brainstrust
the brain cancer people

National Cancer Patient Experience Survey (NCPES) 2021

What's new for people living with a brain tumour?

This is an overview of the tenth NCPES survey, which has run every year since 2010. There was no report for 2020 due to effects of Covid 19 on data collection. It has become increasingly honed over the years so that we now have oversight of trends over time – some good and some less so. It is an important survey, because it plays an important role in the NHS Cancer Programme.

This places patient experience on a par with clinical effectiveness and safety.

The survey aims to:

- Give the cancer community an opportunity to share its opinion about its experience
- Monitor national progress on cancer care
- Provide information that can be used to drive local improvements
- Assist multi-disciplinary teams, commissioners and NHS Trusts in improving patient services
- Inform the work of charities, like *brainstrust*, in our support of the community.

We look at this data in several ways. We look at comparisons with other cancer sites and we also look at comparisons from year to year with brain cancer. There is a lot of data to process, some of it dating back to 2015.

We've pulled out some of the key messages for you – those that are relevant to living the best life possible when you are diagnosed and living with a brain tumour, whether you are a patient, caregiver or healthcare professional. We too will use these messages to influence our support offer and to drive change in service delivery where it is needed.

What does this really mean for me the patient? And me the caregiver? We know that there need to be six things in place to make life with a brain tumour the best it can be.

You need to feel:

- Able to navigate your clinical care
- Resourced
- Supported
- On top of things
- Less lonely
- That you belong to a community.

So, what are the NCPES findings in relation to each of these? Here we'll discuss the highs and lows from the recently released NCPES data, reflecting on 2021.

Navigating clinical care

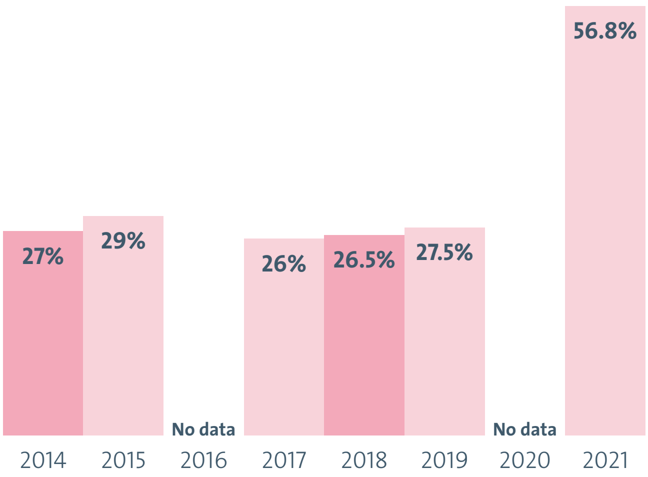
The percentage of brain tumour patients who said they were *definitely involved as much as they wanted to be* in decisions about their treatment was 78.4%. This has slightly decreased from 79% back in 2019. Other cancers ranged from 76.0% to 85.9%.

Further, patients were asked whether *treatment options were explained in a way you could understand* and 64.3% said it was, again, lower than the average of 77.0% across all cancers.

When it came to having a *member of the team helping to create care plan to address needs and concerns*, brain and CNS patients were bang on the average with 56.8%. This is a massive and long-awaited shift for our community, with only 27.5% receiving this help in 2019 and similar stats for the years prior. Knowing **who is in your clinical team** can drastically help to build confidence in who you feel confident talking to and about what.

Our **brain tumour patient guides** can help to navigate this sometimes confusing space.

% of patients given a care plan



The community was also asked if it felt *the length of waiting times at the clinic or day unit used for cancer treatment were about right* and 71.7% of our community agreed.

This is lower than the average overall percentage across all cancers (79.1%). Cancers other than brain and CNS ranged from 74.4% to 85.3%.

Supported

An above average amount of the community was assigned *a main contact person within the team looking after you, such as a clinical nurse specialist, who would support you through your treatment* at 84.5%, compared to the average across all cancer types being 81.5%.

This is great news, but is still down more than 10% since 2019. Despite this, how good was the support you received?

When asked *how easy it was to contact this main person*, 42.8% of you said it was quite easy. This is low, with the average only being 43.9%, too. This needs exploring further as this reflects a massive drop of around 50% when compared to 2019, with 86% of peple saying it was quite easy.

The drop in these results is undoubtedly a result of the massive strain faced by the NHS throughout Covid 19. Hopefully in following years, we can see these numbers climb again. It means that our support services are more needed than ever.

People were also asked *how helpful the advice they received was*. The average answer across all cancers was 71.1% – a good response but with plenty area for improvement. When it came to brain and CNS, it was slightly lower at 64.0%. This means about 2 in 3 people received advice that they found helpful.

Breaking this down further, the community response reflected that 58.5% of people *were offered practical advice in dealing with immediate side effects*. Again, plenty of room for improvement here, especially when compared with the average of 65.7%.

Next, we see a much-needed win – 70.6% of our community were *given information about where they could access other advice and support in dealing with the immediate side effects of your treatment*. This is significantly higher than the average across all cancers at 63.0%.

So, even though direct support from the NHS may not have been readily available, brain tumour patients are at least being regularly signposted to where they can access additional support. This is a relief – we hate to think that people may miss out on the support they need, which they can so easily access from *brainstrust*.

Finally on to support, we see that before starting treatment, 48.3% of the community had the *possible long-term side effects, including the impact on your day-to-day activities, explained in a way you could understand by hospital staff*.

