

RESEARCH FUNDING FOR BRAIN TUMOURS DEBATE – 9 MARCH

Key Messages

In 2018, the UK Government committed a total of £40m of research funding to be made available via the National Institute for Health Research (NIHR) and to be spent over five years. We are, however, five years on and there **are no new treatments** and the five-year survival for patients is still just 12%. Brain tumours remain the **biggest cancer killer of children and adults under the age of 40**.

As of the 25th January 2023, just £15m of the £40m had been awarded, with £6m of this not easily identifiable as relevant to brain tumours. **For comparison, in this time The Brain Tumour Charity has spent over £15m on research in the UK as well as over 13m globally. In the last year alone (21/22), we as a charity spent just under £5.1m.** We are committed to increasing this year on year.

This needs to change. Research is essential to drive progress in developing our understanding of how brain tumours develop, faster diagnosis and in finding long-awaited new treatments. That is why we are recommending that the government prioritise three key areas:

- Recognising research into brain tumours as a **critical priority and developing a strategic plan** for adequately resourcing and funding discovery, translational and clinical research by 2024
- **Improving access to clinical trials** and awareness of research participation
- Ring-fence £110 million of current and new funding for discovery, translational and clinical research

Why research spend into brain tumours must increase?

Brain tumours are the biggest cancer killer of children and adults under 40 and overall survival rates are still worryingly low. Meanwhile, **paediatric survival rates have remained unchanged for over two decades**. Despite these stark statistics, when compared to other cancers, brain tumours have not had the same level of research funding.

Notably, since 2002, NCRI partners have funded £10 billion of cancer research. **However, only 1.3% (£126m) of this was spent on research into brain tumours** (this does not include The Brain Tumour Charity's contribution, despite efforts to share our data). During this time, £775m (7.8%) and £551m (5.5%) was spent on breast cancer and leukaemia research respectively. In terms of improvement in treatment and five-year survival, the results are clear, rising to 85% and 54% respectively. Meanwhile, this remains at 12% for brain tumour patients. Whilst funding levels for brain tumours have improved in recent years, we still have a long way to go.

The Government **must urgently address the barriers to spending the remaining £25m of declared funding on world class research**. They must also commit to prioritising research into brain tumours as a Medical Research Council (MRC) challenge, which would bring £50m funding over 14 years, and a further £35m to improve Translational Research trial readiness.

Improving research participation and access to clinical trials

But it is not all just about the money. According to the recently published All Party-Parliamentary Group for Brain Tumour's (APPGBT) *Pathway to a Cure* report there are clear problems that must be resolved to help ensure those affected by brain tumours have the best access to clinical trials.

The report's findings concluded 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 resources to support those patients on funded research studies.

Our own **Improving Brain Tumour Care (IBTC) surveys revealed worrying levels of research participation** within the brain tumour community:

- **Just 42%** of respondents to the survey were even informed about research participation.
- **35%** of respondents participated in any form of research.
- **9%** of respondents participated in clinical trials.

We know that brain tumour patients can be excluded from clinical trials that are looking at the benefits of a particular drug for a number of different cancers, because there is a perceived risk they are more susceptible to having an adverse response which would negatively skew trial results. This exclusion right at the beginning of a trial means that people with a brain tumour are never included, even in later trials, and the potential benefits of a drug is never known.

The Medicines and Healthcare Products Regulatory Agency (MHRA) must issue a statement urging the inclusion of brain tumour patients in early phase cancer trials.

Case Study

BRAIN MATRIX and ARISTOCRAT:

The Brain Tumour Charity has provided £2.8m funding for the Tessa Jowell BRAIN MATRIX to **address some of the challenges associated with running clinical trials for brain tumours**. BRAIN MATRIX is a **platform for running clinical trials in the UK by recruiting patients into its central portal** where clinical, molecular, imaging and quality of life data is collated for all patients. The trial has wide recruitment criteria and is open to all adults with a newly diagnosed glioma and is open at 9 centres in the UK, with 5 more to open in the future. ARISTOCRAT is a Phase II trial of cannabinoids in combination with temozolomide in patients with recurrent glioblastoma. Patients will be randomised to either receive the usual treatment (standard of care) or standard of care plus Sativex, a specific combination of cannabinoids in an oral spray. **We hope to be able to announce the opening of the trial imminently, and this is the first trial utilising the infrastructure established by BRAIN MATRIX.**

Simplifying the regulatory process and funding translational research

The APPGBT's *Pathway to a Cure* report revealed that there are currently no brain tumour drugs on the orphan drugs register – a status given to certain drugs which show promise in the treatment, prevention, or diagnosis of rare diseases. **This shows how a lack of funding towards research in this area is having an adverse impact on our progress on finding better treatments or a cure.**

Some of the main reasons pharmaceutical companies choose not to pursue development of brain cancer medicines in the UK are because there is a challenging regulatory system and it is more difficult to get venture capital funding. This is because investors want quick returns on their money so would rather invest in “safer” or “quicker” drug development routes that aren't focused on brain tumours. The Government **needs to simplify the regulatory process and introduce tax reliefs and incentives for investors to encourage investment to develop and deliver new brain tumour drugs.**

But even before we get to drug development stage, researchers find it difficult to access Government funding for translational research. Translational research is integral for research into brain tumours as it is how we move earlier discoveries about the development and growth of brain tumours into practical application in treatment and care. But funding this is still perceived as being “risky” and so researchers have to rely too heavily on charities. **Government must take on funding translational research more proactively so that researchers can make the leaps and bounds we know that are needed to find better treatments and a cure.**

Contact Details

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