

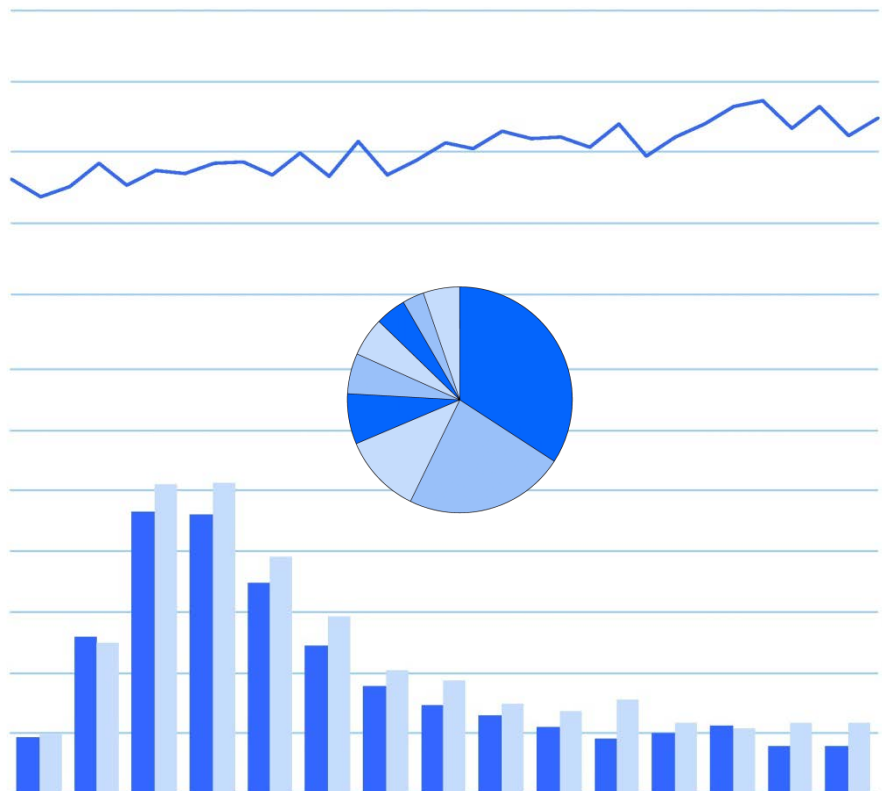
*Deutsches
Kinderkrebsregister*



Jahresbericht / Annual Report 2012



German Childhood Cancer Registry





Deutsches
Kinderkrebsregister

Jahresbericht Annual Report 2012

Deutsches Kinderkrebsregister DKKR
German Childhood Cancer Registry GCCR



UNIVERSITÄTSmedizin.
MAINZ



Institut für Medizinische Biometrie
Epidemiologie und Informatik

Jahresbericht / Annual Report 2012

November, 2013

Deutsches Kinderkrebsregister am
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Vorwort

Der vorliegende Jahresbericht 2012 enthält Daten von 51.883 Kindern und Jugendlichen, bei denen von Beginn unserer Tätigkeit im Jahr 1980 bis zum Jahr 2012 eine Krebserkrankung vor ihrem 15. Geburtstag diagnostiziert wurde. Die meisten Auswertungen beziehen sich auf den aktuell zurückliegenden 10-Jahreszeitraum, dies sind die Jahre 2003-2012. Alle früheren Jahresberichte seit 1997 sind auf der Internetseite www.kinderkrebsregister.de abrufbar.

Die enge Zusammenarbeit mit den behandelnden Kliniken, den Therapieoptimierungsstudien und Diagnoseregistern der GPOH (Gesellschaft für Pädiatrische Onkologie und Hämatologie) charakterisiert die Tätigkeit des Deutschen Kinderkrebsregisters. Den Klinikern und Studienleitungen sei an dieser Stelle herzlich für die vertrauensvolle Zusammenarbeit gedankt. Nicht zuletzt kommt bei der routinemäßigen Meldung erkrankter Kinder und Jugendlicher den in der Dokumentation Tätigen ein besonderer Stellenwert zu. Daher lädt das Deutsche Kinderkrebsregister von Zeit zu Zeit Dokumentare und Dokumentarinnen aus Kliniken und Studienleitungen nach Mainz ein. Im April 2012 wurde ein solcher Informationstag mit 18 externen Teilnehmern durchgeführt. Eingeladen waren diesmal insbesondere neue Kollegen und Kolleginnen, die an der letzten, 2009 ausgerichteten Veranstaltung nicht teilgenommen hatten. Organisatorische, inhaltliche, datenschutzrelevante und dokumentationstechnische Fragen wurden diskutiert und bearbeitet. Für die engagierte und kollegiale Zusammenarbeit möchten wir den in der Dokumentation tätigen Kolleginnen und Kollegen besonderen Dank sagen.

Regelmäßig erfolgt ein Datenabgleich nicht nur mit den klinischen Studien der GPOH, sondern auch zwischen dem Deutschem Kinderkrebsregister und den elf deutschen Landeskrebsregistern. Auch hierbei konnte unsere Arbeit kontinuierlich weitergeführt werden: Zwischen 2007 und 2012 konnten insgesamt 9309 Meldungen neu Erkrankter vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister weitergeleitet werden. Die jeweils landesspezifischen datenschutzrechtlichen Randbedingungen wurden dabei natürlich berücksichtigt.

Die deutsche Kohorte Langzeitüberlebender nach Krebs im Kindesalter, so wie sie am Deutschen Kinderkrebsregister etabliert ist, wurde im Jahr 2012 unter anderem im Bundesgesundheitsblatt beschrieben (34). Es handelt sich um eine einzigartige Datenbasis mit mittlerweile etwa 28.000 Betroffenen, die für Spätfolgenstudien unterschiedlichster Art grundsätzlich verfügbar sind. Darauf aufbauend wurden bislang zwei große wissenschaftliche Studien initiiert (CVSS-Studie zur präklinischen Erkennung kardiovaskulärer Spätfolgen – gefördert von der Deutschen Forschungsgemeinschaft; VIVE-Studie zur systematischen Basis-

Foreword

This annual report for 2012 includes data on 51,833 children and adolescents reported to the German Childhood Cancer Registry as having been diagnosed with cancer at age under 15 from 1980, our starting year, to 2012. Most tables refer to the latest 10-year period 2003-2012. All previous annual reports from 1997 onwards are available at www.kinderkrebsregister.de.

Our procedures are characterized by close cooperation with the treating hospitals and the clinical studies and diagnosis specific registries of the GPOH (Society for Paediatric Oncology and Haematology). At this point sincere thanks are given to all hospitals and clinical studies for the trusting cooperation for many years. We are particular grateful to those working in documentation for the regular and timely reporting of newly diagnosed children and adolescents. These documentalists working at hospitals or clinical studies are hence invited to Mainz from time to time. One such information day with 18 participants took place in April 2012. At that time we particularly invited new colleagues and those who had not been able to attend the 2009 meeting. The relevant topics were organization, documentation, data protection and medical information. We are very happy to have such committed colleagues in documentation.

We regularly exchange data with the GPOH clinical studies as well as with the other German cancer registries (state registries). As in previous years, we passed on 9309 reports of new diagnoses to the respective state registries, allowing for the respective legal basis per state.

We recently published details on the cohort of long-term survivors after childhood cancer, as established at the German Childhood Cancer Registry, in the Bundesgesundheitsblatt (34). This cohort, currently including about 28,000 survivors, is a unique data basis for late effects studies. So far two large scientific studies have recently started, which are using this data base: the CVSS study on preclinical cardiovascular disease as a late effect funded by the Deutsche Forschungsgemeinschaft, and the VIVE-study, a systematic survey on living conditions, health status and quality of life, funded by the German Cancer Aid Foundation. Both

erhebung zu Lebenssituation, Gesundheitszustand und Lebensqualität – gefördert von der Deutschen Krebshilfe). Bei beiden werden Langzeitüberlebende angeschrieben, befragt und in der erstgenannten Studie zu Untersuchungen eingeladen. Die Initiierung und Teilnahme an zwei weiteren, von der EU geförderten europäischen Forschungsvorhaben zu Spätfolgen nach Krebstherapie bei Kindern (laufende Studie „PanCareSurFup“ zu kardiologischen Spätfolgen, Zweittumoren und Spätmortalität; im Jahr 2012 beantragte und in 2013 bewilligte Studie „PanCareLIFE“ zu Fragen der Fertilität, Schwerhörigkeit und Lebensqualität) unter verantwortlicher Einbindung des Deutschen Kinderkrebsregisters können als weitere Beispiele für den hohen Stellenwert der Langzeitnachbeobachtung genannt werden. An dieser Stelle sei allen Förderern dieser Studien gedankt.

Solche Studien bauen auf der langfristigen Finanzierung auf, die zu jeweils einem Drittel vom rheinland-pfälzischen Ministerium für Soziales, Arbeit, Gesundheit und Demografie und vom Bundesgesundheitsministerium getragen wird. Das übrige Drittel teilen sich die 16 Landesgesundheitsministerien anteilig auf. Dafür sei hier ein herzlicher Dank ausgesprochen.

In diesem Zusammenhang möchten wir uns auch bei den Betroffenen dafür bedanken, dass sie uns ihre Daten vertrauensvoll zur Verfügung stellen: bei den Eltern, weil diese ihre Einwilligung zur Datenweitergabe an das Deutsche Kinderkrebsregister geben und uns viele Fragen beantworten und ebenso bei den vielen Patienten, die wir später als Erwachsene regelmäßig kontaktieren und die uns Auskunft über ihren Gesundheitszustand geben.

Peter Kaatsch

Mainz, im November 2013

studies contact long term survivors and question them, the first one also offers a bodily examination. Research on long-term survival increases in importance at the GCCR as can be seen by two more projects: We have co-initiated and participate in EU-funded projects on late effects after cancer therapy in childhood: „PanCareSurFup“ on cardiac late effects, second neoplasms, and late mortality is already in its field phase, while „PanCareLIFE“ on fertility, ototoxicity and quality of life was submitted in 2012 and approved in 2013. We are grateful to all who make these studies possible.

The basis for all these studies is the long-term funding granted by the Rhineland-Palatinate Ministry for Labour, Social Affairs, Health and Demography (one third) and the Federal Ministry for Health (one third). The last third is funded by all 16 state ministries according to population size. We would like to thank all these funding agencies.

Finally we would like to thank all patients and their families for entrusting us with their data. We are grateful for their willingness to consent to data storage and processing and willingness to answer many questions on their health status over the years.

Meldungen von Fällen unter 15 Jahren im Jahr 2012 (Meldungen aus 63 Kliniken):	1685
Durchschnittliche Meldungen von Fällen unter 15 Jahren pro Jahr: (ermittelt aus den Jahren 2003-2012)	1770
vor dem 15. Lebensjahr erkrankt ...	eines von 420 Neugeborenen
Jungen / Mädchen	982 / 788
Meldungen von unter 5-jährigen	781
Meldungen von 5- unter 10-jährigen	475
Meldungen von 10- unter 15-jährigen	514
lymphatische Leukämien (ALL)	465
Durchschnittliche Meldungen von Fällen im Alter von 15- unter 18 Jahren pro Jahr: (ermittelt aus den Jahren 2009-2012)	341
Zahl aller Meldungen unter 15 Jahren von Beginn der Erfassung im Jahr 1980 bis 2012:	51883
in Langzeitnachsicht beobachtet	ca. 28000

Bevölkerung im Alter von unter 15 Jahren (Mio.):	
in 2012	10,9
im Durchschnitt (in den Jahren 2003-2012)	11,4

Prognose der Fälle im Alter von unter 15 Jahren:

- 81 % überleben derzeit eine Krebserkrankung mindestens 15 Jahre
- 88 % überleben derzeit eine lymphatische Leukämie (ALL) mindestens 15 Jahre
- Insgesamt etwa 400 Todesfälle pro Jahr

Zweittumoren nach einer im Kindesalter aufgetretenen Ersterkrankung:

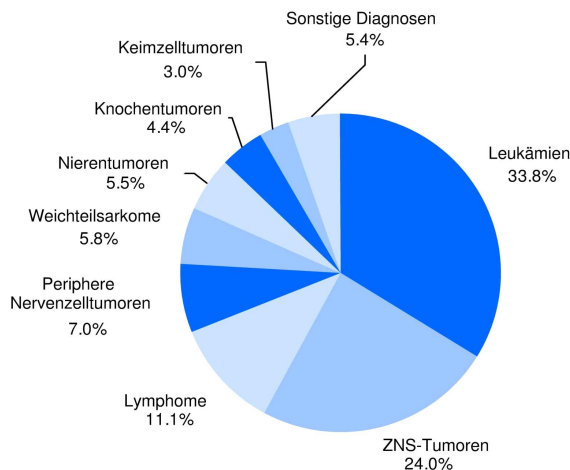
- 4,7 % der Patienten erkranken innerhalb von 25 Jahren nach Diagnose erneut an Krebs
- Insgesamt sind über 1000 Patienten mit Zweittumoren registriert

Durchschnittliche Meldungen von Fällen unter 15 Jahren pro Jahr nach Bundesländern:

(ermittelt aus den Jahren 2003-2012)

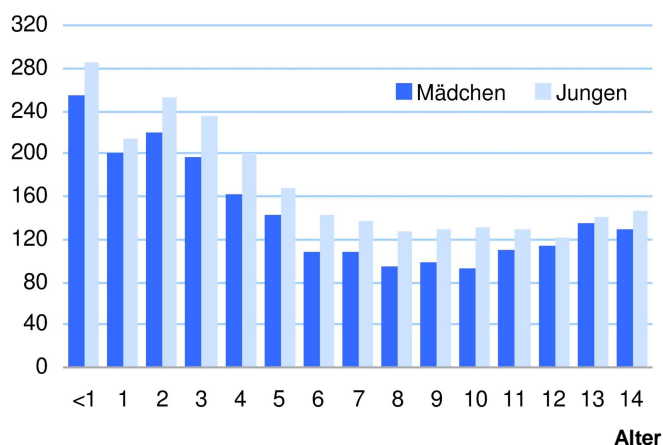
	Alle Erkrankungen	Leukämien		Alle Erkrankungen	Leukämien
Schleswig-Holstein	66	22	Bayern	281	101
Hamburg	33	12	Saarland	20	7
Niedersachsen	178	62	Berlin	64	23
Bremen	12	4	Brandenburg	44	17
Nordrhein-Westfalen	418	136	Mecklenburg-Vorpommern	28	8
Hessen	139	48	Sachsen	77	24
Rheinland-Pfalz	93	28	Sachsen-Anhalt	38	13
Baden-Württemberg	239	82	Thüringen	39	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)*



*2003-2012, basierend auf insgesamt 17697 unter 15-jährige Patienten

I Leukaemias, myeloproliferative and myelodysplastic diseases

Diese hämatologischen Erkrankungen sind die häufigsten bösartigen Erkrankungen im Kindes- und Jugendalter. Betroffen ist eines von 1200 Kindern, Jungen etwa 20% öfter als Mädchen. Etwa die Hälfte der Erkrankungen tritt bereits vor dem Schulalter auf. Bei Kindern überwiegen die akuten Formen, bei Erwachsenen chronische Formen. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100% Vollzähligkeit der Erfassung aus.

Die häufigste Form, die lymphatische Leukämie (früher ALL), nimmt in Deutschland und Europa weiter langsam zu (ca. 0,7% pro Jahr). In der Literatur wird dieser Anstieg als echt und nicht als Registrierungsartefakt bewertet; ursächlich werden Änderungen des Lebensstils vermutet. Die Prognose ist gut (88% Langzeitüberlebende) und steigt weiter.

Akute myeloische Leukämien (AML) sind deutlich seltener und haben eine schlechtere Prognose (69% Langzeitüberlebende); die seit den 1980ern erzielten Verbesserungen der Therapie sind erheblich.

Das myelodysplastische Syndrom (MDS) wurde erst seit Anfang des Jahrtausends (mit Veröffentlichung der ICD-O-3) als bösartig (maligne) klassifiziert. Erkrankungs- und Überlebenszahlen sind damit davor nicht repräsentativ. Ein Teil der MDS entwickelt sich zu einer AML weiter. Es gibt keine abschließende Meinungsbildung unter den Krebsregistern, 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 20% der zweiten und weiteren Krebserkrankungen (subsequent neoplasms (SN)). Dies dürfte überwiegend eine Therapiefolge sein; Patienten mit sekundärer AML haben eine schlechte Prognose.

These hematological diseases are the most frequent malignant diseases in childhood and adolescence. (One child out of 1200 is affected, boys ca. 20% more often than girls). About half of the cases are 5 years and below. Children show mostly acute forms, whereas adults show mostly chronic forms. Based on international comparisons we assume completeness is close to 100%.

The most frequent form, lymphoid leukaemia (used to be ALL), is slowly increasing in Germany and Europe (ca. 0.7% p.a.). In the literature this increase is considered to be real, not a registration artifact, possibly due to changes in lifestyle. The prognosis is good (88% long term survivors) and increases further.

Acute myeloid leukaemias (AML) are much less frequent and have a worse prognosis (69% long term survivors); the improvements in therapy since the 1980s are considerable.

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. Cancer registries have not yet agreed on a unified method of counting such cases, as a consequence comparisons over time or registries are problematic.

20% of the second and subsequent neoplasms (SN) are AML or MDS, this is most likely a consequence of the therapies; patients with secondary AML have a bad prognosis.

II Lymphomas and reticuloendothelial neoplasms

Lymphome (eines von 4000 Kindern) treten im Allgemeinen im Jugend- und Erwachsenenalter und nur selten bei Kleinkindern auf. Burkitt-Lymphome (BL) zählen zu den Non-Hodgkin-Lymphomen (NHL), werden aber für internationale Vergleichbarkeit separat dargestellt. Jungen sind hiervon mehr als doppelt so oft betroffen. Wir gehen von nahezu 100% Vollzähligkeit der Erfassung aus. Unspezifizierte Lymphome werden fast nie gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen. Die Prognose ist gut (92% Langzeitüberlebende). Die Prognose der NHL wurde seit den 1980ern deutlich verbessert. NHL (außer BL) treten auch relativ häufig als weitere Krebserkrankungen (SN) auf.

Bei Patienten mit Morbus Hodgkin ist die Prognose bereits seit vielen Jahrzehnten gut (derzeit 96% Langzeit-Überlebende), daher sind bei dieser Erkrankung die Spätfolgen der Therapie besonders erforscht. Hodgkin-Patienten sind überdurchschnittlich oft von weiteren Krebserkrankungen (fast 10% SN in den ersten 25 Jahren) betroffen.

Lymphomas (one child in 4000) occur mostly in adolescents and adults, while they are rare in small children. Burkitt lymphomas (BL) are a subgroup of the Non-Hodgkin Lymphomas (NHL); they are presented separately for international comparisons. Boys are affected twice as often as girls. We assume completeness is close to 100%. Unspecified lymphoma are rarely reported, this shows the high quality of diagnosis and reports. The prognosis is good (92% long term survivors). The prognosis of NHL has improved considerably since the 1980ies. NHL (except for BL) are relatively frequent as subsequent neoplasms (SN).

Patients with Hodgkin's disease have shown a good prognosis for decades (current long term survival is 96%), so for this entity late effects are particularly well known. Patients with Hodgkin's disease are especially frequently affected by SN (almost 10% within the first 25 years).

III CNS and miscellaneous intracranial and intraspinal neoplasms

Bei diesen Tumoren des zentralen Nervensystems (ZNS, Hirntumore), eines von 1800 Kindern ist betroffen, handelt es sich um eine heterogene Gruppe von Krebserkrankungen mit bösartigen (malignen) und nichtmalignen Formen. Internationale Vergleiche deuten auf eine Untererfassung der nichtmalignen Formen hin. Der beobachtete Anstieg der Erkrankungszahlen zeigt die stetig verbesserte Vollzähligkeit der Erfassung. Jungen sind etwa 30% häufiger betroffen als Mädchen. Die durchschnittliche Langzeitprognose liegt bei 70%. Die scheinbar 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. ZNS-Tumoren, besonders Astrozytome, stellen 22% aller weiteren Krebserkrankungen (SN).

Tumours of the central nervous system (CNS, brain tumours) affect one child in 1800. 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 underreported. The observed increase in cases shows improvements in completeness of registration. Boys have an about 30% higher incidence. Average long term survival is 70%. 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. CNS-tumours, especially astrocytomas comprise 22% of all subsequent neoplasms (SN).

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, Jungen erkranken etwa 20% häufiger als Mädchen. Wir gehen von nahezu 100% Vollzähligkeit der Erfassung aus. Insgesamt überleben etwa 75% der Fälle, 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 Mortalitätssenkung, 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.

Neuroblastomas are embryonal tumours, which are observed mainly in small children. It affects one child in 5700, boys have an about 20% higher incidence than girls. We assume completeness is close to 100%. Overall survival is 75%, 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 considerable numbers 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.

V Retinoblastoma

Retinoblastome, unter 19.000 Kindern tritt ein Fall auf, gehören zu den embryonalen Tumoren von denen Erwachsene nur selten betroffen sind. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus. Jungen sind etwa 20% häufiger betroffen. Die Prognose ist sehr gut (97% Langzeitüberlebende). 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.

One child in 19,000 is affected with a Retinoblastoma. These are embryonal tumours which rarely affect adults. Based on international comparisons we assume completeness is high. Boys have an about 20% higher incidence. The prognosis is very good (97% long term survivors). Retinoblastoma has a known genetic cause and can be inherited, especially bilateral cases. When a case is diagnosed, family members should also be examined.

VI Renal Tumours

Fast alle Nierentumoren sind Nephroblastome (Wilm's Tumour). Ein Kind von 7600 ist betroffen, Mädchen etwas häufiger. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100% Vollzähligkeit der Erfassung aus. Die Prognose ist relativ gut (92% Langzeitüberlebende).

Nierenkarzinome, meist im Erwachsenenalter beobachtet, treten nur selten und wenn, dann bei älteren Kindern und Jugendlichen auf. Die Prognose ist eher gut. Unspezifizierte Nierentumoren wurden gar keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Almost all renal tumours are nephroblastomas (Wilm's tumour). One child in 7600 is affected, girls slightly more often. Based on international comparisons we assume completeness is close to 100%. The prognosis is relatively good (92% long term survivors).

Renal carcinomas, usually observed in adults, are occasionally diagnosed in older children and adolescents. The prognosis is quite good. Unspecified renal tumours are rarely reported, this shows the high quality of diagnosis and reports.

VII Hepatic tumours

Fast alle Lebertumoren (ein Fall unter 32.000 Kindern) sind Hepatoblastome. Jungen sind 40% häufiger betroffen als Mädchen. Wir gehen von hoher Vollzähligkeit der Erfassung aus. Die Prognose ist moderat (76% Langzeitüberlebende) und seit den 1980ern erheblich verbessert.

Leberkarzinome, meist im Erwachsenenalter beobachtet, treten nur sehr selten und wenn, dann bei älteren Kindern und Jugendlichen auf, sie haben trotz Verbesserungen immer noch eine schlechte Prognose. Unspezifizierte Lebertumoren wurden fast keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Almost all hepatic tumours (one of 32,000 children is affected) are hepatoblastomas. Boys have a 40% higher incidence. We assume completeness is high. The prognosis is moderate (76% long term survivors) and has been improving considerably since the 1980s.

Hepatic carcinomas, usually observed in adults, are occasionally diagnosed in older children and adolescents; although there have been improvements, the prognosis is still bad. Unspecified hepatic tumours are rarely reported, this shows the high quality of diagnosis and reports.

VIII Malignant bone tumours

Knochensarkome (ein Kind von 10.000) sind typisch für ältere Kinder und Jugendliche. Die besonders häufigen Typen sind Osteosarkome und Ewing-Tumore. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus. Besonders Osteosarkome werden häufig als zweite Erkrankung (SN) nach einer anderen Krebserkrankung gemeldet. Die Prognose ist etwas unterdurchschnittlich (68% Langzeitüberlebende) und hat sich seit den 1980ern nur leicht verbessert. Unspezifizierte Knochentumoren wurden fast keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Bone sarcomas (one case in 10,000 children) are typical for older children and adolescents. The most frequent forms are osteosarcoma and Ewing tumours. Based on international comparisons we assume completeness is high. Especially osteosarcomas are frequently reported as a second neoplasm (SN). The prognosis is below average (68% long term survivors) and has been improving only slightly since the 1980ies. Unspecified bone tumours are rarely reported, this shows the high quality of diagnosis and reports.

IX Soft tissue and other extraosseous sarcomas

Weichteilsarkome können in allen Altersklassen auftreten, betroffen ist ein Kind von 7000. Das häufigste Weichteilsarkom ist das Rhabdomyosarkom. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus. Jungen sind etwa 20% häufiger betroffen als Mädchen. Die Prognose ist etwas unterdurchschnittlich (68% Langzeitüberlebende) und hat sich seit den 1980ern nur leicht verbessert.

Soft tissue sarcomas occur in all ages in childhood (one child in 7000). The most frequent type is rhabdomyosarcoma. Based on international comparisons we assume completeness is high. Boys have a 20% higher incidence than girls. The prognosis is below average (68% long term survivors) and has been improving only slightly since the 1980ies.

X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

Keimzelltumoren sind eine heterogene Gruppe von Krebserkrankungen, betroffen ist ein Kind von 14.000. 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 etwa 30% häufiger betroffen. Bei den intrakraniellen Formen (im Gehirn lokalisiert) hat es seit etwa 2000 (neue Diagnosenklassifikation 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 verantwortlich. Insgesamt ist die Prognose gut (94% Langzeitüberlebende).

Germ cell tumours are a heterogeneous group of neoplasms, one child in 14,000 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 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. In general the prognosis is good (94% long term survivors).

XI Other malignant epithelial neoplasms and malignant melanomas

Dies ist eine heterogene Gruppe von Neoplasien. Die häufigsten dieser seltenen Erkrankungen sind Karzinome der Nebennierenrinde, der Schilddrüse, des Nasopharynx (Nasen-Rachenraum) und das maligne Melanom („schwarzer“ Hautkrebs). Karzinome treten im Allgemeinen erst im Erwachsenenalter auf. Einige Karzinome bei Kindern sind deutlich untererfasst, jedoch nicht die Nasopharynx-Karzinome und Schilddrüsenkarzinome. Schilddrüsenkarzinome treten häufig als Folgetumoren auf (10% aller SN), daneben auch maligne Melanome und andere Hautkarzinome. Schilddrüsenkarzinome hatten und haben eine gute Prognose (96% Langzeitüberlebende). Bei den malignen Melanomen konnte die Erfassung im Laufe der Jahre verbessert werden.

This is a heterogeneous group of rare cancers. The most frequent among them are adrenocortical carcinoma, thyroid carcinoma, nasopharyngeal carcinoma, and malignant melanoma. Carcinomas are usually observed in adults. Some carcinomas in children are clearly underreported, though not nasopharyngeal carcinomas and thyroid carcinomas. Thyroid carcinomas are frequent as subsequent neoplasms (10% of all SN); this is also true for malignant melanoma and other skin carcinomas. Thyroid carcinomas have a good prognosis (96% long term survivors). The reporting of malignant melanoma has improved over the years.

XII Other and unspecified neoplasms

Dies ist eine heterogene Gruppe von sonst nicht zuzuordnenden, sehr seltenen bösartigen Krebserkrankungen (ein Fall pro 300.000 Kinder). Der häufigste Einzeltumor hiervon ist das Lungenblastom.

This is a heterogeneous group of very rare neoplasms not classifiable anywhere else (one child in 300,000). The most frequent tumour among these is pulmonary blastoma.

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

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

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**Systematische Darstellung epidemiologischer Kenngrößen der häufigsten ICC-3 Diagnosen /
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Systematische Darstellung epidemiologischer Kenngrößen der häufigsten ICCC-3 Diagnosen /
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Eingeschlossene Diagnosen entsprechend ICC-3 (siehe Methoden)

Selected diagnoses according to ICC-3 (see Methods)

Cases in Germany aged under 15 years (1980-2012): 51883

Selected characteristics Germany 2003-2012

Relative frequency: 17697 / 17697 = 100 %

Relative frequency of trial patients: 93.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	7877	9820	17697
Standardized rate *:	149.6	176.6	163.5
Cumulative incidence:	2165	2561	2368
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	1844	5966	4752	5135
Incidence rate:	269.8	210.5	125.7	125.5

Median age at diagnosis: 5 years 11 months

Survival probabilities:	5-year	10-year	15-year
	84 %	82 %	81 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
4129	100.0 %	35.7	517

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

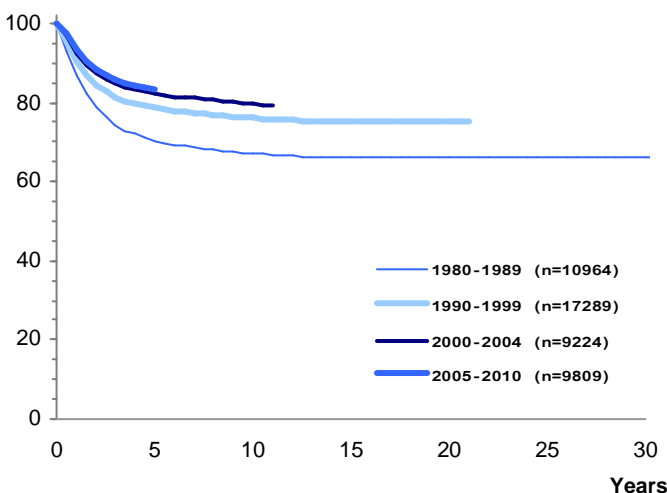
All malignancies

SN after all malignancies

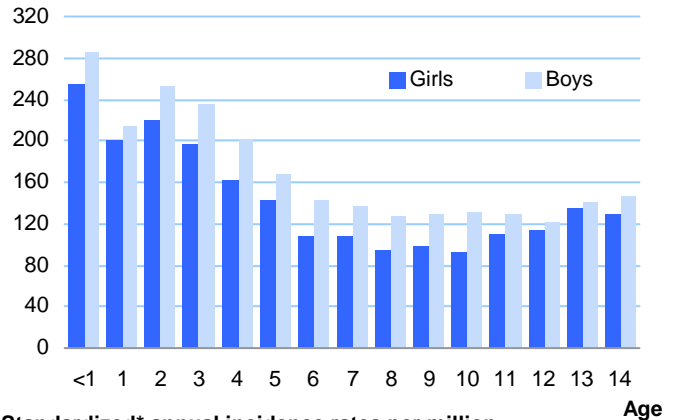
N	% of all 976 SN	Cumulative incidence
976	100.0 %	4.7 %

* Standard: Segi world standard population

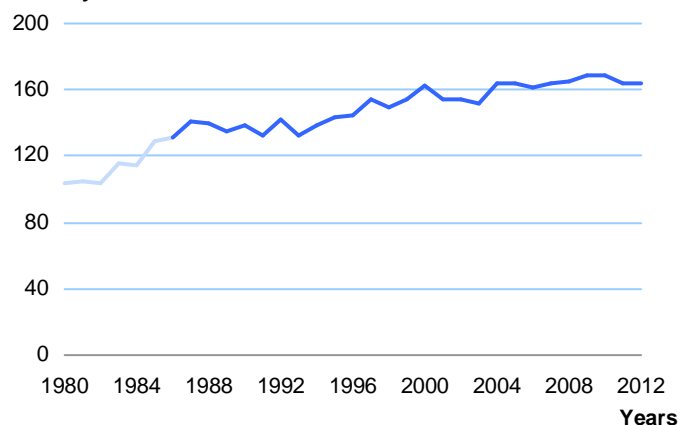
Survival probabilities by year of diagnosis Germany 1980-2010



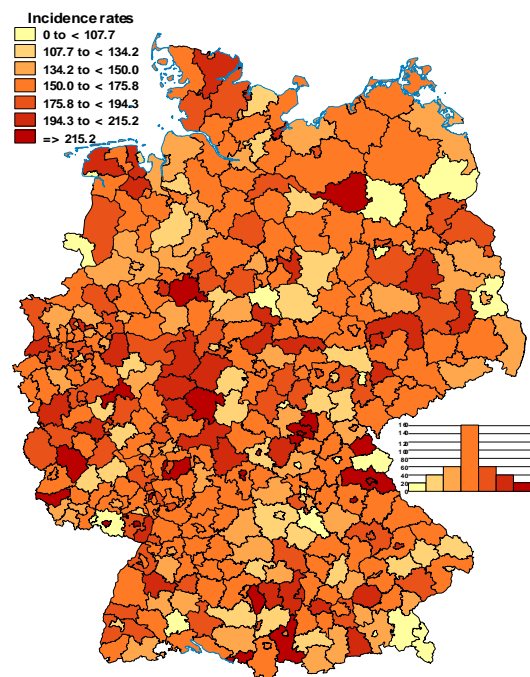
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



- (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 (1980-2012): 17808

Selected characteristics Germany 2003-2012

Relative frequency: 5989 / 17697 = 33.8 %

Relative frequency of trial patients: 99.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	2683	3306	5989
Standardized rate *:	52.2	60.5	56.5
Cumulative incidence:	743	867	807
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	296	2685	1685	1323
Incidence rate:	43.3	94.8	44.6	32.3

Median age at diagnosis: 5 years 0 months

Survival probabilities:	5-year	10-year	15-year
	88 %	86 %	85 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
1358	32.9 %	11.7	170

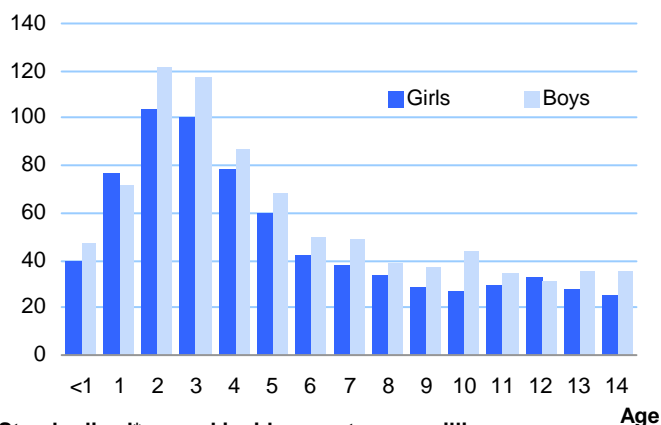
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

I Leukaemias, myeloproliferative and myelodysplastic diseases

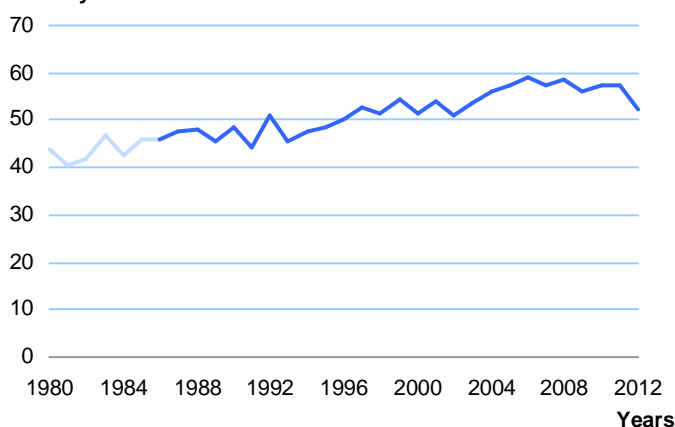
SN after I			I as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
351	36.0 %	4.6 %	248	25.4 %	0.6 %

* Standard: Segi world standard population

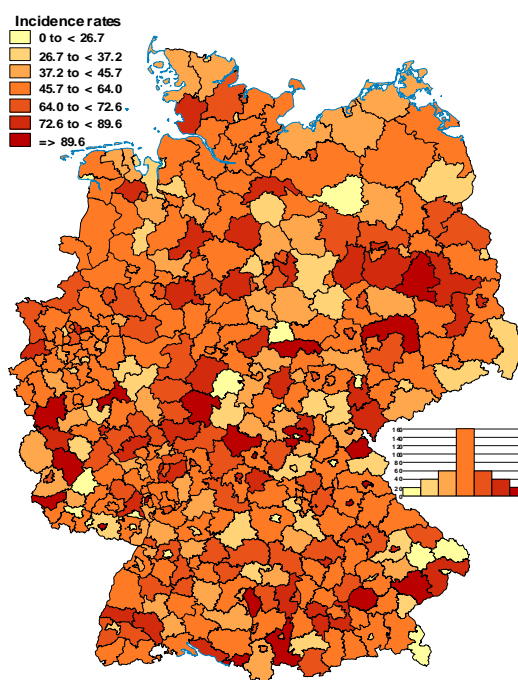
Age- and sex-specific incidence rates per million Germany 2003-2012



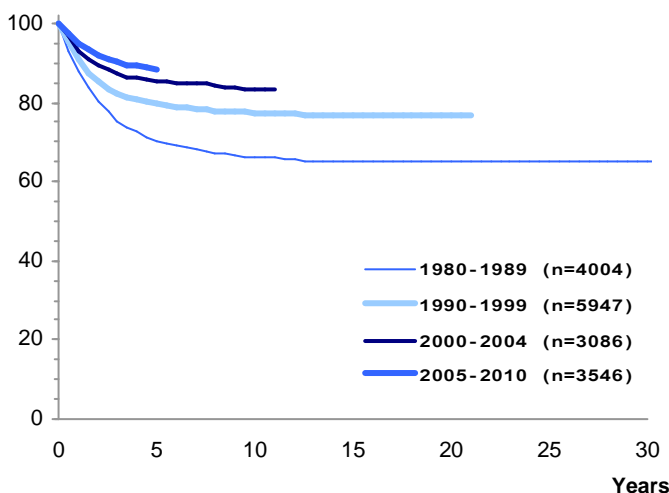
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 14171

Selected characteristics Germany 2003-2012

Relative frequency: 4653 / 17697 = 26.3 %

Relative frequency of trial patients: 99.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	2065	2588	4653
Standardized rate *:	40.5	47.6	44.1
Cumulative incidence:	574	680	628
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	115	2273	1370	895
Incidence rate:	16.8	80.2	36.2	21.9

Median age at diagnosis: 4 years 10 months

Survival probabilities:	5-year	10-year	15-year
	91 %	89 %	88 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
829	20.1 %	7.1	104

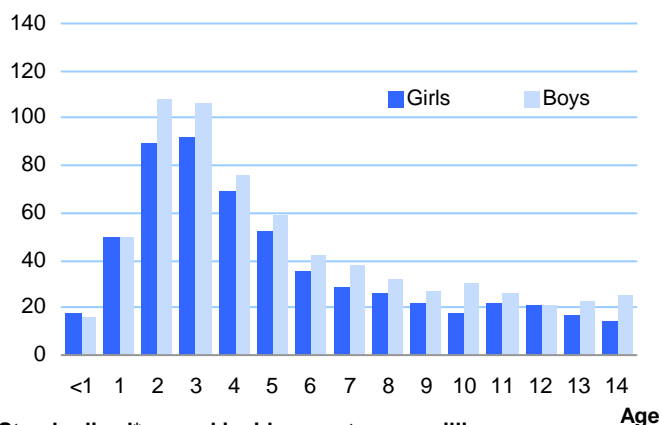
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

I (a) Lymphoid leukaemias

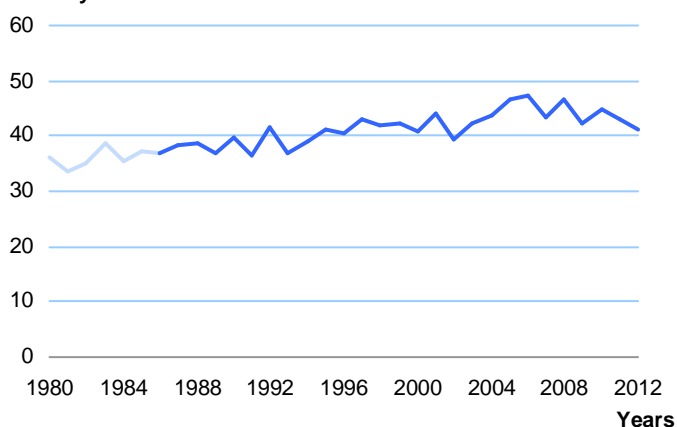
SN after I (a)			I (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
294	30.1 %	4.7 %	48	4.9 %	0.1 %

