



Our Impact

2022-23

Contents

Impact: why it matters	3
Our impact 2022–23	5
The year in numbers	6
Online support and information	7
Thrive with <i>brainstrust</i>	8
Madi's journey with the Thrive platform	8
The impact we are having	9
Methodology	9
In the words of others	10
Patient Research Involvement Movement (PRIME)	13

For more information about *brainstrust*, our work and how the charity is run, you can read our Trustees' Annual Report at brainstrust.org.uk/our-impact.



Impact: why it matters

Measuring impact is about maximising the effectiveness of our work, ensuring that our resources are used efficiently in generating positive change for people with a brain tumour.

We have worked hard over recent years to create a culture where impact is not only at the centre of our processes but also a central part of the conversations we have with the people who need us. Tracking impact is mutually beneficial.

Will Jones

Chief Executive, *brainstrust*

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

Accountability

We are entrusted with resources, often donated by individuals, corporations or governments. Measuring impact allows charities to demonstrate how effectively we are using these resources to achieve our goals.

Resource allocation

Limited resources are a common challenge for charities. By measuring impact, we can identify which of our efforts are delivering the most significant results. This information guides informed decision-making on where 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 is not, we refine our strategies, modify programmes and enhance our approach to better serve the people we are here for.

Agility 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 better equipped to adapt our work appropriately and with confidence.

Advocacy with evidence

When we are pushing for policy changes or increased funding, measuring impact provides tangible evidence of the outcomes we are achieving or demonstrates the gap 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 more 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.

Our impact 2022–23

This year we have grown our team to meet increasing demand and build capacity so that we can continue to help more people than ever before with *brainstrust's* unique and impactful support.

Riding the momentum we carried through the pandemic, we have moved forward this year, with and for our community at pace, and without compromising our impact.

Every day the resourcefulness and resilience of our community inspire and motivate us, and our strategy and structure have enabled us to scale our work across new regions. We hoped that this year would be exciting for *brainstrust*, for our community and for our team, and it has been. This is not to make light of the devastating challenges faced by the people we are here for, but it is a comment on how we have never felt more confident, single-minded and committed to our mission to make life better for people post-diagnosis.

Helen Bulbeck

Co-Founder and Director of Services, *brainstrust*



The year in numbers

During the year,
3,439 people accessed our help

by phone or email, webchat or video call.

This is an increase of 47% on last year (2,339), and 172% on the year before (1,264).



1,306 people came to us for help for the first time.



Of these people, 739 were brain tumour patients, and 567 were caregivers or close friends or family members seeking support. **This is a 58% increase on last year (825).**

We were able to send
368 brain boxes

to people who needed them. This is 34 fewer than last year.



Our volunteer-led welfare and benefits support service

helped 41 people to access financial support worth £94,760.



This comprises Personal Independence Payments (PIP), Disability Living Allowance (DLA) and one-off grants from local organisations.

We provided 372 counselling sessions to 62 people

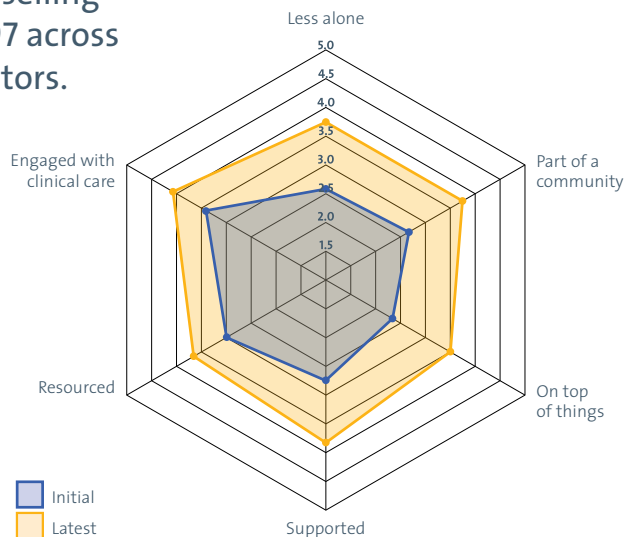


via our network of specially trained and professionally qualified counsellors. On average, people who accessed *brainstrust's* counselling progressed by 0.97 across our impact indicators.

