

BRAIN TUMOURS:

FIGHTING FOR

A FASTER

DIAGNOSIS

CONTENTS

FIGHTING FOR FASTER DIAGNOSIS

- 04. Recommendations
- 06. Introduction
- 08. Earlier or faster diagnosis?
- 10. Why is faster diagnosis in brain tumours important?
- 17. Methods
- 18. Limitations
- 19. How do brain tumour patients present?
- 21. Improving knowledge of signs and symptoms
- 31. Interaction with General Practice
- 35. Referrals and Patient Pathways
- 44. Recommendations
- 45. Conclusion
- 47. References

Our Improving Brain Tumour Care surveys showed that over one in seven (15%) of the respondents took over six months to get a diagnosis from first seeing a healthcare professional for their symptoms, with one in 10 (10%) waiting over a year to be diagnosed

We must see diagnosis times fall for those impacted by brain tumours so that people feel supported and can live better lives with a brain tumour.

Currently, the diagnosis process is too slow and difficult for too many and this has to change.

FIGHTING FOR FASTER DIAGNOSIS

RECOMMENDATIONS

- 1** In order for brain tumours to be included in each devolved nation Government's ambitions to improve early diagnosis of cancer, we must 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. Proxy measure examples could be proportion of emergency diagnoses or time to diagnosis.
- 2** 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 share among healthcare professionals.
- 3** The NHS must trial the implementation of a timed safety netting process or patients with brain tumour symptoms, and a clinical decision support tool for consultations that flags potential brain tumour symptoms to GPs.
- 4** The Government must ensure there is appropriate funding going towards the development of clinical triage tools to detect brain tumours.
- 5** As per recent plans announced in England, the NHS must ensure that universal direct access to MRI and/or CT scans for GP practices across all of the UK is achieved. This must always be available alongside sufficient training to interpret the results, appropriate staffing and systems resource, and a direct referral pathway to neurology.
- 6** The NHS must develop a Best Practice Timed Pathway in England and an Optimal Cancer Diagnostic Pathway in Scotland for brain tumours, so that appropriate referral pathways and the relevant tests required are set out.
- 7** NHS England and Scotland 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.
- 8** 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.¹

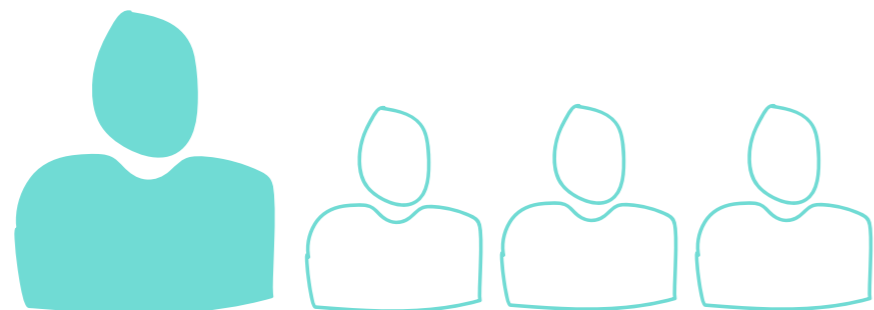


INTRODUCTION

Brain tumours are the biggest cancer killer of children and the under 40s.

From 2001 to 2019, the number of people being diagnosed with a brain tumour in England rose by 50% from 6,577 to 9,960. With approximately 12,000 people being diagnosed every year across the UK we need to take action. What's more is that we know that the diagnosis process for many is not as fast or well-supported as it could be.

One indicator of this is that a disappointingly high proportion of brain tumour patients are diagnosed through A&E. The Rapid Cancer Registration Dashboard² (RCRD) provides a snapshot of recent data on the different routes for brain and central nervous system (CNS) cancer, showing the average from January 2018 to June 2022³. For brain tumour patients in June 2022, this data shows that 41.6% of cases were diagnosed through emergency presentation. Breast cancer, by comparison, had 3.3% of cases diagnosed through emergency presentation in June 2022. There



Nearly one in four respondents had visited their general practitioner (GP) over three times with brain tumour symptoms before getting a diagnosis.

are limitations to this data and it only provides a snapshot; however, it can provide a good indicator of the more general picture. We also know through our own Improving Brain Tumour Care (IBTC) survey that nearly one in four (24%) respondents had visited their general practitioner (GP) over three times with brain tumour symptoms before getting a diagnosis. And nearly one in 12 (8%) respondents had visited their GP over six times⁴.

We also know anecdotally that people can sometimes receive their diagnosis in a disappointing way. A number of people living with a brain tumour spoke in our focus groups of being told their diagnosis on their own without the support of a family member, by a non-specialist who couldn't answer their questions, or receiving it in a non-private place for example on the ward where the only separator between them and other patients was the curtain. They also talked about how they weren't given time to ask questions and weren't given any follow-up information leaving them feeling confused about what their diagnosis meant or what

the next steps would be. All this indicates significant problems in the system that must be improved for those with brain tumour symptoms.

All people who experience brain tumour symptoms deserve the opportunity to have a fast and smooth experience between first noticing symptoms and the diagnosis, or a ruling out, of a brain tumour. Unfortunately we know this is not always the case for brain tumour patients, many of whom attend repeat appointments, are diagnosed with something else first, or experience delays. Faster diagnosis is very important because it can make a huge difference to patients' well-being and their trust in the healthcare system as well as potentially preventing disabilities or, in some cases, improving tolerance for treatment. When you or a loved one is experiencing unusual or worrying symptoms you want and need to find answers as soon as you can.

Striving for a quicker diagnosis of brain tumours has also been identified as one of the top 10 clinical

research priorities for the UK neuro-oncology community⁵, and continues to be considered of great importance to brain tumour patients and their loved ones. It also remains a central pillar of national cancer plans across the UK devolved nations, as explored below. This focus on diagnosis has undoubtedly helped to drive progress and ensure that more people are surviving cancer⁶ in this country than ever before. However, brain tumour survival remains low and little has changed in over a generation⁷ predominantly due to certain unique challenges and their position in the body.

This report aims to provide a better understanding of how improvements could be made on the path to diagnosis for brain tumour patients, and put forward policy recommendations for the government, the NHS and other policymakers to create change in public policy. With these recommendations, we would see an expedited process for patients in receiving their brain tumour diagnosis, and thus improve patients' experiences and quality of care.



Nearly one in 12 respondents had visited their GP over six times.

EARLIER OR FASTER DIAGNOSIS?



Earlier Diagnosis of Cancer

Whilst not all brain tumours are cancerous, early diagnosis is often discussed in the context of the cancer sector. 'Early diagnosis' focuses on detecting patients' cancers as early as possible, and ultimately aims to reduce the proportion of patients who are diagnosed at a late stage. For most cancers, stages one and two are considered to be an early diagnosis, as the cancer has not spread in the body beyond, potentially, the lymph nodes. Other non-cancer diseases, such as multiple sclerosis (MS) or dementia, also focus on early detection and diagnosis, before symptoms start to worsen, but can lack tangible measures for whether a condition has been diagnosed early.

The *NHS Long Term Plan for England* set a target by 2028 for an extra 55,000 people each year to survive for five years or more following their cancer diagnosis⁸. Early diagnosis generally focuses on the stage at diagnosis, with the *NHS Long Term Plan for England* aiming for 75% of cancers to be diagnosed at stage 1 or 2 by 2030⁹. Whilst the cancer strategy in Scotland¹⁰, titled '*Beating Cancer: Ambition and Action*', and the Northern Ireland cancer strategy¹¹ reference progress on the early diagnosis of cancer using stage at diagnosis, neither strategy has a specific target identified. At time of writing, there is no current cancer strategy for Wales. However, the Welsh government released a Cancer Quality Statement¹² in 2021, with an ambition that "more cases of cancer are detected at earlier, more treatable stages through more timely access to diagnostic investigations".

But brain cancer does not behave in the same way as other cancers, and measurements of staging disease by extent of metastasis are not relevant. Brain tumours may migrate within the brain or potentially the spine, but it is very rare for primary brain tumours to spread outside of the brain, or away from the central nervous system. Consequently, while brain tumours are graded they are not staged. This means that there are currently no ambitions to improve early diagnosis of brain tumours as there are for other cancers, but also no way of measuring progress. To ensure brain cancer does not fall behind other cancers, cancers that are not staged need to be recognised in these targets by developing proxy measures so they too can be tracked. Proxy measures could be developed around reducing the proportions of brain tumour patients being diagnosed in an emergency setting or around reducing time to diagnosis measures.

Not all brain tumours are cancerous, so discussions relating to cancer targets and cancer care also won't necessarily relate to all brain tumour patients.

