nach § 108 SGB V zugelassene Krankenhäuser (Vereinbarung zur Kinderonkologie KiOn-RL)“ die Meldung von Fällen unter 18 Jahren mit pädiatrisch-onkologischen Erkrankungen an das Deutsche Kinderkrebsregister vor (37). Das am 9.4.2013 in Kraft getretene Krebsfrüherkennungs- und registergesetz des Bundes (KFRG) (19) schließt mit Hinweis auf die Zuständigkeit des Deutschen Kinderkrebsregisters Fälle unter 18 Jahren mit pädiatrisch-onkologischen Erkrankungen ausdrücklich nicht ein.

Die Förderung des DKKR erfolgt zu je einem Drittel durch das Bundesministerium für Gesundheit, das Ministerium für Soziales, Arbeit, Gesundheit und Demografie des Landes Rheinland-Pfalz und die Gesundheitsministerien der Länder.

Charakterisierung des Deutschen Kinderkrebsregisters

Das DKKR ist seit dem Beginn 1980 am Institut für Medizinische Biometrie, Epidemiologie und Informatik (IMBEI) der Universitätsmedizin der Johannes Gutenberg-Universität Mainz angesiedelt und kooperiert mit der Gesellschaft für Pädiatrische Onkologie und Hä-

Basis of Registration, Methods and Presentation

Legal basis and financial support

The German Childhood Cancer Registry (GCCR) operates without any specific legal basis in accordance with existing legislation on data privacy and security. Patients or their guardians are required to give their consent to registration. The families are committed to the cause, so less than 1% do not give their consent, another less than 1% are missing for other reasons. When the consent is missing, the anonymized cases are registered with minimum information, so the cases can be counted in for the incidence rate estimates. Any later validation, completion, follow-up or direct patient contact are not possible for these cases.

The treating physicians report cases for free and basically voluntarily. Because of this a change of procedure was not necessary when the federal cancer registry law (1.1.1995) and the state registry laws came into effect. Since January 1st 2007 the directive „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämatologisch-onkologischen Krankheiten gemäß § 137 Abs. 1 Satz 1 Nr. 2 SGB V für nach § 108 SGB V zugelassene Krankenhäuser (Vereinbarung zur Kinderonkologie KiOn-RL)“ made reporting cases under 18 to the German Childhood Cancer Registry mandatory (37). The law „Krebsfrüherkennungs- und -registergesetz des Bundes (KFRG)“ (19), in effect since 9th April 2013, explicitly excludes pediatric oncology cases under 18 due to the responsibility of the GCCR.

The funding is guaranteed by the Federal Ministry of Health, the Ministry of Social Affairs, Labour, Health, and Demography of Rhineland-Palatinate and the Ministries of Health of all 16 federal states to a third each.

Characterization of the German Childhood Cancer Registry

The GCCR was established at the Institute for Medical Biostatistics, Epidemiology and Informatics (IMBEI) of the University Medical Center at the Johannes Gutenberg-University Mainz. It co-operates with the scientific society for paediatric oncology and haematology

matologie (GPOH) und den behandelnden Kliniken. Es ist dadurch charakterisiert, dass es neben den üblichen, in einem bevölkerungsbezogenen Krebsregister erfassten Daten auch eine ganze Reihe klinischer Informationen (z. B. Stadium, Grading, immunologische Subtypen) erfasst (4). Dieser klinische Bezug ist gewährleistet durch die enge Kooperation mit den etwa 25 pädiatrisch-onkologischen Therapieoptimierungsstudien (klinischen Studien) bzw. diagnosespezifischen klinischen Registern der GPOH. Der Anteil der hierin erfassten Fälle ist mit über 90% sehr hoch.

Ein weiteres Charakteristikum des DKKR, das in den letzten Jahren immer mehr an Bedeutung gewonnen hat, ist die Realisierung einer aktiven, zeitlich unbefristeten Langzeitnachbeobachtung. Damit stellt das DKKR die Grundlage für die Erforschung von Spätfolgen, wie z.B. Folgeneoplasien, bereit.

Dokumentationsablauf und Datenfluss

Von den kooperierenden Kliniken wird jeweils bei Auftreten einer Neuerkrankung ein kurzer Meldebogen an das DKKR geschickt (DKKR-Erstmeldung). Er enthält u.a. die Verdachtsdiagnose, wesentliche Identifikationsmerkmale, die Bestätigung der Einwilligung zu der Meldung durch Patient und/oder Sorgeberechtigte und die Information, ob und an welcher klinischen Therapieoptimierungsstudie der Patient teilnimmt bzw. an welches diagnosespezifische klinische Register er gemeldet wurde. Die Weiterleitung validierter diagnostischer Detail-Informationen von der Therapiestudienleitung an das DKKR erfolgt später, meist elektronisch, in regelmäßigen Intervallen. Bis auf vereinzelte Ausnahmen sind alle Diagnosen histologisch oder immunologisch verifiziert.

Bis zum Abschluss der primären Therapiephase und im Verlauf der Nachsorge erfolgt normalerweise eine regelmäßige Nachbeobachtung durch die Therapie-Studienleitung bzw. das diagnosespezifische Register. Dies erstreckt sich üblicherweise über die 5 Jahre nach Diagnose. Anschließend erfolgt die Nachbeobachtung durch das DKKR, wobei DKKR und Therapiestudienleitung die Daten jeweils untereinander austauschen. Das DKKR erhält Nachbeobachtungs-Informationen aus mehreren Quellen: der Klinik (solange der Patient dort noch in der Nachsorge ist), Einwohnermeldeämtern, gegebenenfalls Landeskrebsregistern und nicht zuletzt in zunehmendem Maße von den Patienten selbst. Der Dokumentationsablauf und die Synergieeffekte zwischen Therapieoptimierungsstudien und DKKR sind in (4, 5, 8, 14, 23, 25, 37) beschrieben. Die Langzeitnachbeobachtung ist in (11, 15-17) publiziert.

Datengrundlage

Das DKKR nahm 1980 seine Arbeit auf. Die Registerpopulation im engeren Sinne umfasst die Kinder und

(GPOH) and the treating hospitals. The GCCR is a population based registry combined with some features of a clinical registry, registering also clinical details such as staging, grading, and immunological subtypes (4). The clinical information is based on the integrated information exchange and data flow between the ca. 25 GPOH organized therapy optimization trials or respective diagnosis specific registries and the GCCR. More than 90% of all cases are included in these trials or respective diagnosis specific registries.

The GCCR is also characterized by an active open end long-term follow-up of all registered patients. This has become increasingly important in recent years and is the basis for research on late effects, such as subsequent neoplasms.

Documentation and flow of information

After admission of a newly diseased individual to one of the co-operating hospitals, a notification form is sent to the GCCR. This contains patient identification data, a confirmation of consent (patient or guardian) to the registration, a preliminary diagnosis and information on whether this case will be included in one of the on-going therapy optimization trials or respective diagnosis specific registries. Later the centres regularly provide the GCCR with validated diagnostic information, usually annually in electronic form. With few exceptions all diagnoses are histologically or immunologically verified.

