

**Written Evidence from Emeritus Professor Geoff Pilkington, University of Portsmouth
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Relating to brain tumour research

- 1. Has the work of the Tessa Jowell Brain Cancer Mission, and protected funding from NIHR and CRUK, led to a more favourable research environment for brain tumour research (in particular basic/discovery research)? Is this being felt on the ground by the research community, in particular when it comes to the availability of research funding?**

In general, in response to the first part of this question, I would – to put it succinctly – say “No”; this should, however, be qualified by asking “favourable” to whom? In this context the clinical sector and those clinicians alluding to a research (part)-based – long term or short term – career have benefited but those, non-clinical academic researchers who are often rather derogatively called ‘basic scientists’ have not benefited and appear to be significantly dropping in number.

The main thrust of the 2016 initiative (and others which came before) on the lack of research funding in the field of neuro-oncology was to increase the investment in full time dedicated laboratory-based researchers, giving them a suitable career structure and achievable career ‘ladders’ as well as opportunities to gain research grant funding and to be cited in centres where there was a DEDICATED FOCUS on brain tumours (of all types/forms). This is not to negate the essential role of clinicians, but to provide for an orchestrated plan to increase the numbers of non-clinical LABORATORY-BASED scientists who could make findings which would – via suitable pre-clinical testing and translation - provide the basis for improved treatment strategies to be implemented by the clinicians. What we seem to be seeing is an increase in funding opportunities for clinicians to do part-time brain tumour research (including expensive PhD programmes whereby the standard ‘stipend’ is supplemented to ‘buy-out’ their clinical practice time), while the so-called ‘basic’ scientists are – at best – struggling on very short-term funding within an insecure career structure. The result of this is many who complete their doctorates in neuro-oncology are unable to find post-doctoral positions within their chosen field within the UK (they either go abroad and stay in neuro-oncology or carry on in other disciplines IF they are lucky enough to find laboratory-based research posts. Moreover, the non-clinical post-docs struggle with short-term funding/periods of employment (often 1-/3- year periods, but in brain tumour research laboratories this is frequently only for a period of months not years).

- 2. What progress do you feel has been made on improving awareness of brain tumours among GPs and other healthcare professionals since 2016, and reducing misdiagnosis and diagnosis in an emergency setting?**

I would hope this would be a very positive ‘side-effect’ of the press releases and TV/Radio reports which resulted as a consequence of the ‘fall-out’ from the 2016 House of Commons debate. I have many friends who are in General Practice, however, and have not really noted any better acquaintance with the major issues in CNS tumours from them. Moreover, I am still approached by many patients and carers who come to me to help demystify the science behind brain tumours, their biology, diagnosis, treatment and management.

3. How has the situation for an early career researcher looking to specialise in brain tumour research changed since 2016? Are you aware of more researchers now entering or intending to pursue a long-term career in brain tumour research?

For the greater part, my discussions with PhD students, junior post-docs and senior researchers at various levels who are, or were, involved in a dedicated manner with brain tumour research, this situation has got worse since 2016.

I know of many young researchers who would love to work in the field of neuro-oncology but they simply cannot find a suitable niche for this in the UK. The trend, for those who are able to do so, is to seek such employment overseas.

4. Do the new Tessa Jowell Centres of Excellence offer an effective way to concentrate brain tumour clinical and research expertise? What further support could Government offer to help them drive progress in brain tumour care and research?

The short answer to this question is Yes, they do within the clinical sector but seemingly to the detriment of non-clinical, laboratory-based researchers. It should be noted that the Tessa Jowell Centres are, in essence, hospitals **not** research institutes or universities (where the bulk of laboratory-based brain tumour research is carried out). Moreover, the associated funding from NIHR & CRUK should also be qualified: NIHR, as far as I am aware, does NOT fund original, laboratory research while the monies stated in the context of CRUK appears to stay within CRUK centres (which certainly increases the amount of brain tumour research within CRUK institutes but, historically most of the UK's brain tumour research effort has not come from CRUK laboratories). So, if the NIHR does not fund laboratory-based investigations and CRUK is a charity, where is MRC in all this? Why isn't such brain tumour research funding provided via the Research Council structure, in whatever the current reincarnation is, through a Government-associated body appropriate to the needs of the discipline of experimental Neuro-oncology?

