



# Working together to make life better for people with a brain tumour

Annual report and accounts 2018–2019



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# Our challenge

*'I was just a terrified thing in the corner.'*

**Patient**

Essex, December 2018

*'Facing your own mortality is a big thing when you've got young family.'*

**Patient**

Kent, November 2018

**Our challenge remains unchanged, but with your help, it is not insurmountable. More than 60,000 people in the UK are living with a devastating brain tumour diagnosis. 40% 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 fear, isolation, disempowerment and a loss of control. This is where we help.

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

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

In the last 13 years, we've helped thousands of people on their brain tumour journey. Only with your support can we help even more of those who need us.

*'I was isolated right from the start. Hospital was a long, epic journey away, so I only had two visitors in seven weeks, as I was so far away. I used to get upset seeing other people's visitors. All my friends were at work, so I had no one to talk to. My son would drop in once a week, but for weeks at a time, he'd be the only person I'd see. I was frightened to leave home for fear of something else happening.'*

**Patient**

Essex, November 2018



# Introduction



Will Jones

Chris Baker

## Welcome to *brainstrust's* annual report for 2018/19, and thank you for taking an interest in our challenge and our work.

While this report covers yet another exciting period in *brainstrust's* development, which shows further record growth in reach and impact, it also brings to light added granularity on the challenges for the community that we are here to help. People with a brain tumour remain isolated, afraid and distant from their care, and have a lack of understanding of the complex and harmful treatments they have to choose between. There is disparity of support and access to treatment, dependent on diagnosis and postcode, yet the harm caused by a brain tumour is consistently devastating no matter who you are or where you live.

We remain resolute in our commitment to making life better for people who have heard the words 'you have a brain tumour' and their caregivers, and we know that this is possible for all, because we are already doing it for many across the UK. *brainstrust's* challenge is one of achieving scale in a challenging landscape. With over 168,000 charities in the UK, fundraising

is increasingly competitive, and awareness and demand on our support is increasing. However, there is great promise for us at *brainstrust*, which is evidenced by the content of this report. While at face value, income is down, it is the case that we have been fortunate enough to have benefitted from an unrestricted windfall last year that has been reinvested in the growth and sustainability of our organisation. This investment has been multifaceted and is driving an increase in general fundraising (unrestricted and undesignated income is ahead of any previous year in our history), increased and auditable impact for our beneficiaries and stability for our team.

There is a lot about which we, and our supporters, can be proud. The year in review marks the first time we have been able to directly support and coach over 1,000 people. This is the result of incredible hard work and dedication by our team of support specialists and our volunteers who have been busy with outreach work in their communities. This represents

an increase in caseload of 35% year on year (up from 799 to 1,079). Despite this increase in caseload and demand for our coaching, provision of our wider services remains unfaltering, with event attendances up 22% (up from 395 to 483) and resources in more demand than ever before. 431 brain boxes were issued to people who needed them in 2017/18, and 824 were sent to people with a brain tumour last year. This is a 91% increase in demand and supply. Our team and our community has rallied to meet this need with *brainstrust's* first dedicated fundraising appeal, raising enough money to keep up with demand.

Our twin focus for the year ahead is firstly to embed our new strategy, which has grown from the period of our last five-year plan and 13 years of hard work with our incredible and inspiring community of brain tumour patients and caregivers, and secondly to manage costs and timing of income and expenditure meticulously so that we rebuild reserves for a further five years of stellar impact and growth.

Thank you, everybody, for your continued support for our work and the people who so desperately need us.

**Will Jones**

**Chris Baker**

Chief Executive Chair of Trustees



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



*'I felt so lost and confused after my diagnosis, and I was scared, as were my family. I was searching on the internet to try and find some answers and some help, as I did not understand what it was that I had. Then I came across brainstrust.*

*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.'*

**Patient**, London



## ***brainstrust's* vision**

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

## **To make this happen, we aim to**

help people overcome fear

empower people to engage with their challenges and care

eliminate isolation

improve knowledge and understanding

## **through our work in the following areas**

coaching and support

building communities

information and education

regional insight and relevance

clinical engagement, development and network building

engaging people with research

## **which is only possible with**

effective fundraising

efficient marketing and promotion

administrative support

good governance

Work continues apace to move towards attaining our vision, which was established at the beginning of our current five-year cycle in 2014. 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 that will transform life for people with a brain tumour.

# Our work

To realise 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.

This relationship is 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 first 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 caring. 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.

Qualitative studies<sup>1,2,3</sup> 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 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 18 Jul. 2019].

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, and 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.





## 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.

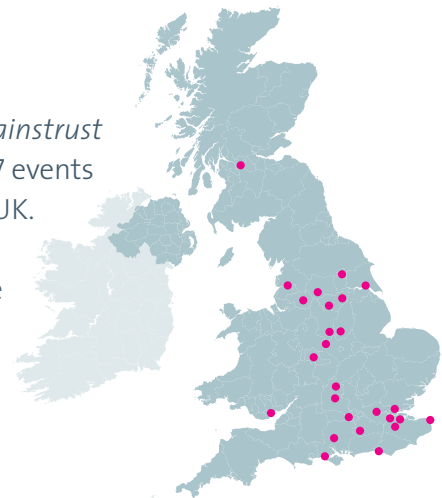
*brainstrust* runs Meetups and workshops nationwide so people with a brain tumour can connect, learn and feel less alone, less afraid and better supported.

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 2,400 people now part of this vital hub for the brain tumour community.



### Building communities in 2018/19

During the year in review, *brainstrust* support specialists hosted 47 events for communities across the UK. These events were attended by 483 people, with coverage as follows:



*'I feel like I am part of a community, and I feel comfortable and confident whenever I need to ask for help. I stopped feeling lonely and scared, as I now know there is always someone there who will help. Having brainstrust has helped me to deal with my diagnosis, and they helped me to cope, and I will be forever grateful.'*

**Patient**, Midlands, March 2019

*'Thank you for arranging another great 'Meetup' – it is, as always, very much appreciated. It was lovely to meet up with you all; always good to talk, laugh and cry, knowing we are special friends together! Thanks for being there.'*

**Patient**, London, March 2019

### 3 Information and education

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

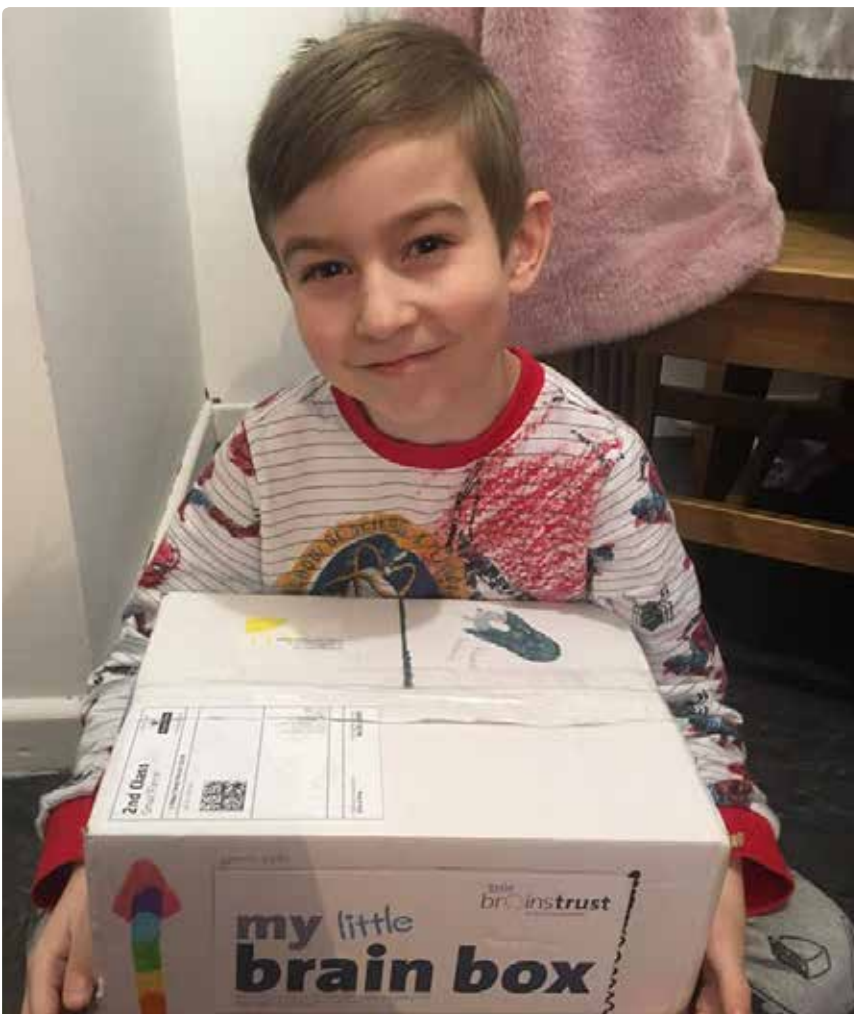
To help people become more confident and engaged, we run events across the UK that cover important topics for the brain tumour community. The events attract leading experts in their fields who cover a diverse but relevant portfolio of topics. In 2018/19, examples

of informative and educational events orchestrated by *brainstrust* include:

- the UK Brain Tumour Symposium, Glasgow
- the UK Paediatric Brain Tumour Symposium, Nottingham
- the brain tumour patient journey workshop, Cliveden
- cannabinoids workshop, London
- nutrition and brain tumours workshop, London
- managing fatigue workshop, London, Glasgow, Birmingham and Preston.
- communicating well workshop, London and Glasgow

Where possible, these events are run 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.

