



Teenagers and Young Adults with Cancer

1st Annual Report of
TYAC Notifications
(2009)



**North West Cancer
Intelligence Service**
Hosted by The Christie NHS Foundation Trust

This version of the report has been modified slightly to protect potentially disclosive data as a result of small numbers.

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Foreword

I am really pleased to be able to introduce this first report on TYAC notification.

Teenage and young adult cancer is an emerging sub-specialty which is in the process of growing considerably. Much of this growth has occurred during the past 10 years and accelerated following publication of the NICE Improving Outcome Guidance for Children and Young People with Cancer in 2005. One of the key recommendations of that guidance was the need to develop a specific registry function for teenagers and young adults with cancer. This has been placed at the North West Cancer Intelligence Service in Manchester and will become the source for very important data and knowledge about the referral pathways, diagnosis, and treatment of teenagers and young adults with cancer.

In parallel with this national registry function, TYAC launched this notification process as a means of gathering knowledge in a more timely fashion about patients that are currently referred to teenage and young adult principal treatment centres (PTCs) in the UK. The importance of this information cannot be over emphasised and will enable PTCs to see how they compare with others and to plot changes in referral and treatment patterns quickly over the next few years. This kind of report formed the basis of major improvements in service provision and outcome for children's cancer from the late 1970's, up to the present.

Actually seeing the production of this report is very exciting. I am very grateful to all those who have contributed to date. This includes the Teenage Cancer Trust and CLIC – Sargent who have funded the TYAC data managers in the PTCs. I would like to thank the clinicians who have enthusiastically supported this process and made room for the Data Managers in their centres. Obviously our Data Managers are really committed to this task and have done a sterling job. It is really encouraging to see that almost 1,000 teenagers and young adults with cancer have been registered through the TYAC notification system in its' first year of operation. I would also particularly like to thank Catherine O'Hara, Tony Moran, and the whole team at the North West Cancer Intelligence Service for their enthusiasm in taking on this project.

I hope you find the information of interest and use. I am sure both TYAC and NWCIS would really welcome feedback and work to make this report increasingly relevant in future years.

Professor Ian Lewis
Chair of TYAC

Introduction: TYAC Registration

The TYAC notification form was launched by TYAC in March 2009 to register all patients in the U.K. who have been referred to a specialist TYA MDT.

The notification form (Appendix 1) is designed to capture detailed demographic, diagnostic, place of care and treatment details. Forms are completed by data managers or MDT co-ordinators based at the TYA Principal Treatment Centres (PTCs) primarily using information provided to the MDTs and from patient case notes. Supplementary information is also obtained by the data managers directly from other hospitals who are involved in the patient's pathway. The completed forms are then sent to the North West Cancer Intelligence Service (NWCIS) within 42 days of referral to be collated and stored securely. The data managers also send with the TYAC form copies of pathology reports and any other supporting documentation. This information is used to code the diagnoses using ICD-03 classification. All details are then abstracted into an electronic database and quality assured.

The North West Cancer Intelligence Service (NWCIS) is the national TYA Cancer Registry, one of the site-specific cancer registries established to support the [National Cancer Intelligence Network](#). As a member of the [UK Cancer Registries](#), NWCIS is permitted to collect data under the National Information Governance Board (NIGB) [legislation](#). The same guidelines for data protection are applied to the TYAC data as is applied to all cancer registration data (see [UKACR](#) for details). Identifiable patient data is never released from the registry without appropriate ethical approval and the registry will never contact individual patients or their relatives. Identifiable data can be shared between cancer registries and can be released to organisations (hospitals, primary care trusts and cancer networks) and individuals (clinicians) providing care for those patients. They are only released to bona fide medical researchers who can justify the use of identifiable data and who have made application to, and been approved by, the relevant Medical Research Ethics Committee and been granted Section 251 support through NIGB.

The purpose of the TYAC notification form is to create a process of quickly identifying TYA patients, providing high quality diagnostic details, and identifying the institutions at which these patients are being managed. Notification of new cancer cases in the 15 to 24 age group will still be made to the regional cancer registries via the usual channels. However, the collation of national registrations from each individual regional cancer registry can be a lengthy process. TYAC notification provides more timely access to data, allowing real-time evaluations of how well the guidelines of the cancer reform strategy are being implemented for this age group and decisions about what further steps are required. This process of notification through the TYA principal treatment centres is hoped to have the same impact on improving services for this age group as was achieved by the introduction of the childhood cancer notification form.

NWCIS undertake 6 monthly audits of the data to ensure quality and completeness are being maintained. Summaries of the data are produced for each TYAC Board meeting and data updates are presented at each TYAC event. Full reports will be produced annually. Requests for data can also be made to NWCIS on an adhoc basis via email chn-tr.tyacnotification@nhs.net.

2009 TYAC Notifications

This report covers all cancer patients diagnosed in 2009 who were referred to a specialist TYA MDT and registered using the TYAC notification form, including patients under the age of 15 years or over the age of 24 years who were registered by one of the TYA principal treatment centres (PTCs). We have also included those patients aged 15 – 24 who were diagnosed in 2009 and registered by the Children's Cancer and Leukaemia Group (CCLG)¹.

This report includes all TYAC registrations of 2009 diagnoses received by NWCIS up to 31st May 2010. Data received were checked, coded and entered into the TYAC database held at NWCIS.

¹ Registrations received from CCRG. CCRG have similarly been notified of patients under the age of 15 years who were registered by TYAC.

Each PTC TYAC lead was then offered the opportunity to audit the Trust's data ahead of this report and any errors notified to us were amended.

Estimation of ascertainment via TYAC registration for England is based on 2005-2007 cancer registration data for England (appendix 3). The number of TYAC cases for Wales, Scotland, N. Ireland and Eire is too small to include a similar estimation of ascertainment for those countries.

The report is divided into three sections. Presentation of the results is not intended to be in anyway hierarchical but to give an over view of the TYAC notification process in its first year. Section 1 covers the number of registrations received and the distribution of these registrations by age group, region and diagnostic classification. The diagnostic classification used throughout this report is detailed in Appendix 2. Section 2 covers referral and treatment patterns and section 3 covers the completeness of the data captured by the TYAC registrations.

Section 1

Table 1.1 shows the number of registrations received for 2009 diagnoses by age group and registering principal treatment centre (PTC). A total of 921 patients were registered for 2009. Tables 1.2 to 1.6 show the distribution of registrations across broad TYA diagnostic groupings, age group, sex, registering PTC and both region and cancer network of patient residence. For England, region of residence is grouped to the level of strategic health authority (SHA). All non-England residential patients have been grouped together because of small numbers. Cancer networks, based on postcode of patient residence, are shown for England only.

The pattern of registration across the diagnostic groups is broadly similar to that of cancer incidence in the 15 – 24 years in England (appendix 3). For patients up to 18 years of age, the three most common diagnoses registered in 2009 were lymphomas (23%), leukaemias (16%) and CNS tumours (14%). In the 19 years and over age group, the three top registrations were germ cell tumours (24%), lymphomas (19%) and carcinomas (15%).

