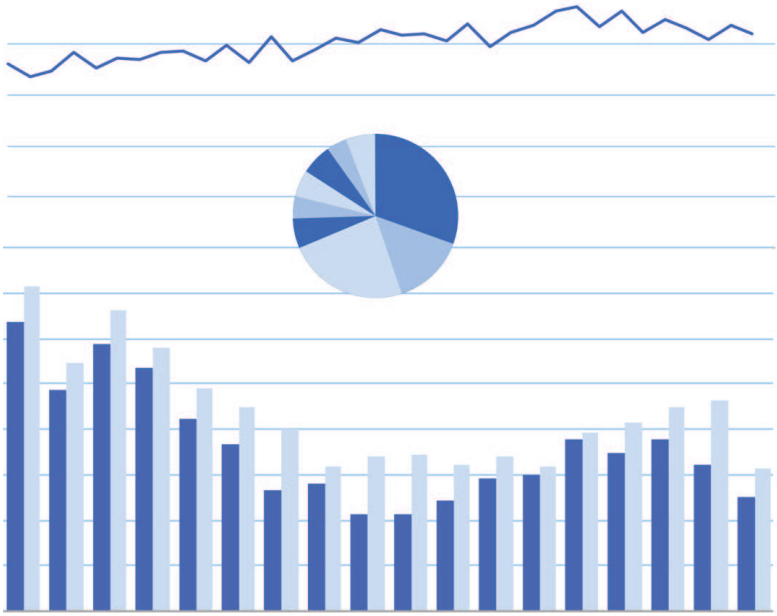
Deutsches
Kinderkrebsregister

Jahresbericht / Annual Report 2019

German Childhood Cancer Registry



Deutsches
Kinderkrebsregister

Jahresbericht
Annual Report
2019

(1980-2018)

Deutsches Kinderkrebsregister DKKR
German Childhood Cancer Registry GCCR

JG|U UNIVERSITÄTSmedizin. MAINZ
IMBEI Institut für Medizinische Biometrie Epidemiologie und Informatik

Jahresbericht / Annual Report 2019 (1980-2018)

September 2020

Deutsches Kinderkrebsregister am
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und Informatik (IMBEI)
Universitätsmedizin
der Johannes Gutenberg-Universität Mainz
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2 Vorwort / Foreword

40 Jahre Deutsches Kinderkrebsregister

Der vorliegende Jahresbericht 2019 erscheint im Jahr nach dem 40-jährigen Jubiläum des Deutschen Kinderkrebsregisters (DKKR). Im Januar 2020 wurde der Geburtstag mit einem zweitägigen wissenschaftlichen Symposium mit international renommierten Referenten aus dem In- und Ausland, mit Wegbegleitern, Betroffenen und politischen Repräsentanten gefeiert.

Das DKKR hat am 1. Januar 1980 auf Initiative der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH; seinerzeit GPO) und mit einer anfänglich fünfjährigen Finanzierung durch die Stiftung Volkswagenwerk seine Arbeit aufgenommen. Man wusste seinerzeit nicht, wieviel Kinder pro Jahr in Deutschland mit welcher Krebserkrankung diagnostiziert wurden. Dies zu wissen war jedoch für die damals beginnenden ersten Therapieoptimierungsstudien der GPOH wichtig für die konkrete Studienplanung.
Das DKKR ist seit Beginn am Institut für Medizinische Biometrie, Epidemiologie und Informatik (IMBEI; vormals IMSD) der Universitätsmedizin Mainz angesiedelt. Direktor des Institutes und damit Leiter des DKKR war seinerzeit Prof. Dr. Jörg Michaelis. Nach seiner Wahl zum Universitätspräsidenten im Jahr 2001 wurde die Leitung an Privatdozent Dr. Peter Kaatsch übergeben, dessen Nachfolge wiederum nach Beginn seines Ruhestands zum 1. März 2020 Dr. Friederike Erdmann antrat.
Das DKKR ist ein epidemiologisches Krebsregister (über die Zeit auch um ausgewählte klinische Daten ergänzt) und erfasst alle malignen Erkrankungen, die vor dem 18. Geburtstag diagnostiziert werden (einschließlich der nicht malignen Tumoren im zentralen Nervensystem). Meldende Stellen sind alle Kliniken für Kinder- und Jugendonkologie in Deutschland. Aktuell sind 66.859 Erkrankungsfälle registriert und jährlich kommen etwa 2.200 hinzu. Fast 40.000 davon werden aktiv nachbeobachtet.
Zwei wichtige Meilensteine sollten genannt werden, die jeweils mit einer Erweiterung der Registerpopulation einhergingen: Ab dem Jahr 1991 wurden auch die nach der deutschen Wiedervereinigung hinzugekommenen Bundesländer mit einbezogen und seit dem Jahr 2009 wurde die Altersgrenze von vormals unter 15-jährigen auf unter 18-jährige erweitert. Im vorliegenden Jahresbericht können daher erstmals Inzidenzen für Patienten im Alter von unter 18 Jahren für einen 10-Jahreszeitraum berichtet werden.
Charakterisiert man die zurückliegenden 40 Jahre, so ist das Register in der ersten Dekade aufgebaut und etabliert worden. In den 1990er Jahre wurden die ersten großen, überwiegend der Ursachenforschung dienenden epidemiologischen Studien durchgeführt.

40 Years German Childhood Cancer Registry

This report is published in the year after the 40th anniversary of the German Childhood Cancer Registry (GCCR). In January 2020 we celebrated the anniversary with a two-day scientific symposium with acclaimed speakers nationally and internationally, together with long-term associates, former patients and political representatives.

The GCCR started out in January 1980 as an initiative of the Society for Pediatric Oncology and Hematology (GPOH, then GPO); supported for the first 5 years by the Stiftung Volkswagenwerk. In these days it was unknown how many children exactly were diagnosed annually with which diagnoses in Germany. The new therapy optimisation studies of the GPOH needed these numbers for planning.

Right from the start the GCCR was hosted by the Institute for Medical Biometry, Epidemiology and Informatics (IMBEI; then IMSD) at the University Medical Center Mainz. The head of the institute and thus head of the GCCR was Prof Dr Jörg Michaelis. After he was elected President of the University Mainz in 2001 he passed on the registry to PD Dr Peter Kaatsch. He retired and was succeeded by Dr Friederike Erdmann in March 2020.

The GCCR is basically an epidemiological registry (over time we added a few selected clinical variables); it registers all malignant diagnoses (including non-malignant tumours in the central nervous system) before the 18th birthday. The reports come from all oncologic clinics for children and adolescents. Currently 66,859 cases are registered and annually another 2,200 are reported. Almost 40,000 of these are in active long-term surveillance.

We would like to point out two important milestones: After the reunification since 1991 the Eastern states were included and since 2009 the age limit was increased from under 15 to under 18. This report is the first one where incidence rates for under 18-year olds can be reported for 10 years.

Characterising the past 40 years we may say that the registry was established in the first decade; the 1990ies saw the first large epidemiologic studies with an emphasis on risk factor research.

Dr. Friederike Erdmann & PD Dr. Peter Kaatsch

Die erste Dekade des neuen Jahrhunderts diente der Etablierung der Langzeitnachbeobachtung und in den 2010er Jahren wurde die Spätfolgenforschung zu einem neuen Arbeitsschwerpunkt des Registers.
An wichtigen, auch international beachteten Studien können unter anderem genannt werden: Fall-Kontrollstudien zur Ursachenforschung (z.B. zu elektromagnetischen Feldern), Studie zur möglichen Etablierung des Neuroblastom-Screenings, strahlenepidemiologische Studien (z.B. zu Kernkraftwerken) oder Zweittumorstudien.
Bedarf an Informationen aus dem DKKR haben nicht nur die Kinderonkologen (Kliniken, Studiengruppen, Fachgesellschaft), sondern auch Ministerien und Behörden (Gesundheitsberichterstattung, Versorgungsaspekte, Bewertung möglicher Krankheitscluster, nationale und internationale Sichtbarkeit) und Betroffene, die insbesondere im Erwachsenenalter einen hohen Informationsbedarf haben. Auch für die Durchführung von epidemiologischen Forschungsprojekten bildet die Datenbasis des DKKR eine exzellente Grundlage.

In the new century the first decade saw the establishment of the long-term follow-up and since about 2010 the focus shifts toward late effects research.

Many important studies with international impact were conducted, just to name a few: Case-control studies on suspected risk factors (such as electromagnetic fields), a study to determine the possible effectiveness of Neuroblastoma-Screening, studies in the field of radiation epidemiology (e.g. with respect to nuclear power stations), as well as second neoplasm studies.
The data from the GCCR is not just needed by pediatric oncologists (hospitals, clinical studies, or medical societies), but also by ministries and administrations (health reporting, medical care planning, cluster evaluation, national and international visibility). A special mention goes to patient families and former patients, who do especially need information in later life. The data basis provided by the GCCR gives an excellent foundation for conducting epidemiological projects.

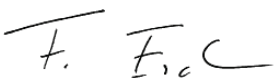
4 Vorwort / Foreword

Forschungsfragen von künftig außerordentlicher Public Health-Relevanz sehen wir in der Versorgungsforschung von Langzeitüberlebenden nach Krebs im Kindes- und Jugendalter. So wird noch im Jahr 2020 eine Studie aus Mitteln des GBA-Innovationsfonds beginnen, in der die DKKR-Daten u.a. mit Daten der gesetzlichen Krankenkassen verlinkt werden, um letztlich aktuelle Nachsorgekonzepte und Versorgungsleitlinien optimieren zu können. Auch im Hinblick auf die Einführung eines Survivor-Passports wird im Herbst 2020 ein Pilotprojekt beginnen.
Im Fokus wird ebenso die weitere Automatisierung der Meldewege zwischen behandelnden Kliniken, klinischen Studien, Landeskrebsregistern und DKKR stehen. Auch für die Durchführung der Langzeitnachbeobachtung (speziell die Befragung Betroffener) werden elektronische Wege etabliert werden.
Die Finanzierung des DKKR erfolgt seit Mitte der 1980er Jahre durch die Gesundheitsministerien von Bund und Ländern (anfangs nur Bund und Rheinland-Pfalz; mittlerweile sind auch die anderen Länder beteiligt); dafür möchten wir uns ganz herzlich bedanken. Besonders danken wir auch der Gesellschaft für Pädiatrische Onkologie und Hämatologie, den behandelnden Klinikern und den GPOH-Studiengruppen. Ohne die von dort eingebrachten Daten und ohne deren ideelle Unterstützung und dem so wichtigen inhaltlichen und visionären Gedankenaustausch hätte sich das DKKR nicht in dieser international beachteten Qualität etablieren können.
Besonders wichtig ist es uns, uns bei den Betroffenen und deren Familien zu bedanken, die uns ihre Daten zur Verfügung stellen. Ohne die entsprechende Vertrauensbasis wäre unsere so vollzählige Erfassung und umfassende Langzeitnachbeobachtung nicht möglich.
Wir wünschen uns für die nächsten vielen Jahre, unsere zahlreichen bestehenden Kooperationen fortzuführen und neue Visionen zu entwickeln, weitere Forschungsinitiativen zu realisieren, die internationale Sichtbarkeit weiter zu intensivieren sowie die Alleinstellungsmerkmale des Deutschen Kinderkrebsregisters zu erhalten und damit mit den Daten des DKKR zu neuen wissenschaftlichen Erkenntnissen im Interesse der Patienten und der ehemaligen Patienten beizutragen.

In the future we consider aspects of healthcare research for long-term survivors after childhood cancer as a major public health issue. In 2020 we will start a study, funded by the GBA-Innovationsfonds, where GCCR-data is linked with, among others, data from statutory health insurances to help with optimising long-term care and care recommendations. Also, 2020 will see the start of a pilot project for the survivor passport.

Another focus is the automation of reporting and data exchange between the GCCR and hospitals, clinical studies and other cancer registries. We are also working on further automating the long-term follow-up including the surveys of former patients.

Since the mid-1980ies funding is provided by the health ministries, federal and state (originally only federal and Rhineland-Palatinate, then followed by the other states); we are very grateful for this. We would also like to offer thanks to the Society for Pediatric Oncology and Hematology, the treating clinicians and the GPOH study groups. Their support with data, ideas and discussion has greatly contributed to the national and internationally acclaimed establishment of the GCCR.
Finally, we are extremely grateful to the patients and families, who trust us with their data. Without this, our complete data and the long-term follow-up would not be possible.
For the next years we hope to continue our numerous cooperations, to develop new visions, to keep our unique features and to use our data for new scientific insight for the patients and former patients


Dr. Friederike Erdmann


PD Dr. Peter Kaatsch


Dr. Desirée Grabow


PD Dr. Claudia Spix

40 Jahre Deutsches Kinderkrebsregister

Das Deutsche Kinderkrebsregister an der Universitätsmedizin Mainz hat sich über viele Jahre weltweite Achtung erarbeitet, die es im Januar 2020 zu feiern galt. Erst unter dem Gründer und langjährigen Leiter, Professor Dr. Jörg Michaelis, zuletzt unter dem ebenfalls langjährig hier aktiven Mitarbeiter und Leiter, Priv.-Doz. Dr. Peter Kaatsch wurde auf der Basis aktueller und sorgfältig zusammengetragener Daten der in Deutschland an Krebs erkrankten Kinder auf vielfältige Art und Weise nicht nur ein höchst bedeutsames Krebsregister einer besonderen Altersgruppe, sondern auch ein Fundus für weiter reichende Untersuchungen auf nationaler und internationaler Ebene geschaffen. Das verdient höchste Anerkennung! Die Ärztinnen und Ärzte in der Gesellschaft für Pädiatrische Hämatologie und Onkologie (GPOH), aber auch viele Betroffene nutzen den reichen Datenfundus des Deutschen Kinderkrebsregisters rege, um sich ein Bild über das Auftreten dieser für viele Menschen sehr bedrohlichen Erkrankungen zu machen. Immer wieder waren beispielsweise die vom Deutschen Kinderkrebsregister beobachteten Cluster Anlass für vertiefte Untersuchungen in speziellen Gebieten der Bundesrepublik. Die Epidemiologie war damit ein wichtiger Eckpfeiler auf der Suche nach Ursachen für das Auftreten von Krebserkrankungen bei Kindern geworden. Während der 40 Jahre des Bestehens des Deutschen Kinderkrebsregisters hat sich der Fokus in der Kinderonkologie von dem Bestreben nach Heilung über die Suche nach Ursachen immer mehr in Richtung der Erfassung von Spätfolgen entwickelt. Letzteres ist für genesene Betroffene ein Herzensanliegen, denn die wenigsten Ärztinnen und Ärzte jenseits der Pädiatrischen Onkologie sind mit den spezifischen Folgen einer Krebsbehandlung bei Kindern nach z.B. 30 Jahren vertraut. Hier liegt neben der vertieften multifaktoriellen Aufklärung der Krankheitsauslöser ein zukünftiger Schwerpunkt der Arbeit des DKKR, der für die mittlerweile viele Tausend ehemals Erkrankten ausgesprochen hilfreich sein könnte.

Die GPOH gratuliert zum 40. Geburtstag!

Im Juni 2020

Prof. Dr. Martin Schrappe, GPOH-Vorsitzender

40 Years German Childhood Cancer Registry

The German Childhood Cancer Registry at the University Medical Center Mainz has acquired worldwide respect through its years of working, which it celebrated in January 2020. The founder and longtime director, Professor Dr. Jörg Michaelis, and his associate and then longtime director Priv.-Doz. Dr. Peter Kaatsch collated complete and up-to-date data on all childhood cancer cases in Germany in a registry for this special age group important in many different ways; and thus provided a basis for extended investigations in national and international context. This is highly appreciated! The physicians of the Society for Pediatric Hematology and Oncology (GPOH), but also many patients and former patients, frequently make use of the comprehensive data pool to obtain further insights into the occurrences of this life-threatening diseases in special areas. For example, the clusters observed by the GCCR to study with. This made epidemiology a cornerstone in obtaining further insights into the causes of cancer in childhood. During the 40 years of its existence the focus of pediatric oncology shifted from the effort to improve the prognosis to the search for causes towards collecting information on late effects. The latter is an important aspect for the survivors, as only a fraction of physicians outside of pediatric oncology are familiar with the specific consequences of cancer treatment after e.g. 30 years. The next years the questions approached by the GCCR will be about clarifying the multiple causes of childhood cancer as well as the late effects, which will help the meanwhile many thousands of survivors.

The GPOH congratulates on the 40th birthday!

June 2020

Deutsches Kinderkrebsregister

40 Jahre Deutsches Kinderkrebsregister

Wissenschaftliches Symposium in Mainz

am 23. und 24. Januar 2020

Donnerstag, 23. Januar 2020

Eröffnung (*K. Strauch, Mainz*)

Begrüßung (*P. Kaatsch, Mainz*)

Grußworte
(Parlamentarische Staatssekretärin S. Weiss; Staatssekretär Dr. A. Wilhelm; Präsident Univ.-Prof. Dr. G. Krausch; Wissenschaftlicher Vorstand Univ.-Prof. Dr. U. Förstermann; GPOH-Vorsitzender Univ.-Prof. Dr. M. Schrappe; PanCare-Chairperson H. van der Pal, MD PhD)

40 Jahre Deutsches Kinderkrebsregister
(J. Michaelis, Mainz; P. Kaatsch, Mainz; DKKR-Mitarbeiter*innen)

Spätfolgenforschung nach Krebserkrankung im Kindes- und Jugendalter (*Vorsitz: L. Hjorth, Lund*)
(L. Hjorth, Lund; J. den Hartogh, Utrecht; M. M. van den Heuvel-Eibrink, Utrecht; I. Schmidtmann, Mainz; M. Eveslage, Münster)

Abendessen und Fortsetzung des Dialogs im Restaurant „Kupferberg Terrassen“

Freitag, 24. Januar 2020

Therapiestudien in der Kinderonkologie (*Vorsitz: M. Schrappe, Kiel*)
(C. Niemeyer, Freiburg)

Möglichkeiten verbesserter Versorgung Langzeitüberlebender (*Moderation: M. Schrappe, Kiel*)
(J. Gebauer, Lübeck; D. Grabow, Mainz; G. Calaminus, Bonn; G. Escherich, Hamburg; T. Langer, Lübeck; C. Randall, Mainz; H. van der Pal, Utrecht)

Internationale Kooperationen (*Vorsitz: M. Blettner, Mainz*)
(V. Pfeiffer, Bern; E. Steliarova-Foucher, Lyon; J. Schüz, Lyon)

Genetische Prädispositionen und molekulare Diagnostik (*Vorsitz: T. Klingebiel, Frankfurt*)
(C. Kratz, Hannover; C. Spix, Mainz; S. Pfister, Heidelberg)

Resümee und Ausblick (*K. Strauch, Mainz*)

Schlusswort (*P. Kaatsch, Mainz*)


40 Jahre Deutsches Kinderkrebsregister
Wissenschaftliches Symposium
am 23. und 24. Januar 2020
Willkommen - Welcome


Das DKKR-Team

8 Ergebnisübersicht / Overview of Results

Meldungen von Fällen unter 18 Jahren im Jahr 2018 (Meldungen aus 61 Kliniken) **:**	2255
Durchschnittliche Meldungen von Fällen unter 18 Jahren pro Jahr: (ermittelt aus den Jahren 2009-2018)	2183
vor dem 18. Geburtstag erkrankt ...	eines von 337 Neugeborenen
Jungen / Mädchen	1215 / 968
Meldungen von unter 5-Jährigen	818
Meldungen von 5- unter 10-Jährigen	466
Meldungen von 10- unter 15-Jährigen	530
Meldungen von 15- unter 18-Jährigen	370
Lymphatische Leukämien (LL)	486
Zahl aller Meldungen unter 15 bzw. 18 Jahren von Beginn der Erfassung im Jahr 1980 bis 2018:	66859
in Langzeitnachbeobachtung befindlich	38467

Bevölkerung im Alter von unter 18 Jahren (Million):

in 2018	13,5
im Durchschnitt (in den Jahren 2009-2018)	13,3

Prognose der Fälle im Alter von unter 18 Jahren:

82 % überleben derzeit eine Krebserkrankung mindestens 15 Jahre

90 % überleben derzeit eine lymphatische Leukämie (LL) mindestens 15 Jahre

Insgesamt ca. 410 Todesfälle pro Jahr innerhalb von 15 Jahren nach Diagnose

Zweitneoplasien nach einer im Kindesalter (unter 18 Jahre) aufgetretenen Ersterkrankung:

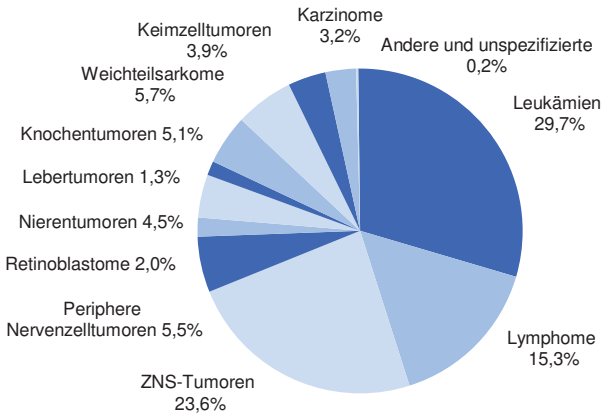
6,8 % der Patienten erkranken innerhalb von 30 Jahren nach Diagnose erneut an Krebs

Insgesamt sind über 1500 Patienten mit Folgeneoplasien registriert

Durchschnittliche Meldungen von Fällen unter 18 Jahren pro Jahr nach Bundesländern:
(ermittelt aus den Jahren 2009-2018)

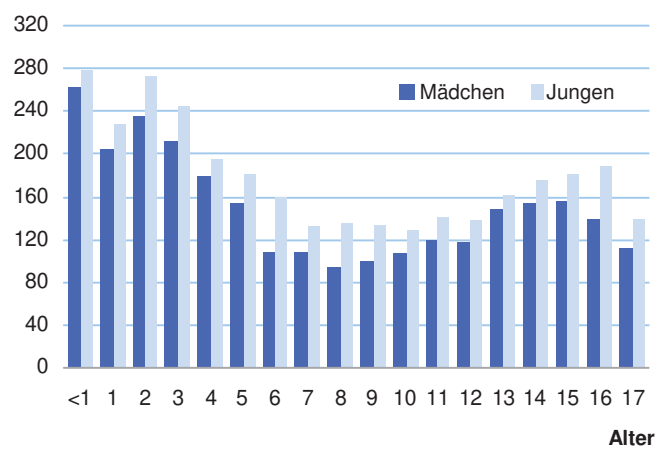
	Alle Erkrankungen	Leukämien		Alle Erkrankungen	Leukämien
Schleswig-Holstein	86	25	Bayern	338	104
Hamburg	49	14	Saarland	23	6
Niedersachsen	214	65	Berlin	87	27
Bremen	14	4	Brandenburg	54	17
Nordrhein-Westfalen	499	145	Mecklenburg-Vorpommern	36	10
Hessen	172	54	Sachsen	106	29
Rheinland-Pfalz	107	30	Sachsen-Anhalt	52	15
Baden-Württemberg	298	88	Thüringen	48	14

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



ZNS: Zentrales Nervensystem

Alters- und geschlechtsspezifische Erkrankungsraten pro 1 Million*



*2009-2018, basierend auf insgesamt 21831 unter 18-jährigen Patienten

Reported cases aged under 18 years in 2018 (Reported cases from 61 hospitals) **:**	2255
Average reported cases aged under 18 per year: (calculated from the years 2009-2018)	2183
diagnosed before the 18th birthday ...	one out of 337 new born children
Boys / Girls	1215 / 968
Reported cases aged under 5	818
Reported cases aged between 5 and under 10	466
Reported cases aged between 10 and under 15	530
Reported cases aged between 15 and under 18	370
Lymphoid leukaemias (LL)	486
Number of all reported cases aged under 15 or under 18 years from the beginning of registration in 1980 until 2018	66859
in long-term surveillance (LTS)	38467

Population aged under 18 (per million):

in 2018	13.5
average (in the years 2009-2018)	13.3

Prognosis of cases aged under 18 years:

82 % currently survive a cancer diagnosis at least 15 years

90 % currently survive a lymphoid leukaemia (LL) at least 15 years

Approx. 410 deaths per year within 15 years after diagnosis

Second neoplasms after initial cancer diagnosis in childhood (aged under 18):

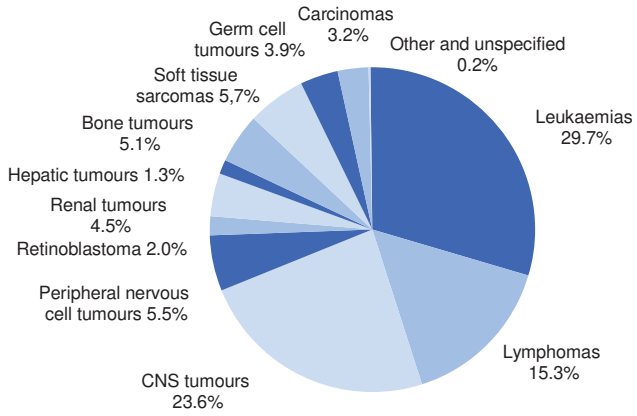
6.8 % of patients diagnosed with cancer are diagnosed again within 30 years

More than 1500 patients registered with second neoplasms

Average reported cases aged under 18 years per year by federal state:
(calculated from the years 2009-2018)

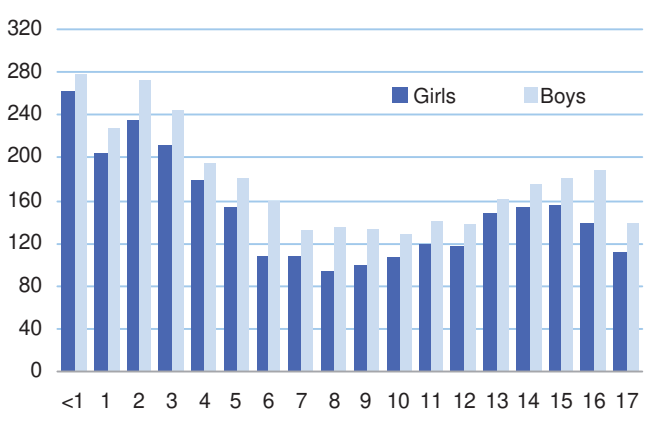
	All diseases	Leukaemias		All diseases	Leukaemias
Schleswig-Holstein	86	25	Bavaria	338	104
Hamburg	49	14	Saarland	23	6
Lower Saxony	214	65	Berlin	87	27
Bremen	14	4	Brandenburg	54	17
North Rhine-Westphalia	499	145	Mecklenburg-Western Pomerania	36	10
Hesse	172	54	Saxony	106	29
Rhineland-Palatinate	107	30	Saxony-Anhalt	52	15
Baden-Württemberg	298	88	Thuringia	48	14

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



CNS: Central nervous system

Age- and sex specific incidence rates per million*



*2009-2018, based on 21831 patients under 18

10 Ergebnisübersicht / Overview of Results

I Leukaemias, myeloproliferative and myelodysplastic diseases (p. 31)

Diese hämatologischen Erkrankungen sind die häufigsten bösartigen Erkrankungen im Kindes- und Jugendalter. Betroffen ist bis unter 18 eines von 1120 Kindern, Jungen etwa 30 % öfter als Mädchen. Knapp die Hälfte der Erkrankungen tritt bereits vor dem Schulalter auf. Bei Kindern und Jugendlichen überwiegen die akuten Formen, bei Erwachsenen chronische Formen, die bei Kindern sehr selten sind. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100 % Vollzähligkeit der Erfassung aus.
Die häufigste Form, die lymphatische Leukämie (früher ALL), nahm in Deutschland und Europa bis Mitte der 2000er langsam zu (ca. 0,7 % pro Jahr), seitdem sehen wir in Deutschland keinen weiteren Anstieg, Ähnliches gilt für Europa. Fast 98 % aller lymphatischen Leukämien sind Vorläuferzell-Leukämien, dies ist damit die bei Kindern und Jugendlichen häufigste Einzeldiagnose überhaupt (ca. 22 % aller Krebserkrankungen unter 18 Jahren). Sie hat einen typischen Altersgipfel im Alter von 2-4. Die Prognose ist gut (90 % Langzeitüberlebende, mindestens 15 Jahre).
Akute myeloische Leukämien (AML) sind deutlich seltener und haben eine schlechtere Prognose (74 % Langzeitüberlebende); die seit den 1980ern erzielten Verbesserungen der Therapie sind erheblich und es werden weiter Verbesserungen erzielt.
Das myelodysplastische Syndrom (MDS) wurde erst seit Anfang des Jahrtausends (mit Veröffentlichung der ICD-O-3) als bösartig (maligne) klassifiziert. Erkrankungs- und Überlebenszahlen davor sind damit nicht repräsentativ. Ein Teil der MDS entwickelt sich zu einer AML weiter. Es gab unterschiedliche Ansätze, wie in diesem Falle mit der Zählung zu verfahren ist. Zeitliche Vergleiche und Vergleiche mit anderen Registern sind daher problematisch.
Die AML und MDS stellen zusammen rund 16 % der zweiten und weiteren Krebserkrankungen (subsequent neoplasms (SN)) innerhalb von 30 Jahren nach einer Krebsdiagnose im Kindesalter.

These hematological diseases are the most frequent malignant diseases in childhood and adolescence. One child out of 1120 under 18 years is affected, boys ca. 30% more often than girls. Almost half of the cases are 5 years and below. Children and adolescents show mostly acute forms, whereas adults show mostly chronic forms, which are very rare in children. Based on international comparisons we assume completeness is close to 100%.

The most frequent form, lymphoid leukaemia (used to be ALL), slowly increased until the mid-2000s in Germany and Europe (ca. 0.7% p.a.), in Germany we see no further increase, similarly for Europe. Almost 98% of all lymphoid leukaemias are precursor cell leukaemias, which makes it the most frequent single diagnosis in childhood and adolescence (about 22% of all cancers under 18). It shows a typical age peak at ages 2-4. The prognosis is good (90% long-term survivors for more than 15 years).

Acute myeloid leukaemias (AML) are much less frequent and have a worse prognosis (74% long-term survivors); the improvements in therapy since the 1980s are considerable and keep increasing.

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

About 16% of the second and subsequent neo- plasms (SN) within 30 years of diagnosis are AML or MDS.

II Lymphomas and reticuloendothelial neoplasms (p. 37)

Lymphome (eines von 2300 Kindern unter 18) treten im Allgemeinen im Jugend- und Erwachsenenalter und nur selten bei Kleinkindern auf.
Wir gehen von nahezu 100 % Vollzähligkeit der Erfassung aus, außer evtl. bei den 17-Jährigen. Von Lymphomen sind Jungen ca. 70 % häufiger betroffen. Bei Patienten mit Hodgkin Lymphom ist die Prognose bereits seit vielen Jahrzehnten gut (derzeit 97 % Langzeitüberlebende), daher sind bei dieser Erkrankung die Spätfolgen der Therapie besonders ausführlich erforscht. Hodgkin Lymphom-Patienten sind überdurchschnittlich oft von SN betroffen, etwa 14 % in den ersten 30 Jahren nach Diagnose.
Burkitt-Lymphome (BL) zählen zu den Non-Hodgkin-Lymphomen (NHL), werden aber für internationale Vergleichbarkeit separat dargestellt. Jungen sind von NHL mehr als doppelt so oft betroffen, von Burkitt-Lymphomen fast 6-mal so oft. Die Langerhanszell-histiozytose (LCH), seit kurzem insgesamt als maligne eingestuft

Lymphomas (one child in 2300 under 18) occur mostly in adolescents and adults, while they are rare in small children.
We assume completeness is close to 100%, except maybe for the 17-year olds. Lymphomas are about 70% more frequent in boys. Patients with Hodgkin lymphoma have shown a good prognosis for decades (current long-term survival is 97%), so for this entity late effects are particularly well known. Patients with Hodgkin lymphoma are especially frequently affected by SN (about 14% within the first 30 years).

Burkitt lymphomas (BL) are a subgroup of the Non-Hodgkin lymphomas (NHL); they are presented separately for international comparisons. Boys are affected by NHL more than twice as often as girls, six times as often by Burkitt lymphoma. All types of Langerhanscellhistiocytosis have recently been reclassified

und daher jetzt mitgezählt, dies führt bei den sonstigen Lymphomen zu scheinbar höheren Inzidenzraten.
Die Prognose ist gut (86 % bzw. 91 % Langzeitüberlebende). Das Risiko einer Folgeneoplasie ist nach NHL überdurchschnittlich hoch, besonders nach Vorläuferzell-Lymphomen (16 % Risiko).
Unspezifizierte Lymphome werden fast nie gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

as malignant and are now included in the miscellaneous lymphomas; this led to seemingly higher incidence rates. The prognosis of NHL is good (NHL/BL 86%/91% long-term survivors). The SN risk after NHL is above average, especially after precursor cell lymphoma (16% risk).
Unspecified lymphomas are rarely reported, this shows the high quality of diagnosis and reports.

III CNS and miscellaneous intracranial and intraspinal neoplasms (p. 43)

Bei den Tumoren des zentralen Nervensystems (ZNS, Hirntumore), eines von 1400 Kindern unter 18 ist betroffen, handelt es sich um eine heterogene Gruppe von Krebserkrankungen mit bösartigen (malignen) und nichtmalignen Formen und entsprechend unterschiedlicher Prognose. Internationale Vergleiche deuten auf eine gewisse Untererfassung der nicht-malignen Formen und bei älteren Jugendlichen hin. Der beobachtete Anstieg der Erkrankungszahlen zeigt die stetig verbesserte Vollzähligkeit der Erfassung, besonders bei Astrozytomen und sonstigen Gliomen. Jungen sind etwa 20 % häufiger betroffen als Mädchen. Die scheinbar seit 1990 schlechter werdende Prognose bei den „sonstigen Gliomen“ ist auf erhebliche Änderungen in der Zusammensetzung dieser Gruppe zurückzuführen, was durch die zunehmende Vollzähligkeit und Veränderungen in der Klassifikation bedingt ist.
Nach Medulloblastomen ist das Risiko einer Folgeneoplasie mit 20 % außergewöhnlich hoch. ZNS-Tumoren stellen ihrerseits 22 % aller SN in den ersten 30 Jahren nach einer Diagnose im Kindesalter, dabei handelt es sich mehrheitlich um Meningiome, gefolgt von den Astrozytomen.

Tumours of the central nervous system (CNS, brain tumours) affect one child in 1400 under 18. They are a heterogeneous group of neoplasms, including malignant and non-malignant forms with very different prognoses. Based on international comparisons we assume especially the non-malignant forms and older adolescent cases to be slightly underreported. The observed increase in cases shows improvements in completeness of registration, especially regarding astrocytomas and other gliomas. Boys have an about 20% higher incidence. The seemingly worsening prognosis of “other gliomas” since 1990 is due to considerable changes in the composition of this group due to improvements in completeness and classification changes.

Medulloblastoma-patients have an unusually high risk of a subsequent neoplasm at 20%. 22% of all SN in the 30 years after primary diagnosis are CNS tumours, most of these are meningiomas, followed by astrocytomas.

IV Neuroblastoma and other peripheral nervous cell tumours (p. 56)

Neuroblastome gehören zu den embryonalen Tumoren, die vor allem bei Kleinkindern auftreten. Betroffen ist eines von 6000 Kindern unter 18, Jungen erkranken etwa 40 % häufiger als Mädchen. Wir gehen von nahezu 100 % Vollzähligkeit der Erfassung aus. Insgesamt überleben etwa 77 % der Fälle langfristig, jedoch haben Patienten mit fortgeschrittener Erkrankung (Stadium IV) nach wie vor eine relativ schlechte Prognose, auch wenn für diese Gruppe seit den 1980ern erhebliche Verbesserungen erzielt wurden.
Bei Neuroblastomen kann sich bei einem Teil der Erkrankungsfälle (insbesondere mit niedrigem Stadium bis etwa zum 2. Geburtstag) der Tumor spontan zurückbilden. Während eines Modellprojekts zur Früherkennung (1995-2000) wurden daher viele zusätzliche Fälle diagnostiziert, was zu einem erkennbaren Anstieg der Erkrankungszahlen führte. Es folgte jedoch nicht die erhoffte 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 6000 under 18, boys have an about 40% higher incidence than girls. We assume completeness is close to 100%. Overall long-term survival is 77%, but patients with advanced disease (stage IV) still have a rather bad prognosis, although it has improved considerably since the 1980ies.

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

12 Ergebnisübersicht / Overview of Results

V Retinoblastoma (p. 57)

Retinoblastome, unter 16.000 Kindern unter 18 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. Die Prognose ist sehr gut (98%). 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 16,000 under 18 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. The prognosis is very good (98%). 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 (p. 58)

Fast alle Nierentumoren im Kindesalter sind Nephroblastome (Wilmstumor). Ein Kind von 7200 bis 17 Jahre ist betroffen, Mädchen etwa 10 % häufiger. Auf der Basis internationaler Vergleiche gehen wir von nahezu 100 % Vollzähligkeit der Erfassung aus, evtl. mit Ausnahme der Karzinome bei älteren Jungendlichen. Die Prognose ist gut (92 % Langzeitüberlebende).
Nierenkarzinome, meist im Erwachsenenalter beobachtet, treten nur selten und wenn, dann bei älteren Kindern und Jugendlichen auf.
Unspezifizierte Nierentumoren wurden keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Almost all renal tumours in childhood are nephroblastomas (Wilms' tumour). One child under 18 in 7200 is affected, girls about 10% more often. Based on international comparisons we assume completeness is close to 100%, except maybe for carcinomas in older adolescents. The prognosis is good (92% long-term survivors).
Renal carcinomas, usually observed in adults, are occasionally diagnosed in older children and adolescents.

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

VII Hepatic tumours (p. 61)

Fast alle Lebertumoren im Kindesalter (ein Fall unter 25.000 Kindern bis 17 Jahre) sind Hepatoblastome. Jungen sind 40 % häufiger betroffen als Mädchen. Wir gehen von guter Vollzähligkeit der Erfassung aus, die seit der Gründung eines Lebertumorregisters für Kinder im Jahre 2011 erkennbar weiter verbessert wurde. Die Prognose ist moderat (84 % Langzeitüberlebende) und seit den 1980ern erheblich verbessert.
Folgeneoplasien sind nach Hepatoblastomen sehr selten, ihrerseits treten sie fast nie als Folgeneoplasien auf. Leberkarzinome, meist im Erwachsenenalter beobachtet, treten nur sehr selten und wenn, dann bei älteren Kindern und Jugendlichen auf.
Unspezifizierte Lebertumoren wurden keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

Almost all hepatic tumours in childhood (one in 25,000 children until 17 years is affected) are hepatoblastomas. Boys have a 40% higher incidence. We assume completeness is good and has visibly improved further since a hepatic tumour registry for children was founded in 2011. The prognosis is moderate (84% long-term survivors) and has been improving considerably since the 1980ies.
Subsequent neoplasms are rare; hepatoblastomas hardly ever are subsequent neoplasms.
Hepatic carcinomas, usually observed in adults, are occasionally diagnosed in older children and adolescents.

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

VIII Malignant bone tumours (p. 63)

Knochensarkome (ein Kind von 7.000 unter 18) sind typisch für ältere Kinder und Jugendliche. Jungen sind etwa 30 % häufiger betroffen. Die besonders häufigen Typen sind Osteosarkome und Ewingsarkome. Auf der

Bone sarcomas (one case in 7,000 children under 18) are typical for older children and adolescents. Boys are affected about 30% more often. The most frequent forms are osteosarcoma and Ewing sarcomas. Based

Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung aus, evtl. mit Ausnahme der 17-Jährigen.
Knochentumore stellen 5 % aller Folgeneoplasien innerhalb von 30 Jahren nach einer Krebsdiagnose im Kindesalter, dabei überwiegen Osteosarkome.
Unspezifizierte Knochentumoren wurden keine gemeldet, dies spricht für die Qualität der Diagnostik und der Meldungen.

on international comparisons we assume completeness is high, except perhaps for 17-year olds.

5% of all subsequent neoplasms within 30 years of the first neoplasm are bone tumours, mostly osteosarcoma. Unspecified bone tumours were not reported, this shows the high quality of diagnoses and reports.

IX Soft tissue and other extraosseous sarcomas (p. 67)

Weichteilsarkome können in allen Altersklassen auftreten, betroffen ist ein Kind von 6000 bis 17 Jahre. Das häufigste Weichteilsarkom im Kindesalter ist das Rhabdomyosarkom. Auf der Basis internationaler Vergleiche gehen wir von hoher Vollzähligkeit der Erfassung zumindest bis zum Alter von 16 aus. Jungen sind etwa 30 % häufiger betroffen als Mädchen. Die Prognose ist unterdurchschnittlich (69 % Langzeitüberlebende).

Soft tissue sarcomas occur in all ages in childhood (one child under 18 in 6000). The most frequent type in childhood is rhabdomyosarcoma. Based on international comparisons we assume completeness is high at least until age 16. Boys have a 30% higher incidence than girls. The prognosis is below average (69% long-term survivors).

X Germ cell tumours, trophoblastic tumours and neoplasms of gonads (p. 74)

Keimzelltumoren sind eine heterogene Gruppe von Krebserkrankungen (bis unter 18 ein Kind von 9.000). Einige treten häufiger mit beginnender Pubertät auf, andere sind typisch für das Kleinkindalter, so dass sie vom 4.-7. Lebensjahr eher selten sind. Wir gehen von hoher Vollzähligkeit der Erfassung aus, mit Ausnahme der älteren Jugendlichen. Insgesamt sind beide Geschlechter gleich häufig betroffen, dies variiert jedoch sehr stark nach Tumortyp. Bei den intrakranialen Formen (im Gehirn lokalisiert) hat es seit etwa 2000 (neue Diagnoseklassifikation ICD-O-3) Zuordnungsänderungen gegeben, so dass einige Keimzelltumoren seither der Hauptgruppe der Hirntumoren (ZNS) zugeordnet werden. Insgesamt ist die Langzeitprognose gut (93 %).

Germ cell tumours are a heterogeneous group of neoplasms; one child under 18 in 9,000 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, except for older adolescents. The incidence rate is the same for boys and girls overall, but this varies considerably by tumour type. Some intracranial forms (localized in the brain) have been reclassified as brain tumours (CNS) since about 2000 (new diagnosis classification ICD-O-3). In general the prognosis is good (93% long-term survivors).

Other malignant epithelial neoplasms and malignant melanomas (p. 82)

Dies ist eine heterogene Gruppe von Neoplasien. Karzinome treten im Allgemeinen erst im Erwachsenenalter auf. Die häufigsten dieser seltenen Erkrankungen im Kindesalter sind Karzinome der Nebennierenrinde, der Schilddrüse (Verbesserung der Erfassung ab 1996), des Nasopharynx (Nasen-Rachenraum) und das maligne Melanom („schwarzer“ Hautkrebs). Einige Karzinome bei Kindern sind deutlich untererfasst, jedoch nicht die Nasopharynx-Karzinome und Schilddrüsenkarzinome, zumindest bis 16 Jahre. Seit 2011 werden Appendix-Karzinoide als maligne eingestuft, daraus erklärt sich die seitdem erheblich gestiegene Anzahl der Meldungen von Appendixkarzinomen. Bei den malignen Melanomen konnte die Erfassung im Laufe der Jahre erheblich verbessert werden, jedoch sind sie vermutlich weiterhin untererfasst.

This is a heterogeneous group of rare cancers. Carcinomas are usually observed in adults. The most frequent among them in childhood are adrenocortical carcinoma, thyroid carcinoma (improved reporting since 1996), nasopharyngeal carcinoma, and malignant melanoma. Some carcinomas in children are clearly underreported, though not nasopharyngeal carcinomas and thyroid carcinomas, at least until age 16. Appendix carcinoids have been reclassified as malignant in 2011, which explains the sudden considerable increase in reported appendix carcinomas since then. The reporting of malignant melanoma has improved over the years, but we assume they continue to be underreported. Only one breast carcinoma has been reported as a primary neoplasm. Thyroid carcinomas have a good prognosis (97% long-term survivors).

Mammakarzinome wurden primär nur eins gemeldet. Schilddrüsenkarzinome haben eine gute Prognose (97 % Langzeitüberlebende).
Karzinome stellen ein Drittel aller Folgeneoplasien innerhalb von 30 Jahren nach Erstdiagnose, besonders zu nennen sind hier Schilddrüsenkarzinome, Hautkarzinome (überwiegend keine malignen Melanome), Mammakarzinome und Darmkrebs. Schon bei den unter 18-Jährigen sind gut 20 % aller gemeldeten Schilddrüsentumore SN.

One third of all subsequent neoplasms within 30 years are carcinomas, particularly thyroid carcinoma, skin carcinoma (mostly not malignant melanoma), breast carcinoma and colon carcinoma. Among the thyroid cancer cases under 18, more than 20% are SN.

XII Other and unspecified neoplasms (p. 91)

Dies ist eine heterogene Gruppe von sonst nicht zuzuordnenden, bei Kindern sehr seltenen bösartigen Krebserkrankungen (ein Fall pro 200.000 Kinder unter 18). 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 18 in 200,000). The most frequent tumour among these is pulmonary blastoma.

Die vier häufigsten Neoplasien bei Kindern nach ICD10

Die häufigste Krebserkrankung im Kindesalter ist eine Leukämie, dabei überwiegen im Gegensatz zu Erwachsenen die akuten Formen. Die Diagnosegruppe entspricht weitgehend der Gruppe I im ICCC-3. Bei seit 1991 weitgehend gleich gebliebener Inzidenzrate folgen die absoluten Zahlen der Geburtenzahl der letzten Jahre. Die Prognose ist für Jungen und Mädchen gleich.
Die zweithäufigste Diagnose sind maligne ZNS-Tumoren. Der Trend in der Inzidenzrate ist gering, im Gegensatz zu nicht-malignen ZNS Tumoren werden diese weitgehend zuverlässig gemeldet. Sie haben eine insgesamt schlechte Prognose, Jungen nochmal leicht schlechter (59 % und 61%).
Hodgkin-Lymphome werden bei ICD und ICCC gleichartig zugeordnet. Die Prognose bis 15 Jahre nach Diagnose ist für Jungen und Mädchen gleich gut (97 %).
Als viertes ergibt sich eine Klasse von Weichteilneoplasien, wobei Mädchen die leicht bessere Prognose aufweisen (75 % vs. 70 %).

The most frequent neoplasm in childhood is a leukaemia. The diagnosis group is similar to ICCC-3 I. The incidence rate stayed almost constant since 1991, but the absolute numbers follow the birth rate. The prognosis is the same for boys and girls.

The second most frequent diagnosis are malignant CNS tumours. There is hardly any trend in the incidence rate; as opposed to non-malignant CNS-tumours they were rather reliably reported. The prognosis is not good, boys are even slightly worse (59% and 61%).
Hodgkin lymphomas are classified identical between ICCC and ICD. Prognosis until 15 years after diagnosis is the same for boys and girls (97%).

The fourth group are various soft tissue neoplasms, with girls having a slightly better prognosis (75% vs 70%).

Die vier häufigsten Neoplasien nach ICD10

Lungenkarzinome sind sehr selten bei Kindern, wenn, dann treten sie im Kleinkindalter auf. Die Prognose ist für ein Kind sehr schlecht, besonders bei Mädchen (71 % vs. 73 %).
Prostatakarzinome traten sehr vereinzelt bei Jungen auf.
Brustkrebs unter 18 Jahre tritt praktisch nicht auf, wenn, dann sowohl bei Jungen als auch bei Mädchen.
Darmkrebs wie bei Erwachsenen tritt bei Kindern nur sehr vereinzelt auf, vor allem ab 15 Jahren. Appendixkarzinoide sind jedoch etwas häufiger und werden seit wenigen Jahren auch als maligne eingestuft.

Lung carcinomas are very rare in children; most are observed in very young children. The prognosis is relatively bad for a childhood cancer, especially in girls (71% vs. 73%).
Prostate carcinomas were observed in very few boys.

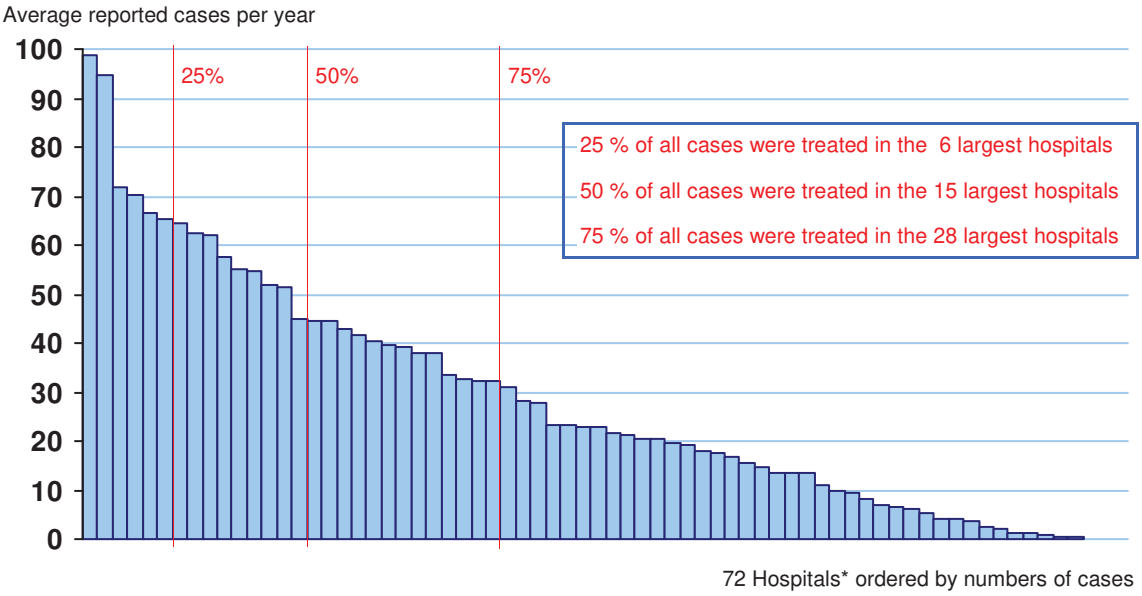
Breast cancer is practically non-existent under the age of 18, but the few cases are girls as well as boys.
Colon cancer as in adults is very rare in children, most cases are 15 or older. However, appendix carcinoids are somewhat more frequent and were reclassified as malignant a few years ago.

16 Tabellen und Abbildungen / Tables and Figures

Abbildung 1:

Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2009-2018, Patienten unter 18 Jahren

Reported cases to the GCCR (registry population) per hospital, period 2009-2018, patients under 18 years



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

Tabelle 1:

Anzahl der gemeldeten Fälle unter 18 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 18, age-standardized incidence rate and cumulative incidence (per million) by ICCC-3 diagnosis groups.

Diagnosis groups		Number of cases 1980-2018		Number of cases 2009-2018		Incidence rates 2009-2018	
		Absolute	Relative (%)	Absolute	Relative (%)	Age-standard.*	Cumu-lative
I	Leukaemias	22023	32.9	6494	29.7	52	893
II	Lymphomas	8691	13.0	3337	15.3	23	439
III	CNS tumours	14615	21.9	5142	23.6	40	702
IV	Peripheral nervous cell tumours	4671	7.0	1203	5.5	11	169
V	Retinoblastoma	1534	2.3	441	2.0	4	62
VI	Renal tumours	3664	5.5	987	4.5	9	139
VII	Hepatic tumours	752	1.1	289	1.3	3	40
VIII	Bone tumours	3265	4.9	1116	5.1	8	146
IX	Soft tissue sarcomas	4045	6.1	1250	5.7	10	169
X	Germ cell tumours	2260	3.4	843	3.9	6	112
XI	Carcinomas	1260	1.9	696	3.2	5	91
XII	Other and unspecified	79	0.1	33	0.2	0	5
	All malignancies	66859	100.0	21831	100.0	170	2966

* Standard: Segi world standard population

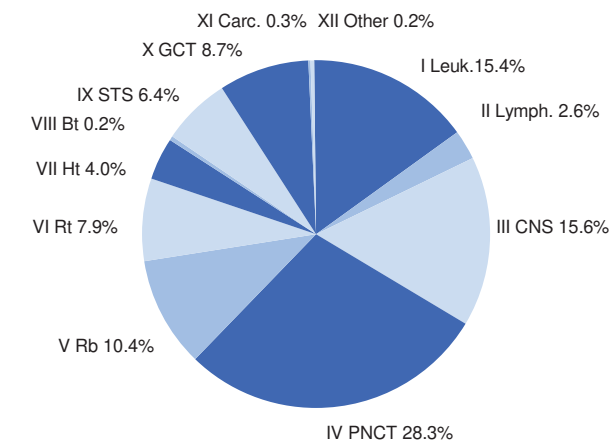
18 Tabellen und Abbildungen / Tables and Figures

Abbildung 2:

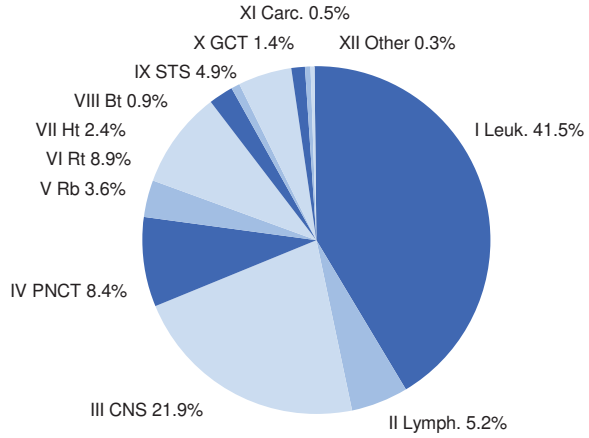
Relative Häufigkeit der gemeldeten Fälle aus der deutschen Wohnbevölkerung nach den häufigsten ICCC-3 Diagnose-Hauptgruppen und Alter (ausführliche ICCC-3 Kategoriebezeichnungen siehe Seite 130)

Relative frequencies of the registered cases in Germany by the main ICCC-3 diagnosis groups and age (for the detailed ICCC-3 category legends see page 130)

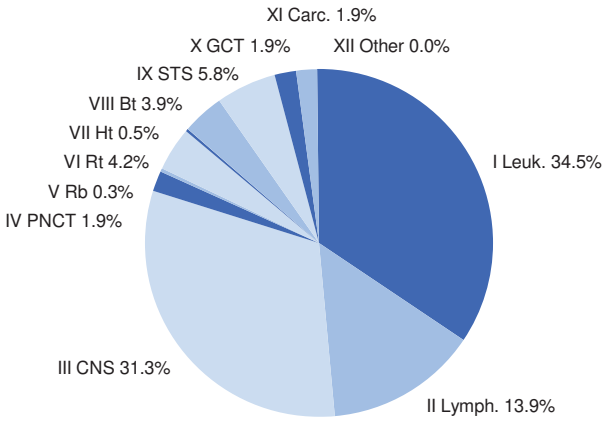
Age 0, 2009-2018 (n=1928)



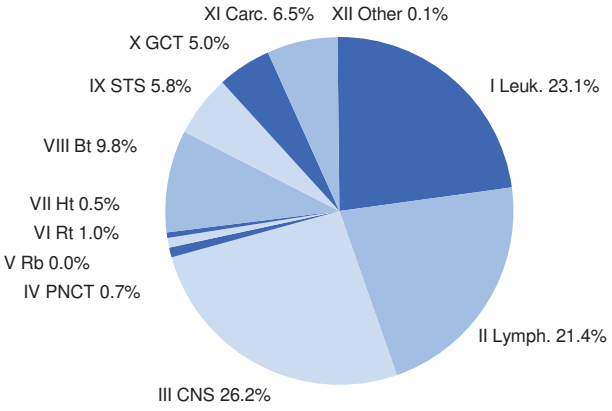
Age 1-4, 2009-2018 (n=6251)



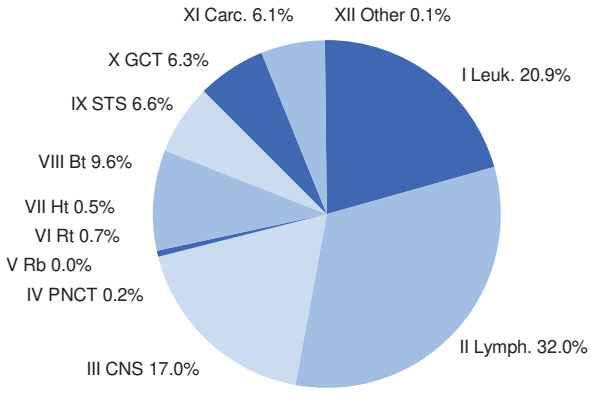
Age 5-9, 2009-2018 (n=4662)



Age 10-14, 2009-2018 (n=5295)



Age 15-17, 2009-2018 (n=3695)



Age 0-17, 2009-2018 (n=21831)

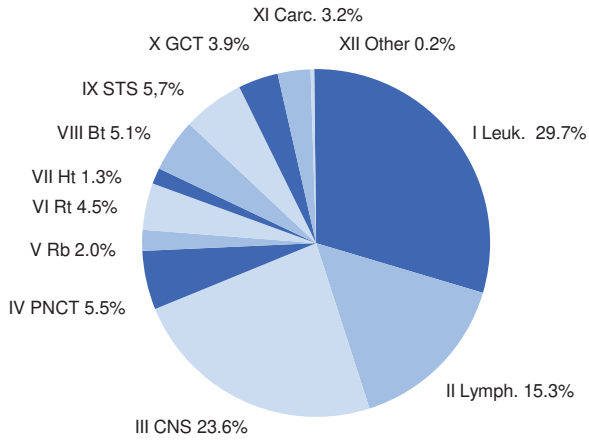


Tabelle 2:

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

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

Years	Number of cases		Incidence rates per million *		Population base (in million)	
	< 15	< 18	<15	< 18	<15	< 18
1980	1017		103		11.187	
1981	1048		105		10.803	
1982	974		103		10.392	
1983	1074		116		9.957	
1984	1032		114		9.539	
1985	1140		129		9.232	
1986	1145		132		9.070	
1987	1215		141		8.903	
1988	1216		140		9.019	
1989	1222		135		9.260	
1990	1301		139		9.621	
1991 #	1668		132		13.013	
1992	1811		142		13.166	
1993	1684		132		13.279	
1994	1768		139		13.298	
1995	1802		143		13.264	
1996	1803		145		13.209	
1997	1909		155		13.139	
1998	1821		149		13.035	
1999	1882		154		12.936	
2000	1978		163		12.836	
2001	1859		155		12.698	
2002	1827		154		12.517	
2003	1775		152		12.288	
2004	1878		165		12.042	
2005	1838		165		11.787	
2006	1773		163		11.544	
2007	1786		166		11.361	
2008	1782		168		11.212	
2009	1801	2156	170	166	11.078	13.579
2010	1769	2080	170	164	10.979	13.408
2011	1742	2100	167	164	10.884	13.277
2012	1765	2125	171	167	10.782	13.187
2013	1783	2120	175	169	10.628	13.050
2014	1765	2170	172	171	10.628	13.062
2015	1846	2264	177	177	10.784	13.219
2016	1848	2223	173	171	10.965	13.398
2017	1947	2338	179	177	11.110	13.504
2018	1870	2255	171	171	11.141	13.458
Total	63164	66859				

* Standard: Segi world standard population

Erweiterung um neue Bundesländer / inclusion of East Germany

Tabelle 3:

Verteilung aller gemeldeten Fälle aus der deutschen Wohnbevölkerung nach Altersgruppen ohne Altersbeschränkung # sowie zusätzlich erfasste Diagnosen (2009-2018)

Distribution of all reported cases in Germany by age groups without age restriction # and additional diagnoses (2009-2018)

Age groups (years)	Diagnoses according to ICCC-3		Additional diagnoses (see Table 4)	
	N	%	N	%
0	1928	8.5	446	29.8
1-4	6251	27.6	266	17.8
5-9	4662	20.6	266	17.8
10-14	5295	23.4	369	24.7
15-17	3695	16.3	120	8.0
0-17	21831	96.4	1467	98.1
18-19 #	241	1.1	6	0.4
20-24 #	212	0.9	6	0.4
≥18 #	820	3.6	28	1.9
≥25 #	367	1.6	16	1.1
reported cases	22651	100.0	1495	100.0

Junge Erwachsene ab 18 Jahren werden nur unvollständig erfasst. / Young adults 18 or older are incompletely registered.