We also have a programme of information production, where content on key topics is researched, written, published

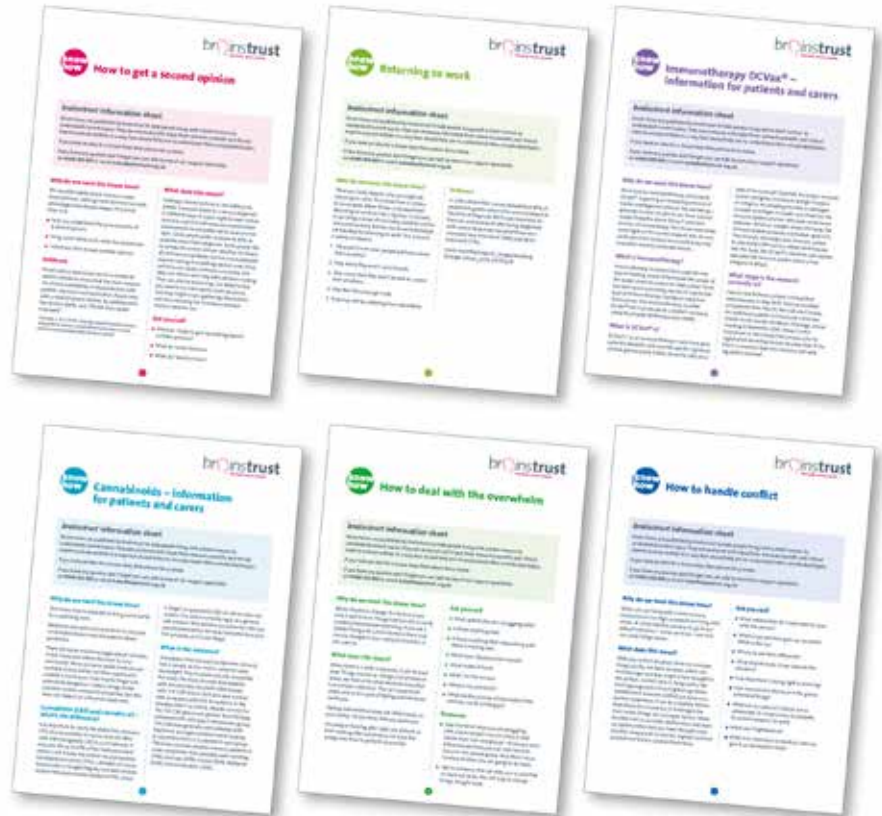






and disseminated to the people who need it. All information is produced in accordance with NHS England's rigorous Information Standard scheme, which ensures accuracy, currency, trustworthiness, clarity and accessibility. Topics on which *brainstrust* produced new information in 2018/19 include:

- seeking a second opinion
- returning to work
- dealing with overwhelm
- immunotherapy
- handling conflict
- cannabis-based brain tumour treatments
- registry-held brain tumour data
- proton beam therapy
- the NICE improving outcomes guidance for people without a clinical background



## 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.

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 (Litchfield) 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.

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](http://www.braintumourhub.org.uk)).





# 5 Clinical engagement, development and network building, *and*

# 6 Engaging people with research

Work in these two areas overlaps significantly, particularly in light of the new and integrated approach adopted by the Tessa Jowell Brain Cancer Mission (TJBCM) and the increasingly ‘joined-up’ clinical and research communities.



With the recent pledges of significant investment in neuro-oncology and the establishment of the TJBCM, our hard work at building clinical engagement over previous years has proved to be worthwhile. *brainstrust* is now the ‘go-to’ organisation for patient and public voice in this space, demonstrated by our representation for the

brain tumour community in national bodies, which include the National Cancer Research Institute, Cancer Research UK, the National Institute of Health Research, the National Institute for Health and Care Excellence, Cochrane, Public Health England and the National Health Service. We are at the forefront of this patient and public involvement (PPI) landscape.

The TJBCM addresses these challenges:

- Brain tumours are complex, rare and intrinsically resistant diseases.
- The brain is a delicate and privileged site.
- We have a small and unsophisticated research community with a lack of transformative discoveries.
- The research community is underperforming.
- Trials are poorly designed, limited in access and lack innovation.
- Organisation of treatment is outdated, and we have an excess of emergency presentations.
- It’s an unlikely career choice.

- Subspecialty training is outdated and limited.
- Bio-banking is not a substitute for research.

The four work streams – basic science, clinical trial design, workforce and patient experience – are well established, with *brainstrust*’s presence in three of them. We know that there is nothing as important as ensuring that everyone’s voice is heard, and our position in the brain cancer community enables us to bring the patient, caregiver and clinical communities together on an equal footing. The cultural shift we want to see from our collaborations is one where our communities are regarded and recognised as a conduit for people to solve collectively and collaboratively the issues that need addressing. Whether it is identifying uncertainties and issues that are significant to all, raising awareness of questions, influencing trajectory, sharing and developing collective intelligence, consulting, collecting, collating, reaching and advocating, there is much that we do that helps to give balanced inclusion of the

patient, caregiver and clinical interests and perspectives, enabling us all to think more widely. We know only too well how important being informed is to achieve the best outcomes – for all concerned when a person is diagnosed with brain cancer.

Our role in the core group for the James Lind Alliance Priority Setting Partnership has led to the identification of the top ten uncertainties for neuro-oncological clinical research. This work now shapes the clinical research agenda for brain cancer, and this is what drives our incubator days. We lead incubator days around these uncertainties; this year we have held meetings on early diagnosis, patient-reported outcome measures, recurrence, and cerebellar mutism in children. These events involve engaging collaboratively with clinical researchers, patients, caregivers and funders to ensure that we can build communities around the themes and strengthen the quality of research submissions. We regularly present at conferences and submit posters about the human condition when living with cancer and also about PPI themes as a representative for NCRI.

These links develop an enduring relationship with the clinical cancer community. Research in quality of life and supportive care is gathering momentum; this year has seen trials being developed in fatigue, shared decision-making, reirradiation,

scanning intervals in low-grade gliomas and assessing quality of life in the elderly, to name a few. Our collaborative work in inclusive, symptom-based trials will allow the majority of patients to have an opportunity to be involved in clinical trials that will improve quality of care in the future. Research shows that patients have better outcomes in research-active centres and that patients who are involved in research know more about their condition. Patients and caregivers have unique experience and expertise that they can bring to the healthcare agenda; we know that active partnership between the public and clinical community ensures that research is relevant and asks the right questions. Such an approach means that collective intelligence will be high, as everyone contributes, bringing different perspectives, different sources of validity, such as non-academic experience, experiential expertise and contexts. This work cannot be done in isolation (of other centres, of other countries and of each other). It is only through looking at the wider picture and making connections that advances will happen.

Clinical engagement on the ground happens in many ways and in different contexts, and pervades our work. It could be putting the kettle on and having a cup of tea with a clinical nurse specialist while we describe our approach to support, or in a more formal setting with a presentation

to an audience of consultant neurosurgeons. The goal is always to have as many neuroscience centres as possible understand who we are, what we do and why we do it, so that our information is placed into the hands of those who need it.

So, what has gained ground during the year under review?

- In 2018/19 we have held incubator days on six priority questions – *lifestyle factors, earlier diagnosis, earlier referral to palliative care services, interventions to help caregivers cope, fatigue management, and extent of resection on survival.*
- Incubator days have also been held on seizure prophylaxis in glioma and cerebellar cognitive affective syndrome.
- Cochrane Priority Reviews are underway for reviews in *lifestyle factors, second GBM recurrence, interventions to help caregivers cope, fatigue management, and extent of resection on survival.*
- Cochrane Complex Reviews are planned following a successful NIHR Cochrane Systematic Review Programme Grant in *interval scanning, earlier diagnosis, earlier referral to palliative care services, molecular subtyping, long-term effects of surgery and/or radiotherapy.*
- 50% of hospitals that were not aware of us now are, and are sharing our information with the people who need us.



