Public Health England

Protecting and improving the nation's health

Childhood Cancer Statistics, England Annual report 2018

Report on behalf of the Children, Teenagers and Young Adults Expert Advisory Group, National Cancer Registration and Analysis Service

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Executive summary

This report contains information on incidence, survival, prevalence and mortality for cancer diagnosed among children under the age of 15 resident in England, based on data from the National Cancer Registration and Analysis Service (NCRAS). The report also provides a summary of Clinical Headline Indicators for childhood cancers for England which inform the commissioning and provision of cancer services and standards of care.

There were 21,289 registered cases of cancer (including non-malignant intracranial and intraspinal tumours) in children under the age of 15 in England during 2001 to 2015, equivalent to 1,420 new registrations per year. Leukaemia accounted for 31% of registrations, CNS and miscellaneous intracranial and intraspinal neoplasms for 25%, lymphomas for 10%, soft-tissue sarcomas for 6.4%, neuroblastoma and other peripheral nervous cell tumours for 6.0%, and renal tumours for 5.7%. No other diagnostic group accounted for more than 5% of registrations. The overall age-standardised incidence was 166 per million in boys and 145 per million in girls, giving a sex ratio M/F=1.14. The cumulative risk of being diagnosed with cancer in the first 15 years of life was 1 in 412 for boys and 1 in 472 for girls. For both boys and girls, incidence was highest in the first 5 years, fell to a minimum at age 5 to 9 years, and was slightly higher at age 10 to 14 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, 5-year survival was 78% for children diagnosed in 2001 to 2005, 82% for those diagnosed in 2006 to 2010, and 84% for those diagnosed in 2011 to 2015. The trend in survival by year of diagnosis was highly significant ($p<0.001$). There were also statistically significant increasing trends in survival over time for children with leukaemia, lymphoma, intracranial and intraspinal tumours, hepatic carcinoma, bone tumours and soft-tissue sarcoma, and for children aged 1 year or over when diagnosed with neuroblastoma. The highest survival rates, over 95% at 5 years after diagnosis, were for Hodgkin lymphoma, several types of non-malignant intracranial tumour, retinoblastoma, and gonadal (testicular and ovarian) germ-cell tumours. Survival also exceeded 90% for precursor lymphoblastic leukaemia (acute lymphoblastic leukaemia, ALL), Wilms tumour, fibrosarcoma, intracranial and intraspinal germinomas, germ-cell tumours in other extragonadal sites, and thyroid carcinoma.

There were around 20,000 people alive at the end of 2015 who had been diagnosed with cancer before their fifteenth birthday in the period 1995 to 2015. This accounts for 1% of the total prevalent population for all ages. Leukaemia, brain tumours, Hodgkin lymphoma, non-Hodgkin lymphoma and cancers of the kidney, renal pelvis and ureter

(essentially kidney cancers in this age group) were the most prevalent cancers at the end of 2015. Around 9,000 children (0 to 14 year olds) were alive at the end of 2015 after having a cancer diagnosis.

In 2016 there were around 190 childhood cancer deaths, accounting for 6% of all childhood deaths (0 to 14 year old). Cancer is the most common cause of death in children aged one to 14 years, accounting for around one-fifth of all deaths in this age group. This compares to cancer accounting for almost 30% of deaths for all ages.

A range of ‘Clinical Headline Indicator’ (CHI) metrics have been provided in this report. It is recognised that currently many of the CHI results do not reflect clinical practice inside the treating centres but rather poor recording of these data items. It is hoped that centres will increase their collection and submission of data to the Cancer Outcomes and Services Dataset (COSD). This would make it possible for future versions of this publication to document more fully the metrics for the childhood cancer-specific data items in COSD and, where data are sufficiently complete, to report outcomes by stage.

Incidence of childhood cancer, 2001 to 2015

Data and methods

Registration data were obtained from the NCRAS Cancer Analysis System (CAS). The incidence data in this report relate to children who were residents of England and under 15 years of age at diagnosis during 2001 to 2015 with any malignant neoplasm or non-malignant CNS tumour included in the *International Classification of Childhood Cancer, 3rd Edition* (ICCC-3)[1]. The total number of registrations was 21,289. Incidence rates were calculated per million child years for the age groups 0 to 4, 5 to 9 and 10 to 14 years based on annual population estimates[2]. For the full age range 0 to 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 to 4, 5 to 9 and 10 to 14 years respectively. Cumulative risk was calculated as the sum of the age-specific incidence rates for the 5-year age groups, each multiplied by 5, the number of years contained in each age group.

Numbers of newly diagnosed cancer cases

Table 1 shows numbers of registrations in the 12 main ICCC-3 cancer groups, together with the percentage recorded as having microscopic verification (%MV) and the percentage registered from a death certificate only (%DCO). Appendix A shows the same data as Table 1 for ICCC-3 subgroups and divisions and certain subsets of particular interest.

The mean number of cancer registrations per year was 1,419. Figure 1 shows the annual numbers for ICCC-3 groups and subgroups with at least 6 cases per year. Similar data for all subgroups are shown in Appendix A. Leukaemia accounted for 31% of registrations, CNS and miscellaneous intracranial and intraspinal neoplasms for 25%, lymphomas for 10%, soft-tissue sarcomas for 6.4%, neuroblastoma and other peripheral nervous cell tumours for 6.0%, and renal tumours for 5.7%. No other diagnostic group accounted for more than 5% of registrations. Overall, 92.5% of registrations were MV. The only main diagnostic groups to have less than 90% MV were CNS tumours (82.6%), retinoblastoma (69.1%) and other and unspecified malignant tumours (54.3%).

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[1] Steliarova-Foucher E[1], Stiller C, Lacour B, Kaatsch P (2005). International Classification of Childhood Cancer, third edition. *Cancer*, 1457-1467

[2] Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Crown Copyright Office for National Statistics, accessed December 2017.

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 0.1% of all 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 those for cancer registries with high-quality data.

There were several distinctive patterns of incidence by age (Figure 2). Leukaemias formed the most frequent diagnostic group before 5 years of age, when they accounted for 37% of all cancers in boys and 36% in girls. At age 5 to 9 years, Leukaemias and CNS and miscellaneous intracranial and intraspinal neoplasms each accounted for 31 to 32% of all cancers in boys and in girls. CNS and miscellaneous intracranial and intraspinal neoplasms were the most frequent group at age 10 to 14, accounting for 25% of all cancers in boys and 24% in girls. For many types of cancer, incidence was highest before 5 years of age and lowest at age 10 to 14. These included lymphoid leukaemia, ependymoma and choroid plexus tumours, intracranial and intraspinal embryonal tumours (mainly medulloblastoma), neuroblastoma, retinoblastoma, nephroblastoma and 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 and intraspinal germ cell tumours (especially in boys), Malignant gonadal germ cell tumours in girls, and nearly all carcinomas. Incidence was lowest at 5 to 9 years of age for acute myeloid leukaemia, and for malignant extracranial germ cell tumours (gonadal and extragonadal) in boys.

Incidence rates

Table 1 also shows incidence rates of childhood cancer by ICCC-3 main group for boys and girls separately. The total ASR was 166 per million in boys and 145 per million in girls. The sex ratio of ASRs was M/F=1.14. The cumulative risk of being diagnosed with cancer in the first 15 years of life was 1 in 412 for boys and 1 in 472 for girls. For both boys and girls, incidence was highest in the first 5 years, fell to a minimum at age 5 to 9 years, and was slightly higher at age 10 to 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. Corresponding data for ICCC-3 subgroups and divisions and for certain subsets are shown in Appendix A.

Among diagnostic categories with at least 50 registrations, the highest sex ratio was for Non-Hodgkin lymphoma (including Burkitt lymphoma), M/F=2.4. There were also relatively marked male excesses for medulloblastoma (M/F=1.8), CNS germ-cell tumours (M/F=1.8) and Hodgkin lymphoma (M/F=1.7). 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=0.36), Malignant gonadal germ cell tumours (M/F=0.55) and other (extracranial and extraspinal) malignant extragonadal germ cell tumours (M/F=0.56). There were smaller female excesses for malignant melanoma (M/F=0.77), nephroblastoma and other nonepithelial renal tumours (M/F=0.79) and retinoblastoma (M/F=0.94).

Table 1: Number of newly diagnosed cancers registered among children under 15 years of age and resident in England, 2001 to 2015, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

Source: National Cancer Registration and Analysis Service, Public Health England, CAS accessed December 2017

% DCO = percentage registered from death certificate only ASR = age standardised rate (World standard population% MV = percentage with microscopic verification

Diagnostic group	Number of cases						Number of cases per million							
							Boys				Girls			
	Boys	Girls	Total	Mean no. of cases per year	% DCO	% MV	Aged 0- 4	Aged 5-9	Aged 10-14	ASR	Aged 0- 4	Aged 5-9	Aged 10-14	ASR
All cancers combined	11,617	9,672	21,289	1,419	0.1%	92.5%	214.07	130.01	141.18	165.79	193.33	102.53	127.75	145.00
I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	3,608	2,906	6,514	434	0.1%	96.9%	79.61	41.31	29.78	52.79	68.95	32.54	25.79	44.67
II Lymphomas and reticuloendothelial neoplasms	1,472	705	2,177	145	0.1%	97.4%	10.24	20.57	30.81	19.55	4.35	7.62	18.94	9.64
III CNS and miscellaneous intracranial and intraspinal neoplasms	2,846	2,385	5,231	349	0.1%	82.6%	43.49	40.67	34.93	40.10	40.46	32.99	31.20	35.36
IV Neuroblastoma and other peripheral nervous cell tumours	669	599	1,268	85	0.0%	96.2%	23.67	3.23	0.91	10.47	21.88	3.21	1.05	9.81
V Retinoblastoma	265	269	534	36	0.0%	69.1%	10.57	0.34	0.08	4.23	11.27	0.36	0.09	4.50
VI Renal tumours	563	645	1,208	81	0.2%	97.7%	18.24	3.95	1.25	8.70	20.92	5.79	1.48	10.40
VII Hepatic tumours	145	122	267	18	0.0%	95.9%	5.02	0.55	0.46	2.25	4.18	0.36	0.79	1.96
VIII Malignant bone tumours	472	416	888	59	0.1%	97.7%	1.58	5.01	13.14	6.04	0.74	5.62	11.91	5.56
IX Soft tissue and other extraosseous sarcomas	786	583	1,369	91	0.0%	98.9%	12.56	9.01	11.27	11.04	10.31	6.37	8.86	8.62
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	319	385	704	47	0.0%	92.5%	6.39	1.40	5.49	4.52	6.70	3.03	7.11	5.64
XI Other malignant epithelial neoplasms and malignant melanomas	402	589	991	66	0.1%	98.0%	1.33	3.23	12.23	5.11	2.22	4.01	19.55	7.83
XII Other and unspecified malignant neoplasms	70	68	138	9	0.0%	54.3%	1.37	0.72	0.83	1.00	1.35	0.62	1.00	1.01

Figure 1: Mean number of newly diagnosed cancer cases per year registered among children under 15 years of age and resident in England, 2001 to 2015, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

