

# BEYOND BRAIN TUMOURS: A FACTBASE

**Report for the Steering Group on the needs, insights and evidence that has shaped our ‘Living longer and better’ strategy.**

**June 2023**

**Please note the following:**

- This Factbase has largely been the work of working group volunteers and we are very grateful for - and appreciative of - their time.
- The Factbase has been compiled from publicly available sources. The work is not exhaustive and there will be omissions.
- The Factbase has been assessed from a largely UK ‘whole system’ perspective, with some global context where readily available, particularly about other organisations who share our common aims.
- The work has been carried out in good faith, to help further progress for those with brain tumours, and should be considered indicative, not definitive.
- The scopes and definitions of terms used in the review have come from different sources and organisations and therefore care should be taken before making direct comparisons.
- We have gathered a large amount of material and any omissions, misinterpretations or errors are ours alone - we apologise and please bring them to our attention so we can amend them.
- Quotations from those contributing to the sources of this document are highlighted in teal and used throughout to highlight points.
- This Factbase has been updated and is a live document for the Steering Group. It will also be shared with the charity team and Trustees.
- The content of this Factbase and linked document can be used freely without permission, in the interests of improving outcomes for those with brain tumours. (Accreditation to the project would be appreciated if using significant amounts of the analysis.)

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# Factbase contents

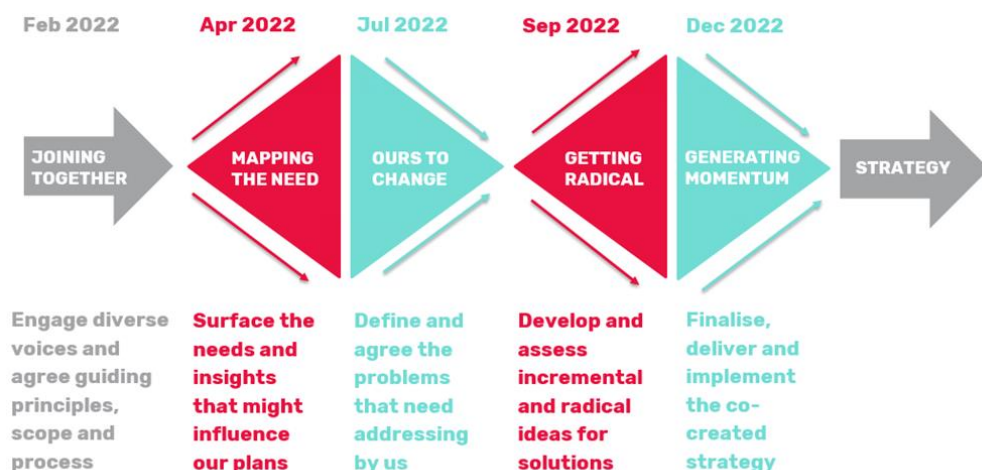
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## 1. Introduction

Brain tumours are the biggest cancer killer of children and young adults in the UK, with high grade tumours reducing life expectancy by an average of 27 years - the greatest reduction of any cancer or significant disease. Regardless of their grade, brain tumours have a unique and often devastating impact on quality of life due to their location. We are determined to change this.

Our new strategy, “Living longer and better”, has been co-created with those that share this aim. It has been led by a Steering Group of 43 people representing a deliberately wide and diverse range of lived experience, skill and knowledge from across the brain tumour community, including those personally affected, researchers, clinicians and other brain tumour charities, in the UK and overseas. We are enormously grateful to them all for their invaluable help in shaping our future direction. As well as enabling the best plan for our future, we also hope that the connections and shared aspirations of the Group will lead to further synergies and connections going forward that can only accelerate positive change for those affected by brain tumours.

The Steering Group met every month to review project material. See [here](#) for an overview of the project and an overview of the stages, which can be summarised as follows:



Our community-created Factbase details the evidence that has helped create our new strategy. This was created under 'Phase 2: Mapping the need' during the strategy development.

## 2. Summary of Unmet Needs and Insights

We have summarised the Factbase insights into:

- A summary of unmet needs of those affected with or working to mitigate brain tumours.
- The key strengths, weaknesses, opportunities and strengths faced by the sector as well as a little on our charity.
- The resulting key strategic drivers

Each insight is referenced with one or more alphabetical sources. Please scroll down for these Source summaries, which also have links to any more significant source reference documents.

### Unmet Community needs

Evidence for the current community unmet needs was gathered from nine sources. Some were initiated for this strategy (eg the ‘What must change’ community survey) and some used existing sources..

A summary of the key needs is set out here:

Key unmet needs
<p><b>Impact on society and its focus on brain tumours</b></p> <ul style="list-style-type: none"><li>• Est. 88,000 are currently living with a brain tumour in the UK. [K: Key brain tumour statistics]</li><li>• Just 13% of adults diagnosed with brain cancer survive five years or more compared to an average across all cancers of 52%. [K: Key brain tumour statistics]</li><li>• Brain tumours are the biggest cancer killer of the under 40s. Of the survivors of childhood brain tumours, 60% do not achieve complete independence as adults. [K: Key brain tumour statistics]</li><li>• The majority of people are diagnosed with a brain tumour via emergency presentation, also associated with the poorest survival rates compared to other routes to diagnosis.[K: Key brain tumour statistics]</li><li>• The burden on society of brain tumours is more significant than other cancers because it reduces life expectancy by 27 years, the greatest reduction of any cancer or significant disease.. [K: Key brain tumour statistics]</li><li>• There is patient-reported and clinical evidence for the wide-ranging and often severe impact of brain tumours on quality of life because of their location. [H: Life with a brain tumour, K: Key brain tumour statistics]</li><li>• There is low awareness of signs and symptoms in the population and among healthcare professionals. [D: Unmet need recurring theme]</li><li>• Brain tumour research funding has increased to £22.3m in the UK but is low compared with other cancers, at only 3.2% of total cancer funding. [K: Key brain tumour statistics]</li></ul>
<p><b>Support &amp; wellbeing</b></p> <ul style="list-style-type: none"><li>• 7 out of 10 have unmet needs across all aspects of wellbeing. [G: Improving Brain Tumour Care]</li><li>• For 9 out of 10 people, their tumour affects their emotional or mental health, and 4 out of 10 need more emotional support. [D: Unmet need recurring theme, E: Landscape review, G: Improving Brain Tumour Care, H: Life with a brain tumour research]</li></ul>

