

LET'S DELIVER CHANGE FOR PEOPLE AFFECTED BY BRAIN TUMOURS IN SCOTLAND

Brain tumours are the biggest cancer killer of those under 40 in the UK. Each year, over 1,000 people will be diagnosed with a brain tumour across Scotland. Across the patient pathway, people affected by brain tumours encounter challenges - 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.

Brain tumour patients, particularly those diagnosed with high grade or cancerous brain tumours, also fall behind in survival rates. Around 40% of adults diagnosed with a high grade brain tumour survive for one year or more, and only 12.9% will survive for five years or longer. According to previous data published by the Less Survivable Cancers Taskforce (2024) **Scotland ranked 24th out of 33 comparable countries in terms of brain tumour survival.**¹

Brain tumour patients face slow diagnosis, limited treatment options, and poor access to clinical trials compared with other cancers. We must do better. In Scotland, The Brain Tumour Charity and its Scottish Steering Committee (SSC) are leading efforts to advocate for delivering such change.

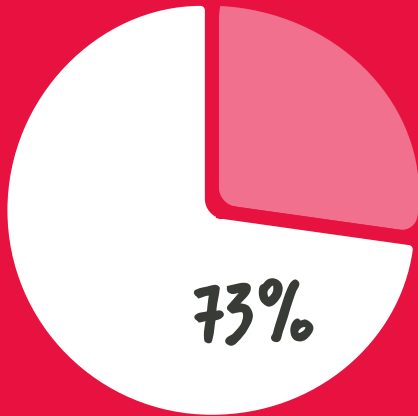
These challenges can be overcome and there is room for optimism. This briefing outlines some of the core challenges the brain tumour community faces in Scotland and how they can be addressed through systematic change and strategic leadership in the form of a National Brain Tumour Strategy.



Brain tumour survival rates by country



A NEED FOR A FASTER, BETTER DIAGNOSIS



In Scotland, the most recent data shows that 73% of brain cancer patients were diagnosed through emergency presentation (2022), the highest of any cancer type.²

41% of respondents to our Improving Brain Tumour Care (IBTC) surveys said they visited their GP three or more times before getting a diagnosis (across the UK).³

Founded in 2018 following a roundtable event in the Scottish Parliament building, The Brain Tumour Charity's Scottish Steering Committee was established to represent those affected by brain tumours in Scotland and to drive and inform the Charity's advocacy efforts.

In Scotland, 73% of brain cancer patients are diagnosed via emergency presentation. This is the highest of any cancer type and compares to 46% of brain cancer patients being diagnosed via emergency presentation in England⁴ and 62% in Northern Ireland⁵.

Detection of a brain tumour can be difficult. With over 100 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.

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. In having a faster diagnosis patients and their families will also have available to them a wider range of support options both locally and nationally.

To support our advocacy efforts, The Brain Tumour Charity has a Scottish Steering Committee (SSC) which is made up of community members based in Scotland. Last year, SSC members chose to focus on delivering a faster, better diagnosis for those impacted by brain tumours.

Achieving this through:

Improving referral pathways for those presenting with brain tumour signs and symptoms.

Embedding innovation in diagnosis across Scotland.

Reducing the number of diagnoses in an emergency setting in Scotland

We're currently gathering and seeking information on why the emergency presentation figure is so high in Scotland and whether this is a major point of concern. We've had good engagement with stakeholders across Scotland but need more data to draw effective conclusions to the information we've gathered so far.

There's hope that a faster, better diagnosis can be delivered. New referral pathways are being established, and promising diagnostic tools are being developed, some of which are being led by Scottish based innovators. We'd be happy to share more information on any of the above if of interest.



Falling through the gaps in policy

Previous actions from NHS Scotland and the Scottish 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 differ fundamentally from most other cancers in their behaviour and classification. Rather than being staged by spread or metastasis, they're graded 1-4 based on tumour biology and aggressiveness. As brain tumours rarely spread beyond the brain or central nervous system, traditional cancer staging - and thereby associated early-diagnosis targets - aren't applicable. This creates a mismatch between existing cancer policy frameworks and the realities of brain tumour diagnosis, highlighting the need for more tailored approaches.

Brain tumours must become a tracked cancer type so that diagnosis improvements can be consistently monitored by health boards across Scotland. We previously welcomed the commitment made in the Cancer Strategy for Scotland to explore the creation of a proxy measure for non-stageable cancer types.⁶

It's vital that conversations to create such a measure are continued. The cancer plan for England commits to the publishing of regular data on the number of blood

and brain cancer patients diagnosed in emergency settings which will act as a proxy for late or ineffective diagnosis.⁷ This is set to act as a metric to help incentivise systems and providers to focus on faster diagnosis of non-stageable cancers.

