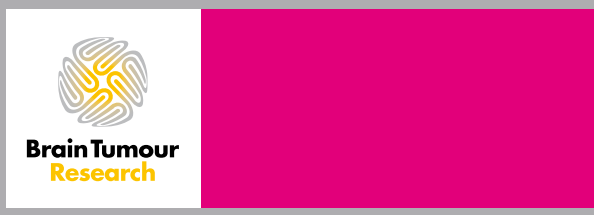
Report on National Research Funding July 2013



Authors: Peter Cuthbertson – PB Political Consulting, Sue Farrington Smith – Brain Tumour Research
Design: Daryl Wilkinson – clearthinkingcreative.co.uk
Advisors: PB Political Consulting, Luther Pendragon

Brain Tumour Research Executive Summary

Almost three quarters (73%) of brain tumour deaths occur in those under 75. For cancer as a whole, it is less than a half (47%). Yet brain cancer continues to receive less than 1% of the national spend on cancer research. This report released by Brain Tumour Research shows that treatments for brain tumours lag seriously behind other cancers.

This report reveals:

- *From 2002 to 2012, total National Cancer Research Institute (NCRI) spending was £4,515 million. Of this only £35 million funded brain tumour research (0.8%).*
- *In 2012, the £4.9 million NCRI spend devoted to brain tumour research was also less than 1% of the total. This represented a substantial fall from £7.1 million the previous year.*
- *There are 6.9 deaths from cancer in the under 45s for every £1 million spent on cancer research by NCRI members. For brain tumours specifically, there are 82.5 deaths in the under 45s for every £1 million spent on brain tumour research.*
- £7,735 was spent in 2012 on leukaemia research for every death by leukaemia, compared to £1,433 for brain tumour deaths. This is in spite of the fact brain tumour deaths in 2011 were only 16% lower than those dying of leukaemia

Other key figures in this report:

- *Brain tumours are one of very few conditions actually becoming more prevalent than a few decades ago. They are much more common now than in 1970.*
- *Cancer patients report a worse experience within the NHS for brain tumours than for any other cancer.*
- *58% of men and women diagnosed with brain cancer die within a year compared to 5% for breast cancer, 35% for leukaemia and 7% for prostate cancer.*
- *Brain cancer is the chief cause of cancer deaths in children. It is also the chief cause of cancer deaths in the under 25s and under 35s.*
- *The consequence of brain tumours striking so young is that the average brain tumour is responsible for over 20 years of life lost in the average patient, making brain tumours the most lethal cancer by this measure.*
- *There are considerable regional variations in incidence, ranging from 108 per million in London to 145 per million in the South West.*

Brain Tumour Research is calling on the government, large cancer charities and the general public to significantly increase the investment into brain tumour research by a factor of 10 and give hope to the thousands of families devastated by the diagnosis of a brain tumour each year.

Brain Tumour Research is also calling on the government to extend the reach of the national cancer register to include all research grants and research work into all cancers across the UK, including brain tumours.

We recommend:

1. *The government's cancer research funding should prioritise deaths under 75.*
2. *A consistent or growing absolute figure should be devoted by government to brain cancer research – where insufficient proposals for research are put forward in a particular year, the money should be held for future years, creating a growing pot to stimulate future research.*
3. *The government should introduce a national register of site-specific cancer research to track* **all** *research grants and research work, ensuring transparency of funding arrangements. This allows shortcomings to be identified and prevents duplication of work.*
4. *Ultimately, the question of curing brain tumours should be viewed in terms of research spend necessary for other cancers: around £30-£35 million per annum over a ten year time-frame.*

Treatments for brain tumours lag seriously behind other cancers

Almost three quarters of brain tumour deaths occur in those under 75. For cancers as a whole, deaths under 75 are less than a half. Yet brain cancer continues to receive less than 1% of the national spend on cancer research.

The extremely high mortality rate for under 75s is particularly significant in light of the government's NHS Outcomes Framework 2012/13. In Domain 1.4 the NHS identifies the under 75 mortality rate from cancer as an improvement area. Tackling brain tumours, a major killer of under 75s, should be at the heart of the government's efforts to meet these objectives. Surely it is time that the government, larger cancer charities and the general public got behind the cause of brain tumours?

This report released by Brain Tumour Research shows that while in the past ten years there have been huge strides forward in the treatments and therefore survival rates for some cancers such as breast cancer and leukaemia, treatments for brain tumours lag seriously behind and at current research spend levels it could take another 100 years to catch up.

To date the argument has been that the incidence of brain tumours is low by comparison to other cancers – but to find a cure for any disease must surely need a similar amount of investment as for any other.

In 2009, Brain Tumour Research's report 'Brain tumours: the forgotten cancer - A report on inequality of funding and profile of brain tumours' revealed how brain tumours are the biggest cancer threat to young people.[1] This remains the case.

Brain tumours continue to kill more children than leukaemia and any other cancer

Brain tumours kill about as many women under the age of 35 as breast cancer

Brain tumours continue to kill more men under the age of 45 than prostate or any other cancer

Brain tumours now kill almost twice as many women as cervical cancer

[1] 'Brain tumours: the forgotten cancer: A report on inequality of funding and profile of brain tumours'…, Brain Tumour Research, 3 July 2009

The National Cancer Research Institute (NCRI) was founded in 2001 to develop common plans for cancer research and is the only national register of spending on cancer research. Its figures demonstrate clearly the inequality in research spending between 2002 and 2012.

£352m	was spent on breast cancer research in those 11 years
£291m	was spent on leukaemia research
£149m	was spent on prostate cancer research
£47m	was spent on cervical cancer research

Only £35m was spent on **brain tumour research**

Government spending through the Medical Research Council (MRC) and Department of Health (DOH) is included in these figures and is relatively low, with only £0.7 million and £1.26m respectively spent on brain tumour research in 2011/12.

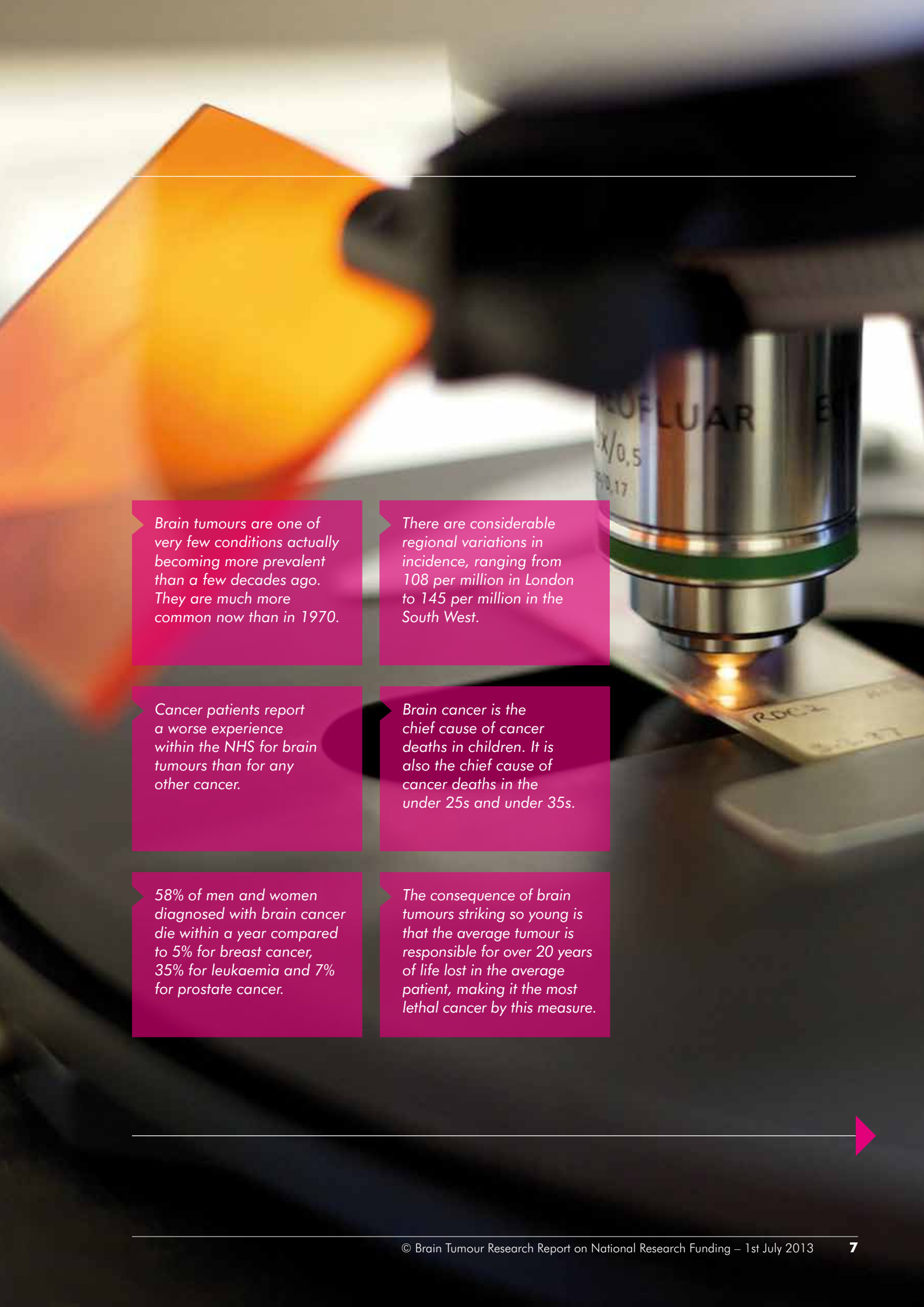
NCRI spend is the consolidated spending of the 22 member organisations (charities and government bodies). The bulk of which (65%) is contributed by Cancer Research UK (CR-UK).[2] Many of the other organisations focus their spending on site specific cancers such as breast and leukaemia and their objectives would not therefore allow spend on brain tumours.

