

I want to do all the things people do.

Not always the things that patients have to do.



We're here to help put you in control of your care. To make you feel involved, confident, supported and connected. Because when you feel all of those things, you are more than a patient.

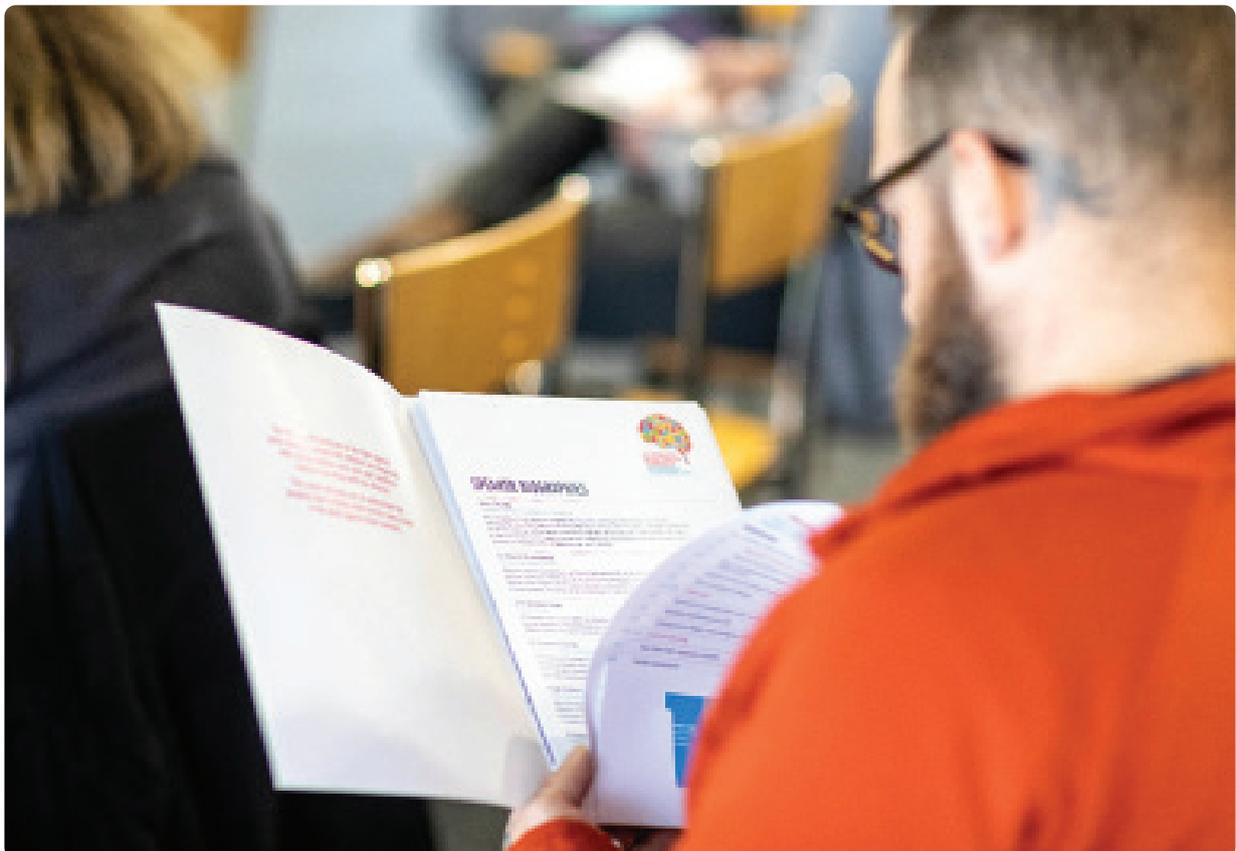
You're a person. And today you can have a great day being you. Let us show you how it feels to thrive.

brainstrust's impact **2019/20**

“ From the moment my son was diagnosed with a tumour, and we contacted brainstrust, in what was the darkest hour of our lives, they gave us hope. ”

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Impact matters.

“Rigorous reporting beyond simply counting beneficiaries remains an open goal for charities. We owe it to all of our supporters to be doing an incredible job at communicating the difference our work makes. And we can only have ongoing or greater impact for the people that need us if we can talk openly and honestly about where we can be doing better.”

Will Jones

Chief Executive

brainstrust

Here we share what we are achieving, as well as where we might be falling short. Storytelling and narrative are a persistent part of our reporting, and we have been working hard in recent years to develop systems and processes that make us best in field at sharing with you what you are helping us to achieve.

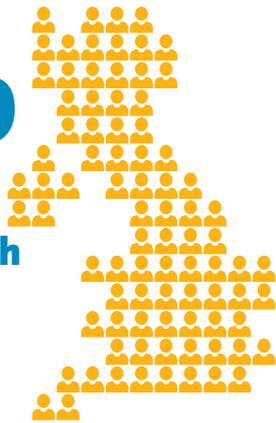


Our challenge is hard. But that it is hard is what motivates us.

