### The Brain Tumour Charity’s response to the mini-inquiry into earlier detection and faster diagnosis of the less survivable cancers

### All-Party Parliamentary Group on Less Survivable Cancers

[The Brain Tumour Charity](https://www.thebraintumourcharity.org/) is the largest dedicated funder of research into brain tumours globally. As a charity we fund new, innovative research, as well as offering support through a dedicated support team, and advocating for necessary change to improve the lives of those affected by this disease.

We welcome the opportunity to submit to this mini-inquiry to highlight the unique differences and barriers in the diagnosis of brain tumours.

### Why is a faster diagnosis important for brain tumours

From [our research and feedback with our community](https://assets.thebraintumourcharity.org/live/uploads/2023/03/Faster-diagnosis-Its-importance-and-how-it-can-be-achieved-final.pdf?_gl=1*jaoyi0*_gcl_au*ODE1NjQ3OTA1LjE3MzczNjM5ODU.*_ga*MTY2NDAwMzQ3OS4xNzM3MzYzOTgz*_ga_1119S81MP1*MTc0Mzc3MzM2MC4xMDYuMS4xNzQzNzczMzc1LjQ1LjAuMTI2NDI5NTUzNw..) we know that brain tumour patient experiences often reference the importance of having symptoms recognised swiftly and for being referred quickly onwards for further testing, like diagnostic scans. They talk of the relief and increased trust in healthcare professionals if they have a faster diagnosis where they do not feel dismissed or frustrated.

For most brain tumours, there **is not the same direct links between early intervention and survivability as there are in other less survivable cancers and diseases.** Not least because there are 120 different types of brain tumour, many of which act differently and develop differently. Regardless of whether a person has a high or low grade brain tumour, it is the location in the brain can affect the symptom presentation as this can be down to what neurological function they are pressing on within the brain. For example, someone could have a much larger tumour that already very well-developed when it is found but, because of its location, didn’t trigger obvious symptoms. While smaller tumours, that have only recently developed, could trigger severe symptoms just because of where it is and what it is pressing on within the brain structure.

Despite there being very little known of the link between survival and faster diagnosis, it does not mean there will be no benefit for the future and more research is still required. Ultimately, there could be new therapies or techniques developed in the future that may be more effective in treating tumours that are caught earlier.

**The more we learn and the more we are able to find out about brain tumours in a pre-cancerous or very early stage, the more we will have to rely on having a quick and strong diagnostic pathway.**

Faster diagnosis can provide patients with the gift of time. During the research for our [*Brain Tumours: Fighting for a Faster Diagnosis* report](https://assets.thebraintumourcharity.org/live/uploads/2023/05/Brain-Tumours-Fighting-for-Faster-Diagnosis.pdf?_gl=1*pmyo63*_gcl_au*ODE1NjQ3OTA1LjE3MzczNjM5ODU.*_ga*MTY2NDAwMzQ3OS4xNzM3MzYzOTgz*_ga_1119S81MP1*MTczOTM2NDQ0NC4yNi4xLjE3MzkzNjQ5MTUuNTMuMC4xMDcwODM2NjE.), patients in the focus groups highlighted how it would have helped if they had been diagnosed sooner. It would have helped them come to terms with their diagnosis earlier, to put personal affairs and arrangements in place, as well as providing more time to explore their options for treatment and care.

Although it is not always possible, many brain tumour patients will undergo surgery as part of their treatment. **A faster diagnosis can reduce the number of initial surgeries that are conducted as emergency procedures – which could then reduce co-morbidities and even the risk of death**. A later diagnosis can lead to the patient presenting more severe symptoms such as increased pressure around the brain (intracranial pressure) which often requires emergency intervention. Having more severe symptoms, such as intracranial pressure, can increase the risk of morbidity or mortality during surgery which is why it is important we reduce the number of emergency surgeries.

There are other health benefits such as being able to **better withstand treatment** if symptoms have not progressed as much, or that some **permanent disabilities associated with low grade tumours could be prevented.**

**Another benefit is that there is greater scope to participate in research**. For some research and clinical trials, people may be excluded from the eligibility criteria if they have **already had surgery or if their symptoms are already too severe** for them to participate. If a patient has had to have emergency surgery because of a delayed diagnosis, then it could mean they find themselves to be ineligible for certain research or clinical trials.

### Patient pathways

We know that the urgent suspected cancer referral route, or the Two Week Wait, is **not suitable for people with symptoms suspicious of a brain tumour** and it is rarely used. This is specifically referred to in the [2023 direct access for GP guidance from NHS England](https://www.england.nhs.uk/long-read/urgent-gp-direct-access-to-diagnostic-services-for-people-with-symptoms-not-meeting-the-threshold-for-an-urgent-suspected-cancer-referral/) where they cite that **only 1% of patients with a brain tumour are referred via an urgent suspected cancer pathway**.

