

# FINDING MYSELF IN YOUR HANDS

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THE REALITY OF BRAIN TUMOUR  
TREATMENT AND CARE

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## 1. A message from our CEO

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours, making a difference every day to the lives of people with a brain tumour and their families. We fund pioneering research to increase survival, raise awareness of the symptoms and effects of brain tumours, and provide support for everyone affected, to improve quality of life.

We are committed to making the greatest possible impact on the lives of everyone affected by a brain tumour, to defending the most amazing part of the human body, and together defeating brain tumours. Our knowledge and experience show that only ambitious goals are adequate to the task of making real and lasting change, so that a diagnosis no longer means a death sentence. This aspiration is reflected in our organisational goals: to double survival within 10 years and to halve the negative impact that brain tumours have on quality of life.

It is with these goals in mind that we commissioned *Life with a Brain Tumour*, a landmark research project which investigated what life is really like for those adults living with a brain tumour and what their experience of treatment and care has been. It is the most comprehensive study of its kind and has paved the way for a further study of the experiences of children, young people and families.

In the sister report to this publication *Losing Myself: The Reality of Life with a Brain Tumour* we presented findings from the research on the daily life of those living with a brain tumour – moving personal stories and stark statistics which demonstrate the extensive impact this disease has on how those affected live day-to-day.

This report, *Finding Myself in your Hands: The Reality of Brain Tumour Treatment and Care*, outlines the findings relating to respondents' experiences of their NHS treatment and care. Our data sadly mirror those from NHS cancer patient experience surveys: although some aspects of treatment and care are positive, many of those with a brain tumour report a poor experience. I would like to thank everyone who took part in this vital research and helped us to reach a deeper understanding of the needs of and challenges faced by our community. I would urge policy makers to work with us in enacting the recommendations contained in this report which, if implemented, will make a huge difference to our community and help improve life today for everyone affected by this terrible disease.

**Sarah Lindsell**  
CEO



## 2. About the project

The findings presented in this report are taken from the *Life with a Brain Tumour* project, conducted by The Brain Tumour Charity in partnership with Alterline, an independent research agency. In total 1,004 people completed the study questionnaire between 13 February and 13 March 2015, of which 927 were valid responses. Following the survey, 15 people took part in in-depth, face-to-face interviews and a further 25 kept reflective diaries over seven days.

The questionnaire used to collect the large-scale data was directly advertised to subscribers to The Brain Tumour Charity's e-newsletter. It was also promoted on The Charity's website and other communication channels, and by The Charity's volunteer and healthcare professional networks. The majority of respondents accessed the questionnaire online, with a small number completing it over the phone.

Alterline also publicised the questionnaire on mainstream social media websites to reach people living with a brain tumour who had no association with The Charity. Developed by Alterline alongside The Charity, the questionnaire covered many aspects of people's lives and medical care, reflecting experiences recounted in pre-survey scoping interviews with people with a brain tumour.

The results reported here include tests of relationships between variables, as well as univariate analysis. Differences between socio-demographic and diagnostic groups that were found to be statistically significant are presented and discussed. The standard provisos for the interpretation of social science survey datasets of this size apply in this case: firstly, some of the bi-variate tests were based on sub-samples that were too small for statistically significant differences, which might exist in the wider population, to be detectable; secondly, the data were

not collected using random sampling. It must also be noted that the tests reported explore associations between variables and do not indicate causal relationships.

The results of this study are presented in this report alongside statistics from the 2014 National Cancer Patient Experience Survey (NCPES) in England and the 2013 Welsh Cancer Patient Experience Survey. Although there are not yet any national experience data available for Scotland and Northern Ireland, our interactions with those affected suggest that the findings hold true across the UK. It is important to note that while the secondary statistics taken from the NCPES are useful for contextualising the primary data reported here, the NCPES only includes patients with high grade tumours, whilst this study includes both high and low grade brain tumour patients.

The quotations that appear in this report are exact transcriptions of words spoken by people who took part in the research; all case studies likewise feature photographic images of study participants.

Our data provide a snapshot of experience at a single point in time. In order to drive improvements that most effectively meet the needs of people with brain tumours throughout the course of their care, it will be important to monitor the experience of patients with both high and low grade tumours over time.

**1 Recommendation:** NHS England, the Scottish Government, the Welsh Government and the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland should collect data on the experiences of people with both low and high grade brain tumours.

Every day 27 people in the UK are diagnosed with a brain tumour<sup>1</sup>

That's 9,678 people diagnosed with a primary brain tumour every year<sup>2</sup>

Best estimates are that around 55,000 people are living with a brain tumour in the UK<sup>3</sup>

### 3. Introduction

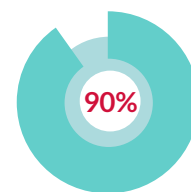
A fundamental difference between a brain tumour and a tumour in other parts of the body is the extent to which it can impact on the characteristics and faculties that make people individuals. As well as causing a range of physical impairments, from chronic fatigue, headaches and balance problems to seizures and paralysis, brain tumours can affect personality, memories, cognition and the ability to communicate with others. The effect of these changes may be felt in all areas of a person's life – the personal, familial, social and professional – placing a strain on relationships, as well as finances. In our report *Losing Myself: The Reality of Life with a Brain Tumour* we examined how people with brain tumours try, fail, struggle and succeed in dealing with the demands of this disease in their daily life.

In this report, we consider what it is like to be treated for a brain tumour in the NHS across the UK, encompassing diagnosis, treatment, support and end-of-life planning. Brain tumours can be difficult to manage, with tough choices facing patients and clinicians alike. At the centre of this process is a person who finds themselves in new and unfamiliar circumstances; who must learn to contend with enormous uncertainty and fear, as well as hope.

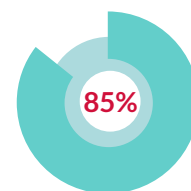
Since brain tumours frequently necessitate major medical intervention, the interactions patients have with the NHS have a substantial impact on their overall experience of living with, and sometimes dying from, this disease. Yet, despite the ongoing interactions with the NHS this typically entails, just over a third (34%) of people spoken to in this study said they do not feel that NHS healthcare professionals understand what life with a brain tumour is like. Meanwhile, over half

(52%) reported that they do not believe the NHS gives brain tumours the level of attention they deserve. Thus, whilst many have confidence in the capacity of the service to treat and care for them, these statistics signal room for improvement – a challenge to healthcare professionals already making great efforts to do more with less, in a climate of increasing pressure on NHS resources.

This report aims to help build on existing good practice and inform improvements to current NHS provision for those living with a brain tumour. It situates the patient experience within the context of current service constraints, and provides a series of actionable recommendations intended to help ensure that brain tumour patients receive the best care possible within present NHS capacity.



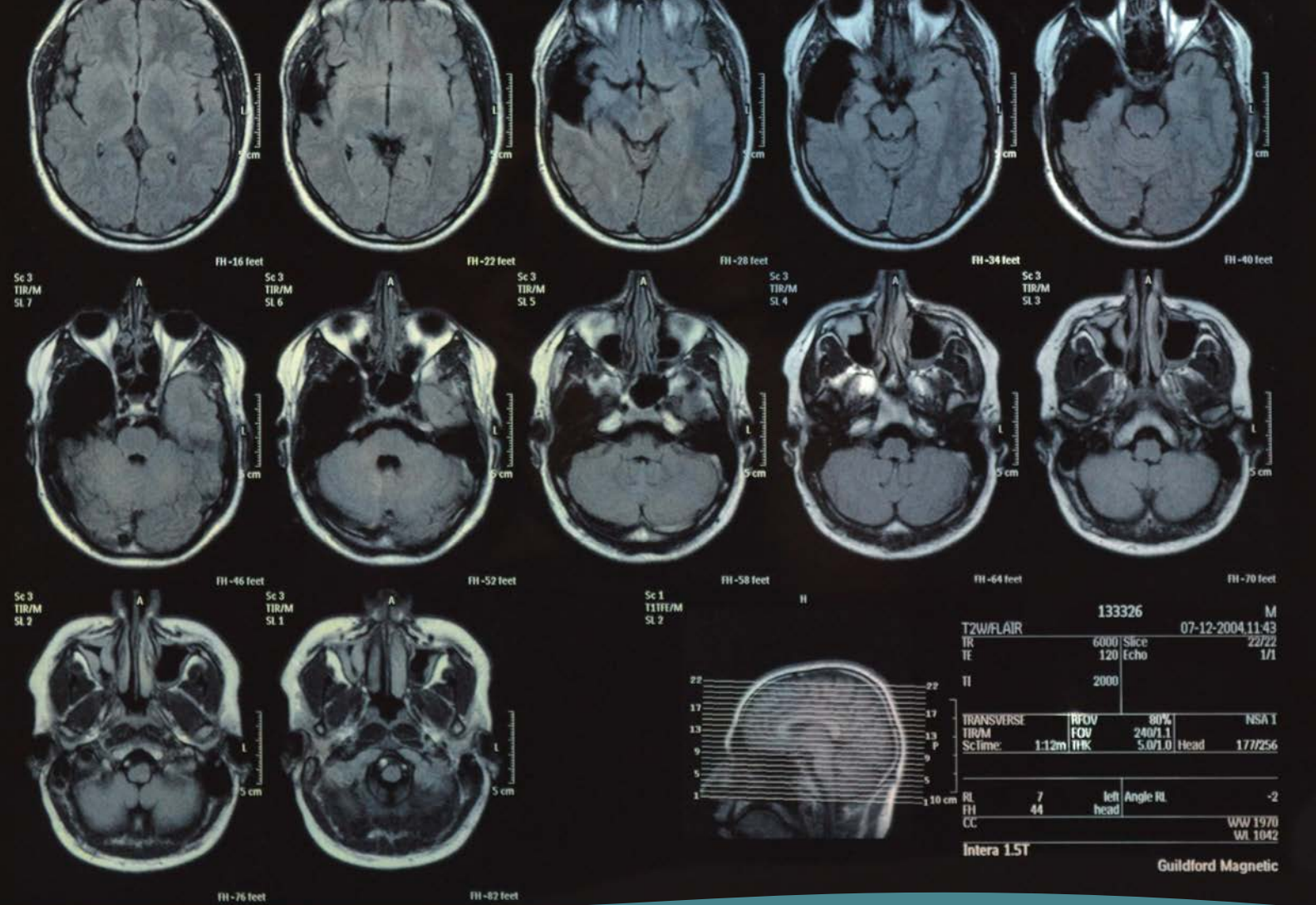
**Nearly 90% of people with brain tumours in this study have received, or are receiving, treatment**



**85% of respondents are satisfied with their experience of surgeons**

1, 2 Based on 2012 statistics from: Cancer Research UK. *Brain, other CNS and intracranial tumours statistics* Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-tumours#heading-Zero> [Accessed 29 October 2015].

3 brainstrust. *Living with a brain tumour*. Available from: [http://www.brainstrust.org.uk/Uploaded/brain\\_tumour\\_infographic.jpg](http://www.brainstrust.org.uk/Uploaded/brain_tumour_infographic.jpg) [Accessed 21 May 2015].