MORE THAN

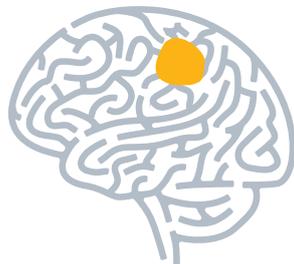
68,000

people in the
UK are living with
a brain tumour
diagnosis



Primary brain cancer
is the **MOST
COMMON** form
of cancer in
people under

40



of **ALL** cancers
spread
to the brain
(secondary
cancer)

“ I feel like I’m in a fight
with my hands tied behind
my back. ”

Caregiver, Liverpool

“ I was just a terrified thing
in the corner. ”

Patient, Essex

“ Facing your own mortality
is a big thing when you’ve got
a young family. ”

Patient, Kent

“ I left work. I cleared the house
out thinking that this was the
end. My family are at a loss
as to what to do with me. ”

Patient, London

But these facts don’t help you when you hear the words
‘you have a brain tumour’.

A brain tumour diagnosis brings with it the double impact of a cancer diagnosis and a progressively debilitating neurological disease. The treatment is complex and nearly always harmful, and diagnosis brings with it enormous impact on well-being and mental health. Fear, isolation, disempowerment and loss of control abound.

This is where we help

We are for a world where 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.

brainstrust helps you live life with a brain tumour. We know that when you hear the words 'you have a brain tumour', you need support from people who not only understand the fear, confusion and isolation but can empower and resource you to overcome it.

We provide personalised 24/7 support from the point of diagnosis and build resources that help people with a brain tumour to become stronger. We also work with people in the clinical setting to secure the best care possible for people with the condition. And because we truly understand the challenges faced by the brain tumour community, we're able to campaign to solve real issues.

In the last 14 years, we've helped thousands of people on their brain tumour journey. Our impact is evidential. Only with your support can we help even more of those who need us.

“ We choose to go to the moon in this decade and do the other things, not because they are easy but because they are hard, because that goal will serve to organise and measure the best of our energies and skills, because that challenge is one that we are willing to accept, one we are unwilling to postpone and one we intend to win. ”

John F. Kennedy

1962

First, we are people.

Our strategy.

In April 2019, we launched our new strategy. Fourteen years in the making, this strategy, '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 these people become less isolated, more in control, more involved with their clinical care and condition, and better resourced. We are acknowledging that before we are patients, we are people. And when we are patients, we are only patients for a small amount of the time. We want to do things that people want to do, not always the things that patients have to do.

We know from our intimately close work with our community of people living with a brain tumour, and their caregivers, that a brain tumour is isolating, confusion abounds following diagnosis, communicating well is hard, behaviour and personality change devastates relationships, fatigue impacts 95% of those diagnosed, and there is a huge financial impact as work stops. These are just some of the challenges, and these challenges are not addressed in either the laboratory or the hospital.



brainstrust's vision

Everyone with a brain tumour should be resourced and resilient so that they can live the life they want to and secure the best outcome for their situation.

To make this happen, we aim to

help people overcome fear

empower people to engage with their challenges and care

eliminate isolation

improve knowledge and understanding

through our work in the following areas

coaching and support

building communities

information and education

regional insight and relevance

clinical engagement, development and network building

engaging people with research

which is only possible with

effective fundraising

efficient marketing and promotion

administrative support

good governance

Our impact.

We have worked tirelessly and closely with our community, our team and our funders to develop robust, auditable and trustworthy impact reporting.

We report on people's progress against six indicators, all of which contribute to addressing the four priorities in our strategy. These six indicators all ensure our beneficiaries are working towards being 'people first'.

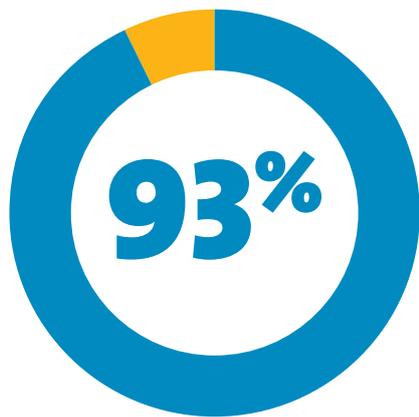
- engagement with care and condition
- reduced isolation
- engagement with communities
- creating control
- feeling supported
- feeling resourced

Everybody who engages with *brainstrust* for help, advice and support is asked to complete a progress tracker at least twice. People complete a progress tracker once at the start of their journey with *brainstrust*, and again either at a fixed point in time (typically three months) or after a one-off interaction (for example, at a workshop or event).

brainstrust's support specialists in their one-on-one coaching work then reflect on the data with the respondent; the reports are used to identify and work on specific, defined needs. The data is also aggregated to give us an indication of overall impact of service. It is this information that we are able to share here.

