NHS

North West Cancer Intelligence Service

Survival in Teenagers and Young Adults with Cancer in the UK

NCIN national cancer intelligence network

Survival in Teenagers and Young Adults (TYA) with Cancer in the UK

A comparative report comparing TYA cancer survival with that of children aged 0 to 14 years and adults aged 25 to 49 years and looking at differences in survival by gender

Authors: C O'Hara, A Moran (NWCIS) and the TYA National Cancer Intelligence Advisory Group [1]

August 2012

[1] Details of the membership and role of this group can be found at www.nwcis.nhs.uk

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Summary

There is evidence that outcomes in TYA cancer patients, as measured by survival rates, are sometimes not as good as those for children. Poorer survival for males than females have also been reported for certain types of cancer. In the light of this evidence, we decided to undertake a detailed study of survival rates in TYA with cancer in the UK, comparing these with outcomes in children and in adults diagnosed between 25 and 49 years of age. Outcomes are also compared by gender. This report has been written by NWCIS and the TYA National Intelligence Advisory Group, which is an informal group of interested clinicians and epidemiologists who support NWCIS in their TYA work. It has been produced under the auspices of the NCIN and the Childhood and TYA Clinical Reference Group.

Age

The pattern of survival rates with age varied markedly by type of cancer for patients diagnosed in 2001-05 in the UK. The most important findings were:

Five-year survival rates decreased markedly from 0 to 49 years in patients with ALL, and to a lesser extent AML. Large differences were present one year after diagnosis showing that early deaths made a major contribution to the drop in survival with age.

Patients aged 15-24 years with STS and with bone tumours had lower five-year survival than either the 0-14 or 25-49 age groups.

TYA patients with CNS tumours had better survival rates than either younger or older patients.

Gender

Females aged 19-24 had statistically significantly better five-year survival than males for STS and melanoma. Rates for females aged 19-24 were more than 5% higher than for males for NLL, ALL and colorectal carcinoma, though these were not statistically significant. In the 15-18 age group females had better survival than males for melanoma and colorectal carcinoma though neither were statistically significant.

For STS males aged 20-29 had poorer survival, but with little difference from 30 years onwards, suggesting that the health behaviour of men in their 20s may be worth investigating. Females had better survival than males for melanoma at all ages examined.

Way forward

Additional analyses are being undertaken for ALL, CNS, STS and bone tumours to help explain these results. Further research is indicated in TYA patients into the biology of their cancers, delays in diagnosis and treatment and the optimal management.

Introduction

There is increasing recognition that teenagers and young adults (TYA) are a distinct group as regards cancer, differing from children, and middle-aged and older adults in many important aspects including response to treatment, health behaviour and wider needs. We defined TYA as those who are diagnosed with cancer from their 15th to 25th birthday. Choice of age range to report is influenced by several factors. 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; 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.

The Improving Outcome Guidance (IOG) for Children and Young People with cancer (2005) recommends that patients aged 15-18 are managed at a Principal Treatment Centre (PTC) for TYA cancers and that those aged 19-24 are given the choice of being managed at a PTC. The National Cancer Intelligence Service (NCIN) has emphasised the importance of TYA by making it a lead registry role; this is undertaken by the North West Cancer Intelligence Service (NWCIS).

There is evidence that outcomes in TYA cancer patients, as measured by survival rates, are sometimes not as good as those for children. Poorer survival for males than females have also been reported for certain types of cancer. In the light of this evidence, we decided to undertake a detailed study of survival rates in TYA with cancer in the UK, comparing these with outcomes in children and in adults diagnosed between 25 and 49 years of age. Outcomes are also compared by gender. This report has been written by NWCIS and the TYA National Intelligence Advisory Group, which is an informal group of interested clinicians and epidemiologists who support NWCIS in their TYA work. It has been produced under the auspices of the NCIN and the Childhood and TYA Clinical Reference Group.

Methods

We identified all patients resident in the UK who were diagnosed 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. We classified patients into those diagnosed at 0-14, 15-24 and 25-49 years, including only the first malignancy recorded for each individual. The 15-24 age group were divided into 15-18 and 19-24 year olds for more detailed analyses. Analyses were also undertaken for each five-year age group from 0-4 to 45-49 years.

Cancers cases that were registered only as a result of a cancer being recorded on a death certificate (DCOs) were excluded as were individuals whose date of death was the same as date of diagnosis (zero survivors). Any five-year age group was excluded from the analysis if the total number of new cases of any diagnosis group per year was less than 5. The 0-14 year age group was excluded if the number of new cases per year was less than 10.

Cases are grouped by diagnoses using the TYA classification scheme (Birch *et al* 2002). Details of the classifications are found in the Appendix.

Survival up to 5-years was estimated for each age group including all cases with a first diagnosis of cancer between 1st January 2001 and 31st December 2005. 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 (Dickman *et al* 2004) 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.

Differences in five-year relative survival by age and gender were modelled by using a multiple regression approach based on generalized 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 (after Dickman *et al* 2004).

Differences were considered statistically significant if *P* values were <0.05 (two-sided). All statistical analyses were conducted using STATA version 11.2.

Study Subjects

Table I. Number of cases in UK diagnosed 2001-2005 that have been included in the survival analyses by gender, age and diagnosis*.

	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	1,064	251	244	851	132	200	1,915	383	444
AML	184	149	679	165	128	654	349	277	1,333
NHL	297	385	3,503	120	234	2,490	417	619	5,993
HL	228	694	1,770	151	651	1,203	379	1,345	2,973
CNS tumours	1,097	641	4,493	883	604	4,442	1,980	1,245	8,935
Bone tumours	207	300	349	210	176	245	417	476	594
STS	228	207	1,362	189	164	1,219	417	371	2,581
testicular germ cell tumours	--	1,260	7,179	--	--	--	--	1,260	7,179
ovarian germ cell tumours	--	--	--	56	116	140	56	116	140
extra-gonadal germ cell tumours	74	88	111	58	17	65	132	105	176
melanomas	29	342	4,981	37	741	7,617	66	1,083	12,598
thyroid carcinomas	18	74	722	42	307	2,547	60	381	3,269
breast carcinomas	--	--	--	--	106	40,111	--	106	40,111
ovarian carcinomas	--	--	--	--	245	4,401	--	245	4,401
cervical carcinomas	--	--	--	--	301	7,405	--	301	7,405
colorectal carcinomas	--	122	4,312	--	115	3,983	--	237	8,295

**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)*

Table II. Number of cases in UK diagnosed 2005-2009 that have been included in the survival analyses by gender, age and diagnosis*.

	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	996	284	270	828	136	197	1,824	420	467
AML	175	156	657	150	133	709	325	289	1,366
NHL	329	403	3,872	115	244	2,556	444	647	6,428
HL	239	730	1,928	134	744	1,353	373	1,474	3,281
CNS tumours	1,104	706	4,807	936	692	5,063	2,040	1,398	9,870
Bone tumours	197	319	389	184	189	301	381	508	690
STS	232	225	1,577	154	174	1,359	386	399	2,936
testicular germ cell tumours	--	1,382	7,558	--	--	--	--	1,382	7,558
ovarian germ cell tumours	--	--	--	68	129	174	68	129	174
extra-gonadal germ cell tumours	74	83	128	55	21	54	129	104	182
melanomas	29	395	5,803	45	801	9,138	74	1,196	14,941
thyroid carcinomas	23	97	919	43	405	3,407	66	502	4,326
breast carcinomas	--	--	--	--	122	42,815	--	122	42,815
ovarian carcinomas	--	--	--	--	280	4,447	--	280	4,447
cervical carcinomas	--	--	--	--	334	8,478	--	334	8,478
colorectal carcinomas	--	133	4,985	--	145	4,614	--	278	9,599

**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)*

Results

Overview of five-year survival by diagnosis and age[2] for patients diagnosed in the UK 2001-2005

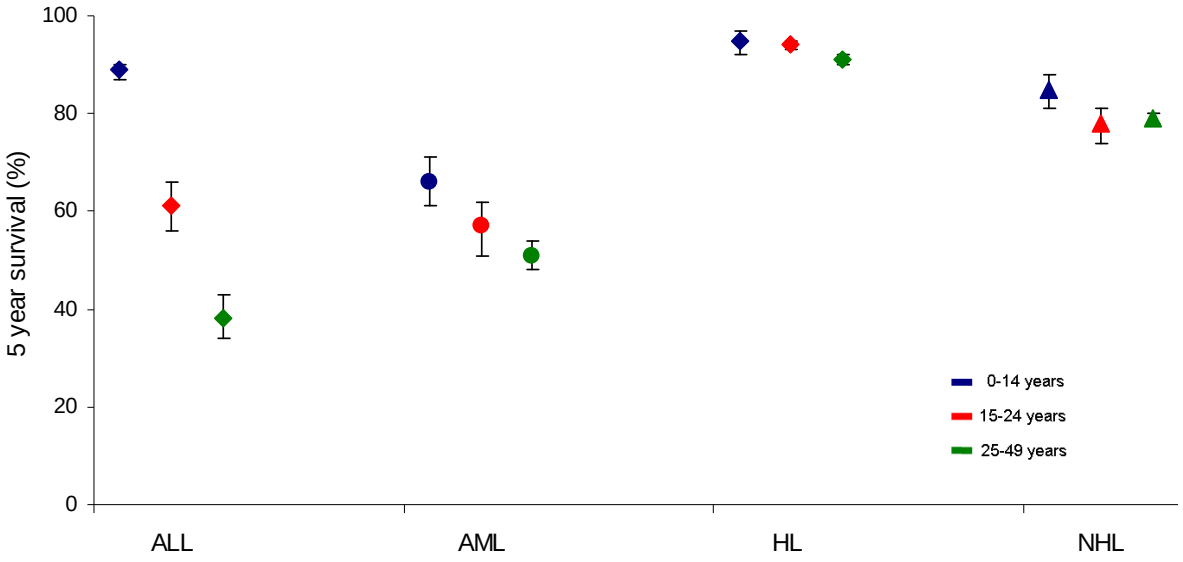

Figure I: Haematological Malignancies – Acute Lymphoblastic Leukaemia (ALL), Acute Myeloid Leukaemia (AML), Non-Hodgkin Lymphoma (NHL) and Hodgkin Lymphoma (HL)

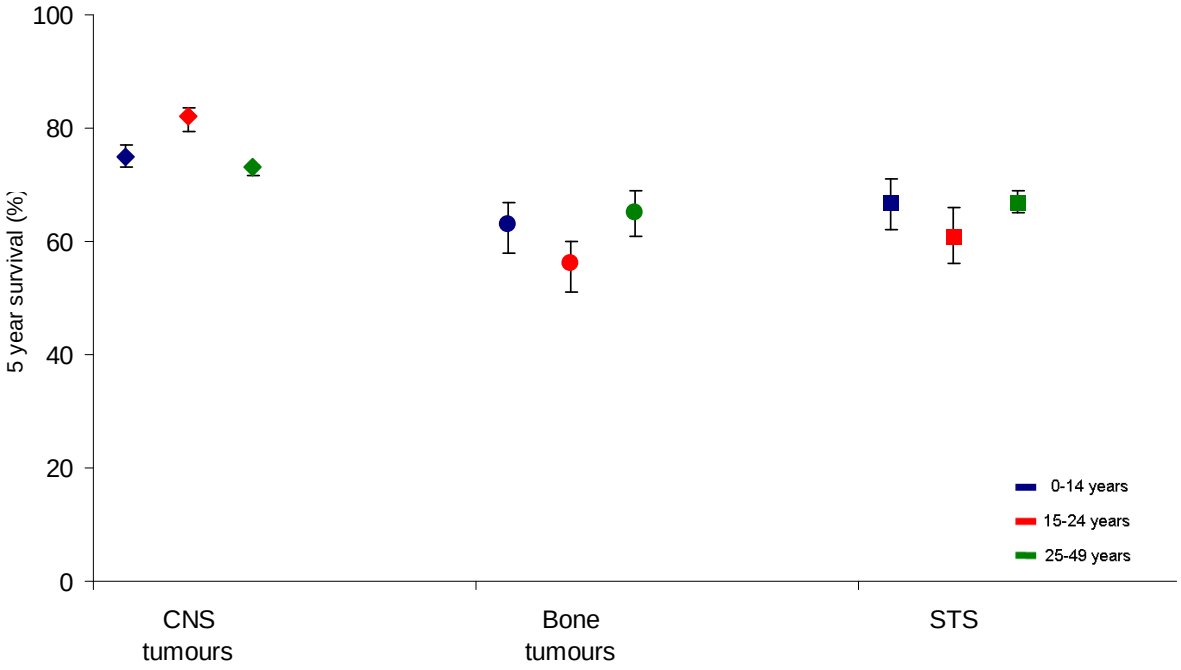

Figure II: CNS Tumours, Bone Tumours and Soft Tissue Sarcomas (STS)

[2] Data for 0 to 14 year age group where number of cases is too small have been excluded.

