

Written Evidence from Brain Tumour Research (BCCR0006) April 2021

Relating to questions on brain tumour and childhood cancer research

Brain tumours kill more children and adults under the age of 40 than any other cancer, yet since national cancer spend records began in 2002, £680 million has been invested in breast cancer, but only £96 million spent on brain tumours¹ – that's a difference of £35 million a year over 17 years. This disparity continues with brain tumour research spend continuing to receive £35 million a year less over the last three years².

Five-year survival for breast and prostate cancer is greater than 70%, leukaemia more than 40%, yet for brain tumours it is just 12%.

Just 1% of the national spend on cancer research has been allocated to brain tumours.

The only way we can improve outcomes and reduce deaths from brain tumours is to invest in research which will help find a cure. At the current rate of spend, it could take up to 100 years for brain cancer to catch up with developments in other diseases and for a cure to be found.

Research into brain tumours must not be left behind – the nation needs to Level Up and invest at least £35 million a year if we are to find a cure for brain tumours in the next 20 years.

Since Brain Tumour Research was established in 2009, the charity has been a driving force for change, shining a spotlight on the urgent need for more funding for research into brain tumours.

In 2015, the charity launched what would become a hugely successful campaign in support of an e-petition, initiated by the Realf family, calling on the Government to fund more research into brain tumours.

The petition was started by Maria Lester in August 2015 to mark the first anniversary of the death of her brother, Stephen Realf, a Royal Air Force pilot from Rugby, who was diagnosed with a brain tumour at just 19 and died at 26. The petition called for funding for research into brain tumours to be increased to £30-35 million a year to bring it into line with funding for other cancers.

With our support and that of the wider brain tumour community, the Realf family's petition quickly gained more than 120,000 signatures, becoming the first to prompt an inquiry by the new House of Commons Petitions Committee and leading to the publication of a landmark report. This was followed by the April 2016 Westminster Hall debate attended by more than 70 MPs, all of whom agreed that more needed to be done.

The House of Commons Petitions Committee declared that *“successive Governments have failed brain tumour patients and their families for decades.”* Its

March 2016 report *Funding for research into brain tumours* quoted the most recently reported investment in brain tumour research (2014) as 1.5% (£7.7 million) of the £498 million national spend on research into cancer.

The establishment of a dedicated Task and Finish Working Group on Brain Tumour Research, run by the Department of Health and Social Care (DHSC), was a milestone in our campaigning and within this we continue to exert our influence.

Two years later, in May 2018, when the report of the DHSC Task and Finish Working Group on Brain Tumour Research was published, the Government committed to a £40 million funding boost, with Cancer Research UK (CRUK) committing to a further £25 million, over five years.

The tragic death of Baroness Tessa Jowell from a brain tumour in May 2018, following a standing ovation in the House of Lords in January for her speech on the devastating disease, also proved to be a catalyst for change and, with the establishment of the Tessa Jowell Brain Cancer Mission, there is an even greater call now to invest in both increased research and greater support for those affected by brain tumours.

These were steps in the right direction, but three years after these positive actions were announced we learn that only £9 million of the promised Government money has been spent and the COVID-19 pandemic has seen CRUK warning of a £150 million downturn in its research spending.

Where does this leave research into brain tumours?

Progress has been made, but there is still so much more to be done.

We believe it is time for the Government to create a legacy for the brain tumour community and make the UK a world leader in finding curative therapies for brain tumours. It is time for the Government, larger cancer charities, and the brain tumour community to focus on finding a cure and give hope to the thousands of UK citizens diagnosed with a brain tumour every year.

It is time for the Government to introduce a dedicated Levelling Up Brain Tumour Research Fund of £105 million and to increase the ongoing national investment in brain tumour research to £35 million a year so that we can stop the devastation of this awful disease.

1. How has Covid-19 affected your ability to support research into brain tumours, including childhood brain tumours?

Brain Tumour Research has invested more than £10 million in sustainable research into brain tumours at dedicated Brain Tumour Research Centres of Excellence since we launched in 2009. Having rapidly grown the charity, half of this was granted in the four years ending June 2019. We were proud to become a National Cancer Research Institute (NCRI) partner in 2017 and were on track to continue to grow the level of research funding each year and expand our network of Centres before the pandemic hit.