Tumour-specific follow-up information is usually provided by the therapy studies until the end of the first clinical treatment phase and during clinical follow-up, which usually lasts about 5 years. After this, the long-term follow-up is conducted by the GCCR, regularly exchanging this information with the therapy trials or respective diagnosis specific registries. The GCCR collects data from various sources, such as the hospitals (during aftercare), state cancer registries, municipalities, and increasingly the patients themselves. This flow of information is described in (4, 5, 8, 14, 23, 25, 37), the follow-up procedures are published in (11, 15-17).

Data basis

In 1980, the GCCR was initiated by the GPOH. It is intended to include all children and adolescents with

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Jugendlichen, die vor ihrem 15. Geburtstag, seit 2009 vor ihrem 18. Geburtstag, an einer malignen Erkrankung (einschließlich der histologisch nicht bösartigen ZNS-Tumoren (Tumoren des Zentralen Nervensystems)) erkranken und zur deutschen Wohnbevölkerung gehören. Seit 1991 sind die neuen Bundesländer mit einbezogen.

Die Klassifizierung der Erkrankungen erfolgt derzeit nach der International Classification of Childhood Cancer 3rd edition (ICCC-3) (9). Sie basiert auf einer Zusammenfassung entsprechender Morphologien und Topographien, codiert jeweils nach der ICD-O-3 (6) und ist am Ende des Berichts wiedergegeben. Damit ist auch festgelegt, welche Erkrankungen bei Kindern und Jugendlichen - gemäß internationaler Konvention - in einem epidemiologischen Krebsregister systematisch zu erfassen sind.

Die Vollzähligkeit der Erfassung für unter 15-Jährige beträgt seit 1987 über 95%; sie entspricht damit den internationalen Anforderungen an epidemiologische Krebsregister. Die Meldung ist für onkologische Kliniken der Kinder- und Jugendmedizin für Fälle bis unter 18 im Prinzip verpflichtend, daher sind auch die Meldungen typisch pädiatrisch-onkologischer Diagnosen für Jugendliche (15-17 Jahre) weitgehend vollzählig. Bei Diagnosen, die auch häufiger oder typischerweise eher im Erwachsenenalter auftreten, fehlen Meldungen.

Neben den in der ICCC-3 definierten Diagnosen werden am DKKR einige weitere Diagnosegruppen systematisch erfasst (Tabelle 5). Seit 2009 wurden entsprechend den Empfehlungen des Gemeinsamen Bundesausschusses noch einige wenige weitere nicht-maligne Diagnosen hinzugenommen (37). Für einige dieser Diagnosen existieren eigene Therapieoptimierungsstudien der Fachgesellschaft GPOH, zumindest die Studienfälle werden systematisch gemeldet. Mit der bereits angelaufenen aber noch nicht abgeschlossenen Umsetzung des KFRG (19) in den Bundesländern werden sich Änderungen bezüglich der Abgleiche mit den Landeskrebsregistern ergeben, die zurzeit noch nicht in Gänze absehbar sind.

Die Erfassung von Zweit-/Folgeneoplasien (SN) ohne Altersbegrenzung erfolgt aus verschiedenen Quellen, darunter freiwillige Angaben von den betroffenen Patienten, die eine Nachfrage bei ihren behandelnden Ärzten erlauben. Trotz aller Bemühungen ist nicht auszuschließen, dass diese Erfassung nicht vollzählig ist, die angegebenen Zahlen sind daher als untere Abschätzung anzusehen.

malignant disease (or - no matter what behaviour code - any form of tumours of the central nervous system (=CNS tumours)) diagnosed before the 15th birthday, since 2009 before the 18th birthday, and resident in Germany at diagnosis. Since 1991, cases from the area of the former German Democratic Republic (GDR) are included.

Classification of diseases is currently based on the International Classification of Childhood Cancer 3rd edition (ICCC-3) (9). The ICCC-3 is an aggregation of morphology and topography codes based on ICD-O-3 (6), included at the end of this report. This also defines internationally which diagnoses in childhood and adolescence are recorded mandatory in an epidemiologic cancer registry.

The completeness of registration for cases under 15 is more than 95% since 1987; this complies with international requirements for an epidemiologic cancer registry. Reporting cases is mandatory for pediatric and adolescent oncology hospitals for cases under 18, thus the reporting of typically pediatric oncologic diagnoses for adolescents (15-17 years) are mostly complete. Diagnoses, which would frequently or typically occur in adults are, however, underrepresented.

Besides the diagnoses defined in ICCC-3, the GCCR records a number of further diagnoses systematically (Table 5). Since 2009 we added a few more rare non-malignant diagnoses (37). For some of these diagnoses, there exist therapy optimization trials within the GPOH, study cases are usually systematically reported. The implementation of the KFRG (19) has begun, but has not been finished yet in the states. There will be changes regarding the data exchange with the state cancer registries.

The ascertainment of second/subsequent neoplasms (SN) without age limit is based on a variety of sources, including voluntary reports from patients themselves who permit their treating physicians to provide information. In spite of all efforts it is possible that the numbers are not complete, thus we consider our numbers to be a lower estimate.

Grundlagen der Registrierung und Arbeitsweise zum Nachlesen

Literaturstellen

- Meldung und Dokumentationsablauf (4, 5, 8, 37)
- Langzeitnachbeobachtung (11, 15-17, 26)
- Statistische Methodik (1-3, 7)
- Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten (37)

Weitere Informationen finden sich auf unserer Homepage (www.kinderkrebsregister.de) und im Literaturverzeichnis:

- Beschluss der 82. Gesundheitsministerkonferenz 2009 (Kinderkrebsregister - Anhebung der Altersgrenze für die Registrierung von Kindern und Jugendlichen) (13)
- Bundeskrebsregisterdatengesetz (12)
- Krebsfrüherkennungs- und -registergesetz (KFRG) (19)
- Notwendigkeit der namensbezogenen Datenspeicherung (38)
- Die Rahmenbedingungen des Deutschen Kinderkrebsregisters (8, 14)
- Positionspapier der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) zu (Langzeit-)Nachbeobachtung, (Langzeit-)Nachsorge und Spätfolgenerhebung bei pädiatrisch-onkologischen Patienten (11)
- DKKR-Regelwerk des Deutschen Kinderkrebsregisters zu datenschutz-relevanten Aspekten (30)
- DKKR-Einwilligungserklärung (27)
- DKKR-Technisches Datenschutz- und Datensicherheitskonzept des Deutschen Kinderkrebsregisters (28)
- Die Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters (15-17)

Maßzahlen und deren Berechnung Inzidenz und allgemeine Kennzahlen

Die Gesamtzahl der Fälle bezieht sich auf die Fälle mit Diagnosealter <15 Jahre, ab 2009 <18 Jahre, mit Hauptwohnsitz zum Zeitpunkt der Diagnose in Deutschland, nach Diagnose, Altersgruppe, Geschlecht und den jeweilig angegebenen Zeitraum. Alle Angaben sind für die letzten 10 Jahre des Berichtszeitraums, soweit nicht anders angegeben. Derzeit liegen für die 15-17-Jährigen noch keine 10 Beobachtungsjahre vor; hier umfassen die Angaben derzeit die zurückliegenden 8 Jahre. Dabei zählen wir im Allgemeinen Fälle, nicht Patienten. Der Anteil der an Therapieoptimierungsstudien oder diagnosespezifischen klinischen Registern der GPOH teilnehmenden Fälle schließt alle Fälle ein, von denen eine Studienleitung in irgendeiner Form Kenntnis hat. Das heißt, in diesem Anteil sind auch Fälle enthalten, die nicht zur Gruppe der Studienteilnehmer im engeren Sinne zu zählen sind.

