



Registered Charity No. 1095931

Values and Strategy

14th October 2024

Contents

1	Introduction	1
1.1	Need for a strategic plan and values	1
1.2	How the plan and values were developed	1
2	The environmental scan	2
2.1	Organisational history and structure.....	2
2.2	The external environment	2
2.2.1	National situation and trends.....	2
2.2.2	Local situation and trends	3
2.2.3	Summary of opportunities and threats	3
2.3	The organisation	3
2.3.1	Scope of activities	3
2.3.2	Program operating model.....	3
2.3.3	Management	4
2.3.4	Governance	4
2.3.5	Summary of strengths and weaknesses.....	4
3	Organisational values and vision	5
3.1	Values:.....	5
3.2	Organisational vision	5
4	Strategies and the organisation in 3 years	6
4.1	Strategic goals	6
4.2	Strategies	6
4.3	Organisation in 3 years.....	7
5	Review	8
5.1	Plans for reviewing and refining the values and strategies.....	8
6	References	9
7	Appendices	10
7.1	Survey Data	10

1 Introduction

1.1 Need for a strategic plan and values

Yorkshire's Brain Tumour Charity (YBTC) was founded in 2002. The charity's name, objects and key personnel have all changed several times, and the culture of the charity has evolved over time, but our research shows the case for keeping a local brain tumour charity remains strong. The strategic plan and values have been developed to provide a framework that is intended to help the charity stay focussed and effective.

1.2 How the plan and values were developed

Two surveys were conducted, one of service users, and another of staff and volunteers. The findings of independent research performed by a corporate partner, and data provided by a related charity, were also incorporated (appendices). The ideas and plans contained within this document have been widely discussed and debated at multiple board meetings and with individual staff members, trustees, ambassadors and volunteers.

A representative group consisting of an ambassador with lived experience, five staff members and three trustees, including one with lived experience, participated in a half-day facilitated meeting on 29th August 2024. The vision, values and strategic goals were selected through a process of discussion and refinement over the course of the event.

Subsequently, this values and strategy document was drafted by the Chair of Trustees and Charity Director, and then reviewed by seven ambassadors and two trustees who had not been involved in the strategy meeting on 29th August. Finally, the document was circulated and presented at a whole team event* on 14th October 2024 before it was formally adopted by the board of trustees on the same day

* All trustees, staff and ambassadors were invited to the whole team event

2 The environmental scan

2.1 Organisational history and structure

The charity was established in 2003 as Andrea's Gift, inspired by Andrea Key, who was diagnosed with a brain tumour in 2001. In 2011, Andrea's Gift became Brain Tumour Research and Support across Yorkshire, and in March 2020 Yorkshire's Brain Tumour Charity.

Harry's Star (in 2015) and Ellie's Fund Brain Tumour Trust (in 2017) were merged with YBTC, and these funds still provide financial help to families with a child undergoing brain tumour treatment. Similarly, in 2020, Will's Way was merged with YBTC and also provides funds to support the charity's activities.

Throughout its history, YBTC has supported people in Yorkshire affected by brain tumours, including running large numbers of peer support groups. YBTC has also funded brain tumour research, notably helping to establish a designated lab and 'tumour tissue bank' in Leeds. In 2024 the charity celebrated its 21st anniversary with a schedule of 21 different events.

2.2 The external environment

2.2.1 National situation and trends

Brain tumours affect all age groups there were 12,746 brain tumours diagnosed per year in the UK between 2017 and 2019, and on average there were 5,456 deaths per year over the same period. The number of brain tumours diagnosed in the UK each year has increased by 24% since 2000, with an average of 15 deaths per day.¹

For a person diagnosed with a brain tumour, the prognosis depends on the type of tumour; some benign tumours have an excellent prognosis, whereas someone with the most aggressive type of malignant tumour may only have a 13% chance of surviving two years.² Treating brain tumours is unusually difficult because the brain is protected by a barrier that stops many medications from reaching the tumour and consequently, there has been slower progress developing effective treatments than with some other types of cancer. Nevertheless, there has been a huge increase in research with more than 6 times as many publications in 2020 than in 2000.³ Since the 1970s, treatment pathways have also improved and survival for malignant tumours has increased by 53%.¹

Both people with brain tumours and the carers of people with brain tumours have unique support needs. Charities have an important role supporting NHS services meeting these needs including providing information, hope, emotional, financial and practical support, communication and peer support.⁴

2.2.2 Local situation and trends

Most medical research is funded by large organisations including for example the Medical Research Council, the National Institute for Health and Care Research, or the Wellcome Trust. Similarly, national specialist funders, including Cancer Research UK and large national brain tumour charities, provide significant funding for brain tumour research across the UK. The role of regional charities is therefore in identifying and funding very early-stage research or researchers so that they can reach the point where more significant funding from larger organisations can be obtained.

