

# Analysis of the cancer registry combined database for use with the Brain and CNS Registry

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Eastern Cancer Registration and Information Centre

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# ***Analysis of the NYCRIS registry combined database for use with the Brain and CNS Registry.***

## ***Introduction***

In 2006 the Eastern Cancer Registry and Information Centre (ecric) became the national registry for Brain and CNS tumours. The other 7 Registries in England were given different tumour sites to create national registries for.

In preparation for this task the Northern & Yorkshire Cancer Registration Information Service (NYCRIS) and Thames Cancer Registry (TCR) created a merged dataset of all registry records and a matched dataset with the National HES records. The dataset covered data from 1990 – 2007. One of the initial tasks undertaken by ecric as the National Brain Tumour Registry (NBTR) was to request a copy of the merged dataset for all Brain and CNS tumours.

NYCRIS and TCR both sent 2 databases containing the information requested:

- NYCRIS Tumour database – 105,923 records (Registry records only)
- NYCRIS Treatments database – 170,300 records (Registry records only)
- TCR Tumour database – 102,318 records (HES linked records only)
- TCR Treatments database – 207,083 (HES linked records only)

Some additional records in the NYCRIS database are thought to be tumours which TCR could not link to a HES record.

This report will only look at the Registry merged data provided from NYCRIS. This decision was made on the fact that they had a larger number of records in their dataset. Each individual column heading has been analysed in turn looking at content, completeness, accuracy and validity. The results are summarised and a bullet point given with the main findings. The report will finish off with some conclusions and recommendations for the NBTR.

## ***NYCRIS Tumour Database***

The original dataset contained 105,923 episodes. A total of 225 exact duplicates were removed leaving 105,698 episodes in the dataset. There are 3,380 extra tumours in the NYCRIS tumour dataset that aren't represented in the one from TCR. The extra tumours are identified as belonging to NY, WM and SW registries.

The NYCRIS tumour dataset contains site codes for brain, CNS and bone tumours that are physically close to the areas defined by the brain and CNS site codes. There are 103,121 brain and CNS tumours and 2,577 bone tumours present in this dataset.

### **Column headings**

The column headings (or field names) present in this dataset are given below:

Tumour number merge; patient number merge; source; nhs no; dob; sex; postcode7; site 3; site 4; type 5; surname; other surname; forename 1; forename 2; dod; cod 1a; cod 1b; cod 1c; diag date; surgery therapy; RT; CT; hormone therapy; ONS stage, original dukes; recoded dukes; description stage; final dukes; TNM; t clin; n clin; m clin; t path; n path; m path; dukes from TMN clin; dukes from TMN path; mets; grade; grade description; place of death; basis of diagnosis; nodes sampled; nodes positive; tumour size; diag date unformatted; dob unformatted; dod unformatted, dco; ethnicity; ICD code; ICD 10 version and description.

Each of the column headings have been taken in turn and analysed with a view to their contents, completeness and validity. Key points have been highlighted.

From NHS number onwards the analysis relates to the brain and CNS tumours only. The bones were removed to enable the process of validating and analysing the data to be simplified. It was not felt appropriate to mix different tumour sets together in terms of results. **It is a recommendation that the future Brain and CNS dataset does not include any bone tumours.**

### **Tumour number merge**

This corresponds to the tumour number in the treatment database.

- This is complete.

### **Patient number merge**

The number corresponds to the patient number in the treatment database. This is a number prefixed by letters indicating the source registry.

- This is complete.

### **Source**

This indicates which registry the information has come from. Table 1 below gives the breakdown of all of the tumours (exact duplicates removed) by registry. Table 2 gives the breakdown with the bone tumours removed. The proportion of tumours seen by each registry is very similar to the

proportion of the population that they serve. While this appears reassuring, in fact the pattern may be expected to differ because of varying distributions of sex, age, deprivation and other potential confounders.

**Table 1:** Breakdown of all tumours in the Northern & Yorkshire Cancer Registry & Information Service dataset by registry

Cancer Registry	Number of episodes (%)	Size of population covered in 2006 (%)*
EC	12,102 (11)	5,606,570 (11)
NW	12,839 (12)	6,567,243 (13)
NY	14,779 (14)	6,724,844 (13)
OX	5,620 (5)	2,829,116 (6)
SW	18,440 (17)	6,953,545 (14)
TH	20,926 (20)	11,760,652 (23)
TR	10,282 (10)	4,954,281 (10)
WM	10,710 (10)	5,366,694 (11)

\*Percentage of the total area served by the 8 registries in 2006

EC: Eastern Cancer Registration & Information Centre  
 NW: North West Cancer Intelligence Service  
 NY: Northern & Yorkshire Cancer Registry & Information  
 OX: Oxford Cancer Intelligence Unit

SW: South West Cancer Intelligence Service  
 TR: Trent Cancer Registry  
 WM: West Midlands Cancer Intelligence Unit

**Table 2:** Breakdown of brain and central nervous system tumours (bones removed) in the Northern & Yorkshire Cancer Registry & Information Service dataset by registry

Cancer Registry	Number of episodes (%)	Size of population covered in 2006 (%)*
EC	11,822 (11)	5,606,570 (11)
NW	12,577 (12)	6,567,243 (13)
NY	14,486 (14)	6,724,844 (13)
OX	5,525 (5)	2,829,116 (6)
SW	17,765 (17)	6,953,545 (14)
TH	20,475 (20)	11,760,652 (23)
TR	10,089 (10)	4,954,281 (10)
WM	10,382 (10)	5,366,694 (11)

\*Percentage of the total area served by the 8 registries in 2006

- This is complete.

**From this point forward the analysis relates to brain and CNS tumours only**

## **NHS no**

This is the NHS number of the patient. Each number should be made up of 10 digits. The older versions of the NHS number had numbers and letters. The NHS has subsequently updated these, but some may still be present in the dataset.

No NHS number: 4463

Potentially invalid codes (e.g. M and N/K): 13

A mix of numbers and letters: 57

- Up to 96% of the tumours have a potentially up to date valid NHS number.

NB: The 225 duplicates removed were additional records that were exact matches for records already present. At this point there are still duplicate records up to a maximum of 3000 tumours where the NHS number is identical to another record but not all of the fields are exact matches. In some cases it could be because an individual has a second or subsequent primary brain/CNS tumour. However there are records where a tumour has been recorded across 2 or more registries or an original diagnosis that was non specific has been allocated more specific codes at a later biopsy or following autopsy. Ideally these “duplicates” need to be checked manually and subjective decision made on whether the record is real or is a “duplicate”. While a less than perfect mechanism for improving accuracy, it should lead to an improvement in the quality of the information in the dataset. Decisions will also need to be made regarding which record to keep e.g. which registry should keep a tumour that has been repeatedly recorded across registries or whether or not to merge information. Attempts were made for cross registry duplicates to identify which record the Office of National Statistics had. Unfortunately in some cases it couldn’t identify either version. Given the rarity of some of these tumours these duplicates may produce significant skewing of the results of analysis work carried out on the dataset. This is an area of further work that needs to be undertaken to improve the validity of the dataset.

After the removal of duplicates of duplicates there were 2,110 pairs of potential cross registry records and 1,065 pairs within registries. These results are shown in the table below. Most duplicates are seen for EC.

**Table 3:** Duplicate pairs of treatment records by registry

Registry	NY	TR	EC	TH	OX	SW	WM	NW	Total
NY	120	206	9	16	2	12	44	24	433
TR	2	66	36		38		239		381
EC	1	162	441	23	41	1	24		693
TH	2	16	51	138	13	117	26	8	371
OX		30	20	4	20	14	41	1	130
SW		32	54	246	37	130	108	1	608
WM		28	1	1	19		37		86
NW	27	13	11	20	4	23	262	113	473

## Dob

This is the date of birth in dd/mm/yyyy format. For 42 tumours this is blank. These are made up of TH and WM tumours, 1 belongs to EC. The earliest dob given was in 1889 and the latest in 2006. There are no birth dates after the date of diagnosis. A visual scan of the dates of birth did not reveal any immediate concerns.

The age of diagnosis has been derived from date of birth and date of diagnosis.

- Almost 100% of the tumours have a date of birth for the patient.

## Sex

This field is self explanatory.

There are 52,486 (51%) males with tumours and 50,632 (49%) females with tumours. In 1 case the field is blank (NY) and in 2 the sex is recorded as unknown (WM).

- Almost 100% of the tumours have the sex of the patient recorded.

## Postcode 7

This is the postcode of the patient at diagnosis. The postcodes have not all been checked for validity. One EC postcode was noted to be invalid. It cannot be assumed that there are no further invalid postcodes.

There are 18 blank records (EC 2, NY 3 and TH 13) and 74 unknowns (all WM).

- Nearly 100% of the tumours have the postcode of the patient recorded.



### Site 3

This field contains the first 3 characters of the International Classification of Diseases Version10 (ICD 10) site code.

This column has not been looked at in detail. Site 4 which gives the ICD 10 site code to 4 characters has been looked at in more depth.

### Site 4

This gives the 4 character ICD 10 site code. The “C” codes are for malignant tumours and the “D” codes for benign tumours. The following codes should be represented:

<b>C70.0</b> Cerebral Meninges;	<b>C72.8</b> Overlapping lesion of brain and other parts of central nervous system;	<b>D33.7</b> Other specified parts of central nervous system;
<b>C70.1</b> Spinal Meninges;		
<b>C70.9</b> Meninges, unspecified;	<b>C72.9</b> Central nervous system, unspecified;	<b>D33.9</b> Central nervous system, unspecified;
<b>C71.0</b> Brain, cerebrum, except lobes & ventricles;	<b>C75.1</b> Pituitary gland;	<b>D35.2</b> Pituitary gland;
<b>C71.1</b> Brain, Frontal lobe;	<b>C75.2</b> Craniopharyngeal duct;	<b>D35.3</b> Craniopharyngeal duct;
<b>C71.2</b> Brain, Temporal lobe;	<b>C75.3</b> Pineal gland;	<b>D35.4</b> Pineal gland;
<b>C71.3</b> Brain, parietal lobe;	<b>C85.7</b> Other specified types of non-hodgkin’s lymphoma (with morphology 9594/3);	<b>D42.0</b> Cerebral meninges;
<b>C71.4</b> Brain, occipital lobe;		<b>D42.1</b> Spinal meninges;
<b>C71.5</b> Brain, cerebral ventricle;	<b>C83*</b> where it is known that this is of CNS origin;	<b>D42.9</b> Meninges, unspecified;
<b>C71.6</b> Brain, cerebellum;	<b>C85*</b> where it is known that this is of CNS origin;	<b>D43.0</b> Brain, supratentorial;
<b>C71.7</b> Brain stem;		<b>D43.1</b> Brain, infratentorial;
<b>C71.8</b> Overlapping lesion of brain;	<b>D32.0</b> Cerebral meninges;	<b>D43.2</b> Brain, unspecified;
<b>C71.9</b> Brain, unspecified;	<b>D32.1</b> Spinal meninges;	<b>D43.3</b> Cranial nerves;
<b>C72.0</b> Spinal cord;	<b>D32.9</b> Meninges, unspecified;	<b>D43.4</b> Spinal cord;
<b>C72.1</b> Cauda Equina;	<b>D33.0</b> Brain, supratentorial;	<b>D43.7</b> Other parts of central nervous system;
<b>C72.2</b> Olfactory nerve;	<b>D33.1</b> Brain, infratentorial;	<b>D43.9</b> Central nervous system, unspecified;
<b>C72.3</b> Optic nerve;	<b>D33.2</b> Brain, unspecified;	<b>D44.3</b> Pituitary gland;
<b>C72.4</b> Acoustic nerve;	<b>D33.3</b> Cranial nerves;	<b>D44.4</b> Craniopharyngeal duct
<b>C72.5</b> Other and unspecified cranial nerves;	<b>D33.4</b> Spinal cord;	<b>D44.5</b> Pineal gland

Appendix 1 shows the number of ICD site codes recorded for each of the 8 English registries over the course of 17 years.

The most common site codes for malignant tumours are C71.9 Brain, unspecified with 20,701 (20%) of the entries, followed by C71.1 Brain, Frontal lobe with 10219 (9.9%). For the benign tumours D32.0 Cerebral meninges is the most recorded site at 12,341 (12%) followed by D35.2 Pituitary gland with 8,892 (8.6%) of the overall tumours. The rarest malignant tumour was C75.2 Craniopharyngeal duct with 5 tumours and for the benign tumours it was D35.3 Craniopharyngeal duct with only 1 tumour over 16 years.

Approximately 62% of the tumours have been classified as malignant. Appendix 1 highlights the SW and NY registries as the only registries in England recording benign tumours with an ICD 10 code of D42.0 onwards. The reasons for this are not clear.

- This field is complete.

## **Type 5**

This is the combined morphology and behaviour codes of the tumour. This describes the tumour. For CNS tumours the grade of the tumour is often linked to the morphology/behaviour code that is given.

This column is blank for 355 tumours. For 956 tumours (all from WM) the codes given are not morphology codes used by ICD 10. They are likely to represent local pathology codes. There are also an additional 958 codes that are not recognised codes. Some of the codes do not represent tumours that are CNS primary tumours. For example there are lung, breast and metastatic tumours that have been included. There are 149 of these.