Only cancer groupings of over 5 cases per year are displayed on the chart

= Main ICCC-3 cancer classification = Subgroup ICCC-3 cancer classification

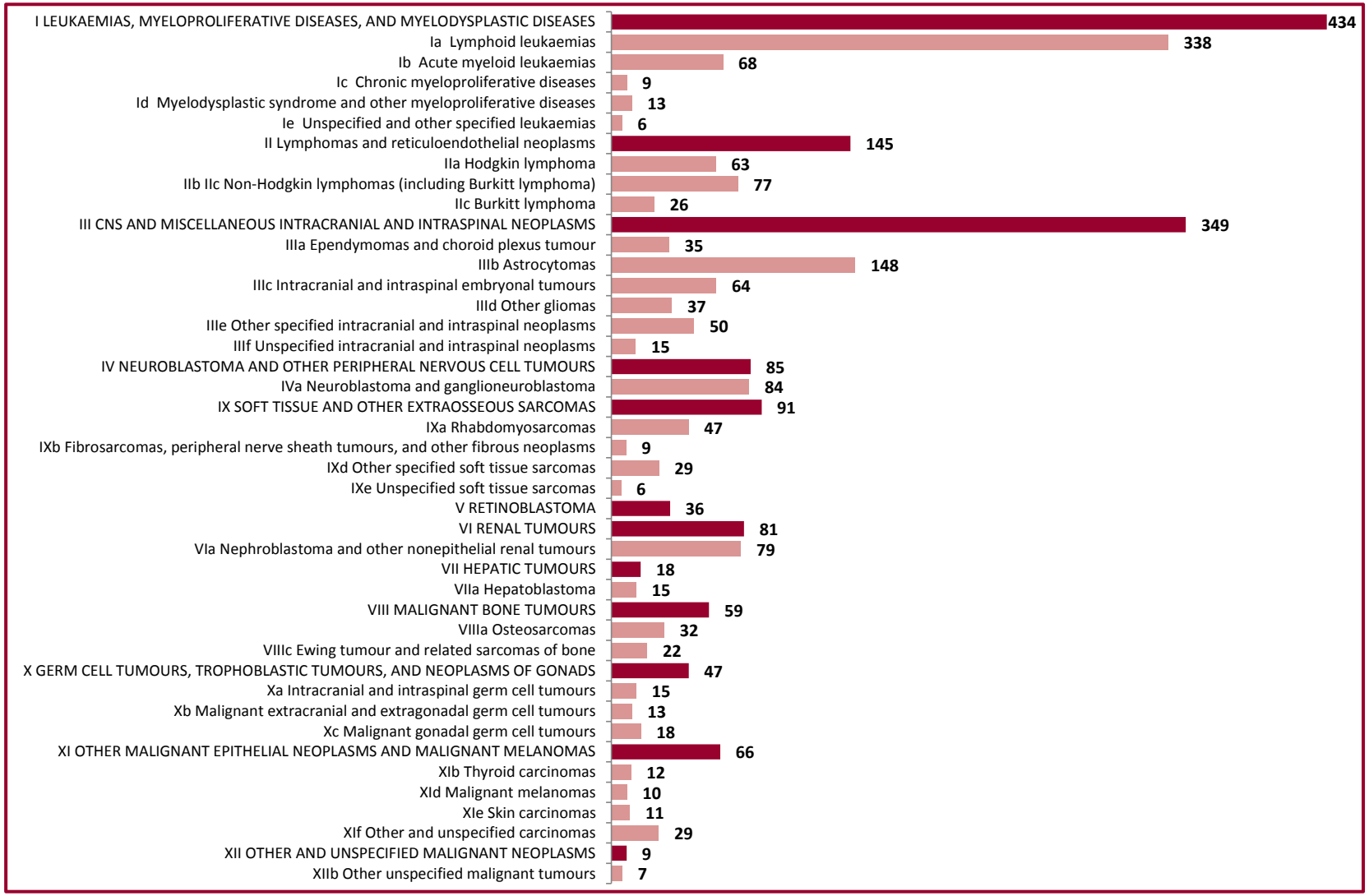
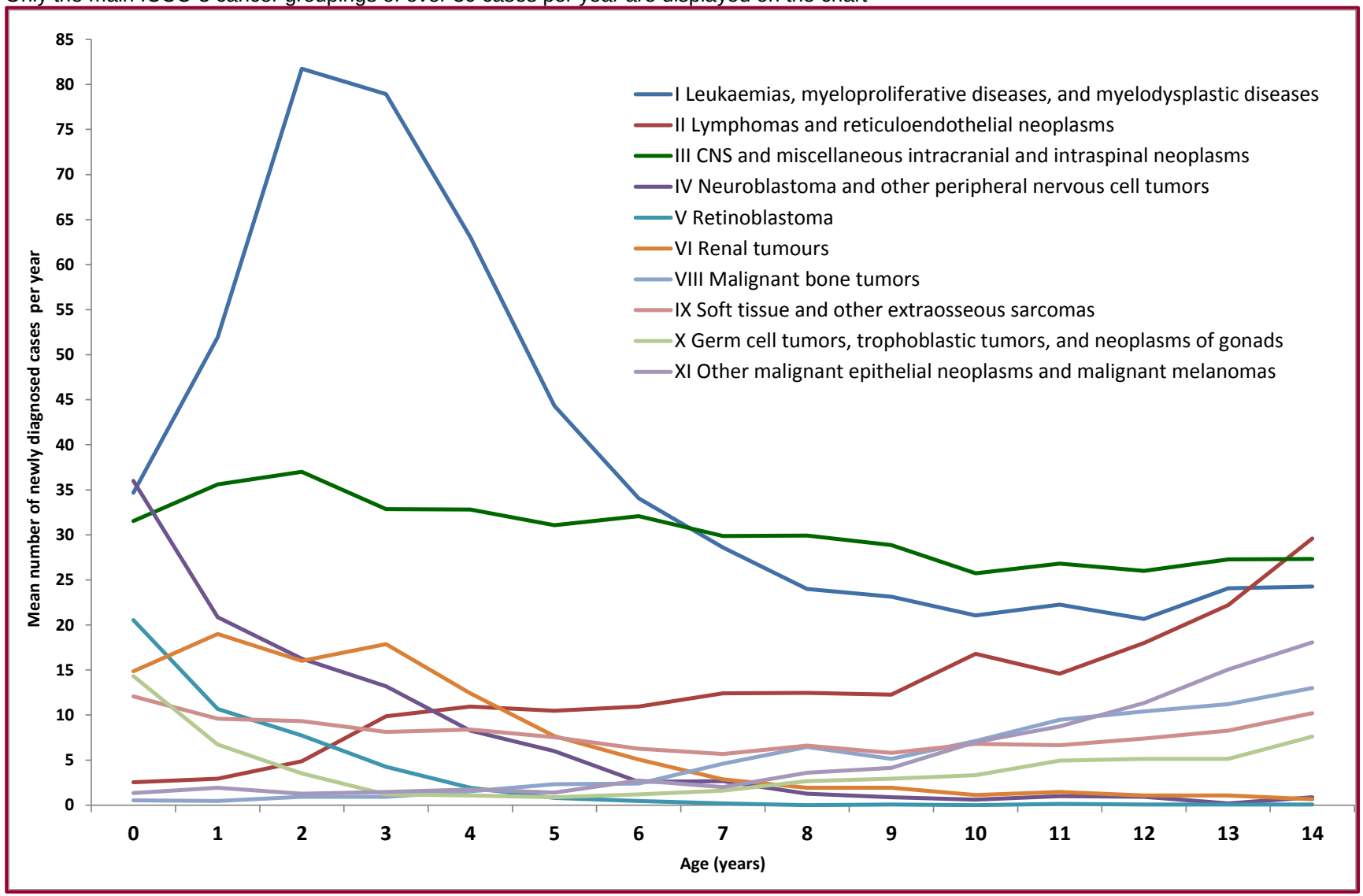


Figure 2: Mean number of newly diagnosed cancer cases per year registered among children under 15 years of age and resident in England, 2001 to 2015, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

Only the main ICCC-3 cancer groupings of over 30 cases per year are displayed on the chart



Population-based survival of children diagnosed with cancer, 2001 to 2015

Data and methods

The survival analyses are for children who were residents of England and under 15 years of age at diagnosis during 2001 to 2015 with any malignant neoplasm or non-malignant CNS tumour included in ICCC-3. The dataset was the same as the incidence analyses, except that cases ascertained by death certificate only were excluded (18 cases). Also, for all cancers combined, only the first primary tumours within the study period were included in the cohort count for people with multiple primary tumours (143 second or third cases were removed)[3]. The total number of cases analysed was 21,128[4]. The study censoring date for follow-up was 31 December 2016. Observed survival was estimated actuarially by Kaplan-Meier analysis using the complete approach. Trend in survival by single 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

Five-year survival rates for all cancers combined and for ICCC-3 main groups are shown in Table 2. Detailed results for cancer subgroups are tabulated in Appendix B. In addition to results for children diagnosed during the single 15-year period 2001 to 2015, results are given for each of the 3 5-year periods 2001 to 2005, 2006 to 2010 and 2011 to 2015 for diagnostic categories with at least 100 registrations analysed.

Overall, 5-year survival was 78% for children diagnosed in 2001 to 2005, 82% for those diagnosed in 2006 to 2010, and 84% for those diagnosed in 2011 to 2015 (Figure 3). The trend in survival by year of diagnosis was highly significant ($p<0.001$). One-year

[3] This follows the principle used for survival analysis published by the Office for National Statistics and Public Health England. In the future historical data prior to the study period will be also examined to help identify people with multiple primary tumours.
[4] The number of cases included in this survival analysis differs from the "*Childhood cancer survival in England: Children diagnosed from 1990 to 2015 and followed up to 2016 (Experimental Statistics)*" National Statistics published by the Office for National Statistics and Public Health England. The cancer cases for the analysis in this report have been classified using ICD-O-3 and with different definitions from those used for the National Statistics. For example cancers of the skin other than melanoma and secondary and unspecified malignant neoplasms were included in our study but were excluded in the National Statistics. The data cleaning process for the analysis in this report also differs from that applied for the National Statistics. For example, validation of historical cases took account of the legacy dataset acquired from the National Registry of Childhood Tumours.

survival increased by 1.3 percentage points between 2001 to 2005 and 2006 to 2010, from 89.8% to 91.1%, and by a further 1.5 percentage points to 92.6% in 2011 to 2015. At all-time points beyond one year from diagnosis, however, the increase in survival between 2006 to 2010 and 2011 to 2015 was smaller than between 2001 to 2005 and 2006 to 2010.

Five-year survival of children with leukaemia increased significantly through the study period, with most of the increase occurring between 2001 to 2005 and 2006 to 2010, when 5-year survival was 83% and 87% respectively; in 2011 to 2015 there was a further, modest increase to 88% (Figure 4). The time trend in survival reflects a similar trend for precursor lymphoblastic leukaemia, also known as acute lymphoblastic leukaemia (ALL) (Figure 5). For this subgroup, 5-year survival was 88% in 2001 to 2005 and 92% in both 2006 to 2010 and 2011 to 2015. The corresponding survival rates for children aged one year and over at diagnosis were 89%, 93% and 94% in the 3 periods. Infants aged under one year with ALL have a markedly worse prognosis than older children, and their 5-year survival remained below 70% with no detectable trend over time. Survival from mature B-cell leukaemia was 85%. Acute myeloid leukaemia had lower survival than lymphoid leukaemia (AML), reaching 71% by 2011 to 2015. Survival increased significantly for chronic myeloproliferative diseases (Figure 6), with most of the increase taking place between 2001 to 2005 and 2006 to 2010.