TYAC registration for England is estimated to have captured almost half of all 15 – 24 year olds diagnosed with cancer (any diagnosis) based on the most recent incidence data available. Table 1.7 shows the estimated notification rate for England by diagnostic group. The highest rate of registration is seen within the groups of leukaemias (61%) followed by soft tissue sarcomas (59%) and germ cell tumours (54%). Some regions show registration numbers in excess of 100% for some diagnostic groups. Care should be taken in interpreting this as an indicator of an increase in incidence between 2007 and 2009 as these percentages are based on small numbers and numbers of TYA cancer cases do fluctuate from year to year. These percentages are provided only to give an indication of rate of registration.

Section 2

Tables 2.1 and 2.2 show the pattern of TYAC registration by region and cancer network of patient residence. The majority of TYAC registrations occur within the residential region and cancer network of the patient. The most common cross regional border referral appears to be from East of England to London (25% of region's registrations) and from East Midlands to Yorkshire and the Humber (17% of region's registrations). In both age groups, more than 77% of patients registered have been referred to a PTC by a non-PTC trust (Table 2.3).

Table 2.4 shows speciality of referring consultant. Across both age groups, where a speciality was given, patients were most commonly referred by an adult surgeon (34%), by "other" (31%) or by an adult haematologist (20%). In 38% of cases no speciality was recorded at all. The majority of patients (68%) were recorded as being referred to the registering PTC at the time of diagnosis (Table 2.5). A further 10% were referred for other purposes including TYA MDT and TYA psychosocial support (Table 2.5B).

Treating hospital locality is recorded as either the registering hospital (PTC), the referring hospital or another hospital. Information on shared care hospitals is still rarely available. Tables 2.8A and 2.8B show the number of patients who were treated at each hospital locality type by diagnostic group. Across all diagnoses, 89% of patients are recorded to be receiving or have treatment planned at the registering PTC. Tables 2.9 and 2.10 show the speciality of the treating consultant by diagnostic group. Across all diagnoses, for patients under the age of 19, the most common speciality recorded is paediatric oncologist (34%) followed by medical oncologist (17%). For the older age group, the two most frequently recorded specialities are medical oncologist (30%) and adult haematologist (21%).

Tables 2.11A and 2.11B show clinical trial status recorded by diagnostic group. Across both age groups, 21% of patients registered are recorded as being recruited onto a clinical trial. Table 2.12 shows the clinical trials that registered patients have been recruited onto.

Treatment details are among the registration fields most likely to be left incomplete (see Section 3) with 34% of registered patients having no treatment recorded. Table 2.13 shows the percentage of patients with a record of each of the three treatment types by diagnostic group and age group. Across all patients, 18% of patients have a record of radiotherapy, 22% have a record of surgery and 47% have a record of chemotherapy.

The final table in Section 2 refers to previous diagnoses recorded by diagnostic group.

Section 3 tables all relate to data capture.

For further information relating to data included in this report or other information on cancer in teenagers and young adults please contact us at chn-tr.tyacnotification@nhs.net. Alternatively please visit our website www.nwcis.nhs.uk and follow the links to our TYA information pages <http://www.nwcis.nhs.uk/tya/>.

SECTION 1

Table 1.1: Total number of TYAC and CCRG patients registered in 2009

Principle Treatment Centre	under 19 years	19+ years	Total Patients
Alder Hey Liverpool	11	0	11
University Hospital Birmingham	22	34	56
Birmingham Children's Hospital	12	0	12
University Hospitals Bristol	30	39	69
Clatterbridge Centre for Oncology Liverpool	24	44	68
Addenbrookes Cambridge	31	29	60
The Christie Manchester	42	88	130
Great Ormond Street London	4	0	4
St. James's University Hospital Leeds	26	44	70
East Midlands Children's and Young Person's Integrated Cancer Centre	29	26	55
Newcastle upon Tyne NHS Hospitals Trust	17	10	27
John Radcliffe Hospital Oxford	15	7	22
Royal Manchester Children's Hospital	9	0	9
Royal Marsden, Sutton	36	55	91
Weston Park Hospital Sheffield	23	39	62
Southampton General Hospital	18	17	35
University College London Hospital	46	27	73
non England PTCs	55	12	67
Total *	450	471	921

* Includes 12 patients with unknown age

Table 1.2: Total number of patients registered by TYA diagnostic classification, 2009

Broad TYA Group	Diagnosis	Diagnostic Group	under 19 years	19+ years	Total
Leukaemias	Acute lymphoid leukaemia (ALL)	110	46	23	69
	Acute myeloid leukaemia (AML)	120	16	13	29
	Chronic myeloid leukaemia (CML)	130	6	2	9
	Other and unspecified myeloid leukaemias	142	1	0	1
	Unspecified leukaemia	144	0	4	4
Lymphomas	Non-Hodgkin lymphoma, specified subtype	211	20	23	44
	Non-Hodgkin lymphoma, subtype not specified	212	7	4	11
	Hodgkin lymphoma, specified subtype	221	64	55	119
	Hodgkin lymphoma, subtype not specified	222	11	7	22
CNS Tumours	Pilocytic astrocytoma	311	13	3	16
	Other low grade astrocytoma	312	3	2	5
	Glioblastoma and anaplastic astrocytoma	313	9	15	25
	Astrocytoma not otherwise specified	314	3	2	5
	Oligodendroglioma	321	1	2	3
	Other specified glioma	322	2	2	4
	Glioma NOS	323	4	3	7
	Ependymoma	330	2	5	7
	Medulloblastoma	341	7	4	11
	Supratentorial PNET	342	4	1	6
	Craniopharyngioma	351	2	2	4
	Pituitary tumours	352	1	0	1
	Meningioma	355	3	0	3
	Other specified tumours	357	5	0	5
	Unspecified malignant intracranial and intraspinal neoplasms	361	1	1	2
	Unspecified non-malignant intracranial and intraspinal neoplasms	362	1	0	1
Bone Tumours	Osteosarcoma	410	19	10	29
	Chondrosarcoma	420	2	1	3
	Ewing sarcoma of bone	431	13	2	15
	Extraskeletal Ewing sarcoma	432	5	4	9
	Ewing sarcoma of unknown site	433	0	1	1
	Unspecified bone tumours	442	0	1	1
Soft Tissue Sarcomas	Dermatofibrosarcoma	513	1	2	3
	Rhabdomyosarcoma	520	10	8	18
	Liposarcoma	531	0	2	2
	Leiomyosarcoma	532	0	1	1
	Synovial sarcoma	533	2	3	5
	Clear cell sarcoma	534	2	0	2
	Blood vessel tumours	535	0	1	1
	Nerve sheath tumours	536	2	2	4
	Miscellaneous specified soft tissue sarcoma	538	1	2	3
	Unspecified soft tissue sarcomas	540	5	9	14
Germ Cell Tumours	Gonadal germ cell & trophoblastic neoplasms	610	34	100	134
	Intracranial germ cell and trophoblastic tumours	621	9	5	14
	Other non-gonadal germ cell and trophoblastic tumours	622	2	7	9

