brainstrust
the brain cancer people

Our impact

2023-24

The impact of brain tumours is under-reported, support and research under-funded, and the true impact of the disease under-acknowledged and misunderstood.

From my point of view, it's about the knowledge I had. I needed to know what would happen to me and where I would go. The level of knowledge needs to be assessed, and lower levels need more support. It's not just falling off a cliff, it's being blindfolded. Even with knowledge, you still feel 'What happens to me next?'

Patient

Collecting impact data about our service is vital to ensure we meet the needs of those we support. With this data, we evaluate the effectiveness of our services, identify areas for improvement and demonstrate the difference we make. Sharing our impact also enables us to advocate for further funding and resources, ensuring our services can continue to meet the needs of those affected by brain tumours. Ultimately, it is through this commitment to understanding and improving our impact that we uphold our mission to provide meaningful, evidence-based support for people living with a brain tumour.

I had to be on the drugs for two years at least, as my tumour was small, but in an area associated with seizures. It devastated me. Everything caught up with me. It was the identity shift that was difficult – I wasn't prepared for going from a 'surgery survivor' to 'epileptic'.

Patient

Our strategy: First, we are people

In April 2019, we launched our current strategy: 'First, we are people'. Thirteen years in the making, 'First, we are people' puts laser focus on the human, practical and cultural contexts in which people find themselves following a brain tumour diagnosis. It sets out our journey to help people living with a brain tumour become less isolated, more in control, more involved with their clinical care and condition, resilient and better resourced.

How we got here

Our direction has been defined with our community. We 'asked the experts' what they need, to understand what matters most.

We heard:

- You spend more time being a person than you do being a patient.
- As a person, you are more resourceful, more proactive and more confident in the face of challenges.
- Emotions and values drive your behaviour, not clinicians. What matters to you is more important than what is the matter with you.
- People look at opportunities. As a person, you grow. Patients tend to focus on problems, and barriers are hard to overcome unless they can be treated or medicated.

Our current strategy has been co-created with our community and delivered with its support. 'First, we are people' helps us to achieve our mission – we are here for a world in which people with a brain tumour are involved, resourced, supported, confident and connected. They are living the life they want, because they are people first and patients second.

I struggle with multiple issues – fatigue, physical and mental problems – but I try to focus on healing and the road to recovery.

Patient

The impact of our support

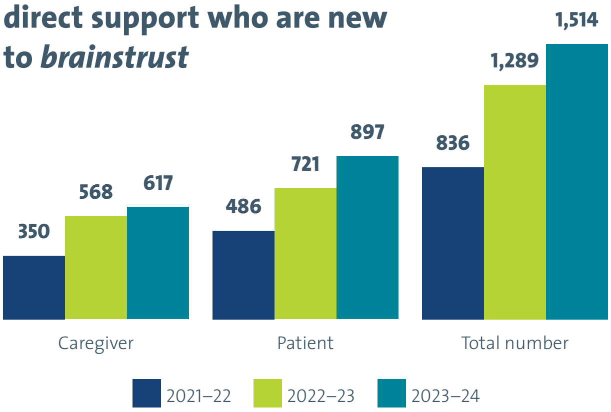
Awareness of *brainstrust* and our work is increasing, with more people than ever before accessing our support and information.

This is the result of concerted work to make sure we reach more people sooner. This is in response to community feedback that consistently tells us 'I wish I'd known about your support earlier on my journey'.

The number of people with a brain tumour that we are helping each year is increasing, and the amount it is increasing by is also growing:

- **125,405 people have engaged with our service.**
- **In 2023–24, 897 people with a brain tumour and 617 caregivers contacted *brainstrust* directly for support for the first time.**
- **This total of 1,514 people accessing our coaching, events or helpline is a 17% increase on the previous year.**

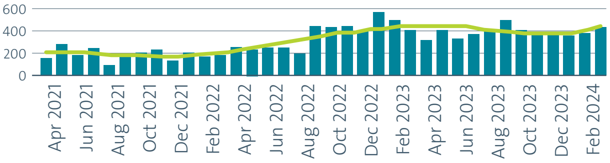
Number of people seeking direct support who are new to *brainstrust*



Once people have contacted *brainstrust* for help, we are here for them wherever they are on their brain tumour journey, and whenever they need us. At the end of the year, we were helping around 400 people a month.

