

# The impact we are having for people with a brain tumour



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## What people need

Andrew is 42. He is recently divorced and has three teenage children. Their care is divided between his ex-wife and himself. He has been diagnosed with a glioblastoma, the most aggressive form of brain cancer. He has lost his driving licence and so has lost his job. He cannot afford to pay child maintenance, is living in rented accommodation and is geographically removed from his parents and brother and sister. He is angry, fearful and sad. He feels he should talk to someone, but he is a proud man and thinks he should be sorting out his problems for himself. He won't ask anyone for help, and his anxiety levels are high. He is losing sleep, his functioning is reduced, and he is becoming isolated. He only has ten minutes with his GP and is unable to articulate what his real concerns are. He believes it is not his GP's role to help him with his stress.

Andrew's challenges are overwhelming. There is the disease trajectory, symptom burden, mental incapacity that comes with the progressive brain cancer, emotion, lack of support, pressure of teleological time, and a focus on treatment. The challenge we face is, how can we make sure that what matters to Andrew is taken into account in the many consultations that he will be having over the remaining months of his life? What matters to Andrew takes us to the very heart of person-centred care, and if we begin to measure what matters to him, we can begin to construct care that places him at the centre.

“ It would be good to see a more holistic approach. After my treatment for a brain tumour had finished, I was left to my own devices. It would be helpful to have a road map for the patient for how to get back to as much normality – if there is such a thing – as possible. Many things required are of a fairly practical nature: moving from independent to assisted living, travel support, dietary support, exercise planning and tracking, hairdressing. ”

**Brain tumour patient**

2019

## The evidence we have

Brain cancer is different from other cancers: not only do patients and their caregivers have to come to terms with the diagnosis of brain cancer, but they do so in the knowledge that this diagnosis will certainly mean progressive neurological and cognitive deficit. Depending upon the location of the tumour and the treatment side effects, patients can experience various neurological and cognitive symptoms that may affect their ability to function independently.<sup>1</sup> Irrespective of the level of functioning or disability, the consequences of a brain tumour can hinder patients in participating fully in vocational and social activities, affecting quality of life for both patients and their family members to a great extent.<sup>2,3,4</sup> As the disease progresses, patients rely more heavily on their loved ones for physical and emotional support. They develop workarounds that sometimes hide a change in their circumstances. Consequently, spouses, family members or close friends assume the role of family caregiver, a role for which they have had no training and have not applied for.

Our day-to-day work with the brain tumour community reveals isolation, a lack of voice, and the daily challenges that people face. People are concerned about vitality, their identity and role, limitations, mental health, emotional well-being – all of these are important decision factors for patients.

These considerations resonate:

- varying survivorship
- variable trajectory, even for non-malignant brain tumour diagnoses
- high frequency of disabling complications
- high severity of disabling complications
- knowledge of increasing cognitive dysfunction
- life context – where there is resilience or a lack of ability to cope.



There is little available through the usual channels of clinicians for this support – only 47% of UK neuro-oncology multidisciplinary teams have access to neuropsychiatry services.<sup>5</sup>

- 1 Mukand J, Blackinton D, Crincoli M, Lee J, Santos B. Incidence of Neurologic Deficits and Rehabilitation of Patients with Brain Tumors. *American Journal of Physical Medicine & Rehabilitation*. 2001;80(5):346-350.
- 2 Aaronson N, Taphoorn M, Heimans J, Postma T, Gundy C, Beute G et al. Compromised Health-Related Quality of Life in Patients With Low-Grade Glioma. *Journal of Clinical Oncology*. 2011;29(33):4430-4435.
- 3 Janda M, Steginga S, Langbecker D, Dunn J, Walker D, Eakin E. Quality of life among patients with a brain tumor and their carers. *Journal of Psychosomatic Research*. 2007;63(6):617-623.
- 4 Taphoorn M, Sizoo E, Bottomley A. Review on Quality of Life Issues in Patients with Primary Brain Tumors. *The Oncologist*. 2010;15(6):618-626.
- 5 Rooney A. Challenges and Opportunities in Psychological Neuro-oncology. *Oncology News*. 2011;6(4).