Tabelle 4:

Nicht in der ICCC-3 definierte, systematisch registrierte Diagnosen, Fälle unter 18 Jahren (2009-2018)

Systematically registered diagnoses not defined in ICCC-3, cases under the age of 18 (2009-2018)

Diagnoses	Sex	Sex ratio	Number of cases						Incidence rates per million							Trial participants
			N	Age groups						Age groups					Age-stand.	Cum.	
		m / f	0-14	0	1-4	5-9	10-14	15-17	0	1-4	5-9	10-14	15-17	World *	0-17	%
Non-malignant	girls		184	64	49	36	24	11	18	4	2	1	1	3	52	84.2
Langerhans cell	boys		270	66	76	50	53	25	18	5	3	3	2	4	72	88.9
histiocytosis	**total**	**1.5**	**454**	**130**	**125**	**86**	**77**	**36**	**18**	**4**	**2**	**2**	**1**	**4**	**63**	**87.0**
Benign/mature teratoma	girls		607	144	61	122	223	57	41	4	7	12	5	10	169	93.1
	boys		154	84	34	19	13	4	23	2	1	1	0	3	42	90.9
	total	**0.3**	**761**	**228**	**95**	**141**	**236**	**61**	**32**	**3**	**4**	**6**	**3**	**6**	**104**	**92.6**
Severe aplastic anaemia	girls		46	3	6	15	17	5	1	0	1	1	0	1	13	91.3
	boys		59	2	9	12	21	15	1	1	1	1	1	1	15	91.5
	total	**1.3**	**105**	**5**	**15**	**27**	**38**	**20**	**1**	**1**	**1**	**1**	**1**	**1**	**14**	**91.4**
Mesoblastic nephroma	girls		18	18	0	0	0	0	5	0	0	0	0	0	5	94.4
	boys		25	23	1	0	1	0	6	0	0	0	0	0	7	92.0
	total	**1.4**	**43**	**41**	**1**	**0**	**1**	**0**	**6**	**0**	**0**	**0**	**0**	**0**	**6**	**93.0**
Other diseases	girls		43	20	9	5	7	2	6	1	0	0	0	1	12	51.2
of blood and	boys		57	22	21	6	8	0	6	1	0	0	0	1	16	61.4
haemopoietic system	**total**	**1.3**	**100**	**42**	**30**	**11**	**15**	**2**	**6**	**1**	**0**	**0**	**0**	**1**	**14**	**57.0**

* Standard: Segi world standard population

Tabelle 5:

Altersstandardisierte* Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert nach Patientenwohnsitz für Fälle unter 18 Jahre (2009-2018)

Age-standardized* incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for cases under 18 by patients residence region (2009-2018)

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	864	186	1.12	1.05-1.20	251	55	1.10	0.97-1.25
Hamburg	487	174	1.03	0.94-1.12	145	53	1.01	0.85-1.19
Niedersachsen	2143	164	0.96	0.92-1.00	651	51	0.99	0.92-1.07
Bremen	142	142	0.83	0.70-0.98	36	37	0.71	0.50-0.98
Nordrhein-Westfalen	4988	173	1.02	0.99-1.05	1452	52	1.00	0.95-1.06
Düsseldorf	1425	175	1.03	0.98-1.09	400	51	0.97	0.88-1.07
Köln	1257	174	1.03	0.98-1.09	350	50	0.97	0.87-1.07
Münster	756	174	1.02	0.95-1.10	239	57	1.10	0.96-1.25
Detmold	596	171	1.00	0.92-1.08	190	57	1.08	0.93-1.24
Arnsberg	954	168	0.99	0.93-1.05	273	49	0.96	0.85-1.08
Hessen	1717	174	1.03	0.98-1.08	540	57	1.09	1.00-1.18
Darmstadt	1093	171	1.02	0.96-1.08	346	56	1.08	0.96-1.19
Gießen	301	190	1.09	0.97-1.22	93	60	1.15	0.92-1.40
Kassel	323	173	1.01	0.91-1.13	101	57	1.08	0.88-1.31
Rheinland-Pfalz	1070	170	1.00	0.94-1.06	304	50	0.96	0.85-1.07
Baden-Württemberg	2979	167	0.98	0.95-1.02	885	51	0.99	0.92-1.05
Stuttgart	1129	167	0.99	0.93-1.05	348	53	1.02	0.92-1.14
Karlsruhe	772	177	1.04	0.97-1.12	228	55	1.04	0.91-1.18
Freiburg	620	165	0.98	0.91-1.06	180	50	0.96	0.83-1.12
Tübingen	458	150	0.87	0.79-0.95	129	43	0.83	0.69-0.99
Bayern	3384	166	0.97	0.94-1.01	1041	52	1.01	0.95-1.07
Oberbayern	1159	156	0.92	0.86-0.97	364	49	0.96	0.86-1.06
Niederbayern	309	158	0.94	0.84-1.05	98	53	1.01	0.82-1.23
Oberpfalz	308	182	1.05	0.94-1.17	87	53	1.01	0.81-1.24
Oberfranken	253	155	0.93	0.82-1.05	77	50	0.96	0.76-1.20
Mittelfranken	441	160	0.94	0.86-1.04	121	45	0.87	0.72-1.04
Unterfranken	368	181	1.06	0.96-1.18	111	56	1.09	0.90-1.31
Schwaben	546	183	1.06	0.97-1.15	183	63	1.20	1.03-1.39
Saarland	231	162	0.96	0.84-1.09	63	45	0.89	0.69-1.14
Berlin	871	164	0.97	0.90-1.03	271	51	0.99	0.87-1.11
Brandenburg	537	155	0.91	0.84-0.99	170	50	0.95	0.82-1.11
Mecklenburg-Vorpommern	356	161	0.95	0.85-1.05	103	47	0.90	0.74-1.09
Sachsen	1063	185	1.09	1.03-1.16	291	51	0.98	0.87-1.10
Sachsen-Anhalt	516	174	1.02	0.94-1.12	147	50	0.96	0.81-1.13
Thüringen	483	163	0.96	0.88-1.05	144	49	0.94	0.80-1.11

* Standard: Segi world standard population

22 Tabellen und Abbildungen / Tables and Figures

Tabelle 6:

Anzahl der verstorbenen Patienten innerhalb von 5, 10 bzw. 15 Jahren nach Diagnose auf Basis des ICCC-3 unter den gemeldeten Patienten unter 15 / 18 Jahren aus der deutschen Wohnbevölkerung und kumulative Mortalität nach Diagnosejahr, 1980-2013 (inklusive neue Länder seit 1991)

Annual number of deaths 5, 10 or 15 years from diagnosis based on ICCC-3 from the group of registered patients aged under 15 / 18 in Germany and cumulative mortality by year of diagnosis 1980-2013 (including East Germany since 1991)

Year of diagnosis	Deaths within 5 years after diagnosis		Deaths within 10 years after diagnosis		Deaths within 15 years after diagnosis	
	No. of cases	Cum. mortality per million	No. of cases	Cum. mortality per million	No. of cases	Cum. mortality per million
1980	344	494	374	539	386	556
1981	342	486	380	539	396	563
1982	314	473	348	522	358	538
1983	319	493	359	557	372	577
1984	326	516	355	562	365	579
1985	322	523	362	586	379	615
1986	319	531	355	590	365	607
1987	328	551	353	593	367	617
1988	318	525	349	577	359	593
1989	291	466	325	522	340	546
1990	326	498	354	541	370	565
1991 #	400	457	445	509	460	526
1992	435	494	472	536	493	560
1993	382	434	427	484	444	504
1994	374	425	409	465	421	479
1995	338	389	385	443	407	468
1996	349	404	386	447	402	465
1997	372	432	417	484	439	510
1998	351	411	392	459	406	476
1999	360	422	399	467	414	484
2000	394	468	429	509	452	536
2001	302	363	341	409	360	432
2002	320	387	358	434	378	459
2003	322	400	362	448	375	464
2004	293	372	342	434		
2005	299	386	327	422		
2006	295	389	331	436		
2007	271	363	294	392		
2008	289	390	320	433		
2009 +	332	442				
2010	315	425				
2011	302	410				
2012	249	343				
2013	257	358				

* Standard: Segi world standard population

\# Erweiterung um neue Bundesländer / inclusion of East Germany

\+ Erweiterung von Patienten unter 18 Jahren / inclusion of patients aged under 18 years

Tabelle 7:

5-, 10- und 15-Jahre-Überlebenswahrscheinlichkeiten und 95%-Konfidenzintervalle für ausgewählte Diagnosen auf Basis des ICCC-3 (1981-2016) der Patienten unter 15 / 18 Jahren aus der deutschen Wohnbevölkerung
(Die nicht hinterlegten Werte sind konventionell geschätzt, die hinterlegten sind Hochrechnungen (8))

5-, 10- und 15-year survival probabilities and 95%-confidence intervals for selected diagnoses based on ICCC-3 (1981-2016) of patients under 15 / 18 in Germany
(The values on a clear background are estimated conventionally, those on a background are projections (8))

Selected diagnoses	Year of diagnosis	Number of cases	Survival probabilities and 95%-confidence intervals		
			5-year	10-year	15-year
All malignancies	1981-1990	11367	69 (69-70)%	66 (65-67)%	65 (64-66)%
	1991-2000	18126	78 (77-78)%	75 (75-76)%	74 (74-75)%
	2001-2010	18754	83 (82-83)%	80 (80-81)%	79 (79-80)%
	2011-2016	13002	87 (86-87)%	85 (84-85)%	84 (83-84)%
Leukaemias	1981-1990	4045	69 (67-70)%	65 (64-66)%	64 (62-65)%
	1991-2000	6124	78 (77-79)%	76 (75-77)%	75 (74-76)%
	2001-2010	6261	86 (85-87)%	85 (84-85)%	84 (83-85)%
	2011-2016	3824	90 (89-91)%	89 (88-90)%	88 (87-89)%
Lymphomas	1981-1990	1328	83 (81-85)%	82 (80-84)%	81 (79-83)%
	1991-2000	2252	91 (90-92)%	90 (89-91)%	89 (88-90)%
	2001-2010	2228	93 (92-94)%	92 (91-93)%	91 (90-92)%
	2011-2016	1996	94 (93-96)%	94 (93-95)%	93 (92-94)%
CNS tumours	1981-1990	2101	62 (60-64)%	58 (55-60)%	55 (53-57)%
	1991-2000	3808	70 (68-71)%	66 (64-67)%	63 (62-65)%
	2001-2010	4438	76 (75-77)%	72 (71-74)%	70 (69-72)%
	2011-2016	3080	82 (81-83)%	79 (77-80)%	77 (76-79)%
Peripheral nervous cell tumours	1981-1990	862	55 (52-59)%	53 (49-56)%	52 (49-56)%
	1991-2000	1513	72 (69-74)%	69 (67-71)%	68 (66-71)%
	2001-2010	1243	77 (74-79)%	74 (72-77)%	73 (71-76)%
	2011-2016	716	82 (80-85)%	81 (78-84)%	80 (77-83)%
Renal tumours	1981-1990	713	83 (80-86)%	82 (80-85)%	82 (79-85)%
	1991-2000	1094	89 (87-91)%	88 (86-90)%	88 (86-90)%
	2001-2010	1007	93 (91-94)%	92 (90-93)%	91 (90-93)%
	2011-2016	588	92 (90-95)%	91 (89-94)%	91 (89-94)%
Hepatic tumours	1981-1990	126	39 (30-48)%	37 (28-45)%	-
	1991-2000	155	62 (54-70)%	61 (53-69)%	-
	2001-2010	222	69 (63-75)%	66 (60-72)%	66 (60-72)%
	2011-2016	179	83 (77-89)%	80 (74-86)%	80 (74-86)%
Soft tissue sarcomas	1981-1990	771	61 (58-64)%	58 (55-61)%	56 (53-60)%
	1991-2000	1107	65 (62-68)%	62 (59-65)%	60 (58-63)%
	2001-2010	1120	68 (65-70)%	64 (62-67)%	63 (60-66)%
	2011-2016	738	75 (72-78)%	72 (69-75)%	71 (68-74)%
Germ cell tumours	1981-1990	351	85 (82-89)%	84 (81-88)%	83 (79-87)%
	1991-2000	624	91 (88-93)%	89 (87-92)%	89 (87-91)%
	2001-2010	585	94 (92-95)%	93 (91-95)%	92 (90-94)%
	2011-2016	521	95 (93-97)%	94 (92-96)%	93 (91-96)%

- unzureichende Datenlage / insufficient data

24 Tabellen und Abbildungen / Tables and Figures

Tabelle 8:

5-, 10- und 15-Jahre-Überlebenswahrscheinlichkeit und Wahrscheinlichkeit ereignisfreien Überlebens für die häufigsten Diagnosen auf Basis des ICCC-3 der Patienten unter 15 / 18 Jahren aus der deutschen Wohnbevölkerung (2007-2016)

5-, 10- und 15-year survival probabilities and event-free survival probabilities for the most common diagnoses based on ICCC-3 of patients aged under 15 / 18 in Germany (2007-2016)

Selected diagnoses	Number of cases *	Probabilities					
		event-free survival			survival		
		5-	10-	15-year	5-	10-	15-year
Leukaemias, myeloproliferative and myelodysplastic diseases	6357	82	80	79	89	88	87
Lymphoid leukaemias	4779	85	84	83	92	91	90
Acute myeloid leukaemias	850	62	60	59	75	74	74
Chronic myeloproliferative diseases	115	95	92	90	97	97	97
Myelodysplastic syndrome and other myeloproliferative diseases	541	80	77	73	84	81	78
Lymphomas and reticuloendothelial neoplasms	2973	87	85	84	94	93	92
Hodgkin lymphomas	1455	90	88	87	98	98	97
Non-Hodgkin lymphomas (except Burkitt lymphoma)	983	82	80	78	88	87	86
Burkitt lymphoma	350	90	89	88	92	91	91
CNS and miscellaneous intracranial and intraspinal neoplasms	4982	53	48	46	80	77	75
Ependymomas and choroid plexus tumour	479	60	54	52	82	74	70
Astrocytomas	2283	46	43	42	84	82	81
Intracranial and intraspinal embryonal tumours	819	56	52	49	67	61	58
Other gliomas	516	34	31	28	53	51	49
Other specified intracranial and intraspinal neoplasms	813	70	65	62	96	94	92
Neuroblastoma and ganglioneuroblastoma	1186	66	64	64	80	78	77
Retinoblastoma	399	94	93	92	99	98	98
Nephroblastoma and other non-epithelial renal tumours	951	87	86	86	93	92	92
Hepatoblastoma	230	78	78	78	86	84	84
Osteosarcomas	547	62	59	58	75	69	69
Soft tissue and other extraosseous sarcomas	1186	61	58	56	73	70	69
Rhabdomyosarcomas	586	58	56	55	70	69	68
Fibrosarcomas, periph. nerve sheath tum. and other fibr. neopl.	129	61	57	55	78	76	74
Other specified soft tissue sarcomas	373	66	62	61	77	71	68
Germ cell tumours, trophoblastic tumours and neopl. of gonads	766	83	81	79	94	93	93
Intracranial and intraspinal germ cell tumours	216	84	80	76	90	87	86
Malignant extracranial and extragonadal germ cell tumours	201	79	79	78	94	94	93
Malignant gonadal germ cell tumours	336	86	83	82	98	98	98
Thyroid carcinomas	205	93	91	88	99	99	97
All malignancies	20806	73	70	69	83	86	82

* with follow up available - insufficient data

Die Definition eines "Ereignisses" umfasst je nach Diagnose und Therapieprotokoll unterschiedliche Ereignisse wie Rezidive, Progress oder neu aufgetretene Fernmetastasen. Das Auftreten eines Folgetumors wird immer als Ereignis gewertet.

The definition of an "event" differs by diagnosis and therapy protocol, it can include events such as relapses, progress, or new distant metastases. A subsequent neoplasm always counts as an event.

Tabelle 9:

Anzahl der am Deutschen Kinderkrebsregister in der Langzeitnachbeobachtung (LTS) befindlichen Patienten mit Erstdiagnose im Alter von unter 15 / 18 (Stand 2018)

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged under 15 / 18 (as of 2018)

Year of diagnosis	1980 - 1989 *	1990 - 1999 *	2000 - 2009 **	2010 - 2018 ***	1980 - 2018**
	N (%)	N (%)	N (%)	N (%)	N (%)
Patients registered	**11033**	**17273**	**18386**	**19392**	**66084** #
deceased	3971 (36,0 %)	4300 (24,9 %)	3468 (18,9 %)	1927 (9,9 %)	13666 (20,7 %)
surviving	**7062 (64,0 %)**	**12973 (75,1 %)**	**14918 (81,1 %)**	**17465 (90,1 %)**	**52418 (79,3 %)**
anonymous+	992 (14,0 %)	1110 (8,6 %)	442 (3,0 %)	173 (1,0 %)	2717 (5,2 %)
identifiable	**6070 (86,0 %)**	**11863 (91,4 %)**	**14476 (97,0 %)**	**17292 (99,0 %)**	**49701 (94,8 %)**
< 5 years since diagnosis	-	-	-	8856 (51,2 %)	8856 (17,8 %)
>= 5 years since diagnosis	**6070 (100 %)**	**11863 (100 %)**	**14476 (100 %)**	**8436 (48,8 %)**	**40845 (82,2 %)**
lost-to-follow-up	771 (12,7 %)	1016 (8,6 %)	483 (3,3 %)	108 (1,3 %)	2378 (5,8 %)
in LTS	**5299 (87,3 %)**	**10847 (91,4 %)**	**13993 (96,7 %)**	**8328 (98,7 %)**	**38467 (94,2 %)**

66084 patients correspond to 66859 cases diagnosed under 15 / 18 years resident in Germany at the date of diagnosis 1980-2018 and diagnosed with a disease included in ICCC-3.

\- Not applicable

\+ Consent not available, refused or withdrawn later.

* First diagnosis under 15.

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

*** First diagnosis under 18.

26 Diagnosen / Diagnoses

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

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

28 Diagnosen / Diagnoses

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

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

Cases in Germany aged under 15/18 years (1980-2018): 66859

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	21831 / 21831 = 100 %
Relative frequency of trial patients:	95.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	9683	12148	21831
Standardized rate *:	155.2	183.2	169.6
Cumulative incidence:	2706	3212	2966
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1928	6251	4662	5295	3695
Incidence rate:	270.4	221.5	130.8	139.4	152.9

Median age at diagnosis:	7 years 8 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	86 %	83 %	82 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
4054	100.0 %	27.8	478

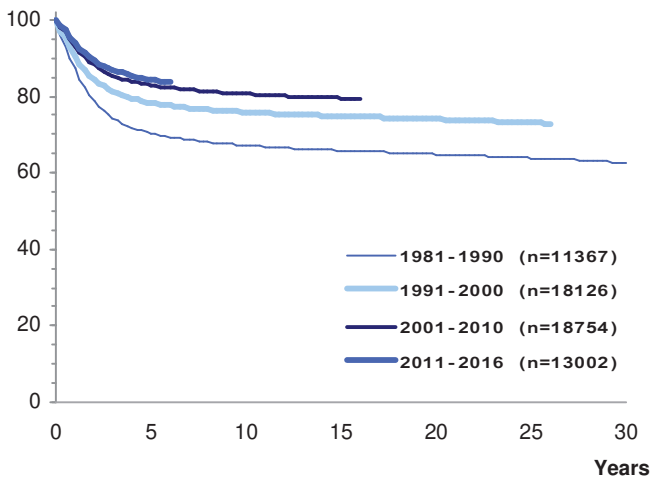
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
All Malignancies

SN after all malignancies

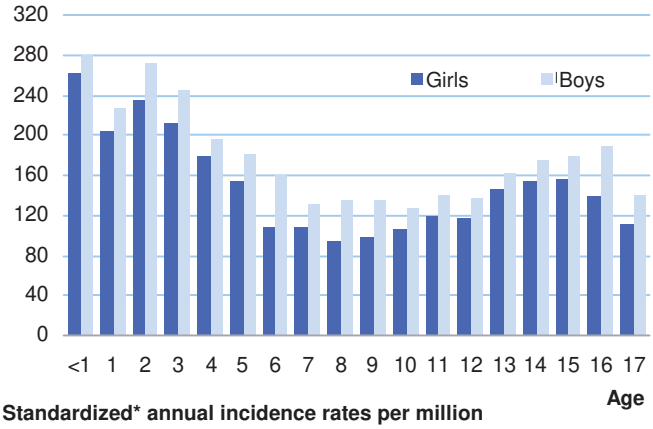
N	% of all 1540 SN	Cumulative incidence
1540	100.0 %	6.8 %

* Standard: Segi world standard population

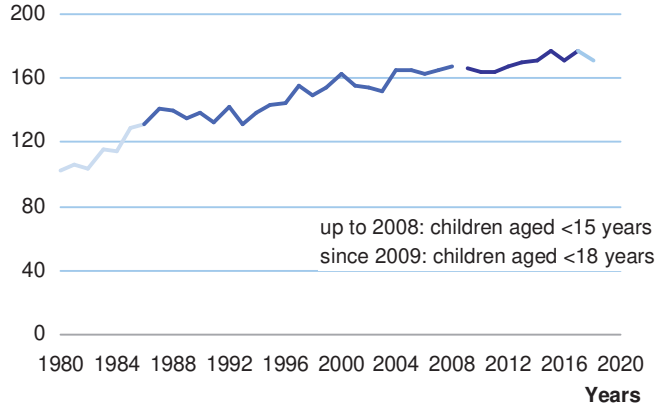
Survival probabilities by year of diagnosis Germany 1981-2016



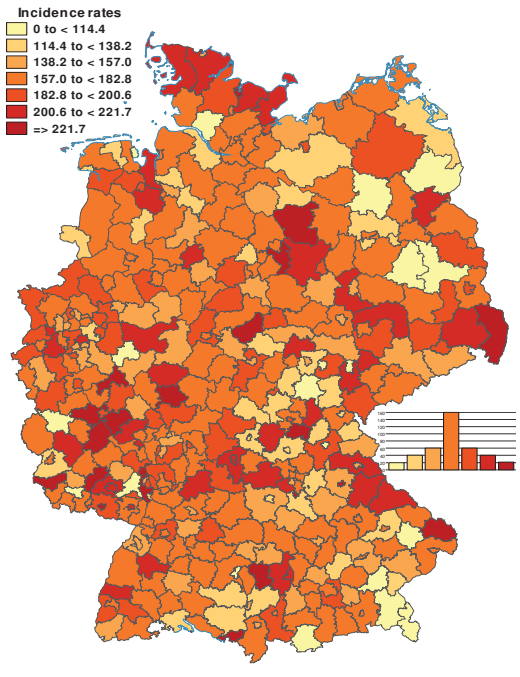
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



(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 15/18 years (1980-2018): 22023

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	6494 / 21831 = 29.7 %
Relative frequency of trial patients:	98.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	2846	3648	6494
Standardized rate *:	47.1	56.3	51.8
Cumulative incidence:	806	975	893
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	296	2595	1610	1221	772
Incidence rate:	41.5	92.0	45.2	32.1	31.9

Median age at diagnosis: 5 years 9 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	89 %	88 %	87 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

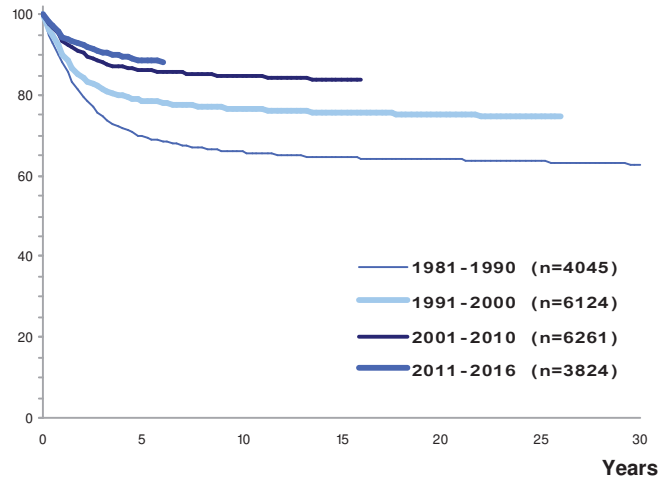
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
1236	30.5 %	8.4	145

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
I Leukaemias, myeloproliferative and myelodysplastic diseases

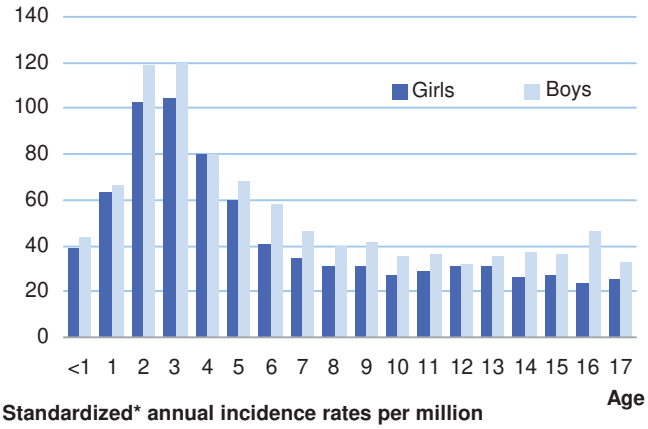
SN after I			I as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
532	34.5 %	6.8 %	316	20.5 %	0.7 %

* Standard: Segi world standard population

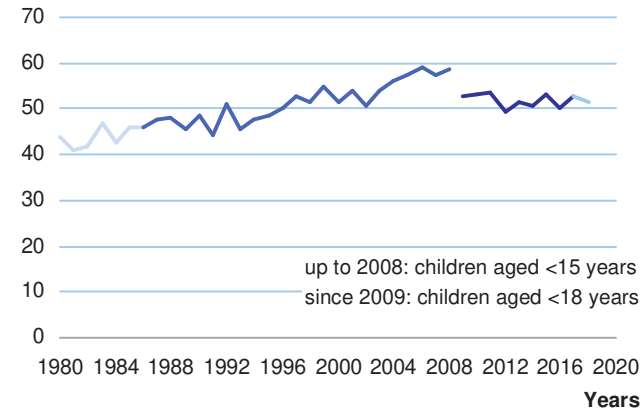
Survival probabilities by year of diagnosis Germany 1981-2016



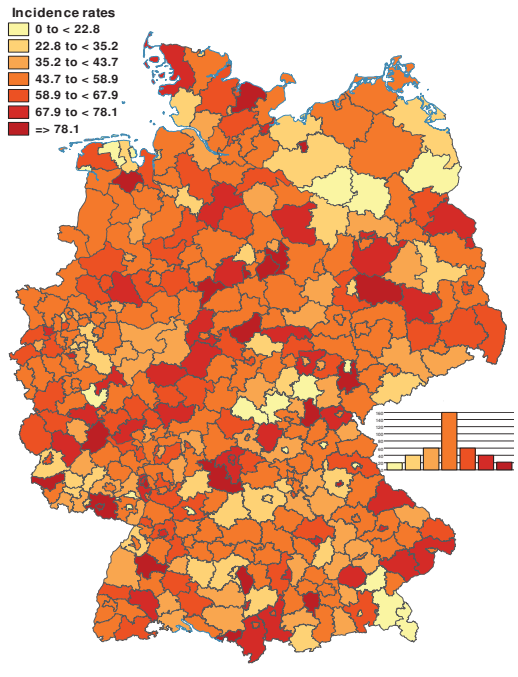
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Diagnoses

32 I (a) Lymphoid leukaemias

Cases in Germany aged under 15/18 years (1980-2018): 17290

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	4863 / 21831 = 22.3 %
Relative frequency of trial patients:	99.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	2091	2772	4863
Standardized rate *:	35.2	43.1	39.3
Cumulative incidence:	597	744	672
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	115	2186	1301	804	457
Incidence rate:	16.1	77.5	36.5	21.2	18.9

Median age at diagnosis: 5 years 3 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	92 %	91 %	90 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

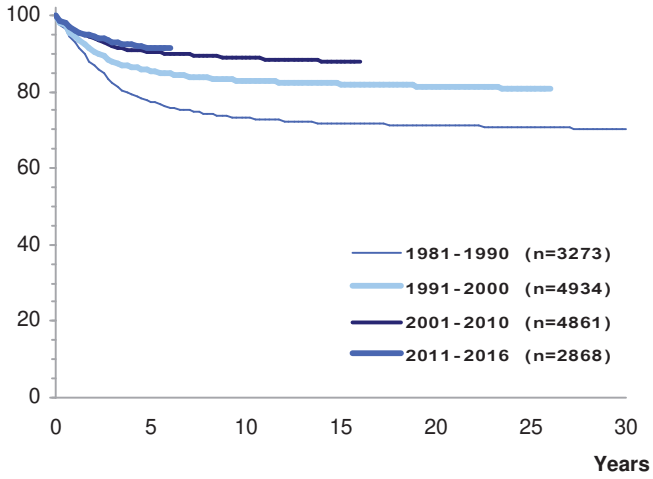
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
734	18.1 %	5.1	87

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
I (a) Lymphoid leukaemias

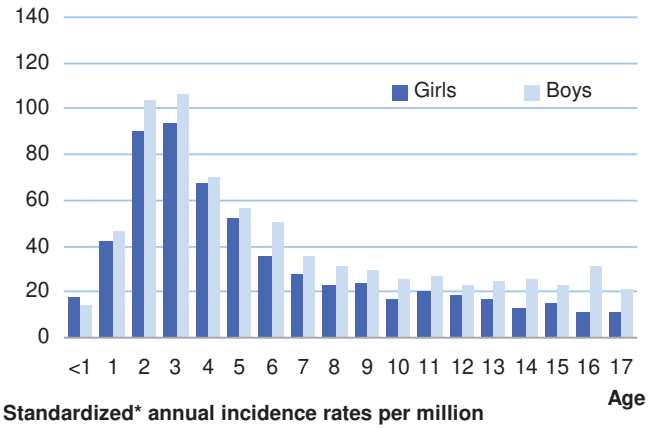
SN after I (a)			I (a) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
438	28.4 %	6.9 %	63	4.1 %	0.1 %

* Standard: Segi world standard population

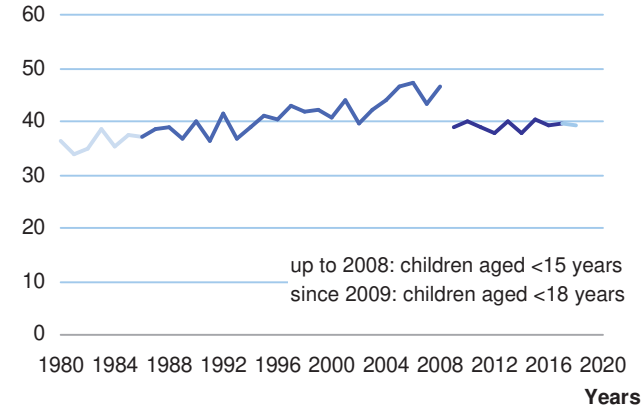
Survival probabilities by year of diagnosis Germany 1981-2016



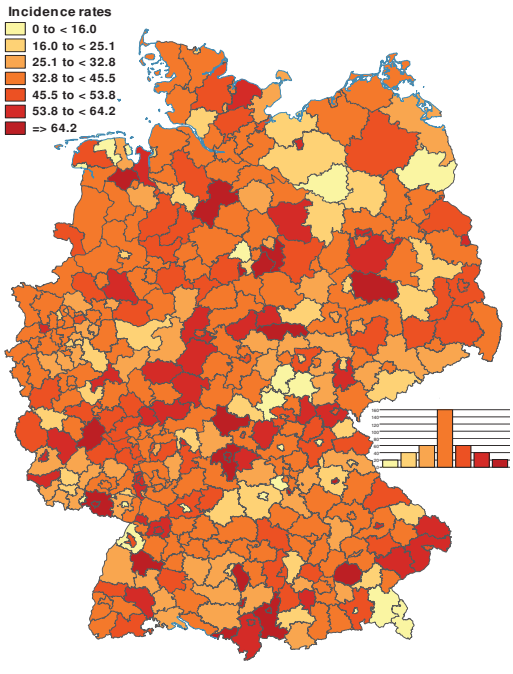
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Germany 2009-2018	N	%
Lymphoid leukaemias	**4863**	**100.0**
1 Precursor cell leukaemias	4754	97.8
2 Mature B-cell leukaemias	107	2.2
3 Mature T-cell and NK cell leukaemias	2	0.0
4 Lymphoid leukaemia, NOS	0	0.0

1 Precursor cell leukaemias

Cases in Germany aged under 15/18 years (1980-2018): 16882

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	4754 / 21831 = 21.8 %
Relative frequency of trial patients:	99.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	2063	2691	4754
Standardized rate *:	34.7	41.9	38.4
Cumulative incidence:	589	722	657

Sex ratio (m/f): 1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	114	2160	1253	780	447
Incidence rate:	16.0	76.6	35.2	20.5	18.5

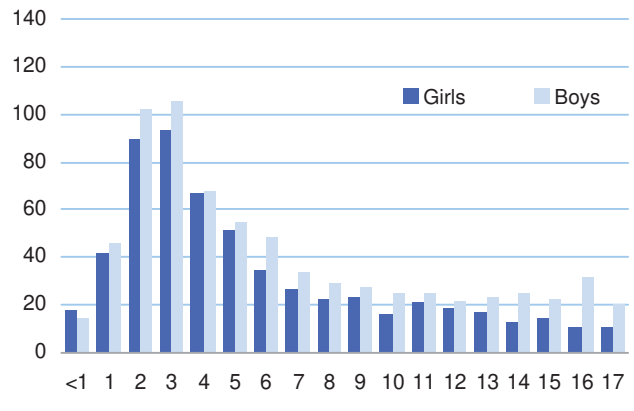
Median age at diagnosis: 5 years 2 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Precursor cell leukaemias

SN after I (a) 1			**I (a) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
425	27.6 %	6.7 %	56	3.6 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Mature B-cell leukaemias

Cases in Germany aged under 15/18 years (1980-2018): 405

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	107 / 21831 = 0.5 %
Relative frequency of trial patients:	100.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	27	80	107
Standardized rate *:	0.4	1.2	0.8
Cumulative incidence:	8	21	15

Sex ratio (m/f): 3.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	25	47	24	10
Incidence rate:	0.1	0.9	1.3	0.6	0.4

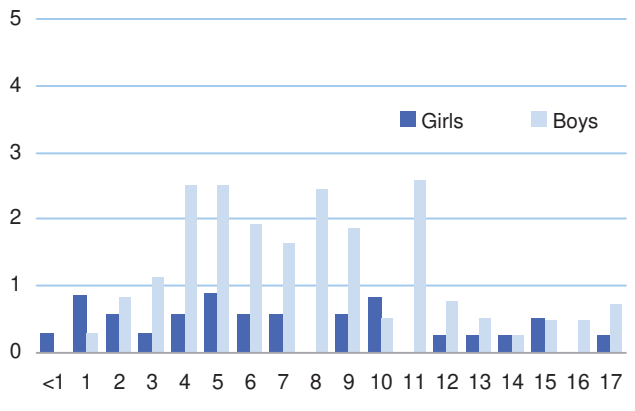
Median age at diagnosis: 7 years 11 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Mature B-cell leukaemias

SN after I (a) 2			**I (a) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
13	0.8 %	-	7	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



34 I (b) Acute myeloid leukaemias

Cases in Germany aged under 15/18 years (1980-2018): 3129

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	902 / 21831 = 4.1 %
Relative frequency of trial patients:	97.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	434	468	902
Standardized rate *:	7.0	7.2	7.1
Cumulative incidence:	121	124	122
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	118	272	145	207	160
Incidence rate:	16.5	9.6	4.1	5.4	6.6

Median age at diagnosis: 7 years 2 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	75 %	74 %	74 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

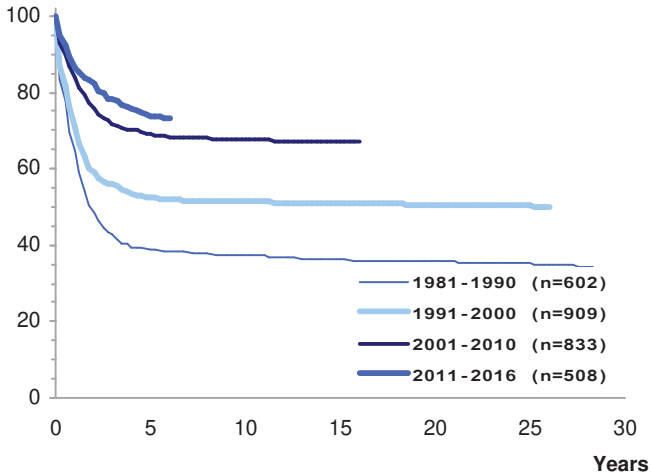
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
355	8.8 %	2.4	42

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
I (b) Acute myeloid leukaemias

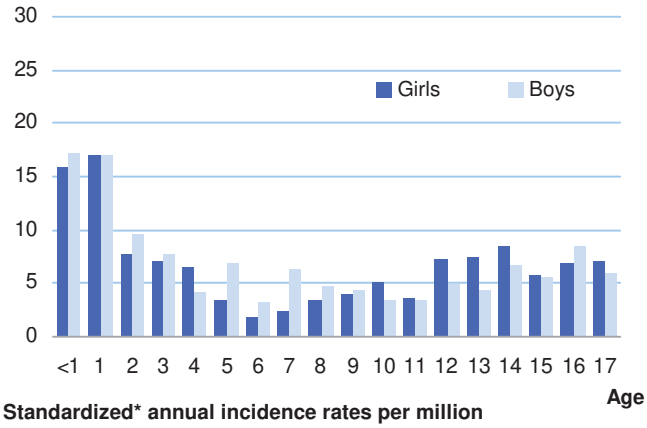
SN after I (b)			**I (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
68	4.4 %	5.8 %	165	10.7 %	0.3 %

* Standard: Segi world standard population

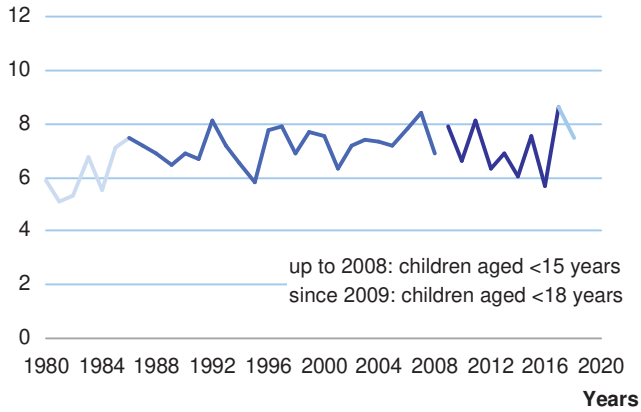
Survival probabilities by year of diagnosis Germany 1981-2016



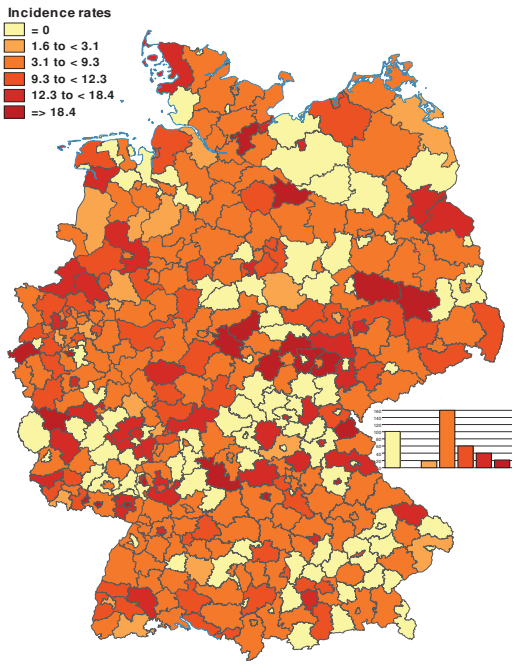
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 336

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	129 / 21831 = 0.6 %
Relative frequency of trial patients:	82.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	50	79	129
Standardized rate *:	0.7	1.0	0.9
Cumulative incidence:	14	20	17
Sex ratio (m/f):			1.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	8	24	47	49
Incidence rate:	0.1	0.3	0.7	1.2	2.0

Median age at diagnosis: 14 years 2 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	97 %	97 %	97 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

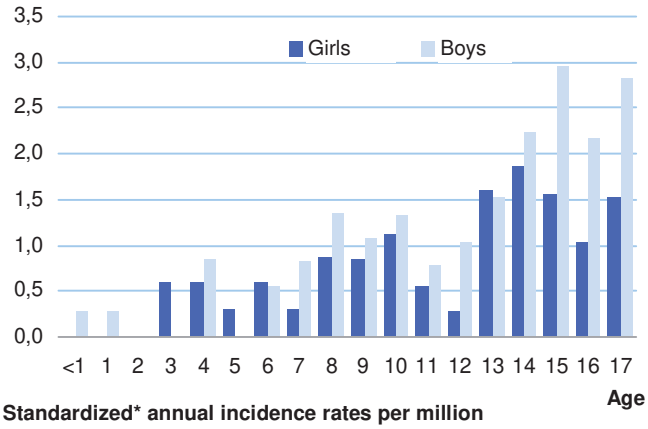
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
32	0.8 %	0.2	4

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
I (c) Chronic myeloproliferative diseases

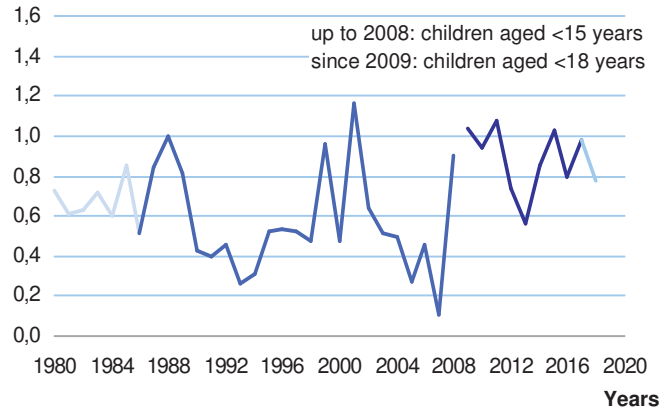
SN after I (c)			**I (c) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
6	0.4 %	-	6	0.4 %	0.0 %

* Standard: Segi world standard population

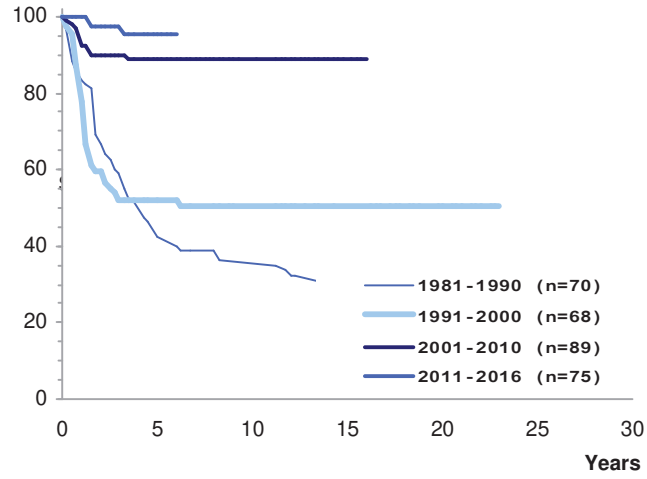
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

36 I (d) Myelodysplastic syndrome and other myeloproliferative diseases

Cases in Germany aged under 15/18 years (1980-2018): 1064

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	542 / 21831 = 2.5 %
Relative frequency of trial patients:	97.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	243	299	542
Standardized rate *:	3.7	4.5	4.1
Cumulative incidence:	67	79	73
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	50	119	128	146	99
Incidence rate:	7.0	4.2	3.6	3.8	4.1

Median age at diagnosis: 9 years 2 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	84 %	81 %	78 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
95	2.3 %	0.7	11

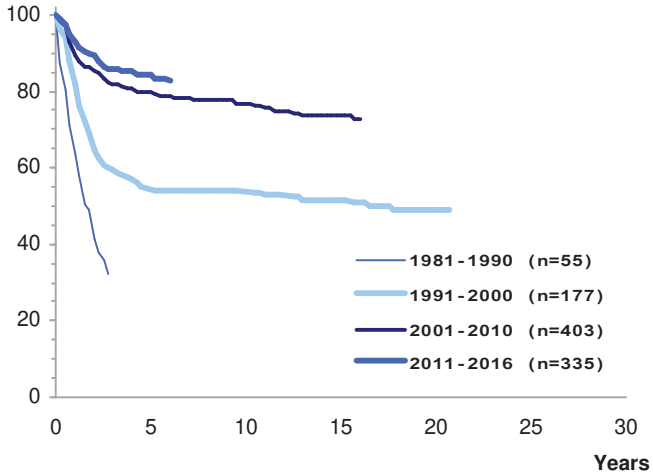
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

I (d) Myelodysplastic syndrome and other myeloproliferative diseases

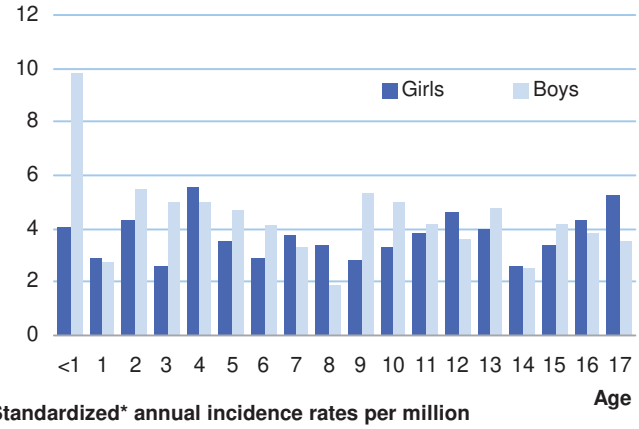
SN after I (d)			**I (d) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
10	0.6 %	-	78	5.1 %	0.2 %

* Standard: Segi world standard population

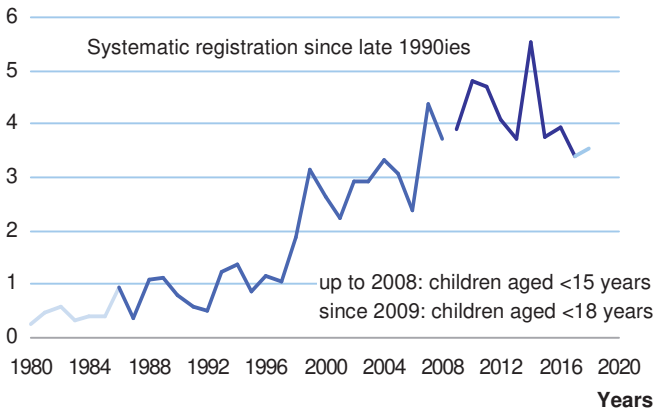
Survival probabilities by year of diagnosis Germany 1981-2016



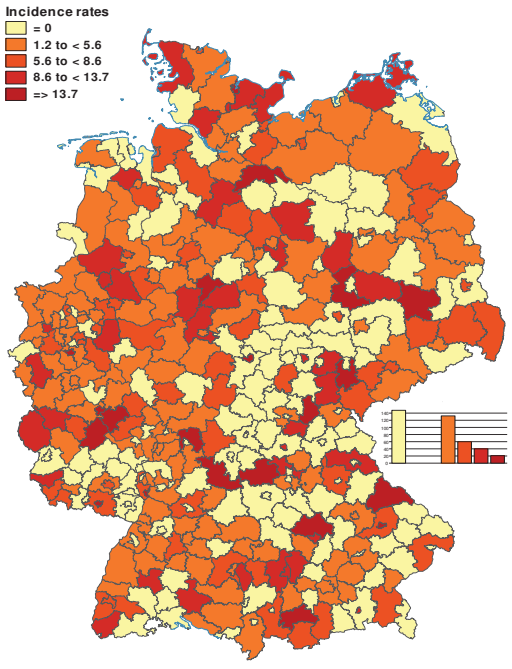
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



(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 15/18 years (1980-2018): 8691

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	3337 / 21831 = 15.3 %
Relative frequency of trial patients:	96.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	1224	2113	3337
Standardized rate *:	17.2	28.8	23.2
Cumulative incidence:	328	544	439
Sex ratio (m/f):			1.7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	51	325	647	1131	1183
Incidence rate:	7.2	11.5	18.2	29.8	49.0

Median age at diagnosis: 13 years 4 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	94 %	93 %	92 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

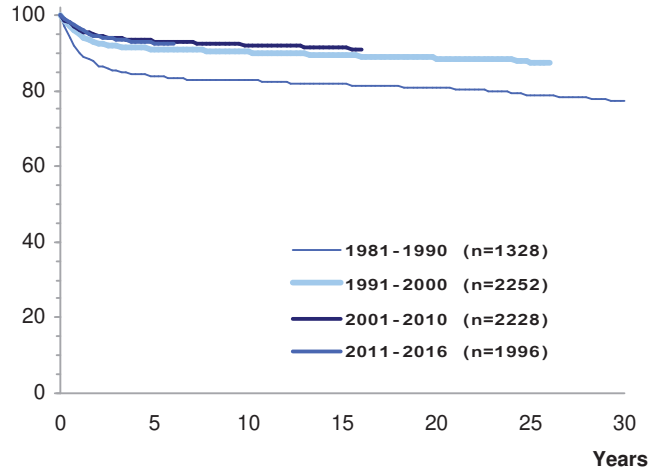
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
236	5.8 %	1.5	27

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
II Lymphomas and reticuloendothelial neoplasms

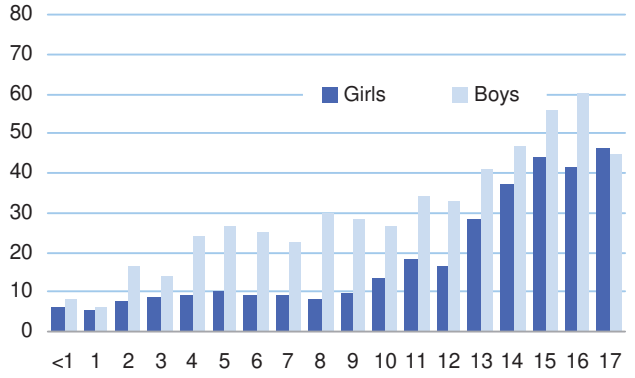
SN after II			**II as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
281	18.2 %	11.0 %	110	7.1 %	0.3 %

* Standard: Segi world standard population

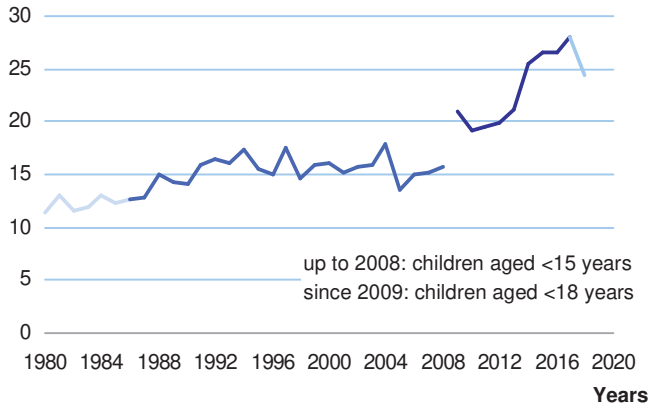
Survival probabilities by year of diagnosis Germany 1981-2016



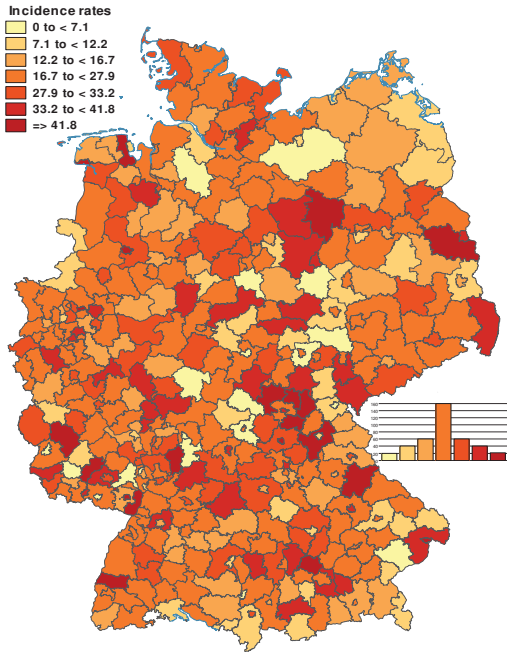
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 3829

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	1634 / 21831 = 7.5 %
Relative frequency of trial patients:	96.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	749	885	1634
Standardized rate *:	10.0	11.5	10.7
Cumulative incidence:	197	223	210
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	34	185	607	808
Incidence rate:	0.0	1.2	5.2	16.0	33.4

Median age at diagnosis: 14 years 11 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	98 %	98 %	97 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

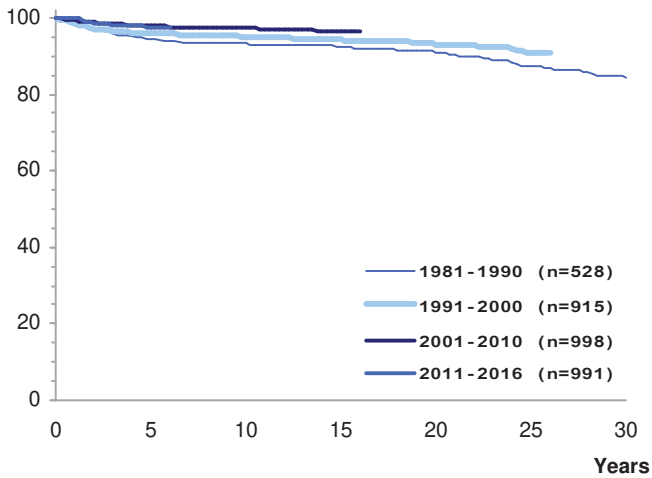
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
44	1.1 %	0.3	5

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
II (a) Hodgkin lymphomas

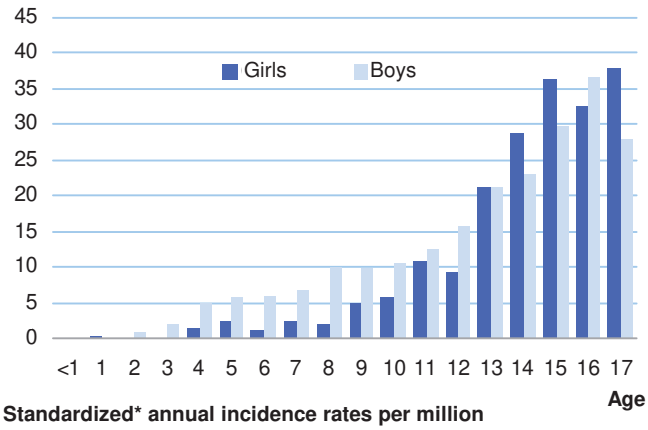
SN after II (a)			II (a) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
165	10.7 %	14.2 %	27	1.8 %	0.1 %