- People are living with significant impairments, e.g. 1 in 3 have visual impairments, 1 in 2 have memory problems. [H: Life with a brain tumour research]
- And people experience significant changes to their circumstances, e.g. 1 in 2 experience financial difficulties. [E: Landscape review, H: Life with a brain tumour research]
- 4 out of 10 lack CNS (Clinical Nurse Specialist) access. [G: Improving Brain Tumour Care]
- There are gaps in people's understanding of their treatment, prognosis and side effects. [G: Improving Brain Tumour Care]
- People are not often told about support available, e.g. 7 out of 10 are not signposted to benefits. [G: Improving Brain Tumour Care]
- 8 out of 10 don't have a personalised care plan. [G: Improving Brain Tumour Care]
- End of life support is lacking and not well integrated e.g. 6 out of 10 people with terminal diagnosis are not given end of life care options. [E: Landscape review, H: Life with a brain tumour research]
- Looking globally there are large inequalities (especially for low and middle income countries) across support/wellbeing, treatment and access to research, by ethnicity, tumour grade etc. [L: Brain tumour sector PESTLE]

#### **Treatment pathway**

- Earlier detection and diagnosis is a top priority, with delayed diagnosis for 3 out of 10. [C: Top 4 unmet needs from community; E: Landscape review; G: Improving Brain Tumour Care, J: Research strategy consultation]
- Best care for everyone is a top priority. [C: Top 4 unmet needs from community, E: Landscape review, J: Research strategy consultation]
- There is poor communication between professionals and those personally affected, leading to gaps in understanding about treatment, prognosis and side effects. [D: Unmet need recurring theme, G: Improving Brain Tumour Care]
- Many people experience poor communication during diagnosis. [G: Improving Brain Tumour Care]
- 4 out of 10 lack CNS (Clinical Nurse Specialist) access. [G: Improving Brain Tumour Care]
- There are big differences in experiences between groups (by geography, gender, grade). [G: Improving Brain Tumour Care]
- There is a need to expand neuro-rehabilitation provision. [E: Landscape review; J: Research strategy consultation, F: Tessa Jowell Centres of Excellence]
- There is need to expand specialised healthcare resource e.g. neuropathology, palliative care, neuropsychiatrists, dedicated CNSs. [J: Research strategy consultation, D: Unmet need recurring theme]

#### **New treatments & research**

- Scale of investment in research is a top priority. [C: Top 4 unmet needs from community]
- Developing new treatments is a top priority, including for treatment of progression. [C: Top 4 unmet needs from community, J: Research strategy consultation, E: Landscape review]
- Only 3 in 10 people say they participated in research. [G: Improving Brain Tumour Care, J: Research strategy consultation]
- 5 in 10 people consider alternatives treatments and/or complementary therapies. [G: Improving Brain Tumour Care]
- We need improved knowledge of the basic biology of tumours to drive research into new treatments. [J: Research strategy consultation, E: Landscape review]
- We must bridge the gap between pre-clinical and clinical testing, turning brain tumour knowledge into treatments. [J: Research strategy consultation, E: Landscape review]
- There is demand for treatment pathways that deliver better quality of life. [D: Unmet need recurring theme, J: Research strategy consultation, E: Landscape review]

- We must improve the ease and speed of conducting clinical trials. [J: Research strategy consultation, E: Landscape review]
- We must invest in people so they see sustainable career paths in brain tumour research. [J: Research strategy consultation]

#### Strong community & collaboration

- People want more collaboration between charities. [C1: Unmet need recurring theme]
- People want more collaboration inside and outside the brain tumour research sector. [J: Research strategy consultation]

#### Use of data

- There is a need for a large open access database of molecular, clinical, imaging and patient reported data. [J: Research strategy consultation, [C1: Unmet need recurring theme]
- We do not measure and act on long term outcomes of everyone diagnosed, including their quality of life. [J: Research strategy consultation]
- There is no universal access to molecular diagnosis. [J: Research strategy consultation, D: Unmet need recurring theme]
- There is a strong patient mandate to use health data. (Caldicott principle) [J: Research strategy consultation, P: Data sharing survey]

## Sector insights

Sector insights on strengths, weakness, opportunities and threats were gathered from five sources. Some were initiated for this strategy (eg the 'Key player' analysis) and some used existing sources.

Each source document has been reviewed for the resulting strengths, weaknesses, opportunities and threats arising for the brain tumour sector. A summary of these insights is presented here:

### Key strengths

#### Support & wellbeing

- A good level of UK support is available for brain tumours from charities. [L:Brain tumour sector PESTLE, N: Player analysis]
- A leader in brain tumour-related apps is currently available and gaining traction with 7000+ UK users and features for support, healthcare, research and patient reported data collection. [O: App landscape review]

#### Treatment pathway

- There is universal access to the NHS for people in the UK. [L:Brain tumour sector PESTLE]
- The Tessa Jowell Centres of Excellence programme is making great progress in recognising and spreading best practice. [L:Brain tumour sector PESTLE]
- The Improving Brain Tumour Care surveys show gaps in patient experience. [L:Brain tumour sector PESTLE]
- A leader in brain tumour-related apps is currently available and gaining traction with 7000+ UK users and features for support, healthcare, research and patient reported data collection. [O: App landscape review]

#### New treatments & research

- There has been a 348% increase in research funding for brain tumours over 10 years to £22.3m in 19/20. [K: Key brain tumour statistics]
- The global research community is growing e.g. US now \$237m/year. [K: Key brain tumour statistics]
- A leader in brain tumour-related apps is currently available and gaining traction with 7000+ UK users and features for support, healthcare, research and patient reported data collection. [O: App landscape review]
- Increased researcher willingness to collaborate and use new technology to improve outcomes. [L: Brain tumour sector PESTLE]

#### **Impact on society and its focus on brain tumours**

- There is an APPG on brain tumours. [L: Brain tumour sector PESTLE]

#### **Strong community & collaboration**

- In the UK, there are strong brain tumour focused charities covering one or more of the following: research, support, awareness, advocacy. [N: Player analysis]
- There is a strong underlying UK propensity to give money and time, boosted by COVID. [L: Brain tumour sector PESTLE]
- There are increasing examples of charities, groups and individuals working together effectively to drive change. [L: Brain tumour sector PESTLE]
- The brain tumour community has a strong desire to share their data to help brain tumour treatment and care. [P: Data sharing survey]

#### **Use of data**

- There is a strong mandate for health data use from the community. [P: Data sharing survey]
- Over a dozen apps have some form of monitoring/reporting functionality offering potential to create a single data repository medical researchers could leverage. [O: App Landscape Review]
- A leader in brain tumour-related apps is currently available and gaining traction with 7000+ UK users and features for support, healthcare, research and patient reported data collection. [O: App landscape review]
- COVID has accelerated adoption of digital health technology and telehealth. [L: Brain tumour sector PESTLE]
- The Brain Matrix programme creates a future platform for accelerated research. [L: Brain tumour sector PESTLE]