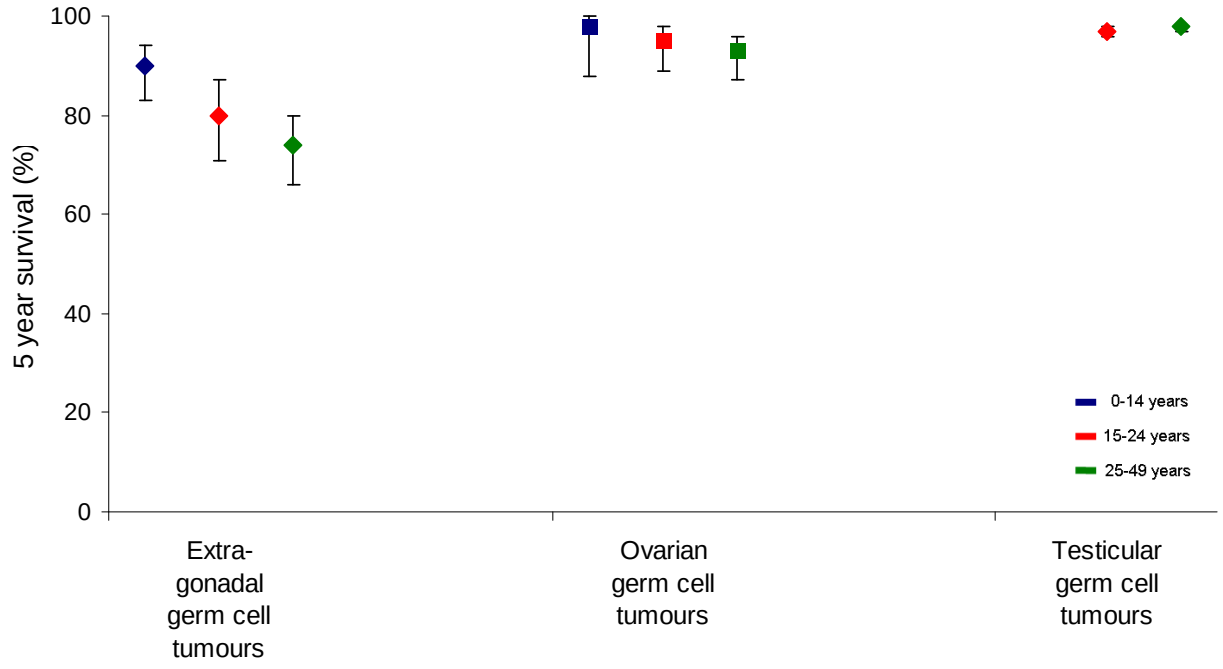

Figure III: Germ Cell Tumours

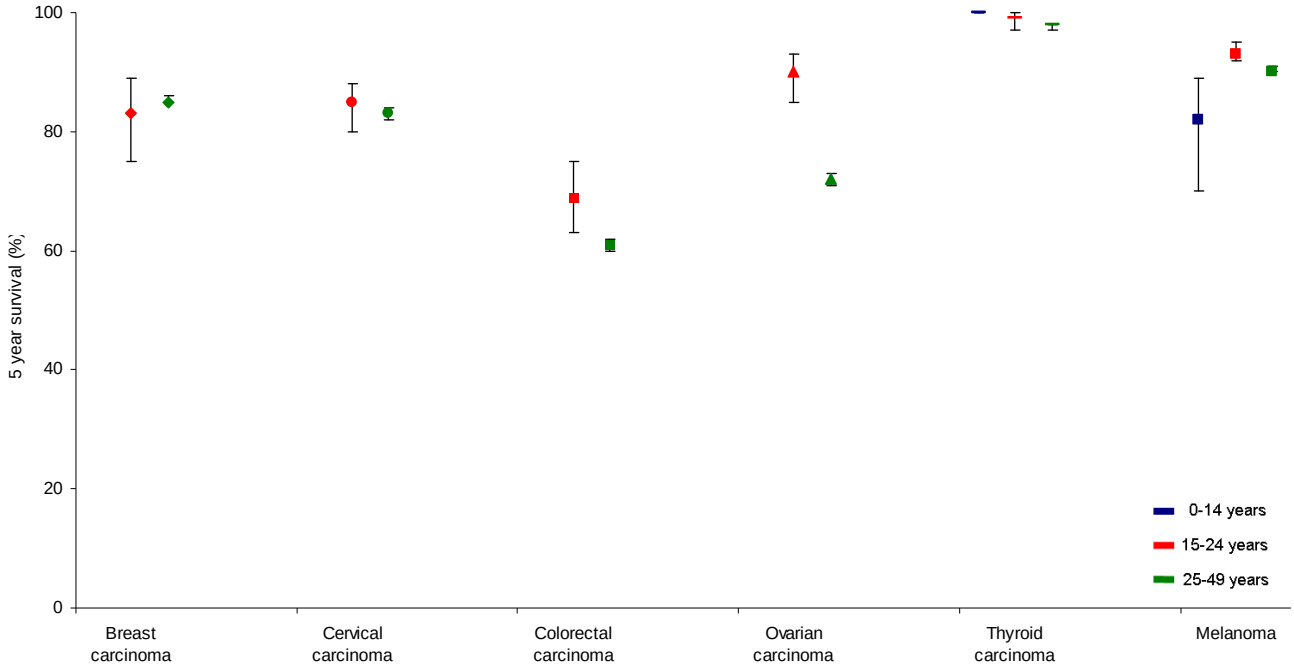

Figure IV: Carcinomas and Melanoma

Results by Diagnosis

The following section provides detailed comparative analyses of 5-year survival for 16 diagnostic groups, looking at differences in outcomes by age and gender for individual diagnostic types. Tabulated data for each of the diagnostic groups examined here are also provided in the Appendix (Tables A.1 and A.2).

1) Acute Lymphoblastic Leukaemia (ALL)

2) Acute Myeloid Leukaemia

3) Non-Hodgkin Lymphoma (HL)

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) Melanoma of the Skin

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 or Rectum

1) Acute Lymphoblastic Leukaemia (ALL)

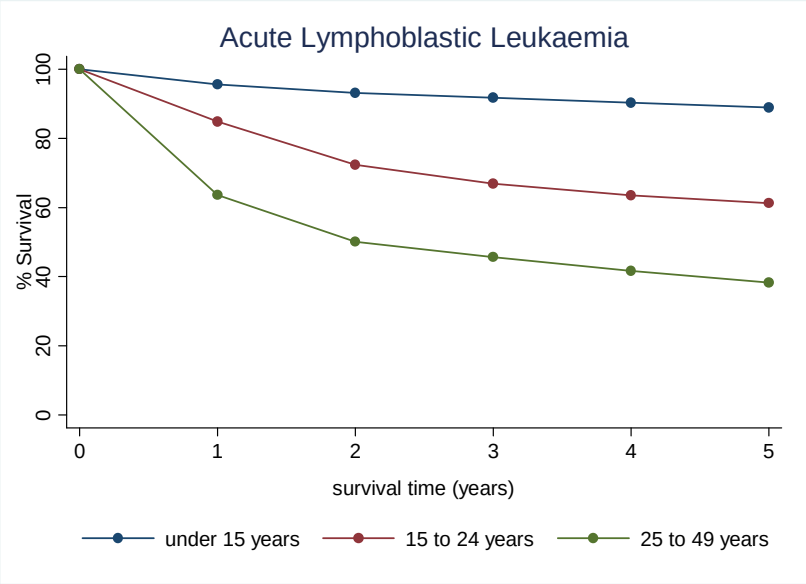

Figure 1.1: 0 to 5 year relative survival for patients diagnosed in 2001- 2005 with ALL in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed between 2001 and 2005, we observed a trend of decreasing survival with age that starts to appear within the first year after diagnosis (Fig 1.1). Five-year relative survival was 20% lower among the TYA age group (15 to 24 years) than among the paediatric age group aged 0 to 14 years but 23% higher than the 25 to 49 year olds (Table 1.1). Even within the TYA age group itself, survival was observed to be lower for the older TYA patients (19 to 24 years) having 17% lower 5-year survival that the 15 to 18 year olds (Table 1.1).

Table 1.1: Five-year survival for those diagnosed with ALL in 2001-2005 by age group, comparing survival among 15 to 24 year olds with the younger and older age groups, and 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	1915	89	87	90	0.22 (0.18-0.28)	0.00
15 to 24 years	383	61	56	66	Ref	--
25 to 49 years	444	38	34	43	2.17 (1.78-2.66)	0.00
15 to 18 years	210	69	62	75	Ref	--
19 to 24 years	173	52	44	59	1.71(1.24-2.38)	0.001

The decreasing trend in 5-year survival was observed for both sexes, although the age differentiation appears to start at a slightly later age in females than males (Fig 1.2). No significant differences were observed between males and females with ALL for any of the age groups examined (Table 1.2 and Fig 1.2).

Table 1.2: Five-year survival for those diagnosed with ALL in 2001-2005, comparing survival for males with females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	1064	88	86	90	Ref	--
	F	851	90	88	92	0.83 (0.63-1.10)	0.20
15 to 24 years	M	251	61	54	66	Ref	--
	F	132	62	53	70	0.97 (0.69-1.36)	0.84
25 to 49 years	M	244	38	32	44	Ref	--
	F	200	39	32	45	1.01 (0.80-1.29)	0.91

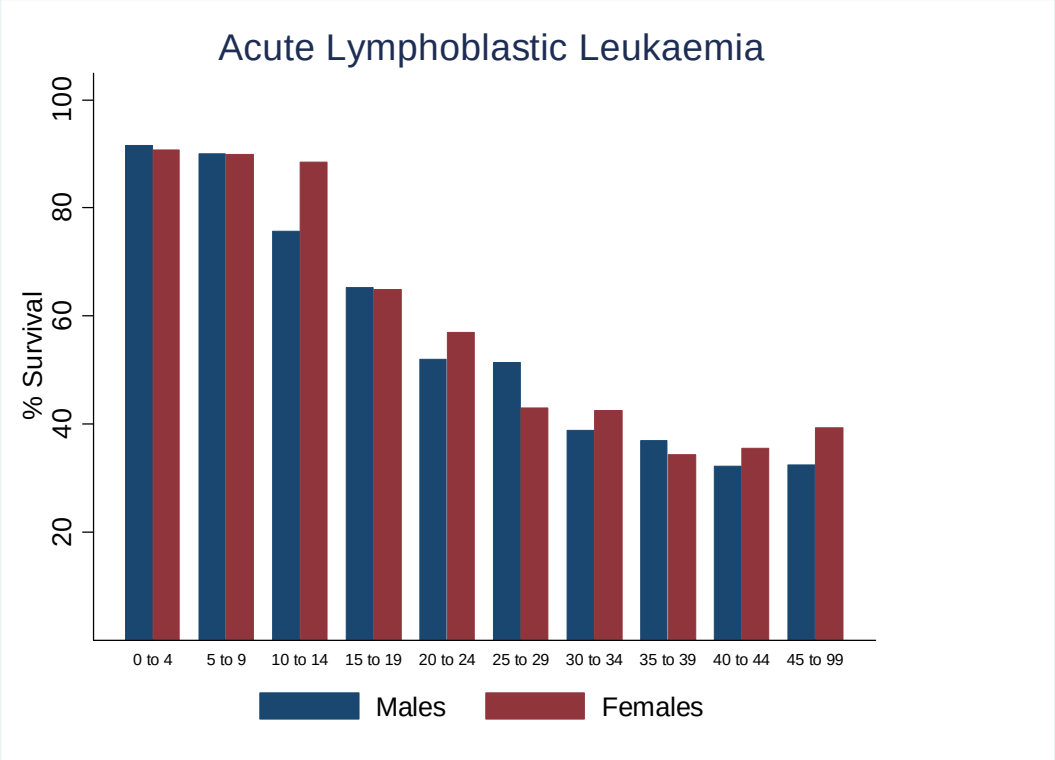

Figure 1.2: Five-year survival for those aged 0 to 49 years diagnosed with ALL in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: *Significant at P< 0.05, **Significant at P< 0.01,***Significant at P< 0.001, No stars = no significant difference.

2) Acute Myeloid Leukaemia

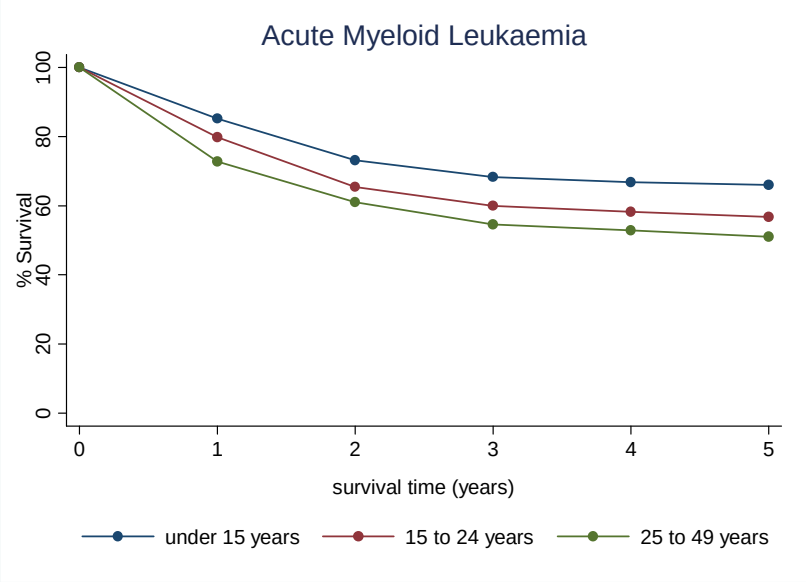

Figure 2.1: 0 to 5 year relative survival for patients diagnosed with AML in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with AML between 2001 and 2005, we again observed a trend of decreasing survival with age that starts to arise within the first year of diagnosis (Fig 2.1). Five-year relative survival was 9% lower among the TYA age group (15 to 24 years) than among the paediatric age group aged 0 to 14 years but 6% higher than the 25 to 49 year olds (Table 1.1). No significant differences were observed within the TYA age group itself (Table 2.1).

Table 2.1: Five-year survival for those diagnosed with AML in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	349	66	61	71	0.71 (0.55-0.92)	0.01
15 to 24 years	277	57	51	62	Ref	--
25 to 49 years	1333	51	48	54	1.22(1.01-1.49)	0.04
15 to 18 years	101	58	47	66	Ref	--
19 to 24 years	176	56	49	63	1.05 (0.72-1.53)	0.8

The decreasing trend by age was observed for both sexes (Fig 1.2). No significant differences were observed between males and females with AML for the paediatric or TYA age groups. However, significant differences were observed between males and females of the 25 to 49 year age group with males having 6% lower 5-year survival than females (Table 1.2) Most of these gender differences appear to occur between 25 and 34 years of age (Fig 2.2).