Broad TYA Group	Diagnosis	Diagnostic Group	under 19 years	19+ years	Total
Melanoma & Skin Carcinoma	Melanoma	710	9	23	32
	Skin carcinoma	720	1	0	1
Carcinoma (except of skin)	Carcinoma of thyroid	810	10	18	28
	Nasopharyngeal carcinoma	821	3	1	5
	Carcinoma of other sites in lip oral cavity and pharynx	822	2	7	9
	Carcinoma of nasal cavity, middle ear, sinuses, larynx and other ill-defined sites in head and neck	823	0	1	1
	Carcinoma of trachea, bronchus, lung and pleura	830	3	3	6
	Carcinoma of breast	840	0	8	8
	Carcinoma of kidney	851	2	3	5
	Carcinoma of ovary	853	2	3	5
	Carcinoma of cervix	854	0	15	15
	Carcinoma of colon and rectum	861	1	5	6
	Carcinoma of stomach	862	1	1	2
	Carcinoma of liver and intrahepatic bile ducts	863	3	1	4
	Carcinoma of pancreas	864	0	1	1
	Carcinoma of other and ill-defined sites in GI tract	865	1	1	2
	Adrenocortical carcinoma	871	0	1	1
	Other carcinomas NEC	872	3	4	7
Miscellaneous Spec. Neoplasms	Wilms tumour	911	1	1	2
	Neuroblastoma	912	2	0	2
	Other paediatric and embryonal, NEC	913	1	0	1
	Other specified gonadal tumours NEC	922	2	0	2
	Myeloma, mast cell tumours and miscellaneous reticuloendothelial neoplasms NEC	923	1	0	1
	Other specified neoplasms NEC	924	0	1	1
Miscellaneous Unspecified Neoplasms	Unspecified Malignant Neoplasms NEC	1000	1	2	3
Other	Non-Malignant tumours and unclassifiable diagnoses	n/a	50	37	90
All diagnoses*			438	471	921

* Totals include 12 patients whose age is unknown

Table 1.3: Number of patients registered by broad TYA diagnostic group, sex and age group, 2009

TYA Diagnostic Group	Males		Females	
	under 19 years	19 + years	under 19 years	19 + years
Leukaemias	42	24	27	18
Lymphomas	53	48	49	41
CNS Tumours	28	20	33	22
Bone Tumours	26	12	13	7
Soft Tissue Sarcomas	16	19	7	11
Germ Cell Tumours	35	100	10	12
Melanoma & Skin Carcinoma	1	9	9	14
Carcinoma (except of skin)	16	23	15	50
Miscellaneous Specified Neoplasms	3	2	4	0
Miscellaneous Unspecified Neoplasms	0	1	1	1
Other	21	15	29	22
Total *	241	273	197	198

* excludes 12 patients age unknown

Table 1.4: Number of patients registered by broad TYA diagnostic group and registering PTC, 2009

PTC	TYA Diagnostic Group											All diagnoses
	Leukaemias	Lymphomas	CNS Tumours	Bone Tumours	Soft Tissue Sarcomas	Germ Cell Tumours	Melanoma & Skin Carcinoma	Carcinoma (except of skin)	Miscellaneous Specified Neoplasms	Miscellaneous Unspecified Neoplasms	Other	
Alder Hey Liverpool	1	3	3	0	0	0	0	1	0	0	3	11
University Hospital Birmingham	6	7	8	1	4	18	4	5	1	0	2	56
Birmingham Children's Hospital	3	0	0	3	1	1	0	1	0	1	2	12
University Hospitals Bristol	11	9	6	2	4	14	7	9	1	1	5	69
Clatterbridge Centre for Oncology Liverpool	5	12	7	2	7	15	4	11	1	0	4	68
Addenbrookes Cambridge	8	16	12	2	1	6	1	9	0	0	5	60
The Christie Manchester	10	29	7	8	12	21	6	20	1	1	15	130
Great Ormond Street London	0	0	2	0	0	0	0	0	0	0	2	4
St. James's University Hospital Leeds	6	17	11	4	2	20	0	9	0	0	1	70
East Midlands Children's and Young Person's Integrated Cancer Centre	7	18	4	0	3	10	0	4	0	0	9	55
Newcastle upon Tyne NHS Hospitals Trust	4	9	2	1	2	2	0	3	2	0	2	27
John Radcliffe Hospital Oxford	2	3	3	5	0	5	0	3	0	0	1	22
Royal Manchester Children's Hospital	3	0	1	2	0	1	0	0	0	0	2	9
Royal Marsden, Sutton	11	18	13	1	7	15	3	14	2	0	7	91
Weston Park Hospital Sheffield	5	10	5	1	4	7	5	11	0	0	14	62
Southampton General Hospital	4	8	5	0	2	9	0	3	1	0	3	35
University College London Hospital	12	13	7	21	3	9	1	1	0	0	6	73
non England PTCs	14	24	9	5	1	4	2	1	0	0	7	67
Total	112	196	105	58	53	157	33	105	9	3	90	921

Table 1.5: Number of patients registered by TYA diagnostic group and region of patient residence, 2009

Region of residence *	TYA Diagnostic Group											Total
	Leukaemias	Lymphomas	CNS Tumours	Bone Tumours	Soft Tissue Sarcomas	Germ Cell Tumours	Melanoma & Skin Carcinoma	Carcinoma (except of skin)	Miscellaneous Specified Neoplasms	Miscellaneous Unspecified Neoplasms	Other	
North East	3	9	2	1	2	1	2	3	2	0	2	27
North West	19	39	13	9	16	34	8	30	1	1	26	196
Yorkshire and the Humber	10	25	12	4	5	23	3	18	0	0	7	107
East Midlands	10	19	7	2	5	15	0	9	0	0	8	75
West Midlands	7	9	10	4	5	17	5	6	1	1	6	71
East of England	10	16	14	10	3	9	1	10	0	0	8	81
London	11	12	11	4	4	15	3	5	2	0	8	75
South East	10	15	5	8	2	5	1	2	0	0	4	52
South Central	7	14	10	6	4	12	0	6	1	0	3	63
South West	10	9	7	3	4	15	6	12	1	1	8	76
Other UK & ROI	15	29	13	7	3	11	4	4	1	0	10	97
Total **	112	196	104	58	53	157	33	105	9	3	90	920

* Region of Residence for England is Strategic Health Authority (SHA).

** excludes one overseas patient

Table 1.6: Number of patients resident in England registered by TYA diagnostic group and cancer network of patient residence, 2009