The support needs of people affected by brain tumours are primarily the responsibility of NHS services and are usually delivered through a clinical nurse specialist or other key worker. National charities, including Macmillan Cancer Support and the national brain tumour charities, are also effective in delivering information and supporting the needs of people affected by brain tumours. Some support activities are best delivered locally, some should be delivered collaboratively with national organisations, and some are better left to the national organisations. Local charities should therefore focus on delivering services that are difficult to provide on a national basis, including for example in-person support and local signposting.

2.2.3 Summary of opportunities and threats

The principal opportunities for the charity are the large number of diverse people affected by brain tumours, the local nature of the charity and the clear need for both support and research funding. The charity has previously been centred in West Yorkshire, and there is now an opportunity to generalise its activities across the whole of the region.

The main threats to the charity are financial risk, failure to adequately focus on the charitable objectives, competitive rather than collaborative attitudes towards and from other organisations and excess demand. The recent sudden curtailment of peer support activities has damaged trust.

2.3 The organisation

2.3.1 Scope of activities

The charity funds brain tumour research and supports people with brain tumours and their carers. All activities are undertaken in the counties of North Yorkshire, West Yorkshire, South Yorkshire and Humberside. The charity's activities are for people of all ages with any type of primary brain tumour.

2.3.2 Program operating model

The charity supports early-stage research and researchers with the aim of facilitating access to larger national funds that will then be used to support ongoing brain tumour research. Research funding is awarded through a transparent, fair and competitive process.

YBTC focuses on local peer support including for example, running a number of groups across the region and delivering peer support walks. The activities are designed to be local and person-centred, providing additional, much needed services to people in Yorkshire with brain tumours and their carers.

YBTC signposts activities that are delivered effectively by statutory or other voluntary sector organisations, including for example patient information, campaigning and professional support. The charity strives to engage collaboratively with all groups that work in this area.

2.3.3 Management

The charity has an operational team led by the Charity Director. Currently, the charity has five staff members whose responsibilities are support, fundraising, administration, finance and management. Additional staff members may be required to meet demand and as the financial situation allows.

The staff are supported by a team of volunteers. Several volunteers, with more significant commitments to the charity, are ambassadors.

2.3.4 Governance

The charity is registered with the Charity Commission in England and Wales (charity number 1095931) and is governed by its articles of association.

The trustees have diverse skills and have ultimate responsibility for the governance of the charity. Trustees meet regularly and focus on strategic decisions; the operational running of the organisation is delegated to the staff team.

2.3.5 Summary of strengths and weaknesses

The charity's strengths include being local, and able to adapt rapidly due to its smaller size. It has an excellent and well-motivated staff team, strong volunteer support, and broad experience in the trustee group. The charity has a long history and proven reputation locally. There is an established network of support groups, able ambassadors, and the charity enjoys strong links with key professionals.

The main weaknesses of the charity are its relatively small size which limits its ability to satisfy all expectations, and its focus on West Yorkshire with limited visibility in North Yorkshire, South Yorkshire and Humberside.

3 Organisational values and vision

3.1 Values:

The charity has adopted the following values

- Integrity

The charity is honest, fair, professional and transparent

- Compassion

The charity addresses the needs and wishes of people with brain tumours, and their carers with sensitivity, empathy and understanding

- Community

The charity delivers services and funds research based exclusively on the needs and wishes of people with brain tumours and their carers. YBTC aims to work collaboratively with all other organisations in this field

- Ambition

The charity aspires to deliver ever more services and fund ever more research whilst ensuring that it works collaboratively with the community and other organisations that provide services or fund research for people with brain tumours and their carers.

3.2 Organisational vision

To improve the lives of people impacted by a brain tumour in Yorkshire, through local support and research.

