Public Health England

Protecting and improving the nation's health

Childhood cancer registration in England: 2015 to 2016

Report on behalf of the Children, Teenagers and Young Adults Site Specific Clinical Reference Group, National Cancer Registration and Analysis Service

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7654 8000
www.gov.uk/phe
Twitter: @PHE_uk
Facebook: www.facebook.com/PublicHealthEngland

Prepared by: PHE National Cancer Registration and Analysis Service
For queries relating to this document, please contact: ncrasenquiries@phe.gov.uk

Published: November 2016
PHE publications gateway number: 2016520

Contents

Executive summary

This report contains information on incidence and survival rates for cancer diagnosed during 2003 to 2012 among children under the age of 15 resident in England. The incidence and survival analyses were based on data extracted from the National Cancer Registration and Analysis Service (NCRAS) ENCORE database after the migration of data from the National Registry of Childhood Tumours, University of Oxford, following the transfer of responsibility for national childhood cancer registration in England to Public Health England in 2013. The report also contains an analysis of the effects of migrating the legacy data for 1993 to 2013 to ENCORE.

There were 14,113 registered cases of cancer (including non-malignant intracranial and intraspinal tumours) in children under the age of 15 in England. Leukaemia accounted for 30% of registrations, central nervous system tumours for 25%, lymphomas for 11%, soft-tissue sarcomas for 7%, neuroblastoma and other peripheral nervous cell tumours for 6%, and renal tumours for 6%. No other diagnostic group accounted for more than 5% of registrations. The total age-standardised incidence was 167 per million in boys and 146 per million in girls, giving a sex ratio M/F=1.15. The cumulative risk of being diagnosed with cancer in the first 15 years of life was 1 in 410 for boys and 1 in 471 for girls. For both boys and girls, incidence was highest in the first five years, fell to a minimum at age 5 to 9 years, and was slightly higher at age 10 to14 years, marking the start of the unbroken rise in incidence that continues throughout adulthood. Relative frequencies of the main diagnostic groups and overall incidence rates were within the ranges reported from other countries in Europe, North America and Oceania.

Overall, five-year survival was 80% for children diagnosed in 2003 to 2007 and 83% for those diagnosed in 2008 to 2012. The trend in survival by year of diagnosis was highly significant ($p<0.001$). There were also statistically significant increasing trends in survival between these periods for children with lymphoma, intracranial and intraspinal tumours, renal tumours and hepatic carcinoma, and for children aged 1 year or over when diagnosed with neuroblastoma. The highest survival rates, over 95% at five years after diagnosis, were for Hodgkin lymphoma, several types of non-malignant intracranial tumour, retinoblastoma, fibrosacroma, synovial sarcoma, testicular and ovarian germ-cell tumours, and thyroid carcinoma. Survival also exceeded 90% for precursor lymphoblastic leukaemia, Wilms tumour, germ-cell tumours in extragonadal sites, and malignant melanoma.

In total, 28,691 childhood cancer registration records were migrated to ENCORE. Of these, 91% could be matched with a record on ENCORE and the remaining 9% were new to ENCORE. The percentage of new cases varied markedly by year of diagnosis, and was lowest (3%) for 2003 to 2007. The merging of migrated records into those already on ENCORE resulted in changes to some data fields for a substantial number of cases, as illustrated by data on the codes for tumour morphology. Among the migrated records for 1995 to 2013 that matched with an ENCORE record, 14% had their morphology code changed as a result of the migration. Of these code changes, 9% were from unspecified tumour to a more specific code, 9% were other changes resulting in a change of main group in the standard childhood cancer classification, and a further 19% resulted in a change of subgroup in the classification. The proportion of changes that were from unspecified tumour to a more specific code tended to increase in more recent years.

Introduction

This report presents information on childhood cancer in England based on data from the National Cancer Registration and Analysis Service (NCRAS). The body of the report is divided into three main chapters, as follows.

- Incidence of childhood cancer during 2003 to 2012
- Survival of children diagnosed with cancer during 2003 to 2012
- Migration of legacy data from the National Registry of Childhood Tumours (NRCT) and incorporation in the ENCORE database

All information presented here is population-based and relates to children who were under 15 years of age and domiciled in England at the time of diagnosis. In future years, it is intended that reports will cover the whole of the UK by making use of data from the national cancer registries of Wales, Scotland and Northern Ireland.

Incidence of childhood cancer, 2003 to 2012

Data and methods

Registration data were obtained from the NCRAS ENCORE database. The incidence data in this report relate to children who were residents of England and under 15 years of age at diagnosis during 2003 to 2012 with any malignant neoplasm or non-malignant CNS tumour included in the 'International Classification of Childhood Cancer, Third Edition' (ICCC-3).

The total number of registrations was 14,113. Incidence rates were calculated per million child years for the age groups 0–4, 5–9 and 10–14 years. For the full age range 0–14, age-standardised rates (ASR) were calculated using the world standard population, which assigns weights of 12, 10 and 9 to the age groups 0–4, 5–9 and 10–14 years, respectively.

Number of registrations

Table 2.1 shows numbers of registrations by ICCC-3 category, together with the percentage recorded as having microscopic verification (%MV) and the percentage registered from a death certificate only (%DCO). The mean number of registrations per year was 1,411. Leukaemia accounted for 29.9% of registrations, CNS and miscellaneous intracranial and intraspinal neoplasms for 24.9%, lymphomas for 10.7%, soft-tissue sarcomas for 6.6%, neuroblastoma and other peripheral nervous cell tumours for 5.9%, and renal tumours for 5.6%. No other diagnostic group accounted for more than 5% of registrations.

Overall, 92.4% of registrations were MV. The only main diagnostic groups to have less than 90% MV were CNS tumours (82.5%), retinoblastoma (69.0%) and other and unspecified malignant tumours (50.9%). The lower %MV for CNS tumours and retinoblastoma are a consequence of the relatively low proportions of children in these categories whose tumours are biopsied, while the low %MV for other and unspecified malignant tumours reflects the provisional nature of the data for a high proportion of patients in this small and miscellaneous group. Only 0.2% of registrations were DCO, and several groups had no DCO registrations. The relative frequencies of the main diagnostic groups were similar to those in cancer registry data from other countries in Europe, North America and Oceania. The %MV and %DCO were typical of typical of those for cancer registries with high-quality data.

Table 2.1 Cancers registered among children under 15 years of age and resident in England, 2003 to 2012, grouped according to 'International Classification of Childhood Cancers, Third Edition' (ICCC-3)

Numbers of registrations (N), percentage with microscopic verification (%MV) and percentage registered from death certificate only (%DCO)

ICCC-3	Diagnostic group	N	%MV	%DCO
I-XII	All cancers	14113	92.4	0.2
I	Leukaemia	4219	97.7	0.2
Ia	Lymphoid leukaemia	3277	98.3	0.1
Ib	Acute myeloid leukaemia	698	97.0	0.3
Ic	Chronic myeloproliferative diseases	63	96.8	1.6
Id	Myelodysplastic syndrome & other myeloproliferative diseases	115	95.7	0.9
Ie	Other & unspecified leukaemias	66	84.8	1.5
II	Lymphoma	1513	96.8	0.1
IIa	Hodgkin lymphoma	620	98.9	0.0
IIb, IIc	Non-Hodgkin lymphoma (including Burkitt lymphoma)	776	96.9	0.0
IId	Miscellaneous lympohoreticular neoplasms	94	88.3	0.0
IIe	Unspecified lymphomas	23	73.9	4.3
III	CNS & miscellaneous intracranial & intraspinal neoplasms	3510	82.5	0.1
IIIa	Ependymoma & choroid plexus tumours	347	97.7	0.0
IIIb	Astrocytoma	1466	85.0	0.0
IIIc	Intracranial & intraspinal embryonal tumours	638	98.9	0.0
IIId	Other gliomas	378	43.7	0.3
IIIe	Other specified intracranial & intraspinal neoplasms	533	89.5	0.0
IIIf	Unspecified intracranial & intraspinal neoplasms	148	25.7	2.7
IV	Neuroblastoma & other peripheral nervous cell tumours	836	96.3	0.0
IVa	Neuroblastoma & ganglioneuroblastoma	830	96.3	0.0
IVb	Other peripheral nervous cell tumours	6	100.0	0.0
V	Retinoblastoma	371	69.0	0.0
VI	Renal tumours	793	97.2	0.1
VIa	Nephroblastoma & other nonepithelial renal tumours	771	97.4	0.1
VIb	Renal carcinomas	18	100.0	0.0
VIc	Unspecified malignant renal tumours	4	50.0	0.0

ICCC-3	Diagnostic group	N	%MV	%DCO
VII	Hepatic tumours	176	95.5	0.6
VIIa	Hepatoblastoma	144	95.8	0.0
VIIb	Hepatic carcinomas	31	96.8	0.0
VIIc	Unspecified malignant hepatic tumours	1	0.0	100.0
VIII	Malignant bone tumours	605	97.5	0.3
VIIIa	Osteosarcoma	334	99.1	0.6
VIIIb	Chondrosarcoma	13	100.0	0.0
VIIIc	Ewing sarcoma family tumours of bone	225	98.7	0.0
VIIId	Other specified malignant bone tumours	19	100.0	0.0
VIIIe	Unspecified malignant bone tumours	14	35.7	0.0
IX	Soft tissue & other extraosseous sarcomas	928	98.7	0.0
IXa	Rhabdomyosarcoma	461	99.3	0.0
IXb	Fibrosarcoma, peripheral nerve sheath tumours & other fibrous neoplasms	93	98.9	0.0
IXc	Kaposi sarcoma	3	66.7	0.0
IXd	Other specified soft tissue sarcomas	298	98.0	0.0
IXe	Unspecified soft tissue sarcomas	73	98.6	0.0
X	Germ cell & gonadal tumours	506	92.1	0.0
Xa	Intracranial & intraspinal germ cell tumours	164	82.9	0.0
Xb	Other malignant extragonadal germ cell tumours	130	93.8	0.0
Xc	Malignant gonadal germ cell tumours	191	97.9	0.0
Xd	Gonadal carcinomas	14	100.0	0.0
Xe	Other & unspecified malignant gonadal tumours	7	100.0	0.0
XI	Other carcinomas & malignant melanomas	544	97.8	0.2
XIa	Adrenocortical carcinoma	17	100.0	0.0
XIb	Thyroid carcinoma	106	100.0	0.0
XIc	Nasopharyngeal carcinoma	26	100.0	0.0
XId	Malignant melanoma	97	95.9	0.0
XIe	Skin carcinoma	111	99.1	0.0
XIf	Other & unspecified carcinomas	187	96.3	0.5
XII	Other & unspecified malignant tumours	112	50.9	2.7
XIIa	Other specified malignant tumours	29	100.0	0.0
XIIb	Unspecified malignant tumours	83	33.7	3.6

Incidence

Table 2.2 shows incidence rates of childhood cancer by ICCC-3 category for boys and girls separately. The total ASR was 167 per million in boys and 146 per million in girls, giving a sex ratio M/F=1.15. The cumulative risk of being diagnosed with cancer in the first 15 years of life was 1 in 410 for boys and 1 in 471 for girls. For both boys and girls, incidence was highest in the first five years, fell to a minimum at age 5–9 years, and was slightly higher at age 10–14 years, marking the start of the unbroken rise in incidence that continues throughout adulthood. Incidence rates were within the ranges reported from other countries in Europe, North America and Oceania.

Among diagnostic categories with at least 50 registrations, the highest sex ratio was for Non-Hodgkin lymphoma (M/F=2.6). There were also relatively marked male excesses for Hodgkin lymphoma (M/F=1.7) and Miscellaneous lympohoreticular neoplasms (M/F=1.6), and smaller male excesses (M/F between 1.5 and 1.0) were found in many other categories. For a few categories, incidence was higher among girls than boys. The categories with at least 50 registrations that had the largest female excesses were Thyroid carcinoma (M/F=0.41), Malignant gonadal germ cell tumours (M/F=0.55), Other (extracranial & extraspinal) malignant extragonadal germ cell tumours (M/F=0.63), and Malignant melanoma (M/F=0.64). There were smaller female excesses for Nephroblastoma & other nonepithelial renal tumours (M/F=0.85) and Retinoblastoma (M/F=0.92).

Leukaemias formed the most frequent diagnostic group before 5 years of age, when they accounted for 37% of all cancers in boys and 35% in girls. At older ages, however, Leukaemias were outnumbered by CNS & miscellaneous intracranial & intraspinal neoplasms, which accounted for 33% of all cancers in boys and 32% in girls at age 5-9 and for 25% in both boys and girls at age 10-14. There were several distinctive patterns of incidence by age. For many types of cancer, incidence was highest before 5 years of age and lowest at age 10-14. These included Lymphoid leukaemia, Ependymoma & choroid plexus tumours, Intracranial & intraspinal embryonal tumours (mainly medulloblastoma), Neuroblastoma, Retinoblastoma, Nephroblastoma & other nonepithelial renal tumours, Hepatoblastoma, and Rhabdomyosarcoma. For other types, incidence was low in the first few years of life and increased throughout childhood. Examples include Hodgkin lymphoma, Non-Hodgkin lymphoma, Osteosarcoma, Ewing sarcoma family tumours, Intracranial & intraspinal germ cell tumours (especially in boys), Malignant gonadal germ cell tumours in girls, and nearly all Carcinomas. Incidence was lowest at 5–9 years of age for Acute myeloid leukaemia, and for Malignant gonadal germ cell tumours in boys.

Table 2.2 Cancer incidence among children under 15 years of age and resident in England, 2003-2012, grouped according to 'International Classification of Childhood Cancers, Third Edition' (ICCC-3)

Incidence per million child-years by five-year age group and age-standardised rates (ASR), separately for males and females. Rates based on fewer than 5 registrations are in *italics.*

ICCC-3	Diagnostic group	Male				Female			
		0-4	5-9	10-14	ASR	0-4	5-9	10-14	ASR
I-XII	All cancers	216.73	129.85	141.50	166.86	197.64	101.64	124.91	145.56
I	Leukaemia	79.71	39.63	27.63	51.66	68.30	32.10	25.81	44.29
Ia	Lymphoid leukaemia	64.29	31.86	19.02	40.68	54.50	26.08	16.58	34.32
Ib	Acute myeloid leukaemia	11.02	6.07	6.32	8.06	10.17	4.52	7.02	7.43
Ic	Chronic myeloproliferative diseases	*0.19*	0.39	1.30	0.58	*0.20*	0.41	1.56	0.66
Id	Myelodysplastic syndrome & other myeloproliferative diseases	2.77	0.85	0.62	1.53	2.11	0.68	0.39	1.15
Ie	Other & unspecified leukaemias	1.45	0.46	0.37	0.82	1.32	0.41	*0.26*	0.72
II	Lymphoma	12.03	21.02	32.52	20.88	5.42	7.32	18.60	9.86
IIa	Hodgkin lymphoma	2.33	6.20	16.17	7.60	*0.26*	2.46	12.16	4.43
IIb, IIc	Non-Hodgkin lymphoma (including Burkitt lymphoma)	7.18	13.51	15.30	11.58	3.37	4.24	6.18	4.47
IId	Miscellaneous lympohoreticular neoplasms	2.14	1.11	0.50	1.33	1.65	0.55	*0.13*	0.85
IIe	Unspecified lymphomas	0.38	*0.20*	0.56	0.37	*0.13*	*0.07*	*0.13*	0.11
III	CNS & miscellaneous intracranial & intraspinal neoplasms	42.94	41.26	35.87	40.35	42.54	33.40	31.54	36.40

ICCC-3	Diagnostic group	Male				Female			
		0-4	5-9	10-14	ASR	0-4	5-9	10-14	ASR
IIIa	Ependymoma & choroid plexus tumours	7.12	2.48	2.17	4.18	5.55	3.29	1.89	3.76
IIIb	Astrocytoma	16.06	18.15	13.88	16.10	19.55	14.24	13.33	16.03
IIIc	Intracranial & intraspinal embryonal tumours	10.01	9.60	4.89	8.39	8.26	4.31	4.23	5.81
IIId	Other gliomas	3.71	4.83	4.58	4.33	3.57	4.31	3.51	3.79
IIIe	Other specified intracranial & intraspinal neoplasms	3.65	5.03	8.92	5.63	3.77	5.95	7.15	5.45
IIIf	Unspecified intracranial & intraspinal neoplasms	2.39	1.18	1.42	1.72	1.85	1.30	1.43	1.55
IV	Neuroblastoma & other peripheral nervous cell tumours	23.61	3.07	0.99	10.42	22.39	3.15	0.85	9.93
IVa	Neuroblastoma & ganglioneuroblastoma	23.61	3.07	0.81	10.36	22.33	3.15	0.72	9.87
IVb	Other peripheral nervous cell tumours	-	-	*0.19*	*0.05*	*0.07*	-	*0.13*	*0.06*
V	Retinoblastoma	10.89	0.52	*0.12*	4.42	12.02	0.34	*0.07*	4.78
VI	Renal tumours	18.26	3.92	1.36	8.73	20.54	5.89	1.56	10.30
VIa	Nephroblastoma & other nonepithelial renal tumours	18.07	3.85	0.99	8.53	20.34	5.89	0.98	10.06
VIb	Renal carcinomas	*0.19*	*0.07*	0.31	0.18	-	-	0.59	0.17
VIc	Unspecified malignant renal tumours	-	-	*0.06*	*0.02*	*0.20*	-	-	*0.08*
VII	Hepatic tumours	4.85	0.65	0.43	2.21	3.96	0.34	1.11	1.97
VIIa	Hepatoblastoma	4.47	0.59	*0.19*	1.97	3.77	*0.14*	*0.13*	1.54
VIIb	Hepatic carcinomas	0.38	*0.07*	*0.25*	0.24	*0.13*	*0.21*	0.98	0.40
VIIc	Unspecified malignant hepatic tumours	-	-	-	-	*0.07*	-	-	*0.03*

ICCC-3	Diagnostic group	Male				Female			
		0-4	5-9	10-14	ASR	0-4	5-9	10-14	ASR
VIII	Malignant bone tumours	1.76	5.16	13.82	6.36	0.79	5.89	11.51	5.55
VIIIa	Osteosarcoma	0.44	2.61	8.18	3.39	*0.20*	3.08	6.96	3.09
VIIIb	Chondrosarcoma	-	*0.20*	0.37	0.17	-	-	*0.26*	*0.08*
VIIIc	Ewing sarcoma family tumours of bone	0.94	2.09	4.58	2.37	0.53	2.46	3.90	2.13
VIIId	Other specified malignant bone tumours	*0.25*	*0.13*	0.50	0.28	-	*0.14*	*0.20*	0.10
VIIIe	Unspecified malignant bone tumours	*0.13*	*0.13*	*0.19*	0.14	*0.07*	*0.21*	*0.20*	0.15
IX	Soft tissue & other extraosseous sarcomas	13.16	9.27	11.59	11.45	10.44	6.37	9.04	8.72
IXa	Rhabdomyosarcoma	8.56	5.55	3.72	6.18	5.81	3.70	2.47	4.16
IXb	Fibrosarcoma, peripheral nerve sheath tumours & other fibrous neoplasms	1.26	0.52	1.61	1.12	0.99	0.41	1.17	0.86
IXc	Kaposi sarcoma	*0.06*	-	*0.06*	*0.04*	-	-	*0.07*	*0.02*
IXd	Other specified soft tissue sarcomas	2.77	2.35	4.96	3.27	2.97	1.92	4.23	3.00
IXe	Unspecified soft tissue sarcomas	0.50	0.85	1.24	0.83	0.66	0.34	1.11	0.69
X	Germ cell & gonadal tumours	6.74	1.37	5.64	4.69	7.53	2.67	8.71	6.31
Xa	Intracranial & intraspinal germ cell tumours	1.13	1.11	4.09	1.98	1.65	0.89	1.63	1.40
Xb	Other malignant extragonadal germ cell tumours	2.64	*0.07*	0.62	1.22	4.76	0.34	-	1.95
Xc	Malignant gonadal germ cell tumours	2.90	*0.13*	0.93	1.43	1.06	1.37	5.98	2.59

ICCC-3	Diagnostic group	Male				Female			
		0-4	5-9	10-14	ASR	0-4	5-9	10-14	ASR
Xd	Gonadal carcinomas	*0.06*	-	-	*0.02*	-	*0.07*	0.78	0.25
Xe	Other & unspecified malignant gonadal tumours	-	*0.07*	-	*0.02*	*0.07*	-	0.33	0.12
XI	Other carcinomas & malignant melanomas	1.07	3.00	10.53	4.44	2.05	3.49	14.89	6.24
XIa	Adrenocortical carcinoma	*0.06*	*0.13*	*0.06*	*0.08*	0.66	*0.07*	*0.13*	0.32
XIb	Thyroid carcinoma	*0.19*	0.46	1.30	0.60	0.33	0.68	3.90	1.48
XIc	Nasopharyngeal carcinoma	-	*0.07*	1.24	0.38	-	*0.07*	*0.26*	0.10
XId	Malignant melanoma	0.44	0.33	1.67	0.76	0.40	1.03	2.41	1.18
XIe	Skin carcinoma	*0.19*	0.65	2.35	0.97	0.33	1.03	2.60	1.21
XIf	Other & unspecified carcinomas	*0.19*	1.37	3.90	1.65	0.33	0.62	5.59	1.95
XII	Other & unspecified malignant tumours	1.70	0.98	0.99	1.26	1.65	0.68	1.24	1.22
XIIa	Other specified malignant tumours	0.57	-	*0.06*	0.24	0.66	*0.27*	0.33	0.44
XIIb	Unspecified malignant tumours	1.13	0.98	0.93	1.02	0.99	0.41	0.91	0.78

Population-based survival of children diagnosed with cancer, 2003 to 2012

Data and methods

The survival analyses are for children who were residents of England and under 15 years of age at diagnosis during 2003 to 2012 with any malignant neoplasm or non-malignant CNS tumour included in ICCC-3. Cases ascertained by death certificate only were excluded. The total number of cases analysed was 14,088. The study closing date for follow-up was 31 December 2014. Observed survival was estimated actuarially by Kaplan-Meier analysis. Trend in survival by year of diagnosis was analysed by Cox regression and tested by the χ^2 test with 1 degree of freedom. A trend was defined as statistically significant if the p-value was less than 0.05.

