



## DEBATE PACK

Number CDP 2016/0083, 13 April 2016

# E-petition debate: Funding of research into brain tumours

This pack has been produced ahead of the debate to be held in Westminster Hall on Monday 18 April at 4.30 pm on e-Petition 105660, **Fund more research into brain tumours, the biggest cancer killer of under-40s**

Brain tumours kill more children and adults under 40 than any other cancer. One of those young lives lost was my brother Stephen, who was diagnosed at just 19 and died aged 26. More funding for research is urgently needed - read on for some shocking statistics from the charity Brain Tumour Research:

- Unlike most cancers, brain cancer incidence is rising.
- Less than 20% of those diagnosed with brain cancer survive beyond 5 years.
- In 2014, brain tumours received 1.5% (£7.7 million) of the £498 million national spend on research into cancer. At this rate, it could take 100 years to catch up with developments in other diseases.

The charity is calling on the Government and larger cancer charities to raise investment to £30-£35 million a year, and this petition aims to support its campaign.

The Government [responded](#) and the Petitions Committee held an [inquiry](#) and published a report, [Funding for research into brain tumours](#) HC554 March 2016

The House of Commons Library prepares a briefing in hard copy and/or online for most non-legislative debates in the Chamber and Westminster Hall other than half-hour debates. Debate Packs are produced quickly after the announcement of parliamentary business. They are intended to provide a summary or overview of the issue being debated and identify relevant briefings and useful documents, including press and parliamentary material. More detailed briefing can be prepared for Members on request to the Library.

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# 1. Summary

There were 10,624 new cases of Brain or other Central Nervous System (CNS) tumours in the UK in 2013.<sup>1</sup> This represented 3% of all cancer cases that year. Around a fifth (19%) of people diagnosed with brain cancer in England and Wales survive their disease for five years or more (2010-11).<sup>2</sup> According to the charity [Brain Tumour Research](#) more people under the age of 40 die as a result of a brain tumour than any other cancer.<sup>3</sup>

[E-petition 105660](#) was started by Maria Lester, whose brother Stephen Realf lost his life as a result of a brain tumour. The petition was supported by the charity, [Brain Tumour Research](#) who are campaigning for increased funding for brain tumour research. It called on the Government to provide more funding for research into brain tumours and received 120,129 signatures. The petition stated:

Fund more research into brain tumours, the biggest cancer killer of under-40s

Brain tumours kill more children and adults under 40 than any other cancer. One of those young lives lost was my brother Stephen, who was diagnosed at just 19 and died aged 26. More funding for research is urgently needed - read on for some shocking statistics from the charity Brain Tumour Research:

- Unlike most cancers, brain cancer incidence is rising.
- Less than 20% of those diagnosed with brain cancer survive beyond 5 years.
- In 2014, brain tumours received 1.5% (£7.7 million) of the £498 million national spend on research into cancer. At this rate, it could take 100 years to catch up with developments in other diseases.

The charity is calling on the Government and larger cancer charities to raise investment to £30-£35 million a year, and this petition aims to support its campaign.<sup>4</sup>

The Government response to the petition said that brain tumour research received 3.3% of site-specific cancer research funding from the National Cancer Research Institute and reported what factors are taken into account when making research funding decisions

The Government and charities work closely together in brain tumour research and other fields of cancer research through the National Cancer Research Institute (NCRI). Factors influencing the level of research funding are discussed in Strategic Analysis 2002: An overview of Cancer Research in the UK directly funded by the NCRI Partner Organisations:

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<sup>1</sup> Cancer Research UK, [Brain, other CNS and intracranial tumours statistics](#) [accessed on 7 April 2016]

<sup>2</sup> *Ibid.*

<sup>3</sup> [Brain Tumour Research, 120 DIFFERENT TYPES... no wonder a brain tumour is notoriously difficult to diagnose](#) [accessed on 15 April 2016]

<sup>4</sup> [E-petition 105660](#) [accessed on 12 April 2016]

There are a number of factors that dictate the level of research funding into a particular issue. These include:

- scientific opportunity – this can be a very important factor. In particular, developments in fundamental research and the introduction of new technologies often stimulate new approaches;
- the burden of disease – the incidence and severity of a type of cancer will influence both researchers and funders;
- researchability – some tumour types are easier to work on than others but can often provide a model system for other cancers, and many researchers are attracted to areas or diseases where there is real evidence or potential for progress;
- fundraising – certain types of cancer may attract more public donations than others; and
- the quality and size of the research workforce – because of the issues listed above some areas attract more high quality researchers than other areas. This will undoubtedly affect the number of quality proposals received by funding bodies.

NCRI partner organisations take these factors into account when making funding decisions. However, the relative importance of each of these in the decision-making process varies for each organisation depending on its corporate aims, culture and procedures.

The NCRI Cancer Research Database includes expenditure on cancer research by NCRI partner organisations. This includes only direct spend on cancer research, or spend which directly supports cancer research. The proportion of cancer research funding directly supporting brain tumour research was 1.5% in 2014. This analysis includes fundamental research (28.8%) and funding relevant to all cancer sites (25.1%). If these elements are excluded, brain tumour research received 3.3% of site-specific cancer research funding. This is a greater proportion than for 40 of the 49 site-specific categories.

The National Institute for Health Research (NIHR) welcomes funding applications for research into any aspect of human health, including brain tumours. These applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and the NHS, value for money and scientific quality. NIHR funding is not ring-fenced for cancer research or for research on brain tumours or other types of cancer. In all disease areas, the amount of NIHR funding depends on the volume and quality of scientific activity.

