

## Written Evidence from The Brain Tumour Charity (BCCR0004) April 2021 Relating to brain tumour and childhood cancer research

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

Thanks to the generosity of our supporters and partners, we are very proud to be the largest dedicated funder of brain tumour research globally, currently funding nearly £37 million of cutting-edge research. But, like so many other charities, we are now having to adapt to our new level of income following the impacts of COVID-19, and to a world where so many of our fundraising activities have not been possible.

As a result of COVID-19, we're expecting our income in 2020-21 to have reduced **by over 40%** (a drop of around £4.8 million) compared to last year. We've therefore had to take significant steps to reduce our costs, including reducing the size of our workforce, to ensure we can continue to fund our current research projects as well as our support and information services.

This shortfall has already had a devastating impact on our ability to fund *new* research: we have been forced to cancel at least the next two grant funding rounds that we had planned, which could ultimately see us **reduce our spend on world-class research by up to £5.5 million over the next five years**. This could be equivalent to 8 fewer research projects, that could have been going further to find a cure or improve quality of life for people affected by a brain tumour, including childhood brain tumours.

With the impacts of the pandemic on our fundraising activities and income continuing, it is not yet clear when we may be able to restore our regular new research grant programme to its pre-pandemic funding levels.

However, to enable us to try to continue investing in new, world-class research to improve survival for adults affected by a glioblastoma, we will also be piloting a new research funding mechanism. In February, [we launched an exceptional grant round](#) with a view to funding [a phase II/III clinical trial of cannabinoids in the treatment of high-grade gliomas in adults later this year](#). Should a research grant application be successfully approved by our Scientific Advisory Board, we would then need to raise this money via an urgent fundraising campaign before the trial can begin.

## **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?**

The long-term impact of Brexit on UK brain tumour research remains uncertain. A major concern for many is whether we will still be able to attract talented researchers from abroad. Indeed, we have been contacted by researchers who have expressed concerns regarding the impact that Brexit will have on the recruitment of research personnel.

Issues around international collaboration have also been expressed as a potential concern. This is a particular issue for clinical trials in paediatric cancers, which are often conducted across multiple international collaborating centres. Due to the rarity of the conditions, international centres collaborate to ensure trials recruit enough patients to enable sufficiently-powered statistical outputs of research studies. Concern has been expressed by members of the brain tumour community about whether those with a brain tumour, particularly children, will be able to participate in European clinical trials going forward. Further concerns have been raised regarding difficulties establishing collaboration agreements between centres in the UK and Europe.

Anecdotally, The Charity has also heard examples of where applicants to international and European collaborative research funding streams have been deterred from selecting UK collaborators on their projects, citing long term concerns over Brexit as the major factor for doing so. It could therefore be that rather than legislative restrictions in the area, attitudes and perceptions around collaborating with UK science could be a hurdle to overcome going forwards.

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

In March this year, the Tessa Jowell Brain Cancer Mission (TJBCM) announced the first round of treatment centres that have been awarded the designation as a '[Tessa Jowell Centre of Excellence](#)'. Led by Professor Kate Bushby and a committee of experts in the field including from The Brain Tumour Charity, the Mission has worked to recognise and award neuro-oncology centres that provide excellent care for patients. Patient insight was at the heart of the process, with the assessments also involving feedback from 880 patients, collected by The Brain Tumour Charity through our Improving Brain Tumour Care Surveys. Designation was based on a range of criteria including clinical practice and training opportunities; emphasis on patient quality of life; providing clinical trials and offering a high standard of research opportunities. 9 of the 20 centres that applied received the award, and the Tessa Jowell Brain Cancer Mission will be working with those that were not successful and those yet to apply, to help improve standards and support them to meet the criteria in the future.

The TJBCM has also played a key role in helping establish the [Tessa Jowell BRAIN MATRIX](#) – a new national network to improve brain tumour patients' access to clinical trials, which is being

co-ordinated by the University of Birmingham and funded by The Brain Tumour Charity. It is fantastic that the BRAIN MATRIX has now opened and has recruited the first patients to the study; this project's role in enabling patients to enrol in biomarker driven glioma trials will represent significant progress for the research environment. Gathering imaging, genetic and clinical data, we are really hopeful that this study will drive much-needed progress towards precision medicine for brain tumours and ensure patients can be matched to trials as soon as new drugs are ready to be tested. For further information on this project, please see our response to Question 5.

