



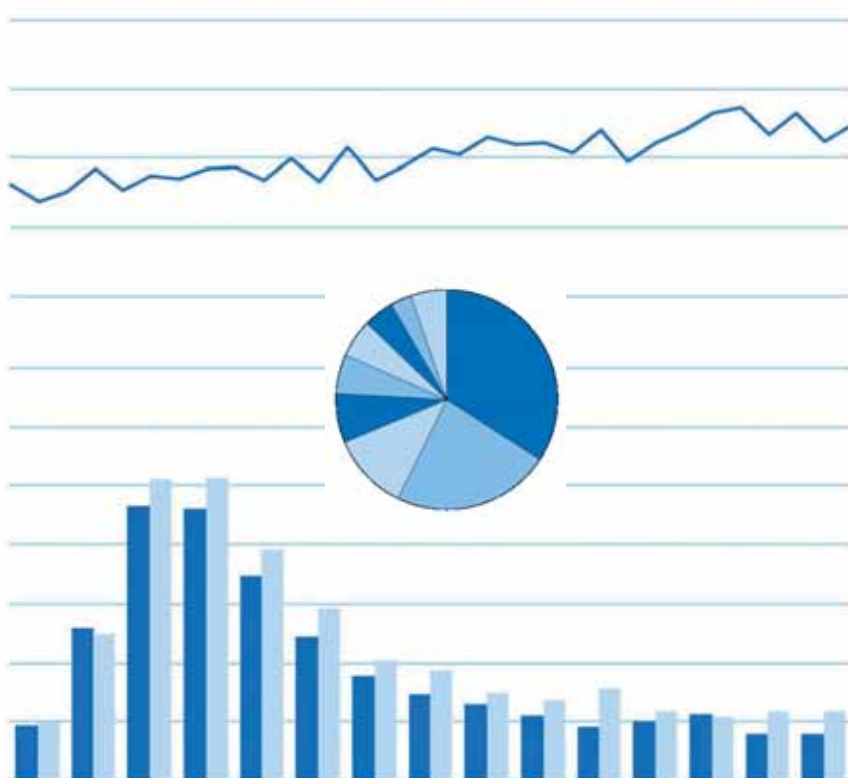
*Deutsches
Kinderkrebsregister*



Jahresbericht / Annual Report 2013/14



German Childhood Cancer Registry



Jahresbericht Annual Report 2013/14

(1980-2013)

Deutsches Kinderkrebsregister DKKR
German Childhood Cancer Registry GCCR

Jahresbericht / Annual Report 2013/14 (1980-2013)

November, 2014

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2 Vorwort / Foreword

Seit vielen Jahren war es der Wunsch der deutschen pädiatrischen Onkologen und Hämatologen, dass das Deutsche Kinderkrebsregister nicht nur Neuerkrankungen erfasst, die vor dem 15. Geburtstag diagnostiziert werden, sondern dass eine Erweiterung bis zum 18. Geburtstag erfolgt. Nicht zuletzt aufgrund einer Vereinbarung des Gemeinsamen Bundesausschusses (GBA) aus dem Jahr 2006 konnte im Jahr 2010 offiziell mit der erweiterten Erfassung aller vor dem 18. Geburtstag Diagnostizierten begonnen werden. Durch entsprechend vorher schon erfolgte Vorarbeiten konnte rasch auch für diese Altersgruppe eine hohe Vollständigkeit erzielt werden. In diesem Jahresbericht 2013/14 des Deutschen Kinderkrebsregisters werden nun erstmals Auswertungen zu 15- bis 17-Jährigen über einen 5-Jahreszeitraum präsentiert.

Die Auswertungen für die unter 15-Jährigen beziehen sich auf den aktuell zurückliegenden 10-Jahreszeitraum (2004-2013), die für die unter 18-Jährigen auf die 5 Jahre 2009-2013. Durchschnittlich wurden pro Jahr 1.774 Neuerkrankungen bei unter 15-Jährigen und 343 Neuerkrankungen bei 15- bis 17-Jährigen erfasst. Insgesamt liegen seit Beginn unserer Tätigkeit im Jahr 1980 Daten von 55.412 Neuerkrankungen vor (davon 53.698 bei unter 15-Jährigen und 1.714 bei 15- bis 17-Jährigen).

Analog zu Tabelle 1 (S. 65 ff.), die wie in den zurückliegenden Jahresberichten systematisch epidemiologische Kenngrößen für alle Einzeldiagnosen bei unter 15-Jährigen zeigt, werden diese nun in Tabelle 9 (S. 83 ff.) zusätzlich für alle unter 18-Jährigen dargestellt. Die Inzidenzraten für beide Gruppen werden in Tabelle 3 (S. 78) einander gegenübergestellt, das unterschiedliche Diagnosespektrum in den unterschiedlichen Altersgruppen zeigt die Abbildung 2 (S. 77).

Die am Deutschen Kinderkrebsregister vorliegende Kohorte Langzeitüberlebender umfasst derzeit 30.322 Betroffene (vorliegende Einwilligung, bekannte aktuelle Adresse, mindestens 5 Jahre überlebend) (Tabelle 8, S. 82). Wir sind sehr froh, durch das Mitwirken ehemaliger Patienten über eine umfassende Datengrundlage für die immer weiter an Relevanz gewinnende Spätfolgenforschung zu verfügen. So befasst sich die Hälfte unserer aktuellen, in Tabelle 11 (S. 100f.) aufgeführten Forschungs- und Kooperationsprojekte mit Fragen möglicher Spätfolgen.

Die Meldungen an das Deutsche Kinderkrebsregister werden grundsätzlich an die Krebsregister der Länder weitergeleitet. Bis zum zurückliegenden Jahr 2013 konnte dies bei mehr als 10.000 Meldungen erfolgen (Tabelle 10, S. 94). Es ist zu hoffen, dass bei anstehenden Gesetzesänderungen, etwa aktuell im Zusammenhang mit der Umsetzung des Krebsregisterfrüherkennungs- und -registergesetzes (KFRG), Regelungen

The pediatric oncologists and hematologists have long been suggesting to the German Childhood Cancer Registry to extend recording new cases systematically not only for cases before the 15th birthday, but also before the 18th birthday. Since the „Vereinbarung des Gemeinsamen Bundesausschusses (GBA)“ issued in 2006 we were able to officially extend the recording to cases under 18 in 2010. The starting phase went well, so relative completeness was reached even earlier. In this annual report 2013/14 we are now able to present analyses for cases aged 15-17 over a period of 5 years for the first time.

All main analyses for cases under 15 years of age are based on the most recent 10-year period (2004-2013), all under 18 years are based on the five years 2009-2013. On average, there are 1,774 new cases aged under 15 per year, and another 343 are observed in adolescents aged 15-17. In total, since the start of the registry in 1980 we have now recorded 55,412 new cases under 15 and 1,714 cases at ages 15-17.

Table 1 (p. 65 ff.) presents all relevant epidemiologic measures systematically for all cases under 15, the analogous information (as far as available) for cases under 18 is presented in Table 9 (p. 83 ff). The incidence rates are compared in Table 3 (p. 78), the different distributions of the diagnoses by age are presented in Figure 2 (p. 77).

The cohort of long-term survivors followed-up by the German Childhood Cancer Registry currently includes 30,322 former patients (with consent, a current address, and at least 5 years survival) (Table 8, p. 82). We are grateful for having such a large basis for research on late effects with the compliance of former patients. Half of the current research presented in Table 12 (p. 102) are research projects and cooperative projects dealing with possible late effects.

The cases reported to the GCCR are generally passed on to the state registries. Until 2013 more than 10,000 reports were passed on (Table 10, p. 94). The local registry laws will have to be adapted to the new „Krebsregisterfrüherkennungs- und -registergesetz (KFRG)“ in the near future; we hope that regulations are created or existing regulations kept, which allow the continuation of the beneficial data exchange between the German

vorgesehen oder beibehalten werden, die die bewährten und inhaltlich wichtigen Datenabgleiche zwischen dem Deutschen Kinderkrebsregister und den Krebsregistern der Länder weiterhin gewährleisten.

Die Tätigkeit des Deutschen Kinderkrebsregisters ist wesentlich durch die enge Zusammenarbeit mit den behandelnden Kliniken, den Therapieoptimierungsstudien und Diagnoseregistern der GPOH (Gesellschaft für Pädiatrische Onkologie und Hämatologie) charakterisiert. Den Klinikern und Studienleitungen sei an dieser Stelle herzlich für die vertrauensvolle Zusammenarbeit ebenso gedankt wie den dort in der Dokumentation tätigen Kolleginnen und Kollegen. Unser Dank gilt auch den Eltern und (ehemaligen) Patienten, die uns ihre Daten vertrauensvoll zur Verfügung stellen und uns viele Fragen beantworten.

Wir bedanken uns für die langdauernde Finanzierung des Deutschen Kinderkrebsregisters bei den Gesundheitsministerien der Länder und dem Bundesgesundheitsministerium: jeweils ein Drittel wird vom rheinland-pfälzischen Ministerium für Soziales, Arbeit, Gesundheit und Demografie und vom Bundesgesundheitsministerium getragen; das übrige Drittel teilen sich die 16 Länder anteilig auf.

Peter Kaatsch

Mainz, im November 2014

Childhood Cancer Registry and the state registries.

A major aspect of the work of the German Childhood Cancer registry is the close cooperation with the hospitals, the therapy studies and the diagnostic registries of the GPOH (Society for pediatric hematology and Oncology). We would like to take this opportunity to thank the clinicians, study leaders, and especially the colleagues working in documentation for their cooperation regarding data and information.

We are also grateful for the continuing funding of the German Childhood Cancer Registry by the Ministries of Health of the states and the Federal Ministry of Health: one third each is funded by the Rhineland-Palatinate Ministry for Social Affairs, Labor, Health and Demography and the Federal Ministry of Health, the remaining third is split between the 16 states.

4 Ergebnis-Übersicht / Overview of Results

Meldungen von Fällen unter 15 Jahren im Jahr 2013 (Meldungen aus 65 Kliniken):	1718
Meldungen von Fällen unter 18 Jahren im Jahr 2013 (Meldungen aus 65 Kliniken):	2051
Durchschnittliche Meldungen von Fällen unter 15 Jahren pro Jahr:	1774
(ermittelt aus den Jahren 2004-2013)	
vor dem 15. Geburtstag erkrankt ...	eines von 420 Neugeborenen
Jungen / Mädchen	981 / 793
Meldungen von unter 5-Jährigen	788
Meldungen von 5- unter 10-Jährigen	469
Meldungen von 10- unter 15-Jährigen	517
lymphatische Leukämien (ALL)	460
Durchschnittliche Meldungen von Fällen im Alter von 15- unter 18 Jahren pro Jahr:	343
(ermittelt aus den Jahren 2009-2013)	
Zahl aller Meldungen unter 15 bzw. 18 Jahren von Beginn der Erfassung im Jahr 1980 bis 2013:	55412
in Langzeitnachsicht beobachtet	ca. 30000

Bevölkerung im Alter von unter 15 / unter 18 Jahren (Mio.):	
in 2013	10,6 / 13,1
im Durchschnitt (in den Jahren 2004-2013 / 2009-2013)	11,2 / 13,4

Prognose der Fälle im Alter von unter 15 Jahren:

- 81 % überleben derzeit eine Krebserkrankung mindestens 15 Jahre
- 89 % überleben derzeit eine lymphatische Leukämie (ALL) mindestens 15 Jahre
- Insgesamt etwa 400 Todesfälle pro Jahr

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

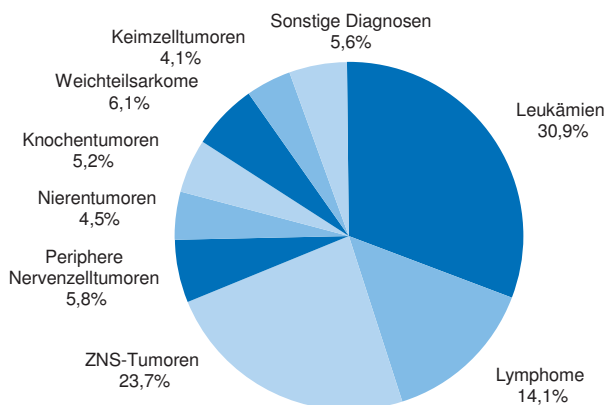
- 4,4 % der Patienten erkranken innerhalb von 25 Jahren nach Diagnose erneut an Krebs
- Insgesamt sind über 1000 Patienten mit Zweitumoren registriert

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

(ermittelt aus den Jahren 2004-2013)

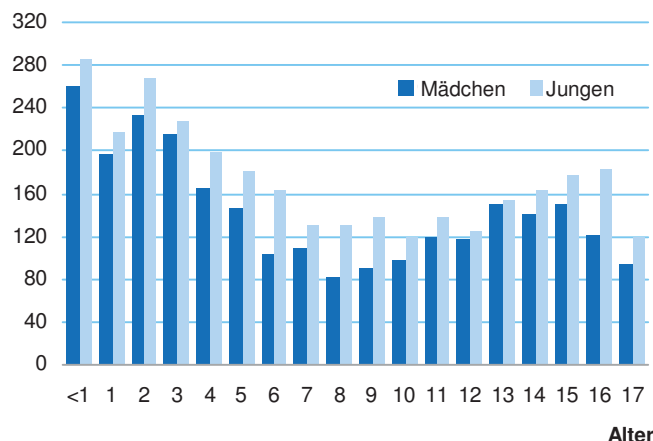
	Alle Erkrankungen	Leukämien		Alle Erkrankungen	Leukämien
Schleswig-Holstein	65	22	Bayern	280	99
Hamburg	35	12	Saarland	20	7
Niedersachsen	180	63	Berlin	66	23
Bremen	12	4	Brandenburg	43	16
Nordrhein-Westfalen	412	132	Mecklenburg-Vorpommern	29	9
Hessen	139	47	Sachsen	80	24
Rheinland-Pfalz	93	29	Sachsen-Anhalt	39	13
Baden-Württemberg	240	80	Thüringen	40	13

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



ZNS: Zentrales Nervensystem

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



*2009-2013, basierend auf insgesamt 10440 unter 18-jährigen Patienten

For the first time: 15 to 17 year old adolescents

In dem Jahresbericht 2013/14 werden erstmals Auswertungen zu 15- bis 17-Jährigen über einen 5-Jahreszeitraum präsentiert. Eine entsprechende Erweiterung um 3 Altersjahre war auf Grundlage einer von Bund und Ländern abgestimmten Konzeption im Jahr 2010 formal verabschiedet worden. Insgesamt liegen seit Beginn unserer Tätigkeit im Jahr 1980 Daten von 55.412 Neuerkrankungen vor (davon 53.698 bei unter 15-Jährigen und 1.714 bei 15- bis 17-Jährigen). Durchschnittlich werden pro Jahr 1.774 Neuerkrankungen bei unter 15-Jährigen und 343 Neuerkrankungen bei 15- bis 17-Jährigen erfasst.

In the annual report 2013/14 we are presenting analyses for cases aged 15-17 for the first time. The relevant extension by 3 years of age was formally decided upon by the states and the federation in 2010. All in all we have registered 55,412 cases since the start of registration in 1980 (53,698 aged under 15, 1,714 aged 15-17). On average we observe 1,774 new cases in children under 15 and 343 new cases in adolescents at ages 15-17 per year.

I Leukaemias, myeloproliferative and myelodysplastic diseases

Diese hämatologischen Erkrankungen sind die häufigsten bösartigen Erkrankungen im Kindes- und Jugendalter. Betroffen ist bis unter 15 eines von 1200 Kindern, Jungen etwa 20% öfter als Mädchen. Etwa die Hälfte der Erkrankungen tritt bereits vor dem Schulalter auf. Bei Kindern und Jugendlichen überwiegen die akuten Formen, bei Erwachsenen chronische Formen. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100% Vollständigkeit 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 (89% Langzeitüberlebende, mindestens 15 Jahre) und steigt weiter.

Akute myeloische Leukämien (AML) sind deutlich seltener und haben eine schlechtere Prognose (71% 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 19% der zweiten und weiteren Krebserkrankungen (subsequent neoplasms (SN)) innerhalb von 25 Jahren nach Diagnose im Kindesalter. 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 under 15 years is affected, boys ca. 20% more often than girls. About half of the cases are 5 years and below. Children and adolescents show mostly acute forms, whereas adults show mostly chronic forms. 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 (89% long term survivors for more than 15 years) and increases further.

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

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 across registries are problematic.

19% of the second and subsequent neoplasms (SN) within 25 years of diagnosis 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 unter 15) 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 von NHL mehr als doppelt so oft betroffen. Wir gehen von nahezu

Lymphomas (one child in 4000 under 15) 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 by NHL more than twice as often as girls. We assume com

6 Ergebnis-Übersicht / Overview of Results

100% Vollständigkeit der Erfassung aus. Unspezifizierte Lymphome werden fast nie gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen. Die Prognose ist gut (89% 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 Hodgkin Lymphom ist die Prognose bereits seit vielen Jahrzehnten gut (derzeit 97% Langzeitüberlebende), daher sind bei dieser Erkrankung die Spätfolgen der Therapie besonders erforscht. Hodgkin Lymphom-Patienten sind überdurchschnittlich oft von weiteren Krebserkrankungen betroffen (8% entwickeln in den ersten 25 Jahren eine SN).

Completeness is close to 100%. Unspecified lymphomas are rarely reported, this shows the high quality of diagnosis and reports. The prognosis of NHL is good (89% 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 lymphoma have shown a good prognosis for decades (current long-term survival is 97%), so for this entity late effects are particularly well known. Patients with Hodgkin lymphoma are especially frequently affected by subsequent neoplasms (almost 8% SN within the first 25 years).

III CNS and miscellaneous intracranial and intraspinal neoplasms

Bei diesen Tumoren des zentralen Nervensystems (ZNS, Hirntumore), eines von 1700 Kindern unter 15 ist betroffen, handelt es sich um eine heterogene Gruppe von Krebserkrankungen mit bösartigen (malignen) und nichtmalignen Formen. Internationale Vergleiche deuten auf eine geringe Untererfassung der nichtmalignen Formen hin. Der beobachtete Anstieg der Erkrankungszahlen zeigt die stetig verbesserte Vollständigkeit der Erfassung. Jungen sind etwa 20% häufiger betroffen als Mädchen. Die durchschnittliche Langzeitprognose liegt bei 71%. Die scheinbar schlechter werdende Prognose bei den „sonstigen Gliomen“ ist auf erhebliche Änderungen in der Zusammensetzung dieser Gruppe zurückzuführen, was durch die zunehmende Vollständigkeit und Veränderungen in der Klassifikation bedingt ist. ZNS-Tumoren, besonders Astrozytome, stellen 22% aller weiteren Krebserkrankungen (SN) in den ersten 25 Jahren nach einer Diagnose im Kindesalter.

Tumours of the central nervous system (CNS, brain tumours) affect one child in 1700 under 15. They are a heterogeneous group of neoplasms, including malignant and non-malignant forms. Based on international comparisons we assume especially the non-malignant forms to be slightly underreported. The observed increase in cases shows improvements in completeness of registration. Boys have an about 20% higher incidence. Average long term survival is 71%. 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 in the first 25 years after a diagnosis in childhood).

IV Neuroblastoma and other peripheral nervous cell tumours

Neuroblastome gehören zu den embryonalen Tumoren, die vor allem bei Kleinkindern auftreten. Betroffen ist eines von 5600 Kindern unter 15, Jungen erkranken etwa 20% häufiger als Mädchen. Wir gehen von nahezu 100% Vollständigkeit der Erfassung aus. Insgesamt überleben etwa 76% der Fälle, jedoch haben Patienten mit fortgeschrittener Erkrankung (Stadium 4) 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 5600 under 15, boys have an about 20% higher incidence than girls. We assume completeness is close to 100%. Overall survival is 76%, but patients with advanced disease (stage 4) still have a rather bad prognosis, although it has improved considerably since the 1980ies.

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

V Retinoblastoma

Retinoblastome, unter 19.000 Kindern unter 15 tritt ein Fall auf, gehören zu den embryonalen Tumoren von denen ältere Kinder (ab ca. 10 Jahren) kaum betroffen sind. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus. Jungen sind etwa 10% 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 under 15 is affected with a Retinoblastoma. These are embryonal tumours which rarely affect older children (10 years or older). Based on international comparisons we assume completeness is high. Boys have an about 10% 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 im Kindesalter sind Nephroblastome (Wilmstumor). Ein Kind von 7700 bis 14 Jahre ist betroffen, Mädchen etwa 10% häufiger. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100% Vollzähligkeit der Erfassung aus. Die Prognose ist relativ gut (92% Langzeitüberlebende).

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

Almost all renal tumours in childhood are nephroblastomas (Wilm's tumour). One child under 15 in 7700 is affected, girls about 10% 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 diagnoses and reports.

VII Hepatic tumours

Fast alle Lebertumoren im Kindesalter (ein Fall unter 34.000 Kindern bis 14 Jahre) sind Hepatoblastome. Jungen sind 50% 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 keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Almost all hepatic tumours in childhood (one in 34,000 children until 14 years is affected) are hepatoblastomas. Boys have a 50% higher incidence. We assume completeness is high. The prognosis is moderate (76% long-term survivors) and has been improving considerably since the 1980ies.

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

VIII Malignant bone tumours

Knochensarkome (ein Kind von 10.000 unter 15) sind typisch für ältere Kinder und Jugendliche. Die besonders häufigen Typen sind Osteosarkome und Ewing-Sarkome. 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 im Kindesalter gemeldet. Die Prognose ist unterdurchschnittlich (70% 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 under 15) are typical for older children and adolescents. The most frequent forms are osteosarcoma and Ewing sarcomas. Based on international comparisons we assume completeness is high. Especially osteosarcomas are frequently reported as a second neoplasm (SN). The prognosis is below average (70% long-term survivors) and has been improving only slightly since the 1980ies. Unspecified bone tumours are rarely reported, this shows the high quality of diagnoses and reports.

8 Ergebnis-Übersicht / Overview of Results

IX Soft tissue and other extraosseous sarcomas

Weichteilsarkome können in allen Altersklassen auftreten, betroffen ist ein Kind bis 14 Jahre von 7100. Das häufigste Weichteilsarkom im Kindesalter ist das Rhabdomyosarkom. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollständigkeit der Erfassung aus. Jungen sind etwa 20% häufiger betroffen als Mädchen. Die Prognose ist etwas unterdurchschnittlich (69% Langzeitüberlebende) und hat sich seit den 1980ern nur leicht verbessert.

Soft tissue sarcomas occur in all ages in childhood (one child under 15 in 7100). The most frequent type in childhood is rhabdomyosarcoma. Based on international comparisons we assume completeness is high. Boys have a 20% higher incidence than girls. The prognosis is below average (69% 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 (bis unter 15 ein Kind von 13.000). Einige treten häufiger mit beginnender Pubertät auf, andere sind typisch für das Kleinkindalter, so dass sie vom 4.-7. Lebensjahr eher selten sind. Wir gehen von hoher Vollständigkeit der Erfassung aus. Mädchen sind bis 14 Jahre etwa 30% häufiger betroffen. Bei den intrakraniellen Formen (im Gehirn lokalisiert) hat es seit etwa 2000 (neue 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 der intraspinalen und intrakraniellen Keimzelltumoren verantwortlich. Insgesamt ist die Langzeitprognose gut (94%).

Germ cell tumours are a heterogeneous group of neoplasms, one child under 15 in 13,000 is affected. Some become more frequent as puberty sets in, others are typical for infants, so they are rare from the 4th to 7th year of life. We assume completeness is high. Girls under 15 have about 30% higher incidence. Some intracranial forms (localized in the brain) have been reclassified as brain tumours (CNS) since about 2000 (new diagnosis classification ICD-O-3), this causes the sudden seeming improvement of the prognosis of intraspinal and intracranial germ cell tumours. In general the prognosis is good (94% long-term survivors).

XI Other malignant epithelial neoplasms and malignant melanomas

Dies ist eine heterogene Gruppe von Neoplasien. Karzinome treten im Allgemeinen erst im Erwachsenenalter auf. Die häufigsten dieser seltenen Erkrankungen im Kindesalter sind Karzinome der Nebennierenrinde, der Schilddrüse, des Nasopharynx (Nasen-Rachenraum) und das maligne Melanom („schwarzer“ Hautkrebs). Einige Karzinome bei Kindern sind deutlich untererfasst, jedoch nicht die Nasopharynx-Karzinome und Schilddrüsenkarzinome. Bei den malignen Melanomen konnte die Erfassung im Laufe der Jahre verbessert werden. Schilddrüsenkarzinome treten häufig als Folgetumoren auf, daneben auch maligne Melanome und andere Hautkarzinome. Schon bei den unter 15-Jährigen sind gut 10% aller gemeldeten Schilddrüsentumore Zweitmalignome. Schilddrüsenkarzinome haben eine gute Prognose (92% Langzeitüberlebende).

This is a heterogeneous group of rare cancers. Carcinomas are usually observed in adults. The most frequent among them in childhood are adrenocortical carcinoma, thyroid carcinoma, nasopharyngeal carcinoma, and malignant melanoma. Some carcinomas in children are clearly underreported, though not nasopharyngeal carcinomas and thyroid carcinomas. The reporting of malignant melanoma has improved over the years. Thyroid carcinomas are frequent as subsequent neoplasms; this is also true for malignant melanoma and other skin carcinomas. Among the thyroid cancer cases under 15, more than 10% are second cancers. Thyroid carcinomas have a good prognosis (92% long-term survivors).

XII Other and unspecified neoplasms

Dies ist eine heterogene Gruppe von sonst nicht zuzuordnenden, bei Kindern sehr seltenen bösartigen Krebserkrankungen (ein Fall pro 300.000 Kinder unter 15). Der häufigste Einzeltumor hiervon ist das Lungenblastom.

This is a heterogeneous group of very rare neoplasms in childhood not classifiable anywhere else (one child under 15 in 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 /
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Cases in Germany aged under 15 years (1980-2013): 53698

Selected characteristics Germany 2004-2013

Relative frequency:	17737 / 17737 = 100 %
Relative frequency of trial patients:	93.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	7925	9812	17737
Standardized rate *:	152.6	178.7	166.0
Cumulative incidence:	2206	2592	2404
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases :	1852	6030	4691	5164
Incidence rate:	272.3	215.2	125.7	128.5

Median age at diagnosis: 5 years 10 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
4179	100.0 %	35.0	507

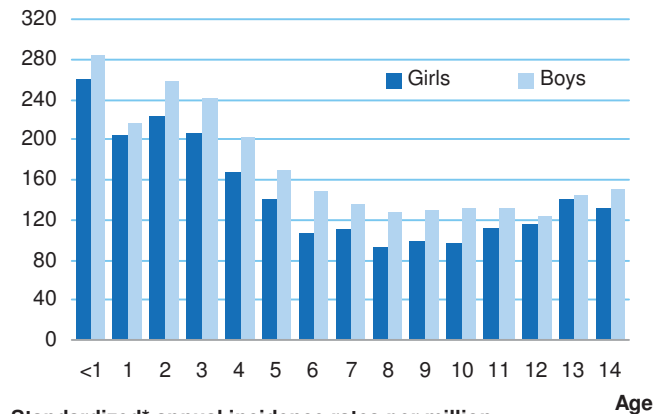
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

All malignancies (ICCC-3)

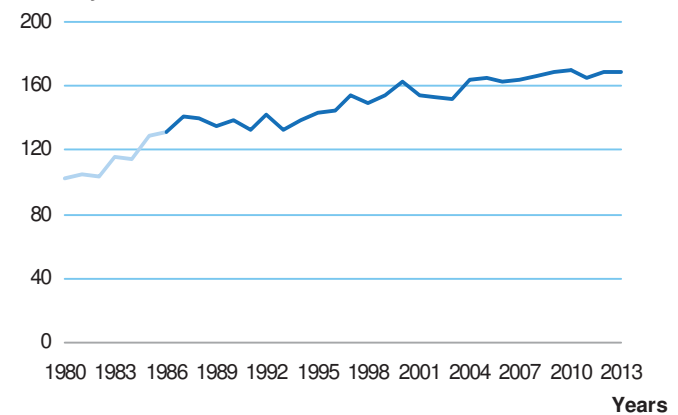
SN after all malignancies		
	% of all	Cumulative
N	1061 SN	incidence
1061	100.0 %	4.4 %

* Standard: Segi world standard population

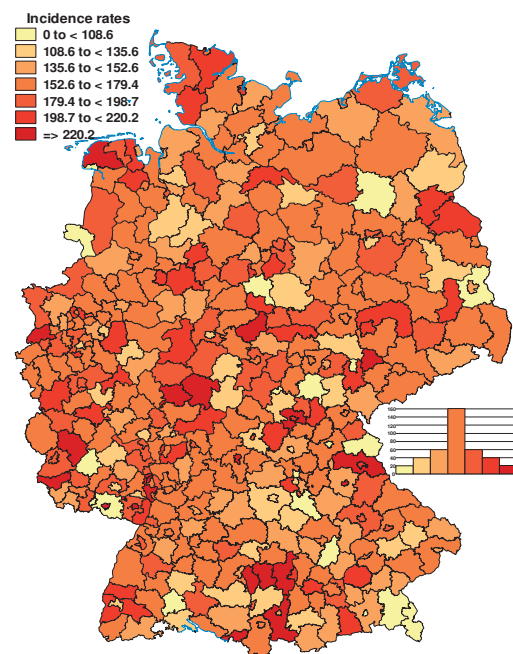
Age- and sex-specific incidence rates per million Germany 2004-2013



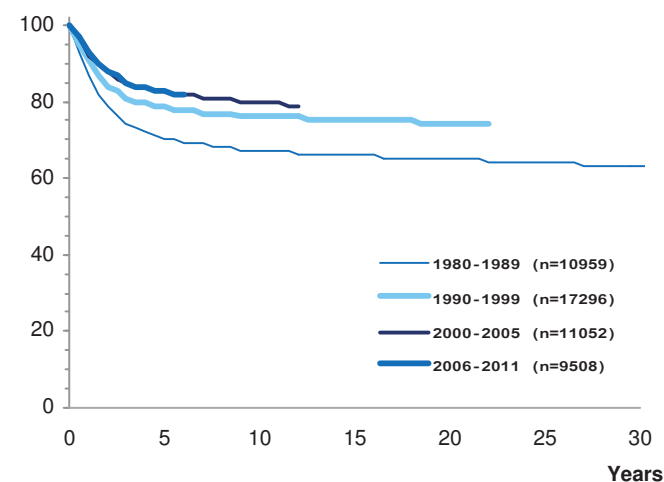
Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



14 | Leukaemias, myeloproliferative and myelodysplastic diseases

(a) Lymphoid leukaemias

(b) Acute myeloid leukaemias

(c) Chronic myeloproliferative diseases

(d) Myelodysplastic syndrome and other myeloproliferative disease

(e) Unspecified and other specified leukaemias

Cases in Germany aged under 15 years (1980-2013): 18362

Selected characteristics Germany 2004-2013

Relative frequency: 5923 / 17737 = 33.4 %

Relative frequency of trial patients: 99.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	2662	3261	5923
Standardized rate *:	52.6	60.6	56.7
Cumulative incidence:	747	867	809
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	294	2688	1648	1293
Incidence rate:	43.2	95.9	44.2	32.2

Median age at diagnosis: 4 years 11 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
1368	32.7 %	11.4	166

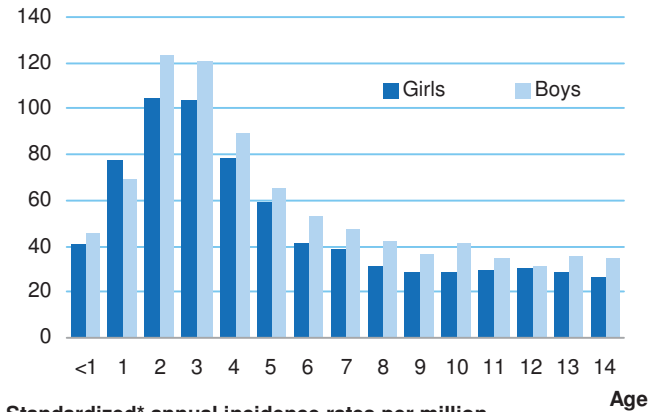
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

I Leukaemias, myeloproliferative and myelodysplastic diseases

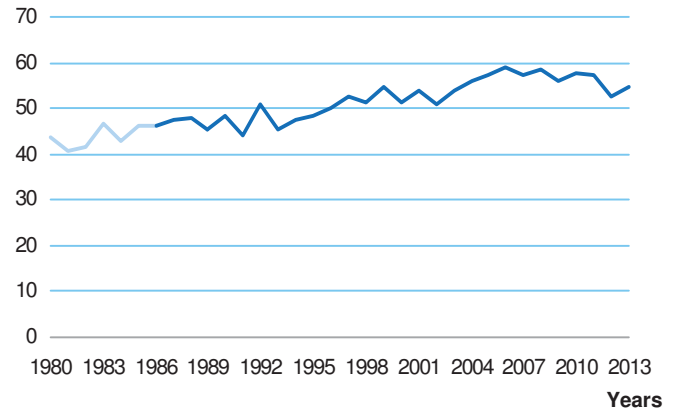
SN after I			I as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
379	35.7 %	4.3 %	258	24.3 %	0.6 %

* Standard: Segi world standard population

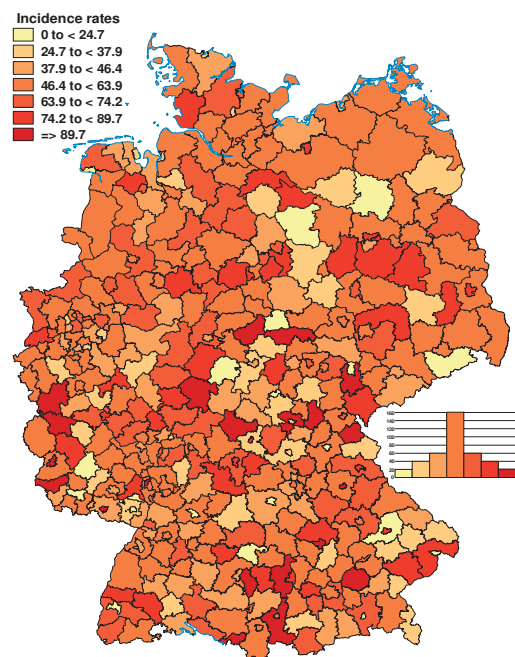
Age- and sex-specific incidence rates per million Germany 2004-2013



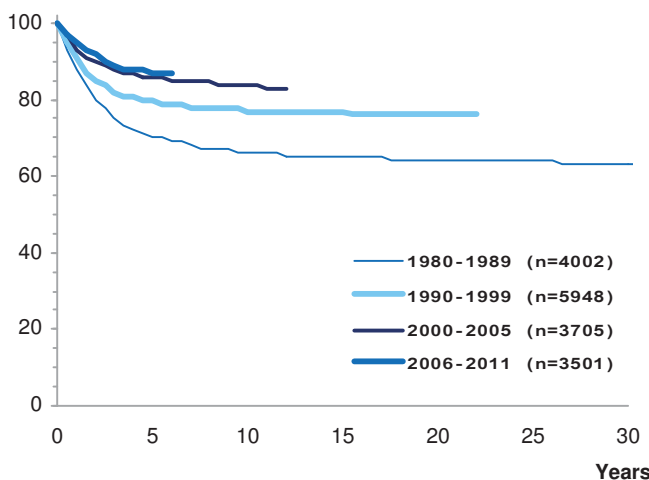
Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



Cases in Germany aged under 15 years (1980-2013): 14600**Selected characteristics Germany 2004-2013**

Relative frequency:	4596 / 17737 = 26.5 %
Relative frequency of trial patients:	99.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	2048	2548	4596
Standardized rate *:	40.9	47.5	44.3
Cumulative incidence:	577	678	629
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	117	2275	1332	872
Incidence rate:	17.2	81.2	35.7	21.7
Median age at diagnosis:	4 years 9 months			

Survival probabilities:	5-year	10-year	15-year
	92 %	90 %	89 %

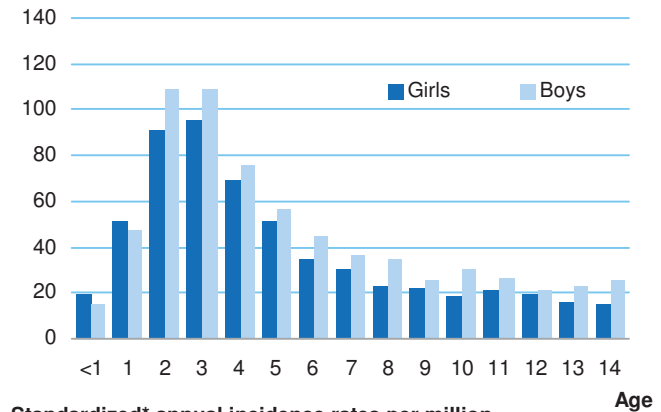
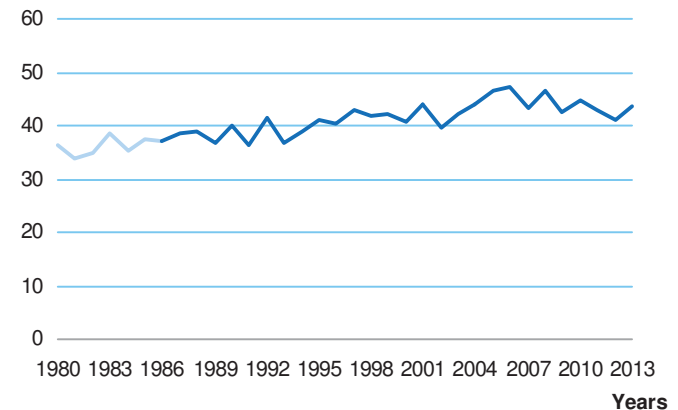
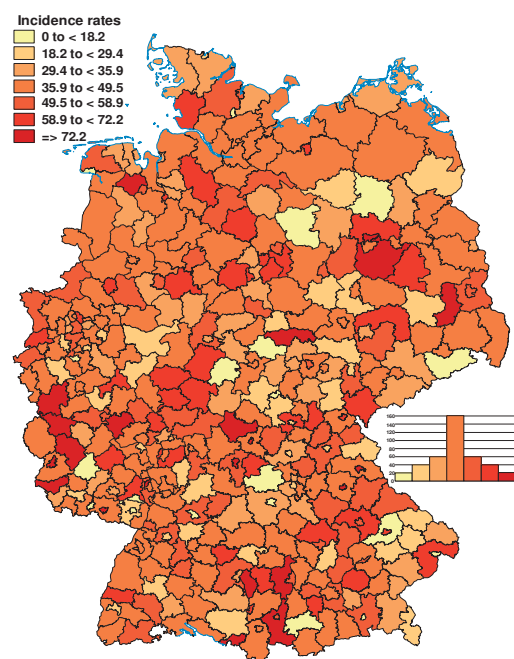
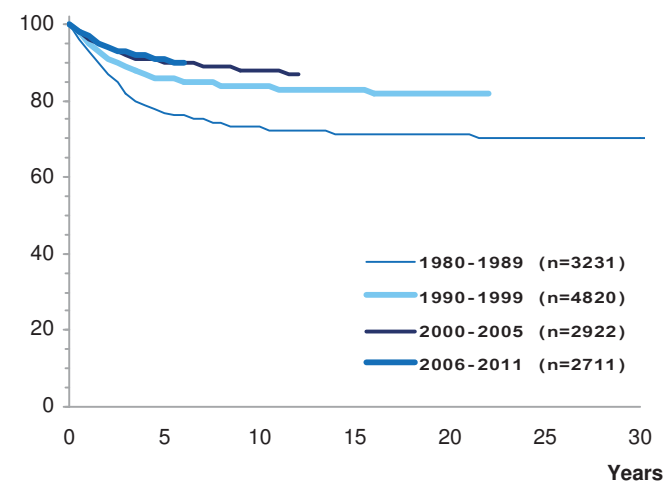
Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
835	20.0 %	6.9	101

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):**I (a) Lymphoid leukaemias**

SN after I (a)			I (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
320	30.2 %	4.4 %	50	4.7 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013**Standardized* annual incidence rates per million Germany 1980-2013****Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013****Survival probabilities by year of diagnosis Germany 1980-2011**

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

Germany 2004-2013	N	%
Lymphoid leukaemias	4596	100.0
Precursor cell leukaemias	4486	97.6
Mature B-cell leukaemias	108	2.3
Mature T-cell and NK cell leukaemias	2	0.0
Lymphoid leukaemia, NOS	0	0.0

1 Precursor cell leukaemias

Cases in Germany aged under 15 years (1980-2013): 14251

Selected characteristics Germany 2004-2013

Relative frequency:	4486 / 17737 = 25.3 %			
Relative frequency of trial patients:	99.8 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	2025	2461	4486	
Standardized rate *:	40.4	46.0	43.3	
Cumulative incidence:	571	656	614	
Sex ratio (m/f):	1.2			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	114	2247	1283	842
Incidence rate:	16.8	80.2	34.4	21.0
Median age at diagnosis:	4 years 8 months			
* Standard: Segi world standard population				

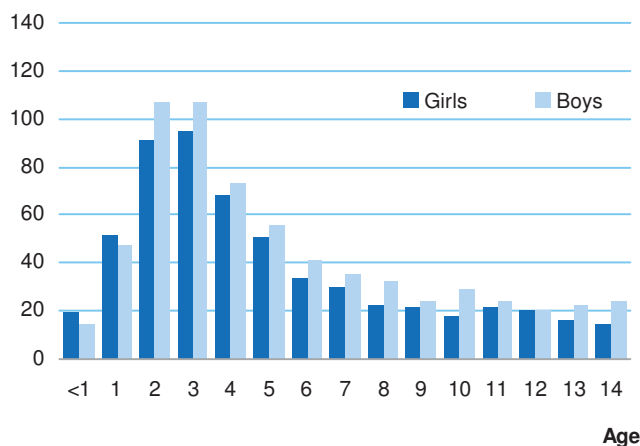
2 Mature B-cell leukaemias

Cases in Germany aged under 15 years (1980-2013): 347

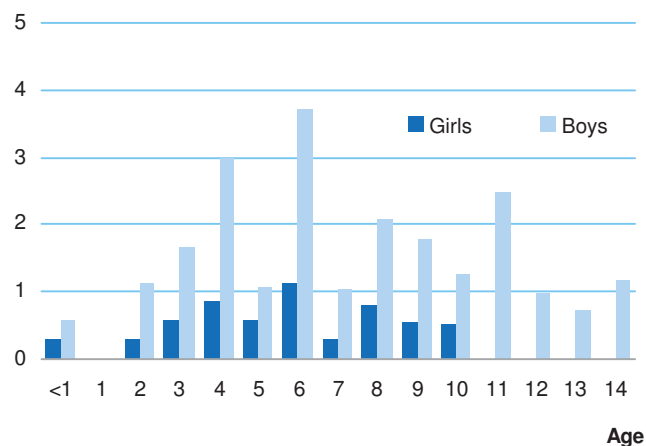
Selected characteristics Germany 2004-2013

Relative frequency:	108 / 17737 = 0.6 %			
Relative frequency of trial patients:	99.1 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	21	87	108	
Standardized rate *:	0.4	1.5	1.0	
Cumulative incidence:	6	23	14	
Sex ratio (m/f):	4.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	3	27	49	29
Incidence rate:	0.4	1.0	1.3	0.7
Median age at diagnosis:	7 years 1 month			
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 2589**Selected characteristics Germany 2004-2013**

Relative frequency:	768 / 17737 = 4.4 %
Relative frequency of trial patients:	97.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	376	392	768
Standardized rate *:	7.4	7.3	7.3
Cumulative incidence:	105	104	105
Sex ratio (m/f):	1.0		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	116	276	155	221
Incidence rate:	17.1	9.9	4.2	5.5

Median age at diagnosis: 4 years 10 months

Survival probabilities:	5-year	10-year	15-year
	73 %	72 %	71 %

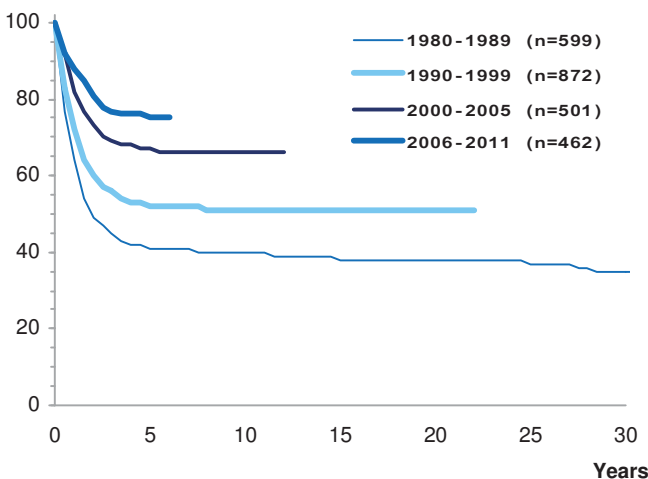
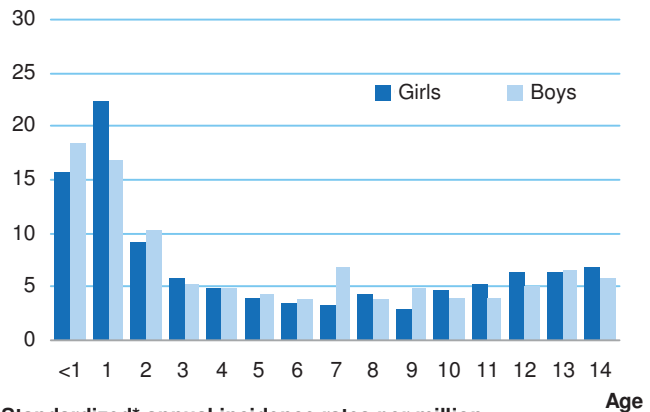
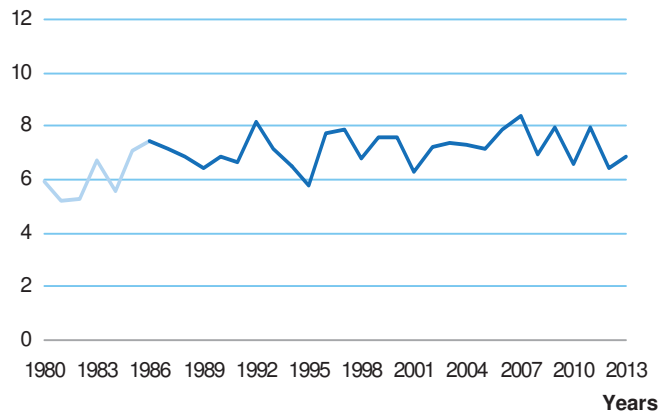
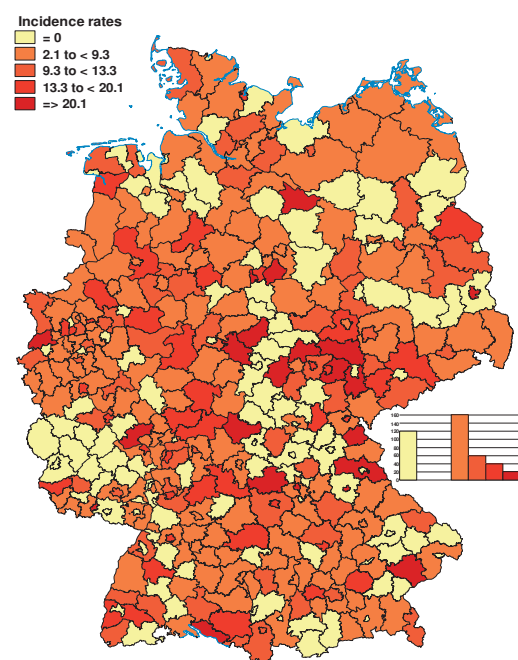
Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
414	9.9 %	3.4	50

