Petitions Committee

Oral evidence: Funding for Research into Brain Tumours, HC 554

Tuesday 3 November 2015

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Written evidence from witnesses:

- Sarah Mee, The Brain Tumour Charity

Watch the meeting

Members present: Helen Jones (Chair), Steve Double, Oliver Double, Paul Flynn, Ben Howlett, David Mackintosh, Kate Osamor, Paul Scully.

Questions 1-59

Witnesses: **Maria Lester**, **Peter Realf**, and **Elizabeth Realf**, petition creators, gave evidence.

Q1 Chair: Good afternoon, everyone. Welcome to the Petitions Select Committee. I would like in particular to welcome our first witnesses, Maria Lester and Peter and Elizabeth Realf. We are very grateful to you for coming this afternoon and also for coming to the launch of this Petitions Committee; two of you were at the launch, at least. We understand that this is very difficult for you because you have been through a very traumatic time as a family, so we hope that some good will come out of your efforts in raising the profile of this issue. But we would also like to say to you that if any time it is difficult for you and you want to pause for a few moments, please let me know and we will do that.

Maria, I think you want to make a brief opening statement before we go into the questioning. Is that right?

***Maria Lester*:** It is, yes.

Chair: Yes, feel free.

Maria Lester: Thank you for inviting me here today. 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. Brain Tumour Research shared my view and issued a statement that read, "The Government has responded to this petition but has failed to consider years of life lost when prioritising research spend". It was therefore a huge relief to hear that the Petitions Committee would be launching its own inquiry and I hope that this is the start of some meaningful action.

What exactly would I like to see happen? First, there needs to be more awareness of brain tumours to help prevent the kind of delays in diagnosis that were highlighted on the web thread. I think the HeadSmart campaign, for example, is a great initiative and I would like to see further progress in this area. Secondly, there needs to be a much greater investment in brain tumour research and I think it is vital that the Government ring-fences funds specifically for this purpose. 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. Finally, I would like to see greater sharing of information so that it is clear precisely who is funding what and when. It would be good to come back to this subject: if we had a proper register, that would help to reduce the risk of wasted resources through duplicated work.

Above all, I would like to stress that we need to start taking action and we need to start taking it now. 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. Thank you.

Q2 Chair: Thank you very much, Maria. That is very helpful and has highlighted a number of issues that are also highlighted in your petition, which the Committee will wish to look at a bit further. You are right that we received a number of comments on the web forum about the difficulty in getting a diagnosis. We do realise that early symptoms of brain tumours can

mimic many other diseases and this can be difficult, but it is something we want to explore with some of the experts later on. In the meantime, I wonder if one of you, perhaps Peter or Maria, could tell us a little bit more about the experiences that Stephen had in trying to get a diagnosis so that we understand the impact on a particular person, a particular family. Peter or Elizabeth, would you like to take that?

***Elizabeth Realf*:** Can I take that to start with? As far as we knew, Stephen was a fit, young, healthy man. He had a full medical before he joined the RAF and because he wanted to be a pilot, he was given an even more detailed medical, so we thought he was a fit, healthy young man. In the year 2007 he completed his initial officer training and in the August of that year, he came home for the bank holiday weekend. On the Tuesday he was going down to have his flying helmet fitted. He said to me on the Monday, "I'm just going for a run around the block. I'll be back in a minute". A few minutes later—and around the block for us is less than a mile; it was a walk in the park for him—he came home, rang the doorbell. When I went to answer the door I found him collapsed on the drive under the wheel of my car. I called my husband and eventually we had to ring the paramedics. He was out cold. He was shaking. His face was dark grey and the whites of his eyes were bright red and he looked like something from Halloween or a Frankenstein movie. The paramedics worked on him for about half an hour on the drive in an ambulance and eventually took him to hospital.

By the time he got to hospital, he had come around. They kept us waiting in A&E for quite a long time, a few hours, and by the time they came and assessed him he was sitting up. He was fine. He knew what day it was; he could count one to 10 backwards; he could follow the finger. They seemed fairly dismissive of him. There was a medical doctor there who said he was an Army medic on secondment to the hospital. He said, "If I don't find out what is wrong with you, the RAF will want to know so I would like to keep you in overnight and do some more tests and maybe a scan". They kept him in overnight, did absolutely nothing; let him out the next day, sent home, fine. They said he must have been dehydrated.

***Peter Realf*:** Could I just add there as well, he had a cut on the back of his head where he had fallen and hit the ground.

***Elizabeth Realf*:** But he did not have a scan, did he?

***Peter Realf*:** No.

***Maria Lester*:** No.

***Elizabeth Realf*:** He did not have a scan. 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; he must have been dehydrated.

In December that year, a couple of months later, he rang up and he said to me, "Mum, I keep getting this ringing in my ear and pins and needles down my right arm. Do you know what it could be?" I just immediately associated it with the fall that he had had, "I think that has something to do with that fall". We were thinking, "Well, maybe you have trapped a nerve; maybe you have a blood clot. Maybe it is something to do with that fall"

but we did not know. He did come home one weekend. We sent him to the osteopath, who checked him out, said everything was all right, he did not have trapped nerves or anything.

He was going back to the RAF after Christmas, beginning of 2008, and he was getting in his car to drive back to Linton and he said, "I'm going to have one of my turns". That was the first one Peter and I had observed him have. He sat in the car. He went very pale. His arm was shaking because he had pins and needles down his arm. It lasted a few seconds. We said, "Are you all right to drive back? Are you sure?" "Yes, I will be all right. I'm fine. It's over now. I've had it." So he went back.

From February these seizures—what we know now were seizures—were getting worse, but he was still passed as fit for flying. The RAF said, "You know, there cannot be much wrong with you, lad. You are young and fit. There cannot be much wrong". In March 2008, on a routine RAF medical, his urine and his blood samples were slightly amiss and also the doctor could not see the disc properly in the back of his eye and he said, "I have never seen that before". He passed him to two other medical people there, both of whom looked at him, and they kept saying, "Oh, never seen that before. Put your hand over your eyes. Can you read the letters? Yes, good. Can you read the letters? Yes, fine". But because his blood and urine were slightly out, he got referred to a consultant physician in Peterborough.

When his appointment came through for this physician I said to my husband, "Go with him. We have seen what happens when he has these turns. Go with him and tell him". Pete went. It was—what was he?—a consultant, Trevor Laundy. He was really annoyed that Stephen had turned up with his father, thought a young officer should not have turned up with his father, was very dismissive and failed to listen to anything Pete was trying to tell him. He was sent home with a follow-up appointment in two weeks and had to do a urine sample for so many days and take it back.

When he went back the second week, two weeks later, Pete again went with him because by this time Stephen himself had stopped driving because we felt he was not safe. He was concerned he was not safe on the roads if he had one of these turns. He went in again to see this physician and he just happened to have one of these turns in front of this guy and then everything changed. Then he was sent for scans and check-ups and all sorts of things and of course that was when it was discovered, that was when it was found.

