

BRAIN TUMOUR PATIENTS IN THE UK FACE POSTCODE LOTTERY

New survey results from The Brain Tumour Charity show worrying variation in care and treatment for brain tumours across the UK

Key Messages

The Brain Tumour Charity is the largest dedicated funder of research into brain tumours globally, having invested £38m in world-class research in UK and internationally over the last five years. We also provide trusted support services for those diagnosed, as well as their families and friends. Brain tumours remain the biggest cancer killer of children and adults under 40 and with over 12,000 people diagnosed in the UK every year, so much more needs to be done. **Our goal is twofold; to double survival and halve the harm that brain tumours have on quality of life in the UK.**

The Brain Tumour Charity has recently published the results from our *Improving Brain Tumour Care* survey (IBTC). These show us that brain tumour patients are being left behind when it comes to their treatment and care needs.

One in six respondents were not given access to a Clinical Nurse Specialist (CNS), which is absolutely vital for support and coordination of care. Not only that, **but just 40% of respondents said they were offered a Holistic Needs Assessment (HNA)** which are key for identifying patient's unique needs and ensuring they are met.

For progress to be made, we know that participation in research is absolutely vital. It is also hugely beneficial for patients who get to access care and treatments that are not available elsewhere. However, our survey shows us that **just 9% of respondents were participating in a clinical trial** and, perhaps even more shocking, that **less than half (42%) of respondents were even informed** about research opportunities.

It is also worrying to see such huge disparities across the country. There was a 48 percentage point range (11.8% to 56.8%) across Cancer Alliances in England in respondents being offered a HNA and a 37 percentage point range (0 to 37.3%) in respondents participating in research. This demonstrates how much of a postcode lottery there is for brain tumour patients across the UK.

To end this postcode lottery, we need the Government to take action by:

- 1. Clarifying how the money announced in the 2021 Spending Review for NHS workforce will be invested in the cancer workforce, including for nurse specialists**
- 2. Ensuring every brain tumour patient (high and low grade) has access to a Clinical Nurse Specialist (CNS) and be offered a Holistic Needs Assessment (HNA) and resulting personalised care plan**
- 3. Ensuring every brain tumour patient is informed about research participation and given the opportunity to take part wherever possible**

About the survey

The Improving Brain Tumour Care (IBTC) survey is run by The Brain Tumour Charity in order to understand the experiences of brain tumour patients in six key areas across the patient pathway. The results included in this briefing were analysed in September 2021, and cover UK adults diagnosed or in treatment for a brain tumour since September 2018. There are 1,494 survey responses included in this analysis.

The survey provides comprehensive patient feedback which, along with the other results, has already been used to help improve care at a local level as part of the expert-led assessments of NHS hospital centres applying to become Tessa Jowell Centres of Excellence – a programme led by the Tessa Jowell Brain Cancer Mission (TJBCM). As of March 2022, 28 of the 30 UK brain tumour centres have participated in this extensive review, with eleven already obtaining excellence status.

Access to a Clinical Nurse Specialist (CNS)

- **1 in 6** respondents were not given access to a CNS or keyworker
- **Only 59%** of respondents were able to speak to their CNS or keyworker whenever they needed to
- There is a **30 percentage point range** (61.1% to 91.1%) in respondents having access to a CNS or keyworker across Cancer Alliances in England

Why is a CNS so important for brain tumour patients?

CNSs play a vital role in providing high-quality cancer care and supporting people diagnosed with a brain tumour, including by requesting scans, accompanying patients to clinics, coordinating their care and signposting to available support services. For those diagnosed with a brain tumour, access to a CNS is crucial due to the challenges associated with coordinating specialised care and treatment for such a complex condition. There are often multiple clinical professionals involved in their care, making the role CNSs play in being an anchor and central point of call for the patient incredibly important. But we know many patients are being left with unmet needs and missing out on this support.

Case Study – Ian and Christine’s Story

Christine Judge lost her husband Ian, 57, in 2022 after he had been diagnosed with a glioblastoma in early 2020. The family were put in touch with a Clinical Nurse Specialist when Ian was first diagnosed, who Christine has praised as being “totally invaluable” as he understood and empathised with the complexities which come with a brain tumour diagnosis.

