

# The story behind the data

## Report 1:

Non-malignant brain tumours (NMBTs)



## **The Get Data Out project, Cancer Outcomes Statistics for Public (COSP) use**

The data behind this report has come from Public Health England's National Cancer Registration and Analysis Service (NCRAS) and is a direct result of the 'Get Data Out' project.

This project provides anonymised population level brain tumour data for public use in the form of standard output tables, accessible here: [cancerdata.nhs.uk/standardoutput](https://cancerdata.nhs.uk/standardoutput)

The project is in pilot stage at the time of writing, with only brain tumour data available. The hope is that data on a wider range of less common cancers will be available to the public in the future.

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# Executive summary

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*brainstrust* is working with partners on a series of reports that bring meaning to recently released brain tumour data.

This first report explores the recent finding that 10% of people diagnosed with a non-malignant brain tumour will die within the first year after being diagnosed. In 2014, 572 people died within the first year of being diagnosed with a NMBT. The report then makes a series of recommendations for those living with, working with or advocating on behalf of those living with a low grade brain tumour.

*brainstrust* recognised that there is need, and scope, for an evolving registration service to develop the conversation about cancer beyond traditional indicators. The policy context for this piece of work is also significant. The All Party Parliamentary Group (APPG) on Cancer inquiry ‘Progress of the England Cancer Strategy: Delivering outcomes by 2020?’ asks ‘for NHS England and Public Health England to increase data transparency by making more of it available to the public’ and that ‘this must include rare and less common cancers, all aspects of the patient pathway, and national and local data.’<sup>1</sup>

In order to fulfil its duty as a public health agency responsible for cancer prevention and control in England, the National Cancer Registration Services of Public Health England (NCRAS) produces evidence about cancer incidence, diagnosis treatment and survival. It fulfils this critical function by a range of outputs, including official statistics and reports, and support for public health research on cancer. Currently the Standard Output Tables are produced

for four statistical areas (incidence, routes to diagnosis, treatment and survival) and for brain tumours only. Since 2015, *brainstrust* has been working with NCRAS to:

- look at National Cancer Registry data in new ways to address important questions for the brain tumour community
- establish a process that can be used by other cancer sites.

Key recommendations from this report include the following:

- We must stop using the word ‘benign’ to describe these tumours.
- There is a need for public understanding, resources and information to support this group of people.
- Support for people living with a NMBT should be stratified more effectively according to a clear set of determinants.
- Relevant models of support for people living with NMBTs must be developed.
- There must be parity of voice between non-malignant and malignant brain tumour patients and caregivers.

These recommendations will be taken forward to make, shape and drive change so that both the quality of life and service delivery for people who are living with a NMBT are more relevant, meaningful and supportive.

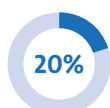
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<sup>1</sup> APPG on Cancer Inquiry December 2017.

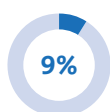
# Non-malignant brain tumours (NMBTs)

## The facts

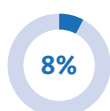
1. NMBTs, which include low grade gliomas, are identified by the ICD-10 data, the 10<sup>th</sup> revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organisation (WHO). It contains codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases. NMBTs include the following:



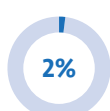
**meningioma** – tumour arising from the membranes covering the brain and spinal cord; this accounts for about 20% of brain tumours.



**schwannoma (also termed acoustic neuroma)** – tumour in the 8<sup>th</sup> cranial nerve arising from Schwann cells; this accounts for about 9% of all brain tumours.



**pituitary adenomas** – pituitary gland tumour; this accounts for about 8% of brain tumours.



**hemangioblastoma** – vascular tissue mass, sometimes cystic; this accounts for about 2% of brain tumours.

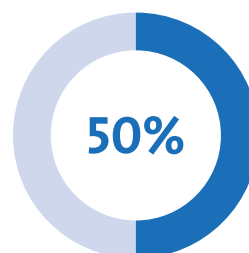


**craniopharyngioma** – a cystic tumour from cell remnants of Rathke's pouch (nasopharynx), usually occurring in children; this accounts for about 1–3% of brain tumours.

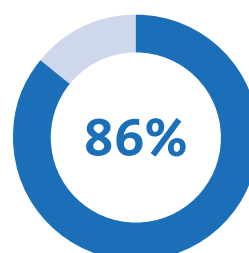


**choroid plexus papilloma** – choroid plexus tissue (the tissue responsible for the production of cerebrospinal fluid or CSF) mass that blocks cerebrospinal fluid flow, usually in children; this accounts for less than 1% of brain tumours.

