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The All-Party Parliamentary Group  
on **Brain Tumours**

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February 2023

# Brain Tumours

## Pathway to a Cure

– breaking down the barriers

Report of the All-Party Parliamentary Group on Brain Tumours Inquiry  
into breaking down the barriers to finding a cure for brain tumours

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## All-Party Parliamentary Group on Brain Tumours

The All-Party Parliamentary Group on Brain Tumours (APPGBT) was established in 2005 by the Right Honourable John Bercow MP, supported by Ali's Dream and The United Brain Tumour Campaign (founding members of Brain Tumour Research). The APPGBT aims to raise awareness of the issues facing the brain tumour community in order to improve research, diagnosis, information, support, treatment and care outcomes.

Since 2005, MPs and Peers from across the political spectrum have worked together in supporting the brain tumour community including researchers, clinicians and most importantly, patients and their families.

APPGBT Membership:

- **Derek Thomas MP**—Chair
- **Rt. Hon Alistair Carmichael MP**—Vice Chair
- **The Lord Carlile of Berriew CBE KC**—Vice Chair
- **Baroness Masham of Ilton**—Vice Chair
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- **The Lord Polak CBE**—Officer
- **Holly Mumby-Croft MP**—Officer
- **Greg Smith MP**—Officer
- **Elliott Colburn MP**—Office

The APPGBT is grateful to the Inquiry panellists, to the professionals and experts who gave written or oral evidence, and to everyone affected by a brain tumour who completed surveys and added their voice.



### Secretariat:

The charity Brain Tumour Research, supported by Healthcomms Consulting, provides the Secretariat for the APPGBT, with contributions from its Member Charities and The Brain Tumour Charity.

Brain Tumour Research is the only national charity in the UK focused on finding a cure for all types of brain tumours through campaigning to increase the national investment in brain tumour research, while fundraising to create a network of seven sustainable Brain Tumour Research Centres of Excellence across the UK.

It supports a network of UK based collaborative groups of scientists progressing world-class research into brain tumours, working tirelessly to glean new layers of understanding about this disease.

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# Foreword

I first became aware of the devastation caused by brain tumours after Sue Farrington Smith MBE, Chief Executive of Brain Tumour Research, brought the issue to my attention when I was a prospective MP.

Joining the All-Party Parliamentary Group on Brain Tumours (APPGBT) was one of the first things I did after being elected to Parliament in 2015. It was with great interest that I watched the Petitions Committee respond to the Realf family's petition with 120,129 signatories, calling for an increase in national funding for research into brain tumours<sup>1</sup>.

The subsequent Westminster Hall debate took place and a Task and Finish Group was established.

Throughout all of these pivotal developments, I have been continually inspired by the campaigning of the brain tumour community and was delighted to take up the position of Chair of the APPGBT in 2017.

Following the publication of the Task and Finish Group's report in early 2018, the Government announced it would allocate £20 million for research into brain tumours and this was boosted by a pledge of £25 million from Cancer Research UK<sup>2</sup>.

After the death of Dame Tessa Jowell from a brain tumour and the establishment of the Tessa Jowell Brain Cancer Mission, the Government allocated a further £20 million<sup>3</sup>.

The provision of £65 million heralded a massive shift in focus towards brain tumours.

Of course, the funding announcement was extremely welcome, especially considering the historic underfunding of research into brain tumours, which has received just 1% of the national spend on cancer research since records began<sup>4</sup>.

However, meetings of the APPGBT over the five years since the funding announcements, reveal a concerning lack of grant deployment into the hands of those best equipped to unlock the complex puzzle that brain tumours pose – the researchers.

For this reason, the APPGBT, decided to conduct the 'Pathway to a Cure – breaking down the barriers' inquiry which aimed to revisit the optimism of 2018, to find out where money has been allocated in the intervening years and to identify any barriers to it flowing to its intended recipients.

To do this we asked those at the coalface of scientific endeavour for their thoughts in both written and oral evidence and it is this evidence that is at the core of this report and its recommendations.



I firmly believe that the Government wants to fund brain tumour research and the researchers clearly want funding so there is supply and there is demand but the mechanism for this to function as an effective market system is broken. The spirit of our inquiry was to seek out the root of this breakage and, with positive intent, identify solutions to the blockages that affect the ability of the scientific and clinical communities to advance options for, and the outcomes of, those affected by this devastating disease.

What has not changed since 2018 is that brain tumours continue to kill more children and adults under the age of 40 than any other cancer<sup>5</sup>.

**We must recognise a uniquely complex disease with a unique response.**

**For those in the brain tumour community, this is an emergency.**

I am honoured to have my position as Chair of this Group and would like to give a huge vote of thanks to the Parliamentarians who are supportive of the APPGBT. My thanks to all my fellow inquiry panellists, to the team at Brain Tumour Research for organising the inquiry and collating evidence and to those professionals, experts and policy makers who gave written or oral evidence. Over the coming months and years, we will use the results of this inquiry to keep brain tumours on the political agenda and improve outcomes for brain tumour patients.

Change can't come soon enough in terms of new options and better outcomes for brain tumour patients and it is the aim of all of us involved in the APPGBT to make a difference. It is a cause we all care very deeply about.

I do hope you find the report and the findings of this Inquiry as informative as I have.

**Derek Thomas MP**

# Stephen's Story



▶ *"My son Stephen was training to be a pilot in the Royal Air Force, going solo after 10 hours tuition, before he'd even passed his driving test. Suddenly at the age of 19, following a five-month spell of having occasional "pins and needles" in his right arm, he was diagnosed with a "benign" grade 2 Astrocytoma.*

*"Overnight he lost his authority to fly, drive a car, and with it his independence. He was signed off work for two years and had to return home. It soon became clear he would most likely lose the career he had worked so hard to achieve.*

*"After diagnosis things moved quickly, and the neurosurgeon removed an orange-sized tumour in his left temporal lobe. Knowing nothing about brain tumours and the devastating impact they can have, we were very shocked when the neurosurgeon announced **"I'm afraid your tumour will re-grow, turn more aggressive, and will kill you"** at a post-operative meeting. At the age of 19 our bright, funny, amazing young man was being told he had five to seven years to live.*

*"After less than two years, the 20% of Stephen's tumour impossible to remove during his neurosurgery, started re-growing. Once again, the family was devastated and Stephen was left to dwell on his future – or lack of it.*

*"Six weeks of radiotherapy were scheduled, followed by weeks of chemotherapy, which his body couldn't tolerate. Each course of treatment had to be abandoned after three or four doses. Having lost his hair, and an interest in food, it was truly heart-breaking to see my young, previously fit son who could run 12 miles with a military Bergen on his back, now struggling to walk 10 feet from our bathroom to his bedroom.*

*"Stephen passed away in August 2014, having just turned 26. He left behind a large circle of family and friends deeply affected by what they had witnessed happening to him.*

**"That is Stephen's story – but as you have read, sadly and unacceptably, our family's situation is far from unique, and survival rates for brain cancer patients remain largely unchanged over the last 30 years."**

**Peter Realf**

*Petitioner*

# Executive Summary

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

## **Petitions Committee – Funding for research into brain tumours report, 14<sup>th</sup> March 2016**

The All-Party Parliamentary Group on Brain Tumours (APPGBT) is calling for wide-ranging changes to be made in how research into the disease, the biggest cancer killer of children and adults under the age of 40, is funded.

This inquiry has found that the current funding system is unfit for purpose. The research funding system has been built in silos and needs to be joined up from basic science through to clinical trials. Patients with brain tumours should have equity of access to trials of new anti-cancer drugs that are currently only available to patients with other malignancies as the current system can exclude them for fear of skewing results.

Patients and families continue to be let down despite the Government's promise of millions of pounds of investment which hasn't materialised. There are issues with the treatment of terminally ill children; some are being denied access to last-resort clinical trials despite their parents wishing for them to participate. The inquiry also highlighted a so-called 'valley of death' in which potential new treatments discovered in the laboratory fail to reach patients because of unnecessary complexity in the way research is funded.

## **Key recommendations:**

- *The Government should recognise brain tumour research as a critical priority, developing a strategic plan for adequately resourcing and funding discovery, translational and clinical research by 2024, ring-fencing £110 million of current and new funding to kick-start this initiative*
- *Cell line isolation and biobanking is happening but only at a minority of sites across the research community. Government must ensure a robust tissue collection and storage infrastructure is in place across the country*
- *Government must do more to build research capacity encouraging and retaining talent through fellowships and research incentives*
- *There are a limited number of clinical trials available for brain tumour patients and the national trials database is not reliable. Government should ensure equity of access to clinical trials and that the clinical trial database is robust and up to date*
- *Pharmaceutical companies are choosing not to pursue the development of brain cancer drugs in the UK. Government should simplify the regulatory process and introduce tax reliefs and incentives for investors, to encourage investment for the longer time periods necessary to develop and deliver new brain tumour drugs*
- *Funding bodies should ring-fence specific funding for research into childhood brain tumours where survival rates for the most aggressive tumours have remained unchanged for decades leading to frustrated families seeking costly and unproven treatment abroad*

# Desperate Voices

## Background:

Following the 2016 Petitions Committee *Funding for research into brain tumours* report and Westminster Hall debate, the then Health Minister George Freeman established a Task and Finish Working Group. Recommendations in this group's 2018 document the *Report on the Task and Finish Working Group on Brain Tumour Research* and a speech made by Dame Tessa Jowell led to the Government committing £20 million of research funding for brain tumour research. Cancer Research UK pledged a further £25 million<sup>6</sup> at the same time. On the death of Tessa Jowell in May 2018 the Government promised a further £20 million<sup>7</sup>. This total of £40 million of government funding was made available via the National Institute for Health Research (NIHR).

However, five years later, there are no new treatments and the five-year survival for patients is still just 12%<sup>8</sup>. Brain tumours remain the biggest cancer killer of children and adults under the age of 40. Of the £40 million Government commitment, on 25<sup>th</sup> January 2023 just £15 million had been awarded since June 2018, with £6 million of this not easily identifiable as relevant to brain tumours<sup>9</sup>. See Appendix 4.

The national investment in cancer research including brain tumour-specific research is measured by the National Cancer Research Institute (NCRI), a partnership of 22 Government (6) and large charity funders (16)<sup>10</sup> who each invest more than £1 million a year in cancer research. Cancer Research UK is the largest contributor investing more in cancer research than Government research funders combined. £630 million of research spend was captured in the NCRI Cancer Research Database in 2020-21 from 20 NCRI Partners<sup>11</sup>. By this method of analysis, which may underestimate spend for non-cancer specific Partners, the Medical Research Council contributed £107 million<sup>12</sup> (17%), and the Department of Health and Social Care (DHSC) contributed £84 million<sup>13</sup> (13%) with Cancer Research UK contributing £310 million<sup>14</sup> (49%).

When focused on research which NCRI have categorised as specific to brain tumour research, the total spend was £17.6 million<sup>15</sup> (2.8%). A conservative estimate based on this analysis for the Medical Research Council and the National Institute for Health and Care Research (NIHR) contribution was £1 million each<sup>16</sup> with Cancer Research UK contributing £13 million<sup>17</sup>.



*"Our lives changed forever the day our beloved daughter Amani collapsed at home. It was 29<sup>th</sup> April 2020 and the UK was learning to live with dramatic changes brought about by the pandemic. Within hours we were told the awful news; it was a brain tumour. Due to Covid-19 restrictions, Amani was forced to spend 12 days alone in two different hospitals having numerous scans and undergoing exploratory surgery. It was brutal, she was frightened and so were we, unable to be by her side. As horrendous as it was, the worst was still to come.*

*"Two days later we learned her tumour was cancerous and inoperable, a grade 4 glioblastoma with H3K27 mutation. Standard of care treatment failed to stop the tumour growing. Thanks to support from friends and our community we were able to pay privately to access a new trial drug but strongly feel the pharmaceutical industry should be compelled to release such drugs on compassionate grounds. Sadly, there was nothing we could do as Amani declined physically, neurologically and emotionally.*

*Despite knowing that change would come too late for her, Amani campaigned for increased investment in research right up until the end. She died in February 2022, six weeks before pop singer Tom Parker with whom she formed a close friendship because of their shared diagnosis."*

**Yasmin Stannard and Khuram Liaquat**

*Bereaved Parents*

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# Executive Summary

## Summary of Evidence:

Since records began in 2002, NCRI partners have funded £10 billion of cancer research. However, only £126 million (1.3%) of this was spent on brain tumour research. In that same time frame £775 million has been spent on breast cancer research (7.8%) and £551 million on leukaemia research (5.5%)<sup>18</sup>, with the resulting improvement in treatment and five-year survival rising to 85%<sup>19</sup> and 54%<sup>20</sup> respectively vs 12%<sup>21</sup> for brain tumour patients. In the last 40 years, survival of those with breast cancer has doubled<sup>22</sup> and with leukaemia quadrupled<sup>23</sup>.

