Guidance on Cancer Services

Improving Outcomes for People with Brain and other Central Nervous System Tumours

An Assessment of Need for Brain and other CNS Tumour Services in England and Wales

A report to the National Collaborating Centre for Cancer

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First draft: November 2005

Acknowledgements

My thanks to:

- Dr Quentin Sandifer, and Dr Penny Bridger, and Dr Iain Robbé who supervised this project and providing advice and constructive input.
- Dr Fergus Macbeth, Clinical Director of the NICE Collaborating Centre for Cancer (NCC-C) for commissioning this work and providing advice.
- Those who partook in the needs assessment project team who have supplied valuable advice and input: Dr Sean Elyan, Prof Garth Cruickshank, Prof David Ellison, Prof Roy Rampling, Dr Brian Cottier and Quentin Sandifer.
- Those who provided data and expert advice including Dr Mike Quinn, Director of the National Cancer Intelligence Centre of the Office for National Statistics, Dr John Steward, Director of the Welsh Cancer Intelligence and Surveillance Unit, Dr Brian Cottier head of National Cancer Services Analysis, and his team, the Office for National Statistics Population Estimates Unit which provided post 2001 census adjusted population estimates. Survival data for malignant brain tumours has been released pre-publication with the agreement of Mike Quinn and Michel Coleman.
- The Society of British Neurological Surgeons for their support of this project and their role in mediating the neurosurgical questionnaire, and Juliet Hardie for following up the surgical questionnaires.
- The Royal College of Radiologists who provided contact details for medical directors / lead clinical oncologists in each radiotherapy centre.
- Thanks are due to the many clinicians throughout the country who have taken the time to complete the questionnaires.
- Others who offered advice, particularly those in the GDG, and also Mr Douglas Guerrero clinical nurse specialist in neuro-oncology, ex-chair of the Association of Neuro-oncology nurses.
- Gareth Davies and Tracy Price, of the Health Information Analysis Team of the National Public Health Service for Wales, for calculating confidence intervals, and compiling the appendices.

Glossary

CNS	Central nervous system
CNSNO	Clinical Nurse Specialist in Neuro-oncology
FCE	Finished consultant episode
HES	Hospital Episode Statistics
MD	Multidisciplinary
MDT	Multidisciplinary team
NATCANSAT	National Cancer Services Analysis Team
ONS	Office for National Statistics
PEDW	Patient Episode Database for Wales
SHA	Strategic Health Authority
WTE	Whole time equivalent

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Executive Summary

The information in this report was used to inform and support the development of the guidance produced by the National Institute for Health and Clinical Excellence "Improving outcomes for people with brain and other central nervous system (CNS) tumours"..

This document describes the burden of disease, and current service provision for people with tumours of the brain and central nervous system in England and Wales. It does not provide evidence of effectiveness, nor evidence of cost effectiveness. The information was used to assist the guidance development group in developing recommendations for services to improve outcomes for these patients.

Methods
This report covers individuals aged 15 and over, thus providing some overlap with the recently published needs assessment for children and young people with cancer.

Subcategories were defined with reference to the WHO classification of tumours of the nervous system, with adjustment for practicalities, including the limitations of availability of data.

The burden of disease was described through analysis of registration and mortality data and available survival and prevalence data, taking into account the potential effect of demographic changes on future incidence. Hospital activity data, provided for England and Wales by the National Cancer Services Analysis Team were analysed for bed days, inpatient episodes and day cases, numbers of individual patients, and procedures. Catchment populations for neurosurgical units were mapped by NACTANSAT using hospital activity data. The derived neurosurgical unit catchment populations were then compared with cancer network catchment populations to assess the degree of overlap.

Questionnaires were sent to all adult neurosurgical units and radiotherapy units in England and Wales to obtain information on current service provision for patients with brain and CNS tumours.

Results
There were about 6,500 tumours of the brain and CNS registered each year in England and Wales in those over 15 years of age, with a registration rate of 15.5 per 100,000. Rates of registration have been increasing particularly in the very elderly and registration peaks at 75-79 years. Brain tumours accounted for 63% of registrations and the vast majority of deaths (91%) attributed to brain or other CNS tumours. The age and trend profile was similar for both registrations and deaths from brain tumours. Survival for malignant brain tumour was poor with approximately one in three remaining alive at one year. With the changing population profile the crude rate of tumours of the brain and CNS is expected to increase from 15.5 to 18.5 per

100,000 by 2041. The increase may be higher if the trend for increased incidence among older age groups continues.

Although most of the care for patients with brain and CNS tumours occurs in the outpatient setting, national hospital activity data are based on inpatient care, and interventions, such as surgery, are easier to quantify than other interventions. Hospital activity for patients with these tumours has been increasing particularly in younger age groups. HES/PEDW recording of "stereotactic ablation of tissue of brain" for patients with these tumours has increased from 163 in 1995/6 to 463 in 2001/2. There were 770 neurological procedures undertaken per year for adults with intracranial metastases. When assigned a unique HES id there were about 22,000 separate patients registered on HES with either primary or secondary tumours of the brain or CNS or phakomatoses. There was substantial variation in hospital activity between Strategic Health Authorities (SHAs), particularly in usage of day case beds.

Neurosurgical unit catchment populations varied widely from over 3.5 million persons to just over quarter of a million. Only 10 of these units covered areas contained within one cancer network; 16 of the other neurosurgical catchment areas covered more than one cancer network area.

All 27 neurosurgical units responded to the questionnaire. There was substantial variation between units in both the numbers of patients seen and the numbers of procedures undertaken. The majority had a defined multidisciplinary team that met regularly (80%) and a clinical nurse specialist in neuro-oncology (81%). Other professions allied to health were not usually involved in these meetings. A quarter of units had no protocols specific for these tumours. There was low recruitment to clinical trials within the previous year.

The response rate from the 52 radiotherapy units was 92%. There was wide variation in numbers of new patients seen; however, similar to neurosurgical units, many radiotherapy units had difficulty providing information at this level. Twenty percent of units did not have a multidisciplinary team; clinical nurse specialists were present in just over half of units. There were examples of cross boundary working in multidisciplinary teams, in some cases involving videoconferencing. Few units reported on-site access to neuropsychology or neuropsychiatry. There was low recruitment to clinical trials within the previous year.

Conclusions

Tumours of the brain and CNS are rare and may affect physical, psychological and cognitive function. Increasing registration rates in the elderly may relate to improved diagnosis, however, rates are expected to continue to increase with changing demography.

The route of care for patients may be complex; catchment areas for neurosurgical units and oncology units often do not coincide, and only ten of the neurosurgical catchment areas are contained within one cancer network

area. Units providing care are heterogeneous, varying not only in size, but also in access to services e.g. clinical nurse specialists in neuro-oncology, neuropsychiatric/psychological services and palliative care. Increasingly patients have access to multidisciplinary teams that meet regularly. There are good examples of multidisciplinary working and cross organisational working within the service.

There are deficiencies in both national and local trust data available for brain and CNS tumours this reduces the ability to assess need and plan appropriately for these tumours.

1 Introduction

The Department of Health (England) and the Welsh Assembly Government asked the National Institute for Clinical Excellence (NICE) “to prepare service guidance for the NHS in England and Wales for tumours of the brain and central nervous system (CNS)”. The National Collaborating Centre for Cancer (NCC-C) published, after consultation, a scope for the guidance with key terms of reference in November 2003 (NICE 2003). A Guidance Development Group (GDG) has been established to take this process forward.

As part of this process the NCC-C requested the National Public Health Service for (NPHS) Wales to undertake a needs assessment. Assessment of the effectiveness of interventions is not included in this document, and was undertaken separately by researchers in the NCC-C as part of the guidance development process.

This document aims to describe burden of disease, and service provision for people with tumours of the brain and CNS in England and Wales, to inform the development of the service guidance.

The information included in this document was presented to the Guidance Development Group. Most of the information was presented early in the stages of guidance development, and other information was included to meet evolving information needs of the GDG during the course of guidance development.

2 Background

2.1 Aetiology

Inherited cancer syndromes and therapeutic irradiation are the only causative factors that have been unequivocally identified for brain and central nervous system (CNS) tumours (IARC 2003). Association has been suggested with a number of occupations, e.g. farming, petrochemical industries and pathology but reports have been conflicting or unconfirmed. The role of radiofrequency radiation e.g. mobile phones 'remain to be substantiated', or that of dietary factors (*N*-nitroso compounds) is unclear (*ibid.*, p 266). Immunosuppression, particularly due to the acquired immune deficiency syndrome (AIDS), is a well-recognised cause of cerebral lymphoma (*ibid*).

2.2 Familial syndromes increasing the risk of CNS cancer

2.2.1 Neurofibromatosis type I (Von Recklinghausen disease)

This is an autosomal dominant disorder, resulting in multiple neurofibroma and is associated with gliomas including optic nerve gliomas, glioblastoma multiforme and astrocytomas (WHO 2000). The prevalence is thought to be about 1/3,000 (Friedman 1999), with no evidence for ethnic variation. The defect is in the NF1 gene on chromosome 17q11, penetrance is near complete, and about half are new mutations. The NF1 gene has an unusually high single locus mutation rate. Defects appear to be paternal and there is at most a modest effect of paternal age. Survival is reduced; in a Swedish population-based study of patients with an average age of diagnosis of 44 years the average age at death was 61.6, as against a life expectancy of 75 years in the general population (extracted from Friedman 1999).

2.2.2 Neurofibromatosis type II

This is also autosomal dominant, and due to a mutation of the NF2 gene on chromosome 22q12 (WHO 2000). Incidence in the UK at birth was found to be 1/33-40,000 in one large population based study (Evans, Sainio, Baser 2000). Schwannoma of the vestibular branch of the eighth cranial nerve (usually bilateral) is a hallmark of the disease, and even with treatment the great majority of subjects become completely deaf (*ibid.*). Other CNS tumours such as meningiomas, astrocytomas and spinal ependymomas are increased in frequency. MRI screening from the age of ten has been recommended for children of parents with this condition (*ibid.*).

2.2.3 Von Hippel-Lindau disease

This autosomal dominant condition is characterised by the development of haemangioblastomas of the CNS, and other sites. It results from a mutation of the VHL tumour suppressor gene on chromosome 3p25-26. A genetic register in the northwest of England set up in 1990 found a live birth incidence of 1/45,500 (Maddock *et al.* 1996), this is similar to that found elsewhere (WHO 2000). Of the 80 people on the register, mean age of onset of symptoms was

26 years, and of death was 41 years. Fifty percent developed cerebellar haemangioblastomas, and 15% spinal haemangioblastomas.

2.2.4 Tuberous sclerosis

This describes a group of autosomal dominant disorders involving benign neoplastic lesions affecting neural tissues and various non-neural tissues. The genes that may be involved are TSC1 gene on chromosome 9q34, and the TSC2 gene on chromosome 16p13. Incidence is thought to be between 1/5,000 and 1/10,000. The most common CNS neoplasm to occur is subependymal giant cell astrocytoma, a benign, slow growing tumour occurring in about 6-16% usually in the first two decades of life (WHO 2000).

2.2.5 Other syndromes

Li Fraumeni syndrome and TP53 mutations

These disorders are due to autosomal dominant mutations of the TP53 gene on chromosome 17p13. They result in an increase in a wide variety of tumour types including breast cancer and sarcomas. About 13.5% of tumours are brain tumours, with a peak in childhood, and a second peak in the third and fourth decade (mainly astrocytomas). This is a very rare syndrome with 143 families being reported between 1990 and 1998 (WHO 2000).

Other syndromes include Cowden's disease (autosomal dominant, NTEN.MMAC1 gene on 10q23) associated with dysplastic gangliocytoma of the cerebellum (Lhermitte-Ducols disease); Turcot's syndrome (various genes, medulloblastoma and glioblastoma) and naevoid basal cell syndrome (Gorlin's syndrome). A population based study of this last syndrome in the north west of England found reported a prevalence of 1 in 55,600 with 29 families affected with medulloblastoma in 5%, and meningioma in 1% (Evans *et al.*, 1993). Medulloblastoma in Gorlin's syndrome is, however, not seen in adults.

2.3 Geographic and ethnic differences

Geographic variation in nervous system tumours is less than for most human neoplasms (IARC, 2003). Less developed countries have a lower incidence than more developed countries, and there is evidence that in multicultural communities those of African or Asian descent have a lower incidence than whites (*ibid.*, Robertson, Gunter & Somes, 2002). Japan is a developed country with particularly low level of reported tumours, it is not clear if this is related to inadequate registration (IARC 2003). Unlike most cancers there is a slight tendency for primary brain tumours to be inversely associated with deprivation (Eaton *et al.* 1997, Quinn *et al.* 2001), as might be expected the reverse trend has been observed for brain metastases (Counsell, Collie & Grant 1996).

3 Methods

3.1 Definitional aspects of the population

For the purposes of this work the population was defined as all those with brain and CNS tumours resident within E&W aged 15 or over. The age limit was chosen on the basis that many adult hospitals will admit patients starting at age 14-16; it also coincides with a standard cut-off point in national statistics. Separate guidance has been developed for services for child and young people with cancer (NICE 2005). This population was designed to overlap with that used in the needs assessment for children and young people with cancer (Griffiths, Fone & Sandifer, 2004).

3.2 Epidemiological data

The time periods included for analysis were 1995-2000 for registrations and mortality, and 1991-2000 to analyse trends in incidence and mortality. Data were acquired for each year by category in five year age bands.

3.2.1 Sub-categories used

Tumours of the brain and CNS were divided into sub-categories, based on anatomical site and pathology. This categorisation was formulated with the advice of the project team. A broad site specific categorisation was defined, based on ICD site code with reference to the WHO classification of tumours of the nervous system (2000).

The main sub-categories are comprised of the following groupings (for ICD codes see Appendix A):

- Intracranial intra-axial, i.e. tumours of the brain.
  Tumours of the pineal gland were excluded from this group
- Intracranial extra-axial, i.e. tumours within the skull vault, and outside the brain itself:
  - Meningeal tumours
  - Cranial nerve tumours
  - Others
- Sellar tumours i.e. tumours of the pituitary gland and craniopharyngeal duct
- Pineal tumours
- Spinal tumours
  - Tumours of the spinal cord
  - Tumours of the spinal meninges

It should be noted that the ICD codes used may not exactly match the categories. For example ‘other intra-cranial intra-axial tumours’ is a group of rare diverse tumours that cannot be captured using standard ICD coding: they may be classified variously as either ‘brain tumours’ (intracranial, intra-axial) or under other ICD codes e.g. mesothelial and soft tissue (ICD-10 C45-9). Similarly brain lymphoma is likely to be classified as a malignant neoplasm of lymphoid, haematopoietic and related tissue (ICD-10 C81-96)

Further subcategories were also defined based on morphology type by subdividing 'intracranial intra-axial' into WHO defined categories such as tumours of the neuroepithelial tissue by grade. However, in the English data provided by ONS 20% of the intra-axial intracranial tumours were classified morphologically as 'neoplasms not otherwise specified', and 16.5% as 'glioma malignant', a highly non-specific term. This leaves 36.5% with no specific morphology. Due to the unreliability of the morphology coding it was felt by the project team that further analysis on the basis of cancer registry derived morphology was likely to be misleading.

Pathology data have been requested from some of the neurosurgical centres to help describe the morphology of those brain/CNS tumours which have had a histological diagnosis Appendix B.

International incidence for malignant brain tumours was accessed from EUCAN (Ferlay *et al*. 1999).

3.2.2 Registration data

Registration data are based on ICD-10, except for trend data which includes years with ICD-9 and ICD-10 codes. Cancer registration data were acquired from the National Cancer Intelligence Unit and the Welsh Cancer Intelligence Surveillance Unit. Regional cancer registries within England collect registration data that are forwarded to the National Cancer Intelligence Unit. Registries use multiple sources to obtain information such as hospital inpatient and outpatient systems, and pathology data (ONS 2003). Benign neoplasms and neoplasms of unspecified nature of the brain, including pineal and pituitary gland are also registered in England and Wales; however ONS provide a caveat that information on benign tumours is likely to be less complete (*ibid*, p 62), and there is likely to be variation in completeness of case ascertainment between registries. In order to explore this further the proportion of non-malignant cases registered in different registries is shown in figure 1. The proportion varied between 35% and 44%, this variation is not as dramatic as might be expected with disparate methods of data collection from region to region, and the influence of true variations in incidence remains unknown.

Two studies have given rise to the suggestion that there is substantial under registration of patients with brain tumours, particularly where they do not undergo surgery, and where the tumour is classified as benign. Both studies involved the use of radiological records (CT +/- MRI) in order to ascertain cases. The first was based in the Lothian region of Scotland (Counsell, Collie & Grant 1996) and the second in Devon and Cornwall (Pobereskin & Chadduk 2000). These studies both found much higher rates than had previously been described in the United Kingdom.

In the Lothian study it was estimated that the registry only identified 85% of malignant tumours. Furthermore, the cancer registry for that region did not collect data on benign tumours. The Devon and Cornwall study estimated that

overall only 52% of brain tumours were registered. Factors that increased likelihood of registration included having an operation, malignant tumour, and being over 60 years. This suggests that the figures presented below are likely to be an underestimate, particularly in those of younger age groups, those with benign tumours, those not operated on, and for certain tumour types: sellar, cranial nerve, and meningeal. The age specific incidence rates from these two studies are presented in Appendix C.

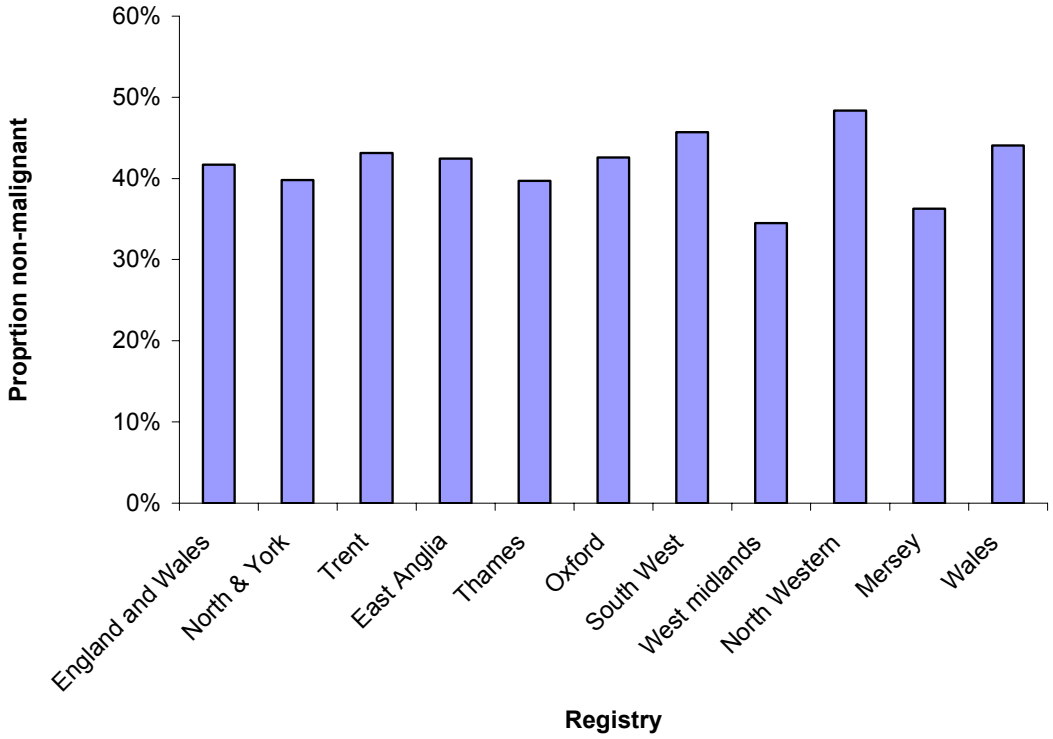


Figure 1 Proportion of brain / CNS tumours registered among non-malignant categories in different regional cancer registries England and Wales (1995-2000).

There has been a significant rise in the incidence and mortality of brain tumours since the 1970s, particularly in the elderly, described in a number of different countries. Although there has been considerable debate about a possible true rise in incidence, it is likely that this is largely as a result of changes in diagnosis particularly with the advent of computed tomography (CT) and magnetic resonance imaging (MRI) (Minn Wrensch & Bondy 2002). Counsell (1998) undertook a systematic review, and concluded that increased case finding methods explained much variation, and the true time and geographical trend was unclear.

3.2.3 Mortality

Mortality data were supplied by the Mortality unit of the Office for National Statistics, and are based on ICD-9 codes.

3.2.4 Analysis of registration and mortality data

Incidence and mortality crude rates as well as age/sex specific rates, and male: female ratios were calculated. European age standardised rates and confidence intervals were calculated using standard methods (Morris & Gardner 2000). Tumours were categorised as either malignant or non-malignant (benign neoplasms or neoplasms of uncertain or unknown behaviour).

3.2.5 Survival and prevalence data

In the timescales available, in discussion with the National Cancer Intelligence Centre (NCIC) it was considered unfeasible to undertake specific studies for the classifications derived. Previous studies on malignant brain tumours were used based on malignant brain tumours (ICD-10 C71). The EUROCARE-3 study is cited for international comparisons (Eurocare 2003).

3.2.6 Projections of future prevalence rates

Predicted future rates were calculated based on population projections from the Government Actuarial Department (GAD 2004). The projections are based on assumptions regarding fertility, mortality, and "net migration and other changes" (*ibid*). Age and sex specific rates based on brain and CNS tumour registrations between 1995 and 2000 were applied to projected populations up to 2041. This method assumes that rates will remain unchanged during this period.

3.3 Hospital activity data

Analyses of hospital activity data are based on the extract of English Hospital Episode Statistics (HES) and Patient Episode Database for Wales (PEDW) provided by the National Cancer Services Analysis team. The financial years 1995/6 – 2001/2 were used, however the NATCANSAT extract was known to be deficient in the financial year 1997/1998, and so these have been excluded from the analysis. The NATCANSAT extract included all patients with a known tumour diagnosis and all patients who have undergone procedures identified by NATCANSAT to be procedures for tumours.

3.3.1 Sub-categories used

The sub-categories used for analyses are the same as those used for the epidemiological data (above). However, the scope of the guidance includes conditions that are not available from routine registry data:

- adults with brain metastases from tumours at other primary sites, in whom complex neurological or neurosurgical intervention is required, and
- adults with syndromes where there is a recognised increased lifelong risk of CNS tumour formation.

For this reason the following additional subcategories were used in some hospital activity data analyses (for ICD Codes see Appendix A):

- Metastases:
    - Intracranial metastases
    - Extracranial metastases

- Phakomatoses
    - Neurofibromatosis
    - Tuberous sclerosis
    - Other phakomatoses

It should be noted for these analyses that some syndromes that do not have a recognised lifelong risk of CNS tumour formation may fall into the category "other phakomatoses".

There were some anomalies found in the extract of HES/PEDW data during analysis, such as multiple counting of procedures (particular insertion of ventriculoperitoneal shunt) and coding anomalies regarding age (particularly over coding of age categories over 95 years). Further analysis of the data for patients with neurological tumour diagnoses suggests that double counting is not, on the whole, a major problem, and on average 5% of procedures were recorded as being done twice on the same individual; in particular for major procedures such as major excision of brain this percentage was low (<3%). Analyses of age excluded patients over 95 years who are likely to be very small in number.

3.3.2 Analysis of hospital activity data

Hospital data analyses included patients with a diagnosis of brain or CNS tumour, irrespective of the reason for admission. For this reason conditions that people are more likely to live a long time with, rather than die of, e.g. sellar tumours, may be over represented in some analyses (e.g. bed days).

Bed days, inpatient episodes and day cases

Analyses were undertaken of bed day use, inpatient episodes and day cases for sub-categories, and for variation by Strategic Health Authority (SHA) of residence of patient.

Analyses of individual patients in England by "HES id"

NATCANSAT identified individual patients who are recorded on the English hospital episode statistics (HES) system. Patients are identified as unique (given a unique HES id) based upon their NHS Number, date of birth and postcode. Unlike other HES data analyses these data are presented for financial years 1998/9-2001/2.

Analyses were undertaken of the number of patients by Trust and year for all ages and all tumour types, including metastases and phakomatoses.

In order to gain further information about individuals' first admission to hospital the unique HES id was used to identify method of admission for individuals with a diagnosis of brain/CNS tumour in this time period.

Procedure based analyses

Analyses of procedures were based on the OPCS codes shown in Appendix D. Procedures are analysed in terms of time, age of patient, sub-category and SHA of residence of patient. As specific procedures were included in the

NATCANSAT extract a proportion of the total procedures which were undertaken for individuals with a tumour diagnosis could be calculated for some procedures.

3.3.3 Catchment populations of neurosurgical centres

The geographical catchment areas of neurosurgical and radiotherapy units were mapped by NATCANSAT. Maps are based on neurological procedures, excluding stereotactic ablation of tissue of brain, for patients with a brain/CNS tumour aged 15 or over attending the 27 adult neurosurgical units in England and Wales. Electoral divisions are mapped to particular units based on the postcode of residence of patients in HES/PEDW. Catchment populations were then derived by NATCANSAT from the resident populations.

3.3.4 Mapping catchment populations of neurosurgical centres and cancer networks

NATCANSAT neurosurgery catchment maps were superimposed with NATCANSAT cancer network maps to assess the degree of overlap between catchment areas.

3.4 Population denominators

Denominators were based on mid year population estimates for each relevant year available from ONS.

3.5 Questionnaires on existing services

Two questionnaires, one for neurosurgical departments and one for radiotherapy departments (Appendix E; Appendix F), were devised with the assistance of the project team. These were based on the model used to assist informing cancer services for children and young people (NICE 2005).

A questionnaire was sent to each neurosurgical department and each radiotherapy department in England and Wales on the 12th January 2004, these were requested for return by 9th February 2004. The neurosurgical questionnaires were sent by the Society of British Neurological Surgeons, and an e-mail reminder was sent soon before the return by date. Non-responding radiotherapy units were followed up with reminder letters and telephone calls.

4 Epidemiological data

Tumours of the brain and CNS are relatively rare and are quoted as counting for 1.6% of all cancers in England and Wales (Quinn *et al.* 2001). They comprise a wide variety of tumour types, and standardisation of histological classification is relatively recent with the WHO 1993 classification (Ogungbo *et al.* 2002), last revised in 2000. Unlike other sites in the body, benign tumours can be as damaging as malignant tumours, due to the closed space in which they occur.

4.1 Incidence

Incidence rates of primary CNS tumours in the United Kingdom has been variously quoted from 5.6/100,000 per year (crude rate) for brain and spinal tumours (Cole, Wilkins & West 1989) to 21/100,000 per year for intracranial tumours alone (Pobereskin & Chadduck 2000) (UK 1991 census standardised). Official publications place the incidence of primary brain cancer in England and Wales at 8.0/100,000 for men, and 5.6/100,000 for women (Quinn *et al.* 2001). Differences in methodology appear to be largely responsible for the different rates described, in particular those after the widespread introduction of CT scanning, and those using radiological sources of data have higher estimated rates (Counsell & Grant 1998).

4.1.1 International comparisons

European Union Incidence and mortality rates for brain and nervous system cancers (malignant tumours) are shown in Table 1. The United Kingdom does not stand out as being particularly high or low. Greece and Sweden both have high rates. The reasons for this are unclear. The Greek rates are indirectly calculated from mortality rates, the Swedish rates are based on the national registry system.

Table 1 Incidence of cancer of the brain and nervous system in the European Union

	Crude incident rate	Incident rate ASR (E)	Crude death rate	Death rate ASR (E)
The Netherlands*	5.93	5.79	5.51	5.19
France**	6.51	6.08	4.97	4.46
Austria***	6.78	6.28	5.5	4.81
Italy***	7.51	6.31	5.07	4.13
Portugal***	7.15	6.57	5.04	4.38
United Kingdom**†	7.19	6.64	5.45	4.94
Germany***	7.78	6.75	6.54	5.35
Finland*	7.37	6.86	5.24	4.63
European Union	7.7	6.91	5.78	4.97
Spain***	7.63	6.99	5.5	4.8
Ireland***	6.84	7.34	5.14	5.61
Denmark*	8.26	7.58	6.41	5.79
Luxembourg**	8.68	8.06	9.38	8.52
Belgium**	9.65	8.62	8.36	6.96
Greece***‡	14.27	11.95	9.97	7.98
Sweden*	14.54	13.27	5.95	5.23

*1998 **1993-1997 ***1993-1997 for most registries in this country
†England Scotland and Northern Ireland. ‡Indirectly calculated from mortality rates.
Source: EUCAN (http://www-dep.iarc.fr/ accessed 2nd March 2004)

4.1.2 Cancer registration data England and Wales

Table 2 provides a summary of the registration of brain tumours in England and Wales for those aged 15 and over. The sub-categories have been divided into malignant and non-malignant due to the likely differences in registration quality for these tumour types. On average there were 6,462 tumours registered per year in those over 15 between 1995-2000. The European age-standardised registration rate for all tumours was 14.30 in those 15 and over. Rates were somewhat higher than those quoted by the Office for National Statistics, as they represent the rate in those aged 15 or over. As has been found in other studies tumours of the brain (intracranial intra-axial) are more common in men, whereas meningeal tumours are more common in women. The relative frequency of these registrations is similar to those in other studies, e.g. Central Brain Tumour Registry of the United States (Davis, McCarthy & Jukich, 1999) who described 60% as being brain tumours, 9% as pituitary, 1% as pineal and 30% as other CNS, and 55% malignant, 45% benign or uncertain.

Age and sex specific incidence rates can be found in Appendix G.

Table 2. Incidence of major brain / CNS tumour types England & Wales, 1995-2000, persons ≥15 years, crude rate per 100,000 population, European standardised rates (EASR), relevant ratios, and relative frequency

	Number (six years)	Average annual number	Crude rate	EASR (95% confidence limits)	M:F (events)	M:F (rates)	Malignant: Non-malignant	Relative frequency
Intracranial intra-axial tumours (excludes pineal)								
Malignant	21298	3550	8.54	7.88 (7.76 to 7.98)	1.33	1.44		54.94
Non-malignant	3118	520	1.25	1.03 (0.99 to 1.06)	0.96	1.04		8.04
Total	24416	4069	9.79	8.90 (8.78 to 9.01)	1.27	1.38	6.83	62.98
Intra cranial extra-axial tumours								
Intracranial meninges								
Malignant	325	54	0.13	0.11 (0.09 to 0.12)	0.79	0.85		0.84
Non-malignant	4549	758	1.82	1.63 (1.57 to 1.67)	0.43	0.46		11.73
Total	4874	812	1.95	1.74 (1.68 to 1.78)	0.45	0.49	0.07	12.57
Cranial nerve								
Malignant	102	17	0.04	0.04 (0.03 to 0.04)	1.17	1.27		0.26
Non-malignant	2474	412	0.99	1.00 (0.95 to 1.03)	0.94	1.02		6.38
Total	2576	429	1.03	1.04 (0.99 to 1.07)	0.95	1.03	0.04	6.64
Sellar								
Malignant	176	29	0.07	0.06 (0.05 to 0.06)	0.91	0.99		0.45
Non-malignant	3963	661	1.59	1.56 (1.5 to 1.6)	1.04	1.13		10.22
Total	4139	690	1.66	1.62 (1.56 to 1.66)	1.03	1.12	0.04	10.68
Pineal								
Malignant	114	19	0.05	0.05 (0.03 to 0.05)	3.96	4.29		0.29
Non-malignant	79	13	0.03	0.03 (0.02 to 0.03)	0.61	0.66		0.20
Total	193	32	0.08	0.08 (0.06 to 0.09)	1.68	1.82	1.44	0.50

	Number (six years)	Average annual number	Crude rate	EASR (95% confidence limits)	M:F (events)	M:F (rates)	Malignant: Non-malignant	Relative frequency
Spinal								
Spinal cord								
Malignant	413	69	0.17	0.16 (0.14 to 0.17)	1.27	1.38		1.07
Non-malignant	335	56	0.13	0.13 (0.11 to 0.14)	1.03	1.12		0.86
Total	748	125	0.30	0.29 (0.27 to 0.31)	1.16	1.25	1.23	1.93
Spinal meninges								
Malignant	32	5	0.01	0.01 (0 to 0.01)	0.60	0.65		0.08
Non-malignant	358	60	0.14	0.13 (0.11 to 0.14)	0.25	0.27		0.92
Total	390	65	0.16	0.14 (0.12 to 0.15)	0.27	0.29	0.09	1.01
Other								
Other meningeal								
Malignant	92	15	0.04	0.03 (0.02 to 0.03)	0.48	0.52		0.24
Non-malignant	1100	183	0.44	0.37 (0.34 to 0.39)	0.47	0.51		2.84
Total	1192	199	0.48	0.40 (0.37 to 0.42)	0.47	0.51	0.08	3.07
Other CNS								
Malignant	52	9	0.02	0.02 (0.01 to 0.02)	1.26	1.37		0.13
Non-malignant	189	32	0.08	0.07 (0.06 to 0.08)	1.12	1.22		0.49
Total	241	40	0.10	0.09 (0.07 to 0.1)	1.15	1.25	0.28	0.62
Total malignant	22604	3767	9.06	8.36 (8.24 to 8.46)	1.31	1.42		58.30
Total non-malignant	16165	2694	6.48	5.95 (5.85 to 6.04)	0.73	0.79		41.70
Total	38769	6462	15.54	14.30 (14.15 to 14.44)	1.03	1.11	1.40	100.00

EASR = European age standardized

Age distribution of incident tumours

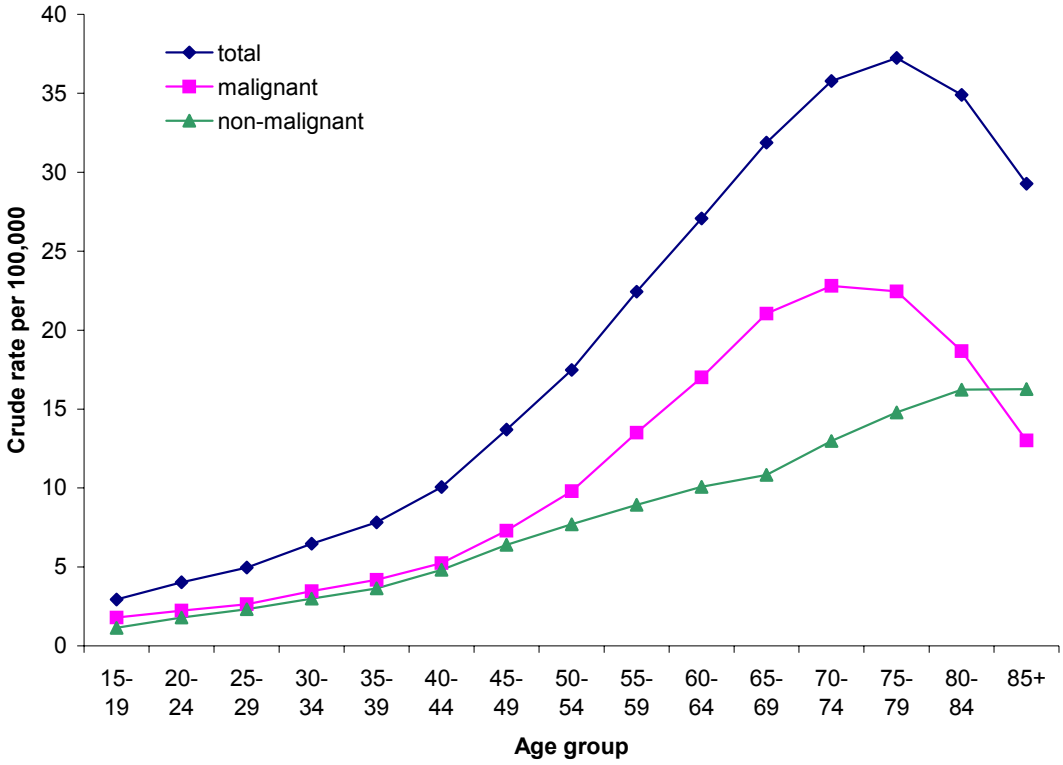
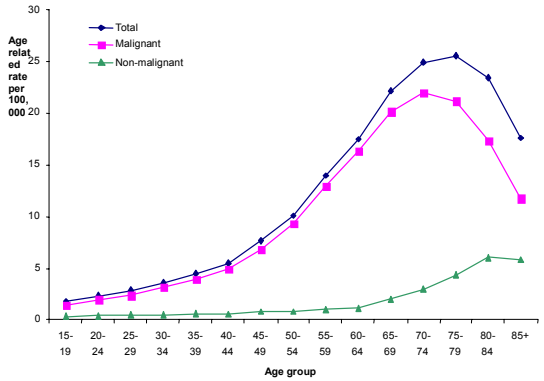
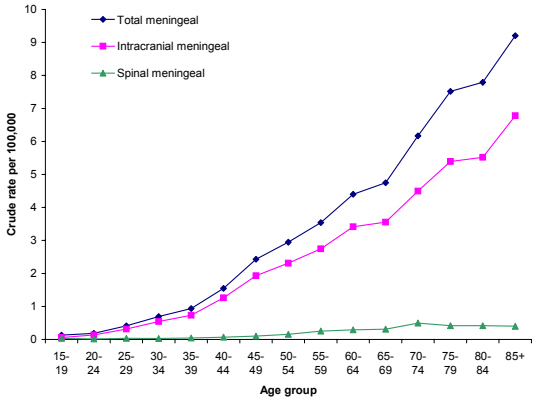


Figure 2 Age related rates per 100,000 population for total primary tumours, subdivided by malignant / non-malignant 1995-2000.

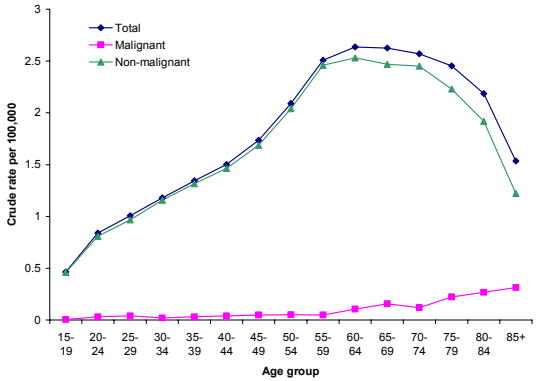
The peak age group for brain and other CNS tumour registration was 75-79 years (Figure 2). This was slightly lower for malignant tumours at 70-74 years and slightly higher in the non-malignant group at 80-84 years. The intracranial intra axial tumour had a very similar pattern, dominating the total picture (Figure 3). The rate of meningeal tumours, in contrast, did not tail off with age, but rather continued to rise, dominated by the intracranial meningeal tumours. Sellar tumours reached a plateau from the mid 50s until the mid 70s. Other tumours showed a less distinct pattern as the numbers became smaller. Pineal tumours became less prominent as adolescence progresses into adulthood. Spinal cord tumours increased throughout adulthood; however there were very few registrations in the over 85 year old age groups for primary spinal cord tumour. This may be due to a true decline in this age group, or perhaps decreased diagnosis or registration in this age group for these tumours.



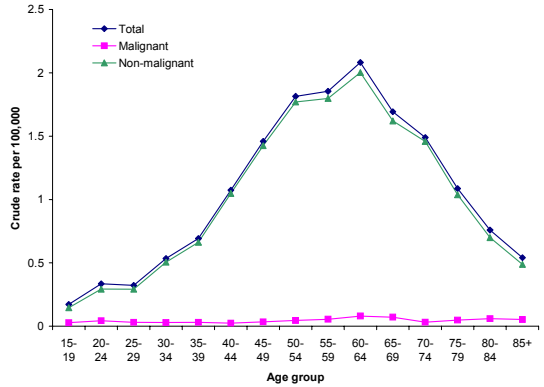
a. Intracranial intra axial tumours (brain tumours; malignant & non-malignant)



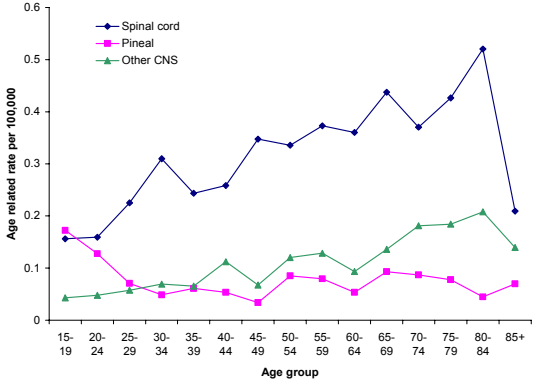
b. Meningeal tumours (intra-cranial and spinal)



c. Sellar tumours (malignant & non-malignant)



d. Cranial nerve tumours (malignant & non-malignant)



e. Spinal cord, pineal and other tumours

Figure 3 Age related rates per 100,000 population of intracranial intra axial, meningeal, sellar, cranial nerve and other tumours, 1995-2000.

Trends incident tumours

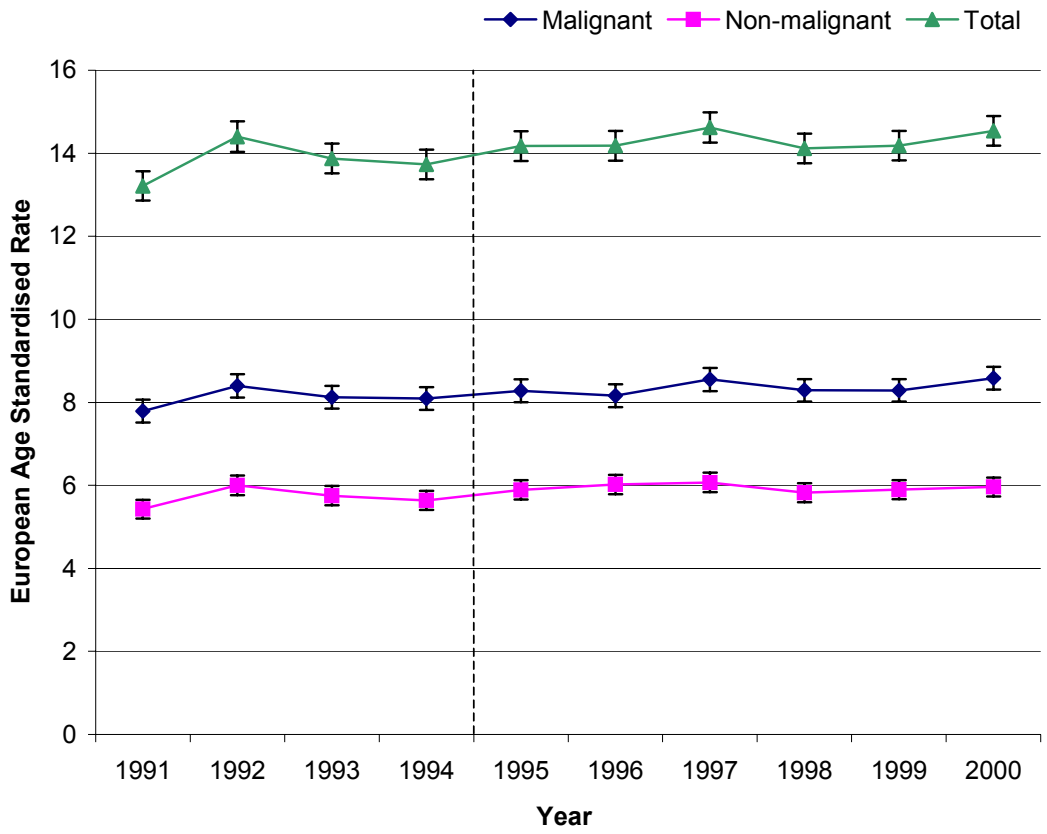
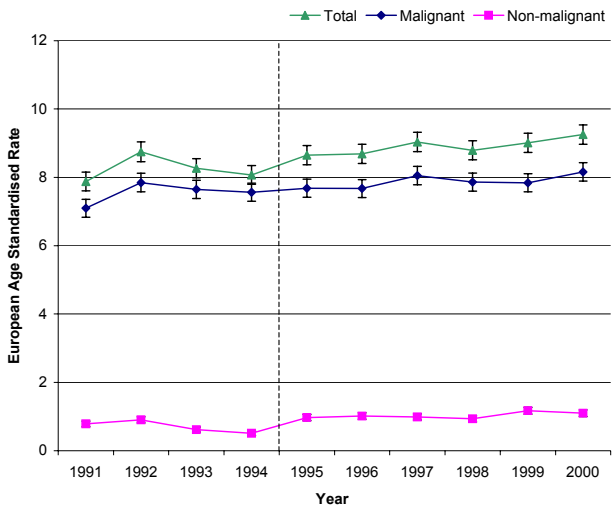
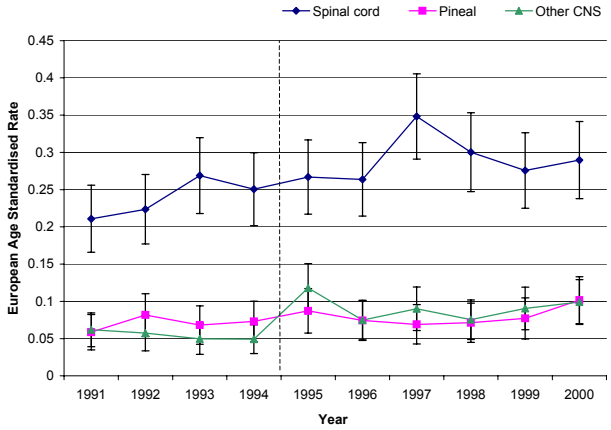


Figure 4 European standardised registration rates per 100,000 population 15 years of age and over brain & CNS tumours 1991-2000.
Dotted line represents ICD9/10 transition.

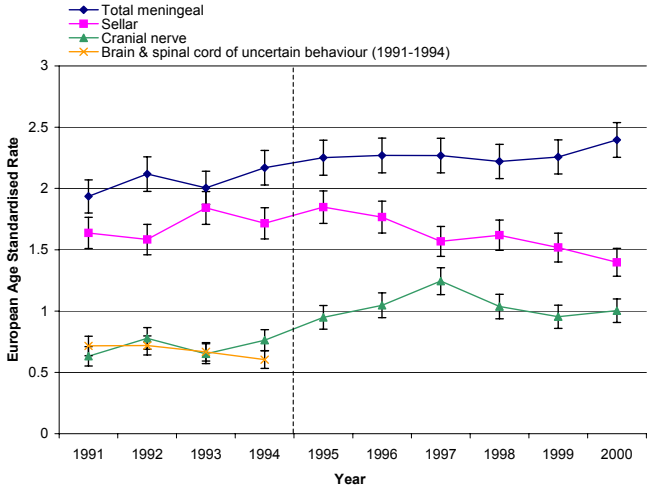
There has been a slight upward trend in registration of tumours over the last ten years (Figure 4). The transition between ICD 9 and 10 is shown, as the coding patterns do not exactly match before and after this period, this is particularly the case for neoplasms of uncertain behaviour. The rise in registration of intracranial intra axial tumours and meningeal tumours has been the dominating factor in this trend (Figure 5). Numbers are smaller for other tumours making trends less definite. Numbers appear also to have increased for cranial nerve tumours, whereas the pattern appears the reverse for pituitary tumours over this period.



a. Intracranial intra axial tumours (total, malignant, benign)



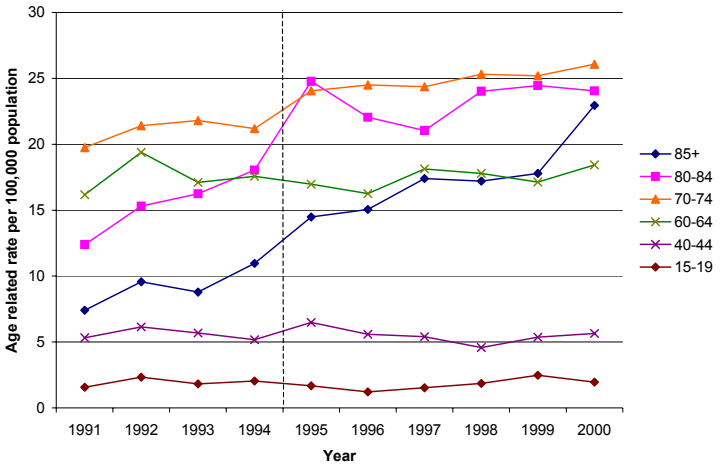
c. Spinal cord, pineal and other CNS tumours.