2. About 9,000 primary brain tumours are diagnosed every year. Of these, 50% (4,500) are non-malignant.



3. About 86% of people living with a NMBT will survive year 1 – but over 1 in 10 will not. In real terms this means that 572 people with a NMBT will die within the year.





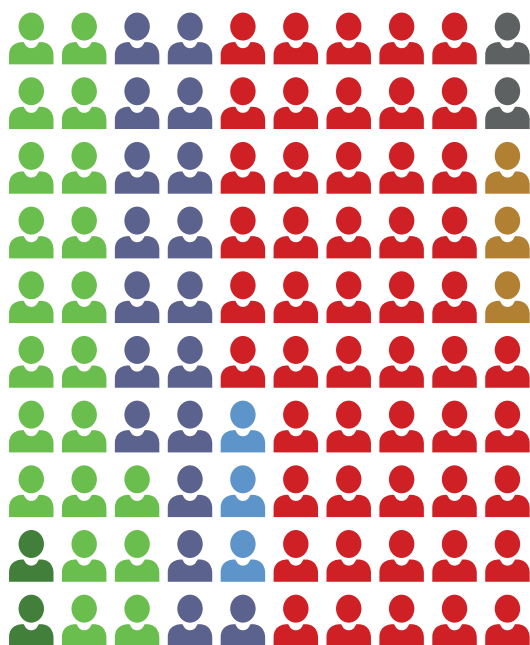
4. Even when crude<sup>2</sup> and net<sup>3</sup> survival data is considered, there is hardly any difference in the > 69 age cohorts:

					Net survival 12m	Crude survival 12m	Initial cohort	Survival cohort
2014	Non-malignant brain tumour	Age 00–19	All England	Persons	96.0	95.9	138	123
2014	Non-malignant brain tumour	Age 20–29	All England	Persons	97.5	97.5	127	120
2014	Non-malignant brain tumour	Age 30–49	All England	Persons	98.3	98.2	818	786
2014	Non-malignant brain tumour	Age 50–69	All England	Persons	93.7	93.1	1394	1358
2014	Non-malignant brain tumour	Age 70+	All England	Persons	65.8	62.8	1262	1187

5. People with a NMBT are much less likely to be diagnosed through A&E:

Patients diagnosed with malignant brain tumours present to the NHS in different ways.

- For every 100 diagnoses, 51.3 are emergency presentations.
- For every 100 diagnoses, 1.9 follow the two-week wait pathway.



Two week wait  
 GP referral  
 Other outpatient  
 Inpatient elective

Patients diagnosed with non-malignant brain tumours present to the NHS in different ways.

- For every 100 diagnoses, 31 are emergency presentations.
- For every 100 diagnoses, 0.6 follow the two-week wait pathway.



Emergency presentation  
 Death certificate only  
 Unknown  
 Not classified

2 Probability of death in the real world where you may die of other causes before the cancer kills you.

3 Probability of death in a hypothetical world where the cancer under study is the only possible cause of death.

## The lives behind the facts

Historically, brain tumours have been classified as malignant or benign (non-malignant). But we know that, for the many people who are living with a 'benign' tumour, this is far from the case. These tumours are life-changing. Themes that have emerged from our daily interactions with patients living with NMBTs, their caregivers and healthcare professionals is the sense of isolation, lack of voice and the daily challenges that they face. Patients are concerned about vitality, their identity and role, limitations, mental health, emotional well-being – all of these are important decision factors for patients who are living with these brain tumours.

These considerations resonate:

- varying survivorship
- variable trajectory, including for benign brain tumour diagnoses
- high frequency of disabling complications
- high severity of disabling complications
- knowledge of increasing cognitive dysfunction
- life context – where there is resilience or a lack of ability to cope.

Research evidence<sup>4</sup> suggests that patients living with a NMBT (meningiomas) are faced with cognitive deficits in several areas affecting function before surgery. Following surgery, most of these patients seem to improve in cognitive functioning. However, they still have impairments in a wide range of cognitive functions compared to healthy controls.

