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Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England

Children and Young Adults CRG

Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England

A report looking at deaths 30 days, 90 days and one year after diagnosis and comparing one year survival with that of children aged 0 to 14 years and adults aged 25 to 49 years

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Please note that from 1st April 2013 the North West Cancer Intelligence Service is part of Public Health England and will be known as North West Knowledge and Intelligence Team. TYA cancer intelligence work will be delivered jointly by the Knowledge and Intelligence Division and the National Cancer Intelligence Network.

The National Cancer Intelligence Network is now operated by Public Health England.

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Executive summary

In common adult cancers one-year survival is often used as a proxy measure for late stage at diagnosis. Deaths in the 30 days following diagnosis may highlight problems with deaths due to the complications of treatment. We decided to look at early deaths in TYA patients (i.e. those aged 15-24 years) with cancer.

We included all patients diagnosed with cancer at ages 15-24 in England in the five-year period 2005-2009. We calculated the number and percentage of deaths occurring in the first year after diagnosis, and in the first 30 and 90 days following diagnosis for 16 types of cancer common in this age group. One-year relative survival rates were calculated for the 15-24, 0-14 and 25-49 age groups, and for males and females.

581(6.9%) of TYA patients in England died within a year of being diagnosed with cancer. This percentage varied from 23.0% for acute myeloid leukaemia (AML) to 0.5% for Hodgkin Lymphoma (HL). More than 10% of patients with acute lymphoblastic leukaemia (ALL), non-Hodgkin lymphoma (NHL) colorectal carcinoma, soft tissue sarcomas (STS) and extra-gonadal germ cell tumours died within the first year.

The number of deaths in the first 30 days was more than 10 for only four diagnoses; AML, ALL, NHL and central nervous system (CNS) tumours; AML had the highest percentage of patients dying within 30 and 90 days at 6.4% and 9.8% respectively. There were no deaths in the first 30 days for six types of cancer and no deaths within 90 days for four diagnoses.

For patients with ALL, AML, NHL and CNS tumours, deaths were relatively more common in the first few months after diagnosis; more than one fifth of deaths in the first year occurred in the first 30 days and between 40% and 55% occurred within 90 days. For STS and colorectal carcinoma deaths were relatively evenly spread throughout the year, while only one of the 39 deaths in patients with bone tumours occurred within 30 days of diagnosis and none of the 17 deaths in those with carcinoma of the uterine cervix were in the first 90 days.

One-year relative survival dropped markedly with increasing age for ALL and moderately for AML. One-year survival for TYA patients with CNS tumours was 6% higher than for 0-14 year olds ($p < 0.001$) and 2% higher than for 25-49 year olds ($p < 0.001$). For those with carcinoma of the ovaries survival in those aged 15-24 was 6% higher than in the 25-49 age group ($p = 0.006$). TYA patients with STS had

survival rates 5% lower than those aged 0-14 years (p =0.05) and 3% lower than those aged 25-49 years (p = 0.18).

One-year survival for female TYA patients with ALL was 10% lower than for males (p = 0.013). However, females had 4% higher survival for melanoma (p = 0.002) and 5% for carcinoma of the colon and rectum, though the latter did not reach statistical significance (p = 0.20).
The most striking finding is the relatively large percentage of patients with haematological malignancies (with the exception of HL) who die in the few months following diagnosis. NWCIS has set up a group that is examining the reasons for early deaths in patients with ALL and AML with a view to identifying ways in which these could be reduced.

A considerable proportion of TYA patients with STS die in the first year after diagnosis and have somewhat worse outcomes than younger and older age groups, suggesting a problem with late stage at diagnosis. With the continuing improvement in the quality of staging data within the national cancer registration, it should be possible in the next 12-18 months to compare stage distributions by age group and area of residence for STS and other cancers for which stage is strongly related to outcome.

Introduction

Cancer survival in teenagers and young adults (TYA) has not been reported on as extensively as that in children or in those aged 50 years or older. Our recent report " Survival in Teenagers and Young Adults with Cancer in the United Kingdom" published by NCIN, looked at five year survival in teenagers and young adults [(1)]. Five year survival is used as a measure of effectiveness of treatment services and one year survival as a proxy measure of the proportion of patients presenting with late stage disease. The report found that survival for TYA cancer patients varies considerably by type of cancer and that this age group have worse five year survival as compared to the younger and older age groups for soft tissue sarcomas and bone tumours.

In the light of this evidence, we decided to undertake a detailed study of mortality and survival in the first year following diagnosis in TYA patients with cancer in England, in 2005-2009, comparing these with outcomes in children and in adults diagnosed between 25 and 49 years of age. We calculated the percentage of patients who died 30 days, 90 days and 1 year after diagnosis, plus one year survival. Mortality within 30 and 90 days of diagnosis are included to try to identify groups of patients in whom deaths due to complications of treatment may be relatively common.

We defined TYA as those who are diagnosed with cancer from their 15th to 25th birthday. We chose this age range to reflect commissioning arrangements for clinical services in England and to span delivery of care between services for children and those for adults; though one could argue for the expansion of the age range to include 13 and 14 years olds and those up to aged 29 or even 39. Approximately 2,000 individuals aged between 15-24 years are diagnosed with cancer each year in the UK. About 300 TYA patients die from cancer each year.

Cancers in TYA are classified mainly by tumour morphology rather than the part of the body in which the tumour arises. The relative frequency of different cancers in TYA is markedly different from that in middle-aged and older adults. It more closely resembles the distribution of cancers seen in childhood, though there are many important differences.

This report has been written by NWCIS under the auspices of the NCIN and the Childhood and TYA Clinical Reference Group. The TYA National Intelligence Advisory Group, which is an informal group of interested clinicians and epidemiologists who support NWCIS in their TYA work, provided helpful comments on the analyses.

Methods

We identified all patients resident in England who were diagnosed from 1st January 2005 to 31st December 2009 with a malignant neoplasm or a benign or borderline CNS tumour between the ages of 0 and 49 years. We used the TYA cancer database held by the North West Cancer Intelligence Service (NWCIS), populated with annual updates from the National Cancer Data Repository (NCDR), which is an amalgamated dataset of all cancer registrations for the UK between 1985 and 2009. Diagnoses are classified using the TYA classification scheme[(2)] . Details of the classifications are found in the Appendix (Table A.1) Gonadal germ cell tumours have been divided into testis and ovary.

Cancer cases that were registered only as a result of a cancer being recorded on a death certificate (DCOs) were excluded. Individuals were also excluded if they had experienced a previous primary diagnosis other than a skin carcinoma prior to 2005. Number of cases excluded are shown in the Study subjects Table I.

Percentage mortality (deaths) was calculated at 30 days, 90 days and one year following the date of diagnosis. Percentage mortality was calculated by dividing the number of deaths that had occurred by 30 days, 90 days and one year by the total number of new cases diagnosed within the 5 year study period for each diagnostic group. The number of deaths that occur within 30 and 90 days are also presented as a proportion of the total deaths that occur within one year. 95% confidence intervals for the percentage deaths were derived using the Binomial distribution based on the Wilson Score method [(3)].

Monthly survival up to 1 year was estimated for each age group. Each case was censored at 31st December 2010 or at death (from any cause) if earlier. Relative survival was estimated using the STATA STRS programme[4] which estimates survival as the ratio of the observed survival of the patients (where all deaths are considered events) to the survival that would be expected if each cancer patient experienced the same survival (life expectancy) as observed in the general population. Using national life tables stratified by age, sex and time, expected survival was estimated using the Ederer II method[(5)].

Differences in one year relative survival by age and gender were modelled using a multiple regression approach based on generalised linear models, assuming a Poisson distribution for the observed number of deaths. The excess hazard ratios (EHRs) of death derived from these models quantifies the extent to which the risk of death in one group differs from that of another or others after considering the background risk of death in the general population[4]. Differences were considered statistically significant if P values were <0.05 (two-sided). All statistical analyses were conducted using STATA version 11.

Results are presented for 16 major diagnostic groups as previously included in our report on five year survival among TYA patients in the UK[1]. Patients are grouped by age at diagnosis as 0-14, 15-24 and 25-49 years. The 0-14 year age group has been excluded from diagnostic group analyses where the average number of new cases per year for that diagnostic group is less than 10.

Results overview

Table I : Number of cases in England diagnosed 2005 to 2009 that have been included in and excluded by gender, age and diagnosis*

Included	MALES			FEMALES			PERSONS		
	0 to 14 years	15 to 24 years	25 to 49 years	0 to 14 years	15 to 24 years	25 to 49 years	0 to 14 years	15 to 24 years	25 to 49 years
ALL	835	239	229	689	114	179	1524	353	408
AML	143	143	618	133	122	613	276	265	1231
HL	211	613	1610	113	626	1145	324	1239	2755
NHL	289	351	3363	103	204	2172	392	555	5535
CNS	790	498	3604	666	436	3693	1456	934	7297
Bone tumours	170	262	333	155	163	266	325	425	599
STS	196	181	1362	130	142	1144	326	323	2506
Melanomas	23	336	4899	36	626	7507	59	962	12406
Testicular germ cell tumours	34	1127	6248	--	--	--	--	--	--
Ovarian germ cell tumours	--	--	--	59	116	148	--	--	--
Extra-gonadal germ cell tumours	60	74	107	47	17	45	107	91	152
Carcinoma of the ovary	--	--	--	--	206	3461	--	--	--
Carcinoma of the uterine cervix	--	--	--	--	258	6919	--	--	--
Carcinoma of the colon & rectum	--	117	4113	--	130	3755	--	247	7868
Carcinoma of the thyroid	20	85	786	34	338	2954	54	423	3740
Carcinoma of the breast	--	--	--	--	110	36112	--	--	--

**Note these figures may differ slightly from published incidence figures for the same time period as some cases are excluded for the purpose of survival analyses (see methods);*