The Government welcomes the commitment by Cancer Research UK to increase spend in research on brain tumours. This will drive further investment by the NIHR. This happens in two ways. Firstly, as scientific breakthroughs are translated into interventions benefitting patients through infrastructure for experimental medicine. Secondly, investment is driven as emerging interventions are investigated in studies and trials through the NIHR Clinical Research Network.<sup>5</sup>

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<sup>5</sup> E-petition 105660, [Government Response](#) [accessed on 12 April 2016]

## Petitions Committee Inquiry

The Petitions Committee conducted an inquiry into funding for research into brain tumours as a result of the petition, and published its report, [Funding for research into brain tumours](#) in March 2016.<sup>6</sup>

The Committee opened a web comment thread and invited members of the public to share their thoughts and personal experiences of brain tumours. The web thread received 1106 posts in just ten days.<sup>7</sup>

Following this, some of those that contributed to the web forum took part in a round table discussion with the Committee.

The Committee also heard evidence from charities, researchers and the Director of the National Cancer Research Institute. Transcripts and videos of the oral evidence sessions are available on the [Petitions Committee website](#).

At the time of the publication of the report, the Chair of the Petitions Committee, Helen Jones said that the evidence was clear- something must be done to improve outcomes for patients and remove barriers to research:

"The [Petitions](#) Committee's first report makes clear recommendations to the [Government](#) about the lack of funding for research into brain tumours. As part of this inquiry we heard testimonies both from victims of this terrible disease, and from clinical specialists working in the area.

The evidence was clear – something must be done to improve outcomes for patients, and barriers to research must be removed. This report was initiated by the public; it is a vitally important issue and I hope the Government takes our recommendations seriously."<sup>8</sup>

The Committee looked at the levels of funding for brain tumour research and concluded that it had been seriously underfunded, putting it behind other cancers in terms of improvements in outcomes.<sup>9</sup> They recommended that the Government gives a clear statement about whether it thinks the level of funding for brain tumour research is adequate and if not what the Government will do to ensure funding increases:

In its response to the petition, the Government has not explained clearly whether it believes that current levels of funding for brain tumour research are adequate. The response failed to address the serious concerns raised by the petition: the lack of progress in survival rates for brain tumours; the burden of the disease, particularly the fact that it is responsible for the highest number of life years lost compared with other cancers; and the impact on quality of life for those who do survive. We recommend that the Government gives a clear statement of whether it thinks funding

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<sup>6</sup> House of Commons Petitions Committee, [Funding for research into brain tumours, First report of Session 2015-16](#), March 2016

<sup>7</sup> Petitions Committee, [Funding for brain tumour research web forum](#)

<sup>8</sup> Petitions Committee, [Brain tumour research funding inadequate and not given sufficient priority](#), 14 March 2016

<sup>9</sup> House of Commons Petitions Committee, [Funding for research into brain tumours, First report of Session 2015-16](#), March 2016 (page 30)

levels are adequate and, if not, what it will do to ensure that funding for brain tumour research increases.

The Petitions Committee report also highlighted other barriers to research into brain tumours which includes difficulty in recruiting PhD students and a lack of coordinated tissue sample collection:

We heard evidence about the barriers that may be preventing increased investment in brain tumour research. Historical funding problems for research into brain tumours and lack of leadership from successive governments in this area appears to have left a gap in the research workforce within the UK; in particular it is increasingly difficult to recruit PhD students and those who complete their PhD often have to change specialisms or work overseas. An absence of co-ordination and awareness has impeded collection of tissue samples, making fundamental research into different tumour types extremely difficult.

Coordinated and adequate tissue collection, a quality workforce and ability to get fundamental 'blue sky' research applications approved could significantly improve progress for brain tumours.

The Government needs to take a leading role in tackling these systemic problems, to unlock the potential for investment in brain tumour research to be increased.<sup>10</sup>

The Committee also recommended a number of measures to increase awareness of brain tumours and improve early diagnosis rates.

The Government response to the report has not yet been published.

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<sup>10</sup> *Ibid*, para 87

## 2. News items

Independent

### **Health officials have 'failed brain tumour patients and their families for decades'**

Damning parliamentary report finds patients are let down at every stage from diagnosis to treatment

Ella Pickover 14 March 2016

<http://www.independent.co.uk/life-style/health-and-families/health-news/health-officials-have-failed-brain-tumour-patients-and-their-families-for-decades-a6929556.html>

BBC News

### **Brain tumour research funding boost**

23 October 2014

<http://www.bbc.co.uk/news/uk-england-london-29748451>

Daily Telegraph

### **Brain tumour survival harmed by popularity of other cancer charities**

It would take 100 years for brain cancer to catch up current developments in other cancers, health experts have warned

Sarah Knapton 30 September 2014

<http://www.telegraph.co.uk/news/science/science-news/11130784/Brain-tumour-survival-harmed-by-popularity-of-other-cancer-charities.html>

BBC News

### **Brain tumour treatment 'lagging behind'**

30 June 2013

<http://www.bbc.co.uk/news/health-23085835>

## 3. Press releases

### **House of Commons Petitions Committee Brain tumour research funding inadequate and not given sufficient priority 14 March 2016**

Committee publishes its report "Funding for research into brain tumours", revealing the distressing experiences of people whose lives have been affected by the disease, as well as exploring the reasons behind the historic underfunding of research under successive governments.

- [Report: Funding for research into brain tumours](#)
- [Report: Funding for research into brain tumours \(PDF 1.22 MB\)](#)
- [Inquiry: Funding for research into brain tumours](#)
- [Petitions Committee](#)

#### *Report key findings*

Key areas covered by the report include:

- Awareness and diagnosis
- Funding levels
- Barriers to research
- Setting research priorities
- Burden of disease
- Availability of therapeutic drugs

This is the Committee's first ever report. The [petition "increase funding into brain tumour research"](#) now has over 120,000 signatures, and will be debated in Parliament.

#### *Watch the launch event*

[Watch Parliament TV: Launch of report on funding for research into brain tumours](#)

#### *Background to the report*

The inquiry was triggered by a petition started by Maria Lester, whose brother Stephen Realf lost his life as a result of a brain tumour. The Committee took evidence on diagnosis and awareness of the condition, as well as on current funding levels, research priorities and the challenges facing brain tumour charities.

