

Frequency of non-specific morphology
codes (ICD-O M) within the National
Cancer Data Repository (2007-09) for
cancer in Teenagers and Young Adults
(TYA)
CTYA SSCRG

Data quality report on the frequency of non-specific morphology codes (ICD-O M) recorded within the National Cancer Data Repository (2007-09) for cancer in Teenagers and Young Adults (TYA)

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TABLE OF CONTENTS

LIST OF TABLES.....	3
BACKGROUND.....	4
METHODS.....	6
RESULTS.....	7
A. NON-SPECIFIC GENERAL MORPHOLOGY CODES.....	7
B. LEUKAEMIA	8
C. LYMPHOMA.....	9
D. CNS AND OTHER INTRACRANIAL AND INTRASPINAL NEOPLASMS.....	10
E. SOFT TISSUE SARCOMA.....	11
F. OVARY	12
DISCUSSION.....	13
REFERENCES	15
APPENDIX.....	16
ACKNOWLEDGEMENTS	25

LIST OF TABLES

- Table 1** Number and percentage of cases registered as "Neoplasm NOS" (ICD-O M8000-M8005) by cancer registry and age group in 2007-2009
- Table 2** Number and percentage of cases of leukaemia registered with a non-specific morphology code by age group in 2007-2009
- Table 3** Number and percentage of cases of leukaemia registered with a non-specific morphology code (ICD-O M9800, M9801, M9820 and M9860) by cancer registry and age group in 2007-2009
- Table 4** Number and percentage of cases of lymphomas registered as "Lymphoma NOS" (ICD-O M9590) by cancer registry and age group in 2007-2009
- Table 5** Number and percentage of cases of CNS and other intracranial and intraspinal malignant neoplasms registered as "Glioma NOS" (ICD-O M9380) by cancer registry and age group in 2007-2009
- Table 6** Number and percentage of cases of soft tissue sarcomas registered as "Sarcoma NOS" (ICD-O M8800) by cancer registry and age group in 2007-2009
- Table 7** Number and percentage of cases of ovarian cancer by morphological type by age group in 2007-2009
- Table 8** Number of cases of ovarian cancer by morphological type by cancer registry and age group in 2007-2009

BACKGROUND

The North West Cancer Knowledge and Intelligence Team and NW Cancer Registry together provide the lead registry function for cancer in teenagers and young adults which is one of the National Cancer Intelligence Network's (NCIN) twelve specialist cancer areas. Each lead intelligence and registry team supports a National Cancer Intelligence Network Site Specific Clinical Reference Group (NCIN SSCRG) for their respective specialist area or tumour site. One of the roles of these lead areas is to examine the completeness and quality of cancer registration data and other routine NHS data sets that form the basis of much of the cancer intelligence published by NCIN and others as well as informing many research projects.

The aim of this data quality report is to examine the frequency of non-specific morphology codes within the National Cancer Data Repository (NCDR) for cancers relevant to teenagers and young adults.

The availability of accurate and detailed morphology codes is important when undertaking detailed descriptive epidemiological analyses and assessing the appropriateness of patient management at a sub-group level. This is particularly so when undertaking analyses on the spectrum of cancers seen in teenagers and young adults. The classification of cancers in terms of primary site according to the International Classification of Diseases (ICD) (World Health Organisation, 1975, 1992; Parkin *et al*, 1997) is broadly satisfactory for late age of onset, cancers which are mainly carcinomas, but in young people carcinomas are much less important numerically (Birch *et al* 2002). The types of cancer that are relevant to teenagers and young adults (15 to 24 year olds) are different than those in older adults and should be presented mainly in terms of morphology. For this purpose a diagnostic classification scheme was developed by Birch and colleagues (2002) based on morphology which is now widely adopted to provide an accurate picture of the cancers in this age group (see Appendix 3). Where only non-specific morphology codes are available, this classification system becomes much less informative.

The National Cancer Data Repository (NCDR) is a merged dataset of all cancer registrations of patients diagnosed in England. The data contain details of each cancer diagnosis and treatment, and demographic information about cancer patients. Site codes within the 2009 NCDR are all classified according to the International Classification of Diseases, Tenth Revision (ICD10). Morphologies are classified either as ICD-02 or ICD-03.

Here we provided details of the number and percentage of cases diagnosed that have only a non-specific general code (e.g. neoplasm NOS) or a code that provides only limited information about the diagnosis (e.g. Glioma NOS) for a selection of diagnosis types relevant to teenagers and young adults. These analyses are provided by age, diagnosis and cancer registry. Cancer registrations are still captured regionally although now registered into a central data system. Cancer data relevant to all new diagnoses are submitted by hospitals and other NHS organisations to their respective regional registries. The regional registries then collate and register all of the information into a central database called Encore. Information on diagnosis that enables a morphological code to be recorded at the point of registration for each cancer diagnosis can be derived from a number of sources, both clinical and diagnostic. Additional information on the basis of diagnosis recorded at the time of registration is also provided here (see Appendix 3-12) as background information on how morphological codes may be derived including which cases have been microscopically verified.

METHODS

Data on all patients aged 0 to 49 years, who were diagnosed between 2007 and 2009 in England, were extracted from the 2009 edition of the National Cancer Data Repository (NCDR). TYA patients have been classified into 15-18 and 19-24 year age groups. The age groups 0-14 and 25-49 years have been used for comparison.

The following morphology codes were chosen as they do not usually allow patients to be classified to a specific diagnostic group for the purposes of descriptive epidemiology or for assessing the appropriateness of their management. However, it should be remembered that several of these are the correct morphological code for certain tumour subtypes.

