



House of Commons
Petitions Committee

Funding for research into brain tumours

First Report of Session 2015–16



House of Commons
Petitions Committee

Funding for research into brain tumours

First Report of Session 2015–16

*Report, together with formal minutes
relating to the report*

*Ordered by the House of Commons to be
printed 1 March 2016*

Petitions Committee

The Petitions Committee is appointed by the House of Commons to consider e-petitions submitted on petition.parliament.uk and public (paper) petitions presented to the House of Commons.

Current membership

[Helen Jones MP](#) (*Labour, Warrington North*) (Chair)

[Ian Blackford MP](#) (*Scottish National Party, Ross, Skye and Lochaber*)

[Steve Double MP](#) (*Conservative, St Austell and Newquay*)

[Jim Dowd MP](#) (*Labour, Lewisham West and Penge*)

[Oliver Dowden MP](#) (*Conservative, Hertsmere*)

[Paul Flynn MP](#) (*Labour, Newport West*)

[Ben Howlett MP](#) (*Conservative, Bath*)

[Mr Nick Hurd MP](#) (*Conservative, Ruislip, Northwood and Pinner*)

[David Mackintosh MP](#) (*Conservative, Northampton South*)

[Kate Osamor MP](#) (*Labour (Co-op), Edmonton*)

[Paul Scully MP](#) (*Conservative, Sutton and Cheam*)

Powers

The powers of the Petitions Committee are set out in House of Commons Standing Orders, principally in SO No. 145A. These are available on the Internet via www.parliament.uk.

Publication

Committee reports are published on the Committee's website at www.parliament.uk/petitions-committee and by The Stationery Office by Order of the House.

Evidence relating to this report is published on the [inquiry page](#) of the Committee's website.

Committee staff

The current staff of the Committee are Anne-Marie Griffiths (Clerk), Emma McIntosh (Petitions and Engagement Officer), Paul Simpkin (Senior Committee Assistant), Sean Harris (Committee Assistant), Thomas Caygill (Intern, Political Studies Association), and Pippa Lansdell (Media Officer).

Contacts

All correspondence should be addressed to the Clerk of the Petitions Committee, House of Commons, London SW1A 0AA. The telephone number for general enquiries is 020 7219 4272; the Committee's email address is petitionscommittee@parliament.uk

Contents

1	Introduction	4
	The Committee's inquiry	4
	The petition	5
	The Government's response	6
	The petitioners' story: the Realf family	7
	Brain Tumour Research	10
	The public stories	11
	Meeting the people behind the stories	14
2	Awareness and diagnosis	16
	Late diagnosis	16
	Scans	16
	Awareness	19
	The Be Clear on Cancer campaign	19
	Early diagnosis: impact	21
	Survival rates	21
	Quality of life	22
	Research	22
	Funding priorities	23
	Conclusion	23
	Recommendation	24
3	Funding levels	25
	How much is currently spent?	25
	Non-site specific research	25
	What type of research is being funded?	27
	Is current funding enough?	27
	Impact of increasing funding levels	30
	Conclusion	30
	Recommendation	31
4	Barriers to research	32
	Tissue collection and bio-banking	32
	Clinical trials	33
	Drug testing	34
	Research data	35
	The review process for research applications	35

Research workforce	36
Conclusion	39
Recommendations	39
5 Setting research priorities	41
Role of the voluntary sector	41
Identifying gaps	41
Government funding	43
NIHR themed calls	44
Conclusion	45
Recommendations	45
6 Burden of disease	46
The most fatal cancer in terms of life years lost	46
The biggest cancer-killer of children	46
The most dangerous location	48
“Benign” brain tumours	50
Number of people affected	51
Conclusion	53
Recommendations	53
7 Availability of non-therapeutic drugs	54
Conclusion	54
Recommendation	54
8 Conclusion	55
Conclusions and recommendations	57
Annex: Summary of informal meeting 17 November 2015	61
Formal Minutes	71
Witnesses	72
Published written evidence	73

Summary

Brain tumours are the biggest cancer killer of children and people under 40. In terms of the numbers of life years lost, it is the most fatal of all cancers. In spite of this, research into brain tumours has been underfunded for decades. As a result, survival rates for brain tumours - unlike those for many other cancers - have improved very little in the last thirty years. Those who do survive can suffer life-altering disabilities.

Brain tumour patients have been let down by a lack of leadership from successive governments. The Government's response to the petition which prompted this inquiry gave us little reason to believe that the Department for Health had grasped the seriousness of this issue. The Government's position seems to be that it has no role to play in identifying gaps in research funding for specific cancers and taking decisive action to provide funding where it is needed. The already-stretched voluntary sector is left to find and fill the gaps in research funding. In doing this, successive governments have failed brain tumour patients and their families for decades. The Government must now put this right.

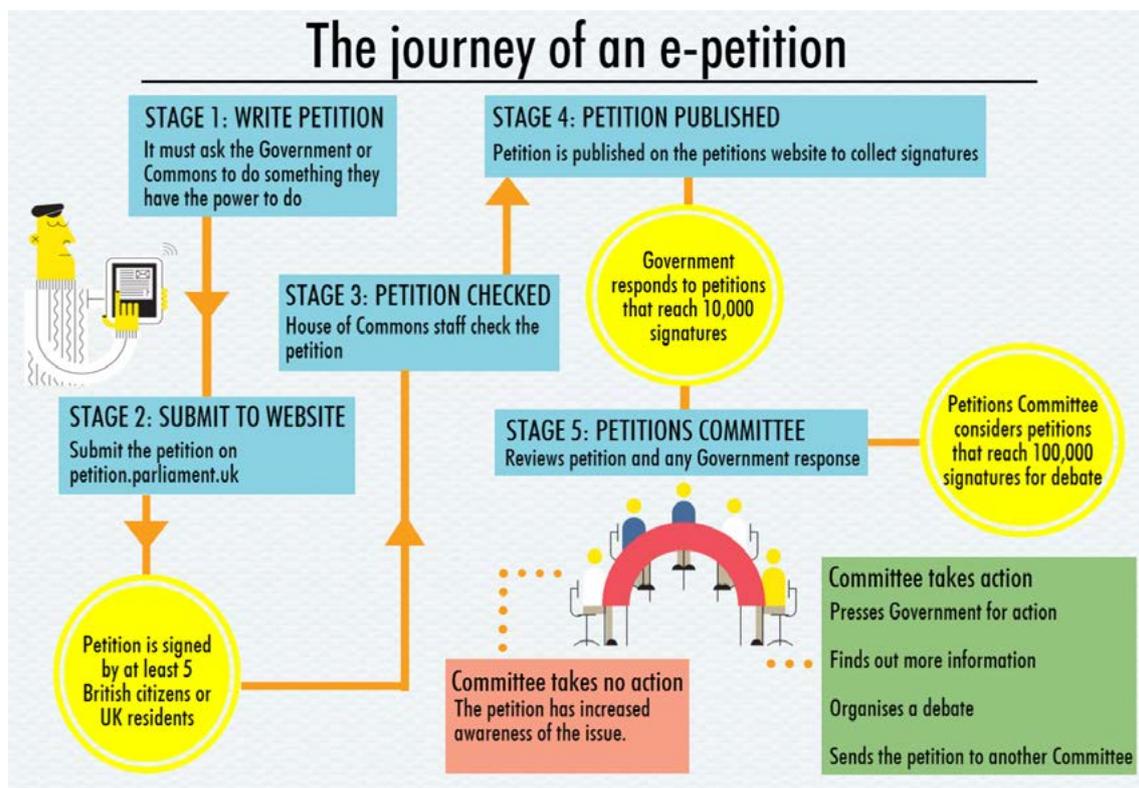
This is a public-led inquiry started by a petition which was signed by over 120,000 members of the public. The creator of the petition, Maria Lester, told us that she was "disappointed with the initial response from the Department of Health, which spoke not in terms of life and death in children but of criteria and process." The Committee hopes that the Government will respond to this report and its recommendations with a different approach.

1 Introduction

The Committee's inquiry

1. This is the first ever inquiry by the House of Commons Petitions Committee into a subject raised by an e-petition. The Committee was set up in July 2015 and has, from the outset, aimed to give the public a direct channel to call for action from the Government and Parliament. The Government responds to all petitions with 10,000 signatures. The Committee considers all petitions with over 100,000 signatures for debate. The Committee can also seek further information, in writing or in person, about the subject of a petition, and can produce reports like this one with recommendations to the Government.

Figure 1: The journey of your e-petition.



2. On 15 September 2015, the Committee considered an e-petition calling on the Government to fund more research into brain tumours. At that stage, the petition had just under 14,000 signatures and had received a response from the Government.

3. The Committee was surprised to see that, in spite of the excellent work done by the All Party Parliamentary Group on Brain Tumours, there had not been any recent debates on brain tumours. The Government's response to the petition did not give the Committee confidence that the Department for Health had grasped the seriousness of the concerns highlighted by the petition. The Committee therefore decided—having first consulted the Health Committee—to start its own inquiry.

4. Funding for brain tumour research is a hugely complex subject. The Committee decided that it needed to gather a wide range of evidence to allow it to make recommendations to the Government. In addition to formal evidence from relevant experts, the Committee also wanted to hear the experiences of members of the public whose lives had been affected by brain tumours. Many people have contributed their own stories to assist the Committee in its work. This report presents the evidence that the Committee has heard, and calls on the Government to look closely at that evidence and to reconsider its initial response to the petition.

The petition

5. The petition was started on petition.parliament.uk by Maria Lester (née Realf) on 3 August 2015. The petition reads:

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:

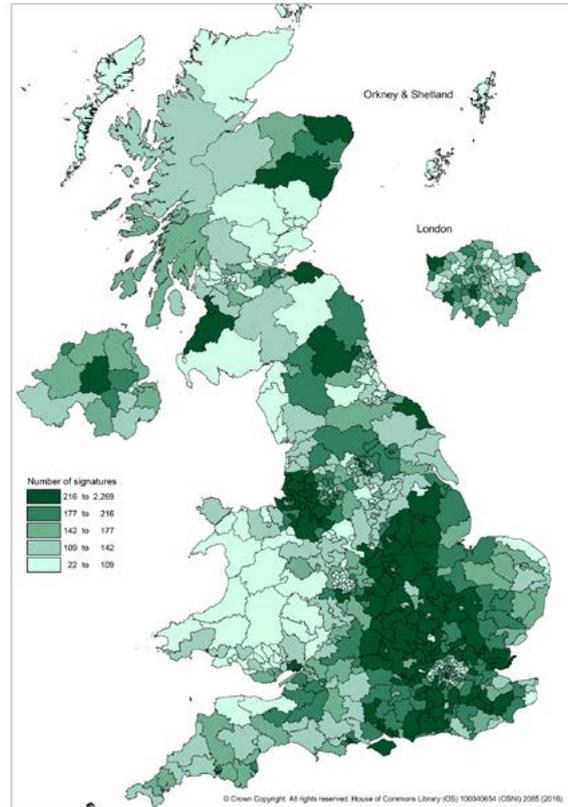
Unlike most cancers, brain cancer incidence is rising; less than 20% of those diagnosed with brain cancer survive beyond 5 years; in 2014, brain tumours received 1.5% (£7.7 million) of the £498 million national spend on research into cancer. At this rate, it could take 100 years to catch up with developments 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.¹

The petition closed on 3 February 2016 with 120,128 signatures. The image below shows a breakdown of signatures by Parliamentary constituency.

1 [Petition, Fund more research into brain tumours, the biggest cancer killer of under-40s](#)

Figure 2: Heat map of signatures to the petition by parliamentary constituency



The Government's response

6. The Government responded to the petition on 7 September 2015.² In its response, the Department for Health confirmed the statistics referred to in the petition: that brain tumour research received 1.5% of the national spend for cancer in 2014. The Government said that, if research relevant to all cancers was excluded from the figures, brain tumour research received 3.3% of the funding granted for 'site specific'³ cancer research. It explained that certain factors influence the level of research funding, including: scientific opportunity; the burden of disease; researchability; fundraising; and the quality and size of the research workforce. It concluded by saying that the Government-funded National Institute for Health Research (NIHR) welcomed all research applications and that its funding was not ring-fenced for cancer research.

2 The Government responds to all petitions which reach 10,000 signatures on [petition.parliament.uk](https://petition.parliament.uk/petitions/105560?reveal_response=yes#response-threshold). The Government response is published here: https://petition.parliament.uk/petitions/105560?reveal_response=yes#response-threshold

3 The site specific cancer categories are: Adrenocortical Cancer; Anal Cancer; Bladder Cancer; Bone Cancer; Brain Tumour; Breast Cancer; Cervical Cancer; Colon and Rectal Cancer; Ear Cancer; Endometrial Cancer; Eye Cancer; Gallbladder Cancer; Heart Cancer; Hodgkin's Disease; Kaposi's Sarcoma; Kidney Cancer; Laryngeal Cancer; Leukaemia; Liver Cancer; Lung Cancer; Melanoma; Myeloma; Nasal Cavity and Paranasal Sinus Cancer; Nervous system cancer; Neuroblastoma; Non-Hodgkin's Lymphoma; Oesophageal Cancer; Oral Cavity and Lip Cancer; Ovarian Cancer; Pancreatic Cancer; Parathyroid Cancer; Penile Cancer; Pharyngeal Cancer; Pituitary Tumour; Primary CNS Lymphoma; Prostate Cancer; Retinoblastoma; Salivary Gland Cancer; Sarcoma; Skin Cancer; Small Intestine Cancer; Stomach Cancer; Testicular Cancer; Thymoma, Malignant; Thyroid Cancer; Vaginal Cancer; Vascular System; Vulva Cancer.

The petitioners' story: the Realf family

Maria and her husband, Robert Lester, sister Kathryn and Stephen.



Peter and Elizabeth Realf with Maria and Stephen



Copyright: Realf Family pictures

7. This inquiry would never have happened without the hard work and determination of the Realf family, who started the petition. With the support of Brain Tumour Research, they have campaigned tirelessly to raise awareness and to press for action from the Government and Parliament. Losing a son and brother is a tragedy that no family should have to experience. The Realf family have chosen to devote their efforts to trying to ensure that other families do not have to suffer what they have gone through. We thank them for the evidence they have given to this inquiry.

8. We were profoundly moved by the story of Stephen Realf, as told to us by his sister and his parents. We present it here in their own words.

9. Maria Lester (née Realf), Stephen's sister, explained to us:

“I started this petition in August 2015, a year after my younger brother, Stephen Realf, was killed by brain cancer. Stephen was an incredibly fit young man who should have had a wonderful future ahead of him, but instead he was diagnosed with an incurable tumour at the age of 19 that eventually robbed him of his ability to walk, to speak, to eat and even to get out of bed. Brain cancer is an incredibly cruel disease that can attack in all kinds of ways, potentially ravaging not just a patient's physical abilities but also their memories and personality. My brother fought bravely for six and a half years with the support of a wonderful medical team, but he sadly died last summer aged just 26, and yet, hard as it is to say, he was supposedly one of the lucky ones. More than 80% of those diagnosed with brain cancer do not survive beyond five years.”

After Stephen's death, I contacted the charity, Brain Tumour Research, who opened my eyes to some shocking statistics. They told me that brain tumours are the biggest cancer killer of children and adults under 40, that around 16,000 people a year are diagnosed with a primary or secondary brain tumour and, unlike most cancers, brain tumour incidence is rising. It was 23% higher for men and 25% higher for women in 2012 than back in 1970. Just as shocking

were the statistics about the woeful lack of funding. They told me that last year brain tumours received just 1.5% 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.

Once I found out that brain tumours were the biggest cancer killer of children, I could not shake that thought from my head, so to mark the anniversary of Stephen's death, I told his story in *The Mail on Sunday's You Magazine* and set up this petition. I was very disappointed with the initial response from the Department of Health, which spoke not in terms of life and death in children, but of criteria and process.⁴

Stephen Realf



“Stephen was truly living his dream”

Ministry of Defence

10. Maria and Stephen's father, Peter Realf, wrote a moving account of their story on the Committee's web thread for this inquiry:

My daughter Maria Lester (née Realf) began the e-petition concerned about a lack of funding for brain tumour research, to mark the first anniversary of Stephen's death.

[...] At the age of 13 on a family holiday in the Lake District, Stephen saw several fast jets undertaking low flying sorties, and in that instant vowed to become an RAF pilot. Having established the level of academic achievement needed to be admitted to flying training, he set about his schoolwork with a quiet determination to achieve his goals. At the age of 17 years he was selected as aircrew and underwent the gruelling 32 week Officer training course, graduating as the second youngest Officer in the RAF at the time, aged 18 years old. A few months later he began his flying training, and loved every minute of it, going solo after 10 hours tuition, before he'd even passed his driving test.

Stephen was truly “living his dream”—flying by day, and enjoying the sports and banter that came with living in the Mess with young like-minded friends and colleagues.

All that changed in April 2008 when after a five month spell of having occasional “pins and needles” in his right arm he was finally given an MRI scan and diagnosed with a “benign” Grade 2 Astrocytoma. Overnight he lost his authority to fly, drive a car, and with it his independence. He was signed off work for two years and had to return home. Rapidly, it became clear he would most likely lose the career he had worked so hard to achieve, but what was not clear to us all at the time, was that he would lose his life too.