* Standard: Segi world standard population

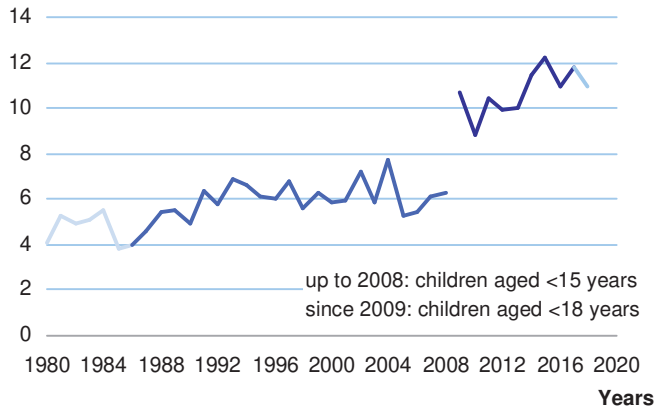
Survival probabilities by year of diagnosis Germany 1981-2016



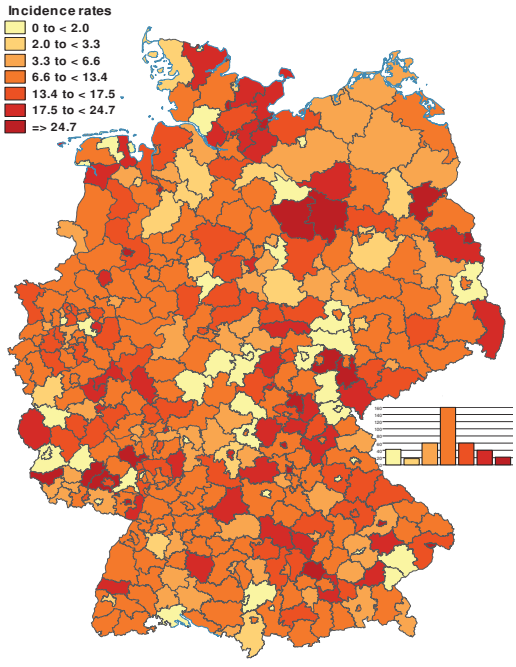
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 3154

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	1071 / 21831 = 4.9 %
Relative frequency of trial patients:	97.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	301	770	1071
Standardized rate *:	4.4	10.6	7.6
Cumulative incidence:	82	199	142
Sex ratio (m/f):			2.6

Age-specific incidence rates per million:	**<1**	**1-4**	**5-9**	**10-14**
Number of cases :	6	136	259	362
Incidence rate:	0.8	4.8	7.3	9.5

Median age at diagnosis: 12 years 0 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	88 %	87 %	86 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

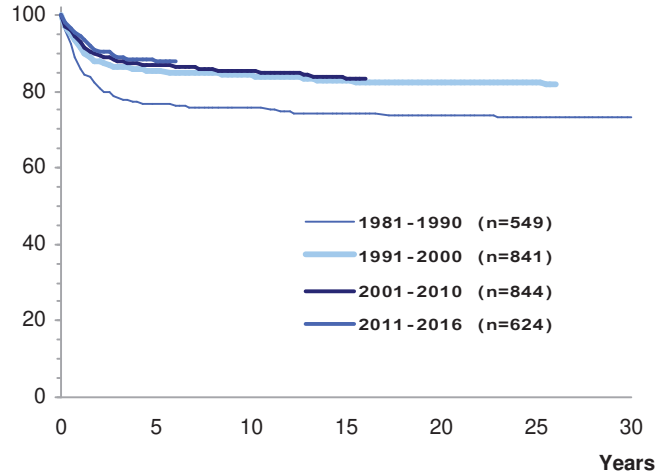
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
144	3.6 %	0.9	17

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
II (b) Non-Hodgkin lymphomas (except Burkitt lymphoma)

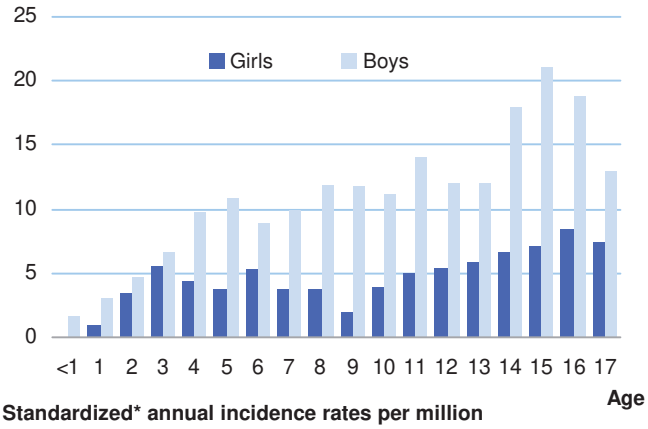
SN after II (b)			**II (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
95	6.2 %	10.5 %	69	4.5 %	0.2 %

* Standard: Segi world standard population

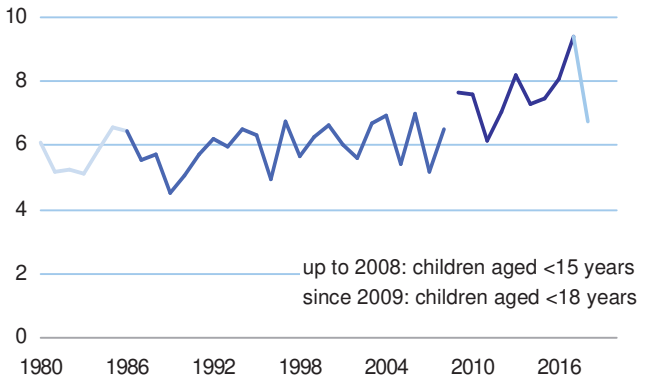
Survival probabilities by year of diagnosis Germany 1981-2016



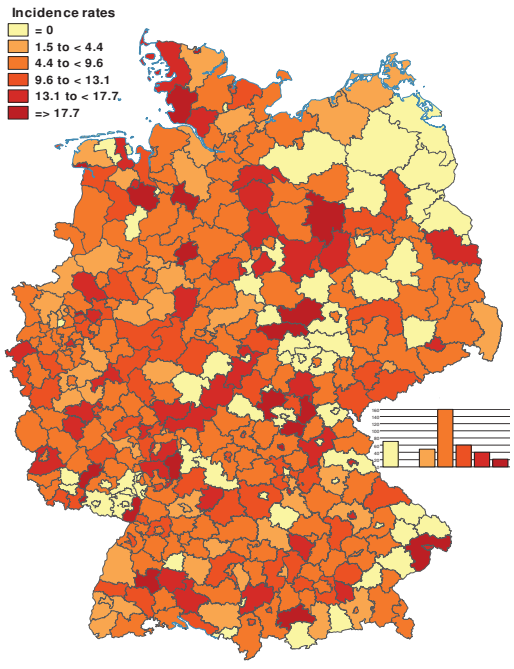
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



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

Germany 2009-2018	N	%
Non-Hodgkin lymphomas (except Burkitt lymphoma)	**1071**	**100.0**
1 Precursor cell lymphomas	319	29.8
2 Mature B-cell lymphomas (except Burkitt lymphoma)	247	23.1
3 Mature T-cell and NK-cell lymphomas	202	18.9
4 Non-Hodgkin lymphomas, NOS	303	28.3

1 Precursor cell lymphomas

Cases in Germany aged under 15/18 years (1980-2018): 1164

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	319 / 21831 = 1.5 %
Relative frequency of trial patients:	95.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	82	237	319
Standardized rate *:	1.3	3.4	2.4
Cumulative incidence:	23	62	43

Sex ratio (m/f): 2.9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	4	66	91	99	59
Incidence rate:	0.6	2.3	2.6	2.6	2.4

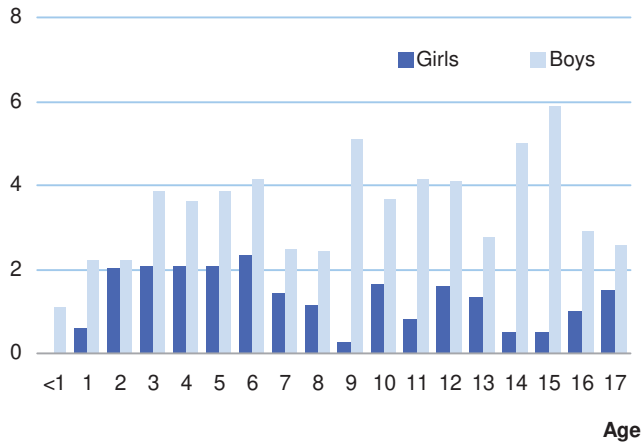
Median age at diagnosis: 9 years 11 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Precursor cell lymphomas

SN after II (b) 1			**II (b) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
54	3.5 %	16.3 %	23	1.5 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Mature B-cell lymphomas (except Burkitt lymphoma)

Cases in Germany aged under 15/18 years (1980-2018): 576

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	247 / 21831 = 1.1 %
Relative frequency of trial patients:	96.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	69	178	247
Standardized rate *:	1.0	2.3	1.7
Cumulative incidence:	19	45	32

Sex ratio (m/f): 2.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	9	50	88	100
Incidence rate:	0.0	0.3	1.4	2.3	4.1

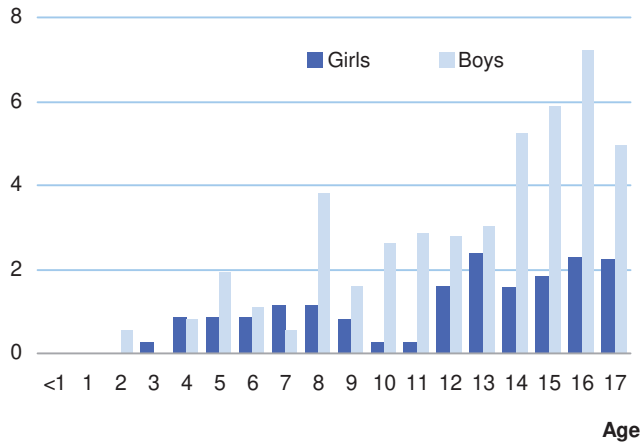
Median age at diagnosis: 14 years 2 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Mature B-cell lymphomas (except Burkitt lymphoma)

SN after II (b) 2			**II (b) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
14	0.9 %	-	18	1.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Germany 2009-2018	N	%
Non-Hodgkin lymphomas (except Burkitt lymphoma)	**1071**	**100.0**
1 Precursor cell lymphomas	319	29.8
2 Mature B-cell lymphomas (except Burkitt lymphoma)	247	23.1
3 Mature T-cell and NK-cell lymphomas	202	18.9
4 Non-Hodgkin lymphomas, NOS	303	28.3

3 Mature T-cell and NK-cell lymphomas

Cases in Germany aged under 15/18 years (1980-2018): 576

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	202 / 21831 = 0.9 %
Relative frequency of trial patients:	99.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	71	131	202
Standardized rate *:	1.0	1.8	1.4
Cumulative incidence:	19	34	27

Sex ratio (m/f): 1.8

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	28	34	85	54
Incidence rate:	0.1	1.0	1.0	2.2	2.2

Median age at diagnosis: 12 years 6 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
3 Mature T-cell and NK-cell lymphomas

SN after II (b) 3			**II (b) 3 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
14	0.9 %	-	8	0.5 %	0.0 %

* Standard: Segi world standard population

4 Non-Hodgkin lymphomas, NOS

Cases in Germany aged under 15/18 years (1980-2018): 838

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	303 / 21831 = 1.4 %
Relative frequency of trial patients:	98.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	79	224	303
Standardized rate *:	1.1	3.1	2.1
Cumulative incidence:	21	58	40

Sex ratio (m/f): 2.8

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	33	84	90	95
Incidence rate:	0.1	1.2	2.4	2.4	3.9

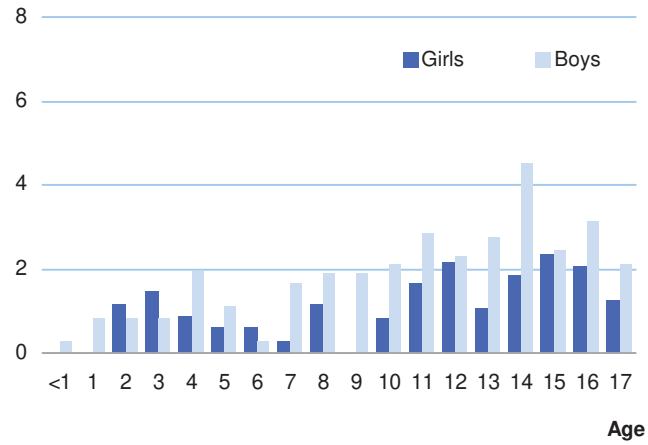
Median age at diagnosis: 11 years 8 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
4 Non-Hodgkin lymphomas, NOS

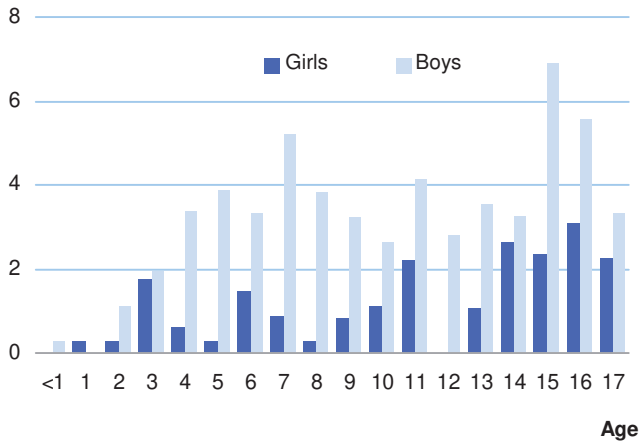
SN after II (b) 4			**II (b) 4 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
13	0.8 %	4.6 %	20	1.3 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Age- and sex-specific incidence rates per million
Germany 2009-2018



42 II (c) Burkitt lymphoma

Cases in Germany aged under 15/18 years (1980-2018): 1300

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	336 / 21831 = 1.5 %
Relative frequency of trial patients:	99.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	49	287	336
Standardized rate *:	0.8	4.1	2.5
Cumulative incidence:	14	76	46
Sex ratio (m/f):			5.9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	67	127	94	48
Incidence rate:	0.0	2.4	3.6	2.5	2.0

Median age at diagnosis: 8 years 8 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	92 %	91 %	91 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

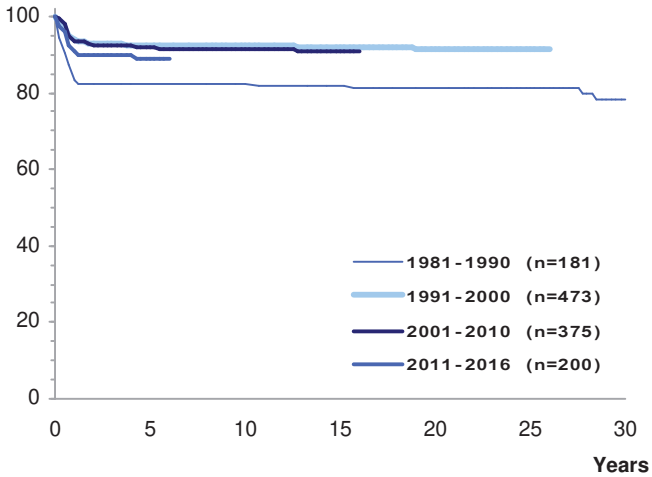
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
39	1.0 %	0.2	4

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
II (c) Burkitt lymphoma

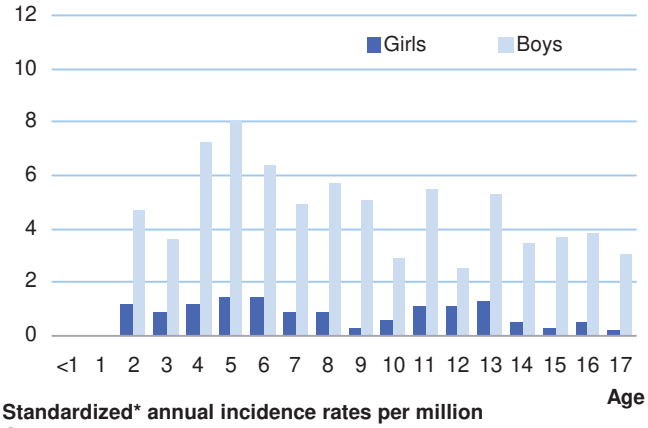
SN after II (c)			II (c) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
21	1.4 %	3.0 %	5	0.3 %	0.0 %

* Standard: Segi world standard population

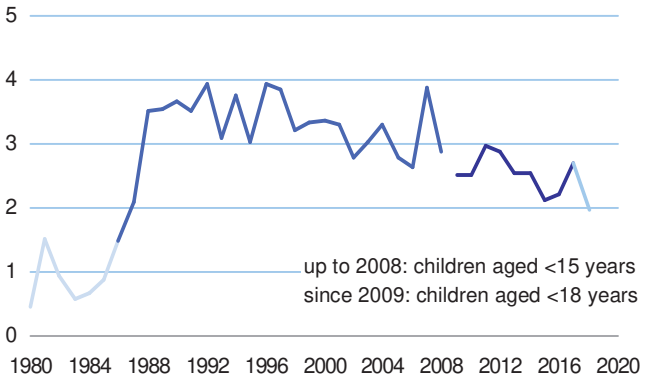
Survival probabilities by year of diagnosis Germany 1981-2016



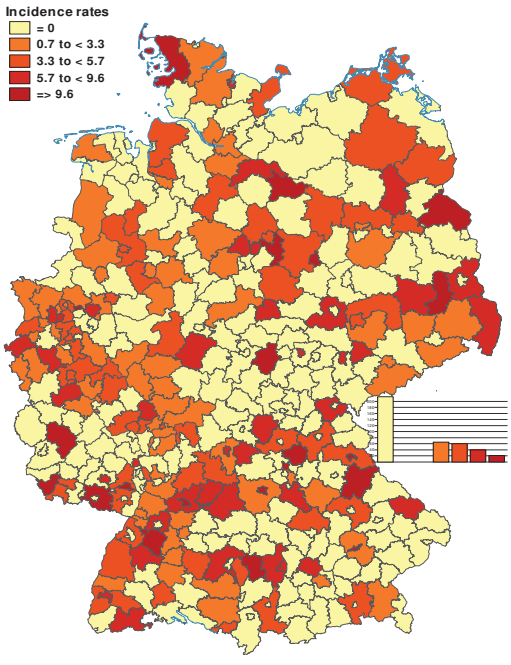
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



(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 15/18 years (1980-2018): 14615

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	5142 / 21831 = 23.6 %
Relative frequency of trial patients:	93.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	2348	2794	5142
Standardized rate *:	37.3	41.9	39.6
Cumulative incidence:	659	742	702
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	300	1369	1458	1388	627
Incidence rate:	42.1	48.5	40.9	36.5	25.9

Median age at diagnosis: 7 years 11 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	80 %	77 %	75 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

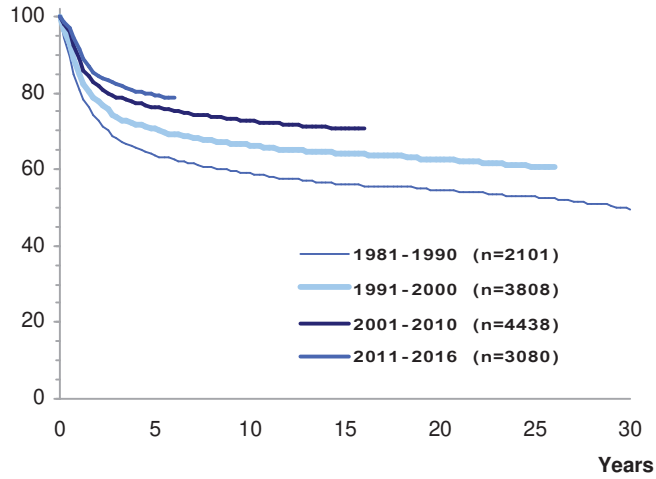
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
1244	30.7 %	8.6	147

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
III CNS and miscellaneous intracranial and intraspinal neoplasms

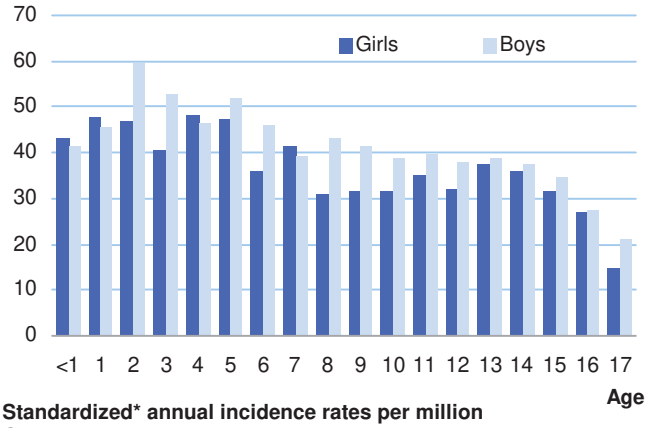
SN after III			III as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
288	18.7 %	7.6 %	344	22.3 %	1.7 %

* Standard: Segi world standard population

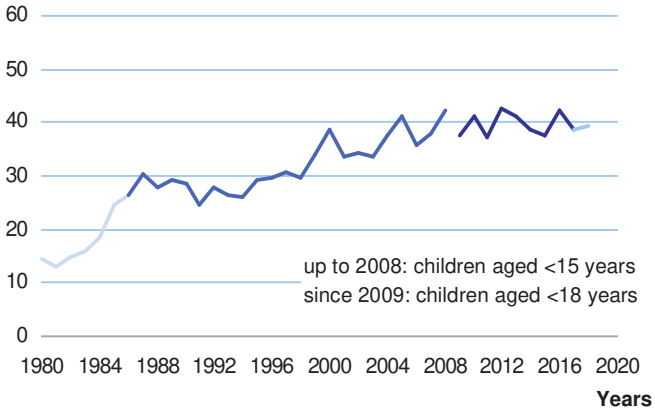
Survival probabilities by year of diagnosis Germany 1981-2016



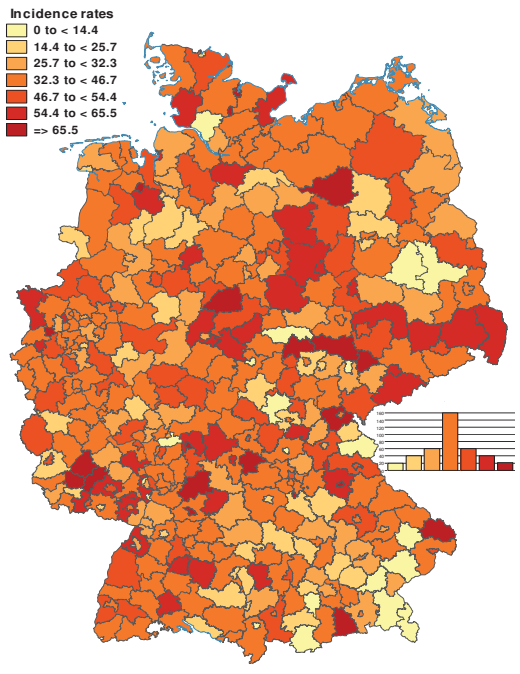
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



44 III (a) Ependymomas and choroid plexus tumour

Cases in Germany aged under 15/18 years (1980-2018): 1415

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	466 / 21831 = 2.1 %
Relative frequency of trial patients:	96.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	199	267	466
Standardized rate *:	3.4	4.3	3.8
Cumulative incidence:	56	72	64
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	69	184	82	90	41
Incidence rate:	9.7	6.5	2.3	2.4	1.7

Median age at diagnosis: 4 years 2 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	82 %	74 %	70 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

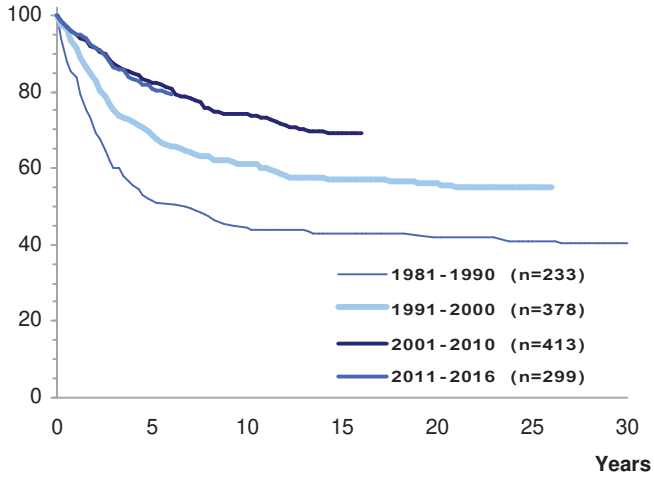
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
125	3.1 %	1.0	15

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
III (a) Ependymomas and choroid plexus tumour

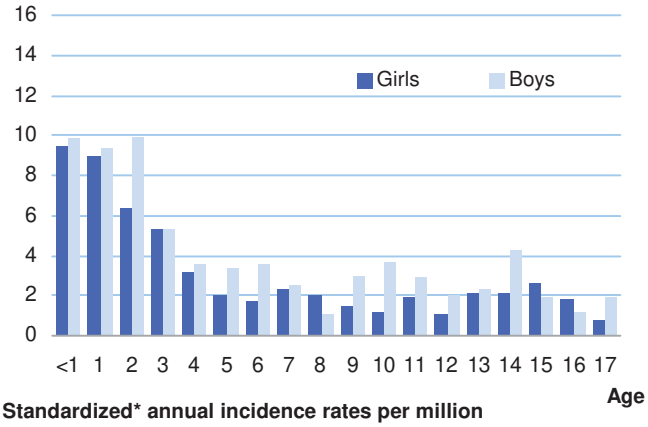
SN after III (a)			**III (a) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
36	2.3 %	-	11	0.7 %	0.0 %

* Standard: Segi world standard population

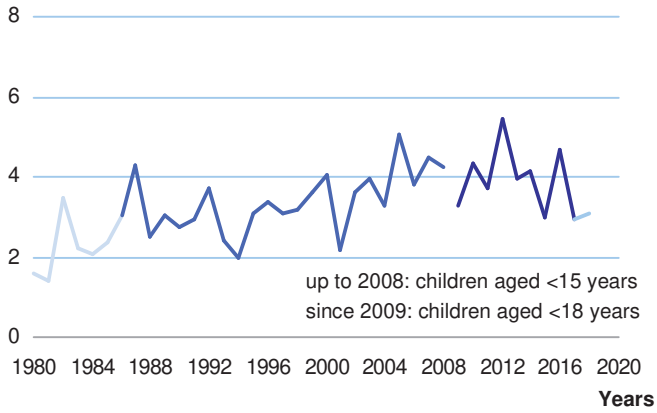
Survival probabilities by year of diagnosis Germany 1981-2016



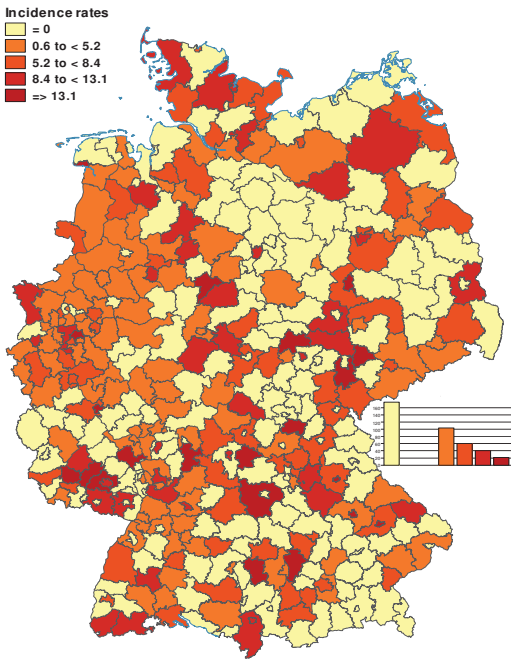
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Germany 2009-2018	N	%
Ependymomas and choroid plexus tumour	**466**	**100.0**
1 Ependymomas	364	78.1
2 Choroid plexus tumour	102	21.9

1 Ependymomas

Cases in Germany aged under 15/18 years (1980-2018): 1129

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	364 / 21831 = 1.7 %
Relative frequency of trial patients:	96.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	151	213	364
Standardized rate *:	2.5	3.3	2.9
Cumulative incidence:	43	57	50

Sex ratio (m/f): 1.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	27	157	65	81	34
Incidence rate:	3.8	5.6	1.8	2.1	1.4

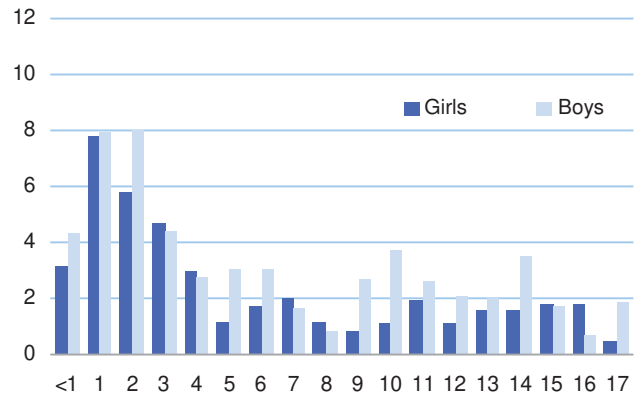
Median age at diagnosis: 4 years 11 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Ependymomas

SN after III (a) 1			**III (a) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
27	1.8 %	-	8	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Choroid plexus tumour

Cases in Germany aged under 15/18 years (1980-2018): 286

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	102 / 21831 = 0.5 %
Relative frequency of trial patients:	94.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	48	54	102
Standardized rate *:	0.9	0.9	0.9
Cumulative incidence:	14	15	14

Sex ratio (m/f): 1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	42	27	17	9	7
Incidence rate:	5.9	1.0	0.5	0.2	0.3

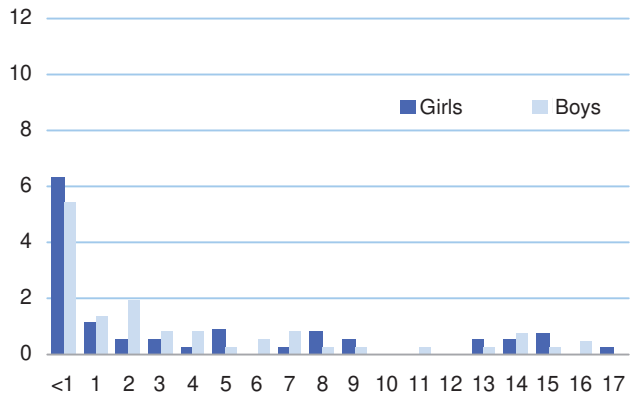
Median age at diagnosis: 1 year 12 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Choroid plexus tumour

SN after III (a) 2			**III (a) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
9	0.6 %	-	3	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



46 III (b) Astrocytomas

Cases in Germany aged under 15/18 years (1980-2018): 6492

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	2317 / 21831 = 10.6 %
Relative frequency of trial patients:	93.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	1122	1195	2317
Standardized rate *:	17.8	17.8	17.8
Cumulative incidence:	315	317	316
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	111	620	663	655	268
Incidence rate:	15.6	22.0	18.6	17.2	11.1

Median age at diagnosis: 8 years 0 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	84 %	82 %	81 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

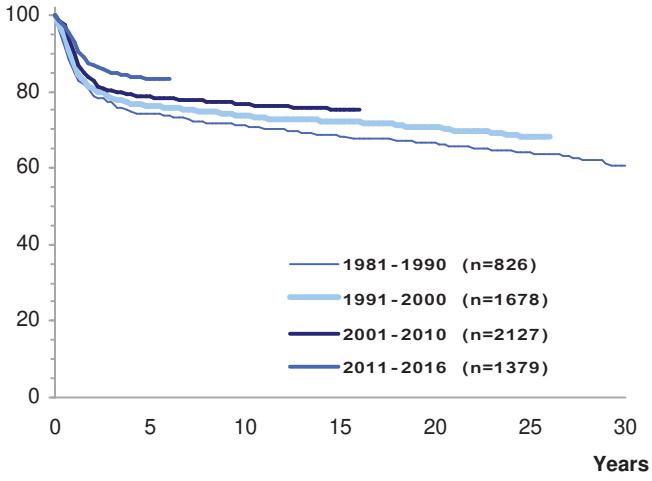
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
467	11.5 %	3.0	54

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
III (b) Astrocytomas

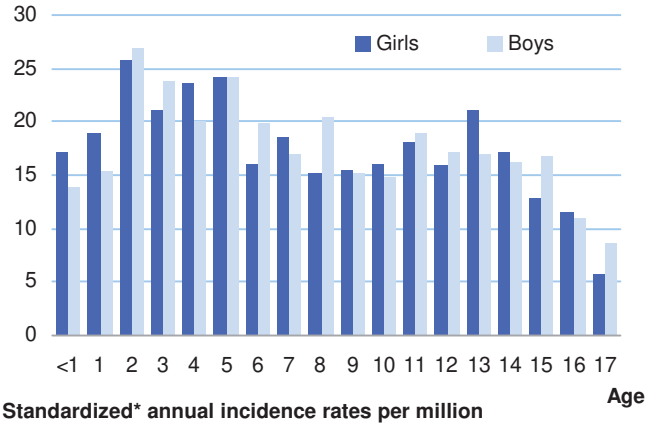
SN after III (b)			**III (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
60	3.9 %	2.7 %	111	7.2 %	0.3 %

* Standard: Segi world standard population

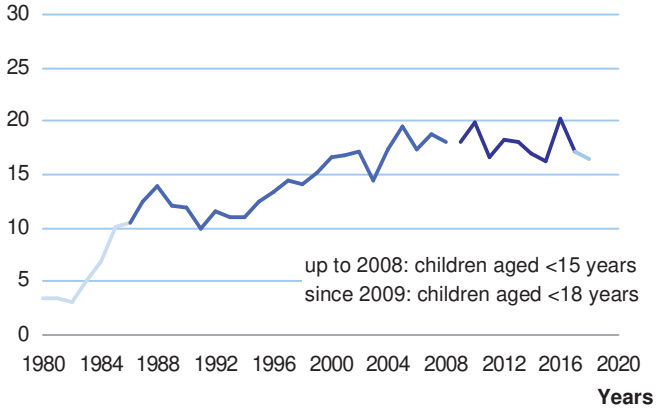
Survival probabilities by year of diagnosis Germany 1981-2016



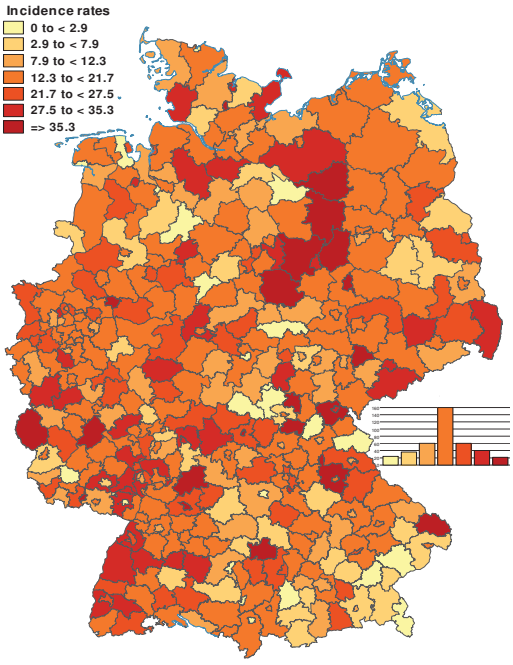
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 3061

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	838 / 21831 = 3.8 %
Relative frequency of trial patients:	96.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	306	532	838
Standardized rate *:	5.1	8.3	6.8
Cumulative incidence:	87	143	116
Sex ratio (m/f):			1.7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	69	299	276	129	65
Incidence rate:	9.7	10.6	7.7	3.4	2.7

Median age at diagnosis: 5 years 9 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	67 %	61 %	58 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

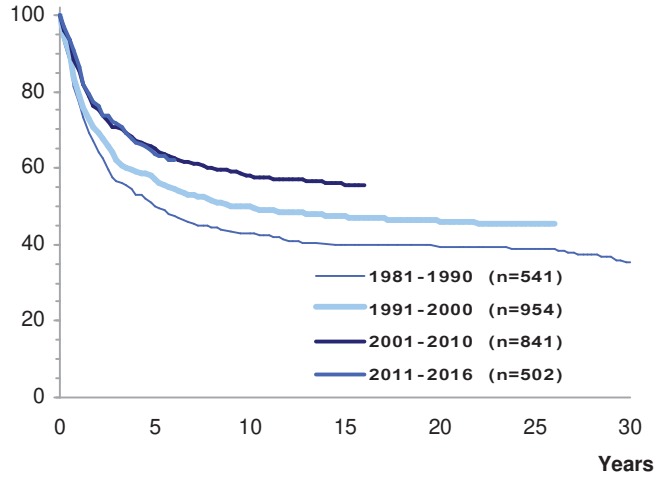
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
441	10.9 %	3.2	53

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
III (c) Intracranial and intraspinal embryonal tumours

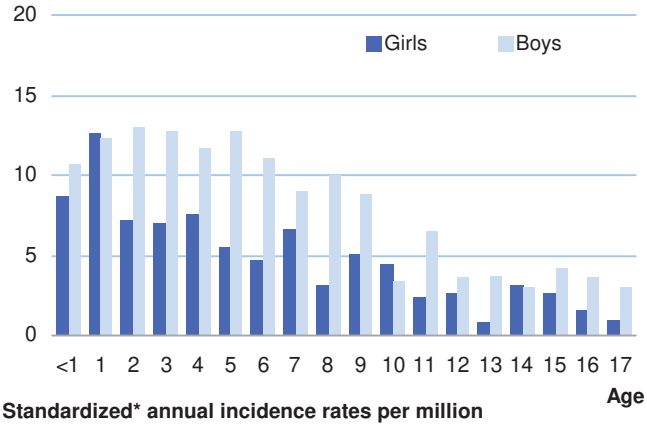
SN after III (c)			III (c) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
165	10.7 %	18.1 %	15	1.0 %	0.0 %

* Standard: Segi world standard population

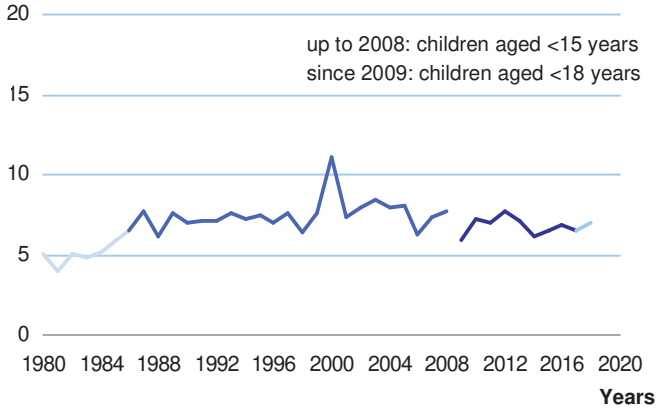
Survival probabilities by year of diagnosis Germany 1981-2016



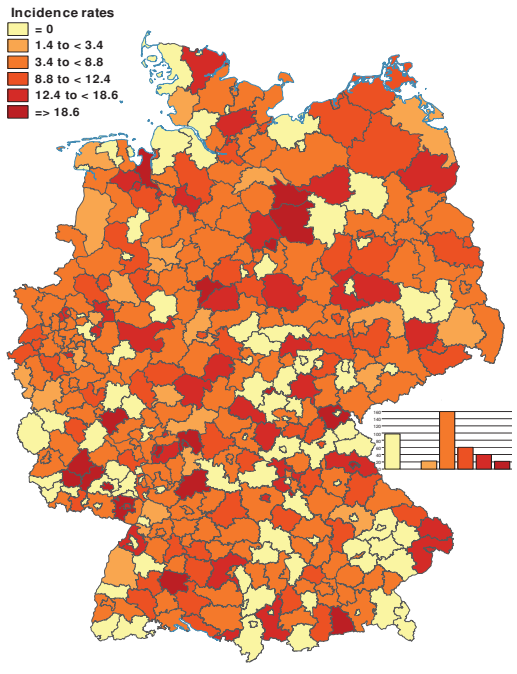
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



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

Germany 2009-2018	N	%
Intracranial and intraspinal embryonal tumours	**838**	**100.0**
1 Medulloblastomas	614	73.3
2 Primitive neuroectodermal tumour (PNET)	70	8.4
3 Medulloepithelioma	18	2.1
4 Atypical teratoid/rhabdoid tumour	136	16.2

1 Medulloblastomas

Cases in Germany aged under 15/18 years (1980-2018): 2331

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	614 / 21831 = 2.8 %
Relative frequency of trial patients:	97.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	206	408	614
Standardized rate *:	3.3	6.2	4.8
Cumulative incidence:	58	109	85

Sex ratio (m/f): 2.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	14	181	244	117	58
Incidence rate:	2.0	6.4	6.8	3.1	2.4

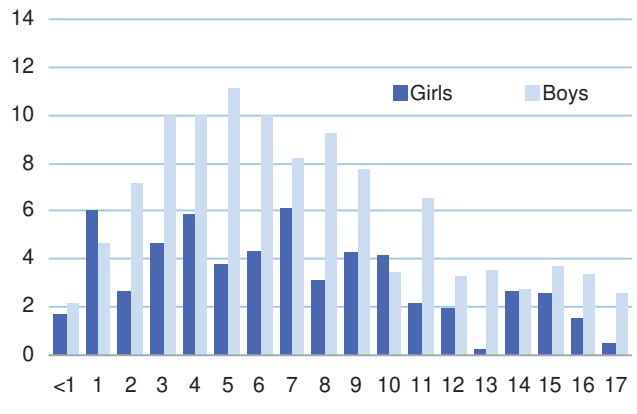
Median age at diagnosis: 7 years 2 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Medulloblastomas

SN after III (c) 1			**III (c) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
143	9.3 %	20.5 %	7	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Primitive neuroectodermal tumour (PNET)

Cases in Germany aged under 15/18 years (1980-2018): 430

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	70 / 21831 = 0.3 %
Relative frequency of trial patients:	94.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	32	38	70
Standardized rate *:	0.6	0.6	0.6
Cumulative incidence:	9	10	10

Sex ratio (m/f): 1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	5	42	13	7	3
Incidence rate:	0.7	1.5	0.4	0.2	0.1

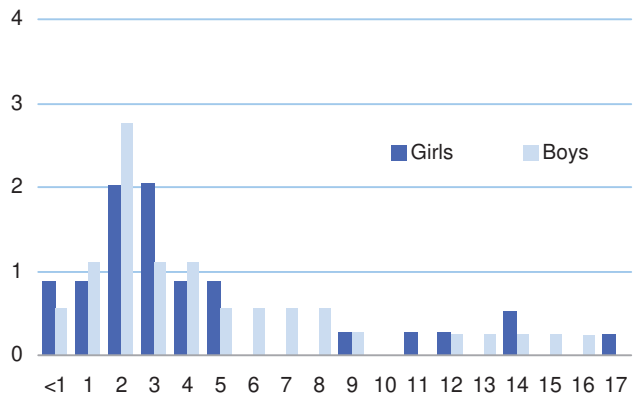
Median age at diagnosis: 3 years 4 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Primitive neuroectodermal tumour (PNET)

SN after III (c) 2			**III (c) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
20	1.3 %	-	8	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Germany 2009-2018	N	%
Intracranial and intraspinal embryonal tumours	**838**	**100.0**
1 Medulloblastomas	614	73.3
2 Primitive neuroectodermal tumour (PNET)	70	8.4
3 Medulloepithelioma	18	2.1
4 Atypical teratoid/rhabdoid tumour	136	16.2

4 Atypical teratoid/rhabdoid tumour

Cases in Germany aged under 15/18 years (1980-2018): 266

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	136 / 21831 = 0.6 %
Relative frequency of trial patients:	94.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	58	78	136
Standardized rate *:	1.1	1.4	1.3
Cumulative incidence:	17	21	19

Sex ratio (m/f): 1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	47	73	14	1	1
Incidence rate:	6.6	2.6	0.4	0.0	0.0

Median age at diagnosis: 1 year 5 months

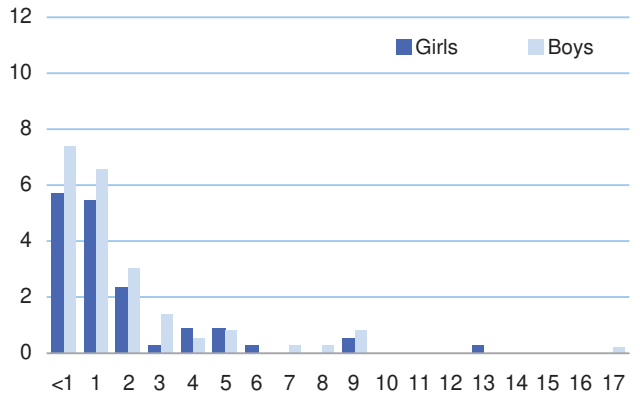
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

4 Atypical teratoid/rhabdoid tumour

SN after III (c) 4			**III (c) 4 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
2	0.1 %	-	0	0.0 %	-

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



50 III (d) Other gliomas

Cases in Germany aged under 15/18 years (1980-2018): 1192

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	554 / 21831 = 2.5 %
Relative frequency of trial patients:	90.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	266	288	554
Standardized rate *:	4.1	4.2	4.2
Cumulative incidence:	75	76	76
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	18	111	195	165	65
Incidence rate:	2.5	3.9	5.5	4.3	2.7

Median age at diagnosis: 8 years 8 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	53 %	51 %	49 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

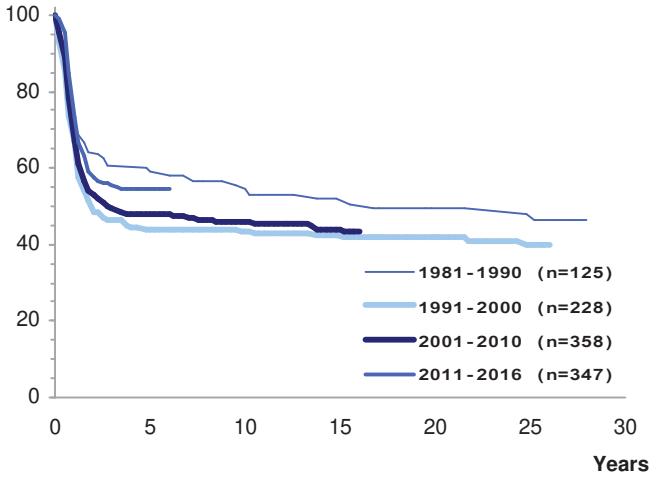
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
135	3.3 %	0.9	16

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
III (d) Other gliomas

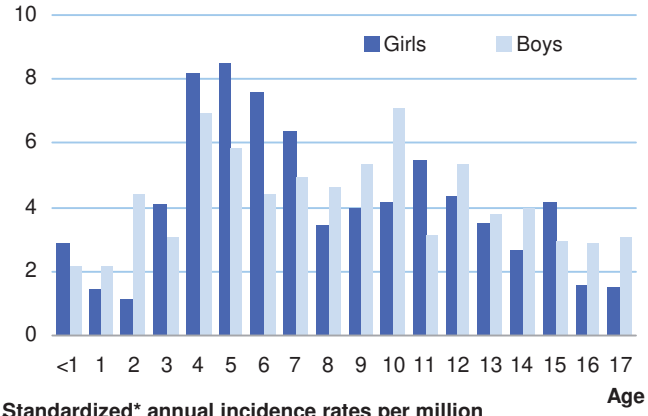
SN after III (d)			**III (d) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	-	27	1.8 %	0.1 %

* Standard: Segi world standard population

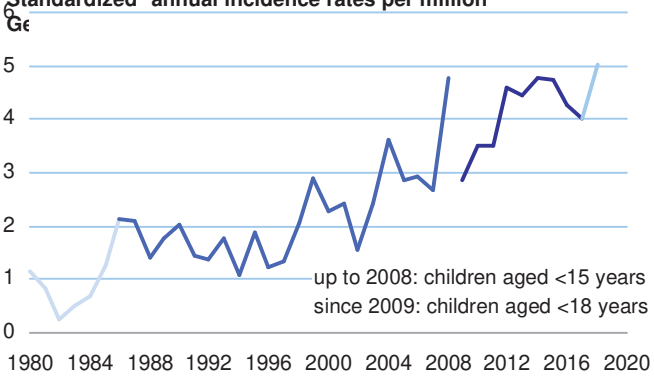
Survival probabilities by year of diagnosis Germany 1981-2016



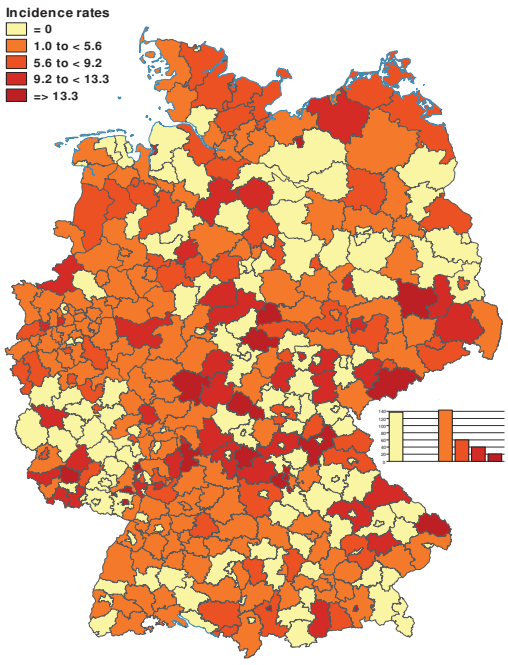
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Germany 2009-2018	N	%
Other gliomas	**554**	**100.0**
1 Oligodendrogliomas	16	2.9
2 Mixed and unspecified gliomas	507	91.5
3 Neuroepithelial glial tumours of uncertain origin	31	5.6

1 Oligodendrogliomas

Cases in Germany aged under 15/18 years (1980-2018): 126

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	16 / 21831 = 0.1 %
Relative frequency of trial patients:	87.5 %

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**	**15-17**
Number of cases :	0	1	2	6	7
Incidence rate:	0.0	0.0	0.1	0.2	0.3

Median age at diagnosis: 14 years 7 months

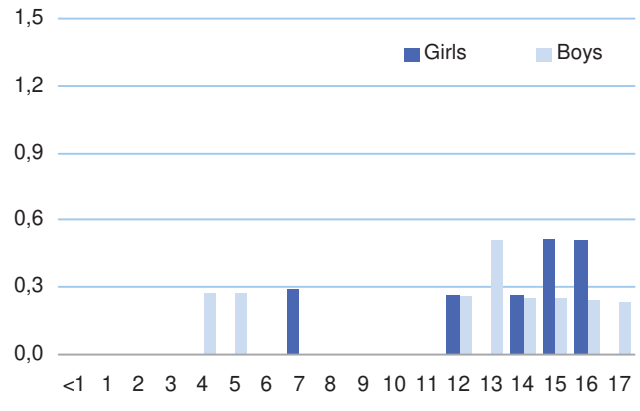
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

1 Oligodendrogliomas

SN after III (d) 1			**III (d) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	5	0.3 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Mixed and unspecified gliomas

Cases in Germany aged under 15/18 years (1980-2018): 1014

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	507 / 21831 = 2.3 %
Relative frequency of trial patients:	89.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	243	264	507
Standardized rate *:	3.8	3.9	3.8
Cumulative incidence:	69	70	69

Sex ratio (m/f): 1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	17	101	188	146	55
Incidence rate:	2.4	3.6	5.3	3.8	2.3

Median age at diagnosis: 8 years 4 months

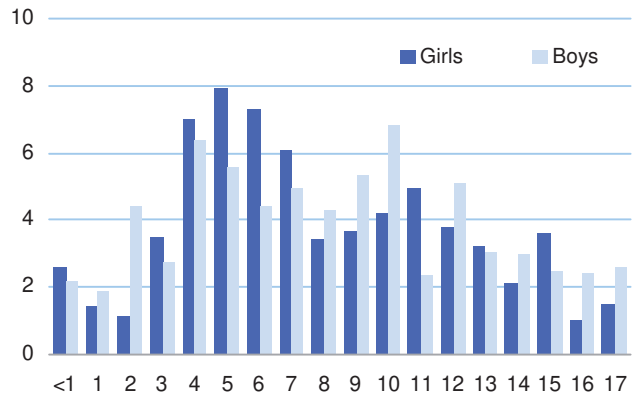
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

2 Mixed and unspecified gliomas

SN after III (d) 2			**III (d) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
3	0.2 %	-	22	1.4 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



52 III (e) Other specified intracranial and intraspinal neoplasms

Cases in Germany aged under 15/18 years (1980-2018): 2061

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	885 / 21831 = 4.1 %
Relative frequency of trial patients:	93.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	409	476	885
Standardized rate *:	6.1	6.8	6.4
Cumulative incidence:	113	124	119
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	28	141	224	317	175
Incidence rate:	3.9	5.0	6.3	8.3	7.2

Median age at diagnosis: 11 years 0 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	96 %	94 %	92 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

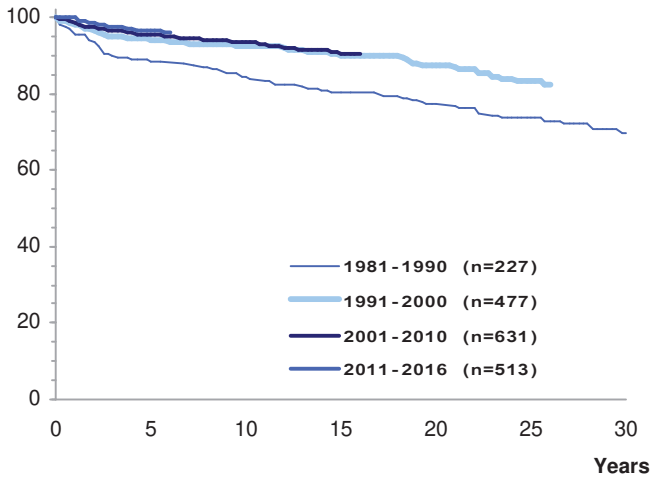
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
46	1.1 %	0.3	5

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
III (e) Other specified intracranial and intraspinal neoplasms

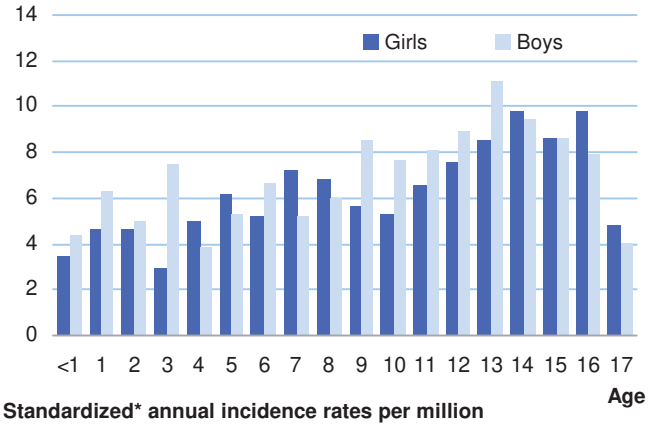
SN after III (e)			III (e) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
21	1.4 %	3.3 %	166	10.8 %	1.2 %

* Standard: Segi world standard population

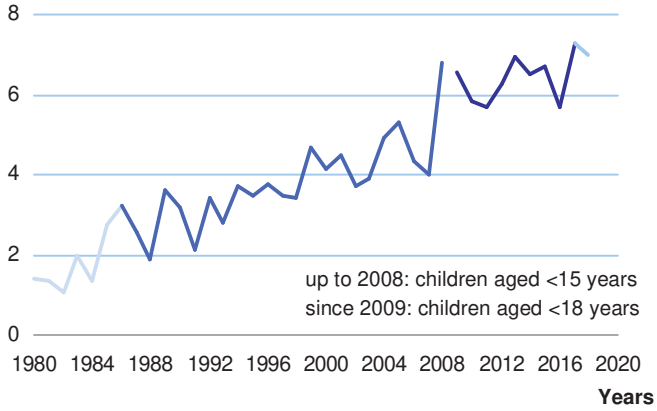
Survival probabilities by year of diagnosis Germany 1981-2016



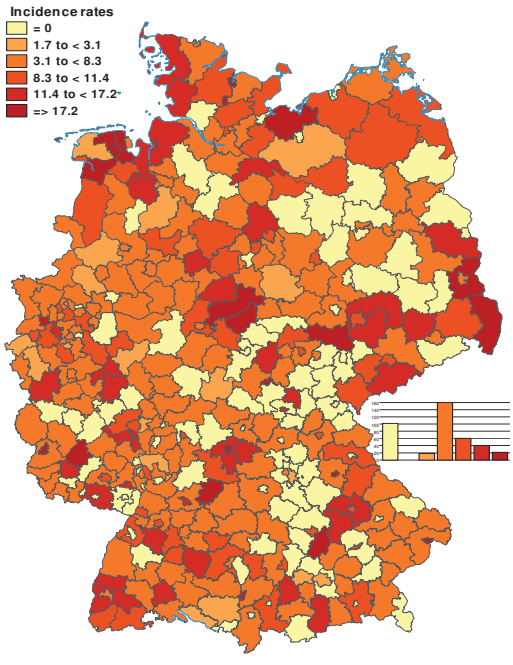
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Germany 2009-2018	N	%
Other specified intracranial and intraspinal neoplasms	**885**	**100.0**
1 Pituitary adenomas and carcinomas	71	8.0
2 Tumours of the sellar region (craniopharyngiomas)	228	25.8
3 Pineal parenchymal tumours	47	5.3
4 Neuronal and mixed neuronal-glial tumours	470	53.1
5 Meningiomas	69	7.8