Survival increased significantly for children with lymphoma, with 5-year survival increasing from 87% in 2001 to 2005 to 93% in 2011 to 2015 (Figure 7). This largely reflected an upward trend for Non-Hodgkin lymphoma (including Burkitt lymphoma), with a steady increase throughout the study period. Five-year survival for Hodgkin lymphoma was already 95% in 2001 to 2005.

Survival also increased significantly for children with intracranial and intraspinal tumours, with 5-year survival increasing from 71% in 2001 to 2005 to 75% in 2011 to 2015 (Figure 8). Survival increased over the study period for many subtypes within this group. There was a significant trend for the combined subgroup of ependymomas and choroid plexus tumours (Figure 9), and for choroid plexus carcinoma within that subgroup. Much of the improvement for ependymoma was at follow-up points beyond 5 years from diagnosis. Significant trends were also seen for embryonal CNS tumour NOS, mixed and unspecified gliomas, and craniopharyngiomas. Survival varied widely between different types of CNS tumour, with 5-year survival ranging from over 90% for choroid plexus papilloma, pituitary adenomas and carcinomas, craniopharyngiomas, neuronal and mixed neuronal-glial tumours, and meningiomas, to below 30% for atypical teratoid/rhabdoid tumour.

Five-year survival from neuroblastoma rose from 64% for children diagnosed in 2001 to 2005 to 71% in 2011 to 2015 (Figure 10). Infants aged under one year with neuroblastoma had a much higher survival rate than older children. There was a

significant increasing trend in survival from neuroblastoma for children aged one to 14; 5-year survival rose from 49% in 2001 to 2005 to 65% in 2011 to 2015. There was also some evidence of a reduction in mortality among children who had already survived for 5 years. Survival from retinoblastoma was well over 95% throughout the study period, regardless of whether the disease was unilateral or bilateral.

Survival of children with renal tumours was high overall, with 5-year survival above 85%, but varied widely between subtypes. Five-year survival from nephroblastoma (Wilms tumour), the most frequent type of childhood renal tumour, increased from 88% in 2001 to 2005 to 92% in 2006 to 2010, with no further increase thereafter. By contrast, the prognosis for children with rhabdoid renal tumour remained very poor, with 5-year survival of only 20%. Hepatic tumours had somewhat lower survival than renal tumours. Five-year survival from hepatoblastoma, an embryonal tumour which mainly affects very young children, was around 80%, with no evidence of a time trend. Hepatic carcinoma, which is much less frequent and occurs mainly in older children, had much lower 5-year survival of 52%, but with a significant increasing trend over time. Survival from hepatic sarcomas (a subset of ICCC-3 group IX, soft-tissue sarcomas, and presented in Appendix B) was similar, 55%, but with no marked change in survival over time.

There was a steady and significant increase in survival from bone tumours during the study period, with 5-year survival rising from 61% in 2001 to 2005 to 71% in 2011 to 2015 (Figure 11). This trend reflected an even more marked trend in survival for osteosarcoma, from 53% to 71% between the same 2 periods. By contrast, 5-year survival from Ewing sarcoma family tumours of bone, the other main type of childhood bone tumour, was constant at 65 to 66% throughout.

Five-year survival from soft-tissue sarcomas also increased significantly, from 65% to 74% (Figure 12). Within this heterogeneous group, there were significant improvements in survival for rhabdomyosarcoma (Figure 13), the most frequent paediatric soft-tissue sarcoma, and for extraosseous Ewing sarcoma family tumours, with the increase being almost entirely between 2001 to 2005 and 2006 to 2010 for both of these subgroups.

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 above 90%. CNS germinomas had somewhat higher survival than other CNS germ-cell tumours.

Five-year survival from thyroid carcinoma was well over 90% throughout the study period. Survival from malignant melanoma was 78% for children diagnosed during 2001 to 2005, and around 90% for those diagnosed during 2006 to 2015.

Table 2: Population-based 5-year survival of children with cancer in England diagnosed 2001 to 2015, by period of diagnosis, grouped according to 'International Classification of Childhood Cancer, Third Edition' (ICCC-3)

Source: National Cancer Registration and Analysis Service, Public Health England, CAS accessed December 2017

The study censoring date for follow-up was 31 December 2016. 95% confidence limits - Lower confidence limit (LCL) and Upper confidence limit (UCL) by period of diagnosis.

Chi-squared test for trend by single 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 10 deaths.

***** = Significant trend with a P-value of <0.05 ****** = Significant trend with a P-value of <0.01 ******* = Significant trend with a P-value of <0.001

x = Not a significant trend ~ = Trend not reported because fewer than 10 deaths

Diagnostic group	No. of cases	Diagnosis period												χ2 (1df) for trend	
		2001-2005			2006-2010			2011-2015			2001-2015				
		%	LCL	UCL	%	LCL	UCL	%	LCL	UCL	%	LCL	UCL		
All cancers combined	**21,128**	**78%**	*77%*	*79%*	**82%**	*81%*	*83%*	**84%**	*83%*	*85%*	**81%**	*81%*	*82%*	**70.63**	***
I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	**6,507**	**83%**	*82%*	*85%*	**87%**	*86%*	*89%*	**88%**	*86%*	*90%*	**86%**	*85%*	*87%*	16.17	***
II Lymphomas and reticuloendothelial neoplasms	**2,174**	**87%**	*84%*	*89%*	**90%**	*88%*	*92%*	**93%**	*91%*	*95%*	**90%**	*89%*	*91%*	11.23	***
III CNS and miscellaneous intracranial and intraspinal neoplasms	**5,227**	**71%**	*68%*	*73%*	**74%**	*72%*	*76%*	**75%**	*73%*	*78%*	**73%**	*72%*	*74%*	13.28	***
IV Neuroblastoma and other peripheral nervous cell tumours	**1,268**	**64%**	*60%*	*69%*	**66%**	*61%*	*71%*	**71%**	*66%*	*76%*	**67%**	*64%*	*70%*	4.37	*
V Retinoblastoma	**534**	**98%**	*95%*	*99%*	**99%**	*96%*	*100%*	**99%**	*96%*	*100%*	**99%**	*98%*	*100%*	~	
VI Renal tumours	**1,206**	**83%**	*79%*	*87%*	**89%**	*85%*	*91%*	**88%**	*84%*	*91%*	**87%**	*85%*	*89%*	3.36	x
VII Hepatic tumours	**267**	**65%**	*54%*	*75%*	**77%**	*66%*	*85%*	**77%**	*67%*	*84%*	**73%**	*67%*	*78%*	1.00	x
VIII Malignant bone tumours	**887**	**61%**	*55%*	*67%*	**65%**	*60%*	*70%*	**71%**	*64%*	*77%*	**65%**	*62%*	*68%*	8.21	**
IX Soft tissue and other extraosseous sarcomas	**1,369**	**65%**	*60%*	*69%*	**72%**	*67%*	*76%*	**74%**	*69%*	*78%*	**70%**	*67%*	*73%*	11.21	***
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	**704**	**93%**	*88%*	*95%*	**92%**	*88%*	*95%*	**94%**	*90%*	*97%*	**93%**	*90%*	*94%*	0.00	x
XI Other malignant epithelial neoplasms and malignant melanomas	**990**	**90%**	*86%*	*93%*	**92%**	*88%*	*95%*	**93%**	*89%*	*95%*	**92%**	*90%*	*93%*	3.11	x
XII Other and unspecified malignant neoplasms	**138**	**92%**	*71%*	*98%*	**88%**	*76%*	*94%*	**86%**	*72%*	*94%*	**88%**	*81%*	*93%*	(0.07)	x

Figure 3: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, all cancers combined

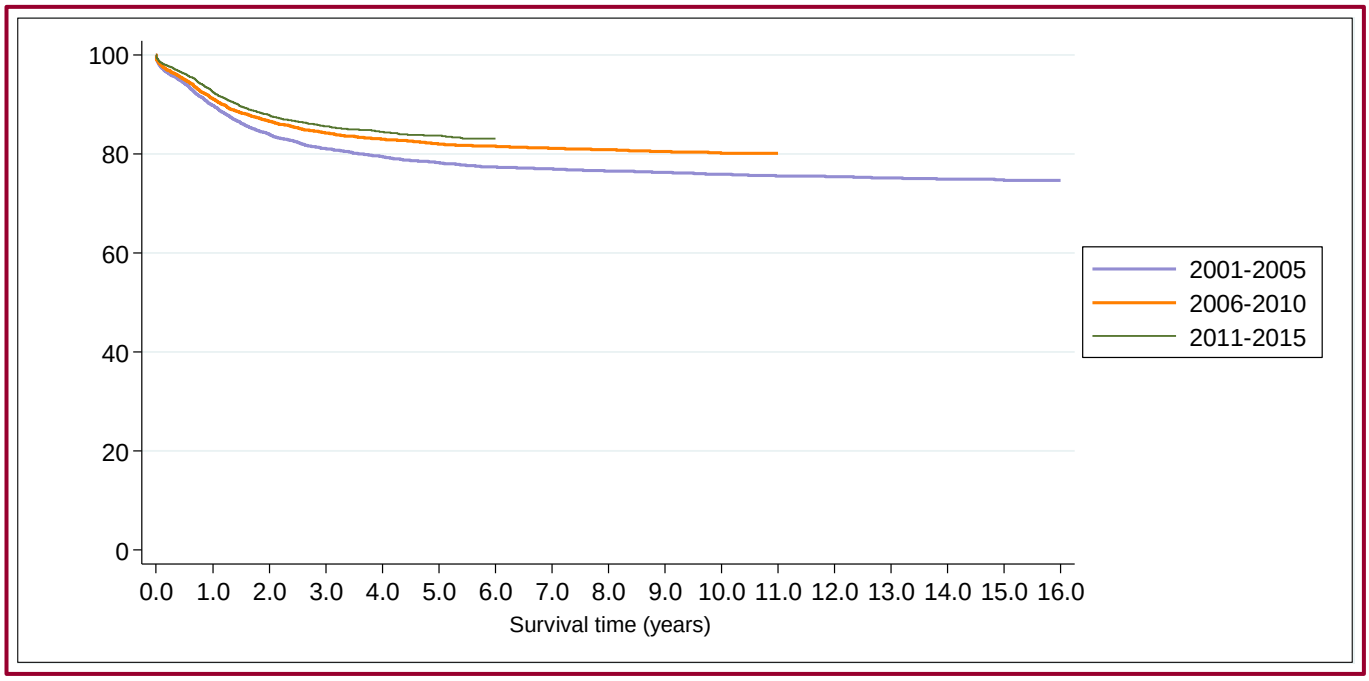


Figure 4: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, leukaemias, myeloproliferative diseases, and myelodysplastic diseases

