



brainstrust's
impact 2021-22

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

Why impact matters

At *brainstrust*, we are dedicated to supporting anyone dealing with a brain tumour diagnosis, whether that means providing coaching via our 24/7 support helpline, hosting webinars and Meetups to resource our community and cater to specific experience, or keeping everyone up to date on news, fundraising and research to inspire and connect us all through a shared mission – for anyone diagnosed to be able to have their best possible day.

While all of these areas are immensely important, it's also crucial that we're accountable for what our impact actually looks like and that we remain vigilant while improving our

support. We also understand that the challenges people face after a brain tumour diagnosis can seem overwhelming and insurmountable, whether that relates to a feeling of isolation,

learning to navigate clinical care or just needing to feel supported by a specialist or the brain cancer community. The insight that is provided to both the *brainstrust* team and our community via the data we collect allows us to ensure we are doing the best possible job to help at such a vulnerable time. This is what makes the data we collect so significant. It informs us of where we're succeeding, where we could be doing better and where things maybe aren't working – all so that we can ensure our work is people-first and provides our community with the tools they need to feel supported, resourced and on top of things.

Here we share what we are achieving and where we might be falling short. We reflect on the achievements and changes of the past year and outline how this impacts our direction going forward.



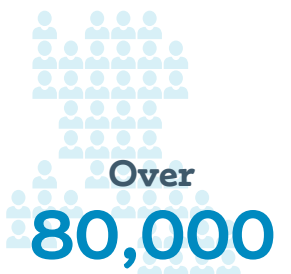
'I can't thank you enough for the support you have given us.'

Healthcare professional


Our challenge

Our brains are incredible – they make us who we are. Your brain sparks the love, the joy and everything else that you feel. It's the most complex organ in the human body – it is the supercomputer that creates everything that defines humanity. The brain is also incredibly delicate, soft and intricately balanced. This makes it susceptible to harm.

When you hear the words 'you have a brain tumour', you face both a potential cancer diagnosis and also the prospect of progressive and debilitating neurological disease. You are afraid, you are alone, you are confused, and your life changes dramatically in an instant.



Over **80,000** people are **living with a brain tumour** in the UK.



Only **12%** of adults survive beyond five years following a diagnosis.



Brain tumours **reduce life expectancy** by an average of **27 years**.

Brain tumours **kill more children** than any other cancer.



Treatment for a brain tumour is brutal and harmful. It hasn't changed in 40 years.

'I have had to learn to live with the uncertainty and accept my life is different now.'

Lin is living with an astrocytoma and has to make complex decisions about her treatment, which is fraught with risk.

'I'm still suffering with tiredness and fatigue, and other people who have been through the same have said this can last months and maybe even years, so I guess this could just be a new way of life that I have to get used to.'

Kay has recently had surgery to remove a large meningioma. She is working hard on recovery and coming to terms with her new normal.

'It was shocking to be told there is no cure. At just 68 years of age, it took away the retirement my dad and his beloved partner, Kath, should have been enjoying. He could no longer drive. His car was his pride and joy.'

Ian Wootton cared for his father, who died after living with a glioblastoma diagnosis for four years.

Our strategy: first, we are people

In April 2019, we launched our current strategy. Thirteen 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 engaged with their clinical care and condition, and better resourced.

The human context sees a forgotten group of people who, following diagnosis, see themselves fall into the chasm between improving clinical care and the scientific pursuit of a cure. In acknowledging that before we are patients, we are people, we can help people navigate this void, for 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.

In practical terms, we know from our intimately close work with our community of people

with a brain tumour, and their caregivers, that a brain tumour is isolating, the journey is confusing, 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. They are addressed at home, where help is hard to find.



How we got here

Our direction has been set in consultation with our community. We ‘asked the experts’ what they needed, in order 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 just 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. This strategy is helping 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 lives they want, because they are people first and patients second.

‘You truly are a ray of light and the support we need at this time, as my father and I feel very much alone in caring for my mother.’

Caregiver

Our goal

A world where people with a brain tumour are involved, resourced, supported, confident and connected. They are living the lives they want, because they are people first and patients second.