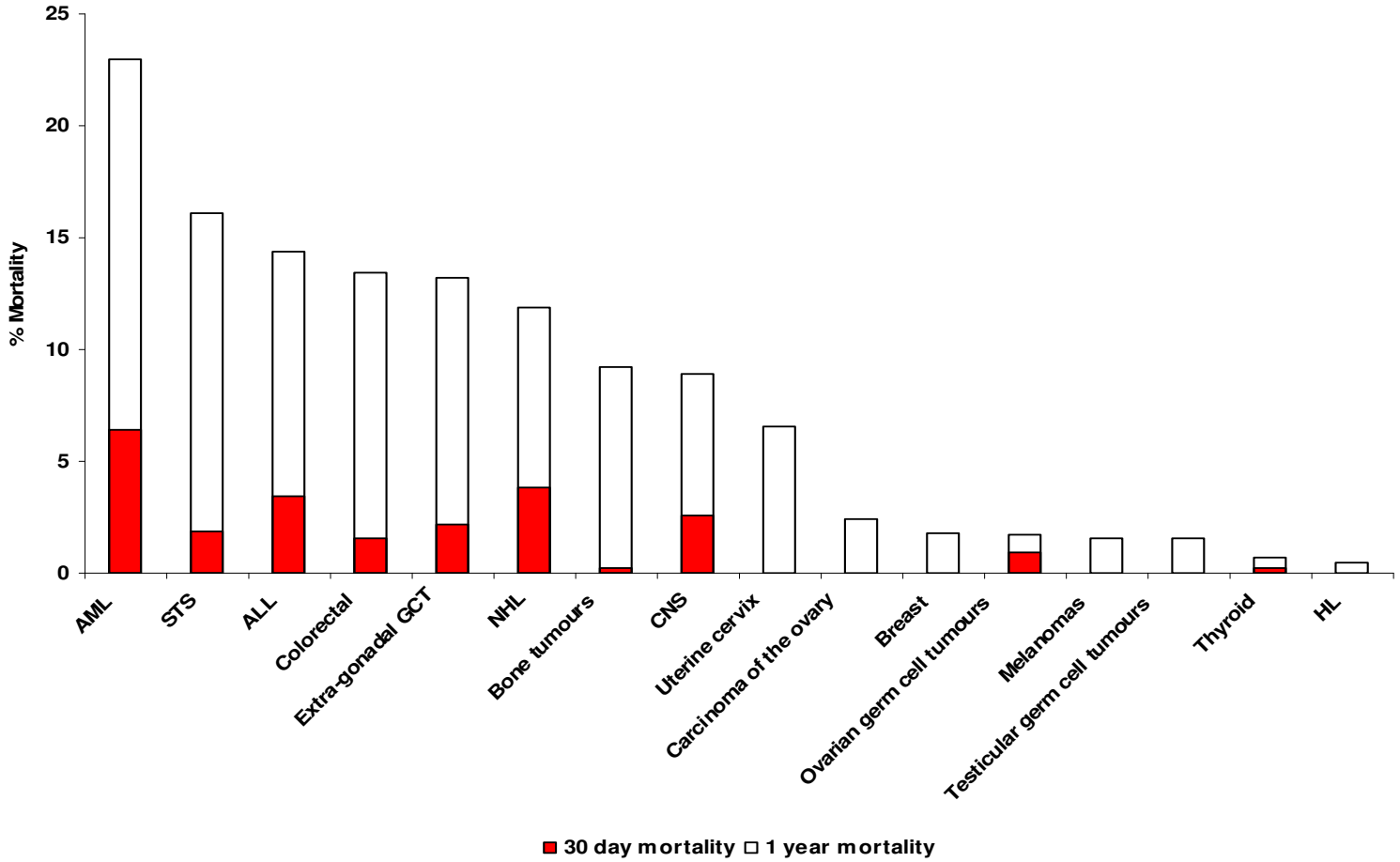

Figure I : 30 day and one year percentage mortality for individuals aged 15-24 diagnosed in England, 2005-2009, by diagnostic group

Table II : Number and percentage of deaths at 30 days, 90 days and one year following diagnosis for 15-24 age group in England in 2005-2009.

	Number of cases	30 day			90 day			1 year	
		Number of deaths	% of patients who die in the first 30 days	% of all deaths in first year	Number of deaths	% of patients who die in the first 90 days	% of all deaths in first year	Number of deaths	% of patients who died in first year
ALL	353	12	3.4	23.5	22	6.2	43.1	51	14.4
AML	265	17	6.4	27.9	26	9.8	42.6	61	23.0
HL	1239	0	0.0	0.0	0	0.0	0.0	6	0.5
NHL	555	21	3.8	31.8	36	6.5	54.5	66	11.9
CNS	934	24	2.6	28.9	33	3.5	39.8	83	8.9
Bone tumours	425	<5	0.2	2.6	6	1.4	15.4	39	9.2
STS	323	6	1.9	11.5	13	4.0	25.0	52	16.1
Melanoma of the skin	962	0	0.0	0.0	<5	0.1	6.7	15	1.6
Testicular germ cell tumours	1127	0	0.0	0.0	<5	0.3	16.7	18	1.6
Ovarian germ cell tumours	116	<5	0.9	50.0	<5	0.9	50.0	<5	1.7
Extra-gonadal GCT	91	<5	2.2	16.7	<5	4.4	33.3	12	13.2
Carcinoma of the ovary	206	0	0.0	0.0	0	0.0	0.0	5	2.4
Uterine cervix	258	0	0.0	0.0	0	0.0	0.0	17	6.6
Colorectal	247	<5	1.6	12.1	8	3.2	24.2	33	13.4
Thyroid	423	<5	0.2	33.3	<5	0.5	66.7	<5	0.7
Breast	110	0	0.0	0.0	0	0.0	0.0	<5	1.8
All other cancers	787	29	3.7	25.0	48	6.1	41.4	116	14.7
All cancers combined	8421	118	1.4	20.3	203	2.4	35.0	581	6.9

Results by Diagnosis

The following section provides detailed results for 30 day, 90 day and one year mortality and one year survival for 16 types of cancer, including differences by age. Tabulated one year survival data for each type of cancer are provided by age group and sex in the Appendix (Tables A2 and A3).

1. Acute Lymphoblastic Leukaemia (ALL)
2. Acute Myeloid Leukaemia (AML)
3. Non-Hodgkin Lymphoma (NHL)
4. Hodgkin Lymphoma (HL)
5. CNS tumours
6. Bone tumours
7. Soft tissue sarcomas (STS)
8. Germ Cell Tumours of the Ovary
9. Germ Cell Tumours of the Testis
10. Extra-gonadal Germ Cell Tumours
11. Melanomas
12. Carcinoma of the Thyroid
13. Carcinoma of the Breast (Females)
14. Carcinoma of the Ovary
15. Carcinoma of the Uterine Cervix
16. Carcinoma of the Colon and Rectum

P values are provided for differences in one-year survival between 15-24 year olds and either of the other age groups, when these are statistically significant. All other differences are not statistically significant.

1. Acute Lymphoblastic Leukaemia (ALL)

Table 1: 30 day, 90 day and 1 year mortality with 95% confidence intervals for those diagnosed with ALL in 2005-2009 aged 15 to 24 years. (Number of patients =353)

Time	Number of deaths	% mortality (95% CI)
30 day	12	3.4 (2.0 - 5.8)
90 day	22	6.2 (4.2 - 9.3)
1 year	51	14.4 (11.2 - 18.5)

14.4% of TYA patients diagnosed with ALL died within the year following diagnosis. 24% of these deaths occurred within 30 days and 43% within 90 days following diagnosis.

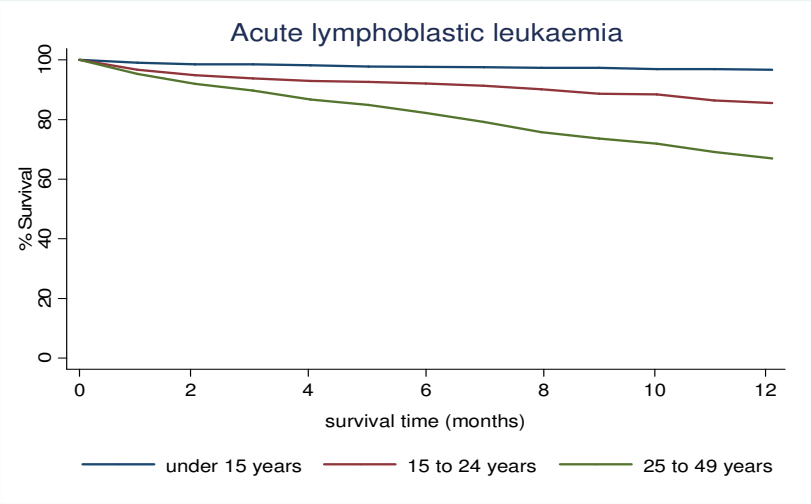

Figure 1: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with ALL in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with ALL, survival decreased with age; this starts to appear within the first couple of months after diagnosis (Fig 1). One year relative survival for those aged 15-24 years was 85.6%, 11% lower than among the paediatric group ($p<0.001$) but 19% higher than for 25 to 49 year olds ($p<0.001$) (Appendix Table A.2). In the TYA age group survival was 88.8% for males and 79.0% for females ($p = 0.013$).

2. Acute Myeloid Leukaemia (AML)

Table 2: 30 day, 90 day and 1 year mortality for those diagnosed with AML in 2005-2009 aged 15 to 24 years. (Number of patients=265)

Time	Number of deaths	% mortality (95% CI)
30 day	17	6.4 (4.0 - 10.0)
90 day	26	9.8 (6.8 - 14.0)
1 year	61	23.0 (18.4 - 28.5)

Of all the cancer groups analysed in this report, AML had the highest mortality, with 23% of TYA patients dying within the year following diagnosis. 28% of these deaths occurred within 30 days and 43% within 90 days following diagnosis.

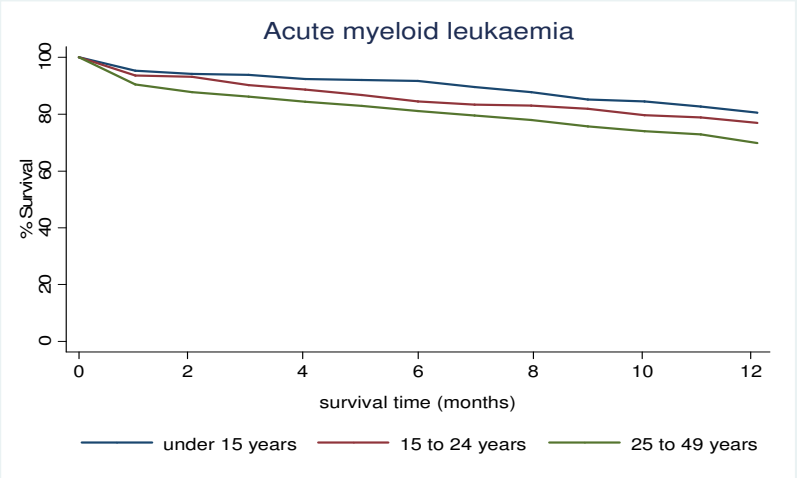

Figure 2: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with AML in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with AML, we again observed a trend of decreasing survival with age that starts to arise within two months of diagnosis (Fig 2). One year relative survival was 77.0% among 15 to 24 year olds, 4% lower than for 0-14 yr olds but 7% higher than for 25 to 49 year olds (p=0.02).

3. Non-Hodgkin Lymphoma (NHL)

Table 3: 30 day, 90 day and 1 year mortality for those diagnosed with NHL in 2005-2009 aged 15 to 24 years. (Number of patients=555)

Time	Number of deaths	% mortality (95% CI)
30 day	21	3.8 (2.5 - 5.7)
90 day	36	6.5 (4.7 - 8.8)
1 year	66	11.9 (9.5 - 14.9)

11.9% of TYA patients diagnosed with NHL died in the year following diagnosis. 32% of these deaths occurred within 30 days and 55% within 90 days following diagnosis.

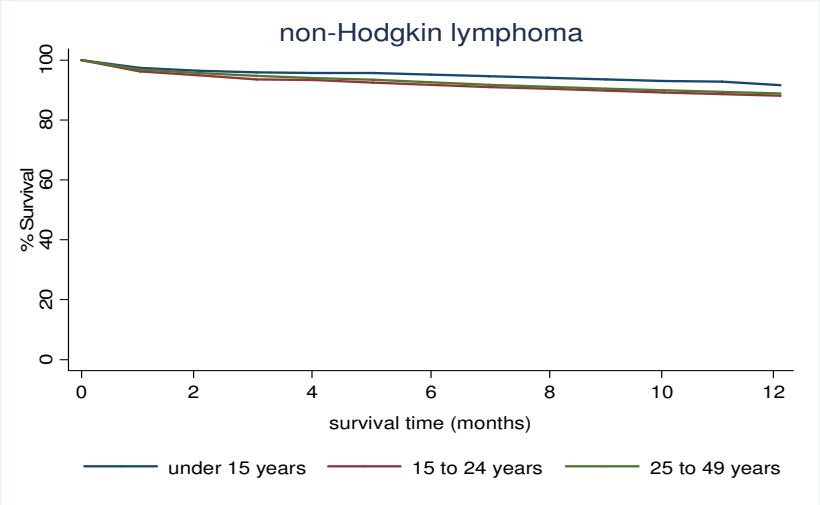

Figure 3: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with NHL in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with NHL, we observed only small differences in survival for the three age groups (Fig 3). One year relative survival among 15 to 24 years was 88.2%, 3% lower compared to the paediatric age group and 1% lower than 25 to 49 year olds.