The situation could be worse because the NCRI does not include research spending by smaller charities, hospital funds, the Lottery Fund trusts and foundations.

Brain Tumour Research is calling on the government, large cancer charities and the general public to significantly increase the investment into brain tumour research by a factor of 10 and give hope to the thousands of families devastated by the diagnosis of a brain tumour each year.

Brain Tumour Research is also calling on the government to extend the reach of the national cancer register to include all research grants and research work into all cancers across the UK, including brain tumours.

[2] NCRI Data Package 2012, National Cancer Research Institute at http://www.ncri.org.uk/includes/Publications/general/Data_package_12.xls and Cancer Research UK accounts at http://apps.charitycommission.gov.uk/Accounts/Ends64%5C0001089464_ac_20120331_e_c.pdf, p.10



Brain tumours are one of very few conditions actually becoming more prevalent than a few decades ago. They are much more common now than in 1970.

There are considerable regional variations in incidence, ranging from 108 per million in London to 145 per million in the South West.

Cancer patients report a worse experience within the NHS for brain tumours than for any other cancer.

Brain cancer is the chief cause of cancer deaths in children. It is also the chief cause of cancer deaths in the under 25s and under 35s.

58% of men and women diagnosed with brain cancer die within a year compared to 5% for breast cancer, 35% for leukaemia and 7% for prostate cancer.

The consequence of brain tumours striking so young is that the average tumour is responsible for over 20 years of life lost in the average patient, making it the most lethal cancer by this measure.

Brain tumour facts

One stark fact after another illustrates the tragedy of brain tumours.

Mortality

In England, 11 people are diagnosed with brain cancer and 9 people die from brain cancer every day.[1] 20% to 40% of all cancers eventually spread to the brain.[2] Although some statistics are only for England we have no reason to think it wouldn't be true across the UK.

Brain tumours are one of very few conditions actually becoming more prevalent than a few decades ago. They are much more common now than in 1970.

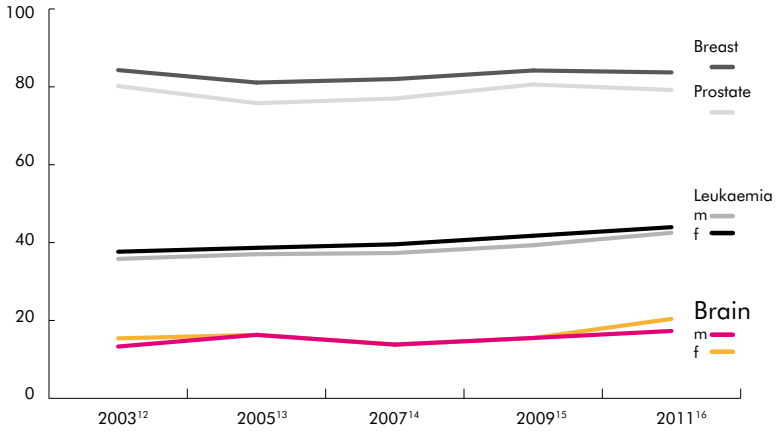
Brain cancer **incidence** is **actually rising**. It was 23% higher for men and 25% higher for women in 2012 than in 1970.[3] In 2011, about 1,700 women and 2,300 men were newly diagnosed - an incidence rate of 53 new cases per million for women and 77 new cases per million for men.[4] It is worth noting that these figures exclude benign/low grade brain tumour patients. Even benign brain tumours can and do kill. They also exclude unregistered brain tumours not recorded on the cancer registry. When these figures are included, the figure rises to an estimated 16,000.[5] Secondary tumours are excluded altogether.

Brain cancer **deaths are rising** unlike most other cancers. These rose 10% for women and 15% for men from 1970 to 2011.[6] From 2001 to 2011, deaths rose from 2,952[7] to 3,443.[8] The annual death rate is 4 per 100,000 women and 6 per 100,000 men.[9]

A substantial majority (58%) of the men and women diagnosed with brain cancer die within a year compared to 5% for breast cancer, 35% for leukaemia and 7% for prostate cancer.[10]

Approximately 80% die within five years – compared to about 20% for cancers of the breast and prostate.[11] Encouragingly, we do see a moderate positive trend in five year survival rates for brain tumours. This could be attributed to surgical and diagnostic techniques and the wider use of the drug temozolomide and of Gliadel wafers.

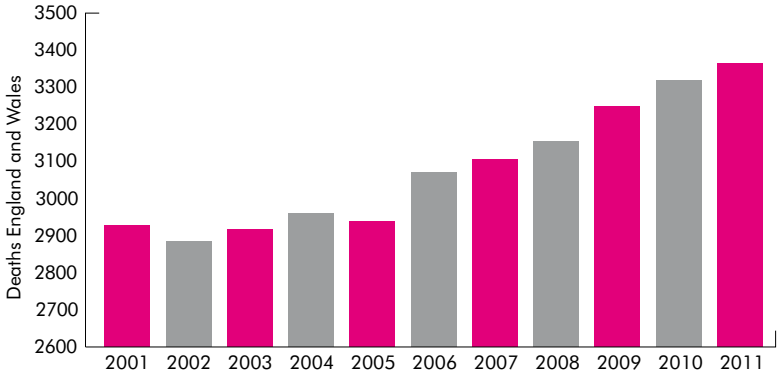
Five year survival rate



The number of people dying from brain tumours is increasing

- *The number of people dying from brain tumours has increased over the past 10 years.*
- *In 2001 there were 2,952 deaths attributed to brain tumours.*
- *In 2011 this had risen to 3,443 deaths attributed to brain tumours.*
- *This is a 16% increase.*

Deaths Caused by Brain Tumour 2001-2011



Years of life lost

Brain cancer strikes at all ages in a way almost unique to cancers. It is the second most common cancer among under 15s, with 1,359 newly diagnosed cases in 2006-2011.[17]

The graph below shows that it is around the age of 40 that brain cancer is overtaken by breast cancer as the biggest killer.

Brain cancer is the chief cause of cancer deaths in children.[19] **It is also the chief cause of cancer deaths in the under 25s and under 35s.**[20] In 2011, 233 under 15s in England and Wales died of cancer – 68 of them from brain cancer.[21]

For other cancers, just 0.12% of deaths were among the under 15s. For brain cancer, the share was 17 times as high, at 2%.[22]

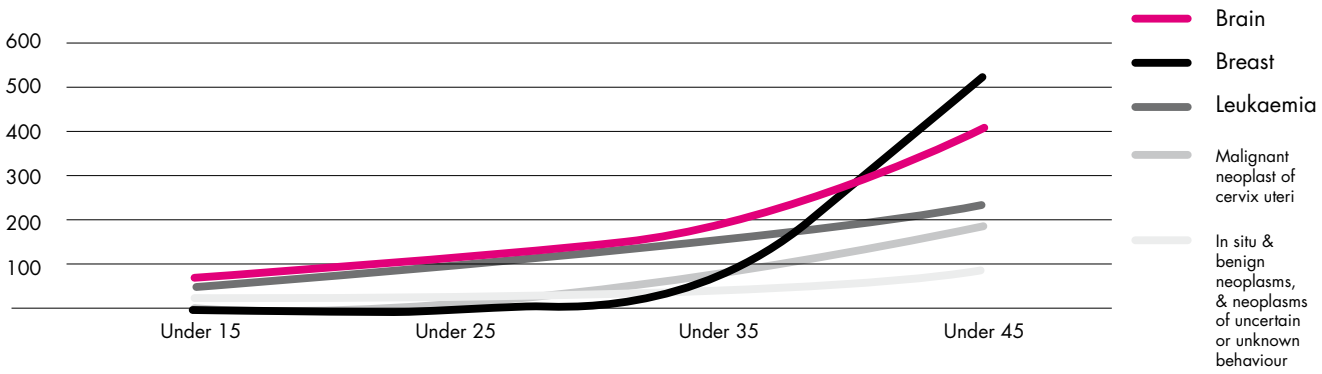
Among the under 25s, the brain cancer share of deaths was 11 times as high. Among the under 35s, it was 7.5 times as high.[23]

Among the under 45s brain cancer is second only to breast cancer as a cause of cancer deaths. Among the under 55s it is the 3rd biggest killing cancer.[24]

Among the under 65s it is the fifth greatest cause of cancer deaths, and still accounts for more than twice the share of cancer deaths as other cancers: almost half of those who die of brain cancer (46%) are under 65. For other cancers the average figure is 21%.[25]

