Think all cancer research is funded equally? Think again…

Brain tumours: the forgotten cancer
A report on inequality of funding and profile of brain tumours

3 JULY 2009

1. Summary

- 16,000 people each year in the UK are diagnosed with a brain tumour
- 20% of all cancers now spread to the brain
- Primary tumours cannot be prevented because their cause is unknown
- More men under the age of 45 and women under the age of 35 die from a brain tumour than any other cancer
- While the five-year survival rate for many cancers is over 50% and rising to over 90% for some cancers, for brain tumours, the five year survival rate for men is 14.1% and women is now 13.8%
- Brain tumours are the most common solid tumour found in children and they have overtaken leukaemia as the biggest cancer killer of children in the UK
- The number of children dying from a brain tumour in 2007 was 33% higher than in 2001; child deaths from leukaemia were 39% lower than in 2001
- Brain tumour research receives less than 1% (0.7%) of cancer research spending in the UK
- The amount the government has spent on cancer research related to brain tumours in 2007-8 is half the ‘official’ figure of £970,000 from the Medical Research Council

Brain Tumour Research recommends that:

- **All intrinsic tumours (grade 1-4) are included in cancer waiting time standards as recommended by NICE**
- **Cancer registries record secondary cancer in mortality statistics**

- **Further analysis is undertaken on the cancer burden in different age groups as well as gender**
- **NCRI partners give brain cancer a priority status and increase levels of funding for research**
- **The government significantly increases the proportion it spends on research related to brain tumours, at least to the levels of expenditure for other cancers**

2. Introduction

Health inequality is a major concern and frequently generates media debate, but the range and scope of inequalities are varied. As stated in the National Cancer Research Initiative (NCRI) Strategic Plan "inequalities can occur in health itself or in access to treatment and other services and also in access to participation in research."[1] This report looks at the broader issue of inequality of national funding for site specific cancer research, focusing on the levels of funds provided for brain tumours. Related to this is the 'inequality of profile' where some site specific cancers have successfully generated more awareness and funding, which has directly led to an improvement in diagnosis and treatment for cancer patients. There are issues of inequality of care and support for brain tumour patients, some of which have been highlighted in the 2006 National Institute for Health and Clinical Excellence (NICE) "Guidance on Cancer Services "Improving outcomes for people with brain and other CNS tumours."[2] This submission will focus primarily on inequality of research. However, the related inequality of profile has implications for quality of care and support for current and future patients with brain tumours.

Research into brain tumours is in its infancy, with very little known about the behaviour of brain tumours, their effective diagnosis and treatment, let alone finding a cure. Funding for this research significantly lags behind other cancers and clinical understanding of these cancers does not readily translate to brain tumours. Other site specific cancer charities are able to generate far more cancer research funding, and levels of UK government funding for brain tumour research is particularly low. Without an increase in funds allocated to brain tumours, Brain Tumour Research believes that there will be a continued and worsening inequality for brain tumour patients in terms of awareness, diagnosis, treatment and outcome.

3. Incidence and diagnosis of brain tumours

- 16,000 people each year in the UK are diagnosed with a brain tumour
- 20% of all cancers now spread to the brain
- Primary brain tumours can affect anyone and cannot be prevented because their cause is unknown

Brain tumours are often cited as 'uncommon' accounting for 2% of all cancers. However, this figure is based on primary malignant tumours. Cancer Research UK (CRUK) figures state "in 2006, 4555 people in the UK were diagnosed with brain and other central nervous system tumours."[3] However, these figures relate to high grade malignant tumours – grade 3 and 4, grades 1 and 2 are not included in this figure. As NICE state "there is evidence of significant under-registration of intracranial tumours in the UK, particularly low-grade tumours. It has been suggested that almost half of intercranial tumours are not recorded by cancer registries."[4]

If you include other primary tumours and secondary brain tumours (originated from other cancer sites) the numbers of people affected by brain tumours is much higher. Research produced by Brain Tumour UK suggests that the numbers of people affected by primary brain tumours is 16,000 and this figure could increase to 48,000 with secondary brain tumours[5].