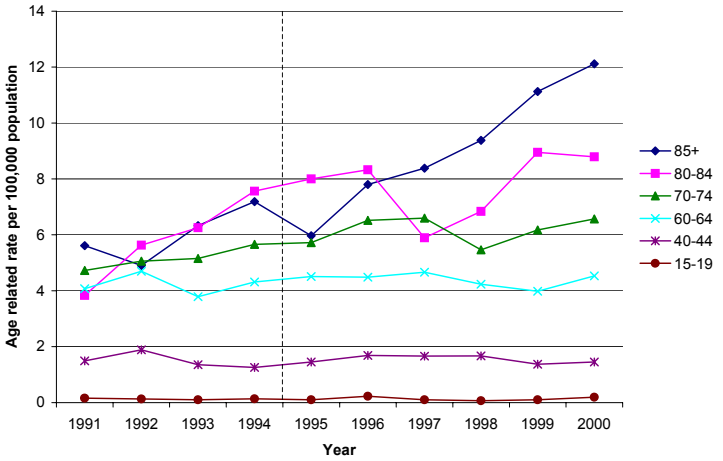
b. Total meningeal, sellar, cranial nerve tumours, and tumours of the brain / spinal cord of uncertain behaviour (1991-1994)

Figure 5 European standardised registration rates per 100,000, age ≥ 15, 1991-2000 (a) intracranial intra axial tumours (b) total meningeal, sellar, cranial nerve (c) spinal cord, pineal and other CNS.

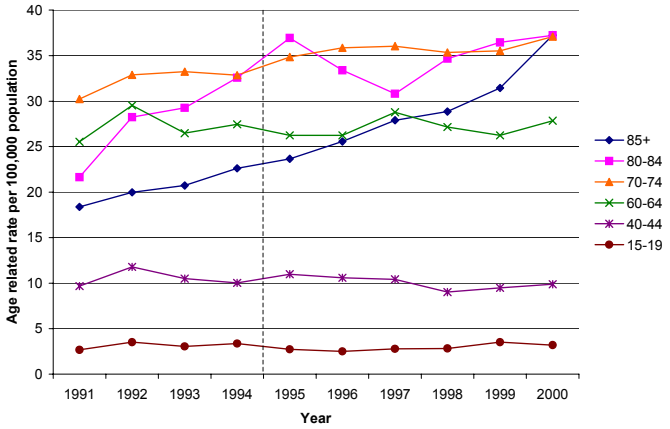
Dotted line represents ICD9/10 transition.



a. Total brain and CNS tumours



c. Meningeal tumours



b. Intracranial intra axial tumours

Figure 6 Age related trends for brain and CNS tumours, intracranial intra-axial tumours, and meningeal tumours, 1991-2000, England and Wales, selected age groups.
Dotted line represents ICD9/10 transition

When trends are examined by age group (Figure 6), registration rates have been relatively stable over the ten year period for those up to the age group 60-64. Beyond this age there was an increasingly upward trend in both total tumours and the intracranial intra-axial grouping. This is most evident in those of 85 years and over, where the trend rose rapidly over the late 1990s. This rising trend in the 85 year and over age group was also evident in meningeal tumours.

4.2 Mortality

Table 3 Mortality from major brain / CNS tumour types England & Wales, 1995-2000, persons ≥15 years, crude and European standardised rates (EASR) *per million* population, relevant ratios, and relative frequency.

	Number (six years)	Average annual number	Crude rate	EASR	(95% confidence limits)	M:F (events)	M:F (rates)	Malignant: Non-malignant	Relative frequency
Intracranial intra-axial tumours (excludes pineal)									
Malignant	16147	2691.2	64.74	59.76	(58.81 to 60.7)	1.35	1.46		72.05
Non-malignant	4195	699.2	16.82	12.95	(12.54 to 13.36)	0.99	1.07		18.72
Total	20342	3390.3	81.56	72.71	(71.67 to 73.73)	1.26	1.37	3.85	90.77
Intra cranial extra-axial tumours									
Intracranial meninges									
Malignant	108	18.0	0.43	0.38	(0.3 to 0.45)	0.77	0.83	0.08	0.48
Non-malignant	1359	226.5	5.45	3.95	(3.72 to 4.16)	0.51	0.55		6.06
Total	1467	244.5	5.88	4.33	(4.09 to 4.55)	0.52	0.57		6.55
Cranial nerve									
Malignant	17	2.8	0.07	0.06	(0.03 to 0.09)	0.70	0.76	0.16	0.08
Non-malignant	107	17.8	0.43	0.33	(0.26 to 0.39)	0.55	0.60		0.48
Total	124	20.7	0.50	0.39	(0.31 to 0.46)	0.57	0.62		0.55
Sellar									
Malignant	47	7.8	0.19	0.17	(0.11 to 0.21)	0.96	1.04	0.25	0.21
Non-malignant	186	31.0	0.75	0.65	(0.55 to 0.74)	1.04	1.13		0.83
Total	233	38.8	0.93	0.82	(0.7 to 0.92)	1.03	1.11		1.04
Pineal									
Malignant	30	5.0	0.12	0.12	(0.07 to 0.16)	2.33	2.53	3.00	0.13
Non-malignant	10	1.7	0.04	0.04	(0.01 to 0.06)	1.50	1.63		0.04
Total	40	6.7	0.16	0.16	(0.11 to 0.21)	2.08	2.25		0.18

	Number (six years)	Average annual number	Crude rate	EASR (95% confidence limits)		M:F (events)	M:F (rates)	Malignant: Non-malignant	Relative frequency
Spinal									
Spinal cord									
Malignant	129	21.5	0.52	0.44	(0.36 to 0.52)	1.15	1.25	25.80	0.58
Non-malignant	5	0.8	0.02	0.02	(0 to 0.03)	4.00	4.33		0.02
Total	134	22.3	0.54	0.46	(0.38 to 0.54)	1.20	1.30		0.60
Spinal meninges									
Malignant	3	0.5	0.01	0.01	(0 to 0.01)	-	-	0.43	0.01
Non-malignant	7	1.2	0.03	0.02	(0 to 0.03)	0.17	0.18		0.03
Total	10	1.7	0.04	0.03	(0.01 to 0.04)	0.67	0.72		0.04
Other									
Uncertain brain and spinal cord									
Non-malignant	46	7.7	0.18	0.17	(0.11 to 0.21)	1.56	1.69	0.00	0.21
Other CNS									
Malignant	12	2.0	0.05	0.04	(0.01 to 0.06)	0.71	0.77	0.00	0.05
Non-malignant	3	0.5	0.01	0.01	(0 to 0.02)	2.00	2.17	0.00	0.01
Total	15	2.5	0.06	0.05	(0.02 to 0.08)	0.88	0.95	0.00	0.07
Total malignant	16493	2748.8	66.13	60.99	(60.03 to 61.94)	1.34	1.45		73.59
Total non-malignant	5918	986.3	23.73	18.14	(17.65 to 18.61)	0.85	0.92		26c.41
Total	22411	3735.2	89.86	79.12	(78.05 to 80.19)	1.19	1.29	2.79	100.00

EASR = European age standardized

There were 22,411 deaths registered for the years 1995-2000 (Table 3). The vast majority of these (90.8%) occurred in the intracranial intra-axial grouping. There were more deaths registered with a benign intracranial intra-axial tumour diagnosis in this period than new tumours registered (4195 deaths registered as against 3118). Deaths from intracranial meningeal tumours occurred at a rate of six per million population aged 15 years and over, and other tumours were rarely cited as the underlying cause of death.

4.2.1 Age distribution of mortality

Figure 7 demonstrates an age distribution for mortality very similar to that as for incidence. In non-malignant tumours the rise of mortality with age is much steeper from 60 years onwards. This is most likely due to the fact that the benign tumour types occurring in younger age groups, e.g. pituitary/cranial nerve, are less likely to cause death.

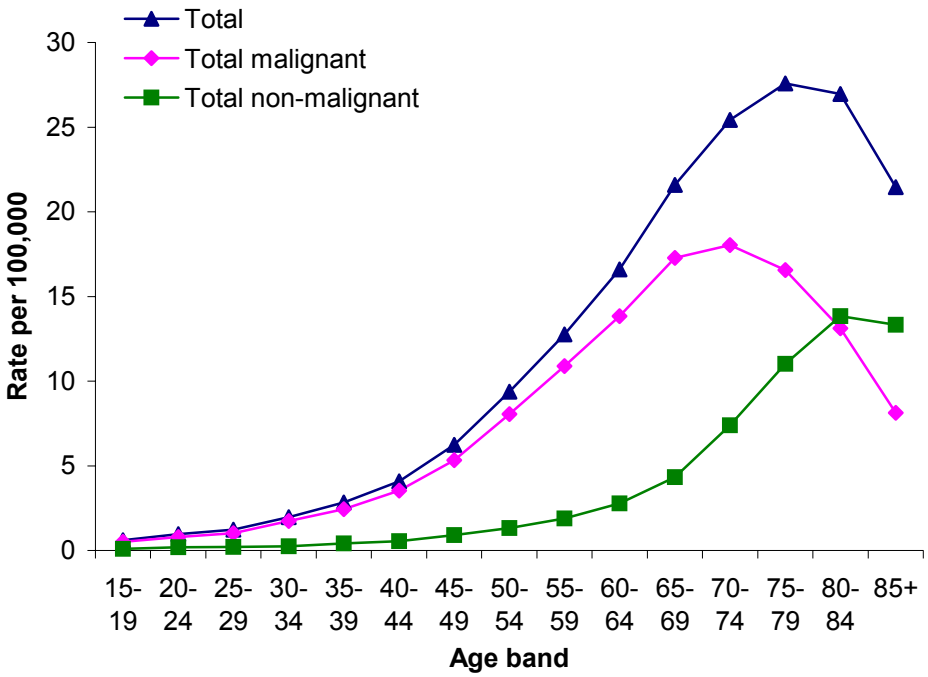
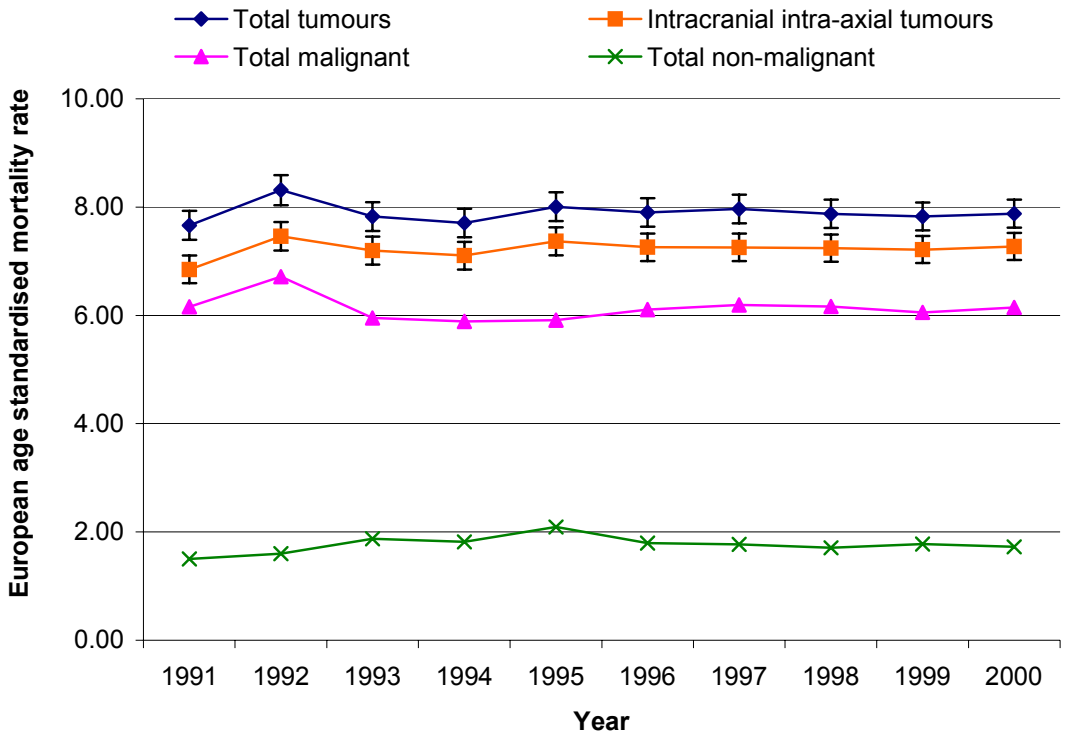


Figure 7 Age distribution of mortality total brain / CNS tumours England and Wales 1995-2000.

4.2.2 Mortality trends

There has not been the same definite rise in overall mortality rates as there has been in registrations of brain and CNS tumours (Figure 8). When analysed by age, rates have been quite stable up to the 70-74 year age band, and then they tend to rise as the decade progresses (1991-2000).



4.2.3 Age related mortality trends

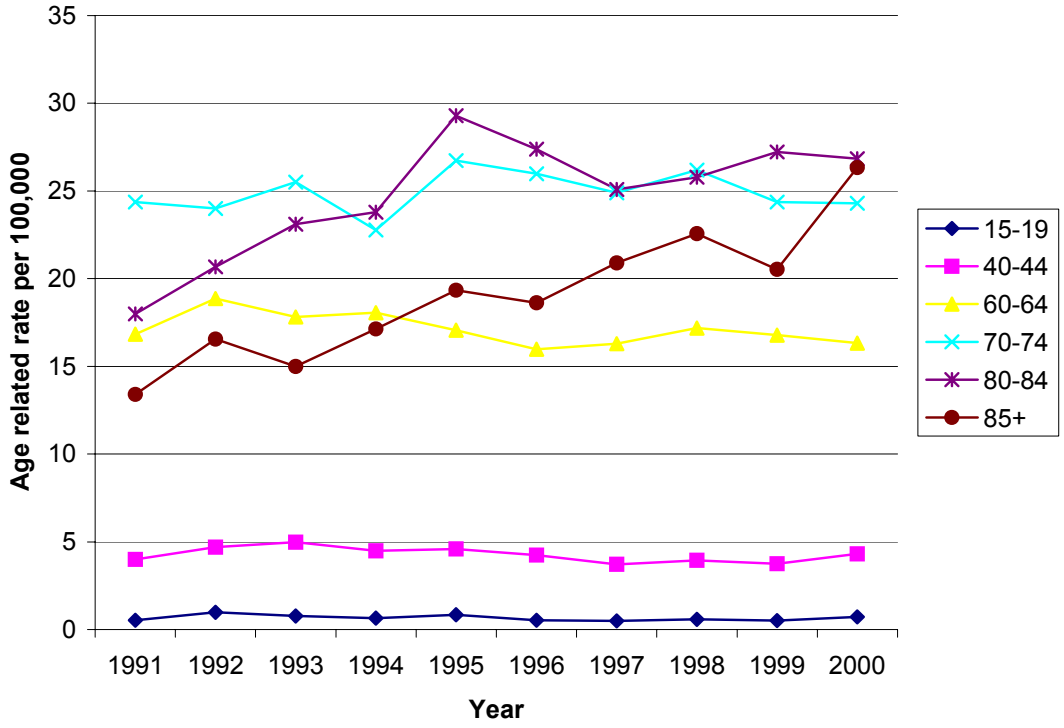


Figure 8 Trends in mortality 1991-2000 by selected age groups

4.3 Prevalence and survival

The most recent available prevalence figures for England and Wales were for three and five years, produced by the office for National Statistics for malignant brain tumours (Quinn *et al*. 2001). They are presented in Table 4.

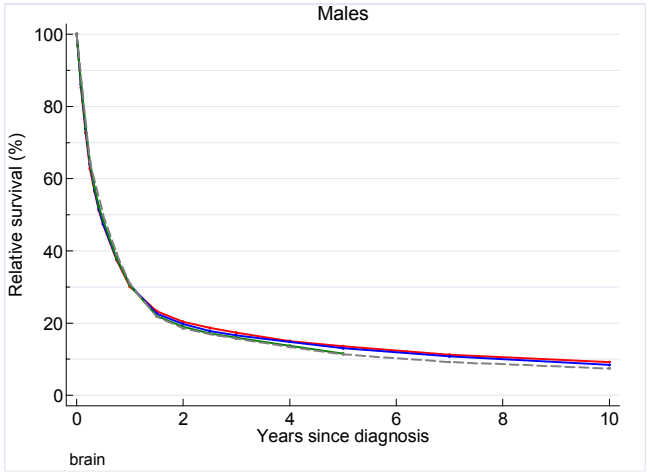
Table 4 Estimated number of patients with brain cancer (ICD C71) by vital status 1st January 1993, diagnosed 1990-1992 (3 year prevalence), and 1983-1992 (10 year prevalence)

		Number			% alive
		Alive	Dead	Total	
3 year prevalence	Males	1,900	3,900	5,700	33
	Females	1,500	2,800	4,200	34
10 year prevalence	Males	3,500	14,100	17,600	20
	Females	2,900	10,300	13,200	22

(Quinn *et al.* 2001, p 19)

Survival figures for malignant brain tumours (ICD C71) have been recently produced (Figure 9, Table 5). Survival for malignant brain tumours was poor, at around 30% one year survival. There is no sign of an improvement in survival rates over time. Previous work by the same authors who produced these survival results have demonstrated little variation in survival between regions in England and Wales, although lower deprivation is associated with improved survival (Coleman *et al.* 1999).

Survival is only one outcome measure. Brain tumours can have multiple effects on physical ability, cognition and psychological well being. A review of studies on outcome in brain tumours (Huang *et al.* 1996) found that physical and functional aspects vary, depending on the tumour type. For example, a study based on Karnofsky's performance scale (Sachsmeheimer *et al.* 1991) found the scale to improve over time with meningiomas and low grade gliomas; high grade gliomas tended to have a relatively stable score for a year and then drop suddenly. Quality of life was affected by emotional distress such as depression anger and fatigue. In depth interviews have found recurrent themes in patients with brain tumours including mind/body illness stigma, the experience of a brain tumour as an invasive disease of the self, likeness to a family disease, and difficulty obtaining medical information.



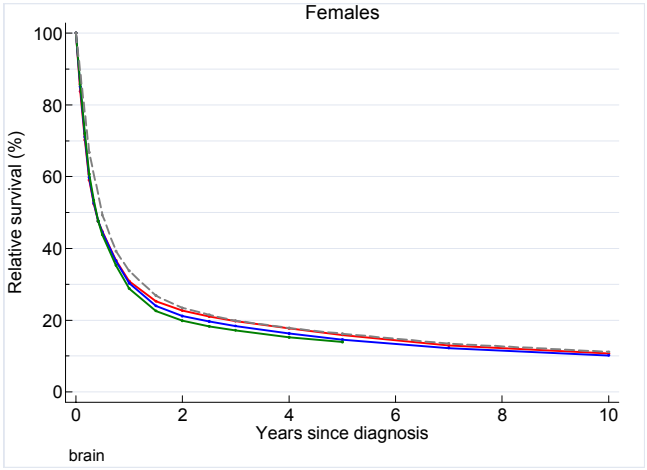


Figure 9 Relative survival in males and females complete analysis for years for malignant brain tumours diagnosed 1996-1999 (green); 1991-1995 (blue); 1968-1990 (red); period analysis (2000-2001).).

brain

	Sex	Complete analysis								Period analysis	
		Relative survival rate (95% CI)						Change in relative survival		Relative survival rate (95% CI)	
		1986-90		1991-95		1996-99				2000-01	
One-year	Men	30.13	(29.0, 31.2)	30.58	(29.6, 31.6)	30.43	(29.3, 31.5)	-0.64	(-2.7, 1.4)	30.86	(26.7, 35.0)
	Women	30.90	(29.6, 32.2)	30.31	(29.1, 31.5)	28.81	(27.5, 30.1)	-0.48	(-2.9, 2.0)	33.73	(28.4, 39.0)
Five-year	Men	13.61	(12.8, 14.5)	13.05	(12.3, 13.8)	11.56	(10.6, 12.5)	-3.06	** (-4.7, -1.4)	11.29	(9.5, 13.1)
	Women	15.89	(14.9, 16.9)	14.62	(13.7, 15.5)	13.96	(12.9, 15.1)	-0.80	(-2.8, 1.3)	16.36	(13.4, 19.3)
Ten-year	Men	9.21	(8.5, 9.9)	8.45	(7.7, 9.2)			-1.99	(-4.4, 0.5)	7.41	(6.1, 8.7)
	Women	10.65	(9.8, 11.5)	10.10	(9.2, 11.0)			-0.27	(-3.3, 2.8)	11.17	(9.0, 13.3)

* p < 0.05; ** p < 0.01

Table 5 Relative survival for malignant brain tumours (ICD C71).

Figure 9 and Table 5 Courtesy of the Office for National Statistics, and the London School of Hygiene and Tropical Medicine.

4.3.1 Comparison with international survival

The EUROCARE-3 study, with participating registries from both England and Wales, showed five year age standardised relative survival rates similar to those among other participating registries of other countries of Europe although both England and Wales were among the lower range for one year survival (Table 6).

Table 6 Age standardised relative survival, adults diagnosed with malignant brain tumours 1990-1994 (ICD-9 191) in Europe, Eurocare 3 study.

	One year			Five year	
Country	**Men**	**Women**	**Country**	**Men**	**Women**
Estonia	25.0	30.0	Czech Republic		15.5
Poland	30.4	33.4	Slovenia	12.3	12.8
England	**31.7**	**34.2**	Poland	12.4	18.9
Netherlands	32.2	34.1	Slovakia	12.7	20.2
Slovenia	32.7	32.0	Netherlands	13.8	18.2
Scotland	32.8	34.3	Denmark	14.1	16.9
Wales	**33.8**	**33.6**	France	14.4	17.5
Spain	34.3	37.0	Scotland	14.8	19.5
Denmark	35.3	37.1	Iceland	15.3	23.4
Switzerland	35.6	37.9	**England**	**15.7**	**17.9**
Slovakia	36.2	41.1	Italy	16.4	18.4
EUROPE	**37.0**	**39.0**	**EUROPE**	**16.4**	**18.5**
Iceland	37.0	44.2	**Wales**	**17.5**	**19.7**
Czech Republic	37.4	28.0	Norway	18.1	26.9
Germany	37.5	42.5	Germany	18.3	17.8
Italy	41.0	42.7	Austria	18.4	24.8
Sweden	43.7	47.6	Estonia	18.4	18.1
France	44.0	41.5	Spain	18.8	17.6
Norway	44.2	46.5	Sweden	21.1	24.3
Finland	45.5	46.1	Finland	22.1	26.2
Austria	47.8	46.7	Switzerland	22.7	17.9
Malta	47.8	47.9	Malta	51.5	15.6

Countries ordered by survival in men.

The results of international survival studies need careful consideration, for example earlier diagnosis, rather than better management, can result in apparently improved survival (Berrino 2003).

4.4 Predicted future crude rates based on current age and sex related rates

	Number							Crude Rate per 100,000 population ≥ 15 years						
	1995-2000	2006	2011	2016	2021	2031	2041	1995-2000	2006	2011	2016	2021	2031	2041
Intracranial intra-axial														
Malignant	3550	3825	4045	4290	4524	4876	5056	8.54	8.72	8.96	9.29	9.59	10.00	10.14
Non-malignant	520	552	585	627	674	772	845	1.25	1.26	1.30	1.36	1.43	1.58	1.70
Total	4069	4385	4637	4924	5205	5655	5908	9.79	10.00	10.28	10.66	11.04	11.59	11.85
Intracranial meningeal	812	875	926	982	1041	1146	1219	1.95	2.00	2.05	2.12	2.21	2.35	2.45
Cranial nerve	429	462	484	501	515	530	535	1.03	1.05	1.07	1.09	1.09	1.09	1.07
Pituitary	690	739	771	804	834	874	895	1.66	1.69	1.71	1.74	1.77	1.79	1.80
Pineal	32	34	35	36	37	38	39	0.08	0.08	0.08	0.08	0.08	0.08	0.08
Spinal														
Spinal cord	125	132	137	142	146	152	156	0.30	0.30	0.30	0.31	0.31	0.31	0.31
Spinal meninges	65	73	76	79	81	85	88	0.16	0.17	0.17	0.17	0.17	0.17	0.18
Other														
Other meningeal	199	213	226	241	257	289	312	0.48	0.49	0.50	0.52	0.55	0.59	0.63
Other CNS	40	43	45	47	49	52	54	0.10	0.10	0.10	0.10	0.10	0.11	0.11
Total malignant	3767	4058	4289	4547	4793	5168	5364	9.06	9.25	9.50	9.84	10.16	10.59	10.76
Total non-malignant	2694	2895	3045	3207	3374	3657	3848	6.48	6.60	6.75	6.94	7.15	7.50	7.72
Total	6462	6953	7334	7754	8166	8825	9213	15.54	15.86	16.25	16.78	17.32	18.09	18.48

As the population ages the crude rate of tumours of the brain and CNS is expected to increase (Figure 10). If age specific registrations continue to increase in the elderly then this rise would be an underestimate.

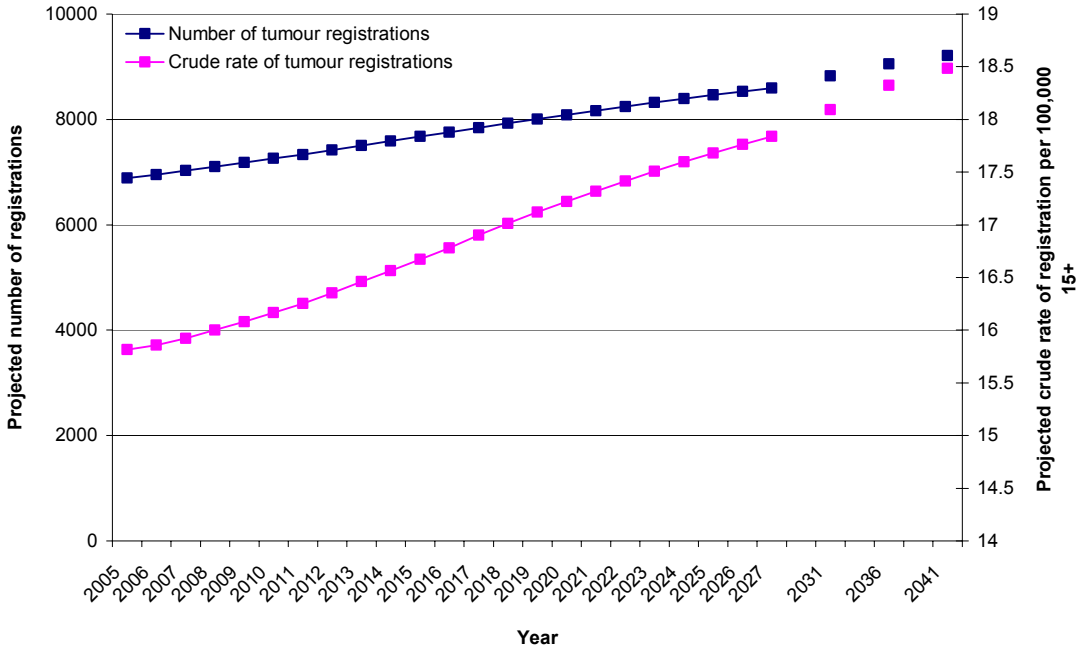


Figure 10 Predicted numbers and crude rates of brain and CNS tumour registrations based on age and sex specific rates 1995-2000; age ≥ 15.

5 Services

Health care services are provided by all sectors for people with tumours of the brain and CNS. General practitioners are likely to see new cases of brain/CNS tumour infrequently (Table 7).

Table 7 Time between new cases of brain and CNS tumours among those aged ≥ 15 in a population of 1,800 [1,458 aged 15 or over] (typical general practice list size per GP).*

All brain / CNS tumours	4.4 years
Intracranial intra-axial	7.0 years
Intracranial meningeal	35.1 years
Sellar tumour	41.3 years
Cranial nerve tumour	66.4 years
Primary Spinal (cord / meningeal)	150.3 years

*Based on crude registration rates for England & Wales (1995-2000). List size per GP is UK: 1,779; England: 1,841; Wales: 1,685.[1]

At the time of undertaking this analysis registration data were not linked to hospital activity data nationally. Published literature gives an impression of how likely individuals with intracranial tumours are to be admitted to hospital and undergo surgery:

Twenty one percent of those with intracranial tumours in the Devon and Cornwall study (Pobereskin 2000, p 469) were never admitted to hospital. Most of these tumours (80%) were 'benign tumours treated medically (e.g. prolactinomas, low grade gliomas) or meningeal and cranial nerve tumours in elderly people that were followed up without surgery'. The mean age of those admitted was considerably lower than those not admitted.

This is higher than in the Lothian study (Counsell, Collie & Grant 1996) which had a rate of non-admission of 12%; that this study did not, however, use MRI scans as a source of cases, and had substantially lower rates of sellar and cranial nerve tumours, the tumours least likely to be admitted in the Devon & Cornwall study.

In the Devon and Cornwall study 70% of males were operated on and 65.3% of females. This gender difference was due entirely to a marked gender difference in treatment of pituitary tumours, with 76.4% of males being operated on, but only 47.2% of females. The overall rate of non-biopsy in the Devon and Cornwall study (34%) is very similar to that in the Lothian study (31%) (Counsell, Collie & Grant 1997).

Those undergoing surgery were significantly younger than those who did not (52.8 years as against 59.7 years). This difference was even greater for pituitary adenomas where there was almost 12 years between the average age of those operated on, and not operated on. Although a higher proportion of malignant tumours (70.3%) were operated on than benign (66.6%) this was not statistically significant.

[1] General practitioners, dentists and opticians1 by NHS Regional Office area, 30 September 2001, Office for National Statistics, available from: http://www.statistics.gov.uk/STATBASE/Expodata/Spreadsheets/D5945.xls (accessed October 2005).

5.1 Hospital activity data

5.1.1 Patient episodes and bed days

An analysis is shown of the number of patient episodes (inpatient and day case) together with the number of bed days (Table 8). The analysis includes metastases and syndromes which predispose to developing CNS tumours (phakomatoses).

Primary brain tumours accounted for approximately 60% of inpatient/day case episodes, and inpatient bed days due to primary neurological tumour. This was not dissimilar to tumour registration. Sellar tumours, less likely to require lengthy admissions, accounted for a much higher proportion of day case episodes than inpatient episodes or bed days.

There has been a general rise in hospital usage for patients diagnosed with tumours of the brain and CNS between 1995/6 and 2001/2. Increases in inpatient bed days has been somewhat parallel to increases seen in registrations (Figure 11, Table 8), with a 9% increase in primary tumours between 1995/6 and 2000/1, corresponding to an 8% increase in registrations for primary brain/CNS tumours at this time. The rise is more prominent among metastasis tumours (22% in that six year period).

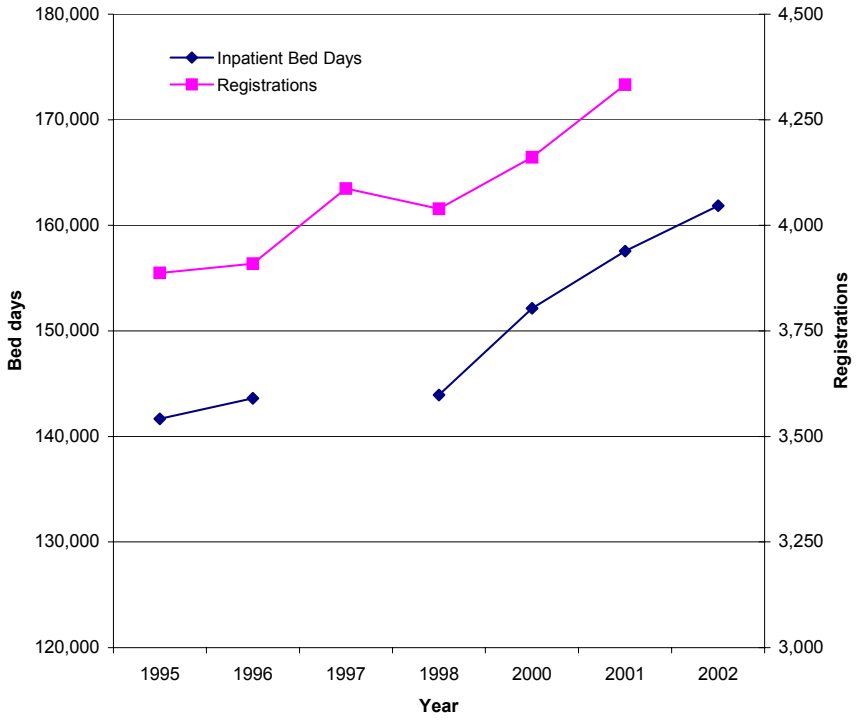


Figure 11 Inpatient bed days and registrations for patients with brain tumours (benign, malignant and uncertain) 1995-2002.

Data supplied by the National Cancer Services Analysis Team (HES/PEDW data; year refers to commencement of financial year; incomplete data available for financial year 1997-8), National Cancer Intelligence Centre of the Office for National Statistics and the Wales Cancer Intelligence and Surveillance Unit.

Day case episodes have more than doubled in this period (including among primary tumours), this increase among day cases may represent a changing approach to hospital management of tumours.

Table 9 demonstrates that the 90-99 year age groups experienced the largest relative increase in bed day use; however in actual number terms the 75-79 age group accounts for the greatest rise. A proportion of this rise may be attributable to admissions for certain procedures, e.g. stereotactic ablation of brain tumours (see procedures analysis).

Analysis by age demonstrated that the elderly accounted for a relatively higher proportion of inpatient service usage and a relatively lower proportion of day-case service usage. For example 59% of inpatient beds were used by patients aged 60 or over, whereas only 23% of day case episodes were accounted for by patients aged 60 or over.

Table 8 Inpatient episodes (a), day case episodes (b) and inpatient bed days (c) in England and Wales among adults (aged 15-99) with neurological tumours / phakomatoses years 1995/6 to 2001/2002 (excluding 1997/8) by tumour type.

a. Number of Inpatient Episodes	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Grand Total	% of total	% of primary
Intracranial intra-axial	11801	12041	12561	13015	13562	13783	76763	37.2%	62%
Intracranial extra-axial									
Intracranial meningeal	1810	1921	2115	2323	2240	2312	12721	6.2%	10.2%
Cranial nerve	958	1058	1080	1229	1187	1159	6671	3.2%	5.3%
Sellar	2183	2345	2516	2597	2564	2651	14856	7.2%	11.9%
Pineal	154	155	148	146	156	124	883	0.4%	0.7%
Spinal									
Spinal: Spinal Cord	259	285	298	287	309	299	1737	0.8%	1.4%
Spinal: Spinal Meninges	213	201	282	239	236	268	1439	0.7%	1.2%
Other primary CNS									
Other Meningeal	1047	1171	1092	1253	1340	1506	7409	3.6%	5.9%
Other CNS	78	77	83	117	80	117	552	0.3%	0.4%
Multiple Tumour Subsites	178	167	178	182	190	181	1076	0.5%	0.9%
Phakomatosis & Tumour Diagnosis	65	86	94	110	112	144	611	0.3%	0.5%
Intracranial metastases	10136	10819	11766	13216	13681	15128	74746	36.3%	
Extracranial metastases	280	314	326	343	383	358	2004	1.0%	
Neurofibromatosis	185	205	493	549	517	588	2537	1.2%	
Tuberous sclerosis	27	22	172	142	123	118	604	0.3%	
Other Phakomatoses	123	183	255	315	346	298	1520	0.7%	
Grand Total	29497	31050	33459	36063	37026	39034	206129	100.0%	

b. Number of Daycase Episodes	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Grand Total	% of total	% of primary
Intracranial intra-axial	1240	1331	2884	3113	2970	2324	13862	39.4%	57%
Intracranial extra-axial									
Intracranial meningeal	21	12	196	252	146	71	698	2.0%	2.9%
Cranial nerve	48	58	53	86	137	66	448	1.3%	1.8%
Sellar	652	666	1534	1741	1561	1680	7834	22.3%	32.3%
Pineal	27	22	37	68	39	65	258	0.7%	1.1%
Spinal									
Spinal: Spinal Cord	45	48	66	204	95	96	554	1.6%	2.3%
Spinal: Spinal Meninges	3	12	9	8	13	16	61	0.2%	0.3%
Other primary CNS									
Other Meningeal	17	17	32	42	54	59	221	0.6%	0.9%
Other CNS	63	18	13	40	18	11	163	0.5%	0.7%
Multiple Tumour Subsites	33	7	27	16	30	20	133	0.4%	0.5%
Phakomatosis & Tumour Diagnosis									
Intracranial metastases	467	505	1723	1862	1749	1510	7816	22.2%	
Extracranial metastases	42	89	76	129	194	74	604	1.7%	
Neurofibromatosis	149	167	247	289	327	251	1430	4.1%	
Tuberous sclerosis	17	10	34	28	31	45	165	0.5%	
Other Phakomatoses	95	118	147	163	206	223	952	2.7%	
Grand Total	2919	3080	7078	8041	7570	6511	35199	100.0%	

c. Number of Inpatient Bed Days	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Grand Total	% of total	% of primary
Intracranial intra-axial	141657	143612	143939	152145	157551	161843	900747	38.9%	61%
Intracranial extra-axial									
Intracranial meningeal	27483	28361	29111	32192	29783	34104	181034	7.8%	12.3%
Cranial nerve	12020	11201	11728	11108	11366	11756	69179	3.0%	4.7%
Sellar	19745	20194	22957	19948	21547	21544	125935	5.4%	8.6%
Pineal	1511	1880	1619	1464	1288	1511	9273	0.4%	0.6%
Spinal									
Spinal: Spinal Cord	4354	4452	4481	4003	5308	4651	27249	1.2%	1.9%
Spinal: Spinal Meninges	3036	3155	4175	3273	2928	4287	20854	0.9%	1.4%
Other primary CNS									
Other Meningeal	17223	17354	15828	17498	19080	23936	110919	4.8%	7.5%
Other CNS	982	652	813	1281	776	978	5482	0.2%	0.4%
Multiple Tumour Subsites	2513	2292	2654	2000	2323	2365	14147	0.6%	1.0%
Phakomatosis & Tumour Diagnosis	921	991	1106	1096	1162	1447	6723	0.3%	0.5%
Intracranial metastases	115341	118171	122849	137418	141273	157303	792355	34.2%	
Extracranial metastases	2832	3080	2811	3406	3194	3460	18783	0.8%	
Neurofibromatosis	1782	1583	4251	3597	4154	4546	19913	0.9%	
Tuberous sclerosis	135	121	810	884	778	1031	3759	0.2%	
Other Phakomatoses	1177	1265	1972	1770	2891	2358	11433	0.5%	
Grand Total	352712	358364	371104	393083	405402	437120	2317785	100.0%	

Table 9 Inpatient episodes (a), day case episodes (b), and inpatient bed days (c) in England and Wales among adults (aged 15-99) with primary brain or CNS tumours (excluding metastases / phakomatoses) years 1995-6 to 2001-2002 (excluding 1997-8) by age group (- signifies a decrease).

a. Inpatient episodes	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Grand Total	Proportion of total	% increase (6 year)	Number increase (6 year)
15-19	418	384	443	499	547	672	2,963	2.4%	61%	254
20-24	492	446	534	416	424	461	2,773	2.2%	-6%	-31
25-29	671	732	721	600	748	619	4,091	3.3%	-8%	-52
30-34	847	921	916	920	1,026	987	5,617	4.5%	17%	140
35-39	995	1,058	1,068	1,231	1,170	1,295	6,817	5.5%	30%	300
40-44	1,225	1,102	1,150	1,345	1,264	1,356	7,442	6.0%	11%	131
45-49	1,532	1,630	1,518	1,466	1,482	1,638	9,266	7.4%	7%	106
50-54	1,679	1,805	2,016	2,156	2,142	1,930	11,728	9.4%	15%	251
55-59	1,946	1,951	1,964	2,137	2,164	2,251	12,413	10.0%	16%	305
60-64	2,020	2,022	2,255	2,282	2,412	2,303	13,294	10.7%	14%	283
65-69	2,147	2,186	2,423	2,440	2,495	2,465	14,156	11.4%	15%	318
70-74	2,125	2,235	2,249	2,376	2,319	2,376	13,680	11.0%	12%	251
75-79	1,269	1,443	1,688	2,032	2,003	2,072	10,507	8.4%	63%	803
80-84	932	868	865	883	969	1,259	5,776	4.6%	35%	327
85-89	345	343	511	534	598	580	2,911	2.3%	68%	235
90-94	73	56	93	130	172	199	723	0.6%	173%	126
blank/95+	30	325	33	51	41	81	561	0.4%	170%	51
Grand Total	18,746	19,507	20,447	21,498	21,976	22,544	124,718	100.0%	20%	3,798

b. Day case episodes	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Grand Total	Proportion of total	% increase (6 year)	Number increase (6 year)
15-19	212	210	199	335	248	535	1,739	7.1%	152%	323
20-24	89	69	365	212	237	175	1,147	4.7%	97%	86
25-29	136	153	357	291	221	219	1,377	5.7%	61%	83
30-34	176	211	381	419	506	357	2,050	8.4%	103%	181
35-39	185	282	426	590	495	349	2,327	9.6%	89%	164
40-44	222	210	438	476	464	454	2,264	9.3%	105%	232
45-49	264	215	555	628	446	470	2,578	10.6%	78%	206
50-54	269	199	593	619	508	467	2,655	10.9%	74%	198
55-59	225	206	418	536	543	439	2,367	9.7%	95%	214
60-64	165	218	500	547	542	365	2,337	9.6%	121%	200
65-69	111	93	308	499	397	263	1,671	6.9%	137%	152
70-74	52	72	212	187	265	179	967	4.0%	244%	127
75-79	22	33	63	175	132	74	499	2.1%	236%	52
80-84	14	13	27	48	38	37	177	0.7%	164%	23
85-89	4		7	5	16	20	52	0.2%	400%	16
90-94	1			1	2	2	6	0.0%	100%	1
blank/95+	2	7	2	2	3	3	19	0.1%	50%	1
Grand Total	2,151	2,195	4,867	5,575	5,096	4,452	24,336	100.0%	107%	2,301

c. Bed days	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Grand Total	Proportion of total	% increase (6 year)	Number increase (6 year)
15-19	3,060	2,825	2,849	3,756	3,561	4,613	20,664	1.4%	51%	1,553
20-24	4,527	3,812	4,665	3,874	3,340	3,679	23,897	1.6%	-19%	-848
25-29	5,658	5,977	5,539	4,401	6,099	4,929	32,603	2.2%	-13%	-729
30-34	7,173	8,570	8,235	7,809	7,784	9,096	48,667	3.3%	27%	1,923
35-39	9,619	9,635	10,312	10,323	10,184	10,700	60,773	4.1%	11%	1,081
40-44	11,744	9,683	12,202	11,839	11,939	12,391	69,798	4.7%	6%	647
45-49	17,158	15,717	15,032	14,341	13,281	15,960	91,489	6.2%	-7%	-1,198
50-54	17,964	19,304	19,967	22,593	22,010	19,334	121,172	8.2%	8%	1,370
55-59	20,919	21,701	21,706	22,541	23,659	24,348	134,874	9.2%	16%	3,429
60-64	25,216	24,248	24,031	24,675	27,138	26,304	151,612	10.3%	4%	1,088
65-69	27,345	28,199	29,467	30,401	29,123	30,020	174,555	11.9%	10%	2,675
70-74	30,765	32,589	30,961	30,648	31,276	34,494	190,733	13.0%	12%	3,729
75-79	22,445	23,034	26,020	30,722	30,907	33,849	166,977	11.3%	51%	11,404
80-84	18,562	16,072	15,370	15,110	16,977	22,171	104,262	7.1%	19%	3,609
85-89	7,391	7,669	9,855	9,778	11,346	11,026	57,065	3.9%	49%	3,635
90-94	1,386	1,238	1,583	2,599	3,871	4,012	14,689	1.0%	189%	2,626
blank/95+	513	3,871	617	598	617	1,496	7,712	0.5%	192%	983
Grand Total	231,445	234,144	238,411	246,008	253,112	268,422	1,471,542	100.0%	16%	36,977

Variation of hospital activity by Strategic Health Authority (SHA) of residence of patient is outlined in Table 10. There is some variation in rates of inpatient bed days, with the highest being 0.5 greater than the lowest. However, the variation is much more marked for day case episodes, with the highest being 15.6 times greater than the lowest (or 3.2 times if two outlying SHAs are excluded).

Table 10 Variation in inpatient / day case episodes and inpatient days by SHA of residence for those with primary neurological tumours, with crude rates among those aged 15 and over years 1995-6 to 2001-2002 (excluding 1997-8) .

SHA of Patient	Numbers			Rates per 100,000		
	Inpatient episodes	Day case episodes	Inpatient bed days	Inpatient episodes	Day case episodes	Inpatient bed days
Avon, Gloucestershire & Wiltshire HA	5,784	1,129	61,004	55.6	10.9	586.7
Bedfordshire & Hertfordshire HA	3,280	373	39,492	43.5	4.9	523.4
Birmingham & The Black Country HA	4,476	421	58,925	41.4	3.9	545.3
Cheshire & Merseyside HA	5,648	937	65,144	49.6	8.2	571.9
County Durham & Tees Valley HA	3,019	444	30,884	54.8	8.1	560.5
Coventry, Warwickshire, Herefordshire &	3,316	228	39,585	45.1	3.1	538.9
Cumbria & Lancashire HA	5,616	4,365	62,620	60.9	47.3	679.3
Dorset & Somerset HA	3,562	353	39,815	61.3	6.1	685.0
Essex HA	3,976	412	48,425	51.4	5.3	626.3
Greater Manchester HA	5,716	4,041	67,474	47.7	33.8	563.6
Hampshire & Isle Of Wight HA	4,575	479	48,540	53.4	5.6	566.6
Kent & Medway HA	3,254	564	37,471	43.2	7.5	497.7
Leicestershire, Northamptonshire & Rutla	3,831	664	41,339	51.9	9.0	559.6
Norfolk, Suffolk & Cambridgeshire HA	5,986	735	72,837	57.0	7.0	693.0
North & East Yorkshire and Northern Linc	3,796	342	43,625	48.4	4.4	555.8
North Central London HA	2,053	287	30,568	36.7	5.1	546.8
North East London HA	3,175	631	46,319	46.1	9.2	672.4
North West London HA	3,171	595	43,170	38.4	7.2	522.9
Northumberland, Tyne & Wear HA	3,656	822	44,368	53.4	12.0	647.9
Shropshire & Staffordshire HA	2,939	636	39,517	40.9	8.8	549.6
South East London HA	2,509	465	33,353	35.5	6.6	471.5
South West London HA	2,837	464	33,298	46.1	7.5	540.8
South West Peninsula HA	4,662	571	44,338	60.8	7.4	578.3
South Yorkshire HA	2,995	176	37,867	48.5	2.8	613.2
Surrey & Sussex HA	6,020	629	68,012	48.5	5.1	547.5
Thames Valley HA	4,316	736	49,818	43.3	7.4	500.0
Trent HA	6,508	1,104	72,253	51.3	8.7	569.5
Wales	7,570	865	97,110	54.0	6.2	692.2
West Yorkshire HA	4,336	676	52,193	43.8	6.8	526.7
(blank)	2,047	159	21,347			
Grand Total	124,718	24,336	1,471,542	49.8	9.7	587.6
Maximum	7,570	4,365	97,110	61.3	47.3	693.0
Minimum	2,047	159	21,347	35.5	2.8	471.5
Maximum as factor of minimum	3.7	27.5	4.5	1.7	16.6	1.5
Average	4,154	810	49,024	49.8	9.7	587.6
Median	3,814	583	44,353	48	7	560

Data supplied by NATCANSAT; denominator: population estimates for strategic health authorities 1995-2001 (excluding 1997), Office for National Statistics.