Q3 Chair: Thank you for that. What I am getting from your particular story is—I do not want to put words in your mouth—a failure to scan when Stephen was first in hospital—

***Elizabeth Realf*:** Yes, very much.

Chair: —and then a series of doctors who were looking at particular things in their role as physicians for the RAF, but not picking up the problem, for whatever reason, and then at the end, finally when he has a fit in front of a doctor, only then was it taken seriously.

***Elizabeth Realf*:** Only when they saw him do it, yes.

***Peter Realf*:** Yet the symptoms that Stephen had described on the first visit were precisely what happened on the second visit when he had the seizure. He had described exactly the type of thing.

***Maria Lester*:** I think that was quite a common theme on the web thread as well, that particularly with the children, they are young, they are healthy and so perhaps it is not immediately obvious sometimes particularly with the children, and there were these delays in diagnoses.

***Elizabeth Realf*:** I would like to add that at this point I was really frustrated. I knew there was something seriously wrong with my son. I knew there was and he was not right. He was getting quite poorly then. He was getting sick and was not eating, he was very tired. I knew there was something really wrong and it was frustrating that we could not get somebody to feel the same way that we did, which is partly why I sent Pete down with him.

Q4 Chair: Yes, I understand that. Maria, you have had a look at this since and obviously you have done a lot of work on it.

***Maria Lester*:** Yes.

Chair: Do you think that GPs in particular do not have sufficient awareness of brain tumour and therefore do not look for it, do not routinely send people for scans? What do you think, in your experience, lies behind this problem of getting a diagnosis?

***Maria Lester*:** It is tricky and I think that would be a good question to ask Sue from Brain Tumour Research. But I think with brain tumours, it is difficult to spot and to treat. It is not like some other cancers and because there are 120 different types of brain tumour, or even more than that, symptoms manifest in a whole variety of ways, so some patients could have problems with movement, it could be vision, it could be all sorts of other things. Certainly in Stephen's case he did not have headaches, which seems to be quite a common symptom with brain tumours, so I think because there are so many different ways the illness can manifest itself it is hard to spot.

***Peter Realf*:** Stephen's tumour was the size of an orange and yet he never had headaches. It is hard to imagine and obviously that makes diagnosis more difficult.

Chair: It is much more difficult.

***Elizabeth Realf*:** His turns were getting worse, I forgot to say, and by the end he was losing his speech as well. He was getting the pins and needles, the tingling down his arm and he was losing his speech for a few seconds as well, so it was getting worse.

Q5 Chair: Yes, I understand that. That is interesting. Can I just ask you one more question before I bring my colleagues in? We read about Stephen's treatment and about how distressing it was. I am wondering whether you think that Stephen, or you as a family, were given sufficient information on the treatment and its effect before it started and the effect that

that treatment would have on its prognosis. Did you feel that you had enough information to make an informed decision and that Stephen had?

***Maria Lester*:** I will let my parents answer the question about the information, but I just wanted to say certainly my brother, he did not like the treatment in terms of the chemotherapy and the radiotherapy one little bit—

Chair: No, it is very unpleasant.

***Maria Lester*:** But because there are no other alternatives, if it is a choice between that or the alternative, then I think he had to have it because it was his last resort.

Chair: Yes, Peter.

Peter Realf: I was going to add to that. I think we were probably made aware and we certainly were given the risks and the figures for that, but as Maria is saying, it was a question of you can either have surgery or you do not have surgery and there were not a lot of other options. Obviously as things progressed it was then, "We think now is the time to do radiotherapy" and ultimately chemotherapy, but there are not many other options.

***Elizabeth Realf*:** They did say, "This might cause this problem" or, "That might cause this problem".

Chair: Yes, so you did have all the information. That is what I am interested in.

***Elizabeth Realf*:** They did try to keep us—yes.

Chair: Yes, that is great. Thank you. Steve Double.

Q6 Steve Double: Thank you very much for coming in today. You mentioned in your opening statement the shocking statistics on brain tumours and you have obviously learned a great deal from your experience. What have you learnt about the reasons why spending on research into brain tumours is relatively low when compared to other cancers?

***Maria Lester*:** Do you want to take that one about the funding?

***Peter Realf*:** I think there are difficulties regarding funding. Again, that maybe is something you would be better to speak to the charities about rather than ourselves.

***Maria Lester*:** But I think it is a catch-22 situation, we were saying yesterday, because 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, so they might want to do something in that field, but if there is much better funding for—

***Peter Realf*:** I made a note here 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 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-22.

***Maria Lester*:** I would just like to jump in there as well, just to give you an idea of the massive differences in funding between some of the cancers. There is a figure here in the Brain Tumour Research report that NCRI spending on cancers between 2002 and 2012, during that period £352 million was spent on breast cancer research and only £35 million was spent on brain tumour research, so literally 10 times less.

Q7 David Mackintosh: Thank you very much for coming here today to tell us your story. It was compelling and thank you for sharing that with us. You have told us a lot about what happened in your circumstances and since then you have obviously done a lot of work with other people. Do you think that your experience is similar to many others and can you perhaps tell us about some of the other experiences you have encountered, and also any of the statistics around this that you have uncovered?

***Elizabeth Realf*:** I have not included the statistics—Maria is best at that—but I read, I hope, all the ones that were on your webpage and they all had that same story, or 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.

Q8 David Mackintosh: What have the doctors said since around the delay?

***Elizabeth Realf*:** For us? The original doctor, the medical officer that Stephen first saw, when he knew Stephen had been diagnosed with a tumour was absolutely apologetic. He said he had never come across anything like that in all his years.

***Peter Realf*:** He was a very caring man, but he said as an RAF officer who had worked with generally very fit young men and women that he had not seen that in 25 years' service. He was wonderful with Stephen, but he was mortified that he did not know, he was not able to diagnose it.

***Elizabeth Realf*:** He just said he had never, ever come across it in his career. He was distraught at the end, wasn't he, that he had missed it, so we do not hold any grudge with that. It was the one at the hospital at Peterborough that we were not so keen on.

***Maria Lester*:** Going back to your question about the statistics, the ones that stand out for me is it is the biggest cancer killer of children and young adults under 40. Similar to that, it is also that it is responsible for over 20 years' of life lost in the average patient, which makes it the most lethal cancer in this measure.

***Peter Realf*:** The disease robs more patients of more years of their lives than any other cancer. If you take Stephen as an example, Stephen was 26. One could reasonably have expected him to have an additional 50 years of life that has been taken from him and it

seems to be a story throughout the entries on the forum: young men, young women, young fathers, young mothers not only dying themselves, but leaving behind young families.

Maria Lester: I think another statistic that really alarmed me was the one that 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.

Q9 David Mackintosh: Thank you. Obviously what you are trying to do from this is to make sure that Stephen's legacy helps other people not have to go through this.

***Maria Lester*:** Yes.

***Peter Realf*:** Very much.

David Mackintosh: People are watching this now and if those families are going through something similar about the early stages, being diagnosed, do you have any advice to them about insisting on medical—

***Elizabeth Realf*:** I would say if you suspect, if you have a feeling that there is something wrong with your loved one, then you badger and badger and badger until you get something done about it.

