Less than 20% of those diagnosed with a brain tumour survive beyond five years compared with an average of 50% across all cancers.

The national investment for research into brain tumours needs to increase to £35 million a year by 2025.

We call on the Government to work with Brain Tumour Research and its partner organisations to:

1. **Grow capacity**
2. **Build infrastructure**
3. **Accelerate treatments**

Brain tumours kill more children and adults under the age of 40 than any other cancer.
Brain tumours kill more children and adults under the age of 40 than any other cancer… yet historically just 1% of the national spend on cancer research has been allocated to this devastating disease.

We are building a network of experts in sustainable research at dedicated Centres of Excellence whilst influencing the Government and larger cancer charities to invest more nationally.

Help us fund the fight. Together we will find a cure.

Cancer site-specific research as a % of national cancer research spend

<table>
<thead>
<tr>
<th>Year</th>
<th>Cancer Total £</th>
<th>Brain Tumours £</th>
<th>%</th>
<th>Breast £</th>
<th>%</th>
<th>Leukaemia £</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>2002/03</td>
<td>297,872,437</td>
<td>967,718</td>
<td>0.3%</td>
<td>22,457,672</td>
<td>7.5%</td>
<td>17,690,579</td>
<td>5.9%</td>
</tr>
<tr>
<td>2008/09</td>
<td>502,573,570</td>
<td>4,149,415</td>
<td>0.8%</td>
<td>43,584,446</td>
<td>8.7%</td>
<td>29,135,148</td>
<td>5.8%</td>
</tr>
<tr>
<td>2013/14</td>
<td>540,459,570</td>
<td>5,970,298</td>
<td>1.1%</td>
<td>42,790,424</td>
<td>7.9%</td>
<td>32,239,796</td>
<td>6.0%</td>
</tr>
<tr>
<td>2016/17</td>
<td>589,869,718</td>
<td>8,615,902</td>
<td>1.5%</td>
<td>46,087,203</td>
<td>7.8%</td>
<td>35,081,014</td>
<td>5.9%</td>
</tr>
</tbody>
</table>

See our website for the full interactive table.

OVERVIEW

Since Brain Tumour Research published its Invest In A Cure manifesto in 2015, we have been fundamental in shining a spotlight on why more funding is needed for research into brain tumours and driving the overall push for change.

Brain Tumour Research first drew the public’s attention to how little was being spent on research into brain tumours in its 2009 The Inequality of Funding report, highlighting how, for decades previously, brain tumours had been largely ignored by key decision-makers. Working tirelessly to hold the Government and larger charities to account, Brain Tumour Research went on to lead the campaign behind the 2015 e-petition, launched by the Realf family calling for the Government to fund more research into brain tumours. Galvanising more than 120,000 signatures, the petition led to the Petitions Committee Inquiry and report, a Westminster Hall debate and the formation of a Department of Health and Social Care (DHSC) Task and Finish Working Group on Brain Tumour Research.

The publication of the Task and Finish Group’s report in February 2018 heralded a significant shift in focus and led to a £20 million Government funding announcement and a pledge of £25 million from Cancer Research UK (CRUK). The tragic death of Dame Tessa Jowell from a brain tumour, following her moving personal testimonies and calls for change, proved a catalyst for the establishment of the Dame Tessa Jowell Brain Cancer Mission (TJBCM). A further £20 million Government funding pledge followed, bringing the total pledge to £65 million (including CRUK’s funding) over the next five years (£13 million per year) to facilitate a cure for brain tumours.

This is all moving in the right direction but there is still so much more to be done if we are to achieve parity with other cancers such as breast and leukaemia. In 2015, we called on the Government and larger cancer charities to Invest In A Cure. Progress has been made and it is now time for the Government, larger cancer charities, and the brain tumour community to work together to Find A Cure and give hope to the thousands of people diagnosed with a brain tumour every year in the UK, along with their families.

GROW CAPACITY

Historical funding problems and a lack of leadership from successive governments have left a gap in the research workforce within the UK1. Consequently, the UK’s research community focused on finding a cure for brain tumours is small. Attracting and retaining talent remains a challenge. A primary driver of career choice for medical researchers is access to funding and it is, therefore, no surprise that it remains a stagnant and impoverished field in terms of growth and talent when taking into account that historically just 1% of national spend on cancer research has been allocated to brain tumours2.

We believe sustainable, dedicated brain tumour research centres are fundamental

Capacity can only be bolstered, sustained and grown by ensuring researchers can operate within a framework that encourages the generation of new ideas and the discovery of breakthroughs from which they can translate their findings from the laboratory bench to the patient’s bedside. This can be effectively facilitated within the environment a research centre creates. Brain Tumour Research has already established four dedicated centres in pioneering research, which is enabling us to attract other funding for these centres as a result.

For progress to occur in medical research, researchers must be motivated by the prospect of continuous research funding, leadership opportunities, and ground-breaking scientific advances. A lack of such incentives will only hamper growth and success.

We are promoting the establishment of clinical fellowships to help grow the number of practising specialist neuro-oncologists

It is now widely acknowledged that there are not enough specialist neuro-oncologists treating brain tumour patients in the UK within the NHS. Working with the TJBCM, we will actively promote and support the implementation of funded schemes designed to encourage young doctors to pursue a career in neuro-oncology.