This represents a 24% improvement.

People who accessed counselling with *brainstrust* reported **feeling more on top of things and less alone** – where for both indicators,

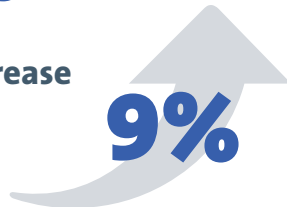
we enabled a 29% improvement.



Online support and information

120,668 people came to brainstrust.org.uk

for the first time for information, a **9% increase** from 110,928 the previous year.



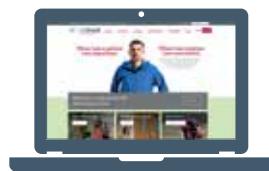
These people accessed

270,716 pages and downloaded 9,384 copies



of long-form health information from our website.

During the year, the most popular information has been about diagnosis, brain tumour types, patient stories, end-of-life care and glioblastoma trials and treatments.



Feedback Form

Thank you for attending our Thrive event; it was lovely to have you with us today. Hopefully you are leaving with some valuable insights and some great new connections. Our feedback form is a great tool to allow us to understand what went well and how we can improve future events. Your feedback will only be shared within the brainstrust team, and we welcome honest comments.

What is your role?

Patient/caregiver/relative:
Healthcare Professional (please state job title):
Charity:
Researcher:
Other (please state):

How useful did you find this event on a scale of 1-10? (Not useful 1 - 10 really useful)

What did you like?

What didn't you like?

How could this event be better?

Any additional comments or suggestions?

Please hand this to us on the way out. Thanks for joining us.

Of the **2,469** people who have provided feedback on our information, **2,219 (90%)** tell us that what they have read has



helped them to feel better resourced and more in control.

The most highly rated information



on our website covers topics that include end-of-life care, the brain box, anatomy and tumour types and brain tumour symptoms and diagnosis.

Thrive with *brainstrust*

I found it helpful to lay out all the things I'm feeling overwhelmed about and what I do and don't have control over and work out the places where I can get more support/information around my treatment and what the next steps are. The exercise of writing things down and categorising those areas was useful and helped get everything out of my head, and I felt supported and heard.

Brain tumour patient,
London

During the pandemic, we accelerated our plans to make our coaching service available online. This work progressed at pace during the year in review, culminating in the launch of the Thrive coaching platform. On this platform, people can select a coach, book sessions and attend via secure video call. Goals and topics are set prior to the call, and evaluation takes place within the platform. Coaching via the Thrive platform gives users structure and direction in the support they receive. The platform allows people to choose when the sessions take place and to set the focus. This sets a clear pathway to attaining their goals. As it is a video platform, people get to see their *brainstrust* support specialist during the sessions, so they can feel as connected as possible with their coaching journeys.

Feedback and outcomes are good, with people scoring their experience as 10/10, from 164 completed sessions on the platform. Our expert coaches have been scored 5/5 from these sessions.

Madi's journey with the Thrive platform

Madi's story shows the significant impact this work can have. Madi has lived with brain tumours for nearly 30 years and is a survivor of multiple surgeries. She recently came to *brainstrust* for support as her third surgery approached and she faced ill-health retirement from a career she had worked hard for and loved. Madi engaged with our coaching service through the Thrive platform and told us: *'There is something about there being a particular place to go that adds value to the sense of belonging and community. It also reminds me that there are other brainstrust resources, such as the fatigue book, that I can go back to. The follow-up emails my coach sends me after each session provide me with an opportunity to respond in writing, as do the feedback and booking forms on Thrive. Writing is a very helpful reflective tool for me and helps me consolidate what I am taking away from each of the face-to-face online sessions. The online sessions are helpful to me, as I don't need to travel and can rest before or after sessions, depending on my fatigue.'*

Madi told us: *'I feel empowered and have the sense of being held in a kind of soft safety net. The questions I've been asked and the relationship I've built with my coach provide an inner voice to challenge some of the less helpful thoughts I may have. I have achieved a sense of relative calm whilst waiting for information about my ill health, retirement and next surgery.'*

Using our progress tracker tool over the four-month period she was engaged in online coaching, Madi improved her overall well-being by 76%, from an initial total score of 17 out of 30 across all six of our key indicators to her most recent maximum total score of 30 out of 30.