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):**I (b) Acute myeloid leukaemias**

SN after I (b)			I (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
41	3.9 %	3.1 %	139	13.1 %	0.3 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1980-2011**Age- and sex-specific incidence rates per million Germany 2004-2013****Standardized* annual incidence rates per million Germany 1980-2013****Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013**

18 I (c) Chronic myeloproliferative diseases

Cases in Germany aged under 15 years (1980-2013): 251

Selected characteristics Germany 2004-2013

Relative frequency: 72 / 17737 = 0.4 %

Relative frequency of trial patients: 84.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	35	37	72
Standardized rate *:	0.6	0.6	0.6
Cumulative incidence:	9	9	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	24	38
Incidence rate:	0.1	0.3	0.6	0.9

Median age at diagnosis: 10 years 1 month

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
31	0.7 %	0.2	4

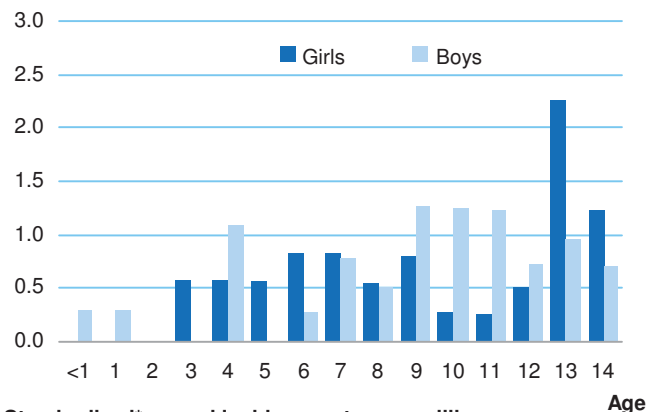
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

I (c) Chronic myeloproliferative diseases

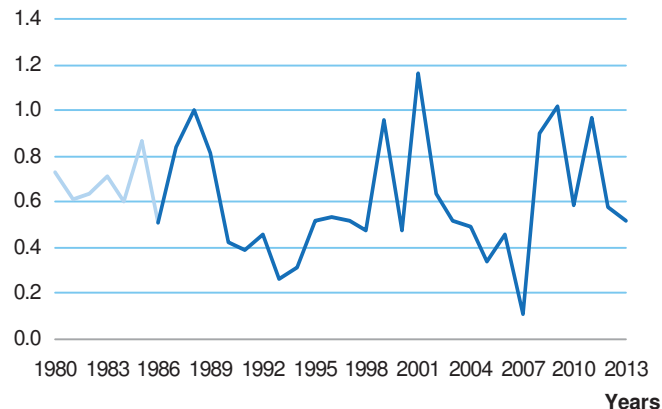
SN after I (c)			I (c) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
5	0.5 %	8.0 %	3	0.3 %	0.0 %

* Standard: Segi world standard population

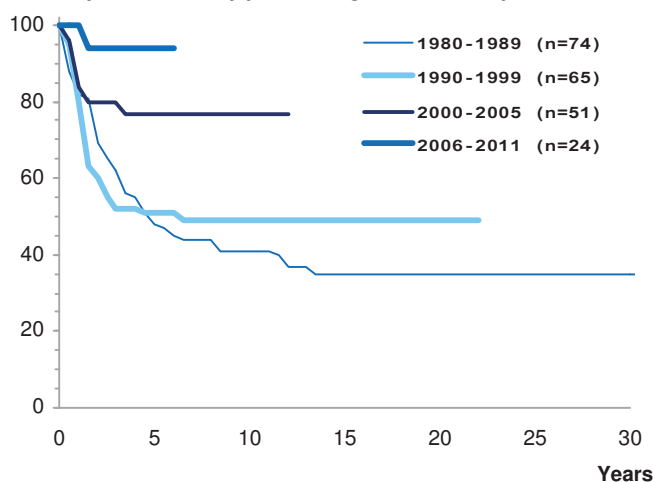
Age- and sex-specific incidence rates per million
Germany 2004-2013



Standardized* annual incidence rates per million
Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

Cases in Germany aged under 15 years (1980-2013): 746

Selected characteristics Germany 2004-2013

Relative frequency:	416 / 17737 = 2.4 %
Relative frequency of trial patients:	98.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	167	249	416
Standardized rate *:	3.1	4.5	3.8
Cumulative incidence:	46	66	56
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	45	111	118	142
Incidence rate:	6.6	4.0	3.2	3.5
Median age at diagnosis:	7 years 2 months			

Survival probabilities:	5-year	10-year	15-year
	79 %	77 %	75 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
68	1.6 %	0.6	8

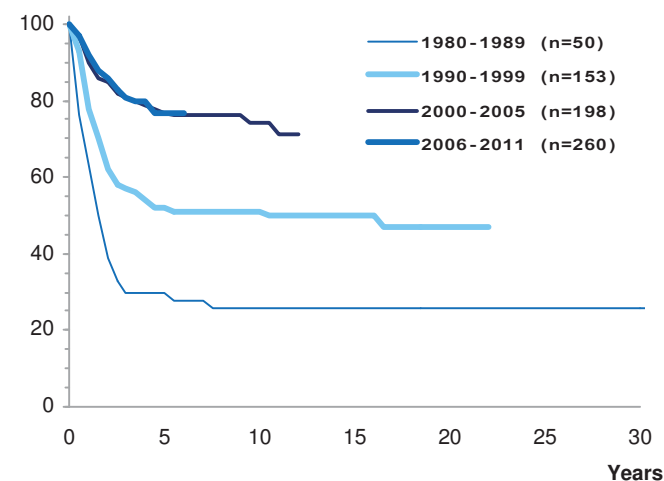
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

I (d) Myelodysplastic syndrome and other myeloproliferative diseases

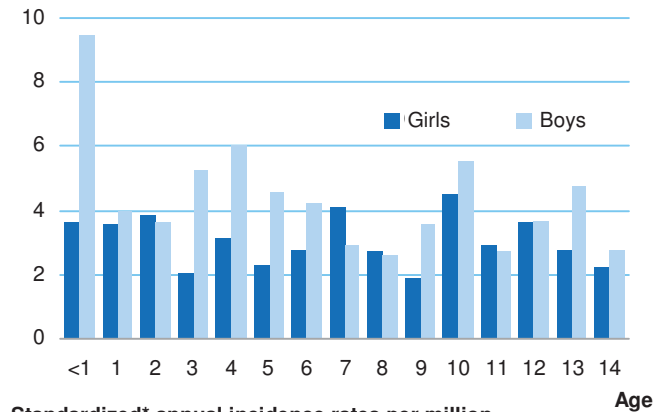
SN after I (d)			I (d) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
6	0.6 %	3.9 %	64	6.0 %	0.2 %

* Standard: Segi world standard population

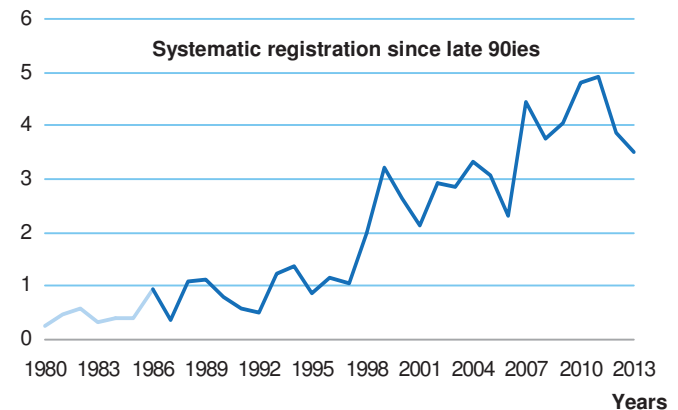
Survival probabilities by year of diagnosis Germany 1980-2011



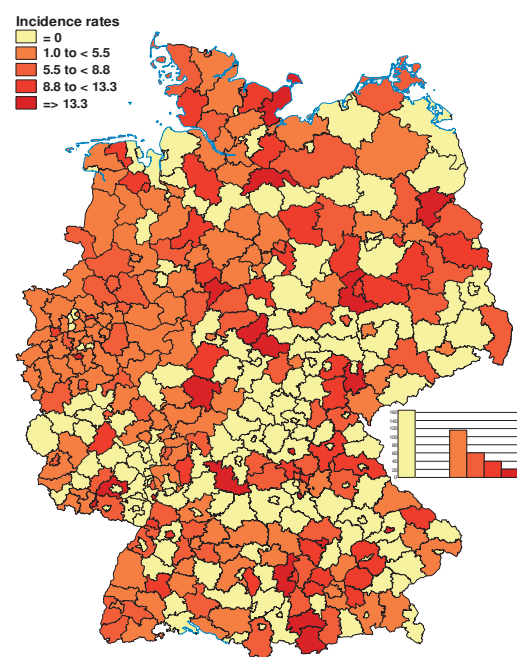
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



20 II Lymphomas and reticuloendothelial neoplasms

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

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

Cases in Germany aged under 15 years (1980-2013): 6310

Selected characteristics Germany 2004-2013

Relative frequency: 1939 / 17737 = 10.9 %

Relative frequency of trial patients: 96.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	633	1306	1939
Standardized rate *:	10.3	21.0	15.8
Cumulative incidence:	167	332	252
Sex ratio (m/f):	2.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	9	222	651	1057
Incidence rate:	1.3	7.9	17.4	26.3

Median age at diagnosis: 10 years 8 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
238	5.7 %	1.9	29

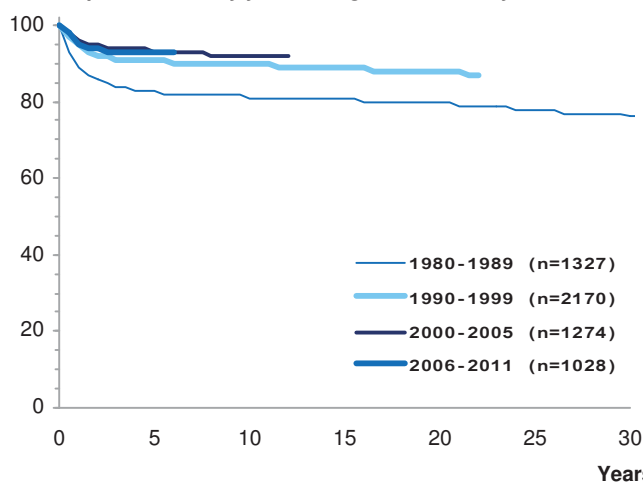
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

II Lymphomas and reticuloendothelial neoplasms

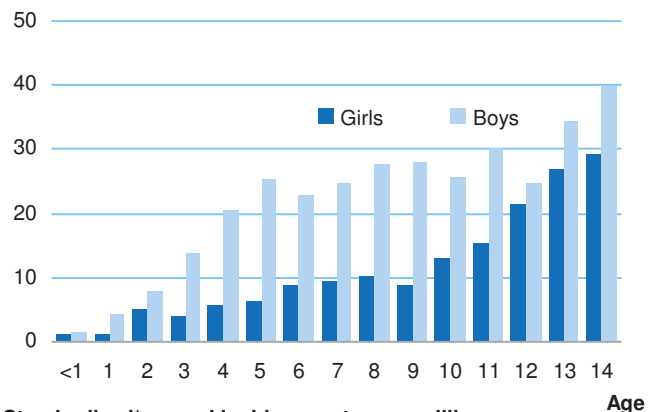
SN after II			II as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
172	16.2 %	6.1 %	90	8.5 %	0.3 %

* Standard: Segi world standard population

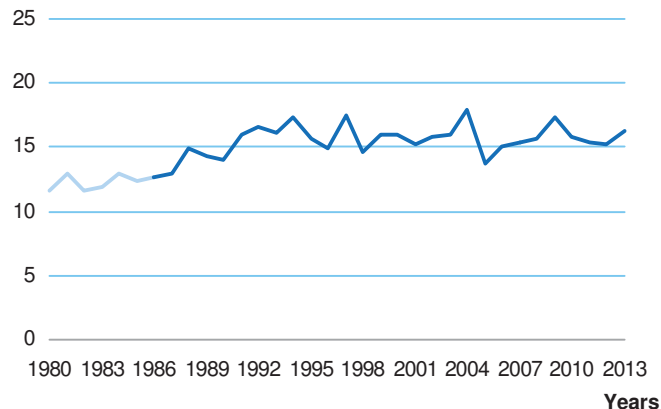
Survival probabilities by year of diagnosis Germany 1980-2011



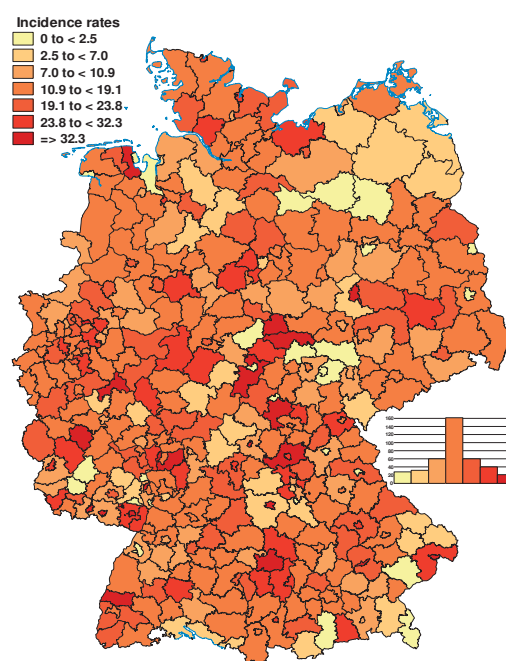
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 2597

Selected characteristics Germany 2004-2013

Relative frequency: 815 / 17737 = 4.7 %

Relative frequency of trial patients: 97.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	322	493	815
Standardized rate *:	4.9	7.5	6.3
Cumulative incidence:	83	123	104
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	34	188	593
Incidence rate:	0.0	1.2	5.0	14.8

Median age at diagnosis: 12 years 5 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
52	1.2 %	0.4	6

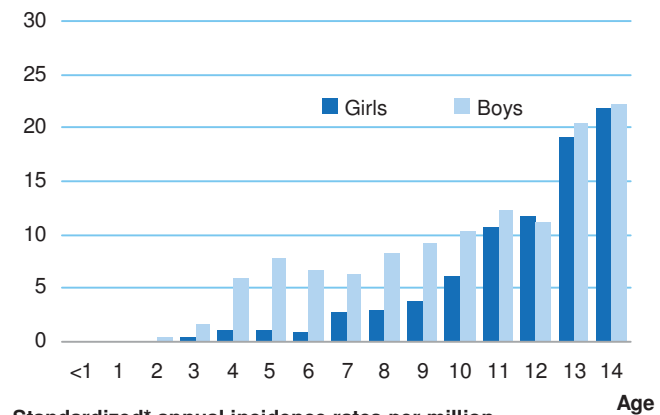
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

II (a) Hodgkin lymphomas

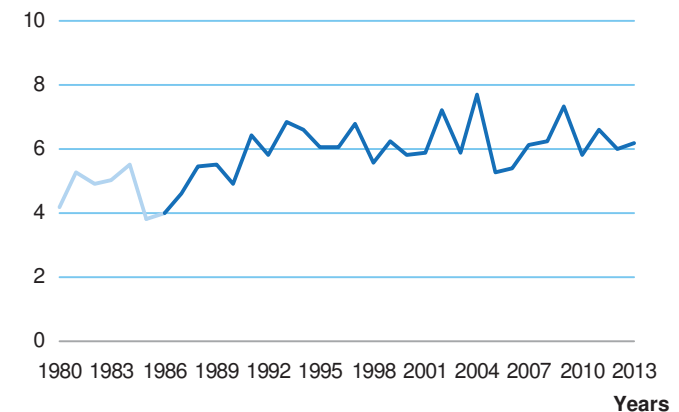
SN after II (a)			II (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
89	8.4 %	8.4 %	19	1.8 %	0.1 %

* Standard: Segi world standard population

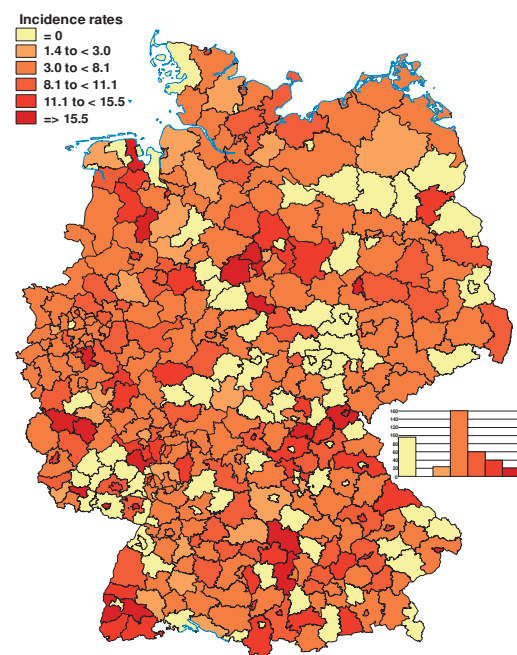
Age- and sex-specific incidence rates per million Germany 2004-2013



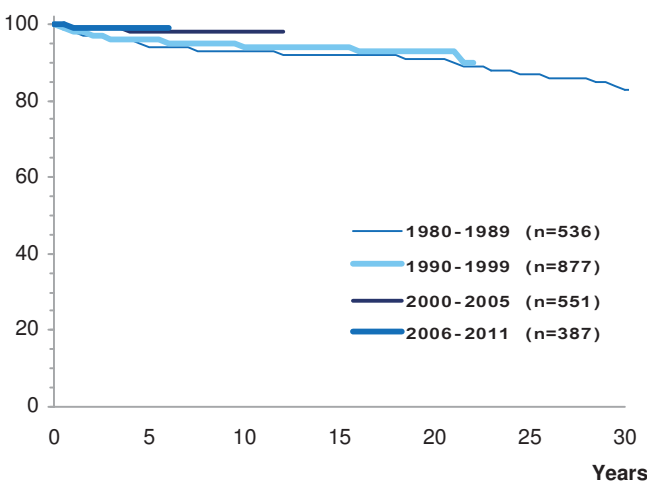
Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



22 II (b) Non-Hodgkin lymphomas

Cases in Germany aged under 15 years (1980-2013): 2474

Selected characteristics Germany 2004-2013

Relative frequency:	773 / 17737 = 4.5 %
Relative frequency of trial patients:	94.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	244	529	773
Standardized rate *:	4.2	8.7	6.5
Cumulative incidence:	66	135	101
Sex ratio (m/f):	2.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	6	124	294	349
Incidence rate:	0.9	4.4	7.9	8.7

Median age at diagnosis: 9 years 4 months

Survival probabilities:	5-year	10-year	15-year
	89 %	87 %	86 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
123	2.9 %	1.0	15

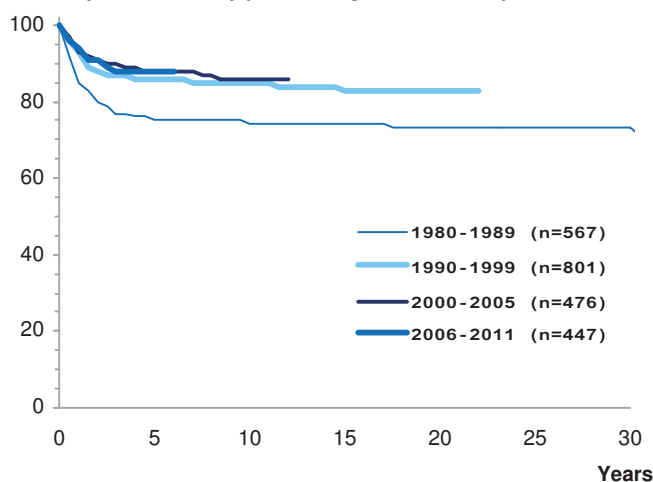
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

II (b) Non-Hodgkin lymphomas

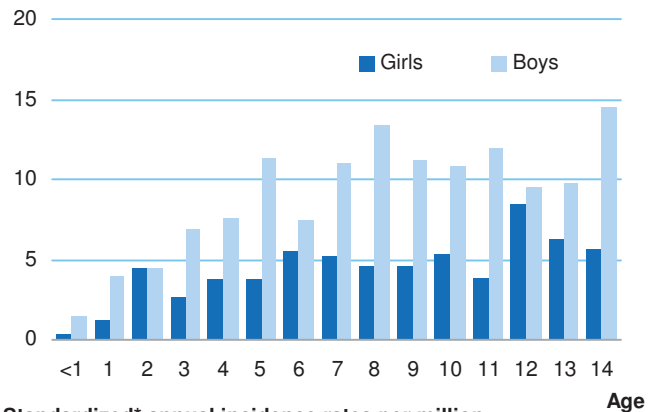
SN after II (b)			II (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
66	6.2 %	5.0 %	59	5.6 %	0.2 %

* Standard: Segi world standard population

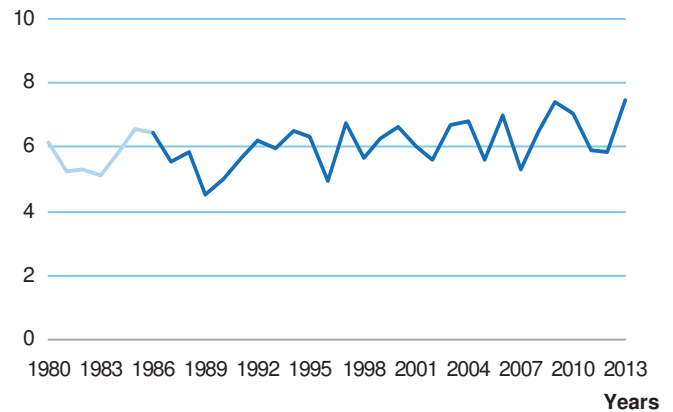
Survival probabilities by year of diagnosis Germany 1980-2011



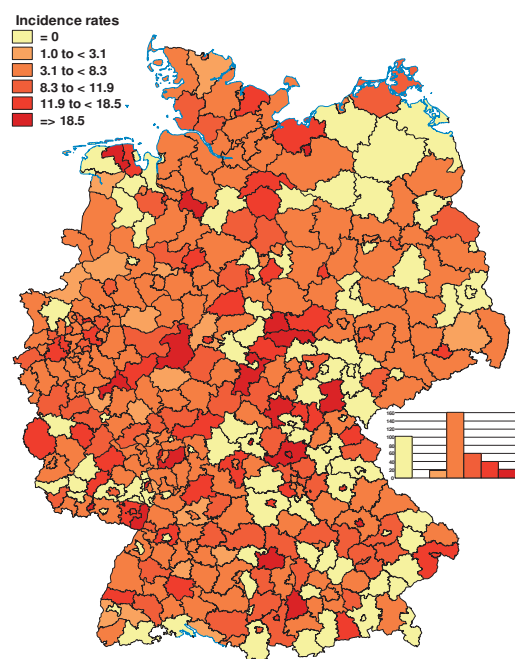
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Germany 2004-2013	N	%
Non-Hodgkin lymphomas	773	100.0
Precursor cell lymphomas	294	38.0
Mature B-cell lymphomas (except Burkitt lymphoma)	147	19.0
Mature T-cell and NK-cell lymphomas	161	20.8
Non-Hodgkin lymphomas, NOS	171	22.1

1 Precursor cell lymphomas

Cases in Germany aged under 15 years (1980-2013): 972

Selected characteristics Germany 2004-2013

Relative frequency:	294 / 17737 = 1.7 %
Relative frequency of trial patients:	93.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	90	204	294
Standardized rate *:	1.6	3.4	2.5
Cumulative incidence:	24	53	39
Sex ratio (m/f):	2.3		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	4	62	120	108
Incidence rate:	0.6	2.2	3.2	2.7
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 (1980-2013): 400

Selected characteristics Germany 2004-2013

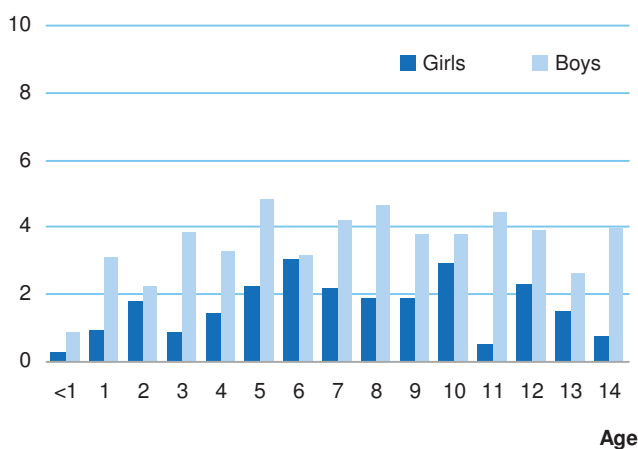
Relative frequency:	147 / 17737 = 0.8 %
Relative frequency of trial patients:	95.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	51	96	147
Standardized rate *:	0.9	1.5	1.2
Cumulative incidence:	14	24	19
Sex ratio (m/f):	1.9		

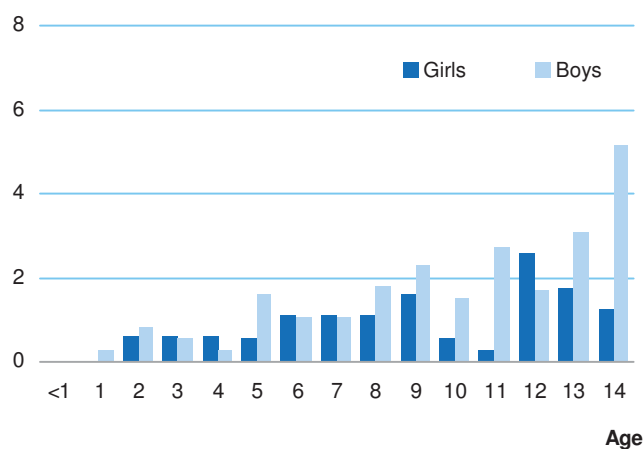
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	13	50	84
Incidence rate:	0.0	0.5	1.3	2.1
Median age at diagnosis:	11 years 3 months			

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013



Age- and sex-specific incidence rates per million Germany 2004-2013



24 II (b) Non-Hodgkin lymphomas - Extended ICC-3

Germany 2004-2013	N	%
Non-Hodgkin lymphomas	773	100.0
Precursor cell lymphomas	294	38.0
Mature B-cell lymphomas (except Burkitt lymphoma)	147	19.0
Mature T-cell and NK-cell lymphomas	161	20.8
Non-Hodgkin lymphomas, NOS	171	22.1

3 Mature T-cell and NK-cell lymphomas

Cases in Germany aged under 15 years (1980-2013): 450

Selected characteristics Germany 2004-2013

Relative frequency:	161 / 17737 = 0.9 %			
Relative frequency of trial patients:	96.9 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	60	101	161	
Standardized rate *:	1.0	1.6	1.3	
Cumulative incidence:	16	26	21	
Sex ratio (m/f):	1.7			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	24	51	85
Incidence rate:	0.1	0.9	1.4	2.1
Median age at diagnosis:	10 years 6 months			
* Standard: Segi world standard population				

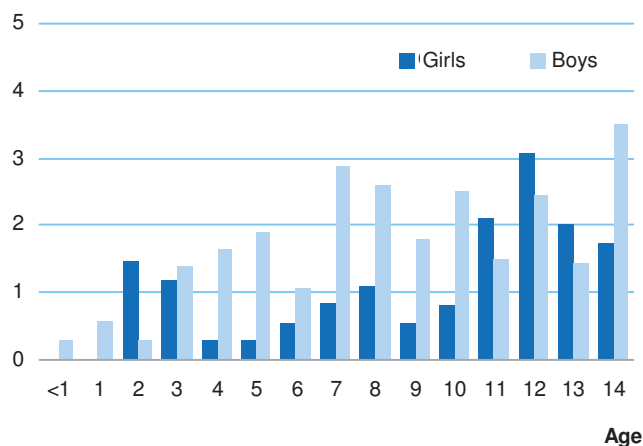
4 Non-Hodgkin lymphomas, NOS

Cases in Germany aged under 15 years (1980-2013): 652

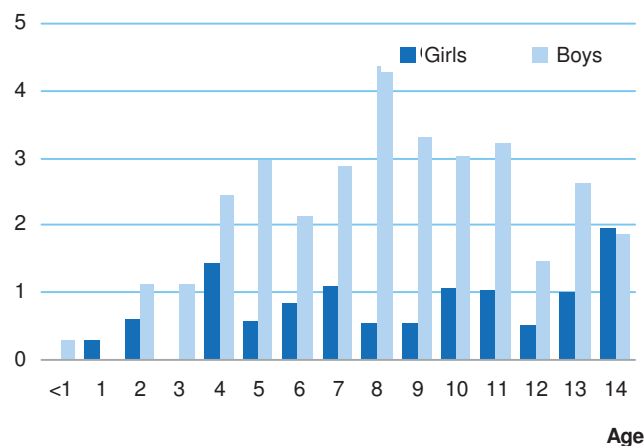
Selected characteristics Germany 2004-2013

Relative frequency:	171 / 17737 = 1.0 %			
Relative frequency of trial patients:	94.2 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	43	128	171	
Standardized rate *:	0.7	2.1	1.4	
Cumulative incidence:	12	33	22	
Sex ratio (m/f):	3.0			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	25	73	72
Incidence rate:	0.1	0.9	2.0	1.8
Median age at diagnosis:	9 years 2 months			
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 1114**Selected characteristics Germany 2004-2013**

Relative frequency:	339 / 17737 = 2 %
Relative frequency of trial patients:	98.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	59	280	339
Standardized rate *:	1.0	4.7	2.9
Cumulative incidence:	16	72	45
Sex ratio (m/f):			4.7

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	63	165	111
Incidence rate:	0.0	2.2	4.4	2.8
Median age at diagnosis:	8 years 2 months			

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

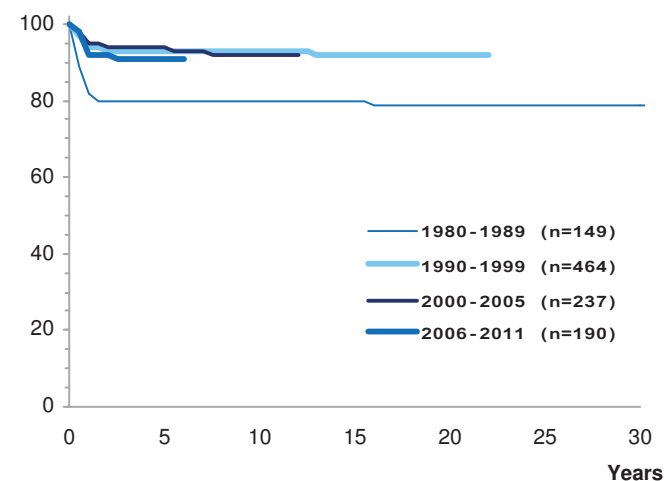
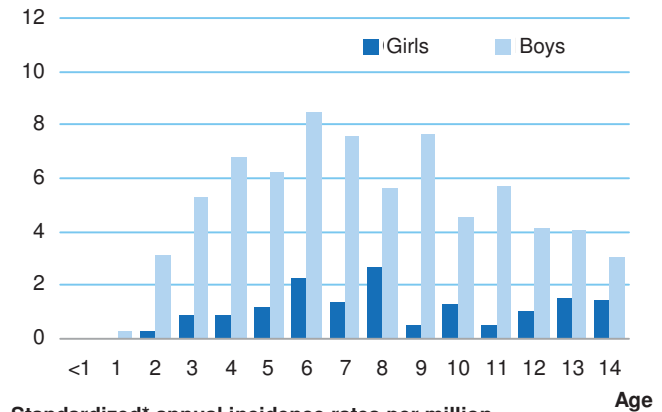
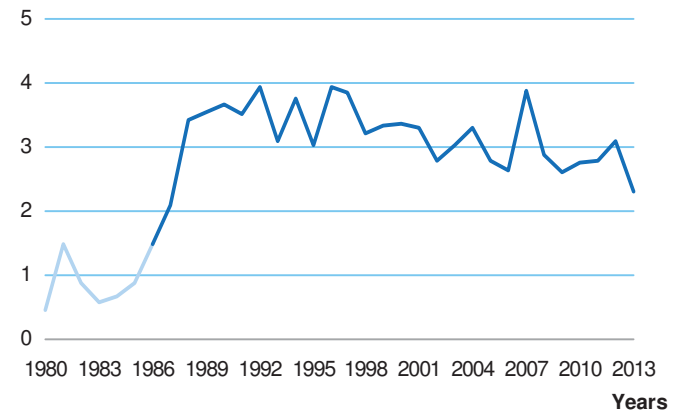
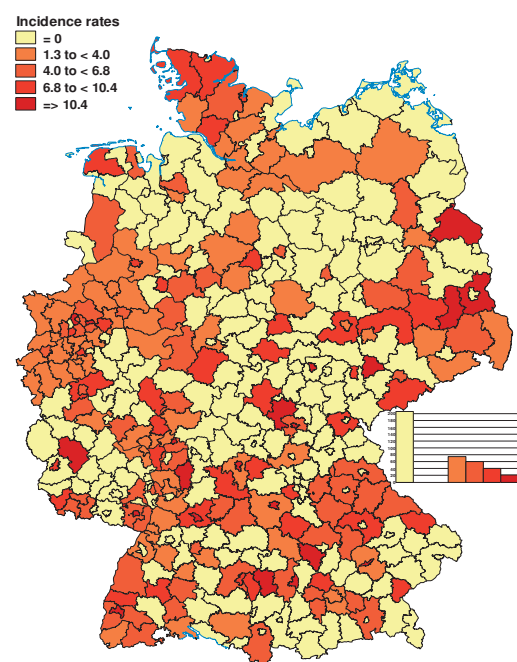
Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
42	1.0 %	0.3	5

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):**II (c) Burkitt lymphoma**

SN after II (c)			II (c) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
17	1.6 %	4.1 %	4	0.4 %	0.0 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1980-2011**Age- and sex-specific incidence rates per million Germany 2004-2013****Standardized* annual incidence rates per million Germany 1980-2013****Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013**

26 III CNS and miscellaneous intracranial and intraspinal neoplasms

(a) Ependymomas and choroid plexus tumour

(b) Astrocytomas

(c) Intracranial and intraspinal embryonal tumours

(d) Other gliomas

(e) Other specified intracranial and intraspinal neoplasms

(f) Unspecified intracranial and intraspinal neoplasms

Cases in Germany aged under 15 years (1980-2013): 11599

Selected characteristics Germany 2004-2013

Relative frequency: 4327 / 17737 = 24.4 %

Relative frequency of trial patients: 93.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	1928	2399	4327
Standardized rate *:	36.1	42.6	39.4
Cumulative incidence:	533	630	582
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	302	1272	1438	1315
Incidence rate:	44.4	45.4	38.5	32.7

Median age at diagnosis: 7 years 0 months

Survival probabilities:	5-year	10-year	15-year
	78 %	74 %	71 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
1164	27.9 %	9.7	141

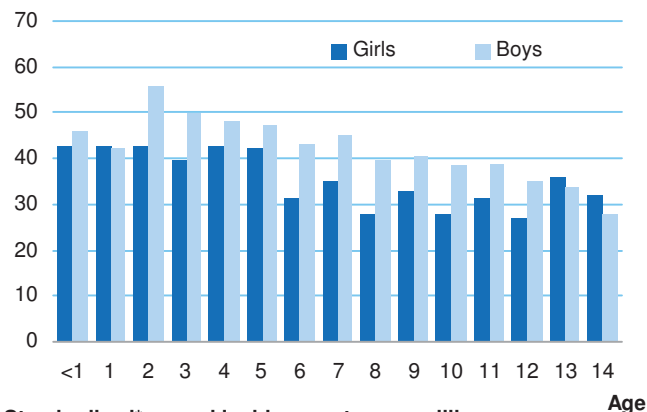
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

III CNS and miscellaneous intracranial and intraspinal neoplasms

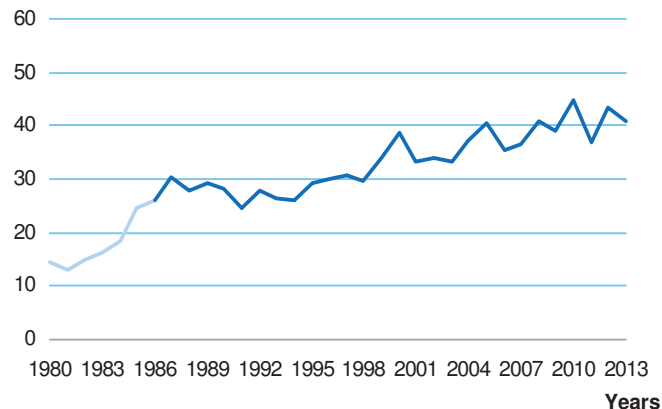
SN after III			III as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
199	18.8 %	4.9 %	236	22.2 %	1.0 %

* Standard: Segi world standard population

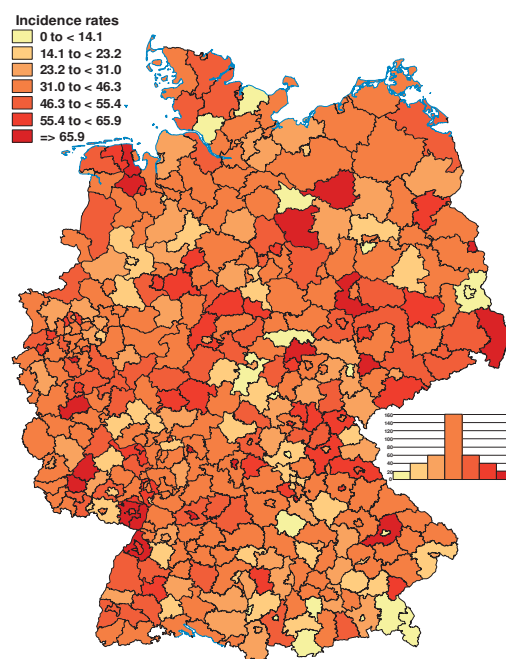
Age- and sex-specific incidence rates per million Germany 2004-2013



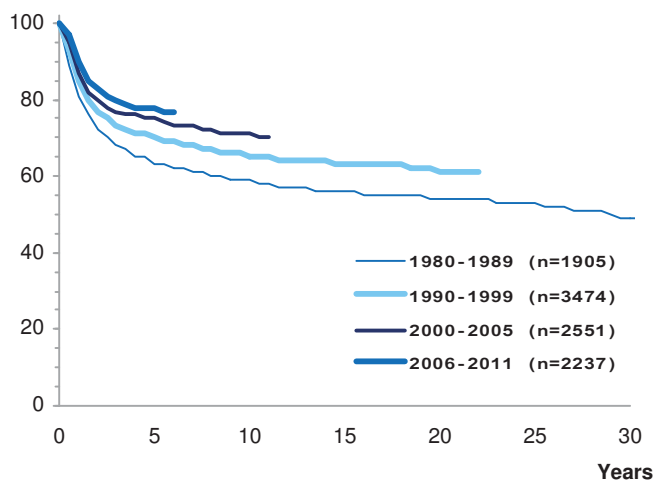
Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



Cases in Germany aged under 15 years (1980-2013): 1167

Selected characteristics Germany 2004-2013

Relative frequency:	435 / 17737 = 2.5 %
Relative frequency of trial patients:	94.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	186	249	435
Standardized rate *:	3.9	4.8	4.3
Cumulative incidence:	53	67	60
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	75	190	87	83
Incidence rate:	11.0	6.8	2.3	2.1
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 (1989-1998):

Number of deaths	Standardized*	Cumulative
N % of all 4179 deaths	mortality rate	mortality
145 3.5 %	1.3	18

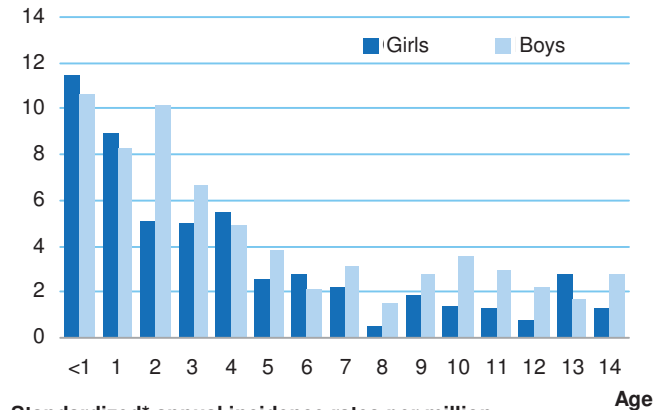
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

III (a) Ependymomas and choroid plexus tumour

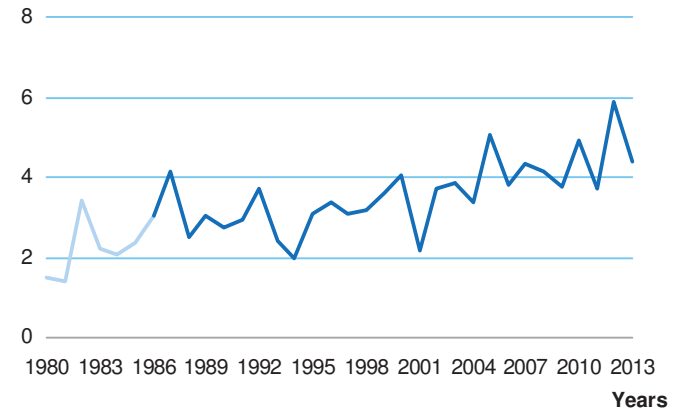
SN after III (a)			III (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
22	2.1 %	3.6 %	9	0.8 %	0.0 %

* Standard: Segi world standard population

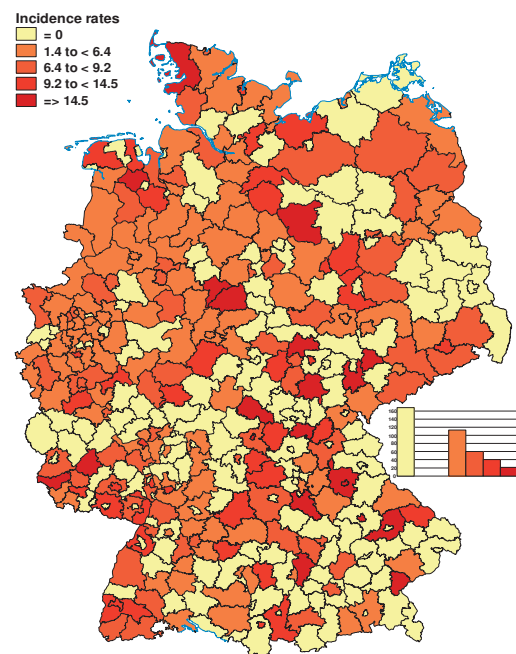
Age- and sex-specific incidence rates per million Germany 2004-2013



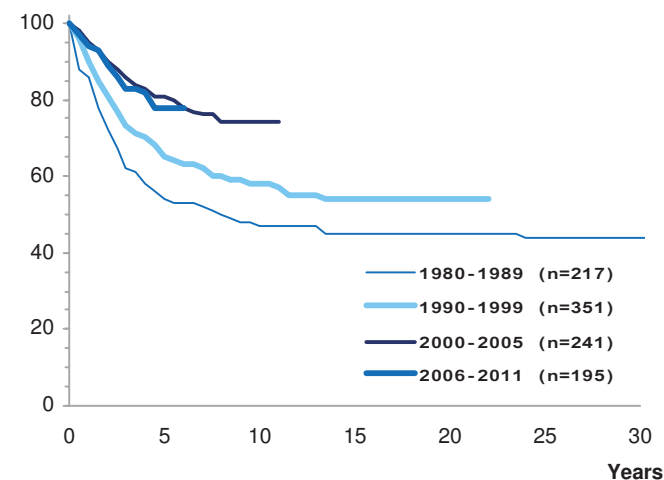
Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



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

Germany 2004-2013	N	%
Ependymomas and choroid plexus tumour	435	100.0
Ependymomas	337	77.5
Choroid plexus tumour	98	22.5