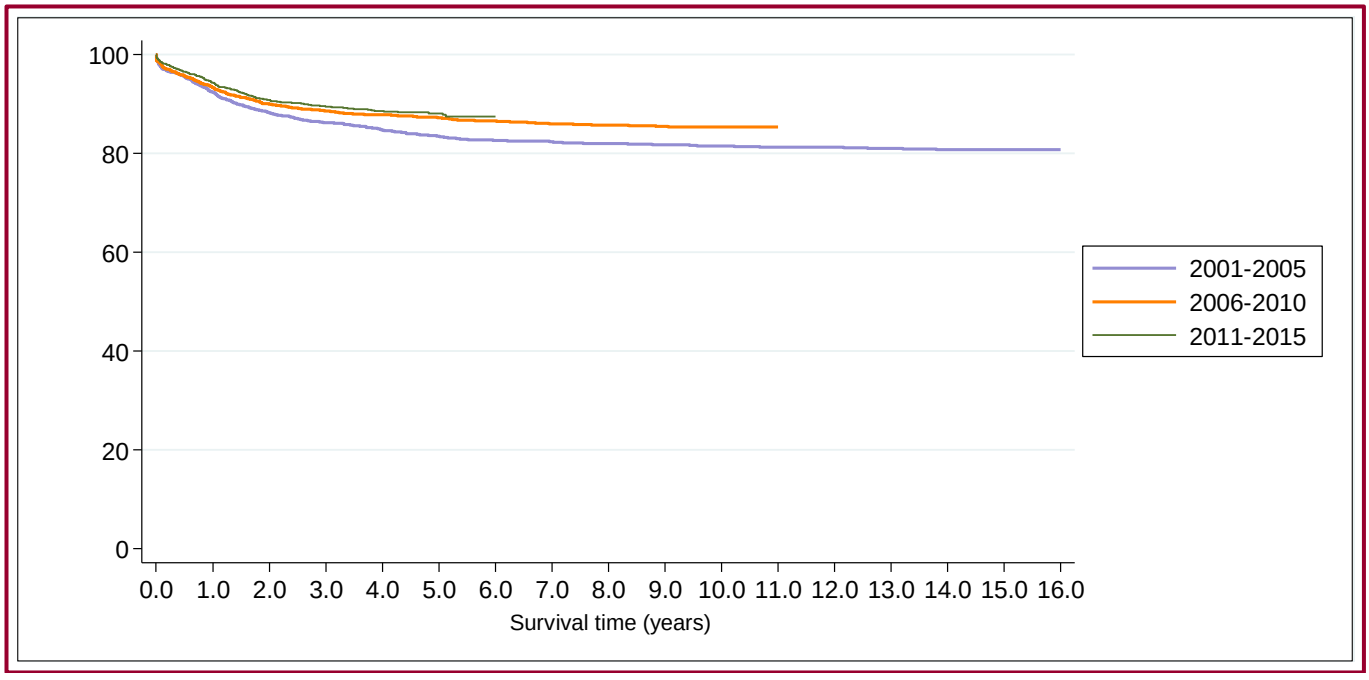


Figure 5: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, precursor lymphoblastic leukaemia

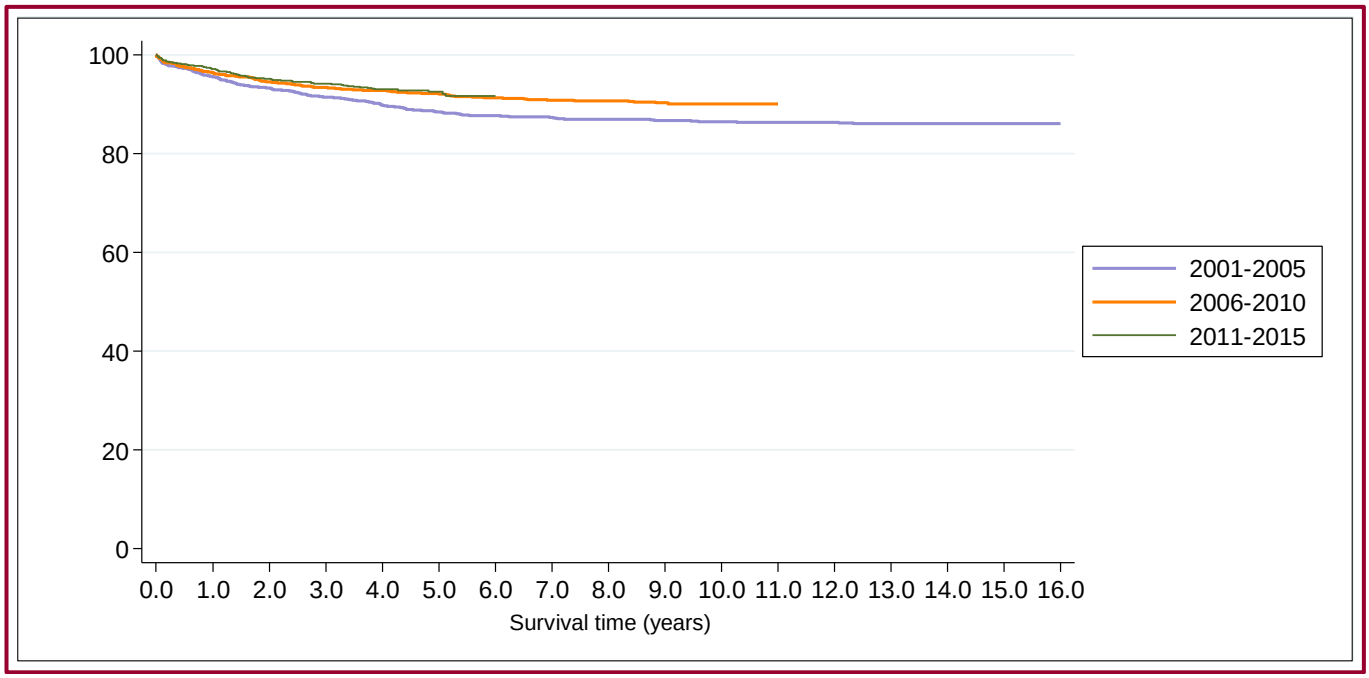


Figure 6: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, chronic myeloproliferative diseases

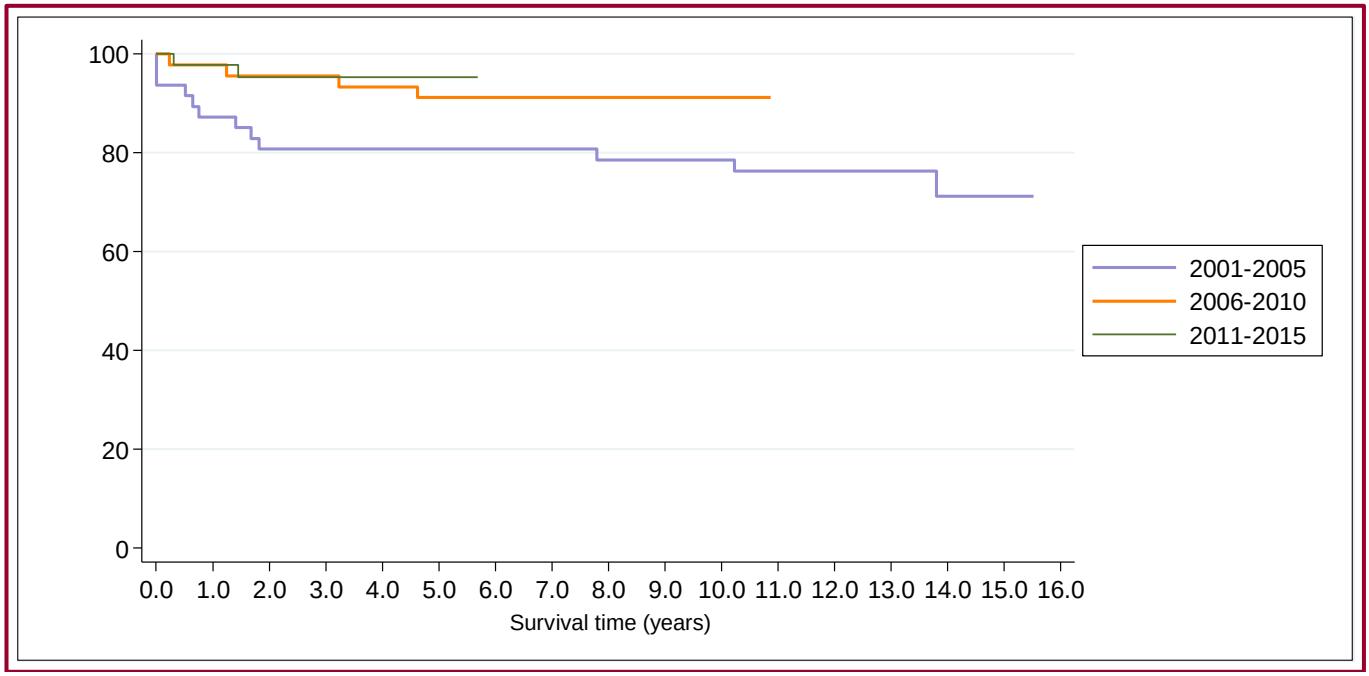


Figure 7: Population-based survival of children aged 0 to14 years with cancer in England diagnosed 2001 to 2015, lymphomas and reticuloendothelial neoplasms

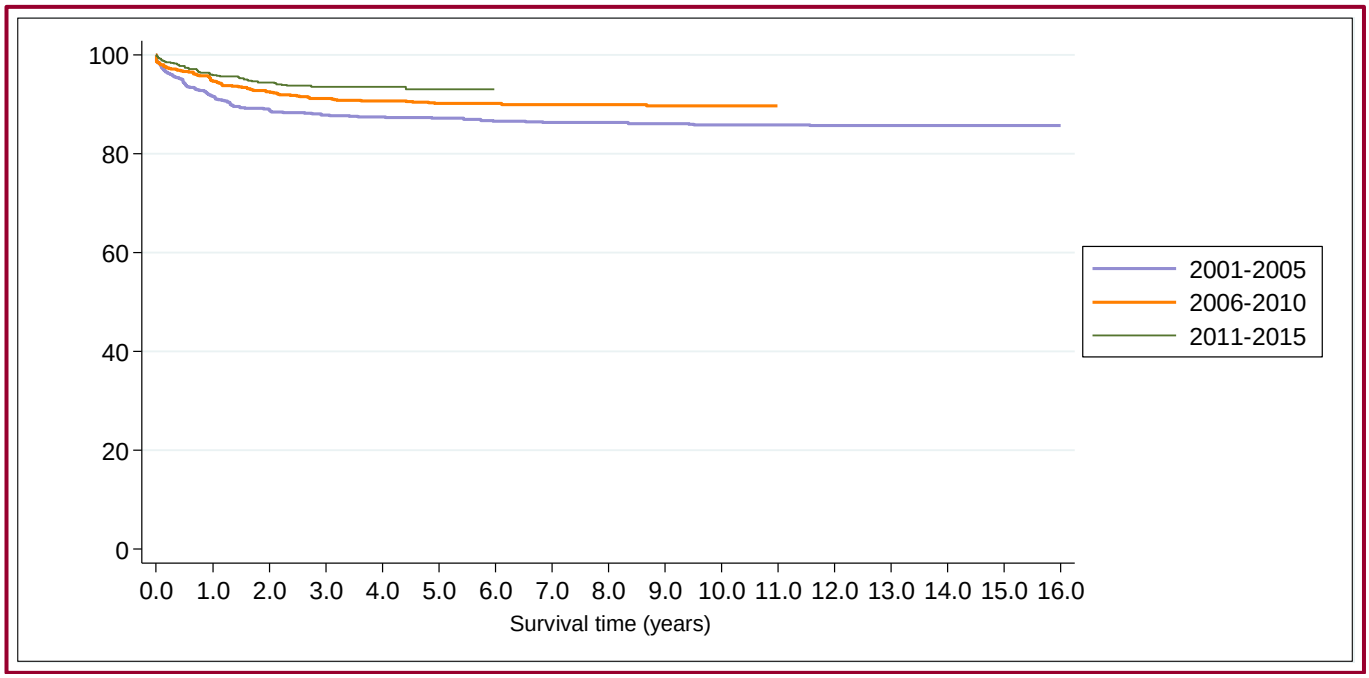


Figure 8: Population-based survival of children aged 0 to14 years with cancer in England diagnosed 2001 to 2015, CNS and miscellaneous intracranial and intraspinal neoplasms