To make this happen, we aim to:

help people overcome fear

help 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 in research

which is only possible with:

effective fundraising

efficient marketing and promotion

administrative support

good governance

Our impact

It has been a challenging yet rewarding year for us. We have struggled with capacity after a significant upturn in activity, which has doubled since Covid-19 restrictions ended. Our team has risen to the challenge, but we are not sure how sustainable this is. Alongside making sure we are as efficient as we can be, we have worked hard to build resilience during the period so that we can scale capacity as we move ahead on our mission.

We are looking forward to expanding our support to build our impact, reach more people and work more sustainably. We have the strategy and structures in place to deliver and scale our work. It's an exciting period ahead for brainstrust and the team.

Helen Bulbeck,
Co-Founder and Director of Services,
brainstrust

‘The help and support has been fantastic so far and came just at the right time. I am starting to find my feet again and am thankful to have such a great connection of support through brainstrust.’

Patient

How we have helped

Direct support for people with a brain tumour

2,339

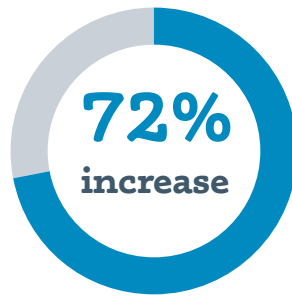
people contacted our team of support specialists for help by phone, webchat, video call or email.



This is over **1,000 more** (an **85% increase**) from the previous year.

825

people were new to *brainstrust*, a **72% increase** from **479 people** the previous year.



404

brain boxes were sent to people who needed them, double the number of the previous year.

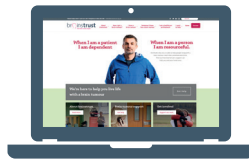


Online support and information

110,928

people accessed our online information for the first time during the year. This is an increase of **4%** from **107,112** the previous year.

There were **5,160** downloads of long-form health information from our website.



1,663

people (**91% of respondents**) have told us that the brain tumour information on our website helped them feel more resourced, more confident or more in control.

Events

We hosted **134 events**

(webinars, Meetups and workshops), a

31% increase

compared to the **102** held the previous year.

Overall attendance was also significantly up, at

1,032

compared to the previous year's **784**.



Understanding the signs and symptoms

Raising awareness of brain tumours, their signs and symptoms to help people feel less afraid and make confident decisions.

As awareness of brain tumours builds, we know that concern in the public about being diagnosed with a brain tumour also grows. This is reflected in growing interest online in brain tumour symptoms.

While more than 11,000 people every year are diagnosed with a primary brain tumour, of which there are more than 150 types, this level of incidence isn't a big number in the context of all cancers. Therefore, the chances of having a brain tumour are relatively low.

But while brain tumours are not that common, it is important to recognise the signs.

The signs of a brain tumour can include severe and persistent headaches, nausea and dizziness, changes in vision, fatigue, seizures and loss of taste and smell.

These signs are acknowledged as being non-specific in terms of arriving at a diagnosis, and knowing if a referral for investigation is needed is not a straightforward decision, unless patients present with very acute symptoms. This is why so many brain tumours

are diagnosed via Accident and Emergency departments (emergency presentation) and can take time to pick up via presentation to a GP.

We have developed dedicated online content to help people understand brain tumour signs and symptoms so that they can assess, with confidence, whether they feel further or urgent investigation is warranted.

As a result of targeted promotion to relevant audiences who might be experiencing symptoms, our 'signs and symptoms' content has been read by over 36,000 people during the year in review.

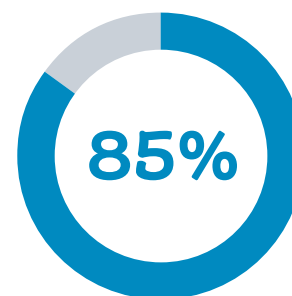
Of the people who responded, 85% (171 of 202 people) said that they found this information helped them to be more informed and more confident.