Over the year in review, our support team helped 4,689 people, a significant increase on the preceding year (2022–23: 3,439 people), and double the number of the year before that (2021–22: 2,339 people).

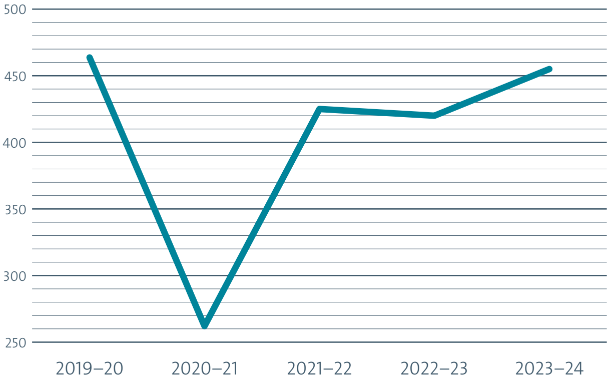
Number of people helped by *brainstrust* each month since 2021



Everyone who seeks support from *brainstrust* receives a brain box free of charge if they would like one. The contents are tailored to their circumstances, and the toolkit helps them to take control, be more resourced, understand their clinical care and feel supported.

In 2023–24, we sent 453 brain boxes to people. This is nearly double the number (262) that we were able to send at the peak of the Covid-19 pandemic in 2020–21, and consistent with pre-pandemic levels.

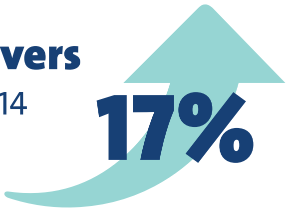
Brain boxes sent to those who need them



As the number of people we help increases, we are working hard to make sure we are working efficiently to cope with scale.

> *I have experienced some heavy-pressure-type headaches. I found this and my balance were often worse if I didn't have my afternoon nap.*
> **Patient**

In 2023–24, **897 people with a brain tumour** and **617 caregivers** contacted *brainstrust* directly for support for the first time. This total of 1,514 people accessing our coaching, events or helpline is a 17% increase.



Helping people online

More people are looking at more information on **brainstrust.org.uk**.

In 2023–24, 125,405 people used **brainstrust.org.uk**, with 306,311 pageviews. This is an increase of 28% in users on the preceding year (2022–23: 98,253) and a 42% increase in pageviews.

The most-accessed pages share information about brain tumour symptoms, end-of-life care, the different types of brain tumours, and the stories of people living with a brain tumour.

3,000 people have now provided feedback on our online information. 89% of these people tell us that the information helped them to be more resourced, more confident or more in control.

Feedback on online information

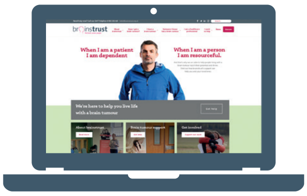
Page title	Helpful/ useful	Not useful
The brain box	**886** (95.78%)	**39** (4.22%)
End-of-life care	**597** (91.28%)	**57** (8.72%)
Anatomy and tumour types	**149** (79.26%)	**39** (20.74%)
Exercise and rest	**103** (87.29%)	**15** (12.71%)
Brain tumour symptoms and diagnosis	**97** (93.27%)	**7** (6.73%)
Recovering from surgery	**58** (71.60%)	**23** (28.40%)
Information about meningiomas	**57** (82.61%)	**12** (17.39%)
Downloads and resources	**44** (89.80%)	**5** (10.20%)

This feedback on online information has enabled us to review what is working well and what is not meeting the community's needs. For example, with this information and talking with the community, we have now produced a resource that helps with the transition to home after surgery and what recovery is like. There is a lot to think about when you or your loved one is being discharged from hospital. This can leave you feeling quite anxious, and it can be hard to know where to start. The resource explores how to ease this worry and help people feel more confident about the transition.

Anyone can access our information any way they wish, and we are seeing a significant increase in downloads of digital versions of our revered printed information. 12,000 digital (PDF) resources were downloaded during the year, a 73% increase on the previous year (2022–23: 6,928).