This demonstrates that the **dedicated urgent suspected cancer pathway is not working for brain tumours.** This is partly because the symptoms can be quite difficult and vague which makes it difficult for GPs to recognise and know how to refer patients on.

Another cancer pathway that exists in England is the Non-Specific Symptoms (NSS) pathway. On this pathway, GPs can refer patients with vague or non-specific cancer symptoms, (for example fatigue, unexplained weight loss or nausea), or if they have a gut feeling it may be cancer. It is meant to help catch cancers where it is not immediately obvious where the primary location is, such as a lump in the breast. The NSS pathway refers a patient to a Rapid Diagnostic Centre (RDC), where multiple tests can be coordinated and carried out, often in one go.

This, however, is another cancer pathway that is not currently helping patients with a suspected brain tumour asthe list of symptoms do not include many that are commonly associated with a brain tumour. In the **final evaluation of the programme, published by Ipsos Mori in April 2024, just 0.4% of the referrals resulted in a brain or central nervous system (CNS) cancer diagnosis**.

We recognise that brain tumour symptoms are not commonly associated with other non-specific primary cancer symptoms (i.e. losing weight without trying, fatigue etc). However, there is more overlap if people have a cancer that have metastasised to the brain, and they are experiencing brain tumour symptoms. Ultimately it could still help with diagnosing other less survivable cancers.

* **Recommendation 1:** **DHSC must widen the list of Non-Specific Symptoms (NSS)** that warrant referral to the NSS pathway so that they include more potential brain tumour symptoms.

### Improvements to diagnostic capacity of GPs

In September 2023, [NHS England published guidance on direct access for GPs](https://www.england.nhs.uk/long-read/urgent-gp-direct-access-to-diagnostic-services-for-people-with-symptoms-not-meeting-the-threshold-for-an-urgent-suspected-cancer-referral/). Their guidance aimed to improve cancer diagnosis times specifically for “urgent GP direct access to diagnostic services for people with symptoms not meeting the threshold for an urgent suspected cancer referral”. As shared above, we know that the current “urgent suspected cancer” referral route, or the Two Week Wait, isn’t suitable for people with symptoms suspicious of a brain tumour. **Alternative diagnostic pathways must be developed, and we welcomed the guidance for direct access and continue to support it.**

However, we recently conducted further research into how the guidance is being used for brain tumours and what the barriers for GPs using it are. Our findings show that:

* There is patchy knowledge about the publication of this guidance amongst GPs (in-depth interviews and a survey of 100 GPs across England and Scotland **where a third (33%) answered that they “did not know that NHS England published guidance stating that you can directly request for MRI brain imaging** if a patient presents with symptoms suspicious of a brain tumour)
* Recognition that there has **not been much work done on a local level to ensure consistent implementation** of the guidance
* There is patchy access for GPs being able to order these tests combined with a lack of knowledge of how GPs can order brain MRIs (in-depth interviews and survey where **one in five (19%) GP respondents stated that they didn’t know “who provides the scan following a GP direct access request for brain MRI/CT head in your area”**)
* If GPs are able to directly order a brain MRI/CT head, knowledge around what to do next was inconsistent. This was both in reality, where our survey results showed that **one in three (34%) of GP respondents who had experience using direct access said they weren’t told what to do next**. But also in perception where the GPs we interviewed talked about their nervousness and **lack of clear pathway that** **put them off** even going down the direct access route for their patients experiencing potential brain tumour symptoms.

Prominent recommendations from this research were as follows:

* **Recommendation 2:** **DHSC must work with Integrated Care Boards (ICBs)** across England to ensure guidance is disseminated and implemented consistently.
* **Recommendation 3: MRI brain and/or CT head must be commissioned locally in every area** to ensure universality across the country so that GPs can order them for patients with symptoms suspicious of a brain tumour
* **Recommendation 4:** DHSC and ICBs must actively monitor the roll-out of the new guidance and **ensure there is a very clear understanding of how to directly order the correct diagnostic test** for someone with symptoms suspicious of a brain tumour

However, **we believe the Department should go even further** than these recommendations and work on ensuring there is a full and comprehensive pathway to support GPs in diagnosing brain tumours. Where we found real progress were in locations where primary and secondary care had worked with local systems to create **a full direct access pathway to support the diagnosis of brain tumours**.