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Supporting people to live their best possible lives

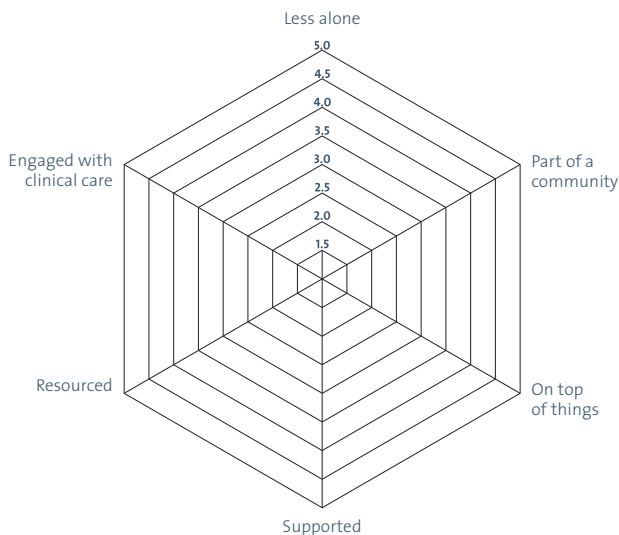
Understanding the impact we are having is vital to all of us at *brainstrust*. We have worked hard to instil this principle in our principles and processes. A genuine interest to understand and report on people's progress sits at the very centre of our work. We track progress against six indicators. 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:

- 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 through the use of 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. In completing a progress tracker, or multiple progress trackers, people help us 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.

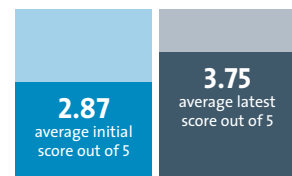


Understanding your needs

On average across all six indicators, we have helped people improve their well-being by



The average initial score was 2.87/5, and the average latest score was 3.75/5.



This is despite facing a progressive, life-limiting, life-changing or terminal diagnosis.

People see the biggest improvements in feeling supported and feeling part of a community with an increase of 0.94/5 and 1.03/5 respectively compared to their initial scores.

Figure 1: *brainstrust* beneficiary-reported outcomes before and after engaging with our services (30 responses from beneficiaries with more than one progress tracker)

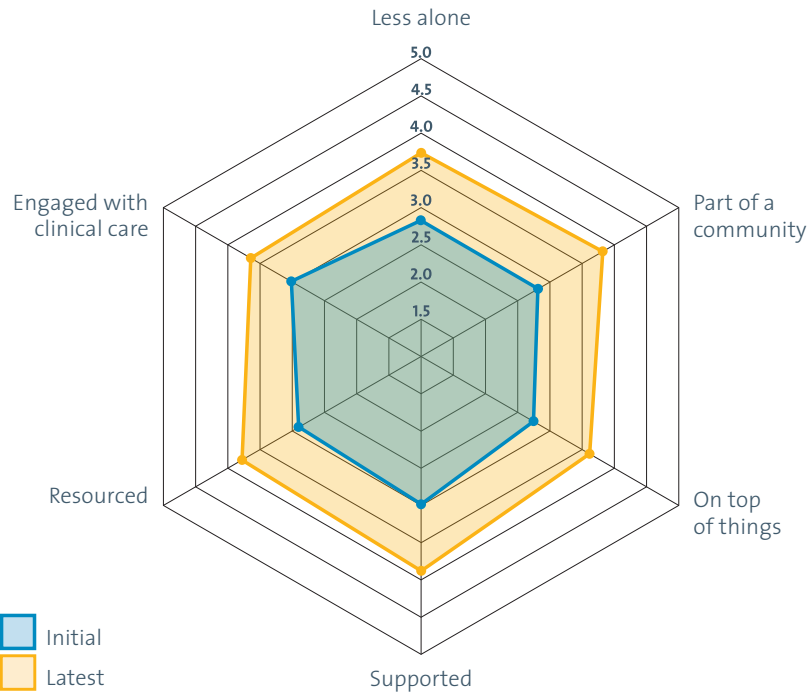
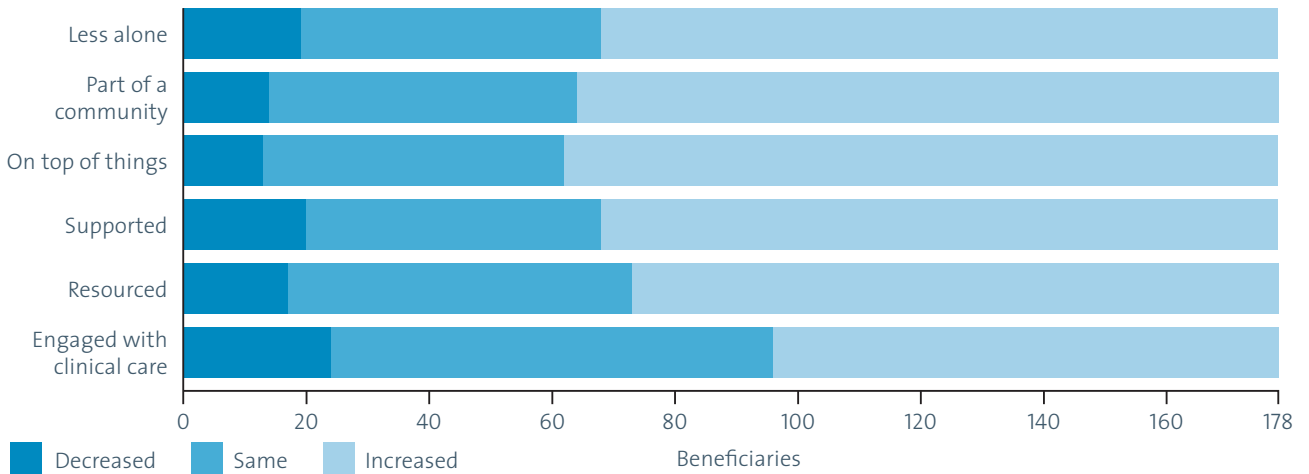