1 Pituitary adenomas and carcinomas

Cases in Germany aged under 15/18 years (1980-2018): 142

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	71 / 21831 = 0.3 %
Relative frequency of trial patients:	83.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	43	28	71
Standardized rate *:	0.6	0.3	0.5
Cumulative incidence:	11	7	9

Sex ratio (m/f): 0.7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	0	3	29	39
Incidence rate:	0.0	0.0	0.1	0.8	1.6

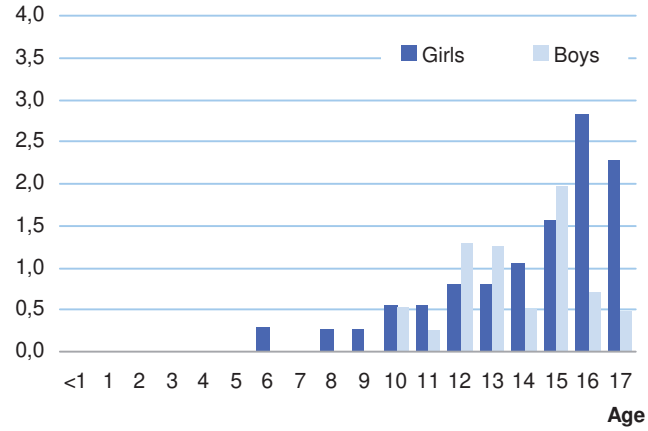
Median age at diagnosis: 15 years 2 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Pituitary adenomas and carcinomas

SN after III (e) 1			**III (e) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	-	7	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Tumours of the sellar region (craniopharyngiomas)

Cases in Germany aged under 15/18 years (1980-2018): 709

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	228 / 21831 = 1.0 %
Relative frequency of trial patients:	99.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	116	112	228
Standardized rate *:	1.8	1.6	1.7
Cumulative incidence:	32	30	31

Sex ratio (m/f): 1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	2	48	76	73	29
Incidence rate:	0.3	1.7	2.1	1.9	1.2

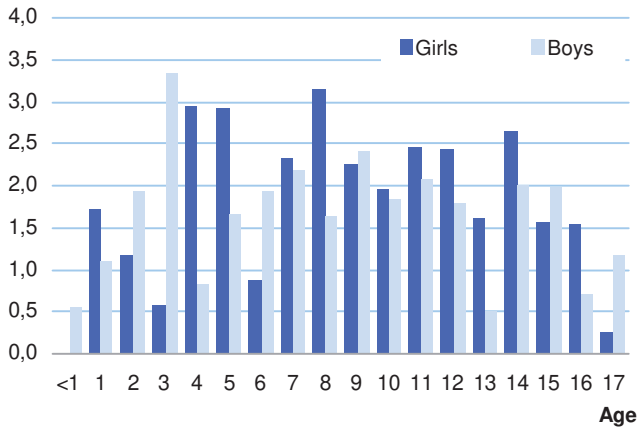
Median age at diagnosis: 9 years 7 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Tumours of the sellar region (craniopharyngiomas)

SN after III (e) 2			**III (e) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	2.3 %	0	0.0 %	-

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



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

Germany 2009-2018	N	%
Other specified intracranial and intraspinal neoplasms	**885**	**100.0**
1 Pituitary adenomas and carcinomas	71	8.0
2 Tumours of the sellar region (craniopharyngiomas)	228	25.8
3 Pineal parenchymal tumours	47	5.3
4 Neuronal and mixed neuronal-glial tumours	470	53.1
5 Meningiomas	69	7.8

3 Pineal parenchymal tumours

Cases in Germany aged under 15/18 years (1980-2018): 147

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	47 / 21831 = 0.2 %
Relative frequency of trial patients:	100.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	27	20	47
Standardized rate *:	0.4	0.3	0.4
Cumulative incidence:	7	5	6

Sex ratio (m/f): 0.7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	4	11	8	15	9
Incidence rate:	0.6	0.4	0.2	0.4	0.4

Median age at diagnosis: 10 years 5 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
3 Pineal parenchymal tumours

SN after III (e) 3			**III (e) 3 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	2	0.1 %	0.0 %

* Standard: Segi world standard population

4 Neuronal and mixed neuronal-glial tumours

Cases in Germany aged under 15/18 years (1980-2018): 875

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	470 / 21831 = 2.2 %
Relative frequency of trial patients:	93.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	194	276	470
Standardized rate *:	2.9	3.9	3.5
Cumulative incidence:	54	72	63

Sex ratio (m/f): 1.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	21	77	122	174	76
Incidence rate:	2.9	2.7	3.4	4.6	3.1

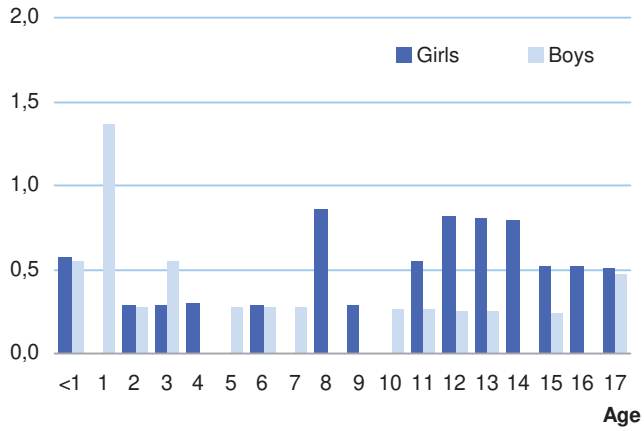
Median age at diagnosis: 10 years 7 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
4 Neuronal and mixed neuronal-glial tumours

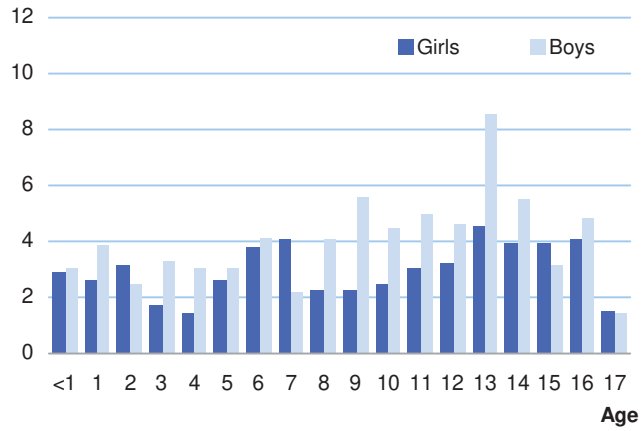
SN after III (e) 4			**III (e) 4 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	-	4	0.3 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Age- and sex-specific incidence rates per million
Germany 2009-2018



Germany 2009-2018	N	%
Other specified intracranial and intraspinal neoplasms	**885**	**100.0**
1 Pituitary adenomas and carcinomas	71	8.0
2 Tumours of the sellar region (craniopharyngiomas)	228	25.8
3 Pineal parenchymal tumours	47	5.3
4 Neuronal and mixed neuronal-glial tumours	470	53.1
5 Meningiomas	69	7.8

5 Meningiomas

Cases in Germany aged under 15/18 years (1980-2018): 188

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	69 / 21831 = 0.3 %
Relative frequency of trial patients:	72.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	29	40	69
Standardized rate *:	0.4	0.5	0.5
Cumulative incidence:	8	10	9

Sex ratio (m/f): 1.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	5	15	26	22
Incidence rate:	0.1	0.2	0.4	0.7	0.9

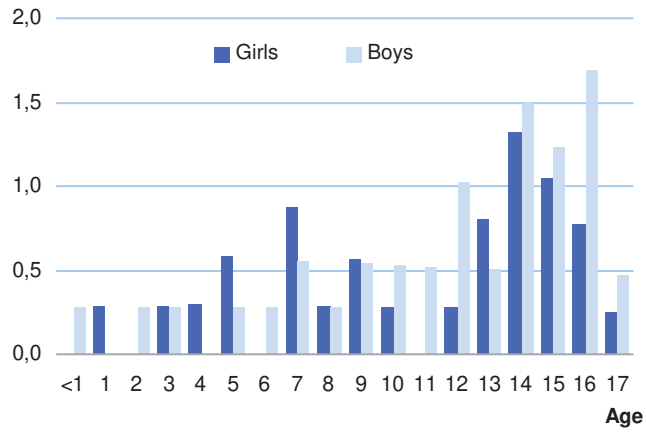
Median age at diagnosis: 13 years 6 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
5 Meningiomas

SN after III (e) 5			**III (e) 5 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
8	0.5 %	-	153	9.9 %	1.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



56 IV (a) Neuroblastoma and ganglioneuroblastoma

Cases in Germany aged under 15/18 years (1980-2018): 4638

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	1192 / 21831 = 5.5 %
Relative frequency of trial patients:	97.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	505	687	1192
Standardized rate *:	9.6	12.4	11.1
Cumulative incidence:	146	188	168
Sex ratio (m/f):			1.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	545	524	86	30	7
Incidence rate:	76.4	18.6	2.4	0.8	0.3

Median age at diagnosis: 1 year 2 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	80 %	78 %	77 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

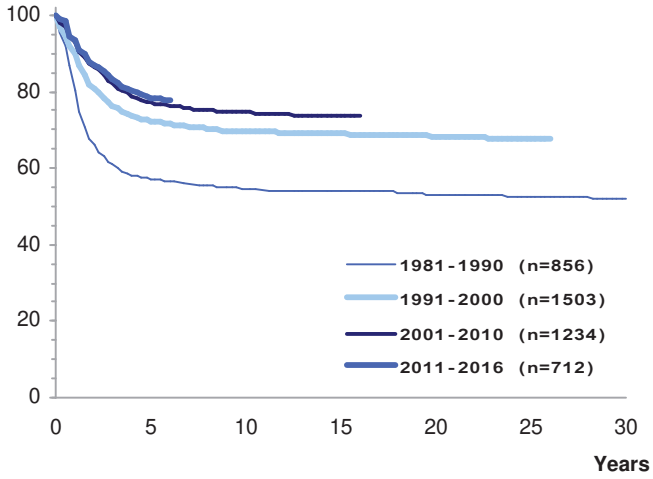
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
391	9.6 %	3.0	48

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
IV (a) Neuroblastoma and ganglioneuroblastoma

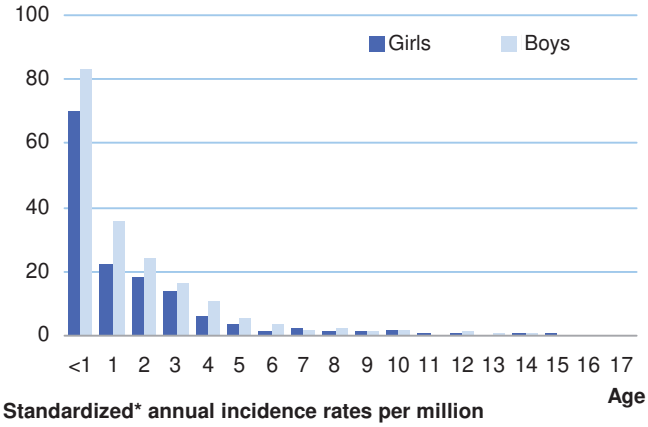
SN after IV (a)			IV (a) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
72	4.7 %	3.2 %	14	0.9 %	0.0 %

* Standard: Segi world standard population

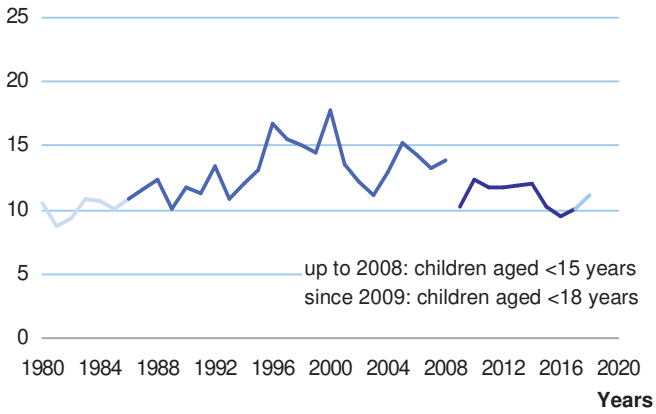
Survival probabilities by year of diagnosis Germany 1981-2016



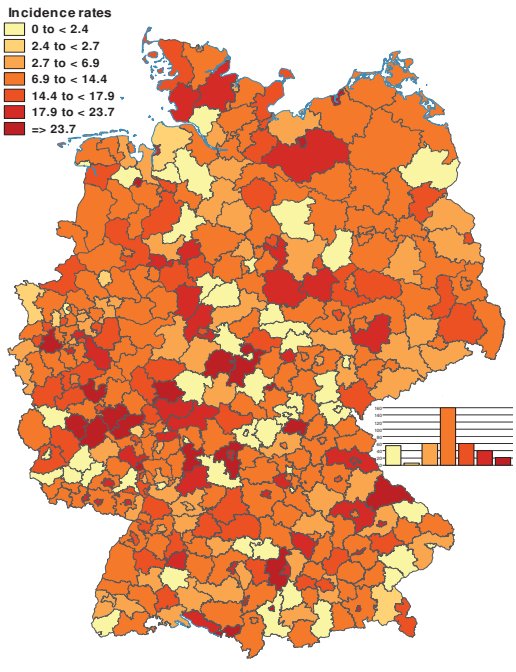
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 1534

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	441 / 21831 = 2 %
Relative frequency of trial patients:	59.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	212	229	441
Standardized rate *:	4.1	4.2	4.2
Cumulative incidence:	61	63	62
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	201	226	12	2	0
Incidence rate:	28.2	8.0	0.3	0.1	0.0

Median age at diagnosis: 1 year 1 month

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	99 %	98 %	98 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

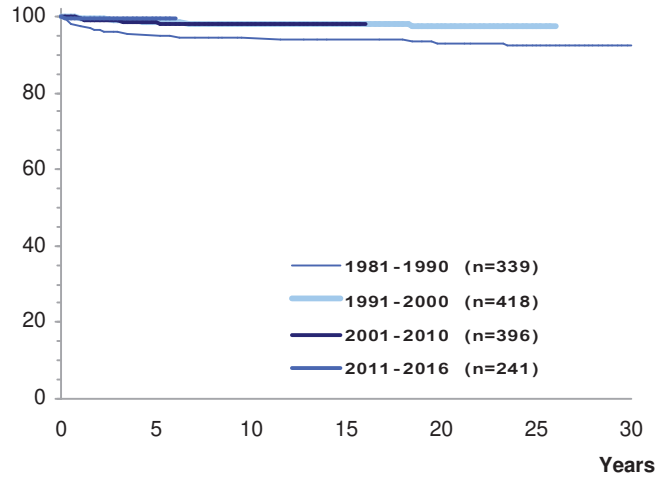
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
10	0.2 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
V Retinoblastoma

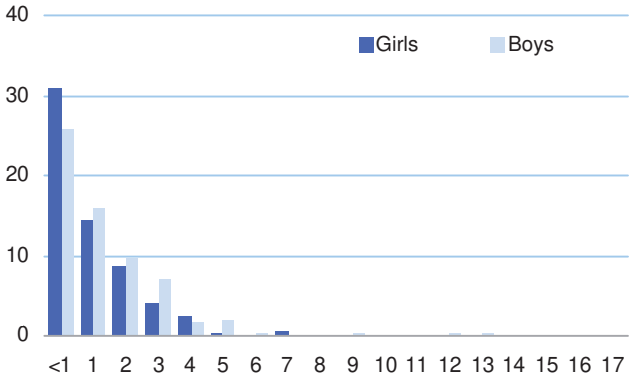
SN after V			V as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
41	2.7 %	7.5 %	3	0.2 %	0.0 %

* Standard: Segi world standard population

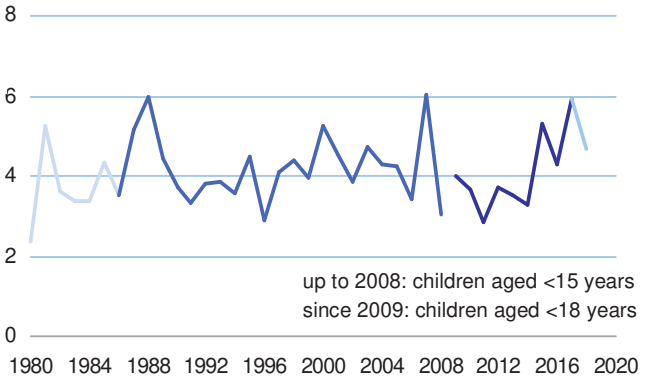
Survival probabilities by year of diagnosis Germany 1981-2016



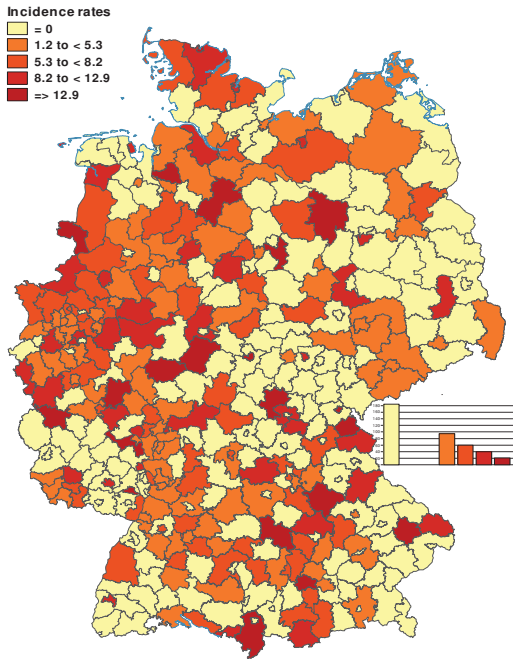
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



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

Cases in Germany aged under 15/18 years (1980-2018): 3577

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	953 / 21831 = 4.4 %
Relative frequency of trial patients:	99.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	513	440	953
Standardized rate *:	9.3	7.6	8.4
Cumulative incidence:	148	121	134
Sex ratio (m/f):			0.9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	151	558	193	39	12
Incidence rate:	21.2	19.8	5.4	1.0	0.5

Median age at diagnosis: 3 years 0 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	93 %	92 %	92 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
108	2.7 %	0.8	13

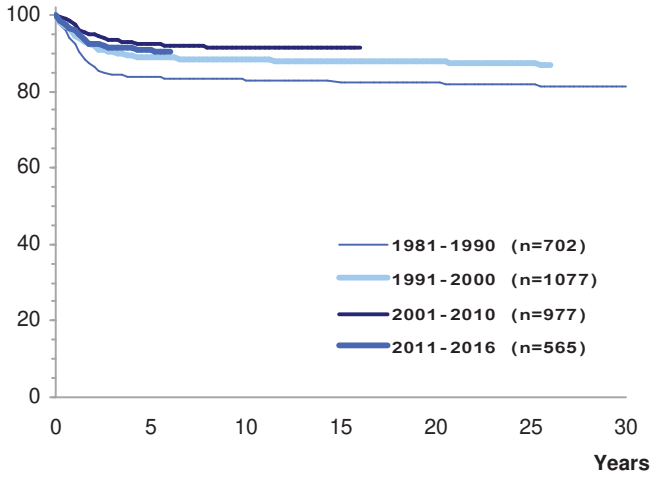
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

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

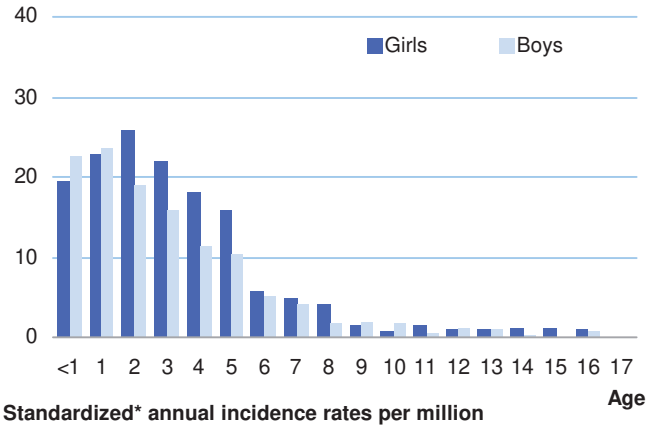
SN after VI (a)			**VI (a) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
55	3.6 %	4.1 %	10	0.6 %	0.0 %

* Standard: Segi world standard population

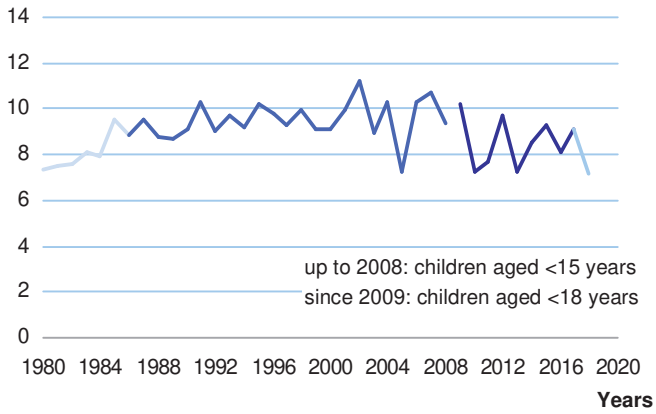
Survival probabilities by year of diagnosis Germany 1981-2016



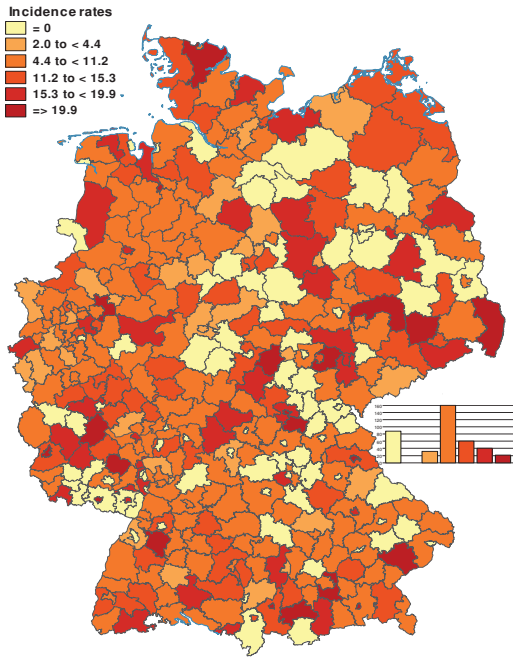
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Germany 2009-2018	N	%
Nephroblastoma and other non-epithelial renal tumours	**953**	**100.0**
1 Nephroblastoma	925	97.1
2 Rhabdoid renal tumour	21	2.2
3 Kidney sarcomas	7	0.7
4 Peripheral neuroectodermal tumour (pPNET) of kidney	0	0.0

1 Nephroblastoma

Cases in Germany aged under 15/18 years (1980-2018): 3457

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	925 / 21831 = 4.2 %
Relative frequency of trial patients:	99.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	497	428	925
Standardized rate *:	9.0	7.4	8.2
Cumulative incidence:	144	117	130

Sex ratio (m/f): 0.9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	139	550	189	37	10
Incidence rate:	19.5	19.5	5.3	1.0	0.4

Median age at diagnosis: 3 years 0 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

1 Nephroblastoma

SN after VI (a) 1			**VI (a) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
51	3.3 %	4.0 %	8	0.5 %	0.0 %

* Standard: Segi world standard population

2 Rhabdoid renal tumour

Cases in Germany aged under 15/18 years (1980-2018): 62

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	21 / 21831 = 0.1 %
Relative frequency of trial patients:	100.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	11	10	21
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	3	3	3

Sex ratio (m/f): 0.9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	10	7	2	1	1
Incidence rate:	1.4	0.2	0.1	0.0	0.0

Median age at diagnosis: 1 year 1 month

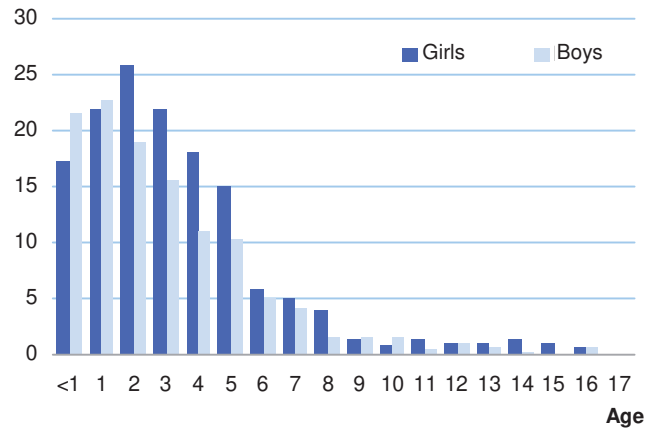
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

2 Rhabdoid renal tumour

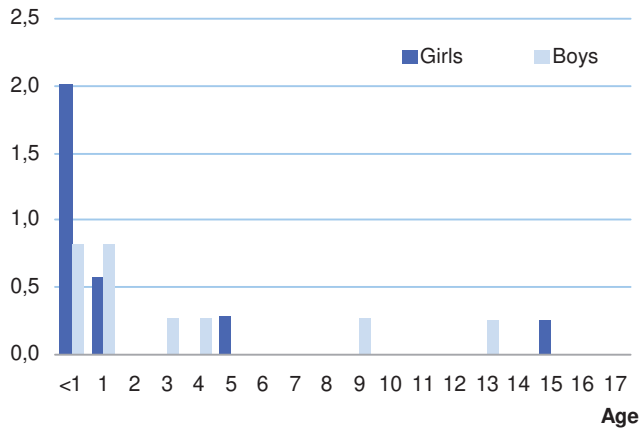
SN after VI (a) 2			**VI (a) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
3	0.2 %	-	2	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Age- and sex-specific incidence rates per million
Germany 2009-2018



60 VI (b) Renal carcinomas

Cases in Germany aged under 15/18 years (1980-2018): 85

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	34 / 21831 = 0.2 %
Relative frequency of trial patients:	85.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	15	19	34
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	4	5	4
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	1	4	15	13
Incidence rate:	0.1	0.0	0.1	0.4	0.5

Median age at diagnosis: 13 years 9 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	92 %	92 %	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

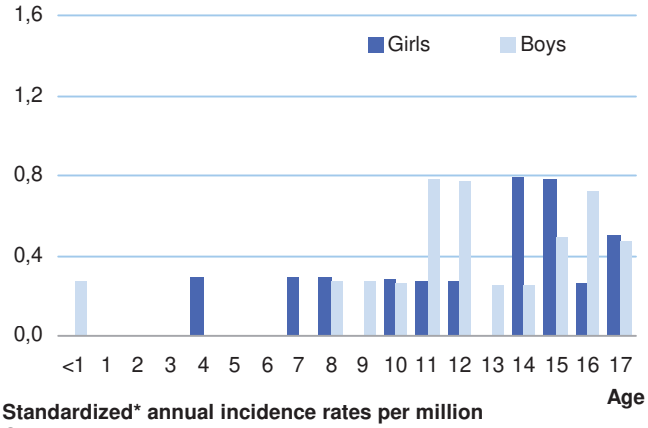
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
2	0.0 %	0.0	0

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
VI (b) Renal carcinomas

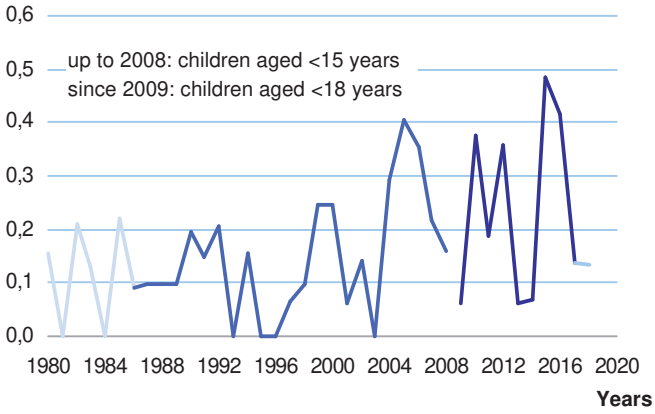
SN after VI (b)			**VI (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	16	1.0 %	0.1 %

* Standard: Segi world standard population

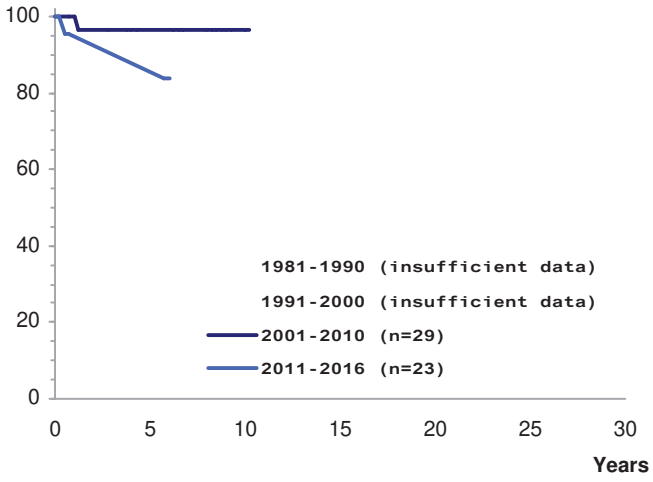
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

Cases in Germany aged under 15/18 years (1980-2018): 612

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	250 / 21831 = 1.1 %
Relative frequency of trial patients:	79.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	105	145	250
Standardized rate *:	2.0	2.6	2.3
Cumulative incidence:	30	40	35
Sex ratio (m/f):			1.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	77	147	15	8	3
Incidence rate:	10.8	5.2	0.4	0.2	0.1

Median age at diagnosis: 1 year 6 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	86 %	84 %	84 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

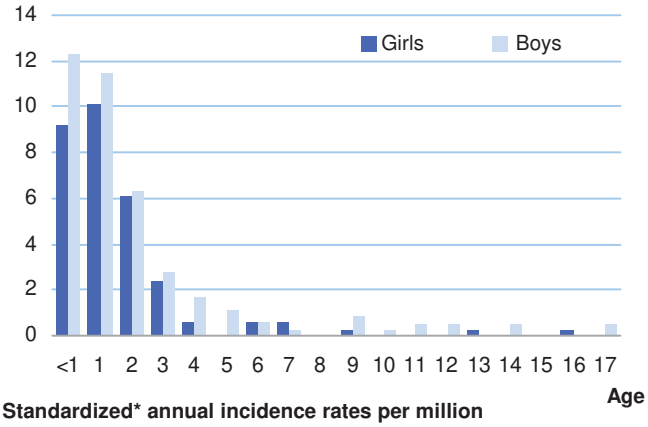
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
42	1.0 %	0.3	5

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
VII (a) Hepatoblastoma

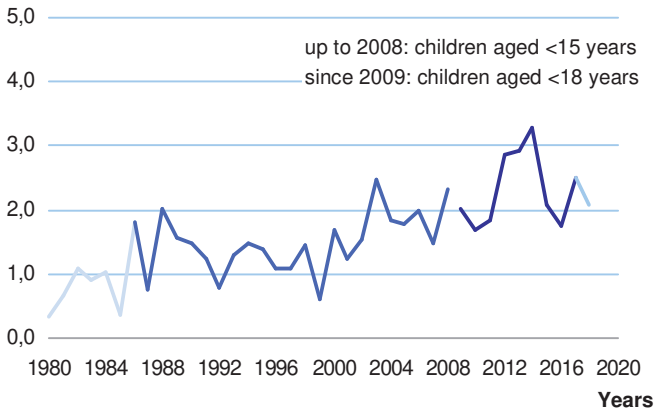
SN after VII (a)			**VII (a) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
3	0.2 %	-	2	0.1 %	0.0 %

* Standard: Segi world standard population

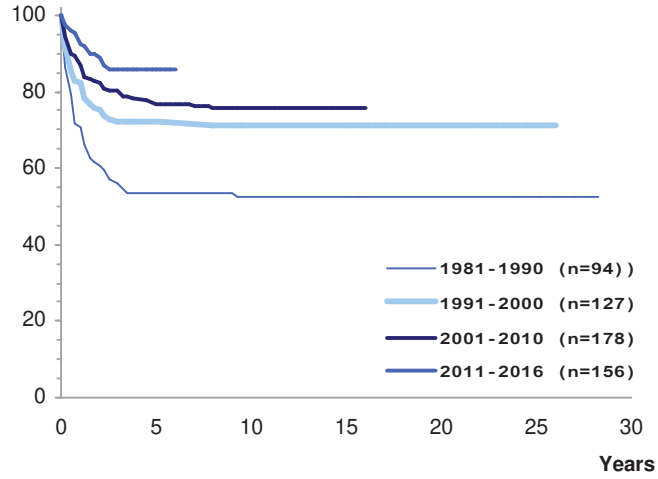
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

62 VII (b) Hepatic carcinomas

Cases in Germany aged under 15/18 years (1980-2018): 139

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	39 / 21831 = 0.2 %
Relative frequency of trial patients:	71.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	24	15	39
Standardized rate *:	0.3	0.2	0.3
Cumulative incidence:	6	4	5
Sex ratio (m/f):			0.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	0	6	16	17
Incidence rate:	0.0	0.0	0.2	0.4	0.7

Median age at diagnosis: 14 years 3 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	47 %	-	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

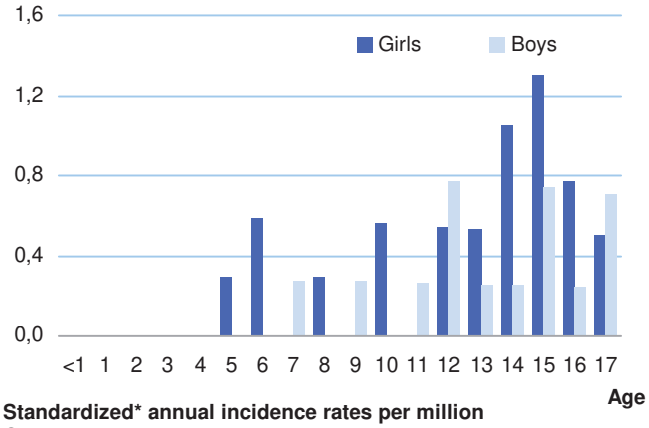
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
23	0.6 %	0.1	3

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
VII (b) Hepatic carcinomas

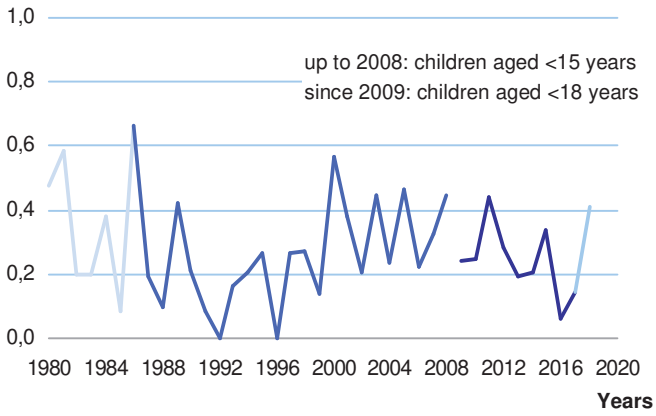
SN after VII (b)			**VII (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	6	0.4 %	0.0 %

* Standard: Segi world standard population

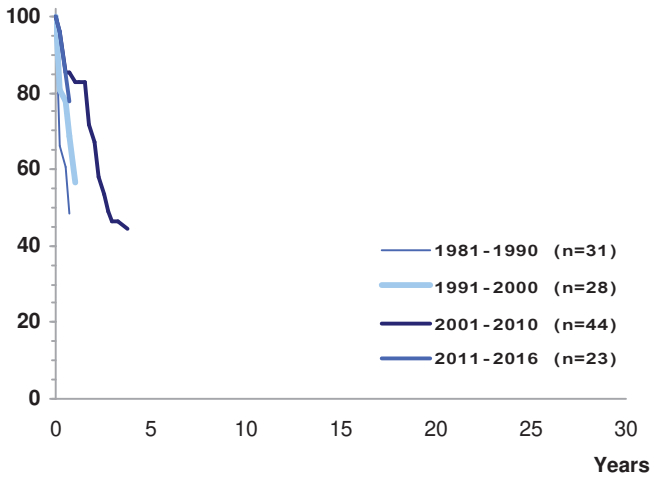
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

(a) Osteosarcomas
(b) Chondrosarcomas
(c) Ewing tumour and related sarcomas of bone
(d) Other specified malignant bone tumours
(e) Unspecified malignant bone tumours

Cases in Germany aged under 15/18 years (1980-2018): 3265

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	1116 / 21831 = 5.1 %
Relative frequency of trial patients:	98.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	486	630	1116
Standardized rate *:	6.8	8.3	7.5
Cumulative incidence:	131	160	146
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	4	54	182	520	356
Incidence rate:	0.6	1.9	5.1	13.7	14.7

Median age at diagnosis: 13 years 7 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

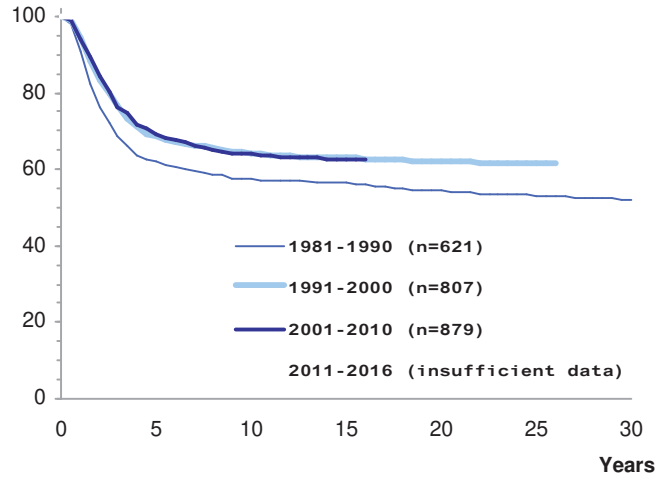
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
273	6.7 %	1.6	30

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
VIII Malignant bone tumours

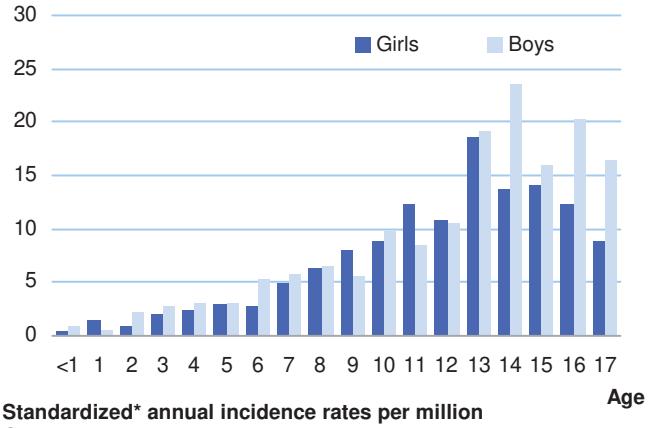
SN after VIII			VIII as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
93	6.0 %	5.2 %	77	5.0 %	0.2 %

* Standard: Segi world standard population

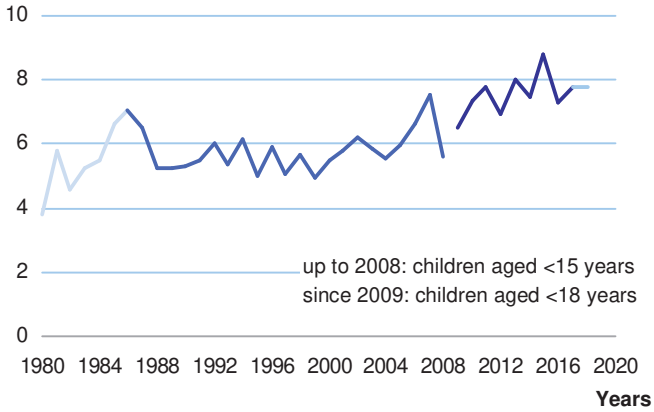
Survival probabilities by year of diagnosis Germany 1981-2016



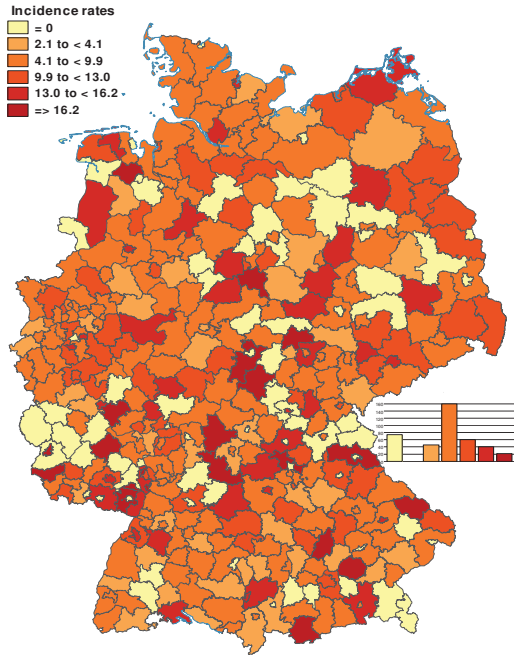
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



64 VIII (a) Osteosarcomas

Cases in Germany aged under 15/18 years (1980-2018): 1704

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	572 / 21831 = 2.6 %
Relative frequency of trial patients:	98.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	247	325	572
Standardized rate *:	3.4	4.2	3.8
Cumulative incidence:	66	82	74
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	9	76	293	194
Incidence rate:	0.0	0.3	2.1	7.7	8.0

Median age at diagnosis: 13 years 11 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	75 %	69 %	69 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

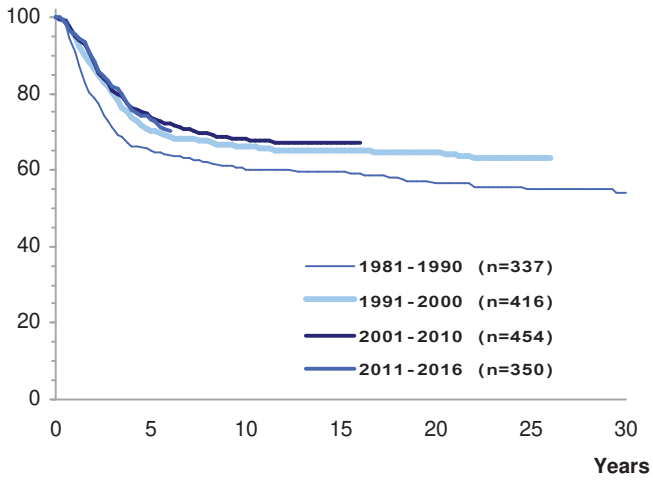
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
124	3.1 %	0.7	14

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
VIII (a) Osteosarcomas

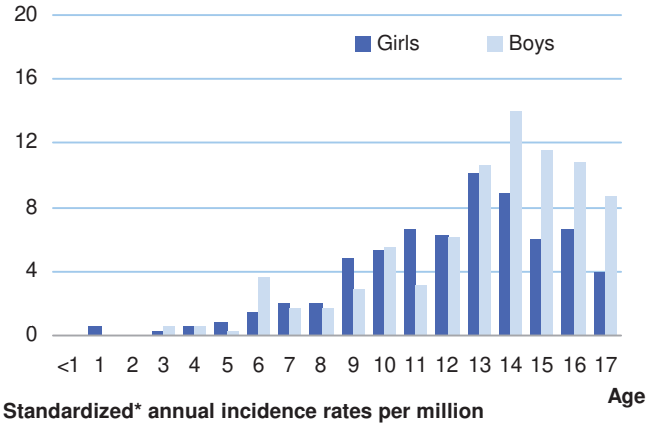
SN after VIII (a)			**VIII (a) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
49	3.2 %	5.8 %	55	3.6 %	0.2 %

* Standard: Segi world standard population

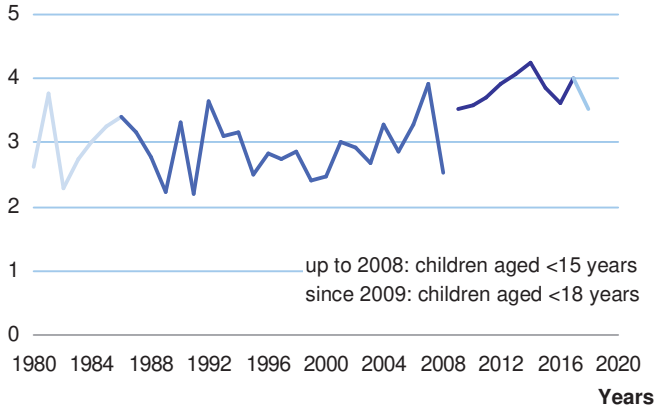
Survival probabilities by year of diagnosis Germany 1981-2016



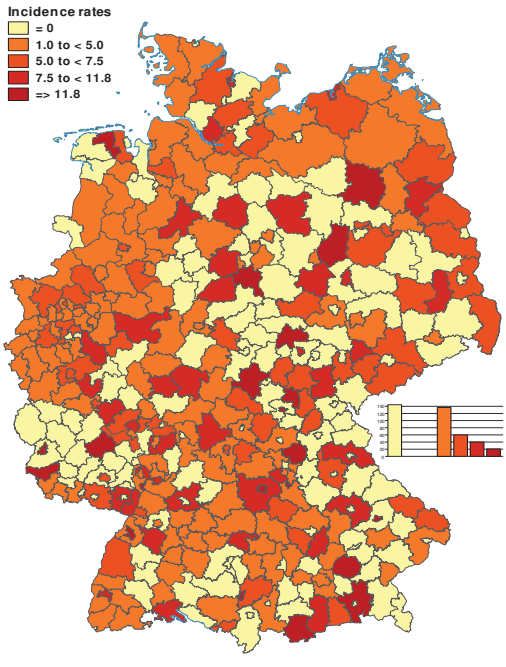
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 1448

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	504 / 21831 = 2.3 %
Relative frequency of trial patients:	98.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	218	286	504
Standardized rate *:	3.1	3.9	3.5
Cumulative incidence:	59	73	66
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	3	43	101	208	149
Incidence rate:	0.4	1.5	2.8	5.5	6.2

Median age at diagnosis: 13 years 1 month

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

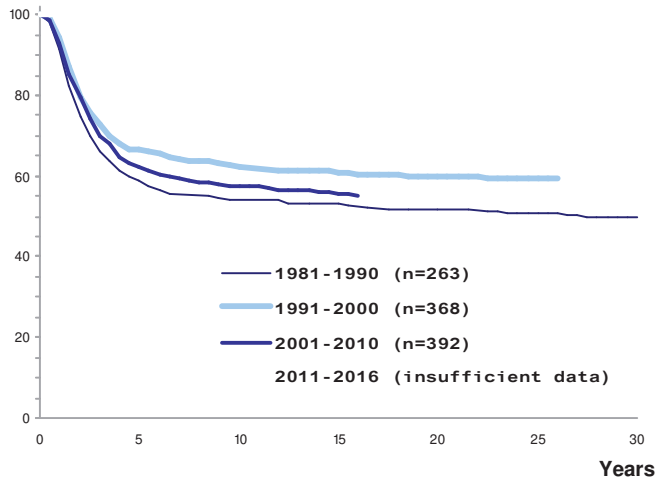
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
140	3.5 %	0.8	16

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
VIII (c) Ewing tumour and related sarcomas of bone

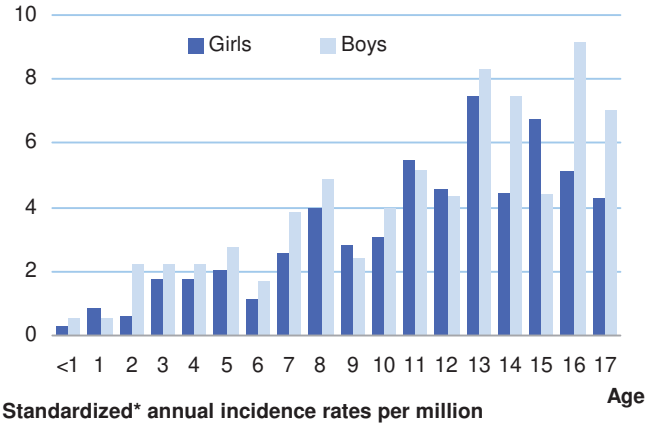
SN after VIII (c)			VIII (c) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
42	2.7 %	4.5 %	18	1.2 %	0.0 %

* Standard: Segi world standard population

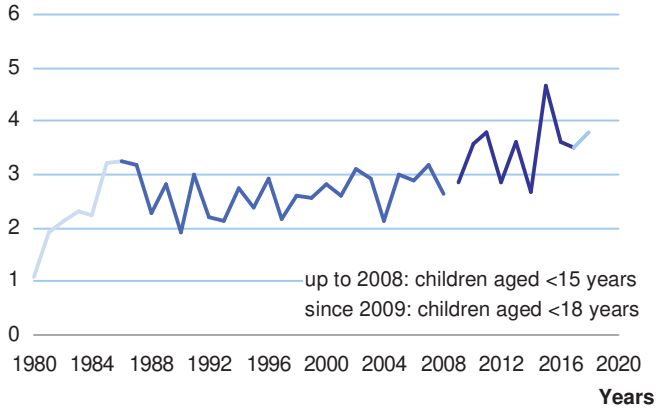
Survival probabilities by year of diagnosis Germany 1981-2016



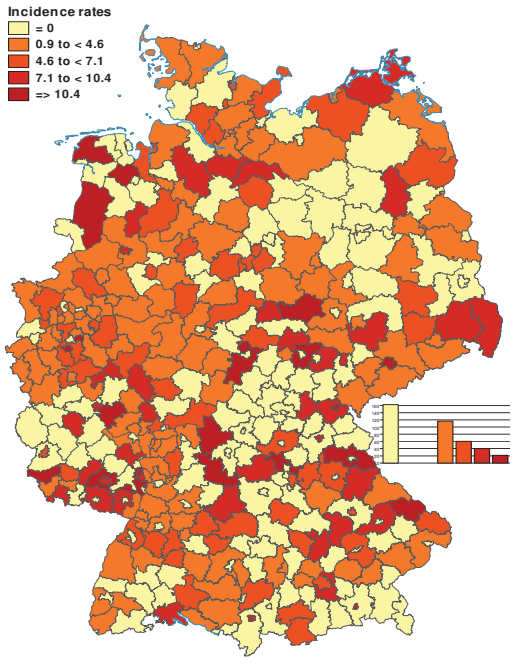
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



VIII (c) Ewing tumour and related sarcomas of bone - Extended ICCC-3

Germany 2009-2018	N	%
Ewing tumour and related sarcomas of bone	**504**	**100.0**
1 Ewing tumour and Askin tumour of bone	488	96.8
2 Peripheral neuroectodermal tumour (pPNET) of bone	16	3.2

1 Ewing tumour and Askin tumour of bone

Cases in Germany aged under 15/18 years (1980-2018): 1275

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	488 / 21831 = 2.2 %
Relative frequency of trial patients:	98.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	209	279	488
Standardized rate *:	3.0	3.7	3.4
Cumulative incidence:	57	71	64

Sex ratio (m/f): 1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	40	97	206	144
Incidence rate:	0.1	1.4	2.7	5.4	6.0

Median age at diagnosis: 13 years 1 month

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Ewing tumour and Askin tumour of bone

SN after VIII (c) 1			**VIII (c) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
35	2.3 %	4.4 %	13	0.8 %	0.0 %

* Standard: Segi world standard population

2 Peripheral neuroectodermal tumour (pPNET) of bone

(1980-2018): 173

Germany 2009-2018

Relative frequency:	16 / 21831 = 0.1 %
Relative frequency of trial patients:	93.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	9	7	16
Standardized rate *:	0.1	0.1	0.1
Cumulative incidence:	2	2	2

Sex ratio (m/f): 0.8

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	2	3	4	2	5
Incidence rate:	0.3	0.1	0.1	0.1	0.2

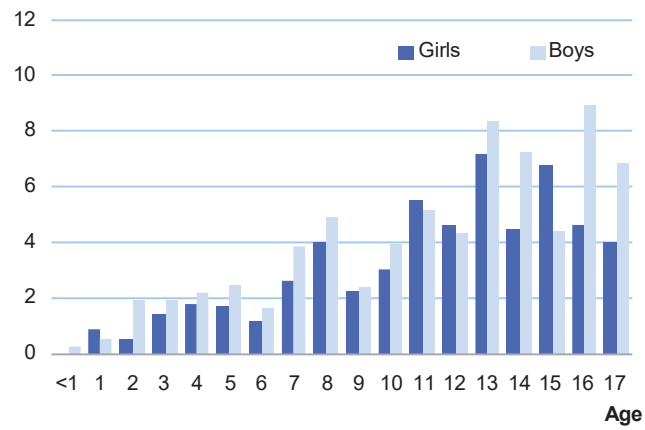
Median age at diagnosis: 9 years 8 months

(1981-2016):
2 Peripheral neuroectodermal tumour (pPNET) of bone

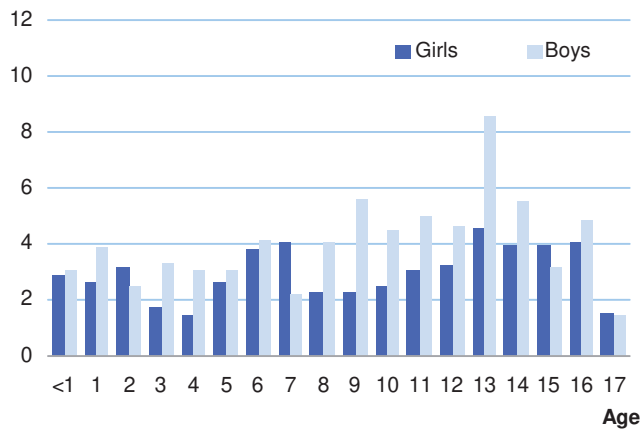
SN after 2			**2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
7	0.5 %	-	5	0.3 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Age- and sex-specific incidence rates per million
Germany 2009-2018



(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 15/18 years (1980-2018): 4045

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	1250 / 21831 = 5.7 %
Relative frequency of trial patients:	98.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	549	701	1250
Standardized rate *:	8.6	10.5	9.6
Cumulative incidence:	153	185	169
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	124	305	270	307	244
Incidence rate:	17.4	10.8	7.6	8.1	10.1

Median age at diagnosis: 8 years 5 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	73 %	70 %	69 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

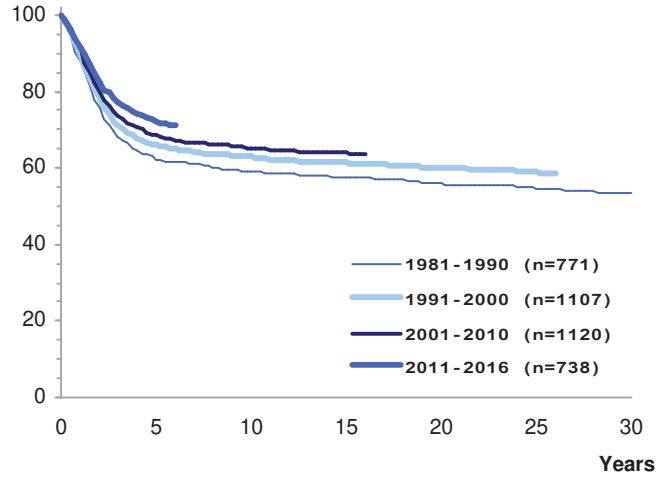
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
380	9.4 %	2.6	45

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
IX Soft tissue and other extraosseous sarcomas

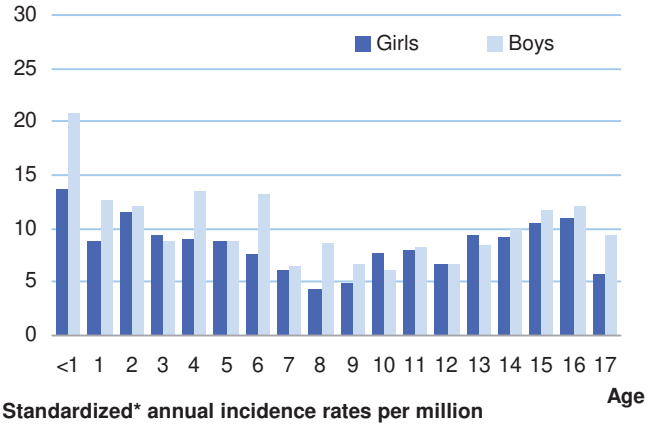
SN after IX			IX as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
114	7.4 %	6.6 %	84	5.5 %	0.3 %

* Standard: Segi world standard population

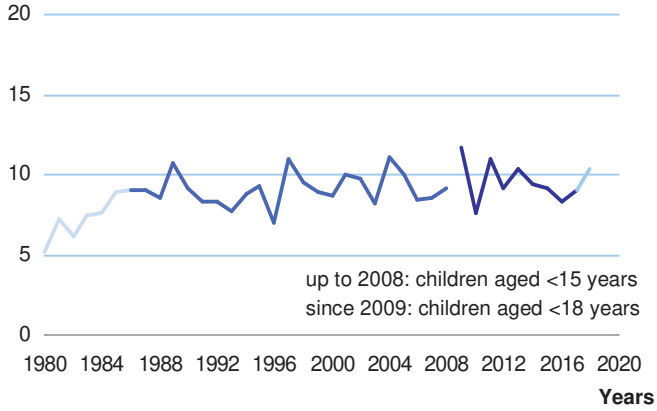
Survival probabilities by year of diagnosis Germany 1981-2016