* Standard: Segi world standard population

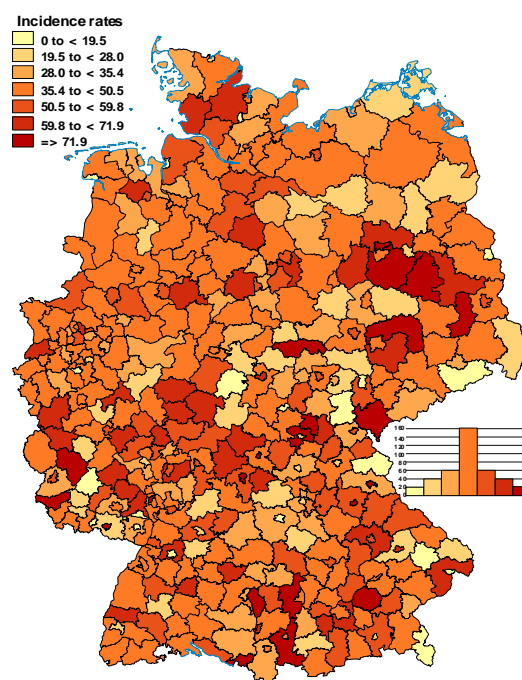
Age- and sex-specific incidence rates per million Germany 2003-2012



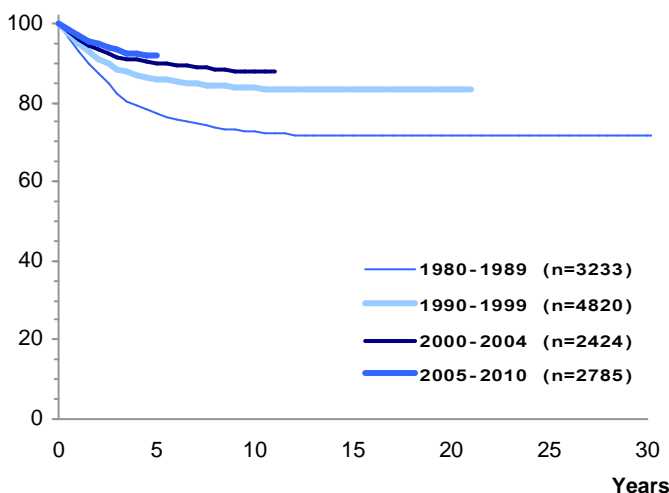
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Germany 2003-2012	N	%
Lymphoid leukaemias	4653	100.0
Precursor cell leukaemias	4539	97.5
Mature B-cell leukaemias	113	2.4
Mature T-cell and NK cell leukaemias	1	0.0
Lymphoid leukaemia, NOS	0	0.0

1 Precursor cell leukaemias

Cases in Germany aged under 15 years (1980-2012): 13832

Selected characteristics Germany 2003-2012

Relative frequency:	4539 / 17697 = 25.6 %
Relative frequency of trial patients:	99.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	2038	2501	4539
Standardized rate *:	40.0	46.1	43.1
Cumulative incidence:	566	658	613
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	112	2244	1321	862
Incidence rate:	16.4	79.2	34.9	21.1

Median age at diagnosis: 4 years 10 months

* Standard: Segi world standard population

2 Mature B-cell leukaemias

Cases in Germany aged under 15 years (1980-2012): 338

Selected characteristics Germany 2003-2012

Relative frequency:	113 / 17697 = 0.6 %
Relative frequency of trial patients:	100 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	26	87	113
Standardized rate *:	0.5	1.5	1.0
Cumulative incidence:	7	22	15
Sex ratio (m/f):	3.3		

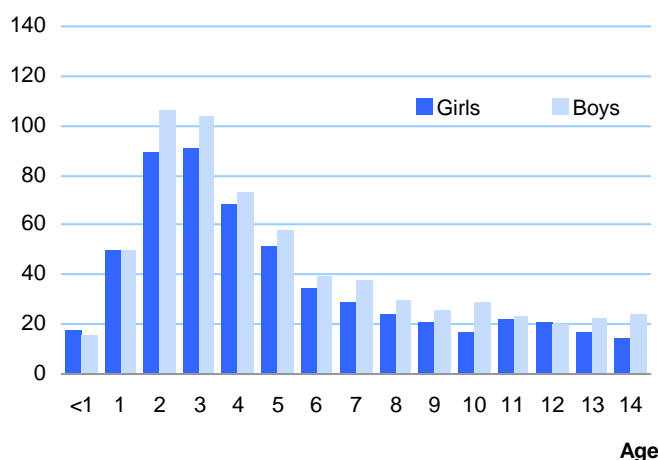
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	3	29	49	32
Incidence rate:	0.4	1.0	1.3	0.8

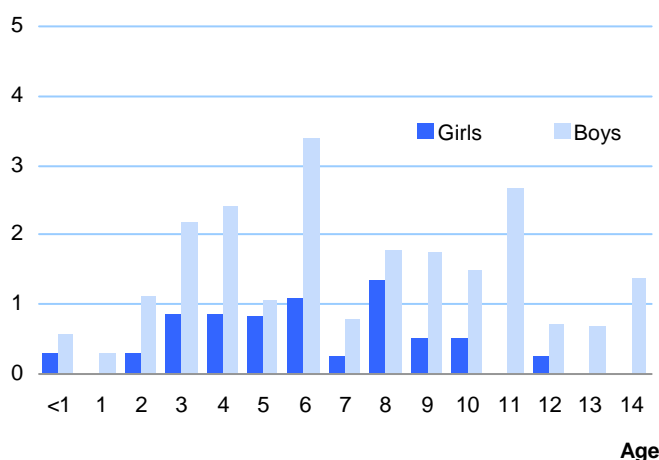
Median age at diagnosis: 7 years 3 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 2517

Selected characteristics Germany 2003-2012

Relative frequency:	782 / 17697 = 4.4 %
Relative frequency of trial patients:	97.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	385	397	782
Standardized rate *:	7.5	7.3	7.4
Cumulative incidence:	106	104	105
Sex ratio (m/f):	1.0		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	120	278	152	232
Incidence rate:	17.6	9.8	4.0	5.7

Median age at diagnosis: 4 years 10 months

Survival probabilities:	5-year	10-year	15-year
	72 %	70 %	69 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
414	10.0 %	3.6	52

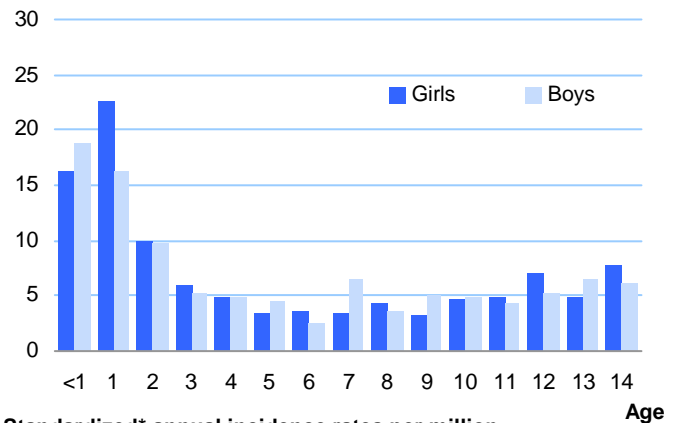
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

I (b) Acute myeloid leukaemias

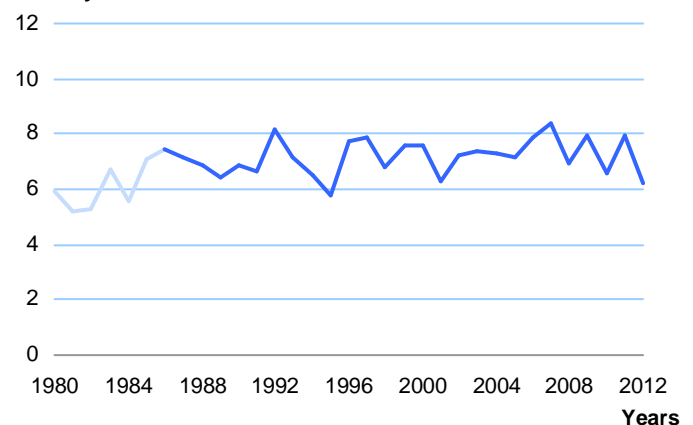
SN after I (b)			I (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
39	4.0 %	3.4 %	134	13.7 %	0.3 %

* Standard: Segi world standard population

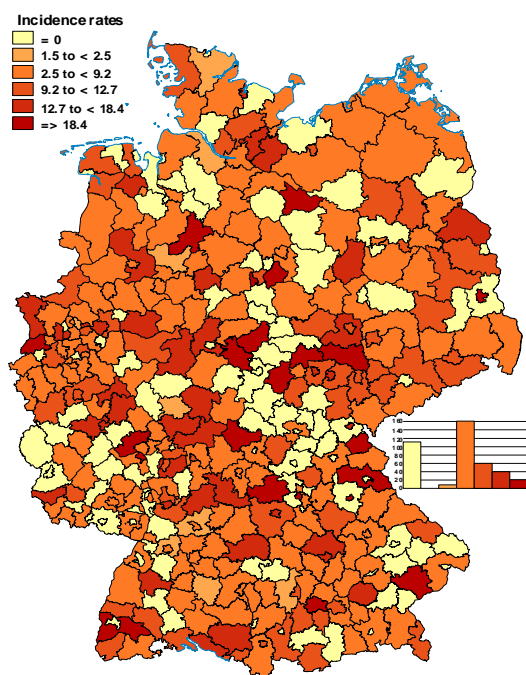
Age- and sex-specific incidence rates per million Germany 2003-2012



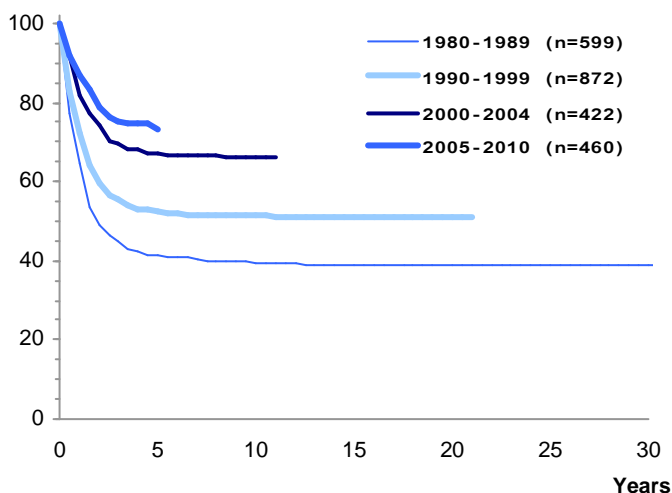
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 245

Selected characteristics Germany 2003-2012

Relative frequency: 73 / 17697 = 0.4 %

Relative frequency of trial patients: 84.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	34	39	73
Standardized rate *:	0.6	0.6	0.6
Cumulative incidence:	9	10	9
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	1	9	25	38
Incidence rate:	0.1	0.3	0.7	0.9

Median age at diagnosis: 10 years 0 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
31	0.8 %	0.3	4

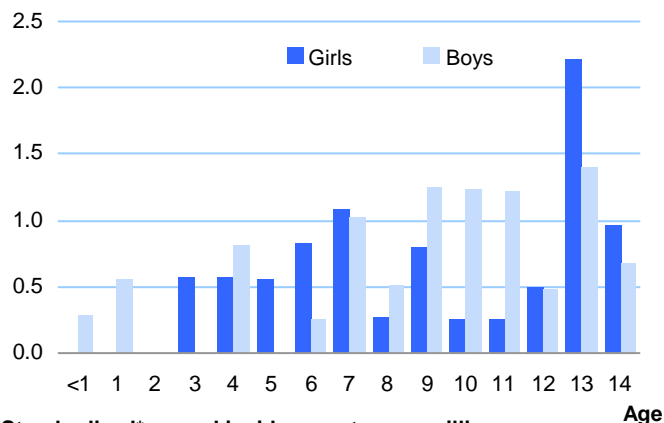
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

I (c) Chronic myeloproliferative diseases

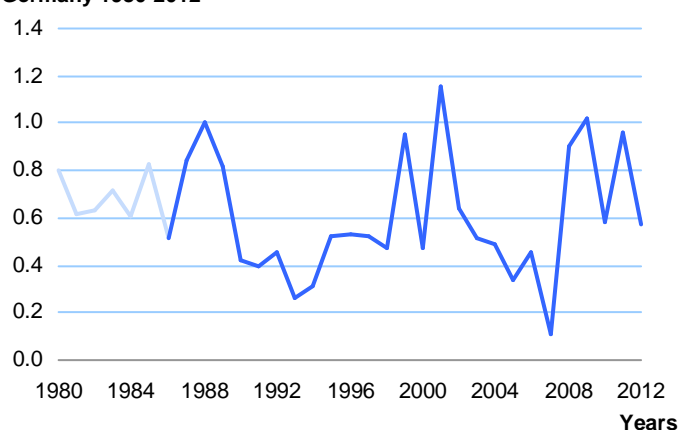
SN after I (c)			I (c) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
5	0.5 %	8.7 %	3	0.3 %	0.0 %

* Standard: Segi world standard population

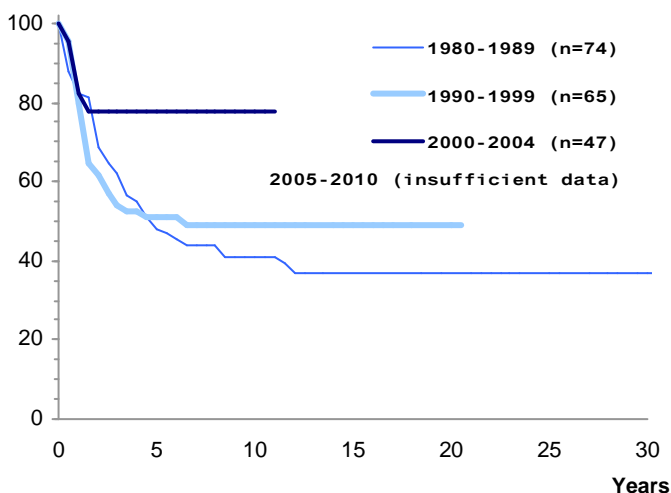
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 706**Selected characteristics Germany 2003-2012**

Relative frequency: 410 / 17697 = 2.3 %

Relative frequency of trial patients: 98.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	166	244	410
Standardized rate *:	3.0	4.3	3.7
Cumulative incidence:	45	63	54
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	43	109	119	139
Incidence rate:	6.3	3.8	3.1	3.4

Median age at diagnosis: 7 years 2 months

Survival probabilities:	5-year	10-year	15-year
	79 %	78 %	77 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

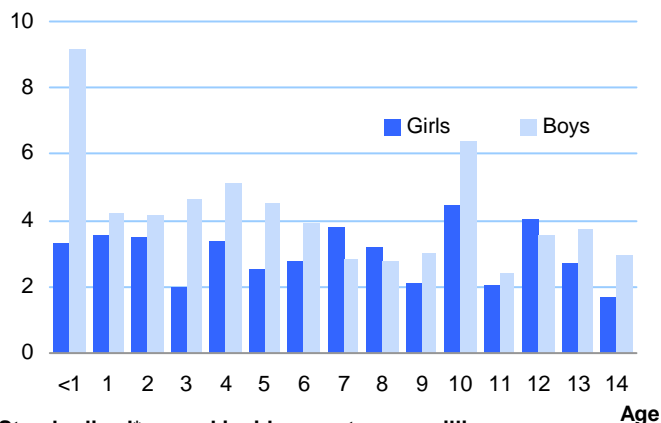
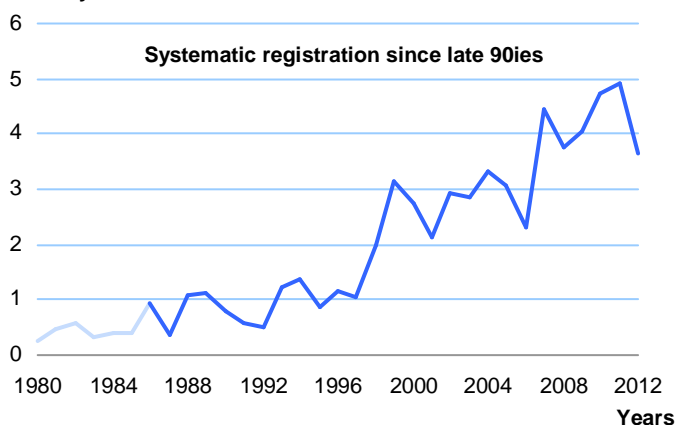
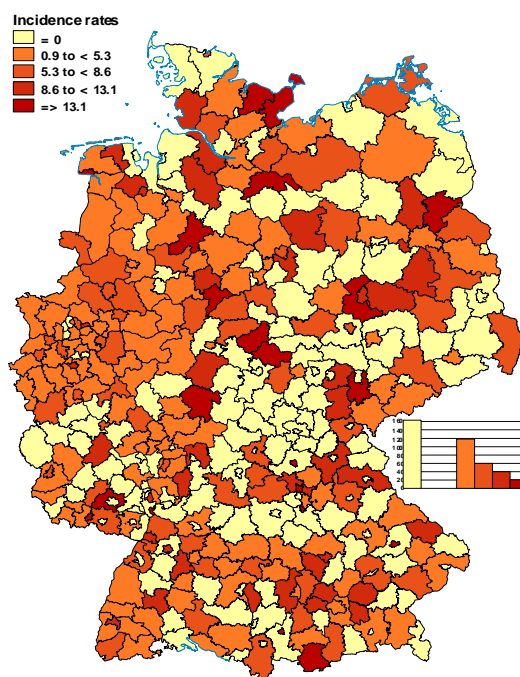
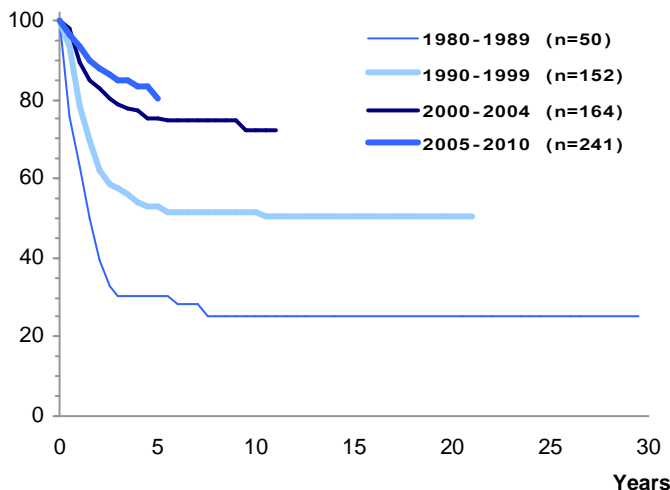
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
64	1.6 %	0.6	8

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

I (d) Myelodysplastic syndrome and other myeloproliferative disease

SN after I (d)			I (d) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
6	0.6 %	4.8 %	62	6.4 %	0.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

- (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 (1980-2012): 6119

Selected characteristics Germany 2003-2012

Relative frequency: 1964 / 17697 = 11.1 %

Relative frequency of trial patients: 96.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	624	1340	1964
Standardized rate *:	10.0	21.2	15.7
Cumulative incidence:	162	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	220	670	1066
Incidence rate:	1.2	7.8	17.7	26.1

Median age at diagnosis: 10 years 7 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
231	5.6 %	1.9	29

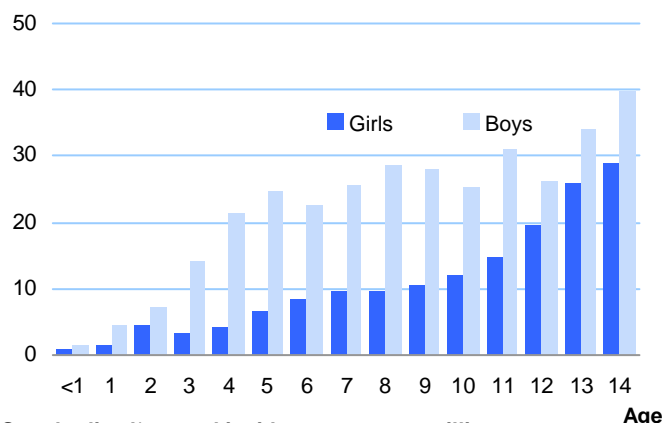
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

II Lymphomas and reticuloendothelial neoplasms

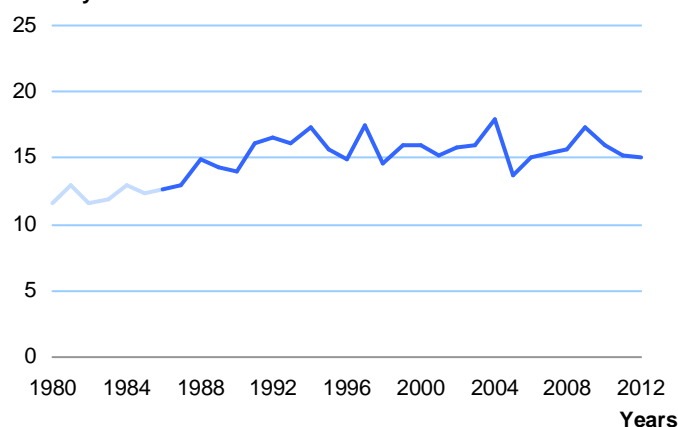
SN after II			II as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
159	16.3 %	7.0 %	84	8.6 %	0.3 %

* Standard: Segi world standard population

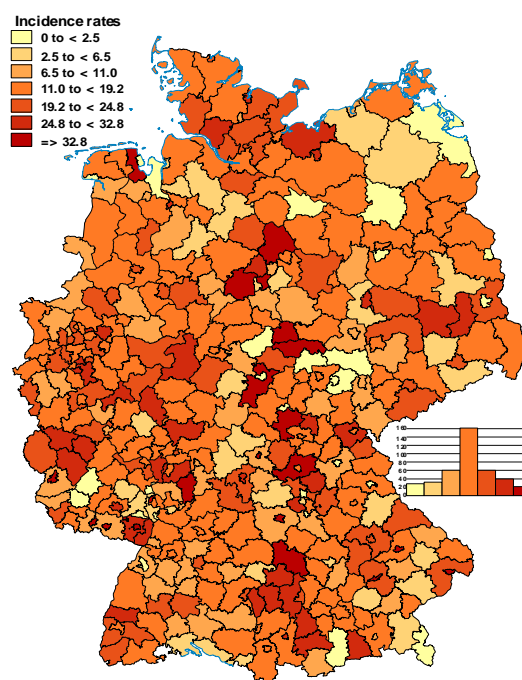
Age- and sex-specific incidence rates per million Germany 2003-2012



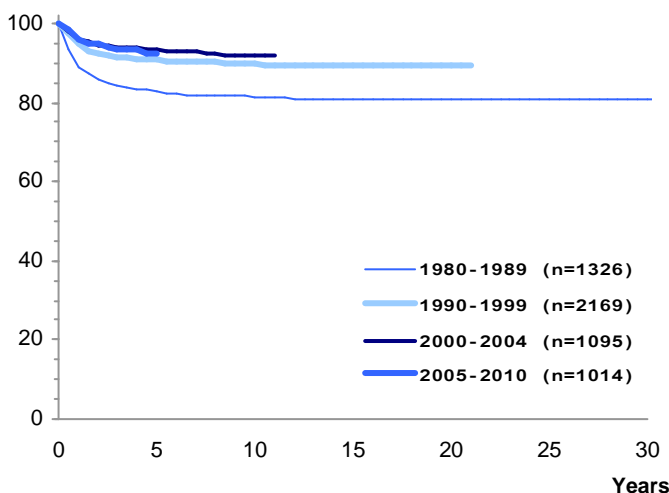
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 2520

Selected characteristics Germany 2003-2012

Relative frequency:	824 / 17697 = 4.7 %
Relative frequency of trial patients:	97.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	323	501	824
Standardized rate *:	4.9	7.6	6.2
Cumulative incidence:	82	123	103
Sex ratio (m/f):	1.6		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	36	193	595
Incidence rate:	0.0	1.3	5.1	14.5

Median age at diagnosis: 12 years 6 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
49	1.2 %	0.4	6

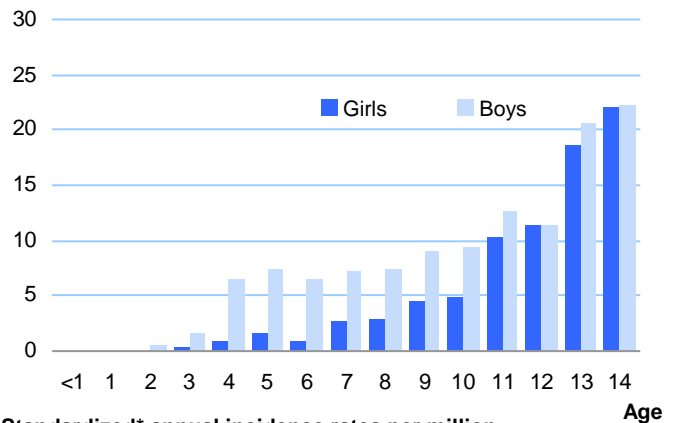
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

II (a) Hodgkin lymphomas

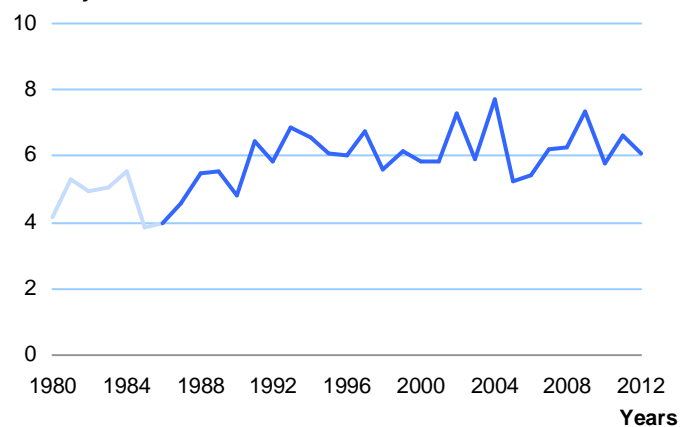
SN after II (a)			II (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
83	8.5 %	9.4 %	18	1.8 %	0.1 %

* Standard: Segi world standard population

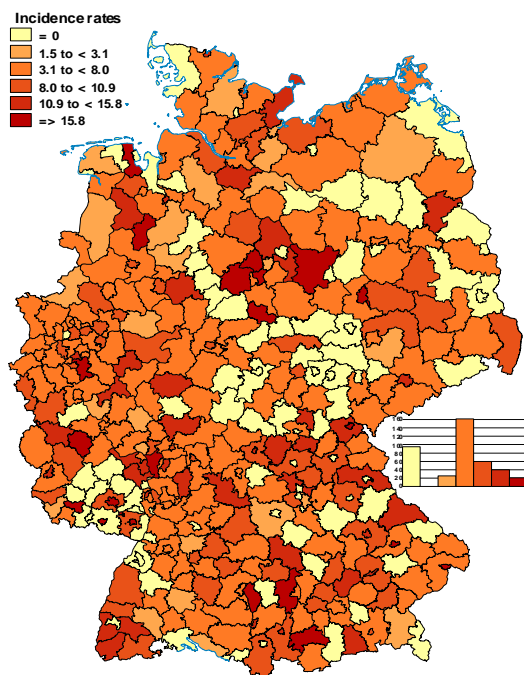
Age- and sex-specific incidence rates per million Germany 2003-2012



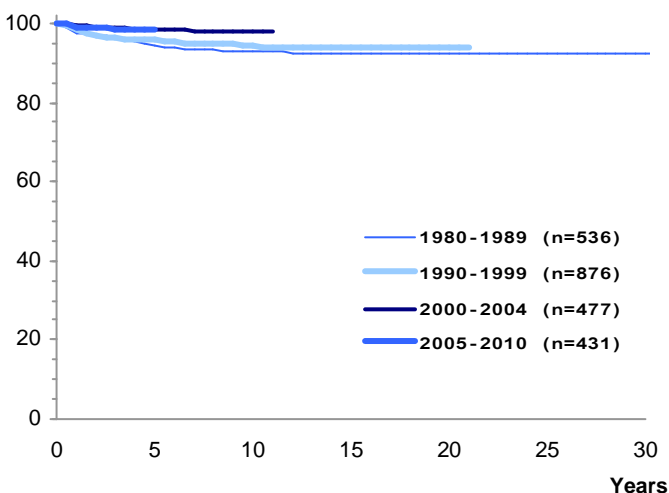
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 2394

Selected characteristics Germany 2003-2012

Relative frequency: 781 / 17697 = 4.4 %

Relative frequency of trial patients: 94.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	237	544	781
Standardized rate *:	4.0	8.8	6.4
Cumulative incidence:	63	137	101
Sex ratio (m/f):	2.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	4	122	302	353
Incidence rate:	0.6	4.3	8.0	8.6

Median age at diagnosis: 9 years 4 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
118	2.9 %	1.0	15

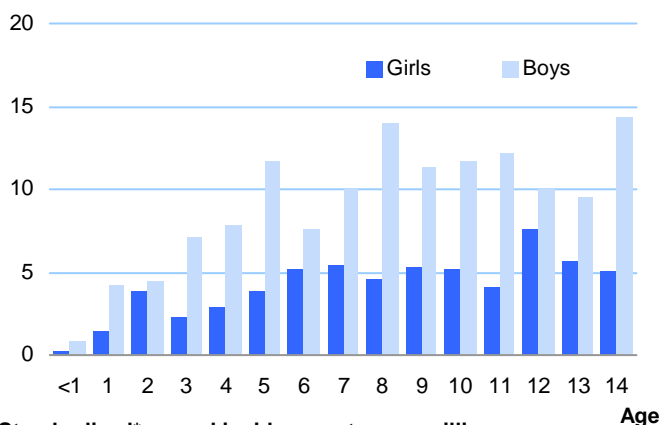
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

II (b) Non-Hodgkin lymphomas

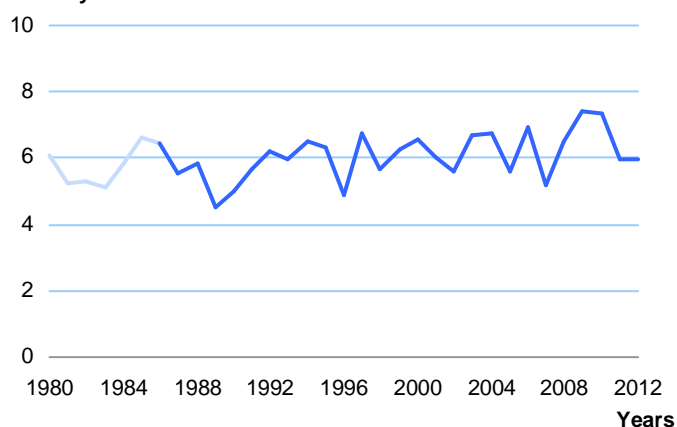
SN after II (b)			II (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
61	6.3 %	5.6 %	54	5.5 %	0.2 %

* Standard: Segi world standard population

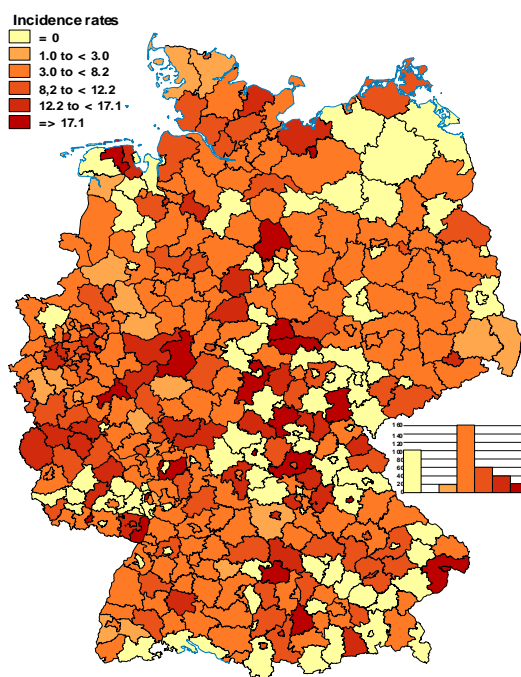
Age- and sex-specific incidence rates per million Germany 2003-2012



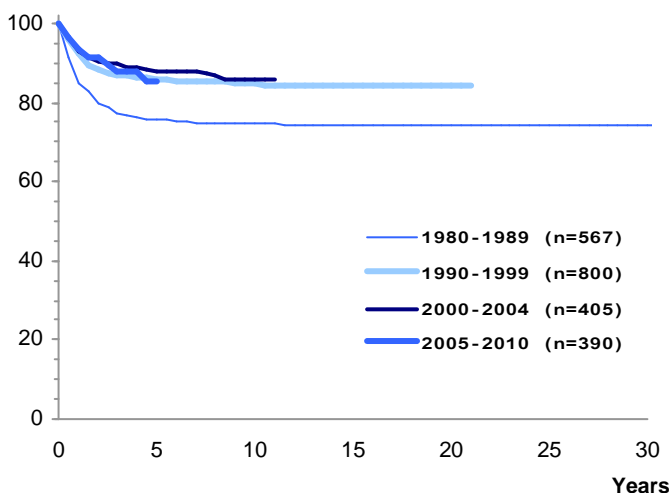
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Germany 2003-2012	N	%
Non-Hodgkin lymphomas	781	100.0
Precursor cell lymphomas	304	38.9
Mature B-cell lymphomas (except Burkitt lymphoma)	145	18.6
Mature T-cell and NK-cell lymphomas	169	21.6
Non-Hodgkin lymphomas, NOS	163	20.9

1 Precursor cell lymphomas

Cases in Germany aged under 15 years (1980-2012): 941

Selected characteristics Germany 2003-2012

Relative frequency:	304 / 17697 = 1.7 %
Relative frequency of trial patients:	94.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	91	213	304
Standardized rate *:	1.6	3.5	2.6
Cumulative incidence:	24	54	40
Sex ratio (m/f):	2.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	3	62	131	108
Incidence rate:	0.4	2.2	3.5	2.6

Median age at diagnosis: 8 years 3 months

* Standard: Segi world standard population

2 Mature B-cell lymphomas (except Burkitt lymphoma)

Cases in Germany aged under 15 years (1980-2012): 379

Selected characteristics Germany 2003-2012

Relative frequency:	145 / 17697 = 0.8 %
Relative frequency of trial patients:	96.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	44	101	145
Standardized rate *:	0.7	1.5	1.1
Cumulative incidence:	12	25	18
Sex ratio (m/f):	2.3		

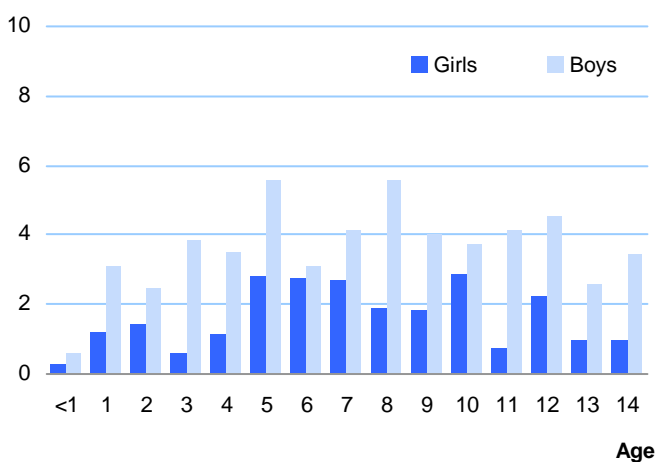
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	0	13	52	80
Incidence rate:	0.0	0.5	1.4	2.0

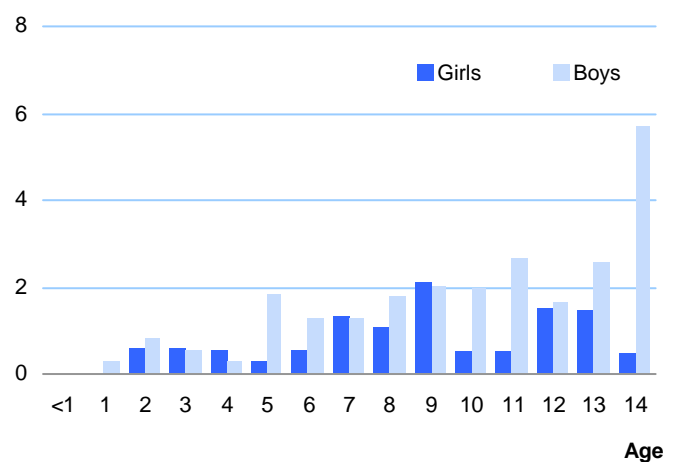
Median age at diagnosis: 10 years 9 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Germany 2003-2012	N	%
Non-Hodgkin lymphomas	781	100.0
Precursor cell lymphomas	304	38.9
Mature B-cell lymphomas (except Burkitt lymphoma)	145	18.6
Mature T-cell and NK-cell lymphomas	169	21.6
Non-Hodgkin lymphomas, NOS	163	20.9

3 Mature T-cell and NK-cell lymphomas

Cases in Germany aged under 15 years (1980-2012): 436

Selected characteristics Germany 2003-2012

Relative frequency:	169 / 17697 = 1.0 %
Relative frequency of trial patients:	94.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	59	110	169
Standardized rate *:	1.0	1.8	1.4
Cumulative incidence:	15	28	22
Sex ratio (m/f):	1.9		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	1	28	55	85
Incidence rate:	0.1	1.0	1.5	2.1

Median age at diagnosis: 10 years 2 months

* Standard: Segi world standard population

4 Non-Hodgkin lymphomas, NOS

Cases in Germany aged under 15 years (1980-2012): 638

Selected characteristics Germany 2003-2012

Relative frequency:	163 / 17697 = 0.9 %
Relative frequency of trial patients:	94.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	43	120	163
Standardized rate *:	0.7	1.9	1.3
Cumulative incidence:	11	30	21
Sex ratio (m/f):	2.8		

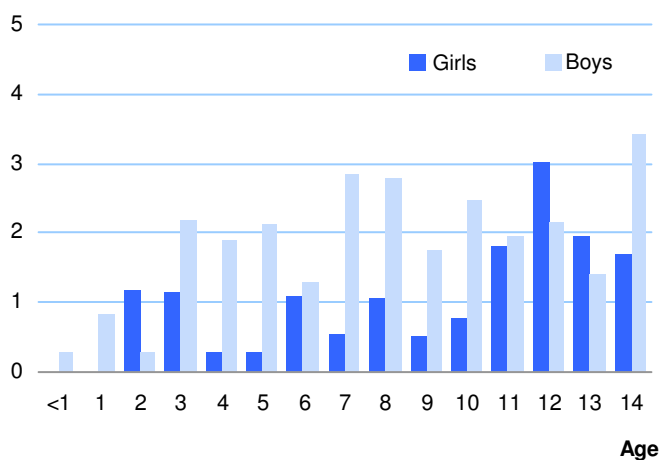
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	0	19	64	80
Incidence rate:	0.0	0.7	1.7	2.0

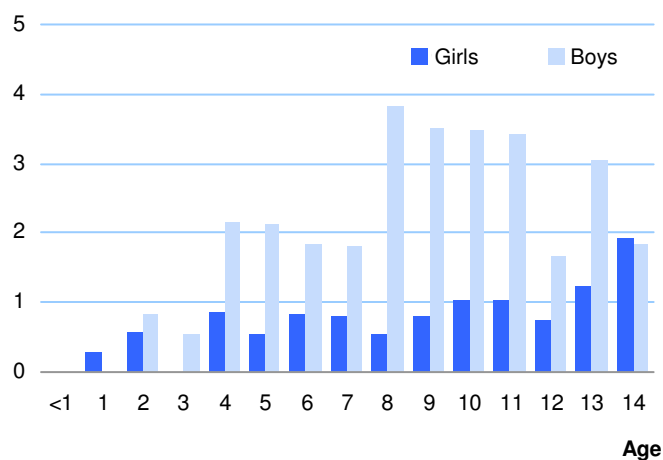
Median age at diagnosis: 9 years 10 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 1083