### **Key weaknesses**

#### **Support & wellbeing**

- There is unequal access to care and support for disadvantaged groups and a lack of data on all these gaps. [L: Brain tumour sector PESTLE]
- There is a lack of emotional support for brain tumours (and other diseases). [L: Brain tumour sector PESTLE]

#### **Treatment pathway**

- There are significant gaps in NHS provision and specialist staff (e.g. CNSs, neuropathology, neurorehabilitation, palliative care) which are worse since COVID [L: Brain tumour sector PESTLE]
- There is a lack of joined-up or integrated care for people with brain tumours across the journey, and across community- and health-care. [L: Brain tumour sector PESTLE] [ F: Tessa Jowell Centres of Excellence]
- There are significant after-effects of COVID in delayed diagnosis and treatment. [L: Brain tumour sector PESTLE]

- There are limits to global collaboration on healthcare and support given different healthcare systems. [N: Player analysis]

#### **New treatments & research**

- There has been a lack of breakthroughs, with no significant new treatments for decades. [L: Brain tumour sector PESTLE]
- We don't measure and act on long term outcomes including quality of life. [J: Research strategy consultation]
- The brain tumour sector is too small to attract Pharma interest. [L:Brain tumour sector PESTLE]
- There is little research focus on recurrence, metastatic tumours, rehabilitation etc. [L:Brain tumour sector PESTLE]
- The majority of brain tumours are not preventable, so a greater demand is made of treatments as the underlying burden cannot be reduced. [L:Brain tumour sector PESTLE]

#### **Impact on society and its focus on brain tumours**

- Research funding for brain tumours has increased to £22.3m in the UK but is low compared with other cancers at only 3.2% of total cancer funding. [K: Key brain tumour statistics]
- There has been no delivery on the £40m committed by the government to research into brain tumours after Tessa Jowell's death. [L:Brain tumour sector PESTLE]
- There is low public awareness in the UK and globally of the incidence and impact of brain tumours. [L:Brain tumour sector PESTLE]
- It is a relatively rare cancer type and with high mortality which limits sustainable pressure for change. [L:Brain tumour sector PESTLE]
- There is over-reliance in UK society on the third sector to provide support and fill gaps in mainstream care and fund essential research. [L:Brain tumour sector PESTLE]

#### **Strong community & collaboration**

- It is a fragmented sector in the UK and globally. [N: Player analysis]
- There is a lack of diversity in UK charity sector organisations. [L:Brain tumour sector PESTLE]
- The brain tumour charity sector is behind other sectors in long-term investment and development areas such as e.g. legacies, research, awareness, campaigning. [L:Brain tumour sector PESTLE]
- We are not empowering people to join a strong global community forcing change on common issues. [L:Brain tumour sector PESTLE]

#### **Use of data**

- We don't measure and act on long-term outcomes including quality of life. [J: Research strategy consultation]

### **Key opportunities**

#### **Support & wellbeing**

- Emerging use of AI, real-time monitoring, healthtech wearables, use of apps, should all enable joined-up personalised support. [L:Brain tumour sector PESTLE]
- The shift to more flexible working benefits carers. [L: Brain tumour sector PESTLE]
- Looking globally, we can increase worldwide access to basic support, and improve outcomes most and at lowest marginal cost for people diagnosed in low and middle income countries. [L:Brain tumour sector PESTLE, N: Player analysis]
- There is opportunity in the UK and globally to grow adoption and usage of a common brain tumour app and data bank eg BRIAN. [O: App landscape review]



#### **Treatment pathway**

- There is opportunity in the UK and globally to grow adoption and usage of a common brain tumour app and data bank eg BRIAN. [O: App landscape review]

#### **New treatments & research**

- We can increase and coordinate research funding globally. [N: Player analysis]
- Emerging use of AI, real-time monitoring, healthtech wearables, use of apps, 5G should all accelerate treatment/research capabilities [L: Brain tumour sector [PESTLE]
- There is opportunity in the UK and globally to grow adoption and usage of a common brain tumour app and data bank eg BRIAN. [O: App landscape review]

#### **Impact on society and its focus on brain tumours**

- We haven't yet uncovered and made a health economics case for greater investment in treatment and research into brain tumours. [L: Brain tumour sector PESTLE]
- There is opportunity to include metastatic as well as primary brain tumours within the scope of the sector, attracting more support from policy makers and the general public. [L: Brain tumour sector PESTLE]

#### **Strong community & collaboration**

- Embrace diversity and involvement within UK charity sector organisations and their partners to improve outcomes. [L: Brain tumour sector PESTLE]
- Hybrid working offers the opportunity for much wider, more diverse participation in the third sector, including effective global collaboration. [L: Brain tumour sector PESTLE]
- We could have closer collaboration by brain tumour charities, UK or globally, on research, influencing, support, data etc. [L:Brain tumour sector PESTLE, N: Player analysis]
- We could have closer working with the wider neurological community for collective impact in campaigning and awareness, research and quality of life. [D: Unmet need recurring theme]; [L:Brain tumour sector PESTLE]
- The Charities Bill 2021 makes collaboration easier. [L: Brain tumour sector PESTLE]
- There is a growth opportunity for funding of brain tumours in UK and global markets given the numbers affected and relatively low current funding. [L: Brain tumour sector PESTLE]

#### **Use of data**

- We can pool clinical and patient-reported data within countries and globally. [N: Player analysis, L: Brain tumour sector PESTLE]
- There is opportunity in the UK and globally to grow adoption and usage of a common brain tumour app and data bank eg BRIAN. [O: App landscape review]
- We have a duty to enable the responsible use of patient data to improve outcomes, based on the community mandate and according to Caldicott Principle 7: The duty to share information can be as important as the duty to protect patient confidentiality. [P: Data sharing survey]

#### **Key threats**

##### **Support & wellbeing**

- There are falling numbers of GPs in the UK - a decline of over 1400 since 2015. [L: Brain tumour sector PESTLE]
- The NHS is under severe pressure which looks set to continue. [L: Brain tumour sector PESTLE]

##### **Treatment pathway**

- There is increasing healthcare inequality in the UK and globally. [L:Brain tumour sector PESTLE]

**New treatments & research**

- There are persistent failures of the market to direct funds according to unmet needs e.g. into new drug development for the paediatric and low grade tumour community [L: Brain tumour sector PESTLE]
- There is a huge cost burden and time delay in bridging the translational gap between early stage research and clinical trials. [L: Brain tumour sector PESTLE]