Mukand et al. (2001) identified the following neurological complications in brain tumour inpatients:

- cognitive deficits, 80%
- weakness, 78%
- visual-perceptual deficit, 53%
- sensory loss, 38%
- bowel and bladder dysfunction, 37%
- cranial nerve palsy, 29%
- dysarthria, 27%
- dysphagia, 26%
- aphasia, 24%
- ataxia, 20%
- diplopia, 10%.<sup>6</sup>



Among inpatients, 75% will have three or more of these neurological complications; 39% will have five or more. Surgery, adjuvant therapies and supportive treatments (e.g. anti-epilepsy medication, corticosteroids) can negatively affect the person living with a brain tumour while at the same time improve patient functioning and extend survival.<sup>7</sup> Furthermore, a patient's appreciation of what constitutes worthwhile quality of life evolves over the course of the illness, so even in the face of mounting physical, neurological and cognitive deficits, patients may feel that their quality of life is good enough to continue with treatment. They can still have their 'best possible day' at end-of-life care.

Catt et al. (2012) have identified that:

- supportive care pathways for patients and their families differ between hospitals
- guidelines either omit important aspects of care and follow-up or are based on assumptions with little empirical support
- as treatments for patients are often palliative, more efforts are needed to ensure good continuity of care
- current follow-up is failing to meet the psychological needs of patients and their caregivers
- there is a need to develop innovative and integrated interventions that effectively support caregivers, such as proactive counselling or problem-solving services.<sup>8</sup>

6 Mukand J, Blackinton D, Crincoli M, Lee J, Santos B. Incidence of Neurologic Deficits and Rehabilitation of Patients with Brain Tumors. *American Journal of Physical Medicine & Rehabilitation*. 2001;80(5):346-350.

7 Taphoorn M, Sizoo E, Bottomley A. Review on Quality of Life Issues in Patients with Primary Brain Tumors. *The Oncologist*. 2010;15(6):618-626.

8 Catt S, Chalmers A, Critchley G, Fallowfield L. Supportive follow-up in patients treated with radical intent for high-grade glioma. *CNS Oncology*. 2012;1(1):39-48.

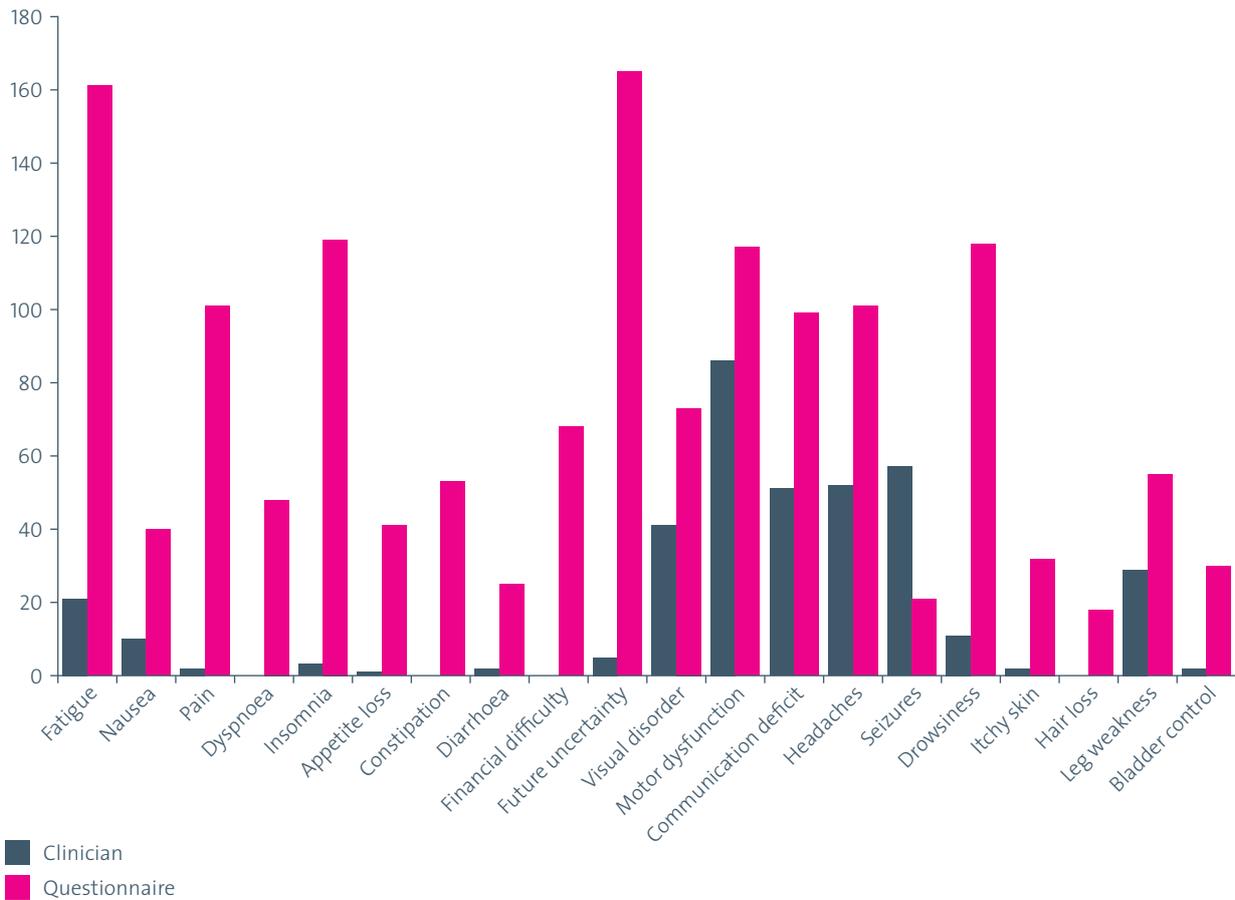
In the UK, there are several barriers to the routine identification of neurocognitive impairment and referral for neurocognitive rehabilitation:

- There are shorter neurosurgical admission periods, with a focus on efficient throughput and waiting times.
- Neurocognitive difficulties are not appreciated by staff, or staff have too little time to assess.
- There is a lack of routine neurocognitive screening at surgical admission.
- Mood-related difficulties (anxiety and depression) are considered a normal reaction, and referrals are not made for support.
- There is uncertainty as to whether patients would be accepted by neurorehabilitation specialist services, or what the referral criteria are.
- The wait for rehabilitation referral may delay surgical discharge.
- There is a lack of awareness of availability of community neurocognitive rehabilitation services.
- There is a lack of resource for the delivery of outpatient neurocognitive or psychological support, resulting in delayed opportunities.
- There is the perception that patients may be too tired during radiotherapy and/or chemotherapy to cope with or benefit from early rehabilitation.
- It is not the patient's priority early in their recovery.<sup>9</sup>



Concordance research has also reflected a disconnect between what patients want to discuss with their clinical team and what the clinicians want to talk about. Measuring health-related quality of life with the standardised QLQ-C30 and BN20 enabled detection of more presenting symptoms than by clinician review alone, with concordance highest for gross neurological deficits. Patients are concerned with future uncertainty and fatigue; clinicians want to discuss visual disorder and motor dysfunction (closest concordance), and headaches – focuses that are more easily explained and treatable.

9 Day J, Gillespie D, Rooney A, Bulbeck H, Zienius K, Boele F et al. Neurocognitive Deficits and Neurocognitive Rehabilitation in Adult Brain Tumors. *Current Treatment Options in Neurology*. 2016;18(5).



Concordance: patients presenting for initial assessment in a neurosurgical oncology clinic were asked to complete the QLQ-C30 and BN20 brain cancer module questionnaires prior to their appointment. Clinician-reported symptoms were determined retrospectively from outpatient clinic letters. Statistical significance was determined using paired t-test and Fisher’s exact test. A total of 181 patients were included in the analysis (96 male, 86 female; median age of 61).<sup>10</sup>

It is much easier to write a script for headache or refer to neurology for seizure control than to provide treatment for how to live with future uncertainty.



<sup>10</sup> Collins J, Santarius T, Watts C, Walter F, Price S, Joannides A. OP36 \* Concordance of Patient and Clinician Reported Presenting Symptoms at Initial Neuro-Oncology Assessment. *Neuro-Oncology*. 2014;16(suppl 6):vi22-vi22.

## What we do

*brainstrust* was established in 2006 to help families with a brain tumour live a better quality of life. Over the last 13 years, we have evolved our understanding of the disease, its impact and the unaddressed challenges that hamper quality of life for people affected by a diagnosis. This culminated in the launch of our new strategy in April 2019, titled 'First, we are people'.

This strategy sees us set out to address the human challenges that come with a brain tumour diagnosis, with the understanding that if a person is engaged with their care, is not alone on their journey, is part of a community, is confident and in control, is feeling resourced and is supported, they can live life to the full.

*brainstrust* provides an around-the-clock service for people with a brain tumour and their families. This service, built around coaching principles and practices, tackles the six challenges that the brain tumour community has identified as being the most important to them. These challenges can be aggregated into four strategic priorities for *brainstrust*. We report on both the challenges and the priorities to evaluate the impact of our work.