## 4. Getting diagnosed

The range and severity of possible symptoms of a brain tumour can make the pre-diagnostic period an alarming and bewildering time for the patient and their loved ones. Fear of the unknown and the pain and distress of symptoms can lead individuals to invest heavily in the expectation that their GP will provide answers and reassurance. The experience of this first stage on a patient's journey, and the manner in which their diagnosis is communicated to them, are pivotal in establishing confidence in the care on which they will subsequently depend.



Just over half of respondents were satisfied with how healthcare professionals dealt with their diagnosis



A third of respondents said they were dissatisfied with their experience with their GP



31% visited a healthcare professional five or more times prior to diagnosis

**“They left me undiagnosed for 3 years and on every hospital admission accused me of attention-seeking, and on one admission they thought I was on illegal drugs.”**

28 year-old woman with a low grade tumour

#### **4.1 Patient satisfaction with the diagnostic experience**

Participants in this study were asked how satisfied they were with the manner in which healthcare professionals handled their diagnosis. Just over half (53%) reported satisfaction, 17% said they were neither satisfied nor dissatisfied and 29% reported dissatisfaction. This suggests that for a substantial minority the symptoms of a brain tumour and the stress of not knowing the cause is not mitigated by their experience as an NHS service-user. Accounts from people with both positive and negative experiences illuminate the factors that define the overall quality of the diagnostic journey from the patient's perspective.

#### **4.2 Speed and difficulty of obtaining a diagnosis**

Recent research shows that the route to diagnosis can have a significant impact on later experience, with those experiencing a straightforward route to diagnosis generally having a more positive experience of care<sup>4</sup>. Many participants in this study reported positive experiences, with the majority of respondents (51%) receiving a diagnosis within three months of their first visit to a medical professional regarding their symptoms. Meanwhile a quarter (24%) were diagnosed

over a year after their first visit, and a third (35%) a year or more after the emergence of symptoms. Most people saw a GP several times in the lead-up to diagnosis, with the majority (55%) visiting a GP three or more times, and one in three (31%) more than five times. The National Cancer Patient Experience Survey (NCPES) in England asks about visits to the GP prior to referral to hospital. 39% of respondents to the 2014 survey with a brain or central nervous system (CNS) tumour reported visiting their GP more than twice prior to referral, compared to 25% of all cancer patients in the survey<sup>5</sup>. This was the second highest proportion across all 13 tumour types, after those with sarcoma.

An analysis of the data from this study examining the relationship between speed of diagnosis and characteristics of patients and their condition found that overall men who participated are more likely to have received a diagnosis in a shorter time period and with fewer visits to a doctor than women. A breakdown of the differences is shown on the following page. Taken together these statistics suggest a worrying disparity between men and women in the speed and ease of obtaining a diagnosis.

4 Mendonca S.C., Abel G.A., Saunders C.L., Wardle J., Lyratzopoulos G. Pre-referral general practitioner consultations and subsequent experience of cancer care: evidence from the English Cancer Patient Experience Survey. *European Journal of Cancer*. 2015; Jul 30. Available from: DOI: 10.1111/ecc.12353 [Accessed 3 September 2015].

5 NHS England. *Cancer Patient Experience Survey 2014 Methodology and Data Tables Supplement*. Available from: <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey> [Accessed 12 Aug 2015].

Men were more likely than women:

- to be diagnosed within a year of initial symptoms
- to see 3 months or less pass between their first visit to a doctor and diagnosis
- to have seen a doctor only once or twice prior to diagnosis.

Women were more likely than men:

- to see between 1 and 3 years and 5 or more years pass between first symptoms and diagnosis
- to wait 10 or more months between their first visit to a doctor and diagnosis
- to have made more than five visits to a doctor prior to diagnosis.

The relationship between income and speed of diagnosis was also examined, for those who gave a response to the income question. Lower earners were found to be more likely to obtain a diagnosis more slowly and with a greater number of visits to a doctor than higher earners.

Respondents with an annual household income of less than £20,000 were:

- more likely than those earning £20,000-£39,999 to see 5 years or more go by between the emergence of symptoms and diagnosis
- more likely than those earning more than £40,000 per year to see more than 12 months pass between their first visit to a doctor and their diagnosis
- more likely than those earning more than £40,000 to visit a doctor more than five times prior to diagnosis.

Respondents with an annual household income of more than £40,000 were:

- more likely than those earning less than £20,000 per year to have less than a year go by between the emergence of symptoms and diagnosis.

These findings are consistent with existing research on inequalities in cancer survival and routes to diagnosis. A longstanding relationship between socio-economic status and cancer survival rates has been found in successive international literature reviews, attributed at least in part to stage of disease at diagnosis<sup>6</sup>. Meanwhile, recent data from

the NHS in England show a higher proportion of diagnoses via emergency presentation amongst patients living in the most deprived areas compared to those resident in the least deprived<sup>7</sup>. The factors explaining these findings are complex, multiple and interacting, and may include aspects of patient behaviour, such as non-identification of symptoms, delay in help-seeking when symptoms are identified, and poor communication with clinicians<sup>6,7</sup>. However, the effect of these issues may be mitigated by greater clinician awareness and sensitivity to the differential obstacles to diagnosis associated with different social-demographic groups.

Finally, a relationship was also found between tumour grade, and speed and ease of getting diagnosed – those with low grade tumours waited longer overall and made more visits to a healthcare professional prior to diagnosis than those with a high grade tumour.

Respondents with a high grade tumour were more likely than those with a low grade tumour:

- to see less than a year pass between first symptoms and diagnosis
- to see less than 4 months pass between their first visit to a doctor and diagnosis
- to visit a doctor only once prior to diagnosis.

Respondents with a low grade tumour were more likely than those with a high grade tumour:

- to see between 1 and 3 years and more than 5 years pass between first symptoms and diagnosis
- to see more than 10 months pass between their first visit to a doctor and diagnosis
- to make 5 or more visits to a doctor prior to diagnosis.

Qualitative data from this study indicate that prior to diagnosis some individuals find themselves fighting to be taken seriously by clinicians in both primary and secondary care. People described GPs refusing to make referrals to specialists equipped to give a diagnosis. Reports of misdiagnosis and of major symptoms being missed were also numerous. One male respondent was dismissed by his GP and was then accused of 'faking it' by hospital doctors prior to diagnosis of a high grade tumour, whilst a female respondent reported being accused of attention-seeking and taking illegal drugs.

6 Woods L.M., Rachet B., Coleman M.P. Origins of socio-economic inequalities in cancer survival: a review. *Annals of Oncology*. 2006; 17: 5–19. Available from: <http://annonc.oxfordjournals.org/content/17/1/5.full> [Accessed 27 October 2015].

7 Public Health England. *Cancer and equality groups: key metrics* 2014. Available from: <http://www.ncin.org.uk/search/equality> [Accessed 27 October 2015].



## “I said ‘That’s my what?’ He assumed I’d already been told I had a brain tumour.”

Joanne used to live in Oldham and work for the police force, but since her diagnosis she has had to give up work. She now lives with her husband in Warrington. She is very interested in researching alternative therapies and treatments for her brain tumour, and always tries to have an extremely positive mental attitude.

“My story started in 2007, but I didn’t have any of the traditional brain tumour symptoms. I had these strange auras, whereby I’d be looking at someone and I’d be aware of everything in the room, but if you were to tell me a joke, I would want to laugh but it would feel like my face wouldn’t move. I usually talk a lot, and very fast, but it would feel as though my speech would slow down.

When it started getting worse, I went to my GP and said it’s probably something and nothing, but I’m having these strange episodes. She thought I was having mini-strokes, and referred me for an MRI. Eventually I went to hospital with my parents to get my MRI results, and the doctor told me that I had inflammation of the brain. I was absolutely distraught — I hadn’t expected that. He wrote a prescription out and passed it to my dad, bearing in mind I was 39 years old at that point. He then told me he would refer me to a neurosurgeon, but said not to worry because it’s not urgent. When we got outside, I’ll never forget the

words my mum said to me, she said ‘Don’t worry love, it could have been worse. He could have told you it was a brain tumour.’

I went to pick up the prescription from my doctors, and the receptionist commented to me that I wouldn’t have to pay for my prescription, because you don’t pay for epilepsy medication. Up until that point, nobody told me I’d got epilepsy, so that was my second big shock.

I waited ages for the appointment, but I never got a letter. I phoned the neurosurgeon I was due to see, but his receptionist said that he wouldn’t be able to see me because he doesn’t have any appointments. I said, ‘What, this week? This month? This year? What does that even mean?’ I phoned my original doctor and he couldn’t believe I hadn’t been seen yet. He arranged for me to see a different neurosurgeon.

When we finally saw the second neurosurgeon, he put up my scans on the wall, and said “Do you see that white bit at the top? That’s your tumour”. I said “That’s my what?” He assumed I’d already been told I had a brain tumour, and I had to tell him all I’d been told was that I’ve got inflammation on the brain. He was absolutely gutted, as was I, as were my mum and dad.”

Joanne, 47, from Warrington



Such accounts provide an insight into the experiences of the third of respondents (34%) in this study who said that they were dissatisfied with their experience with their GP. Indeed, exploration of the relationship between satisfaction with GPs and three measures of speed of diagnosis showed those who received an earlier diagnosis were overall more likely to be satisfied with their GP than those who waited longer.

People who were satisfied and neither satisfied nor dissatisfied with their experience with their GP were more likely than those who were dissatisfied:

- to have seen less than a year pass between first symptoms and diagnosis
- to have seen a month or less pass between their first visit to a doctor and diagnosis
- to have visited a doctor before diagnosis once or twice, in the case of those who were satisfied.

People who were dissatisfied with their experience with their GP were more likely than those who were satisfied:

- to have seen 3 to 4 years and more than 5 years pass between first symptoms and diagnosis.

They were more likely than both those who were satisfied and those who were neither satisfied nor dissatisfied:

- to have seen more than 12 months pass between their first visit to a doctor with symptoms and diagnosis
- to have to have visited a doctor more than five times with symptoms prior to diagnosis.

Furthermore, analysis from the National Cancer Intelligence Network (NCIN) found that 53% of high grade brain tumours are diagnosed as an emergency – among the highest of all cancer types.<sup>8</sup> – more than any other cancer. It is important to underline that the drivers of satisfaction with the diagnostic process are not confined to the primary care setting. The qualitative data obtained in this study confirm that experiences in both primary and secondary care are a source of dissatisfaction with the experience of diagnosis. They include accounts of dismissive or obstructive behaviour, a perceived lack of knowledge of the disease and incorrect attribution of brain tumour symptoms to other conditions.