A review conducted by the Tessa Jowell Brain Cancer Mission (TJBCM) as part of their Centre of Excellence applications, discovered that 28 of 31 Centres had jointly received £100 million funding for lab-based research over the five years ending 2021<sup>24</sup>. Cancer Research UK, The Brain Tumour Charity and Brain Tumour Research had funded 75% of this between them, with Government bodies just 11%<sup>25</sup> and the rest coming from pharmaceutical companies, smaller disease specific charities, charities linked to the institutes in which the research was being done and the host institutes themselves.

Concerned about this lack of progress, the All-Party Parliamentary Group on Brain Tumours (APPGBT) launched the Pathway to a Cure inquiry in 2021. During this process it held six oral evidence sessions with:

- *Convening Bodies*
- *Clinical Researchers*
- *Scientists*
- *Paediatric Specialists*
- *Industry*
- *Charitable Funders*

The APPGBT also received survey responses from 38 leading brain tumour scientists and clinicians across the UK.

The APPGBT had previously heard from the NIHR that they are ready to fund brain tumour projects, but applications have not met the 'quality bar' as currently configured. The inquiry uncovered that there is a gap in research funding along the pathway of discovery, translational and clinical research.

Scientists and Clinicians told the inquiry panel that NIHR funding calls were disproportionately at the clinical end of the research pipeline. However, due to the complex nature of the subject area, there are currently relatively few opportunities for studies in patients. In order to generate new compounds or approaches to test in clinical studies, discovery research must be conducted into the biology of brain tumours. This would develop understanding of the causes and behaviours of brain tumours, why they can become aggressive and take lives within 10 months of diagnosis and provide an understanding of how the biological drivers of malignancy could be targeted.

Witnesses also shared that they are unable to access Government funding for translational research which takes discoveries from research to the bedside of patients, therefore creating a 'valley of death'<sup>26</sup>. Additionally, due to a lack of funding to support early-stage researchers, brain tumour researchers find it difficult to have sustainable careers.

The Inquiry also heard that there is an uneven distribution of clinical trials across the country, inequality of access for trials, a lack of staff time for research and a lack of NHS resource to support those patients on funded research studies.

Industry contributors pointed out how the economic process of delivering new drugs to patients was difficult due to the inflexibility of NICE, the complexity of the regulatory process and the escalating costs of supporting and performing trials in the NHS.



# Desperate Voices

A lack of support for brain tumour research manifests itself as high costs for the NHS during treatment and rehabilitation, loss of tax revenue, and the costs of supporting brain tumour patients and their families via the benefits system. The economic costs of brain tumours among the working age population have been estimated at £578 million per annum, ranking the third highest amongst more common cancers behind lung (£1.2 billion) and breast (£635 million)<sup>27</sup>.

The urgent need for more investment in brain tumour research has not gone away. Charities have suffered a loss of income during the pandemic and are now suffering further due to the cost-of-living crisis. They should not be relied upon to provide funding to advance treatments for brain tumours; Government funders should be taking a leading role.

Having seen the remarkable speed at which joined-up thinking led to treatments for COVID-19, much could be achieved if Government treated brain tumour research as a critical priority.

*"We know that research has led to huge improvements in cancer outcomes, particularly in breast cancer, the area I know best. We know too that, sadly, progress has not been uniform, and it has been woefully slow for some cancer types. This needs to change. As we have heard, it is time to do the really difficult stuff. Brain tumour research must be of enormous concern for the whole cancer research community, not least because, in addition to many patients with primary brain tumours, thousands of patients with breast, lung, skin and bowel cancer will develop metastatic brain tumours, reducing their life expectancy to single figures too."*

## **Baroness Morgan of Drefelin –**

*Chief Executive of the medical research charity Breast Cancer Now and Chair of the National Cancer Research Institute – NHS Cancer Treatments – House of Lords Debate, 25<sup>th</sup> January 2018*

*"For me, the need for improvements in the treatments available for brain tumours is clear and the way to do this is through research."*



*"Combining research with clinical training has been challenging but rewarding. Just as treatment of brain tumours involves collaborative multidisciplinary working, often across institutions, so does the research. This can add additional challenges, from accessing appropriate funding to support collaborative projects and the relevant infrastructure and governance, accessing and managing appropriate biological samples, harmonisation of clinical data collection, to giving excellent dedicated clinicians the time and mental space to leverage their vital expertise to support research studies."*

*"As an early career researcher entering such a field is daunting and a path less well-trodden than for other areas of cancer research. This makes programmes and opportunities that recognise the challenges relating to brain tumour research very important in facilitating the development of future researchers and maximising our learning from the talented NHS workforce."*

## **Dr John Apps**

*Clinical Lecturer*

# Recommendations

*Government organisations who fund research are not getting enough money to brain tumour researchers. This report responds to the need to access funding by the research community and seeks to find solutions which ensure a properly resourced pathway to a cure for brain tumours.*

## **1: Government to recognise brain tumour research as a critical priority; developing a strategic plan for adequately resourcing and funding discovery, translational and clinical research by 2024.**

Funding organisations need to be joined up in their thinking, make further funding available and deliver on their commitments to improve outcomes for brain tumour patients and their families.

In the United States, the Recalcitrant Cancer Research Act calls on the National Cancer Institute (NCI) to develop scientific frameworks for pancreatic and lung cancers and provides the NCI director with the authority to develop frameworks for other similarly devastating cancers, such as brain tumours. Attention and resources are steered into research and the development of strategic plans to combat these deadliest cancers and result in true progress. There is a requirement in the Act for the NCI director to submit a report to Congress on the effectiveness of the frameworks in improving the prevention, detection, diagnosis and treatment of these cancers. Such a government-driven initiative shows best practice and innovation.

We recommend that the UK Government looks to the US and the Recalcitrant Cancer Research Act and delivers a similar framework for progress in the UK. Funding provided by the Departments of Health and Social Care (DHSC) and Science, Innovation and Technology (SIT) will need coordination and leadership across the two departments.

- *DHSC and SIT agree one brain tumour champion to lead coordinating activities across both departments unilaterally, implementing a joint strategy*
- *The Government to ring-fence £110 million of current and new funding for discovery, translational and clinical research*

## **1.1: Discovery Research – Prioritise brain tumour research as a Medical Research Council (MRC) challenge, that would benefit from £50 million funding over 14 years.**

Whilst recognising the recent advances and improvements in molecular testing and prognostic information, there is a requirement for further discovery research. This will improve understanding of disease biology and how best to frame and support pre-clinical trial research. For instance, a particular issue for tackling brain tumours is the complexity of drug absorption through the blood brain barrier. It is crucial that the Government enables the building of critical mass in these elements of the research pipeline.

Currently researchers can access funds for discovery projects through the MRC. However, with no ring-fenced funding to support poorly-funded disease areas such as brain tumours, investment into the disease is not always prioritised.

- *Deliver focused calls for multidisciplinary research into brain tumours*

The APPGBT welcome the 18<sup>th</sup> July 2022 UKRI announcement introducing its challenge-led approach<sup>28</sup> to tackle complex and interdisciplinary health issues. Units will benefit from an investment of £40 million to £50 million over 14 years, providing direction, certainty and long-term financial security.

- *The UKRI, through the MRC, to confirm brain tumours as one of the challenge themes, delivering focused calls for research into brain tumour biology*
- *Make the blood brain barrier a strategic priority, encouraging investment in cutting-edge research, which could yield 'game-changing' results in the treatment of brain tumours and other neurological diseases*

## **1.2: Translational Research – MRC to make a further £35 million available to improve trial readiness by 2024.**

On average, it takes 15 years for an idea to move from the pre-clinical stage to helping a patient. Researchers said they find it challenging to access Government funding for translational research, relying on charities to fund 'risky' elements of the research pipeline. Government must take on funding this 'valley of death' element of the research pipeline, which seeks to move basic science discoveries more quickly and efficiently into practice.

- *Introduce an MRC fund, to be administered by LifeArc, which accelerates the pathway from discovery research to translational development. This should not be restricted to MRC core-funded units and institutes*

## **1.3: Clinical Research – Revisit the NIHR highlight notice and make it easier to access the unspent £25 million of the £40 million commitment.**

It takes at least a year to get a decision from a funding body, and then, if successful, researchers must start engaging with the regulatory pathway. The UK has a less flexible approach than countries such as the US. This means that the UK is frequently a late-comer to trials. There is also a lack of capacity within the NHS to facilitate trials.

For those clinicians working within the brain tumour field, there is a significant challenge to balance clinical commitments with research activity. Neurosurgeons and oncologists are focused on service delivery, with less time available to apply for grants. There is very limited funding available to support research time from Government, with charities stepping in to fill the gap. This is inappropriate; time for clinicians to facilitate research must be funded by Government.

What's more, the significant time that researchers devote to applying for grants, offers limited return on investment and is a deterrent to grant applications due to low success rates.

The inquiry found that there is a perception that review panels have a lack of understanding about the unique nature of brain tumour research, due to a deficit of specialists on panels. During oral evidence sessions, it was also highlighted that a lack of feedback further disincentivised unsuccessful applicants from reapplying.

- *Ensure a brain tumour research specific expert sits on each grant board, providing expert experience during grant deliberation*
- *Provide more detailed feedback for unsuccessful applicants, so they can develop their proposal when reapplying*
- *Develop a continued programme of workshops and a funding toolkit for researchers, supporting navigation of the funding system and increasing success rates*
- *Introduce a pre-application phase to improve success of applications and increase awareness of the Research Design Service*

## **2: Ensure a robust tissue collection and storage infrastructure is in place across the country.**

Access to brain tumour and normal tissue samples is required by the research community for high quality research. In addition, researchers often require a highly-characterised tissue collection system including clinical information. Cell line isolation and biobanking which is happening at individual sites across the research community requires expansion, co-ordination and oversight to maximise the impact for research and patients.

- *Ensure the relevant tissue collection infrastructure is in place to conduct research*
- *Create coordinated storage and centralised data function overseen by BRAIN UK with renewal of MRC funding*
- *NIHR to employ brain tumour research nurses/clinical nurse specialists to collect tissue and help get more patients into trials at each of the 31 neuro-oncology centres and 19 paediatric centres*

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# Recommendations

### **3: NIHR and UKRI to build research capacity, encouraging and retaining talent through fellowships and research incentives.**

Government must do more to encourage and retain talent. Securing research-fellowship funding is key to this, as currently, due to a lack of funding and support, early-stage researchers, especially post-doctoral researchers, are moving away from the field of brain tumour research. They are attracted by more readily available and secure funding in other disease areas. The MRC and NIHR need to ring-fence opportunities to bridge the gap between academic research and clinical practice.

- *Introduce specific brain tumour awards across the research pipeline to build critical mass and attract researchers from other fields*
- *Prioritise funding for a fellowship programme, supporting early-stage researchers to develop their skills in the field of brain tumour research*

We support Cancer Research UK and the Academy of Medical Sciences' recommendation that Government should support NHS staff to undertake research through: staff contracts which provide dedicated research time; monitoring of research engagement and impact; integrated research officers between NHS R&D offices and universities; and opportunities for students to undertake research projects in clinical settings.

