

10-YEAR CANCER PLAN CONSULTATION

Submission from The Brain Tumour Charity

Introduction

The Brain Tumour Charity is the world's leading brain tumour charity and the largest dedicated funder of research into brain tumours globally. As well as investing around £38million in world-class research over the last five years, we provide specialist support services for those diagnosed, as well as their families and friends. **Our goal is twofold; to double survival and halve the harm that brain tumours have on quality of life in the UK.**

We strongly welcome the opportunity to feed into the development of the new 10-year Cancer Plan for England. Brain tumours remain the biggest cancer killer of children and adults under 40 and with 9,900 people diagnosed in England every year, so much more needs to be done. The pandemic has created both a backlog of cancer patients in the system and patients who are 'missing' because they have not presented to the NHS during the pandemic. Our analysis of the COVID-19 rapid cancer registration and treatment data (which is produced by The National Disease Registration Service) suggests the extent of these missing diagnoses for brain tumours to be just under 390 people in England in 2020 compared to 2019 diagnosis levels¹. Alongside the diagnosis backlog, we have also seen delays to patients getting the treatments they desperately need. It is hugely important that the 10-year Cancer Plan builds on ambitions committed to in the NHS Long-Term Plan and sets out a clear and innovative approach to addressing the lasting impacts of the pandemic on cancer care.

Survival rates in brain cancer remain very poor. Of the 21 most common cancers, 12 have ten-year survival rates of 50% or more, and four types – testicular cancer, malignant melanoma, prostate cancer and Hodgkin lymphoma – have survival in excess of 80%². **In contrast, just 12% of adults diagnosed with brain cancer survive five years or more, let alone to the ten year mark.** Recent data from NHS Digital also shows major variation in one-year survival of brain cancer across England, within survival in different Cancer Alliances ranging around 13 percentage points³ from 49.5% to 36.3%, the greatest variation of any cancer. This has resulted in a devastating postcode lottery of treatment and care for brain tumour patients which must be investigated further to understand the root causes, and addressed in the new Cancer Plan. While further analysis is needed to better understand the variation, the possible causes and potential solutions, if survival rates in all Cancer Alliances were brought up to that of the best performing, it is estimated that around 1600 additional people in England would survive one year after their brain tumour diagnosis, creating precious time for these patients to spend with family and loved ones.

Brain tumours are uniquely complex and require a different approach in many areas of cancer care to other cancers. Our response highlights some key areas that the plan needs to address so that outcomes for brain tumours do not fall woefully behind in the progress being made on cancer in the next 10 years.

We urge the Government to use this 10-Year Cancer Plan to outline specific commitments and targets for brain and the less survivable cancers to drive forward the transformational changes we need in diagnosis, treatments and care.

¹ Sourced from Hospital Episodes Statistics (HES), Cancer Waiting Times (CWT) and Cancer Outcomes and Services Data (COSD). Presented by Public Health England (PHE) and National Cancer Registration and Analysis Service (NCRAS) (2021) 'Rapid Cancer Registration Dataset', [online], Available at: <https://www.cancerdata.nhs.uk/covid-19/rcrd>, [Accessed 8 April 2022].

² <https://www.cancerresearchuk.org/health-professional/cancer-statistics/survival/common-cancers-compared#heading-Zero>