General non-specific codes (*CNS tumours only)

- *Neoplasm, benign (ICD-O M8000)**
- *Neoplasm, uncertain whether benign or malignant (ICD-O M8000)**
- *Neoplasm, malignant (ICD-O M8000)*
- *Tumour cells, benign (ICD-O M8001)**
- *Tumour cells, uncertain whether benign or malignant (ICD-O M8001)**
- *Tumour cells, malignant (ICD-O M8001)*
- *Malignant tumour, small cell type (ICD-O M8002)*
- *Malignant tumour, giant cell type (ICD-O M8003)*
- *Malignant tumour, spindle cell type (ICD-O M8004)*
- *Clear cell tumour, NOS (ICD-O M8005)*
- *Malignant tumour, clear cell type (ICD-O M8005)*

Leukaemia

- *Leukaemia, NOS (ICD-O M9800)*
- *Acute leukaemia, NOS (ICD-O M9801)*
- *Lymphoid leukaemia, NOS (ICD-O M9820)*
- *Myeloid leukaemia, NOS (ICD-O M9860)*

Lymphoma

- *Malignant lymphoma, NOS (ICD-O M9590)*

CNS and other intracranial and intraspinal neoplasms

- *Glioma, malignant (ICD-O M9380)*

Soft Tissue Sarcomas

- *Sarcoma, NOS (ICD-O M8800)*

We have also included a breakdown of ovarian cancers by morphology, as the relative proportions which are germ cell tumours and carcinomas are of interest. The following categories have been used:

- *Carcinomas (ICD-O M8010-M8576)*
- *Germ cell (ICD-O M9060-M9105)*
- *Other specific (ICD-O M8590-M9055 and M9110-M9989)*
- *Non-specific (ICD-O M8000-M8005)*

RESULTS

A. NON-SPECIFIC GENERAL MORPHOLOGY CODES

Table 1: Number and percentage of cases registered as "Neoplasm NOS" (ICD-O M8000-M8005) by cancer registry and age group in 2007-2009

Cancer Registry	0-14		15-18		19-24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
NYCRIS	3	1%	3	1%	6	1%	9	1%	115	1%	127	1%
TCR	12	3%	6	4%	10	2%	16	3%	129	1%	157	1%
ECRIC	3	1%	1	1%	5	1%	6	1%	40	0%	49	0%
THAMES	29	3%	12	3%	17	2%	29	2%	284	1%	342	2%
OCIU	11	5%	3	5%	11	4%	14	5%	199	3%	224	3%
SWCIS	35	7%	17	8%	27	5%	44	6%	725	5%	804	5%
WMCIU	7	2%	1	1%	3	1%	4	1%	33	0%	44	0%
NWCIS	39	8%	31	12%	50	9%	81	10%	537	4%	657	4%
ENGLAND	139	3%	74	5%	129	3%	203	4%	2,062	2%	2,404	2%
TOTAL CASES	4,036		1,615		4,068		5,683		97,512		107,231	

B. LEUKAEMIA

Table 2: Number and percentage of cases of leukaemia registered with a non-specific morphology code by age group in 2007-2009

Vague Morphology Code	0-14		15-18		19-24		15-24		25-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
Leukaemia, NOS (ICD-O M9800)	8	1%	5	2%	2	1%	7	1%	12	1%
Acute Leukaemia, NOS (ICD-O M9801)	16	1%	7	3%	7	2%	14	3%	17	1%
Lymphoid Leukaemia, NOS (ICD-O M9820)	22	2%	1	0%	2	1%	3	1%	19	1%
Myeloid Leukaemia, NOS (ICD-O M9860)	7	1%	1	0%	8	3%	9	2%	23	1%
All leukaemias	1,177		216		285		501		1,967	

Table 3: Number and percentage of cases of leukaemia registered with a non-specific morphology code (ICD-O M9800, M9801, M9820 and M9860) by cancer registry and age group in 2007-2009

Cancer Registry	0-14		15-18		19-24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
NYCRIS	3	2%	1	3%	1	3%	2	3%	4	2%	9	2%
TCR	2	2%	1	6%	0		1	2%	3	2%	6	2%
ECRIC	0		2	10%	1	5%	3	8%	2	1%	5	1%
THAMES	9	3%	2	4%	2	3%	4	3%	14	3%	27	3%
OCIU	2	3%	1	10%	2	12%	3	11%	3	2%	8	3%
SWCS	26	17%	3	15%	6	14%	9	14%	29	11%	64	13%
WMCIU	1	1%	1	4%	1	4%	2	4%	4	2%	7	2%
NWCIS	10	7%	3	7%	6	14%	9	11%	12	4%	31	6%
ENGLAND	53	5%	14	6%	19	7%	33	7%	71	4%	157	4%

C. LYMPHOMA

Table 4: Number and percentage of cases of lymphoma registered as "Lymphoma NOS" (ICD-0 M9590) by cancer registry and age group in 2007-2009

Cancer Registry	0-14		15-18		19-24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
NYCRIS	0		0		0		0		8	1%	8	1%
TCR	5	9%	1	2%	4	6%	5	4%	28	5%	38	5%
ECRIC	1	2%	1	2%	0		1	1%	15	3%	17	2%
THAMES	6	5%	5	6%	6	3%	11	4%	107	7%	124	7%
OCIU	0		0		0		0		4	1%	4	1%
SWCS	1	2%	1	2%	1	1%	2	1%	45	6%	48	5%
WMCIU	1	3%	0		0		0		10	2%	11	2%
NWCS	1	2%	0		1	1%	1	1%	39	6%	41	5%
ENGLAND	15	4%	8	2%	12	2%	20	2%	256	5%	291	4%

Though the morphology code lymphoma NOS does not allow one to distinguish between NHL and HL (there are separate codes for NHL NOS and HL NOS), the vast majority of cases with this code have been allocated by the relevant registry to NHL in ICD-10. It is not clear how this has occurred and whether a more specific morphology code should have been used.

