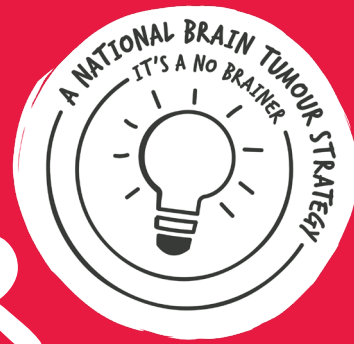


A NATIONAL BRAIN TUMOUR STRATEGY: IT'S A NO BRAINER



For years, people diagnosed with a brain tumour have been falling through the cracks. This can range from multiple misdiagnoses and trips to GPs, to undergoing harsh treatments that haven't changed in decades, or not having access to the support they are entitled to from an allocated Clinical Nurse Specialist (CNS).

There are issues along the entire pathway that we need to solve – including diagnosis, support, treatment and research.

These can only be tackled through systematic change and a comprehensive National Brain Tumour Strategy that covers the whole pathway.

Brain tumours often fall into the 'too difficult' pile due to the nature of the diseaseⁱ. But they are not just one disease; there are more than 120 different types of brain and central nervous system tumoursⁱⁱ. These can be high grade, or low grade (non-malignantⁱⁱⁱ), and as a result this disease does not sit neatly in the cancer nor the rare disease world. Because of the differences in how brain cancers start, develop and are tracked, compared to other cancers, they are often missed by NHS cancer programmes.

49%

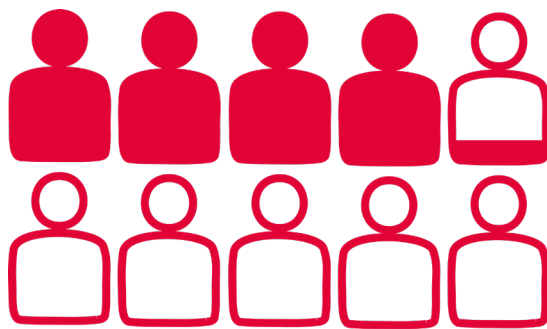
Nearly half (49%)^{iv} of the brain tumour population are neglected in these programmes because they are not diagnosed with a cancerous tumour.

Despite being called "low grade", these tumours are still devastating, and the treatment and care of these, and subsequent long-lasting impacts, can be life altering.

To tackle the broad range of challenges to our community, we need the government to take action by:

Committing to developing a National Brain Tumour Strategy, alongside the devolved nations, that tackles the barriers facing our community in diagnosis, care, treatment and research^{1 2}

A faster, more efficient diagnosis



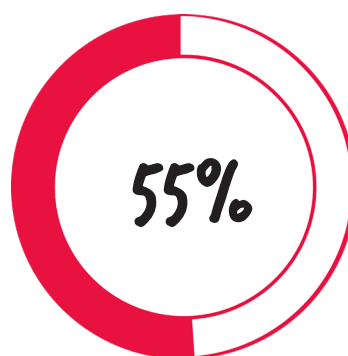
41% of respondents to our Improving Brain Tumour Care (IBTC) surveys said they visited their GP three or more times before getting a diagnosis.^{vi}

Many people with a brain tumour have a lengthy and unsupported diagnosis experience. A national strategy is needed to ensure that every person with a suspected brain tumour has a faster diagnosis.

We know that having a faster diagnosis can open up more options for patients and their families to receive sufficient support. Detecting brain tumours faster can widen the scope of research participation options, can reduce the severity of symptoms, as well as patients being able to better withstand harsh treatments and reduce the need for emergency, higher risk surgery.

Detection of a brain tumour can be difficult. With over 120 different types of tumours, many of which present with vague, non-specific symptoms. Many patients visit their GP multiple times and have often been misdiagnosed before being sent for a referral.

**MORE THAN
12,000
PEOPLE
in the UK are
diagnosed with a
brain tumour every
year, that's
34 PEOPLE
A DAY.^v**



55% of respondents to our Improving Brain Tumour Care surveys reported that their child's brain tumour was originally diagnosed as something else first.^{vii}

Falling through the gaps in policy

Previous actions from the NHS and the Government have not sufficiently addressed patients with brain tumours falling through gaps in the system.

Current targets for early diagnosis, screening and preventative care do not apply to brain tumours.