An article published this month (June 2009) in the medical journal PLoS ONE highlights how secondary brain tumours are a worrying concern as 20% of all cancer patients now develop brain cancer. "Brain metastases are the most common malignant tumour of the (CNS) outnumbering primary brain tumours such as gliobastoma in prevalence by tenfold…the incidence of brain metastasis appears to be increasing."[6] However, if cancer registries continue to record the primary rather than secondary (metastatic) cancer as a cause of death, these will not be recorded accurately.

These figures are supported by anecdotal evidence. Mr Kevin O'Neill, Consultant Neurosurgeon, Honorary Clinical Senior Lecturer at Imperial College London said that "brain tumours are on the increase - reportedly in the region of 2% per year - but in my unit alone we have seen the number of brain tumour cases nearly double in the last year."[7] This is mirrored in other parts of the country; Mr Charles Davis, consultant neurosurgeon, and President of the British Neuro-oncology Society states "in Preston we have a preliminary increase in malignant tumours over last 4 years of nearly 50%."[8]

Not effectively recording brain tumours can have a major effect on statistics and analysis, and goes some way to explain why the profile of brain tumours is so low, in turn having a serious impact on the attention brain tumours are given by policy makers, cancer research funders, the media and the public at large. This directly leads to an inequality of profile and subsequent funding. For example, this month CRUK and partners published a report on cancer inequalities in men "The excess burden of cancer in men in the UK"[9] The first page of the report has a graph of the 'Top ten most common cancer deaths from men.' Yet brain tumours do not appear in the graph. However, if you included deaths from unclassified brain tumours, and secondary cancer brain tumours, it would give a more accurate comparison with other cancers and place brain tumours higher up on the 'rank'. Brain Tumour Research also believes that when looking at the picture of adult cancers, it is also important to look at the different ages of cancer deaths. Analysis published by Brain Tumour Research from latest figures, shows that more men under the age of 45 die from a brain tumour than any other cancer (see section 4). The right statistics are particularly important in the current media environment (crucial for charities to raise funds or lobby policy makers) when the vast majority of media hooks for health stories are based on statistical analysis.

Lack of effective recording of brain tumours has a related impact for the quality of care for all brain tumour patients. Whether malignant, benign or secondary a brain tumour patient will use similar NHS resources. The very nature of the location of a brain tumour means that treatment is complex and potentially life threatening, even for benign tumours. NICE recommend that "all intrinsic CNS tumours (grade 1-4) should be reported under cancer waiting times standards. This will enable quicker access to appropriate treatments for patients with these tumours in order to improve outcomes.[10]"

There are over 120 different types of brain tumour which present in different ways. Early diagnosis is desirable for what is often a fast-growing cancer and earlier attention may prevent acute complications in treatment later. Latest figures from the Department of Health show that for brain tumours, the two week wait from referral for suspected cancer to being seen by a specialist between January and March 2009 was 96.7% compliance[11]. However, as stated earlier, these figures are for 'suspected cancer' i.e. malignant grade 3-4 tumours , whereas due to the complexity of symptoms for brain tumours – headaches, nausea, seizures – rarely is 'cancer' a suspected cause, with many patients being diagnosed with a brain tumour following investigation for other illnesses such as epilepsy. With a diverse range of symptoms, diagnosis can take months delaying the necessary treatment. As explained in the NICE guidance "CNS tumours can result in a wide range of physical, cognitive and psychological symptoms. The list of differential diagnoses is considerable…these may be exhaustively explored before the diagnosis of a CNS tumour is considered. Consequently, for some patients and families there is a long delay from first symptoms to reaching a diagnosis causing considerable stress and anxiety."[12]

Compiling effective data on brain tumours is crucial due to evidence that so many brain tumours are not included in official statistics. Such data collection is entirely feasible, as evidenced by the National Lung Cancer Audit[13].