The impact we are having

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. In turn, these indicators support the four priorities in our strategy. These six indicators are:

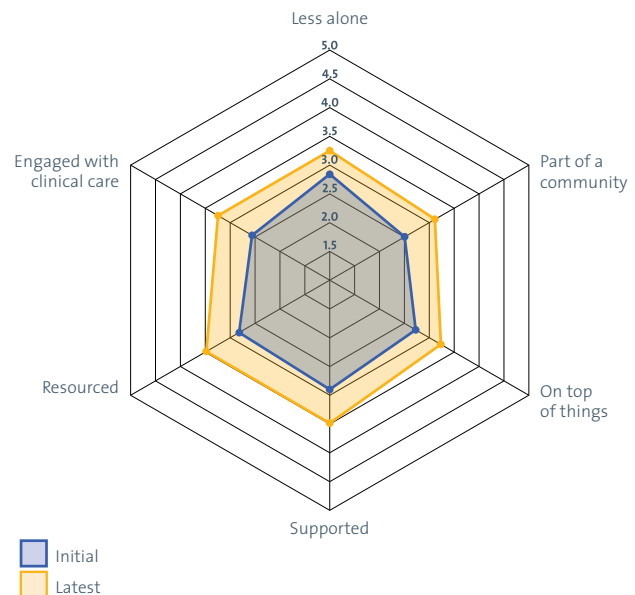
- navigation of clinical care
- reduced feeling of isolation
- engagement with communities
- creating a sense of control
- feeling supported
- feeling resourced.

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 impact. Progress trackers are completed and monitored collaboratively with our beneficiaries. The process isn't unobtrusive, but it is helpful, and engagement with the process encourages people to reflect on how they are feeling about things that are important to their own quality of life. In completing a progress tracker, or multiple progress trackers, we help people to establish where the focus of our support needs to be to help them move forward. To complete a progress tracker, patients and caregivers provide a score of how they are feeling on a scale of 1 to 5 for each of our indicators. They complete multiple progress trackers on their journey with *brainstrust*, and this paints a picture of their progress.

People who have come to us for help in the last year have made progress against our six key impact indicators. On average, people have progressed by 0.57, on a scale from 1 to 5. This equates to a 14.25% average increase in well-

being across the board. This is even greater for some indicators.

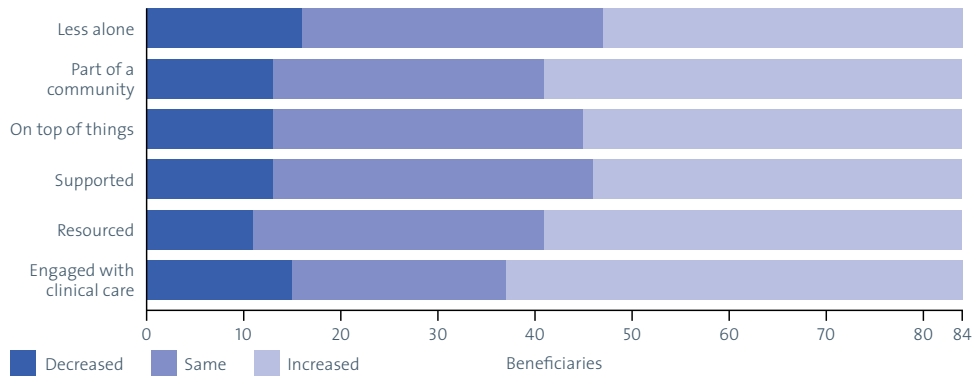
- We helped people improve the most with feeling able to navigate their clinical care, where we saw a 17.25% increase.
- After that we saw a 16.25% increase in feeling resourced.
- An area our focus should turn to from here is helping people to feel less alone, as we saw our smallest increase, of 10%, here.



In total, during this given period, we had 84 people complete their first and second progress trackers and 328 people complete only their first, with an aim to collect their second in the future. We have worked hard and achieved positive outcomes over the year to close the gap, ensuring we are collecting as many second trackers as possible to get an accurate picture of the impact of our services.