### Challenges:

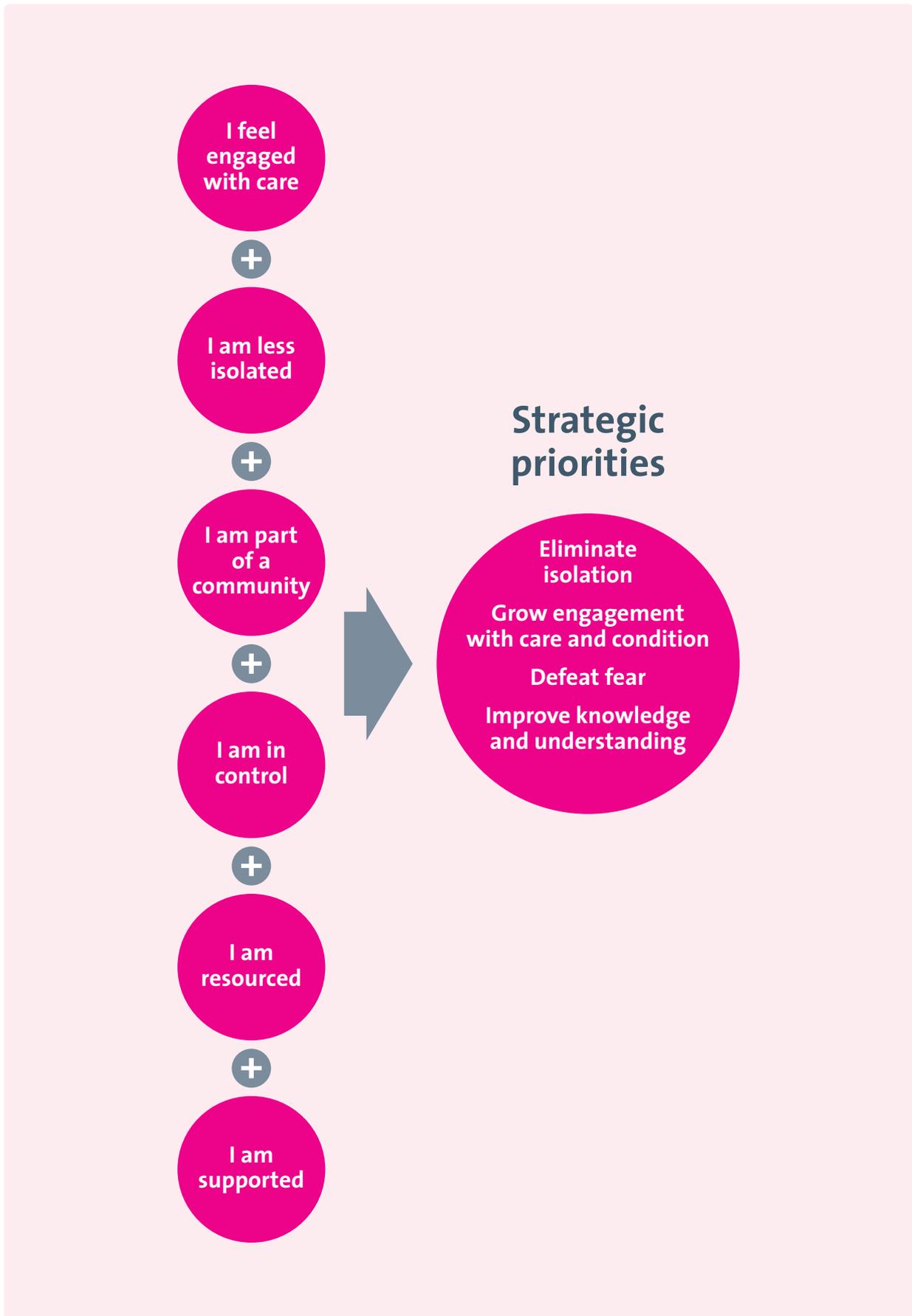
- low engagement with care and understanding
- isolation
- lack of community
- low confidence and control
- lack of resources
- lack of support.

### Strategic priorities:

- eliminate isolation
- grow engagement with care and condition
- defeat fear
- improve knowledge and understanding.



Coaching is delivered by highly trained *brainstrust* support specialists working regionally across the UK. They support beneficiaries over the phone, via email, face to face and through workshops, Meetups and events. Our website also provides information that helps people understand their journey and make informed decisions about their care.



We also campaign for person-centred care, support for caregivers and parity of quality and access to the best clinical care for people with a brain tumour in the UK. All of these activities should drive improvements in quality of life for the brain tumour community.

