

Trustees' annual report and accounts *brainstrust* – the brain cancer people

1 April 2019 – 31 March 2020

‘brainstrust is a lovely place to be’

Patient, October 2019

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

“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

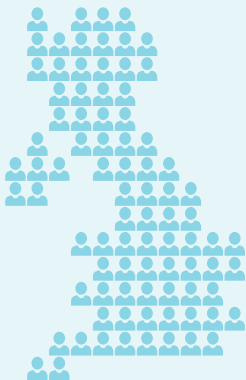
“Facing your own mortality is a big thing when you’ve got a young family.”

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

MORE THAN
60,000
people in the UK
are living with a brain
tumour diagnosis



of ALL cancers
spread
to the brain

It is the MOST
COMMON form
of cancer in
people under
40



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 also 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

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Introduction

In this report, we share another year of work at *brainstrust* and all that we have been able to achieve with the community of people who are living life under the shadow of a brain tumour diagnosis.

We have much to be proud of for the year in review, with continued growth in reach, increased impact, and sustained levels of income, despite our year ending under the shadow of the coronavirus pandemic, which effectively cancelled all public fundraising overnight.

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 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 a 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 and lonely, 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 addressed in neither the laboratory nor the hospital.

As for the cultural landscape, our community is galvanised behind our new strategy because it tells us that as people we are resourceful, whereas patients are passive recipients of care. When we have confidence to act as people, we find that emotions and values drive behaviour, in conjunction with clinical advice, and we have a more hopeful and positive outlook. People look to opportunity, patients at the challenges. This aligns our work seamlessly with the NHS Cancer Plan as it sets out to implement patient-centred care.

Our new strategy sees us more beneficiary-focused than ever before. Twelve months in, we are confident that the refinement and evolution that this work represents is providing evidentially robust improvement in impact and reach. The clarity that this strategy brings to our mission and purpose has also facilitated easier and clearer communication with all stakeholders,





Will Jones



Chris Baker

and provides a distinct difference between our work and that of other charities and organisations who are working on complementary activities in the clinical and research spaces.

We are not without our challenges, and we are not afraid to talk about these. Demand and scale of opportunity to help more people continue to outstrip our ability to deliver the service we strive for – our team is stretched to capacity across the UK. But our models of working are infinitely scalable (very purposely so), and we can do more as revenue grows.

We know that we have a great impact for many but also that our help is not accessed by all. This includes people from different ethnic backgrounds. We are working hard to address this, and the current conversation about inclusion brings purpose and impetus to this work.

We cannot ignore the coronavirus pandemic that struck with full force at the close of the year. This has caused heightened anxiety and uncertainty for people with a brain tumour. It initially destabilised our ways of working, and it stopped public fundraising. However, from this we are learning that our community is resilient and our team robust and committed to our mission. Our community is well versed in tackling

uncertainty and isolation, and our tools to help are more useful now than ever before. Our team has pivoted at lightning pace, taking all services online and with sustained reach and impact. Our funders, supporters and collaborators tell us that they are confident in our ability to deliver, and they are providing additional support and flexibility, for which we are truly grateful. Early calculations suggest that an initial estimate of a 40% drop in revenue has been reduced to 20% thanks to quick and decisive action and this support, but there remains some uncertainty about the lasting impact of coronavirus on the economy and public fundraising in the future. We are, however, an agile organisation and can appropriately adjust our scale to meet this challenge and collaborate where possible to remain efficient and effective for our community.

What is certain is that in the face of these ongoing and existential challenges, brain tumours will not stop. We will continue to see increased demand and need for *brainstrust*'s impact, and our help is more relevant and vital than ever. To deliver this work and to achieve our mission, we will need your support more than ever before.

Will Jones
Chief Executive

Chris Baker
Chair of Trustees

Why we are here and what we do: *brainstrust's* objectives and activities

This report marks the segue between our previous five-year strategy and our new one. The last five years have seen rapid maturing of our organisation, as well as building professionalism, resilience, confidence and focus. This in turn has shone a spotlight on the need for better support for people with a brain tumour, with other organisations now supporting our work or delivering supportive services and advocacy for the brain tumour community. Our growing list of collaborations towards the end of this report is testament to this, and we are proud to have played a key role in facilitating the growth of this ecosystem.

First, we are people.

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engaged with their clinical care and condition, and better resourced.

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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, 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

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.

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

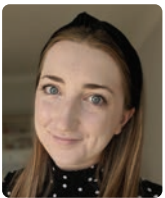
good governance

We are working relentlessly and single-mindedly towards achieving our vision. The framework for strategic planning at brainstrust consists of a 12-month plan, three-year goals and a five-year vision. This is an effective model that affords flexibility and the ability to be reactive to risks or opportunities as they arise, while ensuring we are working to achieve our longer-term goals to transform life for people with a brain tumour.

Our values

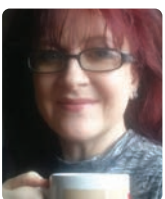
brainstrust is underpinned by a set of values that are core to not only our service but everything we do.

“*brainstrust is much more than a charity. It’s a passionate, understanding and empowering community that I feel lucky to be a part of. As a community fundraiser, there isn’t a day that goes by where I’m not inspired by the work we do, the people we support and the kindness and generosity that keeps us going.*”



Sophie Bryan
Community Fundraiser
brainstrust

“*Working for brainstrust is hugely satisfying. We’re there to support people at any stage on their brain tumour journey, and every day, I see and hear how much this support means. At brainstrust we all work together as a team with a common goal: no one facing a brain tumour diagnosis feels alone.*”



Carol Cochrane
brainstrust Support Specialist
Scotland

We are ...

- tenacious
- honest
- positive
- relevant
- challenging
- personal
- attentive
- strong
- enduring
- curious
- just
- enabling
- community-led



So our community feels ...

- engaged
- acknowledged
- at ease
- expert in themselves
- in control
- able to question
- resourced
- confident
- not alone

“*I really enjoy working for brainstrust so much. The enthusiasm and dedication of the team is awesome and makes each day a pleasure. When I see the fantastic fundraising that goes on, it is truly inspirational, especially hearing the stories behind these donations and knowing how much hard work, and sometimes blood, sweat and tears, it has involved. The selflessness of fundraisers is a true testimony to the support they and their loved ones have received from brainstrust. I honestly can’t think of a better place to work.*”

Kathy Springate
Head of Finance
brainstrust

Activities: how we help

To achieve our vision, we must help people with a brain tumour and their caregivers to overcome fear, engage with care, eliminate isolation and improve knowledge and understanding of their condition and their care. brainstrust delivers activities for people affected by a brain tumour as follows.

1 Coaching and support via round-the-clock phone and email support

“Evidence shows that when we are no longer able to change a situation, we are challenged to change ourselves. You are the person who is ultimately going to have the greatest impact on your life. The coaching relationship we establish with people enables them to face their challenges so that they learn how to develop resilience and utilise resources to their full potential.”



Helen Bulbeck
Director of Services
and Policy
brainstrust

We are proud of the impactful relationships that we build with the people who need us. These relationships are built on collaboration; it is not essential that the coach has more experience of the coachee's situation than the coachee, and they will use questions to facilitate the coachee's thinking.



“At brainstrust we listen deeply and actively, and then ask questions. We focus on achieving specific, immediate goals that relate to specific areas, for example, weighing up the pros and cons of having a particular treatment, or overcoming a problem with caregiving. We also know that through coaching, the people who need us can also experience a sense of healing, as they make courageous decisions about their lives and work. Coaching focuses on the future and the development of a workable solution. It's about developing strategies and clarity to achieve a better quality of life. Our approach further enables patients and caregivers to engage in their care and gain a deeper understanding of what they're facing in terms of treatment and prognosis.”



Jane Gardiner
Support Specialist
London and the South-East
brainstrust

Qualitative studies show that patients and caregivers want to be fully involved in:

- understanding their illness
- exploring their options for treatment and for living with the illness
- sourcing information, knowledge, help and advice.^{1,2,3}

After a coaching conversation with a highly trained *brainstrust* support specialist, people feel resourced and in control, and they have positive actions to take forward, as a small selection of testimonials attests:

“Thank you so, so much for your help and advice the other day. I think the best thing is I feel more in control now, as I have a plan of action as such, while before I was floundering, and I don't have any support network to help me with things.”

Patient, Belfast

“You brought up some very valid points for me. I could not see the wood for the trees, and my perspectives had become obscured because of the panic ... I have made a list from the points you made, and I am using this as my plan of action so I can keep focused on the solutions to this instead of the worry all the time ... You made me think about things differently in your reply, and I am very grateful that you took the time and effort to help me with what I am going through at this time.”

Patient, London

Every component of what we do is rooted in coaching principles, including the way our people interact in the office to keep *brainstrust* thriving.

This year has been the first where we have been challenged to meet capacity, with nearly 5,000 interactions and 911 new patients. But as ever, we saw this as an opportunity to review the way that we work. The outcome has been a stratified, or triaged, approach to delivering coaching support. This has meant we have been able to provide more targeted support to those who need it, including signposting to relevant trials. Stratification and the progress tracker have been exceptional tools in providing insights and channelling the direction of travel.