*“One of the GPs I saw actually made fun of me saying what did I think my headaches were, a brain tumour? I had to request a referral to neurology. I went back repeated times to be given antidepressants, sleep charts, analgesia etc. No-one took me seriously.”*

39 year-old woman with a low grade tumour

These findings must be set in the context of the clinical challenge that diagnosis of a brain tumour presents to healthcare professionals, and particularly GPs. Diagnosis of a brain tumour in primary care can be complex, as the symptoms often mimic those of other conditions. Individual GPs are likely to see very few new brain tumour cases during the course of their career, which may limit their familiarity with symptoms. Indeed, both the relative rarity of brain tumours, and fact that they share symptoms with other more common conditions, makes the consideration and ruling out of alternative diagnoses a necessary step in the initial stage of the diagnostic journey.

**2 Recommendation:**  
NICE should update the *Referral guidelines for suspected cancer*, and Healthcare Improvement Scotland should update the *Scottish referral guidelines for suspected cancer*, on an ongoing basis as new evidence emerges on symptoms that are recurrent, or that occur in combination.

Nevertheless, the clinical challenge facing GPs in diagnosing a brain tumour does not preclude efforts to improve the diagnostic process, by learning lessons from existing patients' experience. It is with this aim that The Brain Tumour Charity is funding research into the diagnostic pathway for adults with a brain tumour, in order to better understand the common symptoms, causes of lengthy diagnosis times, and the impact of a delayed diagnosis on outcomes.

<sup>8</sup> National Cancer Intelligence Network. Routes to diagnosis 2006-2013. Available from: [http://www.ncin.org.uk/publications/routes\\_to\\_diagnosis](http://www.ncin.org.uk/publications/routes_to_diagnosis) [Accessed 30 December 2015].

# 3

## Recommendation:

As further evidence on the causes and impact of delays in adult brain tumour diagnosis emerges, Public Health England, the Scottish Government, Public Health Wales and the Public Health Agency in Northern Ireland should develop a campaign to improve awareness of symptoms amongst the general public, building on the success of the HeadSmart campaign for children.

### 4.3 Quality of communication

Receiving the diagnosis of a tumour in the brain is a frightening and life-changing experience that can leave the individual and their loved ones emotionally overloaded and struggling to comprehend important medical details. Clear and sensitive communication by healthcare professionals is therefore a crucial aspect of the patient-clinician interaction and an area where a significant positive impact can be made, in terms of helping the patient understand and come to terms with the implications of their diagnosis. The 2014 NCPES asked participants whether they were given an explanation of test results in an understandable way, to which over a quarter (27%) of brain and central nervous system cancer patients answered negatively – the highest proportion of all 13 tumour groups included in the survey<sup>9</sup>. Meanwhile, 64% reported that they completely understood the explanation of what was wrong with them – some way below the average of 73% across all tumour types<sup>9</sup>.

In the 2013 Welsh survey, only 61% of brain and central nervous system cancer patients responded affirmatively to this question – the lowest proportion across all cancer types – compared to 75% of all respondents<sup>10</sup>. Brain tumours can be complex and take many forms, increasing the communication challenge for clinicians and the difficulty of comprehension for patients. Furthermore, those affected by a brain tumour may experience cognitive or communication issues (depending on the location of the tumour) making the manner in which a diagnosis is delivered all the more pivotal. Communication of diagnosis therefore requires careful thought and should be tailored to the needs of the individual patient.

The critical role of communication quality was underlined in this study: among people whose

experiences of diagnosis were positive, the honest and straightforward answering of their questions by clinicians was repeatedly cited as an important factor and one that encouraged them to have confidence in the process and the people involved. Amongst those reporting a negative experience, poor explanations and doctors allowing insufficient time for questions were reported as a cause of unnecessary confusion and distress.

*“This was just said straight out — no lead up and no full explanation. The doctor went on to explain that the 14 months’ life span was a median statistic. No explanation of median statistics (our psychologist son explained it to us). The diagnosis was given in too blunt a fashion, causing extra hurt and pain.”*

66 year-old man with a high grade tumour

There can be a lot of information to take in at the time of diagnosis. Absorbing this detail whilst contending with the emotions that the diagnosis of a tumour typically provokes can be very tough indeed. For this reason, the provision of clear written information about a person’s diagnosis that they can refer back to in their own time may be especially helpful for some people. The 2014 NCPES found that only 61% of brain and central nervous system tumour patients said that they had received written information about the type of cancer they had and that it was easy to understand – the third lowest proportion amongst all 13 tumour types – compared to 81% of respondents with skin cancer and 80% of those with prostate cancer<sup>9</sup>. The Brain Tumour Charity provides a comprehensive range of information on brain tumours, from symptoms and tumour types to treatments and managing the impact of living with a brain tumour, which could be used to address this issue.

# 4

## Recommendation:

Multi-disciplinary teams (MDTs) should provide, or signpost towards, The Brain Tumour Charity’s information and support services at the point of diagnosis and throughout treatment and care.

<sup>9</sup> NHS England. *Cancer Patient Experience Survey 2014*, National Report. Available from: <https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey> [Accessed 11 Sept 2015].

<sup>10</sup> Welsh Government, Macmillan Cancer Support, NHS Wales. *Wales Cancer Patient Experience Survey National Report 2013*. Available from: <https://www.quality-health.co.uk/resources/surveys/welsh-cancer-experience-survey/2013-welsh-cancer-experience-survey/wales-cancer-patient-experience-reports-english-language-versions> [Accessed 11 September 2015].

#### 4.4 Kindness, sensitivity and emotional support

Many of those whose experience of diagnosis was positive commented on the kindness, sensitivity and professionalism of those involved in their care. It is clear that consideration of the emotional health of the patient can help to mitigate the trauma of diagnosis. In the 2014 NCPES, 81% of brain and central nervous system patients said they were told sensitively that they had cancer<sup>9</sup>. This is encouraging, but raises questions about the remaining fifth of patients who felt that this could be improved. Participants in our study who reported a negative diagnostic experience gave accounts of a disturbing lack of compassion and a failure to appreciate the impact on the individual of receiving a life-changing diagnosis. A lack of post-diagnostic support for both patients and carers was also highlighted. Conversely, those whose experience was positive gave high praise to healthcare professionals in a range of roles for their kindness, care and professionalism.

*“From the locum GP back in 2007 up until now I have had brilliant help in all areas. Everyone has been very caring, understanding, helpful — all the good things.”*

28 year-old woman with a low grade tumour

The NCPES has consistently demonstrated the positive impact that clinical nurse specialists have on experience. Clinical nurse specialists can provide or signpost towards sources of emotional support – a contribution which may be of particular importance at certain stages of the patient journey, including at the time of diagnosis. The NICE manual<sup>11</sup>, *Improving Outcomes for People with Brain and Other Central Nervous System Tumours* states that, ‘Clinical nurse specialists should be core members of the neuroscience brain and other central nervous system tumours MDT [multidisciplinary team]... They are likely to take on the role of key worker for many patients, especially during the early stages of their clinical care, providing supportive care, information and continuity of care with other healthcare professionals.’ However, in the 2014 NCPES, 29% of brain and central nervous system cancer respondents did not find it easy to contact their clinical nurse specialist<sup>9</sup>. It is unclear whether this is due to caseload, inadequate contact information or another

reason. The support that the clinical nurse specialist can provide is important for people with both low grade and high grade tumours.

Unlike the NCPES, which only speaks to high grade tumour patients, the study reported on here surveyed both high and low grade tumour groups. It found that those with a high grade tumour were statistically significantly more likely to agree that they had a single point of contact than those with a low grade tumour. Just over half (53%) of low grade tumour patients said they had a single point of contact, compared to three-quarters (76%) of those with a high grade tumour. Such a disparity is cause for concern. It is vitally important to recognise that the need for timely, sensitive communication and support is not determined by the clinical profile and prognosis of the person affected.

**5 Recommendation:** Health Education England, NHS Education for Scotland, Welsh Health Boards and the Northern Ireland Health and Social Care Board should review the capacity and sustainability of the brain tumour clinical nurse specialist workforce in each nation.

11 National Institute for Health and Clinical Excellence. *Improving Outcomes for People with Brain and Other CNS Tumours – The Manual*. 2006. Available from: <https://www.nice.org.uk/guidance/csgbraincns>. [Accessed 14 September 2015].



## 5. Receiving medical treatment

Following a diagnosis, healthcare professionals and patients can face complex treatment decisions. Although brain tumours can be difficult to treat, patients naturally hope that medical intervention will result in a positive outcome. Most brain tumour patients will receive some kind of treatment which is either invasive or which can result in physically debilitating and emotionally traumatising side effects – the reality that many must therefore contend with is that treatment may not entail ‘getting better’, in the conventional sense. This increases the importance of clear communication, the provision of high-quality information, inclusive decision-making and the acknowledgement of the impact of treatment on people’s day-to-day lives outside of the clinical setting.



Nearly 90% of people with brain tumours in this study have received, or are receiving, treatment

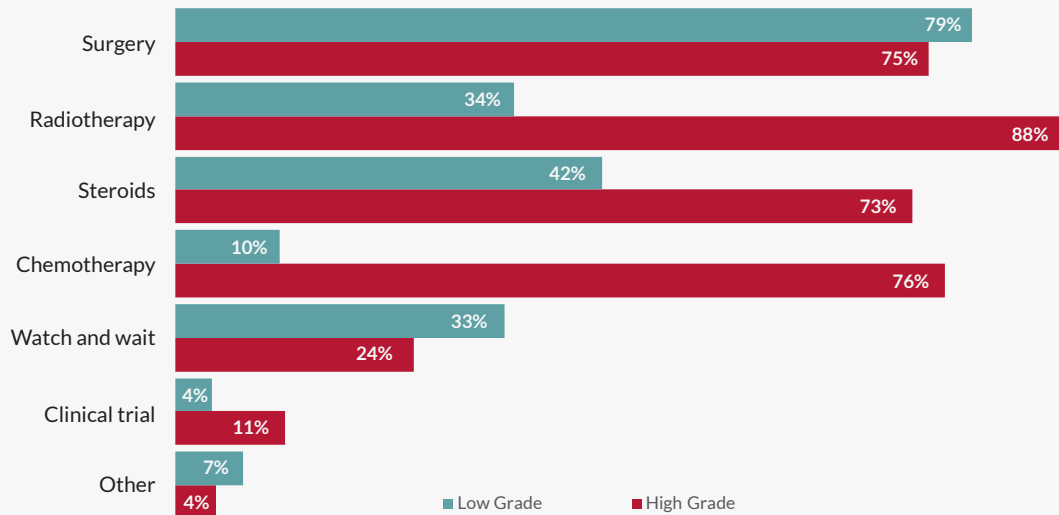


Nearly 80% of low grade tumour patients in this study, and nearly three-quarters of high grade patients, have undergone, or will undergo, surgery



Women were less likely than men to feel the healthcare professionals they talk to understand what life is like with a brain tumour

**Figure 1. Proportion of participants who have received/are receiving various brain tumour treatments, by grade of tumour.** Base: 694



### 5.1 Treatment statistics

The chart above shows the proportions of participants in this study receiving the various types of treatment, by grade of tumour. This is not necessarily reflective of the overall population of people with a brain tumour in the UK.