Results

Results are shown in Table 3.1 and Figures 3.1-3.62. For diagnostic categories with at least 50 registrations analysed, results are given for children diagnosed during each of the two five-year periods 2003 to 2007 and 2008 to 2012. For those with fewer than 50 registrations, results are given for the single 10-year period, 2003 to 2012.

Overall, five-year survival was 80% for children diagnosed in 2003 to 2007 and 83% for those diagnosed in 2008 to 2012. The trend in survival by year of diagnosis was highly significant ($p<0.001$).

Five-year survival of children with leukaemia exceeded 85%. For precursor lymphoblastic leukaemia, or acute lymphoblastic leukaemia (ALL), five-year survival was above 90%. Infants aged under one year with ALL have a markedly worse prognosis than older children, and their five-year survival remained below 70%. Survival from mature B-cell leukaemia was 88%. Acute myeloid leukaemia had lower survival than lymphoid leukaemia, slightly below 70%.

Survival increased significantly for children with lymphoma, from 88% in 2003 to 2007 to 93% in 2008 to 2012. Within this group, there were significant upward trends in survival for both Hodgkin lymphoma and Non-Hodgkin lymphoma.

Survival also increased significantly for children with intracranial and intraspinal tumours, with five-year survival increasing from 71% in 2003 to 2007 to 76% in 2008 to 2012. Survival increased between the two periods for many subtypes within this group, though the trends were only significant for Astrocytoma and Craniopharyngioma. Survival varied widely between different types of CNS tumour, with five-year survival ranging from over 90% for Neuronal & mixed neuronal-glial tumours, Choroid plexus papilloma and Craniopharyngioma to below 30% for Choroid plexus carcinoma and Atypical teratoid/rhabdoid tumour.

Five-year survival from neuroblastoma was 64% for children diagnosed in 2003 to 2007 and 68% in 2008 to 2012. Infants aged under one year with neuroblastoma have a much higher

survival rate than older children. Five-year survival was above 80% for infants and below 60% for older children. There was, however, a significant increasing trend in survival from neuroblastoma for children aged 1-14; five-year survival rose from 52% in 2003 to 2007 to 60% in 2008 to 2012. Survival from retinoblastoma was well over 95% throughout the study period, regardless of whether the disease was unilateral or bilateral.

There was a significant increasing trend in survival of children with renal tumours. For all subtypes combined, five-year survival increased from 84% to 90% between 2003 to 2007 and 2008 to 2012. Five-year survival from Wilms tumour, the most frequent type of childhood renal tumour, was around 90% throughout. Hepatic tumours had a somewhat worse prognosis than renal tumours. Five-year survival from hepatoblastoma, an embryonal tumour which mainly affects very young children was 78-79%, with no evidence of a time trend. Hepatic carcinoma, which is much less frequent and occurs mainly in older children, had much lower five-year survival of 50%, but with an increasing trend over time which just reached statistical significance

Five-year survival from both osteosarcoma and Ewing sarcoma family tumours of bone, the two main types of childhood bone tumour, was in the range 60-70% throughout the study period, with little sign of any trend over time. Five-year survival for all soft-tissue sarcomas was around 70%, but there was considerable variation between subtypes. Survival rates for rhabdomyosarcoma were around 66%, and those for rarer subtypes ranged from over 90% for fibrosarcoma and synovial sarcoma to just over 30% for extrarenal rhabdoid tumour. There was no significant time trend in survival for malignant bone tumours or soft-tissue sarcomas during the study period.

Five-year survival from malignant gonadal germ-cell tumours was over 95% both in boys and in girls. Survival from intracranial and intraspinal germ-cell tumours and from other extragonadal malignant germ-cell tumours was around 90%.

Five-year survival from thyroid carcinoma was well over 95%, and survival from malignant melanoma was around 90%.

Table 3.1 Population-based survival of children with cancer in England diagnosed 2003 to 2012

Number of cases analysed (N), five-year survival *(95% confidence interval)* by period of diagnosis, and result of chi-squared test for trend by year of diagnosis. In the test for trend, brackets around the χ^2 value indicate a negative trend. The test for trend is not reported for diagnostic groups with fewer than 5 deaths.

ICCC-3	Diagnostic group	N	2003-2007	2008-2012	2003-2012	χ^2 (1df) for trend
I-XII	All cancers	14088	80 *(79-80)*	83 *(82-84)*		28.9***
I	Leukaemia	4208	86 *(84-87)*	87 *(86-89)*		2.10
Ia.1	Precursor lymphoblastic leukaemia	3141	91 *(89-92)*	92 *(91-94)*		2.79
Ia.1	Precursor lymphoblastic leukaemia: age <1	115	67 *(53-77)*	64 *(50-75)*		(1.62)
Ia.1	Precursor lymphoblastic leukaemia: age 1-14	3026	92 *(90-93)*	93 *(92-95)*		3.83
Ia.2	Mature B-cell leukaemia	25			88 *(67-96)*	-
Ib	Acute myeloid leukaemia	696	70 *(65-74)*	67 *(61-71)*		(0.65)
Ic (part)	Chronic myeloid leukaemia	61	81 *(64-91)*	92 *(71-98)*		0.14
Id (part)	Myelodysplastic syndrome	55	79 *(60-90)*	73 *(51-86)*		0.08
Id (part)	Juvenile myelomonocytic leukaemia & chronic myelomonocytic leukaemia	58	64 *(46-77)*	68 *(45-83)*		(0.04)
Ie	Other & unspecified leukaemia	65	66 (45-80)	81 *(64-90)*		2.56
II	Lymphoma	1511	88 *(85-90)*	93 *(90-94)*		12.8***
IIa	Hodgkin lymphoma	620	94 *(90-96)*	97 *(94-99)*		3.98*

ICCC-3	Diagnostic group	N	2003-2007	2008-2012	2003-2012	χ^2 (1df) for trend
IIb, IIc	Non-Hodgkin lymphoma (incl. Burkitt lymphoma)	776	84 *(80-87)*	89 *(85-91)*		5.65*
III	Intracranial & intraspinal tumours	3505	71 *(68-73)*	76 *(73-78)*		7.20**
IIIa.1	Ependymoma	251	73 *(64-80)*	77 *(67-85)*		0.98
IIIa.2 (part)	Choroid plexus papilloma	65	97 *(80-100)*	97 *(80-100)*		-
IIIa.2 (part)	Choroid plexus carcinoma	31			26 *(12-44)*	3.30
IIIb	Astrocytoma	1466	79 *(76-82)*	82 *(79-85)*		3.97*
IIIc.1	Medulloblastoma	442	62 *(56-68)*	63 *(55-70)*		(0.72)
IIIc.2	Primitive neuroectodermal tumour	105	30 *(19-43)*	42 *(28-55)*		2.60
IIIc.4	Atypical teratoid/rhabdoid tumour	87	16 *(6-30)*	25 *(14-38)*		1.24
IIId.1	Oligodendroglioma	37			64 *(46-77)*	0.01
IIId.2	Mixed & unspecified glioma	317	45 *(37-52)*	53 *(45-61)*		2.43
IIIe.1	Pituitary adenoma	51	100	95 *(71-99)*		-
IIIe.2	Craniopharyngioma	170	96 *(88-98)*	100		4.46*
IIIe.3	Pineal parenchymal tumours	39			58 *(41-72)*	1.78
IIIe.4	Neuronal & mixed neuronal-glial tumours	225	94 *(87-97)*	98 *(94-100)*		0.63

ICCC-3	Diagnostic group	N	2003-2007	2008-2012	2003-2012	χ^2 (1df) for trend
IIIe.5	Meningioma	45			89 *(75-95)*	(0.36)
IV	Neuroblastoma & other peripheral nervous cell tumours	836	65 *(60-69)*	68 *(63-73)*		1.21
IVa	Neuroblastoma	830	64 *(59-69)*	68 *(63-73)*		1.48
IVa	Neuroblastoma: age <1	285	89 *(82-93)*	83 *(76-88)*		(3.30)
IVa	Neuroblastoma: age 1-14	545	52 *(46-58)*	60 *(53-66)*		6.56*
V	Retinoblastoma	371	98 *(95-99)*	99 *(96-100)*		3.35
V	Retinoblastoma: unilateral	228	98 *(94-100)*	99 *(93-100)*		-
V	Retinoblastoma: bilateral	117	98 *(88-100)*	100		-
VI	Renal tumours	792	84 *(81-88)*	90 *(86-93)*		6.33*
VIa.1	Wilms tumour	716	90 *(86-92)*	91 *(88-94)*		1.14
VIa.2	Rhabdoid renal tumour	25			16 *(5-33)*	2.44
VIa.3	Kidney sarcomas	25			84 *(62-94)*	-
VII	Hepatic tumours	175	71 *(60-80)*	75 *(65-83)*		1.67
VIIa	Hepatoblastoma	144	79 *(67-87)*	78 *(67-86)*		0.10
VIIb	Hepatic carcinoma	31			50 *(31-66)*	3.88*

ICCC-3	Diagnostic group	N	2003-2007	2008-2012	2003-2012	χ^2 (1df) for trend
VIII	Bone tumours	603	65 *(58-70)*	68 *(62-73)*		1.77
VIIIa	Osteosarcoma	332	63 *(55-71)*	63 *(54-70)*		1.15
VIIIc	Ewing sarcoma family tumours of bone	225	62 *(52-70)*	70 *(60-79)*		0.80
IX	Soft tissue sarcomas	928	68 *(64-72)*	71 *(67-75)*		2.80
IXa	Rhabdomyosarcoma	461	65 *(58-71)*	68 *(61-73)*		0.76
IXb.1	Fibrosarcoma	55	100	97 *(83-100)*		-
IXb.2	Malignant peripheral nerve sheath tumour	38			57 *(39-71)*	0.11
IXd.1, IXd.2	Extraosseous Ewing sarcoma family tumours	94	72 *(56-83)*	69 *(53-80)*		0.26
IXd.3	Extrarenal rhabdoid tumour	41			31 *(18-46)*	(0.74)
IXd.7	Synovial sarcoma	57	91 *(74-97)*	100		-
X	Germ cell & gonadal tumours	506	93 *(89-95)*	93 *(89-96)*		1.15
Xa	Intracranial & intraspinal germ cell tumours	164	91 *(82-95)*	91 *(82-96)*		0.08
Xb	Other extragonadal germ cell tumours	130	89 *(78-94)*	91 *(79-96)*		0.98
Xc	Gonadal germ cell tumours: male	63	100	97 *(80-100)*		-
Xc	Gonadal germ cell tumours: female	128	97 *(88-99)*	97 *(78-100)*		-
XIa	Adrenocortical carcinoma	17			74 *(45-90)*	-

ICCC-3	Diagnostic group	N	2003-2007	2008-2012	2003-2012	χ^2 (1df) for trend
XIb	Thyroid carcinoma	106	100	98 *(88-100)*		-
XIc	Nasopharyngeal carcinoma	26			84 *(63-94)*	-
XId	Malignant melanoma	97	89 *(77-94)*	92 *(76-97)*		(0.08)

- Not reported because fewer than 5 deaths
* P<0.05
** P<0.01
*** P<0.001

Figure 3.1 Population-based survival of children aged 0–14 years with cancer in England diagnosed 2003 to 2012

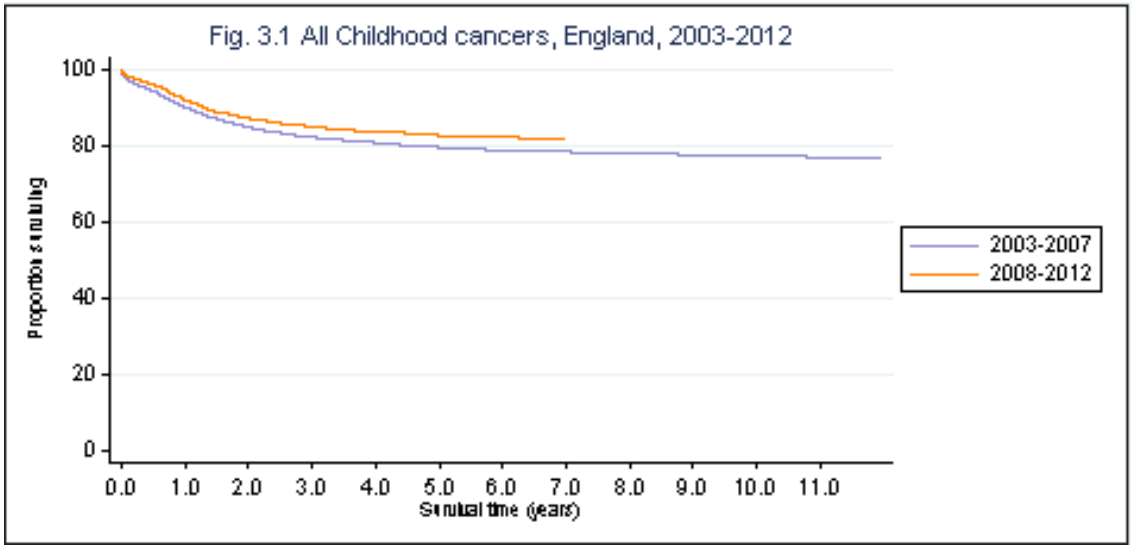


Figure 3.2 Population-based survival of children aged 0–14 years with leukaemia in England diagnosed 2003 to 2012

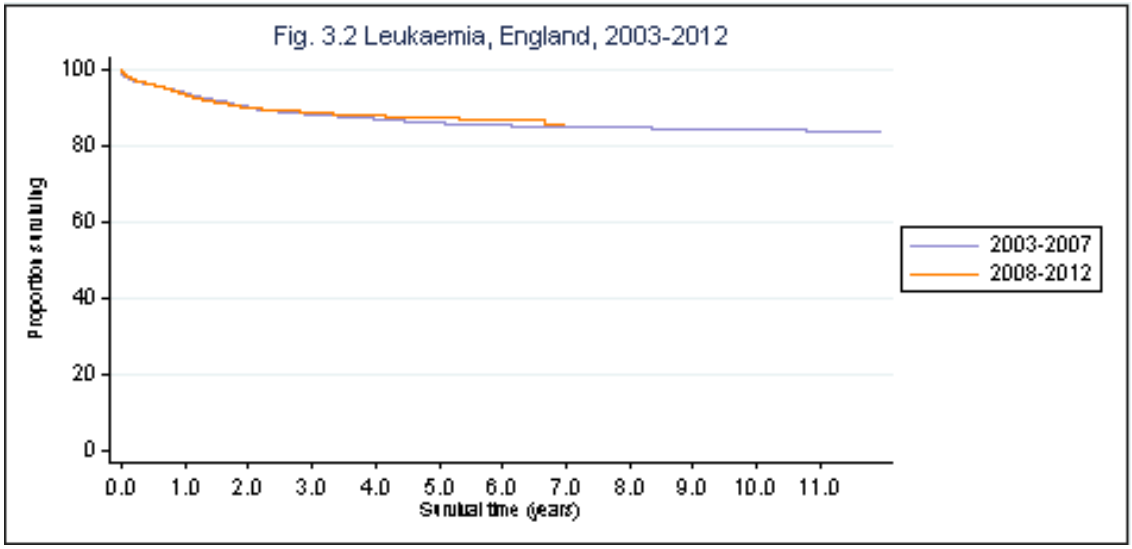


Figure 3.3 Population-based survival of children aged 0–14 years with precursor lymphoblastic leukaemia in England diagnosed 2003 to 2012

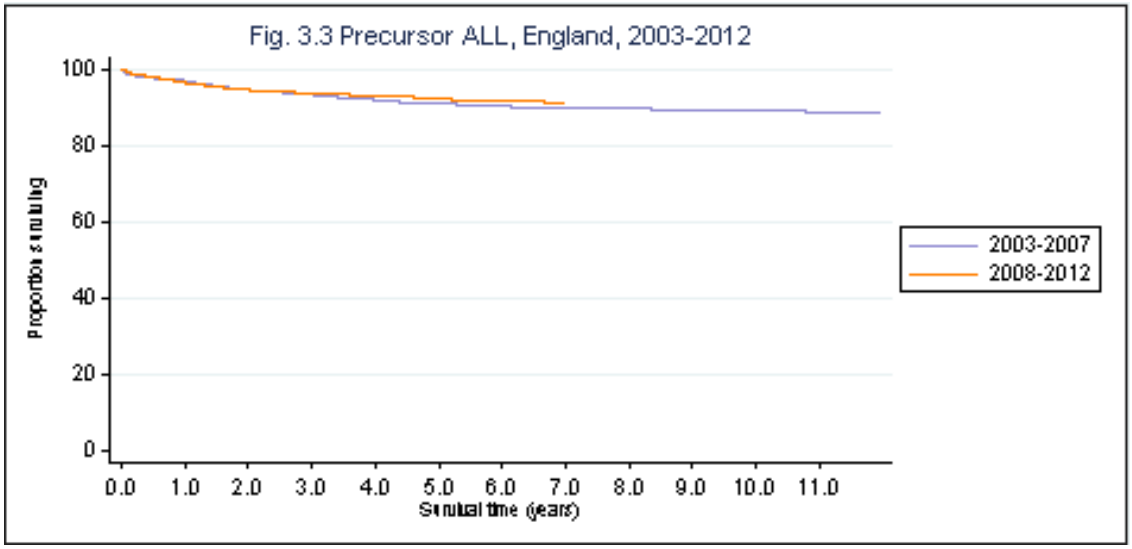


Figure 3.4 Population-based survival of children aged under 1 year with precursor lymphoblastic leukaemia in England diagnosed 2003 to 2012

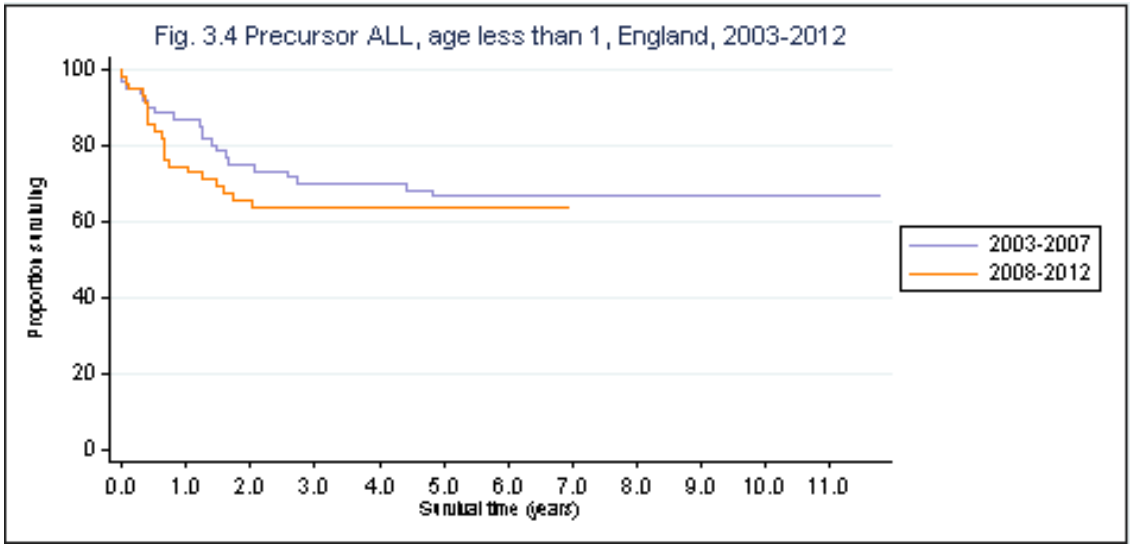


Figure 3.5 Population-based survival of children aged 1–14 years with precursor lymphoblastic leukaemia in England diagnosed 2003 to 2012

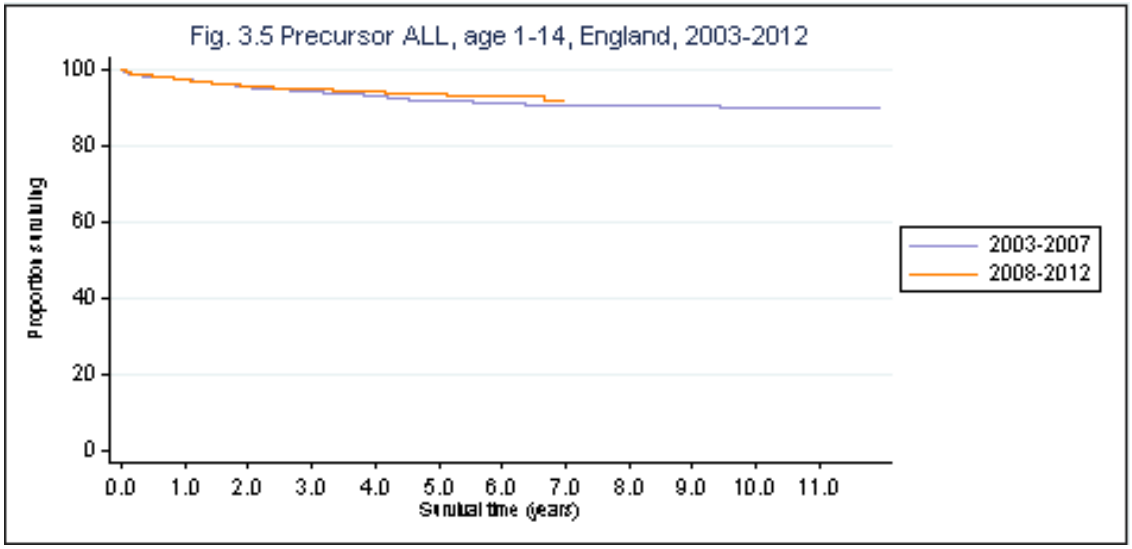


Figure 3.6 Population-based survival of children aged 0–14 years with mature B-cell leukaemia in England diagnosed 2003 to 2012

