

# POTENTIAL FOR MERGER: THE BRAIN TUMOUR CHARITY SECTOR

## The brain tumour charity landscape is moving from fragmentation to greater coordination

Brain tumour charities support people who have or had brain tumours and their families. Charities do this through direct services, research, campaigning and fundraising. We selected this sector for further analysis because:

- brain tumours have a high mortality rate and are the bigger cancer killer of the under 40s;
- brain tumour research is falling behind other cancer research and requires large, coordinated, long-term investment; and
- the sector is populated with many small, new charities, dependent on fundraising, despite medical research needing large coordinated investment.

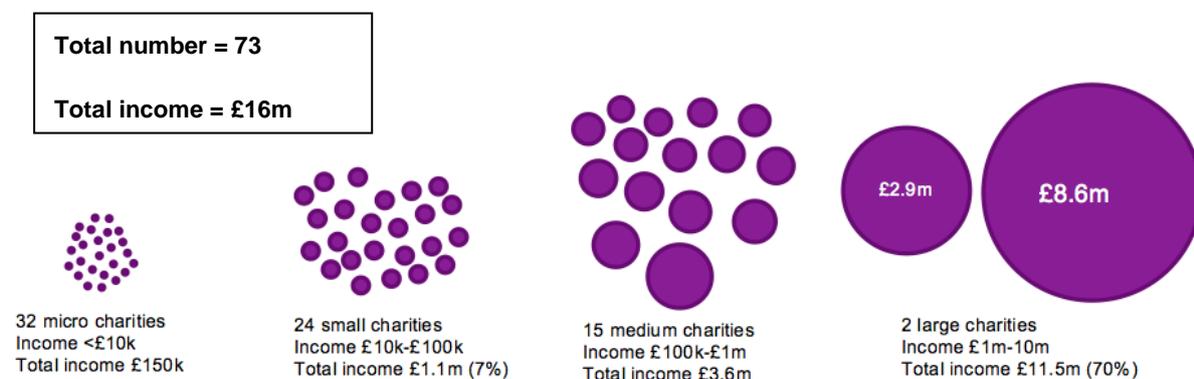
### The sector's resource is fragmented

The vast majority of charities in the brain tumour sector are started and run by someone who has been diagnosed with a brain tumour, or friends and/or family of that person. The charities are often named after those individuals. They tend to be small or micro, fundraising focused and volunteer led.

This is evidenced by the fact that, of 73 brain tumour charities in our dataset<sup>1</sup>, 71 of them have income under £1m. This means 97% of the sector by number represents only 30% of its total income (see Figure 1). The medium charities (although still quite small organisations with income between £100k and £1m) tend to provide information and support services for people diagnosed with brain tumours.

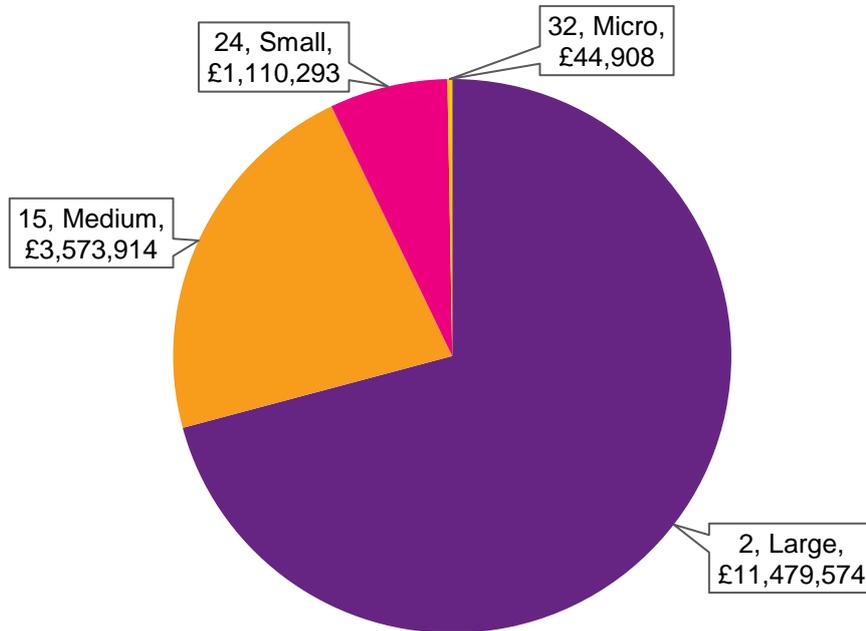
There are two organisations with an income over £1m: Brain Tumour Research (£2.9m in 2017) and The Brain Tumour Charity (£8.6m in 2017), which is still less than a third of the size of an equivalent major player in other cancer subsectors such as Breast Cancer Now (£29m in 2017). There are no major (£10m-£100m) or super major charities (£100m+) in the brain tumour sector, in contrast to other cancer charity sectors.<sup>2</sup>

