



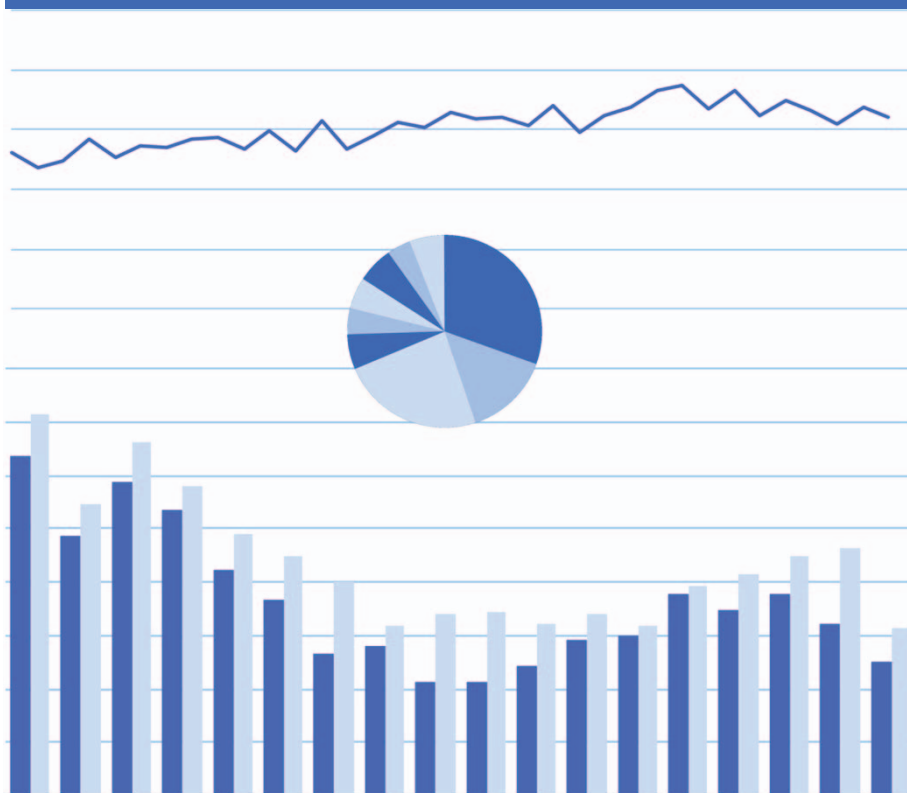
*Deutsches
Kinderkrebsregister*



Jahresbericht / Annual Report 2016



German Childhood Cancer Registry



Jahresbericht Annual Report 2016

(1980-2015)

Deutsches Kinderkrebsregister DKKR
German Childhood Cancer Registry GCCR

Jahresbericht / Annual Report 2016 (1980-2015)

November 2016

Deutsches Kinderkrebsregister am
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Herausgeber:

Deutsches Kinderkrebsregister
(Leitung: PD Dr. Peter Kaatsch)

Druck: Verlag Kirchheim + Co GmbH
Auflage: 800 Exemplare

Zitierweise: Kaatsch P, Grabow D, Spix C. German Childhood Cancer Registry - Annual Report 2016 (1980-2015).
Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI) at the University Medical Center of the
Johannes Gutenberg University Mainz, 2016.

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

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

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2 Vorwort / Foreword

Das Deutsche Kinderkrebsregister legt mit diesem Jahresbericht 2016 erneut eine im 2-Jahres-Rhythmus erscheinende Druckversion des Berichtes vor. Die dazwischen liegenden Berichte erscheinen ausschließlich elektronisch, alle Berichte 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 Vollständigkeit der Erfassung von Krebs im Kindes- und Jugendalter mit mittlerweile fast 60.000 erfassten Neuerkrankungen nicht möglich. Auch deren Bereitschaft zur Teilnahme an Befragungen und die grundsätzliche Offenheit ehemaliger Patientinnen und Patienten, im Rahmen der Langzeitbeobachtung 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!

Eine Ergebnis-Übersicht zu den wichtigsten Kennzahlen (Inzidenzen, Überlebenswahrscheinlichkeiten, Zweitneoplasien etc.) findet sich auf Seite 4 dieses Berichtes. Insgesamt liegen dem Deutschen Kinderkrebsregister seit 1980 Meldungen von 59.772 erkrankten Kindern (bis 2008 nur unter 15-jährige) und Jugendlichen (ab 2009 alle unter 18-jährigen) vor. Davon befinden sich 33.314 derzeit in der Langzeitnachbeobachtung (Tab. 8). Das bedeutet, von diesen liegen uns aktuelle Adressen vor, wir haben regelmäßig Kontakt zu ihnen und haben grundsätzlich Kenntnis darüber, ob eine zweite Krebserkrankung aufgetreten ist. Diese Gruppe der „Langzeitüberlebenden“ bildet eine wichtige Basis zur Erforschung möglicher Spätfolgen; daraus wiederum ergibt sich eine wichtige Grundlage für die Verbesserung der Nachsorgeangebote für ehemalige Patienten.

Die Sichtbarkeit des Deutschen Kinderkrebsregisters ist nach unserer Einschätzung weiterhin national und international hoch. Beispielsweise können Vorträge genannt werden bei Veranstaltungen der Deutschen Krebsgesellschaft (QoCC: Quality of cancer care, Berlin 2015), dem Deutschen Konsortium für Translationale Krebsforschung (DKTK, Heidelberg 2015), beim Schweizerischen Kinderkrebsregister (Bern 2016), einem internationalen Symposium zu „Late effects after tumor therapy in childhood and adolescence“ (5. RISK-Symposium, Hannover 2015). Auch in weiteren Drittmittelprojekten, beispielsweise in EU-Projekten, spielt das Kinderkrebsregister mit dessen Mitarbeiterinnen und Mitarbeitern eine wesentliche Rolle. In

The German Childhood Cancer Registry publishes its Annual Report 2016 again as print version. Printed copies are available every other year, and all past reports 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!

An overview of the results with key figures (incidence, survival probability, subsequent neoplasms etc.) can be found on page 4 of this report. Altogether, the German Childhood Cancer Registry has registered 59,772 cases of children (until 2008 only those under 15 years of age) and adolescents (from 2009 onwards under 18 years) since its establishment in 1980. Thereof, 33,314 are currently in long-term follow-up (Table 8). This means that we have the former patients' current addresses available, we are in regular contact with them, and we know whether a subsequent neoplasm occurred. This group of "long-term survivors" is the basis for investigating potential late effects, which in turn is an important basis for improving the follow-up care of former patients.

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 a meeting of the German Cancer Society (QoCC: Quality of cancer care, Berlin 2015), at a meeting of the German Consortium for Translational Cancer Research (DKTK, Heidelberg 2015), at the Swiss Childhood Cancer Registry (Bern 2016), and at an international symposium about "Late effects after tumor therapy in childhood and adolescence" (5th RISK Symposium, Hannover 2015). Furthermore, the Childhood Cancer Registry and its staff members play an important role in third-party funded projects, such as EU projects. In this context, two

diesem Zusammenhang erscheinen zwei Publikationen unter Beteiligung des Kinderkrebsregisters erwähnenswert: eine Veröffentlichung unter Federführung der International Agency for Research of Cancer (IARC) („Registration of childhood cancer: moving towards a pan-European coverage?“) (35) und aus dem Forschungszentrum der dänischen Krebsgesellschaft („Childhood cancer survivor cohorts in Europe“) (37). Auch wurde 2015 eine Serie mit drei diagnosespezifischen Publikationen über Inzidenzraten und Überlebenswahrscheinlichkeiten, zeitliche Trends und dem Auftreten von Zweitneoplasien fortgeführt: für die pädiatrischen Keimzelltumoren (32), die embryonalen Tumoren (36) und die Knochentumoren (42).

Im Rahmen der in den einzelnen Bundesländern erfolgenden Umsetzung des Krebsregisterfrüherkennungs- 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. Dankenswerterweise haben uns viele Bundesländer die Möglichkeit gegeben, deren aktuelle Gesetzesentwürfe entsprechend zu kommentieren, sodass wir optimistisch sind, auch bei der neuen Gesetzeslage mit den Ländern entsprechende Vereinbarungen treffen zu können. Unabhängig davon 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, November 2016

publications, in which the Childhood Cancer Registry participated, should be mentioned: one article under the auspices of the International Agency for Research of Cancer (IARC) („Registration of childhood cancer: moving towards a pan-European coverage?“) (35) and one from the Danish Cancer Society Research Center („Childhood cancer survivor cohorts in Europe“) (37). Moreover, in 2015 we continued a series of diagnosis-specific publications about incidence rates and survival probabilities, time trends and the occurrence of subsequent neoplasms: about pediatric germ cell tumors (32), embryonal tumors (36), and bone tumors (42).

The federal states are updating their federal laws on cancer registration according to the national „Krebsregisterfrüherkennungs- 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. We are grateful that many federal states gave us the opportunity to comment on the drafts, and thus we are optimistic to come to agreements concerning data exchanges under the new laws. Notwithstanding the above, we continue to transfer cases reported to the German Childhood Cancer Registry to the cancer registries of the federal states as a matter of principle, taking the specific registry laws and data protection legislations into account.

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





4 Ergebnis-Übersicht / Overview of Results

Meldungen von Fällen unter 15 Jahren im Jahr 2015 (Meldungen aus 64 Kliniken):	1758
Meldungen von Fällen unter 18 Jahren im Jahr 2015 (Meldungen aus 66 Kliniken):	2169
Durchschnittliche Meldungen von Fällen unter 15 Jahren pro Jahr: (ermittelt aus den Jahren 2006-2015)	1758
vor dem 15. Geburtstag erkrankt ...	eines von 410 Neugeborenen
Jungen / Mädchen	972 / 786
Meldungen von unter 5-Jährigen	782
Meldungen von 5- unter 10-Jährigen	461
Meldungen von 10- unter 15-Jährigen	516
Lymphatische Leukämien (LL)	446
Durchschnittliche Meldungen von Fällen im Alter von 15- unter 18 Jahren pro Jahr: (ermittelt aus den Jahren 2009-2015)	361
Zahl aller Meldungen unter 15 bzw. 18 Jahren von Beginn der Erfassung im Jahr 1980 bis 2015:	59772
in Langzeitnachsicht beobachtet	ca. 33000

Bevölkerung im Alter von unter 15 / unter 18 Jahren (Million):	
in 2015	10,6 / 13,0
im Durchschnitt (in den Jahren 2006-2015 / 2009-2015)	11,0 / 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. 430 Todesfälle pro Jahr innerhalb von 15 Jahren nach Diagnose.

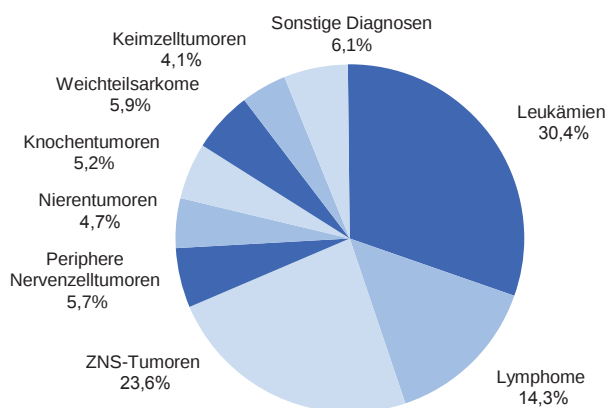
Zweitneoplasien nach einer im Kindesalter (unter 15) aufgetretenen Ersterkrankung:

- 6,6 % der Patienten erkranken innerhalb von 30 Jahren nach Diagnose erneut an Krebs
- Insgesamt sind über 1300 Patienten mit Folgeerkrankungen registriert.

Durchschnittliche Meldungen von Fällen unter 15 Jahren pro Jahr nach Bundesländern: (ermittelt aus den Jahren 2006-2015)

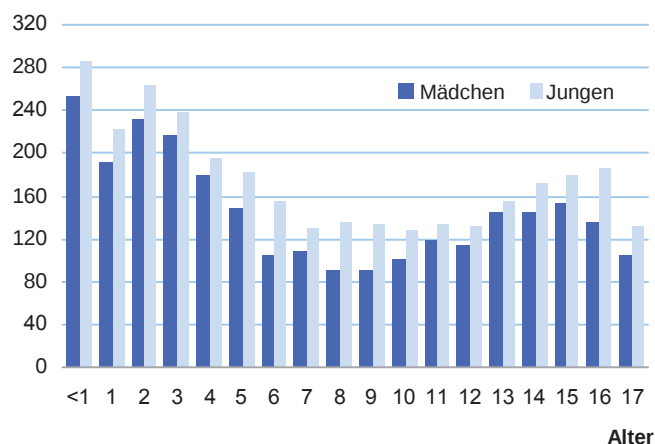
	Alle Erkrankungen	Leukämien		Alle Erkrankungen	Leukämien
Schleswig-Holstein	66	22	Bayern	277	96
Hamburg	37	12	Saarland	19	6
Niedersachsen	174	60	Berlin	66	23
Bremen	12	4	Brandenburg	44	16
Nordrhein-Westfalen	405	126	Mecklenburg-Vorpommern	29	9
Hessen	135	47	Sachsen	84	26
Rheinland-Pfalz	91	29	Sachsen-Anhalt	41	13
Baden-Württemberg	238	77	Thüringen	40	13

Relative Häufigkeiten der an das Deutsche Kinderkrebsregister gemeldeten Erkrankungsfälle nach Diagnose-Hauptgruppen*



ZNS: Zentrales Nervensystem

Alters- und geschlechtsspezifische Erkrankungsrate (pro 1 Million der jeweiligen Altersgruppe)*



*2009-2015, basierend auf insgesamt 14791 unter 18-jährigen Patienten

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 7 Jahre erhältlich. Erkennbar ist, dass die Meldungen der 16-Jährigen und ganz besonders der 17-Jährigen nicht vollzählig sind. Diese 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 7 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 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

Diese hämatologischen Erkrankungen sind die häufigsten bösartigen Erkrankungen im Kindes- und Jugendalter. Betroffen ist bis unter 15 eines von 1200 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. In der Literatur wird dieser Anstieg als echt und nicht als Registrierungsartefakt bewertet; ursächlich werden Änderungen des Lebensstils vermutet. 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) und steigt weiter.

Akute myeloische Leukämien (AML) sind deutlich seltener und haben eine schlechtere Prognose (73% 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 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 1200 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. In the literature this increase is considered to be real, not a registration artifact, possibly due to changes in lifestyle. Almost 98% of all lymphoid leukemias are precursor cell leukemias, 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) and increases further.

Acute myeloid leukaemias (AML) are much less frequent and have a worse prognosis (73% 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.

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

II Lymphomas and reticuloendothelial neoplasms

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, 13% 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 Folgoneoplasie ist nach NHL leicht überdurchschnittlich hoch, besonders nach Vorläuferzell-Lymphomen.

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 13% 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.

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

III CNS and miscellaneous intracranial and intraspinal neoplasms

Bei den Tumoren des zentralen Nervensystems (ZNS, Hirntumore), eines von 1700 Kindern unter 15 ist betroffen, handelt es sich um eine heterogene Gruppe von Krebserkrankungen 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 1980 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 Kraniopharyngiomen ungewöhnlich niedrig und mit 18% 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 1700 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” 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 (18%). 23% of all SN in the 30 years after primary diagnosis are CNS tumours, most of these are meningiomas, followed by astrocytomas.

IV Neuroblastoma and other peripheral nervous cell tumours

Neuroblastome gehören zu den embryonalen Tumoren, die vor allem bei Kleinkindern auftreten. Betroffen ist eines von 5700 Kindern unter 15, Jungen erkranken etwa 30% häufiger als Mädchen. Wir gehen von nahezu 100% Vollzähligkeit der Erfassung aus. Insgesamt überleben etwa 77% der Fälle langfristig, jedoch haben Patienten mit fortgeschrittener 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 Mortalitätsenkung, so dass die Früherkennung 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 5700 under 15, boys have an about 30% higher incidence than girls. We assume completeness is close to 100%. Overall long-term survival is 77%, 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

Retinoblastome, unter 18.000 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 18,000 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

Fast alle Nierentumoren im Kindesalter sind Nephroblastome (Wilmstumor). Ein Kind von 7500 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 Folge-neoplasie leicht 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 70% häufiger.

Almost all renal tumours in childhood are nephroblastomas (Wilm's tumour). One child under 15 in 7500 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 70% more often.

8 Ergebnis-Übersicht / Overview of Results

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

Fast alle Lebertumoren im Kindesalter (ein Fall unter 31.000 Kindern bis 14 Jahre) sind Hepatoblastome. Jungen sind 40% häufiger betroffen als Mädchen. Wir gehen von guter Vollständigkeit der Erfassung aus, die seit der Gründung eines Lebertumorregisters für Kinder im Jahre 2011 weiter verbessert wurde. Die Prognose ist moderat (78% 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, as are renal carcinomas as subsequent neoplasms.

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

Almost all hepatic tumours in childhood (one in 31,000 children until 14 years is affected) are hepatoblastomas. Boys have a 40% higher incidence. We assume completeness is good and has improved further since a hepatic tumour registry for children was funded in 2011. The prognosis is moderate (78% 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.

VIII Malignant bone tumours

Knochensarkome (ein Kind von 10.000 unter 15) sind typisch für ältere Kinder und Jugendliche. Die besonders häufigen Typen sind Osteosarkome und Ewingsarkome. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollständigkeit 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.

Bone sarcomas (one case in 10,000 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.

IX Soft tissue and other extrasosseous sarcomas

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 Vollständigkeit 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.

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.

X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

Keimzelltumoren sind eine heterogene Gruppe von Krebserkrankungen (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 Vollständigkeit 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. Dies ist für die scheinbar plötzliche Verbesserung der Prognose der intraspinalen und intrakraniellen Keimzelltumoren verantwortlich. Insgesamt ist die Langzeitprognose gut (93%).

Das Risiko einer Folgeneoplasie innerhalb von 30 Jahre 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), this causes the sudden seeming improvement of the prognosis of intraspinal and intracranial germ cell tumours. 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

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-Karzinome als maligne eingestuft, daraus erklärt sich die seitdem gestiegene Anzahl der Meldungen von Appendixkarzinomen. Bei den malignen Melanomen konnte die Erfassung im Laufe der Jahre erheblich verbessert werden. 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 increase in reported appendix carcinomas since then. The reporting of malignant melanoma has improved over the years. Breast carcinomas have not been reported as primary neoplasms. Thyroid carcinomas have a good prognosis (95% 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.

10 Ergebnis-Übersicht / Overview of Results

XII Other and unspecified neoplasms

Dies ist eine heterogene Gruppe von sonst nicht zuzuordnenden, bei Kindern sehr seltenen bösartigen Krebserkrankungen (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 /
Systematic Presentation of Descriptive Measures for ICCC-3 Diagnoses**

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14 Diagnosen / Diagnoses

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Cases in Germany aged under 15 years (1980-2015): 57245

Selected characteristics Germany 2006-2015

Relative frequency:	17580 / 17580 = 100 %
Relative frequency of trial patients:	94.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	7856	9724	17580
Standardized rate *:	154.4	180.4	167.8
Cumulative incidence:	2234	2622	2433
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	1855	5963	4607	5155
Incidence rate:	272.0	216.2	127.1	132.1

Median age at diagnosis: 5 years 10 months

Survival probabilities:	5-year	10-year	15-year
	85 %	83 %	82 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
4335	100.0 %	34.4	500

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

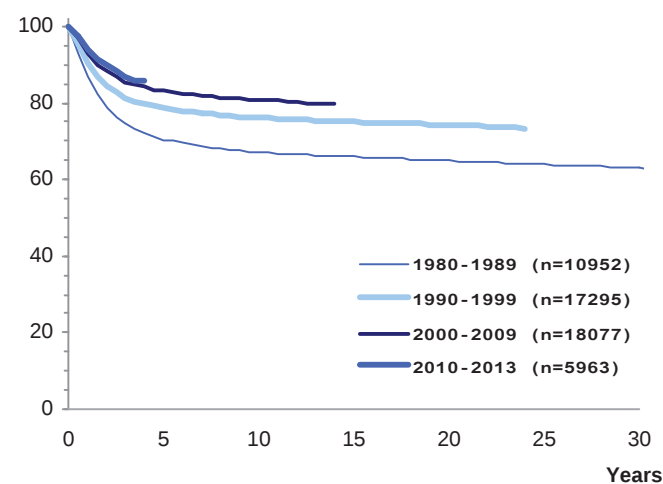
All malignancies

SN after all malignancies

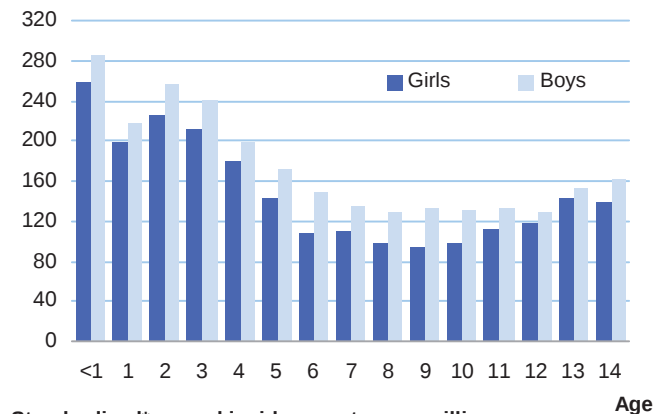
	% of all	Cumulative
N	1253 SN	incidence
1253	100.0 %	6.6 %

* Standard: Segi world standard population

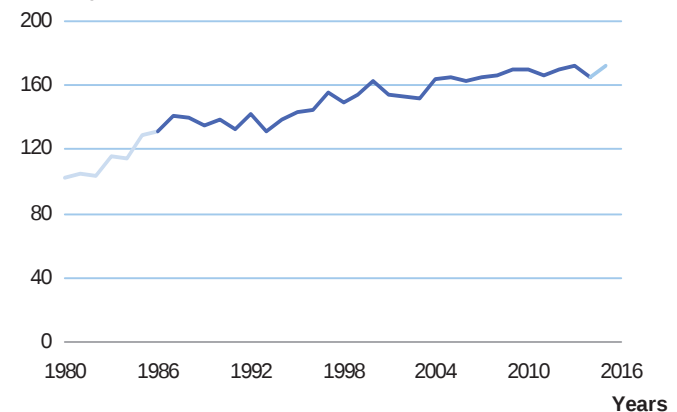
Survival probabilities by year of diagnosis Germany 1980-2013



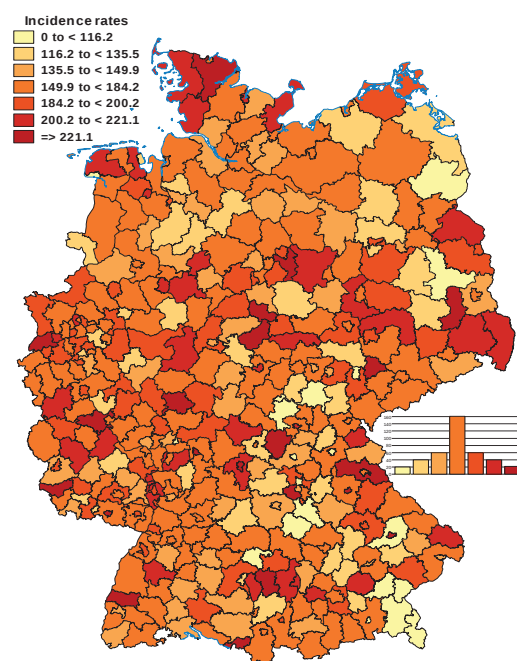
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



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 (1980-2015): 19470

Selected characteristics Germany 2006-2015

Relative frequency: 5783 / 17580 = 32.9 %

Relative frequency of trial patients: 99.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	2588	3195	5783
Standardized rate *:	52.2	60.6	56.5
Cumulative incidence:	742	868	807
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	297	2618	1613	1255
Incidence rate:	43.5	94.9	44.5	32.2

Median age at diagnosis: 4 years 11 months

Survival probabilities:	5-year	10-year	15-year
	89 %	88 %	87 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
1401	32.3 %	11.0	161

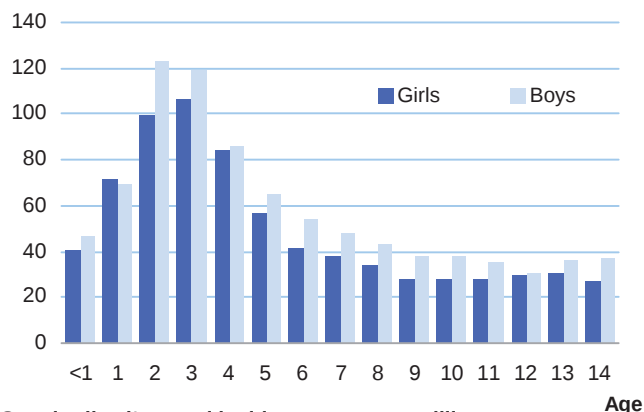
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

I Leukaemias, myeloproliferative and myelodysplastic diseases

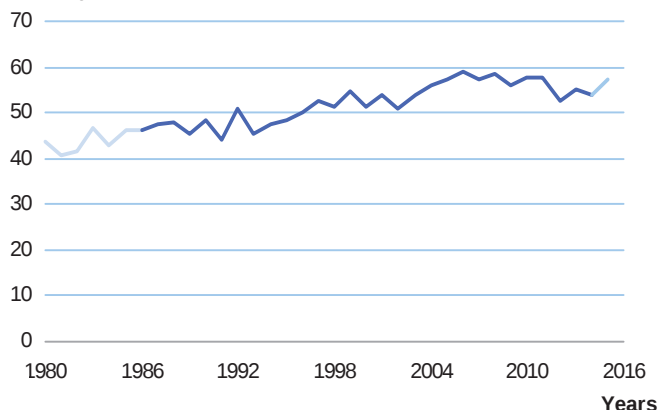
SN after I			I as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
450	35.9 %	6.5 %	260	20.8 %	0.6 %

* Standard: Segi world standard population

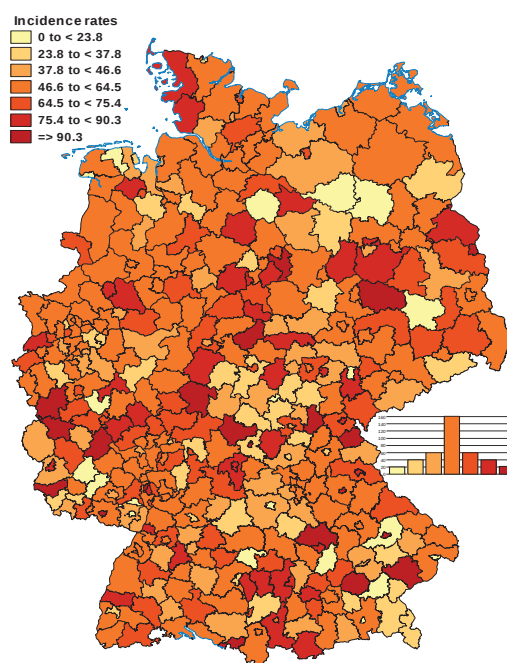
Age- and sex-specific incidence rates per million Germany 2006-2015



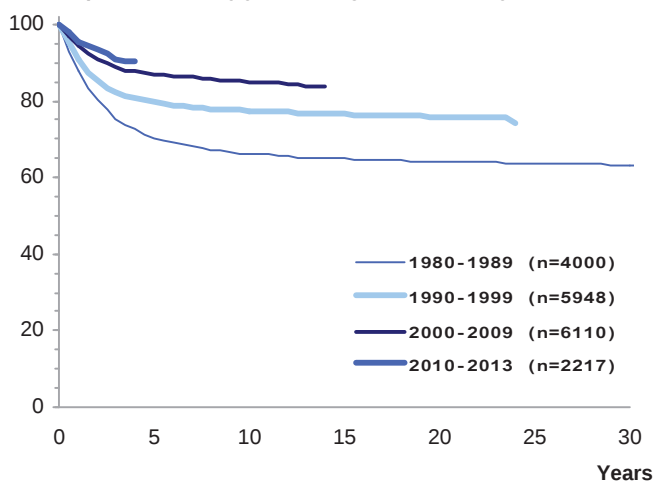
Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Survival probabilities by year of diagnosis Germany 1980-2013



Cases in Germany aged under 15 years (1980-2015): 15447

Selected characteristics Germany 2006-2015

Relative frequency:	4458 / 17580 = 25.8 %
Relative frequency of trial patients:	99.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	1983	2475	4458
Standardized rate *:	40.4	47.1	43.9
Cumulative incidence:	571	673	624
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	113	2212	1299	834
Incidence rate:	16.6	80.2	35.8	21.4
Median age at diagnosis:	4 years 9 months			

Survival probabilities:	5-year	10-year	15-year
	92 %	91 %	90 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
839	19.4 %	6.6	97

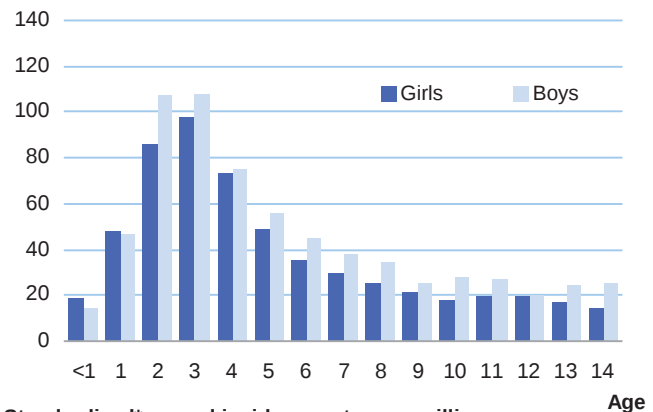
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

I (a) Lymphoid leukaemias

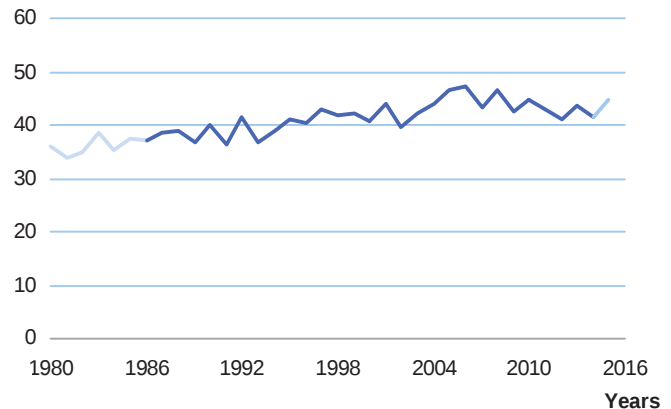
SN after I (a)			I (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
378	30.2 %	6.7 %	50	4.0 %	0.1 %

* Standard: Segi world standard population

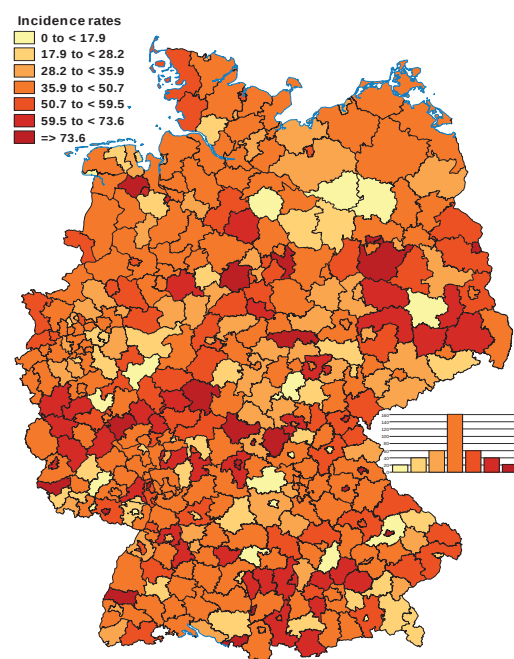
Age- and sex-specific incidence rates per million Germany 2006-2015



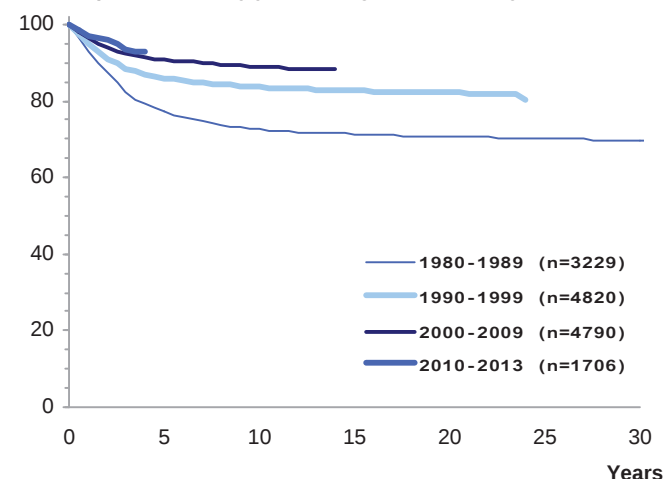
Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Survival probabilities by year of diagnosis Germany 1980-2013



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

Germany 2006-2015		N	%
Lymphoid leukaemias		4458	100.0
1 Precursor cell leukaemias		4352	97.6
2 Mature B-cell leukaemias		104	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 (1980-2015): 15077

Selected characteristics Germany 2006-2015

Relative frequency:	4352 / 17580 = 24.8 %
Relative frequency of trial patients:	99.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	1957	2395	4352
Standardized rate *:	39.9	45.7	42.9
Cumulative incidence:	564	652	609
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	112	2191	1244	805
Incidence rate:	16.4	79.4	34.3	20.6
Median age at diagnosis:	4 years 8 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

1 Precursor cell leukaemias

SN after I (a) 1			I (a) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
369	29.4 %	6.6 %	45	3.6 %	0.1 %

* Standard: Segi world standard population

2 Mature B-cell leukaemias

Cases in Germany aged under 15 years (1980-2015): 367

Selected characteristics Germany 2006-2015

Relative frequency:	104 / 17580 = 0.6 %
Relative frequency of trial patients:	99.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	25	79	104
Standardized rate *:	0.5	1.4	0.9
Cumulative incidence:	7	21	14
Sex ratio (m/f):	3.2		

Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	1	20	54	29
Incidence rate:	0.1	0.7	1.5	0.7
Median age at diagnosis:	7 years 8 months			

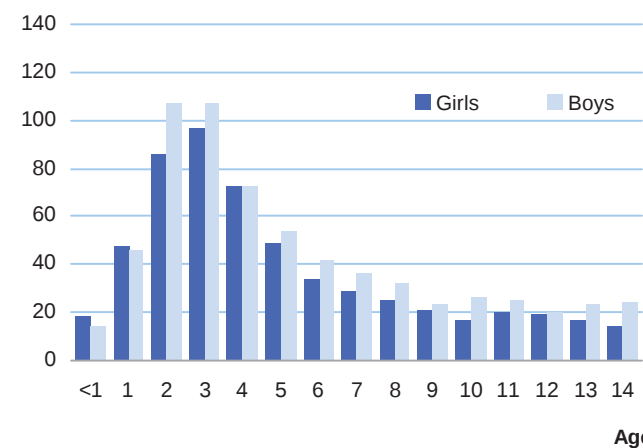
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

2 Mature B-cell leukaemias

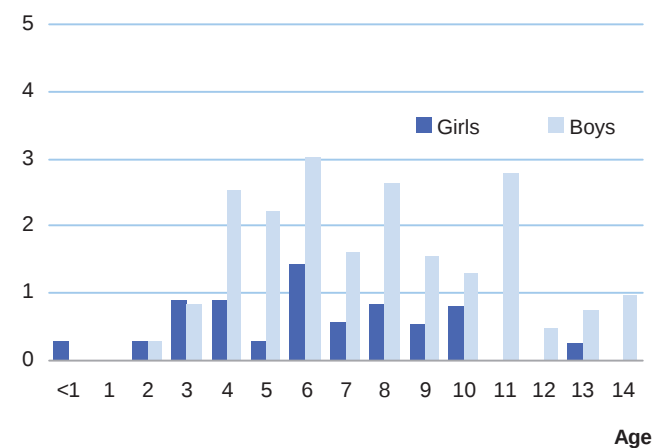
SN after I (a) 2			I (a) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
9	0.7 %	8.4 %	5	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Age- and sex-specific incidence rates per million
Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 2730

Selected characteristics Germany 2006-2015

Relative frequency: 743 / 17580 = 4.3 %

Relative frequency of trial patients: 97.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	350	393	743
Standardized rate *:	7.0	7.6	7.3
Cumulative incidence:	100	107	104
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	124	275	139	205
Incidence rate:	18.2	10.0	3.8	5.3

Median age at diagnosis: 4 years 3 months

Survival probabilities:	5-year	10-year	15-year
	74 %	73 %	73 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
425	9.8 %	3.3	49

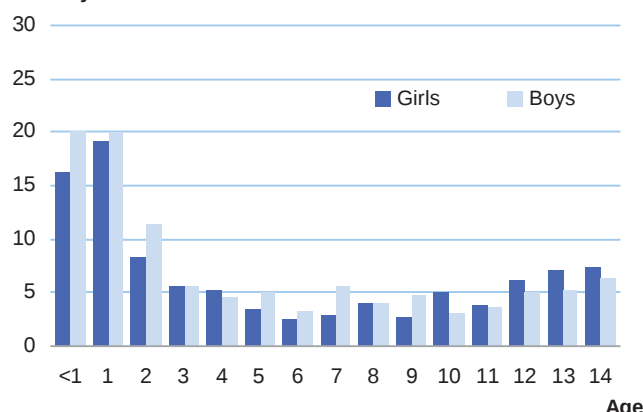
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

I (b) Acute myeloid leukaemias

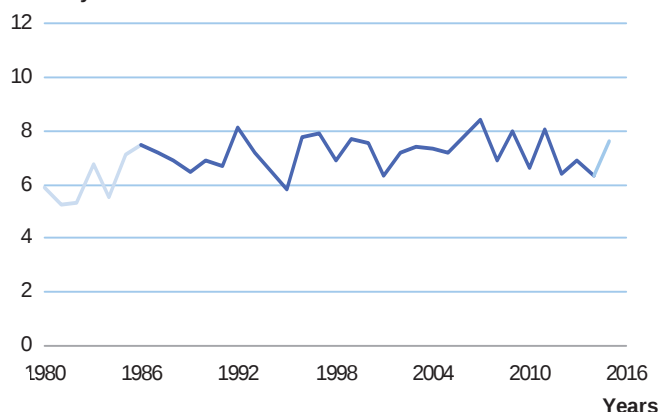
SN after I (b)			I (b) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
51	4.1 %	5.2 %	140	11.2 %	0.3 %

* Standard: Segi world standard population

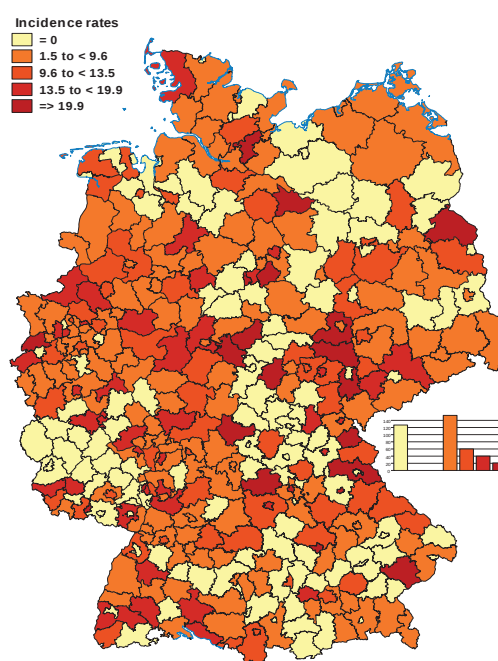
Age- and sex-specific incidence rates per million Germany 2006-2015



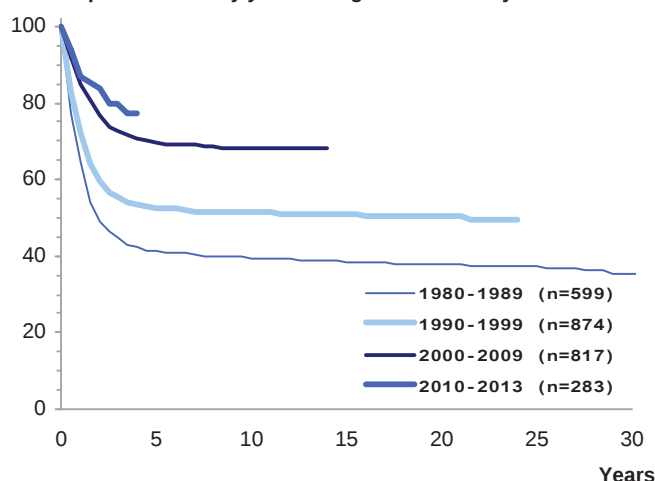
Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Survival probabilities by year of diagnosis Germany 1980-2013



20 I (c) Chronic myeloproliferative diseases

Cases in Germany aged under 15 years (1980-2015): 268

Selected characteristics Germany 2006-2015

Relative frequency:	78 / 17580 = 0.5 %
Relative frequency of trial patients:	85.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	32	46	78
Standardized rate *:	0.5	0.8	0.7
Cumulative incidence:	9	12	10
Sex ratio (m/f):	1.4		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	1	8	28	41
Incidence rate:	0.1	0.3	0.8	1.1

Median age at diagnosis: 10 years 1 month

Survival probabilities:	5-year	10-year	15-year
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
33	0.8 %	0.2	4

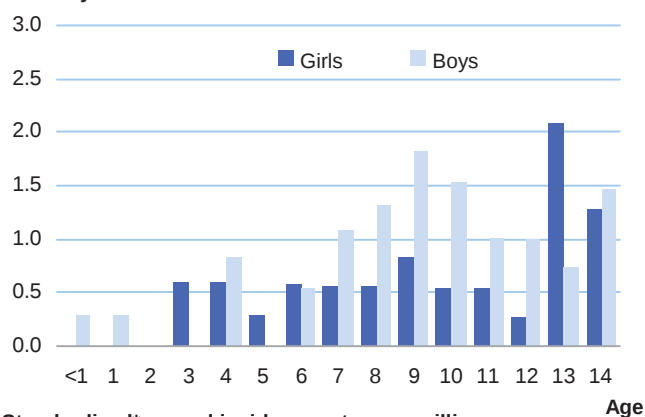
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

I (c) Chronic myeloproliferative diseases

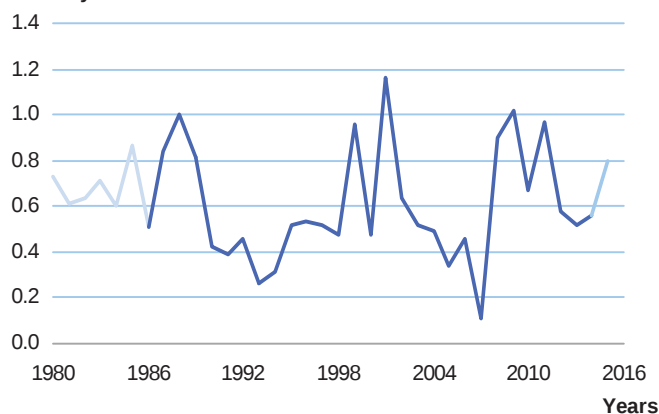
SN after I (c)			I (c) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
6	0.5 %	-	4	0.3 %	0.0 %

* Standard: Segi world standard population

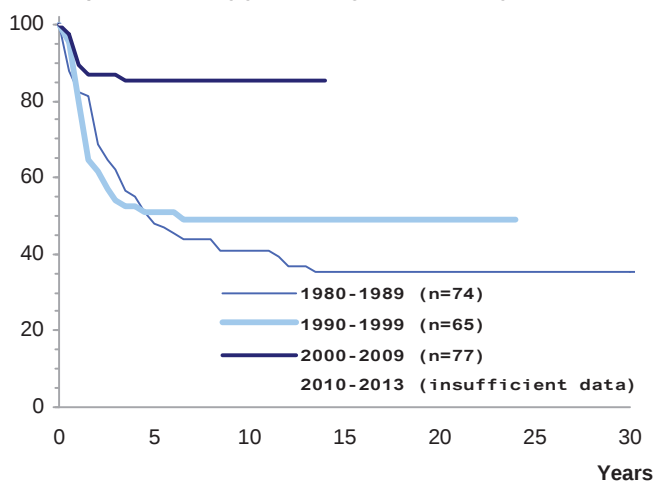
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Cases in Germany aged under 15 years (1980-2015): 839**Selected characteristics Germany 2006-2015**

Relative frequency:	437 / 17580 = 2.5 %
Relative frequency of trial patients:	99.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	188	249	437
Standardized rate *:	3.5	4.5	4.0
Cumulative incidence:	53	67	60
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	44	110	129	154
Incidence rate:	6.5	4.0	3.6	3.9

Median age at diagnosis: 7 years 5 months

Survival probabilities:	5-year	10-year	15-year
	82 %	79 %	76 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

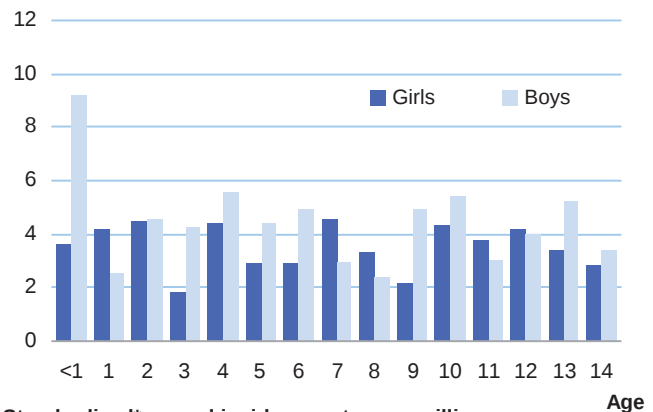
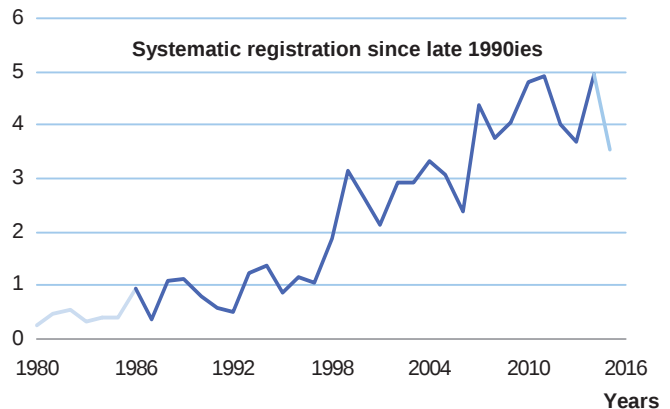
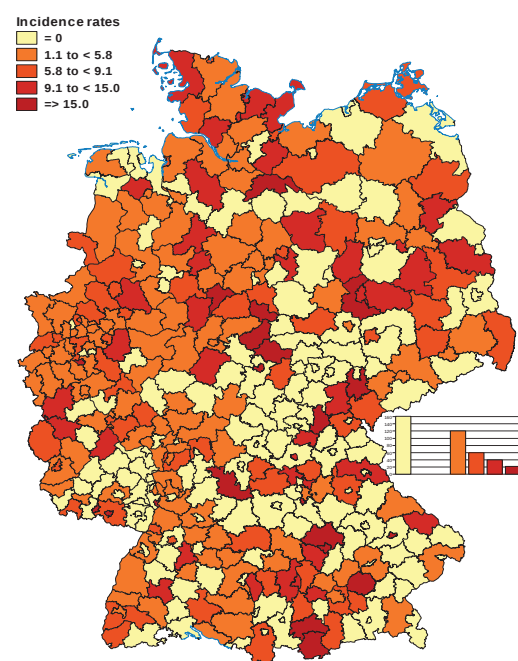
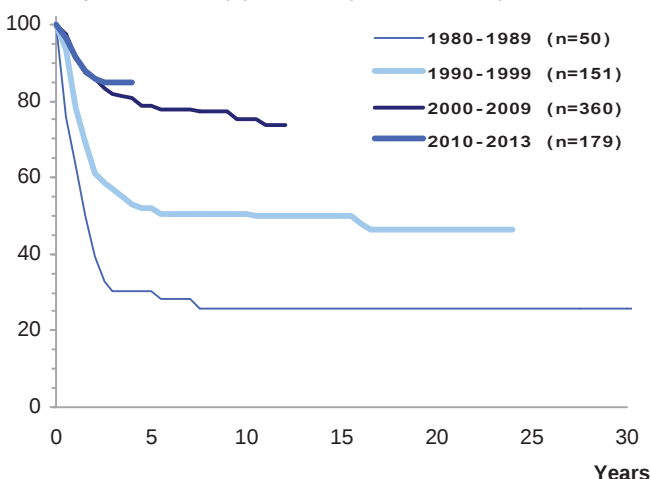
Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
85	2.0 %	0.7	10