4. Hodgkin Lymphoma (HL)

Table 4: 30 day, 90 day and 1 year mortality for those diagnosed with HL in 2005-2009 aged 15 to 24 years. (Number of patients=1239)

Time	Number of deaths	% mortality(95% CI)
30 day	0	-
90 day	0	-
1 year	6	0.5 (0.2 - 1.1)

For TYA patients with Hodgkin lymphoma, one year percentage mortality was low at 0.5%.

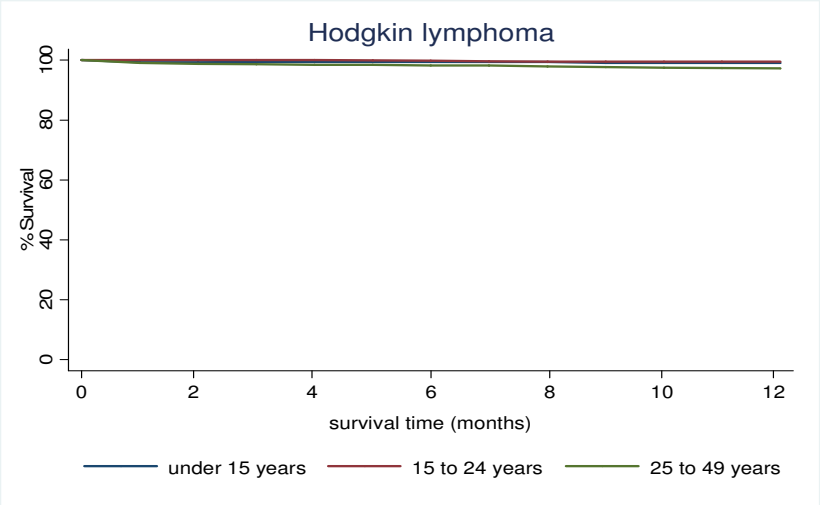

Figure 4: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with HL in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with HL, one year relative survival was 99.6% among the TYA age group (15 to 24 years), 99.1% for the paediatric age group and 97.3% ($p<0.001$) for 25-49 year olds.

5. Brain and other CNS Tumours

Table 5: 30 day, 90 day and 1 year mortality for those diagnosed with brain and other CNS tumours in 2005-2009 aged 15 to 24 years. Number of patients=934

Time	Number of deaths	% mortality(95% CI)
30 day	24	2.6 (1.7 – 3.8)
90 day	33	3.5 (2.5 – 4.9)
1 year	83	8.9 (7.2 – 10.9)

8.9% of TYA patients with brain and other CNS tumours died in the year following diagnosis. 29% of these deaths occurred within 30 days and 40% within 90 days following diagnosis.

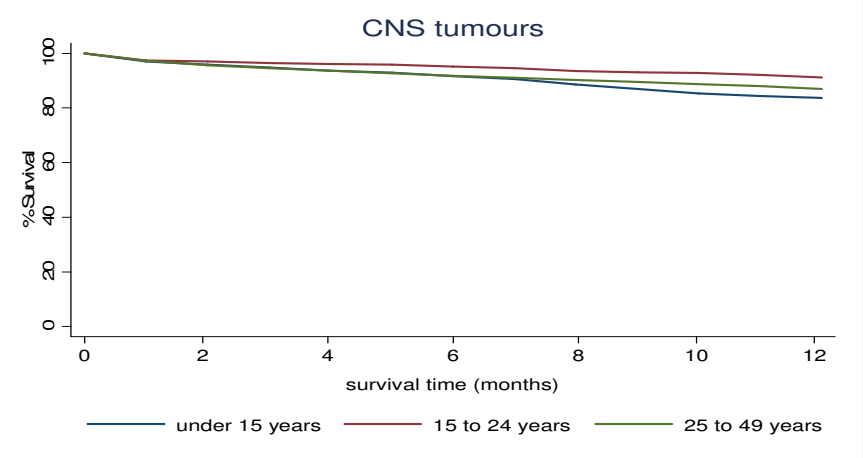

Figure 5: 0 to 1year relative survival for patients diagnosed in 2005 to 2009 with brain and other CNS tumours in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with brain and other CNS tumours, we observed higher one year survival for the TYA age group (Fig 5). One year relative survival was 91.2% among 15 to 24 year olds compared to 83.6% for the paediatric age group ($p<0.001$) and 87.0% for 25 to 49 year olds ($p<0.001$) .

6. Bone Tumours

Table 6: 30 day, 90 day and 1 year mortality for those diagnosed with bone tumours in 2005-2009 aged 15 to 24 years. (Number of patients=425)

Time	Number of deaths	% mortality
30 day	<5	0.2 (0.0 - 1.3)
90 day	6	1.4 (0.6 - 3.0)
1 year	39	9.2 (6.8 - 12.3)

9.2% of TYA patients diagnosed with a bone tumour died in the year following diagnosis. Only 3% of these deaths occurred within 30 days and 15% within 90 days following diagnosis.

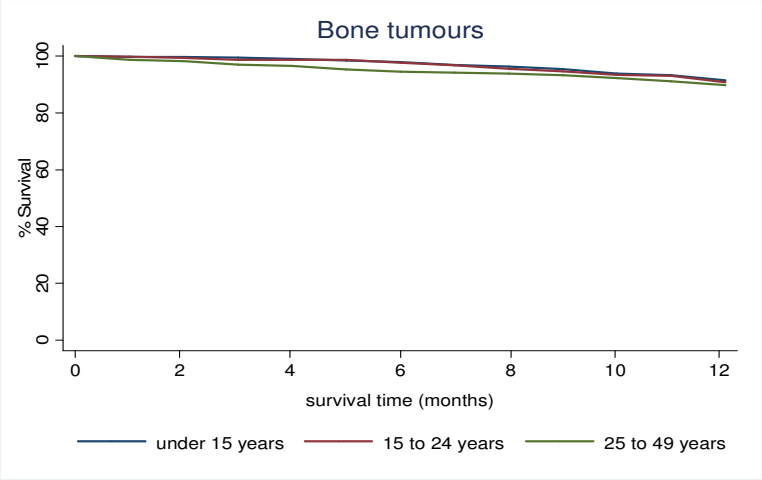

Figure 6: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with bone tumours in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with a bone tumour, one year relative survival was similar across the three age groups (Fig 6) with values for 0-14 and 25-49 year olds within 1% of the 91% survival for 15-24 year olds.

7. Soft Tissue Sarcomas (STS)

Table 7: 30 day, 90 day and 1 year mortality for those diagnosed with soft tissue sarcomas (STS) in 2005-2009 aged 15 to 24 years. (Number of patients=323)

Time	Number of deaths	% mortality(95% CI)
30 day	6	1.9 (0.9 – 4.0)
90 day	13	4.0 (2.4 – 6.8)
1 year	52	16.1 (12.5 - 20.5)

16.1% of TYA patients diagnosed with a soft tissue sarcoma died in the year following diagnosis. 12% of these deaths occurred within 30 days and 25% within 90 days following diagnosis.

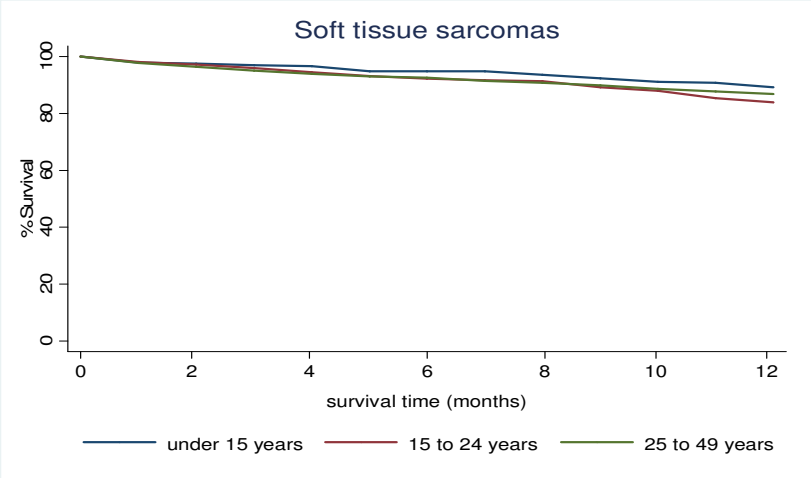

Figure 7: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with soft tissue sarcomas in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with a STS, we observed lower survival in the TYA age group than in either the paediatric or older age group (Fig 7). One year relative survival for TYA patients was 83.9%, 5% lower than 0-14 year olds (p=0.05) and 3% lower than 25-49 year olds (p = 0.18).

8. Germ Cell Tumours of the Ovary

Table 8: 30 day, 90 day and 1 year mortality for females diagnosed with germ cell tumours of the ovary in 2005-2009 aged 15 to 24 years. (Number of patients=116)

Time	Number of deaths	% mortality(95% CI)
30 day	<5	0.9 (0.2 - 4.7)
90 day	<5	0.9 (0.2 - 4.7)
1 year	<5	1.7 (0.5 - 6.1)

For TYA patients with a germ cell tumour of the ovary, deaths in the first year were rare at 1.7%.

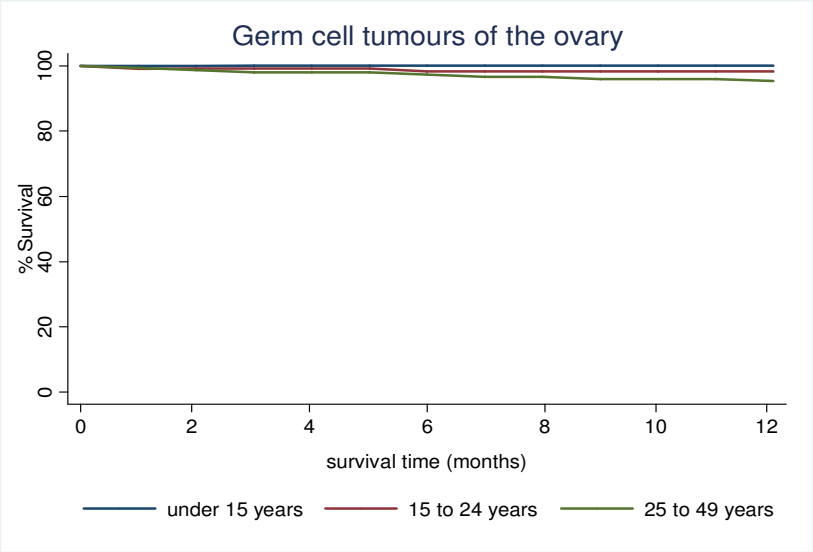

Figure 8: 0 to 1 year relative survival for females diagnosed in 2005 to 2009 with germ cell tumours of the ovary in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with an ovarian germ cell tumour, one year relative survival was 98.3%, 2% lower than for 0-14 year olds but 3% higher than for 25-49 year olds.

9. Germ Cell Tumours of the Testis

Table 9: 30 day, 90 day and 1 year mortality for males diagnosed with germ cell tumours of the testis in 2005-2009 aged 15 to 24 years. (Number of patients=1127)

Time	Number of deaths	% mortality(95% CI)
30 day	0	0
90 day	<5	0.3 (0.1 - 0.8)
1 year	18	1.6 (1.0 – 2.5)

For TYA patients with a germ cell tumour of the testis, deaths in the first year were rare at 1.6%.