Cancer Network	TYA Diagnostic Group											Total
	Leukaemias	Lymphomas	CNS Tumours	Bone Tumours	Soft Tissue Sarcomas	Germ Cell Tumours	Melanoma & Skin Carcinoma	Carcinoma (except of skin)	Miscellaneous Specified Neoplasms	Miscellaneous Unspecified Neoplasms	Other	
Lancashire and South Cumbria	8	7	3	2	2	3	0	8	0	0	5	38
Greater Manchester and Cheshire	6	18	6	4	8	15	6	10	1	1	13	88
Merseyside and Cheshire	5	13	5	4	6	16	2	12	1	0	7	71
Yorkshire	5	12	9	2	1	15	0	8	0	0	2	54
Humber and Yorkshire Coast	1	4	1	2	0	6	0	1	0	0	0	15
North Trent	5	11	5	2	4	3	3	12	0	0	5	50
Pan Birmingham	4	2	8	2	1	9	2	3	0	1	2	34
Arden	1	0	1	1	1	1	1	1	0	0	1	8
Mount Vernon	3	2	1	2	1	2	0	2	0	0	0	13
West London	0	1	1	2	1	1	1	0	0	0	2	9
North London	3	5	2	2	0	5	1	1	0	0	6	25
North East London	2	3	2	0	1	1	0	0	0	0	1	10
South East London	5	0	3	0	1	0	1	1	1	0	1	13
South West London	2	5	3	0	1	10	0	3	1	0	0	25
Peninsula	5	0	1	1	2	1	0	2	1	0	1	14
Dorset	0	0	0	1	0	1	0	1	0	0	2	5
Avon, Somerset and Wiltshire	4	7	5	1	2	13	6	9	0	1	3	51
3 Counties	1	2	1	0	1	0	1	0	1	0	2	9
Thames Valley	3	4	6	3	2	4	0	3	0	0	2	27
Central and South Coast	4	10	5	2	3	7	0	3	1	0	2	37
Surrey, West Sussex and Hampshire	3	6	2	1	0	1	1	0	0	0	2	16
Sussex	1	3	2	3	0	1	0	1	0	0	1	12
Kent and Medway	6	6	1	5	1	2	0	1	0	0	0	22
Greater Midlands	2	5	0	1	2	7	1	2	0	0	3	23
North of England	3	10	2	1	2	2	2	3	2	0	3	30
Anglia	4	13	10	3	1	6	1	8	0	0	6	52
Essex	2	0	3	5	1	0	0	0	0	0	0	11
East Midlands	9	18	4	0	5	14	0	6	0	0	8	64
Total	97	167	92	52	50	146	29	101	9	3	80	826

Table 1.7: Estimated notification rate for England (based on 2005-2007 incidence for England) of patients aged 15 – 24 years, by TYA diagnostic group and Strategic Health Authority of patient residence, 2009**

SHA	TYA Diagnostic group								Total
	Leukaemias	Lymphomas	CNS Tumours	Bone Tumours	Soft Tissue Sarcomas	Germ Cell Tumours	Melanoma & Skin Carcinoma	Carcinoma (except of skin)	
North East	31%	44%	18%	15%	35%	9%	12%	15%	22%
North West	88%	82%	39%	63%	120%	87%	17%	62%	63%
Yorkshire and the Humber	58%	82%	65%	29%	71%	74%	6%	49%	49%
East Midlands	100%	56%	55%	24%	63%	65%	0%	29%	45%
West Midlands	34%	24%	59%	44%	71%	53%	18%	16%	33%
East of England	64%	41%	64%	91%	53%	32%	5%	35%	43%
London	42%	21%	45%	29%	21%	45%	13%	9%	25%
South East	70%	49%	34%	100%	32%	22%	5%	7%	33%
South Central	70%	45%	57%	78%	86%	53%	0%	22%	38%
South West	71%	25%	36%	26%	46%	57%	17%	35%	35%
Total	61%	46%	48%	49%	59%	54%	10%	29%	40%

** Incidence data from NWCIS' national TYA database (2005 - 2007) for 15 – 24 year olds.

Care should be taken in interpreting percentages in excess of 100% as an increase in incidence rate between 2005 - 2007 and 2009. These percentages are based on small numbers and number of TYA cancer cases do fluctuate from year to year. These percentages are provided only to give an indication of rate of registration.

SECTION 2

Table 2.1: Number of patients registered by each PTC by region of patient residence, 2009

PTC	Region of Residence											Total
	North East	North West	Yorkshire and the Humber	East Midlands	West Midlands	East of England	London	South East	South Central	South West	Other UK & ROI	
Alder Hey Liverpool	0	5	0	0	0	0	0	0	0	0	5	10
University Hospital Birmingham	0	0	0	2	51	0	0	0	0	0	3	56
Birmingham Children's Hospital	0	1	0	0	11	0	0	0	0	0	0	12
University Hospitals Bristol	0	0	0	0	1	0	1	0	1	65	1	69
Clatterbridge Centre for Oncology Liverpool	0	58	0	1	0	0	0	0	0	0	9	68
Addenbrookes Cambridge	0	0	0	2	0	56	0	1	0	1	0	60
The Christie Manchester	0	114	3	2	3	0	0	0	0	0	8	130
Great Ormond Street London	0	0	0	0	0	0	3	0	0	1	0	4
St. James's University Hospital Leeds	0	2	65	3	0	0	0	0	0	0	0	70
East Midlands Children's and Young Person's Integrated Cancer Centre	0	0	0	51	2	0	0	1	0	0	1	55
Newcastle upon Tyne NHS Hospitals Trust	24	2	0	0	0	0	0	0	0	0	1	27
John Radcliffe Hospital Oxford	0	0	0	0	0	0	0	0	20	2	0	22
Royal Manchester Children's Hospital	0	7	0	0	1	0	1	0	0	0	0	9
Royal Marsden, Sutton	0	0	1	1	1	4	36	33	9	3	3	91
Weston Park Hospital Sheffield	3	7	38	13	1	0	0	0	0	0	0	62
Southampton General Hospital	0	0	0	0	0	0	1	2	28	4	0	35
University College London Hospital non England PTCs	0	0	0	0	0	20	33	14	5	0	1	73
Total **	27	196	107	75	71	81	75	52	63	76	97	920

** excludes one overseas patient

Table 2.2: Number of patients registered by each PTC by cancer network of residence, 2009

Cancer Network	Alder Hey Liverpool	University Hospital Birmingham	Birmingham Children's Hospital	University Hospitals Bristol	Clatterbridge Centre for Oncology Liverpool	Addenbrookes Cambridge	The Christie Manchester	Great Ormond Street London	St. James's University Hospital Leeds	East Midlands Children's and Young Person's Integrated Cancer Centre	Newcastle upon Tyne NHS Hospitals Trust	John Radcliffe Hospital Oxford	Royal Manchester Children's Hospital	Royal Marsden, Sutton	Weston Park Hospital Sheffield	Southampton General Hospital	University College London Hospital
Lancashire and South Cumbria	0	0	0	0	1	0	30	0	1	0	1	0	3	0	2	0	0
Greater Manchester and Cheshire	0	0	1	0	1	0	80	0	0	0	0	0	4	0	2	0	0
Merseyside and Cheshire	6	0	0	0	57	0	4	0	1	0	0	0	0	0	3	0	0
Yorkshire	0	0	0	0	0	0	1	0	50	0	0	0	0	0	3	0	0
Humber and Yorkshire Coast	0	0	0	0	0	0	0	0	15	0	0	0	0	0	0	0	0
North Trent	0	0	0	0	0	0	3	0	1	0	0	0	0	1	45	0	0
Pan Birmingham	0	25	7	0	0	0	0	0	0	1	0	0	0	1	0	0	0
Arden	0	5	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Mount Vernon	0	0	0	0	0	4	0	0	0	0	0	0	0	2	0	0	7
West London	0	0	0	0	0	0	0	0	0	0	0	0	1	4	0	0	4
North London	0	0	0	1	0	3	0	1	0	0	0	0	0	0	0	0	20
North East London	0	0	0	0	0	0	0	1	0	0	0	0	0	1	0	1	7
South East London	0	0	0	0	0	0	0	1	0	0	0	0	0	8	0	0	4
South West London	0	0	0	0	0	1	0	0	0	0	0	0	0	24	0	0	0
Peninsula	0	0	0	10	0	1	0	0	0	0	0	2	0	1	0	0	0
Dorset	0	0	0	1	0	0	0	1	0	0	0	0	0	1	0	2	0
Avon, Somerset and Wiltshire	0	0	0	50	0	0	0	0	0	0	0	0	0	1	0	0	0
3 Counties	0	4	0	5	0	0	0	0	0	0	0	0	0	0	0	0	0
Thames Valley	0	0	0	1	0	0	0	0	0	0	0	17	0	6	0	0	3
Central and South Coast	0	0	0	0	0	0	0	0	0	0	0	2	0	2	0	32	1
Surrey, West Sussex and Hampshire	0	0	0	0	0	0	0	0	0	1	0	0	0	10	0	0	4
Sussex	0	0	0	0	0	0	0	0	0	0	0	0	0	8	0	0	4
Kent and Medway	0	0	0	0	0	0	0	0	0	0	0	0	0	15	0	0	7
Greater Midlands	0	16	1	0	0	0	3	0	0	1	0	0	1	0	1	0	0
North of England	0	0	0	0	0	0	1	0	0	0	25	0	0	0	4	0	0
Anglia	0	0	0	0	0	45	0	0	0	0	0	0	0	2	0	0	4
Essex	0	0	0	0	0	4	0	0	0	0	0	0	0	0	0	0	7
East Midlands	0	3	0	0	1	2	1	0	2	51	0	1	0	1	2	0	0
Total	6	53	12	68	60	60	123	4	70	54	26	22	9	88	62	35	72