***Peter Realf*:** We would also say consider getting yourself an eye test because we arrived at the point where we were concerned and a colleague suggested taking Stephen for an eye test. We took Stephen for an eye test, it cost us £20-something, not a lot of money, and the optician immediately knew that there was something wrong because she could not see the discs clearly at the back of the eye. She wrote a letter, gave it to Stephen there and then and she said, "You must take this straight away to your GP" and at that point it was a cross-over. We already had a scan booked for the following week, as it happened, but the optician did immediately know that there was something extremely serious wrong. We have spoken to the optician since and we have had a conversation about that. She knew there was something wrong there.

Chair: Thank you. There are a number of people on the web forum who have commented that it was the optician who diagnosed something wrong. The Committee has taken note of that. Any more questions, David? Kate Osamor.

Q10 Kate Osamor: Thank you so much for coming here today. I know it is very difficult and I just applaud you for the support that you have given the forum and the support you are giving us to learn a lot more about what Stephen went through and I just thank you for that.

Maria, I just wanted to pick up a little bit on the outcomes that you mentioned at the very end of your excellent piece that you gave to us. It was around data-sharing. It seems that at many points Stephen had access to a professional and things were maybe diagnosed, or not diagnosed; I am not going to quote totally, I am not going to comment on that totally. But from what you are saying, for instance, he collapsed and you took him to the hospital. He

was not diagnosed—or was he diagnosed—that information was not sent back to the employer, the RAF, so at times he was in isolation and things were happening to him, but that information was not being collated into one place.

***Elizabeth Realf*:** The fact that he had collapsed went back to the RAF.

***Maria Lester*:** Sorry, that was not quite what I meant by that, although that is a very good point.

Kate Osamor: Because I was worried that maybe, if that had been happening, that would have helped, if it was.

***Maria Lester*:** No. I think we were pleased with Stephen's care generally, but I would like to see more information shared between the organisations, the different charities and things. For example, I have been trying to find out this week about how much funds have been spent by different things on brain tumour research and the NCRI told me that last year it was just under £7.7 million was spent on brain tumour research; Cancer Research UK told me it was £9 million. I am sure there is a reason why those figures are not the same, perhaps it is looking at different periods and so forth, but I have found it quite a struggle to get the kind of statistics so that you can do comparables and things. I think 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.

Q11 Kate Osamor: Forgive me, I used to be a practice manager before I became a Member of Parliament, so when I think of data-sharing it is always around the person.

***Maria Lester*:** Sorry.

Kate Osamor: Forgive me. It was me.

***Elizabeth Realf*:** I must say that the RAF did know he had had the fall because he had obviously told them. Stephen had told them himself anyway, but because they said to him he was just dehydrated, I do not think they connected it in the end.

Kate Osamor: Thank you so much.

Q12 Ben Howlett: I echo what everyone else has said and the courage that you are showing in terms of coming forward to our Committee. I know how difficult it is as a new MP to come before a load of new MPs and say, "This is what my story is". It is difficult.

***Elizabeth Realf*:** No, it is not difficult. It is really good to be here, I can assure you, and get it out.

Ben Howlett: I am really pleased you are. We genuinely are. To pick up on a point there and a little bit of clarification about this in relation to the RAF, was he still flying at the time this was all still going on?

Elizabeth Realf: He was still flying at the time it was all going on.

***Peter Realf*:** He grounded himself because he did not feel well. He went and saw his Commanding Officer and said, "I don't feel safe to fly".

***Elizabeth Realf*:** They said that his instructor said to him, "I do not know what is the matter with you now, Realfie. Your hands and feet are doing everything right. Your head does not seem to be following". He said, "I have never had anybody with that problem before. I am not quite sure how we sort this out".

***Peter Realf*:** We now know that obviously spatial situations were affected.

Q13 Ben Howlett: Absolutely. That is incredibly serious as an issue.

***Elizabeth Realf*:** It is incredibly serious and it is more serious, because they do not just learn to fly straight and level, they do spin turns, they have to do stall turns when the engines are stalled. Had he been in one of those for just a few seconds, he could have killed himself, he could have killed his instructor, could have killed people on the ground and they probably would have just said, "Pilot error".

Q14 Ben Howlett: Absolutely. That obviously we probably need to have a look at, aside from this point, but going on to some of the issues you were talking about in terms of research and there are two areas of research here: one from the follow-up of obviously what has happened and how you have found information around research, but also going before that, when you discovered Stephen's condition how did you find the process of finding more information about it and was that straightforward? Were the medical professionals helpful? How would you like to see that improved?

***Maria Lester*:** I do not know about my parents, but I went straight to the internet. That just made for woeful reading and the sad thing is a lot of the things that I read have turned out to be right.

***Elizabeth Realf*:** So did Stephen. He came straight home after his diagnosis and went straight on the computer.

***Peter Realf*:** We tried to dissuade him, but he wanted to know.

***Maria Lester*:** I particularly tried to look at survival rates and that was just tremendously distressing to look at those.

***Peter Realf*:** What I would also say is there were people out there who were prepared to give freely of their time. There is a gentleman here, Professor Pilkington, who spoke to Maria very early on and gave us the benefit of his professional knowledge. There was Professor Cruickshank at Birmingham, who was extremely kind and gave a second opinion when Stephen was not his patient, and he is clearly an extremely busy man. But those people were fundamental to us getting a grip on what was going on and particularly in Stephen's case for giving him some reassurance and some hope back, because when you are told the tumour will come back, it will regrow and it will kill you, it is a pretty damning sort of statement.

Q15 Ben Howlett: I have a similar background with a friend of mine that had a diagnosis of AIDS, for example, a very similar sort of process and that if the information is not necessarily

transferred at the very point, then of course you do have to go off and look on the internet and not everything is factually accurate. But to prevent them having to go down that pathway, to provide that follow-up range of evidence straight away is so important, so that is why I was wondering about that particular question.

***Peter Realf*:** I will not spend too much time on this, but Professor Cruickshank, for example, said to him, "Have you seen the scans? Do you want to see the scans? Do you want me to explain what the scans show?" That was good for Stephen, it really was.

Ben Howlett: That is good to hear.

***Maria Lester*:** I think part of the thing that most upset me was that all the options were all designed to give him a little bit longer, but at no point was there ever an option that was like, "We are going to treat this". That is what I would like to be his legacy, for other people that are diagnosed with brain tumour to have that hope of a cure at some point.

***Elizabeth Realf*:** We were told at the outset that the object of his treatment would be to keep him as well as they could for as long as they could, and to that extent they did what they said. Apart from when he was on chemo, he was reasonably well. We had spells where he was reasonably well up until near the end.

Q16 Ben Howlett: As a final question, Chair, if I may, in relation to the work you have been doing with charities now subsequent to this, you have an awful lot more expertise than me on this, so I would like to hear from yourselves in terms of your understanding of it, but with the resources that need to be targeted would you say that the resources need to be targeted around prevention? Is it greater understanding of the physiology of the brain, for example? Is it more understanding about the brain tumours themselves? What would you say, as you have heard it, are the most important things that we need to be focusing our attention on?

***Maria Lester*:** I do not profess to be an expert in that area and I would leave that up to the medical experts, but I think that the awareness has to go hand in hand with the treatment research into possible treatments, possible cures, because otherwise, if you know earlier but the end result is the same, it is ultimately a longer walk to the grave and they have to come together. We have to have better awareness, catch them early, but be able to do something about them.