- Morphology/behaviour codes are brain/cns tumours in approximately 98% of the tumours. There are also tumours where the morphology and ICD 10 site codes do not correspond. There are over 2000 instances where the site code and the morphology/behaviour code do not match (approximately 2% of all tumours).
- Approximately 96% of the tumours are valid with an appropriate site code

A number of the CNS tumours are incredibly rare across the whole country. This means that in any one year a registry may not see any cases at all. Appendix B shows all tumours, by morphology and behaviour code, across all of the English registries between 1990 and 2007 by sex. The most frequently occurring tumours were Glioblastoma NOS (code 94403) and Meningioma NOS (code 95300). Just under 60% of the tumours had counts under 10.

## **Diagnosis by age group**

Across all registries where a date of diagnosis is given (101,690), the tumours are divided as follows:

- Up to 14 years: 5,508 tumours (5.4% of total).

The most common 5 diagnoses in this age group are:

1. ASTROCYTOMA PILOCYTIC (code 94213) at 937 tumours (17% of 5,508).  
50% of these tumour types are in males
2. GLIOMA MALIGNANT (code 93803) at 723 tumours (13%).  
48% of these tumour types are in males
3. ASTROCYTOMA NOS (code 94003) at 702 tumours (13%).  
52% of these tumour types are in males
4. MEDULLOBLASTOMA NOS (code 94703) at 685 tumours (12%).  
65% of these tumour types are in males
5. EPENDYMOMA NOS (code 93913) at 262 tumours (5%).  
56% of these tumour types are in males

- Between 15 and 24 years: 3,325 tumours (3.3% of total)

The most common 5 diagnoses in this age group are:

1. ASTROCYTOMA NOS (code 94003) at 514 tumours (15% of 3,325).  
56% of these tumour types are in males
2. ADENOMA NOS (code 81400) at 323 tumours (9.7%).  
37% of these tumour types are in males
3. NEURILEMMOMA (code 95600) at 246 tumours (7.4%).  
52% of these tumour types are in males
4. ASTROCYTOMA PILOCYTIC (code 94213) at 236 tumours (7.1%).  
60% of these tumour types are in males
5. GLIOMA MALIGNANT (code 93803) at 190 tumours (5.7%).  
56% of these tumour types are in males

- Over 25 years 92,857 tumours (91% of total)

The most common 5 diagnoses in this age group are:

1. GLIOBLASTOMA NOS (code 94403) at 20,041 tumours (22% of 92,857).  
61% of these tumour types are in males
2. MENINGIOMA NOS (code 95300) at 13,057 tumours (14%).  
30% of these tumour types are in males
3. GLIOMA MALIGNANT (code 93803) at 10,244 tumours (11%).  
54% of these tumour types are in males
4. ASTROCYTOMA NOS (code 94003) at 8,898 tumours (9.6%).  
59% of these tumour types are in males
5. ADENOMA NOS (code 81400) at 6,713 tumours (7.2%).  
54% of these tumour types are in males

## Surname

This field is complete. There are only 2 obvious cases where the individual has a surname that may not be valid (the surname contains some characters other than letters). There may be other surnames that are not valid but it is virtually impossible which these are (if any).

- Nearly 100% of tumours belong to an individual with a potentially valid surname.

## Other surname

This relates to cases where an individual may have been known by another surname in the past. This would cover e.g. maiden name, name before remarriage and change of name by deed poll.

There are 14,962 tumours where the column other surname has been completed for the individual concerned. The majority of episodes relate to females with less than 200 concerning males. In some cases (15 plus) the surname and other surname are the same.

- It is not possible fully ascertain how completely or accurately this column has been completed.

## **Forename 1**

This is taken to be an individual's first name. There were 15 blanks and 1 case where the first name appeared to be a single letter. The rest of the names appeared to be sensible.

- Nearly 100% of tumours belonged to an individual where a forename was present.

## **Forename 2**

This is taken to be an individual's second name. There were 52,167 blanks and at least 1 number has been given as a name. In 11,544 episodes the forename 1 and forename 2 were exactly the same. It was not uncommon for an initial to be used here rather than a full name. For example, there were 1,064 episodes where the person had "A" recorded.

This column was not well completed. Due to lack of complete and variable information in this column it has enabled duplicate tumours to be recorded in some cases.

- It is not possible fully ascertain how completely or accurately this column has been completed.

## **Dod**

This is date of death in dd/mm/yyyy format. This is blank for 38,133 tumours and completed for 64,988. The dates of death range from 2/1/90 to 20/10/2008. The ONS would be able to provide up date information if and when needed.

There are 21 occasions where no dod has been recorded either in this column or the dod unformatted column but a 1A cause of death has.

There are 18,829 deaths recorded without information on 1A cause of death.

- This column, along with cause of death requires up dating before it could be used for analysis

## **cod\_1a, cod \_1b, cod\_1c, cod\_2**

These 4 columns relate to causes of death as laid out on the death certificate.

As mentioned above there are 18,829 deaths recorded for which no 1A cause of death exists (29%).

The causes of deaths across all 4 columns are either recorded as ICD 9 codes, ICD 10 codes, words or a combination of the above. No attempt was made to systematically check if codes used were valid, however within cod 1a, 95 episodes were recorded as "unknown". There were also 506 codes that started with ZZ and 11 had double letter codes, neither of which are true national codes. These were all from NW. Contact with the NW registry revealed that these were old local codes: ZZ11-Disease free, ZZ22-Disease active, ZZ88- Pre88 cause of death cases, ZZ98-Death found at hospital, ZZ99-Not known.

- There were 46,191 records for cod 1a.
- There were 9,247 records for cod 1b
- There were 1,877 records for cod 1c
- There were 11,750 records for cod 2.

Within cod 2 there were 245 occasions where 8999 was used. This code does not exist in ICD 9 or 10. There were 72 uses of 7999 which is for “other unknown and unspecified causes”.

It is quite possible that other errors would also be picked up with a more detailed work up of the causes of death. However there is sufficient evidence here to warrant the need for the data to be updated and presented in a more useable format prior to its use in further research. The cancer dataset has “Death cause cancer” as a key data item, as well as collecting information on the death certificate causes of death. It is asking whether or not the death is related to their cancer. It asks for the information to be collected in the following way:

- 1 – death by first registered primary
- 2 – death by another primary
- 3 – death by other causes/cancer known to be present
- 4 – death by other causes, cancer not mentioned
- 5 – indeterminate cause of death (more than one primary)
- 6 – death from metastatic disease where origin of primary is known
- 7 – death by metastatic disease where origin of primary is unknown.

With accurate complete information on cause of death this looks like it may be a forward step in how to review the death data.

- This column, along with date of death requires up dating before it could be used for analysis

### **diag\_date**

This is the diagnosis date in dd/mm/yyyy format. There are no cases where the date of birth is after diagnosis date but there are 3 instances where the diagnosis is after the death. Two belong to EC and 1 to WM. Previously unknown cancers detected at post mortem should have a diagnosis date that is the same as the date of death.

There are 1,391 blank records. The dates of diagnosis range from 01/01/1990 to 27/12/2007. There are only 13 entries for 2007. These all belong to NW.

- Approximately 99% of the tumours have a potentially valid diagnosis date.

## **Treatment columns**

These contain Y, N, U or are blank for each episode recorded. The columns are surgery Therapy for surgery, RT for radiotherapy, CT for chemotherapy and Hormone Therapy for hormone treatment.

The results presented here are not the same as the results obtained from the treatment database. It is not clear, which, if any, dataset can be relied on for this information.

There is no treatment information for TH or NW.

### **surgery therapy**

Y 37,670

U 3,971

23,830 tumours had surgery only recorded.

### **RT**

Y 17,991

U 6,905

5,493 had radiotherapy only

### **CT**

Y 6,047

U 7,785

2,503 had chemotherapy only

### **Hormone Therapy**

Y 5,352

U 7,983

1,267 had hormone treatment only

## Combinations

7,929 tumours had radiotherapy and surgery only

115 tumours had surgery, radiotherapy, chemotherapy and hormone therapy

725 tumours had chemotherapy and radiotherapy only

989 tumours had surgery and chemotherapy only

There are 54,712 tumours (53%) where N, U or the field is blank for all treatment modalities. These are split across the 8 registries as shown below:

EC 4,171	NY 6,005	SW 9,543	TR 5,435
NW 12,577	OX 2,272	TH 4,327	WM 10,382

- This information cannot be used for analysis

## ONS Stage, Original Dukes, Recoded Dukes, description stage, Final Dukes, TNM, t clin, n clin, m clin, t path, n path, m path, Dukes from TNM Clin, Dukes from TNM Path

These columns are not relevant to CNS tumours and have not been looked at any further.

## Mets

This column indicates whether or not a tumour has metastasized. Metastases are a rare event in tumours of the CNS.

In most cases no report has been given but there are 290 episodes where metastases have been recorded. In 4 of the cases the morphology/behaviour code does not appear to exist.

Table 4 below shows the tumours which have recorded as metastasising. Dr Rous has reviewed these tumours and highlighted those tumours that are unable to or rarely metastasize. In total there are a maximum 21 tumours recorded as having metastasized where this is not thought possible (7%).



**Table 4:** Morphology/behaviour codes of tumours recorded as metastasized across all registries, 1990-2007, with comment on their ability to metastasize.

Morphology/ behaviour code	DESCRIPTION	Can this tumour metastasize?	Count of tumour
80001	NEOPLASM UNCERTAIN BEHAVIOUR	Yes	1
80003	NEOPLASM MALIGNANT	Yes	42
80103	CARCINOMA NOS	Yes	4
80743	SQUAMOUS CA SPINDLE CELL TYPE	Yes	1
81400	ADENOMA NOS	No	1
81403	ADENOCARCINOMA NOS	Yes	1
82463	NEUROENDOCRINE TUMOUR	Yes	1
87203	MELANOMA MALIGNANT NOS	Yes	2
89003	RHABDOMYOSARCOMA NOS	Yes	1
89213	INVALID CODE	N/A	1
89633	RHABDOID SARCOMA	Yes	2
90643	GERMINOMA	Yes	7
90713	ENDODERMAL SINUS TUMOUR	Yes	1
90803	TERATOMA MALIGNANT NOS	Yes	2
90843	DERMOID CYST WITH MAL TRANSFORM	Yes	1
90853	MIXED GERM CELL TUMOUR	Yes	1
91503	HAEMANGIOPERICYTOMA MALIGNANT	Yes	2
91611	HAEMANGIOBLASTOMA	No	1
92603	EWINGS SARCOMA	Yes	8
93623	PINEOBLASTOMA	Yes	6
93643	PERIPHERAL NEUROECTODERMAL TUMOUR	Yes	2

<b>Morphology/ behaviour code</b>	<b>DESCRIPTION</b>	<b>Can this tumour metastasize?</b>	<b>Count of tumour</b>
93703	CHORDOMA	Yes	1
93803	GLIOMA MALIGNANT	Yes	42
93903	CHOROID PLEXUS PAPILLOMA MAL	Yes	2
93913	EPENDYMOMA NOS	Yes	8
93923	EPENDYMOMA ANAPLASTIC TYPE	Yes	3
94003	ASTROCYTOMA NOS	Yes	24
94203	ASTROCYTOMA FIBRILLARY	Yes	1
94213	ASTROCYTOMA PILOCYTIC	Yes	2
94403	GLIOBLASTOMA NOS	Yes	33
94423	GLIOBLASTOMA SARCOMATOUS COMPON	Yes	1
94503	OLIGODENDROGLIOMA NOS	Yes	3
94513	OLIGODENDROGLIOMA ANAPLASTIC	Yes	1
94703	MEDULLOBLASTOMA NOS	Yes	42
94706	INVALID CODE	N/A	1
94713	MEDULLOBLASTOMA DESMOPLASTIC	Yes	5
94733	PRIMITIVE NEUROECTODERMAL TUMOUR	Yes	6
95003	NEUROBLASTOMA NOS	Yes	5
95300	MENINGIOMA NOS	No	13
95303	MENINGIOMA MALIGNANT	Very rarely	6
95313	INVALID CODE	N/A	1
95403	NEUROFIBROSARCOMA	Yes	1
95703	INVALID CODE	N/A	1

- There are 290 tumours recorded as having metastasized. For 25 of these tumours, either the tumour doesn't exist, doesn't metastasize or is very unlikely to metastasize (9%).

## Grade

This column has been poorly filled in. There are concerns about the completeness of information and quality. CNS tumours should be graded between 1 and 4.

The breakdown of information given in this column with the number of tumours that it relates to is shown below:

Blank/unknown/or equivalent: 87,678 (85%)

Grade 1: 3,069

Grade 2: 1,755

Grade 3: 2,640

Grade 4: 7,977

Grade 5: 1

Grade 7: 1

However given that a number of tumours have been diagnosed clinically or through radiological investigations, only those tumours with a histological diagnosis have been looked at below. There are approximately 70,519 (68%) tumours that have a histological diagnosis.

The breakdown of information given in this column for tumours with a histological diagnosis along with the number of tumours that it relates to is shown below:

Blank/unknown/or equivalent: 55,900 (79% of 70,519)

Grade 1: 2,865

Grade 2: 1,723

Grade 3: 2,375

Grade 4: 7,654

Grade 5: 1

Grade 7: 1

The grade of an intracranial tumour may be closely linked with its morphology code, for example a choroid plexus papilloma with a morphology and behaviour code of 93900 would be expected to be

graded as 1. Three tumours (medulloblastoma, pineocytoma and astrocytoma pilocytic) have been examined more closely in terms of grade.