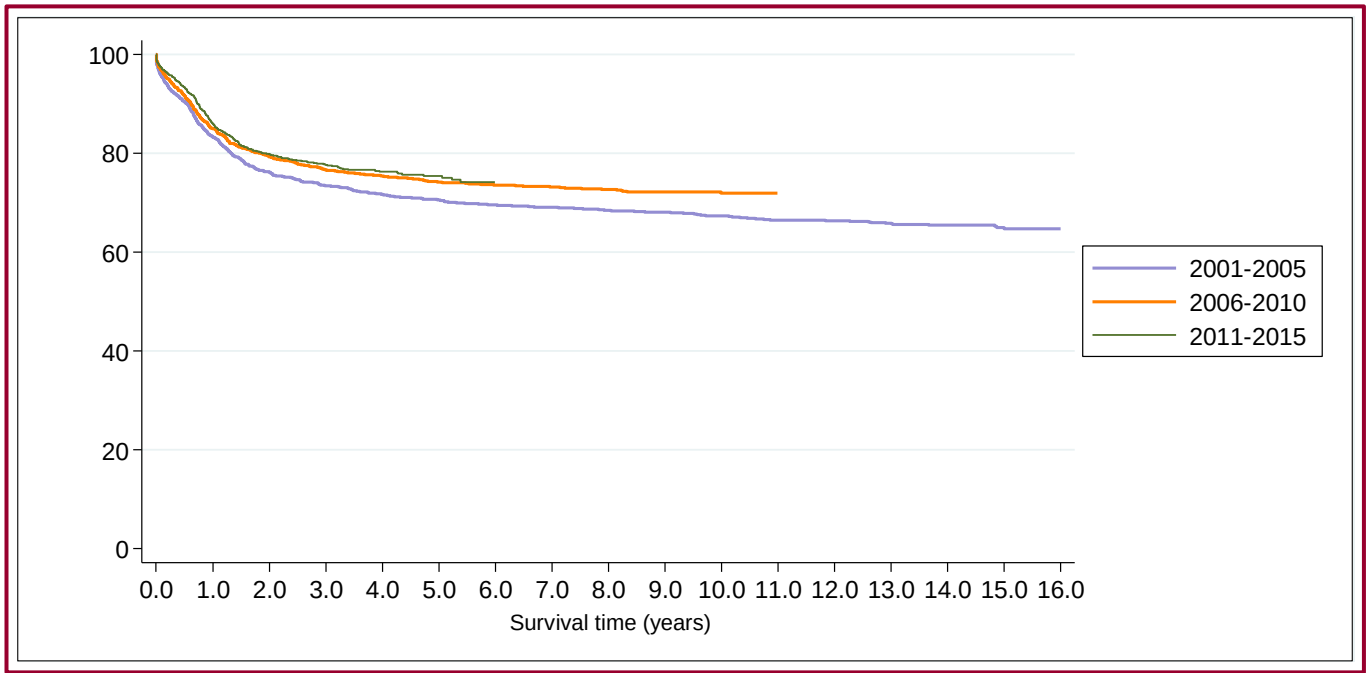


Figure 9: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, ependymomas and choroid plexus tumour

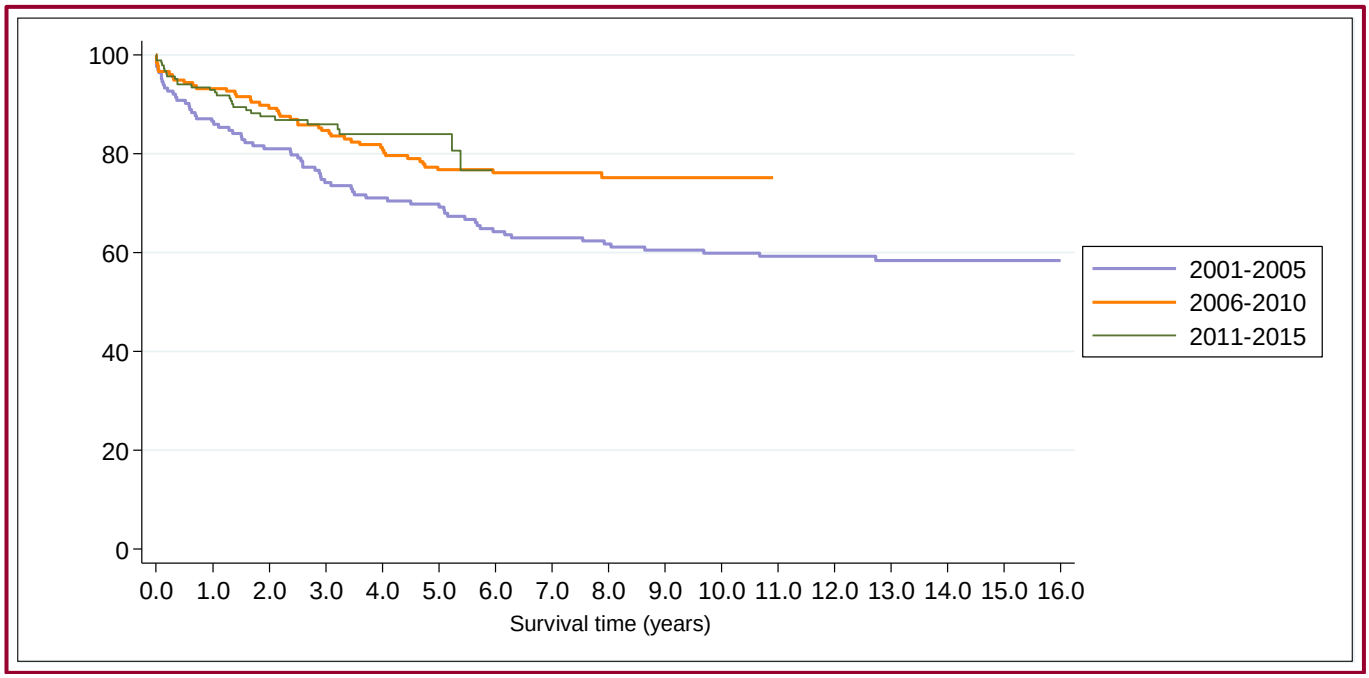


Figure 10: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, neuroblastoma and ganglioneuroblastoma

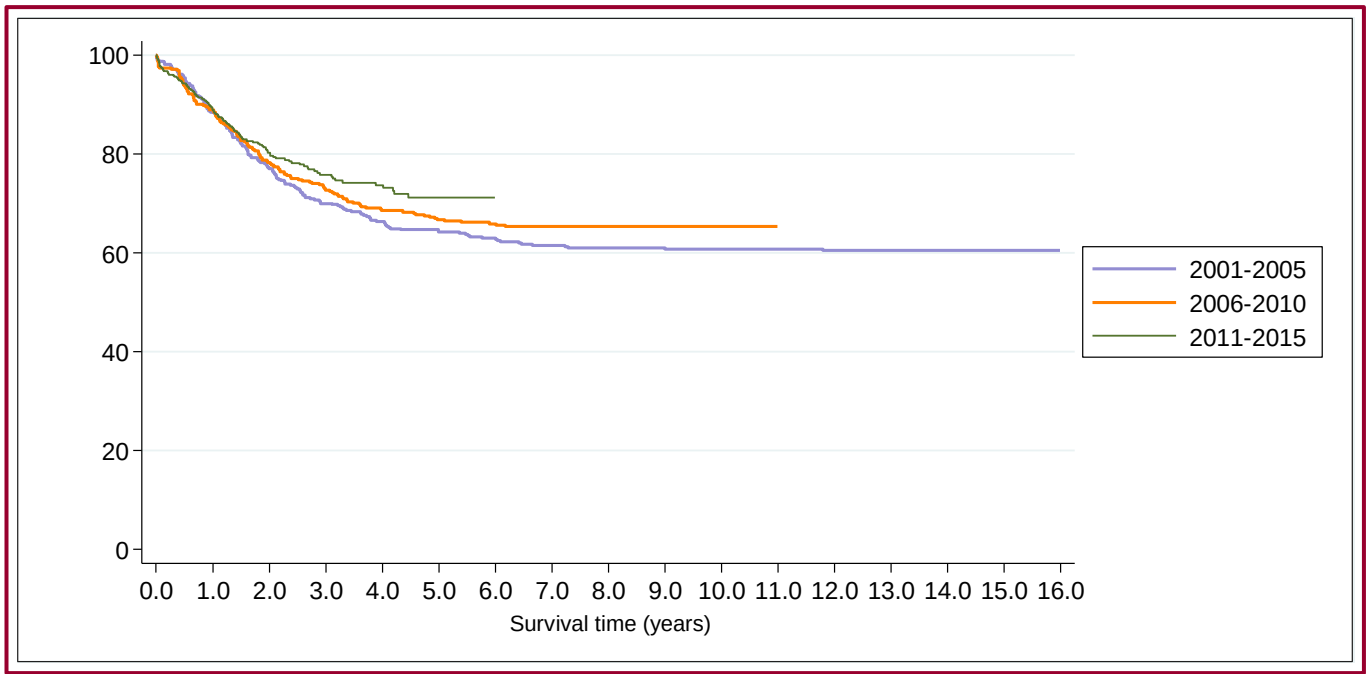


Figure 11: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, malignant bone tumours