1 Ependymomas

Cases in Germany aged under 15 years (1980-2013): 938

Selected characteristics Germany 2004-2013

Relative frequency:		337 / 17737 = 1.9 %		
Relative frequency of trial patients:		95.8 %		
Incidence rates per million:		Girls	Boys	Total
Number of cases:		135	202	337
Standardized rate *:		2.8	3.8	3.3
Cumulative incidence:		38	54	46
Sex ratio (m/f):		1.5		
Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases:	29	164	73	71
Incidence rate:	4.3	5.9	2.0	1.8
Median age at diagnosis:		4 years 1 month		
* Standard: Segi world standard population				

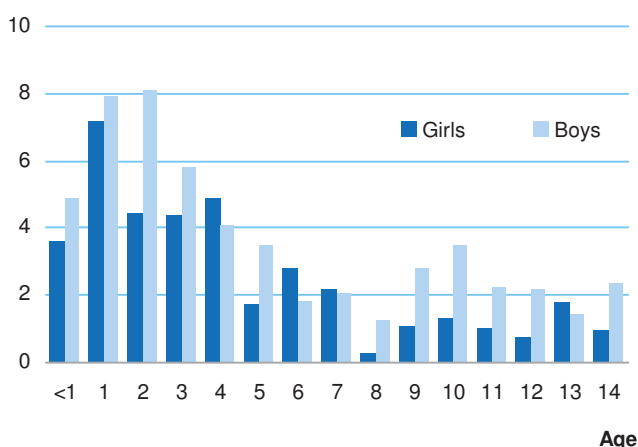
2 Choroid plexus tumour

Cases in Germany aged under 15 years (1980-2013): 229

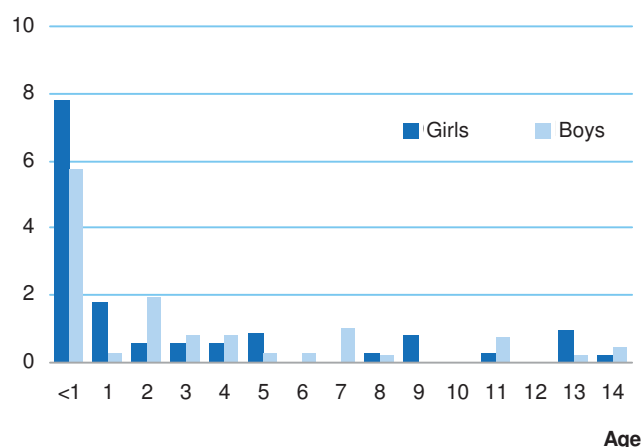
Selected characteristics Germany 2004-2013

Relative frequency:	98 / 17737 = 0.6 %			
Relative frequency of trial patients:	91.8 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	51	47	98	
Standardized rate *:	1.1	1.0	1.0	
Cumulative incidence:	15	13	14	
Sex ratio (m/f):	0.9			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	46	26	14	12
Incidence rate:	6.8	0.9	0.4	0.3
Median age at diagnosis:	1 year 5 months			
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 5114**Selected characteristics Germany 2004-2013**

Relative frequency:	2024 / 17737 = 11.7 %		
Relative frequency of trial patients:	94.1 %		
Incidence rates per million:	Girls	Boys	Total
Number of cases:	964	1060	2024
Standardized rate *:	17.7	18.5	18.1
Cumulative incidence:	265	277	271
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	95	553	714	662
Incidence rate:	14.0	19.7	19.1	16.5
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 (1989-1998):

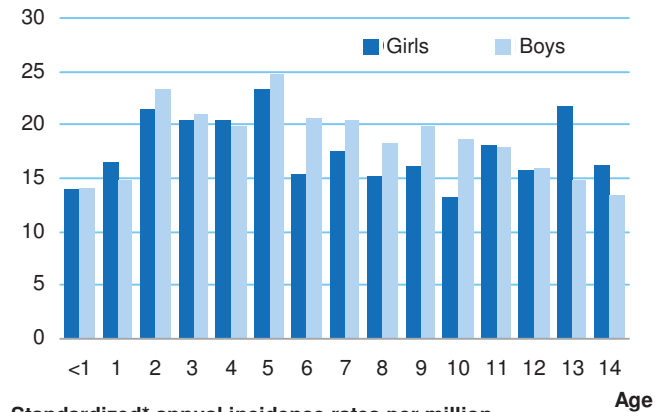
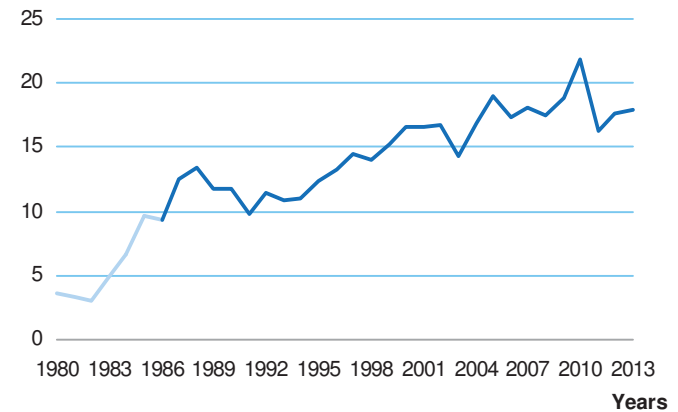
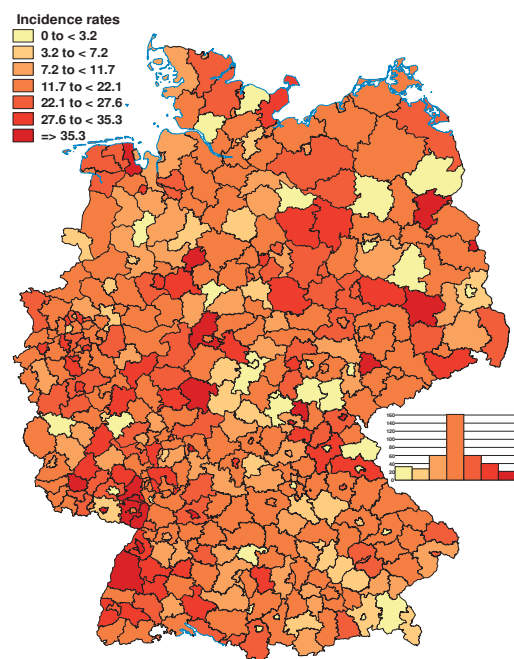
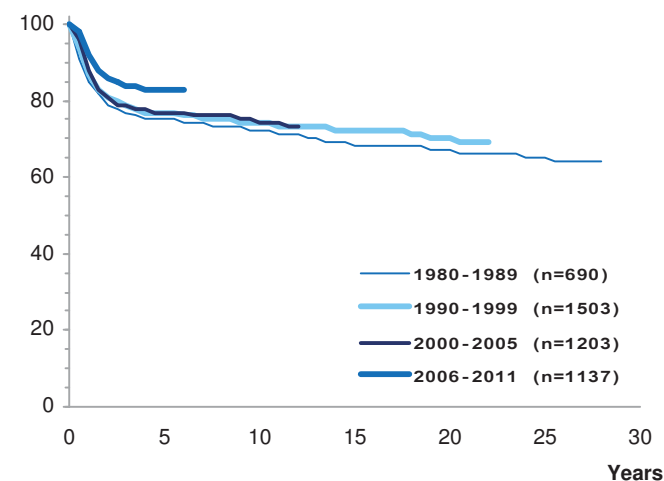
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
377	9.0 %	3.0	45

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

III (b) Astrocytomas

SN after III (b)			III (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
45	4.2 %	2.3 %	95	9.0 %	0.3 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013**Standardized* annual incidence rates per million Germany 1980-2013****Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013****Survival probabilities by year of diagnosis Germany 1980-2011**

30 III (c) Intracranial and intraspinal embryonal tumours

Cases in Germany aged under 15 years (1980-2013): 2618

Selected characteristics Germany 2004-2013

Relative frequency:	791 / 17737 = 4.6 %
Relative frequency of trial patients:	94.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	284	507	791
Standardized rate *:	5.7	9.5	7.7
Cumulative incidence:	80	136	109
Sex ratio (m/f):	1.8		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	89	301	280	121
Incidence rate:	13.1	10.7	7.5	3.0

Median age at diagnosis: 5 years 2 months

Survival probabilities:	5-year	10-year	15-year
	67 %	59 %	56 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
456	10.9 %	3.9	55

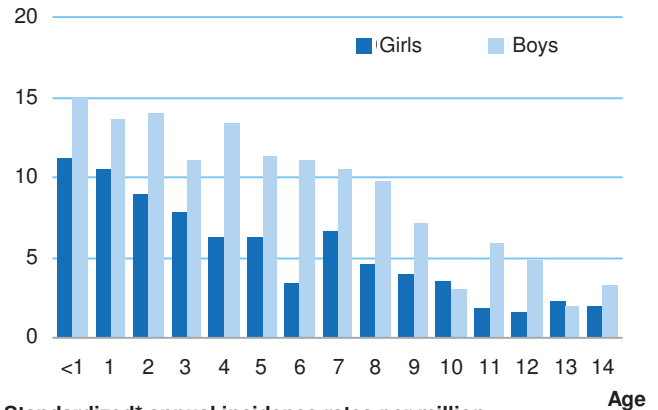
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

III (c) Intracranial and intraspinal embryonal tumours

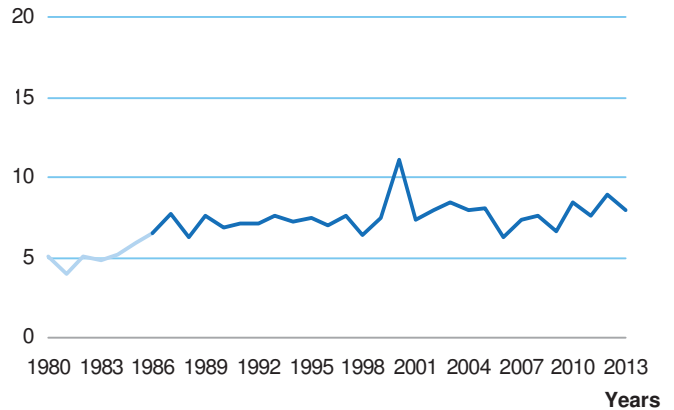
SN after III (c)			III (c) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
109	10.3 %	10.9 %	16	1.5 %	0.0 %

* Standard: Segi world standard population

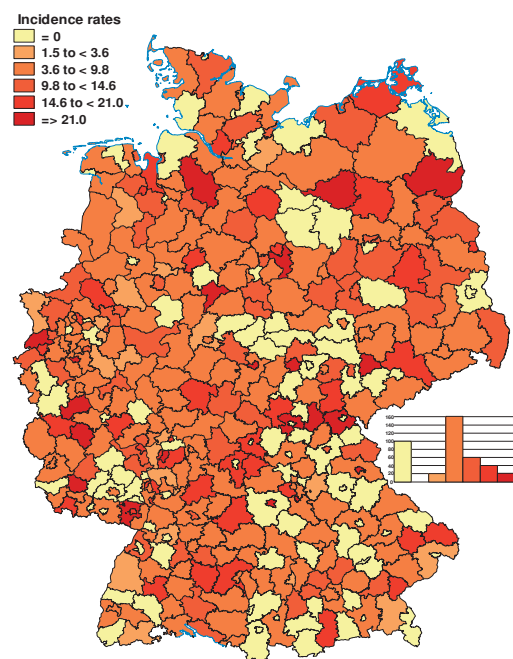
Age- and sex-specific incidence rates per million
Germany 2004-2013



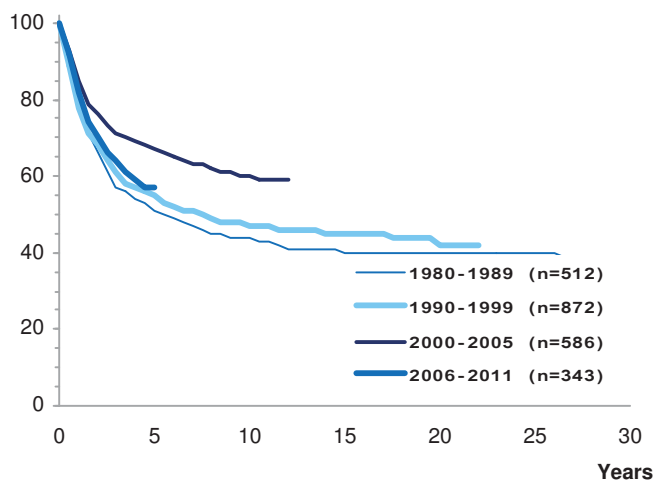
Standardized* annual incidence rates per million
Germany 1980-2013



Standardized* incidence rates per million by districts
(Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



Germany 2004-2013	N	%
Intracranial and intraspinal embryonal tumours	791	100.0
Medulloblastomas	555	70.2
Primitive neuroectodermal tumour (PNET)	90	11.4
Medulloepithelioma	6	0.8
Atypical teratoid/rhabdoid tumour	140	17.7

1 Medulloblastomas

Cases in Germany aged under 15 years (1980-2013): 1984

Selected characteristics Germany 2004-2013

Relative frequency:	555 / 17737 = 3.1 %
Relative frequency of trial patients:	98.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	188	367	555
Standardized rate *:	3.6	6.6	5.2
Cumulative incidence:	53	97	75
Sex ratio (m/f):	2.0		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	23	187	241	104
Incidence rate:	3.4	6.7	6.5	2.6
Median age at diagnosis:	6 years 5 months			

* Standard: Segi world standard population

2 Primitive neuroectodermal tumour (PNET)

Cases in Germany aged under 15 years (1980-2013): 403

Selected characteristics Germany 2004-2013

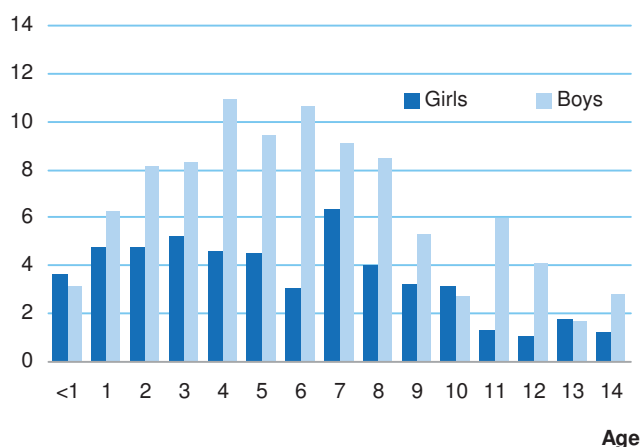
Relative frequency:	90 / 17737 = 0.5 %
Relative frequency of trial patients:	98.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	37	53	90
Standardized rate *:	0.8	1.0	0.9
Cumulative incidence:	10	14	12
Sex ratio (m/f):	1.4		

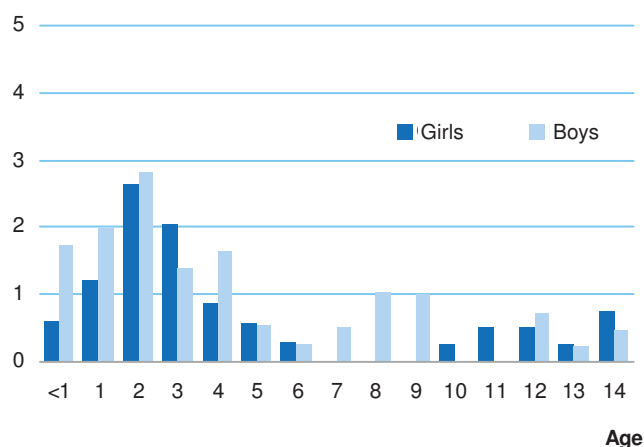
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	8	51	16	15
Incidence rate:	1.2	1.8	0.4	0.4
Median age at diagnosis:	3 years 7 months			

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



32 III (c) Intracranial and intraspinal embryonal tumours - Extended ICC-3

Germany 2004-2013	N	%
Intracranial and intraspinal embryonal tumours	791	100.0
Medulloblastomas	555	70.2
Primitive neuroectodermal tumour (PNET)	90	11.4
Medulloepithelioma	6	0.8
Atypical teratoid/rhabdoid tumour	140	17.7

4 Atypical teratoid/rhabdoid tumour

Cases in Germany aged under 15 years (1980-2013): 212

Selected characteristics Germany 2004-2013

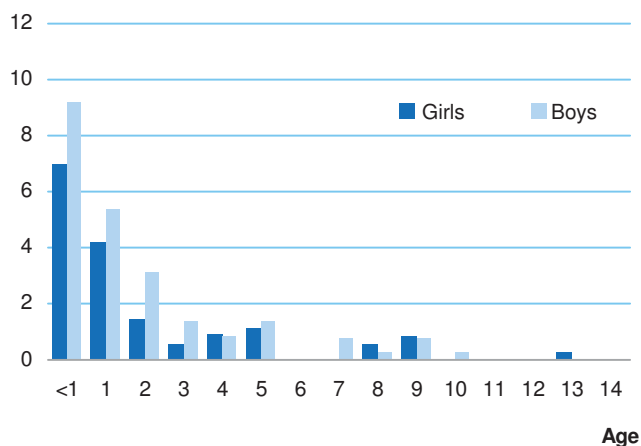
Relative frequency:	140 / 17737 = 0.8 %
Relative frequency of trial patients:	76.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	57	83	140
Standardized rate *:	1.3	1.8	1.5
Cumulative incidence:	17	23	20
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	55	62	21	2
Incidence rate:	8.1	2.2	0.6	0.0
Median age at diagnosis:	1 year 6 months			

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 873

Selected characteristics Germany 2004-2013

Relative frequency:	396 / 17737 = 2.3 %
Relative frequency of trial patients:	89.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	193	203	396
Standardized rate *:	3.5	3.5	3.5
Cumulative incidence:	53	53	53
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	16	91	153	136
Incidence rate:	2.4	3.2	4.1	3.4
Median age at diagnosis:	7 years 9 months			

Survival probabilities:	5-year	10-year	15-year
	49 %	49 %	48 %

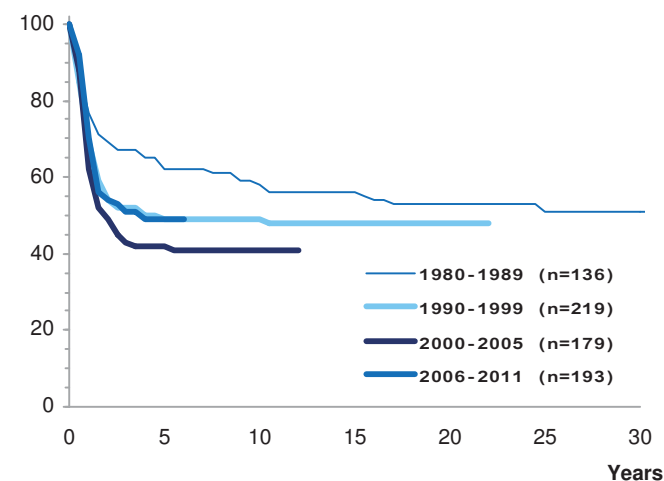
Mortality per million within 15 yrs. of diagnosis (1989-1998):			
Number of deaths	Standardized*	Cumulative	
N % of all 4179 deaths	mortality rate	mortality	
98 2.3 %	0.8	12	

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013): III (d) Other gliomas

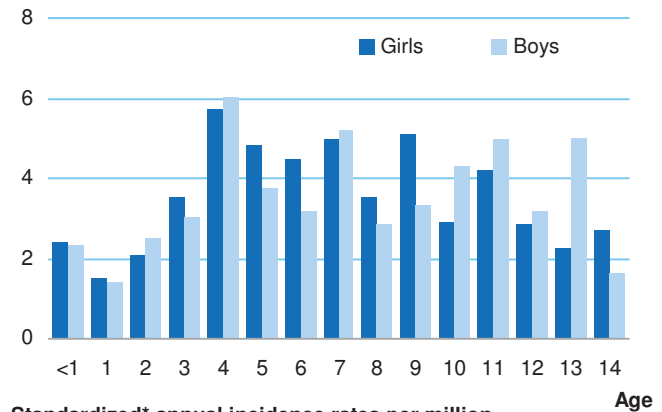
SN after III (d)	III (d) as SN after any primary	
N % of all 1061 SN Cumulative incidence	N % of all 1061 SN Cumulative incidence	
7 0.7 % 1.5 %	22 2.1 % 0.1 %	

* Standard: Segi world standard population

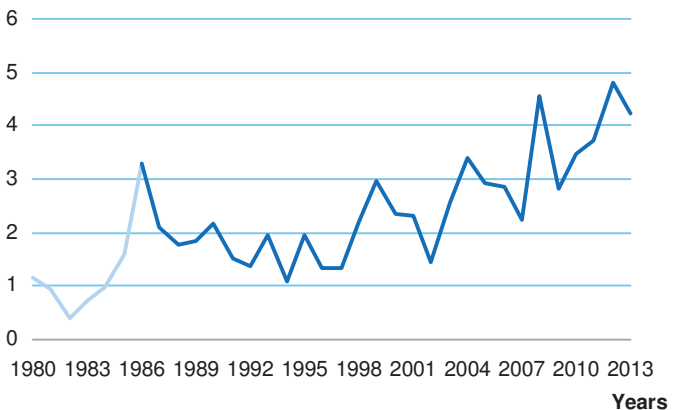
Survival probabilities by year of diagnosis Germany 1980-2011



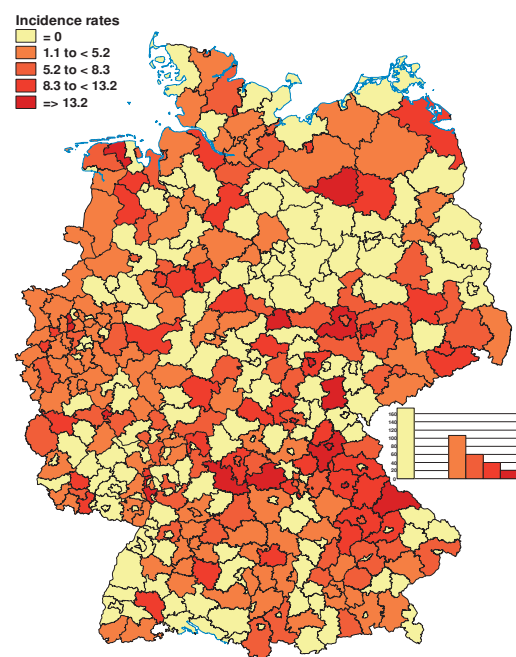
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



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

Germany 2004-2013	N	%
Other gliomas	396	100.0
Oligodendrogliomas	16	4.0
Mixed and unspecified gliomas	366	92.4
Neuroepithelial glial tumours of uncertain origin	14	3.5

1 Oligodendrogliomas

Cases in Germany aged under 15 years (1980-2013): 113

Selected characteristics Germany 2004-2013

Relative frequency:	16 / 17737 = 0.1 %			
Relative frequency of trial patients:	75.0 %			
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	4	11
Incidence rate:	0.0	0.0	0.1	0.3
Median age at diagnosis:	12 years 3 months			
* Standard: Segi world standard population				

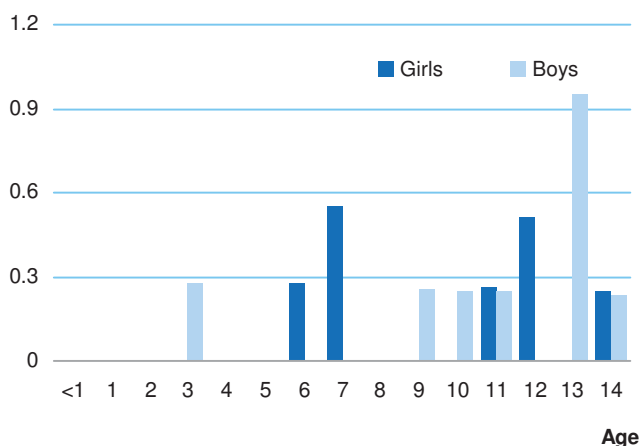
2 Mixed and unspecified gliomas

Cases in Germany aged under 15 years (1980-2013): 731

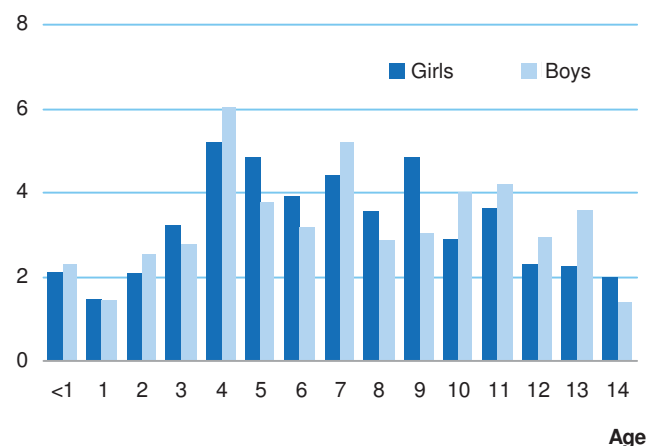
Selected characteristics Germany 2004-2013

Relative frequency:	366 / 17737 = 2.1 %			
Relative frequency of trial patients:	89.6 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	177	189	366	
Standardized rate *:	3.2	3.3	3.2	
Cumulative incidence:	49	49	49	
Sex ratio (m/f):	1.1			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	15	87	147	117
Incidence rate:	2.2	3.1	3.9	2.9
Median age at diagnosis:	7 years 8 months			
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 1479

Selected characteristics Germany 2004-2013

Relative frequency: 609 / 17737 = 3.5 %

Relative frequency of trial patients: 91.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	267	342	609
Standardized rate *:	4.7	5.7	5.2
Cumulative incidence:	72	88	80
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	19	121	188	281
Incidence rate:	2.8	4.3	5.0	7.0

Median age at diagnosis: 9 years 6 months

Survival probabilities:	5-year	10-year	15-year
	96 %	94 %	91 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
39	0.9 %	0.3	5

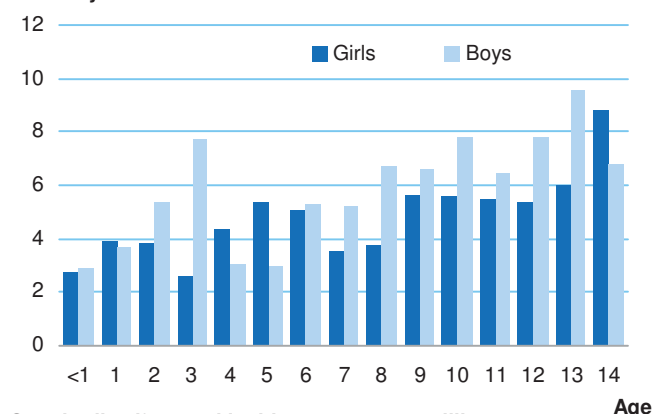
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

III (e) Other specified intracranial and intraspinal neoplasms

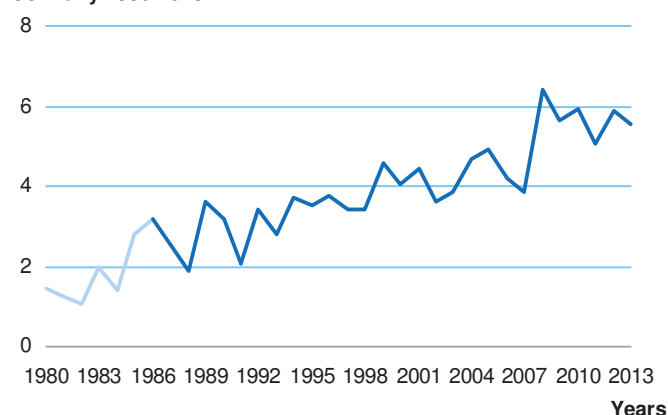
SN after III (e)			III (e) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
14	1.3 %	2.2 %	89	8.4 %	0.5 %

* Standard: Segi world standard population

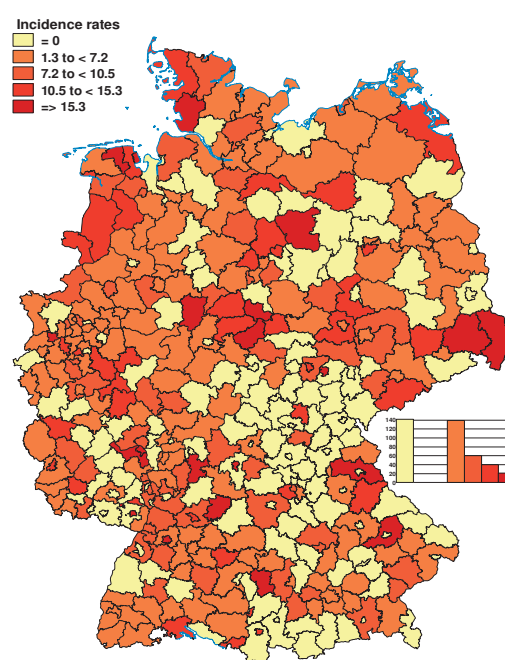
Age- and sex-specific incidence rates per million Germany 2004-2013



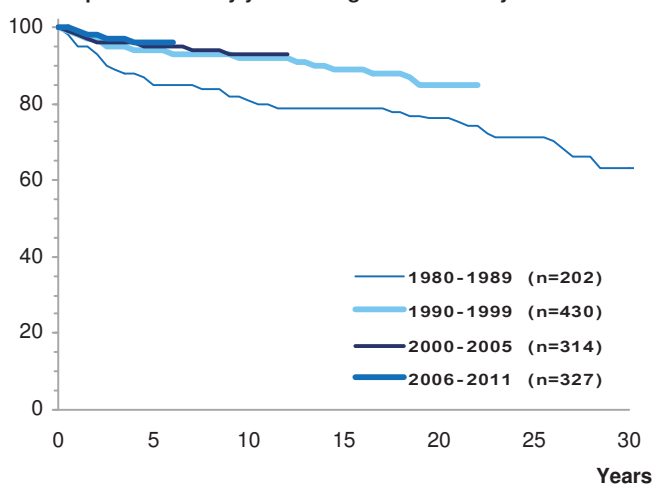
Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



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

Germany 2004-2013	N	%
Other specified intracranial and intraspinal neoplasms	609	100.0
Pituitary adenomas and carcinomas	34	5.6
Tumours of the sellar region (craniopharyngiomas)	194	31.9
Pineal parenchymal tumours	27	4.4
Neuronal and mixed neuronal-glial tumours	305	50.1
Meningiomas	49	8.0

1 Pituitary adenomas and carcinomas

Cases in Germany aged under 15 years (1980-2013): 90

Selected characteristics Germany 2004-2013

Relative frequency:	34 / 17737 = 0.2 %			
Relative frequency of trial patients:	58.8 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	15	19	34	
Standardized rate *:	0.2	0.3	0.3	
Cumulative incidence:	4	5	4	
Sex ratio (m/f):	1.3			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	0	1	3	30
Incidence rate:	0.0	0.0	0.1	0.7
Median age at diagnosis:	12 years 6 months			
* Standard: Segi world standard population				

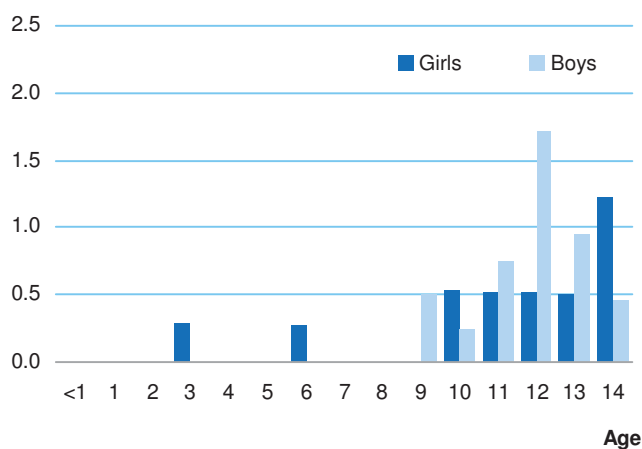
2 Tumours of the sellar region (craniopharyngiomas)

Cases in Germany aged under 15 years (1980-2013): 581

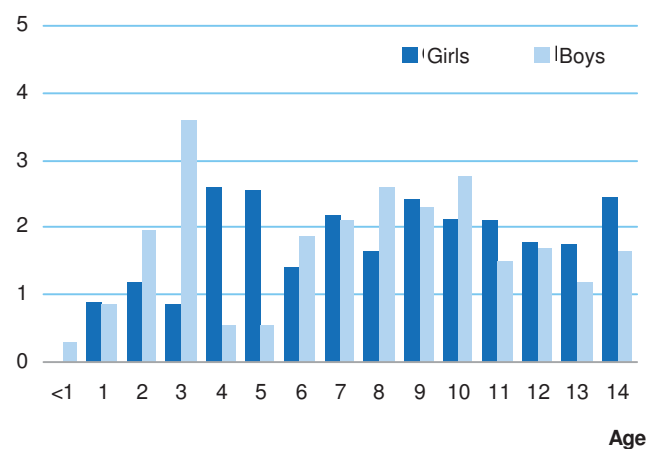
Selected characteristics Germany 2004-2013

Relative frequency:	194 / 17737 = 1.1 %			
Relative frequency of trial patients:	99.0 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	96	98	194	
Standardized rate *:	1.7	1.7	1.7	
Cumulative incidence:	26	25	26	
Sex ratio (m/f):	1.0			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	44	73	76
Incidence rate:	0.1	1.6	2.0	1.9
Median age at diagnosis:	8 years 9 months			
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



Germany 2004-2013	N	%
Other specified intracranial and intraspinal neoplasms	609	100.0
Pituitary adenomas and carcinomas	34	5.6
Tumours of the sellar region (craniopharyngiomas)	194	31.9
Pineal parenchymal tumours	27	4.4
Neuronal and mixed neuronal-glial tumours	305	50.1
Meningiomas	49	8.0

3 Pineal parenchymal tumours

Cases in Germany aged under 15 years (1980-2013): 117

Selected characteristics Germany 2004-2013

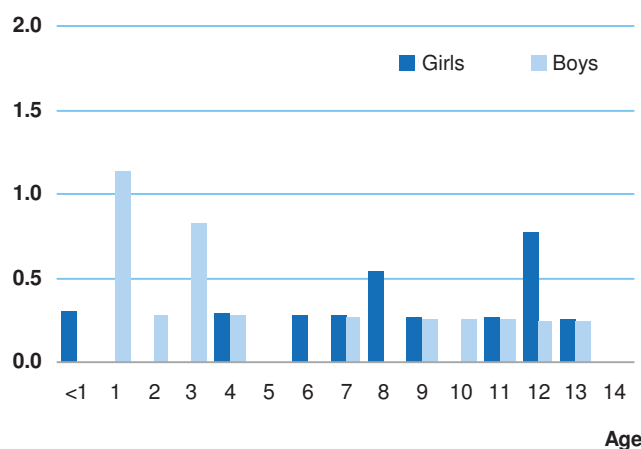
Relative frequency:	27 / 17737 = 0.2 %
Relative frequency of trial patients:	92.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	12	15	27
Standardized rate *:	0.2	0.3	0.2
Cumulative incidence:	3	4	4
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	1	10	7	9
Incidence rate:	0.1	0.4	0.2	0.2
Median age at diagnosis:	7 years 7 months			

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2004-2013



4 Neuronal and mixed neuronal-glial tumours

Cases in Germany aged under 15 years (1980-2013): 549

Selected characteristics Germany 2004-2013

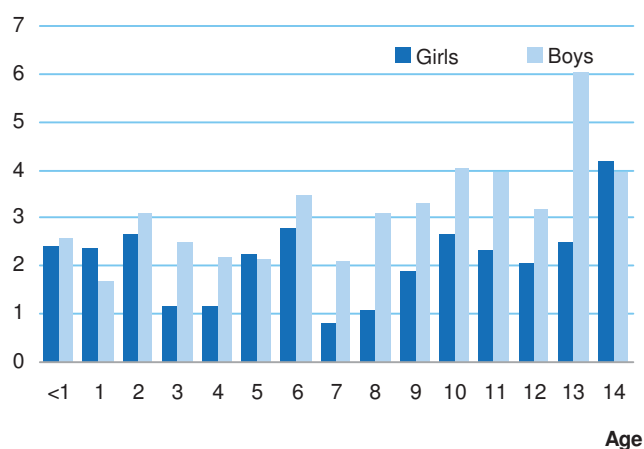
Relative frequency:	305 / 17737 = 1.7 %
Relative frequency of trial patients:	92.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	119	186	305
Standardized rate *:	2.1	3.1	2.6
Cumulative incidence:	32	48	40
Sex ratio (m/f):	1.6		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	17	59	86	143
Incidence rate:	2.5	2.1	2.3	3.6
Median age at diagnosis:	9 years 5 months			

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2004-2013



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

Germany 2004-2013	N	%
Other specified intracranial and intraspinal neoplasms	609	100.0
Pituitary adenomas and carcinomas	34	5.6
Tumours of the sellar region (craniopharyngiomas)	194	31.9
Pineal parenchymal tumours	27	4.4
Neuronal and mixed neuronal-glial tumours	305	50.1
Meningiomas	49	8.0

5 Meningiomas

Cases in Germany aged under 15 years (1980-2013): 142

Selected characteristics Germany 2004-2013

Relative frequency: 49 / 17737 = 0.3 %

Relative frequency of trial patients: 71.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	25	24	49
Standardized rate *:	0.4	0.4	0.4
Cumulative incidence:	7	6	6
Sex ratio (m/f):	1.0		

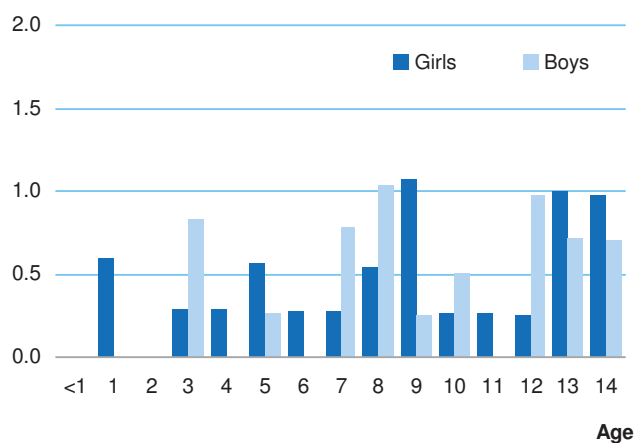
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	0	7	19	23
Incidence rate:	0.0	0.2	0.5	0.6

Median age at diagnosis: 9 years 6 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 4050**Selected characteristics Germany 2004-2013**

Relative frequency:	1236 / 17737 = 7.1 %
Relative frequency of trial patients:	98.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	560	676	1236
Standardized rate *:	12.7	14.7	13.7
Cumulative incidence:	165	190	178
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	579	536	89	32
Incidence rate:	85.1	19.1	2.4	0.8

Median age at diagnosis: 1 year 2 months

Survival probabilities:	5-year	10-year	15-year
	79 %	77 %	76 %

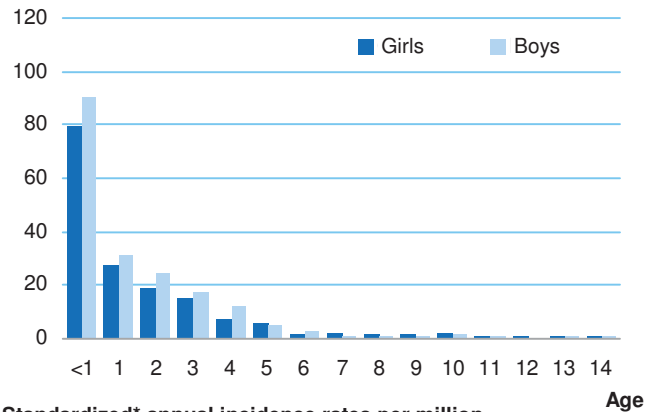
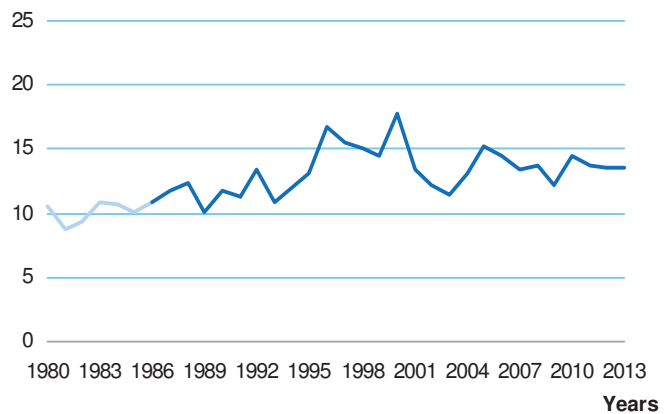
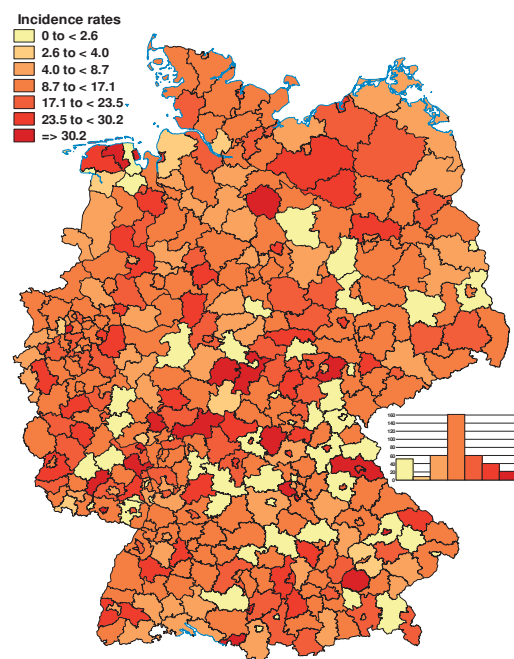
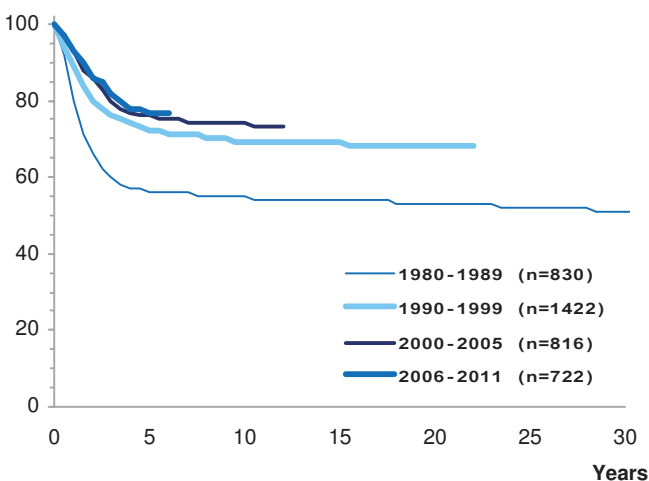
Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
444	10.6 %	4.1	55

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):**IV (a) Neuroblastoma and ganglioneuroblastoma**

SN after IV (a)			IV (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
61	5.7 %	2.7 %	11	1.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013**Standardized* annual incidence rates per million Germany 1980-2013****Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013****Survival probabilities by year of diagnosis Germany 1980-2011**

Cases in Germany aged under 15 years (1980-2013): 1272**Selected characteristics Germany 2004-2013**

Relative frequency:	369 / 17737 = 2.1 %
Relative frequency of trial patients:	1.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	172	197	369
Standardized rate *:	4.0	4.3	4.2
Cumulative incidence:	51	55	53
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	169	184	13	3
Incidence rate:	24.8	6.6	0.3	0.1

Median age at diagnosis: 1 year 1 month

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

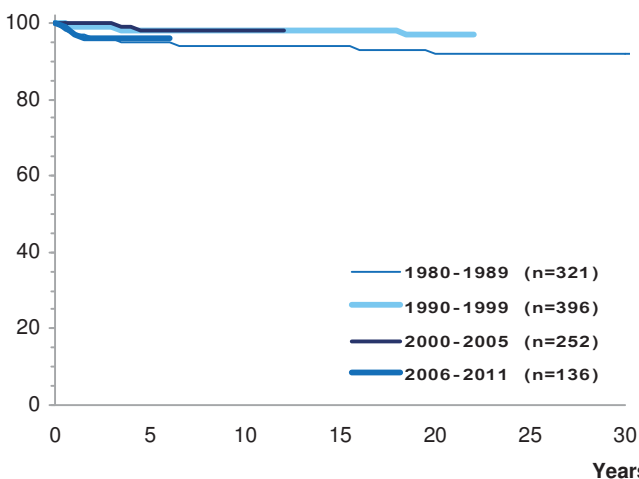
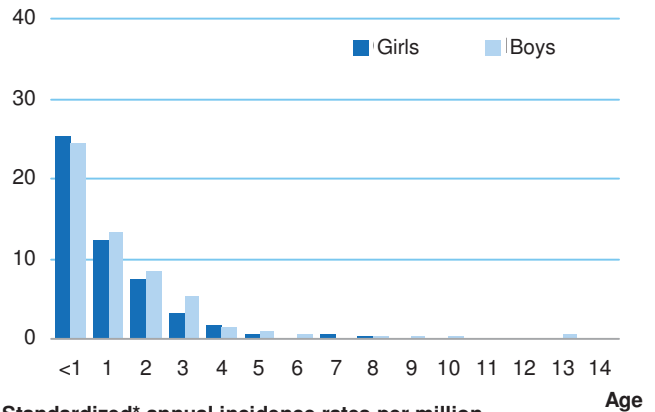
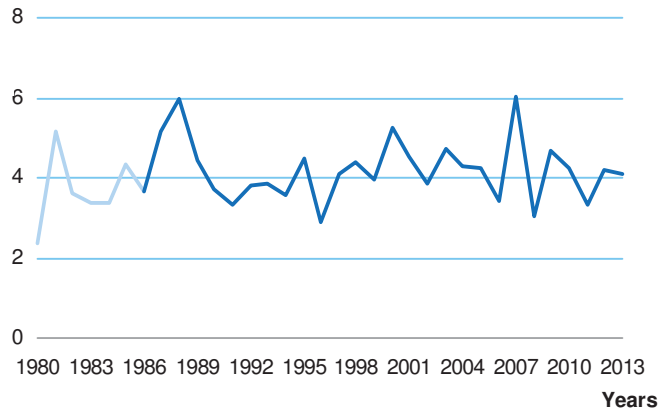
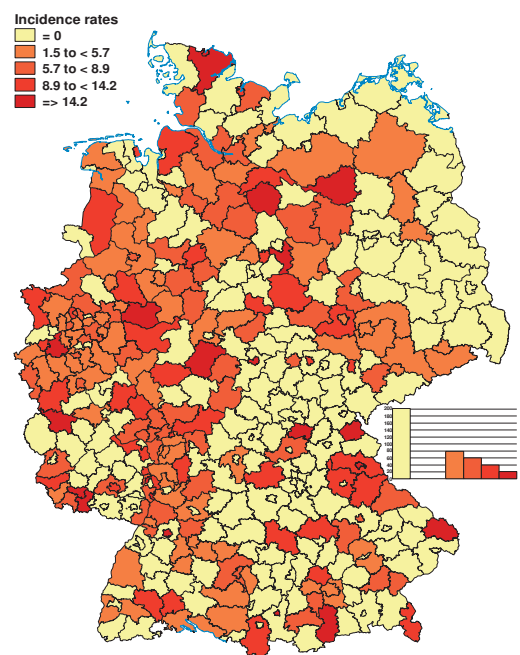
Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
10	0.2 %	0.1	1

