Brain Tumour UK

Register my tumour, recognise me

A campaign to include thousands of missing brain tumour patients in the UK's official health statistics

Brain Tumour Awareness Month MARCH 2009

A special report from Brain Tumour UK, Tower House, Latimer Park, Chesham, Bucks, HP5 1TU
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About Brain Tumour UK

Brain Tumour UK is a caring charity that provides vital support to brain tumour patients and their loved ones. We campaign to raise awareness of brain tumours and we're funding vital research.

Providing support

Brain Tumour UK has an extensive web site full of useful information for patients and carers. We provide personalised support: • by email; • through our busy social networks on Facebook, MySpace, Bebo and Twitter; • with a helpline and telephone chat groups; • and through a growing number of relaxed and friendly support groups.

Raising awareness

Brain Tumour UK works closely with patients, their families, healthcare professionals, scientists and related organisations to raise awareness amongst key decision-makers, service providers and the wider public.

Funding research

Brain Tumour UK, with the help of thousands of generous donors and fundraisers, funds scientific research to improve the quality of life for brain tumour patients, identify better treatments and, ultimately, defeat the disease.

Executive summary

1. Brain Tumour UK believes that approximately half of all primary brain tumour patients – around 8,100 people – are missed from official statistics every year.

2. Many more cases of secondary brain cancer – perhaps 32,000 people – are also not recorded in detail.

3. In all, Brain Tumour UK believes that around 48,000 people each year will develop a brain tumour in the UK.

4. Brain Tumour UK argues that the UK must have comprehensive brain tumour statistics so that NHS in England, Scotland and Wales, and Health Boards in Northern Ireland, can meet the urgent and complex needs of patients whilst science finds effective treatments for the disease.

5. Brain Tumour UK is therefore calling for:

- Health service cancer teams in each country to require data on *all* brain tumours to be reported for cancer waiting times.
- Data on all brain tumours to be collected across the UK, to the standards specified by the National Institute for Clinical Excellence, *by the end of 2009*.
- National governments to specify clear lines of accountability to ensure that comprehensive data is collected.

The experts' opinion

"I very much welcome this report. The NHS needs robust mechanisms whereby anybody who has an abnormal brain scan is properly recorded and then assessed by a neuroscience multi-disciplinary team as soon as possible. If we can get that one thing right, then we can go on to deliver the right level of care to the right people at the right time."

Professor Garth Cruickshank PhD FRCS, Professor of Neurosurgery, Queen Elizabeth Hospital, Birmingham.

"Scientific research to defeat brain tumours depends on robust and comprehensive data. This report makes a clear case for gathering data on all brain tumours so that we can better understand their behaviour and the effects of different treatments over time."

Professor John Darling MSc PhD FIBiol, Director of the Research Institute in Healthcare Science, University of Wolverhampton.

"Services for patients with brain tumours of any type, grade or site within the head will require planned and coordinated management involving many clinical specialities in hospital and good informed primary care services. The route map to improving care starts with identifying people with tumours and planning required services to ensure people have access to the best services for their individual circumstances."

Dr Robin Grant MBChB FRCP FRCP, Lead Clinician, Scottish Adult Neuro-Oncology Network.

"In order to deal effectively with a disease that has such a devastating effect not only on patients but also on those around them, the very least we need is accurate recording of numbers. I congratulate Brain Tumour UK on this report. It is about time that this patient population received the same level of understanding, support and investment as other cancers."

Dr Jacqui Harney MRCPI FFRRCSI, Consultant Oncologist, Belfast City Hospital.

"We very much welcome and support this important work from Brain Tumour UK. Currently neurosurgical services are being reconfigured in Wales and without robust data on all brain tumour patients it will be impossible to design and develop an adequate neuro-oncology service for the people of Wales."

Mr Paul Leach FRCS and Mr Richard Hatfield FRCS, Consultant Neurosurgeons, University Hospital of Wales, Cardiff.

"There are probably around 1,500 patients with high grade brain tumours missing from the official statistics as well as thousands of patients with lower grade and benign tumours. Brain Tumour UK rightly makes the point that unless we record this 'lost' group of patients, we cannot ensure that they benefit from the minimum standards of care they should expect."

Dr David Levy FRCR FRCP, Consultant Oncologist, Weston Park Hospital, Sheffield.