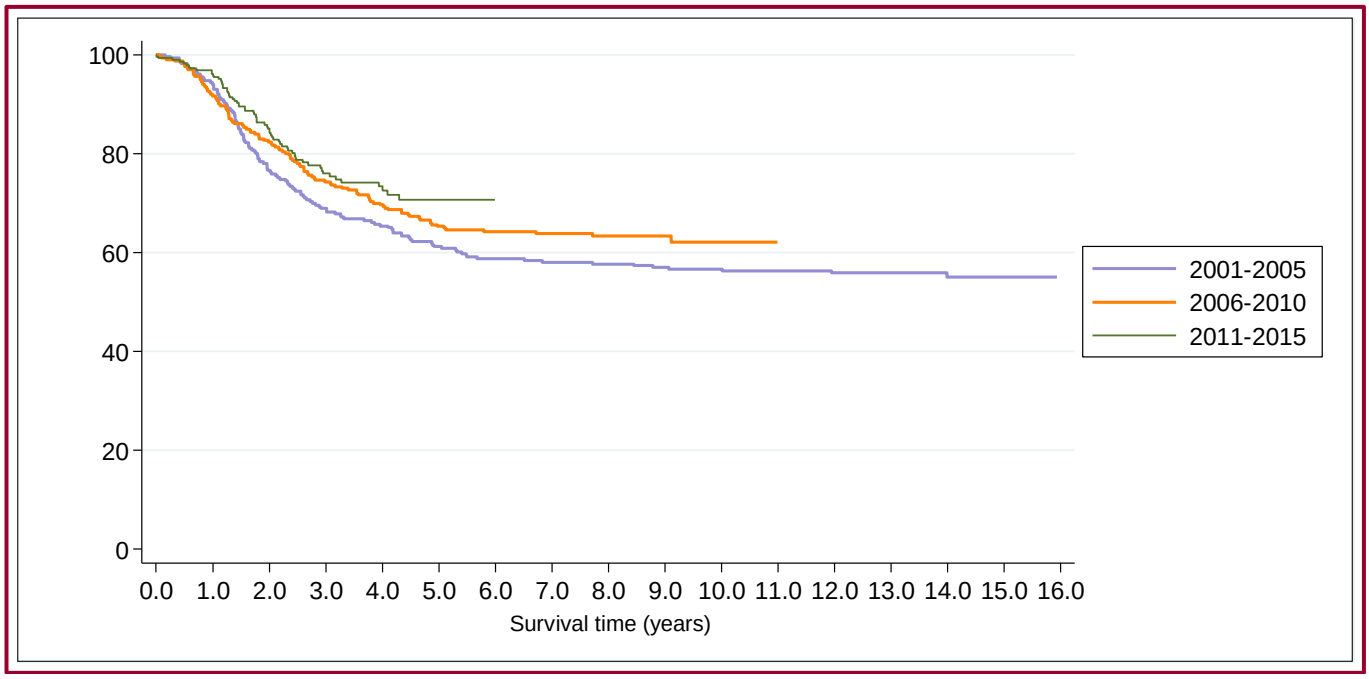


Figure 12: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, soft tissue and other extraosseous sarcomas

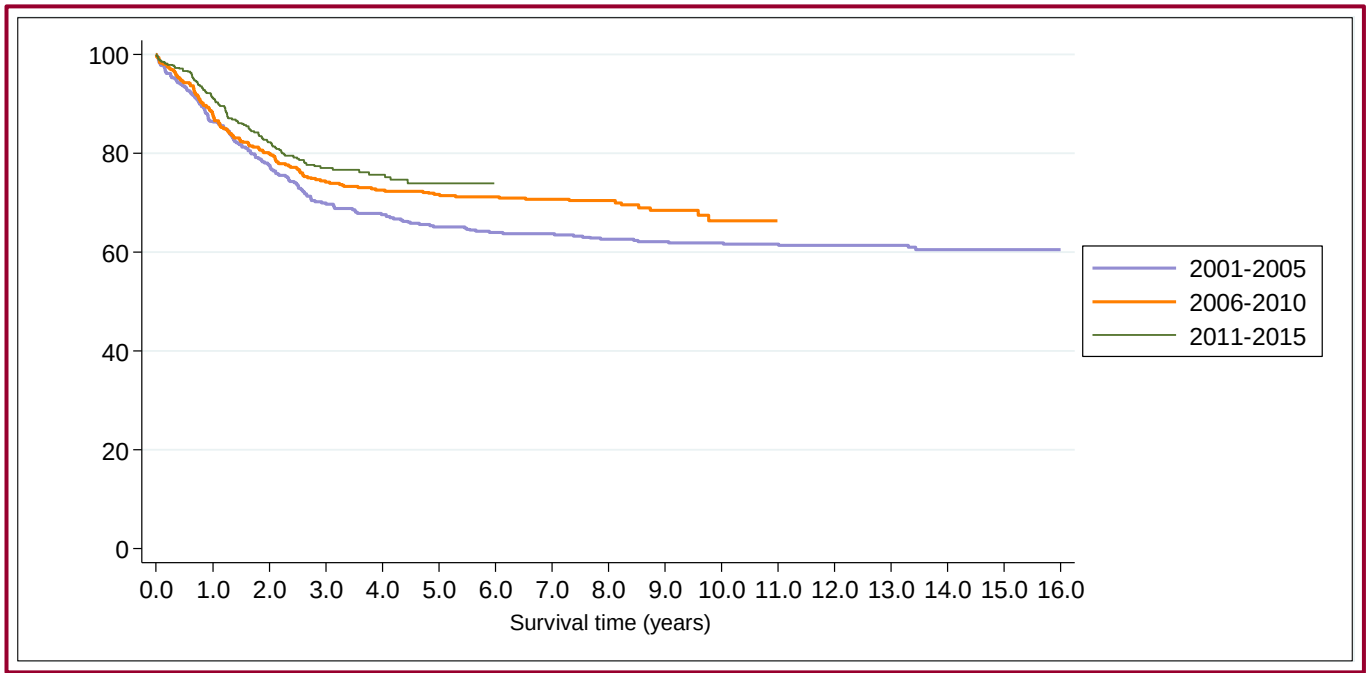
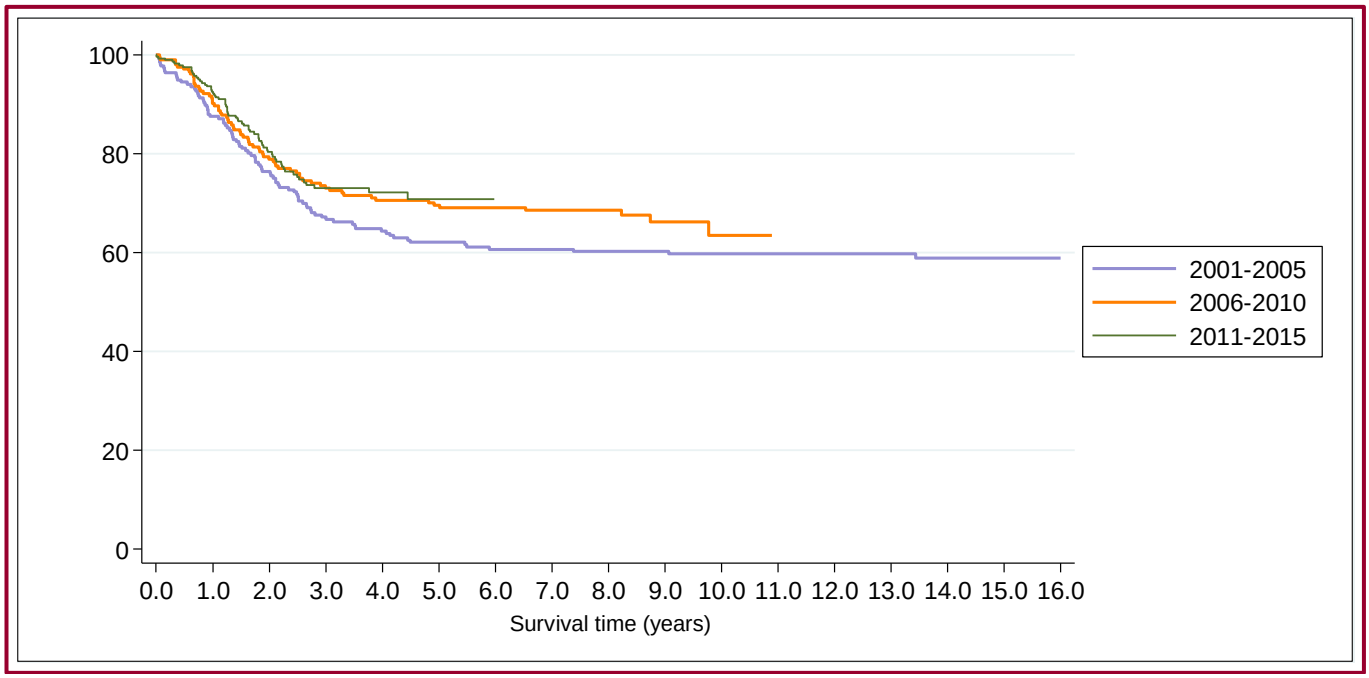


Figure 13: Population-based survival of children aged 0 to 14 years with cancer in England diagnosed 2001 to 2015, rhabdomyosarcomas



Cancer prevalence, 1995 to 2015

Cancer prevalence refers to people alive at a particular point in time who have been diagnosed with cancer. Prevalence has been calculated by linking cancer registrations to mortality records and quantifying how many people who were diagnosed with cancer between 1995 and 2015 were still alive on 31 December 2015 – that is, 21-year prevalence. Prevalence statistics include anyone who has been diagnosed with cancer and was still alive at the end of the 21-year period, regardless of their disease status at that point. These statistics can help inform healthcare planning, commissioning and support services for cancer patients as they provide critical data on the burden of cancer.

The tables here show cancer prevalence separately for those who were aged 0 to 14 at the time of diagnosis of their cancer between 1995 and 2015 and who were still alive at the end of 2015 (Tables 3 and 4), and then for those who were diagnosed with cancer between 1995 and 2015, and were still alive and aged 0 to 14 at the end of 2015 (Tables 5 and 6). The former number is larger because approximately half of the patients aged 0 to 14 at the time of diagnosis who were still alive at the end of 2015 were by then aged 15 or over (the oldest being 35 years of age) and therefore do not contribute to tables 5 and 6. The prevalence data are based on ICD10 coding and non-malignant brain tumours are not included. Therefore these data do not include separate figures for all of the ICCC-3 cancer groups.

There were around 20,000 people alive at the end of 2015 who had been diagnosed with cancer as a child (aged 0 to 14 years) in the period 1995 to 2015. Around 11,000 of these were aged 15 or over at the end of 2015. Leukaemia (ICD10 C91-C95), brain tumours (ICD10 C70-C72), Hodgkin lymphoma (ICD10 C81), non-Hodgkin lymphoma (ICD10 C82-C85) and cancers of the kidney, renal pelvis and ureter (essentially kidney cancers in this age group) (ICD10 C64-C66, C68) were the most prevalent cancers. There were 7,070 people in England still alive at the end of 2015 after having a diagnosis of leukaemia between the age of 0 to 14 years. This compares to 3,677 for brain tumours, 1,290 for Non-Hodgkin lymphomas and 1,190 for Hodgkin lymphoma. Leukaemia and brain cancer accounted for just over half of all cases (53%).

There were around 1,790,000 people alive in England at the end of 2015 who had been diagnosed with cancer at any age in the period 1995 to 2015. People who had been diagnosed with cancer in childhood accounted for 1% of this total. However, this proportion differs by cancer groupings with 25% of all people alive following a diagnosis of brain cancer and 15% of all those who were alive following leukaemia having been diagnosed during childhood. Around a quarter of people alive at the end of 2015 who

had been diagnosed with cancer as a child since 1995 had been diagnosed between 15 and 21 years earlier, and 70% had survived at least 5 years since diagnosis.

Among 9,000 children (0 to 14 year olds) alive at the end of 2015 after having a cancer diagnosis, leukaemia accounted for 38% of cases, followed by brain tumours (17%), Figure 14.

Table 3: 21-year cancer prevalence 1995 to 2015 in England shown by age at diagnosis

Based on patients diagnosed with cancer between 1995 and 2015 and were still alive on 31 December 2015

Source: The prevalence analysis was carried out in partnership between the National Cancer Registration and Analysis Service (NCRAS) and the Transforming Cancer Services Team for London (TCST), part of Healthy London Partnership. This work was also supported by and builds on previous prevalence work carried out by the NCRAS partnership with Macmillan Cancer Support.