Moreover, clinical care, clinical trials and original laboratory-based research are totally different areas and require very different levels and types of funding. I am, however, highly supportive of the concept of Centres of Excellence for laboratory research into brain tumours, indeed, it was I who suggested this approach to the charity sector many years ago and, if planned and orchestrated efficiently with appropriate staff at all levels and with security of tenure for each of the various types of post, I believe this would greatly benefit the UK's national and international strength and contribution which would guide clinical improvements. I also think that lead roles in such centres should be given to non-clinical full time, dedicated research scientists and that appropriate pathways to Professorships for appropriate staff should be built into such programmes.

5. Are there any other developments in the care of and research into brain tumours since the Committee's inquiry in 2016 you would like to draw the Committee's attention to?

There are a few points which are, I believe, relevant to the question posed:

- a) Three factors that have greatly impacted upon brain tumour research activities within the university sector post-2016 with serious detrimental effect are; the Covid-19 pandemic, resultant reduced charity budgets for grant funding and the trend to

transition even further from research to teaching as a priority activity for internal expenditure.

- b) Despite interesting laboratory findings on novel and repurposed agents for brain tumour therapy, these have not gained regulatory approval or funding to transition towards clinical trials/adoption so we are still saddled with the same old DNA alkylating agents in one form/combination or another for treating malignant primary brain tumours after 5+ decades of scientific endeavour.
- c) The 'molecular obsession' since the human genome project has, hitherto, not been central to the development of meaningful new guidelines for high grade or low- grade primary brain tumours. In this context, the so-called 'targeted therapies' approach has not really born fruit. I would also like to see a greater concentration on functional cellular assays in the laboratory. Indeed, there has been heightened interest in the so-called New Approach Methodologies (NAMs) which include complex sophisticated Human multi-cellular 3D *in vitro/ex vivo* systems, including organoids, on-a-chip technologies and use of human induced pluripotent stem cells (iPSCs) for pre-clinical drug testing and delivery studies.
- d) With knowledge of the above and in fairness to patients, especially those with poor prognosis high-grade malignancies such as GBM, surely the use of repurposed or reformulated drugs merit due consideration; these could be fast-tracked to clinic via testing with NAMs as mentioned above. These are already being addressed and championed through the recently formed All Party Parliamentary Group (APPG) on Human Relevant Science.
- e) General comments and conclusions: Although now officially 'retired', I still hold an Emeritus Professorship at Portsmouth and Honorary Professorships at Cardiff and Kings College London. Moreover, I am still in contact with both senior and junior researchers in the brain tumour research field and have elicited their opinions to substantiate my 'written evidence', herein.

My fear is that the charity sector has 'shot itself in the foot' somewhat since the general public has become aware of the mention of these rather large sums of money which is apparently being spent on brain tumour research and so think that this is "job done" so they stop putting money in the collection boxes and donate their charitable monies to other worthwhile causes.

My recommendation would be that the UK's genuine, long-term, committed/dedicated non-clinical, laboratory-based researchers should be recruited to form an advisory panel with the remit of providing a basis for what **they** see as the way forward in UK brain tumour research. In this context, perhaps it should be noted that the people who really put both the professional societies (eg BNOS) and charities 'on the map' within the brain tumour sector were - for the greater part - non-clinical scientists.

While all that is written above is fully representative of my true feelings, I am certainly NOT dismissive of the many major positives coming out of the debate BUT, I do feel we have come somewhat 'off-piste' from the original agenda of universally accessible, increased funding for Basic (pre-clinical), laboratory-based research and researchers.