# Our approach



'We are both personal and positive, with a focus on truth and honesty. We have direct experience of living with a brain tumour and cancer, which is why we set up *brainstrust* in 2006. We did not want others to feel as lost and afraid as we did. With everybody's situation a different situation, with different priorities and pressures, it is not within our gift to tell people what to do, more to help people accept where they are and who they are, and to do what is right for them in their new normal with brain cancer.'

This approach builds resilience, confidence and engagement. It means people are able to live the life they want with a brain tumour, and they are living life as a person first, patient second.'

**Helen Bulbeck**

Director of Policy and Services, *brainstrust*

# Our values

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

## We are ...

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

## So our community feels ...

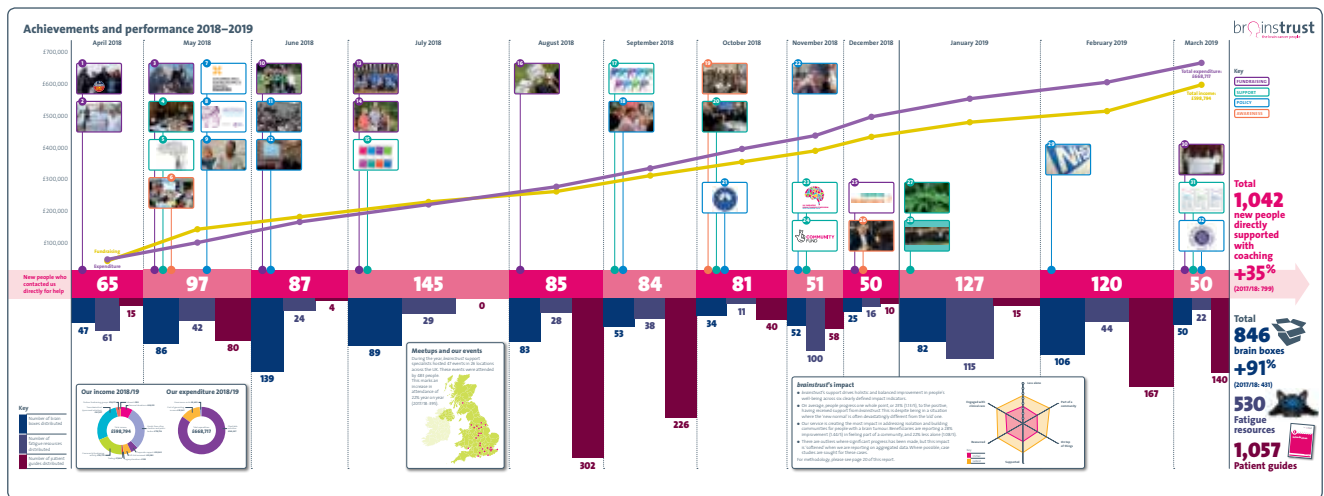
- engaged
- acknowledged
- at ease
- expert – on me
- in control
- able to question
- resourced
- confident
- not alone

*'Working for brainstrust is incredibly fulfilling, because I get to be part of an amazing community of people who continually inspire me. Every day, I hear from individuals who want to give back to the charity despite everything they are going through or have been through, because they know first-hand just how important it is to be able to ask for help and know that brainstrust will be there to support them.'*

**Anna**, Challenge Events Coordinator



# Achievements and performance



The scale, diversity and complexity of our work is such that it is best visualised. For an overview of *braintrust's* achievements and performance during the year in review, please see the throw-out at the end of this report.

# Our impact

In our last report, we laid out our case and hopes for robust, auditable and trustworthy impact reporting. 12 months on, and the *brainstrust* progress tracker is becoming ingrained in our day-to-day work.

We report on people's progress against six indicators, all of which support the four priorities in our strategy. These six indicators are:

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





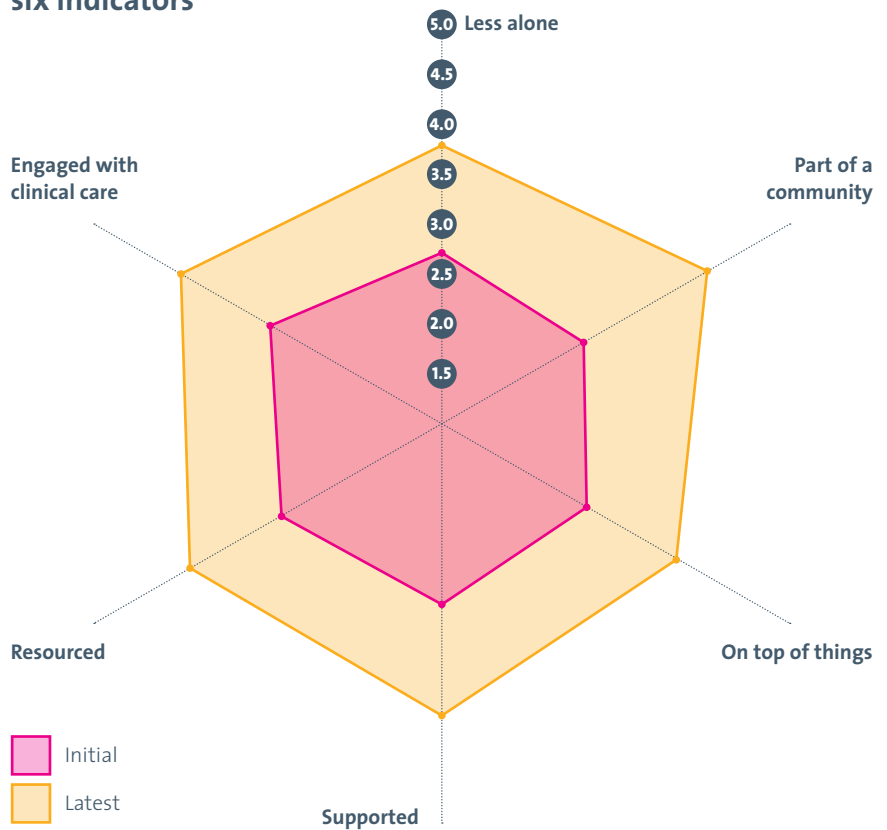


Everybody who engages *brainstrust* for help, advice and support is asked to complete a progress tracker at least twice. People complete a progress tracker once at the start of their journey with *brainstrust*, and again either at a fixed point in time (typically three months), or after a one-off interaction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

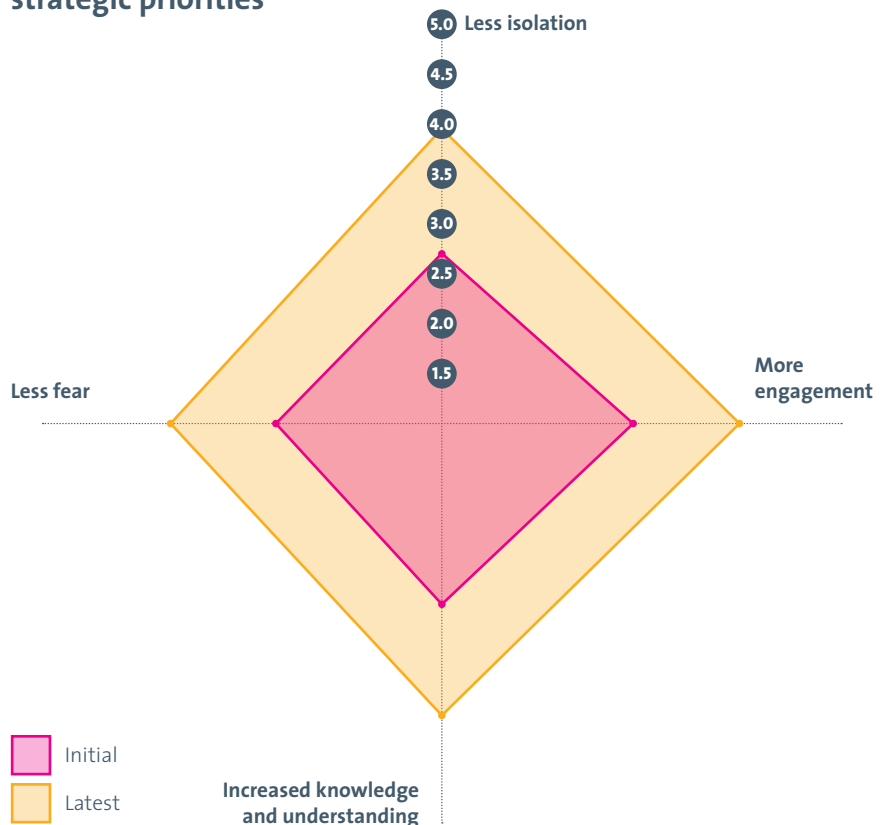
*brainstrust*'s support specialists in their one-on-one coaching work then use the data with the respondent; the reports are used to identify and work on specific, defined needs. The data is also aggregated to give us an indication of overall impact of service. It is this information that we are able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

## brainstrust's impact 2018/19

### Progress against *brainstrust*'s six indicators



### Resultant progress against *brainstrust* strategic priorities



Of the 1,079 patients engaged in this work, 39 completed two or more progress trackers, on which this work is based.