Much of the wider discussion in cancer care focuses on the specifics of 'early' diagnosis which largely includes the detecting of asymptomatic cancers in the early stages, before symptoms have started. These detections come usually through mass screening programmes which are currently unlikely for brain tumours due to the nature of the diagnostic tests combined with the prevalence of the disease. An MRI or a CT scan is the only way of currently detecting a brain tumour so regularly screening certain sections

of the population using MRI or CT scanners would neither be feasible nor appropriate. Not least because of the potential small risks of causing other cancers through the radiation of CT scanners. Routinely scanning can also result in the high incidence of "incidentalomas". Incidentaloma is the medical term for incidentally found asymptomatic tumours¹³. Most of the time, when a scan picks up one of these asymptomatic tumours, it is actually a form of overdiagnosis. Overdiagnosis is where something, in this case a brain tumour, is diagnosed even though that tumour would never have caused symptoms or death of the patient¹⁴. By identifying these tumours though, it can lead to overtreatment and also cause unnecessary worry and concern for the person and their family.

An example of overtreatment in breast cancer is Ductal Carcinoma In Situ (DCIS). DCIS is when certain cells in the lining of the ducts of the breast tissue have started to turn into cancer cells. In some people, DCIS can develop into invasive cancer¹⁵. It is generally picked up through routine mammograms, used in screening, as most people show no symptoms. Not every untreated DCIS will develop into invasive cancer and in some cases DCIS will never develop further or will grow so slowly it never causes harm in the person's lifetime¹⁶. The size and grade can help to tell; however, there is no definitive way of knowing if the

DCIS a person has is one that will never cause harm or grow slowly. Therefore, treatment is offered to all who have it with surgery being the main treatment. But there is controversy around the treatment and whether DCIS is "over treated". There is research ongoing looking at which DCIS cases are more likely to turn into breast cancer which may be able to tackle this but for now, everyone is offered treatment.

It is much less clear what 'early' diagnosis may mean for brain tumour patients, due to the lack of staging and lack of screening programmes. Patient experiences often reference the importance of prompt referrals and faster pathways to diagnosis when early diagnosis is discussed, alongside the importance of being taken seriously, having symptoms recognised swiftly, and having timely access to the right tests and scans. This is why we have chosen to focus this report on 'faster diagnosis' as opposed to 'earlier diagnosis'.

This is defined as providing a definitive diagnosis for **symptomatic** patients as quickly as possible so that treatment interventions and support can be provided to the patient at the earliest opportunity. The term 'faster diagnosis' is more relevant than 'earlier diagnosis' to the recommendations this report seeks to influence and the experience of brain tumour patients.

Recommendation 1: In order for brain tumours to be included in each devolved nation Government's stated ambitions to improve early diagnosis of cancer, we must 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. Proxy measure examples could be proportion of emergency diagnoses or time to diagnosis.

WHY IS FASTER DIAGNOSIS IN BRAIN TUMOURS SO IMPORTANT?

Disabilities and morbidities

People diagnosed with a brain tumour can experience associated symptoms that can lead to disabilities, including acquired neurological disabilities due to brain tumour related brain injury. These neurological deficits are often irreversible, so, if possible, identifying and treating the tumour before they occur can be key.

A brain tumour has the potential to cause significant neurological damage, due to compression of adjacent neural structures, invasion caused by tumour growth, or through developing secondary hydrocephalus (excess fluid on the brain). In some cases, it is possible that over the period of time a tumour develops and grows, it is more likely to cause damage to the brain due to progressive enlargement. For some people, the tumour may grow slowly over a long period of time and so, if discovered sooner, may lead to a reduction in these brain tumour related disabilities. Unfortunately, this is not universal and, for some patients, their brain tumour may grow incredibly quickly and preventing disability through a faster diagnosis may be less feasible.

Additionally, there has been promising research done that shows that earlier treatment in low grade tumours can lead to better survival outcomes. University College London (UCL) published work in 2019¹⁷ that showed patients with low grade gliomas had

a 50% chance of dying within 10 years of diagnosis in 2006 compared to a 4% chance in 2017. Not only that, but there was also a large jump in the number of patients who were seizure free for one year or more, from 22% in 2006 to 42% in 2017. The difference appeared to be due to a change in approach at UCL. In 2017, three times as many patients had surgery within one year of diagnosis to remove their tumour compared to 2006. Until 2006, the favoured approach was to “watch and wait” because of the inherent risks of any surgery. Since then however, neuro-oncology multi-disciplinary teams have been much more proactive in offering and performing surgery much sooner after diagnosis¹⁸.

Faster diagnosis therefore has the potential to bring benefits for those with slower growing tumours and low grade tumours.

Sufficient support

Many patients we spoke to during this project reflected on faster diagnosis in terms of the time it would have given them or their loved one.

There is ongoing debate about whether a prompter diagnosis does actually bring additional survival time to brain tumour patients, particularly with high grade tumours. These discussions are generally around whether in fact that additional time is artificial and is what is known as lead time bias. Lead time bias is defined as

overestimation of survival duration purely because of earlier detection. If survival time is measured from the time of diagnosis, then the apparent increased survival time will just be because they were diagnosed earlier rather than because they were able to survive longer¹⁹.

We know, however, that patients and their families value having more time – even if the time is scientifically artificial. Patients in our focus groups talked with passion about how additional time and being diagnosed sooner would have made a difference to them. Time to process and accept the diagnosis (including exploring counselling), time to put personal affairs and arrangements in place, time to explore options for

treatment and care, and time to be supported in the most appropriate way for the individual, including time to engage with palliative care services as required. One young person also talked about practical arrangements for school exams and coursework that couldn't be put in place because of how quickly their tumour progressed.

Patients feel that being diagnosed earlier may have allowed them to protect their dignity, or that of their loved one, better and to feel as supported as they possible could be in their situation. Faster diagnosis can also lead to greater awareness and understanding for the patient about their symptoms, and more time to process and think of questions to ask their healthcare team.

“What it didn't offer me was the opportunity...to put anything in place, things like contacting my school to let them know I'd had a brain tumour over the holidays... they then didn't have the time to put any provisions in place, we couldn't contact the exam boards in ample time.”

“ The whole diagnosis was an emergency in the end... we had no time to think, no time to react or think this through and it didn't need to be like that. If the GP had asked the right questions or listened to what we were saying, it would have been different ”

Participant whose partner was diagnosed with brain tumour - patient workshop

“ For me, [it] took about eight months for me to get diagnosed with a brain tumour and that was the most painful period of time in my life. I was having splitting headaches, going to numerous health professionals and asking for help and they were just dismissing me and making me feel like the pain and what I was experiencing was normal...you start to get in your head that you're confused. ”

Participant diagnosed with brain tumour - patient workshop

Trust in healthcare professionals

Reducing delays along the diagnostic pathway can also improve trust in primary care and reduce dissatisfaction with the healthcare system²⁰.

Additionally, there is anecdotal evidence that having a smoother diagnosis experience can lead to a positive impact upon quality of life, with people expressing 'relief' at finally having a diagnosis. An early positive experience with healthcare professionals in the diagnosis of a brain tumour can lead to better relationships throughout treatment, and a better quality of life for the patient, as their holistic needs are met and they feel supported in their care and treatment.

Surgery and treatment

Many brain tumour patients will have surgery as part of their treatment, although this is not always possible due to the location of the tumour and the health of the individual at diagnosis.

Interventions that shorten the time to diagnosis of suspected cases of brain tumours can impact the severity of symptoms at diagnosis, allowing different surgical possibilities, such as the resection of a tumour instead of only a biopsy. Having a patient who is fitter for surgery or other treatments at the point of diagnosis, can, in some cases, enable them to withstand treatments better and give them more options, potentially resulting in better tolerance and response to radiation therapy and chemotherapy. If the tumour is in a location that cannot be operated on, however, this will likely not make a difference. But for some, it will.

Faster diagnosis could also potentially reduce the number of initial brain tumour surgeries that are conducted as emergency procedures. Certain

brain tumours will always require emergency surgery because some people will have larger one off symptoms, such as a seizure for example, and prior to that will have encountered no or very mild symptoms. However, there are some tumours that would not necessarily need emergency surgery had they been caught earlier but due to later diagnosis they then present the risk of raised intracranial pressure which then does require more emergency intervention²¹. If a patient is presenting with more severe symptoms, such as raised intracranial pressure, this can also increase the risk of morbidity or mortality²² during surgery.

There will unfortunately always be patients whose very first symptoms are severe or require emergency procedures, due to the nature and location of their individual tumour. However, we know anecdotally that there are others who ultimately require emergency medical attention despite presenting with symptoms to healthcare professionals multiple times prior to this. If we are able to improve the diagnosis speed for that group of patients, then we have the potential to improve the options for surgery in some cases.

For some patients, surgical possibility and its associated outcomes may be dependent largely on the location of the tumour, or how far reaching it is, rather than its size or progression.

