



Petitions Committee

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The Lord Bethell
Parliamentary Under Secretary of State
Department of Health and Social Care

15 June 2021

Dear Lord Bethell,

Thank you for giving evidence to our Committee last month, as part of our work on brain tumour and childhood cancer research, and for the written evidence you submitted on behalf of NIHR ahead of the session.

This was a useful opportunity for us to take stock of how the UK brain tumour research environment has evolved since the Government's commitments in 2018. It is clear from the evidence we heard that initiatives such as the establishment of the Tessa Jowell Brain Cancer Mission are having a positive impact and laying the foundations for more high-quality UK-based future research in this field. But it is equally clear that there remains much more to be done in many areas – in particular, when it comes to promoting basic research into brain tumours, and research into childhood brain tumours with the worst survival outcomes.

Following our session, we wish to request some additional information on a number of points raised during the session, as well as on a small number of topics which we did not have time to cover during the session. We have set out our requests below.¹

1. Basic research

A key theme emerging from our session, where there was consensus across all witnesses, was the need for progress in understanding the basic science of brain tumours, which could ultimately help support later-stage translational and clinical research of the kind funded by NIHR. From your written evidence and your comments during the session, we understand that funding this type of research would fall within the remit of UKRI and the Medical Research Council.

- You indicated that early-stage research of this kind “needs more resources and more support”.² Are there actions the Government is taking to make this happen, beyond its day-to-day support for UKRI and MRC, and its backing for the Tessa Jowell Brain Cancer Mission's convening work and participation in related workshops, which were discussed during the session?

¹ Question numbers cited below refer to the question number given in the transcript of the session: Petitions Committee, Oral evidence: Brain tumour and childhood cancer research, HC 242, Thursday 27 May 2021. Available at:

<https://committees.parliament.uk/event/4542/formal-meeting-oral-evidence-session/>

² Q32

- During our second panel, Professor Chris Jones called for more Government funding for brain tumour research to be filtered via UKRI and MRC, and targeted at basic science.³ While individual funding decisions will remain the operational responsibility of these bodies, have you taken, or do you plan to take, any specific actions to encourage more funding applications for basic brain tumour research – for example, a highlight notice similar to that issued by NIHR in 2018?
- What consideration have you given to amending or redirecting the £40 million funding commitment announced in 2018, which focuses on clinical and translational research funded via NIHR, to also include spending from the UKRI and MRC on basic research into brain tumours?
- During the session, Mike Batley noted: "We [NIHR] have been working with colleagues in UKRI to see what more can be done in the basic science space in a broader and more flexible way".⁴ Can you give more details of the interactions between UKRI and NIHR on this subject, and any expected outputs?
- The work of the Tessa Jowell Brain Cancer Mission to establish closer links between the UK neuroscience and brain tumour research communities, and help drive progress on basic brain tumour research, was cited several times during the session and is a welcome step forward. What consideration have you given to how targeted Government funding could help accelerate this work, for example with regard to Professor Richard Gilbertson's suggestions⁵ in the second panel?

2. International research collaboration:

During our second panel, witnesses emphasised the vitally important role of international collaboration for research into brain tumours and childhood cancers. Since our Committee last took evidence on this topic in 2019, the UK has left the EU, and we would be keen to understand more about your perspective on how this may impact research in this area.

- What plans do you have to build on the Trade and Cooperation Agreement in promoting future collaborations between UK-based and EU-based medical researchers, including for research into brain tumours and childhood cancers?
- In particular, what plans does the Government have to improve access to clinical trials in the UK for families affected by brain and childhood cancers? Will you look into the concerns raised by Professor Jones⁶ in terms of practical, regulatory and governance barriers to international childhood cancer research consortia opening UK arms of existing international trials?

³ Q22

⁴ Q34

⁵ Q19, Q22

⁶ Q21

3. Medical research charity funding:

We are aware from our previous work on this topic that the charitable sector funds the vast majority of site-specific brain tumour research in the UK, and that charitable funding makes up a greater proportion of site-specific brain tumour research spending than for other cancer types.