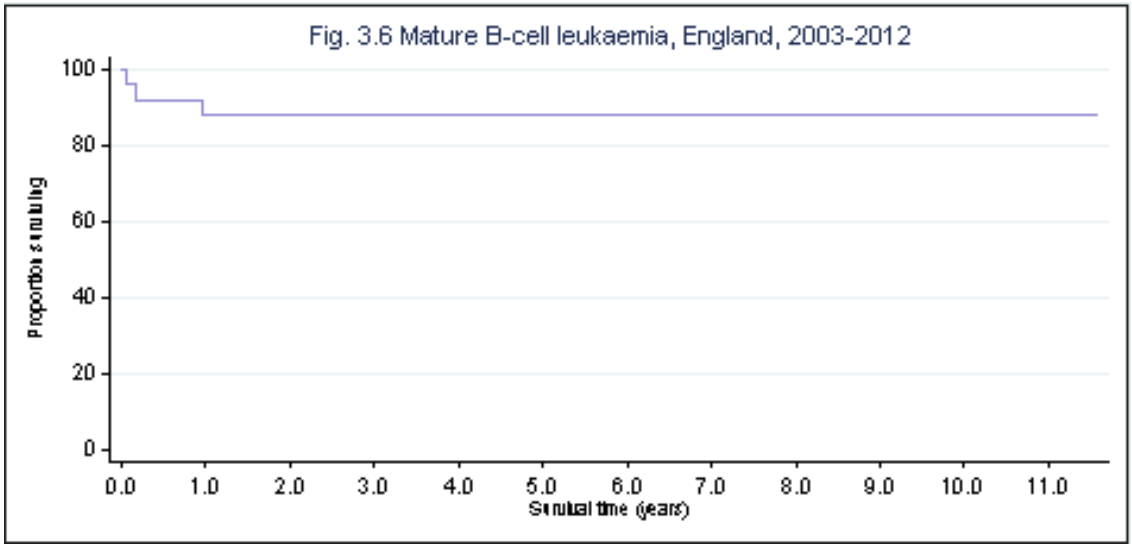


Figure 3.7 Population-based survival of children aged 0–14 years with acute myeloid leukaemia in England diagnosed 2003 to 2012

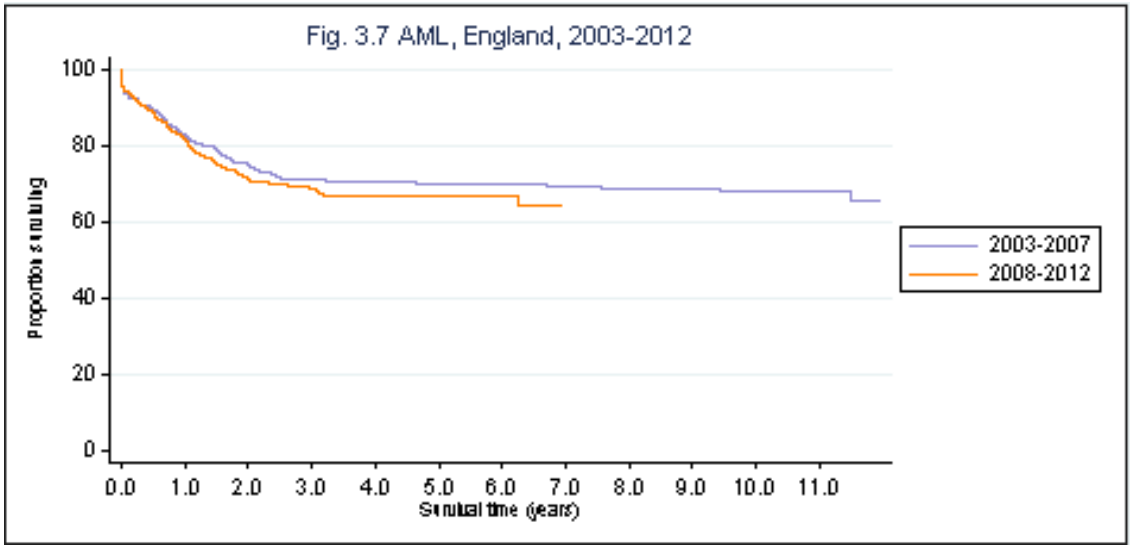


Figure 3.8 Population-based survival of children aged 0–14 years with chronic myeloid leukaemia in England diagnosed 2003 to 2012

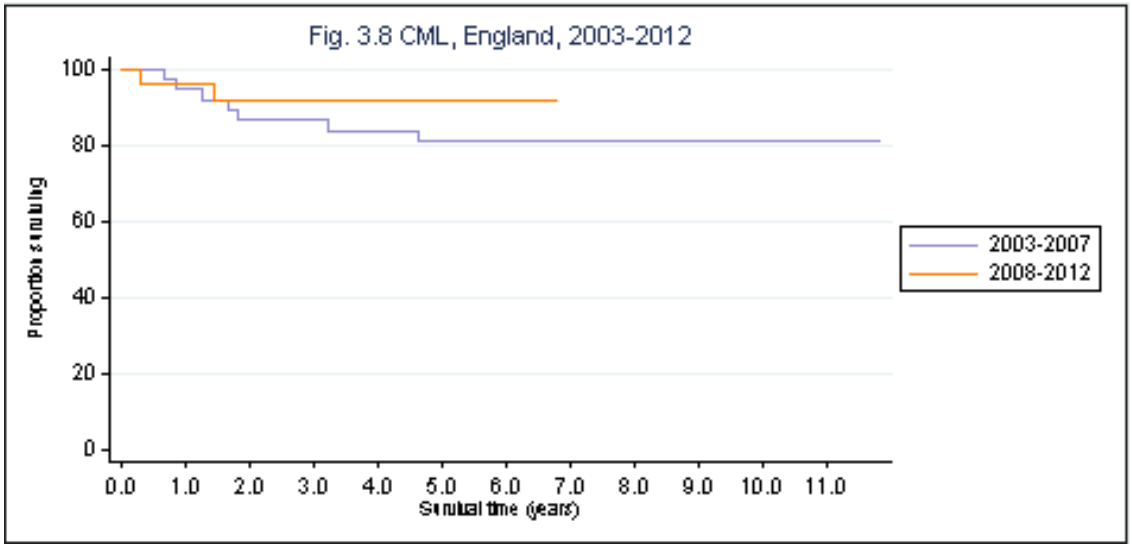


Figure 3.9 Population-based survival of children aged 0–14 years with myelodysplastic syndrome in England diagnosed 2003 to 2012

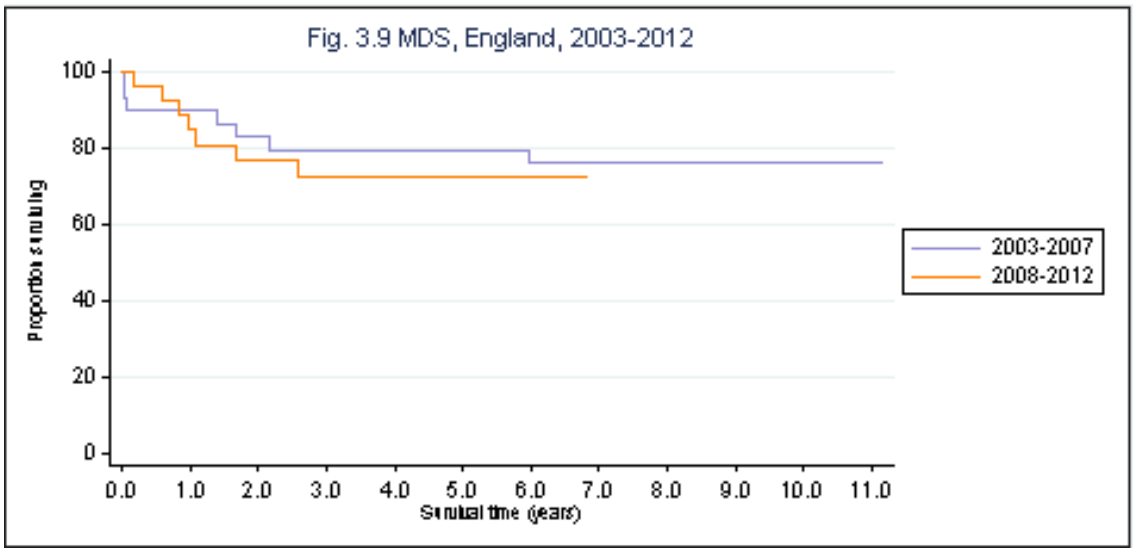


Figure 3.10 Population-based survival of children aged 0–14 years with juvenile myelomonocytic and chronic myelomonocytic leukaemia in England diagnosed 2003 to 2012

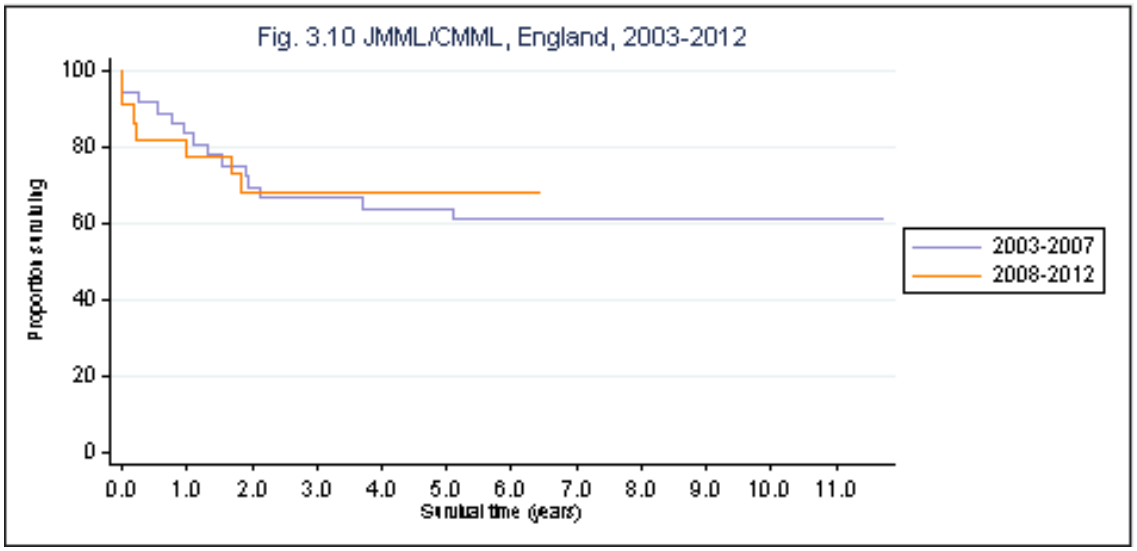


Figure 3.11 Population-based survival of children aged 0–14 years with other and unspecified leukaemia in England diagnosed 2003 to 2012

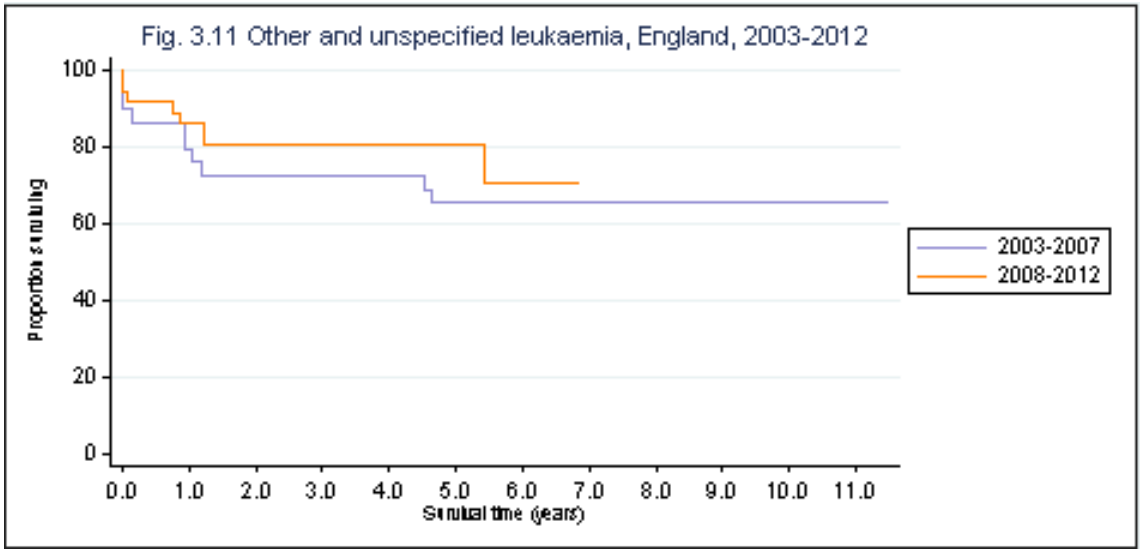


Figure 3.12 Population-based survival of children aged 0–14 years with lymphoma in England diagnosed 2003 to 2012

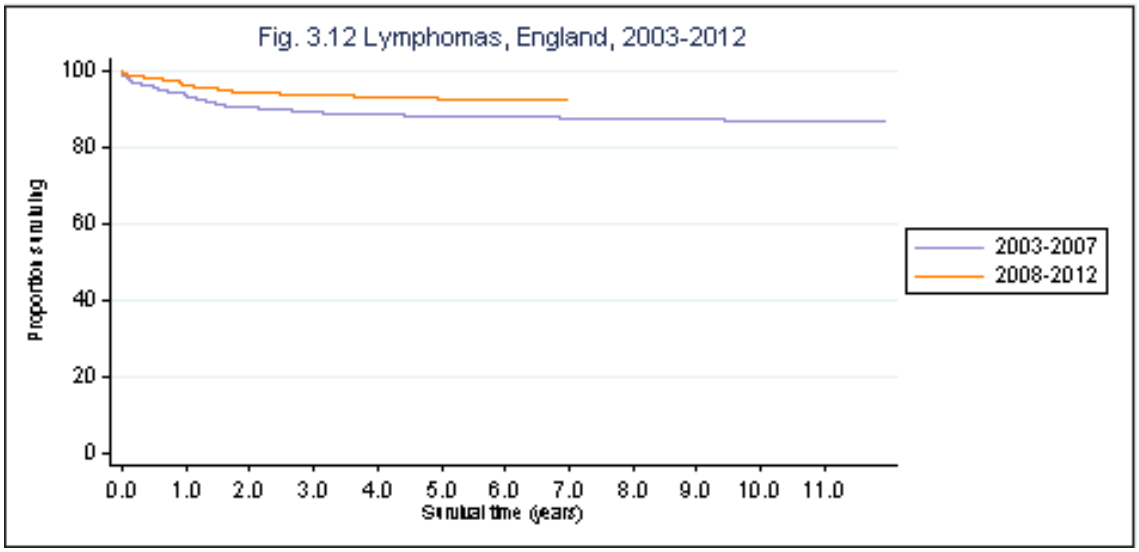


Figure 3.13 Population-based survival of children aged 0–14 years with Hodgkin lymphoma in England diagnosed 2003 to 2012

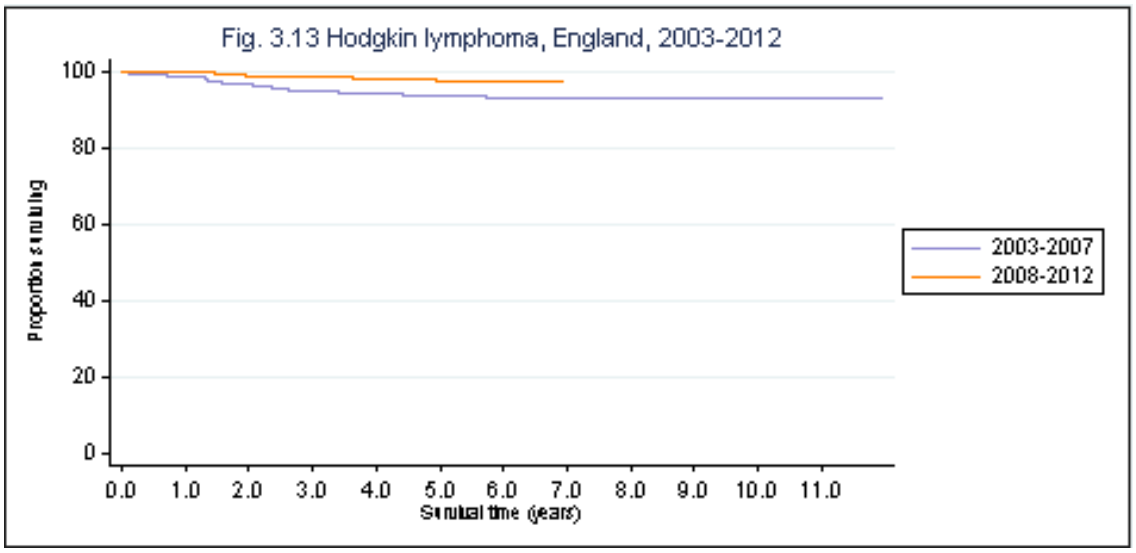


Figure 3.14 Population-based survival of children aged 0–14 years with non-Hodgkin lymphoma (including Burkitt lymphoma) in England diagnosed 2003 to 2012

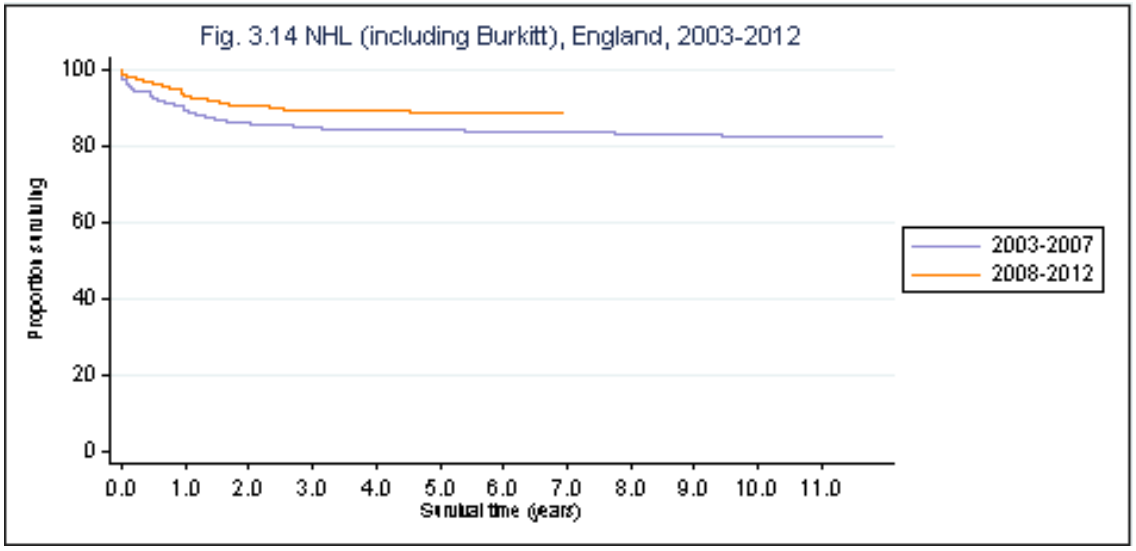


Figure 3.15 Population-based survival of children aged 0–14 years with intracranial and intraspinal tumours in England diagnosed 2003 to 2012

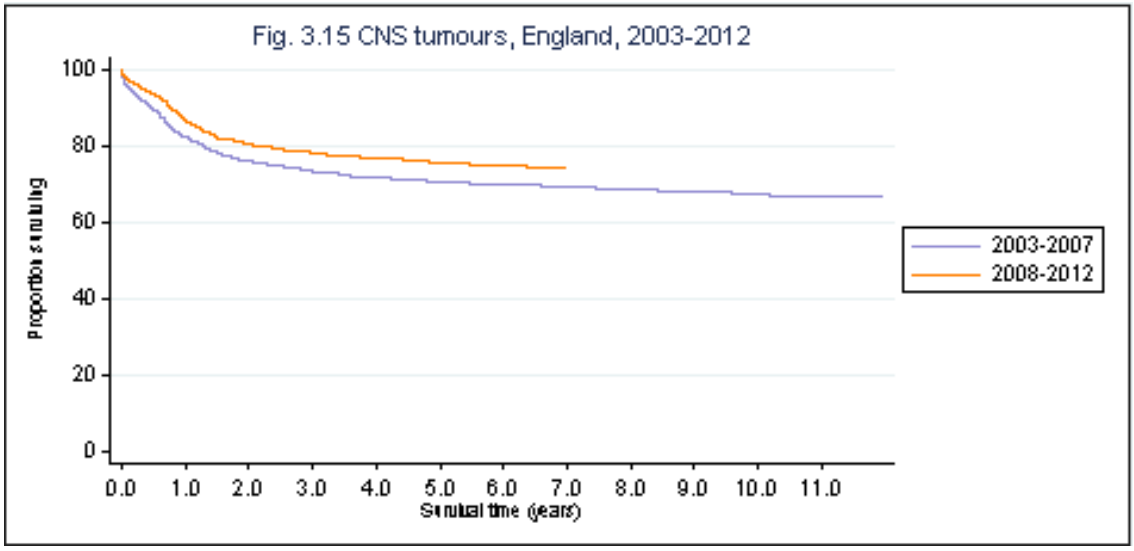


Figure 3.16 Population-based survival of children aged 0–14 years with ependymoma in England diagnosed 2003 to 2012

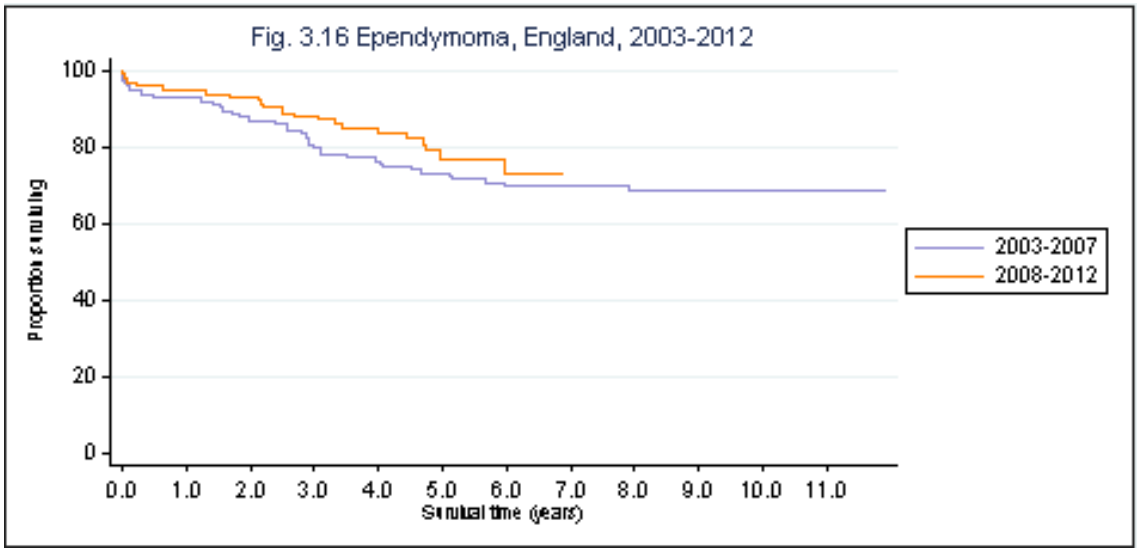


Figure 3.17 Population-based survival of children aged 0–14 years with choroid plexus papilloma in England diagnosed 2003 to 2012