The report now calls for the Government to give a clear [statement](#) of whether it believes that current levels of funding are adequate, and if not, asks what it will do to ensure that funding for brain tumour research increases.

The Committee heard moving examples of the difficulty that patients had had in being diagnosed with a brain tumour, as well as clinical evidence on the challenges involved in identifying the condition early. It recommends that measures be immediately taken to increase awareness amongst health professionals of the symptoms of brain tumours. The report concludes "patients with brain tumours are failed at every stage – from diagnosis and treatment to research funding", placing the onus

on the Government to take remedial action to correct decades of under-funding.

*Chair's comment*

Helen Jones MP, Chair of the Petitions Committee, said:

"The [Petitions](#) Committee's first report makes clear recommendations to the [Government](#) about the lack of funding for research into brain tumours. As part of this inquiry we heard testimonies both from victims of this terrible disease, and from clinical specialists working in the area. The evidence was clear – something must be done to improve outcomes for patients, and barriers to research must be removed. This report was initiated by the public; it is a vitally important issue and I hope the Government takes our recommendations seriously."

*Petition's founder, Maria Lester's comment*

Maria Lester, who started the petition with the support of the charity Brain Tumour Research, said:

"Brain tumours are the biggest cancer killer of people under 40, and it is vital that funding for research is swiftly increased. I welcome this important report by the Petitions Committee, and would like to thank its members for the care and hard work that has gone into compiling it. The evidence makes for powerful reading, and I hope that it will pave the way for fast and meaningful action.

I would urge the Government not to turn a blind eye, but to look at ways in which the UK could become a world leader in brain tumour research. It may be too late for my brother Stephen, but it is not too late to save others from this cruel disease."

**The Brain Tumour Charity  
The Petitions Committee's report on funding for research in to  
brain tumours is released today  
14 March 2016**

*The e-petition calls on larger cancer charities and the government to invest more in research into brain tumours.*

We have ongoing research partnerships and co-funding agreements with some of those, including Cancer Research UK, Children with Cancer UK, Great Ormond Street Children's Charity and the Medical Research Council (the government's research funding arm). CRUK has already named brain tumours as a priority in its current five-year strategy.

In our evidence to MPs, we were able to highlight issues that we believe deserve attention alongside funding. These include awareness of symptoms, delays to diagnosis and lack of support for those living with a brain tumour.

Sarah Lindsell, CEO of The Brain Tumour Charity: *"The findings of this report confirm what we have heard anecdotally and echo the findings from our own research as outlined in our two reports; [Losing Myself](#), which highlights the reality of life with a brain tumour and [Finding Myself in Your Hands](#), which exposes the realities of brain tumour treatment and care.*

*"The lack of funding for research is a part of the much wider issue for brain tumour patients, which includes a lack of awareness of signs and symptoms leading to late diagnosis, which in turn can mean poor outcomes and poor quality of life.*

*"We welcome the recommendation that the government provide greater awareness and leadership among GPs including the incorporation of our HeadSmart campaign into NICE guidelines.*

*"We look forward to a statement from the government which outlines whether there is adequate support for young scientists wishing to move into brain tumour research roles and its determination to address the concerns from patients of red-tape reducing the opportunities for clinical trials.*

*"The Brain tumour Charity will continue to push for increased research, great awareness and funds for this terrible disease. "*

We share a goal with everyone who signed her petition – to defeat brain tumours.

That is why we were pleased to be invited by MPs to give evidence to the inquiry which was triggered by Maria's petition, and which led to this very welcome report.

We will continue to work alongside all groups and individuals that are striving to identify the most promising areas for research and to drive forward progress in the fight against brain tumours.

[Read the full report here](#)

### **Children's Brain Tumour Research Centre welcomes parliamentary report into underfunding of biggest cancer killer among under 40s**

**14 Mar 2016**

Experts in children's brain tumours have today welcomed an historic parliamentary report which says funding for brain tumour research is inadequate in the UK and not given sufficient priority.

Professor David Walker and Professor Richard Grundy gave evidence to a Petition's Committee inquiry last autumn after a petition organised by the sister of a brain tumour victim raised more than 120,000 signatures. Walker and Grundy are Co-Directors of the Children's Brain Tumour Research Centre at The University of Nottingham and Nottingham University Hospitals NHS Trust.

The Petitions Committee, of 11 cross-party MPs, has today published its final report 'Funding for research into brain tumours' revealing the distressing experiences of people whose lives have been affected by the disease, as well as exploring the reasons behind the historic underfunding of research under successive governments.

This is the Committee's first ever report and the successful petition now means the issue will be the subject of a debate in parliament.

The Committee took evidence from families and clinicians on diagnosis and awareness of the condition, as well as on current funding levels, research priorities and the challenges facing brain tumour charities. The report calls for the Government to give a clear statement of whether it believes that current levels of funding are adequate, and if not, asks what it will do to ensure that funding for brain tumour research increases. It also says the prioritisation of research funding should not be left solely to the voluntary sector and the Government should take a more active role in meeting unmet needs in research funding considering the burden of this disease.

Reacting to the report, Professor David Walker said: "[At Children's Brain Tumour Research Centre](#) at The University of Nottingham we recognised in 1997 the absence of priority to research in this area and launched our local fundraising initiative to develop research infrastructure and raise awareness within our cancer translational research programme at the University and the Queen's Medical Centre Campus of the NUH NHS Trust. Brain tumours are now a central and highly valued part of that strategy. We have established a pioneering centre currently consisting of nearly 60 clinical and scientific specialists investigating issues related to brain tumour in children and young people.

"It is gratifying to see that the recent petition has highlighted this area for further prioritisation in 2016 and that the report recognises the impact of brain tumours across all ages as a major cause of human disease, especially in early life, which threatens survival and promotes serious disability.

Professor Richard Grundy, Co-Director of the Children's Brain Tumour Research Centre, added: "A key element is further funding to develop our understanding of the underlying biology of the disease. With that knowledge we could develop personal treatment strategies for patients that have less damaging consequences and reduce the potential of life-changing disabilities that many patients are left to cope with following current therapies."