“The stratification process has presented an excellent opportunity to review individual cases and assess the impact of the ongoing support that we provide. It has allowed me to have a greater focus on those cases where I need to be the most proactive in our support offer. This is in contrast to being mostly reactive, as can be the default working system when managing a large and varied caseload. It feels like already I am working more effectively and efficiently, providing more intensive support to those who most need it, while maintaining a presence and support for those who are more self-sufficient on their journeys.”

***brainstrust* Support Specialist**

¹ Shepherd, S., Cavers, D., Wallace, L., Hacking, B., Scott, S. and Bowyer, D. (2012). 'Navigation' to support decision making for patients with a high grade brain tumour. A qualitative evaluation. *Neuro-Oncology*, 14(2).

² Cavers, D., Hacking, B., Erridge, S., Kendall, M., Morris, P. and Murray, S. (2012). Social, psychological and existential well-being in patients with glioma and their caregivers: a qualitative study. *Canadian Medical Association Journal*, 184(7): E373–82.

³ *brainstrust*. (2013). Share aware pinboard. [online]. Available at: <http://www.brainstrust.org.uk/pinboard/> [Accessed 02 Aug 2020].

2 Building communities

Online groups, as well as events and activities in the real-world setting, are vital in helping people with a brain tumour feel less isolated and seek mutual or peer support rooted in real-world, lived experience.

brainstrust runs Meetups and workshops nationwide so people with a brain tumour can connect, learn and feel less alone, less afraid and better supported.



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

During the year, 478 people attended 41 events, with 262 attendances at 26 Meetups, 108 people at 13 workshops and 108 people at two full-day symposium events.

“*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.*”

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 Gerrard, 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, and behavior 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.



Where possible, we run events in partnership with other charities and organisations to promote diversity of perspective, avoid duplication and drive efficiency. The very nature of the events also serves to help attendees feel less isolated, better connected and part of the brain tumour community, further supporting our strategic goals.

In the virtual world, the *brainstrust* supportive Facebook group is a thriving hub where the brain tumour community comes together to seek advice and solace, or just to share emotion in a safe, comfortable, helpful and easy-to-access community. The group has grown significantly in membership, with 2,719 (up 13% from 2,400) people now part of this vital hub for the brain tumour community. This group is moderated carefully by volunteer members of our community with assistance and guidance from our support team.

“The brainstrust support group means I never feel alone. There is always someone listening to whatever I’m going through or feeling.”

To be a volunteer moderator has given me a purpose to my life, and it is a privilege to share in the journeys of the members ... I can never thank brainstrust enough for giving me a life. Without you and the support group members, my time would have been meaningless.”

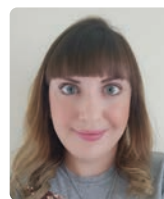
Sarah Andrews

Patient, Volunteer and Moderator of the *brainstrust* Online Support Group

3 Information and education

As well as information and workshop events run across the UK, we also worked hard to respond to community need for trustworthy, easy-to-understand information about current topics.

“Building and disseminating expertise is central to our strategy. When people are informed about their condition and their options, they make more informed decisions about their treatment and care, and they are more confident and comfortable in the choices that they are making.”



Jodie Eveleigh
brainstrust Support Specialist Midlands

We added significantly to our library during the year with resources that covered the following topics:

- coping with behaviour and personality change
- fatigue and brain tumours
- blue badges for hidden disabilities
- driving and brain tumours – working with the DVLA and your rights
- how to find reliable information.

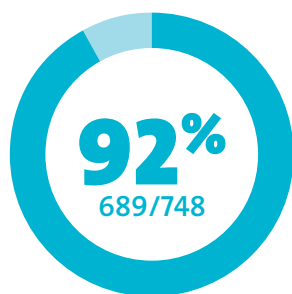


In addition, we were proud to secure accreditation from NICE for our Brain Tumour Patient Guide. NICE's role is to improve outcomes for people using the NHS and other public health and social care services. Applying for a NICE endorsement for our Patient Guide was an opportunity to have one of the most respected and internationally recognised clinical organisations review our work and give us its seal of approval. This also means that the reader can know with absolute certainty that this resource is aligned with evidence-based guidance and will be a real help in understanding the treatment pathway.

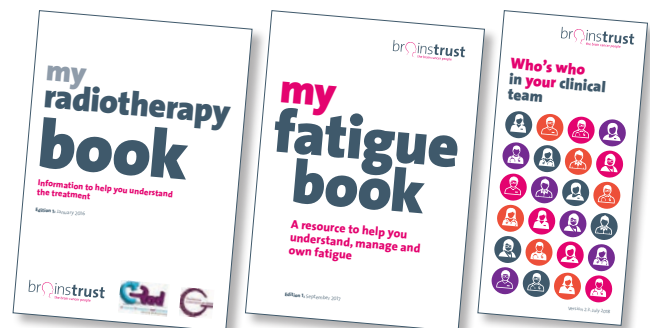


NICE National Institute for Health and Care Excellence

Our pre-existing library of information continues to be popular, with over 10,000 people accessing information on brainstrust.org.uk each month. Of those visitors, 92% (689/748) said that this information helped them feel more resourced, more confident or more in control.



We work closely with the clinical community and provide most of the specialist neurology and neurosurgical centres across the UK with printed information on request. The most popular resources are the brain box, the Who's Who guide to help patients understand the care professionals that they will meet on their journey, My Radiotherapy Book, the Proton Beam Therapy Guide, My Fatigue Book and the aforementioned Patient Guide. We readily circulate information from other organisations if we are confident that it is accurate and trustworthy.



4 Regional insight and relevance

“While UK-wide consistency of care, experience and options would be ideal, we know that on the ground this isn’t the reality for people with a brain tumour, particularly when they are back at home and in their communities, where supportive services are designed and provided at a local level.”

Helen Bulbeck

Director of Services and Policy
brainstrust

Our pragmatic operational strategy facilitates working at scale and reflects our commitment to helping patients maximise the help that is available to them on the ground in their area. The keystone of this strategy is our team of regional support specialists, who for the year in review are operating in the north of England (Leeds), Scotland (Glasgow), London and the south-east, the Midlands (Lichfield) and the central south coast (Cowes). The highly trained team can offer personalised, regionally relevant support because of the links they have fostered in their respective communities for the brain tumour communities they serve. They have built strong links with the clinical teams in their regions, who are routinely referring patients to *brainstrust* for support. Our team are well supported by office hubs on the Isle of Wight (Cowes, registered office) and in Leeds.



In January 2020, we were delighted to secure significant additional support from the National Lottery Community Fund to build capacity for this work over the coming three years. This builds on the support that the NLCF has already provided over the preceding three years to establish coaching in London and the Midlands.

We acknowledge that none of us is as smart as all of us and that collaboration and signposting are vital for our beneficiaries. To this end, we work hard to keep local directories of services up to date and available to all who need them. This information is available in print in our Little White Books and online in the brain tumour hub (www.braintumourhub.org.uk).



5 Clinical engagement, development and network building, and

6 Engaging people with research

These two areas of our work are strongly connected, creating a virtuous circle – you can't do one without the other. As the clinical landscape has become increasingly complex, the focus for 2019/20 has been to **filter, contextualise and involve**, so that at every touch point, we ensure that the narrative for our community has been about:

- capacity
- meeting the needs of those who need it
- being relevant
- being accessible
- forward thinking
- doing less, achieving more
- critical reflection.

Our established roles and direction with the National Cancer Research Institute (NCRI), Tessa Jowell Brain Cancer Mission (TJBCM) and James Lind Alliance (JLA) mean that this year we have been able to pivot to a focused championing of our beneficiaries' cause that integrates seamlessly with our new strategy:

- We enhance policy with additional focus and understanding of the social impact of a brain tumour diagnosis.
- We are providing fuel for the fire by sharing the human perspective to drive credible campaigning activity with and through other active organisations.
- We promote existing work that champions the real-life impact of diagnosis.
- We bring real challenges to real life, helping people address and share the challenges of behaviour and personality change, receiving prompt diagnosis, and measuring what matters to patients.

In an update on progress against the 10-year NHS Cancer Plan, Cally Palmer, NHS England Cancer Director, announced a commitment to developing holistic support for cancer patients, to include navigation and coaching as part of a 'personalised care' agenda. *brainstrust* was at this meeting and has given this agenda traction through its implementation and planning workshop, the non-negotiables of which are:

- maintenance of wellness, not treatment of illness
- keeping the person at the heart
- shared decision-making
- transition points
- the joy of local
- building on current good practice
- evolving models
- robust infrastructure
- prepared patients, trained teams and supportive systems.

Components of personalised care within the NHS 10-Year Plan.