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

I (d) Myelodysplastic syndrome and other myeloproliferative diseases

SN after I (d)			I (d) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
7	0.6 %	2.9 %	64	5.1 %	0.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2006-2015**Standardized* annual incidence rates per million Germany 1980-2015****Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015****Survival probabilities by year of diagnosis Germany 1980-2013**

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 (1980-2015): 6668

Selected characteristics Germany 2006-2015

Relative frequency:	1885 / 17580 = 10.7 %		
Relative frequency of trial patients:	96.4 %		

Incidence rates per million:	Girls	Boys	Total
Number of cases:	600	1285	1885
Standardized rate *:	10.0	21.2	15.8
Cumulative incidence:	163	336	251
Sex ratio (m/f):	2.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	8	228	602	1047
Incidence rate:	1.2	8.3	16.6	26.8

Median age at diagnosis: 10 years 9 months

Survival probabilities:	5-year	10-year	15-year
	94 %	93 %	92 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
245	5.7 %	1.8	28

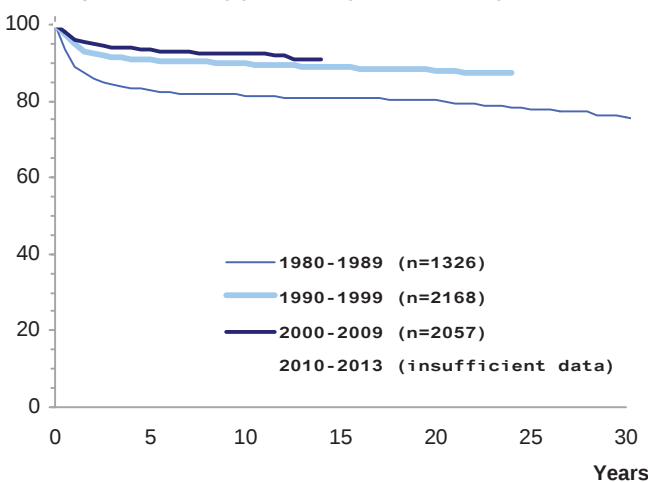
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

II Lymphomas and reticuloendothelial neoplasms

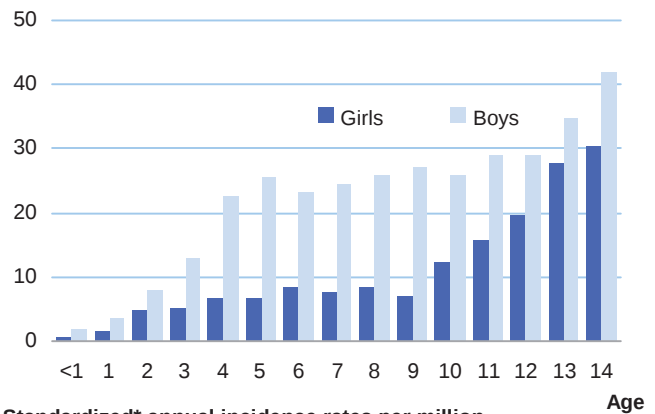
SN after II			II as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
222	17.7 %	10.4 %	94	7.5 %	0.3 %

* Standard: Segi world standard population

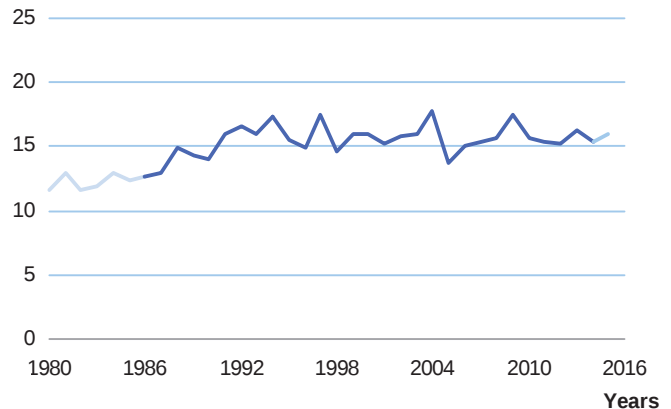
Survival probabilities by year of diagnosis Germany 1980-2013



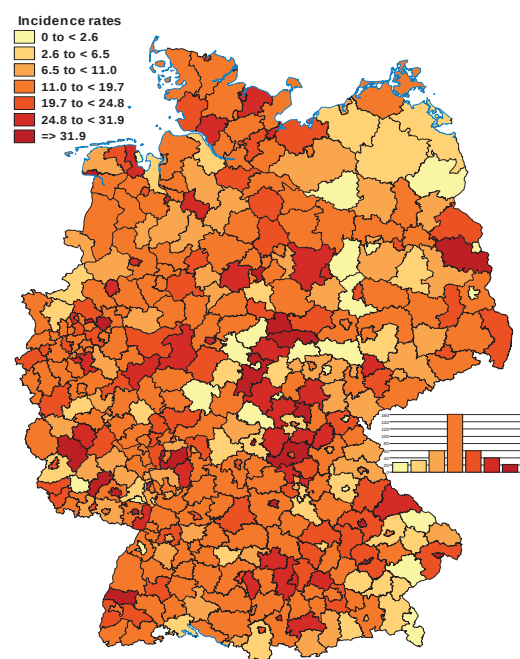
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 2744**Selected characteristics Germany 2006-2015**

Relative frequency:	780 / 17580 = 4.5 %		
Relative frequency of trial patients:	97.7 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	312	468	780
Standardized rate *:	4.9	7.4	6.2
Cumulative incidence:	83	121	102
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	35	174	571
Incidence rate:	0.0	1.3	4.8	14.6
Median age at diagnosis:	12 years 7 months			

Survival probabilities:	5-year	10-year	15-year
	99 %	98 %	97 %

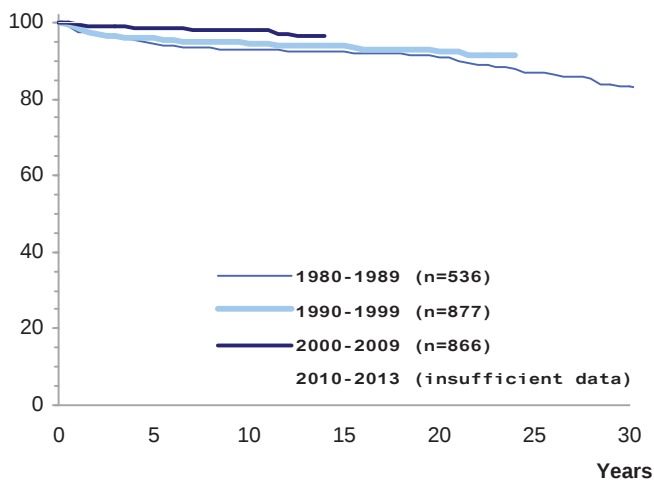
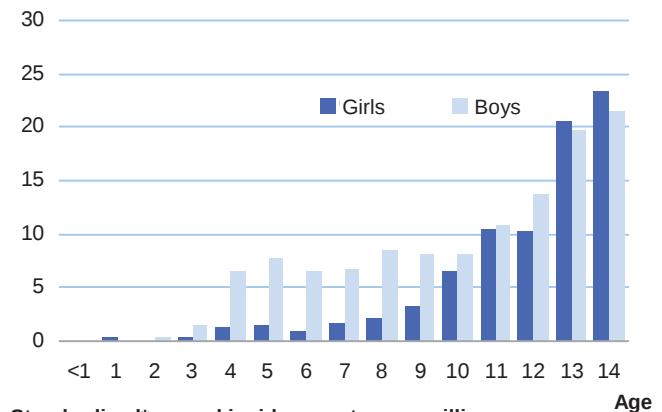
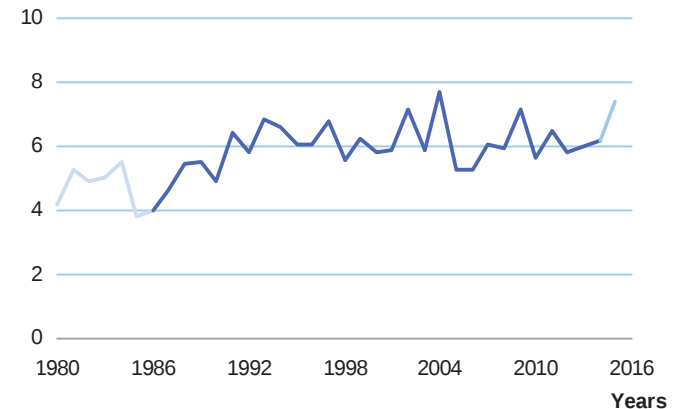
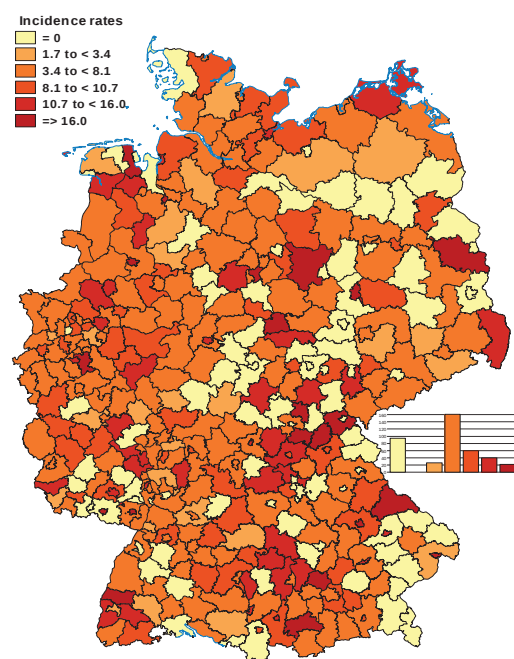
Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
52	1.2 %	0.4	6

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):**II (a) Hodgkin lymphomas**

SN after II (a)			II (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
119	9.5 %	13.2 %	21	1.7 %	0.1 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1980-2013**Age- and sex-specific incidence rates per million Germany 2006-2015****Standardized* annual incidence rates per million Germany 1980-2015****Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015**

24 II (b) Non-Hodgkin lymphomas

Cases in Germany aged under 15 years (1980-2015): 2627

Selected characteristics Germany 2006-2015

Relative frequency:	774 / 17580 = 4.5 %
Relative frequency of trial patients:	95.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	230	544	774
Standardized rate *:	4.1	9.0	6.6
Cumulative incidence:	64	142	104
Sex ratio (m/f):	2.4		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	6	121	276	371
Incidence rate:	0.9	4.4	7.6	9.5

Median age at diagnosis: 9 years 8 months

Survival probabilities:	5-year	10-year	15-year
	89 %	88 %	86 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
142	3.3 %	1.1	16

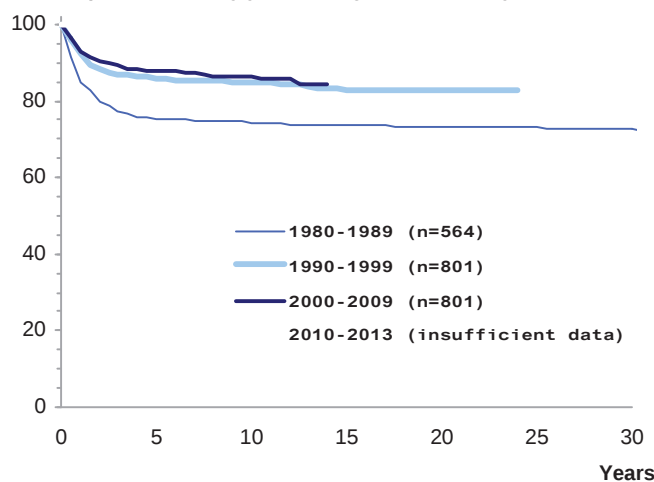
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

II (b) Non-Hodgkin lymphomas

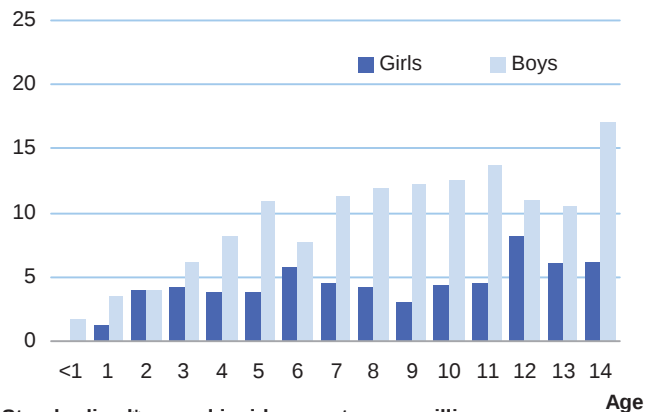
SN after II (b)			II (b) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
86	6.9 %	10.1 %	61	4.9 %	0.2 %

* Standard: Segi world standard population

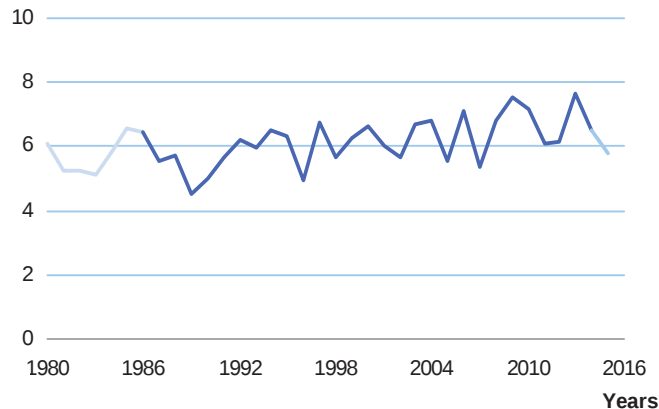
Survival probabilities by year of diagnosis Germany 1980-2013



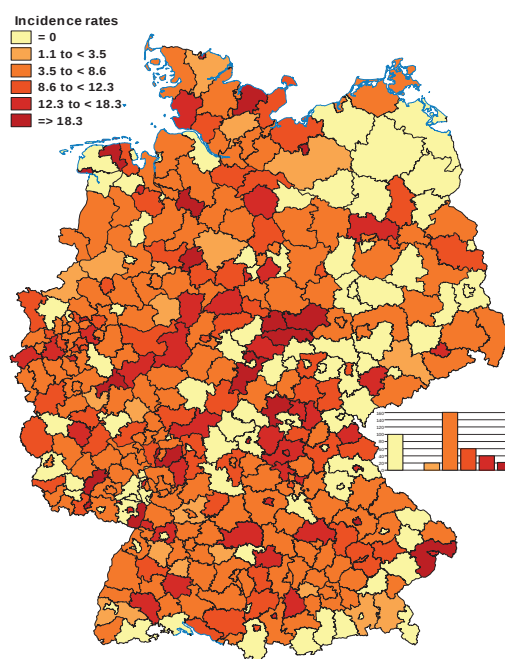
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Germany 2006-2015	N	%
Non-Hodgkin lymphomas	774	100.0
1 Precursor cell lymphomas	274	35.4
2 Mature B-cell lymphomas (except Burkitt lymphoma)	136	17.6
3 Mature T-cell and NK-cell lymphomas	144	18.6
4 Non-Hodgkin lymphomas, NOS	220	28.4

1 Precursor cell lymphomas

Cases in Germany aged under 15 years (1980-2015): 1022

Selected characteristics Germany 2006-2015

Relative frequency:	274 / 17580 = 1.6 %		
Relative frequency of trial patients:	93.4 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	83	191	274
Standardized rate *:	1.5	3.3	2.4
Cumulative incidence:	23	51	37
Sex ratio (m/f):	2.3		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	4	59	106	105
Incidence rate:	0.6	2.1	2.9	2.7
Median age at diagnosis:	8 years 3 months			

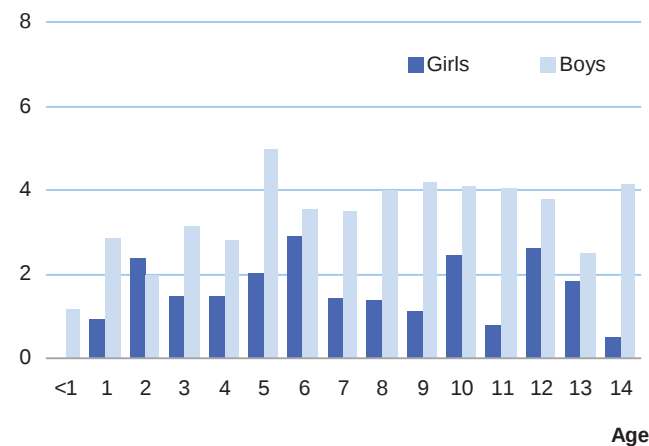
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

1 Precursor cell lymphomas

SN after II (b) 1			II (b) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
51	4.1 %	-	17	1.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Mature B-cell lymphomas (except Burkitt lymphoma)

Cases in Germany aged under 15 years (1980-2015): 422

Selected characteristics Germany 2006-2015

Relative frequency:	136 / 17580 = 0.8 %		
Relative frequency of trial patients:	96.3 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	48	88	136
Standardized rate *:	0.8	1.4	1.1
Cumulative incidence:	13	23	18
Sex ratio (m/f):	1.8		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	10	45	81
Incidence rate:	0.0	0.4	1.2	2.1
Median age at diagnosis:	11 years 6 months			

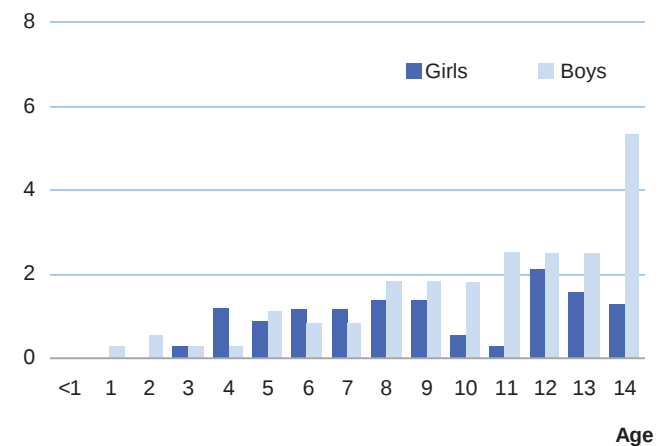
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

2 Mature B-cell lymphomas (except Burkitt lymphoma)

SN after II (b) 2			II (b) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
10	0.8 %	4.9 %	17	1.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



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

Germany 2006-2015	N	%
Non-Hodgkin lymphomas	774	100.0
1 Precursor cell lymphomas	274	35.4
2 Mature B-cell lymphomas (except Burkitt lymphoma)	136	17.6
3 Mature T-cell and NK-cell lymphomas	144	18.6
4 Non-Hodgkin lymphomas, NOS	220	28.4

3 Mature T-cell and NK-cell lymphomas

Cases in Germany aged under 15 years (1980-2015): 472

Selected characteristics Germany 2006-2015

Relative frequency:	144 / 17580 = 0.8 %		
Relative frequency of trial patients:	97.9 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	49	95	144
Standardized rate *:	0.9	1.6	1.2
Cumulative incidence:	13	25	19
Sex ratio (m/f):	1.9		

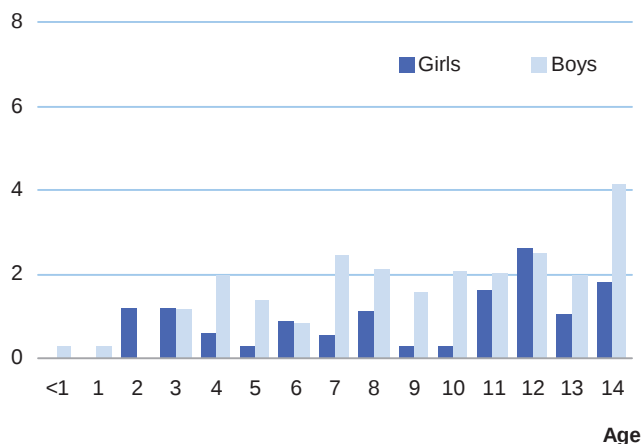
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	22	42	79
Incidence rate:	0.1	0.8	1.2	2.0
Median age at diagnosis:	10 years 11 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
3 Mature T-cell and NK-cell lymphomas

SN after II (b) 3			II (b) 3 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
12	1.0 %	-	8	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



4 Non-Hodgkin lymphomas, NOS

Cases in Germany aged under 15 years (1980-2015): 711

Selected characteristics Germany 2006-2015

Relative frequency:	220 / 17580 = 1.3 %		
Relative frequency of trial patients:	94.1 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	50	170	220
Standardized rate *:	0.9	2.8	1.9
Cumulative incidence:	14	45	30
Sex ratio (m/f):	3.4		

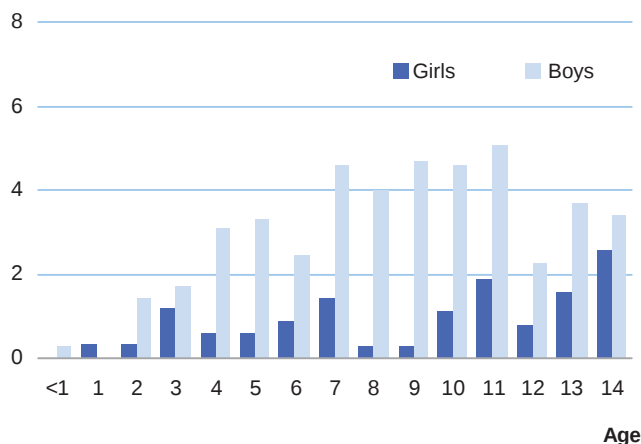
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	30	83	106
Incidence rate:	0.1	1.1	2.3	2.7
Median age at diagnosis:	9 years 9 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
4 Non-Hodgkin lymphomas, NOS

SN after II (b) 4			II (b) 4 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
13	1.0 %	4.5 %	19	1.5 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 1170

Selected characteristics Germany 2006-2015

Relative frequency:	316 / 17580 = 1.8 %
Relative frequency of trial patients:	98.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	50	266	316
Standardized rate *:	0.9	4.7	2.8
Cumulative incidence:	14	71	43
Sex ratio (m/f):			5.3

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	70	148	98
Incidence rate:	0.0	2.5	4.1	2.5
Median age at diagnosis:				7 years 10 months

Survival probabilities:	5-year	10-year	15-year
	93 %	92 %	92 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths	Standardized*	Cumulative
N % of all 4335 deaths	mortality rate	mortality
35 0.8 %	0.3	4

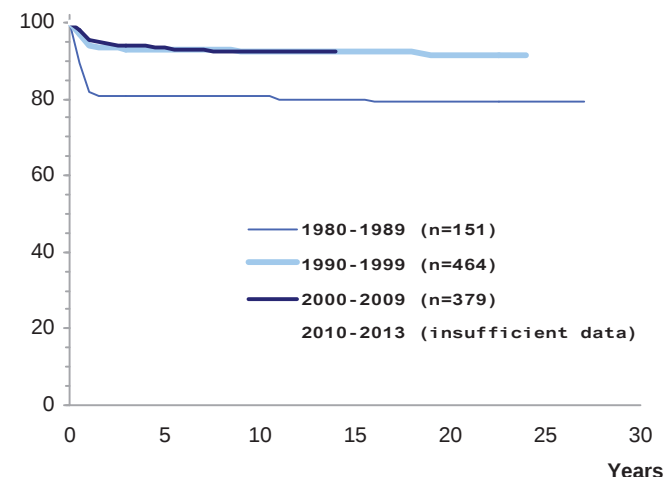
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

II (c) Burkitt lymphoma

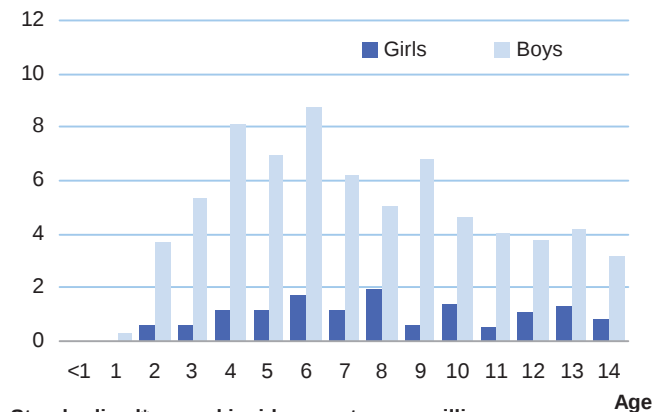
SN after II (c)	% of all	Cumulative	II (c) as SN after any primary	% of all	Cumulative
N 1253 SN	incidence		N 1253 SN	incidence	
17 1.4 %	3.3 %		4 0.3 %	0.0 %	

* Standard: Segi world standard population

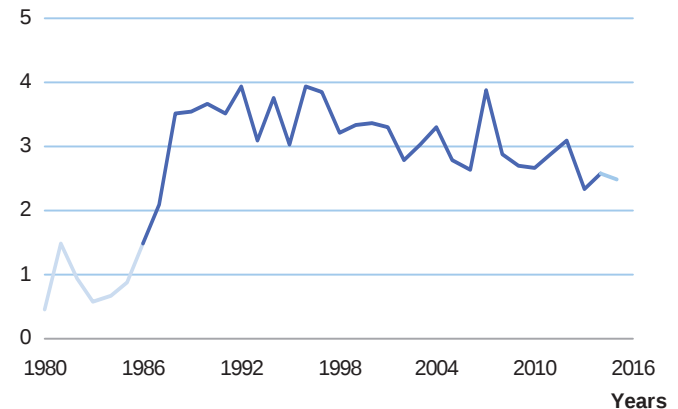
Survival probabilities by year of diagnosis Germany 1980-2013



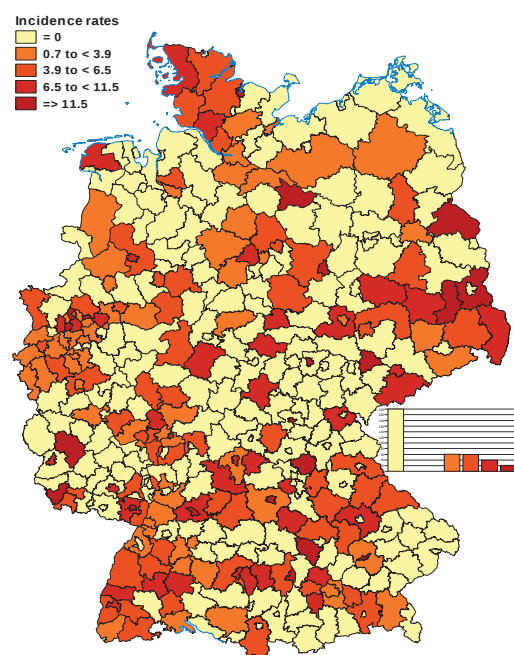
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



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 (1980-2015): 12492

Selected characteristics Germany 2006-2015

Relative frequency: 4317 / 17580 = 24.6 %

Relative frequency of trial patients: 94.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	1948	2369	4317
Standardized rate *:	37.3	42.8	40.1
Cumulative incidence:	551	635	594
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	302	1253	1420	1342
Incidence rate:	44.3	45.4	39.2	34.4

Median age at diagnosis: 7 years 0 months

Survival probabilities:	5-year	10-year	15-year
	78 %	74 %	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
1256	29.0 %	10.0	145

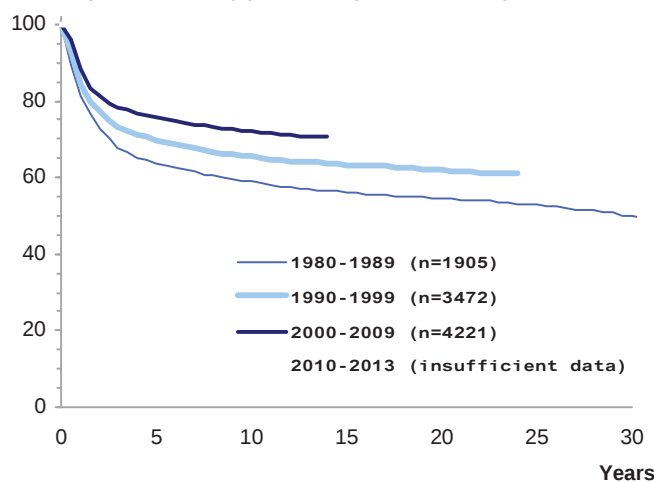
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

III CNS and miscellaneous intracranial and intraspinal neoplasms

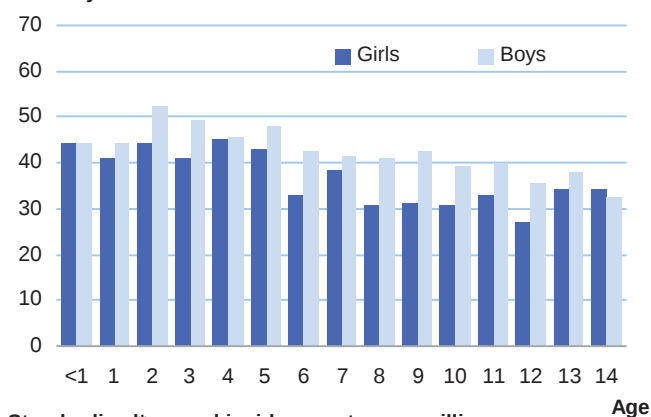
SN after III			III as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
227	18.1 %	7.3 %	287	22.9 %	1.7 %

* Standard: Segi world standard population

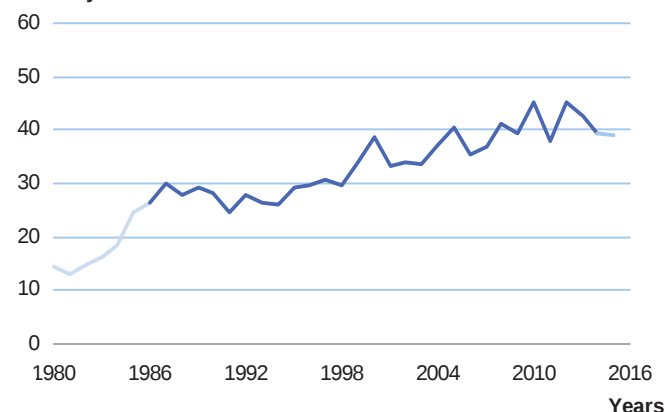
Survival probabilities by year of diagnosis Germany 1980-2013



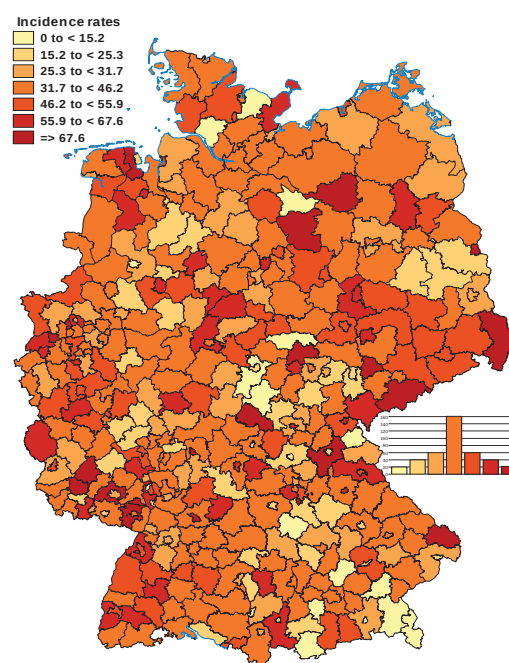
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 1253

Selected characteristics Germany 2006-2015

Relative frequency:	430 / 17580 = 2.5 %
Relative frequency of trial patients:	95.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	185	245	430
Standardized rate *:	3.9	4.7	4.3
Cumulative incidence:	54	67	60
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	81	172	85	92
Incidence rate:	11.9	6.2	2.3	2.4
Median age at diagnosis:	3 years 10 months			

Survival probabilities:	5-year	10-year	15-year
	82 %	75 %	71 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths	Standardized*	Cumulative
N % of all 4335 deaths	mortality rate	mortality
154 3.6 %	1.3	18

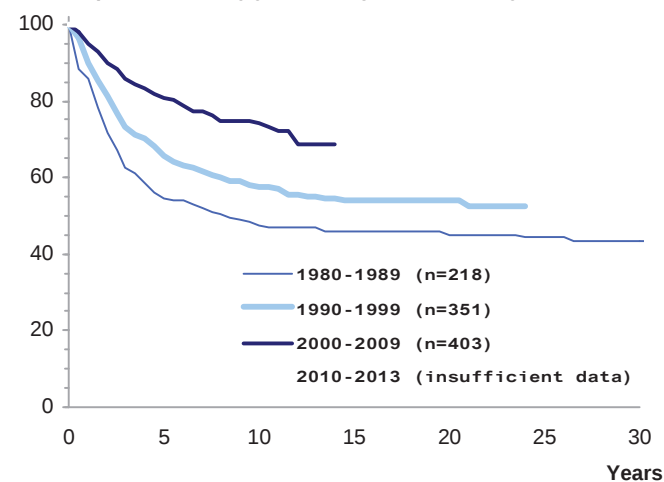
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

III (a) Ependymomas and choroid plexus tumour

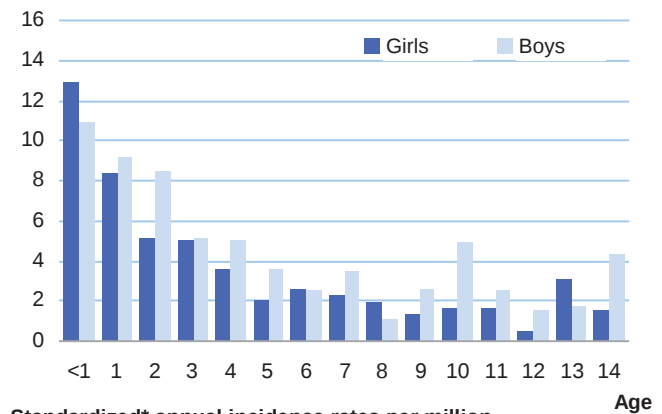
SN after III (a)	% of all 1253 SN		Cumulative incidence	III (a) as SN after any primary	% of all 1253 SN		Cumulative incidence
N				N			
26	2.1 %		7.3 %	10	0.8 %		0.0 %

* Standard: Segi world standard population

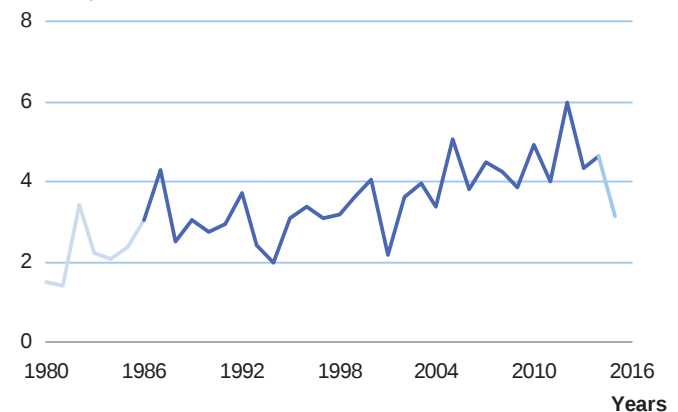
Survival probabilities by year of diagnosis Germany 1980-2013



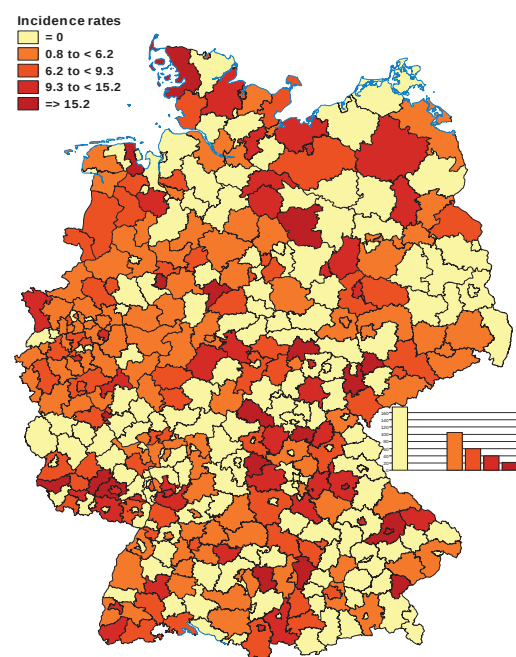
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



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

Germany 2006-2015	N	%
Ependymomas and choroid plexus tumour	430	100.0
1 Ependymomas	330	76.7
2 Choroid plexus tumour	100	23.3

1 Ependymomas

Cases in Germany aged under 15 years (1980-2015): 1004

Selected characteristics Germany 2006-2015

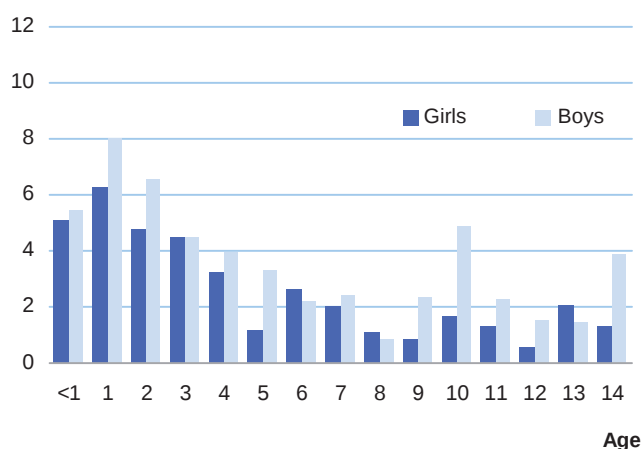
Relative frequency:	330 / 17580 = 1.9 %			
Relative frequency of trial patients:	96.7 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	133	197	330	
Standardized rate *:	2.8	3.7	3.3	
Cumulative incidence:	38	53	46	
Sex ratio (m/f):	1.5			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	36	144	68	82
Incidence rate:	5.3	5.2	1.9	2.1
Median age at diagnosis:	4 years 5 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
1 Ependymomas

SN after III (a) 1			III (a) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
21	1.7 %	8.1 %	7	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Choroid plexus tumour

Cases in Germany aged under 15 years (1980-2015): 249

Selected characteristics Germany 2006-2015

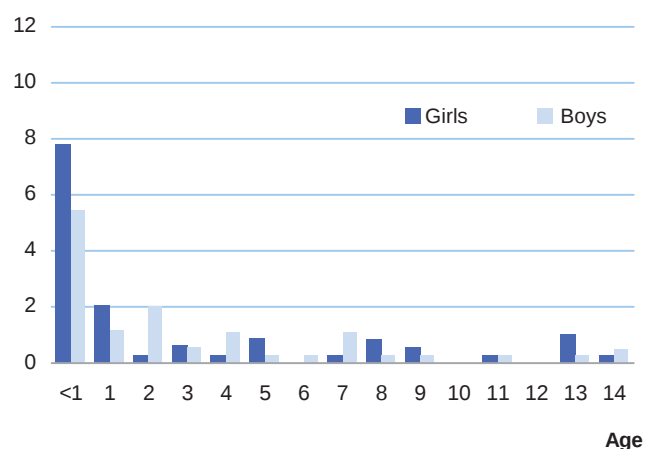
Relative frequency:	100 / 17580 = 0.6 %			
Relative frequency of trial patients:	93.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	52	48	100	
Standardized rate *:	1.1	1.0	1.1	
Cumulative incidence:	15	13	14	
Sex ratio (m/f):	0.9			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	45	28	17	10
Incidence rate:	6.6	1.0	0.5	0.3
Median age at diagnosis:	1 year 5 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
2 Choroid plexus tumour

SN after III (a) 2			III (a) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
5	0.4 %	3.6 %	3	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 5508

Selected characteristics Germany 2006-2015

Relative frequency:	1986 / 17580 = 11.5 %
Relative frequency of trial patients:	95.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	960	1026	1986
Standardized rate *:	18.2	18.4	18.3
Cumulative incidence:	271	274	273
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	103	558	684	641
Incidence rate:	15.1	20.2	18.9	16.4
Median age at diagnosis:	7 years 3 months			

Survival probabilities:	5-year	10-year	15-year
	82 %	79 %	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths	Standardized*	Cumulative
N % of all 4335 deaths	mortality rate	mortality
416 9.6 %	3.1	47

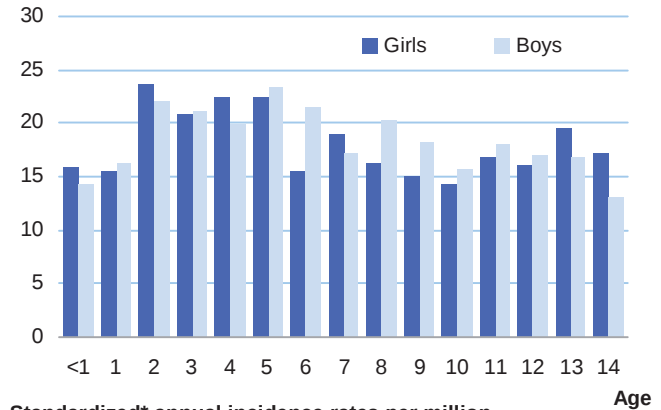
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

III (b) Astrocytomas

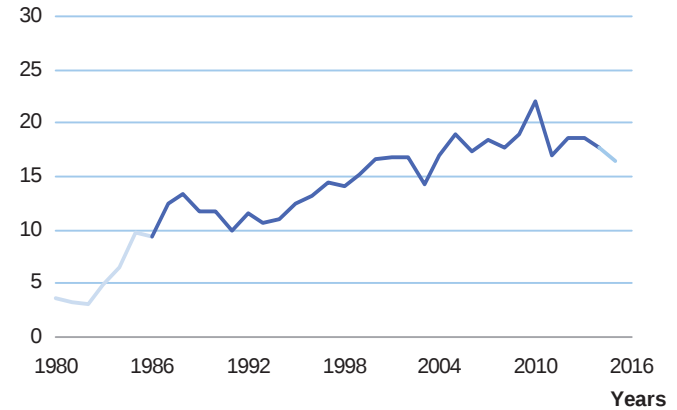
SN after III (b)	III (b) as SN after any primary
N % of all 1253 SN Cumulative incidence	N % of all 1253 SN Cumulative incidence
43 3.4 % 2.2 %	93 7.4 % 0.3 %

* Standard: Segi world standard population

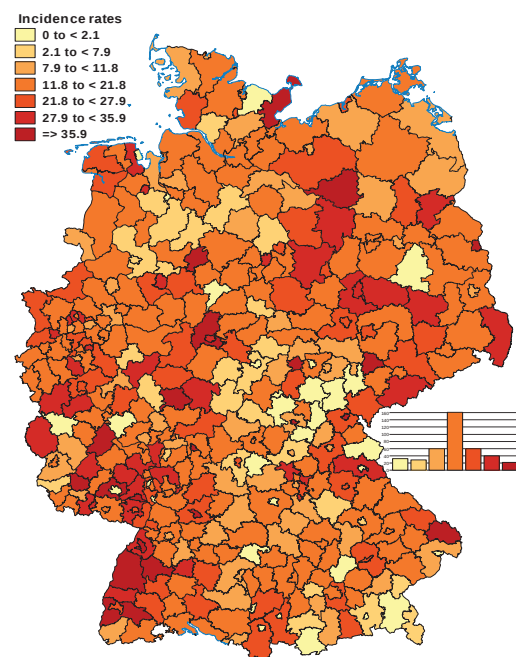
Age- and sex-specific incidence rates per million Germany 2006-2015



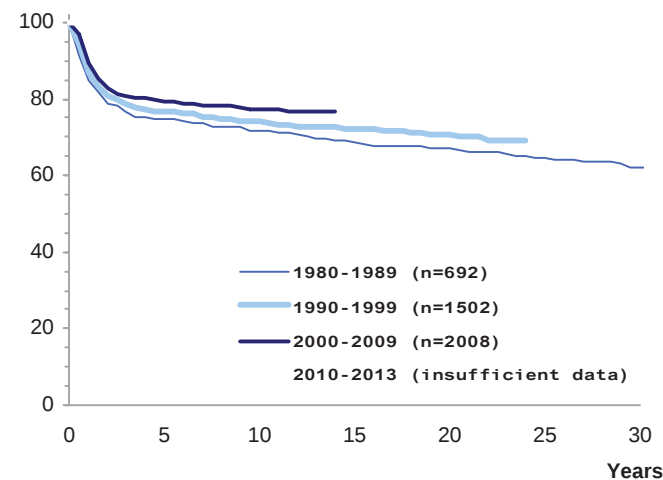
Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Survival probabilities by year of diagnosis Germany 1980-2013



32 III (c) Intracranial and intraspinal embryonal tumours

Cases in Germany aged under 15 years (1980-2015): 2758

Selected characteristics Germany 2006-2015

Relative frequency:	754 / 17580 = 4.4 %
Relative frequency of trial patients:	96.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	288	466	754
Standardized rate *:	5.9	8.9	7.4
Cumulative incidence:	83	127	106
Sex ratio (m/f):	1.6		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	77	290	272	115
Incidence rate:	11.3	10.5	7.5	2.9

Median age at diagnosis: 5 years 3 months

Survival probabilities:	5-year	10-year	15-year
	67 %	60 %	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
486	11.2 %	4.0	57

