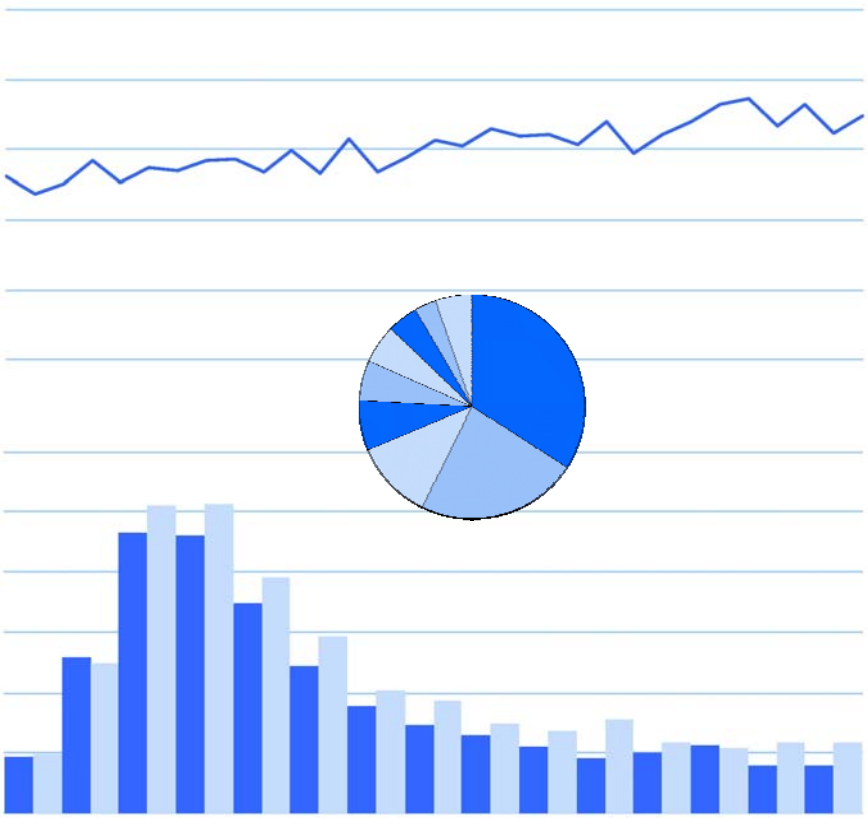
Deutsches
Kinderkrebsregister

Jahresbericht / Annual Report 2011

German Childhood Cancer Registry



Deutsches Kinderkrebsregister

Jahresbericht / Annual Report 2011

September, 2012

Deutsches Kinderkrebsregister am
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Herausgeber:

Deutsches Kinderkrebsregister
(Leitung: PD Dr. Peter Kaatsch)

Druck: Verlag Kirchheim + Co GmbH
Auflage: 900 Exemplare

Zitierweise: Kaatsch P, Spix J. German Childhood Cancer Registry - Annual Report 2011 (1980-2010). Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI) at the University Medical Center of the Johannes Gutenberg University Mainz, 2012.

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30 Jahre Deutsches Kinderkrebsregister

Als das Kinderkrebsregister 1979 ins Leben gerufen wurde, steckte die Krebsbehandlung von Kindern und Jugendlichen in Deutschland noch in ihren Kinderschuhen. Die ersten bedeutsamen Schritte mit gemeinsamen kooperativen, landesweiten Studien waren getan jedoch noch viele Entwicklungen zu bewältigen. Das Kinderkrebsregister ist gemeinsam mit den Fachgesellschaften, die diese Entwicklungen koordiniert und strukturiert haben, und die sich später zur Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) zusammengeschlossen haben, in diesen 30 Jahren zu einer beachtlichen Größe herangewachsen. Anfangs durch eine Finanzierung der Stiftung Volkswagenwerk auf den Weg gebracht, wird das Kinderkrebsregister heute zu je einem Drittel durch das Ministerium für Arbeit, Soziales und Gesundheit Rheinland-Pfalz, das Bundesgesundheitsministerium und einen Zusammenschluss aller Bundesländer finanziert. Das Kinderkrebsregister ist das einzige nationale Krebsregister, das auf der Basis eines intensiven Kontakts mit den betroffenen Patienten und deren Sorgeberechtigten auf einem speziellen Einverständnis der Beteiligten beruht. Die behandelnden Ärzte melden unentgeltlich und auf freiwilliger Basis, jedoch flächendeckend und vollständig. Das Register ist seit Beginn am Institut für Medizinische Biometrie, Epidemiologie und Informatik der Universitätsmedizin Mainz angesiedelt und arbeitet intensiv mit der Fachgesellschaft GPOH zusammen.

Neben den üblichen bevölkerungsbezogenen Daten erfasst es auch wesentliche klinische Informationen, so dass es neben seiner epidemiologischen Funktion auch die Funktion eines klinischen Registers wahrnehmen kann. Es ist in mehr als 20 pädiatrisch onkologischen, von der GPOH geführten, Therapieoptimierungsstudien eingebunden. Aufgrund des Registers wissen wir, dass mehr als 90 Prozent aller in Deutschland erkrankten Kinder an diesen Therapiestudien teilnehmen. Das Register hilft uns auch dabei, die ehemaligen Patienten bis in das Erwachsenenalter zu verfolgen und Erkenntnisse über Spätfolgen der Behandlung, Zweittumore oder genetische Aspekte zu gewinnen. Nicht zuletzt sind in den letzten Jahren einige ganz wesentliche bevölkerungsbezogene Fallkontrollstudien zu kontroversen wissenschaftlichen Fragen durchgeführt worden. Eine Fallkontrollstudie über Leukämien in der Nähe von Nuklearanlagen ist im letzten Jahr in der interessierten Öffentlichkeit breit diskutiert worden.

Ein Blick in die Veröffentlichungsliste des Kinderkrebsregisters zeigt die Themenvielfalt und die Bedeutung des Registers: Mitarbeiter des Registers haben sich mit Langzeitüberlebenden, der Häufigkeit von Krebserkrankungen bei verschiedenen ethnischen Gruppen, den Risikofaktoren für Sekundärmalignomen, der Leukämiehäufigkeit in der Nähe von Atomkraftwerken und der Häufigkeit von Weichteilsarkomen und Rhabdoidtumoren genauso beschäftigt wie mit komplementären und alternativen Behandlungsmethoden.

German Childhood Cancer Registry Turns 30

When the German Childhood Cancer Registry was created in 1979, cancer treatment for children and adolescences in Germany was still in its infancy. The first meaningful steps had been taken for shared, cooperative country-wide studies, but there were still many developments to tackle. Together with the professional associations who coordinated and structured these developments and who later joined forces as the Society for Paediatric Oncology and Haematology (Gesellschaft für Pädiatrische Onkologie und Hämatologie - GPOH), the German Childhood Cancer Registry has become a considerable size in the past 30 years. After having started out with financing from the Volkswagen Foundation, the German Childhood Cancer Registry is now financed in equal parts of one third by the Ministry of Social Affairs, Labour, Health, and Demography in Rhineland Palatinate, the Federal Ministry of Health, and all other Ministries of Health of the German federal states. The German Childhood Cancer Registry is the only national cancer registry that relies upon special agreement of the participants, based on intensive contact with the affected patients and their parents or guardians. The treating physicians register cases voluntarily and on a non-remunerated basis; however coverage is comprehensive and complete. Since its beginning, the registry has been housed at the Institute for Medical Biostatistics, Epidemiology and Informatics at the University Medical Center, Mainz, and has worked intensively with the professional society GPOH.

In addition to the usual population-related data, the registry also captures fundamental clinical information, so that in addition to its epidemiological function, it can also take on the function of a clinical registry. It is an integral part of more than 20 paediatric oncology therapy optimisation studies led by the GPOH. Due to the registry, we know that more than 90 percent of all afflicted children in Germany participate in these therapy studies. The registry also helps to follow former patients into adulthood and to obtain insights into long-term consequences of treatment, secondary tumours and genetic aspects. Last but not least, in recent years several large population-based case-control studies have been conducted on controversial scientific questions. A case-control study on leukaemia within the vicinity of nuclear power plants has been broadly discussed by interested parties in the public in recent years.

A look at the list of the German Childhood Cancer Registry's publications shows the range of topics as well as the importance of the registry: The staff members of the registry have dealt with such topics as long-term survival, the frequency of cancer cases in different ethnic groups, the risk factors for secondary malignant tumours, the frequency of leukaemia around nuclear power plants, and the frequency of soft-tissue sarcomas and rhabdoid tumours as well as complementary and alternative treatment methods.

4 Grußwort des GPOH Vorsitzenden / Greetings from the GPOH-Chairman

Das Kinderkrebsregister hat unsere Kenntnisse über Ursachen, Verlauf und Behandlungsmöglichkeiten von Krebserkrankten im Kindes- und Jugendalter erheblich erweitert und viele Einsichten überhaupt erst ermöglicht.

Wir gratulieren zu 30 Jahren erfolgreicher Arbeit und guter Zusammenarbeit mit der GPOH und wünschen dem Kinderkrebsregister und seinen Mitarbeiterinnen und Mitarbeitern eine erfolgreiche Zukunft.

Frankfurt, 10.12.2009

Prof. Dr. Thomas Klingebiel
Vorsitzender der GPOH

The German Childhood Cancer Registry has considerably expanded our knowledge regarding causes, progression, and treatment options for those diagnosed with cancer during childhood or adolescence, and has made many insights possible for the very first time.

We would like to congratulate the German Childhood Cancer Registry on 30 years of successful work and good cooperation with the GPOH, and wish the registry and its staff a successful future.

Frankfurt, 10 Dec. 2009

Prof. Thomas Klingebiel
Chair of the GPOH

Mit dem vorliegenden Jahresbericht, der Daten von 1980 bis einschließlich 2010 enthält, liegt nun erstmalig seit einigen Jahren wieder ein Jahresbericht als Druckexemplar vor. Er unterscheidet sich von den vorherigen Jahresberichten durch ein neu gewähltes Layout und insbesondere dadurch, dass die dargestellten Diagnosen noch weiter aufgegliedert sind als in den früheren Jahresberichten. Die Einteilung folgt der internationalen Klassifikation von Krebserkrankungen im Kindesalter, ICCC-3. Diese enthält in ihrer sog. „Extended Classification“ eine noch feinere Aufteilung in spezifische Erkrankungen, für die wir nun auch die wichtigsten epidemiologischen Kenngrößen darstellen. In den zurückliegenden Jahren wurde keine Druckversion des Jahresberichts erstellt, auf der Internetseite www.kinderkrebsregister.de sind jedoch alle Jahresberichte mit Grafiken, Tabellen etc. fortgeschrieben worden und sind dort abrufbar.

The annual report presented, which covers data from 1980-2010, is the first one in print for a number of years. It differs from previous reports by its layout and a more detailed presentation of diagnoses. The data is presented by the International Classification of Childhood Cancer, ICCC-3. This classification permits presenting epidemiological measures of specific diseases by the newly introduced „extended classification“. In the last years we did not provide a printed version, but the respective latest data was available with figures and tables on our webpage www.kinderkrebsregister.de.

Der aktuelle Jahresbericht enthält Daten von 48.397 Kindern, die vor ihrem 15. Geburtstag diagnostiziert wurden, sowie von weiteren knapp 4.000 Jugendlichen mit Diagnosestellung zwischen dem 15. und 18. Geburtstag.

This current report is based on the data from 48,397 children diagnosed before their 15th birthday, as well as about 4000 adolescents diagnosed between their 15th and 18th birthday.

Anlässlich des 30-jährigen Bestehens des Deutschen Kinderkrebsregisters hatte der damalige Vorsitzende der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH), Herr Prof. Dr. Thomas Klingebiel ein Grußwort geschrieben, das in diesem Bericht abgedruckt ist. Dies möchten wir zum Anlass nehmen, uns bei der GPOH als Fachgesellschaft, bei den GPOH-Therapieoptimierungsstudien und -Diagnoseregistern sowie bei den behandelnden Kliniken für die langjährige vertrauensvolle Zusammenarbeit zu bedanken. Das Informationsnetzwerk zwischen diesen Beteiligten hat ganz wesentlich zu der hohen Datenqualität und -vollzähligkeit beigetragen, für die das Deutsche Kinderkrebsregister, das größte seiner Art, weltweit anerkannt ist. Ebenso möchten wir diese Gelegenheit nutzen, uns bei den Eltern und den Patienten, die wir später als Erwachsene regelmäßig kontaktieren, dafür zu bedanken, dass sie uns ihre Daten bereitwillig zur Verfügung stellen.

When the German Childhood Cancer Registry celebrated its 30th anniversary the chairman of the society for pediatric hematology and oncology (GPOH), Herr Prof. Dr. Thomas Klingebiel, Frankfurt, provided greetings, which you can find printed in this report. On this occasion we would like to thank the GPOH, the GPOH therapy optimization studies, the GPOH disease registries, and all treating hospitals for many years of trusting cooperation. Our network of information is the basis for the high data quality and completeness of the German Childhood Cancer Registry, the largest of its kind, for which it is internationally acclaimed. Concurrently we would like to thank the parents and the patients, whom we interact with directly as they grow up, for trusting us with their data.

Das Deutsche Kinderkrebsregister wird seit vielen Jahren vom Bundesgesundheitsministerium und von allen 16 Landesgesundheitsministerien finanziert. Stellvertretend hierfür möchte ich dem rheinland-pfälzischen Ministerium für Arbeit, Soziales, Gesundheit und Demografie danken, das mit mehr als einem Drittel des Finanzvolumens den größten Teil der Finanzierung trägt und mit seinen Gesprächspartnern vor Ort in Mainz für die Belange des Deutschen Kinderkrebsregisters immer ein offenes Ohr hat.

For many years the German Childhood Cancer Registry has been funded by the Federal Ministry for health and all 16 State Ministries for health. As a representative we would like to thank the Rhineland-Palatinate Ministry for Labour, Social Affairs, Health and Demography, which contributes more than a third of the funding and is always willing to listen to the needs of the GCCR.

Die zurückliegenden Jahre waren aus Sicht des Deutschen Kinderkrebsregisters erfreulicherweise dadurch geprägt, dass eine Reihe von Gesetzen, Vereinbarungen, verbindlichen Beschlüssen und grundsätzlichen, offiziellen Stellungnahmen verabschiedet wurde, die die Bedeutung des Deutschen Kinderkrebsregisters weiter untermauert haben.

The past years saw a number of laws, agreements and binding resolutions which consolidate the position of the German Childhood Cancer Registry. We would like to call special attention to the agreement of the Gemeinsamen Bundesausschuss in 2006, which made reporting of cases mandatory for all pediatric oncology centers as part of their quality control. On this occasion

Besonders möchten wir auf die Vereinbarung des Gemeinsamen Bundesausschusses von 2006 verweisen, in dem alle kinderonkologischen Zentren verpflichtet wurden, ihre Erkrankungsfälle im Rahmen der Qualitätssicherung an das Deutsche Kinderkrebsregister zu melden. Dies war auch der Anlass, dass in 2009 auch die zwischen dem 15. und 18. Geburtstag an Krebs erkrankten Kinder systematisch in die Registrierung aufgenommen wurden. Dies war ein seit vielen Jahren von Seiten der pädiatrischen Onkologen und Hämatologen bestehender Wunsch, der jedoch aus förderungstechnischen Gründen vorher nicht realisierbar war. Wir sind dankbar dafür, dass die an der Finanzierung des Deutschen Kinderkrebsregisters beteiligten Ministerien die Notwendigkeit für die entsprechende Erweiterung gesehen haben. In diesem Rahmen ist es auch gelungen, eine dauerhafte Finanzierung durch diese Ministerien für die immer stärker in den Fokus gelangende Langzeitnachbeobachtung zu erhalten. Dies ist im Hinblick auf die Erforschung von Spätfolgen wie Organtoxizitäten, Zweitneoplasien (ein Schwerpunkt unserer Tätigkeit) und lebensqualitätsbezogenen Faktoren von ganz großer Bedeutung, nimmt doch die Zahl der langzeitüberlebenden Patienten ständig zu. Der Bericht stellt dar, dass knapp 30.000 Patienten mit aktuell vorhandenen Adressen in unsere aktive Langzeitnachbeobachtung einbezogen sind.

we were also able to extend our registration systematically to cases until their 18th birthday in 2009. This had been requested for years by the pediatric oncologists and hematologists for many years, but had not been covered by our funding. We are grateful the ministries saw the necessity to extend our funding accordingly. On this occasion we were also able to obtain a permanent funding for the increasingly important long-term follow-up. As the number of long-term survivors keeps increasing, research on late effects such as organ toxicities, second neoplasms (a key aspect of our work), and quality of life becomes more important. This report shows that about 30.000 former patients with concurrent address data are now included in the active long-term follow-up.

Die für die Konsolidierung des Deutschen Kinderkrebsregisters relevanten Stellungnahmen und Beschlüsse sind in dem Methodenteil des vorliegenden Jahresberichtes mit den entsprechenden Verweisen aufgeführt. Ebenso sind diese Dokumente über unsere mittlerweile stark überarbeitete Internet-Darstellung abrufbar.

The agreements and decisions which have consolidated the basis of the German Childhood Cancer Registry are listed and referenced in the methods section of this report. All documents are also available on our revised webpage.

Das Deutsche Kinderkrebsregister hat seit vielen Jahren immer wieder zusätzliche, durch weitere Drittmittelgeber finanzierte Forschungsprojekte durchgeführt. Als ein Meilenstein kann die Übernahme eines Arbeitspakets im Rahmen eines EU- Forschungsprojektes genannt werden. Wir sind in PanCareSurFup (FP7 Framework Program, Grant Agreement Nr. 257505) federführend für das Arbeitspaket „Data Base and Harmonization“ verantwortlich. Darin erfolgt eine systematische Evaluation der in Europa verfügbaren Daten über Langzeitüberlebende nach Krebs im Kindes- und Jugendalter. Insofern hat die Kohorte der Langzeitüberlebenden am Deutsche Kinderkrebsregister für die Spätfolgenforschung nicht nur in der deutschen pädiatrischen Onkologie, sondern auch international eine besondere Bedeutung. Nicht nur damit glauben wir, eine anhaltende Bedeutung unserer Arbeit für das Wohlergehen der Patienten erzielt zu haben.

In previous years the German Childhood Cancer Registry has been involved in a number of projects with extra funding. We consider being assigned an EU-research project work package a milestone. Within PanCareSurFup (FP7 Framework Program, Grant Agreement Nr. 257505) we are work package leader for „Data Base and Harmonization“. This project systematically evaluates European data on long term survivors after cancer in childhood and adolescence. Thus the cohort of long term survivors at the German Childhood Cancer Registry is not only important for pediatric oncology in Germany but also internationally. We believe, this contributes further to relevance of our work for the well-being of the patients.

Peter Kaatsch

Mainz, im September 2012

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

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

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Eingeschlossene Diagnosen entsprechend ICCC-3 (siehe Methoden)

Selected diagnoses according to ICCC-3 (see Methods)

Cases in Germany aged under 15 years (1980-2010): 48397

Selected characteristics (Germany 2001-2010)

Relative frequency: 17876 / 17876 = 100 %

Relative frequency of trial patients: 93.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	7985	9891	17876
Standardized rate *:	147.3	172.9	160.4
Cumulative incidence:	2130	2504	2322

Sex ratio (m/f): 1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	1856	6069	4787	5164
Incidence rate:	265.9	208.1	123.3	121.4

Median age at diagnosis: 5 years 11 months

	5-year	**10-year**	**15-year**
Survival probabilities:	83 %	81 %	80 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
4151	100.0 %	33.0	479

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

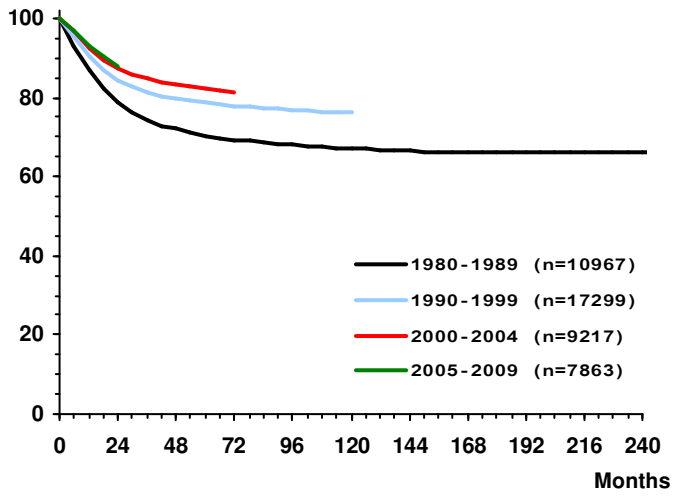
All malignancies

SN after all malignancies

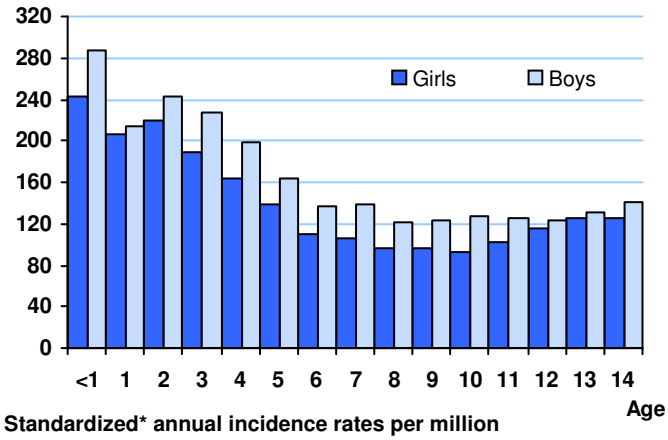
N	% of all 775 SN	Cumulative incidence
775	100.0 %	3.2 %

* Standard: Segi world standard population

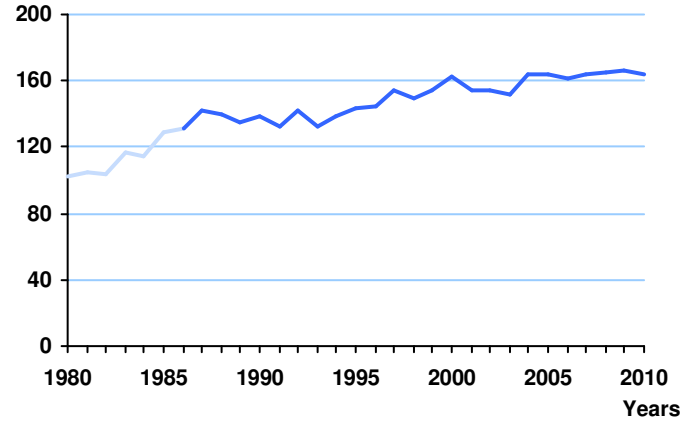
Survival probabilities by year of diagnosis (Germany 1980-2009)



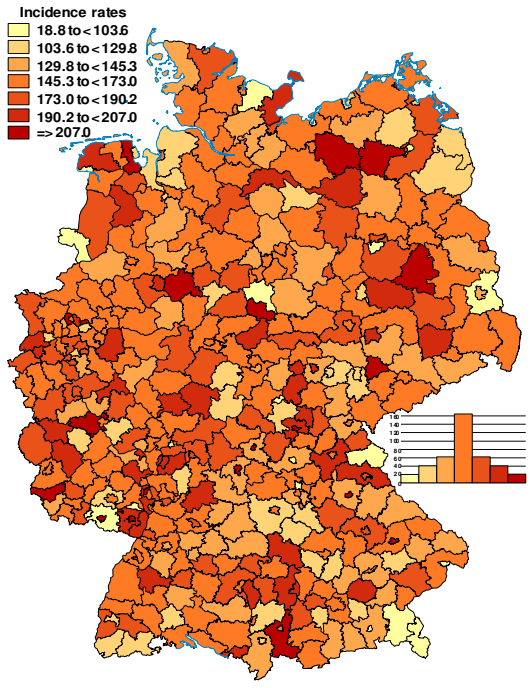
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



12 I Leukaemias, myeloproliferative and myelodysplastic diseases

(a) Hodgkin lymphomas
(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)
(c) Burkitt lymphoma
(d) Myelodysplastic syndrome and other myeloproliferative disease
(e) Unspecified and other specified leukaemias

Cases in Germany aged under 15 years (1980-2010): 16684

Selected characteristics (Germany 2001-2010)

Relative frequency:	6089 / 17876 = 34.1 %
Relative frequency of trial patients:	99.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	2757	3332	6089
Standardized rate *:	52.2	59.3	55.8
Cumulative incidence:	742	848	797
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	308	2756	1678	1347
Incidence rate:	44.1	94.5	43.2	31.7

Median age at diagnosis: 4 years 11 months

	5-year	**10-year**	**15-year**
Survival probabilities:	87 %	84 %	83 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

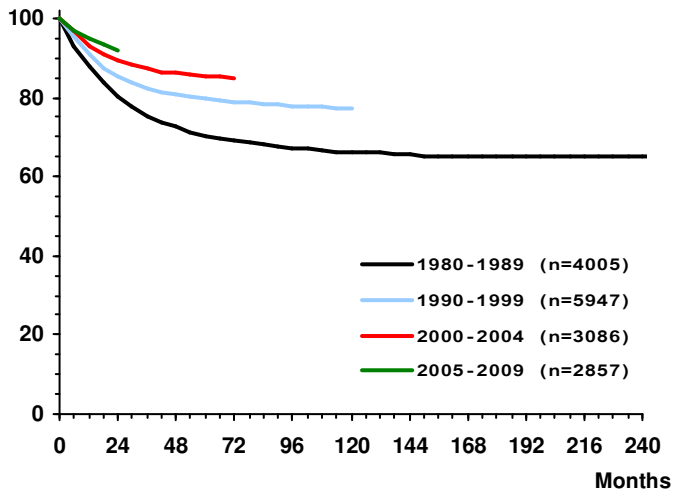
Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
1348	32.5 %	10.6	155

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):
I Leukaemias, myeloproliferative and myelodysplastic diseases

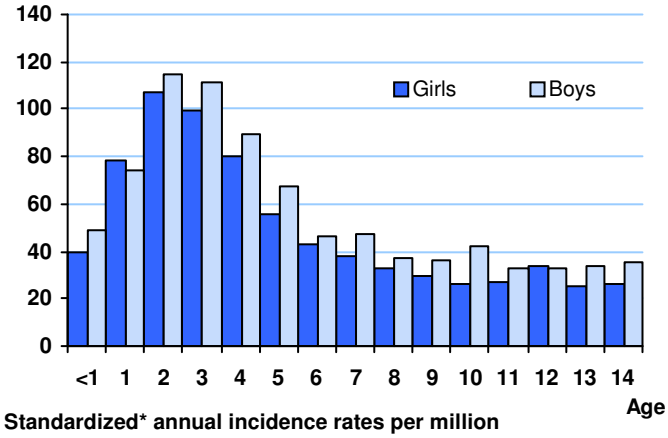
SN after I			I as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
285	36.8 %	3.2 %	223	28.8 %	0.7 %

* Standard: Segi world standard population

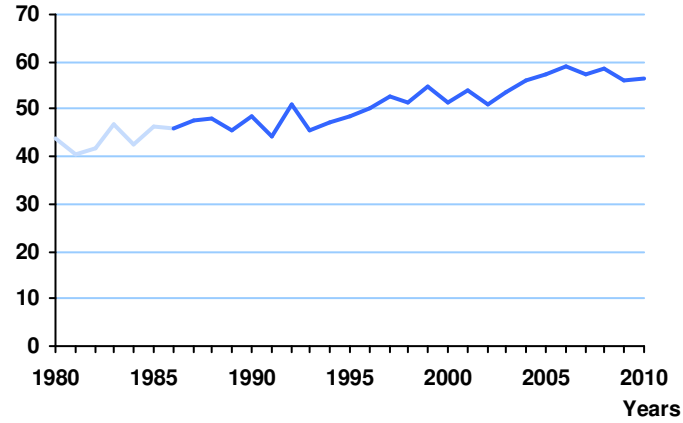
Survival probabilities by year of diagnosis (Germany 1980-2009)



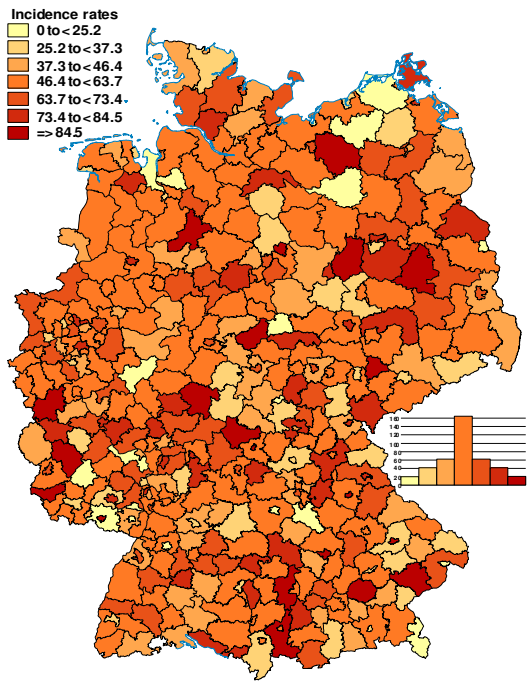
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Until 2004, the average increase in incidence of Lymphoid Leukaemia (LL) was ca. 0.7% per year. This is similar to Europe. The literature considers this increase as real, not a registration artefact, possibly due to changes in life style. Based on international comparisons, completeness of registration is close to 100%. Compared to all childhood cancers, mortality is relatively low. LL is relatively rare as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 13315

Selected characteristics (Germany 2001-2010)

Relative frequency:	4767 / 17876 = 27.2 %
Relative frequency of trial patients:	99.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	2145	2622	4767
Standardized rate *:	41.0	46.9	44.0
Cumulative incidence:	579	669	625
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	134	2339	1376	918
Incidence rate:	19.2	80.2	35.4	21.6

Median age at diagnosis: 4 years 10 months

	5-year	**10-year**	**15-year**
Survival probabilities:	90 %	88 %	87 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
797	19.2 %	6.3	92

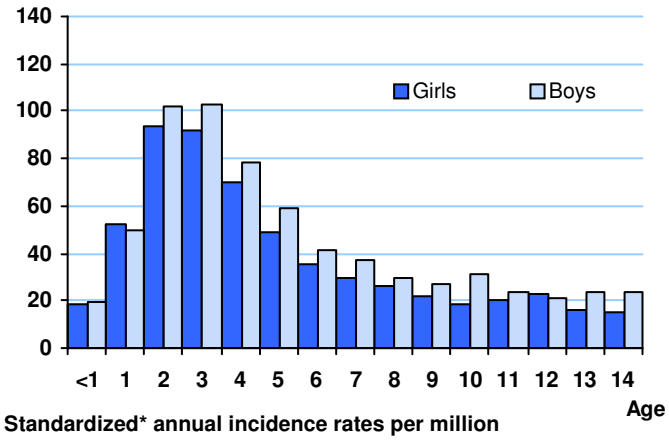
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

I (a) Lymphoid leukaemias

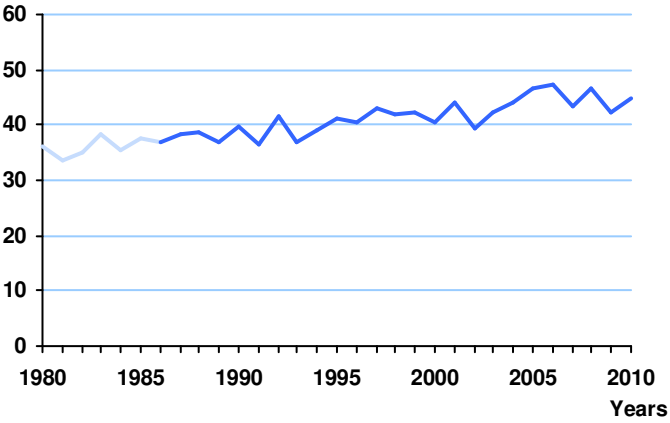
SN after I (a)			I (a) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
238	30.7 %	3.2 %	43	5.5 %	0.1 %

* Standard: Segi world standard population

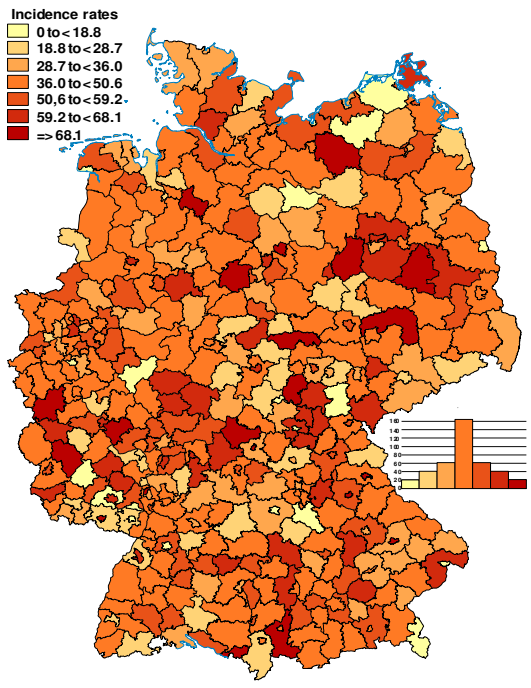
Age- and sex-specific incidence rates per million (Germany 2001-2010)



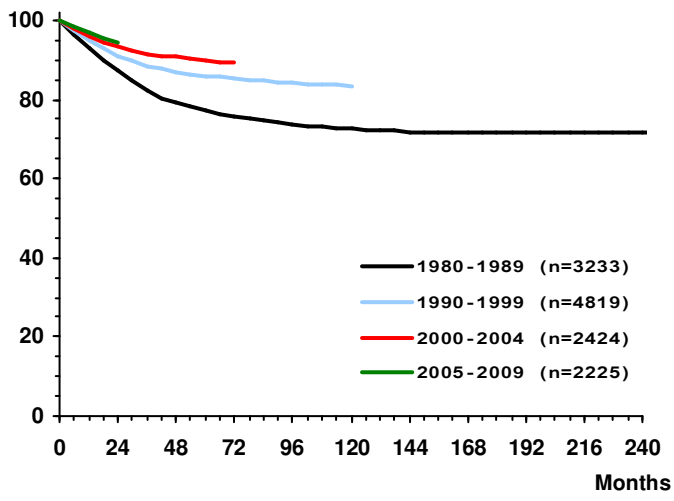
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



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

Germany (2001-2010)	N	%
Lymphoid leukaemias	**4767**	**100.0**
Precursor cell leukaemias	4655	97.7
Mature B-cell leukaemias	111	2.3
Mature T-cell and NK cell leukaemias	1	0.0
Lymphoid leukaemia, NOS	0	0.0

1 Precursor cell leukaemias

Cases in Germany aged under 15 years (1980-2010): 13000

Selected characteristics (Germany 2001-2010)

Relative frequency:	4655 / 17876 = 26.0 %
Relative frequency of trial patients:	99.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	2119	2536	4655
Standardized rate *:	40.5	45.5	43.0
Cumulative incidence:	572	647	611

Sex ratio (m/f): 1.2

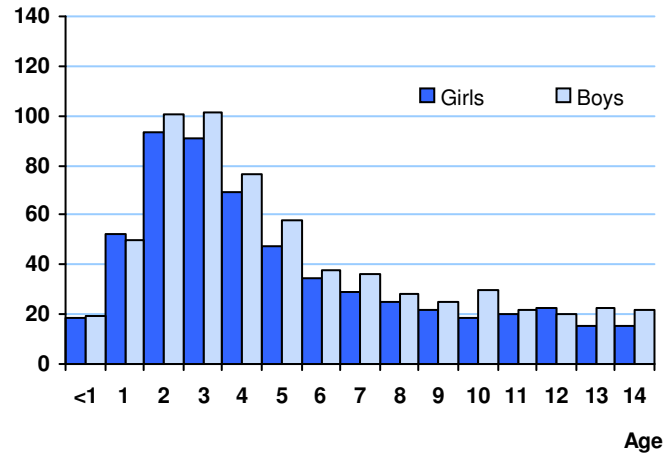
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	131	2313	1326	885
Incidence rate:	18.8	79.3	34.1	20.8

Median age at diagnosis: 4 years 9 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010



2 Mature B-cell leukaemias

Cases in Germany aged under 15 years (1980-2010): 314

Selected characteristics (Germany 2001-2010)

Relative frequency:	111 / 17876 = 0.6 %
Relative frequency of trial patients:	99.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	25	86	111
Standardized rate *:	0.4	1.4	0.9
Cumulative incidence:	7	21	14

Sex ratio (m/f): 3.4

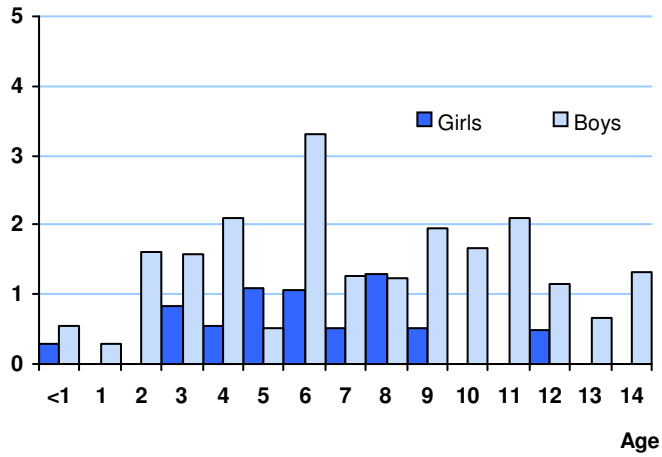
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	3	26	50	32
Incidence rate:	0.4	0.9	1.3	0.8

Median age at diagnosis: 7 years 5 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010



Based on international comparisons, completeness of registration of acute myeloid leukaemias (AML) is close to 100%. Compared to all childhood cancers, mortality is relatively high. Prognosis has improved considerably since 1980. AML occurs relatively frequently as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 2371

Selected characteristics (Germany 2001-2010)

Relative frequency: 795 / 17876 = 4.5 %

Relative frequency of trial patients: 97.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	379	416	795
Standardized rate *:	7.2	7.4	7.3
Cumulative incidence:	102	106	104

Sex ratio (m/f): 1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	115	288	158	234
Incidence rate:	16.5	9.9	4.1	5.5

Median age at diagnosis: 4 years 11 months

	5-year	**10-year**	**15-year**
Survival probabilities:	70 %	68 %	67 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
421	10.1 %	3.3	49

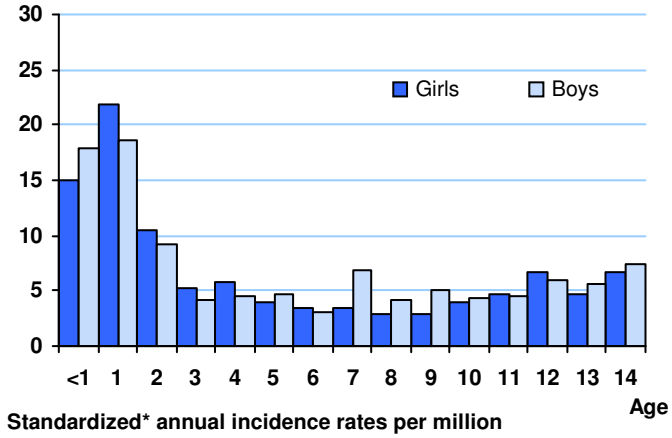
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

I (b) Acute myeloid leukaemias

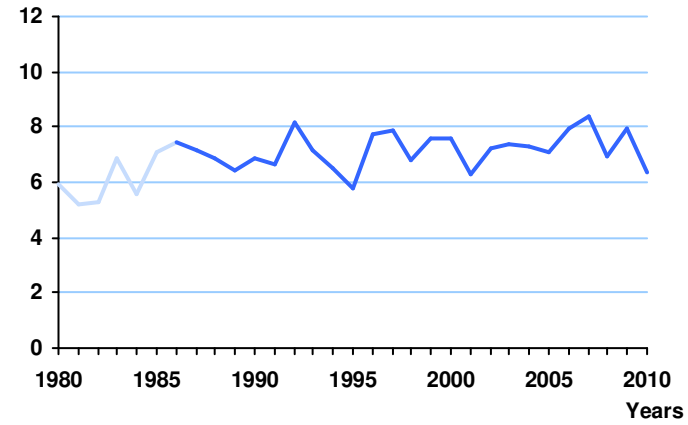
SN after I (b)			**I (b) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
32	4.1 %	2.9 %	124	16.0 %	0.3 %

* Standard: Segi world standard population

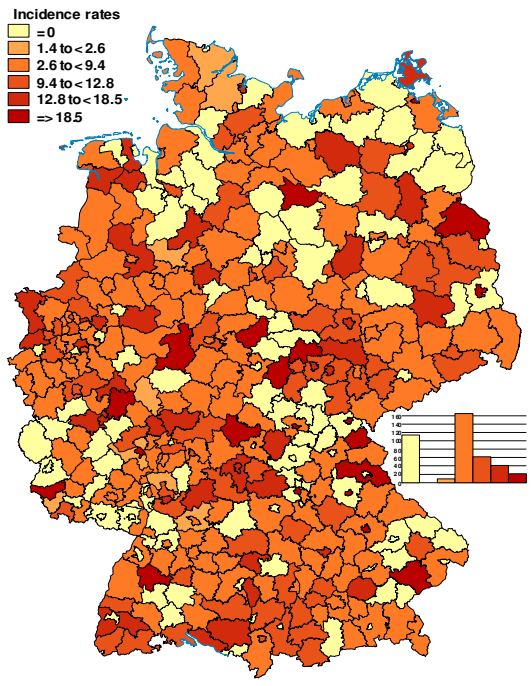
Age- and sex-specific incidence rates per million (Germany 2001-2010)



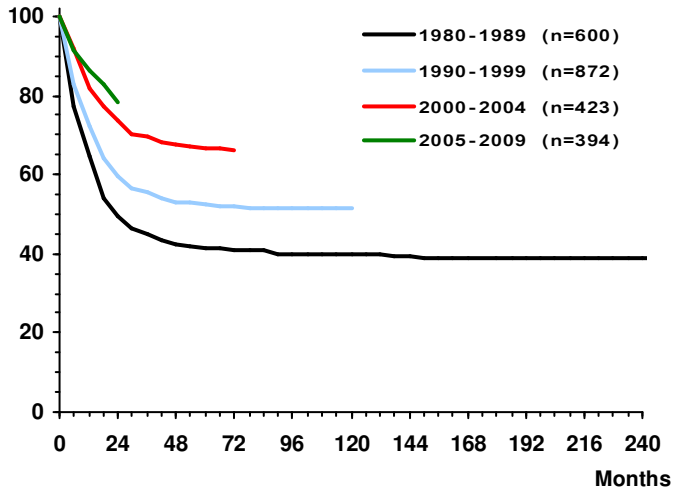
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



16 I (c) Chronic myeloproliferative diseases

Chronic myeloproliferative (CM) diseases are rare in early childhood. Based on international comparisons, completeness of registration is close to 100%. Second neoplasms after CM diseases are relatively rare, underreporting is a possibility.