Table 1.2: Five-year survival for those diagnosed with AML in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	184	68	61	75	Ref	--
	F	165	64	56	71	1.18 (0.82-1.70)	0.36
15 to 24 years	M	149	58	50	65	Ref	--
	F	128	56	47	64	1.10 (0.77-1.58)	0.60
25 to 49 years	M	679	48	45	52	Ref	--
	F	654	54	50	57	0.85 (0.73-0.99)	0.04

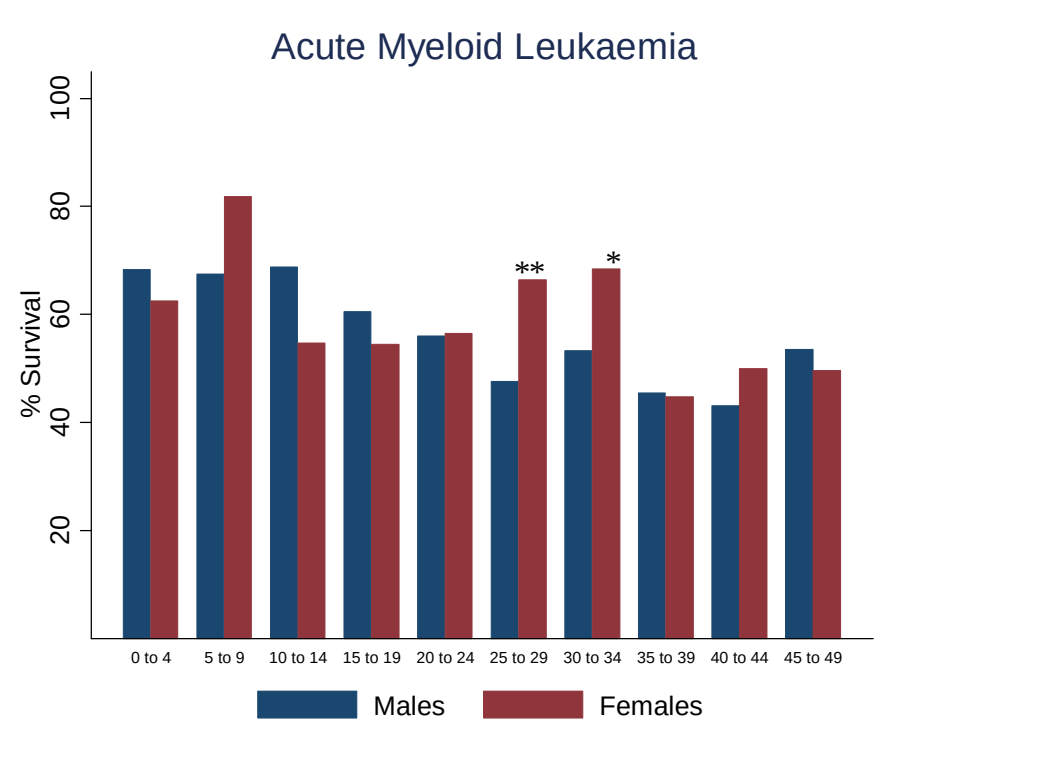

Figure 2.2: Five-year survival for those aged 0 to 49 years diagnosed with AML in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: * Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001, No stars = no significant difference.

3) Non-Hodgkin Lymphoma (HL)

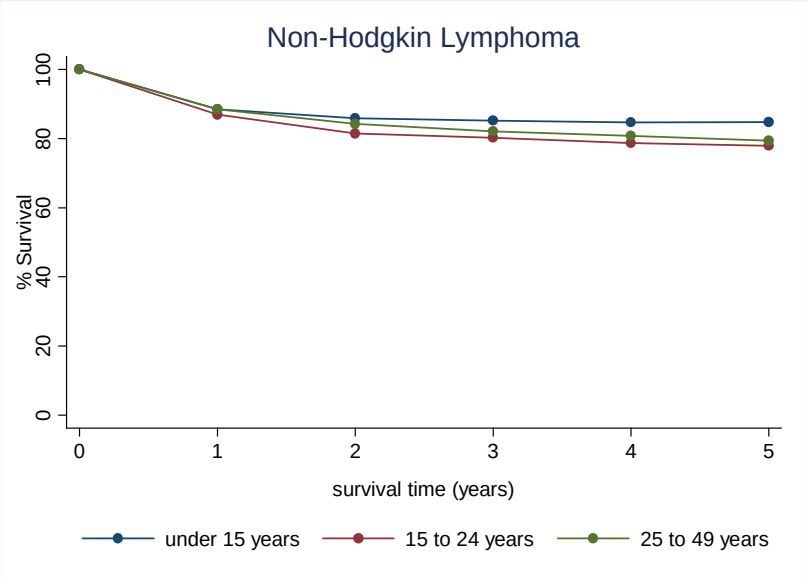

Figure 3.1: 0 to 5 year relative survival for patients diagnosed with NHL in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with NHL between 2001 and 2005, we observed only small differences in survival between the three age groups. However, the paediatric age group showed marginally better relative survival between 2 and 5-years after diagnosis than the two other age groups (Fig 3.1), and had statistically significantly better five-year survival of 85% compared with 78% and 79% for the TYA and 25 to 49 year age groups respectively. We also observed significantly higher 5-year survival among the 15 to 18 years (83%) compared with the 19 to 24 year olds (75%) (Table 3.1).

Table 3.1: Five-year survival for those diagnosed with NHL in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	417	85	81	88	0.66 (0.49-0.89)	0.01
15 to 24 years	619	78	74	81	Ref	--
25 to 49 years	5993	79	78	80	0.92 (0.77-1.1)	0.35
15 to 18 years	222	83	77	87	Ref	--
19 to 24 years	397	75	71	79	1.52 (1.05-2.21)	0.027

No significant differences were observed between males and females with NHL for the paediatric or TYA age groups (Fig 3.2). Significant differences were observed between males and females of the 25 to 49 year age group with males having 3% lower 5-year survival than females (Table 3.2) Most of these gender differences appear to occur towards at the upper end of this age group (Fig 3.2).

Table 3.2: Five-year survival for those diagnosed with NHL in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	297	86	82	90	Ref	--
	F	120	81	73	87	1.48 (0.89-2.48)	0.13
15 to 24 years	M	385	77	73	81	Ref	--
	F	234	79	73	84	0.88 (0.62-1.24)	0.46
25 to 49 years	M	3503	78	77	80	Ref	--
	F	2490	81	79	82	0.87 (0.78-0.98)	0.02

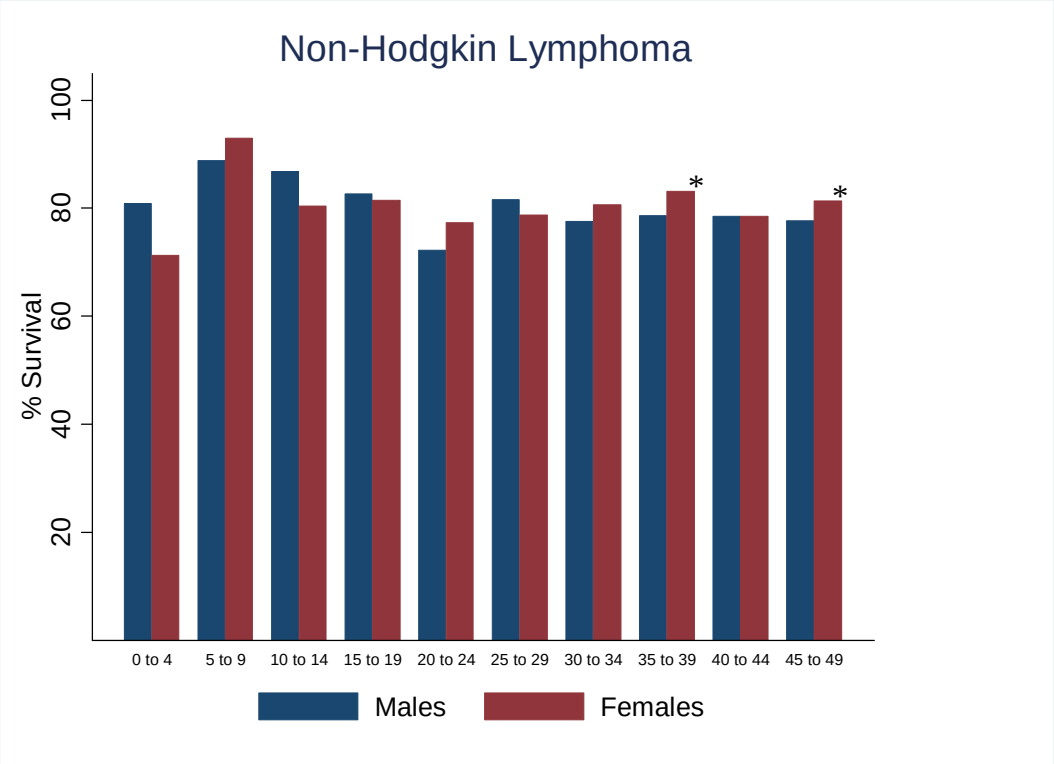

Figure 3.2: Five-year survival for those aged 0 to 49 years diagnosed with NHL in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: *Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001, No stars = no significant difference.

4) Hodgkin Lymphoma (HL)

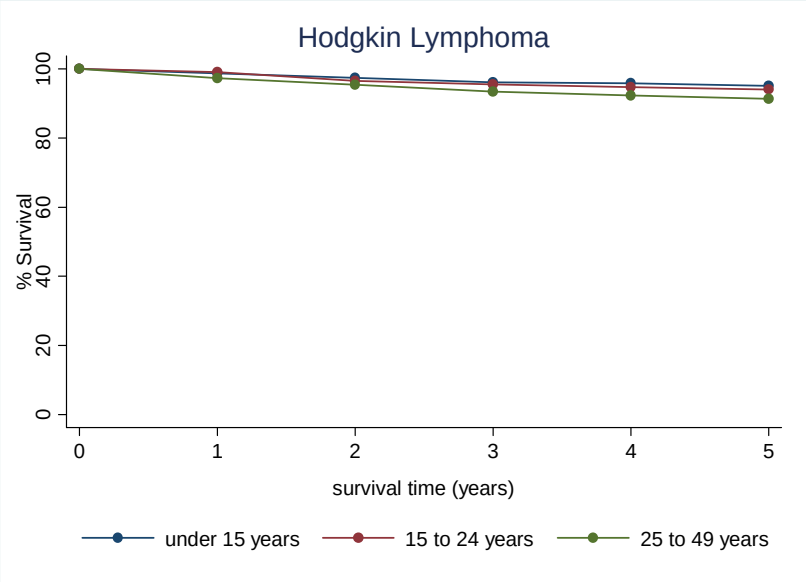

Figure 4.1: 0 to 5-year relative survival for patients diagnosed with HL in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with HL between 2001 and 2005, we observed no difference in survival between the paediatric and TYA age groups (Fig 4.1 and Table 4.1) and no difference in 5-year survival within the TYA age group itself (Table 4.1); patients up to 24 years of age experienced an average of 94% survival at 5 years. However, survival among the older age group (25 to 49 years) was observed to be slightly lower than the TYA age group at 91% (Table 4.1). No significant differences were observed between males and females (Table 4.2 and Fig 4.2).

Table 4.1: Five-year survival for those diagnosed with HL in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	379	95	92	97	0.83 (0.50-1.37)	0.46
15 to 24 years	1345	94	93	95	Ref	--
25 to 49 years	2973	91	90	92	1.49 (1.16-1.92)	0.00
15 to 18 years	458	94	91	96	Ref	--
19 to 24 years	887	94	92	95	1.01 (0.63-1.61)	0.98

Table 4.2: Five-year survival for those diagnosed with HL in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	228	96	93	98	Ref	--
	F	151	93	88	96	1.71 (0.69-4.26)	0.25
15 to 24 years	M	694	94	91	95	Ref	--
	F	651	95	93	96	0.83 (0.53-1.30)	0.42
25 to 49 years	M	1770	91	90	93	Ref	--
	F	1203	91	89	92	1.06 (0.82-1.36)	0.68

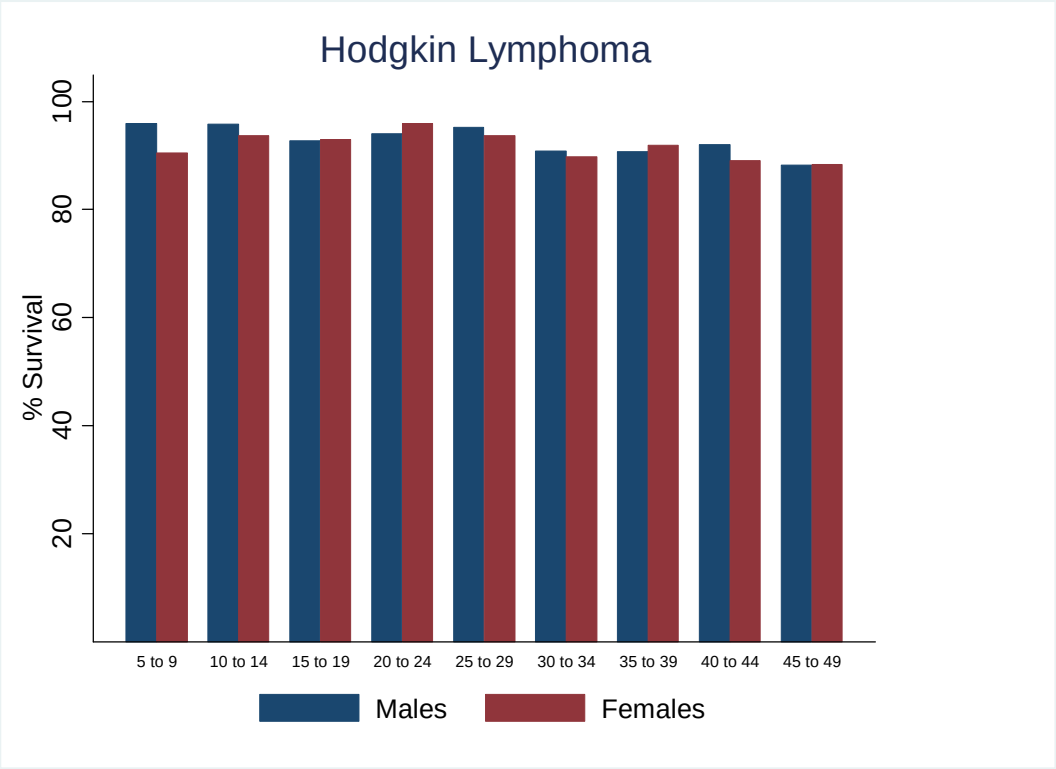

Figure 4.2: Five-year survival for those aged 0 to 49 years diagnosed with HL in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: *Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001, No stars = no significant difference**.** The number of cases for the 0 to 4 age group is too small to include.