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013): V Retinoblastoma

SN after V			V as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
29	2.7 %	4.1 %	3	0.3 %	0.0 %

* Standard: Segi world standard population

Survival probabilities by year of diagnosis Germany 1980-2011**Age- and sex-specific incidence rates per million Germany 2004-2013****Standardized* annual incidence rates per million Germany 1980-2013****Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013**

Cases in Germany aged under 15 years (1980-2013): 3080

Selected characteristics Germany 2004-2013

Relative frequency: 919 / 17737 = 5.3 %

Relative frequency of trial patients: 99.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	485	434	919
Standardized rate *:	10.4	9.0	9.7
Cumulative incidence:	140	120	130
Sex ratio (m/f):	0.9		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	153	539	196	31
Incidence rate:	22.5	19.2	5.3	0.8

Median age at diagnosis: 3 years 1 month

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
132	3.2 %	1.2	16

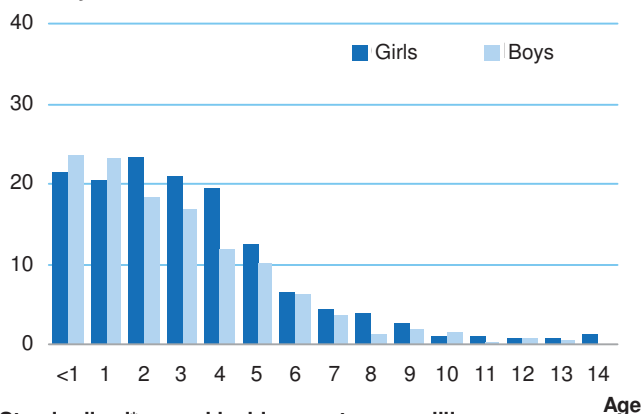
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

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

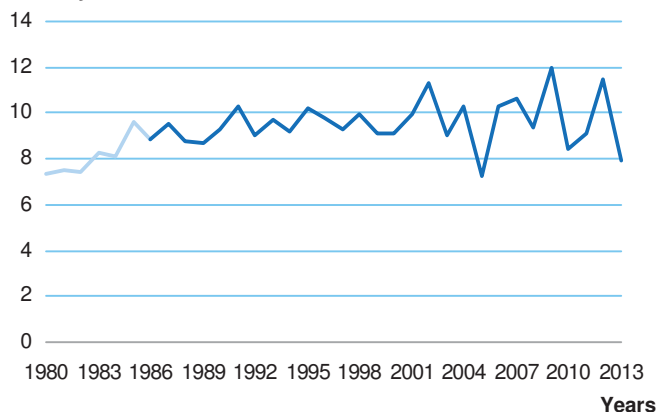
SN after VI (a)			VI (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
37	3.5 %	2.3 %	9	0.8 %	0.0 %

* Standard: Segi world standard population

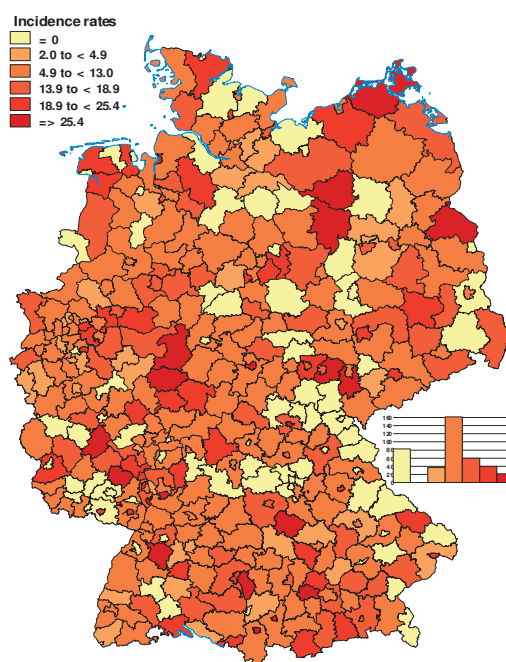
Age- and sex-specific incidence rates per million Germany 2004-2013



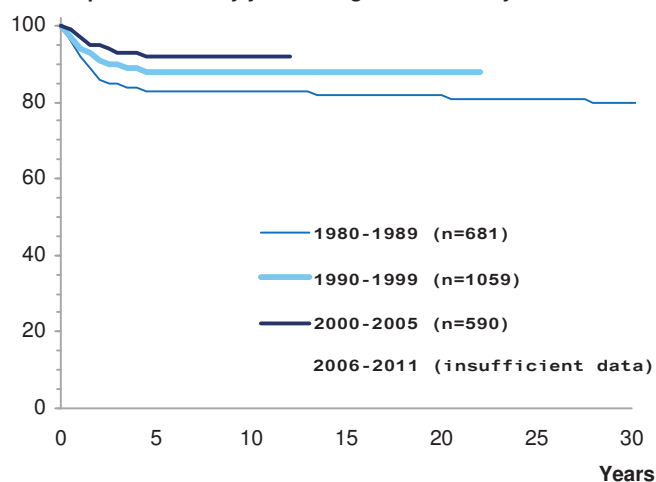
Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



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

Germany 2004-2013	N	%
Nephroblastoma and other non-epithelial renal tumours	919	100.0
Nephroblastoma	897	97.6
Rhabdoid renal tumour	16	1.7
Kidney sarcomas	6	0.7
Peripheral neuroectodermal tumour (pPNET) of kidney	0	0.0

1 Nephroblastoma

Cases in Germany aged under 15 years (1980-2013): 2977

Selected characteristics Germany 2004-2013

Relative frequency:	897 / 17737 = 5.1 %			
Relative frequency of trial patients:	99.4 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	474	423	897	
Standardized rate *:	10.2	8.7	9.4	
Cumulative incidence:	137	117	126	
Sex ratio (m/f):	0.9			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	144	533	191	29
Incidence rate:	21.2	19.0	5.1	0.7
Median age at diagnosis:	3 years 1 month			
* Standard: Segi world standard population				

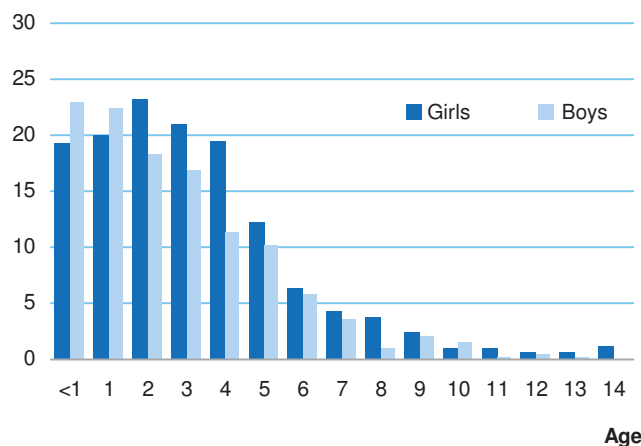
2 Rhabdoid renal tumour

Cases in Germany aged under 15 years (1980-2013): 52

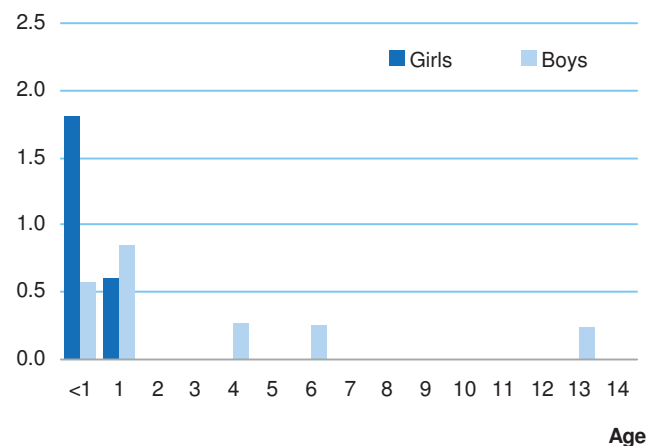
Selected characteristics Germany 2004-2013

Relative frequency:	16 / 17737 = 0.1 %			
Relative frequency of trial patients:	93.8 %			
Incidence rates per million:	Girls	Boys	Total	
Number of cases:	8	8	16	
Standardized rate *:	0.2	0.2	0.2	
Cumulative incidence:	2	2	2	
Sex ratio (m/f):	1.0			
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	8	6	1	1
Incidence rate:	1.2	0.2	0.0	0.0
Median age at diagnosis:	1 year 0 months			
* Standard: Segi world standard population				

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 61**Selected characteristics Germany 2004-2013**

Relative frequency:	29 / 17737 = 0.2 %
Relative frequency of trial patients:	79.3 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	14	15	29
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	1	8	20
Incidence rate:	0.0	0.0	0.2	0.5
Median age at diagnosis:	11 years 6 months			

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

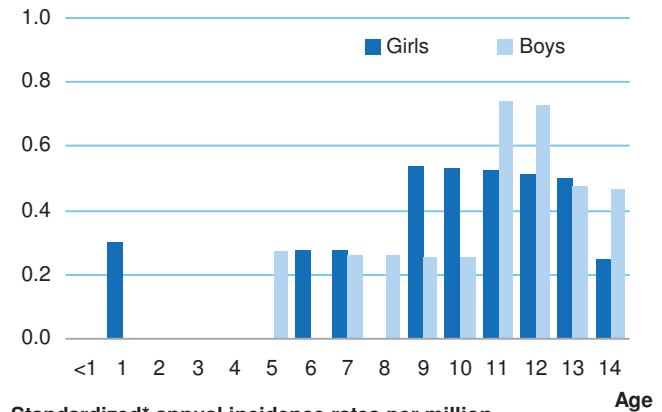
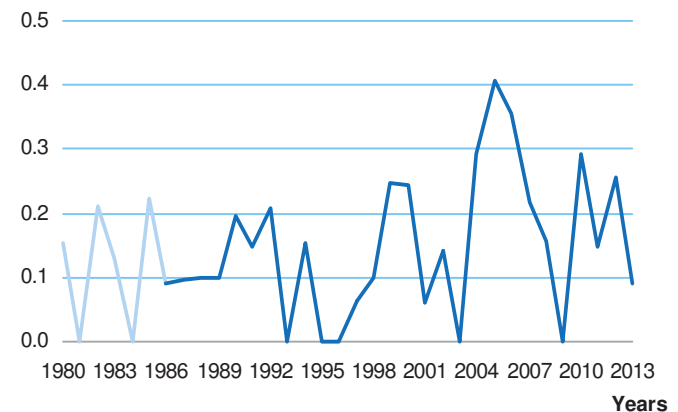
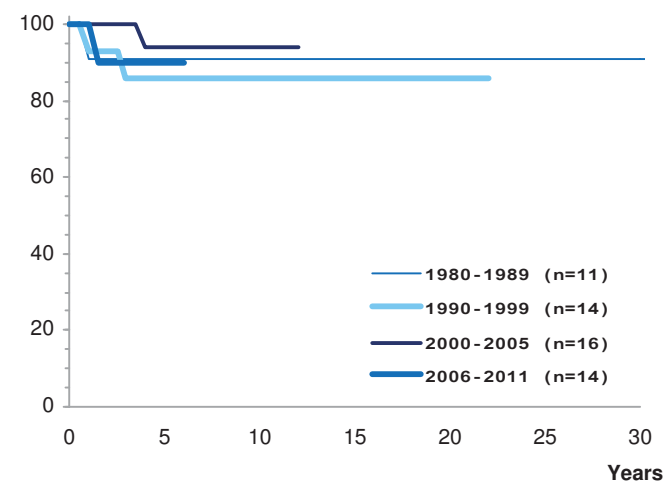
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
1	0.0 %	0.0	0

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

VI (b) Renal carcinomas

SN after VI (b)			VI (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
1	0.1 %	1.8 %	6	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013**Standardized* annual incidence rates per million Germany 1980-2013****Survival probabilities by year of diagnosis Germany 1980-2011**

No map due to sparse data

44 VII (a) Hepatoblastoma

Cases in Germany aged under 15 years (1980-2013): 477

Selected characteristics Germany 2004-2013

Relative frequency: 201 / 17737 = 1.2 %

Relative frequency of trial patients: 78.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	82	119	201
Standardized rate *:	1.9	2.6	2.2
Cumulative incidence:	24	33	29
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	69	117	8	7
Incidence rate:	10.1	4.2	0.2	0.2

Median age at diagnosis: 1 year 4 months

Survival probabilities:	5-year	10-year	15-year
	77 %	76 %	76 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
39	0.9 %	0.4	5

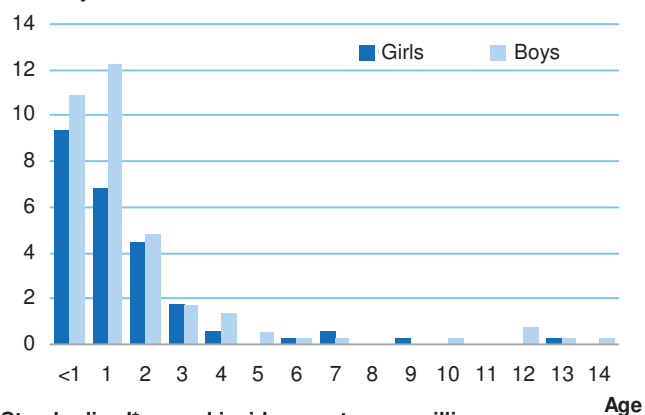
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

VII (a) Hepatoblastoma

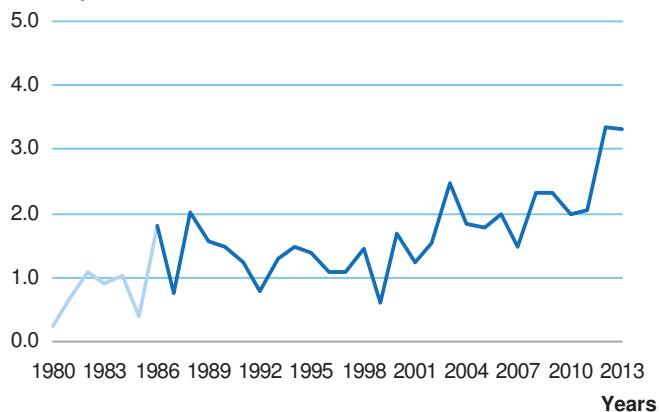
SN after VII (a)			VII (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
3	0.3 %	1.8 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

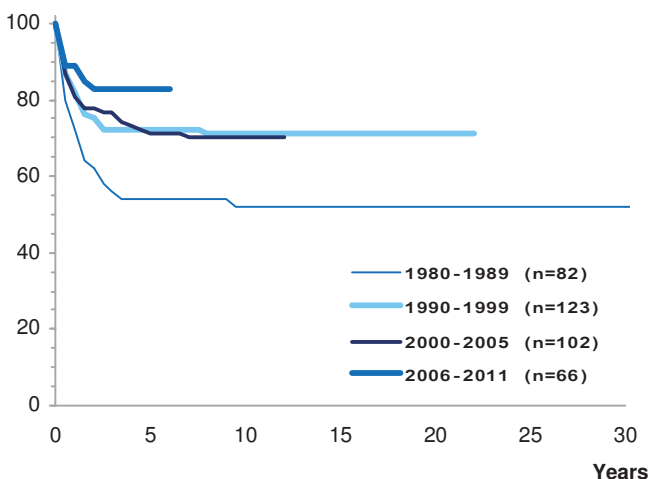
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

Cases in Germany aged under 15 years (1980-2013): 110

Selected characteristics Germany 2004-2013

Relative frequency:	32 / 17737 = 0.2 %
Relative frequency of trial patients:	75.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	13	19	32
Standardized rate *:	0.2	0.3	0.2
Cumulative incidence:	3	5	4
Sex ratio (m/f):	1.5		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	3	5	24
Incidence rate:	0.0	0.1	0.1	0.6
Median age at diagnosis:	12 years 10 months			

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
18	0.4 %	0.1	2

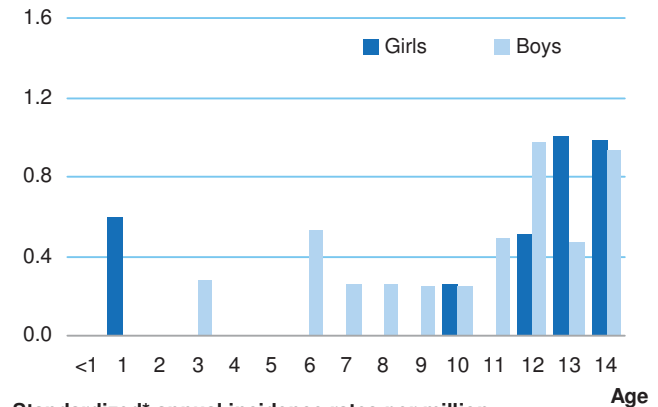
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

VII (b) Hepatic carcinomas

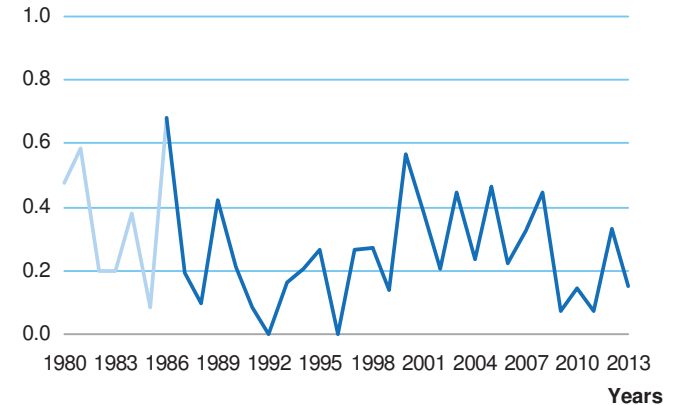
SN after VII (b)			VII (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
1	0.1 %	1.0 %	5	0.5 %	0.0 %

* Standard: Segi world standard population

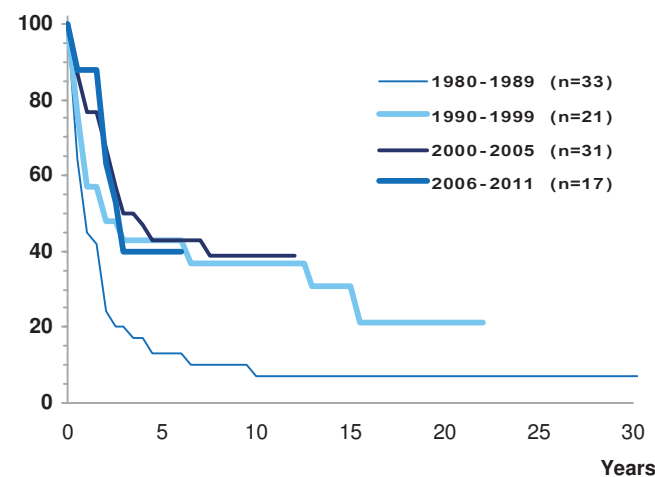
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

46 VIII Malignant bone tumours

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

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

Cases in Germany aged under 15 years (1980-2013): 2519

Selected characteristics Germany 2004-2013

Relative frequency: 784 / 17737 = 4.4 %

Relative frequency of trial patients: 97.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	366	418	784
Standardized rate *:	5.8	6.4	6.1
Cumulative incidence:	96	105	100
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	4	45	209	526
Incidence rate:	0.6	1.6	5.6	13.1

Median age at diagnosis: 11 years 10 months

Survival probabilities:	5-year	10-year	15-year
	72 %	68 %	67 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
261	6.2 %	1.9	31

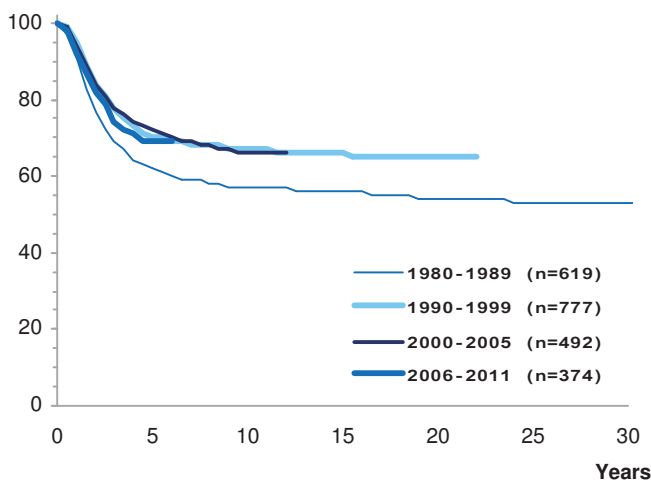
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

VIII Malignant bone tumours

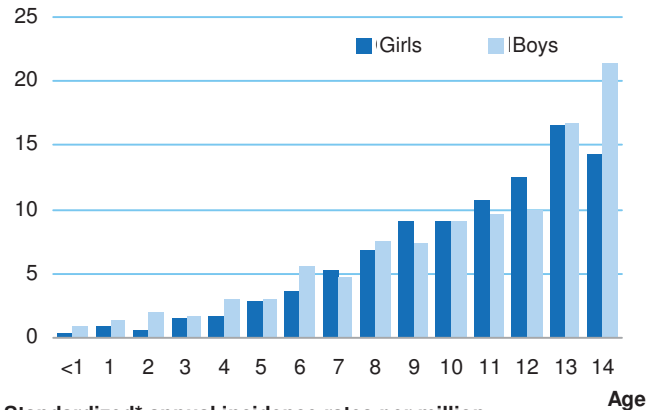
SN after VIII			VIII as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
60	5.7 %	4.4 %	63	5.9 %	0.2 %

* Standard: Segi world standard population

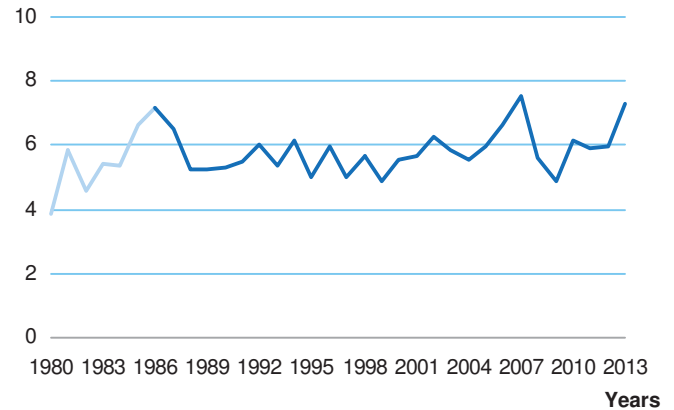
Survival probabilities by year of diagnosis Germany 1980-2011



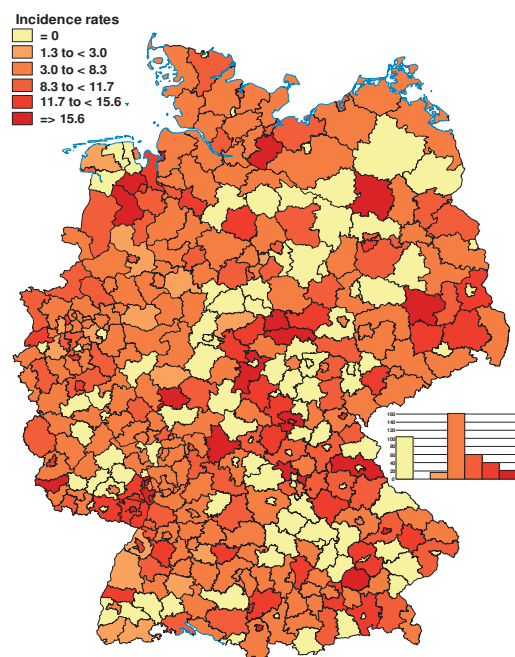
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 1319

Selected characteristics Germany 2004-2013

Relative frequency:	404 / 17737 = 2.3 %
Relative frequency of trial patients:	98.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	200	204	404
Standardized rate *:	3.1	3.0	3.1
Cumulative incidence:	52	50	51
Sex ratio (m/f):	1.0		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	0	8	91	305
Incidence rate:	0.0	0.3	2.4	7.6
Median age at diagnosis:	12 years 6 months			

Survival probabilities:	5-year	10-year	15-year
	75 %	71 %	70 %

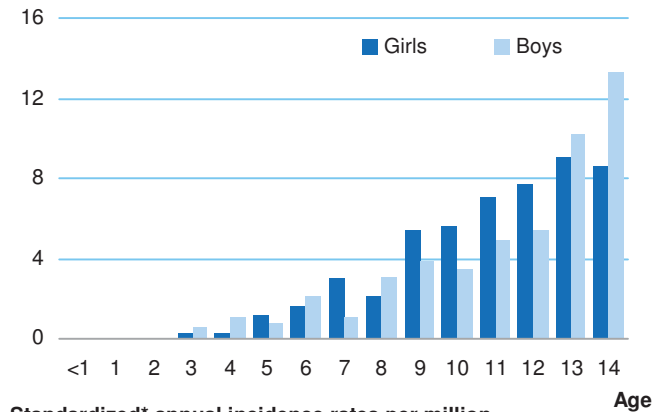
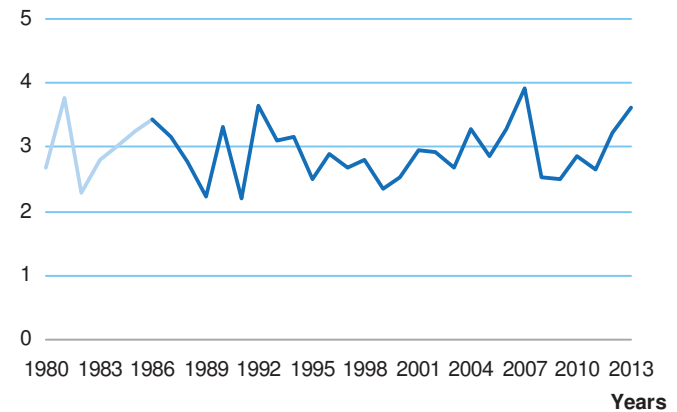
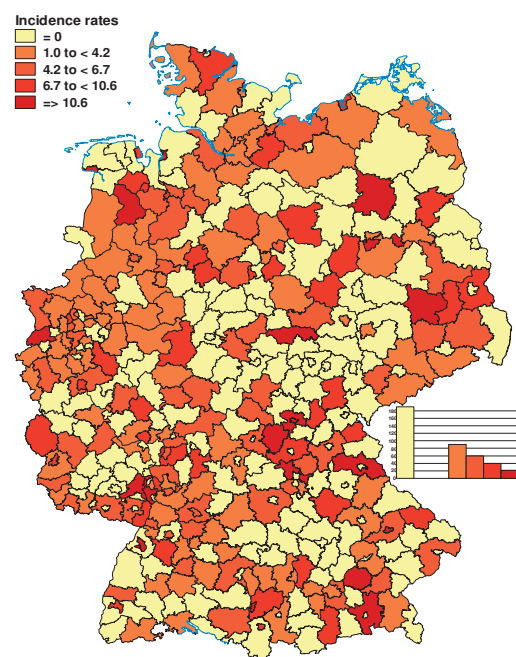
Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
139	3.3 %	1.0	17

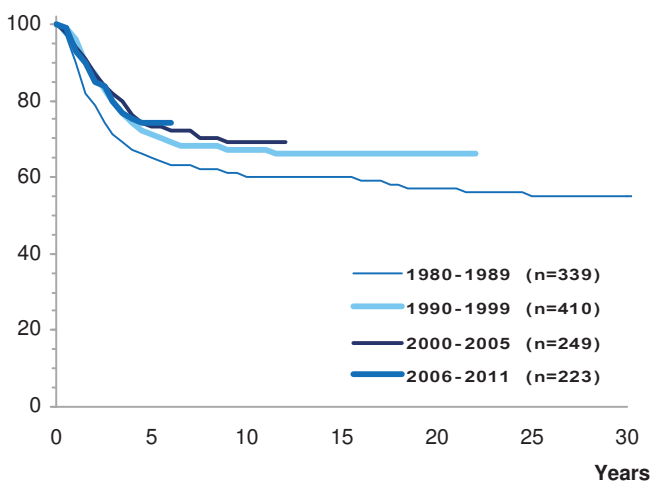
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):
VIII (a) Osteosarcomas

SN after VIII (a)			VIII (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
29	2.7 %	4.7 %	42	4.0 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2004-2013Standardized* annual incidence rates per million
Germany 1980-2013Standardized* incidence rates per million by districts
(Landkreise) Germany 2004-2013

Survival probabilities by year of diagnosis Germany 1980-2011



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

Cases in Germany aged under 15 years (1980-2013): 1115

Selected characteristics Germany 2004-2013

Relative frequency:	348 / 17737 = 2 %
Relative frequency of trial patients:	98.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	151	197	348
Standardized rate *:	2.5	3.1	2.8
Cumulative incidence:	40	50	45
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	3	35	110	200
Incidence rate:	0.4	1.2	2.9	5.0

Median age at diagnosis: 10 years 11 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
115	2.8 %	0.9	14

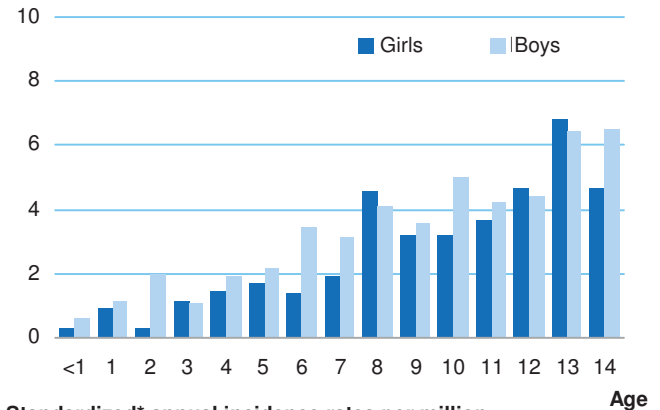
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

VIII (c) Ewing tumour and related sarcomas of bone

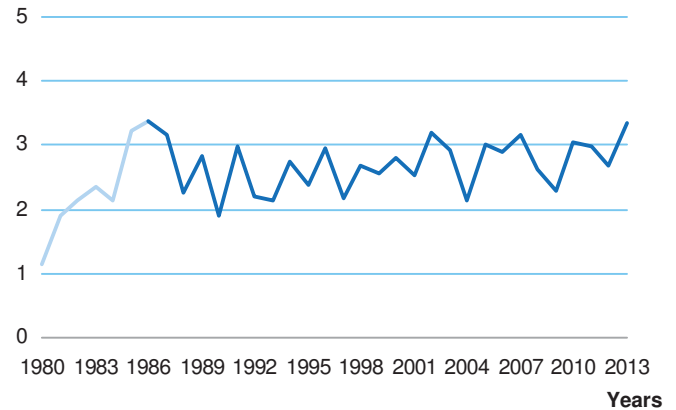
SN after VIII (c)			VIII (c) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
29	2.7 %	3.9 %	17	1.6 %	0.1 %

* Standard: Segi world standard population

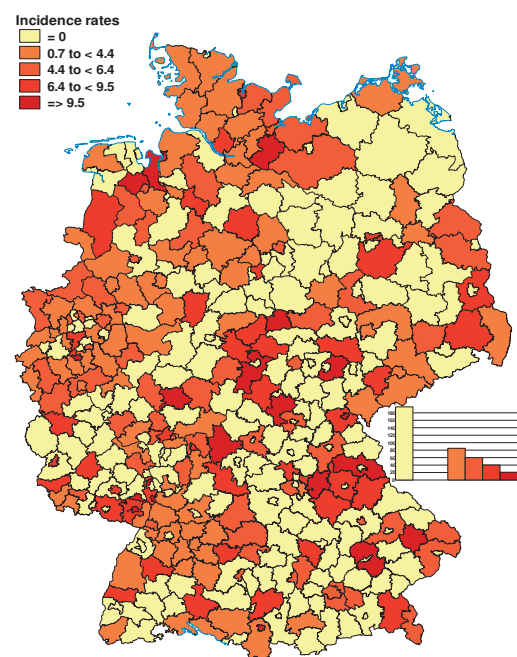
Age- and sex-specific incidence rates per million
Germany 2004-2013



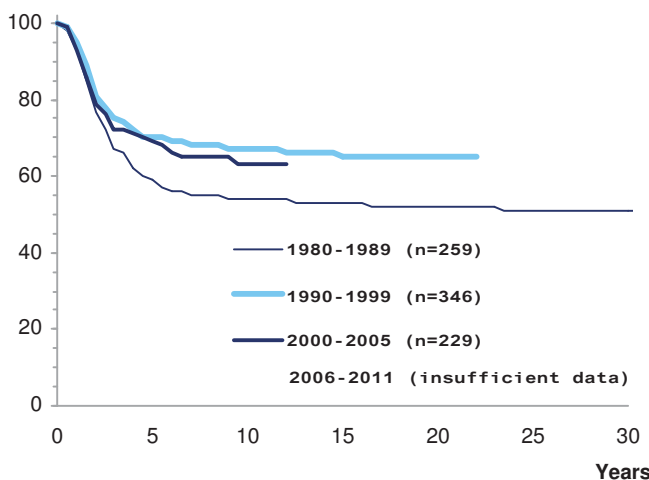
Standardized* annual incidence rates per million
Germany 1980-2013



Standardized* incidence rates per million by districts
(Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



- (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 (1980-2013): 3309

Selected characteristics Germany 2004-2013

Relative frequency:	1042 / 17737 = 5.9 %
Relative frequency of trial patients:	96.9 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	477	565	1042
Standardized rate *:	8.9	10.2	9.6
Cumulative incidence:	132	149	140
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	127	294	265	356
Incidence rate:	18.7	10.5	7.1	8.9
Median age at diagnosis:	6 years 7 months			

Survival probabilities:	5-year	10-year	15-year
	73 %	70 %	69 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
384	9.2 %	3.2	47

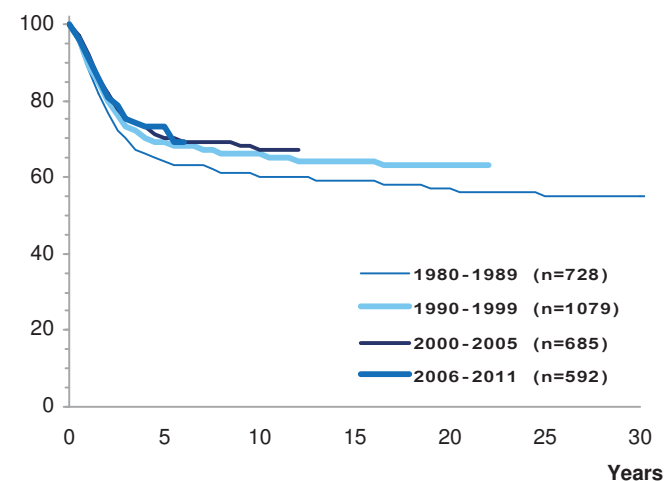
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

IX Soft tissue and other extrasosseous sarcomas

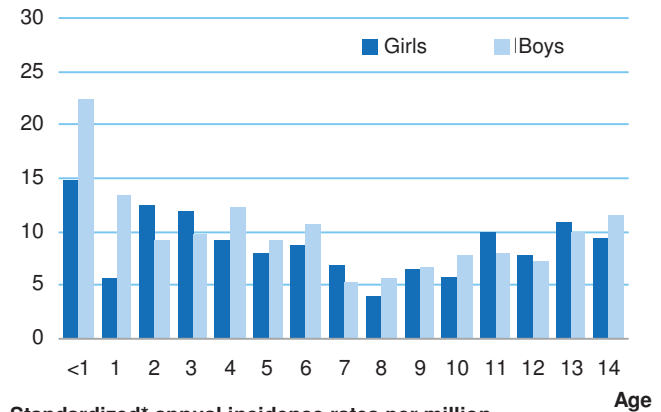
SN after IX			IX as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
82	7.7 %	4.6 %	64	6.0 %	0.3 %

* Standard: Segi world standard population

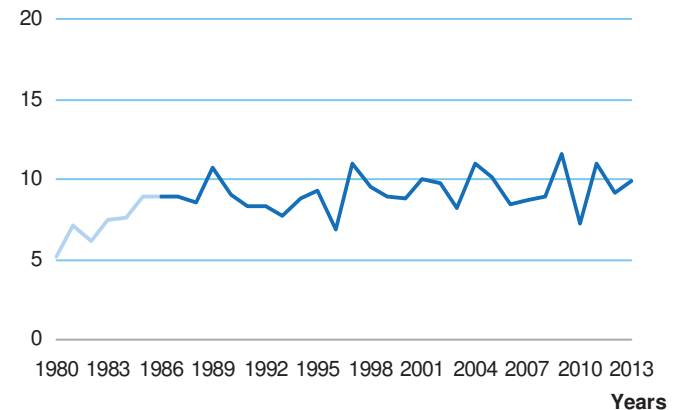
Survival probabilities by year of diagnosis Germany 1980-2011



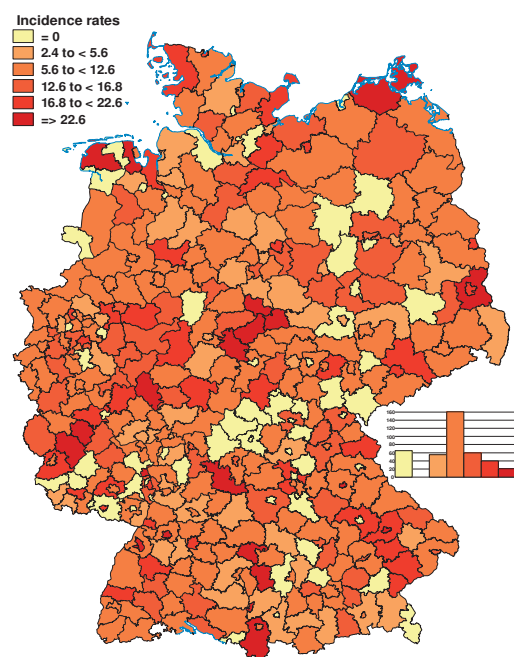
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



50 IX (a) Rhabdomyosarcomas

Cases in Germany aged under 15 years (1980-2013): 1891

Selected characteristics Germany 2004-2013

Relative frequency:	550 / 17737 = 3.2 %
Relative frequency of trial patients:	98.7 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	247	303	550
Standardized rate *:	4.8	5.7	5.2
Cumulative incidence:	69	81	75
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	49	212	164	125
Incidence rate:	7.2	7.6	4.4	3.1

Median age at diagnosis: 5 years 3 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
229	5.5 %	1.9	28

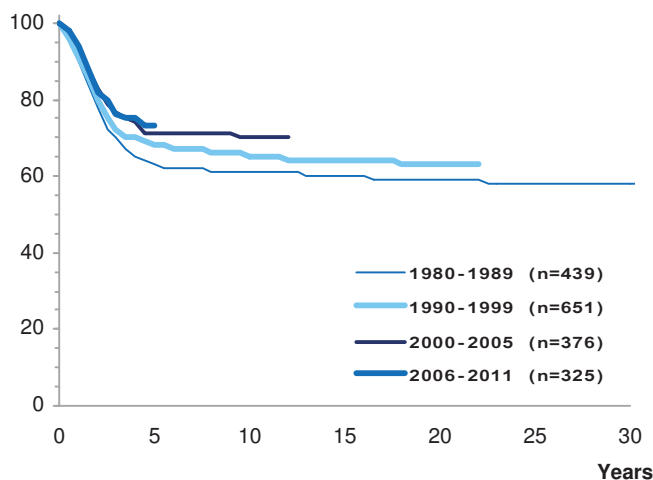
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

IX (a) Rhabdomyosarcomas

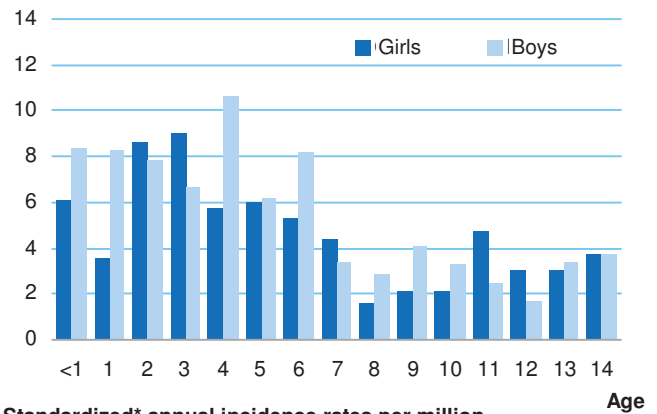
SN after IX (a)			IX (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
55	5.2 %	4.8 %	14	1.3 %	0.0 %

* Standard: Segi world standard population

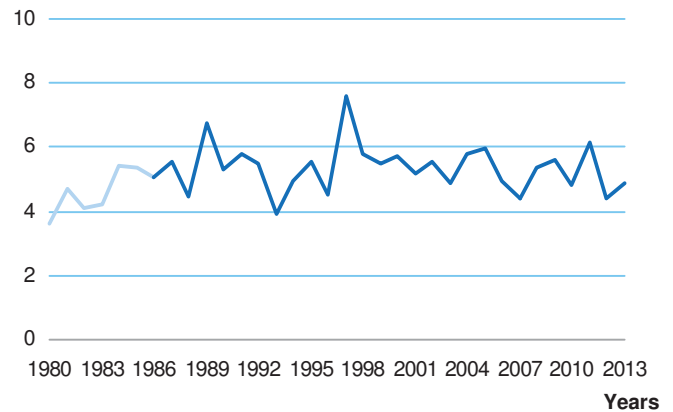
Survival probabilities by year of diagnosis Germany 1980-2011



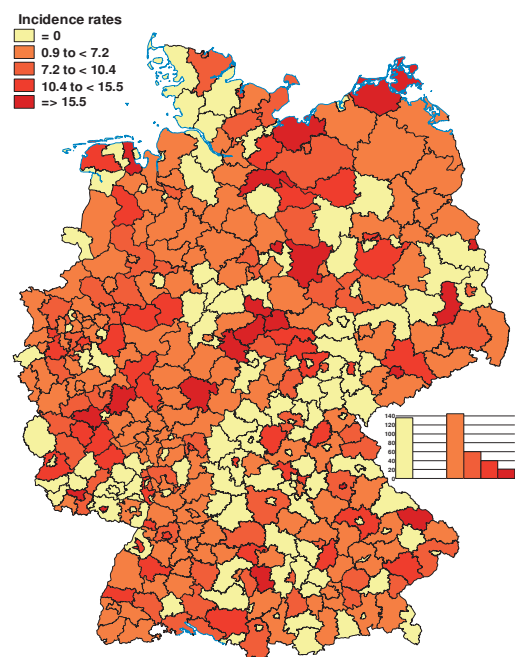
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Standardized* incidence rates per million by districts (Landkreise) Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 303**Selected characteristics Germany 2004-2013**

Relative frequency:	105 / 17737 = 0.6 %
Relative frequency of trial patients:	92.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	48	57	105
Standardized rate *:	0.9	1.0	1.0
Cumulative incidence:	13	15	14
Sex ratio (m/f):	1.2		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	30	18	13	44
Incidence rate:	4.4	0.6	0.3	1.1

Median age at diagnosis: 7 years 4 months

Survival probabilities:	5-year	10-year	15-year
	67 %	65 %	64 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