The Children's Brain Tumour Research Centre has today outlined the greatest challenges in Paediatric Neuro-oncology:

- To reduce the death rates in the resistant childhood tumour types (Diffuse Intrinsic Pontine Glioma DIPG / atypical teratoid rhabdoid tumour / ependymoma / high grade glioma) by searching for new targets for treatment.
- To reduce the harm of the current treatments on the brain and other organ systems by delivering new treatments directly to the brain tumour, by-passing the blood brain barrier by researching into personalised drug delivery techniques.
- To reduce the global harm to the patients' brain by accelerating diagnosis, we designed and launched the HeadSmart Campaign ([www.headsmart.org](http://www.headsmart.org)) and identified and devised strategies to prevent serious brain injury such as cerebellar mutism and blindness associated with brain tumours.
- To support the development of clinical trials of novel therapies as the way to deliver enhanced outcomes to the patients as we treat them.

Professor Walker added: “We have consistently worked closely with our patients and those who share the challenge of raising awareness of the needs of the children and young people who experience brain tumour and have to live with the threat to their lives and consequences of their illness and its treatment for the rest of their lives.

This petition highlights significant priorities for Government and we would welcome a visit to demonstrate the type of development that can be generated, focussing on this area. Our experience is unique in the UK, we are one of a growing network of brain tumour research centres globally.”

The Committee heard moving examples of the difficulty that patients had had in being diagnosed with a brain tumour, as well as clinical evidence on the challenges involved in identifying the condition early. It recommends that measures be immediately taken to increase awareness amongst health professionals of the symptoms of brain tumours. The report concludes: “Patients with brain tumours are failed at every stage — from diagnosis and treatment to research funding, placing the onus on the Government to take remedial action to correct decades of under-funding.”

Helen Jones MP, Chair of the Petitions Committee, said: “The Petitions Committee’s first report makes clear recommendations to the Government about the lack of funding for research into brain tumours. As part of this inquiry we heard testimonies both from victims of this terrible disease, and from clinical specialists working in the area. The evidence was clear — something must be done to improve outcomes for patients, and barriers to research must be removed. This report was initiated by the public; it is a vitally important issue and I hope the Government takes our recommendations seriously.”

Maria Lester, who started the petition with the support of the charity Brain Tumour Research, said: “Brain tumours are the biggest cancer killer of people under 40, and it is vital that funding for research is swiftly increased. I welcome this important report by the Petitions Committee, and would like to thank its members for the care and hard work that has gone into compiling it. The evidence makes for powerful reading, and I hope that it will pave the way for fast and meaningful action. I would urge the Government not to turn a blind eye, but to look at ways in which the UK could become a world leader in brain tumour research. It may be too late for my brother Stephen, but it is not too late to save others from this cruel disease.”

### **Children with Cancer UK Brain Tumour Funding debate in Parliament**

On Monday 18th April, MPs will be debating a report that calls for *an increase in the percentage of national spend on research into cancer to be spent on research for better diagnosis and treatment of brain tumours.*

We urge you to *please email your MP*, using this [letter](#) *before Monday 18th April.*

Find out the [contact details](#) of your local MP.

[Template email to your MP](#)  
[Find your MP and his/ her email address](#)

*Why increased funding for brain tumour research is so important*

- Brain tumours kill more children and adults under the age of 40 than any other cancer, yet just 1% of the national spend on cancer research has been allocated to this devastating disease since 2002
- Brain tumours are one of the most common cancers to affect children and young people
- Many survivors of childhood brain tumours are left with life-altering, long term disabilities
- Incidences of brain tumours are increasing
- Research into brain tumours, in general, and childhood brain tumours, in particular, has not been well-funded in the past despite the very high burden imposed by these tumours.

*The parliamentary debate and report*

The debate is the result of The Petitions Committee publishing its first ever report Funding for research into brain tumours on 14th March. The report covers:

- Awareness and diagnosis
- Funding levels
- Barriers to research
- Setting research priorities
- Burden of disease
- Availability of non-therapeutic drugs.

[Read the report](#)

The report was put together and published after *the petition "Increase funding into brain tumour research" gained over 120,000 signatures* on the Government Petitions website. Find out more about the [Petition](#) and [Petitions Committee](#).

Our Brain Tumour Initiative

In 2014 we launched a new initiative to drive progress in childhood brain tumour research, *committing funds of at least £3 million over three years for new brain tumour research.*

The first tranche of funding was awarded in March 2015 for *four exciting new project grants worth £1.8m in total.*

With this funding, four groups of researchers are taking forward vital research into four different types of childhood brain tumour: ependymoma, medulloblastoma, craniopharyngioma and high grade glioma.

*The debate calls for an increase in the percentage of national spend on research into cancer to be spent on research for better diagnosis and treatment of brain tumours.*

*Read more:* [Our Brain Tumour Initiative](#) | [New brain tumour project grants](#)

*Who you're helping*

*Brain tumours kill more children than any other form of cancer.* Some childhood brain tumours are untreatable and leave few, if any, survivors. Rhiley was diagnosed with a rare spinal and brain tumour at just two years old. She sadly passed away in April 2015, two weeks after her third birthday.

With your help, we aim to increase survival rates and improve life after treatment for children with all types of brain tumours, including those that are currently untreatable.

**National Cancer Research Institute**  
**SCIENTISTS DISCOVER HOW TO BETTER MAP BRAIN TUMOURS**  
**3 November 2015**

SCIENTISTS have discovered a protein that helps map the edge of brain tumours more clearly so they show up on magnetic resonance imaging (MRI) scans, according to new research presented at the National Cancer Research Institute (NCRI) Cancer Conference in Liverpool\* today (Tuesday).

The laboratory research, carried out in rats, could lead to clinical trials aimed at improving the accuracy of brain tumour treatment. For the first time, scientists have identified a protein inside blood vessels found at the invasive edge of brain tumours –highlighting the area from where cancer is most likely to spread.