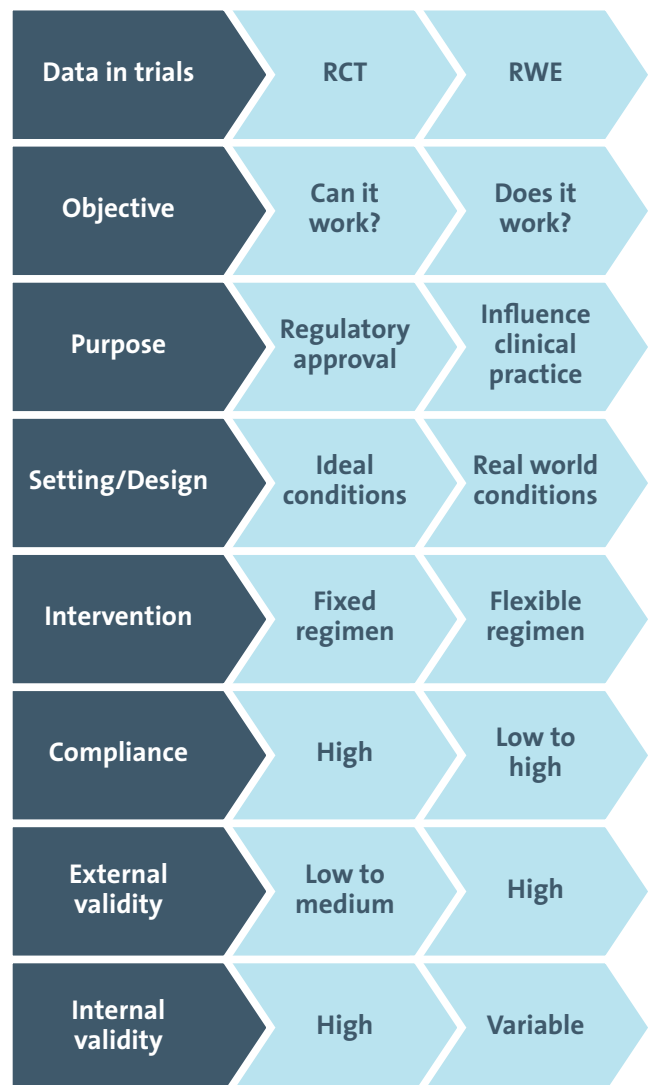




We are recognised as the charity to approach to support brain tumour clinical studies with patient and caregiver input. This agenda is driven by *brainstrust* through the Incubator Days, the aims of which are:

- to find out about current research evidence (Cochrane or other systematic review)
- to explore potential research around interventions that relate to headache +
- to bring a team together to build the submission
- to seek involvement from research development experts (e.g. RDS)
- to develop the proposal with the help of a clinical trials unit (CTU)
- to consider the trial management, protocol, statistics and data management
- to provide robust peer review of research proposal through the National Cancer Research Institute (NCRI)
- to seek the most appropriate funding route for the study with partners
- to apply for funding to the appropriate funder.

Real-world evidence is a growing agenda, and again *brainstrust* is acknowledged as the go-to place for this focus. We were invited to talk at the Embassy of Switzerland and meet with health technology companies to explore what this might look like for the brain cancer community. Real-world evidence brings patient validity, experience and relevance to the agenda and hears a patient voice in a complex system. Managing this successfully can be very powerful and sits well with the ‘First, we are people’ ethos. It can shift cultures and change the way research is being done, changing the RCT model, which hasn’t worked to date for brain cancer, to one where patient experience matters:



Achievements and performance

Your support

In 2019 we raised £606,754. An increase of 2% on last year's income. This was 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

We have very limited income from special purpose fundraising, legacy fundraising and high-net-worth individuals and no investment income.

Highlights for the year include:

- renewed three-year support from the National Lottery Community Fund to expand our regional coaching support
- ongoing support from Children with Cancer UK to deliver services for children and families who are affected by a brain tumour diagnosis
- renewed support from the Rank Foundation by way of their Time to Shine scheme, which provides funding and support for interns and managers for a 12-month period.

People in our community raised an incredible £211,411 through bake sales, dress-down days, marathons and challenges, and of course, our annual Follow the Seagulls walks. The walks in Yorkshire, Devon, Fife and on the Isle of Wight contributed £70,000 to this total.

We are eternally grateful to our corporate supporters, who include Roche, Siemens

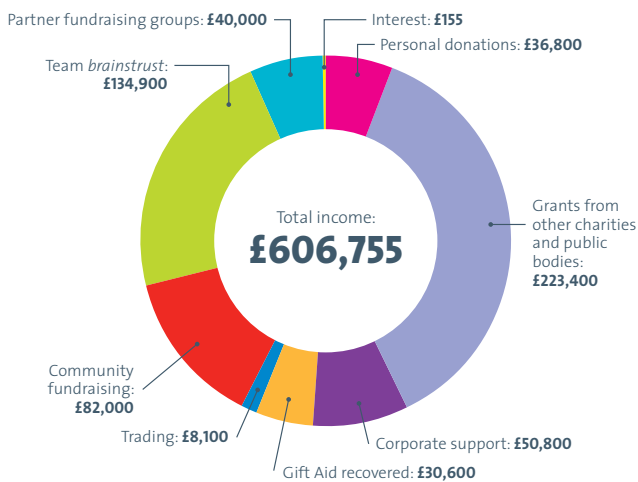


Healthineers, Millgate Homes and RoyaleLife. These organisations contributed £50,733 to our work.

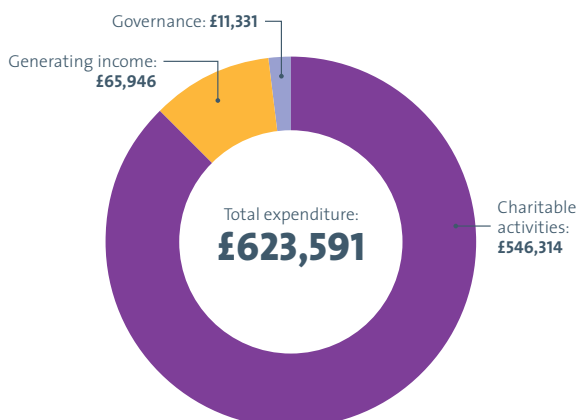
Sadly, many of the people we help do not survive their brain tumour diagnosis. Many families chose to express their gratitude to *brainstrust* by fundraising in memory of a loved one. This activity raised £21,322, which we have used prudently to help others on their brain tumour journey.

Individual and regular donors are playing an increasingly important part of our fundraising, with support here totalling £15,480, of which £6,149 was regular giving. This represents an increase in regular gifts of 29%.

Our income 2019/20



Our expenditure 2019/20



Our support

Of people who looked to us for support, 93% reported a positive outcome.

In 2019 we supported 911 new people with events and/or coaching services. This is consistent with last year.

Our team handled 4,948 patient contacts, including 2,807 caregivers and 2,164 people who have a brain tumour.

We posted 633 brain boxes, 57 of which were to children.

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.

little brainstrust

We also provide dedicated support for children and families who have different and additional needs following a brain tumour diagnosis. While survival is generally higher in the childhood community, the devastating physical and mental impact of a brain tumour and treatments is long-lasting. We hear that relationships are more complicated, the transition between paediatric and adult care is hard, liaising with schools brings added complexity, and emotion is high.

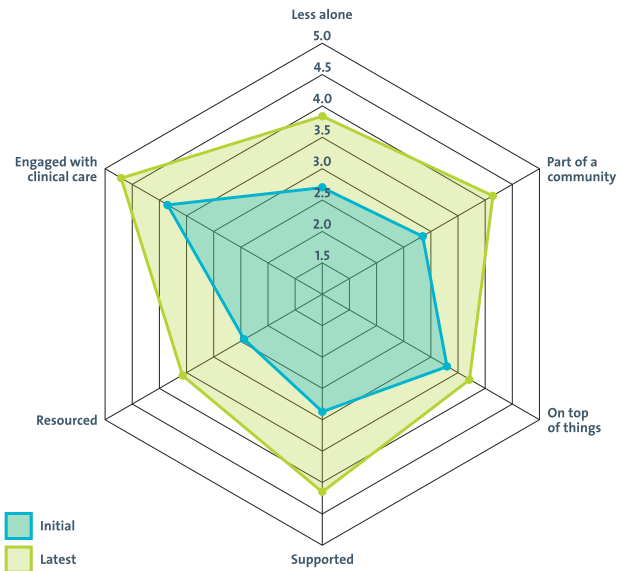
We help families navigate this with our *little brainstrust* brand.



Last year, this component of our work helped 635 families, and in 338 of these instances, we provided direct support to children. Paediatric cases now account for 14% of our caseload.

We actively encourage our community to complete progress trackers.

On average, *little brainstrust's* beneficiaries progress 1.02 points (20%) across our six indicators, moving from a place where things are okay to a place where things are more how they like it. Beneficiaries also report the most progress (1.29 points, or 26%) in feeling supported and part of a community.