Survival

The research and literature on the association between a faster diagnosis of a brain tumour and survival outcomes in patients is not as clear cut as in other cancers. A faster diagnosis of a brain tumour does not necessarily lead to an increase in survival. This is not least

because there are approximately 130 types of brain tumour known to us, many of which act differently and many of which can appear in different and/or multiple areas of the brain, thus, causing different symptoms in different people. Someone could have a much larger tumour that is found when it is already well-developed because its location meant it did not trigger many obvious symptoms while others could have a much smaller tumour which, because of its location, triggered severe symptoms soon after forming.

The concept of faster diagnosis relates in part to the possibility that a brain tumour may be smaller on discovery if diagnosed earlier. Although it seems logical, there is little evidence that diagnosing brain tumours early is a significant predictive factor in improving outcomes generally²³.

As well as not acting in the same way as other cancers in terms of spreading throughout the body, and so not being able to be staged, brain tumours act differently partly because a lot of the damage or potential difficulties are down to the location in the brain rather than the size. A number of studies^{24,25} show that surgical resection for glioblastoma brain tumours, one of the most common forms of the disease, is linked with overall length of survival (although it is still always incurable). The more you are able to remove in surgery, the better the longer term outcomes for the patient in general – as long as surgery is successful. However, some tumours, even at their earliest and/or smallest stage, will not be able to be operated on. This may be because some tumours, even if they are small, are diffuse which means they have quite far reaching tentacles and spread,

making it very complicated to remove. Being able to remove a tumour can also depend on its location in the brain so even if it is very small, it may be in a place that is difficult or impossible to reach through surgery without inflicting damage to the person. On the other hand, some tumours, even when incredibly large and well-established, are able to be removed, at least in part, because it may be easy to reach, in a non-eloquent area of the brain and/or quite contained as a tumour. Size is only one consideration in the ability to remove a brain tumour in surgery, and more often than not, it ultimately comes down to its location and how diffuse it is. This means that better survival is not necessarily related to finding the tumour earlier.

Despite there being no current known link between survival and faster diagnosis, it does not necessarily mean there will be no benefit for the future and more research is still required to further our understanding of how brain tumours start, grow and develop. Ultimately, there could also be new therapies or techniques developed in the future that may actually be more effectively in treating tumours that are caught earlier. We are already starting to see this as last year a paper was published that indicated it may be possible to identify children who will potentially go on to develop a grade 3 or 4 medulloblastoma by looking at the early development of the hindbrain^{26,27}. And whilst this research is still in very early stages and how the knowledge could be used in practical terms is still to be determined, it is an indicator that we still have much to learn and discover about how tumours start and develop. The more we learn and the more we are able to find out about brain tumours in a pre-cancerous

or very early the more we are going to rely on having a quick and strong diagnostic pathway.

We do not know what we may discover about the growth or progression of brain tumours that could mean that faster diagnosis may still improve the survival of people with brain tumours.²⁸ We should strive to improve this for people now.

Research

Faster diagnosis can, in some circumstances, lead to patients having enough time to explore their options, particularly in relation to research participation, and potential clinical trials. Deciding whether to get involved in research can often be

a big decision, with multiple factors to consider for both the patient and their loved ones. Some patients will not be eligible due to their severity of symptoms at diagnosis, which has potential to be reduced in some cases if they had been diagnosed faster

It is also important for the future of brain tumour research that as many patients as possible are able to be involved in all aspects of research. Faster diagnosis may allow more time for researchers to understand an individual's brain tumour and how it progresses, furthering our collective understanding of the biology of brain tumours.

METHODS

A variety of methods have been utilised to gain a better understanding of the current diagnosis experience, to help develop this report and associated recommendations. The time provided by everyone engaged in the project to support this work is greatly appreciated. The project would not have been successful without the expertise and willing from a wide range of individuals across the sector and community.

Literature review

The Brain Tumour Charity undertook a literature review to fully understand the previous research which has been carried out on the faster diagnosis of brain tumours. The literature review also took into consideration data available around this topic in the UK.

This review included a variety of sources, including peer-reviewed journal articles, clinical trials and grey literature from government health bodies. The initial themes identified in this review were; imaging, data, referral pathways, signs and symptom recognition, and triage tools. The findings of this work informed the questions and conversations with stakeholders.

Consultation with stakeholders

18 in-depth interviews were conducted by The Brain Tumour Charity between July and November 2022 with individuals who have expertise of the diagnosis of brain tumours in both primary and secondary care, in a research environment or role, or who have knowledge of charity policy work on the early diagnosis of cancer.

These conversations were vital to getting a view of the current landscape in this area and looking at examples of good practice and new initiatives. The initial themes that came out

of these conversations were; communication, resource and capacity, imaging and scans, funding for research, language and accessibility, and training and awareness. These findings formed the framework around discussions with the patient community.

Consultation with patients and patient advocates

Engagement with those affected by brain tumours were carried out in the form of an initial workshop associated with the strategy development process, and three dedicated workshops held in October 2022.

The workshop on early diagnosis which was undertaken in May 2022 for the strategy development work helped with early insights from patients and patient advocates into this topic.

One dedicated workshop was held with The Brain Tumour Charity's Young Ambassadors, and one workshop was held with The Brain Tumour Charity's Involvement Champions. A third workshop was held for any individual in the Involvement Network or Campaigner Network to sign up to and express their views on faster diagnosis.

Feedback from these workshops was incredibly insightful and helped shape the final themes of the recommendations. The initial themes that came out of these conversations were; communication and feeling listened to, awareness of signs and symptoms, being able to have more time to plan for treatments or surgery, language and accessibility, imaging and scans and research funding.

“ A lot [of trials] say they want to sign you up...before you have surgery or any treatment. And the trouble with getting a diagnosis in A&E and it being an emergency is that you've lost your chance to sign up to lots of those things...you can't sign up for things when you're in the middle of an emergency and you've gone from A&E to hospital to operation with no time. ”

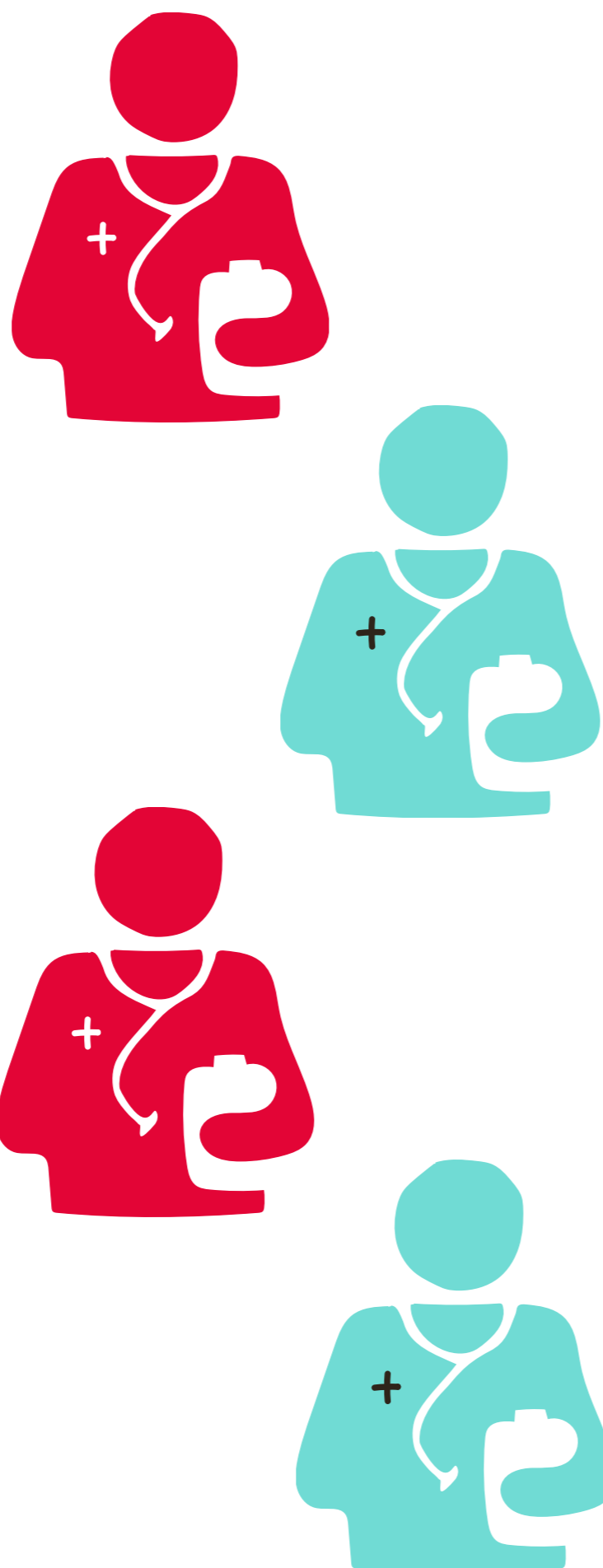
LIMITATIONS

While we endeavoured to speak to people across all the devolved nations, we had the most engagement with England and Scotland. Further research would be required to fully understand the landscape in Wales and Northern Ireland.