Recommendations:

- **All intrinsic tumours (grade 1-4) should be included in cancer waiting time standards as recommended by NICE.**
- **Cancer registries should record the secondary cancer in mortality statistics**
- **A national brain tumour audit should be established**

4. Brain tumour survival rates and trends

- More men under the age of 45 and women under the age of 35 die from a brain tumour than any other cancer
- While the five-year survival rates for many cancers are over 50% and rising to over 90% for some cancers, for brain tumours, the five year survival rate for men is 14.1% and women is now 13.8%
- Brain tumours are the most common solid tumour found in children and they have overtaken leukaemia as the biggest cancer killer of children in the UK
- The number of children dying from a brain tumour in 2007 was 33% higher than in 2001; child deaths from leukaemia were 39% lower than in 2001

While cancer incident rates are important, to get a picture of inequality, it is crucial to also look at mortality and survival rates. Overall, mortality rates from cancer are decreasing, despite increasing incidence. Cancer survival rates have improved steadily for most cancers in recent years. However, if you look at individual cancers the unequal picture emerges. Cancer Research UK (CRUK) latest five year survival rate trend analysis for 1986-1999[14] states that "Cancer survival – cancers with no improvement. For a small group of cancers there were small falls in survival between 1986 and 1999. Survival for brain tumours for both men and women fell slightly but steadily over the 1990's."[15] It is welcome that CRUK mentioned brain tumours as the first cancer of concern in the 'cancers with no improvement' analysis, however this concern has not translated into a significant increase in allocation of resources for research and the situation remains largely unchanged. Latest figures from the ONS up to 2006 show that brain tumours have the fourth lowest survival rate after cancers of the pancreas, lung and oesophagus.[16] The five year survival rate for men is now 14.1% and women, 13.8%.[17]

CRUK's latest cancer mortality analysis from 1978-2007 shows that overall the European age-standardised mortality rates fell by 19%.[18] The vast majority of cancers have seen a significant positive change in mortality rates over the past 30 years. Only four cancers have seen a negative percentage rate change in mortality rate over the last 30 years for cancers that affect both men and women. These are cancers of the brain, kidney, malignant melanomas and pancreatic cancers.

It is also important to look at age of people affected by different cancers. Brain Tumour Research has analysed the latest data from the office of national statistics (ONS) on mortality rates in 2008. They show how brain cancer affects young people significantly more than other cancers. Brain tumours are the leading cause of death from cancer of all women under the age of 35 and all men under the age of 45.[19] If you compare brain tumours to other higher profile cancers, in 2008, brain tumours caused 58% more deaths in women than cervical cancer.[20] Likewise in 2008, 85% more people under the age of 65 died from a brain tumour than from leukaemia.[21] Like brain tumours, leukaemia is a largely unpreventable cancer. Thanks to the extraordinary work of Leukaemia Research, Children with Leukaemia and other charities, the five year survival rate is now over 80% compared to less than 20% 30 years ago.

For children, the trend in outcome for brain tumour patients is as worrying. Brain Tumour Research has highlighted that the number of children dying from a brain tumour in 2007 was 33% higher than in 2001; child deaths from leukaemia were 39% lower than in 2001.[22] In 2007 46% more children died from a brain tumour than from leukaemia[23].