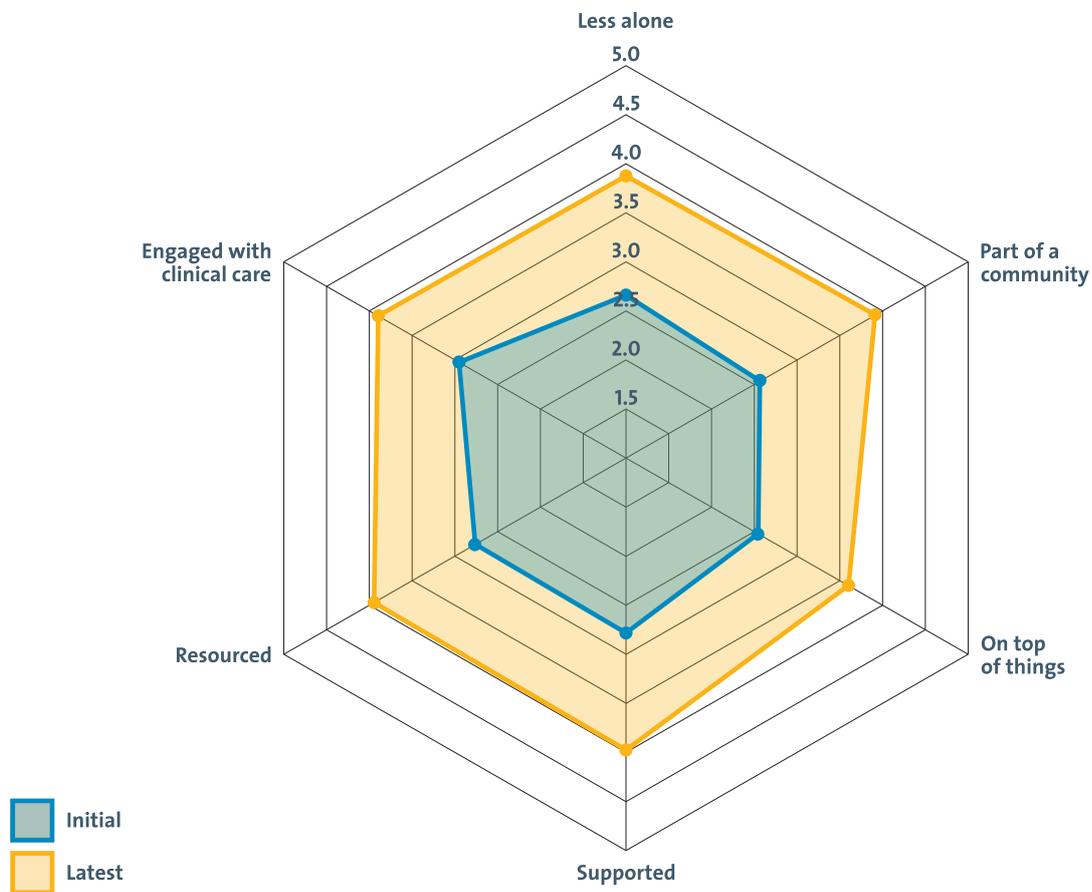


brainstrust's impact 2019/20.