75% or more of people in this study with a high grade brain tumour have received or are receiving treatments that are invasive or can result in serious side effects (surgery, chemotherapy and radiotherapy), with radiotherapy being the most widely received intervention (88% of high grade tumour respondents). Surgery is very common amongst both low and high grade tumour patients, with nearly 80% of low grade tumour respondents currently receiving, or previously having undergone, surgical interventions, compared to 75% of those with a high grade tumour. Treatment with steroids was much more commonly reported by high grade tumour respondents (73%) than by those with a low grade tumour (42%), whilst watch and wait was more frequently reported by those with a low grade tumour (33%, compared with 24%).

### 5.2 The impact of treatment on patient health and wellbeing – not ‘getting better’

As the data reported above show, many people with brain tumours undergo interventions which are invasive or which carry a considerable side effect burden. In line with these statistics, whilst qualitative data on the impact of treatment collected in this study found some participants who reported a positive impact on their overall health, many reported negative effects on their quality of life. Whilst it can be difficult to entirely disentangle the effects of treatment from those caused by the tumour itself, the

reality for many people is that regaining the level of health they enjoyed prior to developing a brain tumour is not possible.

Recovery periods for brain surgery can be very long and some of the side effects may be irreversible. One participant with a low grade tumour was left with permanent hearing loss, facial paralysis and balance problems; another with a high grade tumour developed epilepsy after surgery; another became paralysed below the waist. Radiotherapy and chemotherapy were reported to cause sickness, memory problems, hair loss, agitation and anger, and chronic tiredness, making ordinary, everyday tasks difficult or impossible. Steroid users also reported hair loss, depression, insomnia and weight gain, which severely impacted on their self-esteem. One participant questioned whether it was worth undergoing treatment, given the extent to which it had changed her life for the worse.

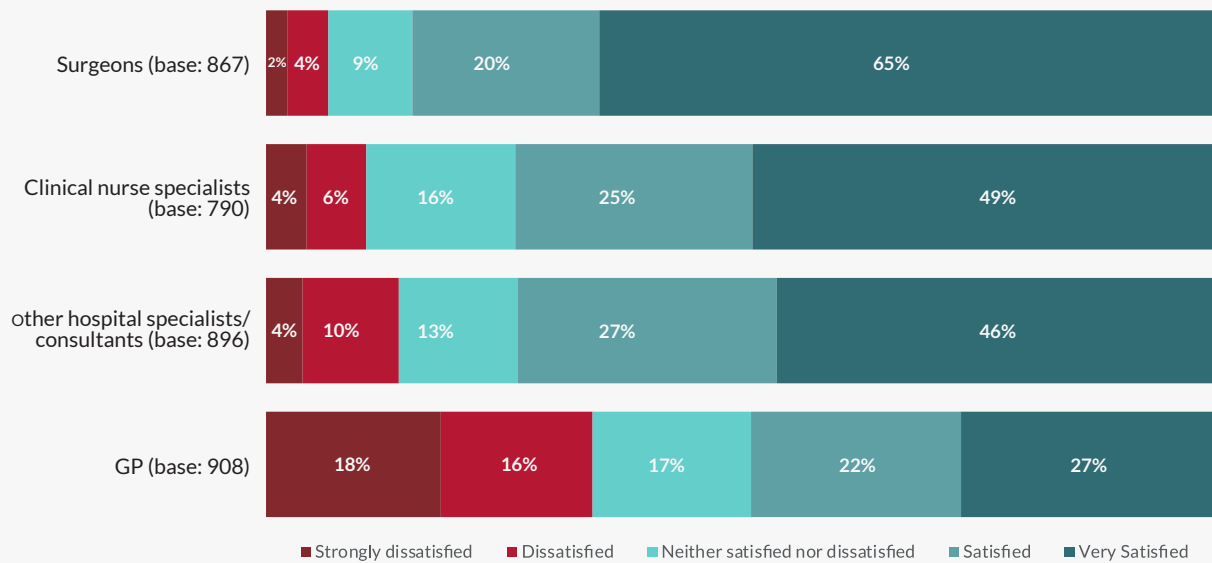
*“I’m fat, I’m tired, I’m depressed, I’m bald...I don’t even know if all this will be worth it because I don’t even know if I want to be alive anyway.”*

34 year-old woman with a high grade tumour

*“I had surgery — it impacted every aspect of my life including appearance, confidence, relationships, can’t have any more children, working life, people interaction, energy and life fulfilment.”*

38 year-old woman with a low grade tumour

**Figure 2. How satisfied or dissatisfied are you with your experience of the following health professionals in relation to your brain tumour?**



*“I think they should be aware of feelings and emotions you may have after the operation. Just because the tumour has been removed does not mean your illness is over.”*

63 year-old woman with a low grade tumour

### 5.3 Relationships with the healthcare team

It is important that the care patients receive during and after treatment addresses their holistic needs and not just the clinical requirements of the tumour. Patients often feel better supported if they have a named contact that they can approach with questions or concerns. This is often a clinical nurse specialist, or another key worker performing a similar role. Whilst the majority (58%) of people who participated in this study reported having a single point of contact with their healthcare team, usually a clinical nurse specialist, nearly a third (32%) did not, with the remainder unsure.

Breaking down the data on access to a clinical nurse specialist by tumour type found that those with a high grade tumour were statistically significantly more likely to say that they had a single point of contact than those with a low grade tumour. Indeed, 76% of respondents with a high grade tumour said that they had a single point of contact, compared to 53% of those with a low grade tumour.

**One in three said they did not have a single point of contact with their healthcare team whom they could go to straightaway if they had concerns.**

**People with a high grade tumour were more likely to say they have a single point of contact than those with a low grade tumour.**

Participants were also asked about their satisfaction with their experience of the various types of healthcare professional involved in their treatment. The results are shown in Figure 2 above.

The overall picture of secondary care experiences is encouraging, with 85% of respondents reporting satisfaction with surgeons and nearly three-quarters reporting satisfaction with other hospital specialists/consultants (73%) and clinical nurse specialists (74%). This contrasts markedly with the proportion who reported satisfaction with their GP (49%).

Care must be taken in making a straightforward comparison between satisfaction ratings across different roles, since the degree to which it is possible to satisfy the overarching patient expectation of doctors to heal or cure is not equal in each case. In the first instance, GPs are clinical detectives, with the challenging task of eliminating lines of enquiry, whilst relying on others to make a diagnosis of complex conditions, such as brain tumours. This is vital work, which clears the way for specialists to determine options for intervention and administer treatment, but its value to the patient may be less clear-cut than that of a surgeon, for example.

Nevertheless, the strikingly low proportion of respondents who were satisfied with their GP in this study suggests that, at the

very least, there is work to be done on the patient-doctor relationship at the primary care level, to improve communication and patient understanding of the diagnostic journey. Indeed, general practice continues to have a role to play in supporting and monitoring patients at a local level once they have been placed under secondary care.

The NCPES asks about experiences in this area: in 2014 only 55% of NCPES respondents with brain and central nervous system tumours thought that the GPs and practice nurses involved in their care (where applicable) did everything they could to support them whilst they were having cancer treatment – the lowest proportion of all cancer types, compared to 66% of all respondents<sup>5,9</sup>. Furthermore, only 51% of people with brain and central nervous system tumours thought that the different people involved in their care (GPs, hospital nurses, specialist nurses and community nurses) always worked well together to give the best possible care, compared to an average of 63% for all cancer types<sup>5,9</sup>. These statistics suggest a need to improve the overarching structure of care put in place for brain tumour patients, which would in turn increase the patient's sense of being properly supported and monitored by healthcare professionals across the services he/she accesses.

The relationship between satisfaction with the four categories of healthcare professionals shown in Figure 2 and tumour grade was examined. No relationship was found between satisfaction with GPs or other hospital specialists/consultants and the tumour grade of the respondent. However, in the case of satisfaction with surgeons, those with a low grade tumour were statistically significantly more likely to say they were neither satisfied nor dissatisfied with their experience than those with a high grade tumour. Respondents with a low grade tumour were also more likely to say they were dissatisfied or neither satisfied nor dissatisfied with their experience of clinical nurse specialists than those with a high grade tumour, whilst the latter were more likely to say they were satisfied.

**People with high grade tumours were more likely to say they were satisfied with their experience of clinical nurse specialists than those with a low grade tumour.**

We know that often services are focused on and geared towards those with high grade tumours and that even after surgery those with a low grade tumour may be discharged without any referral to support services or specialist rehabilitation – indeed, they often do not have access to a clinical nurse specialist or key worker. This can mean that they are left to struggle with serious side effects with little or no support. A clinical nurse specialist, or someone fulfilling a similar function, has an important role to play in signposting towards support services following a diagnosis. This can be critical in ensuring that people are able to access appropriate services following treatment. In addition, a clear written assessment and care plan may provide much needed clarity on different aspects of their care, yet only 21% of brain and central nervous system tumour patients were provided with this, according to the 2014 NCPES<sup>9,12</sup>.

*“Especially in the first few months I think the nurse specialist should have organised scans and appointments far quicker. Since then I’ve only had one visit and I’ve just felt that she was completely overloaded with work and not able to attend adequately to all the patients on her list.”*

44 year-old man with a low grade tumour

The relationships between gender and satisfaction with patient experience of the four types of healthcare professionals was examined, and statistically significant relationships were found in the case of experiences of GPs, surgeons, and other hospital specialists/consultants. Men were more likely than women to be neither satisfied nor dissatisfied with their experience of their GP, and to be satisfied with both surgeons and other hospital specialists or consultants. Women were more likely than men to be neither satisfied nor dissatisfied with their experience of surgeons and to be dissatisfied with other hospital specialists or consultants.

**Men were more likely than women to say they were satisfied with their experience of surgeons and other hospital specialists.**

<sup>12</sup> It should be noted that the corresponding statistic for all respondents to the survey (across 13 cancer types) was only 22%, indicating that brain and CNS tumour patients are far from being unique in their experience of this aspect of their care.



*“I don’t feel the condition was explained that well. I didn’t see eye-to-eye to with the consultant at the hospital, so I paid privately to see another consultant who I now see on the NHS. He explained everything much more clearly and is such a lovely person, too – he shows care for me, my family and my friends. I really can’t remember what support I was offered. I didn’t take any so would presume I wasn’t offered any, other than a few leaflets.*”

*I saw a different doctor every time when I was in hospital so it was hard to achieve any progress or get a clear picture of what was going on. Quite often they would explain something and assume you knew what they were talking about. This was hard, as I wasn’t really well enough to take it all in.”*

Extract from Ben’s diary, a 28 year-old man with a low grade tumour.

Those who were dissatisfied with their experiences of secondary care practitioners reported insufficient contact from, and ability to get in contact with, clinical staff and nurse specialists; dismissiveness, rudeness and a lack of compassion and inadequate or absent help or support, particularly post-intervention. Misdiagnosis and poor clinical outcomes following surgery, with insufficient explanation of the risks, were also mentioned. Such experiences understandably cause distress to patients, and suggest room for considerable improvement in some areas. However, they occur within the context of a service that is now heavily under-resourced and in which most healthcare professionals are trying to provide the very best levels of care to their patients.