³ <https://committees.parliament.uk/writtenevidence/41125/pdf/>

Recommendations

1. The government must support brain tumour research in the UK by setting out an action plan for how the important and welcome £40million already pledged towards brain tumour research is to be invested in world-class research as soon as possible. We then also need to see a commitment to sustained, ongoing investment to brain tumour research once this £40million has been spent.
2. The government should commit to multi-year funding for continued cancer awareness campaigns – including working with the NHS and The Brain Tumour Charity to promote a brain tumour signs and symptoms awareness campaign.
3. In order for brain tumours to be included in the Government's stated ambitions to improve early diagnosis of cancer, we need to see clear targets established that address early detection for cancers that aren't staged in the same way, including developing proxy measures to monitor progress.
4. The government should commit to exploring whether emerging triage tools could improve prompt diagnosis of brain tumours as the evidence develops, including within community diagnostic hubs and rapid diagnostic centres.
5. The government should commit to tackling the variation in direct access for GPs to MRI and CT scans and take action to ensure all GPs have direct access to imaging for suspected brain tumours. They should also commit to tackling variation in access to 5-aminolevulinic acid (5-ALA)-guided resection to ensure all eligible patients with high-grade gliomas have access, as per the NICE Quality Statement.
6. Clarity should be provided on how the money announced in the 2021 Spending Review for NHS workforce will be spent, including for the cancer workforce. This would allow us to move towards the target of every brain tumour patient (high and low grade) having access to a Clinical Nurse Specialist (CNS) or key worker.
7. Action to ensure Holistic Needs Assessments (HNAs) are being routinely offered to brain tumour patients at diagnosis and any key changes in care, with resulting care plans put in place, is essential in ensuring that all patients receive personalised care and sufficient support.
8. Every brain tumour patient should be informed about research and given the opportunity to take part in research wherever possible.

Question

In your opinion, which of these areas would you like to see prioritised over the next decade? (You can select more than one option)

- Raising awareness of the causes of cancer and how it can be prevented
- **Raising awareness of the signs and symptoms of cancer**
- **Getting more people diagnosed quicker**
- **Improving access to and experiences of cancer treatment**
- **Improving after-care and support services for cancer patients and their families**

Delivering these priorities

Question

Do you have any suggestions for how to raise awareness of the causes of cancer and how it can be prevented?

Unfortunately, the current scientific consensus suggests the vast majority of brain tumours are not preventable. Of the factors known to increase the risk of a brain tumour, just two are thought to be

'preventable' – being overweight and exposure to ionising radiation – and these are thought to only cause a very small number of cases: it is thought that just 3% of brain tumours in the UK are preventable⁴.

While this is a small proportion, if we can act to tackle the increase in risk that being overweight can bring, we could still prevent hundreds of cases per year. When it comes to the devastating impact a brain tumour diagnosis can have, anything we can do to bring down the overall number is worthwhile. The Obesity Health Alliance's *Healthy Weight Strategy* (2021)⁵ sets out a range of evidence-led measures that Government should take over the next decade to reduce overweight and obesity and thus the risk of associated cancers including brain tumours.

The lack of understanding around the causes of brain tumours can be incredibly difficult for those diagnosed to accept. Because we cannot prevent most cases or predict or screen for the onset of brain tumours, understanding the signs and symptoms is incredibly important in ensuring more people are diagnosed promptly and can receive the support they need as soon as possible following the onset of symptoms.

With the vast majority of cases not being preventable, it is so important that funding is invested in world-class fundamental research to develop our understanding of how brain tumours develop, grow and behave, and find better ways of detecting, treating and ultimately curing brain tumours. While we have seen significant advancements in knowledge about how other cancers develop and grow to develop effective and targeted treatments, we have just not seen the same progress for brain tumours – and we need government to act.

We are incredibly grateful that the government has pledged £40million for brain tumour research over five years from 2018 to 2023; however, we know there are barriers to that money being spent and that less than 25% has been spent so far. In 2021, the All-Party Parliamentary Group on Brain Tumours launched an inquiry to help identify the barriers to greater investment in brain tumour research in the UK and to provide recommendations for how they could be addressed. We would like to see a commitment in the 10 Year Cancer Plan **for the government to set out an action plan on how it will ensure the important £40million already pledged can be invested in world-class brain tumour research as soon as possible. There also needs to be commitment to sustained, ongoing investment to brain tumour research once this £40million has been spent.**

Question

Do you have any suggestions for how to raise awareness of the signs and symptoms of cancer?