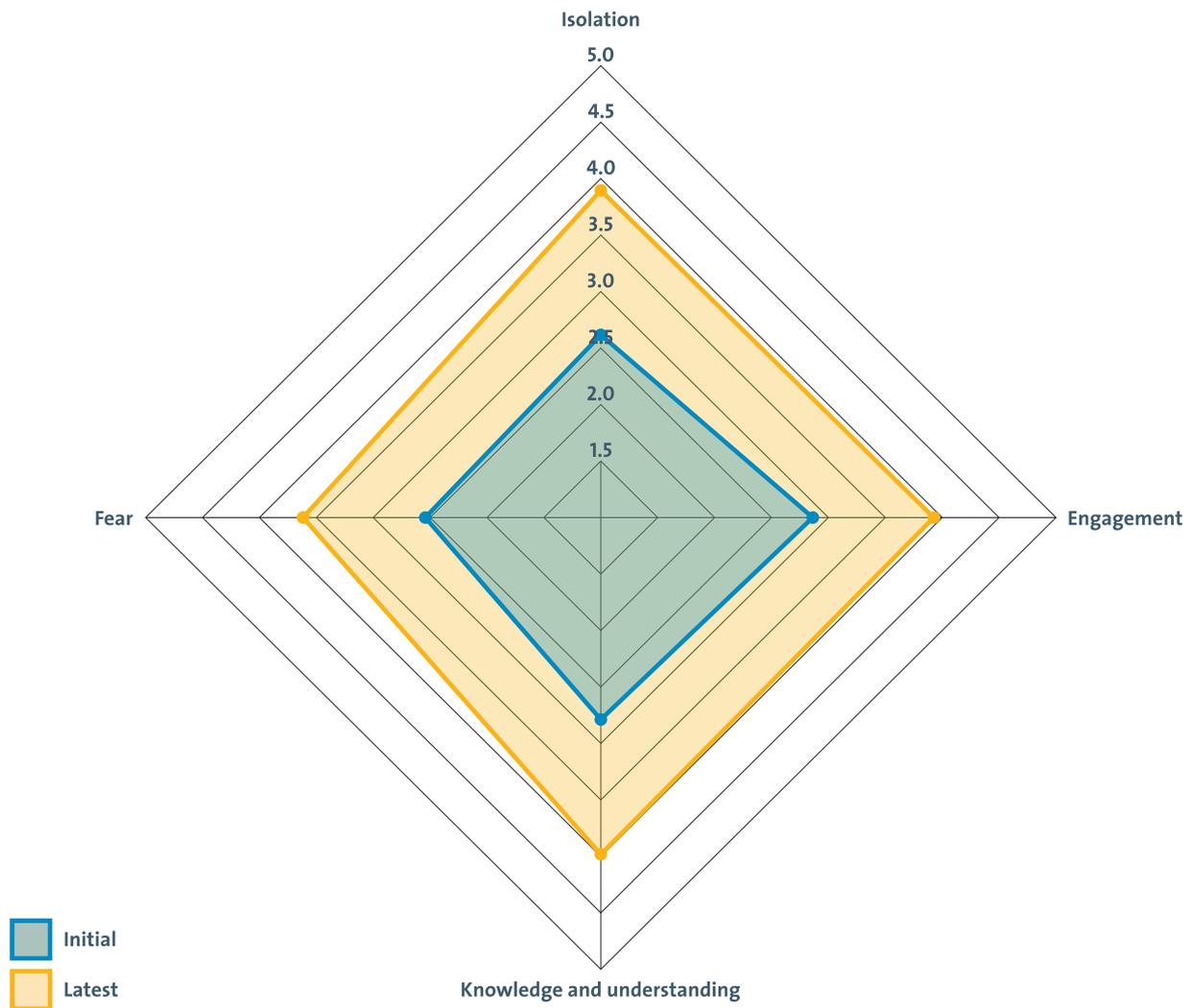


beneficiaries who report a POSITIVE OUTCOME after receiving support from *brainstrust*

Progress against our six indicators

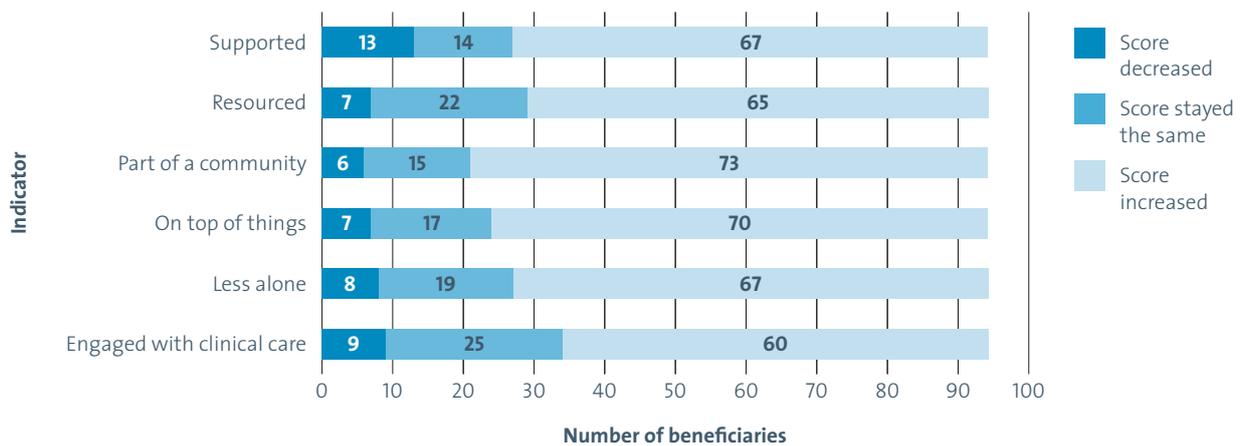


Progress against our strategic priorities



How people change with *brainstrust*

Beneficiary change between first and last progress tracker records, by indicator



About this data

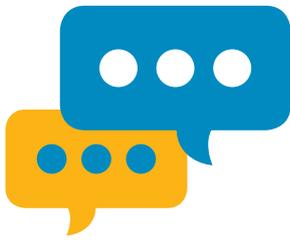
In 2019/20, our team handled just under 5,000 patient or caregiver contacts. 911 people (470 brain tumour patients and 433 caregivers) engaged *brainstrust* directly for help by phone or email, or they attended a supportive event. Currently, 94 people have completed two or more progress trackers (an increase of 42 since last year), from which this data is drawn.