We also are aware that individuals who attended the workshops were self-selecting from a group of patients and loved ones who have already engaged with The Brain Tumour Charity previously. This means their views therefore will not be entirely reflective of everyone with a brain tumour in the UK.

This report has been designed to consider both patients with a high grade brain tumour, and patients with a low grade brain tumours, as faster diagnosis is a topic relevant to, and of interest to, all brain tumour patients.

The engagement with interviewees and in workshops was primarily focused on the experiences of adults who were diagnosed with a brain tumour, although some paediatric experiences were reflected. Further research would be required around the specific experience of children and faster diagnosis.



HOW DO BRAIN TUMOUR PATIENTS PRESENT?

Brain tumour patients are diagnosed through a range of different routes and pathways, the RCRD²⁹ provides a snapshot of recent data on the different routes for brain and CNS cancer. This data shows the average from January 2018 to June 2022³⁰. Some individuals will have interacted with multiple pathways and routes to diagnosis before finally receiving a brain tumour diagnosis. However, this data will only show the place where they received their definitive diagnosis so if someone went to their GP practice³¹ multiple times before eventually being diagnosed in Accident and Emergency (A&E), for example, this will just appear as "Emergency Presentation" in this data.

ROUTE TO DIAGNOSIS (JUN '22)	PERCENTAGE OF BRAIN TUMOUR PATIENTS (JUN '22)
Emergency Presentation	41.6%
GP Referral	17.9%
Two Week Wait Urgent Suspected Cancer Referral	1.3%
Outpatient Referral	30.6%
Other	8.7%

Brain tumour patients can present with symptoms to a variety of healthcare professionals, including GPs, pharmacists, nurses working at GP practices, optometrists, and clinicians working in A&E departments.

As the data above shows, GP referral and the Two Week Wait for urgent suspected cancer referrals have a relatively low proportion of brain tumour patients coming through their route to diagnosis. Breast cancer, for example, in June 2022 had a Two Week Wait for urgent suspected cancer referrals of 51.1% and emergency presentation of 3.3%. Prostate cancer in June 2022 had a Two Week Wait for urgent suspected cancer referrals of 61.4% and emergency presentation of 5.5%.

We know that most brain tumour patients do interact with their GP practice prior to their diagnosis. The Brain Tumour Charity's Improving Brain Tumour Care (IBTC) survey showed that 56% of respondents visited the GP for their symptoms³² at some point before their diagnosis. However, because the percentage of brain tumour patients being diagnosed through a GP referral is so low, it is clear that it is not as simple as visiting the GP practice and getting referred onto a secondary care pathway. This suggests there may currently be opportunities to identify at-risk patients who should be referred for urgent scans that are being missed.

IMPROVING KNOWLEDGE OF SIGNS AND SYMPTOMS

General symptom recognition and awareness

In discussion with patients through the workshops conducted for this project, it was clear that a number of patients felt their initial interaction with a healthcare professional could have resulted in a faster referral if they as the patient were able to better recognise the signs and symptoms of a potential brain tumour.

“ I think our GP failed to ask some significant questions that could have indicated that it might have been a brain tumour, questions that 111 did ask. One question was ‘is the headache worse when you bend forwards’, which was an indicator, and the other was whether there had been any cognitive changes in me, which my partner would have been able to say yes. ”

Participant diagnosed with brain tumour – patient workshop

This also suggests 44% people did not go to their GP practice at any point before their diagnosis, potentially because they attended A&E straight after symptoms occurred, or they were referred for investigation by an optometrist or another healthcare professional. There will always be a cohort of people whose first symptom is so severe, a seizure or paralysis for example, they have to attend A&E in the first instance. However, whilst not all patients interact with primary care on their route to diagnosis, ensuring as many people as possible present to their GP or optometrist as soon as symptoms occur is important to a faster diagnosis.

“ 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 ”

Parent of a child diagnosed with brain tumour – interviewee

The IBTC survey showed that nearly 1 in 4 respondents had visited their GP practice over three times with brain tumour symptoms before getting a diagnosis, and nearly one in 12 respondents had visited their GP practice over six times³³. These results are also reflected in the national Cancer Patient Experience Survey (CPES), where the 2021 results show only 50% of brain cancer patients³⁴ agreed with the statement 'I only spoke to primary care professional once or twice before my cancer diagnosis', compared to 77% for all cancers³⁵. 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, more often than not, 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. As highlighted in research carried out by Walter et al. in 2019, 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"³⁶. Age, and related conditions, can be a compounding factor to being dismissed as well. In the workshop discussions, 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.”

Participant diagnosed with brain tumour – patient workshop

BETTER SAFE
THAN TUMOUR.



72%

of people in the UK
can't name a single
symptom of a
brain tumour.

Untangling key symptoms of brain tumours from those more likely to be caused by other less serious conditions remains a challenge. And this is compounded by GPs being overstretched and under-resourced, meaning appointment times are short and are designed to focus on one issue, which will be discussed in further detail later on. However, a lack of knowledge of signs and symptoms from both patient and healthcare professionals could also mean that symptoms are not disclosed, linked up or are related to other less urgent medical issues instead.

One of the methods used by GPs to know when to refer a patient onto secondary care is positive predicative values (PPV). Any symptoms which have a PPV of greater than 3% for a type of cancer, meaning that 3% of patients with these symptoms are likely to have the cancer, are used to refer on. There are no symptoms associated with brain tumours that have a PPV of higher than 3% on their own. Some researchers

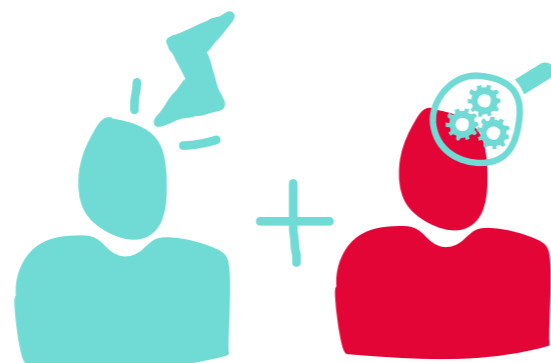
have suggested the use of combined symptom PPVs may be a better indicator. For example headache in adults on its own has a PPV of less than 0.1% for a brain tumour, but headache combined with cognitive symptoms, for example, has a PPV of 7.2% for a brain tumour³⁷. This approach is often referred to as 'headache plus'. While we do have to note that the diverse range of possible symptoms mean that the groups with these are a small proportion of the total number of people presenting with a brain tumour, supporting GP practices to recognise symptoms in combination is still incredibly important.

It is also important that the public has an awareness and understanding of the potential signs and symptoms of a brain tumour, so that they present to a healthcare professional soon after their symptoms start. It can also be helpful for patients to feel empowered and feel as though they can advocate for themselves.

PPV – Positive Predicative Values



HEADACHE (ALONE)
PPV: >0.1%



HEADACHE PLUS COGNITIVE CHANGES
PPV: 7.2%

Positive Predicative Values (PPV) are used by GPs to know when to refer a patient onto secondary care. Unfortunately, there are no symptoms associated with brain tumours that have a PPV of higher than 3% on their own. The use of combined symptom PPVs could provide a better indicator of a potential brain tumour diagnosis.

BETTER SAFE THAN TUMOUR.



In July 2022, The Brain Tumour Charity launched a new campaign to raise awareness of the signs and symptoms of a brain tumour. 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.



Training

As brain tumour symptoms are hard to recognise, there needs to be training continually available and updated for all GPs and healthcare professionals who could see a patient with a brain tumour, including optometrists. Recognising the symptoms of a brain tumour is a part of the training required to be a GP, but GPs are

faced with recognising a huge array of different conditions in their role. Regular refreshment is needed to keep brain tumour symptoms front of mind. A module currently exists on Gateway C, a training platform for GPs, that can be used to refresh on the signs and symptoms of a brain tumour, and infographics have been developed to help guide referrals.

“When we spoke to the two GPs we saw about my son, both said the same thing – ‘we know nothing about brain tumours, this is a very specialist area and we’re unable to help or assist you’ I get that it is rare, but that’s where the education piece should come in”

Parent of a child diagnosed with brain tumour – patient workshop

A challenge for GPs and other healthcare professionals in maintaining ongoing professional development is pressure around resourcing and workforce. Any action taken to support GPs in supporting their ongoing professional development must be considered alongside the issue of an overstretched and under-resourced workforce.