Scotland must similarly explore and agree a suitable alternative proxy measure, ensuring that people with brain tumours aren't disadvantaged by the absence of comparable metrics and accountability. Without this, there is a risk that Scottish patients encounter a less responsive and effective diagnostic system than their counterparts in England.

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 Rapid Cancer Diagnostic Centres, many people are still not getting a fast and efficient diagnosis.

To ensure an effective, fast diagnosis, we need to:



Confirm and establish a proxy measure to enable brain tumours to be included in earlier, faster diagnosis metrics across Scotland.



Develop a new optimal diagnostic pathway for brain tumours in Scotland, ensuring everyone receives a fast and efficient diagnosis of a brain tumour.



Publish more holistic data to understand how and where people with brain tumours are being diagnosed.



Pilot diagnostic tools to help support primary care professionals with the detection of vague and non-specific symptoms associated with brain tumours.

ESSENTIAL CARE AND SUPPORT FOR ALL

Person-centred care is essential for everyone affected by a brain tumour. Because of their location, brain tumours can have wide-ranging and often unpredictable impacts on people's lives.

Patients and their families must not only manage complex physical symptoms - such as loss of vision or speech, seizures and the significant side-effects of surgery and treatment - but also navigate profound cognitive, emotional and behavioural changes. These non-physical impacts can affect personality, relationships, independence and mental well-being, and require care and support that extends beyond traditional clinical pathways.

We know from the people we support, and from exploratory research, 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.⁸

In December 2025, The Brain Tumour Charity published a report examining the full economic impact of a brain tumour diagnosis. It found that cases diagnosed in 2025 alone created a financial

burden of £18.7 billion across the UK, including just over £1.6 billion in Scotland.⁹ This reflects not only the direct costs to health and care services, but the wider and often overlooked societal costs associated with brain tumours.

This high overall burden is driven by a combination of low survival rates, the significant long-term and often disabling effects experienced by many who do survive, and the broader economic consequences of reduced workforce participation, informal caring responsibilities and premature mortality. On average, each primary brain tumour diagnosed in 2025 is associated with a lifetime cost exceeding £1.4 million, underlining the scale of impact for every individual affected.

Crucially, much of this burden does not fall on the NHS, but is borne by individuals, families, carers and the wider economy. This includes lost productivity, increased reliance on welfare support, and the lasting loss of health, independence and quality of life. These figures represent real and often sudden disruptions: a child missing out on education, a working adult forced to leave employment, or a family absorbing the emotional and financial impact of care and bereavement.



£1.6 BILLION in Scotland

£18.7 BILLION across the UK

New brain tumour diagnoses alone in 2025 created a financial burden of £18.7 billion across the UK (£1.6 billion in Scotland) – driven by low survival; long term effects of a brain tumour; and wider losses from reduced earnings, ongoing care needs, and premature death.¹⁰



Falling through the gaps in policy

Current cancer and rare disease policies emphasise taking a whole-person approach to care. The Cancer Strategy for Scotland¹¹ and Neurological Care and Support in Scotland framework¹² committed to ensuring care and treatment are better coordinated and integrated with the life individuals want to lead.

The Cancer Strategy also commits 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, their needs often go unmet and care is not personalised.

This isn't the fault of the incredible neuro-oncology workforce who are working under constrained conditions. The Brain Tumour Charity has mapped that there are around 10 neuro-oncology Clinical Nurse Specialists (CNS) across Scotland, with approximately eight working full time within neuro-oncology. Meanwhile, there are notable gaps in service provision. For example, Dundee - one of the UK's 30 major neuroscience centres - has no neuro-surgical CNS cover, and a key oncology centre in Inverness has no CNS provision at all.

Furthermore, those affected by brain tumours in Scotland continue to face challenges with accessing Whole Genome Sequencing. A report published by The Tessa Jowell Brain Cancer Mission highlighted that Scotland is falling behind the other nations of the United Kingdom in enabling patients to have their genomes sequenced.¹³

Scotland's Neuro-Oncology CNS workforce is limited, with a small team of full-time and part-time staff delivering and coordinating care across a national service.

This must change. Action is needed to:

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



UNLOCKING INNOVATION



Scotland ranks 24th out of 33 comparable countries for survival of a brain tumour.¹⁴

Standard NHS treatment for brain tumours, for both adults and children, has not changed significantly for decades – though progress is being made with the approval of vorasidenib for particular low grade glioma types as well as dabrafenib and trametinib for certain paediatric tumours.