Being diagnosed with a brain tumour is devastating. Because of their location, a brain tumour of any type impacts the very essence of you: who you are and how you tick. But they are also particularly challenging to diagnose, especially as patients with brain tumours often present with vague or non-specific symptoms that can often be signs of other health conditions. Raising awareness of the signs and symptoms of brain tumours alongside investing in research into potential diagnostic and triage tools, could help ensure people receive the diagnosis, treatment and support they need at the earliest opportunity.

Symptoms can include⁶:

- Headaches
- Epileptic seizures (fits)
- Persistent nausea (feeling sick), vomiting, and drowsiness
- Changes in behaviour or personality, trouble thinking, memory problems
- Weakness, or paralysis that develops on one side of the body

⁴ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumours#heading-Three>

⁵ <http://obesityhealthalliance.org.uk/turningthetide/>

⁶ Grant, R., et al. (2020) 'Interventions to reduce the time to diagnosis of brain tumours', *Cochrane Database of Systematic Reviews*, 9.

- Problems with speech or vision

The range of non-specific symptoms, many of which also have low predictive values makes it very challenging for primary healthcare professionals to identify those who are likely to have a brain tumour and who are in need of referral for more specific testing.

Our Improving Brain Tumour Care (IBTC) survey shows the impact of this on patients as **over a quarter (28%) of respondents visited their GP three or more times with their symptoms before being diagnosed**⁷. And we know delays to diagnosis are also not uncommon for brain tumour patients; in our IBTC Survey we found that more than **2 in 10 respondents (21%) did not receive a diagnosis within 3 months. For 17% of respondents, it took over six months**⁸.

Providing continued funding for dedicated training on brain tumour symptoms for healthcare professionals (e.g. through Gateway C), including GPs and opticians, could help support those healthcare professionals to recognise the non-predictive and non-specific symptoms that often are associated with brain tumours.

This is also why it is so important that we raise awareness of the signs and symptoms to improve diagnosis time and quality of life following this. Over ten years ago, The Brain Tumour Charity established HeadSmart. Launched in partnership with the Children's Brain Tumour Research Centre at the University of Nottingham and the Royal College of Paediatrics and Child Health, and accredited by NICE, the HeadSmart campaign aimed to raise awareness of the signs and symptoms of brain tumours in children and young people and to support and equip parents, healthcare professionals and the public to recognise them as soon as possible. The campaign used a combination of tools including posters, symptom cards, campaigners writing to their MPs, and a symptom diary. The HeadSmart campaign has been a success helping to reduce childhood time diagnosis from over 13 weeks to 6.5 weeks⁹.

The Brain Tumour Charity will be re-launching a new signs and symptoms campaign for both adults and children in the near future and we would welcome the Government's support in helping more people to come forward to visit a doctor if they have potential symptoms they are concerned about.

The awareness of the signs and symptoms needs continued efforts and we strongly welcome the recent *Help Us Help You* campaigns led by the NHS. These awareness campaigns require continued investment to be maintained over time in order to see sustained and persistent improvements in diagnosis times. **The government should commit to multi-year funding for continued cancer awareness campaigns - including working with the NHS and The Brain Tumour Charity to promote a brain tumour signs and symptoms awareness campaign.**

Question

Do you have any suggestions for how to get more people diagnosed quicker?

Early diagnosis is a unique challenge for brain tumours, due to their varied and often non-specific symptoms, as well as their location in the body. Presenting symptoms, such as headaches, or cognitive and personality symptoms, may also be more commonly attributable to other conditions, such as migraine, depression or dementia. This also means that diagnosis following an emergency presentation is still relatively common for brain tumour patients. Emergency presentations can also be common because first symptoms can often be severe.

Prior to the pandemic, there was an encouraging reduction in the proportion of diagnoses resulting from following emergency presentations from 49% to 39% in the ten years between 2008 and 2018¹⁰. However, we are yet to see the full impact of the pandemic and 39% diagnoses from emergency presentation is still very high compared to other cancers. **Brain tumour emergency presentations**

⁷ Sample: 245 adults diagnosed with a brain tumour during the last 2 years.