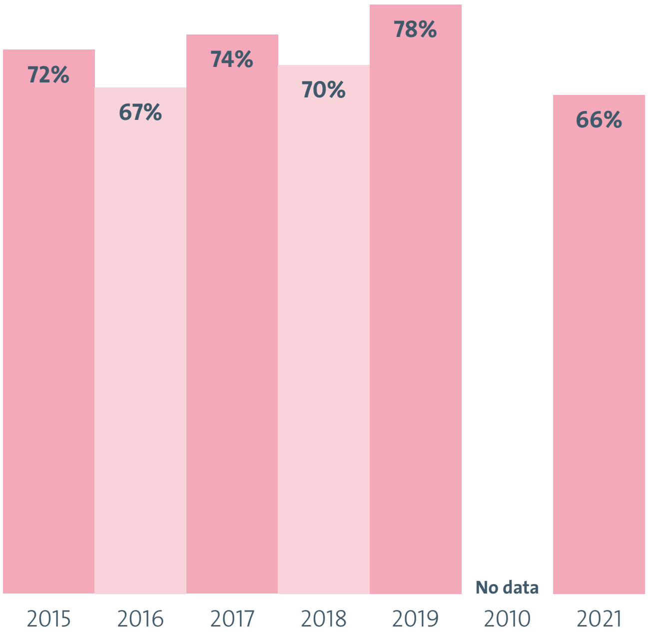
This is too low and is well below the with the average (53.9%). As much as the pandemic probably played a huge role in how comprehensive these conversations were, everybody deserves to understand what the outcome of their treatment might look like. Our **support catalogue** can be accessed online for those needing such guidance. It's stats like this that also drive us to focus on how we can **support research** to improve quality of life.

Resourced

When it comes to being resourced about their condition, treatment and care, cancer patients were asked *if they were offered information about how to get financial help or any benefits you might be entitled to*.

Here, we see a huge benefits for our community when compared to the national average of 34.9%, as 65.8% said they received this information. Although this is way above average, it is still a fairly large decrease since 2019 where the response was 78.0%. This is reflected in our ebenfits and welfare service, where demand and success rate is high.

% of patients given information on financial aid



When asked if *given information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if you had concerns*, the response for the brain/ CNS community was 51.1%, just slightly below the average of 51.6%.

Living in fear of recurrence impacts hugely on people's lives. It means that the slightest symptom makes your blood run cold, often needlessly. Being informed, looking the tiger in eye can remove this fear. So these are important conversations which are not being held. If you are in this position then please read our **guide for talking about advanced cancer**.

On top of things

Feeling 'on top of things' is massively empowering for the community and encapsulates many aspects of the other 5 areas. Knowing **what to expect** after a diagnosis is something we can help with, too.

When asked *if results of the tests were explained in a way they could understand*, the community response was 60.3%. This is significantly lower than the national average of 78.1% and may reflect the complexity of brain cancer, as well as the disconnect between how specialists prioritise information differently to patients.

Additionally, patients were asked if, when they *were first told they had cancer, it was explained to in a way that they could understand*.

The community response was again lower than the national average of 76.1%, at 60.8%. This further reflects the specific problems the community faces in clinical settings and subsequently while navigating life after diagnosis.

Patients were also asked if, *before treatment started, were the possible side effects explained in a way they could understand*. This time, we were much closer to the national average. Our response was 69.6%, whereas the average was slightly higher at 71.2%. This is a much better result, with around 7/10 people having the insight into potential side effects that would help them to feel more in control and on top of things.

Part of a community and less alone

When it comes to feeling part of a community, brain/CNS patients received above average care.

Patients were asked *if hospital staff gave relevant information support or self-help groups, events or resources*. The national average was fairly high, at 73.4% but the community scored even higher, with 4 in 5 people receiving this information, at 79.7%.

This is wonderful to hear, as we all know a good support system and a sense of community can support mental wellbeing. **Having difficult conversations** are a big part of facing what lies ahead in a way that works for you.

Another question that was posed was *since diagnosis, has anyone discussed with you whether there are any cancer research opportunities that you could take part in*.

The response was quite low across the board, with the national average being 26.2%. However, the community leapfrogged that result with their response being 40.6%.

This tells us the research landscape for brain/CNS is being signposted fairly well, although it is frustrating that there are few clinical trials available.

As always, there is room for improvement so that the community is aware of options for treatment and involvement in research.

Summary and key actions

As we've seen, there are some areas where patient care excels for the brain/CNS community, including access to research opportunities, and being signposted to self-help and events. The community is also more likely to be signposted to where it can receive additional information and support.

Unfortunately, there are far too many areas where neuro-oncology service delivery falls under the average and, further, where even the average falls shy of the ideal.

A theme that resonates is one that involves an explanation of a condition, diagnosis, side effects or treatment. The communication needs to improve so that the community feels confident in navigating its care and feeling on top of its situation.

Even with the pandemic massively effecting these areas, we can't accept this as the new standard. Every patient deserves to understand what is happening to them and what their options are.

As a brain cancer charity, *brainstrust* accepts its responsibility to continue pushing for this much needed change in any way that it can while continuing to offer support, insight, guidance and opportunities to those who need us. Our support services are designed with the community, for the community to address the issues highlighted by the NCPES. If you'd like to discuss any points raised here then please email **hello@brainstrust.org.uk**.