Cases in Germany aged under 15 years (1980-2010): 226

Selected characteristics (Germany 2001-2010)

Relative frequency:	80 / 17876 = 0.5 %
Relative frequency of trial patients:	86.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	43	37	80
Standardized rate *:	0.7	0.6	0.6
Cumulative incidence:	11	9	10
Sex ratio (m/f):			0.9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	0	10	29	41
Incidence rate:	0.0	0.3	0.7	1.0

Median age at diagnosis: 10 years 3 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
33	0.8 %	0.2	4

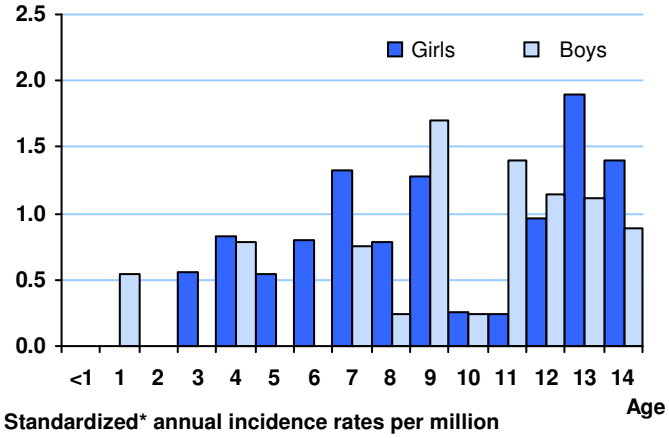
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

I (c) Chronic myeloproliferative diseases

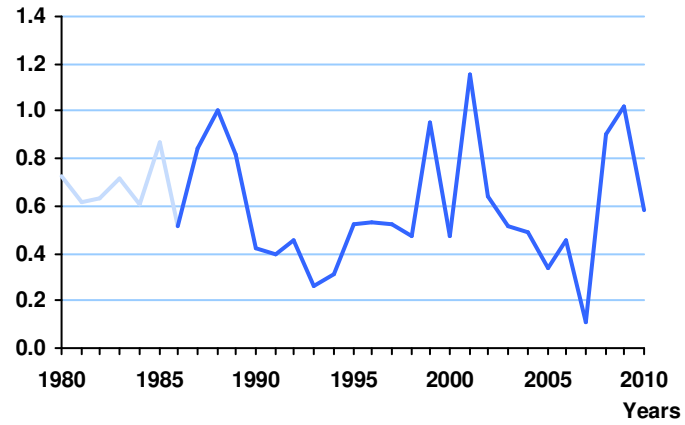
SN after I (c)			I (c) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
2	0.3 %	1.4 %	3	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



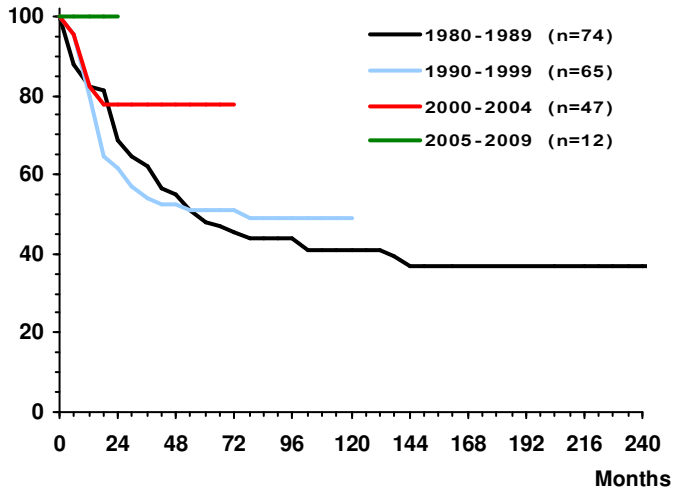
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



I (d) Myelodysplastic syndrome and other myeloproliferative diseases

Myelodysplastic syndrome (MDS) was reclassified as malignant at the introduction of ICD-O-3, so earlier registration is incomplete. The visible trend is a registration artefact. Prognosis has improved considerably since 1980. MDS is relatively frequently followed by a second neoplasm within 20 years of diagnosis. MDS is relatively frequent as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 614

Selected characteristics (Germany 2001-2010)

Relative frequency: 377 / 17876 = 2.2 %

Relative frequency of trial patients: 97.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	159	218	377
Standardized rate *:	2.8	3.8	3.3
Cumulative incidence:	42	55	48

Sex ratio (m/f): 1.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	41	104	97	135
Incidence rate:	5.9	3.6	2.5	3.2

Median age at diagnosis: 7 years 3 months

	5-year	**10-year**	**15-year**
Survival probabilities:	78 %	77 %	75 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
80	1.9 %	0.6	9

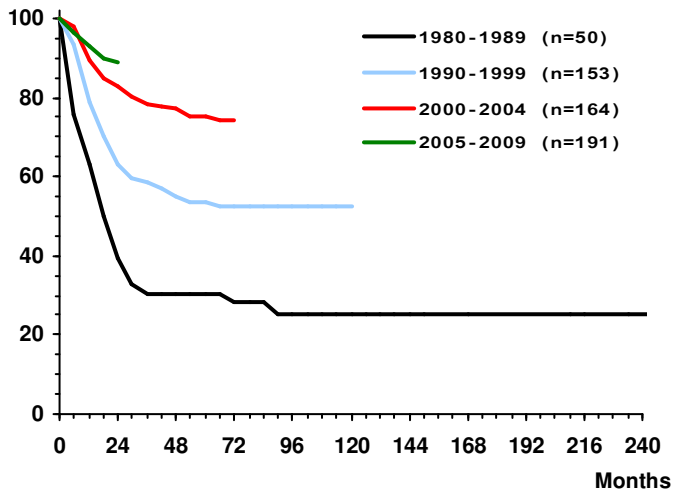
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

I (d) Myelodysplastic syndrome and other myeloproliferative dise

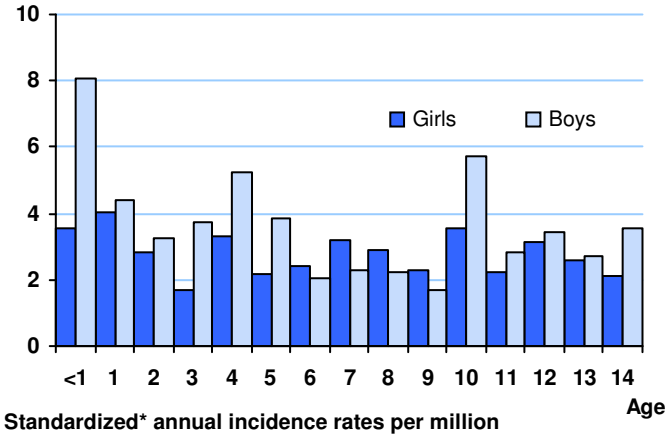
SN after I (d)			**I (d) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
6	0.8 %	5.8 %	52	6.7 %	0.2 %

* Standard: Segi world standard population

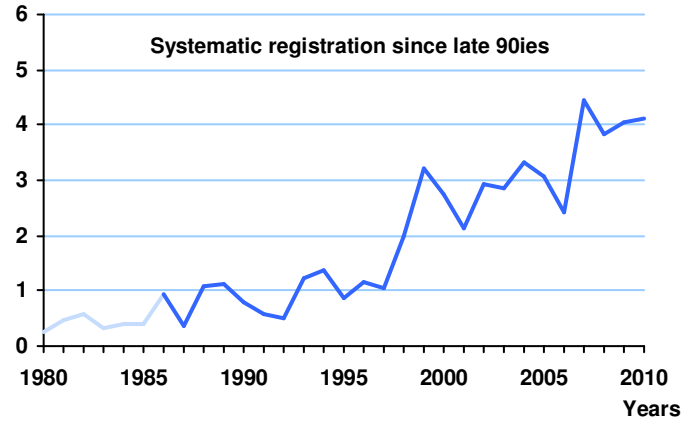
Survival probabilities by year of diagnosis (Germany 1980-2009)



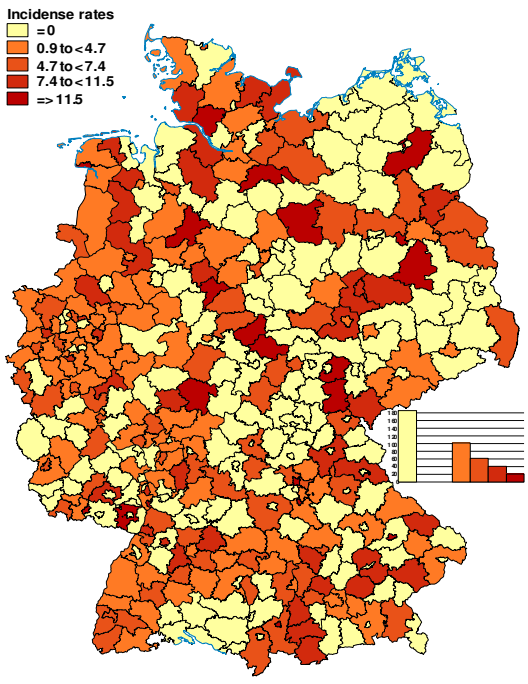
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



18 II Lymphomas and reticuloendothelial neoplasms

(a) Hodgkin lymphomas
(b) Non-Hodgkin lymphomas (except Burkitt lymphoma)
(c) Burkitt lymphoma
(d) Miscellaneous lymphoreticular neoplasms
(e) Unspecified lymphomas

Cases in Germany aged under 15 years (1980-2010): 5762

Selected characteristics (Germany 2001-2010)

Relative frequency:	2037 / 17876 = 11.4 %
Relative frequency of trial patients:	96.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	662	1375	2037
Standardized rate *:	10.2	21.1	15.8
Cumulative incidence:	166	333	252
Sex ratio (m/f):			2.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	13	221	688	1115
Incidence rate:	1.9	7.6	17.7	26.2

Median age at diagnosis: 10 years 7 months

	5-year	**10-year**	**15-year**
Survival probabilities:	94 %	92 %	91 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

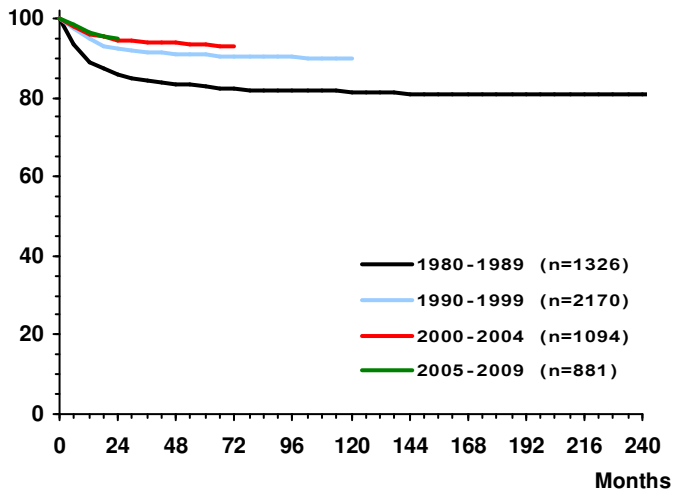
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
225	5.4 %	1.7	26

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):
II Lymphomas and reticuloendothelial neoplasms

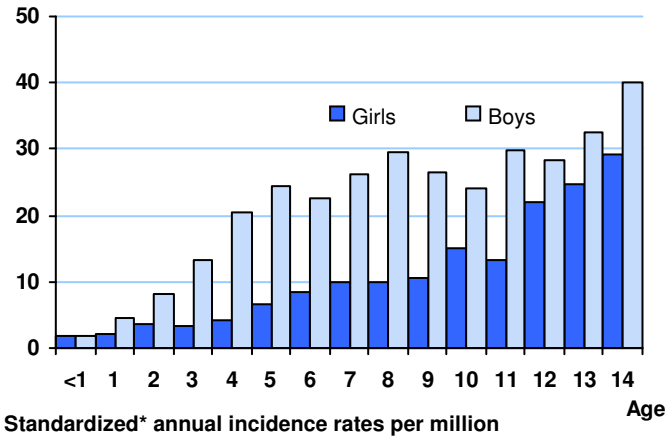
SN after II			**II as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
129	16.6 %	5.1 %	80	10.3 %	0.3 %

* Standard: Segi world standard population

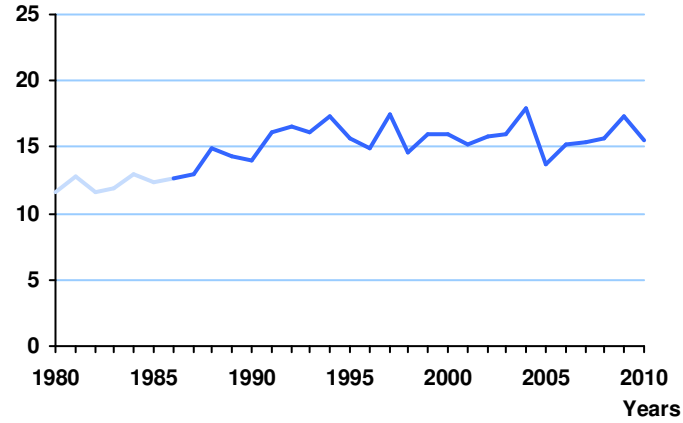
Survival probabilities by year of diagnosis (Germany 1980-2009)



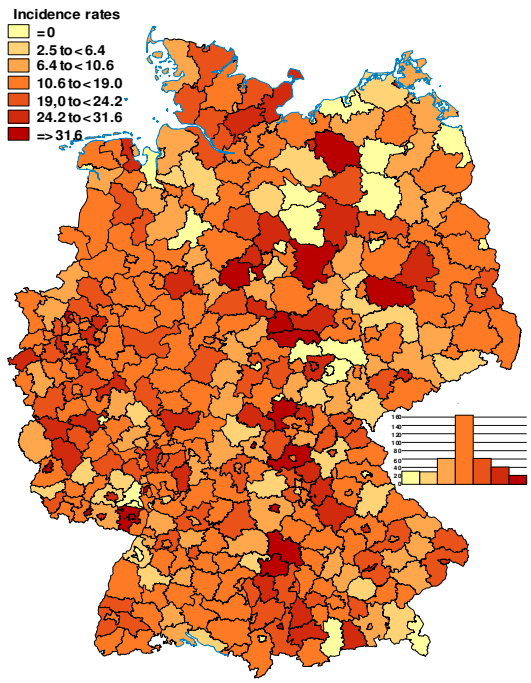
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Hodgkin's diease (HD) is rare in early childhood. Based on international comparisons, completeness of registration is close to 100%. Compared to all childhood cancers, mortality is relatively low. HD is relatively frequently followed by a second neoplasm within 20 years of diagnosis.

Cases in Germany aged under 15 years (1980-2010): 2363

Selected characteristics (Germany 2001-2010)

Relative frequency: 864 / 17876 = 4.9 %

Relative frequency of trial patients: 97.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	343	521	864
Standardized rate *:	5.0	7.6	6.3
Cumulative incidence:	84	124	104

Sex ratio (m/f): 1.5

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	0	33	202	629
Incidence rate:	0.0	1.1	5.2	14.8

Median age at diagnosis: 12 years 6 months

	5-year	**10-year**	**15-year**
Survival probabilities:	98 %	97 %	96 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
45	1.1 %	0.3	5

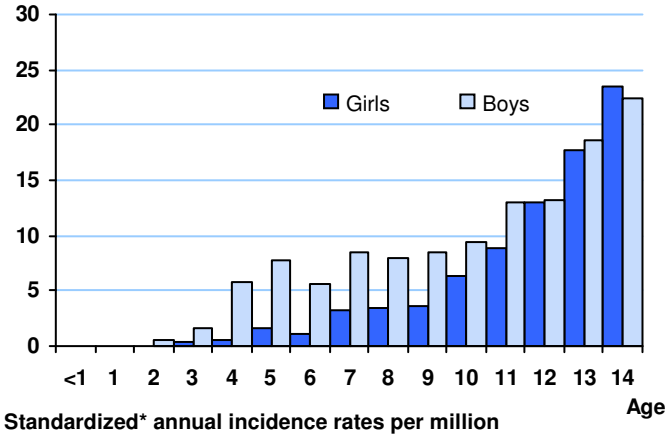
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

II (a) Hodgkin lymphomas

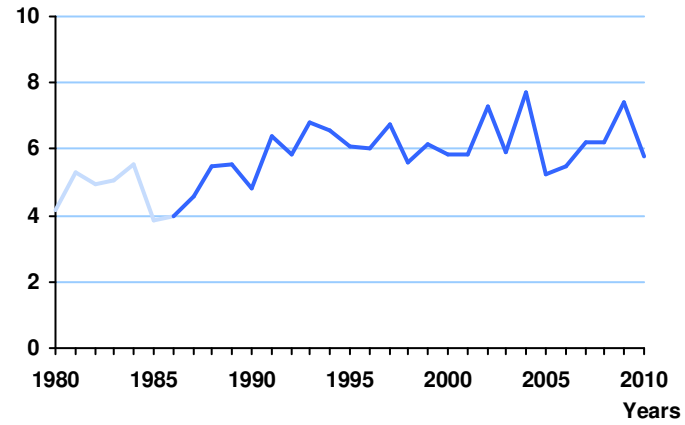
SN after II (a)			**II (a) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
66	8.5 %	10.0 %	17	2.2 %	0.1 %

* Standard: Segi world standard population

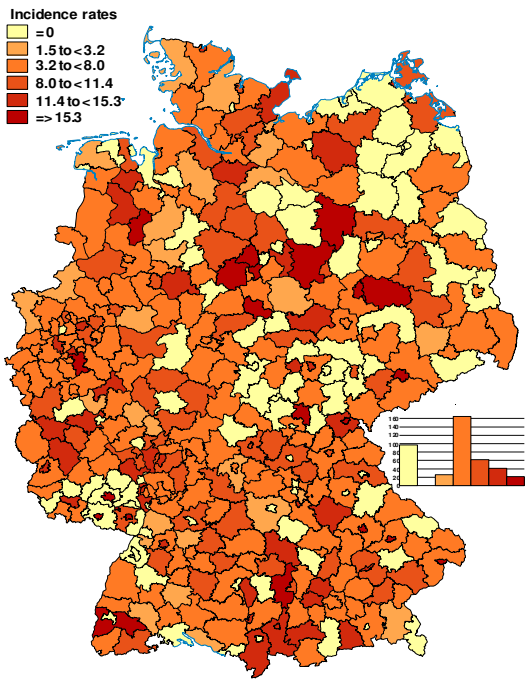
Age- and sex-specific incidence rates per million (Germany 2001-2010)



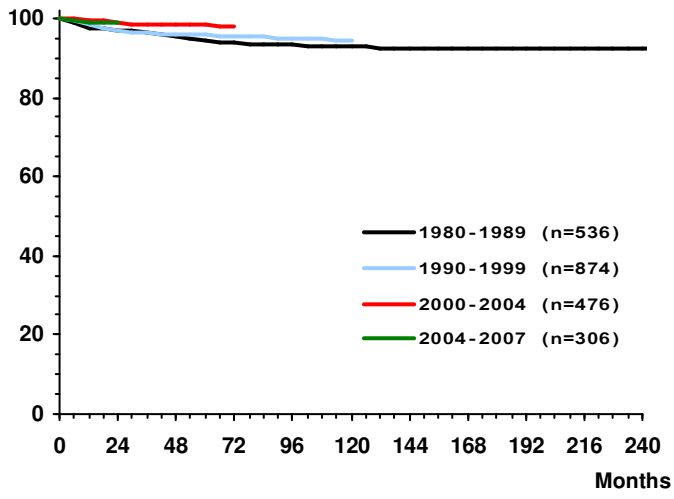
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



20 II (b) Non-Hodgkin lymphomas

Based on international comparisons, completeness of registration is close to 100%. Prognosis has improved considerably since 1980. Burkitt Lymphomas are presented as a separate entity.

Cases in Germany aged under 15 years (1980-2010): 2261

Selected characteristics (Germany 2001-2010)

Relative frequency:	800 / 17876 = 4.6 %
Relative frequency of trial patients:	94.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	251	549	800
Standardized rate *:	4.1	8.6	6.4
Cumulative incidence:	64	134	100
Sex ratio (m/f):			2.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	7	123	309	361
Incidence rate:	1.0	4.2	8.0	8.5

Median age at diagnosis: 9 years 4 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
131	3.2 %	1.0	15

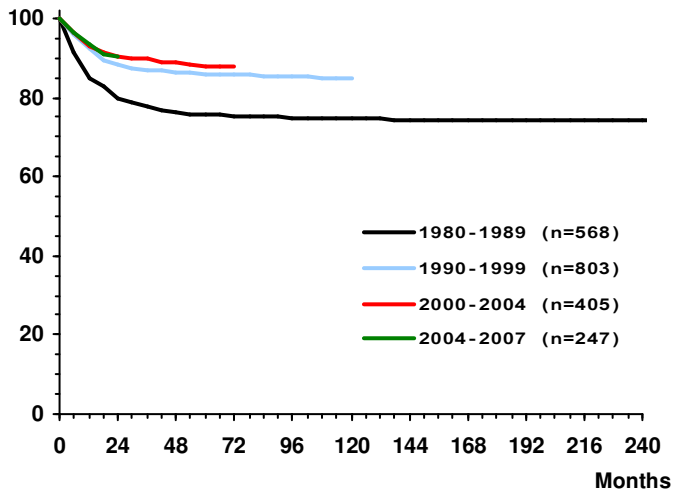
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

II (b) Non-Hodgkin lymphomas

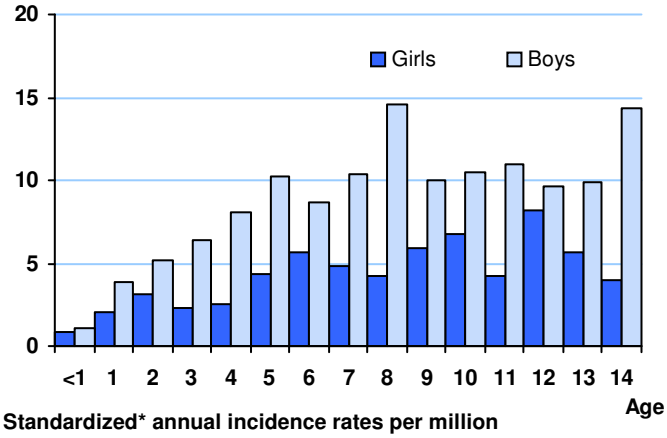
SN after II (b)			**II (b) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
48	6.2 %	3.6 %	52	6.7 %	0.2 %

* Standard: Segi world standard population

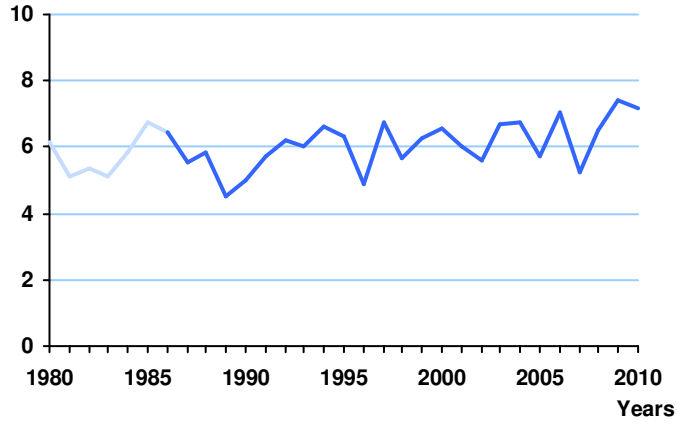
Survival probabilities by year of diagnosis (Germany 1980-2009)



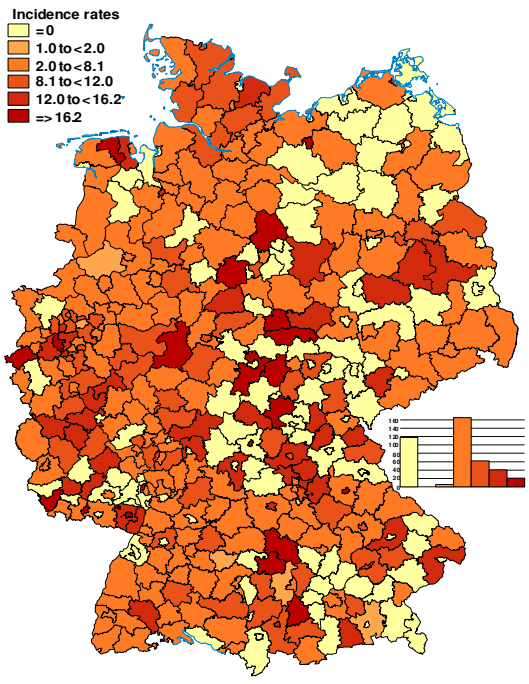
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Germany (2001-2010)	N	%
Non-Hodgkin lymphomas	**800**	**100.0**
Precursor cell lymphomas	327	40.9
Mature B-cell lymphomas (except Burkitt lymphoma)	156	19.5
Mature T-cell and NK-cell lymphomas	165	20.6
Non-Hodgkin lymphomas, NOS	152	19.0

1 Precursor cell lymphomas

Cases in Germany aged under 15 years (1980-2010): 899

Selected characteristics (Germany 2001-2010)

Relative frequency:	327 / 17876 = 1.8 %
Relative frequency of trial patients:	95.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	105	222	327
Standardized rate *:	1.8	3.6	2.7
Cumulative incidence:	27	55	41

Sex ratio (m/f): 2.1

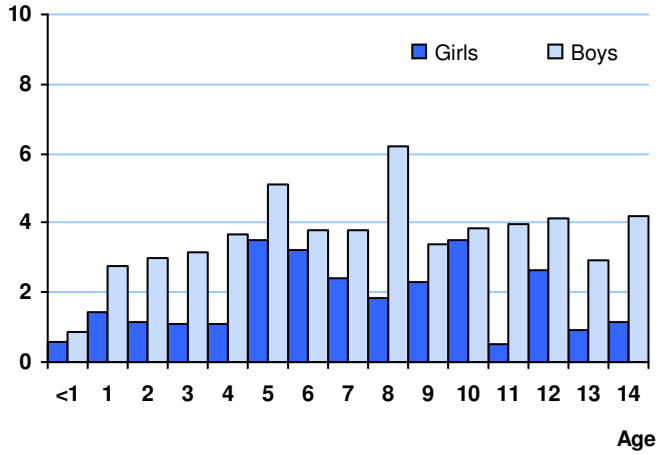
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	5	64	139	119
Incidence rate:	0.7	2.2	3.6	2.8

Median age at diagnosis: 8 years 3 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



2 Mature B-cell lymphomas (except Burkitt lymphoma)

Cases in Germany aged under 15 years (1980-2010): 350

Selected characteristics (Germany 2001-2010)

Relative frequency:	156 / 17876 = 0.9 %
Relative frequency of trial patients:	96.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	46	110	156
Standardized rate *:	0.7	1.6	1.2
Cumulative incidence:	12	26	19

Sex ratio (m/f): 2.4

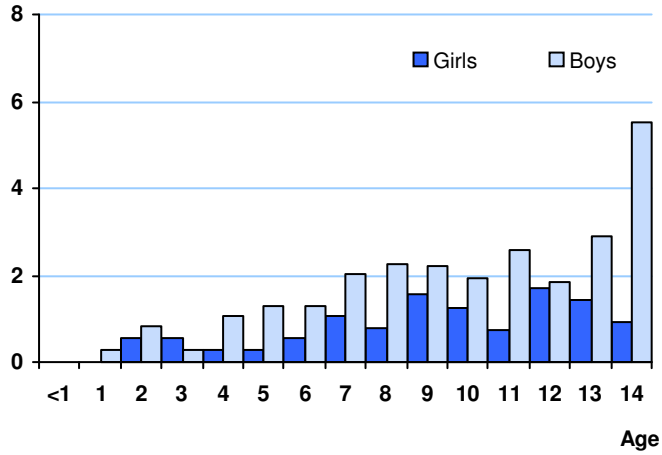
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	0	14	52	90
Incidence rate:	0.0	0.5	1.3	2.1

Median age at diagnosis: 10 years 11 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



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

Germany (2001-2010)	N	%
Non-Hodgkin lymphomas	800	100.0
Precursor cell lymphomas	327	40.9
Mature B-cell lymphomas (except Burkitt lymphoma)	156	19.5
Mature T-cell and NK-cell lymphomas	165	20.6
Non-Hodgkin lymphomas, NOS	152	19.0

3 Mature T-cell and NK-cell lymphomas

Cases in Germany aged under 15 years (1980-2010): 400

Selected characteristics (Germany 2001-2010)

Relative frequency:	165 / 17876 = 0.9 %
Relative frequency of trial patients:	93.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	59	106	165
Standardized rate *:	0.9	1.7	1.3
Cumulative incidence:	15	26	21

Sex ratio (m/f): 1.8

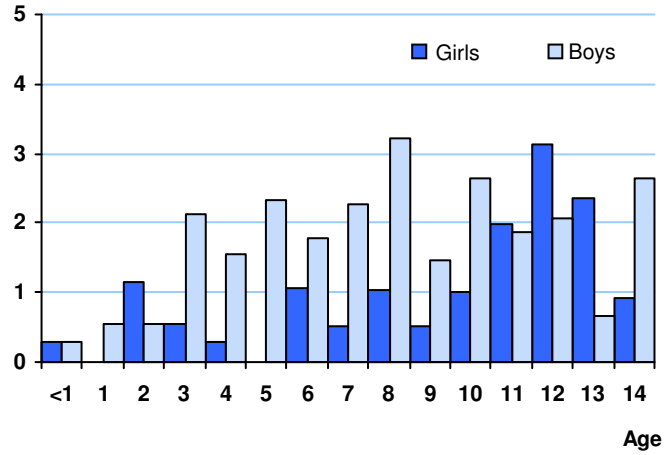
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	2	25	56	82
Incidence rate:	0.3	0.9	1.4	1.9

Median age at diagnosis: 9 years 9 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



4 Non-Hodgkin lymphomas, NOS

Cases in Germany aged under 15 years (1980-2010): 612

Selected characteristics (Germany 2001-2010)

Relative frequency:	152 / 17876 = 0.9 %
Relative frequency of trial patients:	92.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	41	111	152
Standardized rate *:	0.7	1.7	1.2
Cumulative incidence:	11	27	19

Sex ratio (m/f): 2.7

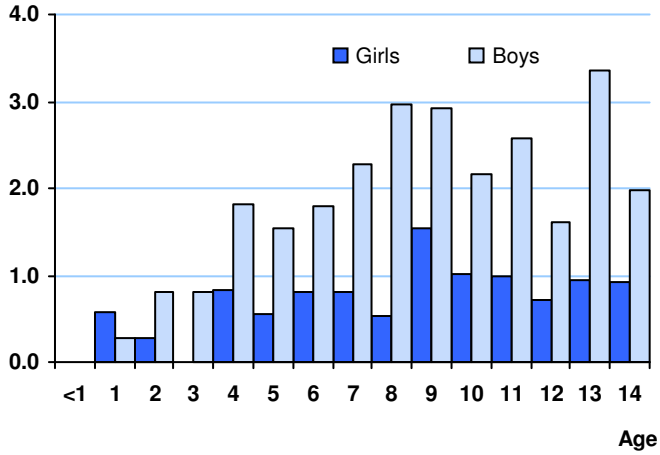
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	0	20	62	70
Incidence rate:	0.0	0.7	1.6	1.6

Median age at diagnosis: 9 years 8 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



Burkitt lymphoma (BL) is a subtype of Non-Hodgkin lymphomas. Based on international comparisons, completeness of registration is close to 100% since 1988. Prognosis has improved considerably since 1980. BL is rare as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 1018

Selected characteristics (Germany 2001-2010)

Relative frequency:	361 / 17876 = 2.1 %
Relative frequency of trial patients:	98.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	63	298	361
Standardized rate *:	1.0	4.8	3.0
Cumulative incidence:	16	74	46
Sex ratio (m/f):			4.7

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	1	63	174	123
Incidence rate:	0.1	2.2	4.5	2.9

Median age at diagnosis: 8 years 3 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
33	0.8 %	0.2	4

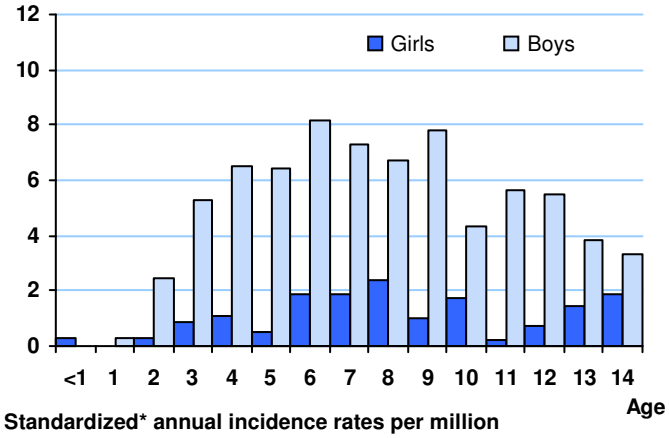
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

II (c) Burkitt lymphoma

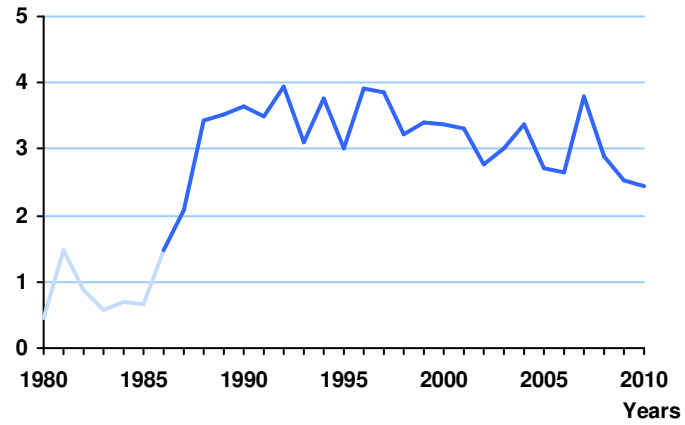
SN after II (c)			II (c) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
15	1.9 %	2.1 %	3	0.4 %	0.0 %

* Standard: Segi world standard population

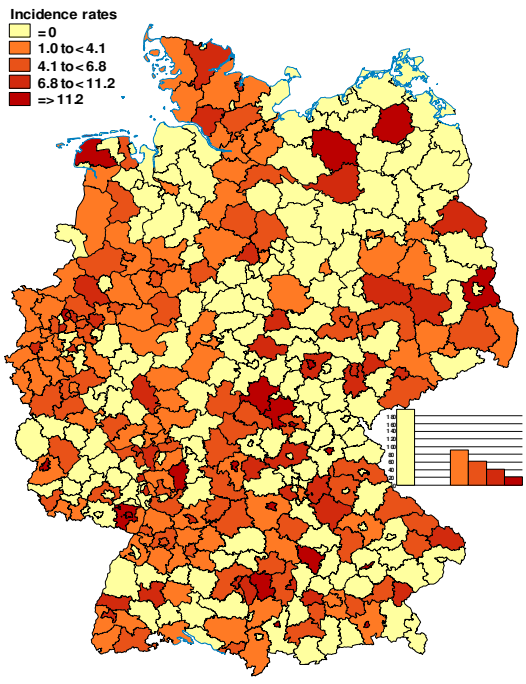
Age- and sex-specific incidence rates per million (Germany 2001-2010)



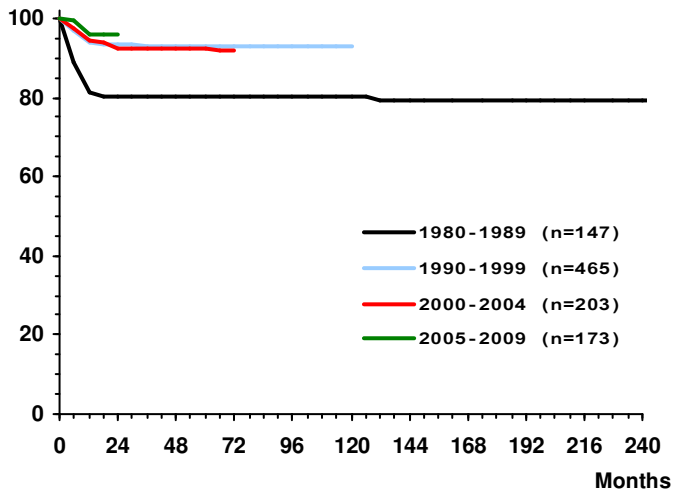
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



24 III CNS and miscellaneous intracranial and intraspinal neoplasms

(a) Ependymomas and choroid plexus tumour
(b) Astrocytomas
(c) Intracranial and intraspinal embryonal tumours
(d) Other gliomas
(e) Other specified intracranial and intraspinal neoplasms
(f) Unspecified intracranial and intraspinal neoplasms

Cases in Germany aged under 15 years (1980-2010): 10216

Selected characteristics (Germany 2001-2010)

Relative frequency:	4159 / 17876 = 23.3 %
Relative frequency of trial patients:	89.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	1856	2303	4159
Standardized rate *:	33.3	39.3	36.4
Cumulative incidence:	491	579	536
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	306	1209	1416	1228
Incidence rate:	43.8	41.5	36.5	28.9

Median age at diagnosis: 6 years 11 months

	5-year	**10-year**	**15-year**
Survival probabilities:	76 %	71 %	69 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

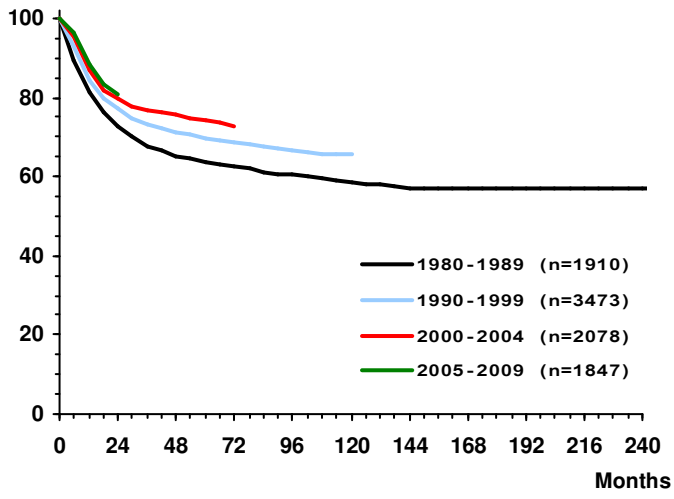
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
1184	28.5 %	9.4	137

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):
III CNS and miscellaneous intracranial and intraspinal neoplasms

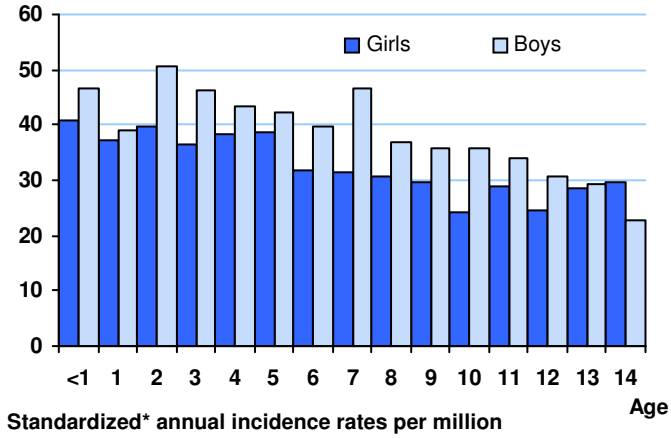
SN after III			**III as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
137	17.7 %	3.2 %	171	22.1 %	0.7 %

* Standard: Segi world standard population

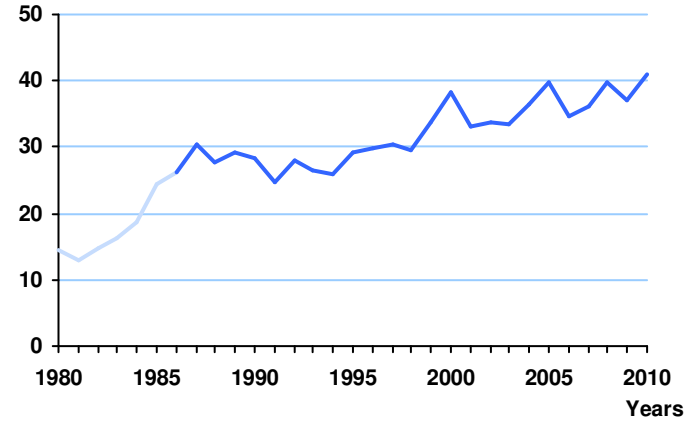
Survival probabilities by year of diagnosis (Germany 1980-2009)



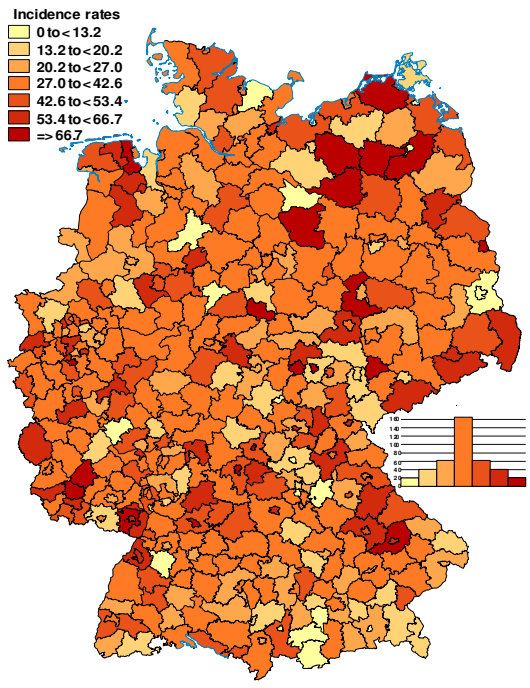
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Non-malignant forms are rare, otherwise completeness of registration exceeds 95% compared to international incidence rates. Ependymomas are relatively rare as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 1030

Selected characteristics (Germany 2001-2010)

Relative frequency: 408 / 17876 = 2.3 %

Relative frequency of trial patients: 91.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	172	236	408
Standardized rate *:	3.4	4.3	3.9
Cumulative incidence:	47	61	54

Sex ratio (m/f): 1.4

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	70	179	73	86
Incidence rate:	10.0	6.1	1.9	2.0

Median age at diagnosis: 3 years 9 months

Survival probabilities:	**5-year**	**10-year**	**15-year**
	80 %	71 %	68 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
138	3.3 %	1.2	16

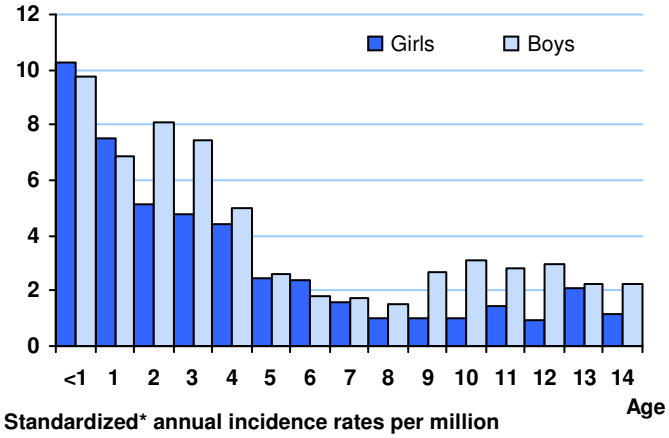
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

III (a) Ependymomas and choroid plexus tumour

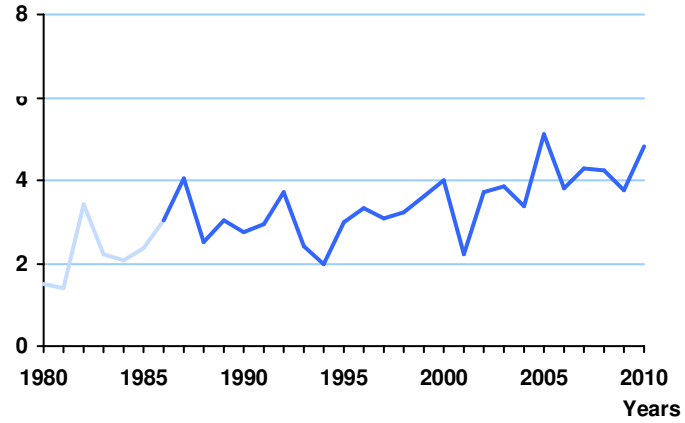
SN after III (a)			**III (a) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
14	1.8 %	2.8 %	7	0.9 %	0.0 %

* Standard: Segi world standard population

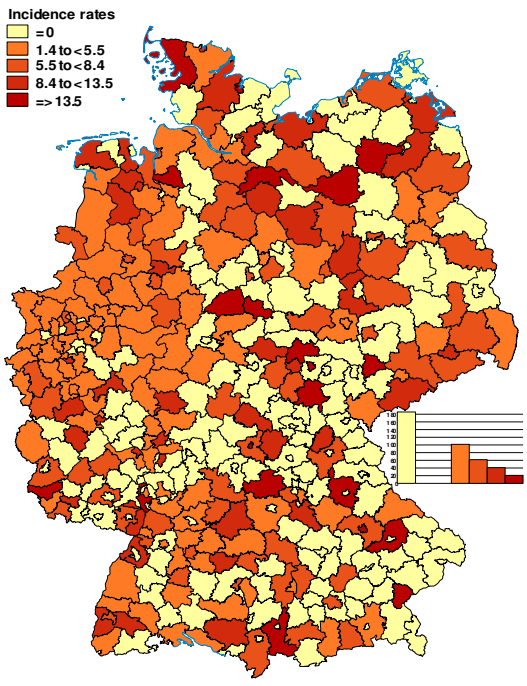
Age- and sex-specific incidence rates per million (Germany 2001-2010)



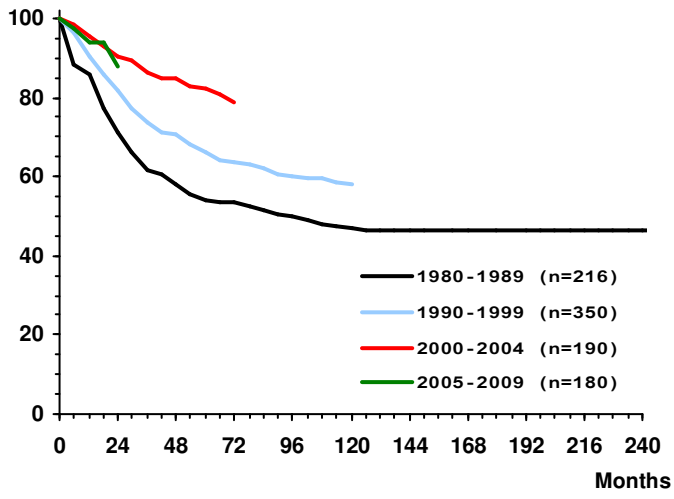
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



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

Germany (2001-2010)	N	%
Ependymomas and choroid plexus tumour	**408**	**100.0**
Ependymomas	322	78.9
Choroid plexus tumour	86	21.1

1 Ependymomas

Cases in Germany aged under 15 years (1980-2010): 833

Selected characteristics (Germany 2001-2010)

Relative frequency: 322 / 17876 = 1.8 %

Relative frequency of trial patients: 93.5 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	129	193	322
Standardized rate *:	2.5	3.5	3.0
Cumulative incidence:	35	49	42

Sex ratio (m/f): 1.5

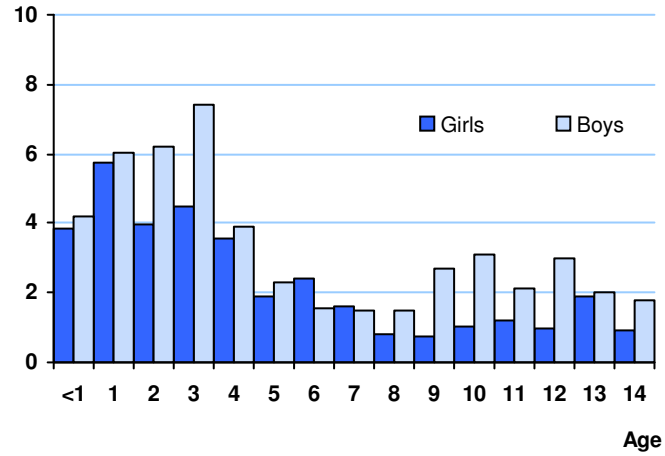
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	28	151	66	77
Incidence rate:	4.0	5.2	1.7	1.8

Median age at diagnosis: 4 years 2 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



2 Choroid plexus tumour

Cases in Germany aged under 15 years (1980-2010): 197

Selected characteristics (Germany 2001-2010)

Relative frequency: 86 / 17876 = 0.5 %

Relative frequency of trial patients: 82.6 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	43	43	86
Standardized rate *:	0.9	0.9	0.9
Cumulative incidence:	12	11	12

Sex ratio (m/f): 1.0

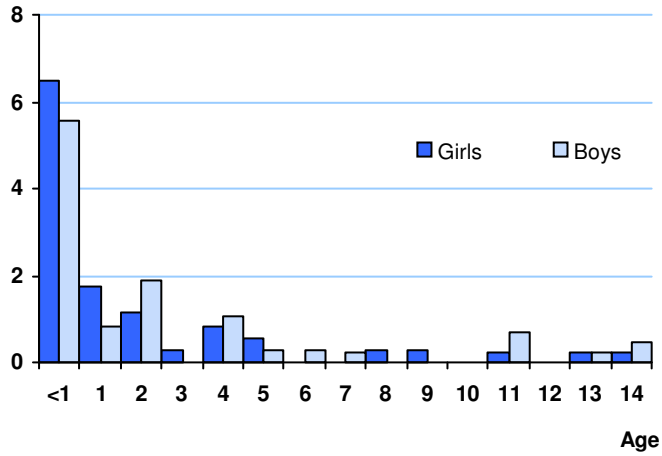
Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases:	42	28	7	9
Incidence rate:	6.0	1.0	0.2	0.2

Median age at diagnosis: 1 year 2 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



Non-malignant forms of astrocytoma are frequent and may be underreported. The temporal trend is due to improvements in registration. Astrocytomas are relatively rarely followed by a second neoplasm within 20 years of diagnosis.

