



## **All-Party Parliamentary Group on Brain Tumours Inquiry: Pathway to a Cure Call for Written Evidence – UK Brain Tumour Researchers**

### **Overview of inquiry**

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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.”*<sup>vi</sup>

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](mailto: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 13<sup>th</sup> February 2022.

Please complete this document, a task that should take between 30 – 60 minutes. The document has some questions directed directly to those of you conducting scientific brain tumour research and some with a bias toward clinical research so please read the document carefully before completing.

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](mailto:hugh@braintumourresearch.org)

**About You**

Title	First name	Surname

What is your job title?

As a brain tumour researcher are you

- Laboratory based Yes/No
- Clinically focused Yes/No
- Other – please give details

What organisation do you work for?

How long have you worked in brain tumour research?

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
- No

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## Your experience

1. What barriers have you or your colleagues experienced in submitting research funding applications for brain tumour research through:

a) The National Institute for Health Research (NIHR)

b) UKRI Medical Research Council (MRC)

c) Health and Care Research Wales

d) HSC Public Health Agency (Northern Ireland)

e) The Chief Scientist Office (Scotland)

f) UKRI Biotechnology and Biological Sciences Research Council (BBSRC)

g) Cancer Research UK

h) Brain Tumour Charities

(please identify which one(s) and detail your experience below for each one)

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2. Following the publication of the [NIHR Highlight Notice](#) originally advertised in May 2018, and then re-advertised in May 2019 did you apply?
- Yes
  - No

3. If you answered no to the above question, why not?

Please skip to question 8

4. If you did apply following the publication of the NIHR Highlight Notice advertised in 2018, did you receive funding?
- Yes
  - No

5. If you answered yes to the above question, was the funding sufficient?

- Yes
- No

6. If you did not get funding, did you receive detailed feedback on your application and was this feedback helpful?

7. If you did not get funding, do you know what you need to do to improve your application to be more likely to succeed next time?

8. Would you consider applying to the NIHR in future?

- Yes
- No

Please explain your decision

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9. Were you aware that the NIHR Highlight Notice had been re-advertised?

- Yes
- No

10. In your view, are there any specific changes required to how the call is managed that would improve its operation?

11. Are you aware of the Research Design Service provided by Government Funders?

- Yes
- No

12. If you answered yes to the above question, have you used it?

- Yes
- No

13. If you answered no to the above question, why not?

14. In your view are there any barriers to recruiting **early career researchers** (up to ten-year post PhD) in brain tumour research?

- Yes
- No

15. What are the barriers?

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16. What is the impact of this on researchers' careers and brain tumour research?

17. Do you conduct **early-stage research** (discovery science/basic research)?

- Yes
- No

If no please skip to question 20

18. What barriers have you or your colleagues experienced in submitting successful research funding applications for early-stage research on brain tumours?

19. How effective do you think current funding opportunities for early-stage brain tumour research are? What do you think could be improved?

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20. 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 research priorities developed by Cancer Research UK](#)

Have you embraced these questions for funding applications?

- Yes
- No
- Some

If you answered some or no to the above question, what are you prioritising instead?

21. Do you enrol brain tumour patients in clinical trials?

- Yes
- No

If you answered **no** to the above question, please skip questions 22-28 and start again at question 29

22. What are the barriers for patients to accessing clinical trials for brain tumours?

23. What are the barriers for clinicians to getting access for their patients to clinical trials for brain tumours?

24. In your view, what would it mean for patients to have increased access to clinical trials?

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25. In your view, what needs to be done to improve access to clinical trials?

26. Do you consider adaptive trials to be an improvement on the clinical trial landscape?

- Yes
- No

27. Does your research involve adaptive trials?

- Yes
- No

If not, why not?

28. In your view, what progress has been made to speed up the adoption of adaptive trials, how much funding has gone toward this and who is providing that funding?

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29. Are the following factors barriers to novel drug delivery and, if so, in what way and what could be the solution to overcoming such barriers?

a. Financial

b. Regulatory

c. Clinical

d. Logistical

e. Are there others? If yes, please elaborate.

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30. Are the following factors barriers to the possibility of repurposing existing drugs and, if so, in what way and what could be the solution to overcoming such barriers?

a. Financial

b. Regulatory

c. Clinical

d. Logistical

e. Are there others? If yes, please elaborate.

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31. The Task and Finish Group on Brain Tumour Research<sup>ii</sup> identified the following areas as priorities for research: detection, pre-clinical models, radiotherapy, surgery, drug development and clinical trials.

Do you believe these are the right priority areas for research?

- Yes
- No

If not please give further detail on what is missing:

32. Are you researching in any of these areas (please highlight or underline your answer)?

- Aetiology Yes / No
- Rare tumours Yes / No
- Detection Yes / No
- Pre clinical models Yes / No
- Radiotherapy Yes / No
- Surgery Yes / No
- Drug development Yes / No
- Clinical trials Yes / No

If you answered no to any or all of the above questions, why not?

33. What priority should be given for research into i) early diagnosis and ii) prevention in order to improve outcomes for patients?

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34. In your view, how effective is research into early diagnosis in finding new treatments and a cure?

35. In your view, how effective is research into prevention in finding a cure?

36. What type of research is needed to identify new therapeutics for brain tumour patients?

37. How reliable do you think tests that determine genomic predisposition to brain tumours are likely to be in the future?

38. How important is data in identifying genomic predispositions and narrowing down and improving the likelihood of test results?

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39. We are keen to understand any barriers to a sustainable, long-term career in brain tumour research. Please could you outline any thoughts on this below.

38. What impact has the lack of new treatment options for brain tumours had on patients?

39. How do you personally feel about the progress made in brain tumour research in the UK? How does it compare with research internationally?

40. How do you personally feel about the lack of treatment options and the messaging given to brain tumour patients and their families?

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

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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:

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<sup>i</sup> 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>

<sup>ii</sup> Department of Health and Social Care, “Report of the Task and Finish Working Group on Brain Tumour Research”, 22 February 2022. Available at:

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