After diagnosis things moved quickly, and Stephen elected to have an awake craniotomy to give the neurosurgeon the best possible chance of removing as much of the tumour as possible and carry out cognitive tests during the operation, thus avoiding sensitive speech centres near the orange sized tumour in his left temporal lobe. Knowing nothing about brain tumours and the devastating impact they can have, we were very shocked when the neuro-surgeon announced “I’m afraid your tumour will re-grow, turn more aggressive, and will kill you” at a post-operative meeting. At the age of 19 our bright, funny, amazing young man was being told he had 5 to 7 years to live. How could this be? No hope? Surely the talented Doctors and Surgeons at this top teaching hospital could do something to change this prognosis? No - they couldn’t!

What caused Stephen to have the tumour? We don’t know, as the cause of brain tumour growth is unknown? Surely in the 21st Century this can’t be so? Sadly it is.

If as a society we know so little about brain tumours, how much research is being done to find a cure, improve survival rates and relieve the suffering? My research since Stephen’s diagnosis indicates nowhere near enough!

After less than two years, the 20% of Stephen’s tumour impossible to remove during his neuro-surgery started re-growing. Once again, the family were devastated and Stephen was left to dwell on his future—or lack of it.

Six weeks of radiotherapy were scheduled, followed by weeks of chemotherapy his body couldn’t tolerate, meaning on each of the three occasions chemotherapy was begun, the prescribed course of treatment had to be abandoned after 3 or 4 doses. Having lost his hair, and an interest in food, it was truly heart-breaking to see my young, previously fit son who could run 12 miles with a military Bergen on his back, now being unable to struggle the ten feet from our bathroom to his bedroom.

I was immensely proud of how, despite all that was thrown at him, Stephen kept his smile through each new setback—I don’t know how he did it. Nevertheless, this cruel disease robbed him of his life, and he passed away in August 2014, having just turned 26. He left behind a large circle of family and friends deeply affected by what they had witnessed happening to him. Stephen seemed to touch those medical professionals who worked with him too, and we are grateful to so many of them for the care and sympathetic consideration they showed him. How hard must it be to tell a patient we have run out of options and there is nothing more we can do for you? I’d like to record my thanks to

them here. That is Stephen's story, but [...], sadly and unacceptably, our family's tragedy is far from unique. [...]

The nature of this disease that strikes at the very part of the body that makes us all the individuals we are is hugely devastating. How much longer is the Government going to allow it to be so woefully underfunded? The larger Cancer charities too have a role to play here, but Government cannot allow this situation to continue where survival rates for brain cancers remain largely unchanged during the last 40 years. More funding is required for research, and it is needed now.⁵

Brain Tumour Research

Realf family with Sue Farrington Smith



Copyright: Realf family

11. The Realf family have worked closely with the charity Brain Tumour Research. Sue Farrington Smith, Chief Executive of the charity, shared the moving story of her young niece, Alison Phelan, whose death motivated her to dedicate her work to campaigning. Sue wrote:

In June 2001, I lost my beloved niece Alison Phelan to a brain tumour - three weeks before her eighth birthday. My sister, her husband, Ali's brothers and the rest of our family and friends were shocked and horrified to discover how little funding there was for research into brain tumours. Brain tumours kill more children and adults under the age of 40 than any other cancer yet until very recently less than 1% of the national spend on cancer has been allocated

5 [Peter Realf web thread comment: 30 October 30 2015 at 05:17 PM](#)

to this devastating disease. A disease that took Ali away from us and the countless other families that we have met along the way. Families who have lost children, children who have lost parents. Grandparents whose children and grandchildren should not have gone before them. Many of those people who survive live with side effects that often mean they cannot work and members of their family have to give up work to care for them. I now run the national charity Brain Tumour Research - we are striving to fund a network of seven dedicated research centres whilst challenging the government and larger cancer charities to invest more in brain tumour research. [...]⁶

The public stories

12. As well as hearing from charities, clinicians and research bodies, we wanted to hear from members of the public who, like the Realf family, had personal experience of brain tumours. We believe that the impact of brain tumours on individuals and families is so devastating that it ought to be given greater consideration. With this in mind, we opened a web comment thread and invited people to share their thoughts and experiences. In just ten days we received 1106 posts.⁷

13. We were struck by the number of incredibly moving stories it received in a short space of time. We were deeply touched by people's willingness to share profoundly tragic and painful stories, in order to help with our inquiry. We read messages from people with brain tumours struggling with treatments and devastating prognoses; from people who had lost children, partners, family members and friends; and those currently supporting a loved one with a brain tumour. It also heard from some brain tumour researchers, doctors and others who work closely with brain tumour patients and their families.

14. Most had, like the Realf family, been shocked at the funding levels for brain tumour research. They also shared the Realf family's motivation of wanting to help prevent others from suffering in the future. We are enormously grateful to everyone who commented for the important contribution that they have made to this report. The full thread is available to read on the Committee's website.⁸

15. Many of the contributions to the web thread echoed the experiences of the Realf family. Talking about the thread, Peter Realf commented:

[...] as you can read in over 1,000 entries on your Website, sadly and unacceptably, our families tragedy is far from unique. It is unlikely that anyone reading those stories could fail to be moved by all that has been shared with the Committee, and my hope is that it will fire up a determination in all concerned that this situation must be improved and quickly.⁹

16. We were indeed struck by the common themes in many of the stories shared: difficulties and delays in getting a diagnosis; lack of treatment options; poor survival rates and the huge burden of the disease on patients and their families. Jackie Caffyn, for

6 [Sue Farrington Smith web thread comment: 20 October 2015 at 17:36](#)

7 [Petitions Committee web comment thread](#)

8 [Petitions Committee web comment thread: 29 October 2015 at 15:34](#)

9 [Peter Realf web comment thread: 30 October 2015 at 17:16](#)

example, tragically lost her brother and then her husband to brain tumours. She explained how they had both struggled to receive the right diagnosis:

I lost my 18 year old brother to a brain tumour over 30 years ago, by the time he was diagnosed it was too late for him. In 2007 my husband had similar symptoms to my brother, I took him to the Doctor, she said it was a bug, I even asked her if it could be a brain tumour; she wouldn't listen. 2 weeks later he died aged 41. So yes, a brain tumour has affected my life, it's devastating to watch someone you love suffer & die & then to have to bring your children up without their dad.¹⁰

Susan Castle-Smith from Brain Tumour Research works closely with patients and their families. She described her experience:

As a PR manager for the charity Brain Tumour Research I have spent the last 12 months working with brain tumour patients and their families, helping them to tell their stories in order to raise awareness of this dreadful disease. One of the most surprising things has been the sheer mix of people who find themselves hearing the dreadful words: "It's a brain tumour." Among others, I have written the stories of a three-month-old baby who was lost just days after diagnosis, a grandma who should be here today enjoying a long and happy retirement, a woman who lost BOTH parents to glioblastoma multiforme (GBM), a young Oxbridge graduate with the brightest of futures who struggled to tell his family of his diagnosis, an emergency services worker who watched, distraught and helpless, as his father died, a gifted composer and virtuoso pianist who passed away, and a young woman who defied the odds to become pregnant during treatment and passed away when her baby was just six months old. Most of these people are strangers yet they tell me the most intimate details of their lives. I cry tears with them. I admire their family photos. I marvel at their courage. I fear for their wellbeing as they struggle with their grief. I wonder who will be next. They are in my thoughts, my dreams sometimes. It is hard to explain to them why so little investment has been made into this hideous disease; it is something I can't understand.¹¹

Heather D described how her son was diagnosed with a brain tumour when he was 5 years old. She explained that, although he is now in remission, her son's life has been severely impacted as a result of his tumour. She wrote:

My son was diagnosed with a Grade III Anaplastic Ependymoma in 2009, aged 5. It took months to get a diagnoses despite multiple visits to his GP, an overnight stay in our local children's hospital (having been rushed in by ambulance) and two visits to out of hour's surgeries. He was SO ill and had classic symptoms but none of these doctors recognised any of them. Finally, four months after his initial symptoms appeared I marched into A&E with him and demanded answers. Within two hours, we had our answer. By this point his tumour was 9cm wide. He had two surgeries and proton beam therapy completing his treatment in May 2010. He's been in remission ever since which I am truly grateful for every day. This all sounds quite easy but the reality is

10 [Jackie Caffyn web comment thread: 29 October 2015 at 15:34](#)

11 [Susan Castle-Smith web content thread: 29 October 2015 at 11:32](#)

it was far from an easy journey. I am fully aware that he's one of the lucky ones but despite being in remission he does have many long term side effects and last year had to attend over 60 medical appointments. He has numerous hormone deficiencies which affect his everyday life. He suffers from chronic fatigue, anxiety, sleep issues, severe unilateral hearing loss, speech difficulties, coordination, and balance issues. He's gone from being a very bright boy [...] to having learning difficulties due to memory problems, hearing loss and development of both ADD and a form of epilepsy. The latest blow we've received is that his optic nerve is now showing signs of damage. I often wonder if his doctors had been more aware and caught this sooner, would the list of side effects be so long. Had the tumour been smaller then surely the extent of the brain injury would have been less? So little is known about brain tumours that if (God forbid) he does relapse, there is literally nothing that could be done apart from more surgery and palliative care chemotherapy. I must say it's extremely disheartening to constantly see the level of campaigning and fundraising that goes on for other cancers when so little consideration is given to brain tumours, the biggest cancer killer of our children and those under 40.¹²

Janet Plowman shared her family's painful story of losing her son and described the effect of the limited treatment available for brain tumour patients. She wrote:

I lost my 34 year old son to a brain tumour this year. He was treated by his GP for migraines for 6 months. The pain became so debilitating he went to A&E. This led to an emergency operation to relieve the pressure and a diagnosis of inoperable Stage 4 Glioblastoma multiform. Prior to this he was a fit and active healthy man. We were told that his type of tumour was unlikely to metastasise. Yet despite this, the only treatment available was to include chemo which was going to have little, if no effect on the tumour but would purge his whole body and eventually kill him. His death certificate placed Brain Cancer as the fourth cause of death, after Diabetes, Sepsis and major organ failure, all caused by drugs. It's too late for my Son, leaving my beautiful 3yr old Granddaughter and my amazingly brave Daughter-in-Law without a Daddy and Husband. He has left a huge whole in our lives and hearts. There desperately needs to be more research done into effective treatments for Brain Cancer, treatments that will cross the blood barrier. Less aggressive treatments that are available in other countries should be researched. So many young people are dying because they are not being offered any alternative treatments.¹³

Toni Bagshaw's comment summed up many of the key frustrations expressed by people on the web thread:

Any family pounced upon by this deadly silent killer GMB 4 knows life expectancy is poor. A lack of research into this disease and the fact that cures, treatment and survival rates for most other cancers are prevalent and published regularly in the media. Why are brain tumours given low priority by the government? When a person young or old is diagnosed with GMB 4 it is always a death sentence and the journey for family is traumatic and devastating. The standard radio, chemo and removal of tumour treatment is

12 [Heather D web comment thread 29 October 2015 at 10:54](#)

13 [Janet Plowman web comment thread 28 October 2015 at 13:28](#)

not enough to ensure survival. On a positive the oncology staff within the NHS are fantastic. I am sure the NHS staff feel aggrieved too with the lack of brain tumour research. Brain tumours are NOT rare in adults or children, it isn't connected to negative lifestyle factors, as oppose to liver disease/cancer (often alcohol related) however I am sure in this type of research and treatment is moving quicker.¹⁴

Meeting the people behind the stories

Discussion event in the House of Commons



Copyright: Parliamentary copyright

17. Following the comment thread on our website, we invited some of those who had shared their stories to take part in an informal round table discussion at the Houses of Parliament. People shared with us their personal experiences of living with a brain tumour or caring for loved ones with the disease. A full summary of the informal discussion and the list of those we spoke to can be found in the [annex to this report](#).

18. Those the Committee met included Anna Swabey, who was diagnosed with a terminal brain tumour in January 2015 at the age of just 23. Anna told us about her experience and explained how she had started to write her own blog, *Inside my Head*, partly to help others but also partly to help herself release some of her feelings by writing them down.¹⁵ Tom Greenway's son had died at the age of 28 from a medulloblastoma, just a few months before he met the Committee. Mr Greenway shared his son's story of late diagnosis and his subsequent treatment which had initially appeared successful. Caroline Critchlow travelled down from Orkney to share her experience with us. Caroline explained how her husband had been diagnosed with a brain tumour. She described how she had been struck by the conditions in her local neuro-ward in Aberdeen where her husband was treated. She subsequently started a charity which had raised £130,000 to help refurbish the ward. Although she supported more funding for research, Caroline was passionate

14 [Toni Bagshaw web comment thread 29 October 2015 at 15:25](#)

15 [Anna Swabey blog *Inside my Head*](#)

that something should be done for those currently suffering. When talking about the underfunding of her local ward, she said “this underfunding we found is reflected in anything to do with brain tumours”.¹⁶ Julia Manning told us how many considered her to be ‘lucky’ because her tumour was “benign”. She described the devastation that she and her family had felt after doctors explained that her tumour was inoperable and growing. She argued that “it was a case of quality not quantity of life”.¹⁷

19. We heard in detail the problems with diagnosis, treatment, care, support, awareness and funding for research. Although everyone we spoke to focussed on the need for more research funding, the key message was that “at every stage it fails”. The whole process of having a brain tumour was described as “one big fight”: fighting for diagnosis, for treatment, for support, awareness and funding whilst also fighting for life. We heard that patients had little choice in the treatments available once they had been diagnosed.

20. Rachael Mason, whose son had 18 months of chemotherapy for a tectal plate glioma, described the treatment protocols as “barbaric.” Hannah Jones, who was diagnosed with a brain tumour at the age of 15, told us that doctors simply hadn’t developed protocols for how to treat brain tumour patients because they were considered so rare.¹⁸

21. We heard how the discovery of the funding levels for research often dealt a final blow for people who are left with little hope for possible near-future improvements. This was echoed by Maria Lester, who told the Committee:

“[...] less than 20% of those diagnosed with a brain tumour survive beyond five years, so I just think how frightening it must be to know that you have something like that and that the odds are very much stacked against you, that you are even going to be around for another five years. That lack of hope was something that came through for me on the web thread, you have all these people and the medical community would love to be able to help and treat these people and people are desperate for a cure, but at the minute we just need more funding.”¹⁹

22. No one who we met wanted money to be taken away from other cancers. They did, however, want brain tumours to be treated as seriously as other cancers and given more resources. They told us that, while survival rates for many other cancers were getting much better with improvements in awareness, diagnosis, treatment and prevention, those with brain tumours were left behind with little or no hope for the future.

23. We were deeply moved by the courage and strength of everyone we met and we would like to record our thanks to them.

16 [Caroline Critchlow web comment thread 27 October 2015 at 08:55](#)

17 [Julia Manning web comment thread 29 October 2015 at 15:56](#)

18 Annex: summary of informal round table 17 November 2016

19 Q8

2 Awareness and diagnosis

Late diagnosis

24. We heard that early diagnosis of brain tumours was difficult and that people with brain tumours were often initially misdiagnosed. A recent study by the Cancer Intelligence Research Network found that 61% of brain tumour patients were diagnosed in A&E²⁰—one of the highest emergency presentation rates of all cancers. Emma Greenwood, Head of Policy Development at Cancer Research UK, told us:

If you look at the proportion of people that tend to get diagnosed in A&E, which usually means they are at quite a late stage—they might have been to their GP a number of times or other healthcare professionals—it is disproportionately high in brain.²¹

25. A large number of the comments on the web thread described some of the difficulties people had faced in receiving a diagnosis. The symptoms described included: headaches, fits, dizziness and back pain, hiccups, numb fingers, flu-like symptoms, a ‘funny smell’ and déjà vu. The range of initial misdiagnoses was equally varied—from stress, depression and hormone problems to epilepsy, poor eyesight and vertigo. When talking about the Committee’s web thread responses, Elizabeth Realf commented that:

[...] nearly all had the same story, of misdiagnosis. Some people were treated with migraines for years, some people were treated with depression for years. I read one that the gentleman, his wife had had a baby four weeks before, and he was told it was post-birth stress. Where they dreamt that one up, I do not know, but there is that common theme, a diagnosis sometimes takes years and it is not until something drastic happens that the tumour is found.²²

Scans

26. Clinicians told us that the only way to confirm that someone has a brain tumour is by doing a scan.²³ We heard how people often struggled to get a scan. Vicky Ringer for example shared her experience with us:

My little boy Levi tragically died of a brain tumour, aged just 6 years old. He was diagnosed after his symptoms were missed by a consultant paediatrician. Levi was in fact diagnosed when WE demanded a CT scan, frustrated and concerned that although we were repeating ourselves, we weren’t being heard. The scan revealed the devastating news that Levi had a brain tumour on his brain stem and cerebellum. We had been irreversibly let down by a hospital system and staff who lacked awareness about brain tumours. We had been told several times there was ‘nothing to be worried about’ previous to Levi’s diagnosis—this could not have been further from the truth. Levi died in my

20 [National Cancer Intelligence Network, Routes to Diagnosis 2006-2013 workbook](#)

21 Q46

22 Q7

23 Q63

arms just 6 weeks after diagnosis, devastating the lives of his family beyond words or repair.²⁴

27. We received a petition on petition.parliament.uk on this issue during our inquiry. The petition was started by Antonella Goulding whose daughter Lucy died tragically aged 16 after her brain tumour failed to be diagnosed. Her petition calls for “Urgent brain tumour scans, education for the public and health professionals.” It reads:

At only 16, my daughter, Lucy Goulding tragically lost her life. Lucy died through lack of knowledge of brain tumours among health professionals and also myself. Lucy died due to an undiagnosed raised intracranial pressure (accumulation of fluid in the brain) due to the most benign brain tumour.