Cases in Germany aged under 15 years (1980-2010): 4441

Selected characteristics (Germany 2001-2010)

Relative frequency:	1962 / 17876 = 11.2 %
Relative frequency of trial patients:	90.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	922	1040	1962
Standardized rate *:	16.3	17.5	16.9
Cumulative incidence:	243	260	252
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	97	550	692	623
Incidence rate:	13.9	18.9	17.8	14.7

Median age at diagnosis: 7 years 3 months

	5-year	**10-year**	**15-year**
Survival probabilities:	80 %	77 %	75 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
384	9.3 %	2.9	44

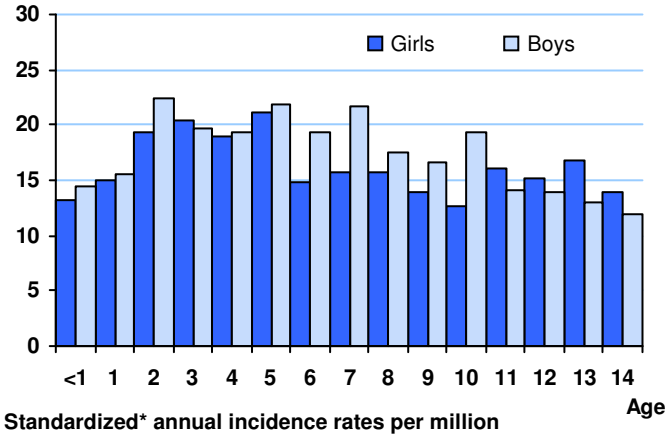
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

III (b) Astrocytomas

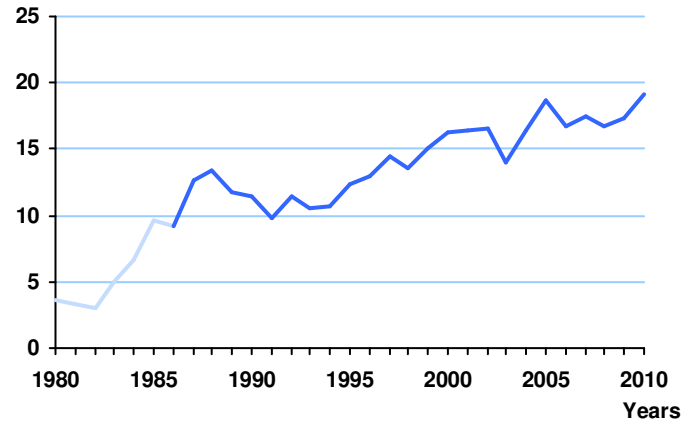
SN after III (b)			**III (b) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
32	4.1 %	1.9 %	80	10.3 %	0.3 %

* Standard: Segi world standard population

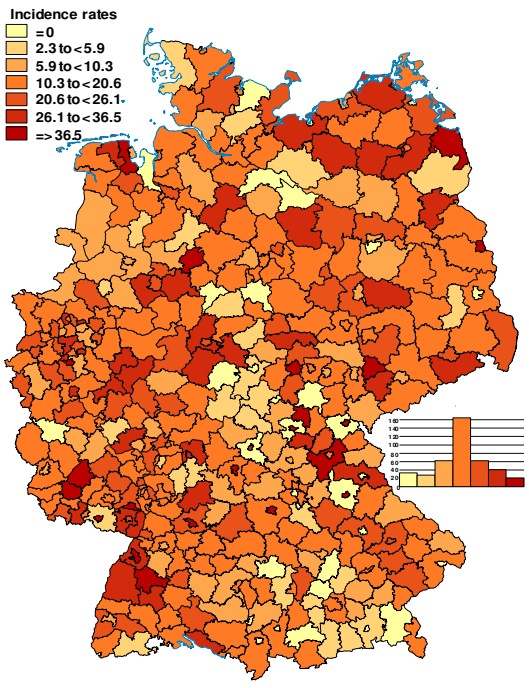
Age- and sex-specific incidence rates per million (Germany 2001-2010)



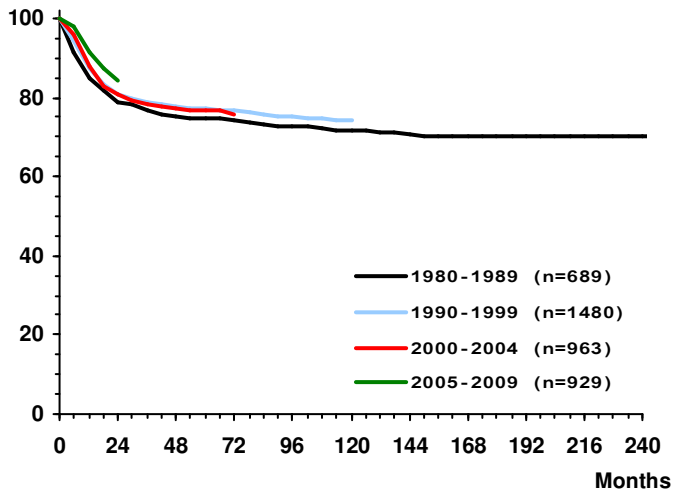
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



28 III (c) Intracranial and intraspinal embryonal tumours

All registered tumours are malignant. Based on international comparisons, completeness of registration exceeds 95%. Compared to all childhood cancers, mortality is relatively high. These tumours are relatively frequently followed by a second neoplasm within 20 years of diagnosis. These tumours are relatively rare as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 2374

Selected characteristics (Germany 2001-2010)

Relative frequency: 831 / 17876 = 4.7 %

Relative frequency of trial patients: 92.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	318	513	831
Standardized rate *:	6.0	9.1	7.6
Cumulative incidence:	86	131	109

Sex ratio (m/f): 1.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	88	275	322	146
Incidence rate:	12.6	9.4	8.3	3.4

Median age at diagnosis: 5 years 10 months

	5-year	**10-year**	**15-year**
Survival probabilities:	66 %	59 %	56 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
459	11.1 %	3.8	53

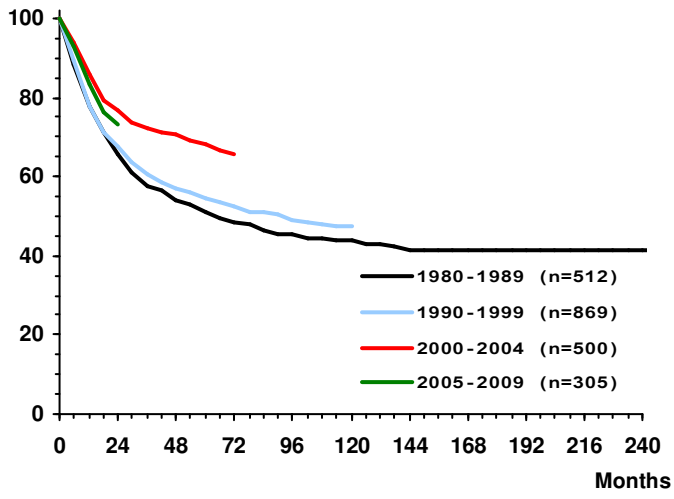
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

III (c) Intracranial and intraspinal embryonal tumours

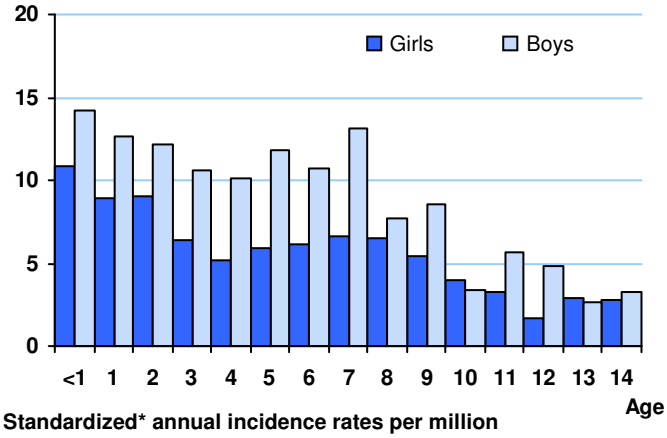
SN after III (c)			**III (c) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
72	9.3 %	6.3 %	14	1.8 %	0.1 %

* Standard: Segi world standard population

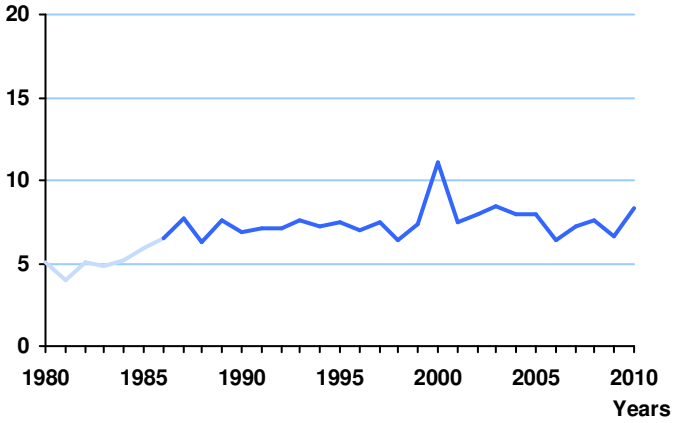
Survival probabilities by year of diagnosis (Germany 1980-2009)



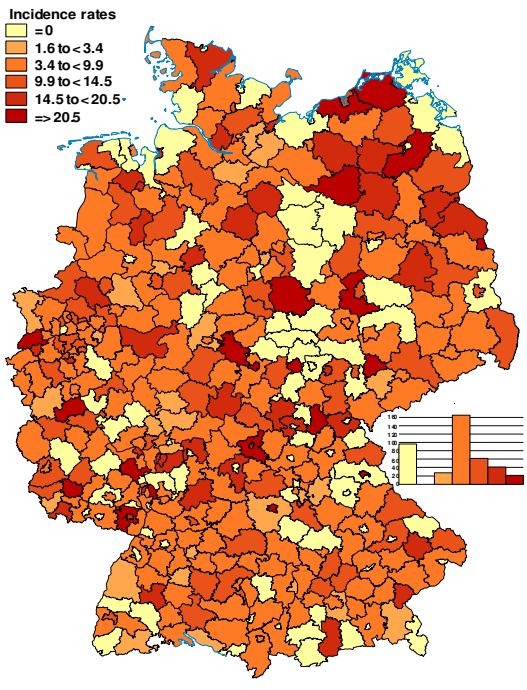
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Germany (2001-2010)	N	%
Intracranial and intraspinal embryonal tumours	**831**	**100.0**
Medulloblastomas	595	71.6
Primitive neuroectodermal tumour (PNET)	107	12.9
Medulloepithelioma	7	0.8
Atypical teratoid/rhabdoid tumour	122	14.7

1 Medulloblastomas

Cases in Germany aged under 15 years (1980-2010): 1820

based on International Classification of Childhood Cancer, 3rd edition

Selected characteristics (Germany 2001-2010)

Relative frequency: 595 / 17876 = 3.3 %

Relative frequency of trial patients: 98.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	223	372	595
Standardized rate *:	4.0	6.4	5.2
Cumulative incidence:	59	94	77

Sex ratio (m/f): 1.7

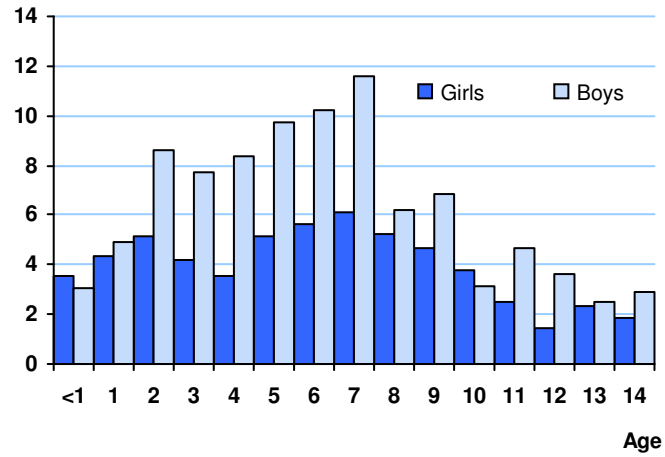
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	23	172	278	122
Incidence rate:	3.3	5.9	7.2	2.9

Median age at diagnosis: 6 years 8 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



2 Primitive neuroectodermal tumour (PNET)

Cases in Germany aged under 15 years (1980-2010): 376

Selected characteristics (Germany 2001-2010)

Relative frequency: 107 / 17876 = 0.6 %

Relative frequency of trial patients: 93.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	44	63	107
Standardized rate *:	0.9	1.1	1.0
Cumulative incidence:	12	16	14

Sex ratio (m/f): 1.4

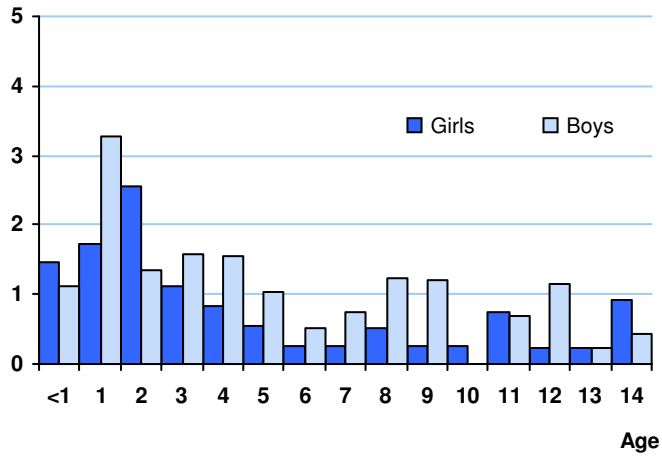
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	9	51	26	21
Incidence rate:	1.3	1.7	0.7	0.5

Median age at diagnosis: 4 years 3 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



Germany (2001-2010)	N	%
Intracranial and intraspinal embryonal tumours	831	100.0
Medulloblastomas	595	71.6
Primitive neuroectodermal tumour (PNET)	107	12.9
Medulloepithelioma	7	0.8
Atypical teratoid/rhabdoid tumour	122	14.7

4 Atypical teratoid/rhabdoid tumour

Cases in Germany aged under 15 years (1980-2010): 162

Selected characteristics (Germany 2001-2010)

Relative frequency:	122 / 17876 = 0.7 %
Relative frequency of trial patients:	61.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	47	75	122
Standardized rate *:	1.0	1.5	1.3
Cumulative incidence:	13	20	17

Sex ratio (m/f): 1.6

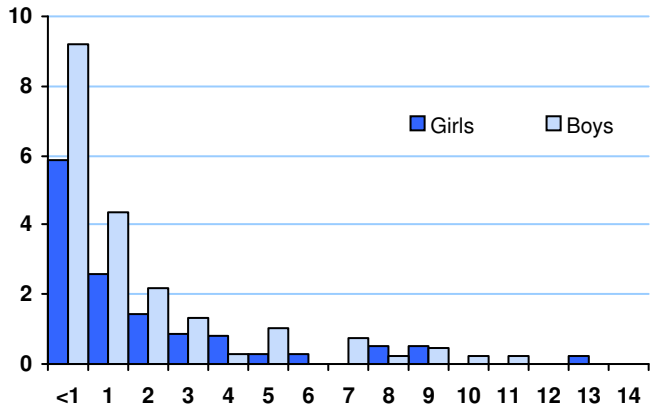
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	53	50	16	3
Incidence rate:	7.6	1.7	0.4	0.1

Median age at diagnosis: 1 year 4 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



All registered tumours are malignant. Based on international comparisons, completeness of registration approaches 95%. The temporal trend is due to improvements in registration. Gliomas are relatively rarely followed by a second neoplasm (SN) within 20 years of diagnosis, underreporting of SN is a possibility.

Cases in Germany aged under 15 years (1980-2010): 743

Selected characteristics (Germany 2001-2010)

Relative frequency:	342 / 17876 = 2.0 %
Relative frequency of trial patients:	83.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	167	175	342
Standardized rate *:	2.9	2.9	2.9
Cumulative incidence:	44	44	44
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	16	82	130	114
Incidence rate:	2.3	2.8	3.3	2.7

Median age at diagnosis: 7 years 8 months

Survival probabilities:	**5-year**	**10-year**	**15-year**
	42 %	41 %	41 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4151 deaths		
123	3.0 %	0.9	14

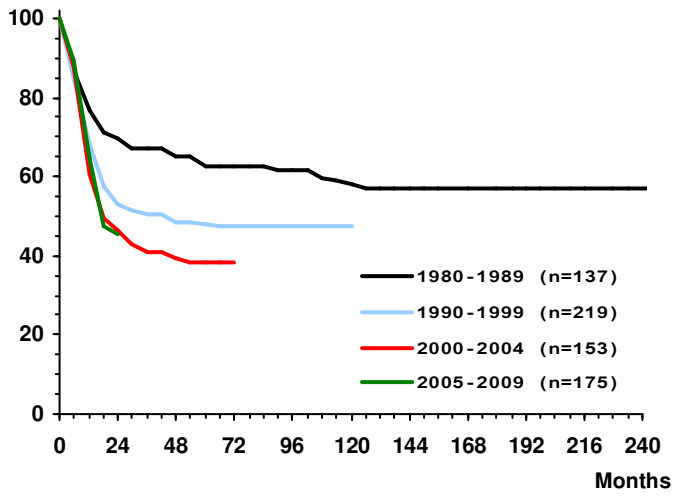
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

III (d) Other gliomas

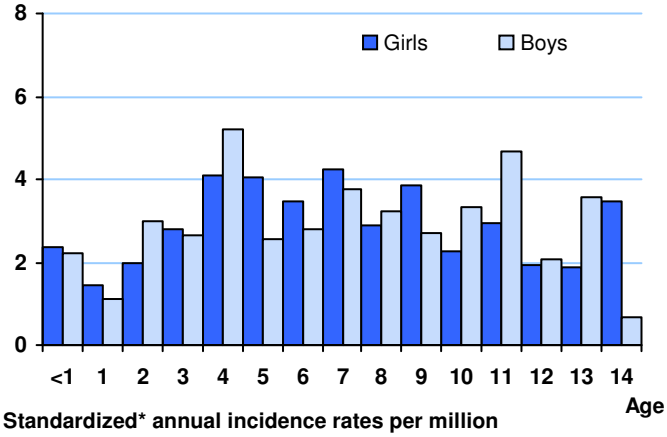
SN after III (d)			III (d) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
6	0.8 %	1.3 %	19	2.5 %	0.1 %

* Standard: Segi world standard population

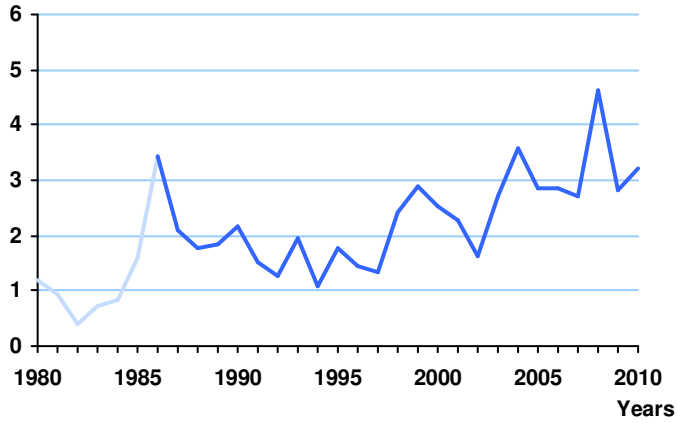
Survival probabilities by year of diagnosis (Germany 1980-2009)



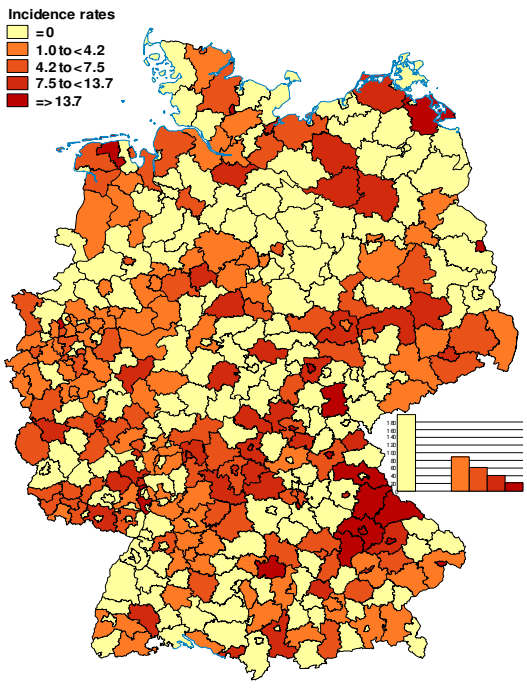
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



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

Germany (2001-2010)	N	%
Other gliomas	**342**	**100.0**
Oligodendrogliomas	20	5.8
Mixed and unspecified gliomas	308	90.1
Neuroepithelial glial tumours of uncertain origin	14	4.1

1 Oligodendrogliomas

Cases in Germany aged under 15 years (1980-2010): 110

Selected characteristics (Germany 2001-2010)

Relative frequency:	20 / 17876 = 0.1 %
Relative frequency of trial patients:	70.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	10	10	20
Standardized rate *:	0.2	0.1	0.2
Cumulative incidence:	3	2	2

Sex ratio (m/f): 1.0

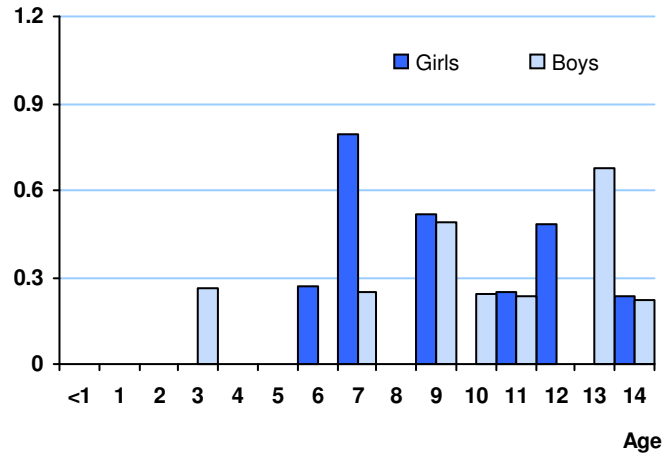
Age-specific incidence rates per million:

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

Median age at diagnosis: 10 years 5 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



2 Mixed and unspecified gliomas

Cases in Germany aged under 15 years (1980-2010): 611

Selected characteristics (Germany 2001-2010)

Relative frequency:	308 / 17876 = 1.7 %
Relative frequency of trial patients:	84.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	150	158	308
Standardized rate *:	2.6	2.6	2.6
Cumulative incidence:	39	39	39

Sex ratio (m/f): 1.1

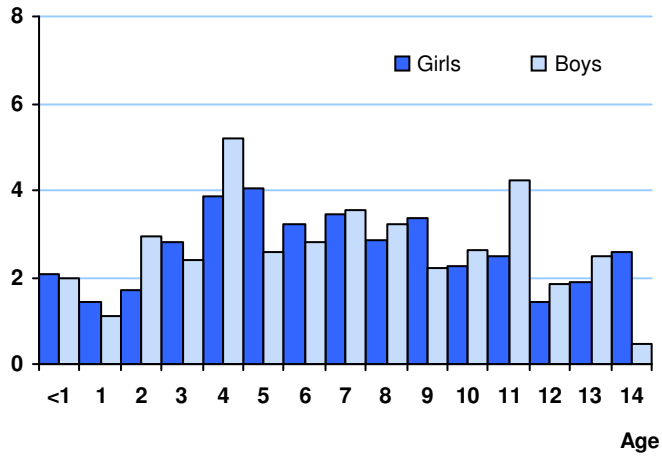
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	14	79	121	94
Incidence rate:	2.0	2.7	3.1	2.2

Median age at diagnosis: 7 years 7 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



III (e) Other specified intracranial and intraspinal neoplasms

Non-malignant forms are frequent and may be underreported. The temporal trend is due to improvements in registration. These tumours are relatively rarely followed by a second neoplasm (SN) within 20 years of diagnosis, underreporting of SN is a possibility. These tumours are relatively frequent as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 1265

Selected characteristics (Germany 2001-2010)

Relative frequency:	550 / 17876 = 3.1 %
Relative frequency of trial patients:	88.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	250	300	550
Standardized rate *:	4.2	4.8	4.5
Cumulative incidence:	65	74	69
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	22	109	182	237
Incidence rate:	3.2	3.7	4.7	5.6

Median age at diagnosis: 9 years 2 months

	5-year	**10-year**	**15-year**
Survival probabilities:	95 %	93 %	90 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
32	0.8 %	0.2	4

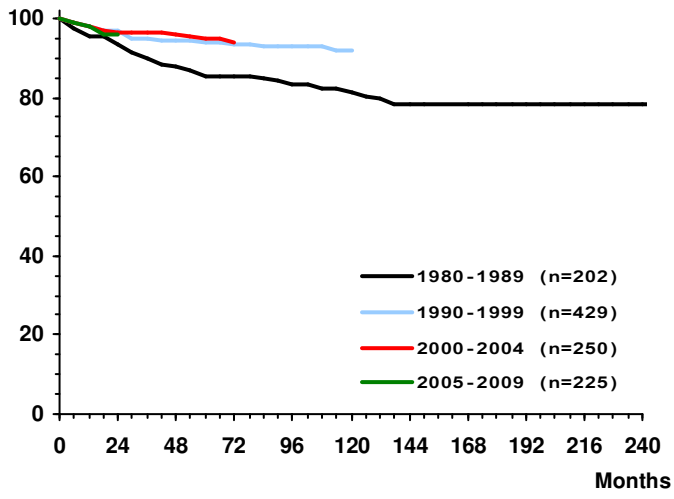
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

III (e) Other specified intracranial and intraspinal neoplasms

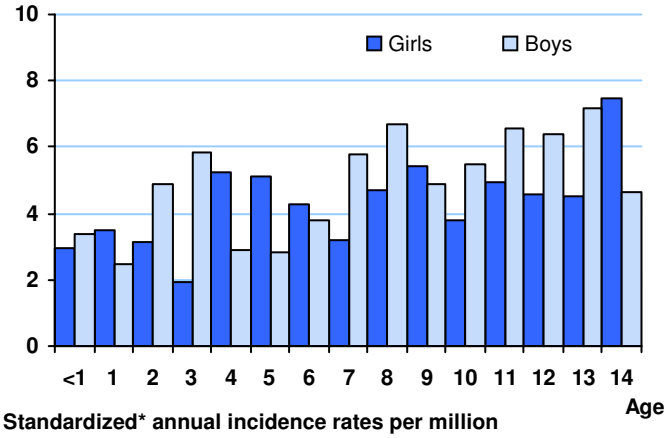
SN after III (e)			**III (e) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
12	1.5 %	2.4 %	46	5.9 %	0.3 %

* Standard: Segi world standard population

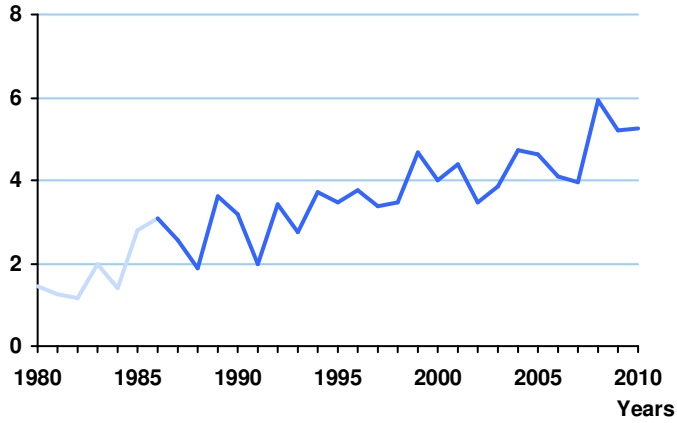
Survival probabilities by year of diagnosis (Germany 1980-2009)



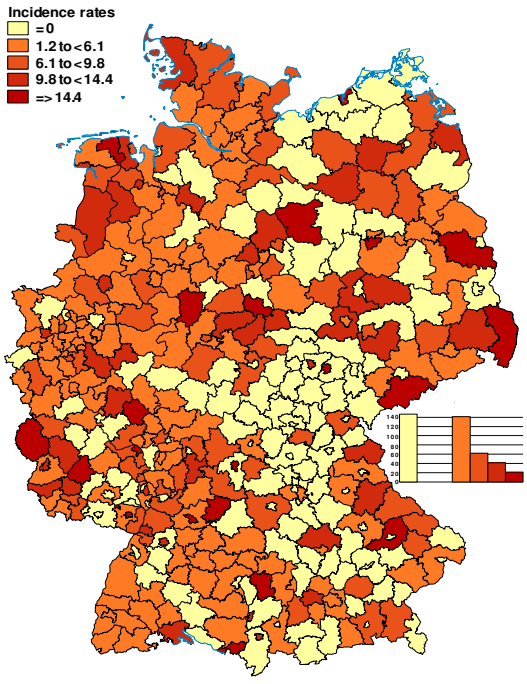
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



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

Germany (2001-2010)	N	%
Other specified intracranial and intraspinal neoplasms	**550**	**100.0**
Pituitary adenomas and carcinomas	30	5.5
Tumours of the sellar region (craniopharyngiomas)	194	35.3
Pineal parenchymal tumours	30	5.5
Neuronal and mixed neuronal-glial tumours	243	44.2
Meningiomas	53	9.6

1 Pituitary adenomas and carcinomas

Cases in Germany aged under 15 years (1980-2010): 77

Selected characteristics (Germany 2001-2010)

Relative frequency:	30 / 17876 = 0.2 %
Relative frequency of trial patients:	63.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	15	15	30
Standardized rate *:	0.2	0.2	0.2
Cumulative incidence:	4	3	4

Sex ratio (m/f): 1.0

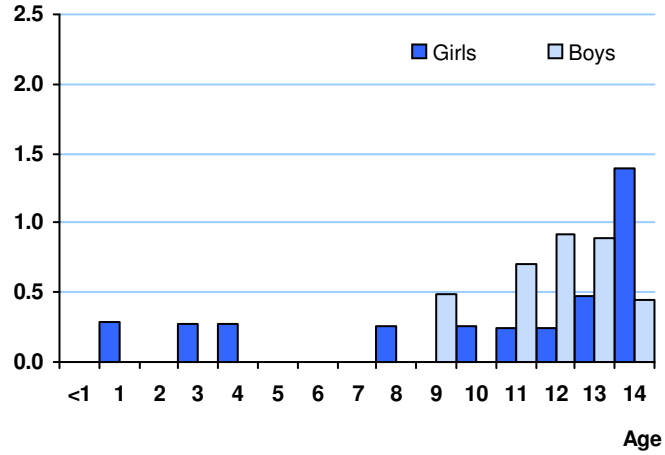
Age-specific incidence rates per million:

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

Median age at diagnosis: 12 years 9 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



2 Tumours of the sellar region (craniopharyngiomas)

Cases in Germany aged under 15 years (1980-2010): 520

Selected characteristics (Germany 2001-2010)

Relative frequency:	194 / 17876 = 1.1 %
Relative frequency of trial patients:	97.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	94	100	194
Standardized rate *:	1.6	1.6	1.6
Cumulative incidence:	24	25	24

Sex ratio (m/f): 1.1

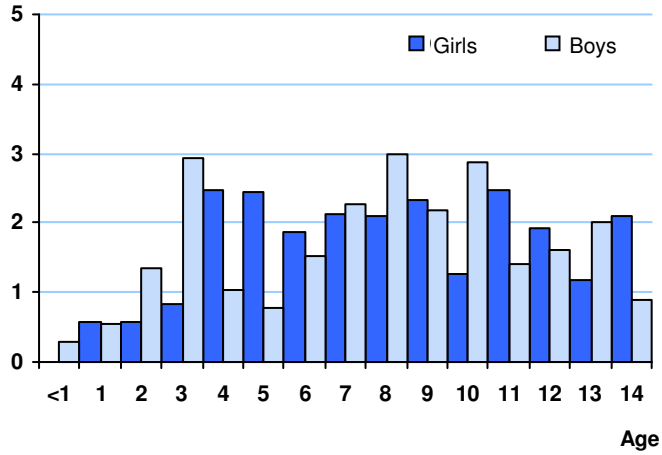
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	1	38	80	75
Incidence rate:	0.1	1.3	2.1	1.8

Median age at diagnosis: 8 years 10 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



Germany (2001-2010)	N	%
Other specified intracranial and intraspinal neoplasms	**550**	**100.0**
Pituitary adenomas and carcinomas	30	5.5
Tumours of the sellar region (craniopharyngiomas)	194	35.3
Pineal parenchymal tumours	30	5.5
Neuronal and mixed neuronal-glial tumours	243	44.2
Meningiomas	53	9.6

3 Pineal parenchymal tumours

Cases in Germany aged under 15 years (1980-2010): 109

Selected characteristics (Germany 2001-2010)

Relative frequency:	30 / 17876 = 0.2 %
Relative frequency of trial patients:	86.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	13	17	30
Standardized rate *:	0.2	0.3	0.3
Cumulative incidence:	3	4	4

Sex ratio (m/f): 1.3

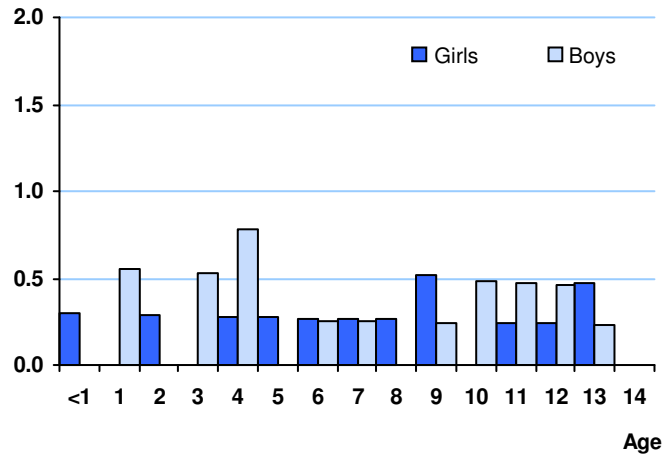
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	1	9	9	11
Incidence rate:	0.1	0.3	0.2	0.3

Median age at diagnosis: 7 years 10 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



4 Neuronal and mixed neuronal-glial tumours

Cases in Germany aged under 15 years (1980-2010): 433

Selected characteristics (Germany 2001-2010)

Relative frequency:	243 / 17876 = 1.4 %
Relative frequency of trial patients:	87.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	100	143	243
Standardized rate *:	1.7	2.3	2.0
Cumulative incidence:	26	35	31

Sex ratio (m/f): 1.4

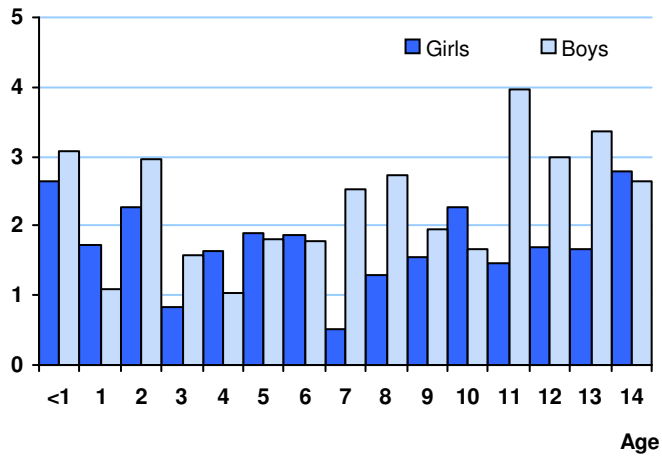
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	20	48	70	105
Incidence rate:	2.9	1.6	1.8	2.5

Median age at diagnosis: 8 years 8 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



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

Germany (2001-2010)	N	%
Other specified intracranial and intraspinal neoplasms	**550**	**100.0**
Pituitary adenomas and carcinomas	30	5.5
Tumours of the sellar region (craniopharyngiomas)	194	35.3
Pineal parenchymal tumours	30	5.5
Neuronal and mixed neuronal-glial tumours	243	44.2
Meningiomas	53	9.6

5 Meningiomas

Cases in Germany aged under 15 years (1980-2010): 126

Selected characteristics (Germany 2001-2010)

Relative frequency:	53 / 17876 = 0.3 %
Relative frequency of trial patients:	75.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	28	25	53
Standardized rate *:	0.5	0.4	0.4
Cumulative incidence:	7	6	7

Sex ratio (m/f): 0.9

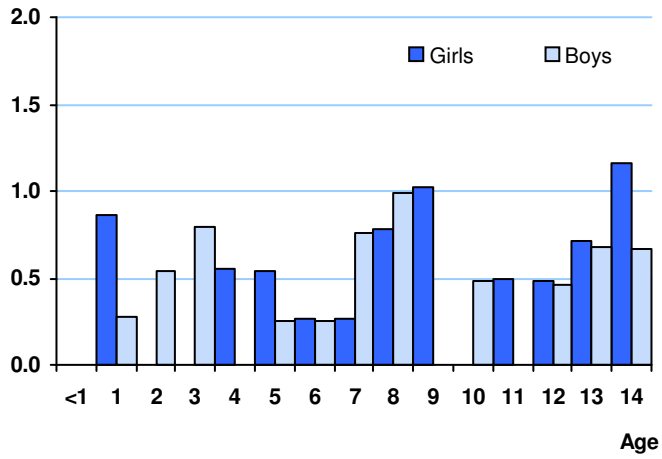
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	0	11	20	22
Incidence rate:	0.0	0.4	0.5	0.5

Median age at diagnosis: 8 years 10 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



IV (a) Neuroblastoma and ganglioneuroblastoma

Neuroblastoma (NB) is an embryonal tumor of early childhood. Spontaneous regression has been observed. A large study showed that screening does not reduce mortality. The higher incidence rate 1995-2001 is due to the screening study. Based on international comparisons, completeness of registration is close to 100%. Prognosis has improved considerably since 1980. NB is very rare as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 3690

Selected characteristics (Germany 2001-2010)

Relative frequency:	1240 / 17876 = 7.1 %
Relative frequency of trial patients:	99.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	570	670	1240
Standardized rate *:	12.5	14.1	13.3
Cumulative incidence:	162	182	172
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	575	536	101	28
Incidence rate:	82.4	18.4	2.6	0.7

Median age at diagnosis: 1 year 2 months

	5-year	**10-year**	**15-year**
Survival probabilities:	78 %	75 %	74 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
445	10.7 %	3.9	53

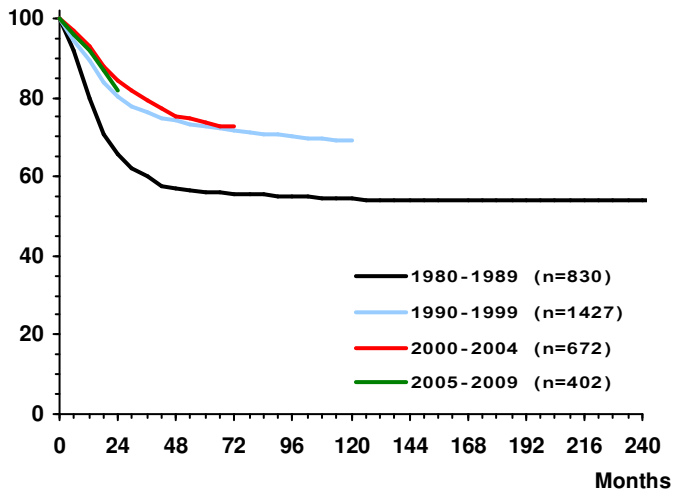
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

IV (a) Neuroblastoma and ganglioneuroblastoma

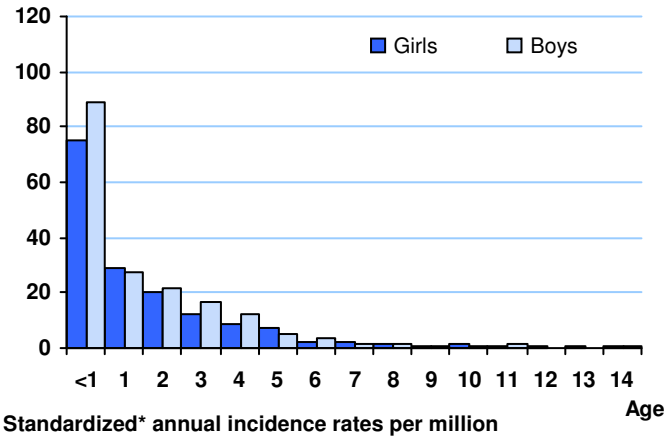
SN after IV (a)			**IV (a) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
49	6.3 %	2.5 %	9	1.2 %	0.0 %

* Standard: Segi world standard population

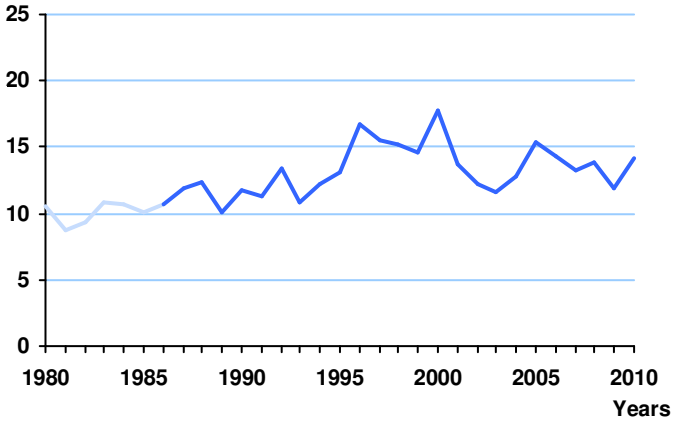
Survival probabilities by year of diagnosis (Germany 1980-2009)



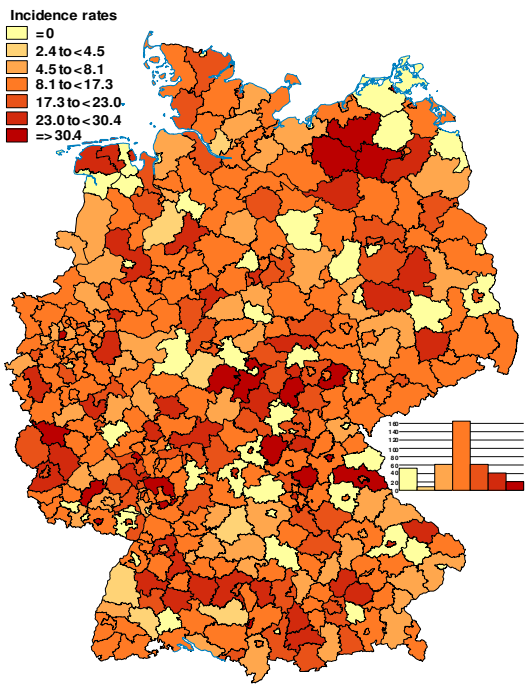
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



38 V Retinoblastoma

Retinoblastoma (RB) is an embryonal tumor of early childhood. The gene variant leading to RB is known. Hereditary cases are earlier than spontaneous mutations and often bilateral. Based on international comparisons, completeness of registration is close to 100%. RB is very rare as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 1170

Selected characteristics (Germany 2001-2010)

Relative frequency: 396 / 17876 = 2.3 %

Relative frequency of trial patients: -

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	179	217	396
Standardized rate *:	4.0	4.6	4.3
Cumulative incidence:	51	59	55

Sex ratio (m/f): 1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	173	203	18	2
Incidence rate:	24.8	7.0	0.5	0.0

Median age at diagnosis: 1 year 2 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
9	0.2 %	0.1	1

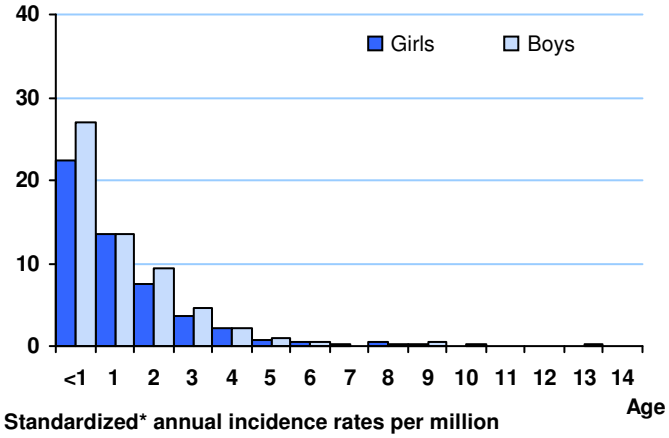
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

V Retinoblastoma

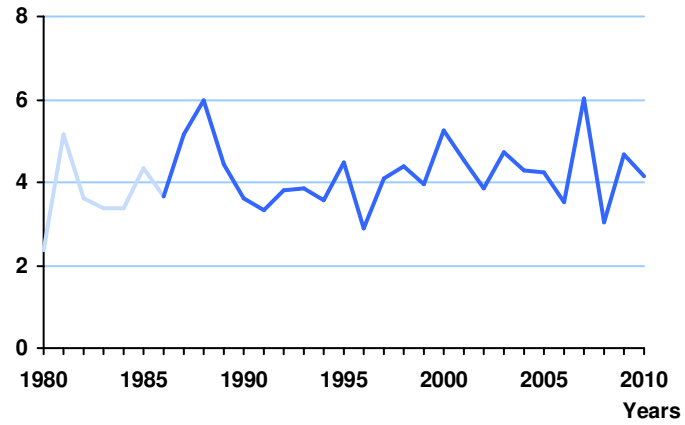
SN after V			**V as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
24	3.1 %	3.1 %	3	0.4 %	0.0 %

* Standard: Segi world standard population

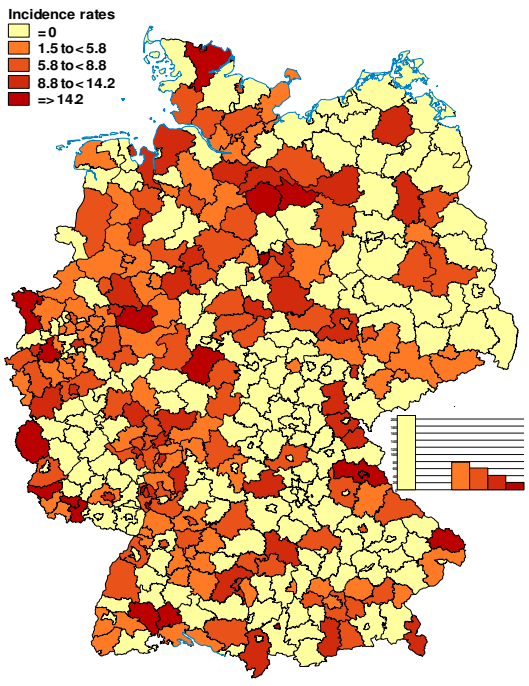
Age- and sex-specific incidence rates per million (Germany 2001-2010)



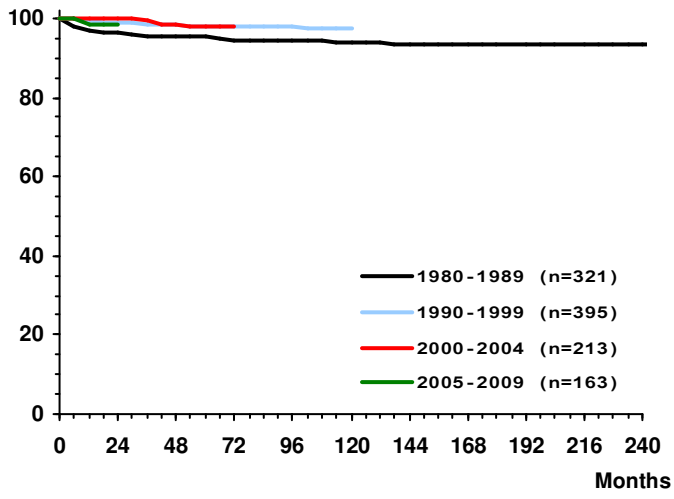
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