Selected characteristics Germany 2003-2012

Relative frequency:	347 / 17697 = 2.0 %
Relative frequency of trial patients:	98.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	58	289	347
Standardized rate *:	1.0	4.8	2.9
Cumulative incidence:	15	74	45
Sex ratio (m/f):	5.0		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	61	172	114
Incidence rate:	0.0	2.2	4.5	2.8

Median age at diagnosis: 8 years 2 months

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

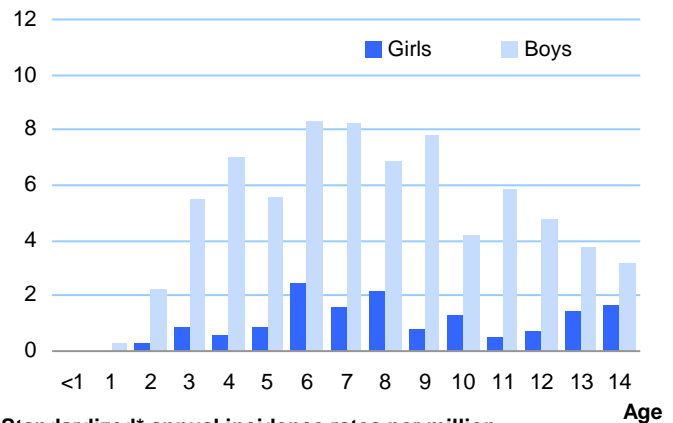
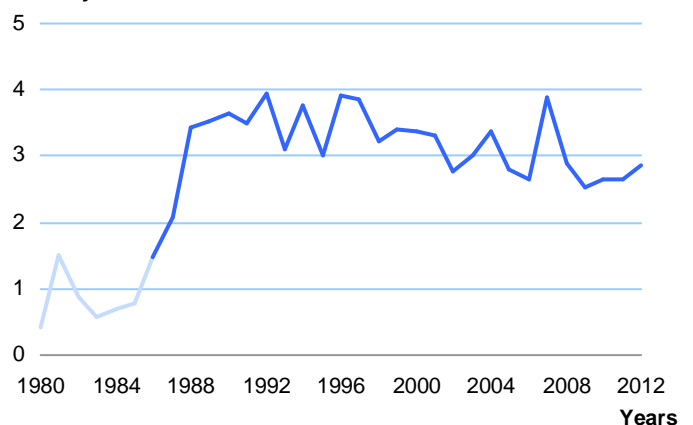
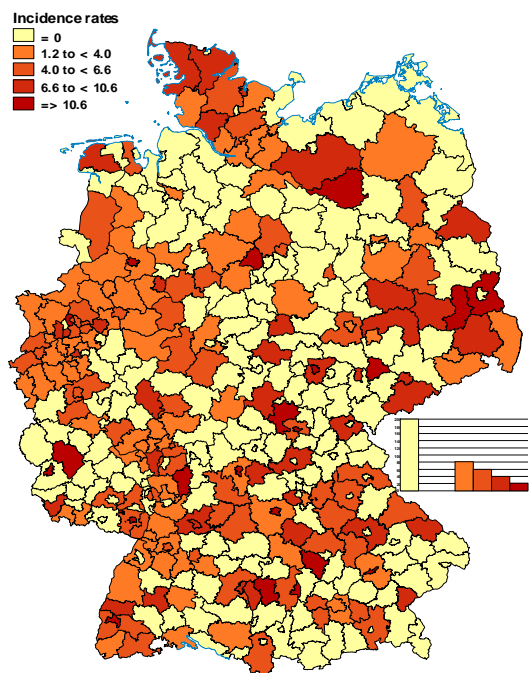
Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
44	1.1 %	0.4	5

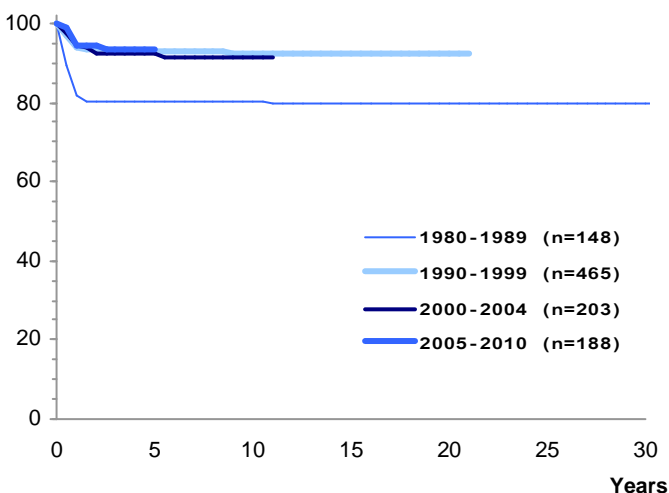
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):
II (c) Burkitt lymphoma

SN after II (c)			II (c) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
15	1.5 %	4.0 %	4	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012Standardized* annual incidence rates per million
Germany 1980-2012Standardized* incidence rates per million by districts
(Landkreise) Germany 2003-2012

Survival probabilities by year of diagnosis Germany 1980-2010



- (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 (1980-2012): 11129

Selected characteristics Germany 2003-2012

Relative frequency: 4254 / 17697 = 24.0 %

Relative frequency of trial patients: 92.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	1887	2367	4254
Standardized rate *:	34.9	41.5	38.3
Cumulative incidence:	515	613	565
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	317	1222	1426	1289
Incidence rate:	46.4	43.1	37.7	31.5

Median age at diagnosis: 7 years 0 months

Survival probabilities:	5-year	10-year	15-year
	77 %	73 %	70 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
1140	27.6 %	9.8	142

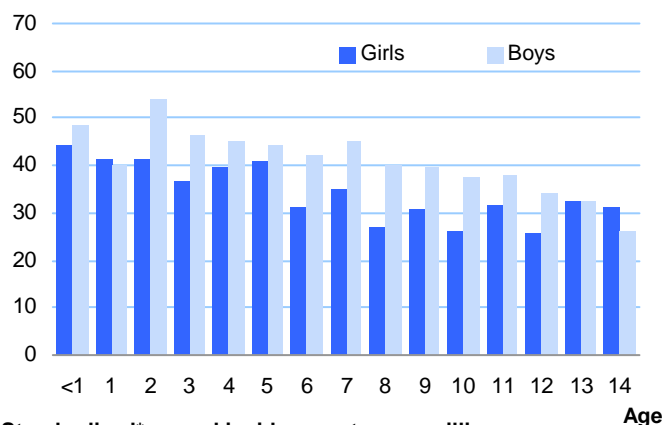
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

III CNS and miscellaneous intracranial and intraspinal neoplasms

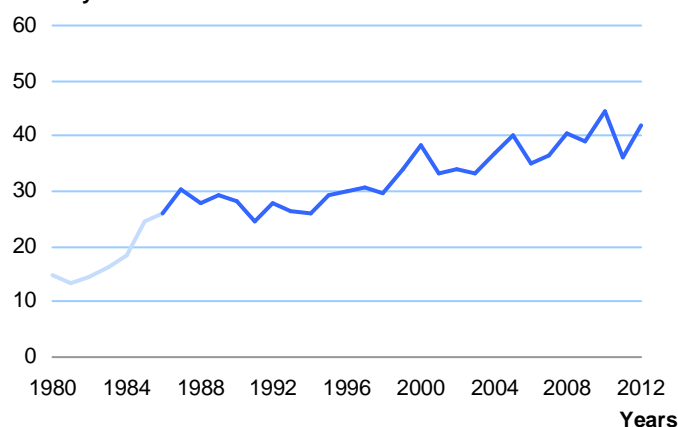
SN after III			III as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
182	18.6 %	5.1 %	216	22.1 %	1.0 %

* Standard: Segi world standard population

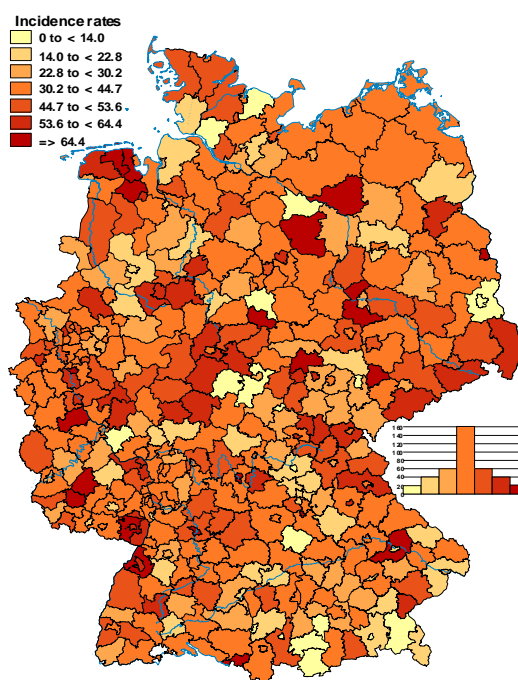
Age- and sex-specific incidence rates per million Germany 2003-2012



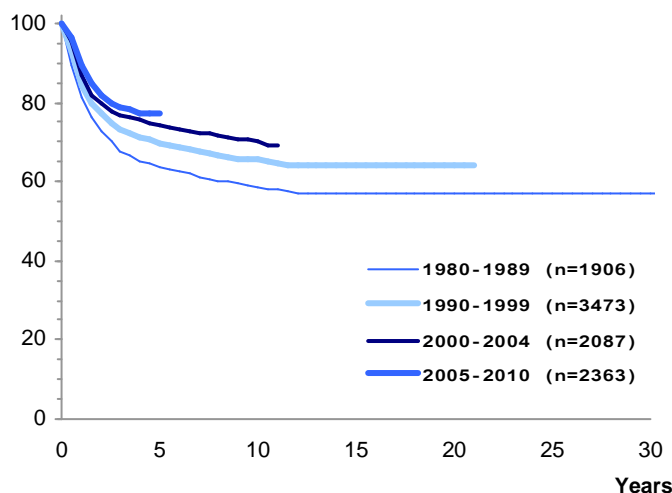
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 1122

Selected characteristics Germany 2003-2012

Relative frequency:	433 / 17697 = 2.4 %
Relative frequency of trial patients:	94.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	185	248	433
Standardized rate *:	3.8	4.7	4.3
Cumulative incidence:	52	66	59
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	79	185	86	83
Incidence rate:	11.6	6.5	2.3	2.0

Median age at diagnosis: 3 years 9 months

Survival probabilities:	5-year	10-year	15-year
	81 %	73 %	69 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
142	3.4 %	1.3	18

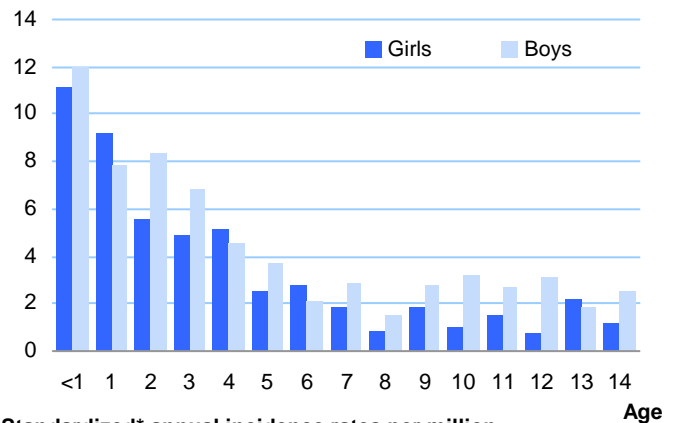
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

III (a) Ependymomas and choroid plexus tumour

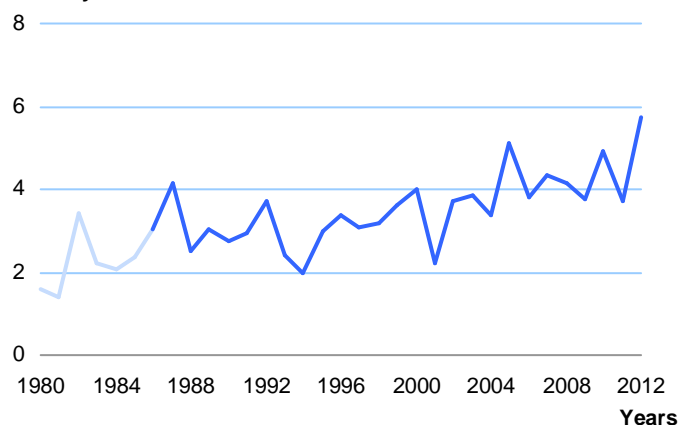
SN after III (a)			III (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
21	2.2 %	3.3 %	8	0.8 %	0.0 %

* Standard: Segi world standard population

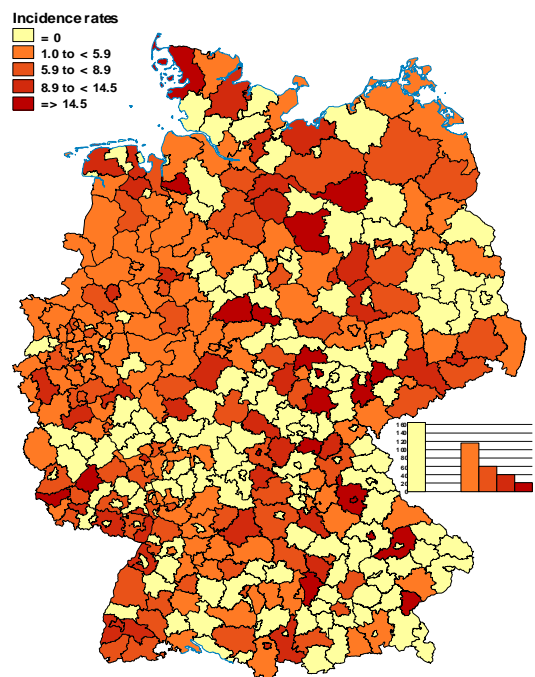
Age- and sex-specific incidence rates per million Germany 2003-2012



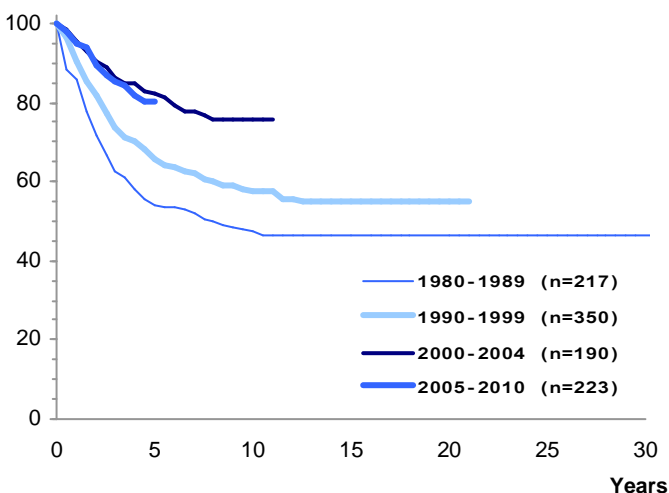
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Germany 2003-2012	N	%
Ependymomas and choroid plexus tumour	433	100.0
Ependymomas	335	77.4
Choroid plexus tumour	98	22.6

1 Ependymomas

Cases in Germany aged under 15 years (1980-2012): 903

Selected characteristics Germany 2003-2012

Relative frequency: 335 / 17697 = 1.9 %
Relative frequency of trial patients: 95.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	135	200	335
Standardized rate *:	2.7	3.7	3.2
Cumulative incidence:	38	53	45
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	32	157	73	73
Incidence rate:	4.7	5.5	1.9	1.8

Median age at diagnosis: 4 years 1 month

* Standard: Segi world standard population

2 Choroid plexus tumour

Cases in Germany aged under 15 years (1980-2012): 219

Selected characteristics Germany 2003-2012

Relative frequency: 98 / 17697 = 0.6 %
Relative frequency of trial patients: 89.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	50	48	98
Standardized rate *:	1.1	1.0	1.0
Cumulative incidence:	14	13	14
Sex ratio (m/f):	1.0		

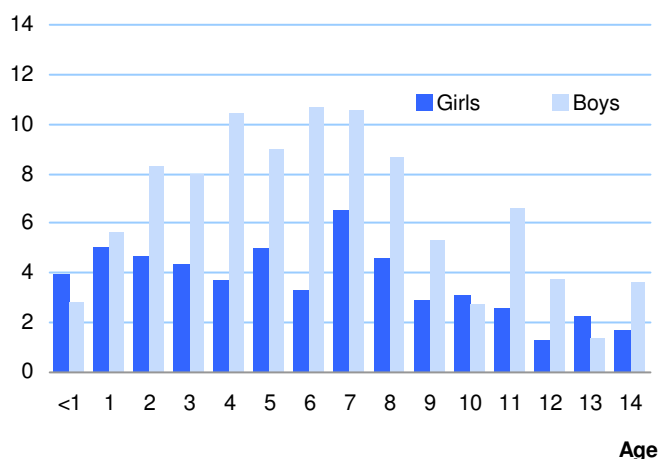
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	47	28	13	10
Incidence rate:	6.9	1.0	0.3	0.2

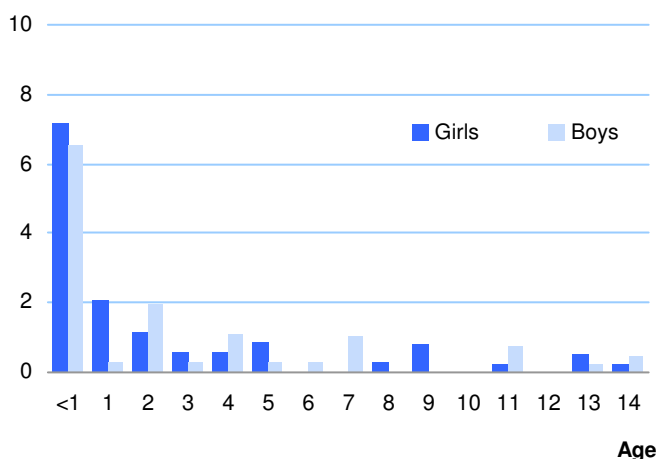
Median age at diagnosis: 1 year 5 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 4865

Selected characteristics Germany 2003-2012

Relative frequency:	1960 / 17697 = 11.1 %
Relative frequency of trial patients:	93.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	931	1029	1960
Standardized rate *:	16.9	17.8	17.3
Cumulative incidence:	252	265	259
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	98	534	685	643
Incidence rate:	14.3	18.8	18.1	15.7

Median age at diagnosis: 7 years 5 months

Survival probabilities:	5-year	10-year	15-year
	81 %	79 %	77 %

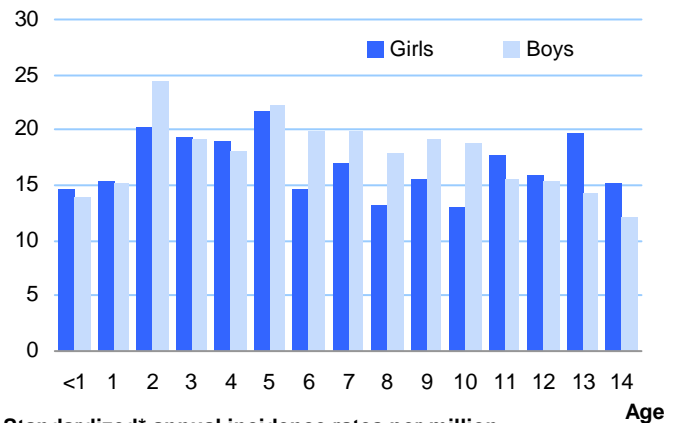
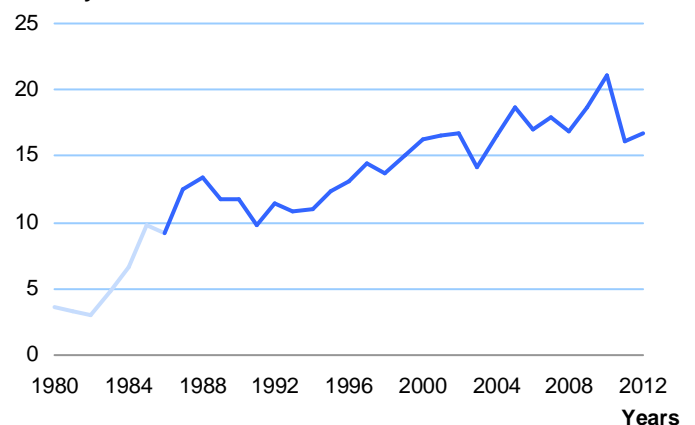
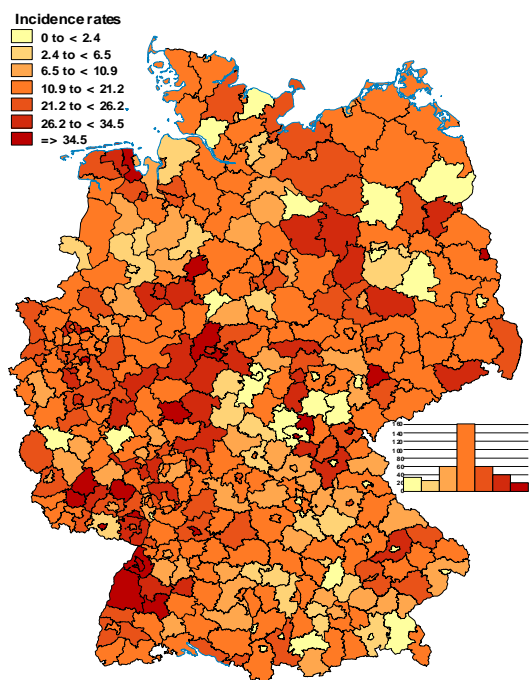
Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
363	8.8 %	3.0	45

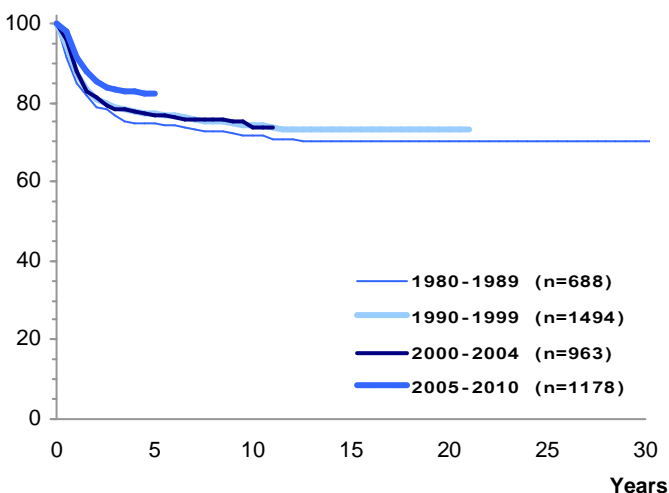
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):
III (b) Astrocytomas

SN after III (b)			III (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
42	4.3 %	2.3 %	88	9.0 %	0.3 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012Standardized* annual incidence rates per million
Germany 1980-2012Standardized* incidence rates per million by districts
(Landkreise) Germany 2003-2012

Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 2541

Selected characteristics Germany 2003-2012

Relative frequency: 814 / 17697 = 4.6 %

Relative frequency of trial patients: 93.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	298	516	814
Standardized rate *:	5.8	9.5	7.7
Cumulative incidence:	83	136	110
Sex ratio (m/f):	1.7		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	92	288	296	138
Incidence rate:	13.5	10.2	7.8	3.4

Median age at diagnosis: 5 years 5 months

Survival probabilities:	5-year	10-year	15-year
	67 %	60 %	56 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
451	10.9 %	3.9	56

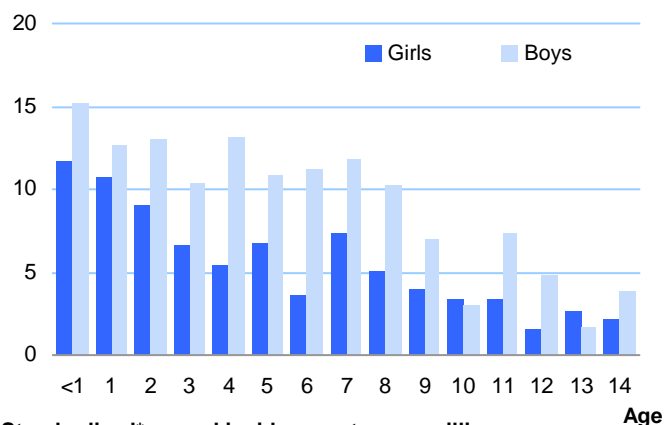
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

III (c) Intracranial and intraspinal embryonal tumours

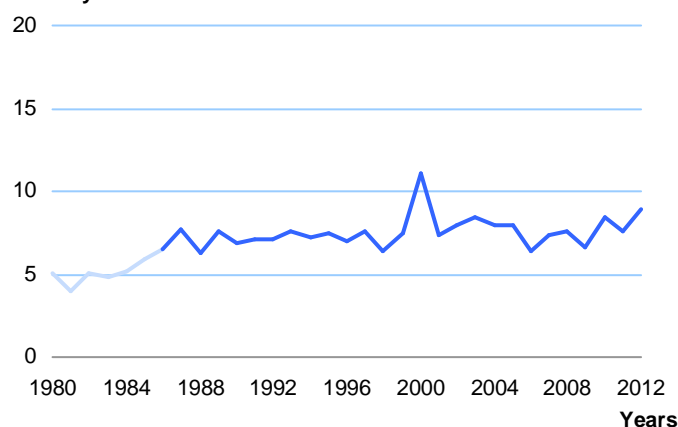
SN after III (c)			III (c) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
97	9.9 %	11.6 %	15	1.5 %	0.0 %

* Standard: Segi world standard population

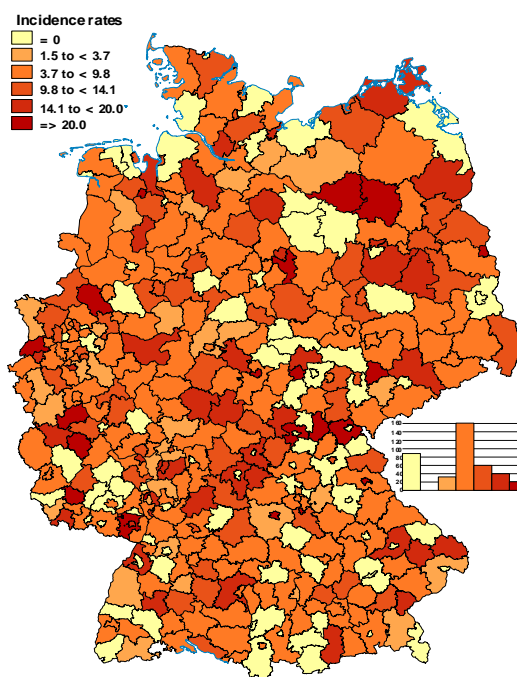
Age- and sex-specific incidence rates per million Germany 2003-2012



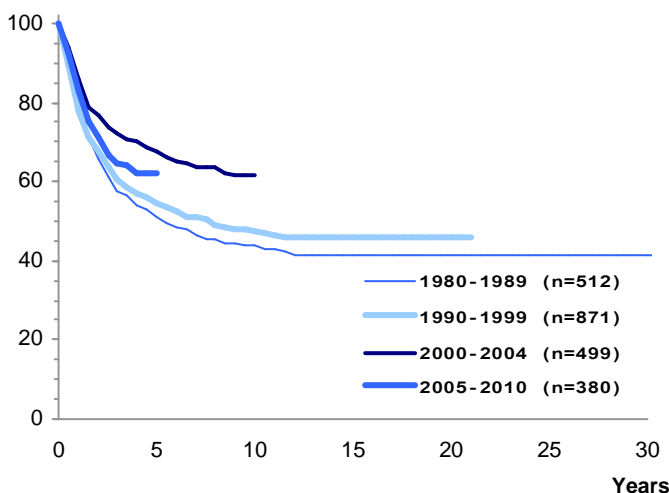
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Germany 2003-2012	N	%
Intracranial and intraspinal embryonal tumours	814	100.0
Medulloblastomas	574	70.5
Primitive neuroectodermal tumour (PNET)	92	11.3
Medulloepithelioma	6	0.7
Atypical teratoid/rhabdoid tumour	142	17.4

1 Medulloblastomas

Cases in Germany aged under 15 years (1980-2012): 1929

Selected characteristics Germany 2003-2012

Relative frequency:	574 / 17697 = 3.2 %
Relative frequency of trial patients:	98.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	199	375	574
Standardized rate *:	3.7	6.6	5.2
Cumulative incidence:	55	98	77
Sex ratio (m/f):	1.9		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	23	179	253	119
Incidence rate:	3.4	6.3	6.7	2.9

Median age at diagnosis: 6 years 8 months

* Standard: Segi world standard population

2 Primitive neuroectodermal tumour (PNET)

Cases in Germany aged under 15 years (1980-2012): 393

Selected characteristics Germany 2003-2012

Relative frequency:	92 / 17697 = 0.5 %
Relative frequency of trial patients:	94.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	36	56	92
Standardized rate *:	0.7	1.1	0.9
Cumulative incidence:	10	15	13
Sex ratio (m/f):	1.6		

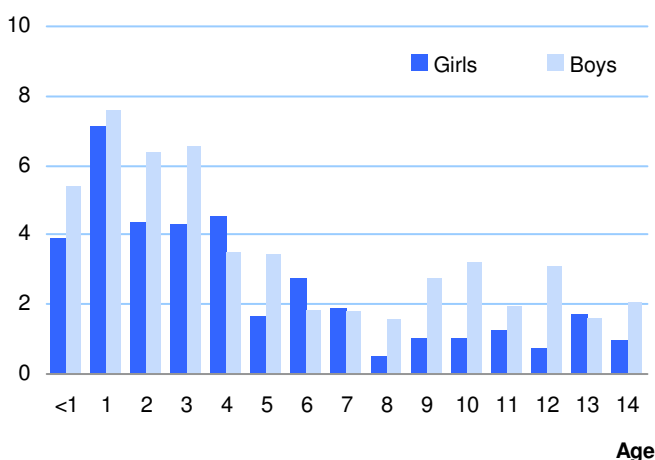
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	8	49	19	16
Incidence rate:	1.2	1.7	0.5	0.4

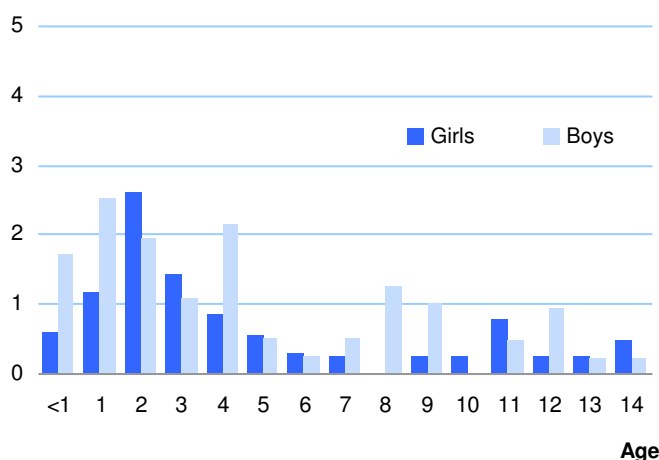
Median age at diagnosis: 3 years 11 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Germany 2003-2012	N	%
Intracranial and intraspinal embryonal tumours	814	100.0
Medulloblastomas	574	70.5
Primitive neuroectodermal tumour (PNET)	92	11.3
Medulloepithelioma	6	0.7
Atypical teratoid/rhabdoid tumour	142	17.4

4 Atypical teratoid/rhabdoid tumour

Cases in Germany aged under 15 years (1980-2012): 201

Selected characteristics Germany 2003-2012

Relative frequency: 142 / 17697 = 0.8 %

Relative frequency of trial patients: 73.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	60	82	142
Standardized rate *:	1.3	1.7	1.5
Cumulative incidence:	17	23	20
Sex ratio (m/f):	1.4		

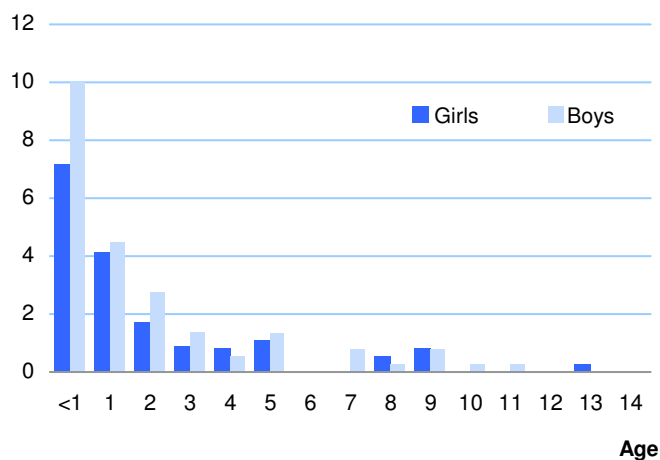
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	59	59	21	3
Incidence rate:	8.6	2.1	0.6	0.1

Median age at diagnosis: 1 year 4 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 844

Selected characteristics Germany 2003-2012

Relative frequency:	390 / 17697 = 2.2 %
Relative frequency of trial patients:	87.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	187	203	390
Standardized rate *:	3.4	3.4	3.4
Cumulative incidence:	51	52	51
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	18	90	153	129
Incidence rate:	2.6	3.2	4.0	3.2

Median age at diagnosis: 7 years 7 months

Survival probabilities:	5-year	10-year	15-year
	44 %	44 %	-

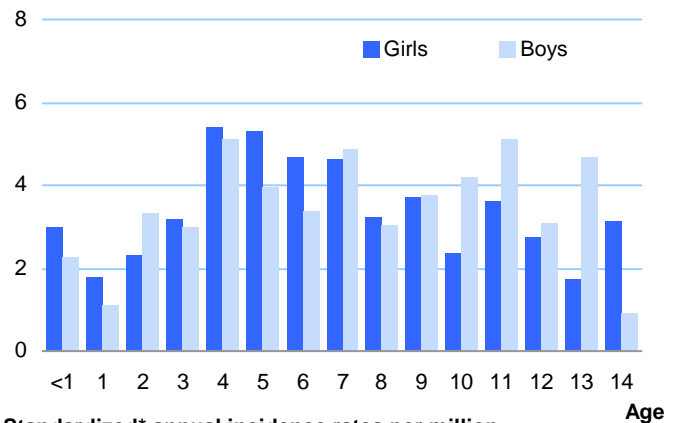
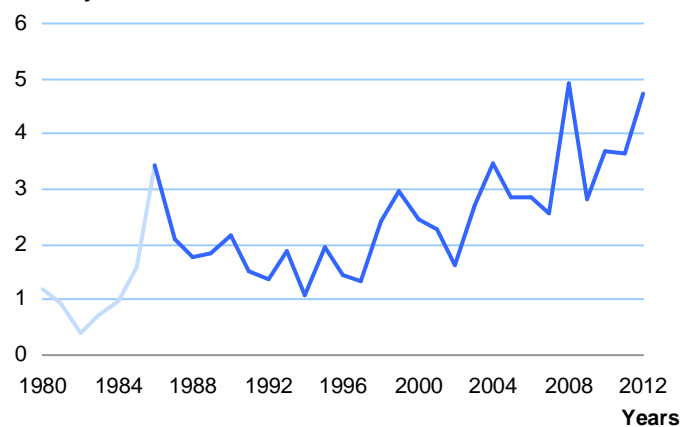
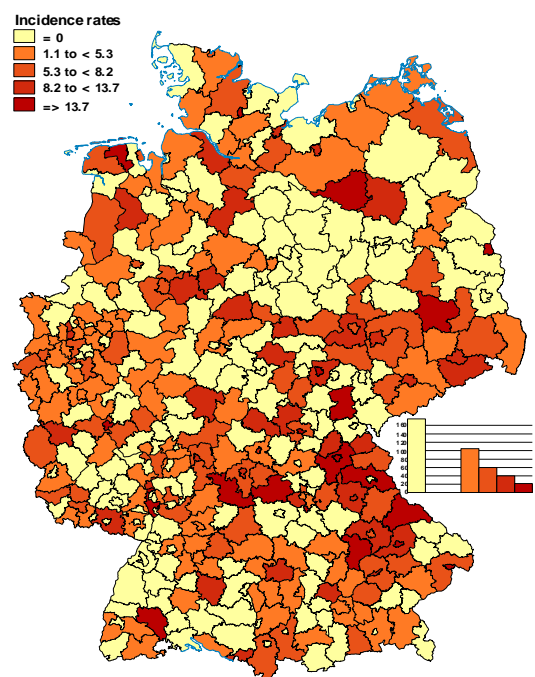
Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
90	2.2 %	0.7	11

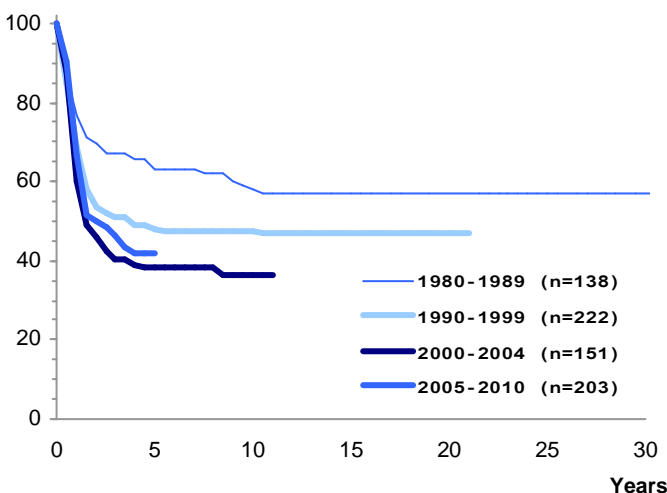
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):
III (d) Other gliomas

SN after III (d)			III (d) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
6	0.6 %	1.2 %	20	2.0 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012Standardized* annual incidence rates per million
Germany 1980-2012Standardized* incidence rates per million by districts
(Landkreise) Germany 2003-2012

Survival probabilities by year of diagnosis Germany 1980-2010



Germany 2003-2012	N	%
Other gliomas	390	100.0
Oligodendrogliomas	16	4.1
Mixed and unspecified gliomas	360	92.3
Neuroepithelial glial tumours of uncertain origin	14	3.6

1 Oligodendrogliomas

Cases in Germany aged under 15 years (1980-2012): 111

Selected characteristics Germany 2003-2012

Relative frequency: 16 / 17697 = 0.1 %

Relative frequency of trial patients: 68.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	7	9	16
Standardized rate *:	0.1	0.1	0.1
Cumulative incidence:	2	2	2
Sex ratio (m/f):			1.3

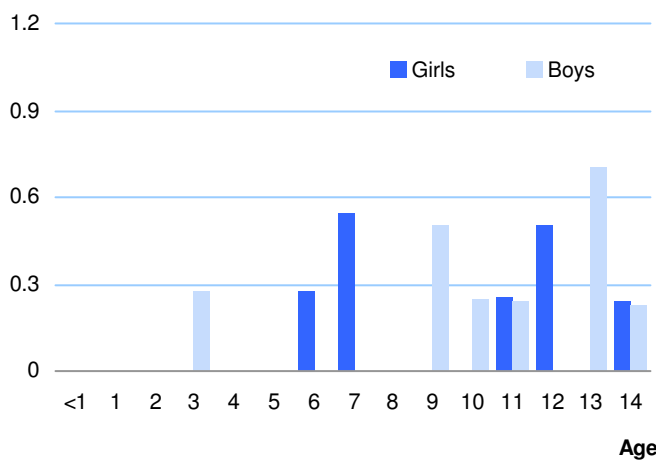
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	0	1	5	10
Incidence rate:	0.0	0.0	0.1	0.2

Median age at diagnosis: 11 years 7 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012