Brain tumours are unique from most other cancers and rare diseases in that they do not behave in the same way. Rather than being staged like most other cancer types, brain tumours are graded 1-4. Cancer staging describes the spread and metastases of a cancer around the body. However, brain tumours very rarely spread outside of the brain or central nervous system, so they cannot be staged in the same way. This means that initiatives and targets to improve diagnosis at an earlier stage are not as relevant to brain tumours.

Currently, the only way to diagnose a brain tumour is through an MRI or CT scan. Although imaging scans can be accessed through primary care direct access programmes and through community diagnostic centres, many people are still not getting a fast and efficient diagnosis.

There are national measures in place to ensure that patients receive a timely diagnosis, one of which is the NHS Faster Diagnosis Standard. The standard sets a target of 28 days for the time patients have to wait between having an urgent cancer GP referral and receiving a diagnosis. While the Faster Diagnosis Standard reveals some insight into the experience of people with a suspected brain tumour, it does not cover all routes to diagnosis.

It only covers diagnoses made through standard cancer pathways, and we know that a large number of diagnoses for brain tumours are made outside of these pathways, for example through emergency presentation. Therefore, while we are, in theory, meeting the Faster Diagnosis Standards, in practice, we know that there is a large group of patients who are not receiving a timely diagnosis.



In England, 47% of patients were diagnosed with a cancerous brain tumour through emergency presentation (A&E, Emergency GP and other emergency routes), in comparison to 18.5% for all cancers.^{viii}

To ensure an effective, fast diagnosis, we want a National Brain Tumour Strategy to:

Develop a new optimal diagnostic pathway across all four devolved nations, ensuring everyone receives a fast and efficient diagnosis of a brain tumour.



Essential care for all



“WE STILL DON'T REALLY KNOW WHAT TO EXPECT FROM THE FUTURE APART FROM A SHORT LIFESPAN”

(Quote from respondent to our Improving Brain Tumour Care Survey^{ix)})

Around **88,000 people** across the UK are living with a brain tumour. Patients and their families tell us that more can be done to provide better care and support in getting their diagnosis, understand their treatment and care plans, and provide them with advice and better holistic support during after care and palliative care where needed.

37% were not told about their diagnosis in a sensitive manner

85% felt they had unmet needs

59% felt they needed more help in understanding their brain tumour

(of the respondents to our Improving Brain Tumour Care survey)^x

Person-centred care is crucial for all patients with a brain tumour. Because of the location of brain tumours, they can impact people in a multitude of ways. Not only do patients and their families need to comprehend the physical symptoms, including sight loss, speech loss, and/or seizures, and the aggressive side effects of surgery and treatment, but they are often left navigating the additional impacts of their tumour that are span beyond physical. We know from the people we support, and from previous reports, that there can be personality changes which can be difficult to deal with as well as the social, financial and emotional aspects that can have a significant impact on quality of life for them and those around them.^{xi}

Falling through the gaps in care

Current cancer and rare disease policies emphasise taking a whole-person approach to care. Both the NHS Long Term Plan^{xii} and the interim Major Conditions Strategy^{xiii} commit to ensuring care and treatment are better coordinated and integrated with the life individuals want to lead. They also commit to providing all cancer patients access to expertise and support through a dedicated Clinical Nurse Specialist (CNS) and a Holistic Needs Assessment (HNA). But we know that for our community (patients with both high and low grade tumours), their needs often go unmet and care is not personalised.

58%

58% needed more support managing the symptoms/side effects of their brain tumour

58%

58% needed more support coping with the emotional effects



65%

65% were not told about rehabilitation support



41%

and 41% were not told about support from charities.

(of the respondents to our Improving Brain Tumour Care survey)^{xiv}

The postcode lottery of care

Accessing the best support and care should not depend on where you live. Yet we know that there is a postcode lottery when it comes to brain tumour care and treatment. A national strategy will ensure that there is a standard best practice for care across each country, where everyone will receive the highest quality, wrap around support from the first signs of a brain tumour, continuing right throughout their pathway.