- *Incentivise research into brain tumours by offering buy-out time for clinical researchers and research active healthcare professionals as part of the Workforce Plan*
- *Develop NIHR fellowships to specifically support brain tumour researchers, including extending the NIHR Academic Clinical Fellowships and Clinical Lectureships*

The Tessa Jowell Brain Cancer Mission (TJBCM) is successfully funding two teaching fellowships with matched funding from the NIHR, but this number needs to increase – learning about brain tumours early in careers results in researchers going on to choose the discipline.

- *When optimised, roll out teaching fellowships across the network of 31 centres*

### **4: Ensure patients have equity of access to clinical trials and that the clinical trial database is robust and up to date.**

Only 5% of brain tumour patients are entering the limited number of trials available. Often brain tumour patients are excluded from early phase cancer clinical trials due to concern that the side effects they could experience may negatively impact trial results. Clinicians cited that many trials for which patients with brain tumours are eligible to enter are not accessible to patients who often have physical disabilities, as participants are expected to travel long distances across the UK. Poor health and the cost implications were key barriers to patients entering studies that were available to them.

A survey carried out by Brain Tumour Research highlighted that 72% of patients that responded would consider participating in a research or clinical trial<sup>29</sup>. Only 21% believed healthcare professionals gave sufficient information about opportunities to participate in clinical research, including trials, with only 12% taking part in a trial<sup>30</sup>.

Access to multi-site cancer trials is sometimes denied for brain tumour patients. This is because industry is concerned about a perceived risk that brain tumour patients are more vulnerable to adverse responses, and therefore will jeopardise trial results. This approach does not take account of the benefits that new and repurposed therapeutics could provide for brain tumour patients. If brain tumour patients are excluded at an early stage it means possible benefits for brain tumour patients are not identified and carried forward in later trials. Access to trials should not be assessed by the location of the tumour but rather by other, individual criteria such as genomic profile and medical history.

- *NIHR to invest more in 'basket studies' looking at specific mutation rather than a specific disease to increase the number of trials available to brain tumour patients*
- *The Medicines and Healthcare Products Regulatory Agency (MHRA) to issue a statement urging the inclusion of brain tumour patients in early phase cancer trials*



*“As a clinician I want to be able to sit down with my patient and input all the relevant data about their brain tumour type and their treatment pathway and then, to search an up-to-date, progressive UK trial registry. This would enable me to discuss appropriate trial options there and then, giving the patient choices that a modern health provider should be able to offer.”*

**Mr Babar Vaqas** *Neurosurgeon*

Normal trial rules should be adapted for brain tumour patients who don't have time on their side. The inquiry found that brain tumour patients were concerned about being given a placebo. It was also demonstrated that clinicians are risk adverse to children accessing early phase trials despite parents' wishes. Frustrations with these limitations encourages patients to travel overseas in pursuit of treatments not available in the UK.

- *Explore how the MHRA, HTA, and NICE can cooperate better to enable new treatments to be made available in the UK, such as immune vaccination, and immune cell therapy which use a patient's own specific antigens and dendritic cells respectively*
- *Where possible, external controls such as previous trials data to replace placebos for brain tumour patients*
- *As the UK embarks on an ambitious plan to accelerate research into mRNA cancer vaccines with German pharmaceutical company BioNTech, the NIHR must both support brain tumour patient inclusion in this research and where appropriate prioritise such inclusion*

Currently, the national database for trials on the NHS Be Part of Research website is not always up to date, and early phase trials are not included. Clinicians cited that they find the US site **clinicaltrials.gov** more useful. The NIHR database is hard to access in the limited amount of time clinicians are allocated to spend with patients.

- *The NIHR trials database should be highlighted and readily accessible to all clinicians across the UK, with clearly defined and regularly updated eligibility criteria and location information*
- *Deliver an awareness campaign through the NHS to ensure that the trial database is available to both clinicians and patients*

#### **5: Simplify the regulatory process and introduce tax reliefs and incentives for investors, to encourage investment for the longer time periods necessary to develop and deliver new brain tumour drugs.**

Pharmaceutical companies are choosing not to pursue development of brain cancer medicines in the UK due to a lack of incentives, and the challenging regulatory environment.

The inquiry heard that one of the fundamental challenges is early access to venture capital for therapies. Investors want a return on investment and are disproportionately interested in safer, shorter projects rather than 10-year projects which could have a more successful return in the long term.

There are currently no brain tumour drugs on the orphan drugs register. To encourage more drug development in the UK, we ask the Government to:

- *Enhance the MHRA Orphan Medicinal Products Guidance, to offer a development pathway that is financially beneficial to pharmaceutical companies who invest in drug development for brain tumours*

Industry raised that the economic process of delivering new drugs to patients was difficult due to the inflexibility of NICE, the complexity of the regulatory process and the escalating costs of supporting and performing trials in the NHS.

It was suggested that industry is reluctant to trial drugs known to be effective against other cancers on brain tumour patients. This was due to concerns that the high-risk nature of brain tumour patients would adversely skew trial results. The Experimental Cancer Medicine Centres (ECMC) alongside the BRAIN MATRIX should support industry by providing academic studies in small numbers of patients, as proof of principle. If successful, industry could then take the trials forward. This is integral to ensuring that brain tumour therapies are then included in later stage trials, leading to cures.

- *ECMC and BRAIN MATRIX to provide academic studies in small cohorts to provide proof of principle and proof of delivery*

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# Recommendations

Brain tumour treatments are inevitably expensive due to the low numbers of treatable patients. Lessons could be learnt from the US's FDA programme on Humanitarian Devices Exemption (HDE). This is a mechanism through which companies can acquire market approval at a much earlier stage for certain health conditions, for instance in rare cancers, or on humanitarian grounds. A programme similar to the HDE pathway would enable investors to enter the new market with a smaller monetary investment.

- *Government to introduce a humanitarian programme by which companies can acquire market approval at a much earlier stage for brain tumours and other rare cancers and recalcitrant diseases*

## **6: Ring-fence specific funding for research into childhood brain tumours.**

Paediatric brain cancer is viewed by researchers as different to adult brain tumours. This is because brain tumours in children are linked to physical development, rather than ageing. Current treatments have significant long-term side effects, more research into kinder treatments and novel drug delivery for children is needed, alongside tackling resulting brain injury issues and its consequences.

Central nervous system (CNS) tumours represent the most common solid tumours in children. Approximately 450 new cases are diagnosed per annum in the UK among children aged under 15, with a further 150 cases annually in those aged 15-19<sup>31</sup>.

Survival rates remain unchanged over two decades, not demonstrating the same upward trajectory that we have seen in other malignant diseases such as leukaemia. This is despite improvements in neurosurgical techniques, supportive care, and more refined imaging and molecular diagnostics.

CNS tumours often demonstrate a poor outcome, requiring multimodal therapy (surgery, radiotherapy, chemotherapy). Increasingly molecular-based therapy is also used. There are national/international clinical trials for certain tumour types to aid management, but the majority of patients do not have a tumour type covered by a Phase III trial. In the US, CAR-T Therapy is having positive results yet is not being trialled in the UK in spite of the UK being a world leader in developing this technology.

Critically, children and young people with CNS tumours carry the greatest burden of long-term side effects from cancer survivors. It is estimated that the lifetime cost of care for a child with significant impairments following CNS tumour therapy to live an independent life is £15-30 million (based on medico-legal awards)<sup>32</sup>.

The management of CNS tumours in children and young people has become increasingly complex. Individual oncologists (even internationally recognised experts) or treatment teams cannot carry the knowledge required for the whole range of tumour types and sub-types, disease scenarios and therapeutic options that now exist at relapse. There is increasing demand for national and international second opinions and strong support for the establishment of formal advisory groups for specific CNS tumour types, particularly rare tumour entities and complex clinical cases.

The complexity of managing these rare and complex tumours means there is a desperate need for a National Rare and Complex Paediatric Brain Tumour Advisory panel.

- *The NIHR via the Clinical Research Network (CRN) and the ECMC alongside the Research Councils must work together and invest in clinical trial infrastructure which enables complex drug delivery studies in children*
- *NHSE to implement a national / virtual multi-disciplinary advisory group for rare, complex and relapsed childhood tumours, with fully funded infrastructure and administrative support*



# The Patient View

*"If you have hope you have life. If there's no hope then they will give up."*

**Loss of hope, devastation, depression, frustration and desperation. Just some of the feelings patients and carers used to describe the lack of treatment options for those diagnosed with a brain tumour.**

*"Gut wrenching, heart-breaking, demoralising, worrying, impacts negatively on all aspects. Scary frightening. When you continue to have options, you can continue to have hope."*

*"Sad it's like brain tumours don't exist. People are unaware. The amount of times I'm told by family just get up, you're fine, is pretty sad. There is no understanding of the affects it has on our lives."*

*"The treatment my son received was largely the same as Astronaut Neil Armstrong's daughter was given in 1962, being chemotherapy and radiotherapy. How many new drugs for treating brain tumours have been developed since the turn of the century?"*

**In October 2022, Brain Tumour Research conducted a patient survey on its digital media channels and through its networks to support the All-Party Parliamentary Group on Brain Tumours Inquiry: Pathway to a Cure<sup>33</sup>.**

**The survey aimed to understand the experiences and thoughts of UK brain tumour patients and their families on the clinical pathway. Responses were received from and on behalf of 276 patients, many of whom had sadly died from this devastating disease.**

*"I think the prognosis for most brain tumour patients is incredibly bleak. Being told you have an incurable illness is devastating and robs the patient of perhaps the most important thing of all – hope."*

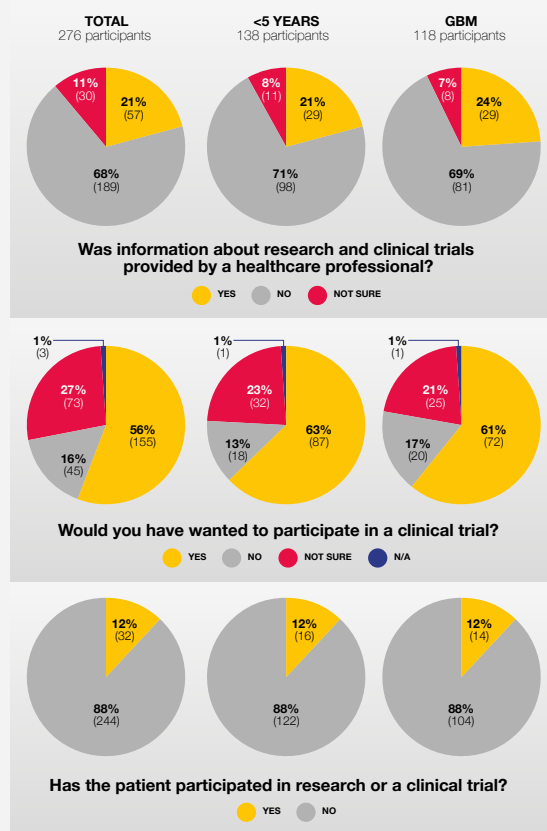
*"... my treatment options are still the same as 10 plus years ago. It doesn't give much hope."*

*"Disappointed, for her 21 years living with cancer there was no real advances other than more targeted radiotherapy."*

**We discovered an overwhelming feeling of doom from patients and their families, with death and reducing quality of life ahead of them. What's more, the lack of new treatment options was found to be detrimental to mental health, leaving families feeling abandoned and angry.**

*"Detrimental to mental health. You know there's nothing to be done, just living with this ticking time bomb that's slowly eroding who you are, you may as well not be alive at all."*

**Responses revealed that only 21% were provided with information about research and clinical trials by their healthcare professionals, with 72% indicating that they would have considered participating, but only 12% taking part in a trial.**



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# The Patient View

**Of the 138 diagnosed more recently in the last five years (2018-2022) just 21% were provided with information and a higher 76% would have considered participating, and still only 12% took part in a trial, demonstrating no improvement in recent years.**

*"Disgusted. Let down. Traumatized. My life is ruined. I'm waiting to die to be with my son, but here for my other two children."*

*"It's appalling!! Behind the times and behind progress made in other cancer types. It feels as though no one cares."*