2 Mixed and unspecified gliomas

Cases in Germany aged under 15 years (1980-2012): 707

Selected characteristics Germany 2003-2012

Relative frequency: 360 / 17697 = 2.0 %

Relative frequency of trial patients: 88.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	171	189	360
Standardized rate *:	3.1	3.2	3.2
Cumulative incidence:	47	48	48
Sex ratio (m/f):			1.1

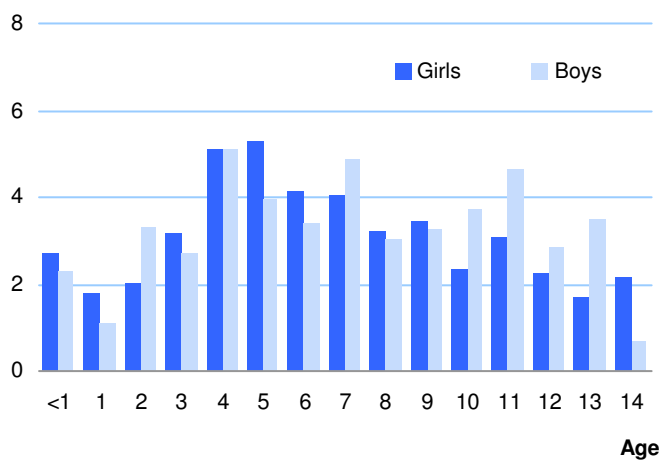
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	17	87	146	110
Incidence rate:	2.5	3.1	3.9	2.7

Median age at diagnosis: 7 years 5 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 1402

Selected characteristics Germany 2003-2012

Relative frequency:	584 / 17697 = 3.3 %		
Relative frequency of trial patients:	90.2 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	255	329	584
Standardized rate *:	4.4	5.4	4.9
Cumulative incidence:	68	83	76
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	21	111	186	266
Incidence rate:	3.1	3.9	4.9	6.5

Median age at diagnosis: 9 years 5 months

Survival probabilities:	5-year	10-year	15-year
	95 %	94 %	91 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
38	0.9 %	0.3	5

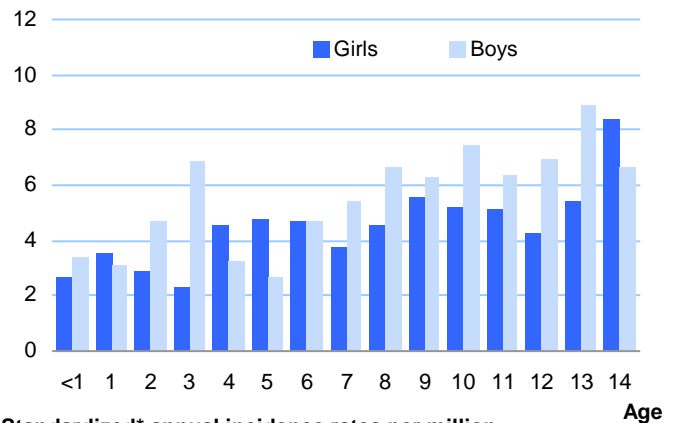
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

III (e) Other specified intracranial and intraspinal neoplasms

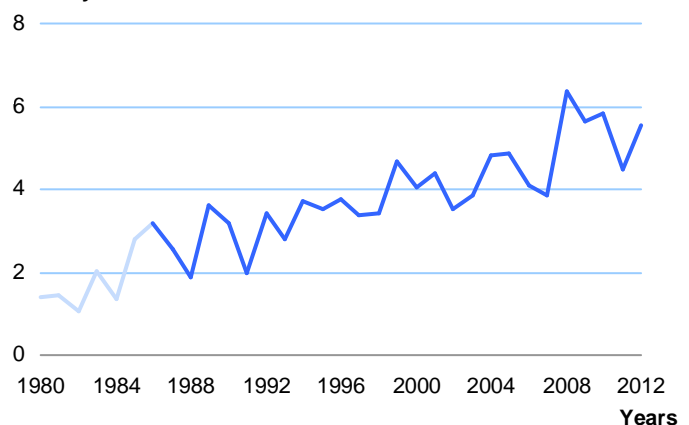
SN after III (e)			III (e) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
14	1.4 %	2.5 %	80	8.2 %	0.6 %

* Standard: Segi world standard population

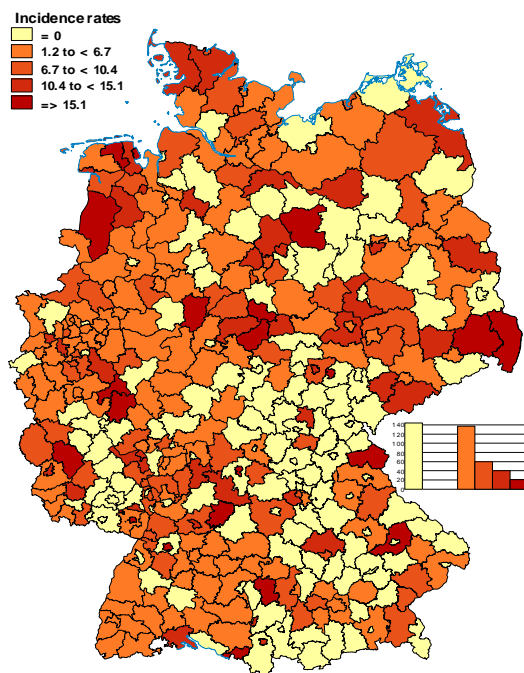
Age- and sex-specific incidence rates per million Germany 2003-2012



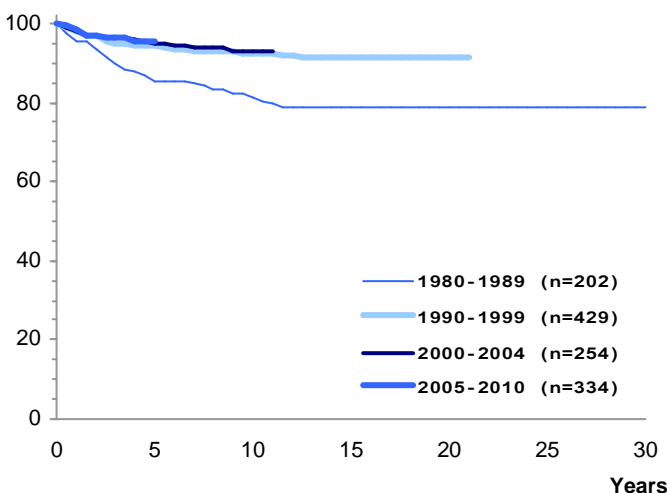
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Germany 2003-2012	N	%
Other specified intracranial and intraspinal neoplasms	584	100.0
Pituitary adenomas and carcinomas	31	5.3
Tumours of the sellar region (craniopharyngiomas)	183	31.3
Pineal parenchymal tumours	26	4.5
Neuronal and mixed neuronal-glial tumours	293	50.2
Meningiomas	51	8.7

1 Pituitary adenomas and carcinomas

Cases in Germany aged under 15 years (1980-2012): 85

Selected characteristics Germany 2003-2012

Relative frequency:	31 / 17697 = 0.2 %
Relative frequency of trial patients:	54.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	15	16	31
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	4	4	4
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	0	2	4	25
Incidence rate:	0.0	0.1	0.1	0.6

Median age at diagnosis: 12 years 7 months

* Standard: Segi world standard population

2 Tumours of the sellar region (craniopharyngiomas)

Cases in Germany aged under 15 years (1980-2012): 551

Selected characteristics Germany 2003-2012

Relative frequency:	183 / 17697 = 1.0 %
Relative frequency of trial patients:	98.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	88	95	183
Standardized rate *:	1.5	1.6	1.5
Cumulative incidence:	23	24	24
Sex ratio (m/f):	1.1		

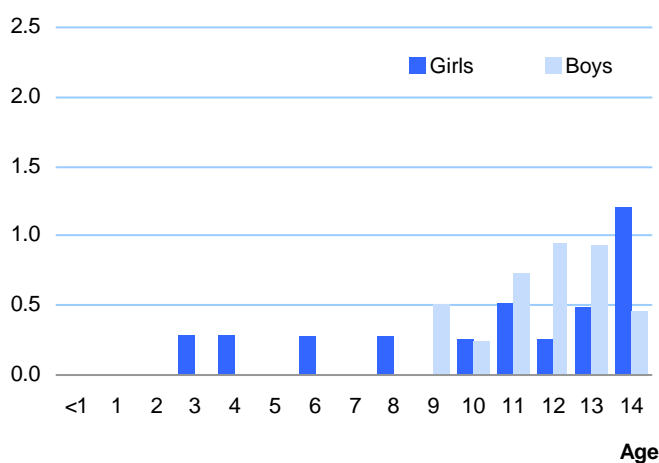
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	1	39	69	74
Incidence rate:	0.1	1.4	1.8	1.8

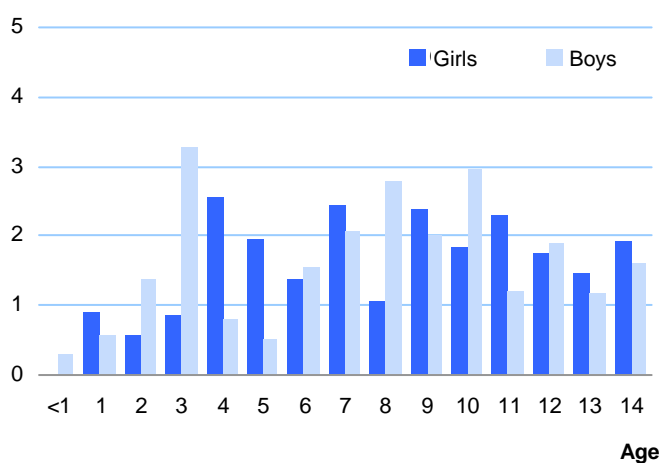
Median age at diagnosis: 8 years 11 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Germany 2003-2012	N	%
Other specified intracranial and intraspinal neoplasms	584	100.0
Pituitary adenomas and carcinomas	31	5.3
Tumours of the sellar region (craniopharyngiomas)	183	31.3
Pineal parenchymal tumours	26	4.5
Neuronal and mixed neuronal-glial tumours	293	50.2
Meningiomas	51	8.7

3 Pineal parenchymal tumours

Cases in Germany aged under 15 years (1980-2012): 114

Selected characteristics Germany 2003-2012

Relative frequency:	26 / 17697 = 0.1 %
Relative frequency of trial patients:	92.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	12	14	26
Standardized rate *:	0.2	0.3	0.2
Cumulative incidence:	3	4	3
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	1	8	7	10
Incidence rate:	0.1	0.3	0.2	0.2

Median age at diagnosis: 8 years 7 months

* Standard: Segi world standard population

4 Neuronal and mixed neuronal-glial tumours

Cases in Germany aged under 15 years (1980-2012): 512

Selected characteristics Germany 2003-2012

Relative frequency:	293 / 17697 = 1.7 %
Relative frequency of trial patients:	91.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	115	178	293
Standardized rate *:	2.0	2.9	2.5
Cumulative incidence:	31	45	38
Sex ratio (m/f):	1.5		

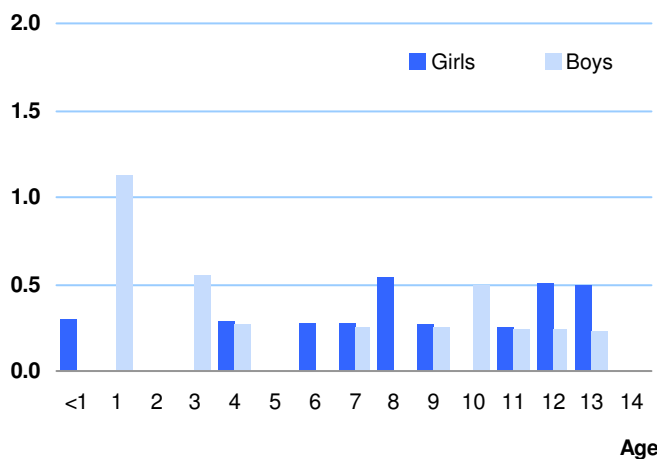
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	19	55	85	134
Incidence rate:	2.8	1.9	2.2	3.3

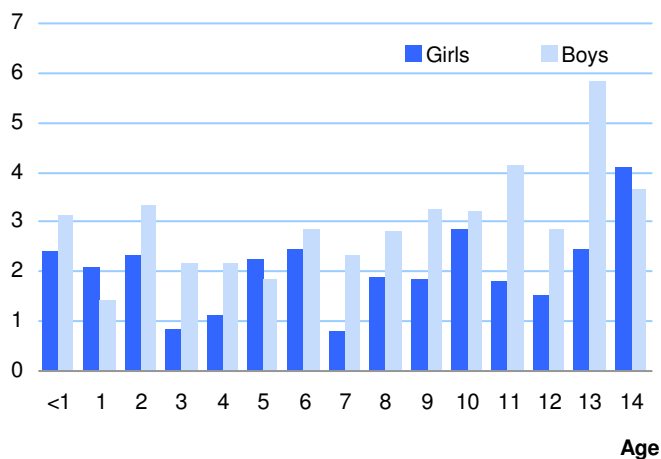
Median age at diagnosis: 9 years 4 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Germany 2003-2012	N	%
Other specified intracranial and intraspinal neoplasms	584	100.0
Pituitary adenomas and carcinomas	31	5.3
Tumours of the sellar region (craniopharyngiomas)	183	31.3
Pineal parenchymal tumours	26	4.5
Neuronal and mixed neuronal-glial tumours	293	50.2
Meningiomas	51	8.7

5 Meningiomas

Cases in Germany aged under 15 years (1980-2012): 140

Selected characteristics Germany 2003-2012

Relative frequency: 51 / 17697 = 0.3 %

Relative frequency of trial patients: 70.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	25	26	51
Standardized rate *:	0.4	0.4	0.4
Cumulative incidence:	7	6	7
Sex ratio (m/f):	1.0		

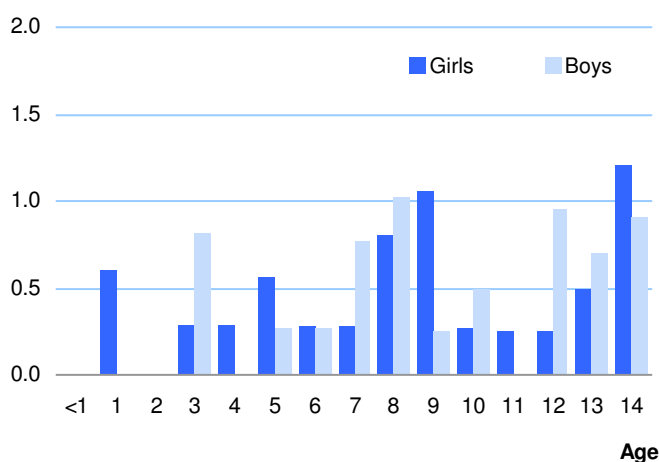
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	0	7	21	23
Incidence rate:	0.0	0.2	0.6	0.6

Median age at diagnosis: 9 years 5 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 3925**Selected characteristics Germany 2003-2012**

Relative frequency: 1222 / 17697 = 6.9 %

Relative frequency of trial patients: 98.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	556	666	1222
Standardized rate *:	12.5	14.4	13.5
Cumulative incidence:	162	185	174
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	575	521	97	29
Incidence rate:	84.1	18.4	2.6	0.7

Median age at diagnosis: 1 year 2 months

Survival probabilities:	5-year	10-year	15-year
	79 %	76 %	75 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

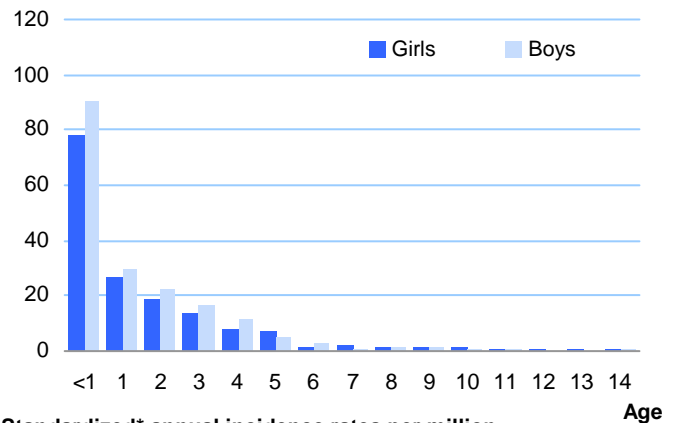
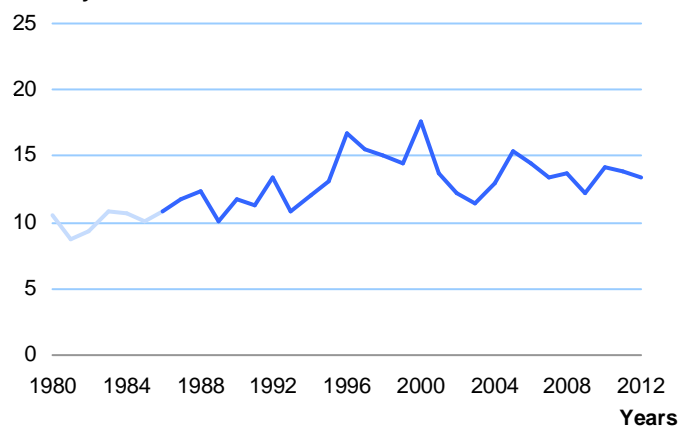
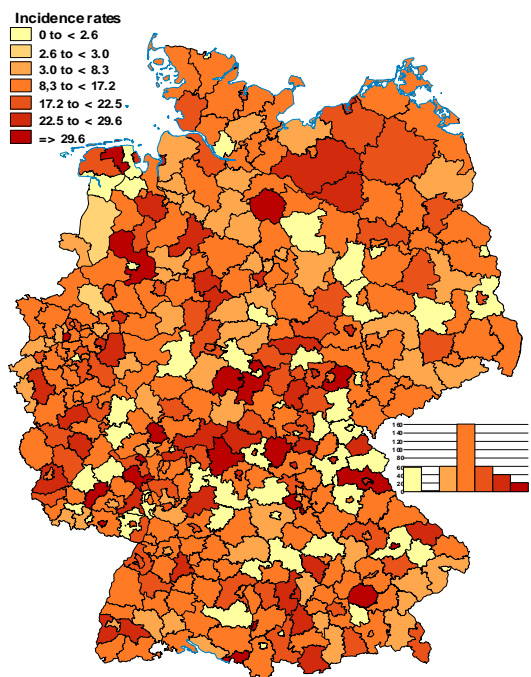
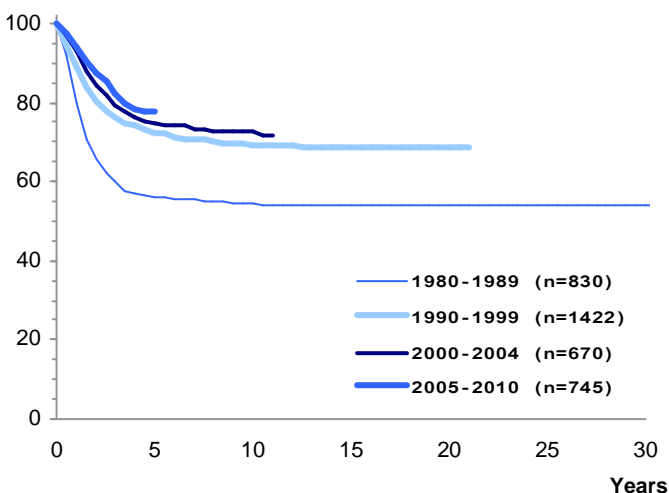
Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
447	10.8 %	4.2	56

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

IV (a) Neuroblastoma and ganglioneuroblastoma

SN after IV (a)			IV (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
58	5.9 %	3.1 %	10	1.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

Cases in Germany aged under 15 years (1980-2012): 1227

Selected characteristics Germany 2003-2012

Relative frequency: 370 / 17697 = 2.1 %

Relative frequency of trial patients: -

Incidence rates per million:	Girls	Boys	Total
Number of cases:	170	200	370
Standardized rate *:	3.9	4.3	4.1
Cumulative incidence:	50	56	53
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	170	185	13	2
Incidence rate:	24.9	6.5	0.3	0.0

Median age at diagnosis: 1 year 1 month

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
12	0.3 %	0.1	2

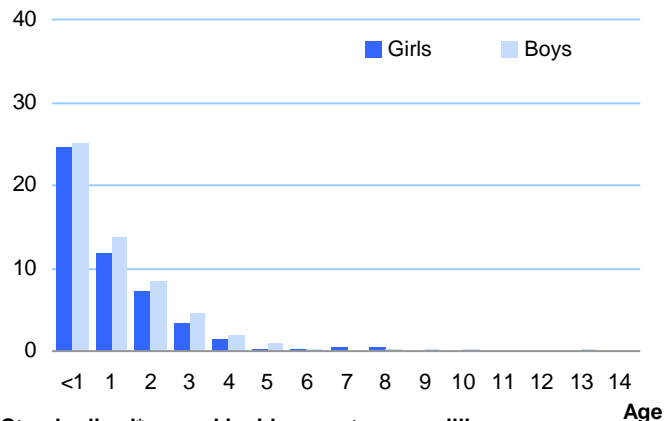
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

V Retinoblastoma

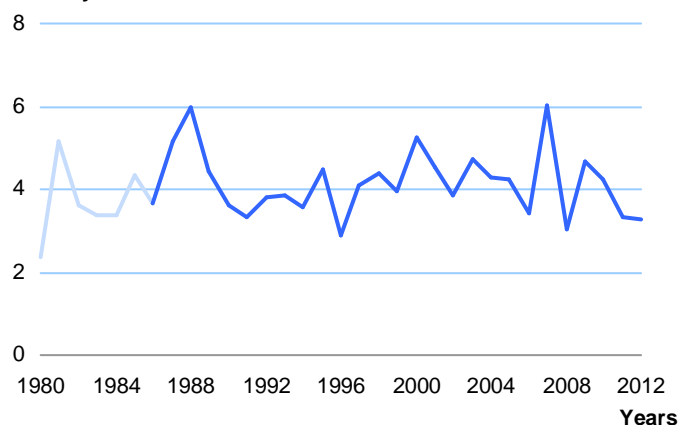
SN after V			V as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
28	2.9 %	4.4 %	3	0.3 %	0.0 %

* Standard: Segi world standard population

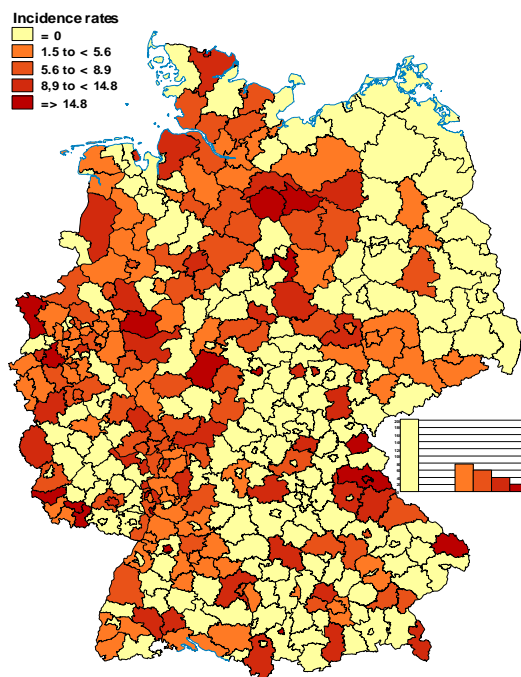
Age- and sex-specific incidence rates per million Germany 2003-2012



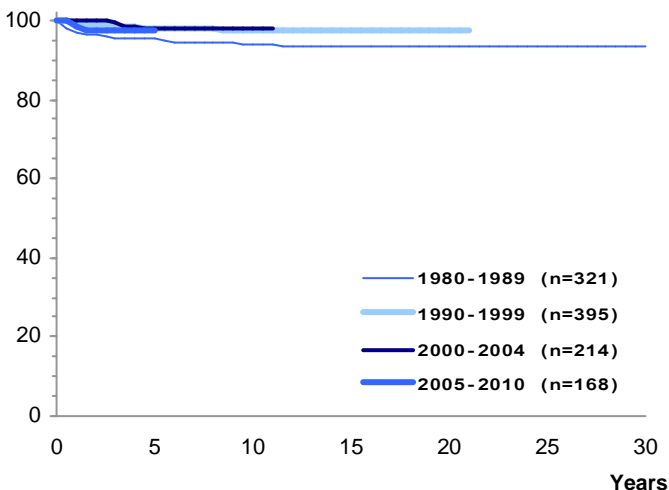
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 3005

Selected characteristics Germany 2003-2012

Relative frequency:	938 / 17697 = 5.3 %
Relative frequency of trial patients:	99.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	490	448	938
Standardized rate *:	10.4	9.1	9.7
Cumulative incidence:	140	122	131
Sex ratio (m/f):	0.9		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	150	549	205	34
Incidence rate:	21.9	19.4	5.4	0.8

Median age at diagnosis: 3 years 2 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
131	3.2 %	1.2	17

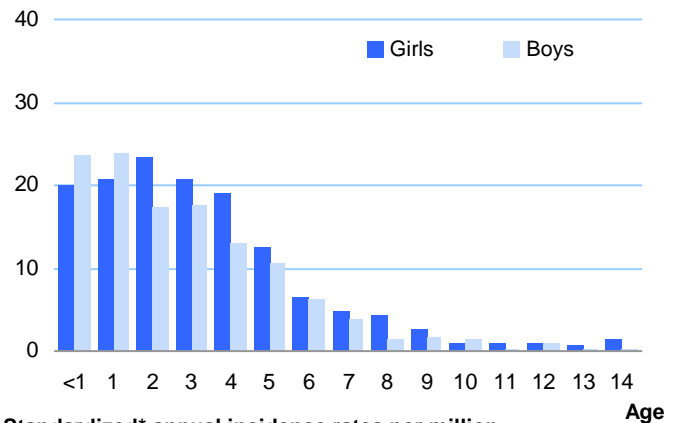
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

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

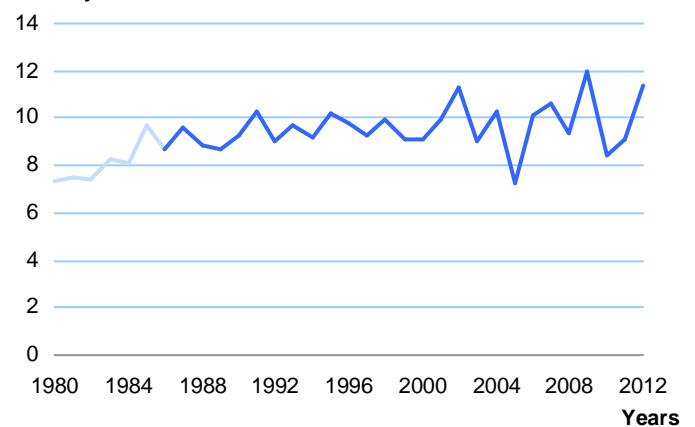
SN after VI (a)			VI (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
36	3.7 %	2.5 %	9	0.9 %	0.0 %

* Standard: Segi world standard population

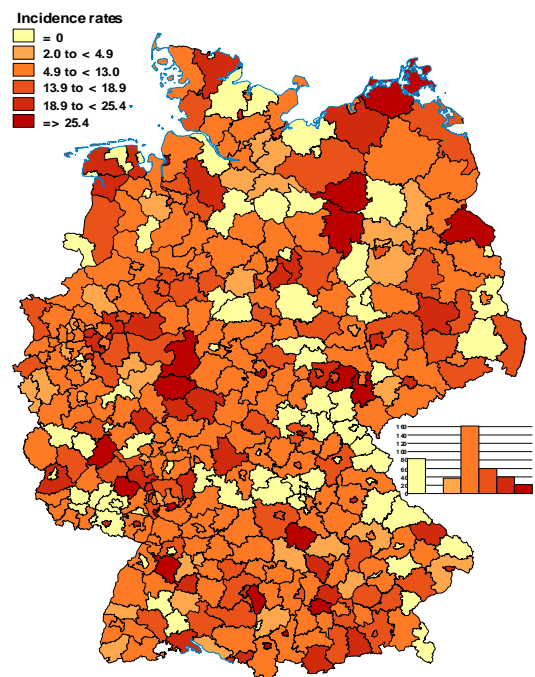
Age- and sex-specific incidence rates per million Germany 2003-2012



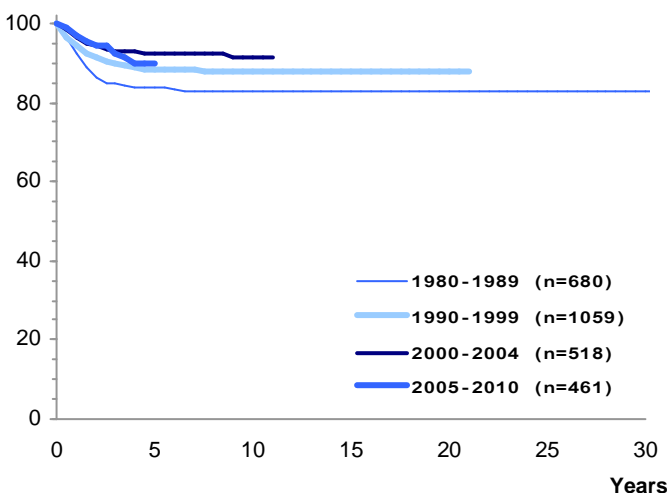
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Germany 2003-2012	N	%
Nephroblastoma and other non-epithelial renal tumours	980	100.0
Nephroblastoma	959	97.9
Rhabdoid renal tumour	13	1.3
Kidney sarcomas	7	0.7
Peripheral neuroectodermal tumour (pPNET) of kidney	1	0.1

1 Nephroblastoma

Cases in Germany aged under 15 years (1980-2012): 2908

Selected characteristics Germany 2003-2012

Relative frequency:	919 / 17697 = 5.2 %
Relative frequency of trial patients:	99.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	480	439	919
Standardized rate *:	10.1	9.0	9.5
Cumulative incidence:	137	120	128
Sex ratio (m/f):	0.9		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	141	545	200	33
Incidence rate:	20.6	19.2	5.3	0.8
Median age at diagnosis:	3 years 2 months			

* Standard: Segi world standard population

2 Rhabdoid renal tumour

Cases in Germany aged under 15 years (1980-2012): 48

Selected characteristics Germany 2003-2012

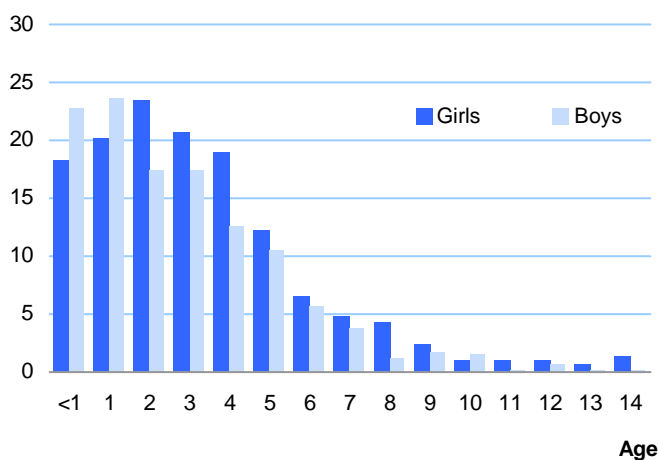
Relative frequency:	14 / 17697 = 0.1 %
Relative frequency of trial patients:	78.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	8	6	14
Standardized rate *:	0.2	0.1	0.2
Cumulative incidence:	2	2	2
Sex ratio (m/f):	0.8		

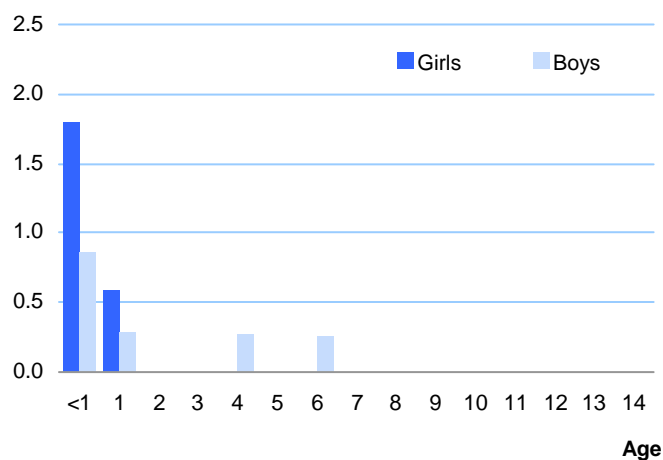
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	9	4	1	0
Incidence rate:	1.3	0.1	0.0	0.0
Median age at diagnosis:	0 years 10 months			

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 58**Selected characteristics Germany 2003-2012**

Relative frequency: 26 / 17697 = 0.1 %
Relative frequency of trial patients: 76.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	13	13	26
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 :	0	1	5	20
Incidence rate:	0.0	0.0	0.1	0.5
Median age at diagnosis:	11 years 10 months			

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

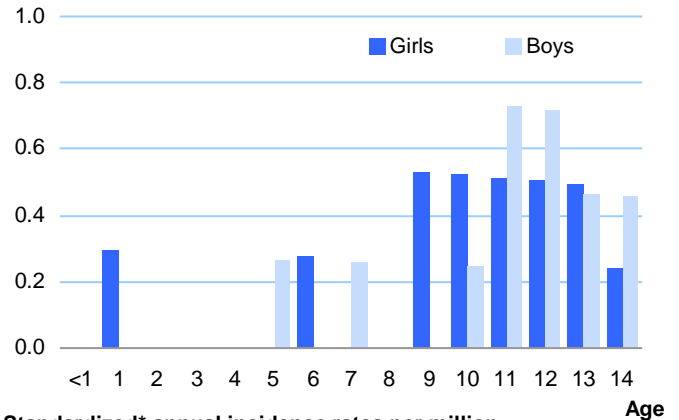
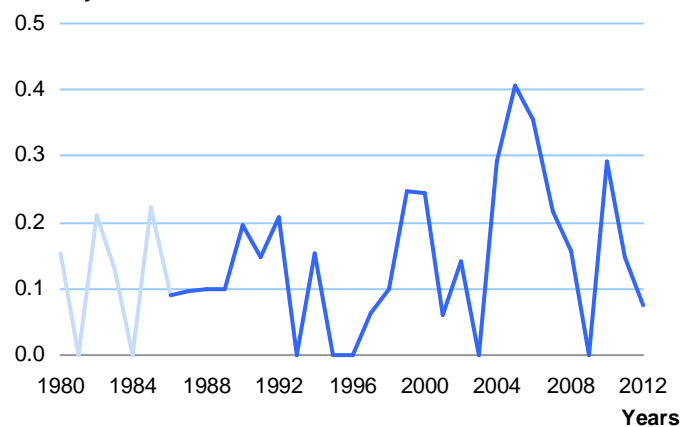
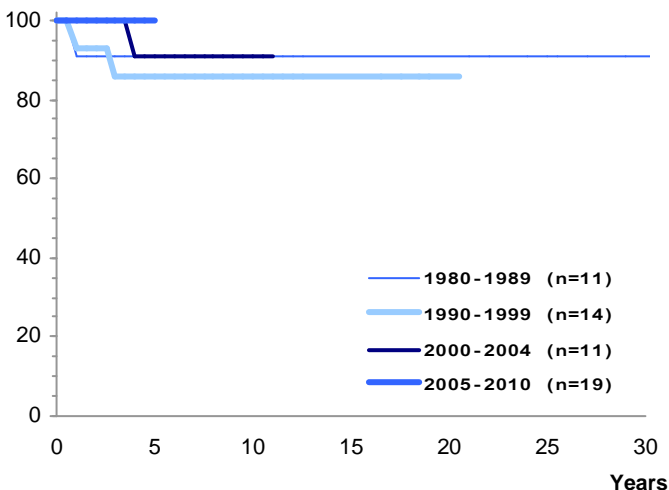
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
1	0.0 %	0.0	0

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

VI (b) Renal carcinomas

SN after VI (b)			VI (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
1	0.1 %	1.9 %	5	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 448

Selected characteristics Germany 2003-2012

Relative frequency: 196 / 17697 = 1.1 %

Relative frequency of trial patients: 79.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	85	111	196
Standardized rate *:	1.9	2.4	2.1
Cumulative incidence:	25	31	28
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	70	111	7	8
Incidence rate:	10.2	3.9	0.2	0.2

Median age at diagnosis: 1 year 4 months

Survival probabilities:	5-year	10-year	15-year
	78 %	76 %	76 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
40	1.0 %	0.4	5

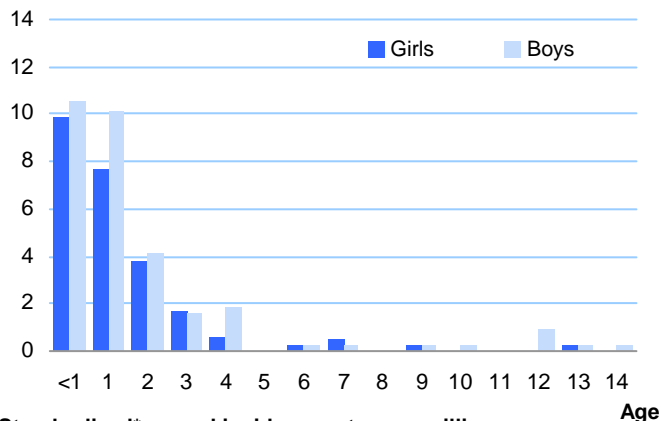
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

VII (a) Hepatoblastoma

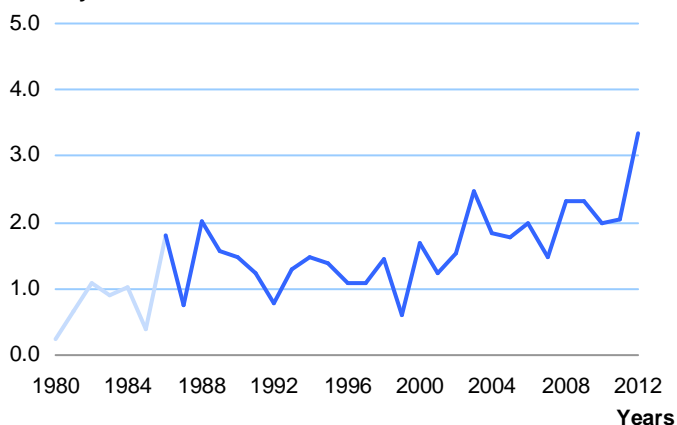
SN after VII (a)			VII (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
3	0.3 %	2.2 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

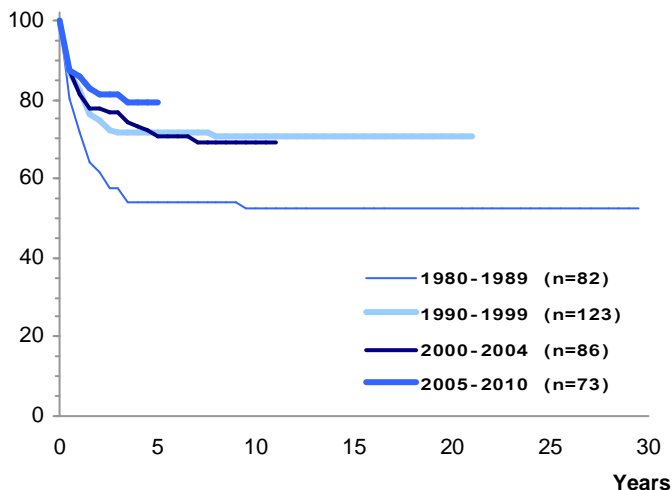
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Survival probabilities by year of diagnosis Germany 1980-2010



No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 107

Selected characteristics Germany 2003-2012

Relative frequency: 35 / 17697 = 0.2 %

Relative frequency of trial patients: 77.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	12	23	35
Standardized rate *:	0.2	0.3	0.3
Cumulative incidence:	3	6	4
Sex ratio (m/f):	1.9		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	3	8	24
Incidence rate:	0.0	0.1	0.2	0.6