Medulloblastomas (code 94703) are expected to be a grade 4. In this dataset there are 938 histologically diagnosed medulloblastomas. In 111(12%) cases the grade is given as 4. In 813 episodes the grade is not given. Pineocytomas (code 93611) are expected to be grade 2. Of these tumours with a histological diagnosis (31) 3 have a grade of 2 and 27 are unknown (87%).

- This information cannot be used for analysis

## **grade\_Description**

This column is largely incomplete. For 65% of the tumours the field is blank or reported as unknown. There are 8,904 entries for “not applicable to site” and 5,302 for “Histology report available by differentiation not apparent” (WM).

Where a grade has been given in the previous column and text accompanies it in this column it is largely appropriate. ECRIC has recorded 4 tumours with a grade of 9 (which may represent unknown) and text “borderline grade”.

- This information cannot be used for analysis

## **Place of death**

This is given as death location type in the current version of the cancer dataset.

The cancer dataset asks for the information to be collected in the following way:

1. Hospital
2. NHS hospice/specialist palliative care unit
3. Voluntary hospice/specialist palliative care unit
4. Patients own home
5. Care home
9. Other

This is not how all the information has been recorded within this brain and CNS dataset.

There are 64,988 tumours with a date of death. For these tumours place of death was blank in 23030 (35%) cases. It was unknown or not stated for 5,448 (8%).

Hospital (1) – 3,699

NHS hospice/specialist palliative care unit (2) – 2,116

Voluntary hospice/specialist palliative care unit (3) - 709

Patients own home (4) - 636

Care home (5) – 212

Those deaths recorded as occurring in 1 (hospital) represented approximately 6% of all deaths.

In some cases the words rather than the codes have been used, e.g. there are 2,048 entries for “hospital”. However in the majority of cases postcodes, addresses and names of nursing homes and hospitals have been given. For those entries that are not postcodes or addresses only it would be possible to decipher the correct coding for some of the deaths e.g. Southampton General Hospital would become 1.

- This column has been poorly completed it cannot be used for analysis.

## **Basis of diagnosis**

This category is found within the cancer dataset. Information should be recorded as follows:

### **Non-microscopic**

0 – Death Certificate (The only information available is from a death certificate)

1 – Clinical (Diagnosis made before death but without the benefit of any of the following (2- 7))

2 – Clinical Investigation (Includes all diagnostic techniques (e.g. X-rays, endoscopy, imaging, ultrasound, exploratory surgery and autopsy) without a tissue diagnosis)

4 – Specific Tumour Markers (Includes biochemical and/or immunological markers which are specific for a tumour site)

### **Microscopic**

5 – Cytology (Examination of cells whether from a primary or secondary site, including fluids aspirated using endoscopes or needles. Also including microscopic examination of peripheral blood films and trephine bone marrow aspirates).

6 – Histology of a metastasis (Histological examination of tissues from a metastasis, including autopsy specimens)

7 – Histology of a primary tumour (Histological examination of tissue from the primary tumour, however obtained, including all cutting and bone marrow biopsies. Also includes autopsy specimens of a primary tumour)

9 – Not known (No information on how the diagnosis has been made (e.g. PAS or HISS record only)) (Default)

A table of the counts of the various “basis of diagnosis” present is given below. A subjective decision as to which code should be applied has been made by the author and is also shown in the table.

**Table 5:** Basis of diagnosis of tumours, with subjective classification according to cancer dataset coding for all registries between 1990 and 2007

Basis of diagnosis (in dataset)	Official code (author's opinion)	Count
	9	1603
1	1	3
13	9	18
17	9	1
3	9	1
4	4	11
Biochemical and immunological tests	4	4
Bone marrow	5	1
BT Specific tumour marker	4	4
CH Cytology/haematology	5	23
CI Clinical Investigation	2	2724
CL	1 or 2	1
CL Clinical	1	916
clinical	1	7993
Clinical (conf by GP)	1	68
Clinical Diagnosis	1	670
Clinical Imaging	2	1138
clinical invest	2	1108
Clinical Investigation	2	1876
Clinical opinion only	1	1068
Computed tomography	2	859
cytology	5	133
DC	0	1
DCO	0	587

Basis of diagnosis (in dataset)	Official code (author's opinion)	Count
death cert	0	111
Death Certificate	0	170
Death Certificate Initiated	0	314
Exploratory	9	18
H	9	3
Haematology	5	15
HI	9	39
histology	6 or 7	44466
Histology of a primary tumour	6	8644
histology of met	6	1
Histology of Metastases	6	9
Histology of Metastases	6	9
histology of mets	6	4
Histology of Primary	7	7024
HM Histology metastases	6	7
HP Histology of primary tumour	7	10344
I	9	1
Isotope scan	2	2
L	9	1
MA	9	1
Marker	4	8
MRI	2	330
NK Unknown	9	115
No	9	29
Non post mortem ONS Death	9	157

Basis of diagnosis (in dataset)	Official code (author's opinion)	Count
Not known	9	2448
Not Known (Default)	9	159
other	9	43
Other special tests	9	222
Other tests	9	1959
Post mortem	6 or 7	121
Post Mortem histology	6 or 7	41
SC	9	8
Scan	2	2643
Specific Tumour Markers	4	28
Surgical Diagnosis	2	10
T	9	2
tumour markers	4	1
Ultrasound	2	6
unknown	9	2193
Waiting times	9	17
Waiting times with death	9	1
X-ray	2	559
XX	9	2
Yes	9	25

This results in a breakdown of the potential official codes as follows. Absolute numbers are given with percentages.

0: Death Certificate 1,183 (1%)

1: Clinical 10,718 (10%)

2: Clinical Investigation 3,915 (4%)



1 or 2: 1

4: Specific Tumour Markers 56 (0.05%)

5: Cytology 172 (0.17%)

6: Histology of a metastasis 30 (0.03%)

7: Histology of a primary tumour 26,012 (25%)

6 or 7: 44,628

9: Not known 16,406 (16%)

- With the data in the revised format it may be possible (for some tumour subsets) to use the information in a more meaningful way

## **nodes\_sampled**

This column was largely left blank (101,258 episodes, 98%)

Other results in this column included 1 (2 tumours), 2 (1), 20 (1), 99, N and X.

- This column has largely been left blank

## **nodes\_positive**

There were 7 cases where this field contained a “y”. This coincided with a “y” in nodes\_sampled in 1 case only, the remaining 6 being blank.

Overall this column was largely blank, with N and X also being seen.

- This column has largely been left blank

## **tumour\_size**

This is known as invasive lesion site in the most recent version of the cancer dataset. It is the maximum diameter of the tumour in mm.

This column is largely empty. There are 98,468 (95%) cases where the field is blank or contains “0”. Numbers in the remaining episodes range from 1 to 999. 888 and 999 may represent unknown codes. When these are removed the next highest number is 500.

- This field has not been completed for approximately 95% of tumours

## **diag\_date\_unformatted**

Dates in this column are given in various formats.

There are 2 blank fields and 1,390 entries which contain an incomplete date e.g. year only. These correspond to blanks in the diag\_date column. Dates run from 1/1/1990 to 27/12/2007 which is the same as for the diag\_date column.

No other checks have been made as to whether the dates (in what ever format) are the same in both of the date of diagnosis columns.

- There is additional information in this column that is missing from the diagnosis date column

## **dob\_unformatted**

Dates in this column are given in various formats.

There are 20 blank fields and 24 year only entries. Of all of these 44 episodes there are only 2 cases where a date of birth is given in the dob column.

No other checks have been made as to whether the dates (in what ever format) are the same in both of the date of birth columns.

- There is additional information in this column that is missing from the date of birth column

## **dod\_unformatted**

Dates in this column are given in various formats.

There are 33,940 blank fields and 7 year only entries. There are 4,195 cases where dod is blank but there is an entry in the dod\_unformatted column.

- There is additional information in this column that is missing from the date of death column

## **DCO**

DCO stands for death certificate only. It relates to cases where a tumour is first brought to the attention of the cancer registry by a death certificate mentioning a tumour. It has not been previously registered.

This column is blank in 2 cases, contains "N" in 98,970, "U" in 6 and "Y" in 4,143 (4%).

This column does not correlate with "basis of diagnosis" where a death certificate diagnosis was recorded in 1,183 instances.

- DCO has been recorded 4,143 times (4%). It does correlate with basis of diagnosis. It is not clear how helpful this information is.

## **Ethnicity**

This dataset transverses a time frame that covers 2 separate official classifications for ethnicity. The most recent relates to the census 2001 classification which uses letter codes. The classification before this was number based. The majority of the codes are directly transferable. Unfortunately codes relating those individuals who consider themselves “White” or of “Mixed” background are not.

It is possible that HES data could be used to further populate this field. Ethnicity information has been more consistently collected as time has gone by and in 2006 approximately 92% of cancer patients had a HES ethnicity recorded (Cancer Incidence & Survival). In some cases patients have multiple ethnicities recorded in HES, in which case the NCIN used the most frequently recorded ethnicity in their analysis. Where this wasn’t clear the ethnicity was recorded as unknown.

In this NYCRIS CNS dataset only 23% of the tumours have an ethnicity assigned to the individual concerned.

## **ICDCode**

This is the ICD 10 site code and corresponds to the field site 4. There are 210 episodes where the ICDCode is empty but the site 4 field completed. In the remaining 102,911 the fields are identical.

- This field is almost complete. Complete information is found in field 4

## **ICDVersion**

This describes which ICD version has been used for site coding. This is completed in 102,911 cases, and is “10”.

- This field is almost complete and is version “10”

## **Description**

This details the ICD 10 site code in words. For example C711 is given as Brain, Frontal lobe.

- This field is almost complete

## ***NYCRIS treatment database***

### **Introduction**

This database contains 170,300 treatment episodes. Some of these entries are duplicates. The duplicates identified by the computer programme were not all exact duplicates and were therefore not removed. In order to address this more fully, a further manual check of the duplicates is required. This was not attempted at this point but could be carried out at a later date. The issue of duplicates has been largely addressed by carrying out the analysis on “unique records” only.

There are 23,693 tumours in the NYCRIS tumour database without recorded treatment in the NYCRIS treatment database. The Thames registry tumours make up 20,926 (88%) of these. There is no recorded treatment at all for Thames registry patients. The remaining tumours without recorded treatment episodes are shared between the South West Cancer Intelligence Service (SW)-2642, the West Midlands Cancer Intelligence Service (WM)-119 and NYCRIS (6). For most of these tumours treatment information is also not present in the tumour database.

### **Column headings**

The column headings (or field names) present in this dataset are given below:

Patient number; ONS number; Source; Tumour number; Treatment date; Hospital PAS number; Consultant code; Treatment type; OPCS codes; Hospital codes; Hospital names; Hospital address; Radiotherapy; Radiotherapy type; Chemotherapy; Surgery; Hormone therapy; Other treatment and No treatment.

Each of the column headings have been taken in turn and analysed with a view to their contents, completeness and validity. Where appropriate the data collected has been compared against the criteria defined in the national cancer dataset (version 4.5) and the NHS dictionary. Key points have been highlighted. Column headings have been used as they appear in the database.

### **Patient number**

This refers to a unique patient identifier.

34,684 episodes are blank (20%). This relates to all of the West Midlands episodes.

- 80% of episodes have a patient number

## ONS number

The significance of this field is not clear. It is similar or identical (except for cancer registry prefix) to the tumour number. It is possible that this is used to identify patients within ONS databases.

- This field is complete.

## Source

This field indicates which registry the information belongs to. However there is no recorded Registry treatment for Thames Cancer Registry. Treatment information for Thames is included in the Thames dataset received. The total population served by the 7 included registries in 2006 was 39,002,293. The dataset covers 16 years during which time cancer registry boundaries have changed.

The number and percentage of episodes for each of the English registries represented within the dataset from NYCRIS is given in the table below.

**Table 6:** Number and percentage of treatment episodes by registry

Cancer Registry	Number of episodes (%)
EC	33,194 (19)
NW	22,744 (13)
NY	35,511 (21)
OX	9,785 (6)
SW	21,246 (12)
TR	13,136 (8)
WM	34,684 (20)

EC: Eastern Cancer Registration & Information Centre

NW: North West Cancer Intelligence Service

NY: Northern & Yorkshire Cancer Registry & Information

OX: Oxford Cancer Intelligence Unit

SW: South West Cancer Intelligence Service

TR: Trent Cancer Registry

WM: West Midlands Cancer Intelligence Unit

- This field is complete.

## Tumour number

This is the unique identifier given to a tumour. It is not the same as the patient identifier. An individual patient may have more than one tumour.

EC, NW, NY and TR registries indicate clearly (by the number after/) whether the tumour under consideration is a 1<sup>st</sup>, 2<sup>nd</sup> or subsequent primary tumour.

- This field is complete.

## Treatment date

This field is self explanatory.

There is no treatment date for 27,256 episodes (16%). For 6,657 (24%) of these a “no” has been given to radiotherapy, chemotherapy, surgery, hormone therapy and other treatment. It is not clear why these have been included in the treatment database.

There are 13,884 (8%) episodes where the 1<sup>st</sup> treatment is earlier than diagnosis. These are sourced to the following registries:

**Table 7:** The number and percentage of treatment episodes occurring prior to diagnosis by registry

Cancer Registry	Number of episodes (%)
EC	3,896 (28)
NW	43 (0.3)
NY	7,986 (58)
OX	104 (0.7)
SW	381 (2.7)
TR	99 (0.7)
WM	1,375 (9.9)

The earliest treatment date given is 4.6.1933

In 4,650 episodes the treatment date is given as 7777-07-07. These all belong to NY (13% of the NY episodes overall).