D. CNS AND OTHER INTRACRANIAL AND INTRASPINAL NEOPLASMS

Table 5: Number and percentage of cases of CNS and other intracranial and intraspinal malignant neoplasms registered as "Glioma NOS" (ICD-0 M9380) by cancer registry and age group in 2007-2009

Cancer Registry	0-14		15-18		19-24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
NYCRIS	23	19%	1	3%	2	4%	3	3%	15	2%	41	5%
TCR	14	13%	0		2	3%	2	2%	15	3%	31	4%
ECRIC	12	10%	4	11%	0		4	5%	15	3%	31	4%
THAMES	35	15%	5	10%	7	9%	12	9%	30	3%	77	5%
OClU	15	23%	0		0		0		9	3%	24	6%
SWCS	14	11%	2	7%	3	6%	5	7%	24	3%	43	4%
WMClU	12	11%	2	8%	1	3%	3	5%	7	2%	22	4%
NWCS	16	12%	1	2%	0		1	1%	15	2%	32	4%
ENGLAND	141	14%	15	6%	15	4%	30	4%	130	3%	301	5%

E. SOFT TISSUE SARCOMA

Table 6: Number and percentage of cases of soft tissue sarcomas registered as "Sarcoma NOS" (ICD-0 M8800) by cancer registry and age group in 2007-2009

Cancer Registry	0-14		15-18		19-24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
NYCRIS	0		1	14%	2	12%	3	13%	16	7%	19	7%
TCR	0		2	15%	2	9%	4	11%	10	6%	14	7%
ECRIC	5	19%	0		0		0		14	8%	19	8%
THAMES	6	10%	2	12%	2	4%	4	6%	52	8%	62	8%
OCIU	0		0		1	11%	1	8%	10	7%	11	7%
SWCS	1	3%	3	33%	3	13%	6	18%	20	9%	27	10%
WMCIU	0		1	9%	1	20%	2	13%	8	5%	10	5%
NWCS	2	8%	1	6%	0		1	3%	14	6%	17	6%
ENGLAND	14	6%	10	11%	11	7%	21	9%	144	7%	179	7%

F. OVARY

Table 7: Number and percentage of cases of ovarian cancer by morphological type by age group in 2007-2009

Vague Morphology Code	0-14		15-18		19-24		15-24		25-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
Carcinomas (ICD-O M8010-M8576)	8	17%	26	38%	134	73%	160	63%	2,539	91%
Germ cell (ICD-O M9060-M9105)	35	74%	35	51%	43	23%	78	31%	104	4%
Other specific (ICD-O M8590-M9055 & M9110-M9989)	3	6%	7	10%	3	2%	10	4%	78	3%
Non-specific (ICD-O M8000-M8005)	1	2%	1	1%	3	2%	4	2%	68	2%
All ovarian cases	47		69		183		252		2,789	

Table 8: Number of cases of ovarian cancer by morphological type by cancer registry and age group in 2007-2009

Cancer Registry	Carcinomas			Germ cell			Other specific			Non-specific		
	0-14	15-24	25-49	0-14	15-24	25-49	0-14	15-24	25-49	0-14	15-24	25-49
NYCRIS	3	17	318	5	9	13	0	1	5	0	0	4
TCR	0	22	294	2	9	9	0	0	6	0	0	9
ECRIC	0	24	309	6	6	10	1	0	6	0	0	0
THAMES	0	40	545	5	18	31	1	4	24	0	2	6
OCIU	0	2	129	2	3	8	1	0	2	0	0	7
SWCIS	1	24	367	6	15	14	0	1	13	0	0	12
WMCIU	3	10	290	4	10	9	0	3	11	0	0	0
NWCIS	1	21	287	5	8	10	0	1	11	1	2	30
ENGLAND	8	160	2539	35	78	104	3	10	78	1	4	68

DISCUSSION

Knowing the histological or morphological type of cancer for TYA patients is very important, as the diagnostic classification and management of patients are largely based on the histological type of tumour. We, therefore, decided to review the proportion of TYA patients with a non-specific morphological diagnosis, based on the International Classification of Diseases for Oncology Morphology (M) code, as a measure of the quality of data on the National Cancer Registry Database.

We used non-specific codes at two levels. The first, which we termed general non-specific codes, refers to when a patient was allocated a M code of tumour/neoplasm/cancer not otherwise specified (NOS), with or without a simple descriptive term such as small, giant or spindle shaped. It is not possible to classify most patients with this code into one of the specific major diagnostic groups in the TYA cancer classification system (Birch et al 2002). There are another group of NOS M codes, which allow the patient to be allocated to one of the major diagnostic groups but provide no further details. An example is soft tissue sarcoma NOS. Analyses have been undertaken for such codes. ICD-O includes a third larger group of NOS codes, for example fibrosarcoma NOS, most of which provide sufficient information for the types of analyses that are undertaken on datasets based on cancer registration. We have not included analyses on such codes in this report.

Three percent of TYA patients diagnosed with cancer in 2007-2009 in England were allocated a non-specific general code; this varied by registry from 1% to 9%. A higher proportion of patients with Leukaemia (7%), CNS tumours (7%) and STS (9%) had non-specific codes than had patients with lymphoma or ovarian tumours. The proportion of patients with leukaemia, CNS tumours and STS was higher than 10% for several registries, though such % was often based on only a handful of cases. Results for TYA patients are generally similar to those for the 0-14 and 25-49 age groups.

There are a number of reasons why patients may be allocated a non-specific morphology code. The amount of data available on a given patient's tumour may be limited, especially if the tumour was not verified microscopically. Several codes which we have included as non-specific, such as sarcoma NOS and glioma NOS, are the correct morphological codes for certain subtypes of tumour. It is, therefore, to be expected that a proportion of patients will be given a non-specific morphology code. However, this notwithstanding may also be indicative of difficulties in cancer registries accessing all information relating to any one patient. This may particularly be the case if patients are managed by more than one Trust and the flow of data from Trust to Registry is impeded.