Median age at diagnosis: 12 years 9 months

Survival probabilities:

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
16	0.4 %	0.1	2

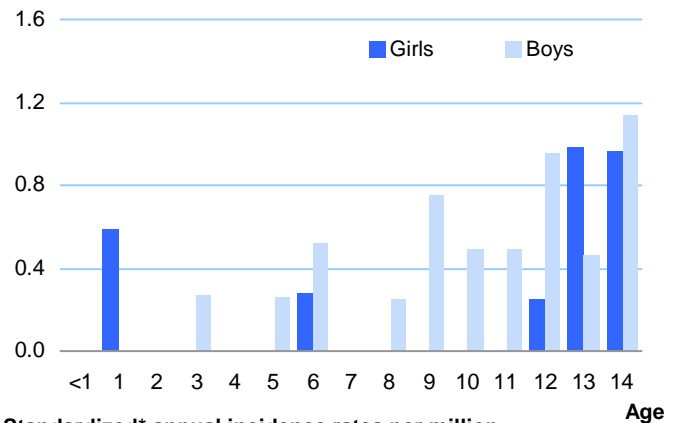
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

VII (b) Hepatic carcinomas

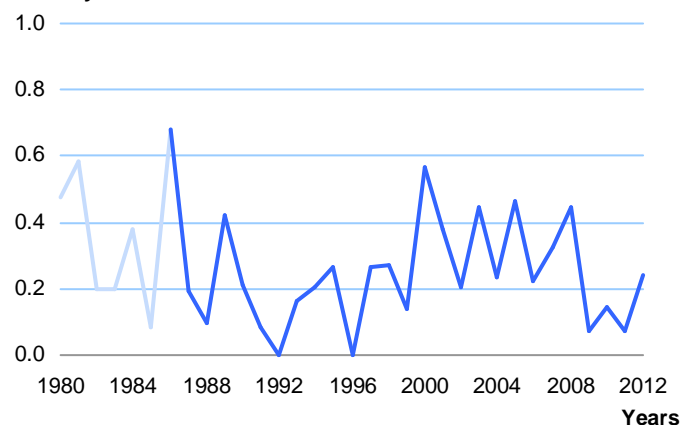
SN after VII (b)			VII (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
1	0.1 %	1.0 %	5	0.5 %	0.0 %

* Standard: Segi world standard population

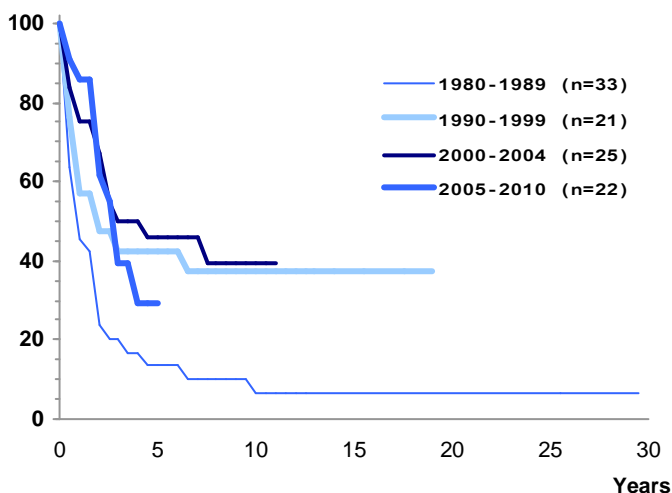
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Survival probabilities by year of diagnosis Germany 1980-2010



No map due to sparse data

- (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 (1980-2012): 2431

Selected characteristics Germany 2003-2012

Relative frequency: 778 / 17697 = 4.4 %

Relative frequency of trial patients: 97.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	369	409	778
Standardized rate *:	5.8	6.2	6.0
Cumulative incidence:	95	101	98
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	5	42	214	517
Incidence rate:	0.7	1.5	5.7	12.6

Median age at diagnosis: 11 years 9 months

Survival probabilities:	5-year	10-year	15-year
	74 %	69 %	68 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
259	6.3 %	2.0	32

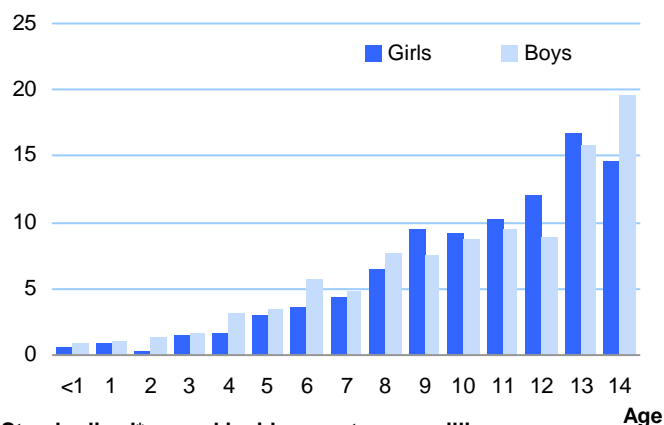
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

VIII Malignant bone tumours

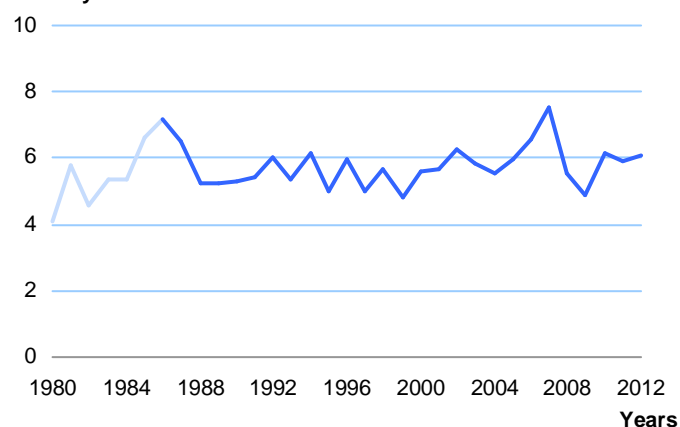
SN after VIII			VIII as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
54	5.5 %	4.4 %	54	5.5 %	0.2 %

* Standard: Segi world standard population

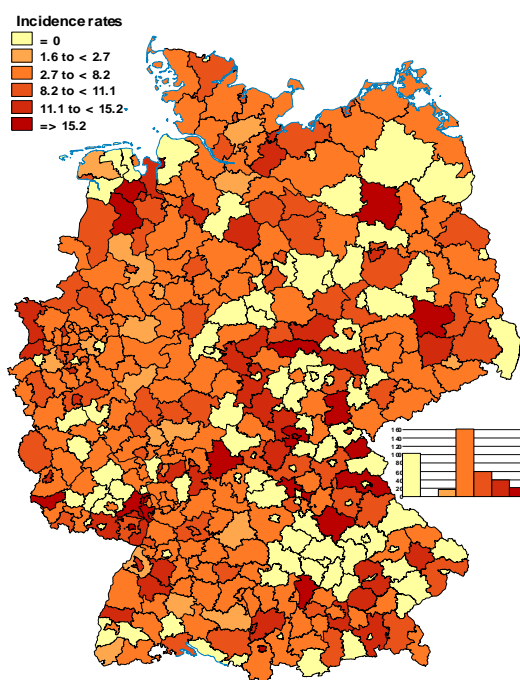
Age- and sex-specific incidence rates per million Germany 2003-2012



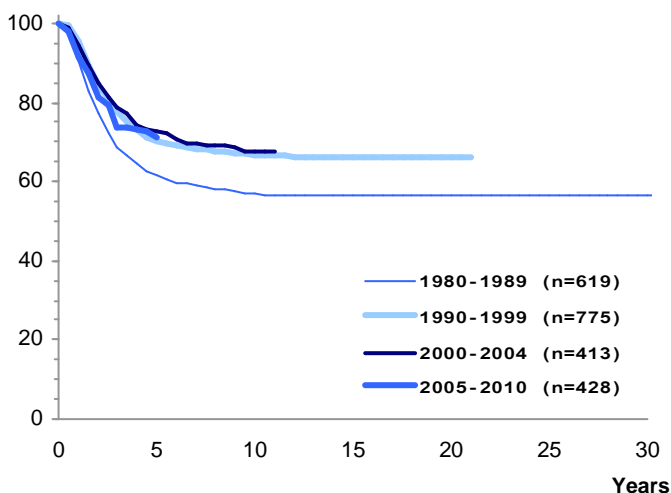
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 1272

Selected characteristics Germany 2003-2012

Relative frequency: 395 / 17697 = 2.2 %

Relative frequency of trial patients: 98.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	202	193	395
Standardized rate *:	3.1	2.8	3.0
Cumulative incidence:	52	47	49
Sex ratio (m/f):	1.0		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	8	95	292
Incidence rate:	0.0	0.3	2.5	7.1

Median age at diagnosis: 12 years 6 months

Survival probabilities:	5-year	10-year	15-year
	76 %	72 %	71 %

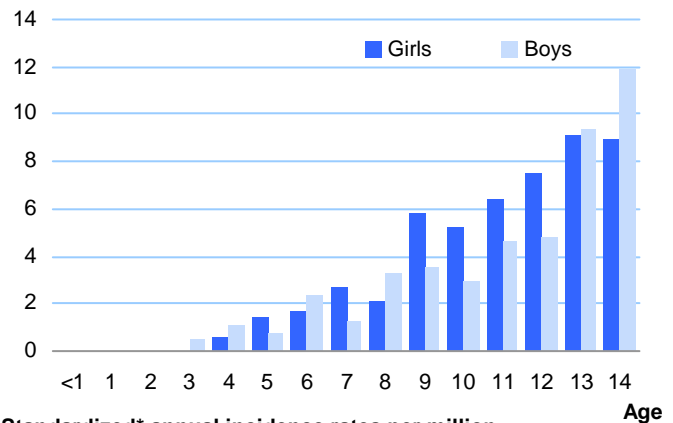
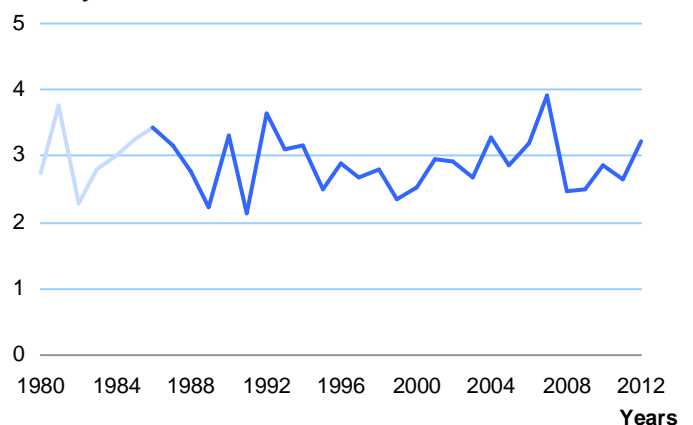
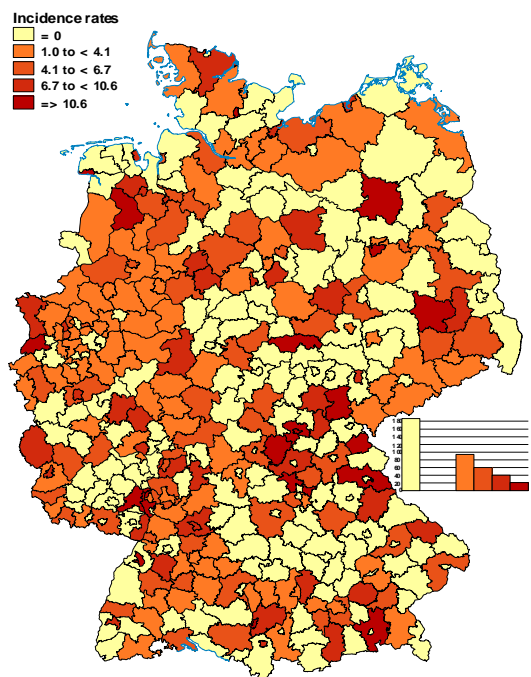
Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
135	3.3 %	1.0	17

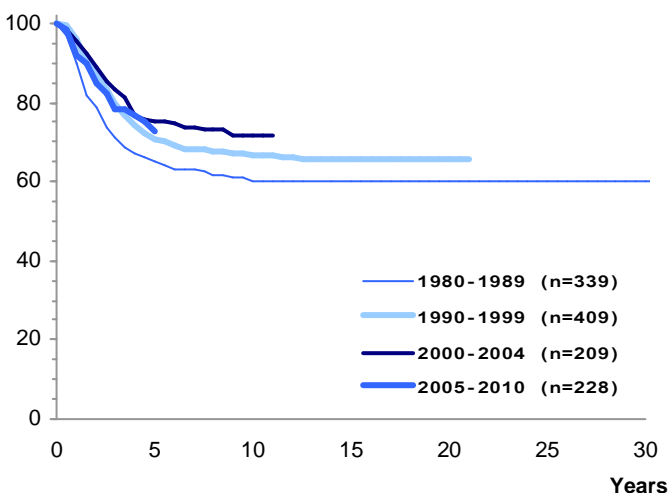
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):
VIII (a) Osteosarcomas

SN after VIII (a)			VIII (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
25	2.6 %	4.6 %	36	3.7 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012Standardized* annual incidence rates per million
Germany 1980-2012Standardized* incidence rates per million by districts
(Landkreise) Germany 2003-2012

Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 1077

Selected characteristics Germany 2003-2012

Relative frequency: 349 / 17697 = 2.0 %

Relative frequency of trial patients: 98.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	151	198	349
Standardized rate *:	2.4	3.1	2.8
Cumulative incidence:	39	49	44
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	5	33	109	202
Incidence rate:	0.7	1.2	2.9	4.9

Median age at diagnosis: 10 years 10 months

Survival probabilities:	5-year	10-year	15-year
	70 %	66 %	65 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
117	2.8 %	0.9	15

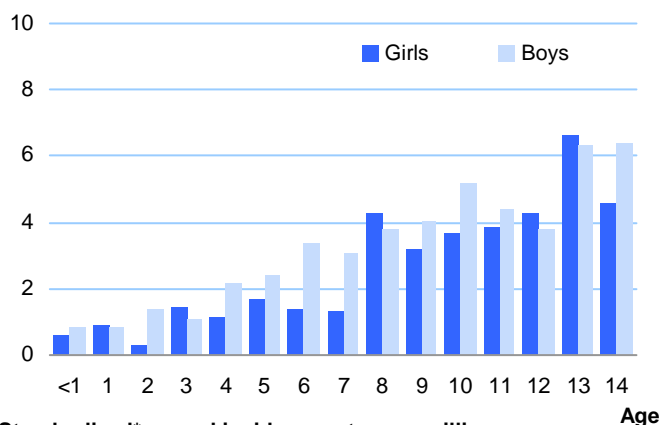
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

VIII (c) Ewing tumour and related sarcomas of bone

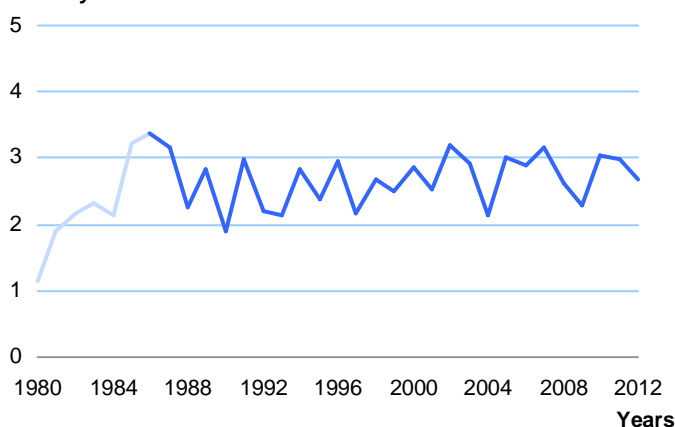
SN after VIII (c)			VIII (c) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
27	2.8 %	4.0 %	14	1.4 %	0.1 %

* Standard: Segi world standard population

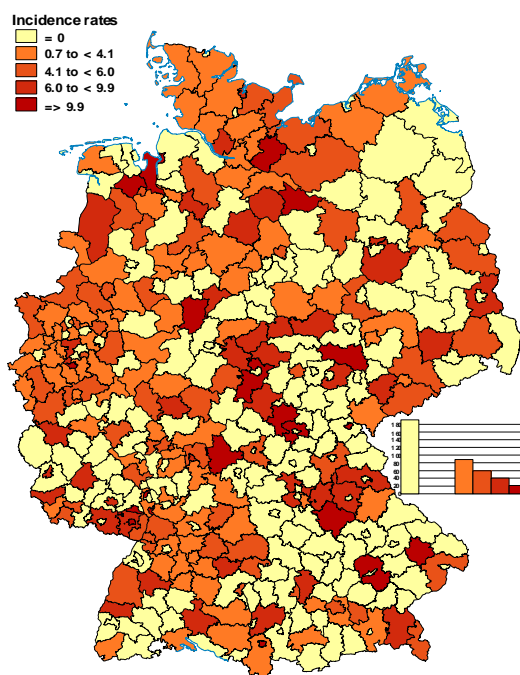
Age- and sex-specific incidence rates per million Germany 2003-2012



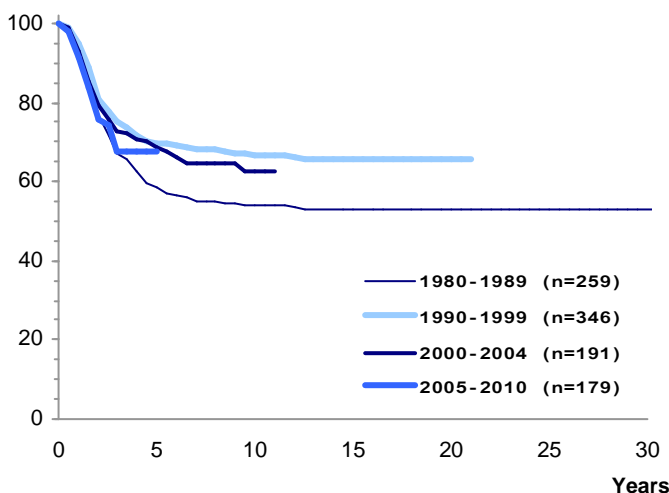
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



- (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 (1980-2012): 3197

Selected characteristics Germany 2003-2012

Relative frequency: 1029 / 17697 = 5.8 %

Relative frequency of trial patients: 96.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	473	556	1029
Standardized rate *:	8.7	9.9	9.3
Cumulative incidence:	129	145	137
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	115	301	265	348
Incidence rate:	16.8	10.6	7.0	8.5

Median age at diagnosis: 6 years 7 months

Survival probabilities:	5-year	10-year	15-year
	72 %	69 %	68 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
369	8.9 %	3.2	46

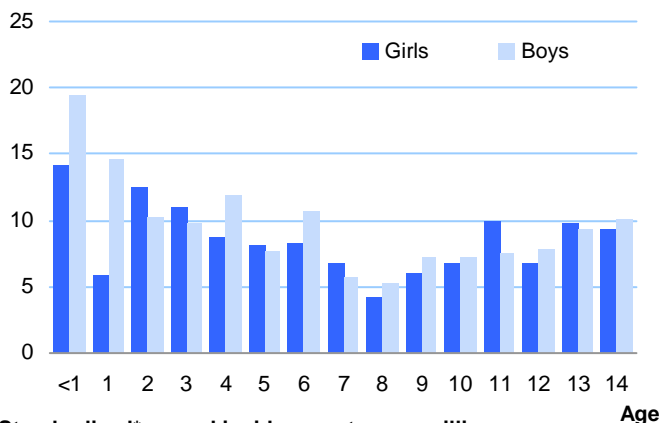
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

IX Soft tissue and other extraosseous sarcomas

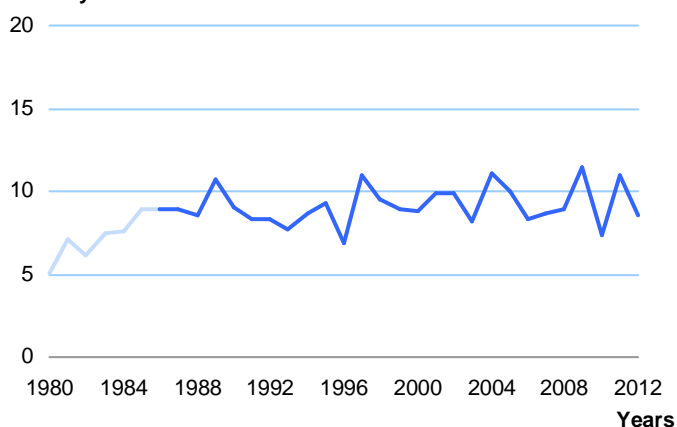
SN after IX			IX as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
68	7.0 %	4.5 %	60	6.1 %	0.3 %

* Standard: Segi world standard population

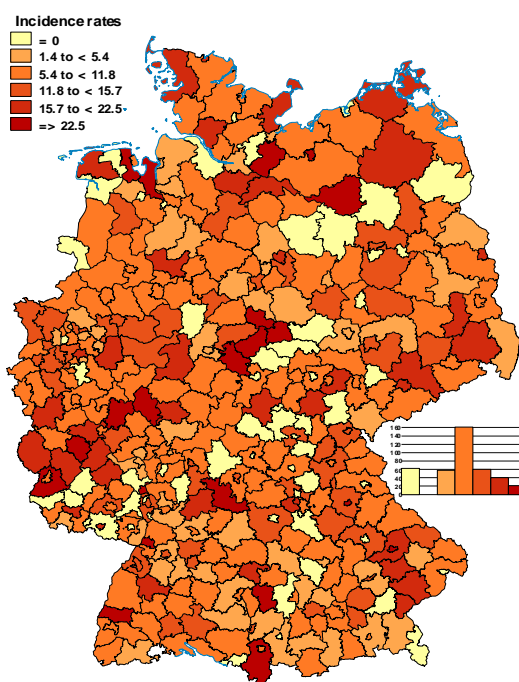
Age- and sex-specific incidence rates per million Germany 2003-2012



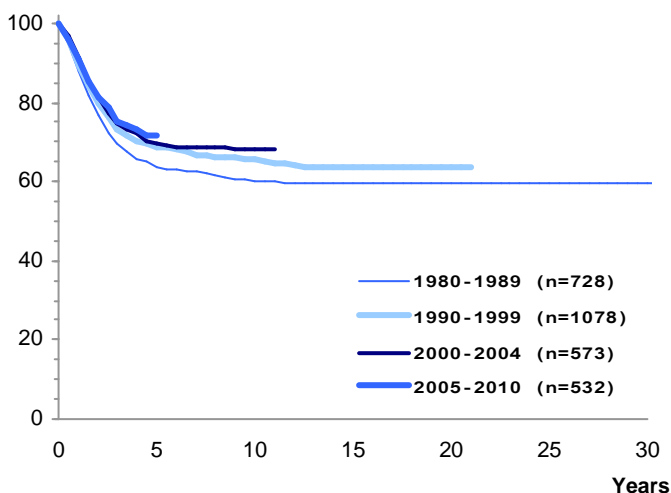
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 1842

Selected characteristics Germany 2003-2012

Relative frequency: 554 / 17697 = 3.1 %

Relative frequency of trial patients: 98.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	247	307	554
Standardized rate *:	4.7	5.7	5.2
Cumulative incidence:	68	81	75
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	50	219	166	119
Incidence rate:	7.3	7.7	4.4	2.9

Median age at diagnosis: 5 years 2 months

Survival probabilities:	5-year	10-year	15-year
	72 %	71 %	69 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
211	5.1 %	1.8	26

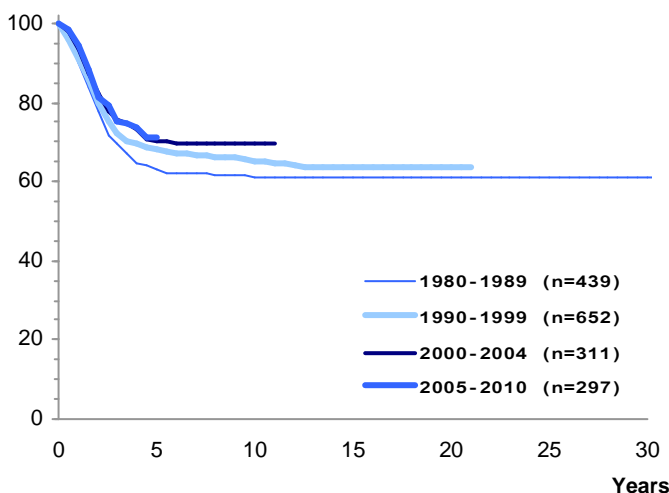
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

IX (a) Rhabdomyosarcomas

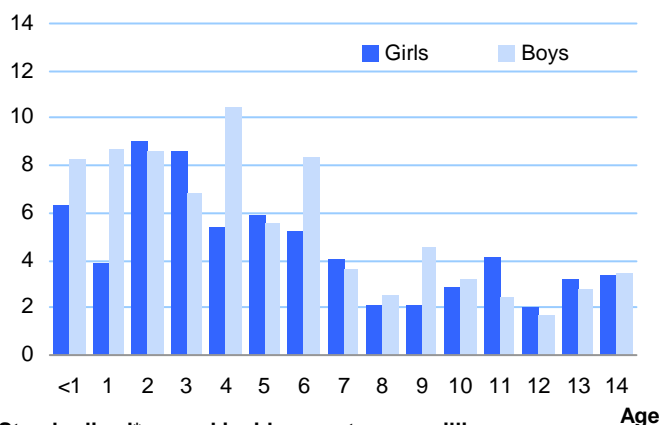
SN after IX (a)			IX (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
47	4.8 %	5.0 %	14	1.4 %	0.0 %

* Standard: Segi world standard population

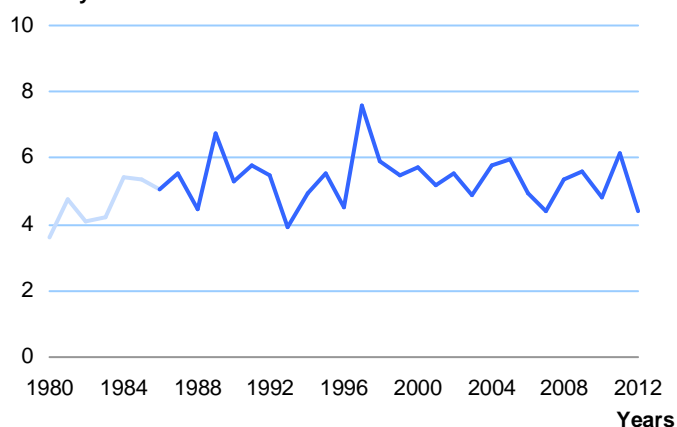
Survival probabilities by year of diagnosis Germany 1980-2010



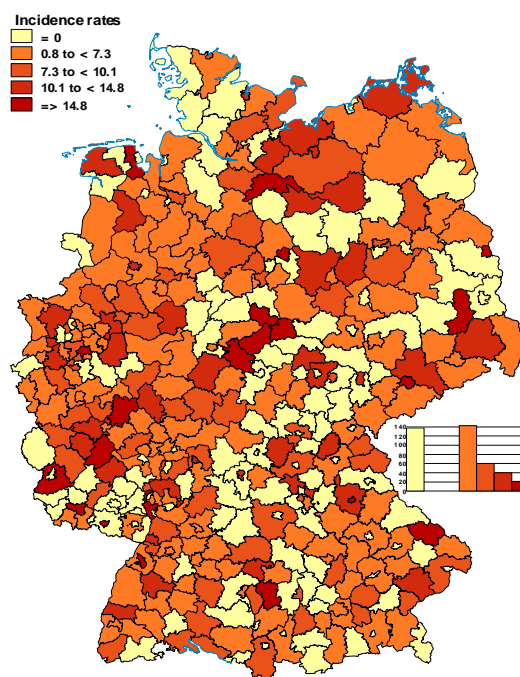
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 286**Selected characteristics Germany 2003-2012**

Relative frequency: 100 / 17697 = 0.6 %

Relative frequency of trial patients: 91.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	46	54	100
Standardized rate *:	0.8	1.0	0.9
Cumulative incidence:	12	14	13
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	23	18	15	44
Incidence rate:	3.4	0.6	0.4	1.1

Median age at diagnosis: 8 years 7 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

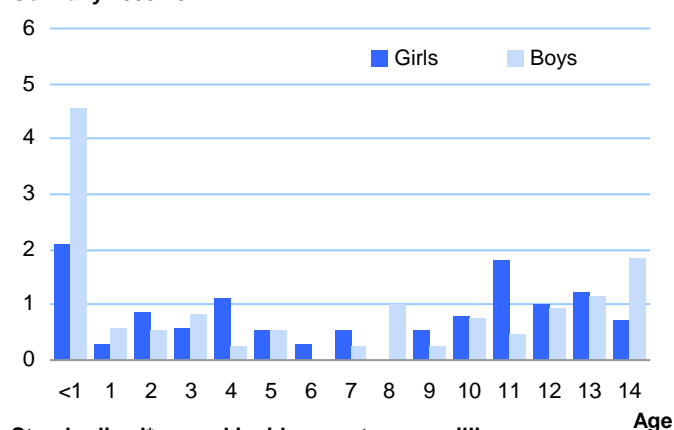
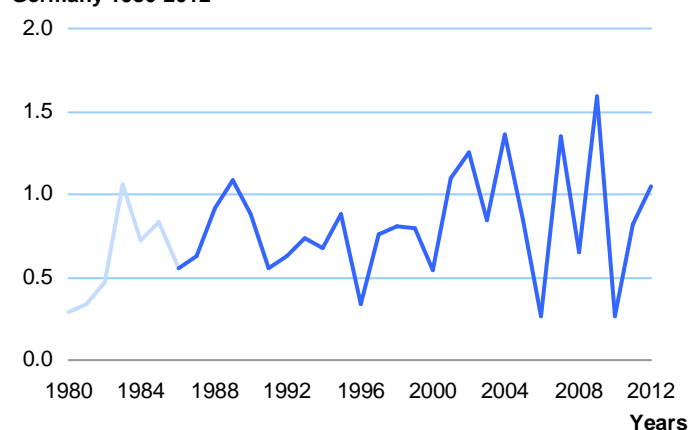
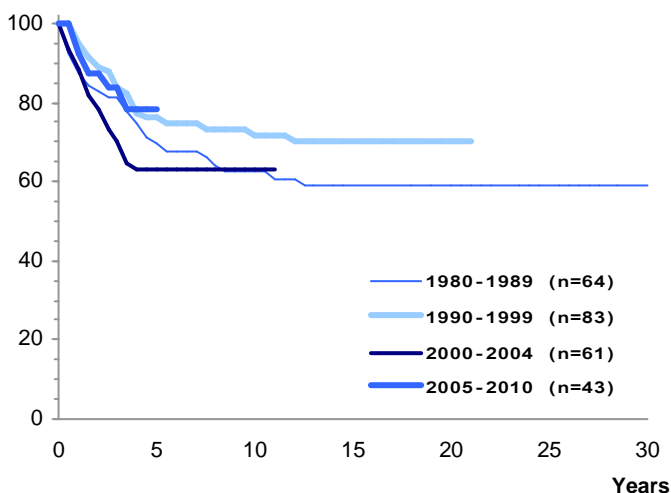
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
27	0.7 %	0.2	3

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

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 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
4	0.4 %	2.1 %	18	1.8 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

No map due to sparse data

Germany 2003-2012	N	%
Fibrosarcomas, peripheral nerve sheath tumours and other	100	100.0
Fibroblastic and myofibroblastic tumours	54	54.0
Nerve sheath tumours	46	46.0
Other fibrous neoplasms	0	0.0

1 Fibroblastic and myofibroblastic tumours

Cases in Germany aged under 15 years (1980-2012): 134

Selected characteristics Germany 2003-2012

Relative frequency: 54 / 17697 = 0.3 %

Relative frequency of trial patients: 92.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	24	30	54
Standardized rate *:	0.5	0.6	0.5
Cumulative incidence:	7	8	7
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	19	12	7	16
Incidence rate:	2.8	0.4	0.2	0.4

Median age at diagnosis: 4 years 1 month

* Standard: Segi world standard population

2 Nerve sheath tumours

Cases in Germany aged under 15 years (1980-2012): 152

Selected characteristics Germany 2003-2012

Relative frequency: 46 / 17697 = 0.3 %

Relative frequency of trial patients: 89.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	22	24	46
Standardized rate *:	0.4	0.4	0.4
Cumulative incidence:	6	6	6
Sex ratio (m/f):	1.1		

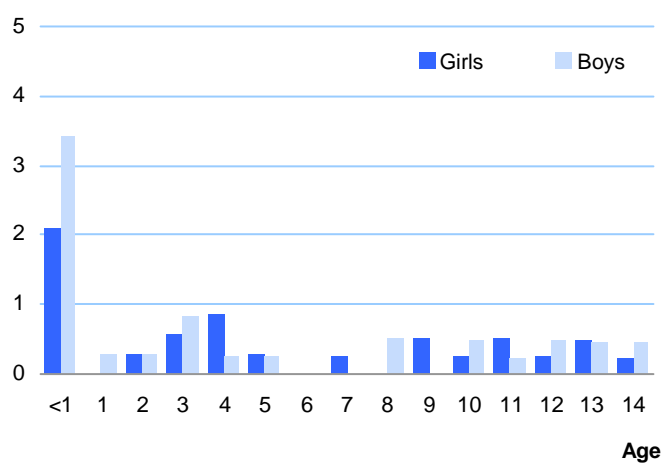
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	4	6	8	28
Incidence rate:	0.6	0.2	0.2	0.7

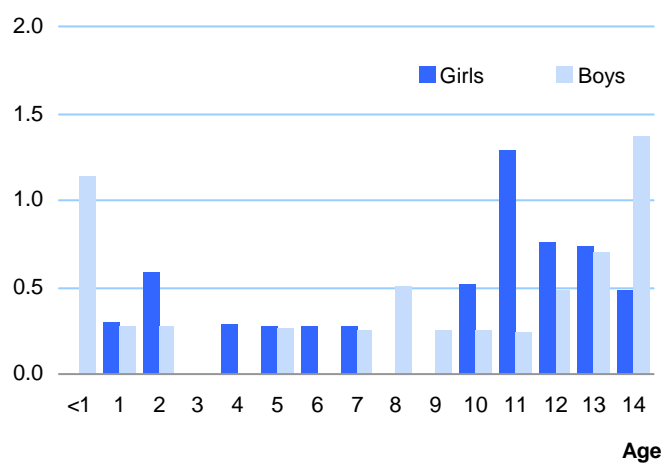
Median age at diagnosis: 11 years 5 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2003-2012



Age- and sex-specific incidence rates per million
Germany 2003-2012



Cases in Germany aged under 15 years (1980-2012): 866**Selected characteristics Germany 2003-2012**

Relative frequency:	297 / 17697 = 1.7 %
Relative frequency of trial patients:	94.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	139	158	297
Standardized rate *:	2.4	2.6	2.5
Cumulative incidence:	37	40	39
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	30	46	69	152
Incidence rate:	4.4	1.6	1.8	3.7

Median age at diagnosis: 10 years 2 months

Survival probabilities:	5-year	10-year	15-year
	74 %	70 %	67 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

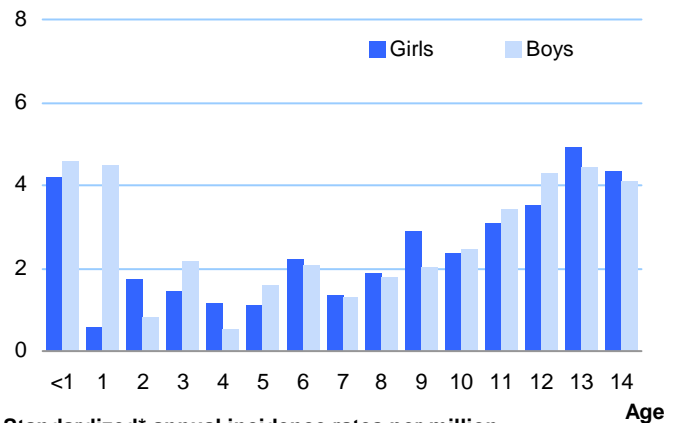
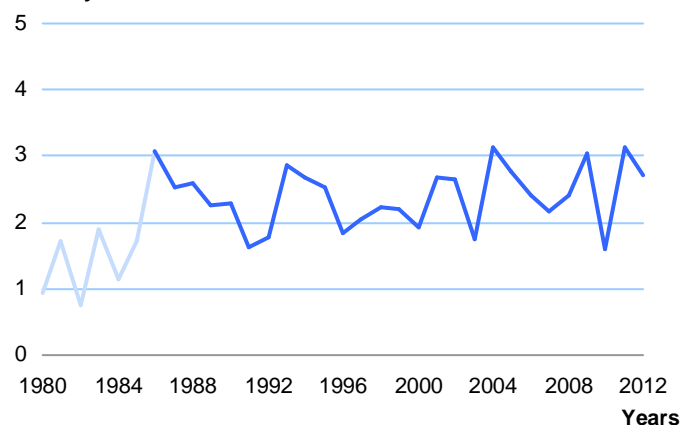
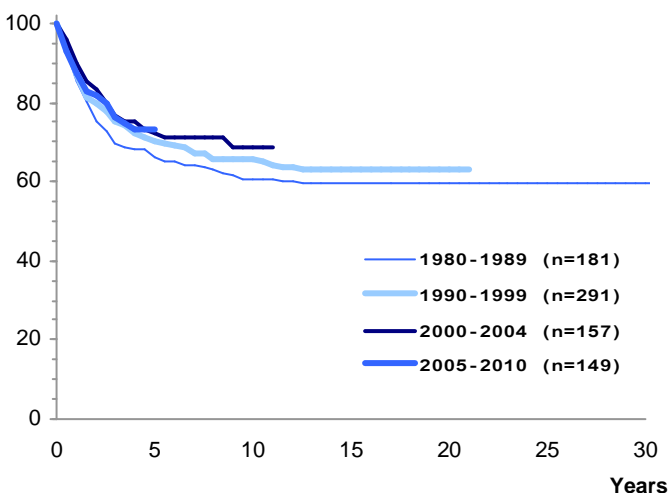
Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
110	2.7 %	0.9	14

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

IX (d) Other specified soft tissue sarcomas

SN after IX (d)			IX (d) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
14	1.4 %	3.9 %	24	2.5 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

No map due to sparse data

- (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 (1980-2012): 1642

Selected characteristics Germany 2003-2012

Relative frequency: 530 / 17697 = 3.0 %

Relative frequency of trial patients: 95.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	314	216	530
Standardized rate *:	5.7	3.9	4.8
Cumulative incidence:	85	56	70
Sex ratio (m/f):	0.7		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	132	75	87	236
Incidence rate:	19.3	2.6	2.3	5.8

Median age at diagnosis: 9 years 0 months

Survival probabilities:	5-year	10-year	15-year
	95 %	94 %	94 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
68	1.6 %	0.6	9

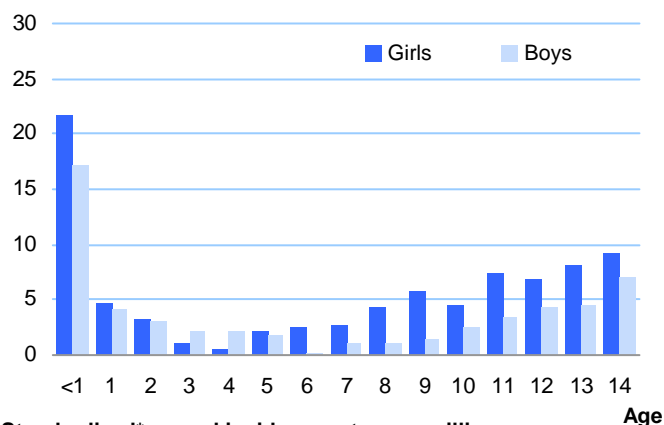
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