5.1.2 Procedure based analysis

Major procedure types

The most common neurosurgical procedure for tumours of the brain and CNS is “excision of lesion of tissue of brain”, followed by “extirpation of lesion of meninges of brain” (Table 11). Eighty-four percent of “excision of lesion of tissue of brain” procedures were undertaken for patients with a diagnosis of brain/CNS tumour; CNS metastasis or phakomatoses.

Table 11 Ten most commonly performed procedures, rates per million population, including metastases and phakomatoses (financial years 1995/6-2001/2; excluding 1997/8; age ≥ 15)

Procedure	Number for brain / CNS tumours	Rate per million population per year	% of total procedures performed
Excision of Lesion of Tissue of Brain	12,216	48.8	84.5%
Other Biopsy of Lesion of Tissue of Brain	6,281	25.1	78.5%
Extirpation of Lesion of Meninges of Brain	5,556	22.2	95.4%
Excision of Lesion of Cranial Nerve	3,050	12.2	90.4%
Excision of Pituitary Gland	2,290	9.1	94.9%
Open Biopsy of Lesion of Tissue of Brain	2,020	8.1	76.1%
Stereotactic Ablation of Tissue of Brain*	2,006	8.0	-*
Creation of Connection From Ventricle of Brain	1,905	7.6	54.2%
Transluminal Operations On Cerebral Artery	1,362	5.4	18.6%
Major Excision of Tissue of Brain	1,023	4.1	46.0%

*Due to data extract from HES / PEDW this calculation is not valid on this procedure

Trends in procedures

The number of rate of neurosurgical procedures has increased between 1995/6 and 2001/2 (Table 12).

Table 12 Number of procedures performed, five most commonly performed procedures, and three selected others, type and year, for individuals with a diagnosis of brain/CNS tumours including metastases and phakomatoses (financial years 1995/6-2001/2; excluding 1997/8; age ≥ 15).

	Numbers of procedures							Rate of procedures per million persons ≥ 15						
	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Total	1995-1996	1996-1997	1998-1999	1999-2000	2000-2001	2001-2002	Overall
Excision of Lesion of Tissue of Brain	1,920	1,964	1,959	2,084	2,136	2,153	12,216	46.5	47.5	47.1	49.9	50.9	50.7	48.8
Other Biopsy of Lesion of Tissue of Brain	1,021	1,045	1,054	998	1,090	1,073	6,281	24.7	25.3	25.3	23.9	26.0	25.3	25.1
Extirpation of Lesion of Meninges of Brain	850	921	903	973	947	962	5,556	20.6	22.3	21.7	23.3	22.6	22.6	22.2
Excision of Lesion of Cranial Nerve	478	557	552	521	492	450	3,050	11.6	13.5	13.3	12.5	11.7	10.6	12.2
Excision of Pituitary Gland	255	339	382	429	441	444	2,290	6.2	8.2	9.2	10.3	10.5	10.5	9.1
Open Biopsy of Lesion of Tissue of Brain	283	295	375	402	328	337	2,020	6.9	7.1	9.0	9.6	7.8	7.9	8.1
Stereotactic Ablation of Tissue of Brain	163	259	272	427	422	463	2,006	4.0	6.3	6.5	10.2	10.0	10.9	8.0
Major Excision of Tissue of Brain	167	177	186	165	177	151	1,023	4.0	4.3	4.5	4.0	4.2	3.6	4.1
Grand Total	6,805	7,200	7,434	7,940	7,888	7,820	45,087	165.0	174.1	178.8	190.1	187.8	184.1	180.0

The rates of individual procedures performed recorded on HES/PEDW relative to the rate during 1995/6 has not changed dramatically for most procedure types. It has increased somewhat for pituitary procedures, but has risen steeply for stereotactic ablation of tissue of brain (Figure 12).

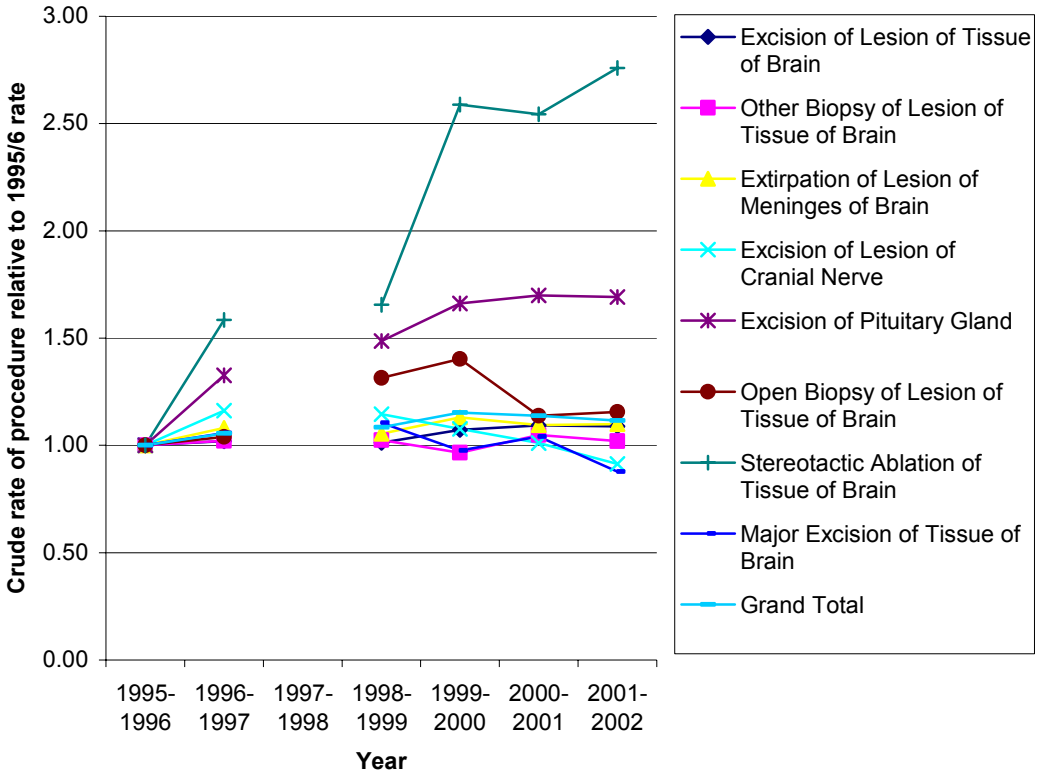


Figure 12 Rate of procedure performed relative to 1995-1996 rate for the five most commonly performed procedures, three selected others and all procedures (brain/CNS tumours including metastases and phakomatoses; financial years 1995/6-2001/2; excluding 1997/8; age ≥ 15).
Source of data: NATCANSAT and ONS.

Table 13 Number of procedures undertaken by year and age group (individuals with a diagnosis of brain/CNS tumours including metastases and phakomatoses; age ≥ 15)

Age Band	1995-1996	1996-1997		1998-1999	1999-2000	2000-2001	2001-2002	Grand Total
15-19	162	143		153	185	221	201	1,065
20-24	212	167		201	183	180	200	1,143
25-29	277	313		310	260	300	277	1,737
30-34	362	380		425	413	433	427	2,440
35-39	398	480		471	564	499	527	2,939
40-44	542	467		543	589	558	610	3,309
45-49	674	693		712	690	711	673	4,153
50-54	713	778		891	1,001	962	859	5,204
55-59	775	786		824	973	915	936	5,209
60-64	764	824		889	903	928	938	5,246
65-69	833	817		874	912	882	914	5,232
70-74	676	687		665	684	706	667	4,085
75-79	281	339		367	429	423	429	2,268
80-84	114	98		67	102	121	133	635
85-89	17	22		31	32	37	23	162
90-94	1	1		3		1	2	8
Blank or 90+	4	205		8	20	11	4	252
Grand Total	6,805	7,200		7,434	7,940	7,888	7,820	45,087

Aged over 90 is included among "blank" entries as some ages were misclassified in the extract among those aged 90+.

Trends in numbers and rates of procedures performed are rising less markedly in the elderly than incidence and mortality (Table 13, Figure 13).

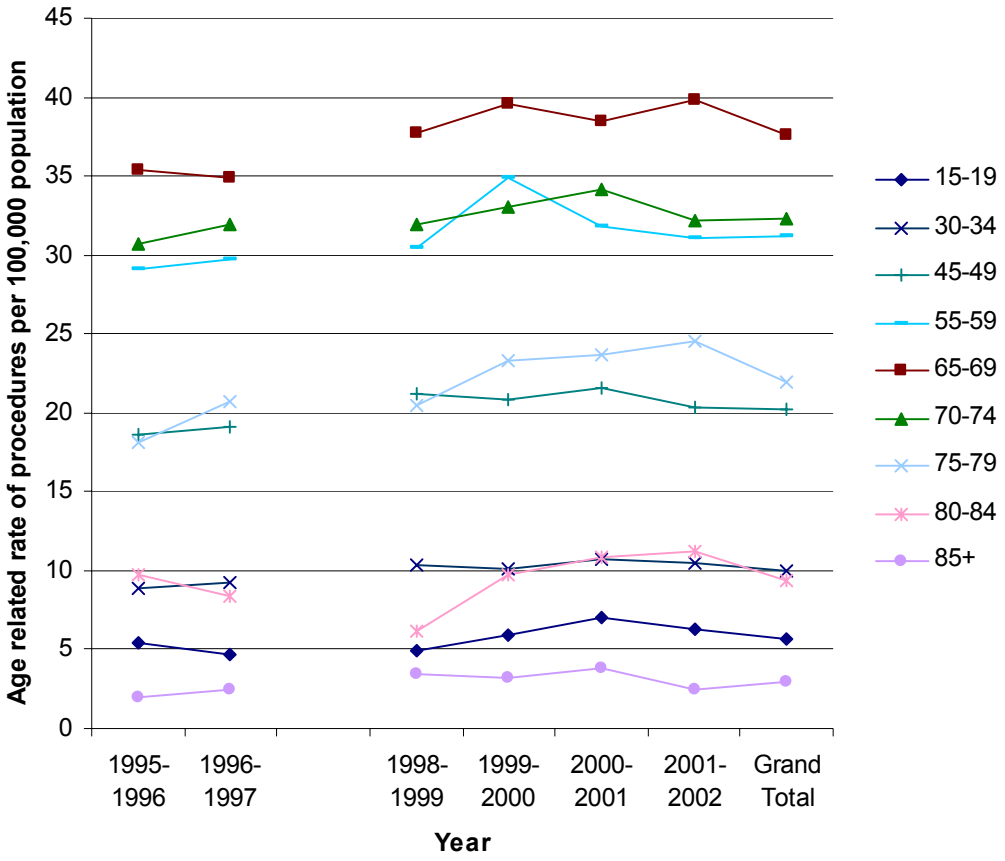


Figure 13 Age related rates of procedures selected age groups
Source of data: NATCANSAT and ONS. (rate in 85+ uses a numerator of 85-94 and a denominator of 85+)

Procedures by sub-categories

There were typically 7,515 neurological procedures recorded per annum in England and Wales for these patients (Table 14); 46% for intracranial intra-axial tumours, 11% for cranial nerve, and 10% for intracranial metastases. Annually approximately 769 neurological procedures were undertaken for intracranial metastases.

Table 14 Number and rate/million population/year: total procedures, most common procedure and stereotactic ablation of tissue of brain in persons aged ≥15 by diagnostic categories (Financial years 1995/6-1996/7; 1998/9-2001/2).

a. Primary tumours	Number	Average per annum	Rate per million population per year
Intracranial intra-axial			
Total	**20,691**	**3448.5**	**82.62**
Excision of Lesion of Tissue of Brain	8,547	1424.5	34.13
Stereotactic Ablation of Tissue of Brain	338	56.3	1.35
Intracranial meningeal			
Total	**7,016**	**1169.3**	**28.02**
Extirpation of Lesion of Meninges of Brain	4,562	760.3	18.22
Stereotactic Ablation of Tissue of Brain	26	4.3	0.10
Cranial nerve			
Total	**4,795**	**799.2**	**19.15**
Excision of Lesion of Cranial Nerve	2,902	483.7	11.59
Stereotactic Ablation of Tissue of Brain	980	163.3	3.91
Sellar		**0.0**	**0.00**
Total	**3,581**	**596.8**	**14.30**
Excision of Pituitary Gland	2,275	379.2	9.08
Stereotactic Ablation of Tissue of Brain	110	18.3	0.44
Pineal			
Total	**388**	**64.7**	**1.55**
Operations On Pineal Gland	99	16.5	0.40
Stereotactic Ablation of Tissue of Brain	7	1.2	0.03
Spinal: Spinal Cord			
Total	**541**	**90.2**	**2.16**
Partial Extirpation of Spinal Cord	366	61.0	1.46
Spinal: Spinal Meninges		**0.0**	**0.00**
Total	**725**	**120.8**	**2.90**
Other Operations On Meninges of Spinal Cord	539	89.8	2.15
Other Meningeal			
Total	**1,581**	**263.5**	**6.31**
Extirpation of Lesion of Meninges of Brain	684	114.0	2.73
Stereotactic Ablation of Tissue of Brain	395	65.8	1.58
Other CNS			
Total	**22**	**3.7**	**0.09**
Partial Extirpation of Spinal Cord	6	1.0	0.02
Multiple Tumour Subsites			
Total	**385**	**64.2**	**1.54**
Partial Extirpation of Spinal Cord	152	25.3	0.61
Stereotactic Ablation of Tissue of Brain	2	0.3	0.01
Phakomatosis & Tumour Diagnosis			
Total	**311**	**51.8**	**1.24**
Excision of Lesion of Tissue of Brain	103	17.2	0.41
Stereotactic Ablation of Tissue of Brain	1	0.2	0.00

Table 14 continued:

b. Secondary tumours	Number	Average per annum	Rate per million population per year
Intracranial metastases			
Total	**4,611**	**768.5**	**18.41**
Excision of Lesion of Tissue of Brain	2,572	428.7	10.27
Stereotactic Ablation of Tissue of Brain	138	23.0	0.55
Extracranial metastases			
Total	**152**	**25.3**	**0.61**
Other Operations On Meninges of Spinal Cord	53	8.8	0.21
Stereotactic Ablation of Tissue of Brain	1	0.2	0.00

c. Phakomatoses	Number	Average per annum	Rate per million population per year
Neurofibromatosis			
Total	**172**	**28.7**	**0.69**
Operations On Spinal Nerve Root	43	7.2	0.17
Stereotactic Ablation of Tissue of Brain	4	0.7	0.02
Tuberous sclerosis			
Total	**19**	**3.2**	**0.08**
Therapeutic Spinal Puncture	6	1.0	0.02
Other Phakomatoses			
Total	**97**	**16.2**	**0.39**
Excision of Lesion of Tissue of Brain	34	5.7	0.14
Stereotactic Ablation of Tissue of Brain	4	0.7	0.02
Grand Total)	**45,087**	**7514.5**	**180.04**

Variation in procedures performed by Strategic Health Authority (SHA)

There is a two-fold variation by SHA in the rate of procedures performed (Table 15). A proportion of this may be related to coding variation.

Table 15 Numbers and rates, per 100,000 population per year, of neurological procedures in people aged ≥15 with tumours of the brain and CNS, including metastases and phakomatoses, by residence of patient: Strategic Health Authorities (England) and Wales.

SHA of Patient	Number			Rate /100,000 population /year		
	Total procedures	Excision of Lesion of Tissue of Brain	Other Biopsy of Lesion of Tissue of Brain	Total procedures	Excision of Lesion of Tissue of Brain	Other Biopsy of Lesion of Tissue of Brain
Avon, Gloucestershire & Wiltshire HA	2,281	739	224	21.9	7.1	2.2
Bedfordshire & Hertfordshire HA	1,216	241	235	16.1	3.2	3.1
Birmingham & The Black Country HA	1,744	471	259	16.1	4.4	2.4
Cheshire & Merseyside HA	1,857	451	313	16.3	4.0	2.7
County Durham & Tees Valley HA	1,086	324	149	19.7	5.9	2.7
Coventry, Warwickshire, Herefordshire &	1,162	419	97	15.8	5.7	1.3
Cumbria & Lancashire HA	1,959	418	411	21.2	4.5	4.5
Dorset & Somerset HA	1,305	307	198	22.5	5.3	3.4
Essex HA	1,356	260	361	17.5	3.4	4.7
Greater Manchester HA	1,722	490	189	14.4	4.1	1.6
Hampshire & Isle Of Wight HA	1,716	354	323	20.0	4.1	3.8
Kent & Medway HA	946	244	133	12.6	3.2	1.8
Leicestershire, Northamptonshire & Rutl	1,176	354	160	15.9	4.8	2.2
Norfolk, Suffolk & Cambridgeshire HA	2,132	333	141	20.3	3.2	1.3
North & East Yorkshire and Northern Lir	1,655	527	159	21.1	6.7	2.0
North Central London HA	753	164	152	13.5	2.9	2.7
North East London HA	1,014	271	198	14.7	3.9	2.9
North West London HA	1,061	242	210	12.9	2.9	2.5
Northumberland, Tyne & Wear HA	1,621	405	217	23.7	5.9	3.2
Shropshire & Staffordshire HA	1,139	337	149	15.8	4.7	2.1
South East London HA	801	235	108	11.3	3.3	1.5
South West London HA	1,252	410	62	20.3	6.7	1.0
South West Peninsula HA	1,440	427	144	18.8	5.6	1.9
South Yorkshire HA	1,058	275	146	17.1	4.5	2.4
Surrey & Sussex HA	2,493	701	375	20.1	5.6	3.0
Thames Valley HA	1,535	427	209	15.4	4.3	2.1
Trent HA	2,009	607	339	15.8	4.8	2.7
Wales	2,355	735	336	16.8	5.2	2.4
West Yorkshire HA	2,009	764	147	20.3	7.7	1.5
Total Engalnd and Wales	43,853	12,216	6,281	17.5	4.9	2.5
Maximum	2,493	764	411	23.7	7.7	4.7
Minimum	753	164	62	11.3	2.9	1.0
Maximum as factor of minimum	3.3	4.7	6.6	2.1	2.6	4.6
Average	1,512.2	411.4	211.9	17.5	4.7	2.5
Median	1,440	405	198	16.8	4.5	2.4

5.1.3 Analysis of individual patients in England by "HES id"

Ninety-five percent of records in the years 1998/9-2001/2 could be assigned a "HES id".

Numbers of individual patients

NATCANSAT undertook an analysis of all individual patients who had an inpatient episode appear on the inpatient data (HES) for each Trust in England. Results are shown in Table 16. The diagnostic group used in the analysis includes metastases and phakomatoses. There were over 20,000 patients in each year with unique HES ids, with a typical median number of patients seen per Trust in a year of 46.

Table 16 Individual patients appearing on HES system of England with tumours of the brain / CNS *including all metastases and phakomatoses, all ages*.

Patients on Hospital Episode Statistics (England)	1998-1999	1999-2000	2000-2001	2001-2002	Summed total of patients in all years*	Annual Average	Total (individual patients in all years)
Minimum for Trust	0	0	0	0	1	0.3	1
Maximum for Trust	730	883	769	789	3157	789.3	2947
Average (mean) for Trusts	82.9	86.9	87.9	91.3	348.9	87.2	312.8
Mode for Trusts	0	0	0	1	1	0.25	1
Median for Trusts	43	46	47	46	182	45.5	169
Summed total of patients in all Trusts*	23789	24942	25216	26189	100136	25034.0	89786
Total individual patients, all Trusts	21557	22334	22479	22968	89338	22334.5	77843

*"Summed totals" are more than the number of individual patients, and comparison with the number of individual patients gives an impression of the extent of which patients appear in multiple Trusts / multiple years on the HES system.

Method of first admission to hospital

Using the unique HES id an analysis was also undertaken of how patients with a diagnosis of brain or CNS tumours were admitted (Table 17). It should be noted that the first recorded episode with a diagnosis of brain or CNS tumour may not be the first admission during which that diagnosis was known, especially for cases that may have been admitted in years prior to the period of analysis. Almost half of patients' first admissions by this method are emergency admissions, with just under 40% elective.

Table 17 Method of admission, first admission of patients with a unique HES id with a recorded diagnosis of primary brain or CNS tumour, age ≥15, 1998/9- 2001/2.

Admission Method	Total	Percent
Elective: booked	4,712	11.1
Elective: from waiting list	8,867	21.0
Elective: planned	2,783	6.6
Total elective	16,362	38.7
Emergency: other means, including patients who arrive via the A&E department of another health care provider	4,331	10.2
Emergency: via Accident and Emergency (A&E) services, including the casualty department of the provider	8,207	19.4
Emergency: via Bed Bureau, including the Central Bureau	578	1.4
Emergency: via consultant out-patient clinic	1,235	2.9
Emergency: via General Practitioner (GP)	6,290	14.9
Total emergency	20,641	48.8
Maternity	187	0.4
Transfer from another provider (non-emergency)	5,046	11.9
Not known	79	0.2
Grand Total	42,315	100.0

Numbers of first admissions for individuals with a unique HES id have been showing a downward trend for all admission types for primary tumours. This might suggest an increasing tendency to manage patients in an outpatient setting. There is, however, an increasing trend for first admissions with a diagnosis of CNS metastases by emergency methods (Figure 14).

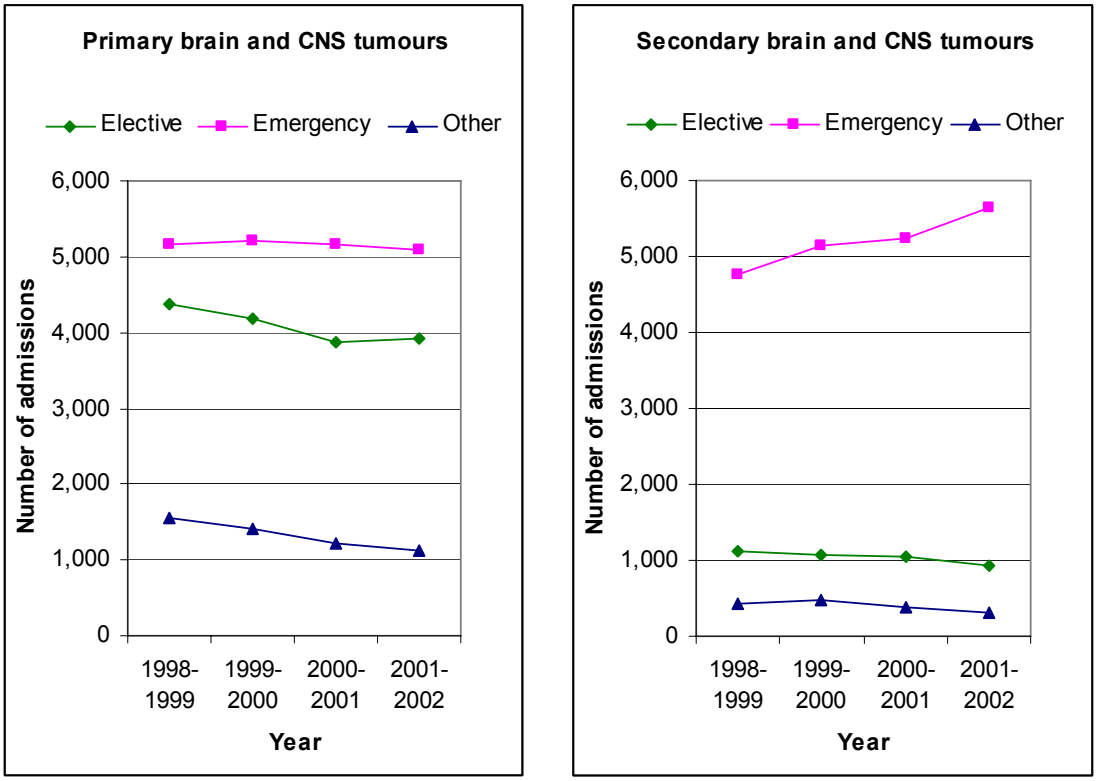


Figure 14 Time trend 1998/9-2001/2 method of admission, first admissions adults with tumours of the brain and CNS, primary and secondary tumours, age ≥15.

5.1.4 Neurosurgical unit catchment areas

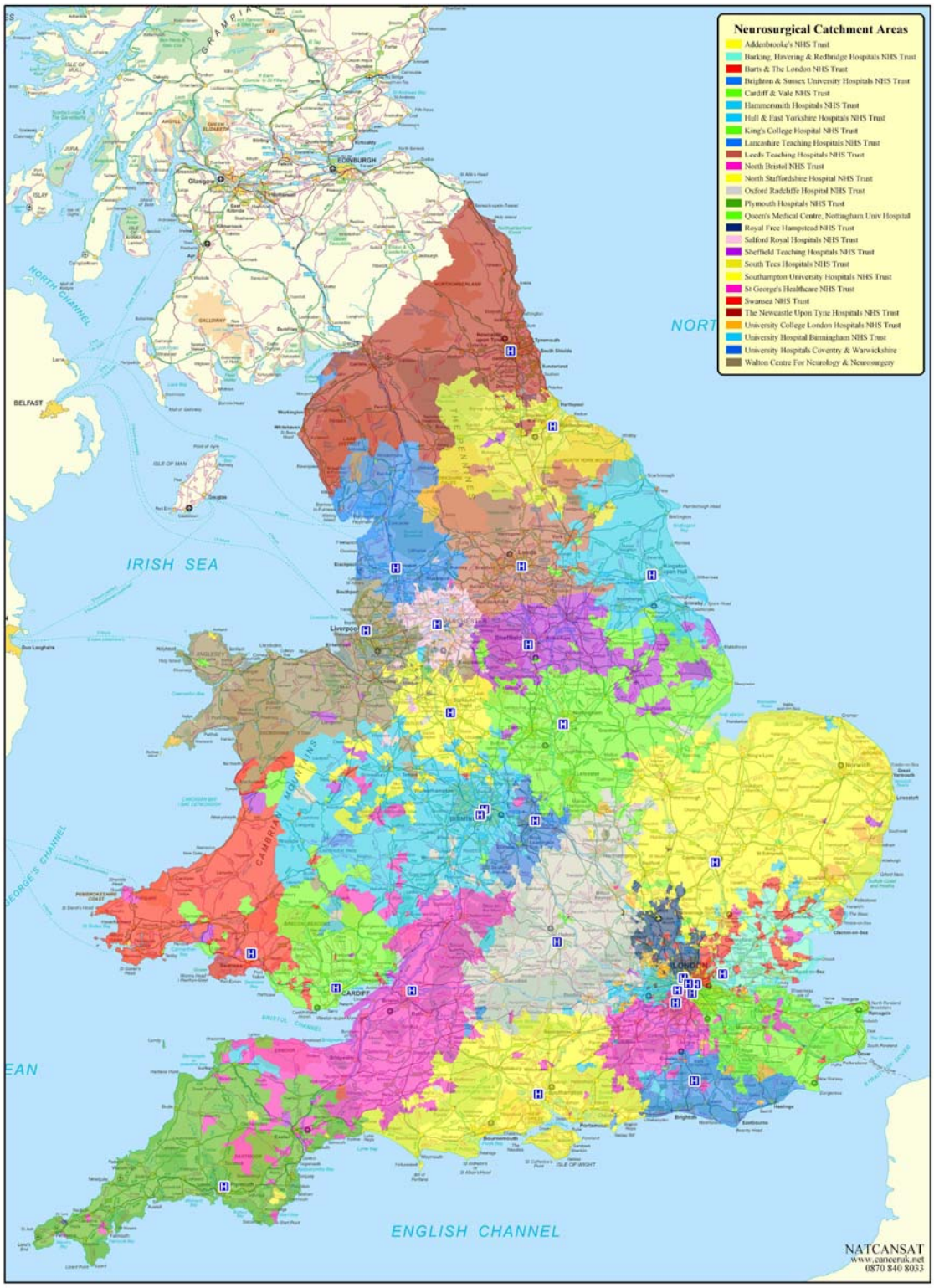
There is a large variation in unit size from over 3.5 million persons to just over quarter of a million persons (Table 18).

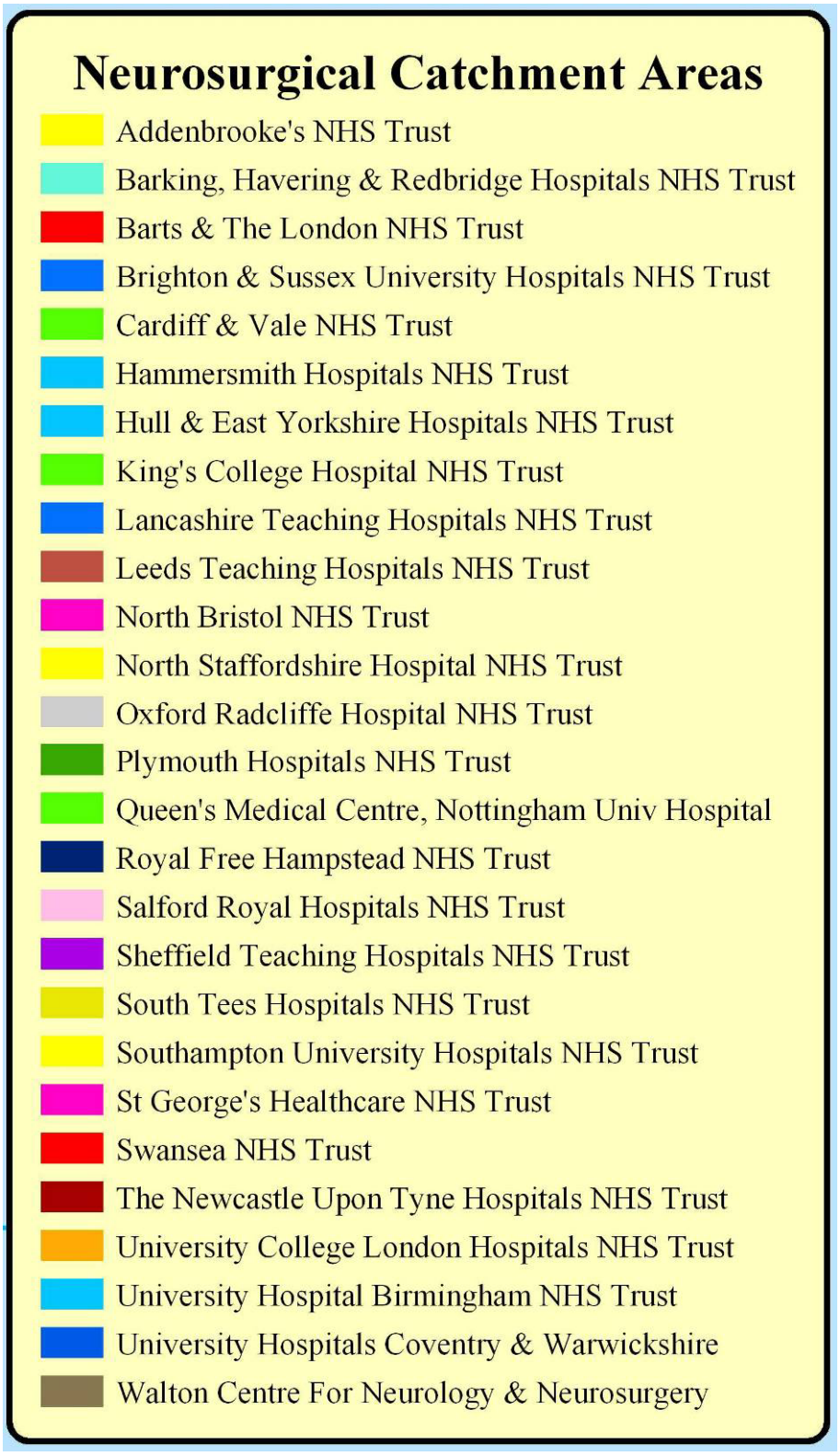
Table 18 Neuro-oncology catchment populations of adult neurosurgical units, England and Wales (based on patients aged ≥15) (Source: NATCANSAT, 2004).

Trust of Neurosurgical unit	Estimated catchment population (all ages)
University Hospital Birmingham NHS Trust	3,562,971
King's College Hospital NHS Trust	2,802,916
Queen's Medical Centre, Nottingham Univ Hospital	2,793,438
Addenbrooke's NHS Trust	2,756,675
Walton Centre For Neurology & Neurosurgery	2,742,507
Oxford Radcliffe Hospital NHS Trust	2,710,675
St George's Healthcare NHS Trust	2,626,425
Southampton University Hospitals NHS Trust	2,555,752
Leeds Teaching Hospitals NHS Trust	2,522,893
Salford Royal Hospitals NHS Trust	2,477,007
North Bristol NHS Trust	2,401,424
Sheffield Teaching Hospitals NHS Trust	2,066,319
The Newcastle Upon Tyne Hospitals NHS Trust	1,988,963
Royal Free Hampstead NHS Trust	1,726,414
Hammersmith Hospitals NHS Trust	1,702,681
Barking, Havering & Redbridge Hospitals NHS Trust	1,507,338
Lancashire Teaching Hospitals NHS Trust	1,498,243
Barts & The London NHS Trust	1,468,290
Plymouth Hospitals NHS Trust	1,458,398
University College London Hospitals NHS Trust	1,388,298
Cardiff & Vale NHS Trust	1,316,503
Brighton & Sussex University Hospitals NHS Trust	1,206,435
Hull & East Yorkshire Hospitals NHS Trust	1,124,113
North Staffordshire Hospital NHS Trust	1,110,610
South Tees Hospitals NHS Trust	975,649
Swansea NHS Trust	785,439
University Hospitals Coventry & Warwickshire	765,543
England and Wales	**52,041,916**

A map of these catchment areas is shown on the following page (Figure 15).

Figure 15 Dominant catchment areas of adult neurosurgical units in England and Wales, produced by NATCANSAT.




Neurosurgical Catchment Areas
Addenbrooke's NHS Trust
Barking, Havering & Redbridge Hospitals NHS Trust
Barts & The London NHS Trust
Brighton & Sussex University Hospitals NHS Trust
Cardiff & Vale NHS Trust
Hammersmith Hospitals NHS Trust
Hull & East Yorkshire Hospitals NHS Trust
King's College Hospital NHS Trust
Lancashire Teaching Hospitals NHS Trust
Leeds Teaching Hospitals NHS Trust
North Bristol NHS Trust
North Staffordshire Hospital NHS Trust
Oxford Radcliffe Hospital NHS Trust
Plymouth Hospitals NHS Trust
Queen's Medical Centre, Nottingham Univ Hospital
Royal Free Hampstead NHS Trust
Salford Royal Hospitals NHS Trust
Sheffield Teaching Hospitals NHS Trust
South Tees Hospitals NHS Trust
Southampton University Hospitals NHS Trust
St George's Healthcare NHS Trust
Swansea NHS Trust
The Newcastle Upon Tyne Hospitals NHS Trust
University College London Hospitals NHS Trust
University Hospital Birmingham NHS Trust
University Hospitals Coventry & Warwickshire
Walton Centre For Neurology & Neurosurgery

5.1.5 Mapping catchment populations: neurosurgical units and cancer networks

Details of how individual units and cancer networks map are shown in Appendix H. Mapping of catchment populations: neurosurgical units and cancer networks
Merseyside & Cheshire and North Wales considered as one network for this analysis.

Neurosurgical units that manage adult patients with tumours of the brain / CNS and their relation to Cancer Networks

Units outside London:

- 10 Neurosurgical units have their catchment area within one cancer network [Four of these networks overlap with other neurosurgical units]
- 6 Neurosurgical units have their catchment area covering one network and overlapping with the area of a second or third network
- 4 Neurosurgical units have their catchment covering at least two networks areas

Units within Greater London

Within the London area the neurosurgical catchment areas are more difficult to define. However:

- 6 units are related to more than one cancer network, and for one unit the relationship appears less clear.

Cancer Networks and neurosurgical units that manage adult patients with tumours of the brain / CNS

Cancer networks relating to units outside London

- 16 networks cover an area covered by a single neurosurgical unit
- 13 networks cover areas covered by more than one unit

Cancer networks relating to units within London

Within the London area the neurosurgical catchment areas are more difficult to define. However:

- 5 Networks appear to relate primarily to one neurosurgical unit.
- 2 Networks appear to relate to more than one unit

5.2 Questionnaires

5.2.1 Neurosurgical unit questionnaire results

All 27 adult neurosurgery units in England and Wales responded to the questionnaire. The full responses are given in Appendix K. Most (78%) of these units are located in university hospitals, and a further 11% stated they have teaching links (Figure 16).

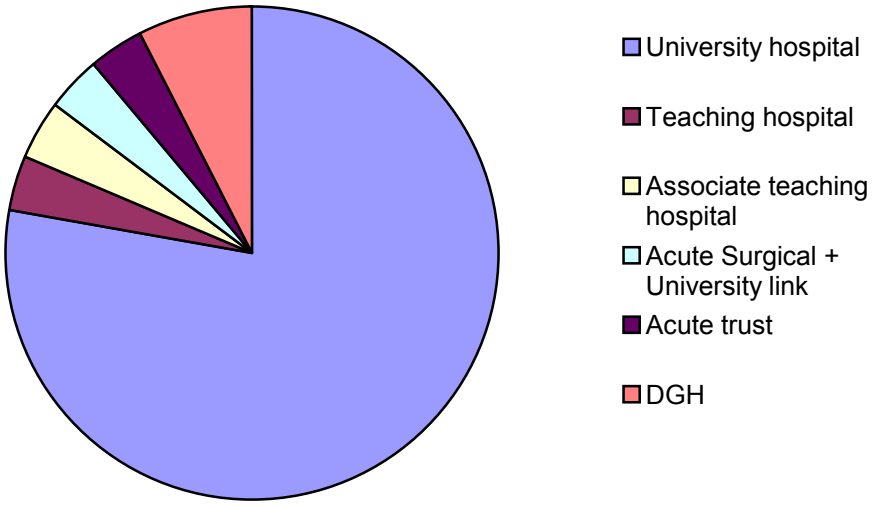


Figure 16 Location of unit / type of hospital

Size of units

Estimated catchment population ranged from 1,000,000 to 3,500,000 (Table 19; median 2,200,000; mean 2,226,000). Methods for deriving figures where supplied were usually "SBNS"/"Safe neurosurgery" figures or PCT / census data. The total catchment population summed to over 60 million for England and Wales.

Details for the numbers of designated beds for units are shown in Table 21. Beds were often shared with other specialities, especially critical care beds. Scheduled neurosurgical theatre time ranges from 18 to 144 hours / week.

Table 19 Neurosurgical estimated catchment populations

Catchment population	N	%
1.0 - 1.49 million	6	22.2
1.5-1.99 million	4	14.8
2.0-2.49 million	6	22.2
2.5-2.99 million	2	7.4
3 + million	9	33.3
Total	27	100.0

Table 20 Brain / CNS tumour patients seen in unit in a year

No. patients / year	N	%
50-99	2	7.4
100-149	4	14.8
150-199*	2	7.4
200-249	3	11.1
250	2	7.4
400	1	3.7
600-700	1	3.7
Unknwon/unanswered	12	44.4

* In one case refers to operated-on patients only as there is no reliable data for others.

Table 21 Number of designated beds in neurosurgical units.

	Ward beds	High dependency	Critical care	Total
Minimum	22	0	0	27
Maximum	68	13	17	84
Mean	40.2	6.3	7.1	53.1
Median	36	6	7	47.5
Responses included	26	22	23	24

Number of patients seen in units

Many units could not supply a single figure for the total number of new patients (all types) seen by the department in a year; there appeared to often be unlinked information relating to outpatients / elective admissions / emergency admissions. However for those that did this ranged from 1,143 to 5,000 (median 1,877; mean 2,039). The numbers of patients with brain / CNS tumours seen in the unit varied from 63 in a year to 600-700 (Table 20; median 190, mean 211). Very few units could supply finished consultant episodes relating only to brain / CNS tumours. When they did this ranged from 318 to 1,400. The number of finished consultant episodes (FCEs) do not correlate well with either the number of new brain / CNS tumour patients seen in the year, nor the estimated catchment population size.

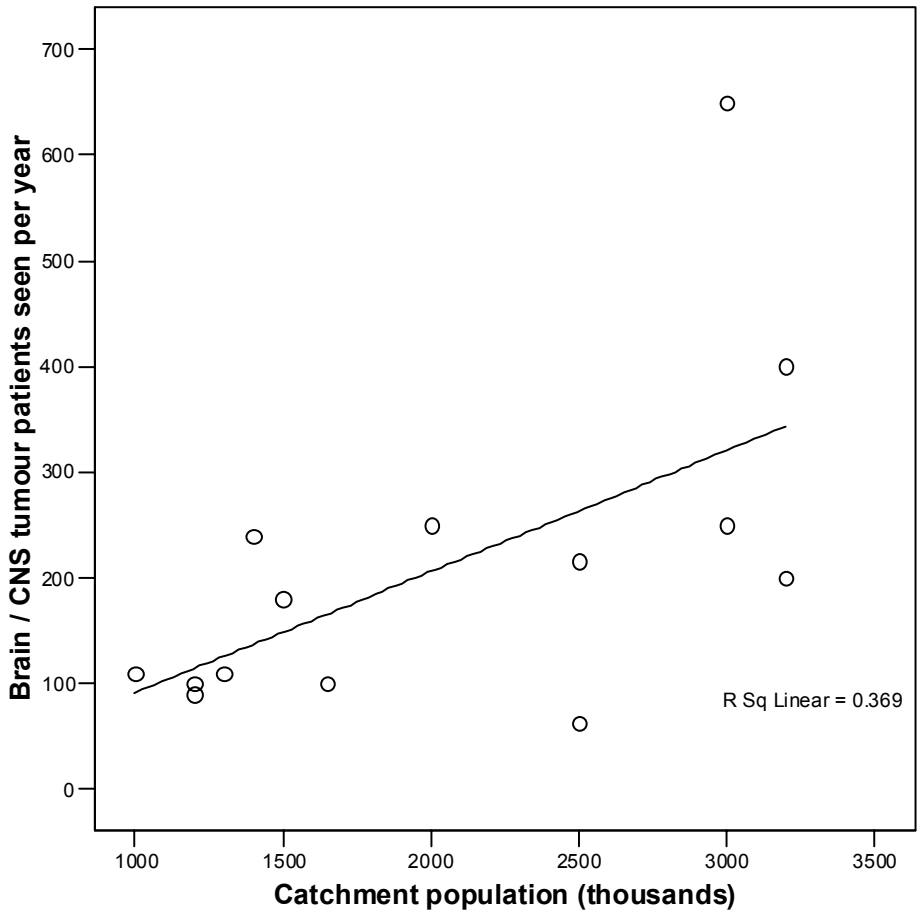


Figure 17 Scattergram of the number of brain / CNS tumours patients seen per year against catchment population for neurosurgical units.

Procedures

There was wide variation evident between the units regarding the numbers of procedures undertaken in a year for brain / CNS tumours. Six of the twenty units (30%) that provided data for the total number of open procedures for brain / CNS tumours performed less than 100 in a year. For more specialist procedures it was not uncommon for units to be undertaking less than 10 per year, e.g. 30% of units supplying data for acoustic/base of skull surgery. In contrast some units undertook very high numbers of these procedures, e.g. one unit said they undertook ~100 acoustic /base of skull procedures for brain / CNS tumours in a year (Table 22).

Table 22 Number of procedures done by neurosurgical units per year

	All procedures (all types)	Procedures for brain / CNS tumours						
		Total (brain / CNS)	Open	Stereotactic biopsy	Spinal (primary)	Spinal (metastatic)	Pituitary / cranioph.	Acoustic / skull base
Minimum	800	115	30	4	1	0	8	2
Maximum	2700	2440	736	92	38	44	150	100
Mean	1590.8	653.9	194.9	38.5	15.5	13.7	36.2	26.6
Median	1400	389	165	34	17	10	30	23
Responses included	25	18	20	20	16	15	21	20

Where a unit did not enter any number for a procedure number this has been excluded from the analysis (although it may be the case that no procedures of this type were undertaken).

Staffing and specialisation

Consultants

In most centres all neurosurgeons undertook some brain/CNS tumour work (Table 23), the main exception to this is one unit where one dedicated neurosurgeon, and two occasional[2] of the 5.5 whole time equivalent (WTE) neurosurgeons undertook brain/CNS tumour work. The relationship between self estimated population catchment size and staffing is shown (Figure 18). For pituitary / craniopharyngeal surgery there was a high degree of specialisation evident; in 39% of units there was only one WTE consultant undertaking this work, and no unit has more than 4 WTE consultants undertaking this work. Acoustic nerve / skull base tumour surgery had a similarly high degree of specialisation, with only one or two WTE consultants undertaking this type of work in three quarters of units, however in one unit 10 of the 11 WTE undertook this type of work. With spinal tumour surgery there was not such a high degree of specialisation.

[2] This unit did however specify that for spinal tumours there were 3 consultants with two others occasionally undertaking this type of work.

Table 23 Whole time equivalent (WTEs) consultant neurosurgeons undertaking procedure types.