4 Strategies and the organisation in 3 years

4.1 Strategic goals

The charity has defined the following strategic goals:

- We will invest responsibly in valuable and innovative local research to improve health outcomes
- We will provide support that meets the needs of our local community
- We will build awareness of the charity's work to increase visibility and funding
- We will provide an environment that optimises our resources, systems and teams

4.2 Strategies

Skill based teams

YBTC has organised itself into four teams: research, support, publicity and fundraising, and Infrastructure. Each team is comprised of a mix of staff, trustees and lay volunteers (when required). The individuals within a team generally have expertise or an interest in that specific aspect of the charity's work. Teams will meet monthly except when there is a full board meeting: Meetings may be face to face or remote as indicated.

Board of trustees

The full board of trustees will meet quarterly and alternate between face to face and remote meetings. The board is responsible for governance and "big picture" decisions, whenever possible it will avoid duplicating the work of the four skill based teams or the operational running of the charity which is delegated to the staff team. As trustees reach the end of their terms, the diversity, skill mix and numbers of trustees will need to be maintained.

Staff team

The staff team, led by the Charity Director, meets regularly and works collaboratively on the day-to-day running of the charity. The number of staff is kept to the minimum that can reasonably be expected to deliver the activities of the charity, and is limited by financial constraints. In future years, as the charity grows and the financial situation allows, the number of staff will almost certainly need to increase slightly.

Volunteers and ambassadors

The charity welcomes, values and depends on the support of its volunteers, especially for their work running peer review groups and promoting the charity. YBTC would like to increase the number of volunteers in the future.

Focus on support and research

The charity will focus on its core objects of delivering support and research. If undertaken, any commercial activities must support these charitable objects.

Geography

The charity's objects require that it provides support and funds research across the whole of Yorkshire. In future years the charity will progressively expand its activities in North Yorkshire, South Yorkshire and Humberside.

Location

Previously the charity derived benefit from having a location where staff could work that also provided visibility and a place to engage with volunteers, ambassadors, trustees and, people with brain tumours and their families. As the financial situation permits, the charity may need to consider whether to reestablish facilities which service users and volunteers can access and where staff can work.

Collaboration

The charity will work collaboratively with NHS professionals and national charities by signposting their resources and focussing YBTC efforts on activities that are more effectively provided by a regional organisation. In the first instance activities will be face to face peer support groups, other support activities and funding local research. Because of our limited staffing resources, it is vital to collaborate with the local community to help raise funds for YBTC.

Incorporation

To manage risk, the charity needs to become incorporated. Incorporation requires that a new charity is established, activities and assets will be transferred and the old charity will subsequently be closed.

Fundraising

The charity wants to increase its activity but this depends on increasing income. YBTC is 100% dependant on fundraising; raising awareness with professionals and the entire Yorkshire community is critical.

4.3 Organisation in 3 years

YBTC is ambitious. By 2027 we expect that the charity will:

- Run many more peer support groups and support activities right across Yorkshire
- Become an important local funder of early stage brain tumour research
- Work collaboratively with NHS professionals and national organisations
- Employ a small but enthusiastic, capable, happy and loyal staff team
- Develop an active and extensive network of ambassadors and volunteers
- Be supported by an enthusiastic and capable board of trustees
- Increase visibility and presence across the entire region

5 Review

5.1 Plans for reviewing and refining the values and strategies

This document and progress against it will be reviewed at the annual general meeting by the board of trustees; at the latest it will need to be redrafted in Autumn 2027.

6 References

1. Cancer Research UK website <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumours#heading-Two>. Accessed 21/9/24
2. Brown NF, Ottaviani D, Tazare J, Gregson J, Kitchen N, Brandner S, Fersht N, Mulholland P. Survival Outcomes and Prognostic Factors in Glioblastoma. *Cancers (Basel)*. 2022 Jun 28;14(13):3161. doi: 10.3390/cancers14133161. PMID: 35804940; PMCID: PMC9265012.
3. Montes-Escobar, K., de la Hoz-M, J., Castillo-Cordova, P. *et al*. Glioblastoma: a comprehensive approach combining bibliometric analysis, Latent Dirichlet Allocation, and HJ-Biplot. *Neurosurg Rev* **47**, 209 (2024). <https://doi.org/10.1007/s10143-024-02440-x>
4. National Guideline Alliance (UK). Evidence reviews for supporting people living with a brain tumour: Brain tumours (primary) and brain metastases in adults: Evidence Report D. London: National Institute for Health and Care Excellence (NICE); 2018 Jul. (NICE Guideline, No. 99.) Care needs of people with brain tumours. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK570056/>