5) CNS tumours (Central Nervous System & other Intracranial & Intraspinal Neoplasms including borderline and benign)

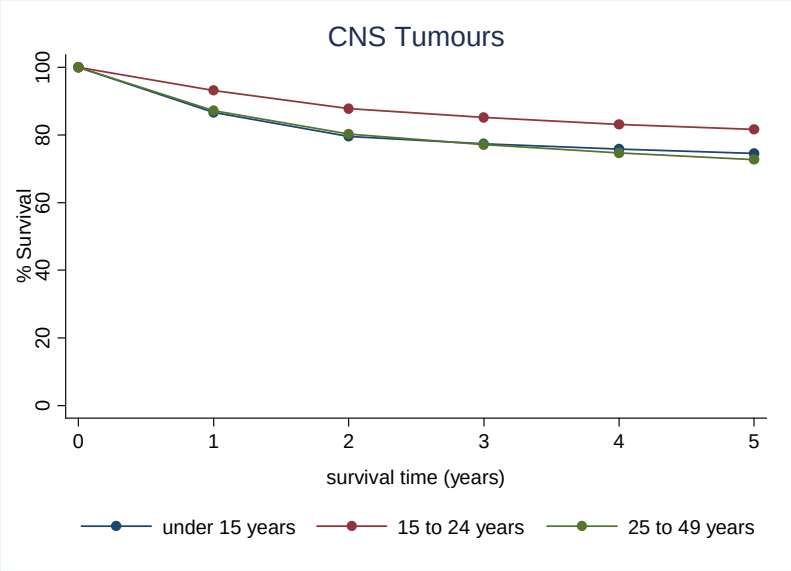

Figure 5.1: 0 to 5 year relative survival for patients diagnosed with a CNS tumour in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with a CNS tumour between 2001 and 2005, we observed higher survival among the TYA age group (82%) than both the paediatric age group (75 %) and the older age group of 25 to 49 years (73%) (Fig 5.1 and Table 5.1). No significant difference was observed within TYA age group itself (Table 5.1).

Table 5.1: Five-year survival for those diagnosed with CNS tumours in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	1980	75	73	77	1.49 (1.28-1.77)	0.00
15 to 24 years	1245	82	79	84	Ref	--
25 to 49 years	8935	73	72	74	1.62 (1.41-1.86)	0.00
15 to 18 years	467	81	77	84	Ref	--
19 to 24 years	778	82	79	85	0.91 (0.70-1.19)	0.5

No significant differences were observed between males and females within the paediatric or TYA age groups (Table 5.2). However, among patients aged 25 to 49 years, significant differences were observed in 5-year survival between males and females (Table 5.2) with females having between 10% and 20% higher 5-year survival than males across the age group (Fig 5.2).

Table 5.2: Five-year survival for those diagnosed with a CNS tumour in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	1097	74	73	78	Ref	--
	F	883	76	71	76	0.92 (0.78-1.11)	0.41
15 to 24 years	M	641	80	77	83	Ref	--
	F	604	83	80	86	0.86 (0.66-1.12)	0.27
25 to 49 years	M	4493	65	64	67	Ref	--
	F	4442	80	79	81	0.50 (0.46-0.54)	0.00

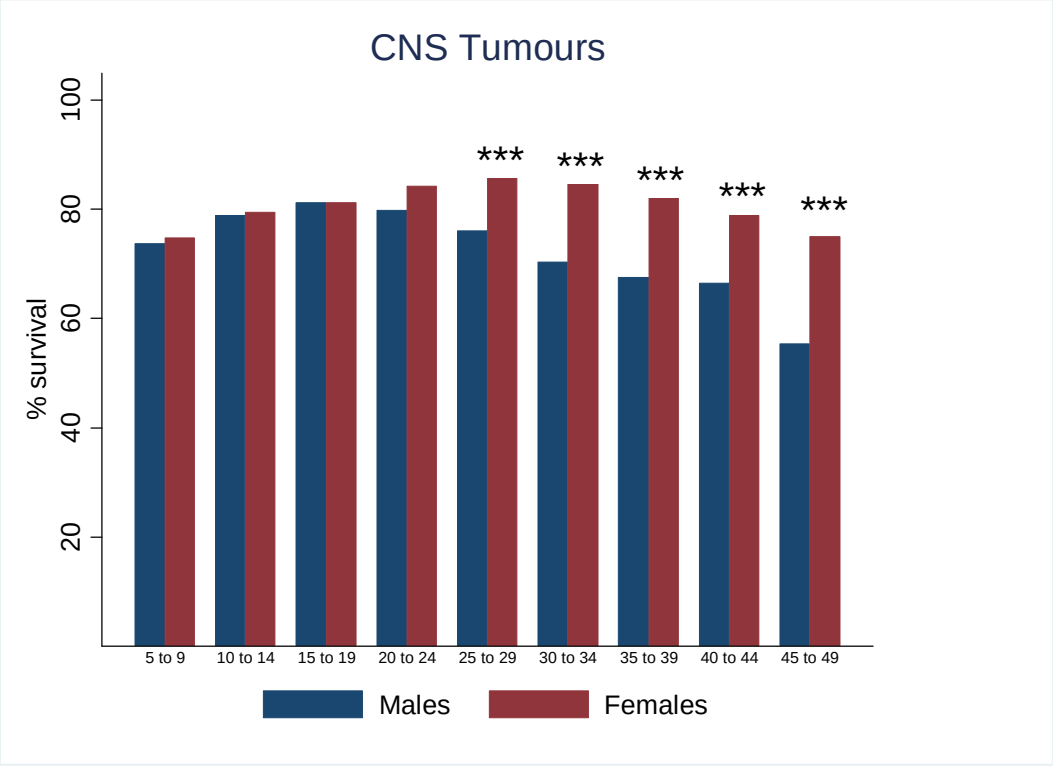

Figure 5.2: Five-year survival for those aged 0 to 49 years diagnosed with a CNS tumour in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: *Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001, No stars = no significant difference.

6) Bone tumours (Osseous and Chondromatous Neoplasms, Ewing tumour and other Neoplasms of Bone)

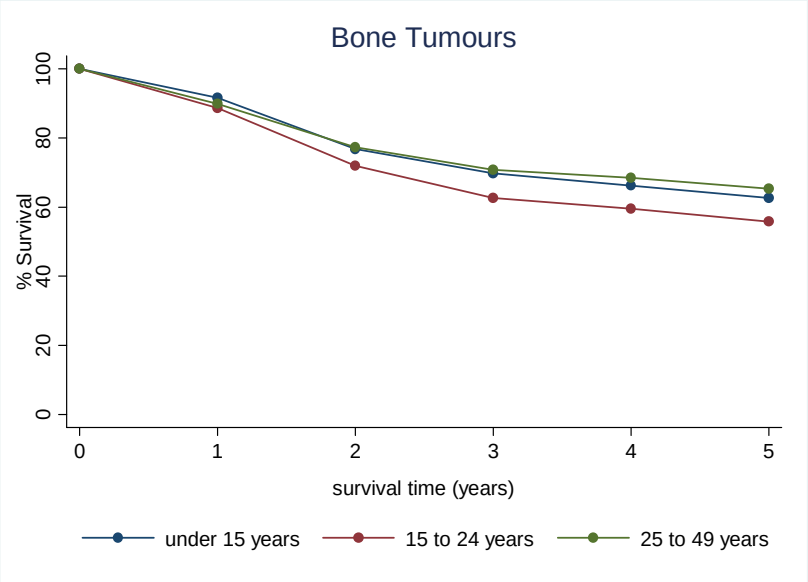

Figure 6.1: 0 to 5 year relative survival for patients diagnosed with a bone tumour in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with a bone tumour between 2001 and 2005, survival among TYA patients was significantly lower (56%) than that of both paediatric patients (63%) and the older age group (65%) (Table 6.1) - a difference that appears to start to arise between 1 and 2 years following diagnosis (Fig 6.1). No significant difference in survival was observed within the TYA age group itself (Table 6.1).

Table 6.1: Five-year survival for those diagnosed with a bone tumour in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	417	63	58	67	0.79 (0.64-0.97)	0.03
15 to 24 years	476	56	51	60	Ref	--
25 to 49 years	594	65	61	69	0.73 (0.60-0.89)	0.001
15 to 18 years	243	56	50	62	Ref	--
19 to 24 years	233	55	48	61	1.01 (0.77-1.33)	0.93

No significant differences were observed between males and females except within the older age group, aged 25 to 49 years (Table 6.2) where males had 9% lower 5-year survival than females. The only 5 year age band in which the difference between males and females was shown to be statistically significant was the 30 to 34 year age band (Fig 6.2).

Table 6.2: Five-year survival for those diagnosed with a bone tumour in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	207	66	59	72	Ref	--
	F	210	60	53	66	1.24 (0.90-1.69)	0.19
15 to 24 years	M	300	56	50	61	Ref	--
	F	176	56	48	63	1.03 (0.78-1.37)	0.83
25 to 49 years	M	349	62	56	66	Ref	--
	F	245	71	64	76	0.71 (0.53-0.94)	0.02

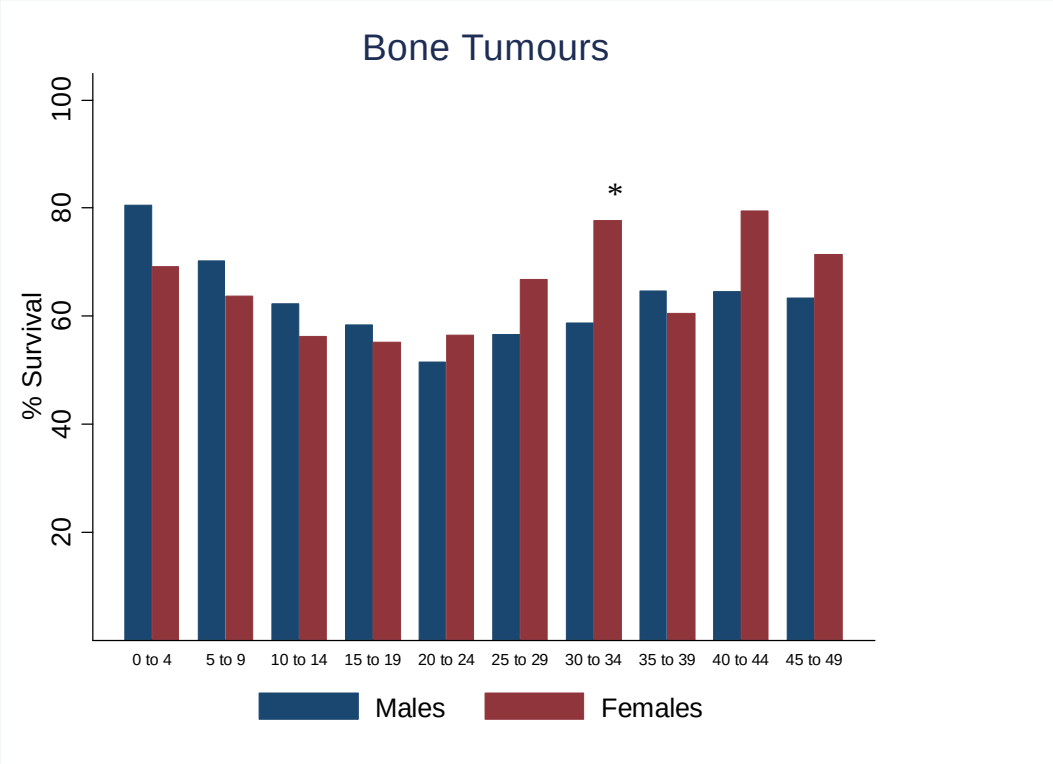

Figure 6.2: Five-year survival for those aged 0 to 49 years diagnosed with a bone tumour in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: *Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001, No stars = no significant difference.

7) Soft tissue sarcomas (STS)

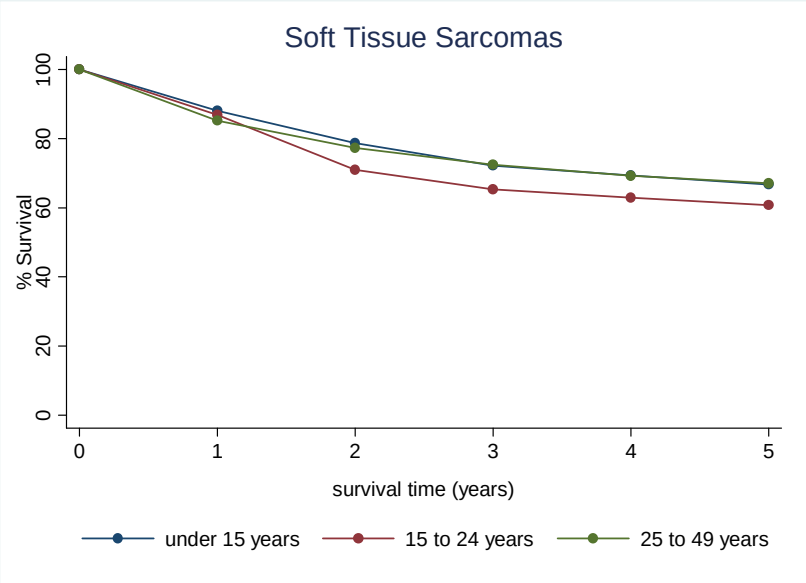

Figure 7.1: 0 to 5 year relative survival for patients diagnosed with STS in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with a STS between 2001 and 2005, we observed lower survival in the TYA age group than in both the paediatric and the older age group, that appears to arise between one and two years following diagnosis (Fig 7.1). Five-year survival for TYA patients was 6% lower at 61% than for paediatric patients and 25 to 49 year olds both which had 67% 5-year survival (Table 7.1). The 19 to 24 year olds also had higher 5-year survival at 64% than the 15 to 18 year olds (55%) although this did not reach statistical significance.

Table 7.1: Five-year survival for those diagnosed with STS in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	417	67	62	71	0.79 (0.62-0.99)	0.04
15 to 24 years	371	61	56	66	Ref	--
25 to 49 years	2581	67	65	69	0.79 (0.66-0.94)	0.009
15 to 18 years	141	55	47	63	Ref	--
19 to 24 years	230	64	57	70	0.75 (0.54-1.04)	0.09

Significant differences were observed between males and females within the TYA age group (Table 7.2) with females having higher 5-year survival rates (68%) than males (55%). These gender differences are particularly marked in the 20 to 24 year age group (Fig 7.2). Females also have better survival in some of the 5 year age bands under 15 years of age but these were not found to be statistically significant (Fig 7.2). No gender differences were evident for ages 25 to 49 years.