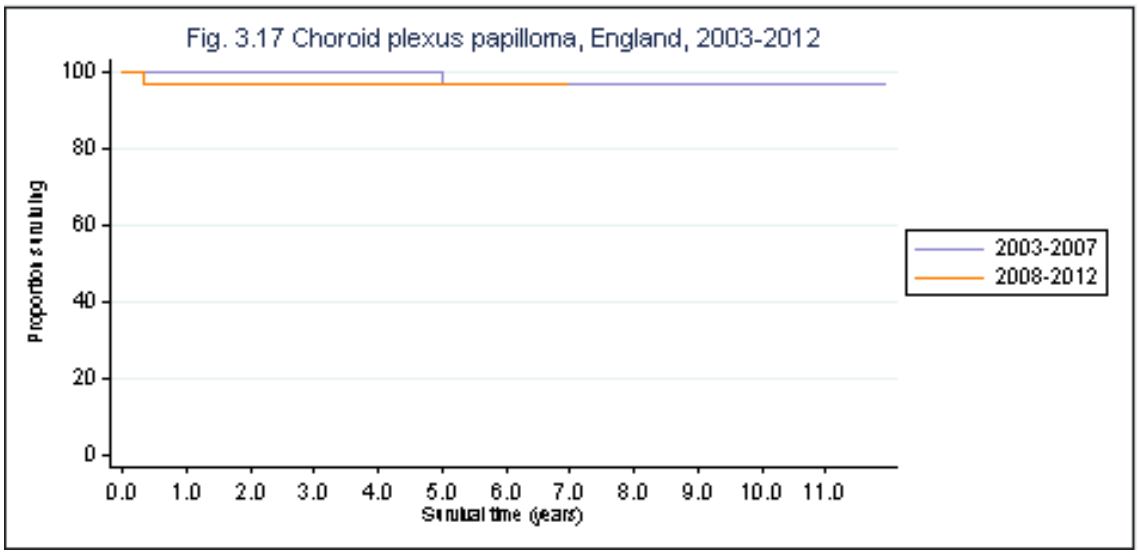


Figure 3.18 Population-based survival of children aged 0–14 years with choroid plexus carcinoma in England diagnosed 2003 to 2012

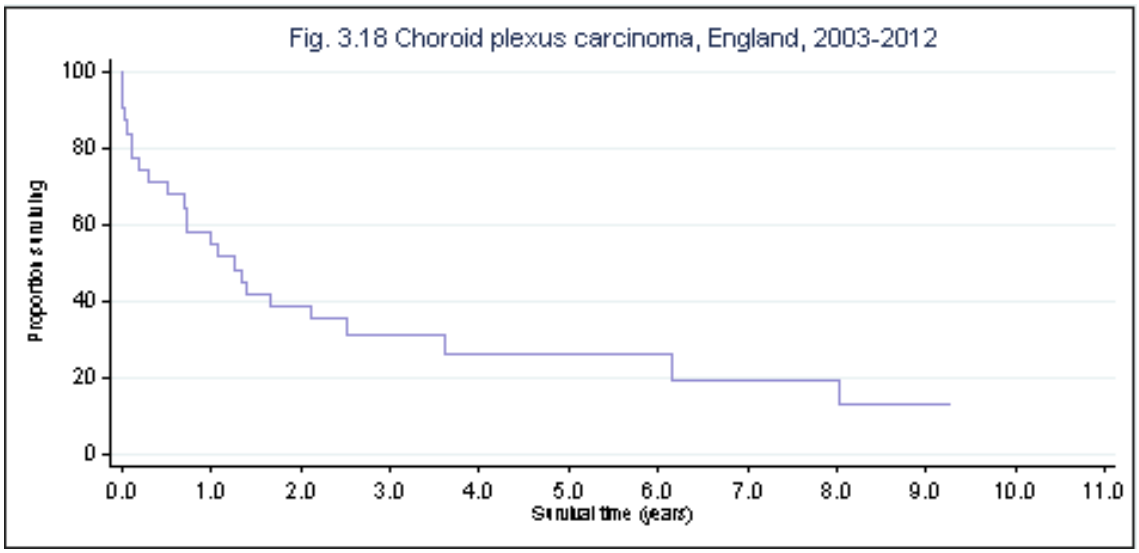


Figure 3.19 Population-based survival of children aged 0–14 years with astrocytoma in England diagnosed 2003 to 2012

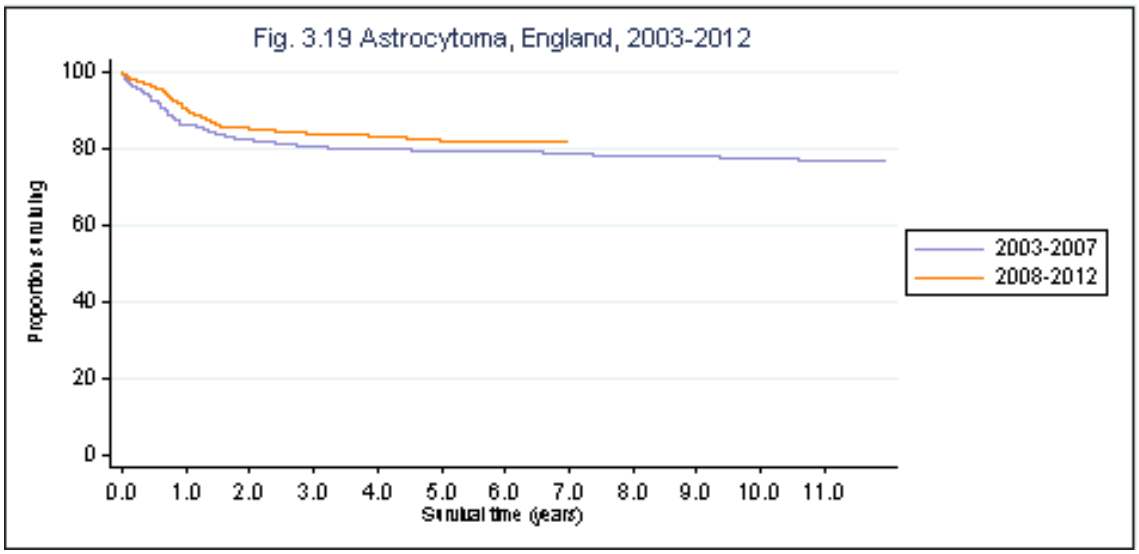


Figure 3.20 Population-based survival of children aged 0–14 years with medulloblastoma in England diagnosed 2003 to 2012

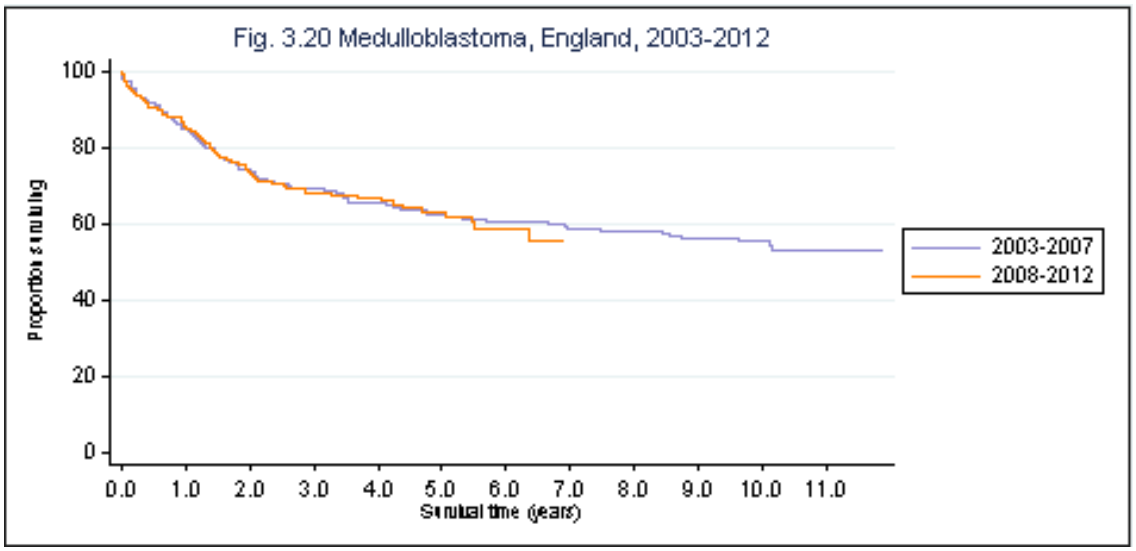


Figure 3.21 Population-based survival of children aged 0–14 years with primitive neuroectodermal tumour in England diagnosed 2003 to 2012

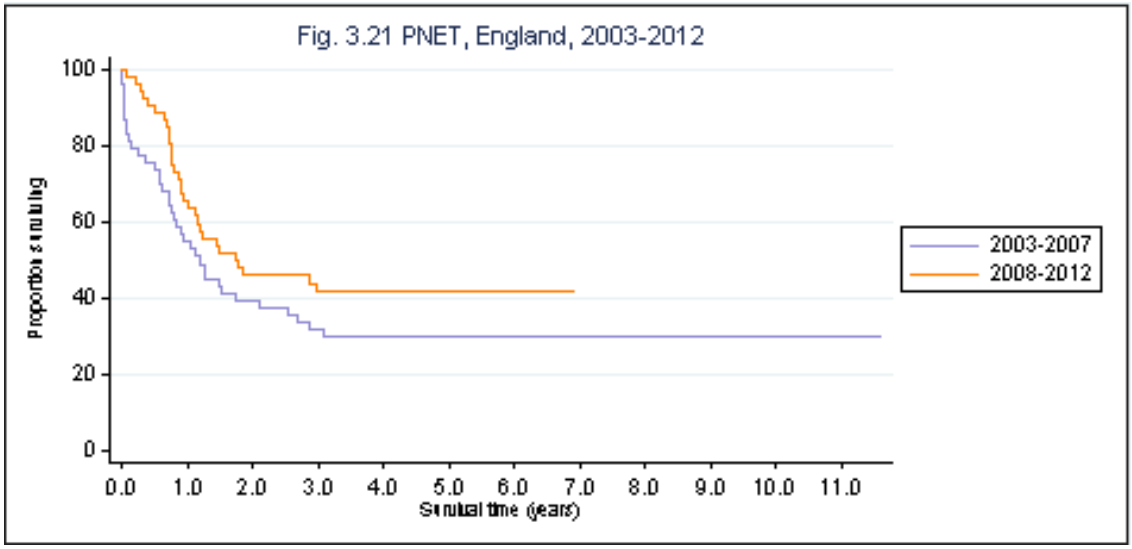


Figure 3.22 Population-based survival of children aged 0–14 years with atypical teratoid/rhabdoid tumour in England diagnosed 2003 to 2012

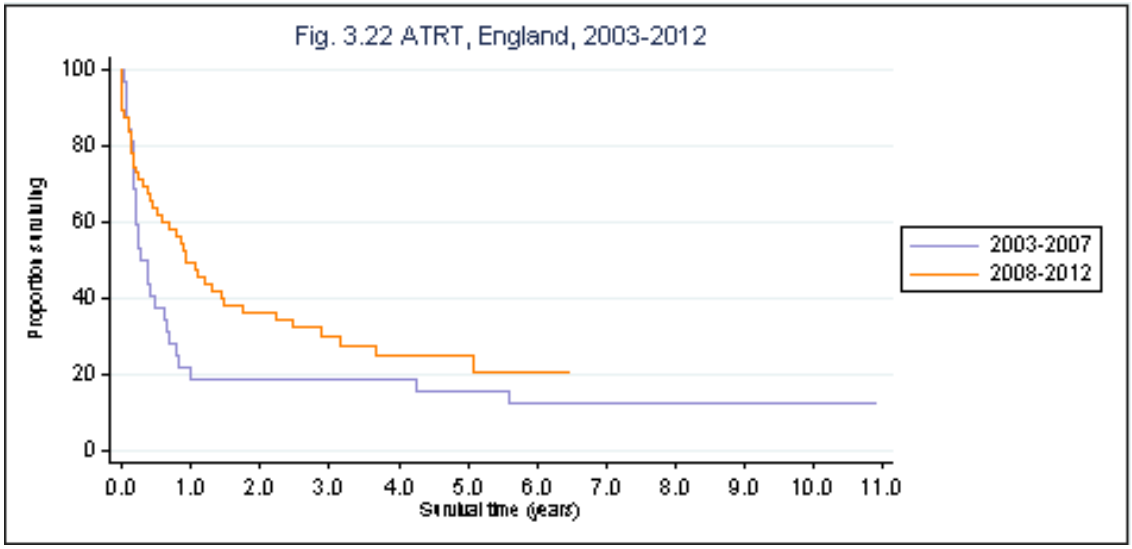


Figure 3.23 Population-based survival of children aged 0–14 years with oligodendroglioma in England diagnosed 2003 to 2012

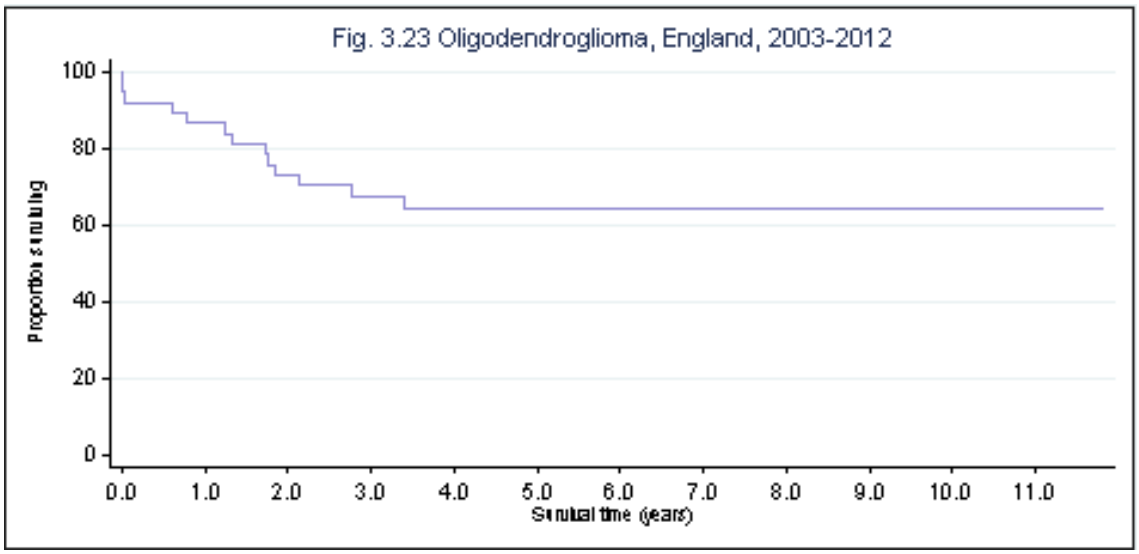


Figure 3.24 Population-based survival of children aged 0–14 years with mixed and unspecified glioma in England diagnosed 2003 to 2012

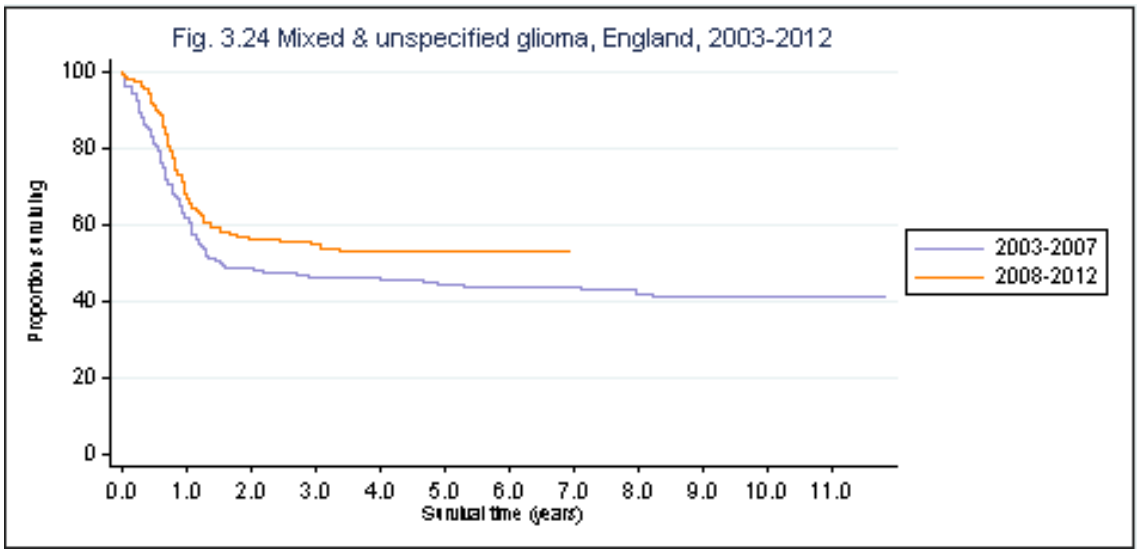


Figure 3.25 Population-based survival of children aged 0–14 years with pituitary adenoma and carcinoma in England diagnosed 2003 to 2012

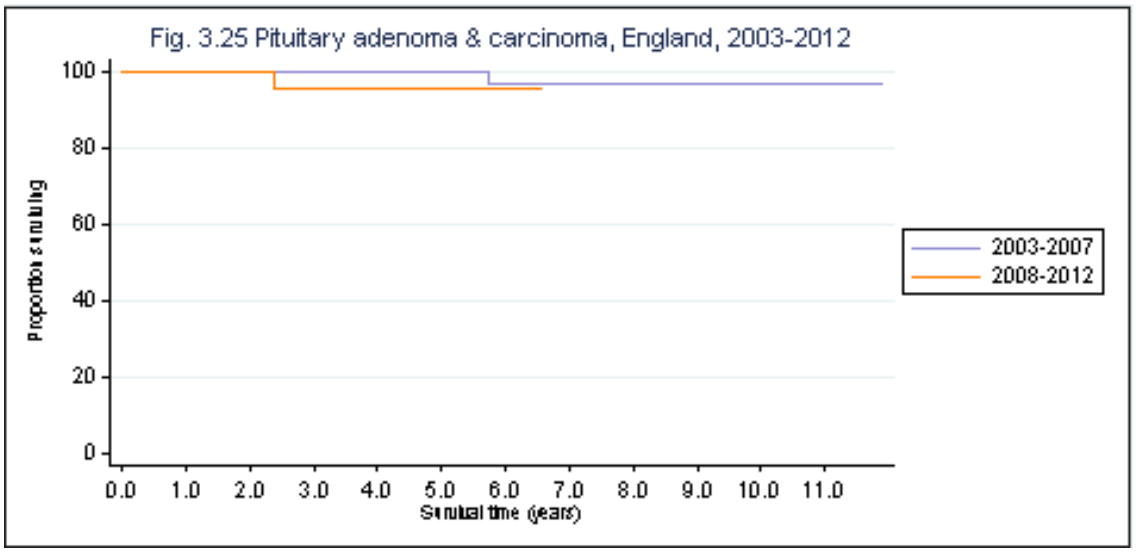


Figure 3.26 Population-based survival of children aged 0–14 years with craniopharyngioma in England diagnosed 2003 to 2012

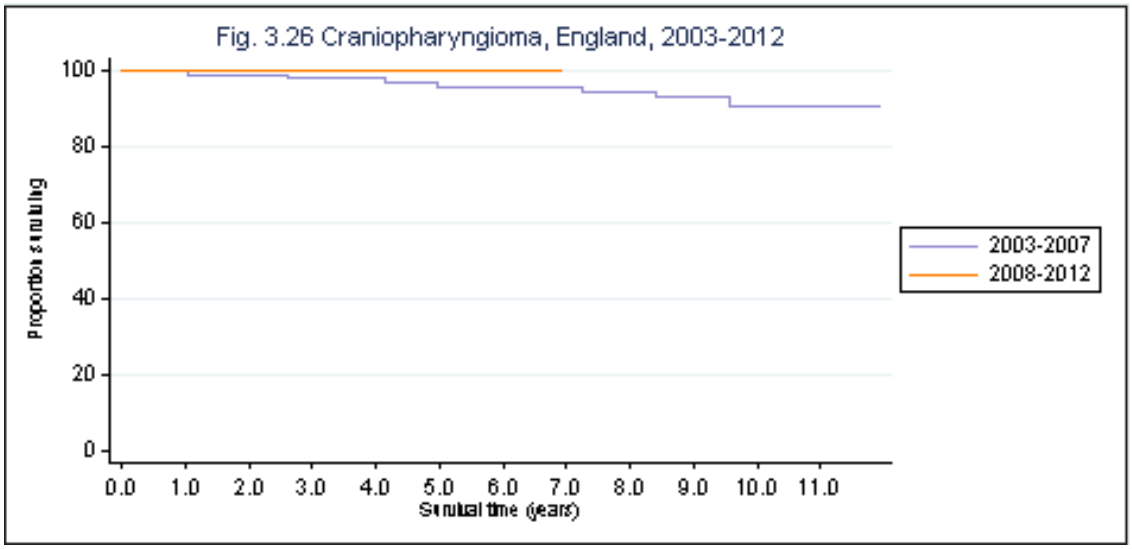


Figure 3.27 Population-based survival of children aged 0–14 years with pineal parenchymal tumours in England diagnosed 2003 to 2012