There is major variation across England in experience and outcomes for patients with brain tumours. Across Cancer Alliances, the one-year survival rate ranges from 49.4% to 37.2%.^{xv}

The Tessa Jowell Brain Cancer Mission report highlights a significant variation across 28 NHS brain cancer centres in the UK. they found substantial difference in service access, patient support, symptom management and patient quality of life services.^{xvi}

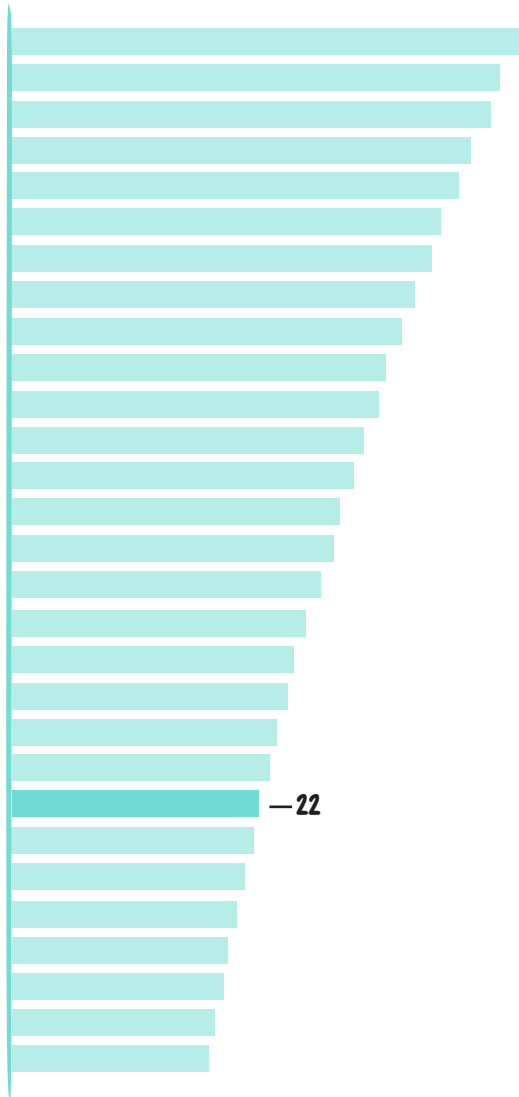
This must change. A National Brain Tumour Strategy is needed to:

Ensure every brain tumour patient and their family has good access to wraparound support, meeting all of their collective needs.





Access to new and better treatments



The UK ranks 22nd out of 29 comparable countries for survival of a brain tumour.^{xvii}

Standard NHS treatment for brain tumours, for both adults and children, has not changed significantly for more than 20 years.

When comparing the innovations in treatment options for other cancer types, the options for brain tumour patients today are very limited.

Our BrainBank describe brain tumours, particularly glioblastomas (the most aggressive type of tumour) as ‘the neglected disease in the cancer treatment revolution’.^{xviii}

Falling through the gaps in treatment options

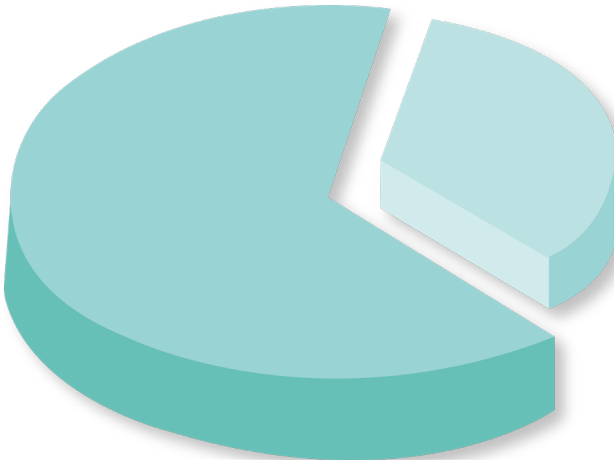
Brain tumours can be complicated to treat, as depending on their specific location in the brain, interference can be dangerous. Additionally, some drugs cannot cross the blood brain barrier – the membrane that protects the brain from harmful substances in the blood – which means it is challenging to repurpose drugs used for other cancers.

Participating in potentially life prolonging research is vital to understand brain tumours, improve early diagnostics techniques, and to advance treatments. This is the only way to make a real impactful change on people’s quality of life and to find a cure.

However, The Institute of Cancer Research suggests that brain tumour clinical trials have the lowest recruitment levels.^{xix}

There are some emerging treatments for brain tumours that are being explored in academic and industry research teams both in the UK and internationally.