Meningioma patients also report<sup>5</sup> clinically worse health-related quality of life (HRQoL) than healthy controls. Radiotherapy seems to improve some areas of HRQoL in the short term, while HRQoL decreased to pre-radiotherapy levels in the long term. Tumour resection increases HRQoL, but long-term follow-up shows persistent reduced HRQoL compared with healthy controls. It suggests an impaired HRQoL in meningioma patients, even years after antitumour treatment.

4 Meskal I, et al. Cognitive functioning in meningioma patients: a systematic review. *Journal of Neuro-Oncology*. 2016;128(2):195–205.

5 Zamanipour Najafabadi A, et al. Impaired health-related quality of life in meningioma patients—a systematic review. *Neuro-Oncology*. 2017;19(7):897–907.

There had to be some explanation for my constant migraines, hands that trembled and an increasing everyday struggle to find words. I constantly forgot things like work assignments, and I would faint flat out on the floor at random times of the day and in public places. I would suddenly be completely blind for a few moments, as though my eyes were tight shut when in fact they were wide open. My symptoms were dramatic, and they were taking their toll. I was scared and depressed. My GP put it down to stress, but I knew something was wrong and went to an optician, as the moments of blindness were getting worse. They immediately said there was severe pressure behind my eyes and sent me straight to hospital. I was given scans and then referred to Atkinson Morley's Neurology Dept – a brain tumour, the size of a grapefruit, had shown up on the scan. The consultant booked me in for an urgent operation to remove an intraventricular meningioma two days later.

It was incredible that overnight I had gone from being an independent woman living life at full tilt to someone who was very ill and depending on others. I had lost my speech, couldn't find even the most straightforward words; I was partially blind, very weak on one side, and often didn't even know where I was. And even with the tumour removed, I was going to have to take seizure medication for life due to internal scarring from the operation. And with all that, there was also the constant overwhelming feeling of fatigue and getting confused easily. I had been tired before, but this was like nothing I had ever felt. This was turbocharged tiredness. It was like trying to walk through treacle; my arms and legs felt heavy, and even just getting up from a chair felt like a major effort. I now have hyperacusis and tinnitus, spasms in my legs and neck and terrible anxiety.

I need to take things at my own pace now. My dreams to be a successful business woman in London with a nine-to-six job are no longer possible. I can't be relied on to do my job well. It is sad, but it is true. But that has not stopped me finding other ways to achieve my goals. Yes, I can't earn the money I once did, but I now have my own projects that I can do in my own time.

I have lost some friends because we have lost touch, as our lives do not cross paths like they used to, but I have found new friends within the brain tumour community.

Since my diagnosis I have written a book and have a second one coming out at the end of this year. I did a book tour around the UK and visited many charities to share my story with other brain tumour patients. I set up and presented a volunteer radio show for nearly four years that was very successful. I didn't do it alone but I did do it. Even with my fumbling words and memory loss, I find my way.

I still need support and medication, counselling and have attended several clinics in hospitals for issues I still suffer from. But I don't say still for long. I cry when I find it too much, and then I pick myself up and carry on.



At the end of February 2017, I had my first ever symptom – what I now know to be a seizure. I was in bed at 8 a.m., woke up, felt cramp all over my body, was unable to move and then fell unconscious for several seconds. My partner called 999 but I regained consciousness during the call, so he was referred to NHS 111, who told us to go to A&E.

I was checked over at A&E and sent home, as the tests all came back normal. Later that week I saw my GP as a precaution, who suspected I may have had a pseudo-seizure and referred me to a neurologist.

The NHS neurology appointment was arranged for May, so my parents suggested I use our family medical insurance. I arranged an appointment at Queen Square for the following week with a neurological consultant recommended by one of my parents' friends.

I went alone, as there was no obvious cause for concern at this stage. When I met the consultant, he did not seem worried either. He suggested I had simply woken up with bad cramp and had a panic attack, but sent me for an EEG and MRI anyway. I was told I would probably not need to return to see him.

I had the tests, was called back in for another MRI with tracer, and then was summoned to see the consultant again. I still didn't think anything was wrong, but Mum insisted she come with me just in case.

At the appointment, I was shown the scan with an obvious shadowy patch on one side. It was a lot to take in, but I kept calm and took everything in as facts without processing what that really meant for me and my life. The consultant I was seeing was not an expert in my type of tumour, but, in a step which I still think was excellent, he had pre-empted that I might want to see an expert in low grade gliomas and had arranged for my current consultant to see me half an hour later. He confirmed the diagnosis, prescribed Keppra and suggested I go on watch and wait.