Although being a rare cancer, the mortality rate due to brain tumours has increased over the past 13 years and kills more children than leukaemia or any other cancer. There is frequently reluctance among healthcare professionals to undertake a scan of children who may have a brain tumour until clinical signs become apparent—one of the reasons being that the initial symptoms of a brain tumour frequently mimic those that occur with many common childhood conditions. So referral time is critical.²⁵

28. Like the Realf family, Mrs Goulding started her petition motivated to help prevent others from going through the same tragedy she did. In her own words, Mrs Goulding shares her story in more detail:

Lucy Goulding



“Lucy Goulding was an amazingly talented, strong and determined 16 year old ...

Copyright: Antonella Goulding

who tragically died of an undiagnosed raised intracranial pressure due to a cystic astrocytoma, a most benign brain tumour but also the most common amongst young people.

Lucy was absolutely determined to achieve straight A's in her GCSE's and her strength and determination was truly tested in April 2013. This is when Lucy

24 [Vicky Ringer web comment thread 30 October 2015 at 14:04](#)

25 [Petition by Antonella Goulding](#)

started complaining of headaches and started taking painkillers on a daily basis, whilst bravely carrying on her revision and school work.

From 27th May 2013, Lucy attended four consultations with her GP. The doctor thought that Lucy was suffering from 'tension' type headaches due to the stress of her exams.

The last emergency appointment was held on 25th June. In the morning Lucy had started vomiting. I rang Worthing Hospital and asked if I could take my daughter to A & E to have an emergency scan, but I was told that I had to go through my GP, despite the fact that Lucy had already seen the GP on three previous occasions and despite the fact of how ill she had become. At this GP appointment, Lucy needed to be aided as she could not stand up straight and all she could do was to lay on my lap with her eyes shut. During her consultation, Lucy's vomiting continued. At this last consultation with the GP, a scan was refused as Lucy did not present enough evidence of a tumour.

On Wednesday 26th June, Lucy's condition continued to deteriorate and she was taken to Paediatric A&E at Worthing Hospital by ambulance at around 2pm. Lucy was suffering from constant headache and intermittently she would shout out that her head hurt. At this point, Lucy would become hot and clammy, then cold and then she would start shivering but without feeling cold or having a temperature. Neither the paramedic, who had been monitoring Lucy at home for two hours, or any doctor at the hospital could give me an explanation for these symptoms—Lucy was suffering from hydrocephalic attacks (A build-up of pressure on the brain).

Later the same afternoon, Wednesday 26th June, the doctors wanted to discharge Lucy to my care at home as she had nothing 'clinically' wrong with her. Seeing how Lucy seemed to be fading away and witnessing her pain, what the doctors said, made no sense to me—but no one recognised this important fact. Due to my insistence that Lucy was seriously ill, as I could see no changes to her symptoms, Lucy was finally admitted to Bluefin Ward at Worthing Hospital, where she continued to deteriorate. Her severe pain and suffering was not acknowledged or questioned by any of the doctors and despite showing clear signs of raised intracranial pressure, no neurological examinations were carried out.

On Thursday 27th June, just before 3am, holding my hand, Lucy suffered a massive seizure. This is when her brain stem collapsed. She stopped breathing, went into a coma and had to be rushed by ambulance to Southampton General Hospital. By the time she arrived at Southampton General Hospital, it was 8am and despite the Neurosurgeon's best efforts to drain the fluid that had accumulated in her brain and to remove her tumour (the most benign tumour), Lucy did not recover and the life support machine was switched off at 9pm that evening the day before her Prom.

Lucy would not have suffered her terrible ordeal and she would not have died if the health professionals in charge of her care were able to recognise symptoms

of brain tumours and raised intracranial pressure. Lucy most certainly would not have died if I, her mother, would have known the signs of brain tumours.²⁶

Awareness

29. With scans being the only way to diagnose a brain tumour, we asked about the challenges faced by GPs and other healthcare professionals in deciding when a referral for a scan should be made. Professor Garth Cruickshank, Professor of Neurosurgery at the University Hospitals Birmingham NHS Foundation Trust, explained some of the issues involved:

The frightening figure [...] is 60 to 70% are having their diagnosis through A&E [...]. That implies that there is something going wrong in the system, if you think they may have been to see their GP several times beforehand. [...] the GP is not recognising there is a problem, but the family and the patients certainly are. This is a very difficult issue. It is to do with perhaps the changes in the way that primary care works, the fact that patients often see several different doctors. I think it is also to do with the fact that symptoms are quite difficult as well. For example, the idea that all people with a brain tumour would have a headache is wrong; we know that only about 40% of them do. They may have a range of other odd symptoms that are often difficult to pick out. If you see a patient and you say, "I do not know what is going on here. Come back in two weeks' time" in a cycle or in a process in which six weeks is critical between whether you can treat them and you cannot treat them, two weeks lost is another nail in the coffin [...].²⁷

30. We heard that brain tumours were relatively rare and that most GPs would typically only ever see two or three cases during their careers. Sarah Mee, Head of Policy and Campaigns, at the Brain Tumour Charity explained: "It is a relatively less common tumour type, so most GPs might not necessarily see that many brain tumours during the course of their careers."²⁸ Professor Cruickshank told the Committee: "I have a lot of sympathy for general practice, among all the other things they have to deal with, picking out these cases that are relatively rare."²⁹ Elizabeth Realf told the Committee how apologetic the first medical officer Stephen had seen was, once he was diagnosed with a brain tumour. He had explained to her that he "had never come across anything like that in all his years."³⁰

The Be Clear on Cancer campaign

31. We heard that some people were frustrated by the Government's omission of brain tumours from its national campaign to raise awareness of cancer symptoms called *Be Clear on Cancer*. Sacha Langton-Gilks, whose son died of a brain tumour at just 16 years old, explained her frustration on the Committee's web thread:

My 16 year-old-son died of the commonest cancerous brain tumour in children. At his death he was suffering with the mobility issues & pain associated with

26 Antonella Goulding [Lucy's Story and symptoms of brain tumours](#)

27 Q63

28 Q47

29 Q63

30 Q8

spinal tumours and severe dementia. I was appalled to discover that brain tumours are the biggest killer as a disease in the UK between the ages of 2 & 24, but that the amount of money going into research is negligible compared to other cancers. Children and young people are doubly hit because they have also been excluded from the government's "Be Clear on Cancer Campaign", which would raise awareness throughout all the NHS & PHE affiliated pathways and websites, because inclusion is judged solely on the criterion of numbers affected. Clearly cancer is rarer in children & young people than in the elderly, but to exclude them when the UK has a slower diagnosis time for brain tumours than similar countries seems incredible.³¹

32. In answer to a Parliamentary Question from Mr Roger Godsiff MP, asking why brain tumours were not included in the *Be Clear on Cancer* campaign, the Government said: "A number of factors are taken into account when deciding which campaigns to develop and run, with one of the main criteria being the number of deaths that could be avoided through earlier diagnosis. The focus for national campaigns so far has therefore been on lung, breast (in women over 70), bowel, kidney and bladder, and oesophago-gastric cancers."³² These national campaigns have shown success in improving survival rates and raising awareness amongst the public.³³

33. The emphasis by the Government on the number of avoidable deaths in deciding on the focus for its national awareness campaigns puts rarer cancers at an instant disadvantage. We are concerned that the high proportion of children and young people affected by brain tumours, and the number of life years lost, is not taken into account. This, as Ms Langton-Gilks explained above, means that children and young people will always be at the bottom of the list because cancer is rarer in young people. Being young and seemingly fit could in fact, as was the experience of Stephen Realf, mean that GPs and healthcare professionals are less likely to think that there is a serious problem. Elizabeth Realf told us that, after his first seizure, Stephen went to A&E and that, despite being kept in overnight, he did not have a scan. She explained: "Nothing was done. He was just sent home, told he was probably dehydrated. They could not understand why a fit young man would pass out [...]."³⁴

34. Clinicians explained to us that the guidance for GPs about when they should refer patients for a scan needed to be clearer. They also explained that the cost of scanning patients needed to be carefully considered. Professor Cruickshank told the Committee:

There is an initiative [...] from Suspected Cancer³⁵ in which we say, "Right, we are prepared to have 5% normal scans, as opposed to only 3%" so that is a step in the right direction. But we are still left with this area of uncertainty for the GPs as to who and when they should get a scan. The way forward is for us to try to come up with a way of dealing with this that is more straightforward and simple for them. The Suspected Cancer guidelines are two sides of A4; it is too long when you are a GP. We need things that are quite simple and straightforward, like in someone who is 50 years old, "Is this the first headache

31 Sacha Langton-Gilks [web comment thread 21 October 2015 at 11:28](#)

32 [Written Question 225785](#) asked by Mr Rodger Godsiff MP on 27 February 2015

33 See for example: [Public Health England *Be clear on cancer: campaign continues March 2015*](#) and [Cancer Research UK](#)

34 Q2

35 National Institute for Health and Care Excellence (NICE) [Suspected Cancer Guidelines](#)

you have ever had? If it is, then you should probably get a scan.” “Is this different from your normal headaches?” “Yes, it is.” “Then maybe you should get a scan.” “Do you have more than one symptom that could be attributed to the CNS [central nervous system]? Then you should have a scan.” That means we are going to scan quite a lot of people and that is going to cost a lot of money. That is going to eat into the £25 million that has been ascribed for diagnostic purposes for Suspected Cancer and we have to think whether that is the best thing for us to be able to do. [...] But unfortunately, until you have a scan, we do not know what you have, and that is the truth of it.³⁶

The Head Smart campaign

35. We heard about the excellent work of the Head Smart campaign which aims to increase GP awareness of brain tumour symptoms in children and young people.³⁷ The guidance breaks down the symptoms into three age groups: the under 5s (pre-school); children aged 5-11 years; and young people aged 12-18 years.³⁸ The Committee heard that the campaign had been showing signs of success in reducing the time taken for diagnosis. Sara Mee from the Brain Tumour Charity explained that the campaign “has been really successful so far [...] before its launch in 2011 diagnosis times were more than 12 weeks and that has subsequently dropped to less than seven.”³⁹

36. The Committee was concerned, however, to hear that the 2015 updated National Institute for Health and Care Excellence (NICE) guidelines (designed to help GPs with recognition and referral of suspected cancer) did not contain the same specific lists of symptoms associated with the three age groups. Sara Mee from the Brain Tumour Charity explained these concerns to the Committee:

“[...] all of the detail [...] on which symptoms should trigger a referral for brain tumours in children has been lost [...] we are [...] concerned about the potential conflict between the HeadSmart guideline, which is NICE accredited and endorsed by the Royal College of Paediatrics and Child Health, and the latest version of the referral for suspected cancer guidelines.”⁴⁰

Early diagnosis: impact

Survival rates

37. We heard that earlier diagnosis could increase survival rates for patients with brain tumours, especially children. Referring to the high numbers of children diagnosed in A&E, research included in the HeadSmart Campaign states that the “risk of peri-operative morbidity [death related to surgery] is increased in children who present as an emergency.”⁴¹

36 Q63

37 [“The HeadSmart campaign](#) is run by a partnership between the Children’s Brain Tumour Research Centre (CBTRC) at the University of Nottingham, the Royal College of Paediatrics and Child Health (RCPCH) and The Brain Tumour Charity (formerly Samantha Dickson Brain Tumour Trust), and has been funded by The Health Foundation and The Brain Tumour Charity.”

38 [The HeadSmart campaign](#)

39 Q46

40 Q46

41 HeadSmart, [Research on diagnosing brain tumours](#)

38. Professor Cruickshank told the Committee that a study looking at the benefits to patients from current treatment suggests that earlier diagnosis could have a positive impact on survival:

There is a very recent NCIN [National Cancer Intelligence Network] paper published by one of my colleagues, Andy Brodbelt, and he has shown, looking at 10,000 patients over the last 10 years or so, that if you do diagnose them, treat them with surgery, radiotherapy, chemotherapy to the standards that we use at the moment, virtually all the patients through all age groups get benefit from it.⁴² That means that there is probably an element of lead bias in that [...] and it is worthwhile doing this.⁴³

Quality of life

39. We heard that early diagnosis could have a significant impact on the quality of life of brain tumour patients, especially children and young people. The HeadSmart Campaign states that the development of additional symptoms and signs during the period between when a patient first experiences symptoms to when they are diagnosed shows “progressive neurological damage due to either the direct effects of the tumour on the brain or raised intracranial pressure” and that “many children with brain tumours have life-long visual impairment, cognitive deficits and endocrinopathies”. It concludes that “[r]educing the symptom interval experienced by children diagnosed with a brain tumour should reduce the long term disability they experience.”⁴⁴

40. Jane Muir described on the web thread how her son’s quality of life could have been improved through earlier diagnosis:

My son was diagnosed with an inoperable astrocytoma aged 11. By the time he was diagnosed he was a very unwell child and had lost considerable vision. Aged 25, he now, in addition, suffers from epilepsy. Prior to diagnosis my instinct was that something was seriously wrong, however to my eternal regret, I felt I couldn’t challenge those in the medical profession. Had I done so, my son’s eyesight might have been less impaired.⁴⁵

Research

41. We heard that earlier diagnosis could also improve the opportunities for research because it would increase the availability of tissue samples from earlier stages of the disease and enable a larger number of brain tumour patients to take part in clinical trials. We heard that patients who were diagnosed late, with little time left to live, were rarely able to take part in trials. Emma Greenwood from Cancer Research UK told the Committee:

Sadly, especially if you think about new treatments, one of the challenges is if you are diagnosing quite a lot of people quite late, and we have heard already about some of those shocking statistics about how many people do not even

42 European Journal of Cancer 2015 5:(4):533-42 Glioblastoma in England: 2007-2011

43 Q64

44 HeadSmart, [Research on diagnosing brain tumours](#)

45 Jane Muir [web comment thread 29 October 2015 at 19:54](#)

survive a year, then getting those people into clinical trials to develop new treatments, you can see that it is a kind of cyclical challenge.⁴⁶

42. We also heard that greater awareness in general could help increase public donations to brain tumour research charities. We discuss this later on in the chapter on setting research priorities.

Funding priorities

43. Throughout our inquiry we have heard that brain tumours fail at every hurdle. Diagnosis is the first hurdle for brain tumour patients and it is clear from our evidence that they are being seriously disadvantaged from the outset. The Government has the ability to influence what messages are sent to GPs and healthcare professionals and what national awareness campaigns are launched. Without leadership from the Government, charities in the sector who are working with limited funds are forced to make difficult decisions about where to spend their money. Neil Meemaduma, Research Grants Manager from Children with Cancer told us:

Diagnosis is definitely a problem. It is partly because these cancer types are so rare and it is particularly difficult for the diagnosis of children as well. As we heard, the symptoms can be misinterpreted, so it is tough. What is difficult is for a charity to invest in those diagnostics and treatments and also invest in the basic research that underpins these cancer types. It is often a real problem having this balancing act between we do need to drive forward the fundamental basic research in this area and we also need to have better treatments.⁴⁷

Sue Farrington Smith from Brain Tumour Research explained why it had decided to focus its efforts on research rather than diagnosis:

Anybody that would have read the web thread will see that most of the stories are about late diagnosis. However, I know in 2006 when we campaigned for temozolomide to be available on the NHS that was about extending life by four months. At the moment you can be diagnosed with a brain tumour, but there is still not the cure at the other end of it for those that get the most aggressive form. That is where we have to spend our money: what can we do once somebody has been diagnosed with it.⁴⁸

44. Maria Lester told us that “[...] awareness has to go hand in hand with [...] research into possible treatments [and] possible cures, because otherwise, if you know earlier but the end result is the same, it is ultimately a longer walk to the grave [...]”.⁴⁹

Conclusion

45. A number of measures are needed to address the needs of brain tumour patients. The first step should be to increase the awareness of brain tumours and to increase the numbers of tumours diagnosed early. It is clear that brain tumour patients are being failed repeatedly.

46 Q56

47 Q46

48 Q46

49 Q16

46. Earlier diagnosis could improve survival rates and improve patients' quality of life. Earlier diagnosis could also help to increase the numbers of patients able to take part in clinical trials as well as the diversity of tissue samples available for researchers. Moreover, it would clearly be less distressing for patients and their families if they could be diagnosed before their symptoms become so severe that they present at Accident and Emergency.

47. Earlier diagnosis will rely to a large extent on increasing awareness amongst GPs and other front line healthcare professionals about the symptoms of brain tumours. The Committee was impressed by the HeadSmart campaign which shows how guidance can have such a positive impact in a relatively short space of time without over burdening GPs.

Recommendation

48. *The Government should provide greater leadership and support to raise awareness of brain tumours amongst GPs and other healthcare professionals in order to increase earlier diagnosis of brain tumours. It should:*

- *consider the evidence in this report about the differences between the HeadSmart guidance for GPs and the recently updated National Institute for Health and Care Excellence (NICE) guidelines for the recognition of and referral for suspected cancer in children, young people and adults, and ensure that NICE reconsiders its guidelines.*
- *work with professional bodies and Clinical Commissioning Groups to ensure that GPs and other health care professionals receive appropriate training, perhaps as part of their Continuing Professional Development, on the symptoms of brain tumours.*
- *take urgent steps to raise general awareness of brain tumours—either as part of the Be Clear on Cancer Campaign, or as part of other public health awareness initiatives.*

3 Funding levels

How much is currently spent?