> *I feel very fortunate to have the support of* brainstrust*. They are the only brain tumour charity focused on providing emotional support throughout the brain tumour journey. Helping people find out what is most important to them and encouraging them to develop resilience and engagement with their own treatment is empowering and the absolutely most useful thing that can be done when someone is living the journey.*
>
> **Patient**

More people are looking at **more information** on **brainstrust.org.uk**



There are nine pillars that drive our efforts to understand the impact of our work

Accountability

We are trusted to deliver impact for the brain tumour community with resources funded by individuals, companies and other charities. Measuring and reporting on our impact enables us to demonstrate how effectively we are using these resources to achieve our goals.

Application of our resources

Many charities are constrained by limited available resources. By measuring impact, we can identify which of our efforts are delivering the most impactful results. Our impact data guides decision-making on how we allocate resources for maximum effectiveness.

Improvement

Regularly assessing impact enables us to identify areas for improvement. By understanding what is working well and what isn't, we refine our strategies, modify programmes and enhance our approach to serve better the brain tumour community.

Learning and adaptation

The landscape in which we operate changes rapidly. Measuring impact helps us to stay agile and responsive to evolving needs. When we can track changes in our beneficiaries' lives, we are more able to adapt our work appropriately and with confidence.

Advocacy with evidence

When we are pushing for policy changes, or increased funding, measuring impact provides evidence of the outcomes we are achieving, and demonstrates the gaps that we need to close.

Effective communication

Sharing our impact data allows us to communicate our achievements effectively. It makes our stories relatable and understandable, enabling us to connect with a broader audience and inspire people to join our cause.

Engaged supporters

People and institutions want to know that their contributions are making a difference. Impact measurement provides donors with a clear picture of how their support is creating positive change.

Strategic planning

Impact data informs our planning. We can set realistic and achievable goals when we have a clear understanding of the outcomes we can deliver, based on past performance.

A learning culture

A focus on impact cultivates a culture of continuous learning and improvement. We are more open to experimentation and innovation as we seek out the best possible ways to achieve our mission.

Methodology

We track progress against six indicators. These have been defined as being important to quality of life by our community of patients and their caregivers. These six indicators are:

- engagement with care and condition
- reduced isolation
- engagement with communities
- creating control
- feeling supported
- feeling resourced.

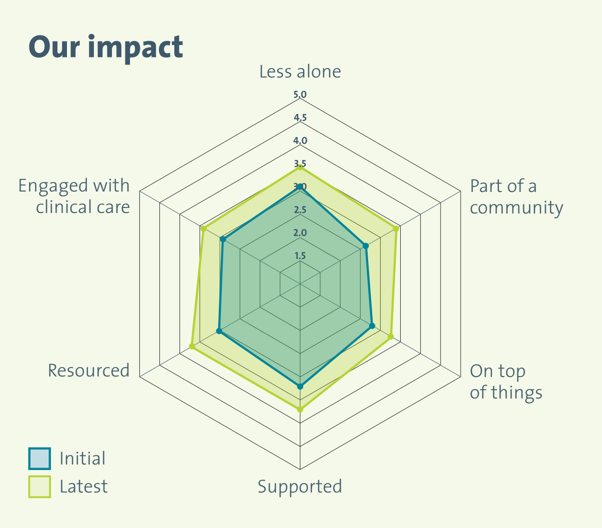
We learn how people are doing against these indicators using our bespoke progress tracker tool. This gives us a simple, flexible and human approach to understanding our impact. Progress trackers are completed and reviewed collaboratively with our beneficiaries. In completing a progress tracker, or multiple progress trackers, we help people to establish where the focus of our support needs to be so that they can move forward. Patients and caregivers provide a score of how they are feeling on a scale of 1 to 5 for each of our indicators, 5 indicating it is as good as it can be, given the circumstances. They complete multiple progress trackers on their journey with *brainstrust*, and this paints a picture of their progress.

Our impact

You can see below how we have helped our community to navigate the complicated journey of living with a brain tumour diagnosis in the last year. The inner hexagon represents where people were on average when they first contacted us, and the outer hexagon represents their average latest scores.

We helped people the most in feeling a part of a community – taking the score from 2.6 to 3.4, a 20% improvement in the context of the 1 to 5 scale*. This jump represents the strength of our webinar and peer support services and also our fundraising events. All of these activities bring our community together and connect people with others who share similar goals, challenges and experiences.