Over 200 people have completed the first tracker, giving us scope to quantify and report on attitudes at first engagement of *brainstrust* beyond anecdote and testimony. This benchmarking has validated our vision and activities, providing robust and quantifiable evidence that people need support in overcoming fear and isolation, and need strategies to build engagement and understanding after a brain tumour diagnosis.

What we know.

- Our work continues to drive positive, holistic change in people's well-being across six indicators, which closely reflect the challenges our community faces.
- On average, people progress just over one point, or 23% (1.16/5), across the six indicators having received support from brainstrust, showing sustained impact since last year. Initial and final scores indicate that people move from a place of difficulty to a place where things are more how they like it.
- Progress tracker scores in all six areas increase much more frequently than they decrease or stay the same. FUTURE FOCUS: while this is what we would expect to see, more work can be done to ensure even fewer people go backwards in their scores and more people transition from scoring the same to moving forward.
- We are having the most impact in tackling isolation and building communities for people with a brain tumour. Beneficiaries are reporting a 27% improvement (1.35/5) in feeling part of a community, and are 24% less alone (1.22/5).
- Concurrently, feeling part of a community and on top of things are the areas where most people report increases in their score over time (73 and 70 of 94 respectively).
- FUTURE FOCUS: where people report the least progress (18% or 0.93/5) is in feeling engaged with their clinical care. Out of all six indicators, this is also the one where the largest number of people (25 of 94) report no change in their score over time.
- FUTURE FOCUS: the area where the most people (13 of 94) report a decrease in their score is in feeling supported. We know from feedback that this is because people are reporting on their feelings about their clinical care, which in turn affects engagement with our support.

How we made an impact.



OUR TEAM handled **4,948 patient contacts**, including **2,807 caregivers** and **2,164 people who have a brain tumour.**

This is much greater than previous years and indicates that people are engaging more with our services.

IN 2019 we supported **911 new people with events and/or coaching services.**

Slightly fewer people than last year, where we reached 1,042 new people.



WE POSTED 633 brain boxes, 57 of which were to children.

This is fewer brain boxes than last year (846), but we have worked hard this year to distribute brain boxes more carefully to ensure relevance and improve impact, so we are heartened by this change.



A TOTAL of **111,605 people** came to our website for help, and they looked at **220,668 pages.**

Of these, 109,993 people were new to our website. These people were most interested in supporting people at end-of-life stage, the stories of other people living with a brain tumour and brain tumour diagnosis. Of the respondents, 92% said that the information on our website helped them to feel more resourced, more confident or more in control.

Our impact, one on one.

It's difficult to capture progress in a clear and structured way when living with a brain tumour is neither of these things.

Visualising aggregated data validates that our support drives positive change, but it can hide the true impact we have for people at a personal level. It is vital to look at people's stories, which bring to life the everyday challenges and successes our community faces as part of diagnosis.

Sarah's progress with *brainstrust*

In March 2018, Sarah was diagnosed with a meningioma. She reached out to *brainstrust* after searching for help and answers online, and she has since received regular support from Jodie, our Midlands support specialist. Sarah has also been fundraising many thousands of pounds for *brainstrust*'s work with the support of her husband, Paul, and their FootGolf league.



Resources such as the brain box and My Fatigue Book, together with coaching from Jodie, have helped Sarah move from a place where she felt lost and confused to a place where she feels confident and part of a community.

“ Thanks to *brainstrust*, I now feel like I am part of a community and feel comfortable and confident whenever I have needed to ask for help. I stopped feeling lonely and scared, as I now know there is always someone who will help. When you hear the words 'you have a brain tumour', your life changes in a split second. Having *brainstrust* there has helped me to deal with it, and I will be forever grateful. ”

Sarah has now completed three progress trackers since 2018, so we can visualise her journey and reflect on it with her to identify areas we can work on together.

- When Sarah first connected with *brainstrust*, her average score was 2.3, meaning she started in a place where 'things are difficult but I'm working on it'.
- From July 2018 to April 2020, Sarah reported a 43% improvement (2/5 points) across all areas of well-being.
- The greatest improvement has been in how supported, resourced and part of a community Sarah feels. She scored 5 points for these areas, equating to 'I'm as good as I can be in the circumstances'.