The 2019 Paediatric Brain Tumour Symposium, Nottingham

The second of our Paediatric Brain Tumour Symposiums brought greater depth of content and increased attendance than the inaugural event. At *brainstrust's* lead, four charities collaborated, and we attracted 83 delegates. The event took place at the Children's Brain Tumour Research Centre (CBTRC) in Nottingham and featured speakers from *brainstrust*, CBTRC and Brain Tumour Research.

Our event brought together healthcare professionals, consultants, researchers, charitable organisations, young adults impacted by a brain tumour, families and caregivers to learn about progress being made across many fronts in the work against paediatric brain tumours. We had a wide range of talks from speakers within our community, including a parent of a child undergoing treatment for a brain tumour, and a young adult who shared his experience of being diagnosed with a brain tumour in his teens.

“It was amazing to have so many parents in the room alongside healthcare professionals who were keen to answer questions and listen to patients’ stories. This event has grown year on year, and we hope to continue to provide families with this opportunity to learn all they can and meet other parents. Feedback from this year was excellent, and we will use the lessons learned to make next year bigger and better for our community.”



Khadijha Sundus

Support Specialist for Children and Families

The programme covered cannabinoids and the ketogenic diet, acceptance and commitment theory for children, an overview of the role of occupational therapy, patient experiences and stories, modelling medulloblastoma, campaigning for change, paediatric ependymoma, proton beam therapy, physiotherapy and rehabilitation.

We collated feedback from 41 attendees, with 100% of respondents recommending that we run a similar event in the future. Of the attendees, 92% found the event to be useful, with a rating between 8/10 and 10/10.

Policy highlights

Research must meet the needs of the people it is set to benefit. The work *brainstrust* is doing with the Cochrane Neuro-Oncology Group and NCRI brain CSG members is now two years into the three-year NIHR Systematic Review Programme Grant, and reviews have been progressing well, so that all reviews will be complete by October 2020. The topics are:

- intraoperative imaging technology to maximise extent of resection for glioma
- tests for co-deletion of chromosomal arms 1p and 19q in people with glioma
- prognostic value of tests for methyl guanine methyl transferase (MGMT) promoter methylation in people with glioblastoma
- long-term side effects of radiotherapy with or without chemotherapy for glioma
- interval brain imaging for glioma
- guidelines and protocols for the diagnosis of brain tumours
- treatment interventions for recurrent glioblastoma
- treatment for glioblastoma in the elderly.

Studies must be relevant and well designed. Three Incubator Days facilitated by *brainstrust*, have been held, on optometry for diagnosis of brain tumours, quality-of-life interventions and exercise in brain tumours. Incubator Days are structured interactive workshops intended to drive the development of a clinical trial. They link up researchers, methodologists and clinical trials unit (CTU) staff to produce the best trials proposals, and direct them to the most likely funders.

More must be done for people with advanced cancer. Working with the Advanced Cancers Coalition (a collaboration of charities supported by Roche), *brainstrust* has played an active role in raising awareness of advanced cancer and the lack of opportunities and support for patients when their brain tumours return.

No parent in the UK will have to struggle to find the money to pay for their child's funeral again, as the Children's Funeral Fund is now available for families in England to access. Through our work at *little brainstrust*, we campaigned alongside other children's charities to make this happen.



COVID-19 and our work

The global COVID-19 pandemic struck the UK with full force during the last month of our reporting year, so while technically its impact for this period was limited and could be ignored for this report, it would be imprudent to ignore this existential threat to our work, and the impact it has had on the people who need us.

We immediately reviewed and revised our goals in mid-March with the onset of the coronavirus pandemic and cancellation of all face-to-face events and public fundraising.

We are proud of the pace at which we pivoted, and the difficult decisions that we implemented, and believe that as a result, we are in a position of strongest possible health to bounce back from this challenging situation. This is contingent on resumption of some public fundraising in the autumn, and the continued support of our funders, who will be facing their own challenges.

With the mission of being invaluable to those who need us most at this difficult time, we have taken all services online, with successful webinars for our community, and weekly social events so beneficiaries can stay connected. We have placed additional focus on patient information, bringing planned work around uncertainty and anxiety to the top of our project plan, as well as information for caregivers. We are also using the phone a lot more, reaching out to vulnerable members of our community who have had treatment delayed or are even more isolated than usual because they are self-isolating or shielding. All of our beneficiaries have heightened anxiety and uncertainty as a result of the pandemic. They are more isolated, and the treatment pathway is more confusing than before.

Short-term furloughing of staff, cessation of travel and cancellation of public events, alongside an emergency fundraising strategy, have enabled us to maintain impact, manage caseload and sustain reserves. At the time of writing, we have balanced our budget year to date and rebuilt reserves to four months of core costs.

Initially, we anticipated a drop in income of £218,000 (32%) due to the coronavirus pandemic, but we have appraised this in recent weeks and currently expect a £140,000 (20%) reduction to our budget. We are grateful to our funders and key supporters for their belief and commitment to our work during this period.

Our impact

Over the previous two years, we have worked hard and in consultation with our community, our team and our funders to develop robust, auditable and trustworthy impact reporting. Now, the *braintrust* progress tracker is ingrained in our day-to-day work, and we can report on people's progress against six indicators, all of which support 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



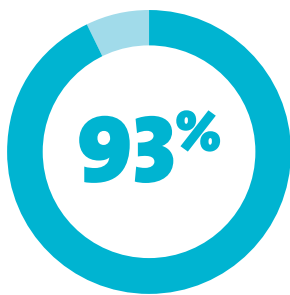
2019 Paediatric Brain Tumour Symposium, Nottingham



Everybody who engages *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 use 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**



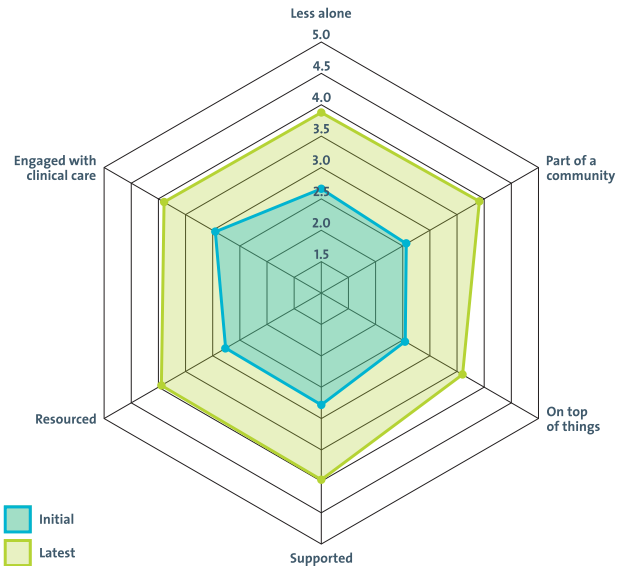
beneficiaries* who report a positive outcome after receiving support from *brainstrust*.

*based on data from 100 beneficiaries.

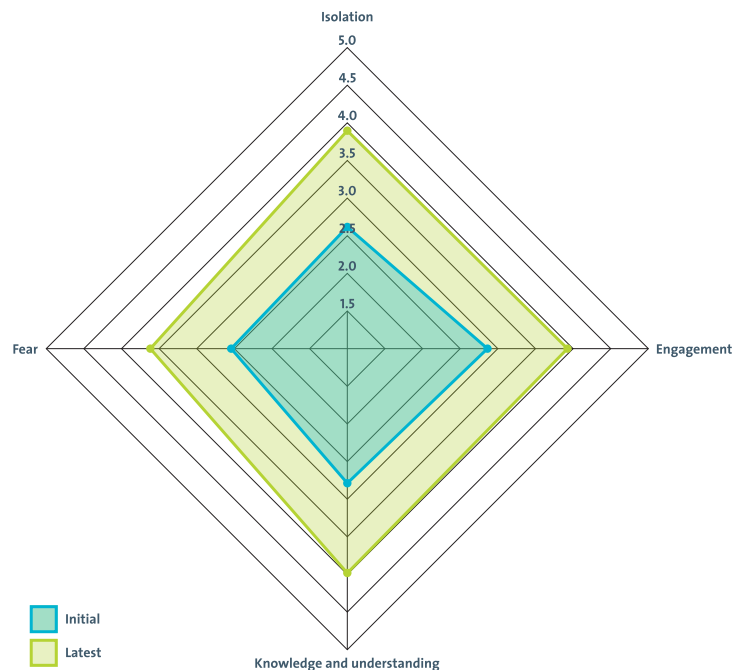
- We continue to drive holistic improvement in people’s well-being across six clearly defined impact indicators, which reflect the challenges our community faces.
- On average, people progress just over one point, or 23% (1.16/5), across the six indicators having received support from *brainstrust*. Initial and final scores indicate that people move from a place of difficulty to a place where things are more how they like it.
- This tells us that our impact has been sustained from last year.
- Our service is creating the most impact in addressing 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).
- We are having the least impact in helping people to feel engaged with their clinical care (18% or 0.93/5).

