

# National Cancer Patient Experience Survey (NCPES) 2019

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

This is an overview of the ninth NCPES survey, which has run every year since 2010. 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. This year, this process has been made easier for us with a new dashboard, which saves pouring over lots of lovely spreadsheets.

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. For example, last year only 57% of you said you were entitled to free prescriptions, so we produced a **Know How** on financial benefits when living with a brain tumour as first quick win.

## 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:

- Engaged with your clinical team.
- Resourced
- Supported
- On top of things
- Less lonely
- That you belong to a community who knows what you are going through

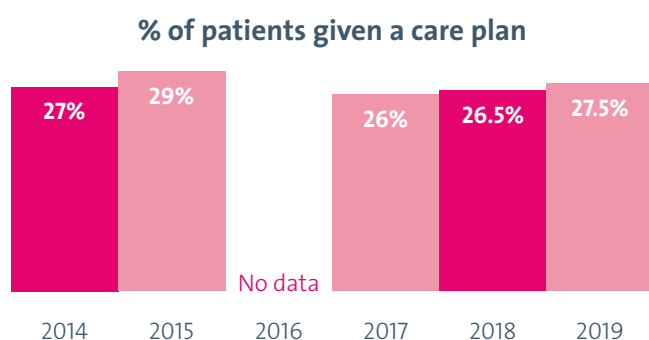
So what are the NCPES findings in relation to each of these? Here we'll discuss the highs and lows from the NCPES.

## Engaged with your clinical team

For the first time, a question has been asked about whether you were involved as much as you wanted to be in the decision making around your care and treatment. This means that we can only compare the results to those for other cancer sites.

79% of you felt you had been involved, and this is on a par with other sites. We're delighted with this – much of *brainstrust's* interaction with patients and caregivers is about how you can have voice, helping you to work out what is important to you and how to make sure that your needs and wishes are taken into account.

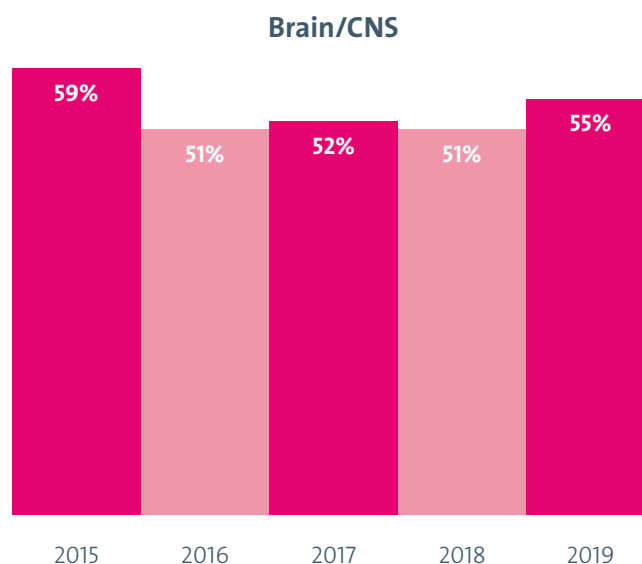
Let's move on to other aspects of your care. The next question: *Different people treating and caring for patient always work well together to give the best possible care* is a mixed bag – but a better result this year. 60% of you have felt that people who are treating and caring for you are working well together, but then this still leaves 40% of you who don't feel this. And whilst this 60% is the highest figure to date, brain cancer is the lowest, compared to other cancer sites which range from 68% to 79%. We need to do more here. And too, whilst 27.5% of you were given a care plan, an upward trend, this still means that we 2/3 of you are not being given a care plan. This figure hasn't really shifted at all since 2014; we'll be looking at what the barriers are to this. In the meantime it's important to note that care plans feature in the **NICE guidelines** so there is no excuse. What can you do to help? Ask for a care plan. Do your bit.



We know that having a good conversation can have a huge impact on your health and well-being; that's why so much of our support is based around surfacing what really matters to you if you are to live the life you want. So how much did you find hospital staff to discuss worries or fears with during your inpatient visit? Well, 45% of you found staff that you could chat to about your fears and worries. The good news that this is an increase of 12% (from 33% in 2018) but we still think this is too low. And this is reflected in that compared to other cancer sites. Brain cancer is the lowest score, but the range is quite low across for all cancer sites (45% – 56%).

For outpatients, more (66%) find someone to talk with, but this hasn't really shifted since 2015 when it was 63%.

Your interactions with your GP aren't as good as they could be. You felt that 55% of General Practice staff definitely did everything they could to support you during your treatment, and the trend is upwards in 2019. It still means though that just under half of you feel unsupported by your GP surgery. We'll be asking what good support would look like for you so that we see how we can best help GPs improve this score.



## Supported

There is good news around how well you felt supported by the clinical nurse specialist (CNS) in 2019. 95% of you were given the name of CNS who would support you through your treatment. The really good news about this though is that compared to other cancer sites in 2019, brain is among highest, with cancer sites ranging from 85% – 95%. And 86% of you found it quite easy to contact your CNS, which has shown a steady increase since 2015. Again, compared to other cancer sites in 2019, brain is among highest, with cancer sites ranging from 80% – 90%.