**Those diagnosed with a glioblastoma (GBM), the most lethal of brain tumours, represented 118, or 43% of respondents. A slightly higher 24% were given information and more of these patients at 78% thinking about participating, yet still only 12% took part in a trial.**

*"A diagnosis of GBM is a death sentence, there are no hopeful conversations, just a 12-month prognosis and a suggestion to go out and make memories. We should be making the advances seen in breast cancer and leukaemia treatment and offering hope."*

*"Patients have less time with their loved ones. Treatment is harsh on their body as the same medication has been used for more than 10 years."*

**The survey found that 10% of patients travelled abroad to get their treatment, whilst others cited affordability as a reason why they didn't travel for treatment.**

*"More deaths and heartbreak – having to crowdfund and beg strangers for help."*

*"We obtained medication from abroad as not available in the UK. Nor were any trials of that being done here in the UK."*

*"It's traumatic, disheartening and for some, patients give up the fight early because there's not enough treatment options and they aren't able to go abroad. In some cases, brain tumours are found too late."*

**Responses on behalf of 25 children revealed that 28% were enrolled on trials, with two patients obtaining medication not available in the UK from abroad and three citing receiving treatment in Germany.**

*"It's devastating and living with a time bomb in your head. Just keep going on chemo getting sicker. My young son would have been more proactive and tried anything offered to have the chance to live a life. He had his whole life ahead snuffed out. It is heart-breaking."*

**Overwhelmingly 84% believed that the Government doesn't allocate enough funding to brain tumour research.**

*"Appears poor in comparison to other countries like the USA and Germany."*

*"Not very good. Plenty of studies and research without producing anything significant or effective to treat brain tumours. Good results from the US and Europe but it takes too long for them to be adopted here in the UK."*

*"It's slow. As a mother who has lost two children and a mother to cancer, two of them with brain tumours, I believe more funding for research will result in more effective treatment and even one day a cure."*

*"I feel the activism and the brain tumour family has created momentum that has opened channels to seek answers from those that make decisions around funding such as APPG, the noise made is being heard more. Sadly, it often takes a high-profile public figure to suffer or lose their fight to really bring the subject to a head. Tiny steps but at least steps."*

## Desperate Voices

*"I think that improvements are being made all the time but with more money invested in research these improvements could be made more swiftly."*

*"We are so far behind other countries, it's unbelievable. More needs to be done in the UK."*

*"It is too slow considering the high mortality rate in children and young adults. Much more funding needs to be directed towards research to help find cures for this devastating disease."*

*"Progress is too slow and not enough to make a real difference to patients in the UK."*

*"Very exciting developments, but progress is slow. More funding would help expedite this research."*

*"I know that there are significant developments being discovered each day by dedicated scientists and this is marvellous, but more funding would mean swifter discoveries for people whose prognosis is usually just a few months."*

*"We lost our brave, inspiring son George at the age of 13 to glioblastoma (GBM) and simply cannot understand why, in this day and age, so few treatment options are available for this horrific disease."*



*Families like ours have no other option than to try to raise huge sums of money, in our case more than £300,000, to give our precious boy a chance. When we exhausted treatment options in the UK we managed, against the odds, to get treatment in the US but we were fighting a losing battle.*

*George became dangerously ill on the flight and had to go straight into surgery. By then he was too poorly to take part in the trial. We fought for George as hard as we could. Now, despite our loss, we continue to fight in the hope it will help other families in the future.*

*We are activists in a world we never wanted to be part of because it is what George would have wanted. Despite and perhaps because of the horror of never seeing our son grow into a man we will never stop trying to make a difference for future young brain tumour patients."*

**Louise and Matt Fox**

*Bereaved parents*

# Convening Bodies

In the oral evidence session with convening bodies the panel heard from the Tessa Jowell Brain Cancer Mission (TJBCM) and the National Cancer Research Institute (NCRI) brain group.

## TJBCM

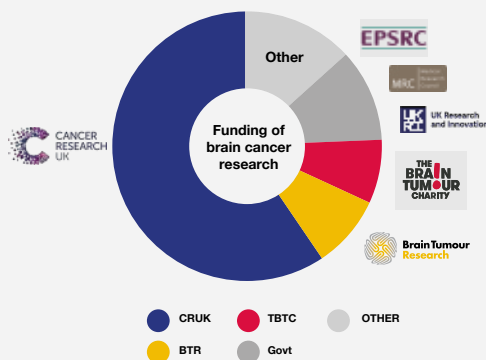
As part of their Centre of Excellence accreditation application process TJBCM had asked neuro-oncology centres to explain the type of research their staff conducted and indicate who funded their work. They received responses from 28 of the 31 centres.

It was reported that nearly £100 million was given to advance brain tumour research in the five years to 2021 and that money went to infrastructure (£37m), discovery (£18m) and translational (£45m) research. This funded over 210 different programmes<sup>34</sup>.

They shared that Cancer Research UK, The Brain Tumour Charity and Brain Tumour Research together account for 75% of basic and translational grant giving, the government (UKRI, MRC, EPSRC and NIHR) funds about 11%. Of the other 15% (£13m approx.) pharmaceutical companies and disease-specific charities are the largest funders<sup>35</sup>.

Furthermore, they shared that all hospitals were participating in trial activity, but most activity is concentrated in the largest centres. It is the largest multi-centre trials that offer opportunities for smaller centres to participate.

In the information gathered, centres reported 90 unique brain tumour trials, 43 were interventional, 22 of those were testing novel compounds (repurposed, first in man or first in brain tumour), majority (13) were for glioblastoma<sup>36</sup>.



A lack of dedicated research staff, stringent eligibility criteria, patient participation barriers and difficulties accessing equipment were issues identified that can prevent centres from carrying out more clinical studies.

In respect of improving the quality of applications to the NIHR, the DHSC and TJBCM jointly organised and co-hosted seven research workshops on:

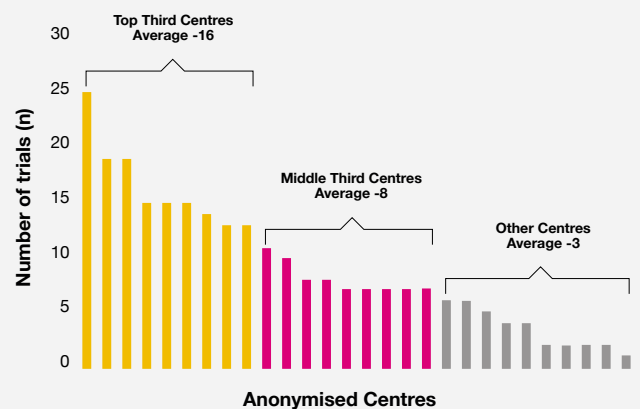
1. How to improve scientists' understanding of open funding calls
2. How to write a good application
3. Common pitfalls

The NIHR will fund the research element of every Tessa Jowell Trainee fellow when they undertake a research project. The TJBCM is successfully funding two teaching fellowships with matched funding from the NIHR, but this number needs to increase – learning about brain tumours early in careers results in researchers going on to choose the discipline.

The TJBCM is working to launch a new project to get pre-clinical compounds into human trials.

The TJBCM will also provide a clinical trial finder.

Small patient numbers (brain tumours are a rarer cancer) proved a disincentive, particularly in smaller centres, to opening and running clinical trials. There has been talk of having dedicated brain tumour research nurses in centres and this would make a huge difference.



With thanks to the Tessa Jowell Brain Cancer Mission for sharing these charts

# Desperate Voices

## NCRI Brain Group

The NCRI brain group reported that most spending has been on treatment and then cancer biology but we still don't know what causes brain cancer. The inquiry heard that there have been no advances in early detection or prevention. Advances in molecular testing have improved prognostic information but this hasn't progressed into better, targeted therapies. There have been no new treatments for GBM since 2005. What's more they heard that in the last five years, every large clinical trial has failed to improve outcomes meaning many years of research have been lost, with resulting costs to patients' lives.

### When asked by the panel what needs to be done to accelerate research into brain tumours and increase impact, proposals fell into several categories:

- *Better integration of basic scientists with clinicians. This would help develop and deliver translational research training for basic scientists. It can be very difficult to access funding for translational research, as it does not qualify for Government funding. For example, much of the basic and translational research would not qualify for NIHR money which has a 'limited scope'. We need to encourage more flexibility of funding schemes and more high-risk / high-reward funding opportunities. We should be trying to identify and influence funding gaps in the NIHR/MRC processes and priority setting programmes as they do take 'soundings' in this area. There is no precedent for MRC highlight notices for brain tumour research. Maybe it is time there is one?*
- *Preclinical models of brain tumours are not representative – we should be progressing working 'in patients' as an alternative. Patients want this. Lobbying NIHR to allow patients to be enrolled onto trials without models is one thing we could really change in the next five years. There has been progress in brain tumour sub-typing but that was in 'describing' the tumour and not in developing drugs to target the tumour. One of the reasons for this again was lack of availability of good lab models for each subtype*



*"The first thing I asked myself when I was told I had a brain tumour was 'what will happen to my wife and our beautiful children?'"*

*"Three years on, we try to make the very best of every day, but the question still remains. The location of my tumour means any surgery would be extremely high risk and my treatment options are limited. I am determined this won't defeat me, but it is hard to understand why so little is known about this disease especially when it affects so many children and young people. It's staggering to think that one in three people know someone affected by a brain tumour and it's important we make our voices heard to bring about the change that is so desperately needed."*

### Sam Suriakumar

Patient



*"I look forward to a future where the fear of brain tumour research is broken down – from discovery science to optimisation of novel compounds for brain penetration to prioritisation for clinical trial inclusion. The role of CRUK, MRC and NIHR are critical here. As they become more active in supporting and scaling up research efforts, we will accelerate progress towards a cure."*

### Dr Juanita Lopez

Medical Oncologist



*"Heavy dependency on a small group of charitable funders for support for basic research is a significant weakness. The lack of funding diversity in this sector puts many studies and jobs at risk if research priorities were to change in this small group of funders"*

### Dr Nicky Huskens

CEO Tessa Jowell Brain Cancer Mission

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# Convening Bodies

- *Better utilisation of Cancer Research UK's Experimental Cancer Medicine Centres (ECMCs). We do have drugs that have worked in other cancers that would be worth testing for brain tumour patients but if industry is too risk averse to try it then an academic clinical trial which is funded could be the answer. This could be taken on by ECMCs alongside the BRAIN MATRIX infrastructure or as part of a mixed model with industry. The idea would be for an academic study in small numbers at first to mitigate the pharma industry's perceived risk of involving brain tumour patients in early phase trials. This would help to ensure that brain tumour patients are not excluded from clinical trials and could assist industry involvement at a slightly later stage*
  - *We should leverage insights from other cancer types and access and evaluate targeted therapies that penetrate the brain in academic and clinical trials. Some brain tumour patients are showing progress on multi-cancer site trials but sometimes brain tumour researchers have to wait for a drug to be licensed in another cancer site before getting access to it, meaning double the wait for progress for patients. There are opportunities for drug repurposing here. It was explained that the blood brain barrier adds a layer of complexity to any brain tumour work*
  - *Noted was the early success of TJBCM in setting up 'The Tessa Jowell BRAIN MATRIX', a platform for testing multiple agents efficiently and cost-effectively. This has been instrumental in bringing scientists and clinicians together and should be a prelude to clinical trials, but this hasn't happened yet. The panel was informed that we need industry to invest into BRAIN MATRIX and for there to be academic studies leading to recruitment. BRAIN MATRIX is 'hugely ambitious' but is being done on a 'shoestring' and needs more funding to be quicker and to harness its effectiveness*
  - *Engage with industry (nationally and internationally) to access agents. There needs to be a testing pipeline with a scalability that, as it is funded and rolled out, engages pharma. NCRI could 'broker' interactions with industry and charities could play a role, but Government should incentivise industry investment in brain tumours too. The Government role could be to 'bolster the pipeline' before industry get involved*
- In response to this last proposal, it was reported by the TJBCM that of the many promising research results, few therapeutics progress into successful clinical trials. This is especially concerning for brain tumours for which every large clinical trial has failed to improve outcomes. The recently launched Brain Tumour Research Novel Therapeutics Accelerator, funded by Brain Tumour Research in partnership with the TJBCM, is a programme which aims to bridge the gap between promising research findings and the number of these findings which progress into successful clinical trials. It will provide infrastructure to ensure that the most promising therapies reach patients as quickly as possible. Each review meeting will identify potential pitfalls in clinical trial design and give independent, transparent advice to the researchers. This advice will help the applicant position the candidate compound along a realistic and well-informed pathway to clinical trial and eventual registration.
- It is expected that the programme will see:
- *More agents successfully entering human trials*
  - *More research focused on drug discovery encouraged and stimulated*
  - *Improved relationships with industry and academia*
  - *De-risking of trials*

# Clinical Researchers

In the oral evidence session on clinical research, the panel heard from a neurosurgeon and neuro-oncologists engaged in research.