**Impact on society and its focus on brain tumours**

- There is a lower share of attention for brain tumours given the economy, wars/pandemics, climate change etc. [L:Brain tumour sector PESTLE]
- There is lower attention for brain tumours compared to other diseases, given the ageing population and rapid growth in diseases like dementia. [L:Brain tumour sector PESTLE, N: Player analysis]
- Corporate brands have moved into offering 'purpose' and social good, and are competing with the charity sector for resource and awareness. [L:Brain tumour sector PESTLE]

**Strong community & collaboration**

- The fragmented sector in the UK and globally limits speed of progress, productivity, strength of voice of the community and ability of potential partners to work with the sector at scale. [N: Player analysis]
- Proliferation of founder charities and support groups continuously adds to fragmentation of the charity sector. [L:Brain tumour sector PESTLE]

**Use of data**

- The charity sector overall is behind the curve in digital technology and data skills, and challenged in attracting these specialist skillsets at charity salaries. [L:Brain tumour sector PESTLE]

### 3. Strategy scope

#### Source B: Community scoping survey ([source document](#))

A survey of our community's thoughts on the scope of our strategy was used to shape our thinking in November 2021, with 200 responses. The results were (on a range of -100% to +100% approval) that:

- Strong approval of our current Charity vision and goals (above +82%)
- Strong approval of continuing to work across all four areas of funding research (+87%), providing support (+81%), raising awareness (+77%) and championing change (+74%)
- Strong approval of continuing to fund the best research globally (+69%)
- Approval of increasing our geographical reach beyond the UK to raising awareness (+35%), providing support (+26%) and championing change (+28%)
- Strong approval of focussing on: adults with high grade tumours (+88%); children (under 18 years) with high grade tumours (+82%); children (under 18 years) with low grade tumours (+71%); adults with low grade tumours (+68%); families and carers of those with brain tumours (+64%); and those with metastatic (secondary) tumours in the brain (+59%)

The following themes in the detailed feedback should be taken into account during the development of the strategy content:

#### Charity vision, goals and scope of work

1. Realistic Charity goals
2. Maintain strong focus on research
3. Continue across all service areas
4. Go global with others, but protect UK progress
5. Focus on everyone affected
6. Don't forget neglected groups (e.g. carers, people with a low grade diagnosis)
7. Prioritise people with a high grade diagnosis and the young

#### Key issues to address

8. More treatment options:  
*"Currently aggressive brain tumours have very little viable treatment options and the treatment available brings some horrendous life changing side effects."; "To allow the use of repurposed drugs when conventional treatment has failed."*
9. More and better support:  
*"This is a vastly underestimated and misunderstood area - speaking as a survivor. There's little or no real life support."*
10. Access to early stage treatments:  
*"Patients diagnosed with a terminal diagnosis should have a "right to try" whereby consultants can prescribe repurposed drugs."*
11. More cross-sector collaboration:  
*"There needs to be more collaboration within the cancer sector. From research to innovation to campaigning. A more joined up approach could lead to more cut through."*
12. Raising public awareness:  
*"Raising awareness in the wider community so people we come across or meet have more knowledge about what living with a tumour can entail and what support can help."*
13. Earlier diagnosis:  
*"Better understanding and screening. This may identify issues sooner. It took me years to finally be diagnosed as symptoms were unusual and quite hard to explain."*

14. Emotional / mental health support:

*“being present in the journey is key in living your life the best you can and for it to have quality especially when the end result is death”*

15. Equality and inclusion across all areas of diversity:

*“Awareness and open communication with those from ethnic minorities and/or language difficulties/barriers on their experiences to improve outcomes and ensure equality.”*

Scope: key insights

- The survey gives us a mandate for a strategy scope that should remain broad, across research, awareness and support, considering the needs of all those affected by brain tumours and with solutions that are increasingly global in both considering the needs and developing the solutions.

## 4. Community unmet needs

### Source C: ‘What Must Change’ community survey

Survey results [source document](#)

Qualitative comments [source document](#)

We carried out a survey to ask the community ‘What must change?’, asking questions across 14 issues on which were the most important and which needed the most attention. 720 personally affected and professionally involved people responded (giving us a statistically valid sample based on the estimated 88,000 people living with a brain tumour in the UK - see Source document K) and had the following profile:

- 42% of respondents were self-reporting (64% of whom had a low grade tumour diagnosis); 44% were reporting as parents or carers of others (72% of whom had a high grade diagnosis); 13% were health care professionals (researchers or clinicians); and 1% were charities
- Of the 86% personally affected, 50% had experience of having a high grade tumour, 42% of having a low grade tumour and 8% had a mixed grade tumour diagnosis or didn't yet know.
- 35% were in their 50s, 22% in their 40s, 19% in their 60s and 12% in their 30s
- 92% respondents came from the UK
- 92% were white

The respondents were asked to rate 14 issues on a priority scale of: 1: Not important; 2: Of little importance; 3: Of moderate importance; 4: Very important; 5: Critical. These were then plotted as percentages, with the results as follows:

### Survey results

#### Ranking of issue importance

(% of people saying very important or critical)

1. Development of new or improved treatments: 98%
2. Scale of investment in research: 96%

3. Best care for everyone: 95%
4. Earlier diagnosis: 93%
5. Using clinical and patient reported data to improve care: 93%
6. Development of research capability or productivity: 93%
7. Understanding the impact of a brain tumour on quality of life: 90%
8. Practical information and support to cope with a brain tumour: 89%
9. Collaboration across the sector: 89%
10. Scale of participation in research and clinical trials: 89%
11. Raising awareness of brain tumours: 88%
12. Emotional support for those affected: 88%
13. Influencing policy and clinical practice: 88%
14. Connecting people to support each other and create change: 78%

In summary, the top three issues were:

- Development of new or improved treatments  
*“Effective treatments are not all available on NHS”*  
*“Without more investment and opportunities to participate in clinical trials the future looks grim.”*
- Scale of investment in research  
*“Greater investment and research in defeating brain tumours is desperately needed. Other cancers seem to be higher profile and subsequently appear to have more money and research given to them. Why is this?”*
- Best care for everyone  
*“We were offered no treatment, no care and no explanation of what the months ahead would be like”*

When asked how satisfied people were with progress in the same areas, and then looking at the biggest gaps, a slightly different ranking comes out of where people think an issue is very important or critical AND they are unsatisfied with progress in the sector:

#### **Ranking of issues by priority for change**

**(% of people who said it was very important or critical AND they're unsatisfied or very unsatisfied with progress in the sector):**

1. Scale of investment in research: 56%
2. Development of new or improved treatments: 49%
3. Earlier diagnosis: 49%
4. Best care for everyone: 40%
5. Scale of participation in research and clinical trials: 38%
6. Understanding the impact of a brain tumour on quality of life: 38%
7. Development of research capability or productivity: 38%
8. Emotional support for those affected: 35%
9. Collaboration across the sector: 35%
10. Influencing policy and clinical practice: 33%
11. Using clinical and patient reported data to improve care: 33%
12. Raising awareness of brain tumours: 30%
13. Practical information and support to cope with a brain tumour: 29%
14. Connecting people to support each other and create change: 21%

In the top three rankings by priority to change, scale of research was considered the top priority and earlier diagnosis also came into the top 3. Differences emerge between groups based on assessments of current progress:

- Those with high grade diagnosis have lowest satisfaction and prioritise more: research spend, productivity, participation, new treatments, best care, policy change.
- Those with low grade diagnosis prioritise more: understanding quality of life and support.
- Professionals priorities focus on all aspects of research.