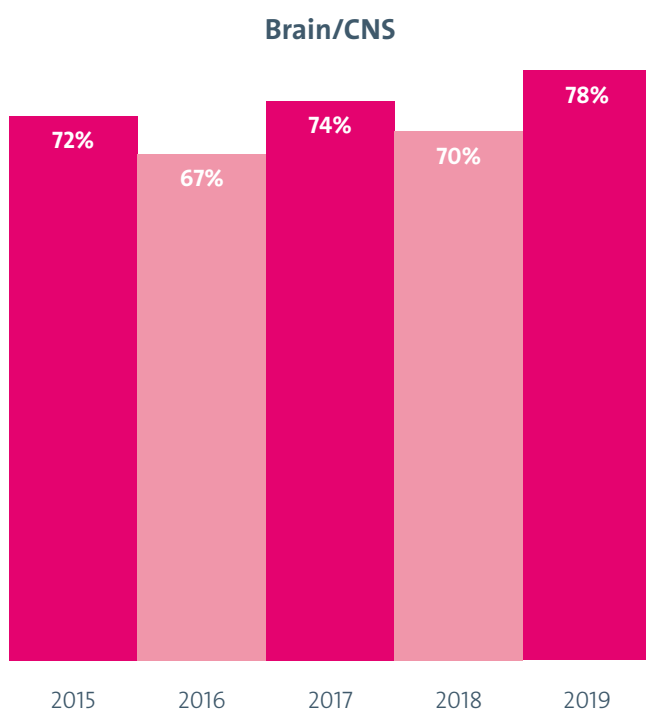
Things aren't quite so seamless though when information is needed for caregivers or support is needed from health or social services. Brain cancer is lowest with a third of you not being given practical advice support in dealing with side effects of treatment. This is a downward trend too. And only 58% of your families or a close person were given all the information needed to help care at home.

It gets worse too. During treatment, in 2019 a mere 42% of you were given enough support from health or social services **during** treatment, which has been a steady drop of 10% since 2015. Compared to other cancer sites in 2019 brain is the lowest. All other cancer sites range from 45% – 60%. This downward trend is reflected in the support you felt you were given from health or social services **after** treatment. There was a drop of 9% since 2018 to 39% and again brain scored the lowest compared other cancer sites, so there is lots of work to be done here.

## Resourced

So how resourced did you feel last year? There's good news about financial information. 78% of you are being given information on financial help, and increase of 8% on 2018, and an upward trend too in those of you being told you are entitled to free prescriptions.

The trend since 2015 has fluctuated between 67% and 74% in the last 5 years, with 2019 outcome the highest in the last five years.



A high percentage of you (84%) were given information or had the opportunity to talk about the impact cancer could have on your day to day activities, but there is room for improvement in the way your test results are explained to you, with 71% feeling confident that you understood what was being said; that means that just under 30% didn't feel confident. Compared to other cancer sites in 2019 again, brain was the lowest. All other cancer sites range from 76% – 84%. We're still not happy that only 2/3 of you were given written information about the type of cancer you have and that brain still remains the lowest. There is no excuse for this – the information is widely available and all your clinical teams need to do is to signpost you to *brainstrust*. This is something we could work on together.

## On top of things

Sadly, brain cancer is the lowest scorer of cancer sites here to, with 63% of you being given practical advice and support in dealing with side effects of treatment, which has remained pretty stable since 2015. And whilst 82% of you were given understandable answers from important questions all or most of the time, this is a downward trend and again, compared to other cancer sites, brain is the lowest. All other cancer sites range from 86% – 93%.

## Part of a community and less alone

Gold star here! Hospital staff gave 92% of you information about support or self-help groups for people with cancer, an upward trend which means that compared to other cancer sites in 2019, brain is among highest. Our **brain tumour hub** and **little white books** may be playing a key part here.

Progress is being made when it comes to being part of the brain cancer research community, too. 42% of you being able to talk about whether you would like to take part in cancer research may sound low, but it is the highest result yet.

## Top notes

There are some diamonds in this year's survey, but sadly we think there is still too much coal.

Brain cancer scored the lowest of all cancer sites in too many key indicators. Answers not mentioned above include:

- Patient felt they were told sensitively that they had cancer  
2019 outcome: 79%. All other cancer sites range from 81% – 89%
- Patient's family or someone close definitely felt able to talk to a doctor  
2019 outcome: 67%. All other cancer sites range from 69% – 75%
- Patient always given enough privacy when discussing condition or treatment  
2019 outcome: 78%. All other cancer sites range from 81% – 88%
- Patient felt length of time for attending clinics and appointments for cancer was about right  
2019 outcome: 56%. All other cancer sites range from 64% – 76%
- Patient given enough information about whether chemotherapy was working in a completely understandable way  
2019 outcome: 54%. All other cancer sites range from 57% – 79%.

## So key actions for *brainstrust*?

We need to talk with you, our community, to find out how care could look, with a laser focus on key areas. We think being given a care plan would be a good start, as so much of this could cover some of the above. We have mapped out what your care should look like according to the National Institute for Care and Health Excellence (NICE) so that we now know where the gaps are in service delivery.

We have been asked to join the Rare and Less Common Cancer Improvement Collaborative Steering Group, because brain cancer has scored so low on so many indicators and because *brainstrust* is recognised to be the 'go to' charity for improving patient experience. The Cancer Improvement Collaborative programme was set up in 2019 to improve the patient experience and quality of care in NHS cancer care services, drawing on data from the annual national Cancer Patient Experience Survey (CPES) and other sources of information. Trusts across the country have used their CPES data to develop specific projects where improvements can be made to patients' experience of care. The involvement of patients and those affected by cancer and who had insights into using cancer services was at the heart of these projects with all hospital trusts meeting to share and learn from each other.

So, there is lots to be done together – but with a sharp focus on what's going to enable everyone living with a brain tumour to have their best possible experience of the care services to which we are all entitled.

HB/ED July 2020