This protein is produced as part of an inflammatory response caused by the brain tumour. Mapping this inflammation gives scientists a more complete picture of the cancer.

The scientists have developed a special dye that recognises and sticks to the protein –VCAM-1 –on the brain blood vessels and this can be seen on MRI scans. Importantly, the protein is on the inside of the vessels, providing an accessible target from the bloodstream.

This new research gives scientists the most complete picture of brain tumours yet, and for the first time the edge of a growing tumour has been mapped. These cells are the most important to catch as they are the most likely to spread.

Clinical MRI techniques can show images of leaky blood vessels in patients, often a sign of brain tumours. Unfortunately, blood vessels near the edge of brain tumours are often intact, so the MRI fails to reveal the whole tumour.

Each year around 9,700 people in the UK are diagnosed with a tumour in their brain or in other parts of their central nervous system: that's 27 people every day.

Professor Nicola Sibson, study author and Cancer Research UK scientist at The University of Oxford, said: "If we can't map the edge of the tumour, surgery and radiotherapy often fail to remove aggressive tumour cells –and the brain tumour can grow back.

“This research shows that we can improve imaging of brain tumours, which could help both surgeons and radiotherapists with more effective treatment.”

Professor Charlie Swanton, chair of the 2015 NCRI Cancer Conference, said: “Brain tumours are very difficult to treat and take the lives of too many patients each year.

This important research identifying the edge of tumours –the area most likely to grow and spread -has potential to really help doctors treat patients and help save more lives.”

Harpalkumar, Cancer Research UK’s chief executive, said: “Brain cancers continue to have very poor survival rates, which is why research into how to treat them is a top priority for Cancer Research UK. Being able to delineate the edges of brain tumours is an exciting step towards better surgery and radiotherapy for patients. The holy grail would be to be able to completely remove brain tumours with the help of this new imaging technique –reducing recurrence of the disease and saving more lives.”

This study was funded by Cancer Research UK and the Medical Research Council.

*Notes to Editors:*

\* This research was presented by Dr Sebastien Serres. NCRI conference abstract: <http://abstracts.ncri.org.uk/abstract/detection-of-brain-tumours-using-translational-molecularly-targeted-magnetic-resonance-imaging-2/>

\*\*Video: <https://youtu.be/36UOlatUldE>

*About the NCRI*

The National Cancer Research Institute (NCRI) was established in 2001. It is a UK-wide partnership between cancer research funders which promotes collaboration in the field. Its member organisations work together to maximise the value and benefits of cancer research for patients and the public.

NCRI members are: Biotechnology and Biological Sciences Research Council; Bloodwise(formerly Leukaemia & Lymphoma Research); Breast Cancer Now; Cancer Research UK; Children with Cancer UK, Department of Health; Economic and Social Research Council; Macmillan Cancer Support; Marie Curie; Medical Research Council; Northern Ireland Health and Social Care Public Health Agency (Research & Development Department); Prostate Cancer UK; Roy Castle Lung Cancer Foundation; Scottish Government Health Directorates (Chief Scientist Office); Tenovus Cancer Care; The Wellcome Trust; Welsh Assembly Government (Health and Care Research Wales); and Worldwide Cancer Research (formerly AICR).

For more information visit [www.ncri.org.uk](http://www.ncri.org.uk)

*About the NCRI Cancer Conference*

The NCRI Cancer Conference is the UK’s major forum for showcasing the best British and international cancer research.

- The Conference offers unique opportunities for networking and sharing knowledge by bringing together world-leading experts from all cancer research disciplines.
- The NCRI Cancer Conference is taking place from 1–4 November 2015 at the BT Convention Centre in Liverpool.
- For more information visit [www.conference.ncri.org.uk](http://www.conference.ncri.org.uk)

The *Medical Research Council* is at the forefront of scientific discovery to improve human health. Founded in 1913 to tackle tuberculosis, the MRC now invests taxpayers' money in some of the best medical research in the world across every area of health. Thirty-one MRC-funded researchers have won Nobel prizes in a wide range of disciplines, and MRC scientists have been behind such diverse discoveries as vitamins, the structure of DNA and the link between smoking and cancer, as well as achievements such as pioneering the use of randomised controlled trials, the invention of MRI scanning, and the development of a group of antibodies used in the making of some of the most successful drugs ever developed. Today, MRC-funded scientists tackle some of the greatest health problems facing humanity in the 21st century, from the rising tide of chronic diseases associated with ageing to the threats posed by rapidly mutating micro-organisms.

[www.mrc.ac.uk](http://www.mrc.ac.uk)

*About Cancer Research UK* Cancer Research UK is the world's leading cancer charity dedicated to saving lives through research. Cancer Research UK's pioneering work into the prevention, diagnosis and treatment of cancer has helped save millions of lives. Cancer Research UK receives no government funding for its life-saving research. Every step it makes towards beating cancer relies on every pound donated. Cancer Research UK has been at the heart of the progress that has already seen survival in the UK double in the last forty years. Today, 2 in 4 people survive their cancer for at least 10 years. Cancer Research UK's ambition is to accelerate progress so that 3 in 4 people will survive their cancer for at least 10 years within the next 20 years.

Cancer Research UK supports research into all aspects of cancer through the work of over 4,000 scientists, doctors and nurses. Together with its partners and supporters, Cancer Research UK's vision is to bring forward the day when all cancers are cured.

For further information about Cancer Research UK's work or to find out how to support the charity, please call 0300 123 1022 or visit [www.cancerresearchuk.org](http://www.cancerresearchuk.org). Follow us on Twitter and Facebook

**Queen Mary University of London**  
**New brain tumour research Centre of Excellence is unveiled at QMUL**  
**23 October 2014**

Patients, carers, scientists, clinicians and charities from across the UK will gather today for the launch of a ground-breaking new partnership between the charity Brain Tumour Research and Queen Mary University of London (QMUL) in collaboration with the UCL Institute of Neurology.