Between March 2020 and our financial year-end of June 2020, we experienced an income shortfall of c. £1 million as our flagship Wear A Hat Day event which takes place at the end of March each year and the Virgin London Marathon event along with other participation events had to be cancelled due to the lockdown. This had an immediate impact on the amount we were able to grant to research. We worked with our Centre partners to mitigate the risk. They furloughed some of their researchers and gave us extended payment terms and we were able to keep the research going.

We granted just £0.8 million instead of the £1.2 million planned and restructured the organisation losing 25% of our headcount.

During the current financial year ending June 2021, we have been able to initiate virtual fundraising and, as a result, have been able to support our research Centres at previous levels.

As a smaller charity, we have been able to be more agile than many charities in our sector.

Medical research charities make a significant contribution to the UK's research landscape, totalling [£1.9 billion in 2019](#). However, the projected fall in fundraising revenue could profoundly damage UK research and its position as a home for world-leading science. Since the start of the pandemic, larger medical research charities have been forced to make dramatic cuts to their research budgets. Members of the Association of Medical Research Charities (AMRC) are [projecting a shortfall](#) in research spend of between £252 million and £368 million in 2020/21 alone. We support the AMRC's call for a [Life-Sciences Partnership Fund](#), to ensure the UK is equipped to continue ground-breaking and lifesaving research.

2. What impact has Brexit had on UK research into brain tumours, including childhood brain tumours? Following the end of the transition period, are there further steps the Government could take to protect and enhance the UK's ability to collaborate internationally on such research?

We welcome the Government's confirmation that the UK will associate to Horizon Europe – the EU's flagship research funding programme. Together with other [medical research charities](#), our view is that there should be no negative impact on patients within the UK and across the EU. This means that patients must be able to continue to:

- Participate in vital pan-EU clinical trials
- Have speedy access to new medical innovations
- Experience no disruption in the supply of medicines and treatments
- Benefit from the fruits of innovative research collaborations across the UK and EU

We also want the Government to ensure:

- The UK is positioned as an attractive destination for global research talent and expertise
- An aligned and compatible regulatory framework is implemented between the UK and the EU for medical research
- The European Medicines Agency on EU regulatory frameworks and agreements for medicines and medical devices confirms patients will have timely access to new health innovations
- Continued participation in EU funding programmes and collaborative opportunities to progress the discovery and understanding of disease and ill health
- No disruptions to the supply and trade of medicine and other health technologies as a result of the UK's new relationship with the EU

Our Research Centres have experienced challenges this year, including fewer applications from European scientists to work here, delays to recruitment and also delays in the delivery of materials that are important for research. COVID is contributing to these challenges and it is difficult to say what additional effect Brexit is having. It is highly important that the Government ensures unhindered access to global research talent and the materials required for research.

3. What impact is the Tessa Jowell Brain Cancer Mission initiative having in supporting the brain tumour research environment?

Brain Tumour Research is represented on the Joint Steering Group and we welcome the recent announcement confirming the first nine NHS Hospital Brain Tumour Centres receiving Tessa Jowell Centre of Excellence status. This recognition will make an important contribution to further improving the quality and consistency of care to brain tumour patients across the UK.

Alongside the delivery of care, the Centres were also selected on their proactive engagement in research, particularly through clinical trials. The development of new treatments for brain tumours requires joined-up thinking and strong collaboration between clinicians and researchers. The Government needs to ensure that a strong clinical academic workforce exists, with clinicians able to engage in research, within a healthcare system that truly values research. Effective interactions between researchers and clinicians are vital for translating new discoveries into potential new treatments.

4. Has the work of the Tessa Jowell Brain Cancer Mission, and protected funding from NIHR and CRUK, helped raise the profile and priority given to research into brain tumours since the Committee's 2016 report? Has it led to a more favourable research funding environment?

National Institute for Health Research (NIHR) Strategy

The NIHR commissions and funds research into several areas: health; public health; social care; health and social care services and organisation; clinical evaluation and translation; and technology development. They fund research to produce evidence for healthcare professionals, policy makers and patients to make informed decisions about healthcare and new interventions. A major emphasis is on the evaluation of new health and social care interventions that have a likelihood of delivering patient benefit within five to 10 years – for further information, see our [blog](#) on the research pathway from bench to bedside.

Therefore, most NIHR programmes fund research that is relatively advanced along the research pathway, such as evaluative research including large-scale, pragmatic clinical trials. The NIHR does not fund early-stage discovery science or basic research.