Further Information on the Basis of Registration and Procedures

References

- Notification and documentation (4, 5, 8, 37)
- Long-term surveillance (11, 15-17, 26)
- Statistical methods (1-3, 7)
- Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten (37)

Further information can be found on our homepage (www.kinderkrebsregister.de) and in the references:

Descriptive measures Incidence and general measures

The total number of cases refers to the cases diagnosed at age <15 years, from 2009 onwards <18 years, resident in Germany at the time of diagnosis, broken down by diagnosis, age group, sex and time periods. All figures are given for the most recent 10 years of the reporting period, unless otherwise stated. So far, there are not yet 10 years of observation available for cases aged 15-17; so for these we currently report the last eight years. We usually count cases, not patients. The relative frequency of trial cases includes all cases the trial centre or respective diagnosis specific registry is informed of. This also includes cases who may not be treated according to protocol.

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Die Inzidenzrate (Neuerkrankungsrate) bezieht die Anzahl der neu aufgetretenen Fälle in einem bestimmten Gebiet und Zeitraum auf die zugehörige Wohnbevölkerung im entsprechenden Alter. Alle Inzidenzraten in diesem Bericht sind Durchschnittsangaben für den jeweiligen Zeitraum und werden als Rate pro 1000000 (Million) Personenjahre dargestellt

Die altersspezifische Inzidenzrate I_{ij} für die Altersgruppe j im Zeitraum i errechnet sich als

$$I_{ij} = \frac{N_{ij}}{B_{ij}} \cdot 1000000$$

mit N_{ij} Anzahl der Neuerkrankungen im Alter j im Zeitraum i und B_{ij} Bevölkerung im Alter j im Zeitraum i. In der Regel werden in diesem Bericht altersspezifische Inzidenzraten für die unter 1-jährigen (j=1), die 1- bis 4-jährigen (j=2), die 5- bis 9-jährigen (j=3) und die 10- bis 14-jährigen Kinder (j=4) berechnet, ab 2009 auch für die 15- bis 17-jährigen (j=5). Die (direkt) altersstandardisierte Inzidenzrate für unter 15- bzw. 18-Jährige errechnet sich mit Hilfe der Gewichte w_j des von Segi erarbeiteten WHO-Welt-Standards (2) (Tabelle M.1) als:

The incidence rate relates the number of new cases in a certain area and period to the resident population in the relevant age group. All incidence rates in this report are averages for the relevant period and are given as rates per 1000000 (million) person years.

The age-specific incidence rate I_{ij} for the age group j in the time period i is calculated as

$$I_{ij} = \frac{N_{ij}}{B_{ij}} \cdot 1000000$$

with N_{ij} the number of new cases at age j in time period i and B_{ij} the population at age j in time period i. This report usually gives age-specific incidence rates for children under age 1 (j=1), ages 1-4 (j=2), ages 5-9 (j=3), and ages 10-14 (j=4). From 2009 onwards we also include ages 15-17 (j=5). The directly standardized incidence rate for cases under 15 or 18 is calculated using the weights w_j of the Segi WHO world standard (2) (Table M.1):

Tabelle M. 1 / Table M. 1

Zusammensetzung der Segi Weltbevölkerung für Kinder unter 15 bzw. 18 Jahren im Vergleich zur durchschnittlichen deutschen Wohnbevölkerung 2009-2016

Composition of the Segi world standard for children under 15 resp. 18 years compared to the German population 2009-2016

Age-groups (years)	German population 2009-2016			World standard population	
	Absolute	Relative < 15	< 18	Weights < 15	< 18
0	691,345	0.06	0.05	0.08	0.07
1-4	2,757,725	0.26	0.21	0.31	0.26
5-9	3,539,877	0.33	0.27	0.32	0.27
10-14	3,824,502	0.35	0.29	0.29	0.25
15-17	2,467,479	-	0.19	-	0.15
Total		1.00	1.00	1.00	1.00

Die altersstandardisierte Inzidenzrate D_i gibt die Neuerkrankungsrate im Zeitraum i an, die man in der untersuchten Population erwarten würde, wenn die Altersstruktur mit der Standardbevölkerung übereinstimmen würde.

The age standardized incidence rate D_i gives the incidence rate in period i, which would be expected if the age structure in the report area were identical to the standard population.

$$D_i = \sum_j w_j I_{ij}$$

$$D_i = \sum_j w_j I_{ij}$$

Die kumulative Inzidenz C_i bis 15 bzw. 18 Jahre errechnet sich als Summe der altersspezifischen Inzidenzraten,

$$C_i = \sum_j I_{ij}$$

wobei hier gewöhnlich 15 bzw. 18 Einzelaltersjahrsklassen verwendet werden ($j=1, \dots, 15$ oder 18). Sie kann interpretiert werden als das Risiko (die Wahrscheinlichkeit) eines neugeborenen Kindes, bis zum 15. oder 18. Geburtstag an einer Krebskrankung zu erkranken.

Die in pädiatrisch onkologischen Publikationen gern verwendete Darstellung der Inzidenzrate oder der kumulativen Inzidenz als $1/K_i$ Kinder (d.h. eins von K_i Kindern ist betroffen) ergibt sich über die Umrechnungen

$$K_i = \frac{1000000}{D_i} \quad \text{oder} \quad K_i = \frac{1000000}{C_i} .$$

Die Bevölkerungszahlen für das Jahr 2016 lagen bei Erstellung des Jahresberichts noch nicht vor und wurden hochgerechnet. Aus diesem Grund ist das letzte Jahr in der Trenddarstellung ebenso blassblau gekennzeichnet wie die Jahre 1980-87, wo die Meldungen des Registers überwiegend noch nicht vollzählig waren.

Innerhalb des Zeitraums bis unter 15 Jahren sind die Hälfte der Fälle bei Diagnose jünger und die andere Hälfte älter als das mediane Alter bei Diagnose (angegeben in Monaten).

Neben den im Jahresbericht veröffentlichten Tabellen und Abbildungen finden sich auf der Homepage des Deutschen Kinderkrebsregisters noch weitere detaillierte Zahlen zum Abruf (36).

Daten für Überlebenswahrscheinlichkeit, Mortalität und Folgeneoplasien

Das Follow-up in den jeweils aktuellsten Jahren des Registers ist immer erst mit einer gewissen Zeitverzögerung vollständig. Auch wurden in den ersten Registerjahren relativ viele Fälle anonym registriert, die nicht nachbeobachtet werden können. Um zu entscheiden, für welchen Zeitraum und für welche maximale Nachbeobachtungszeit verlässliche Angaben zu Überlebenszeit, Mortalität und der kumulativen Inzidenz von Folgeneoplasien gemacht werden können benötigt man eine Qualitätsgrenze und eine Metrik zur Berechnung dieser Grenze. Für jeden Patienten liegt am DKKR ein aktuelles letztes Beobachtungsdatum vor. Für die Verstorbenen endet die Beobachtung an diesem Datum, die Übrigen könnten prinzipiell bis zu einem Stichtag nachbeobachtet werden. Bezogen auf den Stichtag lässt sich dann errechnen, wieviel % der maximal möglichen Nachbeobachtungszeit vorliegen.