The TJBCM has also experienced successes drawing research expertise from outside of the field of brain tumours, initiating collaborative partnerships and cross-field learning to positively impact the research environment. Additionally, further work around the development of fellowships in clinical oncology could also bring long-term benefit to the research environment. Unfortunately, efforts to facilitate collaborative partnerships and secure funding for fellowship positions have been impacted by COVID-19, with the re-deployment of clinical staff and the drop in charity funded medical research putting this progress at risk.

While the basic research outputs of the TJBCM are yet to be fully implemented and felt, we are encouraged about the potential impact that additional funding and collaboration could bring.

**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?**

Since the House of Commons Petitions Committee report in 2016, a number of new programs to fund and drive progress of research into brain tumours have been initiated. Notably, the founding of the Tessa Jowell Brain Cancer Mission, the Government's commitment to fund £40 million of research into brain tumours through the National Institute of Health Research (NIHR), and the commitment from Cancer Research UK (CRUK) to spend £25 million on ring-fenced, targeted initiatives, have all represented very positive steps.

The Government's 2018 commitment to fund £40 million of research into brain tumours in particular was very welcome news, with many families in our community hoping that this additional investment would drive progress in a research field that had historically been left behind. Three years on however, only a small proportion of this commitment has so far been invested.

This commitment has aided the funding of a range of clinical and infrastructure projects in the field, however, there is an urgent need to ensure this promised £40 million can be spent on the highest quality research as soon as possible, to drive much-needed progress on for brain tumour patients.

While the NIHR's 'highlight notice' on brain tumours was very welcome to try to encourage the submission of collaborative applications in the field, this has not been sufficient to attract enough high-quality proposals from the UK's brightest minds and so has unfortunately only translated into a relatively modest increase in funding on research into brain tumours to date. Of the £40 million pledged in February 2018, recent figures suggest that less than a quarter of this has been allocated to date.

A range of potential barriers to research funding have been explored by various partners and through the All-Party Parliamentary Group on Brain Tumours, including that brain tumour research applications are placed in mixed disease area funding rounds, with submissions being judged against project proposals for research into far more established scientific fields, which can put brain tumour researchers at a significant disadvantage when seeing their projects considered for funding.

While we completely agree that the Government's welcome commitment of £40m must only be spent on world-class research and recognise that there may be a number of barriers to this, we urgently need to see leadership and action from the Government to address these barriers and ensure that this funding can be spent on the best possible science to drive progress for patients as soon as possible.

We believe that more innovative and targeted funding initiatives may be required to ensure that the committed money successfully attracts high-quality brain tumour research proposals from the UK's brightest minds – and The Brain Tumour Charity would be extremely willing to work with the Government to help achieve this.

As part of the development of The Charity's new research strategy, we have engaged world-leading experts in brain tumour research and initiated collaborative partnerships to identify barriers to success and progress in the field. This new research strategy will be launching next year and we would welcome the opportunity to discuss the identified research priorities with the Government, and to explore how we could work together to improve the research funding environment and deliver progress in the areas of the greatest unmet patient need.

We will continue to collaborate with the NIHR in this area, working to better understand and overcome barriers to research funding, and would also welcome the opportunity to increase patient involvement in discussions to address these barriers – helping to build greater understanding of how this money could be swiftly allocated in the most impactful way and in areas of greatest need.

The commitment of funds to research into brain tumours from CRUK also provided an important emphasis on the unmet need of research in the area, with specific focus on areas identified as of particular importance. The range of clinical, translational and infrastructure funding is helping to drive change in the field, however sustained, long-term funding and Government support is urgently needed to ensure that any established momentum is not lost,

particularly in the context of the potentially devastating impact of the COVID-19 pandemic on charity-funded medical research.