Figure 1: Brain tumour charities by number and income



Although the sector is dominated by two charities over £1m in size, its history is fragmented and there remains over 70 charities, with £4.5m of valuable funding, operating at less than optimal scale.

Figure 2: Total income of each size category of brain tumour charities (number of charities in brackets)



### Strategic research requires large, coordinated investment

The lack of major or super charities makes it harder for the brain tumour sector to rally the resources to speak with a unified voice and have significant influence. As brain tumour research receives a relatively small amount of funding in comparison to other conditions, there are unmet research needs such as the genetics and biology of tumour development.<sup>3</sup> Brain cancer research is complex, expensive, and difficult. Good research funding needs three elements:

- **Financial scale.** Research is expensive and long term. Financial heft and commitment achieves more than bits and bobs. The second largest brain tumour charity, Brain Tumour Research, estimates that one working day of research at one of their centres costs £2,740. This equates to about £600,000 per year to run a centre.
- **Expertise.** Funding good research requires a strategy, and for this you need access to independent scientific and research expertise to identify and evaluate opportunities within the context of greatest need. Developing and executing a strategy requires intensive resources.
- **Coordination and profile.** Ambitious research programmes involve scientific institutions and funders, from around the world. Resources to co-ordinate, mobilise and influence are required to get such programmes off the ground. Successful research funding is as much about influencing other funders to engage with the research, as raising funds directly.

The sector also needs a strong collective voice to campaign for faster diagnoses and the committed application of treatments by the NHS. Small organisations will find it hard to get their voice heard, while policy-makers prefer to listen to one or two informed organisations, rather than multiple campaigners.

## **Other benefits of merger for people affected by brain tumours**

We have used the evidence of our qualitative research across the charity sector, including the experience of The Brain Tumour Charity, and applied this to the brain tumour sector in the areas where we see opportunities for change through merger.

### **More strategic and efficient spending**

Combining resources to fund pioneering, long-term research and support could contribute to improvements in diagnosis, treatment and care. The Brain Tumour Charity already co-funds research programmes to ensure that the funds they raise make a bigger impact than they would do on their own.<sup>4</sup>

### **Pooling expertise**

The current small, volunteer led, nature of the sector and many of the charities within it has created a potential hothouse of talent. People with no prior experience of the charity sector have set up charities and become skilled fundraisers, gained an understanding of charity administration, and the grant-making process. However, these people are isolated in small teams who may lack the skills to maximise their impact. By bringing these organisations together, there is a far greater opportunity to create a balanced team.

### **Stronger voice when speaking to policy actors and experts**

As a fragmented sector, brain tumour charities lack a unified focus and voice. This could prevent them from influencing regulators, funders and other decision makers who control policy and future funding. Improvements in diagnosis, research funding and care will require a coordinated approach to transform the research and funding environment for brain tumours.

### **Greater capacity to raise awareness among the general public**

Improving both diagnosis rates and fundraising income depends to an extent on improving public awareness of brain tumour symptoms and severity. Reaching the general public requires strategic campaigning in partnership with health services, schools and others, something that small, volunteer-led charities cannot do at scale.