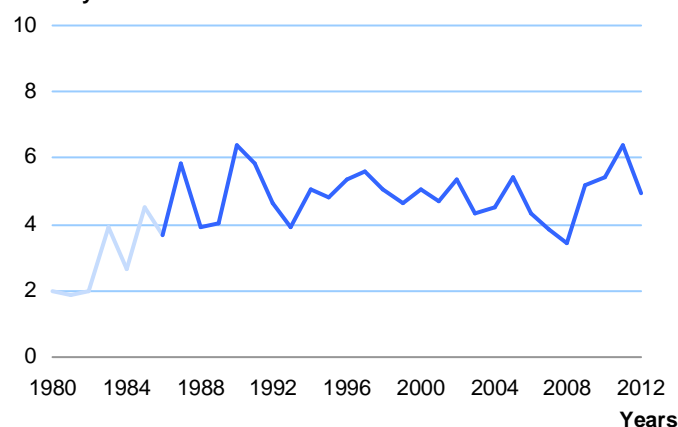
SN after X			X as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
24	2.5 %	6.0 %	10	1.0 %	0.1 %

* Standard: Segi world standard population

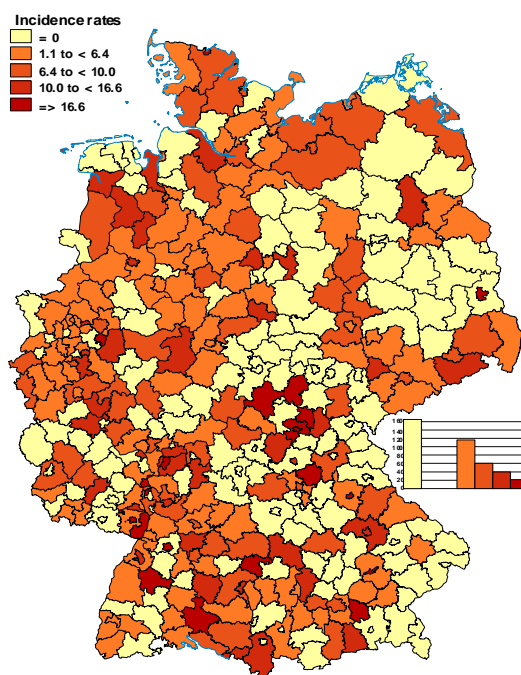
Age- and sex-specific incidence rates per million Germany 2003-2012



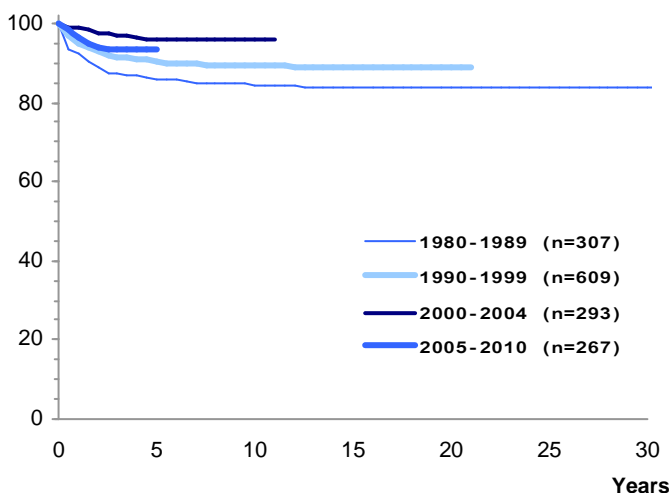
Standardized* annual incidence rates per million Germany 1980-2012



Standardized* incidence rates per million by districts (Landkreise) Germany 2003-2012



Survival probabilities by year of diagnosis Germany 1980-2010



Cases in Germany aged under 15 years (1980-2012): 442**Selected characteristics Germany 2003-2012**

Relative frequency:	146 / 17697 = 0.8 %
Relative frequency of trial patients:	94.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	58	88	146
Standardized rate *:	1.0	1.3	1.1
Cumulative incidence:	15	22	19
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	6	7	41	92
Incidence rate:	0.9	0.2	1.1	2.2

Median age at diagnosis: 11 years 2 months

Survival probabilities:	5-year	10-year	15-year
	91 %	89 %	-

Mortality per million within 15 yrs. of diagnosis (1988-1997):

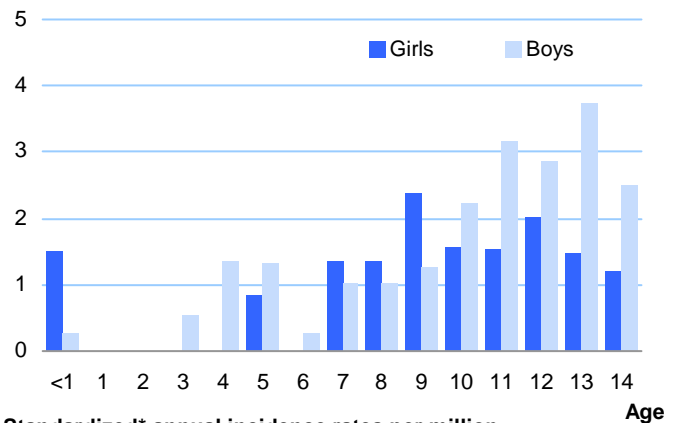
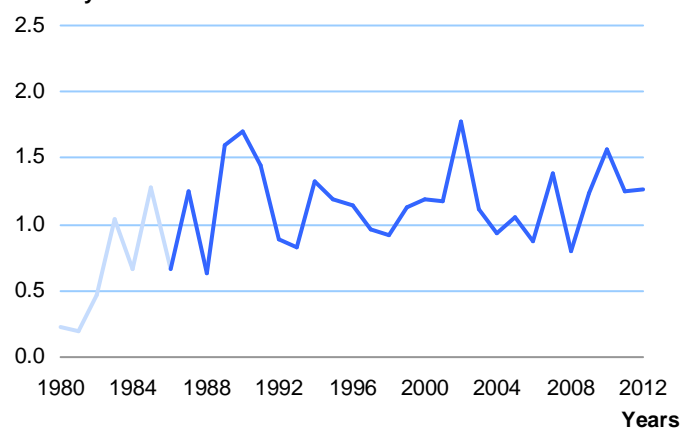
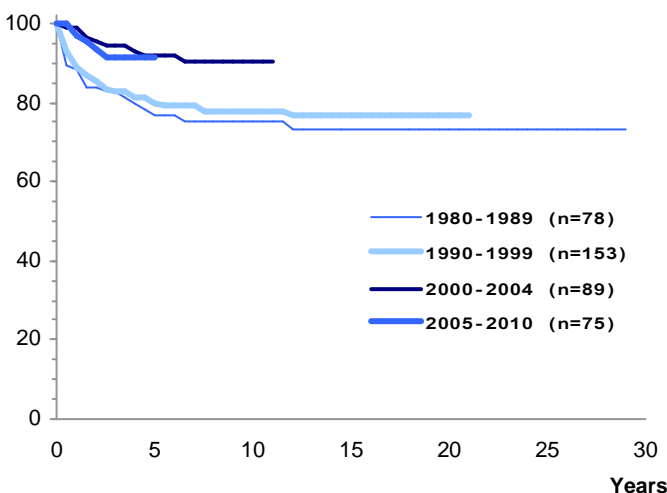
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
35	0.8 %	0.3	4

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

X (a) Intracranial and intraspinal germ cell tumours

SN after X (a)			X (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
11	1.1 %	15.3 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 476

Selected characteristics Germany 2003-2012

Relative frequency: 150 / 17697 = 0.8 %

Relative frequency of trial patients: 93.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	100	50	150
Standardized rate *:	2.3	1.0	1.7
Cumulative incidence:	29	14	21
Sex ratio (m/f):	0.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	95	40	3	12
Incidence rate:	13.9	1.4	0.1	0.3

Median age at diagnosis: 0 years 3 months

Survival probabilities:	5-year	10-year	15-year
	95 %	94 %	94 %

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
20	0.5 %	0.2	3

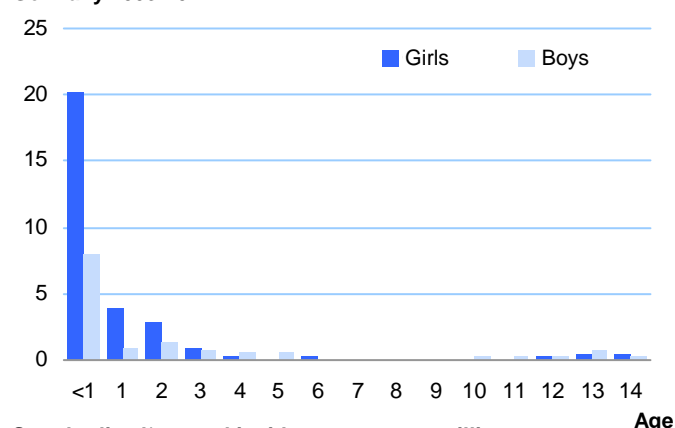
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

X (b) Malignant extracranial and extragonadal germ cell tumours

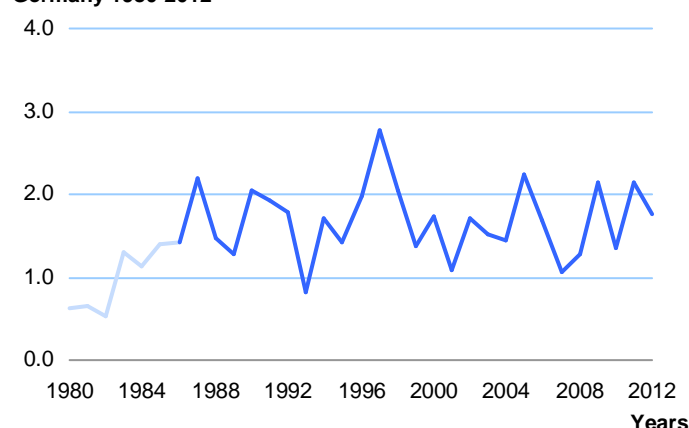
SN after X (b)			X (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
6	0.6 %	4.9 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

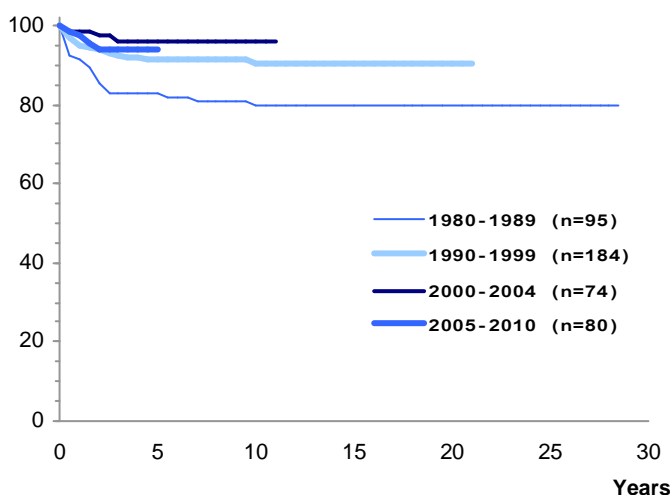
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Survival probabilities by year of diagnosis Germany 1980-2010



No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 683**Selected characteristics Germany 2003-2012**

Relative frequency: 227 / 17697 = 1.3 %

Relative frequency of trial patients: 97.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	149	78	227
Standardized rate *:	2.3	1.5	1.9
Cumulative incidence:	38	21	29
Sex ratio (m/f):	0.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	31	28	42	126
Incidence rate:	4.5	1.0	1.1	3.1

Median age at diagnosis: 11 years 3 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

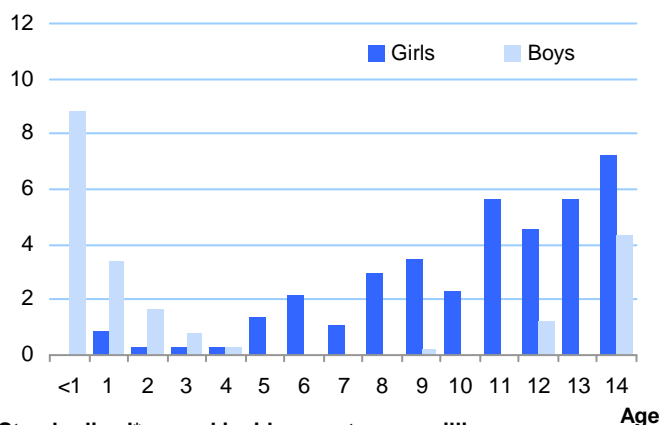
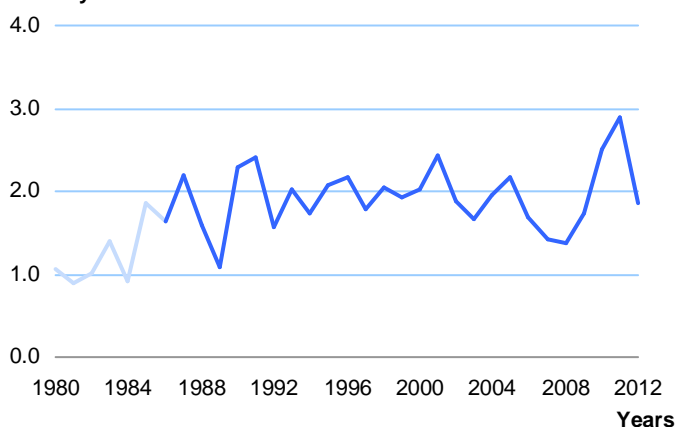
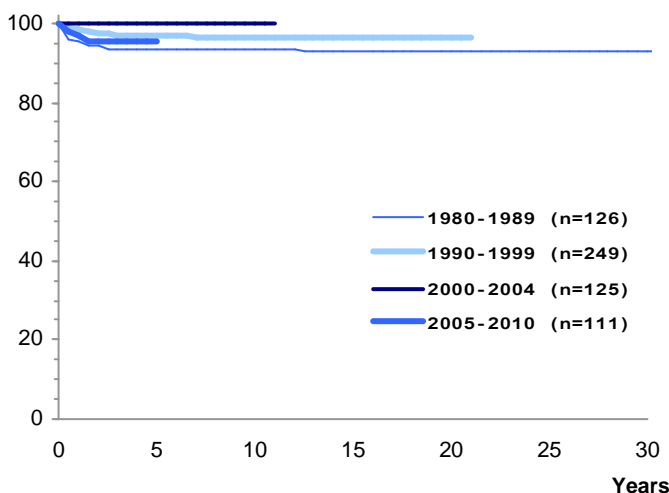
Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
7	0.2 %	0.1	1

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

X (c) Malignant gonadal germ cell tumours

SN after X (c)			X (c) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
7	0.7 %	3.1 %	6	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 66

Selected characteristics Germany 2003-2012

Relative frequency: 25 / 17697 = 0.1 %

Relative frequency of trial patients: 100 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	20	5	25
Standardized rate *:	0.4	0.1	0.2
Cumulative incidence:	5	1	3
Sex ratio (m/f):	0.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	1	12	7	5
Incidence rate:	0.1	0.4	0.2	0.1

Median age at diagnosis: 3 years 11 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
6	0.1 %	0.1	1

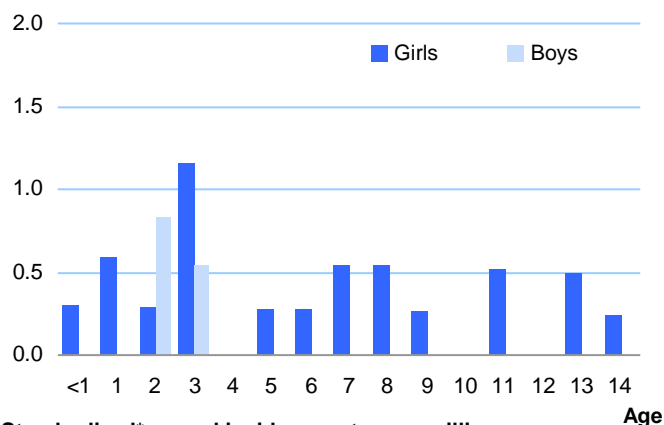
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

XI (a) Adrenocortical carcinomas

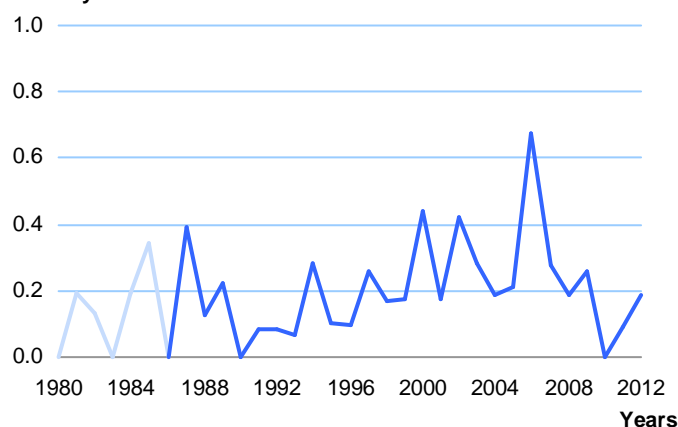
SN after XI (a)			XI (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
4	0.4 %	6.4 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

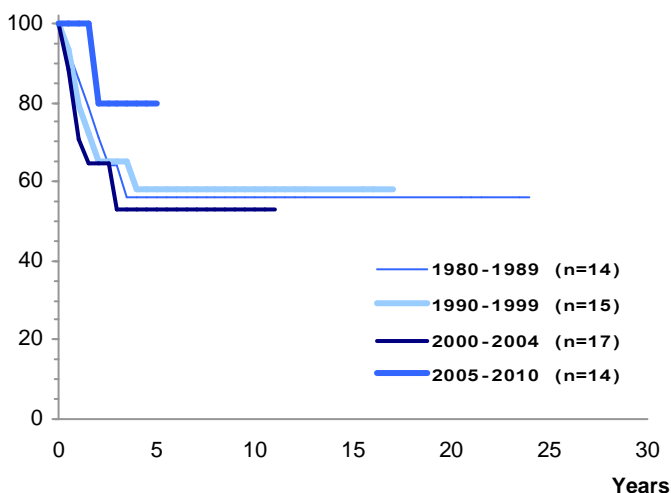
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Survival probabilities by year of diagnosis Germany 1980-2010



No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 296**Selected characteristics Germany 2003-2012**

Relative frequency:	135 / 17697 = 0.8 %
Relative frequency of trial patients:	89.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	85	50	135
Standardized rate *:	1.3	0.7	1.0
Cumulative incidence:	22	12	17
Sex ratio (m/f):	0.6		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	2	4	28	101
Incidence rate:	0.3	0.1	0.7	2.5

Median age at diagnosis: 12 years 8 months

Survival probabilities:	5-year	10-year	15-year
	97 %	96 %	-

Mortality per million within 15 yrs. of diagnosis (1988-1997):

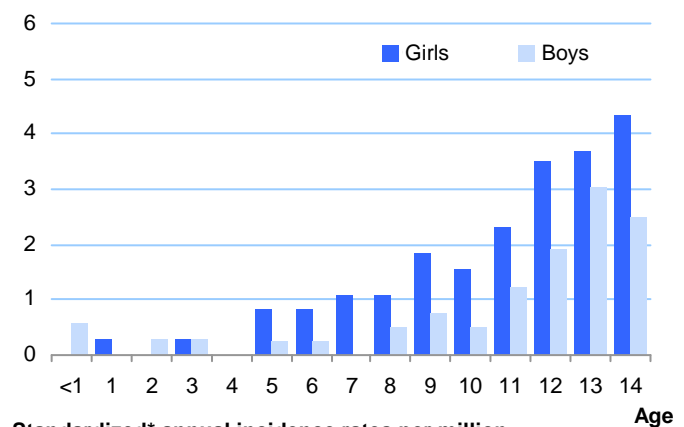
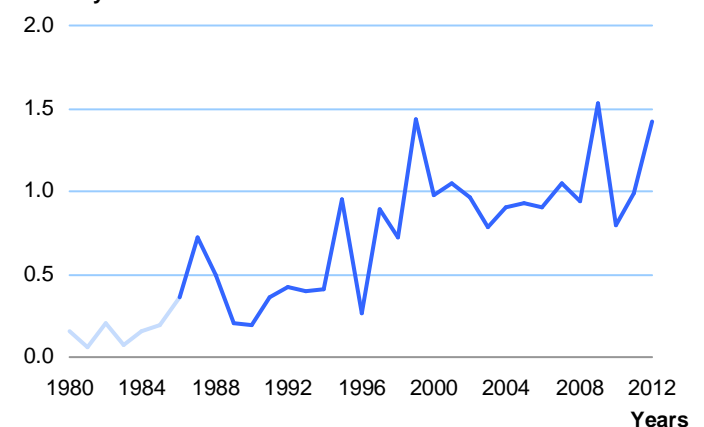
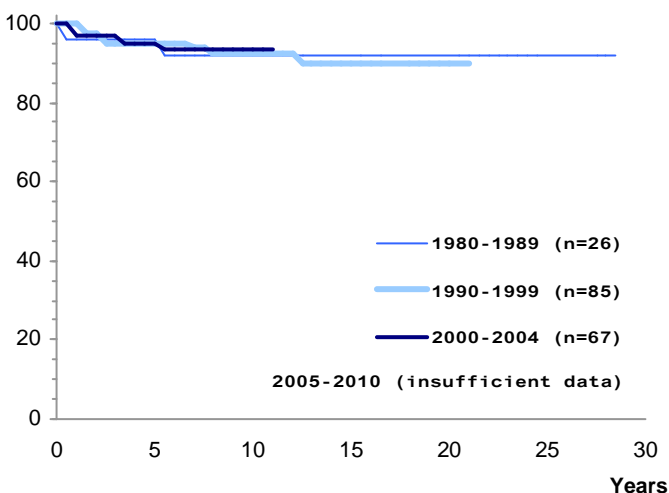
Number of deaths		Standardized*	Cumulative
N	% of all 4129 deaths	mortality rate	mortality
8	0.2 %	0.1	1

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

XI (b) Thyroid carcinomas

SN after XI (b)			XI (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
2	0.2 %	3.7 %	99	10.1 %	0.6 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 70

Selected characteristics Germany 2003-2012

Relative frequency: 25 / 17697 = 0.1 %

Relative frequency of trial patients: 100 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	6	19	25
Standardized rate *:	0.1	0.3	0.2
Cumulative incidence:	2	5	3
Sex ratio (m/f):	3.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	1	0	24
Incidence rate:	0.0	0.0	0.0	0.6

Median age at diagnosis: 13 years 0 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
9	0.2 %	0.1	1

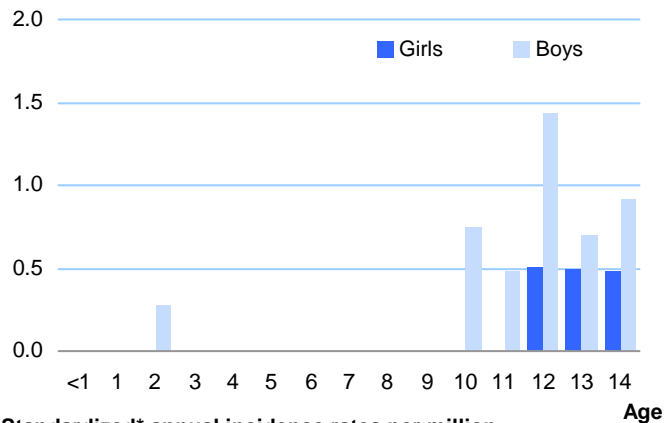
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

XI (c) Nasopharyngeal carcinomas

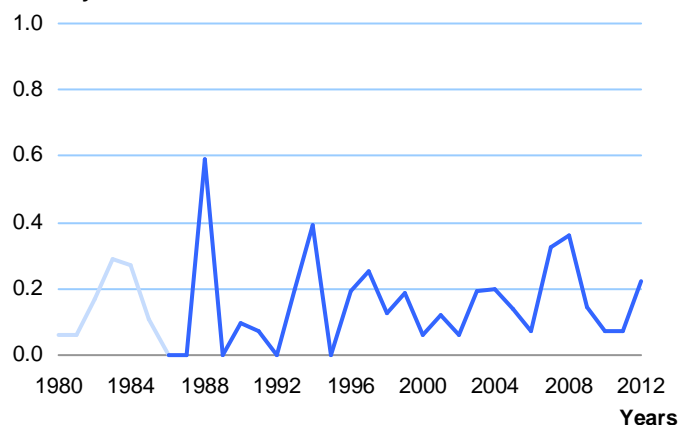
SN after XI (c)			XI (c) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
0	0.0 %	0.0 %	3	0.3 %	0.0 %

* Standard: Segi world standard population

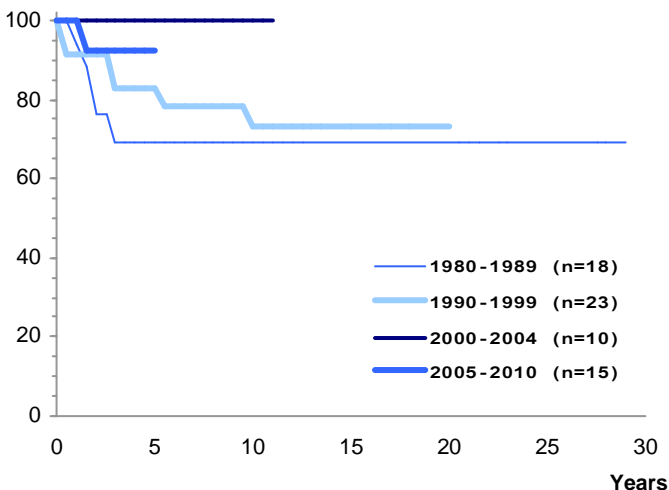
Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



Survival probabilities by year of diagnosis Germany 1980-2010



No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 93**Selected characteristics Germany 2003-2012**

Relative frequency: 57 / 17697 = 0.3 %

Relative frequency of trial patients: 1.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	26	31	57
Standardized rate *:	0.5	0.5	0.5
Cumulative incidence:	7	8	7
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	3	12	15	27
Incidence rate:	0.4	0.4	0.4	0.7

Median age at diagnosis: 9 years 7 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

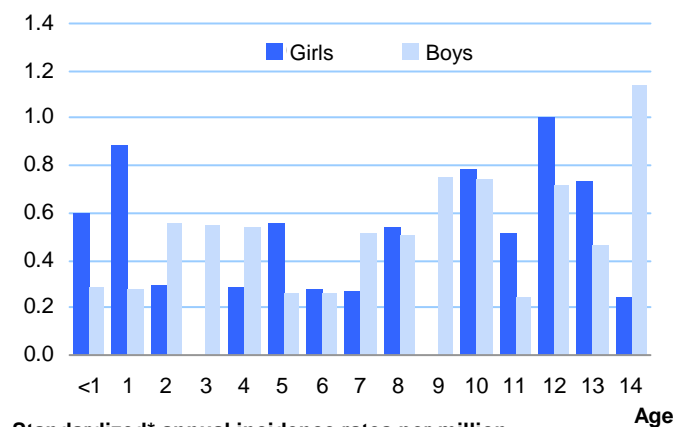
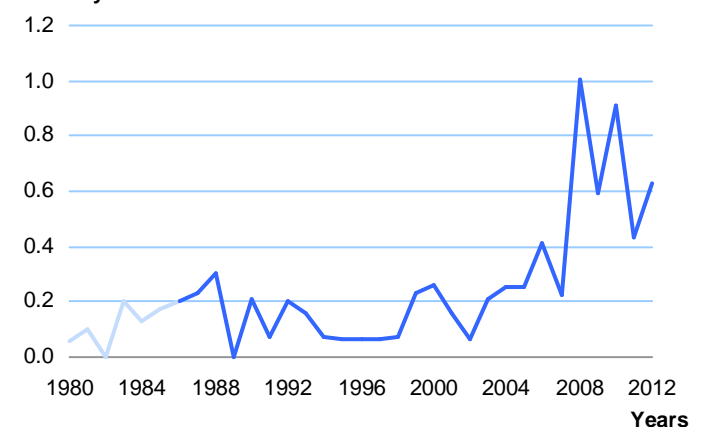
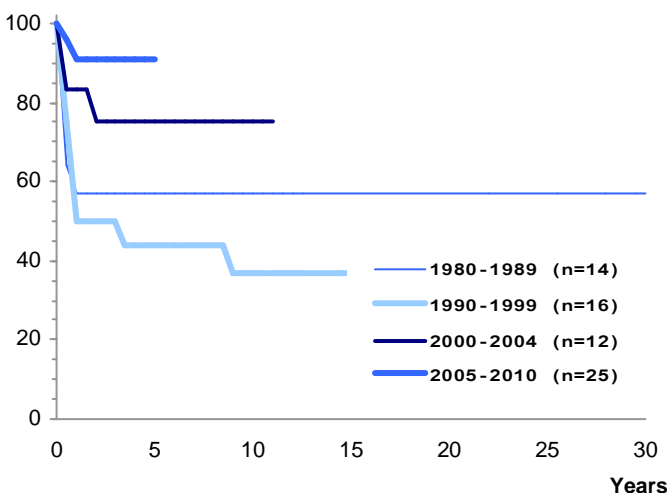
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
9	0.2 %	0.1	1

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

XI (d) Malignant melanomas

SN after XI (d)			XI (d) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
1	0.1 %	17.4 %	21	2.2 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012**Standardized* annual incidence rates per million Germany 1980-2012****Survival probabilities by year of diagnosis Germany 1980-2010**

No map due to sparse data

Cases in Germany aged under 15 years (1980-2012): 42

Selected characteristics Germany 2003-2012

Relative frequency: 20 / 17697 = 0.1 %

Relative frequency of trial patients: 85.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	10	10	20
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 :	0	13	3	4
Incidence rate:	0.0	0.5	0.1	0.1

Median age at diagnosis: 3 years 5 months

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

Mortality per million within 15 yrs. of diagnosis (1988-1997):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4129 deaths		
4	0.1 %	0.0	1

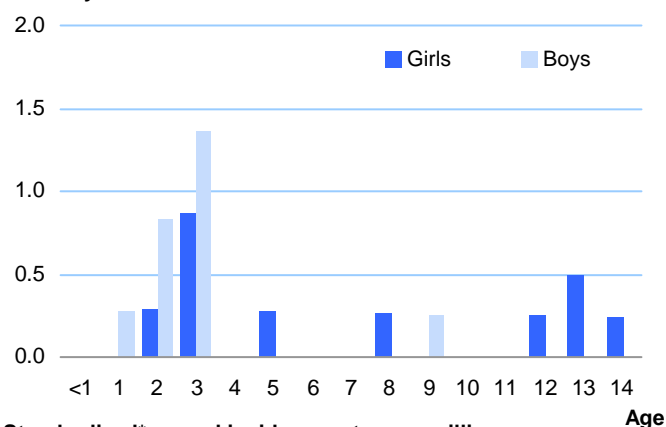
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2012):

XII (a) Other specified malignant tumours

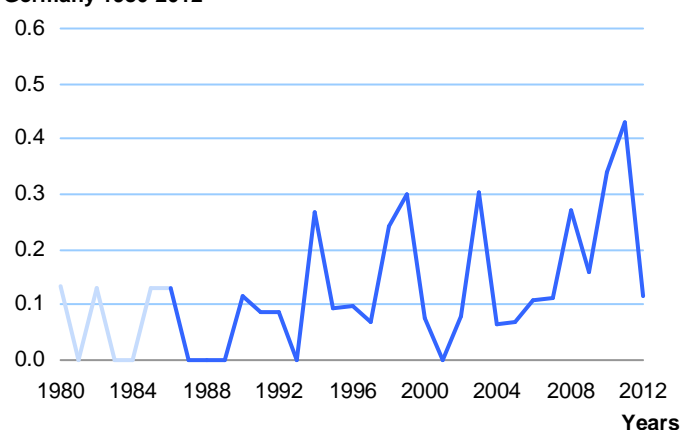
SN after XII (a)			XII (a) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
1	0.1 %	2.5 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2003-2012



Standardized* annual incidence rates per million Germany 1980-2012



No map due to sparse data

No survival curves due to sparse data

Tabelle 1 / Table 1

Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Kinder unter 15 Jahren aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2003-2012) /

Number of cases and incidence rates per million children under the age of 15 years in Germany by diagnoses classified according to ICCC-3, age, and sex (2003-2012)

65

Abbildung 1 / Figure 1

Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2003-2012 /

Reported cases to the GCCR (registry population) per hospital, period 2003-2012

75

Tabelle 2 / Table 2

Anzahl der gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung, altersstandardisierte Inzidenzrate und kumulative Inzidenz (pro Million) nach ICCC-3-Diagnosegruppen /

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

75

Tabelle 3 / Table 3

Anzahl der gemeldeten Patienten unter 15 Jahren auf Basis des ICCC-3, altersstandardisierte Inzidenzrate und Bevölkerungsbezug nach Jahren für Gesamtdeutschland sowie West- und Ostdeutschland /

Annual number of registered cases aged under 15 based on ICCC-3, age-standardized incidence rate and population base by calendar year for all of Germany, as well as West and East Germany

76

Abbildung 2 / Figure 2

Relative Häufigkeit der gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung nach den häufigsten ICCC-3 Diagnose-Hauptgruppen (2003-2012) /

Relative frequencies of the registered patients aged under 15 in Germany by the most common main ICCC-3 diagnosis groups (2003-2012)

77

Tabelle 4 / Table 4

Verteilung aller Registermeldungen aus der deutschen Wohnbevölkerung nach Altersgruppen bei Diagnosestellung ohne Altersbeschränkung sowie zusätzlich erfasste Diagnosen (2003-2012) /

Distribution of all reported cases in Germany by age groups at diagnosis without any restriction of age and additional diagnoses (2003-2012)

77

Tabelle 5 / Table 5

Ausgewählte Kenngrößen für ausgewählte, systematisch registrierte, nicht in der ICC-3 definierte nicht-maligne Diagnosen der Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung (2003-2012) /

Summary data for systematically registered selected non-malignant diagnoses not defined in ICC-3 of patients under 15 in Germany (2003-2012)

78

Tabelle 6 / Table 6

Altersstandardisierte Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert für alle Malignome der Patienten unter 15 Jahren und ausgewählte Diagnosen auf Basis des ICC-3 (2003-2012) /

Age-standardized incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for all malignancies of patients under 15 and selected diagnoses by region based on ICC-3 (2003-2012)

79

Tabelle 7 / Table 7

Anzahl der verstorbenen Patienten innerhalb von 5, 10 bzw. 15 Jahren nach Diagnose auf Basis des ICC-3 unter den gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung und alterstandardisierte Mortalitätsraten nach Diagnosejahr, 1980-2007 /

Annual number of deaths 5, 10 or 15 years from diagnosis based on ICC-3 from the group of registered cases aged under 15 in Germany and age standardized mortality rates by year of diagnosis 1980-2007

80

Tabelle 8 / Table 8

Anzahl der am Deutschen Kinderkrebsregister in der Langzeitnachsorge befindlichen Patienten mit Erstdiagnose im Alter von unter 15 (2012) /

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged < 15 (2012)

81

Tabelle 9 / Table 9

Zahl der vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister (LKR) bis einschließlich 2012 weitergeleiteten Meldungen /

Number of forwarded reports from the German Childhood Cancer Registry to the state cancer registries (LKR) up to and including 2012

82

Tabelle 1:

Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Kinder unter 15 Jahren aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2003-2012). *ICCC-3 extended Subklassifikation kursiv dargestellt.*

Number of cases and incidence rates per million children under the age of 15 years in Germany by diagnoses classified according to ICCC-3, age, and sex (2003-2012). *ICCC-3 extended subclassification in italics.*

Diagnoses	Sex	Sex ratio	N	Relative	Number of cases				Incidence rates per million						Trial participants	Survival probabilities(%)			
		Group			Age groups			Age-specific			Age-stand.	Cum.							
	m / f	%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%	5-yrs	10-yrs	15-yrs		
All malignancies	girls		7877	100	100	846	2688	2024	2319	254	195	110	116	150	2165	93.3	84	82	81
	boys		9820	100	100	998	3278	2728	2816	285	226	141	134	177	2561	93.8	84	81	80
	total	1.2	17697	100	100	1844	5966	4752	5135	270	211	126	125	163	2368	93.6	84	82	81
Leukaemias, myeloproliferative and myelodysplastic diseases	girls		2683	34	100	131	1240	744	568	39	90	40	29	52	743	99.1	88	86	85
	boys		3306	34	100	165	1445	941	755	47	99	49	36	61	867	99.2	87	85	84
	total	1.2	5989	34	100	296	2685	1685	1323	43	95	45	32	56	807	99.1	88	86	85
Lymphoid leukaemias	girls		2065	26	77	59	1038	601	367	18	75	33	18	41	574	99.7	92	90	89
	boys		2588	26	78	56	1235	769	528	16	85	40	25	48	680	99.8	91	89	88
	total	1.3	4653	26	78	115	2273	1370	895	17	80	36	22	44	628	99.8	91	89	88
Precursor cell leukaemias	girls		2038	26	76	58	1031	586	363	17	75	32	18	40	566	99.7	92	90	89
	boys		2501	26	76	54	1213	735	499	15	83	38	24	46	658	99.8	91	89	88
	total	1.2	4539	26	76	112	2244	1321	862	16	79	35	21	43	613	99.8	91	89	89
Mature B-cell leukaemias	girls		26	0	1	1	7	15	3	0	1	1	0	0	7	100.0	83	-	-
	boys		87	1	3	2	22	34	29	1	2	2	1	1	22	100.0	85	85	83
	total	3.3	113	1	2	3	29	49	32	0	1	1	1	1	15	100.0	84	84	83
Mature T-cell and NK cell leukaemias	girls		1	0	0	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	0	0	1	0	0	0	0	0	0.0	-	-	-
Lymphoid leukaemia, NOS	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	-	-	-	-
Acute myeloid leukaemias	girls		385	5	14	54	148	66	117	16	11	4	6	7	106	97.4	72	71	70
	boys		397	4	12	66	130	86	115	19	9	4	5	7	104	97.0	71	69	68
	total	1.0	782	4	13	120	278	152	232	18	10	4	6	7	105	97.2	72	70	69
Chronic myeloproliferative diseases	girls		34	0	1	0	4	13	17	0	0	1	1	1	9	88.2	-	-	-
	boys		39	0	1	1	5	12	21	0	0	1	1	1	10	82.1	-	-	-
	total	1.1	73	0	1	1	9	25	38	0	0	1	1	1	9	84.9	-	-	-
Myelodysplastic syndrome and other myeloproliferative diseases	girls		166	2	6	11	43	53	59	3	3	3	3	3	45	97.6	80	79	77
	boys		244	3	7	32	66	66	80	9	5	3	4	4	63	98.4	79	77	77
	total	1.5	410	2	7	43	109	119	139	6	4	3	3	4	54	98.0	79	78	77