Examples of projects funded by the NIHR in the last two years include the assessment of potential new surgical and imaging approaches for glioblastoma and a quality-of-life study to reduce seizures in patients following surgery for meningioma.

Priorities for research into brain tumours

There are over 120 different types of brain tumour, each one requiring a different approach to diagnosis and treatment. However, science's understanding of these different types is very poor and the development of new, targeted treatments lags far behind other cancers, such as breast, prostate and leukaemia. A key priority for research is to improve the understanding of the molecular defects that contribute to different types of brain tumour and accelerate the development of innovative treatments and diagnostics. To achieve this, a substantial investment in basic and translational research is required, as discussed in our recent [blog](#).

The research priorities described above do not fall within the NIHR's strategy. To increase investment in basic and translational research for brain tumours, Government funding should also be allocated to the Medical Research Council (MRC), which is a major funder of earlier stage, discovery and translational research. Alternative approaches could consider a Government / charity partnership model for allocating funding to the basic and translational research community.

Communication

Whilst we welcome the Government's promise of £40 million investment in brain tumour research, so much more needs to be done to improve outcomes for patients up to a level comparable for many other types of cancer. As noted above, we need to see a substantially increased investment in discovery research to develop new and more effective ways of treating brain tumours. When communicating the Government's announcement of increased funding, it would be helpful to highlight the important role of medical research charities – who fund the majority of brain tumour research in the UK – and that we depend on the continuing generosity of the public to make advances in this field.

5. Are there any other recent significant developments in brain tumour research and patient care you would like to draw the Committee's attention to?

We have highlighted [previously](#) the challenges faced by the research community when seeking funding. For example, of 27 applications in brain tumour research submitted to the NIHR in 2019/20, only three were funded. This low success rate is part of the reason why only £9 million of the £40 million allocated to the NIHR has been awarded. To help address this situation we have called for i) research grant funding panels to contain the right mix of expertise across appropriate fields, ii) speeding up the grant funding decision-making process, and iii) support to the research community to strengthen future grant applications. On this last point, we are pleased to see that the NCRI will be holding a [Brain Proposal Guidance](#) meeting on 27th May 2021. The aim of this meeting is to help investigators with ideas for studies and develop them into an application, which can subsequently be submitted to a funding committee. We are also aware of the Research Design Service offered by Government funders.

In addition, through the TJBCM we are working to organise workshops with unsuccessful applicants to NIHR funding to help them communicate their project designs appropriately.

6. What are the most important actions Government could take to improve the research environment for brain tumours (including childhood brain tumours) and patient outcomes? Are the conclusions from the Committee's 2016 report still valid?

We welcome the increase in research spend on brain tumour research, in which spend by partners of the NCRI has grown from £8.3 million in 2015/16 to £15 million in 2018/19. Nevertheless, the majority of this increase has been possible through the commitment of medical research charities and the generosity of their supporters. For many years, we have campaigned for parity with other cancers such as breast and leukaemia and an annual national investment of £30-£35 million a year into brain tumour research.

We received 112,260 signatures on our Brain Tumour Research petition which closed on 12th April 2021, calling on the Government to increase the national investment into brain tumour research to £35 million a year.

Our Level Up and Stop the Devastation Report which will be presented to Boris Johnson by Derek Thomas MP, Chair of the All-Party Parliamentary Group on Brain Tumours calls on the Government to:

- Introduce a new Levelling Up brain tumour research fund of £105 million
- Increase the national investment into brain tumour research to £35 million a year
- Demonstrate joined-up thinking for investment across the brain tumour research pipeline

So much more needs to be done before we can improve outcomes for patients. The conclusions and recommendations from the Petition Committee's 2016 report remain highly relevant, particularly:

- Funding for brain tumour research remains inadequate and does not receive sufficient priority
- We are still losing talented researchers from this field because they are unable to access sufficient funding
- There has been little improvement in prognosis for brain tumour patients
- Brain tumours are still the biggest cancer killer of children and adults under the age of 40

The following two paragraphs from the Petitions Committee 2016 report remain as pertinent now as they did when published:

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

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

Background information

House of Commons Petitions Committee; Funding for research into brain tumours;

[First Report of Session 2015–16](#)

[Debate on the 2020 petition](#)

[Previous evidence \(2019\)](#)