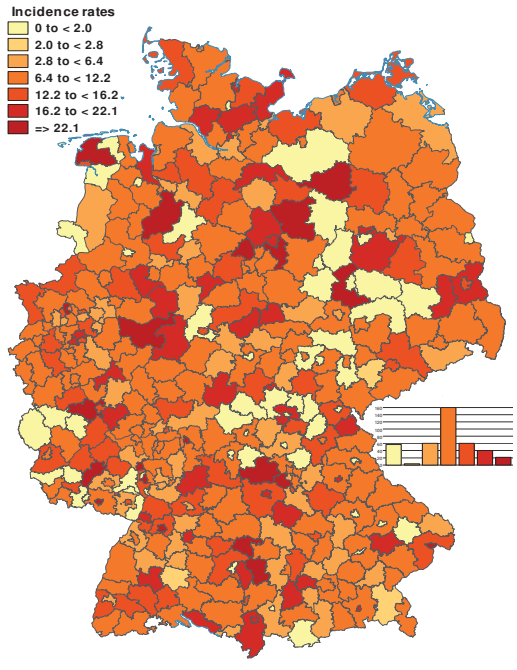
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 2248

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	623 / 21831 = 2.9 %
Relative frequency of trial patients:	99.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	256	367	623
Standardized rate *:	4.1	5.7	4.9
Cumulative incidence:	72	98	85
Sex ratio (m/f):			1.4

Age-specific incidence rates per million:	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	46	208	162	109	98
Incidence rate:	6.5	7.4	4.5	2.9	4.1

Median age at diagnosis: 6 years 3 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	70 %	69 %	68 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

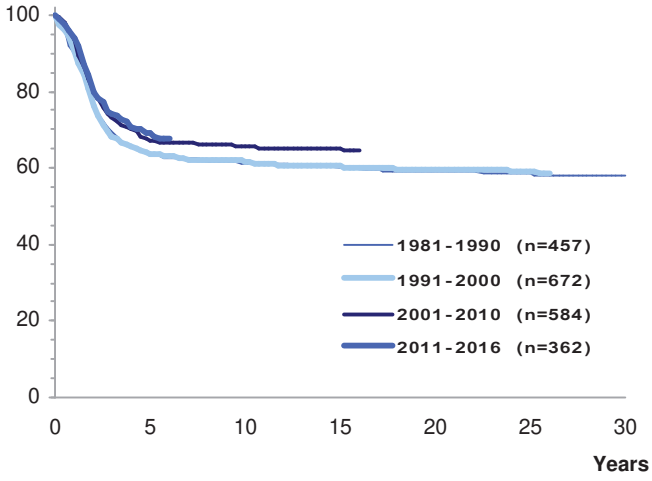
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
218	5.4 %	1.5	26

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
IX (a) Rhabdomyosarcomas

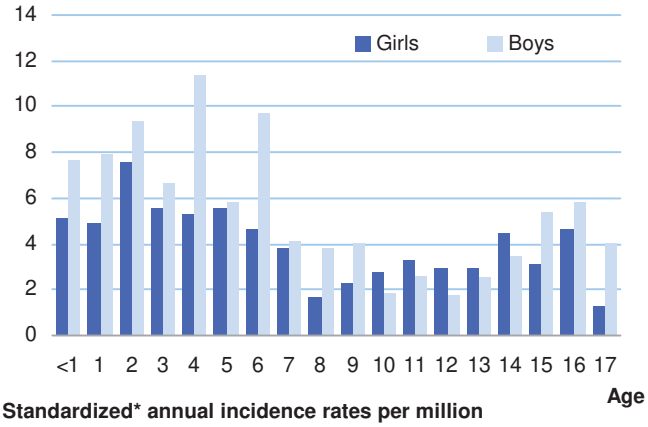
SN after IX (a)			IX (a) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
78	5.1 %	7.5 %	16	1.0 %	0.0 %

* Standard: Segi world standard population

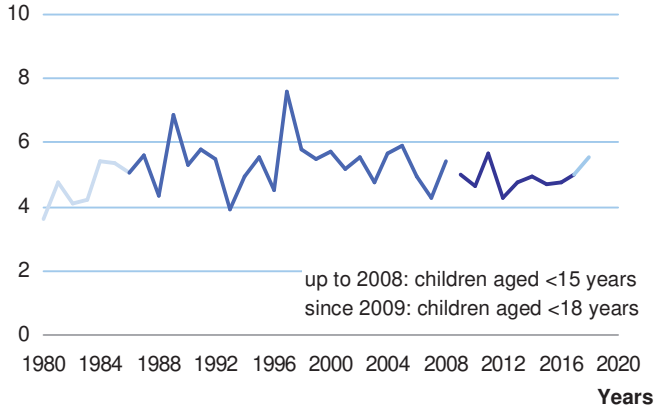
Survival probabilities by year of diagnosis Germany 1981-2016



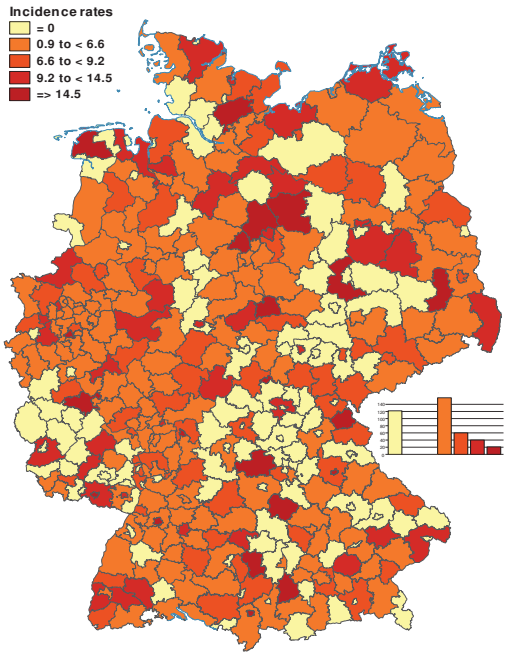
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 380

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	127 / 21831 = 0.6 %
Relative frequency of trial patients:	95.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	56	71	127
Standardized rate *:	0.9	1.1	1.0
Cumulative incidence:	15	19	17
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	27	17	19	38	26
Incidence rate:	3.8	0.6	0.5	1.0	1.1

Median age at diagnosis: 10 years 8 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	78 %	76 %	74 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
36	0.9 %	0.2	4

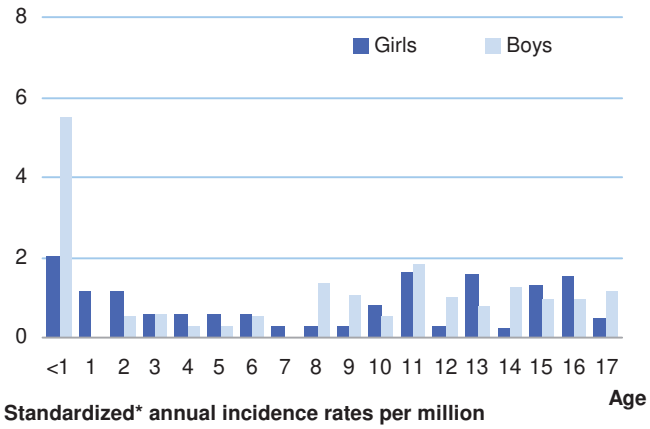
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

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

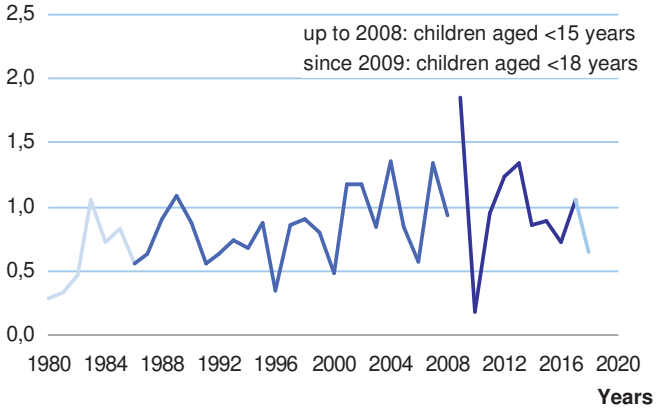
SN after IX (b)			**IX (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
9	0.6 %	-	24	1.6 %	0.1 %

* Standard: Segi world standard population

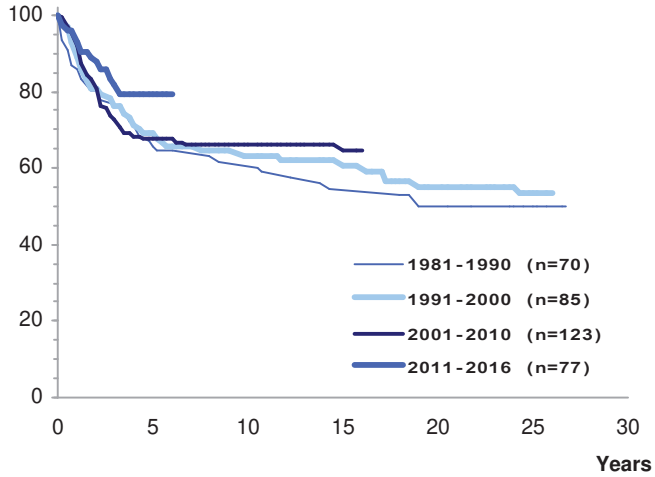
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

Germany 2009-2018	N	%
Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	**127**	**100.0**
1 Fibroblastic and myofibroblastic tumours	61	48.0
2 Nerve sheath tumours	66	52.0
3 Other fibrous neoplasms	0	0.0

1 Fibroblastic and myofibroblastic tumours

Cases in Germany aged under 15/18 years (1980-2018): 181

Selected characteristics under 18 years Germany 2009-2018

Relative frequency: 61 / 21831 = 0.3 %

Relative frequency of trial patients: 95.1 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	27	34	61
Standardized rate *:	0.5	0.6	0.5
Cumulative incidence:	8	9	8

Sex ratio (m/f): 1,3

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14	15-17
Number of cases :	22	10	9	12	8
Incidence rate:	3.1	0.4	0.3	0.3	0.3

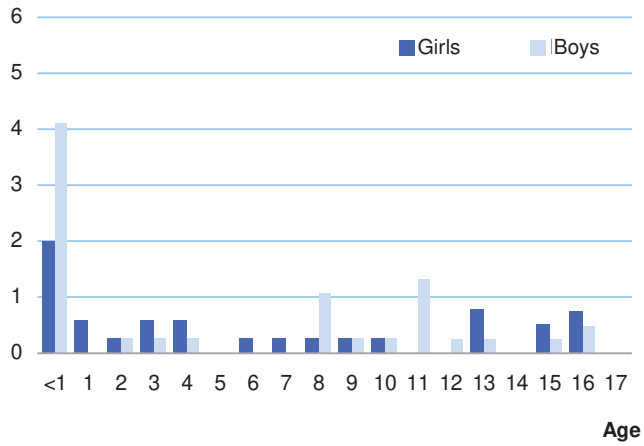
Median age at diagnosis: 4 years 4 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Fibroblastic and myofibroblastic tumours

SN after IX (b) 1			IX (b) 1 as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
5	0.3 %	-	7	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Nerve sheath tumours

Cases in Germany aged under 15/18 years (1980-2018): 199

Selected characteristics under 18 years Germany 2009-2018

Relative frequency: 66 / 21831 = 0.3 %

Relative frequency of trial patients: 95.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	29	37	66
Standardized rate *:	0.4	0.5	0.5
Cumulative incidence:	8	10	9

Sex ratio (m/f): 1.3

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14	15-17
Number of cases :	5	7	10	26	18
Incidence rate:	0.7	0.2	0.3	0.7	0.7

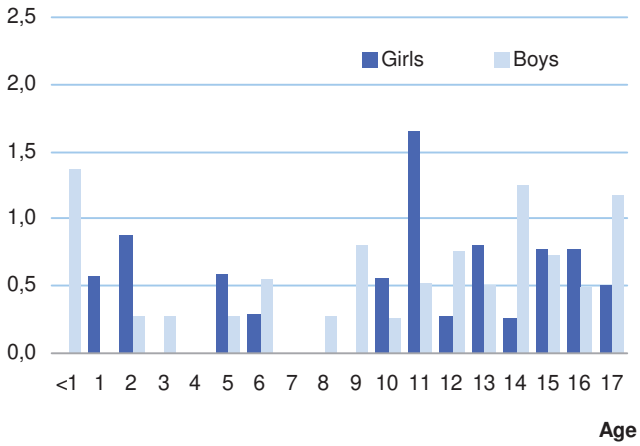
Median age at diagnosis: 12 years 2 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Nerve sheath tumours

SN after IX (b) 2			IX (b) 2 as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	-	17	1.1 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 1148

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	396 / 21831 = 1.8 %
Relative frequency of trial patients:	97.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	193	203	396
Standardized rate *:	2.9	2.9	2.9
Cumulative incidence:	53	53	53
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	38	56	72	131	99
Incidence rate:	5.3	2.0	2.0	3.4	4.1

Median age at diagnosis: 11 years 6 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	77 %	71 %	68 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

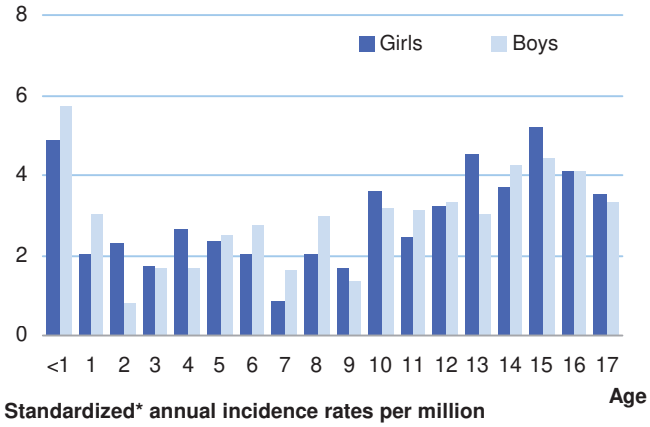
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
98	2.4 %	0.6	11

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
IX (d) Other specified soft tissue sarcomas

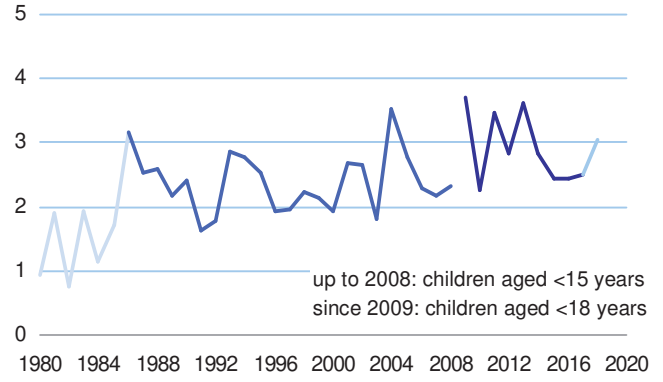
SN after IX (d)			**IX (d) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
23	1.5 %	5.9 %	33	2.1 %	0.1 %

* Standard: Segi world standard population

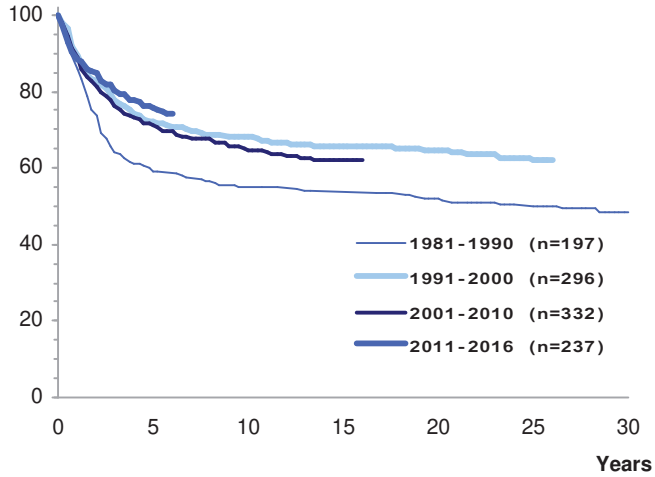
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

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

Germany 2009-2018	N	%		N	%
Other specified soft tissue sarcomas	**396**	**100.0**			
1 Ewing tumour and askin tumour of soft tissue	77	19.4	7 Synovial sarcomas	95	24.0
2 Peripheral neuroectodermal tumour (pPNET) of soft tissue	14	3.5	8 Blood vessel tumours	12	3.0
3 Extrarenal rhabdoid tumour	67	16.9	9 Osseous and chondromatous neoplasms of soft tissue	9	2.3
4 Liposarcomas	15	3.8	10 Alveolar soft parts sarcoma	18	4.5
5 Fibrohistiocytic tumours	46	11.6	11 Miscellaneous soft tissue sarcomas	40	10.1
6 Leiomyosarcomas	3	0.8			

1 Ewing tumour and askin tumour of soft tissue

Cases in Germany aged under 15/18 years (1980-2018): 225

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	77 / 21831 = 0.4 %
Relative frequency of trial patients:	98.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	41	36	77
Standardized rate *:	0.6	0.5	0.5
Cumulative incidence:	11	9	10

Sex ratio (m/f): 0,9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	11	16	27	23
Incidence rate:	0.0	0.4	0.4	0.7	1.0

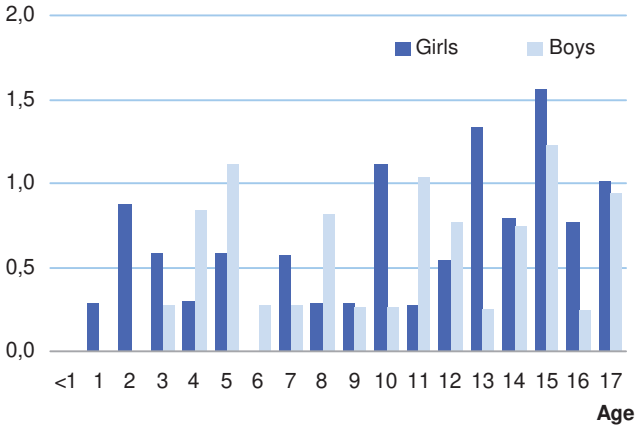
Median age at diagnosis: 12 years 8 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Ewing tumour and askin tumour of soft tissue

SN after IX (d) 1			**IX (d) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
8	0.5 %	-	6	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



3 Extrarenal rhabdoid tumour

Cases in Germany aged under 15/18 years (1980-2018): 112

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	67 / 21831 = 0.3 %
Relative frequency of trial patients:	95.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	34	33	67
Standardized rate *:	0.6	0.6	0.6
Cumulative incidence:	10	9	9

Sex ratio (m/f): 1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	31	20	8	5	3
Incidence rate:	4.3	0.7	0.2	0.1	0.1

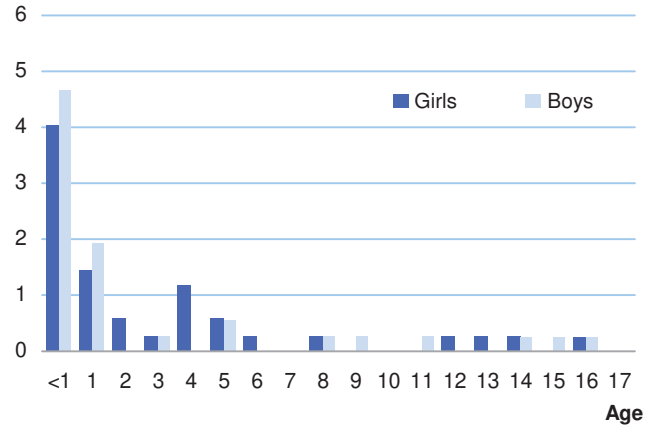
Median age at diagnosis: 1 year 0 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
3 Extrarenal rhabdoid tumour

SN after IX (d) 3			**IX (d) 3 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Germany 2009-2018	N	%		N	%
Other specified soft tissue sarcomas	**396**	**100.0**			
1 Ewing tumour and askin tumour of soft tissue	77	19.4	7 Synovial sarcomas	95	24.0
2 Peripheral neuroectodermal tumour (pPNET) of soft tissue	14	3.5	8 Blood vessel tumours	12	3.0
3 Extrarenal rhabdoid tumour	67	16.9	9 Osseous and chondromatous neoplasms of soft tissue	9	2.3
4 Liposarcomas	15	3.8	10 Alveolar soft parts sarcoma	18	4.5
5 Fibrohistiocytic tumours	46	11.6	11 Miscellaneous soft tissue sarcomas	40	10.1
6 Leiomyosarcomas	3	0.8			

5 Fibrohistiocytic tumours

Cases in Germany aged under 15/18 years (1980-2018): 104

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	46 / 21831 = 0.2 %
Relative frequency of trial patients:	97.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	24	22	46
Standardized rate *:	0.4	0.3	0.4
Cumulative incidence:	7	6	6
Sex ratio (m/f):			0,9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	3	12	9	16	6
Incidence rate:	0.4	0.4	0.3	0.4	0.2

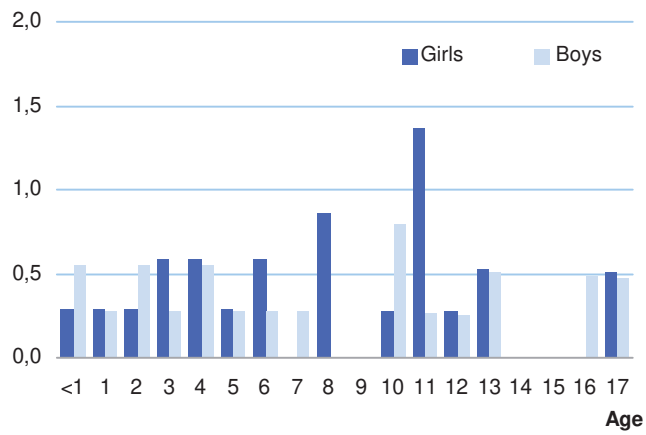
Median age at diagnosis: 8 years 8 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
5 Fibrohistiocytic tumours

SN after IX (d) 5			IX (d) 5 as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
2	0.1 %	-	7	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



7 Synovial sarcomas

Cases in Germany aged under 15/18 years (1980-2018): 275

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	95 / 21831 = 0.4 %
Relative frequency of trial patients:	98.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	47	48	95
Standardized rate *:	0.6	0.6	0.6
Cumulative incidence:	13	12	12
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	2	17	47	28
Incidence rate:	0.1	0.1	0.5	1.2	1.2

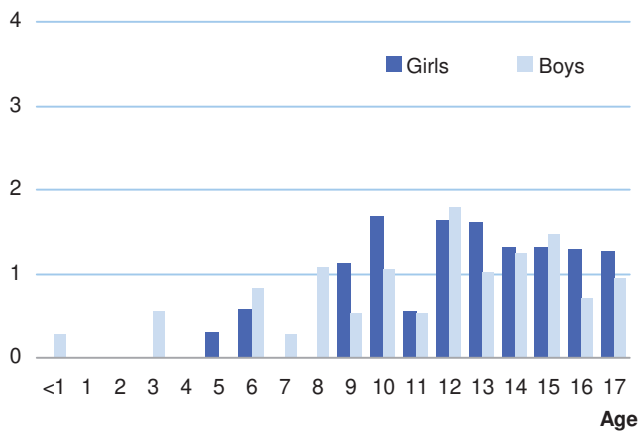
Median age at diagnosis: 13 years 3 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
7 Synovial sarcomas

SN after IX (d) 7			IX (d) 7 as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	-	6	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



74 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 15/18 years (1980-2018): 2260

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	843 / 21831 = 3.9 %
Relative frequency of trial patients:	94.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	426	417	843
Standardized rate *:	6.7	6.0	6.3
Cumulative incidence:	118	107	112
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	168	90	88	264	233
Incidence rate:	23.6	3.2	2.5	6.9	9.6

Median age at diagnosis: 11 years 7 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	94 %	93 %	93 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

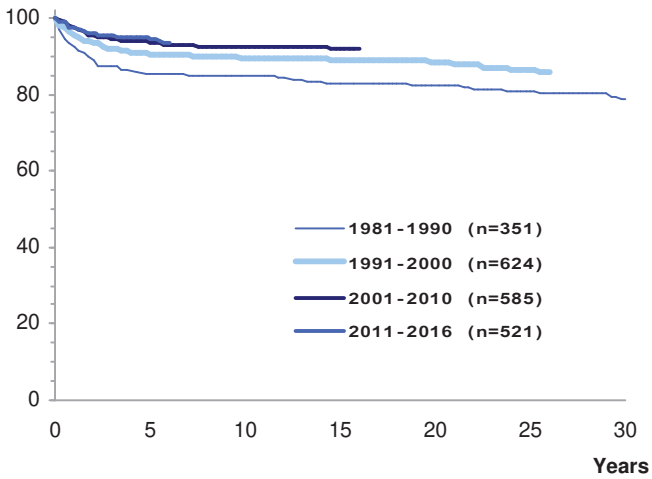
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
39	1.0 %	0.2	4

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

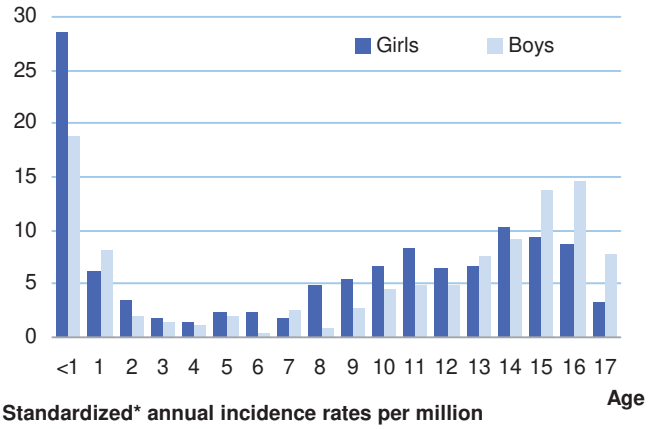
SN after X			X as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
43	2.8 %	6.2 %	18	1.2 %	0.1 %

* Standard: Segi world standard population

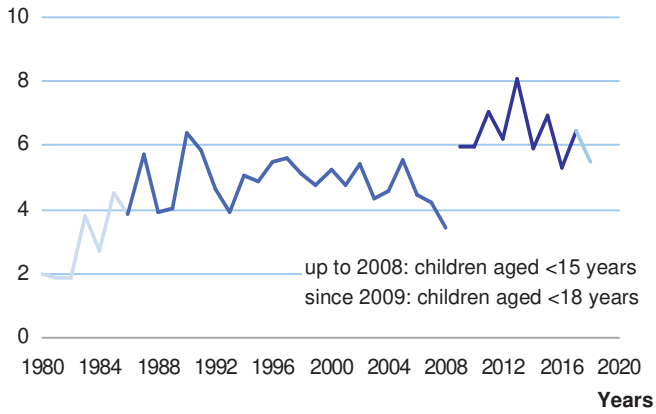
Survival probabilities by year of diagnosis Germany 1981-2016



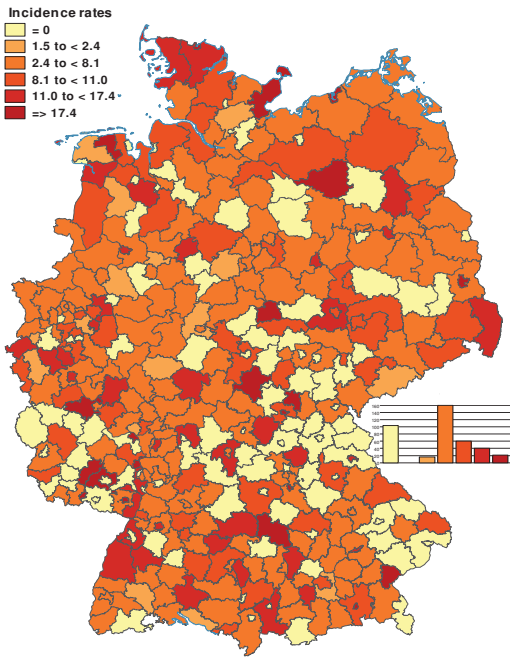
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Standardized* incidence rates per million by districts (Landkreise) Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 616

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	237 / 21831 = 1.1 %
Relative frequency of trial patients:	92.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	66	171	237
Standardized rate *:	1.0	2.3	1.6
Cumulative incidence:	18	44	31
Sex ratio (m/f):			2.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	11	8	44	122	52
Incidence rate:	1.5	0.3	1.2	3.2	2.2

Median age at diagnosis: 12 years 7 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	90 %	87 %	86 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

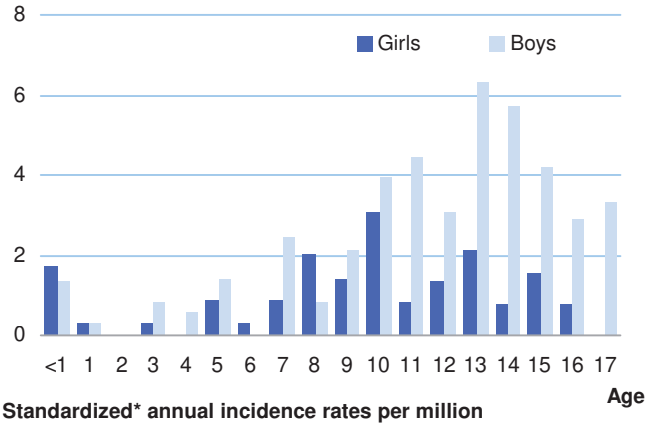
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
20	0.5 %	0.1	2

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
X (a) Intracranial and intraspinal germ cell tumours

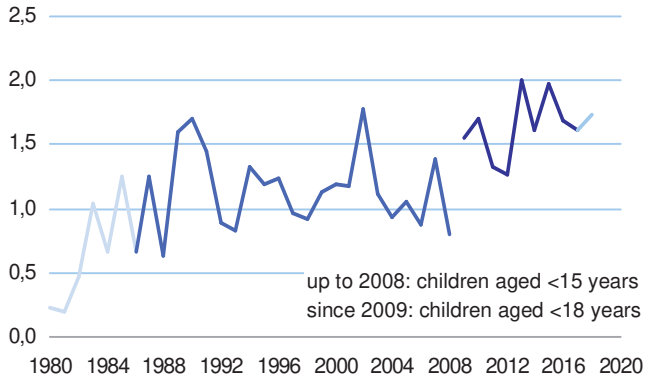
SN after X (a)			**X (a) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
17	1.1 %	-	3	0.2 %	0.0 %

* Standard: Segi world standard population

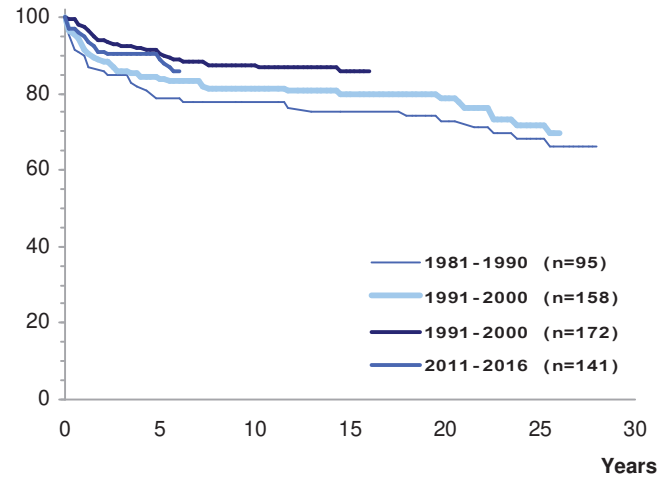
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

76 X (a) Intracranial and intraspinal germ cell tumours - Extended ICCC-3

Germany 2009-2018	N	%
Intracranial and intraspinal germ cell tumours	**237**	**100.0**
1 Intracranial and intraspinal germinomas	143	60.3
2 Intracranial and intraspinal teratomas	28	11.8
3 Intracranial and intraspinal embryonal carcinomas	0	0.0
4 Intracranial and intraspinal yolk sac tumour	7	3.0
5 Intracranial and intraspinal choriocarcinoma	4	1.7
6 Intracranial and intraspinal tumours of mixed forms	55	23.2

1 Intracranial and intraspinal germinomas

Cases in Germany aged under 15/18 years (1980-2018): 338

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	143 / 21831 = 0.7 %
Relative frequency of trial patients:	95.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	35	108	143
Standardized rate *:	0.5	1.4	0.9
Cumulative incidence:	10	27	19

Sex ratio (m/f): 3,1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	17	82	43
Incidence rate:	0.0	0.0	0.5	2.2	1.8

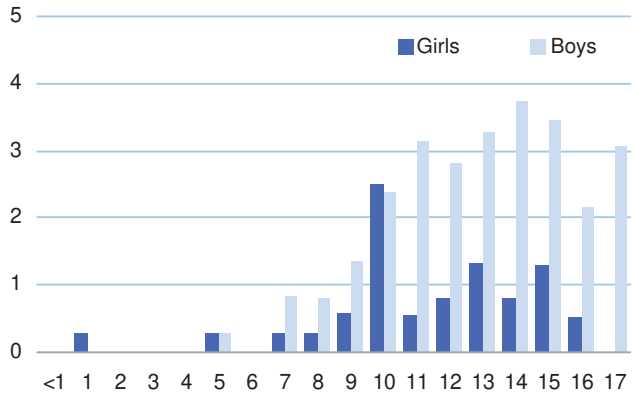
Median age at diagnosis: 13 years 6 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Intracranial and intraspinal germinomas

SN after X (a) 1			**X (a) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
9	0.6 %	-	2	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Intracranial and intraspinal teratomas

Cases in Germany aged under 15/18 years (1980-2018): 96

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	28 / 21831 = 0.1 %
Relative frequency of trial patients:	78.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	10	18	28
Standardized rate *:	0.2	0.3	0.2
Cumulative incidence:	3	5	4

Sex ratio (m/f): 1.8

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	9	5	7	5	2
Incidence rate:	1.3	0.2	0.2	0.1	0.1

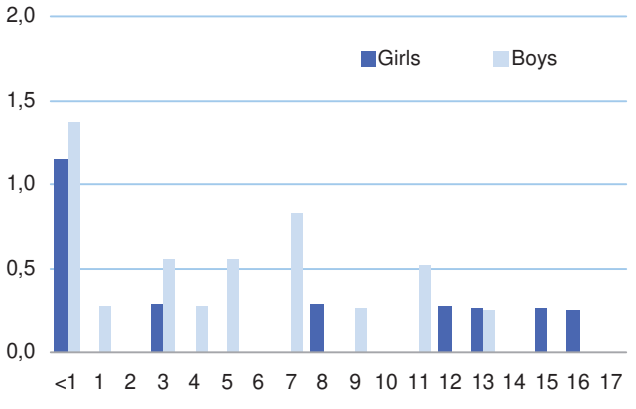
Median age at diagnosis: 5 years 0 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Intracranial and intraspinal teratomas

SN after X (a) 2			**X (a) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 639

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	226 / 21831 = 1 %
Relative frequency of trial patients:	95.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	143	83	226
Standardized rate *:	2.7	1.4	2.0
Cumulative incidence:	41	22	31
Sex ratio (m/f):			0.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	129	52	4	17	24
Incidence rate:	18.1	1.8	0.1	0.4	1.0

Median age at diagnosis: 0 years 5 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	94 %	94 %	93 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

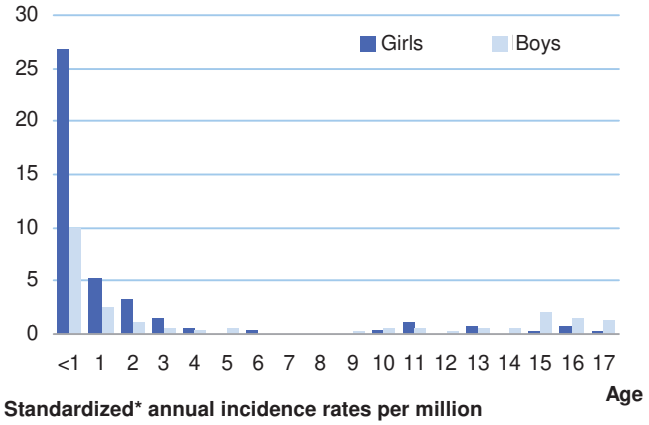
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
11	0.3 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
X (b) Malignant extracranial and extragonadal germ cell tumours

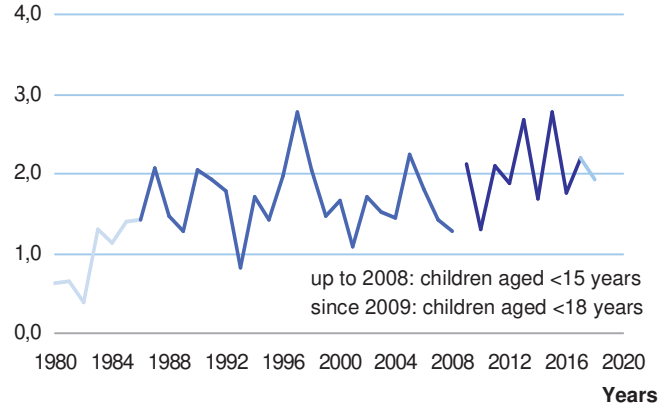
SN after X (b)			**X (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
9	0.6 %	3.2 %	2	0.1 %	0.0 %

* Standard: Segi world standard population

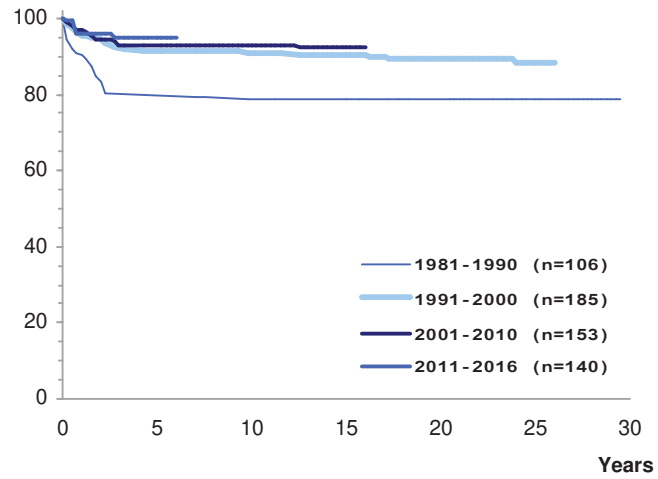
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

78 X (b) Malignant extracranial and extragonadal germ cell tumours - Extended ICCC-3

Germany 2009-2018	N	%
Malignant extracranial and extragonadal germ cell tumours	**226**	**100.0**
1 Germinomas of extracranial and extragonadal sites	27	11.9
2 Malignant teratomas of extracranial and extragonadal sites	106	46.9
3 Embryonal carcinomas of extracranial and extragonadal sites	0	0.0
4 Yolk sac tumour of extracranial and extragonadal sites	54	23.9
5 Choriocarcinomas of extracranial and extragonadal sites	2	0.9
6 Other and unspecified malignant mixed germ cell tumours of extracranial an	37	16.4

2 Malignant teratomas of extracranial and extragonadal sites

Cases in Germany aged under 15/18 years (1980-2018): 288

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	106 / 21831 = 0.5 %
Relative frequency of trial patients:	92.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	72	34	106
Standardized rate *:	1.4	0.6	1.0
Cumulative incidence:	21	9	15

Sex ratio (m/f): 0,5

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	98	5	0	3	0
Incidence rate:	13.7	0.2	0.0	0.1	0.0

Median age at diagnosis: 0 years 0 months

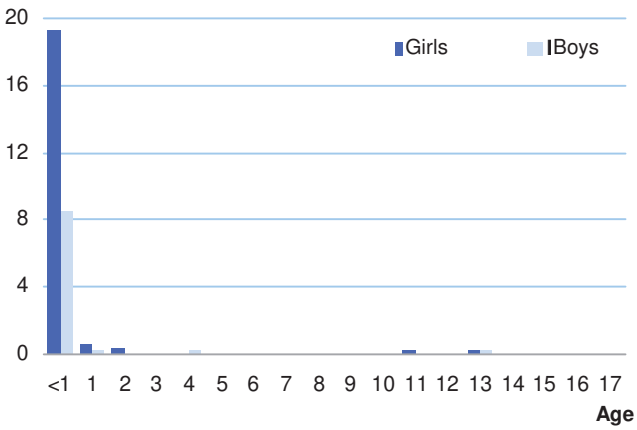
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

2 Malignant teratomas of extracranial and extragonadal sites

SN after X (b) 2			**X (b) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
3	0.2 %	-	0	0.0 %	-

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



4 Yolk sac tumour of extracranial and extragonadal sites

Cases in Germany aged under 15/18 years (1980-2018): 237

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	54 / 21831 = 0.2 %
Relative frequency of trial patients:	98.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	38	16	54
Standardized rate *:	0.7	0.3	0.5
Cumulative incidence:	11	4	8

Sex ratio (m/f): 0.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	15	32	0	1	6
Incidence rate:	2.1	1.1	0.0	0.0	0.2

Median age at diagnosis: 1 year 6 months

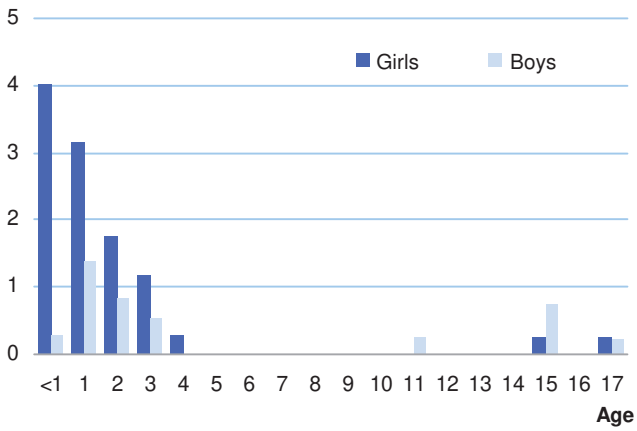
Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):

4 Yolk sac tumour of extracranial and extragonadal sites

SN after X (b) 4			**X (b) 4 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	-	0	0.0 %	-

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Cases in Germany aged under 15/18 years (1980-2018): 947

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	361 / 21831 = 1.7 %
Relative frequency of trial patients:	95.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	198	163	361
Standardized rate *:	2.7	2.3	2.5
Cumulative incidence:	53	41	47
Sex ratio (m/f):			0.8

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	28	30	39	118	146
Incidence rate:	3.9	1.1	1.1	3.1	6.0

Median age at diagnosis: 14 years 3 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	98 %	98 %	98 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

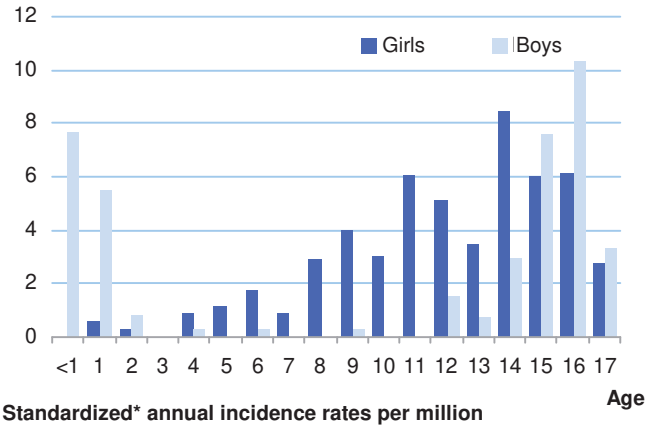
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
6	0.1 %	0.0	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
X (c) Malignant gonadal germ cell tumours

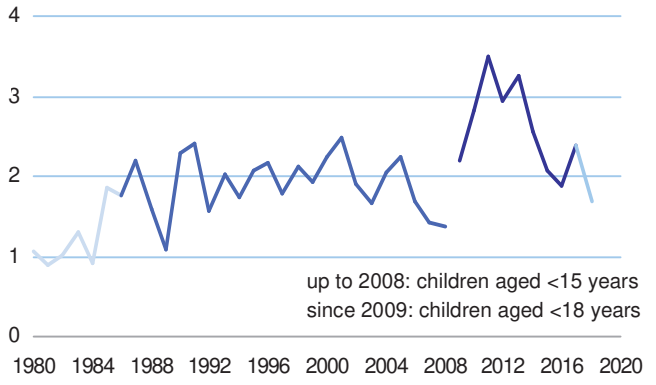
SN after X (c)			**X (c) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
16	1.0 %	6.9 %	12	0.8 %	0.0 %

* Standard: Segi world standard population

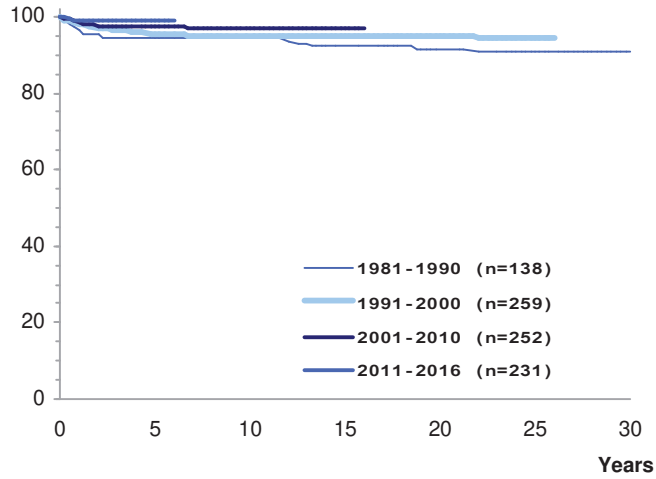
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

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

Germany 2009-2018	N	%
Malignant gonadal germ cell tumours	**361**	**100.0**
1 Malignant gonadal germinomas	61	16.9
2 Malignant gonadal teratomas	57	15.8
3 Gonadal embryonal carcinomas	14	3.9
4 Gonadal yolk sac tumour	65	18.0
5 Gonadal choriocarcinoma	17	4.7
6 Malignant gonadal tumours of mixed forms	147	40.7
7 Malignant gonadal gonadoblastoma	0	0.0

1 Malignant gonadal germinomas

Cases in Germany aged under 15/18 years (1980-2018): 130

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	61 / 21831 = 0.3 %
Relative frequency of trial patients:	95.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	52	9	61
Standardized rate *:	0.7	0.1	0.4
Cumulative incidence:	14	2	8

Sex ratio (m/f): 0,2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	3	7	27	24
Incidence rate:	0.0	0.1	0.2	0.7	1.0

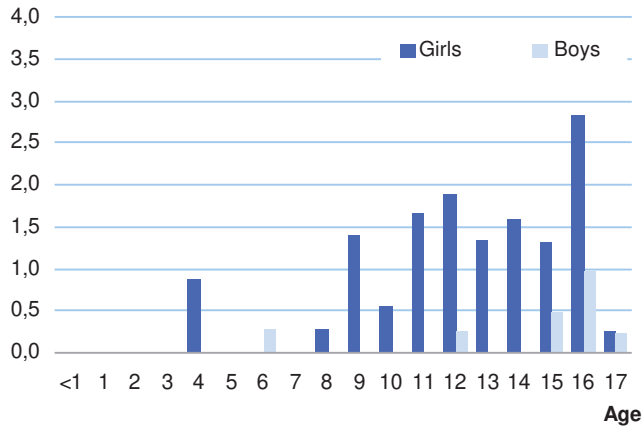
Median age at diagnosis: 13 years 10 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Malignant gonadal germinomas

SN after X (c) 1			**X (c) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
2	0.1 %	-	5	0.3 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Malignant gonadal teratomas

Cases in Germany aged under 15/18 years (1980-2018): 198

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	57 / 21831 = 0.3 %
Relative frequency of trial patients:	89.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	38	19	57
Standardized rate *:	0.5	0.3	0.4
Cumulative incidence:	10	5	8

Sex ratio (m/f): 0.5

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	9	1	9	25	13
Incidence rate:	1.3	0.0	0.3	0.7	0.5

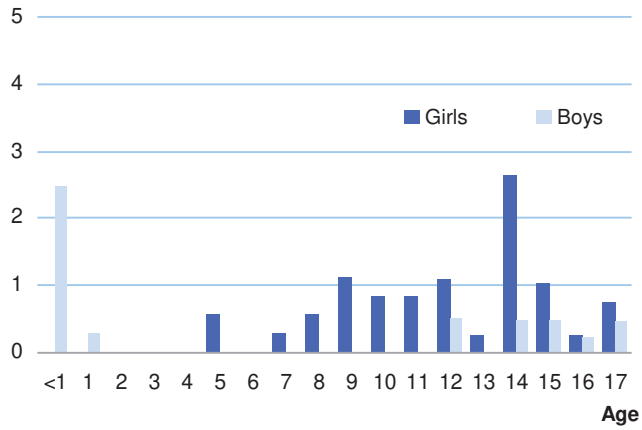
Median age at diagnosis: 12 years 10 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Malignant gonadal teratomas

SN after X (c) 2			**X (c) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
2	0.1 %	-	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



Germany 2009-2018	N	%
Malignant gonadal germ cell tumours	**361**	**100.0**
1 Malignant gonadal germinomas	61	16.9
2 Malignant gonadal teratomas	57	15.8
3 Gonadal embryonal carcinomas	14	3.9
4 Gonadal yolk sac tumour	65	18.0
5 Gonadal choriocarcinoma	17	4.7
6 Malignant gonadal tumours of mixed forms	147	40.7
7 Malignant gonadal gonadoblastoma	0	0.0

4 Gonadal yolk sac tumour

Cases in Germany aged under 15/18 years (1980-2018): 339

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	65 / 21831 = 0.3 %
Relative frequency of trial patients:	96.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	34	31	65
Standardized rate *:	0.5	0.6	0.5
Cumulative incidence:	9	8	9
Sex ratio (m/f):			0,9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	10	21	8	15	11
Incidence rate:	1.4	0.7	0.2	0.4	0.5

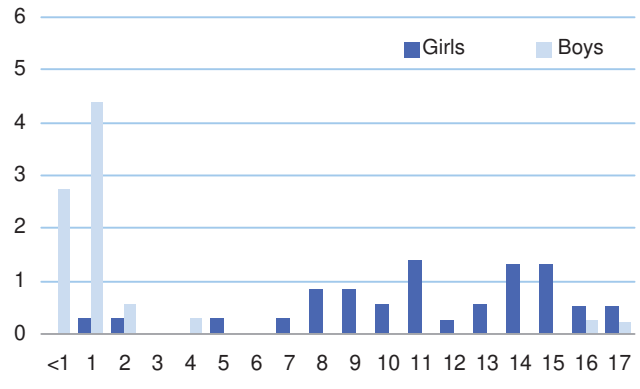
Median age at diagnosis: 7 years 10 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
4 Gonadal yolk sac tumour

SN after X (c) 4			**X (c) 4 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
9	0.6 %	8.2 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



6 Malignant gonadal tumours of mixed forms

Cases in Germany aged under 15/18 years (1980-2018): 201

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	147 / 21831 = 0.7 %
Relative frequency of trial patients:	96.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	68	79	147
Standardized rate *:	0.9	1.0	1.0
Cumulative incidence:	18	20	19
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	9	4	15	44	75
Incidence rate:	1.3	0.1	0.4	1.2	3.1

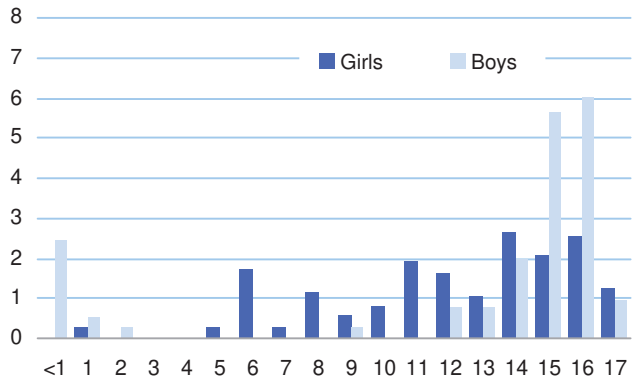
Median age at diagnosis: 15 years 1 month

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
6 Malignant gonadal tumours of mixed forms

SN after X (c) 6			**X (c) 6 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
2	0.1 %	-	3	0.2 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



82 XI Other malignant epithelial neoplasms and malignant melanomas

(a) Adrenocortical carcinomas
(b) Thyroid carcinomas
(c) Nasopharyngeal carcinomas
(d) Malignant melanomas
(e) Skin carcinomas
(f) Other and unspecified carcinomas

Cases in Germany aged under 15/18 years (1980-2018): 1260

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	696 / 21831 = 3.2 %
Relative frequency of trial patients:	79.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	409	287	696
Standardized rate *:	5.6	3.8	4.7
Cumulative incidence:	110	73	91
Sex ratio (m/f):			0.7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	6	33	88	345	224
Incidence rate:	0.8	1.2	2.5	9.1	9.3

Median age at diagnosis: 13 years 9 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	91 %	89 %	87 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

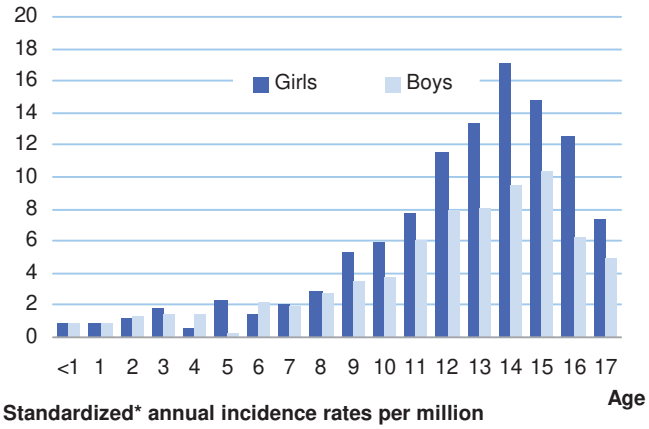
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
58	1.4 %	0.4	7

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XI Other malignant epithelial neoplasms and malignant melanomas

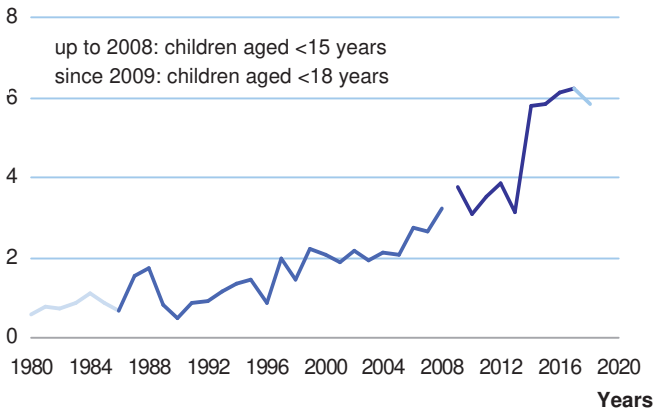
SN after XI			**XI as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
14	0.9 %	-	527	34.2 %	3.4 %

* Standard: Segi world standard population

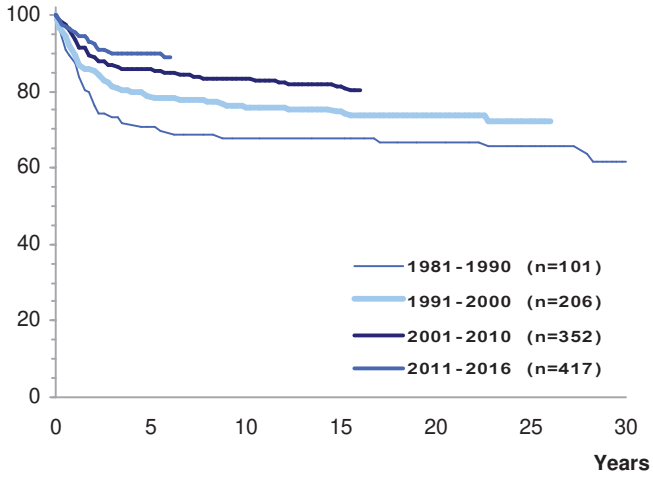
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

Cases in Germany aged under 15/18 years (1980-2018): 82

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	22 / 21831 = 0.1 %
Relative frequency of trial patients:	95.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	13	9	22
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	4	2	3
Sex ratio (m/f):			0.7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	2	10	3	4	3
Incidence rate:	0.3	0.4	0.1	0.1	0.1

Median age at diagnosis: 4 years 1 month

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

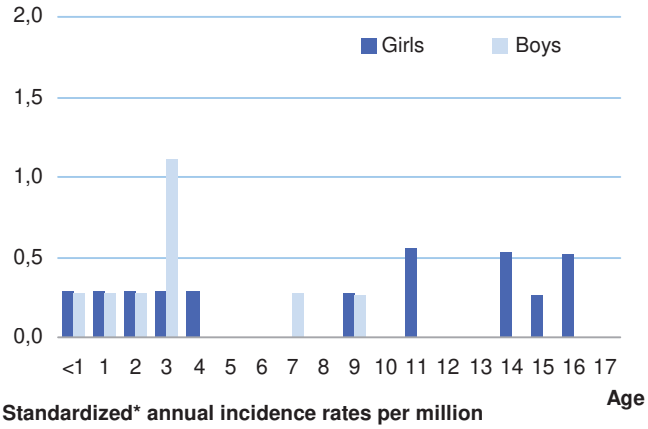
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
12	0.3 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XI (a) Adrenocortical carcinomas