Christine said “Our CNS was such a massive source of comfort. Nothing was a stupid question and we could talk in confidence about whatever was on my mind. He really was amazing – I couldn’t fault him. We had a great rapport and he was incredibly supportive and understanding of just what a brain tumour diagnosis means. The CNS knew we couldn’t predict what was going to happen and he always kept that in mind.”

When Ian’s treatment stopped and he was moved onto palliative care, Christine found it difficult to update friends and family on how he was doing. Their CNS stepped in to field all the enquiries, which gave Christine the time and space she needed to care for Ian and look after her own wellbeing too.

Christine added: “I honestly don’t know what we would have done without our CNS to turn to – we were able to message him whenever we needed to. I knew that I had to be Ian’s voice and so, if there was anything wrong, I would always speak up about it. It would have been horrible for us not to have someone to turn to with the questions and concerns which we would inevitably have in that situation.”

What do we know about CNS provision?

The Brain Tumour Charity’s recent IBTC survey showed us that **just 1 in 6** respondents (15.3%) were not given access to a CNS or keyworker, despite it being recommended in NICE clinical guidance (NG99) in England and committed to in the NHS Long Term Plan. No brain tumour patient should have to face their treatment and care without this crucial lifeline of support.

“I have a fantastic relationship with my nurse specialist. They are always at the end of a phone call to answer any questions I may have. I would be lost without their support at this difficult time.”

– Survey Respondent

How well is the care package working for people who do have access to a CNS?

The IBTC survey also identified that **59%** of respondents felt they were able to speak to their CNS and ask them anything at any time, which is fantastic. However it is worrying that over a third (36%) do not, because it shows that sometimes even when patients **do** have access to a CNS or key worker, they still are not able to get the support and care they need.

Variation in Care across the UK

There is a **30 percentage point range** between Cancer Alliances across England in patients having access to any CNS or keyworker according to the Improving Brain Tumour Care survey. The highest percentage of respondents stating that they did have access to a CNS was 91.3%, with the lowest percentage of respondents at 61.1%.

This represents a significant 'postcode lottery' for patients in the type of care and support they are receiving based on where they are treated in the UK. All patients should receive access to a CNS or named healthcare professional who they feel able to speak to at any time, no matter where they are in the UK.

Ultimately, this comes down to capacity within the NHS workforce. In the 2021 Spending Review, the Government announced funding specifically for the NHS workforce for the coming financial years. This is incredibly welcome but we now need to see clarity on exactly how that funding will be used to boost the cancer workforce including nurse specialists. In doing this, we can move towards the goal of every patient diagnosed with a brain tumour (high and low grade) having access to a CNS or key worker.

The Government must provide clarity on how funding announced in the 2021 Spending Review will be used to invest the cancer workforce, to ensure everyone diagnosed with a brain tumour (high grade or low grade) has access to a CNS or keyworker.

Holistic Needs Assessment Provision

- **Only 40%** of respondents said they were offered a HNA
- **Just over 1 in 5** respondents had a HNA and resulting care plan that they feel is working well
- There is a **48 percentage point range** (11.8% to 56.8%) in respondents being offered a HNA and care plan across Cancer Alliances in England.

Why is a HNA so important for brain tumour patients?

Holistic Needs Assessments (HNA) are extremely important for good patient experience as the assessment is used to ensure patients' needs are met and identify areas where extra support or signposting to other services is required. This assessment is often carried out by a CNS, reiterating the importance of having access to a CNS or keyworker. HNAs are not just used for after treatment has finished but also for those undergoing treatment. So it is very important they are conducted at the right time – which guidance suggests should be throughout the patient pathway and not just at the post-treatment stage.

“We only had one virtual consultation, but in that hour we had such a holistic consultation covering a range of topics, followed up by the CNS referring us to palliative care, accessing physio and occupational health and also referring us for some help with finances.

– Survey Respondent

What do we know about HNA Provision?

The Brain Tumour Charity's IBTC survey showed that only **40%** of respondents said they were offered a HNA. This is incredibly concerning, as all brain tumour patients should be offered this assessment and have a resulting care plan that works well for them and identifies their unmet needs so appropriate and holistic support can be provided.