Impact of our service is evaluated using the *brainstrust* 'progress tracker', a simple tool designed to work in the 'real world'.

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.



## Our impact 2018–19

Of the 1,042 people to access coaching support during the year in review, 56 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.

***brainstrust's* support drives holistic and balanced improvement in people's well-being across six clearly defined impact indicators. People generally approach *brainstrust* feeling that 'things are difficult' but leave with things 'how they like them to be'.**

**On average, people progress 28% (1.42/5) 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.**

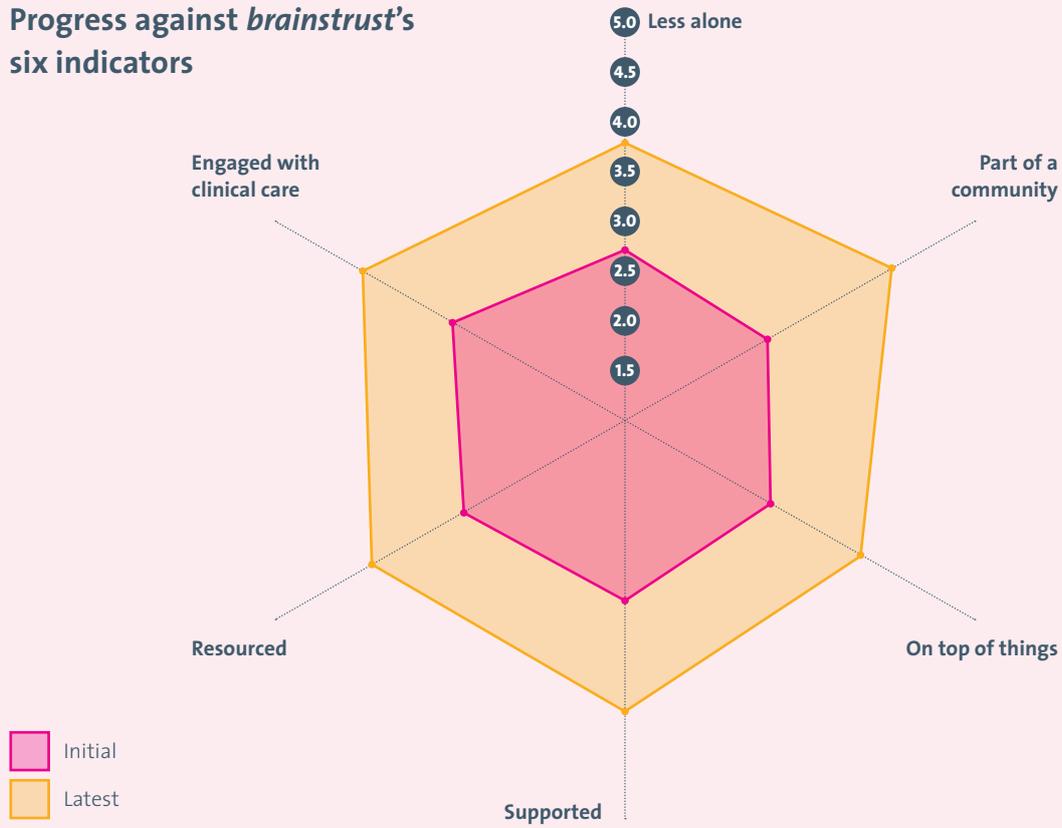
**Coaching at *brainstrust* is creating the most impact in driving engagement with care and building communities for people with a brain tumour. Beneficiaries are reporting a 32% (1.61/5) improvement in feeling part of a community, and a 28% (1.41/5) increase in engagement with clinical care.**