One group we spoke to in the West Midlands has a fully functioning pathway for GPs to use direct access for patients with suspected brain tumour symptoms. The GPs had been provided with appropriate training and very specific sets of guidance around when they should be referring people with suspected brain tumour symptoms and when they shouldn’t. The scan is conducted in an urgent manner and any patients with suspicious findings then being listed for the next Multi-Disciplinary Team (MDT) meeting – which happen weekly.

If the scan is negative for a tumour, the patient would need further investigation if their symptoms were still present. In this scenario, the GP was fully supported with what to do next and could refer in for a secondary opinion from neurology or to take it forward in a different way with the patient.

If there is something on the scan that’s suspected not to be a brain tumour, for example, a pituitary lesion or a skull-based lesion, they will be redirected to the relevant speciality which may be Ear Nose and Throat (ENT) or to the pituitary team. At this point, though, they’ll confidently have been able to rule out a brain tumour.

Key to ensuring radiology didn’t become overwhelmed in the West Midlands is **the creation of a chronic headache pathway which remains separate to their brain tumour pathway**. A lot of patients present with chronic headaches and there are specific criteria for those people which means that they’ll get a scan within six weeks and see a neurologist on a separate pathway. This means that radiology can prioritise and cope with the demand placed on them**.** This is completely necessary and vital to radiology not becoming overwhelmed because chronic daily headaches affect up to [5% of the population](https://pubmed.ncbi.nlm.nih.gov/21144199/) and the annual primary care consultation rate for headache is [4.4 per 100 patients](https://pmc.ncbi.nlm.nih.gov/articles/PMC2077680/).

We were also made aware of a similar pathway in Nottingham during our previous research. Below is the case study published in our [*Brain Tumours: Fighting for a Faster Diagnosis*](https://assets.thebraintumourcharity.org/live/uploads/2023/05/Brain-Tumours-Fighting-for-Faster-Diagnosis.pdf?_gl=1*kpj190*_gcl_au*ODE1NjQ3OTA1LjE3MzczNjM5ODU.*_ga*MTY2NDAwMzQ3OS4xNzM3MzYzOTgz*_ga_1119S81MP1*MTc0NDc5MDM0Mi4xMjkuMC4xNzQ0NzkxODE0LjYwLjAuNjc5NjM3MzA5)report:

#### East Midlands Direct Access – Case Study

*The Nottingham Neuroradiology Department and Stuart Smith, Clinical Associate Professor of Neurosurgery, have led a team to implement a process of direct access to MRI imaging for East Midlands GPs if they are concerned their patient has a brain tumour. They use the current NICE referral guidance that states a patient can be referred by a GP for an MRI if they have “progressive, sub-acute loss of central neurological function”. The project has simplified the diagnostic pathway with patients being triaged appropriately to Neurosurgery, Oncology, Neurology or Primary Care after the definitive MR imaging investigation. The traditional two-week clinic appointment (nearly inevitably followed by a further wait for an MRI) has been superseded by direct access to two week wait (2WW) imaging, thus speeding up the diagnostic pathway directly from their GP to appropriate specialist or MDT.*

It was also reported in Nottingham **that there wasn’t a huge flood of referrals from primary care and radiology didn’t become overwhelmed.** This was because GPs in their area were well supported on who to refer, who not to refer and what would happen after the scan.

The need for a full and appropriate pathway was echoed in our survey results. We asked the responding GPs in England to rank different options that could help improve GP direct access to imaging for brain MRI/CT head. For the GPs who responded, there were two answers that appeared in the top three rankings the most. These were “**clearer guidance around how and when to directly order a brain MRI/CT head**” and “**a clear pathway from ordering the imaging, how it’s reported back and how it’s referred on (if there’s a concerning result**”. Nearly **three quarters (74%) of responding GPs** in England placed one of these two in their top three answers demonstrating how key it is for there to be a comprehensive brain tumour pathway for GPs to use.

This again indicates to us that, despite the huge challenges facing radiologists currently, **there are ways of improving GP direct access for brain tumours without overwhelming the system**. The main way being to have a **properly mapped out and comprehensive pathway**.

However, this must come together with a very clear set of criteria for scans for a suspected brain tumour, that doesn’t include chronic headaches on their own, so that radiologists know they won’t be overwhelmed.

Further recommendations around creating a specific brain tumour diagnostic pathway:

* **Recommendation 5:** **Brain tumours must be recognised as a difficult to diagnose condition** and DHSC must direct ICBs to **undertake work to create a full and comprehensive pathway** for suspected brain tumours to enable GPs to use direct access effectively, including who to scan, what action to take following the report and a direct onwards referral pathway.
* **Recommendation 6:** Implementation of **these pathways must be piloted and monitored** to ensure it’s being used efficiently, and radiology departments don’t become overwhelmed.