- Only 73% of episodes have a potentially valid treatment date that is after the date of diagnosis.

## Hospital Pas Number

A patient’s first visit to a hospital will generate a PAS number that is specific to that hospital. This then remains with them for life. A visit to another hospital will give generate a separate PAS number for that hospital. One patient could accumulate a number of different PAS numbers from various hospitals across their lifetime.

There are 40,126 episodes without a PAS number (24%). This includes 47 NW episodes recorded as “Non C death Cert”.

Where a number is present the validity has not been taken into account. For example NY uses NH0999 and NH0906 for a number of different patients.

A PAS number is helpful to identify patient records at a particular hospital.

- Approximately 76% of episodes have a PAS number. Validity of numbers not ascertained.

## Consultant code

This should be the GMC number prefixed by a C for the consultant overseeing the treatment episode. Other numbers are likely to be local codes. In theory it should be possible to check back with the registries concerned to get the appropriate national code.

Sixteen codes are given as 09.

18,990 episodes are recorded as xxx which represents “unknown” and have EC as their source.

In 45,122 (26%) of the episodes the field is either blank or contains “?”. Table 8 below shows how these are spread across the registries.

**Table 8:** Breakdown of 45,122 consultant code entries which are blank or contain “?” by registry

Cancer Registry	Number of episodes (%)
EC	52 (0.1)
NW	19,161 (42)
NY	1,207 (3)
OX	990 (2)
SW	21,246 (47)
TR	805 (2)
WM	1,661 (4)

- There are 6 D codes (Dental consultants) and 66,247 C codes that have face value validity. This represents only 39% of all the episodes. In approximately 41% of the episodes the consultant code is blank/?/not valid/xxx.

## Consultant name

This should be the name of the consultant identified by their GMC or GDC number in the preceding column. This column has been left blank in over 50% of treatment episodes. Where names have been given no attempt has been made to validate them.

- This field is largely incomplete.

## Treatment type

In the cancer dataset the item that most closely resembles this column is “Planned cancer treatment type”. Information should be collected on “what treatments (s) are planned for the patient”. The purpose is described as “To determine patterns of primary treatment. To enable analysis of discrete groups of patients particularly where several modalities are used”.

The codes used in this context are given below in box 1:

**Box 1:** Planned cancer treatment type, Cancer dataset version 4.5

01 – Surgery
02 – Teletherapy
03 – Chemotherapy
04 – Hormone Therapy
05 – Specialist Palliative Care
06 – Brachytherapy
07 – Biological
08 – Other
09 – Active Monitoring
99 – Not known (default)

There is also another item in the cancer dataset headed “Treatment type (cancer morbidity)”. It is described as “Any morbidity, relevant to previous treatments that the patient has received, recorded at any subsequent patient contact”. The purpose is to “To determine patterns of adverse events associated with a treatment”. The treatment codes are given in box 2 below:



**Box 2:** Treatment type (cancer morbidity), Cancer dataset version 4.5

- |                  |
|------------------|
| 1 – Surgery      |
| 2 – Chemotherapy |
| 3 – Radiotherapy |
| 4 – Combination  |

The national cancer dataset was integrated into the NHS Dictionary in 2002. Data within this tumour dataset largely predates this.

This column is confusing. It appears the treatment type column in the NYCRIS dataset is made up of clinical episodes for cancer patients that relate to their cancer. For some patients this also includes outpatient review appointments. Historically information was only collected on treatments that had a curative intent, and so in the main for this dataset surgery/chemotherapy/radiotherapy are likely to have been given with curative intent although it is not possible to be certain of this.

It is not very clear how helpful information recorded in this field will be or how it can be used. Hospital visits and procedures for diagnosis could be removed along with other items that don't appear to be related to cancer treatment (such as "found at PM"). However where chemotherapy and especially chemotherapy admission have been recorded it is not known if courses of chemotherapy have been recorded as one episode or whether the individual treatments have been included. Whether the recording of this information is consistent across the registries is also unknown. The same reasoning can be applied to radiotherapy/radiotherapy admission. It would be helpful if "other" could be specified. The individual treatment columns e.g. radiotherapy Y, N may be more helpful.

Looking to the future, it is absolutely right that information on planned cancer treatment type should be collected. Recording the treatment intent (curative/palliative) along side would be helpful. In addition actual treatments given should then be recorded along with an indication of whether this meets with the plan or has deviated (and why). Treatment that is given due to recurrence should be highlighted along with intent (where relevant) so that it can be separated from primary treatment.

Appendix D looks at the different sorts of "treatment type" recorded. In approximately 28% of the episodes treatment type has been left blank, the majority of these belonging to NW, TR and EC. Most of the episodes recorded as unknown come from EC. The categories present in the dataset have been matched by the author to the planned care treatment type codes from the cancer dataset given in box 1 above. For the remaining episodes the treatment type is considered unknown. The official coding has been put in brackets next to the original term used.

A breakdown of the revised codes is given in table 9 below:

**Table 9:** Breakdown of treatment episodes by codes used for “planned cancer treatment type” in the national cancer dataset version 4.5

Cancer dataset Code	Number of episodes (%)
<b>01 Surgery</b>	23,690 (14%)
<b>02 Teletherapy</b>	13,689 (8%)
<b>03 Chemotherapy</b>	3,798 (2%)
<b>04 Hormone Therapy</b>	1,078 (0.6%)
<b>05 Specialist Palliative Care</b>	268 (0.16%)
<b>06 Brachytherapy</b>	2 (0.0%)
<b>08 Other</b>	32,683 (19%)
<b>99 Unknown</b>	95,092 (56%)

**Total 170,300 (100)**

- Approximately 46% of the episodes have a recognisable “treatment type”

## OPCS codes

These are codes given to procedures/interventions carried out on/with patients. They are commonly associated with surgical procedures but not exclusively so. Most codes relate to surgical procedures. Codes do exist for radiotherapy and chemotherapy for example as they do for smoking cessation therapy, pacemaker testing and cognitive behaviour therapy amongst others.

OPCS codes have been looked at for those episodes for which are recorded as “Y” in the surgery column. None of the “additional pathology” and “biopsy only” episodes described in the treatment type column were recorded as surgical in the Surgery column and so do not show up in the figures below. Only 8 episodes with an OPCS code that relate to biopsy that were given Y in the surgery column have been noted. These are all EC.

There are 34,594 episodes in total that were considered surgical.

For each registry there are a number of codes that have been used that do not appear to be directly concerned with cancer treatment for this tumour database. Examples include venepuncture, emergency removal of appendix, excision of breast and vacuum extraction of products of conception. The biopsy episodes have also been included in this category. It is possible that some of

the codes identified by the author as not being related to the cancer treatment may in fact be so. This may be particularly evident where the primary tumour is a bone tumour and the operation described is part of a wide tumour clearance. Further clarification would require each of the 8000 plus episodes to be reviewed with the registry of origin. A full list of the codes not considered relevant can be found in appendix E.

Hospital Episode Statistics data may help to make more sense of this information.

NW is not represented in the table below. This is because none of their treatment episodes were recorded as surgical. There were no NW episodes that were identified as having chemotherapy, radiotherapy, hormone therapy or other treatment either. The majority of episodes were recorded as “no treatment”. However, of the 22,744 NW episodes, 4,455 have OPCS codes. Approximately 4,387 of the episodes have codes that suggest surgical treatment (4455-68). The remaining codes were either not surgery related, or not thought to be relevant to this dataset, e.g. breast reconstruction. However, due to the subjective nature of this decision making, it is possible that some codes have been included when they are not relevant and vice versa (e.g. should intravertebral disc removal be included or not?)

Table 10 below details the number and percentage of potentially non relevant OPCS codes for each of the included registries.

**Table 10:** Number and percentage of blank and potentially non relevant OPCS codes by registry

Cancer Registry	Number of episodes deemed surgical	Absolute Number of non relevant OPCS codes for episodes deemed surgical	Number of blank OPCS codes for episodes deemed surgical	Percentage of non relevant and blank OPCS codes for episodes deemed surgical
EC	6,378	1,202	16	20.0
NY	7,300	85	0	1.2
OX	2,211	501	0	22.7
SW	8,240	227	0	2.8
TR	4,541	0	4,541	100.0
WM	5,924	30	4,742	80.6

- There was a valid OPCS code for 67% of the episodes considered surgical for the 6 registries above.

## Hospital codes

This field refers to the hospital or alternative health centre where the treatment was undertaken. National codes for centres that undertake NHS treatment should be prefixed by "R".

There are 2,085 episodes where the column is blank or contains "?". The non valid codes are made up of local codes, nonsense codes, unknowns and private premises.

- There are 106975 (63%) potentially valid R codes

## Hospital names

This is the official name given to the treatment centre (usually a hospital).

There are 995 episodes for which this is blank. There are local names, nonsense names, unknowns and unknown private premises for approximately 7,500 episodes. This part of the analysis has been largely subjective.

- Approximately 96% of episodes had an officially recognisable treatment centre recorded.

## Hospital address

This represents the address of the treatment centre.

- This was blank or unknown for 137,928 episodes (81%).  
The remaining addresses range from name of town e.g. Cambridge to a full postal address.

## Treatment columns (Radiotherapy, Chemotherapy, Surgery, Hormone therapy, other treatment, no treatment)

These contain Y, N, U or are blank for each episode recorded except for "radiotherapy type" which is discussed in more detail below.

Note NW have given N for all treatment modalities. The "no treatment" column is completed mainly with "Y" for NW patients.

## Radiotherapy

18,803 episodes recorded. This equates to 16,520 unique tumours in the treatment database which are recorded as having received radiotherapy.

- 4,827 unique tumours had radiotherapy as the only recorded treatment (7% where NW and TH are excluded: 4827/69178 and 6% where NW has been included: 4827/82017)

Additional: of the 2,755 tumours in the tumour database that are not represented in the treatment database (Thames excluded) 1 had Radiotherapy as the only treatment recorded in the tumour dataset. This gives a total of 4,827 unique tumours where radiotherapy is the only recorded treatment (total number of unique tumours overall is 105,698)

## Radiotherapy type

Of the 18,803 episodes of radiotherapy recorded 3,935 were external beam, 14 intercavity, 2 isotopes, the remainder are unknown.

- For 79% of radiotherapy entries this is unknown

## Chemotherapy

There are 5,098 episodes recorded. This equates to 4,297 unique tumours in this database that are recorded as having received chemotherapy.

- 729 unique tumours had chemotherapy as the only recorded treatment (**1%** where NW and TH are not included: 729/69178, 1% where NW has been included: 729/82017)

## Surgery

Overall 34,594 episodes are recorded. This equates to 31,125 unique tumours in this database that are recorded as having had surgery.

- 15,870 unique tumours had surgery as the only recorded treatment (**23%** where NW and TH are excluded: 15870/69178 or 19% where NW has been included: 15870/82017)

## Hormone therapy

There are 2,021 episodes recorded. This equates to 1,968 unique tumours in this database that are recorded as having had hormone therapy.

- 369 unique tumours had hormone therapy as the only recorded treatment (**0.5%** where NW and TH are excluded: 369/69178 or 4% where NW has been included: 369/82017)

## Other treatment

The type of treatment that this refers to is not further specified. There are 24,953 episodes recorded as “other treatment”. This equates to 16,720 unique tumours in this database that are recorded as having had “other treatment”.

- 7,048 unique tumours had other treatment as their only recorded treatment (**10%** where NW and TH are not excluded: 7048/69178 or 9% where NW has been included: 7048/82017)

## No treatment

In total there are 18,334 episodes recorded as “no treatment”. This equates to 45 unique tumours (excluding NW) in this database that are recorded as having “No treatment”.

- When NW is included 35,006 unique tumours either have had no treatment reported or treatment status is unknown (43%: 35006/82017).

Additional: of the 2,755 tumours in the tumour database that are not represented in the treatment database (Thames excluded) 2,752 either have no treatment reported or treatment status is unknown. This gives a total of 37,758 (45%: 37758/82017+ 2755) tumours where treatment status is unknown or where there was no treatment.

## Combinations

- There were 4,983 unique tumours which had surgery and radiotherapy as their only recorded treatments (6%: 4983/82017).

Additional: of the 2,755 tumours in the tumour database that are not represented in the treatment database (Thames excluded) 2 had radiotherapy and surgery as the only treatments recorded within the tumour dataset. This gives a total of 4,984 unique tumours where radiotherapy and surgery are the only recorded treatments (total number of unique tumours in tumour dataset is 105,698, total excluding Thames patients is 84,772).

- 683 (8%: 683/82017) unique tumours had surgery and chemotherapy as their only recorded treatments.
- 40 unique tumours (0.05%: 40/82017) had chemotherapy, radiotherapy, surgery and hormone therapy recorded as their only treatments.

Other combinations exist but have not been shown here.

## Conclusions and recommendations

The dataset in its current format is limited in its ability to give accurate meaningful information that could improve our knowledge and have a potential impact on the health and wellbeing of individuals living in England.

It would be possible to address some of the short comings of the dataset and then under take some limited analysis. Improvements can be made to the dataset by:

- Removing non brain tumours
- Removing NHS number duplicates
- Removing tumours where site code and morphology/behaviour codes do not correspond
- Updating death information
- Removing 2007 data

This may enable tumour counts by age, sex and location to be made. It may be possible to undertake survival analysis for some of the tumours present.

This is an opportunity to design a brain/CNS dataset that will be able to impact on health of the population in the future. Careful consideration must be given to the information that will be requested to populate a future brain tumour database. By determining the outcomes that are expected from such a dataset it should be possible to select suitable information categories.