Table 2.3: Number of patients referred to a PTC by a Non-PTC hospital, by TYA diagnostic group and age group, 2009

TYA Diagnostic Group	Under 19 years		19+ years	
	Number of patients	% of patients	Number of patients	% of patients
Leukaemias	55	80%	28	67%
Lymphomas	75	74%	67	75%
CNS Tumours	48	79%	34	81%
Bone Tumours	31	79%	18	95%
Soft Tissue Sarcomas	21	91%	25	83%
Germ Cell Tumours	34	76%	84	75%
Melanoma & Skin Carcinomas	8	80%	21	91%
Carcinoma (except of skin)	27	87%	56	77%
Miscellaneous Specified Neoplasms	5	71%	2	100%
Miscellaneous Unspecified Neoplasms	1	100%	1	50%
Other	32	64%	33	89%
Total	337	77%	368	78%

Table 2.4: Speciality of referring consultant by TYA diagnostic group, 2009

Referring Consultant Specialist	Patient age group		
	Under 19 years	19 + years	Total*
Paediatric Oncologist	19	1	20
TYA Oncologist	0	0	0
Medical Oncologist	7	21	29
Paediatric Haematologist	7	1	8
Adult Haematologist	44	67	112
Paediatric Surgeon	5	3	8
Adult Surgeon	66	127	193
Radiotherapist/Clinical Oncologist	8	11	19
Other	83	92	178
Not stated	199	148	354
Total	438	471	921

* Total includes 12 patients whose age is unknown

Table 2.5A: Reason for referral by TYA diagnostic group, 2009

TYA Diagnostic Group	Reason for referral									
	Referred at time of diagnosis		Referred at relapse/recurrence		Registering hospital only responsible for follow up		Other - see table 2.5B includes referral for TYA psychosocial MDT		Not stated	
	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients
Leukaemias	77	69%	2	2%	2	2%	11	10%	20	18%
Lymphomas	120	61%	0	0%	7	4%	26	13%	43	22%
CNS Tumours	74	70%	2	2%	2	2%	8	8%	19	18%
Bone Tumours	47	81%	0	0%	0	0%	3	5%	8	14%
Soft Tissue Sarcomas	41	77%	0	0%	2	4%	3	6%	7	13%
Germ Cell Tumours	110	70%	0	0%	4	3%	9	6%	34	22%
Melanoma & Skin Carcinomas	21	64%	1	3%	0	0%	7	21%	4	12%
Carcinoma (except of skin)	67	64%	0	0%	1	1%	14	13%	23	22%
Miscellaneous Specified Neoplasms	7	78%	0	0%	0	0%	0	0%	2	22%
Miscellaneous Unspecified Neoplasms	2	67%	0	0%	0	0%	0	0%	1	33%
Other	62	69%	0	0%	4	4%	8	9%	16	18%
Total	628	68%	5	1%	22	2%	89	10%	177	19%

Table 2.5B: “Other” Reason for referral, 2009

Other reason for referral	No of patients	% of patients
TYA support	9	10
TYA MDT	40	45
Emergency	1	1
Part of treatment	28	31
Patient choice to transfer treatment	2	2
Unknown	9	10
Total	89	100

Table 2.6: Time between diagnosis and first MDT, 2009

Age group	Number of months from diagnosis to 1st MDT date*				Total patients with a MDT date recorded
	Prior to diagnosis	Within one month	2- 3 months	> 3 months	
under 19 years	4	209	12	3	228
19+ years	4	302	22	18	346
Total *	8	511	34	21	574

Table 2.7: Time between diagnosis and second MDT, 2009

Age group	Number of months from diagnosis to second MDT date*				Total patients with a MDT date recorded
	Prior to diagnosis	Within one month	2- 3 months	> 3 months	
under 19 years	1	65	11	3	80
19+ years	1	114	16	12	143
Total *	2	179	27	15	223

* excludes patients where no date for the MDT was recorded or no MDT information provided

Table 2.8A: Treating hospital of patients aged under 19 years, by TYA diagnostic group, 2009

TYA Diagnostic Group	Treating Hospital							
	Registering hospital (PTC)		Referring hospital		Other hospital		Not Stated	
	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients
Leukaemias	65	94%	2	3%	1	1%	1	1%
Lymphomas	90	88%	10	10%	2	2%	0	0%
CNS Tumours	55	90%	1	2%	4	7%	1	2%
Bone Tumours	37	95%	1	3%	0	0%	1	3%
Soft Tissue Sarcomas	22	96%	0	0%	1	4%	0	0%
Germ Cell Tumours	39	87%	3	7%	2	4%	1	2%
Melanoma & Skin Carcinomas	6	60%	2	20%	2	20%	0	0%
Carcinoma (except of skin)	26	84%	4	13%	0	0%	1	3%
Miscellaneous Specified Neoplasms	6	86%	0	0%	1	14%	0	0%
Miscellaneous Unspecified Neoplasms	1	100%	0	0%	0	0%	0	0%
Other	42	84%	7	14%	0	0%	1	2%
Total	389	89%	30	7%	13	3%	6	1%

Table 2.8B: Treating hospital of patients aged 19+ years, by TYA diagnostic group, 2009

TYA Diagnostic Group	Treating Hospital							
	Registering hospital (PTC)		Referring hospital		Other hospital		Not Stated	
	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients
Leukaemias	32	76%	9	21%	0	0%	1	2%
Lymphomas	63	71%	20	22%	4	4%	2	2%
CNS Tumours	37	88%	2	5%	3	7%	0	0%
Bone Tumours	18	95%	1	5%	0	0%	0	0%
Soft Tissue Sarcomas	26	87%	3	10%	1	3%	0	0%
Germ Cell Tumours	97	87%	8	7%	4	4%	3	3%
Melanoma & Skin Carcinomas	13	57%	9	39%	1	4%	0	0%
Carcinoma (except of skin)	56	77%	11	15%	3	4%	3	4%
Miscellaneous Specified Neoplasms	2	100%	0	0%	0	0%	0	0%
Miscellaneous Unspecified Neoplasms	2	100%	0	0%	0	0%	0	0%
Other	34	92%	2	5%	1	3%	0	0%
Total	380	81%	65	14%	17	4%	9	2%