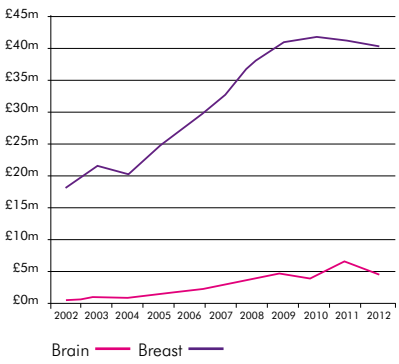
For the under 75s it is still the eighth greatest cause of cancer deaths. **Almost three quarters of those who die of brain cancer (73%) are under 75. For other cancers the average figure is 47%.**[26]

Young cancer deaths in 2011[18]

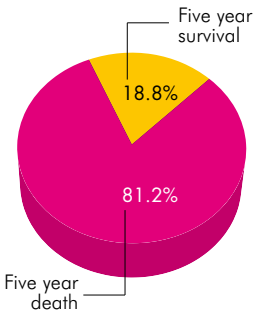


Brain tumours have received limited funding and survival rates are low compared to cancers like breast[A]

NCRI Research Funding – Brain & Breast

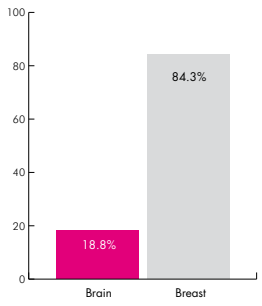


Brain Tumour: Five year survival and death rates ONS

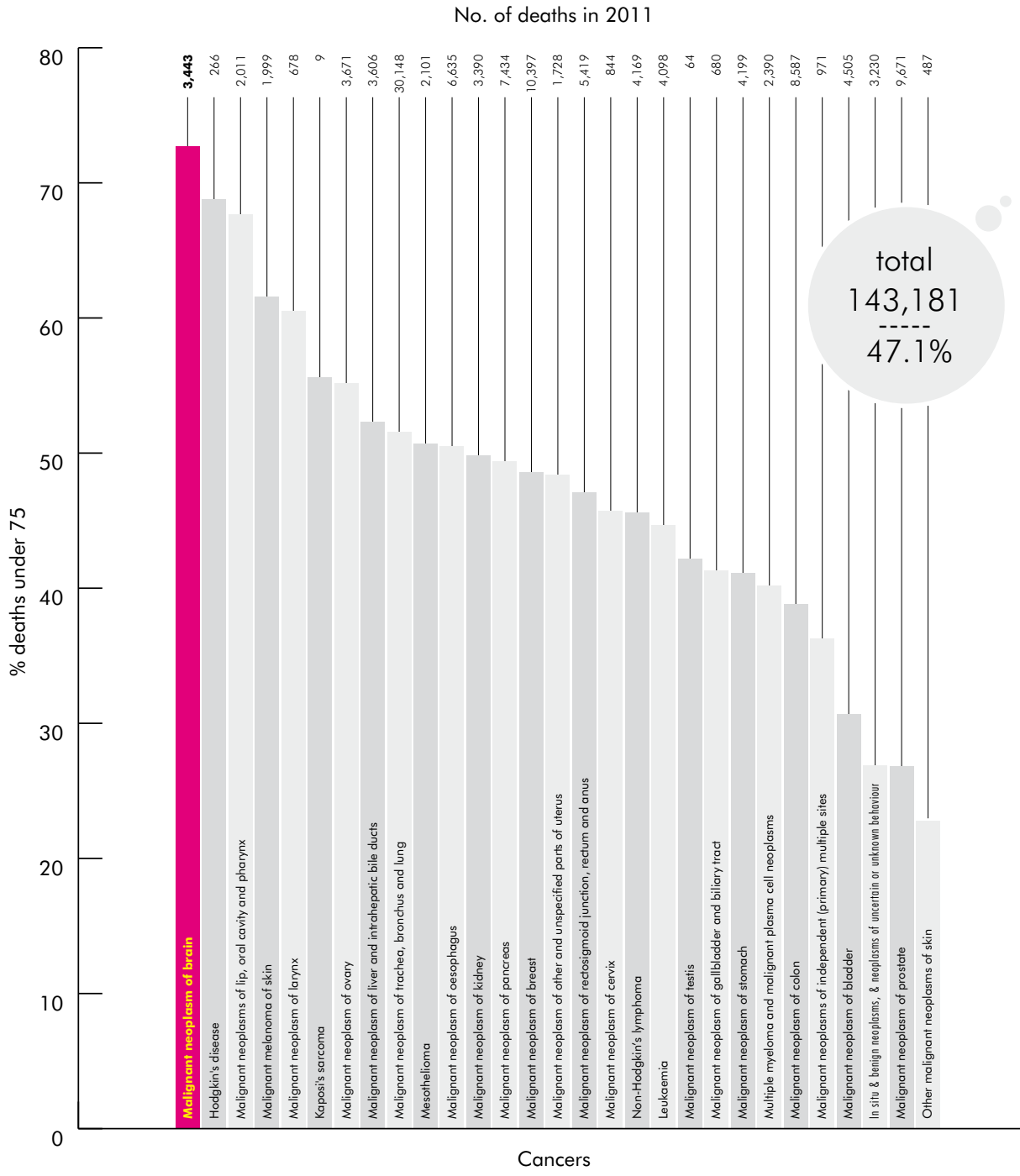


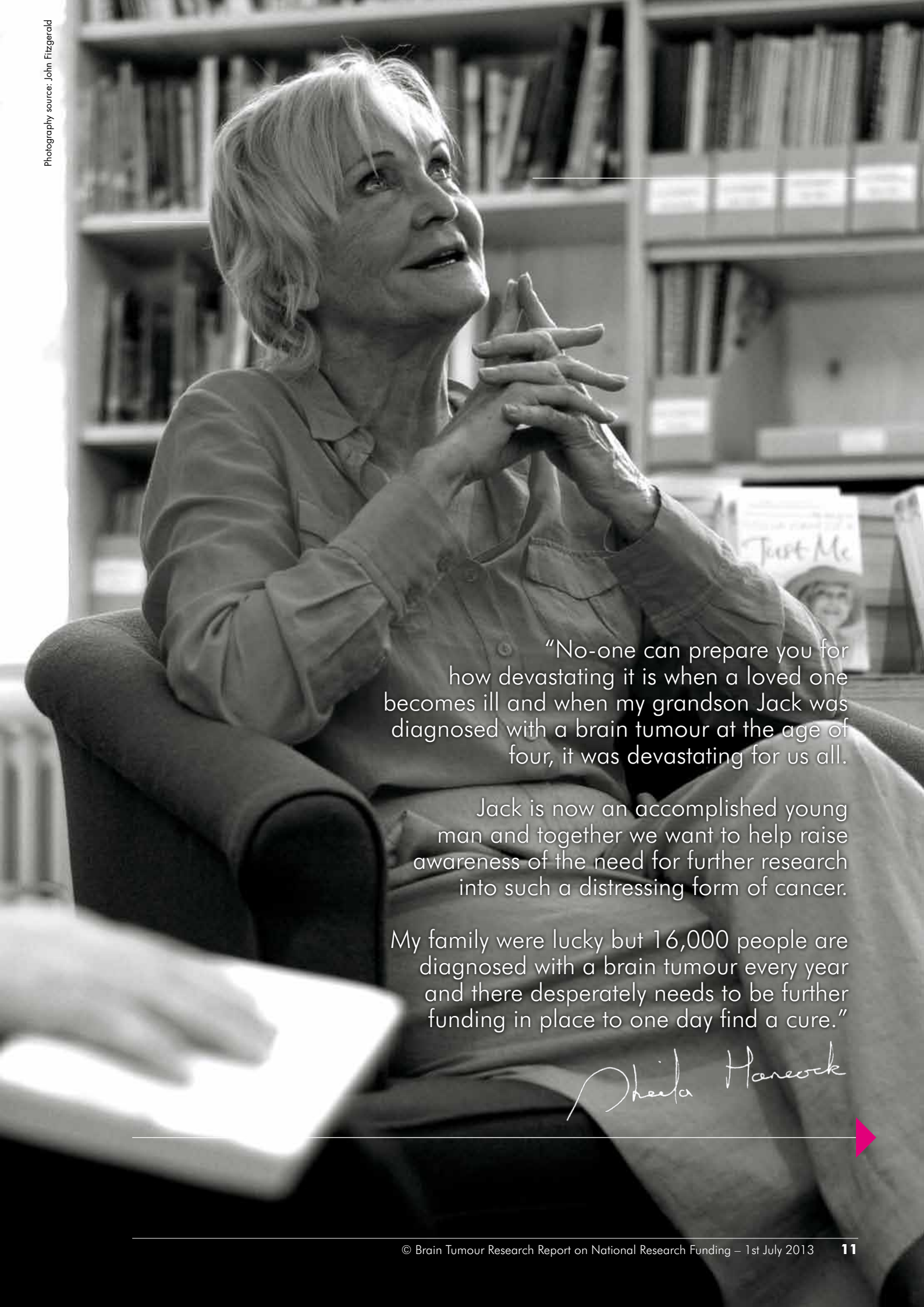
Brain / Breast: Five year survival and death rates ONS

2011 latest ONS figures	Brain	Breast
Diagnosed England Only	4,014	41,826
Died England & Wales	3,443	10,397



The table below shows the total number of deaths for each cancer, and what percentage of those was of under 75s.[27]





Photography source: John Fitzgerald

"No-one can prepare you for how devastating it is when a loved one becomes ill and when my grandson Jack was diagnosed with a brain tumour at the age of four, it was devastating for us all.