49. In its response to the petition the Government said:

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.⁵⁰

50. The most comprehensive source of data for research spending on different types of cancer is the Cancer Research Database which is produced and managed by the National Cancer Research Institute (NCRI). It contains research funding information from all of its partner organisations.⁵¹ The NCRI told the Committee that research funded by NCRI partners had remained around £500 million since 2009 and that in 2014, approximately £498 million of research was funded by NCRI partners.⁵²

51. The amount of research funding can be divided into “non-site specific research” which includes fundamental research said to be relevant to all cancer types, and “site-specific” research which focusses on a particular type of cancer.⁵³ Funding for site-specific cancer research in 2014 was £230 million, out of which £7.7million was spent on brain tumours (the 3.3% figure quoted in the Government’s response).⁵⁴

Non-site specific research

52. In its response, the Government said that “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%).” The NCRI also said that a proportion of non-site specific research would contribute to the understanding of brain tumours and to the treatment, care and support of patients with brain tumours. Unlike the Government, however, it said that it was not possible to put a figure on this.⁵⁵

50 [Government response](#) to the petition

51 Partner organisations of the NCRI: Biotechnology and Biological Research Council, Bloodwise, Breast Cancer Now, Cancer Research UK, Chief Scientist Office Scotland, Children with Cancer UK, Department of Health (which includes the National Institute of Health Research), Economic and Social Research Council, Health and Care Research Wales, Public Health Agency Northern Ireland, Macmillan Cancer Support, Marie Curie, Medical Research Council, Prostate Cancer UK, Royal Castle Lung Cancer Foundation, Tenovus Cancer Care, Wellcome Trust, Worldwide Cancer Research.

52 [Written evidence](#) from the National Cancer Research Institute

53 The site specific categories are: Adrenocortical Cancer; Anal Cancer; Bladder Cancer; Bone Cancer; Brain Tumour; Breast Cancer; Cervical Cancer; Colon and Rectal Cancer; Ear Cancer; Endometrial Cancer; Eye Cancer; Gallbladder Cancer; Heart Cancer; Hodgkin’s Disease; Kaposi’s Sarcoma; Kidney Cancer; Laryngeal Cancer; Leukaemia; Liver Cancer ; Lung Cancer ; Melanoma; Myeloma; Nasal Cavity and Paranasal Sinus Cancer; Nervous system cancer; Neuroblastoma; Non-Hodgkin’s Lymphoma; Oesophageal Cancer; Oral Cavity and Lip Cancer; Ovarian Cancer; Pancreatic Cancer; Parathyroid Cancer; Penile Cancer; Pharyngeal Cancer ; Pituitary Tumour; Primary CNS Lymphoma; Prostate Cancer; Retinoblastoma; Salivary Gland Cancer; Sarcoma ; Skin Cancer ; Small Intestine Cancer; Stomach Cancer; Testicular Cancer; Thymoma, Malignant; Thyroid Cancer; Vaginal Cancer; Vascular System; Vulva Cancer.

54 [Written evidence](#) from the National Cancer Research Institute

55 [Ibid](#)

53. We heard that brain tumours do not always benefit from spending on general cancer research as much as other site specific cancers such as breast and lung. Professor Tracy Warr of the Brain Tumour Research Centre at the University of Wolverhampton explained to the Committee:

It is a very complex disease and a lot of the general non-site specific translational work from other tumours cannot be applied to brain tumours because of the complexity not only in location and particularly delivery of therapeutics.⁵⁶

Brain Tumour Research told the Committee:

[...] the Blood Brain Barrier, which protects the brain, also prevents standard cancer treatments from working as a significant number of drugs will not enter the brain to treat the tumours. Therefore, the knowledge built up for other cancers is not always transferable to brain cancer.⁵⁷

54. The Government's inclusion of figures for fundamental research and research relevant to all cancer sites in its response to the petition suggests a lack of awareness of the complexities of brain tumours which mean that, unlike some other site specific cancers, it does not always benefit from general cancer research. Evidence given by the NCRI was not helpful in clarifying these matters. It told us that it was not possible to put a figure on the non-site specific research that might benefit brain tumours.⁵⁸ Dr Karen Kennedy, Director for the National Cancer Research Institute explained to the Committee:

In terms of the data that we collect from our partners, the only figure that we can be absolutely sure about that is absolutely dedicated to brain tumour research is the 3.3% figure, because that is work that has been carried out specifically on brain cancer. It is very hard to make an estimate of what the other research would be.⁵⁹

55. We heard that there was no official central record of spending by non NCRI partners and that this would help create a better picture of cancer research funding. Brain Tumour Research has called on the Government to "introduce a national register of site-specific cancer research to track all research grants and research work, ensuring transparency of funding arrangements." It argues that this would allow "shortcomings to be identified and prevents duplication of work."⁶⁰ In its report on research funding, Brain Tumour Research outlined how little the Government knew about its own spending on Brain Tumour Research:

...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.

56 Q61

57 [Written evidence](#) from Brain Tumour Research

58 [Written evidence](#) from NCRI

59 Q84

60 [Brain Tumour Research Report](#) on National Research Funding July 2013

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.⁶¹

What type of research is being funded?

56. We heard that there were different types of research which needed to be funded but that the NCRI database did not distinguish between quantitative research and qualitative lab based research and clinical trials. We heard that, in order to ensure that progress was made, it would be important to record and analyse what types of research were being funded. Professor Geoff Pilkington from the University of Portsmouth, told the Committee:

If we take it right from a basic level, we have what is called basic science, which would include working on genes and proteins and so on; then applied science, which might mean the biological behaviour that is inherent in the expression of those genes; then we go into translational, where we can use either animal models or in vitro tissue culture models and so on and then finally into clinical trials, so there are a number of different areas there. This is quantitative research, so this is generation of original data from new experiments. But there are also other forms of research like qualitative research, which might be focused more on quality of life through questionnaires, nursing and some epidemiological studies and so on. They would require different types of funding, so at the final end of this stream with clinical trials, those turn out to be pretty expensive, whereas the qualitative work at the other side is relatively inexpensive.⁶²

Brain Tumour Research told the Committee:

Spending on brain tumour research must increase in order to support the ground-breaking science desperately needed to find a cure for this terrible disease. Well-funded, pioneering research will significantly broaden the understanding of this devastating disease, helping to reduce the unacceptable and unnecessary deaths that occur every year from brain tumours and bring us closer to ultimately finding a cure.⁶³

57. The way in which current funding is recorded is inadequate and does not provide the Government, cancer research funders or Parliament with a full picture of what research is taking place. This makes it difficult to analyse whether the correct balance of different types of research is being met to ensure the best outcomes for brain tumour patients.

Is current funding enough?

58. The NCRI told the Committee that funding for brain tumour research had increased more than ten times since 2002, from £740 thousand to £7.7million.⁶⁴ The Government also stated in its response that brain tumours received “a greater proportion [of funding] than for 40 of the 49 site-specific categories.” Although this may sound encouraging, we heard that brain tumour research had historically been underfunded compared to

61 [Brain Tumour Research Report](#) on National Research Funding July 2013

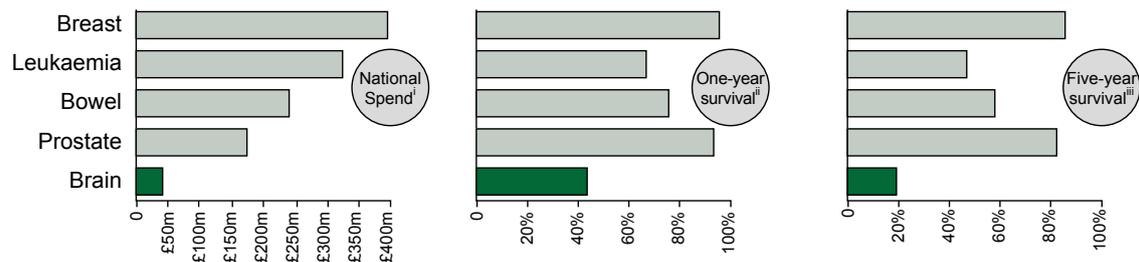
62 Q61

63 [Written evidence](#) from Brain Tumour Research

64 [Written evidence](#) from the National Cancer Research Institute (NCRI)

many other cancers—putting it far behind in terms of progress and improvements in survival rates. Over the 11 years from 2002 to 2012, just £35 million out of £4.5 billion of spending on cancer research had been on brain tumours (0.78% of the total cancer spend by NCRI partners). In comparison, £351 million had been spent on breast cancer and £290 million on leukaemia during that period.⁶⁵ As recently as 2012, spending on brain tumour research was under 1% of the total cancer research spend by NCRI partners. There is a clear correlation between the amount of money spent on breast cancer and leukaemia with improvements in survival rates for those patients.

Figure 3: Spend on research and improvements in survival rates



Source: Brain Tumour Research, *Report Update on National Research Funding July 2014*

i NCRI Data Package 2013, Table 3: NCRI spend by cancer site, National Cancer Research Institute

ii Cancer survival rates, [Cancer Survival in England: Patients Diagnosed 2007-2011 and Followed up to 2012](#)

iii Ibid

59. Emma Greenwood from Cancer Research UK explained to us how little improvement in terms of outcomes for brain tumour patients had been seen, compared to other cancers:

If we look at cancer survival and compare current rates for five year or one-year survival with the 1970s there have been improvements in brain, but not as great as in other cancer areas. Brain was already so far behind almost that you do not feel the impact in the same way.⁶⁶

Maria Lester told us that at the current rate of funding “it could take 100 years to catch up with developments in other diseases.”⁶⁷ Lisa Williams, whose father has a brain tumour, told the Committee:

[...] It’s dismaying to learn that whilst so much progress has been made with survival rates for many other forms of cancer, median survival rates for cancerous brain tumours has remained largely unchanged for 40 years and the outlook is very bleak. Brain tumour research seems to be the poor relation of cancer research [...].⁶⁸

60. The Government did not express a view about whether or not the current level of funding for brain tumours was sufficient. The NCRI was unable to comment as a whole, although two of its partner organisations, Cancer Research UK and Children with Cancer, told us that they had recently announced the prioritisation of brain tumour research as a cancer of ‘unmet need’. Cancer Research UK told the Committee:

65 [Written evidence](#) from Brain Tumour Research

66 Q33

67 Q1

68 Lisa Williams [web comment thread 30 October 2015 at 08:18](#)

CRUK's strategic ambition is to improve survival rates from cancer from two in four to three in four by 2034. A key part of this ambition is our focus on four cancers of unmet need, namely brain, lung, oesophageal and pancreas. We are focusing on these tumour types as there has been little improvement in survival rates over the last 20 years. In addition, there is a low base of researchers investigating these tumour types, which is highlighted in the low levels of funding relative to their incidence and mortality rates. Our ambition is to increase our investment two to three fold in these tumour types over the next five years to strengthen long-term research capacity.⁶⁹

61. Neil Meemaduma from Children with Cancer told the Committee:

[...] we have undertaken over the last couple of years our own analysis of childhood cancer [...] what has derived from our analysis is that there was a large deficit in brain tumour research. We launched our own brain tumour initiative that looked to spend £3 million in three years [...] that is a substantial amount of our research budget going towards that.⁷⁰

62. Brain Tumour Research told us that £30-35 million each year over the course of this Parliament was needed for brain tumours to catch up with other cancers. Sue Farrington Smith from Brain Tumour Research explained to us:

It is simply that is the amount of money that has been spent on breast and leukaemia over the last 14 years and there are now cures and treatments. When my sister's little girl, Alison Phelan, was diagnosed in 2001, at that time leukaemia killed more children than brain tumours, but the advances in treatments now is that 90% of children with leukaemia do survive.⁷¹

63. In its report, Brain Tumour Research states that "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. £569 was spent on research for every year of life lost to leukaemia. For brain tumours, it was £71."⁷²

64. We heard that, when taking into account only the deaths of those under the age of 45, significantly less money was spent per death on brain tumour patients compared to all other cancers. Brain Tumour Research told us:

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.⁷³

69 [Written evidence](#) from Cancer Research UK

70 Q30

71 Q39

72 Brain tumour research [Brain Tumour Research National Funding Report July 2013](#)

73 [Written evidence](#) from Brain Tumour Research

Impact of increasing funding levels

65. We heard that increased levels of funding could significantly improve the survival rates of people with brain tumours, as had been the case with leukaemia. Maria Lester explained to us:

History has shown that where funding leads, breakthroughs follow. Just look at the improved survival rates for breast cancer and leukaemia since the 1970s. I would like to add here that I do not wish to see money redirected from other cancers but for overall investment to be increased so that brain cancer achieves parity of funding.⁷⁴

66. Improvements in treatments for patients would in turn relieve some of the socio-economic impacts of brain tumours, which are discussed in more detail in the later chapter on burden of disease.

67. It is believed by many that a cure for the DIPG brain tumour, which primarily affects children and currently has no treatment or cure, could result in a cure for almost every other type of cancer due to its complexity. A couple of fairly recent examples where brain tumour research has indeed helped other cancers were highlighted to us by Professor Cruickshank.⁷⁵ In a later chapter, we suggest that the Government should seriously consider this potential impact when looking at how priorities for cancer research are determined.

68. We also heard that increased levels of funding for research into brain tumours could make the UK a world leader in this area. Neil Meemaduma from Children with Cancer told us:

The US and Europe are ahead of us, but in the UK we have tremendous research institutions and scientists here. We have the resources here to do this. It is a question of redirecting those resources and incentivising institutions to tackle this.⁷⁶

Conclusion

69. Brain tumour research has been seriously underfunded over decades, putting it far behind many other cancers in terms of the improvements in outcomes for patients. The Committee has heard evidence which suggests that there is a correlation between the amount of funding of research into a specific cancer and improved survival rates and/or reduced incidences. It is clear that existing levels of funding have not been sufficient for researchers to be able to make significant advances in their understanding of this devastating disease. Increased investment into research into the causes of brain tumours and into potential treatments is urgently needed.

74 Q1

75 The identification of the mechanism of sensitivity to temozolomide (Hegi et al-2006) and the identification of the IDH1 mutation as altering the prognosis of patients with GBM by 50% [has been investigated in other tumours notably AML acute myeloid leukaemia and exploited to allow new therapy.](#)

76 Q55

Recommendation

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

4 Barriers to research

71. We learned about the various barriers to brain tumour research, particularly for fundamental research and clinical trials. We heard that some of these barriers, such as a limited research workforce, can be attributed to the historic underfunding of brain tumour research.

Tissue collection and bio-banking

72. The Committee heard that the collection of brain tumour tissue to be used in research was difficult, and the chance to donate tissue was not always offered to patients. A recent survey had found that only 30% of brain tumour patients were offered the opportunity to consent for their brain tumour tissue to be used in research. Yet a poll by *brainstrust* suggested that over 90 per cent of patients would be keen for their tissue to be used.⁷⁷ Increased awareness of the importance of tissue collection amongst healthcare professionals and patients, along with more trained support nurses, could help to increase the amount of tissue collected. Sue Farrington Smith from Brain Tumour Research explained to the Committee:

[...] a lot of people I know do want to give their tissue but find it difficult to give. We have had several instances of, “Can I give my brain when I have died?” and that is a bureaucratic nightmare.⁷⁸

Professor Pilkington told the Committee:

The site within the brain, encased within the bony cranium, renders tissue availability for important research programmes scarce and this is not helped by a somewhat cumbersome ethics permissions system.⁷⁹

Cancer Research UK told the Committee:

There are difficulties in obtaining high quality samples during surgery, which include access to tumour site and the potential to impact on the patient’s quality of life. Access to research nurse support is vital to collect and process samples collected during surgery.⁸⁰

Brain Tumour Research told the Committee:

There is a shortage of qualified staff to transfer the tissue/tumour from the patient to the laboratory. There is also a lack of general awareness of the need for research in this area and therefore not enough researchers willing to take part in such an initiative.⁸¹

Clare Mitchell from Southampton University wrote on the Committee web thread:

Our project has provided a relatively low cost solution to locate suitable tissues for brain tumour researchers, by providing access to tissue left over after

77 University of Bristol press release, [Save lives - be a brain tumour tissue donor](#) 24 February 2015

78 Q57

79 [Written evidence](#) from Professor Pilkington

80 [Written evidence](#) from Cancer Research UK

81 [Written evidence](#) from Brain Tumour Research

diagnosis, but funding for this area is woefully inadequate. Despite this, so far around £60k of charity funding has provided this support and a rapid ethics approval process to 19 research projects but so much more could be done if this area was better funded and prioritised by the government.⁸²

73. The problem of awareness amongst health care professionals, discussed in our earlier chapter on diagnosis, is reflected here. An understanding of the importance of brain tumour tissue for research does not appear to be reaching the front line; patients are often unaware that they could contribute to research in this way. This problem is exacerbated by a lack of research nurse support. The Government here has an opportunity to provide leadership and send a strong message to all healthcare professionals about the importance of brain tumour tissue collection and ensure that they have the right skills and support to facilitate it.