We call on the Government to speed up access to curative treatments by stimulating further increases in the national investment for research into brain tumours to £35 million a year by 2025
Patients in research-active institutions have better outcomes than those in other institutions and are more likely to benefit from earlier access to new treatments, technologies and approaches. Yet, we know that NHS clinicians cite a range of barriers, including time constraints, financial pressures, and a lack of skills and expertise within the workforce, that prevent them from carrying out clinical research. Anecdotally, we know that neurosurgeons in particular are facing increased workloads from not only a rising incidence of primary and secondary brain tumours, but also a specialization that sees them consult with and perform surgery for a range of disorders. For them, protected time for clinical research is essential.

**BUILD INFRASTRUCTURE**

Successful research and innovation must be underpinned by solid, robust infrastructure and a united approach – both in terms of people and systems.

We will advocate for the creation of a national register of all site-specific cancer research to track all research work, grants and results to avoid duplication and enable collaboration.

A national register would allow researchers, universities, research institutions and the Government to present in one place exactly what research is being funded and the results that are being achieved. Furthermore, all relevant stakeholders would be able to easily see what diseases and specific cancer sites are receiving funding and how successful this funding is. It will open up the debate about need and value for money, as well as prevent duplication and encourage collaboration across the brain tumour community.

Less than 20% of those diagnosed with a brain tumour survive beyond five years.

**ACCELERATE TREATMENTS**

Brain tumours, a rare but often deadly disease, are complex. With more than 120 types of brain tumours, unlike many other forms of generally more common and well-known cancers, the scientific knowledge underpinning an interpretation of why and how this cancer develops is still in its infancy. Their complexity, rarity, biological distinctiveness as well as the blood-brain barrier all mean that innovative approaches must be taken to find a cure. Patients and their families live in the knowledge that there have been no new treatments developed and approved for use on brain tumours since 1999, yet there have been 64 approved for blood cancers and 15 for breast cancer. Consequently, surgery, radiotherapy and chemotherapy remain the only treatment for brain tumours, despite their frequent ineffectiveness.

This is simply unacceptable.

We call on the National Institute for Health Research (NIHR) to encourage and facilitate the successful applications for research into brain tumours needed to find a cure.

Discovery science, specifically the basic science that translates to clinical trials, is essential to the development of safe and effective therapies. It has been recognised that one of the barriers to discovering breakthrough treatments for brain tumours is “the relative lack of fundable research applications currently being received, compared to the clear need”. In 2018, the NIHR, which is funded by the DHSC to improve the health of the nation through research, announced that the Government’s £40 million funding will be allocated through the NIHR to support a wide range of research from early translational through to clinical and applied research, with the aim of encouraging high-quality, innovative, and competitive proposals.

However, the reality remains as at December 2018 only two out of 20 applications for funding for research into brain tumours were successful since the start of that financial year and only 17 out of 113 since the NIHR was established.

Working with the NIHR’s Research Design Service, this situation must change if progress is to be made.

We will hold the Government and larger cancer charities to account around the allocation of research funding and evidence of progress.

Through our role as Secretariat of the All-Party Parliamentary Group on Brain Tumours and our position on the Steering Group of the TJBCM, Brain Tumour Research will continue to hold decision makers to account and call for increased funding to address infrastructure inadequacies and the longstanding lack of treatments available for brain tumour patients.

We will work with BRAIN UK to increase its reach across the nation, investing in the infrastructure and the regulation required for brain tumour tissue samples.

Accessible, properly categorised brain tumour tissue is an essential resource for any brain tumour researcher. Currently, not enough samples are collected from patients. Brain Tumour Research has backed fellow charity braintrust’s initiative and is funding the BRAIN UK tissue banking registry at the University of Southampton. Gains have been made in dementia, Parkinson’s disease and multiple sclerosis through Government investment in tissue banks and this should be replicated for brain tumours.

We will work with BRAIN UK to increase its reach across the nation, investing in the infrastructure and the regulation required for brain tumour tissue samples.

We call on the Government to promote drug repurposing and emerging therapies.

Brain Tumour Research continues to call for greater repurposing of drugs that have been developed for other disease areas but which may have some effectiveness against brain tumours, and urges the Government to encourage pharma and other relevant stakeholders to embrace innovative approaches to drug development and be open to emerging therapies, such as medicinal cannabis and the ketogenic diet.

We support the ambition for at least 15% of brain tumour patients to be participating in clinical trials by 2025.

The NIHR has previously reported that only 6.4% of brain tumour patients are participating in clinical trials compared to 13.3% for breast cancer and 61.4% for leukaemia. In its 2018 report, the Task and Finish Working Group on Brain Tumour Research recognised the UK for its strong performance in recruiting paediatric brain tumour patients to trials but noted the low recruitment of adult patients. While small patient numbers present a challenge to researchers, with increased investment and collaboration across existing networks – in the UK and further afield – these challenges could be overcome and the number of clinical trials available for brain tumour patients increased.
Together we will find a cure

Our Centre of Excellence Partners

Imperial College Healthcare NHS Trust

Our Member Charities

Our Fundraising Groups

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#FundingTheFight

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REFERENCES:
[9] Ibid.