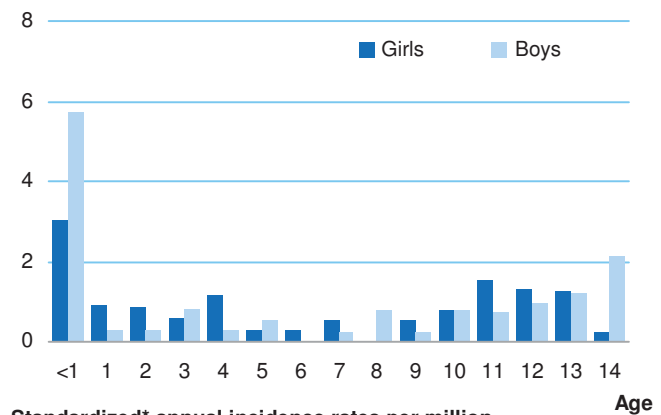
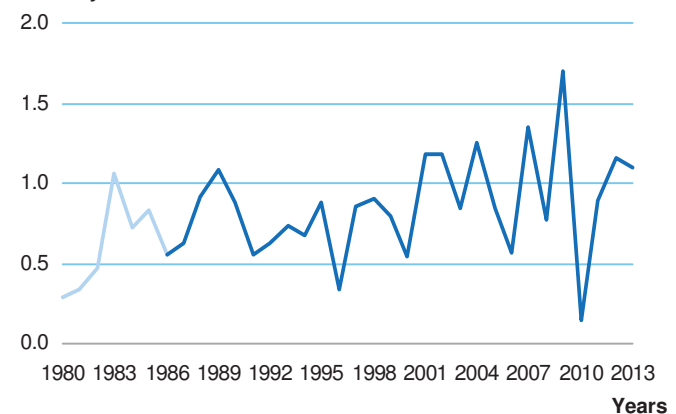
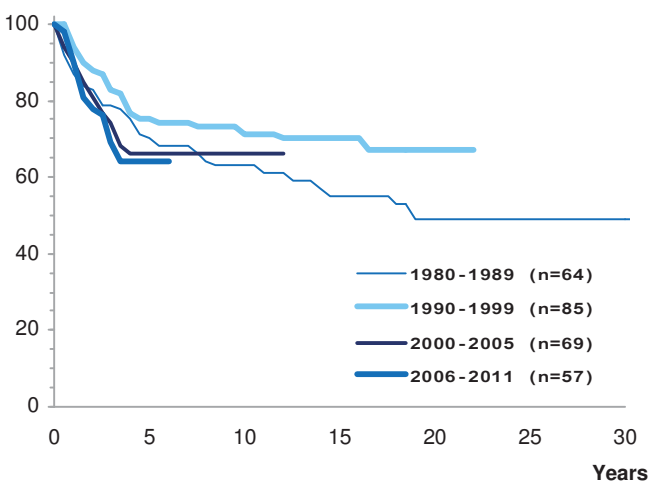
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
28	0.7 %	0.2	3

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

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

SN after IX (b)			IX (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
6	0.6 %	4.2 %	19	1.8 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013**Standardized* annual incidence rates per million Germany 1980-2013****Survival probabilities by year of diagnosis Germany 1980-2011**

No map due to sparse data

Germany 2004-2013	N	%
Fibrosarcomas, peripheral nerve sheath tumours and other	105	100.0
Fibroblastic and myofibroblastic tumours	58	55.2
Nerve sheath tumours	47	44.8
Other fibrous neoplasms	0	0.0

1 Fibroblastic and myofibroblastic tumours

Cases in Germany aged under 15 years (1980-2013): 144

Selected characteristics Germany 2004-2013

Relative frequency:	58 / 17737 = 0.3 %
Relative frequency of trial patients:	93.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	25	33	58
Standardized rate *:	0.5	0.7	0.6
Cumulative incidence:	7	9	8
Sex ratio (m/f):	1.3		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	25	12	6	15
Incidence rate:	3.7	0.4	0.2	0.4
Median age at diagnosis:	3 years 3 months			

* Standard: Segi world standard population

2 Nerve sheath tumours

Cases in Germany aged under 15 years (1980-2013): 159

Selected characteristics Germany 2004-2013

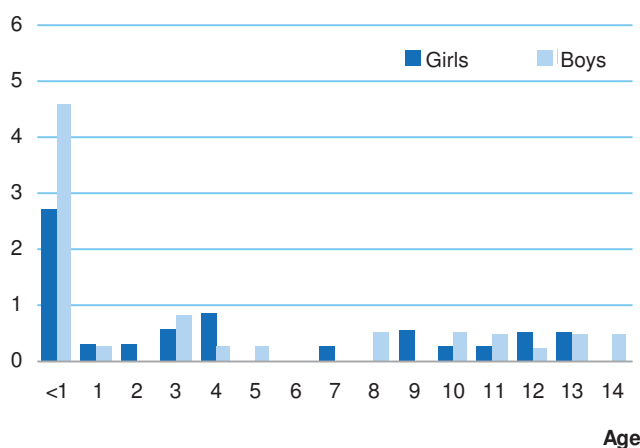
Relative frequency:	47 / 17737 = 0.3 %
Relative frequency of trial patients:	91.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	23	24	47
Standardized rate *:	0.4	0.4	0.4
Cumulative incidence:	6	6	6
Sex ratio (m/f):	1.0		

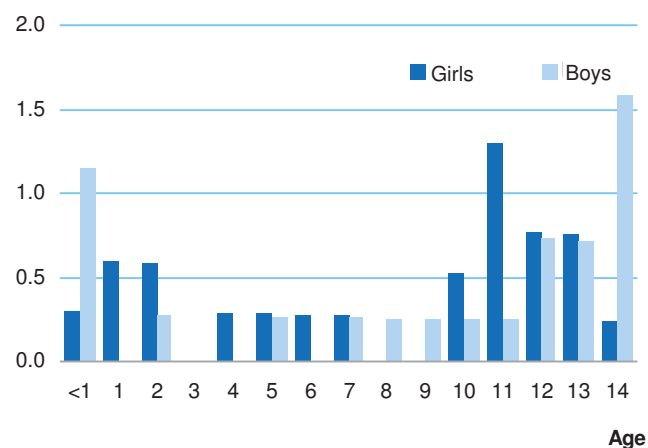
Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases:	5	6	7	29
Incidence rate:	0.7	0.2	0.2	0.7
Median age at diagnosis:	11 years 5 months			

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2004-2013



Age- and sex-specific incidence rates per million
Germany 2004-2013



Cases in Germany aged under 15 years (1980-2013): 901

Selected characteristics Germany 2004-2013

Relative frequency: 308 / 17737 = 1.8 %

Relative frequency of trial patients: 95.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	145	163	308
Standardized rate *:	2.5	2.8	2.7
Cumulative incidence:	39	42	41
Sex ratio (m/f):	1.1		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	35	47	71	155
Incidence rate:	5.1	1.7	1.9	3.9

Median age at diagnosis: 10 years 1 month

Survival probabilities:	5-year	10-year	15-year
	75 %	71 %	68 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
106	2.5 %	0.9	13

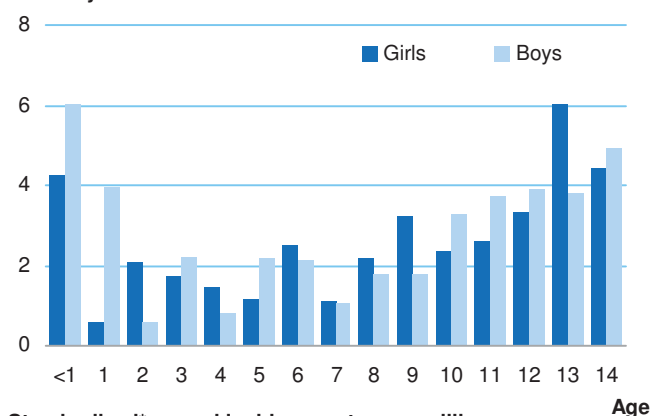
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

IX (d) Other specified soft tissue sarcomas

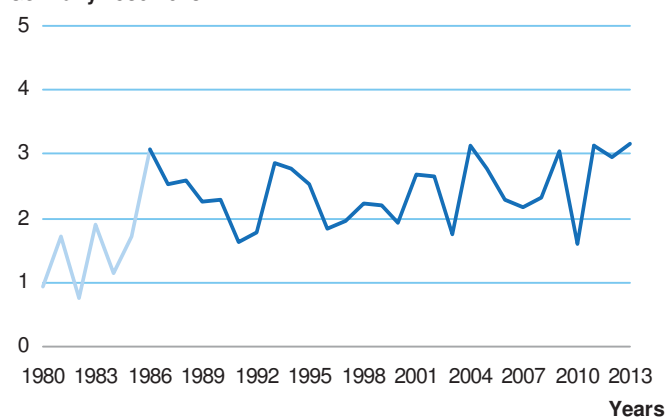
SN after IX (d)			IX (d) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
17	1.6 %	3.9 %	26	2.5 %	0.1 %

* Standard: Segi world standard population

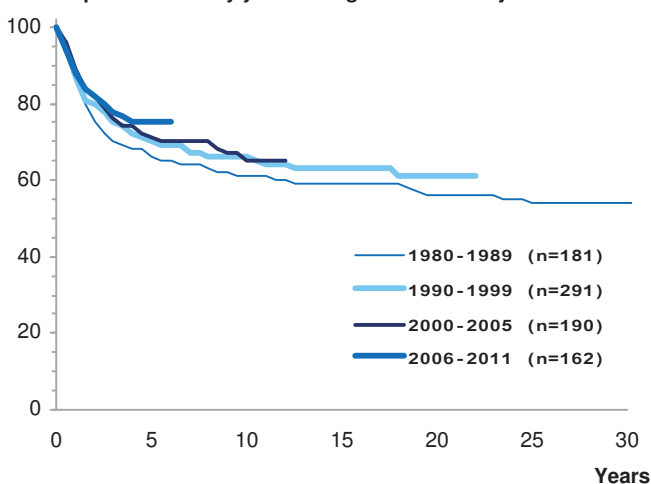
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

54 X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

- (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 (1980-2013): 1722

Selected characteristics Germany 2004-2013

Relative frequency:	561 / 17737 = 3.2 %
Relative frequency of trial patients:	95.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	329	232	561
Standardized rate *:	6.1	4.2	5.1
Cumulative incidence:	90	61	75
Sex ratio (m/f):	0.7		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	140	82	86	253
Incidence rate:	20.6	2.9	2.3	6.3

Median age at diagnosis: 9 years 1 month

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
67	1.6 %	0.5	8

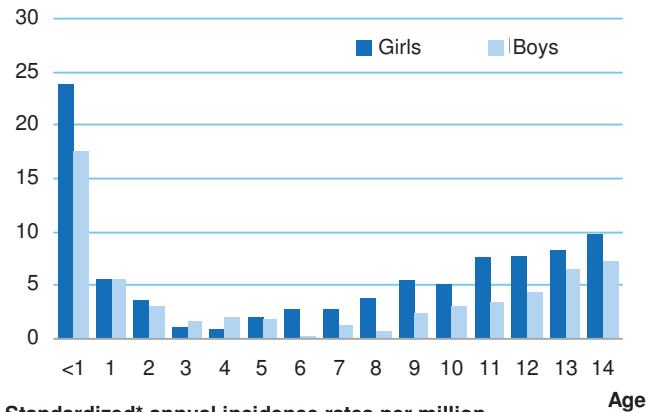
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

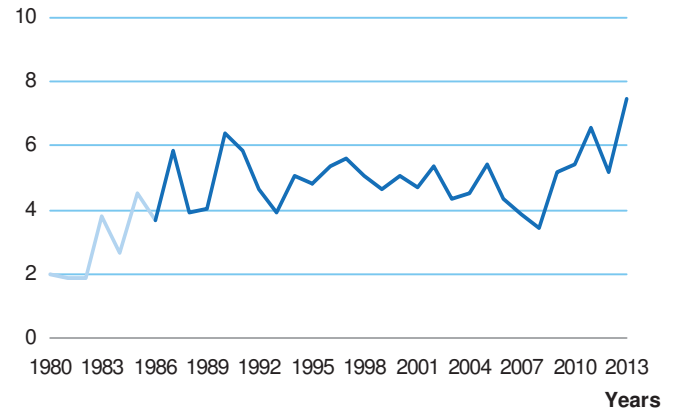
SN after X			X as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
25	2.4 %	5.0 %	10	0.9 %	0.1 %

* Standard: Segi world standard population

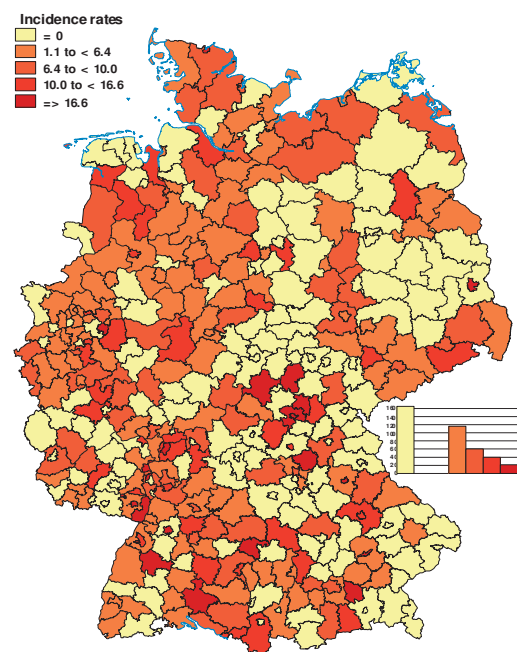
Age- and sex-specific incidence rates per million
 Germany 2004-2013



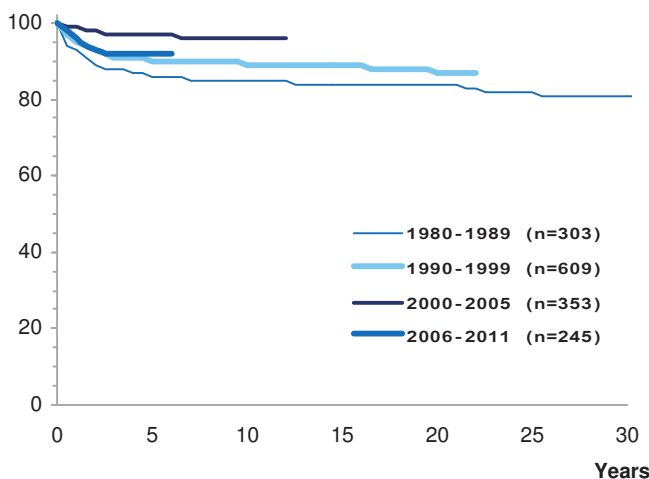
Standardized* annual incidence rates per million
 Germany 1980-2013



Standardized* incidence rates per million by districts
 (Landkreise) Germany 2004-2013



Survival probabilities by year of diagnosis Germany 1980-2011



Cases in Germany aged under 15 years (1980-2013): 465**Selected characteristics Germany 2004-2013**

Relative frequency: 153 / 17737 = 0.9 %

Relative frequency of trial patients: 94.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	57	96	153
Standardized rate *:	1.0	1.5	1.2
Cumulative incidence:	15	24	20
Sex ratio (m/f):	1.7		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	7	8	41	97
Incidence rate:	1.0	0.3	1.1	2.4

Median age at diagnosis: 11 years 2 months

Survival probabilities:

	5-year	10-year	15-year
	92 %	89 %	88 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):

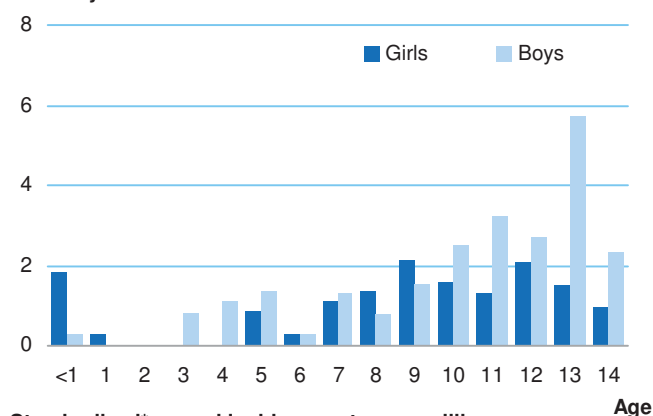
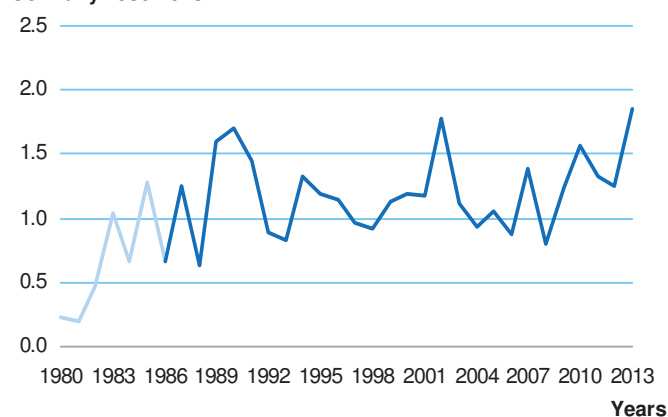
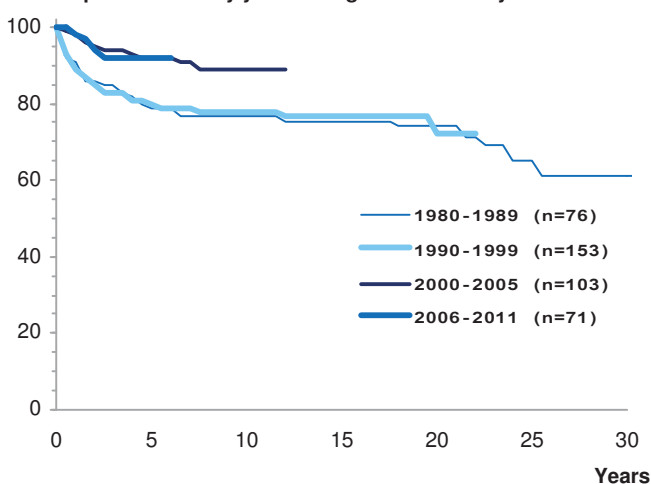
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
36	0.9 %	0.3	4

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

X (a) Intracranial and intraspinal germ cell tumours

SN after X (a)			X (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
11	1.0 %	11.6 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013**Standardized* annual incidence rates per million Germany 1980-2013****Survival probabilities by year of diagnosis Germany 1980-2011**

No map due to sparse data

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

Cases in Germany aged under 15 years (1980-2013): 504

Selected characteristics Germany 2004-2013

Relative frequency:	166 / 17737 = 1 %
Relative frequency of trial patients:	94.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	113	53	166
Standardized rate *:	2.6	1.1	1.8
Cumulative incidence:	33	15	24
Sex ratio (m/f):	0.5		

Age-specific incidence rates per million:				
	<1	1-4	5-9	10-14
Number of cases :	101	44	6	15
Incidence rate:	14.8	1.6	0.2	0.4
Median age at diagnosis:	0 years 5 months			

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
18	0.4 %	0.2	2

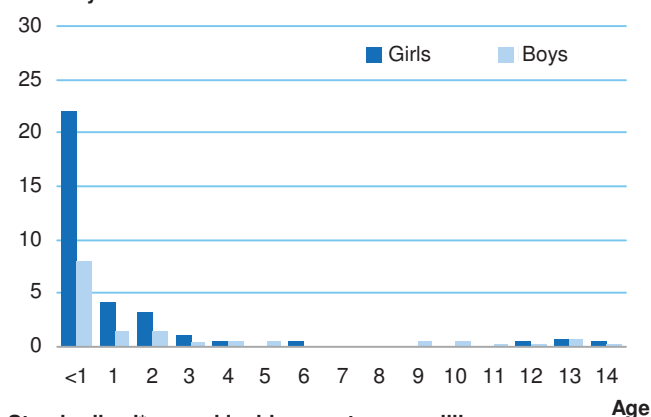
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

X (b) Malignant extracranial and extragonadal germ cell tumours

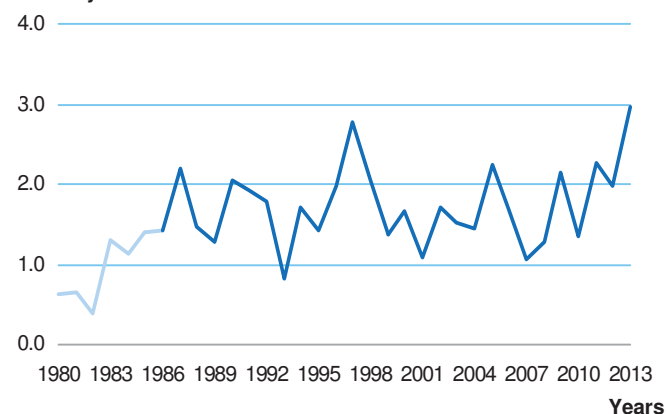
SN after X (b)			X (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
6	0.6 %	3.4 %	2	0.2 %	0.0 %

* Standard: Segi world standard population

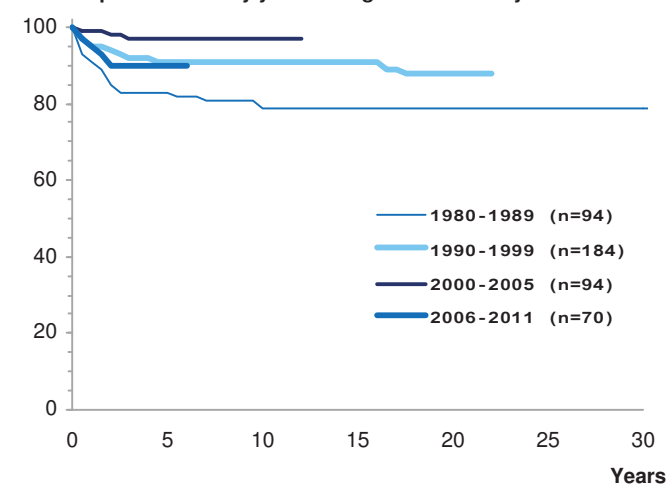
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

Cases in Germany aged under 15 years (1980-2013): 711**Selected characteristics Germany 2004-2013**

Relative frequency:	235 / 17737 = 1.4 %
Relative frequency of trial patients:	97.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	152	83	235
Standardized rate *:	2.4	1.6	2.0
Cumulative incidence:	40	22	31
Sex ratio (m/f):	0.5		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	32	30	38	135
Incidence rate:	4.7	1.1	1.0	3.4
Median age at diagnosis:	11 years 4 months			

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

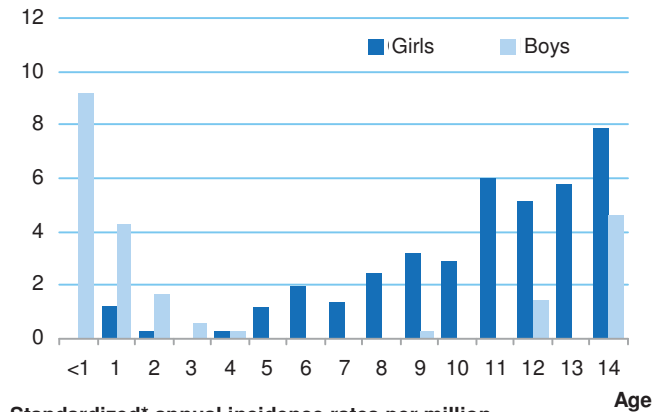
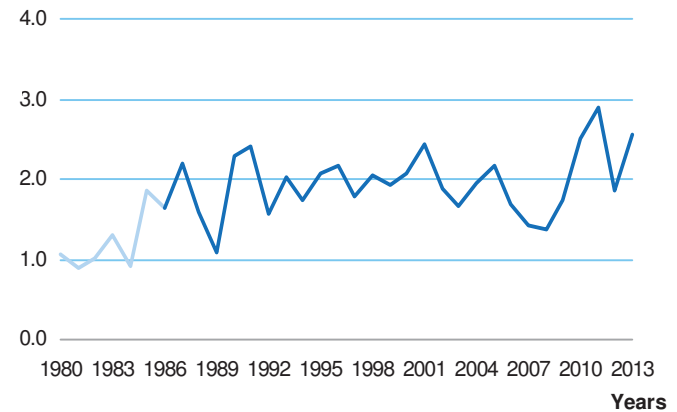
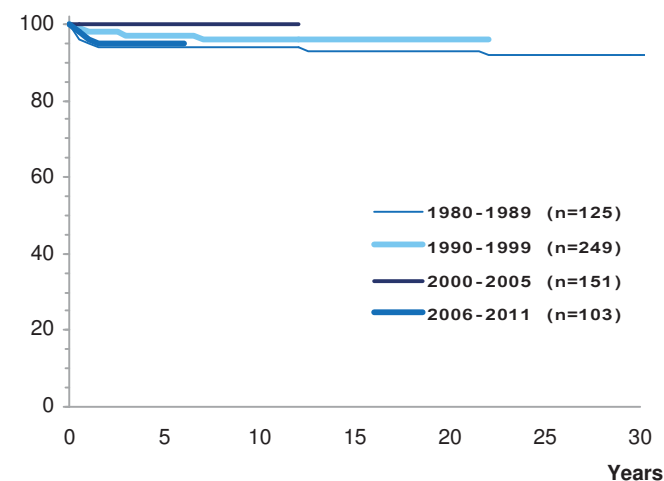
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
8	0.2 %	0.1	1

Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

X (c) Malignant gonadal germ cell tumours

SN after X (c)			X (c) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
8	0.8 %	3.6 %	6	0.6 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2004-2013**Standardized* annual incidence rates per million Germany 1980-2013****Survival probabilities by year of diagnosis Germany 1980-2011**

No map due to sparse data

58 XI (a) Adrenocortical carcinomas

Cases in Germany aged under 15 years (1980-2013): 67

Selected characteristics Germany 2004-2013

Relative frequency:	23 / 17737 = 0.1 %
Relative frequency of trial patients:	100.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	17	6	23
Standardized rate *:	0.3	0.1	0.2
Cumulative incidence:	5	2	3
Sex ratio (m/f):	0.4		

Age-specific incidence rates per million:

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

Median age at diagnosis: 5 years 1 month

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
6	0.1 %	0.1	1

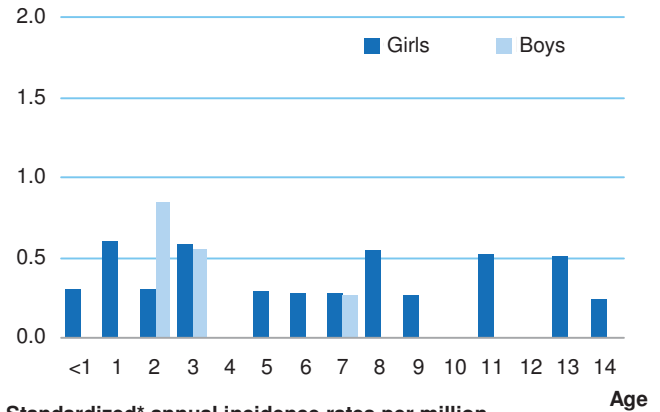
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

XI (a) Adrenocortical carcinomas

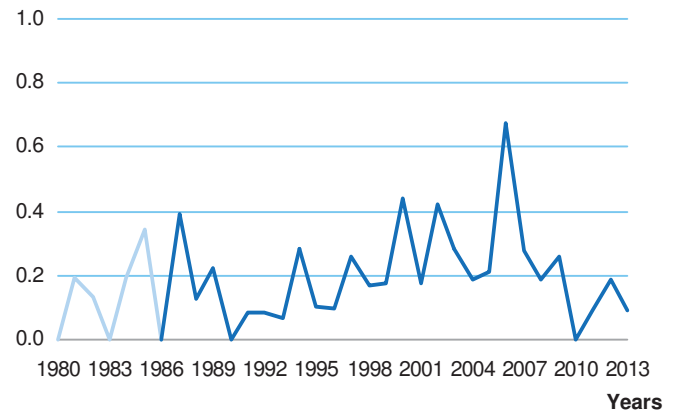
SN after XI (a)			XI (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
4	0.4 %	6.3 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

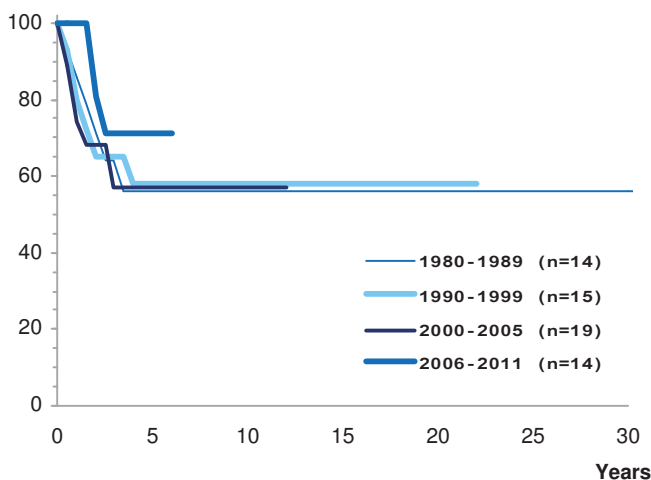
Age- and sex-specific incidence rates per million
Germany 2004-2013



Standardized* annual incidence rates per million
Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

Cases in Germany aged under 15 years (1980-2013): 313

Selected characteristics Germany 2004-2013

Relative frequency:	141 / 17737 = 0.8 %
Relative frequency of trial patients:	89.4 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	85	56	141
Standardized rate *:	1.3	0.8	1.1
Cumulative incidence:	22	14	18
Sex ratio (m/f):	0.7		

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	2	2	30	107
Incidence rate:	0.3	0.1	0.8	2.7
Median age at diagnosis:	12 years 7 months			

Survival probabilities:	5-year	10-year	15-year
	97 %	96 %	92 %

Mortality per million within 15 yrs. of diagnosis (1989-1998):			
Number of deaths		Standardized*	Cumulative
N	% of all 4179 deaths	mortality rate	mortality
8	0.2 %	0.1	1

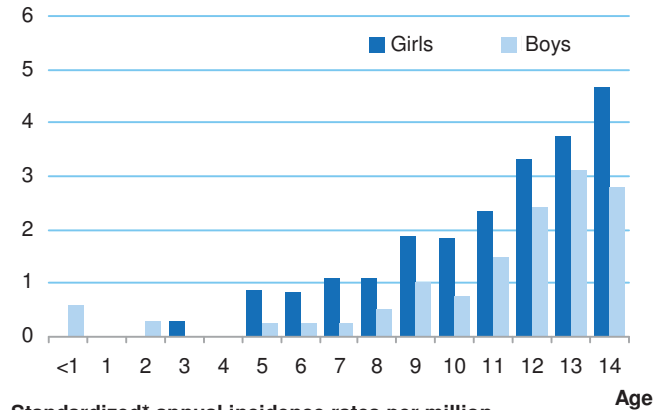
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

XI (b) Thyroid carcinomas

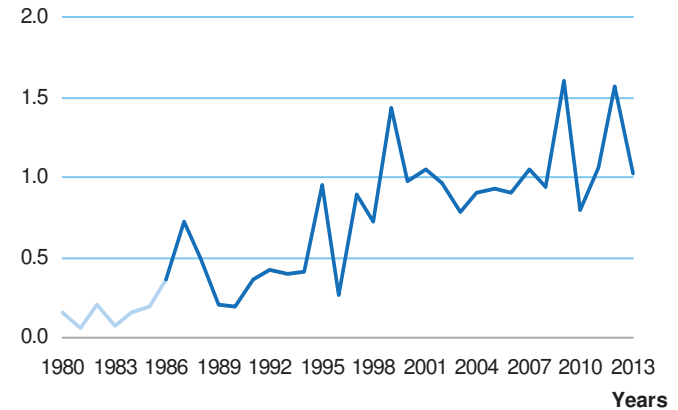
SN after XI (b)			XI (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
2	0.2 %	2.6 %	110	10.4 %	0.6 %

* Standard: Segi world standard population

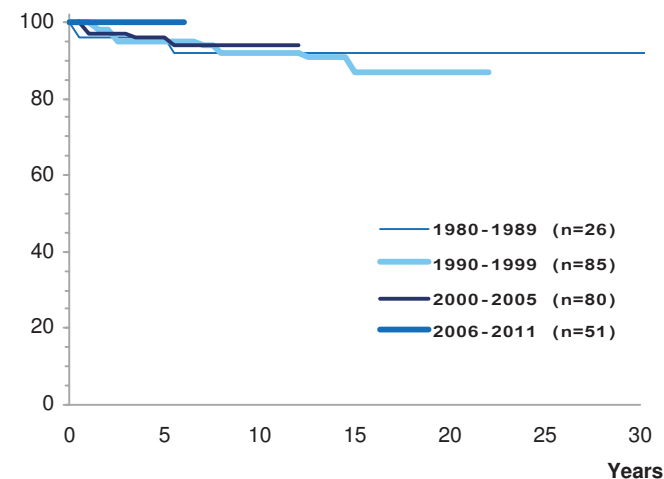
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

60 XI (c) Nasopharyngeal carcinomas

Cases in Germany aged under 15 years (1980-2013): 71

Selected characteristics Germany 2004-2013

Relative frequency:	23 / 17737 = 0.1 %
Relative frequency of trial patients:	100.0 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	5	18	23
Standardized rate *:	0.1	0.3	0.2
Cumulative incidence:	1	4	3
Sex ratio (m/f):	3.6		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	1	0	22
Incidence rate:	0.0	0.0	0.0	0.5

Median age at diagnosis: 12 years 10 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
6	0.1 %	0.0	1

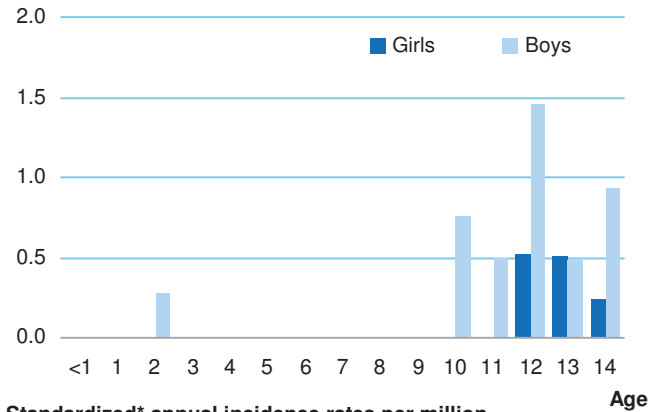
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

XI (c) Nasopharyngeal carcinomas

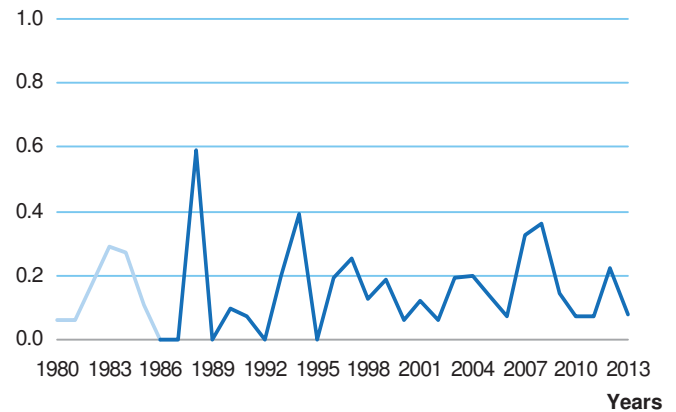
SN after XI (c)			XI (c) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
0	0.0 %	0.0 %	3	0.3 %	0.0 %

* Standard: Segi world standard population

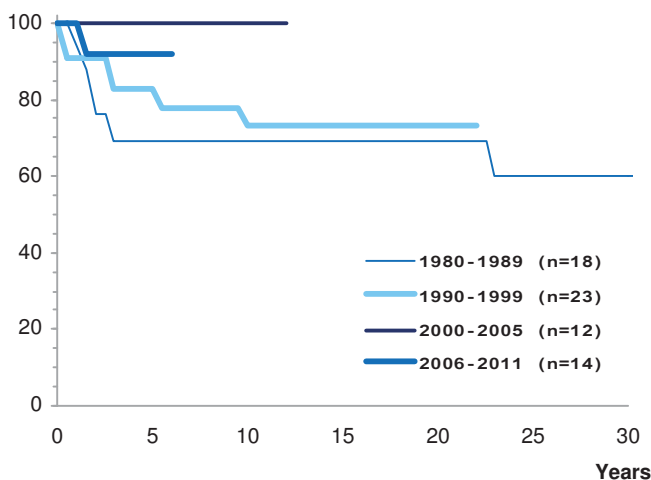
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

Cases in Germany aged under 15 years (1980-2013): 98

Selected characteristics Germany 2004-2013

Relative frequency:	59 / 17737 = 0.3 %
Relative frequency of trial patients:	6.8 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	27	32	59
Standardized rate *:	0.5	0.5	0.5
Cumulative incidence:	7	8	8
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:	<1	1-4	5-9	10-14
Number of cases :	3	13	16	27
Incidence rate:	0.4	0.5	0.4	0.7
Median age at diagnosis:				9 years 6 months

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

Mortality per million within 15 yrs. of diagnosis (1989-1998):			
Number of deaths	Standardized*	Cumulative	
N % of all 4179 deaths	mortality rate	mortality	
9 0.2 %	0.1	1	

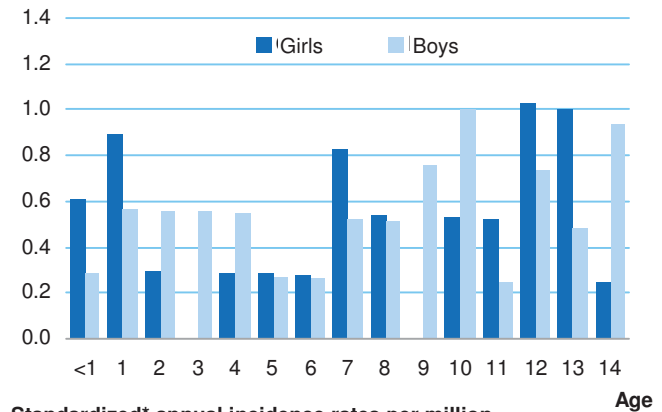
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

XI (d) Malignant melanomas

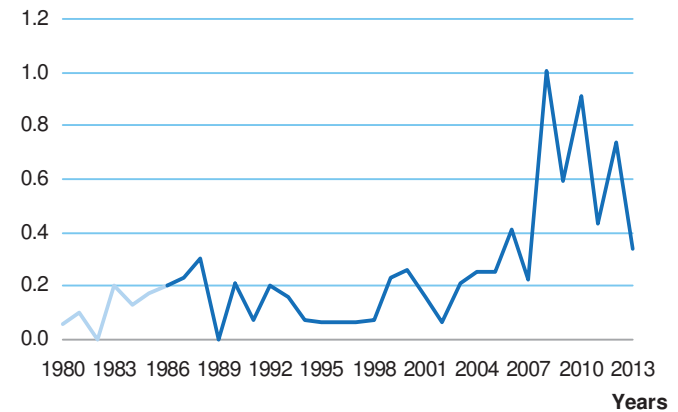
SN after XI (d)			XI (d) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
1	0.1 %	14.2 %	22	2.1 %	0.1 %

* Standard: Segi world standard population

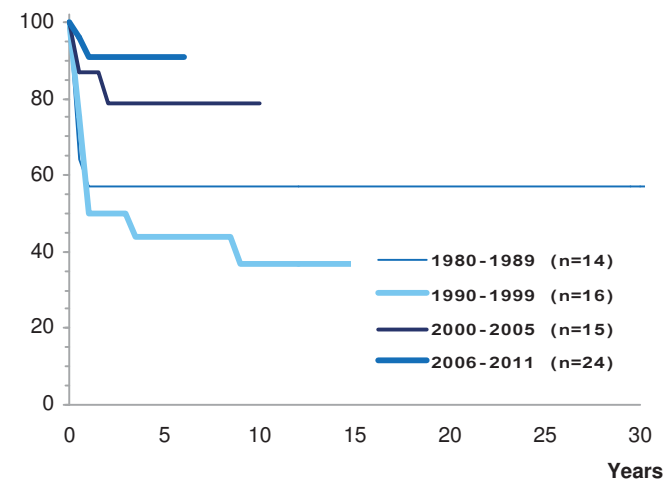
Age- and sex-specific incidence rates per million Germany 2004-2013



Standardized* annual incidence rates per million Germany 1980-2013



Survival probabilities by year of diagnosis Germany 1980-2011



No map due to sparse data

62 XII (a) Other specified malignant tumours

Cases in Germany aged under 15 years (1980-2013): 44

Selected characteristics Germany 2004-2013

Relative frequency: 19 / 17737 = 0.1 %

Relative frequency of trial patients: 84.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	10	9	19
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	3	2	3
Sex ratio (m/f):	0.9		

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	0	12	3	4
Incidence rate:	0.0	0.4	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 (1989-1998):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4179 deaths		
4	0.1 %	0.0	0

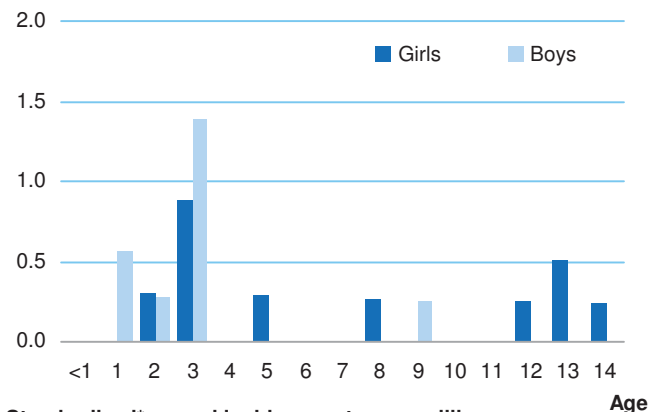
Second neoplasms (SN) within 25 yrs. of diagnosis (1980-2013):

XII (a) Other specified malignant tumours

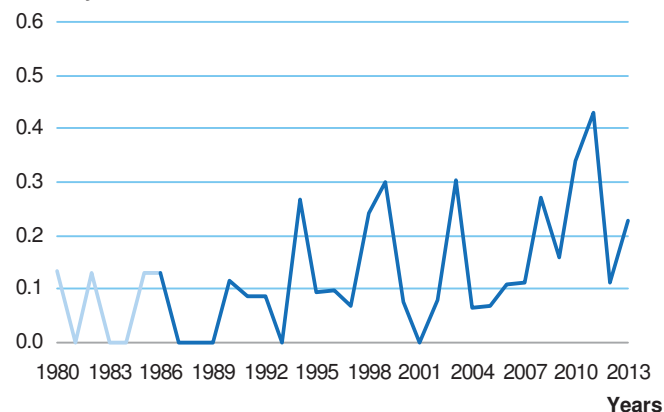
SN after XII (a)			XII (a) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
2	0.2 %	7.4 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2004-2013



Standardized* annual incidence rates per million
Germany 1980-2013



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 (2004-2013) /

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 (2004-2013)

65

Abbildung 1 / Figure 1

Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2004-2013, Patienten unter 18 Jahren /

Reported cases to the GCCR (registry population) per hospital, period 2004-2013, patients under 18 years

76

Tabelle 2 / Table 2

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

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

76

Abbildung 2 / Figure 2

Relative Häufigkeit der gemeldeten Patienten aus der deutschen Wohnbevölkerung nach den häufigsten ICCC-3 Diagnose-Hauptgruppen und Alter /

Relative frequencies of the registered patients in Germany by the main ICCC-3 diagnosis groups and age

77

Tabelle 3 / Table 3

Anzahl der gemeldeten Patienten unter 15 Jahren, 15 bis < 18 Jahren und unter 18 Jahren auf Basis des ICCC-3, altersstandardisierte Inzidenzrate und Bevölkerungsbezug nach Jahren für Gesamtdeutschland /

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

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Tabelle 4 / Table 4

Verteilung aller Registermeldungen aus der deutschen Wohnbevölkerung nach Altersgruppen bei Diagnosestellung ohne Altersbeschränkung sowie zusätzlich erfasste Diagnosen (2004-2013) /

Distribution of all reported cases in Germany by age groups at diagnosis without any restriction of age and additional diagnoses (2004-2013)

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Tabelle 5 / Table 5

Nicht in der ICCC-3 definierte, systematisch registrierte Diagnosen der Patienten unter 15 Jahren (2004-2013) /
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Tabelle 6 / Table 6

Altersstandardisierte Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert für Patienten unter 15 Jahren (2004-2013) /

Age-standardized incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for patients under 15 by region (2004-2013)

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Tabelle 7 / Table 7

Anzahl der verstorbenen Patienten innerhalb von 5 bzw. 10 Jahren nach Diagnose auf Basis des ICCC-3 unter den gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung und alterstandardisierte Mortalitätsraten nach Diagnosejahr, 1980-2008 (inkl. Neue Länder seit 1991) /

Annual number of deaths 5 or 10 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 1980-2008 (incl. East Germany since 1991)

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Anzahl der am Deutschen Kinderkrebsregister in der Langzeitnachbeobachtung (LTS) befindlichen Patienten mit Erstdiagnose im Alter von unter 18 (Stand 2013) /

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged under 18 (as of 2013)

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Tabelle 9 / Table 9

Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Jugendliche unter 18 aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2009-2013) /

Number of cases and incidence rates per million adolescents aged under 18 years in Germany by diagnoses classified according to ICCC-3, age and sex (2009-2013)

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Zahl der vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister (LKR) bis einschließlich 2013 weitergeleiteten Meldungen /

Number of forwarded reports from the German Childhood Cancer Registry to the state cancer registries (LKR) up to and including 2013

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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 (2004-2013). *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 (2004-2013).
ICCC-3 extended subclassification in italics.