74. We also heard how increased tissue collection had to go hand in hand with co-ordinated bio-banking to make sure that research into different brain tumour types can take place. Sarah Mee from the Brain Tumour Charity explained:

There are other issues that need to be addressed first around tissue collection. For example, having a co-ordinated system for bio banking in the UK would go a long way. At the moment, particularly for adult brain tumours, there is a fairly disparate collection of local tissue banks and it can be quite difficult to get the required tissue samples if you are looking at a particular tumour type to get enough numbers. There are around 140 different tumour types, so sample collection can be difficult without a good co-ordinated system.⁸³

[...] There are local tissue banks at the moment, but each of those might have different procedures for accessing that tissue. If, for example, you are a researcher looking at a particular tumour type that is essentially quite rare, you might end up having to go to an awful lot of different places to try to get permission to access sufficient samples. In addition to that, you have the issue that was mentioned earlier around those samples not being systematically collected and then it does become quite difficult to sufficiently power research using samples.⁸⁴

Clinical trials

75. We heard that the approval administrative process was often a barrier to running clinical trials. Professor Pilkington told us that the Government should “work closely with the charity sector representing brain tumours in pressing for increased speed of translation from laboratory findings to clinical application.”⁸⁵ We also heard about the impact of short survival rates and late diagnosis on the opportunities for patients to take part in clinical trials and research. Emma Greenwood from Cancer Research UK told us:

Sadly, with brain cancer, it is one of those areas that is disproportionately affected by some of the regulatory hurdles you have to go through to set up a clinical trial in this country and we are getting new European legislation in,

82 Claire Mitchell, [Web thread comment 27 October 2015 at 11:134am](#)

83 Q42

84 Q58

85 [Written evidence](#) from Professor Pilkington

which we are optimistic will shift that so it is easier to set up clinical trials. But when you have such small numbers—and so recruitment is going to be challenging anyway—anything that gets in the way and presents a barrier to doing that is a disincentive to a clinician to getting that off the ground. I do think there is a role for regulatory bodies, the NHS more broadly, to have an open shop in terms of clinical research and making sure that we take every opportunity to be telling patients about possible research projects, sharing clinical trial opportunities across the whole of the UK.⁸⁶

Drug testing

76. During the Committee’s inquiry, the House of Commons debated the Off-patent Drugs Bill, presented by Nick Thomas-Symonds MP. The aim of the Bill was “to establish a process to enable off-patent drugs [drugs no longer subject to marketing protection] be made routinely available when there is evidence of their effectiveness in new indications [a new clinical use].”⁸⁷ This in effect would enable researchers to repurpose existing drugs.

77. The debate raised important points which were also reflected in evidence to the Committee. We heard that rarer diseases, including brain tumours, could significantly benefit from the repurposing of drugs. Sue Farrington Smith from Brain Tumour Research told us: “I think that is a very good place to start and look at some of the drugs that are available that could be repurposed to help cure brain tumours.”⁸⁸

78. We heard that brain tumours were not attractive to pharmaceutical companies for new drugs. Professor Cruickshank told the Committee:

What often happens with brain tumour drugs is that they have been tested in other cancers, other areas and so on, and if it has not worked in breast and it has not worked in colon or melanoma, “We have a little bit of money left in the pot. Let us just try it on brain and see what happens”. They would not go to brain straight away with a new drug, because if it fails, as it often does because it is not formulated for that, they may lose a big commercial drive to get it. The drug temozolomide that we use, for example, only started making any money for the drug companies in the last nine months almost of its patent time as far as brain tumours were concerned. So no self-respecting pharma would look at brain tumours as a prime area to put money into, because the return is virtually zero.⁸⁹

79. Emma Greenwood from Cancer Research UK told the Committee:

The other thing is increasingly the role of the charity sector working with pharmaceutical companies. We have a technology transfer arm, we quite often take on drugs that the pharmaceutical companies are not interested in, have a look at them in a different indication because they are a strategic priority for us. Not everyone can do that, but the more that we can do that sort of

86 Q45

87 [Off patent Drugs Bill 2015-2016 and explanatory notes](#)

88 Q37

89 Q69

collaboration the more opportunity for looking at some of these rarer cancers or these cancers of unmet need there will be.⁹⁰

Research data

80. We heard that the collection and sharing of data on current and previous research could be improved to prevent repetition and help researchers. Maria Lester told us:

“[...] if there was just greater freedom of information and transparency over who is funding what research and what trials and things are being done that you would avoid duplication, you would avoid wasting any resources by different bodies doing similar things.”⁹¹

Emma Greenwood told us:

[...] if we can share the results from clinical trials, even if we do not necessarily directly think it is relevant for certain tumour types, that could enhance everyone’s learning so that we are making the best of research that has already happened.⁹²

The review process for research applications

81. The Committee heard that the review process for research applications could be improved. Professor Pilkington told the Committee:

The fact of the matter is that brain tumour researchers get very little money from the MRC [Medical Research Council] and CRUK [Cancer Research UK]. Indeed, many researchers have chosen to simply give up applying to these organisations. The reasons for this are complex and politically sensitive. The ‘quality’ is often questioned (although I have refereed innumerable applications from both these bodies on sound brain tumour research projects which have not been funded). This outcome may be due to lack of appropriate brain tumour representation on MRC/CRUK committees. Lead roles are also frequently taken by clinicians rather than laboratory based scientists and the competition for sparse funds has sadly led to a lack of collegiality and even ‘back stabbing’.

It is also apparent that many grant giving bodies are only interested in funding ‘no-risk’ research programmes, thus applicants frequently have to produce a considerable amount of pilot data before they can even apply for funding. This in itself may limit the flare, flexibility and enthusiasm of dedicated career based neuro-oncology researchers and funding streams might better be placed around at least some ‘blue skies’ type research. The need for centres with a critical mass of experienced researchers is evident. Moreover, waiting for periods of 20 or more years for translation from the laboratory to clinic is wholly unacceptable.

90 Q38

91 Q10

92 Q38

Other factors, which limit the effectiveness of research endeavour might result from the over bureaucratising of national bodies and the perception that centralisation of research to Russell group centres such as Oxbridge and UCL ignores the huge volume of excellent work in our field which emanates from smaller, less prestigious centres/universities, such as Nottingham Trent University, Plymouth University, Portsmouth University, University of Central Lancashire and University of Wolverhampton, to name a few. In most cases the lead players in these centres moved out of environments which were more prestigious, but unsympathetic to the growth of brain tumour research within the UK.⁹³

Professor Warr told the Committee:

As a nation of scientists, we are very innovative. The way a lot of our academic and educational institutions are set up, universities, for example, there is a great degree of intra-disciplinary collaboration. We are quite good as a nation at thinking outside the box and joining up the dots and collaborating, and I think exactly that, being able to fund some very innovative ideas and move away from this very risk-averse idea of funding streams, we could benefit a huge amount.⁹⁴

Research workforce

82. The Government's response to the petition stated that the size and quality of the workforce was one of the factors that determined the level of research funding. It said that the other factors (scientific opportunity; the burden of disease; researchability; and fundraising) meant that "some areas attract more high quality researchers than others" and that "[t]his will undoubtedly affect the number of quality proposals received by funding bodies."

83. We heard that a lack of funding for brain tumour research (discussed in the previous chapter) resulted in a shortage of neuro-oncology specialists. Maria Lester told the Committee:

"[...] it is a catch-22 situation [...] if the funding is not there you then do not attract the researchers into that field because there is not the funding for them to do work with [...]"⁹⁵

Peter Realf told the Committee:

"[...] relating to the Department of Health's response to the petition. They said that, "Factors include the quality and size of research workforce" and I would suggest that it becomes hard to recruit substantial numbers of high-quality researchers when they know that a particular area such as brain tumours is substantially under-funded. If you are starting out in a career as a research scientist and you want to make a name for yourself, surely you are more likely to choose a branch of research where funds are available, first, to keep you employed, and secondly, to do meaningful research that you want to explore. I

93 [Written evidence](#) from Professor Pilkington

94 Q82

95 Q6

think saying, as the Department has, that it is about looking at the numbers of researchers available in that field is a little bit of a catch-22⁹⁶

Dr Suzanne Miller from Nottingham University shared her experience with the Committee:

Funding for brain tumour research is vital if we are to better diagnose and treat these tumours. Better genetic and histological classifications are needed, with treatments tailored to the particular subtype of tumour. I have a PhD in the genetics of childhood brain tumours and unfortunately due to the recession and lack of funding I was unable to continue researching this area. In my personal life, my Auntie has recently been diagnosed with a Grade 4 GBM and I would greatly wish to move back into this area if only more vital funding was available.⁹⁷

We heard that many young scientists interested in neuro-oncology left the UK as a result. Professor Pilkington told us:

I have had 30 PhD students in my labs over the years. I have examined 35 or thereabouts. Very few of them are in gainful employment in neuro-oncology. Some of them lead their own groups in the United States, in Norway and places like that, but sadly, we lose most of them because that funding structure has not been present. That is very important for the scientists.⁹⁸

Sarah Mee from the Brain Tumour Charity described some of the workforce shortages to the Committee:

[...]we have relatively fewer numbers of research active neurosurgeons in the UK than other countries and also there is a need for more medical oncologists sub-specialising in brain tumours and that will be important, for example, for driving early phase research trials. There is a workforce issue there.⁹⁹

84. The Committee heard that the complexity of brain tumours and a lack of career certainty is a problem in attracting researchers. Professor Pilkington told us:

If you are a young, bright-eyed, bushy-tailed young researcher coming on board, you would go first where there is money, so there is much more money in many of the other forms of cancer research. There is also, the complexity of the system: the brain is a very complex organ, so we see lots of different forms of cell, over 120 different types of tumour. In fact, when the World Health Organisation new classification of tumours comes in next May, we will see that escalate quite considerably because of the molecular profiling data that is coming through. It can scare some people off and the lack of security for young researchers is paramount.¹⁰⁰

We heard about the importance of dedicated neuro-oncology researchers due to the uniqueness of brain tumours. Professor Cruickshank told us:

96 Q6

97 Dr. Suzanne Miller, [web comment thread 29 October 2015 at 16:02](#)

98 Q61

99 Q36

100 Q61

We are dealing with something that is almost a Cinderella compared with other cancers. [...] we have to think a little bit more about the specifics of what we are dealing with if we are not going to waste a huge amount of money just trying to copy what has been done in one cancer and translate it into another. That presents a very important point: how do we attract people into this kind of work when it seems very niche? That is where it comes down to people like myself and Geoff¹⁰¹ to go out and sell it to the young people of this world: that, as medical students and researchers and so on, they have to do that. There is a huge educational element, a role that we have to play and we are not being allowed to play this role quite as much as we were before because of constraints on medical training and so on.¹⁰²

The Brain Tumour Charity explained the relationship between funding levels, the workforce and the quality of research applications:

The perception of a commitment to funding and the creation of a positive research environment in a particular field can help to attract the best international researchers to the UK. This may in turn result in an increase in high quality, successful applications to open funding calls and the reputation of UK centres as being internationally competitive.

Whilst it is true that grants from the National Institute for Health Research (NIHR) and the Research Councils are open to applications from researchers working on any condition and judged in open competition, the priorities of institutions and individual researchers also will be influenced by perceptions of Government priorities. Success breeds success, with grants awarded in a theme attracting researchers to work in that area. Actions such as the designation of centres as NIHR Biomedical Research Centres (BRCs) may help to contribute to the positive perception of the UK as a desirable place to conduct brain tumour research.

There is clearly a need for research-led improvements in our understanding of, and treatments for, brain tumours. We are not suggesting that lower quality applications should be prioritised, but the Government should support the recruitment and retention of outstanding scientists working in neuro-oncology.¹⁰³

85. We heard that there was an incomplete career path in the UK for scientists who wanted to specialise in brain tumour research after completing their PhDs. Professor Pilkington explained to us:

Limited funding exists for dedicated researchers and this has led to missing rungs in the ladder. I am talking more specifically about the basic science and the applied science and the translational science when I say that we just do not have a tenure track system running in this country. If you compare parallels with overseas, with the United States and with some of the wealthier and more active countries in mainland Europe, they have a far more flourishing system because there is some security of tenure for young researchers moving up that

101 [Written evidence](#), Professor Geoff Pilkington

102 Q61

103 [Written evidence](#) from the Brain Tumour Charity

ladder. We need to put those rungs back in the ladder and we need to have a mechanism [...] to build career progression pathways for junior researchers. The lack of research funding support has led to many PhD students who have graduated in neuro-oncology having to find employment working on other diseases and, as a result, well qualified postdoctoral researchers in this discipline have dwindled. While recruiting senior scientists with experience in other cancer fields may in part be a short term answer to the problem, brain tumours are so different from generic cancers that the learning curve for these researchers is steep indeed. The real answer therefore is to recruit some senior researchers from overseas and to steadily build up our own home-grown research stars of the future.¹⁰⁴

86. As mentioned in the previous chapter, we heard that increased levels of funding for research into brain tumours could make the UK a world leader in this area. At the moment however some of our best and brightest in this field are either being forced to change career paths or move abroad.

Conclusion

87. **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.**

Recommendations

88. *The Government should examine the evidence the Committee has taken and consider what action it can take to address the barriers to brain tumour research described by expert witnesses. In particular:*

- *The Government should use its powerful influence on funding levels to send a clear message that brain tumour research is a major priority for the UK.*
- *The Government should ensure that there is adequate support for young scientists who wish to pursue a career in brain tumour research, so that they can stay and progress in their areas of specialism.*
- *The Government should address the concerns raised by witnesses about the ‘red-tape barriers’ which may be reducing the opportunities for clinical trials, and explain what it will do to address these, while balancing this with the need for proper safeguards.*

- *The Government should ensure there is effective coordination of bio-banking and tissue collection, to facilitate brain tumour research.*
- *In response to the Off-patent Drugs Bill, the Government has said that legislation was not needed to achieve the aims of the bill. The Government should provide a full explanation, with expected timescales, of the steps it is taking to ensure that off-patent drugs in new indications are being made available to patients consistently across the country, providing appropriate safeguards are maintained.*

5 Setting research priorities

Role of the voluntary sector

89. The Committee heard that funding for research into brain tumours was heavily reliant on charities. Professor Pilkington told the Committee, “without the charity sector today there would be very little, if any, meaningful brain tumour research in the UK.”¹⁰⁵ Brain Tumour Research told the Committee:

There appears to be little understanding amongst the general public that research into cancer in the UK is driven by charities, trusts and private donations which support research undertaken in Universities and Hospitals throughout the UK.¹⁰⁶

90. The Committee heard that the smaller charities dedicated solely to brain tumours often struggled to attract public donations. Sue Farrington Smith from Brain Tumour Research explained “our fundraising is all from the general public and mainly obviously from families that have been affected by a brain tumour. We receive no Government funding.”¹⁰⁷ She explained that when her niece Alison Phelan tragically died of a brain tumour three weeks before her eighth birthday in 2001, she had contacted her local MP, the Rt Hon John Bercow, who organised the first adjournment debate in the House of Commons on the subject of brain tumours. She told the Committee that “the whole awareness of brain tumours is now much higher than it was 10 years ago, but it is certainly not as high as it needs to be in order to get the general public behind giving the funds to this disease area.”¹⁰⁸

The Committee heard that obtaining funding for research into brain tumours had become increasingly difficult. Professor Pilkington told the Committee:

I started my brain tumour research career in 1971 when obtaining funding for brain tumour research was reasonably straightforward. In those days both the Medical Research Council (MRC) and the Cancer Research Campaign (CRC) were the major source. [...] In the early 1990s, however, grant funding was sparse and at that stage I was centrally involved with the formation and nurturing of a number of brain tumour charities. These charities have undergone change and development and are now the major source of income for laboratory based researchers such as me. Some of the brain tumour charities have chosen to support research into different forms of brain tumour, while others have concentrated more on patient support and education.¹⁰⁹

Identifying gaps

91. The Committee heard that the National Cancer Research Institute (NCRI) as a whole only identifies gaps in funding for areas of research which would benefit all cancers

105 Q61

106 [Written evidence](#) from Brain Tumour Research

107 Q43

108 Q44

109 [Written Evidence](#) from Professor Pilkington

rather than identify gaps in specific types. Dr Karen Kennedy, the Director of the NCRI explained to the Committee:

As NCRI, we work with our partners to try to identify areas where we can, as a collective, make most impact. Those tend to be areas that cross-cut, rather than in a specific cancer type.¹¹⁰

92. Responsibility for the identification of gaps in research for specific cancer types rests with the individual partner organisations which work together through the NCRI. We heard that individual partner organisations set their own priorities for research which influence the types of research that they choose to fund.

93. We heard that two NCRI partners, Cancer Research UK and Children with Cancer had recently identified brain tumours as a priority for their organisations. In its response to the petition the Government stated:

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.¹¹¹

94. The Committee heard that there is no official measurement for determining which factors are the most important when NCRI partners consider what research projects to fund. Each partner sets its own priorities for research funding. The Brain Tumour Charity told the Committee:

Although our own research commitment is an important part of the combined effort to improve survival and quality of life for people with a brain tumour, it should not be left to charities to step in where Government funding is insufficient. There are a number of reasons why continued Government commitment is essential to maximise the return on our investment for people with a brain tumour.

Firstly, we have a duty to our donors to ensure that as much as possible of the money that they give goes towards the activities that they want us to invest in. This means that, like most charities, we are not able to pay for the full economic cost (FEC) of the grants that we award. Although top-up support to provide parity with Research Councils grants is available to institutions in the form of the Charity Research Support Fund (CRSF), the value of this fund has been falling in real terms over the last few years. There is a risk that this may make charity grants less attractive.