### **Reduced levels of confusion about service provision and support**

For those people living with brain tumours and their families, knowing where to go for information and support is critical. Without coordinated hubs of information and services, especially during the critical early days of their diagnosis, navigating the sector could be a challenge for those people the sector hopes to serve.

## **What might prevent mergers within the sector and how might resistance be overcome?**

Brain tumour charities will face the usual barriers to mergers we identified in the main report. In addition, we have found that many of these charities are a poignant expression of an individual or family loss. Merging in a way that would erode personal connections and experiences could be emotionally distressing and isolating to those who had invested significant resources. It may also affect their ability to fundraise. The white-labelling alternative—when funds raised by small, local charities are passed to a larger charity to spend—could harness this power while ensuring effective distribution of funds raised. The expertise and lived experience of the small charity staff and volunteers should also be used and respected.

### **Collaboration at scale: The Brain Tumour Charity\***

Brain tumours arise in all demographics of people. It is wonderful that so often the agony and grief associated with losing loved ones to brain tumours engenders a generous philanthropic response. We should not lose the benefit and hope that this brings.

But NPC has in the past questioned whether 74 different brain tumour charities offer the best solution to the urgent problem of finding effective treatments, and campaigning to make those treatments available. Progress on brain cancer research lags behind other site-specific cancers such as blood or breast cancers. Some of the difference can be accounted for by scientific complexity, but the scale of investment offered by leading blood and breast cancer charities is likely to be part of the explanation for this progress.

In 2014 three brain tumour charities, the Samantha Dickson Brain Tumour Trust, Brain Tumour UK and Joseph Foote Trust merged to form The Brain Tumour Charity, now turning over £9m.

### **A powerful voice achieves more for the people affected**

Since the merger, The Brain Tumour Charity's campaign team has quadrupled in size and led a successful campaign to reduce diagnosis times by half. The charity says it could not have achieved this result without having the scale to run such a campaign.

### **White labelling—best of both worlds raising and channelling funds: Brain Tumour Research and The Brain Tumour Charity\***

Brain cancer research is complex, expensive, and difficult. Good research funding needs large-scale investment, expensive expertise and major campaigns to be effective. A myriad of small grants from small charities could not meet these criteria. Through operating a **white labelling model**, which allows small charities with individual connections to raise funds and then channel them to a charity with research spending expertise and infrastructure.

### **The Brain Tumour Charity's supporter groups and the white labelling model harnesses the emotional energy of people to achieve results**

Supporter groups are founded to raise money in the name of a deceased loved one, or by people who are recovering from brain tumours who want to make a difference. They operate day to day in similar fashion to a large group of independent micro and small charities that exist across the sector. While maintaining their own individual identity and brands, eg, the Kevin Ackling Fund, these groups receive wider support from The Brain Tumour Charity, which receives income from them and channels it to the cause. The supporter groups maintain the strength of a local agile fundraising base and respect the importance of the memory of the deceased while providing the benefits of acting within a large organisation. Without this model being available, many of these organisations would have founded as independent charities. The supporter group currently contains approximately 300 organisations and, in some cases,, have raised significant funds. The Hannah Louise Jones fund set up by a young person living with a brain tumour has raised just over £210,000 since it was founded. It has also been involved in a wide range of campaigning and awareness raising. This white label approach could provide an interesting model to be adapted by other charities engaged in a sector where there are similar levels of emotional investment in the founding of charities.

### **Brain Tumour Research also uses a white labelling model with 18 local charity members**

Brain Tumour Research, another brain tumour charity, has 18 local charity members, plus a further 36 fundraising groups that funnel research funding through Brain Tumour Research without losing the valuable personal contact, and fundraising appeal of these smaller charities. Brain Tumour Research provides PR and fundraising support to these local charities and groups to help bring in more funds.

Brain Tumour Research is also a member of the National Cancer Research Institute (NCRI), a collaboration of research charities, aiming to improve the impact of research through collaboration.