If more than 5%, and definitely more those 10%, of patients within a given diagnostic group (or of all cancers with a non-specific general code), are allocated a non-specific M code and if this based on more than a few cases, steps should be taken to understand the reasons and where possible to decrease the problem.

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APPENDIX

Table A1: TYA diagnostic classification system (version 12)

GROUP 1 – Leukaemias	5.3.4 Clear cell sarcoma
1.1 Acute lymphoid leukaemia (ALL)	5.3.5 Blood vessel tumours
1.2 Acute myeloid leukaemia (AML)	5.3.6 Nerve sheath tumours
1.3 Chronic myeloid leukaemia (CML)	5.3.7 Alveolar soft part sarcoma
1.4 Other and unspecified leukaemia (Other Leuk)	5.3.8 Miscellaneous specified soft tissue sarcoma
1.4.1 Other and unspecified lymphoid leukaemias	5.4 Unspecified soft tissue sarcomas
1.4.2 Other and unspecified myeloid leukaemias	
1.4.3 Other specified leukaemias, NEC	
1.4.4 Unspecified leukaemia	
GROUP 2 – Lymphomas	GROUP 6 – Germ Cell & Trophoblastic Neoplasms (Germ cell tumours)
2.1 Non-Hodgkin lymphoma (NHL)	6.1 Gonadal germ cell & trophoblastic neoplasms
2.1.1 Non-Hodgkin lymphoma, specified subtype	6.2 Germ cell & trophoblastic neoplasms of non-gonadal sites
2.1.2 Non-Hodgkin lymphoma, subtype not specified	6.2.1 Intracranial germ cell and trophoblastic tumours
2.2 Hodgkin lymphoma (HL)	6.2.2 Other non-gonadal germ cell and trophoblastic tumours
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)	GROUP 7 – Melanoma and Skin Carcinoma
3.1 Astrocytoma	7.1 Melanoma
3.1.1 Pilocytic astrocytoma	7.2 Skin carcinoma
3.1.2 Other low grade astrocytoma	
3.1.3 Glioblastoma and anaplastic astrocytoma	GROUP 8 – Carcinomas (except of skin)
3.1.4 Astrocytoma not otherwise specified	8.1 Carcinoma of thyroid
3.2 Other gliomas	8.2 Other carcinoma of head and neck
3.2.1 Oligodendroglioma	8.2.1 Nasopharyngeal carcinoma
3.2.2 Other specified glioma	8.2.2 Carcinoma of other sites in lip oral cavity and pharynx
3.2.3 Glioma NOS	8.2.3 Carcinoma of nasal cavity, middle ear, sinuses, larynx and other ill-defined sites in head and neck
3.3 Ependymoma	8.3 Carcinoma of trachea, bronchus, lung and pleura
3.4 Medulloblastoma and other primitive neuroectodermal tumours (Medulloblastoma)	8.4 Carcinoma of breast
3.4.1 Medulloblastoma	8.5 Carcinoma of genito-urinary (GU) tract
3.4.2 Supratentorial PNET	8.5.1 Carcinoma of kidney
3.5 Other specified intracranial and intraspinal neoplasms (Other CNS)	8.5.2 Carcinoma of bladder
3.5.1 Craniopharyngioma	8.5.3 Carcinoma of ovary
3.5.2 Pituitary tumours	8.5.4 Carcinoma of cervix
3.5.3 Pineal tumours	8.5.5 Carcinoma of other and ill-defined sites in GU
3.5.4 Choroid plexus tumours	8.6 Carcinoma of gastro-intestinal (GI) tract
3.5.5 Meningioma	8.6.1 Carcinoma of colon and rectum
3.5.6 Nerves sheath tumour of the brain	8.6.2 Carcinoma of stomach
3.5.7 Other specified tumours	8.6.3 Carcinoma of liver and intrahepatic bile ducts
3.6 Unspecified intracranial and intraspinal neoplasms tumours	8.6.4 Carcinoma of pancreas
3.6.1 Unspecified malignant intracranial and intraspinal neoplasms	8.6.5 Carcinoma of other and ill-defined sites in GI tract
3.6.2 Unspecified non-malignant intracranial and intraspinal neoplasms	8.7 Carcinomas of other & ill-defined sites not elsewhere classified (NEC)
GROUP 4 – Osseous and Chondromatous Neoplasms, Ewing Ewing tumour and other Neoplasms of Bone (Bone Tumours)	8.7.1 Adrenocortical carcinoma
4.1 Osteosarcoma	8.7.2 Other carcinomas NEC
4.2 Chondrosarcoma	GROUP 9 – Miscellaneous Specified Neoplasms NEC
4.3 Ewing sarcoma	9.1 Embryonal tumours NEC
4.3.1 Ewing sarcoma of bone	9.1.1 Wilms tumour
4.3.2 Extraskeletal Ewing sarcoma	9.1.2 Neuroblastoma
4.3.3 Ewing sarcoma of unknown site	9.1.3 Other embryonal tumours NEC
4.4 Other specified and unspecified bone tumours (Other bone tumours)	9.2 Other rare miscellaneous specified neoplasms
4.4.1 Other specified bone tumours	9.2.1 Paraganglioma and glomus tumours
4.4.2 Unspecified bone tumours	9.2.2 Other specified gonadal tumours NEC
GROUP 5 – Soft Tissue Sarcomas (STS)	9.2.3 Myeloma, mast cell tumours and miscellaneous reticuloendothelial neoplasms NEC
5.1 Fibromatous neoplasms (Fibrosarcoma)	9.2.4 Other specified neoplasms NEC
5.1.1 Fibrosarcoma	GROUP 10 – Unspecified Malignant Neoplasms NEC
5.1.2 Malignant fibrous histiocytoma	GROUP “OTHER”: non-malignant non-CNS diagnoses registered by TYAC
5.1.3 Dermatofibrosarcoma	1. Aplastic anaemia
5.2 Rhabdomyosarcoma	2. Carcinoid tumour
5.3 Other specified soft tissue sarcomas	3. Desmoid tumour
5.3.1 Liposarcoma	4. Fibromatosis
5.3.2 Leiomyosarcoma	5. Ganglioneuroma
5.3.3 Synovial sarcoma	6. Gestational trophoblastic neoplasm
	7. Haematoma
	8. Hydatidiform mole
	9. Juvenile granulosa cell tumour
	10. Langerhans
	11. Lymphoroliftrative 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