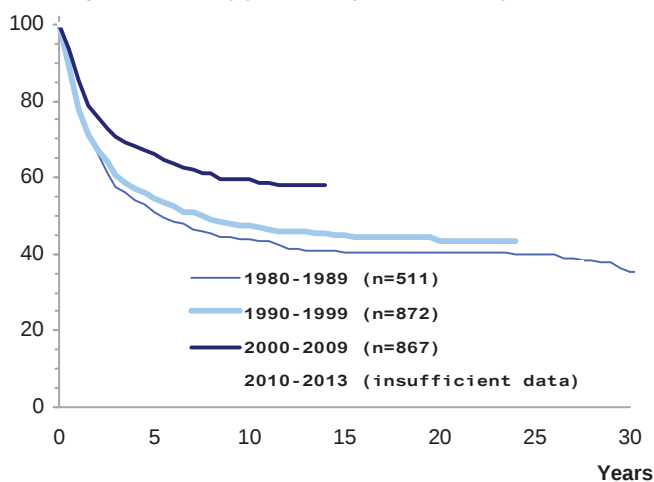
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

III (c) Intracranial and intraspinal embryonal tumours

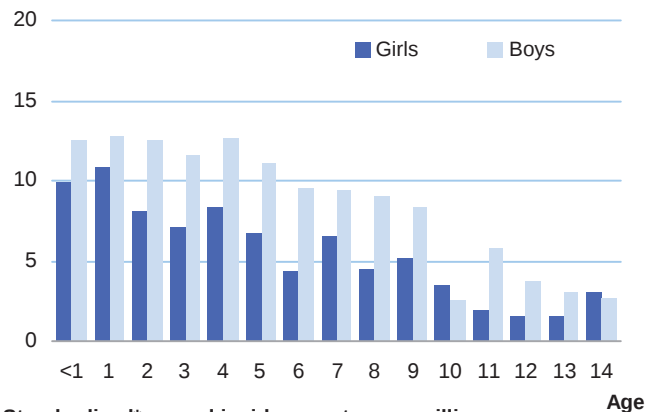
SN after III (c)			III (c) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
132	10.5 %	16.6 %	15	1.2 %	0.0 %

* Standard: Segi world standard population

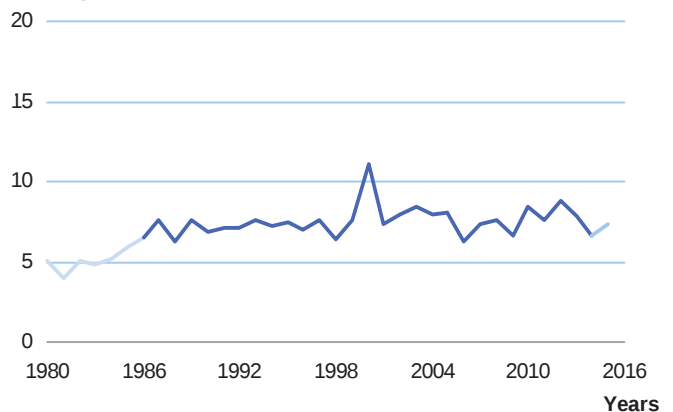
Survival probabilities by year of diagnosis Germany 1980-2013



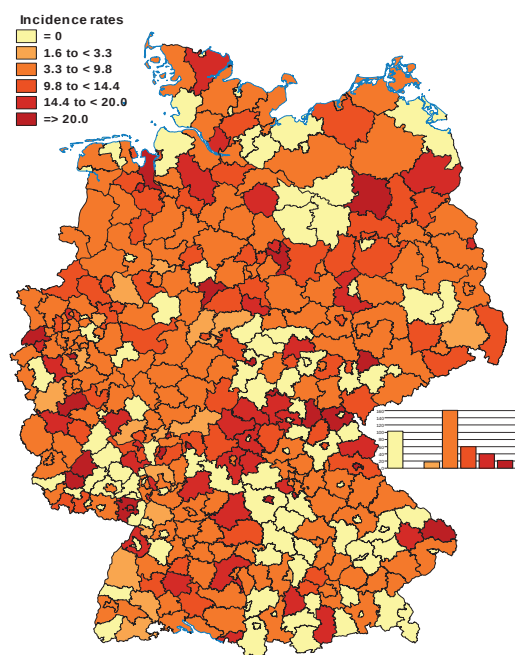
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Germany 2006-2015	N	%
Intracranial and intraspinal embryonal tumours	754	100.0
1 Medulloblastomas	535	71.0
2 Primitive neuroectodermal tumour (PNET)	71	9.4
3 Medulloepithelioma	8	1.1
4 Atypical teratoid/rhabdoid tumour	140	18.6

1 Medulloblastomas

Cases in Germany aged under 15 years (1980-2015): 2096

Selected characteristics Germany 2006-2015

Relative frequency:	535 / 17580 = 3.0 %
Relative frequency of trial patients:	99.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	194	341	535
Standardized rate *:	3.8	6.3	5.1
Cumulative incidence:	55	92	74
Sex ratio (m/f):	1.8		

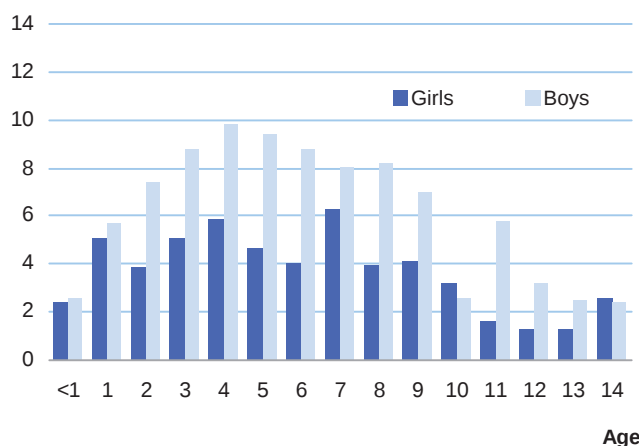
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	17	179	235	104
Incidence rate:	2.5	6.5	6.5	2.7
Median age at diagnosis:	6 years 7 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
1 Medulloblastomas

SN after III (c) 1			III (c) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
114	9.1 %	18.4 %	6	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Primitive neuroectodermal tumour (PNET)

Cases in Germany aged under 15 years (1980-2015): 406

Selected characteristics Germany 2006-2015

Relative frequency:	71 / 17580 = 0.4 %
Relative frequency of trial patients:	98.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	31	40	71
Standardized rate *:	0.7	0.8	0.7
Cumulative incidence:	9	11	10
Sex ratio (m/f):	1.3		

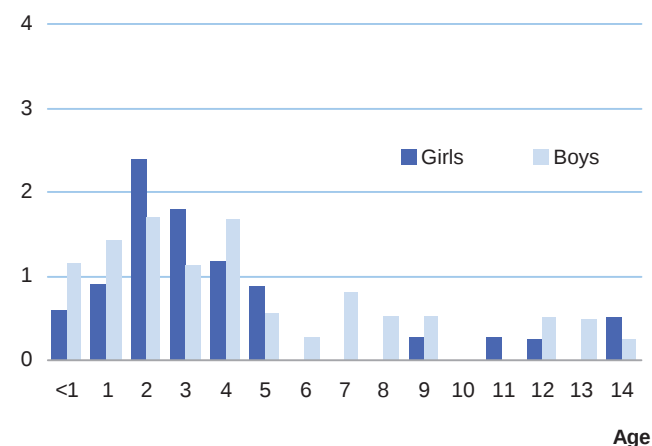
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	6	42	14	9
Incidence rate:	0.9	1.5	0.4	0.2
Median age at diagnosis:	3 years 7 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
2 Primitive neuroectodermal tumour (PNET)

SN after III (c) 2			III (c) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
16	1.3 %	7.4 %	8	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



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

Germany 2006-2015	N	%
Intracranial and intraspinal embryonal tumours	754	100.0
1 Medulloblastomas	535	71.0
2 Primitive neuroectodermal tumour (PNET)	71	9.4
3 Medulloepithelioma	8	1.1
4 Atypical teratoid/rhabdoid tumour	140	18.6

4 Atypical teratoid/rhabdoid tumour

Cases in Germany aged under 15 years (1980-2015): 234

Selected characteristics Germany 2006-2015

Relative frequency:	140 / 17580 = 0.8 %
Relative frequency of trial patients:	86.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	60	80	140
Standardized rate *:	1.4	1.7	1.5
Cumulative incidence:	18	23	20
Sex ratio (m/f):	1.3		

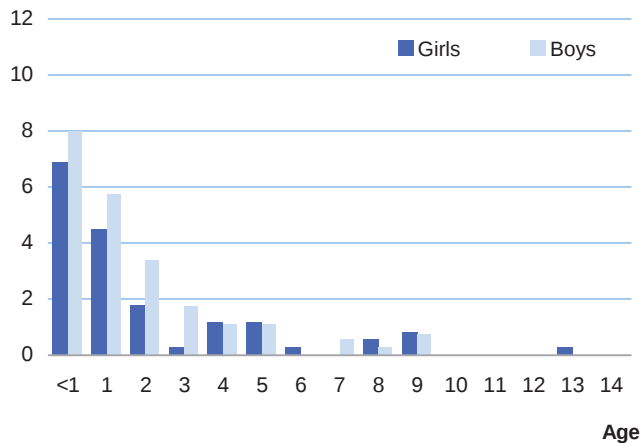
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	51	68	20	1
Incidence rate:	7.5	2.5	0.6	0.0
Median age at diagnosis:	1 year 6 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
4 Atypical teratoid/rhabdoid tumour

SN after III (c) 4			III (c) 4 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	1.0 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 995

Selected characteristics Germany 2006-2015

Relative frequency:	445 / 17580 = 2.6 %		
Relative frequency of trial patients:	92.4 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	213	232	445
Standardized rate *:	3.9	4.0	4.0
Cumulative incidence:	60	61	61
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	12	101	172	160
Incidence rate:	1.8	3.7	4.7	4.1
Median age at diagnosis:	7 years 11 months			

Survival probabilities:	5-year 50 %	10-year -	15-year -
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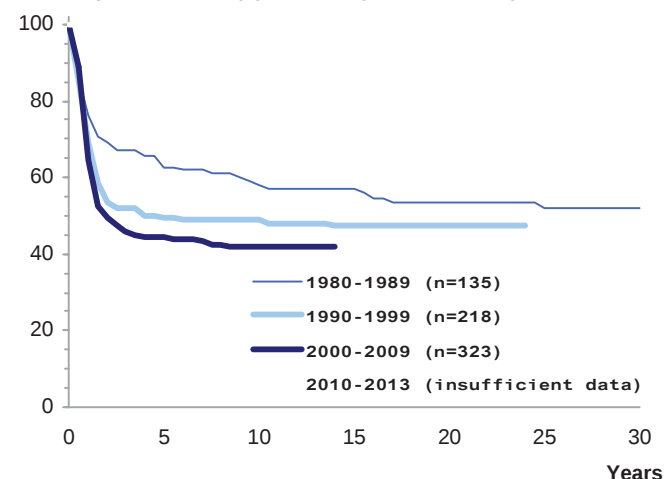
Mortality per million within 15 yrs. of diagnosis (1991-2000):			
Number of deaths	Standardized*	Cumulative	
N % of all 4335 deaths	mortality rate	mortality	
120 2.8 %	0.9	14	

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013): III (d) Other gliomas

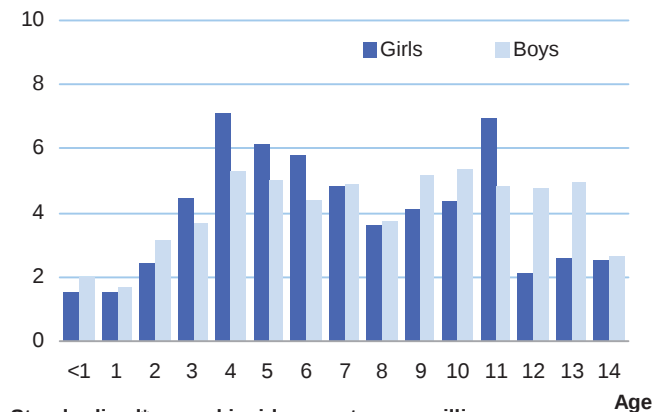
SN after III (d)			III (d) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
8	0.6 %	1.9 %	23	1.8 %	0.1 %

* Standard: Segi world standard population

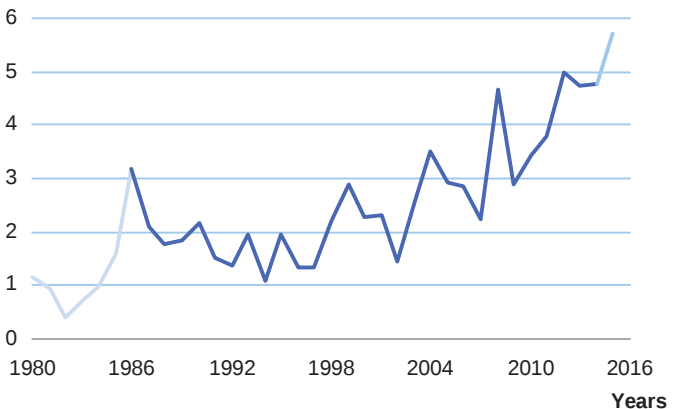
Survival probabilities by year of diagnosis Germany 1980-2013



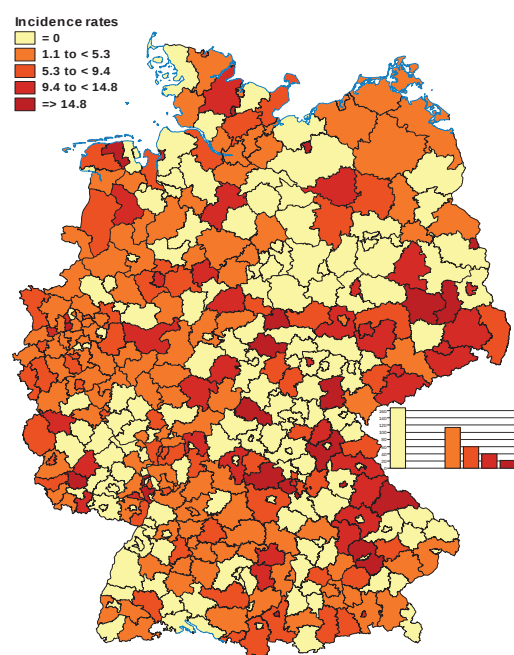
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



36 III (d) Other gliomas - Extended ICC-C-3

Germany 2006-2015	N	%
Other gliomas	445	100.0
1 Oligodendrogliomas	10	2.2
2 Mixed and unspecified gliomas	417	93.7
3 Neuroepithelial glial tumours of uncertain origin	18	4.0

1 Oligodendrogliomas

Cases in Germany aged under 15 years (1980-2015): 115

Selected characteristics Germany 2006-2015

Relative frequency:	10 / 17580 = 0.1 %		
Relative frequency of trial patients:	80.0 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	3	7	10
Standardized rate *:	0.0	0.1	0.1
Cumulative incidence:	1	2	1
Sex ratio (m/f):	2.3		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	1	1	8
Incidence rate:	0.0	0.0	0.0	0.2
Median age at diagnosis:	13 years 3 months			

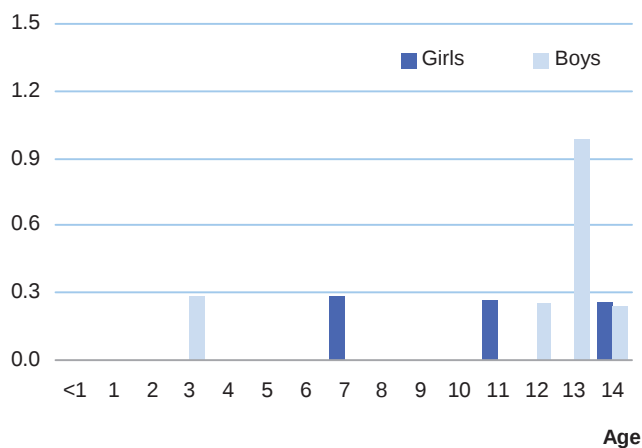
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

1 Oligodendrogliomas

SN after III (d) 1			III (d) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	1.4 %	5	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Mixed and unspecified gliomas

Cases in Germany aged under 15 years (1980-2015): 846

Selected characteristics Germany 2006-2015

Relative frequency:	417 / 17580 = 2.4 %			
Relative frequency of trial patients:	92.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	200	217	417	
Standardized rate *:	3.7	3.8	3.7	
Cumulative incidence:	56	58	57	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	11	95	168	143
Incidence rate:	1.6	3.4	4.6	3.7
Median age at diagnosis:	7 years 10 months			

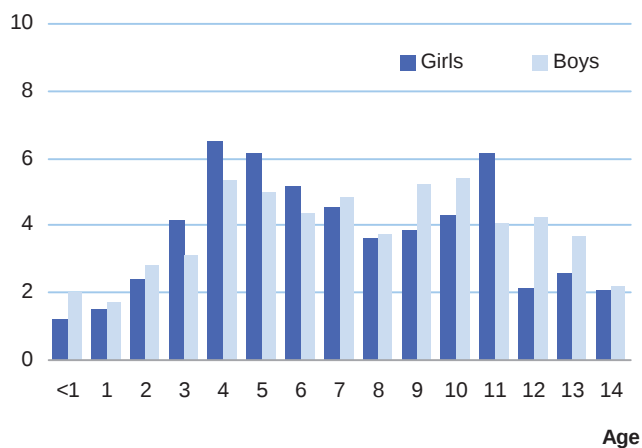
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

2 Mixed and unspecified gliomas

SN after III (d) 2			III (d) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
7	0.6 %	2.1 %	18	1.4 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 1622

Selected characteristics Germany 2006-2015

Relative frequency: 631 / 17580 = 3.7 %

Relative frequency of trial patients: 92.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	269	362	631
Standardized rate *:	4.8	6.2	5.5
Cumulative incidence:	75	95	85
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	22	120	192	297
Incidence rate:	3.2	4.4	5.3	7.6

Median age at diagnosis: 9 years 8 months

Survival probabilities:	5-year	10-year	15-year
	96 %	94 %	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
41	0.9 %	0.3	5

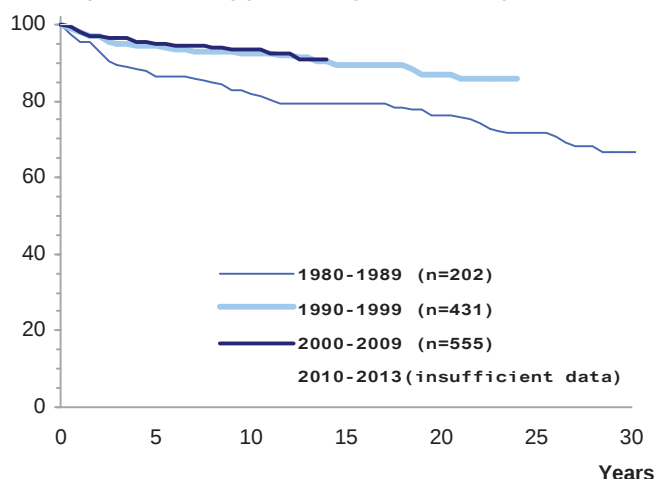
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

III (e) Other specified intracranial and intraspinal neoplasms

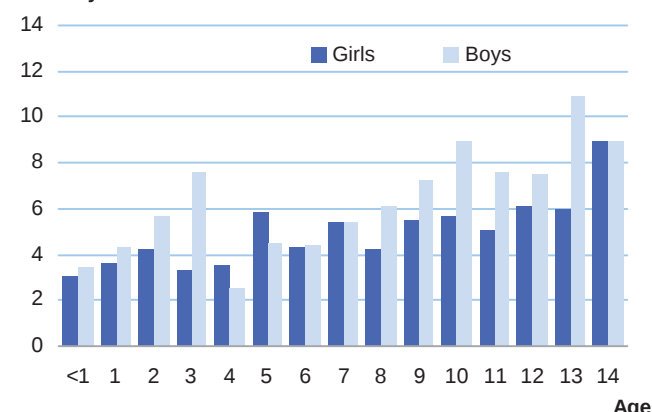
SN after III (e)			III (e) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
16	1.3 %	2.6 %	137	10.9 %	1.2 %

* Standard: Segi world standard population

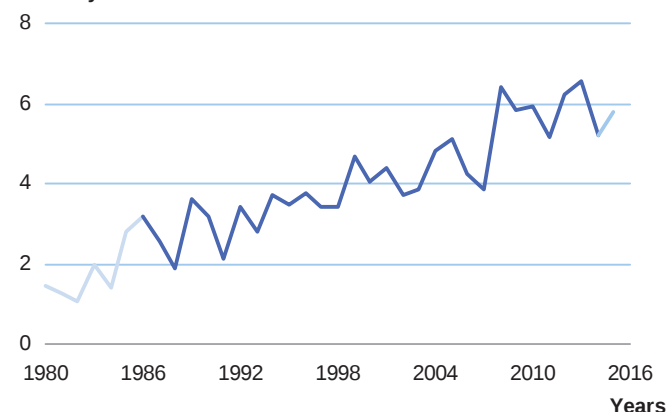
Survival probabilities by year of diagnosis Germany 1980-2013



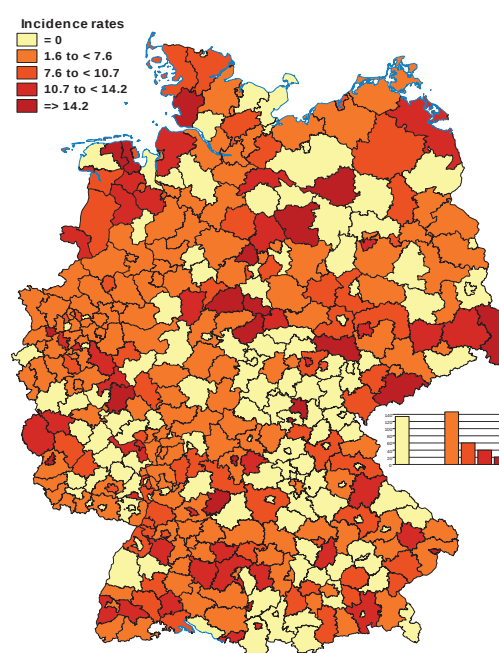
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



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

Germany 2006-2015		N	%
Other specified intracranial and intraspinal neoplasms		631	100.0
1 Pituitary adenomas and carcinomas		34	5.4
2 Tumours of the sellar region (craniopharyngiomas)		191	30.3
3 Pineal parenchymal tumours		30	4.8
4 Neuronal and mixed neuronal-glial tumours		332	52.6
5 Meningiomas		44	7.0

1 Pituitary adenomas and carcinomas

Cases in Germany aged under 15 years (1980-2015): 94

Selected characteristics Germany 2006-2015

Relative frequency:	34 / 17580 = 0.2 %		
Relative frequency of trial patients:	64.7 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	15	19	34
Standardized rate *:	0.2	0.3	0.3
Cumulative incidence:	4	5	4
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	1	4	29
Incidence rate:	0.0	0.0	0.1	0.7
Median age at diagnosis:	12 years 8 months			

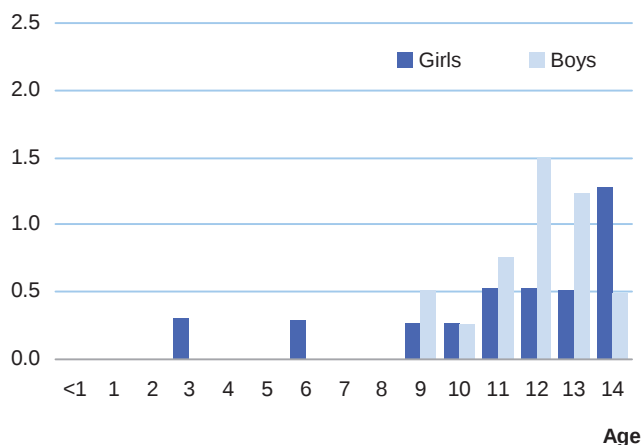
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

1 Pituitary adenomas and carcinomas

SN after III (e) 1			III (e) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	5.2 %	6	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Tumours of the sellar region (craniopharyngiomas)

Cases in Germany aged under 15 years (1980-2015): 617

Selected characteristics Germany 2006-2015

Relative frequency:		191 / 17580 = 1.1 %		
Relative frequency of trial patients:		99.5 %		
Incidence rates per million:		Girls	Boys	Total
Number of cases:		99	92	191
Standardized rate *:		1.8	1.6	1.7
Cumulative incidence:		28	24	26
Sex ratio (m/f):		0.9		
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	2	43	73	73
Incidence rate:	0.3	1.6	2.0	1.9
Median age at diagnosis:		8 years 5 months		

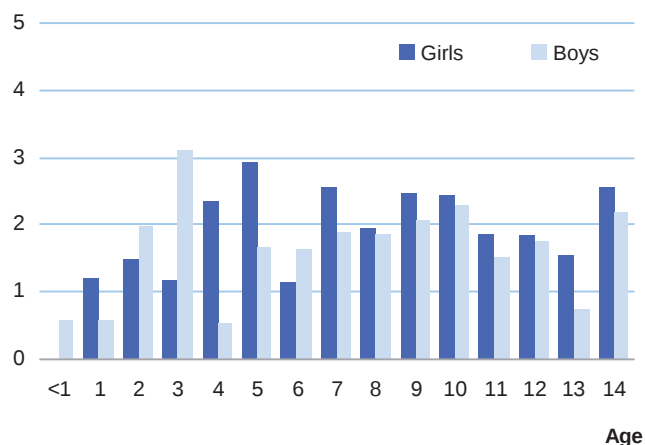
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

2 Tumours of the sellar region (craniopharyngiomas)

SN after III (e) 2			III (e) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
3	0.2 %	1.0 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Germany 2006-2015	N	%
Other specified intracranial and intraspinal neoplasms	631	100.0
1 Pituitary adenomas and carcinomas	34	5.4
2 Tumours of the sellar region (craniopharyngiomas)	191	30.3
3 Pineal parenchymal tumours	30	4.8
4 Neuronal and mixed neuronal-glial tumours	332	52.6
5 Meningiomas	44	7.0

3 Pineal parenchymal tumours

Cases in Germany aged under 15 years (1980-2015): 125

Selected characteristics Germany 2006-2015

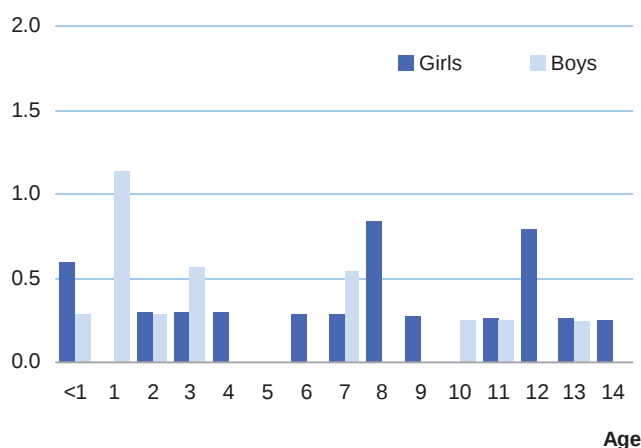
Relative frequency:	30 / 17580 = 0.2 %			
Relative frequency of trial patients:	100.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	17	13	30	
Standardized rate *:	0.3	0.3	0.3	
Cumulative incidence:	5	4	4	
Sex ratio (m/f):	0.8			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	3	10	8	9
Incidence rate:	0.4	0.4	0.2	0.2
Median age at diagnosis:	7 years 7 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
3 Pineal parenchymal tumours

SN after III (e) 3			III (e) 3 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	1.5 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



4 Neuronal and mixed neuronal-glial tumours

Cases in Germany aged under 15 years (1980-2015): 635

Selected characteristics Germany 2006-2015

Relative frequency:	332 / 17580 = 1.9 %		
Relative frequency of trial patients:	93.7 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	120	212	332
Standardized rate *:	2.2	3.6	2.9
Cumulative incidence:	33	56	45
Sex ratio (m/f):	1.8		

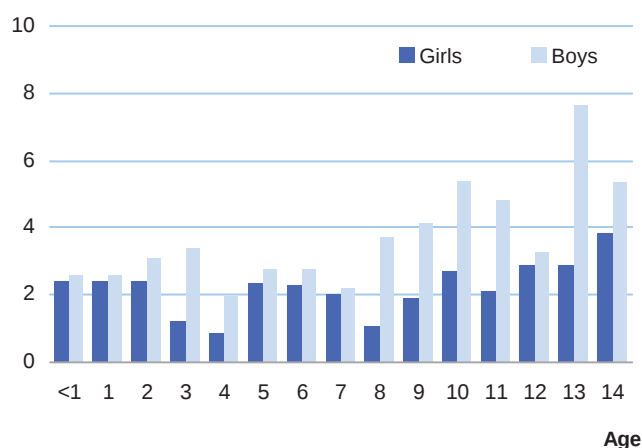
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	17	62	92	161
Incidence rate:	2.5	2.2	2.5	4.1
Median age at diagnosis:	9 years 9 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
4 Neuronal and mixed neuronal-glial tumours

SN after III (e) 4			III (e) 4 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	1.9 %	4	0.3 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



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

Germany 2006-2015		N	%
Other specified intracranial and intraspinal neoplasms		631	100.0
1 Pituitary adenomas and carcinomas		34	5.4
2 Tumours of the sellar region (craniopharyngiomas)		191	30.3
3 Pineal parenchymal tumours		30	4.8
4 Neuronal and mixed neuronal-glial tumours		332	52.6
5 Meningiomas		44	7.0

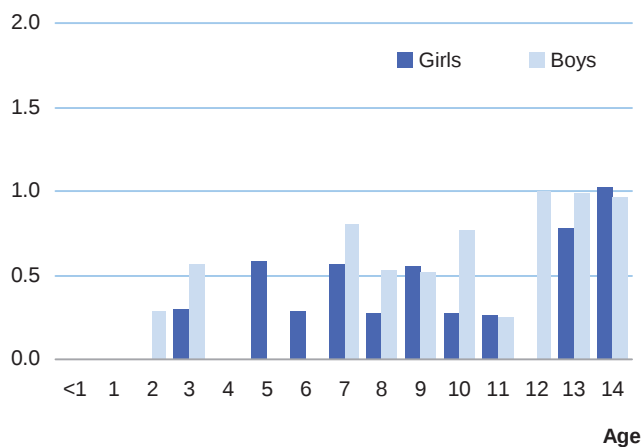
5 Meningiomas

Cases in Germany aged under 15 years (1980-2015): 151

Selected characteristics Germany 2006-2015

Relative frequency:		44 / 17580 = 0.3 %		
Relative frequency of trial patients:		68.2 %		
Incidence rates per million:		Girls	Boys	Total
Number of cases:		18	26	44
Standardized rate *:		0.3	0.4	0.4
Cumulative incidence:		5	7	6
Sex ratio (m/f):		1.4		
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	0	4	15	25
Incidence rate:	0.0	0.1	0.4	0.6
Median age at diagnosis:		10 years 9 months		
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):				
5 Meningiomas				
SN after III (e) 5			III (e) 5 as SN after any primary	
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN
8	0.6 %	13.7 %	125	10.0 %
				Cumulative incidence
				1.2 %
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 4286**Selected characteristics Germany 2006-2015**

Relative frequency: 1205 / 17580 = 7 %

Relative frequency of trial patients: 99.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	523	682	1205
Standardized rate *:	12.0	14.9	13.5
Cumulative incidence:	156	193	175
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	562	533	84	26
Incidence rate:	82.4	19.3	2.3	0.7

Median age at diagnosis: 1 year 2 months

Survival probabilities:	5-year	10-year	15-year
	80 %	78 %	77 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

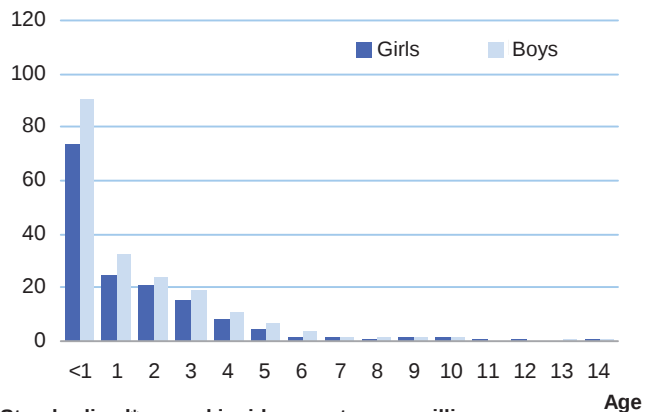
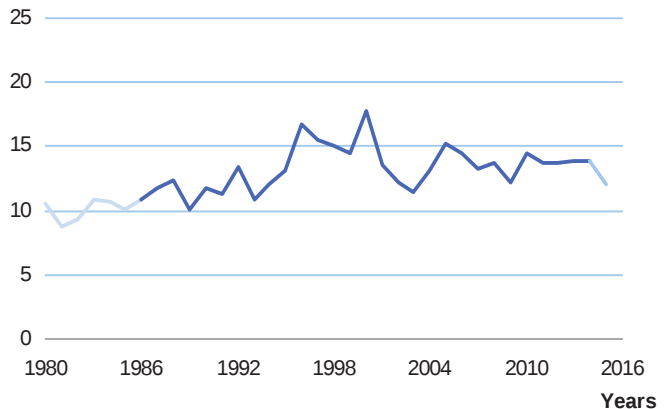
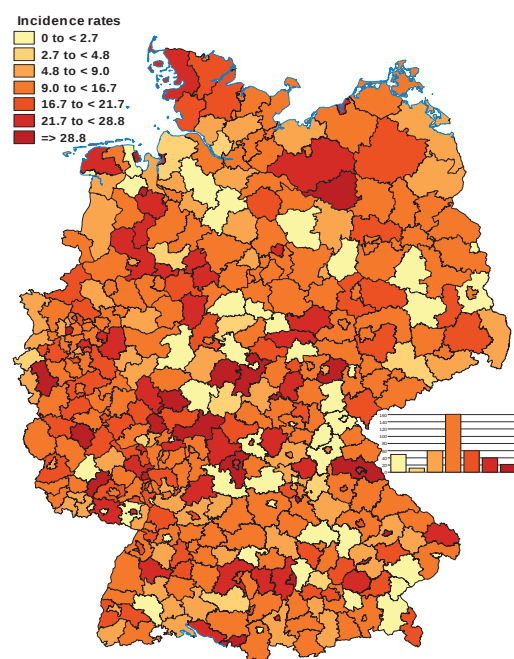
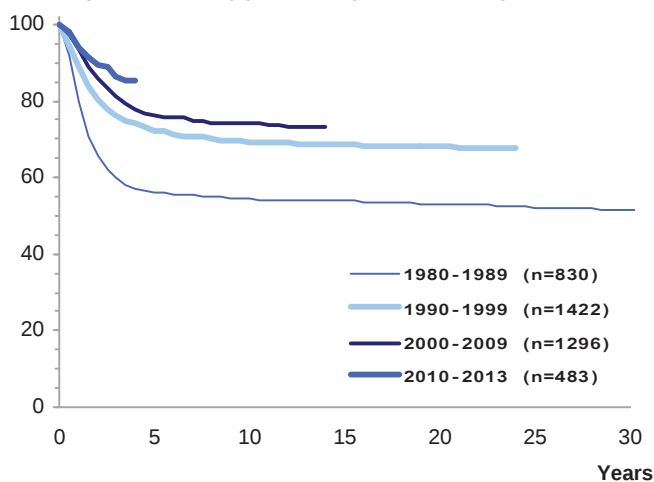
Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
456	10.5 %	4.0	54

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

IV (a) Neuroblastoma and ganglioneuroblastoma

SN after IV (a)			IV (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
63	5.0 %	2.8 %	11	0.9 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2006-2015**Standardized* annual incidence rates per million Germany 1980-2015****Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015****Survival probabilities by year of diagnosis Germany 1980-2013**

42 V Retinoblastoma

Cases in Germany aged under 15 years (1980-2015): 1364

Selected characteristics Germany 2006-2015

Relative frequency:	382 / 17580 = 2.2 %
Relative frequency of trial patients:	-

Incidence rates per million:	Girls	Boys	Total
Number of cases:	179	203	382
Standardized rate *:	4.2	4.5	4.3
Cumulative incidence:	54	57	56
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	170	199	9	4
Incidence rate:	24.9	7.2	0.2	0.1

Median age at diagnosis: 1 year 2 months

Survival probabilities:	5-year	10-year	15-year
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
9	0.2 %	0.1	1

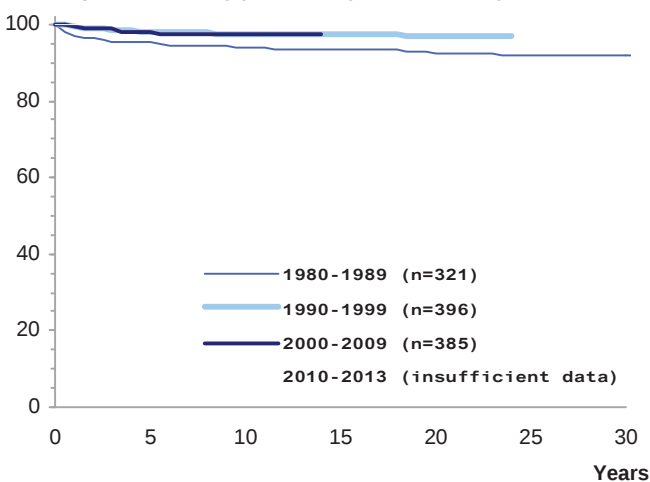
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

V Retinoblastoma

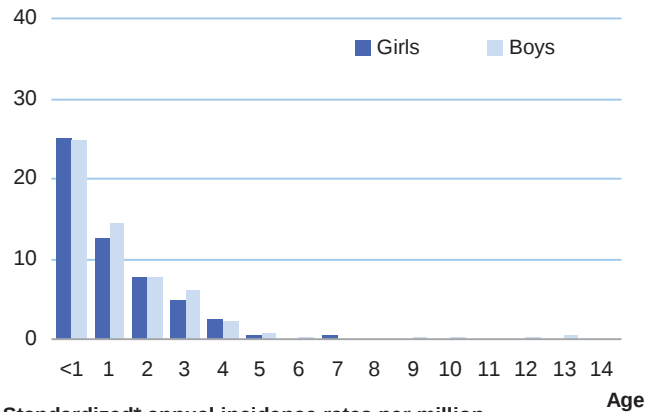
SN after V			V as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
36	2.9 %	6.4 %	3	0.2 %	0.0 %

* Standard: Segi world standard population

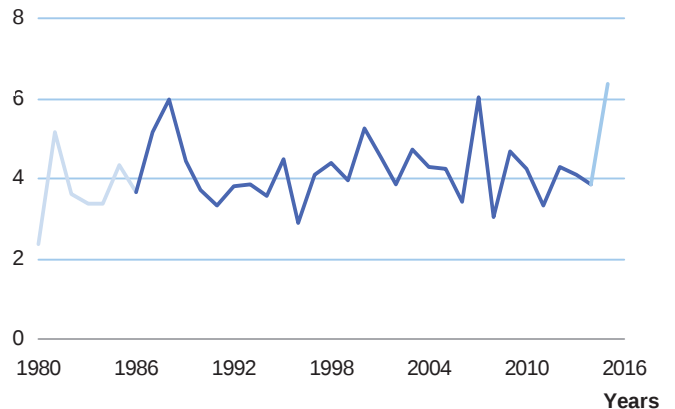
Survival probabilities by year of diagnosis Germany 1980-2013



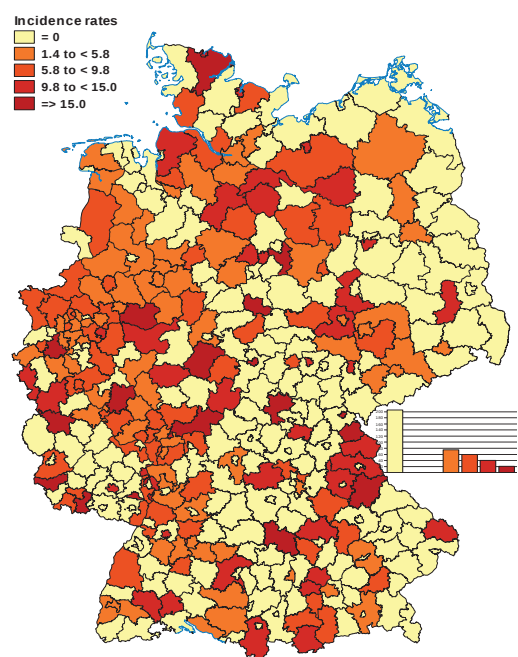
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 3281

Selected characteristics Germany 2006-2015

Relative frequency:	950 / 17580 = 5.5 %
Relative frequency of trial patients:	99.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	509	441	950
Standardized rate *:	11.1	9.2	10.1
Cumulative incidence:	149	123	136
Sex ratio (m/f):			0.9

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	157	547	210	36
Incidence rate:	23.0	19.8	5.8	0.9
Median age at diagnosis:				3 years 1 month

Survival probabilities:	5-year	10-year	15-year
	94 %	93 %	93 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths	Standardized*	Cumulative
N % of all 4335 deaths	mortality rate	mortality
123 2.8 %	1.1	15

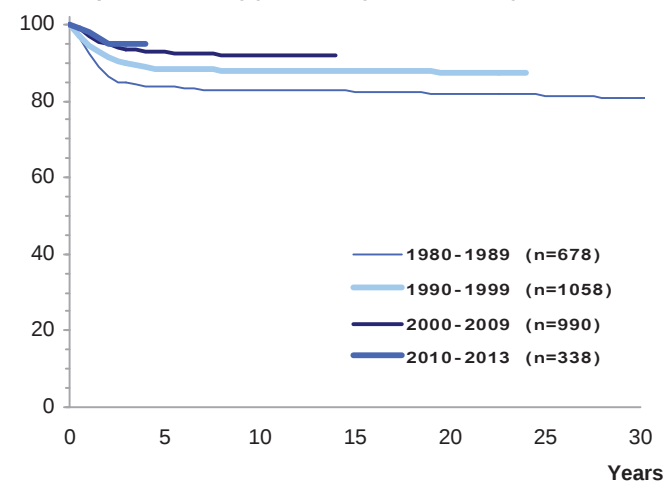
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

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

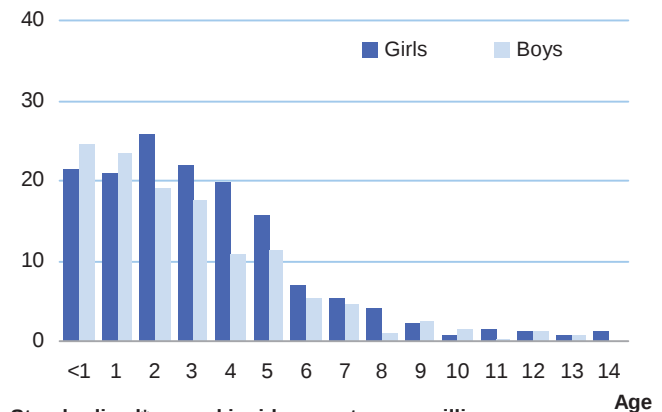
SN after VI (a)	VI (a) as SN after any primary
% of all 1253 SN	% of all 1253 SN
Cumulative incidence	Cumulative incidence
46 3.7 % 4.2 %	8 0.6 % 0.0 %

* Standard: Segi world standard population

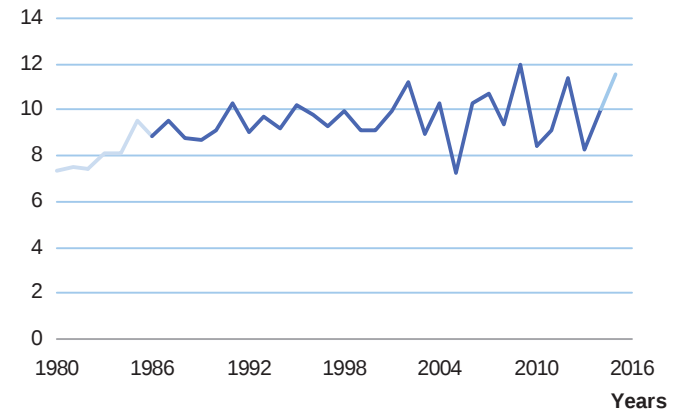
Survival probabilities by year of diagnosis Germany 1980-2013



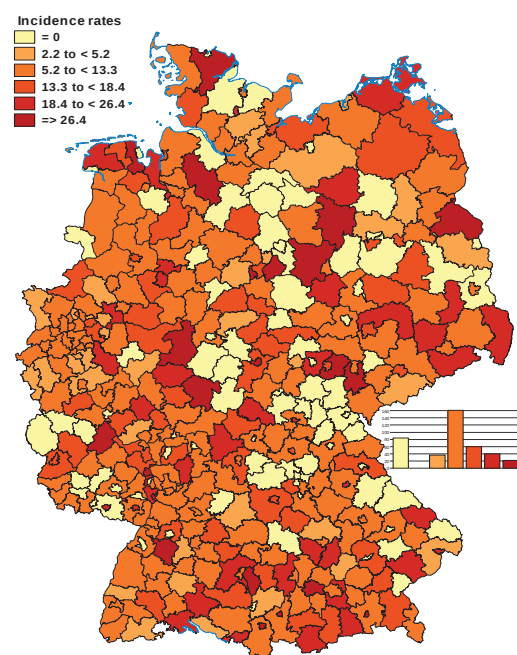
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



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

Germany 2006-2015	N	%
Nephroblastoma and other non-epithelial renal tumours	950	100.0
1 Nephroblastoma	926	97.5
2 Rhabdoid renal tumour	18	1.9
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 (1980-2015): 3172

Selected characteristics Germany 2006-2015

Relative frequency:	926 / 17580 = 5.3 %		
Relative frequency of trial patients:	99.4 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	496	430	926
Standardized rate *:	10.8	9.0	9.9
Cumulative incidence:	146	120	133
Sex ratio (m/f):	0.9		

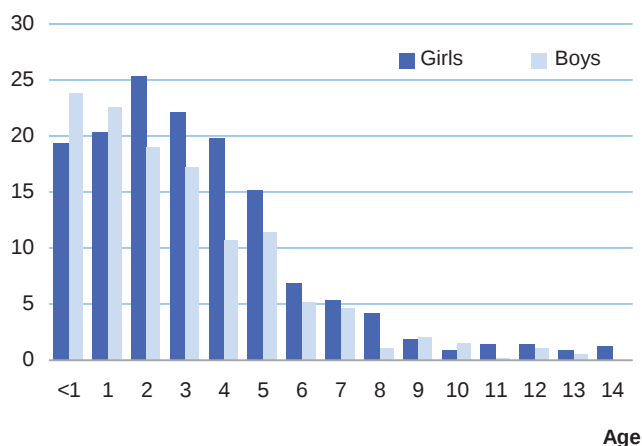
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	147	539	206	34
Incidence rate:	21.6	19.5	5.7	0.9
Median age at diagnosis:	3 years 2 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
1 Nephroblastoma

SN after VI (a) 1			VI (a) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
43	3.4 %	4.2 %	7	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Rhabdoid renal tumour