Figure 2: *brainstrust* beneficiary outcomes – overview of cohort's progress by indicator (178 responses from beneficiaries)



The people behind the numbers

Meet Luke

Luke was diagnosed with a low-grade brain tumour. When we first started talking in March, he struggled with anxiety, panic and avoidance. We had regular coaching calls. During our dialogue, I sent him links to our Know Hows on driving, mindfulness, scanxiety and how to live with uncertainty, as well as our information about acceptance.

We talked about how hypnotherapy may help him to learn techniques to recentre when he is most overwhelmed or anxious. At first he was slightly dubious but thought he would give it a try. He now attends most of the weekly resets and says that it's been so helpful for him. He has now attended the Brighton Meetup and the 'tea and a wee blether', virtual brew and low-grade Meetups.

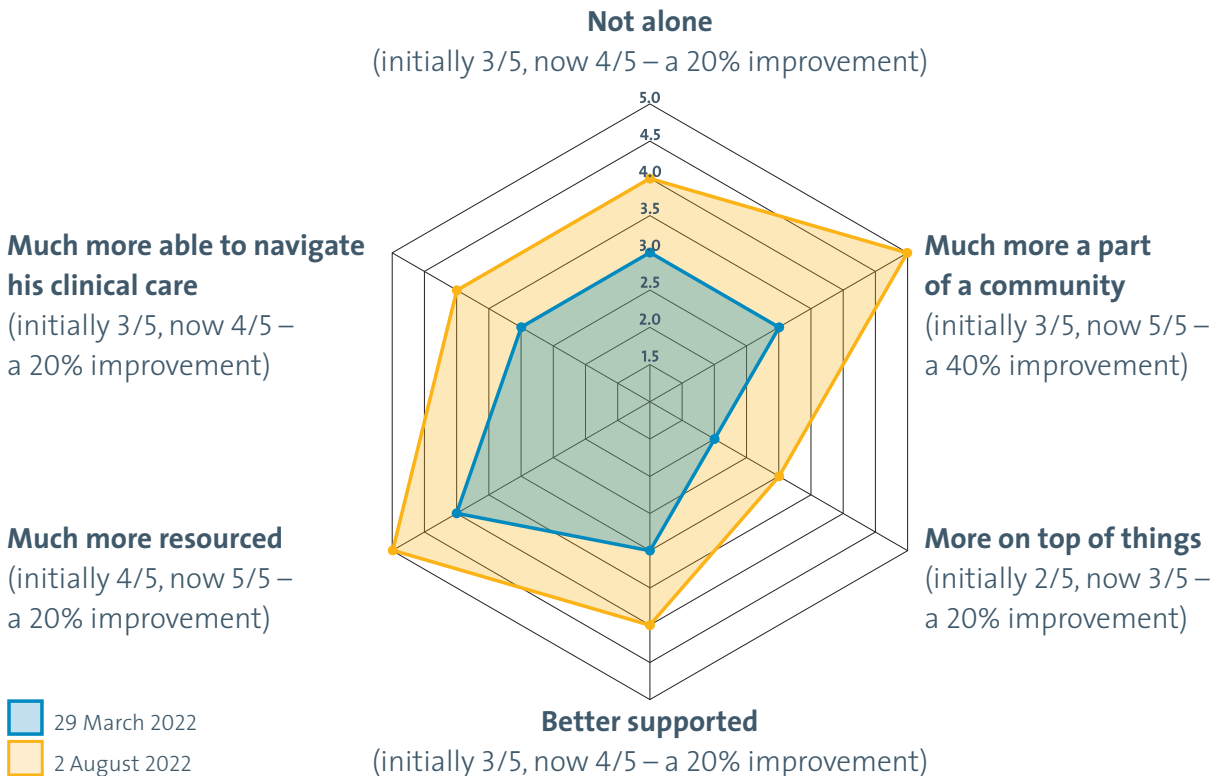
Luke has completely transformed in the time I have known him. He is now a lot more confident and assured in himself. We no longer need our monthly phone check-ins, but I do email to see how he's doing every two months, as he has now moved from shared care to supported self-care in our triage system.