Brain tumour deaths represent 2.3% of cancer overall[24] but analysis of the figures for 2008 by age group shows how they affect younger age groups. (See Fig 1)

Fig 1: Brain Tumour Research analysis of deaths from brain tumours, as a percentage of total cancer deaths and rank, source ONS mortality statistics 2008 [25]

Age Group	**Male**	**Female**	**Total and rank for total**	
Under 15	35.4%	33.3%	34.5%	Highest
Under 25	24.7%	22.4%	23.8%	Highest
Under 35	20.6%	13.7%	17.2%	Highest
Under 45	16.9%	7.4%	11.5%	2nd highest
Under 55	10.7%	5.1%	7.6%	3rd highest
Under 65	6.2%	3.8%	5.0%	5th highest

It is important to note that these figures are unlikely to include recording of secondary brain tumours which could further increase the proportion of people who die from a brain tumour related to other cancers. Unless more funding is given for brain tumour research, this could have an impact on many more cancer patients. Patients who have their lives extended by improved treatment for primary cancer, will face limited options if the cancer spreads to the brain, unless there is greater research to advance treatment.

Recommendation:

- **Further analysis is needed on the cancer burden in different age groups as well as gender.**

5. Levels of funding of brain tumour research

- Brain tumour research receives less than 1% of cancer research spending in the UK

The National Cancer Research Institute (NCRI) states in its strategic plan that "Prevention is the most effective form of cancer control."[26] However, it is impossible to prevent or screen for primary brain tumours as their cause is unknown, for these non-preventative cancers it is even more crucial to fund research to help understand their causes. Despite evidence to suggest a rise in the levels of brain tumours and the low level of survival rates, research for brain tumours remains severely underfunded. Professor Geoff Pilkington, Professor of Cellular and Molecular Neuro-oncology, University of Portsmouth, has argued that brain tumours are a 'poor relation to other cancers.'[27] Addressing this inequality must be a priority.

Latest figures show that in 2007 brain and nervous system (CNS) expenditure by partners in the NCRI was £3million, total NRCI expenditure was £426 million, brain and CNS expenditure as a percentage of that total amounted to 0.7%.[28] To compare, NCRI expenditure for leukaemia research was £29 million, almost 90% more than research funding than brain tumours.[29]

The NCRI itself recognises the problem of funding disparity. The NCRI analysis of the national cancer research portfolio states "Percentage spend versus percentage mortality: Cancers differ by incidence and mortality and it can be illuminating to consider the spend by disease site in this context. …Some of the cancers with the lowest five-year survival rates have the lowest relative spend by NCRI partners. Conversely leukaemia and breast cancer have higher survival rates, to some extent reflecting past research successes."[30] As mentioned in the previous section – brain tumours currently have the 4th lowest cancer five-year survival rate behind cancer of the pancreas, oesophagus and lung. The NCRI state that "Although from time to time NCRI is asked to give special consideration to other particular tumour types, it is not realistic for the NCRI to respond to all of these with a detail review."[31] However, whereas NCRI members are addressing the other cancers with the lowest survival rates, brain tumours are not receiving the same attention. The NCRI strategic plan 2008-2013 states "One NCRI partner, the Roy Castle Lung Cancer Foundation, together with the Colin Montgomerie Charitable Foundation, is planning a major new initiative in lung cancer…In 2007 Cancer Research UK organised a strategic workshop on pancreatic cancer at which a number of research needs were identified and prioritised; a similar workshop on oesophageal cancer is planned."[32] It is welcome that the NRCI have identified these priorities for cancer research: Brain Tumour Research believes that brain tumours should also be given a priority status.

The inequality of funding causes a further negative spiral if researchers move into other areas of cancer research which are better funded. As Professor Geoff

Pilkington explains "during a student's PhD we often see many promising and encouraging findings emerging but then once the students finish their PhD the research ends as no funding is available for them to continue. Each study may give us a glimmer of hope - then it is over. It is, therefore, imperative that we are given the opportunity to take these studies further. Ultimately we need long term research programmes of dedicated brain tumour research."[33]

It is clear that the levels of funding for site specific cancers also directly impacts on representation and further profile-raising. To date there is no representation of brain tumour charities within the NCRI as representation depends on the amount of money the charity generates. As mentioned earlier, higher profile charities are able to generate far more income so are well represented on the NCRI. For example there are representations from 2 leukaemia charities and 2 breast cancer charities on the NCRI, but currently no brain tumour charities are represented. As a group, Brain Tumour Research generates over £1million of funding for research (a criteria for admission) so would like to be considered for admission to the NCRI. Until that time, brain tumour charities, and patients, are reliant on the large charities to profile the issue within the NCRI.