Diagnoses		Sex	Sex ratio	N	Relative		Number of cases			Age groups			Incidence rates per million					Trial participants		Survival probabilities(%)	
		m / f	0 - 14	%	%	Group	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World *	0 - 14	Cum.	%	5-yrs	10-yrs 15-yrs	
All malignancies		girls		7925	100	100	861	2732	1986	2346	260	200	109	120	153	2206		93.6	84	83	81
		boys		9812	100	100	991	3298	2705	2818	284	229	141	137	179	2592		94.0	84	82	80
		total	1.2	17737	100	100	1852	6030	4691	5164	272	215	126	129	166	2404		93.9	84	82	81
Leukaemias, myeloproliferative and myelodysplastic diseases		girls		2662	34	100	135	1246	720	561	41	91	40	29	53	747		99.1	88	86	85
		boys		3261	33	100	159	1442	928	732	46	100	48	36	61	867		99.2	88	86	85
		total	1.2	5923	33	100	294	2688	1648	1293	43	96	44	32	57	809		99.1	88	86	85
Lymphoid leukaemias		girls		2048	26	77	64	1049	581	354	19	77	32	18	41	577		99.6	92	90	89
		boys		2548	26	78	53	1226	751	518	15	85	39	25	48	678		99.8	91	89	88
		total	1.2	4596	26	78	117	2275	1332	872	17	81	36	22	44	629		99.7	92	90	89
Precursor cell leukaemias		girls		2025	26	76	63	1042	569	351	19	76	31	18	40	571		99.7	92	90	89
		boys		2461	25	76	51	1205	714	491	15	84	37	24	46	656		99.8	91	89	88
		total	1.2	4486	25	76	114	2247	1283	842	17	80	34	21	43	614		99.8	92	90	89
Mature B-cell leukaemias		girls		21	0	1	1	6	12	2	0	0	1	0	0	6		95.2	78	78	78
		boys		87	1	3	2	21	37	27	1	1	2	1	1	23		100.0	86	86	85
		total	4.1	108	1	2	3	27	49	29	0	1	1	1	1	14		99.1	85	85	83
Mature T-cell and NK cell leukaemias		girls		2	0	0	0	1	0	1	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	1	0	1	0	0	0	0	0	0		50.0	-	-	-
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		376	5	14	52	143	65	116	16	10	4	6	7	105		97.9	72	72	71
		boys		392	4	12	64	133	90	105	18	9	5	5	7	104		96.7	73	72	71
		total	1.0	768	4	13	116	276	155	221	17	10	4	6	7	105		97.3	73	72	71
Chronic myeloproliferative diseases		girls		35	0	1	0	4	13	18	0	0	1	1	1	9		88.6	82	82	82
		boys		37	0	1	1	5	11	20	0	0	1	1	1	9		81.1	93	93	93
		total	1.1	72	0	1	1	9	24	38	0	0	1	1	1	9		84.7	87	87	87
Myelodysplastic syndrome and other myeloproliferative diseases		girls		167	2	6	12	43	50	62	4	3	3	3	3	46		98.2	78	77	75
		boys		249	3	8	33	68	68	80	9	5	4	4	4	66		99.2	79	76	75
		total	1.5	416	2	7	45	111	118	142	7	4	3	4	4	56		98.8	79	77	75

* Standard: Segi world standard population

- insufficient data

Table 1 cont.

Diagnoses		Sex ratio	Sex m / f	N	Relative	Number of cases		Age groups				Incidence rates per million					Trial participants		Survival probabilities(%)	
						Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World*	0-14	%	5-yrs	10-yrs
Unspecified and other specified leukaemias	girls		36	1	1	7	7	11	11	2	1	1	1	1	1	10	100.0	65	65	58
	boys		35	0	1	8	10	8	9	2	1	0	0	1	1	9	97.1	64	64	64
	total	1.0	71	0	1	15	17	19	20	2	1	1	0	1	1	10	98.6	65	65	61
Lymphomas and reticuloendothelial neoplasms	girls		633	8	100	4	54	158	417	1	4	9	21	10	167	96.8	92	91	91	
	boys		1306	13	100	5	168	493	640	1	12	26	31	21	332	96.2	94	93	92	
	total	2.1	1939	11	100	9	222	651	1057	1	8	17	26	16	252	96.4	94	93	92	
Hodgkin lymphomas	girls		322	4	51	0	5	42	275	0	0	2	14	5	83	99.1	98	97	97	
	boys		493	5	38	0	29	146	318	0	2	8	15	8	123	96.6	99	98	98	
	total	1.5	815	5	42	0	34	188	593	0	1	5	15	6	104	97.5	99	98	97	
Non-Hodgkin lymphomas	girls		244	3	39	1	41	86	116	0	3	5	6	4	66	94.7	84	83	83	
	boys		529	5	41	5	83	208	233	1	6	11	11	9	135	94.9	91	89	88	
	total	2.2	773	4	40	6	124	294	349	1	4	8	9	6	101	94.8	89	87	86	
Precursor cell lymphomas	girls		90	1	14	1	17	41	31	0	1	2	2	2	24	90.0	85	84	83	
	boys		204	2	16	3	45	79	77	1	3	4	4	3	53	95.6	89	88	87	
	total	2.3	294	2	15	4	62	120	108	1	2	3	3	3	39	93.9	88	87	85	
Mature B-cell lymphomas (except Burkitt lymphoma)	girls		51	1	8	0	6	20	25	0	0	1	1	1	14	96.1	87	85	83	
	boys		96	1	7	0	7	30	59	0	0	2	3	1	24	94.8	95	92	92	
	total	1.9	147	1	8	0	13	50	84	0	0	1	2	1	19	95.2	93	90	89	
Mature T-cell and NK-cell lymphomas	girls		60	1	10	0	10	12	38	0	1	1	2	1	16	96.7	80	80	80	
	boys		101	1	8	1	14	39	47	0	1	2	2	2	26	97.0	89	89	86	
	total	1.7	161	1	8	1	24	51	85	0	1	1	2	1	21	96.9	86	86	84	
Non-Hodgkin lymphomas, NOS	girls		43	1	7	0	8	13	22	0	1	1	1	1	12	100.0	86	86	86	
	boys		128	1	10	1	17	60	50	0	1	3	2	2	33	92.2	92	90	88	
	total	3.0	171	1	9	1	25	73	72	0	1	2	2	1	22	94.2	90	89	87	
Burkitt lymphoma	girls		59	1	9	0	7	29	23	0	1	2	1	1	16	98.3	94	93	93	
	boys		280	3	21	0	56	136	88	0	4	7	4	5	72	98.6	93	92	91	
	total	4.7	339	2	18	0	63	165	111	0	2	4	3	3	45	98.5	93	92	92	
Miscellaneous lymphoreticular neoplasms	girls		5	0	1	3	0	1	1	1	0	0	0	0	1	60.0	-	-	-	
	boys		2	0	0	0	0	1	1	0	0	0	0	0	1	0.0	-	-	-	
	total	0.4	7	0	0	3	0	2	2	0	0	0	0	0	1	42.9	-	-	-	

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	N	Relative		Number of cases		Age groups				Incidence rates per million				Trial participants		Survival probabilities(%)	
Sex	m / f	0 - 14	%	%	Group	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World*	0 - 14	%	5-yrs	10-yrs	15-yrs
Unspecified lymphomas		girls	3	0	1	0	1	0	2	0	0	0	0	0	0	1	66.7	-	-
		boys	2	0	0	0	0	2	0	0	0	0	0	0	0	1	100.0	-	-
		total	0.7	5	0	0	1	2	2	0	0	0	0	0	0	1	80.0	-	-
CNS and miscellaneous intracranial and intraspinal neoplasms		girls	1928	24	100	141	570	614	603	43	42	34	31	36	533	92.8	79	76	74
		boys	2399	24	100	161	702	824	712	46	49	43	35	43	630	93.1	76	71	69
		total	1.2	4327	24	100	302	1272	1438	1315	44	45	39	39	582	93.0	78	74	71
Ependymomas		girls	186	2	10	38	83	36	29	11	6	2	1	4	53	96.8	84	81	77
and choroid plexus tumour		boys	249	3	10	37	107	51	54	11	7	3	3	5	67	93.6	79	67	63
		total	1.3	435	3	10	75	190	87	83	11	7	2	4	60	94.9	81	73	69
Ependymomas		girls	135	2	7	12	71	29	23	4	5	2	1	3	38	97.0	82	79	75
		boys	202	2	8	17	93	44	48	5	6	2	2	4	54	95.0	77	66	61
		total	1.5	337	2	8	29	164	73	71	4	6	2	3	46	95.8	79	72	67
Choroid plexus tumour		girls	51	1	3	26	12	7	6	8	1	0	0	1	15	96.1	90	85	80
		boys	47	1	2	20	14	7	6	6	1	0	0	1	13	87.2	84	72	72
		total	0.9	98	1	2	46	26	14	12	7	1	0	1	14	91.8	87	78	76
Astrocytomas		girls	964	12	50	46	269	317	332	14	20	17	17	18	265	94.5	83	80	79
		boys	1060	11	44	49	284	397	330	14	20	21	16	19	277	93.8	80	77	75
		total	1.1	2024	11	47	95	553	714	662	14	20	19	18	271	94.1	81	79	77
Intracranial and intraspinal embryonal tumours		girls	284	4	15	37	114	90	43	11	8	5	2	6	80	93.3	67	62	58
		boys	507	5	21	52	187	190	78	15	13	10	4	10	136	94.7	67	58	55
		total	1.8	791	5	18	89	301	280	121	13	11	8	3	109	94.2	67	59	56
Medulloblastomas		girls	188	2	10	12	66	77	33	4	5	4	2	4	53	97.3	77	71	65
		boys	367	4	15	11	121	164	71	3	8	9	3	7	97	98.4	77	66	64
		total	2.0	555	3	13	23	187	241	104	3	7	6	3	75	98.0	77	68	64
Primitive neuroectodermal tumour (PNET)		girls	37	1	2	2	23	3	9	1	2	0	0	1	10	97.3	59	52	52
		boys	53	1	2	6	28	13	6	2	2	1	0	1	14	100.0	46	43	40
		total	1.4	90	1	2	8	51	16	15	1	2	0	1	12	98.9	51	47	45
Medulloepithelioma		girls	2	0	0	0	1	1	0	0	0	0	0	0	1	50.0	-	-	-
		boys	4	0	0	3	0	1	0	1	0	0	0	0	1	100.0	-	-	-
		total	2.0	6	0	0	3	1	2	0	0	0	0	0	1	83.3	-	-	-

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex	N	Relative	Number of cases		Age groups			Incidence rates per million					Trial participants		Survival probabilities(%)			
		m / f	0 - 14	%	%	Group	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	Age-specific	Age-stand.	Cum.	%	5-yrs	10-yrs	15-yrs
Atypical teratoid/rhabdoid tumour		girls	57	1	3	23	24	9	1	7	2	0	0	1	17		17	78.9	22	-	-
		boys	83	1	4	32	38	12	1	9	3	1	0	2	23		23	74.7	38	-	-
		total	1.5	140	1	3	55	62	21	2	8	2	1	0	2	20		20	76.4	32	-
Other gliomas		girls	193	2	10	8	44	83	58	2	3	5	3	4	53		53	87.0	49	49	49
		boys	203	2	9	8	47	70	78	2	3	4	4	3	53		53	91.6	50	49	48
		total	1.1	396	2	9	16	91	153	136	2	3	4	3	3	53		53	89.4	49	49
Oligodendrogliomas		girls	7	0	0	0	0	3	4	0	0	0	0	0	2		2	71.4	-	-	-
		boys	9	0	0	0	1	1	7	0	0	0	0	0	2		2	77.8	-	-	-
		total	1.3	16	0	0	0	1	4	11	0	0	0	0	0	2		2	75.0	-	-
Mixed and unspecified gliomas		girls	177	2	9	7	41	78	51	2	3	4	3	3	49		49	87.0	45	45	45
		boys	189	2	8	8	46	69	66	2	3	4	3	3	49		49	92.1	47	46	45
		total	1.1	366	2	9	15	87	147	117	2	3	4	3	3	49		49	89.6	46	46
Neuroepithelial glial tumours of uncertain origin		girls	9	0	1	1	3	2	3	0	0	0	0	0	2		2	100.0	-	-	-
		boys	5	0	0	0	0	0	5	0	0	0	0	0	1		1	100.0	-	-	-
		total	0.6	14	0	0	1	3	2	8	0	0	0	0	0	2		2	100.0	-	-
Other specified intracranial and intraspinal neoplasms		girls	267	3	14	9	50	85	123	3	4	5	6	5	72		72	91.0	98	95	92
		boys	342	4	14	10	71	103	158	3	5	5	8	6	88		88	91.2	94	92	89
		total	1.3	609	3	14	19	121	188	281	3	4	5	7	5	80		80	91.1	96	94
Pituitary adenomas and carcinomas		girls	15	0	1	0	1	1	13	0	0	0	1	0	4		4	53.3	100	100	-
		boys	19	0	1	0	0	2	17	0	0	0	1	0	5		5	63.2	100	100	-
		total	1.3	34	0	1	0	1	3	30	0	0	0	1	0	4		4	58.8	100	100
Tumours of the sellar region (craniopharyngiomas)		girls	96	1	5	0	19	37	40	0	1	2	2	2	26		26	100.0	100	98	95
		boys	98	1	4	1	25	36	36	0	2	2	2	2	25		25	98.0	98	96	90
		total	1.0	194	1	5	1	44	73	76	0	2	2	2	2	26		26	99.0	99	97
Pineal parenchymal tumours		girls	12	0	1	1	1	5	5	0	0	0	0	0	3		3	100.0	80	80	-
		boys	15	0	1	0	9	2	4	0	1	0	0	0	4		4	86.7	64	60	-
		total	1.3	27	0	1	1	10	7	9	0	0	0	0	0	4		4	92.6	71	68
Neuronal and mixed neuronal-glial tumours		girls	119	2	6	8	25	32	54	2	2	2	3	2	32		32	90.8	98	95	92
		boys	186	2	8	9	34	54	89	3	2	3	4	3	48		48	94.1	94	94	94
		total	1.6	305	2	7	17	59	86	143	2	2	2	4	3	40		40	92.8	96	95

Tabelle 1 Forts. Table 1 cont.

Diagnoses	Sex ratio m / f	Sex ratio	N	Relative %	Number of cases					Incidence rates per million					Trial participants		Survival probabilities(%)	
					Age groups					Age-specific					Cum.		5-10-15 yrs	
					0	1-4	5-9	10-14	15-19	0	1-4	5-9	10-14	15-19	0-14	15-19	5-10-15 yrs	15-19 yrs
<i>Meningiomas</i>	girls		25	0	1	0	4	10	11	0	0	1	1	0	7	76.0	96	92
	boys		24	0	1	0	3	9	12	0	0	0	1	0	6	66.7	88	82
	total	1.0	49	0	1	0	7	19	23	0	0	1	1	0	6	71.4	92	91
Unspecified intracranial and intraspinal neoplasms	girls		34	0	2	3	10	3	18	1	1	0	1	1	9	67.6	76	76
	boys		38	0	2	5	6	13	14	1	0	1	1	1	10	73.7	78	72
	total	1.1	72	0	2	8	16	32	32	1	1	0	1	1	10	70.8	78	75
Neuroblastoma and other peripheral nervous cell tumours	girls		565	7	100	263	236	46	20	79	17	3	1	13	166	98.2	78	76
	boys		681	7	100	316	305	44	16	91	21	2	1	15	191	98.8	80	77
	total	1.2	1246	7	100	579	541	90	36	85	19	2	1	14	179	98.6	79	77
Neuroblastoma and ganglioneuroblastoma	girls		560	7	99	263	232	46	19	79	17	3	1	13	165	98.8	78	76
	boys		676	7	99	316	304	43	13	91	21	2	1	15	190	99.0	80	77
	total	1.2	1236	7	99	579	536	89	32	85	19	2	1	14	178	98.9	79	77
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		172	2	100	84	83	5	0	25	6	0	0	4	51	2.3	98	97
	boys		197	2	100	85	101	8	3	24	7	0	0	4	55	0.5	97	96
	total	1.1	369	2	100	169	184	13	3	25	7	0	0	4	53	1.4	97	97
Renal tumours	girls		500	6	100	71	289	111	29	21	21	6	1	11	144	99.0	94	93
	boys		449	5	100	82	251	93	23	24	17	5	1	9	123	98.4	91	91
	total	0.9	949	5	100	153	540	204	52	22	19	5	1	10	133	98.7	93	92
Nephroblastoma and other non-epithelial renal tumours	girls		485	6	97	71	288	107	19	21	21	6	1	10	140	99.6	94	93
	boys		434	4	97	82	251	89	12	24	17	5	1	9	120	99.1	91	91
	total	0.9	919	5	97	153	539	196	31	22	19	5	1	10	130	99.3	93	92
<i>Nephroblastoma</i>	girls		474	6	95	64	286	105	19	19	21	6	1	10	137	99.6	95	94
	boys		423	4	94	80	247	86	10	23	17	4	0	9	117	99.3	92	92
	total	0.9	897	5	95	144	533	191	29	21	19	5	1	9	126	99.4	94	93
<i>Rhabdoid renal tumour</i>	girls		8	0	2	6	2	0	0	2	0	0	0	0	2	100.0	-	-
	boys		8	0	2	2	4	1	1	1	0	0	0	0	2	87.5	-	-
	total	1.0	16	0	2	8	6	1	1	1	0	0	0	0	2	93.8	-	-

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	N	Relative	Number of cases		Age groups				Incidence rates per million					Trial participants		Survival probabilities(%)	
		m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World *	0 - 14	%	5-yrs	10-yrs	15-yrs
Kidney sarcomas	girls		3	0	1	1	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	1.0	6	0	1	1	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	-	100	100	100
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	100	100	100
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	-	100	100	100
Renal carcinomas	girls		14	0	3	0	1	4	9	0	0	0	0	0	4	78.6	100	-	-
	boys		15	0	3	0	0	4	11	0	0	0	1	0	4	80.0	85	-	-
	total	1.1	29	0	3	0	1	8	20	0	0	0	0	0	4	79.3	93	-	-
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		95	1	100	31	48	4	12	9	4	0	1	2	28	72.6	69	67	67
	boys		138	1	100	38	72	9	19	11	5	0	1	3	38	81.2	75	72	70
	total	1.5	233	1	100	69	120	13	31	10	4	0	1	2	33	77.7	72	70	69
Hepatoblastoma	girls		82	1	86	31	46	4	1	9	3	0	0	2	24	74.4	74	74	74
	boys		119	1	86	38	71	4	6	11	5	0	0	3	33	80.7	80	77	77
	total	1.5	201	1	86	69	117	8	7	10	4	0	0	2	29	78.1	77	76	76
Hepatic carcinomas	girls		13	0	14	0	2	0	11	0	0	0	1	0	3	61.5	-	-	-
	boys		19	0	14	0	1	5	13	0	0	0	1	0	5	84.2	-	-	-
	total	1.5	32	0	14	0	3	5	24	0	0	0	1	0	4	75.0	-	-	-
Unspecified malignant hepatic tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	100	100	100
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	100	100	100
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	-	100	100	100
Malignant bone tumours	girls		366	5	100	1	16	101	248	0	1	6	13	6	96	96.7	72	68	67
	boys		418	4	100	3	29	108	278	1	2	6	13	6	105	97.6	73	68	67
	total	1.1	784	4	100	4	45	209	526	1	2	6	13	6	100	97.2	72	68	67
Osteosarcomas	girls		200	3	55	0	2	49	149	0	0	3	8	3	52	98.5	76	73	71
	boys		204	2	49	0	6	42	156	0	0	2	8	3	50	98.5	74	69	68
	total	1.0	404	2	52	0	8	91	305	0	0	2	8	3	51	98.5	75	71	70

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	Sex	Number of cases			Age groups							Incidence rates per million							Trial participants		Survival probabilities(%)	
				N	Relative	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World*	0-14	%	5-yrs	10-yrs	15-yrs			
Chondrosarcomas		girls	6	0	2	0	0	2	4	0	0	0	0	0	0	2	66.7	-	-					
		boys	7	0	2	1	0	0	6	0	0	0	0	0	0	2	71.4	-	-					
		total	13	0	2	1	0	2	10	0	0	0	0	0	0	2	69.2	-	-					
Ewing tumour and related sarcomas of bone		girls	151	2	41	1	13	47	90	0	1	3	5	2	40	97.4	-	-						
		boys	197	2	47	2	22	63	110	1	2	3	5	3	50	99.5	-	-						
		total	348	2	44	3	35	110	200	0	1	3	5	3	45	98.6	-	-						
Other specified malignant bone tumours		girls	6	0	2	0	1	2	3	0	0	0	0	0	2	83.3	-	-						
		boys	7	0	2	0	1	3	3	0	0	0	0	0	2	71.4	-	-						
		total	13	0	2	0	2	5	6	0	0	0	0	0	2	76.9	-	-						
Malignant fibrous neoplasms of bone		girls	1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-						
		boys	1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-						
		total	1.0	2	0	0	0	0	2	0	0	0	0	0	0	100.0	-	-						
Malignant chordomas		girls	3	0	1	0	1	2	0	0	0	0	0	0	1	100.0	-	-						
		boys	5	0	1	0	0	3	2	0	0	0	0	0	1	60.0	-	-						
		total	1.7	8	0	1	0	1	5	2	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	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	50.0	-	-						
Unspecified malignant bone tumours		girls	3	0	1	0	0	1	2	0	0	0	0	0	1	33.3	-	-						
		boys	3	0	1	0	0	0	3	0	0	0	0	0	1	33.3	-	-						
		total	1.0	6	0	1	0	0	1	5	0	0	0	0	1	33.3	-	-						
Soft tissue and other extraosseous sarcomas		girls	477	6	100	49	134	123	171	15	10	7	9	9	132	97.5	73	70	68					
		boys	565	6	100	78	160	142	185	22	11	7	9	10	149	96.5	73	71	69					
		total	1.2	1042	6	100	127	294	265	356	19	10	7	9	10	140	96.9	73	70	69				
Rhabdomyosarcomas		girls	247	3	52	20	92	70	65	6	7	4	3	5	69	99.2	72	70	68					
		boys	303	3	54	29	120	94	60	8	8	5	3	6	81	98.3	76	74	74					
		total	1.2	550	3	53	49	212	164	125	7	8	4	3	5	75	98.7	74	72	71				

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex	Sex	N		Relative		Number of cases		Age groups			Incidence rates per million						Trial participants		Survival probabilities(%)	
		m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World*	0 - 14	%	5 - yrs	10 - yrs	15 - yrs			
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	girls	48	1	10	10	12	6	20	3	1	0	1	1	13	91.7	62	62	62				
	boys	57	1	10	20	6	7	24	6	0	0	1	1	15	93.0	71	67	64				
	total	1.2	105	1	10	30	18	13	44	4	1	0	1	14	92.4	67	65	64				
Fibroblastic and myofibroblastic tumours	girls	25	0	5	9	7	3	6	3	1	0	0	1	7	92.0	80	80	-				
	boys	33	0	6	16	5	3	9	5	0	0	0	1	9	93.9	79	79	-				
	total	1.3	58	0	6	25	12	6	15	4	0	0	1	8	93.1	80	80	-				
Nerve sheath tumours	girls	23	0	5	1	5	3	14	0	0	0	1	0	6	91.3	43	43	43				
	boys	24	0	4	4	1	4	15	1	0	0	1	0	6	91.7	61	52	47				
	total	1.0	47	0	5	5	6	7	29	1	0	0	1	6	91.5	52	48	47				
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	-	-	-	-				
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	-	-	-				
Other specified soft tissue sarcomas	girls	145	2	30	14	20	37	74	4	1	2	4	3	39	96.6	81	77	74				
	boys	163	2	29	21	27	34	81	6	2	2	4	3	42	95.1	70	66	63				
	total	1.1	308	2	30	35	47	71	155	5	2	2	4	3	95.8	75	71	68				
Unspecified soft tissue sarcomas	girls	37	1	8	5	10	10	12	2	1	1	1	1	10	97.3	65	62	-				
	boys	41	0	7	8	7	7	19	2	0	0	1	1	11	95.1	73	65	65				
	total	1.1	78	0	8	13	17	17	31	2	1	0	1	10	96.2	69	63	63				
Germ cell tumours, trophoblastic tumours and neoplasms of gonads	girls	329	4	100	79	38	61	151	24	3	3	8	6	90	95.4	96	95	95				
	boys	232	2	100	61	44	25	102	17	3	1	5	4	61	94.8	94	93	93				
	total	0.7	561	3	100	140	82	86	253	21	3	2	6	5	95.2	95	94	94				
Intracranial and intraspinal germ cell tumours	girls	57	1	17	6	1	21	29	2	0	1	1	1	15	96.5	95	89	86				
	boys	96	1	41	1	7	20	68	0	0	1	3	1	24	93.8	91	89	89				
	total	1.7	153	1	27	7	8	41	97	1	0	1	2	1	94.8	92	89	88				
Malignant extracranial and extragonadal germ cell tumours	girls	113	1	34	73	31	2	7	22	2	0	0	3	33	93.8	96	96	96				
	boys	53	1	23	28	13	4	8	8	1	0	0	1	15	94.3	92	92	92				
	total	0.5	166	1	30	101	44	6	15	15	2	0	0	2	94.0	94	94	94				

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio		N	Relative		Number of cases		Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
		m / f	0 - 14		%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World*	0 - 14	Cum.	%	5-yrs	10-yrs	15-yrs	
Malignant gonadal germ cell tumours		girls		152	2	46	0	6	37	109	0	0	2	6	2	40		97.4	98	98		
		boys		83	1	36	32	24	1	26	9	2	0	1	2	22		96.4	98	98		
		total	0.5	235	1	42	32	30	38	135	5	1	1	3	2	31		97.0	98	98		
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	-	-		
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		185	2	100	3	13	40	129	1	1	2	7	3	49		62.7	91	89		
		boys		154	2	100	3	16	30	105	1	1	2	5	2	39		60.4	83	79		
		total	0.8	339	2	100	6	29	70	234	1	1	2	6	3	44		61.7	87	84		
Adrenocortical carcinomas		girls		17	0	9	1	5	6	5	0	0	0	0	0	5		100.0	-	-		
		boys		6	0	4	0	5	1	0	0	0	0	0	0	2		100.0	-	-		
		total	0.4	23	0	7	1	10	7	5	0	0	0	0	0	3		100.0	-	-		
Thyroid carcinomas		girls		85	1	46	0	1	21	63	0	0	1	3	1	22		88.2	99	97		
		boys		56	1	36	2	1	9	44	1	0	0	2	1	14		91.1	95	93		
		total	0.7	141	1	42	2	2	30	107	0	0	1	3	1	18		89.4	97	96		
Nasopharyngeal carcinomas		girls		5	0	3	0	0	0	5	0	0	0	0	0	1		100.0	-	-		
		boys		18	0	12	0	1	0	17	0	0	0	1	0	4		100.0	94	-		
		total	3.6	23	0	7	0	1	0	22	0	0	0	1	0	3		100.0	96	-		
Malignant melanomas		girls		27	0	15	2	5	7	13	1	0	0	1	0	7		7.4	-	-		
		boys		32	0	21	1	8	9	14	0	1	0	1	1	8		6.3	-	-		
		total	1.2	59	0	17	3	13	16	27	0	0	0	1	1	8		6.8	-	-		
Skin carcinomas		girls		7	0	4	0	0	2	5	0	0	0	0	0	2		14.3	-	-		
		boys		0	0	0	0	0	0	0	0	0	0	0	0	0		-	-	-		
		total	0.0	7	0	2	0	0	2	5	0	0	0	0	0	1		14.3	-	-		
Other and unspecified carcinomas		girls		44	1	24	0	2	4	38	0	0	0	2	1	11		36.4	80	-		
		boys		42	0	27	0	1	11	30	0	0	1	1	1	10		38.1	69	-		
		total	1.0	86	1	25	0	3	15	68	0	0	0	2	1	11		37.2	74	71		

* Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex ratio	N	Relative	Number of cases			Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
		m / f	0 - 14	%	%	0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World*	0 - 14	%	%	5-yrs	10-yrs	15-yrs	
Carcinomas of salivary glands	girls		12	0	7	0	0	1	11	0	0	0	0	1	0	3	0.0	-	-	-	
	boys		9	0	6	0	0	4	5	0	0	0	0	0	0	2	11.1	-	-	-	
	total	0.8	21	0	6	0	0	5	16	0	0	0	0	0	0	3	4.8	-	-	-	
Carcinomas of colon and rectum	girls		6	0	3	0	1	0	5	0	0	0	0	0	0	2	16.7	-	-	-	
	boys		7	0	5	0	0	1	6	0	0	0	0	0	0	2	28.6	-	-	-	
	total	1.2	13	0	4	0	1	1	11	0	0	0	0	0	0	2	23.1	-	-	-	
Carcinomas of appendix	girls		5	0	3	0	0	0	5	0	0	0	0	0	0	1	100.0	-	-	-	
	boys		5	0	3	0	0	1	4	0	0	0	0	0	0	1	100.0	-	-	-	
	total	1.0	10	0	3	0	0	1	9	0	0	0	0	0	0	1	100.0	-	-	-	
Carcinomas of lung	girls		2	0	1	0	0	0	2	0	0	0	0	0	0	1	100.0	-	-	-	
	boys		7	0	5	0	0	3	4	0	0	0	0	0	0	2	57.1	-	-	-	
	total	3.5	9	0	3	0	0	3	6	0	0	0	0	0	0	1	66.7	-	-	-	
Carcinomas of thymus	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
Carcinomas of breast	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
Carcinomas of cervix uteri	girls		1	0	1	0	0	0	1	0	0	0	0	0	0	0	0.0	-	-	-	
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	total	0.0	1	0	0	0	0	0	1	0	0	0	0	0	0	0	0.0	-	-	-	
Carcinomas of bladder	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-	-	
Carcinomas of eye	girls		0	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	0.0	-	-	-	
	total	-	2	0	1	0	0	0	2	0	0	0	0	0	0	0	0.0	-	-	-	
Carcinomas of other specified sites	girls		16	0	9	0	1	3	12	0	0	0	0	1	0	4	50.0	-	-	-	
	boys		10	0	7	0	0	2	8	0	0	0	0	0	0	2	30.0	-	-	-	
	total	0.6	26	0	8	0	1	5	20	0	0	0	0	0	0	3	42.3	-	-	-	

Tabelle 1 Forts. Table 1 cont.

Diagnoses		Sex		Number of cases				Age groups					Incidence rates per million					Trial participants		Survival probabilities(%)	
		ratio	N	Relative	Group	%	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World*	0-14	Cum.	%	5-yrs	10-yrs	15-yrs
		m / f	0-14	%																	
Carcinomas of unspecified site	girls		2	0	1	0	0	0	2	0	0	0	0	0	0	1		1	0.0	-	-
	boys		2	0	1	0	1	0	1	0	0	0	0	0	0	1		1	50.0	-	-
	total	1.0	4	0	1	0	1	0	3	0	0	0	0	0	0	1		1	25.0	-	-
Others and unspecified malignant neoplasms	girls		13	0	100	0	5	3	5	0	0	0	0	0	0	4		4	53.8	-	-
	boys		12	0	100	0	8	1	3	0	1	0	0	0	0	3		3	91.7	-	-
	total	0.9	25	0	100	0	13	4	8	0	0	0	0	0	0	3		3	72.0	-	-
Other specified malignant tumours	girls		10	0	77	0	4	2	4	0	0	0	0	0	0	3		3	70.0	-	-
	boys		9	0	75	0	8	1	0	0	1	0	0	0	0	2		2	100.0	-	-
	total	0.9	19	0	76	0	12	3	4	0	0	0	0	0	0	3		3	84.2	-	-
Gastrointestinal stromal tumour	girls		2	0	15	0	0	0	2	0	0	0	0	0	0	1		1	100.0	-	-
	boys		1	0	8	0	0	1	0	0	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	0		0	100.0	-	-
Pancreatoblastoma	girls		2	0	15	0	0	2	0	0	0	0	0	0	0	1		1	0.0	-	-
	boys		0	0	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	0.0	-	-
Pulmonary blastoma and pleuropulmonary blastoma	girls		4	0	31	0	4	0	0	0	0	0	0	0	0	1		1	100.0	-	-
	boys		8	0	67	0	8	0	0	0	1	0	0	0	0	2		2	100.0	-	-
	total	2.0	12	0	48	0	12	0	0	0	0	0	0	0	0	2		2	100.0	-	-
Other complex mixed and stromal neoplasms	girls		1	0	8	0	0	0	1	0	0	0	0	0	0	0		0	100.0	-	-
	boys		0	0	0	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		0	100.0	-	-
Mesothelioma	girls		1	0	8	0	0	0	1	0	0	0	0	0	0	0		0	0.0	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	0		0	-	-	-
	total	0.0	1	0	4	0	0	0	1	0	0	0	0	0	0	0		0	0.0	-	-
Other specified malignant tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	0		0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	0		0	-	-	-
	total	-	0	0	0	0	0	0	0	0	0	0	0	0	0	0		0	-	-	-
Other unspecified malignant tumours	girls		3	0	23	0	1	1	1	0	0	0	0	0	0	1		1	0.0	-	-
	boys		3	0	25	0	0	0	3	0	0	0	0	0	0	1		1	66.7	-	-
	total	1.0	6	0	24	0	1	1	4	0	0	0	0	0	0	1		1	33.3	-	-

* Standard: Segi world standard population

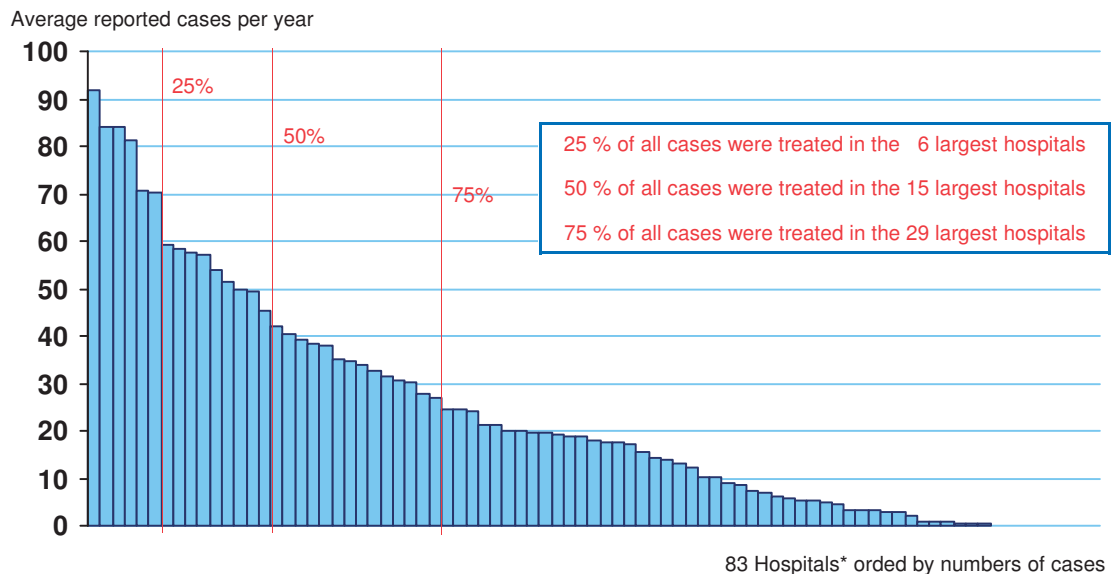
- insufficient data

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Abbildung 1:

Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2004-2013, Patienten unter 18 Jahren (unter 15 Jahren bis 2008)

Reported cases to the GCCR (registry population) per hospital, period 2004-2013, patients under 18 years (under 15 years until 2008)



* One hospital with 9 cases is a collection of "other hospitals"

Tabelle 2

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

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

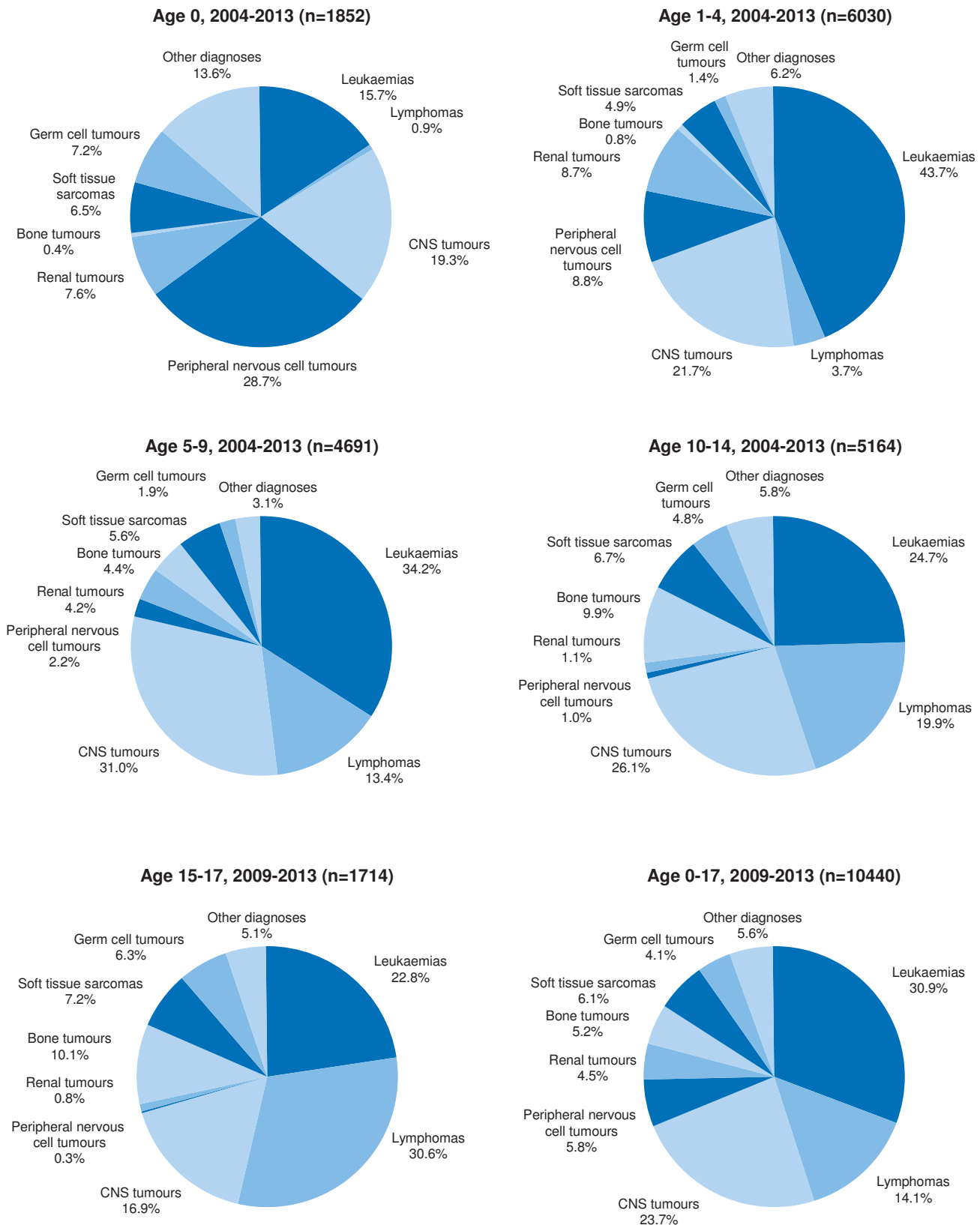
Diagnoses	Number of cases 1980-2013		Number of cases 2004-2013		Incidence rates 2004-2013	
	Absolute	Relative (%)	Absolute	Relative (%)	Age-standard.*	Cumulative
I Leukaemias	18362	34.2	5923	33.4	57	809
II Lymphomas	6310	11.8	1939	10.9	16	252
III CNS tumours	11599	21.6	4327	24.4	39	582
IV Peripheral nervous cell tumours	4077	7.6	1246	7.0	14	179
V Retinoblastoma	1272	2.4	369	2.1	4	53
VI Renal tumours	3143	5.9	949	5.4	10	133
VII Hepatic tumours	589	1.1	233	1.3	2	33
VIII Bone tumours	2519	4.7	784	4.4	6	100
IX Soft tissue sarcomas	3309	6.2	1042	5.9	10	140
X Germ cell tumours	1722	3.2	561	3.2	5	75
XI Carcinomas	737	1.4	339	1.9	3	44
XII Others and unspecified	59	0.1	25	0.1	0	3
All malignancies	53698	100.0	17737	100.0	166	2404

* Standard: Segi world standard population

Abbildung 2:

Relative Häufigkeit der gemeldeten Patienten aus der deutschen Wohnbevölkerung nach den häufigsten ICCC-3 Diagnose-Hauptgruppen und Alter

Relative frequencies of the registered patients in Germany by the main ICCC-3 diagnosis groups and age



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Tabelle 3:

Anzahl der gemeldeten Patienten unter 15 Jahren, 15 bis unter 18 Jahren und unter 18 Jahren auf Basis des ICC3-3, altersstandardisierte Inzidenzrate und Bevölkerungsbezug nach Jahren für Gesamtdeutschland

Annual number of registered cases aged under 15, 15 to under 18 years and under 18 years based on ICC3-3, age-standardized incidence rate and population base by calendar year for all of Germany

Years	Number of cases		Incidence rate per million *		Population base (in million)	
	< 15		<15		<15	
1980	1018		103		11.187	
1981	1046		105		10.803	
1982	974		103		10.392	
1983	1076		116		9.957	
1984	1032		114		9.539	
1985	1140		129		9.232	
1986	1144		132		9.070	
1987	1216		141		8.903	
1988	1217		140		9.019	
1989	1222		135		9.260	
1990	1299		139		9.621	
1991 #	1667		132		13.013	
1992	1813		143		13.166	
1993	1685		132		13.279	
1994	1769		139		13.298	
1995	1803		143		13.264	
1996	1804		145		13.209	
1997	1907		155		13.139	
1998	1822		149		13.035	
1999	1880		154		12.936	
2000	1975		162		12.836	
2001	1850		154		12.698	
2002	1826		154		12.517	
2003	1776		152		12.288	
2004	1871		164		12.042	
2005	1833		165		11.787	
2006	1769		162		11.544	
2007	1771		164		11.361	
2008	1767		166		11.212	

Years	Number of cases			Incidence rates per million *		Population base (in million)	
	< 15	15 to < 18	< 18	<15	< 18	<15	< 18
2009	1785	354	2139	169	165	11.078	13.579
2010	1764	315	2079	169	163	10.979	13.408
2011	1719	355	2074	165	162	10.884	13.277
2012	1740	357	2097	168	165	10.782	13.187
2013	1718	333	2051	168	164	10.644	13.065
Total	53698	1714	55412				

* Standard: Segi world standard population

Erweiterung um neue Bundesländer / inclusion of East Germany

Tabelle 4:

Verteilung aller Registermeldungen aus der deutschen Wohnbevölkerung nach Altersgruppen bei Diagnosestellung ohne Altersbeschränkung # sowie zusätzlich erfasste Diagnosen (2004-2013)

Distribution of all reported cases in Germany by age groups at diagnosis without any restriction of age # and additional diagnoses (2004-2013)

Age groups (years)	Diagnoses according to ICCC-3		Additional diagnoses (see Table 5)	
	N	%	N	%
0	1852	8.5	445	27.3
1-4	6030	27.6	335	20.5
5-9	4691	21.5	327	20.0
10-14	5164	23.6	383	23.5
0-14	17737	81.2	1490	91.2
15-17	3324	15.2	122	7.5
18-19	296	1.4	7	0.4
20-24	243	1.1	6	0.4
≥25	239	1.1	8	0.5
≥15	4102	18.8	143	8.8
reported cases	21839	100.0	1633	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 (2004-2013)

Systematically registered diagnoses not defined in ICCC-3 for patients under the age of 15 (2004-2013)

Diagnoses	Sex		Number of cases					Incidence rates per million					Trial participants	
	Sex	ratio	N	Age groups				Age groups				Age-stand.	Cum.	participants
		m / f	0-14	0	1-4	5-9	10-14	0	1-4	5-9	10-14	World	* 0-14	%
Non-malignant	girls		288	79	90	72	47	24	7	4	2	6	82	86.5
Langerhans cell	boys		424	88	125	106	105	25	9	6	5	8	113	86.8
histiocytosis	total	1.5	712	167	215	178	152	25	8	5	4	7	98	86.7
Benign/mature teratoma	girls		439	125	46	90	178	38	3	5	9	8	121	95.0
	boys		135	83	29	15	8	24	2	1	0	3	38	93.3
	total	0.3	574	208	75	105	186	31	3	3	5	6	79	94.6
Severe aplastic anaemia	girls		53	3	10	24	16	1	1	1	1	1	15	92.5
	boys		63	3	23	14	23	1	2	1	1	1	16	93.7
	total	1.2	116	6	33	38	39	1	1	1	1	1	16	93.1
Mesoblastic nephroma	girls		24	23	1	0	0	7	0	0	0	1	7	87.5
	boys		27	25	1	1	0	7	0	0	0	1	8	92.6
	total	1.1	51	48	2	1	0	7	0	0	0	1	7	90.2
Other diseases	girls		17	10	4	2	1	3	0	0	0	0	5	52.9
of blood and	boys		17	6	6	1	4	2	0	0	0	0	5	64.7
haemopoietic system	total	1.0	34	16	10	3	5	2	0	0	0	0	5	58.8

* Standard: Segi world standard population

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Tabelle 6:

Altersstandardisierte* Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert für Patienten unter 15 Jahre (2004-2013)

Age-standardized* incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for patients under 15 by region (2004-2013)

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	654	169	1.03	0.95-1.11	219	58	1.03	0.90-1.18
Hamburg	349	157	0.94	0.85-1.05	125	57	1.00	0.83-1.19
Niedersachsen	1797	165	0.99	0.94-1.03	627	58	1.03	0.96-1.12
Bremen	118	146	0.88	0.73-1.05	35	45	0.82	0.57-1.15
Nordrhein-Westfalen	4124	169	1.02	0.99-1.05	1317	56	0.98	0.93-1.03
Düsseldorf	1161	172	1.04	0.98-1.10	363	56	0.97	0.88-1.08
Köln	1024	170	1.04	0.97-1.10	314	54	0.95	0.85-1.06
Münster	631	171	1.03	0.95-1.11	227	63	1.12	0.98-1.27
Detmold	503	171	1.01	0.93-1.11	160	56	0.97	0.82-1.13
Arnsberg	805	166	1.00	0.93-1.07	253	54	0.94	0.83-1.07
Hessen	1389	171	1.03	0.97-1.08	473	59	1.04	0.95-1.14
Darmstadt	858	166	1.00	0.93-1.07	298	58	1.03	0.92-1.16
Gießen	270	198	1.17	1.03-1.31	89	67	1.16	0.93-1.42
Kassel	261	164	0.98	0.86-1.10	86	55	0.97	0.77-1.20
Rheinland-Pfalz	926	175	1.04	0.98-1.11	289	56	0.98	0.87-1.10
Baden-Württemberg	2404	161	0.97	0.93-1.01	800	55	0.97	0.90-1.03
Stuttgart	906	162	0.97	0.91-1.04	306	56	0.98	0.88-1.10
Karlsruhe	612	169	1.02	0.94-1.10	197	56	0.98	0.85-1.13
Freiburg	494	157	0.97	0.89-1.06	167	55	0.98	0.84-1.14
Tübingen	392	152	0.91	0.82-1.00	130	52	0.90	0.76-1.07
Bayern	2797	164	0.98	0.95-1.02	988	59	1.04	0.98-1.11
Oberbayern	945	159	0.95	0.89-1.01	345	58	1.03	0.93-1.15
Niederbayern	256	155	0.94	0.83-1.06	80	51	0.89	0.70-1.10
Oberpfalz	263	182	1.08	0.95-1.22	93	66	1.15	0.93-1.41
Oberfranken	235	165	1.02	0.90-1.16	78	57	1.02	0.81-1.28
Mittelfranken	311	139	0.83	0.74-0.92	106	48	0.85	0.69-1.02
Unterfranken	298	172	1.03	0.91-1.15	104	63	1.08	0.88-1.31
Schwaben	489	192	1.16	1.06-1.27	182	74	1.30	1.12-1.50
Saarland	198	163	0.98	0.85-1.13	67	56	1.00	0.78-1.27
Berlin	658	161	0.96	0.89-1.04	233	58	1.01	0.88-1.15
Brandenburg	434	158	0.95	0.86-1.05	162	60	1.05	0.90-1.23
Mecklenburg-Vorpommern	293	163	0.98	0.87-1.10	90	51	0.89	0.72-1.09
Sachsen	799	176	1.06	0.99-1.13	243	54	0.95	0.83-1.08
Sachsen-Anhalt	393	160	0.97	0.87-1.07	127	52	0.92	0.77-1.10
Thüringen	400	168	1.00	0.91-1.11	128	54	0.95	0.79-1.13

* Standard: Segi world standard population

Tabelle 7:

Anzahl der verstorbenen Patienten innerhalb von 5 bzw. 10 Jahren nach Diagnose auf Basis des ICCC-3 unter den gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung und alterstandardisierte Mortalitätsraten nach Diagnosejahr, 1980-2008 (inklusive neue Länder seit 1991)

Annual number of deaths 5 or 10 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 1980-2008 (including East Germany since 1991)

Year of diagnosis	Deaths within 5 years after diagnosis		Deaths within 10 years after diagnosis	
	No. of cases	Mortality rate per million*	No. of cases	Mortality rate per million*
1980	349	35	377	38
1981	343	33	379	36
1982	313	33	348	36
1983	319	34	359	39
1984	326	36	355	39
1985	324	36	365	40
1986	321	37	356	41
1987	329	38	354	41
1988	318	37	350	40
1989	293	33	326	36
1990	326	35	355	38
1991 #	399	32	444	35
1992 #	437	34	473	37
1993 #	383	30	428	34
1994 #	374	29	409	32
1995 #	338	27	385	30
1996 #	349	28	386	31
1997 #	372	30	417	33
1998 #	351	28	392	31
1999 #	360	29	399	32
2000 #	395	32	429	35
2001 #	302	25	339	28
2002 #	320	27	356	30
2003 #	322	27	361	31
2004 #	293	26		
2005 #	297	26		
2006 #	296	27		
2007 #	267	24		
2008 #	274	25		

* Standard: Segi world standard population

Including East Germany since 1991

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Tabelle 8:

Anzahl der am Deutschen Kinderkrebsregister in der Langzeitnachbeobachtung (LTS) befindlichen Patienten mit Erstdiagnose im Alter von unter 18 (Stand 2013)

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged under 18 (as of 2013)

Year of diagnosis	1980 - 1989	1990 - 1999	2000 - 2009	2010 - 2013	1980 - 2013
	N (%)	N (%)	N (%)	N (%)	N (%)
Patients registered	10999	17248	18298	8164	54709 #
deceased	3893 (35.4 %)	4196 (24.3 %)	3207 (17.5 %)	583 (7.1 %)	11879 (21.7 %)
surviving	7106 (64.6 %)	13052 (75.7 %)	15091 (82.5 %)	7581 (92.9 %)	42830 (78.3 %)
anonymous ⁺	983 (13.8 %)	1103 (8.5 %)	417 (2.8 %)	75 (1.0 %)	2578 (6.0 %)
identifiable	6123 (86.2 %)	11949 (91.5 %)	14674 (97.2 %)	7506 (99.0 %)	40252 (94.0 %)
< 5 years since diagnosis	-	-	784 (5.3 %)	7506 (100 %)	8290 (20.6 %)
>= 5 years since diagnosis	6123 (100 %)	11949 (100 %)	13890 (94.7 %)	-	31962 (79.4 %)
lost-to-follow-up	680 (11.1 %)	760 (6.4 %)	200 (1.4 %)	-	1640 (5.1 %)
in LTS	5443 (88.9 %)	11189 (93.6 %)	13690 (98.6 %)	-	30322 (94.9 %)

54709 patients correspond to 55412 cases diagnosed under 18 years resident in Germany at the date of diagnosis 1980-2013 and diagnosed with a disease included in ICCC-3

- no data yet

+ Consent not available, refused or withdrawn later

Tabelle 9:
Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Jugendliche unter 18 aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICC-3, Alter und Geschlecht (2009-2013). *ICC-3 extended Subklassifikation kursiv dargestellt.*
Number of cases and incidence rates per million adolescents aged under 18 years in Germany by diagnoses classified according to ICC-3, age, and sex (2009-2013).
ICC-3 extended subclassification in italics.