"There is no doubt that the number of brain tumours has been under-reported for years. The very poor prognosis for brain tumour patients and the unique biology of brain tumours demands a high level of investment, yet spending on patient care is totally inadequate and funding for research is woefully insufficient."

Professor Geoff Pilkington PhD FIBiol FRCPath, Professor of Cellular and Molecular Neuro-Oncology, Institute of Biomedical and Biomolecular Science, University of Portsmouth.

"I am delighted that Brain Tumour UK has highlighted the serious ramifications of this missing data. Compared to Europe our brain tumour survival rates look poor, but if you are missing large numbers of patients from the statistics, they don't give a true picture."

Mr Louis Pobereskin, Consultant Neurosurgeon, Plymouth Hospitals NHS Trust.

"Most health service investment is on high grade tumours because they are the ones that get recorded. But low grade and benign tumours can have the same devastating consequences and for longer. Good data on all brain tumours will help in health service planning for all patients who need support."

Elizabeth Preston RGN BA MBA, Head of Service, Cancer and Palliative Care, NHS Lothian.

"Despite the fact that routinely collected data is used to inform decisions which have major financial and pubic health implications, there is little information about the data's accuracy and completeness."

Louis Pobereskin, Consultant Neurosurgeon, Plymouth Hospitals NHS Trust

Introduction

Recording every brain tumour is the first step towards acknowledging that a significant number of people, facing real personal challenges, are in need of the care of the National Health Service.

But Brain Tumour UK believes that around 8,100 patients with primary brain tumours are left off the UK's official statistics every year. And an uncertain number of metastatic (secondary) brain tumour cases – perhaps as many as 32,000 – are also not recorded in detail.

In a world driven by information technology, it is impossible to plan and deliver care for this vulnerable group of people when they are "missing" from the healthcare system. Brain Tumour UK wants every brain tumour to be recorded and is today launching a campaign to encourage governments and health services across the UK to add those thousands of missing brain tumour patients to the UK's official statistics.

Why aren't all brain tumours recorded?

1. **Only malignant tumours are regularly recorded**. Patients with benign and potentially malignant tumours who also need access to acute cancer services are not recorded. In England and Wales, official guidance[13] on recording brain tumours, from the Cancer Action Team, states:

   4.39 Which grades of brain tumour do we report for cancer waiting times?
   Grade 3 and 4 tumours are considered malignant and should be reported for cancer waits.
   Grade 1 and 2 tumours are benign and so should not be recorded for cancer waits.

   This narrow focus on malignant tumours encourages the under-recording of low grade and benign tumours. A similar problem exists in Northern Ireland and Scotland.
2. **The surgery required to obtain a sample for pathology can be impossible**, due to the type and location of the tumour. With benign tumours, open-skull surgery to obtain a sample may not be justified. In the case of malignant tumours, surgery may simply be too risky for the patient. In the absence of pathology, brain tumour records are often not added to the Cancer Registry. Pobereskin[1] has found that two thirds of brain tumour patients who did not have surgery were not recorded on the Cancer Registry.
3. **Even patients who undergo surgery may not be recorded**. The lack of a clear standard for recording brain tumours means that these patients may not be entered onto the Registry. Pobereskin[1] found that one third of patients who had undergone surgery were not on the Registry.
4. **Thousands of secondary (metastatic) brain tumours are not recorded** in the Cancer Registry because the brain tumour is secondary to the primary cancer.

So, how many brain tumours are there each year?

According to Cancer Research UK:

> *In 2005, 4,555 people in the UK were diagnosed with brain and other central nervous system tumours*[14].

But although this figure is widely used by the media when reporting on brain tumour stories, it is a significant under-estimate of the true number of brain tumours. By taking into account three critical pieces of information, Brain Tumour UK has found that the number of people affected by brain tumours each year in the UK could be as high as 48,000.

1. Increase to 8,170, by including benign and low grade brain tumour patients.

Cancer Research UK is, quite rightly, focused on cancer. But as a result, its figure excludes brain tumours which are "benign" or which display "uncertain behaviour". When these are added, the number of brain tumours in the UK rises by a factor of approximately 1.86 to 8,170*.

2. Increase to around 16,000, by including the primary brain tumours that are never registered.

Cancer Research UK and Government agencies use data from Cancer Registries. But there is good evidence that only around 50% of all brain tumours are recorded on the Cancer Registry[1, 2] (see Box 1).