Table 7.2: Five-year survival for those diagnosed with STS in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	228	65	59	71	Ref	--
	F	189	69	62	75	0.87 (0.62-1.21)	0.41
15 to 24 years	M	207	55	48	61	Ref	--
	F	164	68	61	75	0.62 (0.44-0.87)	0.006
25 to 49 years	M	1362	67	65	70	Ref	--
	F	1219	67	64	69	1.01 (0.88-1.16)	0.85

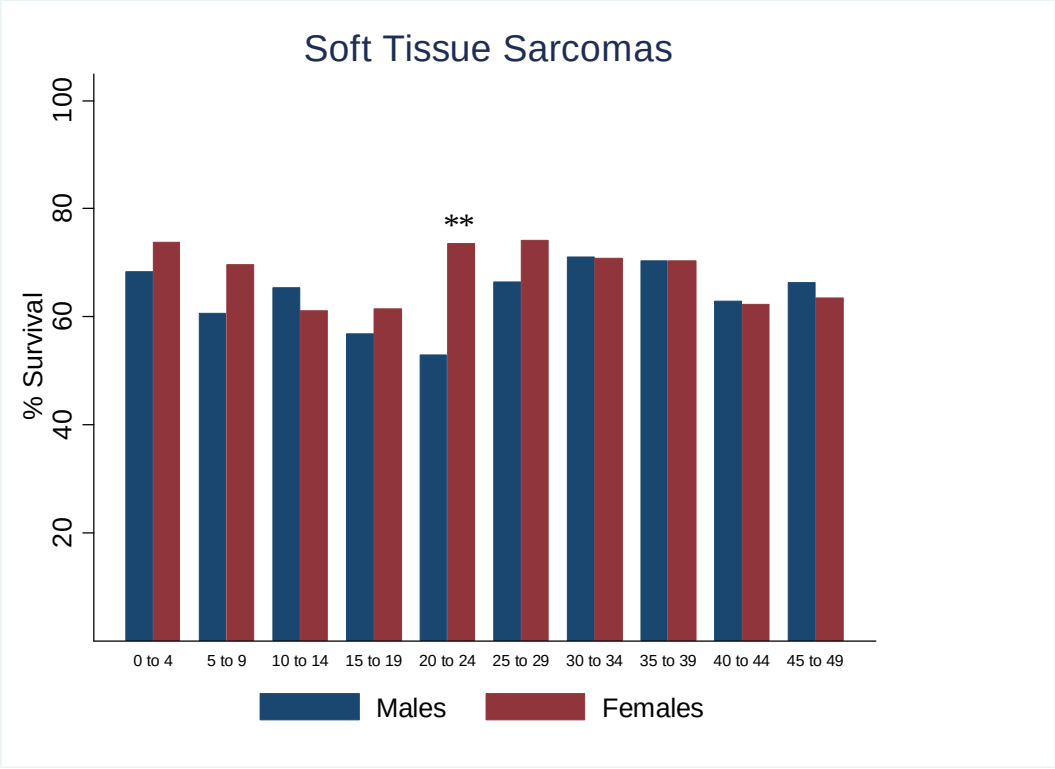

Figure 7.2: Five-year survival for those aged 0 to 49 years diagnosed with a STS in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: *Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001, No stars = no significant difference.

8) Germ Cell Tumours of the Ovary

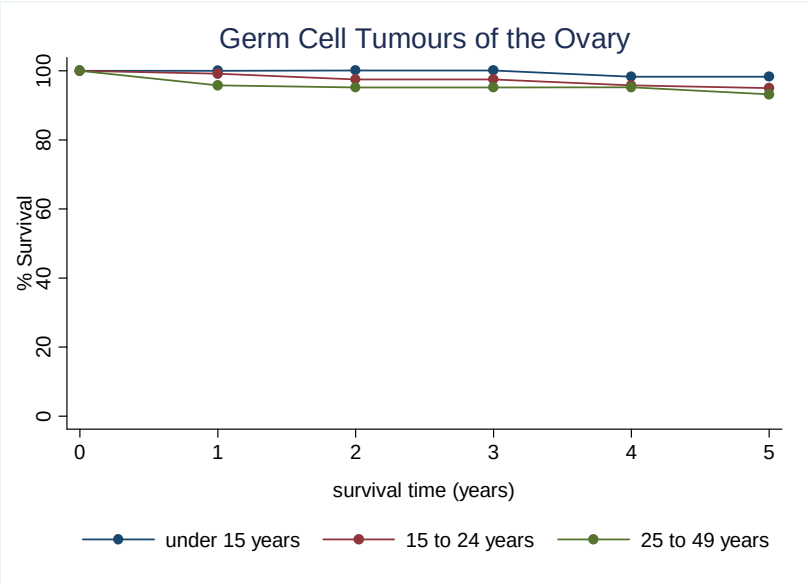

Figure 8.1: 0 to 5 year relative survival for patients diagnosed in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For female patients diagnosed with an ovarian germ cell tumour between 2001 and 2005, we observed no difference in survival between the TYA age groups and the younger or older age groups or within the TYA age group itself (Fig 8.1 and Table 8.1). It should be noted however that the number of cases within each of these age groups are small and particularly so in the 0 to 14 age group.

Table 8.1: Five-year survival for females diagnosed with an ovarian germ cell tumour in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	56	98	88	100	0.30 (0.03-3.38)	0.33
15 to 24 years	116	95	89	98	Ref	--
25 to 49 years	140	93	87	96	1.39 (0.49-3.93)	0.54
15 to 18 years	55	91	80	96	Ref	--
19 to 24 years	61	98	89	100	0.16 (0.016-1.62)	0.12

9) Germ Cell Tumours of the Testis

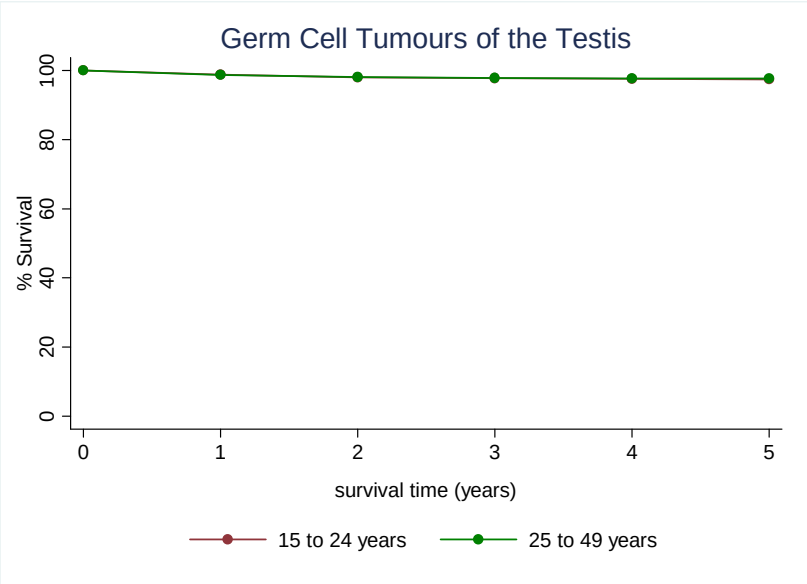

Figure 9.1: 0 to 5 year relative survival for male patients diagnosed in 2001-2005 with a testicular germ cell tumour in the UK at ages 15 to 24 and 25 to 49 years*. The number of cases of testicular germ cell tumours in the 0 to 14 age group is too small to include in these analyses.

For male patients diagnosed with a testicular germ cell tumour between 2001 and 2005, we observed no difference in survival between the TYA age groups and the older age groups or within the TYA age group itself (Fig 9.1 and Table 9.1).

Table 9.1: Five-year survival for males diagnosed with a testicular germ cell tumour in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	1260	97	96	98	Ref	--
25 to 49 years	7179	98	97	98	0.95 (0.63-1.41)	0.78
15 to 18 years	206	96	92	98	Ref	--
19 to 24 years	1054	98	97	99	0.55 (0.24-1.24)	0.15

10) Extra-gonadal Germ Cell Tumours

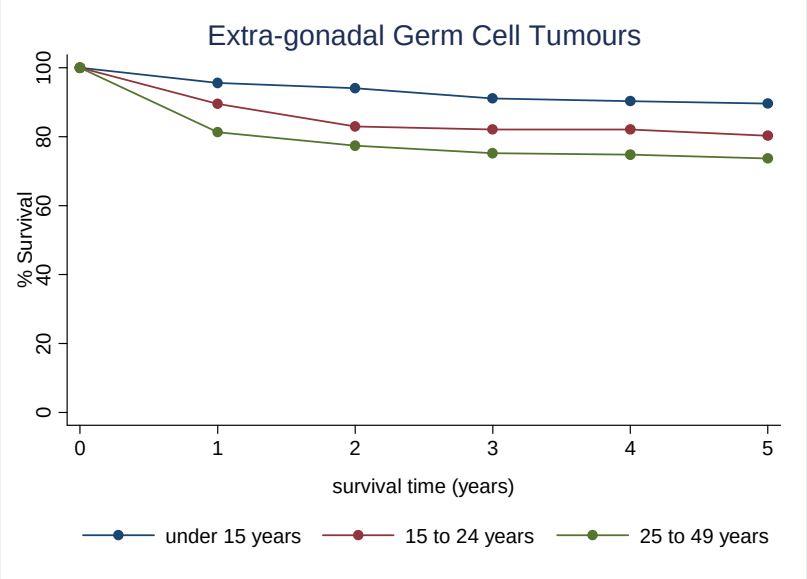

Figure 10.1: 0 to 5 year relative survival for patients diagnosed in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with an extra-gonadal germ cell tumour between 2001 and 2005, we observed decreasing survival with age within the first year after diagnosis (Fig 10.1) with the paediatric patients have significantly higher 5-year survival of 90% compared with the TYA age group (80%). TYA patients had higher survival that the 25 to 49 year olds (74%) but this difference was not statistically significant (Table 10.1).

Table 10.1: Five-year survival for those diagnosed with an extra-gonadal germ cell tumour in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	132	90	83	94	0.46 (0.23-0.94)	0.03
15 to 24 years	105	80	71	87	Ref	--
25 to 49 years	176	74	66	80	1.44 (0.86-2.43)	0.17
15 to 18 years	43	86	72	94	Ref	--
19 to 24 years	62	76	63	85	1.93 (0.74-5.04)	0.18

No significant differences were observed between males and females in the paediatric or TYA age groups (Table 10.2). However in the 25 to 49 age group, males appear to have significantly lower 5-year survival (65%) than females (88%). An examination of these differences by 5 year age band shows some gender differences to be evident in most age bands over 25 years of age as well as to some extent in the 15 to 19 age band (Fig 10.2). However the number of cases within each age band is too small to confirm the statistical significance of these differences - some differences may be due to chance.

Table 10.2: Five-year survival for those diagnosed with an extra-gonadal germ cell tumour in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	M	74	90	80	95	Ref	--
	F	58	91	79	96	0.93 (0.30-2.89)	0.90
15 to 24 years	M	88	80	70	87	Ref	--
	F	17	82	55	94	0.86 (0.25-2.95)	0.81
25 to 49 years	M	111	65	56	73	Ref	--
	F	65	88	77	94	0.27 (0.13-0.59)	0.001

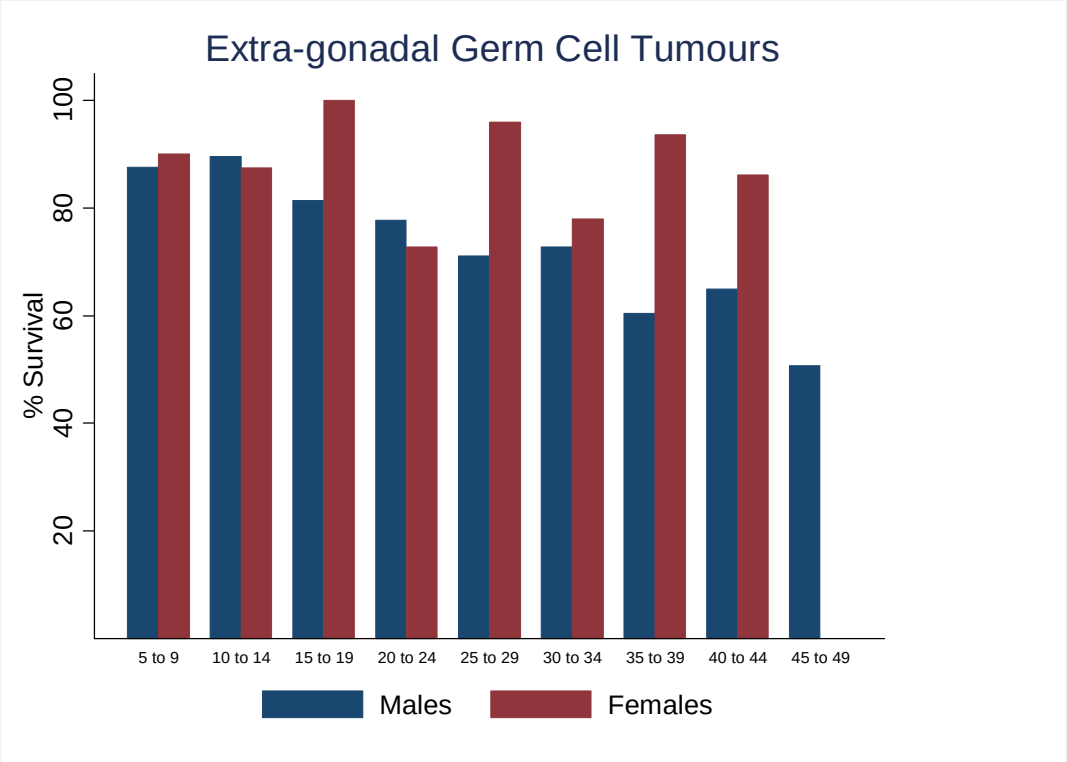

Figure 10.2: Five-year survival for those aged 0 to 49 years diagnosed with an extra-gonadal germ cell tumour in 2001-2005 by five-year age group and gender. The number of cases of extra-gonadal germ cell tumours is too small to allow robust statistical analyses of survival by gender and 5 year age band.

11) Melanoma of the Skin

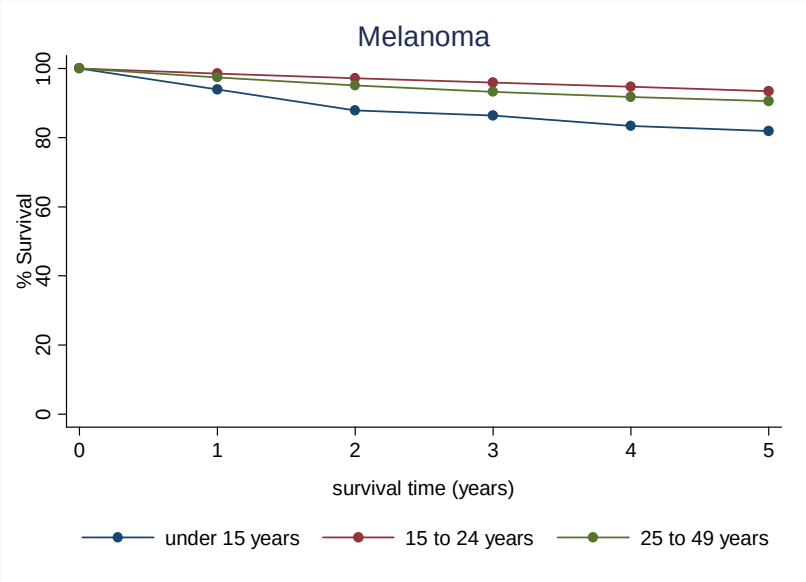

Figure 11.1: 0 to 5 year relative survival for patients diagnosed with skin melanoma in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with skin melanoma between 2001 and 2005 we observed higher survival among TYA patients than both paediatric patients aged 0 to 14 years and patients aged 25 to 49 years. These age related differences appear to begin to arise between and two years following diagnosis (Fig 11.1). Five-year relative survival for patients aged 15 to 24 years was 93% compared with 82% for those aged 0 to 14 years although it should be noted that the number of cases for the younger age group is very small (Table 11.1). The difference in 5-year survival between TYA and the older age group is smaller than between TYA and the paediatric age group but the difference is still statistically significant (Table 11.1). No difference was observed within the TYA age group itself.