GatewayC

Gateway C

Gateway C is a free online cancer education platform developed for primary care professionals across England, aiming to improve cancer outcomes by facilitating earlier diagnosis and improving patient experience. Dr Catherine McBain, Consultant Clinical Oncologist at The Christie in Manchester, has worked closely with Gateway C to develop important tools used by GPs to understand the symptoms and clinical pathways for brain tumours. Leading a team of neurology specialists, Dr McBain has worked on webinars, an infographic (commissioned by Greater Manchester Cancer Alliance), an early diagnosis for brain tumours course and other resources to help GPs better recognise the signs and symptoms of a brain tumour. At time of writing, the early diagnosis for brain tumours course is the second most popular course.



Diagnostic support tools for GPs

Another way to ensure GPs are being supported to recognise signs and piece together various symptoms is through different IT tools available to them.

The challenge of symptom recognition for brain tumours is demonstrated by one of the common symptoms of a brain tumour being a headache. Chronic daily headaches affect up to 5% of the population³⁸, and the NHS has previously noted that headache is an extremely frequent symptom encountered in primary care with an estimated consultation rate of 4.4 per 100 patients. Of these patients, only 3% are referred to secondary care for further assessment³⁹. Headache is often the first symptom a patient with a brain tumour has, and is present in up to half of adult brain tumour patients by the time they are diagnosed⁴⁰.

It is not true to say that GPs, or other primary care clinicians, do not know or recognise that headaches can be a symptom of a brain tumour. However, in reality the probability of a patient presenting to them with a headache having a brain tumour is incredibly low. This means that the GP or primary care clinician will likely look to rule out the more common causes of headaches before approaching the idea it could be a brain tumour. It is also true that they cannot send everyone who has headaches for urgent MRI or CT scans. For children, however, a headache is much more unusual which makes it far clearer for GPs or primary care clinicians to know who to refer. Clinical decision support tools and safety netting could be a way of approaching these problems for GP practices.

Safety netting can help to ensure patients return to their GP practice if symptoms, like headaches, persist or worsen, or new symptoms start. GP practices can utilise safety netting systems to empower patients to return, mainly through asking a patient to return in a certain timeframe if their symptoms persist or get worse. Cancer Research UK have produced information for GP practices around safety netting for cancer including flowcharts and guidance⁴¹. While Target Ovarian Cancer have also been working with local Integrated Care Boards to request GPs explore the use of safety netting IT tools in local areas⁴².

Electronic, timed safety netting tool could support this work and ensure those who need to be assessed again do return and make an appointment before their symptoms worsen significantly. This could take the form of SMS texts to patients, asking if their symptoms are still present at a time interval determined by their GP.

Clinical decision support tools could also potentially help with faster diagnosis, flagging to GPs, or other practice team members, on an electronic system when the combination of symptoms a patient presents with could be possible signs of a brain tumour. This is a potentially useful way to help alert healthcare professionals of the possibility of a brain tumour, and also support them with decisions around referrals. There are systems already available which provide this service on GP practice software, and trials being piloted, such as the ERICA⁴³ trial, to see how effective this could be in referring the right people for further tests and scans. The ERICA trial is looking at the use of a clinical decisions support tool

developed by Macmillan (the Cancer Diagnosis Support Tool⁴⁴) in Primary Care IT systems. They are focused on six cancers – lung, oesophago-gastric, kidney, bladder, ovary and colorectal.

Whilst clinical decision support tools may be an incredibly helpful tool for GP practices, GPs should always be empowered to make the choice to override tools and tests if they think something may be wrong, or if they have a gut feeling that the individual needs further investigation based on their clinical acumen. Implementation would require sufficient training in the software, and diagnostic capacity.



GP with patient who has a headache



Patient at home with a headache



Patient getting a text reminding them to book follow up appointment



Recommendation 2: 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 share among healthcare professionals.

Recommendation 3: The NHS must trial the implementation of a timed safety netting process for patients with brain tumour symptoms, and a clinical decision support tool for consultations that flags potential brain tumour symptoms to GPs.

INTERACTION WITH GENERAL PRACTICE

As mentioned, most brain tumour patients will interact with primary care at some point with their symptoms before receiving a diagnosis. But it can be very challenging for GPs and other primary healthcare professionals to identify the symptoms as a potential brain tumour and refer appropriately. However, there are other reasons why a brain tumour diagnosis may encounter delays and obstacles.

Systemic issues for GPs

GP practice teams are there to help patients with their concerning symptoms through trying to triage the right patients onto the right referral pathways that help get them to a diagnosis quickly.

It can be difficult to assess a patient's symptoms sufficiently in a 10 minute appointment, where patients are encouraged to discuss only one symptom per appointment. This can be particularly difficult for brain tumour patients where the symptoms may appear quite wide-ranging and unrelated, as detailed above. People in our community focus groups also told us they found it more challenging to express a fuller medical situation and symptoms via online or telephone appointments, which are more common following the COVID-19 pandemic, as opposed to face to face.

There are also concerns of continuity of care in primary care, as seeing the same GP for all appointments has become less common across the UK. This may mean if a patient attends primary care multiple times, either

with the same symptom or different but related symptoms, as is often the case for brain tumours, it may not be as easy for different GPs or practice team members to piece together their concerns and build a picture of the patient.

Despite the best intentions and work of GP practices across the country, the continued lack of funding, resources and capacity in the NHS and primary care fuels delays and impacts on diagnosis times for patients. GPs, and the wider NHS system, are under a huge amount of capacity and resourcing pressures which makes it significantly harder to gain the information required to diagnose a potential brain tumour in an appointment.

According to the Royal College of GPs (RCGP), in 2021, GPs carried out almost 370 million consultations in England which was an increase of 18.5% from 2019. As of July 2022, each GP looked after 2,247 patients which is an increase of 16% since 2015.⁴⁵ Faced with these huge increases in workload, clinicians are being forced to reduce their contracted clinical hours and many are leaving the profession altogether, with the RCGP's 2022 survey estimating that 39% of the GP workforce across the UK are seriously considering leaving the profession over the next five years.⁴⁶ The government needs to seriously consider these capacity issues within general practice and how they are impacting a range of disease areas across the country.

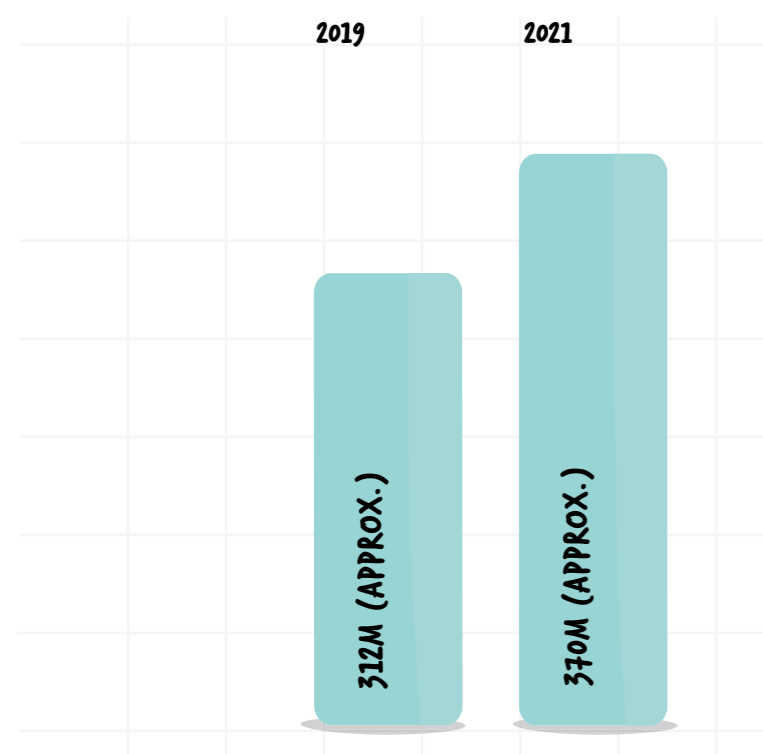
Triage tools

Currently, the only way to detect a brain tumour is by using an MRI or a CT scan, although an MRI scan is the most accurate way. 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 referral⁴⁷.

The cancer landscape is evolving rapidly, with triage tools becoming ever more key to more streamlined diagnoses and can support GP practice clinicians to recognise cancer in a primary care setting. The NHS

is trialling a number of blood tests and different tools that could help recognise who should be referred for further tests in different disease areas. Unfortunately much of this work being trialled does not include tests for brain tumours, as they can be harder to identify. One large scale trial underway within the NHS is the NHS-Galleri trial⁴⁸. This is trialling a blood test that can detect early cancer markers in people's DNA and currently around 140,000 volunteers aged 50 to 77 have registered to take part in the trial. However, this blood test does not detect brain cancers⁴⁹.