	Total WTE	WTE undertaking work for brain/CNS tumour type			
		All	Piuitary / cranioph	Acoustic / skull base	Spinal
Minimum	3.8	3	1	1	2
Maximum	11	10	4	10	9
Mean	6.4	6.2	1.9	2.3	5.0
Median	6	6	2	2	5
Responses included	27	26	26	26	25

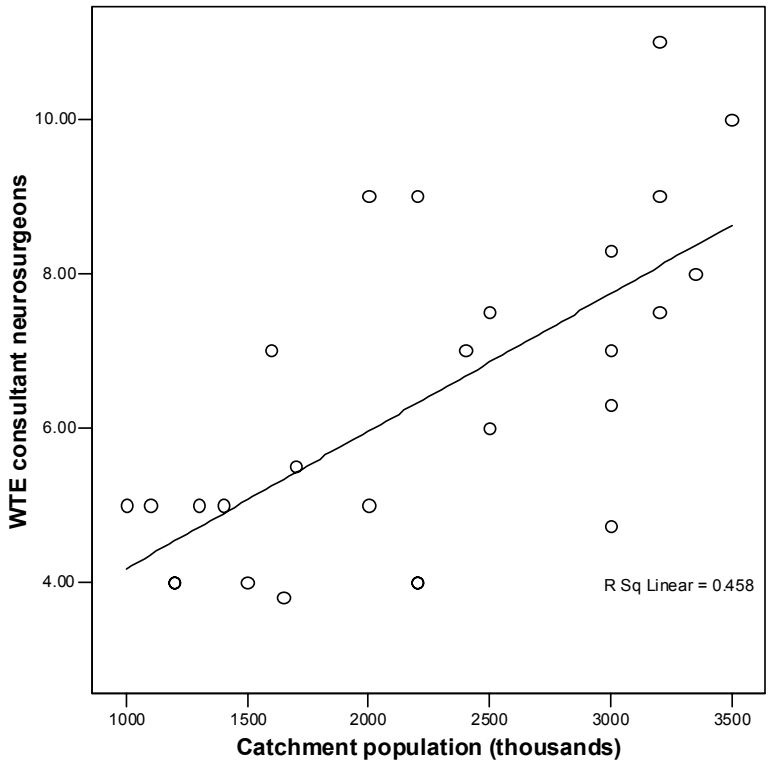


Figure 18 Scattergram of WTE consultant neurosurgeons against estimated catchment population for unit.

Clinical nurse specialists in neuro-oncology

Twenty-two of the 27 units responded that they had a clinical nurse specialist in neuro-oncology (CNSNOs). It is likely that many CNSNOs care for patients across both surgical and non-surgical services; three of these neurosurgical units said they had CNSNOs who undertook "non-surgical" work only. The units with no CNSNOs were all among the smaller units.

Multidisciplinary teams

Twenty-two units had an MDT[3] (Figure 19). Sixteen of these (73%) met weekly, three met fortnightly / twice per month, and three met monthly. The number of patients discussed at each meeting varied from 2-5 up to 35-40. Half of the units only discussed pre-operative cases if they were complex or unusual, rarely or not at all (Table 24). Fourteen units (64%) discussed all

[3] One further unit answered 'yes' to this question, but went on to explain that there was no specific MDT, but there were joint clinics for pituitary tumours and base of skull.

cases post-operatively, and the remainder discussed some post-operatively. Membership of the MDTs is detailed in Figure 20. The psychological / psychiatric professionals cited were a clinical psychiatrist, and neuropsychologist, another unit expected a neuropsychologist due to start September 2004.

Other disciplines specified were: radiotherapists; data clerk; and in the neurofibromatosis 2 MDT a clinical geneticist and ENT surgeon. Other MDTs are shown in Table 25.

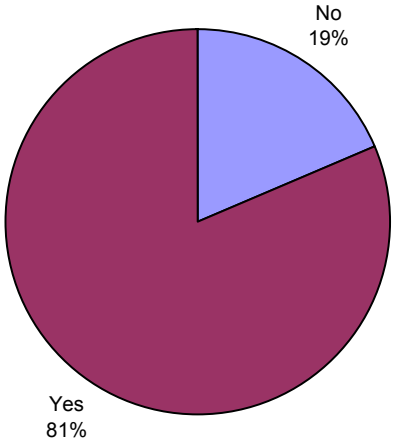


Figure 19 Presence or absence of MDTs

Table 24 Preoperative patients discussed at MDT

Type of preoperative cases discussed	N	%
All new patients referred	6	27.3
All patients in whom surgery is being considered	2	9.1
Most new patients referred	1	4.5
Complex or unusual cases preoperatively only	8	36.4
"Rarely" discuss preoperative cases	1	4.5
No cases preoperatively	2	9.1
Blank	2	9.1

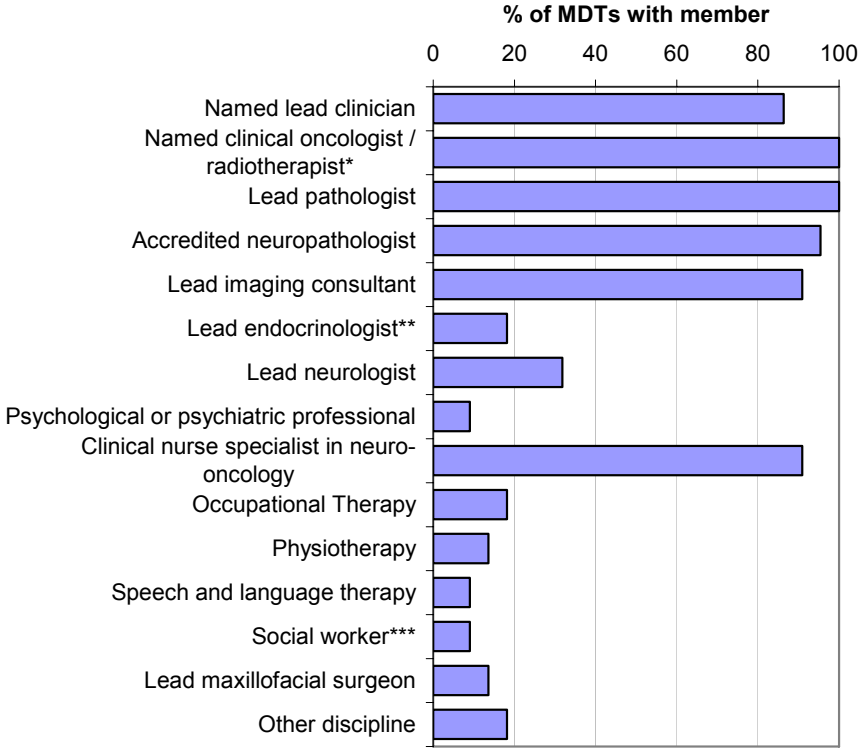


Figure 20 Membership of MDTs neurosurgical units.

*In one case does not attend due to workload. ** In two other cases endocrinologist attends separate pituitary MDT. ***Not funded. One unit specified that the focus of the MDT is around treatment plans, radiotherapy rather than operational care of the patient, and OT, physiotherapy etc. are intimately involved in the care of the patients.

Table 25 Other MDTs associated with neurosurgical units

MDT	N	%
Pituitary	13	48.1
Base of skull	7	25.9
Spine	2	7.4
Head and neck	1	3.7
Acoustic neuroma	1	3.7
NF 2	1	3.7
Paediatric oncology	1	3.7
Vascular (informal)	1	3.7
Any other MDT	16	59.3

Other forms of multidisciplinary working

Of the five units with no defined multidisciplinary teams for brain / CNS tumours each described some form of multidisciplinary (MD) working. One unit had joint radiology meetings including radiology, neurosurgery, neuro-oncology, and neurology monthly, as well as close links with neuro-oncology. Another described separate neuropathology and neuroradiology meetings for the two teams (of 3) who handle most brain tumour patients. One had a pituitary MDT, and the remaining two had specific combined clinics (pituitary/skull base in one; neuro-oncology, pituitary and meningioma in the other).

A further two units also described other joint meetings: a combined neurology / neurosurgery / neuroradiology review, and a monthly pituitary surgical meeting.
Details regarding eleven units with joint / special clinics are given in Table 26.

Table 26 Joint clinics / other relevant clinics specified associated with neurosurgical unit.

Joint clinic	Other disciplines involved	N	%
Neuro-onoclogy	Oncologists / specialist nurses / neurologists	6	22.2
Pituitary	Endocrinologist	5	18.5
Skull base	ENT/radiotherapist	3	11.1
Acoustic	ENT	1	3.7
Paediatirc	Paediatric onoclogy	1	3.7
Other clinics specified			
Neuro-oncology nurse specialist & epilepsy nurse specialist			
Nurse led low grade glioma			
Tumour clinic with liaison nurse			
Meningioma clinic			

Combined ward rounds and cancer network CNS tumour group meetings were also specified as methods of MD working.

Related services

Details of related services are given in Figure 21. The two other services specified giving added value are a counselling service, and a CNSNO

allowing for follow-up support care at home. Nine units (33%) had neither a palliative care consultant nor a palliative care nurse on-site.

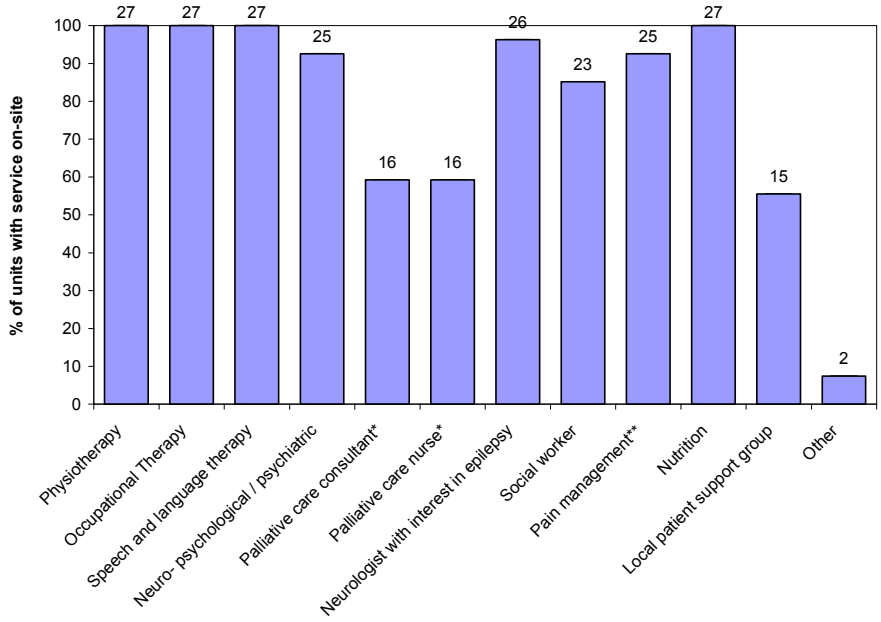


Figure 21 Percentage (number) of units with various services on-site.

*In one unit specified that both of these are available as part of palliative care service. ** V limited in one unit.

Neuropsychological / neuropsychiatric services available

Twenty-five units stated they have neuropsychological / neuropsychiatric services on-site. When asked to specify neuropsychological / neuropsychiatric services available six units stated 'both'; three units stated neuropsychological one unit stated diagnostic psychological only, and one unit said a complete service including use of behavioural medicine department.

Other facilities

Twenty-six (96%) units said they have access to a specialist neurorehabilitation unit, although in one case they said there was insufficient staff/beds. Seven units have access to videoconferencing facilities (26%) (Figure 22). One of these units said they find it very useful, another said it was newly installed. Seven of the units without videoconferencing thought they would benefit from it. In contrast to radiotherapy units, it is the larger neurosurgical units that tend to have access to videoconferencing.

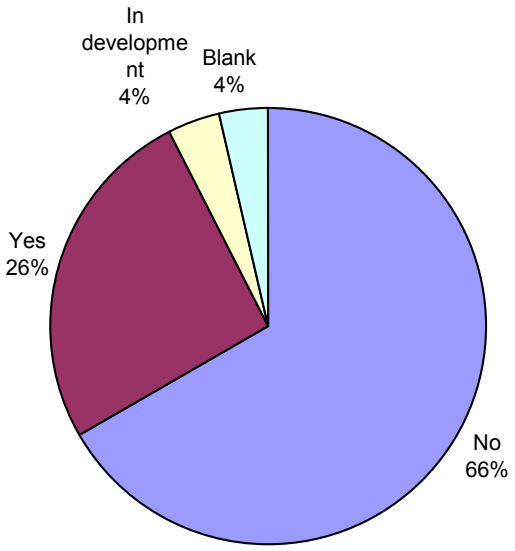


Figure 22 Access to videoconferencing (neurosurgery units).

Table 27 Access to CT, MRI, PET and SPECT together with routine outpatient waiting times.

	Access		Waiting time for routine OPD appointment				
	n	%	Mean (days)	Median (days)	Minimum	Maximum	Units included
CT	27	100.0	37.1	21	Nil*	4-5 months	14
MRI	27	100.0	221.8	210	Nil*	18 months	17
PET	9	33.3	4 weeks (only answer given)				1
SPECT	18	66.7	40.3	24	Nil*	3 months	6

* Nil / as requested. Ambiguous answers / those that explicitly did not apply to tumours excluded.

Access and waiting times for diagnostic imaging are shown in Table 27. It should be noted that interpretation of routine outpatient appointment may have varied between units. Two units stated they did not have access to conventional image guided surgery. Other facilities specified were stereotactic radiosurgery and functional MR. Access to other facilities is shown in Table 28.

Table 28 Access to other facilities in neurosurgical units.

	n	%
Frameless stereotaxy	22	81.5
Computer access to histopathology	17	63.0
Molecular histopathology	13	48.1
Intra-operative histopathology	25	92.6
24 hour intra-operative histopathology	15	55.6
Other	2	7.4

Protocols

The most common protocols available are those for pituitary tumours, 13 of the 27 units (Figure 23). No unit stated it had protocols other than those asked about. Seven units had no relevant protocols, although one of these said that protocols were being finalised with the cancer network but did not specify which protocols.

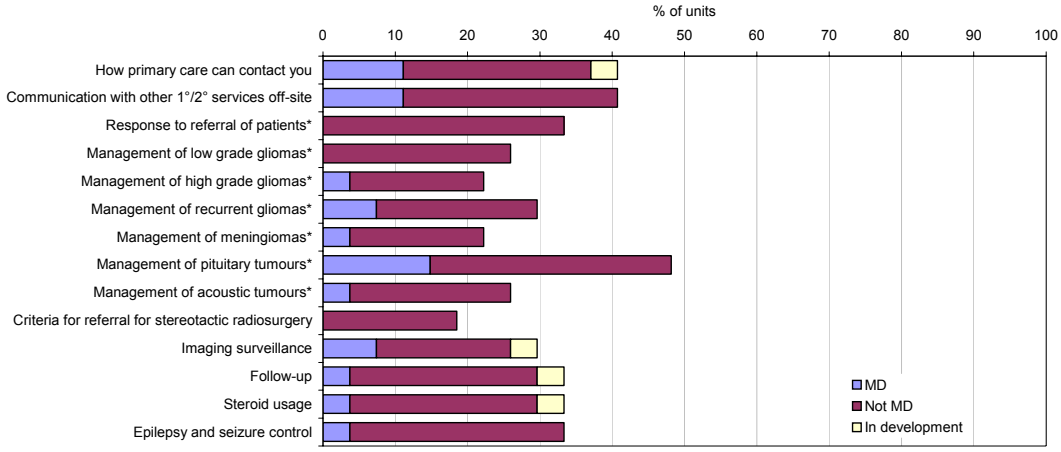


Figure 23 Presence of protocols in neurosurgical units and whether they are multidisciplinary (MD).

* One other unit stated: "No sheet of paper but all go into MDT / trial protocols"

Referral patterns and follow-up

In nine units patients were usually referred for radiotherapy on-site, and in eleven units they are usually referred to a single local regional centre (Table 29). In one unit patients are referred back to the referring hospital for radiotherapy, and it is the referring hospital that usually follows patients up after surgery. Follow-up patterns are shown below (Table 30).

Table 29 Where patients are usually referred for radiotherapy

	N	%
On site	6	22.2
On site + local regional centre	1	3.7
On site/ one of a number of surrounding hospitals	2	7.4
One of a number of surrounding hospitals	6	22.2
Referring hospital	1	3.7
Single local regional centre	9	33.3
Single local regional centre or convenient local facility for patient	1	3.7
Single local regional centre or one other centre	1	3.7

Table 30 Who normally follows up patients after surgery

	N	%
Designated oncologist	6	22.2
Designated oncologist & Referral back to referring clinician	1	3.7
Designated oncologist & neurourgeon	1	3.7
Specialist clinic in neurosurgical dept	5	18.5
Specialist clinic in neurosurgical dept + designated oncologist	1	3.7
Specialist clinic in neurosurgical dept with oncology	1	3.7
Joint clinics with designated oncologists	1	3.7
Oncologist close to patients residence	5	18.5
Oncologist close to patients residence & neurosurgical clinic	2	7.4
Oncologist close to patients residence / designated oncologist & neurosurgical clinic	1	3.7
Referring clinician	2	7.4
All apply depending on tumour type and local pt services	1	3.7

Stereotactic radiosurgery

Twenty-one of the 27 units (including Sheffield) refer patients for stereotactic radiosurgery to Sheffield Teaching Hospitals NHS Trust. Three units refer to Barts and the London NHS Trust, two refer to the Royal Marsden NHS Trust, and one to the Royal Free Hampstead NHS Trust. Four other sites apart from those mentioned above undertake stereotactic radiosurgery locally.

When asked how many patients are referred for stereotactic radiosurgery from the department per year answers ranged from ~5 to 100 (3 were left blank; mean 24; median 15).

Routine collection of outcome data

Mortality post surgery/biopsy is the most widely collected routine outcome data in neurosurgical units with 23 collecting such data, in a further unit an individual collects personal data for this (Figure 24). One unit said it also collects transfer / waiting times. One unit commented on the lack of resources to collect such data.

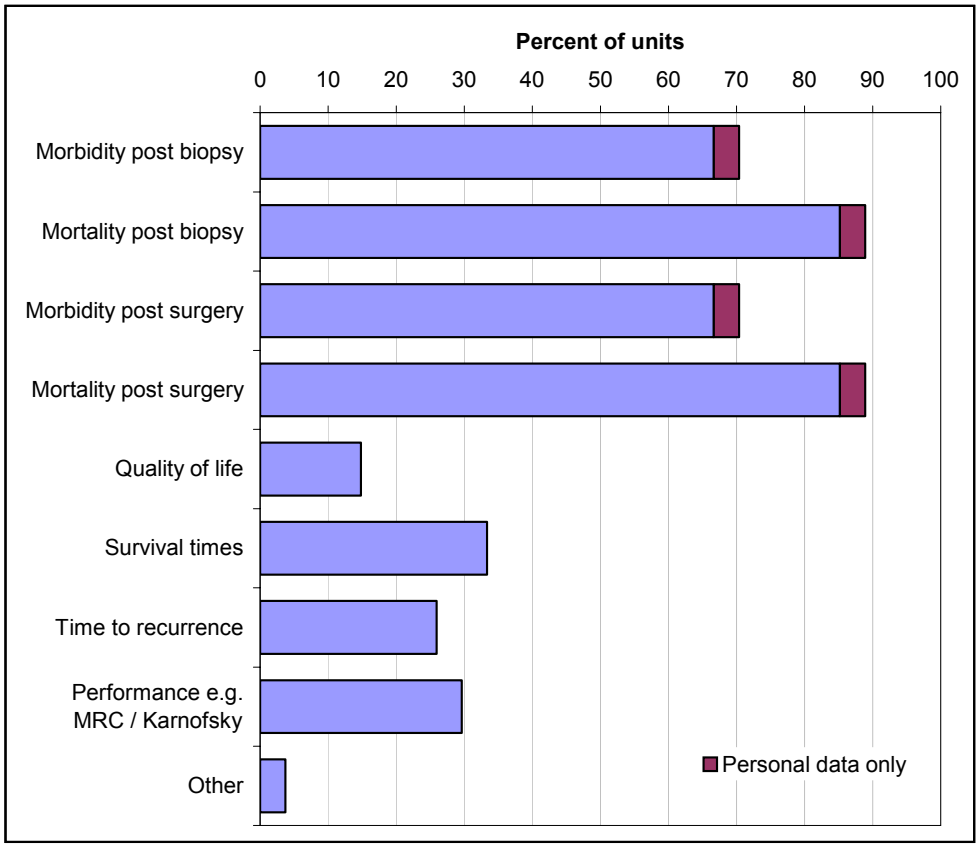


Figure 24 Routine collection of outcome data in neurosurgery units.

Clinical Trials

Twelve of the 27 units said they recruited no patients to clinical trials in the previous year, and a further 6 units left the space for a number blank (Table 31). The most common reasons cited for lack of recruitment were no suitable trial available, and patient did not wish to participate (Table 32).

Table 31 Number of patients recruited to clinical trials in the previous year.

Number recruited	N	%	Cumulative %
Blank	6	22.2	22.2
0	12	44.4	66.7
1-4	3	11.1	77.8
5-9	3	11.1	88.9
20	1	3.7	92.6
70	1	3.7	96.3
Unknown	1	3.7	100.0

Table 32 Reason given as most significant for lack of recruitment in clinical trials.

	N	%
No suitable trial available	9	33.3
No suitable trial available + lack of resources	2	7.4
Lack of resources	6	22.2
Eligibility criteria not appropriate	4	14.8
Patient did not wish to participate	1	3.7
Blank	5	18.5

Other comments

Resources

- Neurosurgery department grossly undermanned at consultant level, no signs of improvement. **Infrastructure (intensive care, junior staff, consultant staff, beds) inadequate**. Any improvements (e.g. MDT meetings) totally dependent on additional consultants.

- The greatest problem we have other than the huge international problem of trying to effectively treat and 'cure' malignant brain tumours is **clerical / logistic support**. Even a form like this is taxing for us! Large increases in the clinicians caring for these patients are not the answer. Any increase must be supported with **practical, constructive, active administrative support** to make use of clinicians' time and skills more fully.

- We would like financial assistance to re-start the **data collection activity** which we set up several years ago, and the Trust would not fund its continuation (£6-7,000 p.a. for part time data assistant).

Networks

- CNS Tumour Group for Cancer network has had two meetings.

- Regional network in development

Other

- We would like assistance with development of guidelines/protocols for the management of gliomas.

- Demographics are in a fluid state, and likely to increase significantly in the next year or two.

- Separate spinal unit deals with extradural spinal metastases.

Summary – Neurosurgical units questionnaire

All adult neurosurgical units responded to this questionnaire. Neurosurgical units are less diverse in size than oncology units and most are located in University or teaching hospitals.

It was difficult for units to supply information on the total number of patients seen by the unit, due to data collection problems. Although the catchment population varies 3.5-fold, the number of brain / CNS tumour patients seen in a year varies 10-fold, and this variation does not relate well to the estimated catchment population. The variation in total procedures for brain / CNS tumours is 21-fold, and the variation for open procedures is 25-fold. Low numbers (<10) of procedures performed per year for some of the rarer tumour types are evident in a number of centres (e.g. spinal / acoustic).

There is evidence of some degree of specialisation in tumour work in almost all units[4], but this is most evident in pituitary / craniopharyngeal surgery and acoustic/skull base surgery, and much less evident for brain/CNS tumour work in general. Most units (81%) had a clinical nurse specialist in neuro-oncology although smaller units were less likely to have one.

Most units (80%) have defined MDTs, predominately comprised of neurosurgeon, clinical oncologist, pathologist, imaging consultant and CNSNO. Professions allied to health are not usually involved in these team meetings. More than half of units have other MDTs e.g. pituitary / base of skull. Joint clinics are common either with oncology or with ENT surgeons. Many of the professions allied to health are available on site, and only two neurosurgical units did not have neuro-psychological / neuropsychiatric services available on-site. However, one third of units had neither a palliative care consultant nor a palliative care nurse available on-site.

There is good access to specialist neurorehabilitation units from the neurosurgical units. Access to videoconferencing is low (26% of units). Only one third of units said they had access to PET, and two units said they did not have access to conventional image guided surgery. Twenty-six percent of units had no relevant protocols, and protocols regarding management of pituitary tumours were the most common (48%).

There are varying patterns for onward referral of patients, but the tendency to refer back to the referring clinician in the referring hospital after surgery was evident in at least one unit. Eight units were cited as undertaking stereotactic radiosurgery. A large number of units collected data relating to mortality (85% of units), and to a lesser extent morbidity (67% of units), however few collected quality of life or performance score measures. A large proportion of units had not recruited any patients to clinical trials in the previous year. The most common reasons cited were lack of available trials and lack of resources to manage patients in the trial setting.

Conclusions – Neurosurgical units

Although neurosurgical units appear to be a less heterogeneous group than radiotherapy units with regard to catchment populations there is substantial diversity in the numbers of patients seen and procedures undertaken for those with tumours of the brain and CNS. Data collection appeared to be a problem in many units, although a large proportion collect data on mortality and/or morbidity following surgery. There is evidence of good examples of multidisciplinary working with many services having joint clinics, and most units having defined multidisciplinary teams, although palliative care and professions allied to health tend to be poorly represented on these teams. There is evidence that cancer networks are in the early stages of addressing brain and CNS tumours.

[4] One unit did not respond to this section.

5.2.2 Radiotherapy unit questionnaire results

Of the 52 radiotherapy centres in England and Wales responses were received from 48, giving an overall response rate of 92%. The non-responders were from 4 different cancer networks (Central South Coast; Devon and Cornwall; Dorset and Arden), see Appendix I.

Three units did not undertake brain / CNS work (all patients in their catchment areas are seen in units that have responded to the survey). Forty-five units' responses are included in the analysis. One unit (32) only undertakes palliative treatment.

Ten of the 45 units treated children as well as adults; two adult units had specific exceptions to their adult only rule. Due to the large number of units, an analysis of the effect of unit size is also shown.

Location of units

Forty-two percent of units said they were in a university or teaching hospital (Figure 25).

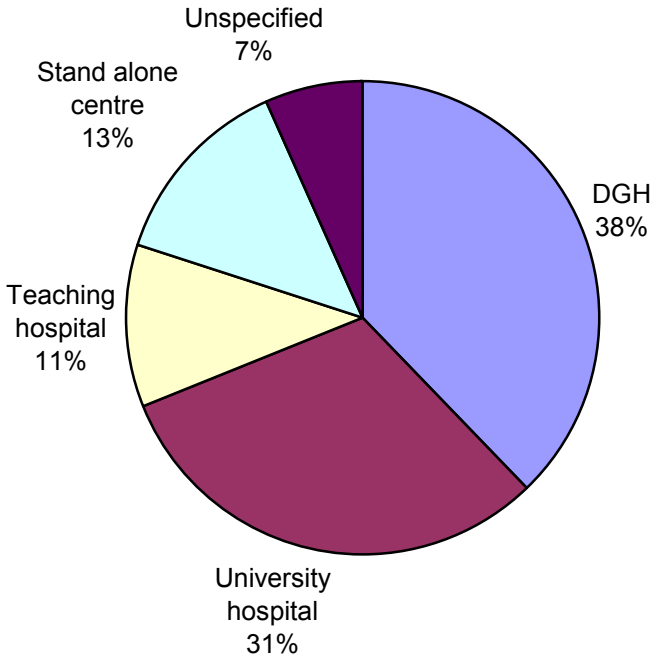


Figure 25 Location of units / hospital type (n=45).

Size of units

Estimated catchment population for neuro-oncology ranged from 250,000 to 3,200,000 (Table 33; median 1,050,000; mean 1,360,000). Methods of deriving these numbers were various (e.g. geographical boundaries / network data). In 2 units a specific study (Brian Cottier study) was cited. Number of beds in the unit ranged from 6 to 120 (Table 34; median 34, mean 41).

It was evident that referral patterns may be complex, e.g. unit 5 unsure of its neuro-oncology catchment population as referrals depended on neurosurgical units, and so were much smaller than standard oncology catchment.

Table 33 Neuro-oncology catchment populations

Catchment population	N	%
up to 500,000	6	14.6
>500,000 to 1,000,000	14	34.1
>1,000,000 to 1,500,000	7	17.1
>1,500,000	14	34.1
Total	41	100.0

No data for 4 units

Table 34 Number of beds in unit

Bed no.	N	%
<20	6	13.3
20-39	19	42.2
40-59	12	26.7
60-79	3	6.7
80+	5	11.1
Total	45	100.0

Number of patients seen in units

The number of new patients (all types) seen in a year ranged from 707 to 10,975 (Table 35, median 2700; mean 3385). The number of CNS tumour patients seen in a year varied from 17 to 350. (Table 36, median 70, mean 108 after exclusion of answers that include metastases). The relationship with self reported catchment area is shown (Figure 26). The range of glioma patients was from 5 to 180 (Table 37; median 50, mean 70 after removal of ambiguous answers). There was an average of 82 new brain /CNS tumour patients per 1,000 catchment population for those units supplying information on both.

Table 35 Number of new patients (all types) seen by department in a year.

New pt seen/year	N	%
<1000	1	2.3
1000-1999	9	20.5
2000-2999	15	34.1
3000-3999	7	15.9
4000-4999	4	9.1
5000-5999	2	4.5
6000+	6	13.6
Total	44	100.0

Table 36 Number of new patients with brain / CNS tumours seen by department in a year

CNS tumour pt / year	N	%
<50	12	30.8
50-99	10	25.6
100-149	6	15.4
150-199	3	7.7
200-249	4	10.3
250-299	3	7.7
300+	1	2.6
Total	39	100.0

Table 37 Number of glioma patients seen by department in a year.

Glioma pt / year	N	%
<25	5	12.8
25-49	13	33.3
50-74	6	15.4
75-99	3	7.7
100-124	4	10.3
125-149	5	12.8
150-174	2	5.1
175+	1	2.6
Total	39	100.0

Finished consultant episodes (FCEs) are poor indicators of activity for neuro-oncology, very few units could provide separate FCEs for neuro-oncology, and these ranged from 10 to 1173 in a year.

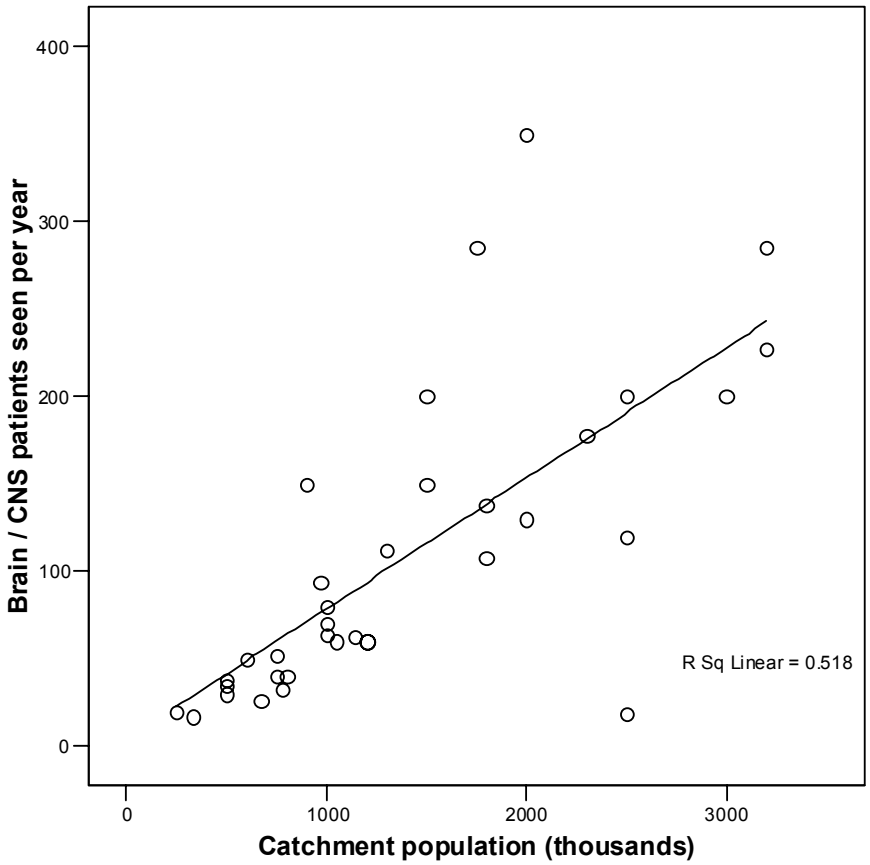


Figure 26 Scattergram of number of brain / CNS patients seen per year against catchment population for neuro-oncology.

Interventions for brain / CNS tumours

Units were asked about the proportion of glioma patients that receive chemotherapy. The responses ranged widely from 1 out of 52 (2%) recorded to 60-70% over the course of illness. (median 15%; mean 25%). In a few centres the results were based on audit and these ranged from 30 to 60%. The highest proportions cited were in upper-mid range of catchment size units (Appendix J).

Units were asked the proportion of glioma patients that receive radiotherapy. The responses ranged from 44% (30/68 with the comment “seems a bit low to me”) to >90% (median 70%; mean 73%). There was a slight tendency for the higher proportions to be among the larger units (Appendix J).

Wide variation was evident in reported waiting times for different interventions for neuro-oncology (Table 38); the length of wait did not correlate with the size of unit in any systematic fashion (Appendix J).

Table 38 Reported waiting times for interventions, radiotherapy units.

	Radiotherapy		Chemotherapy	
	Radical	Palliative	Inpatient	Outpatient
Mean (days)	35.7	17.0	10.4	9.6
Median (days)	32	14	10	8
Minimum	< 1 week	<1 week	nil	nil
Maximum	8-12 weeks	6 weeks	3-4 weeks	37 days
No. of responses included	39	41	27	41

Staffing and specialisation

Consultants

Whole time equivalent (WTE) consultant staff varied from 1.6 to 20.7, with a mean of 8.2 WTE per unit (median 6.3). The relationship with catchment population is shown (Figure 27). In all but one unit (98%) a degree of specialisation in brain / CNS work was evident, 30 of the 45 units had one consultant specialising [other non-specialising consultants may also deal with these tumours].

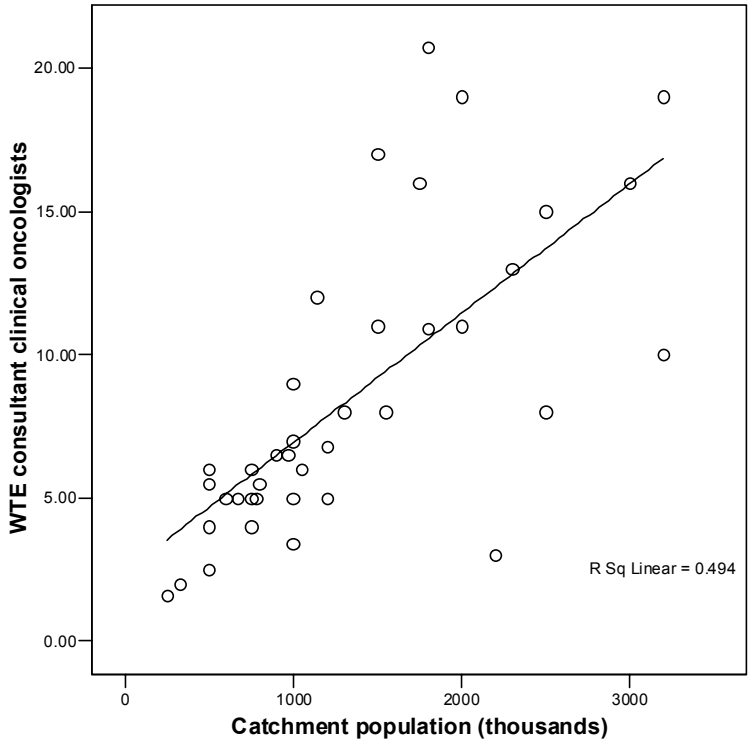


Figure 27 Scattergram of WTE consultant clinical oncologists against catchment population for neuro-oncology.

Clinical Nurse Specialists in neuro-oncology

Twenty (56%) of the units responded that they had some input from a clinical nurse specialist in neuro-oncology (CNSNO). It is likely that many CNSNOs care for patients across both surgical and non-surgical services; in two of these units the CNSNO undertook “surgical” work only. In only one unit was there more than one CNSNO who was not classed as undertaking “surgical” work only. Units that had a CNSNO were larger than those that did not (Appendix J, p =0.001).

Multidisciplinary teams (MDT)

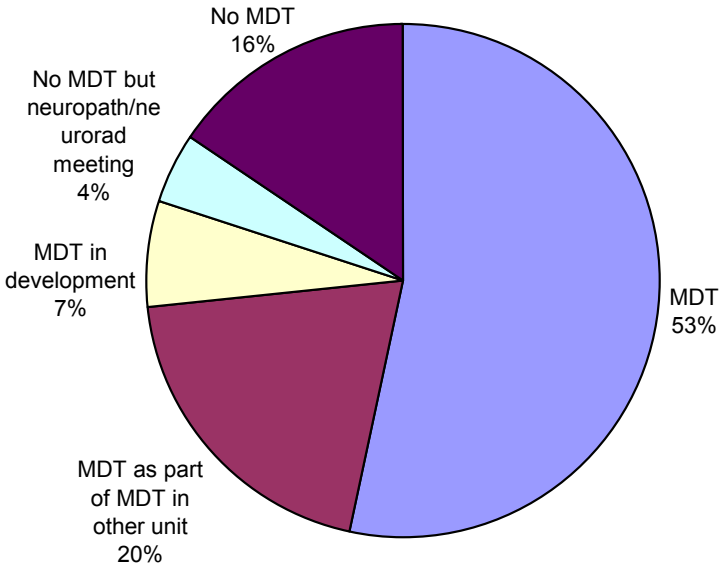


Figure 28 Presence or absence of MDT (n = 45; one of the "No MDT" units may feed into another unit's MDT).

The proportion of units with/without MDTs is shown in Figure 28. Smaller units were more likely either not to have an MDT, or to partake in the MDT of a larger unit (Appendix J).

Units with no MDTs

Nine units[5] (20%) had no defined MDT for brain / CNS tumours; five (11%) of these described no other forms of multidisciplinary working (7, 24•, 2, 38•, 5). The other four described the following:

- May feed into neuropathology meeting at unit 37, but does not attend (unit 28), also has joint monthly clinics.
- Weekly neuroradiology conference; monthly neuropathology meeting (unit 41).
- Weekly meeting with neurologist and radiologist (unit 22).
- Plans for a weekly neurosurgical clinic adjacent the oncology clinic to allow joint discussions (unit 40).
- Patients are referred after clinical / radiological diagnosis to a regional unit (with MDT), and referred back for radiotherapy (unit 11).

Units with MDTs in development

Three units (7%) said that MDTs were under development. One of these (23) planed to do this through a video link with another unit (45).

[5] One other unit said it has no defined team, but holds regular multidisciplinary meetings, this unit has been counted among those units with a multidisciplinary team.

• Unit 27 said they may discuss patients from unit 38 at their MDT, and surrounding region, e.g. unit 24.

Units where the MDT was as part of MDT in larger unit

Nine other units described participating in the MDT associated with a larger unit.

These links are:
With videoconferencing:

- Units 9, 19 and 30 participated in the MDT of unit 15 by videoconference "with their oncologists/radiologists/nurses". Some of the patients from unit 19 were treated by neurosurgeons related to unit 35, and unit 19 had no input into the MDT related to unit 35.

Without videoconferencing:

- Patients from units 3 and 18 were discussed at unit 10. Handwritten MDT conclusions were meant to be faxed by the SHO with the referral letter. There were plans to set up videoconferencing between these sites.

- Patients from unit 16 & 17 were discussed in the MDT of unit 33, conclusions were e-mailed to the oncologist.

- Patients from unit 32 were discussed in the MDT of unit 27, and conclusions were sent via an MDT form to the relevant oncologist in unit 32 (who did not attend).

- Patients from unit 14 were discussed in the MDT of a unit that did not respond to the questionnaire. As the oncologist from unit 14 had never attended they could not provide details.

Two of these units also had local teams / expert groups these consisted of

- Clinical oncologist, support specialist, palliative care consultant (unit 17).

- Neuro clinical oncologist, all 3 neurologists, neuroradiologist & others with an interest (unit 3).

Other unit MDTs

The remaining twenty-four units described MDTs, and their responses are detailed below (one of those described stated they had no defined MDT, but did have multidisciplinary meetings; one said the MDT was in the context of a neuropathology meeting).

In 71% of these units (17) the MDT met weekly, in 21% (5) fortnightly, and in 8% (2) monthly. The typical number of cases discussed varied from 5 to 28-35 (mean 12, median 10). Forty-two percent of units (10) said that preoperative cases were routinely discussed at the MDT meetings. Nineteen (79%) discussed all or most new patients referred (Table 39). Twenty-two MDTs

(92%) had a named lead clinician. Other details are shown below (Figure 29; Table 40).

Table 39 Which patients are discussed at MDT meeting.

Patients discussed at MDT meeting	N	%
All new patients referred	10	43.5
All post-op patients referred	1	4.3
All for stereotactic radiotherapy	1	4.3
All new / most patients referred	2	8.7
Most patients referred	7	30.4
Some / occasional patients referred	1	4.3
Occasional cases only	1	4.3

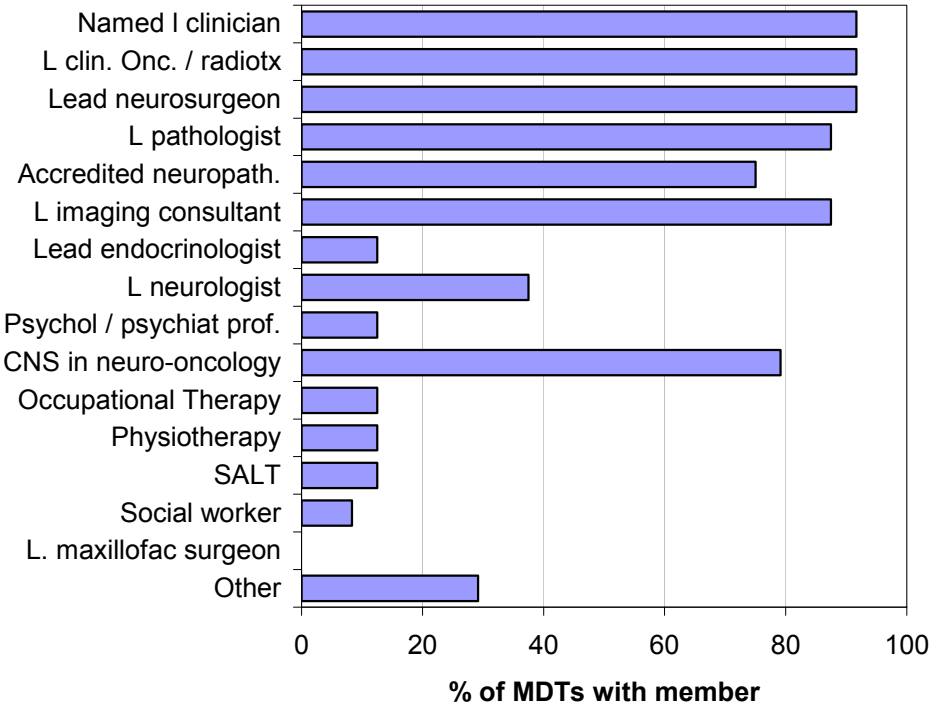


Figure 29 Membership of MDT (24 MDTs included; L = lead; SALT = Speech & Language Therapy; CNS = clinical nurse specialist).

Table 40 Other disciplines specified as members of MDT

Palliative care nurses; Community Macmillan nurses
Ward nurses, other specialist nurses, trainees, MDT Coordinator
Medical Oncology x 2
Neurosurgical specialist nurse
Specialist Radiographer - neuro-oncology(therapy)
Research staff (laboratory and trial based)
Paediatric oncology + paediatric neurosurgery

Other multidisciplinary teams

Separate pituitary / endocrine MDTs were present in sixteen of the 45 units (36%); one unit was planning for such an MDT; one had access to such an

MDT in another centre; and as well as this MDT one also had a pituitary radiotherapy MDT meeting.
One unit had a spinal MDT, one a skull base MDT and late effect MDT, one a stereotactic radiosurgery MDT, and three units had relevant MDTs for paediatric patients.

Other important forms of multidisciplinary working

Twenty-eight units described other forms of multidisciplinary working. Joint clinics were described by 25 units (56%), with a further three (7%) in the process of setting up / planning to set up such clinics, usually with neurosurgery. A surgical base of skull clinic was cited by one unit including ear nose & throat /maxillofacial surgeons.

Some other form of multidisciplinary team was described by 5 units, e.g. a local expert group, or meeting with professions allied to medicine / social worker / community liaison nurse. Close working with other professionals was cited including with neuro-radiology in another unit, neurologist for epilepsy control, and therapeutic (/MacMillan) radiographers.

Other Services

Many disciplines were well represented on-site in radiotherapy units (see Figure 30). All units had palliative care on-site (the one unit without a palliative care nurse had a palliative care consultant). Just under half of units (47%) had neuropsychological / neuropsychiatric services on-site (Table 41), and a third had local patient support groups.

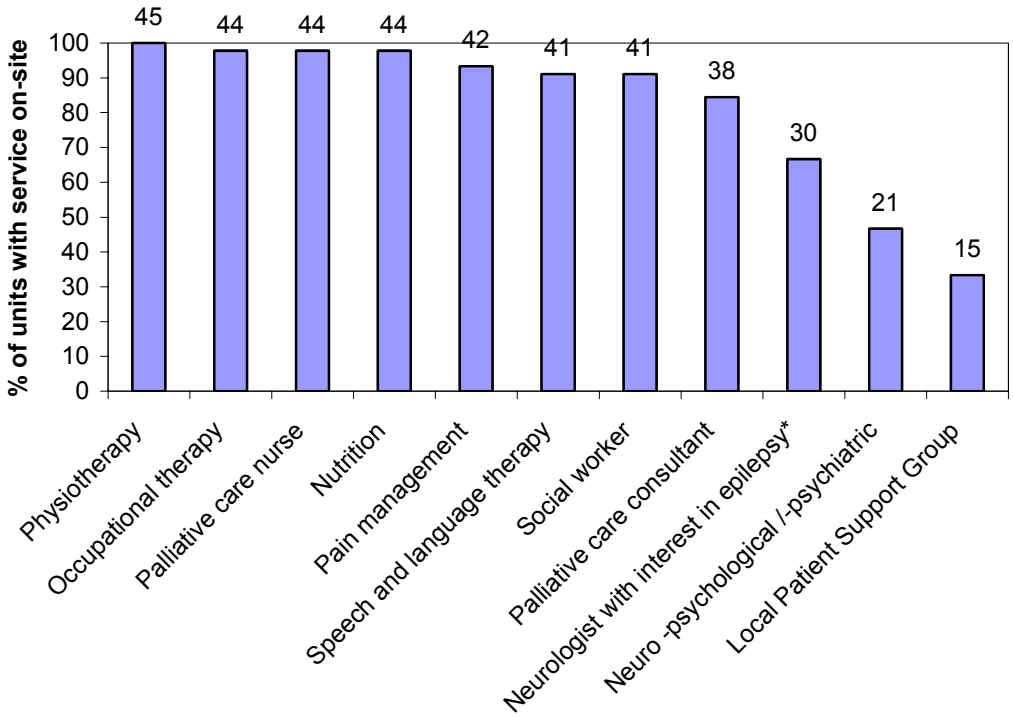


Figure 30 Percent (number) of radiotherapy units with various services on-site.
* Two other units had access ("visiting"/"200 yards away"); one other "general neurologist on site".

Table 41 Neuropsychological / neuropsychiatric services specified.

Neuropsychological / neuropsychiatric services specified
Liaison psychiatrist Liaison psychiatrist via palliative care charity (Tenovus) Neuropsychologist Both neuropsychology & neuropsychiatric Specialist unit in mental health 2 x neuropsychologist (1 adult, 1 paediatric) Consultant available for referrals
Other comments where neuropsychological / psychiatric service not available on-site:
Available by referral offsite: 2 clinical psychologists, one with a specific interest in brain / CNS tumour patients Oncology health centre (psychology)

Other services listed included community (home) chemotherapy service; complementary therapist; and MacMillan support centre.

For most services there was no evidence that smaller units were less likely to have these services on-site. The unit without OT on-site was quite a large unit (catchment population 2 million). Larger units were more likely to have palliative care consultants on-site and SALT on-site, although this was not statistically significant (see Appendix J).