The cumulative incidence C_i until age 15 or 18 is estimated as the sum of the age-specific incidence rates,

$$C_i = \sum_j I_{ij}$$

usually using 15 or 18 single-year age classes ($j=1, \dots, 15$ or 18). It can be interpreted as the risk (the probability) of a new born to become a cancer case until his/her 15th or 18th birthday.

Paediatric-oncology publications like to present incidence rates or the cumulative incidence in an alternative form, namely as $1/K_i$ children (one of K_i children will be affected). This can be derived by

$$K_i = \frac{1000000}{D_i} \quad \text{or} \quad K_i = \frac{1000000}{C_i} .$$

For 2016 population data was not yet available; we are thus using estimated numbers. So the last year and the years 1980-87, where most of the registry data was not complete yet, are indicated in pale blue in the trend graphics.

Until the 15th birthday half of the cases are younger than the median age at diagnosis, and the other half are older (presented in months).

In addition to the Tables and Figures in this report, more detailed numbers can be obtained from the homepage of the German Childhood Cancer registry (36).

Data for Survival probability and mortality, and subsequent neoplasms

The Follow-up in the respective most recent years of the registry is usually completed with a delay. Also in the first years of the registry, a relatively large number of anonymous cases was registered, who cannot be followed-up. We need to decide, for which time period and which maximal follow-up time we can give reliable numbers for survival, mortality and the cumulative incidence of subsequent neoplasms. For this we need a decision rule and a metric for this decision rule. For each patient, we record a current last observation date. For a deceased patient, follow-up ends at that date, all others and theoretically be followed-up until a set date. Relative to that date we can calculate, which percentage of the maximally possible follow-up time is available. We set the limit at 80%. Based on this we need to exclude 1980 from the estimation of survival and subsequent neoplasms incidence. Only data until 2013

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Entsprechendes kann für einen maximalen Nachbeobachtungszeitraum errechnet werden. Gefordert wurden mindestens 80%. Daraus ergab sich die Notwendigkeit, die Fälle von 1980 aus Berechnungen von Überleben, und kumulativer Folgeneoplasie-Inzidenz herauszunehmen und nur Daten bis 2013 einzubeziehen. Die maximale Nachbeobachtungszeit sind 30 Jahre. Überlebenszeitkurven werden nur bis zu der Nachbeobachtungszeit berechnet und dargestellt, wenn noch mindestens 25 Patienten unter Risiko sind; die kumulative Folgeneoplasieinzidenz wird nur angegeben, wenn nach 30 Jahren noch mindesten 20 Patienten unter Risiko sind.

Berechnung von Überlebenswahrscheinlichkeit und Mortalität

Die Berechnung der Überlebenswahrscheinlichkeiten erfolgt nach der von Brenner und Spix vorgeschlagenen Modifikation des Sterbetafel-Verfahrens (7). Die Werte sind mit der Schätzung nach Kaplan-Meier (1) vergleichbar, jedoch erlaubt dieses Verfahren auch für die erst in den letzten Jahren Erkrankten sowohl eine Hochrechnung für einen darüber hinausgehenden Zeitraum als auch eine stabilere Abschätzung des Langzeiterlebens. Dargestellt werden die Überlebenswahrscheinlichkeiten nach Diagnosejahren für die erste und zweite Dekade, die dritte und die angefangene vierte Dekade werden kombiniert, bis aus der vierten Dekade mindestens 5 Jahre verwendet werden können.

Die Berechnung der Mortalitätsrate und der kumulativen Mortalität erfolgt analog zur Inzidenzrate und kumulativen Inzidenz. Es werden die Todesfälle der 5, 10 und 15 Jahre nach Diagnose betrachtet bezogen auf einen entsprechend um 5/10/15 Jahre zurückverlegten Diagnosezeitraum.

Zweit-/Folgeneoplasien

Eine Zweit-/Folgeneoplasie ist eine weitere Neubildung, die nach der ersten bzw. vorangegangenen Neoplasie bei dem gleichen Patienten auftritt. Die englischen Begriffe hierzu sind ‚second neoplasm‘ oder ‚subsequent neoplasm‘, abgekürzt SN.

Die Berechnung der kumulativen Inzidenz der innerhalb von 30 Jahren nach Diagnose aufgetretenen zweiten Krebserkrankungen (SN) bezieht sich nur auf in der ICCC-3 definierte Krebserkrankungen. Gutartige weitere Erkrankungen (außer den in der ICCC-3 eingeschlossenen ZNS-Tumoren) werden hier nicht mitgezählt.

Die Bezugsbevölkerung für die Berechnung der im Jahresbericht angegebenen kumulativen Inzidenz der zweiten Krebserkrankungen ist die Gruppe aller Patienten mit einer ersten Krebserkrankung (nach ICCC-3) im Alter von unter 15 Jahren in der deutschen Wohnbevöl-

can be used and the maximal follow-up which can be reported is 30 years. Survival probability estimates and curves are presented only as long as there are still 25 patients under risk; cumulative subsequent neoplasm incidence for 30 years is reported only, if 20 or more patients are still under risk.

Estimating survival probability and mortality

Survival probabilities were computed using the life table method extension proposed by Brenner and Spix (7). These estimates can be directly compared to the more commonly used estimates by Kaplan-Meier (1), but also permit making statements for more recently diagnosed cases regarding a) extrapolated long-term survival and b) more stable short-term survival estimates. We present the survival curves for the first and second decade, the third and the beginning of the fourth decade are combined until we can use at least five years out of the fourth.

The mortality rate and the cumulative mortality are computed in analogy to the incidence rate and the cumulative incidence. We include only deaths within a 5-, 10-, and 15-year follow-up after diagnosis referring to the diagnosis period from 5/10/15 years earlier.

Second/Subsequent neoplasms

A second or subsequent neoplasm (SN) is a neoplasm, which occurred after the primary or preceding neoplasm in the same patient.

The cumulative incidence of second neoplasms (SN) within 30 years of diagnosis includes only ICCC-3 defined cases. Non-malignant diseases (unless they are non-malignant CNS-tumours included in ICCC-3) are not counted here.

The population base for these calculations are all patients with a primary disease (as defined in ICCC-3) at age <15, resident in Germany. The cumulative incidence is given per 100 person years under risk (%). As the number of deaths is relatively high, we estimate the

kerung. Die Angabe der kumulativen Inzidenz erfolgt pro 100 Personenjahre unter Risiko (%). Wegen der relativ hohen Zahl an Todesfällen wird zur Berechnung der kumulativen Inzidenz mit dem Aalen-Johansen-Schätzer (3) eine Variante des Kaplan-Meier-Verfahrens (1) angewendet, das diesen Umstand als konkurrierendes Risiko berücksichtigt. Angegeben wird die kumulative Inzidenz einer zweiten Krebserkrankung nach der jeweils dargestellten Ersterkrankung, sowie umgekehrt die jeweils betrachtete Krebserkrankung ihrerseits als zweite Erkrankung nach einer beliebigen vorangegangenen Krebserkrankung.