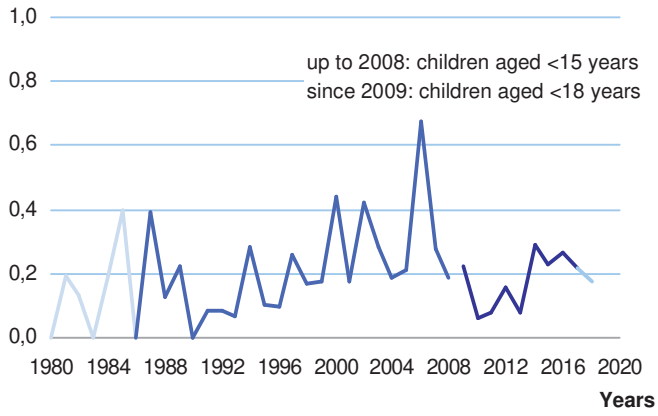
SN after XI (a)			**XI (a) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
4	0.3 %	-	1	0.1 %	0.0 %

* Standard: Segi world standard population

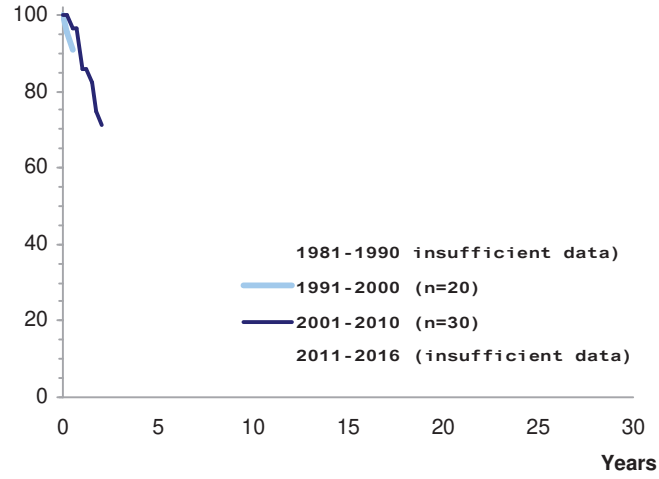
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

84 XI (b) Thyroid carcinomas

Cases in Germany aged under 15/18 years (1980-2018): 448

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	210 / 21831 = 1 %
Relative frequency of trial patients:	86.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	136	74	210
Standardized rate *:	1.8	1.0	1.4
Cumulative incidence:	36	19	27
Sex ratio (m/f):			0.5

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	0	30	113	66
Incidence rate:	0.1	0.0	0.8	3.0	2.7

Median age at diagnosis: 13 years 10 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	99 %	99 %	97 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

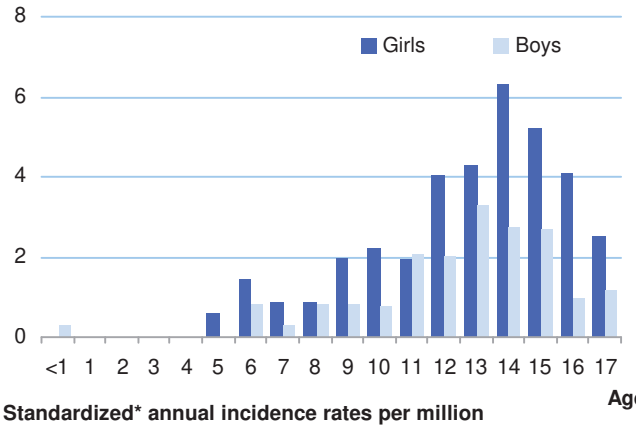
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
10	0.2 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XI (b) Thyroid carcinomas

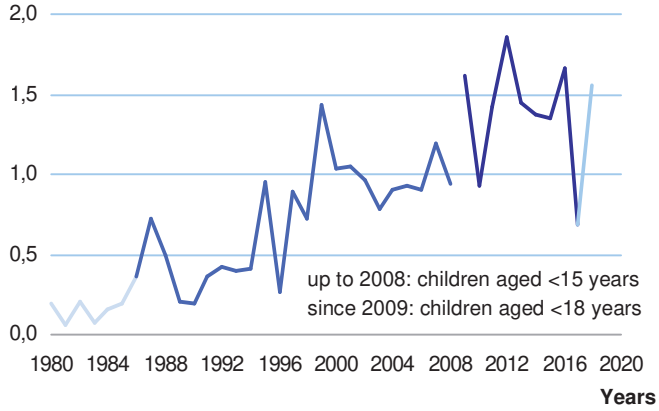
SN after XI (b)			**XI (b) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
3	0.2 %	-	175	11.4 %	0.8 %

* Standard: Segi world standard population

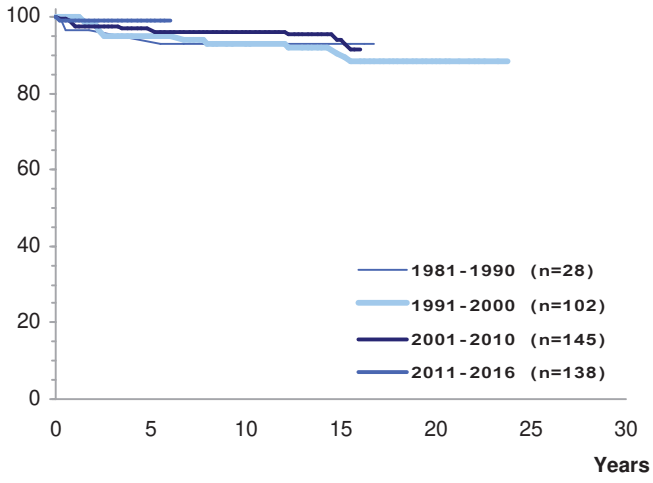
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

Cases in Germany aged under 15/18 years (1980-2018): 93

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	30 / 21831 = 0.1 %
Relative frequency of trial patients:	83.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	6	24	30
Standardized rate *:	0.1	0.3	0.2
Cumulative incidence:	2	6	4
Sex ratio (m/f):			4.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	0	0	16	14
Incidence rate:	0.0	0.0	0.0	0.4	0.6

Median age at diagnosis: 14 years 10 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	90 %	90 %	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

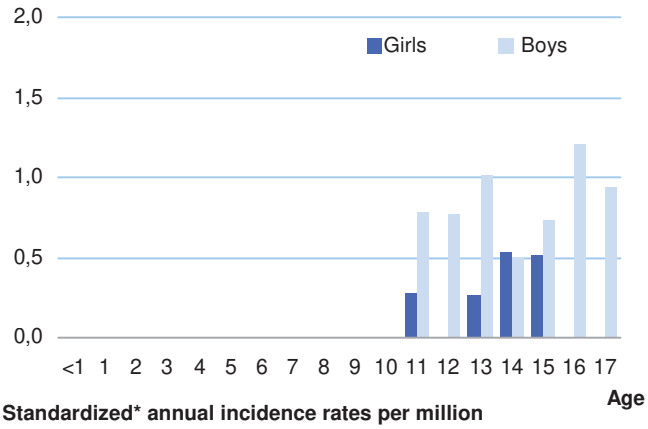
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4054 deaths		
5	0.1 %	0.0	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XI (c) Nasopharyngeal carcinomas

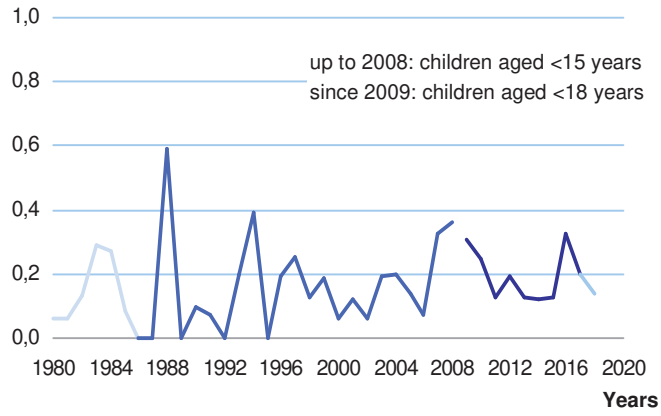
SN after XI (c)			XI (c) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	3	0.2 %	0.0 %

* Standard: Segi world standard population

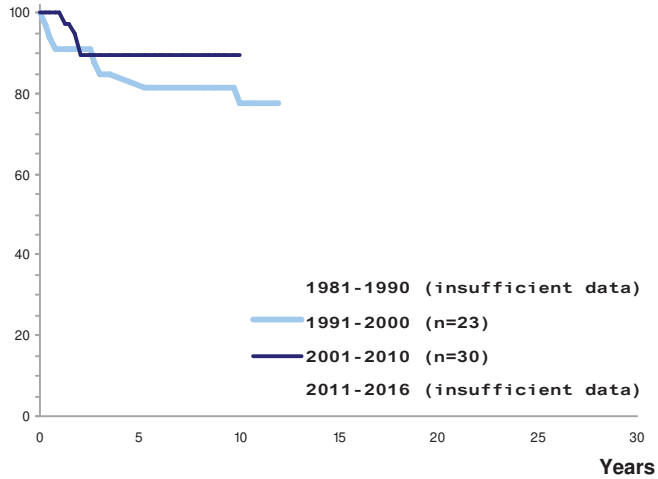
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

Cases in Germany aged under 15/18 years (1980-2018): 162

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	98 / 21831 = 0.4 %
Relative frequency of trial patients:	55.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	50	48	98
Standardized rate *:	0.8	0.7	0.7
Cumulative incidence:	14	12	13
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	3	18	21	36	20
Incidence rate:	0.4	0.6	0.6	0.9	0.8

Median age at diagnosis: 10 years 10 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	90 %	-	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

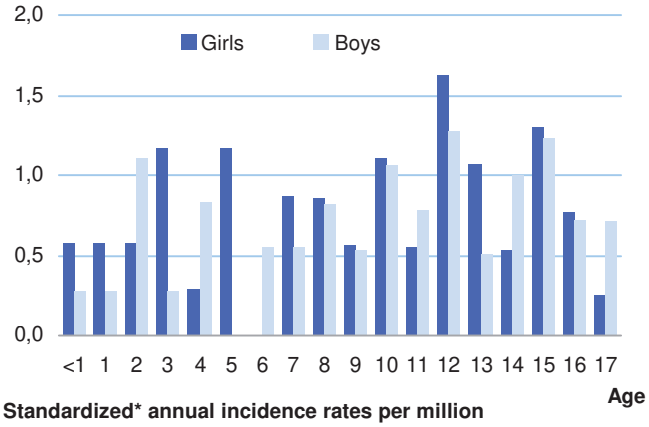
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
8	0.2 %	0.1	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XI (d) Malignant melanomas

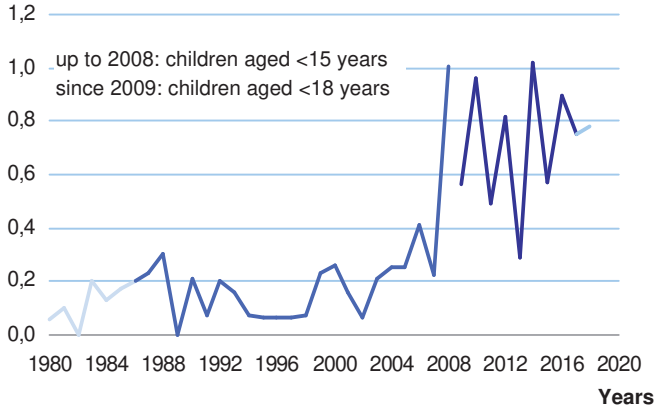
SN after XI (d)			**XI (d) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
0	0.0 %	-	45	2.9 %	0.2 %

* Standard: Segi world standard population

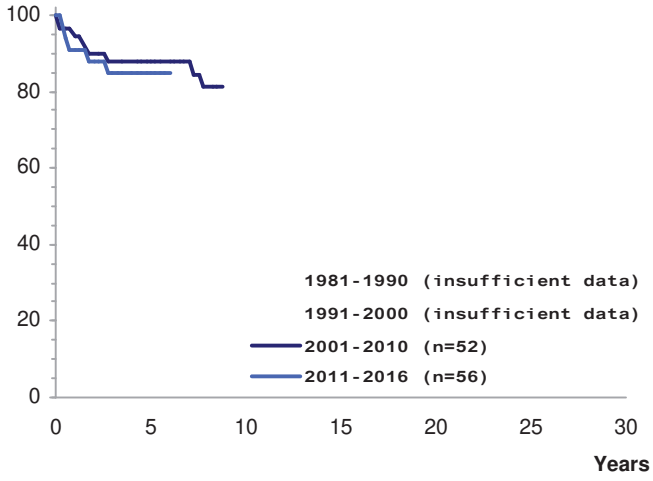
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

Cases in Germany aged under 15/18 years (1980-2018): 24

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	12 / 21831 = 0.1 %
Relative frequency of trial patients:	33.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	6	6	12
Standardized rate *:	0.1	0.1	0.1
Cumulative incidence:	2	2	2
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	2	6	3
Incidence rate:	0.0	0.0	0.1	0.2	0.1

Median age at diagnosis: 13 years 5 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

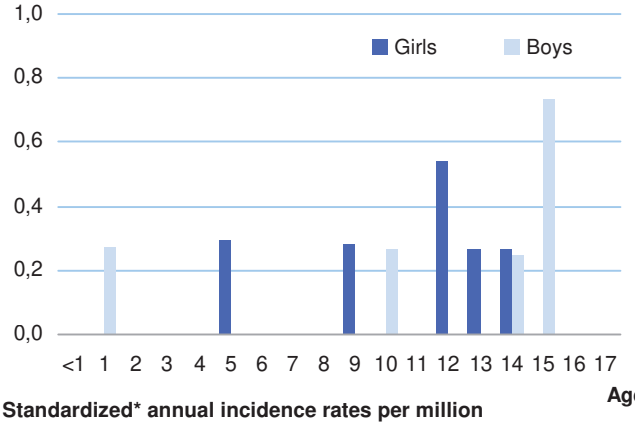
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
2	0.0 %	0.0	0

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XI (e) Skin carcinomas

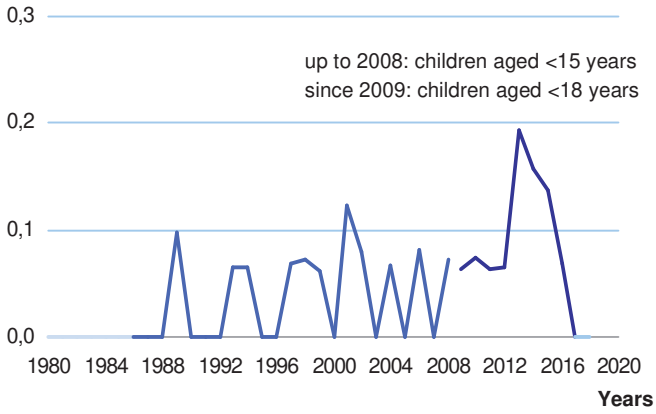
SN after XI (e)			**XI (e) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	140	9.1 %	1.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



No map due to sparse data

No survival curves due to sparse data

88 XI (f) Other and unspecified carcinomas

Cases in Germany aged under 15/18 years (1980-2018): 451

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	324 / 21831 = 1.5 %
Relative frequency of trial patients:	83.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	198	126	324
Standardized rate *:	2.7	1.6	2.1
Cumulative incidence:	53	32	42
Sex ratio (m/f):			0.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	4	32	170	118
Incidence rate:	0.0	0.1	0.9	4.5	4.9

Median age at diagnosis: 14 years 3 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	86 %	78 %	76 %

Mortality per million within 15 yrs. of diagnosis (1994-2003):

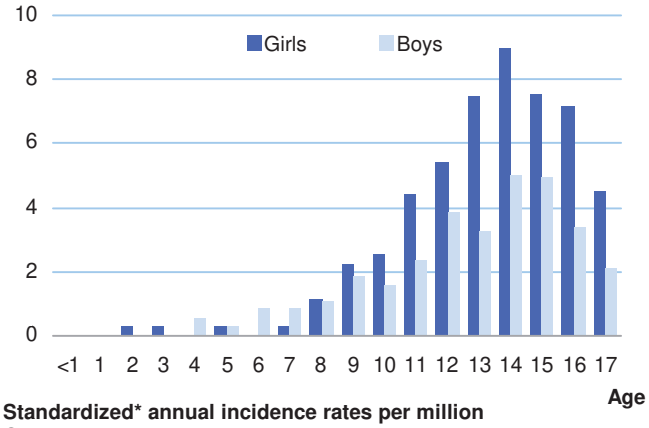
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
21	0.5 %	0.1	2

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XI (f) Other and unspecified carcinomas

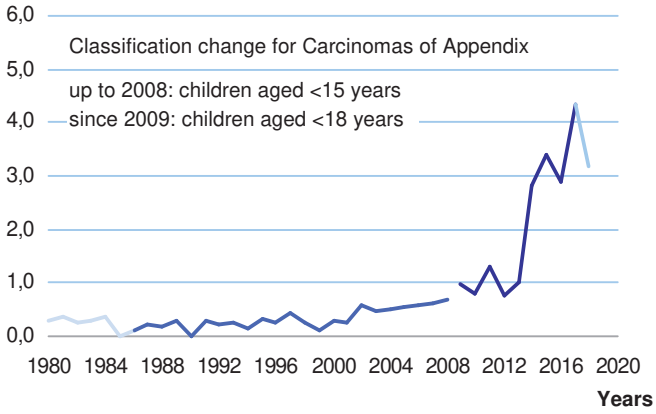
SN after XI (f)			**XI (f) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
5	0.3 %	-	163	10.6 %	1.2 %

* Standard: Segi world standard population

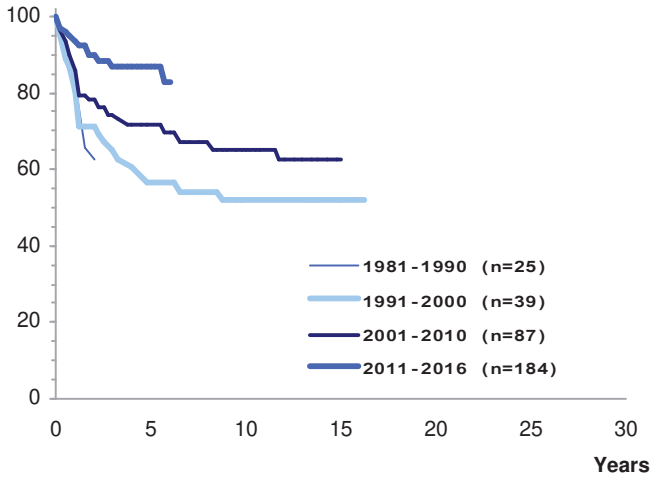
Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



Survival probabilities by year of diagnosis Germany 1981-2016



No map due to sparse data

Germany 2009-2018	N	%		N	%
Other and unspecified carcinomas	**324**	**100.0**			
1 Carcinomas of salivary glands	25	7.7	7 Carcinomas of cervix uteri	2	0.6
2 Carcinomas of colon and rectum	22	6.8	8 Carcinomas of bladder	4	1.2
3 Carcinomas of appendix	185	57.1	9 Carcinomas of eye	2	0.6
4 Carcinomas of lung	26	8.0	10 Carcinomas of other specified sites	42	13.0
5 Carcinomas of thymus	2	0.6	11 Carcinomas of unspecified site	12	3.7
6 Carcinomas of breast	2	0.6			

1 Carcinomas of salivary glands

Cases in Germany aged under 15/18 years (1980-2018): 47

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	25 / 21831 = 0.1 %
Relative frequency of trial patients:	44.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	15	10	25
Standardized rate *:	0.2	0.1	0.2
Cumulative incidence:	4	3	3
Sex ratio (m/f):			0,7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	4	17	3
Incidence rate:	0.0	0.0	0.1	0.4	0.1

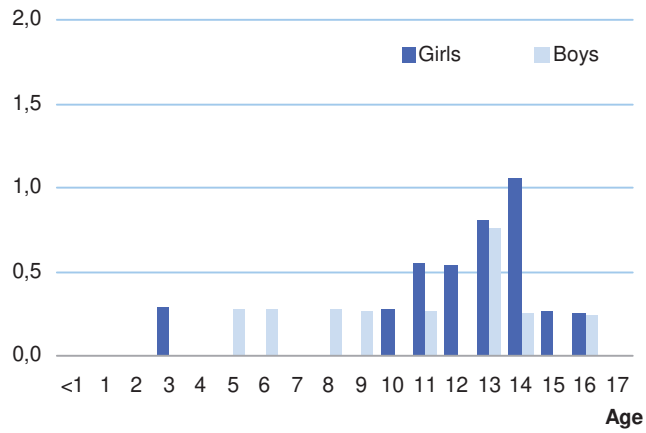
Median age at diagnosis: 13 years 5 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
1 Carcinomas of salivary glands

SN after XI (f) 1			**XI (f) 1 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	15	1.0 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



2 Carcinomas of colon and rectum

Cases in Germany aged under 15/18 years (1980-2018): 46

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	22 / 21831 = 0.1 %
Relative frequency of trial patients:	54.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	5	17	22
Standardized rate *:	0.1	0.2	0.1
Cumulative incidence:	1	4	3
Sex ratio (m/f):			3.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	1	8	12
Incidence rate:	0.0	0.0	0.0	0.2	0.5

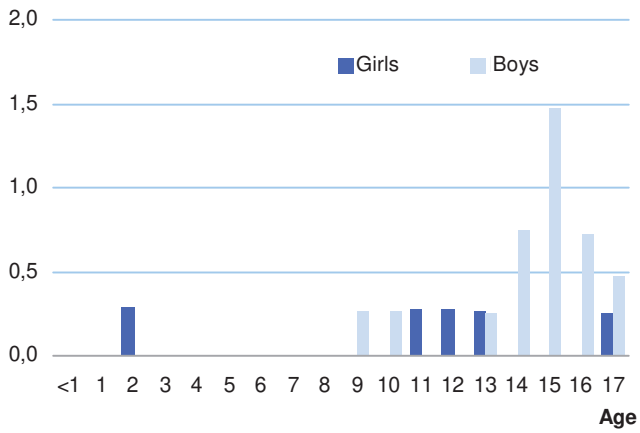
Median age at diagnosis: 15 years 1 month

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
2 Carcinomas of colon and rectum

SN after XI (f) 2			**XI (f) 2 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
1	0.1 %	-	24	1.6 %	0.2 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



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

Germany 2009-2018	N	%		N	%
Other and unspecified carcinomas	**324**	**100.0**			
1 Carcinomas of salivary glands	25	7.7	7 Carcinomas of cervix uteri	2	0.6
2 Carcinomas of colon and rectum	22	6.8	8 Carcinomas of bladder	4	1.2
3 Carcinomas of appendix	185	57.1	9 Carcinomas of eye	2	0.6
4 Carcinomas of lung	26	8.0	10 Carcinomas of other specified sites	42	13.0
5 Carcinomas of thymus	2	0.6	11 Carcinomas of unspecified site	12	3.7
6 Carcinomas of breast	2	0.6			

3 Carcinomas of appendix

Cases in Germany aged under 15/18 years (1980-2018): 187

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	185 / 21831 = 0.8 %
Relative frequency of trial patients:	96.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	130	55	185
Standardized rate *:	1.7	0.7	1.2
Cumulative incidence:	35	14	24
Sex ratio (m/f):			0,4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	0	15	114	56
Incidence rate:	0.0	0.0	0.4	3.0	2.3

Median age at diagnosis: 13 years 11 months

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
3 Carcinomas of appendix

SN after XI (f) 3			**XI (f) 3 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
0	0.0 %	-	0	0.0 %	-

* Standard: Segi world standard population

6 Carcinomas of breast

Cases in Germany aged under 15/18 years (1980-2018): 2

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	2 / 21831 = 0.0 %
Relative frequency of trial patients:	50.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	1	1	2
Standardized rate *:	0.0	0.0	0.0
Cumulative incidence:	0	0	0
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	0	0	1
Incidence rate:	0.0	0.0	0.0	0.0	0.0

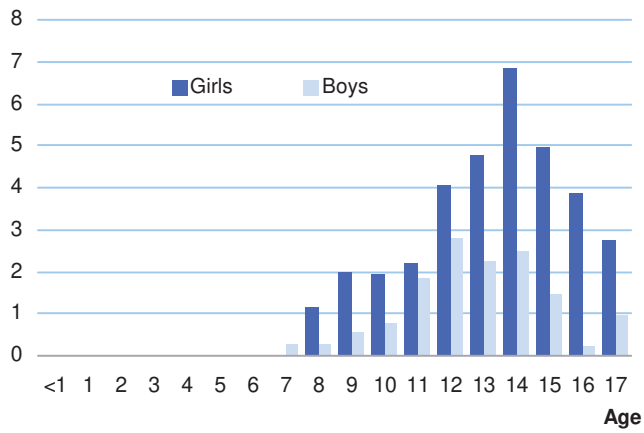
Median age at diagnosis: 10 years 1 month

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
6 Carcinomas of breast

SN after XI (f) 6			**XI (f) 6 as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
0	0.0 %	-	73	4.7 %	0.6 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million
Germany 2009-2018



No incidence rates due to sparse data

Cases in Germany aged under 15/18 years (1980-2018): 58

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	25 / 21831 = 0.1 %
Relative frequency of trial patients:	84.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	11	14	25
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	3	4	3
Sex ratio (m/f):			1.3

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	18	2	2	2
Incidence rate:	0.1	0.6	0.1	0.1	0.1

Median age at diagnosis: 3 years 3 months

Survival probabilities (2007-2016):	**5-year**	**10-year**	**15-year**
	-	-	-

Mortality per million within 15 yrs. of diagnosis (1994-2003):

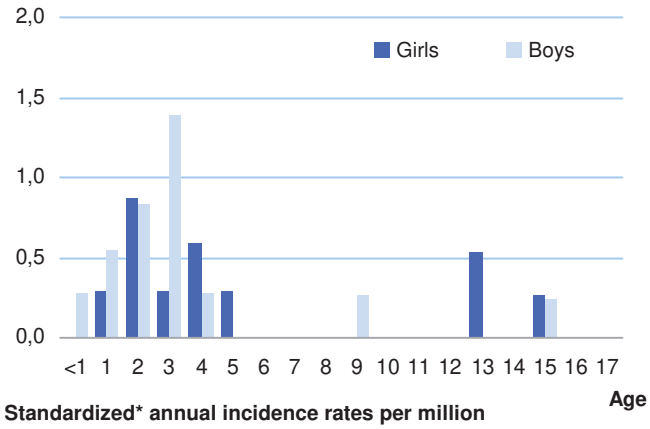
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4054 deaths		
7	0.2 %	0.0	1

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
XII (a) Other specified malignant tumours

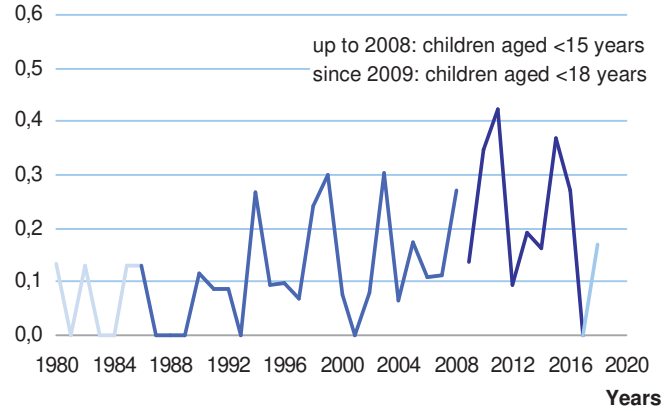
SN after XII (a)			**XII (a) as SN after any primary**		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
2	0.1 %	-	2	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million Germany 2009-2018



Standardized* annual incidence rates per million Germany 1980-2018



No map due to sparse data

No survival curves due to sparse data

Systematische Darstellung epidemiologischer Kenngrößen der vier häufigsten pädiatrischen Diagnosen nach ICS-10 (Auswahl der Kenngrößen kompatibel mit „Krebs in Deutschland“) /

Systematic Presentation of descriptive measures for the four most frequent pediadric diagnoses by ICD-10 (selection of measures compatible with „Cancer in Germany“)

Cases in Germany aged under 15/18 years (1980-2018): 20847

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	5951 / 21831 = 27.3 %
Relative frequency of trial patients:	99.0 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	2591	3360	5951
Raw incidence rate:	4.0	4.9	4.5
Standardized rate *:	4.0	4.9	4.5
Cumulative incidence:	73,5	89,9	81,9
Sex ratio (m/f):			1.3

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	124	1135	627	462	243
Incidence rate:	3.6	8.3	3.6	2.5	2.1

Median age at diagnosis: 5 years 2 months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	148	1319	853	609	431
Incidence rate:	4.0	9.1	4.7	3.1	3.5

Median age at diagnosis: 5 years 10 months

Survival probabilities (2007-2016):

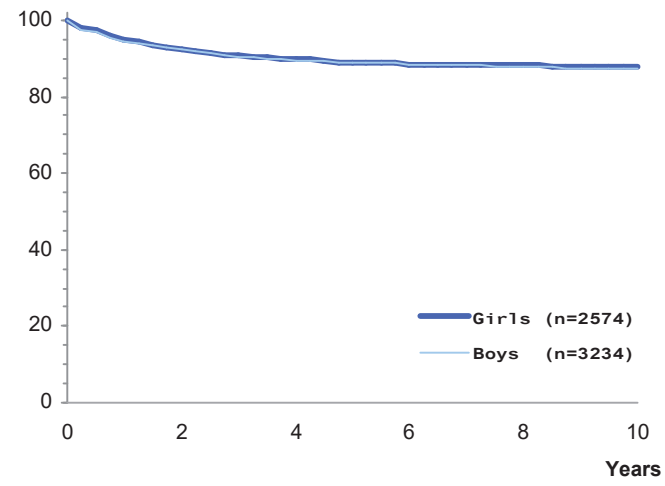
	5-year	**10-year**	**15-year**
Girls	90 %	89 %	88 %
Boys	90 %	88 %	88 %

Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

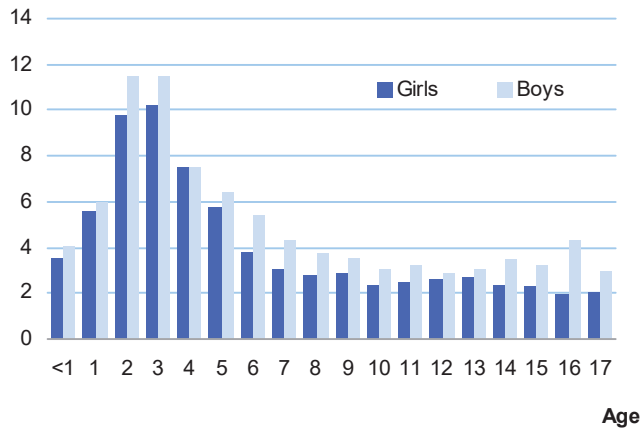
	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	463	11.4 %	0.6	11
Boys	679	16.7 %	0.8	16

* Standard: European standard population

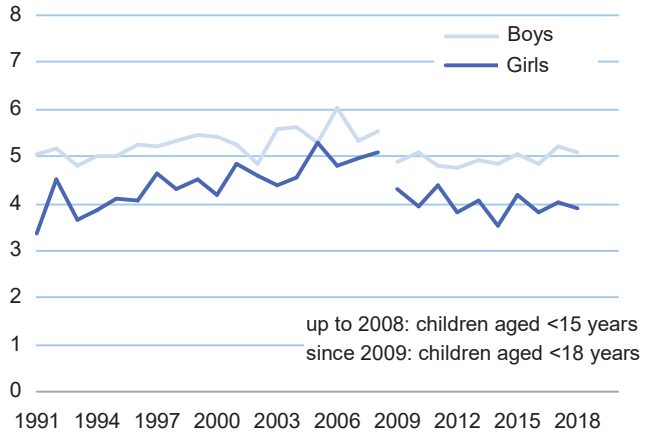
Absolute survival probabilities by sex Germany 2007-2016



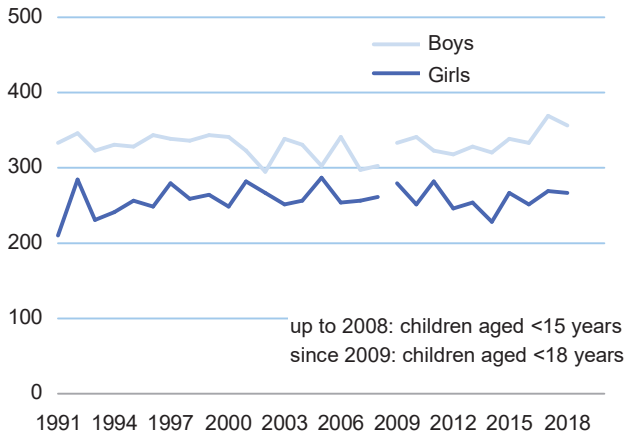
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



Cases in Germany aged under 15/18 years (1980-2018): 9336

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	3117 / 21831 = 14.3 %
Relative frequency of trial patients:	92.2 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	1356	1761	3117
Raw incidence rate:	2,1	2,6	2,3
Standardized rate *:	2,1	2,5	2.3
Cumulative incidence:	38,2	46,8	42,6
Sex ratio (m/f):			1.3

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	100	409	383	319	145
Incidence rate:	2.9	3.0	2.2	1.7	1.2

Median age at diagnosis: 6 years 11 months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	105	492	486	464	214
Incidence rate:	2.9	3.4	2.7	2.4	1.7

Median age at diagnosis: 7 years 8 months

Survival probabilities (2007-2016):

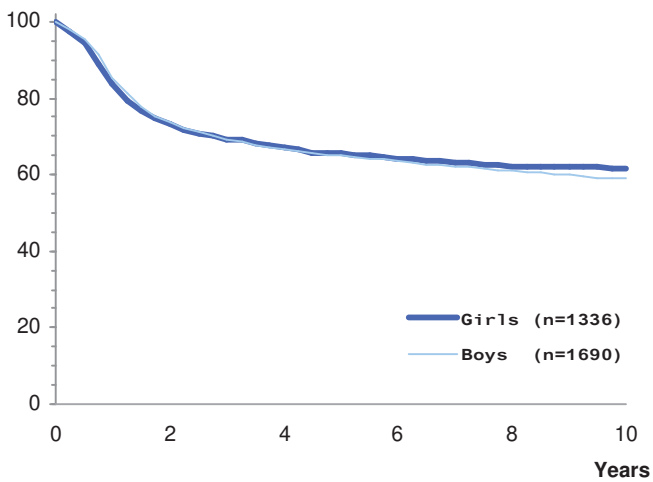
	5-year	**10-year**	**15-year**
Girls	67 %	63 %	61 %
Boys	67 %	61 %	59 %

Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

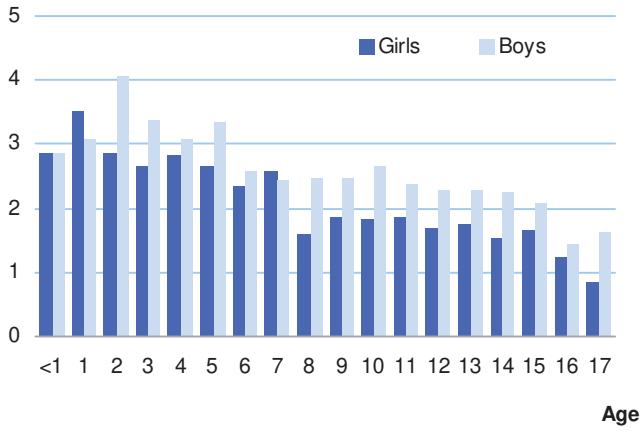
	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	473	11.7 %	0,6	11
Boys	672	16.6 %	0,8	15

* Standard: European standard population

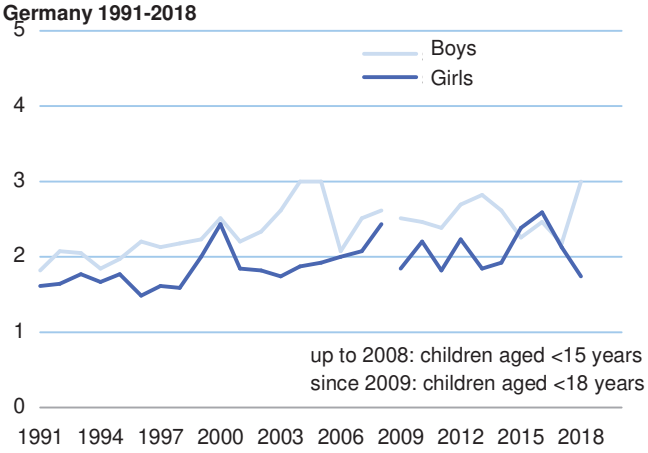
Absolute survival probabilities by sex Germany 2007-2016



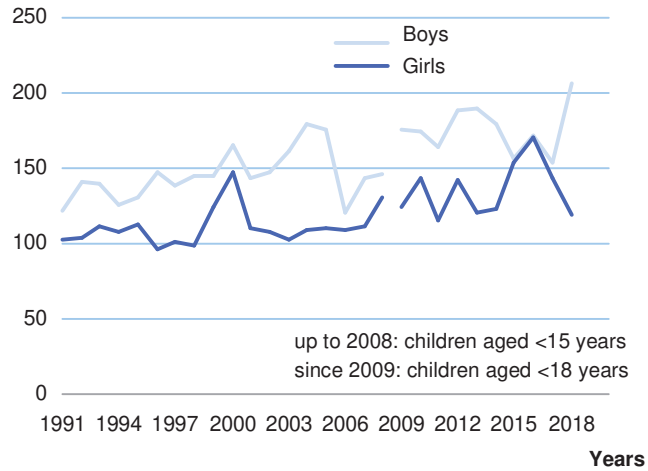
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



Cases in Germany aged under 15/18 years (1980-2018): 3829

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	1634 / 21831 = 7.5 %
Relative frequency of trial patients:	96.8 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	749	885	1634
Raw incidence rate:	1,2	1,3	1,2
Standardized rate *:	1,3	1,4	1.3
Cumulative incidence:	19,7	22,3	21
Sex ratio (m/f):			1.2

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	6	44	282	417
Incidence rate:	0.0	0.0	0.3	1.5	3.6

Median age at diagnosis: 15 years 3 months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	28	141	325	391
Incidence rate:	0.0	0.2	0.8	1.7	3.1

Median age at diagnosis: 14 years 5 months

Survival probabilities (2007-2016):

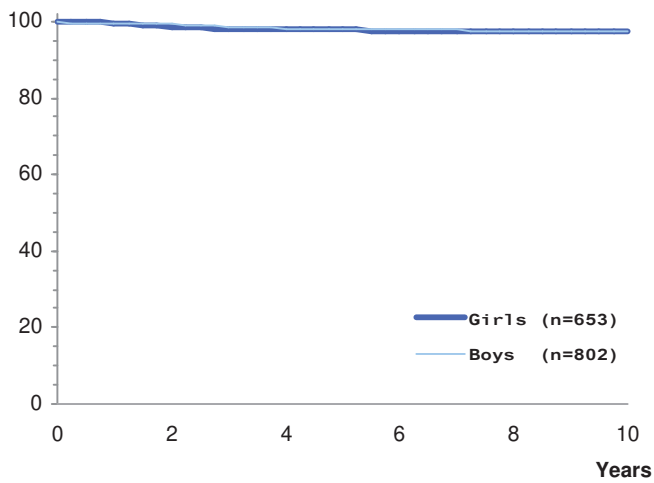
	5-year	**10-year**	**15-year**
Girls	98 %	98 %	97 %
Boys	98 %	98 %	97 %

Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

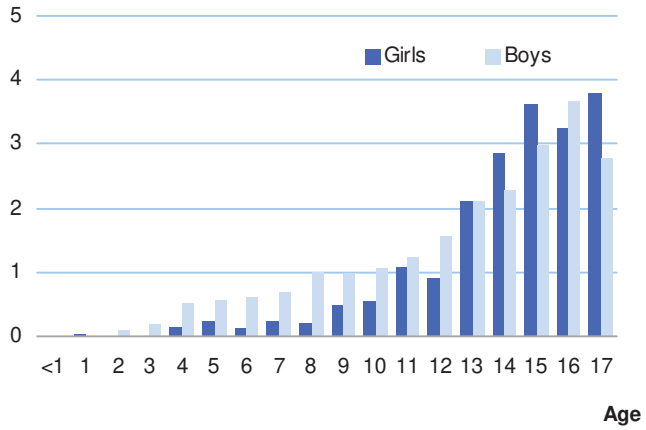
	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	18	0.4 %	0,0	0
Boys	26	0.6 %	0,0	1

* Standard: European standard population

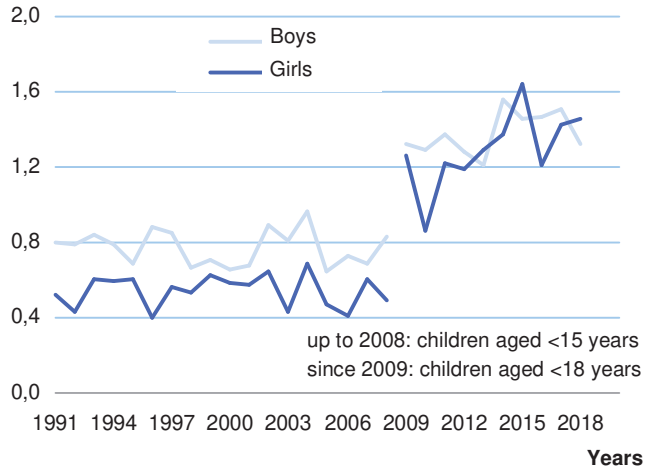
Absolute survival probabilities by sex Germany 2007-2016



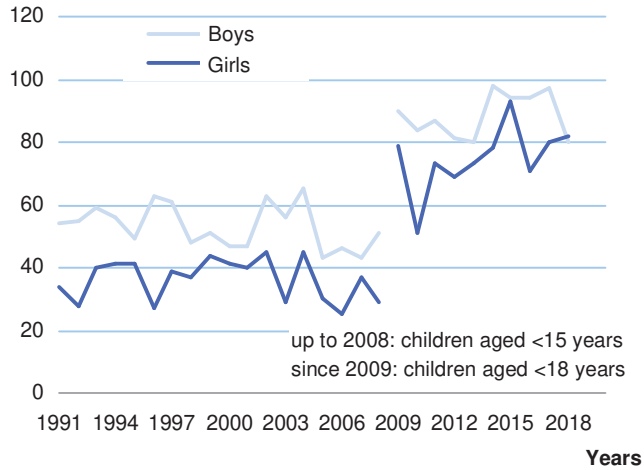
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



96 Soft tissue without Mesothelioma C46-C49

Cases in Germany aged under 15/18 years (1980-2018): 5214

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	1516 / 21831 = 6.9 %
Relative frequency of trial patients:	97.9 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	729	787	1516
Raw incidence rate:	1,1	1,2	1,1
Standardized rate *:	1,2	1,2	1.2
Cumulative incidence:	20,6	21,1	20,9
Sex ratio (m/f):			1.1

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	225	219	85	118	82
Incidence rate:	6.5	1.6	0.5	0.6	0.7

Median age at diagnosis: 2 years 9 months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	206	270	112	113	86
Incidence rate:	5.6	1.9	0.6	0.6	0.7

Median age at diagnosis: 3 years 4 months

Survival probabilities (2007-2016):

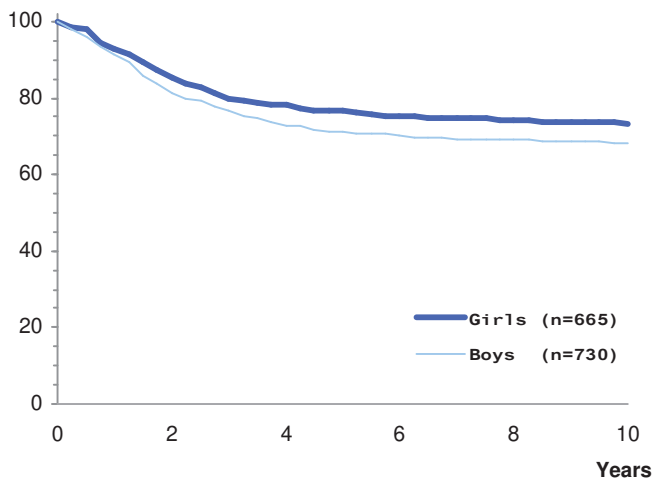
	5-year	**10-year**	**15-year**
Girls	79 %	76 %	75 %
Boys	73 %	71 %	70 %

Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

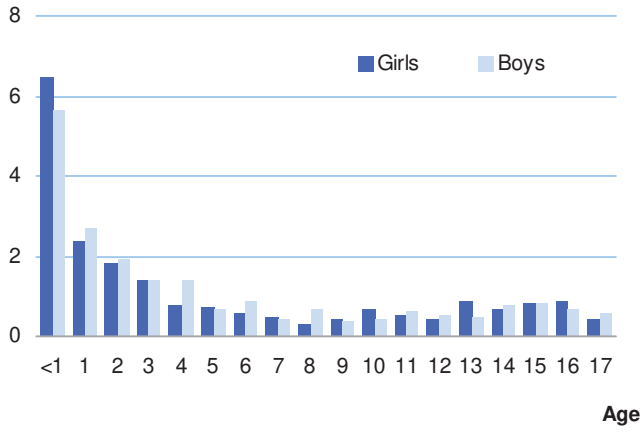
	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	215	5.3 %	0,3	5
Boys	234	5.8 %	0,3	5

* Standard: European standard population

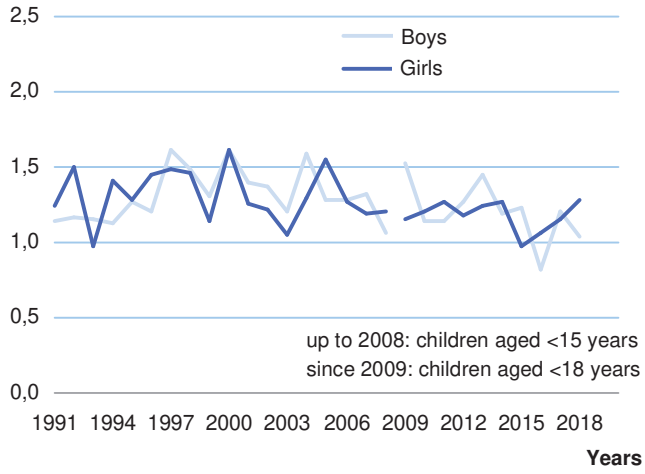
Absolute survival probabilities by sex Germany 2007-2016



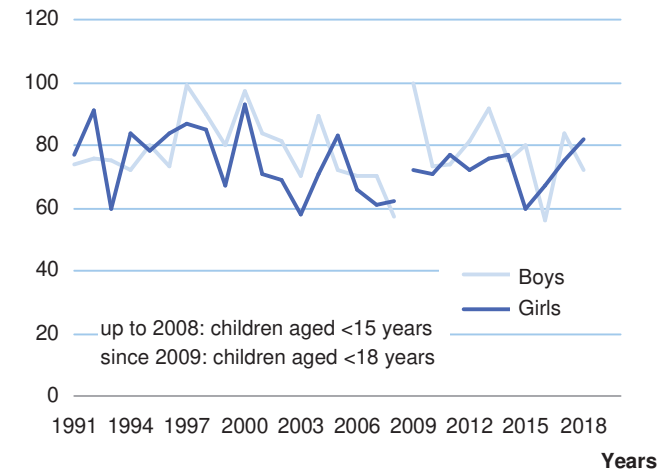
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



Cases in Germany aged under 15/18 years (1980-2018): 315

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	82 / 21831 = 0.4 %
Relative frequency of trial patients:	96.3 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	37	45	82
Raw incidence rate:	0,1	0,1	0,1
Standardized rate *:	0,1	0,1	0.1
Cumulative incidence:	1,1	1,2	1,2
Sex ratio (m/f):			1.2

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	8	25	2	2	0
Incidence rate:	0.2	0.2	0.0	0.0	0.0

Median age at diagnosis: 1 year 6 months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	8	30	5	2	0
Incidence rate:	0.2	0.2	0.0	0.0	0.0

Median age at diagnosis: 1 year 9 months

Survival probabilities (2007-2016):

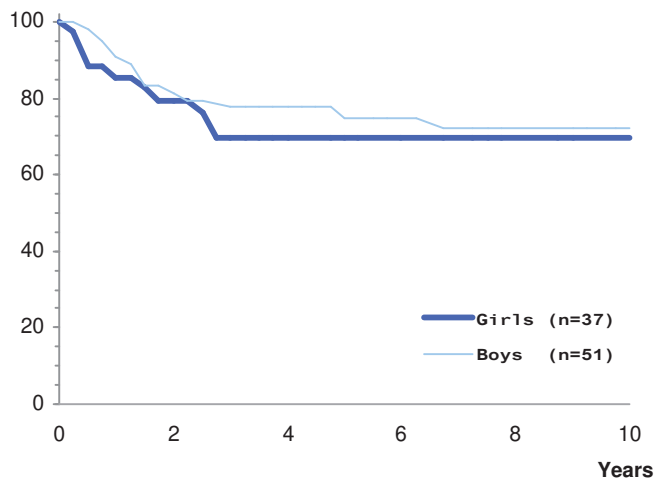
	5-year	**10-year**	**15-year**
Girls	71 %	71 %	71 %
Boys	76 %	73 %	-

Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

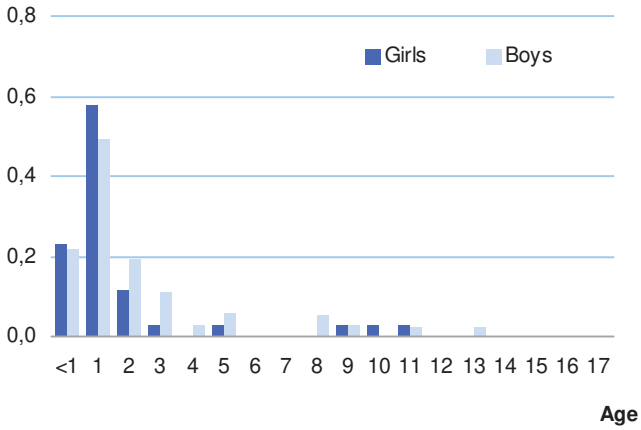
	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	18	0.4 %	0,0	0
Boys	19	0.5 %	0,0	0

* Standard: European standard population

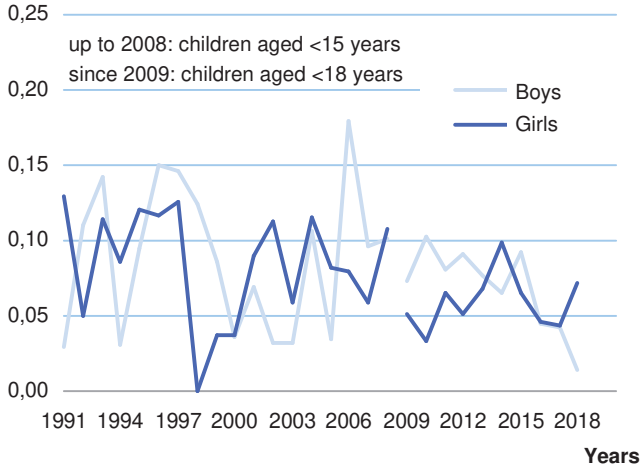
Absolute survival probabilities by sex Germany 2007-2016



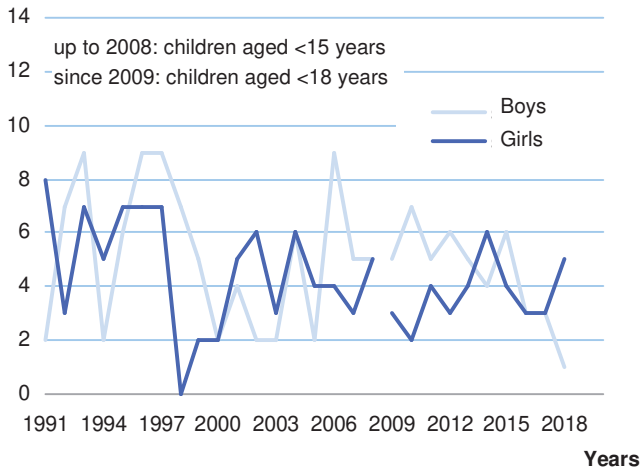
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



Cases in Germany aged under 15/18 years (1980-2018): 37

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	7 / 21831 = 0 %
Relative frequency of trial patients:	100 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	0	7	7
Raw incidence rate:	0	0	0
Standardized rate *:	0,0	0,0	0.0
Cumulative incidence:	0	0,2	0,1
Sex ratio (m/f):			

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	0	0	0	0
Incidence rate:	0.0	0.0	0.0	0.0	0.0

Median age at diagnosis: years months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	1	1	1	2	2
Incidence rate:	0.0	0.0	0.0	0.0	0.0

Median age at diagnosis: 11 years 0 months

Survival probabilities (2007-2016):

	5-year	**10-year**	**15-year**
Girls	-	-	-
Boys	-	-	-

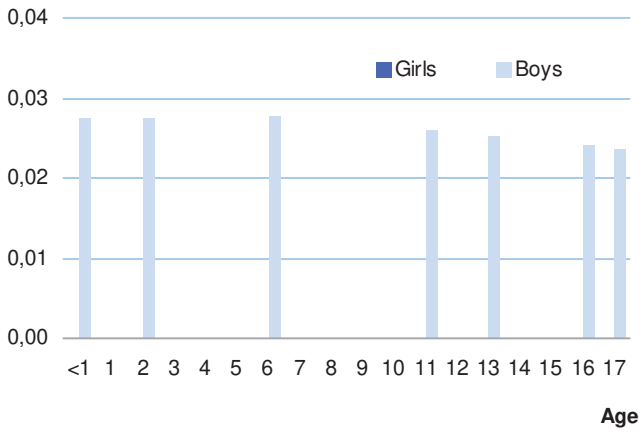
Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	0	0.0 %	0,0	0
Boys	2	0.0 %	0,0	0

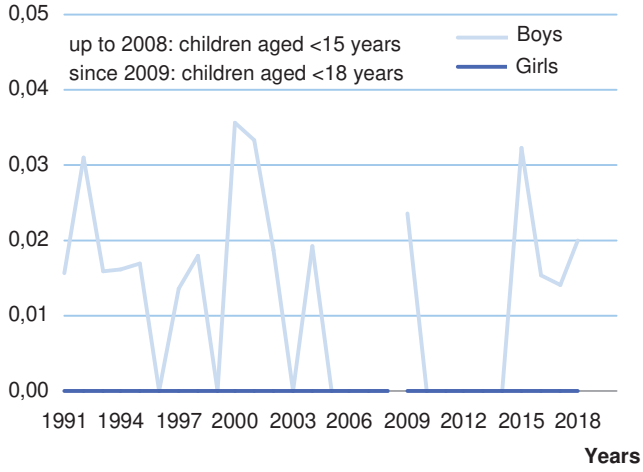
* Standard: European standard population

No survival curves due to sparse data

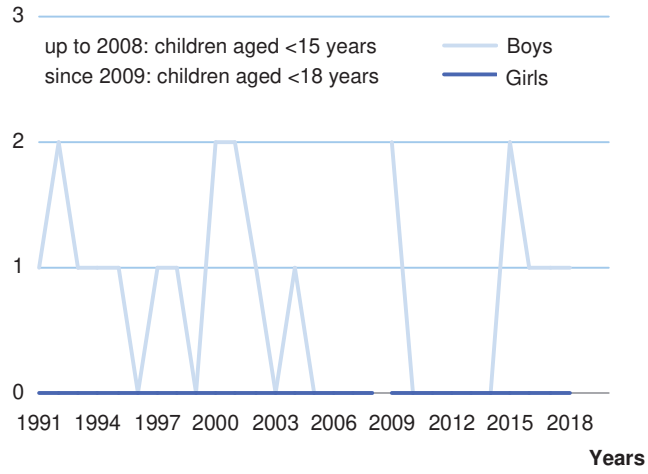
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



Cases in Germany aged under 15/18 years (1980-2018): 7

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	5 / 21831 = 0 %
Relative frequency of trial patients:	80.0 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	3	2	5
Raw incidence rate:	0	0	0
Standardized rate *:	0,0	0,0	0.0
Cumulative incidence:	0,1	0,1	0,1
Sex ratio (m/f):			0.7

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	0	0	0	3
Incidence rate:	0.0	0.0	0.0	0.0	0.0

Median age at diagnosis: 15 years 2 months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	0	1	0
Incidence rate:	0.0	0.0	0.0	0.0	0.0

Median age at diagnosis: 9 years 5 months

Survival probabilities (2007-2016):

	5-year	**10-year**	**15-year**
Girls	-	-	-
Boys	-	-	-

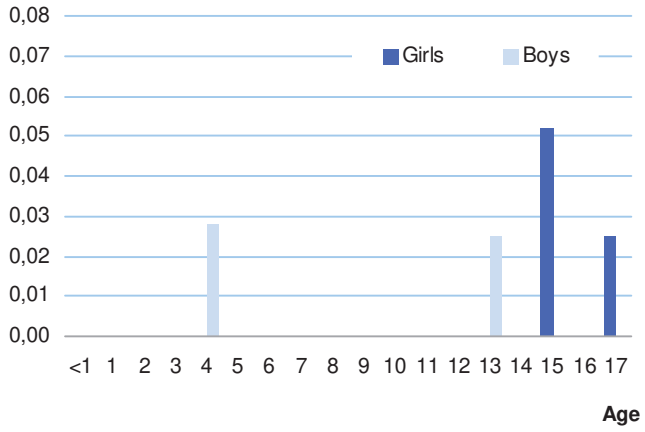
Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	-			
Boys	-			