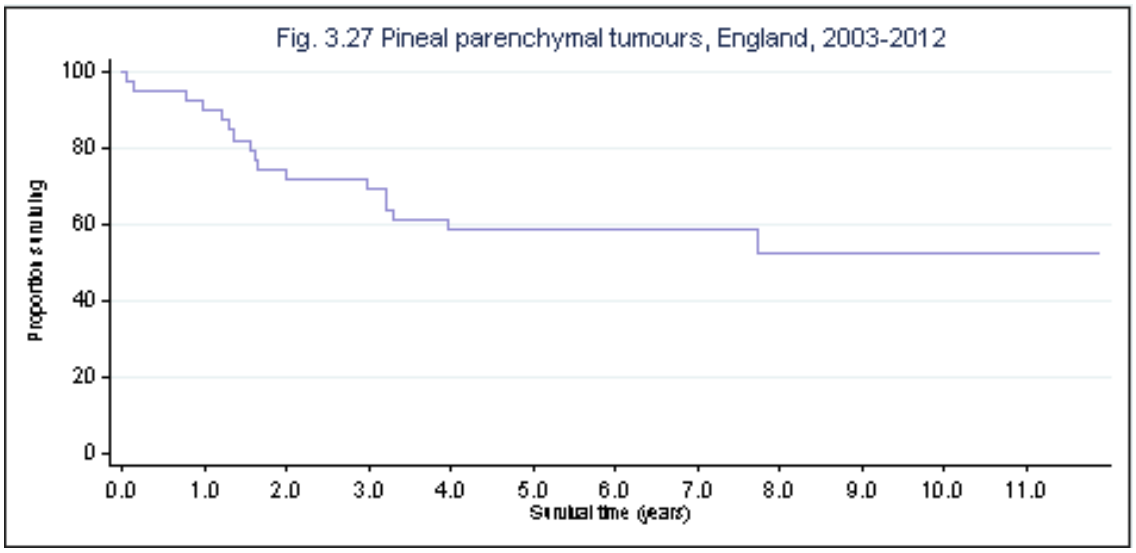


Figure 3.28 Population-based survival of children aged 0–14 years with neuronal and mixed neuronal-glial tumours in England diagnosed 2003 to 2012

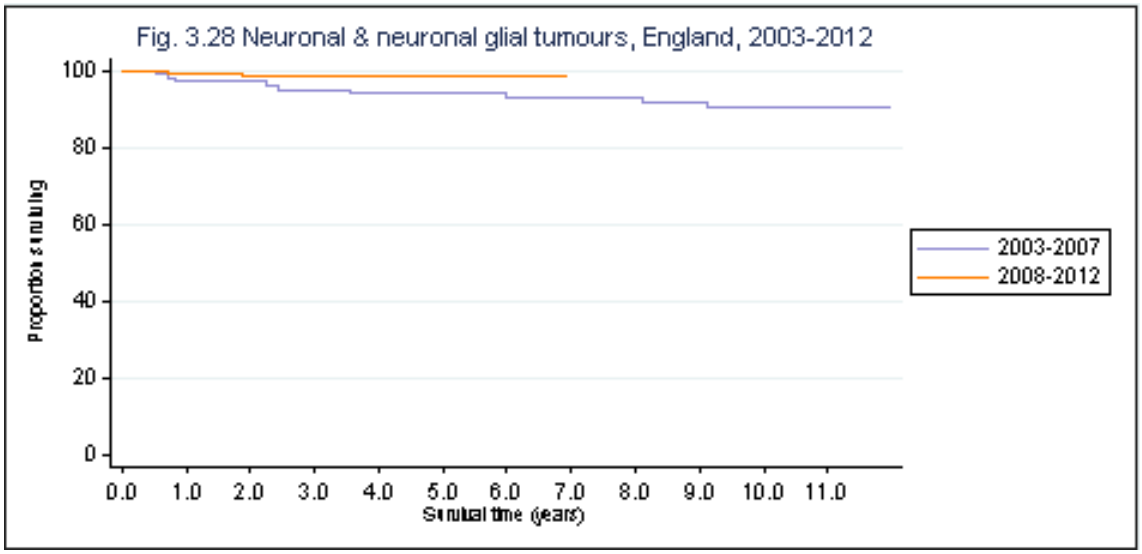


Figure 3.29 Population-based survival of children aged 0–14 years with meningioma in England diagnosed 2003 to 2012

Figure 3.30 Population-based survival of children aged 0–14 years with neuroblastoma and other peripheral nervous cell tumours in England diagnosed 2003 to 2012

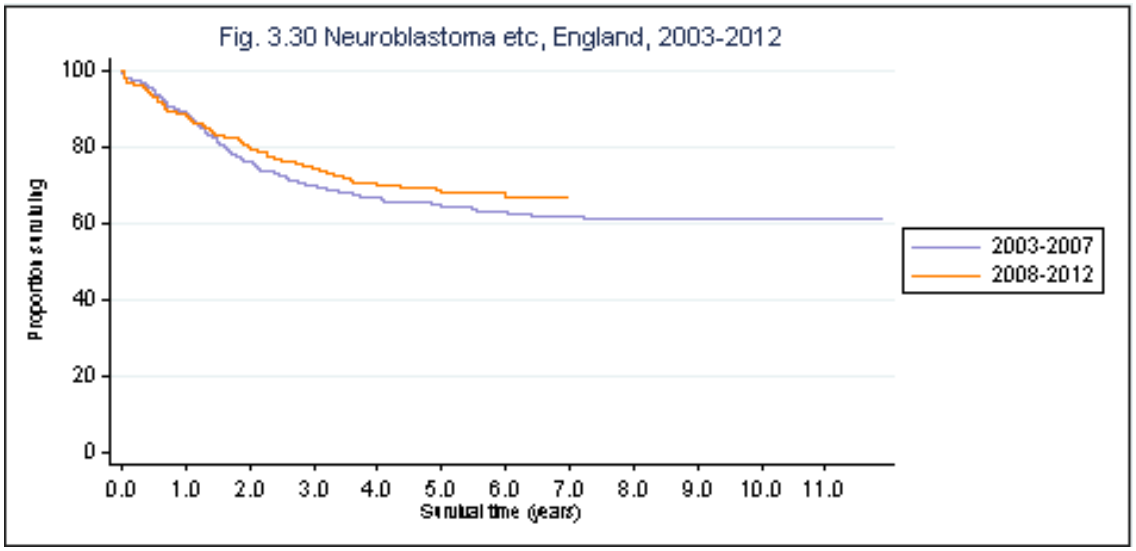


Figure 3.31 Population-based survival of children aged 0–14 years with neuroblastoma in England diagnosed 2003 to 2012

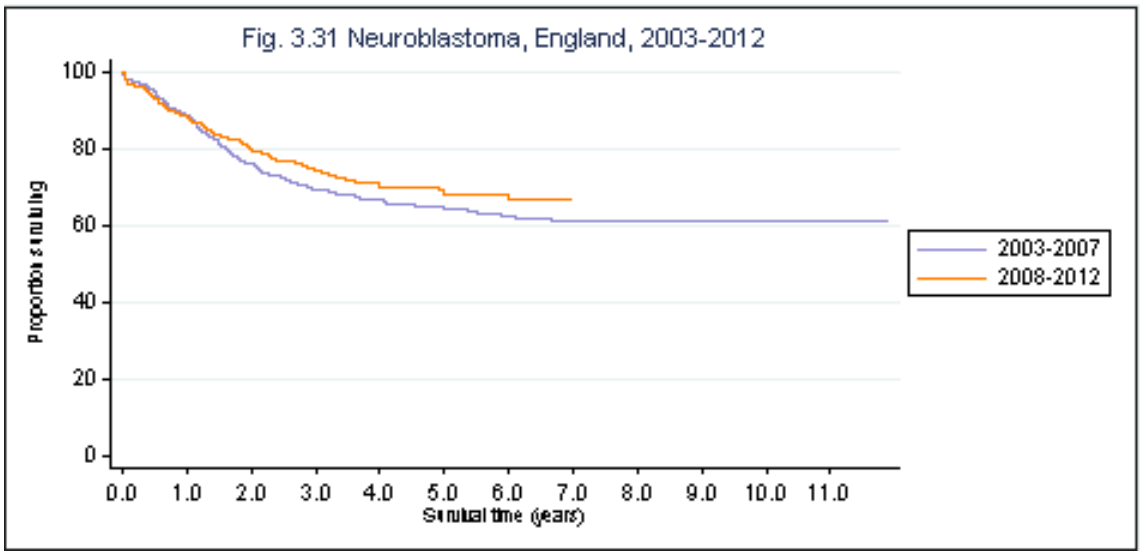


Figure 3.32 Population-based survival of children aged under 1 year with neuroblastoma in England diagnosed 2003 to 2012

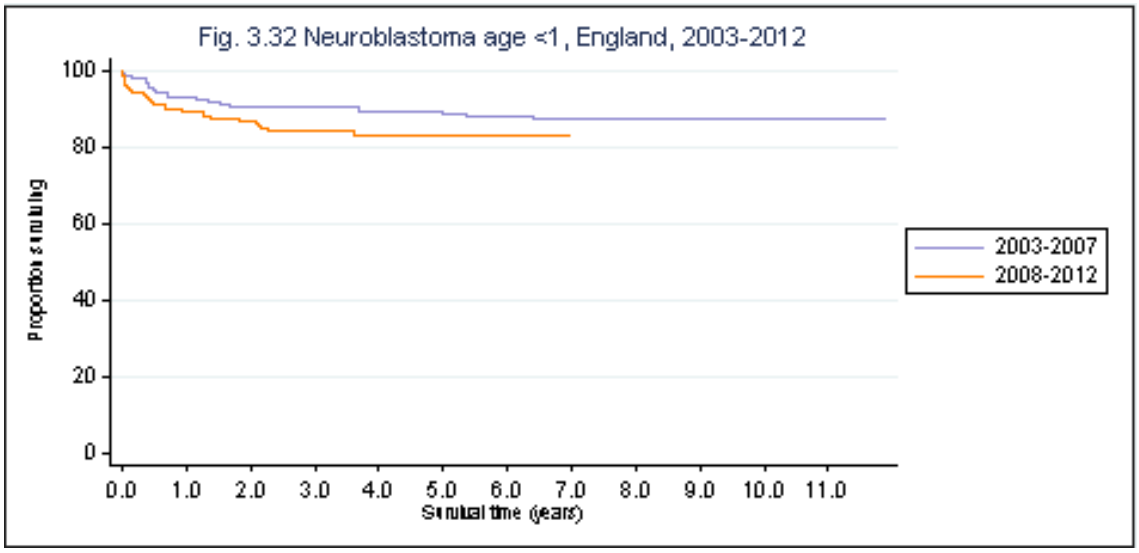


Figure 3.33 Population-based survival of children aged 1–ß14 years with neuroblastoma in England diagnosed 2003 to 2012

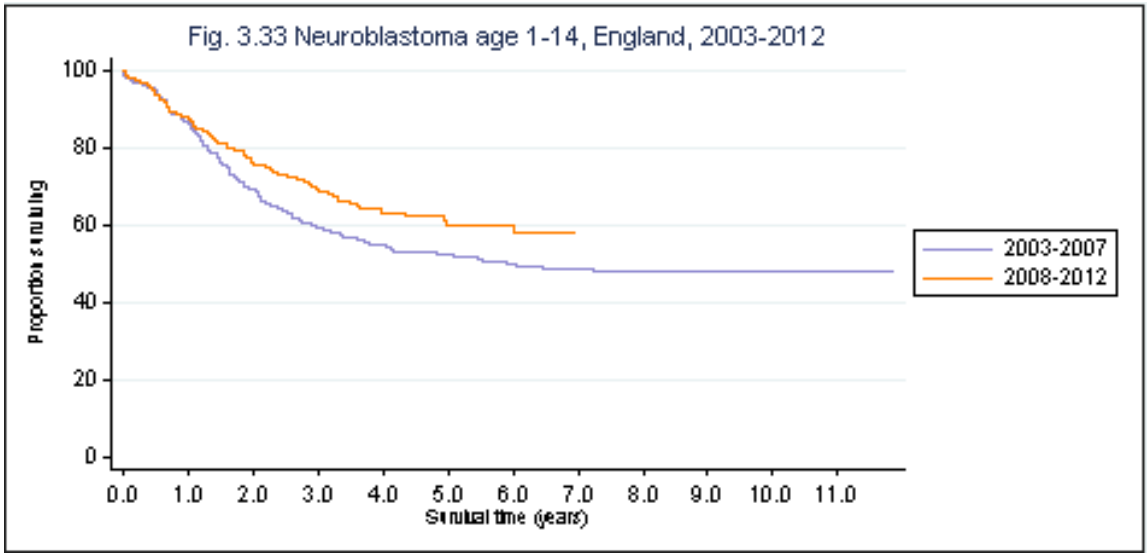


Figure 3.34 Population-based survival of children aged 0–14 years with retinoblastoma in England diagnosed 2003 to 2012

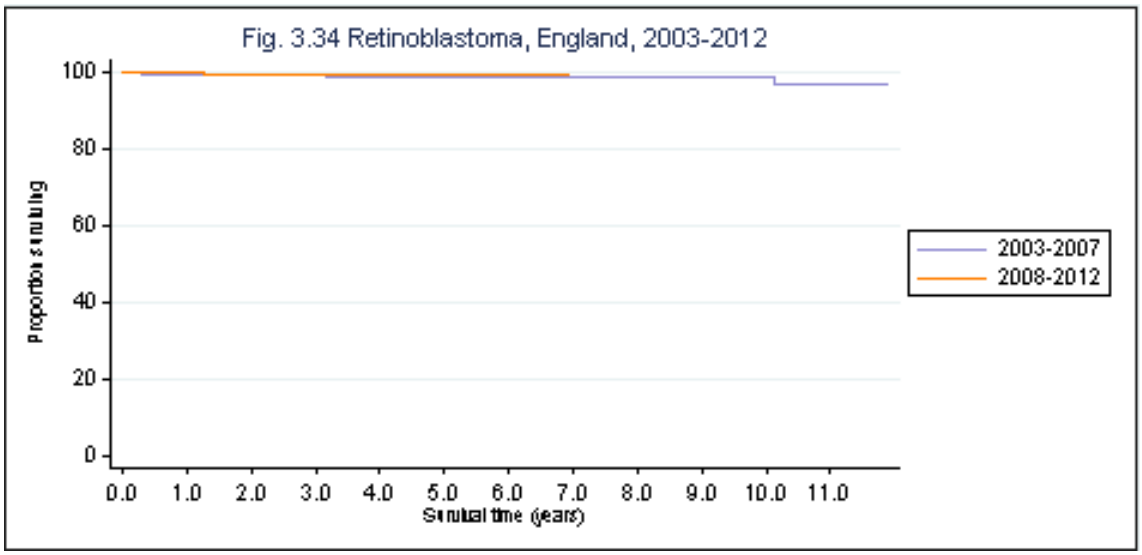


Figure 3.35 Population-based survival of children aged 0–14 years with unilateral retinoblastoma in England diagnosed 2003 to 2012

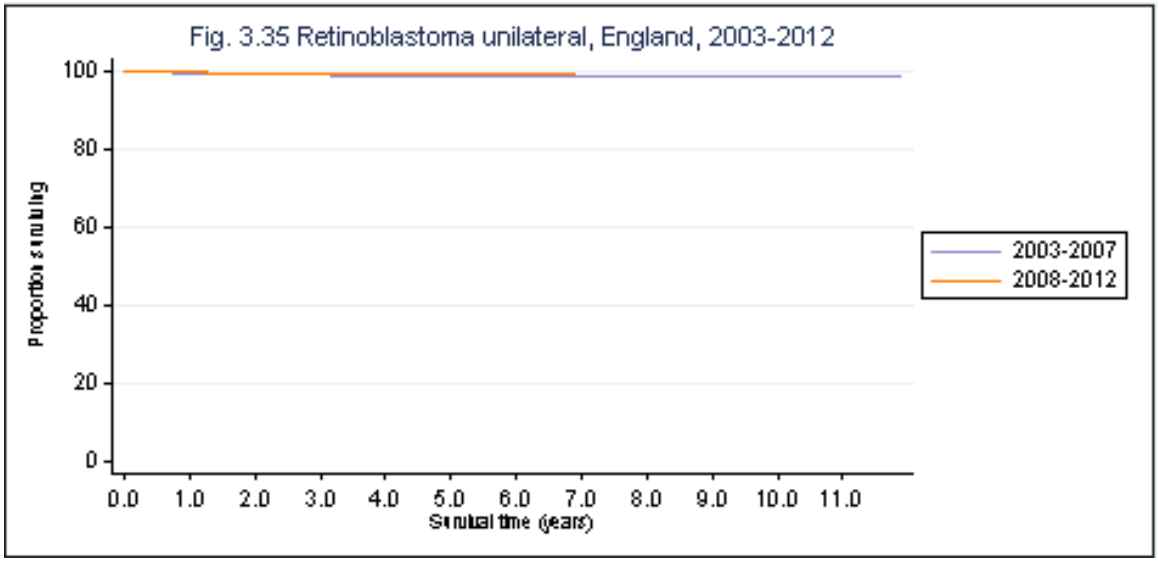


Figure 3.36 Population-based survival of children aged 0–14 years with bilateral retinoblastoma in England diagnosed 2003 to 2012

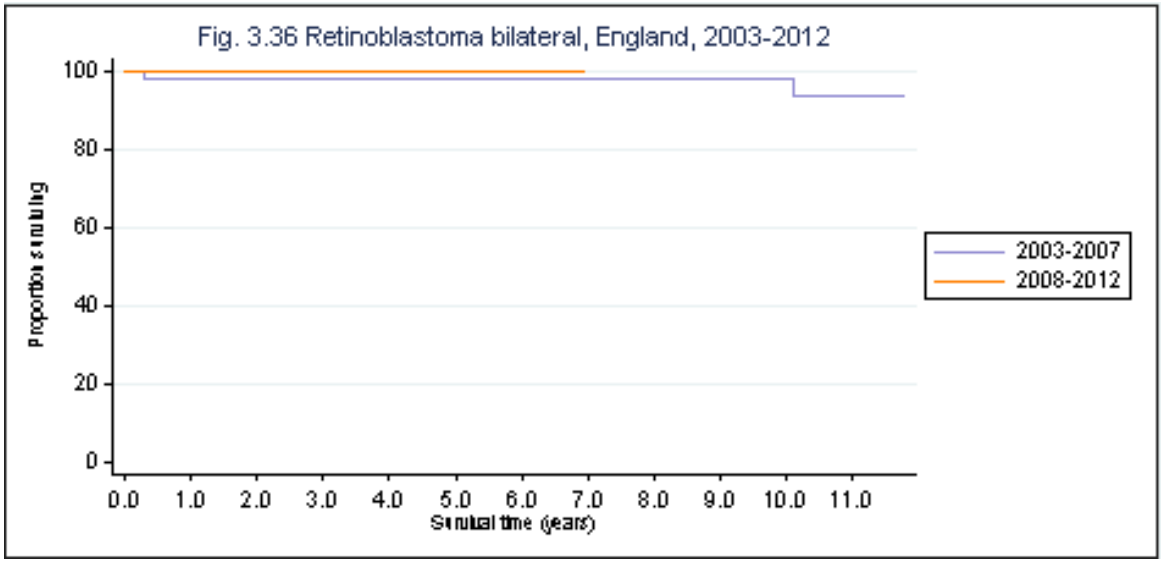


Figure 3.37 Population-based survival of children aged 0–14 years with malignant renal tumours in England diagnosed 2003 to 2012

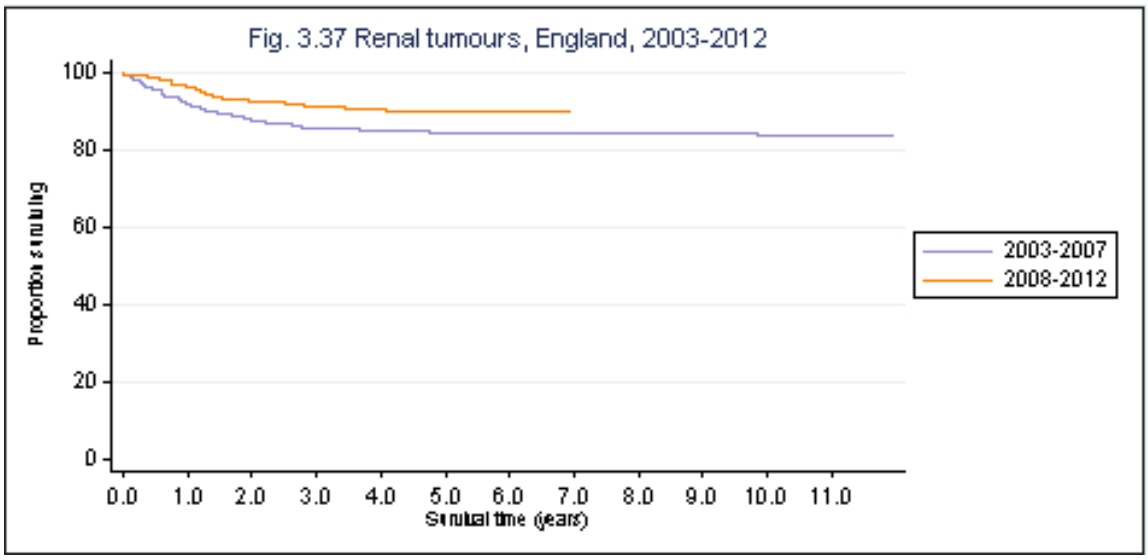


Figure 3.38 Population-based survival of children aged 0–14 years with Wilms tumour in England diagnosed 2003 to 2012