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

Nephroblastoma is an embryonal tumor of early childhood. Based on international comparisons, completeness of registration is close to 100%. Nephroblastoma is rare as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 2823

Selected characteristics (Germany 2001-2010)

Relative frequency: 980 / 17876 = 5.6 %

Relative frequency of trial patients: 98.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	509	471	980
Standardized rate *:	10.5	9.3	9.9
Cumulative incidence:	141	125	133
Sex ratio (m/f):			0.9

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	167	557	212	44
Incidence rate:	23.9	19.1	5.5	1.0

Median age at diagnosis: 3 years 1 month

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
123	3.0 %	1.1	15

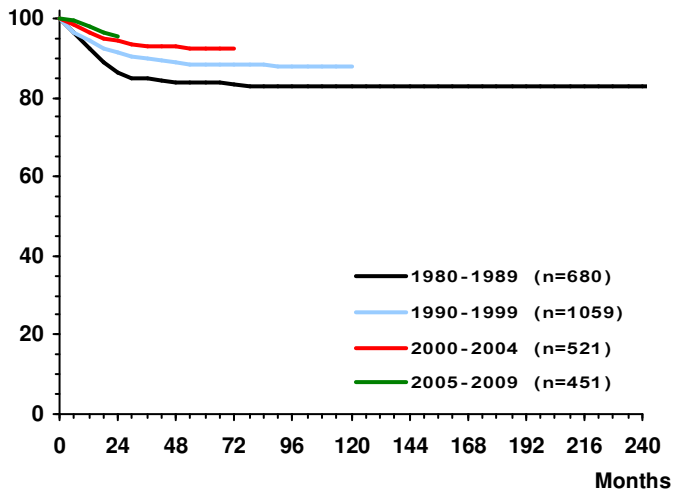
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

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

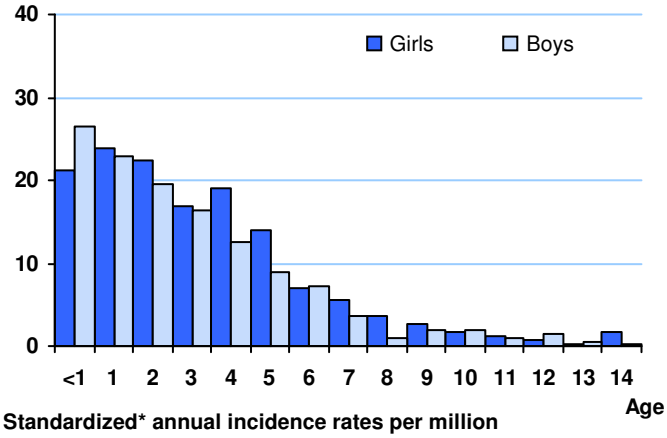
SN after VI (a)			**VI (a) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
31	4.0 %	2.1 %	8	1.0 %	0.0 %

* Standard: Segi world standard population

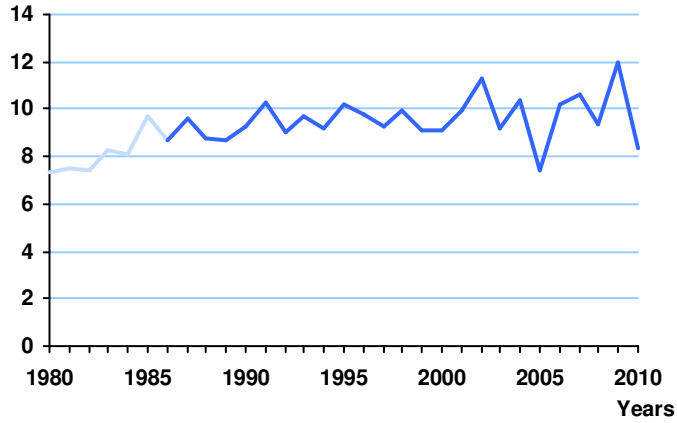
Survival probabilities by year of diagnosis (Germany 1980-2009)



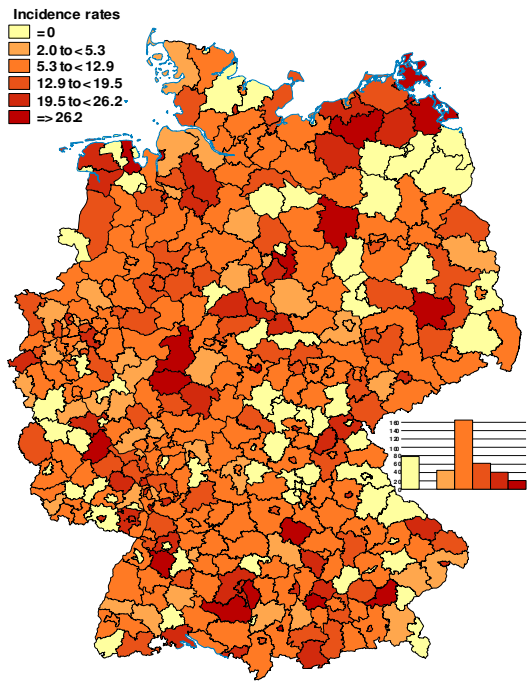
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



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

Germany (2001-2010)	N	%
Nephroblastoma and other non-epithelial renal tumours	**980**	**100.0**
Nephroblastoma	959	97.9
Rhabdoid renal tumour	13	1.3
Kidney sarcomas	7	0.7
Peripheral neuroectodermal tumour (pPNET) of kidney	1	0.1

1 Nephroblastoma

Cases in Germany aged under 15 years (1980-2010): 2732

Selected characteristics (Germany 2001-2010)

Relative frequency:	959 / 17876 = 5.4 %
Relative frequency of trial patients:	99.0 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	501	458	959
Standardized rate *:	10.3	9.1	9.7
Cumulative incidence:	139	121	130

Sex ratio (m/f): 0.9

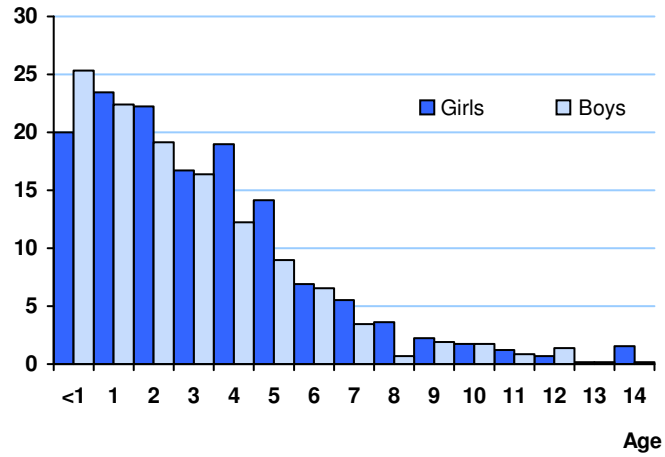
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	159	550	208	42
Incidence rate:	22.8	18.9	5.4	1.0

Median age at diagnosis: 3 years 1 month

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



2 Rhabdoid renal tumour

Cases in Germany aged under 15 years (1980-2010): 45

Selected characteristics (Germany 2001-2010)

Relative frequency:	13 / 17876 = 0.1 %
Relative frequency of trial patients:	76.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	6	7	13
Standardized rate *:	0.1	0.1	0.1
Cumulative incidence:	2	2	2

Sex ratio (m/f): 1.2

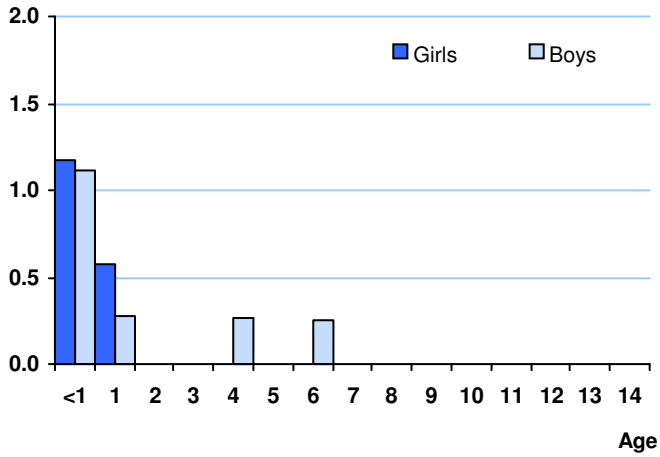
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	8	4	1	0
Incidence rate:	1.1	0.1	0.0	0.0

Median age at diagnosis: 0 years 10 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



Renal carcinomas are very rare in childhood and rarely treated in pediatric oncology units. Registration is likely to be incomplete.

Cases in Germany aged under 15 years (1980-2010): 53

Selected characteristics (Germany 2001-2010)

Relative frequency: 24 / 17876 = 0.1 %

Relative frequency of trial patients: 70.8 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	14	10	24
Standardized rate *:	0.2	0.1	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**
Number of cases :	0	1	6	17
Incidence rate:	0.0	0.0	0.2	0.4

Median age at diagnosis: 11 years 9 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
3	0.1 %	0.0	0

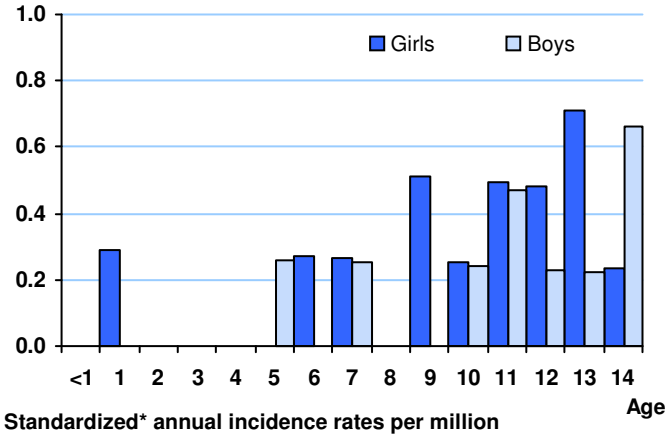
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

VI (b) Renal carcinomas

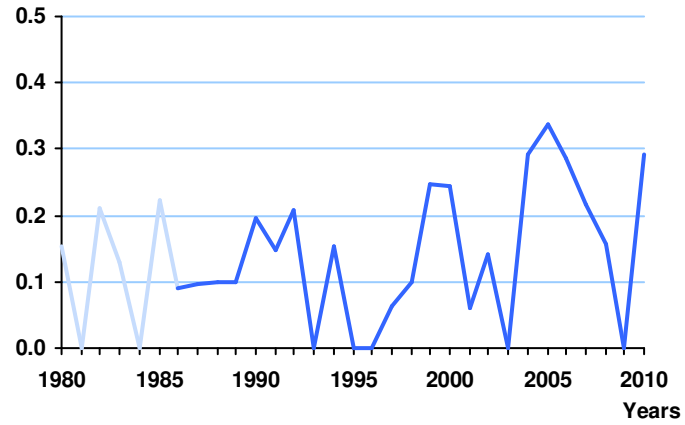
SN after VI (b)			VI (b) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
1	0.1 %	2.3 %	4	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



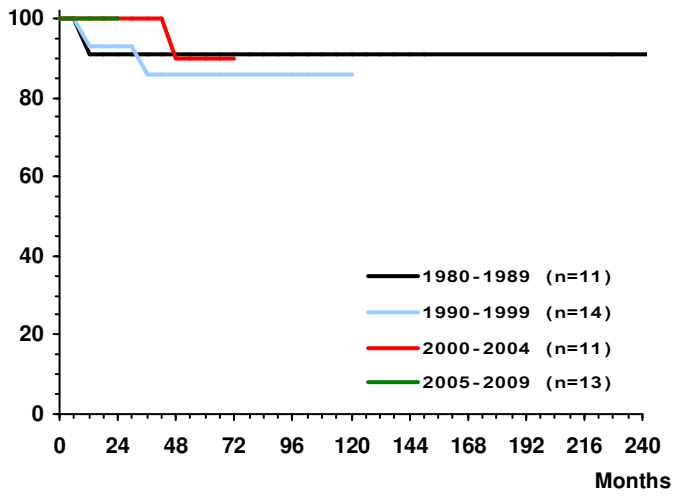
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



42 VII (a) Hepatoblastoma

Hepatoblastoma is an embryonal tumor of early childhood. Based on international comparisons, completeness of registration is close to 100%. Prognosis has improved considerably since 1980.

Cases in Germany aged under 15 years (1980-2010): 404

Selected characteristics (Germany 2001-2010)

Relative frequency:	179 / 17876 = 1.0 %
Relative frequency of trial patients:	98.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	73	106	179
Standardized rate *:	1.6	2.2	1.9
Cumulative incidence:	21	28	25
Sex ratio (m/f):			1.5

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	60	99	11	9
Incidence rate:	8.6	3.4	0.3	0.2

Median age at diagnosis: 1 year 5 months

	5-year	**10-year**	**15-year**
Survival probabilities:	75 %	74 %	74 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
37	0.9 %	0.3	4

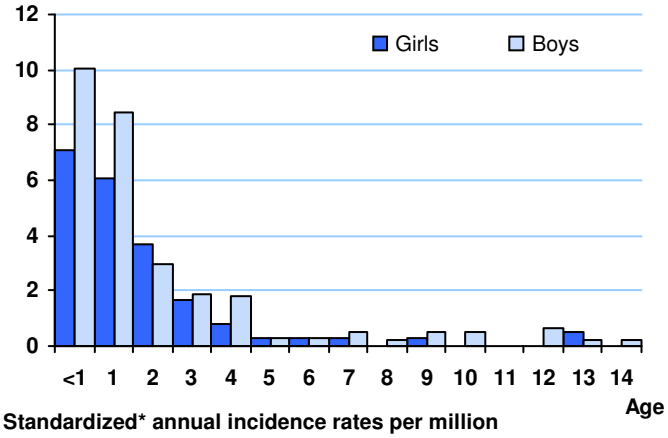
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

VII (a) Hepatoblastoma

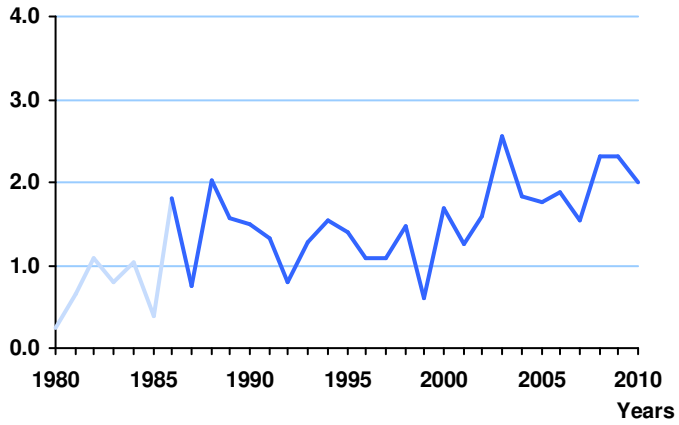
SN after VII (a)			**VII (a) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
3	0.4 %	2.8 %	2	0.3 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



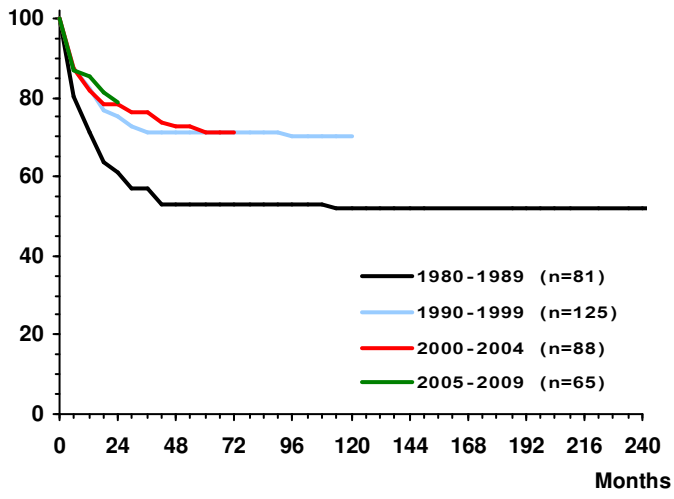
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



Hepatic carcinomas are rare in childhood. Registration may be incomplete. Prognosis has improved considerably since 1980. So far, no second neoplasm (SN) has been observed after a hepatic carcinoma within 20 years of diagnosis, underreporting of SN is a possibility.

Cases in Germany aged under 15 years (1980-2010): 100

Selected characteristics (Germany 2001-2010)

Relative frequency: 36 / 17876 = 0.2 %

Relative frequency of trial patients: 80.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	13	23	36
Standardized rate *:	0.2	0.3	0.3
Cumulative incidence:	3	5	4
Sex ratio (m/f):			1.8

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	0	3	11	22
Incidence rate:	0.0	0.1	0.3	0.5

Median age at diagnosis: 12 years 6 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
16	0.4 %	0.1	2

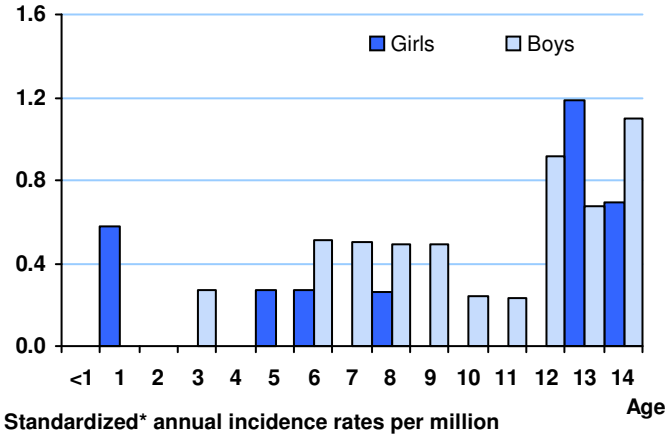
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

VII (b) Hepatic carcinomas

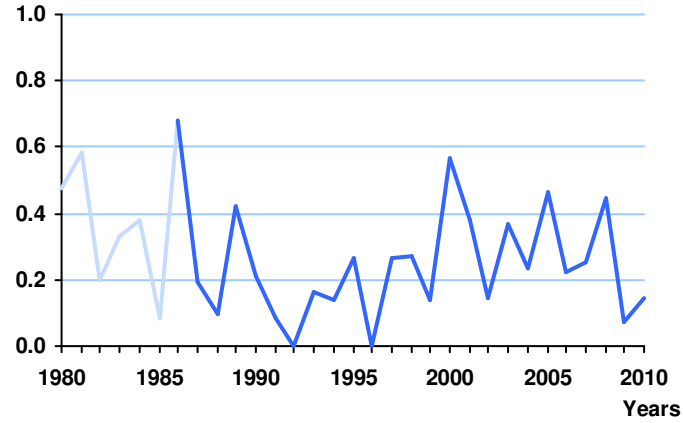
SN after VII (b)			VII (b) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
0	0.0 %	0.0 %	4	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



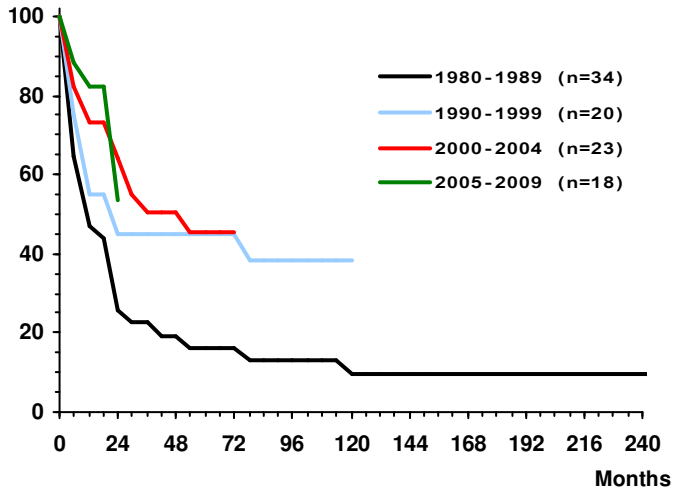
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



44 VIII Malignant bone tumours

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

Cases in Germany aged under 15 years (1980-2010): 2285

Selected characteristics (Germany 2001-2010)

Relative frequency:	802 / 17876 = 4.5 %
Relative frequency of trial patients:	97.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	379	423	802
Standardized rate *:	5.8	6.2	6.0
Cumulative incidence:	95	101	98
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	5	51	209	537
Incidence rate:	0.7	1.7	5.4	12.6

Median age at diagnosis: 11 years 8 months

Survival probabilities:	**5-year**	**10-year**	**15-year**
	73 %	69 %	68 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

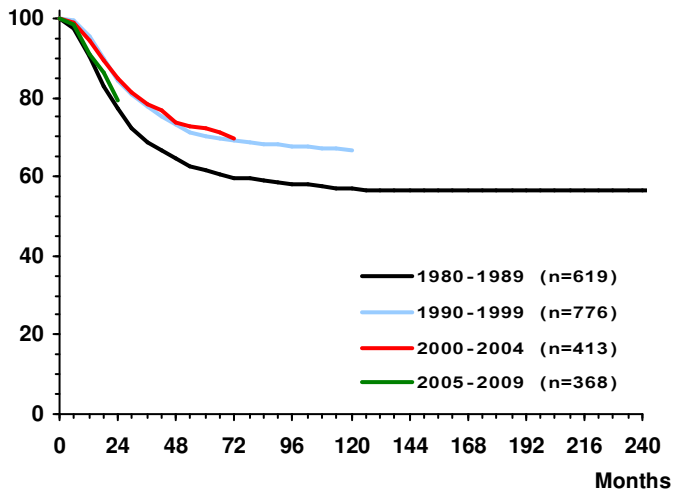
Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4151 deaths		
265	6.4 %	1.8	30

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):
VIII Malignant bone tumours

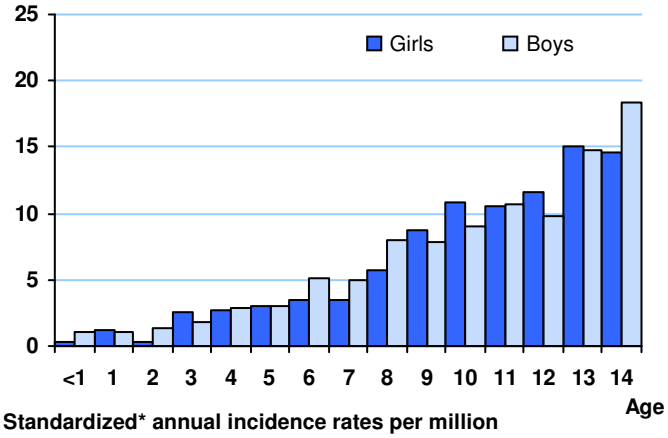
SN after VIII			VIII as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
42	5.4 %	3.0 %	48	6.2 %	0.2 %

* Standard: Segi world standard population

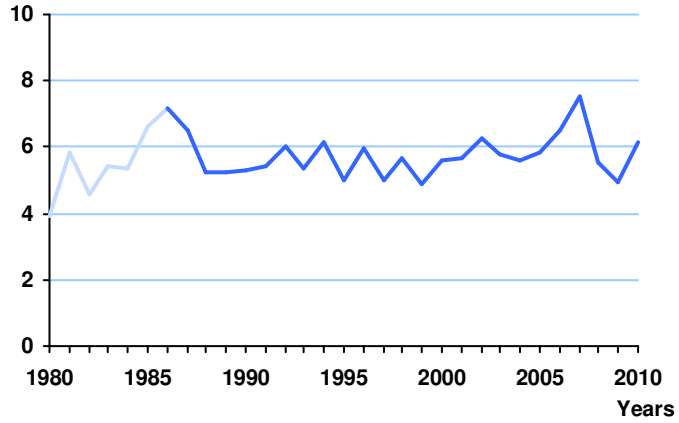
Survival probabilities by year of diagnosis (Germany 1980-2009)



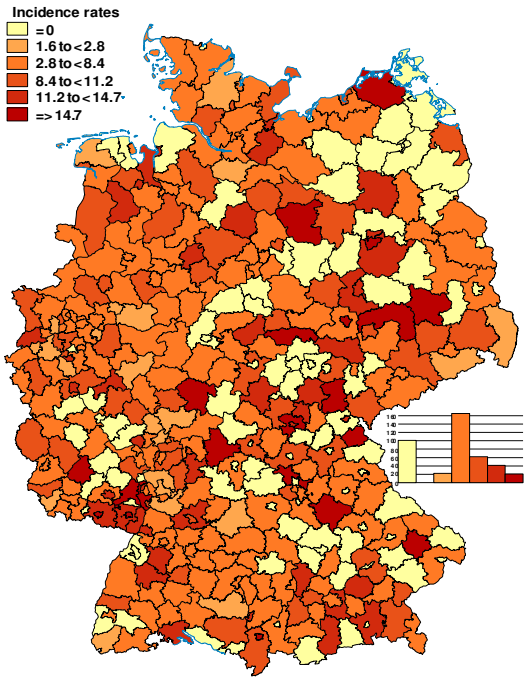
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Osteosarcomas are rare in early childhood. Based on international comparisons, completeness of registration exceeds 95%. Osteosarcomas are relatively frequent as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 1200

Selected characteristics (Germany 2001-2010)

Relative frequency:	410 / 17876 = 2.3 %
Relative frequency of trial patients:	98.3 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	204	206	410
Standardized rate *:	3.0	2.9	3.0
Cumulative incidence:	50	48	49
Sex ratio (m/f):			1.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	0	11	89	310
Incidence rate:	0.0	0.4	2.3	7.3

Median age at diagnosis: 12 years 4 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4151 deaths		
137	3.3 %	0.9	15

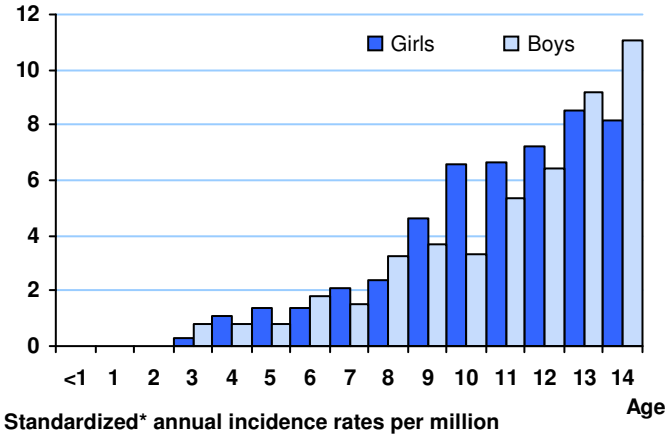
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

VIII (a) Osteosarcomas

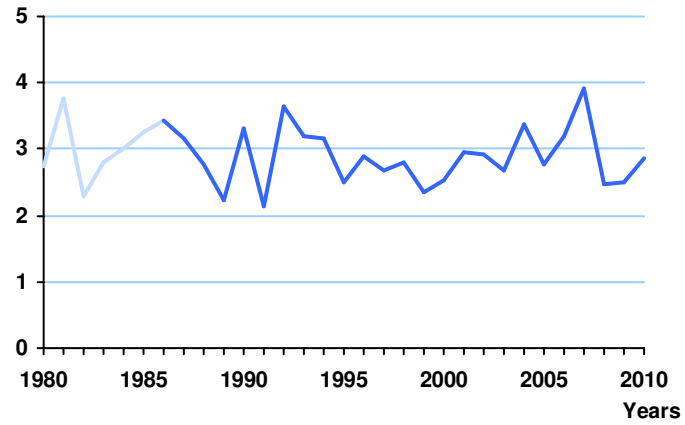
SN after VIII (a)			VIII (a) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
16	2.1 %	2.2 %	33	4.3 %	0.1 %

* Standard: Segi world standard population

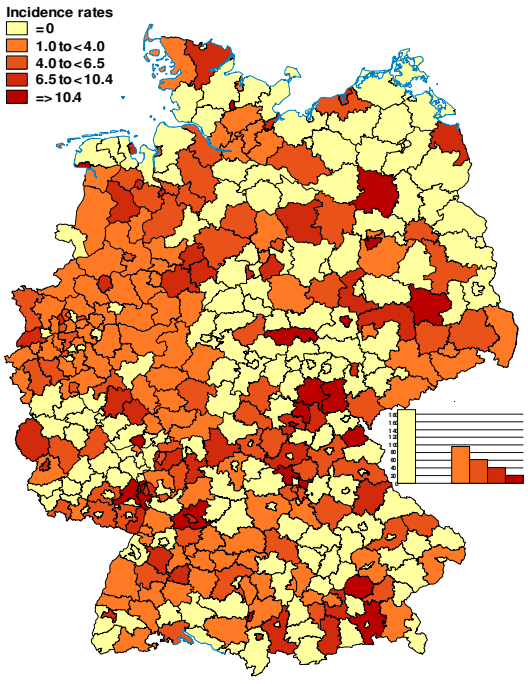
Age- and sex-specific incidence rates per million (Germany 2001-2010)



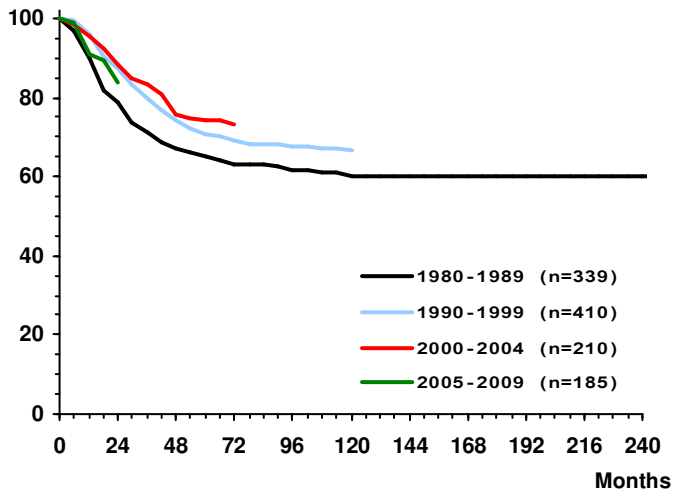
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



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

Based on international comparisons, completeness of registration exceeds 95%.

Cases in Germany aged under 15 years (1980-2010): 1010

Selected characteristics (Germany 2001-2010)

Relative frequency: 361 / 17876 = 2.1 %

Relative frequency of trial patients: 99.2 %

Incidence rates per million:	Girls	Boys	Total
Number of cases:	157	204	361
Standardized rate *:	2.5	3.1	2.8
Cumulative incidence:	40	49	45

Sex ratio (m/f): 1.3

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	5	37	112	207
Incidence rate:	0.7	1.3	2.9	4.9

Median age at diagnosis: 10 years 9 months

Survival probabilities:	5-year	10-year	15-year
	71 %	66 %	65 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4151 deaths		
120	2.9 %	0.8	13

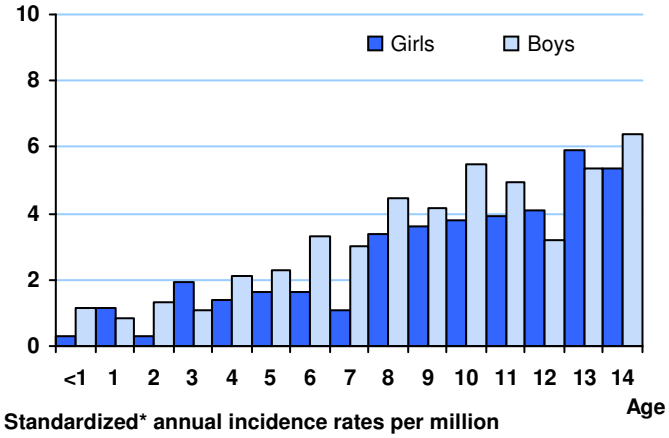
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

VIII (c) Ewing tumour and related sarcomas of bone

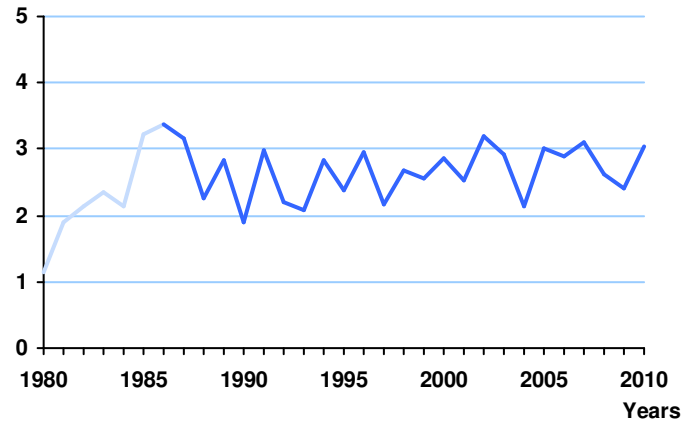
SN after VIII (c)			VIII (c) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
24	3.1 %	4.0 %	12	1.5 %	0.0 %

* Standard: Segi world standard population

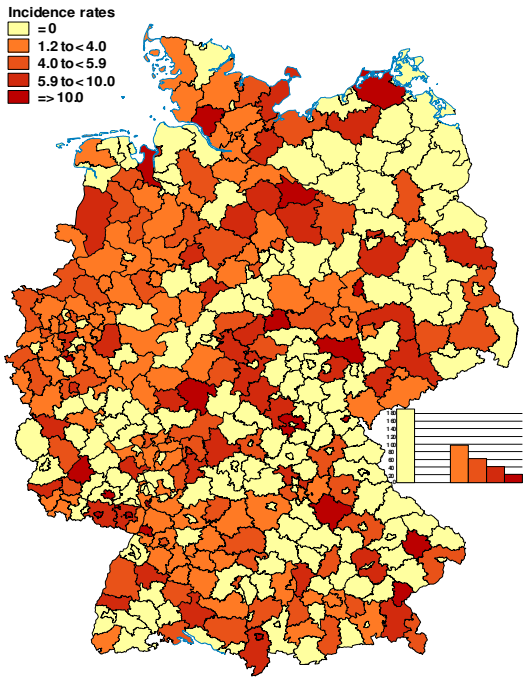
Age- and sex-specific incidence rates per million (Germany 2001-2010)



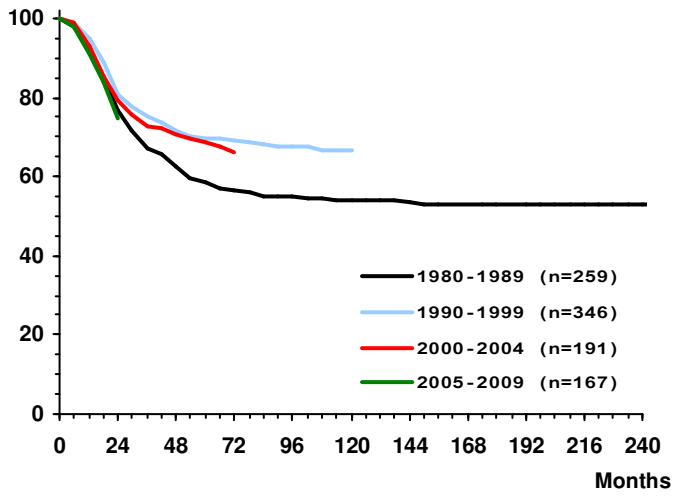
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



Survival probabilities by year of diagnosis (Germany 1980-2009)



(a) Rhabdomyosarcomas
(b) Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms
(c) Kaposi sarcoma
(d) Other specified soft tissue sarcomas
(e) Unspecified soft tissue sarcomas

Cases in Germany aged under 15 years (1980-2010): 2990

Selected characteristics (Germany 2001-2010)

Relative frequency:	1064 / 17876 = 6.0 %
Relative frequency of trial patients:	95.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	488	576	1064
Standardized rate *:	8.7	10.0	9.4
Cumulative incidence:	129	146	137
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	124	301	278	361
Incidence rate:	17.8	10.3	7.2	8.5

Median age at diagnosis: 6 years 9 months

	5-year	**10-year**	**15-year**
Survival probabilities:	73 %	70 %	68 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

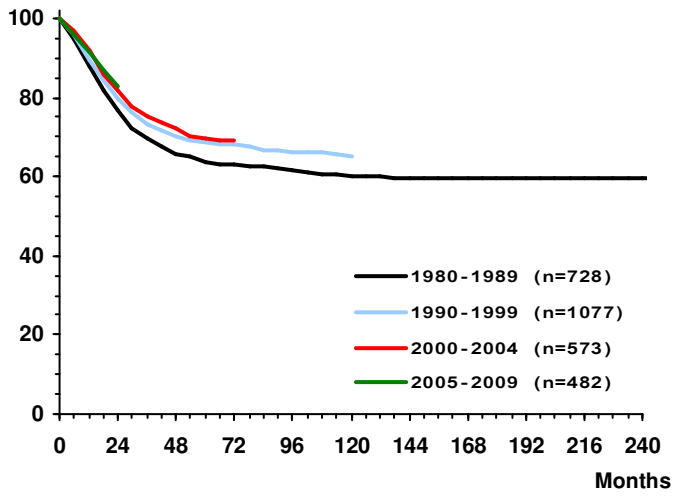
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
376	9.1 %	3.0	43

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):
IX Soft tissue and other extraosseous sarcomas

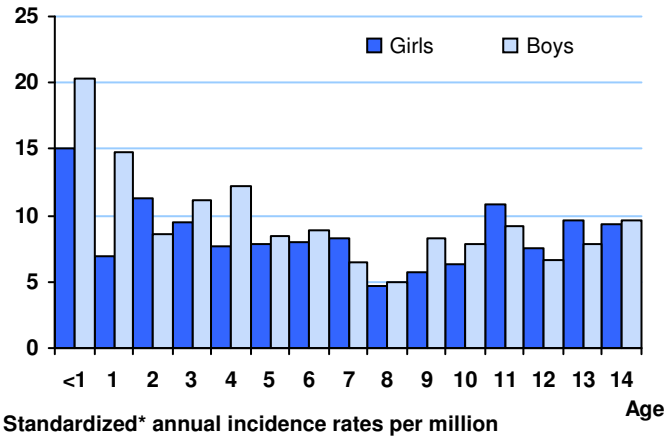
SN after IX			**IX as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
52	6.7 %	3.0 %	52	6.7 %	0.2 %

* Standard: Segi world standard population

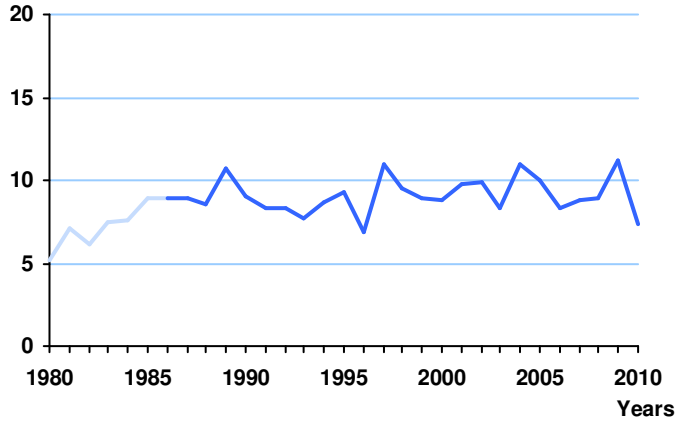
Survival probabilities by year of diagnosis (Germany 1980-2009)



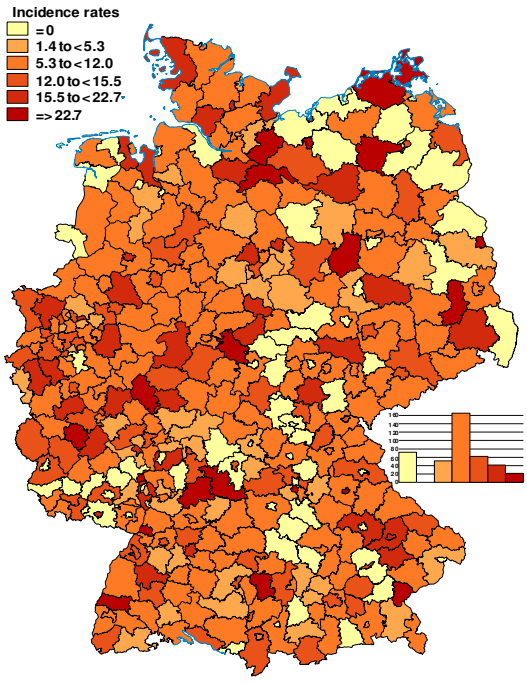
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



48 IX (a) Rhabdomyosarcomas

Based on international comparisons, completeness of registration exceeds 95%. Compared to all childhood cancers, mortality is relatively high.

Cases in Germany aged under 15 years (1980-2010): 1734

Selected characteristics (Germany 2001-2010)

Relative frequency:	572 / 17876 = 3.3 %
Relative frequency of trial patients:	98.4 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	259	313	572
Standardized rate *:	4.8	5.6	5.2
Cumulative incidence:	69	80	75
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	47	229	173	123
Incidence rate:	6.7	7.9	4.5	2.9

Median age at diagnosis: 5 years 2 months

Survival probabilities:	**5-year**	**10-year**	**15-year**
	73 %	71 %	70 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
231	5.6 %	1.9	27

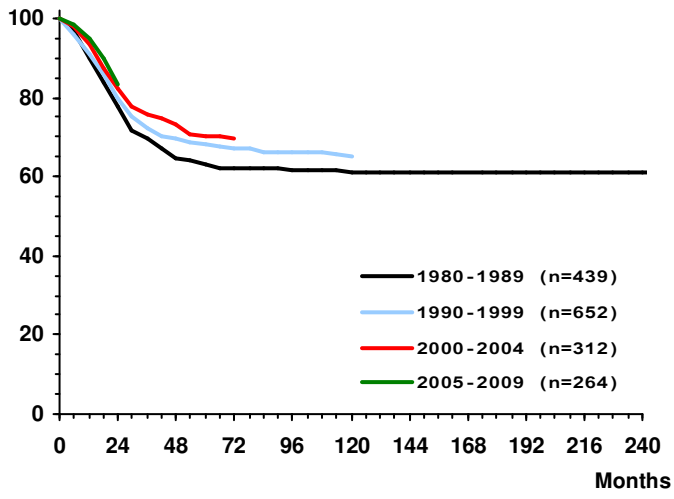
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

IX (a) Rhabdomyosarcomas

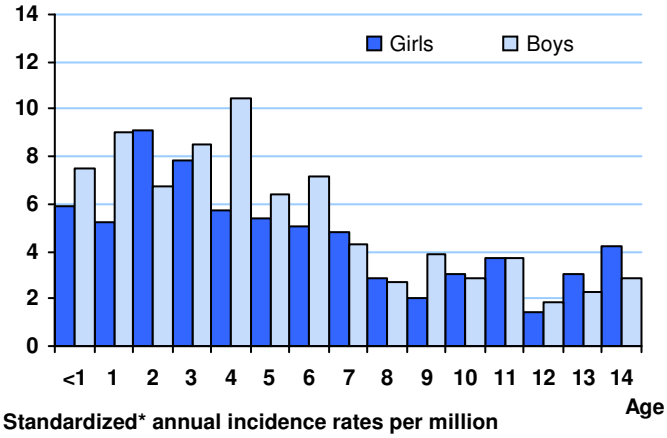
SN after IX (a)			IX (a) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
37	4.8 %	3.4 %	12	1.5 %	0.0 %

* Standard: Segi world standard population

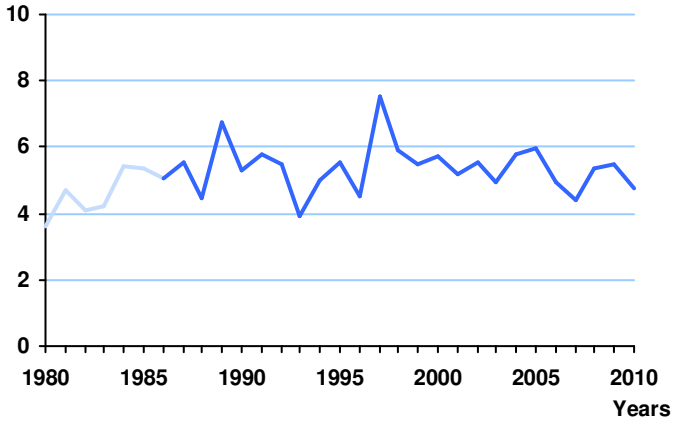
Survival probabilities by year of diagnosis (Germany 1980-2009)



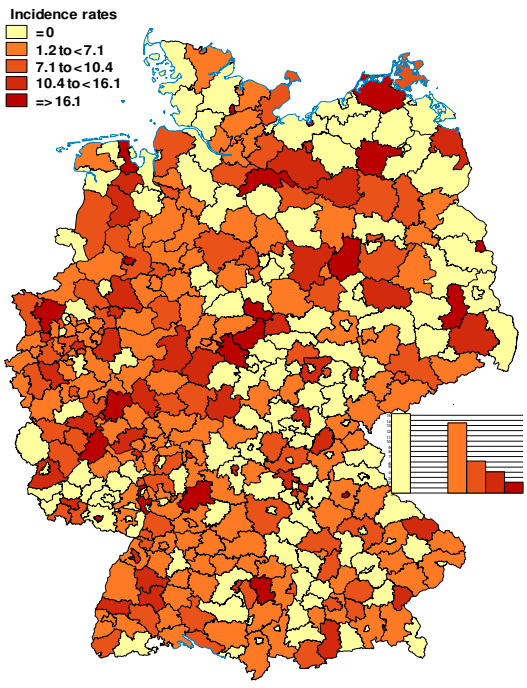
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



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

Based on international comparisons, completeness of registration exceeds 95%. These tumours are relatively frequent as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 265

Selected characteristics (Germany 2001-2010)

Relative frequency:	109 / 17876 = 0.6 %
Relative frequency of trial patients:	87.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	52	57	109
Standardized rate *:	0.9	1.0	1.0
Cumulative incidence:	14	14	14
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	29	13	18	49
Incidence rate:	4.2	0.4	0.5	1.2

Median age at diagnosis: 8 years 6 months

Survival probabilities:	**5-year**	**10-year**	**15-year**
	68 %	64 %	61 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
23	0.6 %	0.2	3

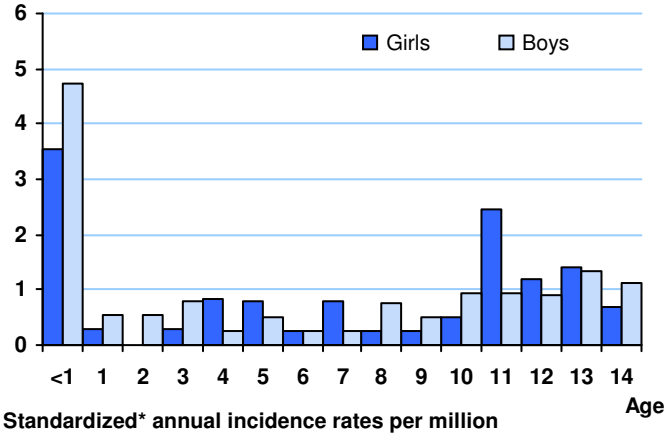
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

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

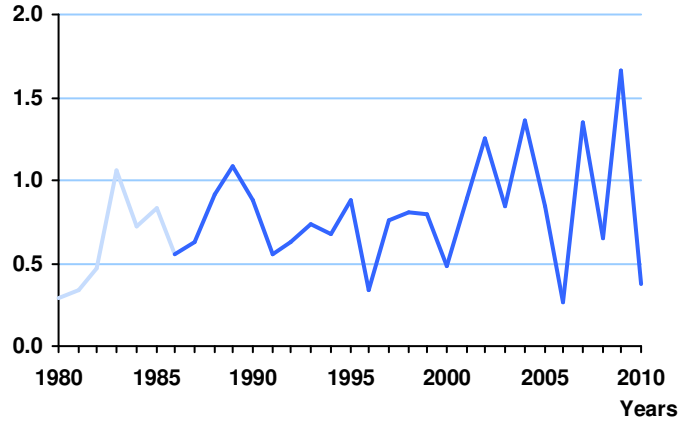
SN after IX (b)			IX (b) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
4	0.5 %	2.4 %	14	1.8 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



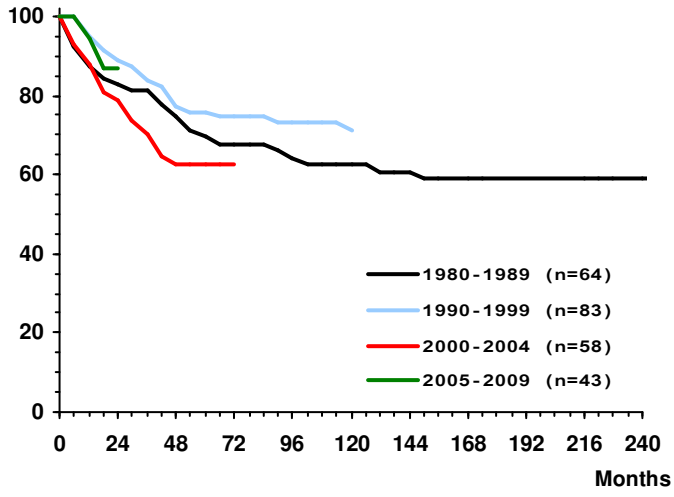
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



50 IX (b) Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms - Extended ICCC-3

Germany (2001-2010)	N	%
Fibrosarcomas, peripheral nerve sheath tumours and other	**109**	**100.0**
Fibroblastic and myofibroblastic tumours	62	56.9
Nerve sheath tumours	47	43.1
Other fibrous neoplasms	0	0.0

1 Fibroblastic and myofibroblastic tumour

Cases in Germany aged under 15 years (1980-2010): 129

Selected characteristics (Germany 2001-2010)

Relative frequency:	62 / 17876 = 0.3 %
Relative frequency of trial patients:	91.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	27	35	62
Standardized rate *:	0.5	0.6	0.6
Cumulative incidence:	7	9	8

Sex ratio (m/f): 1.3

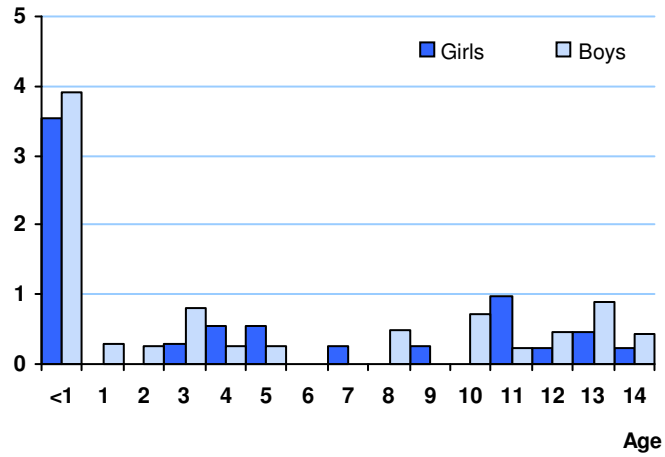
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	26	9	7	20
Incidence rate:	3.7	0.3	0.2	0.5

Median age at diagnosis: 3 years 8 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



2 Nerve sheath tumours

Cases in Germany aged under 15 years (1980-2010): 136

Selected characteristics (Germany 2001-2010)

Relative frequency:	47 / 17876 = 0.3 %
Relative frequency of trial patients:	80.9 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	25	22	47
Standardized rate *:	0.4	0.4	0.4
Cumulative incidence:	6	5	6

Sex ratio (m/f): 0.9

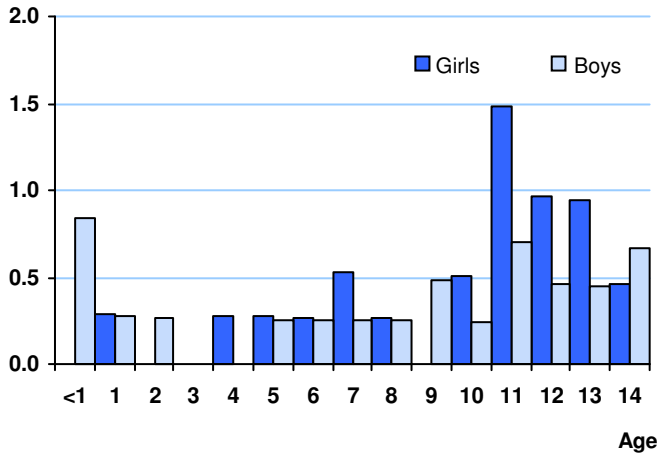
Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases:	3	4	11	29
Incidence rate:	0.4	0.1	0.3	0.7

Median age at diagnosis: 11 years 5 months

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



Based on international comparisons, completeness of registration approaches 95%. These tumours are relatively rarely followed by a second neoplasm (SN) within 20 years of diagnosis, underreporting of SN is a possibility.