The panel heard that there is a small community of brain tumour researchers and that they face difficulties when trying to access the funds that are available. Persistent issues have been identified including a lack of clinical researchers, there being no critical mass and that we aren't making a difference for brain tumour patients due to poor collaborative working and sub-standard funding applications.

Other issues include working in a non-academic medical centre where the focus isn't on how to recruit patients onto clinical trials, and the career decision facing a clinical researcher as to whether to pursue an academic career, a clinical career or go for a 50/50 split. Even having 'carved out' time in their NHS post to conduct some research, finding funded PhD post doc opportunities is limited.

Large academic research centres such as Imperial College London, University of Oxford, University College London and University of Cambridge are good at getting funding and it was suggested that this 'golden triangle' receives most of the biomedical research funding available. These centres do not spend much of this funding on brain tumour research, therefore the challenge is to get institutions that are good at attracting these big grants to prioritise brain tumour research.

It was noted that hospitals with the best academic centres do not always have the biggest patient cohorts, and it was recognised that the paediatric brain tumour community was good at networking trials. A point was made that experienced brain tumour clinicians do not have the 'mental space' to open trials – the more workload pressure, the harder it is to find time to open studies. The studies are becoming more complicated and bureaucratic, so the effort needed to start one is even more onerous.

It was felt that patients have a basic right to have access to local trials, especially if they are too ill to travel or from areas of deprivation. To ask such patients to travel frequently into, for example, Central London would be particularly detrimental. The benefits of trial involvement include more

face-to-face time with a clinician and there was consensus that it is important there is equitable access for deprived communities. It was commented that the benefit of engaging patients in observational trials was that they did not need to travel.

Trial bureaucracy was considered a real issue which could be resolved by networking trials, where if two or more local trusts have agreed to do a network trial, most of the paperwork only happens once, reducing workload.

It was agreed that there needs to be an effective strategy to ensure brain cancer doesn't miss out when treatment grants are accessed. Too often neuroscience was seen to be squeezed out by other disciplines in hospital – cardiovascular, for example. There are challenges when comparing the effort of clinical staff vs the benefit, particularly when working in a rare disease area, where only one or two patients may come forward for a trial. There is a need for those who run interventional studies to share samples with others doing similar research, maximising the benefit for those who cannot run their own interventional studies.

A panel member shared that a constituent of theirs had commented that there was no clear system or process for getting onto trials. It was agreed by the clinicians that although there is a system, it is not complete and sometimes out of date. It is also hard to access in the limited amount of time clinicians spend with patients. On the subject of trial registry, the panel was told that the most current trial registry is not up to date and early phase trials often don't make it onto the database.

It was stressed to the panel that we need to embed clinical trials into 'standard service delivery' as an NHS, basic human right – with the suggestion that a webpage, to be used at the patient's bedside containing all trial information, should be made available – a single point of access.

Recruitment of those from ethnic minority communities into clinical trials was described as woeful, and this comes down to communication when trials are discussed. Under representation of ethnic minorities in research leads to an unconscious bias.

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# Clinical Researchers

The MRC doesn't publish data on ethnic researchers accessing funds and ethnic involvement or recruitment into clinical trials isn't published. It was suggested this should be a key measurable metric.

It was identified that pharma doesn't often release information on what is currently being trialled as they sometimes run small centre, small cohort trials. Also, those conducting 'basket studies' (where multiple cancer types with a specific genetic determinant are treated with the same regimen) may not provide information on what they are doing to teams outside of their own disease area.

There is a need for more early-stage evidence to support larger applications. In addition, there is a benefit of patients being involved in 'basket studies' looking at a specific mutation rather than specific disease, as this increases the number of trials available to brain tumour patients.

One quick solution proposed by a witness was that recruitment periods for trials could be adaptive and once closed, they should be re-opened in suitable cases. It was noted there are not that many trials and trial funding calls aren't continuous. For example, calls for cannabinoid trial funding had ended six months before potential applicants were ready to apply. They were left feeling that the study would have been a perfect match and that better communication could have led to further cannabinoid calls for which applicants could have been successful.

Novel treatment trials need in-human evidence, which needs huge investment. The struggle is to get initial funding to provide evidence. There is a catch 22 scenario where researchers need funding to get the evidence needed to get the funding for a trial. Also, crucial data and learnings from pharma aren't being harvested from occasions where compassionate usage of a drug has been allowed outside of conventional trial structure, such that 'evidence' becomes anecdotal.

Regarding patient involvement in clinical trials, one witness made note of the lack of national tissue banks stating the reason for this was the amount of regulation to set them up, and general attitudes towards storing human tissue. With more tissue banks, patients could travel to a centre once, but then their tissue could be used for research on multiple occasions.

On being questioned why we weren't better at bio-banking it was explained that there was quite a bit of bureaucracy surrounding it (The Human Tissue Authority etc) but also unhelpful attitudes: "What is the point of banking tissue, this isn't an academic centre?" Tissue banking is not a core clinical service, which perpetuates the status quo and stifles ambition in smaller centres. It was also highlighted that brain tumours need Multidisciplinary Team (MDT) care with different specialities – radiotherapy, surgery, therapeutics etc – with so many people involved you can only go as fast as the slowest team member who might be the one putting the pieces of tumour in a fridge – these were identified as support service barriers.

The panel was told that the Tessa Jowell Brain Cancer Mission is carrying out the Matrix study where they are collecting samples and data on patients, with collective research being carried out on previous individual studies. It was also reported to the panel that the MATRIX is about current patients not past studies. This is particularly useful when working in research areas which have very few patients per year. Sharing data could be a way of sharing best practice. Tissue banks need to link to patient data.

On researcher recruitment, there was agreement that researchers in their medical or research career do not learn about brain tumours, a niche area, until later in their career when they may have already chosen what they would like to specialise in. The later you come to brain tumour research as an interest, the harder it is to get funding because you do not already have the research credentials or a track record of looking after patients – so you are competing for funding at a disadvantage to other specialities.

Taking up a full-time NHS position could allow one afternoon for research, and there is a clinical trials scholar programme which allows two extra PAs (programmed activities) a week, but if a clinician's time is spent on PA who is going to take their place in the clinic? Are there enough people to drive this forward?

By conducting research, clinicians can only give value for money for their NHS trust if it attracts money. To stay in research, clinicians need a fellowship. However for a clinician to have 50/50 research/clinical split would mean that they would



# Desperate Voices

have two masters (one clinical, one academic) and far from splitting their workload 50/50 the clinical and academic demands mean they could be working 80/80 and thus risk burning out. It was agreed that clinicians are 'time poor' for both these activities and it was suggested a solution could be to better utilise the research-trained staff within the health care system who are now in delivery-focused roles.

Rejected applications for research funding through organisations such as CRUK and NIHR are not always given helpful feedback. There is a feeling that the reviewers aren't able to provide an expert review of brain tumour applications. There is an apparent lack of knowledge on the epidemiology, background, and problems of treating brain tumours by panels assessing funding applications. The 'opportunity cost' of putting together large grant applications was noted. Neurosurgeons and oncologists are focused on treatment delivery (they traditionally haven't had a research focus) and their experience as practitioners is required when applying for grants, however, it does mean they have less time to apply, with grant applications being expensive in terms of time required.

It was explained that brain tumours are a multidisciplinary disease and need many different disciplines to treat them, which is good for the patient but not for the individual doctor/researcher as collaboration is not rewarded for research papers and funding. Track records can be impacted if a contributor is not a first or last author on a publication. Teamwork is not rewarded.

The issue was thought to boil down to critical mass as brain tumours are not a priority for the NHS due to the lower numbers of cases.

It was suggested that we should have good communication and an iterative process with potential large funders. The NIHR doesn't appear to lack the appetite to fund brain tumour research and has acknowledged some problem areas – feedback, experts on panels etc. There was agreement that a 'pre application' phase for funders to work with potential project applications to improve the chances of success would be useful. NIHR mechanisms for spending might not be appropriate for where we are on the research pipeline with brain tumour research currently.

*"Every week I have to tell patients that there is nothing more we can offer. I have now been a consultant for 10 years and these conversations are the same now as when I started. We could make progress, but that depends on building and sustaining a pathway from patients to labs and back to clinic, and that needs delivery on promised funding and support. I do not want to be having the same conversations in 10 years' time."*

## **Dr Matt Williams**

*Clinical Oncologist*



*"In the confusion and despair that accompanied my husband Did's diagnosis with an aggressive brain tumour, we sought the help of our MP Holly Mumby-Croft. At a time when we felt so alone, she supported us and took Did's story to Parliament, asking a Prime Minister's Question, later becoming a member of the APPGBT inquiry panel which produced this report. Now Did has left us, we, his grieving family, will continue to campaign, to ask difficult questions and to do whatever we can to ensure that brain tumour research gets the funding it needs and that researchers can turn this funding into better treatments. Patients and families deserve better."*

## **Nicki Hopkins**

*Widow*



# Scientists

In the oral evidence session with scientists the panellists heard from laboratory researchers.

Opening discussions noted that research funding for brain tumours needs to be less risk-averse and that there are too many research proposals being rejected due to a perception among grant panels that research into brain tumours does not yield the same results as other areas. Recruiting and retaining specialists who focus on brain tumour research was also identified as an issue as they often decide to move into other specialities. This could explain why brain tumour research has not made real progress.

It was felt that there is funding for cancer research, but brain tumour research is not being prioritised to the same extent as other areas of cancer research by institutions like the NIHR.

The NIHR was seen to be a part of a very risk-averse funding culture and this has hampered the implementation of new patient-centred technologies for the treatment of brain tumours. It was felt that the NIHR often does not approve new patient-centred projects, because they tend not to meet its patient/cost-effectiveness standards.

It was also highlighted that grant panels often do not include specialists in brain tumour research, which can hinder funding opportunities for researchers. Having brain tumour experts on grant panels could help prevent experts from different specialisms introducing a level of bias and risk-aversion to granting brain tumour researchers funding.

Currently, rejecting a grant proposal is in effect, rejecting a year of research and the whole team who helped to put this proposal together. It could discourage further applications and encourage researchers to move away from brain tumours and specialise in a different field.

With regard the Medical Research Council (MRC) there is a perception that there is not a lot of support for researchers in identifying regulatory requirements and other aspects assuming funding applicants will be aware of these. The development of a toolkit or road map for researchers who are applying for pre-clinical funding was proposed as a potential solution to this barrier. A single point

of entry to which researchers could submit their research applications was also proposed as that would remove the hurdle of researchers trying to fit their research into the right funding stream. It was shared that there is a lot of back and forth between MRC and NIHR that researchers have to navigate which vastly complicates funding opportunities.

Issues in securing funding for research fellowships is seen as a major factor in researchers moving onto other tumour areas and it was noted that we need a specific pathway or a brain tumour research fellowship scheme and more long-term retention schemes such as the Future Leaders Scheme to ensure that brain tumour specialists are not leaving the field.

The Centre model was identified as being an example of how to support established researchers to gain funding and the need to show more support for junior researchers with mentoring opportunities was emphasised.