⁸ Sample: 245 adults diagnosed with a brain tumour during the last 2 years.

⁹ Liu, J. F., *et al.* (2017). 'REDUCING TIME TO DIAGNOSIS OF PAEDIATRIC BRAIN TUMOURS IN THE UK – HEADSMART AWARENESS CAMPAIGN (WWW.HEADSMART.ORG.UK)', *Neuro-Oncology*, 19(Suppl 4), iv57. <https://doi.org/10.1093/neuonc/nox083.236>

¹⁰ NHS Digital (2022) Routes to Diagnosis, 2018. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/routes-to-diagnosis/2018#>

are the 4th highest of the 24 cancer groups¹¹. Eight of the cancers reported have diagnoses from emergency presentations of less than 10%. The percentage of diagnoses from emergency presentations for all cancers combined in 2018 was 18.5%. **Data on emergency presentations and routes to diagnosis should also be used as trackers of progress and a target to reduce emergency presentations for brain tumour diagnoses should be set.**

It is essential that all brain tumours are diagnosed at the earliest possible opportunity, with people being supported to recognise the signs and seek help if they are concerned about a potential symptom, alongside healthcare professionals being supported to identify when patients need to be referred for appropriate tests. While the NHS Long Term Plan has welcome goals for 75% of cancers to be diagnosed at stage 1 or 2 by 2030, it is unclear how and progress on early detection of brain tumours may be included in this ambition and in action to reach this target. Brain tumours act differently to other cancers and so are not staged in the same way and we know that figures on how many people are diagnosed at stage 1 or 2, provided by the NHS, are not representative for brain tumour patients. **In order for brain tumours to be included in the Government's ambitions to improve early diagnosis, we need to see clear targets that address early detection for cancers that aren't staged in the same way, including developing proxy measures to monitor progress.**

Direct access to MRI (or CT) scans for GPs is an important aspect of promoting early diagnosis^{12,13,14}. The NICE Quality Standard¹⁵ for brain tumours published in December 2021 highlighted direct access to imaging (MRI) as a means to speeding up the diagnosis process and reducing the number of outpatient appointments needed. The development of this quality statement by NICE was prompted by anecdotal evidence that direct access to imaging for GPs is variable across the UK. **The government should commit to tackling the variation in access for GPs and taking action to ensure all GPs have direct access to imaging for suspected brain tumours.**

The introduction of community diagnostic hubs and the Rapid Diagnostic Centre model is also really promising for many cancers, but whether these hubs will provide a direct benefit for those with brain tumour symptoms is currently unclear. In a pilot study¹⁶ of this approach run by Cancer Research UK, 239 diagnoses of cancer were made from 2961 referrals. Of the 239 diagnoses only one was for brain cancer (unspecified). The small sample size means we cannot draw any definitive conclusions on their benefit. **We would welcome consideration of how community diagnostic hubs could help improve brain tumour diagnosis and patients' experiences in England in future.**

Greater investment in research to better understand how brain tumours develop and grow, and the barriers to early detection, will be critical to developing new and effective interventions and tools to help get more people diagnosed quicker. Funding to develop diagnostic and triage tools specifically for brain tumours will also be vital and is desperately needed, especially because the exciting multi-cancer early detection blood test being piloted by NHS England unfortunately does not detect brain cancer. **The government should commit to exploring whether emerging triage tools could improve prompt diagnosis of brain tumours as the evidence develops,** including within community diagnostic hubs and rapid diagnostic centres.

¹¹ Ibid.

¹² Simpson, G. C., *et al.* (2010) 'Impact of GP direct-access computerised tomography (DACT) for the investigation of chronic daily headache', *British Journal of General Practice*, 897-901.

¹³ NHS (2012) 'Direct Access to Diagnostic Tests for Cancer Best Practice Referral Pathways for General Practitioners', Department of Health.