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 brain tumour diagnosis.

## Headlines

- *brainstrust*'s support drives holistic and balanced improvement in people's well-being across six clearly defined impact indicators.

- On average, people progress one whole point, or 23% (1.13/5), to the positive, having received support from *brainstrust*. This is despite being in a situation where the 'new normal' is often devastatingly different from the 'old' one.
- Our service is creating the most impact in addressing isolation and building communities for people with a brain tumour. Beneficiaries are reporting a 28% (1.44/5) improvement in feeling part of a community, and a 22% (1.08/5) improvement in feeling less alone.
- 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.

## Headwinds and mitigating activity

- Engagement is still low. We are working hard on processes and practices to increase beneficiary engagement. Of course, for many people, the brain tumour journey is a long one, and as such, we expect to see an uplift in second trackers completed in the coming months.
- It is hard to drive positive progress in the face of such a devastating and debilitating disease that often results in death or severe physical and mental impairment. The 'new normal' in which people find themselves is never better than the 'old normal'. For now we must accept this and acknowledge that our role is to continue to do all that we can to help people manage this shift. Acceptance and commitment in coaching are a key part of this, and already a cornerstone of our work.
- The human condition. The disease is messy and chaotic, and structure is often lost. Participating in and completing evaluation in a structured way is hard in this context. Under the premise that support must come first, we will strive to do evaluation where and when we can and as robustly as we can, but we must acknowledge that sometimes this may feel less than scientific. The data that we do capture, however, will be reported on with clarity and transparency.







*'I feel like I am part of a community, and I 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 there who will help. Having brainstrust has helped me to deal with my diagnosis, and they helped me to cope, and I will be forever grateful.'*

**Brain tumour patient**  
Midlands, April 2019

# Financial review

The Trust's published statutory accounts for 2018/2019 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 2019, 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 2018/19 was £598,794 (2017/18, £552,614). The net deficit for the year was £69,923 (2017/18, surplus of £89,006).

The Trust's income is derived from the usual charity mix – grants, normally 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. 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 families, from the point of a brain

cancer diagnosis. Our support team has an emphasis on good geographical coverage, supported by the Big Lottery Fund and others.

While it is rare for any organisation to plan for a deficit, in *brainstrust's* case a significant cash injection was received a couple of years ago, due to the hard work, fundraising skills and dedication of one family, and these funds have been applied in the year under review to strengthen the power of our support for the brain cancer community.

The Trust has only cash investments, deposited with NatWest Bank and The Co-operative Bank. At 31 March 2019, the Trust had cash reserves, including our restricted income funds, of £202,490 (2018, £272,413), which included net unrestricted reserves of £108,635 (2018,

£173,638) and net restricted reserves of £93,855 (2018, £98,775). The deficit for the year under review has therefore been comfortably absorbed within our reserves.

The Trust has a target of holding unrestricted reserves to cover four months of defined core costs. At 31 March 2019, unrestricted reserves were sufficient to cover 2.5 months of core costs, so an early plan is to restore the target coverage.

2019/20 and beyond will see continuing financial challenges for the charity sector, with much uncertainty in the political and economic spectra. Our management plan, defining our direction for the next five years, is in place, and our strategies will see us striving 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

*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.

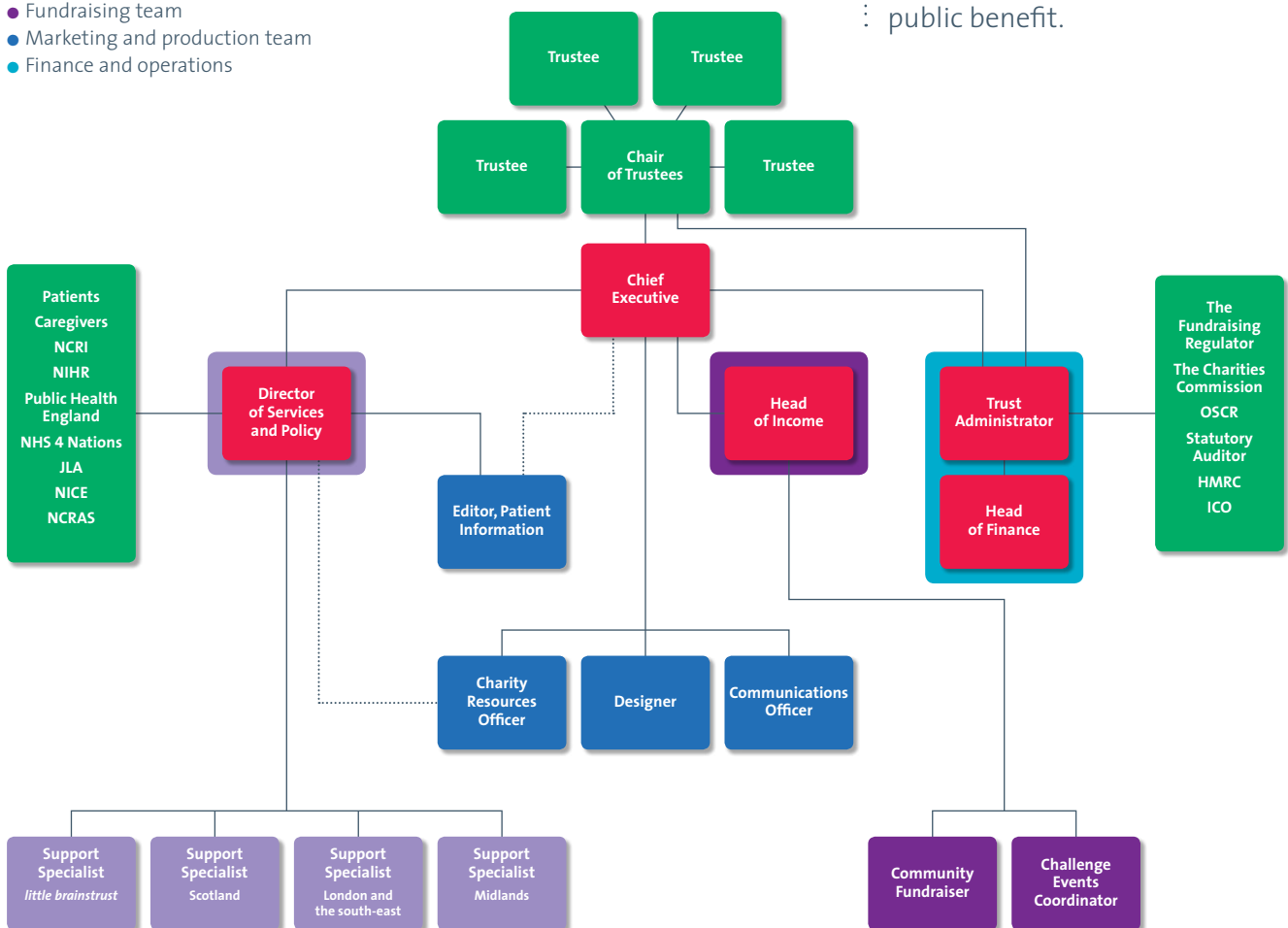
This places overall responsibility for the proper governance of the Trust with the appointed trustees. Day-to-day management of the Trust is delegated to William Jones, who has been appointed chief executive of the Trust. The

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.

## 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





## Senior staff contacts

**William Jones,**  
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[tom@brainstrust.org.uk](mailto:tom@brainstrust.org.uk)



## Trustees

*brainstrust's* trustees for the year in review are Chris 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 Trust Deed dated 4 March 2006:

- (i) There must be at least three trustees. Apart from the first trustee, 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 13th 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.

*'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



**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 chair of trustees at *brainstrust* for over three years.

**Kevin Higgs**  
Trustee

Kevin is a financial adviser and has been a trustee for nearly 10 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. Kevin knew immediately 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. 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. 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 TimeInc, 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 that we have received from the following organisations:

- **The National Lottery Community Fund** – support for expansion of our coaching service in line with our regional model, and also resources to help patients tackle fatigue.
- **Children with Cancer UK** – support for *little brainstrust*, our dedicated service for children and families, and the first ever UK Paediatric Brain Tumour Symposium, held in Nottingham, December 2018.
- **The Rank Foundation** – building capacity in our fundraising team with a supported internship as part of their ‘Time to Shine’ programme.
- **The Souter Charitable Trust** – a generous contribution to the running costs of our rapid-access professional counselling service.
- **The Wyseliot Rose Charitable Trust** – support for the brain box appeal so that we could meet increased demand for this vital resource.