Cases in Germany aged under 15 years (1980-2010): 802

Selected characteristics (Germany 2001-2010)

Relative frequency:	302 / 17876 = 1.7 %
Relative frequency of trial patients:	94.7 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	137	165	302
Standardized rate *:	2.3	2.7	2.5
Cumulative incidence:	35	41	38
Sex ratio (m/f):			1.2

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	37	45	69	151
Incidence rate:	5.3	1.5	1.8	3.6

Median age at diagnosis: 10 years 0 months

Survival probabilities:	**5-year**	**10-year**	**15-year**
	75 %	70 %	67 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
95	2.3 %	0.7	11

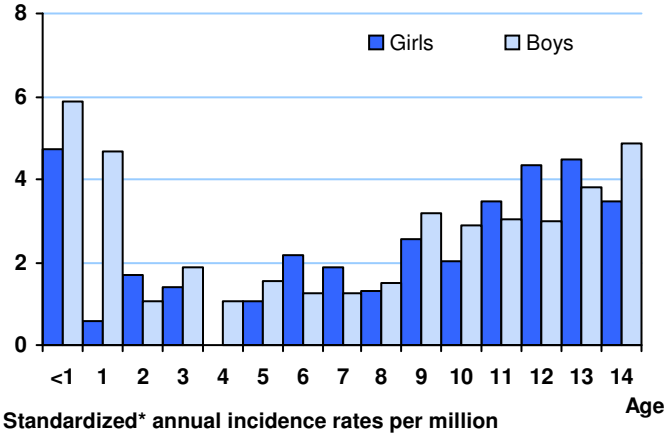
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

IX (d) Other specified soft tissue sarcomas

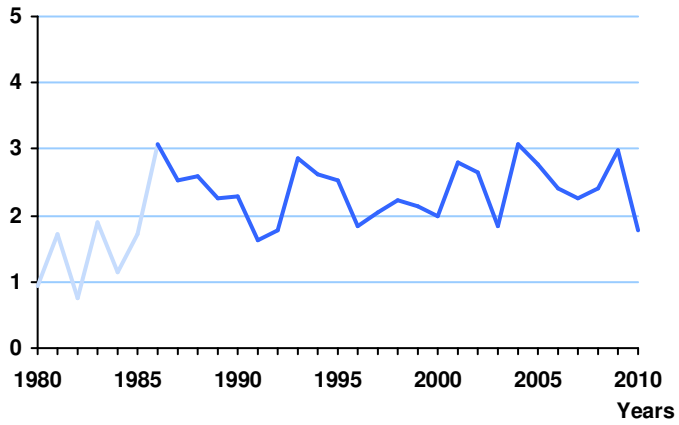
SN after IX (d)			IX (d) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
9	1.2 %	1.8 %	23	3.0 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



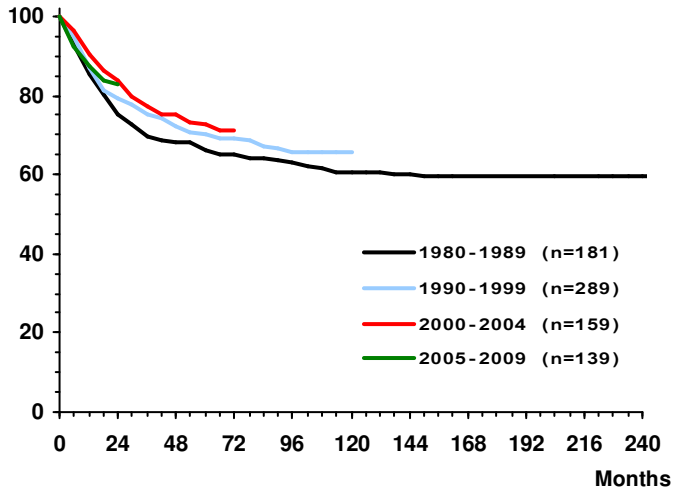
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



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

(a) Intracranial and intraspinal germ cell tumours
(b) Malignant extracranial and extragonadal germ cell tumours
(c) Malignant gonadal germ cell tumours
(d) Gonadal carcinomas
(e) Other and unspecified malignant gonadal tumours

Cases in Germany aged under 15 years (1980-2010): 1521

Selected characteristics (Germany 2001-2010)

Relative frequency:	531 / 17876 = 3.0 %
Relative frequency of trial patients:	97.2 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	300	231	531
Standardized rate *:	5.3	4.0	4.6
Cumulative incidence:	79	58	68
Sex ratio (m/f):			0.8

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	119	89	90	233
Incidence rate:	17.0	3.1	2.3	5.5

Median age at diagnosis: 9 years 0 months

	5-year	**10-year**	**15-year**
Survival probabilities:	95 %	94 %	93 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

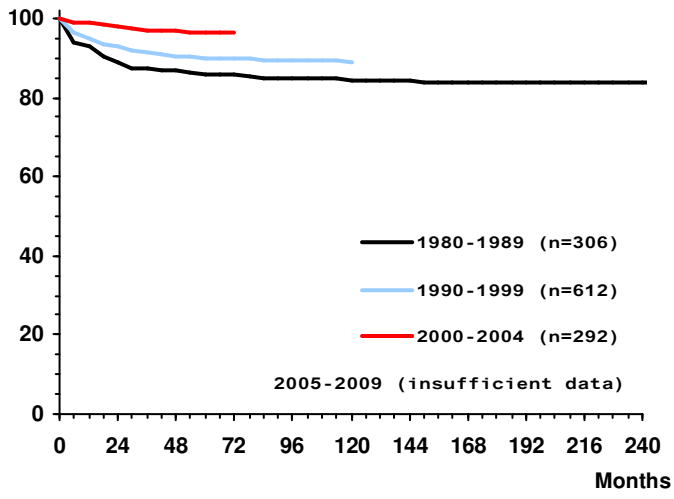
Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
59	1.4 %	0.4	7

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):
X Germ cell tumours, trophoblastic tumours and neoplasms of gonads

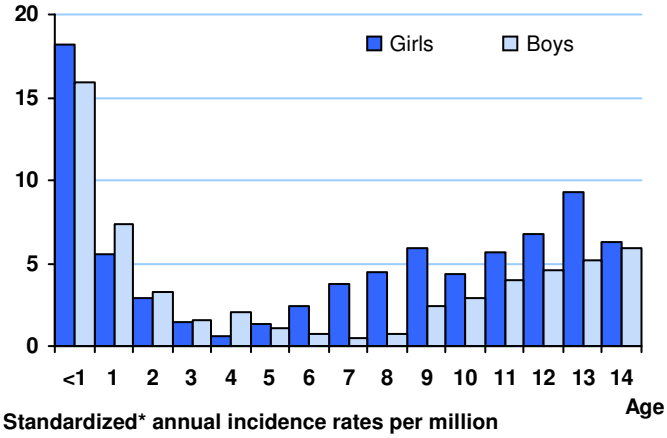
SN after X			**X as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
14	1.8 %	1.6 %	6	0.8 %	0.0 %

* Standard: Segi world standard population

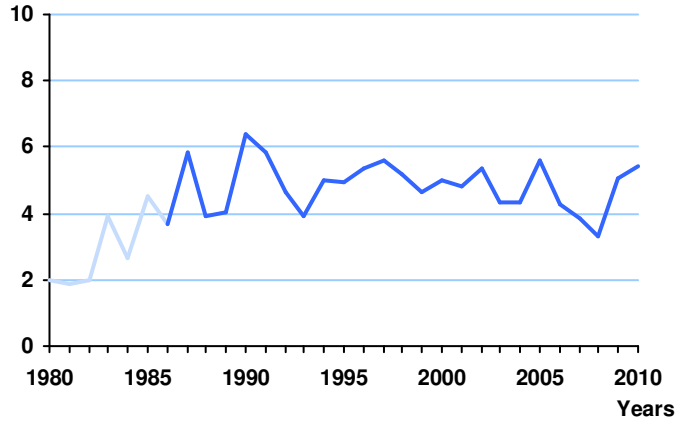
Survival probabilities by year of diagnosis (Germany 1980-2009)



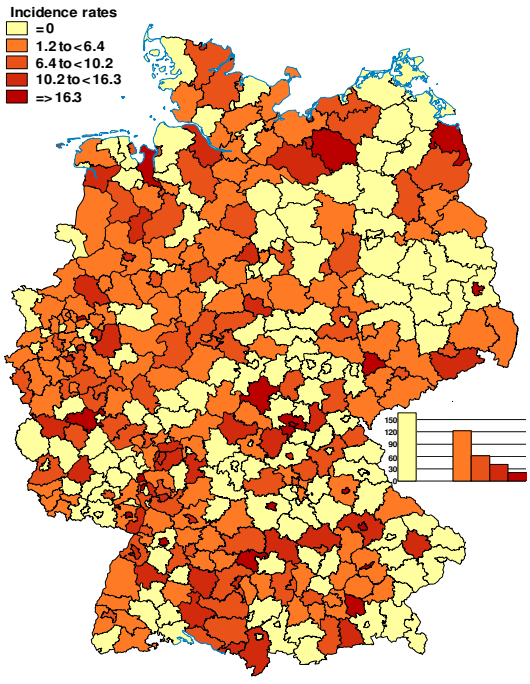
Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)



X (a) Intracranial and intraspinal germ cell tumours

Most frequent form is germinoma (malignant). Non-malignant forms constitute about 10%, early childhood cases are rare, some underreporting is likely. These tumours are very rare as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 410

Selected characteristics (Germany 2001-2010)

Relative frequency:	156 / 17876 = 0.9 %
Relative frequency of trial patients:	95.5 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	61	95	156
Standardized rate *:	1.0	1.4	1.2
Cumulative incidence:	16	22	19
Sex ratio (m/f):			1.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	4	7	47	98
Incidence rate:	0.6	0.2	1.2	2.3

Median age at diagnosis: 11 years 1 month

	5-year	**10-year**	**15-year**
Survival probabilities:	90 %	87 %	86 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
32	0.8 %	0.2	4

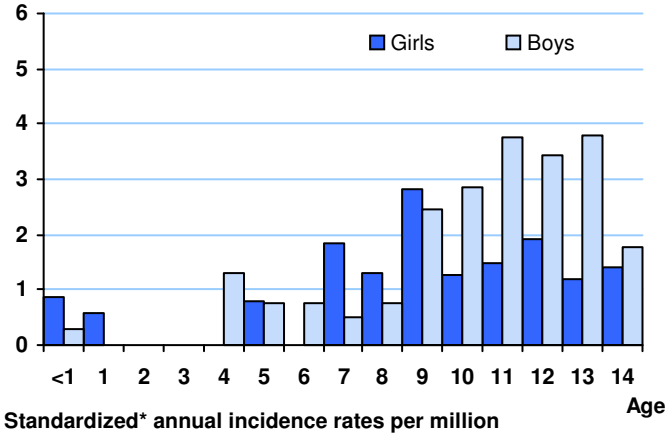
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

X (a) Intracranial and intraspinal germ cell tumours

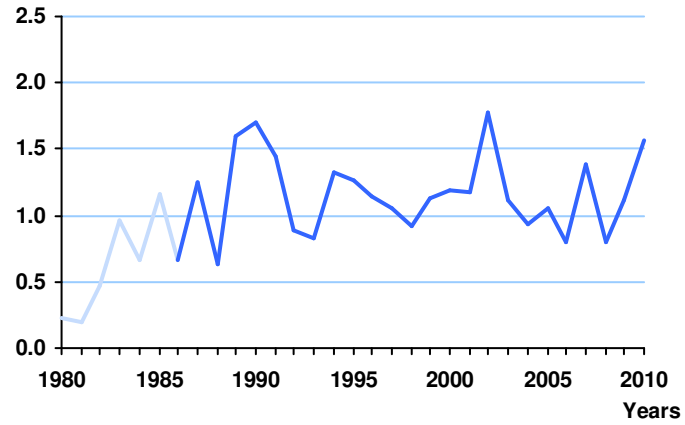
SN after X (a)			**X (a) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
5	0.6 %	2.0 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



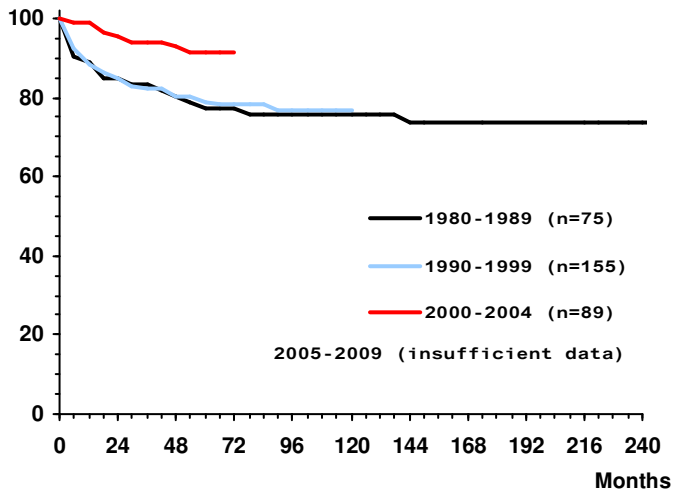
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



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

Based on international comparisons, completeness of registration exceeds 95%. These tumours are relatively rarely followed by a second neoplasm within 20 years of diagnosis. These tumours are very rare as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 444

Selected characteristics (Germany 2001-2010)

Relative frequency:	146 / 17876 = 0.8 %
Relative frequency of trial patients:	96.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	95	51	146
Standardized rate *:	2.1	1.0	1.6
Cumulative incidence:	27	14	20
Sex ratio (m/f):			0.5

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	86	42	4	14
Incidence rate:	12.3	1.4	0.1	0.3

Median age at diagnosis: 0 years 9 months

Survival probabilities:	**5-year**	**10-year**	**15-year**
	96 %	95 %	95 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
14	0.3 %	0.1	2

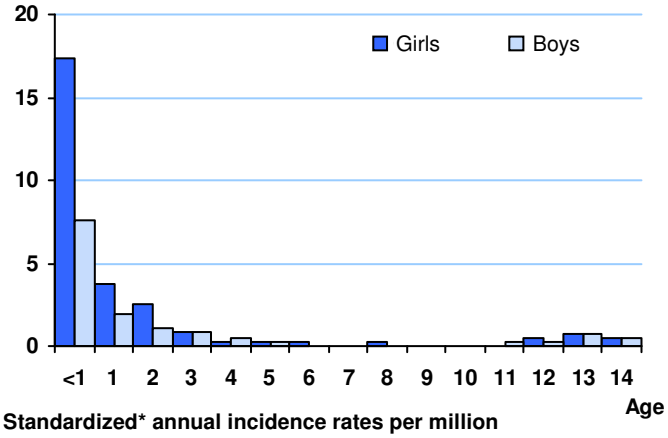
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

X (b) Malignant extracranial and extragonadal germ cell tumours

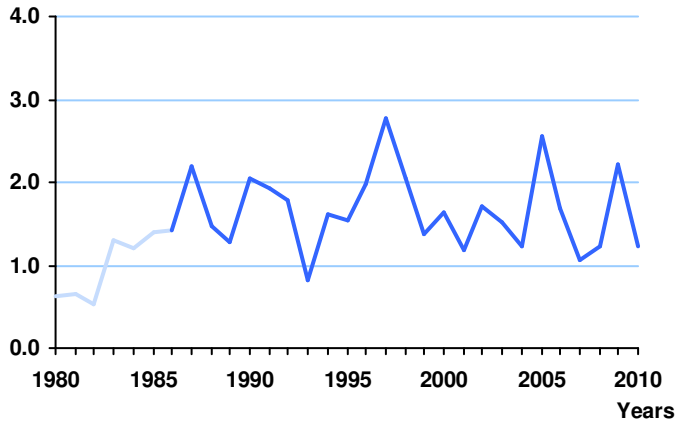
SN after X (b)			X (b) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
4	0.5 %	1.5 %	1	0.1 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



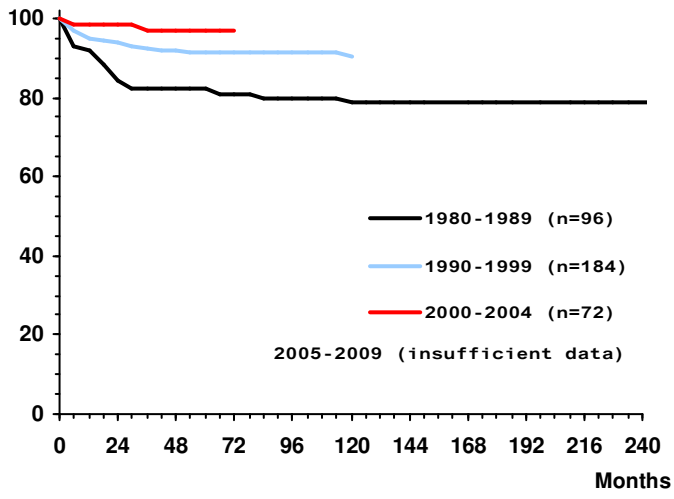
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



X (c) Malignant gonadal germ cell tumours

Girls are more and earlier affected than boys in puberty, boys are more likely to be affected in infancy. Age at diagnosis peaks at infancy and with puberty. Based on international comparisons, completeness of registration approaches 95%. These tumours are relatively rarely followed by a second neoplasm within 20 years of diagnosis. These tumours are rare as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 627

Selected characteristics (Germany 2001-2010)

Relative frequency:	224 / 17876 = 1.3 %
Relative frequency of trial patients:	99.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	139	85	224
Standardized rate *:	2.1	1.6	1.9
Cumulative incidence:	35	22	28
Sex ratio (m/f):			0.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	29	40	38	117
Incidence rate:	4.2	1.4	1.0	2.8

Median age at diagnosis: 10 years 7 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
9	0.2 %	0.1	1

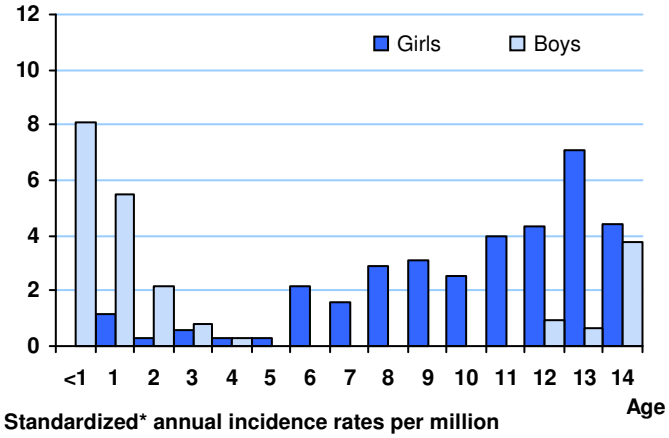
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

X (c) Malignant gonadal germ cell tumours

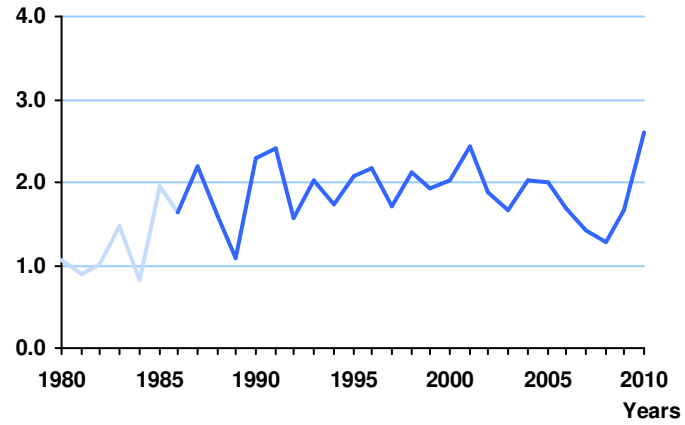
SN after X (c)			X (c) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
5	0.6 %	1.5 %	4	0.5 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



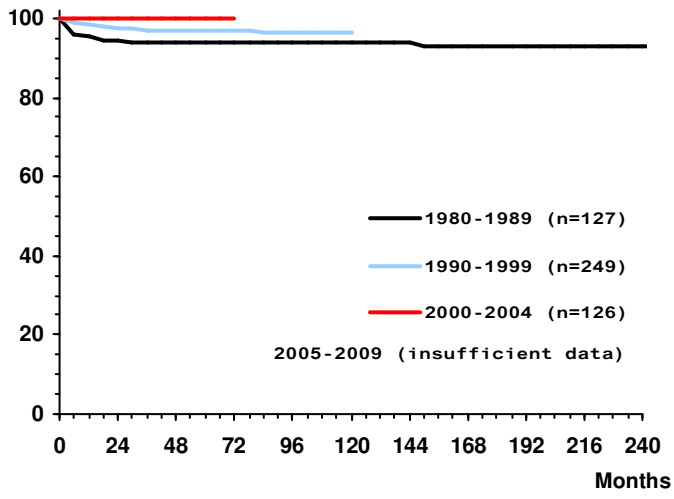
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



56 XI (a) Adrenocortical carcinomas

Based on international comparisons, completeness of registration is by now close to 100%. The temporal trend is due to improvements in registration. These carcinomas are relatively frequently followed by a second neoplasm within 20 years of diagnosis. These carcinomas have so far not been reported as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 63

Selected characteristics (Germany 2001-2010)

Relative frequency:	29 / 17876 = 0.2 %
Relative frequency of trial patients:	96.6 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	20	9	29
Standardized rate *:	0.4	0.2	0.3
Cumulative incidence:	5	2	4
Sex ratio (m/f):			0.5

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	3	12	8	6
Incidence rate:	0.4	0.4	0.2	0.1

Median age at diagnosis: 3 years 11 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
8	0.2 %	0.1	1

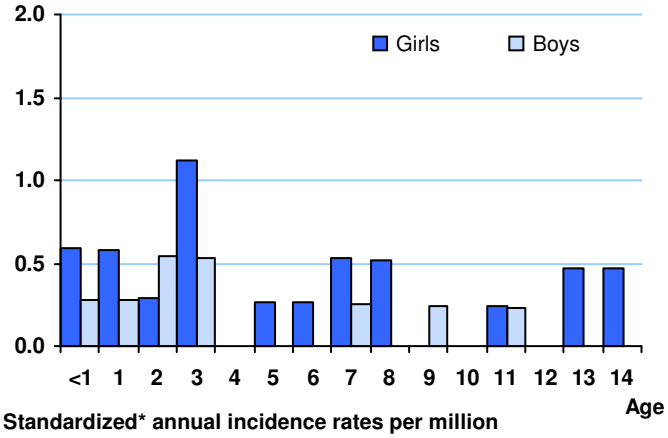
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

XI (a) Adrenocortical carcinomas

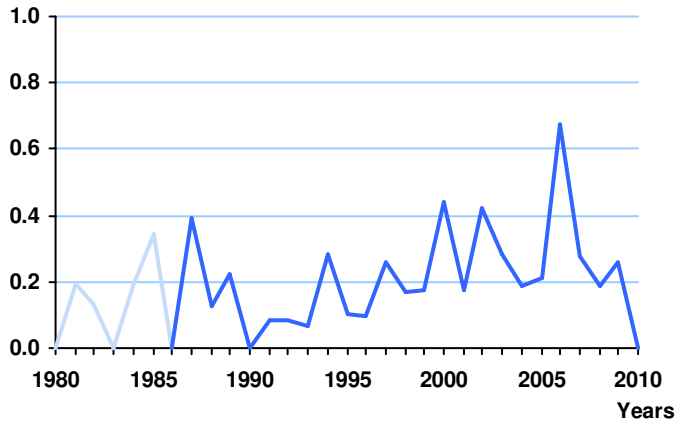
SN after XI (a)			XI (a) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
4	0.5 %	8.0 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



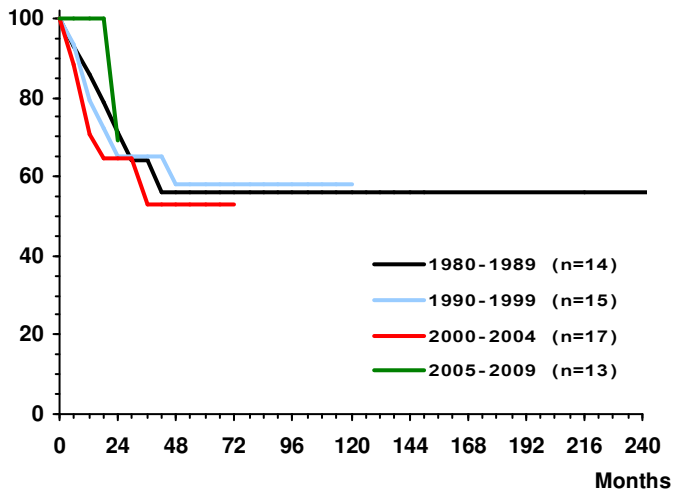
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



Thyroid carcinomas are rare in early childhood. Based on international comparisons, completeness of registration approaches 95%. Thyroid carcinomas are relatively rarely followed by a subsequent neoplasm within 20 years of diagnosis, a large fraction of them are second neoplasms. Thyroid carcinoma is relatively frequent as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 262

Selected characteristics (Germany 2001-2010)

Relative frequency: 131 / 17876 = 0.7 %

Relative frequency of trial patients: 90.1 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	80	51	131
Standardized rate *:	1.2	0.7	1.0
Cumulative incidence:	20	12	16

Sex ratio (m/f): 0.6

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	1	3	33	94
Incidence rate:	0.1	0.1	0.8	2.2

Median age at diagnosis: 12 years 6 months

	5-year	**10-year**	**15-year**
Survival probabilities:	96 %	92 %	87 %

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		**Standardized* mortality rate**	**Cumulative mortality**
N	% of all 4151 deaths		
6	0.1 %	0.0	1

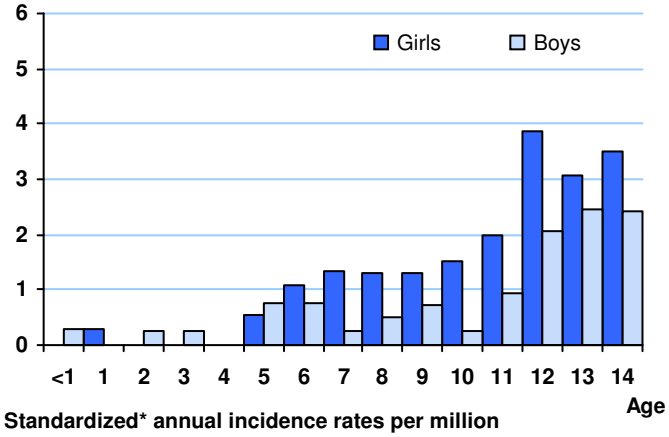
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

XI (b) Thyroid carcinomas

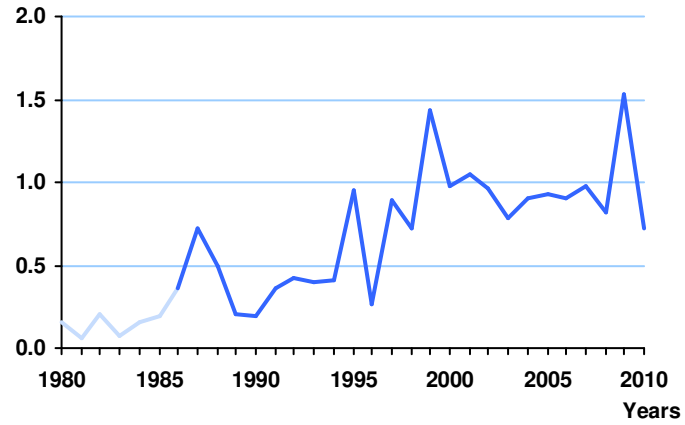
SN after XI (b)			**XI (b) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
1	0.1 %	0.6 %	71	9.2 %	0.4 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



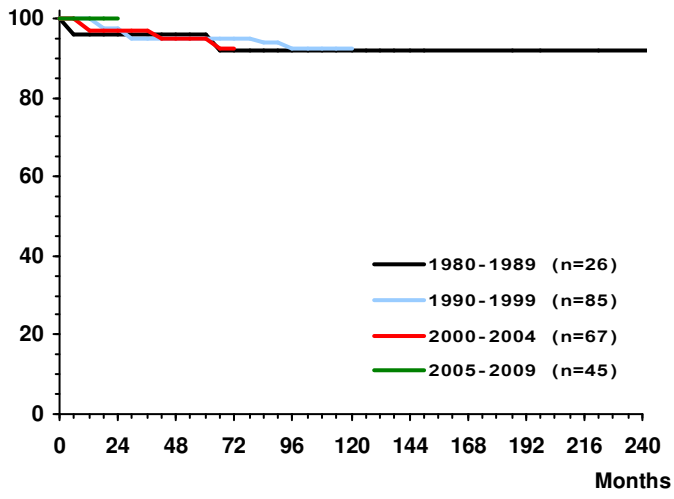
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



58 XI (c) Nasopharyngeal carcinomas

Nasopharyngeal carcinomas are rare in early childhood. Based on international comparisons, completeness of registration is close to 100%. So far no second neoplasm after this carcinoma has been reported.

Cases in Germany aged under 15 years (1980-2010): 66

Selected characteristics (Germany 2001-2010)

Relative frequency:	24 / 17876 = 0.1 %
Relative frequency of trial patients:	100 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	6	18	24
Standardized rate *:	0.1	0.2	0.2
Cumulative incidence:	1	4	3
Sex ratio (m/f):			3.0

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	0	1	0	23
Incidence rate:	0.0	0.0	0.0	0.5

Median age at diagnosis: 13 years 0 months

	5-year	**10-year**	**15-year**
Survival probabilities:	100 %	-	-

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
6	0.1 %	0.0	1

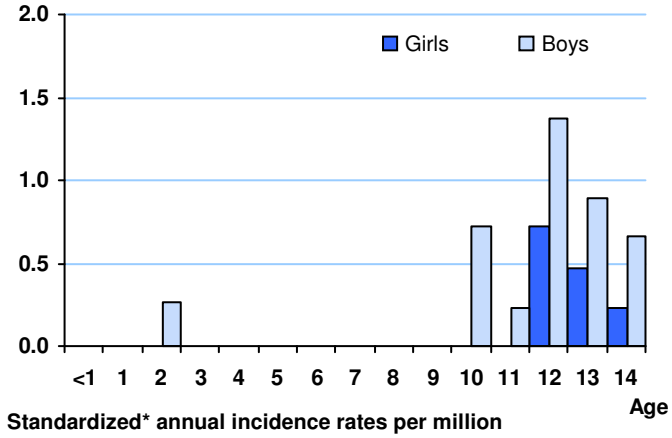
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

XI (c) Nasopharyngeal carcinomas

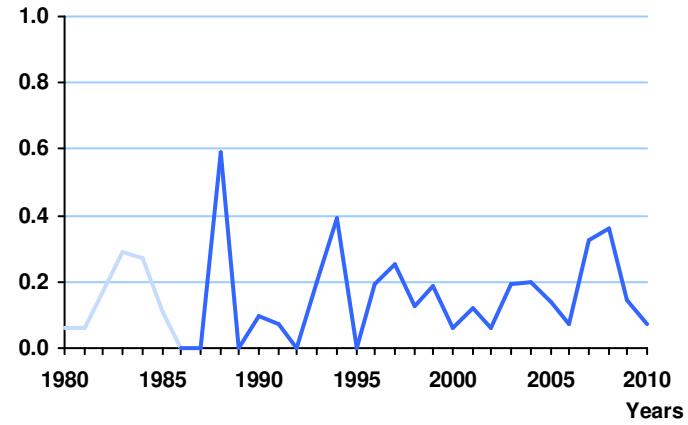
SN after XI (c)			XI (c) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
0	0.0 %	0.0 %	3	0.4 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



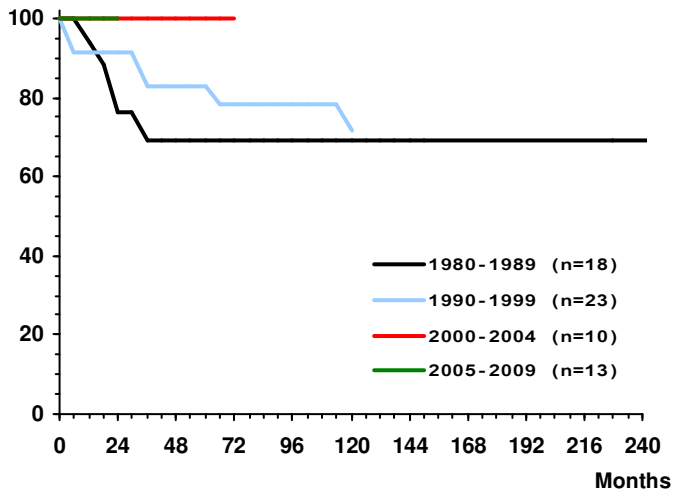
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



Early childhood cases of Malignant Melanoma (MM) are rare. Some underreporting is likely. The temporal trend is due to improvements in registration. So far no second neoplasm (SN) after MM has been reported, underreporting of SN is a possibility. Malignant melanoma is relatively frequent as a second neoplasm.

Cases in Germany aged under 15 years (1980-2010): 79

Selected characteristics (Germany 2001-2010)

Relative frequency: 46 / 17876 = 0.3 %

Relative frequency of trial patients: -

Incidence rates per million:	Girls	Boys	Total
Number of cases:	23	23	46
Standardized rate *:	0.4	0.4	0.4
Cumulative incidence:	6	6	6

Sex ratio (m/f): 1.0

Age-specific incidence rates per million:

	<1	1-4	5-9	10-14
Number of cases :	2	10	11	23
Incidence rate:	0.3	0.3	0.3	0.5

Median age at diagnosis: 9 years 11 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized* mortality rate	Cumulative mortality
N	% of all 4151 deaths		
11	0.3 %	0.1	1

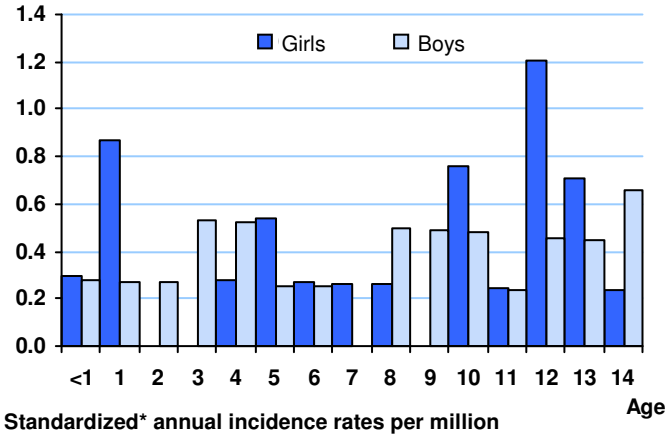
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

XI (d) Malignant melanomas

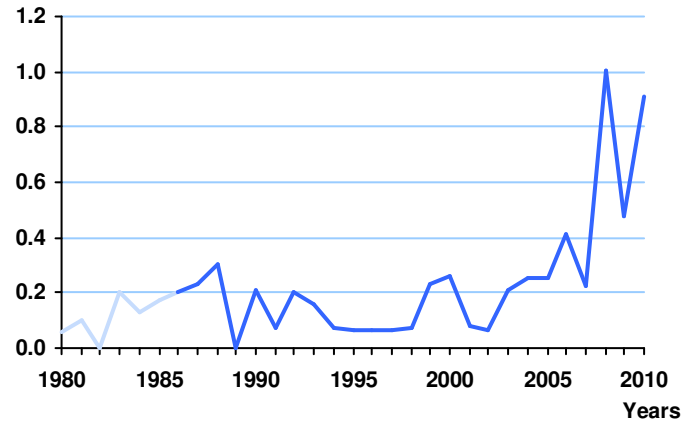
SN after XI (d)			XI (d) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
0	0.0 %	0.0 %	16	2.1 %	0.1 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



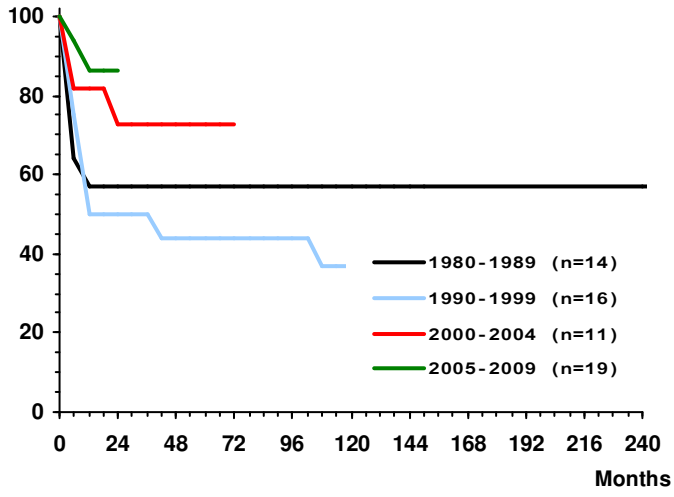
Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)



60 XII (a) Other specified malignant tumours

Most frequent form is pulmonary blastoma. Underreporting is likely. These carcinomas have so far not been reported as second neoplasms.