When returning to the question of how to make sure ring-fenced NIHR funding is spent, it was suggested that those who are unsuccessful should be supported to reapply. There was general agreement that the quality of feedback given by funders should be much better.

Three solutions were suggested: more diverse grant panels; swifter decision-making process through the system of grant giving; and more detailed feedback.

It was asked whether other cancers are similarly underfunded, and secondly, if there is credible evidence in the UK, or internationally, of the total volume of money invested in a specific cancer research being increased and as a result significant progress being yielded.

In response, the example of leukaemia and breast cancer where more money has been invested leading to significant benefits was given.

Circling back, it was stated that now was the time to be less risk averse and encourage funding panels to invest in the projects currently visible and not wait for the perfect project. It was argued that brain tumour research is too complex to do alone, and that collaboration across different disciplines, such as physics or chemistry, was key to success.

# Desperate Voices

Specialist neuroscience research in areas such as Alzheimer's disease could potentially prove beneficial to brain tumour research.

The topic of tissue banking, referencing the cost of storing and processing tissue samples was raised. It was advised that there are excellent mechanisms in place to archive diagnostic tissue. However, there is a perception that Trusts believe all the tissue required is already stored, ignoring that researchers require a highly characterised tissue collection system for which the infrastructure is not in place. Specifically archiving frozen tissue required for both research and innovative patient treatment plans does not get the funding support required from Government.

In order to carry out the highest quality research, the scientific brain tumour community must be able to access brain tumour tissue. Brain UK is funded by Brain Tumour Research and is a virtual brain bank. Brain UK doesn't store any tissue samples itself but catalogues the tissue left over from diagnosis, either from post-mortem or from living patients being operated on (biopsies), in a centralised database. This database identifies the location of tissue across the NHS archives of the collaborating NHS Neuropathology Centres. Most of the tissue is formalin fixed, paraffin embedded (FFPE). However some research will require samples stored differently, for example, frozen. In addition, other researchers may require a highly characterised tissue collection system including clinical information.

Cell line isolation and biobanking which is happening at individual sites across the research community requires expansion, co-ordination and oversight to maximise the impact for research and patients. Following MRC's decision to withdraw funding for Brain UK, it is recommended that the Government makes a commitment to support an effective and comprehensive brain tumour bank that truly supports the broad needs of the research community.

The session's final comment was on the need to treat brain tumour research as an emergency in the same capacity that the COVID-19 pandemic had been treated.



*"At Queen Mary University of London, the centre funding model has been game changing in that it has allowed us to explore a very ambitious research direction at pre-clinical level, and once sufficient preliminary data had been generated, it enabled us to secure the buy-in of additional stakeholders to maximise the research impact."*

*The continued investments of the charity in our Centre have made a significant impact on capacity building, by offering retention opportunities to the best scientists. It has also had a powerful translational impact, including attracting complementary funding for a clinical research platform to benefit local patients, and the recognition as Tessa Jowell Centre of Excellence for our neuro-oncology service.*

*"It would be very difficult to access funding from the Government and larger cancer charities without the support of dedicated charities in the first instance."*

**Professor Silvia Marino**  
Neuropathologist



*"It is hard enough to lose a loved one and it is never right to lose a child. Aaron was 24 when he died, but he was still my baby. I have shared our story because I don't want Aaron's legacy to die, I don't want his name to be forgotten. Aaron was a fit and healthy young man on the brink of a life full of promise and meaning when he was struck down by this awful disease. Prior to his diagnosis we had no idea about the numbers of people affected by brain tumours and the dreadful prognosis which so many face. How can it be that, in this day and age, there is so little funding for research and so few treatment options?"*

**Crystal Wood**  
Bereaved Mum

# Paediatric Specialists

In the oral evidence session with paediatric specialists, the panel heard that treating children with brain tumours is not the same as treating adults. Children's tumours are tumours of growth, not aging and this presents a different clinical challenge. As the tumours are growing in a developing brain, they react differently, and respond differently, to treatments.

Every child with a symptom of a brain tumour begins to acquire brain injury. Surgery, radiotherapy, and drug therapy can exacerbate this brain injury further. 70% of children can be cured, but 60% of those will have brain injury causing moderate to severe disability<sup>39</sup>.

Children and young people with central nervous system (CNS) tumours carry the greatest burden of long-term side effects. The scope for harm including lifelong neurological and neurocognitive disability is disproportionately high in the management of CNS tumours, with the very real costs of damaged lives being borne by the child, the family, the NHS and society. It is estimated that the lifetime cost of care for a child with significant impairments following CNS tumour therapy to live an independent life is some £15-30 million (based on medico-legal awards)<sup>40</sup>.

Novel methods of drug delivery would reduce the damaging toxicity of current therapeutics. The focus needs to be on drugs that work via alternative delivery methods, including electric field therapy, the use of ultrasound, direct-to-tumour, and trans-mucosal methods.

It was noted that the chance of a child developing a brain tumour is 1 in 500<sup>41</sup>. It is therefore important to accelerate the diagnosis of brain cancers in children, detecting brain tumours before they are symptomatic and before there is any damage to the brain.

The challenges of securing funding for translational research and running clinical trials were discussed. The majority of funding comes from charitable sources rather than the Government; it was suggested that the Government should ring-fence funding for these. The panel heard that it takes at least a year to get a decision from Government funding bodies like the MRC and NIHR and researchers must then start engaging with regulatory pathways. Processes abroad were noted to have less rigid funding cycles and much more flexibility. Researchers can submit funding

applications more frequently internationally than in the UK. Collaboration with Europe and America, essential when running childhood trials, is often delayed, with the UK frequently being a late comer to trials due to systemic funding issues.

It was shared that University College London applied to the MRC for funding to trial a CAR T Cell therapy for use in paediatric brain cancer. The application was not successful because of concerns that children shouldn't be used in trials even though these children were going to die. The highly aggressive nature of the children's tumours meant that parents and carers were very keen to include their children in such a trial. Three years later Stanford University, US performed the same trial with interesting results, leading to many parents wanting to travel to America for their children to receive the treatment. Now this US trial has happened, the UK may open a trial, but this is too late for many patients. The UK missed the opportunity to lead the way and offer innovative trials for patients due to risk-averse decision making.

The lack of capacity within the NHS to facilitate trials was flagged. Experience shows that clinical departments often don't have the specialists required, or if they do, these specialists don't have the time to support the trials. In very intensive studies, funding doesn't cover all aspects of care, and it is not always possible for the NHS to supply resources – a barrier not found in North American or European institutions. With funding insufficient, especially when it is an academic clinical trial, and with some brain tumours not attractive to pharma to sponsor, a joint funding initiative to fund infrastructure to enable trials to be opened was proposed.

Survival after treatment for brain tumours needs to be prioritised just as much as the treatment itself. Even benign tumours can be malign due to their position within the brain. We should be targeting the position in the brain rather than the histology of the tumour. A big disconnect between those who cure children with brain cancer and those who look after them in the long-term when they have been affected by brain injuries was noted. It was suggested that further clinical trials are needed, focusing on more than just survival rates, but rather the consequences of brain injury, planning not just for the next five years, but the next 50 years of a patient's life. The sector should focus on improving the quality of survival.

# Desperate Voices

The panel heard that Universities favour Research Councils' funding due to the full economic costing that it provides compared to that from charities which provide just the direct costs of the research. However, the Research Councils don't have the knowledge and expertise that dedicated brain tumour charities usually have. It was proposed therefore that charities and the Research Councils partner to harness the funding and the brain tumour specific commitment to better meet the needs of the research and clinical community. Such an arrangement would hopefully help to speed up the decision-making process and provide the flexibility required to apply for funding at the most appropriate time for the studies.

The management of CNS tumours in children and young people has become increasingly complex. Individual oncologists (even internationally recognised experts) or treatment teams cannot carry the knowledge required for the whole range of tumour types and sub-types, disease scenarios and therapeutic options at relapse that now exist. There is increasing demand for national and international second opinions and strong support for the establishment of formal advisory groups for specific CNS tumour types, particularly rare tumour entities and complex clinical cases. The complexity of managing these rare and complex tumours means there is a desperate need for a National Rare and Complex Paediatric Brain Tumour Advisory panel.



*"It's too late for our son Fin and our hearts continue to break to see other families going through the same journey with no new hope on the horizon. Fundraising and campaigning for Brain Tumour Research became an integral part of our lives when Fin was diagnosed with a glioblastoma in 2014. It gave us all a positive focus, a healthy distraction and made us feel we were part of trying to instigate change, not just for Fin but for others too."*

*"Since he passed away at the age of 11, we have felt it part of Fin's legacy to continue trying to improve outcomes for others facing this devastating disease."*

*"We fought as hard as we could for 17 months. We discovered at first hand the sickening truth that the treatment for brain cancer is antiquated and barbaric, as cruel as the disease itself. I am ashamed to admit that there came a stage when I wished Fin had leukaemia. I felt that would be better, there were more treatments and investment into that, it may not have been the death sentence that his brain tumour was. There are no words to describe the anger and frustration I feel at this dreadful injustice and it is unimaginable that families continue to feel the pain we went through."*

## **Penny Church**

*Bereaved Mum*



*"Brain tumours continue to be the most common cause of cancer death in children and the cost of survival is too high for many. It is essential to invest in the specialist infrastructure to be able to deliver innovative clinical trials of kinder and more precise treatments."*

## **Professor Darren Hargrave**

*Paediatric Neuro-oncologist*



# Industry

In the oral evidence session with industry representatives, the panel heard from Northwest Biotherapeutics, QV Bioelectronics, Extruded Pharmaceuticals and Oncologica.

It was acknowledged that there has been progress in understanding the biology of brain cancer but that this has not been matched by an extension to patients' five-year survival which is just 12%<sup>42</sup>, compared to 54% for all cancers<sup>43</sup>.

It was suggested that there is a fundamental flaw in clinical trial design, requiring a placebo arm and that this is a significant obstacle to the development of new treatments. Patients do not want to join trials where they believe there is a chance they will receive a placebo. This can also create high rates of patient drop out. At later stage studies, the role of the placebo is to show the real efficiency of treatments. The work of The Brain Tumour Charity to collect real world data on the ethical argument for not using placebos in trials was referenced.

Three possible regulatory reforms were highlighted that could potentially accelerate trials, increase patient participation and cut costs.

Firstly, the use of a placebo in patients should be replaced by 'external controls', such that new medical trials would use data from patients in previous trials or from pre-existing databases. Witnesses believe that the UK is ideally positioned given the existence of NHS data.

Secondly, a more pragmatic approach to current definitions of 'efficacy' was called for as the current situation is causing trials to be declared failures and unnecessarily halting the development of products.

Thirdly, current rules state that novel drugs must be better than existing treatments, rather than simply showing equal efficacy and this was criticised.

It was also noted that legislators should consider the importance of increased funding for advanced manufacturing, which would help to enable new drugs to be affordable and be produced on a large scale.

In addition to the development of novel drugs, and whilst surgery remains the most effective treatment step in prolonging patients' life expectancy, it was noted that the important role of medical devices is too frequently overlooked.

Lessons could be learnt from the US's FDA programme on Humanitarian Devices Exemption (HDE). This is a mechanism through which companies can acquire market approval at a much earlier stage for certain health conditions, for instance in rare cancers, or on humanitarian grounds.

In addition, the merits of a pre-submission process, during which companies can have scientific meetings with the regulator early in the development of products was explained to the panel. This can help ensure they meet regulatory requirements by the time they get to human trials.

Issues related to raising investment for long-term technologies in the UK were criticised, with the need to encourage investors to support long-term therapies noted.

It was said that funding for drug delivery and manufacturing is an issue in the UK and that this is the result of a lack of understanding and could lead to treatments for brain tumours being late to arrive in the UK as companies source investment from elsewhere. Nevertheless, it was reported to the panel that the changes in regulation coming into force with the MHRA are creating an opportunity to reinvent in the system.

For instance, there could be a lowering of the barrier to enter early clinical trials, especially for brain tumour patients who are generally approaching end of life stages. At the same time, there is currently the challenge of moving patients around the country to different trusts for very rare conditions, calling for a more centralised process of helping patients access trials regardless of where they are in the country. With 3,000 new cases of glioblastoma patients each year<sup>44</sup> it can be challenging to recruit into new clinical trials. A centralised funding pot for trials moving forward was suggested.