*“Brain tumours need to be made more widely known about. The number of people with tumours disappear into the background, because they cannot be seen, sufferers don't have the same support as that given to people with "visible" disabilities”*

*“The hopelessness of the diagnosis is still hard to bear.”*

*“Progress must be made and lauded so patients can have some confidence going forward.”*

No other issues came out strongly when people were asked about anything missed from the list. The significant areas coming out from themes in the qualitative comments were:

- **Research:** Investment, new knowledge, new research, experience of clinical trials, new treatments, drug industry, research participation, lack of progress and inconsistent statistics.
- **Support and Quality of life:** Support for loved ones, patient advocacy, community voice, specialist support, access to emotional support, understanding quality of life, practical & financial support, access to information, living with a diagnosis, regional support access, bereavement support and holistic care.
- **Improving Brain tumour care and treatment:** Experience of diagnosis, impact of side effects and symptoms, standard of care, limited treatment options, prognosis, disparity of care, lack of after care and palliative care, better communication, training, impact on quality of life, non-standardised treatments, NHS system.
- **Awareness:** faster diagnosis; earlier diagnosis; impact of earlier diagnosis; signs and symptoms; education; workplace; and government responsibility.
- **Data:** sharing, using and comparing data.
- **Collaboration:** on research, support and campaigning.

*“There is a lack of interest in the patient as a whole person and how the diagnosis has affected their life and that of their families”*

*“I think collaboration. You see other charities openly working together and it helps to feel that everyone is working towards the same mission”*

Unmet needs: key insights from community survey

**The overall community unmet needs (very important/critical AND they're unsatisfied or very unsatisfied) are:**

1. Scale of investment in research: 56%
2. Development of new or improved treatments: 49%
3. Earlier diagnosis: 49%
4. Best care for everyone: 40%
5. Scale of participation in research and clinical trials: 38%

6. Understanding the impact of a brain tumour on quality of life: 38%
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## Source D: 'What Must Change' workshops

Following the key issues identified in the surveys (see Section C), we arranged four online workshops with 41 personally affected and professionally involved people on the following issues to explore them in more detail. The following themes came out from the workshops:

### Research

- Scale of investment into research into brain tumours needs to match the number of lives affected and the devastation.
- The speed of trials needs to be faster.
- There needs to be much greater visibility on research for people so they can access something that makes their experience directly better or extracts meaning from their experience for others.
- Research is the only way to get a better cure and treatment but it is not integrated in the standard pathway and it needs to be. It should be routine that everyone gets this opportunity and can take part in research.
- There is a lack of adequate engagement with and respect for patients in the research process.

### Support and quality of life

- All the things people don't talk about should be talked about. e.g. palliative care, psychological impact.
- People do not have visibility of what's to come and what to expect or what support is available
- People don't get the opportunity to talk about what their needs and their family's particular needs are. This could be resolved through structured holistic needs conversations.
- Timing of support is critical with people needing the right intervention at the right time. Sometimes too much is overwhelming.
- Support needs to come from someone who knows you and knows your name. It is hard having to answer all the same questions over again. That person needs to be someone 'who will walk alongside you' giving continuity in support.
- A massive culture change is needed. The ethos of 'supportive care' should thread through everything that we do and palliative care should be offered at an earlier stage in the pathway. Everybody's individual changing needs should then be understood. All the right core services should be there to wrap around you and your family with the right people to deliver it.
- There would be benefit from links to the wider neurological community given how much we have in common, including understanding and supporting people with quality of life affected by impacts on the brain and the incidence of dementia in brain tumour patients.

### Best care everywhere

- We need a situation where people's care reflects their very individual needs and circumstances and that includes thinking about people's cultural background, the impairments they have, cognitive impairments and the anxiety that people are experiencing.
- You need processing time in your treatment journey and better, more joined-up communication. It is the responsibility of healthcare professionals and people supporting you to make what they are telling you about your tumour, treatment and prognosis really understandable.
- Diagnosis is one of the hardest parts of the pathway.  $\frac{2}{3}$  people visit A&E en route to diagnosis and  $\frac{1}{3}$  people are first told they have a tumour at A&E. But the A&E diagnosis pathway is not good, with people first told they have a brain tumour by a non-specialist and consequently having a poorer experience.
- Everyone appreciates that centres want to improve. So we are all pulling in the same direction but there are evident, extreme shortages in the NHS. We need to have more investment into brain tumours. We need to change policy.
- More treatments need to be available which means more investment is required.
- We should be seeking samples of everyone's tumour and using this to inform better treatments.

#### Earlier diagnosis

- Individuals have, unfortunately, experienced dismissiveness when they present symptoms.
- Clearly, this is a very difficult disease to diagnose. It is a really amorphous/varied set of symptoms that are different for everybody as everybody's brain tumour is different and in a different location in the brain. There is confusion with different causes and you are often diagnosed first with something else. This can affect certain groups more, e.g older people.
- People experience numerous GP visits and they constantly feel like they are having to battle and persist, with the responsibility on them rather than on healthcare professionals. GP awareness of signs and symptoms can be improved.
- People experience extreme anxiety through an extended diagnosis experience, knowing something is wrong but not sure how to reach a diagnosis.
- We need to distinguish between diagnosing people before they notice symptoms and fast diagnosis when people present symptoms.
- In this group there was strong consensus that earlier diagnosis does make a difference to people's experience: The brain tumour is smaller, treated faster, recovery is better, lasting effects are minimised, and, provided early treatment is also offered, it means better quality of life and less anxiety.
- Signs and symptoms awareness is needed across the population and this needs to extend to GPs.
- Other means to accelerate diagnosis identified in the discussion included: targeted screening scans, blood and urine tests for all cancers including brain tumours, increased availability and use of scans, eye tests and verbal tests.
- It is important to consider the whole system and make sure we don't break it. eg screening scans would be targeted.