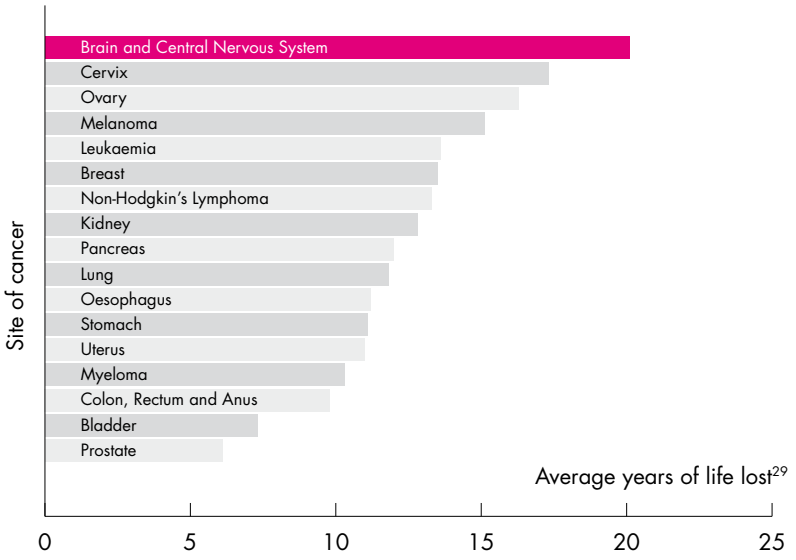
Jack is now an accomplished young man and together we want to help raise awareness of the need for further research into such a distressing form of cancer.

My family were lucky but 16,000 people are diagnosed with a brain tumour every year and there desperately needs to be further funding in place to one day find a cure."

Sheila Hancock

The extremely high mortality rate for under 75s is particularly significant in light of the government's NHS Outcomes Framework 2012/13. In Domain 1.4 the NHS identifies the under 75 mortality rate from cancer as an improvement area.[28] Tackling brain tumours, a major killer of under 75s, should be at the heart of the government's efforts to meet these objectives.

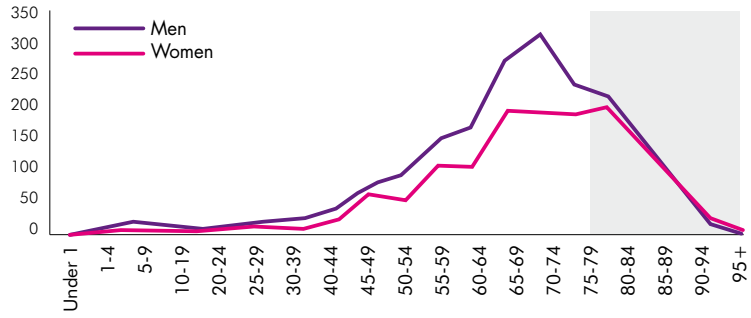
The consequence of brain tumours striking so young is that the average brain tumour is responsible for over 20 years of life lost in the average patient, making brain tumours the most lethal cancer by this measure.



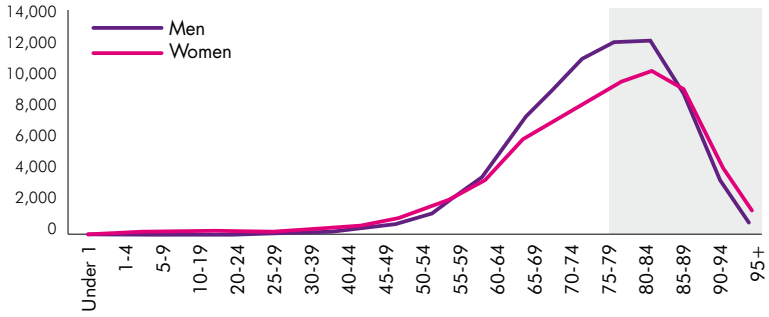
The relative age at which people get brain tumours explains the large number of average life years lost

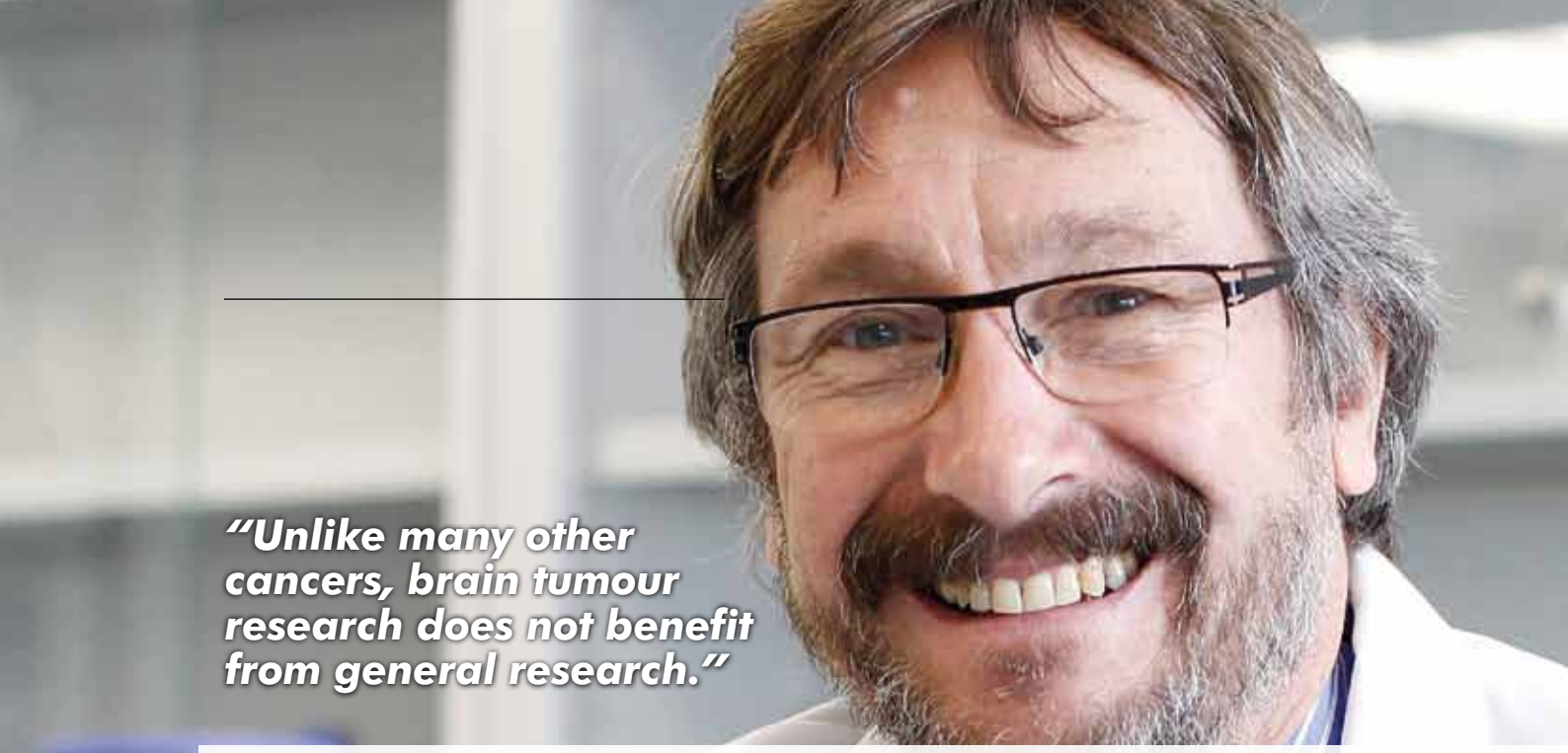
- *Brain tumours account for a large proportion of childhood tumours.*
- *Brain tumours kill both men and women in their prime of life.*
- *Deaths climb and peak in middle age – for men peaking age 65-69, and women reaching a plateau in their 60s and 70s.*
- *The age of death in other cancers combined, peaks much later – for men peaking age 75-79, for women over age 80.*

Brain Tumour Deaths by Age 2011[B]



All Cancer Deaths by Age 2011[B]





"Unlike many other cancers, brain tumour research does not benefit from general research."

Prof Geoff Pilkington, Professor of Cellular & Molecular Neuro-oncology

- *Brain tumours are very different from other cancers.*
- *The 'blood-brain barrier' protects the brain from toxins in the blood, but this can also hinder brain tumour treatment. Many treatments, like chemotherapy, run through the blood and so cannot be used for fighting brain tumours. Brain tumours are therefore one of the most inaccessible tumours, and it is important to investigate specific new ways to deliver treatments.*
- *There are over 120 types of brain tumour, making research difficult. Furthermore, brain tumours are comprised of lots of different types of cells, which react differently to different forms of treatment. The cells that comprise other tumours are usually more uniform in their response to treatments.*
- *Many brain tumours are cellularly heterogeneous making them harder to treat. At the other extreme, all liver cells behave in the same way, so research into liver cancer treatment is less complicated in this regard.*
- *Discoveries in general cancer research or from work on other sites are unlikely to have a major impact on brain tumour research.*

Why brain tumour research is so vital

If finding the cures for other cancers, or ways to ameliorate them, automatically translated into solutions for brain tumours, then funding brain tumour research specifically would not be as important.