## Collaborations to improve support

- 35 neurosurgical centres plus satellite hospitals
- 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 Cancer 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
- NCRI Brain and Central Nervous System CSG
- NCRI Neuro-Oncology Palliative Care Subgroup





- NCRI 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
- 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
- Cancer 52
- 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 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 for late effects
- Teenage and young adult therapy radiographer



# Reference and administrative details

## Helping you

Talk to our team 24/7 on 01983 292 405, or email [hello@brainstrust.org.uk](mailto:hello@brainstrust.org.uk).

## Helping us

Make a donation at [www.brainstrust.org.uk/donate](http://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

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

[www.brainstrust.org.uk](http://www.brainstrust.org.uk)  
[www.braintumourhub.org.uk](http://www.braintumourhub.org.uk)

## 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: **31 July 2019**

Signature:

Full name: **Kevin Higgs**  
Position: **Trustee**  
Date: **31 July 2019**



'walking is such therapy and has helped me through a lot of dark days, just putting one foot in front of another and not having to think about things you don't want to think about. The feeling of achievement for yourself and everyone you walk with is incredible, sharing an experience that only those on that weekend can ever have. It reaffirms what you are doing this for and knowing that you are not alone with whatever you have gone or are going through, gives you so much strength and hope.'

**Andrew Chalmers, *brainstrust* supporter  
and Follow the Seagulls finisher**  
Fife, 2019



# **Report of the Trustees and Audited Financial Statements for the year ended 31 March 2019 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 2019**

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## ***brainstrust* – Report of the trustees for the year ended 31 March 2019**

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The trustees present their report with the financial statements of the charity for the year ended 31 March 2019. 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 2015).

### **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).

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 **31 July 2019** 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 2019 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 2019 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.

### Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees’ use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charity’s ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

### 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.

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

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

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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 Act 2011 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 Responsibility 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**

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.

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](http://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 of the Independent Auditors to the trustees of *brainstrust*

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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: **31 July 2019**

### **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 2019

	Notes	Unrestricted fund	Restricted funds £	2019 Total funds £	2018 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies	2	212,472	77,251	289,723	319,126
Other trading activities	3	289,015	19,873	308,888	233,421
Investment income	4	183	–	183	67
<b>Total</b>		<b>501,670</b>	<b>97,124</b>	<b>598,794</b>	552,614
<b>EXPENDITURE ON</b>					
Raising funds	5	87,926	3,135	91,061	67,439
<b>Charitable activities</b>	6				
Charity activities		478,747	98,909	577,656	396,169
<b>Total</b>		<b>566,673</b>	<b>102,044</b>	<b>668,717</b>	463,608
<b>NET INCOME/(EXPENDITURE)</b>		<b>(65,003)</b>	<b>(4,920)</b>	<b>(69,923)</b>	89,006
<b>RECONCILIATION OF FUNDS</b>					
<b>Total funds brought forward</b>		<b>173,638</b>	<b>98,775</b>	<b>272,413</b>	183,407
<b>TOTAL FUNDS CARRIED FORWARD</b>		<b>108,635</b>	<b>93,855</b>	<b>202,490</b>	272,413

The notes form part of these financial statements

## brainstrust – Balance sheet at 31 March 2019

	Notes	Unrestricted fund £	Restricted funds £	2019 Total funds £	2018 Total funds £
<b>FIXED ASSETS</b>					
Tangible assets	11	6,088	–	6,088	8,118
<b>CURRENT ASSETS</b>					
Debtors	12	42,281	–	42,281	28,996
Cash at bank		114,825	93,855	208,680	310,256
		<b>157,106</b>	<b>93,855</b>	<b>250,961</b>	339,252
<b>CREDITORS</b>					
Amounts falling due within one year	13	(54,559)	–	(54,559)	(74,957)
<b>NET CURRENT ASSETS</b>		<b>102,547</b>	<b>93,855</b>	<b>196,402</b>	264,295
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<b>108,635</b>	<b>93,855</b>	<b>202,490</b>	272,413
<b>NET ASSETS</b>		<b>108,635</b>	<b>93,855</b>	<b>202,490</b>	272,413
<b>FUNDS</b>					
Unrestricted funds	15			108,635	173,638
Restricted funds				93,855	98,775
<b>TOTAL FUNDS</b>				<b>202,490</b>	272,413

The financial statements were approved by the Board of Trustees on **31 July 2019** 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 2019**

	Notes	2019 £	2018 £
<b>Cash flows from operating activities:</b>			
Cash generated from operations	1	<b>(101,759)</b>	(163,884)
<b>Net cash provided by (used in) operating activities</b>		<b>(101,759)</b>	(163,884)
<b>Cash flows from investing activities:</b>			
Purchase of tangible fixed assets		–	(8,118)
Sale of tangible fixed assets		–	1
Interest received		<b>183</b>	67
<b>Net cash provided by (used in) investing activities</b>		<b>183</b>	(8,050)
<b>Change in cash and cash equivalents in the reporting period</b>		<b>(101,576)</b>	(171,934)
<b>Cash and cash equivalents at the beginning of the reporting period</b>		<b>310,256</b>	482,190
<b>Cash and cash equivalents at the end of the reporting period</b>		<b>208,680</b>	310,256

The notes form part of these financial statements

## **brainstrust – Notes to the cash flow statement for the year ended 31 March 2019**

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### **1. Reconciliation of net income/(expenditure) to net cash flow from operating activities**

	<b>2019</b>	2018
	<b>£</b>	£
<b>Net income/(expenditure) for the reporting period (as per the statement of financial activities)</b>	<b>(69,923)</b>	89,006
<b>Adjustments for:</b>		
Depreciation charges	<b>2,030</b>	–
Interest received	<b>(183)</b>	(67)
Increase in debtors	<b>(13,285)</b>	(13,262)
Decrease in creditors	<b>(20,398)</b>	(239,561)
<b>Net cash provided by (used in) operating activities</b>	<b>(101,759)</b>	(163,884)

# **brainstrust – Notes to the financial statements for the year ended 31 March 2019**

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## **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 2015)', 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



## **brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019**

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### **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**

	<b>2019</b>	2018
	<b>£</b>	£
Donations	<b>48,322</b>	60,290
Grants from awarding entities	<b>178,756</b>	186,485
Corporate grants and donations	<b>30,062</b>	13,813
Gift Aid tax recovered	<b>32,083</b>	33,220
Legacies	<b>500</b>	25,318
	<b>289,723</b>	319,126

### **3. Other trading activities**

	<b>2019</b>	2018
	<b>£</b>	£
Fundraising events	<b>105,447</b>	87,884
Sale of 'brainstrust' items	<b>7,984</b>	9,293
Sponsored activities	<b>167,257</b>	115,121
Schools and colleges	<b>8,327</b>	1,828
Activities of partner groups	<b>19,873</b>	19,295
	<b>308,888</b>	233,421

### **4. Investment income**

	<b>2019</b>	2018
	<b>£</b>	£
Deposit account interest	<b>183</b>	67

**brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019**

**5. Raising funds**

**Raising donations and legacies**

	2019 £	2018 £
Fundraising fees	9,853	12,603
Promotional expenses	21,884	19,577
	<b>31,737</b>	<b>32,180</b>

**Other trading activities**

	2019 £	2018 £
Trading costs and purchases	5,684	4,927
Event costs	20,010	10,709
Sponsored activities costs	33,630	19,623
	<b>59,324</b>	<b>35,259</b>
Aggregate amounts	<b>91,061</b>	<b>67,439</b>

**6. Charitable activities costs**

	Direct costs £	Support costs (See note 7) £	Totals £
Charity activities	569,007	8,649	577,656

**7. Support costs**

	Governance costs £
Charity activities	<b>8,649</b>

## brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019

### 8. Trustees' remuneration and benefits

There were no trustees' remuneration or other benefits for the year ended 31 March 2019 nor for the year ended 31 March 2018.

#### Trustees' expenses

There were no trustees' expenses paid for the year ended 31 March 2019 nor for the year ended 31 March 2018.

### 9. Staff costs

Total gross salaries, benefits in kind and employers national insurance costs for the year ending 31st March 2019 were £400,687 (2018 – £423,586).