However, there is some preliminary work on triage tools for brain tumours being conducted. This includes the development of a different potential blood test, *Dxcover*, which could help GPs prioritise who to refer for a scan,⁵⁰ and is showing promising levels of sensitivity for further investigation⁵¹. 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 individual⁵².



According to the Royal College of GPs (RCGP), in 2021, GPs carried out almost 370 million consultations in England which was an increase of 18.5% from 2019.

Dxcover and Verbal Fluency Test

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.

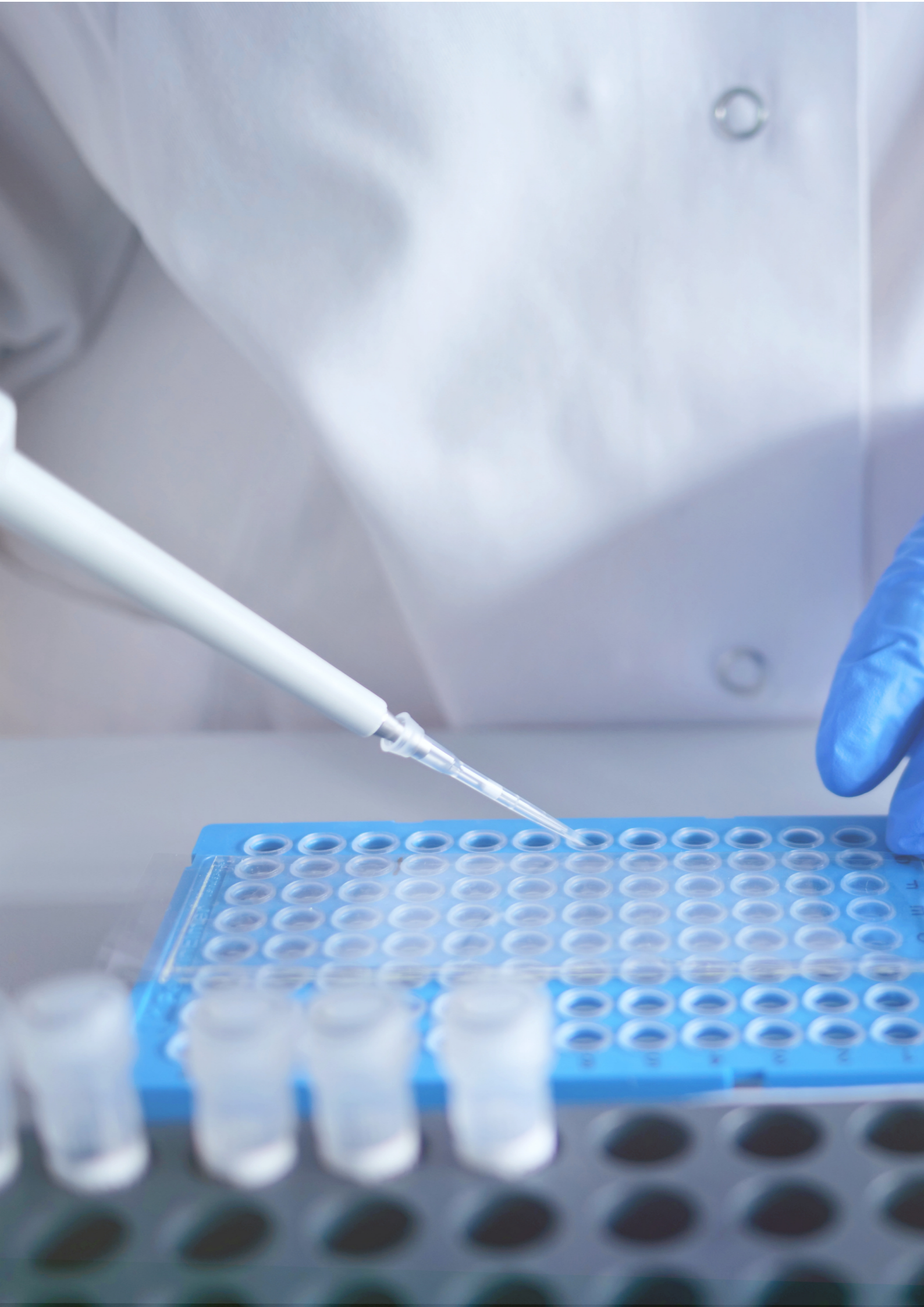
The Verbal Fluency Test (VFT) is a simple language test which asks people to name as many animals as they can in 60 seconds. Dr Brennan and his colleagues in Edinburgh showed in a clinical study that the VFT could help GPs identify which people with common but vague symptoms, such as headaches, are more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

Whether a blood test, such as Dxcover, would be possible to implement in a primary care setting is yet to be seen, but there could be potential use for it in England's Community Diagnostic Centres (CDCs), and their respective schemes in the devolved nations, or in secondary care to help prioritise investigations. CDCs were introduced in England to try to reduce pressure on the NHS by increasing diagnostic capacity as they provide a whole range of diagnostic tests, usually in one hub in the community. The aim is to reduce the pressure on hospitals and secondary care by GPs being able to send patients to access diagnostic tests quickly and conveniently for them.

It is essential that further research is carried out into these potential tests, as there are currently questions around their suitability and where they would be best utilised. 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, with further research these tests have the potential to have a big impact supporting GP practice clinicians.

Recommendation 4: The Government must ensure there is appropriate funding going towards the development of clinical triage tools to detect brain tumours.



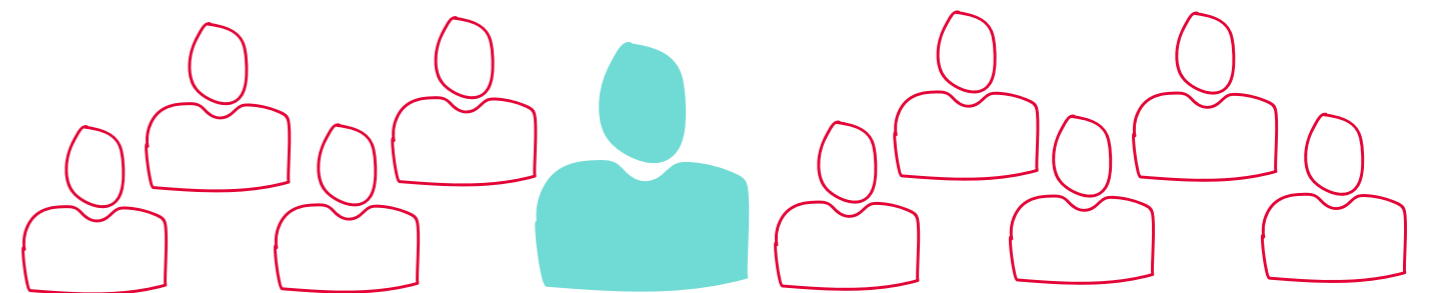
REFERRALS AND PATIENT PATHWAYS

There are a number of different pathways and referrals that may lead a brain tumour patient to their diagnosis; therefore, ensuring these pathways are as efficient as possible is incredibly important. Currently, patients sometimes experience challenges when it comes to getting referred onto the right pathway or seeing the right healthcare professional within an appropriate timeframe.

The IBTC survey showed that over one in seven (15%) of the respondents took over six months to get a diagnosis from first seeing a healthcare professional for their symptoms, with one in 10 (10%) waiting over a year to be diagnosed⁵³. Ensuring patients have the fastest route possible to diagnosis is vital, and referral pathways into and through secondary care make up a big part of this.

In discussion through interviews and workshops, individuals discussed the experience of referrals, and the issues associated with getting the right appointment, with the right

person so they can have the right diagnostic tests, at the right time. Many patients and their loved ones talked about having appointments in secondary care before necessary tests had been undertaken, which increased the time to diagnosis and made their experience worse. It was also highlighted that communication can often feel like a barrier. This was discussed in the focus groups in relation to conversations between healthcare professionals and patients about expectations and next steps, but also between different healthcare professionals through the various pathways, who may struggle to get the full picture of a patients' needs or medical history. Patients felt they had to relay their story and symptoms multiple times to multiple healthcare professionals which ultimately slowed down the process. Or they were left without clear next steps in the process because different hospital departments were not coordinated so test results went missing or they were not kept updated on progress.