Other facilities

Sixty percent (27) of radiotherapy units had access to a specialist neuro-rehabilitation unit; larger units were not more likely to have access than smaller units (Appendix J).

Fourteen units had access to videoconferencing (Figure 31), and of these eleven (79%) found it useful, one said it would probably be useful, and one said it wasn't useful. Of the remaining 31 units 13 (42%) said that they thought they would find videoconferencing useful.

There was a non-significant tendency for units with access to videoconferencing to be smaller than those without (Appendix J); this may relate to the greater need to share expertise.

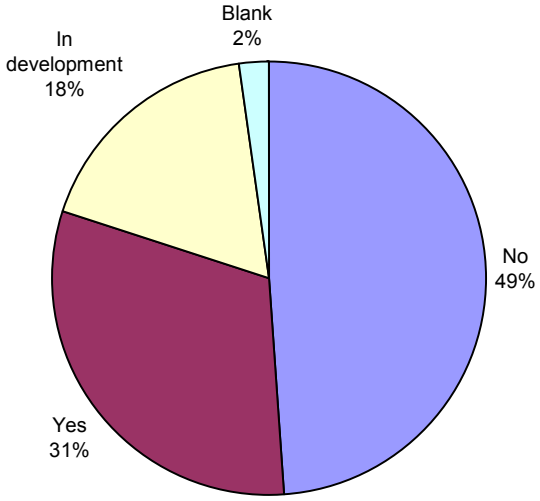


Figure 31 Access to videoconferencing (radiotherapy units).

Table 42 Access to CT, MRI, PET and SPECT in radiotherapy departments and reported routine OPD waiting times.

	Access		Typical waiting time for routine OPD appt			
	n	%	Mean (days)	Median (days)	Minimum	Maximum
CT	45	100.0	22.7	14	0	3-4 months
MRI	45	100.0	47.3	28	0	13-14 months
PET	21	46.7	29.5	28	0	2 months
SPECT	17	37.8	20.3	10	<1 week	2 months

Twenty-five (56%) of the radiotherapy units had computer access to histopathology reports (neurosurgery is often on a different site). Fourteen (31%) said they had access to molecular analysis to supplement histopathological diagnosis (e.g. 1p19q status for oligodendroglioma), one unit said this was ‘a real lack’, and routine cases took ‘ages’ while there was no service for urgent cases. Only three units identified a waiting time for molecular analysis (‘routine OPD’), varying between 3 weeks and 2-3 months. Other facilities identified included PACS (picture archiving and communication system), stereotactic radiosurgery, and stereotactic planning / dedicated open MRI for planning / research.

Reported access and waiting times for diagnostic imaging are shown (Table 42); responders may have interpreted “routine OPD appointment” differently.

Protocols

Management of specific tumour types were the most common protocols in the units (Figure 32), with 37 (82%) units having protocols for management of high-grade gliomas. Just over a quarter of units (12) had protocols for how primary care can contact the unit. The minority were multidisciplinary (MD). Other protocols are shown below (Table 43).

Table 43 Other protocols specified

Advice on how patients contact us, & on how other drs in 2º care contact us (MD)
CNS lymphoma
Guidelines for stereotectic treatment
Palliative brain
Radiotherapy for CNS tumours (2 units)
Various research trial
One unit unspecified

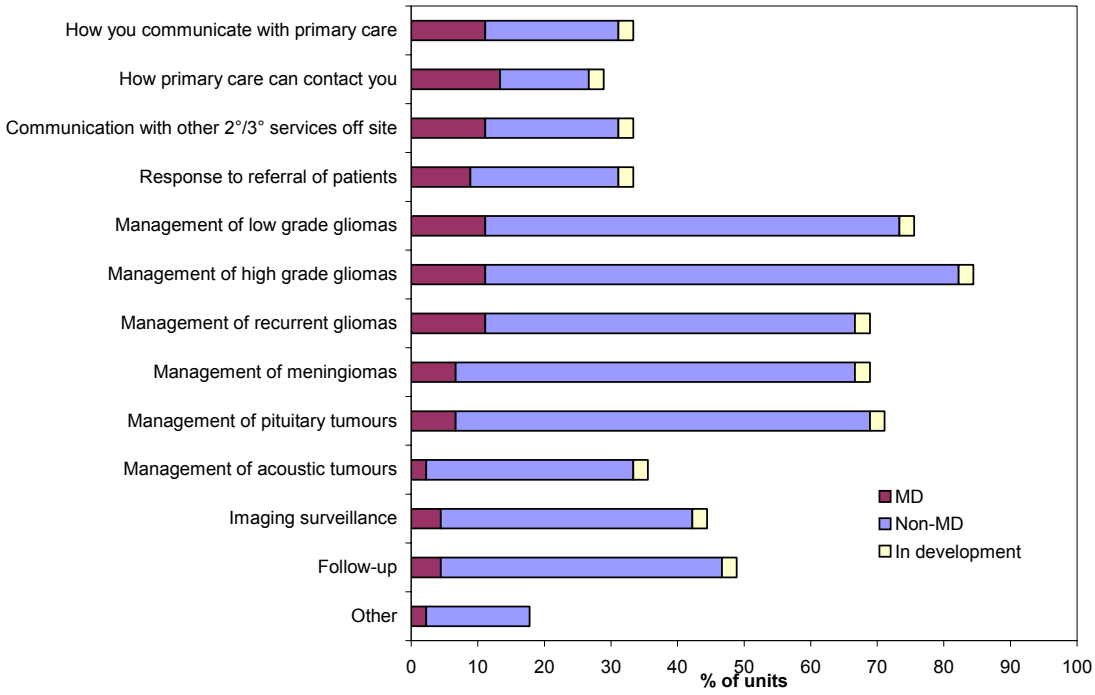


Figure 32 Presence of protocols in unit and whether they are multidisciplinary (MD).

Routine collection of outcome data

Less than half of units (19) collected, or were developing collection of any routine outcome data. The most commonly collected outcome data is survival (17 units; Figure 33). Other data cited as routinely collected includes 'date of death'; audit data; endocrine – hearing; treatment parameters, and one unit said they collected radiotherapy & chemotherapy dose, treatment of relapse, surgeon, procedure, and performance status at decision to treat.

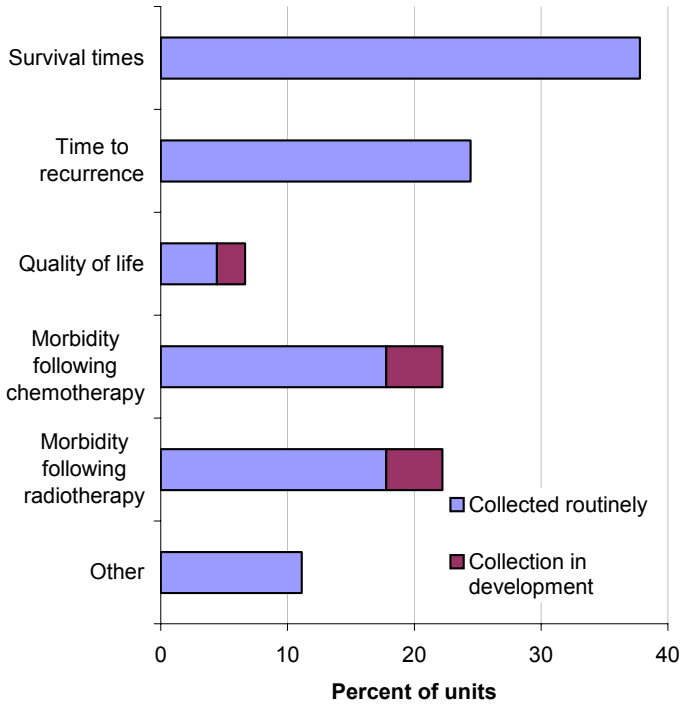


Figure 33 Routine collection of outcome data in radiotherapy units.

Clinical trials

Almost half of radiotherapy centres said their service had not recruited any patients for clinical trials in the previous year. Details are given in Table 44. Twenty-three units gave "no suitable trial" as the most significant reason for lack of recruitment and a further four units cited this as well as other reasons (Figure 34). The next most commonly cited reason was a lack of resources to manage patients in the trial setting. The other reason cited for lack of recruitment was not getting the trial through the LREC as yet.

Table 44 Recruitment to clinical trials by service in last year

Number of patients recruited within last year	Number of units	Percent of units	Cumulative % of units
Blank	4	8.9	8.9
0	22	48.9	57.8
1-5	13	28.9	86.7
20	1	2.2	88.9
40 ("studies")	1	2.2	91.1
50	1	2.2	93.3
80	1	2.2	95.6
90	1	2.2	97.8
586 (all tumour types)	1	2.2	100
Total	45	100.0	

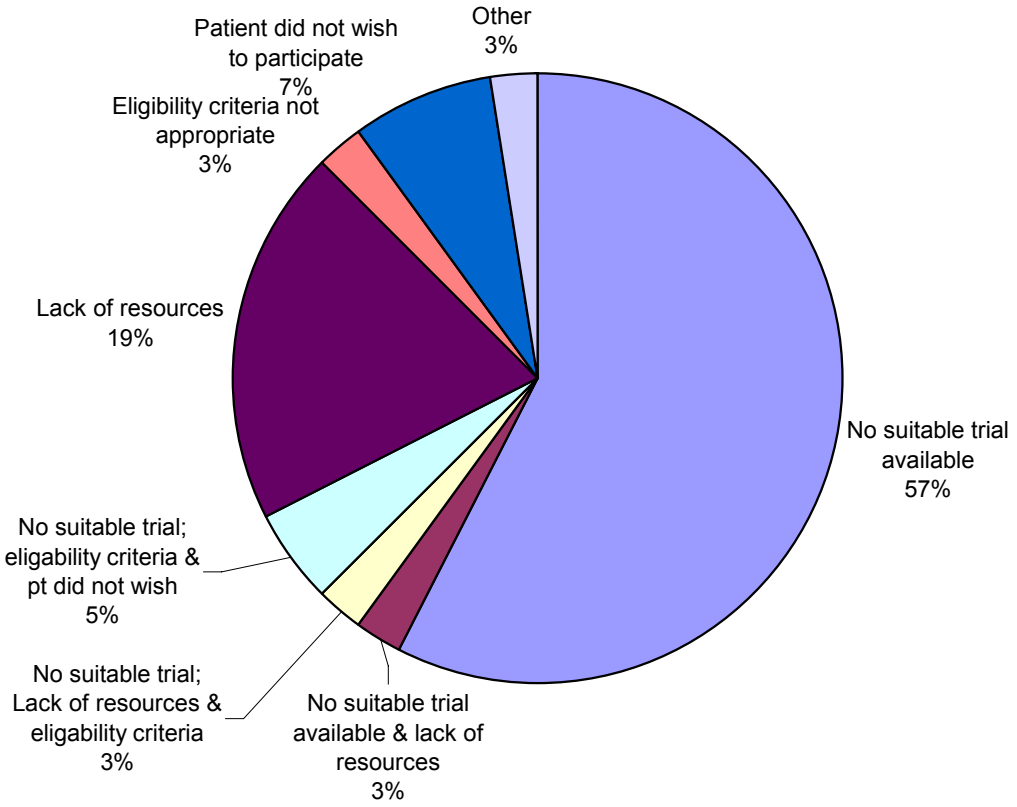


Figure 34 Most significant reason for lack of recruitment where patients may have been suitable for a trial, but were not recruited.

[No reason given by 5 units]

Other comments

Most comments related to areas requiring more resources/investments.

Resources / areas suggested for investment

Unit 22

Most useful areas of further investment for us are:

- Faster **access to radiotherapy**
- **Nurse specialists**
- **Psychologists and rehab**
- Patient/carer **support groups**.

Unit 27

We need increased funding to:

- Improve patient **data collection**
- Enable us to undertake phase I-III **trials**; currently there are no research nurses.

Unit 43: Options for nursing care are very limited for disabled patients – they fall between acute hospital/hospice care & usually are not appropriate for non-specialist nursing homes. An **intermediate level of care with rehab/palliative** care input would be very useful.

Unit 30: "I find it difficult to get my **patients who recur** seen at **neurosurgical clinic** because surgeons are overstretched."

Unit 41: “We are very understaffed as regards **consultant oncologists**… We don’t have enough time for a neuro-oncology clinic yet”.
Unit 28: “we are very keen to develop these services and are aware of gaps which need to be plugged”.

Other comments

Other comments included a diagram of how units related within a cancer network (unit 16/17); chemotherapy was supplied by a neurosurgical colleague in unit 41 (see comment above). One respondent pointed out that the management of low/high grade gliomas was very different and probably needed different arrangements for follow-up. “Of course, the role of radiotherapy for Grade II gliomas is likely to change again in the next 1-2 years to be used in selected low grade gliomas”.

Summary – radiotherapy questionnaire

There has been a high response rate (92%), and forty-five units are included in this questionnaire analysis. Units varied widely in terms of size (estimated catchment population, and numbers of new patients seen). There was also wide variation relating to the proportion of gliomas to receive chemotherapy, and to a lesser extent radiotherapy. Many centres showed marked difficulty in getting meaningful information to answer questions such as this regarding practice in the department.

There was evidence of specialisation by oncologists in the field of neuro-oncology within all but one unit, and 56% of units had a clinical nurse specialist in neuro-oncology. There were examples of well functioning cross-site MDTs; in one case in particular videoconferencing is used between four sites, and they are working towards joint protocols across these units. Twenty percent of units have no MDT, but in some cases they did take part in multidisciplinary meetings e.g. neuropathology meeting. Few MDTs had members from allied health professions, although 80% had a clinical nurse specialist in neuro-oncology. Many (16) had separate endocrinology MDTs. Over half of units had joint outpatient clinics.

Although palliative care, OT and physiotherapy were well represented on-site in radiotherapy units, only 21 units had neuro-psychological / neuropsychiatric services on-site, and only 15 had a relevant local patient support group. Less than half of units routinely collected outcome data, survival being the most commonly collected, and quality of life the least commonly collected (2 units).

Conclusions for radiotherapy questionnaire

Radiotherapy units represented a broad spectrum from small units often located in district general hospitals to large stand-alone centres. Collection of data appeared generally low, with many units having to estimate the proportion of patients who receive specific treatments. Most units had access to a multidisciplinary team for their patients, but this is at different levels of development across the England and Wales. Over half of units had not entered any patients into clinical trials in the previous year. The reason most commonly cited for this was a lack of suitable trials, although a lack of resources was also cited by 30%. Suggestions were made regarding areas for suggested investment.

6 Conclusion

Tumours of the brain and CNS are rare and affect physical, psychological and cognitive function. Registration rates have been increasing in the elderly, which may be related to improved diagnosis. Survival rates for malignant brain tumours have not improved. Hospital activity is also increasing, but in a younger age group. Increasing hospital activity may relate, to some extent, to new technologies, e.g. stereotaxic ablation of tissue of brain. As the population profile changes the numbers of new cases of brain/CNS tumour is expected to rise.

There are deficiencies in national data available and there is evidence that these tumours are under registered. National registration codes do not conform to the internationally accepted WHO classification of Tumours of the Nervous System, and a substantial proportion of nationally registered brain tumours do not have a precise pathological coding. National survival data have focussed on malignant brain tumour, with little information available for other tumour types. Collection of data at trust level was often poor.

The route of care for patients may be complex; catchment areas for neurosurgical units and oncology units often did not coincide, and only ten of the neurosurgical catchment areas were contained within one cancer network area.

Units providing care are heterogeneous, varying not only in size, but also in access to services e.g. clinical nurse specialists in neuro-oncology, neuropsychiatric/ psychological services and palliative care. The number of multidisciplinary teams that meet regularly has been increasing. However, many patients did not have access to these teams. Clinical nurse specialists were available in many of the specialist units, and often provided a key-worker function. Some units have devised ways working across organisations, including the use of videoconferencing, and the establishment of local expert groups.

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8 Appendix A. ICD codes used to categorise brain and central nervous system tumours

ICD9 codes used for registrations 1991-1994 and mortality 1991-2000

	ICD9 code
Intracranial intra-axial	191 - Malignant neoplasm of brain 225.0 - Benign neoplasm of brain 239.6 – Neoplasm of unspecified nature, brain
Intracranial extra-axial: Intracranial meningeal	192.1 - Malignant neoplasm of cerebral meninges 225.2 - Benign neoplasm of cerebral meninges
Intracranial extra-axial: Cranial nerve	192.0 - Malignant neoplasm of cranial nerves 225.1 - Benign neoplasm of cranial nerves
Sellar	194.3 - Malignant neoplasm of pituitary gland & craniopharyngeal duct 227.3 - Benign neoplasm of pituitary gland & craniopharyngeal duct 237.0 – Neoplasm of uncertain behaviour of pituitary gland & craniopharyngeal duct
Pineal	194.4 - Malignant neoplasm of pineal gland 227.4 - Benign neoplasm of pineal gland 237.1 - Neoplasm of uncertain behaviour of pineal gland
Spinal: Spinal cord	192.2 - Malignant neoplasm of spinal cord 225.3 - Benign neoplasm of spinal cord
Spinal: Spinal meninges	192.3 - Malignant neoplasm of spinal meninges 225.4 - Benign neoplasm of spinal meninges
Other: Uncertain behaviour brain & spinal cord	237.5 - Neoplasm of uncertain behaviour of brain and spinal cord
Other: Other central nervous system (CNS) and meninges	192.8 - Malignant neoplasm of other & unspecified parts of nervous system, other 192.9 - Malignant neoplasm of other & unspecified parts of nervous system, unspecified 225.8 - Benign neoplasm of brain and other parts of nervous system, other 225.9 - Benign neoplasm of brain and other parts of nervous system, part unspecified 237.6 - Neoplasm of uncertain behaviour of meninges 237.9 - Neoplasm of uncertain behaviour of other & unspecified parts of CNS
Total malignant	All codes above beginning with 19
Total non-malignant	All codes above beginning with 22 and 23
Total	All codes above

ICD10 codes used for registrations 1995-2000 and hospital activity analyses

	ICD10 code
Intracranial intra-axial	C71 - Malignant neoplasm of brain D33.0 - Benign neoplasm of brain, supratentorial D33.1 - Benign neoplasm of brain, infratentorial D33.2 - Benign neoplasm of brain, unspecified D43.0 - Neoplasm of uncertain or unknown behaviour of brain, supratentorial D43.1 - Neoplasm of uncertain or unknown behaviour of brain, infratentorial D43.2 - Neoplasm of uncertain or unknown behaviour of brain, unspecified
Intracranial extra-axial: Intracranial meningeal	C70.0 - Malignant neoplasm of meninges D32.0 - Benign neoplasm of cerebral meninges D42.0 - Neoplasm of uncertain or unknown behaviour of cerebral meninges
Intracranial extra-axial: Cranial nerve	C72.2 - Malignant neoplasm of olfactory nerve C72.3 - Malignant neoplasm of optic nerve C72.4 - Malignant neoplasm of acoustic nerve C72.5 - Malignant neoplasm of other and unspecified cranial nerves D33.3 - Benign neoplasm of cranial nerves D43.3 - Neoplasm of uncertain or unknown behaviour of cranial nerves
Sellar	C75.1 - Malignant neoplasm of pituitary gland C75.2 - Malignant neoplasm of craniopharyngeal duct D35.2 - Benign neoplasm of pituitary gland D35.3 - Benign neoplasm of craniopharyngeal duct D44.3 - Neoplasm of uncertain or unknown behaviour of pituitary gland D44.4 - Neoplasm of uncertain or unknown behaviour of craniopharyngeal duct
Pineal	C75.3 - Malignant neoplasm of pineal gland D35.4 - Benign neoplasm of pineal gland D44.5 - Neoplasm of uncertain or unknown behaviour of pineal gland
Spinal: Spinal cord	C72.0 - Malignant neoplasm of spinal cord C72.1 - Malignant neoplasm of cauda equina D33.4 - Benign neoplasm of spinal cord D43.4 - Neoplasm of uncertain or unknown behaviour of spinal cord
Spinal: Spinal meninges	C70.1 - Malignant neoplasm of spinal meninges D32.1 - Benign neoplasm of spinal meninges D42.1 - Neoplasm of uncertain or unknown behaviour of spinal meninges
Other: Other meningeal	C70.9 - Malignant neoplasm of meninges, unspecified D32.9 - Benign neoplasm of meninges, unspecified D42.9 - Neoplasm of uncertain or unknown behaviour of meninges, unspecified
Other: Other central nervous system (CNS)	C72.8 - Malignant neoplasm of overlapping lesion of brain and other parts of CNS C72.9 - Malignant neoplasm of CNS, unspecified D33.7 - Benign neoplasm of other specified parts of CNS D33.9 - Benign neoplasm of CNS, unspecified D43.7 - Neoplasm of uncertain or unknown behaviour of other parts of CNS D43.9 - Neoplasm of uncertain or unknown behaviour of CNS, unspecified
Total malignant	All codes above beginning with C
Total non-malignant	All codes above beginning with D
Total	All codes above

ICD10 codes used for additional hospital activity analyses

	ICD10 code
Metastases: intracranial metastases	C79.3 - Secondary malignant neoplasm of brain and cerebral meninges
Metastases: extracranial metastases	C79.4 - Secondary malignant neoplasm of other and unspecified parts of nervous system
Phakomatoses: neurofibromatosis	Q85.0 - Neurofibromatosis (non-malignant)
Phakomatoses: tuberous sclerosis	Q85.1 - Tuberous sclerosis
Phakomatoses: Other phakomatoses	Q85.8 - Other phakomatoses, not elsewhere classified Q85.9 – Phakomatosis, unspecified

9 Appendix B. Summary of pathology data from four neurosurgical centres

	Newcastle (5 years)	Oxford (1 year)	Cardiff (5 years; 678 cases)	Cambridge (5 years; 1,814 cases)
Glioblastoma / anaplastic astrocytoma	25%	22%	28%	19%
Astrocytoma	10%	8%	6%	5%
Oligodendroglioma	3%	3%	5%	4%
Ependymoma	1%	4%	3%	1.7%
Meningioma	15%	19%	18%	18%
Schwannoma	5%	8%	6%	16%
Pituitary adenoma	5%	14%	3%	1.4%
PNET	2%	0%	1%	0.7%
Craniopharyngioma	1%	2%	1%	1.4%
Metastatic carcinoma	15%	10%	10%	5.5%
Lymphoma			2%	2.6%*
Other	18%	10%	17%	25%

*Site codes unspecific, may be an over-estimate

10 Appendix C. Age specific incidence rates reported in Lothian study & Devon and Cornwall study

AGE SPECIFIC INCIDENCE RATES FOR EACH TUMOUR TYPE (Counsell, Collie & Grant 1996)

	Age (y) 0-14		15-24		25-34		35-44		45-54	
All primary	3.50	(1.6-6.6)	6.10	(3.4-10.1)	10.40	(6.8-15.2)	13.70	(9.1-19.8)	18.30	(12.4-26.1)
Neuroepithelial	3.50	(1.6-6.6)	2.90	(1.1-5.9)	3.60	(1.6-6.8)	7.30	(4.1-12.1)	8.50	(4.7-14.3)
Meningeal	0.00	(0.0-1.4)	0.40	(0.0-2.3)	1.60	(0.4-4.1)	2.40	(0.8-5.7)	4.90	(2.1-9.6)
Sellar	0.00	(0.0-1.4)	1.60	(0.4-4.2)	4.40	(2.2-7.9)	2.90	(1.1-6.4)	1.20	(0.1-4.4)
Cranial nerve	0.00	(0.0-1.4)	0.00	(0.0-1.5)	0.00	(0.0-1.5)	1.00	(0.1-3.5)	3.10	(1.0-7.1)
CNS lymphoma	0.00	(0.0-1.4)	0.40	(0.0-2.3)	0.40	(0.0-2.2)	0.00	(0.0-1.8)	0.60	(0.00-3.4)
All secondary	1.50	(0.4-3.9)	0.40	(0.0-2.3)	2.00	(0.6-4.7)	7.80	(4.5-12.7)	19.50	(13.4-27.6)

Values are incidence/100000/year (95% CI)

AGE AND SEX SPECIFIC INCIDENCE RATES FOR ALL PRIMARY TUMOURS AND FOR THE FOUR CATEGORIES WITH MORE THAN 50 CASES (Pobereskin & Chadduck 2000)

		Age 0-14		15-24		25-34		35-44		45-54	
Diagnosis	Sex										
All Primary	F	5.7	(4.0-7.9)	9.3	(6.7-12.5)	14.7	(11.4-18.5)	21.9	(18.1-26.4)	26.3	(21.8-31.6)
	M	5.3	(3.6-7.3)	6.5	(4.4-9.2)	12.2	(9.2-15.7)	16.6	(13.1-20.5)	25.5	(21.0-30.7)
Neuroepithelial	F	5.3	(3.6-7.3)	2.9	(1.6-4.9)	4.8	(3.0-7.2)	7.0	(4.8-9.7)	10.1	(7.3-13.5)
	M	4.5	(3.0-6.4)	4.6	(2.8-6.9)	5.9	(3.9-8.5)	8.8	(6.3-11.)	12.4	(9.3-16.1)
Meningeal	F	0.0	(0.0-0.0)	1.1	(0.3-2.5)	1.4	(0.5-2.9)	3.1	(1.7-5.0)	7.6	(5.2-10.6)
	M	0.2	(0.0-0.8)	0.2	(0.0-1.2)	1.2	(0.4-2.7)	1.4	(0.5-2.8)	3.4	(1.8-5.5)
Sellar	F	0.2	(0.0-0.8)	3.8	(2.2-5.9)	6.3	(4.2-9.0)	9.2	(6.7-12.)	4.8	(2.9-7.3)
	M	0.5	(0.0-1.3)	1.0	(0.3-2.4)	2.9	(1.6-4.9)	3.7	(2.1-5.8)	3.4	(1.9-5.6)
Cranial nerves	F	0.0	(0.0-0.0)	0.9	(0.2-2.2)	1.2	(0.4-2.7)	2.0	(1.5-4.9)	2.9	(1.5-4.9)
	M	0.0	(0.0-0.0)	0.4	(0.0-1.5)	1.1	(0.3-2.4)	1.8	(0.8-3.4)	5.3	(3.3-7.9)

Values are incidence/100000 person-years (95% CI)

AGE SPECIFIC INCIDENCE RATES FOR EACH TUMOUR TYPE (Counsell, Collie & Grant 1996)

	45-54		55-64		65-74		75-84		³ 85	
All primary	18.30	(12.4-26.1)	29.70	(21.6-39.7)	36.90	(27.0-49.2)	33.40	(21.8-49.0)	19.20	(5.2-49.2)
Neuroepithelial	8.50	(4.7-14.3)	15.20	(9.6-22.7)	24.00	(16.2-34.3)	18.00	(9.8-30.2)	9.60	(1.1-34.7)
Meningeal	4.90	(2.1-9.6)	6.60	(3.1-12.1)	7.20	(3.3-13.7)	9.00	(3.6-18.5)	4.80	(0.1-26.8)
Sellar	1.20	(0.1-4.4)	5.90	(2.7-11.2)	2.40	(0.5-7.0)	3.80	(0.8-11.3)	0.00	(0.0-17.7)
Cranial nerve	3.10	(1.0-7.1)	0.60	(0.0-3.7)	0.80	(0.0-4.5)	0.00	(0.0-4.7)	4.80	(0.1-26.8)
CNS lymphoma	0.60	(0.00-3.4)	1.30	(0.1-4.7)	2.40	(0.5-7.0)	2.60	(0.3-9.3)	0.00	(0.0-17.7)
All secondary	19.50	(13.4-27.6)	39.50	(30.2-50.9)	53.70	(41.6-68.2)	36.00	(23.9-52.0)	4.80	(0.1-26.8)

Values are incidence/100000/year (95% CI)

AGE AND SEX SPECIFIC INCIDENCE RATES FOR ALL PRIMARY TUMOURS AND FOR THE FOUR CATEGORIES WITH MORE THAN 50 CASES

Diagnosis	Sex	45-54		55-64		65-74		>75		Total	
All Primary	F	26.3	(21.8-31.6)	34.0	(28.7-40.1)	41.6	(35.8-48.1)	26.5	(22.0-31.8)	20.24	(16.61-24.60
	M	25.5	(21.0-30.7)	46.4	(40.0-53.8)	61.7	(50.7-73.3)	52.1	(43.5-62.1)	21.88	(17.78-26.69)
Neuroepithelial	F	10.1	(7.3-13.5)	16.1	(12.0-20.5)	19.4	(15.0-24.6)	21.7	(16.0-28.4)	8.23	(5.95-11.16)
	M	12.4	(9.3-16.1)	23.5	(18.9-28.7)	30.4	(25.0-36.8)	27.1	(20.9-34.4)	11.57	(8.77-15.06)
Meningeal	F	7.6	(5.2-10.6)	8.5	(5.9-11.7)	14.1	(10.0-18.0)	10.6	(7.7-14.0)	4.83	(3.32-6.89)
	M	3.4	(1.8-5.5)	4.7	(2.8-7.2)	9.1	(6.4-12.3)	8.1	(5.6-11.1)	3.09	(1.90-4.99)
Sellar	F	4.8	(2.9-7.3)	4.1	(2.3-6.6)	6.2	(3.8-9.3)	3.7	(1.6-7.0)	4.26	(2.74-6.42)
	M	3.4	(1.9-5.6)	9.2	(6.4-12.7)	10.1	(7.1-14.0)	5.7	(3.1-9.6)	3.73	(2.28-5.88)
Cranial nerves	F	2.9	(1.5-4.9)	5.9	(3.8-8.7)	5.7	(3.6-8.3)	1.6	(0.6-3.2)	2.33	(1.28-3.98)
	M	5.3	(3.3-7.9)	6.1	(3.9-9.1)	7.6	(5.0-11.0)	4.1	(1.9-7.5)	2.44	(1.42-4.04)

Values are incidence/100000 person-years (95% CI)

11 Appendix D. OPCS codes used for Procedure based analysis

A01	**Major Excision of Tissue of Brain**	**All subcodes**
A02	**Excision of Lesion of Tissue of Brain**	**All subcodes**
A03	**Stereotactic Ablation of Tissue of Brain**	**All subcodes**
A04	**Open Biopsy of Lesion of Tissue of Brain**	**All subcodes**
A051	Drainage of Lesion of Tissue of Brain	Drainage of Abscess of Tissue of Brain
A054	Drainage of Lesion of Tissue of Brain	Evacuation of Intracerebral Haematoma NEC
A072	Other Open Operations On Tissue of Brain	Removal of Foreign Body From Tissue of Brain
A073	Other Open Operations On Tissue of Brain	Exploration of Tissue of Brain
A078	Other Open Operations On Tissue of Brain	Other Open Operations On Tissue of Brain (Other Specified)
A08	**Other Biopsy of Lesion of Tissue of Brain**	**All subcodes**
A091	Neurostimulation of Brain	Implantation of Neurostimulator Into Brain
A104	Other Operations On Tissue of Brain	Aspiration of Lesion of Tissue of Brain NEC
A109	Other Operations On Tissue of Brain	Other Operations On Tissue of Brain (Unspecified)
A124	Creation of Connection From Ventricle of Brain	Creation of Ventriculoperitoneal Shunt
A125	Creation of Connection From Ventricle of Brain	Creation of Subcutaneous Cerebrospinal Fluid Reservoir
A142	Other Operations On Connection From Ventricle of Brain	Revision of Cerebroventricular Shunt NEC
A143	Other Operations On Connection From Ventricle of Brain	Removal of Cerebroventricular Shunt
A148	Other Operations On Connection From Ventricle of Brain	Other Operations On Connection From Ventricle of Brain (Other Specified)
A17	Therapeutic Endoscopic Operations On Ventricle of Brain	All subcodes
A181	Diagnostic Endoscopic Examination of Ventricle of Brain	All subcodes
A201	Other Operations On Ventricle of Brain	Drainage of Ventricle of Brain NEC
A203	Other Operations On Ventricle of Brain	Monitoring of Pressure In Ventricle of Brain
A243	Graft To Cranial Nerve	Microsurgical Graft To Facial Nerve (Vii) NEC
A259	Intracranial Transection of Cranial Nerve	Intracranial Transection of Cranial Nerve (Unspecified)

A29	**Excision of Lesion of Cranial Nerve**	**All subcodes**
A324	Other Decompression of Cranial Nerve	Decompression of Facial Nerve (Vii)
A329	Other Decompression of Cranial Nerve	Other Decompression of Cranial Nerve (Unspecified)
A331	Neurostimulation of Cranial Nerve	Introduction of Neurostimulator Into Cranial Nerve
A34	Exploration of Cranial Nerve	All subcodes
A361	Other Operations On Cranial Nerve	Hypoglossofacial Anastomosis
A363	Other Operations On Cranial Nerve	Biopsy of Lesion of Cranial Nerve
A368	Other Operations On Cranial Nerve	Other Operations On Cranial Nerve (Other Specified)
A38	**Extirpation of Lesion of Meninges of Brain**	**All subcodes**
A399	Repair of Dura	Repair of Dura (Unspecified)
A401	Drainage of Extradural Space	Evacuation of Extradural Haematoma
A411	Drainage of Subdural Space	Evacuation of Subdural Haematoma
A412	Drainage of Subdural Space	Drainage of Abscess of Subdural Space
A422	Other Operations On Meninges of Brain	Biopsy of Lesion of Meninges of Brain
A44	**Partial Extirpation of Spinal Cord**	**All subcodes**
A452	Other Open Operations On Spinal Cord	Open Chordotomy of Spinal Cord NEC
A454	Other Open Operations On Spinal Cord	Open Biopsy of Lesion of Spinal Cord
A478	Other Destruction of Spinal Cord	Other Destruction of Spinal Cord (Other Specified)
A481	Other Operations On Spinal Cord	Biopsy of Lesion of Spinal Cord NEC
A483	Other Operations On Spinal Cord	Insertion of Neurostimulator Adjacent To Spinal Cord
A484	Other Operations On Spinal Cord	Attention To Neurostimulator Adjacent To Spinal Cord
A489	Other Operations On Spinal Cord	Other Operations On Spinal Cord (Unspecified)
A499	Repair of Spina Bifida	Repair of Spina Bifida (Unspecified)
A511	Other Operations On Meninges of Spinal Cord	Extirpation of Lesion of Meninges of Spinal Cord
A513	Other Operations On Meninges of Spinal Cord	Biopsy of Lesion of Meninges of Spinal Cord
A533	Drainage of Spinal Canal	Creation of Syringoperitoneal Shunt
A534	Drainage of Spinal Canal	Creation of Lumboperitoneal Shunt
A535	Drainage of Spinal Canal	Drainage of Cerebrospinal Fluid NEC
A548	Therapeutic Spinal Puncture	Therapeutic Spinal Puncture (Other Specified)
A571	Operations On Spinal Nerve Root	Extirpation of Lesion of Spinal Nerve Root
A572	Operations On Spinal Nerve Root	Rhizotomy of Spinal Nerve Root

A651	Release of Entrapment of Peripheral Nerve At Wrist	Carpal Tunnel Release
A679	Release of Entrapment of Peripheral Nerve At Other Site	Release of Entrapment of Peripheral Nerve At Other Site (Unspecified)
A731	Other Operations On Peripheral Nerve	Biopsy of Lesion of Peripheral Nerve
B012	Excision of Pituitary Gland	Transphenodial Hypophysectomy
B014	Excision of Pituitary Gland	Transcranial Hypophysectomy
B042	Other Operations On Pituitary Gland	Biopsy of Lesion of Pituitary Gland
B06	**Operations On Pineal Gland**	**All subcodes**
E423	Exteriorisation of Trachea	Temporary Tracheostomy
L295	Reconstruction of Carotid Artery	Endarterectomy of Carotid Artery NEC
L332	Operations On Aneurysm of Cerebral Artery	Clipping of Aneurysm of Cerebral Artery
L342	Other Open Operations On Cerebral Artery	Anastomosis of Cerebral Artery
L35	Transluminal Operations On Cerebral Artery	Percutaneous Transluminal Embolisation of Cerebral Artery
L671	Excision of Other Artery	Biopsy of Artery NEC
L751	Other Arteriovenous Operations	Excision of Congenital Arteriovenous Malformation
L753	Other Arteriovenous Operations	Embolisation of Arteriovenous Abnormality
S419	Suture of Skin of Head or Neck	Suture of Skin of Head or Neck (Unspecified)
S429	Suture of Skin of Other Site	Suture of Skin of Other Site (Unspecified)
T819	Biopsy of Muscle	Biopsy of Muscle (Unspecified)
V013	Plastic Repair of Cranium	Opening of Suture of Cranium
V018	Plastic Repair of Cranium	Plastic Repair of Cranium (Other Specified)
V019	Plastic Repair of Cranium	Plastic Repair of Cranium (Unspecified)
V033	Opening of Cranium	Reopening of Cranium and Reexplor of Intracran Oper Site NEC
V038	Opening of Cranium	Opening of Cranium (Other Specified)
V053	Other Operations On Cranium	Elevation of Depressed Fracture of Cranium
V058	Other Operations On Cranium	Other Operations On Cranium (Other Specified)
V059	Other Operations On Cranium	Other Operations On Cranium (Unspecified)
V119	Fixation of Bone of Face	Fixation of Bone of Face (Unspecified)
V179	Fixation of Mandible	Fixation of Mandible (Unspecified)
V228	Primary Decompression Operations On Cervical Spine	Primary Decompression Operations On Cervical Spine (Other Specified)

V239	Revisional Decompression Operations On Cervical Spine	Revisional Decompression Operations On Cervical Spine (Unspecified)
V249	Decompression Operations On Thoracic Spine	Decompression Operations On Thoracic Spine (Unspecified)
V259	Primary Decompression Operations On Lumbar Spine	Primary Decompression Operations On Lumbar Spine (Unspecified)
V269	Revisional Decompression Operations On Lumbar Spine	Revisional Decompression Operations On Lumbar Spine (Unspecified)
V298	Primary Excision of Cervical Intervertebral Disc	Primary Excision of Cervical Intervertebral Disc (Other Specified)
V309	Revisional Excision of Cervical Intervertebral Disc	Revisional Excision of Cervical Intervertebral Disc (Unspecified)
V319	Primary Excision of Thoracic Intervertebral Disc	Primary Excision of Thoracic Intervertebral Disc (Unspecified)
V374	Primary Fusion of Joint of Cervical Spine	Fusion of Atlantooccipital Joint
V469	Fixation of Fracture of Spine	Fixation of Fracture of Spine (Unspecified)
V479	Biopsy of Spine	Biopsy of Spine (Unspecified)
V541	Other Operations On Spine	Transoral Excision of Odontoid Process of Axis
V549	Other Operations On Spine	Other Operations On Spine (Unspecified)
X459	Donation of Organ	Donation of Organ (Unspecified)
X559	Other Operations On Unspecified Organ	Other Operations On Unspecified Organ (Unspecified)
X599	Anaesthetic Without Surgery	Anaesthetic Without Surgery (Unspecified)

12 Appendix E. Neurosurgical department questionnaire

Improving outcomes for people with tumours of the brain and central nervous system

Please complete the questionnaire for the department as a whole. All the questions below apply to the neurosurgical service, and not to services such as stereotactic radiotherapy, unless otherwise specified.

The questionnaire takes the following format

1. General
2. Structure
3. Patient activity
4. Staffing
5. Multidisciplinary team (MDT)
6. Related services and other aspects of care
7. Clinical Trials
8. Other

1. General

1.1. Name of department: _____

1.2. Type of hospital (e.g. University Hospital, District General Hospital, etc):

_____

1.3. What is the size of the catchment population of the department and how do you arrive at this figure (if known)?

_____

2. Structure

2.1. How many designated neurosurgical beds does the department have access to?

a. Ward beds _____
b. High dependency / step-down beds _____
c. Critical care beds _____
d. Total: _____

2.2. How many sessions (or hours, please specify) of scheduled operating theatre time are devoted to neurosurgery per week?

_____

3. Patient activity

3.1. How many new patients does your department see in a year? _____

3.2. How many of these are brain / CNS tumour patients? _____

3.3. How many surgical procedures are undertaken in a year in your department? _____

3.4. How many patients (approximately) are referred for stereotactic radiosurgery annually from the department _____

If the information is available, please complete the following:

3.5. How many of the following procedures were undertaken for brain / CNS tumours during the last year data is available for:

Year: _____

a. Total procedures _____
b. Open operations (craniotomies / craniectomies) _____
c. Stereotactic biopsies _____
d. Spinal operations for primary CNS tumours _____
e. Spinal operations for metastases _____
f. Operations for pituitary / craniopharyngeal tumours _____
g. Operations for acoustic nerve / base of skull tumours _____

3.6. Do you have access to finished consultant episode (FCE) activity related to brain / CNS cancer for the department? _____

If so, how many were there for 2001-2002? _____

4. Staffing

4.1. How many whole time equivalent (WTE) consultant neurosurgeons are there in the department? _____

4.2. How many undertake the following types of surgery?

a. Brain / CNS tumour surgery _____

b. Pituitary / craniopharyngeal tumour surgery _____

c. Acoustic nerve / other base of skull tumour surgery _____

d. Surgery for tumours affecting the spine _____

4.3. How many clinical nurse specialists in neuro-oncology (WTE) are there who undertake the following types of work?

Surgical only	
Non-surgical only	
Combined surgical & non-surgical	

5. Multidisciplinary team (MDT)

5.1. Are there defined multi-disciplinary teams for patients with brain and /or CNS tumours (Y/N)? _____

If no then please go to section 5.7, if yes then please continue:

5.2. How often does this team meet? _____

5.3. What is the typical number of cases discussed at each MDT meeting? _____

5.4. Which of the following describes the patients discussed at the MDT meeting?

	Please tick
Preoperative:	
All new patients referred	
All patients in whom surgery is being considered	
Complex or unusual cases preoperatively only	
No cases preoperatively	

Postoperative:	
All cases postoperatively	
Some cases postoperatively	
No cases postoperatively	

5.5. Does the MDT include the following members?

	Yes	**No**
Named lead clinician		
Named clinical oncologist / radiotherapist		
Lead pathologist		
If yes is this an accredited neuropathologist?		
Lead imaging consultant		
Lead endocrinologist		
Lead neurologist		
Psychological or psychiatric professional Job title:		
Clinical nurse specialist in neuro-oncology		
Occupational Therapy		
Physiotherapy		
Speech and language therapy		
Social worker		
Lead maxillofacial surgeon		
Other discipline (please specify)		

5.6. Are there other relevant MDTs associated with the department (e.g. pituitary tumour, spinal tumours; please specify)? _____
_____

5.7. Please list any other important forms of multidisciplinary working relevant to brain / CNS tumour patients (e.g. joint outpatients with neuro-oncologist / other disciplines), please specify, continue on separate sheet if necessary.

6. Related services and other aspects of care

6.1. Which of the following services are available on site?

	Yes	No
Occupational Therapy		
Physiotherapy		
Speech and language therapy		
Neuropsychological / neuropsychiatry services (please specify)		
Palliative care consultant		
Specialist nurse in palliative care		
Neurologist with a special interest in epilepsy		
Social worker		
Pain management		
Nutrition		
Local patient support group for brain / CNS tumours		
Other relevant services that provide added value (please specify)		

6.2. Do you have access to a specialist neuro-rehabilitation unit? _____

6.3. Do you have access to videoconferencing to facilitate working with services at other sites? _____

If yes, do you find it a useful resource (Y/N)? _____

If no, do you think you would benefit from it (Y/N)? _____

6.4. Do you have access to the following (please tick if yes) and what is the typical waiting time for a routine outpatient appointment (if known)?

	Yes	No	Waiting time
CT			
MRI			
PET			
SPECT			
Conventional image guided surgery			
Frameless stereotaxy			
Computer access to histopathology reports on wards / in clinics			
Molecular analysis to supplement histopathological diagnosis e.g. 1p19q status data for oligodendrogliomas			
Other relevant facilities (please specify)			

6.5. Does the pathology department offer intra-operative histological evaluation of tumours (Y/N)? _____

If yes is this available 24 hours per day (Y/N)? _____

6.6. Do you have protocols for the following aspects of patient care, and are these multidisciplinary (MD) (please tick)?

	Yes	**No**	**MD**
How you communicate with primary care			
How primary care can contact you			
Communication with other secondary / tertiary services off site (e.g. transfer of notes / X-rays)?			
Response to referral of patients (e.g. telephone call from A&E)			
Management of **low grade gliomas**			
Management of **high grade gliomas**			
Management of **recurrent gliomas**			
Management of **meningiomas**			
Management of **pituitary tumours**			
Management of **acoustic tumours**			
Criteria for referral for stereotactic radiosurgery			
Imaging surveillance			
Follow-up			
Steroid usage			
Epilepsy and seizure control			
Other relevant protocols			

6.7. Where are patients usually referred for radiotherapy to a department (please tick one)?

a. On site ☐
b. At a single local regional centre ☐
c. In one of a number of surrounding hospitals ☐
d. Other (please specify) ☐

_____

6.8. After surgery who normally follows up patients (please tick one)?

a. A referral back to the referring clinician ☐
b. An oncologist close to the patient's residence ☐
c. A designated oncologist ☐
d. Specialist clinics in the neurosurgical department ☐
e. Other (please specify) ☐

_____

6.9. Where are patients referred for stereotactic radiosurgery?

_____

6.10. Do you routinely collect the following outcome data (please tick)?

	Yes	**No**
Morbidity post biopsy		
Mortality post biopsy		
Morbidity post surgery		
Mortality post surgery		
Quality of life		
Survival times		
Time to recurrence		
Performance e.g. MRC / Karnofsky		
Other (please specify)		

7. Clinical Trials

7.1. How many patients with brain / CNS tumours have been recruited by your service for clinical trials within the last year? _____

7.2. Where patients may have been suitable for such trials, but were not recruited what was the most significant reason for lack of recruitment (please tick one)?

a. No suitable trial available ☐
b. Eligibility criteria were not appropriate for the patient ☐
c. Patient did not wish to participate ☐
d. A lack of resources to manage patients in the trial setting ☐
e. Other (please specify) ☐

_____

8. Other

8.1. Would you be happy for us to contact you to follow-up some of the information you have supplied (Y/N)? _____

If yes please supply a contact name and contact details:

Name: _____

Address: _____

_____ Tel: _____

e-mail: _____

Neurosurgical department questionnaire

Improving outcomes for people with tumours of the brain and central nervous system

We are interested to know the annual level of investment in brain and CNS cancer in your area. Please could you give the name and contact details of the financial director who might be able to help with respect to your department?

Name: _____

Address: _____

_____ Tel: _____

e-mail: _____

Please add any other relevant comments (continue on a separate page if necessary).

Thank you for taking the time, and effort, to complete this questionnaire. The information will be used in the development of NICE guidance on services for brain and central nervous system tumours.

Kindly return the completed questionnaire to:

Dr Ciarán Humphreys
National Public Health Service
Tel: 01267 225225
Fax: 01267 232179
e-mail: ciaran.humphreys@nphs.wales.nhs.uk

St David's Hospital
PO Box 13
Jobswell Road
Carmarthen
SA31 3YH

13 Appendix F. Oncology / radiotherapy department questionnaire

Improving outcomes for people with tumours of the brain and central nervous system

One questionnaire should be completed in each oncology / radiotherapy department, for the department as a whole. This **8-page** questionnaire takes the following format:

1. General
2. Structure
3. Patient activity
4. Staffing
5. Multidisciplinary team (MDT)
6. Related services and other aspects of care
7. Clinical Trials
8. Other

1. General

1.1. Name of department: _____

1.2. Location (e.g. University Hospital, District General Hospital, etc)

_____

1.3. Does the department care for patients with brain / central nervous system (CNS) tumours (Y/N)? _____

If no, please state where such patients from your catchment area are treated, and kindly return, as specified in section 8.