- There are outliers where significant progress has been made, but this impact is ‘softened’ when we are reporting on aggregated data. Where possible, case studies are sought for these cases.

Progress against *brainstrust's* six indicators



Resultant progress against *brainstrust* strategic priorities



In 2019/20, 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, from which this data is drawn.

Over 200 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.

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.



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 5/5 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



Sarah and Paul have been incredibly committed to their fundraising efforts, and they haven't let the coronavirus pandemic stop them. During lockdown, the UK National FootGolf Club League has held two online race nights: ‘From both events, we have raised £131 for *brainstrust* through people's donations and from an auction race where participants had the chance to become the horse's owner.’

And now, thanks to Sarah, the Buxton Virtual Garden Trail is supporting *brainstrust*. People can enjoy beautiful gardens and stunning shots of nature from the comfort and safety of their home, with a pay-as-you-feel donation coming to *brainstrust*. Search for ‘The Buxton Garden Trail’ on Facebook to find out more.

Financial review

The Trust's published statutory accounts for the year ended 31 March 2020 are incorporated in this report and include considerable detail on the source and application of funds, and the financial position of the Trust at 31 March 2020, as required by the SORP for UK charities, published by the Charity Commission. This report comments on the main points of interest.

In summary, gross income generated in 2019/20 was £607K (2018/19: £599K). The net deficit for the year was £17K (2018/19: £70K).

Income towards the close of 2019/20 had already been impacted by the onset of the COVID-19 pandemic, with a number of valuable fundraising events already cancelled, which would normally generate significant income in the final months of the financial year. It is estimated that this cost the Trust £50K in revenue in the month of March 2020 alone. Revenue in March 2019 was £81K, and by comparison, in March 2020 it was £27K. So the deficit for 2019/20 may fairly be attributed to the dramatic early effects of the pandemic on national life.

From April 2020, the Trust's monthly costs were cut by 30%, and significant revenue was generated from government support schemes and other emergency grants, so 2020/21 has started very viably, but too late to impact on 2019/20 figures.

The Trust's income is derived from the usual charity mix – grants, often for specific projects, and community fundraising in its very many forms. We are very grateful to our volunteers and supporters who contribute through running, cycling and walking immense distances, and many other activities, including, of course, the ever-popular mud-wallowing. Added to this are the very many social events and activities

organised by our volunteers for our benefit. Thank you to all of you!

The majority of income, both general and restricted, is applied to supporting patients, their caregivers and their families, from the point of a brain cancer diagnosis. Our support team has an emphasis on UK-wide geographical coverage, supported by the National Lottery Community Fund and other substantial funders.

The Trust has only cash investments, deposited with NatWest Bank and The Co-operative Bank. At 31 March 2020, the Trust had cash reserves, including our restricted income funds, of £174K (2019: £202K). Including non-cash items, net unrestricted reserves were £79K (2019: £109K), and net restricted reserves were £107K (2019: £94K). The deficit for the year under review has been absorbed within our reserves.

The Trust has a target of holding unrestricted reserves to cover four months of defined core costs. At 31 March 2020, unrestricted reserves were sufficient to cover 1.5 months of core costs, the shortfall mostly attributable to the loss of revenue in March 2020, to which reference has been made. By June 2020, the cover had been rebuilt to three months.

Clearly, the impact of COVID-19 will have a significant impact on the charity sector in 2020/21 and beyond, and we will see continuing financial challenges for the sector, possibly as great as for any sector. Our management plan, put in place in 2019 and defining our direction for the years to 2024, now faces additional challenges, but the results for the first few months of 2020/21 are encouraging, and our strategies will see us striving even harder to consolidate and grow financially so that our support, for those affected by a brain cancer diagnosis, can grow in parallel.

Structure governance and management

“We believe good governance is an essential component of our success, particularly as we grow. It underpins our integrity, reinforces the trust and confidence our patients and partners place in us, and contributes to a strong high-performance culture.”



Chris Baker
Chair of Trustees

“Focused discussions, an agile and adaptable approach to planning and sound cooperation between the appointed trustees and the managers of the Trust have ensured that brainstrust has continued to provide support and guidance for our patients, in accordance with its aims, while maintaining a secure financial footing.”

Gillian Bilbo
Trustee, brainstrust

brainstrust is constituted as a trust, governed by its Declaration of Trust, dated 4 March 2006.

The overall guidelines for the management and administration of the Trust are incorporated in the Declaration of Trust, dated 4 March 2006, as amended by Deeds of Amendment adopted by the trustees under the terms of the original deed and notified to the Charity Commission.

This places overall responsibility for the proper governance of the Trust with the appointed trustees. Day-to-day management of the Trust is delegated to William Jones, who has been appointed chief executive of the Trust. The chief executive, supported by the leadership team, makes recommendations to the trustees on the Trust’s vision, patient and caregiver support, related research, financial fundraising, promotional activities and ensuring that funds raised are spent as efficiently as possible on resources that will be useful to people affected by brain cancer.

brainstrust’s trustees have had regard to the guidance issued by the Charity Commission on public benefit.

Senior staff contacts

William Jones
Chief Executive
will@brainstrust.org.uk

Dr Helen Bulbeck
Director of Services and Policy
helen@brainstrust.org.uk

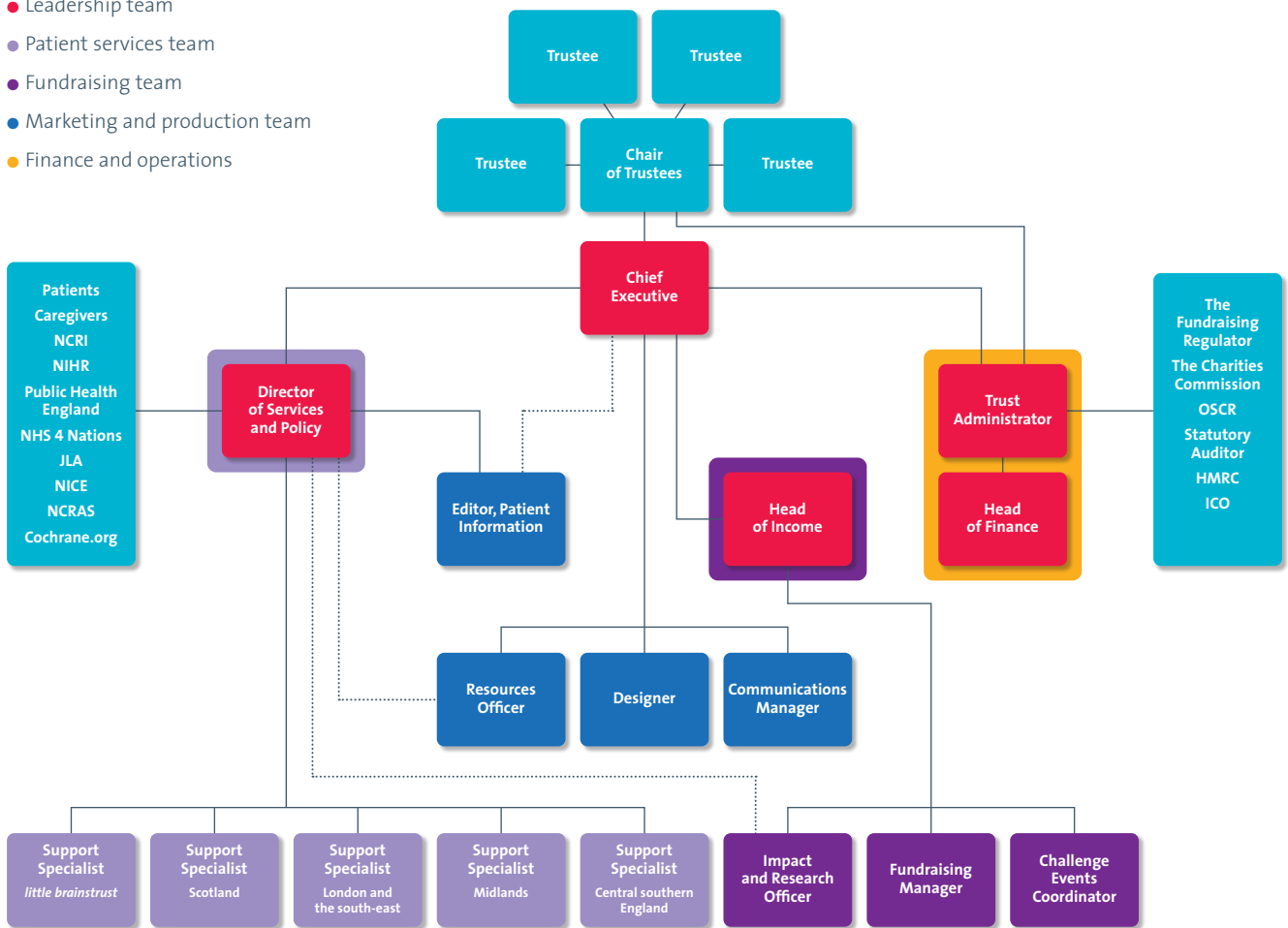
Peter Bulbeck
Trust Administrator and Clerk to Trustees
hq@brainstrust.org.uk

Kathy Springate
Head of Finance
kathy@brainstrust.org.uk

Tom Cowie
Head of Income
tom@brainstrust.org.uk

Key

- Governing, statutory and other bodies to whom we are accountable
- Leadership team
- Patient services team
- Fundraising team
- Marketing and production team
- Finance and operations



Trustees

brainstrust's trustees for the year in review are Christopher Baker, Kevin Higgs, Stephen Warrington, Gillian Bilbo and Ben Young.