Table 11.1: Five-year survival for those diagnosed with HL in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	66	82	70	89	2.99 (1.61-5.54)	0.001
15 to 24 years	1083	93	92	95	Ref	--
25 to 49 years	12598	90	90	91	1.49 (1.17-1.90)	0.001
15 to 18 years	184	93	88	96	Ref	--
19 to 24 years	899	94	92	95	0.94 (0.51-1.73)	0.84

Significant differences were observed between males and females across all age groups (Table 11.2 and Fig 11.2) (note: number of cases under the 15-years of age is too small for this analysis).

Table 11.2: Five-year survival for those diagnosed with skin melanoma in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	M	342	88	84	91	Ref	--
	F	741	96	94	97	0.30 (0.19-0.49)	0.000
25 to 49 years	M	4981	85	84	86	Ref	--
	F	7617	94	93	94	0.41 (0.36-0.46)	0.00

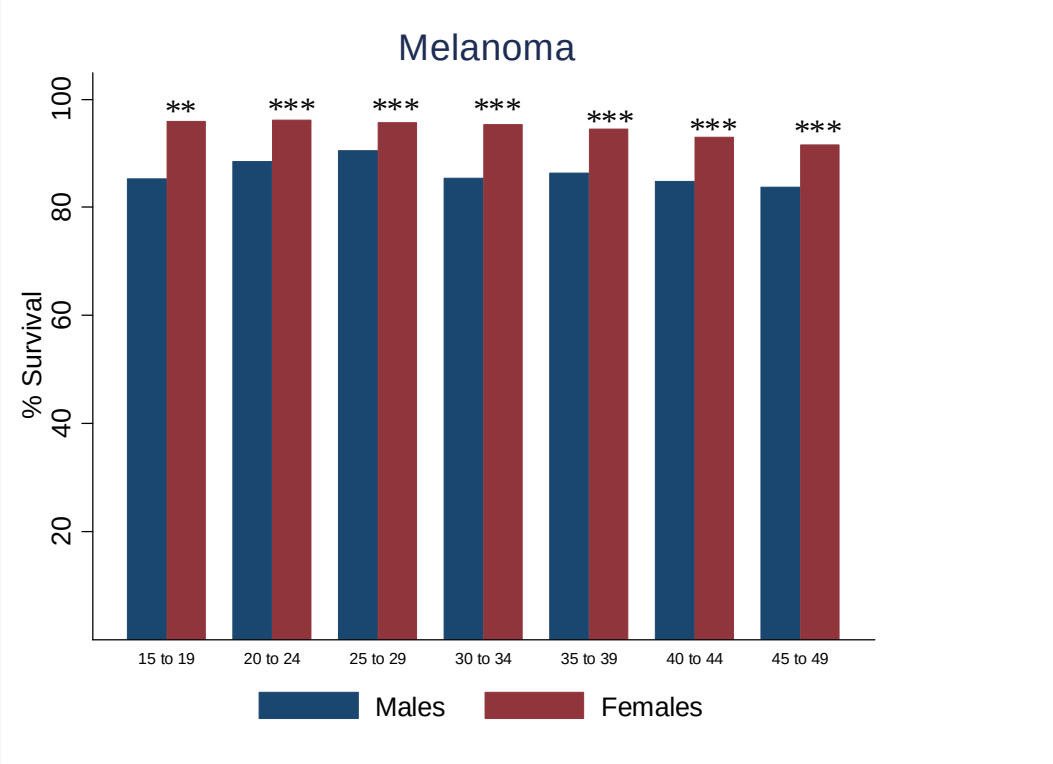

Figure 11.2: Five-year survival for those aged 0 to 49 years diagnosed with skin melanoma in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: *Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001, No stars = no significant differences. Number of cases in patients under 15 years of age is too small for inclusion here.

12) Carcinoma of the Thyroid

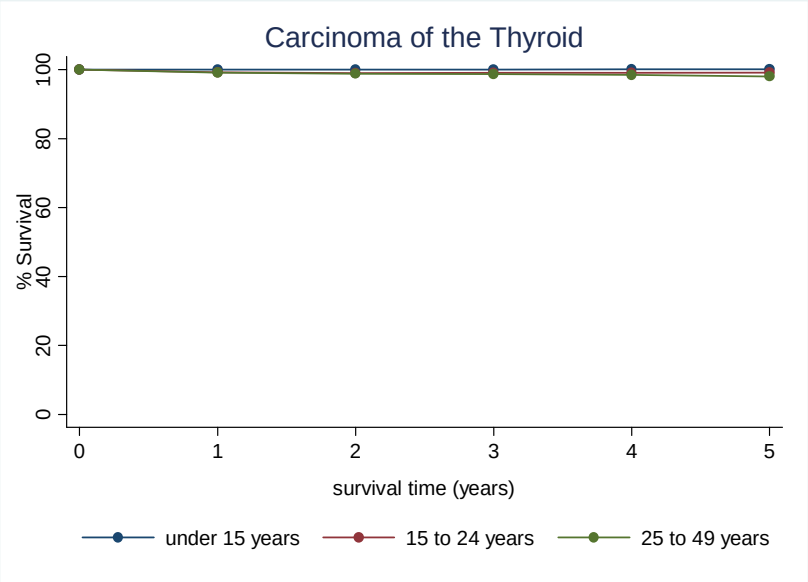

Figure 12.1: 0 to 5 year relative survival for patients diagnosed in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years.

For patients diagnosed with a thyroid carcinoma between 2001 and 2005, we observed no difference in survival between the TYA age groups and those aged 0 to 14 years or those aged 25 to 49 years (Fig 12.1) and no difference in 5-year survival within the TYA age group itself (Table 12.1); patients up to 49 years of age experienced an average of 98% survival at 5-years

Table 12.1: Five-year survival for those diagnosed with a thyroid carcinoma in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds*.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
0 to 14 years	60	100	100	100	--	--
15 to 24 years	381	99	97	100	Ref	--
25 to 49 years	3269	98	97	98	2.34 (0.71-1.76)	0.16
15 to 18 years	97	100	100	100	--	--
19 to 24 years	284	99	96	100	--	--

** Number of cases and deaths in the under 15-years and in the 15 to 18 year age group are too small to undertake EHR analysis for these age groups.*

No significant differences were observed between males and females in the TYA age group (Table 12.2) but were evident in the 25 to 49 year olds with females having slightly higher 5-year survival than males, particularly in the 35 to 44 year age groups (Fig 12.2).

Table 12.2: Five-year survival for those diagnosed with a thyroid carcinoma in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	M	74	98	90	100	Ref	--
	F	307	99	98	100	0.22 (0.02-2.23)	0.20
25 to 49 years	M	722	95	93	97	Ref	--
	F	2547	99	98	99	0.9 (0.84-0.97)	0.003

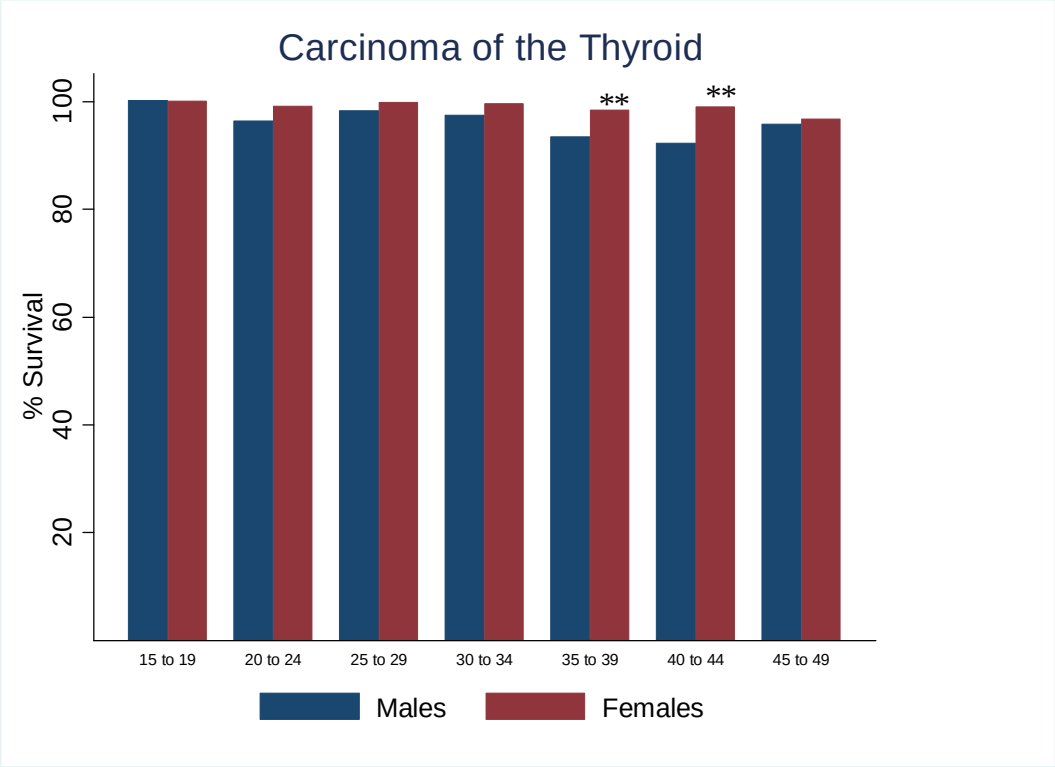

Figure 12.2: Five-year survival for those aged 0 to 49 years diagnosed with a thyroid carcinoma in 2001-2005 by five year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: * Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001. No stars = no significant difference. Number of cases in patients under 15-years of age is too small for inclusion here.

13) Carcinoma of the Breast (females)

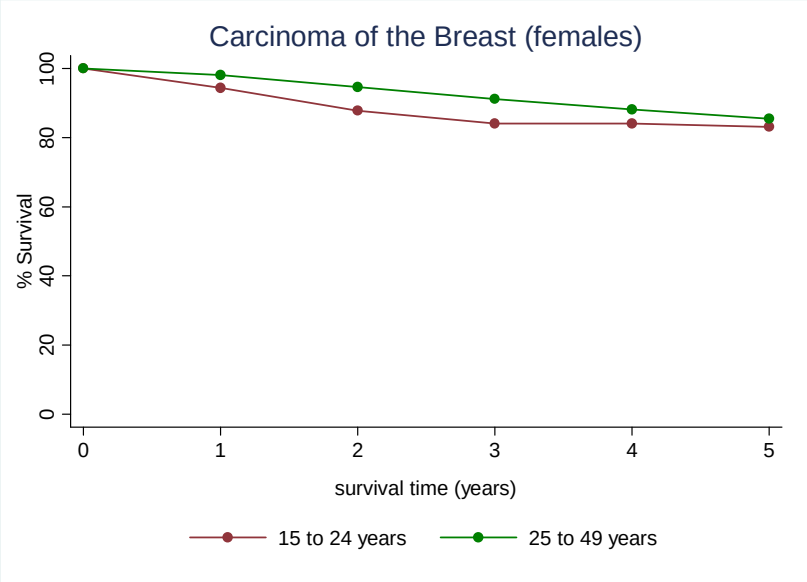

Figure 13.1: 0 to 5 year relative survival for patients diagnosed with breast carcinoma in 2001-2005 in the UK at ages 15 to 24 and 25 to 49 years. Number of cases in the under 15-years age group is too small to be included.

For females diagnosed with a breast carcinoma between 2001 and 2005, we observed no difference in survival between the TYA age groups and the 25 to 49 year olds (Fig 13.1 and Table 13.1)

Table 13.1: Five-year survival for those diagnosed with HL in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the older age group*

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	106	83	75	89	Ref	--
25 to 49 years	40219	85	85	86	0.83 (0.52-1.32)	0.420

**Number of cases within the 15 to 18 year age group is too small to include as comparison with the 19 to 24 age group.*

14) Carcinoma of the Ovary

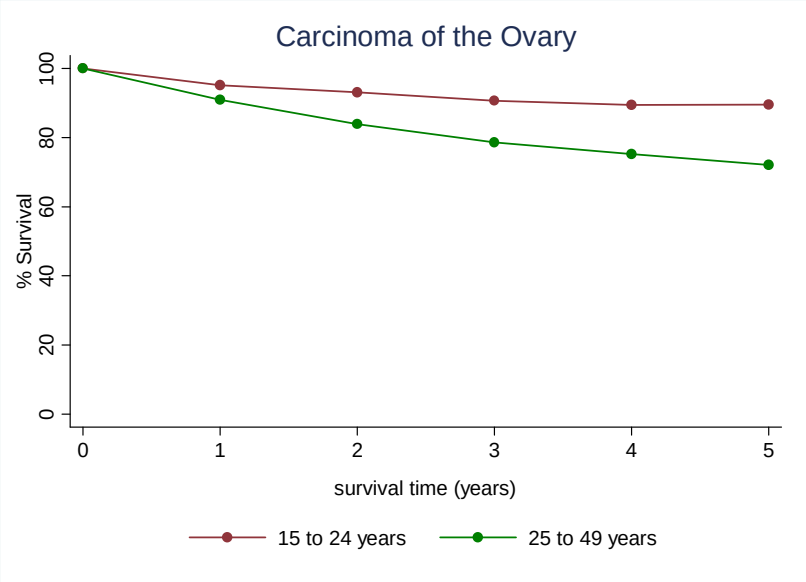

Figure 14.1: 0 to 5 year relative survival for patients diagnosed in 2001-2005 in the UK at ages 15 to 24 and 25 to 49 years. The number of cases in the under 15 years age group is too small to be included.