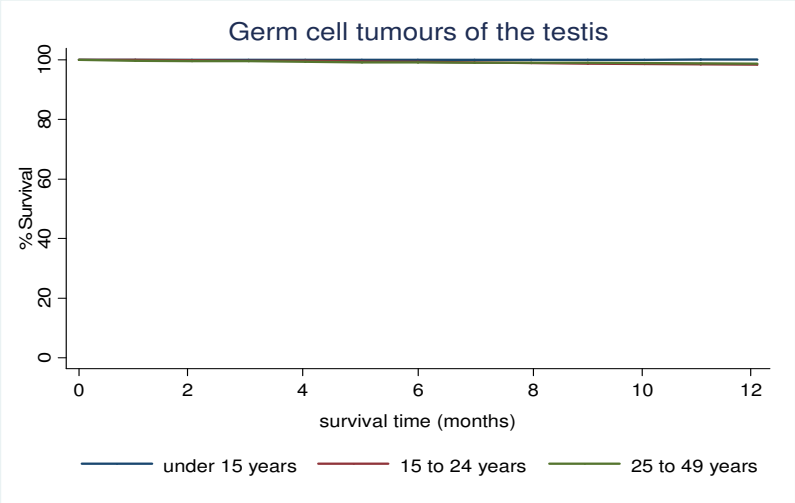

Figure 9: 0 to 1 year relative survival for males diagnosed in 2005 to 2009 with germ cell tumours of the testis in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with a testicular germ cell tumour, we observed very little difference in survival between the different age groups, ranging from a one year relative survival of 100% for 0-14 year olds to 98.5% for 15-24 year olds and 98.8% for 25 to 49 year olds.

10. Extra-gonadal Germ Cell Tumours

Table 10: 30 day, 90 day and 1 year mortality for those diagnosed with extra-gonadal germ cell tumours in 2005-2009 aged 15 to 24 years. (Number of patients=91)

Time	Number of deaths	% mortality(95% CI)
30 day	<5	2.2 (0.6 - 7.7)
90 day	<5	4.4 (1.7 - 10.8)
1 year	12	13.2 (7.7 - 21.6)

13.2% of TYA patients diagnosed with an extra-gonadal germ cell tumour died in the year following diagnosis. 17% of these deaths occurred within 30 days and 33% within 90 days following diagnosis.

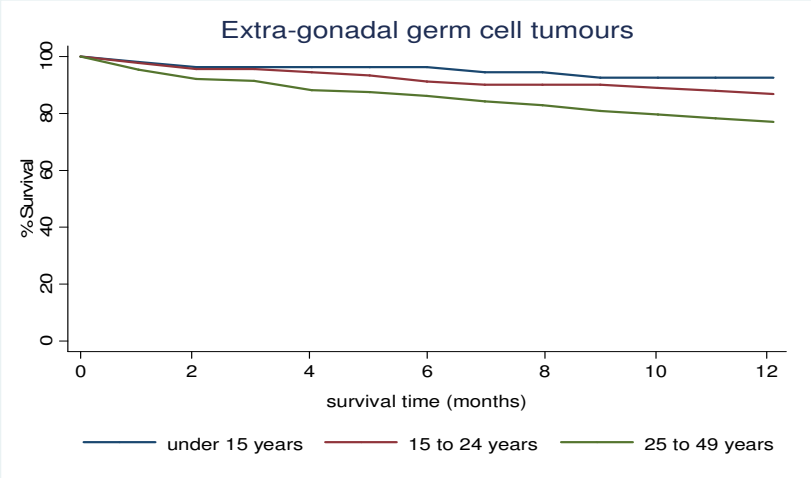

Figure 10: 0 to 1-year relative survival for patients diagnosed in 2005 to 2009 with extra-gonadal germ cell tumours in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with an extra-gonadal germ cell tumour, we observed decreasing survival with age, though this did not reach statistical significance (Fig 10). One year relative survival for those aged 15-24 years was 86.9%, 6% lower than among 0-14 year olds but 10% higher than for 25-49 year olds.

11. Melanomas

Table 11: 30 day, 90 day and 1 year mortality for those diagnosed with melanomas of the skin in 2005-2009 aged 15 to 24 years. (Number of patients=962)

Time	Number of deaths	% mortality(95% CI)
30 day	0	-
90 day	<5	0.1 (0.0 - 0.6)
1 year	15	1.6 (0.9 - 2.6)

For TYA patients with a melanoma, deaths in the first year were rare at 1.6%. One year survival was 99.7% for females compared with 96.2% for males (p = 0.002).

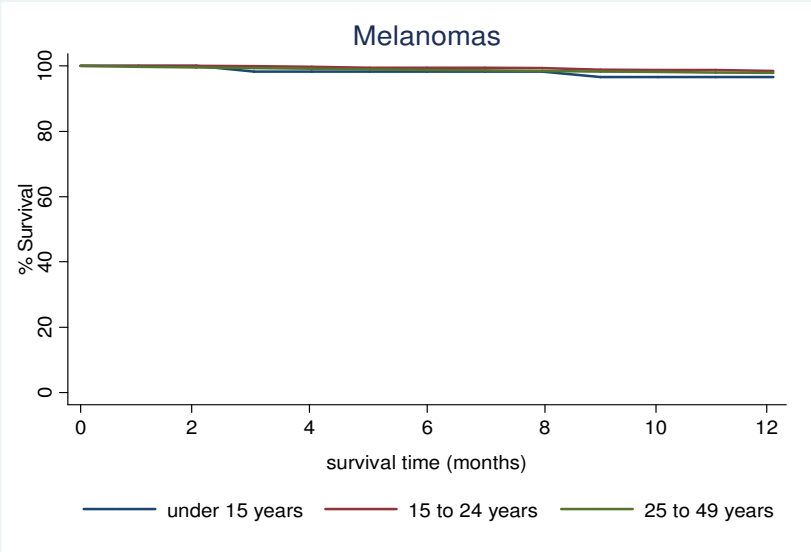

Figure 11: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with extra-gonadal germ cell tumours in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with a melanoma, one year relative survival for 15-24 year olds was 98.5%, 2% higher than for 0-14 year olds and 1% higher than for the 25-49 age group.

12. Carcinoma of the Thyroid

Table 12: 30 day, 90 day and 1 year mortality for those diagnosed with carcinoma of the thyroid in 2005-2009 aged 15 to 24 years. Number of patients=423

Time	Number of deaths	% mortality(95% CI)
30 day	<5	0.2(0.0 - 1.3)
90 day	<5	0.5(0.1 - 1.7)
1 year	<5	0.7(0.2 - 2.1)

For TYA patients with carcinoma of the thyroid deaths in the first year were rare at 0.7%.

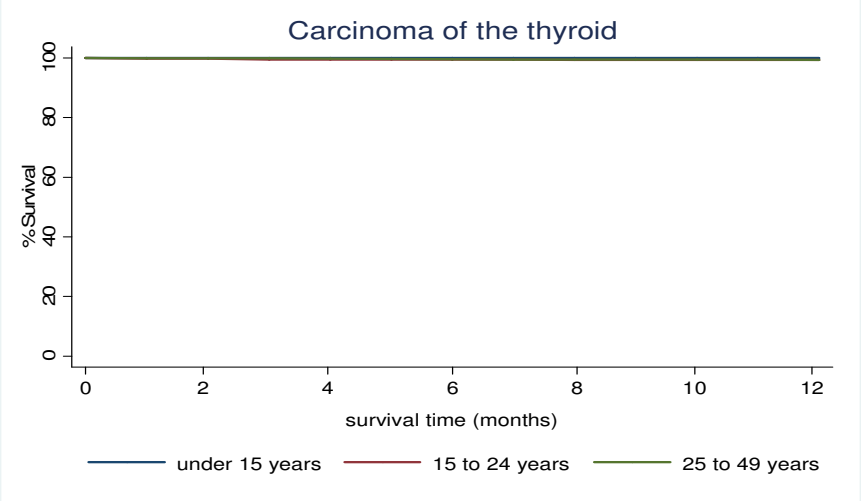

Figure 12.1: 0 to 1 year relative survival for patients diagnosed in 2005 to 2009 with carcinoma of the thyroid in England at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients with a carcinoma of the thyroid, one year relative survival was 99.3% for 15-24 year olds, within 1% of the rates for the other two age groups.

13. Carcinoma of the Breast

Table 13: 30 day, 90 day and 1 year mortality for females diagnosed with carcinoma of the breast in 2005-2009 aged 15 to 24 years. Number of patients=110.

Time	Number of deaths	% mortality(95% CI)
30 day	0	-
90 day	0	-
1 year	<5	1.8 (0.5 - 6.4)

For TYA women diagnosed with breast cancer, deaths in the first year were rare at 1.8%.

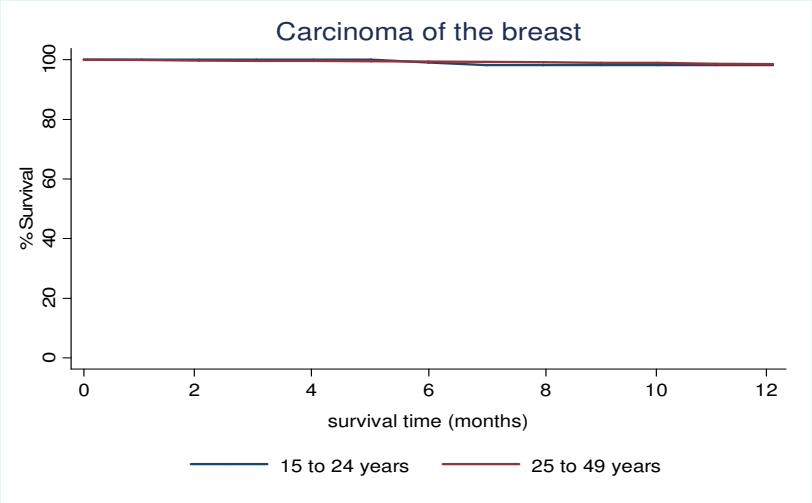

Figure 13: 0 to 1 year relative survival for females diagnosed in 2005 to 2009 with carcinoma of the breast in England at ages 15 to 24 and 25 to 49 years.

For patients diagnosed with a carcinoma of the breast, one year relative survival was 98.2% for 15-24 year olds, similar to rates for the older age group.

14. Carcinoma of the Ovary

Table 14: 30 day, 90 day and 1 year mortality for those diagnosed with carcinoma of the ovary in 2005-2009 aged 15 to 24 years. Number of patients=206

Time	Number of deaths	% mortality(95% CI)
30 day	0	-
90 day	0	-
1 year	5	2.4 (1.0 - 5.6)

2.4% of TYA patients with carcinoma of the ovary died in the year after diagnosis.

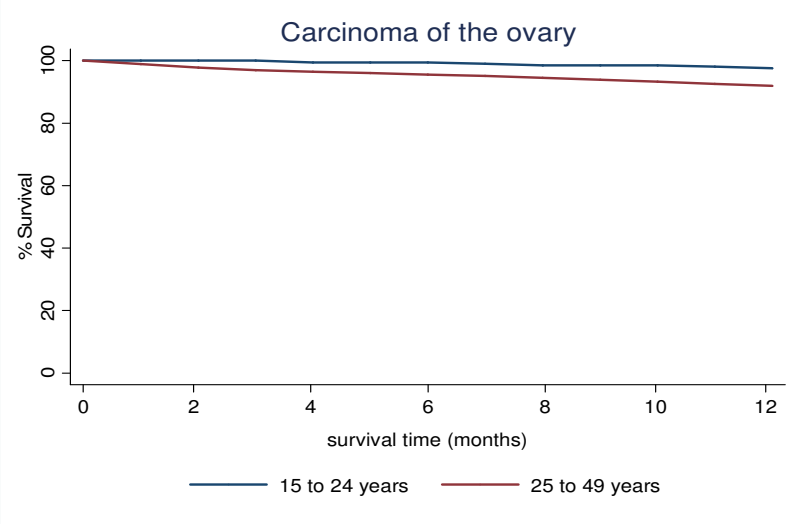

Figure 14: 0 to 1 year relative survival for females diagnosed in 2005 to 2009 with carcinoma of the ovary in England at ages 15 to 24 and 25 to 49 years.

For patients with carcinoma of the ovary, one year relative survival was 97.6% among 15-24 year olds, 6% higher than in those aged 25-49 years (p=0.006).