Table A2: Cancer registry codes

Cancer Registry Name		Code
NYCRIS	Northern and Yorkshire Cancer Registry and Information Service	Y0201
TCR	Trent Cancer Registry	Y0301
ECRIC	Eastern Cancer Registration and Information Centre	Y0401
THAMES	Thames Cancer Registry	Y0801
OCIU	Oxford Cancer Intelligence Unit	Y0901
SWCIS	South West Cancer Intelligence Service	Y1001
WMCIU	West Midlands Cancer Intelligence Unit	Y1201
NWCIS	North West Cancer Intelligence Service	Y1701

Table A3: Basis of diagnosis codes recommended by the International Agency for Research on Cancer (IARC) for each cancer registration

Code	Description	Criteria
0	Death certificate only	Information provided is from a death certificate.
Non-microscopic	1 Clinical	Diagnosis made before death, but without any of the following (codes 2-7).
	2 Clinical investigation	All diagnostic techniques, including X-ray, endoscopy, imaging, ultrasound, exploratory surgery and autopsy, without a tissue diagnosis.
	4 Specific tumour markers	Including biochemical and/or immunologic markers that are specific for a tumour site.
Microscopic	5 Cytology	Examination of cells from a primary or secondary site, including fluids aspirated by endoscopy or needle; also includes the microscopic examination of peripheral blood and bone marrow aspirates.
	6 Histology of a metastasis	Histologic examination of tissue from a metastasis, including autopsy specimens.
	7 Histology of a primary tumour	Histologic examination of tissue from primary tumor, however obtained, including all cutting techniques and bone marrow biopsies; also includes autopsy specimens of primary tumor.
9	Unknown	

For the analyses on patients with a basis of diagnosis which was microscopically verified (Codes 5 to 7 in Table A3), the tumour groups included were:

- a. Leukaemia
 - *Acute Lymphoblastic Leukaemia (ALL)*
 - *Acute Myeloid Leukaemia (AML)*
 - *Other Leukaemias*
- b. Lymphoma
 - *Non Hodgkin Lymphoma (NHL)*
 - *Hodgkin Lymphoma (HL)*
- c. CNS and other Intracranial and Intraspinial Neoplasms
 - *Benign*
 - *Borderline*
 - *Malignant*
- d. Soft Tissue Sarcomas (STS)
- e. Germ Cell Tumours of the Ovary
- f. Carcinomas of the Ovary

Table A4: Basis of diagnosis codes for acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML) and other leukaemias (groups 1.3 and 1.4 in Table A1) by age group in 2007-09

	Basis of Diagnosis	0 - 14		15 - 18		19 - 24		15-24		25-49		0-49	
		no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
ALL	0 Death Certificate Only	1	0%	1	1%	0		1	0%	3	1%	5	0%
	1 Clinical	44	5%	8	8%	4	4%	12	6%	12	4%	68	5%
	2 Clinical investigation	0		0		0		0		0		0	
	4 Specific tumour markers	0		0		0		0		0		0	
	5 Cytology	184	20%	22	21%	27	26%	49	23%	60	22%	293	21%
	6 Histology of a metastasis	0		0		1	1%	1	0%	1	0%	2	0%
	7 Histology of a primary tumour	675	74%	74	70%	73	70%	147	70%	188	70%	1,010	73%
	9 Unknown	3	0%	0		0		0		3	1%	6	0%
	Total	907		105		105		210		267		1,384	
<i>5to7 Total MV</i>	<i>859</i>	<i>95%</i>	<i>96</i>	<i>91%</i>	<i>101</i>	<i>96%</i>	<i>197</i>	<i>94%</i>	<i>249</i>	<i>93%</i>	<i>1,305</i>	<i>94%</i>	
AML	0 Death Certificate Only	1	1%	0		0		0		6	1%	7	1%
	1 Clinical	7	4%	5	7%	10	9%	15	8%	78	10%	100	9%
	2 Clinical investigation	0		1	1%	0		1	1%	3	0%	4	0%
	4 Specific tumour markers	0		1	1%	0		1	1%	1	0%	2	0%
	5 Cytology	35	19%	20	28%	33	30%	53	29%	215	27%	303	26%
	6 Histology of a metastasis	0		0		0		0		0		0	
	7 Histology of a primary tumour	137	76%	45	63%	66	61%	111	61%	482	61%	730	63%
	9 Unknown	0		0		0		0		6	1%	6	1%
	Total	180		72		109		181		791		1,152	
<i>5to7 Total MV</i>	<i>172</i>	<i>96%</i>	<i>65</i>	<i>90%</i>	<i>99</i>	<i>91%</i>	<i>164</i>	<i>91%</i>	<i>697</i>	<i>88%</i>	<i>1,033</i>	<i>90%</i>	
Other	0 Death Certificate Only	2	2%	0	0%	1	1%	1	1%	1	0%	4	0%
	1 Clinical	8	9%	3	8%	9	13%	12	11%	85	9%	105	9%
	2 Clinical investigation	0		0		0		0		5	1%	5	0%
	4 Specific tumour markers	0		0		0		0		9	1%	9	1%
	5 Cytology	30	33%	8	21%	17	24%	25	23%	259	29%	314	28%
	6 Histology of a metastasis	0		0		0		0		0		0	
	7 Histology of a primary tumour	48	53%	28	72%	44	62%	72	65%	541	60%	661	60%
	9 Unknown	2	2%	0		0		0		7	1%	9	1%
	Total	90		39		71		110		907		1,107	
<i>5to7 Total MV</i>	<i>78</i>	<i>87%</i>	<i>36</i>	<i>92%</i>	<i>61</i>	<i>86%</i>	<i>97</i>	<i>88%</i>	<i>800</i>	<i>88%</i>	<i>975</i>	<i>88%</i>	