_____

1.4. What is the size of the department's catchment population for neuro-oncology and how do you arrive at this figure (if known)?

_____

2. Structure

2.1. How many designated oncology (all types) beds does your department have access to? _____

3. Patient activity

3.1. How many new patients does the department see in a year? _____

3.2. How many are brain / CNS tumour patients (if known)? _____

3.3. How many are patients with gliomas (if known)? _____

3.4. What proportion of glioma patients in the department receives chemotherapy (if known), and how did you arrive at this figure?

_____

_____

3.5. What proportion of glioma patients in the department receives radiotherapy (if known), and how did you arrive at this figure?

_____

_____

3.6. What is the minimum age of patients seen? _____

3.7. What is average (mean) waiting time in the department for brain / CNS tumour patients to start the following (if known)?

e. Radical radiotherapy _____

f. Palliative radiotherapy _____

g. Inpatient chemotherapy _____

h. Outpatient chemotherapy _____

3.8. Do you have access to finished consultant episode (FCE) activity for the department related to brain / CNS cancer? _____

If so, how many were there for 2001-2002?

_____

4. Staffing

4.1. How many whole time equivalent (WTE) consultant clinical oncologists are there? _____

4.2. How many specialise in brain / CNS tumours work? _____

4.3. How many clinical nurse specialists in neuro-oncology (WTE) are there who undertake the following types of work?

Surgical only	
Non-surgical only	
Combined surgical & non-surgical	

5. Multidisciplinary team (MDT)

5.1. Are there defined multi-disciplinary teams for patients with brain and /or CNS tumours (Y/N)? _____

If no then please go to section 5.8, if yes then please continue:

5.2. How often does this team meet? _____

5.3. What is the typical number of cases discussed at each MDT meeting? _____

5.4. Do you routinely discuss pre-operative patients at MDT meetings? _____

5.5. Which of the following describes the patients discussed at MDT meetings?

	Please tick
All new patients referred	
Most patients referred	
Some patients referred	
Occasional cases only	

5.6. Does the MDT include the following members?

	Yes	**No**
Named lead clinician		
Lead clinical oncologist / radiotherapist		
Lead neurosurgeon		
Lead pathologist		
If yes is this an accredited neuropathologist?		
Lead imaging consultant		
Lead endocrinologist		
Lead neurologist		
Psychological or psychiatric professional		
Job title:		
Clinical nurse specialist in neuro-oncology		
Occupational Therapy		
Physiotherapy		
Speech and language therapy		
Social worker		
Lead maxillofacial surgeon		
Other discipline (please specify)		

5.7. Are there other relevant MDTs associated with the department (e.g. pituitary / endocrine tumours, please specify)? _____
_____

5.8. Please list any other important forms of multidisciplinary working relevant to brain / CNS tumour patients (e.g. joint outpatients with neuro-oncologist / other disciplines), please specify, continue on separate sheet if necessary.

6. Related services and other aspects of care

6.1. Which of the following services are available on site?

	Yes	No
Occupational Therapy		
Physiotherapy		
Speech and language therapy		
Neuropsychological / neuropsychiatry services (please specify)		
Palliative care consultant		
Specialist nurse in palliative care		
Neurologist with a special interest in epilepsy		
Social worker		
Pain management		
Nutrition		
Local patient support group for brain / CNS tumours		
Other relevant services that provide added value (please specify)		

6.2. Do you have access to a specialist neuro-rehabilitation unit? _____

6.3. Do you have access to videoconferencing to facilitate working with services at other sites? _____

If yes, do you find it a useful resource? _____

If no, do you think you would benefit from it? _____

6.4. Do you have access to the following (please tick if yes) and what is the typical waiting time for a routine outpatient appointment (if known)?

	Yes	No	Waiting time
CT			
MRI			
PET			
SPECT			
Computer access to histopathology reports on wards / in clinics			
Molecular analysis to supplement histopathological diagnosis e.g. 1p19q status data for oligodendrogliomas			
Other relevant facilities (please specify)			

6.5. Do you have protocols for the following aspects of patient care, are they multidisciplinary (MD) (please tick)?

	Yes	**No**	**MD**
How you communicate with primary care			
How primary care can contact you			
Communication with other secondary / tertiary services off site (e.g. transfer of notes / X-rays)?			
Response to referral of patients			
Management of **low grade gliomas**			
Management of **high grade gliomas**			
Management of **recurrent gliomas**			
Management of **meningiomas**			
Management of **pituitary tumours**			
Management of **acoustic tumours**			
Imaging surveillance			
Follow-up			
Other relevant protocols			

6.6. Which of the following outcome data is routinely collected (tick as appropriate)?

Survival times	
Time to recurrence	
Quality of life	
Morbidity following chemotherapy	
Morbidity following radiotherapy	
Other (please specify)	

7. Clinical Trials

7.1. How many patients have been recruited by your service for clinical trials within the last year?

_____

7.2. Where patients may have been suitable for a trial, but were not recruited what was the most significant reason for lack of recruitment (please tick one)?

f. No suitable trial available ☐
g. Eligibility criteria were not appropriate for the patient ☐
h. Patient did not wish to participate ☐
i. A lack of resources to manage patients in the trial setting ☐
j. Other (please specify) ☐

_____

8. Other

8.1. Would you be happy for us to contact you to follow-up some of the information you have supplied (Y/N)? _____

If yes please supply a contact name and contact details:

Name: _____

Address: _____

_____ Tel: _____

e-mail: _____

8.2. We are interested to know the annual level of investment in brain and CNS cancer in our area. Please could you give the name and contact details of the financial director who might be able to help with respect to your department?

Name: _____

Address: _____

_____ Tel: _____

e-mail: _____

Please add any other relevant comments (continue on a separate page if necessary).

Thank you for taking the time, and effort, to complete this questionnaire. The information will be used in the development of NICE guidance on services for brain and central nervous system tumours.

Kindly return the completed questionnaire before the 9th February to:

Dr Ciarán Humphreys
National Public Health Service
Tel: 01267 225225
Fax: 01267 232179
e-mail: ciaran.humphreys@nphs.wales.nhs.uk

St David's Hospital
PO Box 13
Jobswell Road
Carmarthen
SA31 3YH

14 Appendix G. Age and sex specific incidence and mortality rates

Persons: annual age specific registration rates per 100,000 population, 1995-2000 England & Wales

		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	total
Intracranial intra-axial	malignant	1.44	1.97	2.38	3.16	3.90	4.94	6.85	9.30	12.93	16.32	20.12	21.92	21.12	17.36	11.75	**8.54**
(excludes pineal)	non-malignant	0.35	0.37	0.49	0.47	0.59	0.57	0.79	0.79	1.02	1.13	2.02	2.99	4.37	6.02	5.82	**1.25**
	total	1.79	2.33	2.87	3.63	4.49	5.51	7.63	10.09	13.94	17.46	22.15	24.90	25.49	23.38	17.57	**9.79**
Intracranial extra-axial	malignant	0.01	0.02	0.02	0.02	0.03	0.05	0.11	0.10	0.15	0.21	0.29	0.28	0.51	0.51	0.52	**0.13**
Intracranial meningeal	non-malignant	0.05	0.12	0.30	0.52	0.71	1.21	1.82	2.22	2.59	3.20	3.26	4.22	4.88	5.01	6.26	**1.82**
	total	0.06	0.14	0.32	0.54	0.73	1.26	1.93	2.31	2.75	3.42	3.56	4.50	5.39	5.52	6.78	**1.95**
Intracranial extra-axial	malignant	0.03	0.04	0.03	0.03	0.03	0.02	0.03	0.05	0.06	0.08	0.07	0.03	0.05	0.06	0.05	**0.04**
Cranial nerve	non-malignant	0.15	0.29	0.29	0.51	0.66	1.05	1.43	1.77	1.80	2.00	1.62	1.46	1.04	0.70	0.49	**0.99**
	total	0.17	0.33	0.32	0.53	0.69	1.07	1.46	1.81	1.85	2.08	1.69	1.49	1.09	0.76	0.54	**1.03**
Sellar	malignant	0.01	0.03	0.04	0.02	0.03	0.04	0.05	0.05	0.05	0.11	0.16	0.12	0.22	0.27	0.31	**0.07**
	non-malignant	0.46	0.81	0.97	1.16	1.31	1.46	1.69	2.04	2.46	2.53	2.47	2.45	2.23	1.92	1.22	**1.59**
	total	0.46	0.84	1.01	1.18	1.35	1.50	1.73	2.09	2.51	2.64	2.62	2.57	2.45	2.19	1.53	**1.66**
Pineal	malignant	0.15	0.10	0.04	0.04	0.03	0.03	0.01	0.02	0.04	0.01	0.05	0.06	0.01	0.03	0.07	**0.05**
	non-malignant	0.02	0.03	0.03	0.01	0.03	0.02	0.02	0.07	0.04	0.04	0.04	0.03	0.07	0.01	0.00	**0.03**
	total	0.17	0.13	0.07	0.05	0.06	0.05	0.03	0.09	0.08	0.05	0.09	0.09	0.08	0.04	0.07	**0.08**
Spinal	malignant	0.12	0.06	0.12	0.17	0.14	0.13	0.20	0.18	0.21	0.18	0.22	0.21	0.27	0.31	0.12	**0.17**
Spinal cord	non-malignant	0.04	0.10	0.10	0.14	0.10	0.13	0.15	0.16	0.16	0.18	0.22	0.16	0.16	0.21	0.09	**0.13**
	total	0.16	0.16	0.23	0.31	0.24	0.26	0.35	0.34	0.37	0.36	0.44	0.37	0.43	0.52	0.21	**0.30**
Spinal	malignant	0.01	0.00	0.00	0.01	0.01	0.00	0.01	0.02	0.01	0.03	0.04	0.02	0.03	0.01	0.03	**0.01**
Spinal meninges	non-malignant	0.02	0.02	0.03	0.02	0.04	0.07	0.09	0.14	0.25	0.27	0.27	0.48	0.39	0.40	0.37	**0.14**
	total	0.03	0.02	0.04	0.03	0.05	0.07	0.11	0.16	0.26	0.29	0.32	0.50	0.42	0.42	0.40	**0.16**
Other	malignant	0.01	0.00	0.00	0.01	0.01	0.01	0.03	0.04	0.04	0.05	0.06	0.13	0.16	0.09	0.14	**0.04**
Other meningeal	non-malignant	0.03	0.03	0.06	0.11	0.14	0.20	0.36	0.45	0.50	0.63	0.81	1.04	1.55	1.77	1.88	**0.44**
	total	0.04	0.03	0.06	0.12	0.16	0.21	0.39	0.48	0.54	0.69	0.87	1.17	1.71	1.86	2.02	**0.48**
Other	malignant	0.02	0.02	0.00	0.02	0.01	0.02	0.01	0.05	0.02	0.01	0.03	0.03	0.08	0.03	0.00	**0.02**
Other CNS	non-malignant	0.03	0.03	0.06	0.05	0.06	0.09	0.06	0.07	0.10	0.09	0.11	0.15	0.11	0.18	0.14	**0.08**
	total	0.04	0.05	0.06	0.07	0.07	0.11	0.07	0.12	0.13	0.09	0.14	0.18	0.18	0.21	0.14	**0.10**
Total malignant		**1.79**	**2.23**	**2.64**	**3.47**	**4.19**	**5.24**	**7.30**	**9.79**	**13.50**	**17.00**	**21.05**	**22.80**	**22.45**	**18.67**	**13.00**	**9.06**
Total non-malignant		**1.14**	**1.80**	**2.32**	**2.99**	**3.64**	**4.81**	**6.40**	**7.69**	**8.93**	**10.08**	**10.83**	**12.97**	**14.79**	**16.23**	**16.26**	**6.48**
Total		**2.93**	**4.03**	**4.96**	**6.46**	**7.83**	**10.05**	**13.71**	**17.48**	**22.43**	**27.08**	**31.88**	**35.77**	**37.24**	**34.89**	**29.27**	**15.54**

Males: annual age specific registration rates per 100,000 population, 1995-2000 England & Wales

		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	total
Intracranial intra-axial	malignant	1.60	2.24	2.77	3.45	4.58	6.04	8.74	11.42	15.72	20.09	24.22	27.98	26.62	23.06	18.52	**10.15**
(excludes pineal)	non-malignant	0.42	0.40	0.55	0.50	0.66	0.65	0.87	0.87	1.13	1.33	2.28	3.29	4.59	7.18	7.85	**1.27**
	total	2.01	2.63	3.31	3.96	5.24	6.68	9.61	12.29	16.85	21.42	26.51	31.27	31.21	30.25	26.38	**11.42**
Intracranial extra-axial	malignant	0.01	0.01	0.03	0.02	0.04	0.07	0.09	0.10	0.16	0.23	0.33	0.19	0.50	0.42	0.72	**0.12**
Intracranial meningeal	non-malignant	0.03	0.10	0.23	0.36	0.40	0.59	0.86	1.32	1.69	2.15	2.12	3.17	3.81	4.03	5.69	**1.14**
	total	0.04	0.11	0.26	0.39	0.44	0.66	0.94	1.42	1.85	2.38	2.45	3.36	4.31	4.45	6.41	**1.26**
Intracranial extra-axial	malignant	0.02	0.03	0.04	0.02	0.04	0.03	0.03	0.04	0.05	0.14	0.08	0.04	0.07	0.08	0.07	**0.05**
Cranial nerve	non-malignant	0.15	0.29	0.30	0.49	0.61	1.18	1.53	1.72	1.94	2.00	1.53	1.34	1.09	0.59	0.39	**1.00**
	total	0.17	0.32	0.35	0.51	0.65	1.21	1.56	1.76	1.99	2.14	1.60	1.37	1.17	0.67	0.46	**1.05**
Sellar	malignant	0.00	0.01	0.04	0.03	0.04	0.03	0.05	0.05	0.04	0.11	0.23	0.11	0.19	0.34	0.52	**0.07**
	non-malignant	0.29	0.58	0.59	0.87	1.17	1.42	1.81	2.33	2.71	2.87	3.25	3.35	2.88	3.19	2.68	**1.69**
	total	0.29	0.59	0.64	0.90	1.21	1.45	1.86	2.38	2.75	2.98	3.48	3.45	3.07	3.53	3.21	**1.76**
Pineal	malignant	0.23	0.20	0.08	0.07	0.06	0.04	0.03	0.02	0.05	0.00	0.06	0.11	0.00	0.04	0.13	**0.08**
	non-malignant	0.02	0.02	0.01	0.02	0.02	0.01	0.02	0.06	0.02	0.01	0.05	0.05	0.07	0.00	0.00	**0.03**
	total	0.26	0.22	0.09	0.08	0.08	0.05	0.05	0.08	0.07	0.01	0.11	0.16	0.07	0.04	0.13	**0.10**
Spinal	malignant	0.15	0.06	0.20	0.16	0.13	0.08	0.26	0.22	0.23	0.23	0.27	0.28	0.31	0.42	0.26	**0.19**
Spinal cord	non-malignant	0.05	0.13	0.13	0.22	0.10	0.14	0.15	0.16	0.15	0.19	0.20	0.12	0.17	0.13	0.00	**0.14**
	total	0.20	0.19	0.32	0.39	0.23	0.22	0.41	0.38	0.38	0.42	0.47	0.40	0.48	0.55	0.26	**0.34**
Spinal	malignant	0.01	0.00	0.01	0.00	0.02	0.00	0.01	0.01	0.01	0.03	0.02	0.00	0.02	0.04	0.00	**0.01**
Spinal meninges	non-malignant	0.03	0.02	0.02	0.02	0.04	0.03	0.05	0.04	0.10	0.08	0.09	0.28	0.07	0.08	0.20	**0.06**
	total	0.04	0.02	0.03	0.02	0.06	0.03	0.06	0.05	0.11	0.11	0.11	0.28	0.10	0.13	0.20	**0.07**
Other	malignant	0.01	0.00	0.00	0.01	0.01	0.00	0.01	0.05	0.04	0.03	0.09	0.11	0.10	0.00	0.00	**0.03**
Other meningeal	non-malignant	0.02	0.04	0.04	0.11	0.10	0.13	0.22	0.28	0.28	0.50	0.59	0.70	1.24	1.60	1.57	**0.29**
	total	0.03	0.04	0.04	0.12	0.11	0.13	0.23	0.33	0.32	0.53	0.68	0.81	1.33	1.60	1.57	**0.32**
Other	malignant	0.03	0.02	0.00	0.02	0.01	0.02	0.02	0.07	0.04	0.00	0.05	0.00	0.07	0.04	0.00	**0.02**
Other CNS	non-malignant	0.04	0.06	0.07	0.04	0.08	0.11	0.06	0.10	0.09	0.05	0.09	0.14	0.14	0.25	0.26	**0.08**
	total	0.07	0.09	0.07	0.06	0.09	0.13	0.08	0.17	0.12	0.05	0.14	0.14	0.21	0.29	0.26	**0.11**
Total malignant		**2.07**	**2.58**	**3.17**	**3.79**	**4.93**	**6.30**	**9.24**	**11.99**	**16.33**	**20.85**	**25.34**	**28.81**	**27.88**	**24.45**	**20.23**	**10.71**
Total non-malignant		**1.06**	**1.64**	**1.93**	**2.63**	**3.17**	**4.25**	**5.55**	**6.88**	**8.12**	**9.19**	**10.20**	**12.45**	**14.06**	**17.06**	**18.65**	**5.71**
Total		**3.12**	**4.22**	**5.10**	**6.42**	**8.10**	**10.55**	**14.79**	**18.86**	**24.45**	**30.04**	**35.54**	**41.26**	**41.94**	**41.50**	**38.88**	**16.42**

Females: annual age specific registration rates per 100,000 population, 1995-2000 England & Wales

		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	total
Intracranial intra-axial	malignant	1.29	1.70	2.00	2.88	3.22	3.85	4.97	7.20	10.18	12.70	16.43	17.01	17.34	14.23	9.29	**7.05**
(excludes pineal)	non-malignant	0.27	0.34	0.43	0.44	0.53	0.49	0.71	0.71	0.90	0.94	1.79	2.74	4.22	5.39	5.08	**1.23**
	total	1.56	2.04	2.43	3.31	3.75	4.34	5.68	7.91	11.08	13.64	18.22	19.75	21.56	19.62	14.37	**8.28**
Intracranial extra-axial	malignant	0.00	0.02	0.02	0.02	0.02	0.04	0.13	0.09	0.15	0.20	0.26	0.36	0.52	0.55	0.45	**0.14**
Intracranial meningeal	non-malignant	0.08	0.15	0.36	0.67	1.00	1.82	2.78	3.10	3.48	4.22	4.29	5.06	5.61	5.55	6.46	**2.45**
	total	0.08	0.17	0.37	0.69	1.02	1.86	2.91	3.19	3.63	4.42	4.55	5.42	6.14	6.10	6.91	**2.59**
Intracranial extra-axial	malignant	0.03	0.05	0.02	0.03	0.02	0.02	0.04	0.05	0.06	0.03	0.07	0.03	0.03	0.05	0.05	**0.04**
Cranial nerve	non-malignant	0.14	0.30	0.28	0.52	0.72	0.92	1.33	1.82	1.66	2.01	1.70	1.56	1.00	0.76	0.52	**0.98**
	total	0.17	0.35	0.30	0.56	0.73	0.94	1.36	1.87	1.72	2.03	1.77	1.58	1.03	0.81	0.57	**1.02**
Sellar	malignant	0.01	0.05	0.03	0.01	0.02	0.05	0.05	0.05	0.06	0.10	0.10	0.13	0.25	0.23	0.24	**0.07**
	non-malignant	0.63	1.03	1.33	1.44	1.46	1.50	1.57	1.76	2.21	2.20	1.76	1.73	1.78	1.22	0.69	**1.50**
	total	0.64	1.09	1.37	1.45	1.48	1.55	1.61	1.81	2.27	2.31	1.85	1.85	2.03	1.45	0.93	**1.57**
Pineal	malignant	0.07	0.00	0.00	0.01	0.01	0.02	0.00	0.01	0.02	0.03	0.04	0.01	0.02	0.02	0.05	**0.02**
	non-malignant	0.02	0.03	0.05	0.01	0.03	0.04	0.02	0.08	0.06	0.07	0.04	0.01	0.07	0.02	0.00	**0.04**
	total	0.09	0.03	0.05	0.02	0.04	0.06	0.02	0.09	0.08	0.09	0.08	0.03	0.08	0.05	0.05	**0.06**
Spinal	malignant	0.09	0.05	0.05	0.17	0.16	0.17	0.13	0.14	0.19	0.13	0.16	0.16	0.25	0.25	0.07	**0.14**
Spinal cord	non-malignant	0.02	0.07	0.08	0.06	0.10	0.13	0.15	0.15	0.17	0.17	0.25	0.19	0.15	0.25	0.12	**0.13**
	total	0.11	0.13	0.13	0.23	0.26	0.30	0.29	0.29	0.36	0.30	0.41	0.34	0.39	0.51	0.19	**0.27**
Spinal	malignant	0.01	0.00	0.00	0.02	0.00	0.00	0.02	0.02	0.00	0.03	0.07	0.03	0.03	0.00	0.05	**0.02**
Spinal meninges	non-malignant	0.01	0.01	0.04	0.02	0.03	0.12	0.13	0.24	0.40	0.45	0.44	0.64	0.61	0.58	0.43	**0.22**
	total	0.02	0.01	0.04	0.03	0.03	0.12	0.15	0.26	0.40	0.47	0.50	0.67	0.64	0.58	0.48	**0.24**
Other	malignant	0.01	0.00	0.00	0.01	0.02	0.02	0.05	0.02	0.04	0.08	0.04	0.16	0.20	0.14	0.19	**0.05**
Other meningeal	non-malignant	0.03	0.02	0.09	0.12	0.19	0.27	0.50	0.61	0.72	0.76	1.01	1.31	1.77	1.87	2.00	**0.58**
	total	0.04	0.02	0.09	0.13	0.21	0.29	0.55	0.63	0.75	0.84	1.05	1.47	1.96	2.00	2.19	**0.63**
Other	malignant	0.00	0.01	0.00	0.02	0.01	0.03	0.00	0.03	0.01	0.01	0.01	0.06	0.08	0.02	0.00	**0.02**
Other CNS	non-malignant	0.01	0.00	0.04	0.06	0.03	0.07	0.06	0.04	0.12	0.12	0.12	0.16	0.08	0.14	0.10	**0.07**
	total	0.01	0.01	0.04	0.08	0.04	0.10	0.06	0.07	0.13	0.13	0.14	0.21	0.16	0.16	0.10	**0.09**
Total malignant		**1.51**	**1.89**	**2.13**	**3.16**	**3.47**	**4.20**	**5.40**	**7.61**	**10.72**	**13.30**	**17.18**	**17.93**	**18.71**	**15.50**	**10.38**	**7.54**
Total non-malignant		**1.22**	**1.95**	**2.70**	**3.34**	**4.11**	**5.36**	**7.24**	**8.50**	**9.72**	**10.93**	**11.40**	**13.40**	**15.29**	**15.77**	**15.40**	**7.20**
Total		**2.73**	**3.84**	**4.83**	**6.50**	**7.57**	**9.56**	**12.64**	**16.12**	**20.44**	**24.23**	**28.58**	**31.33**	**34.00**	**31.27**	**25.78**	**14.74**

Persons: annual age specific mortality rates per 1,000,000 population, 1995-2000 England & Wales

		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	total
Intracranial intra-axial	malignant	4.69	7.49	10.02	16.83	23.77	34.48	52.46	79.35	107.06	135.54	169.39	177.25	161.95	126.13	77.92	**64.74**
(excludes pineal)	non-malignant	0.75	1.43	1.15	1.83	3.22	4.39	6.81	9.22	13.70	20.22	31.27	53.59	78.16	96.53	86.46	**16.82**
	total	5.45	8.93	11.17	18.67	26.99	38.87	59.27	88.57	120.77	155.77	200.66	230.84	240.11	222.66	164.38	**81.56**
Intracranial extra-axial	malignant	0.05	0.05	0.04	0.00	0.13	0.15	0.14	0.50	0.61	1.07	1.29	0.95	1.36	1.34	1.22	**0.43**
Intracranial meningeal	non-malignant	0.00	0.16	0.35	0.20	0.52	0.88	1.40	2.31	3.55	5.87	8.89	16.55	25.99	36.74	42.36	**5.45**
	total	0.05	0.21	0.40	0.20	0.65	1.02	1.55	2.81	4.16	6.94	10.18	17.50	27.35	38.08	43.58	**5.88**
Intracranial extra-axial	malignant	0.05	0.00	0.00	0.04	0.09	0.10	0.00	0.15	0.00	0.07	0.07	0.08	0.39	0.00	0.17	**0.07**
Cranial nerve	non-malignant	0.05	0.00	0.18	0.08	0.04	0.05	0.14	0.40	0.37	0.40	0.65	0.87	2.72	2.38	1.92	**0.43**
	total	0.11	0.00	0.18	0.12	0.13	0.15	0.14	0.55	0.37	0.47	0.72	0.95	3.10	2.38	2.09	**0.50**
Sellar	malignant	0.00	0.00	0.00	0.04	0.13	0.10	0.19	0.10	0.24	0.47	0.36	0.63	0.48	0.89	0.00	**0.19**
	non-malignant	0.22	0.16	0.22	0.20	0.22	0.15	0.53	0.90	0.73	1.20	1.79	1.89	2.62	2.08	2.09	**0.75**
	total	0.22	0.16	0.22	0.24	0.35	0.24	0.72	1.00	0.98	1.67	2.15	2.52	3.10	2.97	2.09	**0.93**
Pineal	malignant	0.22	0.16	0.09	0.16	0.00	0.05	0.10	0.05	0.31	0.20	0.14	0.08	0.00	0.15	0.17	**0.12**
	non-malignant	0.00	0.00	0.13	0.00	0.00	0.00	0.00	0.10	0.12	0.00	0.00	0.16	0.00	0.15	0.00	**0.04**
	total	0.22	0.16	0.22	0.16	0.00	0.05	0.10	0.15	0.43	0.20	0.14	0.24	0.00	0.30	0.17	**0.16**
Spinal	malignant	0.05	0.11	0.04	0.20	0.17	0.39	0.34	0.20	0.61	0.93	1.36	1.26	1.16	2.53	1.57	**0.52**
Spinal cord	non-malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.05	0.00	0.00	0.22	0.00	0.10	0.00	0.00	**0.02**
	total	0.05	0.11	0.04	0.20	0.17	0.39	0.34	0.25	0.61	0.93	1.58	1.26	1.26	2.53	1.57	**0.54**
Spinal	malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.08	0.19	0.00	0.00	**0.01**
Spinal meninges	non-malignant	0.00	0.00	0.00	0.00	0.00	0.05	0.00	0.00	0.00	0.00	0.14	0.08	0.10	0.00	0.35	**0.03**
	total	0.00	0.00	0.00	0.00	0.00	0.05	0.00	0.00	0.00	0.00	0.14	0.16	0.29	0.00	0.35	**0.04**
Other	malignant	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	**-**
Uncertain behaviour brain &	non-malignant	0.00	0.11	0.13	0.08	0.09	0.05	0.10	0.30	0.31	0.07	0.29	0.71	0.58	0.30	0.17	**0.18**
spinal cord	total	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	**-**
Other	malignant	0.00	0.05	0.00	0.04	0.04	0.05	0.05	0.10	0.00	0.00	0.07	0.08	0.10	0.15	0.17	**0.05**
Other central nervous system	non-malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.05	0.00	0.06	0.00	0.00	0.00	0.00	0.15	0.00	**0.01**
(CNS) and meninges	total	0.00	0.05	0.00	0.04	0.04	0.05	0.10	0.10	0.06	0.00	0.07	0.08	0.10	0.30	0.17	**0.06**
Total malignant		**5.07**	**7.86**	**10.20**	**17.32**	**24.34**	**35.31**	**53.28**	**80.45**	**108.84**	**138.28**	**172.69**	**180.40**	**165.63**	**131.19**	**81.23**	**66.13**
Total non-malignant		**1.02**	**1.86**	**2.16**	**2.40**	**4.09**	**5.56**	**9.03**	**13.28**	**18.84**	**27.76**	**43.24**	**73.85**	**110.26**	**138.33**	**133.35**	**23.73**
Total		**6.09**	**9.72**	**12.36**	**19.73**	**28.43**	**40.87**	**62.32**	**93.73**	**127.68**	**166.04**	**215.93**	**254.24**	**275.89**	**269.51**	**214.59**	**89.86**

Males: annual age specific mortality rates per 1,000,000 population, 1995-2000 England & Wales

		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	total
Intracranial intra-axial	malignant	4.48	8.99	11.64	18.80	28.24	42.11	68.63	97.69	135.08	162.10	206.66	223.44	201.99	170.13	121.09	**77.46**
(excludes pineal)	non-malignant	0.64	1.93	1.34	2.39	4.03	5.30	7.68	10.17	16.28	24.07	34.80	58.46	90.17	120.56	130.25	**17.41**
	total	5.12	10.91	12.98	21.19	32.28	47.41	76.32	107.87	151.36	186.17	241.46	281.90	292.16	290.70	251.34	**94.87**
Intracranial extra-axial	malignant	0.00	0.11	0.00	0.00	0.18	0.29	0.10	0.40	0.49	1.09	1.06	0.88	0.95	2.10	1.96	**0.39**
Intracranial meningeal	non-malignant	0.00	0.21	0.45	0.25	0.53	0.69	1.17	2.22	3.58	5.03	6.20	14.79	19.03	30.67	37.31	**3.83**
	total	0.00	0.32	0.45	0.25	0.70	0.98	1.26	2.62	4.07	6.12	7.26	15.67	19.98	32.77	39.27	**4.22**
Intracranial extra-axial	malignant	0.11	0.00	0.00	0.00	0.09	0.10	0.00	0.00	0.00	0.14	0.00	0.00	0.71	0.00	0.00	**0.06**
Cranial nerve	non-malignant	0.00	0.00	0.09	0.08	0.09	0.10	0.10	0.20	0.62	0.27	0.15	0.70	2.38	2.94	1.31	**0.32**
	total	0.11	0.00	0.09	0.08	0.18	0.20	0.10	0.20	0.62	0.41	0.15	0.70	3.09	2.94	1.31	**0.38**
Sellar	malignant	0.00	0.00	0.00	0.08	0.09	0.10	0.39	0.20	0.12	0.27	0.61	0.70	0.24	0.84	0.00	**0.19**
	non-malignant	0.32	0.32	0.27	0.33	0.35	0.20	0.68	0.50	0.62	1.77	1.82	1.41	2.85	2.52	5.24	**0.79**
	total	0.32	0.32	0.27	0.41	0.44	0.29	1.07	0.71	0.74	2.04	2.42	2.11	3.09	3.36	5.24	**0.99**
Pineal	malignant	0.43	0.32	0.18	0.25	0.00	0.00	0.10	0.10	0.12	0.14	0.30	0.18	0.00	0.42	0.65	**0.18**
	non-malignant	0.00	0.00	0.18	0.00	0.00	0.00	0.00	0.10	0.25	0.00	0.00	0.18	0.00	0.00	0.00	**0.05**
	total	0.43	0.32	0.36	0.25	0.00	0.00	0.10	0.20	0.37	0.14	0.30	0.35	0.00	0.42	0.65	**0.23**
Spinal	malignant	0.11	0.11	0.09	0.41	0.26	0.39	0.39	0.20	0.62	1.09	1.06	1.41	1.67	2.94	3.93	**0.58**
Spinal cord	non-malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.10	0.00	0.00	0.45	0.00	0.00	0.00	0.00	**0.03**
	total	0.11	0.11	0.09	0.41	0.26	0.39	0.39	0.30	0.62	1.09	1.51	1.41	1.67	2.94	3.93	**0.61**
Spinal	malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.18	0.48	0.00	0.00	**0.03**
Spinal meninges	non-malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.65	**0.01**
	total	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.18	0.48	0.00	0.65	**0.03**
Other	malignant	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	**-**
Uncertain behaviour brain &	non-malignant	0.00	0.21	0.27	0.00	0.00	0.10	0.10	0.30	0.49	0.14	0.61	1.06	0.48	0.42	0.00	**0.23**
spinal cord	total	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	**-**
Other	malignant	0.00	0.11	0.00	0.08	0.09	0.00	0.10	0.00	0.00	0.00	0.00	0.18	0.00	0.00	0.00	**0.04**
Other central nervous system	non-malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.10	0.00	0.12	0.00	0.00	0.00	0.00	0.00	0.00	**0.02**
(CNS) and meninges	total	0.00	0.11	0.00	0.08	0.09	0.00	0.19	0.00	0.12	0.00	0.00	0.18	0.00	0.00	0.00	**0.06**
Total malignant		**5.12**	**9.63**	**11.90**	**19.62**	**28.95**	**42.99**	**69.70**	**98.60**	**136.44**	**164.82**	**209.69**	**226.96**	**206.03**	**176.43**	**127.63**	**78.93**
Total non-malignant		**0.96**	**2.67**	**2.60**	**3.05**	**5.00**	**6.38**	**9.82**	**13.60**	**21.96**	**31.28**	**44.03**	**76.59**	**114.91**	**157.11**	**174.76**	**22.69**
Total		**6.07**	**12.30**	**14.50**	**22.67**	**33.95**	**49.37**	**79.52**	**112.20**	**158.39**	**196.09**	**253.71**	**303.56**	**320.95**	**333.54**	**302.40**	**101.62**

Females: annual age specific mortality rates per 1,000,000 population, 1995-2000 England & Wales

		15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+	total
Intracranial intra-axial	malignant	4.91	6.02	8.45	14.91	19.36	26.95	36.49	61.17	79.50	109.95	135.80	139.81	134.39	102.01	62.25	**53.00**
(excludes pineal)	non-malignant	0.87	0.95	0.96	1.29	2.42	3.49	5.95	8.28	11.17	16.51	28.09	49.65	69.90	83.36	70.57	**16.27**
	total	5.78	6.97	9.41	16.20	21.78	30.44	42.44	69.45	90.66	126.47	163.88	189.46	204.29	185.37	132.82	**69.28**
Intracranial extra-axial	malignant	0.11	0.00	0.09	0.00	0.09	0.00	0.19	0.60	0.73	1.05	1.50	1.00	1.64	0.92	0.95	**0.47**
Intracranial meningeal	non-malignant	0.00	0.11	0.26	0.16	0.52	1.07	1.63	2.39	3.52	6.68	11.32	17.98	30.77	40.07	44.19	**6.95**
	total	0.11	0.11	0.35	0.16	0.61	1.07	1.82	2.99	4.25	7.73	12.82	18.97	32.41	40.99	45.14	**7.42**
Intracranial extra-axial	malignant	0.00	0.00	0.00	0.08	0.09	0.10	0.00	0.30	0.00	0.00	0.14	0.14	0.16	0.00	0.24	**0.08**
Cranial nerve	non-malignant	0.11	0.00	0.26	0.08	0.00	0.00	0.19	0.60	0.12	0.52	1.09	1.00	2.95	2.07	2.14	**0.53**
	total	0.11	0.00	0.26	0.16	0.09	0.10	0.19	0.90	0.12	0.52	1.23	1.14	3.11	2.07	2.38	**0.61**
Sellar	malignant	0.00	0.00	0.00	0.00	0.17	0.10	0.00	0.00	0.36	0.66	0.14	0.57	0.65	0.92	0.00	**0.19**
	non-malignant	0.11	0.00	0.17	0.08	0.09	0.10	0.38	1.30	0.85	0.66	1.77	2.28	2.46	1.84	0.95	**0.70**
	total	0.11	0.00	0.17	0.08	0.26	0.19	0.38	1.30	1.21	1.31	1.91	2.85	3.11	2.76	0.95	**0.89**
Pineal	malignant	0.00	0.00	0.00	0.08	0.00	0.10	0.10	0.00	0.49	0.26	0.00	0.00	0.00	0.00	0.00	**0.07**
	non-malignant	0.00	0.00	0.09	0.00	0.00	0.00	0.00	0.10	0.00	0.00	0.00	0.14	0.00	0.23	0.00	**0.03**
	total	0.00	0.00	0.09	0.08	0.00	0.10	0.10	0.10	0.49	0.26	0.00	0.14	0.00	0.23	0.00	**0.10**
Spinal	malignant	0.00	0.11	0.00	0.00	0.09	0.39	0.29	0.20	0.61	0.79	1.64	1.14	0.82	2.30	0.71	**0.46**
Spinal cord	non-malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.16	0.00	0.00	**0.01**
	total	0.00	0.11	0.00	0.00	0.09	0.39	0.29	0.20	0.61	0.79	1.64	1.14	0.98	2.30	0.71	**0.47**
Spinal	malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	**0.00**
Spinal meninges	non-malignant	0.00	0.00	0.00	0.00	0.00	0.10	0.00	0.00	0.00	0.00	0.27	0.14	0.16	0.00	0.24	**0.05**
	total	0.00	0.00	0.00	0.00	0.00	0.10	0.00	0.00	0.00	0.00	0.27	0.14	0.16	0.00	0.24	**0.05**
Other	malignant	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	**-**
Uncertain behaviour brain &	non-malignant	0.00	0.00	0.00	0.16	0.17	0.00	0.10	0.30	0.12	0.00	0.00	0.43	0.65	0.23	0.24	**0.14**
spinal cord	total	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	**-**
Other	malignant	0.00	0.00	0.00	0.00	0.00	0.10	0.00	0.20	0.00	0.00	0.14	0.00	0.16	0.23	0.24	**0.05**
Other central nervous system	non-malignant	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.23	0.00	**0.01**
(CNS) and meninges	total	0.00	0.00	0.00	0.00	0.00	0.10	0.00	0.20	0.00	0.00	0.14	0.00	0.16	0.46	0.24	**0.06**
Total malignant		**5.02**	**6.12**	**8.54**	**15.07**	**19.80**	**27.72**	**37.07**	**62.47**	**81.68**	**112.71**	**139.34**	**142.67**	**137.83**	**106.39**	**64.39**	**54.32**
Total non-malignant		**1.09**	**1.06**	**1.74**	**1.77**	**3.20**	**4.75**	**8.26**	**12.97**	**15.78**	**24.38**	**42.54**	**71.62**	**107.06**	**128.03**	**118.32**	**24.69**
Total		**6.11**	**7.18**	**10.28**	**16.84**	**22.99**	**32.47**	**45.32**	**75.44**	**97.46**	**137.08**	**181.88**	**214.29**	**244.89**	**234.42**	**182.71**	**79.01**

15 Appendix H. Mapping of catchment populations: neurosurgical units and cancer networks

Neurosurgical units that manage adult patients with tumours of the brain / CNS and their relation to Cancer Networks

Units outside London

Neurosurgical unit	Cancer network
Neurosurgical units with a catchment area within one cancer network	
Newcastle General Hospital, NEWCASTLE	• Northern
Middlesbrough General Hospital MIDDLESBROUGH†	• Teesside, South Durham and North Yorkshire†
Royal Preston Hospital, PRESTON	• Lancashire & South Cumbria
Hull Royal Infirmary HULL	• Humber & Yorkshire Coast
Leeds General Infirmary, LEEDS	• Yorkshire
Hope Hospital, SALFORD, Manchester	• Greater Manchester and Cheshire*
Walton Centre for Neurology & Neurosurgery, LIVERPOOL	• Merseyside & Cheshire; & North Wales (who refer neuro-oncology patients to Merseyside & Cheshire)* [Also Small overlap with Lancashire & South Cumbria]
Walsgrave Hospital, COVENTRY	• Arden*
Morriston Hospital, SWANSEA	• South West Wales*
Derriford Hospital, PLYMOUTH	• Peninsula
Neurosurgical units with catchment are covering one network and overlapping with the area of a second or third network	
Royal Hallamshire Hospital, SHEFFIELD	• North Trent • [Overlaps with part of Mid Trent•]
University Hospital of Wales, CARDIFF	• South East Wales • [Overlaps with part of South West Wales]
North Staffordshire Hospital, STOKE on TRENT	• North West Midlands [part] • Greater Manchester and Cheshire [part] • [small overlap with part of Merseyside & Cheshire]
Frenchay Hospital, BRISTOL	• Avon, Somerset & Wiltshire [part] • 3 Counties [part]
Oxford Radcliffe Hosptials, OXFORD	• Thames Valley* • Leicestershire, Northamptonshire & Rutland [part]

	• Avon, Somerset & Wiltshire [part] • [& Small part of 3 counties]
Hurstwood Park Neurological Centre, HAYWARDS HEATH, West Sussex	• Sussex • [Overlaps with part of Surrey, West Sussex & Hampshire]
Neurosurgical units with their catchment areas covering at least two networks	
Queen's Medical Centre NOTTINGHAM	• Mid Trent* • Derby/Burton • Leicestershire, Northamptonshire & Rutland [part]
Queen Elizabeth Hospital BIRMINGHAM	• Pan Birmingham • Black Country • Arden [part] • North West Midlands [part] • 3 Counties [part] [South West Wales, part]‡
Addenbrooke's Hospital, CAMBRIDGE	• West Anglia* • Norfolk & Waveney • Mid Anglia [part] • [Overlaps with part of Mount Vernon]
Southampton General Hospital SOUTHAMPTON	• Central South Coast • Dorset

*Network spans more than one neurosurgery catchment

•This overlap is confirmed by commented on in questionnaire responses

† Although an area of the Neurosurgical unit lies beyond the boundaries of the network, the radiotherapy unit catchment areas of that network also lie beyond the network boundaries in a similar distribution.

‡ The radiotherapy units covering this part of Wales are part of other Networks included that overlap with Queen Elizabeth Birmingham neurosurgery catchment areas

London and Greater London based Neurosurgical Units
(See comment re London based units)

Neurosurgical unit	**Cancer network**
Oldchurch Hospital ROMFORD Essex	• South Essex • North East London [part] • Mid Anglia [part]
Atkinson Morley's Hospital (St George's) LONDON	• South West London • Surrey, West Sussex & Hampshire [part]
King's College Hospital LONDON	• South East London • Kent & Medway
Charing Cross Hospital LONDON	• West London • [Overlaps with part of Thames Valley]
Royal Free Hospital LONDON	• North London • Mount Vernon [part]
St Bartholomew's and The Royal London Hospitals, LONDON	• North East London [part] • West Anglia [part]
Institute of Neurology National Hospital for Neurology & Neurosurgery, LONDON	*Catchment unclear – appears to include parts of*: • West London • Mount Vernon • And others

Cancer Networks and neurosurgical units that manage adult patients with tumours of the brain / CNS

Units outside London

Cancer Network	Neurosurgical unit
Network covers an area covered by a single neurosurgical unit	
Northern	• Newcastle General Hospital, NEWCASTLE
Teesside, South Durham and North Yorkshire†	• Middlesbrough General Hospital MIDDLESBROUGH†
Lancashire & South Cumbria	• Royal Preston Hospital, PRESTON [Small overlap with Walton Centre for Neurology & Neurosurgery, LIVERPOOL]
Humber & Yorkshire Coast	• Hull Royal Infirmary, HULL
Yorkshire	• Leeds General Infirmary, LEEDS
Merseyside & Cheshire; & North Wales (Refers neuro-oncology patients to Merseyside & Cheshire)	• Walton Centre for Neurology & Neurosurgery, LIVERPOOL [Small overlap with North Staffordshire Hospital, STOKE on TRENT]
North Trent	• Royal Hallamshire Hospital, SHEFFIELD
Derby/Burton	• Queen's Medical Centre, NOTTINGHAM
Norfolk & Waveney	• Addenbrooke's Hospital, CAMBRIDGE
Black Country	• Queen Elizabeth Hospital, BIRMINGHAM
Pan Birmingham	• Queen Elizabeth Hospital, BIRMINGHAM
South East Wales	• University Hospital of Wales, CARDIFF
Central South Coast	• Southampton General Hospital, SOUTHAMPTON
Peninsula	• Derriford Hospital, PLYMOUTH
Dorset	• Southampton General Hospital, SOUTHAMPTON
Sussex	• Hurstwood Park Neurological Centre, HAYWARDS HEATH, West Sussex
Network covers areas covered by more than one unit	
Greater Manchester and Cheshire	• Hope Hospital, SALFORD, Manchester • North Staffordshire Hospital, STOKE on TRENT
Mid Trent	• Queen's Medical Centre, NOTTINGHAM • Royal Hallamshire Hospital, SHEFFIELD•
Leicestershire, Northamptonshire & Rutland	• Queen's Medical Centre, NOTTINGHAM • Oxford Radcliffe Hosptials, OXFORD
South West Wales	• Morriston Hospital, SWANSEA

	• University Hospital of Wales, CARDIFF [Queen Elizabeth Hospital. BIRMINGHAM]‡
North West Midlands	• North Staffordshire Hospital, STOKE on TRENT • Queen Elizabeth Hospital, BIRMINGHAM
West Anglia*	• Addenbrooke's Hospital, CAMBRIDGE • St Bartholomew's and The Royal London Hospitals, LONDON
Arden	• Walsgrave Hospital, COVENTRY • Queen Elizabeth Hospital, BIRMINGHAM
3 Counties	• Frenchay Hospital, BRISTOL • Queen Elizabeth Hospital, BIRMINGHAM [Small part of Oxford Radcliffe Hosptials, OXFORD]
Thames Valley*	• Oxford Radcliffe Hosptials, OXFORD • Charing Cross Hospital, LONDON [Overlap]
Mid Anglia*	• Addenbrooke's Hospital, CAMBRIDGE • Oldchurch Hospital, ROMFORD, Essex
Mount Vernon*	• Addenbrooke's Hospital, CAMBRIDGE • Royal Free Hospital, LONDON • +/- Institute of Neurology National Hospital for Neurology & Neurosurgery, LONDON
Avon, Somerset & Wiltshire [part]	• Frenchay Hospital, BRISTOL • Oxford Radcliffe Hosptials, OXFORD
Surrey, West Sussex & Hampshire	• Atkinson Morley's Hospital, (St George's) LONDON • Hurstwood Park Neurological Centre, HAYWARDS HEATH, West Sussex

*Network spans neurosurgery catchment area based in London

•This overlap is confirmed by commented on in questionnaire responses

† Although an area of the Neurosurgical unit lies beyond the boundaries of the network, the radiotherapy unit catchment areas of that network also lie beyond the network boundaries in a similar distribution.

‡ The radiotherapy units covering this part of Wales are part of other Networks included that overlap with Queen Elizabeth Birmingham neurosurgery catchment areas

London and Greater London based Neurosurgical Units
(See comment re London based units; also units in above table marked with * include some London based units' neurosurgery catchment areas).