Cancer diagnostic group (based on ICD10)	Number of people diagnosed with cancer between 1991-2015 and still alive at the end of 2015, by age at diagnosis																							
	Persons by age at diagnosis								Males by age at diagnosis								Females by age at diagnosis							
	0-14 years				Other age groups and all ages			% 0-14 year olds	0-14 years				Other age groups and all ages			% 0-14 year olds	0-14 years				Other age groups and all ages			% 0-14 year olds
	0-4	5-9	10-14	0-14	15-24	25+	All Ages		0-4	5-9	10-14	0-14	15-24	25+	All Ages		0-4	5-9	10-14	0-14	15-24	25+	All Ages	
All cancers combined	**9,534**	**5,125**	**5,527**	**20,186**	25,233	1,745,947	1,791,366	1%	**5,101**	**2,931**	**2,964**	**10,996**	12,907	782,041	805,944	**1%**	**4,433**	**2,194**	**2,563**	**9,190**	12,326	963,906	985,422	**1%**
Leukaemia (ICD10 C91-C95)	**3,905**	**1,908**	**1,257**	**7,070**	1,787	39,034	47,891	15%	**2,115**	**1,083**	**693**	**3,891**	1,082	23,142	28,115	14%	**1,790**	**825**	**564**	**3,179**	705	15,892	19,776	16%
Hodgkin lymphoma (ICD10 C81)	**81**	**285**	**824**	**1,190**	4,551	14,835	20,576	6%	**69**	**200**	**484**	**753**	2,297	8,542	11,592	6%	**12**	**85**	**340**	**437**	2,254	6,293	8,984	5%
Non-Hodgkin lymphoma (ICD10 C82-C85)	**279**	**482**	**529**	**1,290**	1,689	77,761	80,740	2%	**197**	**358**	**374**	**929**	1,056	40,781	42,766	2%	**82**	**124**	**155**	**361**	633	36,980	37,974	1%
Brain (ICD10 C70-C72)	**1,374**	**1,256**	**1,047**	**3,677**	1,431	9,896	15,004	25%	**721**	**700**	**549**	**1,970**	809	5,435	8,214	24%	**653**	**556**	**498**	**1,707**	622	4,461	6,790	25%
Kidney, renal pelvis and ureter (ICD10 C64-C66, C68)	**1,094**	**257**	**52**	**1,403**	160	54,081	55,644	3%	**544**	**114**	**27**	**685**	78	33,473	34,236	2%	**550**	**143**	**25**	**718**	82	20,608	21,408	3%

Table 4: 21-year cancer prevalence 1995 to 2015 in England shown by time since diagnosis for people that were diagnosed with cancer between the age of 0 to 14 years

Based on patients diagnosed with cancer between 1995 and 2015 and were still alive on 31 December 2015

Source: The prevalence analysis was carried out in partnership between the National Cancer Registration and Analysis Service (NCRAS) and the Transforming Cancer Services Team for London (TCST), part of Healthy London Partnership. This work was also supported by and builds on previous prevalence work carried out by the NCRAS partnership with Macmillan Cancer Support.

Cancer diagnostic group (based on ICD10)	Number of people diagnosed with cancer at the age of 0-14 years between 1991-2015 and still alive at the end of 2015, by time since diagnosis													
	Number							Percentage						
	< 1 yr	1 yrs - < 2 yrs	2 yrs - < 5 yrs	5 yrs - < 10 yrs	10 yrs - < 15 yrs	15 yrs - < 21 yrs	21 year total	< 1 yr	1 yrs - < 2 yrs	2 yrs - < 5 yrs	5 yrs - < 10 yrs	10 yrs - < 15 yrs	15 yrs - < 21 yrs	21 year total
All cancers combined	**1,355**	**1,239**	**3,296**	**4,969**	**4,451**	**4,876**	**20,186**	**7%**	**6%**	**16%**	**25%**	**22%**	**24%**	**100%**
Leukaemia (ICD10 C91-C95)	483	429	1,127	1,716	1,617	1,698	7,070	7%	6%	16%	24%	23%	24%	100%
Hodgkin lymphoma (ICD10 C81)	57	65	194	286	280	308	1,190	5%	5%	16%	24%	24%	26%	100%
Non-Hodgkin lymphoma (ICD10 C82-C85)	70	76	209	347	281	307	1,290	5%	6%	16%	27%	22%	24%	100%
Brain (ICD10 C70-C72)	281	219	551	950	791	885	3,677	8%	6%	15%	26%	22%	24%	100%
Kidney, renal pelvis and ureter (ICD10 C64-C66, C68)	93	89	226	327	321	347	1,403	7%	6%	16%	23%	23%	25%	100%

Table 5: 21-year cancer prevalence in England shown by chronological age at the end of 2015

Based on children diagnosed with cancer 1995 to 2015 and were still alive at the end of 2015

Source: The prevalence analysis was carried out in partnership between the National Cancer Registration and Analysis Service (NCRAS) and the Transforming Cancer Services Team for London (TCST), part of Healthy London Partnership. This work was also supported by and builds on previous prevalence work carried out by the NCRAS partnership with Macmillan Cancer Support.

Cancer diagnostic group (based on ICD10)	Number of people who were diagnosed with cancer between 1991-2015 and still alive at the end of 2015, by age at the end of 2015							
	0-14 year olds					Other age groups and all ages		
	0-4	5-9	10-14	0-14	Crude rates per 100,000	15-24	25+	All ages
All cancers combined	**1,523**	**3,355**	**4,170**	**9,048**	**92.4**	14,969	1,767,349	1,791,366
Leukaemia (ICD10 C91-C95)	**516**	**1,373**	**1,538**	**3,427**	35.0	3,623	40,841	47,891
Hodgkin lymphoma (ICD10 C81)	**10**	**52**	**168**	**230**	2.3	1,810	18,536	20,576
Non-Hodgkin lymphoma (ICD10 C82-C85)	**19**	**145**	**265**	**429**	4.4	1,071	79,240	80,740
Brain (ICD10 C70-C72)	**236**	**565**	**755**	**1,556**	15.9	2,068	11,380	15,004
Kidney, renal pelvis and ureter (ICD10 C64-C66, C68)	**163**	**333**	**314**	**810**	8.3	588	54,246	55,644

Table 6: Cancer prevalence in England for children aged 0-14 at the end of 2015, shown by time since diagnosis

Based on children diagnosed with cancer 1995 to 2015 and were still alive and aged 0-14 at the end of 2015

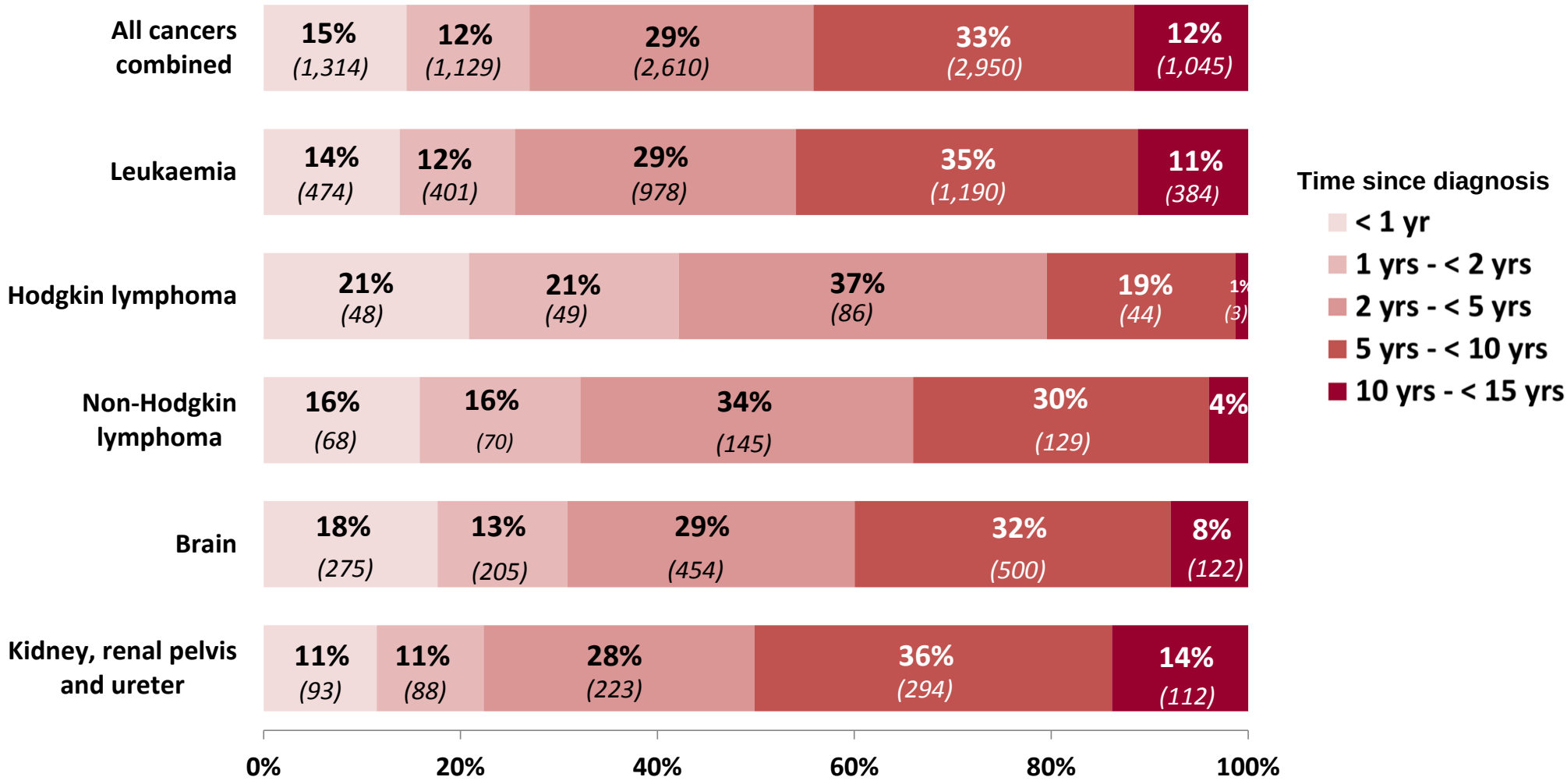
Source: The prevalence analysis was carried out in partnership between the National Cancer Registration and Analysis Service (NCRAS) and the Transforming Cancer Services Team for London (TCST), part of Healthy London Partnership. This work was also supported by and builds on previous prevalence work carried out by the NCRAS partnership with Macmillan Cancer Support.