Cases in Germany aged under 15 years (1980-2010): 36

Selected characteristics (Germany 2001-2010)

Relative frequency:	15 / 17876 = 0.1 %
Relative frequency of trial patients:	80 %

Incidence rates per million:	**Girls**	**Boys**	**Total**
Number of cases:	7	8	15
Standardized rate *:	0.1	0.2	0.1
Cumulative incidence:	2	2	2
Sex ratio (m/f):			1.1

Age-specific incidence rates per million:

	<1	**1-4**	**5-9**	**10-14**
Number of cases :	0	9	2	4
Incidence rate:	0.0	0.3	0.1	0.1

Median age at diagnosis: 3 years 5 months

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

Mortality per million within 10 yrs. of diagnosis (1991-2000):

Number of deaths		Standardized*	Cumulative
N	% of all 4151 deaths	mortality rate	mortality
7	0.2 %	0.1	1

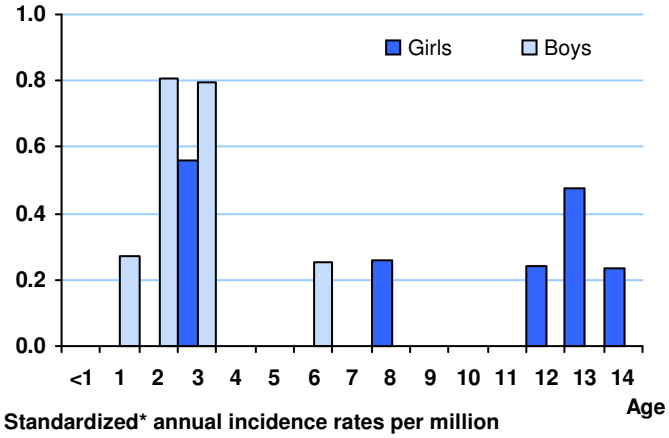
Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):

XII (a) Other specified malignant tumours

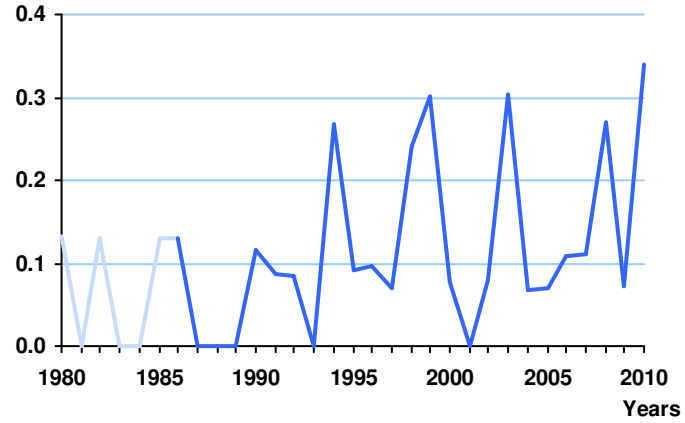
SN after XII (a)			XII (a) as SN after any primary		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
1	0.1 %	3.5 %	0	0.0 %	0.0 %

* Standard: Segi world standard population

Age- and sex-specific incidence rates per million (Germany 2001-2010)



Standardized* annual incidence rates per million (Germany 1980-2010)



Standardized* incidence rates per million by districts (Landkreise) (Germany 2001-2010)

No map due to sparse data

Survival probabilities by year of diagnosis (Germany 1980-2009)

No figure due to sparse data

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Tabelle 1:

Anzahl der gemeldeten Fälle und Inzidenzraten bezogen auf eine Million Kinder unter 15 Jahren aus der deutschen Wohnbevölkerung nach Diagnose auf Basis des ICCC-3, Alter und Geschlecht (2001-2010). ***ICCC-3 extended Subklassifikation kursiv dargestellt.***

Number of cases and incidence rates per million children under the age of 15 years in Germany by diagnoses classified according to ICCC-3, age, and sex (2001-2010). ***ICCC-3 extended subclassification in italics.***

Diagnoses	Sex	Sex ratio	Number of cases							Incidence rates per million						Trial participants(%)	Survival probabilities(%)	
			N	Relative (%)	Group (%)	Age groups				Age-specific				Age-stand.	Cum.			
		m / f				0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14		5-year	10-year
All malignancies	girls		7985	100	100	824	2765	2060	2336	242	195	109	113	147	2130	93.0	84	82
	boys		9891	100	100	1032	3304	2727	2828	288	221	137	130	173	2504	93.5	83	81
	total	**1.2**	**17876**	**100**	**100**	**1856**	**6069**	**4787**	**5164**	**266**	**208**	**123**	**121**	**160**	**2322**	**93.3**	**83**	**81**
Leukaemias, myeloproliferative and myelodysplastic diseases	girls		2757	35	100	134	1297	749	577	39	91	40	28	52	742	99.2	87	85
	boys		3332	34	100	174	1459	929	770	49	97	47	35	59	848	99.2	86	84
	total	**1.2**	**6089**	**34**	**100**	**308**	**2756**	**1678**	**1347**	**44**	**94**	**43**	**32**	**56**	**797**	**99.2**	**87**	**84**
Lymphoid leukaemias	girls		2145	27	78	64	1091	608	382	19	77	32	18	41	579	99.7	91	89
	boys		2622	27	79	70	1248	768	536	20	83	39	25	47	669	99.8	90	88
	total	**1.2**	**4767**	**27**	**78**	**134**	**2339**	**1376**	**918**	**19**	**80**	**35**	**22**	**44**	**625**	**99.8**	**90**	**88**
Precursor cell leukaemias	girls		2119	27	77	63	1086	591	379	19	76	31	18	40	572	99.8	91	89
	boys		2536	26	76	68	1227	735	506	19	82	37	23	45	647	99.8	90	88
	total	**1.2**	**4655**	**26**	**76**	**131**	**2313**	**1326**	**885**	**19**	**79**	**34**	**21**	**43**	**611**	**99.8**	**91**	**88**
Mature B-cell leukaemias	girls		25	0	1	1	5	17	2	0	0	1	0	0	7	100.0	-	-
	boys		86	1	3	2	21	33	30	1	1	2	1	1	21	98.8	85	85
	total	**3.4**	**111**	**1**	**2**	**3**	**26**	**50**	**32**	**0**	**1**	**1**	**1**	**1**	**14**	**99.1**	**84**	**84**
Mature T-cell and NK cell leukaemias	girls		1	0	0	0	0	0	1	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**0.0**	**1**	**0**	**0**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Lymphoid leukaemia, NOS	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Acute myeloid leukaemias	girls		379	5	14	51	153	63	112	15	11	3	5	7	102	97.6	71	70
	boys		416	4	13	64	135	95	122	18	9	5	6	7	106	97.6	69	67
	total	**1.1**	**795**	**4**	**13**	**115**	**288**	**158**	**234**	**16**	**10**	**4**	**6**	**7**	**104**	**97.6**	**70**	**68**
Chronic myeloproliferative diseases	girls		43	1	2	0	5	18	20	0	0	1	1	1	11	88.4	-	-
	boys		37	0	1	0	5	11	21	0	0	1	1	1	9	83.8	-	-
	total	**0.9**	**80**	**0**	**1**	**0**	**10**	**29**	**41**	**0**	**0**	**1**	**1**	**1**	**10**	**86.3**	**-**	**-**
Myelodysplastic syndrome and other myeloproliferative diseases	girls		159	2	6	12	42	49	56	4	3	3	3	3	42	98.1	78	77
	boys		218	2	7	29	62	48	79	8	4	2	4	4	55	97.2	78	77
	total	**1.4**	**377**	**2**	**6**	**41**	**104**	**97**	**135**	**6**	**4**	**2**	**3**	**3**	**48**	**97.6**	**78**	**77**

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Unspecified	girls		31	0	1	7	6	11	7	2	0	1	0	1	8	100.0	65	-
and other specified leukaemias	boys		39	0	1	11	9	7	12	3	1	0	1	1	10	100.0	64	64
	total	**1.3**	**70**	**0**	**1**	**18**	**15**	**18**	**19**	**3**	**1**	**0**	**0**	**1**	**9**	**100.0**	**65**	**65**
Lymphomas	girls		662	8	100	6	47	173	436	2	3	9	21	10	166	96.7	92	91
and reticuloendothelial neoplasms	boys		1375	14	100	7	174	515	679	2	12	26	31	21	333	96.2	94	93
	total	**2.1**	**2037**	**11**	**100**	**13**	**221**	**688**	**1115**	**2**	**8**	**18**	**26**	**16**	**252**	**96.4**	**94**	**92**
Hodgkin lymphomas	girls		343	4	52	0	3	49	291	0	0	3	14	5	84	98.0	98	-
	boys		521	5	38	0	30	153	338	0	2	8	15	8	124	97.1	99	98
	total	**1.5**	**864**	**5**	**42**	**0**	**33**	**202**	**629**	**0**	**1**	**5**	**15**	**6**	**104**	**97.5**	**98**	**97**
Non-Hodgkin lymphomas	girls		251	3	38	3	35	94	119	1	2	5	6	4	64	95.2	86	84
	boys		549	6	40	4	88	215	242	1	6	11	11	9	134	94.4	89	88
	total	**2.2**	**800**	**5**	**39**	**7**	**123**	**309**	**361**	**1**	**4**	**8**	**8**	**6**	**100**	**94.6**	**88**	**86**
Precursor cell lymphomas	girls		105	1	16	2	17	50	36	1	1	3	2	2	27	94.3	87	84
	boys		222	2	16	3	47	89	83	1	3	4	4	4	55	95.5	86	85
	total	**2.1**	**327**	**2**	**16**	**5**	**64**	**139**	**119**	**1**	**2**	**4**	**3**	**3**	**41**	**95.1**	**86**	**85**
Mature B-cell lymphomas	girls		46	1	7	0	5	16	25	0	0	1	1	1	12	95.7	-	-
(except Burkitt lymphoma)	boys		110	1	8	0	9	36	65	0	1	2	3	2	26	97.3	94	92
	total	**2.4**	**156**	**1**	**8**	**0**	**14**	**52**	**90**	**0**	**0**	**1**	**2**	**1**	**19**	**96.8**	**93**	**91**
Mature T-cell and NK-cell lymphomas	girls		59	1	9	1	7	12	39	0	0	1	2	1	15	94.9	-	-
	boys		106	1	8	1	18	44	43	0	1	2	2	2	26	93.4	87	87
	total	**1.8**	**165**	**1**	**8**	**2**	**25**	**56**	**82**	**0**	**1**	**1**	**2**	**1**	**21**	**93.9**	**85**	**84**
Non-Hodgkin lymphomas, NOS	girls		41	1	6	0	6	16	19	0	0	1	1	1	11	97.6	81	-
	boys		111	1	8	0	14	46	51	0	1	2	2	2	27	90.1	93	-
	total	**2.7**	**152**	**1**	**7**	**0**	**20**	**62**	**70**	**0**	**1**	**2**	**2**	**1**	**19**	**92.1**	**89**	**-**
Burkitt lymphoma	girls		63	1	10	1	8	29	25	0	1	2	1	1	16	100.0	93	93
	boys		298	3	22	0	55	145	98	0	4	7	4	5	74	98.3	95	95
	total	**4.7**	**361**	**2**	**18**	**1**	**63**	**174**	**123**	**0**	**2**	**4**	**3**	**3**	**46**	**98.6**	**95**	**94**
Miscellaneous	girls		4	0	1	2	0	1	1	1	0	0	0	0	1	50.0	-	-
lymphoreticular neoplasms	boys		6	0	0	3	1	1	1	1	0	0	0	0	2	83.3	-	-
	total	**1.5**	**10**	**0**	**1**	**5**	**1**	**2**	**2**	**1**	**0**	**0**	**0**	**0**	**1**	**70.0**	**-**	**-**
Unspecified lymphomas	girls		1	0	0	0	1	0	0	0	0	0	0	0	0	-	-	-
	boys		1	0	0	0	0	1	0	0	0	0	0	0	0	100.0	-	-
	total	**1.0**	**2**	**0**	**0**	**0**	**1**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**50.0**	**-**	**-**
CNS and miscellaneous intracranial	girls		1856	23	100	139	539	615	563	41	38	33	27	33	491	88.5	78	74
and intraspinal neoplasms	boys		2303	23	100	167	670	801	665	47	45	40	30	39	579	90.4	74	70
	total	**1.2**	**4159**	**23**	**100**	**306**	**1209**	**1416**	**1228**	**44**	**41**	**36**	**29**	**36**	**536**	**89.5**	**76**	**71**

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Ependymomas	girls		172	2	9	35	77	32	28	10	5	2	1	3	47	93.6	83	79
and choroid plexus tumour	boys		236	2	10	35	102	41	58	10	7	2	3	4	61	89.4	77	65
	total	**1.4**	**408**	**2**	**10**	**70**	**179**	**73**	**86**	**10**	**6**	**2**	**2**	**4**	**54**	**91.2**	**80**	**71**
Ependymomas	girls		129	2	7	13	63	28	25	4	4	1	1	3	35	97.7	81	79
	boys		193	2	8	15	88	38	52	4	6	2	2	3	49	90.7	76	64
	total	**1.5**	**322**	**2**	**8**	**28**	**151**	**66**	**77**	**4**	**5**	**2**	**2**	**3**	**42**	**93.5**	**78**	**70**
Choroid plexus tumour	girls		43	1	2	22	14	4	3	6	1	0	0	1	12	81.4	91	82
	boys		43	0	2	20	14	3	6	6	1	0	0	1	11	83.7	87	-
	total	**1.0**	**86**	**0**	**2**	**42**	**28**	**7**	**9**	**6**	**1**	**0**	**0**	**1**	**12**	**82.6**	**89**	**78**
Astrocytomas	girls		922	12	50	45	262	306	309	13	18	16	15	16	243	89.7	81	78
	boys		1040	11	45	52	288	386	314	15	19	19	14	18	260	91.0	79	76
	total	**1.1**	**1962**	**11**	**47**	**97**	**550**	**692**	**623**	**14**	**19**	**18**	**15**	**17**	**252**	**90.4**	**80**	**77**
Intracranial	girls		318	4	17	37	105	116	60	11	7	6	3	6	86	90.9	68	61
and intraspinal embryonal tumours	boys		513	5	22	51	170	206	86	14	11	10	4	9	131	93.4	66	58
	total	**1.6**	**831**	**5**	**20**	**88**	**275**	**322**	**146**	**13**	**9**	**8**	**3**	**8**	**109**	**92.4**	**66**	**59**
Medulloblastomas	girls		223	3	12	12	61	101	49	4	4	5	2	4	59	97.3	78	71
	boys		372	4	16	11	111	177	73	3	7	9	3	6	94	99.2	75	66
	total	**1.7**	**595**	**3**	**14**	**23**	**172**	**278**	**122**	**3**	**6**	**7**	**3**	**5**	**77**	**98.5**	**76**	**68**
Primitive neuroectodermal tumour	girls		44	1	2	5	22	7	10	1	2	0	0	1	12	93.2	-	-
(PNET)	boys		63	1	3	4	29	19	11	1	2	1	1	1	16	93.7	-	-
	total	**1.4**	**107**	**1**	**3**	**9**	**51**	**26**	**21**	**1**	**2**	**1**	**0**	**1**	**14**	**93.5**	**-**	**-**
Medulloepithelioma	girls		4	0	0	0	2	2	0	0	0	0	0	0	1	100.0	-	-
	boys		3	0	0	3	0	0	0	1	0	0	0	0	1	100.0	-	-
	total	**0.8**	**7**	**0**	**0**	**3**	**2**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**
Atypical teratoid/rhabdoid tumour	girls		47	1	3	20	20	6	1	6	1	0	0	1	13	57.4	-	-
	boys		75	1	3	33	30	10	2	9	2	1	0	2	20	64.0	-	-
	total	**1.6**	**122**	**1**	**3**	**53**	**50**	**16**	**3**	**8**	**2**	**0**	**0**	**1**	**17**	**61.5**	**-**	**-**
Other gliomas	girls		167	2	9	8	37	70	52	2	3	4	3	3	44	77.8	41	40
	boys		175	2	8	8	45	60	62	2	3	3	3	3	44	88.6	42	42
	total	**1.0**	**342**	**2**	**8**	**16**	**82**	**130**	**114**	**2**	**3**	**3**	**3**	**3**	**44**	**83.3**	**42**	**41**
Oligodendrogliomas	girls		10	0	1	0	0	6	4	0	0	0	0	0	3	60.0	-	-
	boys		10	0	0	0	1	3	6	0	0	0	0	0	2	80.0	-	-
	total	**1.0**	**20**	**0**	**0**	**0**	**1**	**9**	**10**	**0**	**0**	**0**	**0**	**0**	**2**	**70.0**	**-**	**-**
Mixed and unspecified gliomas	girls		150	2	8	7	35	64	44	2	2	3	2	3	39	78.0	36	35
	boys		158	2	7	7	44	57	50	2	3	3	2	3	39	89.9	39	39
	total	**1.1**	**308**	**2**	**7**	**14**	**79**	**121**	**94**	**2**	**3**	**3**	**2**	**3**	**39**	**84.1**	**38**	**37**

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Neuroepithelial glial tumours	girls		7	0	0	1	2	0	4	0	0	0	0	0	2	100.0	-	-
of uncertain origin	boys		7	0	0	1	0	0	6	0	0	0	0	0	2	71.4	-	-
	total	**1.0**	**14**	**0**	**0**	**2**	**2**	**0**	**10**	**0**	**0**	**0**	**0**	**0**	**2**	**85.7**	**-**	**-**
Other specified intracranial	girls		250	3	14	10	49	86	105	3	3	5	5	4	65	88.4	97	95
and intraspinal neoplasms	boys		300	3	13	12	60	96	132	3	4	5	6	5	74	88.7	93	91
	total	**1.2**	**550**	**3**	**13**	**22**	**109**	**182**	**237**	**3**	**4**	**5**	**6**	**5**	**69**	**88.5**	**95**	**93**
Pituitary adenomas and carcinomas	girls		15	0	1	0	3	1	11	0	0	0	1	0	4	66.7	-	-
	boys		15	0	1	0	0	2	13	0	0	0	1	0	3	60.0	100	-
	total	**1.0**	**30**	**0**	**1**	**0**	**3**	**3**	**24**	**0**	**0**	**0**	**1**	**0**	**4**	**63.3**	**100**	**-**
Tumours of the sellar region	girls		94	1	5	0	16	41	37	0	1	2	2	2	24	95.7	100	99
(craniopharyngiomas)	boys		100	1	4	1	22	39	38	0	1	2	2	2	25	99.0	98	95
	total	**1.1**	**194**	**1**	**5**	**1**	**38**	**80**	**75**	**0**	**1**	**2**	**2**	**2**	**24**	**97.4**	**99**	**97**
Pineal parenchymal tumours	girls		13	0	1	1	2	6	4	0	0	0	0	0	3	100.0	-	-
	boys		17	0	1	0	7	3	7	0	0	0	0	0	4	76.5	-	-
	total	**1.3**	**30**	**0**	**1**	**1**	**9**	**9**	**11**	**0**	**0**	**0**	**0**	**0**	**4**	**86.7**	**-**	**-**
Neuronal	girls		100	1	5	9	23	27	41	3	2	1	2	2	26	85.0	98	95
and mixed neuronal-glial tumours	boys		143	1	6	11	25	43	64	3	2	2	3	2	35	89.5	93	93
	total	**1.4**	**243**	**1**	**6**	**20**	**48**	**70**	**105**	**3**	**2**	**2**	**2**	**2**	**31**	**87.7**	**95**	**94**
Meningiomas	girls		28	0	2	0	5	11	12	0	0	1	1	0	7	82.1	-	-
	boys		25	0	1	0	6	9	10	0	0	0	0	0	6	68.0	-	-
	total	**0.9**	**53**	**0**	**1**	**0**	**11**	**20**	**22**	**0**	**0**	**1**	**1**	**0**	**7**	**75.5**	**-**	**-**
Unspecified intracranial	girls		27	0	2	4	9	5	9	1	1	0	0	1	7	51.9	-	-
and intraspinal neoplasms	boys		39	0	2	9	5	12	13	3	0	1	1	1	10	64.1	65	-
	total	**1.4**	**66**	**0**	**2**	**13**	**14**	**17**	**22**	**2**	**0**	**0**	**1**	**1**	**9**	**59.1**	**-**	**-**
Neuroblastoma	girls		575	7	100	256	251	51	17	75	18	3	1	13	164	98.4	77	74
and other peripheral	boys		675	7	100	319	290	51	15	89	19	3	1	14	183	98.7	78	75
nervous cell tumours	**total**	**1.2**	**1250**	**7**	**100**	**575**	**541**	**102**	**32**	**82**	**19**	**3**	**1**	**13**	**173**	**98.6**	**77**	**75**
Neuroblastoma	girls		570	7	99	256	247	51	16	75	17	3	1	13	162	99.1	77	74
and ganglioneuroblastoma	boys		670	7	99	319	289	50	12	89	19	3	1	14	182	98.8	78	75
	total	**1.2**	**1240**	**7**	**99**	**575**	**536**	**101**	**28**	**82**	**18**	**3**	**1**	**13**	**172**	**99.0**	**78**	**75**
Other peripheral nervous cell tumours	girls		5	0	1	0	4	0	1	0	0	0	0	0	1	20.0	-	-
	boys		5	0	1	0	1	1	3	0	0	0	0	0	1	80.0	-	-
	total	**1.0**	**10**	**0**	**1**	**0**	**5**	**1**	**4**	**0**	**0**	**0**	**0**	**0**	**1**	**50.0**	**-**	**-**
Retinoblastoma	girls		179	2	100	76	94	9	0	22	7	0	0	4	51	-	99	99
	boys		217	2	100	97	109	9	2	27	7	0	0	5	59	-	97	96
	total	**1.2**	**396**	**2**	**100**	**173**	**203**	**18**	**2**	**25**	**7**	**0**	**0**	**4**	**55**	**-**	**98**	**98**

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Renal tumours	girls		523	7	100	72	292	127	32	21	21	7	2	11	145	98.9	95	94
	boys		481	5	100	95	266	91	29	27	18	5	1	9	127	97.1	92	91
	total	**0.9**	**1004**	**6**	**100**	**167**	**558**	**218**	**61**	**24**	**19**	**6**	**1**	**10**	**136**	**98.0**	**93**	**93**
Nephroblastoma and other non-epithelial renal tumours	girls		509	6	97	72	291	123	23	21	20	7	1	10	141	99.4	95	94
	boys		471	5	98	95	266	89	21	27	18	4	1	9	125	97.9	92	91
	total	**0.9**	**980**	**6**	**98**	**167**	**557**	**212**	**44**	**24**	**19**	**5**	**1**	**10**	**133**	**98.7**	**93**	**93**
Nephroblastoma	girls		501	6	96	68	288	122	23	20	20	6	1	10	139	99.6	95	95
	boys		458	5	95	91	262	86	19	25	18	4	1	9	121	98.3	93	92
	total	**0.9**	**959**	**5**	**96**	**159**	**550**	**208**	**42**	**23**	**19**	**5**	**1**	**10**	**130**	**99.0**	**94**	**94**
Rhabdoid renal tumour	girls		6	0	1	4	2	0	0	1	0	0	0	0	2	83.3	-	-
	boys		7	0	1	4	2	1	0	1	0	0	0	0	2	71.4	-	-
	total	**1.2**	**13**	**0**	**1**	**8**	**4**	**1**	**0**	**1**	**0**	**0**	**0**	**0**	**2**	**76.9**	**-**	**-**
Kidney sarcomas	girls		2	0	0	0	1	1	0	0	0	0	0	0	1	100.0	-	-
	boys		5	0	1	0	2	2	1	0	0	0	0	0	1	100.0	-	-
	total	**2.5**	**7**	**0**	**1**	**0**	**3**	**3**	**1**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**
Peripheral neuroectodermal tumour (pPNET) of kidney	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-
	total	**-**	**1**	**0**	**0**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**
Renal carcinomas	girls		14	0	3	0	1	4	9	0	0	0	0	0	4	78.6	-	-
	boys		10	0	2	0	0	2	8	0	0	0	0	0	2	60.0	-	-
	total	**0.7**	**24**	**0**	**2**	**0**	**1**	**6**	**17**	**0**	**0**	**0**	**0**	**0**	**3**	**70.8**	**-**	**-**
Unspecified malignant renal tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Hepatic tumours	girls		87	1	100	24	45	7	11	7	3	0	1	2	24	95.4	66	64
	boys		130	1	100	36	58	15	21	10	4	1	1	3	34	96.2	71	68
	total	**1.5**	**217**	**1**	**100**	**60**	**103**	**22**	**32**	**9**	**4**	**1**	**1**	**2**	**29**	**95.9**	**69**	**66**
Hepatoblastoma	girls		73	1	84	24	43	4	2	7	3	0	0	2	21	98.6	68	68
	boys		106	1	82	36	56	7	7	10	4	0	0	2	28	99.1	79	78
	total	**1.5**	**179**	**1**	**83**	**60**	**99**	**11**	**9**	**9**	**3**	**0**	**0**	**2**	**25**	**98.9**	**75**	**74**
Hepatic carcinomas	girls		13	0	15	0	2	3	8	0	0	0	0	0	3	76.9	-	-
	boys		23	0	18	0	1	8	14	0	0	0	1	0	5	82.6	-	-
	total	**1.8**	**36**	**0**	**17**	**0**	**3**	**11**	**22**	**0**	**0**	**0**	**1**	**0**	**4**	**80.6**	**-**	**-**
Unspecified malignant hepatic tumours	girls		1	0	1	0	0	0	1	0	0	0	0	0	0	100.0	-	-
	boys		1	0	1	0	1	0	0	0	0	0	0	0	0	100.0	-	-
	total	**1.0**	**2**	**0**	**1**	**0**	**1**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Malignant bone tumours	girls		379	5	100	1	24	93	261	0	2	5	13	6	95	97.4	74	70
	boys		423	4	100	4	27	116	276	1	2	6	13	6	101	97.9	72	68
	total	**1.1**	**802**	**5**	**100**	**5**	**51**	**209**	**537**	**1**	**2**	**5**	**13**	**6**	**98**	**97.6**	**73**	**69**
Osteosarcomas	girls		204	3	54	0	5	45	154	0	0	2	7	3	50	99.0	78	75
	boys		206	2	49	0	6	44	156	0	0	2	7	3	48	97.6	72	67
	total	**1.0**	**410**	**2**	**51**	**0**	**11**	**89**	**310**	**0**	**0**	**2**	**7**	**3**	**49**	**98.3**	**75**	**71**
Chondrosarcomas	girls		8	0	2	0	0	2	6	0	0	0	0	0	2	62.5	-	-
	boys		5	0	1	0	0	0	5	0	0	0	0	0	1	60.0	-	-
	total	**0.6**	**13**	**0**	**2**	**0**	**0**	**2**	**11**	**0**	**0**	**0**	**0**	**0**	**2**	**61.5**	**-**	**-**
Ewing tumour	girls		157	2	41	1	17	43	96	0	1	2	5	2	40	98.1	69	64
and related sarcomas of bone	boys		204	2	48	4	20	69	111	1	1	3	5	3	49	100.0	72	68
	total	**1.3**	**361**	**2**	**45**	**5**	**37**	**112**	**207**	**1**	**1**	**3**	**5**	**3**	**45**	**99.2**	**71**	**66**
Other specified malignant bone tumours	girls		8	0	2	0	2	2	4	0	0	0	0	0	2	100.0	-	-
	boys		5	0	1	0	1	3	1	0	0	0	0	0	1	80.0	-	-
	total	**0.6**	**13**	**0**	**2**	**0**	**3**	**5**	**5**	**0**	**0**	**0**	**0**	**0**	**2**	**92.3**	**-**	**-**
Malignant fibrous	girls		2	0	1	0	0	0	2	0	0	0	0	0	0	100.0	-	-
neoplasms of bone	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**0.0**	**2**	**0**	**0**	**0**	**0**	**0**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**
Malignant chordomas	girls		5	0	1	0	2	2	1	0	0	0	0	0	1	100.0	-	-
	boys		4	0	1	0	0	3	1	0	0	0	0	0	1	75.0	-	-
	total	**0.8**	**9**	**0**	**1**	**0**	**2**	**5**	**2**	**0**	**0**	**0**	**0**	**0**	**1**	**88.9**	**-**	**-**
Odontogenic malignant tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		1	0	0	0	1	0	0	0	0	0	0	0	0	100.0	-	-
	total	**-**	**1**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**
Miscellaneous malignant	girls		1	0	0	0	0	0	1	0	0	0	0	0	0	100.0	-	-
bone tumours	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**0.0**	**1**	**0**	**0**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**
Unspecified malignant bone tumours	girls		2	0	1	0	0	1	1	0	0	0	0	0	1	-	-	-
	boys		3	0	1	0	0	0	3	0	0	0	0	0	1	66.7	-	-
	total	**1.5**	**5**	**0**	**1**	**0**	**0**	**1**	**4**	**0**	**0**	**0**	**0**	**0**	**1**	**40.0**	**-**	**-**
Soft tissue	girls		488	6	100	51	126	130	181	15	9	7	9	9	129	95.9	71	69
and other extraosseous sarcomas	boys		576	6	100	73	175	148	180	20	12	7	8	10	146	95.5	74	71
	total	**1.2**	**1064**	**6**	**100**	**124**	**301**	**278**	**361**	**18**	**10**	**7**	**8**	**9**	**137**	**95.7**	**73**	**70**
Rhabdomyosarcomas	girls		259	3	53	20	99	76	64	6	7	4	3	5	69	98.8	68	66
	boys		313	3	54	27	130	97	59	8	9	5	3	6	80	98.1	77	76
	total	**1.2**	**572**	**3**	**54**	**47**	**229**	**173**	**123**	**7**	**8**	**4**	**3**	**5**	**75**	**98.4**	**73**	**71**

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Fibrosarcomas, peripheral	girls		52	1	11	12	5	9	26	4	0	0	1	1	14	86.5	-	-
nerve sheath tumours	boys		57	1	10	17	8	9	23	5	1	0	1	1	14	87.7	75	-
and other fibrous neoplasms	**total**	**1.1**	**109**	**1**	**10**	**29**	**13**	**18**	**49**	**4**	**0**	**0**	**1**	**1**	**14**	**87.2**	**68**	**64**
Fibroblastic	girls		27	0	6	12	3	4	8	4	0	0	0	1	7	88.9	-	-
and myofibroblastic tumours	boys		35	0	6	14	6	3	12	4	0	0	1	1	9	94.3	-	-
	total	**1.3**	**62**	**0**	**6**	**26**	**9**	**7**	**20**	**4**	**0**	**0**	**0**	**1**	**8**	**91.9**	**-**	**-**
Nerve sheath tumours	girls		25	0	5	0	2	5	18	0	0	0	1	0	6	84.0	-	-
	boys		22	0	4	3	2	6	11	1	0	0	1	0	5	77.3	-	-
	total	**0.9**	**47**	**0**	**4**	**3**	**4**	**11**	**29**	**0**	**0**	**0**	**1**	**0**	**6**	**80.9**	**-**	**-**
Other fibrous neoplasms	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Kaposi sarcoma	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Other specified soft tissue sarcomas	girls		137	2	28	16	13	34	74	5	1	2	4	2	35	96.4	83	79
	boys		165	2	29	21	32	35	77	6	2	2	4	3	41	93.3	67	62
	total	**1.2**	**302**	**2**	**28**	**37**	**45**	**69**	**151**	**5**	**2**	**2**	**4**	**3**	**38**	**94.7**	**75**	**70**
Unspecified soft tissue sarcomas	girls		40	1	8	3	9	11	17	1	1	1	1	1	10	87.5	-	-
	boys		41	0	7	8	5	7	21	2	0	0	1	1	10	95.1	70	63
	total	**1.0**	**81**	**1**	**8**	**11**	**14**	**18**	**38**	**2**	**0**	**0**	**1**	**1**	**10**	**91.4**	**65**	**62**
Germ cell tumours,	girls		300	4	100	62	36	68	134	18	3	4	6	5	79	97.7	95	94
trophoblastic tumours	boys		231	2	100	57	53	22	99	16	4	1	5	4	58	96.5	94	93
and neoplasms of gonads	**total**	**0.8**	**531**	**3**	**100**	**119**	**89**	**90**	**233**	**17**	**3**	**2**	**5**	**5**	**68**	**97.2**	**95**	**94**
Intracranial	girls		61	1	20	3	2	26	30	1	0	1	1	1	16	96.7	92	88
and intraspinal germ cell tumours	boys		95	1	41	1	5	21	68	0	0	1	3	1	22	94.7	89	87
	total	**1.6**	**156**	**1**	**29**	**4**	**7**	**47**	**98**	**1**	**0**	**1**	**2**	**1**	**19**	**95.5**	**90**	**87**
Malignant extracranial	girls		95	1	32	59	26	3	7	17	2	0	0	2	27	95.8	95	94
and extragonadal germ cell tumours	boys		51	1	22	27	16	1	7	8	1	0	0	1	14	98.0	98	-
	total	**0.5**	**146**	**1**	**28**	**86**	**42**	**4**	**14**	**12**	**1**	**0**	**0**	**2**	**20**	**96.6**	**96**	**95**
Malignant gonadal germ cell tumours	girls		139	2	46	0	8	38	93	0	1	2	4	2	35	100.0	99	98
	boys		85	1	37	29	32	0	24	8	2	0	1	2	22	97.6	98	98
	total	**0.6**	**224**	**1**	**42**	**29**	**40**	**38**	**117**	**4**	**1**	**1**	**3**	**2**	**28**	**99.1**	**98**	**98**
Gonadal carcinomas	girls		5	0	2	0	0	1	4	0	0	0	0	0	1	80.0	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**0.0**	**5**	**0**	**1**	**0**	**0**	**1**	**4**	**0**	**0**	**0**	**0**	**0**	**1**	**80.0**	**-**	**-**

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Other and unspecified malignant gonadal tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Other malignant epithelial neoplasms and malignant melanomas	girls		171	2	100	3	12	37	119	1	1	2	6	3	43	63.7	90	86
	boys		138	1	100	3	16	29	90	1	1	1	4	2	33	59.4	79	-
	total	**0.8**	**309**	**2**	**100**	**6**	**28**	**66**	**209**	**1**	**1**	**2**	**5**	**2**	**38**	**61.8**	**85**	**81**
Adrenocortical carcinomas	girls		20	0	12	2	7	6	5	1	0	0	0	0	5	95.0	-	-
	boys		9	0	7	1	5	2	1	0	0	0	0	0	2	100.0	-	-
	total	**0.5**	**29**	**0**	**9**	**3**	**12**	**8**	**6**	**0**	**0**	**0**	**0**	**0**	**4**	**96.6**	**-**	**-**
Thyroid carcinomas	girls		80	1	47	0	1	21	58	0	0	1	3	1	20	90.0	98	94
	boys		51	1	37	1	2	12	36	0	0	1	2	1	12	90.2	92	-
	total	**0.6**	**131**	**1**	**42**	**1**	**3**	**33**	**94**	**0**	**0**	**1**	**2**	**1**	**16**	**90.1**	**96**	**92**
Nasopharyngeal carcinomas	girls		6	0	4	0	0	0	6	0	0	0	0	0	1	100.0	-	-
	boys		18	0	13	0	1	0	17	0	0	0	1	0	4	100.0	100	-
	total	**3.0**	**24**	**0**	**8**	**0**	**1**	**0**	**23**	**0**	**0**	**0**	**1**	**0**	**3**	**100.0**	**100**	**-**
Malignant melanomas	girls		23	0	14	1	4	5	13	0	0	0	1	0	6	-	94	-
	boys		23	0	17	1	6	6	10	0	0	0	0	0	6	-	-	-
	total	**1.0**	**46**	**0**	**15**	**2**	**10**	**11**	**23**	**0**	**0**	**0**	**1**	**0**	**6**	**-**	**82**	**-**
Skin carcinomas	girls		4	0	2	0	0	2	2	0	0	0	0	0	1	-	-	-
	boys		2	0	1	0	0	1	1	0	0	0	0	0	0	-	-	-
	total	**0.5**	**6**	**0**	**2**	**0**	**0**	**3**	**3**	**0**	**0**	**0**	**0**	**0**	**1**	**-**	**-**	**-**
Other and unspecified carcinomas	girls		38	1	22	0	0	3	35	0	0	0	2	1	9	31.6	79	-
	boys		35	0	25	0	2	8	25	0	0	0	1	1	8	25.7	60	-
	total	**0.9**	**73**	**0**	**24**	**0**	**2**	**11**	**60**	**0**	**0**	**0**	**1**	**1**	**9**	**28.8**	**69**	**-**
Carcinomas of salivary glands	girls		12	0	7	0	0	1	11	0	0	0	1	0	3	-	100	-
	boys		6	0	4	0	0	3	3	0	0	0	0	0	1	16.7	-	-
	total	**0.5**	**18**	**0**	**6**	**0**	**0**	**4**	**14**	**0**	**0**	**0**	**0**	**0**	**2**	**5.6**	**100**	**-**
Carcinomas of colon and rectum	girls		4	0	2	0	0	0	4	0	0	0	0	0	1	-	-	-
	boys		7	0	5	0	0	1	6	0	0	0	0	0	2	-	-	-
	total	**1.8**	**11**	**0**	**4**	**0**	**0**	**1**	**10**	**0**	**0**	**0**	**0**	**0**	**1**	**-**	**-**	**-**
Carcinomas of appendix	girls		1	0	1	0	0	0	1	0	0	0	0	0	0	100.0	-	-
	boys		3	0	2	0	0	1	2	0	0	0	0	0	1	100.0	-	-
	total	**3.0**	**4**	**0**	**1**	**0**	**0**	**1**	**3**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**
Carcinomas of lung	girls		3	0	2	0	0	0	3	0	0	0	0	0	1	100.0	-	-
	boys		5	0	4	0	0	2	3	0	0	0	0	0	1	20.0	-	-
	total	**1.7**	**8**	**0**	**3**	**0**	**0**	**2**	**6**	**0**	**0**	**0**	**0**	**0**	**1**	**50.0**	**-**	**-**

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Carcinomas of thymus	girls		1	0	1	0	0	0	1	0	0	0	0	0	0	-	-	-
	boys		1	0	1	0	0	0	1	0	0	0	0	0	0	-	-	-
	total	**1.0**	**2**	**0**	**1**	**0**	**0**	**0**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Carcinomas of breast	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Carcinomas of cervix uteri	girls		1	0	1	0	0	0	1	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**0.0**	**1**	**0**	**0**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Carcinomas of bladder	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Carcinomas of eye	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		2	0	1	0	0	0	2	0	0	0	0	0	0	-	-	-
	total	**-**	**2**	**0**	**1**	**0**	**0**	**0**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Carcinomas of other specified sites	girls		14	0	8	0	0	2	12	0	0	0	1	0	3	57.1	-	-
	boys		9	0	7	0	1	1	7	0	0	0	0	0	2	22.2	-	-
	total	**0.6**	**23**	**0**	**7**	**0**	**1**	**3**	**19**	**0**	**0**	**0**	**0**	**0**	**3**	**43.5**	**-**	**-**
Carcinomas of unspecified site	girls		2	0	1	0	0	0	2	0	0	0	0	0	0	-	-	-
	boys		2	0	1	0	1	0	1	0	0	0	0	0	0	100.0	-	-
	total	**1.0**	**4**	**0**	**1**	**0**	**1**	**0**	**3**	**0**	**0**	**0**	**0**	**0**	**0**	**50.0**	**-**	**-**
Others and unspecified malignant neoplasms	girls		8	0	100	0	2	1	5	0	0	0	0	0	2	62.5	-	-
	boys		10	0	100	0	7	1	2	0	0	0	0	0	3	80.0	-	-
	total	**1.3**	**18**	**0**	**100**	**0**	**9**	**2**	**7**	**0**	**0**	**0**	**0**	**0**	**2**	**72.2**	**-**	**-**
Other specified malignant tumours	girls		7	0	88	0	2	1	4	0	0	0	0	0	2	71.4	-	-
	boys		8	0	80	0	7	1	0	0	0	0	0	0	2	87.5	-	-
	total	**1.1**	**15**	**0**	**83**	**0**	**9**	**2**	**4**	**0**	**0**	**0**	**0**	**0**	**2**	**80.0**	**-**	**-**
Gastrointestinal stromal tumour	girls		2	0	25	0	0	0	2	0	0	0	0	0	0	100.0	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**0.0**	**2**	**0**	**11**	**0**	**0**	**0**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**
Pancreatoblastoma	girls		1	0	13	0	0	1	0	0	0	0	0	0	0	-	-	-
	boys		1	0	10	0	0	1	0	0	0	0	0	0	0	-	-	-
	total	**1.0**	**2**	**0**	**11**	**0**	**0**	**2**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Pulmonary blastoma and pleuropulmonary blastoma	girls		2	0	25	0	2	0	0	0	0	0	0	0	1	100.0	-	-
	boys		6	0	60	0	6	0	0	0	0	0	0	0	2	100.0	-	-
	total	**3.0**	**8**	**0**	**44**	**0**	**8**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**100.0**	**-**	**-**

Standard: Segi world standard population

- insufficient data

Tabelle 1 Forts. **Table 1 cont.**

Diagnoses	Sex	Sex ratio	Number of cases N	Relative (%)	Group (%)	Age groups 0	1 - 4	5 - 9	10 - 14	Incidence rates per million Age-specific 0	1 - 4	5 - 9	10 - 14	Age-stand. World #	Cum. 0 - 14	Trial participants(%)	Survival probabilities(%) 5-year	10-year
		m / f																
Other complex mixed	girls		1	0	13	0	0	0	1	0	0	0	0	0	0	100.0	-	-
and stromal neoplasms	boys		1	0	10	0	1	0	0	0	0	0	0	0	0	100.0	-	-
	total	**1.0**	**2**	**0**	**11**	**0**	**1**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**100.0**	**-**	**-**
Mesothelioma	girls		1	0	13	0	0	0	1	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**0.0**	**1**	**0**	**6**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Other specified malignant tumours	girls		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	boys		0	0	0	0	0	0	0	0	0	0	0	0	0	-	-	-
	total	**-**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**-**	**-**	**-**
Other unspecified malignant tumours	girls		1	0	13	0	0	0	1	0	0	0	0	0	0	-	-	-
	boys		2	0	20	0	0	0	2	0	0	0	0	0	0	50.0	-	-
	total	**2.0**	**3**	**0**	**17**	**0**	**0**	**0**	**3**	**0**	**0**	**0**	**0**	**0**	**0**	**33.3**	**-**	**-**

Standard: Segi world standard population

- insufficient data

Tabelle 2:

Ausgewählte Kenngrößen für ausgewählte, systematisch registrierte, nicht in der ICCC-3 definierte nicht-maligne Diagnosen der Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung (2001-2010)

Summary data for selected systematically registered non-malignant diagnoses not defined in ICCC-3 of patients under 15 in Germany (2001-2010)

Diagnoses	Sex	Sex ratio	Number of cases					Incidence rates per million						Trial participants(%)
			N	Age groups				Age groups				Age-stand.	Cum.	
		m / f		0	1 - 4	5 - 9	10 - 14	0	1 - 4	5 - 9	10 - 14	World #	0 - 14	
All selected non-malignant diseases	girls		717	217	138	165	197	64	10	9	10	14	194	92.2
	boys		666	181	186	141	158	51	12	7	7	12	172	89.8
	total	**0.9**	**1383**	**398**	**324**	**306**	**355**	**57**	**11**	**8**	**8**	**13**	**183**	**91.0**
Non-malignant	girls		258	68	83	62	45	20	6	3	2	5	71	89.5
Langerhans cell histiocytosis	boys		425	79	134	107	105	22	9	5	5	8	109	88.0
	total	**1.6**	**683**	**147**	**217**	**169**	**150**	**21**	**7**	**4**	**4**	**6**	**90**	**88.6**
Benign/mature teratoma	girls		352	123	35	68	126	36	2	4	6	7	94	95.2
	boys		113	70	24	8	11	20	2	0	1	2	30	92.9
	total	**0.3**	**465**	**193**	**59**	**76**	**137**	**28**	**2**	**2**	**3**	**4**	**62**	**94.6**
Severe aplastic anaemia	girls		77	2	17	33	25	1	1	2	1	1	20	97.4
	boys		95	2	28	25	40	1	2	1	2	2	23	95.8
	total	**1.2**	**172**	**4**	**45**	**58**	**65**	**1**	**2**	**1**	**2**	**1**	**22**	**96.5**
Mesoblastic nephroma	girls		19	18	1	0	0	5	0	0	0	0	6	84.2
	boys		29	28	0	1	0	8	0	0	0	1	8	89.7
	total	**1.5**	**48**	**46**	**1**	**1**	**0**	**7**	**0**	**0**	**0**	**1**	**7**	**87.5**

Standard: Segi world standard population

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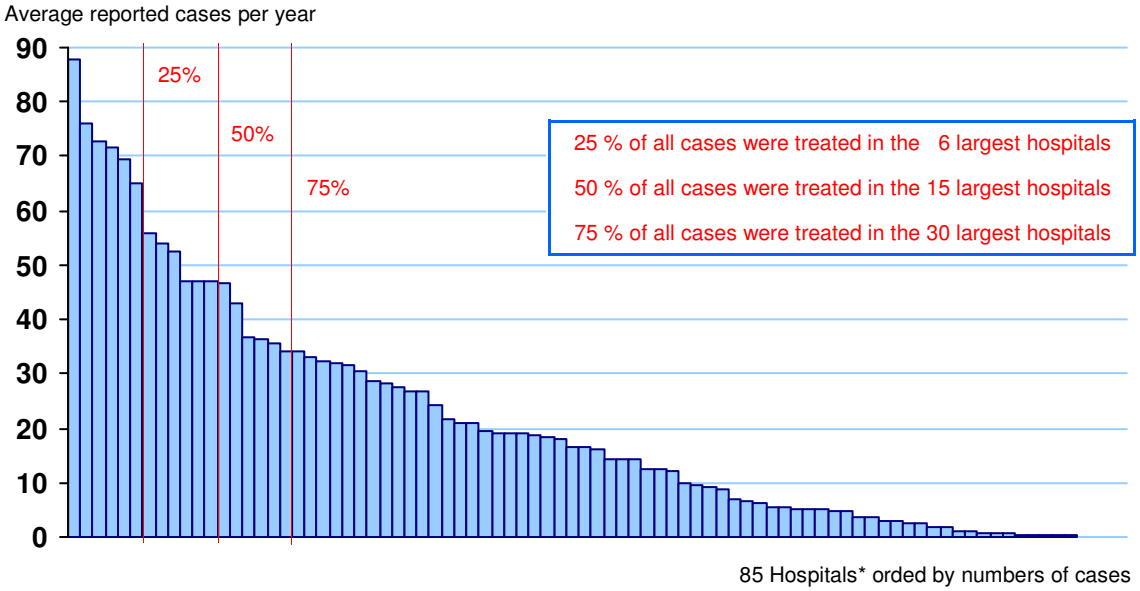
Abbildung 1:

Meldungen an das DKKR (Registerpopulation) je Klinik, Zeitraum 2001-2010

Reported cases to the GCCR (registry population) per hospital, period 2001-2010



* One hospital with 15 cases is a collection of "other hospitals"

Tabelle 3

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

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

Diagnoses		Number of cases 1980-2010		Number of cases 2001-2010		Incidence rates 2001-2010	
		Absolute	Relative (%)	Absolute	Relative (%)	Age-standard.*	Cumu-lative
I	Leukaemias	16684	34.5	6089	34.1	56	797
II	Lymphomas	5762	11.9	2037	11.4	16	252
III	CNS tumours	10216	21.1	4159	23.3	36	536
IV	Peripheral nervous cell tumours	3716	7.7	1250	7.0	13	173
V	Retinoblastoma	1170	2.4	396	2.2	4	55
VI	Renal tumours	2877	5.9	1004	5.6	10	136
VII	Hepatic tumours	507	1.0	217	1.2	2	29
VIII	Bone tumours	2285	4.7	802	4.5	6	98
IX	Soft tissue sarcomas	2990	6.2	1064	6.0	9	137
X	Germ cell tumours	1521	3.1	531	3.0	5	68
XI	Carcinomas	621	1.3	309	1.7	2	38
XII	Others and unspecified	48	0.1	18	0.1	0	2
	All malignancies	48397	100.0	17876	100.0	160	2322

* Standard: Segi world standard population

Tabelle 4:

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

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

Years	Number of cases			Incidence rates per million *			Population base (in million)		
	Total	West # Germany	East # Germany	Total	West # Germany	East # Germany	Total	West # Germany	East # Germany
1980	1019	987	-	103	102	-	11.187	10.903	-
1981	1045	1020	-	105	105	-	10.803	10.525	-
1982	979	955	-	104	104	-	10.392	10.121	-
1983	1077	1055	-	116	117	-	9.957	9.694	-
1984	1032	1002	-	114	114	-	9.539	9.283	-
1985	1142	1113	-	129	129	-	9.232	8.979	-
1986	1143	1111	-	132	132	-	9.070	8.815	-
1987	1220	1190	-	142	142	-	8.903	8.652	-
1988	1217	1172	-	140	139	-	9.019	8.758	-
1989	1221	1196	-	135	137	-	9.260	8.986	-
1990	1297	1253	-	139	138	-	9.621	9.333	-
1991	1670	1292	320	132	137	118	13.013	9.625	2.842
1992	1813	1433	315	143	148	123	13.166	9.889	2.731
1993	1685	1343	275	132	136	113	13.279	10.123	2.611
1994	1768	1426	294	139	143	128	13.298	10.275	2.485
1995	1807	1446	282	144	145	132	13.264	10.376	2.361
1996	1803	1475	255	145	147	126	13.209	10.449	2.244
1997	1907	1583	266	155	158	152	13.139	10.504	2.132
1998	1823	1522	234	149	152	129	13.035	10.514	2.035
1999	1879	1516	290	154	151	165	12.936	10.527	1.938
2000	1974	1633	282	162	162	168	12.836	10.534	1.842
2001	1846	1554	236	154	156	147	12.698	10.506	1.743
2002	1827	1521	236	154	153	153	12.517	10.436	1.643
2003	1780	1518	210	152	155	141	12.288	10.311	1.549
2004	1863	1558	236	164	163	166	12.042	10.155	1.470
2005	1825	1533	227	164	164	166	11.787	9.975	1.403
2006	1760	1486	223	161	162	167	11.544	9.770	1.370
2007	1765	1465	240	164	162	178	11.361	9.583	1.374
2008	1750	1467	237	165	165	174	11.212	9.411	1.392
2009	1753	1454	235	166	166	169	11.078	9.249	1.415
2010	1707	1426	214	164	165	153	10.979	9.117	1.441
Total	48397	41705	5107						

* Standard: Segi world standard population

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

Abbildung 2:

Relative Häufigkeit der gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung nach den häufigsten ICCC-3 Diagnose-Hauptgruppen (2001-2010) (n = 17.876)

Relative frequencies of the registered patients aged under 15 in Germany by the most common main ICCC-3 diagnosis groups (2001-2010) (n = 17,876)

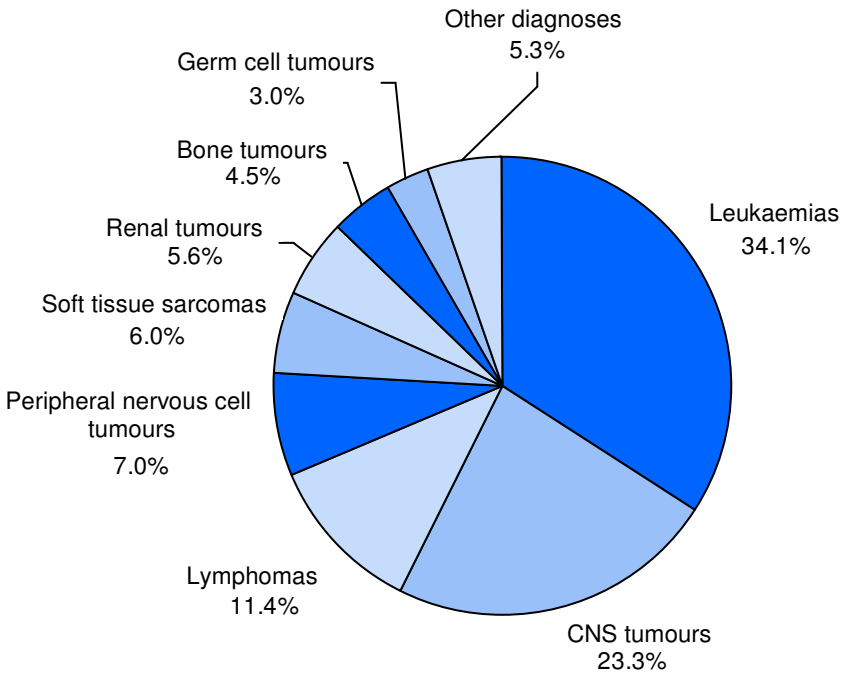


Tabelle 5:

Verteilung aller Registermeldungen aus der deutschen Wohnbevölkerung nach Altersgruppen bei Diagnosestellung ohne Altersbeschränkung* sowie zusätzlich erfasste Diagnosen (2001-2010)

Distribution of all reported cases in Germany by age groups at diagnosis without any restriction of age* and additional diagnoses (2001-2010)

Age groups (years)	Diagnoses according to ICCC-3		Additional diagnoses (see Table 2)	
	N	%	N	%
0	1856	8.6	398	26.4
1-4	6069	28.2	324	21.5
5-9	4787	22.2	306	20.3
10-14	5164	24.0	355	23.6
0-14	17876	83.0	1383	91.8
15-17	3007	14.0	109	7.2
18-19	303	1.4	9	0.6
20-24	205	1.0	5	0.3
≥25	150	0.7	1	0.1
≥15	3665	17.0	124	8.2
reported cases	21541	100.0	1507	100.0

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

Until 2008 patients were systematically registered until the age of 14; since 2009 patients are systematically registered until the age of 17. Older patients are not part of the registry population and are not representative for the German population.