Lesehilfe am Beispiel der Akuten Myeloischen Leukämie (ICCC-3 Ib) (**Tabelle M.2**):

Tabelle M.2 / Table M.2:

**Zweitneoplasieinformationen am Beispiel der AML (I(b)) /
Second neoplasm Information for AML (I(b)) as an Example**

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2013)					
I (b) Acute myeloid leukaemias			I (b) as SN after any primary		
SN after I (b)				I (b) as SN after any primary	
N	% of all 1245 SN	Cumulative incidence	N	% of all 1245 SN	Cumulative incidence
54	4.3 %	9.5 %	139	11.2 %	0.4 %

Bei den in den Jahren 1981-2013 mit einer AML unter 15 Jahren als erster Krebserkrankung diagnostizierten Patienten wurden in den folgenden bis zu 30 Jahren 54 zweite Krebserkrankungen diagnostiziert. Das sind 4,3% von allen 1245 innerhalb von 30 Jahren nach Diagnose in den Jahren 1981-2013 an das DKKR gemeldeten zweiten Krebserkrankungen. Bei 9,5% aller primären AML Patienten wird innerhalb von 30 Jahren nach Erstdiagnose eine weitere Krebserkrankung diagnostiziert, das ist überdurchschnittlich im Vergleich zum durchschnittlichen SN-Risiko nach allen Malignomen von 8,0%.

Nach einer ersten Krebserkrankung beliebigen Typs im Alter von unter 15 in den Jahren 1981-2013 wurde bei 139 Patienten anschließend in den nächsten 30 Jahren eine AML diagnostiziert. 11,2% aller 1245 dem DKKR innerhalb von 30 Jahren nach Diagnose in den Jahren 1981-2013 gemeldeten zweiten Krebserkrankungen sind AML, im Vergleich zu dem Anteil von AML an allen Krebserkrankungen im Kindesalter (4,1%) ist das ungewöhnlich viel. Bei 0,4% aller kindlichen Krebspatienten wird innerhalb von 30 Jahren nach Erstdiagnose eine AML als zweite Krebserkrankung diagnostiziert.

Räumliche Verteilung

Die kartographische Darstellung präsentiert standardisierte Inzidenzraten unter 15 Jahren auf Kreisebene in 7 Gruppen, die jeweils 5%, 10%, 15%, 40%, 15%, 10%

cumulative incidence by the Aalen-Johansen-estimator (3), an extension of the Kaplan-Meier-procedure (1), which accounts for competing risks. We present the cumulative incidence of a second neoplasm after the respective primary neoplasm and then the respective diagnosis as SN after any primary neoplasm.

The tables should be read as follows, using acute myeloid leukaemia (ICCC-3 Ib) as an example (**Table M.2**):

Within 30 years of diagnosis, 54 second neoplasms were diagnosed out of the patients with an AML as a first diagnosis at age under 15 in the years 1981-2013. These are 4.3 % of all 1245 recorded second neoplasms within 30 years of diagnosis in the years 1981-2013 at the GCCR. 9.5% of all primary AML patients are diagnosed with a second neoplasm within 30 years of diagnosis in the years 1980-2013, this is higher than the average cumulative incidence of 8.0% for all malignancies.

After any primary neoplasm at age under 15 in 1981-2013, 139 patients were diagnosed with AML as second neoplasms within 30 years of diagnosis. 11.2% of all 1245 second neoplasms within 30 years of diagnosis of the primary disease in the years 1981-2013 reported at the GCCR are AML, compared to 4.1% AML in general, this is a large number. 0.4% of all childhood cancer patients are diagnosed with a second AML within 30 years of diagnosis.

Spatial distribution

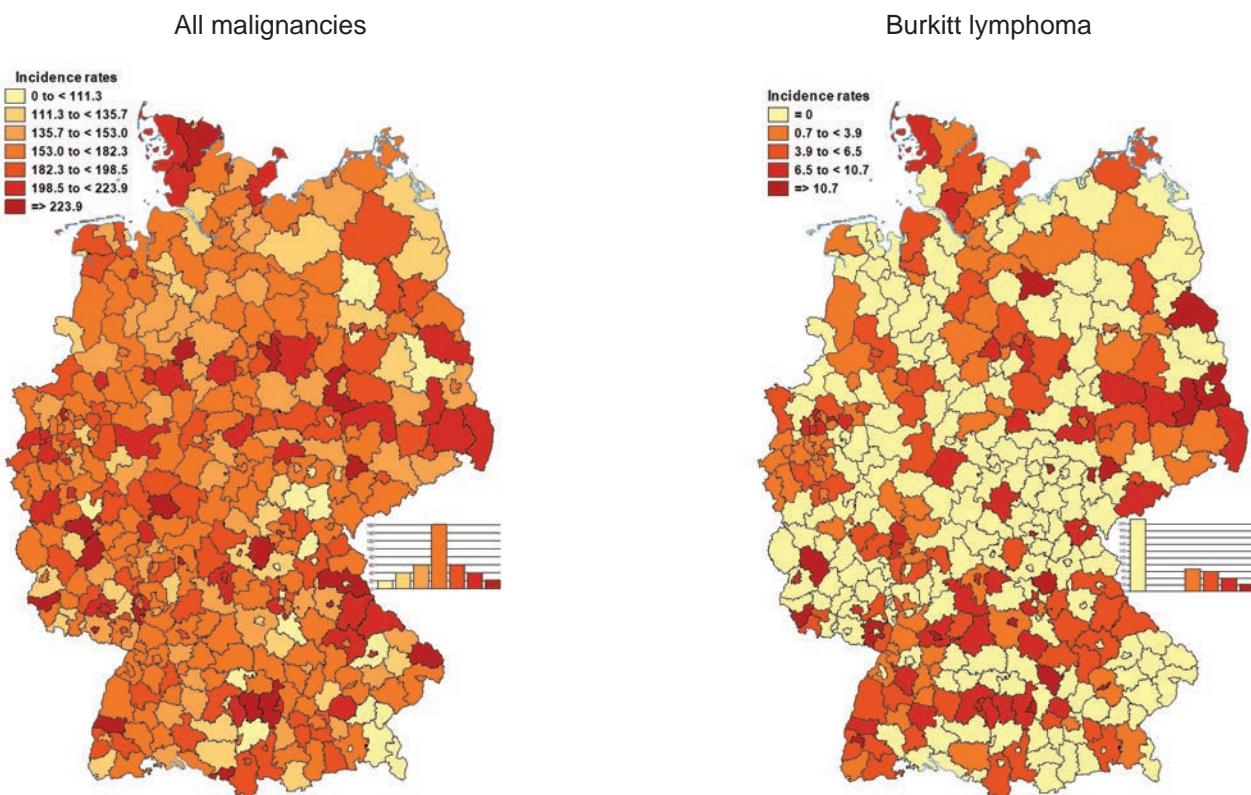
The map presentation shows the standardized incidence rates for ages under 15 in 7 classes, each covering 5%, 10%, 15%, 40%, 15%, 10% and 5% of all

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und 5% der Kreise (Landkreise und kreisfreie Städte) von der niedrigsten bis zur höchsten Inzidenzrate umfassen. Bei seltenen Diagnosen werden in mehr als 5% (bzw. 15% usw.) der Kreise keine Fälle beobachtet und diese werden entsprechend zusammengefasst (siehe rechte Beispielkarte). Die sich daraus ergebenen Klassengrenzen sind in der Legende links oben erkennbar. Die Verteilung ist in dem Histogramm rechts ablesbar. Bei sehr seltenen Diagnosen ist eine kartographische Darstellung nicht mehr sinnvoll.