15. Carcinoma of the Uterine Cervix

Table 15: 30 day, 90 day and 1 year mortality for females diagnosed with carcinoma of the cervix in 2005-2009 aged 15 to 24 years. Number of patients=258

Time	Number of deaths	% mortality(95% CI)
30 day	0	-
90 day	0	-
1 year	17	6.6 (4.2 - 10.3)

6.6% of TYA patients with carcinoma of the uterine cervix died in the year following diagnosis.

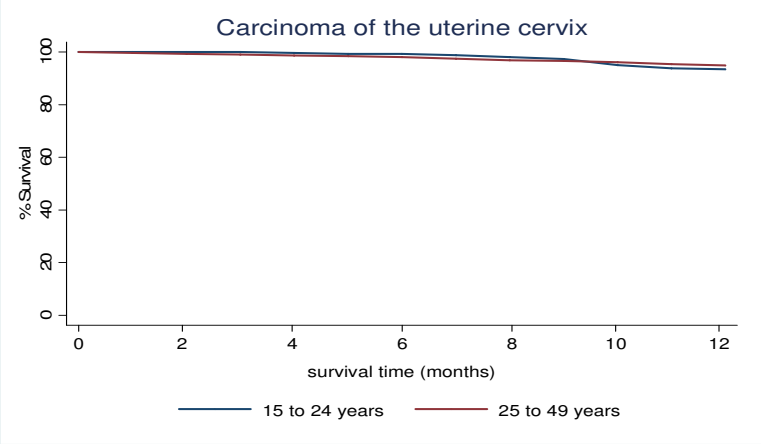

Figure 15: 0 to 1 year relative survival for females diagnosed in 2005 to 2009 with carcinoma of the uterine cervix in England at ages 15 to 24 and 25 to 49 years.

For patients with a carcinoma of the uterine cervix, one year relative survival was 93.4% in those aged 15-24 years, 1.5% lower than for the older age group.

16. Carcinoma of the Colon and Rectum

Table 16: 30 day, 90 day and 1 year mortality for those diagnosed with carcinoma of the colon and rectum in 2005-2009 aged 15 to 24 years. Number of patients=247

Time	Number of deaths	% mortality(95% CI)
30 day	<5	1.6 (0.6 - 4.1)
90 day	8	3.2 (1.7 - 6.3)
1 year	33	13.4 (9.7 - 18.2)

13.4% of TYA patients with colorectal cancer died in the year following diagnosis. 12% of these deaths occurred within 30 days and 24% within 90 days following diagnosis.

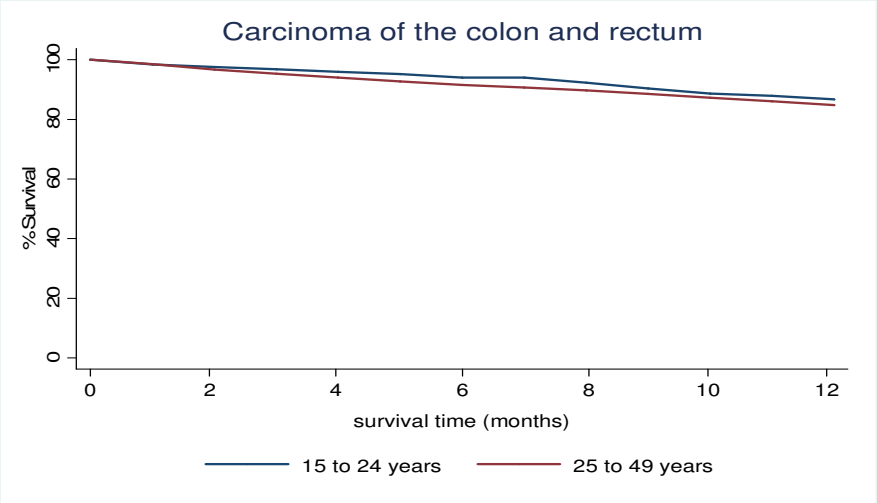

Figure 16: 0 to 1 year relative survival for those diagnosed in 2005 to 2009 with carcinoma of the colon and rectum in England at ages 15 to 24 and 25 to 49 years.

For TYA patients with a carcinoma of the colon and rectum one year relative survival was 86.7%, 2% higher than for those aged 25-49 years. Survival was 83.8% for TYA males and 89.3% for TYA females (p = 0.20).

Discussion

581(6.9%) of TYA patients in England died within a year of being diagnosed with cancer. Though this is not a large number compared with deaths at older ages, deaths at such an early age make a disproportionately large contribution to the number of years of life lost due to premature mortality; the prevention of which is a NHS and public health priority [6,7].

The percentage of TYA patients who died in the twelve months following diagnosis varied greatly by type of cancer. AML had the highest proportion of deaths at one year (23%), 90 days (10%) and 30 days (6%). More than 10% of patients with ALL and NHL died within the first year; between one quarter and one third of these deaths occurred within the first 30 days. One year survival rates dropped markedly by age from 0 to 49 years for patients with ALL; in the TYA age group males had better survival than females. 16% of patients with soft tissue sarcomas (STS) and 13% of those with colorectal carcinoma died within the first year. One year survival for TYA patients with STS was lower than in those aged 0-14 and 25-49 years.

One year survival rates are often used as a proxy measure of the proportion of patients presenting with late stage solid tumours, which in turn is due, in many cases, to delay in diagnosis and treatment. We provide results for the proportion of deaths occurring within twelve months of diagnosis. These include deaths from any cause, but in this age group the vast majority of deaths are due to the cancer in question or to complications of its treatment. Results are also provided for one-year relative survival rates, which take into account deaths from causes other than the cancer in question, but as such deaths are relatively rare in this age group over a relatively short period of time, the percentage of deaths in the first year can be taken as 100% minus one-year relative survival. Using the proportion of deaths has the advantage of being easier to calculate and interpret by a non-statistical audience than survival, and allows one to examine the pattern of deaths during the first year. The number of early deaths also shows the size of the problem for a given type of cancer, and reviewing details on these patients may identify the reasons for such deaths and suggest ways in which they could be reduced. We used the same inclusion criteria for deaths as for survival, excluding patients for whom the only data was a death certificate mentioning cancer or who had previously been diagnosed with cancer prior to our study period.

30 day post-operative mortality is used to assess the quality of surgical services for the common cancers of later life [8]. However, its usefulness in the TYA age group is not clear, as surgery is either not part of standard primary treatment or is often preceded by chemotherapy. We have provided values for the percentage of patients who died within 30 and 90 days of diagnosis, which in the vast majority of cases is the date of histological or cytological diagnosis. The aim is to identify groups of patients in whom a considerable proportion die of complications of their treatment, in the expectation that more detailed investigation might identify patients who would have survived with better management.

A relatively high percentage of patients with ALL, AML and NHL died in the first year after diagnosis, with a large proportion of these deaths occurring in the first few months. Delay in the diagnosis of ALL and AML would seem unlikely in more than a few cases, as most patients present with symptoms that are quickly brought to medical attention. Not responding to or suffering severe complications from treatment are probably more common causes of early deaths for these diagnoses. One year survival decreased markedly over the 0–49 year age range for patients with ALL and moderately for AML. Similar findings have been reported for ALL patients in the US [9]. This is mainly explained by genetic subgroups with a favourable prognosis being more common in younger age groups. The greater participation levels of children with ALL in clinical trials and uncertainty as to the optimal regimen for TYA patients may contribute to lower survival in this age group [10,11].

One year survival in ALL was 89% for males and 79% for females (p = 0.013) in the 15-24 age group. It was also better for males aged 25-49 years (71% v 62%) but similar for those aged 0-14 years (96% for males and 97% for females). Five year survival for TYA patients diagnosed in 2001-2005 showed little difference by gender, though survival was higher for males in the 25-29 age group. The reasons for the better one year survival in males are not clear. Undertaking an audit of the management of patients who died in the months after diagnosis may be useful to identify any preventable factors. A group, with clinical, NWCIS and NYCRIS representation, has been set up to explore, for TYA patients with ALL and AML, the reasons for early deaths, why for ALL is survival worse in females and why it declines so markedly with increasing age. We also intend to calculate the % of those patients who died in the first year who were enrolled in clinical trials.

The introduction of the Clinical Outcomes and Services Dataset (COSD) over the next few years should result in detailed data on key prognostic and treatment variables being collected on every patient with cancer in England [12]. This should allow for those types of cancer with sufficient

numbers case mix adjustment by age, gender, stage (where appropriate) and trust at which patient managed, and help identify suboptimal management.

Patients with STS had the second highest percentage of deaths in the first year at 16%. Unlike haematological malignancies these were spread throughout the year. Delay in diagnosis is a possible explanation for many of these deaths. A survey undertaken by the Teenage Cancer Trust reported that one in four TYA cancer patients was referred by their GP to a specialist only after at least four visits [(13).]. Robust guidelines have been drawn up listing the symptoms and signs with which teenagers and young adults should attend their GP to rule out a diagnosis of cancer [(14)]. It is vital that as many young people and their parents are aware of these guidelines.

One year survival for TYA patients with STS was 5% lower than for 0-14 year olds (p = 0.05) and 3% lower than for 25-49 year olds (p = 0.18). Possible explanations include (a) differences by age group in the relative distribution of types of STS with varying prognosis, (b) the biology of tumours in the TYA age group may differ from those in other age groups or (c) TYA patients may on average present later. NWCIS has compared the distribution of types of STS in 15-24 year olds with those aged 25-49 years; the results varied considerably between the two groups and so could explain the survival differences. We will compare the distribution of types of STS in 0-14 and 15-24 year olds. The quality and completeness of staging details within cancer registration data is improving rapidly. It should be possible in the next 18 months to compare stage distributions by age groups to determine if a higher percentage of TYA patients are presenting with last stage disease. Where numbers are sufficiently large, stage-specific survival rates will be calculated. Those who commission and provide TYA cancer services should be able to monitor the stage distribution of patients for whom they are responsible, not only for STS but also for other types of cancer for which outcome is strongly influenced by stage.

Relatively high proportions of patients with bone tumours (9%), carcinomas of the uterine cervix (7%) and large bowel (10%) died in the period three to twelve months after diagnosis. It will be useful to examine the stage distribution of patients with these conditions, when the data become available. As one year survival for males with colorectal carcinoma is 6% lower than for females (p = 0.20), stage distribution by gender will also be reviewed. Extra-gonadal germ cell tumours also had a high proportion of deaths in the first year, but as this is based on only 12 deaths over the five-year period, it is difficult to interpret.

For CNS tumours one-year survival for patients aged 15-24 was 8% higher ($p < 0.001$) than for 0 to 14 year olds and 4% higher than for those aged 25-49 ($p < 0.001$). In the US patients aged 15-24 had better one-year survival than those aged 10-14 years [9]. Analyses similar to those for STS will be undertaken to determine the contribution of differences in the type and grade of CNS tumours to these differences. Patients aged 15-24 with ovarian carcinoma had survival rates 6% higher than those aged 25-49 years ($p =0.006$). This may be due to differences by age in the proportions of histological subtypes with varying prognosis. Females with melanoma had a four percent higher one-year survival than males ($p = 0.002$) which is similar to older age groups.

We have allocated patients to the 16 groups using both site and morphology codes based on the International Classification of Disease for Oncology (ICD-0). Therefore, patients who had a tumour of the large bowel other than a carcinoma were not counted as carcinomas. The proportion of patients whose morphology code was too vague to allow allocation to a group was small. Though these points support the robustness of the results, it should be remembered that the accuracy of morphological coding from pathology reports by cancer registries has not been audited extensively. Many of the findings are based on relatively small number of cases and of deaths. With so many comparisons, it is likely that a few statistically significant results are due to chance. Relatively large differences that are not statistically significant, such as the 5% higher survival in females in the 15-24 age group for colorectal carcinoma, should not be discounted but taken as interesting findings worthy of further investigation. For the less rare types of cancer relatively small differences may be statistically significant. One needs to consider the clinical importance of such differences and also their validity, as there is considerable noise in the estimation of population-based survival rates. Further work is required to determine why TYA patients die in the year following diagnosis, in order to identify measures that could result in a reduction of such deaths. It would also be useful for surveillance purposes to understand for those types of cancer in which a sizeable proportion of patients die in the first year, how the causes of death vary within the twelve month period.