Table 2.9: Percentage of patients under 19 years of age treated by each consultant speciality, by TYA diagnostic group, 2009

TYA Diagnostic Group	Treating consultant speciality								
	Paediatric oncologist	TYA oncologist	Medical oncologist	Paediatric haematologist	Adult haematologist	Paediatric surgeon	Adult surgeon	Radiotherapist / Clinical oncologist	Other
Leukaemias	15%	0%	2%	39%	41%	0%	0%	2%	0%
Lymphomas	53%	0%	6%	12%	24%	0%	0%	4%	1%
CNS Tumours	51%	0%	10%	0%	0%	0%	10%	15%	13%
Bone Tumours	40%	23%	23%	3%	0%	0%	0%	7%	3%
Soft Tissue Sarcomas	31%	6%	38%	0%	0%	0%	6%	19%	0%
Germ Cell Tumours	17%	6%	46%	0%	3%	0%	6%	14%	9%
Melanoma & Skin Carcinomas	0%	0%	22%	0%	0%	0%	33%	0%	44%
Carcinoma (except of skin)	5%	0%	29%	0%	0%	0%	29%	33%	5%
Miscellaneous Specified Neoplasms	50%	0%	33%	0%	0%	0%	0%	17%	0%
Miscellaneous Unspecified Neoplasms	NA	NA	NA	NA	NA	NA	NA	NA	NA
Other	38%	0%	12%	4%	12%	8%	8%	12%	8%
All diagnoses	34%	3%	17%	9%	14%	1%	6%	10%	6%

NB. A total of 306 patients under the age of 19 had a response for treating consultant speciality

Table 2.10: Percentage of patients aged 19+ years treated by each consultant speciality, by TYA diagnostic group, 2009

TYA Diagnostic Group	Treating consultant speciality								
	Paediatric oncologist	TYA oncologist	Medical oncologist	Paediatric haematologist	Adult haematologist	Paediatric surgeon	Adult surgeon	Radiotherapist / Clinical oncologist	Other
Leukaemias	3%	0%	0%	3%	90%	0%	0%	3%	3%
Lymphomas	1%	0%	16%	0%	62%	0%	0%	20%	1%
CNS Tumours	5%	2%	7%	0%	0%	2%	19%	57%	7%
Bone Tumours	22%	39%	22%	0%	0%	0%	6%	11%	0%
Soft Tissue Sarcomas	4%	8%	35%	0%	0%	0%	19%	31%	4%
Germ Cell Tumours	4%	6%	55%	0%	0%	1%	12%	11%	12%
Melanoma & Skin Carcinomas	0%	0%	23%	0%	0%	0%	41%	5%	32%
Carcinoma (except of skin)	0%	0%	29%	0%	2%	0%	27%	29%	13%
Miscellaneous Specified Neoplasms	20%	0%	0%	0%	60%	0%	20%	0%	0%
Miscellaneous Unspecified Neoplasms	0%	0%	0%	0%	0%	0%	0%	50%	50%
Other	0%	0%	66%	0%	0%	0%	19%	13%	3%
All diagnoses	3%	4%	30%	0%	21%	0%	14%	20%	8%

NB. 438 patients over the age of 19 years had a response to treating consultant speciality.

Table 2.11A: Clinical trial status of patients under 19 years of age, by TYA diagnostic group, 2009

TYA Diagnostic group	Clinical Trial Status													
	EE- Patient eligible, consented and entered trial		EN- Not offered trial/physician decision		NE- Not eligible or no applicable trial available		ED - Offered trial but does not wish to participate		EO - Reason unknown		EX - Patient deceased (early death)		Not stated	
	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients
Leukaemias	35	51%	2	3%	23	33%	1	1%	2	3%	0	0%	6	9%
Lymphomas	38	37%	3	3%	42	41%	2	2%	8	8%	0	0%	9	9%
CNS Tumours	16	26%	3	5%	32	52%	1	2%	5	8%	0	0%	4	7%
Bone Tumours	23	59%	3	8%	8	21%	2	5%	0	0%	0	0%	3	8%
Soft Tissue Sarcomas	6	26%	1	4%	9	39%	1	4%	4	17%	0	0%	2	9%
Germ Cell Tumours	2	4%	4	9%	29	64%	0	0%	5	11%	0	0%	5	11%
Melanoma & Skin Carcinomas	0	0%	0	0%	7	70%	0	0%	3	30%	0	0%	0	0%
Carcinoma (except of skin)	2	6%	2	6%	18	58%	0	0%	5	16%	0	0%	4	13%
Miscellaneous Specified Neoplasms	3	43%	1	14%	7	100%	0	0%	1	14%	0	0%	0	0%
Miscellaneous Unspecified Neoplasms	0	0%	0	0%	1	100%	0	0%	0	0%	0	0%	0	0%
Other	1	2%	1	2%	31	62%	1	2%	6	12%	0	0%	5	10%
Total	126	29%	20	5%	207	47%	8	2%	39	9%	0	0%	38	9%

Table 2.11B: Clinical trial status of patients aged 19+ years, by TYA diagnostic group, 2009

TYA Diagnostic group	Clinical Trial Status													
	EE- Patient eligible, consented and entered trial		EN- Not offered trial/physician decision		NE- Not eligible or no applicable trial available		ED - Offered trial but does not wish to participate		EO - Reason unknown		EX - Patient deceased (early death)		Not stated	
	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients	No of patients	% of patients
Leukaemias	22	52%	0	0%	10	24%	3	7%	3	7%	2	5%	2	5%
Lymphomas	13	15%	2	2%	33	37%	4	4%	17	19%	0	0%	20	22%
CNS Tumours	2	5%	5	12%	21	50%	0	0%	4	10%	0	0%	10	24%
Bone Tumours	8	42%	2	11%	3	16%	0	0%	4	21%	0	0%	2	11%
Soft Tissue Sarcomas	5	17%	3	10%	14	47%	0	0%	5	17%	0	0%	3	10%
Germ Cell Tumours	10	9%	8	7%	66	59%	5	4%	12	11%	0	0%	11	10%
Melanoma & Skin Carcinomas	1	4%	3	13%	14	61%	0	0%	3	13%	0	0%	2	9%
Carcinoma (except of skin)	3	4%	4	5%	37	51%	1	1%	13	650%	0	0%	15	21%
Miscellaneous Specified Neoplasms	1	50%	0	0%	1	50%	0	0%	0	0%	0	0%	0	0%
Miscellaneous Unspecified Neoplasms	0	0%	1	50%	1	50%	0	0%	0	0%	0	0%	0	0%
Other	1	3%	2	5%	24	65%	0	0%	6	16%	0	0%	4	11%
Total	66	14%	30	6%	224	48%	13	3%	67	14%	2	0%	69	15%