“Kreise” (counties), ordered from the smallest to the largest incidence rate. For rare diagnoses, a number of Kreise do not observe a single case and the lower classes have to be aggregated (see right side sample map). The class limits derived from this are shown in the legend on the left. The distribution can be seen in the histogram on the right. For very rare diagnoses map presentations are not useful.

Abbildung M.1 / Figure M.1:
Zwei Beispielkarten / Two Sample Maps



Bei den Auswertungen zur regionalen Verteilung von Neuerkrankungshäufigkeiten (Tabelle 6) wird neben den altersstandardisierten Inzidenzraten auch das standardisierte Inzidenzverhältnis (SIR - Standardized Incidence Ratio) angegeben. Dieses ergibt sich aus dem Quotienten von beobachteter und erwarteter Erkrankungszahl. Die beobachtete Anzahl N_{ir} ist die Zahl aller Fälle unter 15 Jahren an der fraglichen Diagnose im Zeitraum i in der Region r. Der erwartete Wert berechnet sich aus der Zahl der Einwohner in den einzelnen Altersgruppen j in der untersuchten Region r im Zeitraum i (B_{ijr}) und den bundesweiten, altersspezifischen Inzidenzraten I_{ij} im gleichen Zeitraum i.

$$SIR_{ir} = \frac{N_{ir}}{\sum_j B_{ijr} \frac{I_{ij}}{1000000}}$$

$$SIR_{ir} = \frac{N_{ir}}{\sum_j B_{ijr} \frac{I_{ij}}{1000000}}$$

In Table 6 we present some tabulated data on regional standardized incidence rates. It includes the Standardized Incidence Ratio (SIR), which is computed as the ratio of the observed and expected number of cases. The observed number N_{ir} is the number of all cases under 15 years with the diagnosis in question in time period i in the region r. The expected number is calculated using the number of inhabitants per age-group j in region r in period i (B_{ijr}) and the German age-specific incidence rates I_{ij} in the same time period i.

SIR-Werte über dem Referenzwert von 1 bedeuten, dass in der untersuchten Region mehr Erkrankungsfälle beobachtet wurden als im Vergleich mit der Inzidenzrate aus der gesamten Bundesrepublik zu erwarten wären und umgekehrt. Zur Beurteilung des SIR werden 95% Konfidenzintervalle (95%-KI), die auf der Poisson-Verteilung beruhen, berechnet. Ein SIR gilt als statistisch unauffällig, wenn das zugehörige Konfidenzintervall den Wert 1 einschließt. Ein 95%-KI jenseits von 1 bedeutet, dass es sich mit 5%-iger Wahrscheinlichkeit um eine zufällige Abweichung der regionalen Inzidenzrate von der bundesweiten Inzidenzrate handelt. Dies bedeutet auch, dass in ca. 5% aller Regionen rein zufällig entsprechend auffallend hohe oder niedrige Inzidenzraten erwartet werden, ohne dass dies von besonderer Bedeutung ist. Bei derzeit 401 Kreisen wären also zufällig etwa 20 Kreise mit ungewöhnlich hohen oder niedrigen Inzidenzraten zu erwarten, tatsächlich waren es beispielsweise für alle ICCC-3 Diagnosen für den Zeitraum 2006-2016 28 Kreise, davon 13 mit besonders hohen und 15 mit besonders niedrigen Fallzahlen.

SIR values above the reference value 1 mean that in the region in question more new cases were observed than expected based on the nationwide incidence rate and vice versa. To assess the SIR, we compute 95%-confidence intervals (95%-CI). The SIR is statistically non-significant when the CI includes 1. A 95%-CI beyond 1 means that there is a 5% probability that the deviation from the nationwide incidence rate is random. However, we must expect about 5% of all regions to have randomly unusually high or low incidence rates, without this being relevant. For the currently 401 Kreise we would thus randomly expect about 20 with unusual incidence rates. For the time period 2006-2015 for all ICCC-3 diagnoses we actually observed 28, 13 with unusually high and 15 with unusually low numbers of cases.

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Internationale Klassifikation der Krebserkrankungen bei Kindern (ICCC-3)
 Zuordnung von ICD-O-3-Codes für Morphologie und Topographie zu diagnostischen Kategorien

International Classification of Childhood Cancer (ICCC-3)
 Categorization of morphology and topography codes, corresponding to ICD-O-3

adapted from: Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, Third Edition. Cancer 103, 1457-1467, 2005.

DIAGNOSTIC GROUP	MORPHOLOGY	TOPOGRAPHY	ICD-O-3 CODES
I LEUKAEMIAS, MYELOPROLIFERATIVE AND MYELODYSPLASTIC DISEASES			
(a) Lymphoid leukaemias			9820, 9823, 9826, 9827, 9831-9837, 9940, 9948
1 Precursor cell leukaemias			9835, 9836, 9837
2 Mature B-cell leukaemias			9823, 9826, 9832, 9833, 9940
3 Mature T-cell and NK cell leukaemias			9827, 9831, 9834, 9948
4 Lymphoid leukaemia, NOS			9820
(b) Acute myeloid leukaemias			9840, 9861, 9866, 9867, 9870-9874, 9891, 9895-9897, 9910, 9920, 9931
(c) Chronic myeloproliferative diseases			9863, 9875, 9876, 9950, 9960-9964
(d) Myelodysplastic syndrome and other myeloproliferative diseases			9945, 9946, 9975, 9980, 9982-9987, 9989
(e) Unspecified and other specified leukaemias			9800, 9801, 9805, 9860, 9930
II LYMPHOMAS AND RETICULOENDOTHELIAL NEOPLASMS			
(a) Hodgkin lymphomas			9650-9655, 9659, 9661-9665, 9667
(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)			9591, 9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698-9702, 9705, 9708, 9709, 9714, 9716-9719, 9727-9729, 9731-9734, 9760-9762, 9764-9769, 9970
1 Precursor cell lymphomas			9727, 9728, 9729
2 Mature B-cell lymphomas # (except Burkitt lymphoma)			9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698, 9699, 9731-9734, 9761, 9762, 9764-9766, 9769, 9970
3 Mature T-cell and NK-cell lymphomas			9700-9702, 9705, 9708, 9709, 9714, 9716-9719, 9767, 9768 ⁺
4 Non-Hodgkin lymphomas, NOS			9591, 9760
(c) Burkitt lymphoma			9687
(d) Miscellaneous lymphoreticular neoplasms			9740-9742, 9750, 9754-9758
(e) Unspecified lymphomas			9590, 9596

[#] Burkitt lymphoma (IIC), as a mature B-cell non-Hodgkin lymphoma, may be pooled with IIb2 for overall presentation of B-cell lymphomas.