**6 Recommendation:** MDTs should ensure that all brain tumour patients are provided with a care plan, in language appropriate to their needs, before they are discharged from hospital.

Only 41% of participants in this study said they felt that practitioners they talk to understand what life with a brain tumour is like, whilst 60% said they felt that healthcare professionals understand brain tumours. Meanwhile, only a quarter of respondents agreed that the NHS gives brain tumours the level of attention they deserve.

**Two-fifths of respondents feel the healthcare professionals they talk to understand what life with a brain tumour is like.**

**6 in 10 feel the healthcare professionals they talk to understand brain tumours.**

An examination of the relationship between the characteristics of participants in this study and their responses to the two questions regarding practitioner understanding of brain tumours and life with a brain tumour indicates a disparity in the perceptions of certain groups, specifically between men and women, and high and low grade tumour patients.

Women were more likely than men to:

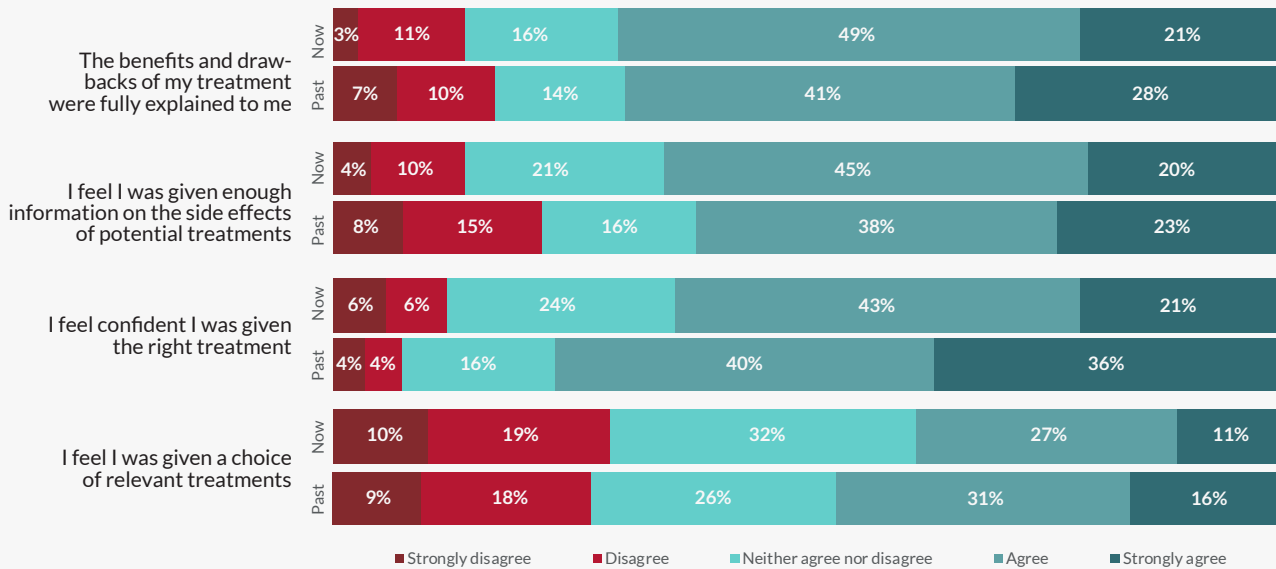
- disagree that healthcare professionals they talk to understand brain tumours
- disagree that healthcare professionals they talk to understand what life is like with a brain tumour.

Low grade tumour patients were more likely than those with a high grade tumour to:

- disagree that healthcare professionals they talk to understand brain tumours
- disagree that healthcare professionals understand what life is like with a brain tumour.



**Figure 3. Thinking about the treatment you receive in the past/now, to what extent do you agree or disagree with the following statements?** Base: Past 571, Now 248



A positive relationship was also found between agreeing that ‘healthcare professionals understand brain tumours’, agreeing that ‘healthcare professionals understand what life is like with a brain tumour’ and the measures of satisfaction with experiences of the four practitioner types shown in Figure 2. Those who agreed, as well as those who neither agreed nor disagreed, were more likely to report satisfaction with their experience of all four practitioner types than those who disagreed. Those who disagreed were more likely to report dissatisfaction in all four cases.

These findings suggest that patient satisfaction with healthcare professionals is related to their perceptions of both the clinical expertise and knowledge they demonstrate (how well they understand brain tumours themselves) and their understanding of the wider impact of brain tumours on the patient’s life, beyond the hospital ward or GP surgery.

Having, and being able to demonstrate, knowledge and insight into both the nature of a patient’s condition and the implications it has for their day-to-day life, may help them have greater confidence in their care, and feel more secure in facing the challenges of their journey.

The sister report to this publication *Losing Myself – The Reality of Life with a Brain Tumour* is a valuable resource for understanding the experience of living with a brain tumour, and would be a useful reference for anyone involved in the care and treatment of brain tumour patients. The Brain Tumour Charity is able to run learning sessions around this report for healthcare professionals and MDTs.

### 5.4 Communication regarding treatment choices and effects

Participants were asked about their perceptions of the treatment information and choices offered to them. Figure 3 above shows the responses to these questions for previous and current recipients of treatment.

Nearly two-thirds (64%) of those currently receiving treatment, and over three-quarters (76%) of those who previously received treatment, agree that they are confident that their treatment is right for them. However, less than half (47%) of people no longer receiving treatment and less than two-fifths (38%) of those currently receiving treatment felt they were given a choice of relevant treatments. Over a quarter (27%) of previous treatment recipients and nearly one in three of the current group (29%) disagreed that they were given a choice. This may be partly attributable to the fact that for many people there is only a limited range of treatment options available that are appropriate to the type of brain tumour they have. However, it is important that, where they exist, options are well-communicated, and that those affected are empowered and involved in decision-making – indeed, this is no less applicable when there is only a single option or none at all. In such cases the protection of patient dignity, autonomy and power is crucial. Individuals should be provided with the relevant information, delivered in a comprehensible way, so that they feel included in the clinician’s assessment of their choices, however bleak they may be.



## “I was discharged 9 days after the operation and told to take it easy and rest.”

Gary lives in Glasgow with his wife, two children and his cat and works as a finance manager in the NHS. He was diagnosed with a Grade 2 meningioma in May 2014. He completed the Glasgow 'Kilt Walk' in April 2015 which is a marathon length walk through Glasgow to Loch Lomond, whilst wearing a kilt. This was to raise money for HeadSmart, The Brain Tumour Charity's campaign to raise awareness of the signs and symptoms of brain tumours in children and young people, to reduce diagnosis times, including guidance/awareness for the healthcare profession.

“I had been not quite myself for one or two years prior to being diagnosed with a brain tumour. I would just sit in the same seat every day and watch the television. I didn't really want to get involved in too much, and my family and friends started worrying about me. I started to have alarming episodes where I would sink to my knees, and I began to get more and more headaches.

I went to the GP a few times about my symptoms but it was only when I saw the third GP, who was the senior partner in the same practice, with my wife that we started to get somewhere. This GP referred me to

a neurologist, who in turn sent me for an MRI. Straight after the MRI I was told they had found a large Grade 2 meningioma, and I had a craniotomy operation 6 days after diagnosis.

I was discharged 9 days after the operation and told to take it easy and rest. That was really all that was said to me, and then I was sent home to my family. The operation left me tired, emotional, physically and mentally weak, and worried about my future, and my family's future. I felt quite alone when I came out of hospital and don't feel I was given enough support. My wife was only with me for the first week as life goes on and she had to return to work, so from then on I spent my time recovering in front of the television. I felt very emotional, but I didn't know why. I kept looking at myself in the mirror and wondering when the swelling was going to go down. I didn't know how I was supposed to be, or how I was supposed to feel. My wife once said to me that there is no manual for having a baby, and I quickly realised there was no manual to having a brain tumour either. It was a very worrying time for me and my family, you have to find your own support or aftercare, you are just told to 'go home and rest'.”

**Gary, 45, from Glasgow**



*“At the initial appointment with the GP nothing was explained other than that I should get an appointment from the neurologist. The following weeks were agony with worry and stress, as I heard nothing from anyone for weeks. I was taking the epilepsy tablets and felt like I could’ve broken down at any point. One day I woke up with swollen glands, temperature and a fever, and later I had a seizure. I spoke to a nurse at the surgery on the phone and was told that we didn’t need to be telling the GP about this, and if we rang an ambulance, we could be fined. This was really unhelpful, as we knew nothing and were offered no support. My epilepsy meds were increased, and 2 days later I had a reaction. Tears, fear, panic – every horrid emotion came over me. With the lack of information, support or help, I actually thought I was going to die from the tumour.”*

Extract from Jane’s diary, 38 year-old woman with a low grade tumour.

**Over a quarter of previous treatment recipients, and nearly three out of ten people currently receiving treatment, feel that they were not given a choice of relevant treatments.**

*“The doctors don’t tell you about these things. They are interested in taking the tumour out, but not about what happens afterwards. You just aren’t prepared for how your life may change.”*

53 year-old woman with a low grade tumour

*“I was dealt with in a fast, professional way from start to finish and was included in all decisions to be made.”*

62 year-old woman with a high grade tumour

The statistics for receiving sufficient information on side effects and a full explanation of the benefits and drawbacks of treatment are more encouraging, though nearly a quarter (23%) of previous treatment recipients disagreed that they had received enough information and nearly a fifth (17%) disagreed that the benefits and drawbacks of their treatment were fully explained to them. The 2014 NCPES provides a similar picture, with 25% of respondents with a brain or central nervous system tumour reporting that the possible side effects of treatment were not explained to them in an understandable way<sup>5</sup>.

The relationship between characteristics of the respondents to this study and the measures of provision of information on side

effects and explanations of the benefits and drawbacks of treatment were examined, revealing some statistically significant relationships with annual income of the respondent, and tumour grade, amongst those currently receiving treatment.

Those with a household income of less than £20,000 a year were more likely than those earning £20,000-£39,999 to disagree that the benefits and drawbacks of their treatment were fully explained to them, and that they were given enough information about the side effects of potential treatments. Those earning £20,000-£39,999 were more likely to agree with both statements, and those with an income of £40,000 or above were more likely to agree with the second statement, regarding side effects. Low grade tumour patients were more likely than those with a high grade tumour to disagree that they were given enough information on the side effects.

As at other points in the patient journey, the clinical nurse specialist can play a vital role in providing information here to reduce such disparities. Indeed, it is important that where clinical nurse specialist capacity is stretched, this is not something that is neglected. The Brain Tumour Charity produces Information Standard certified fact sheets about various treatment options which healthcare professionals can obtain free of charge.

**7 Recommendation:** MDTs should ensure that possible side effects are fully explained to people with a brain tumour in advance of treatment, with supporting written information such as that provided by The Brain Tumour Charity.