Tabelle 6:

Altersstandardisierte* Inzidenzraten (pro Million), standardisierte Inzidenzverhältnisse (SIR) und 95%-Konfidenzintervalle (CI) regional gegliedert für alle Malignome der Patienten unter 15 Jahren und ausgewählte Diagnosen auf Basis des ICCC-3 (2001-2010)

Age-standardized* incidence rates (per million), standardized incidence ratios (SIR) and 95%-confidence intervals (CI) for all malignancies of patients under 15 and selected diagnoses by region based on ICCC-3 (2001-2010)

Bundesländer und Regierungsbezirke States and counties	All malignancies				Leukaemias			CNS tumours			Neuroblastomas		
	No. of cases	Incidence rate	SIR	95%-CI	Incidence rate	SIR	95%-CI	Incidence rate	SIR	95%-CI	Incidence rate	SIR	95%-CI
Schleswig-Holstein	643	158	1.00	0.92-1.08	54	0.99	0.86-1.13	35	0.97	0.82-1.14	12	0.90	0.64-1.23#
Hamburg	329	149	0.93	0.83-1.03	55	0.99	0.83-1.19	28	0.75	0.57-0.96	13	0.96	0.63-1.41#
Niedersachsen	1819	158	0.98	0.93-1.02	56	1.00	0.92-1.08	36	0.95	0.86-1.05	12	0.87	0.72-1.05#
Braunschweig	340	154	0.96	0.86-1.07	52	0.93	0.76-1.12	34	0.92	0.72-1.15	11	0.80	0.48-1.25
Hannover	469	159	0.99	0.90-1.08	58	1.05	0.89-1.22	35	0.93	0.76-1.13	11	0.85	0.56-1.24
Lüneburg	390	155	0.96	0.86-1.06	57	1.02	0.86-1.20	32	0.83	0.65-1.03	11	0.85	0.54-1.28
Weser-Ems	620	161	1.00	0.92-1.08	55	0.99	0.86-1.13	40	1.07	0.90-1.25	13	0.97	0.69-1.32
Bremen	123	148	0.92	0.77-1.10	54	0.95	0.68-1.27	40	1.13	0.79-1.58	4	0.57	0.12-1.66#
Nordrhein-Westfalen	4283	167	1.04	1.01-1.07	57	1.01	0.96-1.07	39	1.08	1.01-1.14	13	0.98	0.87-1.10#
Düsseldorf	1192	168	1.05	0.99-1.11	57	1.00	0.90-1.11	40	1.12	0.99-1.25	12	0.94	0.74-1.18
Köln	1076	172	1.08	1.02-1.15	58	1.05	0.94-1.16	41	1.15	1.02-1.30	14	1.06	0.83-1.33
Münster	651	163	1.03	0.95-1.11	60	1.10	0.96-1.25	35	0.96	0.80-1.13	12	0.94	0.67-1.28
Detmold	533	171	1.05	0.96-1.14	52	0.90	0.77-1.06	44	1.21	1.02-1.42	14	1.02	0.71-1.42
Arnsberg	832	159	1.00	0.93-1.07	55	0.98	0.87-1.11	33	0.95	0.81-1.09	12	0.93	0.70-1.22
Hessen	1369	164	1.01	0.96-1.07	57	1.02	0.93-1.11	36	0.98	0.87-1.09	15	1.13	0.93-1.37
Darmstadt	855	163	1.01	0.95-1.09	58	1.05	0.93-1.17	35	0.94	0.81-1.08	17	1.24	0.98-1.55
Gießen	256	176	1.07	0.94-1.21	62	1.05	0.84-1.30	35	1.00	0.76-1.30	13	1.09	0.63-1.78
Kassel	258	153	0.94	0.82-1.06	49	0.87	0.70-1.09	38	1.05	0.82-1.33	11	0.89	0.51-1.44
Rheinland-Pfalz	953	168	1.05	0.99-1.12	54	0.97	0.86-1.08	41	1.14	1.00-1.30	16	1.18	0.92-1.48
Koblenz	352	164	1.02	0.92-1.13	60	1.03	0.86-1.24	39	1.07	0.85-1.32	11	0.92	0.55-1.44
Trier	132	182	1.14	0.96-1.35	62	1.15	0.84-1.53	36	1.00	0.66-1.45	23	1.73	0.92-2.96
Rheinhessen-Pfalz	469	168	1.05	0.96-1.15	48	0.87	0.73-1.03	44	1.24	1.04-1.47	18	1.33	0.95-1.82

Tabelle 6 Forts. **Table 6 cont.**

Bundesländer und Regierungsbezirke States and counties	All malignancies				Leukaemias			CNS tumours			Neuroblastomas		
	No. of cases	Incidence rate	SIR	95%-CI	Incidence rate	SIR	95%-CI	Incidence rate	SIR	95%-CI	Incidence rate	SIR	95%-CI
Baden-Württemberg	2444	157	0.97	0.94-1.01	54	0.97	0.91-1.04	36	0.97	0.89-1.05	13	0.98	0.84-1.14#
Stuttgart	904	154	0.96	0.90-1.02	56	1.01	0.90-1.13	36	0.98	0.85-1.12	12	0.91	0.69-1.17
Karlsruhe	625	167	1.03	0.95-1.11	52	0.93	0.80-1.07	40	1.08	0.92-1.27	16	1.18	0.87-1.56
Freiburg	482	147	0.93	0.85-1.02	54	0.99	0.85-1.15	34	0.94	0.77-1.13	10	0.73	0.48-1.08
Tübingen	434	160	0.98	0.89-1.08	54	0.94	0.79-1.11	31	0.84	0.68-1.04	16	1.24	0.87-1.71
Bayern	2783	156	0.97	0.94-1.01	57	1.02	0.95-1.08	32	0.87	0.80-0.94	14	1.06	0.92-1.22
Oberbayern	890	148	0.92	0.86-0.98	55	0.98	0.88-1.09	25	0.68	0.57-0.79	16	1.24	0.99-1.53
Niederbayern	263	153	0.94	0.83-1.07	56	0.96	0.77-1.18	36	0.98	0.76-1.26	8	0.70	0.36-1.22
Oberpfalz	263	170	1.04	0.92-1.18	60	1.04	0.84-1.28	44	1.21	0.94-1.52	11	0.85	0.46-1.42
Oberfranken	245	162	1.02	0.90-1.16	53	0.98	0.77-1.22	33	0.89	0.66-1.18	17	1.25	0.77-1.94
Mittelfranken	313	133	0.83	0.74-0.92	48	0.87	0.72-1.05	28	0.71	0.55-0.91	12	0.91	0.58-1.36
Unterfranken	323	168	1.07	0.95-1.19	67	1.19	0.99-1.42	43	1.24	1.00-1.53	14	1.12	0.68-1.73
Schwaben	486	180	1.13	1.04-1.24	65	1.17	1.00-1.36	31	0.88	0.71-1.08	14	1.10	0.75-1.55
Saarland	218	166	1.04	0.91-1.19	53	0.99	0.77-1.25	53	1.42	1.11-1.80	10	0.83	0.40-1.52
Berlin	600	147	0.92	0.85-0.99	57	1.02	0.90-1.16	28	0.77	0.63-0.92	12	0.88	0.63-1.18
Brandenburg	445	159	0.99	0.90-1.09	62	1.11	0.95-1.29	36	0.99	0.81-1.20	14	1.09	0.75-1.52
Mecklenburg-Vorpommern	290	157	0.97	0.86-1.09	50	0.89	0.71-1.09	41	1.15	0.91-1.43	16	1.22	0.80-1.78
Sachsen	766	168	1.05	0.98-1.13	53	0.95	0.84-1.08	47	1.28	1.12-1.47	13	1.01	0.76-1.31
Chemnitz	275	164	1.03	0.91-1.16	51	0.92	0.74-1.14	46	1.24	0.98-1.55	13	0.99	0.59-1.54
Dresden	301	163	1.03	0.91-1.15	47	0.85	0.68-1.05	53	1.47	1.20-1.79	15	1.11	0.72-1.64
Leipzig	190	180	1.11	0.96-1.28	65	1.18	0.92-1.49	37	1.01	0.72-1.38	12	0.93	0.48-1.62
Sachsen-Anhalt	418	162	1.02	0.92-1.12	57	1.02	0.86-1.20	41	1.13	0.93-1.36	12	0.98	0.64-1.42
Thüringen	391	159	0.99	0.89-1.09	56	1.00	0.84-1.18	37	1.01	0.81-1.24	18	1.37	0.98-1.87

Mit den Jahren 2000, 2004, 2005 und 2008 wurden in Rheinland-Pfalz, Sachsen-Anhalt, Niedersachsen und Sachsen die Regierungsbezirke abgeschafft. Die neu geschaffenen Direktionen, außer in Sachsen-Anhalt, behalten jedoch die räumliche Einteilung bei.
Since 2000, 2004, 2005 and 2008 Rhineland-Palatinate, Saxony-Anhalt, Lower Saxony and Saxony are no longer separated into Regierungsbezirke. The new Direktionen-structure, except in Saxony-Anhalt, however, follows the same borders.

* Standard: Segi world standard population

\# Inzidenzrate möglicherweise aufgrund einer Screeningmaßnahme in den Jahren 1995-2001 tendenziell erhöht. / Inicidence rate may be above average due to a screening project in 1995-2001.

Tabelle 7:

Anzahl der verstorbenen Patienten innerhalb von 5 bzw. 10 Jahren nach Diagnose auf Basis des ICCC-3 unter den gemeldeten Patienten unter 15 Jahren aus der deutschen Wohnbevölkerung und alterstandardisierte Mortalitätsraten nach Diagnosejahr, 1980-2005 (inklusive neue Länder seit 1991)

Annual number of deaths 5 or 10 years from diagnosis based on ICCC-3 from the group of registered cases aged under 15 in Germany and age standardized mortality rates by year of diagnosis 1980-2005 (including East Germany since 1991)

Year of diagnosis	Deaths within 5 years after diagnosis		Deaths within 10 years after diagnosis	
	No. of cases	Mortality rate per million*	No. of cases	Mortality rate per million*
1980	350	35	378	38
1981	343	33	378	36
1982	314	33	349	37
1983	319	34	359	39
1984	326	36	355	39
1985	324	36	365	40
1986	320	37	355	41
1987	330	38	355	41
1988	318	37	350	40
1989	293	33	326	36
1990	325	35	354	38
1991 #	399	32	444	35
1992 #	437	34	473	37
1993 #	383	30	428	34
1994 #	374	29	409	32
1995 #	338	27	384	30
1996 #	349	28	386	31
1997 #	372	30	416	33
1998 #	350	28	391	31
1999 #	358	29	395	31
2000 #	392	32	425	35
2001 #	300	25		
2002 #	321	27		
2003 #	321	27		
2004 #	287	25		
2005 #	289	26		

* Standard: Segi world standard population

\# Including East Germany since 1991

Tabelle 8:

Anzahl der am Deutschen Kinderkrebsregister in der Langzeitnachbeobachtung befindlichen Patienten mit Erstdiagnose im Alter von unter 15 (Stand 2010) *

Number of patients in Long-Term-Surveillance (LTS) at the German Childhood Cancer Registry first diagnosed aged < 15 (as of 2010) *

Year of diagnosis	1980 - 1989	1990 - 1999	2000 - 2009	2010	1980 - 2010
	N (%)	N (%)	N (%)	N (%)	N (%)
Patients registered	**11008**	**17252**	**17894**	**1683**	**47837** #
deceased	3806 (34.6 %)	4117 (23.9 %)	2750 (15.4 %)	51 (3.0 %)	10724 (22.4 %)
surviving	**7202 (65.4 %)**	**13135 (76.1 %)**	**15144 (84.6 %)**	**1632 (97.0 %)**	**37113 (77.6 %)**
anonymous +	970 (13.5 %)	1098 (8.4 %)	406 (2.7 %)	16 (1.0 %)	2490 (6.7 %)
identifiable	**6232 (86.5 %)**	**12037 (91.6 %)**	**14738 (97.3 %)**	**1616 (99.0 %)**	**34623 (93.3 %)**
< 5 years since diagnosis	-	-	5042 (34.2 %)	1616 (100 %)	6658 (19.2 %)
>= 5 years since diagnosis	**6232 (100 %)**	**12037 (100 %)**	**9696 (65.8 %)**	**-**	**27965 (80.8 %)**
lost-to-follow-up	566 (9.1 %)	566 (4.7 %)	108 (1.1 %)	-	1240 (4.4 %)
in LTS	**5666 (90.9 %)**	**11471 (95.3 %)**	**9588 (98.9 %)**	**-**	**26725 (95.6 %)**

* Modified based on [41]

47837 Patients correspond to 48397 cases diagnosed under 15 years resident in Germany at the date of diagnosis 1980-2010 and diagnosed with a disease included in ICCC-3

\- no data yet

\+ Consent not available, refused or withdrawn later

Tabelle 9:

Zahl der vom Deutschen Kinderkrebsregister an die jeweiligen Landeskrebsregister (LKR) bis einschließlich 2010 weitergeleiteten Meldungen

Number of forwarded reports from the German Childhood Cancer Registry to the state cancer registries (LKR) up to and including 2010

State cancer registry	Diagnosis period from	to	Cases
Krebsregister Schleswig-Holstein	11.03.2002	01.11.2010	512
Hamburgisches Krebsregister	09.02.2004	01.11.2010	244
Epidemiologisches Krebsregister Niedersachsen	01.01.2002	01.11.2010	1278
Bremer Krebsregister	09.01.2004	01.11.2010	79
Epidemiologisches Krebsregister NRW +	01.01.1998	01.11.2010	3138
Hessisches Krebsregister	11.03.2002	01.11.2010	839
Krebsregister Rheinland-Pfalz	01.01.2002	01.11.2010	635
Bevölkerungsbezogenes Krebsregister Bayern	01.01.2002	01.11.2010	1649
Epidemiologisches Krebsregister Saarland	01.12.2004	01.11.2010	143
Gemeinsames Krebsregister GKR *	01.01.2004	01.11.2010	1722
Gesamt			**10239**

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

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

Anmerkung/Note:

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

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Tabelle 11 / Table 11

Neues zu Forschungsprojekten / News on Research Projects

Tabelle 10:

Forschungsprojekte und internationale Kooperationsprojekte seit 2009 (see Table 11 for the English version)

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
Zweitmalignome nach Krebs im Kindesalter: Fall-Kontroll-Studie zu den Risikofaktoren für das Entstehen von sekundären malignen Neoplasien	Fall-Kontroll-Studie	8, 22	DKKR	ja	Bundesministerium für Bildung und Forschung (Kompetenznetzförderung)
ACCIS: Automated Childhood Cancer Information System	Internationale Datenbank	13	IARC, Lyon, Frankreich	nein	-
EUROCARE: Survival of cancer patients in Europe	Follow-up Studie	21	Istituto Nazionale dei Tumori, Mailand, Italien	nein	-
Strukturoptimierung zur Gewährleistung einer qualitätsgesicherten Langzeitbeobachtung ehemaliger pädiatrisch-onkologischer Patienten	Strukturelles Projekt	10, 16, 28, 34, 35, 39, 41	DKKR	ja	Deutsche Kinderkrebsstiftung (Anschubfinanzierung)
KiKK: Epidemiologische Studie zu Kinderkrebs in der Nähe von Kernkraftwerken	Fall-Kontroll-Studie	17, 18, 19, 25	DKKR	ja	Bundesministerium für Umwelt, Naturschutz und Reaktorsicherheit über das Bundesamt für Strahlenschutz

Tabelle 10 Forts. Table 10 cont.

Projektbezeichnung	Studientyp	Literatur	Projektleitung	Eingeworbene Finanzmittel am DKKR/IMBEI	Fördernde Institution
Befragungsprojekte ehemaliger Kinderkrebspatienten in Zusammenarbeit zwischen externen Kooperationspartnern und dem DKKR	Registerbasierte Umfragen	20, 23, 26, 27, 29, 30, 31, 32, 33, 38, 40	DKKR; Uni.-Klinik Ulm; Otto-Heubner-Zentrum für Kinder- und Jugendmedizin Berlin; Zentrum für Kinder- und Jugendmedizin Giessen; Uni. Erlangen;BIOGUM, Uni. Hamburg	vom externen Kooperationspartner mitfinanziert	Deutsche Kinderkrebsstiftung, Deutsche Krebshilfe, Eigenmittel der ext. Kooperationspartner, 6. EU-FRP "ACGT-Advancing Clinico-Genomic Clinical Trials on Cancer"
PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies (PanCareSurFup) im Rahmen des PanCare Netzwerkes	Internationales Netzwerk		Gesamtleitung: Lund University Hospital, Schweden; Leitung Work-package 1 (Data Collection and Harmonization): DKKR	ja	Europäische Kommission EU FP7
GENKIK: Systematische Expressionsanalyse von DNA-Reparaturgenen bei kindlichen Malignomerkrankungen	Fall-Kontroll-Studie	37	DKKR, IMBEI, Institut für Humangenetik der Universitätszsmedizin Mainz	ja	Stiftung Rheinland-Pfalz für Innovation
Todesursachenuntersuchung und Validierung von Zweittumoren auf Basis der regelmäßigen Statusabfrage früherer pädiatrisch onkologischer Patienten	Strukturelles Projekt		DKKR	ja	Deutsche Kinderkrebsstiftung
Kinderkrebsrisiko nach Exposition durch computertomographische Untersuchungen im Kindesalter - KiCT	Kohortenstudie	36, 42	IMBEI	ja	Bundesministerium für Bildung und Forschung

IMBEI: Institut für Medizinische Biometrie, Epidemiologie und Informatik

DKKR: Deutsches Kinderkrebsregister

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

Tabelle 11

Research projects and international cooperations since 2009 (see table 10 for the German version)

Name of the project	Type of study	References
Second malignant neoplasms after childhood cancer: Risk factors for the development of second malignant neoplasms	Case-Control Study	8, 22
ACCIS: Automated Childhood Cancer Information System	International data base on childhood cancer	13
EUROCARE: Survival of cancer patients in Europe	Follow-up Study	21
Improving the structure of long-term surveillance of former childhood cancer patients	Structural project	10, 16, 28, 34, 35, 39, 41
KiKK: Epidemiological study on childhood cancer in the vicinity of nuclear power plants	Case-Control Study	17, 18, 19, 25
Survey-projects on former childhood cancer patients in cooperation between external cooperation partners and the German Childhood Cancer Registry	Registry-based study	20, 23, 26, 27, 29, 30, 31, 32, 33, 38, 40
PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies (PanCareSurFup) within the PanCare Network	International network	
GENKIK: Systematische Expressionsanalyse von DNA-Reparaturgenen bei kindlichen Malignomerkrankungen	Case-Control Study	37
Cause of death investigation and second neoplasia validation connected to the German Childhood Cancer Registries regular core data survey from former paediatric oncology	Structural project	
Risk of childhood cancer after computed tomography in childhood (KiCT)	Kohortenstudie	36, 42

ACCIS und EUROCARE

In ACCIS, einem europäischen Projekt wurden bis 1997 die Daten sämtlicher bevölkerungsbezogenen Krebsregister zu Kindern und Jugendlichen in Europa in Bezug auf Inzidenz und Überlebenswahrscheinlichkeiten zusammengeführt (13). Derzeit werden die Daten für eine aktualisierte Fassung mit Daten bis 2008 bei der IARC (International Agency for Research on Cancer) gesammelt.

Das **EUROCARE**-Projekt ist ein von der EU finanziertes Projekt, das Ende der achtziger Jahre begann und in dem Überlebenswahrscheinlichkeiten bei Krebspatienten im internationalen Vergleich und unter Berücksichtigung zeitlicher Trends systematisch und umfassend analysiert werden. Zuletzt wurden die Daten der EUROCARE-4-Studie, die die Jahre bis 2002 abdeckt, publiziert (21). Derzeit werden die Datensätze für EUROCARE-5 vorbereitet.

Das Deutsche Kinderkrebsregister trägt zu beiden Projekten seine Daten bei.

ACCIS and EUROCARE

The European project **ACCIS,** collected all data from all European population based registries with data on children and adolescents with respect to incidence and survival probabilities. They published the data available until 1997. (13). Currently data is being collected at IARC (International Agency for Research on Cancer) for an updated version until 2008.

EUROCARE is an EU funded project, founded in the late 1980ies, which aims at comparing and analyzing international survival data on cancer patients. Regarding children, the latest published data from EUROCARE-4 covers the years until 2002 (21). Currently data sets for EUROCARE-5 are being prepared.

The German Childhood Cancer registry contributes its data to both projects.

Strukturoptimierung zur Gewährleistung einer qualitätsgesicherten Langzeitnachbeobachtung ehemaliger pädiatrisch-onkologischer Patienten

Mit der Zunahme an Langzeitüberlebenden nach Krebs im Kindesalter treten Fragen zu möglichen Spätfolgen oder zur Lebensqualität und Lebenssituation immer mehr in den Vordergrund. Studien unter Einbeziehung von Langzeitüberlebenden erhalten, auch im internationalen Kontext, einen immer höheren Stellenwert. Das Deutsche Kinderkrebsregister investiert neben der Aufnahme und Speicherung neuer Krebserkrankungsfälle bei Kindern bis zum Alter von 17 Jahren somit zunehmend Arbeitsaufwand in die Langzeitnachbeobachtung ehemals pädiatrisch-onkologischer Patienten (10).

Das Ziel des von der Deutschen Kinderkrebsstiftung geförderten Projektes „Strukturoptimierung zur Gewährleistung einer qualitätsgesicherten Langzeitnach-beobachtung ehemaliger pädiatrisch-onkologischer Patienten“ war es, Aussagen zur Qualität (z.B. Vollständigkeit, Response) der Langzeitnach-beobachtung in der deutschen pädiatrischen Onkologie und Hämatologie aufgrund der am Deutschen Kinderkrebsregister (DKKR) dazu etablierten Strukturen zu machen (16). Die am Deutschen Kinderkrebsregister bestehenden Strukturen zur Durchführung der Langzeitbeobachtung konnten vor allem durch diese Projektfinanzierung strukturell und qualitativ deutlich ausgebaut werden.

Das DKKR aktualisiert durch Kontaktaufnahme mit Eltern und Patienten kontinuierlich Minimalinformationen zum Gesundheitszustand (unter anderem Spätrezidive, sekundäre Neoplasien, die aktuelle Anschrift) und tauscht diese Informationen regelmäßig mit den entsprechenden Therapieoptimierungsstudien aus.

Improving the structure of long-term surveillance of former childhood cancer patients

As the number of long-term survivors of childhood cancer increases, questions concerning late effects, quality of life, and living-circumstances become more and more prevalent. Studies on long-term survivors are gaining increasing interest, nationally and internationally. On top of the routine registration and storage of all new cases until the age of 17, the GCCR dedicates an increasing amount of time to the long-term follow-up of former paediatric oncology patients (10).

The objective of this project „Improving the structure of long-term surveillance of former childhood cancer patients“ was to provide information about the quality (e.g. completeness, response) of long-term surveillance in German paediatric oncology and haematology based on the structures implemented by the German Childhood Cancer Registry (GCCR) (16). This extension, with respect to structure and to quality, was enabled by the financial support within the competence network Paediatric Oncology and by the German Children’s Cancer Foundation.

The GCCR contacts parents or patients to collect and update information on a minimal set of follow-up health status data (e.g. late relapses, subsequent neoplasms, current address) and exchanges this information regularly with the appropriate clinical trials.

Zwischen 2006 und 2010 wurden insgesamt circa 20.000 Patienten im Rahmen der Langzeitnachbeobachtung durch das DKKR kontaktiert (erste persönliche Kontaktaufnahme im Alter von 16 Jahren sowie generelle Anfragen zum Gesundheitszustand). 11.000 aktuelle Adressen der ehemaligen Patienten wurden dazu über Einwohnermeldeämter recherchiert. Die Rücklaufraten lagen zwischen 56% bis 68%, die Recherchen bei Einwohnermeldeämtern erbrachten zu 93 bis 96% valide aktuelle Adressen. Von den 46.115 zwischen 1980 und 2009 diagnostizierten Patienten befinden sich im Jahr 2010 25.283 in der Langzeitnachbeobachtung (35, 39, 41).

Um die Aktualisierung minimaler Informationen regelmäßig zu gewährleisten, ist ein hoher logistischer Aufwand mit jährlichem Versand tausender Briefe erforderlich. Die Langzeitnachbeobachtung ist unverzichtbar um ein besseres Verständnis der Spätfolgen, sekundären Neoplasien und der Lebensqualität von ehemals an Krebs erkrankten Kindern zu entwickeln und um in der Lage zu sein, ehemalige Patienten in Studien zu Spätfolgen adäquat einbeziehen zu können (28, 34).

Between 2006 and 2010, GCCR approached a total of about 20,000 patients (contact at the age of 16 years, inquiry concerning the health status) in the context of long-term surveillance. 11,000 addresses of former patients had to be researched via municipal registrar's offices. The response rates ranged from 56% to 68%, the research in municipal offices provided 93% to 96% valid addresses. Of 46,115 patients diagnosed between 1980 and 2009, 25,283 are in long-term surveillance in 2010 (35, 39, 41).

Long-term surveillance requires considerable logistic effort at GCCR and requires that thousands of letters be mailed each year in order to ensure regularly updated information. Long-term surveillance is indispensable for a better understanding of late effects, subsequent neoplasms and quality of life of former childhood cancer patients. It is a prerequisite enabling researchers to include former patients adequately in late effects studies (28, 34).

Befragungsprojekte ehemaliger Kinderkrebspatienten in Zusammenarbeit zwischen externen Kooperationspartnern und dem DKKR

Ehemalige Krebspatienten im Kindes- und Jugendalter werden über das Deutsche Kinderkrebsregister (DKKR) kontaktiert, welches hierzu eine umfassende Struktur, Logistik und epidemiologische Beratungskompetenz bereitstellt. Im Rahmen von Befragungsprojekten zu unterschiedlichen Schwerpunktthemen arbeitet das DKKR mit kooperierenden Ärzten und Wissenschaftlern anderer Fachrichtungen zusammen. Einige Projekte externer Kooperationspartner mit dem DKKR wurden in den letzten Jahren abgeschlossen.

„Psychosoziale Adaptation langzeitüberlebender onkologischer Patienten nach Erkrankung in der Adoleszenz“ (Herr Prof. Lutz Goldbeck, Universitätsklinik für Kinder- und Jugendpsychiatrie/ Psychotherapie, Ulm) (20, 23, 26, 27, 29, 30, 31, 32, 33)

„Fertilität nach Chemo- und Strahlentherapie im Kindes- und Jugendalter (FeCt)“ (Frau Dr. Anja Borgmann-Staudt, Otto-Heubner-Centrum für Kinder- und Jugendmedizin, Klinik für Pädiatrie m. S. Onkologie/Hämatologie, Charité, Berlin) (38, 40)

„Familiäre Prädisposition für Non-Hodgkin-Lymphome im Kindes- und Jugendalter“ (Herr Prof. Alfred Reiter, Zentrum für Kinder- und Jugendmedizin, Abt. Päd. Hämatologie und Onkologie, NHL-BFM Studienzentrale, Giessen)

„Endokrinologische Begleituntersuchung und Spätfolgen nach Behandlung innerhalb der Hirntumorstudie HIT´91“ (Herr Prof. H.-G. Dörr, Kinder- und Jugendklinik der Universität Erlangen, Schwerpunkt Endokrinologie und Diabetologie, Erlangen)

Survey-projects on former childhood cancer patients in cooperation between external cooperation partners and the German Childhood Cancer Registry

Former cancer patients are contacted for surveys by the GCCR, which provides the necessary structures, logistics and epidemiologic counselling. Such cooperative surveys are initiated by physicians and scientists from a broad range of faculties. We are listing a number of projects recently concluded and currently being published.

„Psychosoziale Adaptation langzeitüberlebender onkologischer Patienten nach Erkrankung in der Adoleszenz“ (Herr Prof. Lutz Goldbeck, Universitätsklinik für Kinder- und Jugendpsychiatrie/ Psychotherapie, Ulm) (20, 23, 26, 27, 29, 30, 31, 32, 33)

„Fertilität nach Chemo- und Strahlentherapie im Kindes- und Jugendalter (FeCt)“ (Frau Dr. Anja Borgmann-Staudt, Otto-Heubner-Centrum für Kinder- und Jugendmedizin, Klinik für Pädiatrie m. S. Onkologie/Hämatologie, Charité, Berlin) (38, 40)

„Familiäre Prädisposition für Non-Hodgkin-Lymphome im Kindes- und Jugendalter“ (Herr Prof. Alfred Reiter, Zentrum für Kinder- und Jugendmedizin, Abt. Päd. Hämatologie und Onkologie, NHL-BFM Studienzentrale, Giessen)

„Endokrinologische Begleituntersuchung und Spätfolgen nach Behandlung innerhalb der Hirntumorstudie HIT´91“ (Herr Prof. H.-G. Dörr, Kinder- und Jugendklinik der Universität Erlangen, Schwerpunkt Endokrinologie und Diabetologie, Erlangen)

„Einstellungen und Erwartungen von Eltern erkrankter Kinder zu Krebsforschung und Datenschutz“ (Prof. Dr. Regine Kollek und Dr. Imme Petersen, FSP BIOGUM, Forschungsgruppe Technologiefolgenabschätzung der modernen Biotechnologie in der Medizin, Hamburg)

PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies (PanCareSurFup) im Rahmen des PanCare Netzwerkes (EU Projekt)
www.pancare.eu/en/
www.pancaresurfup.eu/

Im Anschluss an das ESLCCC 2007-Meeting (European Symposium on Late Complications After Childhood Cancer) in Lund (Schweden) begannen die Planungen für ein pan-europäisches Netzwerk, welches alle Aspekte der Langzeitbeobachtung ehemaliger Krebspatienten im Kindes- und Jugendalter umfassen sollte. Im März 2008 wurde PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) in Lund bei einem Gründungstreffen, an dem 26 Ärzte und Wissenschaftler aus 14 Ländern teilnahmen, ins Leben gerufen.

Nach mittlerweile zehn Meetings umfasst das PanCare-Netzwerk einige hundert Mitglieder aus über 25 Ländern. Das Netzwerk besteht aus Mitgliedern aus den Bereichen der Pädiatrischen Onkologie, der Epidemiologie, der Radioonkologie, der Psychologie, der Pädiatrischen Neurologie, der Pädiatrischen Endokrinologie, ehemaligen Patienten und Elternvertretern. PanCare ist Partner eines erfolgreich gestellten Health-2010 Forschungsantrag für ein „Exzellenznetzwerk der pädiatrischen und adoleszenten Onkologie“ des 7. Forschungsrahmenprogrammes der von SIOP-E (Europäische Gesellschaft für Pädiatrische Onkologie) an die Europäische Kommission gestellt wurde. Das PanCare-Netzwerk war ebenfalls erfolgreich in der Beantragung eines eigenen EU-Projektes zur Vorhersage von Spätfolgen nach einer Krebserkrankung im Kindes- und Jugendalter. Das erste EU-geförderte Projekt des PanCare-Netzwerkes mit dem Namen PanCareSurFup (PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies) läuft seit Februar 2011 (Förderzeitraum: 5 Jahre). Es umfasst 16 Partner. Weitere Projekte im Rahmen von PanCare befinden sich in Planung.

Im Rahmen dieser Verbund-Forschung sollen Richtlinien entwickelt werden, um die Nachsorge ehemaliger Patienten zu optimieren und eine Grundlage für forschungsbezogene Informationen, die alle Spätfolgen der Krebstherapie betreffen, bereitzustellen. Das Deutsche Kinderkrebsregister leitet eines der acht Arbeitspakete innerhalb von PanCareSurfUp („Data collection and harmonization“). Eine große Europäische Kohorte von etwa 80.000 ehemaligen Patienten mit einer Krebserkrankung im Kindes- und Jugendalter soll aufgebaut, nachbeobachtet und mögliche Spätfolgen erfasst werden. Nach der Erarbeitung des Studien-protokolls läuft derzeit die Datensammlung. Zu den

„Einstellungen und Erwartungen von Eltern erkrankter Kinder zu Krebsforschung und Datenschutz“ (Prof. Dr. Regine Kollek und Dr. Imme Petersen, FSP BIOGUM, Forschungsgruppe Technologiefolgenabschätzung der modernen Biotechnologie in der Medizin, Hamburg)

PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies (PanCareSurFup) within the PanCare Network (EU project
www.pancare.eu/en/
www.pancaresurfup.eu/

Following ESLCCC 2007 (European Symposium on Late Complications after Childhood Cancer) in Lund (Sweden) several participants began planning for a pan-European network to address all aspects of childhood and adolescent cancer survivorship. In March 2008, PanCare (Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer) was founded in Lund, Sweden at a meeting attended by 26 doctors and scientists from 14 European countries.

Up to now, the network held 7 meetings and is supported by 200 members from 25 countries. Members come from paediatric oncology, epidemiology, radio oncology, psychology, paediatric neurology, paediatric endocrinology, or they are former patients or parent representatives. PanCare is a partner of the successful application in Health-2010 „Network of Excellence in paediatric and adolescent oncology“, which SIOP-E (European Society for Paediatric Oncology) applied for in FP7 of the European Commission. The PanCare network also successfully applied for its own EU-project on predicting late effects of childhood cancer. The first EU-project within the PanCare-network, called, PanCareSurFup (PanCare Childhood and Adolescent Cancer Survivor Care and Follow-up Studies) starts in February 2011. It consists of 16 partners.

This research network aims at developing guidelines for long-term care of former patients. It will provide a basis for research in late effects of cancer therapy. The Germany Childhood Cancer Registry heads on of the work packages within PanCareSurfUp („Data collection and harmonization“). We assemble a cohort of about 80.000 former childhood and adolescent patients, follow them and register late effects. The late effects in question are subsequent neoplasias, cardiac late effects and late deaths (more than 5 years after diagnosis).

Spätfolgen die in dem Projekt untersucht werden, zählen das Auftreten von Zweittumoren, Herzschädigungen und das Versterben der Patienten mehr als fünf Jahre nach der Erkrankung.

Die Ziele von PanCare sind mit der Europäischen Gemeinschaft zusammen zu arbeiten, um die Nachsorge ehemaliger Patienten durch die Entwicklung von Richtlinien und bereitgestellter Aufklärung und Informationen zu steigern, Verbundforschung zu betreiben und eine Grundlage für forschungsbezogene Informationen, die alle Spätfolgen der Krebstherapie betreffen, bereitzustellen. Das langfristige strategische Ziel von PanCare ist es sicherzustellen, dass jeder europäische ehemalige Patient einer Krebserkrankung im Kindes- und Jugendalter eine optimale Langzeit-nachsorge erhält.

PanCare's aims are to work with the European Community to improve care for survivors by developing guidelines and providing education, to perform collaborative research, and to be a resource for research-based information concerning all late side-effects of cancer treatment. The long-term strategic aim of PanCare is to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care.

Kinderkrebsrisiko nach Exposition durch computertomographische Untersuchungen im Kindesalter (KiCT)

Aus radiologischen Patientenakten soll eine historische Kohorte von kindlichen Patienten erstellt werden, die vor der Vollendung des 15. Lebensjahres mindestens eine computertomographische (CT) Untersuchung hatten. Die individuelle Strahlenexposition wird aus Datenbeständen klinischer, radiologischer Institute bestimmt. Durch einen Abgleich mit dem Deutschen Kinderkrebsregister werden die an Krebs neu erkrankten Kinder identifiziert. Mittels interner und externer Vergleiche wird das durch die Strahlendosis verursachte Krebsrisiko geschätzt (36, 42).

Risk of childhood cancer after computed tomography in childhood (KiCT)

We are construction a historic cohort of children exposed to at least one computed tomography examination (CT) before their 15th birthday from hospital records. The individual exposure is estimated from the data of the clinical radiology departments. We match this data with the German Childhood Cancer registry identifying incident cases in the cohort. On this basis we estimate the cancer risk attributable to radiation dose (36, 42).

Datengrundlage, Methoden und Ergebnisdarstellung

Rechtliche Grundlagen und Finanzierung des Registers

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

Die behandelnden Ärzte melden unentgeltlich und auf freiwilliger Basis. Aufgrund dieser Voraussetzungen war durch das Inkrafttreten des Krebsregistergesetzes des Bundes (1.1.1995) und der diversen Landeskrebsregistergesetze eine Änderung in der Verfahrensweise zur systematischen Erfassung der Erkrankungsfälle nicht erforderlich.

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

Charakterisierung des Registers

Das Register ist seit dem Beginn 1980 am Institut für Medizinische Biometrie, Epidemiologie und Informatik (IMBEI) (vormals Institut für Medizinische Statistik und Dokumentation (IMSD)) der Universitätsmedizin der Johannes Gutenberg-Universität Mainz angesiedelt und kooperiert mit der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) und den behandelnden Kliniken. Es ist dadurch charakterisiert, dass es neben den üblichen, in einem bevölkerungs-bezogenen Krebsregister erfassten Daten auch eine ganze Reihe klinischer 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 (klinische Studien) der GPOH. Da der Anteil der in eine der klinischen Studien aufgenommenen Patienten mit über 90% sehr hoch ist, kommt diesem Aspekt der integrierten Dokumentation eine ganz wesentliche Bedeutung zu.

Ein weiteres Charakteristikum des Kinderkrebsregisters ist die Realisierung einer aktiven, zeitlich unbefristeten Langzeitnachbeobachtung. Damit stellt das Register die

Basis of Registration, Methods and Presentation

Legal basis and financial support

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

The treating physicians report patients for free and voluntarily. Because of this a change of procedure was not necessary when the federal cancer registry law (1.1.1995) and the state registry laws came into effect.

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

Characterization of the registry

The registry was established at the Institute for Medical Biostatistics, Epidemiology and Informatics (IMBEI) (previously Institute for Medical Statistics and Documentation (IMSD)) of the Universitätsmedizin at the Johannes Gutenberg-University Mainz. It co-operates with the scientific society for paediatric oncology and haematology (GPOH) and the treating hospitals. The registry is a population based registry combined with some features of a clinical registry, registering also clinical details such as staging, grading, and immunological subtypes (5). The clinical information is based on the integrated information exchange and data flow between the ca. 25 GPOH organized therapy optimization trials and the GCCR. This is of special importance because more than 90% of all patients are included in these trials.

The registry is also characterized by an active open end long-term follow-up of all registered patients. This is the basis for research on late effects as e.g.second neoplasms.

Grundlage für die Erforschung von Spätfolgen, wie z.B. Zweitneoplasien, bereit.

Dokumentationsablauf und Datenfluss

Von den kooperierenden Kliniken wird jeweils bei Auftreten einer Neuerkrankung ein kurzer Meldebogen an das Register geschickt (DKKR-Erstmeldung). Er enthält u.a. die Verdachtsdiagnose, wesentliche Identifikationsmerkmale, die Bestätigung der Einwilligung zu der Meldung durch Patient und/oder Sorgeberechtigte und die Information, ob und an welcher klinischen Therapieoptimierungsstudie der Patient teilnimmt. Daraufhin wird vom Register an die Klinik ein diagnosespezifischer Erhebungsbogen verschickt. Mit diesen mit den Leitern der Therapieoptimierungsstudien abgestimmten Bögen werden Einzelheiten der klinischen Diagnose und der Therapie erfasst. Im Fall einer Studienteilnahme werden die ausgefüllten Bögen von der Klinik direkt an die Studienleitung geschickt. Die Weiterleitung entsprechend validierter diagnostischer Detail-Informationen von der Therapiestudienleitung an das Deutsche Kinderkrebsregister erfolgt anschließend, meist elektronisch, in regelmäßigen Intervallen. Bis auf vereinzelte Ausnahmen sind alle Diagnosen histologisch oder immunologisch verifiziert.

Bis zum Abschluss der primären Therapiephase und im Verlauf der Nachsorge erfolgt normalerweise eine regelmäßige Nachbeobachtung durch die Therapie-Studienleitung. Anschließend erfolgt dies durch das Deutsche Kinderkrebsregister, wobei diese die Daten jeweils untereinander austauschen. Das Kinderkrebsregister erhält Nachbeobachtungs-Informationen aus mehreren Quellen: der Klinik (solange der Patient noch in der Nachsorge ist), Einwohnermeldeämtern (im Rahmen von Adressrecherchen), gegebenenfalls Landeskrebsregistern und nicht zuletzt in zunehmendem Maße von den Patienten selbst. Der Dokumentationsablauf und die Synergieeffekte zwischen Therapieoptimierungsstudien und Kinderkrebsregister sind in (4, 5, 9) beschrieben. Die Langzeitnachbeobachtung ist in (10, 16, 35, 39, 41) publiziert.

Datengrundlage

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

Die Klassifizierung der Erkrankungen erfolgt nach der International Classification of Childhood Cancer 3rd edition (ICCC-3) (11). Sie basiert auf einer Zusammenfassung entsprechender Morphologien und Topographien, codiert

Documentation and flow of information

After admission of a newly diseased individual to one of the co-operating hospitals, a notification form is sent to the registry. This contains patient identification data, a confirmation of consent to the registration, a tentative diagnosis and information on whether this patient will be included in one of the ongoing therapy optimization trials. In response to this notification, the registry sends a set of tumour-specific basic documentation forms to the cooperating clinician. For patients included in the therapy optimization trials, this basic documentation is to be returned directly to the relevant trial centre. The centres regularly provide the GCCR with validated diagnostic information, usually annually in electronic form. With few exceptions all diagnoses are histologically or immunologically verified.

Tumour-specific follow-up information is usually provided until the end of the first clinical treatment phase and during clinical follow-up. After this, further follow-up is conducted by the GCCR, regularly exchanging this information with the therapy trials. The GCCR collects data from various sources, such as the hospitals, state cancer registries, municipalities, and last but not least the patients themselves. This flow of information is described in (4, 5), the follow-up procedures are published in (16, 35).

Data basis

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

Classification of diseases is based on the International Classification of Childhood Cancer 3rd edition (ICCC-3) (11). The ICCC-3 is an aggregation of morphology and topography codes based on ICD-O-3 (6), included at the

jeweils nach der ICD-O-3 (6), und ist am Ende des Berichts wiedergegeben. Damit ist auch festgelegt, welche Erkrankungen bei Kindern - gemäß internationaler Konvention - in einem epidemiologischen Krebsregister systematisch zu erfassen sind.

Die Vollzähligkeit der Erfassung beträgt seit 1987 über 95%. Sie entspricht damit den internationalen Anforderungen an epidemiologische Krebsregister.

Neben den in der ICCC-3 definierten Diagnosen werden am Deutschen Kinderkrebsregister einige weitere Diagnosegruppen systematisch erfasst (Tabellen 2, 5). Seit 2009 wurden entsprechend den Empfehlungen des Gemeinsamen Bundesausschusses noch einige wenige weitere nicht-maligne Diagnosen hinzugenommen (12). Für einige dieser Diagnosen existieren eigene Therapieoptimierungsstudien der Fachgesellschaft GPOH.

end of the report. This also defines internationally which diagnoses in childhood are recorded mandatory in an epidemiologic cancer registry.

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

Besides the diagnoses defined in ICCC-3, the GCCR records a number of further diagnoses systematically (Tables 2, 5). Since 2009 we added a few more rare non-malignant diagnoses. For some of these diagnoses, there exist therapy optimization trials within the GPOH.