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Appendix

Table A.1: TYA Cancer Diagnostic Groups (after Birch *et al* 2002 – updated to version 12)

Diagnostic Code	Diagnostic Group
GROUP 1: Leukaemias	
1.1.	Acute lymphoid leukaemia (ALL)
1.2.	Acute myeloid leukaemia (AML)
1.3.	Chronic myeloid leukaemia (CML)
1.4.	Other and unspecified leukaemia (Other Leuk)
1.4.1.	Other and unspecified lymphoid leukaemias
GROUP 2: Lymphomas	
2.1.	Non-Hodgkin lymphoma (NHL)
2.1.1.	Non-Hodgkin lymphoma, specified subtype
2.1.2.	Non-Hodgkin lymphoma, subtype not specified
2.2.	Hodgkin lymphoma (HL)
2.2.1.	Hodgkin lymphoma, specified subtype
2.2.2	Hodgkin lymphoma, subtype not specified
GROUP 3: Central Nervous System & other Intracranial & Intraspinal Neoplasms (CNS tumours)	
3.1.	Astrocytoma
3.1.1.	Pilocytic astrocytoma
3.1.2.	Other low grade astrocytoma
3.1.3.	Glioblastoma and anaplastic astrocytoma
3.1.4.	strocytoma not otherwise specified
3.2.	Other gliomas
3.2.1.	Oligodendroglioma
3.2.2.	Other specified glioma
3.2.3	Glioma NOS
3.3.	Ependymoma
3.4	Medulloblastoma and other primitive neuroectodermal tumours
3.4.1	Medulloblastoma
3.4.2	Supratentorial PNET.
3.5.	Other specified intracranial and intraspinal neoplasms (Other CNS)
3.5.1	Craniopharyngioma
3.5.2	Pituitary tumours
3.5.3	Pineal tumours
3.5.4	Choroid plexus tumours
3.5.5	Meningioma
3.5.6	Nerves sheath tumour of the brain
3.5.7	Other specified tumours
3.6	Unspecified intracranial and intraspinal neoplasms tumours
3.6.1.	Unspecified malignant intracranial and intraspinal neoplasms
3.6.2.	Unspecified non-malignant intracranial and intraspinal neoplasms

GROUP 4: Osseous and Chondromatous Neoplasms, Ewing tumour and other Neoplasms of Bone (Bone Tumours)

4.1.	Osteosarcoma
4.2.	Chondrosarcoma
4.3.	Ewing sarcoma
4.3.1	Ewing sarcoma of bone
4.3.2	Extraskeletal Ewing sarcoma
4.3.3	Ewing sarcoma of unknown site
4.4.	Other specified and unspecified bone tumours (Other bone tumours)
4.4.1.	Other specified bone tumours
4.4.2.	Unspecified bone tumours

GROUP 5: Soft Tissue Sarcomas (STS)

5.1.	Fibromatous neoplasms (Fibrosarcoma)
5.1.1.	Fibrosarcoma
5.1.2.	Malignant fibrous histiocytoma
5.1.3.	Dermatofibrosarcoma
5.2.	Rhabdomyosarcoma
5.3.	Other specified soft tissue sarcomas
5.3.1.	Liposarcoma
5.3.2.	Leiomyosarcoma
5.3.3.	Synovial sarcoma
5.3.4	Clear cell sarcoma
5.3.5	Blood vessel tumours
5.3.6	Nerve sheath tumours
5.3.7	Alveolar soft part sarcoma
5.3.8	Miscellaneous specified soft tissue sarcoma
5.4	Unspecified soft tissue sarcomas

GROUP 6: Germ Cell & Trophoblastic Neoplasms (Germ cell tumours)

6.1	Gonadal germ cell & trophoblastic neoplasms
6.2	Germ cell & trophoblastic neoplasms of non-gonadal sites
6.2.1.	Intracranial germ cell and trophoblastic tumours
6.2.2.	Other non-gonadal germ cell and trophoblastic tumours

GROUP 7: Melanoma and Skin Carcinoma

7.1.	Melanoma
7.2.	Skin carcinoma

GROUP 8: Carcinomas (except of skin)

8.1.	Carcinoma of thyroid
8.2.	Other carcinoma of head and neck
8.2.1.	Nasopharyngeal carcinoma
8.2.2.	Carcinoma of other sites in lip oral cavity and pharynx
8.2.3.	Carcinoma of nasal cavity, middle ear, sinuses, larynx and other ill-defined sites in head and neck
8.3.	Carcinoma of trachea, bronchus, lung and pleura
8.4.	Carcinoma of breast
8.5.	Carcinoma of genitor-urinary (GU) tract
8.5.1.	Carcinoma of kidney
8.5.2.	Carcinoma of bladder

8.5.3.	Carcinoma of ovary
8.5.4.	Carcinoma of cervix
8.5.5.	Carcinoma of other and ill-defined sites in GU
8.6.	Carcinoma of gastro-intestinal (GI) tract
8.6.1.	Carcinoma of colon and rectum
8.6.2.	Carcinoma of stomach
8.6.3.	Carcinoma of liver and intrahepatic bile ducts
8.6.4.	Carcinoma of pancreas
8.6.5.	Carcinoma of other and ill-defined sites in GI tract
8.7.	Carcinomas of other & ill-defined sites not elsewhere classified (NEC)
8.7.1.	Adrenocortical carcinoma
8.7.2.	Other carcinomas NEC
GROUP 9: Miscellaneous Specified Neoplasms NEC	
9.1.	Embryonal tumours NEC
9.1.1.	Wilms tumour
9.1.2.	Neuroblastoma
9.1.3.	Other embryonal tumours NEC
9.2	Other rare miscellaneous specified neoplasms
9.2.1.	Paraganglioma and glomus tumours
9.2.2.	Other specified gonadal tumours NEC
9.2.3.	Myeloma, mast cell tumours and miscellaneous reticuloendothelial
9.2.4.	Other specified neoplasms NEC
GROUP 10: Unspecified Malignant Neoplasms NEC	

Table A.2: 0 to 1-year survival for patients diagnosed in 2005-2009 in England at ages 0 to 14, 15 to 24 and 25 to 49 years by diagnosis and number of months of follow-up.

		0 to 14 years			15 to 24 years			25 to 49 years		
diagnosis	months of follow up	% survival	LCL	UCL	% survival	LCL	UCL	% survival	LCL	UCL
ALL	1	99.1	98.5	99.5	96.6	94.1	98.1	95.4	92.8	97.0
	2	98.5	97.7	99.0	94.9	92.0	96.8	91.9	88.8	94.2
	3	98.4	97.7	99.0	93.8	90.7	95.9	89.7	86.4	92.3
	4	98.2	97.4	98.7	92.9	89.7	95.2	86.8	83.1	89.7
	5	97.8	96.9	98.4	92.7	89.4	94.9	84.9	81.0	88.0
	6	97.7	96.8	98.3	92.1	88.7	94.5	82.2	78.1	85.6
	7	97.5	96.6	98.2	91.2	87.8	93.8	79.2	75.0	82.9
	8	97.3	96.4	98.0	90.1	86.5	92.8	75.8	71.3	79.7
	9	97.3	96.4	98.0	88.7	84.9	91.6	73.6	69.0	77.6
	10	96.9	95.9	97.7	88.4	84.6	91.3	71.9	67.3	76.0
	11	96.9	95.9	97.7	86.4	82.4	89.6	69.2	64.5	73.4
	12	96.8	95.7	97.5	85.6	81.5	88.9	67.0	62.2	71.3
AML										
	1	95.3	92.0	97.2	93.6	89.9	96.0	90.5	88.7	92.0
	2	94.2	90.7	96.4	93.2	89.4	95.7	87.8	85.9	89.5
	3	93.9	90.3	96.1	90.2	85.9	93.2	86.1	84.1	88.0
	4	92.4	88.6	95.0	88.7	84.2	92.0	84.4	82.2	86.3
	5	92.1	88.2	94.7	86.8	82.1	90.4	82.8	80.6	84.8
	6	91.7	87.8	94.4	84.6	79.6	88.4	81.1	78.8	83.2
	7	89.5	85.3	92.6	83.4	78.4	87.4	79.6	77.2	81.7
	8	87.7	83.2	91.1	83.0	78.0	87.1	77.9	75.5	80.1
	9	85.2	80.4	88.9	81.9	76.7	86.1	75.6	73.1	77.9
	10	84.5	79.6	88.3	79.7	74.3	84.0	74.0	71.5	76.4
	11	82.7	77.7	86.7	78.9	73.5	83.3	72.9	70.3	75.3
	12	80.5	75.3	84.7	77.0	71.5	81.6	69.9	67.2	72.4
NHL										
	1	97.5	95.3	98.6	96.2	94.3	97.5	96.9	96.4	97.4
	2	96.4	94.1	97.9	95.0	92.8	96.5	95.7	95.1	96.2
	3	95.9	93.4	97.5	93.5	91.1	95.3	94.8	94.1	95.3
	4	95.7	93.1	97.3	93.4	90.9	95.1	93.9	93.3	94.5
	5	95.7	93.1	97.3	92.5	89.9	94.4	93.4	92.7	94.0
	6	95.2	92.5	96.9	91.7	89.1	93.8	92.6	91.9	93.3
	7	94.7	91.9	96.5	91.0	88.3	93.1	91.8	91.0	92.5
	8	94.1	91.3	96.1	90.5	87.7	92.7	91.1	90.3	91.9
	9	93.6	90.7	95.7	89.8	86.9	92.0	90.5	89.7	91.3
	10	93.1	90.1	95.2	89.2	86.3	91.5	90.0	89.2	90.8
	11	92.9	89.8	95.0	88.7	85.7	91.1	89.4	88.6	90.2
	12	91.6	88.4	94.0	88.2	85.2	90.6	88.8	87.9	89.6