Brain tumours remain the biggest cancer killer of children and adults under 40. With few new treatment options in a generation and just 12% of people diagnosed with a brain tumour surviving five years or more, progress is needed now more than ever and urgent and sustained investment in the area is essential. The critical need for further investment has only been exacerbated by the COVID-19 pandemic, which has had a significant impact on charity-funded medical research. This further highlights the need to ensure the charity sector work closely with the NIHR to ensure committed funding is appropriately spent.

## **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?**

### **Tessa Jowell BRAIN MATRIX**

One of the most recent significant developments in research and care for people with a brain tumour is the opening and recruitment of the first patients to the Tessa Jowell BRAIN MATRIX. BRAIN MATRIX provides a platform to trial precision medicine, using its multi-centre "portal" protocol to recruit patients and enable enrolment into biomarker-driven trials. All participants in BRAIN MATRIX will have their tumour tested in a lab to uncover its molecular profile. In addition to the information about molecular changes in the tumour, imaging, treatment and other clinical and quality of life data from each participant will be collected and analysed at a central hub. This will allow for more powerful analysis than ever before. By having molecular profiles ready-to-hand future trials will be a step ahead and people will know, sooner, if the new experimental treatments could be appropriate for them. BRAIN MATRIX represents a significant step towards providing the infrastructure to facilitate the opening of glioma clinical trials in the UK as well as ensuring the feasibility of genetic testing in a clinically relevant timeframe.

### **BRIAN**

We have built an app and associated database called [BRIAN](#) (Brain tumouR Information & Analysis Network). BRIAN allows those affected by a brain tumour to record information about their symptoms, treatments, appointments, medications and quality of life, share this quality of life data with researchers and their clinical team and view aggregated data insights on others' experiences, through either a secure web-app or a mobile app. In addition, BRIAN allows brain tumour patients to search for clinical trials that might be suitable for them and access information on financial benefits they may be eligible for.

Developed in collaboration with researchers, the app also includes interactive stability and memory challenges. These are quick tests that are designed to help people keep their brain active and are being studied to see if they can be used to track changes in the user over time, to, for example, help monitor for signs of disease progression. So far, around 4,000 patients, carers and healthcare professionals have signed up to BRIAN.

The power of BRIAN comes from the database behind the app, which combines national brain tumour datasets that The Charity has obtained from organisations such as NHS Digital and Public Health England with patient-entered data. The intention is that we will make these datasets available – in an ethical, responsible manner – to researchers, clinicians and patients in order to drive improvements in quality of life and accelerate progress towards cures for brain tumours. We have recently received our first two requests from researchers for access to BRIAN data and are currently in the process of producing the datasets required to meet these requests.

### **ClinSpec DX**

As outlined in The Committee’s 2016 report, brain tumours represent a major diagnostic problem. Patients often report subtle changes to their wellbeing and present with vague symptoms or those that are far more likely to be caused by less serious conditions. Moreover, GPs may see just a few brain tumour patients in their working lifetime making it challenging to develop expertise. It’s estimated that almost a third of brain tumour patients visit a healthcare professional five or more times before receiving their diagnosis, which can lead to significant emotional distress while they wait to understand what is causing their symptoms.

Currently, triage tools to support primary care professionals to identify those presenting with non-focal symptoms for an urgent scan are not effective. However, a new low-cost blood test developed in Scotland – ClinSpec DX – has shown promise in improving the diagnostic pathway. In a study published in [Nature Communications](#) in October 2019, ClinSpec DX was found to identify more than 90% of glioblastomas (the most common type of high-grade brain tumour) and more than 80% of all other brain tumours in a study in NHS Lothian. This low-cost blood test uses infra-red spectroscopy analysis to compare the pattern of molecules in the blood to previous patients with and without brain cancer, using a machine learning algorithm developed from hundreds of patient samples.

This rapid, low-cost test can be performed on a routine serum blood sample and the outcome reported as high or low risk of brain tumour, helping to inform the next steps in the patient pathway. This test result can then be integrated with the clinical history and examination by the primary care doctor. Where the clinical suspicion of tumour is low, and the blood test reinforces this, a decision can be taken that brain imaging is not needed. By contrast, clinically high-risk patients can be expedited for imaging.

