



All-Party Parliamentary Group on Brain Tumours Inquiry: Pathway to a Cure Call for Written Evidence – Charity Funders

Overview of inquiry

The landmark 2016 Petitions committee report into funding for brain tumour research stated: *“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.”^{vi}*

Since then, there has been another report into brain tumour research from the Department of Health and Social Care (DHSC), oral evidence sessions from the Petitions Committee, a £40 million funding announcement from the National Institute for Health Research (NIHR) and Westminster Hall debates. Many Parliamentary Questions have been asked and comments made in debates, but funding issues for vital brain tumour research continue to be raised and barriers continue to be identified.

The APPG on Brain Tumours (APPGBT) inquiry will seek to move from ‘talk to action’ and focus on solutions rather than problems, whilst acknowledging that the complexity of brain tumours means it continues to be very difficult for researchers to access funds that have been allocated for ‘general research’ into cancers and that there has been a failure to ring-fence funding for research into brain tumours. Key areas of focus will include early-stage research, novel drug delivery research and development, and clinical trials.

The APPGBT will collect evidence via a literature review, written evidence, oral evidence sessions in Parliament and written communication to Government. The inquiry is set to culminate in a written report which is planned for launch in early 2023, with regular updates to APPGBT meetings during the year.

The APPGBT are inviting stakeholders to submit written evidence. Evidence can be submitted via email to inquiry@braintumourappg.org using the pro forma below. Where questions state “Yes/No”, please bold and underline to indicate your answer.

We would like to hear from you about current practice and experience, existing barriers to funding brain tumour research, and suggestions for solutions. These will all inform the key recommendations of the report.

We will be accepting written evidence until Sunday 3rd July 2022.

Please complete this document, a task that should take between 30 – 60 minutes.

Your help in changing the rhetoric and moving this forward will bring hope to thousands of patients and their families

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Please note that we may use comments from written evidence in the inquiry and invite you to share your comments in front of the panel, over Zoom or in person. If you would rather not have your comments included, please state this in your submission.

If you would like any further information about the inquiry or the APPGBT's work, please contact the group's secretariat, Brain Tumour Research, at hugh@braintumourresearch.org

About You

Title	First name	Surname
Mrs	Lowri	Griffiths

What is your job title?

Director of Support, Policy and Insight

What organisation do you work for?

Tenovus Cancer Care

How long have you worked in the field of brain tumours?

N/A

Would you be happy for the APPGBT to quote your answers in the inquiry report? (Please highlight)

- Yes
- No

Would you be happy to be contacted by the APPGBT to discuss your answers or participate in an oral evidence session for the inquiry?

- Yes to discussing our contribution but we would be unable to take part in an oral session for the inquiry
- No

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Your experience

- 1) What specific action has been taken by your organisation to increase and improve research for brain tumours?

Over the last ten years, through a series of research funding projects and initiatives, Tenovus Cancer Care has supported Brain Tumour projects with over £354,000 worth of funding across a number of areas including patient survivorship, treatment development and developments to support new approaches around genetics.

Since 2020, we have ceased funding any new research projects, though have increased our focus on brain tumours as part of our ongoing commitment to improve outcomes through campaigning and influencing NHS systems in Wales for those diagnosed with any of the six less survivable cancers (lung, stomach, pancreatic, liver, and oesophageal being the other five)

- 2) What are the barriers to progress in brain tumour research, and what progress has been made to address these, by you and by others?

Tenovus Cancer Care is a member of the Welsh Parliament's Cross-Party Group on Medical Research and in being so, contributes to the group as it seeks to advocate for a strong research community in Wales. In February 2021, the Cross-Party Group published the report: Next Steps for Wales to achieve its potential in Medical Research¹. In this report, it was acknowledged that Wales was a long way off achieving its potential and had gone little way to implement the recommendations made by Professor Graham Reid in 2007² which call for the establishment of:

- a new Welsh Research and Innovation Office in London to increase the visibility and influence of Welsh research.
- an additional fund of £30m a year, to incentivise researchers to win greater funding from business and from outside Wales; and
- a single overarching brand for its research and innovation funding to increase the visibility, coherence and impact of Welsh Government-funded research and innovation in Wales.