But this is untrue for a number of reasons.[40]

First, 'research' can cover a broad range of work: clinical trials, epidemiology, qualitative/questionnaire-based research, services audits and lab-based research. Each of these may serve laudable ends, but it is only the last that has a chance of preventing brain tumour deaths. Research into prevention, for example, may cut lung cancer deaths, but without knowing the cause of tumours that start in the brain this research cannot be used to prevent brain tumours.

Second, the blood-brain barrier. The nature of the brain's blood vessels is such that attacking cancerous cells through many cytotoxic agents cannot be applied. The brain has much greater protection against toxins than other areas of the body.

Third, cellular heterogeneity in the brain – that is, the enormous variation of cells in the brain – is unlike any other organ. To put it crudely, one liver cell is much like another. Brain cells vary massively, greatly complicating brain science and means researchers need to have far broader experience – encompassing both oncology and neuroscience - than for other cancers.

Fourth, with over 120 types of brain tumour, research is much more difficult. Other cancers tumours are comprised of cells that tend to be uniform in their response to treatments.

Fifth, the brain is such that even a benign tumour can kill. The chest can expand – the skull cannot.

Conclusion:

It is only through giving directly to brain tumour charities, funding laboratory-based research, that all types of brain tumours – adult, paediatric, low-grade / benign, high-grade / malignant – will be cured.

Funding for research into brain tumours

Given the facts laid out previously, one might expect brain tumour research to be among the best funded forms of cancer research. Among the cancers, it is the biggest killer of children, of under 25s and under 35s. It takes more years of life per patient than any other cancer. Death rates are rising and are now much higher than in 1970. Patients report a worse experience of the NHS. In light of so much devastation, finding better treatments or cures for various types of brain tumour would be a massive step forward.

How does brain tumour research funding compare to research funding for other cancers?

The National Cancer Research Institute collects data on cancer research spending in the UK by 14 different charities, 7 government bodies and a pharmaceutical association which each funded at least £1 million of research per annum when the NCRI was established in 2001.

For the whole 2002 to 2012 period, total NCRI spending was £4,515 million. Of this only £35 million funded brain tumour research (0.78%).[31]

Breast cancer and leukaemia continue to receive more from high-profile charities.

Cancer	2012 Spending	%	Total spending since 2002	%
Brain Tumour	£4,934,039	0.97%	£35,232,161	0.78%
Breast Cancer	£40,822,170	8.05%	£351,533,707	7.80%
Leukaemia	£31,699,173	6.25%	£290,918,157	6.45%
Colon and Rectal Cancer	£24,525,900	4.83%	£212,600,895	4.72%
Prostate Cancer	£20,950,042	4.13%	£149,132,179	3.31%
Ovarian Cancer	£12,287,239	2.42%	£103,531,888	2.30%
Lung Cancer	£14,817,164	2.92%	£89,928,299	1.99%
Non-Hodgkin's Lymphoma	£7,333,955	1.45%	£77,513,504	1.72%
Cervical Cancer	£3,768,088	0.74%	£46,609,335	1.03%
Melanoma	£5,944,311	1.17%	£45,959,122	1.02%
Skin Cancer	£4,000,538	0.79%	£44,279,618	0.98%
Oesophageal Cancer	£5,950,820	1.17%	£38,436,563	0.85%
Myeloma	£5,313,795	1.05%	£35,215,059	0.78%
Pancreatic Cancer	£4,497,416	0.89%	£31,157,066	0.69%
Bladder Cancer	£3,029,340	0.60%	£27,510,648	0.61%
Kidney Cancer	£3,781,102	0.75%	£25,754,019	0.57%
Hodgkin's Disease	£2,793,053	0.55%	£24,842,728	0.55%
Liver Cancer	£3,040,547	0.60%	£24,014,321	0.53%
Sarcoma	£2,018,671	0.40%	£21,422,375	0.48%
Stomach Cancer	£1,536,005	0.30%	£19,033,198	0.42%
Pharyngeal Cancer	£1,974,556	0.39%	£18,891,573	0.42%
Endometrial Cancer	£3,344,716	0.66%	£18,628,464	0.41%
Testicular Cancer	£1,138,821	0.22%	£14,904,128	0.33%
Oral Cavity and Lip Cancer	£1,950,828	0.38%	£14,130,314	0.31%
Kaposi's Sarcoma	£786,557	0.16%	£12,980,228	0.29%
Wilm's Tumour	£845,469	0.17%	£12,747,529	0.28%
Laryngeal Cancer	£1,688,427	0.33%	£10,993,414	0.24%
Neuroblastoma	£1,248,861	0.25%	£9,642,150	0.21%
Nervous system	£1,063,922	0.21%	£9,028,513	0.20%

continues over...

continued...

Cancer	2012 Spending	%	Total spending since 2002	%
Bone Cancer	£373,038	0.07%	£5,765,271	0.13%
Anal Cancer	£380,788	0.08%	£4,851,659	0.11%
Thyroid Cancer	£264,354	0.05%	£4,379,937	0.10%
Vulva Cancer	£465,062	0.09%	£4,270,135	0.09%
Pituitary Tumour	£209,549	0.04%	£1,866,815	0.04%
Penile Cancer	£334,630	0.07%	£1,863,237	0.04%
Vaginal Cancer	£248,789	0.05%	£1,721,351	0.04%
Salivary Gland Cancer	£248,575	0.05%	£1,709,843	0.04%
Eye Cancer	£78,005	0.02%	£1,304,170	0.03%
Small Intestine Cancer	£202,647	0.04%	£1,205,901	0.03%
Adrenocortical Cancer	£39,607	0.01%	£1,138,503	0.03%
Nasal Cavity and Paranasal Sinus Cancer	£110,797	0.02%	£921,914	0.02%
Retinoblastoma	£56,013	0.01%	£771,558	0.02%
Vascular System	£0	0.00%	£689,889	0.02%
Parathyroid Cancer	£71,799	0.01%	£624,063	0.01%
Gallbladder Cancer	£0	0.00%	£422,058	0.01%
Primary of Unknown Origin	£85,844	0.02%	£327,910	0.01%
Primary CNS Lymphoma	£23,765	0.00%	£269,030	0.01%
Heart Cancer	£0	0.00%	£129,315	0.00%
Thymoma, Malignant	£49,894	0.01%	£49,894	0.00%
Total site-specific	£220,328,659	43.43%	£850,853,609	40.90%
All Sites*	£112,343,784	22.15%	£867,652,743	19.25%
Fundamental Research*	£174,611,194	34.42%	£1,796,489,985	39.85%
Total	£507,283,659	100%	£4,514,996,337	100%

*Spend on All Sites and Fundamental Research includes basic biology research that is not yet linked to a particular tumour type eg. pain in cancer patients

In 2012, the £4.9 million devoted to brain tumour research was less than 1% of the total.[32] This also represented a substantial fall from £7.1 million the previous year.[33] In our most recent report by New Philanthropy Capital, Brain Tumour Research, Funding Flows, we welcomed this new high in 2011[34] – in recent years it has previously ranged from just below £4 million to just below £5 million.[35]

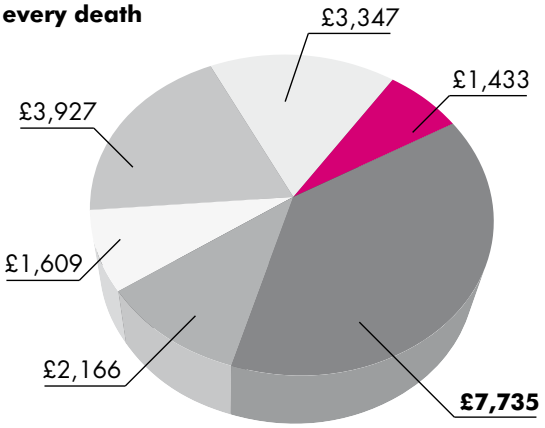
The 2012 figure – back in that range – suggests this was a peak rather than the start of a positive trend.