Collecting information in the NHS, in particular information that it not presently collected in a readily available format is expensive. Requests for additional data fields must be clearly justifiable. Collecting information badly represents poor use of NHS resources.

Suggestions for further data items for a future brain/CNS dataset:

- Information on co morbidity
- Treatment intent
- Working diagnosis
- Treatment planned e.g. 3 courses of chemotherapy
- Further details on treatment such as drug names, chemotherapy regime, fractions received, deviations from planned treatment
- Recurrence information
- Performance status/outcome measure(s) following treatment

In the current brain dataset certain items such as nodes positive and Dukes stage can be removed.

The 8 registries in England currently collect information and record information in different ways as well as having different methods of validating that information. The information available is presented as a mix of local and national codes. This can makes interpretation of information on a national basis confusing. Given the rarity of brain and CNS tumour regional analysis would not be appropriate. In order to collect a greater number of cases and to see greater accuracy than is possible by amalgamating regional data it is recommended that all registrations for these tumours go through 1 registry. There also needs to be more standardisation and enforcement of standards across registries to improve opportunities for meaningful data analysis.

## **Recommendations**

- Standardisation across registries on how information should be recorded. Performance management of standards
- Further data items to be collected for a future brain dataset, some items to be removed
- All brain/CNS registrations to come through 1 registry
- Not to include bone tumours in this dataset
- Improved registration of benign tumours
- Improved recording of ethnicity/use of HES for ethnicity



## Appendix A: Count of site code by registry for 1990-2007 for Brain & CNS tumours in England

ICD 10 site code	Description	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Total count
		WM	TR	SW	TH	OX	NY	EC	NW	
C70.0	Cerebral Meninges	28	33	81	242	37	63	100	156	740
C70.1	Spinal Meninges	4	12	21	18	4	8	10	9	86
C70.9	Meninges, unspecified	26	59	124	54	37	13	18	6	337
C71.0	Brain, cerebrum, except lobes & ventricles	296	438	880	503	129	152	288	361	3047
C71.1	Brain, Frontal lobe	1139	944	1875	2072	510	1202	1294	1183	10219 (9.9)
C71.2	Brain, Temporal lobe	799	682	1270	1269	348	1003	889	891	7151
C71.3	Brain, parietal lobe	848	887	1292	1436	407	1268	1081	1493	8712
C71.4	Brain, occipital lobe	182	124	338	319	82	218	212	243	1718
C71.5	Brain, cerebral ventricle	64	69	134	65	19	25	71	107	554
C71.6	Brain, cerebellum	138	255	462	347	94	277	246	243	2062
C71.7	Brain stem	174	144	201	258	52	112	149	184	1274
C71.8	Overlapping lesion of brain	564	457	428	1637	167	60	706	610	4629
C71.9	Brain, unspecified	2179	2014	2392	4535	1274	4012	1968	2327	20701 (20)
C72.0	Spinal cord	132	107	169	286	61	167	132	87	1141
C72.1	Cauda Equina	3	1	7	0	0	1	2	0	14
C72.2	Olfactory nerve	11	3	4	7	0	3	5	0	33
C72.3	Optic nerve	36	23	40	85	1	34	44	16	279
C72.4	Acoustic nerve	0	2	3	22	6	6	1	1	41
C72.5	Other and unspecified cranial nerves	15	15	26	35	6	20	26	55	198
C72.8	Overlapping lesion of brain and other parts of central nervous	1	1	5	1	0	2	4	6	20

ICD 10 site code	Description	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Total count
		WM	TR	SW	TH	OX	NY	EC	NW	
	system									
C72.9	Central nervous system, unspecified	6	5	30	43	3	11	11	16	125
C75.1	Pituitary gland	104	22	74	121	27	50	42	59	499
C75.2	Craniopharyngeal duct	0	1	1	3	0	0	0	0	5
C75.3	Pineal gland	50	36	67	90	24	76	55	54	452
C85.7	Other specified types of non-hodgkin's lymphoma (with morphology 9594/3)	1	0	2	10	0	11	58	1	83
D32.0	Cerebral meninges	1145	978	2104	2768	629	1221	1281	2215	12341 (12)
D32.1	Spinal meninges	132	149	141	216	75	167	161	132	1173
D32.9	Meninges, unspecified	573	774	1027	655	284	1050	599	0	4962
D33.0	Brain, supratentorial	28	51	77	68	27	6	55	43	355
D33.1	Brain, infratentorial	12	16	22	12	6	2	15	39	124
D33.2	Brain, unspecified	40	100	131	119	247	103	110	87	937
D33.3	Cranial nerves	637	623	1467	981	330	661	1143	512	6354
D33.4	Spinal cord	98	56	51	150	59	137	89	0	640
D33.7	Other specified parts of central nervous system	4	1	21		4	2	8	104	144
D33.9	Central nervous system, unspecified	4	2	5	45	1	5	8	8	78
D35.2	Pituitary gland	906	1002	940	2001	574	1202	939	1328	8892 (8.6)
D35.3	Craniopharyngeal duct	0	0	0	0	0	0	1	0	1 (0.001)
D35.4	Pineal gland	3	3	3	2	1	0	1	1	14
D42.0	Cerebral meninges	0	0	54	0	0	5	0	0	59

ICD 10 site code	Description	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Count of site code	Total count
		WM	TR	SW	TH	OX	NY	EC	NW	
D42.1	Spinal meninges	0	0	9	0	0	0	0	0	9
D42.9	Meninges, unspecified	0	0	51	0	0	3	0	0	54
D43.0	Brain, supratentorial	0	0	255	0	0	44	0	0	299
D43.1	Brain, infratentorial	0	0	114	0	0	17	0	0	131
D43.2	Brain, unspecified	0	0	900	0	0	710	0	0	1610
D43.3	Cranial nerves	0	0	7	0	0	8	0	0	15
D43.4	Spinal cord	0	0	47	0	0	50	0	0	97
D43.7	Other parts of central nervous system	0	0	4	0	0	0	0	0	4 (0.004)
D43.9	Central nervous system, unspecified	0	0	35	0	0	100	0	0	135
D44.3	Pituitary gland	0	0	218	0	0	78	0	0	296
D44.4	Craniopharyngeal duct	0	0	123	0	0	94	0	0	217
D44.5	Pineal gland	0	0	33	0	0	27	0	0	60
										<b>103121</b>

**Appendix B:** Recorded Brain & CNS tumours by morphology and behaviour code, sex and registry for 1990-2007

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
80000	NEOPLASM BENIGN	Y	567	908	1475
80001	NEOPLASM UNCERTAIN BEHAVIOUR	Y	944	946	1890
80003	NEOPLASM MALIGNANT	Y	2941	2835	5776
80006	NEOPLASM METASTATIC	N	2	2	4
80009	NEOPLASM UNCERT PRIM/MET SITE	N	24	29	53
80010	TUMOUR BENIGN	Y	7	6	13
80011	TUMOUR UNCERTAIN BEHAVIOUR	Y	12	14	26
80013	TUMOUR CELLS MALIGNANT	Y	85	126	211
80023	MALIGNANT TUMOUR SMALL CELL TYP	Y	2	0	2
80033	MALIGNANT TUMOUR GIANT CELL TYP	Y	2	1	3
80043	MALIG TUMOUR FUSIFORM CELL TYPE	Y	2	0	2
80100	EPITHELIAL TUMOUR BENIGN	Y	15	21	36
80103	CARCINOMA NOS	Y	345	312	657
80106	CARCINOMA METASTATIC NOS	N	2	3	5
80109	CARCINOMA NOS UNCERTAIN PRIMARY SITE	N	17	10	27
80126	LARGE CELL CA MET	N	2	2	4
80203	CARCINOMA UNDIFFERENTIATED NOS	Y	1	0	1
80206	CARCINOMA UNDIFFERENTIATED METASTATIC	N	1	0	1
80209	CARCINOMA UNDIFF UNCERTAIN PRIMARY SITE	N	1	0	1
80213	CARCINOMA ANAPLASTIC TYPE NOS	Y	1	1	2
80216	CARCINOMA ANAPLASTIC NOS METASTATIC	N	2	1	3
80323	SPINDLE CELL CARCINOMA	Y	1	1	2

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
80333	PSEUDOSARCOMATOUS CARCINOMA	Y	0	1	1
80413	SMALL CELL CARCINOMA NOS	N	0	1	1
80426	CARCINOMA OAT CELL METASTATIC	N	2	2	4
80500	PAPILLOMA NOS	Y	1	2	3
80703	SQUAMOUS CARCINOMA NOS	Rare	4	0	4
80713	SQUAMOUS CA KERATINISING NOS	Rare	2	0	2
80716	SQUAMOUS CA KERATINISING METASTATIC NOS	N	2	1	3
80743	SQUAMOUS CA SPINDLE CELL TYPE	Rare	1	0	1
81400	ADENOMA NOS	Y	3807	3365	7172
81401	BRONCHIAL ADENOMA NOS	N	13	5	18
81403	ADENOCARCINOMA NOS	Y	56	46	102
81460	ADENOMA MONOMORPHIC	Y	1	2	3
81900	TRABECULAR ADENOMA	Y	0	9	9
82003	ADENOID CYSTIC CARCINOMA	N	0	1	1
82401	CARCINOID TUMOUR NOS	Y	0	1	1
82403	CARCINOID TUMOUR MALIGNANT	Y	1	1	2
82463	NEUROENDOCRINE TUMOUR	Y	9	9	18
82600	PAPILLARY ADENOMA	Y	4	1	5
82633	ADENOCARCINOMA IN TUBULOVILLOUS ADENOMA	Possibly	1	0	1
82700	CHROMOPHE ADENOMA	Y	348	328	676
82703	CHROMOPHE CARCINOMA	Y	10	12	22
82710	PROLACTINOMA	Y	137	132	270
82800	ACIDOPHIL ADENOMA	Y	66	44	110
82803	ACIDOPHIL CARCINOMA	Y	1	2	3
82810	MIXED ACIDOPHIL BASOPHIL ADENOM	Y	1	2	3

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
82813	MIXED ACIDOPHIL BASOPHIL CARCIN	Y	0	1	1
83000	BASOPHIL ADENOMA	Y	7	22	29
83203	GRANULAR CELL CARCINOMA	Y	0	1	1
83230	MIXED CELL ADENOMA	Y	6	1	7
83340	MACROFOLLICULA ADENOMA	N	2	2	4
83601	MULTIPLE ENDOCRINE ADENOMAS	N	0	1	1
84403	CYSTADENOCARCINOMA NOS	May be used to describe a pituitary tumour	1	0	1
84521	PAPILLARY CYSTIC TUMOUR	Possibly. Code may be used as the code for the actual tumour may not exist	0	1	1
84813	ADENOCARCINOMA MUCIN PRODUCING	Y	1	0	1
84816	ADENOCARCINOMA MUCINOUS METASTATIC PNK	N	1	0	1
85006	DUCT INFILTRATING CA METASTATIC PNK	N	0	1	1
86801	PARAGANGLIOMA NOS	Y	4	5	9
86803	PARAGAGLIOMA MALIGNANT	Y	0	1	1
86933	PARAGANGLIOMA EXTRA ADRENAL MAL	Y	1	0	1
87203	MELANOMA MALIGNANT NOS	Y	17	11	28
87206	MELANOMA MALIGNANT NOS METASTATIC	N	0	1	1
87209	MELANOMA MALIGNANT UNCERT PRIMARY SITE	N	1	0	1
87260	MAGNOCELLULAR NAEVUS	N	1	2	3
87400	JUNCTIONAL NAEVUS	N	0	1	1
88003	SARCOMA NOS	Y	16	9	25

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
88013	SARCOMA SPINDLE CELL	Y	2	6	8
88023	SARCOMA GIANT CELL	Y	2	1	3
88033	SARCOMA SMALL CELL	Y	1	0	1
88100	FIBROMA NOS	Y	3	0	3
88103	FIBROSARCOMA NOS	Y	1	0	1
88113	FIBROMYXOSARCOMA	Y	1	1	2
88301	ATYPICAL FIBROUS HISTIOCYTOMA	Rare	0	1	1
88303	FIBROUS HISTIOCYTOMA MAL	Y	3	1	4
88400	MYXOMA NOS	Y	2	0	2
88403	MYXOSARCOMA	Y	0	1	1
88500	LIPOMA NOS	Y	0	2	2
88503	LIPOSARCOMA NOS	Y	0	1	1
88523	MYXOID LIPOSARCOMA	Y	2	0	2
88610	ANGIOLIPOMA NOS	Very rare	0	2	2
88900	LEIOMYOMA NOS	Y	1	0	1
88903	LEIOMYOSARCOMA NOS	Y	2	4	6
88913	LEIOMYOSARCOMA EPITHELOID	Y	0	1	1
88943	ANGIOMYOSARCOMA	N	1	0	1
89003	RHABDOMYOSARCOMA NOS	Y	6	2	8
89103	RHABDOMYOSARCOMA EMBRYONAL	Y	3	5	8
89203	RHABDOMYOSARCOMA ALVEOLAR	Y	0	1	1
89400	PLEOMORPHIC ADENOMA	N	5	2	7
89633	RHABDOID SARCOMA	Possibly. May be used to represent malignant rhabdoid tumour	10	15	25
89806	CARCINOSARCOMA METASTATIC	N	1	0	1
90403	SYNOVIAL SARCOMA NOS	Y	1	0	1