¹⁴ Kernick, D. P., *et al.* (2008) 'Imaging patients with suspected brain tumour: guidance for primary care', *British Journal of General Practice*, 58(557).

¹⁵ <https://www.nice.org.uk/guidance/qs203/chapter/Quality-statement-1-GP-direct-access-to-MRI>

¹⁶ Key messages from the evaluation of Multidisciplinary Diagnostic Centres (MDC), Cancer Research UK, https://www.cancerresearchuk.org/sites/default/files/key_messages_from_the_evaluation_of_the_mdcs.pdf. Last accessed August 2021.

Question

Do you have any suggestions for how to improve access to and experiences of cancer treatment?

All brain tumour patients should have access to the best and most appropriate care for them, including receiving holistic support tailored to their needs before, during and after treatment.

For many brain cancer patients, however, the treatment options remain limited – and survival rates overall are still worryingly low with just 12% of adults diagnosed with brain cancer surviving five years or more. So as well as improving access to existing treatments and care for brain tumour patients, it is critical we focus on developing the new innovative treatments we need to improve survival. That's why we believe an action plan for how the £40million pledged can be invested in world-class brain tumour research as soon as possible, is essential and must be prioritised. This should include how the current barriers to funding will be overcome and will ultimately help us better understand the disease, develop more effective treatments and help to improve quality of life. There also needs to then be commitment to sustained, ongoing investment into brain tumour research once this initial £40million has been spent.

Where there are treatments or interventions, access to them can be patchy across the country. It is recommended that eligible patients with high-grade gliomas should have access to 5-aminolevulinic acid (5-ALA)-guided resection as set out in the NICE Quality Standard (NG99, 1.2.36)¹⁷ for brain tumours, and then highlighted as an area for quality improvement in a new NICE Quality Standard¹⁸, published in December 2021. The development of this quality statement was prompted by the anecdotal evidence that access to 5-ALA is variable across the UK. Although it is not possible to cure high-grade gliomas, 5-ALA-guided resection is more likely to result in complete or near-complete removal of the tumour and improves progression-free survival, and **therefore this should be provided to all eligible patients.**

When it comes to improving the experiences of treatment, a Clinical Nurse Specialist (CNS) can be essential in helping patients better understand, coordinate and advocate for their care needs. It is already recommended by NICE that “adults with brain tumours have a named healthcare professional who coordinates their health and social care support”¹⁹. This is because of the recognition that the care surrounding brain tumours is incredibly complex to coordinate.

However, we unfortunately know that access to this can vary. Only 79% of respondents to our IBTC survey said they were given access to a CNS or a keyworker²⁰ and the survey showed a 30 percentage point range between Cancer Alliances in England in access to a CNS²¹, meaning there is a significant ‘postcode lottery’. It is crucial to improving care that **every brain tumour patient (whether they have a high- or low- tumour grade) has access to a Clinical Nurse Specialist (CNS) or key worker, no matter where they live**, who is able to explain treatments and answer any ongoing questions.

In order for this to happen, there needs to be clarity on how the welcome investment announced in the 2021 Spending review for NHS workforce will be spent, including for the cancer workforce. Regular workforce projections should be published with a duty on the Secretary of State for Health and Social Care to respond to these projections.

Research is absolutely essential to enable developments in improving cancer prevention, diagnosis and treatment, but it is also key in achieving the goal of meeting the needs of those affected by brain tumours. Accessing clinical trials gives patients the opportunity to access potentially helpful or life prolonging treatments they wouldn't otherwise have access to. However, we know from our IBTC survey that many patients are not informed about research participation opportunities, with only 42% of respondents to our survey stating they had been informed about potential opportunities²². Increasing the proportion of brain tumour patients who are given the opportunity to participate in research could

¹⁷ <https://www.nice.org.uk/guidance/ng99/chapter/recommendations>, 1.2.36

¹⁸ <https://www.nice.org.uk/guidance/qs203/chapter/Quality-statement-3-5-aminolevulinic-acid-guided-resection>

¹⁹ <https://www.nice.org.uk/guidance/qs203/chapter/Quality-statement-2-Named-healthcare-professional>

²⁰ Sample: 1487 adults diagnosed or in active treatment for a brain tumour during the last 2 years.