“ I have had email and phone support from Jodie, who is one of the support specialists. Whatever questions I have, or if I am struggling with things, I contact Jodie, who always helps me. We have recently started regular coaching sessions over the phone, as after my operation I was struggling with my confidence. Jodie has talked to me, listened to my worries and helped me to come up with ideas for how to rebuild my confidence. ”

Sarah Boulton

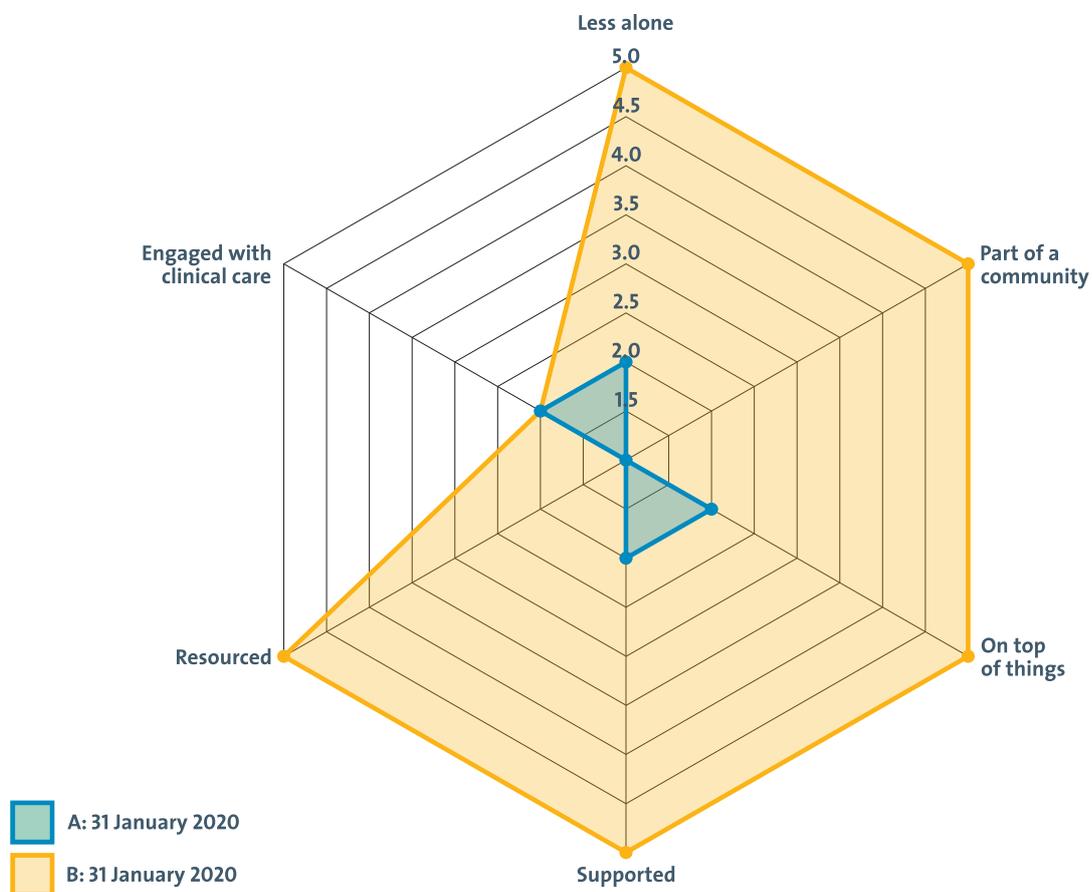
A picture of personal progress

Patient, Midlands

Engaged with: a *brainstrust* workshop

“ I feel more equipped to deal with fatigue, and I have tools I can now use. ”

- *brainstrust* workshops offer the opportunity to dive deep into specific challenges faced by the brain tumour community, while meeting others going through a similar experience. This beneficiary improved 4 points in feeling part of a community and resourced, and 3 points in feeling on top of things, less alone and supported, after just one workshop.
- **Next steps:** our support specialist can offer additional information and advice to help this person feel more engaged with their clinical care.