This led the National Institute for Clinical Excellence (NICE) to observe that "almost half of intracranial tumours are not recorded by cancer registries"[3].

We can therefore double the number of primary brain tumours currently recorded by the Cancer Registry, to reach an estimate of 16,000 primary tumours per annum.

3. Increase to around 48,000, by including secondary brain tumours.

Cancer Registries record the primary cancer but often only limited information about secondary (metastatic) cancer, even though the secondary cancer may be the actual cause of death. With no reliable records being held for secondary cancer in the brain, calculating the incidence is, at best, crude. However, two groups of authors, in wide-ranging reviews, argue that "the incidence of brain metastasis is more than double the number of primary brain tumours"[4, 5] (see Box 2).

We can therefore double our estimate of 16,000 primary brain tumours per annum, to add an additional 32,000 brain tumour cases to the total.

In all, therefore, Brain Tumour UK believes that around 48,000 people will develop primary or secondary brain tumours during any one year. Breakdowns by country and English region are given in Appendix 2.

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* The factor of 1.86 uses data from the UK Statistics Authority for England. This records 3,837 malignant brain tumours for England and 3,029 benign and uncertain behaviour tumours. Data for benign and uncertain behavour tumours is only available online for England. We have therefore multiplied the number of malignant tumours in Northern Ireland, Scotland and Wales by 1.86 to generate an overall estimate for the UK.

Box 1: How many primary brain tumours are missing from official UK data?

Two studies have suggested that only around half of all brain tumours are recorded on the Cancer Registry.

In Lothian, Counsell and colleagues[2] found that of 228 patients with primary intracranial tumours, only 54% were in the Scottish Cancer Registry. Only one in five meningiomas were in the Registry and no cranial nerve tumours at all.

A second study, by Pobereskin, compared five years'-worth of CT and MRI scan records held by Devon and Cornwall hospitals with records held by the South and West Cancer Intelligence Unit (now, Cancer Registry)[1, 6]. Of 1,480 primary brain tumours which could have been added to the Registry, only 776 (52%) were.

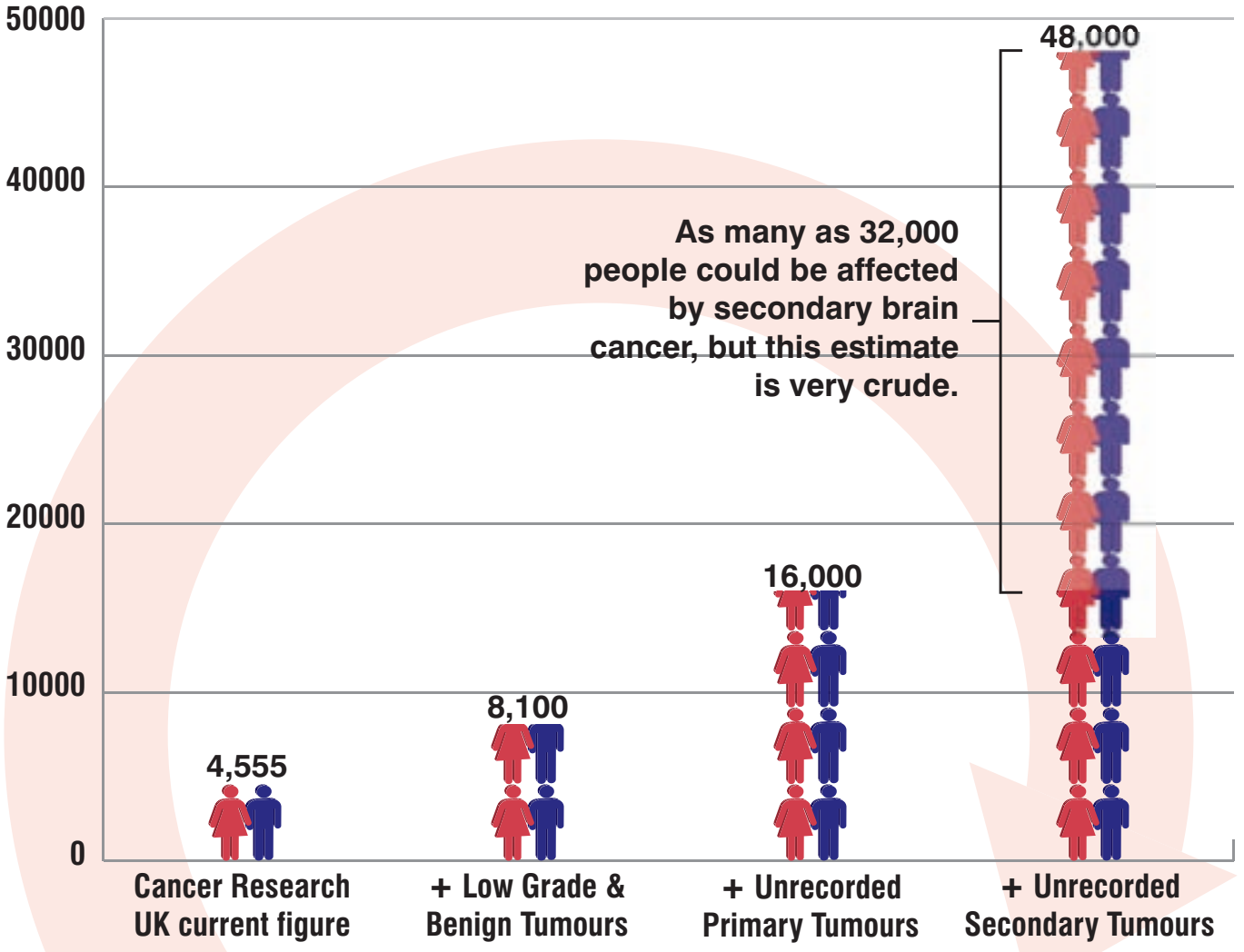
Pobereskin consequently concluded: "Official figures from the cancer intelligence units significantly underestimate brain tumour incidence, especially for benign tumours."