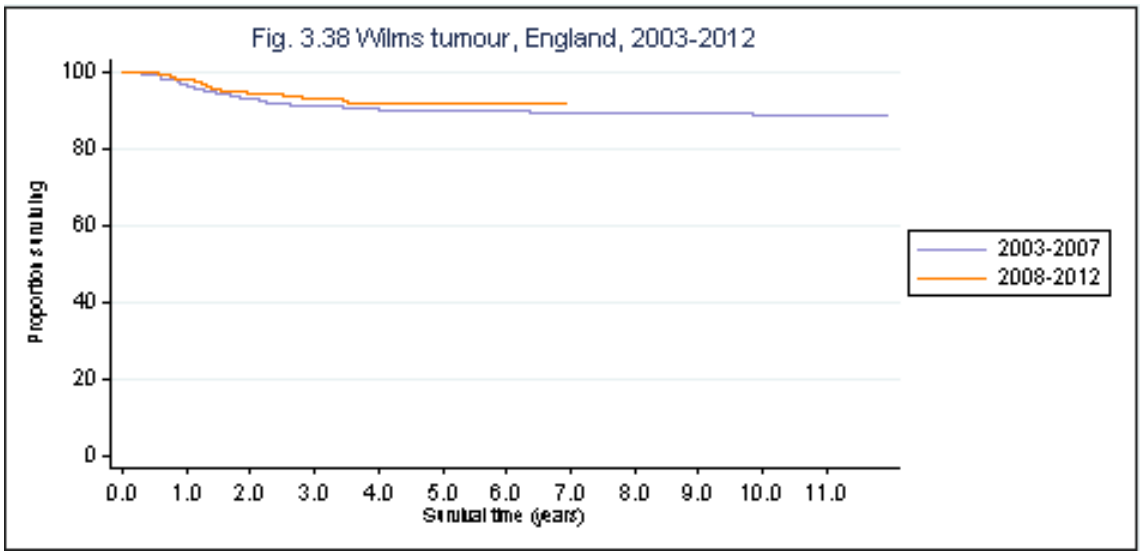


Figure 3.39 Population-based survival of children aged 0–14 years with rhabdoid renal tumour in England diagnosed 2003 to 2012

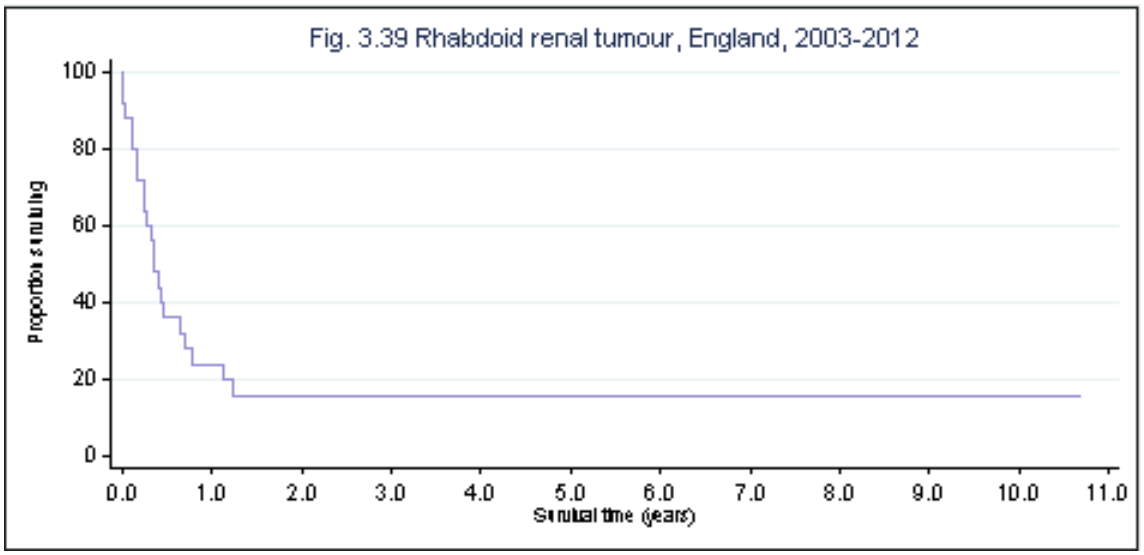


Figure 3.40 Population-based survival of children aged 0–14 years with kidney sarcoma in England diagnosed 2003 to 2012

Figure 3.41 Population-based survival of children aged 0-–14 years with malignant hepatic tumours in England diagnosed 2003 to 2012

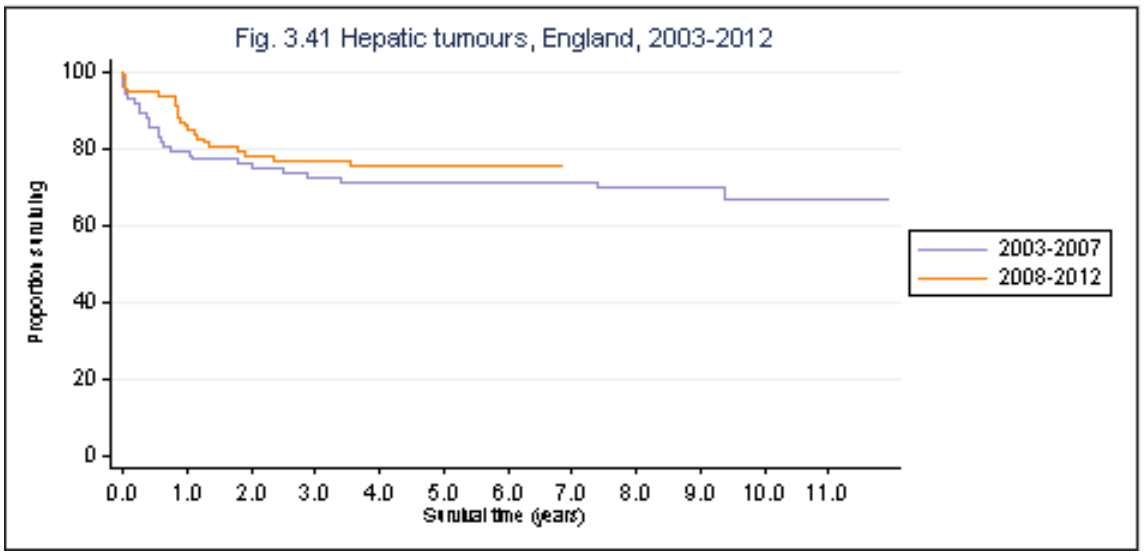


Figure 3.42 Population-based survival of children aged 0–14 years with hepatoblastoma in England diagnosed 2003 to 2012

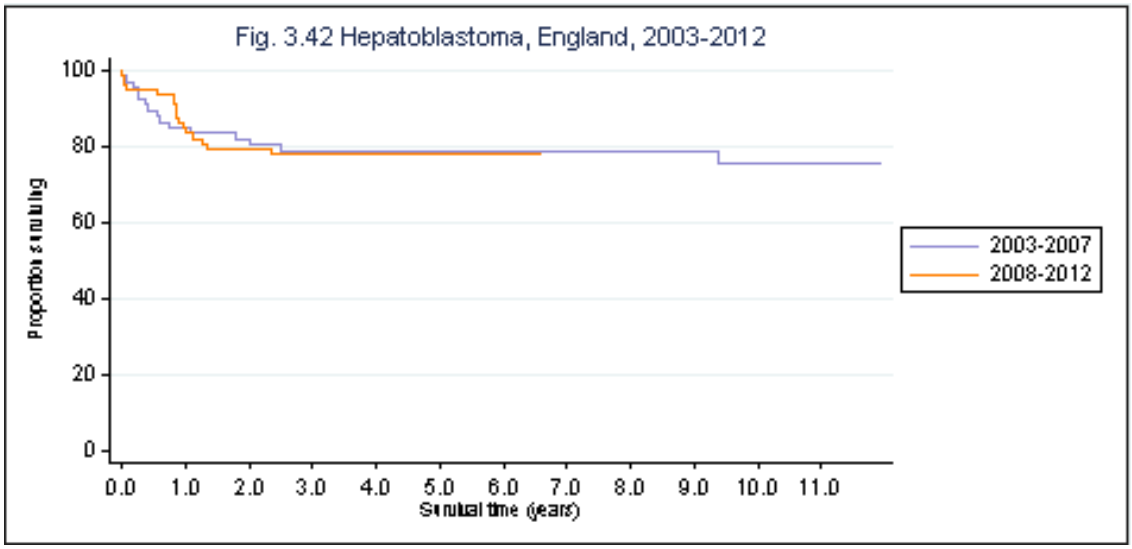


Figure 3.43 Population-based survival of children aged 0–14 years with hepatic carcinoma in England diagnosed 2003 to 2012

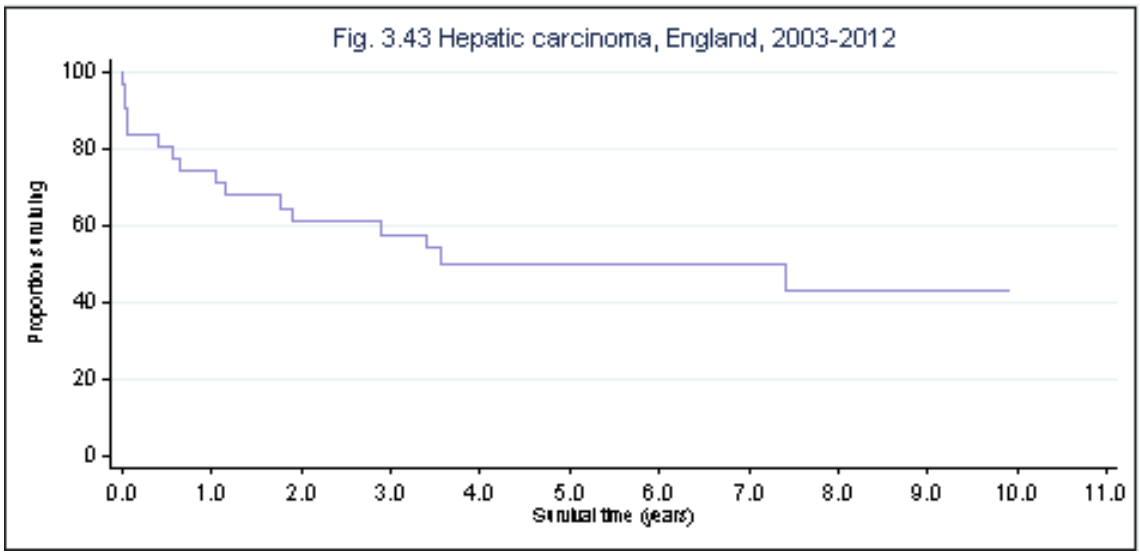


Figure 3.44 Population-based survival of children aged 0–14 years with malignant bone tumours in England diagnosed 2003 to 2012

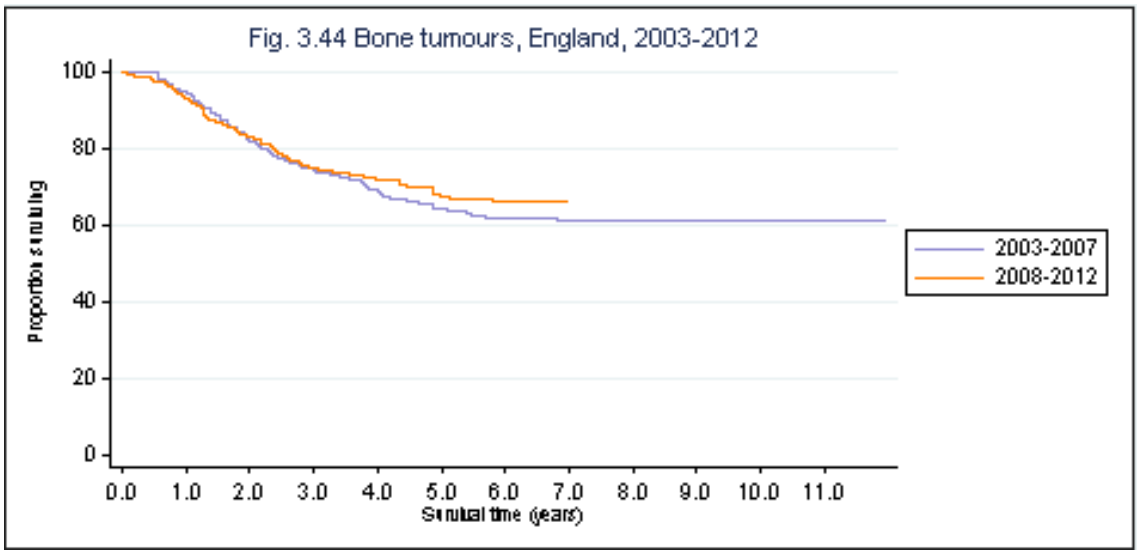


Figure 3.45 Population-based survival of children aged 0–14 years with osteosarcoma in England diagnosed 2003 to 2012

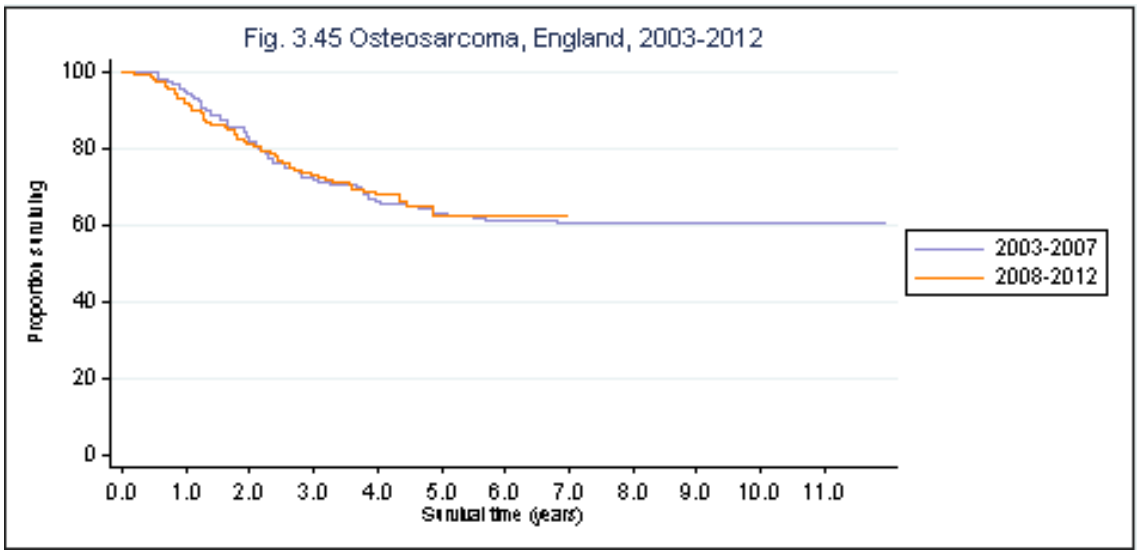


Figure 3.46 Population-based survival of children aged 0–14 years with Ewing sarcoma family tumours of bone in England diagnosed 2003 to 2012

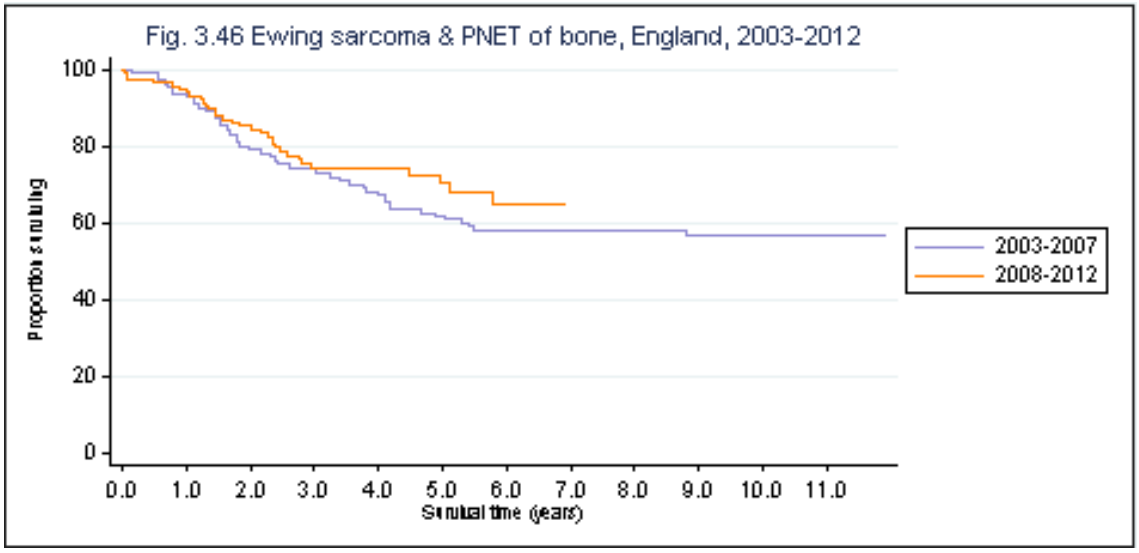


Figure 3.47 Population-based survival of children aged 0–14 years with soft tissue sarcomas in England diagnosed 2003 to 2012

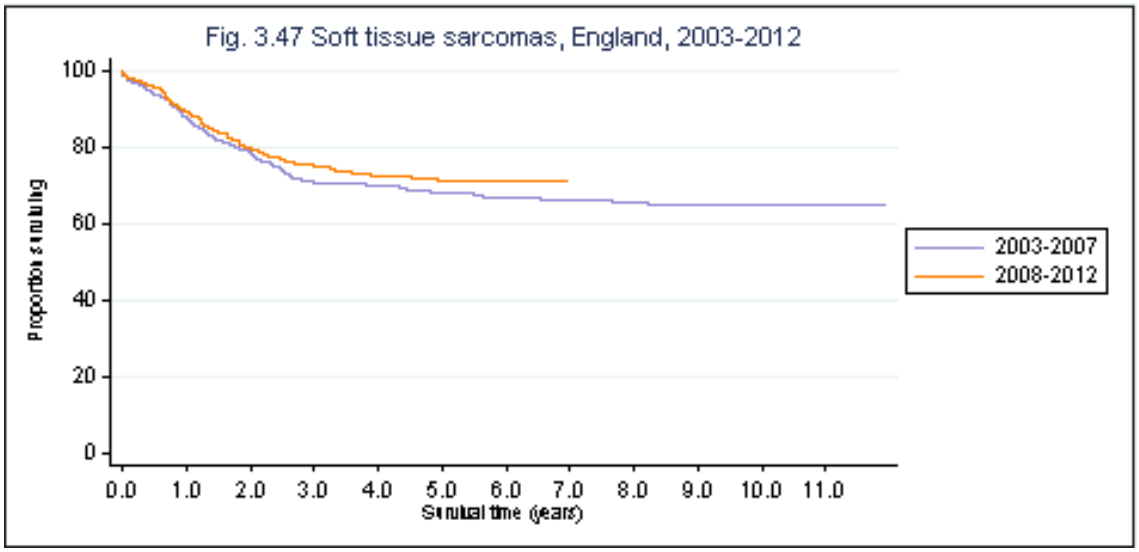


Figure 3.48 Population-based survival of children aged 0–14 years with rhabdomyosarcoma in England diagnosed 2003 to 2012

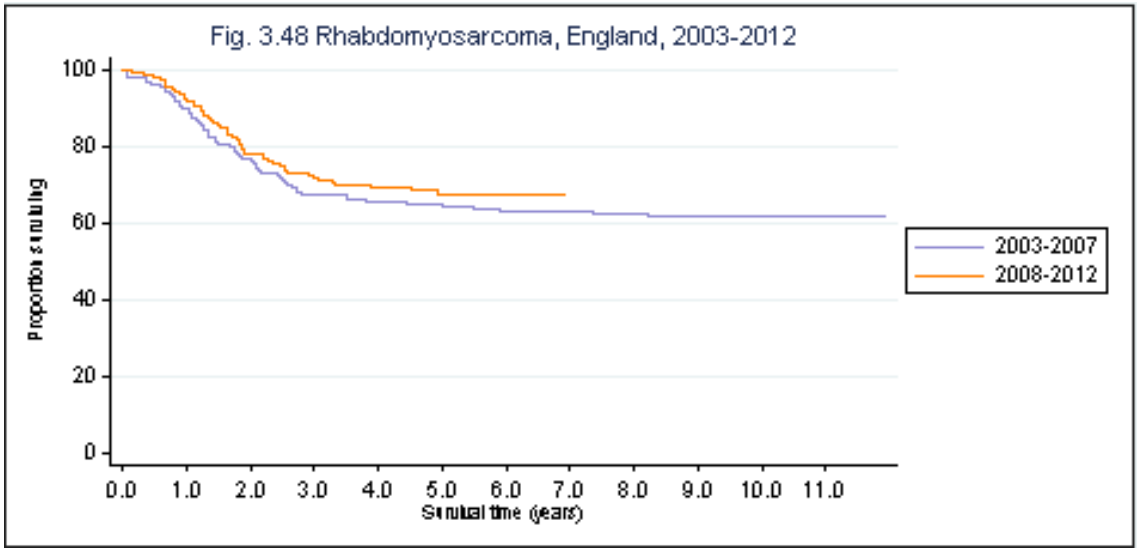


Figure 3.49 Population-based survival of children aged 0–14 years with fibrosarcoma in England diagnosed 2003 to 2012

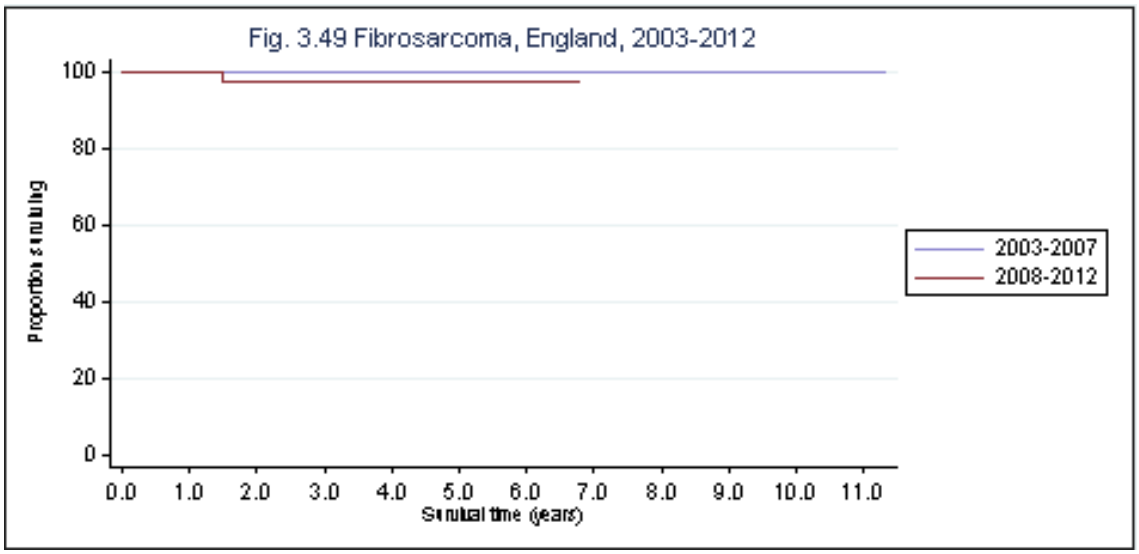


Figure 3.50 Population-based survival of children aged 0–14 years with malignant peripheral nerve sheath tumour in England diagnosed 2003 to 2012