The board of trustees meets formally four times a year to ratify the broad strategy and areas of activity for the Trust. In addition, trustees may meet with members of the team to work on specific projects. All trustees give their time freely, and no remuneration is paid.

In accordance with clause 9 of the Declaration of Trust dated 4 March 2006:

- (i) There must be at least three trustees. Apart from the first trustees, every trustee must be appointed by a resolution of the trustees passed at a special meeting called under clause 15 of this deed.

- (ii) In selecting individuals for appointment as trustees, the trustees must have regard to the skills, knowledge and experience needed for the effective administration of the charity.
- (iii) The trustees must keep a record of the name and address and the dates of appointment, reappointment and retirement of each trustee.
- (iv) The trustees must make available to each new trustee, on his or her first appointment:
 - (a) a copy of this deed and any amendments made to it
 - (b) a copy of the charity's latest report and statement of accounts.

There are no exemptions from disclosure applicable to or within this report, and neither the charity nor any of its trustees are acting as custodian trustees.

Now in our 14th year of operation, we have an established national footprint across all elements of our activity. This is delivered with public benefit at the heart by a professional team with a professional leadership structure.

Chris Baker

Chair of Trustees

Chris is senior vice president at a global cloud content management company and has over 20 years' experience driving growth at some of the highest-profile software companies in the world, including Microsoft and Salesforce. Chris has been a trustee for nearly nine years and the chair of trustees at *brainstrust* for four years.

Kevin Higgs

Trustee

Kevin is a financial adviser and has been a trustee for 12 years. In a chance meeting while at a previous employer, Kevin was immediately taken by the dedication and commitment of the charity to focus on the support and well-being of patients and families diagnosed with a brain tumour. He knew that he wanted to be a part of the 'journey' that *brainstrust* has been on since 2006.

Stephen Warrington

Trustee

Stephen brings to the organisation extensive experience leading professional services businesses and consulting for major multinationals, and has been a trustee for four years. Stephen's teenage son was diagnosed with a brain tumour and underwent successful surgery.

Gillian Bilbo

Trustee

Gillian is a retired headteacher and is now a school inspector, and she has been a trustee for eight years. She brings a listening ear and an objective viewpoint to the board and is supportive of fundraising initiatives.

Ben Young

Trustee

A former journalist, Ben has spent more than 25 years helping to inform, entertain and engage a wide range of audiences across multiple platforms. This has taken him from writing editorial, into advertising as a creative director, and on to the role of HR director at Time Inc, Warner Bros. and Ogilvy UK. He now works as a strategic storyteller. He is married, with four children, and lives in Northamptonshire. He joined the board of *brainstrust* in 2018.

None of us is as smart as all of us: *brainstrust* collaborations that are creating change

Support from other charities and public bodies

Our work continues to attract the support of other charities and funding bodies that recognise the outstanding quality of our work. Of particular note for the year in review is the funding for projects and our core work that we have received from the following organisations:

- **The National Lottery Community Fund** – renewed support to further expand our coaching service in line with our regional model in England, and an outreach programme to better support our community in more isolated areas of Scotland.
- **Children with Cancer UK** – continued support for little brainstrust, our dedicated service for children and families, with increased funding for our second annual UK Paediatric Brain Tumour Symposium in November 2019.
- **The Rank Foundation** – building capacity in our fundraising and research teams with a supported internship as part of their Time to Shine programme.
- **The Souter Charitable Trust** – generous co-funding alongside the National Lottery Community Fund to enable our outreach in Scotland to be fully realised.
- **The Wyseliot Rose Charitable Trust** – support to develop our essential behaviour and personality change suite of resources.
- **The Garfield Weston Foundation** – generous unrestricted support towards our core operating costs, allowing us to be there for every member of our brain tumour community who needs us.
- **Hospital Saturday Fund** – generous unrestricted support towards our core operating costs, allowing us to be there for every member of our brain tumour community who needs us.

Collaborations to improve support

- 35 neurosurgical centres plus satellite hospitals
- National Council for Palliative Care
- CHAIN (the Contact, Help, Advice and Information Network)
- Cancer Campaigning Group (CCG)
- Independent Cancer Patients' Voice (ICPV)
- The King's Fund
- Patient Information Forum (PIF)
- National Council for Palliative Care (NCPC)
- use MY data
- The Yorkshire and Humber Association of Neurological Organisations (YHANO)
- The Advanced Cancers Coalition (Roche)

Collaborations to improve clinical care

- British Neuro-Oncology Society (BNOS)
- Society of British Neurosurgeons (SBNS)
- Society of Neuro-Oncology (SNO)
- Scottish Adult Neuro-Oncology Network (SANON)
- European Association of Neuro-Oncology (EANO)
- British Psycho-Oncology Society

- NCRl Brain and Central Nervous System CSG
- NCRl Neuro-Oncology Palliative Care Subgroup
- NCRl Psychosocial and Supportive Care CSG
- National Cancer Research Network (NCRN)
- National Institute of Health Research (NIHR)
- Clinical and Translational Radiotherapy Research Working Group and executive (CTRad)
- British Neuropathology Society
- James Lind Alliance (JLA)
- Cochrane Collaboration
- The National Institute of Health Research (NIHR)
- Public Health England (PHE)
- National Cancer Registration and Analysis Service (NCRAS) Brain and CNS CRG National Institute for Clinical Excellence (NICE)
- BRAIN UK
- Cancer Research UK
- Medical Research Council

Collaborations to improve efficiency

- Children with Cancer UK
- International Brain Tumour Alliance (IBTA)
- Brain Tumour Research and member charities
- The Rarer Cancers Foundation
- Cancer52
- The Brain Tumour Charity
- Brain Tumour Support
- Brainwaves NI
- Macmillan
- Marie Curie
- Astro Brain Tumour Fund
- CLIC Sargent

Our patient and caregiver advisory panel: ‘the *brainstrust*’

All our information is produced with our body of patients, caregivers and healthcare professionals, known as ‘the *brainstrust*’. This team oversees and contributes to the development of content and is a sounding board for new initiatives. This ensures that our activity is relevant and meaningful for our community. Each information project on which we embark has its own team hand-picked from the *brainstrust*. These teams are formed carefully so that conflict of interest is avoided and so that the patients, their caregivers and clinicians with the most relevant experiences are called upon for insight.

For the year in review, 46 advisers gave their time and expertise freely to ‘the *brainstrust*’: 23 volunteer members represent the clinical community; 12 are patients; and 11 are caregivers. The clinical community has a broad reach and includes the following roles:

- Specialist nurse
- Consultant neurologist
- Medical oncologist
- Consultant neurosurgeon
- Scientific adviser
- Clinical psychologist
- Consultant palliative care specialist
- Expert coach, consultant and trainer
- Clinical fellow
- Radiation oncologist
- Clinical specialist radiographer
- Psychotherapist
- Consultant clinical oncologist
- Professor of targeted therapy and oncology
- Senior nurse specialist, stereotactic radiosurgery
- Therapeutic radiographer
- Advanced nurse practitioner, late effects
- Teenage and young adult therapy radiographer



Report of the Trustees and Audited Financial Statements for the year ended 31 March 2020 for *brainstrust*

Harrison Black Limited

Statutory Auditor
Pyle House
136/137 Pyle Street
Newport
Isle of Wight
PO30 1JW

***brainstrust* – Contents of the financial statements for the year ended 31 March 2020**

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Notes to the Cash Flow Statement	43
Notes to the Financial Statements	44 to 54
Detailed Statement of Financial Activities	55 to 56

***brainstrust* – Report of the trustees for the year ended 31 March 2020**

The trustees present their report with the financial statements of the charity for the year ended 31 March 2020. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

Structure, governance and management

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an unincorporated charity.

Reference and administrative details

Registered Charity number

1114634

Principal address

4 Yvery Court
Castle Road
Cowes
Isle of Wight
PO31 7QG

Trustees

C Baker
K Higgs
G Bilbo
S Warrington
B Young

Auditors

Harrison Black Limited
Statutory Auditor
Pyle House
136/137 Pyle Street
Newport
Isle of Wight
PO30 1JW

brainstrust is also a Scottish Charity, SC044642, regulated by the Scottish Charity Regulator (OSCR).