Diagnoses		Sex ratio	Sex m / f	N	Relative		Number of cases		Age group				Incidence rates per million				Trial participants	
					N	%	%	%	0 - 14	15 - 17	Age stand. *	0 - 14	15 - 17	0 - 17	0 - 17	Cum.	%	
All malignancies				girls	4604	100	100	3885	719	154	122	149	2591	94.3				
				boys	5836	100	100	4841	995	181	160	178	3114	94.8				
				total	1.3	10440	100	100	8726	1714	168	141	164	2859	94.6			
Leukaemias, myeloproliferative and myelodysplastic diseases				girls	1416	31	100	1258	158	51	27	47	807	99.5				
				boys	1806	31	100	1574	232	60	37	57	975	99.1				
				total	1.3	3222	31	100	2832	390	56	32	52	893	99.3			
Lymphoid leukaemias				girls	1042	23	74	958	84	39	14	35	599	99.6				
				boys	1364	23	76	1213	151	46	24	43	738	99.7				
				total	1.3	2406	23	75	2171	235	43	19	39	670	99.7			
Precursor cell leukaemias				girls	1030	22	73	947	83	39	14	35	592	99.6				
				boys	1321	23	73	1176	145	45	23	42	715	99.7				
				total	1.3	2351	23	73	2123	228	42	19	38	655	99.7			
Mature B-cell leukaemias				girls	11	0	1	10	1	0	0	0	6	100.0				
				boys	43	1	2	37	6	1	1	1	23	100.0				
				total	3.9	54	1	2	47	7	1	1	1	15	100.0			
Mature T-cell and NK cell leukaemias				girls	1	0	0	1	0	0	0	0	1	100.0				
				boys	0	0	0	0	0	0	0	0	0	0	-			
				total	0.0	1	0	0	1	0	0	0	0	0	100.0			
Lymphoid leukaemia, NOS				girls	0	0	0	0	0	0	0	0	0	-				
				boys	0	0	0	0	0	0	0	0	0	0	-			
				total	-	0	0	0	0	0	0	0	0	0	-			
Acute myeloid leukaemias				girls	222	5	16	179	43	7	7	7	124	99.5				
				boys	228	4	13	185	43	7	7	7	122	97.4				
				total	1.0	450	4	14	364	86	7	7	7	123	98.4			
Chronic myeloproliferative diseases				girls	30	1	2	21	9	1	2	1	16	96.7				
				boys	31	1	2	22	9	1	1	1	16	87.1				
				total	1.0	61	1	2	43	18	1	1	1	16	91.8			
Myelodysplastic syndrome and other myeloproliferative diseases				girls	102	2	7	83	19	3	3	3	56	99.0				
				boys	168	3	9	141	27	5	4	5	90	98.8				
				total	1.6	270	3	8	224	46	4	4	4	74	98.9			

* Standard: Segi world standard population

- Insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio m / f	Sex N	Number of cases			Age group			Incidence rates per million Age stand. *			Trial participants	
			Relative	Group	%	Age group			Age stand. *			Cum.	%
						0 - 14	15 - 17		0 - 14	15 - 17	0 - 17		
Unspecified and other specified leukaemias	girls	20	0	1	1	17	3		1	1	1	11	100.0
	boys	15	0	1	1	13	2		1	0	1	8	100.0
	total	35	0	1	1	30	5		1	0	1	10	100.0
Lymphomas and reticuloendothelial neoplasms	girls	525	11	100	308	217			10	37	14	278	97.5
	boys	948	16	100	641	307			21	49	26	486	97.5
	total	1473	14	100	949	524			16	43	20	384	97.5
Hodgkin lymphomas	girls	344	8	66	158	186			5	31	9	179	98.3
	boys	422	7	45	243	179			8	29	11	212	97.9
	total	766	7	52	401	365			6	30	10	196	98.0
Non-Hodgkin lymphomas	girls	153	3	29	123	30			4	5	4	84	96.1
	boys	369	6	39	265	104			9	17	10	191	96.7
	total	522	5	35	388	134			7	11	7	138	96.6
Precursor cell lymphomas	girls	38	1	7	37	1			1	0	1	21	92.1
	boys	107	2	11	90	17			3	3	3	56	94.4
	total	145	1	10	127	18			2	1	2	39	93.8
Mature B-cell lymphomas (except Burkitt lymphoma)	girls	35	1	7	27	8			1	1	1	19	97.1
	boys	80	1	8	47	33			1	5	2	40	96.3
	total	115	1	8	74	41			1	3	2	30	96.5
Mature T-cell and NK-cell lymphomas	girls	46	1	9	37	9			1	2	1	25	95.7
	boys	62	1	7	49	13			2	2	2	32	100.0
	total	108	1	7	86	22			1	2	2	29	98.1
Non-Hodgkin lymphomas, NOS	girls	34	1	7	22	12			1	2	1	18	100.0
	boys	120	2	13	79	41			3	7	3	62	97.5
	total	154	2	11	101	53			2	4	2	41	98.1
Burkitt lymphoma	girls	23	1	4	22	1			1	0	1	13	100.0
	boys	153	3	16	130	23			5	4	4	81	99.3
	total	176	2	12	152	24			3	2	3	48	99.4
Miscellaneous lymphoreticular neoplasms	girls	3	0	1	3	0			0	0	0	2	66.7
	boys	2	0	0	1	1			0	0	0	1	0.0
	total	5	0	0	4	1			0	0	0	1	40.0

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex m / f	N 0-17	Relative Group		Number of cases		Age group			Incidence rates per million			Trial participants	
					%	%	0 - 14	15 - 17	0 - 14	15 - 17	0 - 17	0 - 17	Cum.	%		
Unspecified lymphomas				girls	2	0	0	2	0	0	0	0	0	1	100.0	
				boys	2	0	0	2	0	0	0	0	1	100.0		
				total	1.0	4	0	0	4	0	0	0	1	100.0		
CNS and miscellaneous intracranial and intraspinal neoplasms				girls	1124	24	100	984	140	38	24	36	632	95.0		
				boys	1349	23	100	1199	150	44	24	41	721	94.8		
				total	1.2	2473	24	100	2183	290	41	24	38	678	94.9	
Ependymomas and choroid plexus tumour				girls	108	2	10	96	12	4	2	4	62	96.3		
				boys	130	2	10	124	6	5	1	4	72	96.2		
				total	1.2	238	2	10	220	18	5	1	4	67	96.2	
Ependymomas				girls	84	2	8	73	11	3	2	3	48	96.4		
				boys	106	2	8	100	6	4	1	3	58	96.2		
				total	1.3	190	2	8	173	17	4	1	3	53	96.3	
Choroid plexus tumour				girls	24	1	2	23	1	1	0	1	14	95.8		
				boys	24	0	2	24	0	1	0	1	14	95.8		
				total	1.0	48	1	2	47	1	1	0	1	14	95.8	
Astrocytomas				girls	549	12	49	486	63	18	11	17	308	96.4		
				boys	588	10	44	515	73	19	12	17	313	95.1		
				total	1.1	1137	11	46	1001	136	18	11	17	310	95.7	
Intracranial and intraspinal embryonal tumours				girls	146	3	13	138	8	6	1	5	85	95.9		
				boys	279	5	21	257	22	10	4	9	152	96.8		
				total	1.9	425	4	17	395	30	8	2	7	119	96.5	
Medulloblastomas				girls	88	2	8	81	7	3	1	3	50	97.7		
				boys	205	4	15	186	19	7	3	6	111	97.6		
				total	2.3	293	3	12	267	26	5	2	5	81	97.6	
Primitive neuroectodermal tumour (PNET)				girls	19	0	2	18	1	1	0	1	11	94.7		
				boys	25	0	2	23	2	1	0	1	14	100.0		
				total	1.3	44	0	2	41	3	1	0	1	12	97.7	
Medulloepithelioma				girls	2	0	0	2	0	0	0	0	1	50.0		
				boys	2	0	0	2	0	0	0	0	1	100.0		
				total	1.0	4	0	0	4	0	0	0	0	1	75.0	

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio	Sex m / f	N	Relative %	Number of cases			Age group			Incidence rates per million			Trial participants	
					Group	%	%	Age group		Cum.	Age stand. *		Cum.	0 - 17	%
								0 - 14	15 - 17		0 - 14	15 - 17			
<i>Atypical teratoid/rhabdoid tumour</i>	girls		37	1	3			37	0		2	0	1	22	94.6
	boys		47	1	4			46	1		2	0	2	27	91.5
	total	1.3	84	1	3			83	1		2	0	2	25	92.9
Other gliomas	girls		109	2	10			97	12		4	2	3	61	93.6
	boys		123	2	9			113	10		4	2	4	65	96.7
	total	1.1	232	2	9			210	22		4	2	4	63	95.3
<i>Oligodendrogliomas</i>	girls		2	0	0			0	2		0	0	0	1	100.0
	boys		3	0	0			3	0		0	0	0	1	100.0
	total	1.5	5	0	0			3	2		0	0	0	1	100.0
<i>Mixed and unspecified gliomas</i>	girls		100	2	9			90	10		3	2	3	56	93.0
	boys		115	2	9			107	8		4	1	3	61	96.5
	total	1.2	215	2	9			197	18		4	1	3	59	94.9
<i>Neuroepithelial glial tumours of uncertain origin</i>	girls		7	0	1			7	0		0	0	0	4	100.0
	boys		5	0	0			3	2		0	0	0	2	100.0
	total	0.7	12	0	1			10	2		0	0	0	3	100.0
Other specified intracranial and intraspinal neoplasms	girls		191	4	17			150	41		5	7	6	104	92.1
	boys		208	4	15			171	37		6	6	6	108	90.9
	total	1.1	399	4	16			321	78		6	6	6	106	91.5
<i>Pituitary adenomas and carcinomas</i>	girls		25	1	2			10	15		0	3	1	13	76.0
	boys		14	0	1			9	5		0	1	0	7	64.3
	total	0.6	39	0	2			19	20		0	2	0	10	71.8
<i>Tumours of the sellar region (craniopharyngiomas)</i>	girls		62	1	6			56	6		2	1	2	34	100.0
	boys		51	1	4			45	6		2	1	2	27	98.0
	total	0.8	113	1	5			101	12		2	1	2	31	99.1
<i>Pineal parenchymal tumours</i>	girls		12	0	1			10	2		0	0	0	7	100.0
	boys		8	0	1			7	1		0	0	0	4	100.0
	total	0.7	20	0	1			17	3		0	0	0	5	100.0
<i>Neuronal and mixed neuronal-glial tumours</i>	girls		79	2	7			62	17		2	3	2	43	92.4
	boys		119	2	9			99	20		3	3	3	62	94.1
	total	1.5	198	2	8			161	37		3	3	3	53	93.4

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex	N		Relative		Number of cases		Age group			Incidence rates per million			Trial participants	
		m / f		0-17		%	%	0 - 14	15 - 17	0 - 14	15 - 17	0 - 17	0 - 17	Cum.		%	
Meningiomas		girls		13		0	1	12	1		0	0	0	7		76.9	
		boys		16		0	1	11	5		0	1	0	8		62.5	
		total	1.2	29	0	1	23	6		0	0	0	8		69.0		
Unspecified intracranial and intraspinal neoplasms		girls		21		1	2	17	4		1	1	1	11		81.0	
		boys		21		0	2	19	2		1	0	1	11		81.0	
		total	1.0	42	0	2	36	6		1	0	1	11		81.0		
Neuroblastoma and other peripheral nervous cell tumours		girls		267		6	100	265	2		12	0	11	160		98.1	
		boys		338		6	100	335	3		15	0	13	193		99.4	
		total	1.3	605	6	100	600	5		14	0	12	177		98.8		
Neuroblastoma and ganglioneuroblastoma		girls		265		6	99	263	2		12	0	11	159		98.5	
		boys		336		6	99	333	3		15	0	13	192		99.4	
		total	1.3	601	6	99	596	5		14	0	12	176		99.0		
Other peripheral nervous cell tumours		girls		2		0	1	2	0		0	0	0	1		50.0	
		boys		2		0	1	2	0		0	0	0	1		100.0	
		total	1.0	4	0	1	4	0		0	0	0	1		75.0		
Retinoblastoma		girls		87		2	100	87	0		4	0	4	53		4.6	
		boys		92		2	100	92	0		4	0	4	53		1.1	
		total	1.1	179	2	100	179	0		4	0	4	53		2.8		
Renal tumours		girls		252		6	100	245	7		11	1	9	149		99.2	
		boys		223		4	100	217	6		9	1	8	125		98.7	
		total	0.9	475	5	100	462	13		10	1	9	137		98.9		
Nephroblastoma and other non-epithelial renal tumours		girls		247		5	98	242	5		11	1	9	146		99.6	
		boys		212		4	95	210	2		9	0	8	120		100.0	
		total	0.9	459	4	97	452	7		10	1	8	133		99.8		
Nephroblastoma		girls		238		5	94	235	3		10	1	9	141		99.6	
		boys		205		4	92	203	2		9	0	7	116		100.0	
		total	0.9	443	4	93	438	5		9	0	8	128		99.8		
Rhabdoid renal tumour		girls		6		0	2	5	1		0	0	0	4		100.0	
		boys		6		0	3	6	0		0	0	0	3		100.0	
		total	1.0	12	0	3	11	1		0	0	0	3		100.0		

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex	N	Relative	Number of cases		Age group			Incidence rates per million			Trial participants	
		m / f		0-17	%	Group	%	0 - 14	15 - 17		0 - 14	15 - 17	0 - 17	Cum.	%
Kidney sarcomas	girls		3		0	1		2	1		0	0	0	2	100.0
	boys		1		0	0		1	0		0	0	0	0	100.0
	total	0.3	4		0	1		3	1		0	0	0	1	100.0
Peripheral neuroectodermal tumour (pPNET) of kidney	girls		0		0	0		0	0		0	0	0	0	-
	boys		0		0	0		0	0		0	0	0	0	-
	total	-	0		0	0		0	0		0	0	0	0	-
Renal carcinomas	girls		5		0	2		3	2		0	0	0	3	80.0
	boys		11		0	5		7	4		0	1	0	6	72.7
	total	2.2	16		0	3		10	6		0	0	0	4	75.0
Unspecified malignant renal tumours	girls		0		0	0		0	0		0	0	0	0	-
	boys		0		0	0		0	0		0	0	0	0	-
	total	-	0		0	0		0	0		0	0	0	0	-
Hepatic tumours	girls		60		1	100		53	7		2	1	2	35	55.0
	boys		78		1	100		72	6		3	1	3	44	64.1
	total	1.3	138		1	100		125	13		3	1	3	39	60.1
Hepatoblastoma	girls		48		1	80		48	0		2	0	2	29	58.3
	boys		68		1	87		67	1		3	0	3	39	64.7
	total	1.4	116		1	84		115	1		3	0	2	34	62.1
Hepatic carcinomas	girls		12		0	20		5	7		0	1	0	6	41.7
	boys		10		0	13		5	5		0	1	0	5	60.0
	total	0.8	22		0	16		10	12		0	1	0	6	50.0
Unspecified malignant hepatic tumours	girls		0		0	0		0	0		0	0	0	0	-
	boys		0		0	0		0	0		0	0	0	0	-
	total	-	0		0	0		0	0		0	0	0	0	-
Malignant bone tumours	girls		244		5	100		178	66		6	11	7	131	98.4
	boys		299		5	100		192	107		6	17	8	151	97.0
	total	1.2	543		5	100		370	173		6	14	7	141	97.6
Osteosarcomas	girls		127		3	52		96	31		3	5	3	68	99.2
	boys		156		3	52		92	64		3	10	4	78	97.4
	total	1.2	283		3	52		188	95		3	8	4	73	98.2

Tabelle 9 Forts. Table 9 cont.

Diagnoses	Sex ratio	Sex m / f	N	Relative %	Number of cases			Age group			Incidence rates per million			Trial participants	
			0-17	%	Group	%	0-14	15-17	0-14	15-17	0-14	15-17	0-17	Cum.	%
Chondrosarcomas	girls		2	0	1		1	1			0	0	0	1	100.0
	boys		4	0	1		4	0			0	0	0	2	100.0
	total	2.0	6	0	1		5	1			0	0	0	2	100.0
Ewing tumour and related sarcomas of bone	girls		111	2	46		78	33			3	6	3	60	99.1
	boys		134	2	45		92	42			3	7	4	68	97.8
	total	1.2	245	2	45		170	75			3	6	3	64	98.4
Other specified malignant bone tumours	girls		3	0	1		2	1			0	0	0	2	33.3
	boys		3	0	1		3	0			0	0	0	2	66.7
	total	1.0	6	0	1		5	1			0	0	0	2	50.0
<i>Malignant fibrous neoplasms of bone</i>	girls		0	0	0		0	0			0	0	0	0	-
	boys		1	0	0		1	0			0	0	0	0	100.0
	total	-	1	0	0		1	0			0	0	0	0	100.0
<i>Malignant chordomas</i>	girls		2	0	1		1	1			0	0	0	1	50.0
	boys		2	0	1		2	0			0	0	0	1	50.0
	total	1.0	4	0	1		3	1			0	0	0	1	50.0
<i>Odontogenic malignant tumours</i>	girls		0	0	0		0	0			0	0	0	0	-
	boys		0	0	0		0	0			0	0	0	0	-
	total	-	0	0	0		0	0			0	0	0	0	-
<i>Miscellaneous malignant bone tumours</i>	girls		1	0	0		1	0			0	0	0	1	0.0
	boys		0	0	0		0	0			0	0	0	0	-
	total	0.0	1	0	0		1	0			0	0	0	0	0.0
Unspecified malignant bone tumours	girls		1	0	0		1	0			0	0	0	1	100.0
	boys		2	0	1		1	1			0	0	0	1	50.0
	total	2.0	3	0	1		2	1			0	0	0	1	66.7
Soft tissue and other extraosseous sarcomas	girls		273	6	100		224	49			9	8	9	152	98.5
	boys		367	6	100		293	74			11	12	11	194	97.5
	total	1.3	640	6	100		517	123			10	10	10	174	98.0
Rhabdomyosarcomas	girls		125	3	46		111	14			4	2	4	71	100.0
	boys		180	3	49		155	25			6	4	6	97	99.4
	total	1.4	305	3	48		266	39			5	3	5	84	99.7

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex m / f	N	Number of cases			Age group			Incidence rates per million			Trial participants	
					Relative	Group	%	0 - 14	15 - 17	%	0 - 14	15 - 17	0 - 17	Cum.	%
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	girls		35	1	13		26	9		1	2	1	19	91.4	
	boys		35	1	10		26	9		1	1	1	18	97.1	
	total	1.0	70	1	11		52	18		1	1	1	19	94.3	
Fibroblastic and myofibroblastic tumours	girls		18	0	7		14	4		1	1	1	10	88.9	
	boys		12	0	3		11	1		0	0	0	7	91.7	
	total	0.7	30	0	5		25	5		1	0	1	8	90.0	
Nerve sheath tumours	girls		17	0	6		12	5		0	1	0	9	94.1	
	boys		23	0	6		15	8		0	1	1	12	100.0	
	total	1.4	40	0	6		27	13		0	1	1	10	97.5	
Other fibrous neoplasms	girls		0	0	0		0	0		0	0	0	0	-	
	boys		0	0	0		0	0		0	0	0	0	-	
	total	-	0	0	0		0	0		0	0	0	0	-	
Kaposi sarcoma	girls		0	0	0		0	0		0	0	0	0	-	
	boys		1	0	0		1	0		0	0	0	0	0.0	
	total	-	1	0	0		1	0		0	0	0	0	0.0	
Other specified soft tissue sarcomas	girls		91	2	33		66	25		2	4	3	50	98.9	
	boys		122	2	33		90	32		3	5	3	63	96.7	
	total	1.3	213	2	33		156	57		3	5	3	57	97.7	
Unspecified soft tissue sarcomas	girls		22	1	8		21	1		1	0	1	12	100.0	
	boys		29	1	8		21	8		1	1	1	15	93.1	
	total	1.3	51	1	8		42	9		1	1	1	14	96.1	
Germ cell tumours, trophoblastic tumours and neoplasms of gonads	girls		219	5	100		183	36		7	6	7	122	95.9	
	boys		207	4	100		135	72		5	12	6	107	98.1	
	total	0.9	426	4	100		318	108		6	9	6	114	96.9	
Intracranial and intraspinal germ cell tumours	girls		33	1	15		30	3		1	1	1	18	97.0	
	boys		78	1	38		57	21		2	3	2	39	96.2	
	total	2.4	111	1	26		87	24		1	2	2	29	96.4	
Malignant extracranial and extragonadal germ cell tumours	girls		64	1	29		63	1		3	0	3	39	98.4	
	boys		40	1	19		32	8		1	1	1	22	97.5	
	total	0.6	104	1	24		95	9		2	1	2	30	98.1	

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex		Relative		Number of cases		Age group			Incidence rates per million			Trial participants	
		ratio	N	%	%	Group	%	0 - 14	15 - 17	Age stand. *	0 - 14	15 - 17	0 - 17	Cum.	%
Sex	m / f	0-17													
Malignant gonadal germ cell tumours	girls	113	3	52			86	27		3	5	3	60		97.3
	boys	89	2	43			46	43		2	7	3	46		100.0
	total	0.8	202	2	47		132	70		2	6	3	53		98.5
Gonadal carcinomas	girls	7	0	3			3	4		0	1	0	4		42.9
	boys	0	0	0			0	0		0	0	0	0		-
	total	0.0	7	0	2		3	4		0	0	0	2		42.9
Other and unspecified malignant gonadal tumours	girls	2	0	1			1	1		0	0	0	1		100.0
	boys	0	0	0			0	0		0	0	0	0		-
	total	0.0	2	0	1		1	1		0	0	0	1		100.0
Other malignant epithelial neoplasms and malignant melanomas	girls	131	3	100			95	36		3	6	4	70		63.4
	boys	118	2	100			82	36		3	6	3	60		60.2
	total	0.9	249	2	100		177	72		3	6	3	64		61.8
Adrenocortical carcinomas	girls	5	0	4			4	1		0	0	0	3		80.0
	boys	3	0	3			3	0		0	0	0	2		100.0
	total	0.6	8	0	3		7	1		0	0	0	2		87.5
Thyroid carcinomas	girls	64	1	49			47	17		1	3	2	34		87.5
	boys	38	1	32			31	7		1	1	1	19		92.1
	total	0.6	102	1	41		78	24		1	2	1	26		89.2
Nasopharyngeal carcinomas	girls	3	0	2			1	2		0	0	0	2		100.0
	boys	13	0	11			7	6		0	1	0	6		100.0
	total	4.3	16	0	6		8	8		0	1	0	4		100.0
Malignant melanomas	girls	18	0	14			15	3		1	1	1	10		16.7
	boys	23	0	20			19	4		1	1	1	12		8.7
	total	1.3	41	0	17		34	7		1	1	1	11		12.2
Skin carcinomas	girls	4	0	3			4	0		0	0	0	2		25.0
	boys	1	0	1			0	1		0	0	0	0		0.0
	total	0.3	5	0	2		4	1		0	0	0	1		20.0
Other and unspecified carcinomas	girls	37	1	28			24	13		1	2	1	19		43.2
	boys	40	1	34			22	18		1	3	1	20		45.0
	total	1.1	77	1	31		46	31		1	3	1	20		44.2

* Standard: Segi world standard population

- insufficient data

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	Sex m / f	N	Relative		Number of cases		Age group			Incidence rates per million			Trial participants	
				0-17	%	Group	%	0 - 14	15 - 17	0 - 14	15 - 17	0 - 17	Cum.	0 - 17	%	
Carcinomas of salivary glands		girls		5	0	4		5	0		0	0	3	0.0		
		boys		6	0	5		6	0		0	0	3	0.0		
		total	1.2	11	0	4		11	0		0	0	3	0.0		
Carcinomas of colon and rectum		girls		4	0	3		3	1		0	0	2	50.0		
		boys		12	0	10		4	8		0	1	6	41.7		
		total	3.0	16	0	6		7	9		0	1	4	43.8		
Carcinomas of appendix		girls		6	0	5		5	1		0	0	3	100.0		
		boys		3	0	3		3	0		0	0	1	100.0		
		total	0.5	9	0	4		8	1		0	0	2	100.0		
Carcinomas of lung		girls		4	0	3		1	3		0	1	2	100.0		
		boys		7	0	6		4	3		0	0	3	71.4		
		total	1.8	11	0	4		5	6		0	0	3	81.8		
Carcinomas of thymus		girls		1	0	1		0	1		0	0	1	0.0		
		boys		0	0	0		0	0		0	0	0	-		
		total	0.0	1	0	0		0	1		0	0	0	0.0		
Carcinomas of breast		girls		1	0	1		0	1		0	0	1	0.0		
		boys		0	0	0		0	0		0	0	0	-		
		total	0.0	1	0	0		0	1		0	0	0	0.0		
Carcinomas of cervix uteri		girls		1	0	1		1	0		0	0	1	0.0		
		boys		0	0	0		0	0		0	0	0	-		
		total	0.0	1	0	0		1	0		0	0	0	0.0		
Carcinomas of bladder		girls		1	0	1		0	1		0	0	1	0.0		
		boys		0	0	0		0	0		0	0	0	-		
		total	0.0	1	0	0		0	1		0	0	0	0.0		
Carcinomas of eye		girls		0	0	0		0	0		0	0	0	-		
		boys		1	0	1		1	0		0	0	0	0.0		
		total	-	1	0	0		1	0		0	0	0	0.0		
Carcinomas of other specified sites		girls		13	0	10		8	5		0	1	7	30.8		
		boys		6	0	5		2	4		0	1	3	33.3		
		total	0.5	19	0	8		10	9		0	1	5	31.6		

Tabelle 9 Forts. Table 9 cont.

Diagnoses		Sex ratio	N	Relative	Number of cases		Age group			Incidence rates per million			Trial participants		
Sex	m / f	0-17	%	0-17	%	Group	0 - 14	15 - 17	0 - 14	15 - 17	0 - 17	Cum.	Age stand. *	0 - 17	%
Carcinomas of unspecified site															
girls		1	0	1	1		1	0		0	0	1		0	0.0
boys		5	0	4	2		2	3		0	0	3		0	60.0
total	5.0	6	0	2	3		3	3		0	0	2		0	50.0
Others and unspecified malignant neoplasms															
girls		6	0	100	5		5	1		0	0	3		0	50.0
boys		11	0	100	9		9	2		0	0	6		0	90.9
total	1.8	17	0	100	14		14	3		0	0	5		0	76.5
Other specified malignant tumours															
girls		5	0	83	4		4	1		0	0	3		0	60.0
boys		9	0	82	8		8	1		0	0	5		0	88.9
total	1.8	14	0	82	12		12	2		0	0	4		0	78.6
Gastrointestinal stromal tumour															
girls		1	0	17	1		1	0		0	0	1		0	100.0
boys		1	0	9	1		1	0		0	0	1		0	100.0
total	1.0	2	0	12	2		2	0		0	0	1		0	100.0
Pancreatoblastoma															
girls		1	0	17	1		1	0		0	0	1		0	0.0
boys		1	0	9	0		0	1		0	0	0		0	0.0
total	1.0	2	0	12	1		1	1		0	0	1		0	0.0
Pulmonary blastoma and pleuropulmonary blastoma															
girls		2	0	33	2		2	0		0	0	1		0	100.0
boys		7	0	64	7		7	0		0	0	4		0	100.0
total	3.5	9	0	53	9		9	0		0	0	3		0	100.0
Other complex mixed and stromal neoplasms															
girls		0	0	0	0		0	0		0	0	0		0	-
boys		0	0	0	0		0	0		0	0	0		0	-
total	-	0	0	0	0		0	0		0	0	0		0	-
Mesothelioma															
girls		1	0	17	0		0	1		0	0	1		0	0.0
boys		0	0	0	0		0	0		0	0	0		0	-
total	0.0	1	0	6	0		0	1		0	0	0		0	0.0
Other specified malignant tumours															
girls		0	0	0	0		0	0		0	0	0		0	-
boys		0	0	0	0		0	0		0	0	0		0	-
total	-	0	0	0	0		0	0		0	0	0		0	-
Other unspecified malignant tumours															
girls		1	0	17	1		1	0		0	0	1		0	0.0
boys		2	0	18	1		1	1		0	0	1		0	100.0
total	2.0	3	0	18	2		2	1		0	0	1		0	66.7

* Standard: Segi world standard population

- insufficient data

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Tabelle 10:

Zahl der vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister (LKR) bis einschließlich 2013 weitergeleiteten Meldungen

Number of forwarded reports from the German Childhood Cancer Registry to the state cancer registries (LKR) up to and including 2013

State cancer registry	Diagnosis period		Cases
	from	to	
Krebsregister Schleswig-Holstein	01.01.2008	15.07.2013	469
Hamburgisches Krebsregister	01.01.2008	15.07.2013	215
Epidemiologisches Krebsregister Niedersachsen	01.01.2008	15.07.2013	1119
Bremer Krebsregister	01.01.2008	15.07.2013	86
Epidemiologisches Krebsregister NRW *	01.01.2008	15.07.2013	2667
Hessisches Krebsregister	01.01.2008	15.07.2013	1009
Krebsregister Rheinland-Pfalz	01.01.2008	15.07.2013	552
Bevölkerungsbezogenes Krebsregister Bayern	01.01.2008	15.07.2013	1674
Epidemiologisches Krebsregister Saarland	01.01.2008	15.07.2013	117
Gemeinsames Krebsregister GKR *	01.01.2008	15.07.2013	2206
Gesamt			10114

+ 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

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Zweitmalignome nach Krebs im Kindesalter: Fall-Kontroll-Studie zu den Risikofaktoren für das Entstehen von sekundären malignen Neoplasien

Im Rahmen des Kompetenznetzes Pädiatrische Onkologie und Hämatologie (Förderkennzeichen 0GJ0419) wurde die prospektive Erfassung sekundärer Neoplasien (SN) am Deutschen Kinderkrebsregister etabliert. Die bis Ende 2002 erfassten Zweitmalignom-Fälle wurden im Rahmen einer Zweitmalignom-Studie mit Kontrollen mit nur einer Neoplasie hinsichtlich ihrer Therapie verglichen. Bislang sind zwei Arbeiten mit Auswertungen hierzu erschienen. Chemotherapie, insbesondere Alkylantien, erhöhen das Zweitneoplasierisiko deutlich (15); für solide Zweittumoren konnte kein Einfluss der Chemotherapie gefunden werden. Eine 2014 erschienene Publikation zeigt, dass eine Strahlentherapie das Risiko einer weiteren soliden Tumors in der bestrahlten Körperregion erheblich erhöht (33).

Second malignant neoplasms after childhood cancer: Case control study on risk factors

The GCCR established a prospective registration of second neoplasms (SN) as part of the competence network for Paediatric Oncology and Haematology (Grant No. 0GJ0419). The SN cases registered until 2002 were analysed in a case control study with single neoplasm cases as controls and therapy as the exposure. So far two major analyses have been published. Chemo therapy, specifically alkylating agents, lead to a major increase in SN risk (15); for solid second tumours an effect of chemo therapy could not be shown. In a publication from 2014 we show radiation therapy to increase the risk of a second tumour in the field of radiation considerably (33).

PanCare: Forschungsprojekte im Rahmen des PanCare-Netzwerkes

Das Netzwerk PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) ist ein Zusammenschluss von Experten (z.B. Medizinern, Epidemiologen) und Betroffenen (Eltern und Langzeitüberlebende). Ziel ist es, Häufigkeit, Schwere und Auswirkungen von Spätfolgen der Therapie bei Kindern und Jugendlichen mit einer Krebserkrankung zu reduzieren. Das langfristige strategische Ziel ist es sicherzustellen, dass jeder europäische ehemalige Patient eine optimale Langzeitnachsorge erhält (34).

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

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

PanCareSurFup (www.pancaresurfup.eu) startete im Februar 2011 und umfasst 16 Partner. Im Rahmen dieser Verbund-Forschung sollen Richtlinien entwickelt werden, um die Nachsorge ehemaliger Patienten zu optimieren und eine Grundlage für forschungsbezogene Informationen bereitzustellen, die alle Spätfolgen der Krebsterapie betreffen. Eine große europäische Kohorte von über 100.000 ehemaligen Patienten mit einer Krebserkrankung im Kindes- und Jugendalter wird aufgebaut, nachbeobachtet und mögliche Spätfolgen werden speziell untersucht. Dazu zählt das Auftreten von Zweittumoren, Herzschädigungen und das Versterben der Patienten mehr als fünf Jahre nach der Erkrankung (late mortality) (34).

PanCare: Research in the Framework of the PanCare Network

PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) is a multidisciplinary pan-European network of professionals (such as clinicians and epidemiologists), survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer. The long-term strategic aim of PanCare is to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care (34).

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

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

PanCareSurFup (www.pancaresurfup.eu) started in February 2011 and includes 16 partners. The joint research aims to provide a basis for establishing guidelines for follow-up in Europe, as well as a basis for research generating information on late effects of cancer therapies. The project collates a large European cohort of more than 100,000 former patients with cancer in childhood or adolescence, their follow-up and potential late effects. These include cardiac disease, second cancers and late mortality (more than 5 years after diagnosis) (34).

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

An dem im November 2013 neu begonnenen EU-finanzierten Forschungsprojekt PanCareLIFE (www.pancarelife.eu) sind Wissenschaftler aus acht europäischen Nationen beteiligt. Fertilität, Ototoxizität und gesundheitsbezogene Lebensqualität stehen im Focus dieses Projektes. Insgesamt fließen die Daten von rund 12.000 Betroffenen in das Vorhaben ein. Anhand dieser Daten wollen die beteiligten Forscher Risikofaktoren identifizieren, die möglicherweise im Zusammenhang mit Infertilität und Ototoxizität stehen. Dazu wird DNA untersucht werden um festzustellen, welche genetischen Varianten potentiell mit diesen Spätfolgen assoziiert sind. Auch Guidelines zur Fertilitätserhaltung werden erarbeitet (27, 34).

KiCT: Kinderkrebsrisiko nach Exposition durch computertomographische Untersuchungen im Kindesalter

In großen epidemiologischen Kohortenstudien wurden unlängst Zusammenhänge zwischen Computertomographien (CT) im Kindesalter und darauf folgenden Krebserkrankungen beschrieben. In Deutschland wurde eine landesweite Studie durchgeführt, um das Krebsrisiko für CT-exponierte Kinder vor dem 15. Geburtstag abzuschätzen. Es wurden Daten aus 20 großen Kliniken gesammelt. Die Krebsfälle im Kindesalter wurden über das Deutsche Kinderkrebsregister identifiziert. 50.865 Kinder, die zwischen 1983 und 2010 untersucht worden waren, erfüllten die Einschlusskriterien. Mit einer Latenzzeit von 24 Monaten und nach Berücksichtigung der Befundtexte aus dem RIS und der Meldungen an das Kinderkrebsregister wurden 39 neue Krebsfälle beobachtet. Die SIR für Leukämien beträgt 1,72 (n= 12, 95% KI: 0,89 - 3,01), für ZNS-Tumoren 1,35 (n= 7, 95% KI: 0,54 - 2,78) und für alle Krebsarten gemeinsam 1,87 (n= 39, 95% KI: 1,33 - 2,55). Ursachenumkehrung und Confounding durch Indikation könnten dazu geführt haben, dass diese Zusammenhänge überschätzt sind (19).

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

Die Heilungschancen nach Krebs im Kindesalter liegen mittlerweile je nach Erkrankungsart bei 70 - 95 Prozent. Die notwendigen Therapien (u.a. Operation, Chemo- und Strahlentherapie) können Spätfolgen verursachen; diese werden im Rahmen des Projekts VIVE näher untersucht. Dazu werden die

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

Scientists from eight European nations contribute to the EU-funded research project PanCareLIFE (www.pancarelife.eu). The main issues of this project are fertility, ototoxicity and quality of life. Data from 12,000 former patients are included in the project. The researchers will identify risk factors for ototoxicity and infertility. This includes an examination of DNA, which may modify the risk for these late effects. The project includes a work package which develops guidelines for fertility preservation (27, 34).

KiCT: Risk of childhood cancer after exposure to computed tomographies in childhood

Exposure with computed tomographies (CT) in childhood was recently linked to increased cancer risk in large epidemiological cohort studies. In Germany, a nationwide cohort study aimed to investigate the cancer risk of children exposed to CT before the age of 15. Cohort data were collected from 20 large hospitals. Cancer cases were identified using the German Childhood Cancer Registry. 50,865 children examined between 1983 and 2010 fulfilled the inclusion criteria. 39 incident cancer cases were observed after a latency period of 24 months after CT, taking into account diagnostic information from the RIS and the GCCR. The SIR for leukemia was 1.72 (n= 12, 95% CI: 0.89 - 3.01), for CNS-tumours 1.35 (n= 7, 95% CI: 0.54 - 2.78) and for all cancers combined 1.87 (n= 39, 95% CI: 1.33 - 2.55). Reverse causation and confounding by indication may have led to overestimating these associations (19).

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

The Chances of Survival after cancer in childhood nowadays are between 70 - 95%, depending on the disease entity. The therapies necessary for this (such as surgery, chemo- and radiotherapy) can potentially cause late effects; these are the research topic of VIVE. For this, all former patients who are

ehemaligen, jetzt erwachsenen Patienten (mindestens 25 Jahre alt) mittels Fragebogen in einer umfassenden Basiserhebung befragt: nach (psycho-) somatischen Spätfolgen, ihrem jetzigen Gesundheitszustand und ihrer Lebensqualität.

Die Gesamtkoordination, zusammenfassende Auswertung und Veröffentlichung der Ergebnisse erfolgt durch die Projektleitung in Münster (Klinik für Kinder- und Jugendmedizin des Universitätsklinikums). Das Deutsche Kinderkrebsregister in Mainz führt die eigentliche Befragung (mittels Fragebogen) durch und wertet zudem die Angaben zu den Zweitmalignomen aus. Die VIVE-Arbeitsgruppe TOS in Hannover ordnet die Patientendaten den ehemaligen Therapien mit Hilfe einer Therapiedatenbank zu.

Die Befragung der etwa 10.000 ehemaligen Patienten begann im Jahre 2014 (25).

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

Bei Langzeitüberlebenden von Krebserkrankungen im Kindesalter sind neben einer weiteren Krebserkrankung Herz-Kreislaufkrankungen die schwerwiegendste Spätfolge. Für die auch bei Krebserkrankungen im Kindesalter sehr häufig und erfolgreich verwendeten Anthrazykline ist die Herzinsuffizienz als Spätfolge bekannt. Das Deutsche Kinderkrebsregister führt eine systematische Langzeitnachsbeobachtung durch, die das Ansprechen aller ehemaligen Kinderkrebspatienten ermöglicht. Die etablierte Gutenberg-Gesundheitsstudie (GHS) an der Universitätsmedizin Mainz bietet eine umfassende, standardisierte Plattform für kardiovaskuläre Untersuchungen. Die CVSS-Studie wird an der Universitätsmedizin Mainz als interdisziplinäres, kooperatives Projekt des Deutschen Kinderkrebsregisters am IMBEI, der Pädiatrischen Hämatologie/Onkologie/Hämostaseologie des Zentrums für Kinder- und Jugendmedizin und der Präventiven Kardiologie und Medizinischen Prävention an der II. Medizinischen Klinik und Poliklinik durchgeführt. Es werden rund 1000 Erwachsene, die im Zeitraum von 1980 bis 1990 als Kind oder Jugendlicher an Krebs (außer einem Hodgkin Lymphom) erkrankt waren, auf Herz-Kreislaufkrankungen untersucht. Das Programm beinhaltet auch Untersuchungen, die üblicherweise nicht im Rahmen allgemeiner ärztlicher Untersuchungen durchgeführt werden. Ein besonderes Augenmerk liegt auf subklinischen Veränderungen. Die unmittelbar erhobenen und medizinisch relevanten Untersuchungsergebnisse werden den Teilnehmern in einem umfassenden Bericht zur Besprechung mit dem Haus- oder Facharzt ausgehändigt.

Die Gesundheitsdaten werden anschließend im Zusammenhang mit den vorliegenden Daten zur Chemo- und Strahlentherapie der Patienten sowie wei

adults now (at least 25 years of age) are invited to participate in a baseline survey of their current situation: (psycho-) somatic late effects, current health status, and quality of life.

The coordination, analysis and publication of the whole project lies with the principal investigators in Münster (Klinik für Kinder- und Jugendmedizin des Universitätsklinikums). The German Childhood Cancer Registry conducts the technical side of the survey (with a questionnaire) and analyses the second neoplasm information. The VIVE-working group in Hannover retrospectively assigns the therapy data with the help of a therapy data base.

The survey, including about 10,000 former patients, started in 2014 (25).