Alternative primary care pathways

Another primary care route that **could be improved for brain tumour patients is that of optometry.** For brain tumour patients, an optician can often be their route into being diagnosed. This can happen because certain brain tumours may affect their field of vision or eye muscle coordination. Symptoms such as blurred or double vision, particularly if associated with a headache, can mean people make an appointment with their optometrist first rather than their GP. Alternatively, someone could attend their GP with vision issues and the GP recommends they visit their optician instead.

However, **in England there is currently no formal, dedicated optometry pathway for patients experiencing ocular symptoms that are suspected of being caused by a brain tumour**. This means the GP or other primary healthcare professional may recommend to the patient that they make an appointment with their optometrist for a sight test, rather than that appointment being made by their GP practice, as they would if they were being referred to secondary care in a hospital, for example. It is then up to the patient to make that appointment, usually pay for it out of their own pocket and know what tests to ask for from the optician.

The sight test, however, is not a good way of detecting brain tumours. Some but not all investigations that make up a statutory sight test may be necessary and some other tests that can help in the diagnosis of brain tumours cost above and beyond a regular sight test. And a patient may not necessarily know to ask for those. Therefore, a sight test is not an appropriate mechanism to access relevant ocular examinations where patients are experiencing headaches that are suspected of being caused by a brain tumour.

In Scotland, we are aware that dedicated local commissioned pathways which include the appropriate tests (such as fundus/optic disc examination and visual field testing) are available. This means **that GPs and other health professionals in some areas of Scotland can refer patients to a dedicated and accessible service locally where clinically indicated, quickly and cost-effectively.**

Patients across **England could stand to benefit from a specific pathway in optometry** if they are experiencing ocular symptoms that could be indicative of a brain tumour. Provision would depend on what is available and commissioned locally; however, if a recommended pathway were developed in collaboration with relevant stakeholders in the area, then this could be adapted and implemented in other local areas.

* **Recommendation 7:** NHS bodies across the **UK must develop a recommended optometry pathway for people with a suspected brain tumour,** drawing upon expertise from The College of Optometrists and The Brain Tumour Charity that can then be used and adapted to local circumstances by local commissioners

### Improving awareness of the signs and symptoms of brain tumours

When we carried out our original research for our [*Brain Tumours: Fighting for a Faster Diagnosis*](https://assets.thebraintumourcharity.org/live/uploads/2023/05/Brain-Tumours-Fighting-for-Faster-Diagnosis.pdf?_gl=1*kpj190*_gcl_au*ODE1NjQ3OTA1LjE3MzczNjM5ODU.*_ga*MTY2NDAwMzQ3OS4xNzM3MzYzOTgz*_ga_1119S81MP1*MTc0NDc5MDM0Mi4xMjkuMC4xNzQ0NzkxODE0LjYwLjAuNjc5NjM3MzA5)report, it was clear that a number of patients we spoke to felt their initial interaction with healthcare professionals could have resulted in a faster referral if they themselves were better able to spot key signs and symptoms. One parent in a focus group told us that:

*“You see it on our parents’ Facebook page, the parents that knew or carers that knew the symptoms would say ‘could it be…’ and they would get through. There is no way around the fact that we need symptoms awareness in the public”*

We also know from our [Improving Brain Tumour Care Surveys (IBTC)](https://www.thebraintumourcharity.org/living-with-a-brain-tumour/get-support/improving-brain-tumour-care-surveys/) that 41% of respondents who sought help from their GP, said they visited their GP three or more times before getting a diagnosis and 55% of respondents said that their child’s brain tumour was diagnosed as something else first. This experience is mirrored in the most recent round of the [NHS National Cancer Patient Experience Survey (NCPES)](https://www.ncpes.co.uk/), published in July 2024. It showed that 22% of people who’d contacted their GP practice said they had to speak to a healthcare professional three or more times before their cancer diagnosis. However, for people specifically diagnosed with a brain tumour this rose to 43%.

This can contribute to delayed diagnoses, a lack of trust in the healthcare system and an overall poor experience of diagnosis for patients if they feel they aren’t being listened to. One of the reasons people visit their GP practice multiple times could be due to a lack of recognition and awareness of the signs and symptoms of a brain tumour – both on the patient side but also on the healthcare professional side.