Table 2.12: Clinical trials recruited to by age group, 2009

Trial name	Under 19 years		19+ years	
	No of Recruits	%	No of Recruits	%
18-30	1	1%	3	5%
AML 17	1	1%	8	12%
AVAS-M	0	0%	1	2%
CNS 2004 03 (LOW GRADE GLIOMA 2 SIOP-LGG2 2003)	14	11%	1	2%
DTI Nephrotoxicity Cisplatin study	0	0%	1	2%
EORTC 62012	0	0%	1	2%
EORTC 62012	0	0%	1	2%
EPSSG protocol RMS2005	0	0%	1	2%
ET 2000 03 (EURO-E.W.I.N.G. 99)	10	8%	2	3%
EURAMOS 1	13	10%	6	9%
Escalated ABVD	1	1%	2	3%
EuroNet PHL-C1 Hodgkin's (HD 2007/10)	28	22%	0	0%
Folate study	1	1%	0	0%
GC 2005 04	1	1%	0	0%
HiLo	0	0%	2	3%
MRC UKALL 2003	35	28%	13	20%
Medulloblastoma feasibility study	1	1%	0	0%
NHL 2006 01 (Relapsed ALCL)	3	2%	0	0%
OEPA1	1	1%	0	0%
RAPID (formerly PET Trial in Hodgkin's Disease)	3	2%	3	5%
RATHL	0	0%	6	9%
RCC SORCE	0	0%	1	2%
SPIRIT 2	1	1%	1	2%
STS 2006 04 RMS 2005 (ESSG1)	6	5%	1	2%
Significant II	0	0%	1	2%
TE23	0	0%	2	3%
TE3	1	1%	3	5%
TRANSCAL (CNS 2007 13)	1	1%	1	2%
TRISST	0	0%	3	5%
VORTEX	0	0%	1	2%
WT 2002 01 (SIOP Wilms)	1	1%	1	2%
Not stated	3	2%	0	0%
Total patients recruited to clinical trial (EE)	126	100%	66	100%

Table 2.13: Percentage of patients by age and TYA diagnostic group with a recorded treatment decision**

Age	Treatment	TYA Diagnostic Group											All Patients
		Leukaemias	Lymphomas	CNS	Bone	STS	Germ Cell	Skin	Carcinomas	Misc Spec	Misc Unspec	Other	
Under 19 years	Chemotherapy	54%	71%	25%	38%	26%	38%	10%	39%	29%	0%	16%	42%
	Radiotherapy	1%	20%	38%	10%	43%	16%	0%	23%	14%	0%	6%	17%
	Surgery	0%	5%	30%	26%	30%	20%	70%	32%	29%	0%	16%	17%
19 + years	Chemotherapy	71%	71%	29%	53%	53%	54%	4%	49%	50%	50%	38%	52%
	Radiotherapy	0%	15%	64%	11%	33%	5%	0%	37%	50%	0%	5%	19%
	Surgery	0%	3%	40%	16%	37%	36%	43%	36%	100%	0%	27%	26%

** Includes both definitive and deferred decisions. Missing data or data shown as "unknown" are not included

NB. Does not include the 12 patients whose age is unknown

Surgery includes bone marrow transplants.

40 patients are recorded as having "other" treatment which includes other medication, stem cell harvesting, egg harvesting and distraction therapy

Table 2.14: Number of patients with a previous diagnosis recorded, by TYA diagnostic group, 2009

TYA Diagnostic Group for 2009 diagnosis	Previous diagnosis recorded	No previous diagnosis recorded
Leukaemias	2	110
Lymphomas	0	196
CNS Tumours	7	98
Bone Tumours	2	56
Soft Tissue Sarcomas	1	52
Germ Cell Tumours	0	157
Melanoma & Skin Carcinomas	1	32
Carcinoma (except of skin)	4	101
Miscellaneous Specified Neoplasms	0	9
Miscellaneous Unspecified Neoplasms	0	3
Other	2	88
All diagnoses	19	902

SECTION 3

Table 3.1: Percentage of TYAC forms received within 42 days of diagnosis in each calendar year quarter by PTC, 2009

PTC	Q1	Q2	Q3	Q4	Total
Alder Hey Liverpool	na	0%	100%	na	50%
University Hospital Birmingham	0%	25%	8%	36%	16%
Birmingham Children's Hospital	na	na	na	na	na
University Hospitals Bristol	0%	0%	0%	13%	2%
Clatterbridge Centre for Oncology Liverpool	0%	29%	24%	40%	21%
Addenbrookes Cambridge	0%	50%	36%	25%	27%
The Christie Manchester	0%	6%	45%	63%	25%
Great Ormond Street London	na	na	na	na	na
St. James's University Hospital Leeds	0%	14%	22%	29%	16%
East Midlands Children's and Young Person's Integrated Cancer Centre	0%	7%	33%	43%	21%
New castle upon Tyne NHS Hospital Trust	0%	11%	0%	20%	10%
John Radcliffe Hospital Oxford	0%	na	67%	67%	50%
Royal Manchester Children's Hospital	na	na	na	na	na
Royal Marsden, Sutton	0%	16%	26%	18%	15%
Weston Park Hospital Sheffield	0%	24%	80%	60%	39%
Southampton General Hospital	0%	0%	27%	17%	13%
University College London Hospital	40%	62%	50%	17%	46%
non England PTCs	29%	0%	0%	0%	7%
Total	3%	20%	31%	36%	22%

Table 3.2: Percentage TYAC and CCRG forms received with a complete data field, 2009

DEMOGRAPHICS				
Data field	15 yrs and under	16 - 18 yrs	19+ yrs	All ages
NHS number	55%	81%	94%	84%
Ethnic group	87%	89%	92%	90%
Sex	100%	99%	100%	99%
Surname	100%	100%	100%	100%
Forename	100%	100%	100%	100%
Diagnosis country	87%	80%	76%	79%
Birth country	41%	44%	49%	46%
Birth town	31%	27%	24%	25%
Birth date	100%	100%	100%	100%
Patient number	97%	97%	96%	96%
HOSPITAL/CONSULTANT				
Data field	15 yrs and under	16 - 18 yrs	19+ yrs	All ages
Pathology lab number	84%	83%	86%	83%
Pathologist	87%	88%	86%	86%
Treating hospital	99%	99%	98%	98%
Treating consultant name	97%	98%	98%	98%
Treating consultant specialist	47%	80%	93%	81%
Referring hospital	91%	90%	93%	92%
Referring consultant	66%	73%	79%	75%
Referring consultant specialist	43%	59%	68%	61%
Diagnosis hospital	44%	65%	79%	69%
Referral reason	80%	81%	81%	81%
DIAGNOSIS				
Data field	15 yrs and under	16 - 18 yrs	19+ yrs	All ages
Diagnosis	100%	100%	99%	99%
Diagnosis basis (not 9)	86%	94%	95%	92%
Diagnosis date used	55%	74%	79%	73%
Diagnosis date	100%	100%	100%	99%
Stage	26%	38%	47%	40%
TREATMENT				
Data field	15 yrs and under	16 - 18 yrs	19+ yrs	All ages
Surgery	49%	49%	53%	51%
Surgery date (if yes)	50%	65%	64%	64%
Radiotherapy	50%	48%	47%	48%
Radiotherapy date (if yes)	77%	75%	89%	83%
Chemotherapy	59%	67%	72%	68%
Chemotherapy date (if yes)	60%	66%	62%	63%
1st MDT name	43%	69%	81%	71%
1st MDT date	43%	69%	81%	71%
Clinical trial status	94%	90%	86%	88%
Clinical trial name (if EE)	100%	99%	100%	100%