## 5.5 Experiences of monitoring and review

Monitoring and review brings specific challenges and anxieties for the patient. Participants in this study were asked about the extent to which they were satisfied with their current level of monitoring and review and whether they felt that the amount of time they had to wait for the results of tests or scans was reasonable. Seven in ten (71%) indicated that they were satisfied with their current level of monitoring and review, whilst 16% disagreed, and 14% neither agreed nor disagreed. However, only 56% agreed that waiting times for results were reasonable, with nearly a quarter (24%) disagreeing. Those who were dissatisfied with their current level of monitoring and review stated that length of waiting time for results, poor communication from healthcare professionals responsible for monitoring, and having no-one to talk to about their condition, were the principal causes.

8

**Recommendation:** NHS England, the Scottish Government, the Welsh Government and the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland should review the underlying causes of variation in waiting times for test results across the UK.

**One in four do not feel the amount of time they have to wait for the results of tests/scans is reasonable.**

Waiting for results can be a difficult time for many people with brain tumours, whether this is to find out about the effect of treatment, or as part of a 'watch and wait' protocol. Good communication is critical to helping patients cope with this inevitable uncertainty, particularly if they are in poor health at the time of appointments, or experience memory impairment. Three-quarters of participants in this study said they worry about upcoming scans or tests, with only 11% saying they do not (the remaining 14% neither agreed nor disagreed that they did), and several of those who commented on this worry used the term 'scanxiety' to characterise their experience in the run-up to scans and whilst waiting for results. Others described heightened distress surrounding the scanning process due to the need to make expensive journeys over long distances to get to appointments. However, scans can also provide reassurance and help some people feel that they remain in good hands once they leave the hospital or surgery.

*"My treatment was in a centre 250 miles from home. I was advised review would be six months, then a letter from the local hospital giving me a ten-month appointment. I feel there is no ownership of my care. I'm scared but feel unable to contact anyone."*

45 year-old woman with a low grade tumour



*"My only feeling of support comes from the fact that I am being scanned regularly. It makes me feel there is still a link."*

"The scans make me feel like I am being looked after. They bring me comfort. When I first came out of hospital, I felt like I'd dropped off the edge of a cliff. I was given no support, I didn't know where to go to, or how to get any help. My only feeling of support comes from the fact that I am being scanned regularly. It makes me feel there is still a link. Without that link, I am on my own. If something goes wrong, how would I know without the scans? It's a massive confidence builder for me. When I get to the stage where I am a week before having my next scan, however, I get very nervous and emotional. It brings on anxiety, you think 'I hope everything goes OK'. You don't want to face life afterwards if you get given news that you don't want to hear. In some ways it's great you're being monitored, but in other ways it builds anxiety every time."

Stuart lives with his wife and two children in Cheshire. He was diagnosed with an anaplastic ependymoma in 2011.



## 6. Accessing support

As well as attending to the medical aspects of treatment, people with brain tumours hope that practitioners from across the spectrum of healthcare professionals involved in their care will have regard for the practical and emotional reality of living with a brain tumour, both within and outside the clinical setting. Many patients find themselves facing a range of new and frightening challenges in their daily life, impacting on their capacity to work, their education, relationships and finances, which may require support to learn to cope with or overcome. Access to good quality ancillary support services is therefore vital, both during and after treatment, and in the painful process of addressing end-of-life decisions.



30% have accessed physiotherapy or occupational therapy

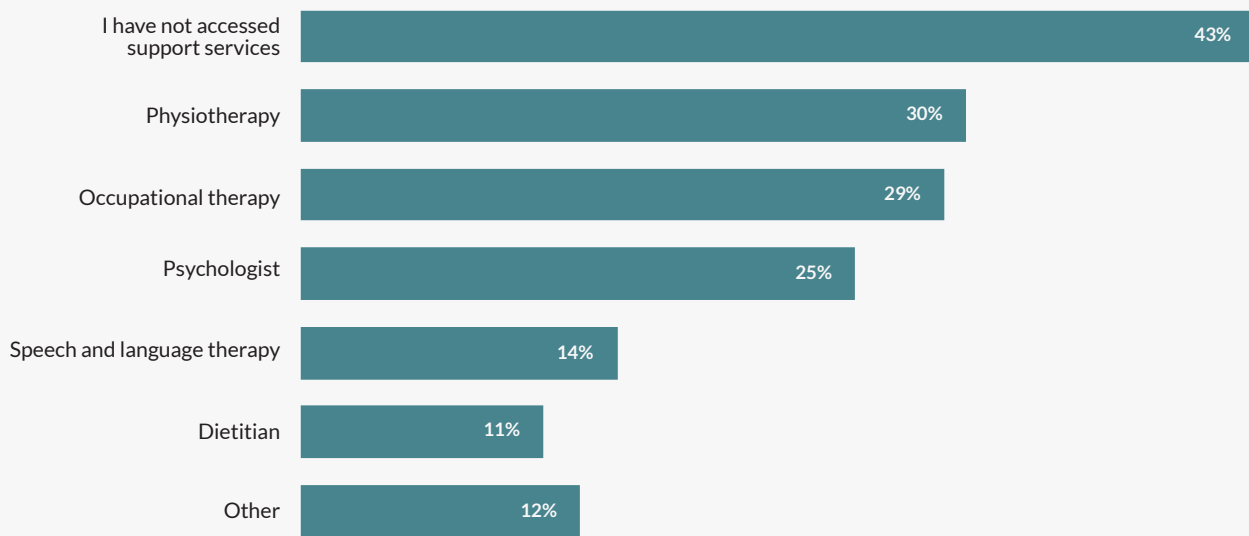


Two thirds of those who have seen a speech and language therapist are satisfied with their experience



1 in 5 of those who have seen a dietitian are dissatisfied with their experience

**Figure 4. Which of the following support services have you had access to?** Base: 533



### 6.1 Support service access statistics

Figure 4 above shows the percentage of participants in this study who have used each of five types of support offered to brain tumour patients.

The type of support service appropriate for the individual patient depends on the type and grade of their tumour and the treatment they have received, though the necessary support may not always be offered or obtained. Physiotherapy is the service most frequently accessed by both high and low grade tumour participants in this study, although the most common response amongst low grade patients was to say that they had not accessed any support service at all.

The NCPES asks about care and help after leaving hospital, specifically whether respondents feel they were given enough care and help from health or social services (for example district nurses, home helps or physiotherapists). Just over half (54%) of brain and central nervous system cancer respondents to the 2014 NCPES said they were definitely given enough care and help, the third lowest across the 13 cancer types<sup>9,13</sup>. The finding that a large minority are inadequately supported after discharge is consistent with qualitative data obtained in this study, suggesting a lack of post-treatment support.

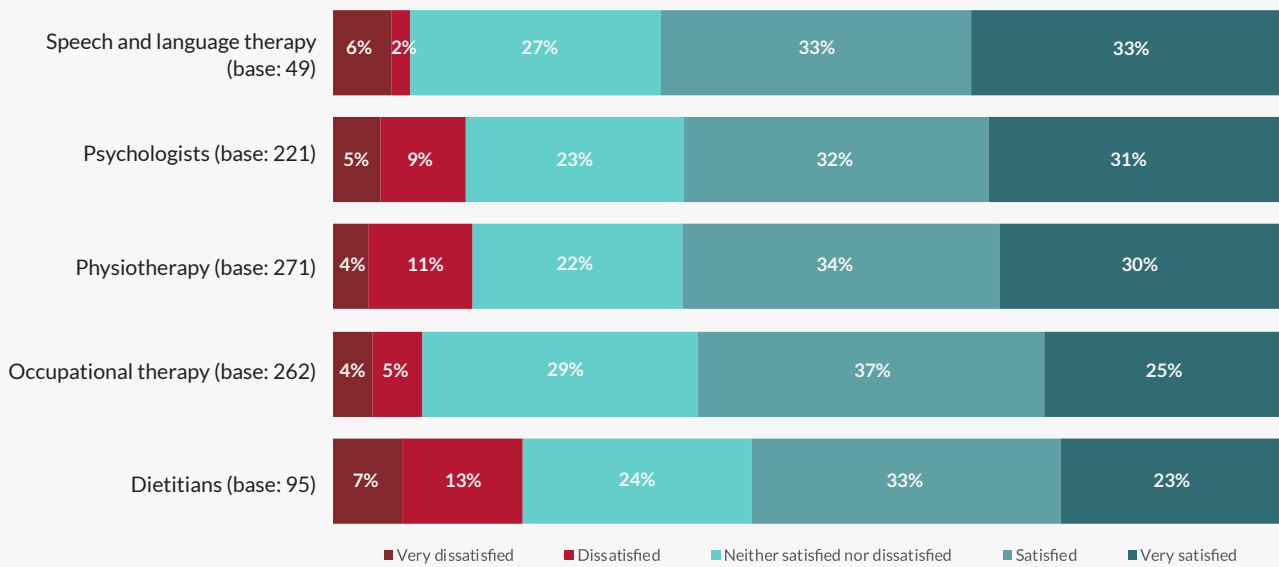
*“Being ‘left’ with a ‘go and carry on with your life’ statement without the offer of a point of contact/plan for the future/ any level of support utterly undervalues what it means to walk round with a brain tumour and have no-one to talk to. It does not prepare you for the fears and management of symptoms, how to tell/not tell others/family, how to deal with insurance questions.”*

48 year-old woman with a low grade tumour

The NCPES survey also asks about access to two types of informational support for those who reported needing it – provision of information about support groups and discussion of the impact of one’s cancer on work or education. The percentage of respondents to the 2014 survey with brain or central nervous system cancer who reported having been given information about support or self-help groups was just short of the percentage of all respondents, at 82%, compared to 83%<sup>5</sup>, while the percentage who said staff had discussed the impact their

<sup>13</sup> It should be noted that the percentages for all 13 cancer types included in the 2014 NCPES were quite low with a corresponding statistic of 57% for all survey respondents.

**Figure 5. How satisfied for dissatisfied are you with your experience of the following?**



cancer could have on work life or education was 74% – again just below the 75% figure for all cancers<sup>5</sup>. In Wales the percentage of respondents to the 2013 survey with brain or central nervous system cancer who reported having been given information about support groups was 74% which, whilst lower than in England, is actually well above the figure in Wales across all cancer types, of 69%<sup>11</sup>.

Once again, the role of the clinical nurse specialist can be vital in signposting patients to support services following treatment. It is important that this happens before discharge, as patients may not know who to contact, or find it difficult to get through to the right person, once they have left hospital.

**9 Recommendation:** MDTs should put in place a package of follow-up services, with details included in the written care plan provided to patients before they are discharged from hospital. Providers and commissioners should ensure that this is adequately resourced and signpost towards appropriate voluntary sector resources.

### 6.2 Satisfaction with experience of support

Figure 5 above shows data on patient satisfaction with their experience of the five support services asked about in this study.