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	Sex ratio	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
						0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14						
		m / f		%	%	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		33	0	1	7	7	11	8	2	1	1	0	1	9	100.0	67	-	-
	boys		38	0	1	10	9	8	11	3	1	0	1	1	10	100.0	65	-	-
	total	1.2	71	0	1	17	16	19	19	2	1	1	0	1	10	100.0	66	-	-
Lymphomas and reticuloendothelial neoplasms	girls		624	8	100	3	47	167	407	1	3	9	20	10	162	96.5	93	92	91
	boys		1340	14	100	5	173	503	659	1	12	26	31	21	336	96.1	94	93	93
	total	2.1	1964	11	100	8	220	670	1066	1	8	18	26	16	251	96.2	94	93	92
Hodgkin lymphomas	girls		323	4	52	0	4	47	272	0	0	3	14	5	82	98.5	98	96	96
	boys		501	5	37	0	32	146	323	0	2	8	15	8	123	96.6	99	98	98
	total	1.6	824	5	42	0	36	193	595	0	1	5	15	6	103	97.3	98	98	97
Non-Hodgkin lymphomas	girls		237	3	38	1	36	90	110	0	3	5	6	4	63	94.1	86	85	83
	boys		544	6	41	3	86	212	243	1	6	11	12	9	137	95.0	90	89	88
	total	2.3	781	4	40	4	122	302	353	1	4	8	9	6	101	94.8	89	88	86
Precursor cell lymphomas	girls		91	1	15	1	15	44	31	0	1	2	2	2	24	91.2	84	84	81
	boys		213	2	16	2	47	87	77	1	3	4	4	4	54	95.3	89	88	86
	total	2.3	304	2	16	3	62	131	108	0	2	3	3	3	40	94.1	87	86	85
Mature B-cell lymphomas (except Burkitt lymphoma)	girls		44	1	7	0	6	20	18	0	0	1	1	1	12	95.5	-	-	-
	boys		101	1	8	0	7	32	62	0	0	2	3	2	25	97.0	-	-	-
	total	2.3	145	1	7	0	13	52	80	0	0	1	2	1	18	96.6	-	-	-
Mature T-cell and NK-cell lymphomas	girls		59	1	10	0	9	13	37	0	1	1	2	1	15	94.9	-	-	-
	boys		110	1	8	1	19	42	48	0	1	2	2	2	28	94.5	-	-	-
	total	1.9	169	1	9	1	28	55	85	0	1	1	2	1	22	94.7	-	-	-
Non-Hodgkin lymphomas, NOS	girls		43	1	7	0	6	13	24	0	0	1	1	1	11	97.7	89	-	-
	boys		120	1	9	0	13	51	56	0	1	3	3	2	30	93.3	91	-	-
	total	2.8	163	1	8	0	19	64	80	0	1	2	2	1	21	94.5	91	-	-
Burkitt lymphoma	girls		58	1	9	0	6	29	23	0	0	2	1	1	15	100.0	92	92	92
	boys		289	3	22	0	55	143	91	0	4	7	4	5	74	97.9	94	93	93
	total	5.0	347	2	18	0	61	172	114	0	2	5	3	3	45	98.3	93	93	93
Miscellaneous lymphoreticular neoplasms	girls		4	0	1	2	0	1	1	1	0	0	0	0	1	50.0	-	-	-
	boys		5	0	0	2	0	1	2	1	0	0	0	0	1	60.0	-	-	-
	total	1.3	9	0	1	4	0	2	3	1	0	0	0	0	1	55.6	-	-	-
Unspecified lymphomas	girls		2	0	0	0	1	0	1	0	0	0	0	0	1	50.0	-	-	-
	boys		1	0	0	0	0	1	0	0	0	0	0	0	0	100.0	-	-	-
	total	0.5	3	0	0	0	1	1	1	0	0	0	0	0	0	66.7	-	-	-
CNS and miscellaneous intracranial and intraspinal neoplasms	girls		1887	24	100	147	548	606	586	44	40	33	29	35	515	91.7	79	75	73
	boys		2367	24	100	170	674	820	703	49	46	42	33	41	613	92.4	76	71	68
	total	1.3	4254	24	100	317	1222	1426	1289	46	43	38	32	38	565	92.1	77	73	70

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	Sex ratio	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
						%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4						
		m / f														%			
Ependymomas and choroid plexus tumour	girls		185	2	10	37	85	36	27	11	6	2	1	4	52	96.8	82	79	75
	boys		248	3	11	42	100	50	56	12	7	3	3	5	66	92.7	79	68	65
	total	1.3	433	2	10	79	185	86	83	12	7	2	2	4	59	94.5	81	73	69
Ependymomas	girls		135	2	7	13	70	29	23	4	5	2	1	3	38	97.8	80	77	73
	boys		200	2	8	19	87	44	50	5	6	2	2	4	53	94.5	78	67	63
	total	1.5	335	2	8	32	157	73	73	5	6	2	2	3	45	95.8	78	71	67
Choroid plexus tumour	girls		50	1	3	24	15	7	4	7	1	0	0	1	14	94.0	93	84	-
	boys		48	1	2	23	13	6	6	7	1	0	0	1	13	85.4	87	75	-
	total	1.0	98	1	2	47	28	13	10	7	1	0	0	1	14	89.8	90	79	-
Astrocytomas	girls		931	12	49	49	255	302	325	15	18	16	16	17	252	92.9	83	80	79
	boys		1029	11	44	49	279	383	318	14	19	20	15	18	265	93.4	79	77	75
	total	1.1	1960	11	46	98	534	685	643	14	19	18	16	17	259	93.2	81	79	77
Intracranial and intraspinal embryonal tumours	girls		298	4	16	39	109	98	52	12	8	5	3	6	83	92.6	68	62	57
	boys		516	5	22	53	179	198	86	15	12	10	4	9	136	94.0	67	58	56
	total	1.7	814	5	19	92	288	296	138	13	10	8	3	8	110	93.5	67	60	56
Medulloblastomas	girls		199	3	11	13	61	82	43	4	4	4	2	4	55	98.0	78	71	64
	boys		375	4	16	10	118	171	76	3	8	9	4	7	98	98.4	76	66	64
	total	1.9	574	3	14	23	179	253	119	3	6	7	3	5	77	98.3	77	68	64
Primitive neuroectodermal tumour (PNET)	girls		36	1	2	2	21	5	8	1	2	0	0	1	10	94.4	-	-	-
	boys		56	1	2	6	28	14	8	2	2	1	0	1	15	94.6	-	-	-
	total	1.6	92	1	2	8	49	19	16	1	2	1	0	1	13	94.6	-	-	-
Medulloepithelioma	girls		3	0	0	0	1	2	0	0	0	0	0	0	1	66.7	-	-	-
	boys		3	0	0	2	0	1	0	1	0	0	0	0	1	100.0	-	-	-
	total	1.0	6	0	0	2	1	3	0	0	0	0	0	0	1	83.3	-	-	-
Atypical teratoid/rhabdoid tumour	girls		60	1	3	24	26	9	1	7	2	0	0	1	17	75.0	-	-	-
	boys		82	1	4	35	33	12	2	10	2	1	0	2	23	73.2	39	20	-
	total	1.4	142	1	3	59	59	21	3	9	2	1	0	2	20	73.9	34	25	-
Other gliomas	girls		187	2	10	10	44	79	54	3	3	4	3	3	51	85.0	44	-	-
	boys		203	2	9	8	46	74	75	2	3	4	4	3	52	90.6	44	44	-
	total	1.1	390	2	9	18	90	153	129	3	3	4	3	3	51	87.9	44	44	-
Oligodendrogliomas	girls		7	0	0	0	0	3	4	0	0	0	0	0	2	57.1	-	-	-
	boys		9	0	0	0	1	2	6	0	0	0	0	0	2	77.8	-	-	-
	total	1.3	16	0	0	0	1	5	10	0	0	0	0	0	2	68.8	-	-	-
Mixed and unspecified gliomas	girls		171	2	9	9	42	74	46	3	3	4	2	3	47	85.4	40	-	-
	boys		189	2	8	8	45	72	64	2	3	4	3	3	48	91.5	41	41	-
	total	1.1	360	2	9	17	87	146	110	2	3	4	3	3	48	88.6	40	40	-

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	Sex ratio m / f	N	Number of cases						Incidence rates per million						Trial participants %	Survival probabilities(%)		
				Relative %	Group %	Age groups				Age-specific				Age-stand. World #	Cum. 0 - 14		5-yrs	10-yrs	15-yrs
						0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14						
Neuroepithelial glial tumours of uncertain origin	girls		9	0	1	1	2	2	4	0	0	0	0	0	2	100.0	-	-	-
	boys		5	0	0	0	0	0	5	0	0	0	0	0	1	80.0	-	-	-
	total	0.6	14	0	0	1	2	2	9	0	0	0	0	0	2	92.9	66	66	66
Other specified intracranial and intraspinal neoplasms	girls		255	3	14	9	46	86	114	3	3	5	6	4	68	90.2	97	95	92
	boys		329	3	14	12	65	100	152	3	4	5	7	5	83	90.3	93	92	89
	total	1.3	584	3	14	21	111	186	266	3	4	5	7	5	76	90.2	95	94	91
Pituitary adenomas and carcinomas	girls		15	0	1	0	2	2	11	0	0	0	1	0	4	53.3	-	-	-
	boys		16	0	1	0	0	2	14	0	0	0	1	0	4	56.3	100	-	-
	total	1.1	31	0	1	0	2	4	25	0	0	0	1	0	4	54.8	100	-	-
Tumours of the sellar region (craniopharyngiomas)	girls		88	1	5	0	17	34	37	0	1	2	2	2	23	100.0	100	99	96
	boys		95	1	4	1	22	35	37	0	2	2	2	2	24	97.9	98	96	91
	total	1.1	183	1	4	1	39	69	74	0	1	2	2	2	24	98.9	99	97	93
Pineal parenchymal tumours	girls		12	0	1	1	1	5	5	0	0	0	0	0	3	100.0	-	-	-
	boys		14	0	1	0	7	2	5	0	0	0	0	0	4	85.7	-	-	-
	total	1.2	26	0	1	1	8	7	10	0	0	0	0	0	3	92.3	-	-	-
Neuronal and mixed neuronal-glial tumours	girls		115	2	6	8	22	34	51	2	2	2	3	2	31	89.6	97	94	91
	boys		178	2	8	11	33	51	83	3	2	3	4	3	45	93.3	93	93	93
	total	1.5	293	2	7	19	55	85	134	3	2	2	3	2	38	91.8	95	94	92
Meningiomas	girls		25	0	1	0	4	11	10	0	0	1	1	0	7	76.0	-	-	-
	boys		26	0	1	0	3	10	13	0	0	1	1	0	6	65.4	-	-	-
	total	1.0	51	0	1	0	7	21	23	0	0	1	1	0	7	70.6	-	-	-
Unspecified intracranial and intraspinal neoplasms	girls		31	0	2	3	9	5	14	1	1	0	1	1	8	67.7	77	-	-
	boys		42	0	2	6	5	15	16	2	0	1	1	1	11	73.8	75	-	-
	total	1.4	73	0	2	9	14	20	30	1	0	1	1	1	10	71.2	76	-	-
Neuroblastoma and other peripheral nervous cell tumours	girls		561	7	100	259	233	51	18	78	17	3	1	13	164	98.2	79	76	75
	boys		671	7	100	316	293	47	15	90	20	2	1	14	186	98.8	79	76	75
	total	1.2	1232	7	100	575	526	98	33	84	19	3	1	14	175	98.5	79	76	75
Neuroblastoma and ganglioneuroblastoma	girls		556	7	99	259	229	51	17	78	17	3	1	12	162	98.7	79	77	75
	boys		666	7	99	316	292	46	12	90	20	2	1	14	185	98.9	79	76	75
	total	1.2	1222	7	99	575	521	97	29	84	18	3	1	13	174	98.9	79	76	75
Other peripheral nervous cell tumours	girls		5	0	1	0	4	0	1	0	0	0	0	0	1	40.0	-	-	-
	boys		5	0	1	0	1	1	3	0	0	0	0	0	1	80.0	-	-	-
	total	1.0	10	0	1	0	5	1	4	0	0	0	0	0	1	60.0	-	-	-
Retinoblastoma	girls		170	2	100	82	82	6	0	25	6	0	0	4	50	0.0	98	98	98
	boys		200	2	100	88	103	7	2	25	7	0	0	4	56	0.0	98	97	97
	total	1.2	370	2	100	170	185	13	2	25	7	0	0	4	53	0.0	98	97	97

Table 1 Forts.

Table 1 cont.

Diagnoses	Sex	Sex ratio	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
						%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4						
		m / f		%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%	5-yrs	10-yrs	15-yrs
Renal tumours	girls		504	6	100	67	290	116	31	20	21	6	2	11	143	99.0	94	93	93
	boys		461	5	100	83	260	94	24	24	18	5	1	9	125	98.0	92	91	91
	total	0.9	965	6	100	150	550	210	55	22	19	6	1	10	134	98.5	93	92	92
Nephroblastoma and other non-epithelial renal tumours	girls		490	6	97	67	289	113	21	20	21	6	1	10	140	99.6	94	93	93
	boys		448	5	97	83	260	92	13	24	18	5	1	9	122	98.7	91	91	91
	total	0.9	938	5	97	150	549	205	34	22	19	5	1	10	131	99.1	93	92	92
Nephroblastoma	girls		480	6	95	61	287	111	21	18	21	6	1	10	137	99.8	95	94	94
	boys		439	5	95	80	258	89	12	23	18	5	1	9	120	99.1	93	92	92
	total	0.9	919	5	95	141	545	200	33	21	19	5	1	10	128	99.5	94	93	93
Rhabdoid renal tumour	girls		8	0	2	6	2	0	0	2	0	0	0	0	2	87.5	-	-	-
	boys		6	0	1	3	2	1	0	1	0	0	0	0	2	66.7	-	-	-
	total	0.8	14	0	2	9	4	1	0	1	0	0	0	0	2	78.6	-	-	-
Kidney sarcomas	girls		2	0	0	0	0	2	0	0	0	0	0	0	1	100.0	-	-	-
	boys		3	0	1	0	0	2	1	0	0	0	0	0	1	100.0	-	-	-
	total	1.5	5	0	1	0	0	4	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		13	0	3	0	1	3	9	0	0	0	0	0	3	76.9	-	-	-
	boys		13	0	3	0	0	2	11	0	0	0	1	0	3	76.9	-	-	-
	total	1.0	26	0	3	0	1	5	20	0	0	0	0	0	3	76.9	-	-	-
Unspecified malignant renal 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	100.0	-	-	-
Hepatic tumours	girls		98	1	100	33	49	5	11	10	4	0	1	2	28	74.5	68	66	-
	boys		134	1	100	37	65	10	22	11	4	1	1	3	36	82.1	73	70	69
	total	1.4	232	1	100	70	114	15	33	10	4	0	1	2	32	78.9	71	68	67
Hepatoblastoma	girls		85	1	87	33	47	4	1	10	3	0	0	2	25	75.3	74	74	-
	boys		111	1	83	37	64	3	7	11	4	0	0	2	31	82.0	80	78	78
	total	1.3	196	1	85	70	111	7	8	10	4	0	0	2	28	79.1	78	76	76
Hepatic carcinomas	girls		12	0	12	0	2	1	9	0	0	0	0	0	3	66.7	-	-	-
	boys		23	0	17	0	1	7	15	0	0	0	1	0	6	82.6	-	-	-
	total	1.9	35	0	15	0	3	8	24	0	0	0	1	0	4	77.1	-	-	-
Unspecified malignant hepatic tumours	girls		1	0	1	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	100.0	-	-	-

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	Sex ratio	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
						%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4						
		m / f		%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%	5-yrs	10-yrs	15-yrs
Malignant bone tumours	girls		369	5	100	2	15	100	252	1	1	5	13	6	95	96.7	74	70	69
	boys		409	4	100	3	27	114	265	1	2	6	13	6	101	97.6	73	69	68
	total	1.1	778	4	100	5	42	214	517	1	1	6	13	6	98	97.2	74	69	68
Osteosarcomas	girls		202	3	55	0	2	51	149	0	0	3	7	3	52	99.0	78	75	74
	boys		193	2	47	0	6	44	143	0	0	2	7	3	47	97.9	74	70	69
	total	1.0	395	2	51	0	8	95	292	0	0	3	7	3	49	98.5	76	72	71
Chondrosarcomas	girls		7	0	2	0	0	2	5	0	0	0	0	0	2	57.1	-	-	-
	boys		6	0	2	0	0	1	5	0	0	0	0	0	1	66.7	-	-	-
	total	0.9	13	0	2	0	0	3	10	0	0	0	0	0	2	61.5	-	-	-
Ewing tumour and related sarcomas of bone	girls		151	2	41	2	13	44	92	1	1	2	5	2	39	97.4	68	63	62
	boys		198	2	48	3	20	65	110	1	1	3	5	3	49	100.0	72	68	67
	total	1.3	349	2	45	5	33	109	202	1	1	3	5	3	44	98.9	70	66	65
Other specified malignant bone tumours	girls		6	0	2	0	0	2	4	0	0	0	0	0	2	83.3	-	-	-
	boys		8	0	2	0	1	4	3	0	0	0	0	0	2	75.0	-	-	-
	total	1.3	14	0	2	0	1	6	7	0	0	0	0	0	2	78.6	-	-	-
Malignant fibrous neoplasms of bone	girls		2	0	1	0	0	0	2	0	0	0	0	0	1	100.0	-	-	-
	boys		1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-	-
	total	0.5	3	0	0	0	0	0	3	0	0	0	0	0	0	100.0	-	-	-
Malignant chordomas	girls		2	0	1	0	0	2	0	0	0	0	0	0	1	100.0	-	-	-
	boys		6	0	2	0	0	4	2	0	0	0	0	0	2	66.7	-	-	-
	total	3.0	8	0	1	0	0	6	2	0	0	0	0	0	1	75.0	-	-	-
Odontogenic malignant tumours	girls		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	100.0	-	-	-
	total	-	1	0	0	0	1	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	1	50.0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	total	0.0	2	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	1	33.3	-	-	-
	boys		4	0	1	0	0	0	4	0	0	0	0	0	1	50.0	-	-	-
	total	1.3	7	0	1	0	0	1	6	0	0	0	0	0	1	42.9	-	-	-
Soft tissue and other extraosseous sarcomas	girls		473	6	100	47	132	123	171	14	10	7	9	9	129	96.6	70	68	66
	boys		556	6	100	68	169	142	177	19	12	7	8	10	145	96.0	73	70	69
	total	1.2	1029	6	100	115	301	265	348	17	11	7	9	9	137	96.3	72	69	68
Rhabdomyosarcomas	girls		247	3	52	21	93	71	62	6	7	4	3	5	68	99.2	68	66	63
	boys		307	3	55	29	126	95	57	8	9	5	3	6	81	98.4	75	75	74
	total	1.2	554	3	54	50	219	166	119	7	8	4	3	5	75	98.7	72	71	69

Tabelle 1 Forts. Table 1 cont.

Diagnoses	Sex	Sex ratio	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
						%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4						
		m / f		%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%	5-yrs	10-yrs	15-yrs
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	girls		46	1	10	7	10	7	22	2	1	0	1	1	12	89.1	-	-	-
	boys		54	1	10	16	8	8	22	5	1	0	1	1	14	92.6	-	-	-
	total	1.2	100	1	10	23	18	15	44	3	1	0	1	1	13	91.0	-	-	-
Fibroblastic and myofibroblastic tumours	girls		24	0	5	7	6	4	7	2	0	0	0	0	7	91.7	-	-	-
	boys		30	0	5	12	6	3	9	3	0	0	0	1	8	93.3	-	-	-
	total	1.3	54	0	5	19	12	7	16	3	0	0	0	1	7	92.6	-	-	-
Nerve sheath tumours	girls		22	0	5	0	4	3	15	0	0	0	1	0	6	86.4	-	-	-
	boys		24	0	4	4	2	5	13	1	0	0	1	0	6	91.7	-	-	-
	total	1.1	46	0	5	4	6	8	28	1	0	0	1	0	6	89.1	-	-	-
Other fibrous neoplasms	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
Kaposi sarcoma	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	0.0	-	-	-
	total	-	1	0	0	0	0	0	1	0	0	0	0	0	0	0.0	-	-	-
Other specified soft tissue sarcomas	girls		139	2	29	14	17	35	73	4	1	2	4	2	37	95.7	81	78	75
	boys		158	2	28	16	29	34	79	5	2	2	4	3	40	93.7	67	64	-
	total	1.1	297	2	29	30	46	69	152	4	2	2	4	3	39	94.6	74	70	67
Unspecified soft tissue sarcomas	girls		41	1	9	5	12	10	14	2	1	1	1	1	11	92.7	-	-	-
	boys		36	0	7	7	6	5	18	2	0	0	1	1	9	94.4	71	-	-
	total	0.9	77	0	8	12	18	15	32	2	1	0	1	1	10	93.5	66	-	-
Germ cell tumours, trophoblastic tumours and neoplasms of gonads	girls		314	4	100	72	33	65	144	22	2	4	7	6	85	95.5	96	95	94
	boys		216	2	100	60	42	22	92	17	3	1	4	4	56	94.4	94	93	93
	total	0.7	530	3	100	132	75	87	236	19	3	2	6	5	70	95.1	95	94	94
Intracranial and intraspinal germ cell tumours	girls		58	1	19	5	0	22	31	2	0	1	2	1	15	96.6	93	-	-
	boys		88	1	41	1	7	19	61	0	0	1	3	1	22	93.2	90	88	-
	total	1.5	146	1	28	6	7	41	92	1	0	1	2	1	19	94.5	91	89	-
Malignant extracranial and extragonadal germ cell tumours	girls		100	1	32	67	27	1	5	20	2	0	0	2	29	93.0	95	94	94
	boys		50	1	23	28	13	2	7	8	1	0	0	1	14	94.0	95	95	95
	total	0.5	150	1	28	95	40	3	12	14	1	0	0	2	21	93.3	95	94	94
Malignant gonadal germ cell tumours	girls		149	2	48	0	6	41	102	0	0	2	5	2	38	98.0	98	97	97
	boys		78	1	36	31	22	1	24	9	2	0	1	2	21	96.2	98	98	98
	total	0.5	227	1	43	31	28	42	126	5	1	1	3	2	29	97.4	98	97	97
Gonadal carcinomas	girls		6	0	2	0	0	1	5	0	0	0	0	0	2	66.7	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	total	0.0	6	0	1	0	0	1	5	0	0	0	0	0	1	66.7	-	-	-

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	Sex ratio	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
						%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4						
		m / f		%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%	5-yrs	10-yrs	15-yrs
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	100.0	-	-	-
Other malignant epithelial neoplasms and malignant melanomas	girls		182	2	100	3	14	39	126	1	1	2	6	3	47	62.1	91	89	-
	boys		147	2	100	3	18	27	99	1	1	1	5	2	36	57.1	82	77	-
	total	0.8	329	2	100	6	32	66	225	1	1	2	5	3	42	59.9	87	84	-
Adrenocortical carcinomas	girls		20	0	11	1	7	7	5	0	1	0	0	0	5	100.0	-	-	-
	boys		5	0	3	0	5	0	0	0	0	0	0	0	1	100.0	-	-	-
	total	0.3	25	0	8	1	12	7	5	0	0	0	0	0	3	100.0	-	-	-
Thyroid carcinomas	girls		85	1	47	0	2	21	62	0	0	1	3	1	22	88.2	99	97	-
	boys		50	1	34	2	2	7	39	1	0	0	2	1	12	92.0	-	-	-
	total	0.6	135	1	41	2	4	28	101	0	0	1	2	1	17	89.6	97	96	-
Nasopharyngeal carcinomas	girls		6	0	3	0	0	0	6	0	0	0	0	0	2	100.0	-	-	-
	boys		19	0	13	0	1	0	18	0	0	0	1	0	5	100.0	95	-	-
	total	3.2	25	0	8	0	1	0	24	0	0	0	1	0	3	100.0	96	-	-
Malignant melanomas	girls		26	0	14	2	5	6	13	1	0	0	1	0	7	0.0	-	-	-
	boys		31	0	21	1	7	9	14	0	0	0	1	1	8	3.2	-	-	-
	total	1.2	57	0	17	3	12	15	27	0	0	0	1	0	7	1.8	-	-	-
Skin carcinomas	girls		5	0	3	0	0	2	3	0	0	0	0	0	1	0.0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	total	0.0	5	0	2	0	0	2	3	0	0	0	0	0	1	0.0	-	-	-
Other and unspecified carcinomas	girls		40	1	22	0	0	3	37	0	0	0	2	1	10	30.0	79	-	-
	boys		42	0	29	0	3	11	28	0	0	1	1	1	10	31.0	66	-	-
	total	1.1	82	1	25	0	3	14	65	0	0	0	2	1	10	30.5	73	-	-
Carcinomas of salivary glands	girls		12	0	7	0	0	1	11	0	0	0	1	0	3	0.0	-	-	-
	boys		8	0	5	0	0	4	4	0	0	0	0	0	2	12.5	-	-	-
	total	0.7	20	0	6	0	0	5	15	0	0	0	0	0	2	5.0	-	-	-
Carcinomas of colon and rectum	girls		5	0	3	0	0	0	5	0	0	0	0	0	1	0.0	-	-	-
	boys		8	0	5	0	0	1	7	0	0	0	0	0	2	12.5	-	-	-
	total	1.6	13	0	4	0	0	1	12	0	0	0	0	0	2	7.7	-	-	-
Carcinomas of appendix	girls		3	0	2	0	0	0	3	0	0	0	0	0	1	100.0	-	-	-
	boys		4	0	3	0	0	1	3	0	0	0	0	0	1	100.0	-	-	-
	total	1.3	7	0	2	0	0	1	6	0	0	0	0	0	1	100.0	-	-	-
Carcinomas of lung	girls		2	0	1	0	0	0	2	0	0	0	0	0	1	100.0	-	-	-
	boys		6	0	4	0	0	3	3	0	0	0	0	0	1	50.0	-	-	-
	total	3.0	8	0	2	0	0	3	5	0	0	0	0	0	1	62.5	-	-	-

Tabelle 1 Forts.

Table 1 cont.

Diagnoses	Sex	Sex ratio	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
						%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4						
		m / f		%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%	5-yrs	10-yrs	15-yrs
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	0	1	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	0.0	-	-	-
Carcinomas of other specified sites	girls		15	0	8	0	0	2	13	0	0	0	1	0	4	46.7	-	-	-
	boys		11	0	8	0	1	2	8	0	0	0	0	0	3	18.2	-	-	-
	total	0.7	26	0	8	0	1	4	21	0	0	0	1	0	3	34.6	-	-	-
Carcinomas of unspecified site	girls		2	0	1	0	0	0	2	0	0	0	0	0	1	0.0	-	-	-
	boys		3	0	2	0	2	0	1	0	0	0	0	0	1	66.7	-	-	-
	total	1.5	5	0	2	0	2	0	3	0	0	0	0	0	1	40.0	-	-	-
Others and unspecified malignant neoplasms	girls		12	0	100	0	5	2	5	0	0	0	0	0	3	58.3	-	-	-
	boys		13	0	100	0	9	1	3	0	1	0	0	0	3	92.3	-	-	-
	total	1.1	25	0	100	0	14	3	8	0	0	0	0	0	3	76.0	-	-	-
Other specified malignant tumours	girls		10	0	83	0	4	2	4	0	0	0	0	0	3	70.0	-	-	-
	boys		10	0	77	0	9	1	0	0	1	0	0	0	3	100.0	-	-	-
	total	1.0	20	0	80	0	13	3	4	0	0	0	0	0	3	85.0	-	-	-
Gastrointestinal stromal tumour	girls		2	0	17	0	0	0	2	0	0	0	0	0	1	100.0	-	-	-
	boys		1	0	8	0	0	1	0	0	0	0	0	0	0	100.0	-	-	-
	total	0.5	3	0	12	0	0	1	2	0	0	0	0	0	0	100.0	-	-	-
Pancreatoblastoma	girls		2	0	17	0	0	2	0	0	0	0	0	0	1	0.0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-
	total	0.0	2	0	8	0	0	2	0	0	0	0	0	0	0	0.0	-	-	-
Pulmonary blastoma and pleuropulmonary blastoma	girls		4	0	33	0	4	0	0	0	0	0	0	0	1	100.0	-	-	-
	boys		8	0	62	0	8	0	0	0	1	0	0	0	2	100.0	-	-	-
	total	2.0	12	0	48	0	12	0	0	0	0	0	0	0	2	100.0	-	-	-

Standard: Segi world standard population

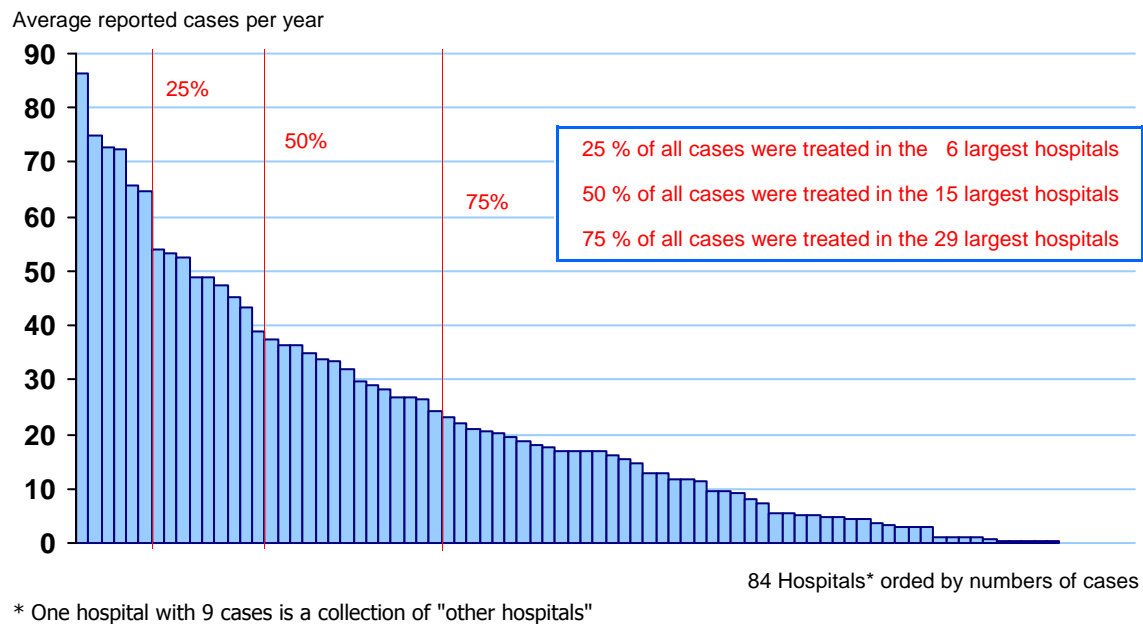
- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses	Sex	Sex ratio	N	Number of cases						Incidence rates per million						Trial participants	Survival probabilities(%)		
				Relative	Group	Age groups			Age-specific				Age-stand.	Cum.					
	m / f	%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%	5-yrs	10-yrs	15-yrs		
Other complex mixed and stromal neoplasms	girls		1	0	8	0	0	0	1	0	0	0	0	0	100.0	-	-	-	
	boys		1	0	8	0	1	0	0	0	0	0	0	0	100.0	-	-	-	
	total	1.0	2	0	8	0	1	0	1	0	0	0	0	0	100.0	-	-	-	
Mesothelioma	girls		1	0	8	0	0	0	1	0	0	0	0	0	0.0	-	-	-	
	boys		0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	total	0.0	1	0	4	0	0	0	1	0	0	0	0	0	0.0	-	-	-	
Other specified malignant tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	boys		0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
Other unspecified malignant tumours	girls		2	0	17	0	1	0	1	0	0	0	0	1	0.0	-	-	-	
	boys		3	0	23	0	0	0	3	0	0	0	0	1	66.7	-	-	-	
	total	1.5	5	0	20	0	1	0	4	0	0	0	0	1	40.0	-	-	-	

Standard: Segi world standard population

- insufficient data

Abbildung 1:**Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2003-2012****Reported cases to the GCCR (registry population) per hospital, period 2003-2012****Tabelle 2****Anzahl der gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung, altersstandardisierte Inzidenzrate und kumulative Inzidenz (pro Million) nach ICCC-3-Diagnosegruppen.****Number of registered cases in Germany aged under 15, age-standardized incidence rate and cumulative incidence (per million) by diagnostic groups as defined by ICCC-3.**

Diagnoses	Number of cases 1980-2012		Number of cases 2003-2012		Incidence rates 2003-2012	
	Absolute	Relative (%)	Absolute	Relative (%)	Age-standard.*	Cumulative
I Leukaemias	17808	34.3	5989	33.8	56	807
II Lymphomas	6119	11.8	1964	11.1	16	251
III CNS tumours	11129	21.5	4254	24.0	38	565
IV Peripheral nervous cell tumours	3952	7.6	1232	7.0	14	175
V Retinoblastoma	1227	2.4	370	2.1	4	53
VI Renal tumours	3065	5.9	965	5.5	10	134
VII Hepatic tumours	557	1.1	232	1.3	2	32
VIII Bone tumours	2431	4.7	778	4.4	6	98
IX Soft tissue sarcomas	3197	6.2	1029	5.8	9	137
X Germ cell tumours	1642	3.2	530	3.0	5	70
XI Carcinomas	700	1.3	329	1.9	3	42
XII Others and unspecified	56	0.1	25	0.1	0	3
All malignancies	51883	100.0	17697	100.0	163	2368

* Standard: Segi world standard population

Tabelle 3:

Anzahl der gemeldeten Patienten unter 15 Jahren auf Basis des ICCC-3, altersstandardisierte Inzidenzrate und Bevölkerungsbezug nach Jahren für Gesamtdeutschland sowie West- und Ostdeutschland[#]

Annual number of registered cases aged under 15 based on ICCC-3, age-standardized incidence rate and population base by calendar year for all of Germany, as well as West and East Germany[#]

Years	Number of cases			Incidence rates per million *			Population base (in million)		
	Total	West # Germany	East # Germany	Total	West # Germany	East # Germany	Total	West # Germany	East # Germany
1980	1019	987	-	103	102	-	11.187	10.903	-
1981	1046	1021	-	105	106	-	10.803	10.525	-
1982	977	953	-	104	104	-	10.392	10.121	-
1983	1077	1055	-	116	117	-	9.957	9.694	-
1984	1033	1003	-	114	114	-	9.539	9.283	-
1985	1140	1111	-	129	129	-	9.232	8.979	-
1986	1143	1111	-	132	132	-	9.070	8.815	-
1987	1218	1188	-	141	142	-	8.903	8.652	-
1988	1217	1172	-	140	139	-	9.019	8.758	-
1989	1221	1196	-	135	137	-	9.260	8.986	-
1990	1297	1253	-	139	138	-	9.621	9.333	-
1991	1667	1289	320	132	137	118	13.013	9.625	2.842
1992	1812	1432	315	143	148	123	13.166	9.889	2.731
1993	1685	1343	275	132	136	113	13.279	10.123	2.611
1994	1769	1428	293	139	143	128	13.298	10.275	2.485
1995	1803	1442	282	143	144	132	13.264	10.376	2.361
1996	1803	1475	255	145	147	126	13.209	10.449	2.244
1997	1907	1583	266	155	158	152	13.139	10.504	2.132
1998	1822	1521	234	149	152	129	13.035	10.514	2.035
1999	1877	1514	290	154	151	165	12.936	10.527	1.938
2000	1976	1635	283	162	163	169	12.836	10.534	1.842
2001	1848	1553	239	154	156	149	12.698	10.506	1.743
2002	1829	1523	236	154	153	153	12.517	10.436	1.643
2003	1774	1512	210	152	155	141	12.288	10.311	1.549
2004	1869	1561	238	164	163	168	12.042	10.155	1.470
2005	1829	1538	226	164	164	165	11.787	9.975	1.403
2006	1762	1488	223	162	162	167	11.544	9.770	1.370
2007	1771	1470	241	164	163	178	11.361	9.583	1.374
2008	1761	1476	239	166	166	175	11.212	9.411	1.392
2009	1782	1477	240	169	169	173	11.078	9.249	1.415
2010	1757	1473	214	169	171	153	10.979	9.117	1.441
2011	1707	1405	218	164	163	154	10.884	8.993	1.463
2012	1685	1391	222	164	165	154	10.731	8.822	1.474
Total	51883	44579	5559						

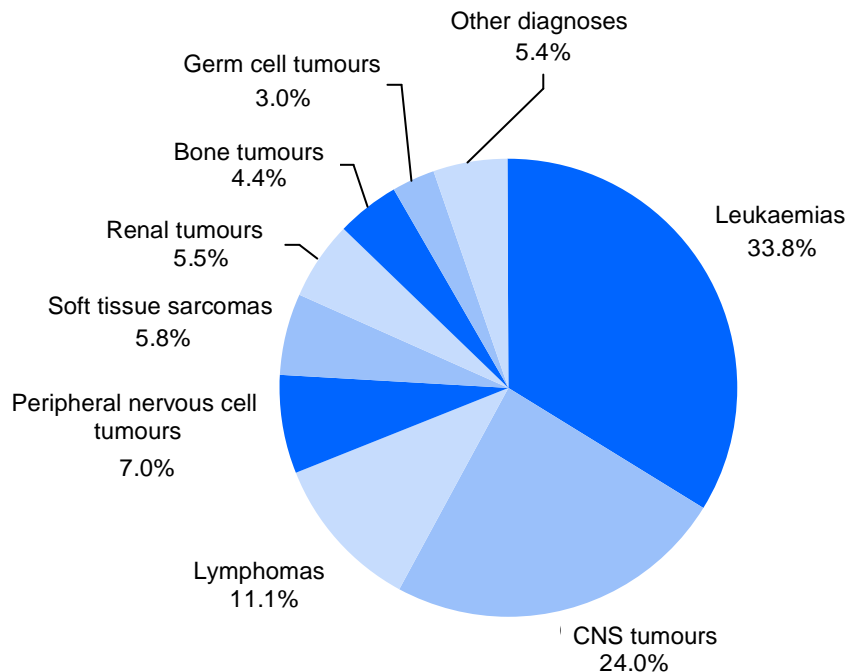
* Standard: Segi world standard population

[#] Without Berlin. As of 2001 it is no longer possible to segregate the Berlin population data into East- and West Berlin.

Abbildung 2:

Relative Häufigkeit der gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung nach den häufigsten ICCC-3 Diagnose-Hauptgruppen (2003-2012) (n = 17.697)

Relative frequencies of the registered patients aged under 15 in Germany by the most common main ICCC-3 diagnosis groups (2003-2012) (n = 17,697)

**Tabelle 4:**

Verteilung aller Registermeldungen aus der deutschen Wohnbevölkerung nach Altersgruppen bei Diagnosestellung ohne Altersbeschränkung* sowie zusätzlich erfasste Diagnosen (2003-2012)

Distribution of all reported cases in Germany by age groups at diagnosis without any restriction of age* and additional diagnoses (2003-2012)

Age groups (years)	Diagnoses according to ICCC-3		Additional diagnoses (see Table 5)	
	N	%	N	%
0	1844	8.5	431	27.0
1-4	5966	27.5	317	19.9
5-9	4752	21.9	328	20.6
10-14	5135	23.7	373	23.4
0-14	17697	81.6	1449	90.8
15-17	3239	14.9	123	7.7
18-19	301	1.4	9	0.6
20-24	220	1.0	6	0.4
≥25	226	1.0	9	0.6
≥15	3986	18.4	147	9.2
reported cases	21683	100.0	1596	100.0

* Bis 2008 wurden systematisch nur Patienten bis 14 Jahren erfasst; seit 2009 werden systematisch Patienten bis 17 Jahren erfasst. Die Älteren gehören nicht zur Registerpopulation und sind nicht repräsentativ für die deutsche Bevölkerung.