Trustees' Responsibility Statement

The trustees are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Trustees' Responsibility Statement – continued

The law applicable to charities in England and Wales, the Charities Act 2011, Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charity will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with the Charities Act 2011, the Charity (Accounts and Reports) Regulations 2008 and the provisions of the trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on **29 July 2020** and signed on its behalf by:



C Baker – Trustee

Report of the Independent Auditors to the trustees of *brainstrust*

Opinion

We have audited the financial statements of *brainstrust* (the ‘charity’) for the year ended 31 March 2020 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charity’s affairs as at 31 March 2020 and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors’ responsibilities for the audit of the financial statements section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC’s Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Material uncertainty related to going concern

As disclosed in the Report of the Trustees, the potential impact of the Covid-19 pandemic creates a material uncertainty regarding going concern within the charitable sector. Fundraising activities, a significant income stream, may be adversely affected in the short-term and the charity may potentially suffer operational challenges as the country remains in restricted conditions. However, detailed projections indicate that increased grants receivable are likely to compensate for this income reduction. The charity has quickly adapted its operations and the budgets illustrate that both projected direct and indirect costs will be reduced.

Based upon the information contained within the projections and the ability of the charity to scale its operations appropriately, our opinion is not modified in respect of this matter.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the Annual Report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Report of the Independent Auditors to the trustees of *braintrust*

Other information – continued

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Charities (Accounts and Reports) Regulations 2008 requires us to report to you if, in our opinion:

- the information given in the Report of the Trustees is inconsistent in any material respect with the financial statements; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the Trustees' Responsibilities Statement, the trustees are responsible for the preparation of the financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Our responsibilities for the audit of the financial statements

We have been appointed as auditors under Section 144 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.


Report of the Independent Auditors to the trustees of *brainstrust*

Our responsibilities for the audit of the financial statements – continued

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council’s website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

Use of our report

This report is made solely to the charity’s trustees, as a body, in accordance with Section 144 of the Charities Act 2011 and regulations made under Section 154 of that Act and under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charity’s trustees those matters we are required to state to them in an auditors’ report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and the charity’s trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Harrison Black Limited
Statutory Auditor
Eligible to act as an auditor in terms of Section 1212 of the Companies Act 2006
Pyle House
136/137 Pyle Street
Newport
Isle of Wight
PO30 1JW

Date: **6 October 2020**

Note:

The maintenance and integrity of the *brainstrust* website is the responsibility of the trustees; the work carried out by the auditors does not involve consideration of these matters and, accordingly, the auditors accept no responsibility for any changes that may have occurred to the financial statements since they were initially presented on the website.

brainstrust – Statement of financial activities for the year ended 31 March 2020

	Notes	Unrestricted fund £	Restricted funds £	2020 Total funds £	2019 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	304,607	36,982	341,589	289,723
Other trading activities	3	225,242	39,770	265,012	308,888
Investment income	4	154	–	154	183
Total		530,003	76,752	606,755	598,794
EXPENDITURE ON					
Raising funds	5	64,774	1,172	65,946	91,061
Charitable activities	6				
Charity activities		518,977	38,668	557,645	577,656
Total		583,751	39,840	623,591	668,717
NET INCOME/(EXPENDITURE)		(53,748)	36,912	(16,836)	(69,923)
Transfers between funds	15	23,894	(23,894)	–	–
Net movement in funds		(29,854)	13,018	(16,836)	(69,923)
RECONCILIATION OF FUNDS					
Total funds brought forward		108,635	93,855	202,490	272,413
TOTAL FUNDS CARRIED FORWARD		78,781	106,873	185,654	202,490

The notes form part of these financial statements

brainstrust – Balance sheet 31 March 2020

	Notes	Unrestricted fund £	Restricted funds £	2020 Total funds £	2019 Total funds £
FIXED ASSETS					
Tangible assets	11	4,059	–	4,059	6,088
CURRENT ASSETS					
Debtors	12	27,456	–	27,456	42,281
Cash at bank		67,358	106,873	174,231	208,680
		94,814	106,873	201,687	250,961
CREDITORS					
Amounts falling due within one year	13	(20,092)	–	(20,092)	(54,559)
NET CURRENT ASSETS		74,722	106,873	181,595	196,402
TOTAL ASSETS LESS CURRENT LIABILITIES		78,781	106,873	185,654	202,490
NET ASSETS		78,781	106,873	185,654	202,490
FUNDS					
Unrestricted funds	15			78,781	108,635
Restricted funds				106,873	93,855
TOTAL FUNDS				185,654	202,490

The financial statements were approved by the Board of Trustees and authorised for issue on **29 July 2020** and were signed on its behalf by:



C Baker – Trustee

The notes form part of these financial statements

brainstrust – Cash flow statement for the year ended 31 March 2020

	Notes	2020 £	2019 £
Cash flows from operating activities			
Cash generated from operations	1	(34,603)	(101,759)
Net cash used in operating activities		(34,603)	(101,759)
Cash flows from investing activities			
Interest received		154	183
Net cash provided by investing activities		154	183
Change in cash and cash equivalents in the reporting period			
		(34,449)	(101,576)
Cash and cash equivalents at the beginning of the reporting period			
		208,680	310,256
Cash and cash equivalents at the end of the reporting period			
		174,231	208,680

The notes form part of these financial statements

brainstrust – Notes to the cash flow statement for the year ended 31 March 2020

1. Reconciliation of net expenditure to net cash flow from operating activities

	2020 £	2019 £
Net expenditure for the reporting period (as per the Statement of Financial Activities)	(16,836)	(69,923)
Adjustments for:		
Depreciation charges	2,029	2,030
Interest received	(154)	(183)
Decrease/(increase) in debtors	14,825	(13,285)
Decrease in creditors	(34,467)	(20,398)
Net cash used in operations	(34,603)	(101,759)

2. Analysis of changes in net funds

	At 1.4.19 £	Cash flow £	At 31.3.20 £
Net cash			
Cash at bank	208,680	(34,449)	174,231
	208,680	(34,449)	174,231
Total	208,680	(34,449)	174,231

The notes form part of these financial statements

brainstrust – Notes to the financial statements for the year ended 31 March 2020

1. Accounting policies

Basis of preparing the financial statements

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donations are recognised when the charity has been notified in writing of both the amount and settlement date. In the event that a donation is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

Grant income is recognised when received. In the event that a grant is subject to conditions that require a level of performance before the charity is entitled to the funds, the income is deferred and not recognised until either those conditions are fully met, or the fulfilment of those conditions is wholly within the control of the charity and it is probable that those conditions will be fulfilled in the reporting period.

Legacy gifts are recognised on a case by case basis following the granting of probate when the administrator/executor for the estate has communicated in writing both the amount and settlement date. In the event that the gift is in the form of an asset, recognition is subject to the value of the gift being reliably measurable with a degree of reasonable accuracy and the title to the asset having been transferred to the charity.

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the charity; this is normally upon notification of the interest paid or payable by the bank.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Fixtures and fittings	-25% on cost
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brainstrust – Notes to the financial statements for the year ended 31 March 2020 – continued

1. Accounting policies – continued

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

2. Donations and legacies

	2020	2019
	£	£
Donations	36,802	48,322
Grants from awarding entities	223,452	178,756
Corporate grants and donations	50,733	30,062
Gift aid tax recovered	30,602	32,083
Legacies	–	500
	341,589	289,723

3. Other trading activities

	2020	2019
	£	£
Fundraising events	79,088	105,447
Sale of 'brainstrust' items	8,063	7,984
Sponsored activities	134,903	167,257
Schools and colleges	3,188	8,327
Activities of partner groups	39,770	19,873
	265,012	308,888

continued...

**brainstrust – Notes to the financial statements for the year ended
31 March 2020 – continued**

4. Investment income

	2020 £	2019 £
Deposit account interest	154	183

5. Raising funds

Raising donations and legacies

	2020 £	2019 £
Fundraising fees	6,245	9,853
Promotional expenses	25,903	21,884
	32,148	31,737

Other trading activities

	2020 £	2019 £
Trading costs and purchases	4,280	5,684
Event costs	13,185	20,010
Sponsored activities costs	16,333	33,630
	33,798	59,324

Aggregate amounts

65,946	91,061
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6. Charitable activities costs

	Direct costs Costs £	Support (see note 7) £	Totals £
Charity activities	546,314	11,331	557,645

continued...

brainstrust – Notes to the financial statements for the year ended 31 March 2020 – continued

7. SUPPORT COSTS

	Governance costs £
Charity activities	
	11,331

8. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 31 March 2020 nor for the year ended 31 March 2019.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 March 2020 nor for the year ended 31 March 2019.

9. Staff costs

Total gross salaries, benefits in kind and employers national insurance costs for the year ending 31 March 2020 were £405,958 (2019 – £400,687).

The average monthly number of employees during the year was as follows:

	2020	2019
Fundraising	3	3
Charitable Activities	8	9
Governance	1	1
Other	1	1
	13	14

No employees received emoluments in excess of £60,000.

continued...