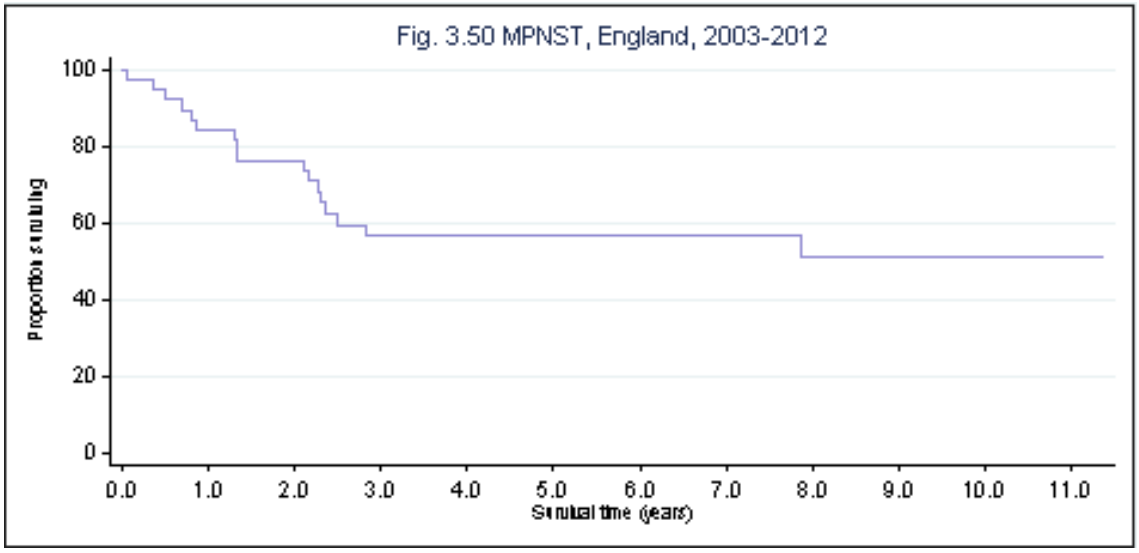


Figure 3.51 Population-based survival of children aged 0–14 years with extraosseous Ewing sarcoma family tumours in England diagnosed 2003 to 2012

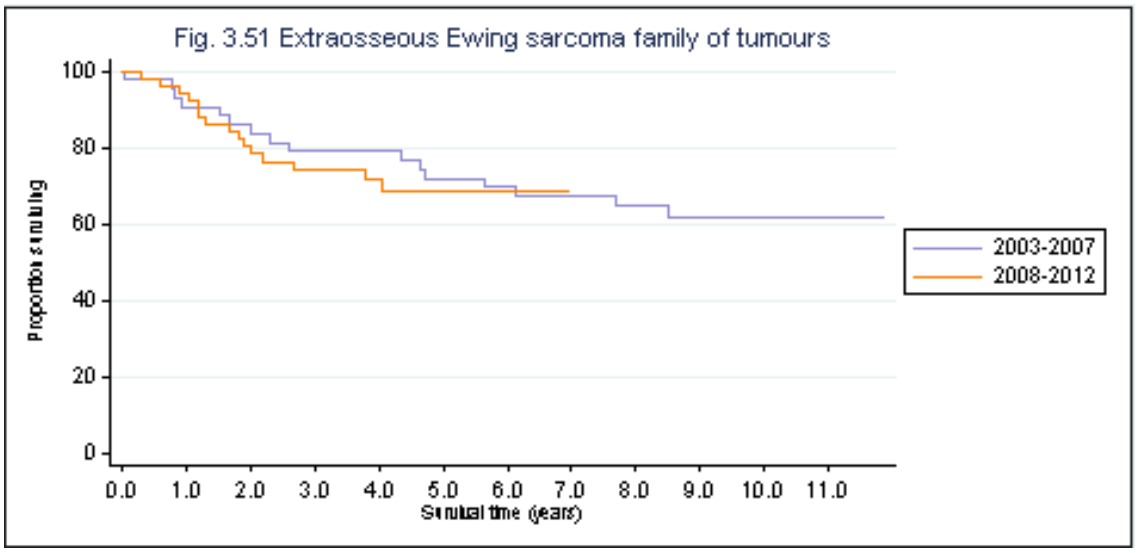


Figure 3.52 Population-based survival of children aged 0–14 years with extrarenal rhabdoid tumour in England diagnosed 2003 to 2012

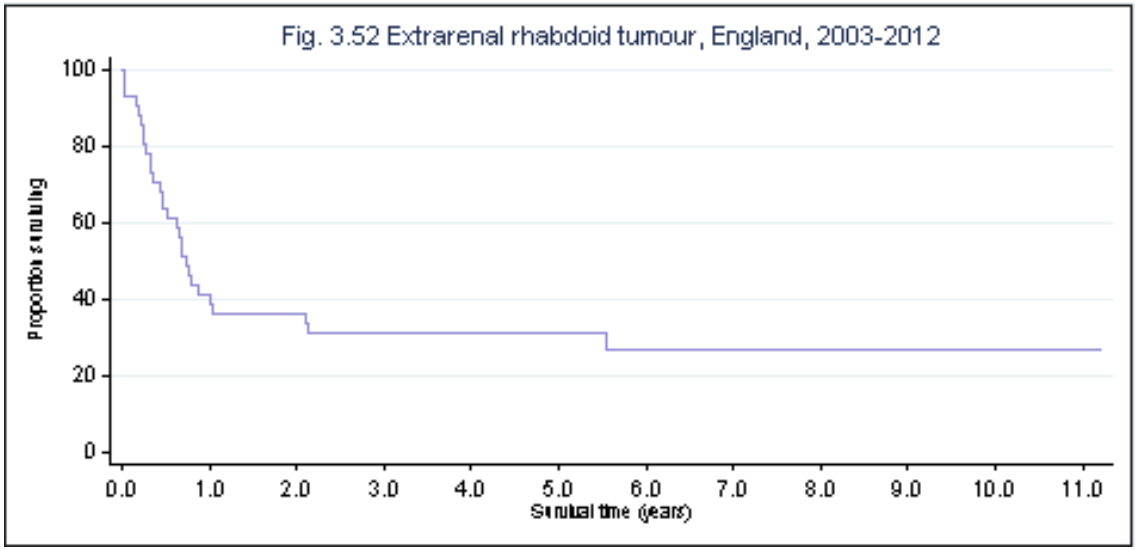


Figure 3.53 Population-based survival of children aged 0–14 years with synovial sarcoma in England diagnosed 2003 to 2012

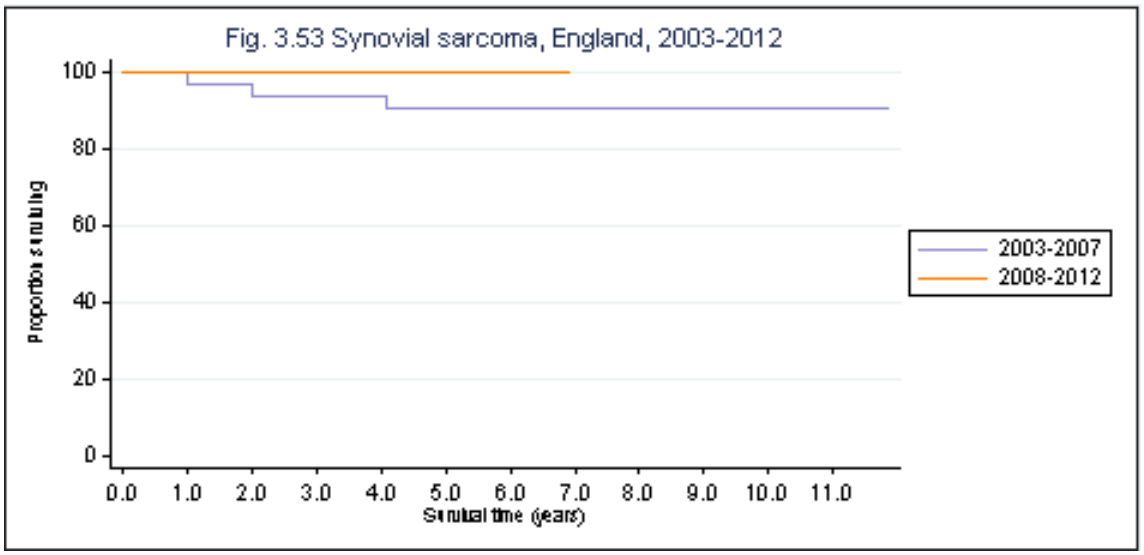


Figure 3.54 Population-based survival of children aged 0–14 years with germ cell and gonadal tumours in England diagnosed 2003 to 2012

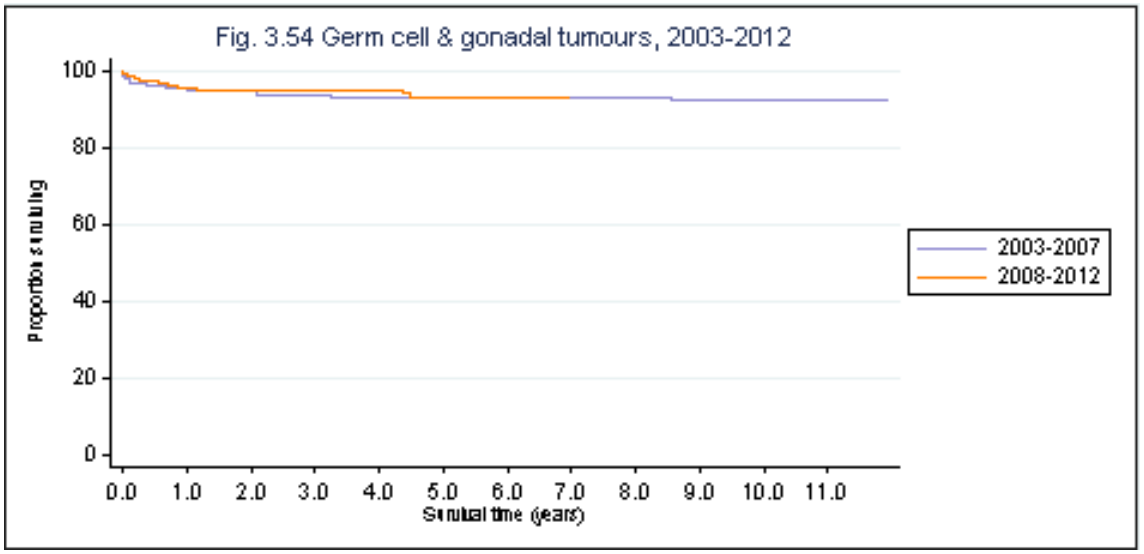


Figure 3.55 Population-based survival of children aged 0–14 years with intracranial and intraspinal germ cell tumours in England diagnosed 2003 to 2012

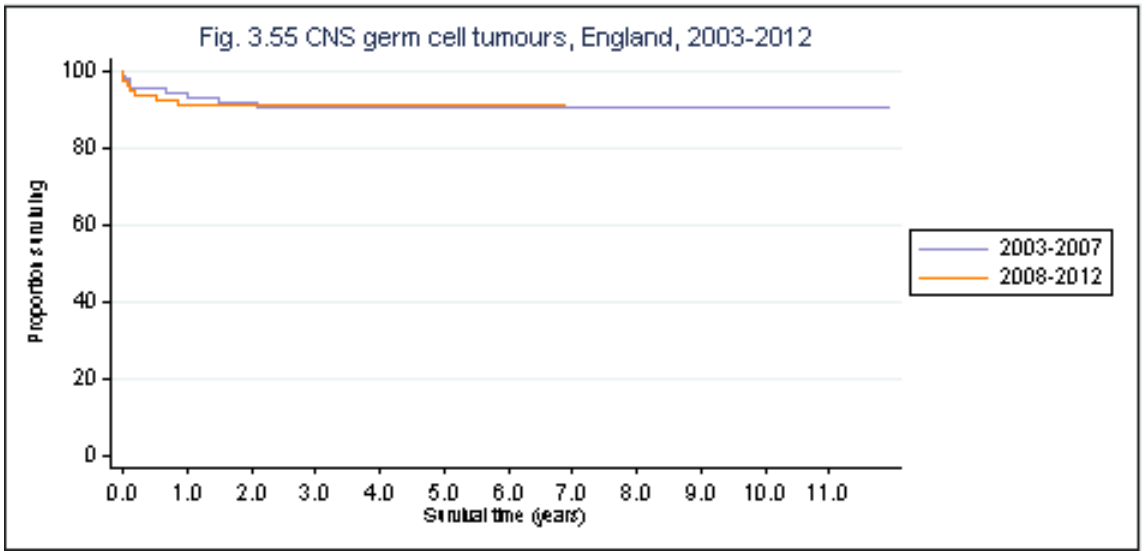


Figure 3.56 Population-based survival of children aged 0–14 years with other extragonadal germ cell tumours in England diagnosed 2003 to 2012

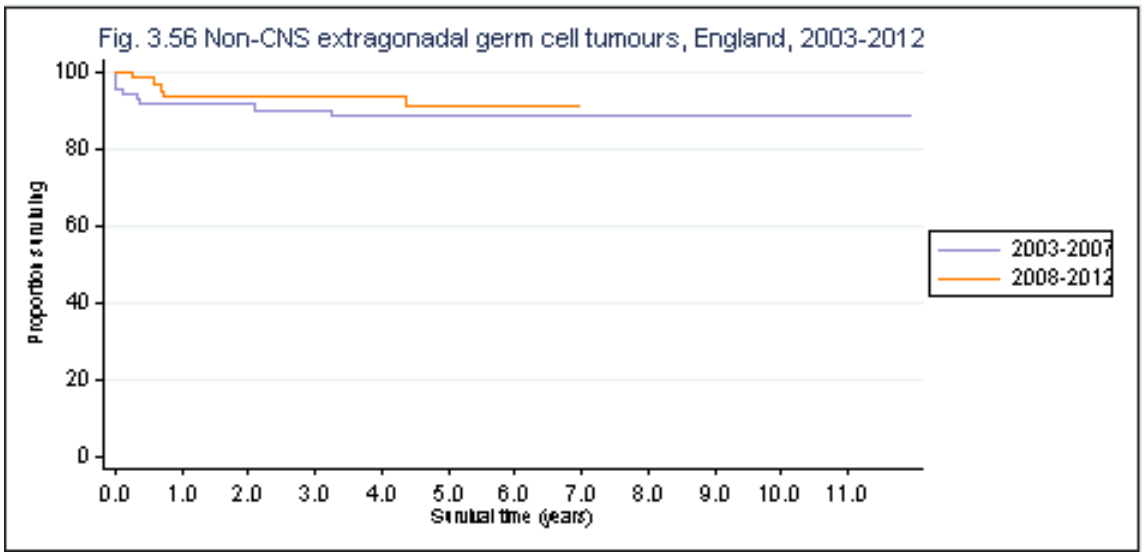


Figure 3.57 Population-based survival of children aged 0–14 years with testicular germ cell tumours in England diagnosed 2003 to 2012

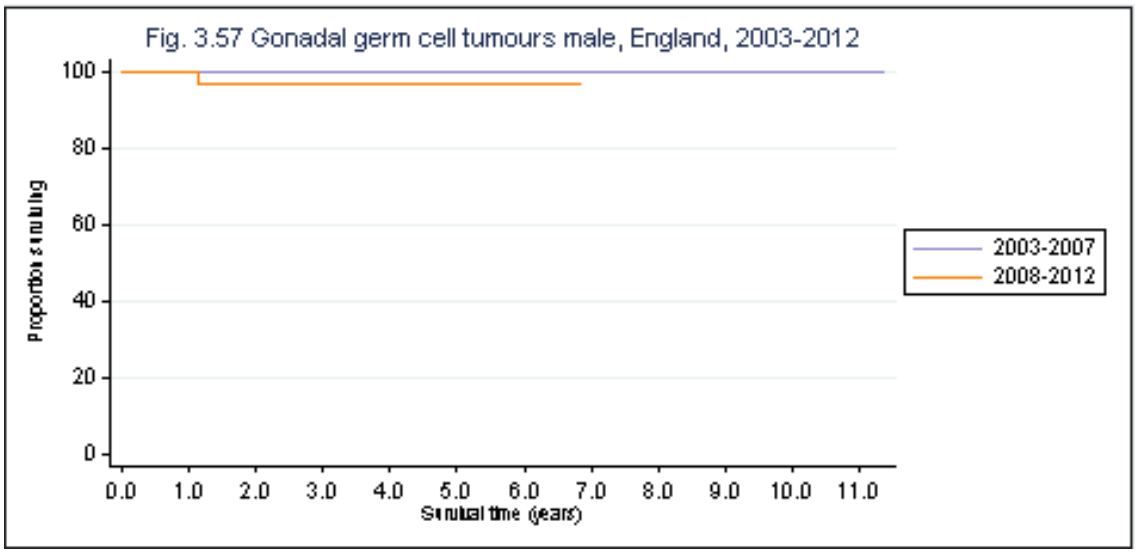


Figure 3.58 Population-based survival of children aged 0–14 years with ovarian germ cell tumours in England diagnosed 2003 to 2012

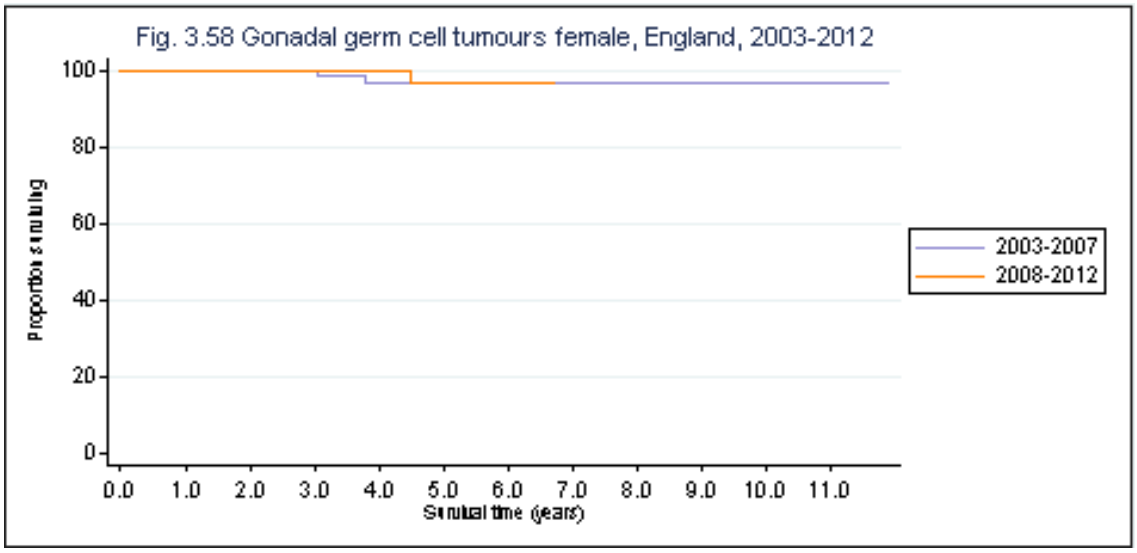


Figure 3.59 Population-based survival of children aged 0–14 years with adrenocortical carcinoma in England diagnosed 2003 to 2012

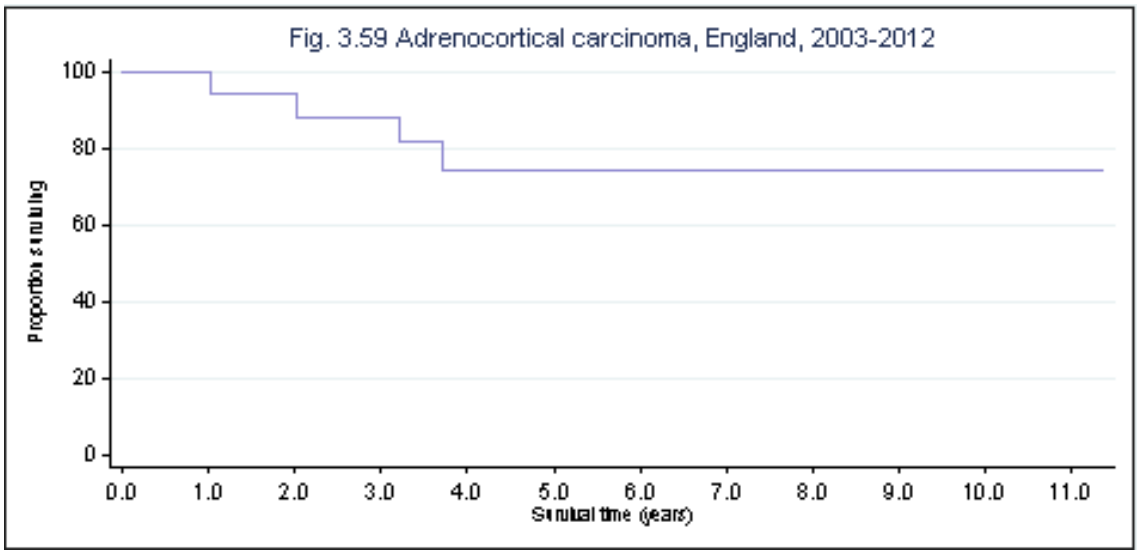


Figure 3.60 Population-based survival of children aged 0–14 years with thyroid carcinoma in England diagnosed 2003 to 2012