**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.**

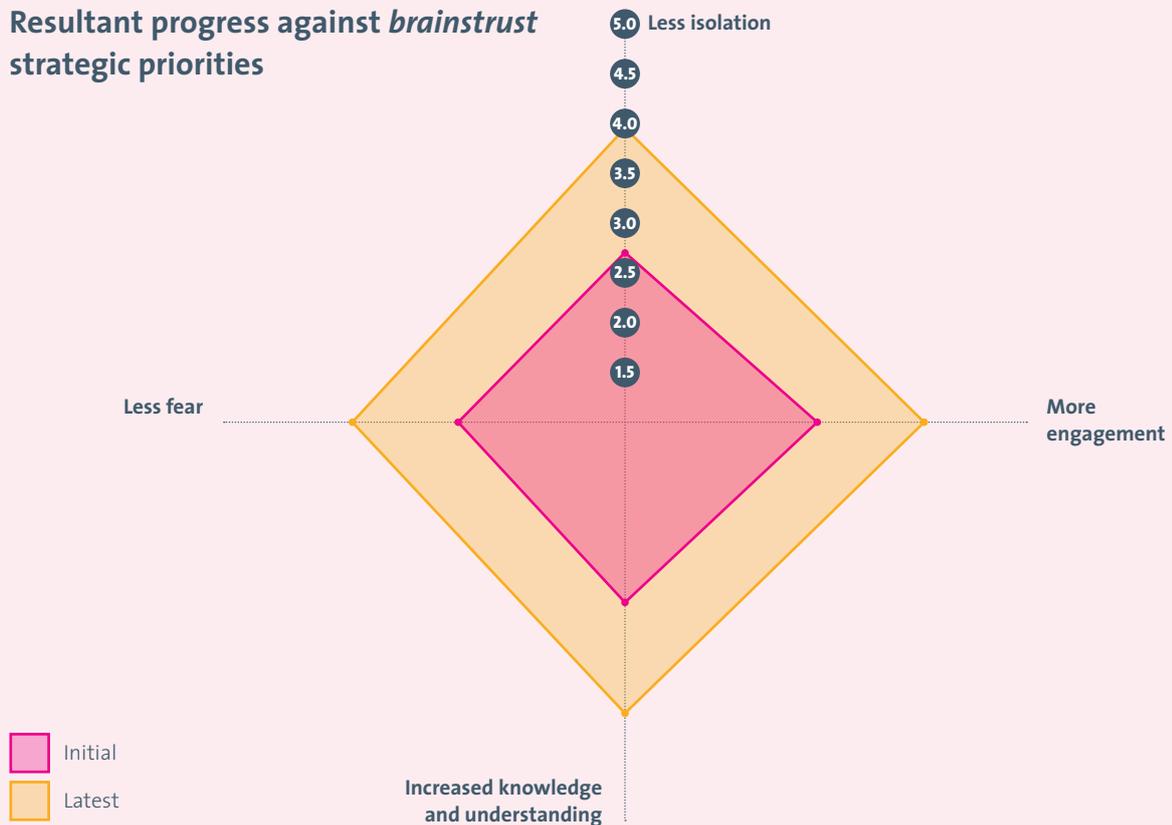
**94% of respondents said that the information on [brainstrust.org.uk](https://brainstrust.org.uk) helped them to feel more resourced, more confident or more in control (101/108 people).**

## brainstrust's impact 2018–19

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



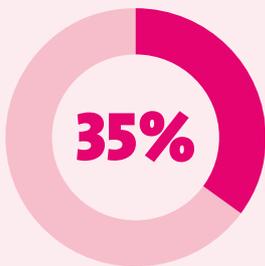
### Resultant progress against *brainstrust* strategic priorities



In 2018–19  
brainstrust helped

**1,042  
people**

directly  
with coaching,  
an increase of



**(1,042/799)**  
on the  
previous year.



We sent out

**846  
brain boxes**

to help people feel  
more resourced  
and more engaged,  
nearly double  
the number sent  
out last year  
**(846/431).**

To help people feel  
less alone, and part  
of the community,  
we held

**47  
events**

across the  
UK, attended by

**483  
people.**



## Eliminating isolation

“ 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. ”

**Patient**

Midlands, March 2019

## Building engagement with care and condition

“ Thank you so much for your time, patience and information, all of which have been so valuable to myself and the entire family at this time. I have secured my mother’s imagery and await any written notes, arming ourselves in the event we will require them.

Having spoken to the family, I believe we will be asking for a second opinion to put our minds at rest and provide a sense of certainty deprived us due to the experience we have received.

Thank you again with deep sincerity for making a difference. ”

**Caregiver**

September 2017

## Defeating fear

“ Just to know that they’re there for you from the very start of this terrifying journey helps so much. ”

**Caregiver**

Portsmouth, July 2019

## Improving knowledge and understanding

“ Thank you so much for your quick response and information, which I reviewed on your amazing website, so much relevant information. What an excellent charity. You truly are a ray of light and the support we need at this time, as my father and I feel very much alone caring for my mother. ”

**Caregiver**

March 2018

## Headwinds

Specific challenges relating to evaluation of the impact that our coaching and support brings have been identified as follows:

- While *brainstrust's* reach is growing, beneficiary engagement in evaluation is still relatively 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, which 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.



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