Table A5: Number and percentage of cases of acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML) and other leukaemias (groups 1.3 and 1.4 in Table A1) microscopically verified by cancer registry and age group in 2007-09

	Cancer Registry	0 - 14		15 - 18		19 -24		15-24		25-49	
		no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
ALL	NYCRIS	113	100%	20	100%	11	100%	31	100%	33	100%
	TCR	85	99%	10	100%	14	100%	24	100%	28	97%
	ECRIC	90	97%	9	100%	9	100%	18	100%	22	96%
	THAMES	228	97%	18	95%	20	95%	38	95%	70	93%
	OCIU	56	100%	5	100%	8	100%	13	100%	19	100%
	SWCIS	106	100%	12	100%	21	100%	33	100%	35	100%
	WMCIU	107	96%	10	91%	9	100%	19	95%	20	83%
	NWCIS	74	69%	12	63%	9	75%	21	68%	22	76%
AML	NYCRIS	28	100%	10	100%	19	100%	29	100%	93	98%
	TCR	26	100%	4	100%	7	100%	11	100%	70	97%
	ECRIC	24	100%	7	100%	5	100%	12	100%	86	98%
	THAMES	47	98%	18	90%	28	97%	46	94%	150	90%
	OCIU	8	100%	4	100%	5	100%	9	100%	55	100%
	SWCIS	16	100%	3	100%	14	100%	17	100%	104	98%
	WMCIU	19	95%	8	100%	10	83%	18	90%	70	84%
	NWCIS	4	40%	11	69%	11	61%	22	65%	69	55%
Other	NYCRIS	4	80%	4	100%	9	100%	13	100%	116	99%
	TCR	8	80%	4	100%	5	83%	9	90%	69	88%
	ECRIC	1	100%	4	100%	6	100%	10	100%	101	98%
	THAMES	10	83%	9	100%	18	95%	27	96%	193	93%
	OCIU	6	100%	1	100%	4	100%	5	100%	65	100%
	SWCIS	30	100%	5	100%	9	100%	14	100%	119	97%
	WMCIU	5	100%	6	100%	4	100%	10	100%	74	93%
	NWCIS	14	67%	3	50%	6	43%	9	45%	63	47%

Table A6: Basis of diagnosis codes for non Hodgkin lymphoma (NHL) and Hodgkin lymphoma (HL) by age group in 2007-09 (cases coded as lymphoma NOS have been included)

	Basis of Diagnosis	0 - 14		15 - 18		19 - 24		15-24		25-49		0-49	
		no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
NHL	0 Death Certificate Only	0		0		1	0%	1	0%	14	0%	15	0%
	1 Clinical	12	5%	9	8%	7	3%	16	5%	123	3%	151	4%
	2 Clinical investigation	4	2%	1	1%	1	0%	2	1%	18	0%	24	1%
	4 Specific tumour markers	0		0		0		0		0		0	
	5 Cytology	10	4%	3	3%	8	3%	11	3%	69	2%	90	2%
	6 Histology of a metastasis	0		0		0		0		4	0%	4	0%
	7 Histology of a primary tumour	202	88%	101	89%	219	92%	320	91%	3,392	93%	3,914	93%
	9 Unknown n	1	0%	0		1	0%	1	0%	8	0%	10	0%
	Total	229		114		237		351		3,628		4,208	
<i>5to7 Total MV</i>	<i>212</i>	<i>93%</i>	<i>104</i>	<i>91%</i>	<i>227</i>	<i>96%</i>	<i>331</i>	<i>94%</i>	<i>3,465</i>	<i>96%</i>	<i>4,008</i>	<i>95%</i>	
HL	0 Death Certificate Only	0		0		0		0		1	0%	1	0%
	1 Clinical	8	4%	6	2%	12	2%	18	2%	34	2%	60	2%
	2 Clinical investigation	0		1	0%	0		1	0%	2	0%	3	0%
	4 Specific tumour markers	0		0		0		0		0		0	
	5 Cytology	1	1%	3	1%	5	1%	8	1%	25	1%	34	1%
	6 Histology of a metastasis	0		0		0		0		0		0	
	7 Histology of a primary tumour	178	95%	237	96%	521	97%	758	96%	1,707	96%	2,643	96%
	9 Unknown n	0		0		1	0%	1	0%	4	0%	5	0%
	Total	187		247		539		786		1,773		2,746	
<i>5to7 Total MV</i>	<i>179</i>	<i>96%</i>	<i>240</i>	<i>97%</i>	<i>526</i>	<i>98%</i>	<i>766</i>	<i>97%</i>	<i>1,732</i>	<i>98%</i>	<i>2,677</i>	<i>97%</i>	

Table A7: Number and percentage of cases of non Hodgkin lymphoma (NHL) and Hodgkin lymphoma (HL) microscopically verified by cancer registry and age group in 2007-09