Over the year, we helped the vast majority of people who contacted us to sustain or improve well-being in the face of progressive neurological disease where, by all clinical measures, deterioration is more than likely.

Beneficiary change 2022–2023



It is important that we are realistic in our expectations, given the context in which many of the seriously or terminally ill people with whom we work find themselves. For many in this space, maintenance of well-being is an important and ambitious goal, and we are proud to help people achieve this.

Adam Thomson,
Patient Involvement
Officer and
Impact Lead



In the words of others

Numbers alone don't always shine a light on the powerful outcomes that *brainstrust* creates for people, or the challenging circumstances they face. Over the year, we have heard a lot about the impact our work is having, directly and unprompted from the people who need us:

I am now at the stage where I really want to share all that I have learnt on my brain tumour journey, and give back to the community. With that in mind, it was perfect timing when I bumped into the lovely team from brainstrust at a brain tumour conference I'd been asked to speak at. Combining my coaching qualifications and experience on my brain tumour journey, I can now support others in coming to terms with where they are at, and then help them start to take powerful, positive action to live their best lives possible.

Damon,
brainstrust volunteer and
brain tumour patient



Area of impact	Beneficiary feedback
Less alone	<p><i>'That's the first time I've been able to talk with other brain tumour patients in person, and I found it very therapeutic.'</i></p> <p><i>'I do feel so incredibly blessed and lucky to have found you and brainstrust. It really does feel so comforting knowing you are there. Thank you from the bottom of my heart.'</i></p> <p><i>'I remember when I got my brain box, it felt like a warm hug and stopped me from feeling alone. I hope someone else gets to feel the same.'</i></p>
Supported	<p><i>'I'm still in shock, but it's because of all the amazing people in my life, like you, who continue to encourage and support me. Thank you for your ongoing support and encouragement. I am very lucky to have such amazing people around me and wouldn't be where I am without you, I am sure.'</i></p> <p><i>'You have been a real beacon of hope for me when I felt all at sea at the beginning of this journey.'</i></p>
On top of things	<p><i>'I found the session very useful. I now feel I am heading in the right direction to be as in control and on top of things as I can be. Mariel put me at ease, as this was the first online interactive thing I have ever done, and she also teased out the positive things I didn't realise I was already doing and some issues that we could address at a later date. Thank you for your advice today.'</i></p>
Resourced	<p><i>'The hypnotherapy helps me to focus on my needs, relax, find a calm place in my head. It reminds me that I need to look after myself. The "Meningioma Matters" sessions give me relevant information and keep me up to date, allowing me to learn from others' experience as well as providing a support network who "get it" in relation to lived experience. The information on the website has been useful in researching things like radiotherapy. The Facebook site gives me that community again; it's nice to feel I can occasionally offer understanding or suggestions to others.'</i></p>

Area of impact

Beneficiary feedback

Part of a community

'For the first time, I felt the group really knew what I was feeling. Acoustic neuromas are rare, so I haven't been able to find people who have been through similar experiences, and this forum was supportive, friendly and informative. I am so grateful to have the opportunity to learn and share ideas with this group. Looking forward to the next one.'

'I have found the online "Family and friends" Meetup very helpful and supportive. It has been interesting to connect with other people who are experiencing similar situations but who obviously have different ways of coping. I have found it a very useful platform for exchanging management/coping skills, and it helps me to feel less alone with my situation.'

'Reading other people's stories has really helped me not feel so alone with the life-changing nature of this diagnosis. I've learnt to accept the new me, and know that while I'm different to how I was – there are certain situations I now find difficult, and I don't have as much energy as before – that's OK. A brain tumour affects different people in different ways. Accepting this, and accepting help from everywhere it's offered, plus talking about it and telling your story, can really help.'

Confident navigating clinical care

'You should know that your advice was instrumental in us obtaining a treatment that saved Caroline's life. I'll always be grateful to you for that.'

'The information webinars (understanding scans) help me understand and ask questions. The information sheets are really useful (radiotherapy, uncertainty), and the new meningioma information is great.'

'In the short time of contacting brainstrust, you changed my future instantly, and you helped me get the care I needed and knew I deserved. I am forever grateful to you for that.'