Only one third of tumours in patients who did not undergo surgery were recorded. Only two thirds of tumours in patients who were admitted to hospital for surgery were recorded. Even 28% of malignant tumours were not recorded.

Although these studies are now historic and were confined to specific parts of the UK, neuroscience healthcare staff advise us that the methodologies for recording brain tumours have changed little in the intervening time and the problem persists.

The National Institute for Clinical Excellence (NICE) recognises that its figures for brain tumour incidence are based on estimated, incomplete data[3].

Around 48,000 brain tumours may occur each year in the UK



Box 2: How many people are affected by secondary (metastatic) brain cancer?

There are two ways of estimating the number of secondary brain tumour patients:

a) Estimating secondary brain cancer incidence from scans.

Pobereskin and Chadduck[6] studied 2,483 scans of brain tumours over a five year period and found that 1,622 were primary and 861 were metastatic. The ratio of primary to secondary was therefore approximately 2:1. This suggests that we can add another 6,500 metastatic patients to our figure of 13,000 primary brain tumour patients, totalling 19,500 patients per annum.

But conversely, Counsell *et al* found 122 primary brain tumours and 214 metastases in their survey of a region of Scotland in 1989-90. The ratio of primary to secondary was therefore approximately 1:2.

Even then, since many patients with secondary cancer in the brain will never be scanned, *both these figures are likely to be an under-estimate*.

b) Estimating secondary brain cancer incidence from post-mortems.

In 2007, Sul and Posner[7] surveyed a wide range of autopsy studies into brain metastases (secondary brain cancer) and found that a great deal of secondary brain cancer goes undetected whilst patients are still alive, and will only be found if a post-mortem of the brain is conducted.

In separate, wide-ranging reviews of post-mortem and other studies, both Posner[5] and Gavrilovic[4] have estimated that the number of patients with secondary brain tumours is likely to be *at least twice that of primary brain tumours*.

It is important to note that secondary brain cancer is not always the cause of death or even contributes to the cause of death. Nevertheless, for a significant number of patients secondary brain cancer will pose substantial health and quality of life challenges and the number of people affected is likely to grow.

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Why does it matter if brain tumours are not registered?

1. Our national health services cannot adequately plan for and fund healthcare for brain tumour patients if it doesn't know they exist.

If we do not register the existence of brain tumours, we cannot recognise and then meet the needs of people who are affected by them.

The National Institute for Clinical Excellence (NICE) has published Improving Outcomes Guidance (IOG) for brain tumour patients[3] in England and Wales, setting clear targets for patient care. Brain Tumour UK hopes that the guidance will be adopted by the Northern Ireland Cancer Network[17] and equivalent guidance will be developed by Quality Improvement Scotland.