The next-highest increase comes from helping people to feel resourced, with an 18% improvement in the context of the 1 to 5 scale* (3.0 to 3.7). We're proud to offer materials that have been co-produced with our community, such as our 'Behaviour and personality change', 'my radiotherapy book' and 'Who's who in your clinical team' resources. These help people to feel more knowledgeable and supported.



Impact indicator	Initial	Latest	Difference	Percentage increase
Less alone	**3.1**	**3.5**	**0.4**	**10%**
Part of a community	**2.6**	**3.4**	**0.8**	**20%**
On top of things	**2.8**	**3.3**	**0.5**	**13%**
Supported	**3.2**	**3.7**	**0.5**	**13%**
Resourced	**3.0**	**3.7**	**0.7**	**18%**
Navigating clinical care	**2.9**	**3.4**	**0.5**	**13%**

* Percentages shown are calculated as distanced travelled on the 1–5 scale. Each point (1 to 2, 2 to 3, 3 to 4 and 4 to 5) represents a 25% change.

Overcoming isolation is still a big challenge for our community, and therefore for *brainstrust*, and our efforts in the future will focus on 'feeling less alone'. Here we saw our smallest increase, of 10%, from 3.1 to 3.5. This feels at odds with our strongest result, helping people to feel part of a community, but feeling lonely even when surrounded by loved ones and a supportive network is still a very real challenge and can heighten isolation.

Our journey at *brainstrust* has been one of constant learning with, from and for our community.

PRiME Patient Research Involvement Movement

PRIME – bringing people closer to research, and research closer to people

I am proud of being in tune with the needs of the brain tumour patient community through our constant dialogue, and that this relationship goes both ways. Because of PRIME, we can help people grow and learn. My work is a conduit that helps people understand brain tumour research.

We do need to help the research community understand the value of PPIE, and sometimes we are constrained by lack of capacity in our volunteer teams.*

Looking ahead, we are thinking bigger, setting ambitious goals and want to make learning about brain tumour research as easy as possible.

Adam Thomson
Patient Involvement Officer, *brainstrust*

In 2021, we created the Patient Research Involvement Movement (PRIME) to bridge the gap between the clinical community and brain tumour patients and their caregivers. Through PRIME, we are able to improve the quality of clinical brain tumour research, ensure trials are more likely to be funded, and contribute to a healthier landscape of treatment for the brain tumour community.

We continue to see a healthy growth in our PRIME community, going from 57 volunteer advocates and partners in 2022, to 115 in 2023 and now 151 in 2024. This community of research-primed and research-engaged individuals is expert by experience and has made huge contributions to brain tumour research, with top-level patient involvement support.

We are improving the standard of PPIE in clinical research, remaining thought leaders in this space and growing our service. We do this by:

- collaborating with other charities, including Brain Tumour Research
- exploring new ways to share our services with clinicians
- having more conversations with researchers and research funders regarding funding for this vital service
- continuing to develop a training and webinar programme for our volunteers
- learning and adapting methods of delivering the best patient involvement.

Brain Tumour Research

> *We had incredibly helpful sessions with patients and caregivers across several domains of interest, including medical device design, clinical trial design and outreach efforts. We would love to continue to work with* brainstrust *and their community in subsequent PPIE efforts.*
>
> **Researcher**

Since its inception, PRIME has successfully supported research applications to the value of £28.2m, with partners who include:

Cochrane
NIHR | National Institute for Health Research
UNIVERSITY OF LEEDS
University of BRISTOL
UNIVERSITY OF CAMBRIDGE
UNIVERSITY OF LIVERPOOL
THE UNIVERSITY of EDINBURGH
Coventry University

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* Patient and public involvement and engagement.

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My diagnosis was delivered over the phone by my GP, which was incredibly hard to deal with. The best way to describe my feelings at the time is a mixture of fear and an overwhelming sense of confusion. As how could this be happening to me? I had just finished my degree, which I had worked hard for. I was starting a new job, which I was excited for, at the end of the week, and I had just turned 24 years of age a few weeks prior. It felt like such a cruel twist of fate for this to happen as my life was just coming together how I wanted.

Patient

What am I not struggling with? I suffer daily symptoms, which range from tinnitus, dizziness, head pressure and pain, which frightens my husband.

Patient

Trusted Information Creator
Patient Information Forum

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