Only a small share of this figure comes from government: a fact that should weigh heavily in the minds of anyone inclined against giving to charities because they believe government can be left to fund a cure. In December 2012, the Health Minister Dr Daniel Poulter told the House of Commons that the Department of Health's funding for brain cancer research fell from £0.9 million in 2010/11 to £0.7 million in 2011/12.[36]

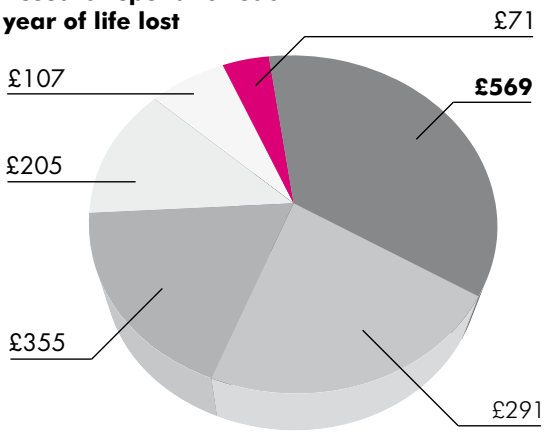
Considering the death rate of brain tumours, funding for brain tumour research is particularly low. Leukaemia, for example, killed 4,098 people in England and Wales in 2011, the latest year for which data is available – a figure comparable to the 3,443 deaths from brain tumours.[37] As in a prior table, the average years of life lost is 13.6 compared to 20.1 for brain tumours.

in 2012, the £4.9 million devoted to brain tumour research was less than 1% of the total.[32]

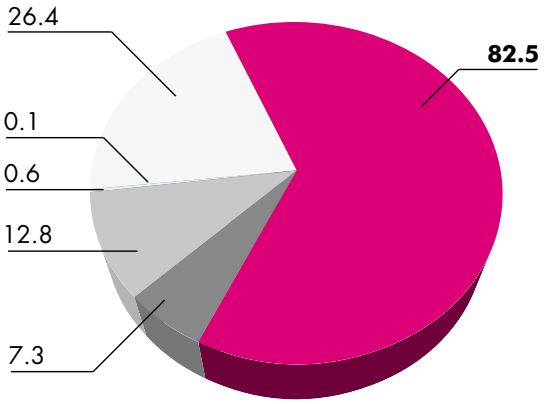
Research spend for every death



Research spend for each year of life lost



Number of under 45 deaths per £1 million research spend



But leukaemia research received £31.7 million in NCRI funding in 2012, compared to the £4.9 million for brain tumours. **This means £7,735 was spent on leukaemia research for each death, compared to £1,433 for brain tumours.**[38]

£569 was spent on research for every year of life lost to leukaemia. For brain tumours, it was £71.

These charts show how great the discrepancy is between brain tumour research and some other cancers.

The bottom chart compares the deaths of under 45s to research spending. There is great variation in this figure depending on site of cancer. **For all cancers, there is an average of 6.9 deaths of men and women under 45 for every £1 million in research spending. For brain tumours there are 82.5 deaths under 45 for every £1 million spent on research.**[39]

It is important to develop a comprehensive picture, going beyond funding into research from the partners of the NCRI. The table at the end of this section sets out what is currently known about brain tumour funding. It is conspicuous by its gaps...

We know from the institutions we work with that they apply to, and receive, funding from trusts and foundations and other brain tumour specific charities – as well as patients and families giving directly. These figures are not officially recorded. So many of the bodies funding cancer research have proved unable to say how much goes towards brain tumours...

...The government's own records on funding for brain cancer are poor. We know from Parliamentary questions that the Department of Health gave £0.7 million in 2011/12, the Medical Research Council gave £1.26 million, with an estimated £250,000 from the Chief Scientist Office in Scotland but no figures were available when we contacted two of the other government members of the NCRI. Two others confirmed they gave no money at all to brain tumour research. Worryingly, these two figures, added to the £4 million claimed by Cancer Research UK, add up to £6.21 million – more than £1.2 million higher than the NCRI's claim for total brain cancer funding (perhaps explained by overlapping time periods and grant commitments versus spend).

The absence of a proper register means it is likely that the right hand doesn't know what the left hand is doing and there is a risk of poor decision-making and extremely scarce resources wasted through duplication of work.

A deeply worrying consequence of poor research funding for brain tumours is that brilliant minds, otherwise inclined to work in the field, are deterred. Working in a small field makes it very difficult to achieve the all-important 'high impact factors' in journal articles – essential for success in a scientific career. When they apply for grants, their applications are more likely to be rejected because panels and those panels' referrers are often very ill-informed about brain tumours and are predictably inclined towards funding what they know. Therefore, many of those who choose the field of brain tumour research end up leaving for alternatives where research spending is plentiful...

Sustainable, serious funding for brain tumour research would enable people to stay within the profession.

A deeply worrying consequence of poor research funding for brain tumours is that brilliant minds, otherwise inclined to work in the field, are deterred.

This table shows publicly available information on brain tumour research funding and other cancer research funding – with question marks where there are gaps. The figures are compiled from the NCRI's own data, information requests to government departments, Brain Tumour Research figures and annual accounts submitted to the Charity Commission.

NCRI		Research into brain tumours (2012/latest year available)	Research into cancer (2012/latest year available)
Government Funding	Biotechnology and Biological Sciences Research Council	£0[41]	?[42]
	Chief Scientist Office (Scotland)	£250,000[43]	£23,961,115[44]
	Department of Health	£700,000[45]	?[46]
	Economic and Social Research Council	£0[47]	£0[48]
	Medical Research Council	£1,260,000[49]	?[50]
	Northern Ireland Health & Social Care – R&D Office	?[51]	?[52]
	Welsh Government – National Institute for Social Care and Health Research	?[53]	£9,600,000[54]
Subtotal:		£2,210,000 + ?	£33,561,115 + ?
Charities	Association for International Cancer Research (Scotland)	£0[55]	£2,111,250[56]
	Breakthrough Breast Cancer	£0[57]	£9,511,000[58]
	Breast Cancer Campaign	£ 0[59]	£4,913,717[60]
	Cancer Research UK	£4,000,000[61]	£332,000,000[62]
	Children With Cancer UK	£0[63]	£2,112,349[64]
	Leukaemia & Lymphoma Research	£0[65]	£11,531,000[66]
	Ludwig Institute for Cancer Research	£0[67]	?[68]
	Macmillan Cancer Support	£0[69]	£0[70]
	Marie Curie Cancer Care	£0[71]	£0[72]
	Prostate Cancer UK	£0[73]	£624,000[74]
	Roy Castle Lung Cancer Foundation	£0[75]	£789,751[76]
	Tenovus	£0[77]	£1,074,541[78]
	Wellcome Trust	£0[79]	£451,200,000[80]
	Yorkshire Cancer Research	£0[81]	£7,532,169[82]
Subtotal:		£4,000,000	£823,399,777 + ?
Pharmaceutical	Association of the British Pharmaceutical Industry	£0[83]	£0[84]
NCRI Total:		**£4,934,039**[85]	**£507,283,659**[86]
Non-NCRI			
Government Funding	European Union funding within the UK	?	?
Charities	Brain tumour 31/41 (objectives state research and some also include support etc)*	£5,263,697[87]	£5,263,697[88]
	Other leukaemia charities 71/104 (objectives state research and some also include support etc)*	£0[89]	£46,677,819[90]
	Other breast charities 41/92 (objectives state research and some also include support etc)*	£0[91]	£20,299,003[92]
	Other prostate charities 20/38 (objectives state research and some also include support etc)*	£0[93]	£7,631,010[94]
	Other cancer charities	?	?
	Direct from Donors to institutions	?	?
	Lottery Fund	?	?
	Trusts and Foundations direct to institutions	?	?
Pharmaceutical	Pharmaceutical	?	?
Non-NCRI Total:		**£5,263,697 + ?**	**£79,871,529 + ?**
Total		**£10,197,736 + ?**	**£587,155,188 + ?**

*Charities not included in NCRI who are known to fund research based on their objectives and their annual returns with the charity commission. Actual amount granted to research not available in all cases. e.g. 31/41 means that of 41 charities with brain tumour in their objectives who have submitted accounts to the charity commission, 31 stated research in their objectives.

More comprehensive data would be useful

- *NCRI data includes the research spend of the membership organisations listed in the table opposite, who invest over £1million annually.*
- *The NCRI data does not take into account the spend of organisation's that invest less than £1million on research annually and who are not members of the Association of Medical Research Charities.*
- *Some organisations, including recently established charities such as Brain Tumour Research, fund site specific research over £1million but are not included in the NCRI data.*
- *The NCRI cancer research database is the most comprehensive source available to analyse cancer research funding.*
- *However, it would be more useful if it were expanded to include funding from other sources, across the range of different cancer sites.*

The challenges of data collection

- *Classification is an issue with all datasets. We heard anecdotal evidence that the classification of research at some NCRI membership bodies was not robust.*
- *Cancer research is a broad term that encompasses both qualitative, quantitative, lab-based research and clinical trials. It would be useful to break down the funding statistics into these strands to understand what is funded.*
- *The ONS data only counts grade 3 and grade 4 brain tumours which are malignant in its figures. Yet according to Prof Geoff Pilkington, all brain tumours are potentially life threatening, regardless of their grade. By virtue of their position in the body, they are biologically malignant because they expand into a restricted space (the skull) causing pressure and interfering with other brain functions.*
- *Furthermore, although grade 2 primary brain tumours are classified as benign, they become malignant with time.*

Patients' experience of brain tumours

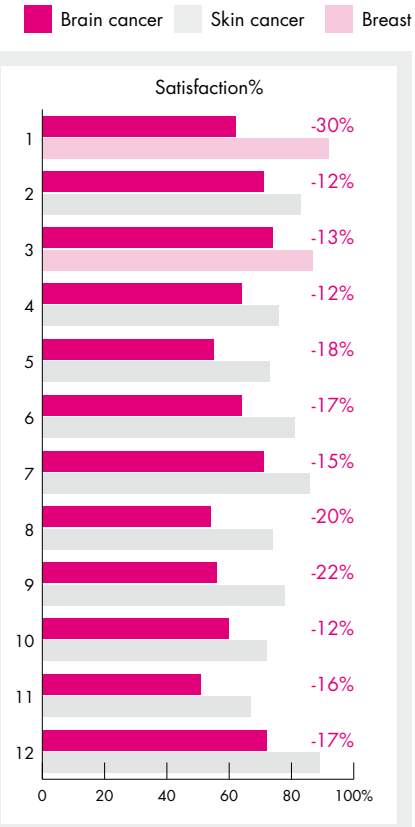
The Cancer Patient Experience Survey is one way the National Health Service tracks patient outcomes across a range of measures.