7 Appendices

7.1 Survey Data

April 2024

Question	Service users		Staff and volunteers	
Which of the following best describes you?	Patient	21 (36.8%)	Ambassador	6 (27.3%)
	Relative	6 (10.5%)	Staff Member	6 (27.3%)
	Carer	3 (5.3%)	Trustee	6 (27.3%)
	Bereaved relative	23 (40.4%)	Other volunteer	4 (18.3%)
	None of above	4 (7.0%)		
What would you like YBTC to focus our funding on in the future?	Research	6 (10.5%)	Research	0 (0.0%)
	Support	9 (15.8%)	Support	2 (9.1%)
	Both	41 (71.9%)	Both	20 (91.0%)
	None of above	0	None of above	0
	Other	1 (1.8%)	Other	0
Which YBTC services have you previously accessed?	Financial grant	14 (25.0%)	n/a	
	1:1 support	19 (33.9%)		
	F2F peer group	15 (26.8%)		
	Online group	9 (16.1%)		
	Peer walks	9 (16.1%)		
	Welfare call	6 (10.7%)		
	Check in & chat	5 (8.9%)		
	Wellbeing day	2 (3.6%)		
	Light up a star	5 (8.9%)		
	Picnic in the park	0		
	Christmas dinner	2 (3.6%)		
	None of above	13 (23.2%)		
	Other	7 (12.5%)		
Which support services would you most like YBTC to focus on in the future?	Peer group	27 (50.0%)	Peer group	13 (59.1%)
	Peer walks	12 (22.2%)	Peer walks	11 (50.0%)
	1:1 support	11 (20.4%)	1:1 support	5 (22.7%)
	1:1 counselling	26 (48.2%)	1:1 counselling	11 (50.0%)
	Support events	21 (38.9%)	Support events	10 (45.5%)
	Financial grants	18 (33.3%)	Financial grants	7 (31.8%)
	Other	7 (13.0%)	Other	2 (9.1%)
How important do you think fundraising is?	4.95 / 5		4.86 / 5	
How likely are you to recommend YBTC?	4.47 / 5		4.68 / 5	

September 2024

Question	Service users	
Which of the following best describes you?	Patient	12 (57.1%)
	Relative	3 (14.3%)
	Carer	2 (9.5%)
	Bereaved relative	4 (19.1%)
	None of above	0
When was the last time you accessed one of our support services?	Last 6 months	9 (42.9%)
	6 – 12 months	0
	1-2 years	8 (38.1%)
	Over 2 years ago	1 (4.8%)
	Never	3 (14.3%)
Which YBTC services have you previously accessed?	F2F peer group	9 (42.9%)
	Online group	7 (33.3%)
	Peer walk	5 (23.8%)
	None of above	7 (33.3%)
Are you interested in an online group with peers?	Yes	9 (45.0%)
	No	11 (55.0%)
When would be the best time for an online group?	Morning	1 (6.3%)
	Afternoon	4 (25.0%)
	Evening	7 (43.8%)
	None of above	4 (25.0%)
	Other	1 (6.3%)
How often should the online group run?	Once a month	10 (66.7%)
	Every 2 months	2 (13.3%)
	Every 3 months	0
	Every 4 months	0
	Every 6 months	0
	None of above	2 (13.3%)
	Other	2 (13.3%)
Are you interested in wellbeing walks?	Yes	15 (71.4%)
	No	6 (28.6%)
When would you like Wellbeing Walks to take place?	Saturday	6 (31.6%)
	Sunday	11 (57.9%)
	Weekday	5 (26.3%)
Where would you like Wellbeing Walks to take place?	North Yorkshire	9 (47.4%)
	East Yorkshire	3 (15.8%)
	South Yorkshire	5 (26.3%)
	West Yorkshire	8 (42.1%)
What information resources are most useful in an online library?	Brain tumours	18 (90.0%)
	Benefits & money	17 (85.0%)
	Family & friends	14 (70.0%)
	Mental wellbeing	10 (100.0%)
	Health & fitness	10 (50.0%)
	Holidays	12 (60.0%)
	Side effects	13 (65.0%)
	After diagnosis	13 (65.0%)
	None of above	0
	Other	3 (15.0%)