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
90540	ADENOMATOID TUMOUR NOS	N	0	1	1
90603	DYSGERMINOMA	Y	9	7	16
90643	GERMINOMA	Y	234	62	296
90703	EMBRYONAL CARCINOMA NOS	Y	3	1	4
90713	ENDODERMAL SINUS TUMOUR	Y	5	1	6
90800	TERATOMA BENIGN	Y	17	6	23
90801	TERATOMA NOS	Y	6	4	10
90803	TERATOMA MALIGNANT NOS	Y	21	11	32
90813	TERATOCARCINOMA	Y	1	1	2
90833	TERATOMA MALIGNANT INTERMEDIATE	Y	2	1	3
90840	DERMOID CYST	Y	25	32	57
90843	DERMOID CYST WITH MAL TRANSFORM	Y	1	1	2
90853	MIXED GERM CELL TUMOUR	Y	13	0	13
91003	CHORIOCARCINOMA	Y	3	0	3
91100	MESONEPHROMA BENIGN	N	0	0	1
91200	HAEMANGIOMA NOS	Y	3	4	7
91203	HAEMANGIOSARCOMA	Rare	4	5	9
91210	HAEMANGIOMA CAVERNOUS	Y	6	0	6
91301	HAEMANGIOENDOTHELIOMA NOS	Rare	1	0	1
91310	HAEMANGIOMA CAPILLARY	Y	0	1	1
91500	HAEMANGIOPERICYTOMA BENIGN	Y	0	4	4
91501	HAEMANGIOPERICYTOMA NOS	Y	8	9	17
91503	HAEMANGIOPERICYTOMA MALIGNANT	Y	22	24	46
91600	ANGIOFIBROMA NOS	Y	1	0	1
91611	HAEMANGIOBLASTOMA	Y	147	96	243
91703	LYMPHANGIOSARCOMA	Y	2	0	2



Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
92000	OESTEOBLASTOMA	Y	1	0	1
92203	CHONDROSARCOMA NOS	Y	2	0	2
92313	MYXOID CHONDROSARCOMA	Y	0	1	1
92403	CHONDROSARCOMA MESENCHYMAL	Y	3	1	4
92603	EWINGS SARCOMA	Y better coded as Primitive neuroectodermal tumour	51	57	108
92903	AMELOBLASTIC ODONTOSARCOMA	N	0	1	1
93501	CRANIOPHARYNGIOMA	Y	154	155	309
93611	PINEOCYTOMA	Y	14	19	33
93623	PINEOBLASTOMA	Y	61	53	114
93630	MELANOTIC NEUROECTODERMAL TUM	Y	2	3	5
93643	PERIPHERAL NEUROECTODERMAL TUMOUR	Y	36	29	65
93703	CHORDOMA	Y	53	53	106
93803	GLIOMA MALIGNANT	Y	6176	5235	11411
93813	GLIOMATOSIS CEREBRAL	Y	31	27	58
93823	GLIOMA MIXED	Y	444	374	818
93831	SUBEPENDYMAL GLIOMA	Y	30	10	40
93841	SUBEPENDY GIANT CELL ASTROCYTOM	Y	12	9	21
93900	CHOROID PLEXUS PAPILLOMA	Y	73	71	144
93903	CHOROID PLEXUS PAPILLOMA MAL	Y	42	21	63
93913	EPENDYMOMA NOS	Y	747	602	1349
93923	EPENDYMOMA ANAPLASTIC TYPE	Y	105	66	171
93931	EPENDYMOMA PAPILLARY		1	3	4
93941	EPENDYMOMA MYXOPAPILLARY	Y	38	40	78
94003	ASTROCYTOMA NOS	Y	6023	4243	10266

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
94013	ASTROCYTOMA ANAPLASTIC TYPE	Y	1133	767	1900
94103	ASTROCYTOMA PROTOPLASMIC	Y	20	17	37
94113	ASTROCYTOMA GEMISOCYTIC	Y	219	123	342
94203	ASTROCYTOMA FIBRILLARY	Y	221	167	388
94213	ASTROCYTOMA PILOCYTIC	Y	752	689	1441
94243	PLEOMORPHIC XANTHOASTROCYTOMA	Y	23	22	45
94303	ASTROBLASTOMA	Y	17	22	39
94403	GLIOBLASTOMA NOS	Y	12597	8048	20645
94413	GLIOBLASTOMA GIANT CELL	Y	97	66	163
94423	GLIOBLASTOMA SARCOMATOUS COMPON	Y	97	56	153
94503	OLIGODENDROGLIOMA NOS	Y	1160	893	2053
94513	OLIGODENDROGLIOMA ANAPLASTIC	Y	406	277	683
94603	OLIGODENDROBLASTOMA	Y	28	18	46
94703	MEDULLOBLASTOMA NOS	Y	629	378	1007
94713	MEDULLOBLASTOMA DESMOPLASTIC	Y	56	34	90
94723	MEDULLOMYOBlastoma	Y	14	3	17
94733	PRIMITIVE NEUROECTODERMAL TUMOUR	Y	170	151	321
94803	CEREBELLAR SARCOMA	Y	1	0	1
94813	MONSTROCELLULAR SARCOMA	Y	2	0	2
94900	GANGLIONEUROMA	Y	12	14	26
94903	GANGLIONEUROBLASTOMA	Y	6	1	7
95003	NEUROBLASTOMA NOS	Y	42	40	82
95013	MEDULLOEPITHELIOMA NOS	Y	1	1	2
95023	MEDULLOEPITHELIOMA TERATOID	Y	1	0	1
95033	NEUROEPITHELIOMA NOS	Y	10	12	22

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
95051	GANGLIOGLIOMA	Y	55	46	101
95060	NEUROCYTOMA	Y	73	60	133
95103	RETINOBLASTOMA NOS	N	0	1	1
95223	NEUROBLASTOMA OLFACTORY	Y	5	2	7
95300	MENINGIOMA NOS	Y	3996	9415	13412
95301	MENINGIOMATOSIS NOS	Y	30	53	83
95303	MENINGIOMA MALIGNANT	Y	393	577	970
95310	MENINGOTHELIOMATOUS MENINGIOMA	Y	466	955	1422
95320	MENINGIOMA FIBROUS	Y	132	590	722
95330	MENINGIOMA PSAMMOMATOUS	Y	83	421	504
95340	MENINGIOMA ANGIOMATOUS	Y	55	67	122
95350	MENINGIOMA HEAMANGIOBLASTIC	Y	21	16	37
95360	MENINGIOMA HAEMANGIOPERICYTIC	Y	15	11	26
95370	MENINGIOMA TRANSITIONAL	Y	516	1302	1818
95381	MENINGIOMA PAPILLARY	Y	0	1	1
95393	MENINGIOMA SARCOMATOUS	Y	3	1	4
95400	NEUROFIBROMA NOS	Y	104	89	193
95403	NEUROFIBROSARCOMA	Y	18	15	33
95410	NEUROFIBROMA MELANOTIC	Y	0	1	1
95500	NEUROFIBROMA PLEXIFORM	Y	2	4	6
95600	NEURILEMMOMA	Y	3125	3287	6412
95601	NEURINOMATOSIS	Y	1	1	2
95603	NEURILEMMOMA MALIGNANT	Y	80	63	143
95613	TRITON TUMOUR MALIGNANT	Y	1	2	3
95620	NEUROTHEKOMA	Y	1	1	2
95700	NEUROMA NOS	Y	114	159	273

Morphology& behaviour code	Description	Could this be a primary brain tumour?  Comments	Number of males	Number of females	Total
95800	GRANULAR CELL TUMOUR NOS	Y	2	3	5
95943	MICROGLIOMA	Y	40	45	85

## Appendix C: Recorded brain and central nervous system tumours in Eastern Cancer Registry and Information Centre by morphology/behaviour code for the years 1990 to 2006

A number of the CNS tumours are incredibly rare across the whole country. This means that in any one year a registry may not see any cases at all. The table below gives a breakdown of all ECRIC recorded tumours by morphology/behaviour for the years 1990 to 2006. Over 60% of the tumours recorded have a count less than 10 over the 17 years. The most frequently occurring tumours were Glioblastoma NOS (94403) and Meningioma NOS (95300).																			
		Description	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
Blank		0	0	0	0	0	1	0	0	0	0	0	0	0	0	1	0	0	2
80000	NEOPLASM BENIGN	25	18	10	3	1	0	3	6	3	3	2	1	1	4	0	3	2	85
80003	NEOPLASM MALIGNANT	17	24	40	14	7	36	61	57	56	48	45	38	44	46	43	39	48	663
*80009	NEOPLASM UNCERT PRIM/MET SITE	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1
80010	TUMOUR BENIGN	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	2
80013	TUMOUR CELLS MALIGNANT	0	0	0	0	0	1	0	4	4	5	3	2	2	4	2	6	1	34
80023	MALIGNANT TUMOUR SMALL CELL TYP	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
80100	EPITHELIAL TUMOUR BENIGN	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1
80103	CARCINOMA NOS	6	0	1	2	0	4	0	2	0	2	0	0	1	1	0	1	0	20
80703	EMBRYONAL CARCINOMA NOS	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1
81400	ADENOMA NOS	40	38	38	32	21	56	65	38	43	44	39	33	31	48	50	63	46	725
81403	ADENOCARCINOMA NOS	4	0	3	0	0	0	0	0	1	0	0	0	0	0	0	1	0	9
81460	ADENOMA MONOMORPHIC	0	0	0	0	0	0	0	0	0	0	0	0	0	2	1	0	0	3
82463	NEUROENDOCRINE TUMOUR	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1
82700	CHROMOPHE ADENOMA	11	9	9	10	3	7	3	6	2	4	4	6	0	4	6	7	9	100
82703	CHROMOPHE CARCINOMA	0	0	0	0	0	0	2	0	0	0	0	1	0	0	0	0	0	3
82710	PROLACTINOMA	0	0	0	3	1	3	3	2	2	2	4	3	5	2	2	1	7	40
82713	INVALID CODE															1			1
82720	INVALID CODE												1	4	5	7			17
82723	INVALID CODE												1		1				2
82800	ACIDOPHIL ADENOMA	1	3	1	4	1	1	0	1	1	0	2	1	1	1	4	1	2	25

82813	MIXED ACIDOPHIL BASOPHIL CARCIN	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1
83000	BASOPHIL ADENOMA	1	2	3	0	0	1	1	0	1	2	0	0	0	0	0	0	1	12
86800	INVALID CODE	0	0	0	0	0	0	0	0	0	0	1	1	0	1	0	0	0	3
87203	MELANOMA MALIGNANT NOS	0	0	1	0	0	0	0	0	0	0	1	1	0	1	0	0	0	4
*87260	MAGNOCELLULAR NAEVUS	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1
*87400	JUNCTIONAL NAEVUS	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
88003	SARCOMA NOS	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
88100	FIBROMA NOS	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	2
88403	MYXOSARCOMA	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1
88610	ANGIOLIPOMA NOS	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1
88943	ANGIOMYOSARCOMA	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1
89003	RHABDOMYOSARCOMA A NOS	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	1
89103	RHABDOMYOSARCOMA A EMBRYONAL	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
89633	RHABDOID SARCOMA	0	0	0	0	0	0	0	0	0	1	0	1	0	1	0	0	0	3
90643	GERMINOMA	0	1	2	0	4	2	2	1	2	1	2	2	3	4	3	3	4	36
90653	INVALID CODE	0	0	0	0	0	0	0	0	1	1	0	0	0	0	0	0	0	2
90703	EMBRYONAL CARCINOMA NOS	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1
90800	TERATOMA BENIGN	0	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	1	3
90803	TERATOMA MALIGNANT NOS	0	1	1	0	0	0	0	0	1	0	0	0	0	0	1	0	0	4
90833	TERATOMA MALIGNANT INTERMEDIATE	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1
90840	DERMOID CYST	0	1	1	0	1	1	0	0	1	1	1	0	0	0	1	2	0	10
90853	MIXED GERM CELL TUMOUR	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1
90933	INVALID CODE	0	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0	2
91003	CHORIOCARCINOMA	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	2
91200	HAEMANGIOMA NOS	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
91203	HAEMANGIOSARCOMA A	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1
91210	HAEMANGIOMA CAVERNOUS	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1	0	2
91500	HAEMANGIOPERICYTOMA BENIGN	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
91503	HAEMANGIOPERICYTOMA MALIGNANT	0	0	1	0	1	1	0	0	0	0	0	1	0	0	0	1	1	6
91610	INVALID CODE	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	1	3