### **The scientific advisory board adds value to funds raised**

As part of its funding process, both charities use scientific advisory boards. The boards assess research applications and help shape the charity's decision-making process. The Brain Tumour Charity has made the findings of this board available to other brain tumour charities. This has let smaller organisations that would lack the capacity to undergo this sort of analysis in normal circumstances use a more evidence focused approach drive their funding decision making, without interfering with their institutional or structural independence. This approach shows how charities can combine elements of their services without engaging in any form of formal merger.

\*Information taken from interviews with the two charities

## **Looking forward**

The brain tumour sector shows the capacity for people who have experienced an unmet social need to create or organisations with a passion for driving change. This is one of its great strengths as it creates a vibrant and passionate sector with great fundraising potential. It is also one of its weaknesses—the small charities supporting the cause lack the infrastructure to maximise the impact of the money they raise for medical research. Investment in medical research needs scale.

The good news is that the sector has already started to consolidate. Mergers, such as the three-way merger to form The Brain Tumour Charity, plus The Brain Tumour Charity's white labelling model to help support groups and small charities channel funds effectively, have the potential to create greater sector focus and serve its beneficiaries better. However, this must be done in a way that does not harm the very real emotional foundations of the sector.

### NPC's 2018 research into mergers

Mergers as a means of stretching scarce charitable resources are an attractive prospect. Mergers offer strategic potential—reaching more beneficiaries; increasing the range of services offered to beneficiaries; greater heft in policy influencing and contract negotiations. Logic suggests cost savings would be achieved. Despite this, mergers are not as common as might be expected. So why are charities not liking them, or doing them? Much has been published on how to merge, ranging from the legal to the practical, and many sources list expected benefits of merger. However there is a gap: objective analysis of the benefits and costs of mergers, and a balanced assessment of in which situations a merger (or similar) may be beneficial or otherwise.

To help fill this gap, NPC has been commissioned by a group of philanthropists to research and write an independent report on mergers and other efficiency savings. This builds upon NPC's well-read [report](#) on mergers in 2009.

NPC's research included a literature review, 30+ interviews with sector experts, charities and funders, sector analysis and five in-depth and themed case studies on mergers. NPC will publish a series of publications in various formats, including a report, webpages outlining case studies and blogs to share key findings from the research.

We hope to follow this research with further work to tackle the barriers to more mergers taking place.

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<sup>1</sup> This was based on a search of Charity Commission annual returns data identifying charities with any of the words brain tumour, medulloblastoma, glioblastoma, or brain cancer, in either their name or charitable objectives. 21 of these charities lacked financial data. This is most likely due to them being too small to need to submit it (under £10,000) for the purpose of the analysis they were therefore categorised as micro-charities with an income of £5000

<sup>2</sup> These figures were drawn from the most recent year that a registered charity submitted accounts. 21 charities lacked financial information this is most likely due to their size due to this they were defined as micro with an income of £5k. Medium and large charities are displayed with a size relative to their share of the total income, micro and small charities are shown with their average size.

<sup>3</sup> [www.assets.thebraintumourcharity.org/live/media/filer\\_public/00/a3/00a3dd32-903b-4376-b057-20b23d3964d4/research\\_strategy\\_rgb\\_digital\\_final\\_online\\_version.pdf](http://www.assets.thebraintumourcharity.org/live/media/filer_public/00/a3/00a3dd32-903b-4376-b057-20b23d3964d4/research_strategy_rgb_digital_final_online_version.pdf)

<sup>4</sup> [www.assets.thebraintumourcharity.org/live/media/filer\\_public/00/a3/00a3dd32-903b-4376-b057-20b23d3964d4/research\\_strategy\\_rgb\\_digital\\_final\\_online\\_version.pdf](http://www.assets.thebraintumourcharity.org/live/media/filer_public/00/a3/00a3dd32-903b-4376-b057-20b23d3964d4/research_strategy_rgb_digital_final_online_version.pdf)