***Elizabeth Realf*:** I think there are so many different types of brain tumours and it is so difficult to find out what is causing them. Again, we are not experts on that, but that seems to be the problem, there are so many different types it is just difficult to find out what is causing them.

***Peter Realf*:** You would need to ask the experts, but one other thing is that brain tumours come from that area of the brain where those cells are designed to protect the brain, so brain tumours are notoriously difficult to treat. They are a difficult type of cancer to treat, because they are trying to protect the brain, in effect.

***Maria Lester*:** That is one other thing that has been coming up when I have been looking into it, that there is obviously research done into general cancer research, but a lot of the time brain tumour is such a specific difficult one that the kind of general stuff is not

tremendously helpful to the brain tumour patients. But I do think there is hope when you look at other cancers that have been well-funded, if you take something like leukaemia, which in the early 1970s had a very similar 10-year survival rate to brain tumours, but 40 years later that has been well-funded and research has been carried out. There is a significant improvement in survival now; I believe about a 40% increase in survival rates.

***Peter Realf*:** I think one of the fundamental differences as well is I actually have leukaemia, but I always knew or always felt that I would be treated and things would be okay again, but I just do not know how Stephen coped because I do not think he ever could feel that. It was always hopeless from the diagnosis, although he was always trying to be optimistic, he was waiting for that next bit of research and he was hoping. We were told right at the very beginning in 2008, "He has got five to seven years" but they said, "but you never know, in five to seven years something new might come along" and he had always hoped that would happen.

***Maria Lester*:** That was one of the things that was hardest for the whole family, that we had to live scan to scan, so you would get one out of the way and one might be, "It is okay, it is a little bit stable at the moment" and you would maybe have a few short months where we would try to do fun stuff and then the dread that it was building up to the next one. We all knew that ultimately one day—you know, it was like having a ticking time bomb in his head, wasn't it? We knew that there would be ones where they would tell us it was bad news and that it was growing. I do not know how he did that, just to live from scan to scan to scan.

***Peter Realf*:** We would see him become increasingly tense in the week before the scan, wouldn't we?

***Elizabeth Realf*:** Yes. In fact, it got so bad for him, he was supposed to have scans three-monthly, but he was just finding that so hard to cope with that in the end they said, "We will go six months and if you are worried about anything, come back and we will fit you in".

***Peter Realf*:** "If anything changes, come back."

***Maria Lester*:** That is another thing with brain tumours, as I said earlier, that around 16,000 people a year are diagnosed with a primary or secondary tumour, but the impact it has on everybody around them, so parents, siblings—the doctors were tremendously fond of him, weren't they—his friends, just Stephen's brain tumour alone affected so many people and he has left such a hole in so many lives, hasn't he? I think it affects so many more people than just the patient.

***Elizabeth Realf*:** Yet I have to say I think we were lucky, he 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 surgery has not been as successful and people have come out of surgery who cannot speak, cannot move, had strokes.

***Peter Realf*:** I was going to say, I once heard a neurosurgeon say, "When I come out of an operation and if the patient is absolutely fine, I wonder if I could have taken some more. If I come out of an operation and the patient has deficits, I wish I had not taken so much".

***Maria Lester*:** I think that goes back to what you were saying earlier about my comments that sometimes the treatment was almost as frightening as the illness. I cannot imagine how scary it must be to be 19 and to be awake through most of an operation where they are taking parts of your brain out.

***Peter Realf*:** His head was bolted to the table.

***Maria Lester*:** Yes, but he did not feel like he had other treatment options.

Q17 Paul Flynn: Can I just echo what my colleagues have said, how grateful we are for the fact that you have given evidence to us today so eloquently and so movingly, as you did at the launch of this Committee, which is a very new Committee, and we are going ahead cautiously. If anything justifies the existence of this Committee it is the evidence that you have given. I think we would all like to do what we can to support you.

One of the most impressive statistics in here that you have given us is about the years lost, because it is a disease that hits very young people. Could you help on the question of the funding? You say it is 1.5% of the total cancer funding. Could you give us an idea of what percentage of the total cancers it is?

***Maria Lester*:** I do not know. That would be a question for Sue, but I do know that last year it got 1.5%, which was £7.7 million of a pot of just below £500 million. It is my understanding that is higher than it has been in previous years, and until very recently it was less than that, it was below 1%.

Q18 Paul Flynn: There is never any exact correlation between the cures that are discovered in research and the amount of money that is spent. The thing that has had the greatest amount of research on it is the common cold and they have solved very little. But certainly there is a relationship between the two and we have seen spectacular successes in other research, AIDS was mentioned and other cancers, a huge move forward. We are absolutely behind you there.

Did you say that there were various types of brain cancer and all presenting different symptoms, because that would present an enormous complexity and challenge to the researchers? Perhaps we can raise it later.

***Elizabeth Realf*:** The medical people and the researchers will be able to cover that.

Q19 Paul Flynn: You have been very successful in bringing the first-ever petition with 10,000 signatures on it to come before this Committee. One of the problems we have is that very few of us have come across instances of brain cancer. The first time I have come across it in my life is a friend's 23 year-old daughter, which was about a fortnight ago. But I have come across dozens of cases in my own family and friends of lung cancer and breast cancer. I think that applies to most people; we have not come across it.

You are going the right way about this and if you use the organs of publicity, for instance, it might make it come home to people if one of the characters of one of the soaps had this on

television. It is something that people could relate to, to realise that this awful disease is a particularly tragic threat to young people, something along those lines. It is not easy to achieve, but something that would bring it home to everyone how terrible this cancer is.

***Maria Lester*:** That is why the brain tumour community is so passionate about this subject. I was the same, I did not know anything about brain cancer whatsoever until Stephen was diagnosed, but I think once you know somebody with it and you see just what a cruel illness it is and what they have to go through, once you have seen it you cannot turn a blind eye to that then.

Q20 Paul Flynn: Perhaps the most shocking part of your narrative is the failure of the initial doctors to recognise how serious this was, when it seems so clear that the alarm bells should surely be ringing. Have you any views on that, of how the medical profession understand this? Are they not alerted to the symptoms you describe, which sound like very alarming symptoms?

***Elizabeth Realf*:** My feeling is he should have had a scan when he collapsed in the very first instance. It was unusual for a young healthy person to collapse and he was collapsed and he was out cold. They said to me was he fitting. I do not know whether it was a fit, but certainly his hand was banging away. They did say it was unusual for a healthy person, "But can't be anything much wrong" instead of saying, "It is unusual for that to happen to a healthy person. Perhaps we better look and see if there is anything". I think maybe scans should be more widely used. I think doctors do not like to send people for scans. I do not know whether they are expensive, whether it is a cost factor, I do not know on that, but sometimes when people present with symptoms it might be better to say, "Hang on, let us rule out that it is anything serious and then we can go on" and then you would rule out brain tumours.

Q21 Paul Flynn: Is it common to others you know who have been in this position that the diagnosis has taken a long time?