I had a functional MRI scan and consultation three months later, and another six months later had a follow-up MRI. I am currently awaiting the results. I have had two focal seizures in the last six months, but each one has been less severe. I understand that I have the option for surgery at any point, but that it is not recommended at this stage, as the risks outweigh the benefits to my quality of life. For now I am OK with that, as I want to feel as normal as possible for as long as possible, although I am starting to wonder about what my options are and how each one could impact my life longer term.

I try not to think about the long term, as I easily find myself getting bogged down with 'what ifs' that can feel overbearing. I stay clear of any information on prognosis. Instead, I am trying to live in the now and take advantage of the relatively good quality of life I have. I still have the same dreams – a successful career, children, to make a difference and see the world – but I know in the back of my mind that when I reach each stage of life, achieving these things is likely to be more complicated. Just before diagnosis I mentioned to a close friend that I felt I could see where my life was headed, and that was reassuring, but I've lost that sense of certainty now. I have plans to travel for three months next year with my partner, which is something I have wanted to do for a while. My diagnosis means I have new things to consider, like medication, insurance, the activities we chose to do and the pace at which we do them, but it feels like if I let my tumour get in the way of doing what I want now, then I might as well give up.

The impact of my diagnosis on my relationships is complex and more difficult to capture in words. Telling people about my diagnosis was and still is a big hurdle to overcome. I dread the questions 'How are you?' or 'What's new?', as saying 'fine' feels like lying, but the truth is way too heavy to explain in some situations. I feel like it would be easier if I had something like diabetes or even regular epilepsy. The phrase 'brain tumour' comes loaded with preconceptions, and it feels awkward for me to explain all the nuances involved in having a low grade form. I have now told most of my friends, but I don't always feel as comfortable sharing as I would like to. This is despite the fact I have only experienced positive things when I do talk to people about it. I am slowly learning to open up more, to let people who care for me share in my difficulties, and to ask for help when I need it.

# What this means for the brain tumour community

Since 2013 *brainstrust* has worked hard through its Wear Grey Campaign to promote understanding of life with a low grade brain tumour.

[www.brainstrust.org.uk/the-day-the-world-turned-grey/](http://www.brainstrust.org.uk/the-day-the-world-turned-grey/)

And now there is empirical evidence to take this conversation to the next level. The following recommendations will be absorbed and promoted in this campaign, and will influence *brainstrust*'s supportive and campaigning work.

**RECOMMENDATION: We must stop using the word 'benign' to describe these tumours.**

*'The definition of "benign" is "does no harm" and we know that all do that whether cancerous or not ... any form of intervention ... surgery/RT/Chemo will cause more brain damage ... I think all of us are now on anti-epilepsy tablets ... most have been and have or are struggling to get off them ... removal of driving licence ... Scanxiety ... I think three things for me would be ... 1. No tumour is benign ... just not cancerous 2. All cause your whole world to change in an instant resulting in a "new normal" and grief for the "old" you and life 3. and so much anger once the shock of diagnosis has worn off ... that it can seem as if your personality has changed ... which sometimes it has.'*

Patient

Facebook, November 17

*'To be diagnosed with a brain tumour is surreal. But hey! It's benign. So that's OK. But actually not so OK. My wife had a craniotomy to remove a 'benign' meningioma. We thought that was the end of it. We carried on until it showed up again 3 years later. This time it was caught soon enough to be treated with Gamma Knife. About two years later – more GK treatment. Today we have no more options, other than more surgery. The tumor might be benign – but you live with threats to all aspects of your life.'*

Caregiver

focus group, November 17

We now know that over 550 people are dying within one year of being diagnosed with the NMBT.

We know too that with this diagnosis comes a significant symptom burden, which for those who do survive has to be lived with for the rest of their lives.

For children, these tumours often result in significant deficits that can worsen over time. With these results, it is clear that families need to be informed of all possible outcomes. This includes supportive provision that is both adequate for the experience and also equal to that provided to people living with cancer.

People must stop thinking that non-malignant brain tumours are harmless. We must work with other charities such as Macmillan, who exclude these tumours from falling within the remit of its support.

We can develop more resources to support this group of people so they feel more resilient, and better able to live with uncertainty and face the challenges ahead.