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

	2019	2018
Fundraising	3	3
Charitable Activities	9	8
Governance	1	1
Other	1	1
	14	13

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

### 10. Comparatives for the statement of financial activities

	Unrestricted fund £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	229,141	89,985	319,126
Other trading activities	214,126	19,295	233,421
Investment income	67	–	67
<b>Total</b>	<b>443,334</b>	<b>109,280</b>	552,614
<b>EXPENDITURE ON</b>			
Raising funds	65,080	2,359	67,439
<b>Charitable activities</b>			
Charity activities	325,576	70,593	396,169
<b>Total</b>	<b>390,656</b>	<b>72,952</b>	463,608
<b>NET INCOME/(EXPENDITURE)</b>	<b>52,678</b>	<b>36,328</b>	89,006

**brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019**

**10. Comparatives for the statement of financial activities – continued**

	Unrestricted fund £	Restricted funds £	Total funds £
<b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	120,960	62,447	183,407
<b>TOTAL FUNDS CARRIED FORWARD</b>	<b>173,638</b>	<b>98,775</b>	<b>272,413</b>

**11. Tangible fixed assets**

	Fixtures and fittings £	Website £	Totals £
<b>COST</b>			
At 1 April 2018 and 31 March 2019	1,494	8,118	9,612
<b>DEPRECIATION</b>			
At 1 April 2018	1,494	–	1,494
Charge for year	–	2,030	2,030
At 31 March 2019	1,494	2,030	3,524
<b>NET BOOK VALUE</b>			
At 31 March 2019	–	6,088	6,088
At 31 March 2018	–	8,118	8,118

**12. Debtors: amounts falling due within one year**

	2019 £	2018 £
Trade debtors	19,978	1,040
Other debtors	22,303	27,956
	<b>42,281</b>	<b>28,996</b>



## brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019

### 13. Creditors: amounts falling due within one year

	2019 £	2018 £
Trade creditors	7,668	30,301
Other creditors	46,891	44,656
	<b>54,559</b>	<b>74,957</b>

Included in Other Creditors is a provision for charitable patient support. An active programme is in place for the treatment and the provision has been measured reliably in consultation with biotechnologists to give an accurate figure of the future costs. The provision at the year end is £41,791 (2018 – £42,156).

### 14. Leasing agreements

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

	2019 £	2018 £
Within one year	24,078	15,090
Between one and five years	61,954	4,844
	<b>86,032</b>	<b>19,934</b>

### 15. Movement in funds

	At 1.4.18 £	Net movement in funds £	At 31.3.19 £
<b>Unrestricted funds</b>			
General fund	173,638	(65,003)	108,635
<b>Restricted funds</b>			
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
	<b>98,775</b>	<b>(4,920)</b>	<b>93,855</b>
<b>TOTAL FUNDS</b>	<b>272,413</b>	<b>(69,923)</b>	<b>202,490</b>

**brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019**

**15. Movement in funds – continued**

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

	Incoming Resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	501,670	(566,673)	(65,003)
<b>Restricted funds</b>			
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
	<b>97,124</b>	<b>(102,044)</b>	<b>(4,920)</b>
<b>TOTAL FUNDS</b>	<b>598,794</b>	<b>(668,717)</b>	<b>(69,923)</b>

**Comparatives for movement in funds**

	At 1.4.17 £	Net movement in funds £	At 31.3.18 £
<b>Unrestricted Funds</b>			
General fund	120,960	52,678	173,638
<b>Restricted Funds</b>			
Big Lottery Fund Grant	(1,004)	24,464	23,460
Fund A	16,868	(2,782)	14,086
Fund B	4,575	–	4,575
Fund C	720	–	720
Fund D	4	–	4
Fund E	41,239	14,598	55,837
Fund F	44	48	92
Fund G	1	–	1
	<b>62,447</b>	<b>36,328</b>	<b>98,775</b>
<b>TOTAL FUNDS</b>	<b>183,407</b>	<b>89,006</b>	<b>272,413</b>

**brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019**

**15. Movement in funds – continued**

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

	Incoming resources £	Resources expended £	Movement in funds £
<b>Unrestricted funds</b>			
General fund	443,334	(390,656)	52,678
<b>Restricted funds</b>			
Big Lottery Fund Grant	89,985	(65,521)	24,464
Fund A	1,070	(3,852)	(2,782)
Fund E	18,177	(3,579)	14,598
Fund F	48	–	48
	<u>109,280</u>	<u>(72,952)</u>	<u>36,328</u>
<b>TOTAL FUNDS</b>	<u>552,614</u>	<u>(463,608)</u>	<u>89,006</u>

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

	At 1.4.17 £	Net movement in funds £	At 31.3.19 £
<b>Unrestricted funds</b>			
General fund	120,960	(12,325)	108,635
<b>Restricted funds</b>			
Big Lottery Fund Grant	(1,004)	2,287	1,283
Fund A	16,868	(555)	16,313
Fund B	4,575	–	4,575
Fund C	720	1	721
Fund D	4	–	4
Fund E	41,239	29,579	70,818
Fund F	44	96	140
Fund G	1	–	1
	<u>62,447</u>	<u>31,408</u>	<u>93,855</u>
<b>TOTAL FUNDS</b>	<u>183,407</u>	<u>19,083</u>	<u>202,490</u>



## **brainstrust – Notes to the financial statements – continued for the year ended 31 March 2019**

### **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 £
<b>Unrestricted funds</b>			
General fund	945,004	(957,329)	(12,325)
<b>Restricted funds</b>			
Big Lottery Fund Grant	167,236	(164,949)	2,287
Fund A	3,297	(3,852)	(555)
Fund C	1	–	1
Fund E	35,774	(6,195)	29,579
Fund F	96	–	96
	<b>206,404</b>	<b>(174,996)</b>	<b>31,408</b>
<b>TOTAL FUNDS</b>	<b>1,151,408</b>	<b>(1,132,325)</b>	<b>19,083</b>

### **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.

**16. Related party disclosures**

During the year the charity purchased services from Fitton Holman Creative Limited totalling £10,530 (2018 – £14,040). 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, £5,760 (2018 – £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 £2,730 at a commercial rate.

**brainstrust – Detailed statement of financial activities for the year ended  
31 March 2019**

	2019 £	2018 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations	48,322	60,290
Grants from awarding entities	178,756	186,485
Corporate grants and donations	30,062	13,813
Gift Aid tax recovered	32,083	33,220
Legacies	500	25,318
	<b>289,723</b>	319,126
<b>Other trading activities</b>		
Fundraising events	105,447	87,884
Sale of 'brainstrust' items	7,984	9,293
Sponsored activities	167,257	115,121
Schools and colleges	8,327	1,828
Activities of partner groups	19,873	19,295
	<b>308,888</b>	233,421
<b>Investment income</b>		
Deposit account interest	183	67
<b>Total incoming resources</b>	<b>598,794</b>	552,614
<b>EXPENDITURE</b>		
<b>Raising donations and legacies</b>		
Fundraising fees	9,853	12,603
Promotional expenses	21,884	19,577
	<b>31,737</b>	32,180
<b>Other trading activities</b>		
Trading costs and purchases	5,684	4,927
Event costs	20,010	10,709
Sponsored activities costs	33,630	19,623
	<b>59,324</b>	35,259

This page does not form part of the statutory financial statements

**brainstrust – Detailed statement of financial activities for the year ended  
31 March 2019**

	2019 £	2018 £
<b>Charitable activities</b>		
Medical grants and costs	1,770	25,270
Patient support and staffing	319,862	321,781
Salaries	136,174	151,757
Travel	41,902	36,063
Administration	43,931	36,980
Research grants and provisions	–	1,942
Office rent & rates	22,298	17,422
Provision for clinical trials written back	–	(203,191)
Bad debts	1,040	–
Depn of website	2,030	–
	<b>569,007</b>	<b>388,024</b>
<b>Support costs</b>		
<b>Governance costs</b>	<b>2,598</b>	<b>2,544</b>
Auditors' remuneration	1,829	900
Insurance	4,222	4,701
Other	8,649	8,145
	<b>668,717</b>	<b>463,608</b>
<b>Total resources expended</b>	<b>668,717</b>	<b>463,608</b>
<b>Net (expenditure)/income</b>	<b>(69,923)</b>	<b>89,006</b>