We now need to see this very promising technology tested at scale to explore its potential to triage those with possible symptoms, diagnose more brain tumours earlier, improve patient experience and provide swift reassurance to those who do not have cancer. We believe there to be a clear opportunity for the Scottish Government to harness the expertise and infrastructure in Scotland to build on the initial study in Lothian, and are calling for this opportunity to be taken to pilot the blood test in primary care in Scotland.

### **Future work**

Despite the ongoing work of researchers and research funders in the area, significant progress on survival and quality of life for brain tumour patients is still lacking. Further funding in basic, clinical and translational research, as well as research infrastructure, is still required to drive progress and change.

Unfortunately, as discussed, COVID-19 is likely to have a long-term impact on brain tumour research and its funding. The Association of Medical Research Charities (AMRC) has estimated that it could be over 4 years until pre-pandemic levels of medical research funding is resumed. We therefore fear that unless the Government takes urgent action to support the medical research sector and address the shortfall, the COVID-19 pandemic is likely to cause additional delays to research progress.

**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?**

Despite renewed Government commitment, cross-party support, the hard work of the clinical and academic communities and significant input from research funders, many of the recommendations made in the Committee's 2016 report remain worryingly valid – and the full potential for progress in the priority areas identified has unfortunately not yet been realised.

In particular, we believe that action to implement key recommendations on improving early diagnosis (recommendations 1-4), increasing spend on world-class research (recommendations 5-7) and showing leadership to establish clear research priorities for UK brain tumour science (recommendations 9-11) is urgently needed and critical to progress on survival and quality of life for everyone affected by a brain tumour.

Improving the prompt and accurate diagnosis of brain tumours remains a unique challenge and is a key priority for The Brain Tumour Charity. Data from NCIN and NCRAS suggests that nearly half of all brain tumour patients are diagnosed via an emergency presentation, and we need to see action and leadership from the Government to continue reducing this proportion as much as is possible – particularly as recent NCRAS data suggests the pandemic has led to an increase in the number of people being diagnosed through an emergency.

We urgently need to see more research into new interventions to help increase the number of brain tumours diagnosed earlier, and believe that action to implement recommendations 3 and 4 from the 2016 Report remains paramount.

As outlined in question 4 above, we are also concerned that just under a quarter of the £40 million committed in 2018 has been invested in world-class research projects to date – with the Committee's report in 2016 having already recognised that barriers existed to getting fundamental research proposals approved (p58). We now need to see leadership and action from the Government to identify, acknowledge and address the current barriers to funding, and to support and encourage high-quality applications in clearly-established priority areas – to ensure this funding can be spent on the best science to drive progress for those affected by brain tumours as soon as possible.

Research into brain tumours has unfortunately not yet seen the same level of investment as has led to significant progress in other health conditions and this has contributed to a research environment that is less advanced than many other disease areas.

We are continuing to do all we can to address this and particularly to support and develop the brain tumour research workforce. For example, we have made significant progress in attracting promising early career researchers to the field through our Future Leaders funding scheme. To date, this programme has invested in five of the most promising post-doctorate level researchers, providing the sustained funding and support to build a career in brain tumour research. Stipulating that researchers collaborate outside of their institution, and targeted at developing talent within the UK and attracting researchers from abroad, we believe this scheme has been a step towards building the field of brain tumour research as an attractive and exciting research field.

Further progress has also been made in the centralisation of bio-banking and tissue collection for glioma, following the launch of the Tessa Jowell BRAIN MATRIX platform. Designed as a platform study to assess the use of genetic testing in a clinically relevant timeframe, BRAIN MATRIX will also provide a central hub for tissue collection and bio-banking.

However, despite some successes, many of the recommendations from The Committee's 2016 report remain unaddressed and we are concerned that, without further Government funding and action, the impacts of COVID could see further delays in this progress being realised.

Despite the commitments to improved research funding, the effects of the COVID-19 pandemic on clinical trials, NHS cancer services and on charity-funded medical research could have a significant long-term impact on progress on brain tumours unless action is taken.

Now more than ever, there is a need for additional government funding of research and infrastructure, with innovative and targeted funding initiatives to ensure funds can be committed to world-class research as soon as possible. Medical research represents such hope for the future for those affected by a brain tumour and we must act now to ensure progress is forthcoming. We cannot let the events of 2020 take that hope away.