# Desperate Voices

On paediatrics, it was reported that brain tumours are different diseases in children to those in adults but they share the same characteristics and this needs to change so that we provide equity in access for children. Due to the high-risk nature of clinical trials, many organisations fail to do paediatric trials in case there are side effects that jeopardise the roll out of the product to the much larger adult market. This leaves children waiting last in line for new therapies. The US HDE policy could encourage companies to invest in studies with children, although the rareness of some cancers in children means that investment in these trials remains financially unfeasible for companies.

It was said that large pharmaceutical companies have drugs which haven't shown the hoped for efficacy and so have been shelved, however these could be repurposed for brain tumours and it was highlighted that companies are investing in research but end up with treatments which cost a lot due to the low numbers of treatable patients. This risked rising health inequalities, with richer patients able to fund travel to receive treatment from abroad.

The mood of the meeting was that in addition to the need for more public money going into brain tumour research, we need to address the fundamental challenge of early access to venture capital for therapies. Investors want a return on investment and are disproportionately interested in safer, shorter projects rather than 10-year projects which could have a more successful return in the long term. It was suggested that the Government look at tax reliefs and incentivises investors who want to invest for longer time periods. It was also highlighted that there is a barrier in the translation of findings from academia into industry.

A final summarising thought was that MHRA funding needs to be much more open and that there needs to be a focus on how drugs are delivered, and how clinicians can reduce toxicity in treatment areas. A set of curated data which could serve as an external control group needs to be developed and more money needs to be spent on research projects.



*"The pharmaceutical industry is vital in the development of new treatments. The relatively low population of patients and increasing specificity of new molecular targeted drugs means there are significant financial disincentives for industry to invest. We need to encourage companies to invest in this sadly neglected area. The Government must help companies cope with the risk profile of developing new treatments in brain tumours."*

**Professor Garth Cruickshank**

*Emeritus Professor of Neurosurgery*



*"Small innovative companies are increasingly driving the development of novel therapies for brain tumours. The cost of development and time to market is the foremost barrier. The USA has systems in place that enable accelerated market access and reimbursement of breakthrough therapies for conditions of high unmet clinical need. Supporting partnerships between industry and the UK's expert academic knowledge base will encourage innovative companies to invest in brain tumour research in the UK and accelerate the delivery of new therapies to NHS patients."*

**Christopher Bullock PhD**

*CEO and Co-Founder QV Bioelectronics*



*"CNS tumours strike children at a critical time in their development, often with devastating life-long consequences. When research funds have been made available for other children's cancers enormous strides have been made. The understanding of the molecular events that force tumour cells to grow has grown rapidly, resulting in improved diagnosis, better ways of choosing the right treatments and, in a small number of tumours, the development of drugs that accurately target the disease. These research projects take time, patience and above all funds."*

**Dr Antony Michalski**

*Paediatric Oncologist*



# Charitable Funders

In the oral evidence session with charity funders the panel heard from: Cancer Research UK, Children with Cancer and Brain Research UK.

In 2014 Cancer Research UK (CRUK) identified brain cancer as a priority cancer of unmet need because 'brain cancers have some of the poorest survival rates of all cancers.' The new strategy that CRUK launched in March 2022 reaffirmed its commitment to driving developments in this field. It was acknowledged that CRUK recognises that brain tumour research is particularly challenging, partly because 'the research community has lacked access to really good pre-clinical models, that reflect the human disease'. Additionally, it was stressed that the research community 'needs more discovery science and translational research' to gain an improved understanding of the ways in which brain tumours develop and how they can be targeted with novel treatments.

Since 2018, Children with Cancer UK has been in a position to support collaborative efforts with researchers and other small charities. The charity's recent strategy focus is on making sure needs are addressed to ensure children receive access to clinical trials. Whereas previously the charity's research has primarily focused on combatting leukaemia, Children With Cancer UK is placing a greater emphasis on brain tumours in recognition of the condition's status as a leading cause of mortality in children affected by cancers.

Brain Research UK has focused on funding three priority areas that have particularly high unmet patient need and particularly poor research investment since 2016. Brain tumours are one of these areas. They shared that brain tumours receive just over a third of the charity's annual research funding budget of £1.5 million. The charity funds both PhD studentships and project grants, targeting 'projects that are impactful in the short to medium term'.

It was said that brain tumours are 'a broad challenge that requires a long-term strategic approach'. This will demand a focus on infrastructure, training the next generation of researchers and including a broader range of capabilities via multidisciplinary teams to address challenges across teams. On the quality of applications, the panel heard that it is critically

important to maintain high standards for funded research to ensure that there is the best long-term output for patients.

In addition, it was thought that the current structures may suit CRUK and NIHR, but this creates competition with other applications such that excellent brain tumour applications will not be funded under a particular specific research approach. The response made note of the independent peer review process and strategic investment which can create competition. However, it was acknowledged that the decrease in charitable funding due to the pandemic (with the AMRC reporting a shortfall of £260 million in research spend 2020/21<sup>45</sup>) has meant charities need to rely more on strategic investment.

The logistical challenge of responding to every individual unsuccessful funding application and co-creating a more substantial application was highlighted. It was stated that CRUK works with communities before submission to bring the right people together and provide guidance.

It was agreed that there needs to be greater visibility and accountability from the NIHR on investment in childhood cancers. It was stressed that there is a need for greater clarity around the relation of findings in the adult sector to childhood cancers and the ways in which researchers can unify their efforts across both sectors. Collaboration with the National Cancer Research Institute (NCRI) is needed to find out how to improve applications and increase capacity to support better quality research. The brain tumour research community needs to 'define what is needed, to find the cure for brain tumours' in order to then request ring-fenced government funding to target these areas.

There was further agreement that 'asking for transparency on spend is entirely reasonable'. And the need to identify the fundamental barriers to research, such as the lack of biological understanding and preclinical models, was noted. Having a clear view as to how money can be best spent, aligned to strategic priorities, would give us a route forward.

# Desperate Voices

A further opportunity is to ensure that the communication between successes and opportunities in adult brain tumours is constantly being relayed to the childhood community.

Collaboration across the research community now includes specialists, including in artificial intelligence (AI), who would not have traditionally been identified as paediatric researchers or brain tumour researchers. We need to acknowledge that the brain tumour research community is relatively small and stress that there are practical things that can be done by encouraging a multidisciplinary approach. The ambition is for the brain tumour research community to create a critical mass. This has already been achieved to an extent by funding centres of excellence, and therefore coordinating capability into specific locations.

Another possible solution to making progress was identified as hypothecating the way funding is granted and a rethink about the way funding is given, with a focus on where the need is and less focus on the pace of progress.

The Government, universities and charities must work together to support investment and make brain tumours a competitive and desirable research opportunity in the UK.



*"We lost my sister's little girl, Alison Phelan in June 2001. We were shocked and horrified to discover how little funding was given to brain tumour research. We formed Ali's Dream and were excited to unite with other brain tumour charities to launch Brain Tumour Research in 2009.*

*"In 2002 the national investment in brain tumour research was less than £1 million<sup>46</sup>. We have been campaigning to increase funding ever since. We were delighted when CRUK identified brain tumours as a strategic priority in 2014 and are pleased that the national investment grew to £17.6 million in 2020/21. This is still not enough. We lag far behind cancers such as leukaemia and breast cancer. Funding shouldn't be left to charities. The Government must do more."*

## **Sue Farrington Smith MBE**

*Chief Executive  
Brain Tumour Research*



*"Funding for research into brain tumours does not equate to the unmet need in the field. A brain tumour diagnosis is devastating and there has been little improvement in treatment options in recent decades. Every pound invested into research must be spent wisely to maximise its impact and improve the lives of those living with a brain tumour.*

*"It is down to the Government and other funders to ensure we work together to support researchers, facilitating collaboration between experts in the field, advancing research and reducing duplication of work.*

*"We must nurture the next generation of brain tumour researchers to learn and discover more and support them to translate this knowledge into treatments that have a real-life impact on patient care."*

## **Dr David Jenkinson**

*Chief Scientific Officer  
The Brain Tumour Charity*



# Appendix 1:

## Inquiry Terms of Reference and Methodology

The Inquiry took as its starting point the 2016 report 'Funding for Research into Brain Tumours' produced by the Petitions Committee and the report of the Task and Finish Group on Brain Tumour Research 2018. Both reports identified key issues including barriers to progress and made recommendations for funding brain tumour research.

The inquiry looked to understand, in the light of these reports, and subsequent evidence sessions, letters and press releases:

- *Where we are now in respect of research funding for brain tumours*
- *How successful the research and development of the treatment for brain tumours is in the UK*

The aim was to provide transparency, clear recommendations and an action plan to address any reported barriers and difficulties

### **Inquiry panellists**

- Derek Thomas MP (Con)
- Holly Mumby Croft MP (Con)
- Hilary Benn MP (Lab)
- Greg Smith MP (Con)
- Ben Lake MP (Plaid Cymru)
- The Lord Polak CBE
- Sue Farrington Smith MBE, Brain Tumour Research
- Dr David Jenkinson, The Brain Tumour Charity
- Professor Garth Cruickshank
- Dr Antony Michalski
- Professor Tony Marson
- Peter Realf (patient representative)

### **Methodology**

The Inquiry was launched at the APPGBT meeting on 13<sup>th</sup> July 2021. A literature review was undertaken during Autumn 2021 and a call for written evidence was made across relevant networks (including BNOS and TJBCM) and on social media to ensure completeness, in early February 2022. Invitations to provide oral evidence were given to a selection of those who provided written evidence and had indicated they would be happy to speak. Six oral evidence sessions were held ending in summer 2022. The inquiry report was written during Autumn / Winter 2022 and the report was launched at a joint House of Commons event with the TJBCM on Tuesday 28<sup>th</sup> February 2023. Updates on progress were provided for APPGBT meetings during the year.

### **Call for evidence**

The APPGBT, supported by Brain Tumour Research, gathered evidence via the following methods:

**Document Review** – during Autumn 2021 a review of reports and transcripts from the Petitions Committee, Task and Finish Group, debates, evidence sessions and press releases from Government Bodies was conducted (see Appendix 3)

**Patient Survey** – in Autumn 2022 Brain Tumour Research invited patients and / or their carers to complete an online survey regarding access to trials and their views on research-funding levels

**Written Submissions from experts** – expert stakeholders from across academia, clinical practice, the third sector and industry were invited to submit written evidence in February 2022

**Oral Evidence Sessions** – from February 2022 to July 2022 the inquiry held oral evidence sessions. During these sessions, the inquiry panel heard from a variety of stakeholders, including Convening Bodies, Clinical Researchers, Scientists, Paediatric Specialists, Industry Representatives and Charitable Funders. A list of those who gave oral evidence at these sessions is included in Appendix 2. Panel members used these sessions to question witnesses and explore in greater depth issues raised in written submissions

# Appendix 2:

## Inquiry Witnesses

### Session 1 – Tuesday 22<sup>nd</sup> February 2022

#### – Convening Bodies

- **Dr Nicky Huskens** – CEO Tessa Jowell Brain Cancer Mission (TJBCM)
- **Professor Anthony Chalmers** – Chair of Clinical Oncology at the University of Glasgow
- **Dr Juanita Lopez** – Consultant Medical Oncologist Royal Marsden and the Institute of Cancer Research
- **Dr Igor Vivanco** – Senior Lecturer at the Institute of Pharmaceutical Science, School of Cancer and Pharmaceutical Sciences.