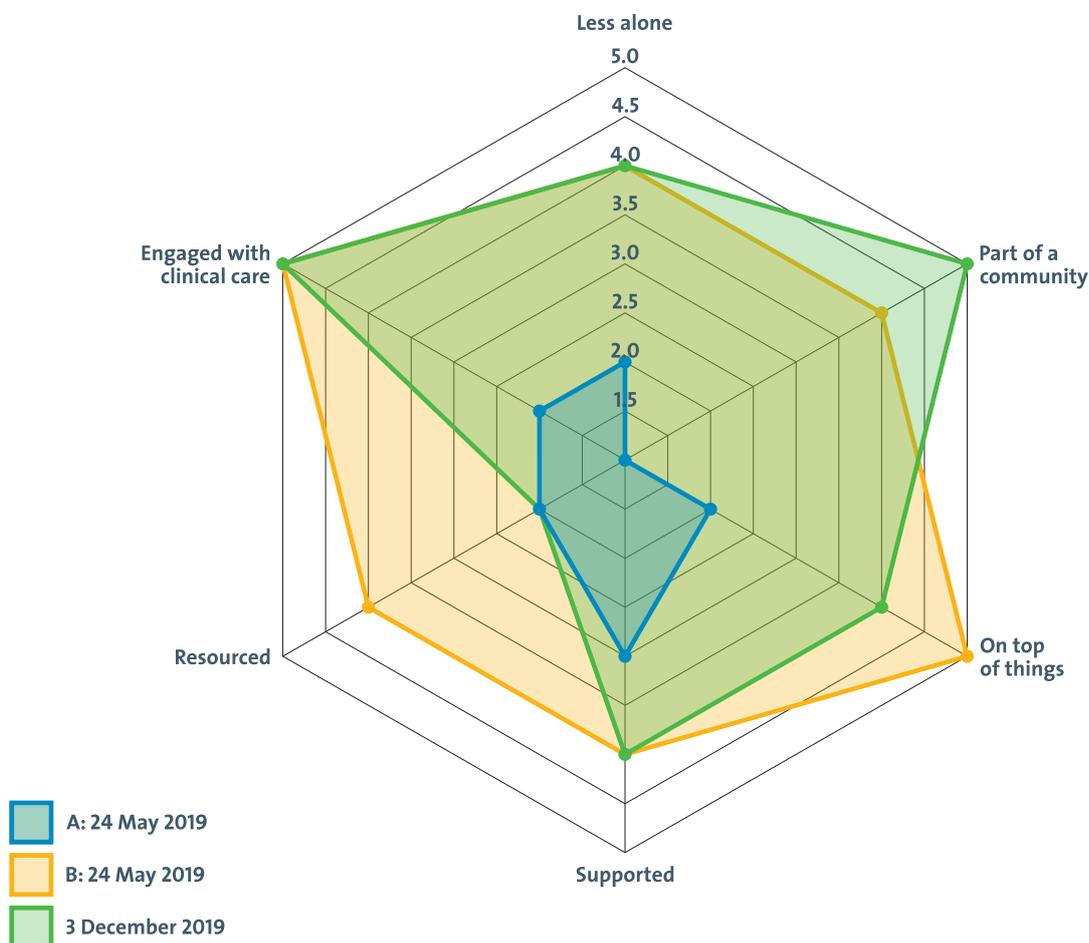


Patient, London

Engaged with: *brainstrust* resources, Meetups and workshops

“ *brainstrust has given me a more positive outlook on life ... and a forum to meet others affected by brain tumours, where we are able to talk openly, guide and support each other. brainstrust has helped me better understand “me” and move forward with life. The past year has been hard both physically and mentally, but friends I have met through the Meetup group have been an amazing support throughout.* ”

- Utilising a range of our support services has helped this beneficiary to progress in all six areas of well-being since first engaging with us. This beneficiary has made significant progress since their first engagement with *brainstrust*, especially in feeling part of a community, which they progressed 5 points in, between May 2019 and December 2019. Their latest record shows some fluctuations in scores in a few areas, for example, in feeling resourced.
- **Next steps:** lower scores are picked up by our support team and will drive and tailor future coaching conversations.