Cases in Germany aged under 15 years (1980-2015): 55

Selected characteristics Germany 2006-2015

Relative frequency:	18 / 17580 = 0.1 %		
Relative frequency of trial patients:	94.4 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	9	9	18
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	3	3	3
Sex ratio (m/f):	1.0		

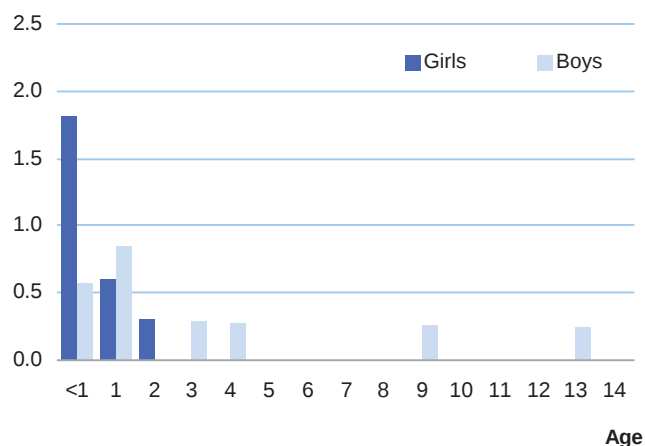
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	8	8	1	1
Incidence rate:	1.2	0.3	0.0	0.0
Median age at diagnosis:	1 year 1 month			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
2 Rhabdoid renal tumour

SN after VI (a) 2			VI (a) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	6.7 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 65

Selected characteristics Germany 2006-2015

Relative frequency:	24 / 17580 = 0.1 %
Relative frequency of trial patients:	83.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	9	15	24
Standardized rate *:	0.1	0.2	0.2
Cumulative incidence:	2	4	3
Sex ratio (m/f):	1.7		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	1	0	4	19
Incidence rate:	0.1	0.0	0.1	0.5
Median age at diagnosis:	12 years 3 months			

Survival probabilities:	5-year	10-year	15-year
	93 %	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
3	0.1 %	0.0	0

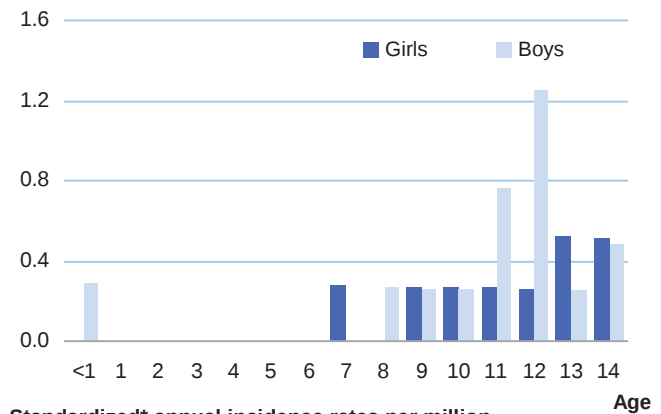
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

VI (b) Renal carcinomas

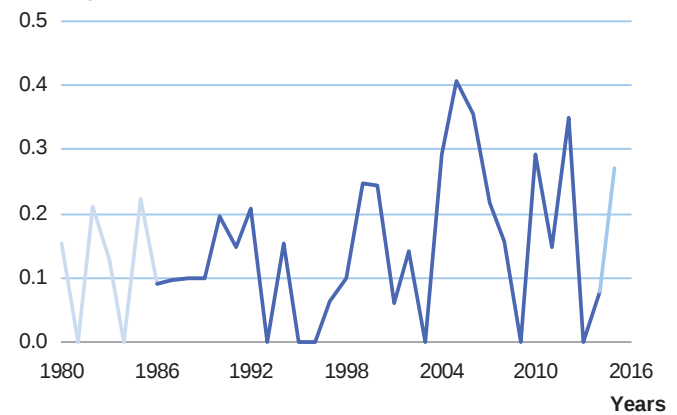
SN after VI (b)			VI (b) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	1.8 %	9	0.7 %	0.0 %

* Standard: Segi world standard population

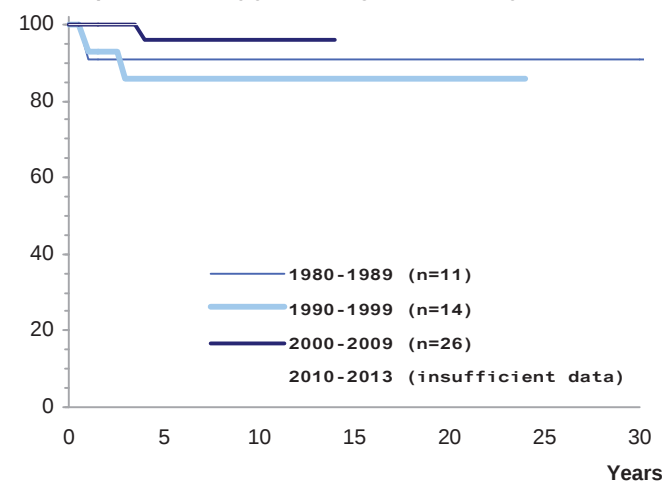
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

46 VII (a) Hepatoblastoma

Cases in Germany aged under 15 years (1980-2015): 533

Selected characteristics Germany 2006-2015

Relative frequency:	224 / 17580 = 1.3 %
Relative frequency of trial patients:	77.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	95	129	224
Standardized rate *:	2.2	2.8	2.5
Cumulative incidence:	28	36	32
Sex ratio (m/f):			1.4

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	74	128	13	9
Incidence rate:	10.8	4.6	0.4	0.2

Median age at diagnosis: 1 year 6 months

Survival probabilities:	5-year	10-year	15-year
	80 %	78 %	78 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

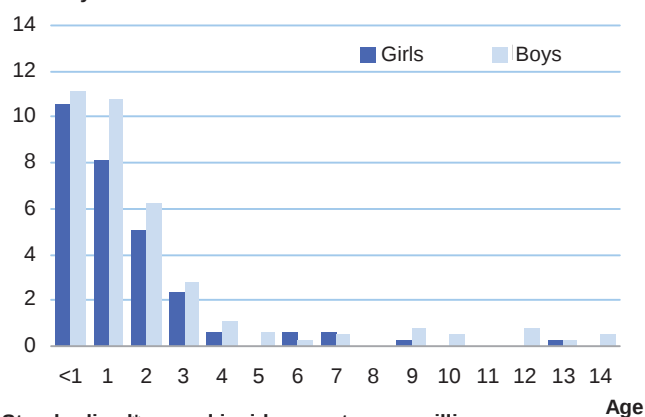
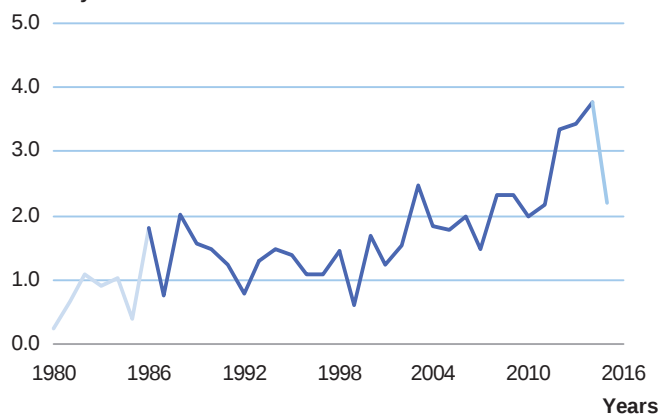
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
36	0.8 %	0.3	4

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

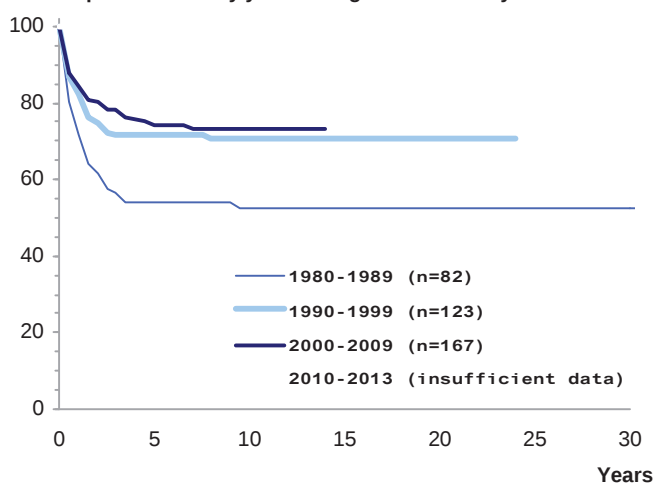
VII (a) Hepatoblastoma

SN after VII (a)			VII (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
3	0.2 %	1.5 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015Standardized* annual incidence rates per million
Germany 1980-2015

Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Cases in Germany aged under 15 years (1980-2015): 115**Selected characteristics Germany 2006-2015**

Relative frequency:	28 / 17580 = 0.2 %
Relative frequency of trial patients:	75.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	13	15	28
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	3	4	4
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	1	6	21
Incidence rate:	0.0	0.0	0.2	0.5
Median age at diagnosis:	12 years 10 months			

Survival probabilities:	5-year	10-year	15-year
	-	-	-

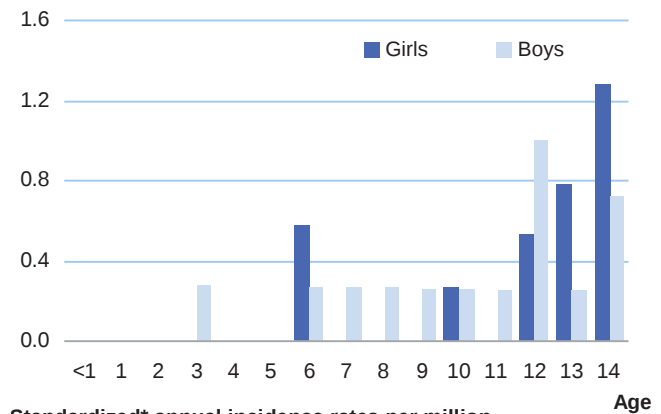
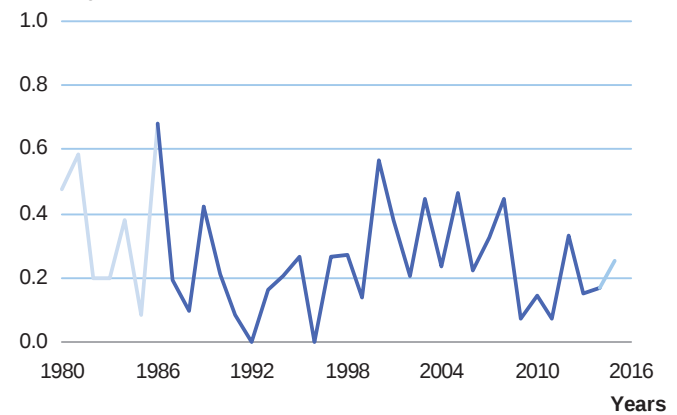
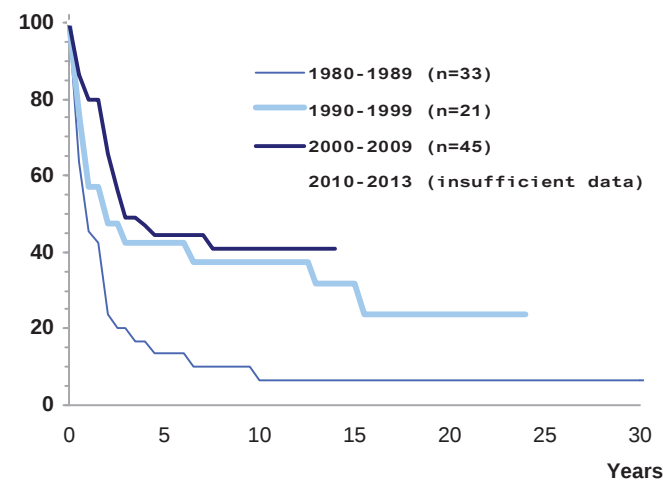
Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
17	0.4 %	0.1	2

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):**VII (b) Hepatic carcinomas**

SN after VII (b)			VII (b) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	1.0 %	5	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2006-2015**Standardized* annual incidence rates per million Germany 1980-2015****Survival probabilities by year of diagnosis Germany 1980-2013**

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 (1980-2015): 2679

Selected characteristics Germany 2006-2015

Relative frequency:	789 / 17580 = 4.5 %		
Relative frequency of trial patients:	97.2 %		

Incidence rates per million:	Girls	Boys	Total
Number of cases:	368	421	789
Standardized rate *:	6.0	6.7	6.4
Cumulative incidence:	99	108	104
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	4	51	208	526
Incidence rate:	0.6	1.8	5.7	13.5

Median age at diagnosis: 11 years 11 months

Survival probabilities:	5-year	10-year	15-year
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
275	6.3 %	1.9	31

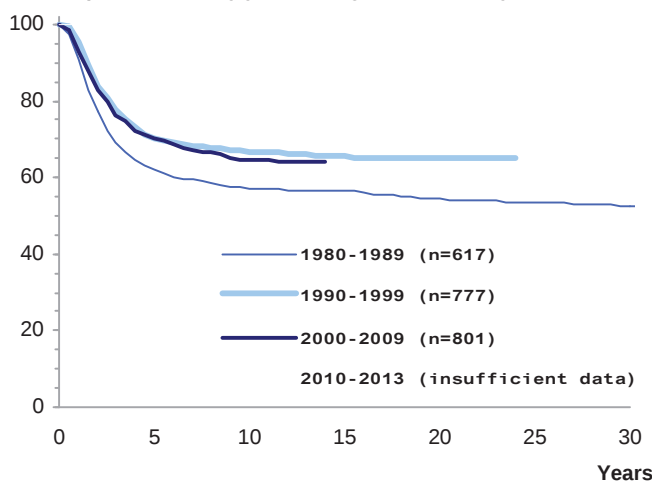
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

VIII Malignant bone tumours

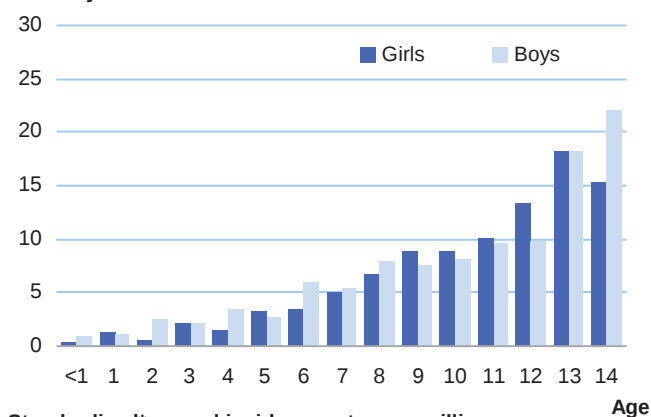
SN after VIII			VIII as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
66	5.3 %	5.2 %	65	5.2 %	0.2 %

* Standard: Segi world standard population

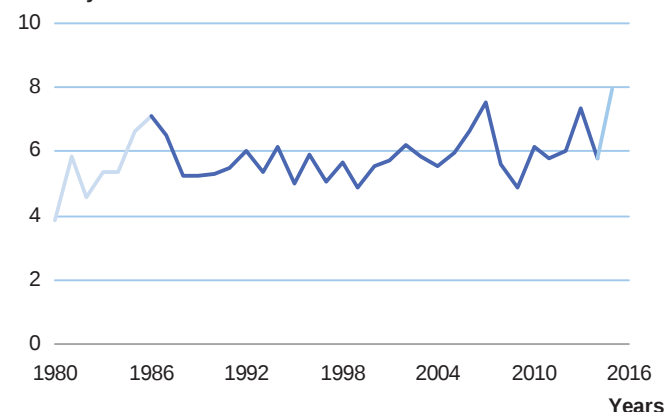
Survival probabilities by year of diagnosis Germany 1980-2013



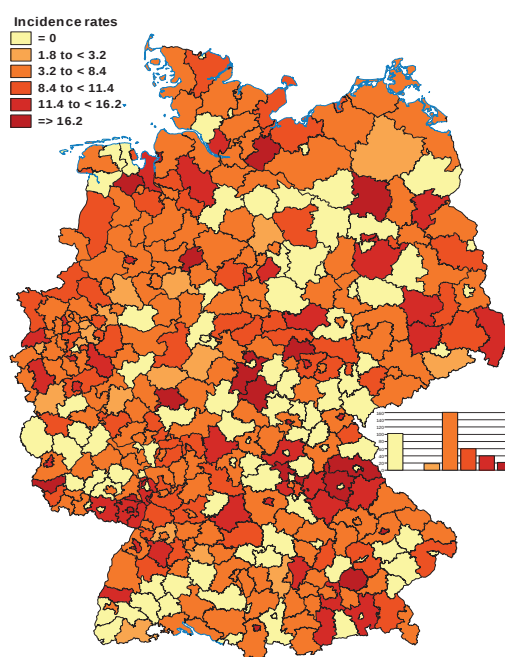
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 1393**Selected characteristics Germany 2006-2015**

Relative frequency:	392 / 17580 = 2.3 %
Relative frequency of trial patients:	98.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	190	202	392
Standardized rate *:	3.0	3.1	3.1
Cumulative incidence:	51	51	51
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	7	89	296
Incidence rate:	0.0	0.3	2.5	7.6

Median age at diagnosis: 12 years 6 months

Survival probabilities:	5-year	10-year	15-year
	76 %	71 %	70 %

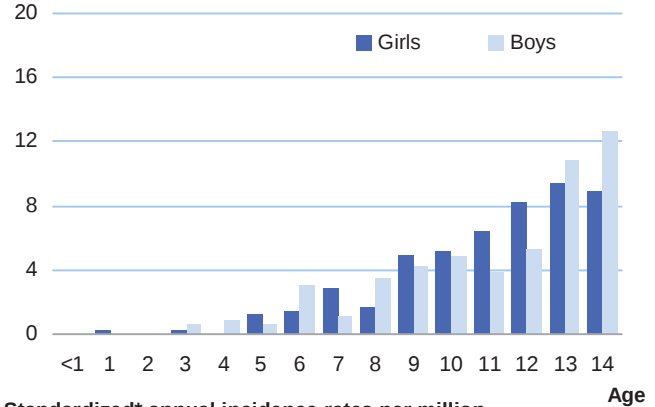
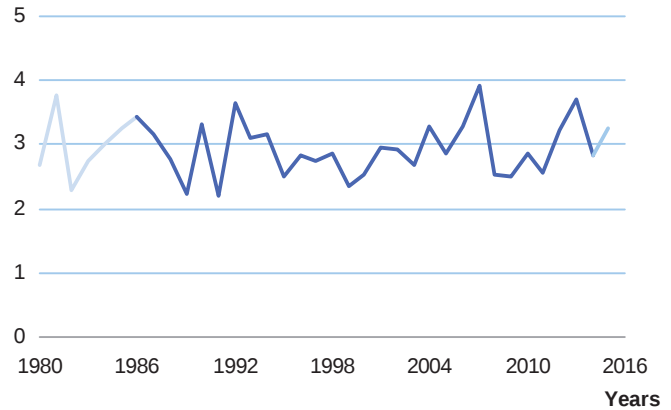
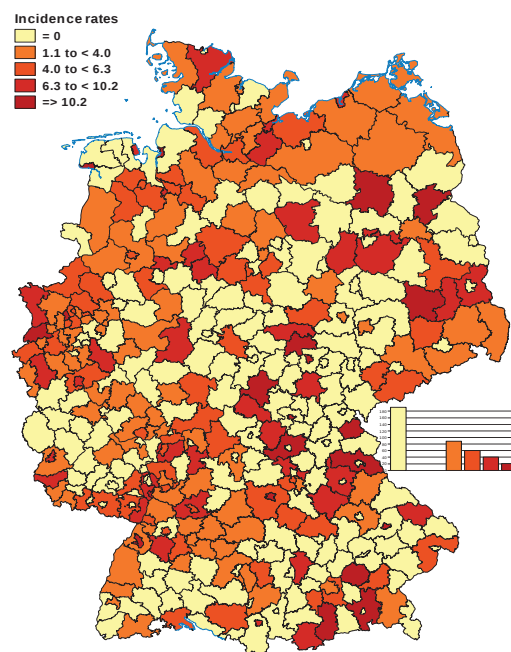
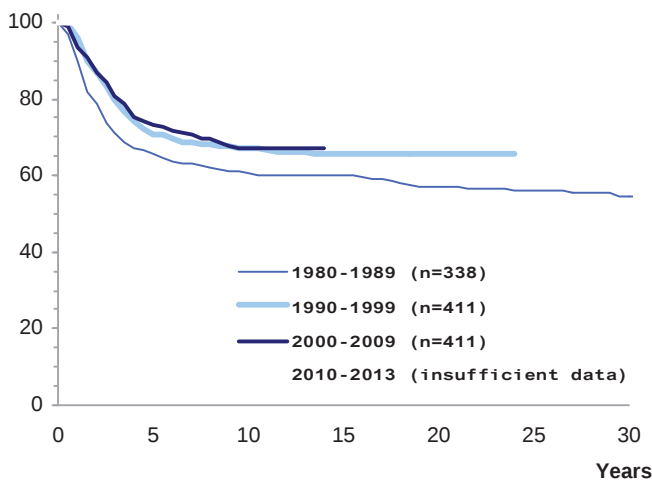
Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
142	3.3 %	1.0	16

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):**VIII (a) Osteosarcomas**

SN after VIII (a)			VIII (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
35	2.8 %	6.1 %	44	3.5 %	0.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2006-2015**Standardized* annual incidence rates per million Germany 1980-2015****Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015****Survival probabilities by year of diagnosis Germany 1980-2013**

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

Cases in Germany aged under 15 years (1980-2015): 1194

Selected characteristics Germany 2006-2015

Relative frequency:	361 / 17580 = 2.1 %
Relative frequency of trial patients:	98.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	161	200	361
Standardized rate *:	2.7	3.3	3.0
Cumulative incidence:	44	52	48
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	3	41	109	208
Incidence rate:	0.4	1.5	3.0	5.3

Median age at diagnosis: 11 years 1 month

Survival probabilities:	5-year	10-year	15-year
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
124	2.9 %	0.9	14

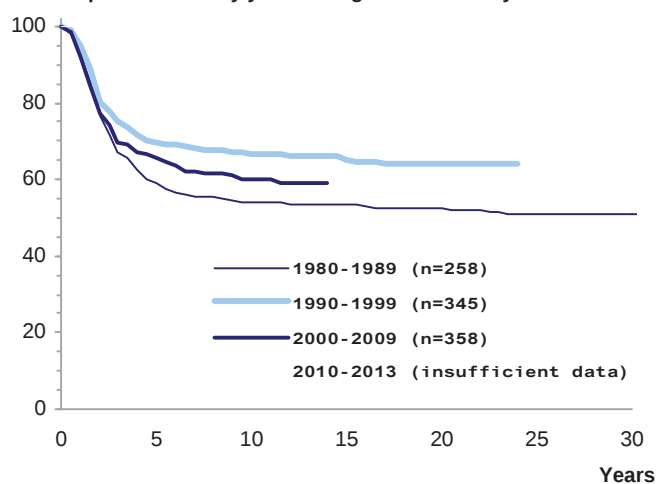
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

VIII (c) Ewing tumour and related sarcomas of bone

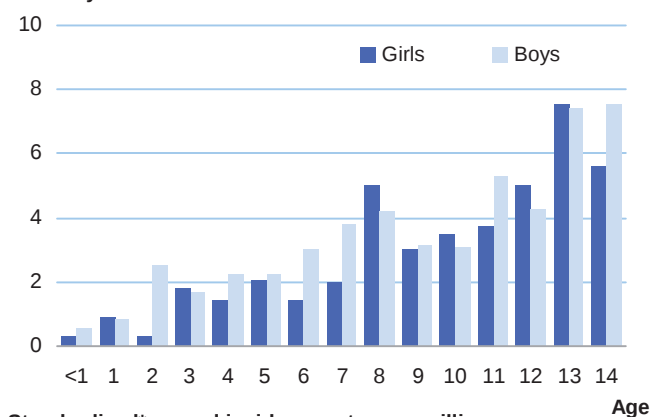
SN after VIII (c)			VIII (c) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
29	2.3 %	3.9 %	17	1.4 %	0.1 %

* Standard: Segi world standard population

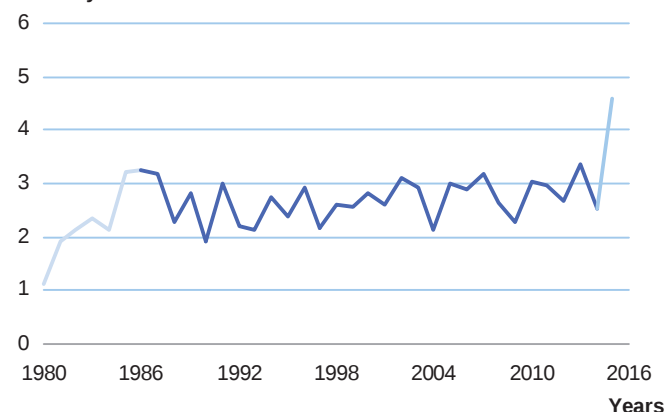
Survival probabilities by year of diagnosis Germany 1980-2013



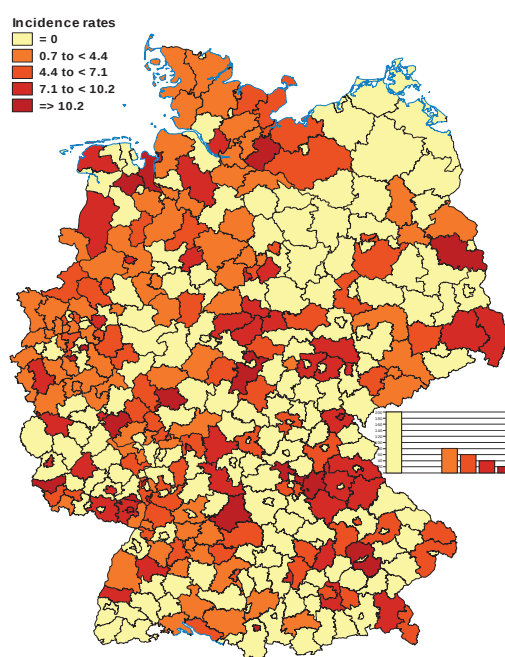
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Germany 2006-2015	N	%
Ewing tumour and related sarcomas of bone	361	100.0
1 Ewing tumour and Askin tumour of bone	340	94.2
2 Peripheral neuroectodermal tumour (pPNET) of bone	21	5.8

1 Ewing tumour and Askin tumour of bone

Cases in Germany aged under 15 years (1980-2015): 1027

Selected characteristics Germany 2006-2015

Relative frequency:	340 / 17580 = 1.9 %		
Relative frequency of trial patients:	98.5 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	151	189	340
Standardized rate *:	2.5	3.1	2.8
Cumulative incidence:	41	49	45
Sex ratio (m/f):	1.3		

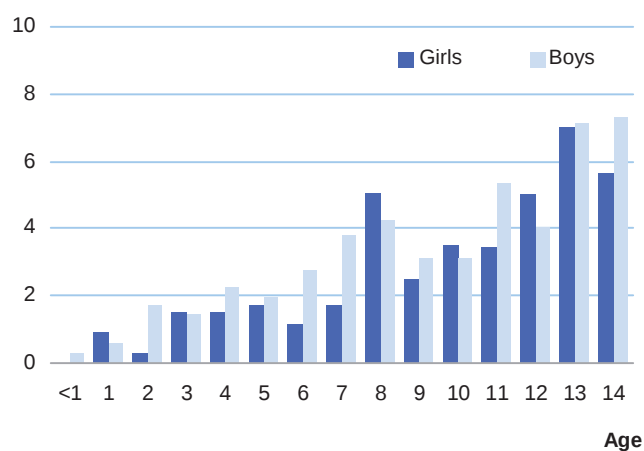
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	35	102	202
Incidence rate:	0.1	1.3	2.8	5.2
Median age at diagnosis:	11 years 4 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
1 Ewing tumour and Askin tumour of bone

SN after VIII (c) 1			VIII (c) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
23	1.8 %	3.6 %	11	0.9 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



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 (1980-2015): 3507

Selected characteristics Germany 2006-2015

Relative frequency: 1001 / 17580 = 5.7 %

Relative frequency of trial patients: 98.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	461	540	1001
Standardized rate *:	8.8	9.9	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 :	126	272	265	338
Incidence rate:	18.5	9.9	7.3	8.7

Median age at diagnosis: 6 years 7 months

Survival probabilities:	5-year	10-year	15-year
	74 %	71 %	70 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
391	9.0 %	3.1	45

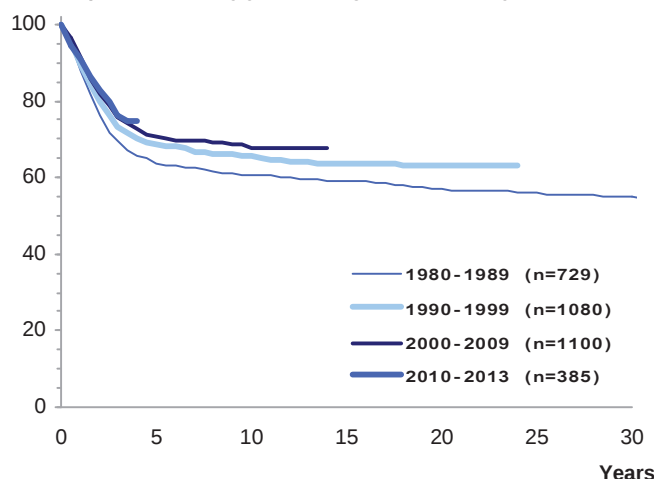
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

IX Soft tissue and other extraosseous sarcomas

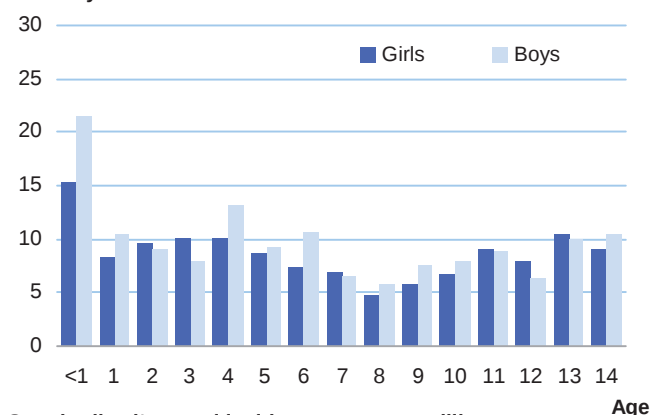
SN after IX			IX as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
94	7.5 %	7.2 %	70	5.6 %	0.3 %

* Standard: Segi world standard population

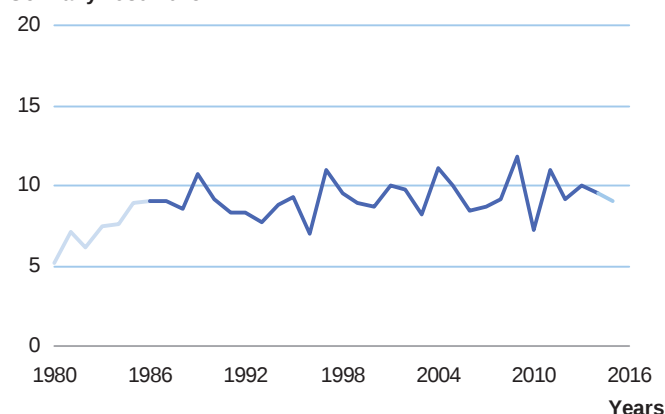
Survival probabilities by year of diagnosis Germany 1980-2013



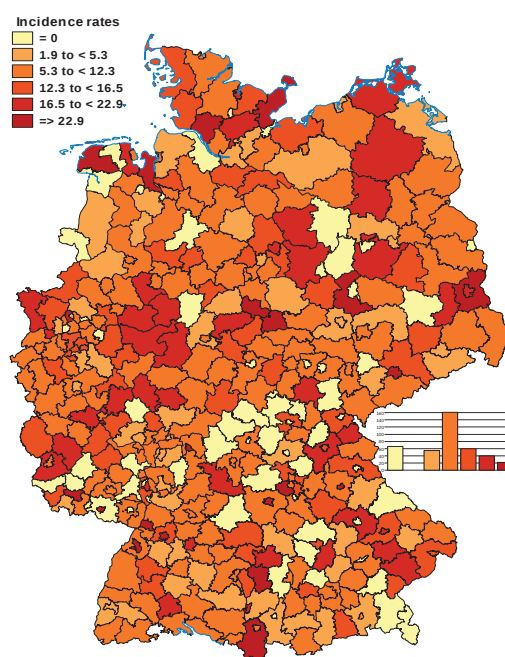
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



Cases in Germany aged under 15 years (1980-2015): 1983

Selected characteristics Germany 2006-2015

Relative frequency:	515 / 17580 = 3 %
Relative frequency of trial patients:	99.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	228	287	515
Standardized rate *:	4.5	5.5	5.0
Cumulative incidence:	65	78	72
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	48	197	155	115
Incidence rate:	7.0	7.1	4.3	2.9
Median age at diagnosis:	5 years 3 months			

Survival probabilities:	5-year	10-year	15-year
	74 %	72 %	71 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths	Standardized*	Cumulative
N % of all 4335 deaths	mortality rate	mortality
237 5.5 %	1.9	27

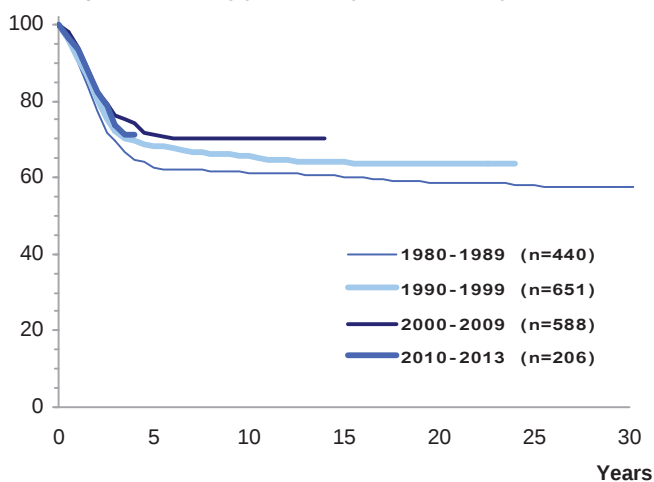
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

IX (a) Rhabdomyosarcomas

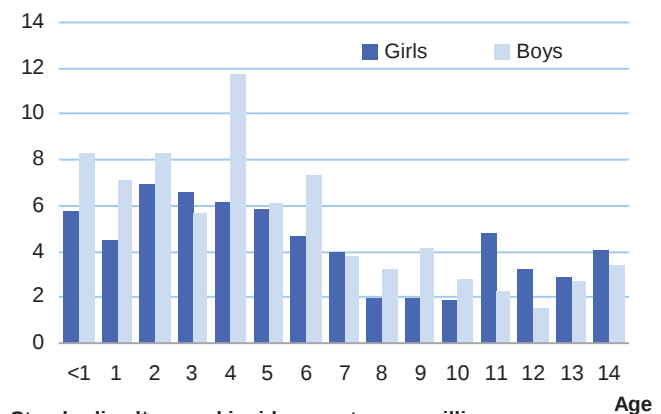
SN after IX (a)			IX (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
63	5.0 %	7.5 %	14	1.1 %	0.0 %

* Standard: Segi world standard population

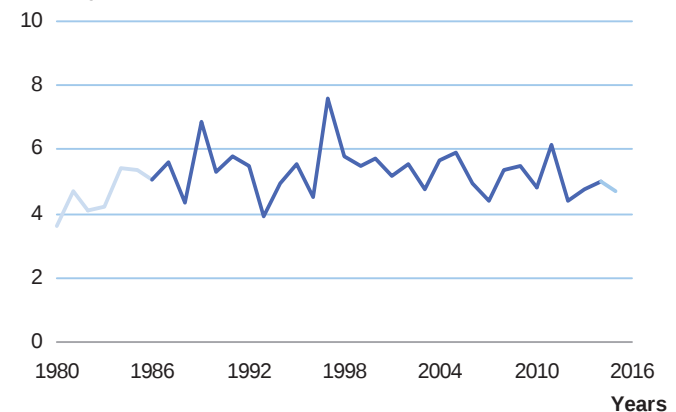
Survival probabilities by year of diagnosis Germany 1980-2013



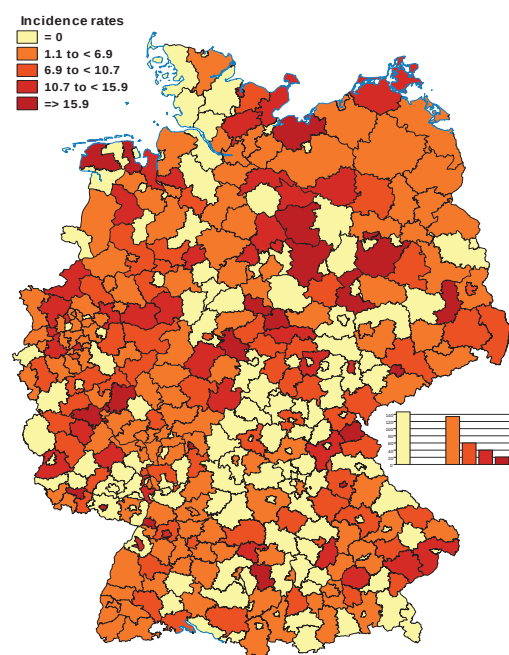
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



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

Cases in Germany aged under 15 years (1980-2015): 329

Selected characteristics Germany 2006-2015

Relative frequency:	106 / 17580 = 0.6 %
Relative frequency of trial patients:	95.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	48	58	106
Standardized rate *:	0.9	1.1	1.0
Cumulative incidence:	14	16	15
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	29	15	21	41
Incidence rate:	4.3	0.5	0.6	1.1

Median age at diagnosis: 7 years 10 months

Survival probabilities:	5-year	10-year	15-year
	72 %	72 %	71 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
26	0.6 %	0.2	3

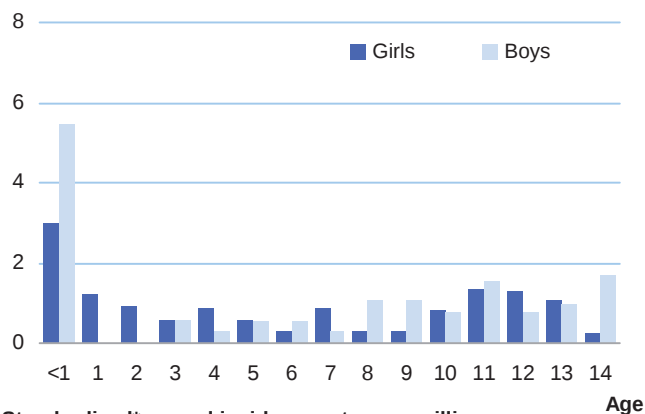
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

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

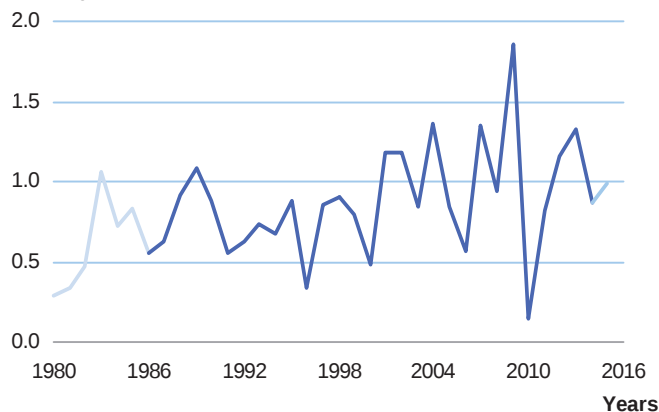
SN after IX (b)			IX (b) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
7	0.6 %	4.1 %	19	1.5 %	0.1 %

* Standard: Segi world standard population

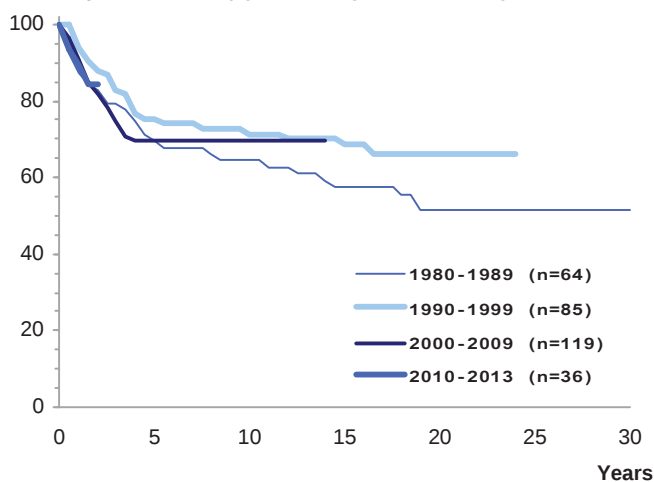
Age- and sex-specific incidence rates per million
Germany 2006-2015



Standardized* annual incidence rates per million
Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Germany 2006-2015	N	%
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	106	100.0
1 Fibroblastic and myofibroblastic tumours	53	50.0
2 Nerve sheath tumours	53	50.0
3 Other fibrous neoplasms	0	0.0

1 Fibroblastic and myofibroblastic tumours

Cases in Germany aged under 15 years (1980-2015): 155

Selected characteristics Germany 2006-2015

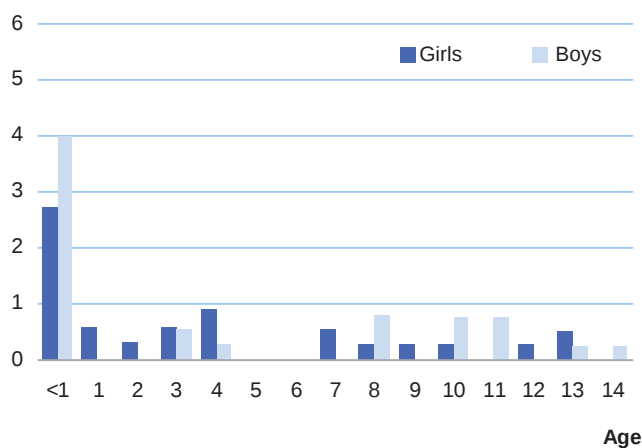
Relative frequency:	53 / 17580 = 0.3 %			
Relative frequency of trial patients:	94.3 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	25	28	53	
Standardized rate *:	0.5	0.6	0.5	
Cumulative incidence:	7	8	7	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	23	11	7	12
Incidence rate:	3.4	0.4	0.2	0.3
Median age at diagnosis:	3 years 0 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
1 Fibroblastic and myofibroblastic tumours

SN after IX (b) 1			IX (b) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
4	0.3 %	6.7 %	5	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Nerve sheath tumours

Cases in Germany aged under 15 years (1980-2015): 174

Selected characteristics Germany 2006-2015

Relative frequency:	53 / 17580 = 0.3 %		
Relative frequency of trial patients:	96.2 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	23	30	53
Standardized rate *:	0.4	0.5	0.5
Cumulative incidence:	6	8	7
Sex ratio (m/f):	1.3		

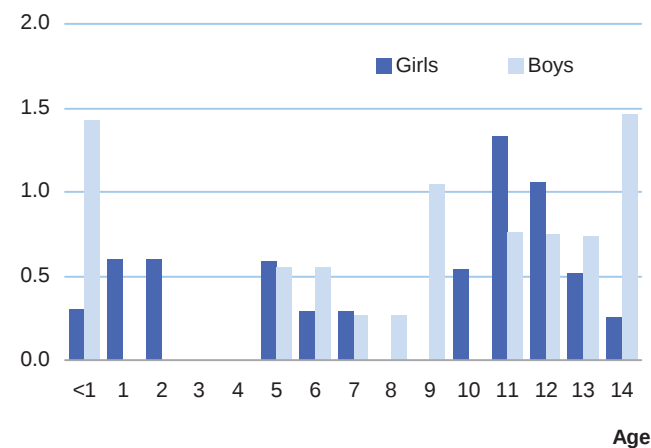
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	6	4	14	29
Incidence rate:	0.9	0.1	0.4	0.7
Median age at diagnosis:	11 years 0 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
2 Nerve sheath tumours

SN after IX (b) 2			IX (b) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
3	0.2 %	2.5 %	14	1.1 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



56 IX (d) Other specified soft tissue sarcomas

Cases in Germany aged under 15 years (1980-2015): 963

Selected characteristics Germany 2006-2015

Relative frequency:	294 / 17580 = 1.7 %
Relative frequency of trial patients:	97.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	147	147	294
Standardized rate *:	2.7	2.5	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 :	36	43	72	143
Incidence rate:	5.3	1.6	2.0	3.7

Median age at diagnosis: 9 years 9 months

Survival probabilities:	5-year	10-year	15-year
	75 %	70 %	68 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
101	2.3 %	0.8	12

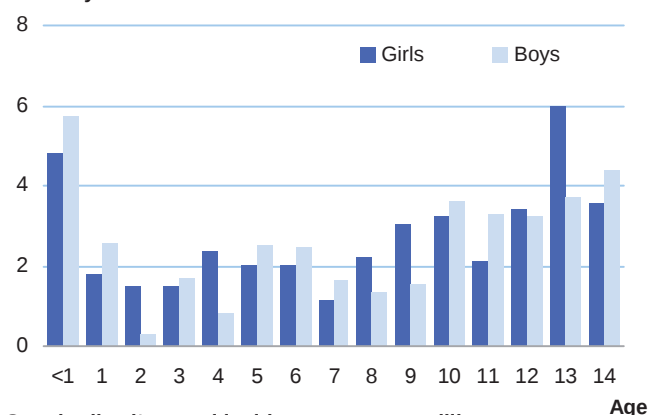
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

IX (d) Other specified soft tissue sarcomas

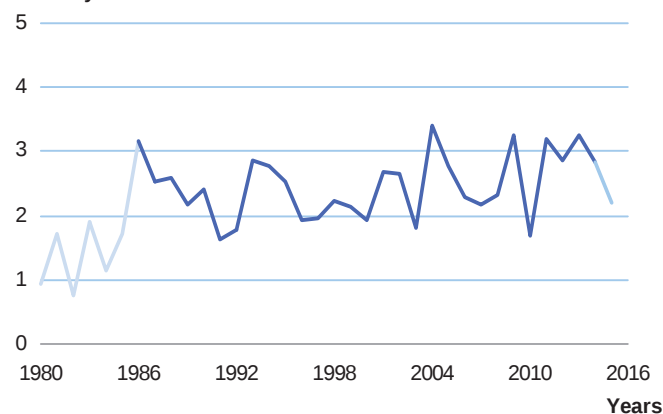
SN after IX (d)			IX (d) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
20	1.6 %	7.4 %	31	2.5 %	0.2 %