The statistics shown in Figure 5 are encouraging insofar as they show that only very small proportions of respondents are dissatisfied with the services they have received, though caution should be taken interpreting these data, given the small number of respondents to some of the questions. Comparing the picture of satisfaction with experiences of the five support services, shown in Figure 5, with satisfaction with the experience of the four types of healthcare practitioner, shown in Figure 2, suggests some room for improvement. The comparison highlights the greater frequency of responses in the neutral (neither satisfied nor dissatisfied) category in Figure 5: an average of 25% of responses are in this category in Figure 5, compared to 14% in Figure 2. The principal concerns articulated by those who expressed dissatisfaction with their experience of support services were: long waiting times between referral and appointment and between prescription and receipt of equipment/adaptations; lack of knowledge or experience relevant to the condition; support offered being unhelpful; poor communication, in terms of lack of contact/ability to reach a practitioner; and appointments being too irregular to be beneficial.

**Figure 6. What plans have you made for end of life? Please tick all that apply.** Base 194



### 6.3 End-of-life planning and support

The low survival rate of those diagnosed with a brain tumour compared to other cancers makes support with planning for end-of-life an important consideration when addressing the overall package of care. A fifth (21%) of participants in this study have received a terminal diagnosis, with more than two-thirds (68%) of those who were willing to report their prognosis indicating that it was less than 3 years. Of those with a terminal diagnosis, many have made a Will but only a minority have undertaken comprehensive end-of-life planning, as reflected in the data presented in Figure 6 above.

These statistics are consistent with findings in relation to talking about dying and the reported coping strategies of those with a terminal prognosis. Only 37% of respondents with a terminal prognosis said they were comfortable talking to others about dying. Meanwhile, the coping strategies they described tended towards a focus on the present, rather than the future. They encompassed: remaining positive, making the most of life, denial, refusal to give up, and seeking alternative treatments. Given the enormous emotional obstacles inherent in the process of planning for death, it may be that people require greater support to deal with this activity.

Participants with a terminal diagnosis were asked whether they had been given a choice of end-of-life care options and whether they had received appropriate information about end-of-life care. Only 21% said they had been given a choice, with 55% saying they had not, and the remainder unsure. Meanwhile only 29% said

they had received appropriate information about end-of-life care, and 49% said they had not. Given the magnitude of these decisions and their significance to the overall package of care that terminal patients receive, these figures are somewhat disappointing.

### 55% of terminal patients said they had not been given end-of-life care options.

A number of participants commented on the support they were given in this area. These data suggest problems both with the provision of too little information, and insensitivity where information was provided, such as offers of end-of-life support being made too early.

Patients with a brain tumour should have the option of discussing palliative care with clinicians from the point of diagnosis, if appropriate for the stage and aggressiveness of their tumour. If such conversations take place in the early stages of the patient pathway, it is more likely that a person with a terminal diagnosis will have the choice and control to exercise important decisions such as the place of their death. However, clinicians should also be sensitive to the wishes of people who are not ready to discuss end-of-life planning, with a mechanism in place for ensuring that the discussion can take place at a later date when the person is ready.

**10 Recommendation:** All staff who provide care to people with life-limiting conditions should be trained to undertake structured discussions about their future care preferences.





## “When it comes to accessing help from support services, I always tell people to take it.”

James lives in Cheshire with his partner Claire, who he has been with for about 30 years. He works for Manchester Airport as an engineer. He was diagnosed with a brain tumour in 2013, after crashing his car as a result of a seizure.

“My diagnosis was very quick. The first seizure I had was when I was driving to work. I blacked out and as a consequence I crashed my car. I was airlifted to the hospital, and given an MRI scan which revealed a brain tumour and a fractured spine from the accident. I was told I was to undergo surgery to have the tumour removed.

After my surgery I returned to work on a phased basis, and worked two days a week. Initially it was great to get back to a sense of normality, and have that ‘next step on the road to recovery’. You think it’s going to be like before you were diagnosed. I slowly realised that things weren’t what they used to be, particularly in terms of concentration levels and work output. I had been told this might be the case because of the tumour, the radiotherapy and the ongoing medication I am on.

During a visit to my oncologist, I was offered the chance to have a psychologist assess me using a series of neuropsychology tests. They identified deficits in my concentration and organisational skills, both of which are important in my job. The psychologist’s recommendation, which has been backed by my employer, is that I should have a low stress environment and only work three days a week.

I have found this one of the most difficult aspects of dealing with the brain tumour. Physical problems you can understand; you can see the tumour on the MRI, you are aware of the radiotherapy because your hair falls out, and you can see your surgery scars. It’s difficult to accept that something “upstairs” might not be as good as it used to be, and that it’s having an effect on the rest of your life.

So when it comes to accessing help from support services, I always tell people to take it. Whether it’s psychological help, physiotherapy or even access to work schemes, absolutely take it. I probably had a jaundiced view beforehand about this type of service, but they really have been excellent.”

James, 50, from Cheshire

## 7. Conclusion

**The body of findings presented in this report provide an overview of both the breadth and depth of experiences, interventions and interactions that make up the journey of a brain tumour patient in the NHS. The path from unexplained symptoms to treatment and beyond can be long, painful and bewildering for the individual. A tumour imposes itself on a person's life without regard for his or her ability to cope, for the resources available to clinicians and carers to treat and care for that person, or for the overall capacity of the NHS itself, now facing severe funding constraints.**

This report has shown that more can be done to ensure that people with brain tumours are able to obtain timely, sensitive, informative, supportive and responsive care when they present with the signs and symptoms of a tumour and from that point onwards. The relative rarity of brain tumour cases, and the variety of forms, symptoms and effects on people's lives that they may entail, should not deter practitioners from taking seriously the individual and the full range of their concerns – including those relating to their daily life, beyond diagnosis and treatment. Furthermore, the complexity of the condition and the invasive and side effect heavy nature of treatment makes it incumbent on healthcare professionals to prioritise the provision of user-friendly information, wherever it is available, and to give as much time and space to hear and respond to patient concerns as is feasible. Indeed, the findings from this study indicate that a substantial difference can be made to the overall patient experience if a person feels that oversight of their care lies in *someone's* hands – a single, named individual; in the words of one respondent, that someone has 'ownership' of their care.

Throughout this report we have seen that some groups are more likely to report poor experiences than others, principally patients with low grade tumours and women, though differences by household income group also stood out in some areas.

The 2014 NCPES also found that women were one of the groups more likely to be critical of their care and treatment<sup>9</sup>. This is an important finding, and one which requires attention. Quality of life is a crucial issue for patients, regardless of the grade of their tumour or whether they have a terminal prognosis. Many low grade tumour patients undergo brain surgery and experience serious and enduring effects of their tumour and/or treatment. The data presented in this report indicate that for many low grade tumour patients their needs are currently not being properly met by the service provided for them. The wider provision of a single point of contact, ideally a clinical nurse specialist, for low grade tumour patients, and more generally for people with brain tumours in the NHS, is to be recommended in addressing these issues. Furthermore, ensuring that professionals within ancillary support services are fully up-to-date regarding the specific needs of brain tumour patients would be a useful complement to this activity.

We recognise the challenge facing the NHS, under conditions of such serious resource scarcity, in caring for and treating individuals living with a condition as complex and polymorphous as a brain tumour. However, with full command of the facts on patient experience, and a willingness to take advantage of relevant input from other organisations working with brain tumour patients, we believe it is possible for healthcare professionals, managers and policymakers to build on existing good practice and improve the current level of service offered. We hope that this research, and other informational resources available from The Brain Tumour Charity, may be of use in taking on the challenge to improve the experience of brain tumour patients in the NHS.

In line with this ambition we make the following recommendations, based on our findings:

## Recommendations

- 1** NHS England, the Scottish Government, the Welsh Government and the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland should collect data on the experiences of people with both low and high grade brain tumours.
- 2** NICE should update the *Referral guidelines for suspected cancer*, and *Healthcare Improvement Scotland* should update the Scottish referral guidelines for suspected cancer, on an ongoing basis as new evidence emerges on symptoms that are recurrent, or that occur in combination.
- 3** As further evidence on the causes and impact of delays in adult brain tumour diagnosis emerges, Public Health England, the Scottish Government, Public Health Wales and the Public Health Agency in Northern Ireland should develop a campaign to improve awareness of symptoms amongst the general public, building on the success of the HeadSmart campaign for children.
- 4** Multi-disciplinary teams (MDTs) should provide, or signpost towards, The Brain Tumour Charity's information and support services at the point of diagnosis and throughout treatment and care.
- 5** Health Education England, NHS Education for Scotland, Welsh Health Boards and the Northern Ireland Health and Social Care Board should review the capacity and sustainability of the brain tumour clinical nurse specialist workforce in each nation.
- 6** MDTs should ensure that all brain tumour patients are provided with a care plan, in language appropriate to their needs, before they are discharged from hospital.
- 7** MDTs should ensure that possible side effects are fully explained to people with a brain tumour in advance of treatment, with supporting written information such as that provided by The Brain Tumour Charity.
- 8** NHS England, the Scottish Government, the Welsh Government and the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland should review the underlying causes of variation in waiting times for test results across the UK.
- 9** MDTs should put in place a package of follow-up services, with details included in the written care plan provided to patients, before they are discharged from hospital. Providers and commissioners should ensure that this is adequately resourced and signpost towards appropriate voluntary sector resources.
- 10** All staff who provide care to people with life-limiting conditions should be trained to undertake structured discussions about their future care preferences.



## About us

### Our vision

Our vision is for a world where brain tumours are defeated.

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours, making a difference every day to the lives of people with a brain tumour and their families. We are committed to having the greatest possible impact on the lives of everyone affected by this disease, to defending the most amazing part of the human body, and together defeating brain tumours.

We fight brain tumours on all fronts through research, awareness and support, to save lives and improve quality of life.

- We fund pioneering research to find new treatments, improve understanding, increase survival rates and bring us closer to a cure
- We raise awareness of the symptoms and effects of brain tumours to reduce diagnosis times, increase treatment access and improve understanding of those living with the disease every day
- We provide information and support for anyone affected to help improve quality of life.

### Our goals

We are committed to having the greatest possible impact for everyone in the UK affected by a brain tumour. It is with this in mind that we have set ambitious goals to

bring about real and lasting change, so that a diagnosis no longer means a death sentence.

- **Double survival within 10 years in the UK**  
Our goal is to halve the average years of life lost to a brain tumour from 20.1 to 10 years by 2025
- **Halve the harm that brain tumours have on quality of life in the UK**  
Our goal is to halve the harm caused by brain tumours by 2020, from a baseline measure which we will agree with clinicians and patient groups by the end of 2015.

### Questions?

If you have been affected by a brain tumour or are worried by any of the findings in this report, please get in touch with our team. We offer an inclusive Information and Support Service for everyone affected by a brain tumour – patients, family, friends and colleagues.

**0808 800 0004**

(Free from landlines and mobiles)

**support@thebraintumourcharity.org**

We rely 100% on voluntary donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us, including fundraising, getting your company involved, leaving a gift in your Will or giving in memory, please visit us at **thebraintumourcharity.org**, email **fundraising@thebraintumourcharity.org** or call us on 01252 749043.