Recommendations:

- **NCRI partners should give brain cancer a priority status and increase levels of funding for research**
- **NCRI should consider Brain Tumour Research joining their membership**

6. Government funding for brain tumours

- In 2007-8 the UK government provided £970,000 for brain tumour research – even this small level has been questioned

This submission has highlighted the inequality of funding and profile of brain tumours in the UK that has led to brain cancer now being the leading cause of cancer death of young people in the UK. For those cancers with unequal national profile and subsequent funding, it is even more crucial that the government addresses the funding inequality. However, the government's spend on brain tumour research is extremely low and in recent weeks major questions have arisen over the low levels of funding that the government gives to brain tumour research. The Medical Research Council (MRC) is one of the main agencies through which the government support medical and clinical research. In 2007/08, the MRC's expenditure on cancer research amounted to £89.5 million.[34] In January 2009, the government outlined the level that it spent on brain tumour research in relation to leukaemia:

Spend area	*2005/06*	*2006/07*	*2007/08*
Research related to leukaemia (£ million)	13.8	13.3	14.0
Research related to brain tumours (£)	900,000	**940,000**	**970,000**

When these figures were published by Brain Tumour Research in April 2009, leading brain tumour researchers were surprised with these figures as they felt that the MRC expenditure was even less than the £970,000 figure quoted. On further investigation, in an email sent to Baroness Tonge in December 2008 the House of Lords Library staff quoted officials from the MRC with very different figures:

"In 2007/08 the MRC's expenditure on cancer research amounted to £89.5million. In 2007/08 the MRC's expenditure on cancer research of particular relevance to brain cancer **amounted to about £412k.** MRC-funded research relevant to brain tumours includes core funding to the MRC Clinical Trials Unit in London for various clinical trials in brain cancer. **Unfortunately there was no reportable MRC expenditure on brain cancer during 2006/07** – this is because programmes of work in this area were winding down, or just getting started and that is why no expenditure was incurred in 2006/07. The clinical trials in brain cancer, which are run by the MRC Clinical Trials Unit in London, were on-going in 2006/07 but make up such a small percentage of the Unit's total research budget that the spend could not be quantified for 2006/07. "[35]

This information suggests that MRC expenditure for brain tumours in 2006-7 could not be quantified (not the £940,000 figure) and in 2007-8 was about £412,000 (not the £970,000 quoted by the Government). Dr Tonge asked the DUIS to explain the disparity - officials from the DUIS gave the following explanation:

"The reason for the difference in figures is because the original figures on MRC expenditure on brain cancer during 2007/08 excluded a few projects of slightly more peripheral relevance to brain cancer, which were later included in the PQ below. Similarly, MRC expenditure on brain cancer during 2006/07 which had previously been reported as nil, was shown as £940k in the PQ as it included projects with some relevance to brain cancer. It is important to note that it is often the case that research which has been classified as being undertaken in one site may well have implications in another, such as brain cancer."

However, when the listed projects were checked with leading brain tumour researchers, the projects did not largely have a relevance to brain cancer – most of the projects were for pituitary tumours (the field of endocrinology), and two of the projects listed were for statistical analysis, so should not have been included in the brain tumour clinical research figures. The NCRI (of which the government is a partner) itself classifies brain tumours and pituitary tumours as separate entities in its own funding classification, so it is misleading for the government to put them together in statements on the level of funding given to brain tumours.[36]

Recommendation:

- **The government should significantly increase the proportion it spends on research related to brain tumours, at least to the levels of expenditure for other cancers**

"Brain Tumour Research" http://www.braintumourresearch.org/ was launched in April 2009 to raise the profile and funding for brain tumour patients and improve their chances. Charities who have united together to create Brain Tumour Research include: Ali's Dream, Andrea's Gift, Anna's Hope, Brain and Spine Foundation, Brain Tumour Action, Brain Tumour Research Campaign, Brainstrust, Brainwaves, Charlie's Challenge, Children's Brain Tumour Research Centre, Ellie Savage Memorial Trust, Hammer Out, Levi's Star and The Diana Ford Trust.