* Standard: Segi world standard population

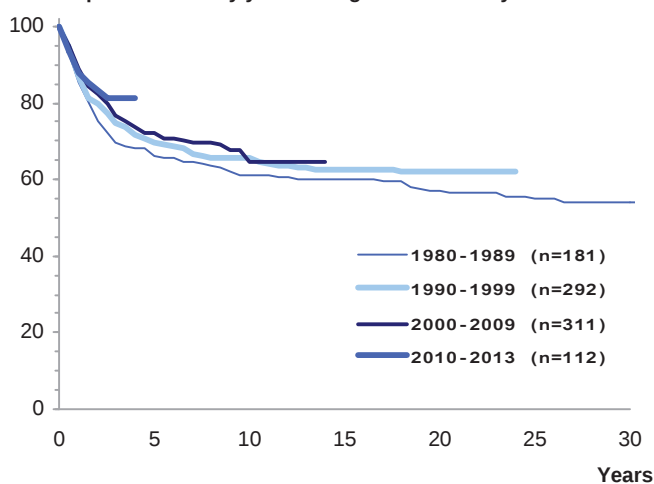
Age- and sex-specific incidence rates per million
Germany 2006-2015



Standardized* annual incidence rates per million
Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Germany 2006-2015	N	%		N	%
Other specified soft tissue sarcomas	294	100.0			
1 Ewing tumour and Askin tumour of soft tissue	68	23.1	7 Synovial sarcomas	64	21.8
2 Peripheral neuroectodermal tumour (pPNET) of soft tissue	14	4.8	8 Blood vessel tumours	9	3.1
3 Extrarenal rhabdoid tumour	49	16.7	9 Osseous and chondromatous neoplasms of soft tissue	5	1.7
4 Liposarcomas	5	1.7	10 Alveolar soft parts sarcoma	12	4.1
5 Fibrohistiocytic tumours	35	11.9	11 Miscellaneous soft tissue sarcomas	32	10.9
6 Leiomyosarcomas	1	0.3			

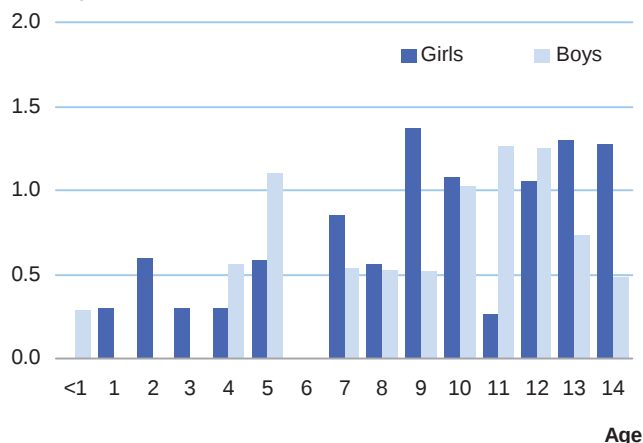
1 Ewing tumour and Askin tumour of soft tissue

Cases in Germany aged under 15 years (1980-2015): 191

Selected characteristics Germany 2006-2015

Relative frequency:	68 / 17580 = 0.4 %				
Relative frequency of trial patients:	98.5 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	36	32	68		
Standardized rate *:	0.6	0.5	0.6		
Cumulative incidence:	10	8	9		
Sex ratio (m/f):	0.9				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	1	7	22	38	
Incidence rate:	0.1	0.3	0.6	1.0	
Median age at diagnosis:	10 years 7 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):					
1 Ewing tumour and Askin tumour of soft tissue					
SN after IX (d) 1		IX (d) 1 as SN after any primary			
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
8	0.6 %	9.4 %	6	0.5 %	0.0 %
* Standard: Segi world standard population					

Age- and sex-specific incidence rates per million
Germany 2006-2015



3 Extrarenal rhabdoid tumour

Cases in Germany aged under 15 years (1980-2015): 86

Selected characteristics Germany 2006-2015

Relative frequency:	49 / 17580 = 0.3 %		
Relative frequency of trial patients:	93.9 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	24	25	49
Standardized rate *:	0.5	0.5	0.5
Cumulative incidence:	7	7	7
Sex ratio (m/f):	1.0		

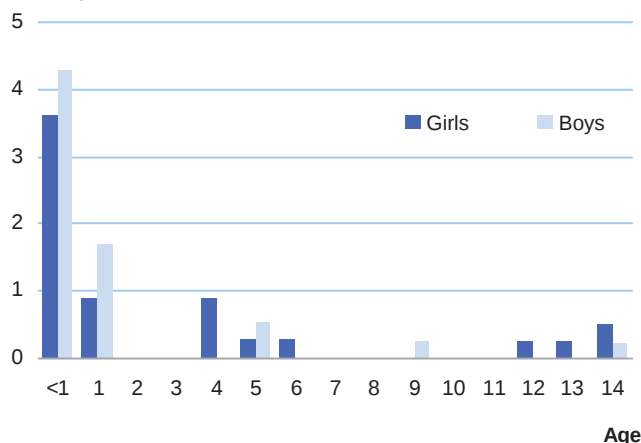
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	27	12	5	5
Incidence rate:	4.0	0.4	0.1	0.1
Median age at diagnosis:	0 years 10 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
3 Extrarenal rhabdoid tumour

SN after IX (d) 3			IX (d) 3 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	5.7 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



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

Germany 2006-2015	N	%		N	%
Other specified soft tissue sarcomas	294	100.0			
1 Ewing tumour and Askin tumour of soft tissue	68	23.1	7 Synovial sarcomas	64	21.8
2 Peripheral neuroectodermal tumour (pNET) of soft tissue	14	4.8	8 Blood vessel tumours	9	3.1
3 Extrarenal rhabdoid tumour	49	16.7	9 Osseous and chondromatous neoplasms of soft tissue	5	1.7
4 Liposarcomas	5	1.7	10 Alveolar soft parts sarcoma	12	4.1
5 Fibrohistiocytic tumours	35	11.9	11 Miscellaneous soft tissue sarcomas	32	10.9
6 Leiomyosarcomas	1	0.3			

5 Fibrohistiocytic tumours

Cases in Germany aged under 15 years (1980-2015): 87

Selected characteristics Germany 2006-2015

Relative frequency:	35 / 17580 = 0.2 %		
Relative frequency of trial patients:	94.3 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	20	15	35
Standardized rate *:	0.4	0.3	0.3
Cumulative incidence:	6	4	5
Sex ratio (m/f):	0.8		

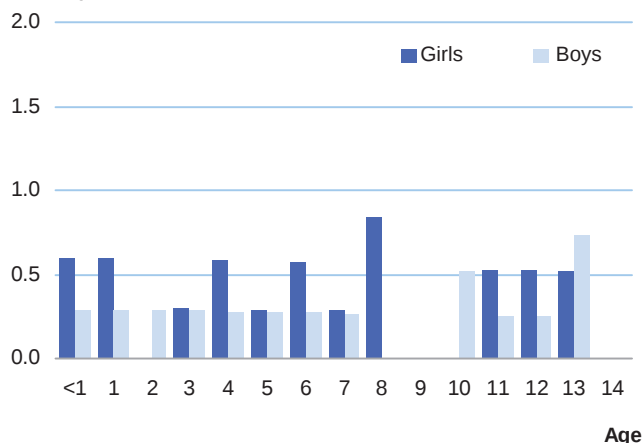
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	3	9	10	13
Incidence rate:	0.4	0.3	0.3	0.3
Median age at diagnosis:	7 years 9 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
5 Fibrohistiocytic tumours

SN after IX (d) 5			IX (d) 5 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 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 2006-2015



7 Synovial sarcomas

Cases in Germany aged under 15 years (1980-2015): 225

Selected characteristics Germany 2006-2015

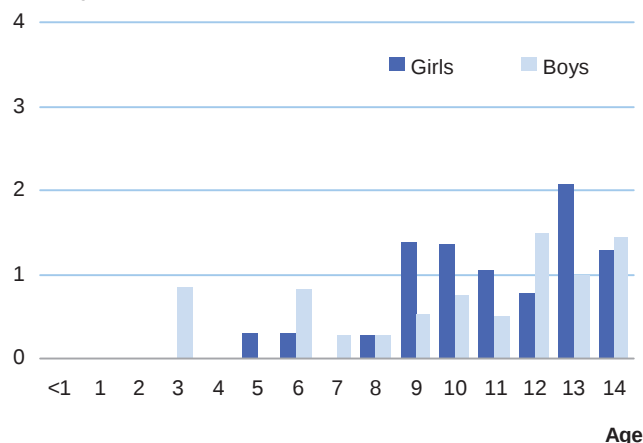
Relative frequency:	64 / 17580 = 0.4 %		
Relative frequency of trial patients:	100.0 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	33	31	64
Standardized rate *:	0.5	0.5	0.5
Cumulative incidence:	9	8	8
Sex ratio (m/f):	0.9		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	3	15	46
Incidence rate:	0.0	0.1	0.4	1.2
Median age at diagnosis:	12 years 1 month			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):					
7 Synovial sarcomas					
SN after IX (d) 7			IX (d) 7 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
4	0.3 %	-	6	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



- (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 (1980-2015): 1842

Selected characteristics Germany 2006-2015

Relative frequency:	566 / 17580 = 3.2 %
Relative frequency of trial patients:	96.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	325	241	566
Standardized rate *:	6.2	4.4	5.3
Cumulative incidence:	91	64	77
Sex ratio (m/f):	0.7		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	147	81	85	253
Incidence rate:	21.6	2.9	2.3	6.5
Median age at diagnosis:	9 years 0 months			

Survival probabilities:	5-year	10-year	15-year
	94 %	93 %	93 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths	Standardized*	Cumulative
N % of all 4335 deaths	mortality rate	mortality
59 1.4 %	0.4	7

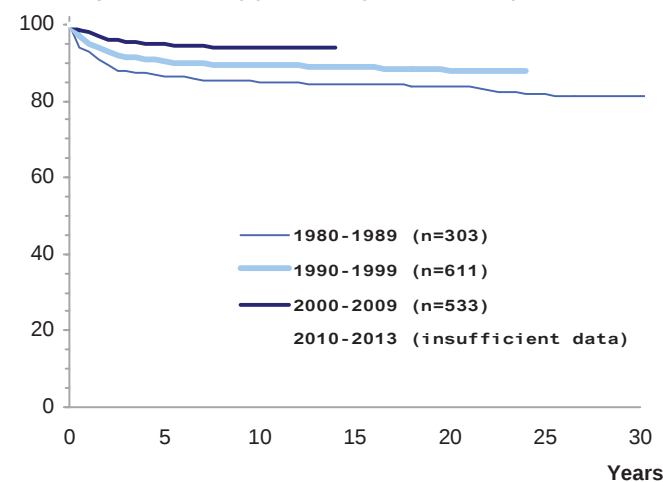
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

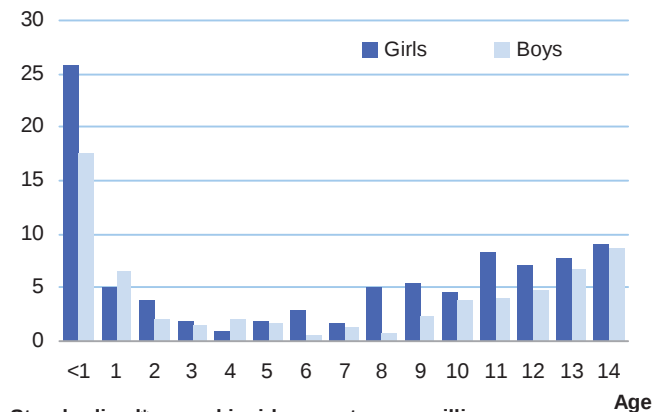
SN after X	X as SN after any primary	
N % of all 1253 SN Cumulative incidence	N % of all 1253 SN Cumulative incidence	
30 2.4 % 7.0 %	12 1.0 % 0.1 %	

* Standard: Segi world standard population

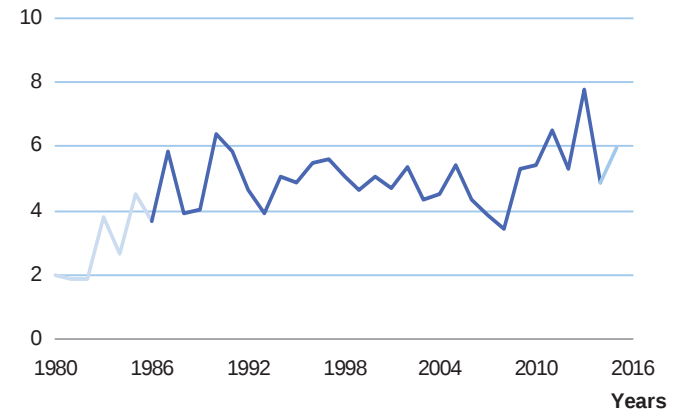
Survival probabilities by year of diagnosis Germany 1980-2013



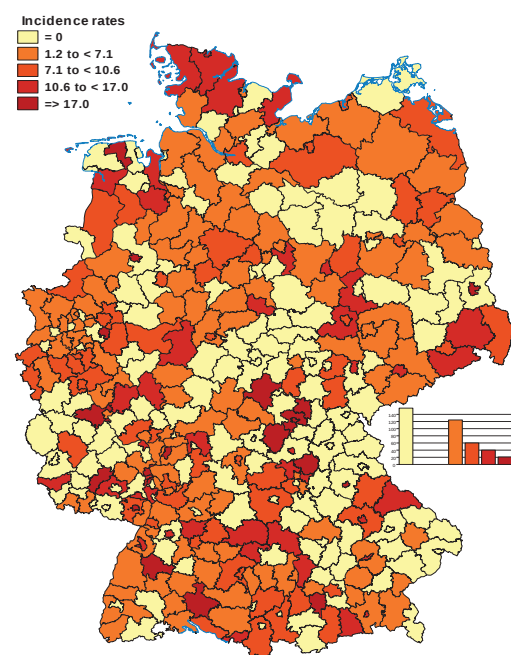
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Standardized* incidence rates per million by districts (Landkreise) Germany 2006-2015



60 X (a) Intracranial and intraspinal germ cell tumours

Cases in Germany aged under 15 years (1980-2015): 506

Selected characteristics Germany 2006-2015

Relative frequency:	166 / 17580 = 1.0 %
Relative frequency of trial patients:	95.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	60	106	166
Standardized rate *:	1.0	1.7	1.4
Cumulative incidence:	17	27	22
Sex ratio (m/f):	1.8		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	8	9	41	108
Incidence rate:	1.2	0.3	1.1	2.8

Median age at diagnosis: 11 years 3 months

Survival probabilities:	5-year	10-year	15-year
	90 %	86 %	86 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
31	0.7 %	0.2	4

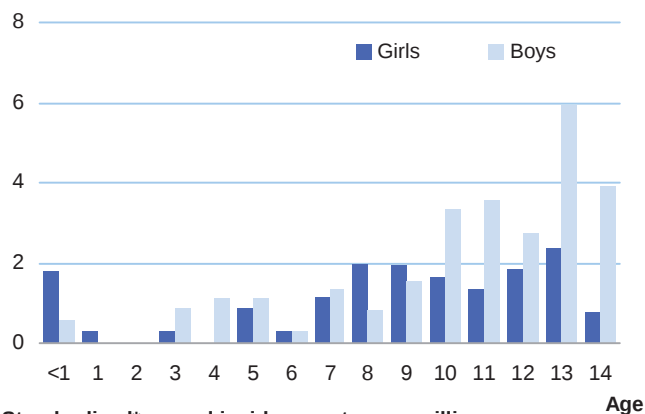
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

X (a) Intracranial and intraspinal germ cell tumours

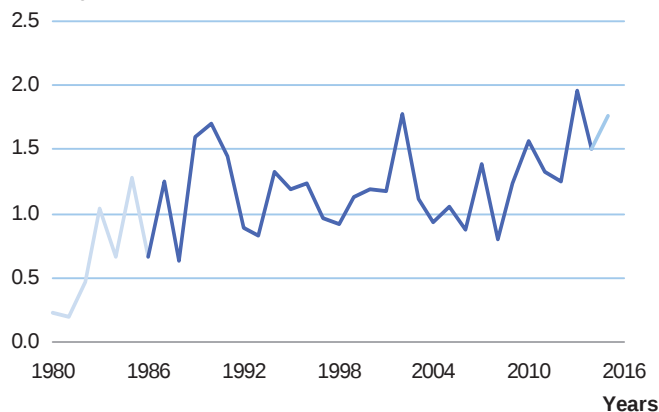
SN after X (a)			X (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
13	1.0 %	12.0 %	3	0.2 %	0.0 %

* Standard: Segi world standard population

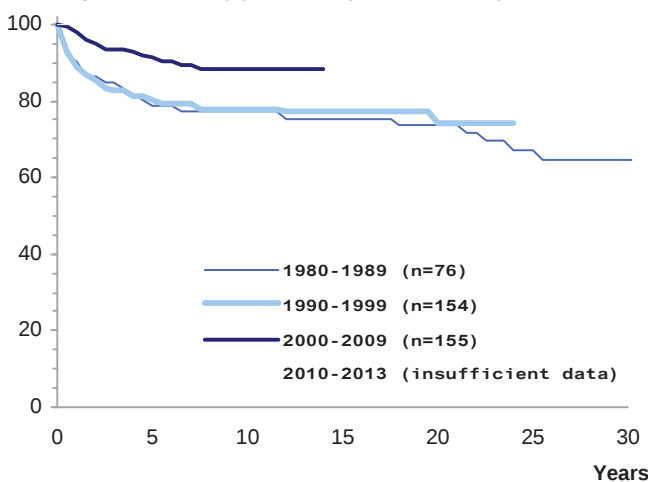
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

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

Cases in Germany aged under 15 years (1980-2015): 548

Selected characteristics Germany 2006-2015

Relative frequency: 176 / 17580 = 1 %

Relative frequency of trial patients: 96.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	121	55	176
Standardized rate *:	2.8	1.2	2.0
Cumulative incidence:	36	15	25
Sex ratio (m/f):	0.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	110	47	5	14
Incidence rate:	16.1	1.7	0.1	0.4

Median age at diagnosis: 0 years 3 months

Survival probabilities:	5-year	10-year	15-year
	93 %	93 %	93 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
15	0.3 %	0.1	2

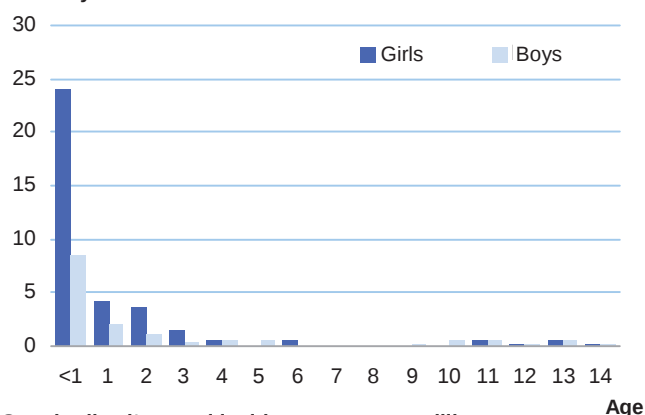
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

X (b) Malignant extracranial and extragonadal germ cell tumours

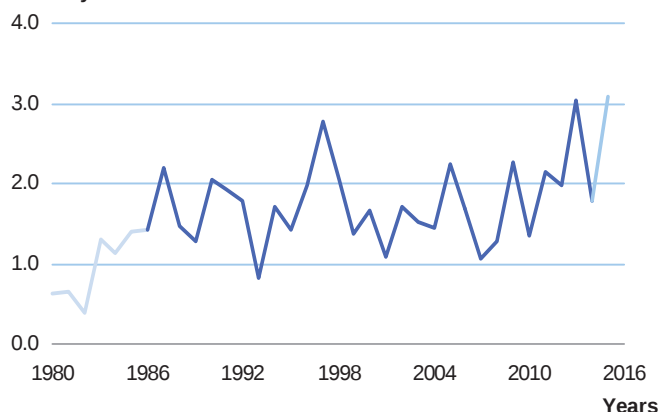
SN after X (b)			X (b) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
7	0.6 %	3.7 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

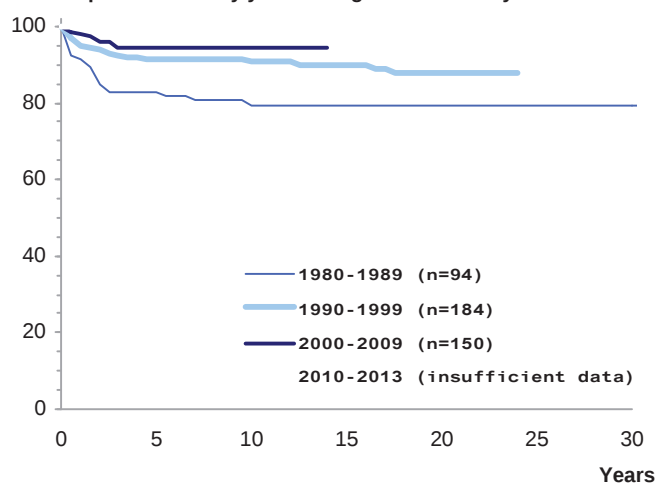
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Germany 2006-2015	N	%
Malignant extracranial and extragonadal germ cell tumours	176	100.0
1 Malignant germinomas of extracranial and extragonadal sites	13	7.4
2 Malignant teratomas of extracranial and extragonadal sites	89	50.6
3 Embryonal carcinomas of extracranial and extragonadal sites	0	0.0
4 Yolk sac tumour of extracranial and extragonadal sites	49	27.8
5 Choriocarcinomas of extracranial and extragonadal sites	2	1.1
6 Other and unspecified malignant mixed germ cell tumours of extracranial and extragonadal sites	23	13.1

2 Malignant teratomas of extracranial and extragonadal sites

Cases in Germany aged under 15 years (1980-2015): 257

Selected characteristics Germany 2006-2015

Relative frequency:	89 / 17580 = 0.5 %			
Relative frequency of trial patients:	96.6 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	61	28	89	
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:	83	5	0	1
Incidence rate:	12.2	0.2	0.0	0.0
Median age at diagnosis:	0 years 0 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
2 Malignant teratomas of extracranial and extragonadal sites

SN after X (b) 2			X (b) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	4.3 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

4 Yolk sac tumour of extracranial and extragonadal sites

Cases in Germany aged under 15 years (1980-2015): 212

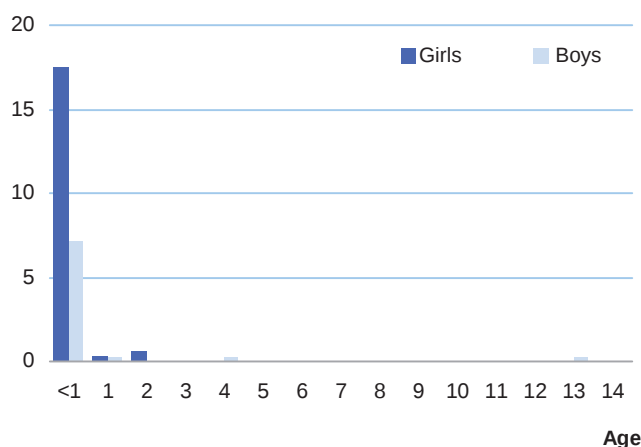
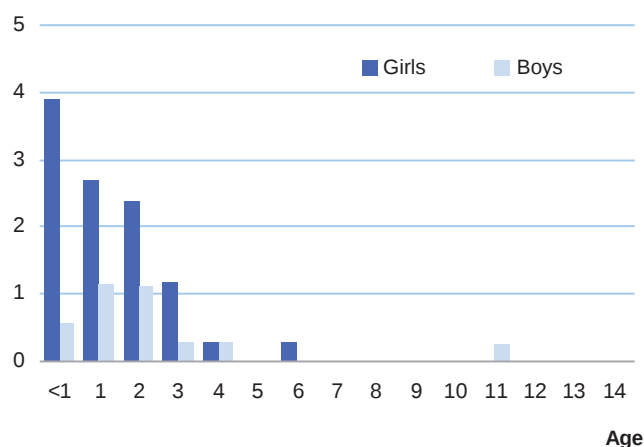
Selected characteristics Germany 2006-2015

Relative frequency:	49 / 17580 = 0.3 %			
Relative frequency of trial patients:	98.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	36	13	49	
Standardized rate *:	0.8	0.3	0.6	
Cumulative incidence:	11	4	7	
Sex ratio (m/f):	0.4			
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	15	32	1	1
Incidence rate:	2.2	1.2	0.0	0.0
Median age at diagnosis:	1 year 7 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
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 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
3	0.2 %	3.2 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015Age- and sex-specific incidence rates per million
Germany 2006-2015

64 X (c) Malignant gonadal germ cell tumours

Cases in Germany aged under 15 years (1980-2015): 745

Selected characteristics Germany 2006-2015

Relative frequency:	219 / 17580 = 1.3 %
Relative frequency of trial patients:	97.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	139	80	219
Standardized rate *:	2.3	1.6	1.9
Cumulative incidence:	37	22	29
Sex ratio (m/f):	0.6		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	29	25	39	126
Incidence rate:	4.3	0.9	1.1	3.2

Median age at diagnosis: 11 years 4 months

Survival probabilities:	5-year	10-year	15-year
	98 %	98 %	98 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
9	0.2 %	0.1	1

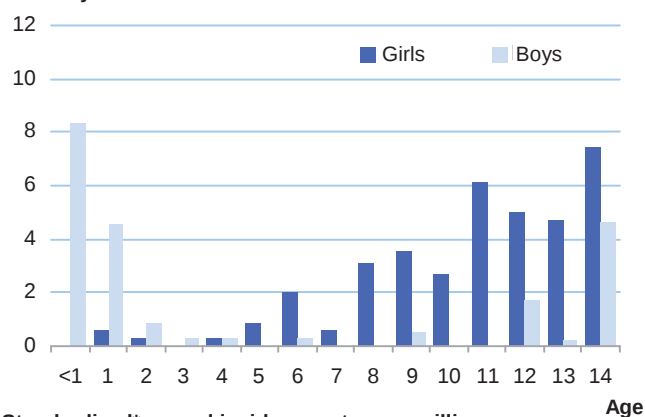
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

X (c) Malignant gonadal germ cell tumours

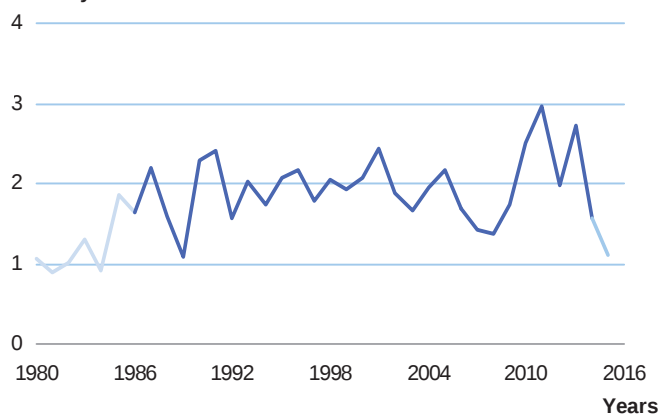
SN after X (c)			X (c) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
10	0.8 %	7.3 %	6	0.5 %	0.0 %

* Standard: Segi world standard population

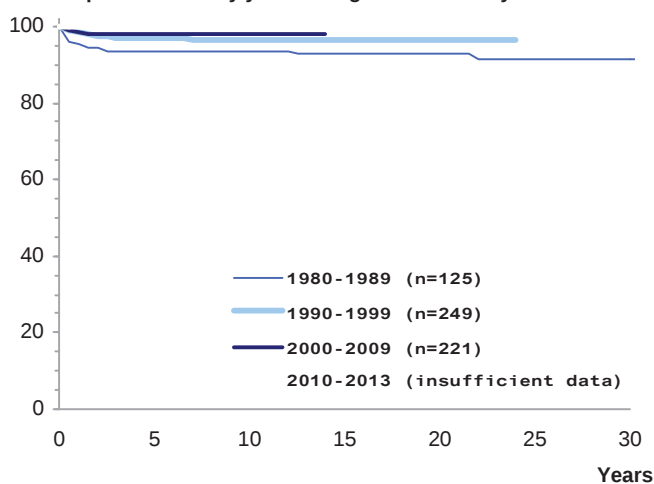
Age- and sex-specific incidence rates per million
Germany 2006-2015



Standardized* annual incidence rates per million
Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Germany 2006-2015	N	%
Malignant gonadal germ cell tumours	219	100.0
1 Malignant gonadal germinomas	40	18.3
2 Malignant gonadal teratomas	49	22.4
3 Gonadal embryonal carcinomas	2	0.9
4 Gonadal yolk sac tumour	48	21.9
5 Gonadal choriocarcinoma	9	4.1
6 Malignant gonadal tumours of mixed forms	71	32.4
7 Malignant gonadal gonadoblastoma	0	0.0

1 Malignant gonadal germinomas

Cases in Germany aged under 15 years (1980-2015): 99

Selected characteristics Germany 2006-2015

Relative frequency:	40 / 17580 = 0.2 %		
Relative frequency of trial patients:	100.0 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	36	4	40
Standardized rate *:	0.6	0.1	0.3
Cumulative incidence:	10	1	5
Sex ratio (m/f):	0.1		

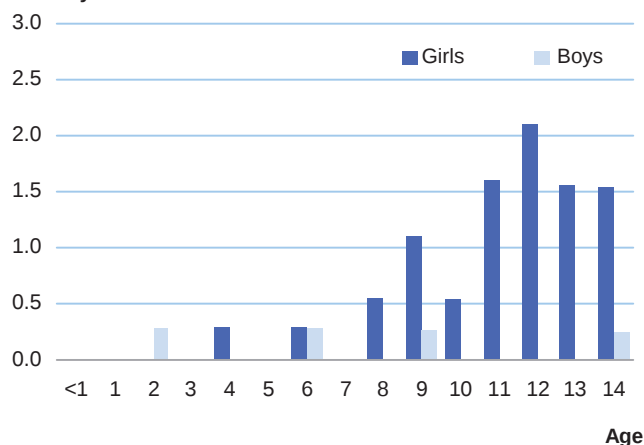
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	2	9	29
Incidence rate:	0.0	0.1	0.2	0.7
Median age at diagnosis:	12 years 0 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
1 Malignant gonadal germinomas

SN after X (c) 1			X (c) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	-	3	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



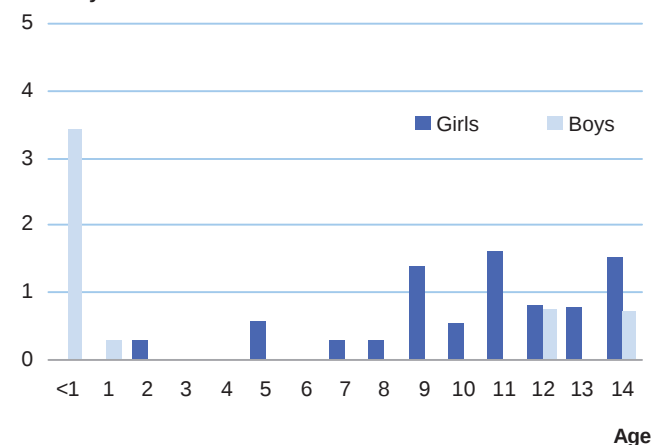
2 Malignant gonadal teratomas

Cases in Germany aged under 15 years (1980-2015): 176

Selected characteristics Germany 2006-2015

Relative frequency:	49 / 17580 = 0.3 %				
Relative frequency of trial patients:	93.9 %				
Incidence rates per million:	Girls	Boys	Total		
Number of cases:	30	19	49		
Standardized rate *:	0.5	0.4	0.4		
Cumulative incidence:	8	5	7		
Sex ratio (m/f):	0.6				
Age-specific incidence rates per million:					
	<1	1-4	5-9	10-14	
Number of cases:	12	2	9	26	
Incidence rate:	1.8	0.1	0.2	0.7	
Median age at diagnosis:	10 years 8 months				
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013): 2 Malignant gonadal teratomas					
SN after X (c) 2			X (c) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	0.8 %	1	0.1 %	0.0 %

Age- and sex-specific incidence rates per million
Germany 2006-2015



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

Germany 2006-2015		N	%
Malignant gonadal germ cell tumours		219	100.0
1 Malignant gonadal germinomas		40	18.3
2 Malignant gonadal teratomas		49	22.4
3 Gonadal embryonal carcinomas		2	0.9
4 Gonadal yolk sac tumour		48	21.9
5 Gonadal choriocarcinoma		9	4.1
6 Malignant gonadal tumours of mixed forms		71	32.4
7 Malignant gonadal gonadoblastoma		0	0.0

4 Gonadal yolk sac tumour

Cases in Germany aged under 15 years (1980-2015): 306

Selected characteristics Germany 2006-2015

Relative frequency:		48 / 17580 = 0.3 %		
Relative frequency of trial patients:		95.8 %		
Incidence rates per million:		Girls	Boys	Total
Number of cases:		23	25	48
Standardized rate *:		0.4	0.6	0.5
Cumulative incidence:		6	7	7
Sex ratio (m/f):		1.1		

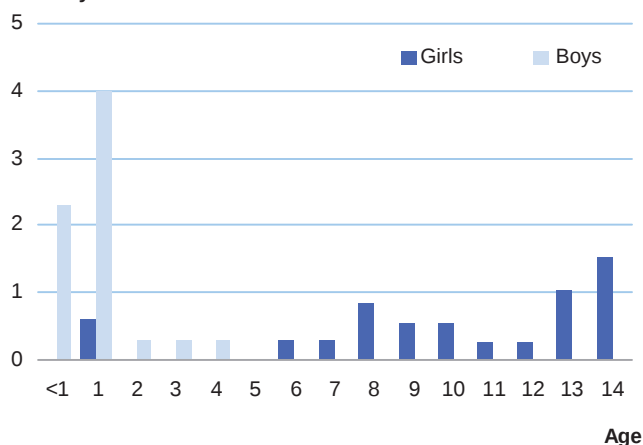
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	8	19	7	14
Incidence rate:	1.2	0.7	0.2	0.4
Median age at diagnosis:		1 year 12 months		

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
4 Gonadal yolk sac tumour

SN after X (c) 4			X (c) 4 as SN after any primary		
	% of all 1253 SN	Cumulative incidence		% of all 1253 SN	Cumulative incidence
N			N		
5	0.4 %	-	0	0.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



6 Malignant gonadal tumours of mixed forms

Cases in Germany aged under 15 years (1980-2015): 115

Selected characteristics Germany 2006-2015

Relative frequency:		71 / 17580 = 0.4 %		
Relative frequency of trial patients:		100.0 %		
Incidence rates per million:		Girls	Boys	Total
Number of cases:		44	27	71
Standardized rate *:		0.7	0.5	0.6
Cumulative incidence:		12	7	9
Sex ratio (m/f):		0.6		

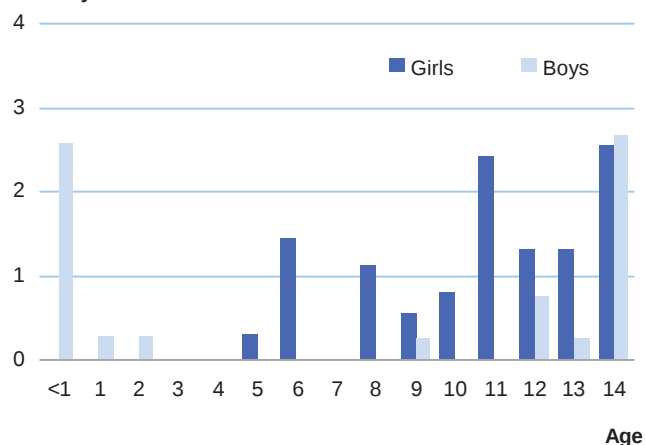
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	9	2	13	47
Incidence rate:	1.3	0.1	0.4	1.2
Median age at diagnosis:	11 years 11 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
6 Malignant gonadal tumours of mixed forms

SN after X (c) 6			X (c) 6 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	1.0 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



- (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 (1980-2015): 844

Selected characteristics Germany 2006-2015

Relative frequency:	387 / 17580 = 2.2 %
Relative frequency of trial patients:	-

Incidence rates per million:	Girls	Boys	Total
Number of cases:	216	171	387
Standardized rate *:	3.6	2.7	3.1
Cumulative incidence:	58	44	51
Sex ratio (m/f):	0.8		

Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases :	6	29	85	267
Incidence rate:	0.9	1.1	2.3	6.8
Median age at diagnosis:	12 years 2 months			

Survival probabilities:			
	5-year	10-year	15-year
	89 %	87 %	85 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
51	1.2 %	0.4	6

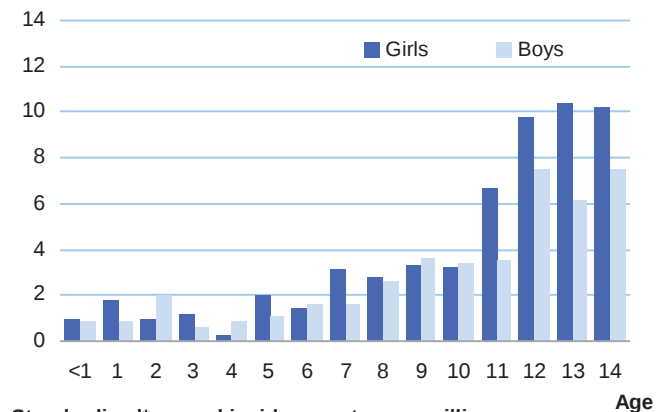
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

XI Other malignant epithelial neoplasms and malignant melanomas

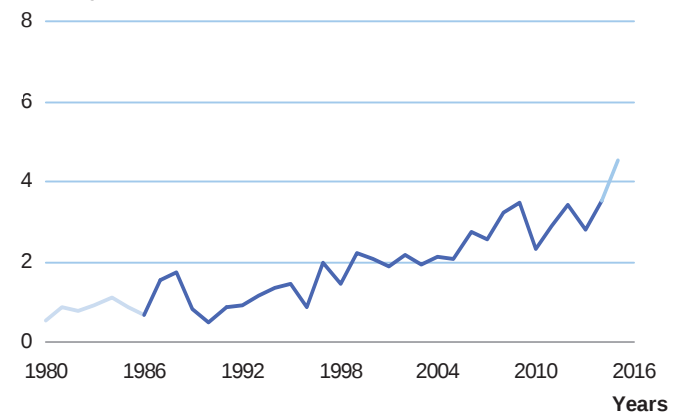
SN after XI			XI as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
12	1.0 %	12.0 %	418	33.4 %	3.2 %

* Standard: Segi world standard population

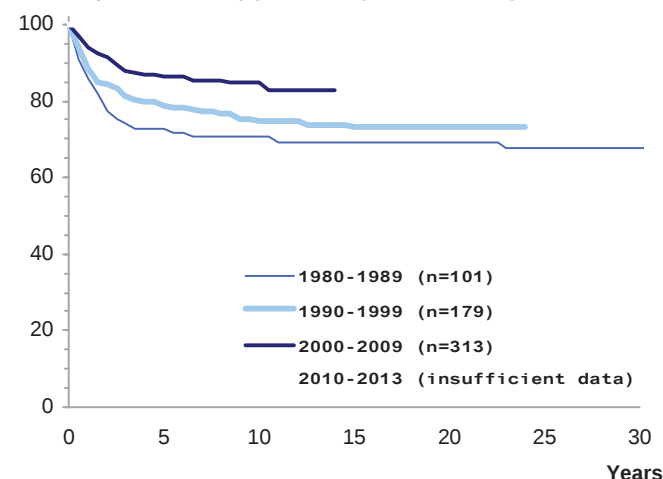
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

68 XI (a) Adrenocortical carcinomas

Cases in Germany aged under 15 years (1980-2015): 72

Selected characteristics Germany 2006-2015

Relative frequency: 24 / 17580 = 0.1 %

Relative frequency of trial patients: 100.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	16	8	24
Standardized rate *:	0.3	0.2	0.2
Cumulative incidence:	5	2	3
Sex ratio (m/f):	0.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	2	10	7	5
Incidence rate:	0.3	0.4	0.2	0.1

Median age at diagnosis: 4 years 4 months

Survival probabilities:	5-year	10-year	15-year
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

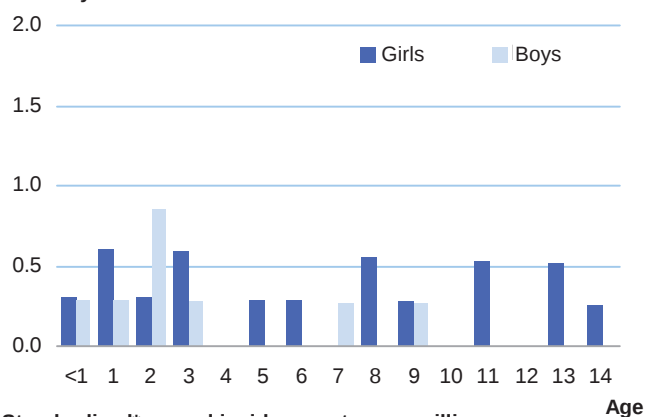
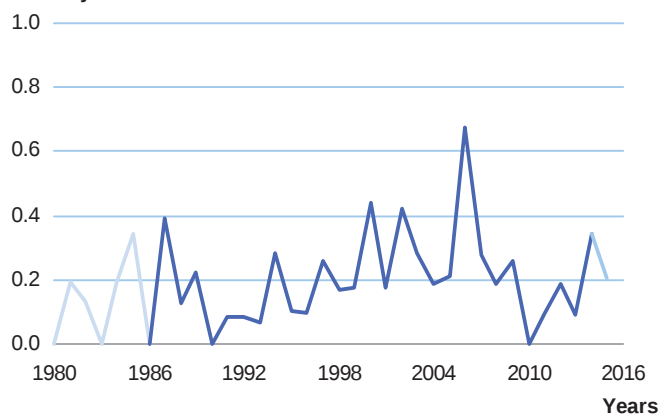
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
8	0.2 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

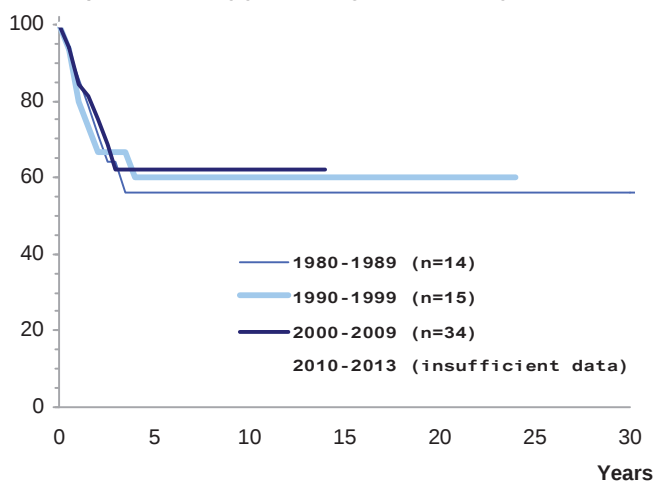
XI (a) Adrenocortical carcinomas

SN after XI (a)			XI (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
4	0.3 %	6.3 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015Standardized* annual incidence rates per million
Germany 1980-2015

Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Cases in Germany aged under 15 years (1980-2015): 344

Selected characteristics Germany 2006-2015

Relative frequency:	145 / 17580 = 0.8 %
Relative frequency of trial patients:	86.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	90	55	145
Standardized rate *:	1.4	0.8	1.1
Cumulative incidence:	24	14	19
Sex ratio (m/f):			0.6

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	2	2	31	110
Incidence rate:	0.3	0.1	0.9	2.8
Median age at diagnosis:	12 years 8 months			

Survival probabilities:	5-year	10-year	15-year
	98 %	98 %	94 %

Mortality per million within 15 yrs. of diagnosis (1991-2000):			
Number of deaths		Standardized*	Cumulative
N % of all 4335 deaths		mortality rate	mortality
8 0.2 %		0.1	1

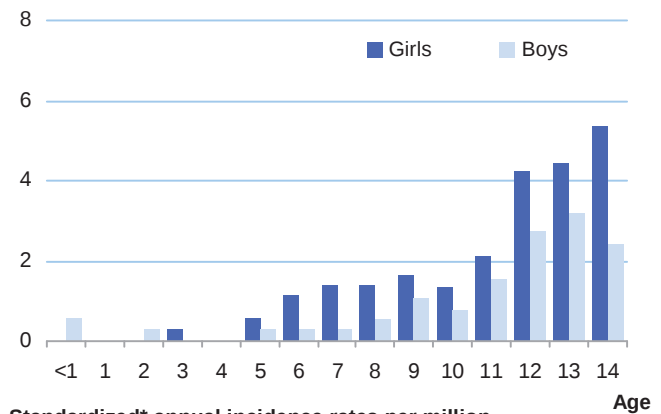
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

XI (b) Thyroid carcinomas

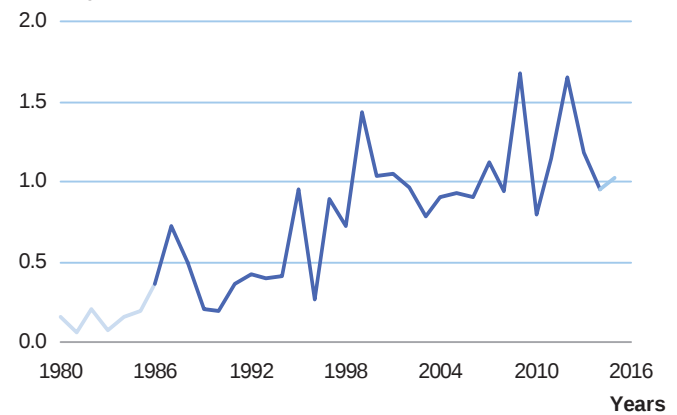
SN after XI (b)			XI (b) as SN after any primary		
	% of all	Cumulative		% of all	Cumulative
N	1253 SN	incidence	N	1253 SN	incidence
2	0.2 %	2.3 %	143	11.4 %	0.9 %

* Standard: Segi world standard population

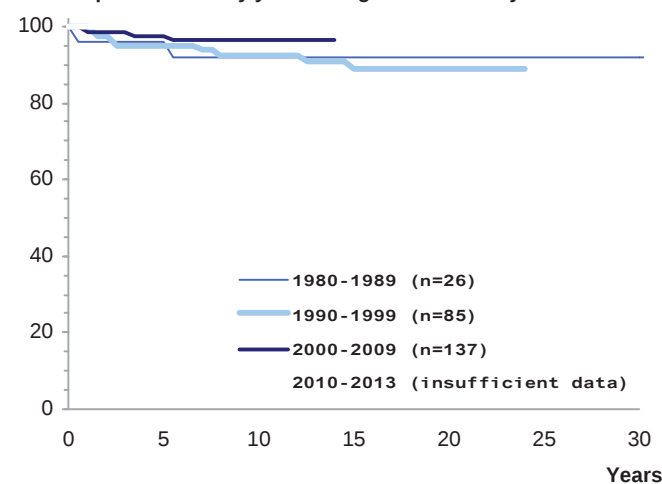
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