The NICE IOG recommends that services should be "adequately resourced" to provide support and rehabilitation services for brain tumour patients. But if there is inadequate data on how many people are affected by brain tumours, it is very difficult for health services to factor "adequate resources" into budgets. The NICE IOG also specifies what data should be collected (see Box 3), but this data collection must surely begin *before* robust and effective decisions about adequate resources can be made.

2. Our health services cannot measure whether they are meeting their targets.

Our health services have clear targets for treating patients within strictly defined time scales*. And for brain tumour patients, time is of the essence. There is clear evidence that early, aggressive intervention for malignant brain tumours, followed by radiotherapy and chemotherapy, maximizes the patient's longevity and quality of life[10]. Even for benign tumours, prompt assessment and treatment such as surgery to "debulk" the tumour can prevent the loss of sight and other harm.

But Pobereskin found that 28% of patients with malignant gliomas were missing from the Cancer Registry. Levy estimates that 1,500 high grade brain tumour patients go unrecorded every year[18]. If the diagnosis of a malignant brain tumour is not recorded, we cannot measure whether targets for its treatment are being delivered.

In England and Wales, secondary brain tumours are also covered by these time scales for treatment. Brain Tumour UK hopes that similar time scales will be set in Northern Ireland and Scotland. Yet, the absence of reliable secondary cancer data makes it well-nigh impossible to determine whether the rule is being met.

Mike Richards, the National Director for Cancer, has therefore ordered that data on recurrent cancer – including brain tumours – should be collected from 1 January 2009[11]. Brain Tumour UK hopes that the Northern Ireland Cancer Network and the Scottish Cancer Taskforce will ensure similar collections of secondary brain cancer data.

Progress on recording this secondary cancer data is now being made in England and Wales. But it surely makes sense to collect primary *and* secondary brain cancer data together, in radiology departments and neuroscience units across the UK, rather than progressing more rapidly with secondary brain tumour data alone or in a piecemeal fashion between countries.

3. Scientific research into brain tumours is hampered.

The more data we have on groups of people affected by brain tumours, the greater the likelihood that possible causes and treatments can be detected. This is particularly important now that studies on brain tumours are going global, bringing together more and more patients to provide more statistically-significant results.

Box 3: NICE specification on what brain tumour data should be collected

"It is therefore important that, as a minimum, information is recorded for clinical audit purposes on:

- all patients with a radiological diagnosis of CNS tumours;
- any further investigations and the confirmed diagnosis (with the cancer registry notified);
- the management plan agreed by the specialist multidisciplinary team (MDT);
- the initial treatment provided;
- outcomes, both short- and long-term."

*In England, Scotland and Wales, no-one should wait more than 18 weeks from GP referral to hospital treatment. For patients with malignant tumours, treatment should begin within 31 days of the decision to treat. Treatment should begin within 62 days of urgent referral when cancer is suspected. In Northern Ireland, at least 98% of patients with malignant tumours should begin treatment within 31 days, whilst at least 95% of patients urgently referred with suspected cancer should begin their first definitive treatment within 62 days.

"The brain may increasingly become the first and only site of [cancer] relapse."
Igor T. Gavrilovic, 2005.

Good data on brain tumour patients helps science in many other ways, too. It is absolutely essential for measuring the effectiveness of new treatments. And it can even determine whether pharmaceutical companies will bother to develop new treatments: if patient groups are thought to be smaller than they really are, because they are under-recorded, companies may feel that it is not economically viable to develop new treatments for them.

4. National health services can spend their limited budgets more efficiently.
For England, Wales and Northern Ireland[17], the National Institute for Clinical Excellence (NICE) evaluates new treatments both before and after they are licensed for use by national health services. In Scotland, a similar service is performed by the Scottish Medicines Consortium and Quality Improvement Scotland (often in partnership with NICE). This evaluation needs evidence.

The better the evidence, the more robust the decision. Cancer Registry data can show whether, on average, patients receiving a specific treatment or combination of treatments survive a little longer or much longer. That evidence is central to making fair decisions about health service expenditure, so that the limited budget goes the longest way.