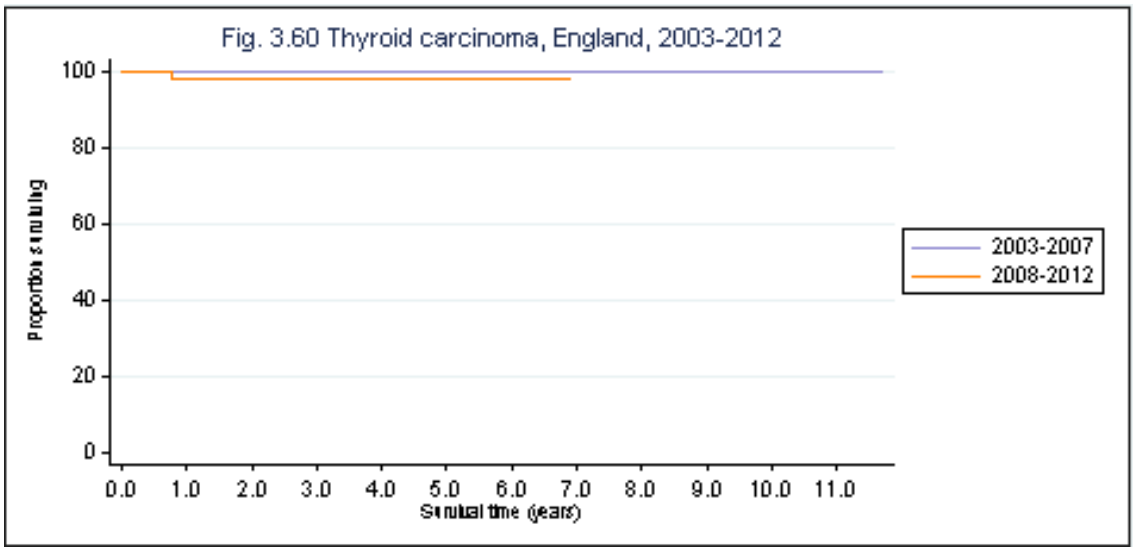


Figure 3.61 Population-based survival of children aged 0–14 years with nasopharyngeal carcinoma in England diagnosed 2003 to 2012

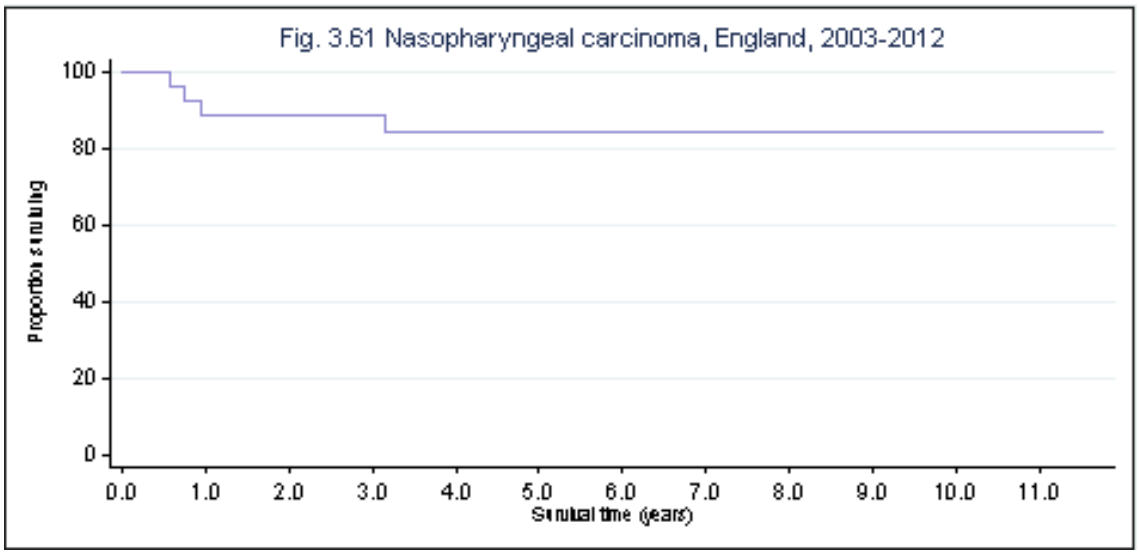
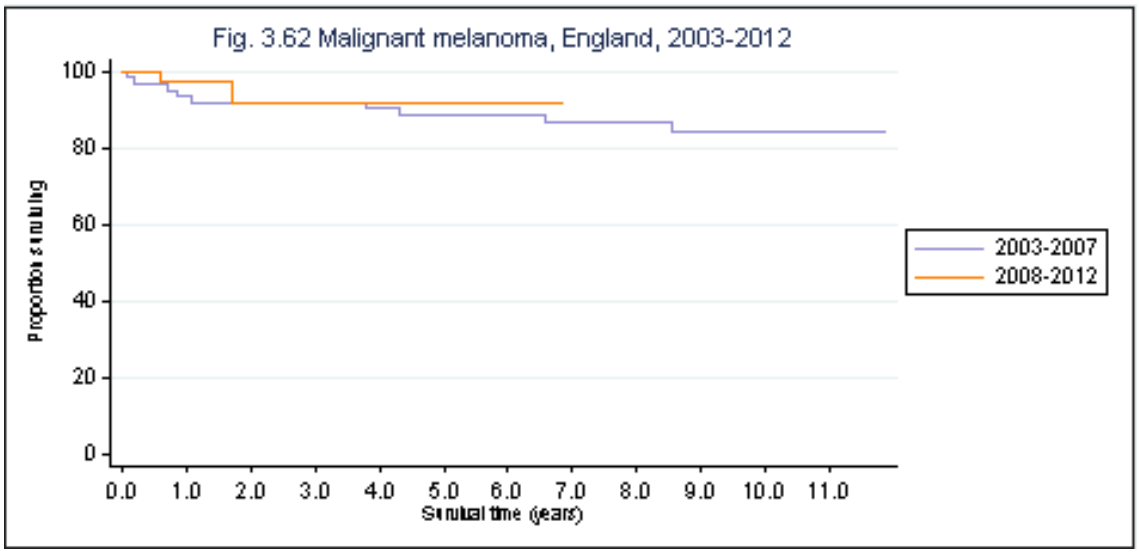


Figure 3.62 Population-based survival of children aged 0–14 years with malignant melanoma in England diagnosed 2003 to 2012



Migration of legacy data from the National Registry of Childhood Tumours and incorporation in the ENCORE database

Data and methods

Responsibility for national childhood cancer registration in England passed from the Childhood Cancer Research Group, University of Oxford, to Public Health England in 2013. PHE then received copies of two sets of registration data for children diagnosed in 1985 to 2013. The first consisted of data for all eligible children from the National Registry of Childhood Tumours (NRCT) database. The second contained the data received from paediatric oncology principal treatment centres (PTCs) that were awaiting validation and incorporation in the NRCT at the time of transfer. The latter included registrations that were sent direct to PHE from PTCs after the transfer.

Data were migrated to the NCRAS ENCORE database in batches of one or more registration years at a time, working backwards from 2013 to the earliest years. The analyses presented here document the effect of data migration for children diagnosed during 1993 to 2013 and are based on the September 2015 Cancer Analysis System data snapshot. Proportions of migrated records that were for cases new to ENCORE were calculated by year of diagnosis.

The merging of migrated records into those already on ENCORE resulted in changes to some data fields for a substantial number of cases, and this is illustrated by data showing the effect on the codes for tumour morphology. This analysis refers to diagnosis years 1995 onwards, because almost 50% of ENCORE records for children diagnosed in 1993 to 1994 that were matched with a record from the NRCT did not previously have morphology coded to ICD-O-2 or ICD-O-3. Proportions of matched cases whose morphology code was changed were calculated by year of diagnosis and with code changes classified as follows:

- change from Tumour, not otherwise specified (NOS) (M 8000-8005) to a more specific code (M 8010-9984)
- other change resulting in a change of main group in ICCC-3
- other change resulting in a change to subgroup in ICCC-3 while remaining in the same ICCC-3 main group
- other changes not resulting in a change to ICCC-3 main group or subgroup, although in some cases they may have resulted in a change to ICCC-3 division

Results

In total, 28,691 registrations were migrated. The mean number per year of diagnosis was 1,366. Table 4.1 shows the numbers by year of diagnosis.

Table 4.1 Cancer registration records for children under 15 years of age and resident in England at diagnosis, 1993-2013. Numbers of registration records migrated from National Registry of Childhood Tumours to ENCORE, by year of diagnosis.

Year of diagnosis	N
1993	1,264
1994	1,300
1995	1,319
1996	1,301
1997	1,332
1998	1,318
1999	1,350
2000	1,307
2001	1,339
2002	1,457
2003	1,329
2004	1,394
2005	1,393
2006	1,423
2007	1,343
2008	1,457
2009	1,455
2010	1,516
2011	1,310
2012	1,395
2013	1,389
Total	**28,691**

Of the 28,691 registrations migrated, 26,136 (91.1%) could be matched with a record on ENCORE and the remaining 2,555 (8.9%) were new to ENCORE. The percentage of new cases varied markedly by year of diagnosis (Figures 4.1, 4.2). The migrated records for 1993 contained 12.5% new cases. The proportion of new cases fell to 3.7% in 1998 to 2002 and 2.7% in 2003 to 2007, then increased slightly to 4.4% in 2008 to 2010. This was followed by a steeper increase to 11.3% in 2011, 17.9% in 2012 and 64.7% in 2013. The reduction in the proportion of new cases from the mid-1990s to 2003 to 2007 can be attributed to improving levels of ascertainment over this period by the former regional cancer registries, whose data had already been migrated to ENCORE when the NRCT data were migrated. The increasing proportion of new cases since then reflects the fact that for the more recent years, and especially for 2013, the lag time from diagnosis to registration tended to be shorter for the NRCT than for the former regional registries.

Figure 4.1 Cancer registration records for children under 15 years of age and resident in England at diagnosis, 1993 to 2012. Percentage of new cases among registration records migrated from National Registry of Childhood Tumours to ENCORE, by year of diagnosis. For 2013, see Figure 4.2.

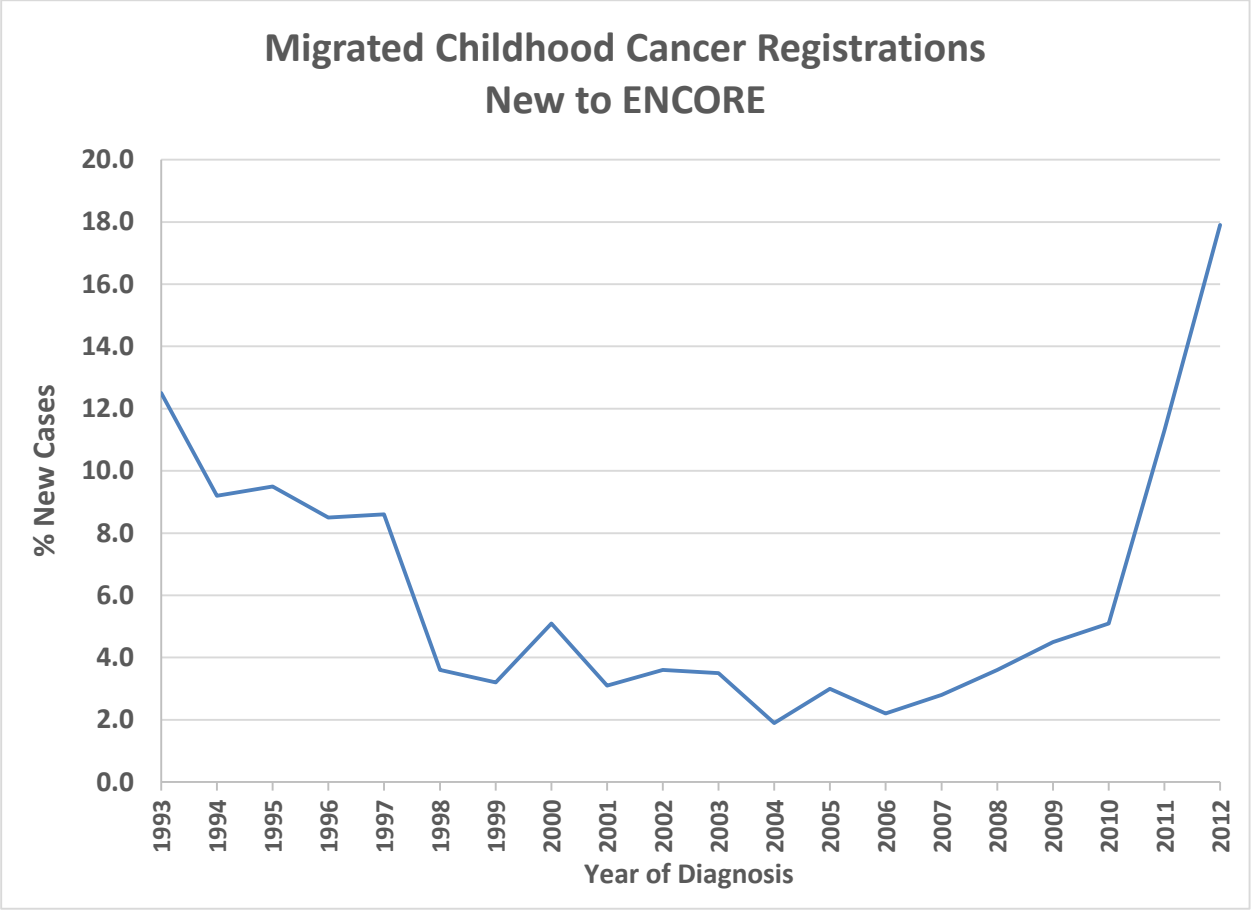
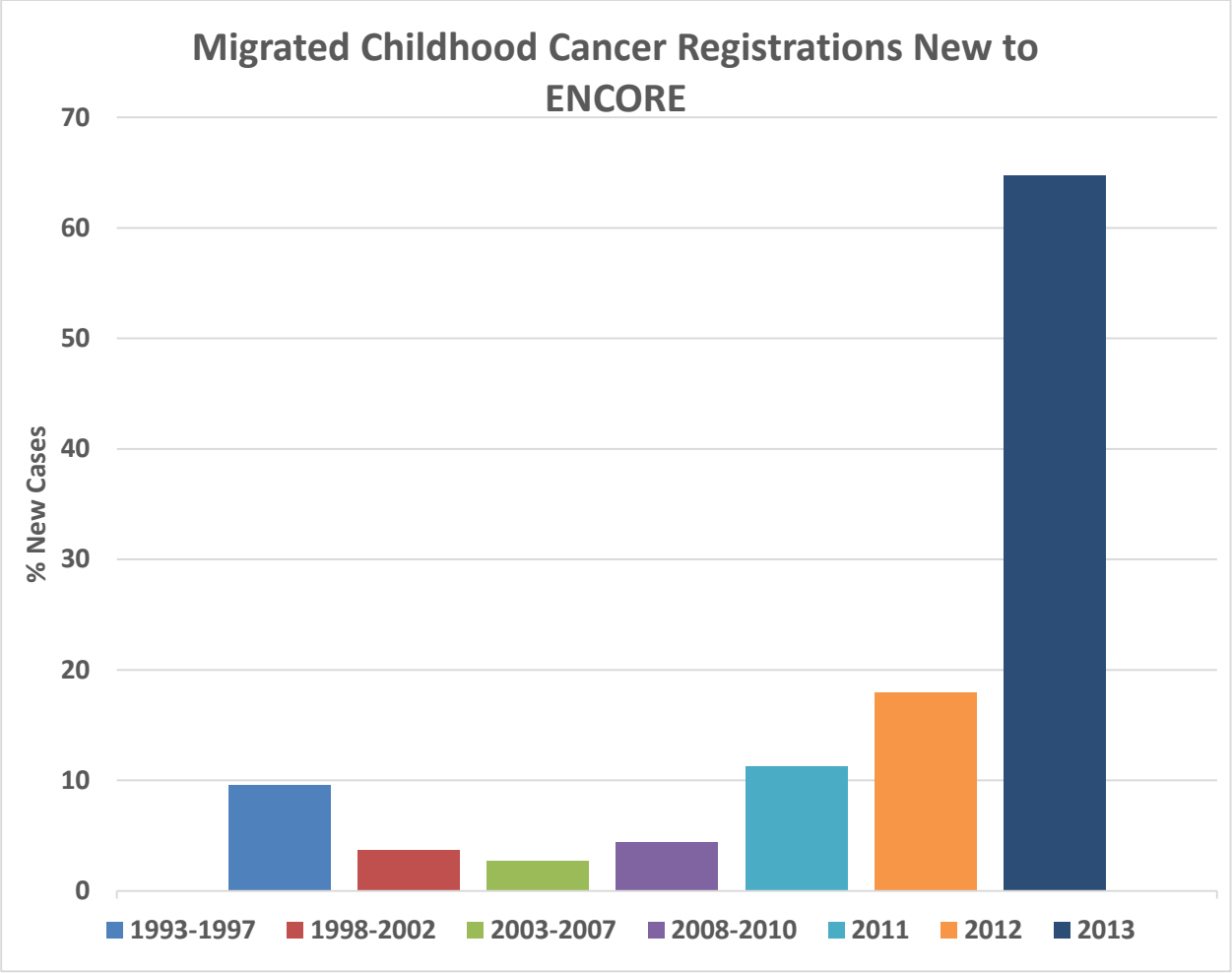


Figure 4.2 Cancer registration records for children under 15 years of age and resident in England at diagnosis, 1993 to 2013. Percentage of new cases among registration records migrated from National Registry of Childhood Tumours to ENCORE, by year of diagnosis.



In total, 23,849 migrated records for 1995 to 2013 matched with an ENCORE record, of which 3,388 (14.2%) had their morphology code changed as a result of the migration. Figure 4.3 shows the proportions with a morphology code change by year of diagnosis. The morphology code was changed for 14.8% of cases diagnosed in 1995-1997. The proportion decreased slightly to 13.4% in 1998 to 2002 and 11.7% in 2003 to 2007, then increased to 19.1% in 2008 to 2013.

Figure 4.3 Cancer registration records for children under 15 years of age and resident in England at diagnosis, 1995 to 2013, where a migrated record from National Registry of Childhood Tumours was matched to an existing record on ENCORE. Percentage of cases whose morphology code changed following migration, by year of diagnosis.

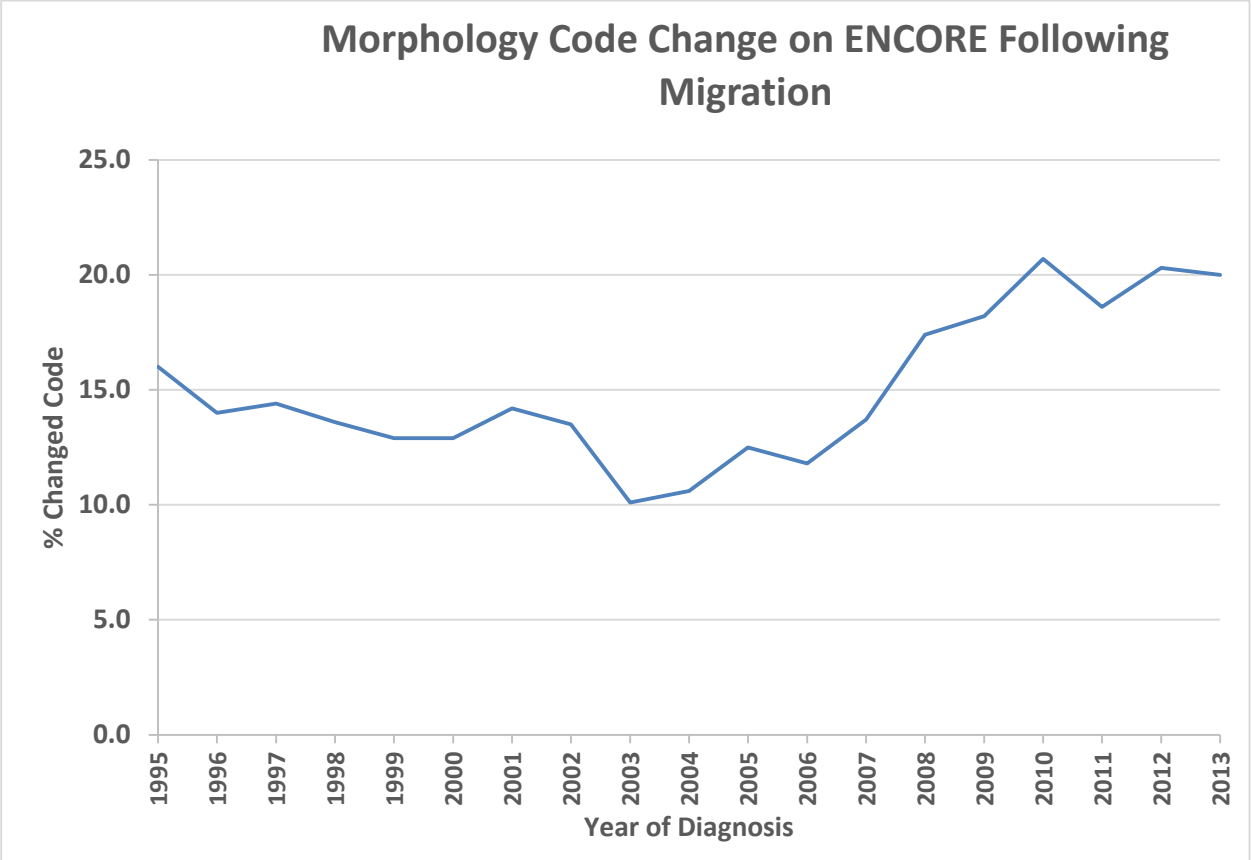


Figure 4.4 shows the numbers of cases with different categories of morphology code change by year of diagnosis. Of the 3,388 code changes, 296 (8.7%) were from Tumour NOS to a more specific code, 318 (9.4%) were other changes resulting in a change of ICCC-3 main group, 635 (18.7%) were other changes resulting in a change of ICCC-3 subgroup, and 2139 (63.1%) were other changes not resulting in a change of ICCC-3 main group or subgroup. The proportion of changes that were from Tumour NOS to a more specific code tended to increase in more recent years, balanced by decreases in the proportion of other types of changes.

Figure 4.4 Cancer registration records for children under 15 years of age and resident in England at diagnosis, 1995 to 2013, where a migrated record from National Registry of Childhood Tumours was matched to an existing record on ENCORE. Numbers of cases with different categories of change to morphology code following migration, by year of diagnosis