For patients diagnosed with carcinoma of the ovary between 2001 and 2005, we observed higher survival among the TYA age group than among the 25 to 49 year olds that appears to start to arise from one year following diagnosis (Fig 14.1). Five-year survival among the 15 to 24 year olds was 18% higher than for the older age group (Table 14.1) although the number of cases in this age group is considerably lower than in the older age group. No difference in 5-year survival was evident within the TYA age group itself (Table 14.1).

Table 14.1: Five-year survival for females diagnosed with a carcinoma of the ovary in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	245	90	85	93	Ref	--
25 to 49 years	4402	72	71	73	2.98 (2.01-4.41)	0.000
15 to 18 years	50	92	80	97	Ref	--
19 to 24 years	195	89	83	93	1.46 (0.49-4.28)	0.5

15) Carcinoma of the Uterine Cervix

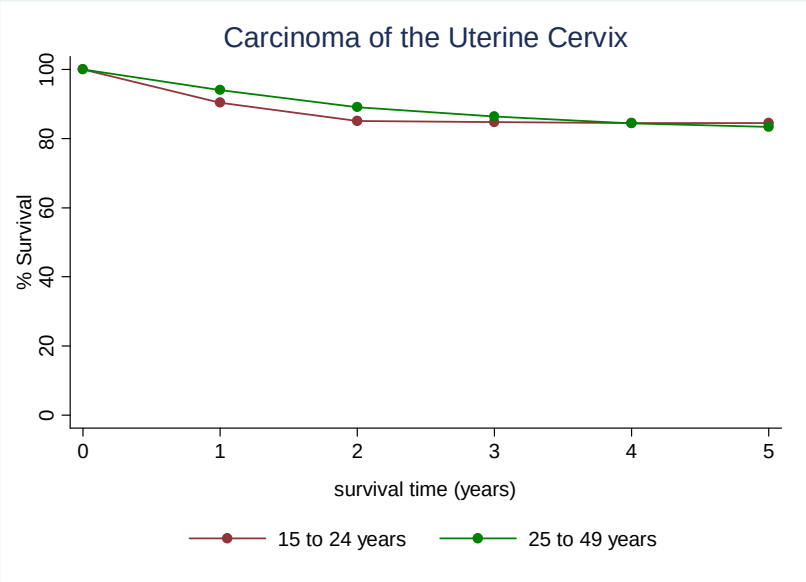

Figure 15.1: 0 to 5 year relative survival for patients diagnosed with carcinoma of the cervix in 2001-2005 in the UK at ages 15 to 24 and 25 to 49 years. Number of cases in the under 15 years age group are too small to be included.

For females diagnosed with carcinoma of the cervix between 2001 and 2005, we observed no difference in survival between the TYA age groups and the 25 to 49 year olds (Fig 15.1 and Table 15.1).

Table 15.1: Five-year survival for females diagnosed with carcinoma of the cervix in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the older age groups*.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	301	85	80	88	Ref	--
25 to 49 years	7405	83	82	84	1.06 (0.79-1.42)	0.690

**Number of cases within the 15 to 18 year age group is too small to include as comparison with the 19 to 24 age group.*

16) Carcinoma of the Colon or Rectum

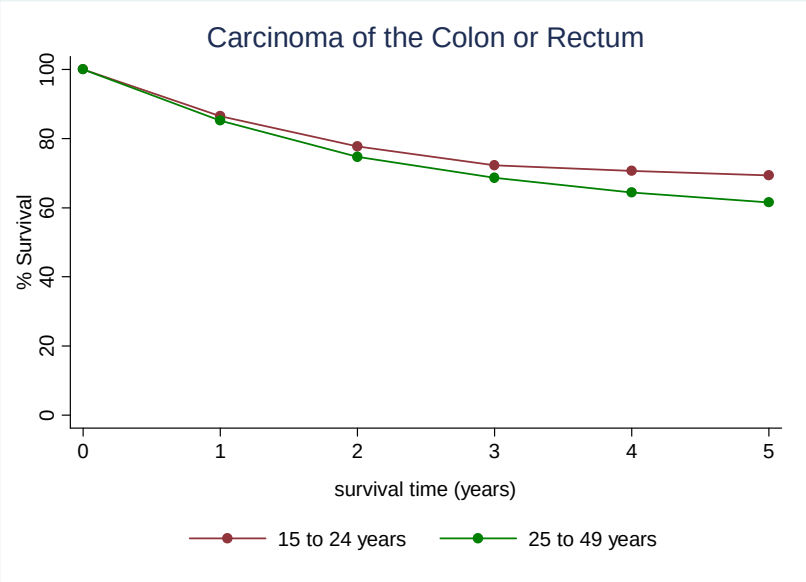

Figure 16.1: 0 to 5-year relative survival for patients diagnosed in 2001-2005 in the UK at ages 15 to 24 and 25 to 49 years. The number of cases in the under 15-years age group are too small to be included.

For patients diagnosed with colorectal carcinoma between 2001 and 2005, we observed higher survival among the TYA age group than for the 25 to 49 year olds (Fig 16.1), however the number of cases among the 15 to 24 year olds is much smaller than among the older age groups (Table 16.1). We also observed lower 5-year survival among the 19 to 24 year olds than the 15 to 18 year olds within the TYA age group itself. Again, however, it should be noted that these differences are based on very small number of cases and may be due to chance – these results should be interpreted with caution.

Table 16.1: Five-year survival for those diagnosed with colorectal carcinoma in 2001-2005 by age group, comparing 5-year survival among 15 to 24 year olds with the younger and older age groups and comparing 15 to 18 year olds with 19 to 24 year olds.

age group	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	237	69	63	75	Ref	--
25 to 49 years	8295	61	60	62	1.33 (1.05-1.67)	0.018
15 to 18 years	39	85	69	93	Ref	--
19 to 24 years	198	66	59	72	2.64 (1.14-6.12)	0.02

Males in the 15 to 24 year age group were observed to have 11% lower 5-year survival than their female counterparts but this did not reach statistical significance (Table 16.2). Gender differences were, however, statistically significant in the 25 to 49 year age group particularly in the 25 to 29 and the 45 to 49 year age groups (Fig 16.2).

Table 16.2: Five-year survival for those diagnosed with colorectal carcinoma in 2001-2005, comparing 5-year survival for males with survival for females for each age group.

age group	sex	n	relsurv	LCL	UCL	EHR (CIs)	P
15 to 24 years	M	122	64	55	72	Ref	--
	F	115	75	66	82	0.71 (0.04-12.55)	0.82
25 to 49 years	M	4312	60	59	62	Ref	--
	F	3983	63	61	64	0.91 (0.85-0.98)	0.008

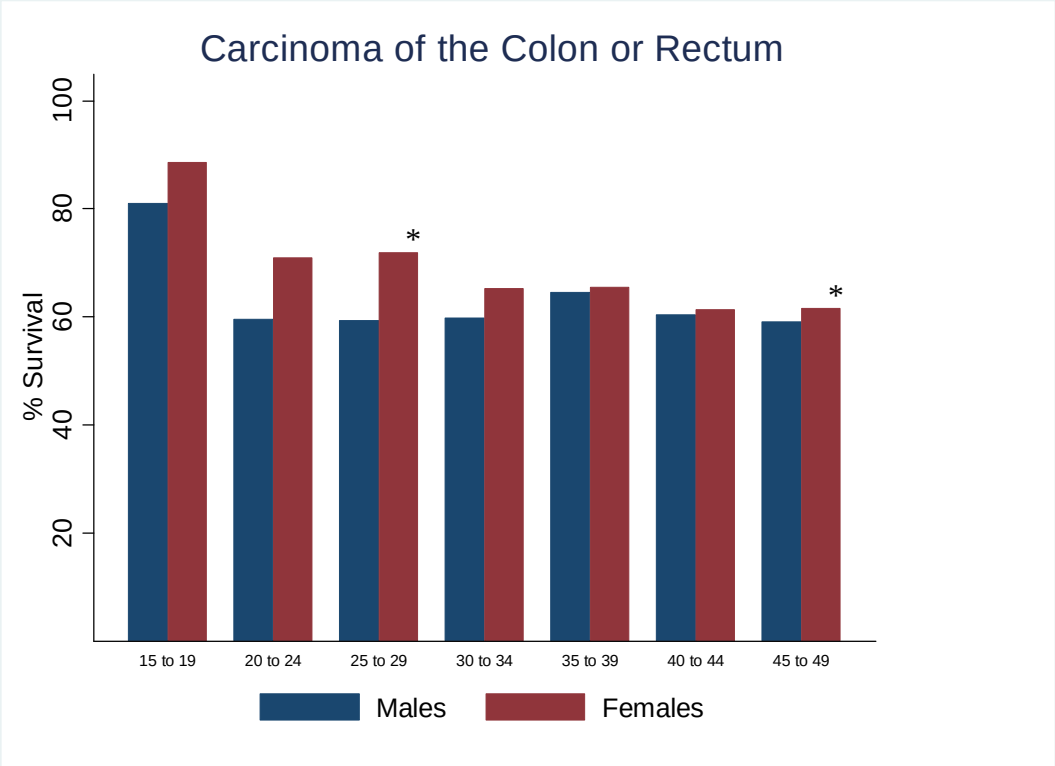

Figure 16.2: Five-year survival for those aged 0 to 49 years diagnosed with colorectal carcinoma in 2001-2005 by five-year age group and gender. Significant differences in 5-year survival between males and females for each age band are indicated by stars above each bar: * Significant at P< 0.05, **Significant at P< 0.01, ***Significant at P< 0.001. No stars = no significant difference. Number of cases in patients under 15 years of age is too small for inclusion here.

Discussion

The pattern of five-year survival rates between 0-14, 15-24 and 25-49 age groups in the UK varied markedly by type of cancer. For patients with acute leukaemia survival decreased with increasing age. For those with STS and bone tumours survival was worse for TYA patients than for either children or the 25-49 age group, while TYA patients with CNS tumours had the best survival. In those aged 19-24 years survival was significantly better for females than males for STS and melanoma.

Caution needs to be taken in interpreting these results. Several of the diagnostic categories used, such as CNS, bone, STS and even NHL, are not single clinical entities but include different cancers with varying prognosis. Ovarian cancers are classified as either germ cell tumours or carcinomas based on the morphology codes recorded either by the pathology laboratory or during the cancer registration process. As such, there may be some variation in the usage of these morphology codes between regions and further work is needed to determine the level of consistency in the allocation of these morphology codes and the subsequent classification of ovarian cancers. Until that time, the results for these groups should be taken as provisional. Furthermore, many of the findings are based on relatively small number of cases and small numbers 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 9% 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. Examples include the 3% and 2% differences in survival between TYA and older adults for HL and melanoma respectively. 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.

Gatta *et al* (2009) reported that five-year relative survival rates for patients with ALL were lower in 15-24 year olds than in 0-14 year olds in the UK and Ireland, and in the rest of Europe for those diagnosed in 1995-99. Analyses based on the SEER database (which covers a proportion of the US population) for 1975-2000 reported lower survival in 15-29 year olds compared with the 0-14 age group for patients with soft tissue rhabdomyosarcomas and embryonal tumours (Bleyer *et al* 2006). They also showed that though survival for all bone sarcomas was similar across 0-14, 15-29 and 30-44 age groups, patients aged 30-44 years with osteosarcoma did better than the 15-29 age group. Birch *et al* (2008) presented survival rates in England for 13-24 year olds diagnosed in 1979-2003 and reported higher survival rates in females for STS and melanoma; the SEER publication showed the same pattern for melanoma.

Possible explanations for these findings include variation by age or gender in

(a) Tumour biology
(b) Different treatment approaches
(c) Patients' response to therapy
(d) Patients' behaviour in seeking medical advice and in adhering to treatment
(e) Relative proportions of different types of tumour within a diagnostic group
(f) Effectiveness of services

Some of these explanations are more plausible for some types of cancer than others and for age rather than gender differences. For example, it is more likely that the effectiveness of services varies by age group than by gender.

The large decrease with age in five-year survival rates for patients with ALL is reflected in a large drop in survival within the first year following diagnosis. A similar finding for the more common cancers of older adult life would suggest that delay in diagnosis and treatment is a major problem. With ALL other explanations such as deaths due to the complications of treatment need to be explored. A small group organised by NWCIS is examining the pattern of deaths in the first year following diagnosis in 0-14, 15-18, 19-24 and 25-49 year olds. One possible explanation for the poor outcomes in TYA patients for bone and STS is that the types of STS or bone tumours with a poorer prognosis are relatively more common in the 15-24 age group. Further analyses are being undertaken to test this explanation.

The better survival in females is much more marked in 19-24 year olds than in those aged 15-18, suggesting a specific problem with males in the older TYA age group. Females had better survival than males for melanoma for all age groups up to 50 years. For STS, females had better survival in the 19-24 and 25-29 age group but after this the gap disappeared. A similar pattern was seen in colorectal cancer, though the differences by gender were not statistically significant. It is possible that males in their 20s may be less likely to attend their GP with certain symptoms without the prompting of a mother or partner. They also come into contact with health services for other reasons less commonly than do females in this age group. Work is underway using existing datasets to compare, by gender, the time from first symptom to diagnosis and treatment, and the number of GP visits prior to diagnosis. Survival rates for males and females will be compared for the most common types of STS, as will differences by gender in the proportions each type contributes to the total number of STS. Similar analyses are being undertaken on CNS cancers to explain the better survival in females from age 25 years upwards.

One important factor in any assessment of outcomes that we have been unable to address is stage of disease at diagnosis. This is largely due to the incompleteness of staging information currently

available for the patients included in this report. The cancer registry community is working hard with their data providers to improve the capture of stage data as part of the transition to the new national cancer registration system (ENCORE) this year and we hope to be able to incorporate this vital aspect of survival analyses into our work in the near future.

Though the results in this report require careful interpretation, the fact that most of our main findings have been replicated for earlier periods in England or in other countries supports the view that they reflect true and important differences in the real world. This report and the planned papers in peer-reviewed journals should highlight where outcomes in TYA patients are most in need of improvement. NWCIS is working with clinicians and epidemiologists to understand these differences. However, a much wider response is required with research into how the biology of tumours, patient behaviour in seeking care and adhering to treatment, management of patients and delivery of services vary by age and gender.

Acknowledgments

Much appreciation is extended to NWCIS' Research and Intelligence Team for help in putting the report together, in particular to Sabrina Sandhu and Busani Ndlela who have made a significant contribution to the report. We are also grateful to Jill Birch and Robert Alston (CRUK Paediatric and Familial Cancer Research Group) for sharing their expertise and classification system with us. Thanks are also due to members of the NCIN children's, teenagers and young adults clinical reference group (CTYA CRG), in particular to the Chair, Mike Stevens, for their helpful comments on the report. Also to the NCIN analysis team for their review of the report and assistance with publication. Finally, we gratefully acknowledge the support of the Teenage Cancer Trust (TCT) and TYAC for supporting NWCIS in their work on cancer in teenagers and young adults.