The IBTC survey showed that one in 10 (10%) of the respondents were waiting over a year to be diagnosed

“ The GP admitted them to hospital for tests where we were being told they’ve maybe had a stroke or maybe it’s an early sign of MS. In fact it was a glioblastoma...but there was no connection or communication between GP and first, or second, hospital we went to. It was completely disorientating and disconnected. ”

**Participant whose partner was diagnosed with brain tumour –
patient workshop**

“ My partner collapsed, they went to A&E and was sent for an MRI scan. At that point, the processes didn’t knit together...the MRI results didn’t come back to the right department and there was confusion about the referral process within the hospital...There was no coordination between neurology and oncology and I spent 6-8 weeks chasing for the next stage of the process. ”

**Participant whose partner was diagnosed with brain tumour –
patient workshop**

Imaging

All brain tumour patients will receive a scan before a diagnosis. This will be either a CT or an MRI scan, although MRIs are more accurate at detecting brain tumours and don't subject the patient to the radiation associated with a CT scan. A formal and specific diagnosis is then provided following biopsy and/or surgery, where in-depth molecular diagnoses of specific brain tumour type and grade are then provided. Specific diagnosis will follow the World Health Organisation (WHO) classification of brain tumour types, and also provide the grade of the brain tumour to the patient.

At what point along the pathway a patient receives a scan is crucial to a fast diagnosis. Whether this scan should be an MRI or CT scan is debated, but both scans will help a patient receive a diagnosis. The current NICE referral guidance on brain tumours⁵⁴ states that GP teams should have direct access to MRI scans for patients with a suspected brain tumour. However, we know that direct access to MRI scans for GPs has been historically patchy despite this NICE guidance for England.

It was welcome to see on 15 November 2022, NHS England commit to every GP team being able to directly order CT scans, ultrasounds or brain MRIs for patients with concerning symptoms, but who may fall outside the NICE guideline threshold for an urgent suspected cancer referral⁵⁵. As we know though, direct access to MRIs has been recommended to GPs for referral of patients with suspected brain tumours for some time but access has not been universal. Therefore, we need to see this be universally available, alongside the appropriate resourcing and systems support required to make it successful.

It is important that this announcement comes alongside sufficient workforce investment and planning to ensure that there are enough radiologists and neurologists to run the scanners and provide the reports, alongside time for GPs to support the patient following results. It is also vital that sufficient numbers of scanners are available to support this initiative. GP teams should also be provided with any training they require in order to be able to interpret radiologists' reports. If they don't have this training, they may not all be able to provide the most appropriate support or referral for the patient after identifying an abnormality on their scan result.

Direct access also can add necessary GP appointments to this process. Regardless of whether the scan is clear or shows something unusual, GPs will have to follow up and have time with the patient to explain the results. If the patient does not have a brain tumour, the GP will still have to work out what tests or referrals the patient may need to embark on next to relieve their symptoms. This has the potential to improve the process as it means GP teams could have more information and are clearer about exactly where to refer patients. However, it also puts more strain on general practice time and resource. This is why it is so important that this initiative comes with adequate resourcing and funding to ensure it genuinely improves patient pathways.

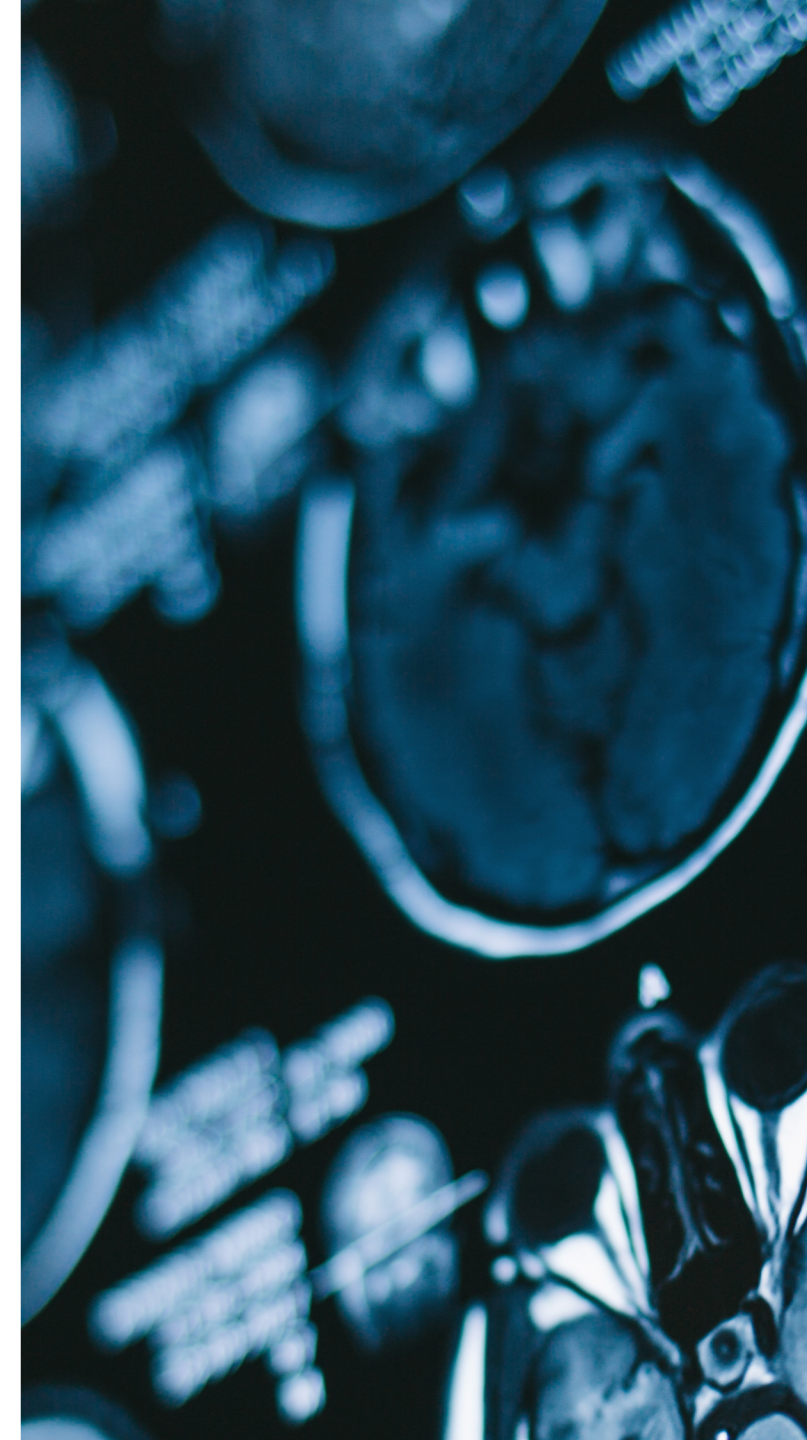
A clear and specific referral pathway for patients whose scan shows something abnormal that may be a brain tumour must also be available for all GPs. GPs need to be able to refer those with abnormal results directly to neurosurgery to get specialist brain tumour care as soon as possible. They should not have to

refer to a more generic secondary care appointment or onto the two week wait for urgent cancer referrals, because those particular pathways would require additional diagnostic tests that would not necessarily be relevant.

If direct access is to work effectively for brain tumours, GPs need to be absolutely clear where they should refer patients with brain tumours onto without the patient having to jump through any more hoops or undergo any further diagnostic tests, unless completely necessary.

East Midlands Direct Access

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"⁵⁶. 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.



Best practice timed pathways

Pathways for patients with suspected brain tumour symptoms can be unclear and varied. Patients can experience multiple different referrals depending on where they live, how well recognised their symptoms are and whether the patient presented at A&E, a GP practice, an optometrist or elsewhere.

One solution to this that NHS England is working on is Best Practice Timed Pathways. These are being set up by NHS England for all cancers, looking at how best to ensure patients receive a diagnosis as quickly as possible, determined by the NHS to be within 28 days. Unfortunately, 28 days can be too long a time period to wait for many patients with brain tumours, particularly if their symptoms are worsening. A time period to aim for of 14 days would better support brain tumour patients to receive a fast diagnosis.

NHS England has not yet developed a Best Practice Timed Pathway for brain tumours but we would welcome this being developed as soon as possible. The consideration of all pathways to diagnosis as part of this work is also vital, including how optometrists may play a role in diagnosis through specific tests and referral into secondary care.

Currently, in Scotland they are developing National Optimal Cancer Diagnostic Pathways which are similar to the Best Practice Timed Pathways but they allow for different provider/commissioner relationships as well as the differences in population distribution and health inequality issues in Scotland. We would also welcome a National Optimal Cancer Diagnostic Pathways for brain tumours being developed in Scotland.

It is important that mapped out and recommended pathways are implemented to support patients as soon as possible across the UK in all the devolved nations. We know, though, that England and Scotland are currently both developing specific pathways for each cancer. Both NHS England and Scotland should develop Pathways for brain tumours, working alongside The Brain Tumour Charity, other brain tumour charities, a range of different healthcare professionals as well as patients and their loved ones.