“I was not provided with any information about free prescriptions or that I could claim PIP. When I eventually submitted a claim I was unable to backdate it so have lost £1200.”

– Survey Respondent

How is the resulting care plan working for people?

The IBTC survey also identified that **just over 1 in 5** respondents felt they had a resulting care plan from their HNA that was working well. This is very worrying, and shows that too many brain tumour patients have needs that are not being identified or addressed and lack the signposting to the support they require.

Variation in Care

Worryingly, there is a **48 percentage point range** between Cancer Alliances across England in patients being offered a HNA according to the IBTC survey. The highest percentage of respondents sharing that they were offered a HNA was 56.8%, with the lowest percentage of respondents at 11.8%. This represents significant variation for patients based on where they are treated across England.

The Government must work with Cancer Alliances to ensure that every patient diagnosed with a brain tumour (high grade and low grade) receives a HNA, at diagnosis or at key changes in care, to provide personalised care

Research Participation

- **Just 42%** of respondents were informed about research participation
- **35%** of respondents participated in any form of research
- **9%** of respondents participated in clinical trials
- There is a **31 percentage** point range in **being informed** about research across Cancer Alliances in England
- There is a **37 percentage** point range in **participation** in research across Cancer Alliances in England

Why is participation in research so important?

Research is essential to drive progress in cancer prevention, diagnosis and in finding long-awaited new treatments for brain tumours. Beyond the potential research benefits, having access to potentially helpful or life prolonging treatments they wouldn't otherwise have access to through clinical trials can be a lifeline for many and provide hope.

Case Study – Steven's Story

Stephen Lee, 62 from Leyland in Lancashire, took part in the phase I trial of cannabis-based drug Sativex in 2015 after his glioblastoma returned following initial treatment. Stephen was first diagnosed in 2010, just a few months after he had very sadly lost his older brother to the same disease.

Steven said “I joined the early trial of Sativex in the hope that it could improve my quality of life, but I also thought it was important to do so as the chemotherapy and radiotherapy I was having had all been trialled by other people before it could be used safely. I thought it only right and proper that I followed in their footsteps and joined a trial to help prove a new drug which could benefit so many people in the future with a recurring glioblastoma.”

While Steven doesn't know whether he had Sativex or the placebo, since the trial finished in 2016, all of his MRI scans have been clear.

What do we know about people being informed about research?

The Brain Tumour Charity's recent IBTC survey showed that just **42%** of respondents were informed about research opportunities.

“My husband was not well enough to join a clinical trial, but we had achieved so much and feel so much better equipped to face what may come. I only wish we had triggered a referral sooner.”

– Survey Respondent

How many people are participating in research?

Our survey also identified that just **35%** of respondents were involved in some form of research from clinical trials, biobanking, donating data, biomarkers and flash freezing. Just **9%** of all respondents had participated in clinical trials.

Variation in Care

There is a **31 percentage point range** between Cancer Alliances across England in patients being informed about research according to the Improving Brain Tumour Care survey. The highest percentage of respondents sharing that they were informed about research was 47.1%, with the lowest percentage of respondents being informed at 15.8%.

There is a **37 percentage point range** between Cancer Alliances across England in patients participating in research according to the Improving Brain Tumour Care survey. The highest percentage of respondents sharing that they did participate in some form of research was 37.3%, with the lowest percentage of respondents participating at 0%.

In 2018, the Government committed to investing £40m in brain tumour research over five years, for which we are incredibly grateful. However, we know there are significant barriers to this money being spent despite there only being one year left. The All-Party Parliamentary Group on Brain Tumours recently launched an Inquiry to identify the barriers to greater investment in brain tumour research in the UK and provide recommendations for how they could be addressed.

The Government must ensure that the barriers to spending the £40m on world-class research are addressed as a matter of urgency as well as ensuring every patient diagnosed with a brain tumour (high grade and low grade) is informed about research opportunities.

Contact Details

For more information about The Brain Tumour Charity, or the Improving Brain Tumour Care survey, please contact Steph, Kate or Baron in the Policy & Campaigns team at policy@thebraintumourcharity.org