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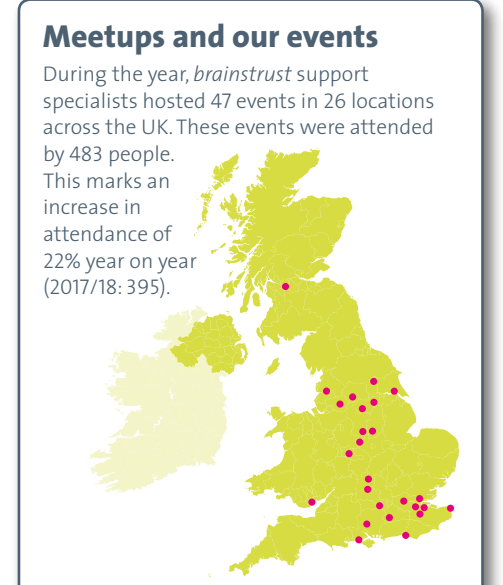
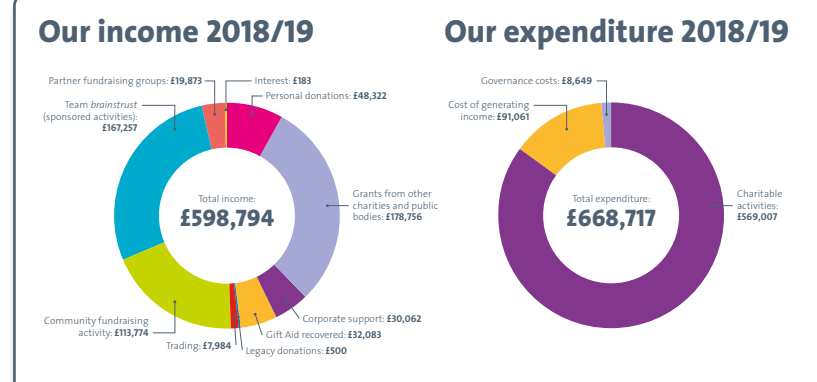
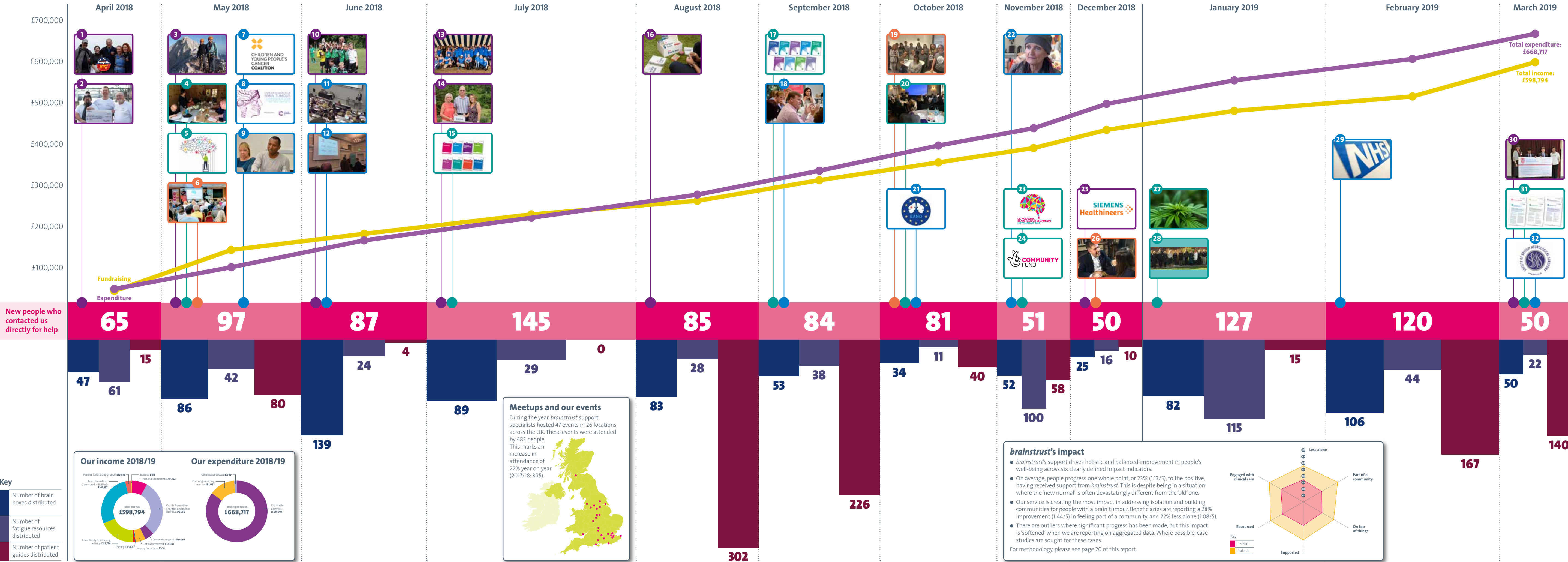




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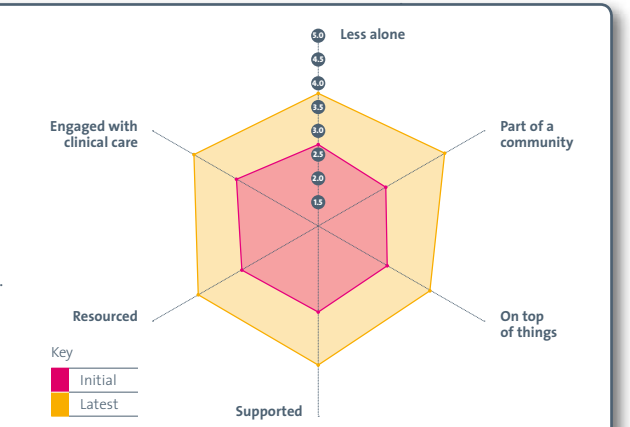
# Achievements and performance 2018–2019



### brainstrust's impact

- brainstrust's support drives holistic and balanced improvement in people's well-being across six clearly defined impact indicators.
- On average, people progress one whole point, or 23% (1.13/5), to the positive, having received support from brainstrust. This is despite being in a situation where the 'new normal' is often devastatingly different from the 'old' one.
- Our service is creating the most impact in addressing isolation and building communities for people with a brain tumour. Beneficiaries are reporting a 28% improvement (1.44/5) in feeling part of a community, and 22% less alone (1.08/5).
- 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.

For methodology, please see page 20 of this report.



# Achievements and performance 2018–2019

## April 2018

### FUNDRAISING

#### Follow the Seagulls – 50-mile treks for *brainstrust*'s work gain more traction

Another record year for Follow the Seagulls. 53 bold *brainstrust* hikers raised over £40,000, with each trekking 50 miles in one of three locations, including a new route in Fife, Scotland.

*'This trek continues to grow year on year and is a cornerstone of our activity, not least because the scale of the challenge matches the scale of passion that people feel for this cause and our work.'* – **Tom Cowie**, Head of Income at *brainstrust*

1

### FUNDRAISING

#### Graydon, Ian, Dan and Richard walk Hadrian's Wall

Graydon Downs, Ian Hardy, Dan Howard and Richard Stewart, all of whom have been diagnosed with a grade 4 brain tumour, tackled an 84-mile walk from Bowness-in-Solway to Wallsend, Newcastle. The group raised £2807.31 for *brainstrust*.

*'Walking 84 miles along Hadrian's Wall over the course of a week might not sound that hard core to serious athletes, but some days we struggle to walk 20 metres as a result of our condition. I hope we have done something for others, to inspire them to do something like this.'* – **Ian Hardy**

2

## May 2018

### FUNDRAISING

#### Hulya and Aiden take on new heights

Hulya Oztel was diagnosed with a brain tumour in 2016. She ordered a brain box and upon receipt said that she hoped to one day be able to fundraise so that she could fund brain boxes for others. Sure enough, in May Hulya and her son, Aiden, took on the challenge of climbing Mount Triglav, Slovenia's tallest mountain. They completed the climb and raised £1,500.

3

### SUPPORT

#### Michelle Charles runs a *brainstrust* workshop 'Managing Stress Through Art'

Our theme was creating a space of sanctuary through art – enabling you to create a space where you can escape the stresses of your life. This was a drawing and mixed-media workshop combined with meditation exercises, designed to encourage relaxation.

4

### SUPPORT

#### New dashboard helps you understand brain tumours in England and Wales

May 2018 sees the launch of the [Brain Tumour Data Dashboard](#). This new tool has been designed to help you navigate and understand brain tumour data.

5

### AWARENESS

#### First Scottish Symposium held in Glasgow

We held the first Brain Tumour Scottish Symposium, organised by us. We wanted to close the information gap for the brain tumour community and establish a collaborative network in Scotland of charities, healthcare professionals, patients and caregivers.

6

### POLICY

#### *brainstrust* joins the Children and Young People with Cancer Charity Coalition

A new coalition of national charities who work to help children with cancer has been formed. It was launched in May with a challenge to then Secretary of State for Health, Jeremy Hunt, to do more for children with cancer. Because of *brainstrust*'s experience and impact supporting families with a brain tumour, we are one of the founding charities of this coalition.

The childhood brain tumour community will be represented by our dedicated service for children and families, *little brainstrust*. Kate Lee, CEO at CLIC Sargent, chairs the coalition. Frank Fletcher, CEO of the Ellen MacArthur Trust, assumes the role of vice chair.

7

### POLICY

#### *brainstrust* attends the inaugural CRUK Brain Cancer three-day conference

This event convened world-leading experts from across a range of disciplines to discuss the latest advances in brain tumour research. This enables us to share the latest information with our community, e.g. a better understanding of the biology of the blood–brain barrier.

8

### POLICY

#### Optometry and early diagnosis

We facilitated an incubator day exploring the role of optometry in early diagnosis. 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.

9

## June 2018

### FUNDRAISING

10

#### Mini-football tournament raises £6,300

Low-grade brain tumour patient, *brainstrust* ambassador and volunteer fundraiser Sharon Springall organised an under 11s football tournament. A fantastic day for parents and children alike, which harnessed the support of Sharon's local village, where many of the residents had been affected by a brain tumour diagnosis in some way.