91613	INVALID CODE	0	0	0	0	0	0	2	0	0	0	0	1	0	1	0	1	0	5
91703	LYMPHANGIOSARCOMA	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1	0	0	2
92000	OESTEOBLASTOMA	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	1
92313	MYXOID CHONDROSARCOMA	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	1
92403	CHONDROSARCOMA MESENCHYMAL	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
93623	PINEOBLASTOMA	1	0	1	0	1	2	0	0	2	1	0	0	0	1	4	1	1	15
93633	INVALID CODE	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2
93643	PERIPHERAL NEUROECTODERMAL TUMOUR	0	0	1	0	0	1	0	0	0	1	0	1	0	0	0	0	0	4
93703	GLIOMA MALIGNANT	0	0	0	0	0	2	0	0	0	2	1	0	0	1	1	1	0	8
93803	GLIOMA MALIGNANT	156	134	112	106	113	118	127	104	100	75	81	66	64	53	49	47	42	1547
93813	GLIOMATOSIS CEREBRAL	1	0	1	0	0	0	0	0	1	2	1	0	2	0	4	1	2	15
93823	GLIOMA MIXED	8	2	1	2	3	1	2	5	6	4	4	5	6	15	10	13	10	97
93900	CHOROID PLEXUS PAPILLOMA	0	0	2	1	3	2	2	1	3	0	2	0	0	0	0	0	2	18
93903	CHOROID PLEXUS PAPILLOMA MAL	0	1	0	1	1	0	0	0	0	0	0	0	0	0	2	1	0	6
93913	EPENDYMOMA NOS	5	10	10	9	10	7	12	7	8	9	10	18	9	9	12	9	9	163
93923	EPENDYMOMA ANAPLASTIC TYPE	1	1	0	0	1	0	1	0	1	2	1	1	1	0	3	5	0	18
94003	ASTROCYTOMA NOS	106	108	127	92	77	73	58	64	61	63	58	52	38	53	48	34	25	1137
94013	ASTROCYTOMA ANAPLASTIC TYPE	40	30	31	34	10	12	11	12	4	12	10	7	5	14	8	12	11	263
94103	ASTROCYTOMA PROTOPLASMIC	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	2
94113	ASTROCYTOMA GEMISOCYTIC	4	1	7	3	2	0	3	3	0	2	1	1	1	1	0	2	0	31
94130	ASTROCYTOMA PROTOPLASMIC	0	0	0	0	0	0	0	0	0	0	0	2	2	1	2	0	0	7
94203	ASTROCYTOMA FIBRILLARY	4	2	0	3	0	1	1	1	2	2	1	4	2	1	1	3	1	29
94210	INVALID CODE	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	2
94213	ASTROCYTOMA PILOCYTIC	5	0	9	9	7	10	13	11	10	20	9	16	12	14	15	11	12	183
94243	PLEOMORPHIC XANTHOASTROCYTOMA	0	0	0	0	0	0	2	0	0	1	0	0	0	0	2	0	1	6
94303	ASTROBLASTOMA	0	0	0	0	0	1	0	2	0	0	0	0	0	1	1	0	0	5
94403	GLIOBLASTOMA NOS	30	22	43	66	87	106	124	161	130	143	193	187	201	178	156	193	202	222

																			2
94413	GLIOBLASTOMA GIANT CELL	1	0	1	0	1	1	2	3	3	3	4	0	2	0	1	0	0	22
94423	GLIOBLASTOMA SARCOMATOUS COMPON	0	0	0	0	0	0	0	2	3	0	3	4	3	0	4	1	0	20
94503	OLIGODENDROGLIOM A NOS	13	15	14	13	18	17	11	21	19	11	22	26	19	11	21	21	16	288
94513	OLIGODENDROGLIOM A ANAPLASTIC	3	2	4	3	7	7	6	4	8	8	7	6	4	10	9	16	9	113
94603	OLIGODENDROBLAST OMA	1	0	0	0	4	3	0	1	0	0	1	0	0	1	0	2	0	13
94703	MEDULLOBLASTOMA NOS	10	7	4	6	5	6	10	6	6	6	3	2	10	6	6	5	9	107
94713	MEDULLOBLASTOMA DESMOPLASTIC	1	0	2	1	1	0	1	0	2	2	0	0	0	3	0	0	0	13
94723	MEDULLOMYOBlasto MA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1
94730	INVALID CODE	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1
94733	PRIMITIVE NEUROECTODERMAL TUMOUR	2	1	2	2	4	2	6	2	3	3	3	2	2	4	5	6	2	51
94813	MONSTROCELLULAR SARCOMA	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	1
94900	GANGLIONEUROMA	0	1	0	0	0	0	0	1	1	1	0	0	0	0	0	0	0	4
94903	GANGLIONEUROBLAST OMA	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	2
95003	NEUROBLASTOMA NOS	1	0	2	1	0	0	0	1	0	0	0	0	0	0	0	1	0	6
95030	INVALID CODE	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	2
95033	NEUROEPITHELIOMA NOS	0	0	0	0	2	0	0	0	0	1	0	0	0	0	0	0	0	3
95050	INVALID CODE	0	0	0	0	2	0	1	4	1	0	3	2	2	0	0	0	2	17
95053	INVALID CODE	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	2	0	3
95060	NEUROCYTOMA	0	1	0	0	0	0	2	0	2	1	1	3	1	2	2	1	3	19
95083	INVALID CODE	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1
95223	NEUROBLASTOMA OLFACTORY	0	0	0	0	1	1	0	0	0	0	2	0	0	1	0	0	0	5
95300	MENINGIOMA NOS	63	64	68	57	68	86	92	98	108	108	93	110	109	115	127	117	110	159 3
95303	MENINGIOMA MALIGNANT	3	1	0	3	4	7	6	7	10	7	8	15	9	10	10	5	5	110
95310	MENINGOTHELIOMAT OUS MENINGIOMA	17	25	17	12	9	32	16	22	7	5	8	10	4	7	4	1	4	200
95313	INVALID CODE	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	0	3
95320	MENINGIOMA FIBROUS	1	5	8	4	4	6	9	5	9	6	5	7	6	4	1	3	3	86



95330	MENINGIOMA PSAMMOMATOUS	1	4	3	1	0	7	4	5	8	6	6	8	3	9	3	3	3	74
95340	MENINGIOMA ANGIOMATOUS	0	0	0	0	1	0	0	0	1	0	0	2	2	4	1	1	0	12
95350	MENINGIOMA HEMANGIOBLASTIC	5	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	7
95360	MENINGIOMA HAEMANGIOPERICYTI C	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	2
95363	INVALID CODE	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	1	0	2
95370	MENINGIOMA HAEMANGIOPERICYTI C	9	0	9	0	4	1	7	5	14	5	9	9	7	2	1	1	11	94
95383	INVALID CODE	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	2
95390	INVALID CODE	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1
95400	NEUROFIBROMA NOS	0	1	3	2	0	0	2	0	0	3	0	0	1	1	1	0	2	16
95403	NEUROFIBROSARCOM A	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1	1	0	3
95423	INVALID CODE	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1
95500	NEUROFIBROMA PLEXIFORM	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	1
95600	NEURILEMMOMA	45	28	38	44	63	78	98	127	84	71	83	97	73	76	58	71	58	119 2
95603	NEURILEMMOMA MALIGNANT	2	3	1	0	1	1	1	1	0	1	1	0	1	1	0	1	0	15
95613	TRITON TUMOUR, MALIGNANT	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	1
95700	NEUROMA NOS	0	1	1	3	2	1	5	3	1	0	0	0	0	1	0	0	1	19
95703	INVALID CODE	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1
95943	MICROGLIOMA	0	0	0	0	0	0	0	0	0	0	0	1	5	15	8	13	16	58
Total		648	574	634	550	561	708	779	808	738	708	744	761	704	754	710	742	699	11,820

\*Not a brain tumour

INVALID CODE: The ICD 10 code used cannot be found in ICD 10.

## Appendix D

Treatment type (official code)	Number of episodes	Registry
Blank	11486	EC
Blank	22744	NW
Blank	13136	TR
Blank	129	WM
Additional Pathology (99)	476	WM
Biopsy only (99)	2203	WM
Brachytherapy (06)	2	NY
C (99)	781	EC
Chemotherapy(03)	719	NY
Chemotherapy (03)	316	OX
Chemotherapy (03)	1668	SW
Chemotherapy (03)	681	WM
Chemotherapy admission (03)	414	WM
Clinical diagnosis (99)	620	WM
Cytological diagnosis (99)	83	WM
D (99)	8534	EC
Death certificate initiated consequence (99)	3977	WM
Diagnosis (99)	4417	OX
Diagnosis from biochemical and immunological tests (99)	4	WM
Diagnosis from imaging (99)	3916	WM
Dummy consequence for death certificates (99)	1	WM
Dummy consequence for postcodes (99)	2	WM

Treatment type (official code)	Number of episodes	Registry
F (99)	7935	EC
Found at PM (99)	70	WM
Histological diagnosis from post mortem (99)	46	WM
Histological diagnosis of nodes and metastases (99)	41	WM
Histological diagnosis of primary (99)	6193	WM
Hormone (04)	295	OX
Hormone (04)	57	SW
Hormone therapy (04)	22	WM
Hormone/endocrine therapy (04)	704	NY
Hospice stay (05)	268	WM
Hospital admission and/or consultation (99)	1406	WM
Hospital consequence (old data only) (99)	325	WM
N/T Not Treated (99)	45	OX
Negative Pathology (99)	9	WM
No further treatment (99)	199	WM
O (08)	1046	EC
Other (08)	8795	SW
Other treatment (08)	22776	NY
Radiotherapy (02)	2486	SW
Radiotherapy (02)	3406	WM
Radiotherapy Admission (02)	2176	WM
RT (02)	1611	OX
Seen by consultant but not treated (99)	901	WM
Surgery (01)	7300	NY

Treatment type (official code)	Number of episodes	Registry
Surgery (01)	2211	OX
Surgery (01)	8240	SW
Surgery (01)	5801	WM
Surgery for nodes and metastases (01)	15	WM
Surgical diagnosis (99)	45	WM
Surgical Procedure (01)	123	WM
T	727	EC
Teletherapy (02)	4010	NY
U (08)	66	EC
U/K Unknown (99)	890	OX
Unabstracted (old data only) (99)	1131	WM
Waiting times diagnosis (type not known) (99)	1	WM
X (99)	2619	EC

EC codes: D=Diagnosis F=Further appointment O=Other treatment T=data from Thames when Registries boundaries changed, effectively unknown U= Other drugs, not chemo or radiotherapy X= Unknown. (Personal communication)

## Appendix E

### OPCS codes not thought to be relevant to surgical treatment for brain/CNS/relevant bone tumours by registry

#### Eastern Cancer Registry and Information Centre

OPCS code	Definition	Count
E296	Excision of larynx: Laryngectomy NEC	1
E511	Diagnostic endoscopic examination of lower respiratory tract using rigid bronchoscope: Diagnostic endoscopic examination of lower respiratory tract and biopsy of lesion of lower respiratory tract using rigid bronchoscope	1
E543	Excision of lung: Lobectomy of lung	5
E545	Excision of lung: Partial lobectomy of lung NEC	2
E551	Open extirpation of lesion of lung: Open decortication of lesion of lung	1
H335	Excision of rectum: Rectosigmoidectomy and closure of rectal stump and exteriorisation of bowel	1
J021	Partial excision of liver: Right hemihepatectomy NEC	1
J029	Partial excision of liver: Unspecified partial excision of liver	1
J183	Excision of gall bladder: Total cholecystectomy NEC	1
L912	Other vein related operations: Insertion of central venous catheter NEC	3
L918	Other vein related operations: Other specified other vein related operations	2
M348	Total excision of bladder: Other specified total excision of bladder	1
M645	Other open operations on outlet of male bladder: Removal of prosthetic collar from around outlet of male bladder	1
Q029	Destruction of lesion of cervix uteri: Unspecified destruction of lesion of cervix uteri	1
Q221	Bilateral excision of adnexa of uterus: Bilateral salpingoophorectomy	1

<b>S048</b>	Other excision of skin: Other specified other excision of skin	<b>1</b>
<b>S065</b>	Other excision of lesion of skin: Excision of lesion of skin of head or neck NEC	<b>1</b>
<b>S068</b>	Other excision of lesion of skin: Other specified other excision of lesion of skin	<b>5</b>
<b>S069</b>	Other excision of lesion of skin: Unspecified other excision of lesion of skin	<b>1</b>
<b>S159</b>	Other biopsy of skin: Unspecified other biopsy of skin	<b>2</b>
<b>T031</b>	Opening of chest: Exploratory median sternotomy	<b>1</b>
<b>T039</b>	Opening of chest: Unspecified opening of chest	<b>4</b>
<b>T309</b>	Opening of abdomen: Unspecified opening of abdomen	<b>6</b>
<b>T851</b>	Block dissection of lymph nodes: Block dissection of cervical lymph nodes	<b>2</b>
<b>T872</b>	Excision or biopsy of lymph node: Excision or biopsy of cervical lymph node NEC	<b>2</b>
<b>T879</b>	Excision or biopsy of lymph node: Unspecified excision or biopsy of lymph node	<b>6</b>
<b>T962</b>	Other operations on soft tissue: Excision of lesion of soft tissue NEC	<b>5</b>
<b>T969</b>	Other operations on soft tissue: Unspecified other operations on soft tissue	<b>2</b>
<b>W391</b>	Other total prosthetic replacement of hip joint: Primary total prosthetic replacement of hip joint NEC	<b>1</b>
<b>W393</b>	Other total prosthetic replacement of hip joint: Revision of total prosthetic replacement of hip joint NEC	<b>1</b>
<b>X091</b>	Amputation of leg: Hindquarter amputation	<b>3</b>
<b>X099</b>	Amputation of leg: Unspecified amputation of leg	<b>6</b>
<b>X141</b>	Clearance of pelvis: Total exenteration of pelvis	<b>2</b>
<b>X362</b>	Blood withdrawal: Venesection	<b>3</b>
<b>X532</b>	Extirpation of unspecified organ: Excision of lesion of unspecified organ	<b>1</b>

<b>X533</b>	Extirpation of unspecified organ: Destruction of lesion of unspecified organ	<b>1</b>
<b>X559</b>	Other operations on unspecified organ: Unspecified other operations on unspecified organ	<b>1113</b>
	<b>Total</b>	<b>1192</b>