Together they have established a new brain tumour research Centre of Excellence at QMUL, bringing a welcome and timely boost to long-term,

sustainable and continuous research into the biggest cancer killer of children and adults under 40.

Statistical research from the charity earlier this year revealed one in 50 people who die under the age of 60 years are dying from a brain tumour. And, just as shockingly, 71% of those who die of a brain tumour will be under 75 years old, compared to 47% for all cancers. The Centre of Excellence is led by Professor Silvia Marino, a leading brain tumour scientist and neuropathologist based at QMUL's Blizard Institute, and will specialise in identifying how glioblastoma multiforme (GBM) forms and grows within the brain with the final aim of identifying more efficient drug treatments. Professor Denise Sheer, also from QMUL, and Professor Sebastian Brandner and Dr Jeremy Rees at the UCL Institute of Neurology will be additional important research partners in this initiative.

Professor Silvia Marino said: "Glioblastomas are a malignant, aggressive type of brain tumour and tragically one of the most common. With Brain Tumour Research's help we will be investigating how the tumours develop, which is key to advancing their treatment. This is a major initiative in an underfunded research area in the UK."

Emily Jones, 27, from London, said: "After my diagnosis I felt I'd been dealt two blows. Having a brain tumour and a disease about which so little is known. Today is a hopeful day for me, a positive step forward which means others may not have to face the devastation my family and I have had to face."

With secure long-term funding covering the crucial salaried positions, researchers at QMUL will be freed from the limitations and frustrations of applying for one specific project grant after another, and instead will be able to pursue the sustainable and continuous research so desperately needed by the scientists and clinicians working in this underfunded field. Promising scientists will be trained up through the ranks to fulfil their potential, rather than being tempted into other cancer research which currently attracts greater funding and with it greater job prospects.

Sue Farrington Smith, Chief Executive of Brain Tumour Research, said: "Today is a milestone for all patients and families whose lives have been affected by this devastating disease. A powerful new team of researchers is being established who will share our ambition of creating a better future for those diagnosed and living with a brain tumour. We are all determined that one day we will find a cure."

Brain Tumour Research currently helps fund – through corporate and public fundraising – an annual £1 million programme of research at their Centre of Excellence in the University of Portsmouth. This relationship with QMUL, along with additional new partnerships with Plymouth University and Imperial College in London, will pave the way for a £20 million investment in brain tumour research over the next five years.

Professor Silvia Marino and the team at QMUL would also like to thank Barts Charity, for their vital supporting role in this partnership.

## **Cancer Research UK**

### **Half of all cancer patients now survive at least 10 years**

**29 April 2014**

Fifty per cent of people diagnosed with cancer today will survive their disease for at least 10 years, [according to landmark figures](#) published by Cancer Research UK today (Tuesday).\*

"... with the continued commitment of our scientists, doctors and nurses and the generous support of the British public, we hope to see our progress accelerate over the coming years to make this a reality." - Harpal Kumar, Cancer Research UK's chief executive.

In the early 1970s just a quarter of people diagnosed with cancer survived 10 years.

Today, Cancer Research UK sets out an ambitious new strategy to accelerate progress with the ambition that three-quarters (75 per cent) of all cancer patients diagnosed in 20 years time will survive at least 10 years.

Women with breast cancer now have a 78 per cent chance of surviving at least a decade, compared to only 40 per cent 40 years ago. Ten-year survival for men with testicular cancer has jumped from 69 to 98 per cent since the 1970s and, for people diagnosed with malignant melanoma, the most serious form of skin cancer, 10-year survival has leapt from 46 to 89 per cent.

But it's not all good news. Just one per cent of pancreatic cancer patients and five per cent of lung cancer patients diagnosed today are expected to survive 10 years. Cancer Research UK has worked to increase research into these cancers but change has been slower than hoped – which is why a renewed focus is needed to make faster progress.

Survival from oesophageal cancer is still far too low at 12 per cent, although 40 years ago it languished at around four per cent. Brain tumour survival is also very low at just 13 per cent, despite more than doubling in the last 40 years.

Saving more lives from all cancers, including those that are hard to treat, is the overriding focus of [Cancer Research UK's new strategy, launched today](#). The strategy details a raft of measures aimed at accelerating the speed of progress.

Ensuring cancer patients are diagnosed at the earliest possible stage of their disease, when treatment is more likely to be successful, is a key priority for the charity. And it plans to fund more scientists from different disciplines because collaboration is key to moving discoveries from the laboratory into the clinic to make sure patients will benefit sooner.

Professor Michel Coleman, head of Cancer Research UK's Cancer Survival Group at the [London School of Hygiene and Tropical Medicine \(link is external\)](#), whose team produced the survival figures, said: "These

results come from detailed analysis of the survival of more than 7 million cancer patients diagnosed in England and Wales since the 1970s. They show just how far we've come in improving cancer survival, but they also shine a spotlight on areas where much more needs to be done.

"We want to see people with every type of cancer get the same chances of living a long life. This won't be easy, but the progress reported here over the last 40 years shows we're moving in the right direction."

Dr Harpal Kumar, Cancer Research UK's chief executive, said: "Every year, tens of thousands more people are surviving cancer a decade after diagnosis, showing that we're gradually reversing the tide on this devastating disease. This is thanks to the work of our scientists and doctors, but none of it would be possible without the generosity of the British public, whose donations we rely on to fund all our research.

"But each year more and more people are diagnosed with cancer. We believe no one should be diagnosed too late for their life to be saved and effective treatments should be available to every patient, no matter what type of cancer they have.

"Achieving our ambition to see three-quarters of all cancer patients surviving their disease in the next 20 years will be challenging. But with the continued commitment of our scientists, doctors and nurses and the generous support of the British public, we hope to see our progress accelerate over the coming years to make this a reality."

For media enquiries contact the Cancer Research UK press office on 020 3469 8300 or, out of hours, on 07050 264 059.