We often seek to co-fund projects alongside other charity and Government funders. For example, we fund a number of Clinical Research Training Fellowships with the Medical Research Council (MRC); and along with Children with Cancer UK and Great Ormond Street Hospital Children's

110 Q87

111 [Government response](#) to the petition

Charity we fund the INSTINCT strategic research network, which brings together leading clinical and research programmes in high-risk paediatric brain tumours. The benefits of co-funding arrangements are not only financial, also allowing funders to share risk, contribute to complementary elements of a research programme, and share skills and expertise. Clearly this sort of funding model can only happen in an environment with a diverse network of different funders.¹¹²

Wendy Fulcher, whose husband died of a brain tumour, told the Committee that there needed to be a national funding effort:

When my husband died from a brain tumour I learnt how little was known about the cause of brain tumours and how little funding was invested in brain tumour research. 15 years later this is still the case and despite brain tumours being the biggest cause of cancer death in young people and causing the highest number of years of life lost, less than 1% of national cancer research funding goes into brain tumour research. This is unacceptable - the charities try desperately to redress this shameful imbalance but it needs a concerted national funding effort to give brain tumour patients a fair chance of better treatments. Scientists and clinicians are fighting for the chance to find a cure for this devastating disease but they need the support of government to receive a fair share of funding to research the causes and possible treatments for these patients.¹¹³

Suzanne Spink, whose father died of a brain tumour, described it as the “forgotten cancer”:

I watched my father die within three months of diagnosis from a glioblastoma. He didn't stand a chance. The tumour was aggressive and took up the majority of his right frontal lobe. He stopped being the man I knew, instead became a shell of his former self. He wanted to be treated and couldn't understand why there was nothing that could substantially extend his life. Radical resection and Palliative radiotherapy may or may not have given him extra time. We tried it but will never really know if the disease just followed its natural progression. My fathers diagnosis was a bitter pill because I am a speech and language therapist. I work on a neurosurgical ward and am involved in surgery to treat low grade brain tumours. The team that I work with was the team who treated my father. I witness lives being changed by this disease but the people who suffer from it are often cognitively impaired and so don't have the same voice as other cancer sufferers. Brain tumours are not sexy, generally people do not survive them. People do not wear pink ribbons etc. It's like the forgotten cancer. I am not saying it's more important than other diseases. I just think it should be equally funded and researched.¹¹⁴

Government funding

95. Brain Tumour Research explained that a reliance on the NCRI partners was not sufficient to support adequate funding for brain tumour research. It explained that the

112 [Written evidence](#) from the Brain Tumour Charity

113 Wendy Fulcher [web comment thread 30 October 2015 at 11:48:](#)

114 Suzanne Spink [web comment thread 24 October 2015 09:27](#)

larger partners drove the priorities. It said that, although the Government-funded partners had spent less than had previously been thought on brain tumours, funding from the Medical Research Council had nevertheless amounted to over 58% of the total it received from all NCRI partners combined. It explained:

[...] initiatives coordinated by the NCRI are perceived to be heavily driven by larger funders [...]. In our subsequent discussions with government funded partners of the NCRI [...] we found the percentage of research spend on brain cancer was even less than we had previously thought.

Last year the total MRC [Medical Research Council] research spend was £772m. This included £76m directly on cancer—just under 10%—yet one in two people will get cancer in their lifetime. Of that spend on brain tumours was a welcome £2.8 million which represents 58% of the total brain tumour spend by the NCRI partners¹¹⁵

Despite welcoming the investment from the Medical Research Council, Brain Tumour Research argued that the Government had failed to consider the burden of the disease in its response to the petition:

The Government's response to the e-petition [...] failed to consider years of life lost when prioritising research spend. Brain tumours kill more children and adults under the age of 40 than any other cancer, yet this is not reflected in the amount of national research funding it receives—last year (2014) saw an increase but it is still just 1.5% of the entire spend on cancer research. This has to change.¹¹⁶

96. In its response to the petition, the Government explained the role of the Government-funded National Institute for Health Research (NIHR). It stated:

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.¹¹⁷

This illustrates another catch-22 for brain tumour research: the Government is saying that there has to be scientific activity to attract more funding, but as discussed in the previous chapter, there has to be funding and support in the first place to promote scientific activity.

NIHR themed calls

97. The Government told the Committee that the National Institute for Health Research (NIHR) issues themed calls “in response to recognition of the need for an increase in

115 [Written evidence](#) from the Brain Tumour Research

116 [Ibid](#)

117 [Government response](#) to the petition

research-based evidence on a particular topic.”¹¹⁸ It said that “[t]ypically themed calls address major strategic needs such as dementia, obesity and antimicrobial resistance. [...] No brain tumour research has been funded as a result of a previous themed call and the NIHR has no current plans to issue a themed call in brain tumour research. NIHR programmes that participate in themed calls all issue regular calls for researcher-led applications and can receive proposals related to brain tumours.”¹¹⁹

98. The Brain Tumour Charity told the Committee that Government priorities had an important role in influencing funding levels:

Whilst it is true that grants from the National Institute for Health Research (NIHR) and the Research Councils are open to applications from researchers working on any condition and judged in open competition, the priorities of institutions and individual researchers also will be influenced by perceptions of Government priorities. Success breeds success, with grants awarded in a theme attracting researchers to work in that area. Actions such as the designation of centres as NIHR Biomedical Research Centres (BRCs) may help to contribute to the positive perception of the UK as a desirable place to conduct brain tumour research.¹²⁰

Conclusion

99. **The Committee welcomes the recent commitments by both Cancer Research UK and Children with Cancer to prioritise brain tumours as a cancer of ‘unmet need’. Nevertheless, responsibility for ensuring that gaps in research funding are filled cannot rest solely with the voluntary sector. The Government must take responsibility for identifying unmet needs in research funding and taking action to rectify them. If the Government showed additional leadership on brain tumour research funding, other institutions and organisations would follow.**

Recommendations

100. *The Government should not leave the prioritisation of research funding only to the voluntary sector. It should consider the burden of disease from brain tumours and take a more active role in setting priorities for brain tumour research funding.*

101. *The Government must ensure greater oversight of research funding to ensure that it is able to identify, and if appropriate take steps to address, any gaps in funding.*

118 [Letter from the Department of Health](#) to the Chair of the Committee 18 December 2015

119 [Ibid](#)

120 [Written evidence](#) from the Brian Tumour Charity

6 Burden of disease

“[...] it is responsible for over 20 years’ of life lost in the average patient, which makes it the most lethal cancer in this measure.” Maria Lester¹²¹

The most fatal cancer in terms of life years lost

102. The Committee heard that brain tumours were the biggest cancer killer of the under 40s and children. Compared to other forms of cancer, brain tumours result in the greatest number of life years lost. Professor Pilkington told us:

They are different tumours, the prognosis and outcome is different, the life years lost is longer than any other cancer; we are talking about something of the order of 21 years against 13 for breast cancer. The socioeconomic impact is incredibly profound and the ages affected range right the way through from even before the child is born to patients in their 80s, 90s and so on.¹²²

The fact that brain tumours can be detected in utero and can affect children and adults of all ages renders them as having the most marked socio-economic impact of all cancers. In this context average life years lost to brain tumours stands at around 21 years while life years lost to breast cancer are approximately 13 years.¹²³

The biggest cancer-killer of children

103. Brain tumours are the biggest cancer-killer of children, and in the course of our inquiry we heard from many parents who had tragically lost their children to a brain tumour. As an example, we heard about a type of brain tumour called a Diffuse (Intrinsic) Pontine Glioma (DIPG)—a childhood brain tumour that is almost universally fatal. More than 90 per cent of children with a DIPG die within 18 months of diagnosis.¹²⁴ During this inquiry we received a petition on petition.parliament.uk from Mr Ahmed who had tragically lost his 6 year old daughter Saira to a DIPG. The petition calls for a: “massive government grant for incurable brain tumour DIPG research.” It reads:

121 Q8

122 Q61

123 [Written evidence](#) from Professor Pilkington

124 [Children with cancer UK](#)

Saira Ahmed



“Every nine days a child in the UK is diagnosed with DIPG”

Copyright Mr Arif Ahmed

My daughter Saira was six & half year old. Our world had turned upside down when she was diagnosed with DIPG this year January with no cure & survived only five months. No children should go through such unimaginable pain & suffering. So our children needed to be save from this vicious monster DIPG.

Every nine days a child in the UK is diagnosed with DIPG. This is the MOST FATAL form of childhood brain cancer which grows in the PONS area of the brainstem making surgery impossible. ‘Terminal at diagnosis’ currently there are NO treatments or CURE available. Less than 2% of the Cancer budget goes towards brain tumour research. So it is woefully underfunded. Families encountering DIPG brain tumours all over this country are subjecting their loved ones to hideous treatments that do not offer a cure.¹²⁵

104. Amanda Walker told us about her daughter Abbie who tragically died of a DIPG when she was 6 years old. Like many we have spoken to and heard from, she has since been working hard to raise money for research after discovering how underfunded the area was:

I now run a charity ‘Abbie’s Army’ raising funds to research a specific childhood brain cancer DIPG. It claimed the life of my 6 year old daughter in 2011 [...] She survived just 5 months past her diagnosis. What we have learned since is completely unacceptable for these children. This is the most fatal brain cancer [...] responsible for 80% of ALL the brain tumour deaths we see in UK children. [...] there is NO effective treatment available, NO open UK trials. When Abbie

125 [Petition by Mr. Arif Ahmed](#)

was diagnosed in 2011 she did not receive ONE drug. The situation is still the same. How can that be? [...] Regardless of whether numbers are statistically insignificant to warrant investment in research, you simply cannot tell a parent that their child is uneconomical. Considering its steady stream of patients and its 0% survival rate someone with the empathy and compassion needs to do something about this is a BIG way! [...] These families cannot keep being told to go home and ‘enjoy’ time they have left.¹²⁶

Figen Rawlinson also shared his story with us:

My 6 year old son was diagnosed with an inoperable and incurable brain tumour (DIPG) in October 2008 and he died just 10 months later in August 2009. Our lives have been turned upside down and being told that “there is nothing that can be done, this is a death sentence, enjoy the time you have left” still haunts me to this day and will do forever. Our two younger sons couldn’t understand why their brother had to leave and couldn’t play with them anymore. Their first Christmas without him, they asked for him to come back and nothing else. As a parent, watching your child go through radiotherapy, chemotherapy, confusion, depression, anxiety, weight loss, weight gain, becoming very insular, angry, inability to eat, walk, talk, sleep, swallow, communicate and finally his inability to breathe is not something that I wish upon anyone. You feel so helpless and feel like you have let your child down. Despite all our efforts, we were unable to save him and it all boils down to funding. It is a known fact that funding=research=cure. Whilst trying to find answers and speak to every medical professional around the world, we realised just how far the UK is behind with treatment options. At the time, we had to fight for our son to receive Temozolomide at the hospital he was being cared for. Why? You may wonder. Because we lived in a different County and it would be too expensive. Thankfully our GP and the hospital staff did all they can and finally he was able to receive the treatment. Did it buy us a little more time? I don’t know, but there were no other options available. We were drained and exhausted but also had to fight for treatment. How can policies and procedures be far more important than a child’s life? We were willing to do anything and sell everything we owned to help save him but this disease took him away from us far too soon. There were no options, there were no alternatives and we have had to pay a heavy price. We now work with Brain Tumour Research and actively fundraise for research because we need a cure. So much of our time is spent on this now and we will continue to do all we can, but the Government really needs to ‘step it up’ and ‘stop putting it off’. Because of the work we do, we talk to so many families that are in the same desperate situation and there is nothing we can do but you can. Make brain tumours a priority.¹²⁷

The most dangerous location

105. We heard about the profound impact on the quality of life for brain tumour patients due to the sensitivity and importance of the brain. Dr David Walker and Dr

126 Amanda Walker, web comment thread 28 October 2015 at 15:46

127 Figen Rawlinson web comment thread 27 October 2015 18:57:

Richard Grundy from the Children's Brain Tumour Research Centre at the University of Nottingham told us that brain tumours:

[...] account for 15-25% of all cancers in people under 25 years of age are the biggest cancer killer under 40 years of age, 1 in 50 deaths in people under 60 yrs. are due to brain tumours, furthermore up to 60% of all cancers across the age span involve the brain, necessitating treatment directed at the brain to deliver higher rates of cure. For those who survive, up to 60% acquire significant disability, such that 1 in 3 experience personality change, 1 in 2 experience memory loss and 1 in 4 have loss of cognitive capacity. This burden of disease and its consequences coupled with the young age profile means that judgements of priority on numbers of new cases and survival alone, is an imperfect way of judging the priority for Society.¹²⁸

Amanda Dixon told us:

My daughter was diagnosed with grade 3 anaplastic ependymoma in Feb 2014 aged 16 - she had surgery which although removed the massive tumour in brain left her with disabilities that she is trying to overcome - she then went through 30 sessions of radiotherapy - she did all this through her GCSE exam period and her prom night which she attended with a walking stick, over weight from steroid treatment and wearing a wig to try and cover her baldness - she has had to teach herself to write with her non dominant hand to enable her to continue to study for her A-levels - she suffers from mental fatigue and memory loss but is trying her best to achieve enough to attend university. Unlike her peers she is unable to learn to drive due to not being eligible for a driving license. She is fighting hard against a tumour that we have been told will most likely recur and take her life. [...] ¹²⁹

Carol Robertson told us:

Having worked with brain tumour patients for the past 15 years, I have witnessed first-hand the devastation of this disease. Every patient, low or high grade is affected by major life affecting symptoms including seizures, palsy, mood changes, memory loss, poor concentration, sight/hearing issues, limb weakness, mobility problems, chronic fatigue, adults generally can't drive post-surgery and often never drive again because of seizures, disability and medication. Patients often can't hold down/return to a job because of points above, they lose their friends and feel completely isolated. If ever a disease needed to be better understood and funded, it is brain tumours.¹³⁰

Elizabeth Realf told the Committee:

"[...] I think we were lucky, [Stephen] had an excellent surgeon who managed to take as much as he could from him, from the brain, but because he had it awake he did not lose any of his speech or his memory, he did not do any sort of permanent damage, because if it is just a fraction too much, somebody is disabled, has a disability for the rest of their life. There are so many cases where

128 [Written evidence](#) from the Children's Brain Tumour Centre, University of Nottingham

129 Amanda Dixon [web comment thread 29 October 2015 at 21:47](#)

130 Carol Robertson [web comment thread 30 October 2015 at 12:01](#)

surgery has not been as successful and people have come out of surgery who cannot speak, cannot move, had strokes.”¹³¹

“Benign” brain tumours

106. The Committee heard that benign tumours classified as grade 1 and 2 are not included in the figures for the incidence of brain tumours, but that they can still be fatal and can have severe impact on people’s lives and even become cancerous. It also heard about possible effects of cysts. Brain Tumour Research told the Committee:

The brain is such that even a benign tumour can kill as the brain cannot expand as the tumour grows in size.¹³²

Lisa Fletcher told us:

There needs to be more funding not only for malignant tumours but also for benign, symptomatic tumours and cysts. In particular I would like to see better training and the use of the most recent case studies and research papers in the UK. In other countries research and training makes it possible to have endoscopic removal of pineal region tumours (C.Teo, D Kim etc al). Whilst benign cysts/tumours smaller than 0.5cm are generally deemed “incidental” findings, cysts over this size can cause symptoms. These can be life altering, as in my case, and in the case the 90 fellow cyst sufferers that I have come across via social media (facebook; pineal cyst and pineal cyst uk) Please, please take these cysts seriously. Too many people are being denied treatment. I haven’t found a single person who had received surgical treatment for this rare condition in the UK.¹³³

Naomi Marley told us:

Once you’ve had a brain tumour you realise how common but hidden they are. Everyone says “oh yes, my aunt, friend, cousin had one, etc.” Mine was benign but rare and very difficult to reach (at base of my skull). So rare it took three months to find anyone else who had had one who I could talk to. I’m one of the lucky ones because I was diagnosed in time. Luckily I worked out for myself that there was something “stuck in my head making me fall over as if I’d drunk ten pints of cider”; luckily my dad is a doctor, guessed what was up and made me ask my doctor to book me a private initial appointment for £200 with a consultant as the wait on the NHS was too long; luckily my GP has a special interest in neurology and immediately thought I had a brain tumour. Luckily we were all aware, interested, pushing for what I needed and had enough money to speed things up. If I’d been somewhere else or someone else or had no funds this might not have been the case. [...] My point is that whilst I’m lucky, very lucky to even have an NHS, surely the rest of it should not be a matter of luck? Due to a woeful lack of research, intracranial epidermoid tumours remain largely unknown, deadly, terrifying, hard to treat. It was very very scary and lonely being diagnosed with one until I found a facebook group

131 Q16

132 [Written evidence](#) from Brain Tumour Research

133 Amanda Fletcher [web comment thread 20 October 2015 at 20:35](#)

based in the US and I could finally talk to someone. It's no fun sitting down with a solicitor in your thirties making provision for brain surgery leaving you a vegetable. It's quite terrifying waiting months for the team you need and meanwhile thinking about how your face may or may not work afterwards. It's scary that no one knows what you're talking about. It's really quite traumatic to have to hide away during the wait. If you go out people who know say "it's ok though, it's benign." And this is because there's no awareness. Why on earth would they know any different? [...] ¹³⁴

Professor Pilkington told the Committee:

[...] any tumour within the brain is potentially life threatening. Indeed, low-grade/benign primary brain tumours in adults almost invariably progress to become high-grade/malignant tumours. Malignancy in fact is somewhat different in primary brain tumours compared with cancers elsewhere in the body. In the latter case malignancy is determined by the propensity of the tumour to metastasise to other sites within the body. Malignant primary brain tumours, however, rarely metastasise, but show a marked propensity for local infiltrative invasion of the surrounding brain tissue. ¹³⁵

Number of people affected

107. The Committee heard that the number of people affected by different cancers had a significant impact when prioritising research funding. Brain tumours were viewed as being relatively rare. We also heard, however, that incidences of brain tumours were rising and that the way in which incidences have been recorded may actually mean that the situation is worse than was thought. Professor Pilkington told the Committee:

The perceived rarity of primary brain tumours is actually questionable and indeed a few short years ago the registration of cases became more realistic and I am sure we will see the number of cases rising quite markedly over the next couple of decades. ¹³⁶

Professor Warr told the Committee:

[...]we do not know what is causing the increase and that puts us in a position where we cannot launch a public health or education initiative to prevent the incidence rising, so you have to concentrate on better treatment. ¹³⁷

108. The Committee heard that secondary brain tumours were not recorded (secondary tumours found in patients who have survived for example breast or lung cancer), which could significantly impact on how rare brain tumours were considered to be. We heard that people who fought successfully against other cancers such as breast sometimes went on to die from a brain tumour. Selena Crossley told us:

I think all people diagnosed with cancer, any primary, should have their brains scanned for secondaries. My husband had bowel cancer, then it spread

134 Naomi Marley, [web comment thread 30 October 2015 at 8:52](#)

135 [Written evidence](#) from Professor Pilkington

136 [Written evidence](#) from Professor Pilkington

137 Q60

to his lung, then bypassed everything else and went straight to his brain. Unfortunately then there was nothing that could be done.¹³⁸

Professor Cruickshank told the Committee:

The NCIN is now in a position to recognise that a brain tumour can be secondary or primary, but up until fairly recently, getting at that figure, the denominator for how many people need a brain tumour pathway, has been very difficult. If it is a secondary from the lung, for example, it has been counted as a lung tumour [...]¹³⁹

That will put weight to what I have been saying about the sheer numbers that are coming along now that we are going to have to deal with. The impact on us for surgery, for stereotactic radiotherapy, for managing these patients, is going to be phenomenal.¹⁴⁰

109. We also heard that research into brain tumours could help cure metastatic disease (secondary tumours in patients who have survived for example breast or lung cancer) in the brain, which is predicted to rise. Professor Cruickshank explained:

[...] the number of patients who are surviving with breast cancer has massively increased. They are living much longer—long enough to get metastatic disease in the brain. That is a brain tumour as much as anything else is. So if you add up the figures for benign and malignant intrinsic brain tumours, you are talking 12,000 or 13,000 a year, double that figure for metastatic disease to the brain. We are talking about in the UK maybe 30,000 people who will survive long enough to have metastatic disease to the brain. If that is not an epidemic of world proportions, I do not know what is. [...]