### Northern & Yorkshire Cancer Registry & Information Service

<b>OPCS code</b>	<b>Definition</b>	<b>Count</b>
<b>E543</b>	Excision of lung: Lobectomy of lung	<b>3</b>
<b>E545</b>	Excision of lung: Partial lobectomy of lung NEC	<b>2</b>
<b>H331</b>	Excision of rectum: Abdominoperineal excision of rectum and end colostomy	<b>1</b>
<b>M025</b>	Total excision of kidney: Nephrectomy NEC	<b>1</b>
<b>S049</b>	Other excision of skin: Unspecified other excision of skin	<b>5</b>
<b>S089</b>	Curettage of lesion of skin: Unspecified curettage of lesion of skin	<b>3</b>
<b>S571</b>	Exploration of other skin of other site: Debridement of skin NEC	<b>1</b>
<b>T331</b>	Open extirpation of lesion of peritoneum: Open excision of lesion of peritoneum	<b>1</b>
<b>T969</b>	Other operations on soft tissue: Unspecified other operations on soft tissue	<b>8</b>
<b>X091</b>	Amputation of leg: Hindquarter amputation	<b>2</b>
<b>X099</b>	Amputation of leg: Unspecified amputation of leg	<b>3</b>
<b>X559</b>	Other operations on unspecified organ: Unspecified other operations on unspecified organ	<b>55</b>
	<b>Total</b>	<b>85</b>

### Oxford Cancer Intelligence Unit

OPCS code	Description	Count
E545	Excision of lung: Partial lobectomy of lung NEC	3
H331	Excision of rectum: Abdominoperineal excision of rectum and end colostomy	1
S049	Other excision of skin: Unspecified other excision of skin	2
T391	Operations on posterior peritoneum: Excision of lesion of posterior peritoneum	1
T962	Other operations on soft tissue: Excision of lesion of soft tissue NEC	5
T968	Other operations on soft tissue: Other specified other operations on soft tissue	1
X091	Amputation of leg: Hindquarter amputation	1
X352	Other intravenous injection: Intravenous chemotherapy	5
X531	Extirpation of unspecified organ: Excision of unspecified organ	1
X539	Extirpation of unspecified organ: Unspecified extirpation of unspecified organ	211
Y902	Other non-operations: Radiotherapy NEC	84
Y909	Other non-operations: Unspecified other non-operations	186
	Total	501

### South West Cancer Intelligence Service

OPCS code	Description	Count
B128	Other operations on thyroid gland: Other specified other operations on thyroid gland	1
B222	Excision of adrenal gland: Bilateral adrenalectomy NEC	1
B223	Excision of adrenal gland: Unilateral adrenalectomy	1



<b>B231</b>	Operations on aberrant adrenal tissue: Excision of lesion of aberrant adrenal tissue	<b>1</b>
<b>B272</b>	Total excision of breast: Total mastectomy and excision of both pectoral muscles NEC	<b>1</b>
<b>B274</b>	Total excision of breast: Total mastectomy NEC	<b>3</b>
<b>B282</b>	Other excision of breast: Partial excision of breast NEC	<b>1</b>
<b>B283</b>	Other excision of breast: Excision of lesion of breast NEC	<b>1</b>
<b>C118</b>	Operations on canthus: Other specified operations on canthus	<b>5</b>
<b>E541</b>	Excision of lung: Total pneumonectomy	<b>1</b>
<b>E543</b>	Excision of lung: Lobectomy of lung	<b>1</b>
<b>E552</b>	Open extirpation of lesion of lung: Open excision of lesion of lung	<b>3</b>
<b>E611</b>	Open operations on mediastinum: Open excision of lesion of mediastinum	<b>1</b>
<b>E621</b>	Therapeutic endoscopic operations on mediastinum: Endoscopic extirpation of lesion of mediastinum	<b>1</b>
<b>G031</b>	Partial excision of oesophagus: Partial oesophagectomy and end to end anastomosis of oesophagus	<b>1</b>
<b>G049</b>	Open extirpation of lesion of oesophagus: Unspecified open extirpation of lesion of oesophagus	<b>1</b>
<b>G432</b>	Fibreoptic endoscopic extirpation of lesion of upper gastrointestinal tract: Fibreoptic endoscopic laser destruction of lesion of upper gastrointestinal tract	<b>1</b>
<b>G491</b>	Excision of duodenum: Gastroduodenectomy	<b>1</b>
<b>G584</b>	Excision of jejunum: Partial jejunectomy and anastomosis of jejunum to ileum	<b>1</b>
<b>G693</b>	Excision of ileum: Ileectomy and anastomosis of ileum to ileum	<b>1</b>
<b>G699</b>	Excision of ileum: Unspecified excision of ileum	<b>1</b>
<b>H012</b>	Emergency excision of appendix: Emergency excision of abnormal appendix NEC	<b>1</b>
<b>H029</b>	Other excision of appendix: Unspecified other excision of appendix	<b>1</b>

<b>H073</b>	Other excision of right hemicolon: Right hemicolectomy and anastomosis NEC	<b>1</b>
<b>H115</b>	Other excision of colon: Colectomy and exteriorisation of bowel NEC	<b>1</b>
<b>H201</b>	Endoscopic extirpation of lesion of colon: Fibreoptic endoscopic snare resection of lesion of colon	<b>1</b>
<b>H202</b>	Endoscopic extirpation of lesion of colon: Fibreoptic endoscopic cauterisation of lesion of colon	<b>1</b>
<b>H231</b>	Endoscopic extirpation of lesion of lower bowel using fibreoptic sigmoidoscope: Endoscopic snare resection of lesion of lower bowel using fibreoptic sigmoidoscope	<b>1</b>
<b>H331</b>	Excision of rectum: Abdominoperineal excision of rectum and end colostomy	<b>1</b>
<b>H335</b>	Excision of rectum: Rectosigmoidectomy and closure of rectal stump and exteriorisation of bowel	<b>6</b>
<b>H412</b>	Other operations on rectum through anus: Peranal excision of lesion of rectum	<b>1</b>
<b>J021</b>	Partial excision of liver: Unspecified partial excision of liver	<b>1</b>
<b>J183</b>	Excision of gall bladder: Total cholecystectomy NEC	<b>3</b>
<b>J578</b>	Other partial excision of pancreas: Other specified other partial excision of pancreas	<b>1</b>
<b>M021</b>	Total excision of kidney: Nephrectomy and excision of perirenal tissue	<b>4</b>
<b>M025</b>	Total excision of kidney: Nephrectomy NEC	<b>8</b>
<b>M421</b>	Endoscopic extirpation of lesion of bladder: Endoscopic resection of lesion of bladder	<b>6</b>
<b>M653</b>	Endoscopic resection of outlet of male bladder: Endoscopic resection of prostate NEC	<b>3</b>
<b>N063</b>	Other excision of testis: Orchidectomy NEC	<b>2</b>
<b>Q033</b>	Biopsy of cervix uteri: Cone biopsy of cervix uteri NEC	<b>1</b>
<b>Q074</b>	Abdominal excision of uterus: Total abdominal hysterectomy NEC	<b>1</b>
<b>Q078</b>	Abdominal excision of uterus: Other specified abdominal excision of uterus	<b>1</b>
<b>Q111</b>	Other evacuation of contents of uterus: Vacuum aspiration of products of conception from uterus NEC	<b>1</b>

<b>Q221</b>	Bilateral excision of adnexa of uterus: Bilateral salpingoophorectomy	<b>5</b>
<b>Q223</b>	Bilateral excision of adnexa of uterus: Bilateral oophorectomy NEC	<b>1</b>
<b>Q231</b>	Unilateral excision of adnexa of uterus: Unilateral salpingoophorectomy NEC	<b>1</b>
<b>Q233</b>	Unilateral excision of adnexa of uterus: Unilateral salpingectomy NEC	<b>1</b>
<b>Q243</b>	Other excision of adnexa of uterus: Oophorectomy NEC	<b>1</b>
<b>S063</b>	Other excision of lesion of skin: Shave excision of lesion of skin of head or neck	<b>1</b>
<b>S064</b>	Other excision of lesion of skin: Shave excision of lesion of skin NEC	<b>1</b>
<b>S065</b>	Other excision of lesion of skin: Excision of lesion of skin of head or neck NEC	<b>31</b>
<b>S068</b>	Other excision of lesion of skin: Other specified other excision of lesion of skin	<b>10</b>
<b>S069</b>	Other excision of lesion of skin: Unspecified other excision of lesion of skin	<b>16</b>
<b>S082</b>	Curettage of lesion of skin: Curettage and cauterisation of lesion of skin NEC	<b>2</b>
<b>S101</b>	Other destruction of lesion of skin of head or neck: Cauterisation of lesion of skin of head or neck NEC	<b>1</b>
<b>S104</b>	Other destruction of lesion of skin of head or neck: Electrolysis to lesion of skin of head or neck	<b>2</b>
<b>S111</b>	Other destruction of lesion of skin of other site: Cauterisation of lesion of skin NEC	<b>1</b>
<b>S131</b>	Punch biopsy of skin: Punch biopsy of lesion of skin of head or neck	<b>3</b>
<b>T013</b>	Partial excision of chest wall: Excision of lesion of chest wall	<b>2</b>
<b>T018</b>	Partial excision of chest wall: Other specified partial excision of chest wall	<b>1</b>
<b>T319</b>	Other operations on anterior abdominal wall: Unspecified other operations on anterior abdominal wall	<b>1</b>
<b>T391</b>	Operations on posterior peritoneum: Excision of lesion of posterior peritoneum	<b>1</b>
<b>T521</b>	Excision of other fascia: Palmar fasciectomy	<b>1</b>

<b>T531</b>	Extirpation of lesion of fascia: Excision of lesion of fascia	<b>1</b>
<b>T773</b>	Excision of muscle: Partial excision of muscle NEC	<b>5</b>
<b>T779</b>	Excision of muscle: Unspecified excision of muscle	<b>1</b>
<b>T838</b>	Other operations on muscle: Other specified other operations on muscle	<b>1</b>
<b>T851</b>	Block dissection of lymph nodes: Block dissection of cervical lymph nodes	<b>4</b>
<b>T852</b>	Block dissection of lymph nodes: Block dissection of axillary lymph nodes	<b>7</b>
<b>T872</b>	Excision or biopsy of lymph node: Excision or biopsy of cervical lymph node NEC	<b>8</b>
<b>T873</b>	Excision or biopsy of lymph node: Excision or biopsy of axillary lymph node	<b>4</b>
<b>T878</b>	Excision or biopsy of lymph node: Other specified excision or biopsy of lymph node	<b>3</b>
<b>T879</b>	Excision or biopsy of lymph node: Unspecified excision or biopsy of lymph node:	<b>1</b>
<b>T962</b>	Other operations on soft tissue: Excision of lesion of soft tissue NEC	<b>19</b>
<b>T968</b>	Other operations on soft tissue: Other specified other operations on soft tissue	<b>3</b>
<b>T969</b>	Other operations on soft tissue: Unspecified other operations on soft tissue	<b>1</b>
<b>W341</b>	Graft of bone marrow: Autograft of bone marrow	<b>2</b>
<b>W342</b>	Graft of bone marrow: Allograft of bone marrow NEC	<b>1</b>
<b>W349</b>	Graft of bone marrow: Unspecified graft of bone marrow	<b>1</b>
<b>X091</b>	Amputation of leg: Hindquarter amputation	<b>2</b>
<b>X099</b>	Amputation of leg: Unspecified amputation of leg	<b>1</b>
<b>X111</b>	Amputation of toe: Amputation of great toe	<b>1</b>
<b>X128</b>	Operations on amputation stump: Other specified operations on amputation stump	<b>1</b>

<b>X532</b>	Extirpation of unspecified organ: Excision of lesion of unspecified organ	<b>1</b>
	<b>Total</b>	<b>227</b>

### West Midlands Cancer Intelligence Unit

<b>OPCS Code</b>	<b>Description</b>	<b>Count</b>
<b>M653</b>	Endoscopic resection of outlet of male bladder: Endoscopic resection of prostate NEC	<b>1</b>
<b>T878</b>	Excision or biopsy of lymph node: Other specified excision or biopsy of lymph node	<b>1</b>
<b>T879</b>	Excision or biopsy of lymph node: Unspecified excision or biopsy of lymph node	<b>2</b>
<b>T962</b>	Other operations on soft tissue: Excision of lesion of soft tissue NEC	<b>1</b>
<b>T968</b>	Other operations on soft tissue: Other specified other operations on soft tissue	<b>1</b>
<b>W052</b>	Prosthetic replacement of bone: Implantation massive endoprosthesis replacement of bone	<b>13</b>
<b>W058</b>	Prosthetic replacement of bone: Other specified prosthetic replacement of bone	<b>1</b>
<b>W328</b>	Other graft of bone: Other specified other graft of bone	<b>1</b>
<b>W391</b>	Other total prosthetic replacement of hip joint: Primary total prosthetic replacement of hip joint NEC	<b>2</b>
<b>W398</b>	Other total prosthetic replacement of hip joint: Other specified other total prosthetic replacement of hip joint	<b>1</b>
<b>X091</b>	Amputation of leg: Hindquarter amputation	<b>2</b>
<b>X092</b>	Amputation of leg: Disarticulation of hip	<b>1</b>
<b>Y049</b>	Replantation of organ NOC: Unspecified replantation of organ NOC	<b>1</b>
<b>Y919</b>	External beam radiotherapy: Unspecified external beam radiotherapy	<b>2</b>
	<b>Total</b>	<b>30</b>