During this exercise, Luke said:

'Thank you very much for this. I appreciate you taking time to help and update me. Looks like I'm doing much better. I feel like I am, with thanks to you and brainstrust.'

Molly Hughes,
brainstrust Support Specialist, London and the South-East

We reflected together recently on his progress tracker changes. Luke tells us that he is feeling:



What we have learned

For the year in review, we have noticed that people are contacting us with a higher initial score than average across all indicators. The average initial score for this period is 3.3/5. This is higher than our historical average of 2.87/5. This may mean that people are getting to us later on their journey, when they are more confident and have a better understanding of their complex pathway. While we are still having a positive impact and improving well-being across all six indicators, we have work to do to ensure those who would benefit from our support are able to access it when they need it most. This reinforces the need for strong clinical engagement and making sure *brainstrust* is accessible, available and a known option for all patients at every point of their pathway.

This higher starting point can also be attributed to Covid-19 having a lesser effect on people's lives this year when compared to the previous year – people are more in control of their circumstances, and clinical pathways are less disrupted.

We see a smaller increase in score when people are in a better place when they reach out to us, but despite this, we still have a significant positive impact on well-being for people who are in a desperate situation. We know that our greatest impact is in helping people to feel part of a community.

This consistency in score increase year on year affirms our planning. We know that we can be even more effective. As we build capacity in the year ahead, we will be able to provide additional and more focused support in regions

where we are not currently as proactive as we would like. This investment will enable us to offer dedicated, accessible regional support in new areas for those who need it most, when they need it most.

'During the year, we saw a growth in demand for quick, accessible information. We adapted our information programme of work to meet this demand and expanded our library of Know Hows significantly. These met the changing needs that people told us they had. Topics included finance and welfare benefits, how to bring structure to your day, how to find a new normal, knowing what to ask at diagnosis and how to find trusted information.'



Jodie Eveleigh,
Support Specialist,
Midlands, and
brainstrust
Information Lead

'We made sure that our events programme remained relevant as we navigated our way through and beyond pandemic restrictions. These often varied between regions and nations, and people told us their appetite for risk was different, depending on their circumstances. We adopted a flexible, hybrid approach, with events running online and offline. This enabled us to support more people, with a more diverse range of topics, while maintaining or improving impact.'



Carol Cochrane,
Support Specialist,
Scotland, and
Events Lead

'We have been travelling less. This has made it harder to connect with some groups, including clinicians. However, we have been able to use the time available to develop deeper, more impactful coaching relationships with people who are in crisis or who need more in-depth and ongoing support. We have spent a lot more time on the phone and honing our skills using new modes of communication.'