⁺ "9702 T-cell lymphoma, NOS" in a child almost always corresponds to code M-9729.

Forts. / cont.

DIAGNOSTIC GROUP		ICD-O-3 CODES
	MORPHOLOGY	TOPOGRAPHY
III CNS AND MISCELLANEOUS INTRACRANIAL AND INTRASPINAL NEOPLASMS		
(a) Ependymomas and choroid plexus tumour	9383, 9390-9394	*
1 Ependymomas	9383, 9391-9394	*
2 Choroid plexus tumour	9390	*
(b) Astrocytomas	9380	*
	9384, 9400-9411, 9420, 9421-9424, 9440-9442	*
(c) Intracranial and intraspinal embryonal tumours	9470-9474, 9480, 9508	*
	9501-9504	*
1 Medulloblastomas	9470-9472, 9474, 9480	*
2 Primitive neuroectodermal tumour (PNET)	9473	*
3 Medulloepithelioma	9501-9504	*
4 Atypical teratoid / rhabdoid tumour	9508	*
(d) Other gliomas	9380	*
	9381, 9382, 9430, 9444, 9450, 9451, 9460	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
1 Oligodendrogiomas	9450, 9451, 9460	*
2 Mixed and unspecified gliomas	9380	*
	9382	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
3 Neuroepithelial glial tumours of uncertain origin	9381, 9430, 9444	*
(e) Other specified intracranial and intraspinal neoplasms	8270-8281, 8300, 9350-9352, 9360-9362, 9412, 9413, 9492, 9493, 9505-9507, 9530-9539, 9582	*
1 Pituitary adenomas and carcinomas	8270-8281, 8300	*
2 Tumours of the sellar region (craniopharyngiomas)	9350-9352, 9582	*
3 Pineal parenchymal tumours	9360-9362	*
4 Neuronal and mixed neuronal-glial tumours	9412, 9413, 9492, 9493, 9505-9507	*
5 Meningiomas	9530-9539	*
(f) Unspecified intracranial and intraspinal neoplasms	8000-8005	C70.0-C72.9, C75.1-C75.3

* Tumours with non-malignant behaviour codes are included

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Forts. / cont.

DIAGNOSTIC GROUP	MORPHOLOGY	TOPOGRAPHY	ICD-O-3 CODES
IV NEUROBLASTOMA AND OTHER PERIPHERAL NERVOUS CELL TUMOURS			
(a) Neuroblastoma and ganglioneuroblastoma	9490, 9500		
(b) Other peripheral nervous cell tumours	8680-8683, 8690-8693, 8700, 9520-9523 9501-9504	C00.0-C69.9, C73.9-C76.8, C80.9	
V RETINOBLASTOMA			
	9510-9514		
VI RENAL TUMOURS			
(a) Nephroblastoma and other non-epithelial renal tumours	8959, 8960, 8964-8967 8963, 9364	C64.9	
1 Nephroblastoma	8959, 8960		
2 Rhabdoid renal tumour	8963	C64.9	
3 Kidney sarcomas	8964-8967		
4 Peripheral neuroectodermal tumour (pPNET) of kidney	9364	C64.9	
(b) Renal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155, 8190-8201, 8210, 8211, 8221-8231, 8240, 8241, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576 8311, 8312, 8316-8319, 8361	C64.9	
(c) Unspecified malignant renal tumours	8000-8005	C64.9	
VII HEPATIC TUMOURS			
(a) Hepatoblastoma	8970		
(b) Hepatic carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8140, 8141, 8143, 8155, 8190-8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244-8246, 8260-8264, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576 8160-8180	C22.0, C22.1	
(c) Unspecified malignant hepatic tumours	8000-8005	C22.0, C22.1	

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
VIII MALIGNANT BONE TUMOURS		
(a) Osteosarcomas	9180-9187, 9191-9195, 9200	C40.0-C41.9, C76.0-C76.8, C80.9
(b) Chondrosarcomas	9210, 9220, 9240 9221, 9230, 9241-9243	C40.0-C41.9, C76.0-C76.8, C80.9
(c) Ewing tumour and related sarcomas of bone	9260 9363-9365	C40.0-C41.9, C76.0-C76.8, C80.9 C40.0-C41.9
1 Ewing tumour and Askin tumour of bone	9260 9365	C40.0-C41.9, C76.0-C76.8, C80.9 C40.0-C41.9
2 Peripheral neuroectodermal tumour (pPNET) of bone	9363, 9364	C40.0-C41.9
(d) Other specified malignant bone tumours	8810, 8811, 8823, 8830 8812, 9250, 9261, 9262, 9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342, 9370-9372	C40.0-C41.9
1 Malignant fibrous neoplasms of bone	8810, 8811, 8823, 8830 8812, 9262	C40.0-C41.9
2 Malignant chordomas	9370-9372	
3 Odontogenic malignant tumours	9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342	
4 Miscellaneous malignant bone tumours	9250, 9261	
(e) Unspecified malignant bone tumours	8000-8005, 8800, 8801, 8803-8805	C40.0-C41.9
IX SOFT TISSUE AND OTHER EXTRASSEOUS SARCOMAS		
(a) Rhabdomyosarcomas	8900-8905, 8910, 8912, 8920, 8991	
(b) Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	8810, 8811, 8813-8815, 8821, 8823, 8834-8835 8820, 8822, 8824-8827, 9150, 9160, 9491, 9540-9571, 9580	C00.0-C39.9, C44.0-C76.8, C80.9
1 Fibroblastic and myofibroblastic tumours	8810, 8811, 8813-8815, 8821, 8823, 8834-8835 8820, 8822, 8824-8827, 9150, 9160	C00.0-C39.9, C44.0-C76.8, C80.9
2 Nerve sheath tumours	9540-9571	
3 Other fibrous neoplasms	9491, 9580	

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Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
IX SOFT TISSUE AND OTHER EXTRAOSSEOUS SARCOMAS (cont.)		
(c) Kaposi sarcoma	9140	
(d) Other specified soft tissue sarcomas		
	8587, 8710-8713, 8806, 8831-8833, 8836, 8840-8842, 8850-8858, 8860-8862, 8870, 8880, 8881, 8890-8898, 8921, 8982, 8990, 9040-9044, 9120-9125, 9130-9133, 9135, 9136, 9141, 9142, 9161, 9170-9175, 9231, 9251, 9252, 9373, 9581	
	8830	C00.0-C39.9, C44.0-C76.8, C80.9
	8963	C00.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
	9180, 9210, 9220, 9240	C49.0-C49.9
	9260	C00.0-C39.9, C47.0-C75.9
	9364	C00.0-C39.9, C47.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
	9365	C00.0-C39.9, C47.0-C63.9, C65.9-C76.8, C80.9
1 Ewing tumour and Askin tumour of soft tissue	9260	C00.0-C39.9, C47.0-C75.9
	9365	C00.0-C39.9, C47.0-C63.9, C65.9-C76.8, 80.9
2 Peripheral neuroectodermal tumour (pPNET) of soft tissue	9364	C00.0-C39.9, C47.0-C63.9, C65.9-C69.9, C73.9-C76.8, 80.9
3 Extrarenal rhabdoid tumour	8963	C00.0-C63.9, C65.9-C69.9, C73.9-C76.8, 80.9
4 Liposarcomas	8850-8858, 8860-8862, 8870, 8880, 8881	
5 Fibrohistiocytic tumours	8830	C00.0-C39.9, C44.0-C76.8, 80.9
	8831-8833, 8836, 9251, 9252	
6 Leiomyosarcomas	8890-8898	
7 Synovial sarcomas	9040-9044	
8 Blood vessel tumours	9120-9125, 9130-9133, 9135, 9136, 9141, 9142, 9161, 9170-9175	
9 Osseous and chondromatous neoplasms of soft tissue	9180, 9210, 9220, 9240 9231	C49.0-C49.9
10 Alveolar soft parts sarcoma	9581	
11 Miscellaneous soft tissue sarcomas	8587, 8710-8713, 8806, 8840-8842, 8921, 8982, 8990, 9373	