As you will be aware, and as was noted by witnesses during our second panel, many medical research charities have seen their incomes drop considerably since the start of the covid-19 pandemic and are planning reductions in research budgets as a result. We are aware that the Government has announced £20 million of funding for medical research charities as part of the BEIS 2021/22 R&D budget allocations,⁷ but Ian Walker suggested during our session that while this funding was welcome, it was not enough to fix the fundamental problem of reductions in charitable medical research budgets.⁸

- Will the Government commit to further conversations with the charitable medical research sector, as witnesses called for during our session,⁹ with the aim of providing specific, targeted support to these charities and protecting future charity-funded medical research?

4. Childhood brain tumours:

During the session, we heard petitioners' concerns about the Government having previously cited initiatives such as the Tessa Jowell Brain Cancer Mission, and existing NIHR funding for brain tumour research projects, as examples of relevant Government-led activity to promote research into childhood brain tumours such as DIPG.¹⁰ We also heard about families' and researchers' continued reliance on funding from small charities, often set up by bereaved parents, to enable research into these cancers.

We appreciate the Minister's concern that funding decisions should not be politicised or based on purely emotional considerations. However, as we heard from petitioners, some diseases such as DIPG have seen no advances in treatment in 60 years. This suggests the current approach is not working, despite recent advances noted by Professor Jones and achieved by him and other researchers. It is not simply "sentimental" to suggest an alternative approach is needed to – as the Minister suggested – "align academic research and activate enthusiasm, interest and collaboration",¹¹ and take advantage of the opportunities our witnesses described to make progress against these diseases.

- In recognition of the disproportionate life years lost, lack of progress in improving survival outcomes, and difficulty of attracting dedicated research funding, will the Government reconsider its position and develop a bespoke research strategy for childhood cancers with the worst survival rates, including DIPG, and allocate targeted research funding aimed at improving outcomes for these patients?

⁷ <https://www.gov.uk/government/publications/beis-research-and-development-rd-budget-allocations-2021-to-2022>

⁸ Q24

⁹ Q28

¹⁰ Q3

¹¹ Q49

5. Future commitments:

The five-year period over which the headline £40 million Government funding commitment for brain tumour research was meant to be allocated ends in 2023. While we are aware that the Tessa Jowell Brain Cancer Mission will continue its work beyond this date, we are keen to understand the Government's wider plans to learn lessons from the experience of allocating this funding and to ensure that funding for, and the focus on, brain tumour research in the UK continues to grow beyond 2023.

- Do you plan to publish a breakdown of NIHR spending on brain tumour research over the 5 years from April 2018 at the end of this period?
- At the end of this period, do you plan to conduct a review of progress in UK brain tumour research in order to inform future Government support for brain tumour research in the UK, and how will you engage with relevant stakeholders – including campaigners and petitioners – in determining this future support?

As I said in my opening remarks in our session, the Petitions Committee is extremely proud of its history of work on brain tumour research in the UK. The Committee's inquiry on this subject in 2015/16 was the first ever inquiry by the Committee into a subject raised by an e-petition, and we remain deeply moved and inspired by the courage and determination of the campaigners and petitioners on whose behalf we have the privilege of continuing to undertake this work.

We therefore intend to continue to monitor developments in this area, and to revisit our work on this topic again before the end of the five-year period covered by the Government's initial commitments following the death of Baroness Jowell in 2018. We look forward to continuing to engage with you on this topic, and we would request that the Department ensures it keeps the Committee up to date with the Government's plans and priorities on this vitally important, yet historically underfunded, area of research.

We would be grateful to receive your response to the points raised in this letter by no later than Thursday 8th July, to allow the Committee to consider your reply before the summer Parliamentary recess.

Yours sincerely,

A handwritten signature in black ink that reads "Catherine". The signature is written in a cursive, flowing style.

Catherine McKinnell MP
Chair of the Petitions Committee