#### Unmet needs: key insights

- Scale of investment into research into brain tumours needs to match the number of lives affected and the devastation.



- Everyone needs to be offered participation in research as a routine part of the standard treatment pathway and that participation needs to be respectful, inclusive and accessible, not intimidating.
- Brain tumours affect emotional or mental health severely and people need more emotional support
- Everybody's individual and changing needs should be understood using a holistic needs assessment and care plan in a guided conversation. Needs change so this conversation needs to start early and be updated at each significant change in wellbeing. All the right core services should be there to wrap around you and your family, including early access to enhanced supportive care, with the right people to deliver it.
- You need someone 'who will walk alongside you' from diagnosis to the end of your journey, giving you and your family continuity in support.
- Centres want to improve and are improving but there are evident, extreme shortages in the NHS. We need to have more investment into brain tumours to deliver the best care everywhere and for everyone in a way that reflects and responds to people's very individual needs and circumstances.
- This includes improving communication between professionals and personally affected people so they fully understand the next steps, their choices, in spite of their cognitive and physical impairments and the extreme anxiety they are experiencing.
- We need more new and improved treatments and a sample of everyone's tumour should be taken for molecular diagnosis to help us get to that.
- Diagnosis is difficult and characterised for many by delays, dismissiveness, poor communication and wrong turns.
- There are opportunities to diagnose people earlier by screening them before they notice symptoms and by responding faster when they first present symptoms to a health professional.
- We need strong awareness of brain tumour signs and symptoms throughout the general population and healthcare professionals.

#### Source E: Literature review ([source document](#)):

A review was carried out of the brain tumour sector status across: research and new treatments, advocacy and awareness and support, with input from the Steering Group, interviews across the charity and a literature review. Case studies of good practice were identified and the following challenges were key:

Unmet needs: key insights

##### Key research and new treatment challenges:

- Redesign the brain tumour research and treatment pipeline
- Leverage the full spectrum of neuroscience research
- Understand the role of the microenvironment in brain tumour biology and treatment
- Develop more predictive pre-clinical models
- Develop drugs for difficult targets in a heterogeneous landscape
- Develop a precision medicine approach
- Reduce treatment for less aggressive tumours

#### Advocacy and awareness challenges:

- Raised and sustained levels of research funding to drive new treatments
- Improved awareness and pathways for swift diagnosis
- Accelerated pathways to bringing new treatments through clinical trials
- Access to the best treatment, care and experience across UK treatment centres
- Access to affordable, early stage pre-approval treatments by patient choice.
- Collecting and sharing of relevant data for decisions

#### Support and information challenges:

- Speed and communication of diagnosis:
- Management of variable range of symptoms via medication, information or signposting.
- Impact on emotional health including invisibility of impact
- Affect on education and finances
- Isolation and impact on relationships and social lives
- Ability to live independently.
- Effect of treatment and monitoring on physical and mental health
- Access to and understanding of healthcare and the NHS staff.
- Access to and experience of health support and services.
- Fear of death

### Source F: Tessa Jowell Centres of Excellence insights ([source document](#))

The Tessa Jowell Centres of Excellence designation initiative recognises and awards neuro-oncology centres for their excellence in patient treatment and care and research.

Questionnaires were sent to 28 UK hospitals to gather data on: 1) Treatment, 2) Patient Quality of Life, 3) Staff training and development, 4) Clinical trials and 5) Preclinical brain cancer research.

This in-depth data collection is the biggest of its kind across NHS brain tumour services. The data has created a comprehensive overview of what improvements need to be made in brain tumour care.

The 2023 full report can be found [here](#).

#### Unmet needs: key insights

- **Rehabilitation:** There is variation in rehabilitation pathways across UK centres by overall pathway; focus of rehabilitation; reliance on community services; and perceived value/investment.
- **Psychological support:** Access to psychological support remains a challenge across the UK, with lack of access to dedicated psychology teams and lengthy referral times.
- **Training AHPs and Nurses:** Brain tumour specific training of AHPs and Nurses is different for every hospital, with generally fewer training opportunities for AHPs and Nurses; less funding for training opportunities for AHPs and Nurses; and fewer networks for AHPs and Nurses.
- **Trial readiness:** Some trusts are well staffed and resourced to open trials and other trusts struggle due to limited funding and lack of access to research staff and/or equipment.
- **Assessing and meeting needs:** Not all hospitals provide Holistic Needs Assessments in a timely and regular manner. The best hospitals have many formalised side-effect clinics whereas, in others, side-effects are managed 'as and when' by a CNS referring to relevant specialists.
- **Community care:** Poor communication between hospital and community team around

referring, tracking and managing community-based care, with lengthy waiting times and a lack of awareness of available community services.

## Source G: Improving Brain Tumour Care survey results

### (Source)

This national report (Round 2 - September 2021) gives the results of 1494 responses from UK adults diagnosed or in treatment in prior 2 years

#### 1. Speed and route to diagnosis

- 79% diagnosed within 3 months of first seeing any HCP, but for 17% it takes over 6mths
- 28% visit the GP 3 or more times for their symptoms
- 52% diagnosed with something else first for their tumour symptoms
- 39% don't visit the GP at all
- 65% diagnosed via A&E & 33% first told by A&E doctor

#### 2. Experience during diagnosis

- 59% first told by a non-specialist in treating brain tumours
- 16% not told in person
- 21% not told sensitively
- 22% not told privately
- 24% not given time to ask questions
- 27% don't understand their tumour
- 38% don't understand their prognosis

#### 3. Access to CNS or keyworker support

- 79% people were given any access to a CNS or keyworker
- 59% people good access to a CNS, when they needed them
- Good CNS access is higher for high grade (68%) than low grade (53%)
- Good CNS access is higher for men (74%) than women (52%)
- 30 percentage point range (49% to 79%) in having good access to a CNS across centres

#### 4. Connecting people to support for their needs

- **A majority have one or more unmet needs**  
74% people have unmet needs in one or more area  
e.g. 41% need more emotional / psychological support  
e.g. 35% need more help managing symptoms & side effects, exploring other treatment options, understanding their tumour and what to expect
- **Too few signposted to basic support**  
Only 50% signposted to emotional support/counselling, with 61 percentage point range (from 14% to 75%) across centres  
Only 55% connected to support charities, with 39 percentage point range (38% to 77%) across centres  
Only 32% signposted to financial help and benefits

- **Holistic needs assessments aren't widespread**

40% offered HNA, but 55% for those with any CNS access, with 63 percentage point range (from 11% to 74%) across centres