Helen Bulbeck,
brainstrust
Co-Founder
and Director
of Services

Your support

In 2021, our supporters raised **£952,203** to fund *brainstrust's* mission. This income continues to come from a diversified mix of traditional charity fundraising activity.

Our funding comes from:

- trusts and foundations
- direct and regular giving
- companies who support our work
- sponsored events and challenges
- community fundraising
- Gift Aid recovery
- in-memory giving
- trading
- government support relating to the Covid-19 pandemic
- special-purpose fundraising to enable communities to access novel treatments and therapies.

We have limited income from legacy fundraising and high-net-worth individuals, and we have minimal investment income, instead keeping cash available to provide liquidity and flexibility so that we can

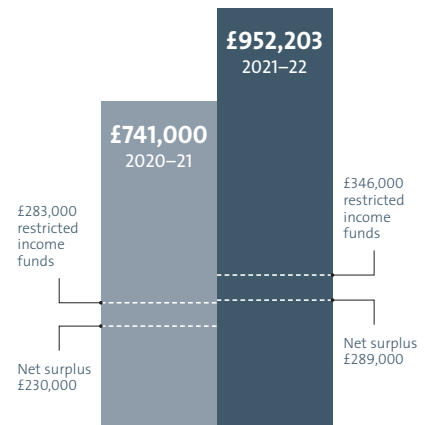
react promptly to the needs of our community.

We were grateful to secure significant support from statutory and philanthropic partners, which helped us to survive an unprecedented year during the pandemic. We are now working to strengthen those relationships as part of a more diverse fundraising portfolio that reduces risk.

With all public fundraising cancelled at the outset of the Covid-19 pandemic, we have since worked hard to reignite supporter fundraising. We have been delighted to see activity and income from community fundraising channels build on last year. This focus is bringing our work closer, once more, to the community we are here to serve.

Of the gross income generated in 2021–22, totalling **£952,203** (2020–21: **£741,000**), **£346,000** related to restricted income

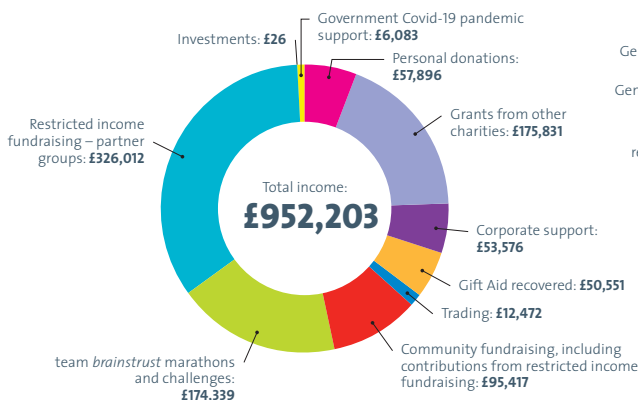
funds. The net surplus for the year was **£289,000** (2020–21: **£230,000**), of which **£283,000** related to restricted income funds.



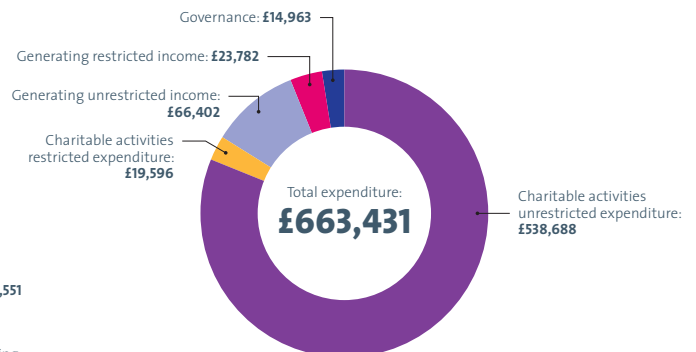
‘Our supporters continue to inspire us with their ideas for fundraising activities, and it’s rewarding to be able to take a tailored and individualised approach to the way we help to realise their ambitions and passions.’

Julia Smith,
Fundraising Manager,
brainstrust

Our income 2021–22



Our expenditure 2021–22



'I feel so well listened to and my feelings acknowledged. This process is helping me work through a lot, and I'm very grateful.'

Patient