Our impact on brain tumour research – bringing patients closer to research this year

Our Patient Research Involvement Movement (PRIME) started in April 2021 with the aim of providing and improving the standard of patient and public involvement and engagement (PPIE) in brain tumour clinical research.

PPIE means utilising the insight and knowledge of the patient and caregiver community in the design of new research through various forms of ongoing communication and review. This ensures new trials and studies have patient needs woven in, making treatments more comfortable and supportive.

Now in its third year, PRIME continues to offer top-level support to researchers and clinicians. Together we are bridging the gap between the clinical community and the patient and caregiver community, enabling the patient voice to be in the DNA of trial and treatment design.

If you are a researcher or clinician and want to find out more about how PRIME can support your research, please contact adam@brainstrust.org.uk.

Growing the Patient Research Involvement Movement

We have a growing community of research advocates, offering their unique insights in direct discussions with neurologists, neurosurgeons and neuro-oncologists. Collectively they aim to

improve the quality of life for people diagnosed with a brain tumour.

Taking on a yet more involved role in the research landscape, our research partners have been attending our regular training sessions – exploring and learning about the research landscape, what makes good PPIE, and the challenges we want to overcome together.

Right now, we have:

- begun training 23 research partners in how to deliver top-level patient involvement
- recruited 137 research advocates, who help researchers shape trials and studies to improve care for future patients
- signed up over 1,200 people to our Monthly Brew research newsletter, providing knowledge and news about the field.

Pushing the standards of patient involvement

As our service continues to reach more people in clinical spaces, we are getting involved in some wonderful, forward-thinking research.

The clinical research community is investigating all angles when it comes to improving quality of life and life expectancy after a brain tumour diagnosis. Helping improve the standard of so many of these studies and trials gives us the motivating responsibility to continue pushing the standards of patient involvement.

In the last year, our patient advocates have been involved in some of the following projects, just to name a few:

- an early phase clinical trial to determine a model for brain tumour patients' diseases
- a study on social cognition assessments for brain tumour patients
- an early phase clinical GBM study on crossing the blood–brain barrier
- a surgery trial for epilepsy and seizure patients
- designing a tool to help those with Acquired Brain Injury (ABI) navigate sexual and mental well-being
- a study aiming to improve cognitive performance
- a study establishing core outcome sets for brain cancer trials.

Some of the aims we have helped researchers achieve include:

- creating core outcome sets
- gathering feedback on pathway proposals
- analysing diagnosis preferences
- determining issues with current treatment
- identifying areas for improvement on trial design
- suggesting new methods of support for patients
- making research accessible
- providing unique perspectives.



PRIME has also been sharing news and insight through our research-focused newsletter: The Monthly Brew. The newsletter is reaching a growing number of research-hungry members of the community and provides opportunities to be involved, highlights from various studies and any need-to-know information about what is happening at the forefront of the clinical landscape.

Other PRIME news and the future

Over the past year, we have strengthened our partnership with Brain Tumour Research. Their support has given PRIME even more capacity to support and provide PPIE to current research. We are aligned in our goal of improving outcomes by contributing to clinical trial design and we look forward to continued collaboration to push this gold standard further.

We are also supported by Naseem's Manx Brain Tumour Charity, a fantastic charity providing brain tumour support to the Isle of Man community.

We are grateful and proud to have relationships with such passionate and inspiring organisations.

Looking ahead, we will continue to provide our support to more exciting and important projects. Together we can transform the care available for anyone affected by a brain tumour, helping them live their best life possible after diagnosis.

Join the movement

To apply your experience and insight to support clinical research, join PRIME today at www.brainstrust.org.uk/prime.

If you have any questions about PRIME or want to access support, call us on **01983 292 405** or email hello@brainstrust.org.uk. You can also visit our **little brainstrust** website, which features support for children affected by brain tumours.



The Rumble family is one of many in our community who have engaged deeply in fundraising endeavours for several years. They have Worn Grey for awareness, conquered Welsh summits, turned their hands to woodwork and craft, and sold this work to support our work. We are profoundly grateful for the Rumble family's steadfast support over these years. Their exceptional dedication and passion have had a profound impact on the brain tumour community.