This major survey of patients revealed the extent to which brain tumour patients are especially poorly served. Cancer patients report a worse experience within the NHS for brain tumours than for any other cancer. As the report summarised it:

"some types of cancer, such as brain and central nervous system and sarcoma, have scores on particular questions which are 20-30 percentage points worse than those given by patients in the best rated cancer groups"[30]

Across twelve different measures, skin cancer usually scored best and brain cancer scored worst (or joint worst). The table to the right shows the percentage of brain cancer, skin cancer and (when in pale pink) breast cancer patients agreeing with certain statements.

1. Saw their GP only once or twice before being referred on to a cancer specialist
2. Had a completely understandable explanation of their tests results
3. Told sensitively that they had cancer
4. Views were definitely taken into account
5. Family or someone close had enough opportunity to talk to a doctor
6. Confidence and trust in all the ward nurses
7. It was never the case that one doctor or nurse said one thing about their condition or treatment and another said something different
8. Felt able to discuss their worries and fears as much as they wanted
9. Staff gave enough emotional support
10. Staff did everything they could to support them
11. Those treating and caring for them always worked well together
12. Did not feel like a set of symptoms

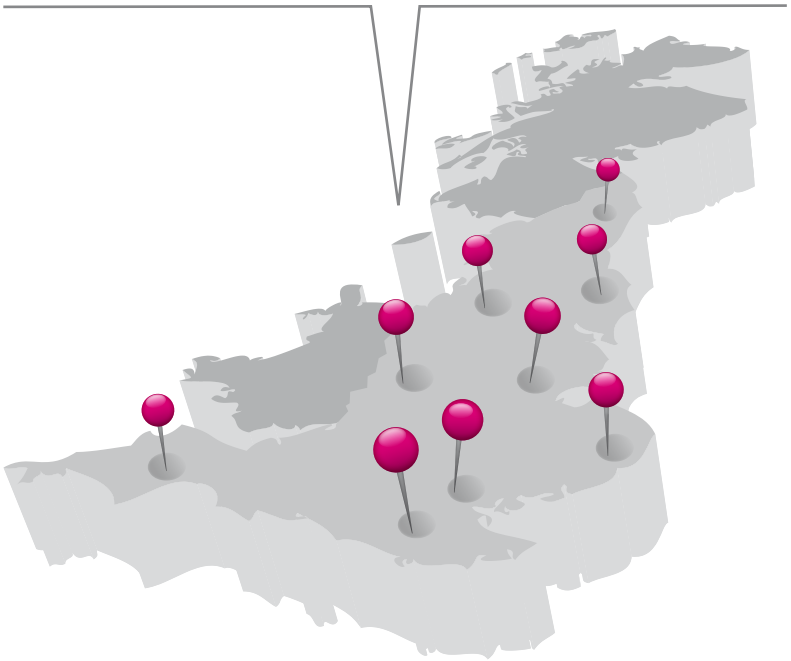


Regional breakdown

4,014 new brain tumours were diagnosed in England in 2011, the latest year for which figures are available. This equates to 130 for every 1 million people. But there is very broad regional variation across England, as shown in the table below. As yet we do not understand the behaviours of brain tumours let alone their causes. So it is hard to explain the regional variation - but understanding this regional variation may help discover some causes.

- The South West has the highest rate of brain tumours diagnosed per million in England with 145 per million in 2011 - 15 more than the national average.
- Yorkshire and the Humber had the second highest with 142 - 12 more than the national average.
- The East Midlands was third highest with 140 -10 more than the national average.
- The North West was fourth highest with 139 - 9 more than the national average.
- The North East was fifth highest with 136 - 6 more than the national average. The North East is average for men, with 77 brain tumour diagnoses per million - but particularly bad for women, with 59 diagnoses per million compared to 53 nationally.
- London has the lowest rate of brain tumours diagnosed per million in England with 108 - 22 less than the national average.
- Outside London, the South East and Eastern regions were the lowest, with 123 - 7 less than the national average.
- However, the Eastern region has just as many female brain tumour diagnoses per million (53) as the average for the rest of the country.
- The South East has the highest absolute number of diagnoses, with 654 in 2011.
- The North West was second with 568.
- The South West was third with 487.
- Yorkshire and The Humber was fourth with 434.
- London was fifth with 430.

New brain tumours diagnosed by region[95]	Total	Male	Female	Total per 1M people	Male per 1M people	Female per 1M people
South West	487	265	222	145	84	61
Yorkshire and The Humber	434	240	194	142	82	60
East Midlands	398	223	175	140	83	57
North West	568	325	243	139	83	56
North East	203	112	91	136	77	59
West Midlands	403	237	166	127	76	51
South East	654	381	273	123	75	48
East	437	240	197	123	70	53
London	430	242	188	108	64	44
England	**4,014**	**2,265**	**1,749**	**130**	**77**	**53**



Recommendations

1. The government's cancer research funding should prioritise deaths under 75. This will enable the government to better meet its own NHS Outcomes Strategy for reducing deaths under 75.

2. A consistent or growing absolute figure should be devoted by government to brain cancer research – where insufficient proposals for research are put forward in a particular year, the money should be held for future years, creating a growing pot to stimulate future research.

3. The government should introduce a national register of site-specific cancer research to track all research grants and research work, ensuring transparency of funding arrangements. This allows shortcomings to be identified and prevents duplication of work.

4. Ultimately, the question of curing brain tumours should be viewed in terms of research spend necessary for other cancers: around £30-£35 million per annum over a ten year time-frame. This is the investment needed to prevent the devastation of brain tumours affecting current and future generations. At the current rate of spend, it could take 100 years.

Brain Tumour Research
Funding the fight

Brain Tumour Research

Brain Tumour Research represents the united campaign voice of the Brain Tumour Research group of charities. Launched in 2009, the charity Brain Tumour Research was established specifically to raise substantial funds for brain tumour research and operates as a separate entity to the member charities.

Originally set up in 2004 as an informal partnership of a number of UK brain tumour charities under the banner of the United Brain Tumour Campaign, these charities committed themselves to working together to achieve a common goal, namely to raise funds for research into the prevention and treatment of brain tumours, as well as ultimately finding a cure.

Each of the members was galvanised into action as a result of personal involvement with brain tumours, having realised that there was relatively little being done to support brain tumour patients or carers, or towards funding research into finding a cure. Together the charities fund research, provide support and information, raise awareness and lobby government on the issues of brain tumours.

Today there are 21 UK brain tumour charities represented within the Brain Tumour Research group, giving the charity nationwide coverage.

Member charities

Alex's Dream – Fight Childhood Tumours
Anna's Hope
astro brain tumour fund
Brain & Spine Foundation
brainstrust – the Meg Jones brain cancer charity
brain tumour – research and support
BTRC
BRAINWAVES NI
Charlie's Challenge
Children's Brain Tumour Foundation
Children's Brain Tumour Research Centre
DfT – The Diana Ford Trust
Ellie Savage Memorial Trust – Remembering Ellie... Helping Others
Ellie's Fund – Brain Tumour Trust
HEADCASE
Katy Holmes Trust
Levi's Star – Shine on – Supporting Children with Brain Tumours
red wellies
The PPR Foundation
Thorne Mason Trust
Trudy's Trust

Sources

1 'Brain cancer rates have risen by a quarter over the past three decades', Office for National Statistics, 26 April 2013, at http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--41--2010/sty-brain-cancer-awareness.html

2 S Bell and G J Pilkington, "The nature and clinical consequences of metastatic spread to the brain" Oncology News NCRI Supplement 6 (5): 6-7 (2011)

3 Ibid

4 Cancer Statistics Registrations, England (Series MB1) - No. 42, 2011, Office for National Statistics, 26 June 2013, at http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--42--2011/index.html

5 Register my tumour, recognise me, Brain Tumour UK, March 2009, at http://www.braintumouruk.org.uk/sites/default/files/register_tumours_web_ed.pdf, p5

6 'Brain cancer rates have risen by a quarter over the past three decades', Office for National Statistics, 26 April 2013, at http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--41--2010/sty-brain-cancer-awareness.html

7 Mortality statistics, Office for National Statistics, Series DH2 no.28, at http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--cause--england-and-wales--series-dh2--discontinued-/no--28--2001/mortality-statistics--cause.pdf, p.32

8 Mortality data from Statistical bulletin: Deaths Registered in England and Wales (Series DR) 2011, Office for National Statistics, 6 November 2012, at http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2011/stb-deaths-registered-in-england-and-wales-in-2011-by-cause.html

9 Ibid

10 'Cancer Survival in England: Patients Diagnosed, 2006–2010 and Followed up to 2011', Office for National Statistics, 23 October 2012, at http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival/2006---2010--followed-up-to-2011/stb-cancer-survival.html