The game is changing now. It used to be palliative care, “Can you keep these people alive for a little bit longer?” With breast cancer and drugs such as herceptin, which now keeps systemic disease under control, if I can control the disease in the brain where herceptin does not reach—which underlies another problem with the drugs we have—not only do they live longer, but they live longer with a better quality of life. This is a really big problem that is creeping up on us.¹⁴¹

Professor Warr told the Committee:

[...] you have the explosion that we predict is going to happen in metastases, and although we are talking about different molecular target drugs, there are still all of the issues with drug delivery to the brain, that any lessons that are learned from pure brain tumour research can be translated easily into that.¹⁴²

When asked what one thing the Government could do to start making the situation better, Emma Greenwood told the Committee:

138 Selena Crossley [web comment thread 29 October 2015 at 16:13](#)

139 Q72

140 Q73

141 Q68

142 Q81

[...] a clear signal to researchers that the UK is open for business. That can feed into various layers of policy, but we have a spending review coming up and while that looks at spend overall on science, I think it is a signal to the research community how seriously we take ourselves as a player in the scientific environment. If there are significant cuts to MRC, to NIHR, that is absolutely going to send the wrong message to the research community at large about what we want to be doing, and that will have a detrimental impact on these difficult areas that need supported infrastructure funding.¹⁴³

Conclusion

110. Brain tumours are the biggest cancer killer of children and young people. In terms of the number of life years lost, it is the most fatal of all cancers. The unique position of the brain has a huge impact on treatment and quality of life for patients. Its classification as a rare cancer conceals the serious societal impact that brain tumours have. Current levels of funding for brain tumour research are not commensurate with the burden of the disease. The Government should take a greater lead in ensuring that this burden is taken into account when research funding is prioritised.

Recommendations

111. The Government should set out clear criteria for research bodies to follow when prioritising funding needs. In doing so, it should consider whether it would be appropriate for these criteria to take into account the burden of disease, particularly numbers of life years lost; survival rates, and in particular an absence of improvement in survival rates; and historic underfunding.

112. The Government should ensure that statistics of secondary brain tumours are adequately recorded so that there is a clear picture of incidences and survival rates for brain tumours.

7 Availability of non-therapeutic drugs

113. Although the Committee was not directly looking into treatment options as part of its inquiry, it was struck by evidence about a drug which could improve the success of surgery to remove brain tumours, causing the least damage to the patient as possible. The Committee heard that, because it was not a therapeutic drug, neither the relevant NHS commissioners nor the National Institute for Health and Care Excellence (NICE) had made a decision on whether it should be funded. Professor Cruickshank explained to the Committee:

In terms of technology for what we do, there are some very obvious things, for example, in Europe you have access to a drug called PharmaMar linolenic acid. It is easily available right across for helping us do better surgery for these patients. The more tumour you can remove when you do surgery safely, the better these patients do through the whole process. It is approved through the EC for all this; it is available. It is not a therapeutic drug, it is a drug that enables us to operate and it is not available in the NHS. It has been turned down by specialised commissioners and NICE were not prepared to consider it because it is not a therapeutic drug. We are left in a limbo where the commissioners will not make an opinion about it and NICE will not make an opinion about it and yet everywhere in Europe is using it, the States are going to be taking it up very soon and we are left sitting there.

Of course there is a sting in the tail: this is expensive, about £900 per patient, but that is subtly different from £30,000 for a therapeutic drug. But the difference for patients will be that about 25% more patients will be able to gain from the treatments that we offer. Then there are some other technologies to do with access to radiation treatment, access to some of the more specialised forms, the robotic stuff. There is very little evidence for robotic surgery in this kind of area. There is evidence for good surgery. It is about having each of the departments that we have properly equipped to be able to deliver that service timeously and quickly. Those are the major issues.¹⁴⁴

Conclusion

114. **It is unclear who is responsible for making the decision on funding for non-therapeutic drugs. This could be a wider administrative problem which could be delaying the potential benefits of non-therapeutic drugs for patients in the UK.**

Recommendation

115. ***The Government should ensure that a decision is made about the use of PharmaMar linolenic acid. It should clarify the procedures for applying for the use of non-therapeutic drugs on the NHS and investigate whether this is a wider administrative problem which could be affecting the availability of these drugs for patients in the UK.***

8 Conclusion

116. For too long, funding for brain tumour research has been inadequate and not given sufficient priority. Britain has dedicated researchers in this area but is losing young, talented people because they are unable to access research funding. The country is losing the chance to be a world leader in this area and is letting down patients and their families.

117. The Committee has heard throughout this inquiry that patients with brain tumours are failed at every stage—from diagnosis and treatment to research funding. There has been little improvement in the prognosis for brain tumour patients over the last 30 years. Brain tumours are often considered to be rare, but they are the biggest cancer killer of children and the most fatal cancer in terms of life years lost—and the incidence of brain tumours is on the rise. The number of life years lost ought to be a major factor in allocating research funding, but it is not given sufficient consideration. Where there has been significant investment into research, the outcomes for sufferers of other cancers, such as breast cancer and leukaemia, have improved dramatically. No one who took part in this inquiry wanted funding to be taken away from other cancers. What they wanted was an equal chance for some progress.

118. Funding for site-specific brain tumour research comes mostly from the voluntary sector. Charities have done incredible work to fund brain tumour research and we commend them for that. However, they face difficulties in fundraising, not least because of a lack of public awareness. The Government must not leave charities to tackle this devastating disease alone.

119. Sole responsibility for deciding on priorities for medical research and for identifying diseases with unmet need should not be left to the voluntary sector. The Government could and should take a greater lead: by playing a role in identifying gaps in funding, by setting priorities for research and by supporting the development of the research workforce required to give those suffering with a brain tumour some hope for the future.

Maria Lester



“For too long fundraising has been driven by the cancer community and the Government must step up and invest its fair share. There is no time to waste. It is too late to save my little brother and I will have to live with that loss for the rest of my days, but with improved funding just think how many other brothers, sisters, fathers, mothers, friends and children could still be saved”.

Copyright Tobi Jenkins

Stephen Realf



Copyright: Ministry of Defence

Conclusions and recommendations

Awareness and diagnosis

1. A number of measures are needed to address the needs of brain tumour patients. The first step should be to increase the awareness of brain tumours and to increase the numbers of tumours diagnosed early. It is clear that brain tumour patients are being failed repeatedly. (Paragraph 46)
2. Earlier diagnosis could improve survival rates and improve patients' quality of life. Earlier diagnosis could also help to increase the numbers of patients able to take part in clinical trials as well as the diversity of tissue samples available for researchers. Moreover, it would clearly be less distressing for patients and their families if they could be diagnosed before their symptoms become so severe that they present at Accident and Emergency. (Paragraph 47)
3. Earlier diagnosis will rely to a large extent on increasing awareness amongst GPs and other front line healthcare professionals about the symptoms of brain tumours. The Committee was impressed by the HeadSmart campaign which shows how guidance can have such a positive impact in a relatively short space of time without over burdening GPs. (Paragraph 48)
4. The Government should provide greater leadership and support to raise awareness of brain tumours amongst GPs and other healthcare professionals in order to increase earlier diagnosis of brain tumours. It should:
 - consider the evidence in this report about the differences between the HeadSmart guidance for GPs and the recently updated National Institute for Health and Care Excellence (NICE) guidelines for the recognition of and referral for suspected cancer in children, young people and adults, and ensure that NICE reconsiders its guidelines.
 - work with professional bodies and Clinical Commissioning Groups to ensure that GPs and other health care professionals receive appropriate training, perhaps as part of their Continuing Professional Development, on the symptoms of brain tumours.
 - take urgent steps to raise general awareness of brain tumours—either as part of the Be Clear on Cancer Campaign, or as part of other public health awareness initiatives. (Paragraph 49)

Funding levels

5. Brain tumour research has been seriously underfunded over decades, putting it far behind many other cancers in terms of the improvements in outcomes for patients. The Committee has heard evidence which suggests that there is a correlation between the amount of funding of research into a specific cancer and improved survival rates and/or reduced incidences. It is clear that existing levels of funding have not been sufficient for researchers to be able to make significant advances in their understanding of this devastating disease. Increased investment into research

into the causes of brain tumours and into potential treatments is urgently needed. (Paragraph 70)

6. 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 levels are adequate and, if not, what it will do to ensure that funding for brain tumour research increases. (Paragraph 71)

Barriers to research

7. 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. (Paragraph 88)
8. The Government should examine the evidence the Committee has taken and consider what action it can take to address the barriers to brain tumour research described by expert witnesses. In particular:
 - The Government should use its powerful influence on funding levels to send a clear message that brain tumour research is a major priority for the UK.
 - The Government should ensure that there is adequate support for young scientists who wish to pursue a career in brain tumour research, so that they can stay and progress in their areas of specialism.
 - The Government should address the concerns raised by witnesses about the ‘red-tape barriers’ which may be reducing the opportunities for clinical trials, and explain what it will do to address these, while balancing this with the need for proper safeguards.
 - The Government should ensure there is effective coordination of bio-banking and tissue collection, to facilitate brain tumour research.
 - In response to the Off-patent Drugs Bill, the Government has said that legislation was not needed to achieve the aims of the bill. The Government should provide a full explanation, with expected timescales, of the steps it is taking to ensure that off-

patent drugs in new indications are being made available to patients consistently across the country, providing appropriate safeguards are maintained. (Paragraph 89)

Setting research priorities

9. The Committee welcomes the recent commitments by both Cancer Research UK and Children with Cancer to prioritise brain tumours as a cancer of ‘unmet need’. Nevertheless, responsibility for ensuring that gaps in research funding are filled cannot rest solely with the voluntary sector. The Government must take responsibility for identifying unmet needs in research funding and taking action to rectify them. If the Government showed additional leadership on brain tumour research funding, other institutions and organisations would follow. (Paragraph 100)
10. The Government should not leave the prioritisation of research funding only to the voluntary sector. It should consider the burden of disease from brain tumours and take a more active role in setting priorities for brain tumour research funding. (Paragraph 101)
11. The Government must ensure greater oversight of research funding to ensure that it is able to identify, and if appropriate take steps to address, any gaps in funding. (Paragraph 102)

Burden of disease

12. Brain tumours are the biggest cancer killer of children and young people. In terms of the number of life years lost, it is the most fatal of all cancers. The unique position of the brain has a huge impact on treatment and quality of life for patients. Its classification as a rare cancer conceals the serious societal impact that brain tumours have. Current levels of funding for brain tumour research are not commensurate with the burden of the disease. The Government should take a greater lead in ensuring that this burden is taken into account when research funding is prioritised. (Paragraph 111)
13. The Government should set out clear criteria for research bodies to follow when prioritising funding needs. In doing so, it should consider whether it would be appropriate for these criteria to take into account the burden of disease, particularly numbers of life years lost; survival rates, and in particular an absence of improvement in survival rates; and historic underfunding. (Paragraph 112)
14. The Government should ensure that statistics of secondary brain tumours are adequately recorded so that there is a clear picture of incidences and survival rates for brain tumours. (Paragraph 113)

Availability of non-therapeutic drugs

15. It is unclear who is responsible for making the decision on funding for non-therapeutic drugs. This could be a wider administrative problem which could be

delaying the potential benefits of non-therapeutic drugs for patients in the UK. (Paragraph 115)

16. The Government should ensure that a decision is made about the use of PharmaMar linolenic acid. It should clarify the procedures for applying for the use of non-therapeutic drugs on the NHS and investigate whether this is a wider administrative problem which could be affecting the availability of these drugs for patients in the UK. (Paragraph 116)

Conclusion

17. For too long, funding for brain tumour research has been inadequate and not given sufficient priority. Britain has dedicated researchers in this area but is losing young, talented people because they are unable to access research funding. The country is losing the chance to be a world leader in this area and is letting down patients and their families. (Paragraph 117)
18. The Committee has heard throughout this inquiry that patients with brain tumours are failed at every stage—from diagnosis and treatment to research funding. There has been little improvement in the prognosis for brain tumour patients over the last 30 years. Brain tumours are often considered to be rare, but they are the biggest cancer killer of children and the most fatal cancer in terms of life years lost—and the incidence of brain tumours is on the rise. The number of life years lost ought to be a major factor in allocating research funding, but it is not given sufficient consideration. Where there has been significant investment into research, the outcomes for sufferers of other cancers, such as breast cancer and leukaemia, have improved dramatically. No one who took part in this inquiry wanted funding to be taken away from other cancers. What they wanted was an equal chance for some progress. (Paragraph 118)
19. Funding for site-specific brain tumour research comes mostly from the voluntary sector. Charities have done incredible work to fund brain tumour research and we commend them for that. However, they face difficulties in fundraising, not least because of a lack of public awareness. The Government must not leave charities to tackle this devastating disease alone. (Paragraph 119)
20. Sole responsibility for deciding on priorities for medical research and for identifying diseases with unmet need should not be left to the voluntary sector. The Government could and should take a greater lead: by playing a role in identifying gaps in funding, by setting priorities for research and by supporting the development of the research workforce required to give those suffering with a brain tumour some hope for the future. (Paragraph 120)
21. Maria Lester: “For too long fundraising has been driven by the cancer community and the Government must step up and invest its fair share. There is no time to waste. It is too late to save my little brother and I will have to live with that loss for the rest of my days, but with improved funding just think how many other brothers, sisters, fathers, mothers, friends and children could still be saved. (Paragraph 121)

Annex: Summary of informal meeting 17 November 2015

Summary

People shared with us their personal experiences of living with a brain tumour or caring for loved ones with the disease. We heard about the problems they experienced with diagnosis, treatment, care and support; the lack of awareness amongst GPs, healthcare professionals and the public of brain tumours and symptoms; the devastating impact on families that brain tumours have; and how important funding for research into brain tumours was to those we spoke to. Although most were particularly focussed on the need for more research funding, the key message was that “at every stage it fails”. The whole process was described as “one big fight”: fighting for diagnosis, for treatment, for support, and for awareness and funding, whilst also fighting for life. No-one we spoke to wanted money to be taken away from other cancers but they wanted brain tumours to be given a “level playing field.” Whilst survival rates for other cancers were getting much better with improvements in awareness, diagnosis, treatments and prevention, those with brain tumours were left behind with little or no hope for the future.

Diagnosis

1) Everyone we spoke to had stories of late diagnosis. The range of symptoms experienced by people ranged from headaches, fits, dizziness and back pain to hiccups, numb fingers, flu-like symptoms, a ‘funny smell’ and déjà vu. The range of initial misdiagnoses they had received was equally varied—from stress, depression and hormone problems to epilepsy, poor eyesight and vertigo. Many felt that GPs were reluctant to refer them for scans due to the cost. Everyone agreed that there was a serious lack of awareness of brain tumours amongst GPs and healthcare professionals as well as the wider public. Vicky for example, whose son tragically died just six months after diagnosis, told us how a CAT scan had initially been refused because they were considered to be too scary for children. Rachel told us how her son, who was 2 years old, had been ‘fobbed off’ when he was just 72 hours away from dying.

Care and support

2) We heard from many about their struggle to find help following their diagnosis and heard that there was a lack of sign-posting to support for those diagnosed with brain tumours.

3) Most of those we spoke to had set up their own charities or were working and fundraising for existing ones to raise money for research as well as to help and support people with brain tumours and their families. Caroline for example had been so struck by the underinvestment in her local neurological ward that she started a charity called *Friends of the Neuro Ward ARI*. She explained that the aim of the charity was to improve patient comfort and care on the ward and purchase an intraoperative MRI scanner. Although she said that research was ultimately how a cure would be found, she felt that brain tumours were so far behind other cancers that she wanted to focus her efforts on those for whom more research would be too late—those who are living with it now.