²¹ Sample: 1467 adults diagnosed or in active treatment for a brain tumour during the last 2 years.

²² Sample: 911 adults diagnosed or in active treatment for a brain tumour during the last 2 years.

not only help benefit those currently undergoing treatment, but could accelerate progress into prevention, diagnosis and treatment. **That's why widening access to research, so that people with brain tumours have the opportunity to be involved across the care whole pathway, is so important. People diagnosed with a brain tumour should be given the opportunity to take part in clinical trials wherever possible.**

With such limited treatment options available for brain tumours, it is vital that we continue to innovate and explore all of the tools available to the NHS, leaving no stone unturned. Research into repurposing drugs for other uses than they were originally developed has shown great promise in finding effective and safe ways to treat some cancers – and drugs being used to treat coronavirus are another example of drug repurposing. Where these drugs are off-patent they are often cheap. The AntiCancer Fund produces a database of all the drug repurposing clinical trials in oncology, which contains over 800 active clinical trials including 72 for Central Nervous System tumours.

We hope that this avenue of research will eventually lead to effective new treatment options for brain tumour patients – however, it can take a huge amount of time and effort for repurposed drugs to consistently be made routinely available to patients. NHS England launched a Medicines Repurposing Programme in 2021 in partnership with the DHSC, NICE, NIHR and MHRA. It is implementing some of the solutions set out in a report, published in 2017 by the Association of Medical Research Charities (AMRC), such as working with generic manufacturers to apply to add additional indications to licences and developing commissioning policies for repurposed drugs. **It is vital that the Medicines Repurposing Programme has the funding and cross-agency support to continue its work, particularly given the potential scale of drug repurposing in oncology.**

Question

Do you have any suggestions for how to improve after-care and support services for cancer patients and their families?

Signposting to after-care and support services for brain tumour patients is worryingly lacking. We know that so many people affected by brain tumours have significant unmet needs during and after their treatment, and this needs to be addressed. Our IBTC survey showed us that **one in five respondents didn't understand what to expect of recovery after treatment**²³. Only half of respondents were signposted to emotional support or counselling, only 55% were connected to support charities and only 32% were signposted to financial and benefits support²⁴.

Holistic Needs Assessments (HNAs) are an extremely important tool for ensuring patients' needs are met and identifying areas where extra support is required. This activity is often carried out by a CNS, making the importance of access to a CNS or keyworker linked with the provision of HNAs and, as such, access to wider support. The provision of a HNA and resulting care plan is essential for good patient experience, and in ensuring that the patient is supported in all aspects of their treatment and care, particularly through signposting and referring to other services. This can include interventions such as access to counselling, financial support and signposting to other charities for support.

However, many patients are missing out on such a crucial element of successful after-care and support services. We found that only 40% of respondents to our IBTC survey were offered a HNA and only 21% of respondents who did have a plan, felt that it was working well²⁵. Even more worrying was that we found a 48 percentage point range between Cancer Alliances in England in patients being offered a HNA²⁶, representing significant variation across England. This is extremely concerning, and shows that many brain tumour patients have needs that are not being identified or addressed and lack the signposting to the support they require. **A commitment to action to ensure HNAs are being routinely offered to brain tumour patients at diagnosis and any key changes in care, with**

²³ Sample: 686 adults diagnosed or in active treatment for a brain tumour during the last 2 years.

²⁴ Sample: 350 adults diagnosed or in active treatment for a brain tumour during the last 2 years.

²⁵ Sample: 1158 adults diagnosed or in active treatment for a brain tumour during the last 2 years.