5. We need to know whether the number of people affected by brain tumours is changing.

Primary brain tumours

The cause of primary brain tumours is unknown. Genetic, environmental and other factors could be at work. Recently, it has been suggested that mobile phones might cause brain tumours, but there is limited evidence to support this hypothesis. If mobile phones were involved, we might expect to see a corresponding increase as more people use mobile phones for longer periods. Good data on brain tumour incidence may help to answer these and other challenging questions.

Secondary brain tumours

Although we don't know how many people are affected by secondary brain cancer each year, the number will probably grow in future as the treatment of primary cancers becomes more successful. For example, 25-30% of breast cancer patients receiving Herceptin may go on to develop metastases in the brain[15,16].

As Gavrilovic[4] explains, secondary cancer may be able to "hide" in the brain, behind the blood-brain barrier. This barrier protects the brain from infection and other harm, but it also obstructs the flow of chemotherapy that might otherwise kill the secondary cancer[12].

"The brain may increasingly become the first and only site of [cancer] relapse," says Gavrilovic, adding: "Most neuro-oncologists believe there is an increasing incidence of brain metastases particularly in those patients whose systemic tumours have responded to chemotherapy."

Brain Tumour UK believes that the brain will become the principal battleground against cancer in the future, as advances are made in treating other, primary cancers. Clear records of secondary brain tumours will reveal whether their incidence is increasing and that evidence could, in turn, justify targeted screening for certain patient groups to identify and tackle secondary cancer in the brain.

6. Our rankings on brain tumour survival may look worse than they are.
Compared to the rest of Europe, our performance on brain tumour treatment appears to be poor. For example, only around 32% of brain tumour patients in England, Scotland and Wales survived for more than one year between 1990 and 1994, compared to 37% in Europe as a whole[9], where some countries report far higher survival rates (e.g. Finland: 54%). But our "poor" performance may be an artefact of data collection rather than a true picture of our healthcare system. Improved consistency in data collection across Europe will provide a far clearer picture of overall standards across Europe.

What needs to be done?

1. The Cancer Action Team should amend its guidance on Cancer Waiting Targets for England and Wales to require that *all* types of brain tumour are recorded for cancer waiting times (see Appendix 1). Equivalent requirements should be set in Northern Ireland and Scotland.
By currently excluding Grade 1 and 2 tumours, the Guidance encourages under-recording of these tumours even though patients may present with acute symptoms requiring acute cancer services. Furthermore, the tumour grade cannot be determined by the scan alone. Therefore, all scans suggestive of abnormalities should be recorded as suspected cancer until a neuroscience centre multi-disciplinary team has made a full assessment of the patient.

2. Data on all brain tumour patients must be collected across the UK to the minimum standards set by NICE *by the end of 2009*.
The NICE Improving Outcomes Guidance for brain tumour patients sets clear standards for data collection (see Box 4). The sooner these standards are met, the faster national health services can plan, resource and deliver the levels of care set out in the guidance.

BOX 4: NICE standards for the collection of brain tumour data

- Data collection systems should be in place that allow entry of information on all patients with a radiological or histopathologically confirmed CNS tumour. Consideration should be given to a web based information system that will allow easy data sharing between healthcare professionals across services, and complies with data protection legislation.
- A local retrieval system that identifies all radiology reports that mention CNS tumours should be developed and maintained until digital, coded reporting systems are universal.
- The lead clinician of the neuroscience MDT and the lead clinician of the cancer network MDT should assume overall responsibility for ensuring that complete data are collected, verified and recorded on all patients reviewed by the teams. Strong links with the local cancer registry should be developed to ensure complete and accurate registration of all patients.
- The data collection responsibilities of the various MDT members should be clearly defined in local protocols.
- Adequate clerical support should be provided for the MDTs to facilitate data collection.
- The national minimum datasets for CNS tumours should be adopted in both England and Wales when they become available.

3. National governments should specify clear lines of accountability to ensure the data is collected.
It is not clear who has absolute responsibility for ensuring that brain tumour data is collected. There are several players involved in each country. It must be clear with whom absolute responsibility for data collection lies, to ensure that the responsibility is met.

Conclusion

The diagnosis of a brain tumour can have a devastating impact on the lives of patients and their loved ones. Understanding how many people are affected will allow our national health services to commission the right healthcare services in the right places, in collaboration with others. Great progress has already been made in the treatment and care of people suffering from other serious diseases. People affected by brain tumours must not be left behind.