¹ [cross-party-group-on-medical-research-report \(2\).pdf](#)

² [Reid Review \(gov.wales\)](#)

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The Cross-Party Group report highlighted that to date, only one recommendation had been achieved – that being to establish a new Welsh Research and Innovation Office in London.

In the context of addressing the barriers that exist to progressing brain tumour research it is important to look holistically at the challenges within the research community where there will always be pockets of good practice. The research infrastructure in Wales is underfunded and there is a shortage of research leaders, as well as a lack of clear career trajectories within research. Despite some excellent research facilities such as CUBRIC, without addressing these issues, Wales will continue to fall behind its potential in the area of brain tumour research.

For research in Wales, there is an institutional barrier to delivering the step change needed in medical research across the board as only Wales achieved significantly less than its share of UK and Global research funding and only receives 2.4% of the UK research spend³

- 3) What is the biomedical research community doing to improve co-ordination and collaboration within the medical research community and with Government to accelerate progress on brain tumour research?

Unknown

- 4) The Task and Finish Group on Brain Tumour Research report recommended that “researchers need access to appropriate brain tumour tissue and blood samples with accompanying clinical data” –what progress has been made to move this recommendation forward?

Unknown

- 5) Since the House of Commons Petitions Committee Report on brain tumour research in 2016, what progress has been made on the availability of clinical trials for brain tumours?

³ [UK-Health-Research-Analysis-2018-for-web-v1-28Jan2020.pdf \(hrcsonline.net\)](#)

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Unknown

- 6) How can the UK life sciences environment be leveraged to position the UK as a leader in clinical trials for brain tumours?

Amongst our partners on the Cross-Party Group on Medical Research is the ABPI in Wales who have echoed the voice of the third sector that clinical trials are an essential part of the research and development (R&D) of new medicines and vaccines, bringing benefits to patients, the NHS, and the economy.

They, alongside their membership and the wider R&D community have consolidated the UK's position as a leader in the global response to mitigating the impact and has worked hard with its partners to demonstrate the value of clinical trials, with research seen as critical to global recovery.⁴

The pandemic has also significantly impacted the type of clinical trials conducted and how these are designed and delivered.

The ABPI and its partners highlight a number of opportunities for the ongoing development of clinical trials in the UK and in Wales which Tenovus Cancer Care would support, and believe a particular focus should be on attracting more participation in clinical trials, especially in Wales where the involvement of people affected by cancer has been historically low and has in fact decreased over recent years with bureaucracy and poor data infrastructure seeming to delay and limit the number of patients in Wales able to take part⁵

It is vital that steps are taken to address this both at UK and Wales level and Tenovus Cancer Care is hopeful that the new All Wales Cancer Research Strategy in Wales which is soon to be published will go some way to address this. By creating a culture of clinical trial involvement across the board – those who take part in brain tumour clinical trials should increase.

- 7) Following the Medical Research Council workshop of brain tumour research communities to explore opportunities for research in 2019, what outcomes of this workshop are you aware of?

⁴ [Clinical research in the UK: an opportunity for growth \(abpi.org.uk\)](https://abpi.org.uk/clinical-research-in-the-uk-an-opportunity-for-growth/)

⁵ [cross-party-group-on-medical-research-report \(1\).pdf](#)

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Unknown

- 8) The Task and Finish Group on Brain Tumour Research report recommended taking forward the recommendations of meetings by the Association of Medical Research Charities and the Department of Health on drug repurposing – what meetings have been held and what were the recommendations?

Unknown

- 9) What advances have the Tessa Jowell Brain Cancer Mission made in basic science research into brain tumours?

Unknown

- 10) The Task and Finish Group on Brain Tumour Research report outlines the principal issue that “the relative lack of fundable research applications currently being received, compared to the clear need which occurs for many reasons and needs to be tackled systematically” – on what metrics are brain tumour research applications falling short and what is currently being done to address this? What opportunities are there in your view to remove barriers and generate “fundable” research applications.

We are no longer funding new research, however, will continue to be active contributors to the research community through our patient and public involvement work which will seek to ensure people affected by cancer and their loved ones are contributing to research in this area.