	Cancer Registry	0 - 14		15 - 18		19 - 24		15-24		25-49	
		no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
NHL	NYCRIS	22	96%	8	100%	34	100%	42	100%	397	99%
	TCR	32	97%	13	100%	27	96%	40	98%	384	98%
	ECRIC	27	90%	12	92%	20	100%	32	97%	343	98%
	THAMES	54	95%	30	97%	56	97%	86	97%	939	96%
	OClU	15	100%	3	100%	14	93%	17	94%	195	94%
	SWCIS	24	92%	16	84%	26	87%	42	86%	451	92%
	WMClU	16	89%	6	100%	15	94%	21	95%	314	98%
	NWCIS	22	81%	16	76%	35	97%	51	89%	442	90%
HL	NYCRIS	23	100%	41	98%	54	100%	95	99%	219	100%
	TCR	20	100%	32	100%	43	100%	75	100%	164	100%
	ECRIC	19	100%	29	97%	67	99%	96	98%	183	98%
	THAMES	55	100%	53	100%	137	99%	190	99%	481	98%
	OClU	12	100%	7	100%	36	100%	43	100%	98	100%
	SWCIS	15	100%	36	95%	72	94%	108	94%	208	95%
	WMClU	16	100%	20	100%	57	100%	77	100%	186	99%
	NWCIS	19	70%	22	88%	60	91%	82	90%	193	92%

Table A8: Basis of diagnosis codes for benign, borderline and malignant CNS and other intracranial and intraspinal neoplasm by age group in 2007-09

	Basis of Diagnosis	0 - 14		15 - 18		19 - 24		15-24		25-49		0-49	
		no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
Benign	0 Death Certificate Only	0		0		0		0		4	0%	4	0%
	1 Clinical	7	9%	6	13%	12	10%	18	11%	97	4%	122	5%
	2 Clinical investigation	12		5	10%	15	13%	20	12%	134	6%	166	7%
	4 Specific tumour markers	0		0		0		0		1	0%	1	0%
	5 Cytology	0		0		0		0		6	0%	6	0%
	6 Histology of a metastasis	0		0		0		0		0		0	
	7 Histology of a primary tumour	61	76%	37	77%	91	77%	128	77%	1,913	88%	2,102	87%
	9 Unknown n	0		0		0		0		10	0%	10	0%
	Total	80		48		118		166		2,165		2,411	
	5to7 Total MV	61	76%	37	77%	91	77%	128	77%	1,919	89%	2,108	87%
Borderline	0 Death Certificate Only	2	1%	0		1	1%	1	1%	14	3%	17	2%
	1 Clinical	16	7%	2	3%	4	5%	6	4%	33	7%	55	7%
	2 Clinical investigation	32	15%	5	8%	5	6%	10	7%	28	6%	70	9%
	4 Specific tumour markers	0		0		0		0		0		0	
	5 Cytology	1	0%	1	2%	0		1	1%	0		2	0%
	6 Histology of a metastasis	0		0		0		0		0		0	
	7 Histology of a primary tumour	165	76%	51	86%	68	86%	119	86%	379	82%	663	81%
	9 Unknown n	0		0		1	1%	1	1%	9	2%	10	1%
	Total	216		59		79		138		463		817	
	5to7 Total MV	166	77%	52	88%	68	86%	120	87%	379	82%	665	81%
Malignant	0 Death Certificate Only	3	0%	0		0		0		27	1%	30	1%
	1 Clinical	50	7%	16	10%	14	6%	30	8%	114	5%	194	6%
	2 Clinical investigation	118	16%	13		8	4%	21	6%	105	4%	244	7%
	4 Specific tumour markers	0		0		0		0		0		0	
	5 Cytology	2	0%	0		0		0		5	0%	7	0%
	6 Histology of a metastasis	1	0%	0		0		0		4	0%	5	0%
	7 Histology of a primary tumour	552	76%	128	82%	198	89%	326	86%	2,069	88%	2,947	85%
	9 Unknown n	0		0		2	1%	2	1%	18	1%	20	1%
	Total	726		157		222		379		2,342		3,447	
	5to7 Total MV	555	76%	128	82%	198	89%	326	86%	2,078	89%	2,959	86%

Table A9: Number and percentage of cases of benign, borderline and malignant CNS and other intracranial and intraspinal neoplasm by cancer registry and age group in 2007-09

	Cancer Registry	0 - 14		15 - 18		19 -24		15-24		25-49	
		no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
Benign	NYCRIS	5	83%	6	100%	8	100%	14	100%	258	93%
	TCR	4	67%	3	75%	15	79%	18	78%	201	85%
	ECRIC	5	50%	3	60%	8	47%	11	50%	193	79%
	THAMES	16	100%	10	91%	22	92%	32	91%	447	93%
	OCIU	4	57%	2	67%	6	86%	8	80%	140	92%
	SWCIS	6	50%	3	60%	14	78%	17	74%	288	83%
	WMCIU	7	78%	0	0%	2	50%	2	40%	147	92%
	NWCIS	14	100%	10	77%	16	76%	26	76%	245	91%

	Cancer Registry	0 - 14		15 - 18		19 -24		15-24		25-49	
		no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
Borderline	NYCRIS	27	96%	10	83%	9	100%	19	90%	42	89%
	TCR	14	82%	6	86%	11	100%	17	94%	50	89%
	ECRIC	8	62%	7	88%	9	64%	16	73%	42	84%
	THAMES	26	67%	9	90%	7	100%	16	94%	71	80%
	OCIU	11	92%	3	100%	7	100%	10	100%	19	83%
	SWCIS	14	70%	3	100%	4	67%	7	78%	52	69%
	WMCIU	34	72%	5	83%	11	100%	16	94%	34	92%
	NWCIS	32	80%	9	90%	10	71%	19	79%	69	80%

	Cancer Registry	0 - 14		15 - 18		19 -24		15-24		25-49	
		no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
Malignant	NYCRIS	64	76%	20	91%	34	94%	54	93%	292	96%
	TCR	70	82%	11	92%	30	94%	41	93%	193	92%
	ECRIC	75	79%	18	82%	20	100%	38	90%	229	91%
	THAMES	147	80%	22	81%	42	82%	64	82%	457	85%
	OCIU	33	72%	7	78%	15	100%	22	92%	122	87%
	SWCIS	68	68%	17	81%	18	78%	35	80%	322	83%
	WMCIU	42	78%	15	83%	23	96%	38	90%	189	95%
	NWCIS	56	71%	18	69%	16	76%	34	72%	274	88%