		0 to 14 years			15 to 24 years			25 to 49 years		
diagnosis	months of follow up	% survival	LCL	UCL	% survival	LCL	UCL	% survival	LCL	UCL
HL										
	1	99.4	97.6	99.9	100.0	100.0	100.0	99.1	98.7	99.4
	2	99.4	97.6	99.9	100.0	100.0	100.0	98.9	98.4	99.2
	3	99.4	97.6	99.9	100.0	100.0	100.0	98.6	98.1	99.0
	4	99.4	97.6	99.9	100.0	100.0	100.0	98.5	98.0	98.9
	5	99.4	97.6	99.9	99.9	99.5	100.0	98.5	97.9	98.9
	6	99.4	97.6	99.9	99.9	99.4	100.0	98.3	97.7	98.7
	7	99.4	97.6	99.9	99.7	99.2	99.9	98.2	97.6	98.7
	8	99.4	97.6	99.9	99.6	99.1	99.9	97.9	97.3	98.4
	9	99.1	97.2	99.7	99.6	99.1	99.9	97.8	97.2	98.3
	10	99.1	97.2	99.7	99.6	99.0	99.8	97.5	96.9	98.1
	11	99.1	97.2	99.7	99.6	99.0	99.8	97.5	96.8	98.0
	12	99.1	97.2	99.7	99.6	99.0	99.8	97.3	96.6	97.8
CNS tumours										
	1	97.0	96.0	97.8	97.4	96.2	98.3	97.2	96.8	97.6
	2	95.9	94.7	96.8	97.1	95.8	98.0	95.6	95.1	96.0
	3	94.8	93.5	95.8	96.5	95.1	97.5	94.6	94.0	95.1
	4	93.6	92.2	94.8	96.2	94.7	97.2	93.6	93.0	94.1
	5	92.9	91.5	94.2	95.8	94.4	97.0	92.7	92.0	93.2
	6	91.6	90.1	93.0	95.2	93.6	96.4	91.8	91.2	92.4
	7	90.6	88.9	91.9	94.6	92.9	95.9	91.1	90.4	91.8
	8	88.6	86.8	90.1	93.5	91.7	94.9	90.3	89.6	90.9
	9	87.1	85.2	88.7	93.1	91.2	94.5	89.5	88.8	90.2
	10	85.3	83.4	87.1	92.9	91.0	94.3	88.7	88.0	89.5
	11	84.3	82.3	86.1	92.1	90.2	93.7	88.0	87.2	88.7
	12	83.6	81.6	85.4	91.2	89.1	92.8	87.0	86.2	87.8
Bone tumours										
	1	99.7	97.8	100.0	99.8	98.3	100.0	98.7	97.4	99.3
	2	99.7	97.8	100.0	99.3	97.8	99.8	98.2	96.7	99.0
	3	99.4	97.6	99.9	98.6	96.9	99.4	97.0	95.3	98.1
	4	99.1	97.2	99.7	98.6	96.9	99.4	96.5	94.7	97.7
	5	98.5	96.4	99.4	98.6	96.9	99.4	95.4	93.4	96.8
	6	97.9	95.5	99.0	97.7	95.7	98.8	94.6	92.4	96.1
	7	96.9	94.4	98.3	96.7	94.5	98.1	94.2	92.0	95.8
	8	96.3	93.6	97.9	95.6	93.1	97.2	93.7	91.5	95.4
	9	95.4	92.5	97.2	94.6	92.0	96.4	93.3	90.9	95.0
	10	93.9	90.6	96.0	93.4	90.6	95.4	92.3	89.8	94.2
	11	93.3	89.9	95.5	93.0	90.1	95.1	91.1	88.5	93.1
	12	91.4	87.8	94.0	90.9	87.7	93.3	89.8	87.0	92.0

		0 to 14 years			15 to 24 years			25 to 49 years		
diagnosis	months of follow up	% survival	LCL	UCL	% survival	LCL	UCL	% survival	LCL	UCL
Soft tissue sarcomas										
	1	97.9	95.6	99.0	98.2	95.9	99.2	97.8	97.1	98.3
	2	97.6	95.2	98.8	97.2	94.7	98.6	96.4	95.6	97.1
	3	97.0	94.4	98.4	96.0	93.2	97.7	95.1	94.1	95.8
	4	96.6	94.0	98.1	94.4	91.3	96.5	94.0	93.0	94.9
	5	94.8	91.8	96.8	93.2	89.9	95.5	93.1	92.0	94.0
	6	94.8	91.8	96.8	92.3	88.8	94.7	92.6	91.5	93.5
	7	94.8	91.8	96.8	91.7	88.1	94.2	91.4	90.3	92.5
	8	93.6	90.3	95.8	91.4	87.7	94.0	90.8	89.6	91.9
	9	92.4	88.9	94.8	89.2	85.3	92.1	89.8	88.6	91.0
	10	91.2	87.5	93.8	88.0	83.9	91.1	88.7	87.3	89.8
	11	90.8	87.1	93.5	85.5	81.1	88.9	87.8	86.4	89.0
	12	89.3	85.4	92.2	83.9	79.5	87.5	86.8	85.4	88.1
Germ cell tumours of the ovary										
	1	100.0	100.0	100.0	99.1	94.0	99.9	99.3	95.3	99.9
	2	100.0	100.0	100.0	99.1	94.0	99.9	98.7	94.7	99.7
	3	100.0	100.0	100.0	99.1	94.0	99.9	98.0	93.9	99.4
	4	100.0	100.0	100.0	99.2	94.1	99.9	98.0	93.9	99.4
	5	100.0	100.0	100.0	99.2	94.1	99.9	98.0	93.9	99.4
	6	100.0	100.0	100.0	98.3	93.3	99.6	97.3	93.0	99.0
	7	100.0	100.0	100.0	98.3	93.3	99.6	96.7	92.1	98.6
	8	100.0	100.0	100.0	98.3	93.3	99.6	96.7	92.1	98.6
	9	100.0	100.0	100.0	98.3	93.3	99.6	96.0	91.2	98.2
	10	100.0	100.0	100.0	98.3	93.3	99.6	96.0	91.3	98.2
	11	100.0	100.0	100.0	98.3	93.3	99.6	96.0	91.3	98.2
	12	100.0	100.0	100.0	98.3	93.3	99.6	95.3	90.4	97.8
Germ cell tumours of the testis										
	1	100.0	100.0	100.0	100.0	100.0	100.0	99.8	99.6	99.9
	2	100.0	100.0	100.0	99.9	99.4	100.0	99.7	99.5	99.8
	3	100.0	100.0	100.0	99.8	99.2	99.9	99.6	99.4	99.7
	4	100.0	100.0	100.0	99.8	99.2	99.9	99.4	99.2	99.6
	5	100.0	100.0	100.0	99.5	98.8	99.8	99.2	99.0	99.4
	6	100.0	100.0	100.0	99.4	98.7	99.7	99.2	98.9	99.4
	7	100.0	100.0	100.0	99.2	98.4	99.6	99.1	98.8	99.3
	8	100.0	100.0	100.0	99.0	98.2	99.4	99.1	98.8	99.3
	9	100.0	100.0	100.0	98.8	98.0	99.3	99.0	98.8	99.3
	10	100.0	100.0	100.0	98.6	97.7	99.2	98.9	98.6	99.2
	11	100.0	100.0	100.0	98.6	97.6	99.1	98.9	98.6	99.2
	12	100.0	100.0	100.0	98.5	97.5	99.1	98.8	98.5	99.1

diagnosis	months of follow up	0 to 14 years			15 to 24 years			25 to 49 years		
		% survival	LCL	UCL	% survival	LCL	UCL	% survival	LCL	UCL
Extra-gonadal germ cell tumours										
	1	98.1	92.8	99.5	97.8	91.5	99.5	95.4	90.6	97.8
	2	96.3	90.4	98.6	95.6	88.7	98.3	92.1	86.5	95.5
	3	96.3	90.4	98.6	95.6	88.7	98.3	91.5	85.8	95.0
	4	96.3	90.4	98.6	94.5	87.3	97.7	88.2	81.9	92.4
	5	96.3	90.4	98.7	93.4	85.9	97.0	87.5	81.1	91.9
	6	96.3	90.4	98.7	91.2	83.2	95.5	86.2	79.7	90.8
	7	94.5	88.0	97.5	90.1	81.9	94.8	84.3	77.4	89.2
	8	94.5	88.0	97.6	90.1	81.9	94.8	83.0	76.0	88.1
	9	92.6	85.7	96.3	90.1	81.9	94.8	81.0	73.8	86.4
	10	92.7	85.7	96.3	89.1	80.6	94.0	79.7	72.4	85.3
	11	92.7	85.7	96.3	88.0	79.3	93.2	78.4	70.9	84.1
	12	92.7	85.7	96.3	86.9	78.0	92.3	77.1	69.5	83.0
Melanomas										
	1	100.0	100.0	100.0	100.0	100.0	100.0	99.8	99.7	99.9
	2	100.0	100.0	100.0	100.0	100.0	100.0	99.6	99.5	99.7
	3	98.3	88.6	99.8	99.9	99.3	100.0	99.4	99.2	99.5
	4	98.3	88.6	99.8	99.8	99.2	100.0	99.2	99.0	99.3
	5	98.3	88.6	99.8	99.5	98.8	99.8	99.0	98.8	99.1
	6	98.3	88.6	99.8	99.4	98.6	99.7	98.8	98.6	99.0
	7	98.3	88.6	99.8	99.4	98.6	99.7	98.6	98.4	98.8
	8	98.3	88.6	99.8	99.3	98.5	99.7	98.5	98.3	98.7
	9	96.6	87.1	99.2	98.9	98.0	99.4	98.3	98.1	98.6
	10	96.6	87.2	99.2	98.8	97.9	99.3	98.2	97.9	98.4
	11	96.7	87.2	99.2	98.8	97.9	99.3	98.1	97.8	98.3
	12	96.7	87.2	99.2	98.5	97.5	99.1	97.9	97.6	98.2
Carcinoma of the thyroid										
	1	100.0	100.0	100.0	99.8	98.3	100.0	99.9	99.7	100.0
	2	100.0	100.0	100.0	99.8	98.3	100.0	99.9	99.7	100.0
	3	100.0	100.0	100.0	99.5	98.1	99.9	99.8	99.6	99.9
	4	100.0	100.0	100.0	99.5	98.1	99.9	99.8	99.5	99.9
	5	100.0	100.0	100.0	99.5	98.1	99.9	99.7	99.5	99.8
	6	100.0	100.0	100.0	99.5	98.1	99.9	99.6	99.4	99.8
	7	100.0	100.0	100.0	99.6	98.1	99.9	99.5	99.2	99.7
	8	100.0	100.0	100.0	99.3	97.8	99.8	99.5	99.2	99.7
	9	100.0	100.0	100.0	99.3	97.8	99.8	99.5	99.2	99.7
	10	100.0	100.0	100.0	99.3	97.8	99.8	99.5	99.1	99.7
	11	100.0	100.0	100.0	99.3	97.9	99.8	99.5	99.1	99.7
	12	100.0	100.0	100.0	99.3	97.9	99.8	99.3	99.0	99.6

diagnosis	months of follow up	0 to 14 years			15 to 24 years			25 to 49 years		
		% survival	LCL	UCL	% survival	LCL	UCL	% survival	LCL	UCL
Carcinoma of the breast										
	1				100.0	100.0	100.0	99.9	99.8	99.9
	2				100.0	100.0	100.0	99.7	99.7	99.8
	3				100.0	100.0	100.0	99.6	99.6	99.7
	4				100.0	100.0	100.0	99.6	99.5	99.6
	5				100.0	100.0	100.0	99.5	99.4	99.6
	6				99.1	93.7	99.9	99.4	99.3	99.5
	7				98.2	92.9	99.6	99.3	99.2	99.4
	8				98.2	92.9	99.6	99.2	99.1	99.3
	9				98.2	92.9	99.6	99.0	98.9	99.1
	10				98.2	93.0	99.6	98.9	98.8	99.0
	11				98.2	93.0	99.6	98.7	98.6	98.8
	12				98.2	93.0	99.6	98.5	98.4	98.6
Carcinoma of the ovary										
	1				100.0	100.0	100.0	98.9	98.5	99.2
	2				100.0	100.0	100.0	97.8	97.2	98.2
	3				100.0	100.0	100.0	97.0	96.3	97.5
	4				99.5	96.6	99.9	96.5	95.8	97.0
	5				99.5	96.6	99.9	96.1	95.4	96.7
	6				99.5	96.6	99.9	95.6	94.9	96.2
	7				99.0	96.2	99.8	95.1	94.4	95.8
	8				98.6	95.6	99.6	94.6	93.8	95.3
	9				98.6	95.6	99.6	94.0	93.1	94.7
	10				98.6	95.6	99.6	93.4	92.5	94.2
	11				98.1	94.9	99.3	92.6	91.7	93.4
	12				97.6	94.3	99.0	92.0	91.0	92.8
Carcinoma of the uterine cervix										
	1				100.0	100.0	100.0	99.7	99.5	99.8
	2				100.0	100.0	100.0	99.3	99.0	99.5
	3				100.0	100.0	100.0	99.0	98.7	99.2
	4				99.6	97.3	100.0	98.7	98.4	98.9
	5				99.2	97.0	99.8	98.4	98.0	98.7
	6				99.2	97.0	99.8	98.1	97.7	98.4
	7				98.9	96.5	99.6	97.5	97.1	97.8
	8				98.1	95.4	99.2	96.9	96.5	97.3
	9				97.3	94.4	98.7	96.6	96.1	97.0
	10				95.0	91.5	97.1	96.1	95.6	96.5
	11				93.8	90.1	96.2	95.5	94.9	95.9
	12				93.4	89.6	95.9	94.9	94.4	95.4