Appendix 1

The Cancer Action Team currently advises that Grade 3 and 4 brain tumours should be recorded for data on cancer waits, but Grade 1 and 2 tumours should not[13]. This encourages under-recording of Grade 1 and 2 tumours, even though they can go on to become malignant and even benign tumours can cause severe problems and even death for patients. Categories of tumour that are currently recorded under Cancer Action Team guidance are shown below in blue. Brain Tumour UK wants all tumours, including those in red, to be recorded throughout the UK.

	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

This table is derived from:
Appendix 8, *Improving Outcomes for People with Brain and Other CNS Tumours – An Assessment of Need for Brain and other CNS Tumour Services in England and Wales*, National Institute for Clinical Excellence, June 2006.

Appendix 2

Estimates of the total number of people affected by brain tumours in the UK in 2005.

2005	England	North East	North West	Yorkshire and the Humber	East Midlands	West Midlands	East	London	South East	South West	Northern Ireland*	Scotland*	Wales*	UK
Total *recorded* primary brain tumours†	**6,866**	353	1,050	593	616	582	767	775	1,186	944	188	647	472	**8,173**
Likely number of primary brain tumours	**13,732**	706	2,100	1,186	1,232	1,164	1,534	1,550	2,372	1,888	376	1,294	944	**16,347**
Likely number of secondary brain tumours	**27,464**	1412	4,200	2,372	2,464	2,328	3,068	3,100	4,744	3,776	751	2,588	1,889	**32,694**
Potential number of all brain tumours in 2005	**41,196**	**2118**	**6,300**	**3,558**	**3,696**	**3,492**	**4,602**	**4,650**	**7,116**	**5,664**	**1,127**	**3,882**	**2,833**	**49,041**
Number of brain tumours missing from published figures	**34,330**	**1,765**	**5,250**	**2,965**	**3,080**	**2,910**	**3,835**	**3,875**	**5,930**	**4,720**	**939**	**3,235**	**2,361**	**44,501**

* Figures for **Total recorded brain primary brain tumours** in Northern Ireland, Scotland and Wales are estimates, because details of brain tumours that are benign or of uncertain behaviour are not currently published online (see point 1, p5). The three countries only publish data for malignant tumours (with the international classification category C71) but it is likely that, as in England, a handful of data for benign and uncertain behaviour tumours is held on their respective Registries. The estimates above are therefore derived by multiplying the number of malignant tumours by 1.86, a factor derived from the more comprehensive dataset available for England. The actual number of C71 brain tumours recorded in the published statistics for each country in 2005 was:

- Northern Ireland 101
- Scotland 348
- Wales 254

† Total recorded primary brain tumours in our data include the following ICD10 categories:

- C70 Malignant neoplasm of meninges
- C71 Malignant neoplasm of brain
- C72 Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system
- D32 Benign neoplasm of meninges
- D33 Benign neoplasm of brain and other parts of central nervous system
- D35.2 Benign neoplasm of pituitary gland
- D35.3 Benign neoplasm of craniopharyngeal duct
- D35.4 Benign neoplasm of pineal gland
- D42 Neoplasm of uncertain or unknown behaviour of meninges
- D43 Neoplasm of uncertain or unknown behaviour of brain and central nervous system
- D44 Neoplasm of uncertain or unknown behaviour of endocrine glands

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9. Eurocare-3, *Survival of Cancer Patients in Europe*. 2003, Istituto Nazionale Tumori / Istituto Superiore di Sanità.
10. Stupp, R., *et al.*, *Changing Paradigms—An Update on the Multidisciplinary Management of Malignant Glioma*. The Oncologist, 2006. **11**(2): p. 165-180.
11. Richards, M., *Going further on cancer waits*, to Medical Directors and Directors of Nursing, personal communication, 2008: London.
12. The blood brain barrier (BBB) regulates the passage of water-soluble molecules from our blood supply to the brain. The BBB helps to reduce the risk of harm to the brain and it also helps the brain to maintain its overall chemical balance. But the BBB can also prevent chemotherapy from reaching the brain and killing tumours, so it is a barrier to effective treatment, too.
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14. *UK Brain and CNS Tumour Statistics*, Cancer Research UK, http://info.cancerresearchuk.org/cancerstats/types/brain/?a=5441, as at 3 March 2009.
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