All witnesses are part of the NCR1 Brain Group

### Session 2 – Tuesday 15<sup>th</sup> March 2022

#### – Clinical Researchers

- **Mr Babar Vaqas** – Consultant Neurosurgeon at Queens Hospital, Romford
- **Professor Susan Short** – Clinical Oncologist at Leeds Institute of Cancer and Pathology
- **Dr John Apps** – Clinical Lecturer at the Cancer Research UK Clinical Trials Unit (CRCTU) at the University of Birmingham
- **Dr Matthew Williams** – Clinical Oncologist Consultant at Imperial College Healthcare

### Session 3 – Tuesday 22<sup>nd</sup> March 2022 – Scientists

- **Professor Silvia Marino** – Professor of Neuropathology at Barts and The London School of Medicine and Dentistry, Queen Mary University of London
- **Dr Ruman Rahman** – Associate Professor of Molecular Neuro-Oncology at the University of Nottingham
- **Professor Sebastian Brandner** – Professor of Neuropathology UCL Queen Square Institute of Neurology
- **Professor Kathreena Kurian** – Professor of Neuropathology and Honorary Consultant at Southmead Hospital, North Bristol Trust

### Session 4 – Tuesday 26<sup>th</sup> April 2022

#### – Paediatric researchers

- **Professor David Walker** – Emeritus Professor Paediatric Oncology
- **Professor Darren Hargrave** – GOSH Children's Charity Clinical Professor in Paediatric Neuro-oncology
- **Dr Helen Spoudeas** – Paediatric Endocrinologist at Great Ormond Street Hospital

### Session 5 – Tuesday 24<sup>th</sup> May 2022 – Industry

- **Linda Powers** – Chairman of Aracaris Limited, a UK biotech company, and Chairman and CEO of Northwest Biotherapeutics the US parent of Aracaris
- **Dr Christopher Bullock PhD** – CEO and Co-Founder of QV Bioelectronics
- **Dr Chris McConville** – Chief Scientific Officer at UK based Extruded Pharmaceuticals
- **Dr Marco Loddo** – Co-founder and Scientific Director at Oncologica

### Session 6<sup>th</sup> – 19<sup>th</sup> July 2022 Charitable Funders

- **Dr Ian Walker** – Executive Director of Policy, Information and Communications Cancer Research UK
- **Christiana Ogunbote** – Research Grants Manager at Children with Cancer
- **Katie Martin** – Research Manager at Brain Research UK

#### The APPGBT received expert written evidence from the following:

Cancer Research UK	Dr John Apps
Brain Research UK	University of Birmingham
Children with Cancer	Dr Juanita Lopez
The Brain Tumour Charity	Royal Marsden and ICR
Tenovus	Dr Kamyar Afarinkia
Yorkshire Brain Tumour Charity	University of Bradford
Children's Cancer and Leukaemia Group (CCLG)	Professor Karen Anthony
Brain Tumour Research	University of Northampton
Amethyst UK	Mr Kevin O'Neill
Servier	Imperial Healthcare
QV Bioelectronics	Professor Kevin Prise
North West Biotherapeutics Inc	University of Belfast
Oncologica	Dr Liyam Laraba
Extruded Pharmaceuticals	University of Plymouth
Mr Ajay Samuel	Dr Matt Williams
Early career researcher	Imperial Healthcare
Mr Babar Vaqas	Professor Darren Hargrave
Consultant Neurosurgeon	Great Ormond Street Hospital
Mr Charles Davis	Professor Oliver Hanemann
Consultant Neurosurgeon	University of Plymouth
Dr Claudia Barros	Professor Silvia Marino
University of Plymouth	Queen Mary University of London
Professor David Walker	Professor Kathreena Kurian
University of Nottingham	Southmead Hospital, North Bristol Trust
Dr Florian A. Siebzehnubl	Professor Michael Jenkinson
University of Cardiff	University of Liverpool
Dr Lucy Stead	Professor Richard Gilbertson
University of Leeds	CRUK Cambridge Centre
Dr Frederico Roncaroli	Dr Richard Pemyman
University of Manchester	Imperial College
Dr Gerald Finnerty	Dr Raman Ruhman
Kings College Hospital	University of Nottingham
Dr Helen Spoudeas	Queen's Square
Great Ormond Street	Professor Steve Pollard
Mr Ibrahim Kismet	University of Edinburgh
Consultant Neurosurgeon	Professor Stuart Green
Dr Igor Vivanco	University Hospital Birmingham
Institute of Pharmaceutical Science	Mr Surash Surash
Professor James Nichol	Consultant Neurosurgeon
BRAIN UK at the University of Southampton	Professor Susan Short
	University of Leeds
	Mr Tom Flannery
	Consultant Neurosurgeon

# Appendix 3:

## Literature Review and References

Petitions Committee Report

– Funding for Research into Brain Tumours – March 2016<sup>47</sup>

Westminster Hall Debate on Brain Tumours

– Transcript – 18<sup>th</sup> April 2016<sup>48</sup>

Dame Tessa Jowell Speech in the House of Lords

– 25<sup>th</sup> January 2018<sup>49</sup>

Report of The Task and Finish Working Group on

Brain Tumour Research – February 2018<sup>50</sup>

DHSC Press Release – 22<sup>nd</sup> February 2018

– Brain cancer research to receive £45 million funding<sup>51</sup>

NiHR Highlight Notice – Advertised May 2018<sup>52</sup>

DHSC Press Release – 14<sup>th</sup> May 2018

– Government announces £40 million for brain cancer research in honour of Tessa Jowell<sup>53</sup>

NiHR Highlight Notice – Re-advertised 29<sup>th</sup> May 2019<sup>54</sup>

Petitions Committee Oral Evidence – Funding for research

into brain tumours. Matt Hancock – 15<sup>th</sup> January 2019<sup>55</sup>

Westminster Hall Debate on Childhood Cancer:

Research – Transcript – 7<sup>th</sup> December 2020<sup>56</sup>

Lord Hunt – Health: Brain Tumours Question

in the House of Lords – 19<sup>th</sup> January 2021<sup>57</sup>

Petitions Committee Written Evidence – Lord Bethell

– April 2021<sup>58</sup>

Petitions Committee Written Evidence

– Cancer Research UK – April 2021<sup>59</sup>

Petitions Committee Written Evidence

– Brain Tumour Research – April 2021<sup>60</sup>

Petitions Committee Oral Evidence

– Sue Farrington Smith MBE, Dr Ian Walker, Professor

Richard Gilbertson, Professor Chris Jones – 27<sup>th</sup> May 2021<sup>61</sup>

Petitions Committee Oral Evidence

– Lord Bethell – 27<sup>th</sup> May 2021<sup>62</sup>

Responses to Petitions Committee Letters

– Lord Bethell – 7<sup>th</sup> July 2021<sup>63</sup>

Responses to Petitions Committee Letters

– Dame Ottoline Leyser (UKRI) – 13<sup>th</sup> July 2021<sup>64</sup>

### References:

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# Appendix 4:

## NIHR Awards since June 2018<sup>65</sup>

Total Amount										£14,571,478
Project Title	Project Status	Programme	Programme Type	Award Amount	Start Date	End Date	Organisation Type	Contracted Organisation		
Precision surgery for glioblastomas: determining individualised tumour resection volumes using advance MRI imaging	Active	NIHR Fellowships	Training	1,041,607	2019-01-01	2024-05-31	Academic	University of Cambridge		
Developing an innovative implanted resection cavity electrotherapy device for the treatment of Glioblastoma Multiforme (GBM).	Complete	Invention for Innovation	Research	150,000	2020-03-01	2021-02-28	For-Profit Company	OV Bioelectronics Ltd		
Improving treatment of glioblastoma: validating the efficacy of a machine learning model to detect pseudoprogression	Active	NIHR Fellowships	Training	240,045	2020-04-01	2026-03-31	Government/ NHS	Guy's and St Thomas' NHS Foundation Trust		
FLU U-FE – GB Trial (Functional and Ultrasound guided Resection of Glioblastoma) A 2- Stage trial, Stage 1 Non-randomised learning phase evaluation of participating centres (an IDEAL study), followed by Stage 2 which is randomised controlled Multicentre Phase III trial with 2 mechanistic substudies	Active	Efficacy and Mechanism Evaluation	Research	1,694,677	2020-10-01	2025-10-31	Academic	University of Oxford		
Social Cognition Assessment and Rehabilitation for Families living with Brain Tumour (SCARF-BT) - a Feasibility Study	Active	Research for Patient Benefit	Research	239,569	2021-02-01	2024-01-31	Government/ NHS	Cambridge University Hospitals NHS Foundation Trust		
APPROACH: Analysis of Proton vs. Photon Radiotherapy in Oligodendroglioma and Assessment of Cognitive Health	Active	Efficacy and Mechanism Evaluation	Research	1,499,804	2021-06-01	2031-05-31	Academic	University of Leeds		
PROgesteone as a Steroid Sparing agent against oedema occurring with secondary brain cancers	Active	Efficacy and Mechanism Evaluation	Research	577,053	2021-08-01	2024-07-31	Government/ NHS	Public Health Scotland		
An artificial intelligence disease monitoring tool for patients with brain tumours	Complete	Artificial Intelligence	Research	145,722	2021-10-01	2022-09-30	Academic	University of Cambridge		
Surgeons Trial Of Prophylaxis for Epilepsy in seizure naïve patients with Meningioma: a randomised controlled trial (STOP-EM)	Active	Health Technology Assessment	Research	1,641,897	2021-10-01	2027-09-30	Academic	University of Liverpool		
Intraoperative hyperspectral imaging for data-driven real-time surgical guidance	Active	Invention for Innovation	Research	1,450,687	2021-10-01	2024-09-30	Academic	King's College London		
<b>8,681,061</b>										
<b>Projects not easily identified as relevant to brain tumours</b>										
Childhood cancer diagnosis: quantifying national diagnostic intervals and developing professional and public decision support tools for earlier diagnosis.	Active	NIHR Fellowships	Training	342,465	2019-01-01	2023-07-31	Academic	The University of Nottingham		
The GHD reversal study	Active	Health Technology Assessment	Research	1,852,245	2020-06-01	2027-11-30	Academic	University College London		
Homonymous Hemianopia in Childhood	Active	HEE/NIHR Integrated Clinical Academic Programme	Training	251,747	2020-07-01	2025-01-31	Government/ NHS	Great Ormond Street Hospital for Children NHS Foundation Trust		
Can Rapid Expiratory Ionisation Mass Spectrometry provide accurate and reliable information on oncological margin status during Trans-Cranial Robotic Surgery for recurrent or second primary Head and Neck Squamous Cell Carcinoma?	Active	NIHR Fellowships	Training	406,341	2020-11-01	2023-10-31	Academic	Imperial College of Science Technology and Medicine		
Detection of treatment-induced early cardiac injury with PET/MR to enable treatment adaptation to reduce side-effects in patients with lymphoma	Active	HEE/NIHR Integrated Clinical Academic Programme	Training	382,171	2021-06-01	2024-05-31	Government/ NHS	Guy's and St Thomas' NHS Foundation Trust		
Mefloquine in L1 Fraumeni (MFL) trial: A Phase II randomised open-label cancer prevention study of mefloquine in adults with L1 Fraumeni Syndrome	Active	Efficacy and Mechanism Evaluation	Research	2,159,740	2022-01-01	2030-12-31	Academic	University of Oxford		
WHITE-DECI: World Hip Trauma Evaluation – Delirium and Cognitive Impairment: a randomised feasibility trial comparing severity of delirium symptomatology between hip fracture patients 60 years and over treated with a peri-operative infusion of anti-TNF or placebo.	Active	Research for Patient Benefit	Research	249,927	2022-07-01	2024-05-31	Government/ NHS	Oxford University Hospitals NHS Foundation Trust		
Digital peer-supported and peer-led self-management of mental and sexual well-being for people with acquired brain injury (HOPE-4AB): a feasibility randomised controlled trial	Contracted	Research for Patient Benefit	Research	266,782	2022-11-01	2024-10-31	Government/ NHS	University Hospitals Coventry and Warwickshire NHS Trust		
<b>5,860,418</b>										

NIHR Funded Portfolio Awards  
Brain Tumour Projects Started Since June 2018  
Accessed on 25<sup>th</sup> January 2023<sup>65</sup>





## The All-Party Parliamentary Group on Brain Tumours

This report was sponsored and produced by Brain Tumour Research.



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Together we will find a cure

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