Cancer network	Neurosurgical unit
• South Essex	• Oldchurch Hospital, ROMFORD, Essex
• South East London	• King's College Hospital, LONDON
• Kent & Medway	• King's College Hospital, LONDON
• North London	• Royal Free Hospital, LONDON
• South West London	• Atkinson Morley's Hospital, (St George's) LONDON
• North East London	• Oldchurch Hospital, ROMFORD, Essex • St Bartholomew's and The Royal London Hospitals, LONDON
• West London	• Charing Cross Hospital, LONDON • +/- Institute of Neurology National Hospital for Neurology & Neurosurgery, LONDON

16 Appendix I. Responses from Questionnaires

RESPONSES FROM RADIOTHERAPY SITES (received in time for inclusion in analysis)			
Department Name	Hospital	RESPONSE RECEIVED	
		Yes	No
N Essex Cancer Partnership	Essex County Hospital	✓	
Suffolk Oncology Centre	Ipswich Hospital	✓	
Oncology Centre (Box 193)	Addenbrooke's Hospital	✓	
Clinical Oncology Department	Southend Hospital	✓	
Clinical Oncology & Radiotherapy Department	Norfolk & Norwich Hospital	✓	
Meyerstein Institute of Oncology	Middlesex Hospital	✓	
Clinical Oncology Department	North Middlesex Hospital	✓	
Clinical Oncology Department	Royal Free Hospital	✓	
Clinical Oncology Department	Oldchurch Hospital	✓	
Radiotherapy Department	Royal London Hospital	✓	
Guy's & St. Thomas' Cancer Centre	St. Thomas' Hospital	✓	
Radiotherapy Department	Royal Marsden Hospital	✓	
Clinical Oncology Department	Charing Cross Hospital	✓	
Radiotherapy Department	Mount Vernon Cancer Centre	✓	
Radiotherapy Department	Christie Hospital	✓	
Lancs & Lakeland Radiotherapy Unit	Royal Preston Hospital	✓	
Radiotherapy Department	Clatterbridge Centre for Oncology	✓	
Clinical Oncology Department	Princess Royal Hospital	✓	
Clinical Oncology Department	Cumberland Infirmary	✓	
Northern Centre for Cancer Treatment	Newcastle General Hospital	✓	
Clinical Oncology Department	South Cleveland Hospital	✓	
Department of Radiotherapy	Cookridge Hospital	✓	
Clinical Oncology Department	Northampton General Hospital	✓	
Clinical Oncology Department	Oxford Radcliffe Hospital	✓	
Clinical Oncology Department	Royal Berkshire Hospital	✓	
Wessex Radiotherapy Centre	Royal South Hants Hospital		×
Portsmouth Oncology Centre	St. Mary's Hospital	✓	
Clinical Oncology Department	Kent & Canterbury Hospital	✓	

RESPONSES FROM RADIOTHERAPY SITES
(received in time for inclusion in analysis)

Department Name	Hospital	RESPONSE RECEIVED	
		Yes	No
Kent Cancer Service	Maidstone Hospital	✓	
St. Luke's Cancer Centre	Royal Surrey County Hospital	✓	
Sussex Oncology Centre	Royal Sussex County Hospital	✓	
Gloucestershire Oncology Centre	General Hospital	✓	
Bristol Oncology Centre	Bristol Royal Infirmary	✓	
Radiotherapy Department	Royal United Hospital	✓	
Clinical Oncology Department	Derriford Hospital	✓	
Clinical Oncology Department	Royal Cornwall Hospital		×
Exeter Oncology Centre	Royal Devon & Exeter Hospital	✓	
Radiotherapy Department	Torbay Hospital	✓	
Dorset Cancer Centre	Poole General Hospital	✓	
Clinical Oncology Department	Derbyshire Royal Infirmary		×
Clinical Oncology Department	Leicester Royal Infirmary	✓	
Clinical Oncology Department	City Hospital	✓	
Clinical Oncology Department	County Hospital	✓	
Clinical Oncology Department	Weston Park Hospital	✓	
Coventry Radiotherapy & Oncology Centre	Walsgrave Hospital		×
Birmingham Oncology Centre	Queen Elizabeth Hospital	✓	
Deanesly Centre for Oncology	New Cross Hospital	✓	
Staffs Oncology Centre	North Staffs Royal Infirmary	✓	
Clinical Oncology Department	Royal Shrewsbury Hospital	✓	
N Wales Cancer Treatment Centre	Glan Clwyd D G Hospital	✓	
Clinical Oncology Department	Singleton Hospital	✓	
S Wales Radiotherapy Service	Velindre Trust	✓	

RESPONSES FROM NEUROSURGICAL SITES

TRUST NAME	RESPONSE RECEIVED	
	Yes	
University Hospital Birmingham NHS Trust	✓	
Queen's Medical Centre, Nottingham University Hospital	✓	
Sheffield Teaching Hospitals NHS Trust	✓	
King's College Hospital NHS Trust	✓	
Oxford Radcliffe Hospital NHS Trust	✓	
Addenbrooke's NHS Trust	✓	
Walton Centre for Neurology & Neurosurgery	✓	
Southampton University Hospitals NHS Trust	✓	
St. George's Healthcare NHS Trust	✓	
Leeds Teaching Hospitals NHS Trust	✓	
North Bristol NHS Trust	✓	
Salford Royal Hospitals NHS Trust	✓	
The Newcastle Upon Tyne Hospitals NHS Trust	✓	
Royal Free Hampstead NHS Trust	✓	
Hammersmith Hospitals NHS Trust	✓	
Lancashire Teaching Hospitals NHS Trust	✓	
Barking, Havering & Redbridge Hospitals NHS Trust	✓	
Barts & The London NHS Trust	✓	
Plymouth Hospitals NHS Trust	✓	
Cardiff & Vale NHS Trust	✓	
University College London Hospitals NHS Trust	✓	
Brighton & Sussex University Hospitals NHS Trust	✓	
Hull & East Yorkshire Hospitals NHS Trust	✓	
North Staffordshire Hospital NHS Trust	✓	
South Tees Hospitals NHS Trust	✓	
Swansea NHS Trust	✓	
University Hospitals Coventry & Warwickshire	✓	

17 Appendix J Variation of radiotherapy unit responses with unit size

For most facilities / waiting times there was little evidence in the size of unit being related to the presence / absence of a facility (Figure 35, Figure 36, Table 45). Larger units were more likely to have their own MDT, and larger units were more likely to have a clinical nurse specialist in neuro-oncology, and palliative care consultant.

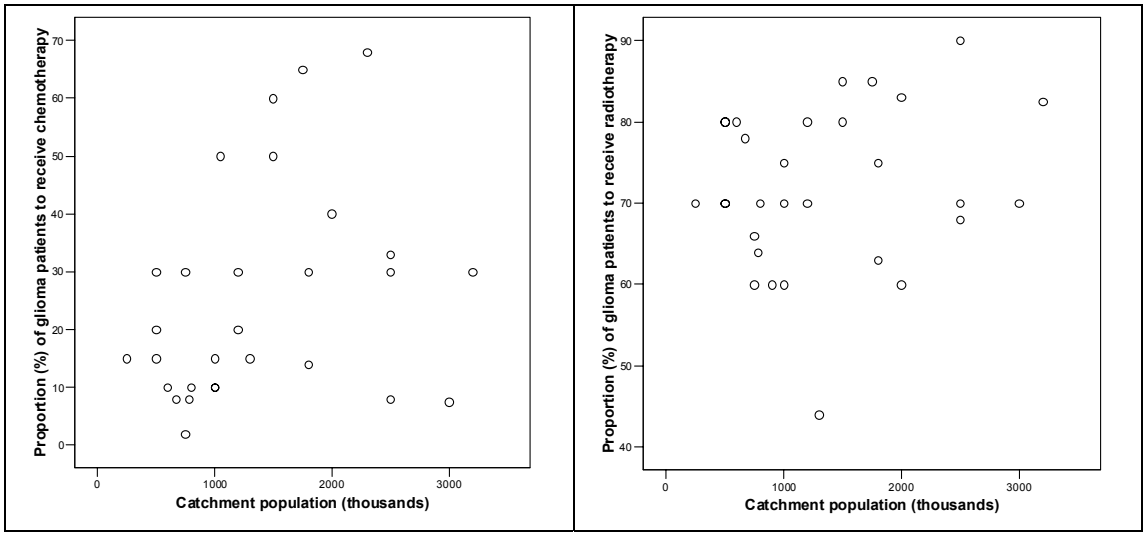

Figure 35 Scattergrams of proportion of patients receiving chemotherapy and radiotherapy against catchment population for neuro-oncology.

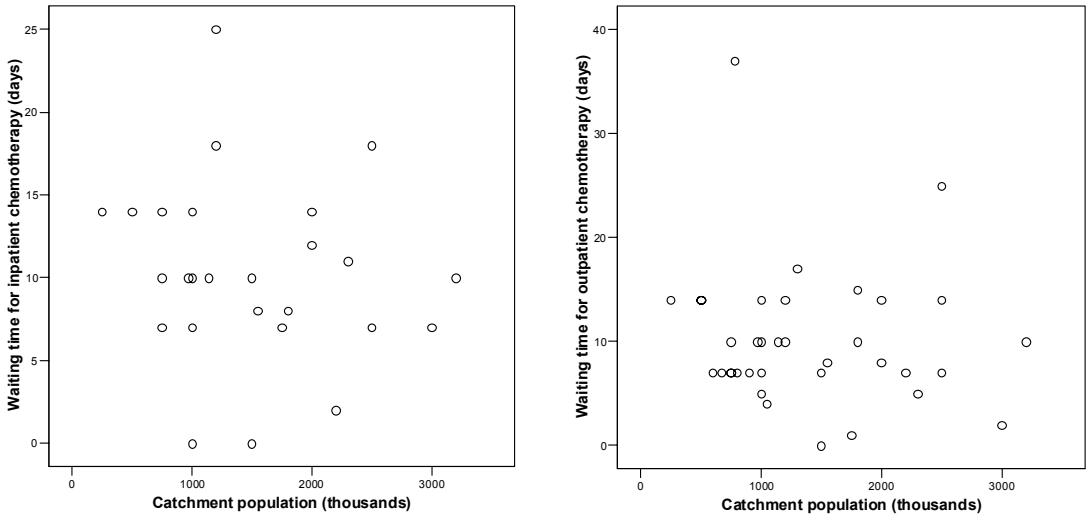

Figure 36 Scattergram of average (mean) waiting times for various neuro-oncology interventions against catchment population for neuro-oncology.

Table 45 Relationship between size of unit (self estimated catchment population size) and presence or absence of services on-site.

	Average catchment pop. size (000's)			P value*
	Units with access	Units without access	Difference	
CNSNO	1,650	857	793	0.001
MDT**	1,525	914	611	0.04
On-site access				
SALT	1,288	2,018	-729	0.10
Social worker	1,388	1,087	301	0.64
Palliative care consultant	1,458	883	575	0.03
Neurologist with epilepsy interest	1,318	1,439	-121	0.81
Neuro-psych.	1,389	1,357	32	0.40
Local patient support group	1,461	1,300	161	0.43
Any access (on/off site)				
Specialist neuro-rehabilitation unit	1,242	1,630	-388	0.25
Videoconferencing	1,109	1,518	-409	0.25
PET	1,420	1,312	107	0.56
SPECT	1,602	1,204	397	0.13
Molecular pathology	1,596	1,237	359	0.12

- indicates units with access have lower mean catchment populations. CNSNO = clinical nurse specialist in neuro-oncology. * Two-tailed t-test; catchment population transformed to natural log (improved normality of variable). ** Yes vs. no (in development excluded).

18 Appendix K. Full neurosurgical unit responses

Order is from lowest to highest self estimated catchment sizes. Exact response is entered where possible (e.g. blanks entries are not assumed to be "0")

General information including numbers of patients seen

id	Location	Estimtd Catchmt pop.	Method of estimation where stated	No. of new pts seen by dept / year	No. new pts that are brain / CNS tumour pts	FCEs for CNS cancers
11	University hospital	1000		423 EIIP, 463 EIP, 1071 OP	100-120	
25	DGH	1100	SBNS figures/local population	1200 OP, 1600 IP	U/K	
1	Acute trust	1200		1143	80-100	
5	University hospital	1200	Census	~2000	~100	900 (2002/3)
2	Teaching	1300		1608	100-120	
16	University hospital	1400		1850	240	
17	University hospital	1500		110 OP, 1269 IP, 704 EA	~180	
19	University hospital	1600	Resident (census data) rises to an estimated 2.0 million for 3-4 months per year	1725	U/K	
12	DGH	1650	PCT	2000	100	
8	University hospital	1700	Safe Neurosurgery 2000	2433*	176**	
7	University hospital	2000		1200	250	
13	Associate teaching hospital	2000				
9	University hospital	2200	Addition of DGH catchment	2294	U/K	
10	University hospital	2200		2400 OP		~1400
20	Acute Surgical & University link	2200		1982	?	
27	University hospital	2400				
15	University hospital	2500		1988 NOP	63	443
23	University hospital	2500		1180	216	318 (2002/3)
6	University hospital	3000	2.8m (safe neurosurgery) to 3.0m (local health authority/PCT totals)	2500 EA & NIP		
14	University hospital	3000	known surrounding population	1296 OP, 1500 EA	600-700	
18	University hospital	3000		5000	250	
21	University hospital	3000	DGH catchments - total SAH cases	1792		
3	University hospital	3200	SBNS/"Safe Neurosurgery"	2000 NIP,1100 NOP		
24	University hospital	3200		2500	400	
26	University	3200			200	
4	University hospital	3350	Trust catchment=750,000 plus Yorkshire Cancer Network=2.6 million	1877		
22	University hospital	3500		1466 OP, 2179 IP	N/A	

U/K = Unknown; (N)IP: (New) Inpatients; (N) OP: (New) Out patients; EIIP Elective Inpatients; EA: Emergency Admissions. *2000-2001. **Operated on; no reliable data for not operated on.

Designated neurosurgical beds (* indicates not designated / shared with other specialities)

id	Ward beds	High dependency/ step down	Critical care	Total	Comments
11	26	12*	12*	50*	8 HDU, 4 Stepdown
25	28	4	16*	48*	Funding recently aquired to develop 4 level 1 beds. On average 4-6 neuro patients in ITU beds
1	30	6	5(6)	41	Adult beds
5	26	4	8*	38*	
2	26	7	4	37	+2 unstaffed ITU beds
16	22	2	3	27	
17	27	7	Variable	34+	
19	41	7	4	52	Ward beds from Oct 2003 when ward opens.Also access to general ITU beds
12	31	3	11	45	
8	39	6	15*	45	
7	50	12	8	70	
13	32	8	3	43	
9	28	7*	10*	45	
10	29		6	35-43	Soon to be 14 ITU
20	53*	6*	10*	71*	+ 2 post-op ventilator beds. Ward beds: 49 x 7-day, 4 x 5-day. Access to further 12 paediatric ward beds; 2 paediatric HDU;
27	36	5		41	5 = High dependency/step-dopwn and critical care beds in total as combination
15	52	8	13	73	
23	38	4	8	50	
6	51(43)	6	7	64(53)	Ward beds closed for hospital savings, ITU beds closed due to lack of staff. (Current numbers). Currently 10 flexible High dependency / ITU beds.
14	64	5	7	76	
18	60	13	8(6)	81	Adults
21	36		17	53	
3	36	8*	14*	36	
24	56	12	4	72	
26	64	4	9+4	77	
4	48	8	7	63	
22	68	8	8	84	

1st DRAFT (issued with 2nd draft of Guidance Manual)

Questions relating to operations.

id	No. of OT sessions	Total proc. of dept	Year of data supplied	Number of procedures for brain / CNS tumours							Other Comments
				Total	Open	Stereotact. biopsies	Spinal (primary)	Spinal (mets.)	Pit./cranio ph.	Acoustic / skull base	
11	14¤	1000-1200	2003§		60	6	4	10	12	2	§
25	15	926**	*04/2003-03/2004	115	74	13	5	7	9	7	*
1	11	800		138	76	23	8	8	11	4	
5	10	~800	2003	136	102	10			8	9	
2	14	938									
16	17¤	1121	2003	1121	186	53			33	30	18 Spinal ops in total (prim and metastases)
17	12¤	842	2003	180	51	13	16	3	26	7	
19	19¤	1300	2003	1300	120+	22	19	20-30 §	21	21	Meningiomas not coded separately (=> 21 acoustic)
12	10¤	1400	2002	121	30	60	3	10	10	8	
8	14	1031	2001 - 2002	176	72	38	1	6	43	16	
7	10¤	1000									
13	15¤										
9	12	1100-1200	2003	1093	103	74	19	8	25	19	
10	11*	1200	2003§			~70			~30		§
20	30	2559	2002	344	297	5	?	?	~40	~25	
27	4.5*										
15	30	2400	2003	413	264	64	24		52	46	
23	27*†	2000	06/2002-5/2003	2440	736	4	10	25	150	47	
6	14¤	~2000							~60	~100	
14	32	2150	2002	537	306	92	18	22	50	41	
18	27¤	2500	2003	250	150	50	20	20	30	30	
21	34¤	2102	2002-2003	2093	279	38	32	44	33	14	
3	30¤	1500	2003	365	186	84	27	0	36	32	
24	36*	1800									
26	29	2700	2003-2004		180						
4	28	1800	2003	445	318††	30	4	10	57	26	Acoustic / base of skull = 2001 figure
22	34	2650‡	04/2003-03/2004	503	307	20	38	8	24	48	

¤ Not specified whether sessions or hours, entered as sessions. * hours given, divided by 4 to calculated sessions. † 108 written, assumed to be hours. ** March 2003-April, 2004 (Reduced capacity July-Oct due to hospital move). ‡ Adults & Children. § Estimated data only. †† Open: 272 maligiant + 46 meningiomas. *Moved hospitals in Autumn 2003. Figures from trawl of log books. May be under estimate.

Staffing (Whole time equivalents)

id	Consultant neurosurgeons	Number undertaking tumour work				Neuro-oncology nurses		
		Brain/ CNS	Pit/Craniop h	Acoustic n/base skull	Spinal	Surgical	Non-surgical	Both
11	5	5	2	1	5	0	0	0
25	5	5*	1	1	5	1	0	0
1	4	4	1	1	4	0	0	0
5	4	4	2	2	4	0	1	0
2	5	5	1	1	5	1		
16	5	5	1.5	1	5			2
17	4	4	1	2	4	2		
19	7**	6	1	1	2	0	0	1
12	38	4	2	2	4			
8	55	3†	2	2††	5†††	0	0	0
7	9					2		
13	5	5	2	3	5			
9	4	4	1	1	4			1
10	4	4	1	1	4	0	1	0
20	9	9	1	4	9	0	0	1
27	7¤	7	1¤¤	1	2			1¤¤¤
15	75	9	2	2	3		1	*
23	6	6	3	3	6			1
6	63	6§	4	2	6	0	0	1
14	83	8	3	2	4	0	0	1
18	7	7	1	2	3	0	0	1
21	47	6	3	3	6	5		
3	75	75	3	1		0	0	1
24	9	9	2	2	9			1
26	11	10	2(4)	10	4	2		
4	8	8	2/3	1+7	8			1
22	10	10	2	1	8	0	1	0

*60-70% of tumours through one surgeon. ** 2 new consultants this year. † 1 dedicated and 2 occasional. †† 1 dedicated and 1 occasional. ††† 3 + 2 occasional
¤ No. of neurosurgeons to increased to 7.5 in July 2004; ¤¤1adult, 2 paediatric. ¤¤¤ No number given, just ticked. § Currently 5.8.‡ 6 surgeons
CPNs are consultant-based not disease-based in neurosurgery 4*

Multidisciplinary Team General / Cases discussed

id	Defined MDT?	How often does MDT meet?	Cases discussed			Other MDTs
			Typical no.	Preop.	Postop.	
11	Yes	Monthly	12	Complex	All postop	
25	Yes	Weekly	33	All new•	All postop	
1	Yes*	Monthly (clinics)	15*	All new•	All postop•	
5	Yes	Monthly***	6-8	All new•	All postop	Pituitary tumours monthly
2	Yes	Twice a month	7	All new•	Some postop	
16	Yes	Twice a month	25	Complex	All postop	
17	Yes	Weekly†	5-8	None preop "rarely"	All postop	
19	Yes	Weekly	15-20	All new	Some postop	Pituitary tumour
12	No					Skull base
8	No					
7	Yes	Weekly	15	All new	All postop	Skull base
13	Yes	Weekly	8-10	All new	All postop	
9	Yes	Weekly	6	None preop	All postop	
10	Yes	Weekly	2-5	Complex	All postop	Pituitary tumour
20	No**				.	Pituitary and skull base
27	Yes	Weekly	*8-12	Complex	All postop	Pituitary (wkly), Head & neck (wkly), skull base (mthly), spinal (wkly)
15	Yes	Weekly	8-10	Most new••	All postop	Pituitary tumours, skull base MDT
23	Yes	Weekly	8-10	Complex	All postop	Pituitary, skull base, spine
6	No					
14	Yes	Weekly	10	None preop	All postop	Pituitary tumours
18	Yes	Weekly	4		Some postop	Vascular (informal)
21	Yes	Weekly	15	All considered for surgery•	Some postop	Pituitary
3	Yes	Weekly	15	Complex	Some postop	Pituitary, acoustic neuroma
24	Yes	Monthly	35-40		Some postop	Pituitary
26	Yes	Weekly	6-8	Complex	Some postop	Combined pituitary meetings, base of skull
4	Yes	Weekly	5-10	Complex	All postop	
22	Yes	Two-weekly‡	6‡	All considered for surgery‡	Some postop‡	Pituitary, NF2 (monthly), Paediatric oncology

All new = "All new patients referred"; Complex = "Complex or unusual cases preoperatively only"; None preop = "No cases preoperatively". Wkly = weekly, mthly = monthly •More than one box ticked. •• As MDT is weekly some emergency cases are admitted and operated on before being discussed at MDT. * Yes ticked - "No specific MDT but all pituitary cases seen at joint clinic of neurosurgeon and endocrinologist and if DXT needed seen by neurosurgeon and radiotherapist". Number refers to outpatients. **Not yet set up due to lack of resources. ***1.Once monthly for CNS tumours, 2.Once monthly neuropath meet, 3.Once monthly for pit. Tumours. †Variable / weekly meetings with pathologist / oncologist / neurosurgeons / nurse practitioners. ‡ Refers to brain MDT, and the following refers to pituitary MDT: weekly meetings; 6 cases / meeting; Complex preop; Some post op (>50% post-op for brain). ¤ 30-35: all new patients 2-5, others on ward ~2, OPD attentenders ~12. Pts in RT ~12, community deaths. 10-6* new, ~2 follow-up.

Membershiop of MDT

id	Named lead clinician	Named oncol. / radiot.	Pathologist	Accredited neuropath	Imaging consultant	Endocrinologist	Neurologist	Psych-ologist/iatrist	Neurooncology Nurse	OT	Physio	SALT	Social Worker	Max-facial surgeon	Other Discipline
11	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N	Y	N	
25	Y	Y*	Y	Y	N	N	N	N**		Y	N	Y	Y‡	N	
1§															
5	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N	N	
2	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	
16	Y	Y	Y	Y	Y										
17	N	Y	Y	Y					Y						
19	Y	Y	Y	Y	Y	N†	Y	N	Y	N	N	N	N	Y	
12															
8															
7	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	N	N	N	
13	Y	Y	Y	Y	Y	N			N	N	N	N	N		
9	N	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	
10	Y	Y	Y	Y	Y		N	N	Y	N	N	N	N	N	
20															
27	N	Y	Y	Y	Y	Y	N	N	Y	N	N	N	N	Y	
15	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	
23	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	N	N	N	Medical oncology, clinical oncology
6															
14	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	
18	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	Radiotherapists (several)
21	Y	Y	Y	Y	Y	Y	Y	N	Y					Y	
3	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	Data clerk
24	Y	Y	Y	Y	Y	N	N	Y ††	Y	N	N	N	N	N	
26	Y	Y	Y		Y	N	N	N	Y	N	N	N	N	N	
4	Y	Y	Y	Y	Y		Y		Y						
22	Y	Y	Y	Y	Y	Y†	N	Y†††	Y	Y	Y	Y	N	N	NF2: Clinical Geneticist ENT surgeon

Nd = Named; ld = lead. *Onoclogist does not attend due to workload. **Neuropsychologist from Sep 2004. †Endocrinolgist attends separate pituitary MDT. ‡Not funded. § All these personnel on site and involved on an "ad hoc" basis. ††Neurospychologist. †††Clinical psychiatrist.

Other forms of multidisciplinary working specified

id	
11	Weekly combined neurology/neurosurgery/neuroradiology review
25	Weekly jt clinic neurosurgeon/neurooncologist/neurooncology nurse specialist, monthly jt clinic neurooncology nurse specialist and epilepsy nurse specialist, monthly jt clinic neurosurgeon/pituitary endocrinologist
1	Combined skull base clinic/combined pituitary clinic. There is a well-estabioished MDT for pelvic oncology in Trust to which one neurosurgeon provides input as requested. Paediatric tumours are all dealt with by a paediatric neurologist in collaboration with a neurosurgeon - and then referred on to a regional cancer centreas indicated.
5	Proposed joint pituitary clinic (neurosurgery, ENT, endocrinologuy) to start Feb2004
2	
16	1.Monthly joint glioma clinic with neurosurgeon, neuro oncologist & Macmillan Nurse 2. Twice per month Joint Pituitary Clinic with Neurosurgeon & Endocrinologist, 3. Cancer Network CNS Tumour Group 3 per year
17	Low grade glioma nurse led clinic. Pituitary surgery meeting monthly
19	Simultaneous neuro/ENT outpatients for joint assessment acoustic nerve tumours. Weekly tumour clinic with liaison nurse
12	Neurooncology part time nurses x 2, weekly neurooncology clinic, weekly ? Meningioma clinic, MDT pituitary clinic 8 weeks
8	Jt radiology meeting - radiology, neurosurgery, neurooncologsts, neurologists present once/month
7	
13	
9	Jt OP with neuro oncologists x2/month, jt OP with ENT/radiotherapist x1/month for skull base tumours, jt pituitary/endocrinology clinic x1/month
10	
20	
27	Outpatients with ENT (skull base), Spine clinic at other hospital
15	
23	Joint clinic for neuro-oncology - oncologist,neurologist, neurosurgeon,clinical nurse specialist
6	1. 2 Neurosurg teams(of 3) handle majority of brain tumours. Each has a weekly neuropathology meeting and neuroradiology meeting. 2. Close liaison between surgeons and neurooncologists including 2 satellite oncology services [Oncology unit 14 & non-responder]
14	
18	
21	
3	Joint OPD with 2 of neurosurgeons and neurooncologists
24	
26	See above regarding MDT make-up. OT, Physiotherapy, etc., are intimately involved in the care of the patients but the focus of the MDT is around treatment plans, radiotherapy rather than operational care of the patient
4	
22	Combined ward rounds adult brain tumours. Combined clinics Paediatric oncology.

Services available on-site

id	OT	Physio	SALT	Neuropsych	Type of neurospych	Palliative consultant	Palliative Nurse	Neurologist (epilepsy)	Social Worker	painmgt	Nutrition	Local pt support gp	Otherservices	Other
11	Y	Y	Y	Y	Neuropsychological	Y	Y	Y	Y	Y	Y	N		
25	Y	Y	Y	Y	Neuropsychological	Y†	Y	Y	Y§	Y	Y	Y		
1	Y	Y	Y	Y		Y	N	Y	Y	Y*	Y	Y	N	
5	Y	Y	Y	Y				Y		Y	Y			
2	Y	Y	Y	Y		N	N	Y	Y	Y	Y	Y		
16	Y	Y	Y	Y	Both	Y	Y	Y	Y	Y	Y	Y		
17	Y	Y	Y	Y		N	N	Y	Y	Y	Y	Y	Y	Counselling service
19	Y	Y	Y	N		Y	Y	Y	Y	Y	Y	N		
12	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y		
8	Y	Y	Y	Y		N	Y	Y	Y	Y	Y	N		
7	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y		
13	Y	Y	Y	Y	Neuropsychological	Y	Y	Y	Y	Y	Y			
9	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y		
10	Y	Y	Y	Y		N	Y	Y	Y	Y	Y	Y		
20	Y	Y	Y	Y	Both	Y	Y	N	Y	Y	Y	Y		
27	Y	Y	Y	Y		N	N	Y	Y	N	Y	Y		
15	Y	Y	Y	Y	Both	Y	Y	Y		Y	Y			
23	Y	Y	Y	Y		N‡	N‡	Y	N	Y	Y	N		
6	Y	Y	Y	Y	Diagnostic neuropsychology only	N		Y	Y	Y	Y	Y		
14	Y	Y	Y	Y		Y		Y	Y	Y	Y			
18	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y		
21	Y	Y	Y	Y	Both	N	N	Y	Y	Y	Y			
3	Y	Y	Y	Y	Both	Y	Y	Y	Y	Y	Y	N		
24	Y	Y	Y	Y		Y	Y	Y	N	Y	Y	Y		
26	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y		
4	Y	Y	Y	N		N		Y	Y	N	Y	N		
22	Y	Y	Y	Y	Complete service*	N	N	Y	Y	Y	Y	Y	Y	Clinical neuro oncology nurse specialist will allow for follow-up care support at home

† Recently appointed (last 3/12) * & use of behavioural medicine department. ‡Palliative care consultant and specialised nurse in palliative care service provided.§ Not dedicated to neuroscience.* Very Limited.

Other Facilities, and typical waiting time for routine outpatient appointment where applicable

id	Specialist Neurorehab Unit	Videoconf.	If yes do you find it useful?	If no, would you benefit?	CT	CT waiting time	MRI	MRI waiting time	PET	PET waiting time	SPECT	SPECT waiting time	Convenl. image guided Sx	C.i.g.s. waiting time	Frameless stereotaxy	Frameless st. waiting time	Computer Histopathology	Molecular pathology	Other (please specify)	Intraop. Histop.	24 hour intraop histopath.
11	Y	N		DK	Y		Y	12/12	N		N		N		N		Y	N		N	
25	Y	Y†			Y	*4-6/52	Y	*40/52	N		Y	*10-14/7	Y		Y		Y	N¤¤¤		Y	Y§§
1	Y*	N		Y	Y	Nil•	Y	Nil•	N		N		Y	1-2/52	N		N	N		Y	Y
5	Y	N‡		Y	Y	4-5/12	Y	10-12/12	N		N		Y		N			N		N	
2	N	N		DK	Y	4/12	Y	3/12	N††		Y	3/12	Y	0	Y	0	Y	Y		Y	N
16	Y	N		N	Y		Y				Y		Y		Y		N	N		Y	N
17	Y	N		Y	Y	3-6/52••	Y	6/12º	N		Y		N		N		Y	Y		Y	Y
19	Y	ID		DK	Y		Y		Y¤		Y		Y		Y		Y	N†††		Y	Y
12	Y	N			Y	2/52	Y	3/12	N		Y	3/12	Y		Y		Y	N		Y	Y
8	Y	N		Y	Y		Y		Y		Y		Y		Y		Y	Y		Y	N
7	Y	N		N	Y	<1/52	Y	<1/52	N		Y		Y		Y		Y	Y		Y	N
13	Y				Y		Y	47/52	Y				Y		Y		N	Y		Y	N
9	Y	N			Y		Y						Y		Y		Y	N		Y	N
10	Y	Y	N	N	Y		Y		Y		Y		Y		Y		Y	Y		Y	Y
20	Y	N			Y	1/12	Y	5-9/12	N		Y		Y		Y		N	Y		Y	Y
27	Y	N		Y	Y	6/52	Y	3/12					Y		Y		Y	N		Y	Y
15	Y	N			Y	10/7	Y	6-9/12	Y¤		N		Y		Y		Y	N		Y	Y§§§
23	Y	N		N	Y	1/52	Y	9/12	N		N		Y	2-4/52	Y	2-4/52	Y	Y		Y	Y
6	Y	N		Y	Y		Y		N		Y		Y		Y		Y¤¤			Y	Y˜
14	Y	N			Y	Nil	Y	15/12	Y		Y		Y		Y		N	Y		Y	N
18	Y	Y	N	Y	Y		Y	18/12	N		Y	1/12	Y		Y		N	Y		Y	N
21	Y	Y	N	DK	Y		Y		N		N		Y		Y		Y	N		Y	Y
3	Y	Y	Y**		Y	3/12	Y	12-18/12	N		Y	Ad hoc	Y		Y		N	N	Stereotaltic radiosurgery	Y	Y
24	Y	Y	***		Y		Y		Y		Y		Y				N	N		Y	Y
26	Y	Y	N		Y		Y		Y		Y		Y		Y		Y	Y		Y	N
4	Y	N		N	Y	1 /52	Y	6/12	N		Y	2-3/52	Y		Y		N	Y		Y	N
22	Y	N		Y	Y	4/52	Y	12-14/52	Y	4/52	Y	2/52	Y		Y		Y	Y	Functional MR	Y	Y

N=No, Y=Yes, DK=Don't know, ID = In development ("methods being trialled"). *Insufficient staff/beds. †Only recently purchased by trust, not used yet. ‡Being planned. §Methods being trolled. **"Yese, very". ***"Newly installed". *Tumours not considered routine. • No delay if tumour. ••No delay if urgent. º2/52 if urgent. †† Monile PET being commissioned. ¤Specified not in Trust. ¤¤On wards only.¤¤¤"Not that I am aware of".†††No local access. §§Consultant to consultant discussion. §§§ But not always a neuropathologist after hours. ˜Ad hoc.

	Presence of Protocols and whether multidisciplinary								Management of tumour type																													
id	How you communicate with primary care	? Multidisciplinary	How primary care contacts you	? Multidisciplinary	Communication with other 2º / 3º care	? Multidisciplinary	Response to patient referral	? Multidisciplinary	Low grade glioma	? Multidisciplinary	High grade glioma	? Multidisciplinary	Recurrent glioma	? Multidisciplinary	Meningioma	? Multidisciplinary	Pituitary Tumour	? Multidisciplinary	Acoustic tumours	? Multidisciplinary	Stereotatic radiosurgery referral criteria	? Multidisciplinary	Imaging surveillance	? Multidisciplinary	Follow-up	? Multidisciplinary	Steroid usage	? Multidisciplinary	Epilepsy / seizure control	? Multidisciplinary	Otherprotocols	
11	Y		Y		Y		Y		N		N		N		N		N		N		N		N		N		N		N		N					
25	N		N		N		N		N		N		N		N		Y	Y††	N		N		N		N		N		N							1
1	N		N		N		N		N		N		N		N		Y		N		N		N		N		Y‡		Y		N					
5	Y	Y	Y	Y	Y	N	Y	N	N		N		N		N		N		N		N		N		Y	N	N		N							
2	N		N		N		N		N		N		N		N		Y	Y	N		N		N		N		N		N							
16	*		*		Y		Y		N		N		Y		Y		Y		Y		N		Y		Y		Y		N							
17	Y		N		Y		N		Y		N		N		N		Y		N		N								Y							
19	N		Y		N		Y		N		N		N		N		N		N		N		N		N		N		N							
12	Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y							
8***	N		N		N		N		N		N		N		N		N		N		N		N		N		N		N							1
7	Y	Y	Y	Y	Y	Y			N						N		N		N		Y		Y	Y	Y	Y	Y	Y	Y	Y						
13																																				1
9	N		N		Y		Y		Y		Y		Y		Y		Y		Y		N		Y		Y		Y		N							
10	N		N		N		N		N		N		N		N		N		N		N		N		N		N		Y							
20	N		N		N		N		N		N		N		N		N		N		N		N		N		N		N							1
27	Y		N		Y	Y			N**		N**		N**		N		Y		Y		Y		Y	Y	Y		Y		N							
15	Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y		Y							
23	N		Y		N		Y		Y		Y		Y		Y						N		N		N		N		Y							
6	N		Y		Y		Y		N		N		N		N		N		N		N		N		N		N		Y							
14	N		N		N		N		N		N		N		N		N		N		N		N		N		N		N							1
18	N		N		N		N		N		N		N		N		N		N		N		N		N		N		N							1
21	N		Y	Y	N		N		N		N		N		N		Y	Y	N		N		N		N		Y		N							
3	N		N		N		N		N		N		N		N		N		N		N		N		N		N		N							1
24	N								Y		Y		Y		Y		Y		Y		Y		*		*		*		Y							
26	N		N		N		N		Y		Y		Y		N		Y		N		N		Y		Y		N		N							
4									N		N		Y	Y	N		Y	Y	Y	Y	N		N		N		N		N							
22	Y	Y	Y		Y	Y	N†		N†		N†		N†		N†		N†		N†		N		N		N		N		N		N					

* Being drawn up. **Discussed with individual consultant. ***Protocols for some of these being finalised by Cancer Network. †No sheet of paper but all go into MDT & trial protocols. ††Perioperative management. ‡For pituitary tumours

7

Referral and stereotaxis

id	Where are patients usually referred	Who usually follows up patients after surgery?	Number referred for stereotactic radiosurgery	Stereorad
11	On site	Designated oncologist	Est.6	Sheffield
25	On site	Specialist clinic in neurosurgical dept**	~10	Sheffield
1	Single local regional centre†	Both neurourgeon & designated oncologist	<6-10	Sheffield
5	On site + local regional centre	Referring clinician	~5	Sheffield
2	Single local regional centre	Specialist clinic in neurosurgical dept	~15*	Sheffield
16	Single local regional centre	Specialist clinic in neurosurgical dept	5	Marsden/Barts/Sheffield
17	Single local regional centre	Oncologist close to patients residence***	15-20	Sheffield
19	One of a number of surrounding hospitals	Oncologist close to patients residence	20	Sheffield
12	On site	Specialist clinic in neurosurgical dept	25	Sheffield
8	Single local regional centre†	Oncologist close to patients residence	81	Same trust
7	On site	Specialist clinic in neurosurgical dept	<50	Sheffield
13	Referring hospital	Referring clinician		Sheffield
9	On site	Specialist clinic in neurosurgical dept	12	Same trust
10	On site	Designated oncologist	10-15	Sheffield
20	One of a number of surrounding hospitals	Joint clinics with designated oncologists	12	Sheffield
27	One of a number of surrounding hospitals††	Designated oncologist + Referral back to referring clinician		Sheffield
15	One of a number of surrounding hospitals	Oncologist close to patients residence	4-5	Same trust
23	Single local regional centre† §	All apply depending on tumour type and local pt services	20	Marsen/Barts/Royal Free
6	On site*	Oncologist close to patients residence	<5	Sheffield
14	One of a number of surrounding hospitals	Designated oncologist	10-15	Sheffield or locally
18	On site/ one of a number of surrounding hospitals	Oncologist close to patients residence	100	Sheffield
21	Single local regional centre§§	Designated oncologist ‡	~16	Sheffield
3	One of a number of surrounding hospitals	Oncologist close to patients residence***	32**	Same trust or Sheffield (or London)
24	Single local regional centre	Designated oncologist	10	Sheffield or Barts
26	Single local regional centre	Oncologist close to patients residence / designated oncologist***	50***	On-site or Sheffield
4	Single local regional centre	Designated oncologist	30	Sheffield
22	Single local regional centre	Specialist clinic in neurosurgical dept + designated oncologist	20-25	Sheffield

*Total (ie vascular, acoustics, etc.). **20 in Sheffield and 12 on-site. ***On-site. †Same Trust, different site. ††Three regional centres. § or to convenient local facility for patient. *Also to two satelite hospitals §§Or one other centre **With oncology. ***And neurosurgical clinic. ‡Depends on tumour type. †††Own SRS Unit due to open Dec 04

	Outcome data								Clinical Trials		
id	Morbidity post biopsy	Mortality post biopsy	Morbidity post surgery	Mortality post surgery	Quality of life	Survival	Recurrence	Performance	How many recruited in last year	Most significant reason for lack of recruitment	Other comment
11	Y	Y	Y	Y	N	N	N	Y	0	Lack of resources	
25¤	Y**	Y**	Y**	Y**	N	N	N	N	<10	No suitable trial available	
1	N	N	N	N	N	N	N	N	0		Agreed patients might be entered by the oncologist/radiotherapist.
5	Y	Y	Y	Y	N	N	N	N	0	Lack of resources	
2	Y	Y	Y	Y	N	N	N	N	0	Lack of resources	
16	N	Y	N	Y	N	N	N	N			
17	N	Y	N	Y	N	N	N	N	0	Lack of resources	10 Paediatric
19	Y	Y	Y	Y	N	Y	N	N	2-3	No suitable trial available	
12	Y	Y	Y	Y	N	Y	N	Y	4	No suitable trial available	
8	Y	Y	Y	Y	N	N	N	N	0	No suitable trial available	
7	Y	Y	Y	Y	Y	Y	Y	Y	12	No suitable trial available	
13	Y	Y	Y	Y	N	N	N	N	0	Lack of resources	
9	Y	Y	Y	Y	Y	Y	Y	Y	?***	Eligibility criteria not appropriate	
10	Y	Y	Y	Y	N	N	N	Y	0		
***20**	N	N	N	N	N	N	N	N	0	Eligibility criteria not appropriate	
27	Y	Y	Y	Y	N*	N*	N*	N*	9	Patient did not wish to participate	Neurosurgery ~5, neuro-oncology ~4. Currently running 1 trial only
15§	N	Y	N	Y	N	N	N	N	0	No suitable trial available	However, 2 have now opened
23	Y	Y	Y	Y	N	N	N	N	1	No suitable trial available	BR12 - December 2003
6	N	Y	N	Y	N	N	N	N	0	Lack of resources	
14	Y	Y	Y	Y	N	N	N	N			
18	N	N	N	N	N	N	N	N	0	No suitable trial available + lack of resources	Lack of Trust and University support for neurosurgery trials unit. ‡
21	Y	Y	Y	Y	N	N	N	N		No suitable trial available + lack of resources	Clinical rials mainly by oncologists
3	N	N	N	N	N	Y†	N	N	5	No suitable trial available	
24	Y	Y	Y	Y	N	Y	Y	N	20	Eligibility criteria not appropriate	
26	Y	Y	Y	Y	Y	Y	Y	N	70	Eligibility criteria not appropriate	
4	N	Y	N	Y	N	Y	Y	Y		No suitable trial available	
22	Y	Y	Y	Y	Y	Y	Y	Y			

Within CHKS. * Collected by neuro-oncology. †"(?Routinely)". ¤ "We started a database about 5 years ago and all this data was being collected. The Trust would not fund the continuation of the project (we wanted a £6,000-£7,000 p.a. for a part time data assistant)". * "No departmental data collected but personal data collected on morbidity post biopsy, mortality post biopsy, morbidity post surgery and mortality post surgery" § CNS data manager appointed Feb 2004. *"Yes, but U/K". ‡ "2 made redundant!".

Other Comments

id	
11	Demographics of department in a fluid state, and likely to increase significantly within the next year or two. Regional network in development
25	
1	We would like assistance with development of guidelines/protocols for management of gliomas. We would like financial assistance to re-start the data collection activity which we set up several years ago.
5	
2	
16	CNS Tumour Group for this Cancer Network is now set up and has had 2 meetings.
17	
19	
12	
8	
7	
13	
9	
10	
20	
27	
15	
23	
6	Neurosurgery Dept. Grossly undermanned at consultant level, no signs of improvement. Infrastructure (intensive care junior staff, consultant staff, beds) inadequate. Any improvements (eg MDT meetings) totally dependent on additional consultants
14	
18	
21	
3	Separate spinal unit deals with extradural spinal metastases
24	We have tried to complete this as best possible. The greatest problem we have, other than the huge international problem of trying to effectively treat and 'cure' malignant brain tumours is clerical/logistic support. Even a form like this is taxing for us! Large increases in the Clinicians caring for these patients are not the answer. Any increase must be supported with practical, constructive, active administrative support to make use of clinicians time and skills more fully.
26	
4	
22	

19 Appendix L Full radiotherapy/oncology unit responses

Oncology units location and catchment population

id	Location	Catchment pop	Method of estimation	Minimum age seen
16	DGH	250	Trust	Adult - 20
7	DGH	330	Geographical populations	21
11	DGH	500	Hospital management	30
17	Teaching hospital	500	Trust	13***
28	DGH	500	Health district population	18
33	Teaching hospital	500**		18
19	DGH	600	Geographical populations	18
24	DGH	670	Population demographics	20
8	DGH	750	Educated guess	18
30	DGH	750	Trust	18
32	University hospital	750	Network data	~20
18	DGH	780	Network data	17
3	DGH	800		
2		900	Geographical populations	18
39	University hospital	970	970,000 Verified Brian Cottier for RT population†	17
6	DGH	1000	Referring centre: 2 million, but ~50% referred to DGH	16
9	University hospital	1000		16
26	DGH	1000		21
29	Stand alone centre	>1000	Geographical populations	18
47	Teaching hospital	1000	Cancer network areas	Non-paed. RT (~maturity)
13	University hospital	1050	Network population	18
10	University hospital	1140	Geographical populations	All ages
22	DGH	1200	Network data	18
36	University hospital	1200	Geographical populations	16
15	Teaching hospital	1300	"Long held data"	All ages
34	Stand alone centre*	1500		3
42	University hospital	1500		17
41	University hospital	1550	Geographical populations	18
20	Stand alone centre	1750‡	Geographical populations	17
23	DGH	1800	Geographical populations	Adult
48	DGH	1800	Network data	All ages
35	University hospital	2000	1.7mill. Network + other geographical	0
40	University hospital	2000	approx	Infants
46	University hospital	2200	From Neurosurgical centre	18
4	Stand alone centre	2300	SHA Records, Network figures, Brian Cottier Study	18
27	University hospital	2500	Geographical populations	16
37	Teaching hospital•	2500	Network population	0
43	University hospital	2500	Approx	20
21	Stand alone centre	3000	Guess	0
25	Stand alone centre	3200	Network population	includes children
45	University hospital	3200		14
38	DGH			27 (Glioblastoma: all)
14	DGH			16
5		††		18
44				3

*Affiliated to University Hospital. • Links wtih unit 28 and neurosurgical unit 20. **Associated neurosurgical centre has catchment of 1.8million. ‡National referrals for stereotactic radiotherapy above this number. † "970,000 Verified Brian Cottier for RT population. + 20% higher incidence for Cancer + neuro centre which takes pts outside catchment area". †† Hospital catchment population: 2million, but neuro-oncology catchment is much smaller as patients referred directly to other units to follow neurosurgical referrals. *** One child's parents requesting Rx here usually children treated elsewhere.