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
IX SOFT TISSUE AND OTHER EXTRASSEOUS SARCOMAS (cont.)		
(e) Unspecified soft tissue sarcomas	8800-8805	C00.0-C39.9, C44.0-C76.8, C80.9
X GERM CELL TUMOURS, TROPHOBlastic TUMOURS AND NEOPLASMS OF GONADS		
(a) Intracranial and intraspinal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100, 9101	* C70.0-C72.9, C75.1-C75.3
1 Intracranial and intraspinal germinomas	9060-9065	*
2 Intracranial and intraspinal teratomas	9080-9084	*
3 Intracranial and intraspinal embryonal carcinomas	9070, 9072	*
4 Intracranial and intraspinal yolk sac tumour	9071	*
5 Intracranial and intraspinal choriocarcinoma	9100	*
6 Intracranial and intraspinal tumours of mixed forms	9085, 9101	*
(b) Malignant extracranial and extragonadal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100-9105	C00.0-C55.9, C57.0-C61.9, C63.0-C69.9, C73.9-C75.0, C75.4-C76.8, C80.9
1 Malignant germinomas of extracranial and extragonadal sites	9060-9065	
2 Malignant teratomas of extracranial and extragonadal sites	9080-9084	
3 Embryonal carcinomas of extracranial and extragonadal sites	9070, 9072	C00.0-C55.9, C57.0-C61.9, C63.0-C69.9, C73.9-C75.0, C75.4-C76.8, 80.9
4 Yolk sac tumour of extracranial and extragonadal sites	9071	
5 Choriocarcinomas of extracranial and extragonadal sites	9100, 9103, 9104	
6 Other and unspecified malignant mixed germ cell tumours of extracranial and extragonadal sites	9085, 9101, 9102, 9105	
(c) Malignant gonadal germ cell tumours	9060-9065, 9070-9073, 9080-9085, 9090, 9091, 9100, 9101	C56.9, C62.0-C62.9
1 Malignant gonadal germinomas	9060-9065	
2 Malignant gonadal teratomas	9080-9084, 9090, 9091	
3 Gonadal embryonal carcinomas	9070, 9072	
4 Gonadal yolk sac tumour	9071	C56.9, C62.0-C62.9
5 Gonadal choriocarcinoma	9100	
6 Malignant gonadal tumours of mixed forms	9085, 9101	
7 Malignant gonadal gonadoblastoma	9073	

* Tumours with non-malignant behaviour codes are included

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Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
X GERM CELL TUMOURS, TROPHOBLASTIC TUMOURS AND NEOPLASMS OF GONADS (cont.)		
(d) Gonadal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8260-8263, 8290, 8310, 8313, 8320, 8323, 8380-8384, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 9000, 9014, 9015	C56.9, C62.0-C62.9
	8441-8444, 8450, 8451, 8460-8473	
(e) Other and unspecified malignant gonadal tumours	8590-8671 8000-8005	C56.9, C62.0-C62.9
XI OTHER MALIGNANT EPITHELIAL NEOPLASMS AND MALIGNANT MELANOMAS		
(a) Adrenocortical carcinomas	8370-8375	
(b) Thyroid carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8510, 8560-8573	C73.9
	8330-8337, 8340-8347, 8350	
(c) Nasopharyngeal carcinomas	8010-8041, 8050-8075, 8082, 8083, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8500-8576	C11.0-C11.9
(d) Malignant melanomas	8720-8780, 8790	
(e) Skin carcinomas	8010-8041, 8050-8075, 8078, 8082, 8090-8110, 8140, 8143, 8147, 8190, 8200, 8240, 8246, 8247, 8260, 8310, 8320, 8323, 8390-8420, 8430, 8480, 8542, 8560, 8570-8573, 8940, 8941	C44.0-C44.9
(f) Other and unspecified carcinomas	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C00.0-C10.9, C12.9-C21.8, C23.9-C39.9, C48.0-C48.8, C50.0-C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C72.9, C75.0-C76.8, C80.9
1 Carcinomas of salivary glands		C07.9-C08.9
2 Carcinomas of colon and rectum	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C18.0, C18.2-C18.9, C19.9, C20.9, C21.0-C21.8
3 Carcinomas of appendix		C18.1
4 Carcinomas of lung		C34.0-C34.9

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
XI OTHER MALIGNANT EPITHELIAL NEOPLASMS AND MALIGNANT MELANOMAS (cont.)		
(f) Other and unspecified carcinomas (cont.)		
5 Carcinomas of thymus		C37.9
6 Carcinomas of breast		C50.0-C50.9
7 Carcinomas of cervix uteri		C53.0-C53.9
8 Carcinomas of bladder		C67.0-C67.9
9 Carcinomas of eye		C69.0-C69.9
10 Carcinomas of other specified sites	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C00.0-C06.9, C09.0-C10.9, C12.9-C17.9, C23.9-C33.9, C38.0-C39.9, C48.0-C48.8, C51.0-C52.9, C54.0-C54.9, C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C66.9, C68.0-C68.9, C70.0-C72.9, C75.0-C75.9
11 Carcinomas of unspecified site		C76.0-C76.8, C80.9
XII OTHER AND UNSPECIFIED MALIGNANT NEOPLASMS		
(a) Other specified malignant tumours		8930-8936, 8950, 8951, 8971-8981, 9050-9055, 9110
	9363	C00.0-C39.9, C47.0-C75.9
1 Gastrointestinal stromal tumour	8936	
2 Pancreatoblastoma	8971	
3 Pulmonary blastoma and pleuropulmonary blastoma	8972, 8973	
4 Other complex mixed and stromal neoplasms	8930-8935, 8950, 8951, 8974-8981	
5 Mesothelioma	9050-9055	
6 Other specified malignant tumours	9110	
	9363	C00.0-C39.9, C47.0-C75.9
(b) Other unspecified malignant tumours		8000-8005
		C00.0-C21.8, C23.9-C39.9, C42.0-C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C69.9, C73.9-C75.0, C75.4-C80.9

144 Publications and Presentations since 2014

Veröffentlichungen mit Beteiligung des Deutschen Kinderkrebsregisters seit 2014

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