NB: 14 forms (12 patients) where age is unknown included in all ages category only

Appendix 1: TYAC Notification Form

TYA CENTRE: PATIENT NOTIFICATION			
(for ages 15 to 24 years)			
Surname/family name			
Forenames			
Address			
Postcode			
Country of residence at diagnosis			
Town of birth	Country of birth		
Birth date	Sex		
Ethnic group			
NHS number			
Registering trust			
Patient's hospital number			
Referring trust			
Referring consultant (name)			
Specialty of referring consultant			
Was diagnosis made at this trust?			
Reason for referral to registering trust			
Other reason for referral			
Main treating trust for this diagnosis			
Other hospital name			
Consultant (name)			
Specialty of consultant at treating trust			
Other specialist treating trust for this diagnosis			
Shared Care Hospital trust at first diagnosis			
Is patient in a clinical trial?			
Name of clinical trial			
Diagnosis (histological type of tumour)			
Please attach copy of pathology report, immuno-phenotyping, cytogenetics	For leukaemia please give highest pre-treatment leucocyte count in box below as applicable:		
Primary site			
Laterality			
Date of diagnosis	Age at diagnosis	0	
Date used as date of diagnosis (see Code List 2)			
Basis for diagnosis			
Pathologist	Path lab number		
Stage	Staging system		
If this is a second or subsequent primary tumour give brief details of previous primary(ies):			
Diagnosis 1	Date 1		
Diagnosis 2	Date 2		
If patient is from a multiple birth give sex (M or F) of twin etc. sibship including case:			
Other conditions in the patient (see Code List 8 Congenital Anomalies for instructions):			
DIAGNOSTIC MDT(S)			
Name	Date		
Name	Date		
TREATMENT DECISIONS AT MDT(S)			
Chemo	Start date		
Radio	Start date		
Surgery	Start date		
Other	Start date		

Form completed by: _____ Date: _____

Appendix 2: TYA Diagnostic Classification

The diagnostic classification used throughout this report is the latest version of the TYA diagnostic groupings described by Birch et al (2002). This latest version is based on ICD03 morphology and topography. An additional classification group of “other” has been included here to comprise non-malignant non-CNS diagnoses which are not usually captured by cancer registration, and a small number of cases where there was insufficient morphological information to classify the diagnosis.

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
 - 1.4.2. Other and unspecified myeloid leukaemias
 - 1.4.3. Other specified leukaemias, NEC
 - 1.4.4. Unspecified leukaemia

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 & Intraspinial 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 (Medulloblastoma)
 - 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 Extraskkeletal 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 histiocyoma
 - 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 neoplasms NEC
 - 9.2.4. Other specified neoplasms NEC

GROUP 10 – Unspecified Malignant Neoplasms NEC

Group “Other”: non-malignant non-CNS diagnoses registered by TYAC

1. Aplastic anaemia
2. Carcinoid tumour
3. Desmoid tumour
4. Fibromatosis
5. Ganglioneuroma
6. Gestational trophoblastic neoplasm
7. Haematoma
8. Hydatidiform mole
9. Juvenile granulosa cell tumour
10. Langerhans
11. Lymphoproliferative disorder
12. MDS
13. Myofibroblastic
14. Neurofibromatosis
15. Non malignant neoplasms
16. Non Seminomatous Germ Cell Tumour
17. Non-malignant tumour
18. Teratoma
19. Other

Appendix 3: Annual number of new cases diagnosed and registered in England, by TYA diagnostic group and SHA of residence (2005 – 2007)

TYA Diagnostic Group	North East	North West	Yorkshire and the Humber	East Midlands	West Midlands	East of England	London	South East	South Central	South West	England
Leukaemias	5	19	19	8	21	14	21	13	10	16	146
Lymphomas	17	47	34	35	36	37	52	29	36	34	357
CNS and other intracranial and intraspinal neoplasms*	12	31	18	11	17	18	20	13	17	21	176
Osseous and chondromatous neoplasms, ewing tumour and other neoplasms of bone	6	13	14	5	11	10	14	6	7	10	98
Soft tissue sarcomas	7	16	5	7	9	7	15	5	5	8	85
Germ cell and trophoblastic neoplasms	12	36	29	23	31	27	28	25	25	23	259
Melanoma and skin carcinomas	15	52	42	26	29	24	19	20	30	32	288
Carcinomas	17	47	41	26	35	29	53	25	31	30	333
Misc specified	1	2	1	1	3	0	3	1	1	2	13
Misc unspecified	0	2	0	0	0	0	0	1	0	1	4
Unclassified	0	0	0	1	1	0	2	2	1	0	7
Total	92	265	204	143	192	166	228	139	162	177	1767

Source: NWCIS' national TYA cancer database – collated using the NCIN NCDR (1990-2007)

Appendix 4: Annual number of new cases diagnosed and registered in England, by TYA diagnostic group and cancer network of residence (2005 – 2007)

Cancer network	Leukaemias	Lymphomas	CNS and other intracranial and intraspinal neoplasms*	Osseous and chondromatous neoplasms, ewing tumour and other neoplasms of bone	Soft tissue sarcomas	Germ cell and trophoblastic neoplasms	Melanoma and skin carcinomas	Carcinomas	Other	Total
Lancashire and South Cumbria	4	9	7	4	3	8	10	9	0	55
Greater Manchester and Cheshire	8	21	15	4	8	16	21	25	3	122
Merseyside and Cheshire	6	15	8	5	5	12	18	11	0	78
Yorkshire	11	18	8	7	3	17	21	18	1	104
Humber and Yorkshire Coast	3	8	4	5	1	6	6	11	0	44
North Trent	6	12	6	2	2	9	18	14	0	69
Pan Birmingham	6	14	5	4	4	12	13	14	2	74
Arden	6	7	6	2	1	4	4	7	0	37
Mount Vernon	3	8	3	1	1	6	4	7	0	33
West London	5	12	6	5	4	6	4	15	1	59
North London	4	12	4	3	3	8	3	8	2	48
North East London	5	11	2	3	3	4	2	13	0	44
South East London	5	8	4	2	2	5	3	10	2	42
South West London	3	12	6	1	4	7	8	9	0	51
Peninsula	5	12	9	5	3	7	14	12	0	68
Dorset	3	4	3	1	1	3	3	4	1	22
Avon, Somerset and Wiltshire	5	14	8	3	3	9	9	11	1	64
3 Counties	2	8	3	1	2	8	5	6	1	36
Thames Valley	5	23	10	5	3	14	15	17	1	93
Central and South Coast	7	14	7	3	2	13	17	14	0	77
Surrey, West Sussex and Hampsh	1	8	3	1	1	7	9	6	0	36
Sussex	4	7	1	3	2	7	4	5	1	34
Kent and Medway	7	13	6	1	1	10	6	13	1	58
Greater Midlands	8	10	5	5	3	8	11	10	1	60
North of England	6	20	14	6	7	14	18	20	1	107
Anglia	8	21	10	5	4	15	14	12	0	89
Essex	2	6	3	2	1	5	5	9	0	34
East Midlands	7	32	10	6	7	21	23	24	1	131
England	146	357	176	98	85	259	288	333	24	1767

Source: NWCIS' national TYA cancer database – collated using the NCIN NCDR (1990-2007)



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