***Elizabeth Realf*:** Yes, a lot of the threads on the website it is one of the common factors, no matter what type of tumour they have, what age they are, whether they are male or female, the common thread through is that they were not diagnosed, the misdiagnosis, and some people for years. I suspect had Stephen not had this seizure in front of this guy at Peterborough he would not have been diagnosed for a long time either. He probably would have been sent back to flying, to be honest.

Paul Flynn: Thank you very much.

Q22 Chair: Just one more question for you before we go on to our next round of evidence. What would you like to see the Government do to raise awareness of this, both among the professionals and the public? If you could have just one or two things done, what would they be?

***Elizabeth Realf*:** I would like to have more awareness, of doctors to have an awareness. I do not think you can say there are classic brain tumour symptoms, many people present with many different symptoms, so it is difficult to say, "This is a classic brain tumour symptom" you do not have a lump, you cannot feel it, you cannot see it. I think there

needs to be more awareness that this thing is more common than they think and it is not a rarity, it is often a possibility. That is on the diagnosis side of it, but as for the—

***Peter Realf*:** Certainly in terms of GP training it would seem that there needs to be a greater awareness of brain tumours among GPs, certainly at the training stage.

Chair: Just as something you rule out at least.

***Peter Realf*:** Obviously a lot of these people are presenting not to hospitals necessarily, but to their GPs.

***Elizabeth Realf*:** A lot of people in their comments on the web were saying they were fit and healthy, they were runners, they ran marathons, they played football, rugby or whatever. If somebody like that presents to a doctor and you think, "Well, they are not the sort of people that come in every week with, 'I have a headache or my big toe hurts, my little finger hurts'" maybe they should be taken more seriously and say, "Okay, before we go any further, let us rule out that it is nothing serious and have a scan done". Rule out that it is nothing serious, then you can go down whatever route, migraines, whatever. But it seems to be the other way around, they go down the migraine route for years and then find out it was a tumour.

***Maria Lester*:** I agree, and I would like to see doctors taking into account, particularly if it is children, if they are going in with their parents and the parents are saying, "This is not normal behaviour, this is something that is very out of character" or, "I am very, very concerned about this because this has never happened before" I would like them to listen to the parents and trust that their mothers and fathers do know what they are like on a day to day basis and if they think something is seriously wrong to properly investigate. I would also like to see some more funding for initiatives like the HeadSmart campaign to raise awareness.

Q23 Chair: Thank you very much, Elizabeth, Maria and Peter, we are very grateful once again for you coming here today, for telling us your story and also telling us about a remarkable young man who was your son and brother. We hope at least you will see something useful come out of this. We are very grateful to you for all your campaigning and for what you have done to try to make something positive come out of a great tragedy and we do wish you and your family all the best for the future.

***Elizabeth Realf*:** Thank you very much for inviting us.

Chair: You are very welcome.

***Peter Realf*:** As you are going to go into a session with the charities, would it possible if I just raise one point?

Chair: Yes, of course.

***Peter Realf*:** I do have some concerns about funding from time to time and I have some concerns about the methods used by the larger charities to allocate research funding. Some of these charities will proudly tell you that they adopt peer to peer funding where ideas put forward for research are examined by a group of fellow researchers before deciding if

funds will be provided. My concern is this: I suspect this system carries with it the danger of creating an environment where researchers start acting in the safest way possible in order to still retain their funding. Coming from Rugby, as we do, and thinking of Stephen's love of aircraft left me wondering would Sir Frank Whittle ever have received peer to peer funding to develop the jet engine? I am not sure he would. Many of his peers were talented, but they did not have his genius, his creativity and his vision and sometimes huge leaps in research require that someone takes a step back and looks at the problem in a different way. Does peer to peer funding systems support those individuals? I am a little concerned that maybe it does not.

Chair: We certainly will want to explore that with some of the experts later on, so thank you very much for raising it. You are very welcome to stay and listen to the rest of the evidence.

Examination of Witnesses

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

Q24 Chair: Can I welcome our next panel of witnesses here: Sue Farrington Smith, Chief Executive of Brain Tumour Research; Neil Meemaduma, Research Grants Manager at Children with Cancer; Sarah Mee, who is Head of Policy and Campaigns at the Brain Tumour Charity; and Emma Greenwood, who is Head of Policy Development at Cancer Research. Thank you all for coming. We are going to get straight into questions. I know that some of you may have other things that you want to say and I would be grateful if you would submit that as written evidence because of the lack of time.

I want to begin by trying to dig into this question of funding a little bit. The petition told us that only 1.5% of national cancer research funding is spent on brain tumour research; the Government says it is 3.3% of site-specific funding. Of course those are two different figures based on two different ways of assessing it. Are the records accurate enough to tell us exactly what is being spent on this area? Sue.

***Sue Farrington Smith*:** The records in the public domain predominantly come from the NCRI and that is made up of the research spending of 22 partner organisations, of which seven are Government funded and the rest are charitable organisations. In that respect I think the total spend will be accurate because I know they collect that data on an annual basis.

***Emma Greenwood*:** The important point here is almost whichever way you cut it—and obviously different people have different mechanisms for assessing site-specific spend on tumour types versus how much of a contribution you could allocate for more basic biology—it is clearly not enough and there needs to be an ambition to grow both the quantity and quality of research in this area.

Chair: Neil, do you have any comments on that?

***Neil Meemaduma*:** The NCRI is a great resource for all of us as charities to determine how much is spent on different types, so we do need it and they provide a great service for us. It is true that the data can be analysed in different ways and that brings in levels of complexity, so if that can be improved then we can drill down to what is being spent on different cancer types.

***Sarah Mee*:** I would echo the comments already made about the value of the NCRI data. The only thing I would add to that is that it does exclude some spend from smaller charities as well as any spend by industry, but it is certainly a good indicator of scale of the spend that is in existence.

Chair: Sue, did you want to add to that?

***Sue Farrington Smith*:** It also excludes research funding at actual universities and hospitals where they receive funds and private donations outside of charitable.

Q25 Chair: The answer is that we can do an estimate but it is not 100% accurate?

***Sue Farrington Smith*:** Yes.

Q26 Chair: But you all agreed, I think, from listening to you, that there is not very much spent on this area, is that right, in comparison?

***Sue Farrington Smith*:** Totally.

Q27 Chair: Emma, how much does Cancer Research receive in funding each year, roughly?

***Emma Greenwood*:** In terms of our income generation, I would have to pull the exact figures for the last financial year and send those in. It is all from the generosity of the British public, we do not get any Government funding. It varies year on year, but it is somewhere in the region of just over £400 million. That, by and large, comes into a central pot, as such, so people do not tend to give us money that is directed to one particular cancer type or other, although there are sometimes some exceptions to that rule.

Q28 Chair: Sue and Sarah, how much do you get in funding in your charity each year? You can give us the figures in writing if you like, but I am just looking for a rough estimate at the moment.

***Sue Farrington Smith*:** Brain Tumour Research was started in 2009. In our first year we raised £6,000; in this current year we are hoping to raise £3.5 million.

***Sarah Mee*:** Again, I can confirm in writing, but our ballpark income for the last financial year was in the region of £7 million. In order to meet our commitments that we have set out in our next five-year strategy, we will be looking to grow that to around £12 million over the next five years.

Q29 Chair: Neil, how much does your charity receive?

***Neil Meemaduma*:** We are spending approximately £6 million in research grants.

Q30 Chair: Of that then for cancer research, Emma, how much is spent in the area of research on brain tumours?

***Emma Greenwood*:** If we look at our annual reports for 2014-15, our brain cancer spend was £9 million. Last year when we published our new research strategy, which I think is referenced in the Government response to this petition, we looked to essentially increase both the quantity and quality of research that we funded across four key cancer types that we felt represented cancers of unmet need. Brain is one of those, but also lung, oesophageal and pancreatic. All four of those represent quite similar challenges, I suppose, in terms of late diagnosis of the disease, lack of treatment options and so on, so we have already identified that over the next five years we want to do much more in the area of brain.

Chair: Neil, how much of yours is spent on that?

***Neil Meemaduma*:** To preface this answer a little bit, we have undertaken over the last couple of years our own analysis of childhood cancer specifically and brain tumours within that. We have our own set of figures and issues around that, which is separate, but 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. This is our largest initiative that we have definitely committed behind and we are looking to spend that across collaborative brain tumour research in the UK, so that is a substantial amount of our research budget going towards that.

Q31 Chair: Thank you, that is very helpful. Is any one of you able to help the Committee by telling us what proportion of cancers in adults and in children—we will look at them separately—are brain cancers compared to how much of research spend goes there? Does anyone know?

***Sue Farrington Smith*:** If we look at today's spend, it is catching up. With children, and we can obviously come back to you to confirm this, a third of cancers are brain tumours and with adults it would be between 1% and 2% are brain tumours. Obviously now that correlates with the spend, but that does not take account of the fact that it is the biggest killer of children, cancer killer, and it is the biggest killer of adults under the age of 40.

***Sarah Mee*:** If I could just add to Sue's comments, I do not think it is necessarily helpful to think of spend per case diagnosed or to think of it in those terms because the amount of investment that is needed to deliver results does not have anything to do with the number of people living with a particular tumour type.

Q32 Chair: Yes, we recognise that. We are trying to get some sense of which cancers are attracting the most funding and whether that is a sensible way to spend the money. Perhaps Sarah or Sue can answer this for me: the Government cites non-specific research as part of the spend. Can you tell us whether you think that kind of research is helpful in dealing with brain cancer or not?

***Sue Farrington Smith*:** The big issue in dealing with brain cancer is the blood-brain barrier. Most standard cancer treatments cannot cross the blood-brain barrier so that is the big area that we have to focus our research on.

***Sarah Mee*:** Even if you remove the non-site specific spend from the analysis, the level of spend on brain tumours as a proportion of site-specific spend is still only 3.3%, so even if you put that to one side, there is still a relatively low level of spend compared to the vast need of improvement that there is in this area.

Q33 Chair: The other bit of evidence that was given to us was that deaths from brain tumours appear to be increasing and we want to try to dig down a little into why that is. Is it that the incidence is increasing, in your experience, or is it simply that we are getting better at diagnosing them?

***Sue Farrington Smith*:** There an element of both of those and also some brain tumours appear as a secondary cancer when they did not even know that the primary cancer was there in an individual in the first place. It is an element of both.

***Emma Greenwood*:** 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. We know that incidences are on the rise and so that overall mortality figure is probably mostly likely linked to that, because if you look at survival that is getting better. However, as Sue has already alluded to, we do not have great data currently on secondary, so we just need to understand that picture a little bit better.

Q34 Chair: Yes. Is that because the data is not collected?

***Emma Greenwood*:** Yes. That is my understanding, yes.

***Sarah Mee*:** I think some of the increase in incidence for brain tumours can be partly attributed to changing diagnostic and registration practices. For example, as diagnostic technology such as MRI became more common, then more brain tumours were picked up. Also my understanding is that there has been a change in registration practices between the different cancer registries over the last few decades, so there has gradually been a catching up in the number of low-grade tumours that are reported. That can account for most of the trend that is being seen in incidence, although not all of it. There are still some tumour types that that cannot fully explain the slight increase in incidence.

Q35 Chair: We can follow that up with some of the experts, but that is very helpful. I also want to raise with you this issue of research. We have had some very interesting evidence that we will want to explore further with some of the clinicians later on about there being very limited funding for PhDs in this area and for post-doctoral research. Therefore the deduction is that we have few experienced researchers in this area because people do not go into it to start off with. Sue, do you have any comment on that? Is that correct and why is it, do you think?

***Sue Farrington Smith*:** Yes, I think that is absolutely the reason why we do not have people going into this area. We are talking at the moment about current spend, but if you

were to go back since the NCRI started in 2002, the average spend on brain tumours has only been £3.8 million a year and it was much below 0.5% even. We are not attracting people into this environment and until recently researchers were having to scrabble around for money and rely on families to give them the money to do the research that they wanted to do in this area.

Chair: Does anyone else want to make any comment on that? Emma.

***Emma Greenwood*:** Essentially this kind of goes to the heart of the issue, which is how do you transform a research environment in the UK that is currently just not established in this area in the way that everyone would like into something where you are seeing a stream of PhD students, you are getting clinicians wanting to run clinical trials? Our approach in the first year of our new research strategy is to focus on trying to get some real leadership in this area so that we can try to generate that long-term buzz about this area of science. We have recruited somebody internationally to lead one of our centres based in Cambridge. We are hoping that that sort of leadership might galvanise all the other levels of the research community, but obviously it takes time and that is the slightly frustrating thing about it.

Q36 Chair: Do other countries have better research establishments in this?

***Emma Greenwood*:** It is an interesting question. If you look at the stats internationally I do not think there is any other country that you could say particularly does much better if you look at survival and those sorts of fundamental stats, which suggest that across the board nowhere is doing exceptional science in a way that is transforming patient outcomes, but we do know that there are some researchers in other countries that have chosen to focus on this area and we have to make the UK an attractive place for them to want to come and build our research environment.

***Sarah Mee*:** If I could add to that, 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.

Q37 Paul Flynn: The pharmaceutical companies: there was an interview this morning on the radio with a scientist who has gone to join the enemy, GlaxoSmithKline, who have a dreadful record on the way that they run their research, they have not reported negative findings and they were fined a huge amount recently in America. But he was making a very strong point about rare diseases and where they should go and trying to introduce a more ethical and a less commercial approach into the activities of the big pharma. I know you are looking for Government money, but is there any way of persuading the pharmaceutical companies to spend their vast resources on these cancers that have been neglected in the past?

***Sue Farrington Smith*:** You have Nick Thomas-Symonds who has his Off-patent Drug Bill on Friday. 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.

Q38 Paul Flynn: We will all be here this Friday for Nick Thomas-Symonds's vote on that. Is this a problem because of the way that the pharmaceutical companies have concentrated on

the popular diseases of stomachaches and headaches and so on where they can sell millions and millions and neglected the rare diseases where their work could make major scientific advances?

***Emma Greenwood*:** I cannot remember who made the point, I think it was Maria earlier, saying there is something about sharing information and data about what research has happened. That is absolutely an area with pharmaceutical companies and all of us as research funders where 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.

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

Q39 Paul Flynn: You said in your evidence earlier that you want the amount in research to be put up, I think it was £35 million you suggested. Can you tell us how you reached that figure?

***Sue Farrington Smith*:** 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, I think.

Q40 Paul Flynn: Are you all convinced that this is a neglected field, brain tumours, and that there does need to be an increase in the attention it gets? Is this a strong feeling that you all have? I know you have, Sue.

***Sarah Mee*:** You only need to look at the outcomes for brain tumours at the moment to see that there is a clear need for improvement in survival and quality of life. Ultimately that needs to be research driven, although in turn that is dependent on the capacity issues that have been discussed previously, so you do need a strong research workforce to deliver the high-quality proposals to deliver that research.

Q41 Paul Flynn: Has anyone found the end of the piece of string somewhere that has some chance of leading to a cure for this or for remission of the disease or has there been little progress on the research for dealing with it over the years?

***Sue Farrington Smith*:** There has been some progress, for example, in children's medulloblastoma there is now greater survival and that is kind of what is skewing the numbers, but in many cases we are still at the very early stages. You have the issues of tissue, not having enough tissue to investigate, so we are sort of 20 years behind leukaemia.

Q42 Paul Flynn: You would approve of the system that is going to be introduced in Wales where there is an assumption that people's bodies, after their death, can be used for research and the organs taken rather than the consent that is given beforehand? That would fulfil a need if there was ample access to tissue for research.

***Sarah Mee*:** There are other issues that need to be addressed first around tissue collection. For example, having a co-ordinated system for biobanking 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.

Q43 Paul Flynn: I spent the morning at another committee with the Chair of the Charity Commissioners and charities are having a rough time at the moment for all sorts of reasons. I will ask Sue, how is the body that you head running? How is it financed and how do you do your fundraising?

***Sue Farrington Smith*:** 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. A lot the charity-bashing relates to charities that have received Government funding in the past—I think we should segment charities—then there are others. I have forgotten my thread a bit.

Q44 Paul Flynn: Your involvement came with an incident involving the child of a friend of yours. Can you think of anything that you could be doing in your organisation to raise public awareness of these tragedies?

***Sue Farrington Smith*:** That is exactly what we do. We have invested a lot of time in raising awareness. When Ali was diagnosed, there was very little in the media about brain tumours. I contacted my local MP, John Bercow, and we had the first-ever adjournment debate on the subject of brain tumours. 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.

Q45 Paul Flynn: Just a final question, is the complexity of the various types of brain tumour a real obstacle to promising research? Do people say, "I am not going to spend the rest of my life doing research when there is little chance of an outcome that is going to affect a wide range of these brain tumours"?

***Emma Greenwood*:** It may be slightly more complex than that, depending on what type of research you are talking about. At the more basic end of the spectrum, it might be that if labs are focused on one area already it is perhaps easier to see that there is a route there for a group and more research. If you are thinking about clinicians who are seeing patients but are also leading research projects they are completely motivated by doing things that are in the best interests of their patients that they see every day. 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, 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.

Paul Flynn: I am grateful to you, thanks.

Chair: That is an interesting point that has not been raised before and one we will want to follow up, I think.

Q46 David Mackintosh: I wanted to talk about the impact on families. We heard a very compelling story earlier about the late diagnosis of someone. I just wondered in your experience if that is typical, if that happens very often and how they are impacted by it.

In terms of the research that could be done, is that looking at a cure or is that looking at prolonging life? Your thoughts, please.

***Sue Farrington Smith*:** 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.

***Neil Meemaduma*:** 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.

***Emma Greenwood*:** There is some data from the NCIN that looks at routes to diagnosis, so where people are getting diagnosed in our health system. 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. I think that kind of reflects the challenge that we are facing from a research perspective. We could focus on potential biomarkers and understanding things to detect the disease earlier. We need to focus on our health system so that we are getting fewer people turning up in emergency rooms and more people, when they present at their GPs, their GPs understanding those signs and symptoms and getting a quick referral as well as treatment options further down the line. CRUK is doing a little bit of work with GPs via the RCGP that is looking at online learning modules so that we can help equip GPs, especially because they hardly see any cases in a given year, so they are a bit more tooled up. We have also got new NICE guidance that shifts the level at which you are meant to refer patients if you suspect cancer. It has only recently been rolled out, so there is a potential huge opportunity there

in terms of education with GPs. You have to take a multifaceted approach and look at the areas that could have the most impact for patients across that whole pathway.

***Sarah Mee*:** If I could just mention something that relates to the new NICE referral guidance, we have a campaign called HeadSmart, which we run in conjunction with the Children's Brain Tumour Research Centre at the University of Nottingham, which raises awareness of the systems of brain tumours in children. That has been really successful so far, so before its launch in 2011 diagnosis times were more than 12 weeks and that has subsequently dropped to less than seven. Part of that campaign is the development of a clinical guideline for health professionals that the University of Nottingham developed, so that sets out to GPs which symptoms they should look out for.

We are a bit concerned about the impact of the latest revision of the NICE guideline, the referral for suspected cancer guideline, because all of the detail within that on which symptoms should trigger a referral for brain tumours in children has been lost due to a change in methodology. Now we are a bit 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 guideline.

Q47 Chair: That is interesting. Can I just ask before we go on to the next question, it is an interesting point, as someone who has been referred a couple of times for screening from my GP, just for the NHS to spend a lot of money proving I am extremely healthy. Is it lack of awareness among GPs, in your experience, or is it that the guidelines are wrong, that people are not being sent for scans through fear of the cost or anything else?

***Sarah Mee*:** It is a difficult tumour type to diagnose because the conditions can often mimic those of other conditions, so things like headaches and so on. It might be a combination of that and awareness. 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. Again, as I mentioned earlier, this new issue with a discrepancy between the new NICE referral guideline and the HeadSmart guideline, which is NICE accredited, may not help.

Q48 Chair: What is the discrepancy between the two; can you enlighten us on that?

***Sarah Mee*:** The HeadSmart guideline sets out a number of symptoms that might be due to paediatric brain tumours and the updated NICE guideline, because they used a methodology using positive predicted values—so they looked at, for different symptoms, what the chances were that that could be due to a particular type of cancer—those symptoms are not listed as needing referral and so there is less detail in the newest version of the guideline than there was in the previous version.

Chair: Thank you, that is very helpful. I am told we are expecting a vote soon so I am going to bring in Oliver Dowden to ask his questions, hopefully before everybody disperses.

Q49 Oliver Dowden: Thank you, and please excuse me for missing most of this session. I did want to come back for the end just to ask you some questions. I just wanted to ask some more about this question of a lack of diagnosis and a lack of awareness for GPs. You talked

about the lack of frequency of this occurring. Are there any other factors you think contribute to this? Are there failings in the teaching or are there further steps that can be taken to improve this diagnosis?

***Sue Farrington Smith*:** It is interesting that so many cases come through opticians, so they are obviously being trained to look into it, although not all brain tumours can be diagnosed through optician referral. I think training is an element of it. My understanding is that an MRI scan is only £250 so I am not sure why people are not being sent for that in the first instance. My own sister's little girl, it was six months before she was diagnosed and eventually it was an optician. We see week in, week out examples of SpecSavers in the paper who diagnose this, so I am not sure.

Q50 Oliver Dowden: Clearly opticians will be carrying out eye tests and will see those irregularities, but you would think it would be the other way around, the doctors—with all due respect to opticians—are far more qualified than an optician. How do you account for the gap in diagnosis?

***Sue Farrington Smith*:** I do not know. It probably is a training issue. As we said before, they might only see one brain tumour patient in the whole of their career.

***Emma Greenwood*:** There are some parallels with things like oral cancer, where we know that dentists are way better at picking up on some of these things and there is obviously something about—given the small number of people that GPs are likely to see and the types of symptoms being associated with so many other things—how can we best equip GPs so that they are educated, they have computer decision tools to help them spot people.

There is also just culturally something in the NHS at the moment around referral for suspected cancer more broadly and our diagnostic capacity. That is across all cancers, it is not specific to brain, but we do have fewer workforce people that do these diagnostic tests. We have fewer bits of kit than any of our European counterparts that you look at that are comparable. There is a culture, because of finances, where we have seen that some CCGs are saying to their GP surgery, "Refer less". With that as the kind of undertone and then the complexities that you layer on with brain, you can understand why it is increasingly difficult for the system to get people through quickly.

Q51 Oliver Dowden: When we are writing our report and making recommendations to Government about how we could improve diagnosis, what would be your number one ask, as it were, of something that could be changed in this regard?

***Emma Greenwood*:** From our perspective, I think there is something quite broadly about positive messaging and reinforcing messaging to those people on the frontline around, "If you are not sure, refer. Refer to be on the safe side, get the tests done. Better safe that it is nothing as a diagnosis and rule something out" and also for there to be a specific focus on those kind of cancers that we are diagnosing quite late, around education for healthcare professionals.

***Sarah Mee*:** I would also say sometimes if parents are quite clearly coming back to the GP more than once and are obviously particularly concerned, having confidence that they know their child better than anyone else, and again, if there is something wrong and if in doubt, then refer.

Q52 Oliver Dowden: On this point about the relative lack of funding of research into brain cancer as opposed to other types of cancer, how much do you think is accounted for by the small number of incidences of it and how much is just a generalised lack of awareness that is meaning that resources are being diverted more towards, for example, breast cancer where there is a very high level of public awareness?

***Sue Farrington Smith*:** The public awareness is key to it, because I do not think the general public realise that cancer research is funded by charities. In NCRI, the budget for the MRC, for example, is only 20% of the overall spend, so the other 80% is coming from charities. Obviously that is something we would ask the Government to do in terms of increasing the MRC spend on brain tumours and encouraging spend there, but equally it is helping to raise awareness so that the general public put their hands in their purse. Maybe we need a celebrity to get a brain tumour, which is what happened with leukaemia. There is only one and a half times as many people get leukaemia as get a brain tumour, yet 7% of national spend is spent on leukaemia research.

Q53 Oliver Dowden: How does it break down in terms of age range? Is there a tendency towards younger or older people or is it fairly uniform across the—

***Sue Farrington Smith*:** For brain tumours it is across the piece. In fact, it is one in 50 people who die under the age of 60 die of a brain tumour, and 75% of all brain tumour deaths are under the age of 70 compared to 47% of all other cancers.

Q54 Oliver Dowden: How much of that is preventable by early diagnosis?

***Sue Farrington Smith*:** I am not sure about that, because I think early diagnosis might help people with the pain of trying to understand what is going wrong, but at the moment you would live with it for longer knowing that they will die at the end of it.

***Neil Meemaduma*:** If I could just quickly say on the early diagnosis, like we heard before about Stephen's case, although we can diagnose it earlier, the treatments that we have currently are limited and in order to develop those we need groundbreaking research here in the UK to drive forward novel, innovative treatments. That goes hand in hand with early diagnosis and new treatments.

Q55 Oliver Dowden: How do we compare to other countries? Forgive me if you have covered this already in the session.

***Neil Meemaduma*:** 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.

Q56 Chair: Although obviously you would all like more money to be spent on research in this area, you are saying it needs more than that, are you not? It needs a building up of

capacity in research and it needs to incentivise people, as Neil said, to work in that area. Is that the case?

***Emma Greenwood*:** It does definitely feel like it is kind of a medium, long-term gain and there are probably not that many quick fixes in terms of transforming the scale of spend and the number of projects overnight. 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 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. It is going to take building up that research platform across all of the areas that we have been discussing, as well as policy interventions within the NHS to kind of shift some of these barriers so that we reach that critical stage, then you would expect things to start to flow in terms of discoveries.

Q57 Chair: Can I just return to this issue about tissue samples, which you mentioned earlier? In your experience, are people not asked to donate tissue samples?

***Sue Farrington Smith*:** The whole consent form process is a bureaucratic nightmare and 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. The whole biobanking needs to be addressed and I know again as charities we are trying to do that, but I think there could be Government intervention here.

Q58 Chair: Someone also referred to the fact—I think it was Sarah—that we need a biobank, that it is difficult to access the tissue that is donated for research.

***Sarah Mee*:** It can be. 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.

Q59 Chair: We have both collection and ensuring that those samples are easily accessible? I do not want to put words in your mouth; I am just trying to make it clear to the Committee what we are looking at.

Before we finish, can I ask each of you probably the most difficult question? If you could get Government to do one thing to start making the situation better, what would it be?

***Neil Meemaduma*:** One of the issues with this particular type of cancer, as we have heard before, is it is like leukaemia was 20 years ago. What we are seeing with leukaemia is that there is an established research area and a well-developed research area; we do not have that necessarily for brain tumours. I would like to see investment in those fundamentals and infrastructure that can drive forward a basic understanding of the biology of what goes on.

***Emma Greenwood*:** It is a bit of a fudge of an answer, but I suppose 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. When we as a charity want to do more research, if that is not backed up by investment from the NIHR, through the NHS or through funding councils, through the universities, it is going to make it increasingly difficult for us to shift that. I think it is about that overall signal that we are taking this seriously and we are open for business.

***Sue Farrington Smith*:** We would look for the Government to ring-fence an innovation fund in order to look into this next generation and find some groundbreaking discoveries as well as support initiatives such as the Off-patent Drug Bill.

***Sarah Mee*:** We would be looking to Government to commit to attracting and retaining a strong research workforce. It is all too easy to fall back on the kind of lines we saw in the response, there are streams of funding available through NIHR and other avenues, but they are not getting sufficient quality applications. If they keep saying that, we are going to retain the status quo, so we would want to see Government working with the research community to see what can be done to build research capacity.

Chair: Thank you very much indeed. I thank all our witnesses on behalf of the Committee. You have given us a number of issues that we want to look at further or we will want to pass on to other Select Committees in the House. We are very grateful to you all for taking the time to come here today and speak to us. If there is any other evidence you would like to give us that has not come out in this session, please feel free to put it in writing to us and we will look at it before we prepare our final report. Thank you very much indeed, and thank you also to all the other people who have come along today to listen or to give evidence. The session is closed. Thank you.