**RECOMMENDATION: There is a need for public understanding, resources and information to support this group of people. Qualitative data from surveys and focus groups tells us that people living with NMBTs need more information about:**

- growth and recurrence (most asked)
- types of NMBTs
- surgery
- causes
- symptoms and side effects
- life expectancy.

**RECOMMENDATION: Support for people living with a NMBT should be stratified more effectively according to a clear set of determinants:**

- the tumour type – even though it may be non-malignant we have a better idea of what could happen
- the treatment – consequences in the longer and shorter term
- the person – their values, their context, their appetite for risk.

**RECOMMENDATION: There must be relevant models of support:**

- supported self-care to reach everyone living with a NMBT, where people are given information, types of support available, how to stay in touch and be part of a community
- shared care to reach those who need a little bit more – regular contact, including coaching to optimise their quality of life
- complex management for the few – intensive support involving external agencies.

These can now be timely, with high-quality information, and include ongoing evaluation, which could include timely involvement of palliative support.

**RECOMMENDATION: There must be parity of voice between non-malignant and malignant brain tumour patients and caregivers.**

Families of children with NMBTs often state that they feel left out of cancer service and support. This report highlights that they can and do face many of the same devastating challenges as those with malignant diagnoses. There needs to be a shift in understanding what an NMBT diagnosis could mean.

**In the words of others...**

*'I have had three craniotomies and two meningiomas. One of my surgeries was twenty hours long. I have had stereotactic radiation. I have many deficits from the tumours, surgeries and radiation. My life is not the same never will be. I have suffered for twenty years now.'*

59-year-old female.

*'Recovery has been tough. The worst part is the creepy crawlies inside my head as the nerves are growing haywire in all directions. At times I wake up with bloody fingernails from scratching the numb scalp. No REM sleep, I feel terribly depressed and lethargic. No follow up appointments to date. I am supposed to be "normal" again, but I feel like crap.'*

62-year-old female.

*'My son was diagnosed with a low grade glioma in 2002 after having headaches and seizures. Previous to this he was hardly ever ill. He had his first craniotomy to remove it and we were told it was highly unlikely that his "benign" tumour would return. How I hate that word "benign"!! It sounds so harmless! Nothing*

*to worry about!! All it means is that it is in the position it originated from. My son had regular scans over the years since and the images showed that it was regrowing. We were told he had five to ten years to live. More seizures, headaches and nausea. Then in 2012 he had an awake craniotomy and he was told it was now a grade 3 anaplastic astrocytoma.*

*He has just undergone a six week course of radiotherapy. He has exceeded his five to ten years by about five years and we don't know how long he has left. Doctors should be more careful with the words they use. "You're cured" should never be said to anyone because that is hardly ever the case.'*

Caregiver, female.

*'I have an acoustic neuroma. It's affected me massively as its size and position severely compressed the brain stem and facial and optic nerves. Had 10 hours of surgery, just over 50% removed. Watch and wait for the remainder which is inoperable.'*

Patient, female.

*'I had a benign tumour in 2014. My symptoms were dizziness, vomiting, slurred speech, couldn't walk and blurred vision. In fact the hospital thought I'd had a stroke until I had the MRI.*

*Most people are under the assumption that benign means its ok – no problems and nothing to worry about. While that may be true for some it is most certainly not true for many others when benign still means inoperable, chemo and radiotherapy and illness. Let's not forget sadly some people have lost their lives to a benign bt. My son had chemo earlier this year but he's once again on watch and wait and his life will never be the same again as is the same for most people. I feel the word benign trivializes it.'*

Caregiver, female.

*'Sadly people too often think that benign means no harmful effects and that is why the medical profession has started to refer to tumours as low grade or non-cancerous. There are some tumours that are nearly always "benign" in their presentation but will eventually prove fatal. I think at worst the dictionary definition of benign as an adjective is "gentle and kind". Words you would never associate with any kind of brain tumour.'*

Patient, female.