²⁶ Sample: 1066 adults diagnosed or in active treatment for a brain tumour during the last 2 years.

resulting care plans put in place, is essential in ensuring that all patients receive personalised care and sufficient support.

Brain tumours are incredibly complex and treatments can be gruelling. Where an individual does receive curative treatment, the impact of the disease often unfortunately does not end when their treatment ends. Later effects such as learning and cognitive difficulties, or permanent disabilities can occur, that the individual and their family often need support managing. These late effects need to be considered early in a person's treatment, and access to support and care packages should be in place for as long as necessary in that individual's life.

Improving data and translating research into practice

Question

Do you have any suggestions for how can we maximise the impact of research and data regarding cancer and cancer services in England, including how we can translate research and data into practice sooner?

Patient data is crucial in providing insights to advance medical research and holds significant potential to deliver benefit to patients, as well as measure progress. We need an increase of good quality research and data in order to increase the knowledge and understanding of brain tumours, accelerate new treatments, and enhance quality of life through evidence-based supportive care. This data needs to be granular to be meaningful, as the impact of brain tumours is so varied depending on type and location in the brain.

Tools like the BRAIN App (Brain tumouR Information and Analysis Network) have a major role to play in harnessing the power of medical and clinical data and patient-reported quality of life information. It is therefore important that these tools and the generated datasets are available in a safe, ethical and responsible manner to researchers, clinicians and patients, in order to help drive improvements in quality of life and accelerate progress towards cures.

Accessing national healthcare datasets, as provided by NHS Digital, is currently costly and can be time-consuming, and there are often mistakes, errors, poor coverage of certain pieces of information and inconsistencies in clinical coding and reporting practices between trusts, which makes trends harder to understand. Access to data and assurance of data quality are key, alongside ensuring accurate linkage of complimentary datasets and making it easier to request additional aspects of data. Greater transparency over the outcomes of every clinical encounter as well as over the technology and services employed in different hospitals would enhance the research value of the data.

It is also essential to improve the process for collecting data, giving consideration to the information required for research.

We would also encourage 31 day waiting time data by month to be reported for brain/CNS cancer as it is for some other cancers, potentially at a national level instead of at hospital trust level so that the risk of disclosure due to small numbers is avoided. This would provide an understanding of the current situation for brain tumour patients in regards to the experience of patients and how long they may be waiting for their treatment to begin following diagnosis. Being able to access comprehensive and consistent data will provide crucial insights to both move towards and measure progress on our goals of doubling survival and halving the harm of brain tumours.

Facilitating collaboration brings together the skills and knowledge of researchers from across the world and from different disciplines, in order to drive innovation in scientific discovery and avoid duplication of effort. A trusted research environment is vital, it could be easier to link data and grant researchers access to the data they require in a timelier manner.

It is essential that research funding into brain tumours is increased in order to grow our knowledge and understanding of brain tumours, accelerate new treatments, and enhance quality of life through evidence-based supportive care. And that's exactly what The Brain Tumour Charity's new research strategy, *Accelerating a Cure*²⁷, looks to achieve.

As stated previously, we are incredibly grateful that the government pledged £40million for brain tumour research over five years from 2018 to 2023; however, we know there are barriers to that money being spent and that less than 25% has been spent so far. In 2021, the All-Party Parliamentary Group on Brain Tumours launched an Inquiry to help identify the barriers to greater investment in brain tumour research in the UK and to provide recommendations for how they could be addressed. We would like to see a commitment in the 10 Year Cancer Plan **for the government to set out an action plan on how it will ensure the important £40million already pledged can be invested in world-class brain tumour research as soon as possible. There also needs to then be commitment to sustained, ongoing investment into brain tumour research once this initial £40million has been spent.**

For further information or questions please email the Policy Team at policy@thebraintumourcharity.org

²⁷ <https://thebraintumourcharity.pagetiger.com/acceleratingacure>