21% have a good needs assessment and good plan, with 38 percentage point range (6% to 44%) across centres

## 5. **Research participation**

- Only 42% say they are informed about and only 35% say they participated in any research. Information and participation is higher for men than women and higher for high grade than low grade. 57 percentage point range (4% to 61%) in participation in research across centres

## 6. **Treatment and after COVID impact**

- 20% people said their treatment was delayed or cancelled because of COVID
- **Improving information and understanding**
- 19% don't understand their tumour, 24% don't understand their prognosis, 11% don't understand their treatment options
- 38% had no written information about tumour type, 40% about treatment options, 36% about side effects
- **Use of alternative treatments**
- 52% people have considered and 32% used one or more alternative treatments alongside or instead of those prescribed by clinicians

## 7. **Differences between high and low tumour grade**

- People with a low grade diagnosis score more poorly across support questions

For example,

Less access to a Clinical Nurse Specialist:

53% with low grade diagnosis have good access to CNS vs 68% with high grade

Signposted to less emotional support, support charities and benefits support:

36% with low grade diagnosis signposted to emotional support vs 69% with high grade

Given less written information on tumour, treatment and side effects:

54% with low grade diagnosis given written information about their tumour vs 71% high grade

## 8. **Differences between centres**

- There are large differences in every aspect of experience between centres

For example,

Good CNS access ranges from 49% to 79% depending on the centre

Patient participation in research ranges from 4% to 61% depending on the centre

Being offered a holistic needs assessment and care plan ranges from 11% to 74% depending on the centre

Having unmet needs with managing symptoms and side effects ranges from 55% to 12% people depending on the centre

Signposting to emotional support ranges from 14% to 75% people depending on the centre

## 9. Differences between women and men

- Men and women have very different experiences; women tend to score lower across support questions

For example,

Less access to a Clinical Nurse Specialist  
52% female respondents vs 74% male had good CNS access

Higher unmet needs including for emotional support  
79% female respondents vs 64% male had one or more unmet needs  
49% female respondents vs 25% male needed more emotional support

Offered holistic needs assessments less  
34% female respondents vs 48% male

Given less written information  
55% female respondents vs 70% male given written information about their tumour

### Unmet needs: key insights from IBTC surveys

1. **Delayed diagnosis for some:** 28% visit GP 3 or more times for their symptoms
2. **Poor diagnosis experiences:** 59% first told by a non-specialist in treating brain tumours
3. **Poor CNS access for many:** 41% don't have good access to a CNS
4. **Gaps in people's understanding about treatment, prognosis and side effects:** 27% don't understand their tumour at diagnosis and still 19% later in journey; 38% don't understand their prognosis at diagnosis and still 24% later in journey.
5. **Majority have unmet needs:** 74% have one or more unmet need, 41% need more emotional support
6. **People aren't signposted to basic support:** 68% not connected to benefits, 50% not connected to emotional support, 45% not connected to any charity
7. **Majority don't have a personalised care plan:** 79% don't have a good holistic needs assessment and plan
8. **Low understanding of and participation in research:** 35% participate in research
9. **Many reaching for alternative treatments and/or complementary therapies:** 52% consider and 32% used alternatives
10. **Big differences between high and low grade experiences:** eg 53% with low grade diagnosis have good access to CNS vs 68% with high grade
11. **Big difference between men and women's experiences:** eg 55% women vs 70% men given written information about their tumour
12. **Big differences in experiences at different centres:** eg Being offered a holistic needs assessment and care plan ranges from 11% to 74%

Source H: 'Life with a brain tumour' reports ([Source documents](#))

In 2015, we commissioned research to find out what life was really like for adults living with a brain tumour diagnosis. 1,004 people completed a comprehensive survey, 15 people were selected to take part in face to face interviews and 25 were asked to keep on-line diaries over 7 days. This is the most comprehensive study of its kind globally and the results were compelling. The were published in three reports available on [our website](#):

- 1) 'Losing myself': This research report outlines the daily struggles faced by the majority of those affected.
- 2) 'Finding Myself in Your Hands', focused on people's interactions with the NHS, healthcare professionals and their treatment.
- 3) 'Losing My Place' based on the survey of 300 young people and their parents following a childhood brain tumour diagnosis.

The key findings were that:

- 9 out of 10 people said their tumour had affected their emotional or mental health.
- 1 in 2 experience memory problems.
- 1 in 2 people experience financial difficulty.
- 31% visited a healthcare professional five or more times prior to diagnosis.
- People with a high grade tumour were more likely to say they have a single point of contact than those with a low grade tumour.
- 55% of terminal patients said they had not been given end-of-life care options.

Amongst the children responding:

- More than eight out of ten (84%) said their brain tumour had made them feel lonely.
- Seven out of ten (70%) said they had difficulty doing things outside the house.
- More than a third (36%) of those who had symptoms said they experienced difficulties with thinking, concentrating and processing information.
- Three out of ten of those with symptoms reported changes to their personality.

Amongst the parents and carers:

- Almost three quarters said their child's brain tumour had had a moderate or severe impact on their own mental health.
- 90% said they felt lonely or isolated as a result of their child's brain tumour diagnosis.

#### Unmet needs: key insights from 'Life with a brain tumour' survey

- 9 out of 10 people said their tumour had affected their emotional or mental health.
- 1 in 2 experience memory problems.
- 1 in 2 people experience financial difficulty.
- 31% visited a healthcare professional five or more times prior to diagnosis
- 55% of terminal patients said they had not been given end-of-life care options
- More than eight out of ten children (84%) said their brain tumour had made them feel lonely
- Seven out of ten children (70%) said they had difficulty doing things outside the house
- Three out of ten children with symptoms reported changes to their personality

- Almost three-quarters of parents and carers said their child's brain tumour had had a moderate or severe impact on their own mental health
- 90% of parents and carers said they felt lonely or isolated as a result of their child's brain tumour diagnosis

## Source I: Fighting for a Faster Diagnosis ([Source document](#))

We have recently launched our campaign 'Brain Tumours: Fighting for Faster Diagnosis'. This report has been in partnership with a range of experts in the field of brain tumours – from healthcare professionals, clinicians and researchers to patients and their loved ones.

In the report, we go into detail about the benefits that faster diagnosis can have for people experiencing symptoms of a brain tumour and identify eight recommendations that policy makers could take that we believe would lead to improvements in the speed of diagnosis for patients.