ShapeEmerging treatment areas include the use of immunotherapies, tumour treating fields, and personalised medicines, as well as the use of cannabinoids in the ARISTOCRAT trial^{xx} to reduce the impact on quality of life while undergoing hars



60% of childhood survivors of brain cancer can't live independently^{.xxi}

Looking internationally where more treatments have been approved and included in the standard of care, it may highlight that there are a number of systematic barriers preventing new treatments from becoming available to NHS patients in the UK.

The UK needs to ensure that it remains a global life sciences hub, and this means a robust, and fast assessment system that enables new treatments to get to patients with a brain tumour as quick as is safe.

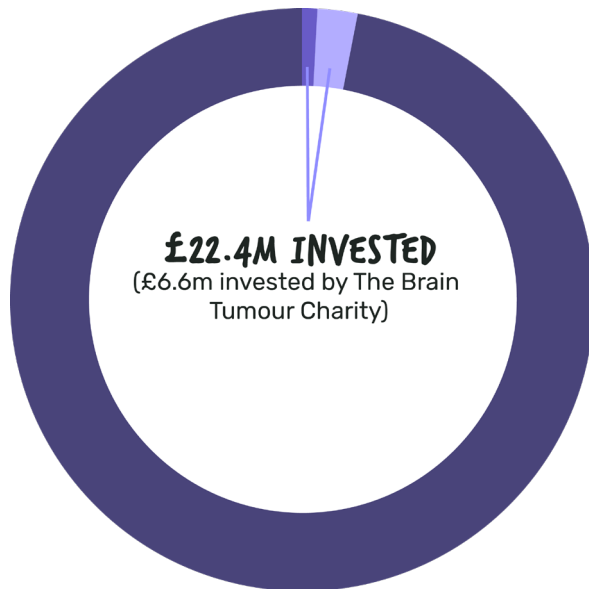
A National Brain Tumour Strategy is needed to get patients the treatments they need.
To get to this point we want to see:

Every brain tumour patient being offered the chance to participate in clinical trials.





Increased pioneering research



Research into brain tumours is chronically underfunded and under resourced. 3.2% (£22.4m) of the over £700 million invested in UK cancer research funding in 2019/20 was spent on brain tumours (this percent includes £6.6m of spending by The Brain Tumour Charity).^{xxii}

We also know that funding is not the only barrier to overcome. Current government funding that has been allocated is not being adequately spent on high-quality research proposals.

£40million of government funding was allocated to research into brain tumours in 2018. An inquiry by the APPG for Brain Tumours reported a concerning lack of grant deployment to researchers and identified a list of recommendations on how to ensure a properly resourced pathway to a cure for brain tumours.^{xxiii}

There is innovative research being conducted, but we need more to push forward faster. Current research with genetics and the biology of brain tumours is increasing our understanding of the development of the tumours, which in turn, helps to identify new ways to diagnose and treat tumours. However, there are still gaps. For example, the advancement from low grade to high grade tumours is still not yet well understood.

There are also large gaps in translational research – translating laboratory discoveries into new effective treatments for patients, extending survival and improving quality of life. There are significant delays in translating laboratory research to clinical trials, and even further delays from clinical trials to medical regulatory approval. This means that brain tumour patients today are missing out on promising new treatments.

A National Brain Tumour Strategy can help support these advancements in research. For the UK to continue being a life science hub, we want to see:

Research into brain tumours recognised as a clinical priority alongside a strategic plan for adequately resourcing and funding for discovery, translational and clinical research.





A NATIONAL BRAIN TUMOUR STRATEGY IS A NO BRAINER

Brain tumours can no longer fall under the 'too difficult' pile. We've highlighted some of the areas across the entire pathway that we need to solve now.

The challenges across diagnosis, care, access to treatments and research can only be tackled through systematic change.

We need the Government to take action, alongside the devolved nations, to commit to a comprehensive National Brain Tumour Strategy that covers this whole pathway of care and research.

- **Develop a new optimal diagnostic pathway across all four devolved nations, ensuring everyone receives a fast and efficient diagnosis of a brain tumour.**
- **Ensure every brain tumour patient and their family has good access to wraparound support, meeting all of their collective needs.**
- **Every brain tumour patient being offered the chance to participate in clinical trials.**
- **Research into brain tumours recognised as a clinical priority alongside a strategic plan for adequately resourcing and funding for discovery, translational and clinical research.**

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