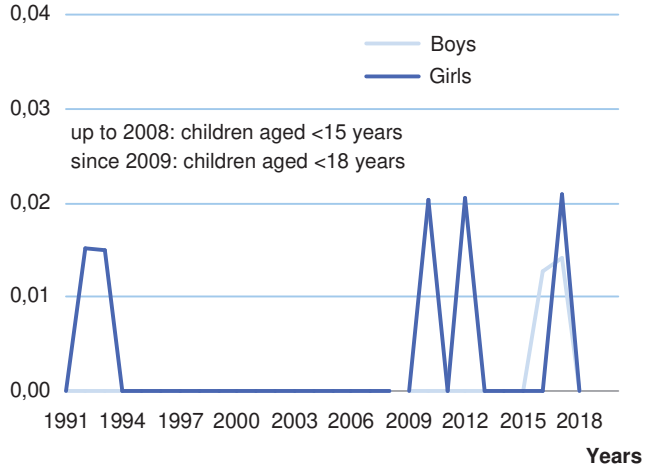
* Standard: European standard population

Absolute survival probabilities by sex Germany 2007-2016

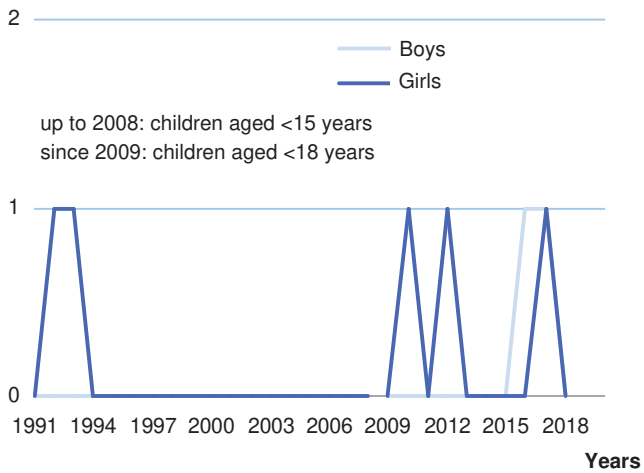
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



100 Colon and rectum C18-C21

Cases in Germany aged under 15/18 years (1980-2018): 235

Selected characteristics under 18 years Germany 2009-2018

Relative frequency:	209 / 21831 = 1 %
Relative frequency of trial patients:	92.3 %

Incidence rates per 100,000:	**Girls**	**Boys**	**Total**
Number of cases:	135	74	209
Raw incidence rate:	0,2	0,1	0,2
Standardized rate *:	0,2	0,1	0.2
Cumulative incidence:	3,6	1,9	2,7
Sex ratio (m/f):			0.5

Age-specific incidence rates per 100,000:

Girls	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	11	77	46
Incidence rate:	0.0	0.0	0.1	0.4	0.4

Median age at diagnosis: 14 years 2 months

Boys	**<1**	**1-4**	**5-9**	**10-14**	**15-17**
Number of cases :	0	1	5	45	23
Incidence rate:	0.0	0.0	0.0	0.2	0.2

Median age at diagnosis: 13 years 9 months

Survival probabilities (2007-2016):

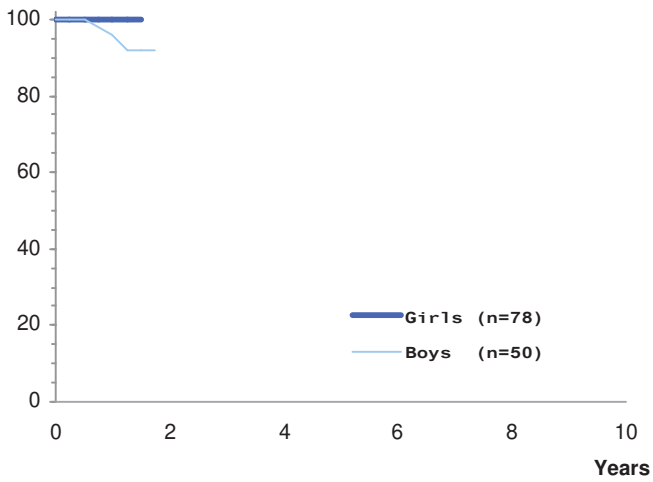
	5-year	**10-year**	**15-year**
Girls	-	-	-
Boys	-	-	-

Mortality per 100,000 within 15 yrs. of diagnosis (1994-2003):

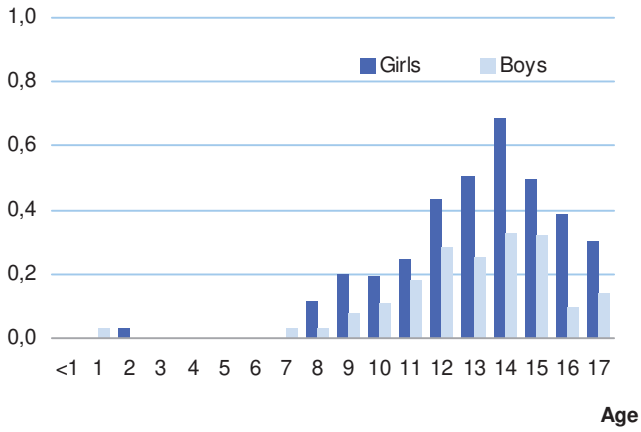
	Number of deaths N	% of all 4054 deaths	**Standardized* mortality rate**	**Cumulative mortality**
Girls	1	0.0 %	0,0	0
Boys	4	0.1 %	0,0	0

* Standard: European standard population

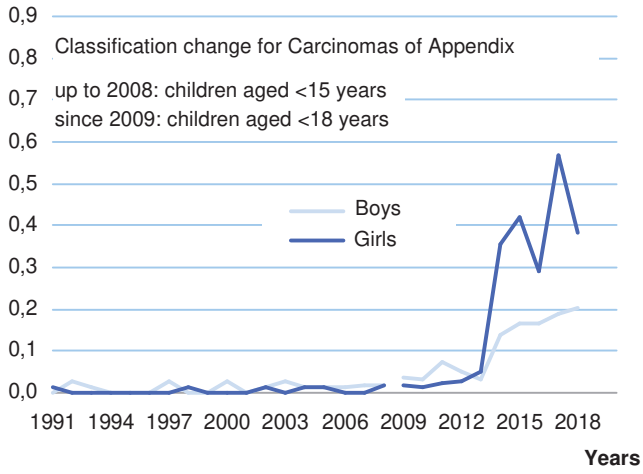
Absolute survival probabilities by sex Germany 2007-2016



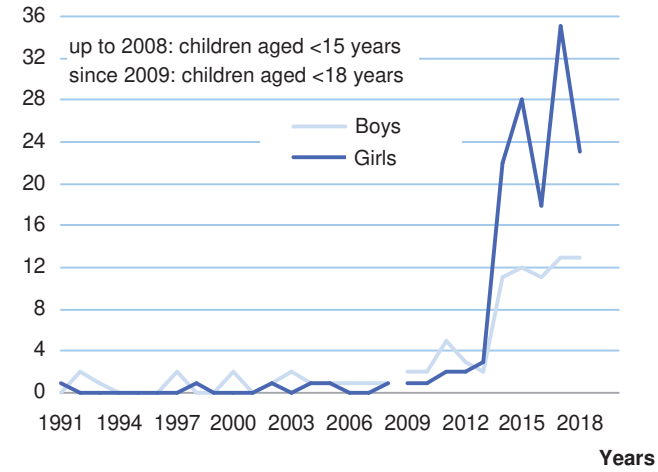
Age- and sex-specific incidence rates per 100,000 Germany 2009-2018



Standardized* annual incidence rates per 100,000 by sex Germany 1991-2018



Absolute number of cases by sex Germany 1991-2018



Gesamttabelle / Overall Table **102**

Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Kinder unter 18 Jahren aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2009-2018) /

Number of cases and incidence rates per million children under the age of 18 years in Germany by diagnosis classified according to ICCC-3, age and sex (2009-2018)

102 Gesamttabelle / Overall Table

Gesamttabelle:

Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Kinder unter 18 Jahren aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2009-2018).
ICCC-3 extended Subklassifikation kursiv dargestellt.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
All malignancies	girls		9683	100	100	909	2848	1952	2389	1585
	boys		12148	100	100	1019	3403	2710	2906	2110
	total	**1.3**	**21831**	**100**	**100**	**1928**	**6251**	**4662**	**5295**	**3695**
Leukaemias, myeloproliferative	girls		2846	29	100	136	1202	683	532	293
and myelodysplastic diseases	boys		3648	30	100	160	1393	927	689	479
	total	**1.3**	**6494**	**30**	**100**	**296**	**2595**	**1610**	**1221**	**772**
Lymphoid leukaemias	girls		2091	22	73	63	1007	558	318	145
	boys		2772	23	76	52	1179	743	486	312
	total	**1.3**	**4863**	**22**	**75**	**115**	**2186**	**1301**	**804**	**457**
Precursor cell leukaemias	girls		2063	21	72	62	998	549	312	142
	boys		2691	22	74	52	1162	704	468	305
	total	**1.3**	**4754**	**22**	**73**	**114**	**2160**	**1253**	**780**	**447**
Mature B-cell leukaemias	girls		27	0	1	1	8	9	6	3
	boys		80	1	2	0	17	38	18	7
	total	**3.0**	**107**	**0**	**2**	**1**	**25**	**47**	**24**	**10**
Mature T-cell and NK cell leukaemias	girls		1	0	0	0	1	0	0	0
	boys		1	0	0	0	0	1	0	0
	total	**1.0**	**2**	**0**	**0**	**0**	**1**	**1**	**0**	**0**
Lymphoid leukaemia, NOS	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Acute myeloid leukaemias	girls		434	4	15	55	132	52	118	77
	boys		468	4	13	63	140	93	89	83
	total	**1.1**	**902**	**4**	**14**	**118**	**272**	**145**	**207**	**160**
Chronic myeloproliferative diseases	girls		50	1	2	0	4	10	20	16
	boys		79	1	2	1	4	14	27	33
	total	**1.6**	**129**	**1**	**2**	**1**	**8**	**24**	**47**	**49**
Myelodysplastic syndrome	girls		243	3	9	14	53	57	68	51
and other myeloproliferative diseases	boys		299	2	8	36	66	71	78	48
	total	**1.2**	**542**	**2**	**8**	**50**	**119**	**128**	**146**	**99**
Unspecified	girls		28	0	1	4	6	6	8	4
and other specified leukaemias	boys		30	0	1	8	4	6	9	3
	total	**1.1**	**58**	**0**	**1**	**12**	**10**	**12**	**17**	**7**
Lymphomas	girls		1224	13	100	21	106	160	422	515
and reticuloendothelial neoplasms	boys		2113	17	100	30	219	487	709	668
	total	**1.7**	**3337**	**15**	**100**	**51**	**325**	**647**	**1131**	**1183**
Hodgkin lymphomas	girls		749	8	61	0	6	44	282	417
	boys		885	7	42	0	28	141	325	391
	total	**1.2**	**1634**	**7**	**49**	**0**	**34**	**185**	**607**	**808**
Non-Hodgkin lymphomas	girls		301	3	25	0	49	64	99	89
	boys		770	6	36	6	87	195	263	219
	total	**2.6**	**1071**	**5**	**32**	**6**	**136**	**259**	**362**	**308**
Precursor cell lymphomas	girls		82	1	7	0	23	25	22	12
	boys		237	2	11	4	43	66	77	47
	total	**2.9**	**319**	**1**	**10**	**4**	**66**	**91**	**99**	**59**

Overall table:

Number of cases and incidence rates per million children under the age of 18 years in Germany by diagnosis classified according to ICCC-3, age and sex (2009-2018).
ICCC-3 extended subclassification in italics.

Incidence rates per million								Trial participants	Survival probabilities(%)		
Age-specific					Age-stand.		Cum.				
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
261	207	113	129	135	155	15	2706	94.8	86	84	83
279	235	148	149	169	183	18	3212	95.4	85	83	82
270	**222**	**131**	**139**	**153**	**170**	**17**	**2966**	**95.1**	**86**	**83**	**82**
39	88	39	29	25	47	4	806	98.9	89	88	87
44	96	51	35	38	56	5	975	98.5	89	88	87
42	**92**	**45**	**32**	**32**	**52**	**5**	**893**	**98.7**	**89**	**88**	**87**
18	73	32	17	12	35	3	597	99.6	92	91	91
14	81	41	25	25	43	4	744	99.6	92	91	90
16	**77**	**37**	**21**	**19**	**39**	**4**	**672**	**99.6**	**92**	**91**	**90**
18	73	32	17	12	35	3	589	99.6	92	91	91
14	80	38	24	24	42	4	722	99.6	92	91	90
16	**77**	**35**	**21**	**18**	**38**	**4**	**657**	**99.6**	**92**	**91**	**90**
0	1	1	0	0	0	0	8	100.0	-	-	-
0	1	2	1	1	1	0	21	100.0	86	86	85
0	**1**	**1**	**1**	**0**	**1**	**0**	**15**	**100.0**	**87**	**87**	**86**
0	0	0	0	0	0	0	0	100.0	-	-	-
0	0	0	0	0	0	0	0	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
16	10	3	6	7	7	1	121	98.2	76	74	74
17	10	5	5	7	7	1	124	95.9	74	73	73
17	**10**	**4**	**5**	**7**	**7**	**1**	**122**	**97.0**	**75**	**74**	**74**
0	0	1	1	1	1	0	14	90.0	94	-	-
0	0	1	1	3	1	0	20	77.2	100	100	-
0	**0**	**1**	**1**	**2**	**1**	**0**	**17**	**82.2**	**97**	**97**	**97**
4	4	3	4	4	4	0	67	96.3	83	81	76
10	5	4	4	4	4	0	79	97.7	84	81	79
7	**4**	**4**	**4**	**4**	**4**	**0**	**73**	**97.0**	**84**	**81**	**78**
1	0	0	0	0	0	0	8	100.0	82	-	-
2	0	0	0	0	0	0	8	100.0	83	83	-
2	**0**	**0**	**0**	**0**	**0**	**0**	**8**	**100.0**	**83**	**83**	**-**
6	8	9	23	44	17	2	328	96.9	94	93	93
8	15	27	36	54	29	3	544	96.3	94	93	92
7	**12**	**18**	**30**	**49**	**23**	**3**	**439**	**96.5**	**94**	**93**	**92**
0	0	3	15	36	10	1	197	97.7	98	98	97
0	2	8	17	31	11	1	223	96.0	98	98	97
0	**1**	**5**	**16**	**33**	**11**	**1**	**210**	**96.8**	**98**	**98**	**97**
0	4	4	5	8	4	0	82	98.0	87	85	84
2	6	11	13	18	11	1	199	97.1	89	88	86
1	**5**	**7**	**10**	**13**	**8**	**1**	**142**	**97.4**	**88**	**87**	**86**
0	2	1	1	1	1	0	23	96.3	86	85	84
1	3	4	4	4	3	0	62	95.4	87	86	85
1	**2**	**3**	**3**	**2**	**2**	**0**	**43**	**95.6**	**87**	**86**	**85**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

104 Gesamttabelle / Overall Table

Forts.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Mature B-cell lymphomas	girls		69	1	6	0	4	17	23	25
(except Burkitt lymphoma)	boys		178	1	8	0	5	33	65	75
	total	**2.6**	**247**	**1**	**7**	**0**	**9**	**50**	**88**	**100**
Mature T-cell and NK-cell lymphomas	girls		71	1	6	0	12	9	28	22
	boys		131	1	6	1	16	25	57	32
	total	**1.8**	**202**	**1**	**6**	**1**	**28**	**34**	**85**	**54**
Non-Hodgkin lymphomas, NOS	girls		79	1	6	0	10	13	26	30
	boys		224	2	11	1	23	71	64	65
	total	**2.8**	**303**	**1**	**9**	**1**	**33**	**84**	**90**	**95**
Burkitt lymphoma	girls		49	1	4	0	11	17	17	4
	boys		287	2	14	0	56	110	77	44
	total	**5.9**	**336**	**2**	**10**	**0**	**67**	**127**	**94**	**48**
Miscellaneous	girls		120	1	10	21	39	35	21	4
lymphoreticular neoplasms	boys		162	1	8	24	48	38	41	11
	total	**1.4**	**282**	**1**	**8**	**45**	**87**	**73**	**62**	**15**
Unspecified lymphomas	girls		5	0	0	0	1	0	3	1
	boys		9	0	0	0	0	3	3	3
	total	**1.8**	**14**	**0**	**0**	**0**	**1**	**3**	**6**	**4**
CNS and miscellaneous intracranial	girls		2348	24	100	149	629	648	637	285
and intraspinal neoplasms	boys		2794	23	100	151	740	810	751	342
	total	**1.2**	**5142**	**24**	**100**	**300**	**1369**	**1458**	**1388**	**627**
Ependymomas	girls		199	2	8	33	82	33	31	20
and choroid plexus tumour	boys		267	2	10	36	102	49	59	21
	total	**1.3**	**466**	**2**	**9**	**69**	**184**	**82**	**90**	**41**
Ependymomas	girls		151	2	6	11	73	24	27	16
	boys		213	2	8	16	84	41	54	18
	total	**1.4**	**364**	**2**	**7**	**27**	**157**	**65**	**81**	**34**
Choroid plexus tumour	girls		48	0	2	22	9	9	4	4
	boys		54	0	2	20	18	8	5	3
	total	**1.1**	**102**	**0**	**2**	**42**	**27**	**17**	**9**	**7**
Astrocytomas	girls		1122	12	48	60	308	310	327	117
	boys		1195	10	43	51	312	353	328	151
	total	**1.1**	**2317**	**11**	**45**	**111**	**620**	**663**	**655**	**268**
Intracranial	girls		306	3	13	30	119	87	50	20
and intraspinal embryonal tumours	boys		532	4	19	39	180	189	79	45
	total	**1.7**	**838**	**4**	**16**	**69**	**299**	**276**	**129**	**65**
Medulloblastomas	girls		206	2	9	6	66	75	41	18
	boys		408	3	15	8	115	169	76	40
	total	**2.0**	**614**	**3**	**12**	**14**	**181**	**244**	**117**	**58**
Primitive neuroectodermal tumour	girls		32	0	1	3	20	4	4	1
(PNET)	boys		38	0	1	2	22	9	3	2
	total	**1.2**	**70**	**0**	**1**	**5**	**42**	**13**	**7**	**3**
Medulloepithelioma	girls		10	0	0	1	2	2	4	1
	boys		8	0	0	2	1	3	0	2
	total	**0.8**	**18**	**0**	**0**	**3**	**3**	**5**	**4**	**3**
Atypical teratoid/rhabdoid tumour	girls		58	1	2	20	31	6	1	0
	boys		78	1	3	27	42	8	0	1
	total	**1.3**	**136**	**1**	**3**	**47**	**73**	**14**	**1**	**1**

cont.

Incidence rates per million								Trial participants	Survival probabilities(%)		
Age-specific					Age-stand.		Cum.				
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
0	0	1	1	2	1	0	19	98.6	89	84	83
0	0	2	3	6	2	0	45	96.1	90	87	86
0	**0**	**1**	**2**	**4**	**2**	**0**	**32**	**96.8**	**90**	**86**	**85**
0	1	1	2	2	1	0	19	97.2	87	87	87
0	1	1	3	3	2	0	34	100.0	88	87	84
0	**1**	**1**	**2**	**2**	**1**	**0**	**27**	**99.0**	**87**	**87**	**85**
0	1	1	1	3	1	0	21	100.0	85	85	-
0	2	4	3	5	3	0	58	98.2	92	90	88
0	**1**	**2**	**2**	**4**	**2**	**0**	**40**	**98.7**	**91**	**89**	**88**
0	1	1	1	0	1	0	14	100.0	93	91	91
0	4	6	4	4	4	0	76	99.0	92	91	91
0	**2**	**4**	**2**	**2**	**2**	**0**	**46**	**99.1**	**92**	**91**	**91**
6	3	2	1	0	2	0	34	88.3	-	-	-
7	3	2	2	1	3	0	43	88.9	-	-	-
6	**3**	**2**	**2**	**1**	**2**	**0**	**39**	**88.7**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	80.0	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**92.9**	**-**	**-**	**-**
43	46	37	34	24	37	4	659	93.1	81	78	76
41	51	44	38	27	42	4	742	93.8	80	76	73
42	**49**	**41**	**37**	**26**	**40**	**4**	**702**	**93.5**	**80**	**77**	**75**
9	6	2	2	2	3	0	56	94.0	85	80	77
10	7	3	3	2	4	0	72	97.8	80	70	65
10	**7**	**2**	**2**	**2**	**4**	**0**	**64**	**96.1**	**82**	**74**	**70**
3	5	1	1	1	3	0	43	95.4	84	78	75
4	6	2	3	1	3	0	57	97.7	78	68	62
4	**6**	**2**	**2**	**1**	**3**	**0**	**50**	**96.7**	**81**	**72**	**67**
6	1	1	0	0	1	0	14	89.6	89	86	82
5	1	0	0	0	1	0	15	98.1	87	81	78
6	**1**	**0**	**0**	**0**	**1**	**0**	**14**	**94.1**	**88**	**84**	**81**
17	22	18	18	10	18	2	315	93.9	85	83	82
14	22	19	17	12	18	2	317	92.9	83	81	79
16	**22**	**19**	**17**	**11**	**18**	**2**	**316**	**93.4**	**84**	**82**	**81**
9	9	5	3	2	5	0	87	96.4	64	61	59
11	12	10	4	4	8	1	143	96.6	68	60	58
10	**11**	**8**	**3**	**3**	**7**	**1**	**116**	**96.5**	**67**	**61**	**58**
2	5	4	2	2	3	0	58	98.1	75	70	68
2	8	9	4	3	6	1	109	97.1	75	66	63
2	**6**	**7**	**3**	**2**	**5**	**0**	**85**	**97.4**	**75**	**68**	**65**
1	1	0	0	0	1	0	9	90.6	60	58	58
1	2	0	0	0	1	0	10	97.4	57	52	50
1	**1**	**0**	**0**	**0**	**1**	**0**	**10**	**94.3**	**60**	**56**	**55**
0	0	0	0	0	0	0	3	90.0	-	-	-
1	0	0	0	0	0	0	2	87.5	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**88.9**	**-**	**-**	**-**
6	2	0	0	0	1	0	17	94.8	-	-	-
7	3	0	0	0	1	0	21	94.9	33	-	-
7	**3**	**0**	**0**	**0**	**1**	**0**	**19**	**94.9**	**28**	**26**	**-**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

106 Gesamttabelle / Overall Table

Forts.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Other gliomas	girls		266	3	11	10	51	103	74	28
	boys		288	2	10	8	60	92	91	37
	total	**1.1**	**554**	**3**	**11**	**18**	**111**	**195**	**165**	**65**
Oligodendrogliomas	girls		7	0	0	0	0	1	2	4
	boys		9	0	0	0	1	1	4	3
	total	**1.3**	**16**	**0**	**0**	**0**	**1**	**2**	**6**	**7**
Mixed and unspecified gliomas	girls		243	3	10	9	45	98	67	24
	boys		264	2	9	8	56	90	79	31
	total	**1.1**	**507**	**2**	**10**	**17**	**101**	**188**	**146**	**55**
Neuroepithelial glial tumours of uncertain origin	girls		16	0	1	1	6	4	5	0
	boys		15	0	1	0	3	1	8	3
	total	**0.9**	**31**	**0**	**1**	**1**	**9**	**5**	**13**	**3**
Other specified intracranial and intraspinal neoplasms	girls		409	4	17	12	59	108	140	90
	boys		476	4	17	16	82	116	177	85
	total	**1.2**	**885**	**4**	**17**	**28**	**141**	**224**	**317**	**175**
Pituitary adenomas and carcinomas	girls		43	0	2	0	0	3	14	26
	boys		28	0	1	0	0	0	15	13
	total	**0.7**	**71**	**0**	**1**	**0**	**0**	**3**	**29**	**39**
Tumours of the sellar region (craniopharyngiomas)	girls		116	1	5	0	22	40	41	13
	boys		112	1	4	2	26	36	32	16
	total	**1.0**	**228**	**1**	**4**	**2**	**48**	**76**	**73**	**29**
Pineal parenchymal tumours	girls		27	0	1	2	3	5	11	6
	boys		20	0	1	2	8	3	4	3
	total	**0.7**	**47**	**0**	**1**	**4**	**11**	**8**	**15**	**9**
Neuronal and mixed neuronal-glial tumours	girls		194	2	8	10	31	52	64	37
	boys		276	2	10	11	46	70	110	39
	total	**1.4**	**470**	**2**	**9**	**21**	**77**	**122**	**174**	**76**
Meningiomas	girls		29	0	1	0	3	8	10	8
	boys		40	0	1	1	2	7	16	14
	total	**1.4**	**69**	**0**	**1**	**1**	**5**	**15**	**26**	**22**
Unspecified intracranial and intraspinal neoplasms	girls		46	0	2	4	10	7	15	10
	boys		36	0	1	1	4	11	17	3
	total	**0.8**	**82**	**0**	**2**	**5**	**14**	**18**	**32**	**13**
Neuroblastoma and other peripheral nervous cell tumours	girls		509	5	100	242	212	34	17	4
	boys		694	6	100	303	316	53	18	4
	total	**1.4**	**1203**	**6**	**100**	**545**	**528**	**87**	**35**	**8**
Neuroblastoma and ganglioneuroblastoma	girls		505	5	99	242	210	34	15	4
	boys		687	6	99	303	314	52	15	3
	total	**1.4**	**1192**	**5**	**99**	**545**	**524**	**86**	**30**	**7**
Other peripheral nervous cell tumours	girls		4	0	1	0	2	0	2	0
	boys		7	0	1	0	2	1	3	1
	total	**1.8**	**11**	**0**	**1**	**0**	**4**	**1**	**5**	**1**
Retinoblastoma	girls		212	2	100	107	102	3	0	0
	boys		229	2	100	94	124	9	2	0
	total	**1.1**	**441**	**2**	**100**	**201**	**226**	**12**	**2**	**0**
Renal tumours	girls		528	5	100	68	306	112	27	15
	boys		459	4	100	84	253	85	27	10
	total	**0.9**	**987**	**5**	**100**	**152**	**559**	**197**	**54**	**25**

cont.

Incidence rates per million								Trial participants	Survival probabilities(%)		
Age-specific					Age-stand.		Cum.				
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
3	4	6	4	2	4	0	75	88.7	49	46	45
2	4	5	5	3	4	0	76	91.3	56	54	52
3	**4**	**5**	**4**	**3**	**4**	**0**	**76**	**90.1**	**53**	**51**	**49**
0	0	0	0	0	0	0	2	100.0	-	-	-
0	0	0	0	0	0	0	2	77.8	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**87.5**	**-**	**-**	**-**
3	3	6	4	2	4	0	69	88.1	45	42	41
2	4	5	4	2	4	0	70	91.3	55	54	50
2	**4**	**5**	**4**	**2**	**4**	**0**	**69**	**89.7**	**50**	**48**	**46**
0	0	0	0	0	0	0	5	93.8	-	-	-
0	0	0	0	0	0	0	4	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**4**	**96.8**	**-**	**-**	**-**
3	4	6	8	8	6	1	113	93.2	96	94	91
4	6	6	9	7	7	1	124	92.9	96	95	92
4	**5**	**6**	**8**	**7**	**6**	**1**	**119**	**93.0**	**96**	**94**	**92**
0	0	0	1	2	1	0	11	86.0	-	-	-
0	0	0	1	1	0	0	7	78.6	100	-	-
0	**0**	**0**	**1**	**2**	**0**	**0**	**9**	**83.1**	**100**	**100**	**100**
0	2	2	2	1	2	0	32	100.0	99	98	96
1	2	2	2	1	2	0	30	98.2	100	99	95
0	**2**	**2**	**2**	**1**	**2**	**0**	**31**	**99.1**	**100**	**99**	**95**
1	0	0	1	1	0	0	7	100.0	-	-	-
1	1	0	0	0	0	0	5	100.0	-	-	-
1	**0**	**0**	**0**	**0**	**0**	**0**	**6**	**100.0**	**61**	**59**	**55**
3	2	3	3	3	3	0	54	92.8	98	95	93
3	3	4	6	3	4	0	72	94.6	97	96	95
3	**3**	**3**	**5**	**3**	**3**	**0**	**63**	**93.8**	**98**	**96**	**94**
0	0	0	1	1	0	0	8	72.4	86	79	-
0	0	0	1	1	1	0	10	72.5	91	88	88
0	**0**	**0**	**1**	**1**	**0**	**0**	**9**	**72.5**	**89**	**84**	**83**
1	1	0	1	1	1	0	13	71.7	92	-	-
0	0	1	1	0	1	0	9	86.1	83	-	-
1	**0**	**1**	**1**	**1**	**1**	**0**	**11**	**78.0**	**88**	**86**	**86**
70	15	2	1	0	10	1	147	96.7	82	80	79
83	22	3	1	0	13	1	190	98.4	79	76	76
76	**19**	**2**	**1**	**0**	**11**	**1**	**169**	**97.7**	**80**	**78**	**77**
70	15	2	1	0	10	1	146	97.0	82	80	79
83	22	3	1	0	12	1	188	98.4	79	77	76
76	**19**	**2**	**1**	**0**	**11**	**1**	**168**	**97.8**	**80**	**78**	**77**
0	0	0	0	0	0	0	1	50.0	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**81.8**	**-**	**-**	**-**
31	7	0	0	0	4	0	61	58.5	98	98	98
26	9	0	0	0	4	0	63	59.4	99	99	99
28	**8**	**0**	**0**	**0**	**4**	**0**	**62**	**59.0**	**99**	**98**	**98**
20	22	6	1	1	9	1	152	98.9	93	92	91
23	17	5	1	1	8	1	126	98.9	92	91	91
21	**20**	**6**	**1**	**1**	**9**	**1**	**139**	**98.9**	**93**	**92**	**91**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

108 Gesamttabelle / Overall Table

Forts.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Nephroblastoma	girls		513	5	97	68	305	110	21	9
and other non-epithelial renal tumours	boys		440	4	96	83	253	83	18	3
	total	**0.9**	**953**	**4**	**97**	**151**	**558**	**193**	**39**	**12**
Nephroblastoma	girls		497	5	94	60	302	107	21	7
	boys		428	4	93	79	248	82	16	3
	total	**0.9**	**925**	**4**	**94**	**139**	**550**	**189**	**37**	**10**
Rhabdoid renal tumour	girls		11	0	2	7	2	1	0	1
	boys		10	0	2	3	5	1	1	0
	total	**0.9**	**21**	**0**	**2**	**10**	**7**	**2**	**1**	**1**
Kidney sarcomas	girls		5	0	1	1	1	2	0	1
	boys		2	0	0	1	0	0	1	0
	total	**0.4**	**7**	**0**	**1**	**2**	**1**	**2**	**1**	**1**
Peripheral neuroectodermal tumour	girls		0	0	0	0	0	0	0	0
(pPNET) of kidney	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Renal carcinomas	girls		15	0	3	0	1	2	6	6
	boys		19	0	4	1	0	2	9	7
	total	**1.3**	**34**	**0**	**3**	**1**	**1**	**4**	**15**	**13**
Unspecified malignant renal tumours	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Hepatic tumours	girls		129	1	100	32	66	9	11	11
	boys		160	1	100	45	81	12	13	9
	total	**1.2**	**289**	**1**	**100**	**77**	**147**	**21**	**24**	**20**
Hepatoblastoma	girls		105	1	81	32	66	5	1	1
	boys		145	1	91	45	81	10	7	2
	total	**1.4**	**250**	**1**	**87**	**77**	**147**	**15**	**8**	**3**
Hepatic carcinomas	girls		24	0	19	0	0	4	10	10
	boys		15	0	9	0	0	2	6	7
	total	**0.6**	**39**	**0**	**13**	**0**	**0**	**6**	**16**	**17**
Unspecified malignant hepatic tumours	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Malignant bone tumours	girls		486	5	100	1	23	86	239	137
	boys		630	5	100	3	31	96	281	219
	total	**1.3**	**1116**	**5**	**100**	**4**	**54**	**182**	**520**	**356**
Osteosarcomas	girls		247	3	51	0	5	39	138	65
	boys		325	3	52	0	4	37	155	129
	total	**1.3**	**572**	**3**	**51**	**0**	**9**	**76**	**293**	**194**
Chondrosarcomas	girls		5	0	1	0	0	1	2	2
	boys		8	0	1	1	0	1	6	0
	total	**1.6**	**13**	**0**	**1**	**1**	**0**	**2**	**8**	**2**
Ewing tumour	girls		218	2	45	1	17	44	93	63
and related sarcomas of bone	boys		286	2	45	2	26	57	115	86
	total	**1.3**	**504**	**2**	**45**	**3**	**43**	**101**	**208**	**149**
Ewing tumour	girls		209	2	43	0	16	41	92	60
and askin tumour of bone	boys		279	2	44	1	24	56	114	84
	total	**1.3**	**488**	**2**	**44**	**1**	**40**	**97**	**206**	**144**

cont.

Incidence rates per million								Trial participants	Survival probabilities(%)		
Age-specific					Age-stand.		Cum.				
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
20	22	6	1	1	9	1	148	99.4	93	92	92
23	17	5	1	0	8	1	121	99.3	92	92	92
21	**20**	**5**	**1**	**0**	**8**	**1**	**134**	**99.4**	**93**	**92**	**92**
17	22	6	1	1	9	1	144	99.4	94	93	93
22	17	4	1	0	7	1	117	99.3	93	92	92
19	**19**	**5**	**1**	**0**	**8**	**1**	**130**	**99.4**	**93**	**92**	**92**
2	0	0	0	0	0	0	3	100.0	-	-	-
1	0	0	0	0	0	0	3	100.0	-	-	-
1	**0**	**0**	**0**	**0**	**0**	**0**	**3**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	100.0	-	-	-
0	0	0	0	0	0	0	1	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	0	0	0	1	0	0	4	80.0	-	-	-
0	0	0	0	1	0	0	5	89.5	-	-	-
0	**0**	**0**	**0**	**1**	**0**	**0**	**4**	**85.3**	**92**	**92**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
9	5	1	1	1	2	0	37	76.7	76	74	74
12	6	1	1	1	3	0	43	79.4	80	76	76
11	**5**	**1**	**1**	**1**	**3**	**0**	**40**	**78.2**	**78**	**75**	**75**
9	5	0	0	0	2	0	30	79.0	85	85	85
12	6	1	0	0	3	0	40	79.3	86	84	84
11	**5**	**0**	**0**	**0**	**2**	**0**	**35**	**79.2**	**86**	**84**	**84**
0	0	0	1	1	0	0	6	66.7	-	-	-
0	0	0	0	1	0	0	4	80.0	-	-	-
0	**0**	**0**	**0**	**1**	**0**	**0**	**5**	**71.8**	**47**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	2	5	13	12	7	1	131	97.9	-	-	-
1	2	5	14	18	8	1	160	98.1	-	-	-
1	**2**	**5**	**14**	**15**	**8**	**1**	**146**	**98.0**	**-**	**-**	**-**
0	0	2	7	6	3	0	66	99.2	79	75	74
0	0	2	8	10	4	0	82	97.8	71	65	64
0	**0**	**2**	**8**	**8**	**4**	**0**	**74**	**98.4**	**75**	**69**	**69**
0	0	0	0	0	0	0	1	100.0	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**100.0**	**-**	**-**	**-**
0	1	3	5	5	3	0	59	98.2	-	-	-
1	2	3	6	7	4	0	73	99.0	-	-	-
0	**2**	**3**	**5**	**6**	**3**	**0**	**66**	**98.6**	**-**	**-**	**-**
0	1	2	5	5	3	0	57	98.6	-	-	-
0	2	3	6	7	4	0	71	98.9	-	-	-
0	**1**	**3**	**5**	**6**	**3**	**0**	**64**	**98.8**	**-**	**-**	**-**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

110 Gesamttabelle / Overall Table

Forts.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Peripheral neuroectodermal tumour	girls		9	0	2	1	1	3	1	3
(pPNET) of bone	boys		7	0	1	1	2	1	1	2
	total	**0.8**	**16**	**0**	**1**	**2**	**3**	**4**	**2**	**5**
Other specified malignant bone tumours	girls		13	0	3	0	1	2	5	5
	boys		9	0	1	0	1	1	4	3
	total	**0.7**	**22**	**0**	**2**	**0**	**2**	**3**	**9**	**8**
Malignant fibrous	girls		0	0	0	0	0	0	0	0
neoplasms of bone	boys		1	0	0	0	0	0	1	0
	total	**-**	**1**	**0**	**0**	**0**	**0**	**0**	**1**	**0**
Malignant chordomas	girls		10	0	2	0	1	1	3	5
	boys		7	0	1	0	1	1	3	2
	total	**0.7**	**17**	**0**	**2**	**0**	**2**	**2**	**6**	**7**
Odontogenic malignant tumours	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Miscellaneous malignant	girls		3	0	1	0	0	1	2	0
bone tumours	boys		1	0	0	0	0	0	0	1
	total	**0.3**	**4**	**0**	**0**	**0**	**0**	**1**	**2**	**1**
Unspecified malignant bone tumours	girls		3	0	1	0	0	0	1	2
	boys		2	0	0	0	0	0	1	1
	total	**0.7**	**5**	**0**	**0**	**0**	**0**	**0**	**2**	**3**
Soft tissue	girls		549	6	100	48	134	109	152	106
and other extraosseous sarcomas	boys		701	6	100	76	171	161	155	138
	total	**1.3**	**1250**	**6**	**100**	**124**	**305**	**270**	**307**	**244**
Rhabdomyosarcomas	girls		256	3	47	18	80	62	61	35
	boys		367	3	52	28	128	100	48	63
	total	**1.4**	**623**	**3**	**50**	**46**	**208**	**162**	**109**	**98**
Fibrosarcomas, peripheral	girls		56	1	10	7	12	7	17	13
nerve sheath tumours	boys		71	1	10	20	5	12	21	13
and other fibrous neoplasms	**total**	**1.3**	**127**	**1**	**10**	**27**	**17**	**19**	**38**	**26**
Fibroblastic	girls		27	0	5	7	7	4	4	5
and myofibroblastic tumours	boys		34	0	5	15	3	5	8	3
	total	**1.3**	**61**	**0**	**5**	**22**	**10**	**9**	**12**	**8**
Nerve sheath tumours	girls		29	0	5	0	5	3	13	8
	boys		37	0	5	5	2	7	13	10
	total	**1.3**	**66**	**0**	**5**	**5**	**7**	**10**	**26**	**18**
Other fibrous neoplasms	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Kaposi sarcoma	girls		2	0	0	0	1	1	0	0
	boys		1	0	0	0	0	0	1	0
	total	**0.5**	**3**	**0**	**0**	**0**	**1**	**1**	**1**	**0**
Other specified soft tissue sarcomas	girls		193	2	35	17	30	31	65	50
	boys		203	2	29	21	26	41	66	49
	total	**1.1**	**396**	**2**	**32**	**38**	**56**	**72**	**131**	**99**
Ewing tumour	girls		41	0	7	0	7	6	15	13
and askin tumour of soft tissue	boys		36	0	5	0	4	10	12	10
	total	**0.9**	**77**	**0**	**6**	**0**	**11**	**16**	**27**	**23**

cont.

Incidence rates per million											
Age-specific					Age-stand.		Cum.	Trial participants	Survival probabilities(%)		
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
0	0	0	0	0	0	0	2	88.9	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**93.8**	**-**	**-**	**-**
0	0	0	0	0	0	0	4	69.2	-	-	-
0	0	0	0	0	0	0	2	88.9	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**3**	**77.3**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	3	80.0	-	-	-
0	0	0	0	0	0	0	2	85.7	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**82.4**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	33.3	-	-	-
0	0	0	0	0	0	0	0	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**50.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	100.0	-	-	-
0	0	0	0	0	0	0	0	50.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**80.0**	**-**	**-**	**-**
14	10	6	8	9	9	1	153	98.4	74	71	69
21	12	9	8	11	11	1	185	98.1	72	69	68
17	**11**	**8**	**8**	**10**	**10**	**1**	**169**	**98.2**	**73**	**70**	**69**
5	6	4	3	3	4	0	72	100.0	68	66	65
8	9	5	2	5	6	1	98	99.7	73	71	70
6	**7**	**5**	**3**	**4**	**5**	**0**	**85**	**99.8**	**70**	**69**	**68**
2	1	0	1	1	1	0	15	91.1	82	82	82
5	0	1	1	1	1	0	19	98.6	74	70	68
4	**1**	**1**	**1**	**1**	**1**	**0**	**17**	**95.3**	**78**	**76**	**74**
2	1	0	0	0	0	0	8	92.6	97	97	-
4	0	0	0	0	1	0	9	97.1	94	94	-
3	**0**	**0**	**0**	**0**	**1**	**0**	**8**	**95.1**	**95**	**95**	**95**
0	0	0	1	1	0	0	8	89.7	-	-	-
1	0	0	1	1	1	0	10	100.0	55	-	-
1	**0**	**0**	**1**	**1**	**0**	**0**	**9**	**95.5**	**60**	**56**	**54**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	100.0	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**66.7**	**-**	**-**	**-**
5	2	2	4	4	3	0	53	98.4	83	74	72
6	2	2	3	4	3	0	53	97.0	71	67	64
5	**2**	**2**	**3**	**4**	**3**	**0**	**53**	**97.7**	**77**	**71**	**68**
0	1	0	1	1	1	0	11	97.6	89	83	-
0	0	1	1	1	0	0	9	100.0	76	-	-
0	**0**	**0**	**1**	**1**	**1**	**0**	**10**	**98.7**	**83**	**78**	**78**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

112 Gesamttabelle / Overall Table

Forts.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Peripheral neuroectodermal tumour	girls		3	0	1	0	1	1	0	1
(pPNET) of soft tissue	boys		11	0	2	0	3	2	5	1
	total	**3.7**	**14**	**0**	**1**	**0**	**4**	**3**	**5**	**2**
Extrarenal rhabdoid tumour	girls		34	0	6	14	12	4	3	1
	boys		33	0	5	17	8	4	2	2
	total	**1.0**	**67**	**0**	**5**	**31**	**20**	**8**	**5**	**3**
Liposarcomas	girls		7	0	1	0	0	0	4	3
	boys		8	0	1	0	0	1	2	5
	total	**1.1**	**15**	**0**	**1**	**0**	**0**	**1**	**6**	**8**
Fibrohistiocytic tumours	girls		24	0	4	1	6	6	9	2
	boys		22	0	3	2	6	3	7	4
	total	**0.9**	**46**	**0**	**4**	**3**	**12**	**9**	**16**	**6**
Leiomyosarcomas	girls		1	0	0	0	0	0	0	1
	boys		2	0	0	0	0	1	0	1
	total	**2.0**	**3**	**0**	**0**	**0**	**0**	**1**	**0**	**2**
Synovial sarcomas	girls		47	0	9	0	0	7	25	15
	boys		48	0	7	1	2	10	22	13
	total	**1.0**	**95**	**0**	**8**	**1**	**2**	**17**	**47**	**28**
Blood vessel tumours	girls		7	0	1	0	2	2	0	3
	boys		5	0	1	0	0	1	3	1
	total	**0.7**	**12**	**0**	**1**	**0**	**2**	**3**	**3**	**4**
Osseous and chondromatous	girls		5	0	1	0	0	1	2	2
neoplasms of soft tissue	boys		4	0	1	0	0	1	1	2
	total	**0.8**	**9**	**0**	**1**	**0**	**0**	**2**	**3**	**4**
Alveolar soft parts sarcoma	girls		11	0	2	0	0	2	5	4
	boys		7	0	1	0	0	1	3	3
	total	**0.6**	**18**	**0**	**1**	**0**	**0**	**3**	**8**	**7**
Miscellaneous soft tissue sarcomas	girls		13	0	2	2	2	2	2	5
	boys		27	0	4	1	3	7	9	7
	total	**2.1**	**40**	**0**	**3**	**3**	**5**	**9**	**11**	**12**
Unspecified soft tissue sarcomas	girls		42	0	8	6	11	8	9	8
	boys		59	0	8	7	12	8	19	13
	total	**1.4**	**101**	**0**	**8**	**13**	**23**	**16**	**28**	**21**
Germ cell tumours,	girls		426	4	100	99	44	58	142	83
trophoblastic tumours	boys		417	3	100	69	46	30	122	150
and neoplasms of gonads	**total**	**1.0**	**843**	**4**	**100**	**168**	**90**	**88**	**264**	**233**
Intracranial	girls		66	1	15	6	2	19	30	9
and intraspinal germ cell tumours	boys		171	1	41	5	6	25	92	43
	total	**2.6**	**237**	**1**	**28**	**11**	**8**	**44**	**122**	**52**
Intracranial and intraspinal germinoma	girls		35	0	8	0	1	5	22	7
	boys		108	1	26	0	0	12	60	36
	total	**3.1**	**143**	**1**	**17**	**0**	**1**	**17**	**82**	**43**
Intracranial and intraspinal teratomas	girls		10	0	2	4	1	1	2	2
	boys		18	0	4	5	4	6	3	0
	total	**1.8**	**28**	**0**	**3**	**9**	**5**	**7**	**5**	**2**
Intracranial	girls		0	0	0	0	0	0	0	0
and intraspinal embryonal carcinoma	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**

cont.

Incidence rates per million											
Age-specific					Age-stand.		Cum.	Trial participants	Survival probabilities(%)		
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
0	0	0	0	0	0	0	1	100.0	-	-	-
0	0	0	0	0	0	0	3	100.0	74	74	65
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**100.0**	**84**	**82**	**77**
4	1	0	0	0	1	0	10	97.1	-	-	-
5	1	0	0	0	1	0	9	93.9	-	-	-
4	**1**	**0**	**0**	**0**	**1**	**0**	**9**	**95.5**	**-**	**-**	**-**
0	0	0	0	0	0	0	2	100.0	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	7	100.0	-	-	-
1	0	0	0	0	0	0	6	95.5	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**6**	**97.8**	**98**	**90**	**-**
0	0	0	0	0	0	0	0	100.0	-	-	-
0	0	0	0	0	0	0	1	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**	**-**
0	0	0	1	1	1	0	13	100.0	96	84	75
0	0	1	1	1	1	0	12	97.9	80	71	69
0	**0**	**0**	**1**	**1**	**1**	**0**	**12**	**98.9**	**88**	**77**	**72**
0	0	0	0	0	0	0	2	100.0	-	-	-
0	0	0	0	0	0	0	1	80.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**91.7**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	100.0	-	-	-
0	0	0	0	0	0	0	1	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	3	100.0	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**100.0**	**96**	**-**	**-**
1	0	0	0	0	0	0	4	92.3	-	-	-
0	0	0	0	1	0	0	7	96.3	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**5**	**95.0**	**-**	**-**	**-**
2	1	0	0	1	1	0	12	97.6	67	64	-
2	1	0	1	1	1	0	15	93.2	66	61	61
2	**1**	**0**	**1**	**1**	**1**	**0**	**14**	**95.0**	**67**	**62**	**62**
28	3	3	8	7	7	1	118	93.4	96	95	94
19	3	2	6	12	6	1	107	94.5	93	92	92
24	**3**	**2**	**7**	**10**	**6**	**1**	**112**	**94.0**	**94**	**93**	**93**
2	0	1	2	1	1	0	18	95.5	96	89	88
1	0	1	5	3	2	0	44	91.8	87	86	85
2	**0**	**1**	**3**	**2**	**2**	**0**	**31**	**92.8**	**90**	**87**	**86**
0	0	0	1	1	0	0	10	97.1	100	97	-
0	0	1	3	3	1	0	27	95.4	92	92	92
0	**0**	**0**	**2**	**2**	**1**	**0**	**19**	**95.8**	**95**	**93**	**93**
1	0	0	0	0	0	0	3	90.0	-	-	-
1	0	0	0	0	0	0	5	72.2	-	-	-
1	**0**	**0**	**0**	**0**	**0**	**0**	**4**	**78.6**	**86**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

114 Gesamttabelle / Overall Table

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Intracranial	girls		1	0	0	0	0	1	0	0
and intraspinal yolk sac tumour	boys		6	0	1	0	0	1	4	1
	total	**6.0**	**7**	**0**	**1**	**0**	**0**	**2**	**4**	**1**
Intracranial	girls		4	0	1	0	0	3	1	0
and intraspinal choriocarcinoma	boys		0	0	0	0	0	0	0	0
	total	**-**	**4**	**0**	**0**	**0**	**0**	**3**	**1**	**0**
Intracranial	girls		16	0	4	2	0	9	5	0
and intraspinal tumours of mixed form	boys		39	0	9	0	2	6	25	6
	total	**2.4**	**55**	**0**	**7**	**2**	**2**	**15**	**30**	**6**
Malignant extracranial	girls		143	1	34	93	36	1	8	5
and extragonadal germ cell tumours	boys		83	1	20	36	16	3	9	19
	total	**0.6**	**226**	**1**	**27**	**129**	**52**	**4**	**17**	**24**
Germinomas of extracranial	girls		12	0	3	3	5	0	3	1
and extragonadal sites	boys		15	0	4	0	3	0	4	8
	total	**1.3**	**27**	**0**	**3**	**3**	**8**	**0**	**7**	**9**
Malignant teratomas of extracranial	girls		72	1	17	67	3	0	2	0
and extragonadal sites	boys		34	0	8	31	2	0	1	0
	total	**0.5**	**106**	**0**	**13**	**98**	**5**	**0**	**3**	**0**
Embryonal carcinomas of extracranial	girls		0	0	0	0	0	0	0	0
and extragonadal sites	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Yolk sac tumour of extracranial	girls		38	0	9	14	22	0	0	2
and extragonadal sites	boys		16	0	4	1	10	0	1	4
	total	**0.4**	**54**	**0**	**6**	**15**	**32**	**0**	**1**	**6**
Choriocarcinomas of extracranial	girls		1	0	0	0	0	0	1	0
and extragonadal sites	boys		1	0	0	0	0	0	0	1
	total	**1.0**	**2**	**0**	**0**	**0**	**0**	**0**	**1**	**1**
Other and unspecified malignant mixe	girls		20	0	5	9	6	1	2	2
germ cell tumours of extracranial	boys		17	0	4	4	1	3	3	6
and extragonadal sites	**total**	**0.9**	**37**	**0**	**4**	**13**	**7**	**4**	**5**	**8**
Malignant gonadal germ cell tumours	girls		198	2	46	0	6	37	97	58
	boys		163	1	39	28	24	2	21	88
	total	**0.8**	**361**	**2**	**43**	**28**	**30**	**39**	**118**	**146**
Malignant gonadal germinomas	girls		52	1	12	0	3	6	26	17
	boys		9	0	2	0	0	1	1	7
	total	**0.2**	**61**	**0**	**7**	**0**	**3**	**7**	**27**	**24**
Malignant gonadal teratomas	girls		38	0	9	0	0	9	21	8
	boys		19	0	5	9	1	0	4	5
	total	**0.5**	**57**	**0**	**7**	**9**	**1**	**9**	**25**	**13**
Malignant gonadal	girls		0	0	0	0	0	0	0	0
embryonal carcinomas	boys		14	0	3	0	1	0	1	12
	total	**-**	**14**	**0**	**2**	**0**	**1**	**0**	**1**	**12**
Malignant gonadal yolk sac tumour	girls		34	0	8	0	2	8	15	9
	boys		31	0	7	10	19	0	0	2
	total	**0.9**	**65**	**0**	**8**	**10**	**21**	**8**	**15**	**11**
Malignant gonadal choriocarcinoma	girls		6	0	1	0	0	0	5	1
	boys		11	0	3	0	0	0	1	10
	total	**1.8**	**17**	**0**	**2**	**0**	**0**	**0**	**6**	**11**

cont.

Incidence rates per million											
Age-specific					Age-stand.		Cum.	Trial participants	Survival probabilities(%)		
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
0	0	0	0	0	0	0	0	100.0	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	100.0	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**	**-**
1	0	1	0	0	0	0	5	93.8	-	-	-
0	0	0	1	0	1	0	10	89.7	81	-	-
0	**0**	**0**	**1**	**0**	**0**	**0**	**7**	**90.9**	**85**	**-**	**-**
27	3	0	0	0	3	0	41	93.7	95	95	95
10	1	0	0	2	1	0	22	97.6	91	91	89
18	**2**	**0**	**0**	**1**	**2**	**0**	**31**	**95.1**	**94**	**94**	**93**
1	0	0	0	0	0	0	3	100.0	-	-	-
0	0	0	0	1	0	0	4	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**4**	**100.0**	**-**	**-**	**-**
19	0	0	0	0	1	0	21	90.3	94	94	94
8	0	0	0	0	1	0	9	97.1	-	-	-
14	**0**	**0**	**0**	**0**	**1**	**0**	**15**	**92.5**	**92**	**92**	**92**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
4	2	0	0	0	1	0	11	97.4	95	95	95
0	1	0	0	0	0	0	4	100.0	-	-	-
2	**1**	**0**	**0**	**0**	**0**	**0**	**8**	**98.1**	**95**	**95**	**95**
0	0	0	0	0	0	0	0	100.0	-	-	-
0	0	0	0	0	0	0	0	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**	**-**
3	0	0	0	0	0	0	6	95.0	-	-	-
1	0	0	0	0	0	0	4	94.1	-	-	-
2	**0**	**0**	**0**	**0**	**0**	**0**	**5**	**94.6**	**95**	**-**	**-**
0	0	2	5	5	3	0	53	95.5	99	98	98
8	2	0	1	7	2	0	41	95.7	98	98	98
4	**1**	**1**	**3**	**6**	**3**	**0**	**47**	**95.6**	**98**	**98**	**98**
0	0	0	1	1	1	0	14	96.2	100	100	100
0	0	0	0	1	0	0	2	88.9	-	-	-
0	**0**	**0**	**1**	**1**	**0**	**0**	**8**	**95.1**	**100**	**100**	**100**
0	0	1	1	1	1	0	10	86.8	100	100	100
2	0	0	0	0	0	0	5	94.7	-	-	-
1	**0**	**0**	**1**	**1**	**0**	**0**	**8**	**89.5**	**100**	**100**	**100**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	1	0	0	3	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**100.0**	**-**	**-**	**-**
0	0	0	1	1	0	0	9	100.0	94	94	94
3	1	0	0	0	1	0	8	93.5	96	96	96
1	**1**	**0**	**0**	**0**	**1**	**0**	**9**	**96.9**	**95**	**95**	**95**
0	0	0	0	0	0	0	2	100.0	-	-	-
0	0	0	0	1	0	0	3	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**100.0**	**87**	**-**	**-**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

116 Gesamttabelle / Overall Table

Forts.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative	Group	Age groups				
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Malignant gonadal tumours	girls		68	1	16	0	1	14	30	23
of mixed forms	boys		79	1	19	9	3	1	14	52
	total	**1.2**	**147**	**1**	**17**	**9**	**4**	**15**	**44**	**75**
Malignant gonadal gonadoblastoma	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Gonadal carcinomas	girls		13	0	3	0	0	0	5	8
	boys		0	0	0	0	0	0	0	0
	total	**-**	**13**	**0**	**2**	**0**	**0**	**0**	**5**	**8**
Other and unspecified	girls		6	0	1	0	0	1	2	3
malignant gonadal tumours	boys		0	0	0	0	0	0	0	0
	total	**-**	**6**	**0**	**1**	**0**	**0**	**1**	**2**	**3**
Other malignant epithelial neoplasms	girls		409	4	100	3	15	49	207	135
and malignant melanomas	boys		287	2	100	3	18	39	138	89
	total	**0.7**	**696**	**3**	**100**	**6**	**33**	**88**	**345**	**224**
Adrenocortical carcinomas	girls		13	0	3	1	4	1	4	3
	boys		9	0	3	1	6	2	0	0
	total	**0.7**	**22**	**0**	**3**	**2**	**10**	**3**	**4**	**3**
Thyroid carcinomas	girls		136	1	33	0	0	20	70	46
	boys		74	1	26	1	0	10	43	20
	total	**0.5**	**210**	**1**	**30**	**1**	**0**	**30**	**113**	**66**
Nasopharyngeal carcinomas	girls		6	0	1	0	0	0	4	2
	boys		24	0	8	0	0	0	12	12
	total	**4.0**	**30**	**0**	**4**	**0**	**0**	**0**	**16**	**14**
Malignant melanomas	girls		50	1	12	2	9	12	18	9
	boys		48	0	17	1	9	9	18	11
	total	**1.0**	**98**	**0**	**14**	**3**	**18**	**21**	**36**	**20**
Skin carcinomas	girls		6	0	1	0	0	2	4	0
	boys		6	0	2	0	1	0	2	3
	total	**1.0**	**12**	**0**	**2**	**0**	**1**	**2**	**6**	**3**
Other and unspecified carcinomas	girls		198	2	48	0	2	14	107	75
	boys		126	1	44	0	2	18	63	43
	total	**0.6**	**324**	**1**	**47**	**0**	**4**	**32**	**170**	**118**
Carcinomas of salivary glands	girls		15	0	4	0	1	0	12	2
	boys		10	0	3	0	0	4	5	1
	total	**0.7**	**25**	**0**	**4**	**0**	**1**	**4**	**17**	**3**
Carcinomas of colon and rectum	girls		5	0	1	0	1	0	3	1
	boys		17	0	6	0	0	1	5	11
	total	**3.4**	**22**	**0**	**3**	**0**	**1**	**1**	**8**	**12**
Carcinomas of appendix	girls		130	1	32	0	0	11	74	45
	boys		55	0	19	0	0	4	40	11
	total	**0.4**	**185**	**1**	**27**	**0**	**0**	**15**	**114**	**56**
Carcinomas of lung	girls		12	0	3	0	0	0	3	9
	boys		14	0	5	0	0	2	5	7
	total	**1.2**	**26**	**0**	**4**	**0**	**0**	**2**	**8**	**16**
Carcinomas of thymus	girls		2	0	0	0	0	0	0	2
	boys		0	0	0	0	0	0	0	0
	total	**-**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**2**

cont.