## Creating a better future together

Whilst survival has doubled across all cancers, survival rates for brain tumours in adults have improved little in over 40 years: 60% of people diagnosed with a high grade brain tumour will not survive one year and just 19% of adults will survive for five years or more<sup>14</sup>. This means that more than 5,000 people lose their lives every year<sup>15</sup>. In addition, brain tumours reduce life expectancy by an average of 20 years, the highest reduction of any cancer<sup>16</sup>. Despite these stark statistics, less than 2% of the £500 million invested in cancer research in the UK every year is spent on brain tumours<sup>17</sup>. We must improve survival rates through the funding of high quality research and the efficient translation of the results into new treatments.

Brain tumours are different from other cancers – they affect the part of the body that makes you the person you are. This is why people with a brain tumour and their families do not simply focus on survival but on their quality of life. Of those currently living with a brain tumour in the UK, most will be coping with a reduced quality of life – in fact, over 62% of children who survive a brain tumour are left with a life-altering, long-term disability<sup>18</sup>. The daily impact that brain tumours have, as well as the trauma of diagnosis, must be understood more widely.

We must reduce the harm caused, not only to the lives of those living with this disease, but to their carers, families and friends. In addition to these two key issues, we have also identified areas of particular concern, where improvement would contribute to better survival and quality of life:

- **Late and inaccurate diagnosis**  
UK diagnosis times must be reduced further across all age ranges, and diagnosis must become more accurate, to maximise treatment options and therefore improve the chances of recovery with a better quality of life.
- **Inconsistent NHS experience**  
The overall consistency and quality of the NHS experience for brain tumour patients must be improved in the UK.
- **Lack of support**  
We must extend our information and support services to everyone who needs help with navigating the system and enhancing their quality of life.

We will address these issues through our five year strategy *Defeating Brain Tumours*, summarised overleaf. Read the strategy in full at [thebraintumourcharity.org/defeatingbraintumours](http://thebraintumourcharity.org/defeatingbraintumours)

<sup>14</sup> Cancer Research UK. *Brain, other CNS and intracranial tumours survival statistics*. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-tumours/survival#undefined> [Accessed 19 May 2015].

<sup>15</sup> Cancer Research UK. *Brain, other CNS and intracranial tumours mortality statistics* [Internet]. 2014 [cited 2015 May 21]. Available from: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/brain/mortality/>

<sup>16</sup> Burnet N.G., Jefferies S.J., Benson R.J., Hunt D.P., Treasure F.P. Years of life lost (YLL) from cancer is an important measure of population burden and should be considered when allocating research funds. *Br J Cancer*. 2005; Jan 31. 92(2): 241–5.

<sup>17</sup> National Cancer Research Institute. *NCRI Cancer Research Database*. Available from: <http://www.ncri.org.uk/what-we-do/research-database/> [Accessed 25 May 2015]

<sup>18</sup> Macedoni-Luksic M., Jereb B., Todorovski L. Long-term sequelae in children treated for brain tumors: impairments, disability, and handicap. *Pediatr Hematol Oncol*. 2003; Mar 20(2): 89–101.

Brain tumours are the  
BIGGEST CANCER  
**KILLER**  
of children and adults under 40

**62%**

of children who survive a brain tumour will be left with a life-altering, long-term disability

**91%**

of people who find that it a emotional o



PASSIONATE

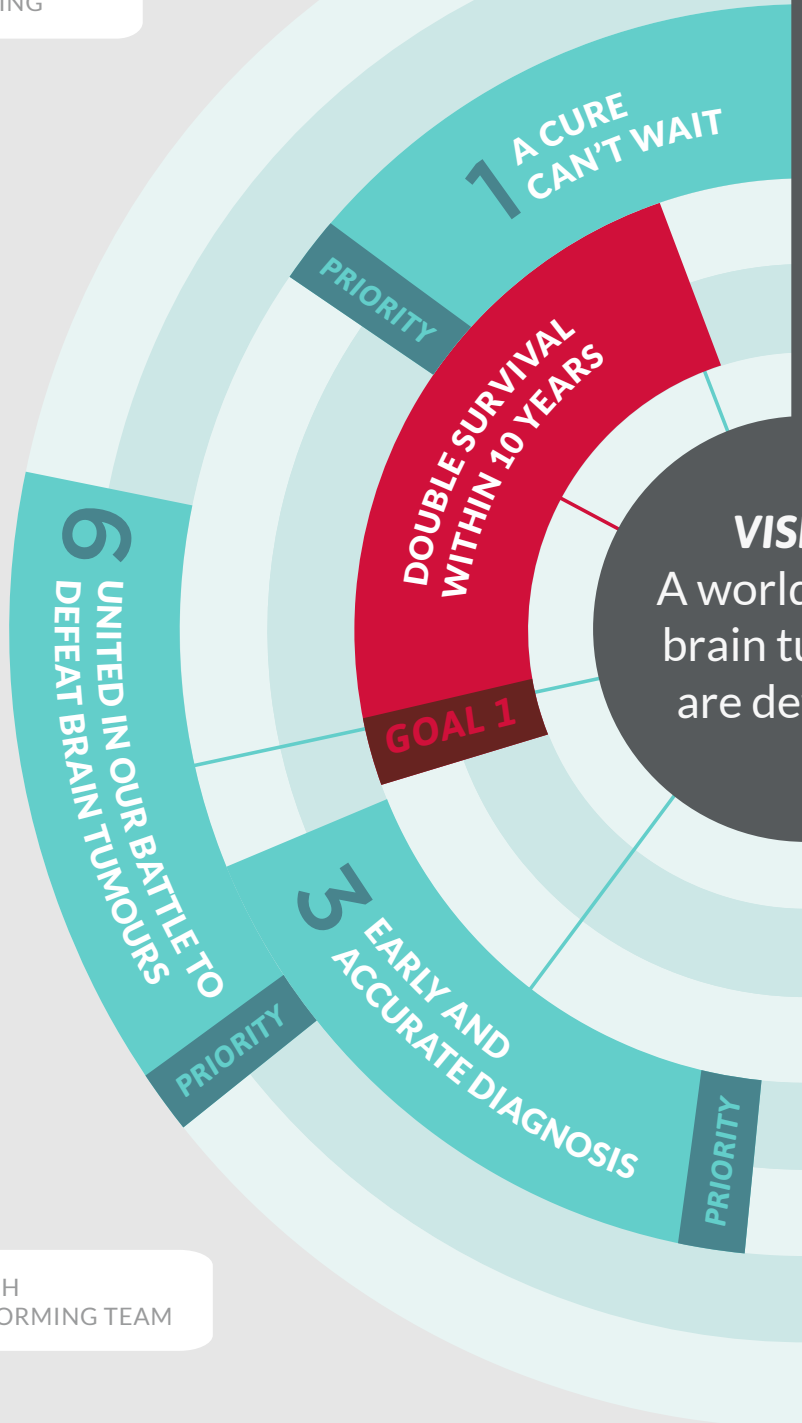
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FUNDING

SMART  
COMMUNICATIONS

A HIGH  
PERFORMING TEAM



SMART



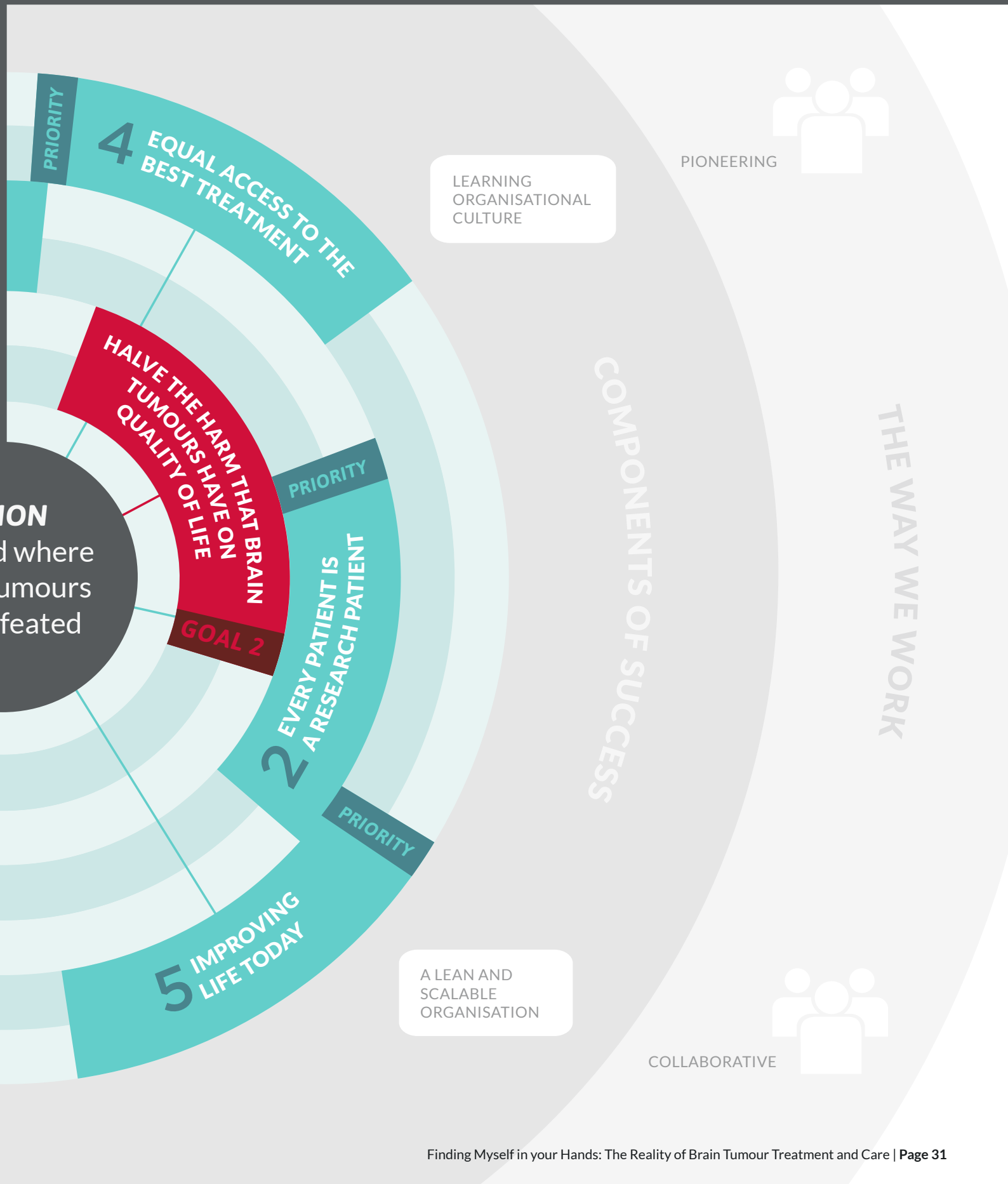
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with a brain tumour affects their mental health

LESS THAN 2%

of the cancer research funding in the UK is spent on brain tumours

Brain tumours reduce life expectancy by on average 20 YEARS



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In partnership with:

alterline

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