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

Lack of progress related to new treatment options impacts patients in a multitude of ways. For instance, data shared by GoFundMe exclusively for The Brain Tumour Charity's Unlocking Innovation report indicated that 1 in 10 brain tumour fundraisers on the platform specifically mention seeking medical intervention overseas.¹⁵

Our report examined how we can better enable the development, approval and adoption of brain tumour related innovations across the health system. Previously the Scottish government made promising statements around the importance of developing and delivering innovation to improve the health of the nation. But whether this ambition can be realised for complex, rare and less survivable conditions such as brain tumours is a critical test of delivery.

It must be determined whether current cost-effectiveness thresholds used by the Scottish Medicines Consortium are adequate for complex and rare conditions like brain tumours. Current measurements rely on Quality Adjusted Life Years which often fail to include the wider impact an innovation may have on a community. Moreover, it should be examined as to whether a more flexible cost threshold could be a catalyst for securing more investment into the life science industry in Scotland which would benefit not only the patient themselves but the wider economy.

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 of any cancer type.¹⁶

Scotland has a strong research base and world-class universities. Researchers in Scotland are leading the way with innovations such as the development of a possibly game-changing blood test¹⁷ to help support the diagnosis of brain tumours and a gene therapy which may comprehensively tackle glioblastoma¹⁸ (the most common high grade primary brain tumour) if successful.

However, to sustain its position as a leading life sciences innovation hub, Scotland must ensure that its assessment and adoption pathways are faster and more responsive. This is particularly important for enabling new treatments for people with rarer and more complex conditions to reach patients as quickly and safely as possible, while continuing to uphold robust and proportionate standards of evidence.

We want to see:

That where possible, every eligible patient with a brain tumour is offered genomic profiling to advance personalised treatment and research opportunities.

Health Technology Assessment bodies introduce a sliding scale of acceptable cost-effectiveness levels between routine appraisals and Highly Specialised Technologies.

GROUNDBREAKING 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).¹⁹

Information requested through a parliamentary question by the Less Survivable Cancers Taskforce showed that the Scottish government's Chief Scientist Office (CSO) funded almost £350,000 into brain cancer research in 2025 – broadly comparable to funding for oesophageal and pancreatic cancer, two of the other less survivable cancers.²⁰

In a constrained funding environment, Scotland's greatest opportunity may lie in leveraging its unique strengths – a smaller, unified National Health Service alongside strong research institutions within one of the biggest life science clusters in Europe. We need to see these strengths being utilised to tackle the biggest cancer killer of those under 40.

Amount of brain cancer research funding awarded through the Chief Scientist Office since 2022:

2023	£299,918
2024	£340,000
2025	£349,033

While innovative brain tumour research is underway, significantly greater progress is needed, and at pace. Advances in genetics and tumour biology are improving our understanding of how brain tumours develop and evolve, helping to identify new approaches to diagnosis and treatment. However, major knowledge gaps remain. In particular, the mechanisms that drive progression from low grade

to high grade tumours are still poorly understood, limiting opportunities for earlier intervention and more effective treatment.

There are also substantial gaps in translational research – the process of turning laboratory discoveries into effective treatments for patients. Delays persist at every stage, from pre-clinical research to clinical trials, and from trials through to regulatory approval. These lengthy timelines mean that people living with brain tumours are too often unable to benefit from promising innovations, resulting in lost opportunities to extend survival and improve quality of life.

This year (2026), the Rare Cancers Act was established by the UK Parliament – part of the acts aim is to incentivise research into rarer forms of cancer. We join our Less Survivable Cancer Taskforce colleagues in calling for the principles of the Rare Cancers Bill to be implemented in Scotland by appointing a government lead for rare and less survivable cancers to develop a strategic mission, review funding barriers, and coordinate UK-wide initiatives.²¹

Ultimately, the patient pathway must be viewed as a connected system. Faster, better diagnosis can increase opportunities for patients to participate in research, but this is only possible if clinical trials are accessible and supported by adequate workforce capacity and research infrastructure. With its strong academic base and integrated health system, Scotland is well placed to lead the change needed – accelerating research, improving access to innovation and delivering better outcomes for people affected by brain tumours.

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.

WE NEED YOUR SUPPORT

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.

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

We need the Scottish government to act and commit to delivering effective change that covers the whole pathway of care and research. Please support us in pushing towards our aims to tackle this exceptional disease of unmet need.

Our asks include:



Meeting with us to find out about challenges that are faced and how we can overcome them and become a brain tumour parliamentary champion.



Considering submitting Parliamentary Questions to understand how the Scottish government is tackling brain tumours and improving outcomes and quality of life for those affected.



Joining our call for the creation of a dedicated Scottish brain tumour strategy to comprehensively overcome challenges related to this disease.



About us

The Brain Tumour Charity is the largest dedicated funder of research into brain tumours globally.

Committed to saving and improving lives, we're moving further, faster to help every single person affected by a brain tumour. We're set on finding new treatments, offering the highest level of support and driving urgent change.

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