# What this means for the research community

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*'The distinction between malignant and so-called benign brain tumours has done a disservice to those whose lives have been traumatically altered and tragically shortened by a low grade diagnosis. We cannot continue to treat these types of tumours as the Cinderella of the orphan cancers. brainstrust's report highlights that we need to push forward to understand causes, treatments and survivorship through a significant increase in dedicated research funding and giving these patients the same priority as those diagnosed with a high grade tumour.'*

**Sue Farrington Smith, MBE**

Chief Executive  
Brain Tumour Research

*'If we are to have true parity, then we need to observe the data for children and act accordingly, in research and in the clinic. The impact of a NMBT reaches far beyond the child. Research into paediatric NMBTs would ensure better outcomes for all.'*

**Claire Bushell**

Children and families support specialist  
brainstrust

*'This data release is the first of four reports where your data tells us what is important. This, along with the collective work we have done with the James Lind Alliance, where the Top Ten priorities for clinical research in neuro-oncology have been identified ([www.neuro-oncology.org.uk/index.php](http://www.neuro-oncology.org.uk/index.php)), mean that we can be responsive and represent the brain cancer community voice in clinical research.'*

brainstrust understands that the only source of data is the patient. And so we have a very clear policy on research. We will support research that has direct impact on the clinical outcomes of our community. It's that simple. So anything that drives a measurable improvement in brain tumour patients' and caregivers' understanding of their condition, their treatment and their care has our attention.

We believe that the people living with a brain tumour should come first. This is core value for us, so we listen to what our community needs and then we look to plug the gaps. This is what sets us apart and is why this project is so important to us. We do our own research, driven by the needs of our community, and we use this as a driver for change. We don't think that researchers should be concentrating on things that don't matter to you. And it is through collaboration with national bodies such as NCRAS, NCRI, CRUK and PHE that we are able to ensure that the right research is being done in the right way, through the proper channels.'

**Helen Bulbeck**

Director of policy and services

# What this means for the clinical community

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*'This is interesting data. Generally these are tumours that increase in frequency with increasing age, and older people obviously die for various reasons. I noticed this very clearly years ago when I looked at outcomes for surgery for cervical myelopathy; quite a lot of the older patients had died within a couple of years, even after "successful" surgery.'*

*There are a number of possibilities as to why 10% of people with non-malignant tumour might die within a year:*

- *Some may be very elderly with major co-morbidity and not suitable for intervention.*
- *Some will be incidental findings and not the cause of death.*
- *Some might die following surgery (but we know this is actually rare).*
- *Some will have had "successful" surgery and die later of other causes.*

*So this report is really insightful and timely, showing how data can give traction to further analysis. Age would be worth looking at, and if had surgery and cause of death.'*

## **Paul Grundy**

Consultant Neurosurgeon, University Hospital Southampton

Divisional Clinical Director of Neurosciences, Cardiovascular and Thoracics, Trauma and Orthopaedics and Radiology

Chair of NHS England Clinical Reference Group for CNS Tumours

Chair of NHS England Expert Reference Group for Stereotactic Radiosurgery

*'The report from brainstrust is both timely and interesting. The data provide an opportunity for the clinical brain tumour community to consider whether the word "benign" is still appropriate. Whilst these tumours are classified as benign by pathologists, their impact on patients and carers is not. Patients undergoing surgery for a benign brain tumour are in effect subjected to a focal head injury that may result in temporary or permanent neurological problems. Many of these may not manifest with a physical disability but may change cognitive function, such as memory or thought processes. Because these tumours can be cured with surgery alone, the long term impact of neurological problems for patients and carers can be life-changing. In my clinical practice, I no longer refer to these tumours as benign, but rather explain they are non-malignant. This report will go some way to changing practice and emphasising the impact of non-malignant brain tumours on patients and carers.'*

## **Michael Jenkinson**

Consultant Neurosurgeon

The Walton Centre, Liverpool

Chair NCRI Brain Tumour Clinical Studies Group

# About *brainstrust*

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*brainstrust* is the only brain tumour charity dedicated to helping patients and their caregivers across the UK. We know a brain tumour diagnosis is confusing, isolating and overwhelming. We know these problems are exacerbated by not being able to access care and information quickly and easily. And we also know that access to proactive support and good information can improve knowledge and understanding, reduce anxiety, increase preparedness for events, instil control and improve satisfaction with treatment in brain tumour patients. That's why we're here.

*brainstrust*:

1. enables patients to stand up for themselves, and therefore secure better outcomes
2. solves real problems collaboratively
3. creates the vision for patients and caregivers to help them understand how their care should be
4. provides the patient/caregiver voice.

We believe that every brain tumour patient and caregiver should feel in control of their situation. We give this community the means to have a voice at the time when they need it most. The result? A feeling of being in control, and better outcomes for brain tumour patients.