**brainstrust – Notes to the financial statements for the year ended
31 March 2020 – continued**

10. Comparatives for the statement of financial activities

	Unrestricted fund £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	212,472	77,251	289,723
Other trading activities	289,015	19,873	308,888
Investment income	183	–	183
Total	501,670	97,124	598,794
EXPENDITURE ON			
Raising funds	87,926	3,135	91,061
Charitable activities			
Charity activities	478,747	98,909	577,656
Total	566,673	102,044	668,717
NET INCOME/(EXPENDITURE)	(65,003)	(4,920)	(69,923)
RECONCILIATION OF FUNDS			
Total funds brought forward	173,638	98,775	272,413
TOTAL FUNDS CARRIED FORWARD	108,635	93,855	202,490

continued...

**brainstrust – Notes to the financial statements for the year ended
31 March 2020 – continued**

11. Tangible fixed assets

	Fixtures and fittings £	Website £	Totals £
COST			
At 1 April 2019 and 31 March 2020	1,494	8,118	9,612
DEPRECIATION			
At 1 April 2019	1,494	2,030	3,524
Charge for year	–	2,029	2,029
At 31 March 2020	1,494	4,059	5,553
NET BOOK VALUE			
At 31 March 2020	–	4,059	4,059
At 31 March 2019	–	6,088	6,088

12. Debtors: amounts falling due within one year

	2020 £	2019 £
Trade debtors	500	19,978
Other debtors	1,800	895
Prepayments	25,156	21,408
	27,456	42,281

13. Creditors: amounts falling due within one year

	2020 £	2019 £
Trade creditors	6,533	7,668
Other creditors	13,559	46,891
	20,092	54,559

continued...

**brainstrust – Notes to the financial statements for the year ended
31 March 2020 – continued**

14. Leasing agreements

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2020 £	2019 £
Within one year	24,081	24,078
Between one and five years	37,972	61,954
	62,053	86,032

15. Movement in funds

	At 1.4.19 £	Net movement in funds £	Transfers between funds £	At 31.3.20 £
Unrestricted funds				
General fund	108,635	(53,748)	23,894	78,781
Restricted funds				
Big Lottery Fund Grant	1,283	(1,283)	–	–
Fund A	16,313	2,815	(18,451)	677
Fund B	4,575	2	(4,577)	–
Fund C	721	–	(721)	–
Fund D	4	–	(4)	–
Fund E	70,818	4,362	–	75,180
Fund F	140	–	(140)	–
Fund G	1	–	(1)	–
Fund H	–	31,016	–	31,016
	93,855	36,912	(23,894)	106,873
TOTAL FUNDS	202,490	(16,836)	–	185,654

continued...

**brainstrust – Notes to the financial statements for the year ended
31 March 2020 – continued**

15. Movement in funds – continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	530,003	(583,751)	(53,748)
Restricted funds			
Big Lottery Fund Grant	36,982	(38,265)	(1,283)
Fund A	2,815	–	2,815
Fund B	1	1	2
Fund C	1	(1)	–
Fund E	5,937	(1,575)	4,362
Fund H	31,016	–	31,016
	76,752	(39,840)	36,912
TOTAL FUNDS	606,755	(623,591)	(16,836)

Comparatives for movement in funds

	At 1.4.18 £	Net movement in funds £	At 31.3.19 £
Unrestricted funds			
General fund	173,638	(65,003)	108,635
Restricted funds			
Big Lottery Fund Grant	23,460	(22,177)	1,283
Fund A	14,086	2,227	16,313
Fund B	4,575	–	4,575
Fund C	720	1	721
Fund D	4	–	4
Fund E	55,837	14,981	70,818
Fund F	92	48	140
Fund G	1	–	1
	98,775	(4,920)	93,855
TOTAL FUNDS	272,413	(69,923)	202,490

continued...

**brainstrust – Notes to the financial statements for the year ended
31 March 2020 – continued**

15. Movement in funds – continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	501,670	(566,673)	(65,003)
Restricted funds			
Big Lottery Fund Grant	77,251	(99,428)	(22,177)
Fund A	2,227	–	2,227
Fund C	1	–	1
Fund E	17,597	(2,616)	14,981
Fund F	48	–	48
	<u>97,124</u>	<u>(102,044)</u>	<u>(4,920)</u>
TOTAL FUNDS	<u>598,794</u>	<u>(668,717)</u>	<u>(69,923)</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 1.4.18 £	Net movement in funds £	Transfers between funds £	At 31.3.20 £
Unrestricted funds				
General fund	173,638	(118,751)	23,894	78,781
Restricted funds				
Big Lottery Fund Grant	23,460	(23,460)	–	–
Fund A	14,086	5,042	(18,451)	677
Fund B	4,575	2	(4,577)	–
Fund C	720	1	(721)	–
Fund D	4	–	(4)	–
Fund E	55,837	19,343	–	75,180
Fund F	92	48	(140)	–
Fund G	1	–	(1)	–
Fund H	–	31,016	–	31,016
	<u>98,775</u>	<u>31,992</u>	<u>(23,894)</u>	<u>106,873</u>
TOTAL FUNDS	<u>272,413</u>	<u>(86,759)</u>	<u>–</u>	<u>185,654</u>

continued...

**brainstrust – Notes to the financial statements for the year ended
31 March 2020 – continued**

15. Movement in funds – continued

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	1,031,673	(1,150,424)	(118,751)
Restricted funds			
Big Lottery Fund Grant	114,233	(137,693)	23,460
Fund A	5,042	–	5,042
Fund B	1	1	2
Fund C	2	(1)	1
Fund E	23,534	(4,191)	19,343
Fund F	48	–	48
Fund H	31,016	–	31,016
	<u>173,876</u>	<u>(141,884)</u>	<u>31,992</u>
TOTAL FUNDS	<u>1,205,549</u>	<u>(1,292,308)</u>	<u>(86,759)</u>

Nature and purpose of funds

General Fund

The ‘free reserves’ after allowing for all restricted funds.

Restricted Funds

Big Lottery Fund Grant

This fund has been set up for the project of high impact coaching for the brain tumour community. The grant awarded by the Big Lottery Fund will support volunteers, employees, recruitment, running expenses, training, travel, equipment, consultancy and overheads.

Other Restricted Funds

All other restricted funds have been created through fundraising or donations for the benefit of individual brain tumour patients. The charity uses the funds for direct treatment or to support research relating to the patients needs.

continued...

***brainstrust* – Notes to the financial statements for the year ended 31 March 2020 – continued**

16. Related party disclosures

During the year the charity purchased services from Fitton Holman Creative Limited totalling £11,745 (2019 – £10,530). The company is directed by one of the co-founder's sister, Catherine Fitton.

During the year the charity paid the co-founders and management employees of Brainstrust, Peter and Helen Bulbeck, £4,960 (2019 – £5,760) for administrative use of their property.

The co-founder's daughter, Leonora Bulbeck, supplied editorial services during the year to the charity totalling £2,310 (2019 – £2,730) at a commercial rate.

This page does not form part of the statutory financial statements

***brainstrust* – Detailed statement of financial activities for the year ended 31 March 2020**

	2020 £	2019 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	36,802	48,322
Grants from awarding entities	223,452	178,756
Corporate grants and donations	50,733	30,062
Gift aid tax recovered	30,602	32,083
Legacies	–	500
	341,589	289,723
Other trading activities		
Fundraising events	79,088	105,447
Sale of ' <i>brainstrust</i> ' items	8,063	7,984
Sponsored activities	134,903	167,257
Schools and colleges	3,188	8,327
Activities of partner groups	39,770	19,873
	265,012	308,888
Investment income		
Deposit account interest	154	183
Total incoming resources	606,755	598,794
EXPENDITURE		
Raising donations and legacies		
Fundraising fees	6,245	9,853
Promotional expenses	25,903	21,884
	32,148	31,737
Other trading activities		
Trading costs and purchases	4,280	5,684
Event costs	13,185	20,010
Sponsored activities costs	16,333	33,630
	33,798	59,324
Charitable activities		
Medical grants and costs	3,645	1,770
Carried forward	3,645	1,770

This page does not form part of the statutory financial statements

**brainstrust – Detailed statement of financial activities for the year ended
31 March 2020**

	2020 £	2019 £
Charitable activities		
Brought forward	3,645	1,770
Patient support and staffing	300,614	319,862
Salaries	153,208	136,174
Travel	30,092	41,902
Administration	26,401	43,931
Office rent & rates	30,325	22,298
Bad debts	–	1,040
Depn of website	2,029	2,030
	546,314	569,007
Support costs		
Governance costs		
Auditors' remuneration	2,960	2,598
Insurance	1,895	1,829
Other	6,476	4,222
	11,331	8,649
Total resources expended	623,591	668,717
Net expenditure	(16,836)	(69,923)

This page does not form part of the statutory financial statements

Reference and administrative details

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

brainstrust
4 Yvery Court
Castle Road
Cowes
Isle of Wight
PO31 7QG

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

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees.

Signature:



Full name: **Chris Baker**

Position: **Chair of Trustees**

Date: **29 July 2020**



braintrust 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.

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