Non-specific symptom pathways

The non-specific symptom (NSS) referral pathway exists in England for GPs to refer patients with vague or non-specific cancer symptoms (such as fatigue, unexplained weight loss or nausea), or if the GP has a gut feeling that a patient may have cancer. This can help patients visit their GP practice fewer times before being referred for tests. The NSS pathway refers a patient to a diagnostic centre, a Rapid Diagnostic Centre (RDC) in England, where multiple tests can be coordinated and carried out. The RDCs in England are designed to assist with diagnostic capacity and they do this via the NSS referral pathway. There are ambitions to also roll out similar diagnostic centres across the devolved nations.

The NSS pathway has the potential to benefit brain tumour patients, but at present the symptoms are not wide enough for most patients to be referred. Although the NSS pathway looks to help with vague or non-specific cancer symptoms such as weight loss or fatigue, these are not the same as the vague or non-specific symptoms associated with a brain tumour. The vague or non-specific

symptoms associated with a brain tumour can be headaches, dizziness or numbness, for example.

Cancer Research UK piloted the concept of Multidisciplinary Diagnostic Centres (MDCs)⁵⁷ based pathways in five projects across England⁵⁸. These were the precursor to RDCs. In the pilot study of MDCs, only one diagnosis was for brain cancer⁵⁹, but the small sample size of the project means that conclusions cannot be drawn from this published data on the effectiveness of the potential approach for brain cancers.

In Scotland, a similar project is currently called the Rapid Cancer Diagnostic Service (RCDS) and was previously known as Early Cancer Diagnostic Centres (ECDC). They are still at pilot stage with the first three RCDS pathways being introduced in NHS Ayrshire & Arran, NHS Dumfries & Galloway and NHS Fife in summer 2021. An interim report on the progress of these three pilots was then published in November 2022. According to that report, there do not seem to be any brain cancer patients diagnosed in the three RCDS pathways so far⁶⁰.

Without the symptoms of a brain tumour being included on the referral list, it is difficult to know how the RDCs in England, or RCDS in Scotland, could help improve diagnosing brain tumours.

As discussed, the non-specific symptoms that are included for a referral do not include more general brain tumour symptoms. Although we describe brain tumour symptoms as vague or non-specific, they are not the same as the vague and non-specific cancer symptoms. By including brain tumour symptoms in

the referral criteria for the NSS pathway that refers patients to RDCs, this has the potential to result in more timely access to the tests which are coordinated in the centres, which often includes MRI or CT scans. Not only does this reduce appointments required, but it can provide a broad assessment of all of a patient's symptoms at once.

The easiest way to do this would be to include what is currently in the NICE guidance for direct MRI access which is "loss of central neurological function (progressive, sub acute) in adults"⁶¹.

Expanding the referral criteria, in England and Scotland, should be carried out alongside an increase in diagnostic capacity, and workforce to support patient referrals to be seen as quickly as possible.

Optometry (written in collaboration with The College of Optometrists)

Another way in which people may be diagnosed with brain tumours is through their local optometrist. 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.

In addition to this, we know that primary healthcare professionals may refer people onto optometry when they present with certain types of headaches or if they are associated with ocular symptoms. However, in England there is currently no formal, dedicated pathway for patients experiencing headaches 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. However, the sight test is not a screening or monitoring service, some but not all investigations that make up a statutory sight test may be necessary, and not all patients are eligible for NHS funded sight tests. 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. While sight tests are free to all in Scotland, there is recognition that this is not an appropriate route to refer patients towards as they may not need a full sight test, it reduces the capacity for those who do and the cost to the NHS may be greater. Therefore, GPs and other health professionals in some areas of Scotland are able to refer patients to a dedicated and accessible service locally where clinically indicated, quickly and cost-effectively.

Patients across the UK could stand to benefit from a specific pathway in optometry given that some patients may present with ocular manifestations of a brain tumour. Although some nations do not currently have universal sight test coverage, this route is not appropriate to access the tests and investigations they need. However, provision for this would depend on local or regional commissioning decisions based on local variability, funding and need. If, however, a recommended pathway were developed in collaboration with relevant stakeholders including the NHS and primary care optometry, this could then be adapted and implemented in all areas based on local need and circumstances. Thus NHS bodies should therefore develop a recommended pathway for this drawing upon the expertise of relevant organisations such as the Clinical Council for Eye Health Commissioning, The College of Optometrists and The Brain Tumour Charity.

Recommendation 5: As per recent plans announced in England, the NHS should ensure that universal direct access to MRI and/or CT scans for GP practices across all of the UK is achieved. This must always be available alongside sufficient training to interpret the results, appropriate staffing and systems resource, and a direct referral pathway to neurology.

Recommendation 6: The NHS must develop a Best Practice Timed Pathway in England and an Optimal Cancer Diagnostic Pathway in Scotland for brain tumours, so that appropriate referral pathways and the relevant tests required are set out.

Recommendation 7: NHS England and Scotland must widen the list of non-specific symptoms (NSS) that warrant referral to the NSS pathway so that they include potential brain tumour symptoms.

Recommendation 8: 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 commissioners⁶²

Optical engagement from The Brain Tumour Charity

One of the ways The Brain Tumour Charity has worked with optometrists across the country to spread awareness of the link between brain tumours and optometry is through our Optical Engagement Manager. This position has allowed us to deliver training, host webinars, work with different professional bodies in the sector and speak at conferences all to help raise awareness of the optical symptoms of a brain tumour.

RECOMMENDATIONS

- 1** In order for brain tumours to be included in each devolved nation Government's ambitions to improve early diagnosis of cancer, we must 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. Proxy measure examples could be proportion of emergency diagnoses or time to diagnosis.
- 2** 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 share among healthcare professionals.
- 3** The NHS must trial the implementation of a timed safety netting process for patients with brain tumour symptoms, and a clinical decision support tool for consultations that flags potential brain tumour symptoms to GPs.
- 4** The Government must ensure there is appropriate funding going towards the development of clinical triage tools to detect brain tumours.
- 5** As per recent plans announced in England, the NHS must ensure that universal direct access to MRI and/or CT scans for GP practices across all of the UK is achieved. This must always be available alongside sufficient training to interpret the results, appropriate staffing and systems resource, and a direct referral pathway to neurology.
- 6** The NHS must develop a Best Practice Timed Pathway in England and an Optimal Cancer Diagnostic Pathway in Scotland for brain tumours, so that appropriate referral pathways and the relevant tests required are set out.
- 7** NHS England and Scotland 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.
- 8** 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.⁶³

CONCLUSION

This report has looked at the faster diagnosis of brain tumours because of the differences in how they act compared to other cancers and other disease areas. Other cancers and disease areas focus on an earlier diagnosis as there are direct links between an earlier diagnosis and better survival outcomes. It can genuinely be the difference between a disease being curable or being terminal. For lots of brain tumours, particularly cancerous or more aggressive tumours, this is not the case. There is no known direct link between a tumour being discovered earlier and a greater survival outcome, although this has not been formally studied due to a lack of understanding of the natural history of the disease. This can be an incredibly difficult thing to come to terms with, but that's not to say a link won't be discovered as there are many aspects of brain tumours, their development and growth, that we still do not know about. We also do not have a way of tracking how early a tumour has been discovered if it is cancerous. Other cancers are given a stage based upon how much it has or hasn't spread around the body. Brain tumours, when they are cancerous, do not spread around the body in the same way and so we cannot provide a stage for how late or early it has been detected. These differences make it all the more difficult to be able to work on catching a tumour "earlier" like other disease areas.

This is why we have chosen to concentrate on improving the speed at which people are diagnosed once they present with symptoms. Having a faster diagnosis does have the potential to be incredibly beneficial

and important to brain tumour patients. There is the potential to minimise permanent neurological disabilities, for people to feel more prepared and that they have more time to come to terms with their diagnosis, for people to potentially withstand treatments better and also for people to have improved trust in healthcare professionals. There is also the potential for future benefit. As more drugs are developed in cancers and brain tumours, there is a very real possibility that certain drugs may work more effectively on tumours that are discovered at an earlier point, as there are in other disease areas.

This report has brought together a range of experts in this area, from clinicians, to patients, to researchers, and healthcare professionals to help identify recommendations that policymakers could take that would lead to improvements in the speed of diagnosis for patients. Too many brain tumour patients are currently being let down by slow and difficult routes to diagnosis and this needs to change. If relevant policymakers were to implement some of these recommendations, we could stand to see significant improvements, not just to patients, but also to healthcare professionals as they are supported as well.

These recommendations demonstrate where there is real possibility to improve the experience for patients, building on existing work and suggesting new areas of exploration. The Brain Tumour Charity will continue to push forward work in this space, but it is also hoped this report will act as a catalyst to propel this work forwards and promote a wider discussion in this area.

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