This area will be a priority area for us as we continue to focus our campaigning and influencing on the less survivable cancers. We are also keen to highlight the personal experiences of those who have Brain Tumours and are increasing our engagement with people who have been directly affected by the disease to help raise the profile of brain tumour and brain cancer with our stakeholders, many of whom are part of the wider research community in Wales. It is vital to bring personal experiences to bear through PPI activity in research.

See below an example of this engagement:

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When Natalie Lewis, 41, was diagnosed with brain cancer it was an emergency. If her grandmother hadn't found her collapsed on the floor of their home and called 999, she would have died.

Natalie hadn't realised the migraines she'd been having were down to a Satsuma sized tumour on her brain. Barely conscious after the life-threatening seizure, she was transferred to hospital and successfully operated on.

The next few months Natalie focused on rehab, learning to walk and talk again, but then she lost her job. Struggling financially, she took out a loan but there was a worst setback to come just over a year later – doctors discovered two smaller tumours on her brain.

Back in hospital fearing for her life, with ongoing money difficulties and worrying how she would financially afford to keep her most prized possession – her beloved horse Ed – Natalie felt deeply depressed. An amateur show jumper, all she could think about was not being to ride again, the thought of which was devastating:

“Being diagnosed with three brain tumours in just over a year was like the end of the world to me, says Natalie from Llandudno. “It seemed like the worst luck in the world and then you lose your job too. How can you recover from three brain tumours when you are worrying if you can afford to eat in a few months’ time?”

Chemotherapy treatment successfully shrank the two new tumours. She's now back on the saddle and taking part in show jumping competitions once more with her beloved Ed.

Now determined to raise awareness, so cancer doesn't become an emergency for others like her, Natalie shares her story when she can. Her story has also been widely reported in the media and she believes if more people do the same, it could become a game-changer for people affected by a less survivable cancer.

- 11) The Task and Finish Group on Brain Tumour Research report recommended that funders state explicitly to the research community that research applications in brain tumours are particularly welcome. Do you explicitly call for applications for funding in brain tumour research and if not why not?

As we are not a site-specific charity, we have never run tumour site specific grant calls, instead selecting applications based on individual merit, as assessed by expert peer review.

- 12) The Task and Finish Group on Brain Tumour Research report recommended that researchers and funders should embrace the top 10 important research questions in brain tumours developed by the James Lind Alliance Priority Setting Partnership and the top six research priorities developed by Cancer Research UK – has your

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organisation as a funding agency embraced these questions for prioritising funding?
If not, why and what questions are being prioritised?

We were involved in the collection of data for the NCRI priority setting partnership and following the release of the recommendations we instructed our patient involvement group who reviewed the applications to our iGrant stream to favour applications which addressed one or more of these priorities, as detailed on submitted application.

13) What is your organisation doing to improve co-ordination and collaboration between the medical research community, funding bodies and Government to accelerate progress on brain tumour research?

As part of the Wales Cancer Alliance, Tenovus Cancer Care will continue to be an active partner in supporting the implementation of the All-Wales Cancer Research Strategy which is soon to be published. As mentioned above, we will be focussing on ensuring that people who have been affected by brain tumours and cancer more widely will be involved in setting the agenda for research initiatives and contributing right from the very beginning. We will provide support to make that happen here in Wales and will seek alliances and collaboration within the medical research community and beyond.

14) Since 2018 how much funding has your organisation allocated to brain tumour research by programme?

Approx. 56K, comprising one IGrant project and the final installation of a 4 yr. PhD

15) How do you prioritise research funding for brain tumours across the pipeline to ensure treatments will be found?

We did not prioritise by cancer site on any of our grant calls.

16) How do you make sure all brain tumour research applications to your organisation are looked at properly and that an objective decision is reached?

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All proposals are peer reviewed by a scientific advisory committee with expertise in cancer research.

**Thank you for supporting the APPG on brain tumours
and taking the time to complete this document.**

Please provide any further comments in the box below.

If you would like a copy of the final inquiry report, please provide your preferred email address.

Email: lowri.griffiths@tenovuscancercare.org.uk

ⁱ House of Commons Petitions Committee, “Funding for research into brain tumours: First Report of Session 2015–16”, 14 March 2016. HC 554. Available at:
<https://publications.parliament.uk/pa/cm201516/cmselect/cmpetitions/554/554.pdf>