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

The most severe late effects after surviving cancer in childhood are subsequent neoplasms and cardiovascular diseases. It is known that anthracyclins, used frequently and successfully in the treatment of childhood cancer, can cause heart failure. The German Childhood Cancer Registry conducts a general long-term surveillance which makes addressing former patients possible. The well-established Gutenberg Health Study (GHS) at the University Medical Center Mainz offers a comprehensive, standardised platform for cardiovascular examinations. The CVSS-Study at the University Medical Center Mainz is conducted jointly by the German Childhood Cancer Registry at the IMBEI, the Pediatric Hematology/Oncology/Hemostaseology at the Center for Childhood and Adolescent Medicine, and the Preventive Cardiology and Medical Prevention at the 2nd Medical Clinic and Polyclinic. About 1000 adults, who had been diagnosed with childhood cancer (except for Hodgkin Lymphoma) between 1980 and 1990, are examined for cardiovascular diseases. The examination program includes techniques not usually available in medical practice. Subclinical diseases are particularly looked at. The patients are provided with the immediately available and medically relevant results of their examinations in a comprehensive report for their general practitioner or medical specialist.

The data on health are then analyzed in the context of the previous chemotherapy or irradiation together with well-known risk factors. The results are

teren Risikofaktoren ausgewertet. Die Ergebnisse sollen helfen, künftig frühzeitig Risikogruppen für das Auftreten von Therapie-Spätfolgen zu identifizieren und Empfehlungen für gezielte Vorsorgeuntersuchungen sowie eine zielgerichtete Nachsorge zu ermöglichen (26, 30).

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

intended to contribute to early identification of risk groups for late-sequelae and the development of recommendations screening and specific follow-up care (26, 30).

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

Tabelle 11:

Forschungsprojekte und internationale Kooperationsprojekte seit 2011 (see Table 12 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	15, 33	DKKR	ja	Bundesministerium für Bildung und Forschung (Kompetenznetzförderung)
ACCIS: Automated Childhood Cancer Information System	Internationale Datenbank	12	IARC, Lyon, Frankreich	nein	-
EUROCARE: Survival of cancer patients in Europe	Follow-up Studie	14, 32	Istituto Nazionale dei Tumori, Mailand, Italien	nein	-
PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	Internationales Netzwerk	34	Gesamtleitung: Lund University Hospital, Schweden; Leitung Workpackage 1 (Data Collection and Harmonization): DKKR	ja	Europäische Kommission EU FP7
GENKIK: Systematische Expressionsanalyse von DNA-Reparaturgenen bei kindlichen Malignomkrankungen	Fall-Kontroll-Studie	20, 21, 31	DKKR, IMBEI, Institut für Humangenetik der Universitätsmedizin Mainz	ja	Stiftung Rheinland-Pfalz für Innovation
KIKME: Identifizierung genetischer Prädispositionen der spontanen und strahleninduzierten Karzinogenese bei Malignomkrankungen im Kindesalter	Fall-Kontroll-Studie		IMBEI	ja	Bundesministerium für Bildung und Forschung

Tabelle 11 Forts. Table 11 cont.

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
KiCT: Kinderkrebsrisiko nach Exposition durch computertomographische Untersuchungen im Kindesalter	Kohortenstudie	19	IMBEI	ja	Bundesministerium für Bildung und Forschung
VIVE: Basiserhebung zu Lebenssituation, Gesundheitszustand und Lebensqualität nach onkologischer Erkrankung im Kindes- und Jugendalter	Kohortenstudie	25	Projektkoordination: Klinik für Kinder- und Jugendmedizin des Universitätsklinikums Münster	ja	Deutsche Krebshilfe
PanCareLife: PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	Internationale Datenbank	27, 34	DKKR	ja	Europäische Kommission EU FP7
CVSS: Kardiale und vaskuläre Spätfolgen bei Langzeitüberlebenden nach Krebserkrankungen im Kindesalter	Kohortenstudie	26, 30	Universitätsmedizin Mainz: DKKR, Pädiatrische Hämatologie und Onkologie, II. Medizinische Klinik	ja	Deutsche Forschungsgemeinschaft

IMBEI: Institut für Medizinische Biometrie, Epidemiologie und Informatik

DKKR: Deutsches Kinderkrebsregister

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

Tabelle 12:

Research projects and international cooperations since 2011 (see table 11 for the German version)

Name of the project	Type of study	References
Second malignant neoplasms after childhood cancer: Case-control study on risk factors	Case-Control Study	15, 33
ACCIS: Automated Childhood Cancer Information System	International Data Base on Childhood Cancer	12
EUROCARE: Survival of cancer patients in Europe	Follow-up Study	14, 32
PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	International Network	34
GENKIK: Systematische Expressionsanalyse von DNA-Reparaturgenen bei kindlichen Malignomkrankungen	Case-Control Study	20, 21, 31
KIKME: Identifying genetic predisposition of spontaneous and radiation induced carcinogenesis in childhood malignomas	Case-Control Study	
KiCT: Risk of childhood cancer after computed tomography in childhood	Cohort Study	19
VIVE: Baseline Survey on Life Situation, Health, and Quality of Life after an Oncological Disease in Childhood or Adolescence	Cohort Study	25
PanCareLife: PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	International Data Base	27, 34
CVSS: Cardiac and vascular late sequelae in long-term survivors of childhood cancer - a multidisciplinary clinical, epidemiological and genetic approach	Cohort Study	26, 30

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Datengrundlage, Methoden und Ergebnisdarstellung

Rechtliche Grundlagen und Finanzierung des Registers

Das Deutsche Kinderkrebsregister (DKKR) wird auf der Basis der geltenden Datenschutzgesetze ohne eigene gesetzliche Grundlage geführt. Das bedeutet, dass von den betroffenen Patienten oder deren Sorgeberechtigten eine spezielle Einwilligung gegeben werden muss. Aufgrund des großen Engagements der Familien liegt der Anteil der nicht gegebenen Einwilligungen bei 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 grundsätzlich freiwillig. Aufgrund dieser Voraussetzungen war durch das Inkrafttreten des Krebsregistergesetzes des Bundes (1.1.1995) und der diversen Landeskrebsregistergesetze eine Änderung in der Verfahrensweise zur systematischen Erfassung der Erkrankungsfälle nicht erforderlich. Seit dem 1.1.2007 (geändert 2013) schreibt die „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten gemäß § 137 Abs. 1 Satz 3 Nr. 2 SGB V für nach § 108 SGB V zugelassene Krankenhäuser (Vereinbarung zur Kinderonkologie KiOn-RL)“ die Meldung von Patienten unter 18 Jahren mit pädiatrisch-onkologischen Erkrankungen an das Deutsche Kinderkrebsregister vor (11). Das am 9.4.2013 in Kraft getretene Krebsfrüherkennungs- und -registergesetz des Bundes (KFRG) (24) schließt mit Hinweis auf die Zuständigkeit des Deutschen Kinderkrebsregisters Patienten unter 18 Jahren mit pädiatrisch-onkologischen Erkrankungen ausdrücklich nicht ein.

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

Charakterisierung des Deutschen Kinderkrebsregisters

Das DKKR ist seit dem Beginn 1980 am Institut für Medizinische Biometrie, Epidemiologie und Informatik (IMBEI) der Universitätsmedizin der Johannes

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 basically voluntarily. Because of this a change of procedure was not necessary when the federal cancer registry law (1.1.1995) and the state registry laws came into effect. Since January 1st 2007 (last change 2013) the directive „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten gemäß § 137 Abs. 1 Satz 3 Nr. 2 SGB V für nach § 108 SGB V zugelassene Krankenhäuser (Vereinbarung zur Kinderonkologie KiOn-RL)“ made reporting cases under 18 to the German Childhood Cancer Registry mandatory (11). The law „Krebsfrüherkennungs- und -registergesetz des Bundes (KFRG)“ (24), in effect since 9th April 2013, explicitly excludes pediatric oncology patients under 18 due to the responsibility of the GCCR.

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

Characterization of the German Childhood Cancer Registry

The GCCR was established at the Institute for Medical Biostatistics, Epidemiology and Informatics (IMBEI) of the University Medical Center at the Johannes

Gutenberg-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 (klinischen Studien) bzw. diagnosespezifischen klinischen Registern der GPOH. Da der Anteil der hierin erfassten Patienten mit über 90% sehr hoch ist, kommt diesem Aspekt der integrierten Dokumentation eine ganz wesentliche Bedeutung zu.

Ein weiteres Charakteristikum des DKKR ist die Realisierung einer aktiven, zeitlich unbefristeten Langzeitnachsorgebeobachtung. Damit stellt das DKKR 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 DKKR geschickt (DKKR-Erstmeldung). Er enthält u.a. die Verdachtsdiagnose, wesentliche Identifikationsmerkmale, die Bestätigung der Einwilligung zu der Meldung durch Patient und/oder Sorgeberechtigte und die Information, ob und an welcher klinischen Therapieoptimierungsstudie der Patient teilnimmt bzw. an welches diagnosespezifische klinische Register er gemeldet wurde. Daraufhin wird vom DKKR an die Klinik ein diagnosespezifischer Erhebungsbogen verschickt. Mit diesen mit den Leitern der Therapieoptimierungsstudien bzw. der klinischen Register abgestimmten Bögen werden Einzelheiten der klinischen Diagnose und der Therapie erfasst. Bei einem Teil der Patienten erfolgt der Datenaustausch zwischen Klinik und Therapieoptimierungsstudie inzwischen direkt und elektronisch. Die Weiterleitung entsprechend validierter diagnostischer Detail-Informationen von der Therapiestudienleitung an das DKKR 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 bzw. das diagnosespezifische Register. Anschließend erfolgt dies durch das DKKR, wobei diese die Daten jeweils untereinander austauschen. Das DKKR erhält Nachsorge-Informationen aus mehreren Quellen: der Klinik (solange der Patient noch in der Nachsorge ist),

Gutenberg-University Mainz. It co-operates with the scientific society for paediatric oncology and haematology (GPOH) and the treating hospitals. The GCCR is a population based registry combined with some features of a clinical registry, registering also clinical details such as staging, grading, and immunological subtypes (4). The clinical information is based on the integrated information exchange and data flow between the ca. 25 GPOH organized therapy optimization trials or respective diagnosis specific registries and the GCCR. This is of special importance because more than 90% of all patients are included in these trials or respective diagnosis specific registries.

The GCCR is also characterized by an active open end long-term follow-up of all registered patients. This 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 GCCR. This contains patient identification data, a confirmation of consent (patient or guardian) to the registration, a preliminary diagnosis and information on whether this patient will be included in one of the on-going therapy optimization trials or respective diagnosis specific registries. In response to this notification, the GCCR sends a set of tumour-specific basic documentation forms to the cooperating clinician. For patients included in the therapy optimization trials or respective diagnosis specific registries, this basic documentation is to be returned directly to the relevant centre. For some patients, the data exchange is now more direct and electronic. Later the centres regularly provide the GCCR with validated diagnostic information, usually annually in electronic form. With few exceptions all diagnoses are histologically or immunologically verified.

Tumour-specific follow-up information is usually provided by the therapy studies until the end of the first clinical treatment phase and during clinical follow-up. After this, further follow-up is conducted by the GCCR, regularly exchanging this information with the therapy trials or respective diagnosis specific registries. The GCCR collects data from various sources, such as the hospitals, state cancer registries, municipalities, and last but not least the patients themselves. This flow of

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Einwohnermeldeämtern (im Rahmen von Adressrecherchen), gegebenenfalls Landeskrebsregistern und nicht zuletzt in zunehmendem Maße von den Patienten selbst. Der Dokumentationsablauf und die Synergieeffekte zwischen Therapieoptimierungsstudien und DKKR sind in (4, 5, 8, 11, 16, 28, 29) beschrieben. Die Langzeitnachsbeobachtung ist in (13, 18, 22, 23) publiziert.

Datengrundlage

Das DKKR nahm 1980 seine Arbeit auf. Die Registerpopulation im engeren Sinne umfasst die Kinder und Jugendlichen, die vor ihrem 15. Geburtstag, seit 2009 vor ihrem 18. Geburtstag, an einer malignen Erkrankung (einschließlich der histologisch nicht bösartigen ZNS-Tumoren (Tumoren des Zentralen Nervensystems)) erkranken und zur deutschen Wohnbevölkerung gehören. Seit 1991 sind die neuen Bundesländer mit einbezogen.

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 und Jugendlichen - gemäß internationaler Konvention - in einem epidemiologischen Krebsregister systematisch zu erfassen sind.

Die Vollzähligkeit der Erfassung für unter 15-Jährige beträgt seit 1987 über 95%; sie entspricht damit den internationalen Anforderungen an epidemiologische Krebsregister.

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

Grundlagen der Registrierung und Arbeitsweise zum Nachlesen

Literaturstellen

- Meldung und Dokumentationsablauf (4, 5, 8, 11)
- Langzeitnachsbeobachtung (17, 30, 22, 23)
- Statistische Methodik (1-3, 7)
- https://www.gmkonline.de/Beschluesse.html?id=82_08.01&jahr=2009

information is described in (4, 5, 8, 11, 16, 28, 29), the long-term follow-up procedures are published in (13, 18, 22, 23).

Data basis

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

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 and adolescence are recorded mandatory in an epidemiologic cancer registry.

The completeness of registration for cases under 15 is more than 95% since 1987; this complies with international requirements for an epidemiologic cancer registry.

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.

Further information on the basis of registration and procedures

References

- Notification and documentation (4, 5, 8, 11)
- Long-term surveillance (17, 30, 22, 23)
- Statistical methods (1-3, 7)
- https://www.gmkonline.de/Beschluesse.html?id=82_08.01&jahr=2009

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

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

- 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
- Krebsfrüherkennungs- und -registergesetz (KFRG) (24)
- Notwendigkeit der namensbezogenen Datenspeicherung
- Die Rahmenbedingungen des Deutschen Kinderkrebsregisters (8, 16)
- Positionspapier der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) zu (Langzeit-)Nachbeobachtung, (Langzeit-)Nachsorge und Spätfolgenenerhebung bei pädiatrisch-onkologischen Patienten (13)
- Datenaustausch zwischen Deutschem Kinderkrebsregister und den Landeskrebsregistern (17)
- DKKR-Regelwerk des Deutschen Kinderkrebsregisters zu datenschutz-relevanten Aspekten
- DKKR-Einwilligungserklärung
- DKKR-Technisches Datenschutz- und Datensicherheitskonzept des Deutschen Kinderkrebsregisters
- Die Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters (18, 22, 23)

Maßzahlen und deren Berechnung Inzidenz und allgemeine Kennzahlen

Die Gesamtzahl der Fälle bezieht sich auf die Fälle mit Diagnosealter <15 Jahre, ab 2009 <18 Jahre, mit Hauptwohnsitz zum Zeitpunkt der Diagnose in Deutschland, nach Diagnose, Altersgruppe, Geschlecht und den jeweilig angegebenen Zeitraum. Alle Angaben sind für die letzten 10 Jahre des Berichtszeitraums, soweit nicht anders angegeben. Derzeit liegen für die 15-17-Jährigen noch keine 10 Beobachtungsjahre vor; hier umfassen die Angaben derzeit die zurückliegenden 5 Jahre. Dabei zählen wir Fälle, nicht Patienten. Der Anteil der an Therapieoptimierungsstudien oder diagnosespezifischen klinischen Registern 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 engeren Sinne zu zählen sind.

Die Inzidenzrate (Neuerkrankungsrate) bezieht die Anzahl der neu aufgetretenen Fälle in einem bestimmten Gebiet und Zeitraum auf die zugehörige Wohnbevölkerung im entsprechenden Alter. Alle Inzidenzraten in diesem Bericht sind Durchschnittsangaben für den jeweiligen Zeitraum und werden als Rate pro 1.000.000 (Million) Personenjahre dargestellt.

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

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

Descriptive measures Incidence and general measures

The total number of cases refers to the cases diagnosed at age <15 years, from 2009 onwards <18 years, resident in Germany at the time of diagnosis, broken down by diagnosis, age group, sex and time periods. All figures are given for the most recent 10 years of the reporting period, unless otherwise stated. So far, there are not yet 10 years of observation available for cases aged 15-17; so for these we currently report the last five years. We count cases, not patients. The relative frequency of trial cases includes all patients the trial centre or respective diagnosis specific registry is informed of. This also includes patients who may not be treated according to protocol.

The incidence rate relates the number of new cases in a certain area and period to the resident population in the relevant age group. All incidence rates in this report are averages for the relevant period and are given as rates per 1,000,000 (million) person years.

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

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

mit N_{ij} Anzahl der Neuerkrankungen im Alter j im Zeitraum i und B_{ij} Bevölkerung im Alter j im Zeitraum i . In der Regel werden in diesem Bericht altersspezifische Inzidenzraten für die unter 1-jährigen ($j=1$), die 1- bis 4-jährigen ($j=2$), die 5- bis 9-jährigen ($j=3$) und die 10- bis 14-jährigen Kinder ($j=4$) berechnet, ab 2009 auch für die 15- bis 17-jährigen ($j=5$). Die (direkt) altersstandardisierte Inzidenzrate für unter 15- bzw. 18-Jährige errechnet sich mit Hilfe der Gewichte w_j des von Segi erarbeiteten WHO-Welt-Standards (2) (Tabelle M.1) als:

with N_{ij} the number of new cases at age j in time period i and B_{ij} the population at age j in time period i . This report usually gives age-specific incidence rates for children under age 1 ($j=1$), ages 1-4 ($j=2$), ages 5-9 ($j=3$), and ages 10-14 ($j=4$). From 2009 onwards we also include ages 15-17 ($j=5$). The directly standardized incidence rate for cases under 15 or 18 is calculated using the weights w_j of the Segi WHO world standard (2) (Table M.1):

Tabelle M. 1 / Table M. 1
Zusammensetzung der Segi Weltbevölkerung für Kinder unter 15 bzw. 18 Jahren im Vergleich zur durchschnittlichen deutschen Wohnbevölkerung 2009-2013
Composition of the Segi world standard for children under 15 resp. 18 years compared to the German population 2009-2013

Age-groups (years)	German population 2009-2013			World standard population	
	Absolute	Relative		Weights	
		< 15	< 18	< 15	< 18
0	671,635	0.06	0.05	0.08	0.07
1-4	2,735,728	0.25	0.20	0.31	0.26
5-9	3,563,968	0.33	0.27	0.32	0.27
10-14	3,902,315	0.36	0.29	0.29	0.25
15-17	2,498,502	-	0.19	-	0.15
Total		1.00	1.00	1.00	1.00

Die altersstandardisierte Inzidenzrate D_i gibt die Neuerkrankungsrate im Zeitraum i an, die man in der untersuchten Population erwarten würde, wenn die Altersstruktur mit der Standardbevölkerung übereinstimmen würde.

The age standardized incidence rate D_i gives the incidence rate in period i , which would be expected if the age structure in the report area were identical to the standard population.

$$D_i = \sum_j w_j I_{ij}$$

$$D_i = \sum_j w_j I_{ij}$$

Die kumulative Inzidenz C_i bis 15 bzw. 18 Jahre errechnet sich als Summe der altersspezifischen Inzidenzraten,

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

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

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

wobei hier gewöhnlich 15 bzw. 18 Einzelaltersjahresklassen verwendet werden ($j=1, \dots, 15$ oder 18). Sie kann interpretiert werden als das Risiko (die Wahrscheinlichkeit) eines neugeborenen Kindes, bis zum 15. oder 18. Geburtstag an einer Krebserkrankung zu erkranken.

usually using 15 or 18 single-year age classes ($j=1, \dots, 15$ or 18). It can be interpreted as the risk (the probability) of a new born to become a cancer case until his/her 15th or 18th birthday.

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

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

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 sowohl eine Hochrechnung für einen darüber hinausgehenden Zeitraum als auch eine stabilere Abschätzung des Langzeitüberlebens.

Die graphische Darstellung in diesem Bericht präsentiert die Überlebenszeitkurven nur bis zum tatsächlichen Beobachtungsende. Dargestellt werden die Überlebenswahrscheinlichkeiten nach Diagnosejahren für die erste 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. Bei sehr wenigen Patienten bzw. unvollständigen Nachbeobachtungsdaten wird keine Überlebenswahrscheinlichkeit in den Tabellen angegeben.

Die Berechnung der Mortalitätsrate und der kumulativen Mortalität erfolgt analog zur Inzidenzrate und kumulativen Inzidenz. Es werden die Todesfälle der 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

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

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

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.

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 neoplasms

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

The cumulative incidence of second neoplasm (SN) within 25 years of diagnosis includes only

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zweiten Krebserkrankungen (SN) bezieht sich nur auf in der ICC-3 definierte Krebserkrankungen. Gutartige weitere Erkrankungen (außer den in der ICC-3 eingeschlossenen ZNS-Tumoren) werden hier nicht mitgezählt.

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

Lesehilfe am Beispiel der Akuten Myeloischen Leukämie (ICC-3 Ib) (Tabelle M.2):

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 (1980-2013):					
I (b) Acute myeloid leukaemias					
SN after I (b)			I (b) as SN after any primary		
N	% of all 1061 SN	Cumulative incidence	N	% of all 1061 SN	Cumulative incidence
41	3.9 %	3.1 %	139	13.1 %	0.3 %

Bei den in den Jahren 1980-2013 mit einer AML unter 15 Jahren als erster Krebserkrankung diagnostizierten Patienten wurden in den folgenden bis zu 25 Jahren 41 zweite Krebserkrankungen diagnostiziert. Das sind 3,9% von allen 1061 innerhalb von 25 Jahren nach Diagnose in den Jahren 1980-2013 an das DKKR gemeldeten zweiten Krebserkrankungen. Bei 3,1% aller AML Patienten wird innerhalb von 25 Jahren nach Erst-diagnose eine weitere Krebserkrankung diagnostiziert, im Vergleich zum SN-Risiko nach allen Malignomen (4,4%) ist das unterdurchschnittlich.

Nach einer ersten Krebserkrankung beliebigen Typs im Alter von unter 15 in den Jahren 1980-2013 wurde bei 139 Patienten anschließend in den nächsten 25 Jahren eine AML diagnostiziert. 13,1% aller 1061 dem DKKR innerhalb von 25 Jahren nach Diagnose in den Jahren 1980-2013 gemeldeten zweiten Krebserkrankungen sind AML. Im Vergleich zu dem Anteil von AML an allen Krebserkrankungen im Kindesalter (4,4%) ist das

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

The population base for these calculations are all cases with a primary disease (as defined in ICC-3) at age <15, resident in Germany. The cumulative incidence is given per 100 person years under risk (%). As the number of deaths is relatively high, we estimate the cumulative incidence by the Aalen-Johansen-estimator (3), an extension of the Kaplan-Meier-procedure (1), which accounts for competing risks. We present the cumulative incidence of a second neoplasm after the respective primary neoplasm and then the respective diagnosis as SN after any primary neoplasm.

The tables should be read as follows, using acute myeloid leukaemia (ICC-3 Ib) as an example (Table M.2):

Within 25 years of diagnosis 41 second neoplasms were diagnosed out of the cases of AML reported at age under 15 in the years 1980-2013. These are 3.9 % of all 1061 recorded second neoplasms within 25 years of diagnosis in the years 1980-2012 at the GCCR. 3.1% of all AML cases are diagnosed with a second neoplasm within 25 years of diagnosis in the years 1980-2013, this is less than the average cumulative risk of SN for all malignancies (4.4%).

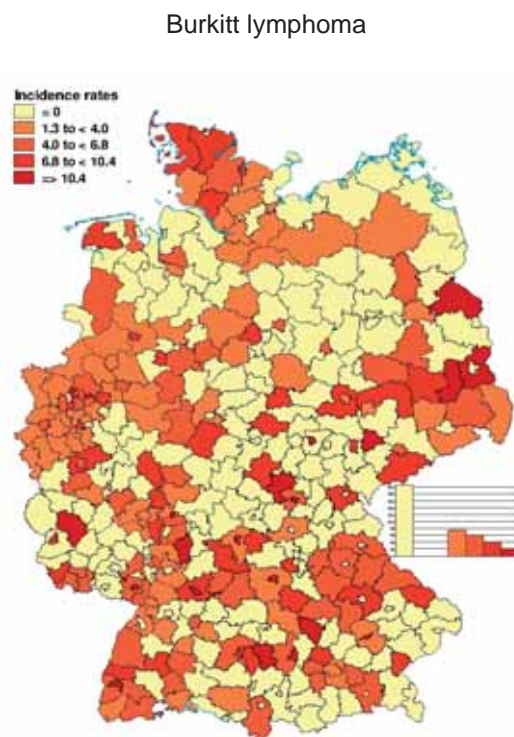
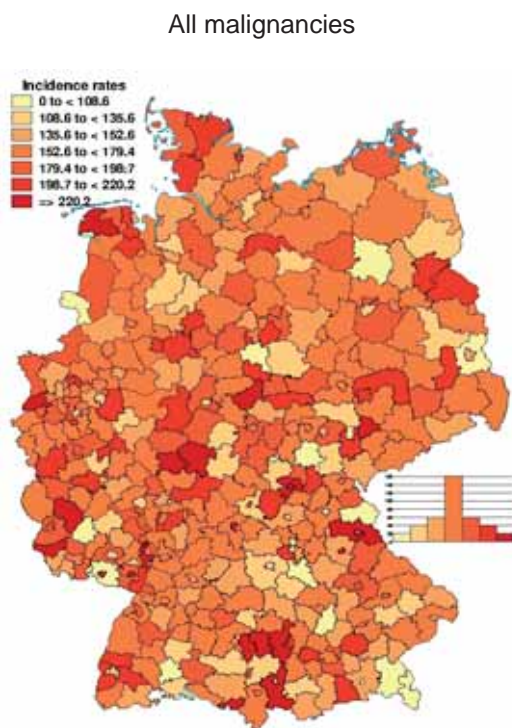
After any primary neoplasm at age under 15 in 1980-2013, 139 patients were diagnosed with AML as second neoplasms within 25 years of diagnosis in the years 1980-2013. 13.1% of all 1061 second neoplasms within 25 years of diagnosis of the primary disease in the years 1980-2013 reported at the GCCR are AML. Compared to 4.4% AML in general, this is a large number. 0.3% of all childhood cancer patients are diag-

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 oben ablesbar. Bei sehr seltenen Diagnosen ist eine kartographische Darstellung nicht mehr sinnvoll.

Abbildung M.1: Zwei Beispielkarten
Figure M.1: Two Sample Maps



Bei den Auswertungen zur regionalen Verteilung von Neuerkrankungshäufigkeiten (Tabelle 6) wird neben den altersstandardisierten Inzidenzraten auch das standardisierte Inzidenzverhältnis (SIR - Standardized Incidence Ratio) angegeben. Dieses ergibt sich aus dem Quotienten von beobachteter und erwarteter Erkrankungszahl. Die beobachtete Anzahl N_{ir} ist die Zahl aller Fälle unter 15 Jahren an der fraglichen Diagnose im Zeitraum i in der Region r . Der erwartete Wert berechnet sich aus der Zahl der Einwohner in den einzel-

nosed 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.

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 .

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nen Altersgruppen j in der untersuchten Region r im Zeitraum i (B_{ijr}) und den bundesweiten, altersspezifischen Inzidenzraten I_{ij} im gleichen Zeitraum i .

$$SIR_{ir} = \frac{N_{ir}}{\sum_j B_{ijr} \frac{I_{ij}}{1000000}} .$$

SIR-Werte über dem Referenzwert von 1 bedeuten, dass in der untersuchten Region mehr Erkrankungsfälle beobachtet wurden als im Vergleich mit der Inzidenzrate aus der gesamten Bundesrepublik zu erwarten wären und umgekehrt. Zur Beurteilung des SIR werden 95% Konfidenzintervalle (95%-KI), die auf der Poisson-Verteilung beruhen, berechnet. Ein SIR gilt als statistisch unauffällig, wenn das zugehörige Konfidenzintervall den Wert 1 einschließt. Ein 95%-KI jenseits von 1 bedeutet, dass es sich mit 5%-iger Wahrscheinlichkeit um eine zufällige Abweichung der regionalen Inzidenzrate von der bundesweiten Inzidenzrate handelt. Dies bedeutet auch, dass in ca. 5% aller Regionen rein zufällig entsprechend auffallend hohe oder niedrige Inzidenzraten erwartet werden, ohne dass dies von besonderer Bedeutung ist. Bei derzeit 402 Kreisen wären also zufällig etwa 20 Kreise mit ungewöhnlich hohen oder niedrigen Inzidenzraten zu erwarten, tatsächlich waren es beispielsweise für alle ICC3-3 Diagnosen für den Zeitraum 2004-2013 22 Kreise, davon 9 mit besonders hohen und 13 mit besonders niedrigen Fallzahlen.

$$SIR_{ir} = \frac{N_{ir}}{\sum_j B_{ijr} \frac{I_{ij}}{1000000}} .$$

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 2004-2013 for all ICC3-3 diagnoses we actually observed 22, 9 with unusually high and 13 with unusually low numbers of cases.

Internationale Klassifikation der Krebserkrankungen bei Kindern (ICCC-3)

Zuordnung von ICD-O-3-Codes für Morphologie und Topographie zu diagnostischen Kategorien

International Classification of Childhood Cancer (ICCC-3)

Categorization of morphology and topography codes, corresponding to ICD-O-3

adapted from: Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, Third Edition. Cancer 103, 1457-1467, 2005.

ICD-O-3 CODES		
DIAGNOSTIC GROUP	MORPHOLOGY	TOPOGRAPHY
I LEUKAEMIAS, MYELOPROLIFERATIVE AND MYELODYSPLASTIC DISEASES		
(a) Lymphoid leukaemias	9820, 9823, 9826, 9827, 9831-9837, 9940, 9948	
1 Precursor cell leukaemias	9835, 9836, 9837	
2 Mature B-cell leukaemias	9823, 9826, 9832, 9833, 9940	
3 Mature T-cell and NK cell leukaemias	9827, 9831, 9834, 9948	
4 Lymphoid leukaemia, NOS	9820	
(b) Acute myeloid leukaemias	9840, 9861, 9866, 9867, 9870-9874, 9891, 9895-9897, 9910, 9920, 9931	
(c) Chronic myeloproliferative diseases	9863, 9875, 9876, 9950, 9960-9964	
(d) Myelodysplastic syndrome and other myeloproliferative diseases	9945, 9946, 9975, 9980, 9982-9987, 9989	
(e) Unspecified and other specified leukaemias	9800, 9801, 9805, 9860, 9930	
II LYMPHOMAS AND RETICULOENDOTHELIAL NEOPLASMS		
(a) Hodgkin lymphomas	9650-9655, 9659, 9661-9665, 9667	
(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)	9591, 9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698-9702, 9705, 9708, 9709, 9714, 9716-9719, 9727-9729, 9731-9734, 9760-9762, 9764-9769, 9970	
1 Precursor cell lymphomas	9727, 9728, 9729	
2 Mature B-cell lymphomas (except Burkitt lymphoma) #	9670, 9671, 9673, 9675, 9678-9680, 9684, 9689-9691, 9695, 9698, 9699, 9731-9734, 9761, 9762, 9764-9766, 9769, 9970	
3 Mature T-cell and NK-cell lymphomas	9700-9702 +, 9705, 9708, 9709, 9714, 9716-9719, 9767, 9768	
4 Non-Hodgkin lymphomas, NOS	9591, 9760	
(c) Burkitt lymphoma	9687	
(d) Miscellaneous lymphoreticular neoplasms	9740-9742, 9750, 9754-9758	
(e) Unspecified lymphomas	9590, 9596	

Burkitt lymphoma (Ilg), as a mature B-cell non-Hodgkin lymphoma, may be pooled with Ilb2 for overall presentation of B-cell lymphomas.

⁺ "9702 T-cell lymphoma, NOS" in a child almost always corresponds to code M-9729.

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
III CNS AND MISCELLANEOUS INTRACRANIAL AND INTRASPINAL NEOPLASMS		
(a) Ependymomas and choroid plexus tumour	9383, 9390-9394	*
1 Ependymomas	9383, 9391-9394	*
2 Choroid plexus tumour	9390	*
(b) Astrocytomas	9380	C72.3
	9384, 9400-9411, 9420, 9421-9424, 9440-9442	*
(c) Intracranial and intraspinal embryonal tumours	9470-9474, 9480, 9508	*
	9501-9504	C70.0-C72.9
1 Medulloblastomas	9470-9472, 9474, 9480	*
2 Primitive neuroectodermal tumour (PNET)	9473	*
3 Medulloepithelioma	9501-9504	* C70.0-C72.9
4 Atypical teratoid / rhabdoid tumour	9508	*
(d) Other gliomas	9380	* C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
	9381, 9382, 9430, 9444, 9450, 9451, 9460	*
1 Oligodendrogliomas	9450, 9451, 9460	*
2 Mixed and unspecified gliomas	9380	* C70.0-C72.2, C72.4-C72.9, C75.1, C75.3
	9382	*
3 Neuroepithelial glial tumours of uncertain origin	9381, 9430, 9444	*
(e) Other specified intracranial and intraspinal neoplasms	8270-8281, 8300, 9350-9352, 9360-9362, 9412, 9413, 9492, 9493, 9505-9507, 9530-9539, 9582	*
1 Pituitary adenomas and carcinomas	8270-8281, 8300	*
2 Tumours of the sellar region (craniopharyngiomas)	9350-9352, 9582	*
3 Pineal parenchymal tumours	9360-9362	*
4 Neuronal and mixed neuronal-glial tumours	9412, 9413, 9492, 9493, 9505-9507	*
5 Meningiomas	9530-9539	*
(f) Unspecified intracranial and intraspinal neoplasms	8000-8005	* C70.0-C72.9, C75.1-C75.3

* Tumours with non-malignant behaviour codes are included

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
IV NEUROBLASTOMA AND OTHER PERIPHERAL NERVOUS CELL TUMOURS		
(a) Neuroblastoma and ganglioneuroblastoma	9490, 9500	
(b) Other peripheral nervous cell tumours	8680-8683, 8690-8693, 8700, 9520-9523	
	9501-9504	C00.0-C69.9, C73.9-C76.8, C80.9
V RETINOBLASTOMA		
	9510-9514	
VI RENAL TUMOURS		
(a) Nephroblastoma and other non-epithelial renal tumours	8959, 8960, 8964-8967	
	8963, 9364	C64.9
1 Nephroblastoma	8959, 8960	
2 Rhabdoid renal tumour	8963	C64.9
3 Kidney sarcomas	8964-8967	
4 Peripheral neuroectodermal tumour (pPNET) of kidney	9364	C64.9
(b) Renal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8155, 8190-8201, 8210, 8211, 8221-8231, 8240, 8241, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	C64.9
	8311, 8312, 8316-8319, 8361	
(c) Unspecified malignant renal tumours	8000-8005	C64.9
VII HEPATIC TUMOURS		
(a) Hepatoblastoma	8970	
(b) Hepatic carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8140, 8141, 8143, 8155, 8190-8201, 8210, 8211, 8230, 8231, 8240, 8241, 8244-8246, 8260-8264, 8310, 8320, 8323, 8401, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8576	C22.0, C22.1
	8160-8180	
(c) Unspecified malignant hepatic tumours	8000-8005	C22.0, C22.1

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
VIII MALIGNANT BONE TUMOURS		
(a) Osteosarcomas	9180-9187, 9191-9195, 9200	C40.0-C41.9, C76.0-C76.8, C80.9
(b) Chondrosarcomas	9210, 9220, 9240	C40.0-C41.9, C76.0-C76.8, C80.9
	9221, 9230, 9241-9243	
(c) Ewing tumour and related sarcomas of bone	9260	C40.0-C41.9, C76.0-C76.8, C80.9
	9363-9365	C40.0-C41.9
1 Ewing tumour and Askin tumour of bone	9260	C40.0-C41.9, C76.0-C76.8, C80.9
	9365	C40.0-C41.9
2 Peripheral neuroectodermal tumour (pNET) of bone	9363, 9364	C40.0-C41.9
(d) Other specified malignant bone tumours	8810, 8811, 8823, 8830	C40.0-C41.9
	8812, 9250, 9261, 9262, 9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342, 9370-9372	
1 Malignant fibrous neoplasms of bone	8810, 8811, 8823, 8830	C40.0-C41.9
	8812, 9262	
2 Malignant chordomas	9370-9372	
3 Odontogenic malignant tumours	9270-9275, 9280-9282, 9290, 9300-9302, 9310-9312, 9320-9322, 9330, 9340-9342	
4 Miscellaneous malignant bone tumours	9250, 9261	
(e) Unspecified malignant bone tumours	8000-8005, 8800, 8801, 8803-8805	C40.0-C41.9
IX SOFT TISSUE AND OTHER EXTRAOSSEOUS SARCOMAS		
(a) Rhabdomyosarcomas	8900-8905, 8910, 8912, 8920, 8991	
(b) Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	8810, 8811, 8813-8815, 8821, 8823, 8834-8835	C00.0-C39.9, C44.0-C76.8, C80.9
	8820, 8822, 8824-8827, 9150, 9160, 9491, 9540-9571, 9580	
1 Fibroblastic and myofibroblastic tumours	8810, 8811, 8813-8815, 8821, 8823, 8834-8835	C00.0-C39.9, C44.0-C76.8, C80.9
	8820, 8822, 8824-8827, 9150, 9160	
2 Nerve sheath tumours	9540-9571	
3 Other fibrous neoplasms	9491, 9580	

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
IX SOFT TISSUE AND OTHER EXTRAOSSEOUS SARCOMAS (cont.)		
(c) Kaposi sarcoma	9140	
(d) Other specified soft tissue sarcomas	8587, 8710-8713, 8806, 8831-8833, 8836, 8840-8842, 8850-8858, 8860-8862, 8870, 8880, 8881, 8890-8898, 8921, 8982, 8990, 9040-9044, 9120-9125, 9130-9133, 9135, 9136, 9141, 9142, 9161, 9170-9175, 9231, 9251, 9252, 9373, 9581	
	8830	C00.0-C39.9, C44.0-C76.8, C80.9
	8963	C00.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
	9180, 9210, 9220, 9240	C49.0-C49.9
	9260	C00.0-C39.9, C47.0-C75.9
	9364	C00.0-C39.9, C47.0-C63.9, C65.9-C69.9, C73.9-C76.8, C80.9
	9365	C00.0-C39.9, C47.0-C63.9, C65.9-C76.8, C80.9
1 Ewing tumour and Askin tumour of soft tissue	9260	C00.0-C39.9, C47.0-C75.9
	9365	C00.0-C39.9, C47.0-C63.9, C65.9-C76.8, 80.9
2 Peripheral neuroectodermal tumour (pPNET) of soft tissue	9364	C00.0-C39.9, C47.0-C63.9, C65.9-C69.9, C73.9-C76.8, 80.9
3 Extrarenal rhabdoid tumour	8963	C00.0-C63.9, C65.9-C69.9, C73.9-C76.8, 80.9
4 Liposarcomas	8850-8858, 8860-8862, 8870, 8880, 8881	
5 Fibrohistiocytic tumours	8830	C00.0-C39.9, C44.0-C76.8, 80.9
	8831-8833, 8836, 9251, 9252	
6 Leiomyosarcomas	8890-8898	
7 Synovial sarcomas	9040-9044	
8 Blood vessel tumours	9120-9125, 9130-9133, 9135, 9136, 9141, 9142, 9161, 9170-9175	
9 Osseous and chondromatous neoplasms of soft tissue	9180, 9210, 9220, 9240	C49.0-C49.9
	9231	
10 Alveolar soft parts sarcoma	9581	
11 Miscellaneous soft tissue sarcomas	8587, 8710-8713, 8806, 8840-8842, 8921, 8982, 8990, 9373	

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
IX SOFT TISSUE AND OTHER EXTRAOSSEOUS SARCOMAS (cont.)		
(e) Unspecified soft tissue sarcomas	8800-8805	C00.0-C39.9, C44.0-C76.8, C80.9
X GERM CELL TUMOURS, TROPHOBLASTIC TUMOURS AND NEOPLASMS OF GONADS		
(a) Intracranial and intraspinal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100, 9101	* C70.0-C72.9, C75.1-C75.3
1 Intracranial and intraspinal germinomas	9060-9065	*
2 Intracranial and intraspinal teratomas	9080-9084	*
3 Intracranial and intraspinal embryonal carcinomas	9070, 9072	*
4 Intracranial and intraspinal yolk sac tumour	9071	*
5 Intracranial and intraspinal choriocarcinoma	9100	*
6 Intracranial and intraspinal tumours of mixed forms	9085, 9101	*
(b) Malignant extracranial and extragonadal germ cell tumours	9060-9065, 9070-9072, 9080-9085, 9100-9105	C00.0-C55.9, C57.0-C61.9, C63.0-C69.9, C73.9-C75.0, C75.4-C76.8, C80.9
1 Malignant germinomas of extracranial and extragonadal sites	9060-9065	C00.0-C55.9, C57.0-C61.9, C63.0-C69.9, C73.9-C75.0, C75.4-C76.8, 80.9
2 Malignant teratomas of extracranial and extragonadal sites	9080-9084	
3 Embryonal carcinomas of extracranial and extragonadal sites	9070, 9072	
4 Yolk sac tumour of extracranial and extragonadal sites	9071	
5 Choriocarcinomas of extracranial and extragonadal sites	9100, 9103, 9104	
6 Other and unspecified malignant mixed germ cell tumours of extracranial and extragonadal sites	9085, 9101, 9102, 9105	
(c) Malignant gonadal germ cell tumours	9060-9065, 9070-9073, 9080-9085, 9090, 9091, 9100, 9101	C56.9, C62.0-C62.9
1 Malignant gonadal germinomas	9060-9065	C56.9, C62.0-C62.9
2 Malignant gonadal teratomas	9080-9084, 9090, 9091	
3 Gonadal embryonal carcinomas	9070, 9072	
4 Gonadal yolk sac tumour	9071	
5 Gonadal choriocarcinoma	9100	
6 Malignant gonadal tumours of mixed forms	9085, 9101	
7 Malignant gonadal gonadoblastoma	9073	

* Tumours with non-malignant behaviour codes are included

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
X GERM CELL TUMOURS, TROPHOBLASTIC TUMOURS AND NEOPLASMS OF GONADS (cont.)		
(d) Gonadal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8260-8263, 8290, 8310, 8313, 8320, 8323, 8380-8384, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 9000, 9014, 9015	C56.9, C62.0-C62.9
	8441-8444, 8450, 8451, 8460-8473	
(e) Other and unspecified malignant gonadal tumours	8590-8671	
	8000-8005	C56.9, C62.0-C62.9
XI OTHER MALIGNANT EPITHELIAL NEOPLASMS AND MALIGNANT MELANOMAS		
(a) Adrenocortical carcinomas	8370-8375	
(b) Thyroid carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8510, 8560-8573	C73.9
	8330-8337, 8340-8347, 8350	
(c) Nasopharyngeal carcinomas	8010-8041, 8050-8075, 8082, 8083, 8120-8122, 8130-8141, 8190, 8200, 8201, 8211, 8230, 8231, 8244-8246, 8260-8263, 8290, 8310, 8320, 8323, 8430, 8440, 8480, 8481, 8500-8576	C11.0-C11.9
(d) Malignant melanomas	8720-8780, 8790	
(e) Skin carcinomas	8010-8041, 8050-8075, 8078, 8082, 8090-8110, 8140, 8143, 8147, 8190, 8200, 8240, 8246, 8247, 8260, 8310, 8320, 8323, 8390-8420, 8430, 8480, 8542, 8560, 8570-8573, 8940, 8941	C44.0-C44.9
(f) Other and unspecified carcinomas	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C00.0-C10.9, C12.9-C21.8, C23.9-C39.9, C48.0-C48.8, C50.0-C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C72.9, C75.0-C76.8, C80.9
1 Carcinomas of salivary glands		C07.9-C08.9
2 Carcinomas of colon and rectum	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C18.0, C18.2-C18.9, C19.9, C20.9, C21.0-C21.8
3 Carcinomas of appendix		C18.1
4 Carcinomas of lung		C34.0-C34.9

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
XI OTHER MALIGNANT EPITHELIAL NEOPLASMS AND MALIGNANT MELANOMAS (cont.)		
(f) Other and unspecified carcinomas (cont.)		
5 Carcinomas of thymus		C37.9
6 Carcinomas of breast		C50.0-C50.9
7 Carcinomas of cervix uteri		C53.0-C53.9
8 Carcinomas of bladder		C67.0-C67.9
9 Carcinomas of eye		C69.0-C69.9
10 Carcinomas of other specified sites	8010-8084, 8120-8157, 8190-8264, 8290, 8310, 8313-8315, 8320-8325, 8360, 8380-8384, 8430-8440, 8452-8454, 8480-8586, 8588-8589, 8940, 8941, 8983, 9000, 9010-9016, 9020, 9030	C00.0-C06.9, C09.0-C10.9, C12.9-C17.9, C23.9-C33.9, C38.0-C39.9, C48.0-C48.8, C51.0-C52.9, C54.0-C54.9, C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C66.9, C68.0-C68.9, C70.0-C72.9, C75.0-C75.9
11 Carcinomas of unspecified site		C76.0-C76.8, C80.9
XII OTHER AND UNSPECIFIED MALIGNANT NEOPLASMS		
(a) Other specified malignant tumours		
	8930-8936, 8950, 8951, 8971-8981, 9050-9055, 9110	
	9363	C00.0-C39.9, C47.0-C75.9
1 Gastrointestinal stromal tumour	8936	
2 Pancreatoblastoma	8971	
3 Pulmonary blastoma and pleuropulmonary blastoma	8972, 8973	
4 Other complex mixed and stromal neoplasms	8930-8935, 8950, 8951, 8974-8981	
5 Mesothelioma	9050-9055	
6 Other specified malignant tumours	9110	
	9363	C00.0-C39.9, C47.0-C75.9
(b) Other unspecified malignant tumours		
	8000-8005	C00.0-C21.8, C23.9-C39.9, C42.0-C55.9, C57.0-C61.9, C63.0-C63.9, C65.9-C69.9, C73.9-C75.0, C75.4-C80.9

Veröffentlichungen mit Beteiligung des Deutschen Kinderkrebsregisters seit 2011

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