4) “It’s a very private disease”. Most described in some way how brain tumours were a lonely and very private disease, that held a certain ‘stigma’. We heard that many people were reluctant to talk about brain tumours unlike other cancers such as leukaemia and breast. Some explained how the experience of visiting a neurological ward was so horrific that when people left they simply didn’t want to or couldn’t talk about it.

5) “Put simply you can’t replace a brain”. We heard about the irreversible changes to people’s personality caused by brain tumours and the wide range of life-changing disabilities they can cause such as loss of senses, body and facial movements. We heard how distressing this was for patients and their families.

6) Most of those we spoke to had found support from online groups and social media channels like Facebook. Anna Swabey, who was diagnosed with a terminal brain tumour at the age of 23, told us how she had started to write her own blog called Inside my Head partly to help others but also partly to help herself release some of her feelings by writing them down. She said that sometimes it was the “less important sounding things” like having to surrender your driving license because of the fits or putting on weight and having a shorter temper as a result of taking steroids to stop the swelling which were really hard to deal with.

7) Those we spoke to with so-called benign tumours felt like they were often dismissed as being the ‘lucky ones’ because their tumours were not considered to be cancerous. We heard that this definition was not always considered helpful as benign tumours also grow in the restricted space of the brain, they can still be fatal, and they can become cancerous.

8) Several people stressed a real lack of support following operations. “There’s no support for those who have gone through surgeries to remove the tumour, even though they are still going through a nightmare.” Julia for example told us how after her operation she couldn’t stop crying. She explained that it was only after finding a community of people online, that she was reassured it was a completely normal after such an operation.

Treatment

9) People told us how many of the generic cancer drugs were not an option for brain tumour patients because of the blood-brain barrier which prevents any medicine submitted through the blood from entering the brain. We heard some very distressing stories of treatments available to those with brain tumours. Rachel, whose son suffered from a brain tumour described treatment protocols as “barbaric.” Hannah told us that doctors simply hadn’t developed protocols for brain tumours because they were considered so rare.

10) The lack of options however available to brain tumour patients meant that they had little choice. We heard from Jenifer, whose son tragically died from a brain tumour just over 10 years ago, that very little had changed since then. She had since changed her career and dedicated her life to raising money and awareness including the role of Chief Executive for the Brain Tumour Charity.

Biobanking

11) Some participants talked about the importance of bio-banking for researchers to be able to access tumour tissue samples. Hannah Jones told us that specialist medical

oncologists in brain tumours were required and that the Government needed to ensure that the UK has the resources required so that the UK is viewed as the best place to do research and attract the world's leading specialists in the area.

Funding and statistics

“It's not just about statistics, I'm a real human being.”

12) All those we spoke to were incredibly knowledgeable about research funding statistics. Some shared with us their experiences of searching online and learning about the survival rates following their diagnosis. They told us that the survival rates had not improved and that less than 20% of people diagnosed with a brain tumour lived beyond 5 years. Many felt that because brain tumours were considered to be rare they had been ignored. People told us how frustrated they were at the lack of awareness and acknowledgement of the fact that brain tumours are the biggest cancer killer of children and those under-40s.

13) There was frustration that secondary tumours were not recorded. We heard for example that if someone survives breast cancer but it then spreads to the brain and the fight is lost there, the death is still recorded as breast cancer, not brain”. There was also a frustration from those who had so-called “benign” tumours that those statistics were often separated from the high-grade cancerous tumours when it came to funding research.

14) Many told us that the difficulty in fundraising for brain tumours was largely due to a lack of public awareness and that the low survival rates, and the speed at which those who were diagnosed with brain tumours died, meant there was a lack of role models and survivors.

15) Tom Greenway, whose son had died just one month previously, told us how the lack of funding for research into brain tumours mean that scientists would often move on to do a different subject. Becky told us that the US was way ahead of Europe in terms of research. She explained how difficult it was to find jobs researching in the area of brain tumours within the UK. Becky also told us about the need for more tissue in order to learn more about brain tumours, but that not everyone was asked about donating tissue after surgery. Kathleen, a PHD student, shared stories of researchers she had met who moved to Norway to continue their work because it was much easier.

16) Many used the example of leukaemia, for which survival rates have improved significantly following a large amount of investment into research. They told us that the money raised by charities was a drop in the ocean compared to what was needed for brain tumours.

Attendees and their web thread comment (if applicable)

Jenifer Baker OBE

I've been affected by brain tumours both personally and professionally. Personally our son, Stephen, was diagnosed with a grade IV glioblastoma in 2003 aged 22 and died 18 months later. Another young life tragically cut short with ongoing impact and consequences for Stephen's younger brother, other family members, girlfriend and his many other young friends who still mourn his loss. Stephen received only the standard and challenging

treatments of the time (little changed today) and was not offered the opportunity of participating in a clinical trial. Whilst highly unlikely to have led to a cure for Stephen this might have extended his life for a period and would have given him hope along the way. Professionally I was the Chief Executive of the UK leading charity - Brain Tumour UK - from 2006 to 2013. Our mission was to provide advice and emotional support for patients, carers and families, to raise funding for research and to raise awareness of the disease. Through daily contact with hundreds of people across the UK through our helpline and our network of patient support groups we were reminded of the agonising challenges of living with a brain tumour diagnosis and the call from all concerned for more scientific and psychosocial research into this complex disease and an increase in the availability of clinical trials.

Caroline Critchlow

Suggested by Alistair Carmichael MP (Orkney and Shetland). “My husband had an enormous acoustic neuroma and underwent a 22 hour operation two years ago. Despite our own problems we were struck by how underfunded and dilapidated ward 205 at Aberdeen royal infirmary was. Despite the very best efforts of dedicated and supportive staff, in order to help we set up a charity friends of the neuro ward and in two years have raised £130000 to help refurb the ward. This underfunding we found is reflected in anything to do with brain tumours and we were horrified that despite it being the biggest cancer killer of the under 40s it only receives 1 percent of cancer research funding. Because the root causes are not being tackled we feel we must try and raise a further 1 million for an interoperative scanner. There isn't one in Scotland which at least will be able to remove more of the tumour... but how much better it would be if we could help prevent them happening at all. Living in Orkney I would love to be more involved and have approached my MP Alistair Carmichael to see if I could be involved we have a lot of contact with folk in the far north of Scotland because of our charity and are here to listen to their issues.”

Bhavna Emery-Jones

Suggested to the Committee by the Brain Tumour Charity.

Wendy Fulcher

Lost her husband to a brain tumour and then founded the charity Brain Tumour Research Campaign. “When my husband died from a brain tumour I learnt how little was known about the cause of brain tumours and how little funding was invested in brain tumour research. 15 years later this is still the case and despite brain tumours being the biggest cause of cancer death in young people and causing the highest number of years of life lost, less than 1% of national cancer research funding goes into brain tumour research. This is unacceptable - the charities try desperately to redress this shameful imbalance but it needs a concerted national funding effort to give brain tumour patients a fair chance of better treatments. Scientists and clinicians are fighting for the chance to find a cure for this devastating disease but they need the support of government to receive a fair share of funding to research the causes and possible treatments for these patients.”

Tom Greenway

My son died last month of a medulloblastoma age 28. Prior to diagnosis he suffered excruciating headaches, balance problems, sickness, and hiccups yet GPs and consultants failed to diagnose a brain tumour. As the symptoms worsened he went again to the GP saying he thought he must have cancer of the brain, but the GP diagnosed migraine though acknowledged he could not explain the hiccups despite the symptoms combined being indicative of a brain tumour. Within three weeks his condition became drastic, he was given a scan and transferred that day by ambulance to another hospital for surgery on a Grade IV tumour. The surgery was successful but there followed intensive radiotherapy and chemotherapy daily for six weeks followed by chemotherapy for a further six months to cure the cancer that had spread to his spine and anything that may be left in the brain. Sadly within two months of this treatment ending, which had appeared successful, he deteriorated and cancer of the bone throughout was found - he died. What needs to be done?

- a) Early diagnosis is essential if treatment is to be successful - GPs need training - their failure to diagnose at an early stage is reported all too often. Public awareness of the symptoms is also required.
- b) The various types of brain tumour need to be better understood. Research into post-operative treatments developed specifically for brain tumours is required.
- c) Brain tumour research is relatively neglected - indeed little mentioned despite these tumours being a major killer of mainly our young; this imbalance must be rectified.

Hannah Jones

Suggested by Chris Matheson MP (City of Chester).

It is disgusting that brain tumours are the biggest cancer killer in the under 40s, yet the research is so poorly funded! Cancer research only give 2% of their funds to brain tumour research, this is why survival rates are not improving as much as other cancers.

Kathleen Keatly

I am currently in the final year of my PhD at the Brain Tumour Centre of Excellence at the University of Portsmouth, studying Glioblastoma multiforme. I am incredibly lucky to be working in an environment populated by scientists passionate about furthering brain tumour research. It is however very apparent how underfunded this field is and that a lab dedicate to this research is not the norm. Funding is disproportionate to those affected by this disease, with only 1% of cancer research spending being dedicated to brain tumour research. The outcome of this on patients and families is clearly evident by the many heart breaking comments on this feed from friends, family members and brain tumour patients themselves and is something we witness first hand when patients and their families visit the lab. From a PhD students point of view, although there are many of us young researchers who want to make a difference in this field, many of us are forced to move to other areas of research or other countries due to lack of funding. Without the brilliant charities who desperately try to bridge the funding gap critical research would further lag behind. As

a young scientist I hope that I will be able to stay within and contribute the field of brain tumour research.”

Julia Manning

According to my neurosurgeon I was lucky my tumour was discovered when I had laser corrective surgery. People with my type of meningioma don't normally see a surgeon until there sight has completely gone and their tumour is the size of an orange! Devastation is the theme that runs through my story and I'm sure plenty of other brain tumour fighters:

Devastation of being told “you have a brain tumour”; Devastation of being told you require surgery to save your sight; Devastation of going through a 12 hour op waking up to complete lose of sight in your right eye, previously it was only partial loss. ; Devastation of being told they could only debulk the tumour as it was too dangerous, not only is it growing around your optic nerve but also around your carotid artery. The tumour is now inoperable but hey it's benign. ; Devastation of being told it's a case of quality rather than quantity of life!; Devastation of being told the tumour is growing again and is threatening the sight in your left eye. Although the tumour is benign they recommend you have radiotherapy to shrink the tumour; Devastation of being so ill during and for a year after the treatment finished; Devastation of seeing your husband and son feeling helpless as you fight this battle, knowing you will never be the old you again; Devastation of finding out Brain tumours are the biggest killer of children and people under 40 yet only receives 1% of any government funding, all other funding is done by charities; Devastation and disbelief that treatment and survival rates for most other cancer are prevalent and published regularly in the media. Yet this government gives a low priority to funding and we rely on charities publishing statistics. How many people have to die before the government will take notice and commit more to research, support for fighters of this disease and ultimately a cure.

Rachael Mason

My son had 18 months of chemo for a tectal plate glioma, numerous MRI & CT scans, biopsy, etv, a port fitted and removed, shunt and 2 shunt revisions. The treatment protocols are barbaric. The time span is devastating. Siblings suffer emotional stress at being separated from one or the other parent for extended periods of time, often having to make unplanned trips to hospital.”

Rebecca Mather

If we look back on the last 50 years of research, breakthroughs in brain tumour treatments are few and far between; we have made such little progress. There are some therapeutic challenges to overcome, but one should not be lack of funding. I currently work as a brain tumour research PhD student in a laboratory funded by brain tumour charities. These charities work tirelessly to drive research in order to partly compensate for the lack of government funding. Charity work is invaluable to us, but we are moving far too slowly as researchers. We are at a major disadvantage. So few scientists can pursue brain tumour research as a career path, so our teams remain small. To add insult to injury, scientists who do have brain tumour research training are often driven out of the field due to its chronic lack of funding to find work in better funded cancer fields or in other pathologies.

I have seen the devastation brain tumours cause to patients, their friends and families, including my own. Driving research will see breakthroughs in treatment and save lives, but this cannot happen without funding.”

Brenda Ravening

My tumour was a grade 1 benign haemangioblastoma which has totally changed my life. When people hear it was benign they totally dismiss me even having a problem. I have severe sensory problems starting in my fingers on my left hand up through all of my left arm then through my left breast in my stomach, which feels like I have a rock in it. My rectum and my ladies area are totally affected, down my left leg through to my toes. The whole of my left side feels numb fat heavy and tight. But because I look normal people forget I am living with this aftermath. I drop things all the time, I am always tired, benign yeah great.

Vicky Ringer

My little boy Levi tragically died of a brain tumour, age just 6 years old. He was diagnosed after his symptoms were missed by a consultant paediatrician. Levi was in fact diagnosed when WE demanded a CT scan, frustrated and concerned that although we were repeating ourselves, we weren't being heard. The scan revealed the devastating news that Levi had a brain tumour on his brain stem and cerebellum. We had been irreversibly let down by a hospital system and staff who lacked awareness about brain tumours. We had been told several times there was 'nothing to be worried about' previous to Levi's diagnosis - this could not have been further from the truth. Levi died in my arms just 6 weeks after diagnosis, devastating the lives of his family, beyond words or repair. Since losing Levi in 2006, we have established Levi's Star Children's Brain Tumour Charity and recognise time and time again the need for greater awareness about brain tumours, the need for early diagnosis and the need for more research into treatment and cures for brain tumours. For us, nothing can be worse than losing a child and the knowledge that brain tumours STILL remain the biggest cancer killer of children in the UK is simply not acceptable. The brain tumour community needs to be heard and heard now. How many more children must suffer the devastating effects of a brain tumour or lose their precious life due to lack of brain tumour research funding and awareness? The government needs to listen, hear, understand and act NOW!

Anna Swabey

In January 2015, at 23 years of age, I was diagnosed with a Grade 3 glioma anaplastic astrocytoma and was told I had, on average, 3 years to live. My whole world changed. Although I have been offered treatment and have undergone radio/chemotherapy and I am on chemotherapy again for a further 12 months, the future looks bleak. Unavoidably, this awful disease will not only take my life, but will destroy the lives of my mother, father, sister, brother, partner, niece, nephews, aunties, friends....my, the list goes on! And since being diagnosed, I have unfortunately come across and met younger, young and older people in the exact same situation; who too worry what they will be leaving their families to deal with when they are gone. I chose to try and not dwell too much on this horrific news and to turn it into some form of positive; I want to make a difference to lives like mine, and to those who are yet to be diagnosed. I decided to start writing a blog called

Inside My Head (www.annaswabey.wordpress.com) detailing my life with a terminal brain tumour - I saw this as a way of helping myself, others alike, and to raise awareness of this severely underfunded cancer (of which I knew nothing about until my diagnosis). Off the back of its popularity, I began fundraising for Brain Tumour Research Campaign (to date I have raised £35k). Research into brain tumours is my only hope of living. I will not stop fighting for more funding into research until my last breath! Forgive me, for I am not a doctor, a scientist, and I by no means profess to be an expert in the field at all, but if brain tumours kill more people under the age of 40 than any other cancer - why does research into brain tumours receive a mere 1% of national cancer research funding?! ...It does baffle me. My diagnosis has changed my life forever. The only change I wish for the future is that there will be a new found hope; different treatments, and ultimately, the best 'C' word I will have ever heard - A CURE.

Carolyn Toshney

Suggested by Stuart Donaldson MP (West Aberdeenshire and Kincardine).

Formal Minutes

Tuesday 1 March 2016

Members present:

Helen Jones, in the Chair

Steve Double

Paul Flynn

Oliver Dowden

David Mackintosh

Paul Scully

Draft Report (*Funding for research into brain tumours*), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 119 read and agreed to.

Annex and Summary agreed to.

Resolved, That the Report be the First Report of the Committee to the House.

Ordered, That the Chair make the Report to the House

The following written evidence was ordered to be reported to the House for publication:

Celia and Melvin Ridley (BTR0008)

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

[Adjourned till Tuesday 8 March at 2.00pm]

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the [inquiry page](#) of the Committee's website.

Tuesday 3 November 2015

Question number

Maria Lester, Peter Realf, and Elizabeth Realf, petition creators

[Q1-23](#)

Emma Greenwood, Head of Policy Development, Cancer Research UK, **Neil Meemaduma**, Research Grants Manager, Children with Cancer, **Sarah Mee**, Head of Policy and Campaigns, The Brain Tumour Charity, and **Sue Farrington Smith**, Chief Executive, Brain Tumour Research.

[Q24-59](#)

Tuesday 24 November 2015

Professor Garth Cruickshank, University Hospitals Birmingham NHS Foundation Trust, **Professor Geoff Pilkington**, University of Portsmouth, and **Professor Tracy Warr**, Brain Tumour Research Centre, University of Wolverhampton

[Q60-82](#)

Dr Karen Kennedy, Director, National Cancer Research Institute

[Q83-109](#)

Published written evidence

The following written evidence was received and can be viewed on the [inquiry page](#) of the Committee's website. BTR numbers are generated by the evidence processing system and so may not be complete.

- 1 Brain Tumour Research ([BTR0004](#))
- 2 Cancer Research UK ([BTR0003](#))
- 3 Celia and Melvin Ridley ([BTR0008](#))
- 4 Children's Brain Tumour Research Centre ([BTR0002](#))
- 5 Letter from the Department of Health ([BTR0007](#))
- 6 National Cancer Research Institute ([BTR0006](#))
- 7 Professor Geoff Pilkington ([BTR0005](#))
- 8 The Brain Tumour Charity ([BTR0001](#))