Until 2008 patients were systematically registered until the age of 14; since 2009 patients are systematically registered until the age of 17. Older patients 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 der Patienten unter 15 Jahren (2003-2012)

Systematically registered diagnoses not defined in ICCC-3 for patients under the age of 15 (2003-2012)

Diagnoses	Sex	Sex ratio	N	Number of cases				Incidence rates per million					Trial	
				Age groups				Age groups				Age-stand.	Cum.	participants
	m / f	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	%		
Non-malignant Langerhans cell histiocytosis	girls		286	76	90	74	46	23	7	4	2	6	81	87.4
	boys		415	85	118	109	103	24	8	6	5	8	109	87.0
	total	1.5	701	161	208	183	149	24	7	5	4	7	95	87.2
Benign/mature teratoma	girls		409	131	40	80	158	39	3	4	8	8	112	94.1
	boys		126	77	28	10	11	22	2	1	1	3	35	92.9
	total	0.3	535	208	68	90	169	30	2	2	4	5	73	93.8
Severe aplastic anaemia	girls		71	4	13	31	23	1	1	2	1	1	19	94.4
	boys		69	3	21	18	27	1	1	1	1	1	18	91.3
	total	1.0	140	7	34	49	50	1	1	1	1	1	18	92.9
Mesoblastic nephroma	girls		21	20	1	0	0	6	0	0	0	1	6	85.7
	boys		26	25	0	1	0	7	0	0	0	1	7	92.3
	total	1.2	47	45	1	1	0	7	0	0	0	1	7	89.4
Other diseases of blood and haemopoietic system	girls		14	8	3	2	1	2	0	0	0	0	4	50.0
	boys		9	2	3	1	3	1	0	0	0	0	2	44.4
	total	0.6	23	10	6	3	4	1	0	0	0	0	3	47.8

Standard: Segi world standard population

Tabelle 6:

Altersstandardisierte* Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert für Patienten unter 15 Jahre (2003-2012)

Age-standardized* incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for patients under 15 by region (2003-2012)

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	658	168	1.03	0.96-1.12	58	1.03	0.90-1.17	
Hamburg	333	150	0.92	0.82-1.02	53	0.95	0.78-1.14	
Niedersachsen	1780	160	0.98	0.93-1.02	56	1.01	0.93-1.09	
Bremen	118	145	0.89	0.74-1.06	44	0.82	0.57-1.14	
Nordrhein-Westfalen	4179	168	1.03	1.00-1.07	57	1.00	0.95-1.05	
Düsseldorf	1164	169	1.04	0.98-1.10	56	0.98	0.88-1.08	
Köln	1045	170	1.06	0.99-1.12	56	1.00	0.90-1.11	
Münster	634	165	1.03	0.95-1.11	61	1.11	0.97-1.26	
Detmold	525	174	1.05	0.96-1.15	56	0.97	0.82-1.13	
Arnsberg	811	163	1.00	0.93-1.07	54	0.96	0.85-1.09	
Hessen	1394	170	1.04	0.98-1.09	59	1.05	0.95-1.14	
Darmstadt	867	167	1.03	0.96-1.10	60	1.08	0.96-1.21	
Gießen	264	190	1.14	1.01-1.29	65	1.12	0.89-1.38	
Kassel	263	162	0.99	0.87-1.11	50	0.89	0.71-1.11	
Rheinland-Pfalz	927	170	1.04	0.98-1.11	54	0.95	0.85-1.07	
Baden-Württemberg	2389	158	0.96	0.93-1.00	55	0.98	0.91-1.05	
Stuttgart	891	157	0.96	0.89-1.02	55	0.98	0.88-1.10	
Karlsruhe	601	165	1.00	0.92-1.08	54	0.95	0.82-1.09	
Freiburg	494	156	0.97	0.88-1.06	57	1.03	0.88-1.19	
Tübingen	403	153	0.93	0.84-1.02	54	0.94	0.79-1.12	
Bayern	2813	163	0.99	0.96-1.03	60	1.06	0.99-1.12	
Oberbayern	937	157	0.95	0.89-1.01	60	1.06	0.95-1.18	
Niederbayern	259	155	0.95	0.83-1.07	54	0.92	0.74-1.14	
Oberpfalz	261	179	1.06	0.94-1.20	66	1.14	0.92-1.39	
Oberfranken	239	163	1.03	0.90-1.17	53	0.96	0.76-1.20	
Mittelfranken	309	135	0.82	0.73-0.92	49	0.87	0.71-1.05	
Unterfranken	311	173	1.06	0.95-1.18	65	1.15	0.94-1.38	
Schwaben	496	191	1.17	1.07-1.28	70	1.24	1.07-1.44	
Saarland	198	158	0.97	0.84-1.12	54	1.00	0.77-1.26	
Berlin	635	156	0.95	0.88-1.03	57	1.01	0.88-1.15	
Brandenburg	436	159	0.97	0.88-1.07	62	1.09	0.93-1.26	
Mecklenburg-Vorpommern	285	158	0.96	0.86-1.08	48	0.83	0.66-1.03	
Sachsen	773	170	1.05	0.97-1.12	53	0.95	0.83-1.08	
Sachsen-Anhalt	383	154	0.95	0.86-1.05	53	0.95	0.80-1.13	
Thüringen	394	165	1.00	0.91-1.11	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 alterstandardisierte Mortalitätsraten nach Diagnosejahr, 1980-2007 (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 cases aged under 15 in Germany and age standardized mortality rates by year of diagnosis 1980-2007 (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	Mortality rate per million*	No. of cases	Mortality rate per million*	No. of cases	Mortality rate per million*
1980	350	35	378	38	390	39
1981	343	33	379	36	395	38
1982	313	33	348	36	358	38
1983	319	34	359	39	372	40
1984	326	36	355	39	365	40
1985	324	36	365	40	382	42
1986	321	37	356	41	366	42
1987	329	38	354	41	368	43
1988	318	37	350	40	360	41
1989	293	33	326	36	340	38
1990	325	35	354	38	370	40
1991 #	399	32	444	35	460	36
1992 #	437	34	473	37	493	39
1993 #	383	30	428	34	445	35
1994 #	374	29	409	32	421	33
1995 #	338	27	385	30	406	32
1996 #	349	28	386	31	399	32
1997 #	372	30	417	33	435	35
1998 #	351	28	392	31		
1999 #	358	29	397	32		
2000 #	396	32	430	35		
2001 #	300	25	336	28		
2002 #	321	27	355	30		
2003 #	322	27				
2004 #	293	26				
2005 #	297	26				
2006 #	291	26				
2007 #	261	24				

* Standard: Segi world standard population

Including East Germany since 1991

Tabelle 8:

Anzahl der am Deutschen Kinderkrebsregister in der Langzeitnachsbeobachtung befindlichen Patienten mit Erstdiagnose im Alter von unter 15 (Stand 2012) *

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged < 15 (as of 2012) *

Year of diagnosis	1980 - 1989	1990 - 1999	2000 - 2009	2012	1980 - 2012
	N (%)	N (%)	N (%)	N (%)	N (%)
Patients registered	11004	17241	17943	5078	51266 #
deceased	3836 (34.9 %)	4155 (24.1 %)	3047 (17.0 %)	252 (5.0 %)	11290 (22.0 %)
surviving	7168 (65.1 %)	13086 (75.9 %)	14896 (83.0 %)	4826 (95.0 %)	39976 (78.0 %)
anonymous ⁺	975 (13.6 %)	1093 (8.4 %)	410 (2.8 %)	37 (0.8 %)	2515 (6.3 %)
identifiable	6193 (86.4 %)	11993 (91.6 %)	14486 (97.2 %)	4789 (99.2 %)	37461 (93.7 %)
< 5 years since diagnosis	-	-	2465 (17.0 %)	4789 (100 %)	7254 (19.4 %)
>= 5 years since diagnosis	6193 (100 %)	11993 (100 %)	12021 (83.0 %)	-	30207 (80.6 %)
lost-to-follow-up	637 (10.3 %)	684 (5.7 %)	152 (1.3 %)	-	1473 (4.9 %)
in LTS	5556 (89.7 %)	11309 (94.3 %)	11869 (98.7 %)	-	28734 (95.1 %)

* Modified based on [41]

51266 Patients correspond to 51883 cases diagnosed under 15 years resident in Germany at the date of diagnosis 1980-2012 and diagnosed with a disease included in ICC-3

- no data yet

+ Consent not available, refused or withdrawn later

Tabelle 9:

Zahl der vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister (LKR) bis einschließlich 2012 weitergeleiteten Meldungen

Number of forwarded reports from the German Childhood Cancer Registry to the state cancer registries (LKR) up to and including 2012

State cancer registry	Diagnosis period		Cases
	from	to	
Krebsregister Schleswig-Holstein	01.01.2007	15.07.2012	462
Hamburgisches Krebsregister	01.01.2007	15.07.2012	204
Epidemiologisches Krebsregister Niedersachsen	01.01.2007	15.07.2012	1075
Bremer Krebsregister	01.01.2007	15.07.2012	90
Epidemiologisches Krebsregister NRW *	01.01.2007	15.07.2012	2609
Hessisches Krebsregister	01.01.2007	15.07.2012	829
Krebsregister Rheinland-Pfalz	01.01.2007	15.07.2012	559
Bevölkerungsbezogenes Krebsregister Bayern	01.01.2007	15.07.2012	1507
Epidemiologisches Krebsregister Saarland	01.01.2007	15.07.2012	119
Gemeinsames Krebsregister GKR *	01.01.2007	15.07.2012	1855
Gesamt			9309

+ ab dem 01.07.2005 für ganz Nordrhein-Westfalen, vorher nur für den Regierungsbezirk Münster / since July 2005 for all of North Rhine-Westphalia, previously only for county Münster

* 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 Hessen und Baden-Württemberg befinden sich die Landeskrebsregister derzeit zum Teil im Aufbau /
in the states of Hesse and Baden-Württemberg the state cancer registries are under development

Neues zu Forschungsprojekten / News on Research Projects

84**Tabelle 10 / Table 10**

Forschungsprojekte und internationale Kooperationsprojekte seit 2010

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Tabelle 11 / Table 11

Research projects and international cooperations since 2010

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Systematische Expressionsanalyse von DNA-Reparaturgenen bei kindlichen Malignomkrankungen (GenKiK)

Die DNA-Reparatur ist ein essentieller Mechanismus für die Beseitigung von spontan entstandenen oder therapieinduzierten DNA-Schäden. Wir gehen davon aus, dass es genetische Unterschiede gibt, welche die Kapazität der verschiedenen DNA-Reparatursysteme modulieren. D.h. bestimmte Menschen könnten aufgrund von ungünstigen Genvarianten oder Mutationen sensibler gegenüber einer Strahlenbehandlung, Chemotherapie oder anderen Umwelteinflüssen sein. Das Institut für Humangenetik hat einen spezialisierten cDNA-Microarray-Chip konstruiert, um die Expression von etwa 600 DNA-Reparatur- und Zellzyklus-assoziierten Genen gleichzeitig zu quantifizieren.

Untersucht wurden 20 Patienten, die nach einer malignen Erkrankung im Kindesalter einen Zweitumor entwickelt hatten und zum Zeitpunkt der Rekrutierung mindestens 18 Jahre alt waren. Als Vergleichsgruppen wurden im „Matched Pair Design“ Patienten mit einem Tumor im Kindesalter, aber ohne Zweitumor untersucht. Neben der inhaltlichen Fragestellung diente das Projekt auch der Klärung der Frage, ob ehemalige Patienten mit Krebs im Kindesalter zur Teilnahme an einer solchen eher invasiven Studie bereit sind, dies konnte prinzipiell bejaht werden. Insgesamt nahmen 46% der angeschriebenen Probanden mit zwei Tumoren und 18% der angeschriebenen Vergleichs-Probanden an der Studie teil. Bei den DNA-Reparaturgenen wurden kleine Unterschiede in der Genexpression von FTH1 und CDKN1A gefunden. Die Bedeutung der beobachteten Genexpressionsunterschiede bei der DNA-Reparatur muss noch weiter untersucht werden.

Todesursachenrecherche und Zweitneoplasie-Validierung

Die Überlebenswahrscheinlichkeit von Krebspatienten im Kindesalter hat sich in den letzten Jahrzehnten erheblich verbessert. Damit rücken die Langzeitfolgen in den Fokus der Aktivitäten des Deutschen Kinderkrebsregisters (DKKR).

Eine der schwerwiegendsten Spätfolgen ist eine zweite Krebserkrankung. Für die entsprechende Forschung sind möglichst vollzählige Daten mit möglichst hoher Qualität essenziell. Das DKKR bittet seit einigen Jahren regelmäßig ehemalige Patienten um eigene Angaben zu ihrem Gesundheitszustand. Mindestens 90% der ehemaligen Patienten können angeschrieben werden und ca. 70% von ihnen senden einen ausgefüllten Bogen zurück. Am Deutschen Kinderkrebsregister sind mittlerweile ca. 1000 Patienten bekannt, die mehr als einmal an Krebs erkrankten, davon wurden bisher 125 Fälle nur von den Patienten selbst mitgeteilt. Es ist davon auszugehen, dass diese Mitarbeit immer wichtiger wird.

Systematic Analysis of Expression of Repair Genes in Children with Malignancies (GENKIK: Gene Expression and Cancer in Childhood)

DNA-repair is an essential mechanism in the regulation of spontaneous or therapy induced DNA damage. We assume that there are genetic differences in the capacity for the regulation of repair genes. Some individuals may genetically be more sensitive towards radiation therapy, chemotherapy or environmental hazards. A specialized 600 gene cDNA-Microarray-Chip developed by the Institute for Human Genetics permits observing the expression of many genes simultaneously.

We recruited 20 adult persons with a malignant disease in childhood and another 20, who had a second malignancy after this, matched by age, year, disease and survival. Besides the research question we also wished to assess, whether former childhood cancer patients could be recruited for such an invasive study at all. This turned out to be basically possible. Out of the invited patients with two neoplasms 46% participated and 18% of the potential controls. With respect to the DNA-repair genes we found small differences in the expression of FTH1 and CDKN1A. The meaning of the observed differences in gene expression needs to be investigated further.

Cause of death investigation and second neoplasia validation

The probability of survival after cancer in childhood has considerably improved in the last decades. This moves late effects into the focus of the activities of the German Childhood Cancer Registry (GCCR).

One of the most severe late effects is a second neoplasia. To facilitate research in this area complete high quality data is needed. For some years the GCCR has asked former patients to provide information on their health status. At least 90% of the former patients can be contacted and about 70% usually send back a completed questionnaire. By now, we know of about 1000 patients who were diagnosed with cancer more than once, about 125 of these cases were reported directly by the patients. We expect his active cooperation to become increasingly important.

In einem von der Kinderkrebsstiftung geförderten Anschubprojekt haben wir die systematische Qualitätssicherung dieser Angaben etabliert. Etwa 700 ehemalige Patienten haben bislang Angaben gemacht, die einer näheren Überprüfung bedurften, darunter auch viele Rezidive oder weniger schwerwiegende Befunde. Da diese Patienten im Allgemeinen die Einwilligung zur Nachfrage beim behandelnden Arzt geben war es meist möglich, diese Angaben zu überprüfen. Die Überprüfung erbrachte eine hohe Zuverlässigkeit der Selbstangaben.

Todesursachen liegen bislang überwiegend für in den ersten Jahren nach Diagnose eingetretene Todesfälle vor. Diese sollen so weit möglich recherchiert und das Grundleiden für alle bekannten Todesfälle festgehalten werden. Die Vorgehensweise wird derzeit mit dem Büro des Landesdatenschutzbeauftragten Rheinland-Pfalz abgesprochen.

The Childhood Cancer Foundation funded a project to establish the quality control of this information. About 700 former patients have so far provided information, which needed to be investigated in detail, among these many relapses and less severe incidents. As most patients provide written consent to contact their treating physician or hospital, almost all of those could be validated. We found their information to be mostly very reliable.

For the currently recorded deaths we have information on cause of death usually only if it occurs within a few years of diagnosis. The missing causes of death and the underlying cause of death should be researched as far as possible. We are currently working on an agreement with the bureau of data protection.

Tabelle 10:

Forschungsprojekte und internationale Kooperationsprojekte seit 2010 (see Table 11 for the English version)

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
Zweitmalignome nach Krebs im Kindesalter: Fall-Kontroll-Studie zu den Risikofaktoren für das Entstehen von sekundären malignen Neoplasien	Fall-Kontroll-Studie	19	DKKR	ja	Bundesministerium für Bildung und Forschung (Kompetenznetzförderung)
ACCIS: Automated Childhood Cancer Information System	Internationale Datenbank		IARC, Lyon, Frankreich	nein	-
EUROCARE: Survival of cancer patients in Europe	Follow-up Studie	18	Istituto Nazionale dei Tumori, Mailand, Italien	nein	-
Strukturoptimierung zur Gewährleistung einer qualitätsgesicherten Langzeitbeobachtung ehemaliger pädiatrisch-onkologischer Patienten	Strukturelles Projekt	25,28,29, 33,34	DKKR	ja	Deutsche Kinderkrebsstiftung (Anschubfinanzierung)
KiKK: Epidemiologische Studie zu Kinderkrebs in der Nähe von Kernkraftwerken	Fall-Kontroll-Studie	14-16,20,23	DKKR	ja	Bundesministerium für Umwelt, Naturschutz und Reaktorsicherheit über das Bundesamt für Strahlenschutz

Tabelle 10 Forts. Table 10 cont.

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
Befragungsprojekte ehemaliger Kinderkrebspatienten in Zusammenarbeit zwischen externen Kooperationspartnern und dem DKKR	Registerbasierte Umfragen	17,24,26, 27,32,37, 39,40	DKKR; Uni.-Klinik Ulm; Otto-Heubner-Zentrum für Kinder- und Jugendmedizin Berlin; Zentrum für Kinder- und Jugendmedizin Giessen; Uni. Erlangen; BIOGUM, Uni. Hamburg	vom externen Kooperationspartner mitfinanziert	Deutsche Kinderkrebsstiftung, Deutsche Krebshilfe, Eigenmittel der ext. Kooperationspartner, 6. EU-FRP "ACGT-Advancing Clinico-Genomic Clinical Trials on Cancer"
PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies (PanCareSurFup) im Rahmen des PanCare Netzwerkes	Internationales Netzwerk		Gesamtleitung: Lund University Hospital, Schweden; Leitung Work-package 1 (Data Collection and Harmonization): DKKR	ja	Europäische Kommission EU FP7
GENKIK: Systematische Expressionsanalyse von DNA-Reparaturgenen bei kindlichen Malignomerkkrankungen	Fall-Kontroll-Studie	31,42	DKKR, IMBEI, Institut für Humangenetik der Universitätsmedizin Mainz	ja	Stiftung Rheinland-Pfalz für Innovation
Todesursachenuntersuchung und Validierung von Zweitumoren auf Basis der regelmäßigen Statusabfrage früherer pädiatrisch onkologischer Patienten	Strukturelles Projekt	41	DKKR	ja	Deutsche Kinderkrebsstiftung
Identifizierung genetischer Prädispositionen der spontanen und strahleninduzierten Karzinogenese bei Malignomerkkrankungen im Kindesalter (KIKME)	Fall-Kontroll-Studie		IMBEI	ja	Bundesministerium für Bildung und Forschung
Kinderkrebsrisiko nach Exposition durch computertomographische Untersuchungen im Kindesalter (KiCT)	Kohortenstudie	30,35,36	IMBEI	ja	Bundesministerium für Bildung und Forschung

IMBEI: Institut für Medizinische Biometrie, Epidemiologie und Informatik

DKKR: Deutsches Kinderkrebsregister

IARC: International Agency for Research on Cancer, Lyon, Frankreich

Tabelle 11

Research projects and international cooperations since 2010 (see table 10 for the German version)

Name of the project	Type of study	References
Second malignant neoplasms after childhood cancer: Risk factors for the development of second malignant neoplasms	Case-Control Study	19
ACCIS: Automated Childhood Cancer Information System	International data base on childhood cancer	
EUROCARE: Survival of cancer patients in Europe	Follow-up Study	18
Improving the structure of long-term surveillance of former childhood cancer patients	Structural project	25,28,29,33,34
KiKK: Epidemiological study on childhood cancer in the vicinity of nuclear power plants	Case-Control Study	14-16,20,23
Survey-projects on former childhood cancer patients in cooperation between external cooperation partners and the German Childhood Cancer Registry	Registry-based study	17,24,26,27,32,37,39,40
PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies (PanCareSurFup) within the PanCare Network	International network	
GENKIK: Systematische Expressionsanalyse von DNA-Reparaturgenen bei kindlichen Malignomkrankungen	Case-Control Study	31,42
Cause of death investigation and second neoplasia validation	Structural project	41
Identifying genetic predisposition of spontaneous and radiation induced carcinogenesis in childhood malignomas (KIKME)	Case-Control Study	
Risk of childhood cancer after computed tomography in childhood (KiCT)	Cohort Study	30,35,36

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Datengrundlage, Methoden und Ergebnisdarstellung

Rechtliche Grundlagen und Finanzierung des Registers

Das Deutsche Kinderkrebsregister 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 nur ca. 1%, weitere rund 1% der Einwilligungen fehlen aus anderen Gründen. Im Falle einer fehlenden Einwilligung erfolgt eine anonymisierte Minimal-Erfassung, um diese Patienten 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 auf freiwilliger Basis. 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.

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

Charakterisierung des Registers

Das Register ist seit dem Beginn 1980 am Institut für Medizinische Biometrie, Epidemiologie und Informatik (IMBEI) (vormals Institut für Medizinische Statistik und Dokumentation (IMSD)) 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 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 (klinische Studien) der GPOH. Da der Anteil der in eine der klinischen Studien aufgenommenen Patienten mit über 90% sehr hoch ist, kommt diesem Aspekt der integrierten Dokumentation eine ganz wesentliche Bedeutung zu.

Ein weiteres Charakteristikum des Kinderkrebsregis-

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 only about 1% do not give their consent, another about 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 patients for free and 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.

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 registry

The registry was established at the Institute for Medical Biostatistics, Epidemiology and Informatics (IMBEI) (previously Institute for Medical Statistics and Documentation (IMSD)) of the Universitätsmedizin at the Johannes Gutenberg-University Mainz. It co-operates with the scientific society for paediatric oncology and haematology (GPOH) and the treating hospitals. The registry is a population based registry combined with some features of a clinical registry, registering also clinical details such as staging, grading, and immunological subtypes (4). The clinical information is based on the integrated information exchange and data flow between the ca. 25 GPOH organized therapy optimization trials and the GCCR. This is of special importance because more than 90% of all patients are included in these trials.

The registry is also characterized by an active open

ters ist die Realisierung einer aktiven, zeitlich unbefristeten Langzeitnachbeobachtung. Damit stellt das Register die Grundlage für die Erforschung von Spätfolgen, wie z.B. Zweitneoplasien, bereit.

Dokumentationsablauf und Datenfluss

Von den kooperierenden Kliniken wird jeweils bei Auftreten einer Neuerkrankung ein kurzer Meldebogen an das Register 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. Daraufhin wird vom Register an die Klinik ein diagnosespezifischer Erhebungsbogen verschickt. Mit diesen mit den Leitern der Therapieoptimierungsstudien abgestimmten Bögen werden Einzelheiten der klinischen Diagnose und der Therapie erfasst. Im Fall einer Studienteilnahme werden die ausgefüllten Bögen von der Klinik direkt an die Studienleitung geschickt. Die Weiterleitung entsprechend validierter diagnostischer Detail-Informationen von der Therapiestudienleitung an das Deutsche Kinderkrebsregister erfolgt anschließend, 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. Anschließend erfolgt dies durch das Deutsche Kinderkrebsregister, wobei diese die Daten jeweils untereinander austauschen. Das Kinderkrebsregister erhält Nachbeobachtungs-Informationen aus mehreren Quellen: der Klinik (solange der Patient 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 Kinderkrebsregister sind in (4, 5, 8, 21) beschrieben. Die Langzeitnachbeobachtung ist in (13, 22, 29, 33, 34) publiziert.

Datengrundlage

Das Register nahm 1980 seine Arbeit auf. Die Registerpopulation im engeren Sinne umfasst die Kinder, die vor Vollendung ihres 15. Lebensjahrs, seit 2009 vor Vollendung des 18. Lebensjahrs, 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.

end long-term follow-up of all registered patients. This is the basis for research on late effects, such as second 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 registry. This contains patient identification data, a confirmation of consent to the registration, a tentative diagnosis and information on whether this patient will be included in one of the on-going therapy optimization trials. In response to this notification, the registry sends a set of tumour-specific basic documentation forms to the cooperating clinician. For patients included in the therapy optimization trials, this basic documentation is to be returned directly to the relevant trial centre. 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 until the end of the first clinical treatment phase and during clinical follow-up. After this, further follow-up is conducted by the GCCR, regularly exchanging this information with the therapy trials. The GCCR collects data from various sources, such as the hospitals, state cancer registries, municipalities, and last but not least the patients themselves. This flow of information is described in (4, 5, 8, 21), the follow-up procedures are published in (13, 22, 29, 33, 34).

Data basis

In 1980, the GCCR was initiated by the GPOH. It is intended to include all children with malignant disease (or - no matter what behaviour code - any form of tumours of the central nervous system (=CNS tumours)) diagnosed at an age younger than 15 years, since 2009 at an age younger than 18 years, and resident in Germany at diagnosis. Since 1991, cases from the area of the former German Democratic Republic (GDR) are included.

Die Klassifizierung der Erkrankungen erfolgt 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 - gemäß internationaler Konvention - in einem epidemiologischen Krebsregister systematisch zu erfassen sind.

Die Vollständigkeit der Erfassung beträgt seit 1987 über 95%; sie entspricht damit den internationalen Anforderungen an epidemiologische Krebsregister.

Neben den in der ICCC-3 definierten Diagnosen werden am Deutschen Kinderkrebsregister einige weitere Diagnosegruppen systematisch erfasst (Tabelle 5). Seit 2009 wurden entsprechend den Empfehlungen des Gemeinsamen Bundesausschusses noch einige wenige weitere nicht-maligne Diagnosen hinzugenommen (11). Für einige dieser Diagnosen existieren eigene Therapieoptimierungsstudien der Fachgesellschaft GPOH.

Classification of diseases is based on the International Classification of Childhood Cancer 3rd edition (ICCC-3) (9). The ICCC-3 is an aggregation of morphology and topography codes based on ICD-O-3 (6), included at the end of this report. This also defines internationally which diagnoses in childhood are recorded mandatory in an epidemiologic cancer registry.

The completeness of registration is more than 95% since 1987; this complies with international requirements for an epidemiologic cancer registry.

Besides the diagnoses defined in ICCC-3, the GCCR records a number of further diagnoses systematically (Table 5). Since 2009 we added a few more rare non-malignant diagnoses (11). For some of these diagnoses, there exist therapy optimization trials within the GPOH.

Grundlagen der Registrierung und Arbeitsweise zum Nachlesen

Literaturstellen

- Meldung und Dokumentationsablauf (4, 5, 8, 11, 21)
- Langzeitnachbeobachtung (22, 25, 28, 29, 33, 34, 41)
- Statistische Methodik (1-3, 7)

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

Further Information on the Basis of Registration and Procedures

References

- Notification and documentation (4, 5, 8, 11, 21)
- Long-term surveillance (22, 25, 28, 29, 33, 34, 41)
- Statistical methods (1-3, 7)

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

- Vereinbarung des Gemeinsamen Bundesausschusses zur Kinderonkologie (11)
- Beschluss der 82. Gesundheitsministerkonferenz 2009 (Kinderkrebsregister - Anhebung der Altersgrenze für die Registrierung von Kindern und Jugendlichen)
- Krebsregistergesetz Rheinland-Pfalz (10)
- Bundeskrebsregisterdatengesetz
- Notwendigkeit der namensbezogenen Datenspeicherung
- Die Rahmenbedingungen des Deutschen Kinderkrebsregisters (8)
- Positionspapier der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) zu (Langzeit-)Nachbeobachtung, (Langzeit-)Nachsorge und Spätfolgenerhebung bei pädiatrisch-onkologischen Patienten (13)
- Datenaustausch zwischen Deutschem Kinderkrebsregister und den Landeskrebsregistern (22)
- DKKR-Regelwerk des Deutschen Kinderkrebsregisters zu datenschutz-relevanten Aspekten
- DKKR-Einwilligungserklärung
- DKKR-Technisches Datenschutz- und Datensicherheitskonzept des Deutschen Kinderkrebsregisters
- Die Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters (29, 33, 34, 41)

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. Dabei zählen wir Fälle, nicht Patienten. Der Anteil der an Therapieoptimierungsstudien der GPOH teilnehmenden Fälle schließt alle Patienten ein, von denen eine Studienleitung in irgendeiner Form Kenntnis hat. Das heißt, in diesem Anteil sind auch Patienten enthalten, die nicht zur Gruppe der Studienteilnehmer im engen Sinne zu zählen sind.

Die Inzidenzrate (Neuerkrankungsrate) bezieht die Anzahl der 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) Personennjahre dargestellt.

Die altersspezifische Inzidenzrate I_{ij} für die Altersgruppe j im Zeitraum i errechnet sich als

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

mit N_{ij} Anzahl der Neuerkrankungen im Alter j im Zeitraum i und B_{ij} Bevölkerung im Alter j im Zeitraum i . In der Regel werden in diesem Bericht altersspezifische Inzidenzraten für die unter 1-jährigen ($j=1$), die 1- bis 4-jährigen ($j=2$), die 5- bis 9-jährigen ($j=3$) und die 10- bis 14-jährigen Kinder ($j=4$) berechnet, ab 2009 auch für die 15- bis 17-jährigen ($j=5$). Die (direkt) altersstandardisierte Inzidenzrate für unter 15-Jährige errechnet sich mit Hilfe der Gewichte w_j des von Segi erarbeiteten WHO-Welt-Standards (2) (Tabelle M.1) als

$$D_i = \sum_{j=1}^4 w_j I_{ij} \quad .$$

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.

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. We count cases, not patients. The relative frequency of trial cases includes all patients the trial centre is informed of. This also includes patients who may not be treated according to protocol.

The incidence rate relates the number of cases in a certain area and period to the resident population in the relevant age group. All incidence rates in this report are averages for the relevant period and are given as rates per 1000000 (million) person years.

The age-specific incidence rate I_{ij} for the age group j in the time period i is calculated as

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

with N_{ij} the number of new cases at age j in time period i and B_{ij} the population at age j in time period i . This report usually gives age-specific incidence rates for children under age 1 ($j=1$), ages 1-4 ($j=2$), ages 5-9 ($j=3$), and ages 10-14 ($j=4$). From 2009 onwards we also include ages 15-17 ($j=5$). The directly standardized incidence rate for cases under 15 is calculated using the weights w_j of the Segi WHO world standard (2) (Table M.1):

$$D_i = \sum_{j=1}^4 w_j I_{ij} \quad .$$

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.

Tabelle M. 1 / Table M. 1

Zusammensetzung der Segi Weltbevölkerung für Kinder unter 15 Jahren im Vergleich zur durchschnittlichen deutschen Wohnbevölkerung 2003-2012

Composition of the Segi world standard for children under 15 years compared to the German population 2003-2012

Age-groups (years)	World standard population	German population 2003-2012	
	Weights	Absolute	Relative
0	0.08	683,511	0.06
1-4	0.31	2,833,561	0.25
5-9	0.32	3,781,490	0.33
10-14	0.29	4,092,017	0.36
Total	1.00	11,390,579	1.00

Die kumulative Inzidenz bis 15 Jahre errechnet sich als Summe der altersspezifischen Inzidenzraten,

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

wobei hier gewöhnlich 15 Einzelaltersjahresklassen verwendet werden ($j=1,\dots,15$). Sie kann interpretiert werden als das Risiko (die Wahrscheinlichkeit) eines neugeborenen Kindes, bis zum Alter von 15 Jahren an einer Krebserkrankung zu erkranken.

Die in pädiatrisch onkologischen Publikationen gern verwendete Darstellung der Inzidenzrate oder der kumulativen Inzidenz als $1/K_i$ Kinder (d.h. eins von K_i Kindern ist betroffen) ergibt sich über die Umrechnungen

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

Innerhalb des Zeitraums bis unter 15 Jahren sind die Hälfte der Patienten bei Diagnose jünger und die andere Hälfte älter als das mediane Alter bei Diagnose (angegeben in Monaten).

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 a) eine Hochrechnung für einen darüber hinausgehenden Zeitraum und b) eine stabilere Abschätzung des Langzeitüberlebens.

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

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

usually using 15 single-year age classes ($j=1,\dots, 15$). It can be interpreted as the risk (the probability) of a new born to become a cancer case until his/her 15th birthday.

Paediatric-oncology publications like to present incidence rates or the cumulative incidence in an alternative form, namely as $1/K_i$ children (one of K_i children will be affected). This can be derived by

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

Until the 15th birthday half of the patients are younger than the median age at diagnosis, and the other half are older (presented in months).

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.

Die graphische Darstellung in diesem Bericht präsentiert die Überlebenszeitkurven nur bis zum tatsächlichen Beobachtungsende. Dargestellt werden die Überlebenswahrscheinlichkeiten nach Diagnosejahren für die erste Dekade, die zweite Dekade, und für die erste und zweite Hälfte der dritten Dekade. Bei einigen Diagnosen liegen noch keine ausreichend vollständigen Nachbeobachtungsdaten aus den letzten Jahren vor, die entsprechende Kurve wird dann nicht dargestellt.

Die Berechnung der Mortalitätsrate und der kumulativen Mortalität erfolgt analog zur Inzidenzrate und kumulativen Inzidenz. Es werden die Todesfälle der ersten 10 Jahre nach Diagnose betrachtet bezogen auf einen entsprechend um 10 Jahre zurückverlegten Diagnosezeitraum.

Zweitneoplasien

Eine Zweitneoplasie ist eine weitere Neubildung, die nach der ersten 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 25 Jahren nach Diagnose aufgetretenen zweiten Krebserkrankungen (SN - second neoplasms) bezieht sich nur auf in der ICCC-3 definierte Krebserkrankungen. Gutartige weitere Erkrankungen (außer den in der ICCC-3 eingeschlossenen ZNS-Tumoren) werden hier nicht mitgezählt.

Die Bezugsbevölkerung für die Berechnung der kumulativen Inzidenz der zweiten Krebserkrankungen ist die Gruppe aller Patienten mit einer ersten Krebserkrankung (nach ICCC-3) im Alter von unter 15 Jahren (ab 2009 unter 18 Jahren) in der deutschen Wohnbevölkerung. Die Angabe der kumulativen Inzidenz erfolgt pro 100 Personen unter Risiko (%). Wegen der relativ hohen Zahl an Todesfällen wird zur Berechnung der kumulativen Inzidenz mit dem Aalen-Johansen-Schätzer (3) eine Variante des Kaplan-Meier-Verfahrens (1) angewendet, das diesen Umstand als konkurrierendes Risiko berücksichtigt. Angegeben wird die kumulative Inzidenz einer zweiten Krebserkrankung nach der jeweils dargestellten Ersterkrankung, sowie umgekehrt die jeweils betrachtete Krebserkrankung ihrerseits als zweite Erkrankung nach einer beliebigen vorangegangenen Krebserkrankung.

Lesehilfe am Beispiel der Akuten Myeloischen Leukämie (ICCC-3 Ib)

The graphical presentation in this report cuts the survival curves at the observed maximum observation time. We present the survival curves for the first and second decade and the first and second half of the third 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.

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 10 year follow-up after diagnosis referring to the diagnosis period from 10 years earlier.

Second neoplasias

A second neoplasia (SN) is a subsequent neoplasia, which occurred after the primary in the same patient.

The cumulative incidence of second neoplasias (SN) within 25 years of diagnosis includes only ICCC-3 defined cases. Non-malignant diseases (unless they are non-malignant CNS-tumours included in ICCC-3) are not counted here.

The population base for these calculations are all cases with a primary disease (as defined in ICCC-3) at age < 15, resident in Germany. The cumulative incidence is given per 100 persons 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 (ICCC-3 Ib) as an example.

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 25 yrs. of diagnosis (1980-2012):

I (b) Acute myeloid leukaemias

SN after I (b)			I (b) as SN after any primary		
N	% of all 976 SN	Cumulative incidence	N	% of all 976 SN	Cumulative incidence
39	4.0 %	3.4 %	134	13.7 %	0.3 %

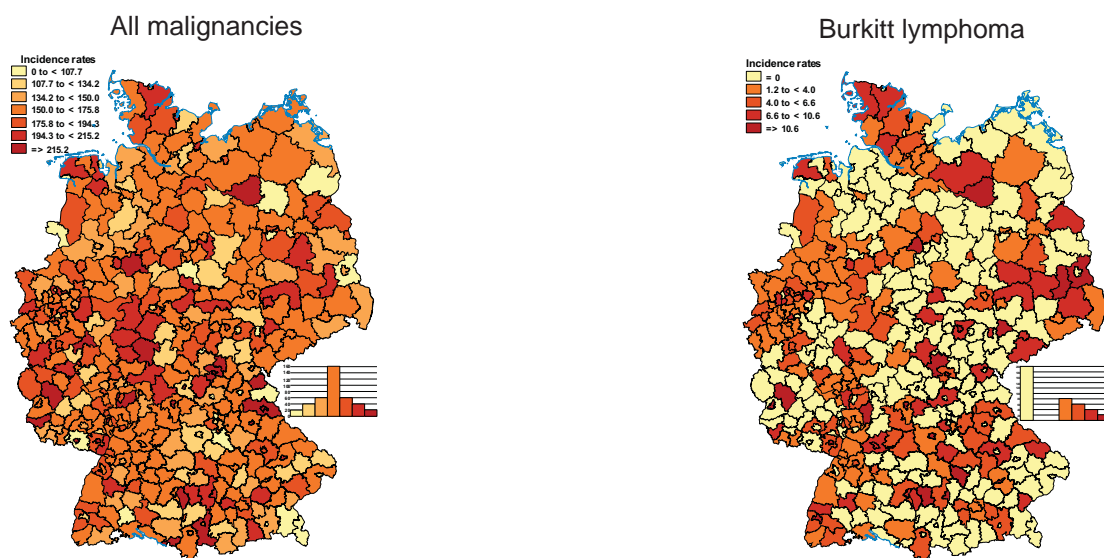
Bei den in den Jahren 1980-2012 mit einer AML unter 15 Jahren als erster Krebserkrankung diagnostizierten Patienten wurden in den folgenden bis zu 25 Jahren 39 zweite Krebserkrankungen diagnostiziert. Das sind 4,0% von allen 976 innerhalb von 25 Jahren nach Diagnose in den Jahren 1980-2012 an das Deutsche Kinderkrebsregister gemeldeten zweiten Krebserkrankungen. Bei 3,4% aller AML Patienten wird innerhalb von 25 Jahren nach Erstdiagnose eine weitere Krebserkrankung diagnostiziert, im Vergleich zum SN-Risiko nach allen Malignomen (4,7%) ist das unterdurchschnittlich.

Nach einer ersten Krebserkrankung beliebigen Typs im Alter von unter 15 in den Jahren 1980-2012 wurde bei 134 Patienten anschließend in den nächsten 25 Jahren eine AML diagnostiziert. 13,7% aller 976 dem Deutschen Kinderkrebsregister innerhalb von 25 Jahren nach Diagnose in den Jahren 1980-2012 gemeldeten zweiten Krebserkrankungen sind AML. Im Vergleich zu dem Anteil von AML an allen Krebserkrankungen im Kindesalter (4,4%) ist das ungewöhnlich viel. Bei 0,3% aller kindlichen Krebspatienten wird innerhalb von 25 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



Within 25 years of diagnosis 39 second neoplasms were diagnosed out of the cases of AML reported at age < 15 in the years 1980-2012. These are 4.0% of all 976 recorded second Neoplasms within 25 years of diagnosis in the years 1980-2012 at the GCCR. 3.4% of all AML cases are diagnosed with a second neoplasm within 25 years of diagnosis in the years 1980-2012, this is less than the average cumulative incidence of 4.7% for all malignancies.

After any primary neoplasm at age under 15 in 1980-2012, 134 patients were diagnosed with AML as second neoplasms within 25 years of diagnosis in the years 1980-2012. 13.7% of all 976 second neoplasms within 20 years of diagnosis of the primary disease in the years 1980-2010 reported at the GCCR are AML. Compared to 4.4% AML in general, this is a large number. 0.3% of all childhood cancer patients are diagnosed with a second AML within 25 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 .

$$SIR_{ir} = \frac{N_{ir}}{\sum_{j=1}^4 B_{ijr} \frac{I_{ij}}{1000000}} .$$

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% CI), die auf der Poisson-Verteilung beruhen, berechnet. Ein SIR gilt als statistisch unauffällig, wenn das zugehörige Konfidenzintervall den Wert 1 einschließt. Ein 95% CI 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 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 2003-2012 20 Kreise.

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 .

$$SIR_{ir} = \frac{N_{ir}}{\sum_{j=1}^4 B_{ijr} \frac{I_{ij}}{1000000}} .$$

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 2003-2012 for all ICC3-3 diagnoses we actually observed 20.

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 MYELOYDYSPLASTIC 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 (pPNET) 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	C70.0-C72.9, C75.1-C75.3
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 8441-8444, 8450, 8451, 8460-8473	C56.9, C62.0-C62.9
(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 8330-8337, 8340-8347, 8350	C73.9
(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

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