Table A10: Basis of diagnosis codes for soft tissue sarcomas by age group in 2007-09

Basis of Diagnosis	0 - 14		15 - 18		19 - 24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
0 Death Certificate Only	1	0%	0		0		0		8	0%	9	0%
1 Clinical	4	2%	2	2%	6	4%	8	3%	65	3%	77	3%
2 Clinical investigation	3	1%	1	1%	1	1%	2	1%	9	0%	14	1%
4 Specific tumour markers	0		0		0		0		0		0	
5 Cytology	1	0%	0		0		0		2	0%	3	0%
6 Histology of a metastasis	2	1%	1	1%	5	3%	6	2%	22	1%	30	1%
7 Histology of a primary tumour	205	94%	84	95%	142	92%	226	93%	1,825	95%	2,256	94%
9 Unknown	1	0%	0		0		0		0		1	0%
Total	217		88		154		242		1,931		2,390	
<i>5to7 Total MV</i>	<i>208</i>	<i>96%</i>	<i>85</i>	<i>97%</i>	<i>147</i>	<i>95%</i>	<i>232</i>	<i>96%</i>	<i>1,849</i>	<i>96%</i>	<i>2,289</i>	<i>96%</i>

Table A11: Number and percentage of cases of soft tissue sarcomas by cancer registry and age group in 2007-09

Cancer Registry	0 - 14		15 - 18		19 - 24		15-24		25-49	
	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
NYCRIS	26	100%	7	100%	17	100%	24	100%	225	100%
TCR	18	100%	13	100%	23	100%	36	100%	154	98%
ECRIC	25	93%	9	90%	13	93%	22	92%	179	96%
THAMES	57	92%	17	100%	44	98%	61	98%	592	95%
OCLU	7	100%	4	100%	8	89%	12	92%	139	94%
SWCIS	29	97%	7	78%	21	88%	28	85%	211	95%
WMCIU	22	100%	11	100%	5	100%	16	100%	159	98%
NWCIS	24	96%	17	100%	16	94%	33	97%	190	88%

Table A12: Basis of diagnosis codes for germ cell tumours of the ovary by age group in 2007-09

Basis of Diagnosis	0 - 14		15 - 18		19 - 24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
0 Death Certificate Only	0		0		0		0		0		0	
1 Clinical	1	3%	0		1	2%	1	1%	1	1%	3	1%
2 Clinical investigation	0		1	3%	0		1	1%	0		1	0%
4 Specific tumour markers	0		0		0		0		0		0	
5 Cytology	0		0		0		0		0		0	
6 Histology of a metastasis	0		0		1	2%	1	1%	2	2%	3	1%
7 Histology of a primary tumour	34	97%	34	97%	41	95%	75	96%	101	97%	210	97%
9 Unknown	0		0		0		0		0		0	
Total	35		35		43		78		104		217	
<i>5to7 Total MV</i>	34	97%	34	97%	42	98%	76	97%	103	99%	213	98%

Table A13: Number and percentage of cases of germ cell tumours of the ovary by cancer registry and age group in 2007-09

Cancer Registry	0 - 14		15 - 18		19 - 24		15-24		25-49	
	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
NYCRIS	5	100%	3	100%	6	100%	9	100%	13	100%
TCR	2	100%	3	100%	6	100%	9	100%	9	100%
ECRIC	6	100%	5	100%	1	100%	6	100%	10	100%
THAMES	5	100%	8	100%	10	100%	18	100%	31	100%
OCIU	2	100%	2	100%	1	100%	3	100%	8	100%
SWCIS	5	83%	4	100%	11	100%	15	100%	13	93%
WMCIU	4	100%	5	83%	4	100%	9	90%	9	100%
NWCIS	5	100%	4	100%	3	75%	7	88%	10	100%

Table A14: Basis of diagnosis codes for carcinomas of the ovary by age group in 2007-09

Basis of Diagnosis	0 - 14		15 - 18		19 - 24		15-24		25-49		0-49	
	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%	no. of cases	%
0 Death Certificate Only	0		0		0		0		9	0%	9	0%
1 Clinical	0		0		2	2%	2	1%	31	1%	33	1%
2 Clinical investigation	0		0		0		0		9	0%	9	0%
4 Specific tumour markers	0		0		0		0		1	0%	1	0%
5 Cytology	0		1	4%	1	1%	2	1%	37	1%	39	1%
6 Histology of a metastasis	0		0		1	1%	1	1%	72	3%	73	3%
7 Histology of a primary tumour	8	100%	25	96%	128	97%	153	97%	2,365	94%	2,526	94%
9 Unknown	0		0		0		0		0		0	
Total	8		26		132		158		2,524		2,690	
<i>5to7 Total MV</i>	8	100%	26	100%	130	98%	156	99%	2,474	98%	2,638	98%

Table A15: Number and percentage of cases of carcinomas of the ovary by cancer registry and age group in 2007-09

Cancer Registry	0 - 14		15 - 18		19 - 24		15-24		25-49	
	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified	no. of cases	% MV verified
NYCRIS	3	100%	2	100%	16	100%	18	100%	320	100%
TCR	0		4	100%	19	100%	23	100%	290	98%
ECRIC	0		2	100%	22	100%	24	100%	312	99%
THAMES	0		4	100%	31	97%	35	97%	494	97%
OCIU	0		0		2	100%	2	100%	126	98%
SWCIS	1	100%	4	100%	20	100%	24	100%	365	98%
WMCIU	3	100%	3	100%	7	100%	10	100%	294	100%
NWCIS	1	100%	7	100%	13	93%	20	95%	273	95%

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

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

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

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

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