---

[1] NCRI strategic plan 2008-2013, April 2008, p.12 http://www.ncri.org.uk/includes/Publications/reports/strategicplan_web.pdf

[2] NICE Guidance on Cancer Services "Improving outcomes for people with brain and other CNS tumours", June 2006 http://www.nice.org.uk/guidance/CSGBraincns

[3] http://info.cancerresearchuk.org/cancerstats/types/brain/?a=5441

[4] NICE Guidance on Cancer Services "Improving outcomes for people with brain and other CNS tumours" op.. cit. p.10

[5] "Recognise my tumour, recognise me" Brain Tumour UK, March 2009

[6] "The vascular basement membrane as "soil in brain metastasis" Carbonel, Ansorge, Sibson, Muschel PLoS ONE Volume 4 Issue 6, June 2009

[7] Email April 2009

[8] Email June 2009

[9] "The excess burden of cancer in men in the UK" Cancer Research UK, Leads Metropolitan University, Men's Health Forum, National Cancer Intelligence Network, June 2009

[10] NICE Guidance on Cancer Services op..cit. p. 9

[11] http://www.performance.doh.gov.uk/cancerwaits/2008/q3/can_9.html

[12] NICE Guidance on Cancer Services "Improving outcomes for people with brain and other CNS tumours"

[13] http://www.ic.nhs.uk/webfiles/Services/NCASP/audits%20and%20reports/7089_Lung_Cancer_V5.pdf
The National Lung Cancer Audit (NLCA) is managed by the National Clinical Audit Support Programme (NCASP). It is commissioned and sponsored by the Health Quality Improvement Programme (HQIP). It was developed in partnership with the Clinical Effectiveness and Evaluation Unit (CEEU) at the Royal College of Physicians (RCP)

[14] http://info.cancerresearchuk.org/cancerstats/survival/fiveyear/?a=5441

[15] Ibid

[16] Office of National Statistics http://www.statistics.gov.uk/downloads/theme_health/cancer-survival-Eng-2001-2006.pdf

[17] Ibid

---

[18] www.cancer.org.uk/cancerstats/mortality/timetrends/?a=5441
[19] Office of National Statistics, Mortality Statistics: Deaths registered in 2008 (provisional)
[20] Ibid
[21] Office of National Statistics, Mortality Statistics: Deaths registered in 2007
[22] Ibid
[23] Office of National Statistics, Mortality Statistics: Deaths registered in 2008 (provisional)
[24] Ibid
[25] Ibid
[26] NCRI Strategic Plan 2008-2013 p. 7
[27] Email April 2009
[28] http://www.ncri.org.uk/includes/Publications/general/Data_package_07.xls
[29] Ibid

[30] www.ncri.org.uk/includes/Publications/reports/analysisReport08.pdf

[31] NCRI Strategic Plan 2008-2013 op…cit. p. 10
[32] Ibid
[33] Email April 2009
[34] House of Commons Hansard 27 Jan 2009: Column 455W
[35] Email to Baroness Tonge from House of Lords Library
[36] http://www.ncri.org.uk/includes/Publications/general/Data_package_07.xls

Brain Tumour Research www.braintumourresearch.org
The Business Centre, Padbury Hill Farm, Padbury, Buckingham, MK18 2BN
Registered charity number: 1093411

For further information please contact:
Sue Farrington Smith
Director
Brain Tumour Research
01296 733011