70 XI (c) Nasopharyngeal carcinomas

Cases in Germany aged under 15 years (1980-2015): 72

Selected characteristics Germany 2006-2015

Relative frequency:	19 / 17580 = 0.1 %
Relative frequency of trial patients:	100.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	5	14	19
Standardized rate *:	0.1	0.2	0.1
Cumulative incidence:	1	4	2
Sex ratio (m/f):	2.8		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	1	0	18
Incidence rate:	0.0	0.0	0.0	0.5

Median age at diagnosis: 13 years 0 months

Survival probabilities:	5-year	10-year	15-year
	91 %	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
6	0.1 %	0.0	1

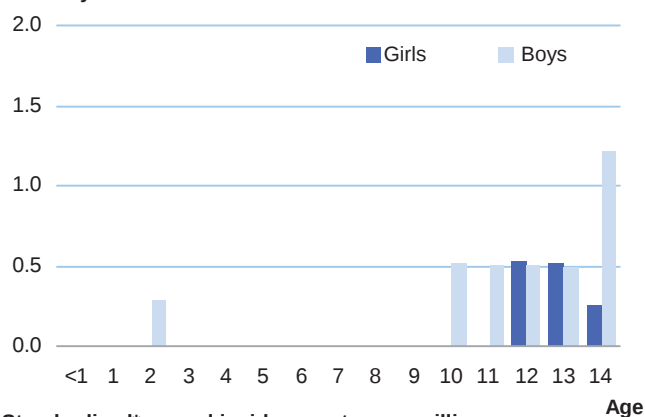
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

XI (c) Nasopharyngeal carcinomas

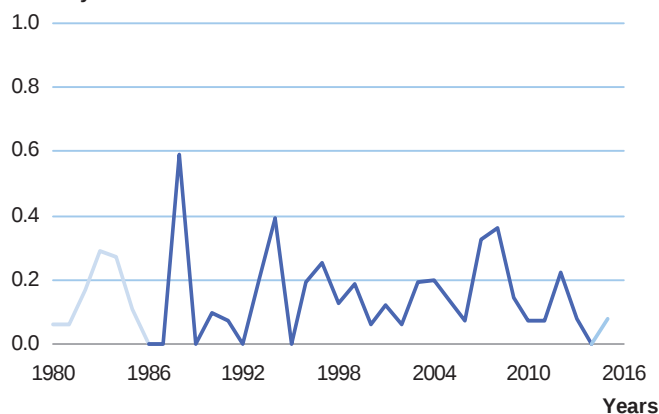
SN after XI (c)			XI (c) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
0	0.0 %	0.0 %	3	0.2 %	0.0 %

* Standard: Segi world standard population

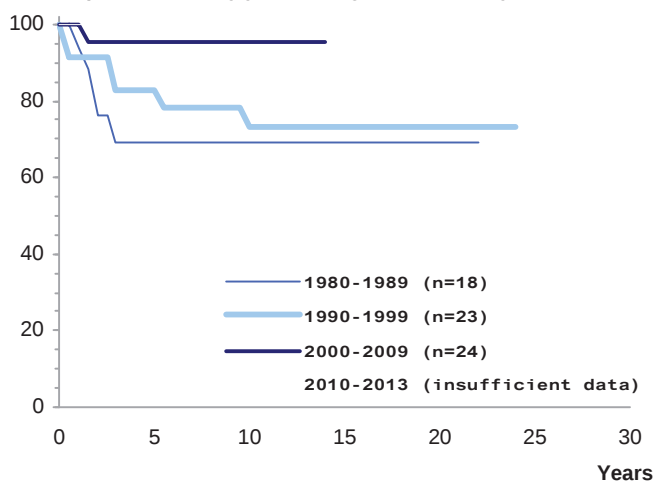
Age- and sex-specific incidence rates per million
Germany 2006-2015



Standardized* annual incidence rates per million
Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

Cases in Germany aged under 15 years (1980-2015): 114

Selected characteristics Germany 2006-2015

Relative frequency:	69 / 17580 = 0.4 %
Relative frequency of trial patients:	-

Incidence rates per million:	Girls	Boys	Total
Number of cases:	32	37	69
Standardized rate *:	0.6	0.6	0.6
Cumulative incidence:	9	10	9
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	2	13	21	33
Incidence rate:	0.3	0.5	0.6	0.8
Median age at diagnosis:				9 years 7 months

Survival probabilities:	5-year	10-year	15-year
	85 %	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):			
Number of deaths		Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate	mortality
11	0.3 %	0.1	1

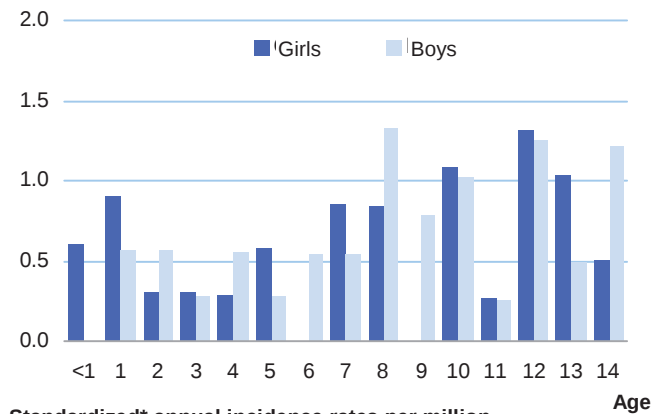
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

XI (d) Malignant melanomas

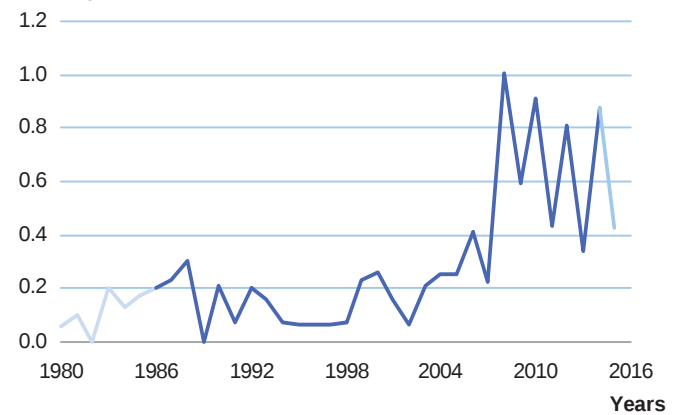
SN after XI (d)			XI (d) as SN after any primary		
	% of all	Cumulative		% of all	Cumulative
N	1253 SN	incidence	N	1253 SN	incidence
1	0.1 %	14.1 %	30	2.4 %	0.2 %

* Standard: Segi world standard population

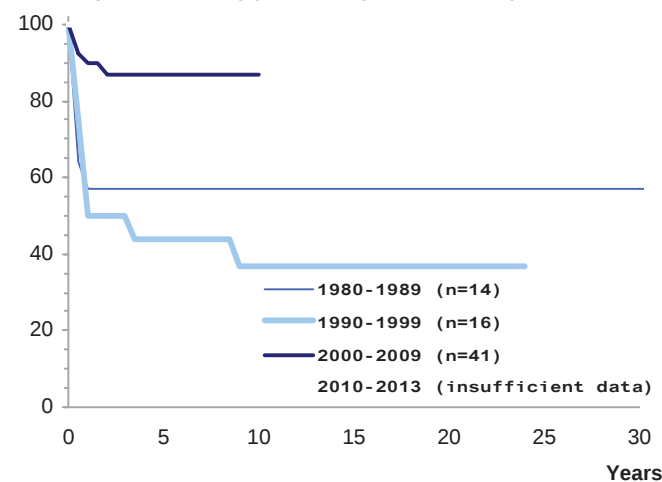
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

72 XI (e) Skin carcinomas

Cases in Germany aged under 15 years (1980-2015): 18

Selected characteristics Germany 2006-2015

Relative frequency: 8 / 17580 = 0 %

Relative frequency of trial patients: -

Incidence rates per million:	Girls	Boys	Total
Number of cases:	7	1	8
Standardized rate *:	0.1	0.0	0.1
Cumulative incidence:	2	0	1
Sex ratio (m/f):	0.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	0	3	5
Incidence rate:	0.0	0.0	0.1	0.1

Median age at diagnosis: 11 years 7 months

Survival probabilities:	5-year	10-year	15-year
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

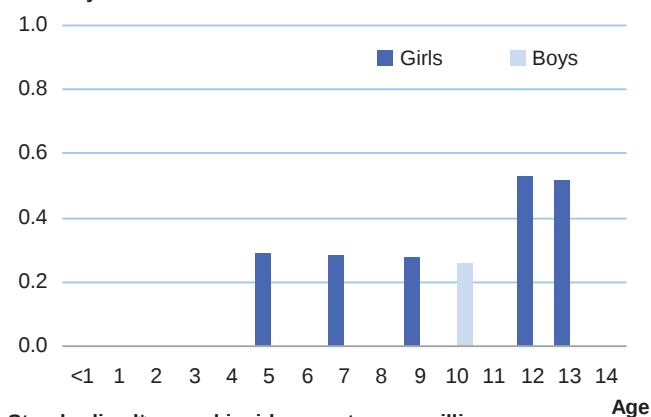
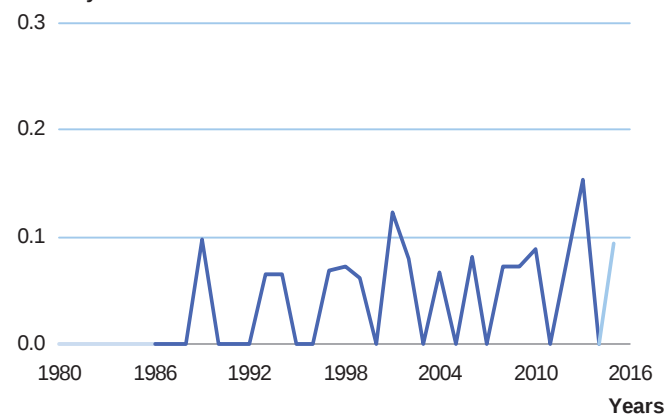
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
1	0.0 %	0.0	0

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

XI (e) Skin carcinomas

SN after XI (e)			XI (e) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
0	0.0 %	0.0 %	105	8.4 %	1.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015Standardized* annual incidence rates per million
Germany 1980-2015

No map due to sparse data

No survival curves due to sparse data

Cases in Germany aged under 15 years (1980-2015): 224

Selected characteristics Germany 2006-2015

Relative frequency:	122 / 17580 = 0.7 %
Relative frequency of trial patients:	-

Incidence rates per million:	Girls	Boys	Total
Number of cases:	66	56	122
Standardized rate *:	1.0	0.9	1.0
Cumulative incidence:	18	14	16
Sex ratio (m/f):	0.8		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	3	23	96
Incidence rate:	0.0	0.1	0.6	2.5
Median age at diagnosis:	12 years 5 months			

Survival probabilities:	5-year	10-year	15-year
	77 %	72 %	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

Number of deaths	Standardized*	Cumulative
N	% of all 4335 deaths	mortality rate
17	0.4 %	0.1
		2

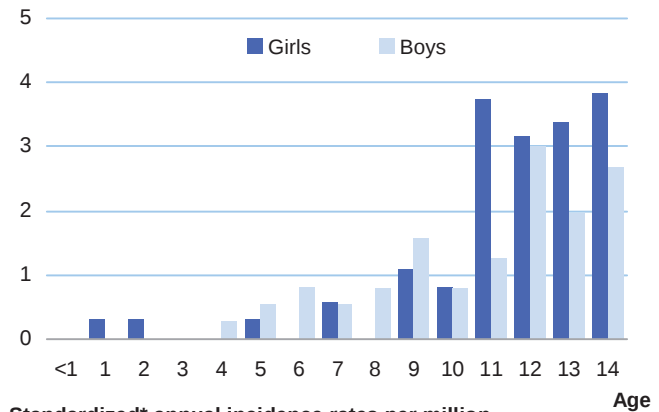
Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

XI (f) Other and unspecified carcinomas

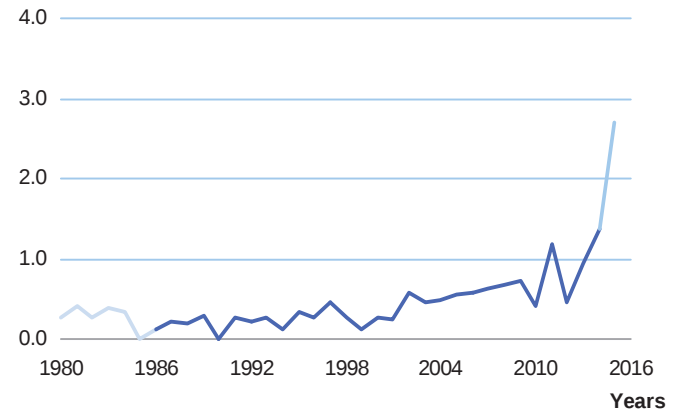
SN after XI (f)	XI (f) as SN after any primary
% of all 1253 SN	% of all 1253 SN
Cumulative incidence	Cumulative incidence
N	N
5	137
0.4 %	10.9 %
29.6 %	1.1 %

* Standard: Segi world standard population

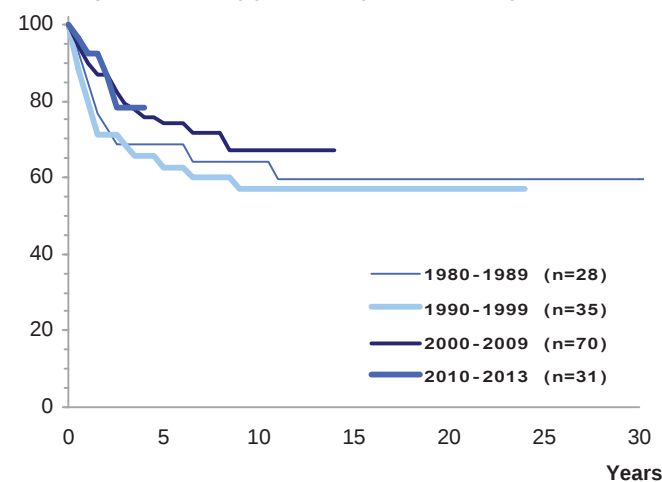
Age- and sex-specific incidence rates per million Germany 2006-2015



Standardized* annual incidence rates per million Germany 1980-2015



Survival probabilities by year of diagnosis Germany 1980-2013



No map due to sparse data

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

Germany 2006-2015	N	%		N	%
Other and unspecified carcinomas	122	100.0			
1 Carcinomas of salivary glands	25	20.5	7 Carcinomas of cervix uteri	1	0.8
2 Carcinomas of colon and rectum	11	9.0	8 Carcinomas of bladder	0	0.0
3 Carcinomas of appendix	47	38.5	9 Carcinomas of eye	2	1.6
4 Carcinomas of lung	7	5.7	10 Carcinomas of other specified sites	26	21.3
5 Carcinomas of thymus	0	0.0	11 Carcinomas of unspecified sites	3	2.5
6 Carcinomas of breast	0	0.0			

1 Carcinomas of salivary glands

Cases in Germany aged under 15 years (1980-2015): 38

Selected characteristics Germany 2006-2015

Relative frequency:	25 / 17580 = 0.1 %		
Relative frequency of trial patients:	24.0 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	14	11	25
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	4	3	3
Sex ratio (m/f):	0.8		

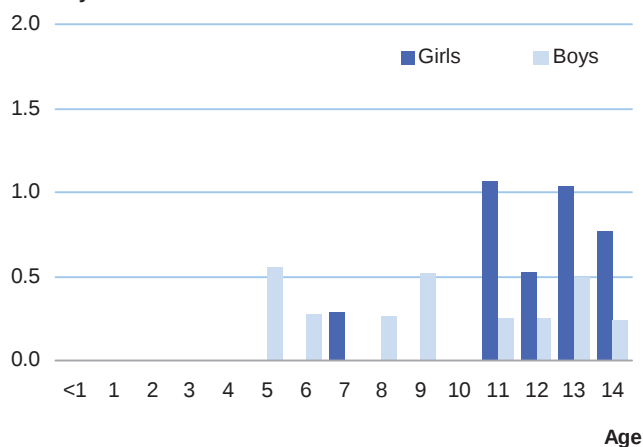
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	0	7	18
Incidence rate:	0.0	0.0	0.2	0.5
Median age at diagnosis:	12 years 7 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
1 Carcinomas of salivary glands

SN after XI (f) 1			XI (f) 1 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	6.7 %	12	1.0 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



2 Carcinomas of colon and rectum

Cases in Germany aged under 15 years (1980-2015): 32

Selected characteristics Germany 2006-2015

Relative frequency:	11 / 17580 = 0.1 %		
Relative frequency of trial patients:	36.4 %		
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		

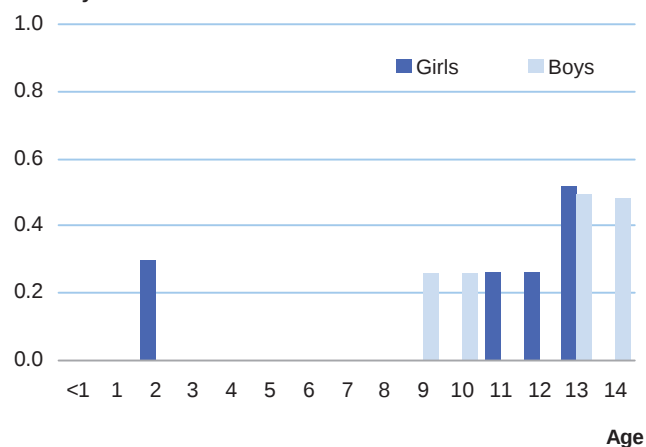
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	1	1	9
Incidence rate:	0.0	0.0	0.0	0.2
Median age at diagnosis:	13 years 2 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
2 Carcinomas of colon and rectum

SN after XI (f) 2			XI (f) 2 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
1	0.1 %	6.9 %	20	1.6 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



Germany 2006-2015	N	%	N	%
Other and unspecified carcinomas	122	100.0		
1 Carcinomas of salivary glands	25	20.5	7 Carcinomas of cervix uteri	1 0.8
2 Carcinomas of colon and rectum	11	9.0	8 Carcinomas of bladder	0 0.0
3 Carcinomas of appendix	47	38.5	9 Carcinomas of eye	2 1.6
4 Carcinomas of lung	7	5.7	10 Carcinomas of other specified sites	26 21.3
5 Carcinomas of thymus	0	0.0	11 Carcinomas of unspecified sites	3 2.5
6 Carcinomas of breast	0	0.0		

3 Carcinomas of appendix

Cases in Germany aged under 15 years (1980-2015): 48

Selected characteristics Germany 2006-2015

Relative frequency:	47 / 17580 = 0.3 %		
Relative frequency of trial patients:	97.9 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	27	20	47
Standardized rate *:	0.4	0.3	0.4
Cumulative incidence:	7	5	6
Sex ratio (m/f):	0.7		

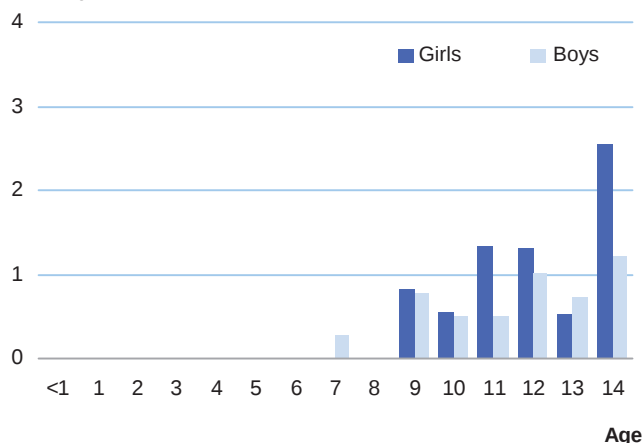
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	0	7	40
Incidence rate:	0.0	0.0	0.2	1.0
Median age at diagnosis:	12 years 11 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
3 Carcinomas of appendix

SN after XI (f) 3			XI (f) 3 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
0	0.0 %	0.0 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015



6 Carcinomas of breast

Cases in Germany aged under 15 years (1980-2015): 0

Selected characteristics Germany 2006-2015

Relative frequency:	0 / 17580 = 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):	0.0		

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:	0 years 0 months			

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):
6 Carcinomas of breast

SN after XI (f) 6			XI (f) 6 as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
0	0.0 %	0.0 %	63	5.0 %	0.6 %

* Standard: Segi world standard population

No incidence rates due to sparse data

76 XII (a) Other specified malignant tumours

Cases in Germany aged under 15 years (1980-2015): 51

Selected characteristics Germany 2006-2015

Relative frequency: 23 / 17580 = 0.1 %

Relative frequency of trial patients: 87.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	12	11	23
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	17	3	3
Incidence rate:	0.0	0.6	0.1	0.1

Median age at diagnosis: 3 years 2 months

Survival probabilities:	5-year	10-year	15-year
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1991-2000):

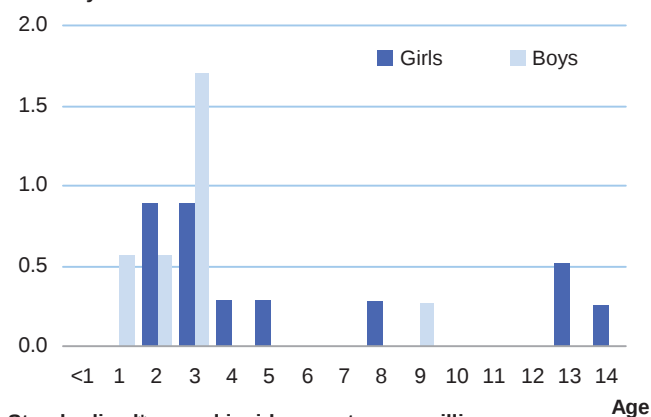
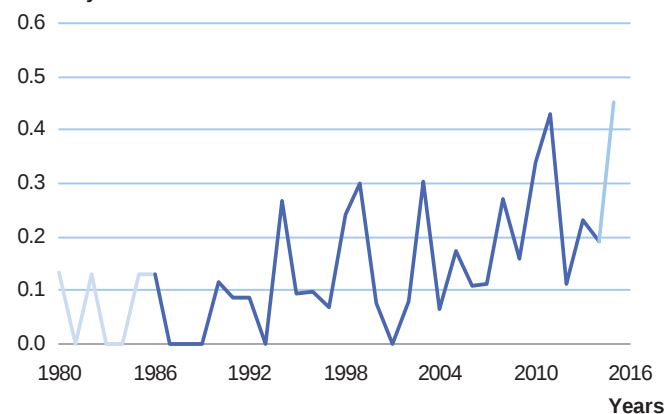
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4335 deaths		
7	0.2 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1980-2013):

XII (a) Other specified malignant tumours

SN after XII (a)			XII (a) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
2	0.2 %	6.8 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2006-2015Standardized* annual incidence rates per million
Germany 1980-2015

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 ICC-3-Diagnosegruppen /
Number of cases aged under 15, age-standardized incidence rate and cumulative incidence (per million) by ICC-3 diagnosis groups*

Abbildung 2 / Figure 2 93

*Relative Häufigkeit der Fälle nach den häufigsten ICC-3-Diagnose-Hauptgruppen und Alter /
Relative frequencies of cases by the main ICC-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 erfasste Diagnosen /
Distribution of all cases without age restriction and additional diagnoses*

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 ICC-3, Alter und Geschlecht (2006-2015). *ICC-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 ICC-3, age and sex (2006-2015).
ICC-3 extended subclassification in italics.

Diagnoses		Sex		Number of cases				Incidence rates per million							Trial participants		Survival probabilities(%)	
		Sex ratio	N	Relative	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World *	Age-stand.	Cum.	%

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex	Sex ratio	N	Relative	Number of cases		Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
Sex		m / f	0 - 14	%	%	Group	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World *	0 - 14	%	5-yrs	10-yrs 15-yrs		
Unspecified and other specified leukaemias	girls		35	0	1	7	7	10	11		2	1	1	1	1	10	100.0	72	72	-	
	boys		32	0	1	8	6	8	10		2	0	0	0	1	9	96.9	70	70	-	
	total	0.9	67	0	1	15	13	18	21	2	2	0	0	1	1	9	98.5	71	71	-	
Lymphomas and reticuloendothelial neoplasms	girls		600	8	100	2	60	133	405	1	4	8	21	10	163	96.8	93	92	91		
	boys		1285	13	100	6	168	469	642	2	12	25	32	21	336	96.2	95	94	92		
	total	2.1	1885	11	100	8	228	602	1047	1	8	17	27	16	251	96.4	94	93	92		
Hodgkin lymphomas	girls		312	4	52	0	6	34	272	0	0	2	14	5	83	99.7	98	97	97		
	boys		468	5	36	0	29	140	299	0	2	8	15	7	121	96.4	99	99	98		
	total	1.5	780	4	41	0	35	174	571	0	1	5	15	6	102	97.7	99	98	97		
Non-Hodgkin lymphomas	girls		230	3	38	0	44	75	111	0	3	4	6	4	64	93.9	85	85	83		
	boys		544	6	42	6	77	201	260	2	5	11	13	9	142	95.4	91	90	88		
	total	2.4	774	4	41	6	121	276	371	1	4	8	10	7	104	95.0	89	88	86		
Precursor cell lymphomas	girls		83	1	14	0	21	31	31	0	2	2	2	2	23	90.4	85	84	81		
	boys		191	2	15	4	38	75	74	1	3	4	4	3	51	94.8	89	88	87		
	total	2.3	274	2	15	4	59	106	105	1	2	3	3	2	37	93.4	88	87	85		
Mature B-cell lymphomas (except Burkitt lymphoma)	girls		48	1	8	0	5	21	22	0	0	1	1	1	13	97.9	86	85	83		
	boys		88	1	7	0	5	24	59	0	0	1	3	1	23	95.5	96	94	94		
	total	1.8	136	1	7	0	10	45	81	0	0	1	2	1	18	96.3	93	91	90		
Mature T-cell and NK-cell lymphomas	girls		49	1	8	0	10	11	28	0	1	1	1	1	13	95.9	85	85	85		
	boys		95	1	7	1	12	31	51	0	1	2	3	2	25	98.9	89	88	84		
	total	1.9	144	1	8	1	22	42	79	0	1	1	2	1	19	97.9	87	87	84		
Non-Hodgkin lymphomas, NOS	girls		50	1	8	0	8	12	30	0	1	1	2	1	14	94.0	87	87	87		
	boys		170	2	13	1	22	71	76	0	2	4	4	3	45	94.1	93	90	88		
	total	3.4	220	1	12	1	30	83	106	0	1	2	3	2	30	94.1	91	89	88		
Burkitt lymphoma	girls		50	1	8	0	8	23	19	0	1	1	1	1	14	98.0	93	92	92		
	boys		266	3	21	0	62	125	79	0	4	7	4	5	71	98.1	93	92	92		
	total	5.3	316	2	17	0	70	148	98	0	3	4	3	3	43	98.1	93	92	92		
Miscellaneous lymphoreticular neoplasms	girls		4	0	1	2	0	1	1	1	1	0	0	0	1	75.0	-	-	-		
	boys		2	0	0	0	0	1	1	0	0	0	0	0	1	0.0	-	-	-		
	total	0.5	6	0	0	2	0	2	2	2	0	0	0	0	1	50.0	-	-	-		
Unspecified lymphomas	girls		4	0	1	0	2	0	2	0	0	0	0	0	1	50.0	-	-	-		
	boys		5	0	0	0	0	2	3	0	0	0	0	0	1	100.0	-	-	-		
	total	1.3	9	0	1	0	2	2	5	0	0	0	0	0	1	77.8	-	-	-		

Table 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex m / f	N 0-14	Relative		Number of cases		Age groups				Incidence rates per million						Trial participants		Survival probabilities(%)	
					%	%	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World *	0-14	Cum.	%	5-yrs	10-yrs
CNS and miscellaneous intracranial and intraspinal neoplasms		girls		1948	25	100	147	576	621	604	44	43	35	32	37	551	94.3	80	77	-		
		boys		2369	24	100	155	677	799	738	44	48	43	37	43	635	94.8	77	72	-		
		total	1.2	4317	25	100	302	1253	1420	1342	44	45	39	34	40	594	94.6	78	74	-		
Ependymomas and choroid plexus tumour		girls		185	2	10	43	74	36	32	13	6	2	2	4	54	96.2	87	84	80		
		boys		245	3	10	38	98	49	60	11	7	3	3	5	67	95.5	79	70	64		
		total	1.3	430	2	10	81	172	85	92	12	6	2	2	4	60	95.8	82	75	71		
Ependymomas		girls		133	2	7	17	63	27	26	5	5	2	1	3	38	97.0	85	81	78		
		boys		197	2	8	19	81	41	56	5	6	2	3	4	53	96.4	77	68	61		
		total	1.5	330	2	8	36	144	68	82	5	5	2	2	3	46	96.7	80	73	68		
Choroid plexus tumour		girls		52	1	3	26	11	9	6	8	1	1	0	1	15	94.2	91	91	87		
		boys		48	1	2	19	17	8	4	5	1	0	0	1	13	91.7	88	80	80		
		total	0.9	100	1	2	45	28	17	10	7	1	0	0	1	14	93.0	90	85	83		
Astrocytomas		girls		960	12	49	53	277	311	319	16	21	18	17	18	271	95.5	83	81	-		
		boys		1026	11	43	50	281	373	322	14	20	20	16	18	274	95.1	80	78	-		
		total	1.1	1986	11	46	103	558	684	641	15	20	19	16	18	273	95.3	82	79	-		
Intracranial and intraspinal embryonal tumours		girls		288	4	15	33	115	96	44	10	9	5	2	6	83	95.8	67	62	-		
		boys		466	5	20	44	175	176	71	13	12	9	4	9	127	97.0	68	58	-		
		total	1.6	754	4	18	77	290	272	115	11	11	8	3	7	106	96.6	67	60	-		
Medulloblastomas		girls		194	3	10	8	67	81	38	2	5	5	2	4	55	99.0	77	71	-		
		boys		341	4	14	9	112	154	66	3	8	8	3	6	92	99.1	75	64	-		
		total	1.8	535	3	12	17	179	235	104	2	6	6	3	5	74	99.1	76	67	-		
Primitive neuroectodermal tumour (PNET)		girls		31	0	2	2	21	4	4	1	2	0	0	1	9	96.8	68	62	-		
		boys		40	0	2	4	21	10	5	1	1	1	0	1	11	100.0	57	52	-		
		total	1.3	71	0	2	6	42	14	9	1	2	0	0	1	10	98.6	61	56	-		
Medulloblastoma		girls		3	0	0	0	1	1	1	0	0	0	0	0	1	66.7	-	-	-		
		boys		5	0	0	3	0	2	0	1	0	0	0	0	1	100.0	-	-	-		
		total	1.7	8	0	0	3	1	3	1	0	0	0	0	0	1	87.5	-	-	-		
Atypical teratoid/rhabdoid tumour		girls		60	1	3	23	26	10	1	7	2	1	0	1	18	86.7	28	-	-		
		boys		80	1	3	28	42	10	0	8	3	1	0	2	23	86.3	39	-	-		
		total	1.3	140	1	3	51	68	20	1	7	2	1	0	2	20	86.4	35	-	-		
Other gliomas		girls		213	3	11	5	52	86	70	2	4	5	4	4	60	90.1	49	-	-		
		boys		232	2	10	7	49	86	90	2	3	5	4	4	61	94.4	50	-	-		
		total	1.1	445	3	10	12	101	172	160	2	4	5	4	4	61	92.4	50	-	-		

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex N	Number of cases			Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
				Relative	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	Age-specific	Age-stand.	Cum.	%	5-yrs	10-yrs
		m / f	0-14	%		%														
Oligodendrogliomas	girls		3	0	0	0	0	0	1	2	0	0	0	0	0	0	1	66.7	-	-
	boys		7	0	0	0	0	1	0	6	0	0	0	0	0	0	2	85.7	-	-
	total	2.3	10	0	0	0	0	1	1	8	0	0	0	0	0	0	1	80.0	-	-
Mixed and unspecified gliomas	girls		200	3	10	4	49	82	65	1	4	5	3	4	4	56	90.0	45	-	-
	boys		217	2	9	7	46	86	78	2	3	5	4	4	58	94.5	48	-	-	
	total	1.1	417	2	10	11	95	168	143	2	3	5	4	4	57	92.3	47	-	-	
Neuroepithelial glial tumours of uncertain origin	girls		10	0	1	1	3	3	3	0	0	0	0	0	3	100.0	-	-	-	
	boys		8	0	0	0	2	0	6	0	0	0	0	0	2	100.0	-	-	-	
	total	0.8	18	0	0	1	5	3	9	0	0	0	0	0	2	100.0	-	-	-	
Other specified intracranial and intraspinal neoplasms	girls		269	3	14	10	49	89	121	3	4	5	6	5	75	92.9	97	95	-	-
	boys		362	4	15	12	71	103	176	3	5	6	9	6	95	92.0	95	94	-	-
	total	1.3	631	4	15	22	120	192	297	3	4	5	8	6	85	92.4	96	94	-	-
Pituitary adenomas and carcinomas	girls		15	0	1	0	1	2	12	0	0	0	1	0	4	66.7	100	100	-	-
	boys		19	0	1	0	0	2	17	0	0	0	1	0	5	63.2	100	100	-	-
	total	1.3	34	0	1	0	1	4	29	0	0	0	1	0	4	64.7	100	100	-	-
Tumours of the sellar region (craniopharyngiomas)	girls		99	1	5	0	21	39	39	0	2	2	2	2	28	100.0	100	98	-	-
	boys		92	1	4	2	22	34	34	1	2	2	2	2	24	98.9	98	97	-	-
	total	0.9	191	1	4	2	43	73	73	0	2	2	2	2	26	99.5	99	97	-	-
Pineal parenchymal tumours	girls		17	0	1	2	3	6	6	1	0	0	0	0	5	100.0	75	-	-	-
	boys		13	0	1	1	7	2	3	0	0	0	0	0	4	100.0	63	-	-	-
	total	0.8	30	0	1	3	10	8	9	0	0	0	0	0	4	100.0	69	-	-	-
Neuronal and mixed neuronal-glial tumours	girls		120	2	6	8	23	34	55	2	2	2	3	2	33	90.8	98	97	-	-
	boys		212	2	9	9	39	58	106	3	3	3	5	4	56	95.3	97	97	-	-
	total	1.8	332	2	8	17	62	92	161	2	2	3	4	3	45	93.7	97	97	-	-
Meningiomas	girls		18	0	1	0	1	8	9	0	0	0	0	0	5	83.3	93	89	-	-
	boys		26	0	1	0	3	7	16	0	0	0	1	0	7	57.7	88	88	-	-
	total	1.4	44	0	1	0	4	15	25	0	0	0	1	0	6	68.2	90	89	-	-
Unspecified intracranial and intraspinal neoplasms	girls		33	0	2	3	9	3	18	1	1	0	1	1	9	72.7	85	85	-	-
	boys		38	0	2	4	3	12	19	1	0	1	1	1	10	84.2	74	74	-	-
	total	1.2	71	0	2	7	12	15	37	1	0	0	1	1	10	78.9	79	79	-	-
Neuroblastoma and other peripheral nervous cell tumours	girls		529	7	100	245	235	34	15	74	17	2	1	12	157	98.3	81	79	78	-
	boys		686	7	100	317	303	50	16	91	21	3	1	15	194	99.4	80	77	76	-
	total	1.3	1215	7	100	562	538	84	31	82	20	2	1	14	176	98.9	80	78	77	-

Table 1 Forts. Table 1 cont.

Diagnoses		Sex	Sex ratio	N	Relative		Number of cases		Age groups				Incidence rates per million				Trial participants		Survival probabilities(%)	
					%	%	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World *	0-14	Cum.	%
Neuroblastoma and ganglioneuroblastoma	girls		523	7	99	245	231	34	13	74	17	2	1	12	156	99.0	81	79	78	
	boys		682	7	99	317	302	50	13	91	21	3	1	15	193	99.6	80	77	77	
	total	1.3	1205	7	99	562	533	84	26	82	19	2	1	14	175	99.3	80	78	77	
Other peripheral nervous cell tumours	girls		6	0	1	0	4	0	2	0	0	0	0	0	2	33.3	-	-	-	
	boys		4	0	1	0	1	0	3	0	0	0	0	0	1	75.0	-	-	-	
	total	0.7	10	0	1	0	5	0	5	0	0	0	0	0	1	50.0	-	-	-	
Retinoblastoma	girls		179	2	100	83	92	4	0	25	7	0	0	4	54	27.9	-	-	-	
	boys		203	2	100	87	107	5	4	25	8	0	0	4	57	22.2	-	-	-	
	total	1.1	382	2	100	170	199	9	4	25	7	0	0	4	56	24.9	-	-	-	
Renal tumours	girls		518	7	100	71	297	122	28	21	22	7	1	11	152	99.4	94	93	93	
	boys		456	5	100	87	250	92	27	25	18	5	1	9	127	98.2	93	92	92	
	total	0.9	974	6	100	158	547	214	55	23	20	6	1	10	139	98.9	94	93	93	
Nephroblastoma and other non-epithelial renal tumours	girls		509	7	98	71	297	120	21	21	22	7	1	11	149	99.8	94	93	93	
	boys		441	5	97	86	250	90	15	25	18	5	1	9	123	98.6	93	93	92	
	total	0.9	950	5	98	157	547	210	36	23	20	6	1	10	136	99.3	94	93	93	
Nephroblastoma	girls		496	6	96	64	294	117	21	19	22	7	1	11	146	99.8	95	94	94	
	boys		430	4	94	83	245	89	13	24	17	5	1	9	120	98.8	94	93	93	
	total	0.9	926	5	95	147	539	206	34	22	20	6	1	10	133	99.4	94	94	94	
Rhabdoid renal tumour	girls		9	0	2	6	3	0	0	2	0	0	0	0	3	100.0	-	-	-	
	boys		9	0	2	2	5	1	1	1	0	0	0	0	3	88.9	-	-	-	
	total	1.0	18	0	2	8	8	1	1	1	0	0	0	0	3	94.4	-	-	-	
Kidney sarcomas	girls		4	0	1	1	0	3	0	0	0	0	0	0	1	100.0	-	-	-	
	boys		2	0	0	1	0	0	1	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	-	-	-	-	
	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	-	-	-	-	
Renal carcinomas	girls		9	0	2	0	0	2	7	0	0	0	0	0	2	77.8	-	-	-	
	boys		15	0	3	1	0	2	12	0	0	0	1	0	4	86.7	85	-	-	
	total	1.7	24	0	3	1	0	4	19	0	0	0	0	0	3	83.3	93	-	-	
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	0	-	-	-	-	

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex m / f	N 0-14	Relative		Number of cases		Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
					%	%	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World *	0-14	%	5-yrs	10-yrs	15-yrs
Hepatic tumours		girls		108	1	100	35	54	7	12	11	4	0	1	2		32	75.9	72	72		
		boys		144	2	100	39	75	12	18	11	5	1	1	3		40	78.5	75	72		
		total	1.3	252	1	100	74	129	19	30	11	5	1	1	1	3	36	77.4	74	72		
Hepatoblastoma		girls		95	1	88	35	54	5	1	11	4	0	0	2	28	76.8	76	76			
		boys		129	1	90	39	74	8	8	11	5	0	0	3	36	78.3	82	80			
		total	1.4	224	1	89	74	128	13	9	11	5	0	0	2	32	77.7	80	78			
Hepatic carcinomas		girls		13	0	12	0	0	2	11	0	0	1	0	3	69.2	-	-	-			
		boys		15	0	10	0	1	4	10	0	0	0	0	4	80.0	-	-	-			
		total	1.2	28	0	11	0	1	6	21	0	0	0	1	0	4	75.0	-	-	-		
Unspecified malignant hepatic 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	0	-	-	-			
Malignant bone tumours		girls		368	5	100	1	18	97	252	0	1	5	13	6	99	96.7	-	-			
		boys		421	4	100	3	33	111	274	1	2	6	14	7	108	97.6	-	-			
		total	1.1	789	5	100	4	51	208	526	1	2	6	13	6	104	97.2	-	-			
Osteosarcomas		girls		190	2	52	0	2	43	145	0	0	2	8	3	51	98.9	79	75			
		boys		202	2	48	0	5	46	151	0	0	2	8	3	51	98.0	72	67			
		total	1.1	392	2	50	0	7	89	296	0	0	2	8	3	51	98.5	76	71			
Chondrosarcomas		girls		6	0	2	0	0	2	4	0	0	0	0	0	2	66.7	-	-			
		boys		8	0	2	1	0	1	6	0	0	0	0	0	2	87.5	-	-			
		total	1.3	14	0	2	1	0	3	10	0	0	0	0	0	2	78.6	-	-			
Ewing tumour and related sarcomas of bone		girls		161	2	44	1	15	48	97	0	1	3	5	3	44	96.9	-	-			
		boys		200	2	48	2	26	61	111	1	2	3	6	3	52	99.5	-	-			
		total	1.2	361	2	46	3	41	109	208	0	1	3	5	3	48	98.3	-	-			
Ewing tumour and askin tumour of bone		girls		151	2	41	0	14	43	94	0	1	2	5	3	41	97.4	-	-			
		boys		189	2	45	1	21	59	108	0	1	3	5	3	49	99.5	-	-			
		total	1.3	340	2	43	1	35	102	202	0	1	3	5	3	45	98.5	-	-			
Peripheral neuroectodermal tumour (pPNET) of bone		girls		10	0	3	1	1	5	3	0	0	0	0	0	3	90.0	-	-			
		boys		11	0	3	1	5	2	3	0	0	0	0	0	3	100.0	-	-			
		total	1.1	21	0	3	2	6	7	6	0	0	0	0	0	3	95.2	-	-			
Other specified malignant bone tumours		girls		8	0	2	0	1	3	4	0	0	0	0	0	2	87.5	-	-			
		boys		8	0	2	0	2	3	3	0	0	0	0	0	2	75.0	-	-			
		total	1.0	16	0	2	0	3	6	7	0	0	0	0	0	2	81.3	-	-			

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	N	Relative	Number of cases		Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
Sex		m / f	0 - 14	%	%	Group	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World *	0 - 14	%	5-yrs	10-yrs	15-yrs
Malignant fibrous neoplasms of bone	girls		1	0	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-	-
	boys		1	0	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-	-
	total	1.0	2	0	0	0	0	0	0	2	0	0	0	0	0	0	100.0	-	-	-
Malignant chordomas	girls		5	0	1	0	1	3	1	0	0	0	0	0	0	1	100.0	-	-	-
	boys		6	0	1	0	1	3	2	0	0	0	0	0	0	2	66.7	-	-	-
	total	1.2	11	0	1	0	2	6	3	0	0	0	0	0	0	2	81.8	-	-	-
Odontogenic malignant tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	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	-	-	-
Miscellaneous malignant bone tumours	girls		2	0	1	0	0	0	2	0	0	0	0	0	0	1	50.0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	total	0.0	2	0	0	0	0	0	0	2	0	0	0	0	0	0	50.0	-	-	-
Unspecified malignant bone tumours	girls		3	0	1	0	0	1	2	0	0	0	0	0	0	1	33.3	-	-	-
	boys		3	0	1	0	0	0	3	0	0	0	0	0	0	1	33.3	-	-	-
	total	1.0	6	0	1	0	0	0	1	5	0	0	0	0	0	1	33.3	-	-	-
Soft tissue and other extraosseous sarcomas	girls		461	6	100	51	128	118	164	15	10	7	9	9	9	130	98.3	75	72	70
	boys		540	6	100	75	144	147	174	21	10	8	9	10	10	145	98.0	73	71	70
	total	1.2	1001	6	100	126	272	265	338	18	10	7	9	9	9	138	98.1	74	71	70
Rhabdomyosarcomas	girls		228	3	50	19	81	64	64	6	6	4	3	4	3	65	99.6	72	70	68
	boys		287	3	53	29	116	91	51	8	8	5	3	6	3	78	99.7	75	74	74
	total	1.3	515	3	51	48	197	155	115	7	7	4	3	5	7	72	99.6	74	72	71
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	girls		48	1	10	10	12	8	18	3	1	0	1	1	1	14	91.7	67	67	67
	boys		58	1	11	19	3	13	23	5	0	1	1	1	1	16	98.3	76	76	73
	total	1.2	106	1	11	29	15	21	41	4	1	1	1	1	1	15	95.3	72	72	71
Fibroblastic and myofibroblastic tumours	girls		25	0	5	9	8	4	4	3	1	0	0	1	1	7	92.0	89	89	-
	boys		28	0	5	14	3	3	8	4	0	0	0	1	1	8	96.4	88	88	-
	total	1.1	53	0	5	23	11	7	12	3	0	0	0	1	1	7	94.3	88	88	-
Nerve sheath tumours	girls		23	0	5	1	4	4	14	0	0	0	1	0	0	6	91.3	45	45	45
	boys		30	0	6	5	0	10	15	1	0	1	1	1	1	8	100.0	62	62	56
	total	1.3	53	0	5	6	4	14	29	1	0	0	1	0	1	7	96.2	54	54	52
Other fibrous neoplasms	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	-	-	-	-

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex	N	Number of cases				Incidence rates per million										Trial participants		Survival probabilities(%)	
					Relative	Group	Age groups				Age-specific				Age-stand.	Cum.	%	5-yrs	10-yrs	15-yrs		
m / f	0-14	%	%	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	0	1-4	5-9	10-14					World *	0-14
Kaposi sarcoma	girls	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	100.0	-	-
	boys	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0.0	-	-
	total	1.0	2	0	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	50.0	-	-
Other specified soft tissue sarcomas	girls	147	2	32	16	24	37	70	5	2	2	4	3	41	98.0	82	76	74				
	boys	147	2	27	20	19	35	73	6	1	2	4	3	39	96.6	68	64	62				
	total	1.0	294	2	29	36	43	72	143	5	2	2	4	3	40	97.3	75	70	68			
Ewing tumour and askin tumour of soft tissue	girls	36	1	8	0	5	12	19	0	1	1	1	1	10	97.2	88	84	-				
	boys	32	0	6	1	2	10	19	0	1	1	1	1	8	100.0	70	70	-				
	total	0.9	68	0	7	1	7	22	38	0	1	1	1	9	98.5	80	77	-				
Peripheral neuroectodermal tumour (pPNET) of soft tissue	girls	5	0	1	0	2	2	1	0	0	0	0	0	1	100.0	-	-	-				
	boys	9	0	2	0	3	2	4	0	0	0	0	0	2	100.0	-	-	-				
	total	1.8	14	0	1	0	5	4	5	0	0	0	0	2	100.0	77	73	68				
Extrarenal rhabdoid tumour	girls	24	0	5	12	6	2	4	4	0	0	0	1	7	100.0	-	-	-				
	boys	25	0	5	15	6	3	1	4	0	0	0	1	7	88.0	-	-	-				
	total	1.0	49	0	5	27	12	5	4	0	0	0	1	7	93.9	-	-	-				
Liposarcomas	girls	2	0	0	0	0	0	2	0	0	0	0	0	1	100.0	-	-	-				
	boys	3	0	1	0	0	1	2	0	0	0	0	0	1	100.0	-	-	-				
	total	1.5	5	0	1	0	0	1	4	0	0	0	0	1	100.0	-	-	-				
Fibrohistiocytic tumours	girls	20	0	4	2	5	7	6	1	0	0	0	0	6	95.0	94	-	-				
	boys	15	0	3	1	4	3	7	0	0	0	0	0	4	93.3	100	-	-				
	total	0.8	35	0	4	3	9	10	13	0	0	0	0	5	94.3	97	-	-				
Leiomyosarcomas	girls	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	100.0	-	-	-				
Synovial sarcomas	girls	33	0	7	0	0	8	25	0	0	0	1	1	9	100.0	90	87	-				
	boys	31	0	6	0	3	7	21	0	0	0	1	0	8	100.0	87	79	-				
	total	0.9	64	0	6	0	3	15	46	0	0	1	1	8	100.0	88	83	-				
Blood vessel tumours	girls	4	0	1	0	2	2	0	0	0	0	0	0	1	100.0	-	-	-				
	boys	5	0	1	0	0	1	4	0	0	0	0	0	1	80.0	-	-	-				
	total	1.3	9	0	1	0	2	3	4	0	0	0	0	1	88.9	-	-	-				
Osseous and chondromatous neoplasms of soft tissue	girls	4	0	1	0	0	2	2	0	0	0	0	0	1	75.0	-	-	-				
	boys	1	0	0	0	0	1	0	0	0	0	0	0	0	100.0	-	-	-				
	total	0.3	5	0	1	0	3	2	0	0	0	0	0	1	80.0	-	-	-				