*Notes to Editor*

\* 49.8% net survival index, all cancers combined, for adults (15-99 years) diagnosed with cancer in England and Wales during 2010-11.

The figures will be available on the Cancer Research UK website:

<http://www.cancerresearchuk.org/cancer-info/cancerstats/survival/>

Trends in survival for all cancer patients who are diagnosed with a particular cancer provide a key insight into the overall effectiveness of the health system in managing that cancer.

Here, we present an all-cancers survival index that was designed as a one-number summary of survival for all types of cancer combined. The index is independent of changes over time in the age profile of cancer patients and changes in the proportion of cancers with high and low survival. It is designed to reflect overall progress in the effectiveness for cancer of the health care system in England and Wales.

It is important to note that the all-cancers survival index does not represent the chance of survival for any particular patient or for any particular cancer.

**Great Ormond Street Hospital  
Scientists target children's brain tumours in £4 million research  
programme  
14 February 2014**

A groundbreaking research programme aims to beat childhood brain tumours. The £4 million study, co-funded by grants from Great Ormond Street Hospital Children's Charity, the Brain Tumour Charity and Children with Cancer UK, will look at new ways to treat some of the deadliest brain tumours affecting children.

Teams from the UCL Institute of Child Health and the Institute of Cancer Research, London (ICR) will use cutting-edge screening techniques to identify critical genetic and biochemical features of aggressive brain tumours in young patients.

The ultimate aim is to assign patients to different clinical trials according to the genetic make-up of their tumour, developing new drugs that will target the specific mutations found in each tumour.

The researchers at the ICH and the ICR will work in tandem with a team at Newcastle University under the umbrella of INSTINCT, a network which brings together the work of leading scientists and clinicians in the field of high-risk paediatric brain cancer.

The aim of INSTINCT is to ensure that paediatric brain tumour research studies translate as quickly and effectively as possible into new treatments.

Between them, the clinical centres working with INSTINCT in Newcastle and London treat more than one in three young brain tumour patients in the UK.

Dr Darren Hargrave, who is leading the research strand at the UCL Institute of Child Health, says the INSTINCT team hopes ultimately to analyse tumour samples from every patient treated in one of its clinical centres and tailor their treatments accordingly.

"Our first aim is to improve survival rates among children with high-risk brain tumours," Dr Hargrave says.

At the same time, the researchers hope it may be possible to reduce the amount of potentially damaging drug therapy offered to children with tumours that are identified as less dangerous.

The ICH team will examine the genetics of some of the rarest and most deadly tumours such as ETANTR (embryonal tumour with abundant neuropil and true rosettes).

The ICR project, led by Dr Chris Jones, will focus on two types of paediatric brain tumour – high-grade glioma (HGG), which is fatal in most cases, and diffuse intrinsic pontine glioma (DIPG), which almost no child survives.

Currently, there is no recognised effective treatment for either type of tumour.

“For HGG, children are usually given the same treatment as adults – and in adults, there is a group of patients who do get some benefit. But in children that’s not really the case,” explains Dr Jones, leader of the glioma team at the ICR..

“For DIPG, there is not really a standard of care. Radiation might shrink the tumour for a couple of months, but then it comes back even stronger.

“This is part of a huge drive to understand these tumours better. They really are completely different biologically from similar tumours which arise in adults.”

The Newcastle scientists will focus on a type of fast-growing tumour known as medulloblastoma.

The INSTINCT research project is part of an overall £10 million investment in UK brain tumour research, funded by £5 million from the Brain Tumour Charity and £5 million in matching grants.

Neil Dickson, vice-chair of The Brain Tumour Charity, described the investment as a major milestone in brain tumour research.

“We are absolutely delighted that The Brain Tumour Charity has been able to award funding for these research projects, which we hope will bring about much-needed improvements in the understanding and treatment of brain tumours.

”

This level of spending on brain tumour research is unprecedented in the UK. It has been made possible by our dedicated supporters and fundraisers around the country, many of whom have personal experience of the devastating effects of a brain tumour.”

## 4. Parliamentary Questions

### [Brain: Tumours](#)

**Asked by: Cunningham, Mr Jim**

To ask the Secretary of State for Health, how much his Department spent on research into brain tumours in each of the last five years; and if he will make a statement.

**Answering member: George Freeman | Department: Department of Health**

The information requested is not available. Spend on research funded directly by the Department's National Institute for Health Research (NIHR) is categorised by Health Research Classification System (HRCS) health categories including 'cancer'. There are no HRCS health sub-categories, such as for brain tumours or other cancer sites.

Investment in cancer research by the NIHR has risen from £101 million in 2010/11 to £135 million in 2014/15. The NIHR works closely with patients, charities and our world-leading life sciences industry to support further research into brain tumours.

**HC Deb 24 March 2016 | PQ 31945**

### [Brain: Tumours](#)

**Asked by: Brake, Tom**

To ask the Secretary of State for Health, if he will make it his policy to increase spending on research into brain tumours to enable faster diagnosis.

**Answering member: George Freeman | Department: Department of Health**

**Spend by the National Institute for Health Research (NIHR) in the Health Research Classification System (HRCS) health category 'cancer'** has increased by a third from £101 million in 2010/11 to £135 million in 2014/15. There are no HRCS health sub-categories such as for brain tumours or other specific cancer sites and information on total current NIHR spend on brain tumour research is not held.

The NIHR welcomes funding applications for research into any aspect of human health, including brain tumours. These applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality. In all disease areas, the amount of NIHR funding depends on the volume and quality of scientific activity.

**HC Deb 10 February 2016 | PQ 26024**

### [Brain: Tumours](#)

**Asked by: Kwarteng, Kwasi**

To ask the Secretary of State for Health, what funding the Government plans to provide for research on diffuse intrinsic pontine glioma brain tumours.

**Answering member: George Freeman | Department: Department of Health**

The usual practice of the Department's National Institute for Health Research and of the Medical Research Council is not to ring-fence funds for expenditure on particular topics: research proposals in all areas compete for the funding available. Both funders welcome funding applications for research into any aspect of human health, including diffuse intrinsic pontine glioma and other brain tumours. These applications are subject to peer review and judged in open competition.