Number of beds & patients per unit

id	Designated oncology beds	New patients (all types) 1,000s	New CNS tumour pt	New glioma pt
16	20*	1100	20	18
7	8	1200	17	5
11	16	1350	35	30
17	24	1900	38	34
28	20	~1000	~100§§§	~30
33	32	1900	~30	25
19	32	<3000	~50	~40
24	36	2500	26	18
8	23	~2200	"Not many"	"Most of them"
30	22	1944	40	35
32	44	~2400	52 •	17♦
18	16	2200	33	25
3	22	2000+	40••	~28
2	34	2500	~150	~100
39	9**	3041	94	Not known
6	22	~2000	~70	~50
9	32	2700	~80	~50
26	44***	3900	55-72•••	~57♦♦
29	42	2400	"No data"	
47	50	3500		
13	35	~2850	60	45
10	~40	3400	63º	50º
22	45†	3500	~60	~45
36	20	2000	60	30
15	44	2800	112ºº	68
34	87	6000	150	125
42	76	2000	200	130-150
41	26	955‡‡	100	
20	6-8	10975	285	140
23	33	~6000	108ººº	96
48	52	5384	138	26
35	120	5700	130	90
40	58	4500	350	180
46	23	707	*	115•
4	~100	~7000	178	118
27	40	4500	200	130
37	50††	4500	~120	~90
43	48	3000	19ººº	14
21	70	>6500	>200¤	~160♦♦♦
25	90†††	10000§	227¤¤	172♦♦♦
45	90	2700§§	285	105
38	30	1500	35	8 confirmed
14	23‡‡	2500	45	45
5	65‡	~4500	~100ººº	~50
44	6	~1600-1800	~255 ¤¤¤	~136 ◘

* Shared with haematology. ** " 9 Dedicated oncology beds. + surgery + heam + neuro". *** + 4 hostel beds (not nursed). † 27 inpatient, 18 daycase. †† 22 of these are in unit 6 and are shared with haematology. ††† 200 total, 90 clinical oncology. ‡Includes 5 haem. unit, likely to be reduced to 60. ‡Excludes haematology. ‡‡ New Out patients in dept, 2626 in cancer network. § New registrations for cancer. §§New courses 3434. §§§ Includes secondaries. •Given Rt. ••2% of 2000 in 2002/3. •••Over last 3 years. ºLikely to be underestimate. ººMDT database. ºººMetastastses not included. * not known accurately on current database. ¤Our neurosurgeons see >350. ¤¤ Excludes pituitary. ¤¤¤ Approx 15% of total. ♦ 17GBM, 10 pituitary, 10 no biopsy, 15 other histology. ♦♦"Approx. 90%". ♦♦♦ Approx 80%. ◘ "Approx. 8% of total".

Glioma patients receiving chemotherapy

id	% Glioma patients to receive chemotherapy, and comment	
16	~15	
7		"1 From dept database"
11		Not known
17	~15	Estimate own practice
28	~20	Probably; own observations
33	~30	Guess
19	~10	Estimate
24	~5-10	Pharmacy data
8		Most at some stage or another
30	30	Official MAISY database
32	(2)	1/52 recorded
18	8	Clinical database: 2/25 glioma
3	<~10	Best estimate
2		
39		[24 brain/CNS patients receiving chemotherapy (from oncology database)]
6	10	Spreadsheet of all brain patients
9	~10	Personal recollection
26	15	Chemotherapy records as % of all brain referred
29		No data available
47		Data awaited
13	~50	Probably about half
10		**
22	~30	Estimate from personal data
36	<20	Chemotherapy data sheet
15	15	10/68 - from chemo module (computer)
34	50	Guestimate (accurate figures - some effort).
42	60	Audit
41		
20	60-70 (15)‡	Estimate
23	~30	24 in last 10/12***
48	14	Individual clinician data
35	*	
40	~40	
46		not known
4	68	Calculated as 80 chemo glioma patients
27	~30	Recent audit
37	~33	1999 Audit. May be >50% now.
43	5-10	Own records
21	5-10	Audit
25		Pharmacy does not code diagnosis
45	25-35	~One third on relapse are fit for chemo
38	13	1/8 patients in 2003
14	~13	Rough estimate ~6 patients per year
5	10	Own data
44	>50	High grades + younger fitter

‡Over course of illness (Time of diagnosis). * No Grade II, almost all grade III - approx 30% grade IV. ** 8 patients given PCV in last 12/12, 2 given Temodal - in one hospital, patients also given chemo in 2 other hospitals by ourselves. ***Mix of palliative, pre RT if wait >8/52 or "induction" for low grades.

Glioma patients receiving chemotherapy

id	% Glioma patients to receive chemotherapy, and comment	
16	~15	
7		"1 From dept database"
11		Not known
17	~15	Estimate own practice
28	~20	Probably; own observations
33	~30	Guess
19	~10	Estimate
24	~5-10	Pharmacy data
8		Most at some stage or another
30	30	Official MAISY database
32	(2)	1/52 recorded
18	8	Clinical database: 2/25 glioma
3	<~10	Best estimate
2		
39		[24 brain/CNS patients receiving chemotherapy (from oncology database)]
6	10	Spreadsheet of all brain patients
9	~10	Personal recollection
26	15	Chemotherapy records as % of all brain referred
29		No data available
47		Data awaited
13	~50	Probably about half
10		**
22	~30	Estimate from personal data
36	<20	Chemotherapy data sheet
15	15	10/68 - from chemo module (computer)
34	50	Guestimate (accurate figures - some effort).
42	60	Audit
41		
20	60-70 (15)‡	Estimate
23	~30	24 in last 10/12***
48	14	Individual clinician data
35	*	
40	~40	
46		not known
4	68	Calculated as 80 chemo glioma patients
27	~30	Recent audit
37	~33	1999 Audit. May be >50% now.
43	5-10	Own records
21	5-10	Audit
25		Pharmacy does not code diagnosis
45	25-35	~One third on relapse are fit for chemo
38	13	1/8 patients in 2003
14	~13	Rough estimate ~6 patients per year
5	10	Own data
44	>50	High grades + younger fitter

‡Over course of illness (Time of diagnosis). * No Grade II, almost all grade III - approx 30% grade IV. ** 8 patients given PCV in last 12/12, 2 given Temodal - in one hospital, patients also given chemo in 2 other hospitals by ourselves. ***Mix of palliative, pre RT if wait >8/52 or "induction" for low grades.

Glioma patients receiving radiotherapy

id	% Glioma patients to receive radiotherapy, and comment	
16	70	
7		"12 From dept database"
11	80	Department statistics
17	70	My own "quick audit"
28	~80	Probably; own observations
33	~70	Guess
19	~80	Estimate
24	75-80**	
8	~66	Guess
30	60	Official MAISY database
32		Denominator unknown***
18	64	Clinical database: 16/25
3	~70	Best estimate (~25% no treatment)
2	60	Personal practice
39		
6	~70	Spreadsheet of all brain patients
9	60	Physics records. 40 radical, 20 palliative
26	75	Manual radiotherapy log, proportion of all referrals
29		No data available
47		Data awaited
13	§	
10	The majority	Personal experience
22	80	Estimate from personal data
36	70	Radiotherapy enrty sheet
15	44	"30/68 - seems low to me."¤
34	85	Guestimate (accurate figures - some effort).
42	80	Audit
41		Don't know
20	80-90(40)‡	Estimate
23	63	
48	75	Individual clinician data
35	83	75/90 Database
40	~60	
46	Not known†	
4	Most	"NB 138 (number of RT pts)/118 (new pt referrals 118)"
27	68	Database information˜
37	~90	1999 audit (probably stable)
43	70	
21	70	Guess (?High/low grade)
25		2002 figures: 219
45	80-85	~1/5 unsuitable
38	88	7/8 patients in 2003 from database
14	~50	HRG data
5	>90	Own data
44	>90	Own data

**Unless performance status does not permit further treatment. ***Primary referral elswhere. § Most Gd III/IV gliomas. ‡Over course of illness (Time of diagnosis). † New patient management system to be installed, if funds available. ¤There may be an error on our RT database. Low grade gliomas are not treated as a rule. ˜Some surveyed / some not treated / some referred to other centres for Rx.

Mean waiting time for brain / CNS tumour patients. Finished consultant episodes (FCEs).

id	Radical radioth.	Palliative radioth.	Inpatient chemoth.	Outpatient chemoth.		FCE for brain / CNS tumours where stated
16	4 weeks	2 weeks	2 weeks	2 weeks		
7	40* †			40*		
11	4*	2 *	2*	2*		
17	5 weeks	3 weeks	2 weeks	2 weeks		
28	4 weeks	1 week	N/A	2 weeks		
33	6 weeks	4 weeks		2 weeks		
19	3 weeks	2 weeks	N/A	<1 week		
24	4 weeks	≤ 2 weeks		1 week		
8	<1 week	< 1 week	<1 week	<1 week		
30	6 weeks	2-3 weeks	2 weeks	1-2 weeks		
32	IR	6 weeks	10 days	1 week		
18	26.9 days	38.7 days	N/A	37 days		39
3	2 weeks ‡	<2 weeks	N/A	<1 week		••
2	2 weeks. **	1 week	N/A	1 week•		
39	6-8 weeks	2 weeks	<2 weeks	<2 weeks		
6	4 weeks	2 weeks	1 week	2 weeks		
9	4 weeks	2 weeks	1-2 weeks	1-2 weeks		
26	5 weeks	2 weeks	0 days	5 days		10 recorded
29	Unknown	Unknown	Unknown	Unknown		
47	6 weeks	2 weeks	2 weeks	1 week		
13	3-4 wks	3-4 wks		3-5 days		
10	8 weeks	2 weeks	1-2 weeks	1-2 weeks		63•••
22	8 weeks	4 weeks	2-3 weeks	1-2 weeks		
36	4 weeks	2 weeks	3-4 weeks	2 weeks		
15	30 days	7 days	N/A	2-3 wks		149
34	4-5 weeks	1-2 weeks	1-2 weeks	≤1 week		
42	6-7 weeks	1-2 weeks	Nil	Nil		
41	8 weeks	29 days	7-10 days	7-10 days		
20	3-6 weeks	1-2 weeks	1 week	1 day		246
23	8-12 weeks	3-4 weeks	N/A	1-2 weeks		
48	6 weeks***	7 days***	7-10 days***	14-16 days ***		
35	4*	2*	10-14 days	7-10 days		
40	4 weeks	2 weeks	2 weeks	2 weeks		
46	4 weeks	2 weeks	2 days	1 week		††
4	20 days	15 days	10-12 days	5 days		1173†††
27	6 weeks	1 week	≤ 1 week	≤ 1 week		
37	4 weeks	2-3 weeks	2-3 weeks	3-4 weeks		
43	6-8 weeks	3-4 weeks	N/A	2 weeks		738
21	7 weeks	3 weeks	1 week	0-2 days		
25	6-8 weeks	3 weeks				
45	5 weeks	2 weeks	1-2 weeks	1-2 weeks		
38	28 days		N/A			
14	6 weeks	3 weeks	N/A	1 week		
5	~6 weeks	~3 weeks	N/A	~7 days		
44	4 weeks	4 weeks	2 weeks	0		

***Not stated if days / weeks / months. †Includes pituitary. ‡ Malignant tumour approx 2 weeks, benign tumour approx 6 weeks eg Pituitary adenoma. ** All times between 1st consultation - start treatment. *** All cancers. •Next clinic. •• Probably available but most is outpatient related activity not captured by FCE. •••"I think not complete as not all diagnoses registered correctly. ††Unable to seperate out as no patient management system. currently to be implemented. †††445 chemo, 728 RT.**

Staffing oncology units

id	Consultant WTE	How many specialise Brain/CNS? (WTE)	Neuro-oncology nurses WTE			
			Surgical	Non-surgical	Both surg & non-surg	Total
16	16	1 (0.4)	0	0	0	0
7	2	2				
11	4	1	0	0	0	0
17	5.5*	1 (0.6)	0	0	0	0
28	2.5	1	0	0	0	0
33	6	1	0	0	1	1
19	5**	1	0	0	0	0
24	5	2	0	0	0	0
8	4	1	0	0	0	0
30	5	1	0	1	0	1
32	6	1	0	0	0	0
18	5	2	0	0	0	0
3	5.5	1	0	0.1	0	0.1
2	6.5	1		0		0
39	6.5	1		1		1
6	5	1	0•	0	0	0•
9	9	1			0.5	0.5
26	7	1	0	0	0	0
29		1	1			1
47	3.4	2	0	0	0	0
13	6	1	1			1
10	10.5***	2 (1.2)§			2	2
22	6.8	1	0	0	0	0
36	5	1			1	1
15	8	1			1	1
34	17†	1	2	1	0	3
42	11	11	1	1	0	2
41	8	2	0	0	0	0
20	16	2	0	0	1	1
23	10.9	1	0	0	0	0
48	20.74	3¤			1	1
35	19	1			1	1
40	11	2			1	1
46	3	1♦			1	1
4	13	3	0	0.8•••	0	0.8•••
27	15	2	4	1		5
37		2			1	1
43	8	1			1	1
21	16-17	2	0	0	1	1
25	19	1			1	1
45	10	1			1	1
38	4.8	1	0	0	0	0
14	5.5	2			1	1
5		1§§	0	0	0	0
44	6	1§§§	0	0	0	0

*** Shared with 2 other centres. ** + 2 vaccancies. ***12 consultants. †"17 hospital, 1 department". ††Includes 3 new posts.‡1 individual. § 2 (0.6 WTE each) for adults, 2 (1 & 0.6 WTE) for children. ¤1 part time. ♦But all 3 do some brain / CNS work (e.g. AVMS; acoustic neuroma). §§ 1 conulant not-NHS funded, and leaving department. §§§ + cover. •One starting March 2004. •••Shared with another unit.**

Basic MDT Details

id	Defined MDT?	How often MDT meets	Typical no of cases	Preop discussed routinely	Referred patients discussed at MDT	Comments
16	Yes	Weekly	14	Yes	Most	MDT of unit 33/nuerosx centre [I cannot attend, I get email of conclusions]
7	No					
11	No					
17	Yes	Weekly*	14(4†)	Yes	Most	MDT of unit 33/ nuerosx centre [I cannot attend, I get email of conclusions]
28	No					May feed into neuropathology meeting at unit 37 (but do not attend)
33	Yes	Weekly	10-15	Yes	All	
19	Yes	Weekly	10	Yes	All	For some patients at unit 15, attend by videoconf. But see footnote§§.
24	No					
8	U/d	Fortnightly	3-ish	Yes***	All	
30	Yes	Weekly	10	No	All	
32	Yes	Monthly	2	No•	All††	MDT of unit 27, see final comment.
18	No					MDT at trust unit 10. Plans for videoconferen link but oncologist time short*
3	Yes	Weekly	10**	Yes	All	Satellite of MDT of unit 10 where pts also discussed. Plans for videoconf.*
2	No					
39	Yes	Monthly	15-20	No	All	
6	Yes	Weekly	~10	Yes	All/Most	
9	Yes	Weekly	10-15	No§	Most	
26	Yes	Monthly	20	No	All	
29	Yes	Fortnightly	5-6	No	Most	
47	U/d	Irregularly		No		
13	Yes	Weekly	6-10	Yes	All	
10	Yes	Weekly	10-15	No	All p.o.‡	1 adult & 1 paediatric. Pts discussed from unit 3& 18.*
22	No					
36	Yes	Fortnightly	10	No	Most	
15	Yes	Weekly	~12	No	All/Most	Videoconf. (Units 9, 19, 30) with their oncologists/radiologists/nurses
34	Yes	Weekly	5	No	Most	
42	Yes	Weekly	7	Yes	All	
41	No					"Currently we are trying to establish an MDT but there is opposition"
20	Yes	Weekly	5-10	No	Occ.	
23	U/d					"Work underway to set up video-linked MDM" related to unit 45
48	No	Weekly				"Weekly MDM but no defined team"
35	Yes	Weekly	20	Yes	All	
40	Yes	Weekly	15	No	All	
46	Yes	Weekly	7		All	
4	Yes	Fortnightly	5	Yes	Some/Occ.	
27	Yes	Weekly	10-12	Yes	Most	Pts discussed relating to unit 27 also, and sometimes other units e.g. 38
37	Yes	Weekly	~8	No••	Most	Meeting is part of combined neuropathology meeting
43	Yes	Weekly	10	Yes	All	
21	Yes	Weekly	10-15	No§	All	
25	Yes	Fortnightly		Yes	Most	At neurosurgical centre
45	Yes	Weekly	28 to 35	Yes	Most	
38	No					
14	Yes	Weekly				In other unit (non-response). Unsure of MDT details (have not attended).
5	No					
44	Yes	2/ month		No	All SR•••	Particularly those for stereotactic radiation therapy

U/d = under development. Occ. = Occasional cases only. †Local Support Group also: Clin Onc, Support Counsellor + Pall Care Cons.**Not all malignant. ***We hope to. • "I don't think so". §Sometimes. •• Not routinely, but do If a preliminary Bx has been taken to discuss plan. ††"In theory". ‡Post op. •••All new referred for stereotactic RT. §§ Some patients attending unit 19 are referred from neurosurgical centre with MDT at unit 35; unit 19 has no input into that MDT. *MDT at trust of unit 10 discusses patients from units 3 & 18 (oncologists do not attend). MDT comments faxed.

MDT membership

id	Named lead clinician	Lead oncol.	Lead Surgeon	Lead path.	Accredited Neuropath.	Lead imaging consultant	Lead endocr.	Lead neurol.	Psycholog. / Psychiatr. Prof.	Neuroonc. nurse	OT	Physio	SALT	Social worker	Maxillofacial	Other
16	Y	N	Y	Y	Y	Y	N	Y	N	Y	DK	DK	DK	DK	DK	
7																
11																
17†	Y	*	Y	Y	Y	Y	N	Y	N	Y	DK	DK	DK	DK	DK	
28																
33	Y	Y	Y	Y	Y	Y	?	Y	N	Y	N	N	N	N	N	
19	Y	**	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	N
24																
8	Y	Y	Y	Y	DK	DK	N	DK	N	¤	Y	Y	Y••	N	N	
30	Y	Y	Y	Y	Y	Y	N***	N***	Y	Y	N§	N§	N§	N§	N§	
32	Y	Y	Y	Y		Y	N	N	N	Y	N	N	N	N	N	
18	º	º	º	º	º	º	º	º	º	º	º	º	º	º	º	
3		Y				Y		Y•••								
2																
39	Y	Y	Y	Y	Y	Y	N	Y	Y,NL	Y	N	N	N	N	N	
6	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	
9	Y	Y	Y	Y		Y				Y						
26	Y	Y	N	N	N	N	Y††		Y	N	Y	Y	Y	Y	N	Y
29		Y	Y	Y	Y	Y				Y						
47	Y	Y	Y	Y	Y	Y	Y	N	N	N	Y	Y	Y	Y	Y	
13	Y	N	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	N	
10	Y	Y	N	Y	Y	Y	N	N	N	Y	N	N	N	N	N	
22																
36	Y	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	
15	Y	Y	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	Y
34	Y	Y	Y	Y	Y	Y	N	N	N	N	N	N	N	N	N	Y
42	Y	Y	Y	Y		Y		Y	N	Y	N	N	Y•	N		Y
41																
20	Y	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	N	N	N	
23																
48‡‡	Y	N	Y	Y	Y	Y	N	N	N	Y	N	N	N	N	N	N
35	Y	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	N	N	N	Y
40	Y	Y	Y	Y		Y	N	N	N	Y	N	N	N	N	N	
46	Y	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	N	N	N	
4	Y	Y	Y	Y	DK	N	N	N	N	Y	N	N	N	N	N	
27	Y	Y	Y	Y	Y	Y	SEM	N	N	Y	N	N	N	N	N	Y
37	N	Y	Y	Y	Y	N	SEM	N	N	Y	N	N	N	N	N	
43	Y	Y	Y	Y	Y	Y	N	Y	N	Y	N	N	N	N	N	
21	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y	Y	N	Y	N	
25	Y	Y	Y			Y										
45	Y	Y	Y	Y	Y	Y	Y	N	Y,NL	Y	N	N	N	N	N	Y
38																
14																
5																
44	Y	Y	Y			Y	SEW									

Dark grey = No MDT; Light grey = main MDT elsewhere; speckled = in development. Y=Yes, N=No, DK = Don't know. SEM = Separate endocrine meeting monthly, SEW=Seperate endocirne meeting weekly. NL = Neuropsychologist. †Refers to unit 33. *I can't attend, consultant from unit 33 can. **Joint videoconference, so lead not appropriate. ºMDT at unit 10. ‡‡ Weekly MDMeetingss but no defined MDT. ***Not lead but accessible. †† Doesn't attend. ¤When appointed. §Available for referrals. •Sometimes. ••When needed.••• 3 neurologists

Other MDT members & Other MDTs

id	Other MDT memebrs	Other MDT in department
16		
7		
11		
17		Pituitary (3 monthly)
28		Endocrine (weekly)
33		Pituitary; spine
19		
24		
8		
30		
32		
18		
3		At unit 10 *
2		•
39		••
6		
9		
26	Palliative care nurses; Community Macmillan nurses	Pituitary**
29		Neuroendocrine (pituitary)
47		
13		Endocrine
10		Pituitary (2/52ly)***. Pituitary RT(2/12ly)†
22		
36		
15	Paed onc. + paed neurosx.	Pituitary (quarterly)
34	Neurosurgical specialist nurse	Paediatrics
42	Medical Oncology x 2	Pituitary endrocrine
41		Pituitary
20		Pituitary
23		
48		Pituitary; endocrine; paediatric
35	Ward nurses, other specialist nurses, trainees, MDT Coordinator!	skull base; late effect; [plan for pituitary]
40		Stereotactic radiosurgery
46		Endocrine; acoustic neuroma¤
4		
27	Specialist Radiographer - neuro-oncology(therapy)	Endocrine (monthly)
37		Pituitary (monthly)‡Paediatric CNS (starting)
43		Pituitary
21		Endocrine
25		
45	Research staff (laboratory and trial based)	Neuroendocrine
38		
14		
5		
44		Endocrine (weekly)

Dark grey = No MDT; Light grey = main MDT elsewhere; speckled = in development. *CNS & endocrine. •"No but access to endocrinologist/ophthalmologist". •• Pituitary tumours included in main MDTM. ** Endocrinologist, neurosurgeon, radiologist, nurses. ***Surgeon + endocrine + radio. † Endocrine + clin onc.¤Also interventional radio. for AVMS. ‡ Followed by joint clinic.

Other forms of multidsciplinary working

id	Other forms of multidsiciplinary working
16	MacMillan Radiographer will provide support and will review patients on ward
11	No MDT. Pts diagnosed clinically & radiologically, then moved to regional centre for histological diagnosis / surgery. They are back to us for radiotherapy and a v small number receive chemotherapy here.
17	Local Expert Group - Clinical Onc., Support Specialist, Palliative Care Cons.
28	Joint monthly clinic (Clinical Oncologists(2); Neurosurgeon (1 + SpR); Neurooncology nurse specialist
19	[Patients are referred here from neurosurgeons at 2 centres (unit 35 & 15). There is an MDT in unit 35 with a lead oncologist but I have no input to it. The MDT described is unit 15's which meets weekly via video conferencing for the Neurosurgery catchment area. There are oncologists specialising in brain/CNS tumours in all 4 locations and we all attend, but none of us is the "lead" for the whole as it would be inappropriate.]
30	Separate neurosurgical (x2/week) and neurology clinics held within hospital. Pts can be discussed outside the MDT in person or over the telephone
3	Regullar discussion with neurologists & radiologists. Excellent links with neuroradiology & neurosurgical centre in same Trust as unit 10. Joint clinic with neurosurgery coming to this centre starting this month.
39	Jt outpatient clinic work neurooncologist + neurosurgeon, jt pituitary clinic with n/surgeon + endocrinologist
6	Working on enlarged neuro-oncology database. Planning links between neurosurgery/oncology now CNS available
26	Close working with neurologists for epilepsy control. Epilepsy nurse advisor
29	Joint neuro-oncology clinics (neurosurgeon/oncologist/nurse specialist) x 2-3 each month, Joint neuro-endocrine clinic (neurosurgeon/oncologist/endocrinologists) monthly
13	weekly joint out-patients in neuro-oncology
10	Neurosurgeons do not attend MDT. Cancer Network CNS tumour BSG has met x 3 (well attended including neurosurgeons)
22	Meeting with neurologists and radiologists - weekly
15	1. Monthly combined clinic with neurosurgeons, neuro-onc nurses for adults. Follow up + treated pts. Only. 2. 2 monthly paed. Neuro onc follow up clinic
42	Joint medical oncology and clinical oncology
41	Neurorad. conference weekly. Neuropath meet monthly; forum to meet neurosurgeons. Otherwise we go round to their offices
20	Additional MDM with OT, physio, clin. Nurse specialist, speech therapist, psychologist, ward nurse, community liaison nurse, social worker
23	Telephone calls with surgeons/surgical neuro-oncology specialist from Neurosurgical centres about pts & to palliative care teams. Review of new patients with dedicated nurse and involvement of MacMillan Radiotherapy Specialist (gives info. Re RT and co-ordinates with pall care teams). Have made occasional visits to neurosurgical centre for MDM/jt clinic there - planning to try and restructure things to enable regular jt clinic in long term (early stages of discussion at present)
48	MDM for adult CNS tumours weekly - neurosurgeon(s), radiolgoist, neuropathologist(s), clinical oncologist(s), clinical nurse specialist but no defined team!
35	Combined clinics/combined consultation, taped consultation, information sheets
40	Neurosurgeons + neurooncologists Clinic x 1/week
46	Monthly jt OP - Clin. Onc & Neurosurg. All OP clncs attended by Neuro-onc.Clinical Nurse Spec and all pts having radioth are seen by Radioth Pract. Weekly new pt, chemo & f/up clinic attended by CNS & if approp, the Radio Pract.
37	Monthly joint brain tumour clinic with neurosurgeons and oncologists but not routinely neurologists at present. There are separate "surgical" skull base clinics with neurosurgeons, ENT/max. fac surgeons and specialised nurses. Paediatric neuro-oncology cases seen jointly with paediatric oncologists in Paediatric Day Unit
43	Joint OP clinics with oncolology, neurosurgery, neorlogy & nurse specialists
21	Neuroradiology + oncology meeting for RT planning
25	Teenage unit: multi disciplinary follow up of paediatric CNS patients
44	We hope Neurosurg. will be starting an OP clinic adjacent to my own every Friday am with joint discussions of oncology patients in mind

None stated:7, 33, 24, 8, 32, 18, 2, 9, 47, 36, 34, 4, 27, 45, 38, 5, 14. Dark grey = No defined MDT for brain/CNS tumours; Light grey = main MDT elsewhere; speckled = in development.

Services available on-site

id	OT	Physio	SALT	Neuropsych	Specify neuropsychological / neuropsychitric service	Pall. Consultant	Pall. Nurse	Epilepsy neurologist	Social worker	Pain management	Nutrition	Local pt support gp	Other services providing added value
16	Y	Y	Y	N		Y	Y	N‡	Y	Y	Y	N	
7	Y	Y	Y	N		Y	Y		Y	Y	Y	Y	
11	Y	Y	Y	N		Y	Y	N§	Y	Y	Y	N	
17	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	N	
28	Y	Y	Y	N		Y	Y	Y	Y	Y	Y	N	
33	Y*	Y*	Y*	Y		Y	Y	Y	Y	Y	Y*	N	
19	Y	Y	Y	N		N	Y	N	Y	Y	Y	N	
24	Y	Y	Y			Y	Y		Y	Y	Y	Y	
8	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	
30	Y	Y	Y	N	General psychology and psychiatry	Y	Y	Y	Y	Y	Y	N*	Home chemotx service
32	Y	Y	Y	N		N	Y	Y	Y	Y	Y	N	
18	Y	Y	Y	N		N	Y	Y	Y	Y	Y	N	
3	Y	Y	Y			N	Y	Y	N	Y	Y		
2	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	
39	Y	Y		Y		Y	Y	Y	Y	Y	Y	Y	
6	Y	Y	Y	Y	Consultant available for referrals	Y	Y	Y	Y	Y	Y	N	
9	Y	Y	Y	Y	Liaison Psychiatrist	Y	Y						
26	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	
29	Y	Y	Y				Y				Y		Onc.-psychology centre
47	Y	Y	Y	Y	Neuropsychologist	Y	Y	Y	Y	Y	Y	N	
13	Y	Y	Y	N		N	Y	Y	Y	Y	Y	Y	
10	Y	Y	Y	Y**		Y	Y	Y**	Y	Y	Y	N*	
22	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	N	
36	Y	Y	Y	Y		N	Y	Y	Y	Y	Y	Y	
15	Y	Y	Y	N		Y	Y	N	Y	Y	Y	N	
34	Y	Y	Y	Y	Liasion psychiatrist via Tenovus	Y	N	N	Y	Y	Y	N	
42	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	
41	Y	Y	Y	Y	Neuropsychology & neuropsychiatric	Y	Y	Y	N	Y	Y	N	
20	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	
23	Y	Y	Y	N		Y	Y	Y§§	Y	Y	Y	N	
48	Y	Y	N	Y	2 x neuropsychologists, 1 adult, 1 paeds	Y	Y	Y	Y		Y	Y	
35	N	Y	Y	N		Y	Y	N•	Y	Y	Y	N	
40	Y	Y	Y	Y	Specialist Unit in mental health	Y	Y	Y	Y	Y	Y	Y	
46	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y		
4††	Y	Y	N	N		Y	Y	N	Y	Y	Y	Y	
27	Y	Y	Y			Y	Y	Y	Y	Y	Y	N	
37	Y	Y	Y	N†		Y	Y	N	Y	Y	Y	Y	
43	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	N	
21	Y	Y	N	N		Y	Y	N	Y	Y	Y	N	
25	Y	Y	Y			Y	Y	N	Y	Y	Y	N	
45	Y	Y	Y	Y		Y	Y	Y	Y	Y	Y	Y	
38	Y	Y	Y	N		Y	Y	Y	Y	Y	Y	N	Complementary therapist
14	Y	Y	Y	N		Y	Y	Y	Y	Y	Y	N	
5	Y	Y	Y	N		Y	Y	N	Y	Y	Y	N	MacMillan Support Centre
44**	Y	Y	Y			Y	Y	Y	Y	Y	Y		

†† Some services available directly through centre for neurology & neurosurgery. * Inpatient only.
**"Site/Trust". †Available by referral off site: 2 clinical psychologists-1 with specific interest in these pts.
‡Visiting. §General neurologist. §§Sessional commitment. • "Tho 200 yards away". *Not yet set up.

Access to services

id	Neurorehab.	Videoconferencing			Access and waiting time for routine outpatient appointment							
		Access	If yes ?useful	If no?woul benefit	CT access	CT routine OPD wait	MRI access	MRI routine OPD wait	PET	PETwait-exact	SPECT	SPECTwait-exact
16	DK	N		Y	Y	4 weeks	Y	4 weeks (onc)	Y	~3 weeks	N	
7	Y	Y	Y		Y		Y		N		Y	
11	N	N		N	Y	4 weeks	Y	4 weeks	N		N	
17	Y	ID		Y§	Y	5 weeks	Y	5 weeks (onc)	Y	3 weeksº	N	
28	Y	N		Y	Y	2 weeks	Y	1 month	N			
33	Y	N			Y	6 weeks	Y	6 weeks	N		Y	1-2 weeks
19	N	Y	Y very!		Y	3-4 weeks¤	Y	2-3 weeks¤	N		N	
24	N	Y	Y		Y		Y		.			
8	Y	Y	Y		Y	0	Y	0	Y	4 weeksº	Y	4 weeksº
30	Y	Y	Y		Y	3-4 months	Y	13-14 months	N			
32	Y	Y	Y		Y	2 weeks	Y	2 weeks	.	º		º
18	N	N		Y	Y	~4 weeks	Y	~6 weeks	N		N	
3	Y	ID		DK	Y		Y		Y		N	
2	Y	N		Y	Y	6 weeks	Y	6 weeks	Y	Nil		
39	Y	Y	Y		Y		Y		Y	4 weeks	N	
6	N	ID			Y	Variable	Y	Variable	N	º	N	º
9					Y	1 week(urgent)	Y	1 week (urgent)	.		Y	
26	Y	N		Y	Y	2 weeks	Y	1 week	Y	º	Y	
29	N	N		DK	Y		Y		Y	Visiting mobile	Y	
47	Y	Y	Y		Y	4 weeks (routine)	Y	12 weeks (routine)	N		N	
13	Y	N		N	Y	a few days	Y	a few days	N		N	
10	Y	ID			Y	6 weeks•	Y	8 weeks•	Y	DK	N	Research only
22	N	N			Y	6 weeks	Y	4 weeks	ID	4 weeks	N	
36	Y	N		Y	Y	1-2 weeks	Y	2-4 weeks	N		N	
15	Y	Y	Y		Y		Y		N		Y	
34	Y*	Y	†		Y	4 weeks	Y	2 weeks	Y	6 weeks	Y	≤ 1 week
42	Y	Y	Y		Y	1 week	Y	variable	Y	2 weeks	Y	1-2 weeks
41	Y	N			Y		Y		N		N	
20	Y	N			Y	2 weeks	Y	3-4 weeks	Y	4-6 weeks	Y	1-2 weeks
23	N	ID			Y	as required	Y		Y	6-8 weeks	N	
48	Y	Y			Y	Days	Y	2 months	Y	º	N	
35	N	N		N	Y	2-3 weeks	Y	6 months	N		N	
40	Y	N		N	Y	8 weeks	Y		Y			
46	Y	N		Y	Y		Y		Y	º	Y	
4	Y**	N‡		Y	Y	1-2 wks	Y	1-2 weeks	N		Y	2-3 wks
27	N	Y‡‡	N		Y		Y		N	N funding	Y	
37	N	N		Y	Y	4 weeks (routine)	Y	4 weeks (routine)	N	starting soon!	Y	DK
43		N			Y	2 weeks	Y	6 months	Y	2 months	Y	2 months
21	Y	N		Y	Y	2 weeks	Y	2 weeks	N		Y	
25	N	N		Y	Y	8 weeks	Y	4 weeks	N		N	
45		ID			Y	7 days	Y		Y			
38	N	Y	Y		Y	3 weeks•	Y	8 weeks•	Y	6 weeks	N	
14	Y***	N		Y very	Y	2 weeks (onc)••	Y	1 month (onc)••	N		N	
5	N	ID			Y	<2 weeks	Y	<2 weeks	Y	<2 weeks□		
44	Y	ID		Y	Y		Y		Y		Y	

DK = Don't know. ID = In development. ¤"For suspected / known tumours". *Not on site. **On site. *** For paitents <65. ‡"Potentially". ‡‡Access but not used for neurooncology. Has been used for other tumour sites. †Not used, would probably be helpful. ††Other teams have used it successfully.§ I could contribute to MDT of unit 33. •1-2 weeks if urgent.••Patients given priority as good links with radiologists, routine wait much longer. ºOff site.□Some funding issues.

Access to facilities

id	Comp. access histopath.	Molecular path.	Routine OP waiting time	Other
16	No*	No		
7	Yes	No		
11	No*	No		
17	No*	No		
28	Yes	Yes	Just starting	
33	Yes	No		
19	No**	Yes	º	
24		No		
8	Yes		º	
30	No	No		
32	Yes	No		
18	Yes	No		
3	Yes			PACS
2	No	No		
39	No	No		
6	No	Yes	º	
9	Yes	No		
26	Yes	Yes		
29	No	No		
47	Yes	Yes		
13	Yes	No		
10	Yes	Yes‡		
22	No*			
36	Yes	No		
15	Yes	No	"Reak lack"§	
34	No	Yes	NK	
42	Yes	Yes	3 weeks	"Yes, all necessary"
41	Yes	No		
20	Yes	No		
23	No	No		
48	No	Yes	NK	
35	Yes	No		
40	Yes	Yes		
46	Yes	No		
4	No	Yes	2-3 months	
27	Yes	No		
37	No	Yes	6 weeks*	Sterotectic planning, Dedicated open MRI for planning (coreg images) and research
43	Yes	Yes		
21	Yes	Yes		Stereotactic radiosurgery
25		No		
45				
38	No	No		
14	Yes	No		
5	†	No		
44	Yes	No	¤	

NK=Not know. *Not for neuropathology. **"Not relevant, surgery not done here". †Yes, but most pathology from outside hospital and not on system. ‡Selected cases only. §"Ages for routine, none for urgent". ¤ Neuropathology in interregnum with retirement of consultant neuropathologist. * Prone to service interuptions!

Presence of protocols & Whether or not multidisciplinary (?MD)

id	Communicate						Response to pt referral	?MD	LGG	?MD	HGG	?MD	Recurrent glioma	?MD	Meningioma	?MD	Pituitary	?MD
	you with 1° care	? MD	1° care with you	?MD	You with other 2° / 3° care	?MD												
16	N		N		N		Y		N		Y		Y		Y		Y	
7	N		N		N		Y		N		N		N		N		N	
11	Y		N		Y		Y		Y		Y		Y		N		N	
17	N¤		N		N		Y		N		Y		Y		Y		Y	
28	N		N		Y*		N		Y		Y		Y		Y		Y	
33	N		N		N		N		N		Y		N		N		N	
19	N		N		N		N		Y		Y		N		Y		Y	
24					N				Y		Y		N		N		Y	
8	Y		Y		Y		Y		Y		Y		Y		N		N	
30	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	
32	N		N		N		N		N		N		N		N		N	
18	Y		Y		Y		Y		Y		Y		Y		Y		Y	
3	Y		Y	Y	Y		N		Y		Y		Y		Y		Y	
2	Y		Y		Y		Y		Y		Y		Y		Y		Y	
39	N		N						Y		Y		Y		Y		Y	
6	N		N		N		N		Y		Y		Y		Y		Y	
9	Y		Y						Y		Y		Y		Y		Y	
26	Y	Y	Y	Y	N		N		Y		Y		Y		Y		Y	
29	N		N		N		N		N		N		N		N		N	
47	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		Y	Y
13	N		N		N		N		N		N		N		N		N	
10	Y		N		N		N		Y	N	Y	N	Y	N	Y	N	Y	N
22	N		N		N				Y		Y		Y		Y		Y	
36	Y		Y		Y		Y		Y		Y		Y		Y		Y	
15	Y	Y	Y	Y					Y	Y	Y	Y	Y	Y	□			
34	ID		ID		ID		ID		ID		ID		ID		ID		ID	
42	N		Y		N		Y		Y		Y		Y		Y		Y	
41	N		N		Y	N	N		Y	N	Y	N	N		N		Y	
20	N		N		N		N		Y		Y		Y		Y		Y	
23	N		N		N		N		Y	N	Y	N	N		Y	N	Y	N
48	N		N		N		N		N		N		N		N		N	
35	N		N		Y		Y		Y		Y		Y		Y		Y	
40	N		N		N				Y		Y		Y		Y		Y	
46	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
4	N		N		N				Y	N	Y	N	Y	N	Y	N	Y	N
27	N		N		N		N		Y		Y		Y		Y		Y	
37	N		N		N				N		Y		N••		N••		N••	
43	N		N		N				Y		Y		Y		Y		Y	
21	Y	N	N		Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
25	N**		N**		N**				Y		Y		N		Y		Y	
45									Y		Y		Y		Y		Y	
38	N		N		N		•		•		•		•		•		•	
14	N		N		Y§	Y	N		N		N		N		N		N	
5	N		N		N		N		Y		Y		Y		Y		Y	
44									Y		Y		Y		Y		Y	

Y=Yes, N=No, ID=In Development. LGG = Low grade glioma. HGG = High Geade Glioma. ¤"Letters sent after every patient". *But protocols need formalising and adopting by the network which is not yet done. **"None specifically for CNS - follow hospital procedures". §"There is an understanding with neurosurgeons that they will send unit where MDT is films with referrals. We now have PACS access so local films are not a problem I have an understanding with neuronocologist in unit of MDT and discuss borderline cases with him. •"All within the paramater of the 2 week waiting list". ••"Verbal policies/not documented, no agreed policy." □"We can't agree"

Presence of protocols & Whether or not multidisciplinary (?MD)

id	Acoustic	?MD	Imaging surveillance	?MD	Follow-up	?MD	Steroid usage	?MD	Other Protocols / comments
16			N		N		Y		RT for brain tumours
7	N		N		N				
11	N		N		Y				
17	DK		N		N		Y		Radiotherapy for CNS tumours
28	Y		Y		Y				
33	N		N		N		N		
19	N/A*		ID		N				We are developing common protocols for all these with units 9, 15, 30
24	N		Y		Y		Y		Palliative brain
8	N		N		N		Y		Various research trial
30	N		Y	Y	Y		Y	N	Working towards multi-site MDT agreed protocols; Have own dept. protocols
32	N		N		N				
18	N		N		N				
3	Y		Y		Y				
2	N		Y		Y				
39			Y		Y				
6	Y		N		N		N		
9									
26	Y		N		N		N		
29	N		N		N		N		
47	N		Y		Y				
13	N								
10	Y	N	N		N				
22	N		Y		Y				
36	N		Y		Y				
15	N		N		Y	Y			
34	ID		ID		ID				Patient pathway/GP proformas are in an advanced stage of development
42	Y		Y		Y				
41	N		N		N				
20	Y		Y		Y				
23	N		N		N		Y	N	CNS lymphoma
48	N		N		N				
35	Y		Y		Y		Y	Y	Advice on how patients contact us, & on how other drs in 2º care contact us
40	Y								
46	Y	Y	Y	Y	Y	Y			
4	Y	N	N		N				
27	Y		Y		Y		N		
37	N		N••		N••		Y		Guidelines for stereotectic treatment
43	Y		Y		Y				
21	N		Y		Y	N			
25	N								
45	Y		Y		Y				
38	•		N		N				
14	N								
5	N		Y		Y				
44	Y		Y		Y				

Y= Yes, N=No, ID=In development, DK = don't know. •"All within the paramater of the 2 week waiting list". ••"Verbal policies/not documented, no agreed policy." *Not done here.

Outcome data routinely collected

id	Survival	Recurrence	Quality of life	Morb. post chemo	Morbidity post RT	Other
16	N	N	N	N	N	
7	Y					
11	N	N	N	N	N	Audit data collected
17	N	N	N	N	N	
28	N	N	N	Y	N	
33						
19*	N	N	N	N	N	
24	N	N	N	N	N	
8**	N	N	N	N	N	
30***	N	N	N	N	N	
32	Y	Y		?	?	
18	Y			Y	Y	
3						Date of death
2						
39						
6§	N	N	N	N	N	
9	N	N	N	N	N	
26	Y†	N	N	Y	Y	
29						
47	Y	Y				
13						
10	N	N	N	N	N	
22						
36						
15	Y			Y	Y	
34	Y	Y	ID	ID	ID	
42	Y	Y	Y	Y	Y	
41					Y	
20	Y	Y	N	N	Y	Endocrine, hearing
23	Y	N	N	N	N	
48						
35	Y	Y	N	N••	N••	RT& chemo dose; Rx of relapse; surgeon; procedure; perfm. status at decision to Rx
40	Y	Y	Y	Y	Y	
46‡						
4						
27	Y	Y	N	N	N	
37	Y			Y		
43	N	N	N	N	N	
21	Y	Y		S	S	
25	N•	N•				
45	Y	Y				
38	Y	Y		Y	Y	Treatment paramerters
14	N	N	N	N	N	
5	N	N	N	N	N	
44	Y					

Y=Yes; N=No; ID=In development; S=Some.. * "I am ashamed to say we collect none here, unit 15 do collect data on survival and recurrent rates and we supply follow up information to them". **None, except in trials.*None at present Collecting data on database from April, 2003 Morbidity data could be retrieved from MAISY. †Through PAS. §"Database being worked on". ‡"Collected in hospital notes at follow-up and will be collected on a database when this is in place". •Clinical follow-up, but not routinely statistically analysed. ••Not recorded in minimum dataset.**

Clinical Trials

id	No. recruited in year by service	Main reason for lack of recruitment
16	1*	No suitable trial
7	0	Lack of resources
11	0	No suitable trial ["We are in the process of joining BR12 trial"]
17	1*	No suitable trial
28	~5	No suitable trial
33	1	No suitable trial
19	0*	No suitable trial
24	0*	
8	0	No suitable trial ["We're in a gap between trials awaiting BR12 etc. "]
30	0‡	No suitable trial; Lack of resources [Hope to join Temo vs PCV tria, pending funding details]
32	**	No suitable trial; Eligability criteria not appropriate; Lack of resources ["No trials for CNS tumorus"]
18	0	No suitable trial
3	0	No suitable trial
2	0*	
39		Lack of resources ["Due to excess drug cost for BR12-Temozoladmide trial"]
6	0*	["Entering patients into MRC trial now it is through ethics"]
9	0	No suitable trial ["Awaiting PCVs Temozolamide trial"]
26	0	No suitable trial ["No active trials"]
29	-	Lack of resources ["In house neurosurgical trials only"]
47	0	Patient did not wish to participate
13	0*•	No suitable trial
10	1‡‡	"Cannot run BR12 because of Excess treatment cost - no other study open for brain tumours"
22	2	Patient did not wish to participate
36	5	Patient did not wish to participate
15	0	Lack of resources
34	2	"BR12 not yet through LREC. Sorry, I haven't yet got round to doing it"
42	80	No suitable trial; Eligability criteria not appropriate; Pt did not wish to participate
41	0	No suitable trial
20	40º	No suitable trial
23	1	No suitable trial
48	***	No suitable trial
35	90	No suitable trial
40	0	Lack of resources
46	U/K	
4	50	No suitable trial
27	0	Lack of resources ["BC12 just opened; no research nurse to support phase III study"]
37	3	No suitable trial
43	1	
21	2	No suitable trial
25	U/K	No suitable trial
45	20	Eligibility criteria not appropriate
38	0	No suitable trial; Eligibility criteria not appropriate; Pt did not wish to participate
14	0	No suitable trial, Lack of resources, ["We have not solve the finance problem for BR12 trial"]
5	5	No suitable trial
44	0	Lack of resources

***CNS only. ‡ No trials last year (participated in Temozolimine trial). **7.5% of total population for all tumours. •80+ for all tumours. ‡‡ Entered into Phase 1 study of Patrin 2 + temodal. º"Studies". *** 586 for all tumours - 18% of total.**

Other comments

id	Comments
16, 17	Map showing cancer network: Unit 16& 17: Radio & Chemo, & shared clinical oncologists (also shared with DGH that refers all to Unit 17 post surgery); Unit 33: Neurosurgery, Radio, Chemo, own clin. Oncs; Other radiotherapy unit (non-responder) has radio, chemo and own clinical oncologists.
28	We are very keen to develop these services and are aware of gaps which need to be plugged
30	I expect you will be receiving feedback from neurosurgeons. I find it difficult to get my patients who recur seen promptly in neurosurgical clinic because surgeons are overstretched. Please give more time in future (I am a core member to 3 weekly MDTs!)
32	Please note the lead oncologist for brain tumours will not complete forms like this. I have done my best but may have given misleading replies about MDT activity with which I am not involved. Unit 27 is involved with these and would give more precise data.
22	For us most useful areas for investment - faster access to radiotherapy, nurse specialists, psychologists and rehab, patient/carer support groups.
41	Our centre is new for onoclogy. Started Feb 1997. There has been neurosurgery on site for many years. We meet our neurosurgical colleagues frequently but informally to discuss patients. The chemotherapy is carried out by a neurosurgeon, who has offered this service for many years. We are very understaffed as regards Consultant Oncologists. Currently we are trying to establish an MDT but there is opposition. We don't have enough time for a neurooncology clinic yet
23	Work underway to set up video-linked MDM in unit 45. Initial discussions underway re MDM/joint clinic with Neurosurgical unit 16. 0.3 WTE dedicated staff nurse in clinic - working towards "upgrading" to clinical nurse specialist role.
35	I am not sure what this Q'aire will achieve. The management of low/high grade gliomas is very different and probably need different follow up arrangements and support. Of course, the role of radiotherapy for Grade II gliomas is likely to change again in the next 1-2 yrs to be used in selected low grade gliomas
27	We need increased funding to improve 1. Patient data collection; 2.To enable us to undertake phase I-III studies - currently there are no research nurses
43	Options for nursing care are very limited for disabled patients - they fall between acute hospital/hospice care & usually not appropriate for non-specialist nursing homes. An intermediate level of care with rehab/palliative care input would be very useful
25	Please accept my apologies for such an incomplete return. It arrived when my colleague was on leave. My colleague deals with our CNS tumours and we have gained funding for a post in 2005 and we have a trainee interested in CNS tumours in adults.