Table 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex	N	Relative	Number of cases		Age groups				Incidence rates per million					Trial participants		Survival probabilities(%)		
		m / f	0-14	%	%	Group	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World *	0-14	Cum.	%	5-yrs	10-yrs	15-yrs
Alveolar soft parts sarcoma	girls		9	0	2	0	1	1	7	0	0	0	0	0	0	0	2	100.0	-	-	-
	boys		3	0	1	0	0	1	2	0	0	0	0	0	0	0	1	100.0	-	-	-
	total	0.3	12	0	1	0	1	2	9	0	0	0	0	0	0	0	2	100.0	-	-	-
Miscellaneous soft tissue sarcomas	girls		10	0	2	2	3	1	4	1	0	0	0	0	0	0	3	100.0	-	-	-
	boys		22	0	4	3	1	6	12	1	0	0	1	0	0	0	6	100.0	-	-	-
	total	2.2	32	0	3	5	4	7	16	1	0	0	0	0	0	0	4	100.0	46	-	-
Unspecified soft tissue sarcomas	girls		37	1	8	6	10	9	12	2	1	1	1	1	1	1	10	100.0	77	-	-
	boys		47	1	9	7	6	8	26	2	0	0	1	1	1	1	12	93.6	72	-	-
	total	1.3	84	1	8	13	16	17	38	2	1	0	1	1	1	1	11	96.4	74	-	-
Germ cell tumours, trophoblastic tumours and neoplasms of gonads	girls		325	4	100	86	39	60	140	26	3	3	7	6	6	91	96.9	96	95	94	
	boys		241	3	100	61	42	25	113	17	3	1	6	4	4	64	96.3	92	91	91	
	total	0.7	566	3	100	147	81	85	253	22	3	2	6	5	7	77	96.6	94	93	93	
Intracranial and intraspinal germ cell tumours	girls		60	1	19	6	2	22	30	2	0	1	2	1	1	17	96.7	91	86	86	
	boys		106	1	44	2	7	19	78	1	0	1	4	2	2	27	95.3	89	87	87	
	total	1.8	166	1	29	8	9	41	108	1	0	1	3	1	1	22	95.8	90	86	86	
Intracranial and intraspinal germinoma	girls		28	0	9	0	1	9	18	0	0	1	1	0	0	8	100.0	97	90	90	
	boys		58	1	24	0	0	7	51	0	0	0	3	1	1	15	98.3	93	93	93	
	total	2.1	86	1	15	0	1	16	69	0	0	0	2	1	1	11	98.8	94	92	92	
Intracranial and intraspinal teratomas	girls		8	0	3	4	1	1	2	1	0	0	0	0	0	2	87.5	-	-	-	
	boys		14	0	6	2	4	4	4	1	0	0	0	0	0	4	78.6	100	93	-	
	total	1.8	22	0	4	6	5	5	6	1	0	0	0	0	0	3	81.8	91	86	-	
Intracranial and intraspinal embryonal carcinoma	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	boys		1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	100.0	-	-	-
	total	-	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	100.0	-	-	-
Intracranial and intraspinal yolk sac tumour	girls		2	0	1	0	0	1	1	0	0	0	0	0	0	1	100.0	-	-	-	-
	boys		4	0	2	0	0	0	4	0	0	0	0	0	0	1	100.0	-	-	-	-
	total	2.0	6	0	1	0	0	1	5	0	0	0	0	0	0	1	100.0	-	-	-	-
Intracranial and intraspinal choriocarcinoma	girls		6	0	2	0	0	4	2	0	0	0	0	0	0	2	100.0	-	-	-	-
	boys		2	0	1	0	1	0	1	0	0	0	0	0	0	1	100.0	-	-	-	-
	total	0.3	8	0	1	0	1	4	3	0	0	0	0	0	0	1	100.0	-	-	-	-
Intracranial and intraspinal tumours of mixed form	girls		16	0	5	2	0	7	7	1	0	0	0	0	0	4	93.8	89	-	-	-
	boys		27	0	11	0	2	7	18	0	0	0	1	0	0	7	96.3	81	-	-	-
	total	1.7	43	0	8	2	2	14	25	0	0	0	1	0	0	6	95.3	84	-	-	-

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses	Sex	Sex ratio	N	Relative	Number of cases					Incidence rates per million										Trial participants		Survival probabilities(%)	
					Age groups					Age-specific					Cum.	%	5-yrs	10-yrs	15-yrs				
					0-14	%	Group	%	0	1-4	5-9	10-14	0	1-4						5-9	10-14	World *	0-14
Malignant extracranial and extragonadal germ cell tumours	girls		121	2	37	80	33	2	6	24	2	0	0	0	3	36	96.7	95	95				
	boys		55	1	23	30	14	3	8	9	1	0	0	1	15	96.4	91	89					
	total	0.5	176	1	31	110	47	5	14	16	2	0	0	2	25	96.6	93	93					
	girls		8	0	3	0	3	0	5	0	0	0	0	0	2	75.0	-	-					
Germinomas of extracranial and extragonadal sites	boys		5	0	2	0	1	0	4	0	0	0	0	0	1	100.0	-	-					
	total	0.6	13	0	2	0	4	0	9	0	0	0	0	0	2	84.6	-	-					
	girls		61	1	19	58	3	0	0	17	0	0	0	1	18	98.4	95	95					
	boys		28	0	12	25	2	0	1	7	0	0	0	1	8	92.9	90	90					
Malignant teratomas of extracranial and extragonadal sites	total	0.5	89	1	16	83	5	0	1	12	0	0	0	1	13	96.6	93	93					
	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	-	-	-					
Yolk sac tumour of extracranial and extragonadal sites	girls		36	1	11	13	22	1	0	4	2	0	0	1	11	97.2	95	95					
	boys		13	0	5	2	10	0	1	1	1	0	0	0	4	100.0	94	94					
	total	0.4	49	0	9	15	32	1	1	2	1	0	0	1	7	98.0	94	94					
	girls		1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-					
Choriocarcinomas of extracranial and extragonadal sites	boys		1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-					
	total	1.0	2	0	0	0	0	0	2	0	0	0	0	0	0	100.0	-	-					
	girls		15	0	5	9	5	1	0	3	0	0	0	0	4	100.0	-	-					
	boys		8	0	3	3	1	3	1	1	0	0	0	0	2	100.0	-	-					
Other and unspecified malignant mixed germ cell tumours of extracranial and extragonadal sites	total	0.5	23	0	4	12	6	4	1	2	0	0	0	0	3	100.0	-	-					
	girls		139	2	43	0	4	36	99	0	0	2	5	2	37	97.8	99	99					
	boys		80	1	33	29	21	3	27	8	1	0	1	2	22	97.5	97	97					
	total	0.6	219	1	39	29	25	39	126	4	1	1	3	2	29	97.7	98	98					
Malignant gonadal germinomas	girls		36	1	11	0	1	7	28	0	0	0	1	1	10	100.0	100	100					
	boys		4	0	2	0	1	2	1	0	0	0	0	0	1	100.0	-	-					
	total	0.1	40	0	7	0	2	9	29	0	0	0	1	0	5	100.0	100	100					
	girls		30	0	9	0	1	9	20	0	0	1	1	0	8	93.3	100	100					
Malignant gonadal teratomas	boys		19	0	8	12	1	0	6	3	0	0	0	0	5	94.7	100	100					
	total	0.6	49	0	9	12	2	9	26	2	0	0	1	0	7	93.9	100	100					
	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-					
	boys		2	0	1	0	0	0	2	0	0	0	0	0	0	100.0	-	-					
Malignant gonadal embryonal carcinomas	total	-	2	0	0	0	0	0	2	0	0	0	0	0	0	100.0	-	-					

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex	Sex ratio	N	Relative		Number of cases		Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
					%	%	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World *	0-14	Cum.	%	5-yrs	10-yrs
Malignant gonadal yolk sac tumour		girls		23	0	7	0	2	7	14	0	0	0	1	0	6	95.7	97	97			
		boys		25	0	10	8	17	0	0	2	1	0	0	1	7	96.0	100	100			
		total	1.1	48	0	9	8	19	7	14	1	1	0	0	0	7	95.8	98	98	98		
Malignant gonadal choriocarcinoma		girls		6	0	2	0	0	1	5	0	0	0	0	2	100.0	-	-	-			
		boys		3	0	1	0	0	0	3	0	0	0	0	1	100.0	-	-	-			
		total	0.5	9	0	2	0	0	1	8	0	0	0	0	0	1	100.0	-	-	-		
Malignant gonadal tumours of mixed forms		girls		44	1	14	0	0	12	32	0	0	1	2	1	12	100.0	100	100	-		
		boys		27	0	11	9	2	1	15	3	0	0	1	0	7	100.0	100	100	-		
		total	0.6	71	0	13	9	2	13	47	1	0	0	1	1	9	100.0	100	100	-		
Malignant gonadal gonadoblastoma		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	-	-	-			
Gonadal carcinomas		girls		4	0	1	0	0	0	4	0	0	0	0	0	1	75.0	-	-	-		
		boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-		
		total	0.0	4	0	1	0	0	0	4	0	0	0	0	0	1	75.0	-	-	-		
Other and unspecified malignant gonadal tumours		girls		1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-	-		
		boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-		
		total	0.0	1	0	0	0	0	0	1	0	0	0	0	0	0	-	-	-	-		
Other malignant epithelial neoplasms and malignant melanomas		girls		216	3	100	3	14	45	154	1	1	3	8	4	58	69.0	93	92	91		
		boys		171	2	100	3	15	40	113	1	1	2	6	3	44	67.3	83	81	77		
		total	0.8	387	2	100	6	29	85	267	1	1	2	7	3	51	68.2	89	87	85		
Adrenocortical carcinomas		girls		16	0	7	1	5	5	5	0	0	0	0	0	5	100.0	-	-	-		
		boys		8	0	5	1	5	2	0	0	0	0	0	0	2	100.0	-	-	-		
		total	0.5	24	0	6	2	10	7	5	0	0	0	0	0	3	100.0	-	-	-		
Thyroid carcinomas		girls		90	1	42	0	1	22	67	0	0	1	4	1	24	83.3	100	99	99		
		boys		55	1	32	2	1	9	43	1	0	0	2	1	14	90.9	96	96	87		
		total	0.6	145	1	38	2	2	31	110	0	0	1	3	1	19	86.2	98	98	94		
Nasopharyngeal carcinomas		girls		5	0	2	0	0	0	5	0	0	0	0	0	1	100.0	-	-	-		
		boys		14	0	8	0	1	0	13	0	0	0	1	0	4	100.0	-	-	-		
		total	2.8	19	0	5	0	1	0	18	0	0	0	0	0	2	100.0	91	-	-		
Malignant melanomas		girls		32	0	15	2	6	8	16	1	0	0	1	1	9	21.9	96	-	-		
		boys		37	0	22	0	7	13	17	0	0	1	1	1	10	24.3	74	-	-		
		total	1.2	69	0	18	2	13	21	33	0	0	1	1	1	9	23.2	85	-	-		

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex N	Number of cases				Incidence rates per million								Trial participants		Survival probabilities(%)		
				Relative	Group	Age groups				Age-specific				Age-stand.	Cum.	%	5-yrs	10-yrs	15-yrs	
m / f	0-14	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World *					0-14
Skin carcinomas	girls	7	0	3	0	0	3	4	0	0	0	0	0	0	0	0	2	28.6	-	-
	boys	1	0	1	0	0	0	1	0	0	0	0	0	0	0	0	0	0.0	-	-
	total	0.1	8	0	2	0	3	5	0	0	0	0	0	0	0	0	1	25.0	-	-
Other and unspecified carcinomas	girls	66	1	31	0	2	7	57	0	0	0	3	1	18	66.7	85	81	-	-	-
	boys	56	1	33	0	1	16	39	0	0	1	2	1	14	60.7	70	65	-	-	-
	total	0.8	122	1	32	0	3	23	96	0	0	1	2	1	63.9	77	72	-	-	-
Carcinomas of salivary glands	girls	14	0	7	0	0	1	13	0	0	0	1	0	4	21.4	-	-	-	-	-
	boys	11	0	6	0	0	6	5	0	0	0	0	0	3	27.3	-	-	-	-	-
	total	0.8	25	0	7	0	0	7	18	0	0	0	0	0	3	24.0	100	-	-	-
Carcinomas of colon and rectum	girls	5	0	2	0	1	0	4	0	0	0	0	0	1	40.0	-	-	-	-	-
	boys	6	0	4	0	0	1	5	0	0	0	0	0	2	33.3	-	-	-	-	-
	total	1.2	11	0	3	0	1	1	9	0	0	0	0	1	36.4	-	-	-	-	-
Carcinomas of appendix	girls	27	0	13	0	0	3	24	0	0	0	1	0	7	96.3	-	-	-	-	-
	boys	20	0	12	0	0	4	16	0	0	0	1	0	5	100.0	-	-	-	-	-
	total	0.7	47	0	12	0	0	7	40	0	0	0	1	0	6	97.9	-	-	-	-
Carcinomas of lung	girls	1	0	1	0	0	0	1	0	0	0	0	0	0	100.0	-	-	-	-	-
	boys	6	0	4	0	0	2	4	0	0	0	0	0	2	66.7	-	-	-	-	-
	total	6.0	7	0	2	0	0	2	5	0	0	0	0	1	71.4	-	-	-	-	-
Carcinomas of thymus	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	-	-	-	-	-
Carcinomas of breast	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	-	-	-	-	-
Carcinomas of cervix uteri	girls	1	0	1	0	0	0	1	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	1	0	0	0	0	1	0	0	0	0	0	0	0	0.0	-	-	-	-
Carcinomas of bladder	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	-	-	-	-	-
Carcinomas of eye	girls	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	-	-
	boys	2	0	1	0	0	0	2	0	0	0	0	0	0	0.0	-	-	-	-	-
	total	-	2	0	1	0	0	0	2	0	0	0	0	0	0.0	-	-	-	-	-

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex	Sex ratio	N	Relative	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	Cum.	%	5-yrs	10-yrs	15-yrs		
Carcinomas of other specified sites		girls	17	0	8	0	1	3	13	0	0	0	1	0	5		70.6	-	-	-		
		boys	9	0	5	0	0	3	6	0	0	0	0	0	0	2		44.4	-	-	-	
		total	0.5	26	0	7	0	1	6	19	0	0	0	0	0	3		61.5	63	-	-	-
Carcinomas of unspecified site		girls	1	0	1	0	0	0	1	0	0	0	0	0	0	0		0.0	-	-	-	
		boys	2	0	1	0	1	0	1	0	0	0	0	0	0	1		50.0	-	-	-	-
		total	2.0	3	0	1	0	1	0	2	0	0	0	0	0	0		33.3	-	-	-	-
Others and unspecified malignant neoplasms		girls	16	0	100	1	8	2	5	0	1	0	0	0	5		68.8	-	-	-	-	
		boys	13	0	100	0	10	1	2	0	1	0	0	0	0	4		92.3	-	-	-	-
		total	0.8	29	0	100	1	18	3	7	0	1	0	0	0	4		79.3	-	-	-	-
Other specified malignant tumours		girls	12	0	75	0	7	2	3	0	1	0	0	0	3		75.0	-	-	-	-	
		boys	11	0	85	0	10	1	0	0	1	0	0	0	0	3		100.0	-	-	-	-
		total	0.9	23	0	79	0	17	3	3	0	1	0	0	0	3		87.0	-	-	-	-
Gastrointestinal stromal tumour		girls	1	0	6	0	0	0	1	0	0	0	0	0	0		100.0	-	-	-	-	
		boys	1	0	8	0	0	1	0	0	0	0	0	0	0	0		100.0	-	-	-	-
		total	1.0	2	0	7	0	0	1	1	0	0	0	0	0	0		100.0	-	-	-	-
Pancreatoblastoma		girls	3	0	19	0	0	2	1	0	0	0	0	0	1		33.3	-	-	-	-	
		boys	0	0	0	0	0	0	0	0	0	0	0	0	0	0		-	-	-	-	-
		total	0.0	3	0	10	0	0	2	1	0	0	0	0	0	0		33.3	-	-	-	-
Pulmonary blastoma and pleuropulmonary blastoma		girls	7	0	44	0	7	0	0	0	1	0	0	0	2		100.0	-	-	-	-	
		boys	10	0	77	0	10	0	0	0	1	0	0	0	0	3		100.0	-	-	-	-
		total	1.4	17	0	59	0	17	0	0	1	0	0	0	0	2		100.0	-	-	-	-
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	0		-	-	-	-	-
		total	-	0	0	0	0	0	0	0	0	0	0	0	0	0		-	-	-	-	-
Mesothelioma		girls	1	0	6	0	0	0	1	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	1	0	3	0	0	0	1	0	0	0	0	0	0		0.0	-	-	-	-
Other specified malignant 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	0		-	-	-	-	-
		total	-	0	0	0	0	0	0	0	0	0	0	0	0	0		-	-	-	-	-
Other unspecified malignant tumours		girls	4	0	25	1	1	0	2	0	0	0	0	0	1		50.0	-	-	-	-	
		boys	2	0	15	0	0	0	2	0	0	0	0	0	0	0		50.0	-	-	-	-
		total	0.5	6	0	21	1	1	0	4	0	0	0	0	0	1		50.0	-	-	-	-

* Standard: Segi world standard population

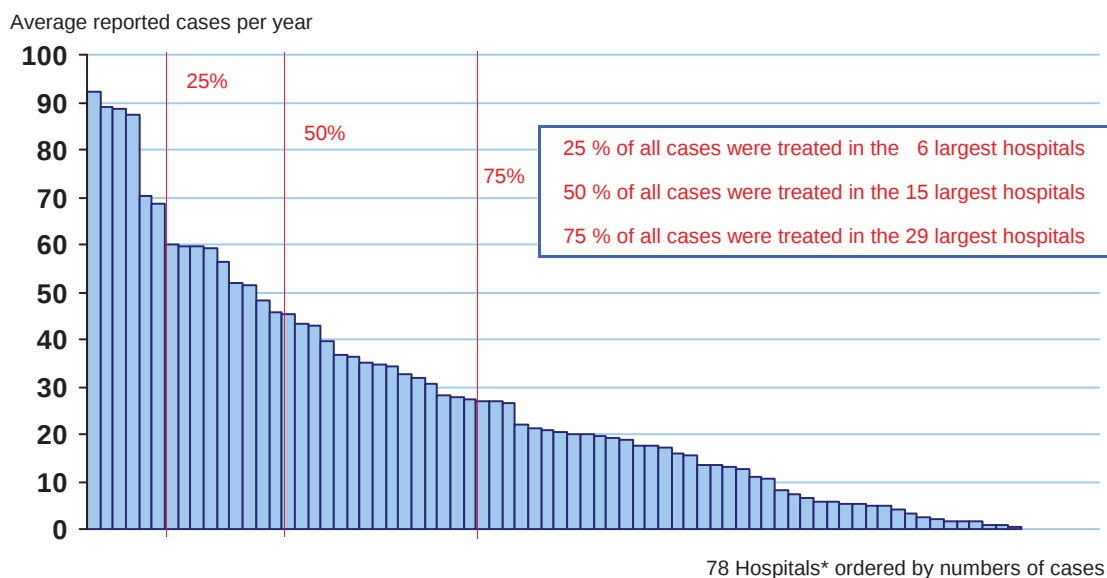
- insufficient data

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Abbildung 1:

Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2006-2015, Patienten unter 15 / 18 Jahren (unter 15 Jahren bis 2008)

Reported cases to the GCCR (registry population) per hospital, period 2006-2015, patients under 15 / 18 years (under 15 years until 2008)



* One hospital with 7 cases is a collection of "other hospitals"

Tabelle 2:

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

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

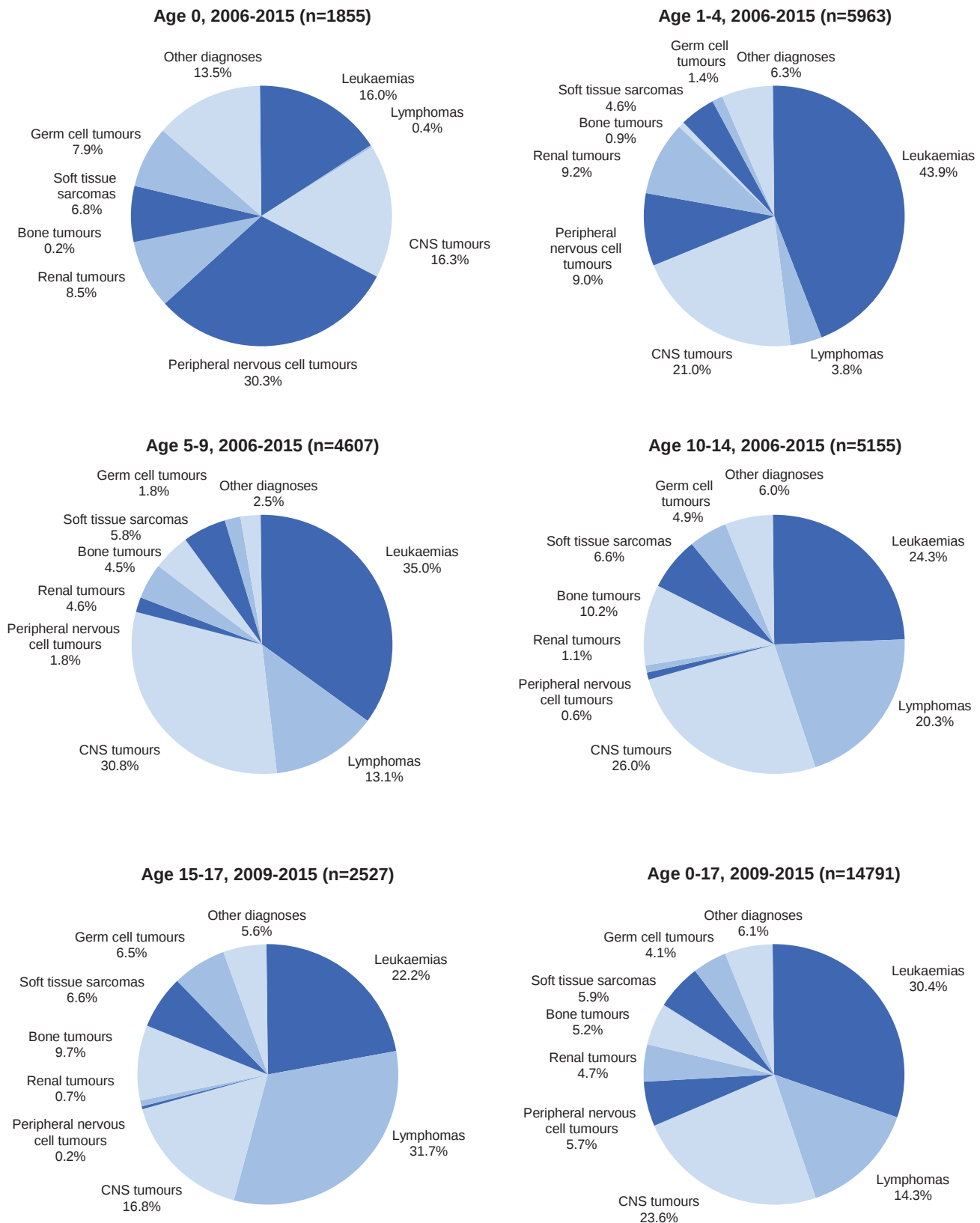
Diagnosis groups		Number of cases 1980-2015		Number of cases 2006-2015		Incidence rates 2006-2015	
		Absolute	Relative (%)	Absolute	Relative (%)	Age-standard.*	Cumulative
I	Leukaemias	19470	34.0	5783	32.9	56	807
II	Lymphomas	6668	11.6	1885	10.7	16	251
III	CNS tumours	12492	21.8	4317	24.6	40	594
IV	Peripheral nervous cell tumours	4314	7.5	1215	6.9	14	176
V	Retinoblastoma	1364	2.4	382	2.2	4	56
VI	Renal tumours	3348	5.8	974	5.5	10	139
VII	Hepatic tumours	649	1.1	252	1.4	3	36
VIII	Bone tumours	2679	4.7	789	4.5	6	104
IX	Soft tissue sarcomas	3507	6.1	1001	5.7	9	138
X	Germ cell tumours	1842	3.2	566	3.2	5	77
XI	Carcinomas	844	1.5	387	2.2	3	51
XII	Others and unspecified	68	0.1	29	0.2	0	4
All malignancies		57245	100.0	17580	100.0	168	2433

* Standard: Segi world standard population

Abbildung 2:

Relative Häufigkeit der gemeldeten Fälle aus der deutschen Wohnbevölkerung nach den häufigsten ICC3-Diagnose-Hauptgruppen und Alter

Relative frequencies of the registered cases in Germany by the main ICC3 diagnosis groups and age



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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 rate per million *		Population base (in million)	
	< 15		<15		<15	
1980	1016		103		11.187	
1981	1046		105		10.803	
1982	973		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	1299		139		9.621	
1991 #	1669		132		13.013	
1992	1813		143		13.166	
1993	1683		132		13.279	
1994	1769		139		13.298	
1995	1802		143		13.264	
1996	1803		145		13.209	
1997	1908		155		13.139	
1998	1822		149		13.035	
1999	1880		154		12.936	
2000	1977		163		12.836	
2001	1854		155		12.698	
2002	1824		153		12.517	
2003	1776		152		12.288	
2004	1873		164		12.042	
2005	1834		165		11.787	
2006	1769		162		11.544	
2007	1775		164		11.361	
2008	1772		167		11.212	

Years	Number of cases			Incidence rates per million *		Population base (in million)	
	< 15	15 to < 18	< 18	<15	< 18	<15	< 18
2009	1797	353	2150	170	166	11.078	13.579
2010	1766	313	2079	169	163	10.979	13.408
2011	1733	357	2090	166	164	10.884	13.277
2012	1765	358	2123	170	167	10.782	13.187
2013	1759	336	2095	172	167	10.628	13.050
2014	1686	399	2085	164	164	10.628	13.062
2015	1758	411	2169	173	173	10.555	12.950
Total	57245	2527	59772				

* 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 (2006-2015)

Distribution of all reported cases in Germany by age groups without age restriction # and additional diagnoses (2006-2015)

Age groups (years)	Diagnoses according to ICCC-3		Additional diagnoses (see Table 5)	
	N	%	N	%
0	1855	8.4	455	26.9
1-4	5963	27.2	336	19.8
5-9	4607	21.0	328	19.4
10-14	5155	23.5	405	23.9
0-14	17580	80.1	1524	90.0
15-17	3487	15.9	133	7.9
18-19	277	1.3	8	0.5
20-24	239	1.1	10	0.6
≥25	372	1.7	18	1.1
≥15	4375	19.9	169	10.0
reported cases	21955	100.0	1693	100.0

Bis 2008 wurden systematisch nur Patienten bis unter 15 Jahren erfasst; seit 2009 werden systematisch Patienten bis unter 18 Jahren erfasst. Patienten ab 18 Jahren gehören nicht zur Registerpopulation und sind nicht repräsentativ für die deutsche Bevölkerung.

Until 2008 patients were systematically registered until under the age of 15; since 2009 patients are systematically registered until under the age of 18. Patients aged 18 years and older are not part of the registry population and are not representative for the German population.

Tabelle 5:

Nicht in der ICCC-3 definierte, systematisch registrierte Diagnosen, Fälle unter 15 Jahren (2006-2015)

Systematically registered diagnoses not defined in ICCC-3, cases under the age of 15 (2006-2015)

Diagnoses	Sex		Number of cases					Incidence rates per million					Trial par-	
	Sex	ratio	N	Age groups				Age groups				Age-stand.	Cum.	ticipants
		m / f	0-14	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World * 0-14	%	
Non-malignant Langerhans cell histiocytosis	girls		282	78	83	72	49	23	6	4	3	6	81	84.4
	boys		408	95	121	93	99	27	9	5	5	8	111	85.0
	total	1.4	690	173	204	165	148	25	7	5	4	7	97	84.8
Benign/mature teratoma	girls		490	125	58	106	201	38	4	6	11	9	138	95.7
	boys		144	86	30	18	10	25	2	1	0	3	40	93.8
	total	0.3	634	211	88	124	211	31	3	3	5	6	88	95.3
Severe aplastic anaemia	girls		41	3	7	17	14	1	1	1	1	1	11	90.2
	boys		57	2	19	15	21	1	1	1	1	1	15	93.0
	total	1.4	98	5	26	32	35	1	1	1	1	1	13	91.8
Mesoblastic nephroma	girls		20	20	0	0	0	6	0	0	0	0	6	85.0
	boys		25	23	1	0	1	7	0	0	0	1	7	96.0
	total	1.3	45	43	1	0	1	6	0	0	0	1	7	91.1
Other diseases of blood and haemopoietic system	girls		22	12	6	2	2	4	0	0	0	0	6	59.1
	boys		32	11	11	4	6	3	1	0	0	1	9	56.3
	total	1.5	54	23	17	6	8	3	1	0	0	1	8	57.4

* Standard: Segi world standard population

Tabelle 6:

Altersstandardisierte* Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert nach Patientenwohnsitz für Fälle unter 15 Jahre (2006-2015)

Age-standardized* incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for cases under 15 by patients residence region (2006-2015)

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	655	174	1.05	0.97-1.13	218	59	1.07	0.93-1.22
Hamburg	372	166	0.99	0.89-1.09	125	57	1.00	0.83-1.19
Niedersachsen	1735	164	0.98	0.93-1.02	595	57	1.03	0.95-1.11
Bremen	122	155	0.92	0.76-1.09	39	51	0.89	0.63-1.21
Nordrhein-Westfalen	4047	172	1.02	0.99-1.06	1263	55	0.97	0.92-1.03
Düsseldorf	1163	176	1.05	0.99-1.11	361	57	1.00	0.90-1.10
Köln	1009	171	1.03	0.97-1.10	297	52	0.92	0.82-1.03
Münster	612	172	1.03	0.95-1.11	218	63	1.12	0.98-1.28
Detmold	487	171	1.01	0.92-1.10	154	55	0.97	0.82-1.14
Arnsberg	776	167	0.99	0.92-1.06	233	51	0.91	0.80-1.03
Hessen	1354	170	1.01	0.96-1.06	468	60	1.06	0.97-1.16
Darmstadt	847	164	0.98	0.92-1.05	298	59	1.04	0.93-1.17
Gießen	254	197	1.13	0.99-1.28	85	67	1.15	0.92-1.43
Kassel	253	163	0.97	0.86-1.10	85	57	1.00	0.80-1.24
Rheinland-Pfalz	908	177	1.05	0.98-1.12	287	57	1.01	0.90-1.14
Baden-Württemberg	2379	163	0.97	0.93-1.01	771	54	0.96	0.89-1.03
Stuttgart	884	161	0.96	0.90-1.03	290	54	0.96	0.85-1.08
Karlsruhe	618	173	1.04	0.96-1.13	203	59	1.04	0.90-1.20
Freiburg	497	163	0.99	0.90-1.08	164	56	0.99	0.85-1.16
Tübingen	380	153	0.90	0.81-0.99	114	48	0.82	0.68-0.99
Bayern	2766	166	0.99	0.95-1.02	959	59	1.04	0.98-1.11
Oberbayern	949	159	0.94	0.88-1.00	341	58	1.02	0.92-1.14
Niederbayern	246	154	0.93	0.81-1.05	77	51	0.89	0.70-1.11
Oberpfalz	261	187	1.10	0.97-1.24	87	65	1.12	0.90-1.38
Oberfranken	209	154	0.94	0.82-1.08	71	56	0.98	0.77-1.24
Mittelfranken	334	150	0.90	0.80-1.00	106	49	0.87	0.71-1.05
Unterfranken	303	181	1.08	0.96-1.21	109	67	1.19	0.98-1.44
Schwaben	464	189	1.12	1.02-1.23	168	70	1.24	1.06-1.45
Saarland	194	165	1.00	0.86-1.15	60	52	0.95	0.72-1.22
Berlin	659	157	0.93	0.86-1.01	232	56	0.99	0.86-1.12
Brandenburg	445	160	0.96	0.87-1.05	157	58	1.01	0.86-1.18
Mecklenburg-Vorpommern	287	158	0.95	0.84-1.06	88	50	0.87	0.70-1.07
Sachsen	844	182	1.09	1.01-1.16	262	57	1.01	0.89-1.14
Sachsen-Anhalt	413	170	1.01	0.92-1.12	131	54	0.97	0.81-1.15
Thüringen	397	166	0.98	0.89-1.08	128	54	0.95	0.79-1.13

* 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, 1980-2010 (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 1980-2010 (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	347	497	375	539	388	556
1981	343	486	379	536	395	559
1982	313	471	347	521	357	536
1983	319	495	359	557	372	577
1984	325	517	354	563	364	580
1985	322	524	362	588	379	616
1986	320	531	355	589	365	605
1987	328	552	353	594	367	618
1988	318	526	349	577	359	594
1989	293	470	327	526	340	547
1990	326	499	354	541	370	566
1991 #	400	458	445	509	460	526
1992 #	437	496	473	537	493	560
1993 #	382	434	427	485	444	504
1994 #	374	425	409	465	421	478
1995 #	338	389	385	442	407	467
1996 #	349	403	386	445	402	463
1997 #	372	432	417	484	439	509
1998 #	351	410	392	458	406	474
1999 #	360	422	399	467	414	484
2000 #	395	468	429	508	449	532
2001 #	302	364	340	409		
2002 #	320	388	358	434		
2003 #	322	399	362	447		
2004 #	293	372	342	433		
2005 #	298	384	324	418		
2006 #	295	389				
2007 #	272	364				
2008 #	288	388				
2009 #	257	350				
2010 #	237	327				

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 2015)

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged under 15 / 18 (as of 2015)

Year of diagnosis	1980 - 1989 *	1990 - 1999 *	2000 - 2009 **	2010 - 2015 ***	1980 - 2015**
	N (%)	N (%)	N (%)	N (%)	N (%)
Patients registered	10993	17245	18323	12442	59003 #
deceased	3895 (35.4 %)	4228 (24.5 %)	3350 (18.3 %)	1084 (8.7 %)	12557 (21.3 %)
surviving	7098 (64.6 %)	13017 (75.5 %)	14973 (81.7 %)	11358 (91.3 %)	46446 (78.7 %)
anonymous +	984 (13.9 %)	1107 (8.5 %)	432 (2.9 %)	113 (1.0 %)	2636 (5.7 %)
identifiable	6114 (86.1 %)	11910 (91.5 %)	14541 (97.1 %)	11245 (99.0 %)	43810 (94.3 %)
< 5 years since diagnosis	-	-	-	8597 (76.5 %)	8597 (19.6 %)
>= 5 years since diagnosis	6114 (100 %)	11910 (100 %)	14541 (100 %)	2648 (23.5 %)	35213 (80.4 %)
lost to follow-up	702 (11.5 %)	857 (7.2 %)	325 (2.2 %)	15 (0.6 %)	1899 (5.4 %)
in LTS	5412 (88.5 %)	11053 (92.8 %)	14216 (97.8 %)	2633 (99.4 %)	33314 (94.6 %)

59003 patients correspond to 59772 cases diagnosed under 15 / 18 years resident in Germany at the date of diagnosis 1980-2015 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 ICC-3, Alter und Geschlecht (2009-2015). *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 ICC-3, age and sex (2009-2015). *ICCC-3 extended subclassification in italics.*

Diagnoses	Sex ratio	Sex m / f	N	Relative %	Number of cases		Incidence rates per million				Trial participants	
					Age group		Age stand. *				Cum.	
					0 - 14	15 - 17	0 - 14	15 - 17	0 - 17	0 - 17	0 - 17	%
All malignancies	girls		6529	100	100	5443	1086	155	131	151	2635	95.3
	boys		8262	100	100	6821	1441	183	165	180	3161	95.7
	total	1.3	14791	100	100	12264	2527	169	149	166	2905	95.5
Leukaemias, myeloproliferative and myelodysplastic diseases	girls		1979	30	100	1759	220	51	27	47	810	99.4
	boys		2522	31	100	2182	340	60	39	57	977	99.1
	total	1.3	4501	30	100	3941	560	56	33	52	896	99.2
Lymphoid leukaemias	girls		1447	22	73	1336	111	39	13	35	598	99.6
	boys		1909	23	76	1684	225	46	26	43	742	99.8
	total	1.3	3356	23	75	3020	336	43	20	39	672	99.7
Precursor cell leukaemias	girls		1429	22	72	1320	109	39	13	35	590	99.6
	boys		1850	22	73	1631	219	45	25	42	719	99.8
	total	1.3	3279	22	73	2951	328	42	19	38	656	99.7
Mature B-cell leukaemias	girls		17	0	1	15	2	0	0	0	7	100.0
	boys		58	1	2	52	6	1	1	1	22	100.0
	total	3.4	75	1	2	67	8	1	0	1	15	100.0
Mature T-cell and 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	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	0	-
Acute myeloid leukaemias	girls		300	5	15	242	58	7	7	7	121	99.7
	boys		316	4	13	261	55	7	6	7	122	97.2
	total	1.1	616	4	14	503	113	7	7	7	121	98.4
Chronic myeloproliferative diseases	girls		37	1	2	26	11	1	1	1	14	94.6
	boys		54	1	2	34	20	1	2	1	20	83.3
	total	1.5	91	1	2	60	31	1	2	1	17	87.9
Myelodysplastic syndrome and other myeloproliferative diseases	girls		170	3	9	134	36	4	4	4	68	98.8
	boys		221	3	9	184	37	5	4	5	84	99.5
	total	1.3	391	3	9	318	73	4	4	4	76	99.2

* Standard: Segi world standard population - insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex		Number of cases				Incidence rates per million				Trial participants	
		Sex ratio	N	Relative	Group	Age group		Age stand. *		Cum.	%		
		m / f	0-17	%	%	0 - 14	15 - 17	0 - 14	15 - 17	0 - 17	0 - 17	%	
Unspecified and other specified leukaemias	girls		25	0	1	21	4	1	0	1	10	100.0	
	boys		22	0	1	19	3	1	0	1	9	100.0	
	total	0.9	47	0	1	40	7	1	0	1	9	100.0	
Lymphomas and reticuloendothelial neoplasms	girls		760	12	100	413	347	10	42	15	289	97.5	
	boys		1353	16	100	899	454	22	52	26	498	97.1	
	total	1.8	2113	14	100	1312	801	16	47	21	396	97.3	
Hodgkin lymphomas	girls		512	8	67	224	288	5	35	10	191	98.0	
	boys		588	7	44	332	256	8	29	11	212	97.6	
	total	1.1	1100	7	52	556	544	6	32	10	202	97.8	
Non-Hodgkin lymphomas	girls		210	3	28	153	57	4	7	4	82	96.7	
	boys		548	7	41	384	164	9	19	11	203	96.4	
	total	2.6	758	5	36	537	221	7	13	8	144	96.4	
Precursor cell lymphomas	girls		54	1	7	49	5	1	1	1	22	94.4	
	boys		155	2	12	126	29	3	3	3	58	94.2	
	total	2.9	209	1	10	175	34	2	2	2	41	94.3	
Mature B-cell lymphomas (except Burkitt lymphoma)	girls		45	1	6	31	14	1	2	1	18	97.8	
	boys		109	1	8	61	48	1	6	2	39	96.3	
	total	2.4	154	1	7	92	62	1	4	1	29	96.8	
Mature T-cell and NK-cell lymphomas	girls		55	1	7	39	16	1	2	1	21	96.4	
	boys		90	1	7	68	22	2	3	2	33	100.0	
	total	1.6	145	1	7	107	38	1	2	1	27	98.6	
Non-Hodgkin lymphomas, NOS	girls		56	1	7	34	22	1	3	1	22	98.2	
	boys		194	2	14	129	65	3	7	4	72	96.4	
	total	3.5	250	2	12	163	87	2	5	3	47	96.8	
Burkitt lymphoma	girls		31	1	4	29	2	1	0	1	12	100.0	
	boys		207	3	15	177	30	5	3	4	79	98.6	
	total	6.7	238	2	11	206	32	3	2	3	47	98.7	
Miscellaneous lymphoreticular neoplasms	girls		4	0	1	4	0	0	0	0	2	75.0	
	boys		5	0	0	1	4	0	0	0	2	60.0	
	total	1.3	9	0	0	5	4	0	0	0	2	66.7	
Unspecified lymphomas	girls		3	0	0	3	0	0	0	0	1	66.7	
	boys		5	0	0	5	0	0	0	0	2	100.0	
	total	1.7	8	0	0	8	0	0	0	0	2	87.5	

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio		Number of cases				Incidence rates per million				Trial participants	
	Sex	m / f	N	Relative Group		Age group		Age stand. *		Cum.	0 - 17	%
				%	%	0 - 14	15 - 17	0 - 14	15 - 17			
CNS and miscellaneous intracranial and intraspinal neoplasms	girls		1565	24	100	1362	203	38	25	36	632	95.7
	boys		1921	23	100	1699	222	44	25	42	737	95.8
	total	1.2	3486	24	100	3061	425	41	25	39	686	95.8
Ependymomas and choroid plexus tumour	girls		139	2	9	125	14	4	2	3	57	96.4
	boys		191	2	10	178	13	5	1	4	75	96.9
	total	1.4	330	2	10	303	27	4	2	4	66	96.7
Ependymomas	girls		106	2	7	94	12	3	1	3	44	97.2
	boys		156	2	8	145	11	4	1	4	61	96.8
	total	1.5	262	2	8	239	23	3	1	3	52	96.9
Choroid plexus tumour	girls		33	1	2	31	2	1	0	1	14	93.9
	boys		35	0	2	33	2	1	0	1	14	97.1
	total	1.1	68	1	2	64	4	1	0	1	14	95.6
Astrocytomas	girls		753	12	48	667	86	18	10	17	304	96.8
	boys		826	10	43	716	110	19	13	18	316	96.0
	total	1.1	1579	11	45	1383	196	18	12	17	310	96.4
Intracranial and intraspinal embryonal tumours	girls		212	3	14	199	13	6	2	5	88	96.7
	boys		366	4	19	337	29	9	3	8	143	98.4
	total	1.7	578	4	17	536	42	8	2	7	116	97.8
Medulloblastomas	girls		140	2	9	128	12	4	1	3	57	99.3
	boys		277	3	14	250	27	7	3	6	107	99.3
	total	2.0	417	3	12	378	39	5	2	5	83	99.3
Primitive neuroectodermal tumour (PNET)	girls		23	0	2	22	1	1	0	1	10	95.7
	boys		26	0	1	25	1	1	0	1	10	100.0
	total	1.1	49	0	1	47	2	1	0	1	10	98.0
Medulloepithelioma	girls		3	0	0	3	0	0	0	0	1	66.7
	boys		4	0	0	4	0	0	0	0	2	100.0
	total	1.3	7	0	0	7	0	0	0	0	1	85.7
Atypical teratoid/rhabdoid tumour	girls		46	1	3	46	0	2	0	1	20	91.3
	boys		59	1	3	58	1	2	0	2	24	93.2
	total	1.3	105	1	3	104	1	2	0	1	22	92.4
Other gliomas	girls		173	3	11	152	21	4	3	4	70	94.8
	boys		198	2	10	181	17	5	2	4	75	98.0
	total	1.1	371	3	11	333	38	4	2	4	73	96.5

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex m / f	N	Relative		Number of cases		Age group			Incidence rates per million				Trial participants													
					0-17	%	%	Group	%	0 - 14	15 - 17	0 - 14	15 - 17	0 - 17	Cum.	%													
Oligodendrogliomas																		girls	3	0	0	0	3	0	0	0	0	1	100.0
																		boys	4	0	0	0	4	0	0	0	0	1	100.0
																		total	1.3	7	0	0	4	3	0	0	0	1	100.0
Mixed and unspecified gliomas																		girls	161	3	10	143	18	4	2	4	65	94.4	
																		boys	185	2	10	170	15	4	2	4	71	97.8	
																		total	1.1	346	2	10	313	33	4	2	4	68	96.2
Neuroepithelial glial tumours of uncertain origin																		girls	9	0	1	9	0	0	0	0	4	100.0	
																		boys	9	0	1	7	2	0	0	0	3	100.0	
																		total	1.0	18	0	1	16	2	0	0	0	4	100.0
Other specified intracranial and intraspinal neoplasms																		girls	263	4	17	199	64	5	8	6	103	93.2	
																		boys	311	4	16	260	51	6	6	6	117	91.3	
																		total	1.2	574	4	17	459	115	6	7	6	110	92.2
Pituitary adenomas and carcinomas																		girls	33	1	2	12	21	0	3	1	12	81.8	
																		boys	18	0	1	11	7	0	1	0	6	72.2	
																		total	0.5	51	0	2	23	28	0	2	0	9	78.4
Tumours of the sellar region (craniopharyngiomas)																		girls	81	1	5	72	9	2	1	2	32	100.0	
																		boys	76	1	4	65	11	2	1	2	29	98.7	
																		total	0.9	157	1	5	137	20	2	1	2	31	99.4
Pineal parenchymal tumours																		girls	20	0	1	15	5	0	1	0	8	100.0	
																		boys	11	0	1	10	1	0	0	0	4	100.0	
																		total	0.6	31	0	1	25	6	0	0	0	6	100.0
Neuronal and mixed neuronal-glial tumours																		girls	113	2	7	87	26	2	3	2	44	92.0	
																		boys	179	2	9	155	24	4	3	4	67	94.4	
																		total	1.6	292	2	8	242	50	3	3	3	56	93.5
Meningiomas																		girls	16	0	1	13	3	0	0	0	6	81.3	
																		boys	27	0	1	19	8	0	1	1	10	59.3	
																		total	1.7	43	0	1	32	11	0	1	0	8	67.4
Unspecified intracranial and intraspinal neoplasms																		girls	25	0	2	20	5	1	1	1	10	84.0	
																		boys	29	0	2	27	2	1	0	1	11	86.2	
																		total	1.2	54	0	2	47	7	1	0	1	10	85.2
Neuroblastoma and other peripheral nervous cell tumours																		girls	358	6	100	356	2	12	0	10	153	98.0	
																		boys	486	6	100	483	3	15	0	13	197	99.8	
																		total	1.4	844	6	100	839	5	13	0	12	175	99.1