**HC Deb 23 November 2015 | PQ 16225**

[Brain: Tumours](#)

**Asked by: Thomas, Derek**

To ask the Secretary of State for Business, Innovation and Skills, how much was spent by the Medical Research Council on research into brain tumours in (a) 2012-13, (b) 2013-14 and (c) 2014-15.

**Answering member: Joseph Johnson | Department: Department for Business, Innovation and Skills**

Medical Research Council spend on research into brain tumours in (a) 2012-13, (b) 2013-14 and (c) 2014-15 is provided below.

<i>Year</i>	<i>Brain Tumour Research (including Brain &amp; Pituitary Tumours)</i>
2012/13	£2.16M
2013/14	£2.56M
2014/15	£2.81M

**HC Deb 15 October 2015 | PQ 11317**

[Brain: Tumours](#)

**Asked by: Thomas, Derek**

To ask the Secretary of State for Business, Innovation and Skills, how much was spent by the Economic and Social Research Council on research into brain tumours in (a) 2012-13, (b) 2013-14 and (c) 2014-15.

**Answering member: Joseph Johnson | Department: Department for Business, Innovation and Skills**

The Economic and Social Research Council has not commissioned research into brain tumours from 2012 to 2015.

Researchers are eligible to apply for grants from all seven of the UK Research Councils, funding is awarded to support excellent research driven by both researcher curiosity (responsive mode grants) and strategic priorities (managed mode grants).

**HC Deb 15 October 2015 | PQ 11316**

[Brain: Tumours](#)

**Asked by: Raab, Mr Dominic**

To ask the Secretary of State for Health, how many people were living with a brain tumour, including all intracranial tumours, on the last date for which figures are available.

**Answering member: Jane Ellison | Department: Department of Health**

The UK Cancer Prevalence Project from the National Cancer Intelligence Network and Macmillan Cancer Support will publish 20-year cancer prevalence data in summer 2015, including new statistics on brain tumour survivors. Previous data can be found at:

<http://www.ncin.org.uk/view.aspx?rid=76>

*Note:* The brain tumour statistic relates to International Classification of Diseases' version 10 codes C70-C72.

**HC Deb 26 March 2015 | PQ 228707**

Brain: Tumours**Asked by: Crouch, Tracey**

To ask the Secretary of State for Health, what assessment he has made of the effect of the HeadSmart Campaign in raising awareness of child brain tumours; and what steps he is taking to ensure that, after diagnosis of such tumours, (a) children and (b) adults receive the support they need for emotional and mental wellbeing.

**Answering member: Jane Ellison | Department: Department of Health**

We are aware of the HeadSmart Be brain tumour aware campaign which was launched in 2011, and fully support the campaign's aims to raise awareness of brain tumours and promote earlier diagnosis in children and young people. In early 2014, I met with representatives of HeadSmart. I subsequently wrote to local health and wellbeing boards, and Public Health England (PHE) contacted all directors of public health in April 2014, encouraging them to support the campaign and drawing their attention to the campaign's awareness-raising materials. PHE and Department of Health officials met with The Brain Tumour Charity on 23 January 2015, which resulted in the HeadSmart team giving a well-received presentation to the School Nursing Partnership Implementation Group on 17 March 2015. In addition, a meeting is being set up with officials from NHS England to discuss the evaluation and impact of the HeadSmart campaign. We will continue to work with stakeholders to see what more can be done to increase awareness of brain tumours. The National Cancer Survivorship Initiative (NCSI) has set out to understand the numbers, needs, and experiences of people living with and beyond cancer, including emotional and psychological needs, and the most effective service solutions to meet the growing numbers of survivors. The NCSI has recommended four priority areas: recovery packages, consequences of treatment and Patient Report Outcome Measures (PROMs), stratified pathways of care and physical activity. To support this work NHS England, in partnership with Macmillan Cancer Support, has established the Living with and Beyond Cancer Programme, a two-year programme of work to embed the four priority areas from NCSI into mainstream commissioning.

NHS England has also established the Teenage and Young Adults Clinical Reference Group (CRG) so that the clinical needs of teenagers and young people with cancer are taken into account as part of cancer commissioning. The CRG is working to ensure that teenagers and young people with cancer have access to dedicated pathways, and that the gaps in the associated services, such as mental health, palliative care and transition, are closed.

**HC Deb 23 March 2015 | PQ 228285**

## 5. Useful links and further reading

House of Commons Petitions Committee *Funding for research into brain tumours* HC554 March 2016

<http://www.publications.parliament.uk/pa/cm201516/cmselect/cmpeiti/ons/554/554.pdf>

Independent Cancer Taskforce *Achieving world-class cancer outcomes: A strategy for England 2015-2020*

[http://www.cancerresearchuk.org/sites/default/files/achieving\\_world-class\\_cancer\\_outcomes\\_-\\_a\\_strategy\\_for\\_england\\_2015-2020.pdf](http://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf)

Brain Tumour Research Report on National Research Funding July 2013

[http://www.braintumourresearch.org/uploads/document/BrainTumourResearchNationalFundingReportJuly\\_2013draft9\\_897.pdf](http://www.braintumourresearch.org/uploads/document/BrainTumourResearchNationalFundingReportJuly_2013draft9_897.pdf)

Brain Tumour Research

<http://www.braintumourresearch.org/>

The Brain Tumour Charity

<https://www.thebraintumourcharity.org/>

Cancer Research UK:

*Our research on brain tumours*

<http://www.cancerresearchuk.org/our-research/our-research-by-cancer-type/our-research-on-brain-tumours>

*Brain tumour organisations*

<http://www.cancerresearchuk.org/about-cancer/type/brain-tumour/brain-tumour-organisations>

Head1st

<http://head1st.org.uk/>

Children's Brain Tumour Foundation

<http://www.cbtf.org.uk/>

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