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Appendix

Table A.1: 0 to 5-year survival for patients diagnosed in 2001-2005 in the UK at ages 0 to 14, 15 to 24 and 25 to 49 years by diagnosis and year of follow-up

diagnosis	years of follow-up	0 to 14 years % survival	0 to 14 years LCL	0 to 14 years UCL	15 to 24 years % survival	15 to 24 years LCL	15 to 24 years UCL	25 to 49 years % survival	25 to 49 years LCL	25 to 49 years UCL
ALL	1	96	95	96	85	81	88	64	59	68
	2	93	92	94	72	68	77	50	45	55
	3	92	90	93	67	62	71	46	41	50
	4	90	89	92	64	59	68	42	37	46
	5	89	87	90	61	56	66	38	34	43
AML	1	85	81	89	80	75	84	73	70	75
	2	73	68	77	65	59	71	61	58	64
	3	68	63	73	60	54	66	55	52	57
	4	67	62	72	58	52	64	53	50	56
	5	66	61	71	57	51	62	51	48	54
NHL	1	89	85	91	87	84	89	89	88	89
	2	86	82	89	81	78	84	84	83	85
	3	85	81	88	80	77	83	82	81	83
	4	85	81	88	79	75	82	81	80	82
	5	85	81	88	78	74	81	79	78	80
HL	1	99	97	99	99	98	99	97	97	98
	2	97	95	99	97	95	97	95	95	96
	3	96	94	98	96	94	97	93	92	94
	4	96	93	97	95	93	96	92	91	93
	5	95	92	97	94	93	95	91	90	92
CNS	1	87	85	88	93	92	94	87	86	88
	2	80	78	81	88	86	89	80	79	81
	3	77	75	79	85	83	87	77	76	78
	4	76	74	78	83	81	85	75	74	76
	5	75	73	76	82	79	84	73	72	74
Bone	1	92	89	94	89	85	91	90	87	92
	2	77	72	81	72	68	76	77	74	81
	3	70	65	74	63	58	67	71	67	74
	4	66	61	71	60	55	64	68	64	72
	5	63	58	67	56	51	60	65	61	69
STS	1	88	85	91	87	83	90	85	84	87
	2	79	74	82	71	66	75	77	76	79
	3	72	68	76	65	60	70	72	71	74
	4	69	65	74	63	58	68	69	67	71
	5	67	62	71	61	56	66	67	65	69
Ovarian Germ Cell	1	100	100	100	99	94	100	96	91	98
	2	100	100	100	97	92	99	95	90	98
	3	100	100	100	97	92	99	95	90	98
	4	98	88	100	96	90	98	95	90	98
	5	98	88	100	95	89	98	93	87	96
Testicular Germ Cell	1				99	98	99	99	98	99
	2				98	97	99	98	98	98
	3				98	97	98	98	97	98
	4				98	97	98	98	97	98
	5				97	96	98	98	97	98
Extra-gonadal Germ Cell	1	96	90	98	90	82	94	81	75	86
	2	94	88	97	83	74	89	77	70	83
	3	91	85	95	82	73	88	75	68	81
	4	90	84	94	82	73	88	75	68	81
	5	90	83	94	80	71	87	74	66	80
Melanoma	1	94	85	98	99	98	99	97	97	98
	2	88	77	94	97	96	98	95	95	95
	3	86	75	93	96	95	97	93	93	94
	4	83	72	90	95	93	96	92	91	92
	5	82	70	89	93	92	95	91	90	91
Thyroid carcinoma	1				99	98	100	99	99	99
	2				99	97	100	99	98	99
	3				99	97	100	99	98	99
	4				99	97	100	98	98	99
	5				99	97	100	98	97	99
Breast carcinoma	1				94	88	97	98	98	98
	2				88	80	93	95	94	95
	3				84	76	90	91	91	91
	4				84	76	90	88	88	88
	5				83	75	89	85	85	86
Ovarian carcinoma	1				95	92	97	91	90	92
	2				93	89	96	84	83	85
	3				91	86	94	79	77	80
	4				89	85	93	75	74	76
	5				90	85	93	72	71	73
Cervical carcinoma	1				90	86	93	94	94	95
	2				85	81	89	89	88	90
	3				85	80	88	86	86	87
	4				84	80	88	84	84	85
	5				85	80	88	83	82	84
Colorectal carcinoma	1				87	81	90	85	84	86
	2				78	72	83	75	74	76
	3				72	66	78	69	68	70
	4				71	64	76	64	63	65
	5				69	63	75	62	60	63

Table A.2: 5-year survival for patients diagnosed in 2001-2005 in the UK by diagnosis, gender and 5 year age band

		MALES				FEMALES				PERSONS			
5 year survival	agegroup	N	% survival	LCL	UCL	N	% survival	LCL	UCL	N	% survival	LCL	UCL
ALL	0	544	92	89	94	449	91	88	93	993	91	89	93
	5	319	90	86	93	246	90	85	93	565	90	87	92
	10	201	76	69	81	156	89	82	93	357	81	77	85
	15	166	65	57	72	88	65	54	74	254	65	59	71
	20	85	52	41	62	44	57	41	70	129	54	45	62
	25	43	51	36	65	42	43	28	57	85	47	36	57
	30	44	39	25	53	33	43	26	58	77	40	29	51
	35	60	37	25	49	38	34	20	49	98	36	27	45
	40	47	32	19	46	51	36	23	49	98	34	25	43
	45	50	32	20	46	36	39	24	55	86	35	25	46
AML	0	80	68	57	77	79	63	51	72	159	65	57	72
	5	40	68	51	80	33	82	64	91	73	74	62	83
	10	64	69	56	79	53	55	40	67	117	62	53	71
	15	63	60	47	71	57	54	41	66	120	58	48	66
	20	86	56	45	66	71	56	44	67	157	56	48	64
	25	76	48	36	58	98	66	56	75	174	58	50	65
	30	100	53	43	63	85	68	57	77	185	60	53	67
	35	144	45	37	53	139	45	36	53	283	45	39	51
	40	171	43	36	50	159	50	42	57	330	46	41	52
	45	188	53	46	60	173	50	42	57	361	52	46	57
NHL	0	62	81	69	89	31	71	52	84	93	78	68	85
	5	107	89	81	94	28	93	74	98	135	90	83	94
	10	128	87	80	92	61	80	68	88	189	85	79	89
	15	182	83	76	87	102	81	72	88	284	82	77	86
	20	203	72	65	78	132	77	69	84	335	74	69	79
	25	256	82	76	86	182	79	72	84	438	80	76	84
	30	474	78	74	81	323	81	76	85	797	79	76	82
	35	699	79	75	82	478	83	79	86	1177	81	78	83
	40	930	79	76	81	661	79	75	82	1591	79	76	81
	45	1144	78	75	80	846	81	78	84	1990	79	78	81
HL	0												
	5	72	96	88	99	21	91	67	98	93	95	88	98
	10	139	96	91	98	125	94	88	97	264	95	91	97
	15	295	93	89	95	295	93	89	95	590	93	90	95
	20	399	94	91	96	356	96	93	98	755	95	93	96
	25	365	95	92	97	325	94	90	96	690	94	92	96
	30	386	91	87	93	315	90	86	93	701	90	88	92
	35	395	91	87	93	236	92	87	95	631	91	89	93
	40	327	92	88	95	183	89	83	93	510	91	88	93
	45	297	88	84	92	144	88	82	93	441	88	85	91

		MALES				FEMALES				PERSONS			
5 year survival	agegroup	N	% survival	LCL	UCL	N	% survival	LCL	UCL	N	% survival	LCL	UCL
CNS	0	371	69	64	74	303	73	67	77	674	71	67	74
	5	372	74	69	78	289	75	69	79	661	74	71	77
	10	354	79	74	83	291	79	74	84	645	79	76	82
	15	315	81	76	85	264	81	76	85	579	81	78	84
	20	326	80	75	84	340	84	80	88	666	82	79	85
	25	457	76	72	80	482	86	83	89	939	81	78	84
	30	727	70	67	74	694	85	82	87	1421	77	75	80
	35	938	67	64	70	940	82	80	85	1878	75	73	77
	40	1092	66	63	69	1097	79	76	81	2189	73	71	74
	45	1279	55	53	58	1229	75	72	77	2508	65	63	67
Bone	0	15	81	50	94	16	69	41	86	31	74	55	86
	5	57	70	57	80	66	64	51	74	123	67	58	74
	10	135	62	54	70	128	56	47	64	263	59	53	65
	15	187	58	51	65	98	55	45	64	285	57	51	63
	20	113	52	42	60	78	56	45	67	191	54	46	60
	25	71	57	44	67	42	67	50	79	113	60	51	69
	30	65	59	46	70	49	78	63	87	114	67	57	75
	35	56	65	51	76	58	61	47	72	114	63	53	71
	40	72	65	52	75	38	79	63	89	110	70	60	78
	45	85	63	52	73	58	71	58	81	143	67	58	74
STS	0	90	68	57	77	79	74	63	82	169	71	63	77
	5	66	61	48	71	56	70	56	80	122	65	56	73
	10	72	65	53	75	54	61	47	73	126	64	55	71
	15	97	57	46	66	70	61	49	72	167	59	51	66
	20	110	53	43	62	94	74	63	81	204	62	55	69
	25	136	66	58	74	127	74	66	81	263	70	64	75
	30	242	71	65	76	167	71	63	77	409	71	66	75
	35	329	70	65	75	241	70	64	76	570	70	66	74
	40	315	63	57	68	297	62	57	68	612	63	59	66
	45	340	66	61	71	387	63	58	68	727	65	61	68
Ovarian germ cell	0												
	5												
	10					35	97	81	100	35	97	81	100
	15					67	93	83	97	67	93	83	97
	20					49	98	87	100	49	98	87	100
	25					43	98	85	100	43	98	85	100
	30					46	98	86	100	46	98	86	100
	35					29	90	72	97	29	90	72	97
	40					13	70	38	88	13	70	38	88
	45					9	90	44	99	9	90	44	99

		MALES				FEMALES				PERSONS			
5 year survival	agegroup	N	% survival	LCL	UCL	N	% survival	LCL	UCL	N	% survival	LCL	UCL
Testicular germ cell	0												
	10												
	15	324	97	94	98					324	97	94	98
	20	936	98	96	99					936	98	96	99
	25	1462	98	97	99					1462	98	97	99
	30	1757	98	97	98					1757	98	97	98
	35	1729	98	97	99					1729	98	97	99
	40	1407	97	96	98					1407	97	96	98
	45	824	96	94	98					824	96	95	98
Extra-gonadal germ cell	0	18	90	63	99	40	91	77	97	58	90	79	96
	5												
	10	48	90	77	96	8	88	39	98	56	89	78	95
	15	48	81	67	90	6	100	100	100	54	84	71	91
	20	40	78	61	88	11	73	37	90	51	77	62	86
	25	24	71	49	85	24	96	74	100	48	84	70	92
	30	29	73	53	86	18	78	51	91	47	75	60	85
	35	30	60	41	75	15	94	61	99	45	72	56	83
	40												
	45												
Melanoma	0												
	5												
	10												
	15	80	85	75	91	191	96	92	98	271	93	89	95
	20	262	88	84	92	550	96	94	97	812	94	92	95
	25	434	90	87	93	920	96	94	97	1354	94	93	95
	30	768	85	83	88	1378	95	94	96	2146	92	91	93
	35	1025	86	84	88	1666	95	93	96	2691	91	90	93
	40	1328	85	83	87	1783	93	92	94	3111	90	88	91
	45	1426	84	82	86	1870	92	90	93	3296	88	87	89
Thyroid carcinoma	0												
	5												
	10												
	15	23	100	100	100	112	100	100	100	135	100	100	100
	20	51	96	86	99	195	99	96	100	246	99	96	100
	25	96	98	92	100	366	100	98	100	462	100	98	100
	30	136	98	93	99	548	100	99	100	684	99	98	100
	35	169	94	88	97	590	98	97	99	759	97	96	98
	40	162	92	87	96	539	99	98	100	701	98	96	99
	45	159	96	91	99	504	97	95	98	663	97	95	98

		MALES				FEMALES				PERSONS			
5 year survival	agegroup	N	% survival	LCL	UCL	N	% survival	LCL	UCL	N	% survival	LCL	UCL
Breast carcinoma	15												
	20					100	83	74	89	100	83	74	89
	25					683	77	73	80	683	77	73	80
	30					2821	79	77	80	2821	79	77	80
	35					7122	82	81	83	7122	82	81	83
	40					12527	86	86	87	12527	86	86	87
	45					16958	87	87	88	16958	88	87	88
Ovarian carcinoma	10												
	15					79	91	82	96	79	91	82	96
	20					166	89	83	93	166	89	83	93
	25					297	90	86	93	297	90	86	93
	30					508	84	81	87	508	84	81	87
	35					773	81	78	84	773	81	78	84
	40					1121	72	69	75	1121	72	70	75
	45					1702	61	58	63	1702	61	59	63
Cervical carcinoma	15					12	67	34	86	12	67	34	86
	20					289	85	81	89	289	85	81	89
	25					1007	88	86	90	1007	88	86	90
	30					1760	88	86	89	1760	88	86	89
	35					1883	85	83	87	1883	85	83	87
	40					1560	81	79	83	1560	81	79	83
	45					1195	72	70	75	1195	73	70	75
Colorectal carcinoma	0												
	10												
	15	26	81	60	92	26	89	68	96	52	85	72	92
	20	96	60	49	69	89	71	60	79	185	65	58	71
	25	115	59	50	68	124	72	63	79	239	66	59	72
	30	257	60	54	66	266	65	59	71	523	63	58	67
	35	618	65	61	68	546	65	61	69	1164	65	62	68
	40	1190	60	58	63	1117	61	58	64	2307	61	59	63
	45	2132	59	57	61	1930	62	59	64	4062	60	59	62

Table A3: TYA Diagnostic Classification System (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.	Astrocytoma 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 genito-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

North West Cancer Intelligence Service (NWCIS) is the NCIN Lead Cancer Registry for cancer in teenagers and young adults.

For more information please visit **www.nwcis.nhs.uk** or email **NWCIS.info@nhs.net**

The National Cancer Intelligence Network 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. For more information please visit www.ncin.org.uk