Incidence rates per million								Trial participants	Survival probabilities(%)		
Age-specific					Age-stand.		Cum.				
0	1-4	5-9	10-14	15-17	World *	Europe+	0-17	%	5-yrs	10-yrs	15-yrs
0	0	1	2	2	1	0	18	97.1	100	98	-
2	0	0	1	4	1	0	20	96.2	100	-	-
1	**0**	**0**	**1**	**3**	**1**	**0**	**19**	**96.6**	**100**	**98**	**98**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	0	0	0	1	0	0	3	46.2	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**46.2**	**-**	**-**	**-**
0	0	0	0	0	0	0	2	100.0	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**	**-**
1	1	3	11	12	6	1	110	81.4	92	90	89
1	1	2	7	7	4	0	73	77.0	90	87	85
1	**1**	**2**	**9**	**9**	**5**	**1**	**91**	**79.6**	**91**	**89**	**87**
0	0	0	0	0	0	0	4	92.3	-	-	-
0	0	0	0	0	0	0	2	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**3**	**95.5**	**-**	**-**	**-**
0	0	1	4	4	2	0	36	84.6	99	99	99
0	0	1	2	2	1	0	19	89.2	99	99	94
0	**0**	**1**	**3**	**3**	**1**	**0**	**27**	**86.2**	**99**	**99**	**97**
0	0	0	0	0	0	0	2	66.7	-	-	-
0	0	0	1	1	0	0	6	87.5	91	-	-
0	**0**	**0**	**0**	**1**	**0**	**0**	**4**	**83.3**	**90**	**90**	**-**
1	1	1	1	1	1	0	14	60.0	-	-	-
0	1	0	1	1	1	0	12	50.0	-	-	-
0	**1**	**1**	**1**	**1**	**1**	**0**	**13**	**55.1**	**90**	**-**	**-**
0	0	0	0	0	0	0	2	33.3	-	-	-
0	0	0	0	0	0	0	2	33.3	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**33.3**	**-**	**-**	**-**
0	0	1	6	6	3	0	53	85.9	89	-	-
0	0	1	3	3	2	0	32	78.6	84	-	-
0	**0**	**1**	**4**	**5**	**2**	**0**	**42**	**83.0**	**86**	**78**	**76**
0	0	0	1	0	0	0	4	53.3	-	-	-
0	0	0	0	0	0	0	3	30.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**3**	**44.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	60.0	-	-	-
0	0	0	0	1	0	0	4	52.9	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**3**	**54.5**	**-**	**-**	**-**
0	0	1	4	4	2	0	35	97.7	-	-	-
0	0	0	2	1	1	0	14	94.5	-	-	-
0	**0**	**0**	**3**	**2**	**1**	**0**	**24**	**96.8**	**-**	**-**	**-**
0	0	0	0	1	0	0	3	83.3	-	-	-
0	0	0	0	1	0	0	4	78.6	-	-	-
0	**0**	**0**	**0**	**1**	**0**	**0**	**3**	**80.8**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**

- insufficient data

* Standard: Segi world standard population (2)

\+ Standard: European standard population (3)

118 Gesamttabelle / Overall Table

Forts.

Diagnoses	Sex	Sex ratio	Number of cases N	Relative Group %	%	Age groups 0	1-4	5-9	10-14	15-17
		m / f	0-17	%	%	0	1-4	5-9	10-14	15-17
Carcinomas of breast	girls		1	0	0	0	0	0	0	1
	boys		1	0	0	0	1	0	0	0
	total	**1.0**	**2**	**0**	**0**	**0**	**1**	**0**	**0**	**1**
Carcinomas of cervix uteri	girls		2	0	0	0	0	0	2	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**2**	**0**	**0**	**0**	**0**	**0**	**2**	**0**
Carcinomas of bladder	girls		2	0	0	0	0	0	0	2
	boys		2	0	1	0	0	0	0	2
	total	**1.0**	**4**	**0**	**1**	**0**	**0**	**0**	**0**	**4**
Carcinomas of eye	girls		1	0	0	0	0	0	1	0
	boys		1	0	0	0	0	0	1	0
	total	**1.0**	**2**	**0**	**0**	**0**	**0**	**0**	**2**	**0**
Carcinomas of other specified sites	girls		24	0	6	0	0	3	10	11
	boys		18	0	6	0	0	5	5	8
	total	**0.8**	**42**	**0**	**6**	**0**	**0**	**8**	**15**	**19**
Carcinomas of unspecified site	girls		4	0	1	0	0	0	2	2
	boys		8	0	3	0	1	2	2	3
	total	**2.0**	**12**	**0**	**2**	**0**	**1**	**2**	**4**	**5**
Others and unspecified malignant neoplasms	girls		17	0	100	3	9	1	3	1
	boys		16	0	100	1	11	1	1	2
	total	**0.9**	**33**	**0**	**100**	**4**	**20**	**2**	**4**	**3**
Other specified malignant tumours	girls		11	0	65	0	7	1	2	1
	boys		14	0	88	1	11	1	0	1
	total	**1.3**	**25**	**0**	**76**	**1**	**18**	**2**	**2**	**2**
Gastrointestinal stromal tumour	girls		1	0	6	0	0	0	1	0
	boys		1	0	6	0	0	1	0	0
	total	**1.0**	**2**	**0**	**6**	**0**	**0**	**1**	**1**	**0**
Pancreatoblastoma	girls		3	0	18	0	1	1	1	0
	boys		2	0	13	0	1	0	0	1
	total	**0.7**	**5**	**0**	**15**	**0**	**2**	**1**	**1**	**1**
Pulmonary blastoma and pleuropulmonary blastoma	girls		6	0	35	0	6	0	0	0
	boys		11	0	69	1	10	0	0	0
	total	**1.8**	**17**	**0**	**52**	**1**	**16**	**0**	**0**	**0**
Other complex mixed and stromal neoplasms	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Mesothelioma	girls		1	0	6	0	0	0	0	1
	boys		0	0	0	0	0	0	0	0
	total	**-**	**1**	**0**	**3**	**0**	**0**	**0**	**0**	**1**
Other specified malignant tumours	girls		0	0	0	0	0	0	0	0
	boys		0	0	0	0	0	0	0	0
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**
Other unspecified malignant tumours	girls		6	0	35	3	2	0	1	0
	boys		2	0	13	0	0	0	1	1
	total	**0.3**	**8**	**0**	**24**	**3**	**2**	**0**	**2**	**1**

cont.

Incidence rates per million Age-specific 0	1-4	5-9	10-14	15-17	Age-stand. World *	Europe+	Cum. 0-17	Trial participants %	Survival probabilities(%) 5-yrs	10-yrs	15-yrs
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**50.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	50.0	-	-	-
0	0	0	0	0	0	0	0	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**75.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	100.0	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**50.0**	**-**	**-**	**-**
0	0	0	1	1	0	0	6	70.8	-	-	-
0	0	0	0	1	0	0	5	77.8	-	-	-
0	**0**	**0**	**0**	**1**	**0**	**0**	**5**	**73.8**	**79**	**-**	**-**
0	0	0	0	0	0	0	1	75.0	-	-	-
0	0	0	0	0	0	0	2	87.5	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**2**	**83.3**	**-**	**-**	**-**
1	1	0	0	0	0	0	5	76.5	-	-	-
0	1	0	0	0	0	0	4	87.5	-	-	-
1	**1**	**0**	**0**	**0**	**0**	**0**	**5**	**81.8**	**71**	**-**	**-**
0	1	0	0	0	0	0	3	81.8	-	-	-
0	1	0	0	0	0	0	4	85.7	-	-	-
0	**1**	**0**	**0**	**0**	**0**	**0**	**3**	**84.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	100.0	-	-	-
0	0	0	0	0	0	0	0	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	1	66.7	-	-	-
0	0	0	0	0	0	0	1	50.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**60.0**	**-**	**-**	**-**
0	0	0	0	0	0	0	2	100.0	-	-	-
0	1	0	0	0	0	0	3	90.9	-	-	-
0	**1**	**0**	**0**	**0**	**0**	**0**	**2**	**94.1**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
0	0	0	0	0	0	0	0	-	-	-	-
0	0	0	0	0	0	0	0	-	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**	**-**
1	0	0	0	0	0	0	2	66.7	-	-	-
0	0	0	0	0	0	0	1	100.0	-	-	-
0	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**75.0**	**-**	**-**	**-**

- insufficient data
* Standard: Segi world standard population (2)
\+ Standard: European standard population (3)

120 Methoden / Methods inc. ICCC-3

Datengrundlage, Methoden und Ergebnisdarstellung – Basis of Registration, Methods and Presentation

Datengrundlage, Methoden und Ergebnisdarstellung – Basis of Registration, Methods and Presentation

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 Patient*innen oder deren Sorgeberechtigten eine spezielle Einwilligung gegeben werden muss. Aufgrund des großen Engagements der Familien liegt der Anteil der nicht gegebenen Einwilligungen bei unter 1 %, weitere unter 1 % der Einwilligungen fehlen aus anderen Gründen. Im Falle einer fehlenden Einwilligung erfolgt eine anonymisierte Minimal-Erfassung, um diese Fälle zumindest mit ihrer Verdachtsdiagnose bei den allgemeinen Inzidenzberechnungen mitzählen zu können. Spätere Datenprüfungen, Ergänzungen, Nachbeobachtung und direktes Ansprechen der Betroffenen sind dann nicht möglich.

Die behandelnden Ärzte melden unentgeltlich und grundsätzlich freiwillig. Aufgrund dieser Voraussetzungen war durch das Inkrafttreten des Krebsregistergesetzes des Bundes (1.1.1995) und der diversen Landeskrebsregistergesetze eine Änderung in der Verfahrensweise zur systematischen Erfassung der Erkrankungsfälle nicht erforderlich. Von 2007-2019 schrieb die „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherug für die stationäre Versorgung von Kindern und Jugendlichen mit hämatoonkologischen Krankheiten gemäß § 137 Abs. 1 Satz 1 Nr. 2 SGB V für nach § 108 SGB V zugelassene Krankenhäuser (Vereinbarung zur Kinderonkologie KiOn-RL)“ die Meldung von Fällen unter 18 Jahren mit pädiatrisch-onkologischen Erkrankungen in Einrichtungen der pädiatrischen Onkologie an das Deutsche Kinderkrebsregister vor (43). Das am 9.4.2013 in Kraft getretene Krebsfrüherkennungs- und registergesetz des Bundes (KFRG) (30) schließt Fälle „die an das Deutsche Kinderkrebsregister zu melden sind“ ausdrücklich nicht ein, ohne dass näher spezifiziert wird, auf welcher Grundlage diese zu melden sind und welche Fälle dies einschließt. Die darauf folgenden Landesgesetzgebungen regeln dies unterschiedlich, so besteht in einigen Ländern auch eine Meldepflicht für Fälle im Kindes- und Jugendalter an das jeweilige klinische Krebsregister.

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

Charakterisierung des Deutschen Kinderkrebsregisters

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

Legal basis and financial support

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

The treating physicians report cases for free and basically voluntarily. Because of this a change of procedure was not necessary when the federal cancer registry law (1.1.1995) and the state registry laws came into effect. From 2007-2019 the directive „Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten gemäß § 137 Abs. 1 Satz 1 Nr. 2 SGB V für nach § 108 SGB V zugelassene Krankenhäuser (Vereinbarung zur Kinderonkologie KiOn-RL)“ made reporting cases under 18 treated in clinics for pediatric oncology to the German Childhood Cancer Registry mandatory (43). The law „Krebsfrüherkennungs- und -registergesetz des Bundes (KFRG)“ (30), in effect since 9th April 2013, explicitly does not include pediatric oncology cases under 18 due to the responsibility of the GCCR. In some federal states, however, reporting cases in childhood and adolescence to the state registry is mandatory by state law.

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

Characterization of the German Childhood Cancer Registry

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

Es ist dadurch charakterisiert, dass es neben den üblichen, in einem bevölkerungsbezogenen Krebsregister erfassten Daten auch klinische Informationen (z. B. Stadium, Grading, immunologische Subtypen) erfasst (5). Dieser klinische Bezug ist gewährleistet durch die enge Kooperation mit den etwa 25 pädiatrisch-onkologischen Therapieoptimierungsstudien (klinischen Studien) bzw. diagnosespezifischen klinischen Registern der GPOH. Der Anteil der hierin erfassten Fälle ist mit über 90 % sehr hoch.

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

Dokumentationsablauf und Datenfluss

Von den kooperierenden Kliniken wird jeweils bei Auftreten einer Neuerkrankung ein kurzer Meldebogen an das DKKR geschickt (DKKR-Erstmeldung). Er enthält u.a. die Verdachtsdiagnose, wesentliche Identifikationsmerkmale, die Bestätigung der Einwilligung zu der Meldung durch Patient*in und/oder Sorgeberechtigte und die Information, ob und bei welcher klinischen Therapieoptimierungsstudie/welchem diagnosespezifischen klinischen Register die Patient*innen gemeldet wurden. Diese Vorgehensweise wird in absehbarer Zeit durch die Möglichkeit einer direkten elektronischen Meldung ersetzt/ergänzt. Die Weiterleitung validierter diagnostischer Detail-Informationen von der Therapiestudienleitung an das DKKR erfolgt später, meist elektronisch, in regelmäßigen Intervallen. Bis auf vereinzelte Ausnahmen sind alle Diagnosen histologisch oder immunologisch verifiziert.

Bis zum Abschluss der primären Therapiephase und im Verlauf der Nachsorge erfolgt normalerweise eine regelmäßige Nachbeobachtung durch die Therapie-Studienleitung bzw. das diagnosespezifische Register. Dies erstreckt sich üblicherweise über die 5 Jahre nach Diagnose. Anschließend erfolgt die Nachbeobachtung durch das DKKR, wobei DKKR und Therapiestudienleitung die Daten jeweils untereinander austauschen. Das DKKR erhält Nachbeobachtungs-Informationen aus mehreren Quellen: der Klinik (solange Patient*innen dort noch in der Nachsorge sind), Einwohnermeldeämtern, gegebenenfalls Landeskrebsregistern und nicht zuletzt in zunehmendem Maße von den Patient*innen selbst. Der Dokumentationsablauf und die Synergieeffekte zwischen Therapieoptimierungsstudien und DKKR sind in (5, 6, 9, 27, 28, 44) beschrieben. Da die Meldegrundlage bei Patient*innen unter 16 gewöhnlich die Einwilligung der Sorgeberechtigten ist, erhält jede*r Patient*in um den 16. Geburtstag vom Deutschen Kinderkrebsregister eine Mitteilung, dass entsprechende Daten am DKKR gespeichert sind. Damit verbunden ist die Ankündigung künftiger Anschreiben. Es besteht Gelegenheit, dies oder die namentliche Speicherung insgesamt abzulehnen, wovon nur ein kleiner Teil der Patient*innen Gebrauch macht. Patient*innen, von denen seit 5 oder mehr Jahren keine aktuellen Informationen mehr vorliegen, werden in jährlichen Aktionen angeschrieben. Die Langzeitnachbeobachtung ist in (16, 20, 21, 71) publiziert.

is a population based registry combined with some features of a clinical registry, registering also clinical details such as staging, grading, and immunological subtypes (5). The clinical information is based on the integrated information exchange and data flow between the ca. 25 GPOH organized therapy optimization trials or respective diagnosis specific registries and the GCCR. More than 90% of all cases are included in these trials or respective diagnosis specific registries.

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

Documentation and flow of information

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

Tumour-specific follow-up information is usually provided by the therapy studies until the end of the first clinical treatment phase and during clinical follow-up, which usually lasts about 5 years. After this, the long-term follow-up is conducted by the GCCR, regularly exchanging this information with the therapy trials or respective diagnosis specific registries. The GCCR collects data from various sources, such as the hospitals (during aftercare), state cancer registries, municipalities, and increasingly the patients themselves. This flow of information is described in (5, 6, 9, 27, 28, 44).

The basis for reporting patients under 16 is usually the consent of the custodian, so every patient is informed around their 16th birthday of their data stored at the GCCR. Along with this more correspondence is announced. This gives them an opportunity to refuse further mail or even identified data storage, both opportunities are usually taken by only few patients. Patients whose most recent contact or new information is 5 years or older are regularly contacted. The follow-up procedures are published in (16, 20, 21, 71).

Datengrundlage

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

Die Klassifizierung der Erkrankungen erfolgt derzeit nach der International Classification of Childhood Cancer 3rd edition (ICCC-3) (10). Sie basiert auf einer Zusammenfassung entsprechender Morphologien und Topographien, codiert jeweils nach der ICD-O-3 (7) 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.

Krebserkrankungen bei Erwachsenen werden gewöhnlich nach ICD (derzeit ICD10), also vorwiegend lokalisationsbezogen berichtet. Um eine Vergleichbarkeit zur Berichterstattung des RKI (51) herzustellen, ergänzen wir die Berichterstattung nach ICCC um 8 Seiten nach den in Deutschland berichteten ICD-10-Gruppen, und zwar die vier häufigsten Krebsarten bei Kindern: Leukämien, maligne ZNS-Tumore, Hodgkin-Lymphome und Neubildungen der Weichteile; sowie die vier häufigsten Krebsarten im Erwachsenenalter: Lungenkarzinome, Prostatakarzinome, Brustkarzinome und Kolorektale Karzinome. Dabei passt sich die Auswahl der dargestellten Maßzahlen soweit möglich an (51) an.
Die Vollzähligkeit der Erfassung für unter 15-Jährige beträgt seit 1987 über 95 %; sie entspricht damit den internationalen Anforderungen an epidemiologische Krebsregister. Auch die Meldungen typisch pädiatrisch-onkologischer Diagnosen für Jugendliche (15-17 Jahre) sind weitgehend vollzählig. Für einige Diagnosen, die auch häufiger oder typischerweise eher im Erwachsenenalter auftreten und auch außerhalb der Kliniken für Kinder- und Jugendonkologie behandelt werden, fehlen jedoch Meldungen.

Neben den in der ICCC-3 definierten Diagnosen werden am DKKR einige weitere Diagnosegruppen systematisch erfasst (Tabelle 4). Für einige dieser Diagnosen existieren eigene Therapieoptimierungsstudien der Fachgesellschaft GPOH, zumindest die Studienfälle werden systematisch gemeldet. In den meisten Landesgesetzen nach KFRG (30) sind Abgleiche epidemiologischer Daten vorgesehen, die derzeit implementiert werden.

Die Erfassung von Zweit-/Folgeneoplasien (SN) ohne Altersbegrenzung erfolgt aus verschiedenen Quellen, darunter freiwillige Angaben von den betroffenen Patient*innen, die eine Nachfrage bei ihren behandelnden Ärzten erlauben. Trotz aller Bemühungen ist nicht auszuschließen, dass diese Erfassung nicht vollzählig ist, die angegebenen Zahlen sind daher als untere Abschätzung anzusehen.

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 18th birthday, since 2009 before the 18th birthday, and resident in Germany at diagnosis. Since 1991, cases from the area of the former German Democratic Republic (GDR) are included.

Classification of diseases is currently based on the International Classification of Childhood Cancer 3rd edition (ICCC-3) (10). The ICCC-3 is an aggregation of morphology and topography codes based on ICD-O-3 (7), 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.

Adult cancer is usually reported by ICD (currently ICD-10), which emphasises localisation. In order to compare to the general German Cancer reporting (51), we supplement the usual reporting by ICCC by 8 pages by ICD-10: the four most frequent cancers in children by ICD-10: Leukaemias, malignant CNS-tumours, Hodgkin-Lymphomas and soft tissue neoplasms; and the four generally most frequent diagnoses by ICD-10: Lung cancer, prostate cancer, breast cancer and colorectal cancer. The measures chosen are as far as possible comparable to those in (51).

The completeness of registration for cases under 15 is more than 95% since 1987; this complies with international requirements for an epidemiologic cancer registry. Reporting of typically pediatric oncologic diagnoses for adolescents (15-17 years) are also mostly complete. Some diagnoses, which would frequently or typically occur in adults and can be treated outside pediatric oncology are, however, underrepresented.

Besides the diagnoses defined in ICCC-3, the GCCR records a number of further diagnoses systematically (Table 4). For some of these diagnoses, there exist therapy optimization trials within the GPOH, study cases are usually systematically reported. Most of the new state cancer registries installed following KFRG (30) provide for a data exchange of epidemiological data, which is currently being implemented.

The ascertainment of second/subsequent neoplasms (SN) without age limit is based on a variety of sources, including voluntary reports from patients themselves who permit their treating physicians to provide information. In spite of all efforts it is possible that the numbers are not complete, thus we consider our numbers to be a lower estimate.

Grundlagen der Registrierung und Arbeitsweise zum Nachlesen

Literaturstellen

- Meldung und Dokumentationsablauf (5, 6, 9, 13, 27, 28, 42, 44, 61)
- Langzeitnachbeobachtung (16, 20, 21, 35)
- Statistische und epidemiologische Methodik (1-4, 7, 8, 10)
- Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten (43)

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

Further Information on the Basis of Registration and Procedures

References

- Notification and documentation (5, 6, 9, 13, 27, 28, 42, 44, 61)
- Long-term surveillance (16, 20, 21, 35)
- Statistical methods (1-4, 7, 8, 10)
- Richtlinie des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten (43)

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

- Beschluss der 82. Gesundheitsministerkonferenz 2009 (Kinderkrebsregister - Anhebung der Altersgrenze für die Registrierung von Kindern und Jugendlichen) (13)
- Bundeskrebsregisterdatengesetz (12)
- Krebsfrüherkennungs- und -registergesetz (KFRG) (30)
- Notwendigkeit der namensbezogenen Datenspeicherung (44)
- Die Rahmenbedingungen des Deutschen Kinderkrebsregisters (9)
- Positionspapier der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) zu (Langzeit-) Nachbeobachtung, (Langzeit-)Nachsorge und Spätfolgenerhebung bei pädiatrisch-onkologischen Patienten (71)
- DKKR-Regelwerk des Deutschen Kinderkrebsregisters zu datenschutz-relevanten Aspekten (48)
- DKKR-Einwilligungserklärung (32)
- DKKR-Technisches Datenschutz- und Datensicherheitskonzept des Deutschen Kinderkrebsregisters, Ergänzende Informationen nach DSGVO (42, 61)
- Die Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters (16, 20, 21)

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 dem jeweilig angegebenen Zeitraum. Alle Angaben sind für die letzten 10 Jahre des Berichtszeitraums, soweit nicht anders angegeben. Dabei zählen wir im Allgemeinen Fälle, nicht Patient*innen. Der Anteil der an Therapieoptimierungsstudien oder diagnosespezifischen klinischen Registern der GPOH teilnehmenden Fälle schließt alle Fälle ein, von denen eine Studienleitung in irgendeiner Form Kenntnis hat. Das heißt, in diesem Anteil sind auch Fälle enthalten, die nicht zur Gruppe der Studienteilnehmer im engeren Sinne zu zählen sind.

Descriptive Measures – Incidence and general measures

The total number of cases refers to the cases diagnosed at age <15 years, from 2009 onwards <18 years, resident in Germany at the time of diagnosis, broken down by diagnosis, age group, sex and time periods. All figures are given for the most recent 10 years of the reporting period, unless otherwise stated. We usually count cases, not patients. The relative frequency of trial cases includes all cases the trial centre or respective diagnosis specific registry is informed of. This also includes cases who may not be treated according to protocol.

Die Inzidenzrate (Neuerkrankungsrate) bezieht die Anzahl der neu aufgetretenen Fälle in einem bestimmten Gebiet und Zeitraum auf die zugehörige Wohnbevölkerung im entsprechenden Alter. Alle Inzidenzraten in diesem Bericht sind Durchschnittsangaben für den jeweiligen Zeitraum und werden als Rate pro 1000000 (Million) Personenjahre dargestellt.

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

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

mit N_{ij} Anzahl der Neuerkrankungen im Alter j im Zeitraum i und B_{ij} Bevölkerung im Alter j im Zeitraum i. In der Regel werden in diesem Bericht altersspezifische Inzidenzraten für die unter 1-jährigen (j=1), die 1- bis 4-jährigen (j=2), die 5- bis 9-jährigen (j=3), die 10- bis 14-jährigen (j=4) und die 15- bis17-jährigen (j=5) Kinder berechnet. Die (direkt) altersstandardisierte Inzidenzrate „Welt" bzw. „Europa" für unter 18-Jährige errechnet sich mit Hilfe der Gewichte w_j des von Segi erarbeiteten WHO-Welt-Standards (2) bzw. des Europa-Standards (3) wie in Tabelle M.1 angegeben:

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

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

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

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

Tabelle M. 1 / Table M. 1

Zusammensetzung der Segi Weltbevölkerung und Europa Bevölkerung für Kinder unter 18 Jahren im Vergleich zur durchschnittlichen deutschen Wohnbevölkerung 2009-2018

Composition of the Segi world standard and european population for children under 18 years compared to the German population 2009-2018

Age-groups (years)	German population 2009-2018		Standard population	
	Absolute	Relative < 18	World Weights < 18	Europe Weights < 18
0	713,127	0.05	0.07	0.06
1-4	2,821,599	0.21	0.26	0.22
5-9	3,563,580	0.27	0.27	0.24
10-14	3,799,683	0.29	0.25	0.24
15-17	2,450,717	0.18	0.15	0.24
Total		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.

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

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

$$C_{ij} = \sum_j I_{ij}$$

wobei hier gewöhnlich 18 Einzelaltersjahresklassen verwendet werden (j=1,...,18). Sie kann interpretiert

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.

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

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

$$C_{ij} = \sum_j I_{ij}$$

usually using 18 single-year age classes (j=1,…, 18). It can be interpreted as the risk (the probability) of a

werden als das Risiko (die Wahrscheinlichkeit) eines neugeborenen Kindes, bis zum 18. Geburtstag an einer Krebserkrankung zu erkranken.

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

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

Die Bevölkerungszahlen für das Jahr 2018 lagen bei Erstellung des Jahresberichts noch nicht vor und wurden hochgerechnet. Die Hochrechnung basiert auf dem Trend der Vorjahre und den Geburtenzahlen des Vorjahrs. Aus diesem Grund ist das letzte Jahr in der Trenddarstellung ebenso blassblau gekennzeichnet wie die Jahre 1980-87, wo die Meldungen des Registers überwiegend noch nicht vollzählig waren.
Innerhalb des Altersfensters bis unter 18 Jahren sind die Hälfte der Fälle bei Diagnose jünger und die andere Hälfte älter als das mediane Alter bei Diagnose (angegeben in Monaten).
Neben den im Jahresbericht veröffentlichten Tabellen und Abbildungen finden sich auf der Homepage des Deutschen Kinderkrebsregisters noch weitere detaillierte Zahlen zum Abruf (41).

Daten für Überlebenswahrscheinlichkeit, Mortalität und Folgeneoplasien

Das Follow-up in den jeweils aktuellsten Jahren des Registers ist immer erst mit einer gewissen Zeitverzögerung vollständig. Auch wurden in den ersten Registerjahren relativ viele Fälle anonym registriert, die nicht nachbeobachtet werden können. Um zu entscheiden, für welchen Zeitraum und für welche maximale Nachbeobachtungszeit verlässliche Angaben zu Überlebenszeit, Mortalität und der kumulativen Inzidenz von Folgeneoplasien gemacht werden können, benötigt man eine Qualitätsgrenze und eine Metrik zur Berechnung dieser Grenze. Für jede*n Patient*in liegt am DKKR ein individuelles letztes Beobachtungsdatum vor. Für die Verstorbenen endet die Beobachtung an diesem Datum, die Übrigen könnten prinzipiell bis zu einem Stichtag nachbeobachtet werden. Bezogen auf den Stichtag lässt sich dann errechnen, welcher Anteil der maximal möglichen Gesamtnachbeobachtungszeit (Personenjahre unter Risiko) vorliegt. Entsprechendes kann für einen gegebenen maximalen Nachbeobachtungszeitraum errechnet werden. Gefordert wurden mindestens 50 %. Daraus ergab sich die Notwendigkeit, die Fälle von 1980 aus Berechnungen von Überleben und kumulativer Folgeneoplasie-Inzidenz herauszunehmen und nur Daten bis 2016 einzubeziehen. Die maximale Nachbeobachtungszeit sind derzeit 30 Jahre; 81 % des insgesamt möglichen follow-up wurden in diesem Zeitraum beobachtet. Überlebenszeitkurven und die kumulative Folgeneoplasie-Inzidenz werden nur bis zu der Nachbeobachtungszeit berechnet, dargestellt und angegeben, wenn noch mindestens 20 Patient*innen am Ende des angegebenen Zeitraums unter Beobachtung sind.

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

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

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

For 2018 population data was not yet available; we are thus using estimated numbers. The estimation is based on the trend of the previous years and the number of births of the previous year. So the last year and the years 1980-87, where most of the registry data was not complete yet, are indicated in pale blue in the trend graphics.
Until the 18th birthday half of the cases are younger than the median age at diagnosis, and the other half are older (presented in months).
In addition to the Tables and Figures in this report, more detailed numbers can be obtained from the homepage of the German Childhood Cancer registry (41).

Data for Survival probability and mortality

The Follow-up in the respective most recent years of the registry is usually completed with a delay. Also in the first years of the registry, a relatively large number of anonymous cases was registered, who cannot be followed-up. We need to decide, for which time period and which maximal follow-up time we can give reliable numbers for survival, mortality and the cumulative incidence of subsequent neoplasms. For this we need a decision rule and a metric for this decision rule. For each patient, we record an individual last observation date. For a deceased patient, follow-up ends at that date, all others can theoretically be followed-up until a set date. Relative to that date we can calculate, which percentage of the maximally possible total follow-up time (person years under risk) is available. A similar calculation is possible for a set maximum follow-up. We set the limit at 50%. Based on this we need to exclude 1980 from the estimation of survival and subsequent neoplasms incidence. Only data until 2016 can be used and the maximal follow-up which can be reported is currently 30 years; for this period 81% of the potential follow-up were actually observed. Survival probability estimates and curves are presented only as long as there are still 20 patients under risk by the end of the reported observation time; cumulative subsequent neoplasm incidence for 30 years is reported only, if 20 or more patients are still under observation.

Berechnung von Überlebenswahrscheinlichkeit und Mortalität

Die Berechnung der Überlebenswahrscheinlichkeiten erfolgt nach der von Brenner und Spix vorgeschlagenen Modifikation des Sterbetafel-Verfahrens (8). 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. Dargestellt werden die Überlebenswahrscheinlichkeiten nach Diagnosejahren für die erste und zweite Dekade, die dritte und die angefangene vierte Dekade werden kombiniert, bis aus der vierten Dekade mindestens 5 Jahre verwendet werden können. Neben der Gesamtüberlebenswahrscheinlichkeit kann für die meisten Diagnosen auch das ereignisfreie Überleben errechnet werden. Die Definition eines „Ereignisses" umfasst je nach Diagnose und Therapieprotokoll unterschiedliche Ereignisse wie Rezidive, Progress oder neu aufgetretene Fernmetastasen. Das Auftreten eines Folgetumors (s.u.) wird immer als Ereignis gewertet.

Die Berechnung der Mortalitätsrate und der kumulativen Mortalität erfolgt analog zur Inzidenzrate und kumulativen Inzidenz. Es werden die Todesfälle der 5, 10 und 15 Jahre nach Diagnose betrachtet bezogen auf einen entsprechend um 5/10/15 Jahre zurückverlegten Diagnosezeitraum.

Zweit-/Folgeneoplasien

Eine Zweit-/Folgeneoplasie ist eine weitere Neubildung, die nach der ersten bzw. vorangegangenen Neoplasie bei dem/der gleichen Patient*in auftritt. Die englischen Begriffe hierzu sind ‚second neoplasm' oder ‚subsequent neoplasm', abgekürzt SN.

Die Berechnung der kumulativen Inzidenz der innerhalb von 30 Jahren nach Diagnose aufgetretenen zweiten Krebserkrankungen (SN) bezieht sich nur auf in der ICCC-3 definierte Krebserkrankungen. Gutartige weitere Erkrankungen (außer den in der ICCC-3 eingeschlossenen ZNS-Tumoren) werden hier nicht mitgezählt.

Die Bezugsbevölkerung für die Berechnung der im Jahresbericht angegebenen kumulativen Inzidenz der zweiten Krebserkrankungen ist die Gruppe aller Patient*innen mit einer ersten Krebserkrankung (nach ICCC-3) im Alter von unter 18 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 (4) eine Variante des Kaplan-Meier-Verfahrens (1) angewendet, das diesen Umstand als konkurrierendes Risiko berücksichtigt. Angegeben wird die kumulative Inzidenz einer zweiten Krebserkrankung nach der jeweils dargestellten Ersterkrankung, sowie umgekehrt die jeweils betrachtete Krebserkrankung ihrerseits als zweite Erkrankung nach einer beliebigen vorangegangenen Krebserkrankung.

Estimating survival probability and mortality

Survival probabilities were computed using the life table method extension proposed by Brenner and Spix (8). These estimates can be directly compared to the more commonly used estimates by Kaplan-Meier (1), but also permit making statements for more recently diagnosed cases regarding a) extrapolated long-term survival and b) more stable short-term survival estimates. We present the survival curves for the first and second decade, the third and the beginning of the fourth decade are combined until we can use at least five years out of the fourth. Besides overall survival most diagnoses allow presenting event free survival. The definition of an "event" differs by diagnosis and therapy protocol, it can include events such as relapses, progress, or new distant metastases. A subsequent neoplasm always counts as event (see below).

The mortality rate and the cumulative mortality are computed in analogy to the incidence rate and the cumulative incidence. We include only deaths within a 5-, 10-, and 15-year follow-up after diagnosis referring to the diagnosis period from 5/10/15 years earlier.

Second/Subsequent neoplasms

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

The cumulative incidence of second neoplasms (SN) within 30 years of diagnosis includes only ICCC-3 defined cases. Non-malignant diseases (unless they are non-malignant CNS-tumours included in ICCC-3) are not counted here.

The population base for these calculations are all patients with a primary disease (as defined in ICCC-3) at age <18, 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 (4), 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.

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

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

Second neoplasms (SN) within 30 yrs. of diagnosis (1981-2016):
I (b) Acute myeloid leukaemias

SN after I (b)			I (b) as SN after any primary		
N	% of all 1540 SN	Cumulative incidence	N	% of all 1540 SN	Cumulative incidence
68	4.4 %	5.8 %	165	10.7 %	0.3 %

Bei den in den Jahren 1981-2016 mit einer AML unter 18 Jahren als erster Krebserkrankung diagnostizierten Patient*innen wurden in den folgenden bis zu 30 Jahren 68 zweite Krebserkrankungen diagnostiziert. Das sind 4,4 % von allen 1540 innerhalb von 30 Jahren nach Diagnose in den Jahren 1981-2016 an das DKKR gemeldeten zweiten Krebserkrankungen. Bei 5,8 % aller primären AML Patient*innen wird innerhalb von 30 Jahren nach Erstdiagnose eine weitere Krebserkrankung diagnostiziert, das ist unterdurchschnittlich im Vergleich zum durchschnittlichen SN-Risiko nach allen Malignomen von 6,8 %.

Within 30 years of diagnosis 68 second neoplasms were diagnosed out of the patients with an AML as a first diagnosis at age under 18 in the years 1981-2016. These are 4.4 % of all 1540 recorded second neoplasms within 30 years of diagnosis in the years 1981-2016 at the GCCR. 5.8% of all primary AML patients are diagnosed with a second neoplasm within 30 years of diagnosis in the years 1980-2016, this is below the average cumulative incidence of 6.8% for all malignancies.

Nach einer ersten Krebserkrankung beliebigen Typs im Alter von unter 18 in den Jahren 1981-2016 wurde bei 165 Patient*innen anschließend in den nächsten 30 Jahren eine AML diagnostiziert. 10,7% aller 1540 dem DKKR innerhalb von 30 Jahren nach Diagnose in den Jahren 1981-2016 gemeldeten zweiten Krebserkrankungen sind AML, im Vergleich zu dem Anteil von AML an allen Krebserkrankungen im Kindesalter (4,1%) ist das ungewöhnlich viel. Bei 0,3 % aller KrebsPatient*innen im Kindes- und Jugendalter wird innerhalb von 30 Jahren nach Erstdiagnose eine AML als zweite Krebserkrankung diagnostiziert, damit ist dies eine der häufigsten Zweitneoplasien.

After any primary neoplasm at age under 18 in 1981-2016, 165 patients were diagnosed with AML as second neoplasms within 30 years of diagnosis. 10.7% of all 1540 second neoplasms within 30 years of diagnosis of the primary disease in the years 1981-2016 reported at the GCCR are AML, compared to 4.1% AML in general, this is a large number. 0.3% of all childhood cancer patients are diagnosed with a second AML within 30 years of diagnosis, making this one of the most frequent second neoplasms.

Räumliche Verteilung

Die kartographische Darstellung präsentiert standardisierte Inzidenzraten unter 18 Jahren auf Kreisebene in 7 Gruppen, die jeweils 5 %, 10 %, 15 %, 40 %, 15 %, 10 % und 5 % der Kreise (Landkreise und kreisfreie Städte) von der niedrigsten bis zur höchsten Inzidenzrate umfassen. Bei seltenen Diagnosen werden in mehr als 5 % (bzw. 15 % usw.) der Kreise keine Fälle beobachtet und diese werden entsprechend zusammengefasst (siehe rechte Beispielkarte). Die sich daraus ergebenden Klassengrenzen sind in der Legende links oben erkennbar. Die Verteilung ist in dem Histogramm rechts ablesbar. Bei sehr seltenen Diagnosen ist eine kartographische Darstellung nicht mehr sinnvoll.

Spatial distribution

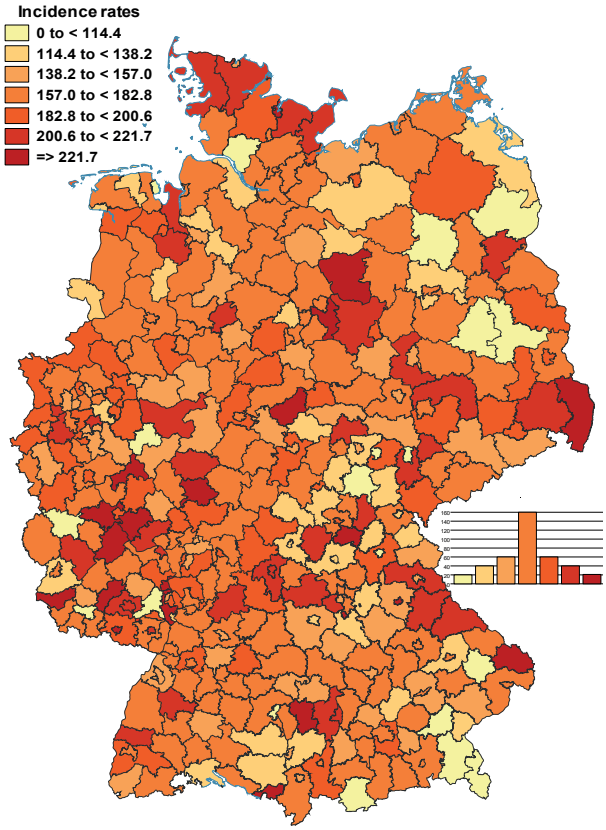
The map presentation shows the standardized incidence rates for ages under 18 in 7 classes, each covering 5%, 10%, 15%, 40%, 15%, 10% and 5% of all “Kreise” (counties), ordered from the smallest to the largest incidence rate. For rare diagnoses, a number of Kreise do not observe a single case and the lower classes have to be aggregated (see right side sample map). The class limits derived from this are shown in the legend on the left. The distribution can be seen in the histogram on the right. For very rare diagnoses map presentations are not useful.

Bei den Auswertungen zur regionalen Verteilung von Neuerkrankungshäufigkeiten (Tabelle 5) 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 18 Jahren an der fraglichen Diagnose im Zeitraum i in der Region r. Der erwartete Wert berechnet sich aus der Zahl der Einwohner in den

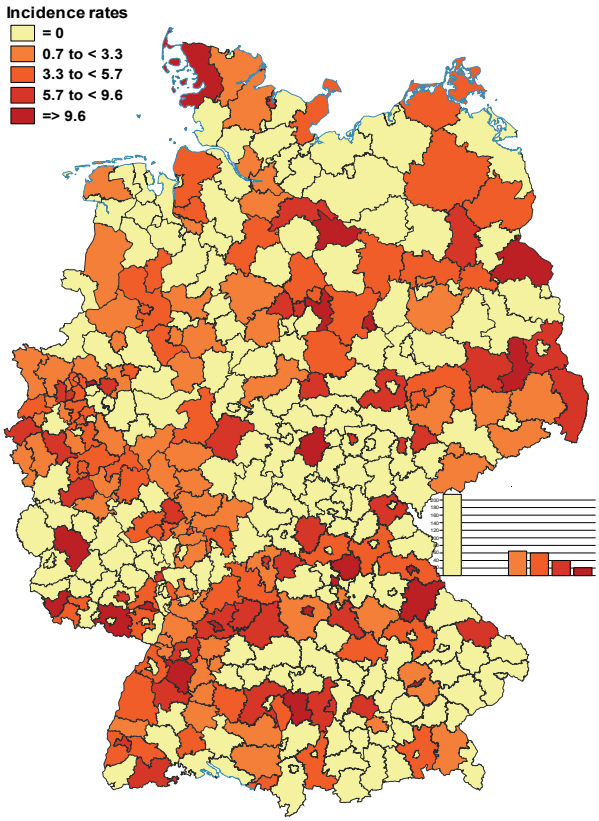
In Table 5 we present some tabulated data on regional standardized incidence rates. It includes the Standardized Incidence Ratio (SIR), which is computed as the ratio of the observed and expected number of cases. The observed number N_{ir} is the number of all cases under 18 years with the diagnosis 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.

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

All malignancies



Burkitt lymphoma



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

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

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 401 Kreisen wären also zufällig etwa 20 Kreise mit ungewöhnlich hohen oder niedrigen Inzidenzraten zu erwarten, tatsächlich waren es beispielsweise für alle ICCC-3 Diagnosen für den Zeitraum 2009-2018 27 Kreise, davon 10 mit besonders hohen und 17 mit besonders niedrigen Inzidenzraten.

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

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 401 Kreise we would thus randomly expect about 20 with unusual incidence rates. For the time period 2009-2018 for all ICCC-3 diagnoses we actually observed 27, 10 with unusually high and 17 with unusually low incidence rates.

Internationale Klassifikation der Krebserkrankungen bei Kindern (ICCC-3)
Zuordnung von ICD-O-3-Codes für Morphologie und Topographie zu diagnostischen Kategorien

International Classification of Childhood Cancer (ICCC-3)
Categorization of morphology and topography codes, corresponding to ICD-O-3

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

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

[#] *Burkitt lymphoma (IIc), as a mature B-cell non-Hodgkin lymphoma, may be pooled with IIb2 for overall presentation of B-cell lymphomas.*

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

Forts. / cont.

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

* *Tumours with non-malignant behaviour codes are included*

Forts. / cont.

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

Forts. / cont.

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

Forts. / cont.

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

* *Tumours with non-malignant behaviour codes are included*

Forts. / cont.

DIAGNOSTIC GROUP	ICD-O-3 CODES	
	MORPHOLOGY	TOPOGRAPHY
X GERM CELL TUMOURS, TROPHOBLASTIC TUMOURS AND NEOPLASMS OF GONADS (cont.)		
(d) Gonadal carcinomas	8010-8041, 8050-8075, 8082, 8120-8122, 8130-8141, 8143, 8190-8201, 8210, 8211, 8221-8241, 8244-8246, 8260-8263, 8290, 8310, 8313, 8320, 8323, 8380-8384, 8430, 8440, 8480-8490, 8504, 8510, 8550, 8560-8573, 9000, 9014, 9015	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		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**

Neues zu Forschungsprojekten – News on Research Projects

PanCare: Pan-europäisches Netzwerk zur Reduktion von Spätfolgen nach einer Krebserkrankung im Kindes- und Jugendalter

Das Netzwerk PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer, http://www.pancare.eu) 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.

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

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

PanCareSurFup (www.pancaresurfup.eu) startete im Februar 2011 und ging Ende Januar 2017 zu Ende. Das Projekt umfasst 16 Partner. Im Rahmen dieser Verbund-Forschung wurden Richtlinien entwickelt, um die Nachsorge ehemaliger Patienten zu optimieren und eine Grundlage für forschungsbezogene Informationen bereitzustellen, die alle Spätfolgen der Krebstherapie betreffen. Eine große europäische Kohorte von über 100.000 ehemaligen Patienten mit einer Krebserkrankung im Kindes- und Jugendalter wurde aufgebaut, nachbeobachtet und mögliche Spätfolgen wurden speziell untersucht. Dazu zählt das Auftreten von Zweittumoren, Herzschädigungen und das Versterben der Patienten mehr als fünf Jahre nach der Erkrankung (late mortality). Die Ergebnisse werden derzeit publiziert (36,39,46,63,64,67,68,69,77,78,80,83).

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

An dem im November 2013 begonnenen und im Jahr 2018 abgeschlossenen EU-finanzierten Forschungsprojekt PanCareLIFE (www.pancarelife.eu) waren Wissenschaftler aus acht europäischen Nationen beteiligt. Fertilität, Ototoxizität und gesundheitsbezogene Lebensqualität standen im Fokus dieses Projektes. Insgesamt flossen die Daten von rund 32.000 Betroffenen in das Vorhaben ein. Dazu wurde DNA untersucht um festzustellen, welche genetischen Varianten potentiell mit diesen Spätfolgen assoziiert sind. Auch Leitlinien zur Fertilitätserhaltung wurden erarbeitet. PanCareLIFE wurde an der Universitätsmedizin Mainz koordiniert. Das Projekt befindet sich derzeit noch in der Auswertephase. (26,65,75,76,81).

PanCare: Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer

PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer http://www.pancare.eu) 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.

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

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

PanCareSurFup (www.pancaresurfup.eu) started in February 2011 and ended in January 2017. It included 16 partners. The joint research aimed to provide a basis for establishing guidelines for follow-up in Europe, as well as a basis for research generating information on late effects of cancer therapies. The project has collated a large European cohort of more than 100,000 former patients with cancer in childhood or adolescence, their follow-up, and potential late effects. These include cardiac disease, second cancers and late mortality (more than 5 years after diagnosis). The results are currently being published (36,39,46,63,64,67,68,69,77,78,80,83).

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

Scientists from 8 European nations contributed to the EU-funded research project PanCareLIFE (www.pancarelife.eu), which ran from 2013 to 2018. The main issues of this project were fertility, ototoxicity, and quality of life. Data from about 32,000 former patients were included in the project. This includes an examination of DNA, which may modify the risk for these late effects. The project included a work package which develops guidelines for fertility preservation. PanCareLIFE was coordinated at the University Medical Centre in Mainz. The data are currently being analyzed (26,65,75,76,81).

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

Folgeneoplasien, also ein weiterer Krebs, sind eine Spätfolge, an der etwa 8 % der Langzeitüberlebenden nach Krebs im Kindesalter in Deutschland innerhalb von 35 Jahren nach ihrer Erstneoplasie erkranken (73). Wichtige Risikofaktoren für Folgeneoplasien sind die Therapien zur Behandlung des Primärtumors.

Basierend auf der Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters wird eine Fall-Kontroll-Studie bestehend aus 1244 Fällen mit einer Folgeneoplasie und gematchten Kontrollen durchgeführt. Die Therapiedaten werden entweder basierend auf den Angaben der jeweiligen Therapieoptimierungsstudien aus der GPOH-Therapieprotokolldatenbank erhoben oder durch Evaluation der Patientenakten aus den Kliniken für pädiatrische Onkologie und Radiotherapiezentren. Es sollen Unterschiede in der Behandlung zwischen Fällen und Kontrollen ermittelt werden.

Primäres Ziel der Studie ist es, das Risiko von Folgeneoplasien durch die medikamentöse Krebstherapie und durch die Radiotherapie zu quantifizieren. Dies kann mithelfen, eine Grundlage dafür zu schaffen, zukünftige Therapieprotokolle so zu gestalten, dass bei einem optimalen Therapieerfolg das Risiko für Folgeneoplasien möglichst gering gehalten wird. Des Weiteren werden Risikogruppen für die Entwicklung einer Folgeneoplasie identifiziert (nach Krebsart, Alter bei Erstdiagnose, Latenzzeit etc.). Diese Informationen können weiterhin einen Beitrag bei der Entwicklung von Nachsorgeleitlinien leisten. Die Datenerhebungsphase der Studie ist abgeschlossen.

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

Second neoplasms, i.e. subsequent cancers, are a late effect, which occurs in about 8% of long-term survivors after cancer in childhood in Germany within 35 years after the first neoplasm (73). Important risk factors for second neoplasms are the therapies for the treatment of the first neoplasm.

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

The primary aim of the study is to quantify the risk for second neoplasms from chemotherapy and radiotherapy of the first neoplasm. This may help to establish a basis for modifying future therapy protocols in a way that minimizes the risk for second neoplasms while holding up a maximum of therapeutic success. Furthermore, the study will identify risk groups for developing second neoplasms (concerning cancer entity, age at first diagnosis, latency time etc.). This information may contribute to the development of follow-up care guidelines. The field phase of the study is over now.

Tabelle 11:

Forschungsprojekte und internationale Kooperationsprojekte seit 2016 (see Table 12 for the English version)

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
ACCIS: Automated Childhood Cancer Information System	Internationale Datenbank	11,38,74	IARC, Lyon, Frankreich	nein	./.
EUROCARE: Survival of cancer patients in Europe	Follow-up Studie	33,50,52	Istituto Nazionale dei Tumori, Mailand, Italien	nein	./.
RICC: Kohortenstudie zur Abschätzung des Krebsrisikos durch diagnostische Strahlenexposition im Kindesalter	Kohortenstudie	14,15,18	IMBEI	ja	Bundesamt für Strahlenschutz
PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	Internationale Kohorten- und Fall-Kontroll-Studie	36,39,46, 63,64,67, 68,69,77, 78,80,83	Gesamtleitung: Lund University Hospital, Schweden; Leitung Work-package 1 (Data Collection and Harmonization): DKKR	ja	Europäische Kommission EU FP7
KiKme: Krebserkrankungen im Kindesalter und molekulare Epidemiologie	Fall-Kontroll-Studie	45	Studienleitung: Leibniz-Institut für Präventionsforschung und Epidemiologie - BIPS, Bremen, Verbundleitung: IMBEI	ja	Bundesministerium für Bildung und Forschung
KiCT/EPI-CT: Kinderkrebsrisiko nach Exposition durch computertomographische Untersuchungen im Kindesalter	Kohortenstudie	17,22,23, 37,47,49, 54,62,79	IMBEI und IARC, Lyon, Frankreich	ja	Bundesministerium für Bildung und Forschung, Europäische Kommission EU FP7
VIVE: Basiserhebung zu Lebenssituation, Gesundheitszustand und Lebensqualität nach onkologischer Erkrankung im Kindes- und Jugendalter	Kohortenstudie	24,55,82	Projektkoordination: Universitätsklinikum Bonn, Zentrum für Kinderheilkunde, Abt. Pädiatrische Hämatologie und Onkologie	ja	Deutsche Krebshilfe

Tabelle 11 Forts. Table 11 cont.

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
PanCareLife: PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	Internationale Kohorten- und Fall-Kontroll-Studie	26,65,75, 76,81	DKKR	ja	Europäische Kommission EU FP7
CVSS: Kardiale und vaskuläre Spätfolgen bei Langzeitüberlebenden nach Krebserkrankungen im Kindesalter	Kohortenstudie	25,29,57, 66,72	Universitätsmedizin Mainz: DKKR, Pädiatrische Hämatologie und Onkologie, II. Medizinische Klinik	ja	Deutsche Forschungsgemeinschaft
Genetische Syndrome und Krebs im Kindesalter	Kohortenstudie	19,56	Abt. päd. Hämatologie und Onkologie Hannover, Institut für Humangenetik Magdeburg, Deutsches Kinderkrebsregister	nein	
FeCt-Studie (Fertilität nach Chemo- und Strahlentherapie im Kindes- und Jugendalter) und FeCt-Studie zum Gesundheitszustand der Nachkommen ehemaliger onkologischer Patienten	Querschnittstudie	31,40,60, 84	Klinik für Pädiatrie mit Schwerpunkt Onkologie und Hämatologie der Charité Universitätsmedizin Berlin; Kinder- und Jugendklinik des Universitätsklinikums Erlangen	ja	Deutsche Kinderkrebsstiftung; Charité Universitätsmedizin Berlin
ISIBELa: Intrinsische Strahlentherapie: Identifikation Biologischer und Epidemiologischer Langzeitfolgen	Fall-Kontroll-Studie		IMBEI	ja	Bundesministerium für Bildung und Forschung
Strukturoptimierung für krebskranke Kinder nach Anthrazyklintherapie	Querschnittsstudie		Klinik für Kinder- und Jugendmedizin, Universitätsklinikum Schleswig-Holstein	ja	Madeleine Schickedanz Kinderkrebsstiftung
STATT-SCAR-Studie (Second Tumour After Tumour Therapy - Second Cancer After Radiotherapy)	Fall-Kontroll-Studie	73	DKKR/IMBEI	ja	Deutsche Krebshilfe und Bundesministerium für Bildung und Forschung (BMBF)
ikidS-OEVA: Onkologische Erkrankung im Vorschulalter und der Übergang in die Schule	Querschnittsstudie	70	IMBEI	ja	Bundesministerium für Bildung und Forschung (BMBF)

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

Tabelle 11 Forts. Table 11 cont.

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
Info-Onko: Evaluation der psychosozialen Situation von Langzeitüberlebenden einer Krebserkrankung im Kindes- oder Jugendalter	Querschnittsstudie		Netzwerk für die Versorgung schwerkranker Kinder und Jugendlicher e.V.	ja	Deutsche Kinderkrebsstiftung
E-SURV: Entwicklung innovativer Strategien zu Datenerhebung, Datenaustausch und Follow-Up nach Krebs im Kindesalter und Verknüpfung epidemiologischer und klinischer Daten	Querschnittsstudie		Projektkoordination: Pädiatrische Hämatologie und Onkologie des Universitätsklinikums Bonn	ja	Deutsche Krebshilfe
IICC: International Incidence of Childhood Cancer	Internationale Datenbank	58,59	IARC, Lyon, Frankreich	nein	-
LEaHL: Spätfolgen nach Hodgkin-Lymphom	Follow-up Studie		Klinik für Pädiatrische Hämatologie und Onkologie der Justus-Liebig-Universität Gießen	ja	Deutsche Kinderkrebsstiftung
Langzeitbeobachtung bei Kindern mit LCH	Follow-up Studie		St. Anna Kinderkrebsforschung e.V.	ja	Österreichische Nationalbank
Krebsrisiko bei Kindern mit Herzkatheteruntersuchung	Kohortenstudie		Klinik für Kinderkardiologie undangeborene Herzfehler, Deutsches Herzzentrum München	nein	

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

Tabelle 12:

Research projects and international cooperations since 2016 (see table 11 for the German version)

Name of the project	Type of study	References
ACCIS: Automated Childhood Cancer Information System	International Data Base on Childhood Cancer	11,38,74
EUROCARE: Survival of cancer patients in Europe	Follow-up Study	33,50,52
RICC: Cohort study for estimating the risk of childhood cancer by diagnostic radiation exposure	Cohort Study	14,15,18
PanCareSurFup: PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies	International Cohort and Case-Control Study	36,39,46,63,64 ,67,68,69,77,7 8,80,83
KiKme: Cancer in childhood and molecular epidemiology	Case-Control Study	45
KiCT/EPI-CT: Risk of childhood cancer after computed tomography in childhood	Cohort Study	17,22,23,37,47 ,49,54,62,79
VIVE: Basic Survey on Life Situation, State of Health, and Quality of Life of Childhood Cancer Survivors in Germany	Cohort Study	24,55,82
PanCareLife: PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood	International Cohort and Case-Control Study	26,65,75,76,81
CVSS: Cardiac and vascular late sequelae in long-term survivors of childhood cancer - a multidisciplinary clinical, epidemiological and genetic approach	Cohort Study	25,29,57,66,72
Genetic Syndromes and cancer in childhood	Cohort Study	19,56
FeCt-Study (Fertility after Chemo- and radiotherapy in childhood and adolescence) and FeCt-Study on the health of the offspring of former oncological patients	Cross-sectional Study	31,40,60,84

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

Name of the project	Type of study	References
ISIBELa: Intrinsic radiation sensitivity: Identification of biological and epidemiological late effects	Case-Control Study	
Structural Optimization for Childhood Cancer Survivors after Anthracycline Therapy	Cross Sectional Study	
STATT-SCAR-Study (Second Tumour After Tumour Therapy - Second Cancer After Radiotherapy)	Case-Control Study	73
ikidS-OEVA: Oncological disease in preschool age and the transition to school	Cross-sectional Study	70
Info-Onko: Evaluation of the psychosocial situation of long-term survivors after cancer in childhood or adolescence	Cross-sectional Study	
E-SURV: Development of comprehensive strategies for assessment, data-sharing and follow-up in childhood cancer survivors linking epidemiological and clinical data	Cross-sectional Study	
IICC: International Incidence of Childhood Cancer	International Data Base on Childhood Cancer	58,59
LEaHL: Late Effects after Hodgkin Lymphoma	Follow-up Study	
LCH: Long-term outcomes in childhood Langerhans cell histiocytosis	Follow-up Study	
Cancer risk in Children after Cardiac Catheterization		

146 Publications and Presentations

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