*'The help and support I got from my friends and family for the tournament completely overwhelmed me. I'm still speechless now as to how they all just threw themselves into the day. Even those that weren't actually helping on the day turned up to support me, as most of them don't have children of that age for the football! I spent most of the day fighting back the tears, as I couldn't believe the support I had from them. I am very lucky. The emotion of the day will stay with me for a very long time!'* – Sharon Springall

### POLICY

11

#### NCRAS Data and Outcomes Conference

Our work on the *brainstrust* dashboard was presented at the NCRAS conference in Manchester.

### POLICY

12

#### Advanced Cancer Coalition

We joined forces with Roche and a small group of charities to explore how improvements can be made to the care and quality of treatment for people living with advanced cancer.

## July 2018

### FUNDRAISING

13

#### Legacy Festival goes from strength to strength to fundraise for rapid-access counselling

From Friday 20 – Sunday 22 July, people flocked to Highbridge Farm, Eastleigh, for the third Legacy Festival, organised as part of Lloyd's Legacy. The festival raised a fantastic £3,337.03.

The annual festival is held in memory of Lloyd Green, who sadly passed away at the age of 34 following a battle with a brain tumour. Lloyd was just one month away from completing a counselling degree when he was diagnosed, and he was unable to complete his course. Following his passing, Lloyd's mum, Lyndsey, set up Lloyd's Legacy in support of *brainstrust*.

### FUNDRAISING

14

#### Incredible legacy for Gill Kennedy

Following an unexpected diagnosis and the sudden death of much-loved wife and mum Gill, her family rallied to raise funds so that others would not feel so lost and afraid following a brain tumour diagnosis. The family raised a staggering £13,000 to kick-start the brain box appeal, having benefitted from *brainstrust's* support on their journey.

### SUPPORT

15

#### New NICE guidance issued to doctors

For the first time since 2006, NICE have updated the clinical guidance for treatment and management of brain tumours. *brainstrust* was heavily involved in developing the updated guidelines, ensuring that patient experience was front and centre. Concurrently we updated and reissued the 'brain tumour patient guide', which explains the guidance for members of the public with a brain tumour, and helps them to know what care they should expect on their journey.

## August 2018

### FUNDRAISING

16

#### *brainstrust's* first appeal secures funding for 520 brain boxes

In 2017/18 380 brain boxes were sent to people around the UK. In 2018/19 we passed that mark in the first quarter of the year. The brain box appeal was launched so that we could meet increased demand for brain boxes, and thanks to the support from other charities, members of the public and businesses, we raised a further £21,000. We have also negotiated with suppliers and reviewed processes with the result that we can bring the cost of brain boxes down so we are able to meet this huge increase in demand.



## September 2018

### SUPPORT

17

#### **brainstrust commissioned to produce patient information for new proton beam therapy service**

Following our audit of media presentation of proton beam therapy (PBT), *brainstrust* was commissioned to produce accurate information for people considering or undergoing treatment, for journalists and for interested clinicians. This resource, comprising nine booklets and dedicated events launched in September 2018, concurrently with the new proton beam therapy centre in Manchester treating its first patient. Written alongside esteemed clinicians, scientists and expert patients and carers, and in accordance with NHS England's Information Standard, this resource addresses popular questions, dispels the myths about PBT that have developed and helps people make informed decisions about proton beam therapy with the most balanced and up-to-date information to hand.

You can access this resource at [www.brainstrust.org.uk/brain-tumour-support/resources/downloads/patient-guides](http://www.brainstrust.org.uk/brain-tumour-support/resources/downloads/patient-guides).

### POLICY

18

#### **First PROMS incubator day held**

Patient-reported outcomes measures are key if clinical research is to reflect what our community wants. So *brainstrust* was delighted to host this event. We need to ensure high-quality trial design, implementation, analysis and reporting to maximise impact and benefits for all stakeholders – especially patients.

## October 2018

### AWARENESS

19

#### **Wearing Grey raises awareness of the hidden impact of brain tumours**

On Monday 1 October, the UK wore grey to raise funds and awareness for brain tumours, and to tell the world about the 'invisible' challenges that a brain tumour brings, which include memory loss, fatigue and loss of identity.

This year, over 2,000 people took part in Wear Grey and made sure to engage peers on the matter at hand. The event raised in excess of £14,000 for our work.

### SUPPORT

20

#### **35 patients and caregivers attended our health and well-being event at Cliveden House**

*'My mother said an amazing thing, in that yesterday really helped her feel stronger about dealing with her condition after meeting you all. So thank you again, because what you do is give people that support which can have magical effects.'* – Carer

### POLICY

21

#### **brainstrust presents at the European Association of Neuro-Oncology**

We were invited to talk on two themes at this European conference. Managing patient and caregiver expectations was keynote, and we followed this by sharing our work on the *brainstrust* dashboard.

## November 2018

### POLICY

22

#### **Tessa Jowell Brain Cancer Mission inaugural meeting**

The first face-to-face meeting of all the parties involved with the TJBCM took place. We represent the brain cancer community in the patient experience, workforce regeneration and trial design workstreams.

### SUPPORT

23

#### **Paediatric Brain Tumour Symposium**

Our arm for children and families, *little brainstrust*, collaborated with other charities to bring together healthcare professionals and affected families to learn about progress being made in support and treatment of childhood brain tumours. The Paediatric Brain Tumour Symposium was an excellent day for families to get an insight into what is happening on the research and treatment front of childhood brain tumours. Healthcare professionals gained an insight into the whole journey of patients, from treatment to management of long-term side effects. The programme covered early diagnosis, challenges with drug delivery, advances in neurosurgery, managing behaviour and personality change, and support for families and caregivers.

### SUPPORT

24

#### **The National Lottery Community Fund approves another year's support for our communities in London and the Midlands**

Following a report that showed marked improvements for the brain tumour community against our six key impact markers in the two regions under review, the National Lottery Community Foundation pledged support for another year's funding for our work in London and the Midlands. People in these regions who engaged *brainstrust's* support reported feeling less isolated, more engaged, better resourced, better supported, more on top of things and part of a community.

## December 2018

### FUNDRAISING

25

#### Siemens Healthineers name *brainstrust* charity of the year

Following a presentation by one of their team, who had recently been diagnosed with a brain tumour, the team at Siemens Healthineers elected *brainstrust* as their charity for 2019. The partnership focuses on raising funds for our work, and also on improving understanding and awareness of brain tumour patient experience across the Healthineers team, whose work has a direct influence on brain tumour imaging.

### AWARENESS

26

#### Six incredible people share their stories on film to raise awareness of the challenges a brain tumour brings

After months of planning, Maria, Pablo, Stephen, Sammy and Sharon met at Wilton's Music Hall in London for a day of filming with renowned producer and director Tommy Chavannes. There was laughter and tears as the stories unfolded. These incredible people came together to share what they are going through, so that others can see that the challenge we face is wider than lack of research funding, and is often invisible.

## January 2019

### SUPPORT

27

#### Understanding Cannabinoids workshop a sell-out success

Cannabis-based treatments are attracting a lot of attention. This workshop was organised by *brainstrust's* support specialist for London and the south-east and provided the platform for leading researcher in the field Dr Wai Liu to present the latest work in the field. All 50 attendees, many of whom had travelled for the day, left feeling more informed and able to make informed decisions on whether to pursue this aspect of brain tumour treatment.

### SUPPORT

28

#### Second sell-out well-being day at Cliveden House

January saw the second Cliveden event, a sell-out with over 50 people attending. They even did the mindful walk in the beautiful, but so very cold, grounds of Cliveden.

## February 2019

### POLICY

29

#### *brainstrust* represents the community on the NHSE review of the patient pathway

Barriers to service access and variation on the patient pathway need to be identified if people living with a brain tumour are to have the best care. We are working with NHSE, looking at gaps in care and what the right care looks like so that barriers can be addressed.

## March 2019

### FUNDRAISING

30

#### Loughborough Grammar School raises £950 for *brainstrust*

After supporting Aiden and Hulya in their fundraising, the school picked *brainstrust* as their chosen charity for Year 8 fundraising. Each of six forms took turns to bake and sell the fruits of their labour to the rest of the school at break times. The 'bake-off' competition drove each form to raise as much money as possible. Perhaps most impressive is how the power of one mum's story, and the impact of *brainstrust's* support has galvanised a whole community, across multiple generations.

### SUPPORT

31

#### *brainstrust* 'Know Hows' published – bite-sized information to help you understand

We have been able to identify key issues where a little information can drive a significant improvement in understanding. March heralded the publication of the first six 'Know Hows': six easy-to-read leaflets that cover the role of a second opinion, returning to work, how to deal with overwhelm, immunotherapy, handling conflict, and cannabinoids.

### POLICY

32

#### New brain tumour subsection of SBNS

The much-needed brain tumour subsection was launched by *brainstrust* at the Society of British Neurosurgeons. This is a new community, formed to improve quality of neuro-oncology surgical service and outcomes for people living with a brain tumour.