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex	Sex ratio	N	Number of cases			Age group			Incidence rates per million			Trial participants	
				Relative	Group	%	0 - 14	15 - 17	Age stand. *	0 - 14	15 - 17	0 - 17	Cum.	%
Neuroblastoma and ganglioneuroblastoma	girls		354	5	99	352	2		12	0	10	151	98.6	
	boys		484	6	100	481	3		15	0	13	196	99.8	
	total	1.4	838	6	99	833	5		13	0	12	174	99.3	
Other peripheral nervous cell tumours	girls		4	0	1	4	0		0	0	0	2	50.0	
	boys		2	0	0	2	0		0	0	0	1	100.0	
	total	0.5	6	0	1	6	0		0	0	0	1	66.7	
Retinoblastoma	girls		134	2	100	134	0		5	0	4	57	37.3	
	boys		137	2	100	137	0		4	0	4	56	32.8	
	total	1.0	271	2	100	271	0		4	0	4	57	35.1	
Renal tumours	girls		368	6	100	358	10		11	1	10	155	99.5	
	boys		321	4	100	313	8		9	1	8	129	98.4	
	total	0.9	689	5	100	671	18		10	1	9	142	99.0	
Nephroblastoma and other non-epithelial renal tumours	girls		361	6	98	354	7		11	1	10	153	99.7	
	boys		305	4	95	303	2		9	0	8	123	99.3	
	total	0.8	666	5	97	657	9		10	1	9	137	99.5	
Nephroblastoma	girls		350	5	95	345	5		11	1	9	148	99.7	
	boys		295	4	92	293	2		9	0	8	119	99.3	
	total	0.8	645	4	94	638	7		10	0	8	133	99.5	
Rhabdoid renal tumour	girls		7	0	2	6	1		0	0	0	3	100.0	
	boys		8	0	3	8	0		0	0	0	3	100.0	
	total	1.1	15	0	2	14	1		0	0	0	3	100.0	
Kidney sarcomas	girls		4	0	1	3	1		0	0	0	2	100.0	
	boys		2	0	1	2	0		0	0	0	1	100.0	
	total	0.5	6	0	1	5	1		0	0	0	1	100.0	
Peripheral neuroectodermal tumour (pPNET) of kidney	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	-	
Renal carcinomas	girls		7	0	2	4	3		0	0	0	3	85.7	
	boys		16	0	5	10	6		0	1	0	6	81.3	
	total	2.3	23	0	3	14	9		0	1	0	4	82.6	
Unspecified malignant renal 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	-	

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex		Sex ratio	Number of cases				Age group					Incidence rates per million				Trial participants	
	Sex	ratio		N	Relative		Group	Age group		Age stand. *			Cum.	%				
					%	%		0 - 14	15 - 17	0 - 14	15 - 17	0 - 17						
Hepatic tumours	girls		91	1	100		82	9		3	1	2	38		69.2			
	boys		112	1	100		104	8		3	1	3	45		70.5			
	total	1.2	203	1	100		186	17		3	1	3	41		70.0			
Hepatoblastoma	girls		73	1	80		73	0		2	0	2	31		71.2			
	boys		100	1	89		98	2		3	0	3	40		71.0			
	total	1.4	173	1	85		171	2		3	0	2	36		71.1			
Hepatic carcinomas	girls		18	0	20		9	9		0	1	0	7		61.1			
	boys		12	0	11		6	6		0	1	0	4		66.7			
	total	0.7	30	0	15		15	15		0	1	0	6		63.3			
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		338	5	100		245	93		6	11	7	130		98.5			
	boys		438	5	100		287	151		7	17	8	159		97.7			
	total	1.3	776	5	100		532	244		6	14	8	145		98.1			
Osteosarcomas	girls		173	3	51		126	47		3	6	3	66		99.4			
	boys		230	3	53		136	94		3	11	4	83		97.8			
	total	1.3	403	3	52		262	141		3	8	4	75		98.5			
Chondrosarcomas	girls		3	0	1		2	1		0	0	0	1		100.0			
	boys		7	0	2		7	0		0	0	0	3		100.0			
	total	2.3	10	0	1		9	1		0	0	0	2		100.0			
Ewing tumour and related sarcomas of bone	girls		153	2	45		112	41		3	5	3	59		98.7			
	boys		194	2	44		139	55		3	6	4	71		98.5			
	total	1.3	347	2	45		251	96		3	6	3	66		98.6			
Ewing tumour and askin tumour of bone	girls		145	2	43		106	39		3	5	3	56		99.3			
	boys		190	2	43		135	55		3	6	4	70		98.4			
	total	1.3	335	2	43		241	94		3	6	3	63		98.8			
Peripheral neuroectodermal tumour (pPNET) of bone	girls		8	0	2		6	2		0	0	0	3		87.5			
	boys		4	0	1		4	0		0	0	0	2		100.0			
	total	0.5	12	0	2		10	2		0	0	0	2		91.7			
Other specified malignant bone tumours	girls		8	0	2		4	4		0	0	0	3		75.0			
	boys		5	0	1		4	1		0	0	0	2		80.0			
	total	0.6	13	0	2		8	5		0	0	0	2		76.9			

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex	Sex ratio	N	Number of cases				Incidence rates per million				Trial participants		
				Relative		Group		Age group		Age stand. *		Cum.	%	
				m / f	0-17	%	%	0-14	15-17	0-14	15-17			0-17
Malignant fibrous neoplasms of bone	girls		0	0	0	0	0	0	0	0	0	0	-	-
	boys		2	0	1	1	1	0	0	0	0	1	100.0	100.0
	total	-	2	0	0	1	1	0	0	0	0	0	100.0	100.0
Malignant chordomas	girls		7	0	2	3	4	0	0	0	0	3	85.7	85.7
	boys		3	0	1	3	0	0	0	0	0	1	66.7	66.7
	total	0.4	10	0	1	6	4	0	0	0	0	2	80.0	80.0
Odontogenic malignant tumours	girls		0	0	0	0	0	0	0	0	0	0	-	-
	boys		0	0	0	0	0	0	0	0	0	0	-	-
	total	-	0	0	0	0	0	0	0	0	0	0	-	-
Miscellaneous malignant bone tumours	girls		1	0	0	1	0	0	0	0	0	0	0.0	0.0
	boys		0	0	0	0	0	0	0	0	0	0	-	-
	total	0.0	1	0	0	1	0	0	0	0	0	0	0.0	0.0
Unspecified malignant bone tumours	girls		1	0	0	1	0	0	0	0	0	0	100.0	100.0
	boys		2	0	1	1	1	0	0	0	0	1	50.0	50.0
	total	2.0	3	0	0	2	1	0	0	0	0	1	66.7	66.7
Soft tissue and other extrasosseous sarcomas	girls		385	6	100	318	67	9	8	9	155	98.7	98.7	
	boys		495	6	100	394	101	10	12	11	188	97.8	97.8	
	total	1.3	880	6	100	712	168	10	10	10	172	98.2	98.2	
Rhabdomyosarcomas	girls		175	3	46	154	21	4	3	4	71	100.0	100.0	
	boys		246	3	50	205	41	6	5	6	95	99.6	99.6	
	total	1.4	421	3	48	359	62	5	4	5	83	99.8	99.8	
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	girls		46	1	12	36	10	1	1	1	18	91.3	91.3	
	boys		51	1	10	40	11	1	1	1	19	98.0	98.0	
	total	1.1	97	1	11	76	21	1	1	1	19	94.8	94.8	
Fibroblastic and myofibroblastic tumours	girls		22	0	6	18	4	1	0	1	9	90.9	90.9	
	boys		19	0	4	17	2	0	0	0	7	94.7	94.7	
	total	0.9	41	0	5	35	6	1	0	0	8	92.7	92.7	
Nerve sheath tumours	girls		24	0	6	18	6	0	1	0	9	91.7	91.7	
	boys		32	0	7	23	9	1	1	1	12	100.0	100.0	
	total	1.3	56	0	6	41	15	1	1	1	11	96.4	96.4	
Other fibrous neoplasms	girls		0	0	0	0	0	0	0	0	0	0	-	-
	boys		0	0	0	0	0	0	0	0	0	0	-	-
	total	-	0	0	0	0	0	0	0	0	0	0	-	-

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex		Sex ratio		N		Relative		Number of cases		Age group			Incidence rates per million			Trial participants	
	Sex	ratio	m	f	0-17	%	0-17	%	Group	%	0-14	15-17	%	0-14	15-17	0-17	Cum.	%
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	2	0	0	0	2	0	2	0	0	0	0	0	50.0	
Other specified soft tissue sarcomas	girls		132	2	34	99	33				3	4	3	52			99.2	
	boys		153	2	31	114	39				3	4	3	57			96.7	
	total	1.2	285	2	32	213	72				3	4	3	55			97.9	
<i>Ewing tumour and askin tumour of soft tissue</i>	girls		30	1	8	21	9				1	1	1	12			96.7	
	boys		29	0	6	22	7				1	1	1	11			100.0	
	total	1.0	59	0	7	43	16				1	1	1	11			98.3	
<i>Peripheral neuroectodermal tumour (pPNET) of soft tissue</i>	girls		3	0	1	2	1				0	0	0	1			100.0	
	boys		7	0	1	6	1				0	0	0	3			100.0	
	total	2.3	10	0	1	8	2				0	0	0	2			100.0	
<i>Extrarenal rhabdoid tumour</i>	girls		21	0	6	20	1				1	0	1	9			100.0	
	boys		23	0	5	21	2				1	0	1	9			91.3	
	total	1.1	44	0	5	41	3				1	0	1	9			95.5	
<i>Liposarcomas</i>	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	
<i>Fibrohistiocytic tumours</i>	girls		16	0	4	15	1				0	0	0	6			100.0	
	boys		18	0	4	14	4				0	0	0	7			94.4	
	total	1.1	34	0	4	29	5				0	0	0	7			97.1	
<i>Leiomyosarcomas</i>	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	0	2				0	0	0	0			100.0	
<i>Synovial sarcomas</i>	girls		29	0	8	21	8				0	1	1	11			100.0	
	boys		35	0	7	24	11				1	1	1	13			97.1	
	total	1.2	64	0	7	45	19				1	1	1	12			98.4	
<i>Blood vessel tumours</i>	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	
<i>Osseous and chondromatous neoplasms of soft tissue</i>	girls		2	0	1	1	1				0	0	0	1			100.0	
	boys		2	0	0	1	1				0	0	0	1			100.0	
	total	1.0	4	0	1	2	2				0	0	0	1			100.0	

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio	Sex m / f	N	Relative %	Number of cases			Incidence rates per million					Trial participants	
					Group	%	Age group	Age stand. *					Cum.	%
								0 - 14	15 - 17	0 - 17	0 - 17	0 - 17		
Alveolar soft parts sarcoma	girls		10	0	3		6	4	0	0	0	4	100.0	
	boys		6	0	1		3	3	0	0	0	2	100.0	
	total	0.6	16	0	2		9	7	0	0	0	3	100.0	
Miscellaneous soft tissue sarcomas	girls		10	0	3		7	3	0	0	0	4	100.0	
	boys		21	0	4		17	4	0	0	0	8	100.0	
	total	2.1	31	0	4		24	7	0	0	0	6	100.0	
Unspecified soft tissue sarcomas	girls		31	1	8		28	3	1	0	1	13	100.0	
	boys		44	1	9		34	10	1	1	1	16	93.2	
	total	1.4	75	1	9		62	13	1	1	1	15	96.0	
Germ cell tumours, trophoblastic tumours and neoplasms of gonads	girls		310	5	100		246	64	7	8	7	123	96.1	
	boys		291	4	100		190	101	5	12	6	108	98.3	
	total	0.9	601	4	100		436	165	6	10	7	115	97.2	
Intracranial and intraspinal germ cell tumours	girls		52	1	17		44	8	1	1	1	21	96.2	
	boys		112	1	39		83	29	2	3	2	41	96.4	
	total	2.2	164	1	27		127	37	2	2	2	31	96.3	
Intracranial and intraspinal germinoma	girls		26	0	8		20	6	0	1	1	10	100.0	
	boys		71	1	24		47	24	1	3	1	25	100.0	
	total	2.7	97	1	16		67	30	1	2	1	18	100.0	
Intracranial and intraspinal teratomas	girls		9	0	3		7	2	0	0	0	4	88.9	
	boys		10	0	3		10	0	0	0	0	4	70.0	
	total	1.1	19	0	3		17	2	0	0	0	4	78.9	
Intracranial and intraspinal embryonal carcinoma	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	-	
Intracranial and intraspinal yolk sac tumour	girls		1	0	0		1	0	0	0	0	0	100.0	
	boys		5	0	2		4	1	0	0	0	2	100.0	
	total	5.0	6	0	1		5	1	0	0	0	1	100.0	
Intracranial and intraspinal choriocarcinoma	girls		4	0	1		4	0	0	0	0	2	100.0	
	boys		0	0	0		0	0	0	0	0	0	-	
	total	0.0	4	0	1		4	0	0	0	0	1	100.0	
Intracranial and intraspinal tumours of mixed for	girls		12	0	4		12	0	0	0	0	5	91.7	
	boys		26	0	9		22	4	1	0	0	10	96.2	
	total	2.2	38	0	6		34	4	0	0	0	7	94.7	

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex m / f	N	Relative			Number of cases			Incidence rates per million						Trial participants	
					0-17	%	N	Group	%	Age group			Age stand. *			Cum.	%	
										0 - 14	15 - 17	0 - 14	15 - 17	0 - 17				
Malignant extracranial and extragonadal germ cell tumours		girls		93	1	30		92	1		3	0	3		40		98.9	
		boys		60	1	21		47	13		1	1	1		23		98.3	
		total	0.6	153	1	26		139	14		2	1	2		31		98.7	
Germinomas of extracranial and extragonadal sites		girls		6	0	2		6	0		0	0	0		2		100.0	
		boys		8	0	3		4	4		0	0	0		3		100.0	
		total	1.3	14	0	2		10	4		0	0	0		3		100.0	
Malignant teratomas of extracranial and extragonadal sites		girls		48	1	16		48	0		2	0	1		21		100.0	
		boys		26	0	9		26	0		1	0	1		11		96.2	
		total	0.5	74	1	12		74	0		1	0	1		15		98.6	
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		25	0	8		24	1		1	0	1		11		96.0	
		boys		12	0	4		9	3		0	0	0		5		100.0	
		total	0.5	37	0	6		33	4		1	0	0		8		97.3	
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 germ cell tumours of extracranial and extragonadal sites		girls		14	0	5		14	0		0	0	0		6		100.0	
		boys		14	0	5		8	6		0	1	0		5		100.0	
		total	1.0	28	0	5		22	6		0	0	0		6		100.0	
Malignant gonadal germ cell tumours		girls		153	2	49		106	47		2	6	3		58		98.0	
		boys		119	1	41		60	59		2	7	2		44		100.0	
		total	0.8	272	2	45		166	106		2	6	3		51		98.9	
Malignant gonadal germinomas		girls		42	1	14		27	15		1	2	1		16		100.0	
		boys		15	0	5		4	11		0	1	0		5		100.0	
		total	0.4	57	0	10		31	26		0	2	1		10		100.0	
Malignant gonadal teratomas		girls		26	0	8		22	4		1	0	1		10		92.3	
		boys		15	0	5		13	2		0	0	0		6		100.0	
		total	0.6	41	0	7		35	6		0	0	0		8		95.1	
Malignant gonadal embryonal carcinomas		girls		0	0	0		0	0		0	0	0		0		-	
		boys		5	0	2		0	5		0	1	0		2		100.0	
		total	-	5	0	1		0	5		0	0	0		1		100.0	

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio	Sex m / f	N	Relative	Number of cases			Incidence rates per million					Trial participants	
					Group	%	Age group	Age stand. *					Cum.	%
								0 - 14	15 - 17	0 - 14	15 - 17	0 - 14		
Malignant gonadal yolk sac tumour	girls		21	0	7		16			0	1	0	8	95.2
	boys		21	0	7		19			1	0	1	8	100.0
	total	1.0	42	0	7		35			0	0	0	8	97.6
Malignant gonadal choriocarcinoma	girls		5	0	2		4			0	0	0	2	100.0
	boys		0	0	0		0			0	0	0	0	-
	total	0.0	5	0	1		4			0	0	0	1	100.0
Malignant gonadal tumours of mixed forms	girls		59	1	19		37			1	3	1	22	100.0
	boys		63	1	22		24			1	4	1	23	100.0
	total	1.1	122	1	20		61			1	4	1	23	100.0
Malignant gonadal gonadoblastoma	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	-
Gonadal carcinomas	girls		10	0	3		3			0	1	0	4	40.0
	boys		0	0	0		0			0	0	0	0	-
	total	0.0	10	0	2		3			0	0	0	2	40.0
Other and unspecified malignant gonadal tumours	girls		2	0	1		1			0	0	0	1	100.0
	boys		0	0	0		0			0	0	0	0	-
	total	0.0	2	0	0		1			0	0	0	0	100.0
Other malignant epithelial neoplasms and malignant melanomas	girls		228	4	100		159			4	8	4	87	72.8
	boys		173	2	100		122			3	6	3	63	68.8
	total	0.8	401	3	100		281			3	7	4	75	71.1
Adrenocortical carcinomas	girls		8	0	4		6			0	0	0	3	87.5
	boys		6	0	4		6			0	0	0	2	100.0
	total	0.8	14	0	4		12			0	0	0	3	92.9
Thyroid carcinomas	girls		99	2	43		69			2	4	2	38	83.8
	boys		48	1	28		38			1	1	1	17	91.7
	total	0.5	147	1	37		107			1	2	1	27	86.4
Nasopharyngeal carcinomas	girls		3	0	1		1			0	0	0	1	100.0
	boys		17	0	10		8			0	1	0	6	94.1
	total	5.7	20	0	5		9			0	1	0	4	95.0
Malignant melanomas	girls		29	0	13		23			1	1	1	11	37.9
	boys		33	0	19		27			1	1	1	12	30.3
	total	1.1	62	0	16		50			1	1	1	12	33.9

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex m / f	N	Relative		Number of cases		Age group			Incidence rates per million				Trial participants	
					0-17	%	%	Group	0 - 14	15 - 17	Age stand. *			Cum.	%		
											0-17	0 - 14	15 - 17			0 - 14	15 - 17
Skin carcinomas		girls		5	0	2		5	0		0	0	0	0	2	40.0	
		boys		3	0	2		1	2		0	0	0	0	1	0.0	
		total	0.6	8	0	2		6	2		0	0	0	0	2	25.0	
Other and unspecified carcinomas		girls		84	1	37		55	29		1	4	2	32	71.4		
		boys		66	1	38		42	24		1	3	1	24	65.2		
		total	0.8	150	1	37		97	53		1	3	1	28	68.7		
Carcinomas of salivary glands		girls		9	0	4		8	1		0	0	0	3	33.3		
		boys		8	0	5		8	0		0	0	0	3	25.0		
		total	0.9	17	0	4		16	1		0	0	0	3	29.4		
Carcinomas of colon and rectum		girls		5	0	2		4	1		0	0	0	2	60.0		
		boys		12	0	7		4	8		0	1	0	4	41.7		
		total	2.4	17	0	4		8	9		0	1	0	3	47.1		
Carcinomas of appendix		girls		39	1	17		27	12		1	1	1	15	97.4		
		boys		21	0	12		19	2		0	0	0	8	100.0		
		total	0.5	60	0	15		46	14		1	1	1	11	98.3		
Carcinomas of lung		girls		6	0	3		1	5		0	1	0	2	66.7		
		boys		10	0	6		5	5		0	1	0	4	70.0		
		total	1.7	16	0	4		6	10		0	1	0	3	68.8		
Carcinomas of thymus		girls		2	0	1		0	2		0	0	0	1	0.0		
		boys		0	0	0		0	0		0	0	0	0	-		
		total	0.0	2	0	1		0	2		0	0	0	0	0.0		
Carcinomas of breast		girls		1	0	0		0	1		0	0	0	0	0.0		
		boys		0	0	0		0	0		0	0	0	0	-		
		total	0.0	1	0	0		0	1		0	0	0	0	0.0		
Carcinomas of cervix uteri		girls		1	0	0		1	0		0	0	0	0	0.0		
		boys		0	0	0		0	0		0	0	0	0	-		
		total	0.0	1	0	0		1	0		0	0	0	0	0.0		
Carcinomas of bladder		girls		2	0	1		0	2		0	0	0	1	50.0		
		boys		1	0	1		0	1		0	0	0	0	100.0		
		total	0.5	3	0	1		0	3		0	0	0	1	66.7		
Carcinomas of eye		girls		0	0	0		0	0		0	0	0	0	-		
		boys		1	0	1		1	0		0	0	0	0	0.0		
		total	-	1	0	0		1	0		0	0	0	0	0.0		

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio	Sex m / f	N	Relative %	Number of cases			Incidence rates per million				Trial participants	
					Age group		Cum.	Age stand. *				Cum.	%
					0 - 14	15 - 17		0 - 14	15 - 17	0 - 17	0 - 17		
Carcinomas of other specified sites	girls		18	0	8	13	5	0	1	0	7	61.1	
	boys		8	0	5	3	5	0	1	0	3	50.0	
	total	0.4	26	0	7	16	10	0	1	0	5	57.7	
Carcinomas of unspecified site	girls		1	0	0	1	0	0	0	0	0	0.0	
	boys		5	0	3	2	3	0	0	0	2	60.0	
	total	5.0	6	0	2	3	3	0	0	0	1	50.0	
Others and unspecified malignant neoplasms	girls		13	0	100	11	2	0	0	0	5	76.9	
	boys		13	0	100	11	2	0	0	0	5	92.3	
	total	1.0	26	0	100	22	4	0	0	0	5	84.6	
Other specified malignant tumours	girls		9	0	69	8	1	0	0	0	4	77.8	
	boys		11	0	85	10	1	0	0	0	4	90.9	
	total	1.2	20	0	77	18	2	0	0	0	4	85.0	
Gastrointestinal stromal tumour	girls		1	0	8	1	0	0	0	0	0	100.0	
	boys		1	0	8	1	0	0	0	0	0	100.0	
	total	1.0	2	0	8	2	0	0	0	0	0	100.0	
Pancreatoblastoma	girls		2	0	15	2	0	0	0	0	1	50.0	
	boys		1	0	8	0	1	0	0	0	0	0.0	
	total	0.5	3	0	12	2	1	0	0	0	1	33.3	
Pulmonary blastoma and pleuropulmonary blastoma	girls		5	0	39	5	0	0	0	0	2	100.0	
	boys		9	0	69	9	0	0	0	0	4	100.0	
	total	1.8	14	0	54	14	0	0	0	0	3	100.0	
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	-	
Mesothelioma	girls		1	0	8	0	1	0	0	0	0	0.0	
	boys		0	0	0	0	0	0	0	0	0	-	
	total	0.0	1	0	4	0	1	0	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	-	
Other unspecified malignant tumours	girls		4	0	31	3	1	0	0	0	2	75.0	
	boys		2	0	15	1	1	0	0	0	1	100.0	
	total	0.5	6	0	23	4	2	0	0	0	1	83.3	

* Standard: Segi 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 2015 weitergeleiteten Meldungen

Number of forwarded reports from the German Childhood Cancer Registry to the state cancer registries (LKR) up to and including 2015

State cancer registry	Diagnosis period		Cases
	from	to	
Krebsregister Schleswig-Holstein	01.01.2010	15.07.2015	469
Hamburgisches Krebsregister	01.01.2010	15.07.2015	238
Epidemiologisches Krebsregister Niedersachsen	01.01.2010	15.07.2015	1160
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	01.01.2015	15.07.2015	1738
Epidemiologisches Krebsregister Saarland	01.01.2010	15.07.2015	134
Gemeinsames Krebsregister GKR *	01.01.2010	15.07.2015	1917
Gesamt			9845

* 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:

In Baden-Württemberg befindet sich das Landeskrebsregister derzeit zum Teil im Aufbau /
in the state of Baden-Württemberg the state cancer registries are under development

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Tabelle 11 / Table 11	118
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Forschungsprojekte und internationale Kooperationsprojekte seit 2013

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Research projects and international cooperations since 2013

114 Neues zu Forschungsprojekten / News on Research Projects

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 (10). Derzeit werden die Daten bis 2009 und zum Teil bis 2012 für eine aktualisierte Fassung im Jahr 2016 bei der IARC (International Agency for Research on Cancer) gesammelt.

Das Deutsche Kinderkrebsregister trägt seine Daten zu dem Projekt bei.

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 (28). Derzeit werden die Datensätze für EUROCARE-6 vorbereitet.

Das Deutsche Kinderkrebsregister trägt zu dem Projekt seine Daten bei.

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. Mediziner, 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 (30, 31, 37).

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 wird offiziell Ende Januar 2017 zu Ende gehen. Das Projekt umfasst 16 Partner. Im Rahmen dieser Verbund-Forschung sollen Richtlinien entwickelt werden, um die Nachsorge ehemaliger Patienten zu optimieren und eine Grundlage für for-

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. The published data is available since 1997 (10). Currently data up to 2009 and partially up to 2012 is being collected at IARC (International Agency for Research on Cancer) for an updated version in 2016.

The German Childhood Cancer registry contributes 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 covers the years until 2007 (28). Survival probabilities for childhood cancers have greatly improved, but differences among countries persist. Currently, data sets for EUROCARE-6 are being prepared.

The German Childhood Cancer registry contributes its data to the project.

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 (30, 31, 37).

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 will officially run out in the end of January 2017. It includes 16 partners. The joint research aims 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 thera-

schungsbezogene Informationen bereitzustellen, die alle Spätfolgen der Krebstherapie betreffen. Eine große europäische Kohorte von über 100.000 ehemaligen Patienten mit einer Krebserkrankung im Kindes- und Jugendalter wurde aufgebaut, nachbeobachtet und mögliche Spätfolgen werden speziell untersucht. Dazu zählt das Auftreten von Zweittumoren, Herzschädigungen und das Versterben der Patienten mehr als fünf Jahre nach der Erkrankung (late mortality). Das Projekt befindet sich in der Auswertephase. Erste Publikationen sind erschienen (37, 41).

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.pancarelife.eu) sind Wissenschaftler aus acht europäischen Nationen beteiligt. Fertilität, Ototoxizität und gesundheitsbezogene Lebensqualität stehen im Focus dieses Projektes. Insgesamt fließen die Daten von rund 12.000 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 werden um festzustellen, welche genetischen Varianten potentiell mit diesen Spätfolgen assoziiert sind. Auch Guidelines zur Fertilitäts-erhaltung werden erarbeitet. PanCareLIFE wird an der Universitätsmedizin Mainz koordiniert (22, 30).

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

pies. 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 effects. These include cardiac disease, second cancers and late mortality (more than 5 years after diagnosis). At present, the analyses are carried out. First publications have come out (37, 41).

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 12,000 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 (22, 30).

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 Fe-

Krebserkrankung im Kindesalter, Studienteilnehmer mit nur einer Krebserkrankung im Kindesalter und Studienteilnehmer ohne Krebserkrankung. Die Krebspatienten wurden über das Deutsche Kinderkrebsregister bestimmt. Die Studie wird vom BMBF finanziert und ist Teil des ISIMEP und 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 Münster (Klinik für Kinder- und Jugendmedizin des Universitätsklinikums). 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.

Die Befragung der etwa 10.000 ehemaligen Patienten begann im Jahre 2014 und endete 2015 (20).

CVSS: Kardiale und vaskuläre Spätfolgen von Langzeit-Überlebenden nach Krebs im Kindes- und Jugendalter

Das Projekt „Kardiale und vaskuläre Spätfolgen von Langzeit-Überlebenden nach Krebs im Kindes- und Jugendalter“ (Cardiac and vascular late sequelae in long-term survivors of childhood cancer, 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 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

Education and Research (BMBF) und ist part of the research consortium ISIMEP and ISIBELa.

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 Münster (Klinik für Kinder- und Jugendmedizin des Universitätsklinikums). 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.

The survey, including about 10,000 former patients, started in 2014 and ended in 2015 (20).

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 Policlinic.

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

pen 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 Kinderkrebsregister 2.657 ehemalige Patienten eingeladen, an der CVSS-Studie teilzunehmen. Über 900 ehemalige Patienten wurden bereits mit einem 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, 25).

Weitere Informationen zur CVSS-Studie finden sich unter www.CVSS-Studie.de.

Beschreibungen der anderen Projekte finden Sie in den vorangegangenen Jahresberichten.

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 the GCCR to participate in the CVSS-study. More than 900 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, 25).

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

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

Tabelle 11:

Forschungsprojekte und internationale Kooperationsprojekte seit 2013 (see Table 12 for the English version)

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
ACCIS: Automated Childhood Cancer Information System	Internationale Datenbank	10, 35	IARC, Lyon, Frankreich	nein	./.
EUROCARE: Survival of cancer patients in Europe	Follow-up Studie	13, 28	Istituto Nazionale dei Tumori, Mailand, Italien	nein	./.
PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	Internationale Kohorten- und Fall-Kontroll-Studie	30, 31, 37, 41	Gesamtleitung: Lund University Hospital, Schweden; Leitung Work-package 1 (Data Collection and Harmonization): DKKR	ja	Europäische Kommission EU FP7
KiKme: Krebserkrankungen im Kindesalter und molekulare Epidemiologie	Fall-Kontroll-Studie		Studienleitung: 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	34, 43	IMBEI	ja	Bundesministerium für Bildung und Forschung
VIVE: Basiserhebung zu Lebenssituation, Gesundheitszustand und Lebensqualität nach onkologischer Erkrankung im Kindes- und Jugendalter	Kohortenstudie	20	Projektkoordination: Klinik für Kinder- und Jugendmedizin des Universitätsklinikums Münster	ja	Deutsche Krebshilfe

Tabelle 11 Forts. Table 11 cont.

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
PanCareLife: PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	Internationale Kohorten- und Fall-Kontroll-Studie	22, 30	DKKR	ja	Europäische Kommission EU FP7
CVSS: Kardiale und vaskuläre Spätfolgen bei Langzeitüberlebenden nach Krebserkrankungen im Kindesalter	Kohortenstudie	21, 25	Universitätsmedizin Mainz: DKKR, Pädiatrische Hämatologie und Onkologie, II. Medizinische Klinik	ja	Deutsche Forschungsgemeinschaft
RASopathien und Krebs im Kindesalter	Kohortenstudie	33	Abt. päd. Hämatologie und Onkologie Hannover, Institut für Humangenetik Magdeburg, Deutsches Kinderkrebsregister	ja	National Institute of Health

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

Tabelle 12:

Research projects and international cooperations since 2013 (see table 11 for the German version)

Name of the project	Type of study	References
ACCIS: Automated Childhood Cancer Information System	International Data Base on Childhood Cancer	10, 35
EUROCARE: Survival of cancer patients in Europe	Follow-up Study	13, 28
PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	International Cohort and Case-Control Study	30, 31, 37, 41
Kikme: Cancer in childhood and molecular epidemiology	Case-Control Study	
KiCT: Risk of childhood cancer after computed tomography in childhood	Cohort Study	34, 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 Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	International Cohort and Case-Control Study	22, 30
CVSS: Cardiac and vascular late sequelae in long-term survivors of childhood cancer - a multidisciplinary clinical, epidemiological and genetic approach	Cohort Study	21, 25
RASopathies and cancer in childhood	Cohort Study	33

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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%, 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 (zuletzt geändert 2016) schreibt die „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-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 (39). 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 Hämatologie (GPOH) und den behandelnden Kliniken. Es ist dadurch charakterisiert, dass es neben den üblichen, in einem bevölkerungsbezogenen Krebsregister erfassten Daten auch eine ganze

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 (last change 2016) the directive „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-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 (39). 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 (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,

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 Langzeitnachsorge. Damit stellt das DKKR die Grundlage für die Erforschung von Spätfolgen, wie z.B. Folge-neoplasien, 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 (im Rahmen von Adressrecherchen), 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, 15, 23, 24, 39) beschrieben. Die Langzeitnachsorge ist in (11, 16-18) publiziert.

Datengrundlage

Das DKKR nahm 1980 seine Arbeit auf. Die Registerpopulation im engeren Sinne umfasst die Kinder und 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)) erkrankten und zur deutschen Wohnbevölkerung gehören. Seit 1991 sind die neuen Bundesländer mit einbezogen.

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, 15, 23, 24, 39), the follow-up procedures are published in (11, 16-18).

Data basis

In 1980, the GCCR was initiated by the GPOH. It is intended to include all children and adolescents with 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.

124 Methoden / Methods inc. ICC-3

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 Vollständigkeit 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 vollständig. Bei Diagnosen, die auch häufiger oder typischerweise eher im Erwachsenenalter auftreten, fehlen Meldungen.

Neben den in der ICC-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 (39). 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-/Folgeneoplasmen (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 vollständig ist, die angegebenen Zahlen sind daher als untere Abschätzung anzusehen.

Grundlagen der Registrierung und Arbeitsweise zum Nachlesen

Literaturstellen

- Meldung und Dokumentationsablauf (4, 5, 8, 39)
- Langzeitnachsichtbeobachtung (11, 16-18, 25)
- 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 (39)

Classification of diseases is currently based on the International Classification of Childhood Cancer 3rd edition (ICCC-3) (9). The ICC-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 ICC-3, the GCCR records a number of further diagnoses systematically (Table 5). Since 2009 we added a few more rare non-malignant diagnoses (39). 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.

Further Information on the Basis of Registration and Procedures

References

- Notification and documentation (4, 5, 8, 39)
- Long-term surveillance (11, 16-18, 25)
- 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 (39)

Weitere Informationen finden sich auf unserer Homepage (www.kinderkrebsregister.de) und im Literaturverzeichnis:

Further information can be found on our homepage (www.kinderkrebsregister.de) and in the references:

- Beschluss der 82. Gesundheitsministerkonferenz 2009 (Kinderkrebsregister - Anhebung der Altersgrenze für die Registrierung von Kindern und Jugendlichen) (14)
- Bundeskrebsregisterdatengesetz (12)
- Krebsfrüherkennungs- und -registergesetz (KFRG) (19)
- Notwendigkeit der namensbezogenen Datenspeicherung (40)
- Die Rahmenbedingungen des Deutschen Kinderkrebsregisters (8, 15)
- 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 (29)
- DKKR-Einwilligungserklärung (26)
- DKKR-Technisches Datenschutz- und Datensicherheitskonzept des Deutschen Kinderkrebsregisters (27)
- Die Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters (16-18)

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 7 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.

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

$$I_{ij} = \frac{N_{ij}}{B_{ij}} \cdot 1000000$$

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 seven 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.

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

$$I_{ij} = \frac{N_{ij}}{B_{ij}} \cdot 1000000$$

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:

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 2009-2015

Composition of the Segi world standard for children under 15 resp. 18 years compared to the German population 2009-2015

Age-groups (years)	German population 2009-2015		World standard population		
	Absolute	Relative		Weights	
		< 15	< 18	< 15	< 18
0	682,505	0.06	0.05	0.08	0.07
1-4	2,734,474	0.25	0.20	0.31	0.26
5-9	3,527,645	0.33	0.27	0.32	0.27
10-14	3,846,082	0.36	0.29	0.29	0.25
15-17	2,474,716	-	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,

The cumulative incidence C_i until age 15 or 18 is estimated as the sum of the age-specific incidence rates,

$$C_i = \sum_j I_{ij} \quad ,$$

$$C_i = \sum_j I_{ij} \quad ,$$

wobei hier gewöhnlich 15 bzw. 18 Einzelaltersjahresklassen 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 Krebserkrankung zu erkranken.

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 newborn to become a cancer case until his/her 15th or 18th birthday.

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

$$K_i = \frac{1000000}{C_i} \quad \text{oder} \quad K_i = \frac{1000000}{C_i} .$$

Die Bevölkerungszahlen für das Jahr 2015 lagen bei Erstellung des Jahresberichts noch nicht vor und wurden hochgerechnet. Die Hochrechnung basiert auf dem Trend der Vorjahre und den Geburtenzahlen des Vorjahrs. 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 (38).

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 Langzeitüberlebens.

Die graphische Darstellung in diesem Bericht präsentiert die Überlebenszeitkurven nur bis zum tatsächlichen Beobachtungsende. Dargestellt werden die Überlebenswahrscheinlichkeiten nach Diagnosejahren für die erste bis dritte Dekade, die zweite Dekade, und die angefangene vierte Dekade. Bei einigen Diagnosen liegen noch keine ausreichend vollständigen Nachbeobachtungsdaten aus den letzten Jahren vor, die entsprechende Kurve wird dann nicht dargestellt und die Angaben in den Tabellen fehlen. Auch bei sehr wenigen Fällen bzw. unvollständigen Nachbeobachtungsdaten wird keine Überlebenswahrscheinlichkeit in den Tabellen angegeben.

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.

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

$$K_i = \frac{1000000}{C_i} \quad \text{or} \quad K_i = \frac{1000000}{C_i} .$$

For 2015 population data was not yet available; we are thus using estimated numbers. The estimation is based on the trend of the previous years and the number of births of the previous year.- 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 (38).

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.

The graphical presentation in this report cuts the survival curves at the observed maximum observation time. We present the survival curves for the first, second and third decade, and the beginning of the fourth decade. For some diagnoses follow-up data for more recently diagnosed cases is still rather incomplete, we then do not present this most recent curve and the corresponding numbers. Few cases under observation and generally incomplete follow-up data also leads to no information about survival and mortality.

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.

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 ICC-3 definierte Krebserkrankungen. Gutartige weitere Erkrankungen (außer den in der ICC-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 ICC-3) im Alter von unter 15 Jahren in der deutschen Wohnbevölkerung. 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 (ICC-3 Ib) (Tabelle M.2):

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 ICC-3 defined cases. Non-malignant diseases (unless they are non-malignant CNS-tumours included in ICC-3) are not counted here.

The population base for these calculations are all patients with a primary disease (as defined in ICC-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 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 (ICC-3 Ib) as an example (Table 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 (1980-2013):

I (b) Acute myeloid leukaemias

SN after I (b)			I (b) as SN after any primary		
N	% of all 1253 SN	Cumulative incidence	N	% of all 1253 SN	Cumulative incidence
51	4.1 %	5.2 %	140	11.2 %	0.3 %

Bei den in den Jahren 1980-2013 mit einer AML unter 15 Jahren als erster Krebserkrankung diagnostizierten Patienten wurden in den folgenden bis zu 30 Jahren 51 zweite Krebserkrankungen diagnostiziert. Das sind 4,1% von allen 1253 innerhalb von 30 Jahren nach Diagnose in den Jahren 1980-2013 an das DKKR gemeldeten zweiten Krebserkrankungen. Bei 4,1% aller primären AML Patienten wird innerhalb von 30 Jahren nach Erstdiagnose eine weitere Krebserkrankung diagnostiziert, das ist unterdurchschnittlich im Vergleich

Within 30 years of diagnosis 51 second neoplasms were diagnosed out of the patients with an AML as a first diagnosis at age under 15 in the years 1980-2013. These are 4.1 % of all 1253 recorded second neoplasms within 30 years of diagnosis in the years 1980-2013 at the GCCR. 4.1% of all primary AML patients are diagnosed with a second neoplasm within 30 years of diagnosis in the years 1980-2013, this is lower than the average cumulative incidence of 6.6% for all malignancies.

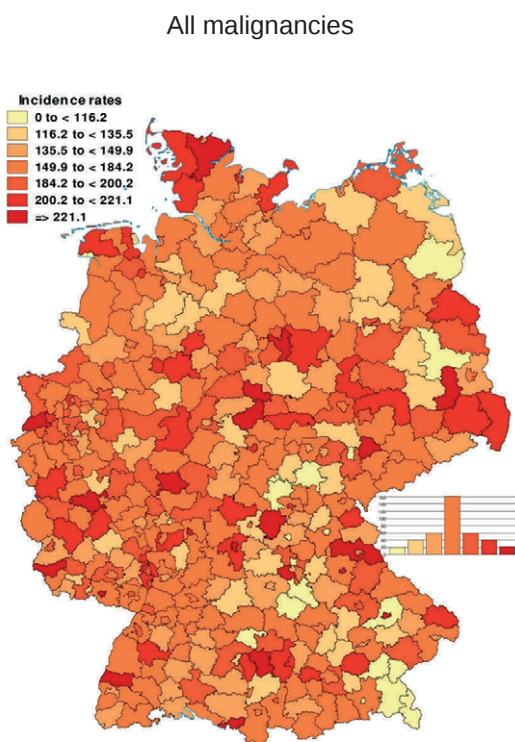
zum durchschnittlichen SN-Risiko nach allen Malignomen von 6,6%.

Nach einer ersten Krebserkrankung beliebigen Typs im Alter von unter 15 in den Jahren 1980-2013 wurde bei 140 Patienten anschließend in den nächsten 30 Jahren eine AML diagnostiziert. 11,2% aller 1253 dem DKKR innerhalb von 30 Jahren nach Diagnose in den Jahren 1980-2013 gemeldeten zweiten Krebserkrankungen sind AML, im Vergleich zu dem Anteil von AML an allen Krebserkrankungen im Kindesalter (4,3%) ist das ungewöhnlich viel. Bei 0,3% 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% 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 ergebenden 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.

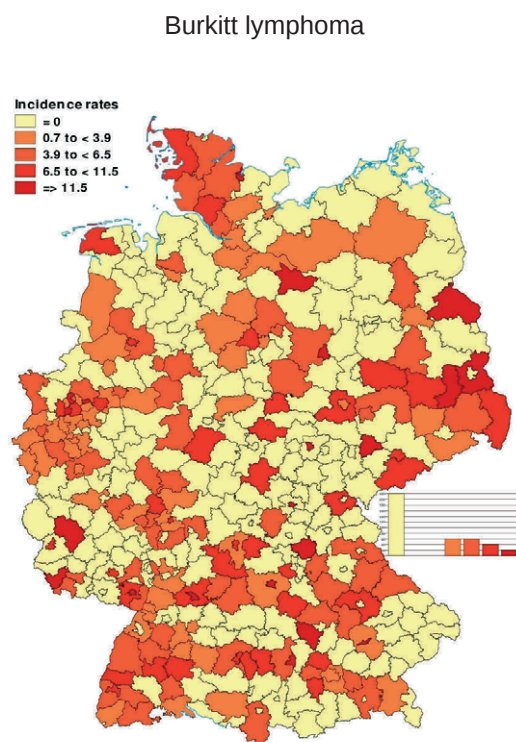
Abbildung M.1: Zwei Beispielkarten
Figure M.1: Two Sample Maps



After any primary neoplasm at age under 15 in 1980-2013, 140 patients were diagnosed with AML as second neoplasms within 30 years of diagnosis in the years 1980-2013. 11.2% of all 1253 second neoplasms within 30 years of diagnosis of the primary disease in the years 1980-2013 reported at the GCCR are AML. Compared to 4.3% AML in general, this is a large number. 0.3% 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 "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.



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 .

$$SIR_{ir} = \frac{N_{ir}}{\sum_j B_{ijr} \frac{I_{ij}}{1000000}} \quad .$$

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 402 Kreisen wären also zufällig etwa 20 Kreise mit ungewöhnlich hohen oder niedrigen Inzidenzraten zu erwarten, tatsächlich waren es beispielsweise für alle ICC3-3 Diagnosen für den Zeitraum 2006-2015 17 Kreise, davon 11 mit besonders hohen und 6 mit besonders niedrigen Fallzahlen.

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 .

$$SIR_{ir} = \frac{N_{ir}}{\sum_j B_{ijr} \frac{I_{ij}}{1000000}} \quad .$$

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 402 Kreise we would thus randomly expect about 20 with unusual incidence rates. For the time period 2006-2015 for all ICC3-3 diagnoses we actually observed 17, 11 with unusually high and 6 with unusually low numbers of cases.

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	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
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	C72.3
	9384, 9400-9411, 9420, 9421-9424, 9440-9442	*
(c) Intracranial and intraspinal embryonal tumours	9470-9474, 9480, 9508	*
	9501-9504	C70.0-C72.9
1 Medulloblastomas	9470-9472, 9474, 9480	*
2 Primitive neuroectodermal tumour (PNET)	9473	*
3 Medulloepithelioma	9501-9504	C70.0-C72.9
4 Atypical teratoid / rhabdoid tumour	9508	*
(d) Other gliomas	9380	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
	9381, 9382, 9430, 9444, 9450, 9451, 9460	*
1 Oligodendrogliomas	9450, 9451, 9460	*
2 Mixed and unspecified gliomas	9380	C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
	9382	*
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

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
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	C64.9
	8311, 8312, 8316-8319, 8361	
(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	C22.0, C22.1
	8160-8180	
(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	C40.0-C41.9, C76.0-C76.8, C80.9
	9221, 9230, 9241-9243	
(c) Ewing tumour and related sarcomas of bone	9260	C40.0-C41.9, C76.0-C76.8, C80.9
	9363-9365	C40.0-C41.9
1 Ewing tumour and Askin tumour of bone	9260	C40.0-C41.9, C76.0-C76.8, C80.9
	9365	C40.0-C41.9
2 Peripheral neuroectodermal tumour (pNET) of bone	9363, 9364	C40.0-C41.9
(d) Other specified malignant bone tumours	8810, 8811, 8823, 8830	C40.0-C41.9
	8812, 9250, 9261, 9262, 9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342, 9370-9372	
1 Malignant fibrous neoplasms of bone	8810, 8811, 8823, 8830	C40.0-C41.9
	8812, 9262	
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 EXTRAOSSEOUS 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	C00.0-C39.9, C44.0-C76.8, C80.9
	8820, 8822, 8824-8827, 9150, 9160, 9491, 9540-9571, 9580	
1 Fibroblastic and myofibroblastic tumours	8810, 8811, 8813-8815, 8821, 8823, 8834-8835	C00.0-C39.9, C44.0-C76.8, C80.9
	8820, 8822, 8824-8827, 9150, 9160	
2 Nerve sheath tumours	9540-9571	
3 Other fibrous neoplasms	9491, 9580	

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	C49.0-C49.9
	9231	
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 EXTRAOSSEOUS 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	C00.0-C55.9, C57.0-C61.9, C63.0-C69.9, C73.9-C75.0, C75.4-C76.8, 80.9
2 Malignant teratomas of extracranial and extragonadal sites	9080-9084	
3 Embryonal carcinomas of extracranial and extragonadal sites	9070, 9072	
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	C56.9, C62.0-C62.9
2 Malignant gonadal teratomas	9080-9084, 9090, 9091	
3 Gonadal embryonal carcinomas	9070, 9072	
4 Gonadal yolk sac tumour	9071	
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

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

Veröffentlichungen mit Beteiligung des Deutschen Kinderkrebsregisters seit 2013

Publications by or in co-operation with the German Childhood Cancer Registry since 2013

2013

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