11 'Cancer Survival in England: Patients Diagnosed, 2006–2010 and Followed up to 2011', Office for National Statistics, 23 October 2012, at http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival/2006---2010--followed-up-to-2011/stb-cancer-survival.html

12 Cancer survival rates, Cancer survival in England and Wales, patients diagnosed 1998-2001 followed up to 2003, at http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-51078

13 Cancer survival rates, Cancer survival in England and Wales, patients diagnosed 2001-2006 followed up to 2007, at http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival-rates/survival-rates-in-england--patients-diagnosed-2001-2006-followed-up-to-2007/survival-rates-in-england---patients-diagnosed-2001-2006-followed-up-to-2007.pdf

14 Ibid

15 Cancer survival in England Patients diagnosed 2004 – 2008, followed up to 2009, 21 April 2011, at http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival-rates/2004---2008--followed-up-to-2009/cancer-survival-rates.pdf

16 Cancer Survival Rates - Cancer Survival in England: Patients Diagnosed, 2006–2010 and Followed up to 2011, 23 October 2012, at http://www.ons.gov.uk/ons/rel/cancer-unit/cancer-survival/2006---2010--followed-up-to-2011/index.html

17 'Brain cancer rates have risen by a quarter over the past three decades', Office for National Statistics, 26 April 2013, at http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--41--2010/sty-brain-cancer-awareness.html and Cancer Statistics Registrations, England (Series MB1) - No. 42, 2011, Office for National Statistics, 26 June 2013, at http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--42--2011/rft-main-tables.xls

18 Death Registrations Summary Statistics, England and Wales, 2011, Office for National Statistics, Table 2 Deaths by age, sex and underlying cause, 2011 registrations

19 'Brain cancer rates have risen by a quarter over the past three decades', Office for National Statistics, 26 April 2013, at 22 http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--41--2010/sty-brain-cancer-awareness.html

20 Death Registrations Summary Statistics, England and Wales, 2011, Office for National Statistics, Table 2 Deaths by age, sex and underlying cause, 2011 registrations

21 Ibid

22 Ibid

23 Ibid

24 Ibid

25 Ibid

26 Ibid

27 Ibid

28 The NHS Outcomes Framework 2012/13, Department of Health, at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/134662/dh_131723.pdf.pdf, p.16

29 All average years of life lost data from Table 3: The AYLL per patient, for 17 tumour sites, in order of descending AYLL, 'Years of life lost (YLL) from cancer is an important measure of population burden – and should be considered when allocating research funds', NG Burnet, SJ Jefferies, RJ Benson, DP Hunt and FP Treasure, British Journal of Cancer (2005) 92, p.244. This excellent data has yet to be updated.

30 Cancer Patient Experience Survey 2011/12: National Report, Department of Health, at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/126880/Cancer-Patient-Experience-Survey-National-Report-2011-12.pdf.pdf

31 NCRI Data Package 2012, 'Spend by disease site', National Cancer Research Institute at http://www.ncri.org.uk/includes/Publications/general/Data_package_12.xls

32 Ibid

33 Ibid

34 See BRAIN TUMOUR RESEARCH – FUNDING FLOWS, Ellen Harries, Iona Joy, Brain Tumour Research & NPC, London, April 2013 http://www.braintumourresearch.org/uploads/document/BrainTumourResearchFundingFlowsMarch2013_896.pdf

35 NCRI Data Package 2012, 'Spend by disease site', National Cancer Research Institute at http://www.ncri.org.uk/includes/Publications/general/Data_package_12.xls

36 House of Commons Hansard, 10 Dec 2012 : Column 110W

37 Mortality data from Statistical bulletin: Deaths Registered in England and Wales (Series DR) 2011, Office for National Statistics, 6 November 2012, at http://www.ons.gov.uk/ons/rel/vsob1/mortality-statistics--deaths-registered-in-england-and-wales--series-dr-/2011/stb-deaths-registered-in-england-and-wales-in-2011-by-cause.html

38 NCRI Data Package 2012

39 Death Registrations Summary Statistics, England and Wales, 2011, Office for National Statistics, Table 2 Deaths by age, sex and underlying cause, 2011 registrations

40 Conversation with Geoffrey J Pilkington, Professor of Cellular and Molecular Neuro-oncology, President British Neuro-Oncology Society, 21 May 2013

41 Email and phone communications, WC 20 June 2013 and WC 27 June 2013

42 Request for data to Chief Scientist Office, which included £1 million for a project that focused on four areas, brain, leukaemia, pancreatic and all sites

43 Request for data to Chief Scientist Office

44 Ibid

45 House of Commons Hansard, 10 Dec 2012 : Column 110W

46 Awaiting answer in Parliament

47 Email and phone communications, WC 20 June 2013 and WC 27 June 2013

48 Ibid

49 House of Commons Hansard, 10 June 2013 : Column 213W

50 Awaiting answer in Parliament

51 Email and phone communications, WC 20 June 2013 and WC 27 June 2013

52 Ibid

53 Ibid

54 Ibid

55 Grants starting Jan 2013 mentions £358,185 of funding spread over next 3 years post Jan 2013 but none before that, at http://www.aicr.org.uk/GrantsstartingJanuary2013.stm

56 Grants starting Jan 2012 and Grants starting Jan 2013 mentions £8,015,649 of funding spread over the next three years, of which £2,111,250 was spent in 2012, at http://www.aicr.org.uk/GrantsstartingJanuary2012.stm and http://www.aicr.org.uk/GrantsstartingJune2012.stm

57 No mention of brain cancer research in latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends36%5C0000062636_AC_20120731_E_C.pdf

58 Ibid, p.42

59 Only breast cancer research is mentioned in latest accounts, at http://apps.charitycommission.gov.uk/Accounts/Ends58%5C0000299758_AC_20120630_E_C.pdf

60 Ibid, p.16

61 See latest accounts, p.4 at http://apps.charitycommission.gov.uk/Accounts/Ends64%5C0001089464_ac_20120331_e_c.pdf

62 Ibid, p.10

63 Most recent accounts at http://apps.charitycommission.gov.uk/Accounts/Ends05%5C0000298405_ac_20111231_e_c.pdf go into details but list nothing on brain cancer

64 Ibid, p.34

65 No mention of brain cancer research in latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends32%5C0000216032_ac_20120331_e_c.pdf

66 Ibid,p.35

67 http://www.licr.org/index.php/Laboratory web site reveals no specific funding for brain cancer

68 Above web site no longer available – LICR does not publish accounts with the Charity Commission

69 Funds support for those with cancer rather than cancer research. Latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends17%5C0000261017_ac_20111231_e_c.pdf

70 Ibid

71 Funds support for those with cancer rather than cancer research. Latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends94%5C0000207994_ac_20120331_e_c.pdf

72 Ibid

73 No mention of brain cancer research in latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends41%5C0001005541_AC_20120331_E_C.pdf

74 Ibid, p.20

75 No mention of brain cancer research in latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends54%5C0001046854_ac_20111231_e_c.pdf

76 Ibid, p.24

77 No mention of brain cancer research in latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends15%5C0001054015_ac_20120331_e_c.pdf

78 Ibid, p.25

79 No mention of brain cancer research in latest accounts at http://apps charitycommission.gov.uk/Accounts/Ends83%5C0000210183_AC_20120930_E_C.pdf

80 Ibid, p.47

81 No mention of brain cancer research in latest accounts at http://apps.charitycommission.gov.uk/Accounts/Ends98%5C0000516898_AC_20120331_E_C.pdf

82 Ibid, p.22

83 Confirmed in telephone conversation on 7 June 2013 that they don't fund cancer research

84 Ibid

85 NCRI Data Package 2012, 'Spend by disease site', National Cancer Research Institute at http://www.ncri.org.uk/includes/Publications/general/Data_package_12.xls

86 Ibid

87 Brain Tumour Research figures, sourced from Charity Commission incomes received for accounts ending during 2011 (excludes NCRI charities)

88 Ibid

89 Ibid

90 Ibid

91 Ibid

92 Ibid

93 Ibid

94 Ibid

95 Cancer Statistics Registrations, England (Series MB1) - No. 42, 2011, Office for National Statistics, 26 June 2013, at http://www.ons.gov.uk/ons/rel/vsob1/cancer-statistics-registrations--england--series-mb1-/no--42--2011/index.html

A BRAIN TUMOUR RESEARCH – FUNDING FLOWS, Ellen Harries, Iona Joy, Brain Tumour Research & NPC, London, April 2013 http://www.braintumourresearch.org/uploads/document/BrainTumourResearchFundingFlowsMarch2013_896.pdf p.14 and p.15 updated

B BRAIN TUMOUR RESEARCH – FUNDING FLOWS, Ellen Harries, Iona Joy, Brain Tumour Research & NPC, London, April 2013 http://www.braintumourresearch.org/uploads/document/BrainTumourResearchFundingFlowsMarch2013_896.pdf p.23

Brain Tumour Research
The Business Centre, Padbury Hill Farm,
Padbury, Buckingham,
Bucks, MK18 2BN

Registered charity no: 1093411

Follow us here: