



Petitions Committee

Oral evidence: Brain tumour and childhood cancer research, HC 242

Thursday 27 May 2021

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[Watch the meeting](#)

Members present: Catherine McKinnell (Chair); Tonia Antoniazzi; Elliot Colburn.

Questions 31 - 50

Witnesses

Lord Bethell of Romford, Parliamentary Under Secretary of State (Minister for Innovation), Department of Health and Social Care; Mike Batley, Deputy Director of Research Programmes, Department of Health and Social Care; Helen Campbell, Portfolio Manager, Department of Health and Social Care.

Written evidence from witnesses:

– [Lord Bethell \(Parliamentary Under Secretary of State for Innovation at Department of Health and Social Care\)](#)



Examination of witnesses

Witnesses: Lord Bethell, Mike Batley and Helen Campbell.

Q31 **Chair:** For the purposes of Zoom, would our panel introduce themselves, so that people understand who you are and where you work in this sphere?

Lord Bethell: Thank you very much indeed, Chair. I am Lord Bethell, the Minister for Life Sciences and for Innovation. I sit in the chair formerly occupied by the great Lord O'Shaughnessy, who is a great inspiration in this area. I very much tread in his footsteps.

Life science research is very much in my bailiwick. I have spoken about the issue in the House of Lords on numerous occasions. Everyone remembers very warmly Lady Jowell's speech on her condition in the House of Lords. It was one of the most impactful interventions in recent memory.

Chair: Thank you. I very much agree.

Mike Batley: I am Mike Batley from the Department of Health and Social Care, where I am deputy director for NIHR research programmes.

Helen Campbell: I am Helen Campbell. I work in the Department of Health and Social Care with Mike. I lead day to day on cancer research.

Chair: Thank you all for being here today. Tonia will kick off the questioning.

Q32 **Tonia Antoniazzi:** My question is initially to Lord Bethell. The written evidence that you helpfully provided for this session states that, of the Government's five-year £40 million commitment to brain tumour research in 2018, only £8.8 million has so far been allocated by the NIHR for dedicated brain tumour research. Could you take this opportunity to update us on progress in meeting the overall £40 million commitment, and provide us with any assessment of the impact that spending is having to date?

Lord Bethell: Thank you very much indeed. You are absolutely right; the update I have provided is accurate. Professor Gilbertson spoke very clearly and presented a challenge, but also a fair representation of the situation we are in. We have put together a big financial package for late-stage research. Where there is a challenge is that the early-stage research and the bringing together of various different specialisms—oncology and neuroscience in particular—to create the spark and the basic science necessary to do further translational work needs more resources and more support. That is why, at the moment, we are focused very much on the earlier stage of the pipeline.

I am not sure if it is helpful to think in terms of a target or an objective of trying to spend that £40 million as quickly as humanly possible, when in fact the science does not necessarily exist to do the translational work



that the money is targeted at. Instead, we need to focus on the early stage, and the workshops that the Tessa Jowell foundation is bringing together, and that we are contributing to, are exactly the right approach for trying to make that magic happen.

If you don't mind, maybe I could defer to Mike or Helen to explain in a little bit more technical detail how we are trying to get the different research organisations aligned to deliver the kind of progress you are looking for.

Tonia Antoniazzi: Okay. Mike, do you want to come in?

Mike Batley: To clarify, the £8.8 million is for research funded through NIHR programmes and the academy. There is also significant NIHR support for research that is put through NIHR infrastructure. That is where we support research across the NHS that is funded by both Government and charities, very importantly, and by commercial entities. We know that there will be a lot of work going on within NIHR infrastructure supporting others' research that will not have been included in these figures but will definitely have been spent on brain tumours. The figures that we have given, exactly as Lord Bethell says, are precise, but, to some extent, they are lower-end estimates of what is actually being spent.

Further to Lord Bethell's point, and as you have heard repeatedly today, the NIHR is there to translate basic new discoveries in science into treatments, through our translational, our clinical and our applied research. That very much depends on the earlier end of the pipeline—the new discoveries and new basic science that can then be translated into treatments.

It was recognised in the task and finish group report that was published around three years ago into brain tumour research around the time of the set-up of the Tessa Jowell mission. The lack of new basic science discoveries is causing a bit of a blockage in the pipeline, which means there is not as much that we can fund, from NIHR's perspective, to turn things into actual treatments.

This is where we have been working with UKRI—UK Research and Innovation—which funds research in the basic science space. They have agreed so far to hold a sandpit event that will bring together neuroscientists with oncologists to see if we can spark more ideas, new approaches and new things that will actually grow the basic science base in this area. They are funding quite a few PhDs and doing a fair amount of capacity-building in this space. We would like to see what more we can do with them to really expand that work.

Q33 **Tonia Antoniazzi:** Listening to Professor Chris Jones earlier, that spark or innovation is there across the world, and I asked him who he thought should be leading on it. I think it needs driving forward. That is what has come through to us as a Committee. This needs to be led and taken



forward. Where does that responsibility lie? To me, it would be the Government. Do you have that ambition?

Mike Batley: From a funding perspective, it would fall to UKRI. It is outside NIHR's immediate ambit of control. Colleagues in UKRI, and particularly in BEIS, will hold the ring on that work.

Q34 **Tonia Antoniazzi:** Is it possible for the Government to be more flexible with their investment? That has been spoken about. They are not flexible with the investment and, as a result, strides are not really being made.

Mike Batley: I am not sure if Lord Bethell wants to come back in.

Lord Bethell: Mike, do you want to address the flexibility question? Then I will come in and build on your point.

Mike Batley: There is flexibility in investment across different funders. It is whether UKRI wishes to put more into that space or do different things in that space. In some respects, that is the decision of UKRI. Certainly, from an NIHR perspective, we have been working really closely with the Tessa Jowell Brain Cancer Mission. We completely agree with Professor Gilbertson that the money is there. We have said that the money is there in the translational, clinical and applied space. What we really need is a growing research community to take advantage of that.

We have been working with the mission on, for example, workshops so that researchers who have applied for our funding and have not been successful have support and do not get discouraged. Hopefully, they keep applying and improving what is coming to us, so that we can then fund more research in the future. There is also the funding that we are putting into the research aspects—the Tessa Jowell Brain Cancer Mission research fellows in neuro-oncology. We think that will help address the need that will grow the research community.

The NIHR is coming at this from a number of different perspectives, because we recognise that there are a number of different challenges and blockers in place that need to be overcome. We have been working with colleagues in UKRI to see what more can be done in the basic science space in a broader and more flexible way.

Tonia Antoniazzi: Lord Bethell, do you want to come in on that?

Lord Bethell: Yes. I think you know this, but just to flag it, the success of the British life sciences business is a combination of three components. There is Government and the NHS, but there is also academia and the private sector, which in this case is represented by philanthropy, by research charities. It is those three pieces working together that mean we make success. Each one has a different piece to bring.

Academia is where the research is going to come from. The Government are there for funding, and the charities are there for championship and leadership. To be direct, the Government on their own cannot find the



cure for diseases. That is not what we can do on our own. What we can try to do is to provide funding in the right places and sponsor thoughtful and promising research.

What Mike was alluding to is the frustrating but unavoidable truth that it is clearer and easier to fund translational work. That is a lower risk and clearer project management exercise, whereas funding the science is a very unpredictable affair, and we cannot guarantee that the environment of early-stage scientific funding will throw up exactly what we need for specific conditions like brain cancer.

What we can try to do is to be catalytic and bring together the correct kinds of people, which has not happened enough in this area. Professor Gilbertson spoke interestingly about the failure in the UK of oncologists and neuroscientists to somehow get on with each other. There is a sort of Mars and Venus problem. That is why I think the route we are going down is the right one, and why we are keen to continue to sponsor it.

Q35 Tonia Antoniazzi: Lord Bethell, you indicated that spending on research infrastructure is not included in the £8.8 million figure. Can you confirm whether the Government consider spending on research infrastructure to be part of the overall £40 million commitment? Will it be included when you calculate whether the £40 million ambition has been met?

Lord Bethell: Tonia, if you don't mind, I will knock that one to Mike because it is quite technical.

Mike Batley: The spending on infrastructure is fundamental to brain tumour research happening across the NHS. As I say, the infrastructure spend absolutely supports a lot of the work done by and funded by charities—for example, the studies that they are running in the NHS. It is a really important part of the brain tumour funding landscape.

The challenge we have is how to actually unpick exactly how much of that is being spent on brain tumour research versus other types of cancer and other types of work. Again, I do not want to get too much into the weeds of this. Our infrastructure is mostly people. We fund people across the system who are likely to be working on a range of different studies at any one time. A large number of them will be clinical or research nurses, who we know are working in cancer and across a range of different cancer studies on wards with different patients. To actually unpick their time, and exactly how much of their time they are spending on a brain tumour study versus another type of study, would put quite a big administrative burden on frontline staff. We have to strike a balance; we would like to know that information, but there is a burden that it would put on people to collect it.

A final point, without trying to get too technical, is that a number of studies are likely to be relevant to a number of different cancers. There are questions about how we unpick that. We would like that information,



but it is not straightforward to try to generally unpick that in a useful way that is not burdensome on the system.

- Q36 **Tonia Antoniazzi:** Is there an attempt to unpick that information and to be able to specify what the infrastructure spending is? Surely, there should be some idea, even if it is a guesstimate, of where the funding is going, or are you just saying, "That's too burdensome and we can't put that on our NHS staff"?

Mike Batley: It is a question of how acceptable a guesstimate would be. It would very much be a guesstimate for this. It is certainly something we could look to do, but I am slightly uncomfortable with putting out what might be misleading figures if we have to guess some of this stuff.

Lord Bethell: If I can come in with a slightly layperson's perspective—forgive me if this sounds too rudimentary—when we are talking about the early-stage science, we have scientists in labs around the country tinkering with the brain and prodding bits of cancer. Who knows what they might turn up with? They may turn up something to do with brain cancer or it might have something to do with ophthalmology. It might turn up something to do with autism. You do not quite know what insight might emerge from their research, or which field of discovery their work might contribute to.

That serendipity and that uncertainty is both unbelievably frustrating and drives all of us nuts—I wouldn't want to be a research administrator for all the tea in China—but it is part of the magic and mystery of scientific discovery and endeavour. It is really frustrating because that is what we are depending on to make advances in a knotty problem like childhood brain cancer. It is not from lack of aptitude or seriousness that we cannot account for this financially.

- Q37 **Tonia Antoniazzi:** But it is about accountability and where the money is going.

Lord Bethell: I'm afraid that it just does not lend itself very easily to the spreadsheet or the P&L.

- Q38 **Chair:** Can I come in, Tonia? These are your questions, but I want to clarify something.

Did you say that the research infrastructure spending will come out of the £40 million commitment? Did you say yes to that, Mike? I think you answered that question.

Mike Batley: I think the spend on infrastructure is very relevant. It is part of the overall NIHR spend.

- Q39 **Chair:** It will come out of the £40 million spend, but then you went on to say that you are not able to specify how much may have been spent on infrastructure spending. Is that a fair reflection of what you said?



Mike Batley: We would like to spend more than the £40 million. To be clear, there is not a specific pot of money where we say, “We will just spend this much on brain tumour research.” If we could spend more than that, we would very happily spend more than that.

Q40 **Chair:** So it is a minimum of £40 million, but will the infrastructure spend be included within that £40 million?

Mike Batley: It is not that we have a ring-fenced pot that somehow limits what we are spending on brain tumour research. For example, if we are spending a lot more on infrastructure in brain tumour research, it does not mean that we will then spend less on brain tumour research elsewhere. We want to maximise our spending right across the system.

Q41 **Chair:** Can you understand the concerns that may potentially flow from that lack of accountability and transparency? I absolutely take on board the point that Lord Bethell made about serendipitous findings as part of generic cancer research. Obviously, all research is good research—there is absolutely no doubt about that—and all money spent on research for cancer is welcome. However, the issue we are looking at today is a chronic, long-standing underfunding of, specifically, brain tumour cancer research and the impact on children. There is huge interest in being sure that the funding that has been promised for that area of research, after such a long time, is actually going on that area of research.

I would have thought that any helpful cross-results that may come out of research that could benefit brain research and other cancer research would be in addition to the core funding that has been promised to this particular research. Obviously, only £8.8 million has so far been allocated, so I think there is some concern to know that it will all be allocated, that there will be sufficient support given to ensure that it is allocated, and that it does not go on infrastructure spending that I am sure is very valuable but does not appear to be very transparently attributable to supporting brain tumour research specifically. Do you want to respond to that, Lord Bethell?

Lord Bethell: I will turn to Mike in the first instance. Thank you.

Mike Batley: We have funded all the fundable proposals we have received for brain tumour research. From an infrastructure perspective, all the brain tumour research that we can support is being supported. The £40 million is not providing some kind of brake on what we are doing. It is not as if we are saying, “We are only going to spend so much on this.” To some extent, our limit is not in the pot or spending the £40 million on this or that. Our limit, as you have heard, is the basic science. It is the fundable ideas coming to us that we can put research into. It is the size of the research community. That is where we are focusing our efforts, because that is what is needed to boost the volume capacity of brain tumour research in this country.

Q42 **Chair:** Is that what you believe will be supported by the infrastructure spending? Is the infrastructure spending aimed at building capacity within



the research community and the research funding bidding capacity as well?

Mike Batley: A lot of the research you have heard about that is being funded by research charities would not be able to happen if it was not for that infrastructure spend. We provide the infrastructure that allows others to run their research programmes and research studies in the NHS. It is very much there to support a range of activities in the brain tumour research space.

Chair: You can carry on, Tonia.

Q43 **Tonia Antoniazzi:** I will try to move the conversation on. Lord Bethell, your written evidence stated that, of the 69 applications for brain tumour research funding that the NIHR had received since April 2018, just 10 have been approved. We have spoken about where the funding goes and how we track it, but doesn't that high rejection rate miss the whole point of the £40 million commitment, which should be dramatically to increase funding for brain tumour research?

Lord Bethell: I can see why you ask that, Tonia, but what we are trying to explain—maybe we are not doing it very well—is exactly the point that Professor Gilbertson was trying to make. I promise you that there is not a big pot of money that we are resistant to spending. It is not that there is 40 million quid and for some reason we have taken it into our mind that we are going to sit on it for ages because we are trying not to spend it. That is not the case. In fact, we are desperate to spend it. We would love to spend it, very much indeed, for all the obvious reasons in Government that you want to spend it.

The problem is that the projects that are coming forward, by any reasonable standard, do not meet the bar of a sufficient return on investment as they are currently coming in. I am the layperson. I am just repeating the feedback that I get. I do not think this is a particularly controversial statement. I do not think a lot of people are saying that we are turning down really strong and well-evidenced proposals. Where there is a problem is that, as Professor Gilbertson said, the environment in the UK has not created a good marriage between oncology and neuroscience. The basic scientific insight that creates the germ of the idea that can then be translated into a therapy or a remedy is not quite there yet.

It is a not uncommon problem. There are a dozen or two dozen areas of clinical research where patient groups, charities and advocates are unbelievably frustrated that there is not greater progress, because of a bottleneck at the very early stage. It is more difficult to agitate for development and change with that kind of problem than in a translational problem. If it is a translational problem, you can throw money at it. You can say, "Right, there are 25 really great ideas. We're going to sponsor half of them, and one of them will throw up something good." That is a relatively straightforward problem. That is not the problem we have, and



that is why we have to think through all of these slightly convoluted and complex solutions, which we hope will get us there in the end.

- Q44 **Tonia Antoniazzi:** On that point, Lord Bethell, I felt really positive in the last panel because of what Professor Chris Jones and Richard were saying. There is the opportunity to work smarter. There is the opportunity not just to throw money at something but to be innovative and to have those ideas, yet we do not know where the money is going. I am not getting the feeling that we are joined up.

I have a question for Helen in a minute, but I will let Mike come in because he indicated first. Is there a miscommunication? Is it not gelling? I felt that there was the opportunity for advancements and great strides to be made after listening to the last panel. You are talking about the infancy of this research.

Mike Batley: Perhaps I could start on the question about the number of applications that have been successful in gaining funding. We funded all the applications that met the science quality bar, the usual NIHR bar on these things. In the applications that were not successful, we recognised that researchers would have put an awful lot of work into getting them together. We do not want to lose that research. We do not want to lose those people to the system because they did not make it over the finish line at their first attempt. That is why we are working with the Tessa Jowell Brain Cancer Mission on workshops for researchers who are unsuccessful, to help them understand why that might be and how they might improve their applications. Hopefully, we can keep them engaged, and they will apply again and be able to get over the funding bar next time.

We are not just giving up on people when they are not successful the first time around. We are working with the mission to try to make the most of people's efforts, whether they are initially successful or not.

- Q45 **Tonia Antoniazzi:** Helen, you were on the working party. Is there anything you would like to add to what has been said?

Helen Campbell: I obviously agree with everything that has been said. I go back to what Richard Gilbertson was saying earlier. If you put in the ambition of being able to spend £40 million over five years, it is a bit of a blunt tool, but it is a good start. Bear in mind that the remit of the NIHR is clinical and applied health and social care research, and that is the research pathway that we focus on.

The number of applications has increased substantially. More than double have been successful, and we still have some being considered and going through the process. That has absolutely made an impact. The projects we are funding are really exciting. They are looking at things like how we get better at speeding up the diagnosis of children with cancer and with brain cancer. They are looking at whether we really need to prescribe anti-epileptics before surgery. They are all things that really help people living with cancer, and the NHS in treating them.



HOUSE OF COMMONS

On their own, they are unlikely immediately to lead to a cure for childhood cancers and for brain cancer. That is why the partnership working across the whole spectrum is so important, and why the Tessa Jowell Brain Cancer Mission is such an incredible step forward. It is a vehicle by which all the key players can get together, undo what the problems are and consider how they might best be tackled and which partner might best contribute to which part.

Q46 Tonia Antoniazzi: You have spoken about the research going on with childhood brain tumours, which is why we are here. It would be nice to know, Helen, how much of that money is going towards that research. That is what we want to know.

Helen Campbell: The technical difficulty is, when is a piece of research relevant to children and when is it not? How long is a piece of string? At this moment, data systems do not allow us to pull out participants in trials by age. Things are under way to try to help that happen. Of course, certain tumours happen only in childhood. Sadly, DIPG is one of them. We can attempt to look at it by searching on the terms of diseases specific to childhood cancers. That is how we approach that issue.

Tonia Antoniazzi: Thank you.

Q47 Elliot Colburn: Lord Bethell, the Government have stated that you want to see more high-quality brain tumour research proposals being submitted. What is being done to help encourage and achieve that outcome?

Lord Bethell: You are absolutely right; that is very much our objective. Maybe I could pass over to Mike or Helen to talk about the specifics of how we are working with research charities, the private sector and academics to get those kinds of research projects over the line.

Mike Batley: I can start; I do not know if Helen will want to come in. Initially, the announcement of the £40 million three years ago sent out a very strong signal to the community that this is an area to move into and an area worth moving into, and that there is funding if they want it. That, hopefully, encourages people in. As you have heard, there are a number of other challenges, particularly with the relatively small research community that is out there.

We want to grow the overall research community in brain tumour research. This is where we have been working with the Tessa Jowell mission on some of their fellowships for neuro-oncology. The initial call that we put out also included the NIHR Academy where people can apply for training, training awards and training grants. Again, we would like to see more people with specific training on brain tumour research.

Getting more applications partly comes back to the issue of the bottleneck that we see in the basic science side of things. If we could increase more novel findings in the basic science space, it would actually improve and increase the number of applications that we could get into



NIHR. There is a whole range of different areas causing bottlenecks and hurdles, and we are working across those.

Elliot Colburn: Thank you very much, Mike. You have actually answered my next question as well, which is about the steps you were going to take to tackle the issue of the brain tumour research workforce and encourage it as a viable career option. I appreciate that we are getting to the end of the session, so I will pass back to the Chair so that we can carry on.

Q48 **Chair:** Thank you, Elliot. Lord Bethell, one of the issues about childhood cancer survival rates is that they are improving overall, but as we have discussed—we have heard the evidence today—some types of brain tumour, like DIPG, have very low survival rates. What is not very clear is whether they are benefiting from the Tessa Jowell funding. Will the Government develop a bespoke research strategy for childhood cancers with the worst survival rates?

Lord Bethell: In some ways, what we are talking about is a research pipeline dedicated to that. We take it very seriously. Brain cancers are particularly pernicious because of their location and because the defences of the brain protect it from many interventions that would work elsewhere in the body. The way they attack children is absolutely heartbreaking. We are very focused on it, and I pay tribute to the Tessa Jowell foundation and to Lord O'Shaughnessy in particular for their evangelism and advocacy on that. It is very much front of mind.

Mike, maybe I could pass to you on what could be described as specifically a childhood brain cancer track, as opposed to our general funding of research proposals that have merit.

Q49 **Chair:** Drawing on some of the comments you made earlier, you referenced the challenge around funding programmes and finding programmes to fund. You mentioned that many are not a good return on investment. One of the big challenges that faces these very rare sub-types is that often you cannot apply the same criteria as you would to other research, potentially. Because it is so difficult to attract charitable funding, this is where campaigners and petitioners, on whose behalf we are here today, would really like to see the Government step up and dedicate additional funding specifically for that purpose. Are you able to give any reassurance on that front?

Lord Bethell: I will turn to Mike in a second, but I will be honest with you. I certainly do not think it is wise for Ministers, who do not have clinical research qualifications, to make decisions about which research applications should be funded and which should not, on personal bias, political or any other grounds.

There is a meritocracy. Surely, we have to fund the applications that have the best return for the general wellbeing of the nation. We defer to our scientists to be able to make those assessments. I do not know if this is what you were driving at, so forgive me if it is not, but we really cannot



HOUSE OF COMMONS

have politicians deciding what gets funded and what does not. That would be a very dangerous place to get to. The CMO would have me off in no time at all if I tried to do that. That is not going to work.

I completely agree with you that there are some conditions where we have to proceed with humanity. The system is not perfect. Where there is advocacy and challenge around a particular condition, it is right to listen to patient groups and to hear the arguments that they make about why there should be a particular effort made about a particular condition. Those efforts are often about trying to align academic research and to try to activate enthusiasm, interest and collaboration. Collaboration is absolutely key, as Professor Gilbertson pointed out. It is getting people working together, sparking off each other and sharing ideas. This is not just a nice to have; it is the fundamental ingredient of successful research.

If you have a pot of money that is earmarked for applications that cross a certain quality threshold, that demonstrates a degree of commitment to an area, but we cannot lower the threshold for one condition over another because of a sentimental or political decision. I am not sure if that was what you were suggesting, but I want to be clear that that would be really undermining—

Q50 Chair: No, not at all. There is nothing sentimental in what I am suggesting. The nature of very rare diseases sometimes requires a different approach. I have had this conversation about a number of rare diseases, not just the subject we are discussing today. We are running out of time, so that is a conversation for another day.

To finish off, Lord Bethell, what plans do the Government have to focus on brain tumour research in the UK beyond what they have already committed to? The petitioners today would like to have reassurance that the Government are focused on brain tumour research. We would like to see the money that has been promised spent, as well as a future for this research, and hope. That is not a sentimental thing. It is a scientific challenge: we need to find a cure, and we need to find the right treatments for these conditions. We need to give hope to the petitioners today that the Government are committed to supporting those who experience these conditions and that, for those working in the field who are very much trying to find those treatments, there is hope in the pipeline in the future.

Lord Bethell: You put it very well, and we share your commitment. I slightly feel that I have said my piece. Mike or Helen, is there anything that you would like to flag to answer Catherine's question about future plans that have not quite got announced yet?

Helen Campbell: Truly and genuinely, the Tessa Jowell centres of excellence are a major step forward. We have an absolute focus across the health service now to really help with specialising neuro-oncology in



HOUSE OF COMMONS

these key centres. I think it will be transformational in the service. All credit to the mission for having gone forward.

One of the beauties of that is that the community will be able to join up in the academy to choose the most important areas for research. What are the most important questions for treating adults and children with cancer and how do we best, as a research community, corral ourselves to get proposals together and put them to the NIHR or the Medical Research Council, where appropriate, depending on the nature of the research question? I genuinely think that that will be transformational. I look forward to looking at the research proposals.

Chair: Thank you, Helen. We are out of time today, but we appreciate you spending this time with us.

Thank you very much to all the witnesses we have heard from today. I think there is plenty to focus on in the future. I am sure that we will be discussing this again. Thank you.