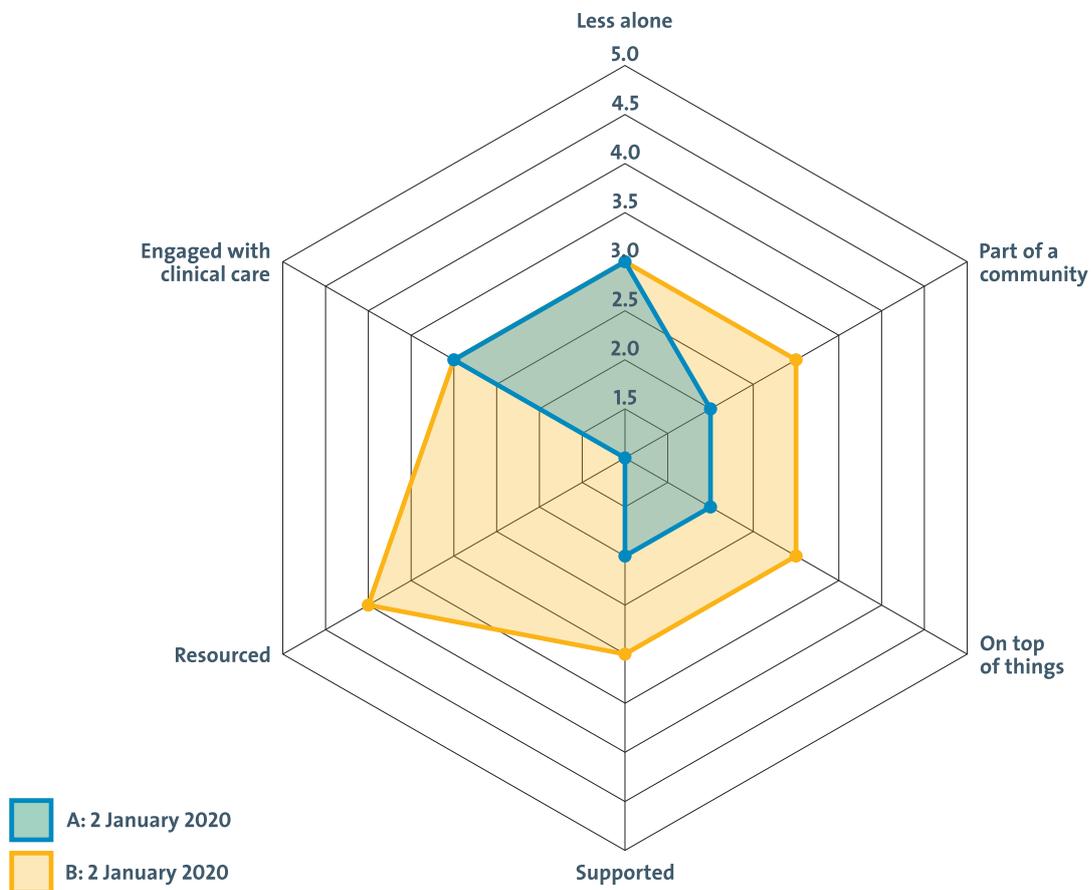


Caregiver, London

Engaged with: coaching

“ My partner was diagnosed with an aggressive brain tumour three weeks ago. We have been trying to digest this awful news, manage his treatment and work out how to live the best way we can despite the diagnosis. The discussion with Helen (brainstrust support specialist) helped us to take stock of where we are in our journey and to recognise areas where we can make positive changes. We did not know what to expect when we made the phone call, but we both found it very helpful – thank you, Helen. ”

- There was improvement in four of the six areas following an initial coaching session after first engaging with *brainstrust*.
- **Next steps:** our *brainstrust* support specialist will work closely with the beneficiary to establish how they can be supported further.



Communities, confidence and capabilities: beneficiary events in 2019/20

“ brainstrust taking the family out was such a lovely treat for all. The children had a fun time playing together, and it was nice to talk to others going through similar experiences. The kindness, support and information the charity has and can provide is what families going through the trauma of brain tumours need. My mum, who has been with us every step of the journey, has now got somewhere she can turn to for help. Thank you. ”

DURING THE YEAR, 478 PEOPLE ATTENDED 41 EVENTS, including 26 Meetups, 13 workshops and two full-day events.



- This year, events for beneficiaries continued to play a vital role in helping us create meaningful impact for people across our key indicators.
- In response to community demand, and in close consultation with patient volunteers Pablo Lievano and Greg Gerard, May 2019 saw us expand our programme beyond social Meetups to include a deep and broad programme of relevant workshops, Meetups and information events.
- Events were run across the four nations, and subjects included coaching and communication, managing fatigue, cannabinoids and cancer, movement, health and well-being, behaviour and personality change as well as traditional social Meetups. Expert guest speakers joined us from the clinical, scientific and holistic therapy communities, and support from Children with Cancer UK has also enabled us to run events dedicated to the unique needs of children and families who are coming to terms with a brain tumour diagnosis.



We're listening.

We have robust policies in place for managing complaints and actively encourage feedback.

In the last 14 years, we have had no complaints about the service that we provide or our fundraising practices. Of course, we are proud of this record and will continue to encourage people to let us know how we might improve the way that we work.

Getting in touch.

Helping you

Talk to our team 24/7 on 01983 292 405, or email hello@brainstrust.org.uk.

Helping us

Make a donation at www.brainstrust.org.uk/donate, or call us on 01983 292 405 during office hours.

Registration

brainstrust is a registered charitable trust. Registered with the Charity Commission for England and Wales as Charity No. 1114634. Registered with the Office of the Scottish Charity Regulator as Charity No. SC044642.

Registered address and south of England office

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www.brainstrust.org.uk

www.braintumourhub.org.uk

Regional office (north of England)

brainstrust, C19–21 Joseph's Well, Hannover Lane, Westgate, Leeds LS3 1AB



***“ I can’t tell you how much better
it has made me feel just reinforcing that
I’m not alone and there’s a whole
community out there. ”***

This work has been supported by the
National Lottery Community Fund