Cancer diagnostic group (based on ICD10)	Number of children diagnosed with cancer at the age of 0-14 years in 1991-2015 and still alive at the end of 2015, by age at the end of 2015 and time since diagnosis											
	Number						Percentage					
	< 1 yr	1 yrs - < 2 yrs	2 yrs - < 5 yrs	5 yrs - < 10 yrs	10 yrs - < 15 yrs	21 year total	< 1 yr	1 yrs - < 2 yrs	2 yrs - < 5 yrs	5 yrs - < 10 yrs	10 yrs - < 15 yrs	21 year total
All cancers combined	**1,314**	**1,129**	**2,610**	**2,950**	**1,045**	**9,048**	**15%**	**12%**	**29%**	**33%**	**12%**	**100%**
Leukaemia (ICD10 C91-C95)	474	401	978	1,190	384	3,427	14%	12%	29%	35%	11%	100%
Hodgkin lymphoma (ICD10 C81)	48	49	86	44	3	230	21%	21%	37%	19%	1%	100%
Non-Hodgkin lymphoma (ICD10 C82-C85)	68	70	145	129	17	429	16%	16%	34%	30%	4%	100%
Brain (ICD10 C70-C72)	275	205	454	500	122	1,556	18%	13%	29%	32%	8%	100%
Kidney, renal pelvis and ureter (ICD10 C64-C66, C68)	93	88	223	294	112	810	11%	11%	28%	36%	14%	100%

Figure 14: Cancer prevalence in England for children aged 0 to 14 at the end of 2015, shown by time since diagnosis

Based on children diagnosed with cancer 1995 to 2015 and were still alive and aged 0 to 14 at the end of 2015

Source: The prevalence analysis was carried out in partnership between the National Cancer Registration and Analysis Service (NCRAS) and the Transforming Cancer Services Team for London (TCST), part of Healthy London Partnership. This work was also supported by and builds on previous prevalence work carried out by the NCRAS partnership with Macmillan Cancer Support



Cancer mortality

Cancer in children accounts for 0.1% of all cancer deaths in England. In 2016 there were around 190 childhood cancer deaths, accounting for 6% of all childhood deaths (0 to 14 year old). Cancer is the most common cause of death in children aged 1 to 14 years, accounting for around one-fifth of all deaths in this age group. This compares to cancer accounting for almost 30% of deaths for all ages[5].

Causes of death following childhood cancer diagnosed during 2001 to 2015:

For this analysis, cause of death was derived from Medical Certificates of the Cause of Death (MCCD) obtained from ONS. The underlying cause of death was used, with the exception that cause of death was assumed to be cancer or benign CNS tumour if cancer was documented at any point in part 1 of the medical certificate or the underlying cause of death. Within the dataset analysed causes of death were grouped by ICD-10 code as follows.

Cancer (including benign CNS tumours): B24, C00-C97, D32, D33, D35.2-D35.4, D42, D43, D44.3-D44.5, D46
Other neoplasms: all other in D00-D48
Infective: A00-A99, B00-B23, B25-B99, G00-G02, J00-J22, T80.2, T81.4, T82.6, T82.7, T83.5, T83.6, T84.5-T84.7, T85.7, T87.4, T88.0
Cardiac: I01, I05-I09, I11, I13, I15-I25, I30-I52
Other: all other

Of approximately 21,300 children diagnosed with cancer between 2001 to 2015, around 4,100 had died at any age by the end of 2016. Cancer (including benign CNS tumours) was recorded as a cause of death in 90% of these deaths, and for other neoplasms in a further 2%. In total, 4% of deaths did not have cancer or other neoplasm as a cause of death. One percent of overall deaths were caused by infection. For 3% of the deaths it was not possible to match the record to a death certificate[6].

Of the 3,752 deaths identified as being caused by cancer or a benign CNS tumour, 10% also had an infection recorded as a cause of the death on the death certificate, and 2% had a cardiac cause. This varies by cancer diagnosis groups. For example, for cancer

[5] ONS Crown Copyright Reserved [from Nomis on 4 April 2018]. Based on C00-D48 II Neoplasms (Cancers). The total number of deaths includes childhood deaths aged less than 28 days where a cause has not been classified.
[6] These cancer cases in the NCRAS cancer registration database (CAS) could not be matched to a death record in the ONS mortality database. This may be because of slight differences in the patient's identifiers between the two datasets.

deaths following a diagnosis of leukaemia, 27% also had an infection recorded as a cause of death on the death certificate.

Table 7: Cause of death for children (0 to 14 year olds) diagnosed with cancer in England, 2001 to 2015, based on deaths recorded up the end of 2016

Cancer cases grouped by cancer diagnosis classifications based on the 'International Classification of Childhood Cancers, Third Edition' (ICCC-3)

Source: National Cancer Registration and Analysis Service, Public Health England, CAS accessed January 2018

Cancer diagnostic group	Number of newly diagnosed cases	Total number of deaths (as at the end of 2016)	Cause of death - number of deaths										Cause of death - percentage					
			Cancer*			Other neoplasms*			Infection*	Cardiac*	Other*	No match to death certificate	Cancer*	Other neoplasms*	Infection*	Cardiac*	Other*	No match to death certificate
			Total	*Infection also listed on death certificate as a COD***	*Cardiac also listed on death certificate as a COD***	Total	*Infection also listed on death certificate as a COD***	*Cardiac also listed on death certificate as a COD***										
I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases	6,514	**942**	**837**	*227*	*24*	**22**	*10*	*0*	**15**	**3**	**33**	**32**	88.9%	2.3%	1.6%	0.3%	3.5%	3.4%
II Lymphomas and reticuloendothelial neoplasms	2,177	**222**	**189**	*37*	*6*	**10**	*4*	*0*	**4**	**0**	**15**	**4**	85.1%	4.5%	1.8%	0.0%	6.8%	1.8%
III CNS and miscellaneous intracranial and intraspinal neoplasms	5,231	**1,452**	**1,358**	*45*	*20*	**24**	*4*	*0*	**9**	**1**	**24**	**36**	93.5%	1.7%	0.6%	0.1%	1.7%	2.5%
IV Neuroblastoma and other peripheral nervous cell tumours	1,268	**408**	**373**	*14*	*7*	**2**	*1*	*0*	**5**	**1**	**8**	**19**	91.4%	0.5%	1.2%	0.2%	2.0%	4.7%
V Retinoblastoma	534	**8**	**6**	*2*	*0*	**0**	*0*	*0*	**0**	**0**	**2**	**0**	75.0%	0.0%	0.0%	0.0%	25.0%	0.0%
VI Renal tumours	1,208	**162**	**146**	*5*	*6*	**0**	*0*	*0*	**4**	**0**	**9**	**3**	90.1%	0.0%	2.5%	0.0%	5.6%	1.9%
VII Hepatic tumours	267	**74**	**65**	*4*	*0*	**1**	*1*	*0*	**2**	**1**	**3**	**2**	87.8%	1.4%	2.7%	1.4%	4.1%	2.7%
VIII Malignant bone tumours	888	**304**	**294**	*18*	*3*	**0**	*0*	*0*	**2**	**0**	**4**	**4**	96.7%	0.0%	0.7%	0.0%	1.3%	1.3%
IX Soft tissue and other extraosseous sarcomas	1,369	**411**	**364**	*14*	*9*	**23**	*1*	*0*	**3**	**0**	**6**	**15**	88.6%	5.6%	0.7%	0.0%	1.5%	3.6%
X Germ cell tumours, trophoblastic tumours, and neoplasms of gonads	704	**54**	**39**	*2*	*2*	**3**	*0*	*0*	**3**	**0**	**2**	**7**	72.2%	5.6%	5.6%	0.0%	3.7%	13.0%
XI Other malignant epithelial neoplasms and malignant melanomas	991	**84**	**68**	*1*	*1*	**3**	*1*	*1*	**3**	**0**	**7**	**3**	81.0%	3.6%	3.6%	0.0%	8.3%	3.6%
XII Other and unspecified malignant neoplasms	138	**15**	**13**	*0*	*1*	**1**	*0*	*0*	**0**	**0**	**1**	**0**	86.7%	6.7%	0.0%	0.0%	6.7%	0.0%
All cancers combined	**21,289**	**4,136**	**3,752**	*369*	*79*	**89**	*22*	*1*	**50**	**6**	**114**	**125**	90.7%	2.2%	1.2%	0.1%	2.8%	3.0%

* Cause of death was derived from Medical Certificates of the Cause of Death (MCCD) obtained from ONS. The cause of death was assumed to be cancer or benign CNS tumour if cancer was documented at any point in part 1 or as the underlying cause of death on the medical certificate. For the remaining deaths the underlying cause of death was used.

** COD = Cause of Death

Clinical headline indicators, 2015

A range of ‘Clinical Headline Indicator’ (CHI) metrics have been provided by Public Health England at a Trust, Strategic Clinical Network and England level since 2013. The generic indicators were initially developed as metrics of quality of care and patient outcomes felt to be of high clinical importance and impact. In addition, childhood-specific metrics were developed based on data fields within the Cancer Outcomes and Services Dataset (COSD) to allow us to report clinical trial recruitment rates at a population level, and survival stratified by disease stage and other key determinants of outcome. The metrics are fed back to clinical teams in the treatment centres and are available at local and network levels via a NHS N3 connection at https://nww.cancerstats.nhs.uk/.

It is recognised that currently many of the CHI results do not reflect clinical practice inside the treating centres but rather poor recording of these data items. The CHIs have been included in this report primarily to show that their completeness is in general below a level that would enable us to produce meaningful stage- and other parameter-specific outcomes. Stage completeness varies considerably by disease type. Not all disease-specific stages and risk groupings are included in this table. Those reported here are the parameters with the most complete data. It is hoped that centres will increase their collection and submission of data to the COSD. This would make it possible for future versions of this publication to document more fully the metrics for the childhood cancer-specific data items in COSD and, where data are sufficiently complete, to report outcomes by stage.

Table 8: Clinical Headline Indicators, 2015, England, childhood 0 to 15 year olds

Source: National Cancer Registration and Analysis Service, Public Health England, CancerStats

Please note the metrics below may not reflect clinical practice but a low level of completeness of these data items.

Clinical Headline Indicator	
Percentage of cases discussed by a multidisciplinary team (MDT)	75%
Percentage of cases having Clinical Nurse Specialist (CNS) contact recorded	26%
Percentage of cases that had a Clinical Nurse Specialist (CNS) present when told their diagnosis	20%
Percentage of cases having surgery	43%
Percentage of cases having chemotherapy	68%
Percentage of cases having radiotherapy	11%
Percentage of cases entered into a clinical trial	26%
Percentage of acute lymphoblastic leukaemia (ALL) cases entered into a clinical trial	52%
Percentage of acute myeloid leukemia (AML) cases entered into a clinical trial	9%
Percentage of other leukaemia cases entered into a clinical trial	30%
Percentage of Hodgkin lymphoma cases entered into a clinical trial	14%
Percentage of Non-Hodgkin lymphoma cases entered into a clinical trial	22%
Percentage of osteosarcoma cases entered into a clinical trial	43%
Percentage of Ewing's sarcoma cases entered into a clinical trial	53%
Percentage of rhabdomyosarcoma cases entered into a clinical trial	41%
Percentage of other soft tissue sarcoma cases entered into a clinical trial	19%
Percentage of cases with a valid stage	19%
Percentage of Hodgkin lymphoma cases with a Ann Arbor stage	83%
Percentage of medulloblastoma cases with a Chang stage	10%
Percentage of neuroblastoma cases with an International Neuroblastoma Staging System stage (INSS)	44%
Percentage of cases of Wilms tumour cases with a Wilms stage	64%
Percentage of other soft tissue sarcoma cases with a Tumour, Node and Metastasis stage (TNM)	24%
Percentage of germ cell tumour cases with a Tumour, Node and Metastasis stage (TNM)	31%