For healthcare professionals, the symptoms of a brain tumour can be challenging, as they can be vague, non-specific, subtle, and often a result of a different condition. Not only this, but brain tumour symptoms can also be noticed more so by family and friends of the patient than the patient themselves, particularly when related to subtler behaviour or character changes. This can cause challenges in relaying the necessary information to the primary care clinician they see at the GP practice, depending on who attends the appointment and what they feel is relevant to disclose. A lack of widespread knowledge of the symptoms can mean that some symptoms seem unrelated to one another which means a patient may not necessarily disclose all their symptoms in one appointment. As highlighted in [research carried out by Walter et al. in 2019](https://pubmed.ncbi.nlm.nih.gov/30858332/), patients “often failed to mention all the changes…because…the consultations [were] too short. Some noted that they were uncertain about which changes were important to discuss”.

Age, and related conditions, can be a compounding factor to being dismissed as well. In the workshop discussions for our 2023 research, individuals talked about feeling that they were not being listened to because of their age. We heard a number of patients in the focus groups talk about how their symptoms were quickly attributed to things such as hormones, the contraceptive pill and lifestyle choices in young people, or menopause, stress, and other conditions such as dementia in older adults.

*“I was 20 when I was diagnosed and that was the biggest barrier. It just wasn’t expected by my GP… Though I didn’t have many symptoms, those that I did have – headaches and sickness – were initially associated with the contraceptive pill I was taking. I was then told my headaches could be due to studying a very stressful degree. This went on for about six months.”*

#### Better Safe Than Tumour – Case Study

In July 2022, The Brain Tumour Charity launched a new campaign to raise awareness of the signs and symptoms of a brain tumour, [*Better Safe Than Tumour*](https://bettersafethantumour.com/). It concentrates on highlighting the variety of symptoms and encouraging people to approach their GP, as soon as possible if are they experiencing more than two symptoms. We have used billboards, bus posters, radio adverts and other digital marketing to try to ensure the signs and symptoms of a brain tumour are not missed by the public. To accompany, we have also created a website that provides support for those who are worried about symptoms including a guide for how to approach a GP appointment. We want people to feel supported and empowered to raise their concerns with their GP. Moving into 2023, the campaign will aim to raise awareness among healthcare professionals and providing resources for those working in the sector.

* **Recommendation 8:** The NHS must ensure that **all general practice clinicians can access readily available training** on the signs and symptoms of a brain tumour and should **partner with The Brain Tumour Charity’s Better Safe Than Tumour campaign** to raise awareness among the general public and healthcare professionals.

Diagnostic tools and triage tests

Currently, the only way to detect a brain tumour is by using an MRI or a CT scan. However, we know there are resourcing and capacity strains across the whole NHS also impacting diagnostic staffing for these machines. It can be difficult for primary healthcare professionals to know when to refer a patient based purely on symptoms that they present with, and capacity issues make it more difficult to send everyone for a scan. This is where having different tools and tests would be of benefit to GP practice staff, even if it just means they are able to determine a priority order for urgent scans more accurately. These could help identify those who may be at a higher risk of having a brain tumour and therefore need an urgent referral.

There is some work on triage tools for brain tumours being conducted. This includes the development of a blood test, [Dxcover](https://www.dxcover.com/), which could help GPs prioritise who to refer for a scan. There is also a verbal fluency test in development that is aimed at giving GPs an easy and cost effective way to determine the risk of an individual.

It is essential that further research is carried out into these potential tests and where they would be best used in a diagnostic pathway. There are also questions about whether the verbal fluency test would work for people who have English as their second language or particular conditions that could impact language. However, these tests have the potential to have a big impact supporting GP practice clinicians.

* **Recommendation 9:** The government must ensure there is **appropriate funding going towards the development of clinical triage tools to detect brain tumours**.

#### DXCOVER and Verbal Fluency Test - Case study

The Dxcover triage test is a low-cost blood test developed in Scotland by Dr Matt Baker. Dr Paul Brennan has collaborated with Dr Baker and led the clinical trials that have shown the test can identify more than 90% of glioblastomas (the most common type of brain tumour) and more than 80% of all other brain tumours, in a study in NHS Lothian. This blood test could help improve the diagnostic pathway for patients with suspected brain tumour.

The Verbal Fluency Test (VFT) is a simple language test which asks people to name as many animals as they can in 60 seconds. Dr Brennan and his colleagues in Edinburgh showed in a clinical study that the VFT could help GPs identify which people with common but vague symptoms, such as headaches, are more likely to have a brain tumour.

Both the VFT and blood test could be valuable additions to clinical assessments to help GPs identify patients in need of an urgent brain scan, while providing reassurance that a period of observation may be appropriate for others. Further research is needed to validate and optimise use of both tests.

Contact details

If you need further information or have other questions, please do not hesitate to contact the team on policy@thebraintumourcharity.org.