		0 to 14 years			15 to 24 years			25 to 49 years		
diagnosis	Months of follow up	% survival	LCL	UCL	% survival	LCL	UCL	% survival	LCL	UCL
Carcinoma of the colon and rectum										
	1				98.4	95.8	99.4	98.3	98.0	98.6
	2				97.6	94.7	98.9	96.6	96.2	97.0
	3				96.8	93.6	98.4	95.1	94.6	95.6
	4				96.0	92.6	97.8	93.8	93.3	94.4
	5				95.2	91.6	97.2	92.6	92.0	93.2
	6				94.0	90.2	96.3	91.4	90.8	92.0
	7				94.0	90.2	96.3	90.5	89.9	91.2
	8				92.3	88.2	95.1	89.6	88.9	90.3
	9				90.3	85.9	93.4	88.5	87.8	89.2
	10				88.7	84.0	92.1	87.1	86.4	87.8
	11				87.9	83.1	91.4	86.0	85.2	86.7
	12				86.7	81.8	90.4	84.7	83.8	85.4

Table A.3: 0 to 1 year survival for patients diagnosed in 2005-2009 in England at ages 15 to 24 by diagnosis and number of months of follow-up by sex

diagnosis	months of follow up	Male			Female		
		% survival	LCL	UCL	% survival	LCL	UCL
ALL							
	1	96.7	93.4	98.3	96.5	90.9	98.7
	2	95.8	92.4	97.7	93.0	86.5	96.4
	3	95.4	91.9	97.4	90.4	83.3	94.5
	4	95.0	91.3	97.1	88.6	81.2	93.2
	5	95.0	91.4	97.1	87.7	80.2	92.5
	6	94.2	90.3	96.5	87.7	80.2	92.6
	7	93.3	89.3	95.9	86.9	79.1	91.9
	8	92.5	88.3	95.2	85.1	77.1	90.5
	9	91.7	87.4	94.6	82.5	74.2	88.3
	10	91.3	86.9	94.2	82.5	74.2	88.3
	11	90.0	85.4	93.2	79.0	70.3	85.4
	12	88.8	84.0	92.2	79.0	70.3	85.4
AML							
	1	93.7	88.3	96.7	93.4	87.3	96.7
	2	93.0	87.4	96.2	93.5	87.3	96.7
	3	89.5	83.2	93.6	91.0	84.3	94.9
	4	88.1	81.6	92.5	89.4	82.4	93.7
	5	86.7	80.0	91.3	86.9	79.5	91.8
	6	84.6	77.6	89.6	84.4	76.7	89.8
	7	83.9	76.8	89.0	82.8	74.8	88.4
	8	83.3	76.0	88.5	82.8	74.9	88.4
	9	83.3	76.1	88.5	80.3	72.1	86.4
	10	79.8	72.2	85.5	79.5	71.2	85.7
	11	79.8	72.2	85.5	77.9	69.4	84.3
	12	77.0	69.2	83.0	77.1	68.5	83.6
NHL							
	1	96.0	93.4	97.6	96.6	74.2	88.3
	2	94.9	92.0	96.8	95.1	74.2	88.3
	3	92.9	89.7	95.1	94.6	70.3	85.4
	4	92.6	89.3	94.9	94.6	70.3	85.4
	5	91.5	88.0	94.0	94.1	87.3	96.7
	6	90.9	87.4	93.5	93.2	87.3	96.7
	7	90.1	86.4	92.8	92.7	84.3	94.9
	8	89.2	85.5	92.0	92.7	82.4	93.7
	9	88.4	84.5	91.3	92.2	79.5	91.8
	10	88.1	84.2	91.1	91.2	76.7	89.8
	11	87.5	83.6	90.6	90.7	74.8	88.4
	12	86.7	82.6	89.8	90.7	74.9	88.4

		Male			Female		
diagnosis	months of follow up	% survival	LCL	UCL	% survival	LCL	UCL
HL	1	100.0	100.0	100.0	100.0	100.0	100.0
	2	100.0	100.0	100.0	100.0	100.0	100.0
	3	100.0	100.0	100.0	100.0	100.0	100.0
	4	100.0	100.0	100.0	100.0	100.0	100.0
	5	99.9	98.9	100.0	100.0	100.0	100.0
	6	99.9	98.9	100.0	99.9	98.9	100.0
	7	99.9	98.9	100.0	99.5	98.5	99.9
	8	99.9	98.9	100.0	99.4	98.3	99.8
	9	99.9	98.9	100.0	99.4	98.3	99.8
	10	99.9	98.9	100.0	99.2	98.1	99.7
	11	99.9	98.9	100.0	99.2	98.1	99.7
	12	99.9	98.9	100.0	99.2	98.1	99.7
CNS tumours							
	1	97.4	95.6	98.5	97.5	95.5	98.6
	2	97.0	95.1	98.2	97.3	95.2	98.4
	3	95.8	93.6	97.2	97.3	95.2	98.4
	4	95.4	93.2	96.9	97.0	94.9	98.3
	5	95.0	92.7	96.6	96.8	94.7	98.1
	6	94.6	92.2	96.3	95.9	93.5	97.4
	7	93.8	91.3	95.6	95.4	93.0	97.0
	8	92.4	89.7	94.4	94.7	92.2	96.5
	9	92.0	89.3	94.1	94.3	91.7	96.1
	10	91.6	88.8	93.7	94.3	91.7	96.1
	11	91.2	88.4	93.4	93.1	90.3	95.2
	12	90.2	87.2	92.5	92.2	89.3	94.4
Bone tumours							
	1	99.6	97.3	100.0	100.0	100.0	100.0
	2	98.9	96.5	99.6	100.0	100.0	100.0
	3	98.5	96.0	99.4	98.8	95.2	99.7
	4	98.5	96.0	99.4	98.8	95.2	99.7
	5	98.5	96.0	99.5	98.8	95.2	99.7
	6	97.7	95.0	99.0	97.6	93.6	99.1
	7	97.0	94.0	98.5	96.3	92.0	98.3
	8	96.2	93.1	98.0	94.5	89.7	97.1
	9	95.5	92.1	97.4	93.3	88.2	96.2
	10	94.3	90.7	96.6	92.0	86.7	95.3
	11	93.9	90.3	96.3	91.4	86.0	94.8
	12	90.5	86.3	93.5	91.4	86.0	94.8

diagnosis	months of follow up	Male % survival	Male LCL	Male UCL	Female % survival	Female LCL	Female UCL
Soft tissue sarcomas							
	1	98.9	95.7	99.7	97.2	92.7	98.9
	2	98.9	95.7	99.7	95.1	89.9	97.6
	3	97.3	93.5	98.9	94.4	89.1	97.2
	4	95.6	91.4	97.8	93.0	87.3	96.2
	5	94.5	90.0	97.0	91.6	85.6	95.1
	6	94.0	89.3	96.6	90.2	83.9	94.1
	7	92.9	88.0	95.8	90.2	83.9	94.1
	8	92.3	87.3	95.4	90.2	83.9	94.1
	9	89.5	84.1	93.2	88.8	82.3	93.0
	10	88.4	82.8	92.3	87.3	80.7	91.8
	11	85.7	79.7	90.0	85.2	78.2	90.1
	12	83.5	77.2	88.2	84.5	77.5	89.5
Extra-gonadal germ cell tumours							
	1	97.3	89.6	99.3	100.0	100.0	100.0
	2	94.6	86.2	98.0	100.0	100.0	100.0
	3	94.6	86.3	98.0	100.0	100.0	100.0
	4	93.3	84.5	97.2	100.0	100.0	100.0
	5	91.9	82.9	96.3	100.0	100.0	100.0
	6	90.6	81.2	95.4	94.1	65.0	99.2
	7	89.2	79.6	94.5	94.1	65.0	99.2
	8	89.2	79.6	94.5	94.1	65.0	99.2
	9	89.2	79.6	94.5	94.1	65.0	99.2
	10	87.9	78.0	93.5	94.1	65.0	99.2
	11	86.5	76.4	92.5	94.1	65.0	99.2
	12	85.2	74.8	91.5	94.1	65.0	99.2
Melanomas							
	1	100.0	100.0	100.0	100.0	100.0	100.0
	2	100.0	100.0	100.0	100.0	100.0	100.0
	3	99.7	97.9	100.0	100.0	100.0	100.0
	4	99.4	97.7	99.9	100.0	100.0	100.0
	5	98.5	96.5	99.4	100.0	100.0	100.0
	6	98.2	96.1	99.2	100.0	100.0	100.0
	7	98.3	96.1	99.2	100.0	100.0	100.0
	8	98.0	95.7	99.0	100.0	100.0	100.0
	9	97.1	94.6	98.4	99.9	98.9	100.0
	10	96.8	94.2	98.2	99.9	98.9	100.0
	11	96.8	94.2	98.2	99.9	98.9	100.0
	12	96.2	93.5	97.8	99.7	98.8	100.0

diagnosis	months of follow up	Male % survival	Male LCL	Male UCL	Female % survival	Female LCL	Female UCL
Carcinoma of the thyroid							
	1	100.0	100.0	100.0	99.7	97.9	100.0
	2	100.0	100.0	100.0	99.7	97.9	100.0
	3	100.0	100.0	100.0	99.4	97.7	99.9
	4	100.0	100.0	100.0	99.4	97.7	99.9
	5	100.0	100.0	100.0	99.4	97.7	99.9
	6	100.0	100.0	100.0	99.4	97.7	99.9
	7	100.0	100.0	100.0	99.4	97.7	99.9
	8	100.0	100.0	100.0	99.1	97.3	99.7
	9	100.0	100.0	100.0	99.1	97.3	99.7
	10	100.1	100.1	100.1	99.1	97.3	99.7
	11	100.1	100.1	100.1	99.1	97.3	99.7
	12	100.1	100.1	100.1	99.1	97.3	99.7
Carcinoma of the colon and rectum							
	1	97.4	92.3	99.2	99.2	94.7	99.9
	2	95.7	90.1	98.2	99.2	94.7	99.9
	3	94.9	89.0	97.7	98.5	94.0	99.6
	4	93.2	86.8	96.5	98.5	94.0	99.6
	5	92.3	85.8	96.0	97.7	93.0	99.3
	6	92.3	85.8	96.0	95.4	90.0	97.9
	7	92.3	85.8	96.0	95.4	90.0	97.9
	8	88.9	81.7	93.4	95.4	90.0	97.9
	9	87.2	79.7	92.1	93.1	87.1	96.4
	10	86.4	78.7	91.4	90.8	84.3	94.7
	11	84.7	76.7	90.1	90.8	84.3	94.7
	12	83.8	75.8	89.4	89.3	82.5	93.5

The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

Sitting within the National Cancer Research Institute (NCRI), the NCIN works closely with cancer services in England, Scotland, Wales and Northern Ireland. In England, the NCIN is part of the National Cancer Programme.

The National Cancer Intelligence Unit will be hosted by Public Health England from 1st April 2013

Our aims and objectives cover five core areas to improve the quality and availability of cancer data from its collection to use:

- **Promoting efficient and effective data collection throughout the cancer journey**
- **Providing a common national repository for cancer datasets**
- **Producing expert analyses, to monitor patterns of cancer care**
- **Exploiting information to drive improvements in cancer care and clinical outcomes**
- **Enabling use of cancer information to support audit and research programmes**