Grundlagen der Registrierung und Arbeitsweise zum Nachlesen

Literaturstellen

- Meldung und Dokumentationsablauf (4, 5, 9, 11, 12, 14, 24)
- Langzeitnachbeobachtung (10, 16, 28, 34, 35, 39, 41)
- Statistische Methodik (2, 3, 7)

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

Further Information on the Basis of Registration and Procedures

References

- Notification and documentation (4, 5, 9, 11, 12, 14, 24)
- Long-term surveillance (10, 16, 28, 34, 35, 39, 41)
- Statistical methods (2, 3, 7)

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

- Vereinbarung des Gemeinsamen Bundesausschusses zur Kinderonkologie (12)
- Beschluss der 82. Gesundheitsministerkonferenz 2009 (Kinderkrebsregister - Anhebung der Altersgrenze für die Registrierung von Kindern und Jugendlichen)
- Krebsregistergesetz Rheinland-Pfalz (14)
- Bundeskrebsregisterdatengesetz
- Notwendigkeit der namensbezogenen Datenspeicherung
- 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. (15)
- Datenaustausch zwischen Deutschem Kinderkrebsregister und den Landeskrebsregistern. (24)
- DKKR-Regelwerk des Deutschen Kinderkrebsregisters zu datenschutz-relevanten Aspekten
- DKKR-Einwilligungserklärung
- DKKR-Technisches Datenschutz- und Datensicherheitskonzept des Deutschen Kinderkrebsregisters
- Die Langzeitnachbeobachtungskohorte des Deutschen Kinderkrebsregisters (10, 16, 35, 39, 41)

Maßzahlen und deren Berechnung

Inzidenz und allgemeine Kennzahlen

Die Gesamtzahl der Fälle bezieht sich auf die Fälle mit Diagnosealter < 15 Jahre (ab 2009 < 18 Jahre), mit Hauptwohnsitz zum Zeitpunkt der Diagnose in Deutschland, nach Diagnose, Altersgruppe, Geschlecht und den jeweilig angegebenen Zeitraum. Alle Angaben sind für die letzten 10 Jahre des Berichtszeitraums, soweit nicht anders angegeben. Dabei zählen wir Fälle, nicht Patienten. Der Anteil der an Therapieoptimierungsstudien der GPOH teilnehmenden Fälle schließt alle Patienten ein, von denen eine Studienleitung in irgendeiner Form Kenntnis hat. Das heißt, in diesem Anteil sind auch Patienten enthalten, die nicht zur Gruppe der Studienteilnehmer im engen Sinne zu zählen sind.

Die Inzidenzrate (Neuerkrankungsrate) bezieht die Anzahl der Fälle in einem bestimmten Gebiet und Zeitraum auf die zugehörige Wohnbevölkerung im entsprechenden Alter. Alle Inzidenzraten in diesem Bericht sind Durchschnittsangaben für den jeweiligen Zeitraum und werden als Rate pro 1000000 (Million) Personenjahre dargestellt.

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

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

mit N_{ij} Anzahl der Neuerkrankungen im Alter j im Zeitraum i und B_{ij} Bevölkerung im Alter j im Zeitraum i. In der Regel werden in diesem Bericht altersspezifische Inzidenzraten für die unter 1-jährigen (j=1), die 1- bis 4-jährigen (j=2), die 5- bis 9-jährigen (j=3) und die 10- bis 14-jährigen Kinder (j=4) berechnet, ab 2010 auch für die 15-17-jährigen (j=5). Die (direkt) altersstandardisierte Inzidenzrate für unter 15-Jährige errechnet sich mit Hilfe der Gewichte w_j des von Segi erarbeiteten WHO-Welt-Standards (2) (Tabelle M.1) als

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

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

Descriptive Measures

Incidence and general measures

The total number of cases refers to the cases diagnosed at age < 15 years (from 2009 onwards < 18 years), resident in Germany at the time of diagnosis, broken down by diagnosis, age group, sex and time periods. All figures are given for the most recent 10 years of the reporting period, unless otherwise stated. We count cases, not patients. The relative frequency of trial cases includes all patients the trial centre is informed of. This also includes patients who may not be treated according to protocol.

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

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

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

with N_{ij} the number of new cases at age j in time period i and B_{ij} the population at age j in time period i. This report usually gives age-specific incidence rates for children under age 1 (j=1), ages 1-4 (j=2), ages 5-9 (j=3), and ages 10-14 (j=4). From 2010 onwards we also include ages 15-17 (j=5). The directly standardized incidence rate f or cases under 15 is calculated using the weights w_j of the Segi WHO world standard (2) (Table M.1):

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

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

Tabelle / Table M. 1:

Zusammensetzung der Segi Weltbevölkerung (2) für Kinder unter 15 Jahren im Vergleich zur durchschnittlichen deutschen Wohnbevölkerung 2001-2010

Composition of the Segi world (2) standard for children under 15 years compared to the German population 2001-2010

Age-groups (years)	World standard population	German population 2001-2010	
	Weights	Absolute	Relative
0	0.08	698,033	0.06
1-4	0.31	2,916,818	0.25
5-9	0.32	3,884,152	0.33
10-14	0.29	4,252,276	0.36
Total	1.00	11,751,278	1.00

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

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

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

Die in pädiatrisch onkologischen Publikationen gern verwendete Darstellung der Inzidenzrate oder der kumulativen Inzidenz als $1/K_i$ Kinder ergibt sich über die Umrechnungen

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

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

Überlebenswahrscheinlichkeit und Mortalität

Die Berechnung der Überlebenswahrscheinlichkeiten erfolgt nach der von Brenner und Spix vorgeschlagenen Modifikation des Sterbetafel-Verfahrens (7). Die Werte sind mit der Schätzung nach Kaplan-Meier (1) vergleichbar, jedoch erlaubt dieses Verfahren auch für die erst in den letzten Jahren Erkrankten a) eine Hochrechnung für einen darüber hinausgehenden Zeitraum und b) eine stabilere Abschätzung des Langzeitüberlebens.

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

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

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

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

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

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

Survival probability and mortality

Survival probabilities were computed using the life table method extension proposed by Brenner and Spix (7). These estimates can be directly compared to the more commonly used estimates by Kaplan-Meier (1), but also permit making statements for more recently diagnosed cases regarding a) extrapolated long-term survival and b) more stable short-term survival estimates.

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

The graphical presentation in this report cuts the survival curves at the observed maximum observation time. We present the survival curves for the first and second decade and the first and second half of the third decade. For some diagnoses follow-up data for more recently diagnosed cases is still rather incomplete, we then do not present this most recent curve.

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

The mortality rate and the cumulative mortality are computed in analogy to the incidence rate and the cumulative incidence. We include only deaths within a 10 year follow-up after diagnosis referring to the diagnosis period from 10 years earlier.

Zweitneoplasien

Eine Zweitneoplasie ist eine weitere Neubildung, die nach der ersten Neoplasie bei dem gleichen Patienten auftritt. Die englischen Begriffe hierzu sind ‚second neoplasm' oder ‚subsequent neoplasm', abgekürzt SN.

Second neoplasias

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

Die Berechnung der kumulativen Inzidenz der innerhalb von 20 Jahren nach Diagnose aufgetretenen zweiten Krebserkrankungen (SN - second neoplasms) bezieht sich nur auf in der ICCC-3 definierte Krebserkrankungen. Gutartige weitere Erkrankungen (außer den in der ICCC-3 eingeschlossenen ZNS-Tumoren) werden hier nicht mitgezählt.

The cumulative incidence of second neoplasias (SN) within 20 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.

Die Bezugsbevölkerung für die Berechnung der kumulativen Inzidenz der zweiten Krebserkrankungen ist die Gruppe aller Patienten mit einer ersten Krebserkrankung (nach ICCC-3) im Alter von unter 15 Jahren in der deutschen Wohnbevölkerung. Die Angabe der kumulativen Inzidenz erfolgt pro 100 Personen unter Risiko (%).Wegen der relativ hohen Zahl an Todesfällen wird zur Berechnung der kumulativen Inzidenz mit dem Aalen-Johansen-Schätzer (3) eine Variante des Kaplan-Meier-Verfahrens (1) angewendet, das diesen Umstand als konkurrierendes Risiko berück-sichtigt. 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.

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

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

The tables should be read as follows, using acute myeloid leukaemia (ICCC-3 Ib) as an example.

Tabelle / Table M. 2:

Zweitneoplasieinformationen am Beispiel der AML (I(b)) / Second neoplasm Information for AML(I(b)) as an Example

Second neoplasms (SN) within 20 yrs. of diagnosis (1980-2010):
I (b) Acute myeloid leukaemias

SN after I (b)			**I (b) as SN after any primary**		
N	% of all 775 SN	Cumulative incidence	N	% of all 775 SN	Cumulative incidence
32	4.1 %	2.9 %	124	16.0 %	0.3 %

Bei den in den Jahren 1980-2010 mit einer AML unter 15 Jahren als erster Krebserkrankung diagnostizierten Patienten wurden in den folgenden bis zu 20 Jahren 32 zweite Krebserkrankungen diagnostiziert. Das sind 4,1 % von allen 775 innerhalb von 20 Jahren nach Diagnose an das Deutsche Kinderkrebsregister gemeldeten zweiten Krebserkrankungen. Bei 2,9% aller AML Patienten wird innerhalb von 20 Jahren nach Erstdiagnose eine weitere Krebserkrankung diagnostiziert, im Vergleich zu allen Malignomen (3,1%) ist das durchschnittlich.

Within 20 years of diagnosis 32 second neoplasms were diagnosed out of the case of AML reported at age <15 in the years 1980-2010. These are 4.1% of all 775 recorded second Neoplasms within 20 years of diagnosis at the GCCR. 2.9% of all AML cases are diagnosed with a second neoplasm within 20 years of diagnosis, this is comparable to the average cumulative incidence of 3.1% for all malignancies.

Nach einer ersten Krebserkrankung beliebigen Typs im Alter von unter 15 in den Jahren 1980-2010 wurde bei 124 Patienten anschließend in den nächsten 20 Jahren eine AML diagnostiziert. 16,0 % aller 775 dem Deutschen Kinderkrebsregister innerhalb von 20 Jahren nach Diagnose gemeldeten zweiten Krebserkrankungen sind AML. Im Vergleich zu dem Anteil von AML an allen Krebserkrankungen im Kindesalter (4,6%) ist das ungewöhnlich viel. Bei 0,3 % aller kindlichen Krebspatienten wird innerhalb von 20 Jahren nach Erstdiagnose eine AML als zweite Krebserkrankung diagnostiziert.

After any primary neoplasm at age under 15 in 1980-2010, 124 patients were diagnosed with AML as second neoplasm within 20 years of diagnosis. 16.0 % of all 775 second neoplasms within 20 years of diagnosis of the primary disease reported at the GCCR are AML. Compared to 4.6% AML in general, this is a large number. 0.3% of all childhood cancer patients are diagnosed with a second AML with 20 years of diagnosis.

Räumliche Verteilung

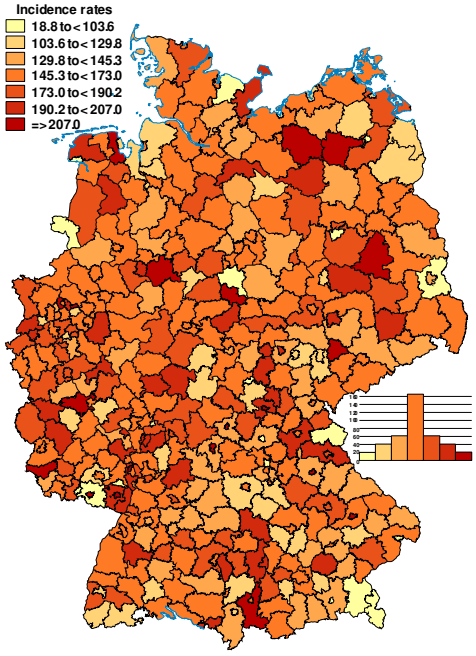
Die kartographische Darstellung präsentiert standardisierte Inzidenzraten unter 15 Jahren auf Kreisebene in 7 Gruppen, die jeweils 5%, 10%, 15%, 40%, 15%, 10% und 5% der Kreise (Landkreise und kreisfreie Städte) von der niedrigsten bis zur höchsten Inzidenzrate umfassen. Bei seltenen Diagnosen werden in mehr als 5% (bzw.

Spatial distribution

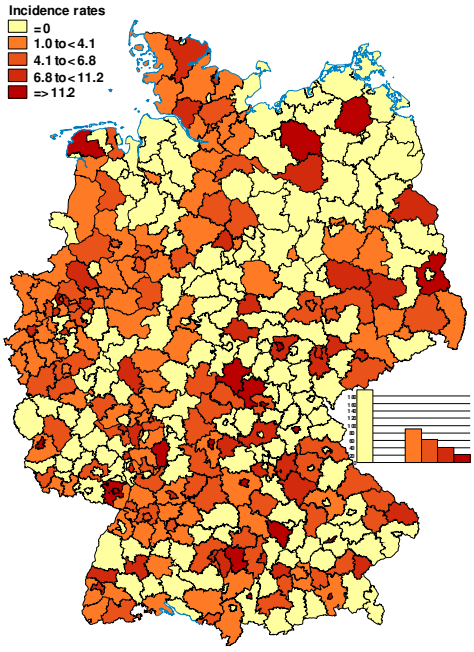
The map presentation shows the standardized incidence rates for ages under 15 in 7 classes, each covering 5%, 10%, 15%, 40%, 15%, 10% and 5% of all „Kreise“ (districts), ordered from the smallest to the largest incidence rate. For rare diagnoses, a number of Kreise do not observe a single case and the lower classes have

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

All malignancies



Burkitt lymhoma



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.

to be aggregated (see right side sample map). The class limits derived from this are shown in the legend on the left. The distribution can be seen in the histogram on the right. For very rare diagnoses map presentations are not useful.

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

In table 6 we present some tabulated data on regional standardized incidence rates. It includes the Standardized Incidence Ratio (SIR), which is computed as the ratio of the observed and expected number of cases. The observed number N_{ir} is the number of all cases under 15 years with the diagnosis in question in time period i in the region r. The expected number is calculated using the number of inhabitants per age-group j in region r in period i (B_{ijr}) and the German age-specific incidence rates I_{ij} in the same time period i.

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

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

SIR-Werte über dem Referenzwert von 1 bedeuten, dass in der untersuchten Region mehr Erkrankungsfälle beobachtet wurden als im Vergleich mit der Inzidenzrate aus der gesamten Bundesrepublik zu erwarten wären und umgekehrt. Zur Beurteilung des SIR werden 95%Konfidenzintervalle (95%CI), die auf der Poisson-Verteilung beruhen, berechnet. Ein SIR gilt als statistisch unauffällig, wenn das zugehörige Konfidenzintervall den Wert 1 einschließt. Ein 95%CI jenseits von 1 bedeutet, dass es sich nur 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 412 Kreisen wären also zufällig etwa 21 Kreise mit ungewöhnlich hohen oder niedrigen Inzidenzen zu erwarten, tatsächlich sind es beispielsweise für alle ICCC-3 Diagnosen für den Zeitraum 2001-2010 18 Kreise.

SIR values above the reference value 1 mean that in the region in question more new cases were observed than expected based on the nation wide 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 only a 5% probability that the deviation from the nation wide incidence rate is random. However, we must expect about 5% of all regions to be randomly significant this way, without this being relevant. For the currently 412 Kreise we would thus randomly expect about 21 with unusual incidences. For the time period 2001-2010 for all ICCC-3 diagnoses we do actually observe 18.

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

* *Tumours with non-malignant behaviour codes are included*

Forts. / cont.

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

Forts. / cont.

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

Forts. / cont.

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

Forts. / cont.

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

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Veröffentlichungen mit Beteiligung des Deutschen Kinderkrebsregisters seit 2009

Publications by or in co-operation with the German Childhood Cancer Registry since 2009

2009

Dieluweit U, Seitz DCM, Besier T, Debling D, Kaatsch P, Debatin KM, Goldbeck L. Psychosocial development of long-term survivors of adolescent cancer: familial and occupational late effects. Psycho-oncology 2009;18(Suppl. 2):43.

Gatta G, Zigon G, Capocaccia R, Coebergh JW, Desandes E, Kaatsch P, Pastore G, Peris-Bonet R, Stiller CA, Eurocare Working Group. Survival of European children and young adults with cancer diagnosed 1995-2002. Eur J Cancer 2009;45(6):992-1005.

Hammer GP, Seidenbusch MC, Schneider K, Regulla DF, Zeeb H, Spix C, Blettner M. A cohort study of childhood cancer incidence after postnatal diagnostic X-ray exposure. Radiation Research 2009;171(4):504-12.

Kaatsch P, Debling D, Blettner M, Spix C. Second malignant neoplasms after childhood cancer in Germany—results from the long-term follow-up of the German Childhood Cancer Registry. Strahlentherapie und Onkologie 2009;185 (Suppl 2):8-10.

Kaatsch P, Reinisch I, Spix C, Berthold F, Janka-Schaub G, Mergenthaler A, Michaelis J, Blettner M. Case-control study on the therapy of childhood cancer and the occurrence of second malignant neoplasms in Germany. Cancer Causes Control 2009;20(6):965-80.

Kaatsch P, Spix C, Jung I, Blettner M. Leukämien bei unter 5-jährigen Kindern in der Umgebung deutscher Kernkraftwerke - Schlusswort. Dtsch Ärztebl. 2009;106(23):394.

Mergenthaler A. Das Deutsche Kinderkrebsregister: Ein Überblick zu Charakteristika und aktueller Datenlage. Ärzteblatt Rheinland-Pfalz 2009;3/2009:17.

Müller HL, Gebhardt U, Schröder S, Kortmann RD, Kaatsch P, Warmuth-Metz M, Pietsch T, Wiegand Ch, Sörensen N. Childhood pituitary adenoma - international registry of children and adolescents from Germany, Austria and Switzerland (HIT-Endo). Horm Res 2009;72 (Suppl. 3):289.

Seitz DCM, Dieluweit U, Besier T, Debling D, Kaatsch P, Debatin KM, Goldbeck L. Prevalence of posttraumatic stress, depression and anxiety in long-term survivors after cancer during adolescence. Psycho-oncology 2009;39(Suppl. 2):36.

Selle B, Graf N, Kaatsch P, Leuschner I. Nierenzellkarzinome bei Kindern: Unterschiede in der Biologie und Therapieerfahrungen gegenüber adulten RCC. Monatsschr Kinderheilkd 2009;157:522.

Spix C, Blettner M. Re: BAKER P.J. & HOEL D.G. (2007) Eur J Cancer Care16, 355-363. Meta-analysis of standardized incidence and mortality rates of childhood leukaemia in proximity to nuclear facilities. Eur J Cancer Care 2009;18(4):429-30.

Spix C, Mergenthaler A, Kaatsch P. [Data exchange between the German Childhood Cancer Registry and the Epidemiological Cancer State Registries]. Klin Padiatr 2009;221(6):398-9. Datenaustausch zwischen Deutschem Kinderkrebsregister und den Landeskrebsregistern.

Spix C, Schulze-Rath R, Kaatsch P, Blettner M. Case-control study on risk factors for leukaemia and brain tumours in children under 5 years in Germany. Klin Padiatr 2009;221(6):362-8.

Stanulla M, Schaeffeler E, Moricke A, Coulthard SA, Cario G, Schrauder A, Kaatsch P, Dordelmann M, Welte K, Zimmermann M, Reiter A, Eichelbaum M, Riehm H, Schrappe M, Schwab M. Thiopurine methyltransferase genetics is not a major risk factor for secondary malignant neoplasms after treatment of childhood acute lymphoblastic leukemia on Berlin-Frankfurt-Munster protocols. Blood 2009;114(7):1314-8.

2010

Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Peter R, Seitz DC, Goldbeck L. Social outcomes of long-term survivors of adolescent cancer. Psycho-oncology 2010;19(12):1277-84.

Goldbeck L, Besier T, Debatin KM, Grabow D, Dieluweit U, Hinz A, Kaatsch P, Seitz DCM. Posttraumatic Stress, Depression, and Anxiety among Adult Long Term Survivors of Cancer in Adolescence. Pediatric Blood and Cancer 2010;55(5):836-7.

Hammer GP, Seidenbusch MC, Schneider K, Regulla D, Zeeb H, Spix C, Blettner M. [Cancer incidence rate after diagnostic X-ray exposure in 1976 - 2003 among patients of a university children's hospital]. RöFo 2010;182(5):404-14. Inzidenz von Kinderkrebs nach Röntgendiagnostik im Patientenkollektiv der Jahre 1976 - 2003 einer Universitäts-Kinderklinik.

Henrich G, Goldbeck L, Schmitz TG, Besier T. [Measuring life satisfaction in children and adolescents—psychometric properties of the „Questions on Life Satisfaction" FLZ(KJ)]. Psychotherapie, Psychosomatik, medizinische Psychologie 2010;60(6):219-26. Erfassung der subjektiven Lebensqualität bei Kindern und Jugendlichen—Psychometrische Eigenschaften der „Fragen zur Lebenszufriedenheit" FLZ(KJ).

Hug K, Grize L, Seidler A, Kaatsch P, Schüz J. Parental occupational exposure to extremely low frequency magnetic fields and childhood cancer: a German case-control study. Am J Epid 2010;171(1):27-35.

Kaatsch P. Epidemiology of childhood cancer. Cancer treatment reviews 2010;36(4):277-85.

Kaatsch P, Scheidemann-Wesp U, Schüz J. Maternal use of antibiotics and cancer in the offspring: results of a case-control study in Germany. Cancer Causes Control 2010;21(8):1335-45.

Längler A, Spix C, Edelhäuser F, Martin DD, Kameda G, Kaatsch P, Seifert G. Anthroposophic medicine in paediatric oncology in Germany: results of a population-based retrospective parental survey. Pediatric blood & cancer. 2010;55(6):1111-7.

Kaatsch, P. Nehmen Krebserkrankungen im Kindesalter zu? Daten aus Deutschland und aus einem europäischen Verbundprojekt. Ärzteblatt Rheinland-Pfalz 2010;11:31.

Schmiedel S, Blettner M, Kaatsch P, Schüz J. Spatial clustering and space-time clusters of leukemia among children in Germany, 1987-2007. Eur J Epid 2010;25(9):627-33.

Seitz DC, Besier T, Debatin KM, Grabow D, Dieluweit U, Hinz A, Kaatsch P, Goldbeck L. Posttraumatic stress, depression and anxiety among adult long-term survivors of cancer in adolescence. Eur J Cancer 2010;46(9):1596-606.

Seitz DCM, Hagmann D, Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Henrich G, Goldbeck L. Life Satisfaction in Adult Survivors of Cancer with Onset during Adolescence. Pediatric Blood and Cancer 2010;55(5):836.

2011

Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Peter R, Seitz DC, Goldbeck L. Educational and vocational achievement among long-term survivors of adolescent cancer in Germany. Pediatric Blood and Cancer 2011;56(3):432-8.

Dieluweit U, Seitz DC, Besier T, Debatin KM, Grabow D, Kaatsch P, Goldbeck L. Utilization of psychosocial care and oncological follow-up assessments among German long-term survivors of cancer with onset during adolescence. Klin Padiatr 2011;223(3):152-8.

Goldbeck L, Holling I, Schlack R, West C, Besier T. The impact of an inpatient family-oriented rehabilitation program on parent-reported psychological symptoms of chronically ill children. Klin Padiatr 2011;223(2):79-84.

Grabow D, Lacher C, Kaatsch P. Former childhood cancer patients need a competent help desk. Klin Padiatr 2011;223(3):187-8.

Grabow D, Spix C, Blettner M, Kaatsch P. Strategy for long-term surveillance at the German Childhood Cancer Registry - an update. Klin Padiatr 2011;223(3):159-64.

Längler A, Spix C, Edelhäuser F, Kameda G, Kaatsch P, Seifert G. Use of homeopathy in pediatric oncology in Germany. Evidence-based complementary and alternative medicine 2011;2011:867151.

Seitz DC, Hagmann D, Besier T, Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Henrich G, Goldbeck L. Life satisfaction in adult survivors of cancer during adolescence: what contributes to the latter satisfaction with life? Quality of life research 2011;20(2):225-36.

Weis E, Schoen H, Victor A, Spix C, Ludwig M, Schneider-Raetzke B, Kohlschmidt N, Bartsch O, Gerhold-Ay A, Boehm N, Grus F, Haaf T, Galetzka D. Reduced mRNA and protein expression of the genomic caretaker RAD9A in primary fibroblasts of individuals with childhood and independent second cancer. PloS One 2011;6(10):e25750.

2012

Brecht IB, Kaatsch P. Epidemiology. In: Schneider DT BI, Olson ThA, Ferrari A editor. Rare tumors in children and adolescents: Springer; 2012. p. 43-61.

Galetzka D, Hansmann T, El Hajj N, Weis E, Irmscher B, Ludwig M, Schneider-Ratzke B, Kohlschmidt N, Beyer V, Bartsch O, Zechner U, Spix C, Haaf T. Monozygotic twins discordant for constitutive BRCA1 promoter methylation, childhood cancer and secondary cancer. Epigenetics 2012;7(1):47-54.

Grabow D, Spix C, Kaatsch P. Langzeitüberlebende nach Krebs im Kindesalter: eine populationsbezogene Kohorte am Deutschen Kinderkrebsregister. Ärzteblatt Rheinland-Pfalz 2012;6.

Kaatsch P, Grabow D. [The German cohort of long-term survivors of childhood cancer : A population-based cohort in the German Childhood Cancer Registry]. Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz 2012;55(6-7):843-51. Die deutsche Kohorte Langzeitüberlebender nach Krebs im Kindesalter : Eine populationsbezogene Kohorte am Deutschen Kinderkrebsregister.

Spix C. Fertility in survivors of childhood cancer. Deutsches Ärzteblatt international 2012;109(7):124-5.

Spix C, Kaatsch P, Blettner M. The German and the French studies on childhood leukemia and nuclear power: differences and similarities. Int J Cancer2012. Epub 2012/04/12. DOI 10.1002/ijc.27584.

Präsentationen mit Beteiligung des Deutschen Kinderkrebsregisters seit 2009

Presentations by or in co-operation with the German Childhood Cancer Registry since 2009

2009

Kaatsch P. Krebserkrankungen bei Kindern: Zeitliche Trends, regionale Unterschiede und Ursachenforschung. 27. Oldenburger Pädiatrisches Kolloquium. Oldenburg, 17.1.2009.

Kaatsch P, Debling D, Spix C. Second malignant neoplasms after Childhood Cancer in Germany: Results from the long-term follow-up at the German Childhood Cancer Registry. 3rd Münster Symposium on Late Effects after Tumour Therapy in Childhood and Adolescence. Münster, 13.-15.1.2009.

Kaatsch P, Blettner M. Umweltbedingte Risikofaktoren für Leukämien bei Kindern – Ergebnisse des Deutschen Kinderkrebsregisters. Saarländisch-pfälzische Internistengesellschaft. 53. Jahreskongress Neustadt/Weinstraße, 5.-7.3.2009.

Blettner M, Kaatsch P. Epidemiologische Studie zu Kinderkrebs in der Umgebung von Kernkraftwerken (KiKK-Studie). 50. Jahrestagung der Deutschen Gesellschaft für medizinischen Strahlenschutz, Dresden, 15.-16.5.2009.

Kaatsch P. Epidemiologie von Zweitmalignomen nach Krebs im Kindesalter. Dt. Gesellschaft für Kinder- und Jugendmedizin (DGKJ). Mannheim, 3.-6. September 2009.

Kaatsch P, Spix C, Michaelis J, Debling D, Maria Blettner M. Sekundäre maligne Neuerkrankungen nach Krebs im Kindesalter - Ergebnisse einer Fall-Kontrollstudie. 54. Jahrestagung der Deutschen Gesellschaft für Medizinische Informatik, Biometrie und Epidemiologie (GMDS), Essen, 7.-10. September 2009.

Spix C, Schulze-Rath R, Kaatsch P, Blettner M. Fall-Kontroll-Studie zu Risikofaktoren für kindliche Leukämien, Lymphomen und ZNS-Tumoren - eine Befragungsstudie am Deutschen Kinderkrebsregister. 54. Jahrestagung der Deutschen Gesellschaft für Medizinische Informatik, Biometrie und Epidemiologie (GMDS), Essen, 7.-10. September 2009.

Spix C. Epidemiological Study on Childhood Cancer in the Vicinity of Nuclear Power Stations (KiKK). Belgian Superior Health Council. Brüssel, 12.10.2009.

Hjorth L, Haupt R, Skinner R, Debling D, Kremer L, de Vathaire F, Hawkins M, Garwicz S, Frey E, Byrne J, Bardi E, Kühni C, Vandecruys E, Krawczuk Rybak M, Widing E, Rechnitzer C, Zadravec Zaletel L, Kepak T, Mesar P, Márquez Vega C, Rutkauskaite V on behalf of all PanCare members. PanCare – A new kid on the European childhood cancer survivor block. (Poster and oral presentation) ESLCCC 2009, Edinburgh 30.10.2009

Debling D, Kremer L, Ronckers C, Panholzer T, Jakab Z, Pastore G, Heyman H, Kuehni CE, Kodytkova D, Rechnitzer C, Mesar P, Hjorth L, Haupt R, Skinner R, Hawkins M on behalf of all PanCare members. The European PanCare-Cohort of Long-term Survivors after Childhood Cancer. (Poster and oral presentation) ESLCCC 2009, Edinburgh, 30.10.2009

Michel G, von der Weid NX, Byrne J, Debling D, Essig S, Hjorth L, Skinner R, Haupt R, Kremer L, Frey E, Bardi E, Kuehni CE, for the PANCARE network. Follow-up care after childhood cancer in Europe: A pilot study. (Poster) ESLCCC 2009, Edinburgh , 30.10.2009

Goldbeck L, Debatin KM, Dieluweit U, Grabow D, Kaatsch P, Seitz D. Psychosoziale Adaptation langzeitüberlebender onkologischer Patienten nach Erkrankung in der Adoleszenz - „Survivor-Studie“. 8. Jahrestagung der PSO (Arbeitsgemeinschaft Psychosoziale Onkologie), „Psychoonkologie: Vernetzung und Integration“ vom 3.-5.12.2009 in Freiburg i.Br., 04.12.2009

2010

Kaatsch P. Krebserkrankungen bei Kleinkindern in der Umgebung von Kernkraftwerken – die KiKK-Studie des Deutschen Kinderkrebsregisters 2 Jahre nach deren Veröffentlichung. 22. Mathematisch-Technisches Kolloquium, RheinAhrCampus. Remagen, 7. Januar 2010.

Spix C. Radiation Epidemiology. Wilhelm and Else Heraeus Physics Summer School „Protection of Humans and Their Environment Against Ionising Radiation", Bad Honnef. 9. – 21. Mai 2010.

Kaatsch P. Childhood cancer registration in Germany: a nationwide population-based cancer registry. 1st Meeting of the National Society of Pediatric Hematology/Oncology of Russia. Moskau, 21.-23. Mai 2010.

Kaatsch P. 30 Jahre Deutsches Kinderkrebsregister: Erfahrungen und Perspektiven. 75. Wissenschaftliche Tagung der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH). Berlin, 28.-29. Mai 2010.

Kaatsch P. Ausgewählte Ergebnisse der epidemiologischen Forschung am Deutschen Kinderkrebsregister. 75. Wissenschaftliche Tagung der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH). Berlin, 28.-29. Mai 2010.

Spix C. Methoden in der Krebsepidemiologie: Ökologische Studien. 75. Wissenschaftliche Tagung der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH). Berlin, 28.-29. Mai 2010.

Kaatsch P, Spix C, Grabow D, Blettner M. Second malignant neoplasms after childhood cancer in Germany - results from the long-term follow-up at the German Childhood Cancer Registry. Poster. 11th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer. (Poster) Williamsburg, USA, 11.-12. Juni 2010.

Grabow D, Lacher C, Kaatsch P. The necessity to establish a competent help desk for former childhood cancer patients. Poster. 11th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer. (Poster) Williamsburg, USA, 11.-12. Juni 2010.

Bardi E, Michel G, von der Weid NX, Byrne J, Grabow D, Kremer L, Frey E, Kuehni CE, Skinner R, Hjorth L, For the PanCare network. What do childhood cancer parent and survivor groups expect from health care providers? A survey of pediatric oncology health care providers within PanCare. (Poster) 11th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Williamsburg, USA, June 11-12, 2010.

Hjorth L, Haupt R, Skinner R, Grabow D, Kremer L, de Vathaire F, Hawkins M, Garwicz S, Frey E, Byrne J, Bardi E, Kühni CE, Vandecruys E, Krawczuk Rybak M, Widing E, Rechnitzer C, Zadravec Zaletel L, Kepak T, Mesar P, Márquez Vega C, Rutkauskaite V, Teixeira A, Tsirou A, Lau LH, Serban M, Harila-Saari A, Bogicevic V, Georgieva I on behalf of all PanCare members. PanCare – A new Network for Care of European Childhood Cancer Survivors. (Poster) 11th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Williamsburg, USA, June 11-12, 2010

Spix C. Strahlenepidemiologie. Berufsgenossenschaft Energie Textil Elektro Medienerzeugnisse. Bad Münstereifel 21.10.2010.

Kaatsch P. Langzeitnachbeobachtung in der pädiatrischen Onkologie und Hämatologie. „Krebsregister und Versorgungsforschung" - Symposium zum 10-jährigen Bestehen des Epidemiologischen Krebsregisters Niedersachsen. Oldenburg, 17.-18. November 2010.

Grabow D, Lacher C, Kaatsch P. Informationsbedürfnis langzeitüberlebender ehemaliger Krebspatienten im Kindesalter. 76. Wissenschaftliche Tagung der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH). Frankfurt, 19.-20. November 2010.

Seitz DCM, Hagmann D, Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Henrich G, Goldbeck L. Life satisfaction of adult survivors of cancer with onset during adolescence. 42nd Congress of the International Society of Paediatric Oncology 2010

Goldbeck L, Besier T, Debatin KM, Grabow D, Dieluweit U, Hinz A, Kaatsch P, Seitz DCM. Posttraumatic stress, depression and anxiety among adult long term survivors of cancer in adolescence. 42nd Congress of the International Society of Paediatric Oncology 2010

2011

Kaatsch P. Epidemiology of malignancies in childhood. II. Inter-Regional Meeting of the Russian National Society of Pediatric Hematologists-Oncologists (NSPHO): Biological basis of therapy of oncological and hematological diseases. Moskau, 1.-4. Juni 2011.

Grabow D. Praktischer Erfahrungsbericht einer erfolgreichen EU-Antragstellerin der Universitätsmedizin (Vortrag). Im Rahmen der Veranstaltung: 7. EU-Forschungsrahmenprogramm – Informationsveranstaltung mit der Nationalen Kontaktstelle Lebenswissenschaften (NKS-L); 17. Juni 2011

Kaatsch P, Klingebiel T, Spix C, Blettner M. Das Deutsche Kinderkrebsregister in Mainz: Nutzung von Synergien zwischen klinischen Studien, behandelnden Kliniken und epidemiologischem Krebsregister. 1. klinischer Forschungstag Rhein-Main: Klinische Forschung in der Onkologie. Frankfurt, 10. September 2011.

Schulze-Rath R, Spix C. Validierung von Selbstangaben zu Schwangerschaft und Kindergesundheit anhand ambulant erstellter medizinischer Unterlagen. (Poster). 56. Jahrestagung der Deutschen Gesellschaft für Medizinische Informatik, Biometrie und Epidemiologie (GMDS), Mainz, 26.-30.9. 2011.

Hennewig U, Kaatsch P. Spix C. Solid second malignant neoplasms by location and dose of preceding radiotherapy in German childhood cancer survivors diagnosed in 1980-2002. ESLCCC 2011, Amsterdam September/Oktober 2011.

2012

Kaatsch P. Die Epidemiologie von Krebserkrankungen im Kindesalter: Häufigkeiten, zeitliche Trends, regionale Unterschiede und Ursachen (ionisierende Strahlung und andere diskutierte Risikofaktoren). Poppelsdorfer Schlossgespräche. Bonn, 19. Januar 2012.

Kaatsch P. Childhood leukaemia clusters near nuclear installations, epidemiology and interpretations. Vorlesungsreihe Strahlen-Epidemiologie, Modul „Radiation Epidemiology and Radio-Ecology“. Helmholtz-Zentrum, München-Neuherberg, 16. Februar 2012

Kaatsch P. Hirntumoren bei Kindern: Erkrankungszahlen, internationaler Vergleich, mögliche Ursachen. Tagung des bundesweiten Behandlungsnetzwerkes HIT: Hirntumoren im Kindes- und Jugendalter. Hamburg, 23.-24. März 2012.

Spix C. Das Deutsche Kinderkrebsregister. 1. Nachwuchsakademie „Pädiatrische Onkologie“ der Gesellschaft für Pädiatrische Onkologie und Hämatologie, Bonn – Bad Godesberg, 1. – 3. März 2012.

Hennewig U, Kaatsch P, Spix C. Induktion von soliden Zweittumoren durch Radiotherapie bei Patienten nach Therapie in den Jahren 1980-2000. 80. Wissenschaftliche Tagung der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH), Hamburg, 14.-15. September 2012.

1. Kaplan EL, Meier P. Nonparametric-Estimation from Incomplete Observations. J Am Stat Assoc. 1958;53(282):457-81.
2. Segi M. Cancer Mortality for Selected Sites in 24 Countries (1950-57). Sendai, Japan Tohoku University of Medicine; 1960.
3. Aalen O, Johansen S. An empirical transition matrix for nonhomogeneous Markov chains based on censored observations. Scan J Stat 1978;5:141-50.
4. Michaelis J, Kaatsch P. Use of information from clinical trials for an integrated cancer registry. Methods of Information in Medicine. 1990;29(2):92-8.
5. Kaatsch P, Haaf G, Michaelis J. Childhood malignancies in Germany—methods and results of a nationwide registry. Eur J Cancer 1995;31A(6):993-9.
6. Fritz A, Percy C, Jack A, Shanmugaratnam K, Sobin L, Parkin D, Whelan Se. International Classification of Diseases for Oncology. Third Edition ed. Geneva: World Health Organisation; 2000.
7. Brenner H, Spix C. Combining cohort and period methods for retrospective time trend analyses of long-term cancer patient survival rates. Br J Cancer 2003;89(7):1260-5.
8. Klein G, Michaelis J, Spix C, Wibbing R, Eggers G, Ritter J, Kaatsch P. Second malignant neoplasms after treatment of childhood cancer. Eur J Cancer 2003;39(6):808-17.
9. Kaatsch P. Das Deutsche Kinderkrebsregister im Umfeld günstiger Rahmenbedingungen. Bundesgesundheitsbl Gesundheitsforsch Gesundheitsschutz 2004;47:437-43
10. Kaatsch P, Blettner M, Spix C, Jürgens H. [Follow up of long-term survivors after childhood cancer in Germany]. Klin Padiatr 2005;217(3):169-75. Das Langzeit-Follow-up in der deutschen pädiatrischen Onkologie als Basis für die Durchführung von Studien mit Langzeitüberlebenden.
11. Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, third edition. Cancer 2005;103(7):1457-67.
12. Vereinbarung des Gemeinsamen Bundesausschusses über Maßnahmen zur Qualitätssicherung für die stationäre Versorgung von Kindern und Jugendlichen mit hämato-onkologischen Krankheiten gemäß § 137 Abs. 1 Satz 3 nr. 2 SGB V für nach § 108 SGB V zugelassene Krankenhäuser (Vereinbarung zur Kinderonkologie). Gemeinsamer Bundesausschuss [Internet]. 2006. Available from: http://www.kinderkrebsinfo.de/e2260/e13266/e13870/Vereinbarung_Onkologie-2006-05-16_ger.pdf. .
13. Steliarova-Foucher E, Coebergh J, Kaatsch P, Pritchard-Jones K, Stiller C, (editors). Cancer in children and adolescents in Europe. Eur J Cancer 2006;42:1913-2190.
14. Erstes Landesgesetz zur Änderung des Landesgesetzes zur Weiterführung des Krebsregisters (LKRG) vom 2.3.2006 Available from: http://www.krebsregister-rheinland-pfalz.de
15. Calaminus G, Kaatsch P. [Position paper of the Society of Pediatric Oncology and Hematology (GPOH) on (long-term) surveillance, (long-term) follow-up and late effect evaluation in pediatric oncology patients]. Klin Padiatr 2007;219(3):173-8. Positionspapier der Gesellschaft für Pädiatrische Onkologie und Hämatologie (GPOH) zu (Langzeit-)Nachbeobachtung, (Langzeit-)Nachsorge und Spätfolgenerhebung bei pädiatrisch-onkologischen Patienten.
16. Debling D, Spix C, Blettner M, Michaelis J, Kaatsch P. The cohort of long-term survivors at the German childhood cancer registry. Klin Padiatr 2008;220(6):371-7.
17. Kaatsch P, Spix C, Jung I, Blettner M. Childhood leukemia in the vicinity of nuclear power plants in Germany. Deutsches Ärzteblatt international 2008;105(42):725-32.
18. Kaatsch P, Spix C, Schulze-Rath R, Schmiedel S, Blettner M. Leukaemia in young children living in the vicinity of German nuclear power plants. Int J Cancer 2008;122(4):721-6.
19. Spix C, Schmiedel S, Kaatsch P, Schulze-Rath R, Blettner M. Case-control study on childhood cancer in the vicinity of nuclear power plants in Germany 1980-2003. Eur J Cancer 2008;44(2):275-84.

20. Dieluweit U, Seitz DCM, Besier T, Debling D, Kaatsch P, Debatin KM, Goldbeck L. Psychosocial development of long-term survivors of adolescent cancer: familial and occupational late effects. Psycho-oncology 2009;18(Suppl. 2):43.

21. Gatta G, Zigon G, Capocaccia R, Coebergh JW, Desandes E, Kaatsch P, Pastore G, Peris-Bonet R, Stiller CA, Group EW. Survival of European children and young adults with cancer diagnosed 1995-2002. Eur J Cancer 2009;45(6):992-1005.

22. Kaatsch P, Reinisch I, Spix C, Berthold F, Janka-Schaub G, Mergenthaler A, Michaelis J, Blettner M. Case-control study on the therapy of childhood cancer and the occurrence of second malignant neoplasms in Germany. Cancer Causes Control 2009;20(6):965-80.

23. Seitz DCM, Dieluweit U, Besier T, Debling D, Kaatsch P, Debatin KM, Goldbeck L. Prevalence of posttraumatic stress, depression and anxiety in long-term survivors after cancer during adolescence. Psycho-oncology. 2009;39(Suppl. 2):36.

24. Spix C, Mergenthaler A, Kaatsch P. [Data exchange between the German Childhood Cancer Registry and the Epidemiological Cancer State Registries]. Klin Padiatr 2009;221(6):398-9. Datenaustausch zwischen Deutschem Kinderkrebsregister und den Landeskrebsregistern.

25. Spix C, Schulze-Rath R, Kaatsch P, Blettner M. Case-control study on risk factors for leukaemia and brain tumours in children under 5 years in Germany. Klin Padiatr 2009;221(6):362-8.

26. Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Peter R, Seitz DC, Goldbeck L. Social outcomes of long-term survivors of adolescent cancer. Psycho-oncology. 2010;19(12):1277-84.

27. Goldbeck L, Besier T, Debatin KM, Grabow D, Dieluweit U, Hinz A, Kaatsch P, Seitz DCM. Posttraumatic Stress, Depression, and Anxiety among Adult Long Term Survivors of Cancer in Adolescence. Pediatric Blood and Cancer 2010;55(5):836-7.

28. Grabow D, Lacher C, Kaatsch P. Informationsbedürfnis langzeitüberlebender ehemaliger Krebspatienten im Kindesalter. Monatsschr Kinderh 2010;158:1007-16.

29. Seitz DC, Besier T, Debatin KM, Grabow D, Dieluweit U, Hinz A, Kaatsch P, Goldbeck L. Posttraumatic stress, depression and anxiety among adult long-term survivors of cancer in adolescence. Eur J Cancer 2010;46(9):1596-606.

30. Seitz DCM, Hagmann D, Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Henrich G, Goldbeck L. Life Satisfaction in Adult Survivors of Cancer with Onset during Adolescence. Pediatric Blood and Cancer 2010;55(5):836.

31. Dieluweit U, Debatin KM, Grabow D, Kaatsch P, Peter R, Seitz DC, Goldbeck L. Educational and vocational achievement among long-term survivors of adolescent cancer in Germany. Pediatric Blood and Cancer 2011;56(3):432-8.

32. Dieluweit U, Seitz DC, Besier T, Debatin KM, Grabow D, Kaatsch P, Goldbeck L. Utilization of psychosocial care and oncological follow-up assessments among German long-term survivors of cancer with onset during adolescence. Klin Padiatr 2011;223(3):152-8.

33. Goldbeck L, Holling I, Schlack R, West C, Besier T. The impact of an inpatient family-oriented rehabilitation program on parent-reported psychological symptoms of chronically ill children. Klin Padiatr 2011;223(2):79-84.

34. Grabow D, Lacher C, Kaatsch P. Former childhood cancer patients need a competent help desk. Klin Padiatr 2011;223(3):187-8.

35. Grabow D, Spix C, Blettner M, Kaatsch P. Strategy for long-term surveillance at the German Childhood Cancer Registry - an update. Klin Padiatr 2011;223(3):159-64.

36. Krille L, Jahnen A, Mildenberger P, Schneider K, Weisser G, Zeeb H, Blettner M. Computed tomography in children: multicenter cohort study design for the evaluation of cancer risk. Eur J Epid 2011;26(3):249-50.

37. Weis E, Schoen H, Victor A, Spix C, Ludwig M, Schneider-Raetzke B, Kohlschmidt N, Bartsch O, Gerhold-Ay A, Boehm N, Grus F, Haaf T, Galetzka D. Reduced mRNA and protein expression of the genomic caretaker RAD9A in primary fibroblasts of individuals with childhood and independent second cancer. PloS One 2011;6(10):e25750.

38. Balcerek M, Reinmuth S, Hohmann C, Keil T, Borgmann-Staudt A. Suspected infertility after treatment for leukemia and solid tumors in childhood and adolescence. Deutsches Ärzteblatt international 2012;109(7):126-31.

39. Grabow D, Spix C, Kaatsch P. Langzeitüberlebende nach Krebs im Kindesalter: eine populationsbezogene Kohorte am Deutschen Kinderkrebsregister. Ärzteblatt Rheinland-Pfalz 2012;6.

40. Jantke A, Rendtorff R, Dittrich R, Muller A, Pfitzer C, Hohmann C, Keil T, Borgmann-Staudt A. Association between self-reported questionnaire data on fertility and results of hormone analyses in women after childhood cancer: A cross-sectional study. The journal of obstetrics and gynaecology research 2012. Epub 2012/05/09.

41. Kaatsch P, Grabow D. [The German cohort of long-term survivors of childhood cancer : A population-based cohort in the German Childhood Cancer Registry]. Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz. 2012;55(6-7):843-51. Die deutsche Kohorte Langzeitüberlebender nach Krebs im Kindesalter: Eine populationsbezogene Kohorte am Deutschen Kinderkrebsregister.

42. Krille L, Zeeb H, Jahnen A, Mildenberger P, Seidenbusch M, Schneider K, Weisser G, Hammer G, Scholz P, Blettner M. Computed tomographies and cancer risk in children: a literature overview of CT practices, risk estimations and an epidemiologic cohort study proposal. Radiation and environmental biophysics. 2012;51(2):103-11.