## Source J: Research strategy insights ([Source document](#))

In December 2021 launched our new research strategy '[Accelerating a Cure' for 2022 to 2027](#). Its focus was based on a consultation with our community, together with a series of workshops with brain tumour researchers. In summary, the feedback was:

### Community insights

The following research areas were identified as being HIGH or HIGHEST priority by at least 84% of respondents:

1. Developing and testing new and safer treatments (99%)
2. Detection of tumour progression, complications and response to treatment (94%)
3. Earlier detection and diagnosis of brain tumours (93%)
4. Improving the accuracy of diagnosis (87%)
5. Reducing the side effects (both physical and mental) that arise from the brain tumour itself or from treatment (87%)
6. Living well with the long-term side effects from the brain tumour itself or from treatment (84%)

### Priority groups

- The majority of respondents indicated that adult and paediatric brain tumours should be given equal priority.
- The majority of respondents indicated that high grade and low grade brain tumours should be given equal priority.

### Researcher insights

These were gathered through a series of 6 workshops in 2019, attended by 52 researchers and clinicians from across the brain tumour field. The key priorities agreed at these workshops were:

#### Discovery

- Develop our understanding of the underlying biology of brain tumours. Key areas of focus include understanding the role of the tumour microenvironment (TME), and identifying cell(s)-of-origin, molecular drivers and molecular signatures.

- Advance imaging techniques and develop other non-invasive strategies for accurately assessing treatment response and detecting tumour progression.

#### Translation

- Bridge the gap between pre-clinical and clinical testing, and improve the success rate of clinical trials.
- Empower patients to access trials and better engage them with their care.

#### Quality of Life

- Improve the quality and standardise the provision of mainline treatment.
- Ensure patient care is maintained throughout, and beyond, primary treatment.
- Conduct research that aims to understand the correlations with long-term side effects.
- Move on from measuring the deficits in quality of life and focus more on developing effective interventions to improve quality of life.
- Explore reducing the intensity of treatments for those with better prognosis.
- Expand resources in neurocognitive rehabilitation.
- Mandate the collection and monitoring of QoL endpoints in clinical trials.

#### Policy support in:

- Developing the infrastructure to ensure equity of access to molecular diagnosis, and ensuring (neuro) pathologists have the necessary knowledge and skills to interpret the molecular data.
- Patient advocacy around access to data and tissue samples for research – it's unethical NOT to share if the patient has consented to their use in research.
- Work with the regulators around improving acceptability of alternative clinical trial designs.
- Improve access to industry compounds.

#### Key enablers

- Establish a large curated database containing molecular and clinical data, including imaging, and ensure both academia and industry can access the data.
- Invest in people and expand the workforce.
- Encourage and facilitate collaborations with expertise outside neuro-oncology.

Unmet needs: key insights from a research perspective

#### Personally affected research priorities

1. Developing and testing new and safer treatments (99%)
2. Detection of tumour progression, complications and response to treatment (94%)
3. Earlier detection and diagnosis of brain tumours (93%)
4. Improving the accuracy of diagnosis (87%)
5. Reducing the side effects (both physical and mental) that arise from the brain tumour itself or from treatment (87%)
6. Living well with the long-term side effects from the brain tumour itself or from treatment (84%)

#### Researcher priorities:

- **Discovery:** develop understanding of the underlying biology of brain tumours; advance imaging techniques and other non-invasive strategies for assessing response and progression.



- **Translation:** bridge the gap between pre-clinical and clinical testing; improve the success rate of clinical trials; empower patients to access trials and better engage them with their care.
- **Quality of Life:** improve the provision of mainline treatment; ensure patient care is maintained; research correlations with long-term side effects; develop effective interventions to improve quality of life; explore reducing the intensity of treatments for those with better prognosis; expand resources in neurocognitive rehabilitation; mandate measuring of QoL endpoints in clinical trials.
- **Policy:** develop equity of access to molecular diagnosis, improve (neuro) pathology skill; patient advocacy around access to data and tissue samples for research (Caldicott Principle 7); improve acceptability of alternative clinical trial designs; improve access to industry compounds.
- **Key enablers:** establish a large open access, curated database containing molecular and clinical data, including imaging; invest in people and expand the workforce; encourage and facilitate collaborations with expertise outside neuro-oncology.

### All-Party Parliamentary Group on Brain Tumours (APPGBT)

The APPGBT have launched their report 'Pathway to a Cure – Breaking Down the Barriers' looking at how the government can best support research into brain tumours.

Further details about the inquiry and the 2023 report can be found [here](#).

### Source K: Key brain tumour statistics ([source document](#))

Key statistics	Date of source Data	Data Lasted checked
Over 12,000 (actual 12,288) people are diagnosed with a primary brain tumour every year <sup>1</sup>	Average 2016 to 2018	May 2023
Brain, other CNS and intracranial tumours is the 9th most common cancer in the UK, accounting for 3% of all new cancer cases (2016-2018). <sup>2</sup>	Average 2016 to 2018	May 2023
Just 13% of adults diagnosed with brain cancer survive five years or more compared to an average across all cancers of 52%. <sup>3</sup>	Report 2023 Data from 2016 to 2020	May 2023

<sup>1</sup> Cancer Research UK. Brain, other CNS and intracranial tumours incidence statistics [Internet]. Cancer Research UK. [cited May 2021]. NB numbers do not add due to scope of underlying data – see source. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-tumours/incidence>

<sup>2</sup> Cancer Research UK. Brain, other CNS and intracranial tumours incidence statistics [Internet]. Cancer Research UK. [cited May]. NB numbers do not add due to scope of underlying data – see source. Available from: <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-tumours/incidence>

<sup>3</sup> [Cancer Survival in England, cancers diagnosed 2016 to 2020, followed up to 2021 - NDRS \(digital.nhs.uk\)](#)

38.9% of patients were diagnosed with a brain tumour through emergency presentation, in comparison to 18.5% for all cancers.. <sup>4</sup>	2018	May 2023
At least 88,000 children and adults are estimated to be living with a brain tumour in the UK currently (England 68,500; Scotland 10,000; Northern Ireland 5,500; Wales 4,000). 86% of the 88,000 are living with low grade tumours and 14% with high grade tumours. <sup>5</sup>	2020	May 2023
Brain tumours are the biggest cancer killer of children and young adults. <sup>6</sup> Of the survivors of childhood brain tumours, 60% do not achieve complete independence as adults. <sup>7</sup>	2019	May 2023
3.2% of the over £700 million invested in UK cancer research funding in 2019/20 was spent on brain tumours. NB this percent includes £6.6m (1%) - of spending by The Brain Tumour Charity. <sup>8</sup>	2019	May 2023
727 people with brain cancer were recruited onto clinical trials in 2020/21, an increase of 28% from the average of the previous 3 years <sup>9</sup> .	2021	May 2023
There are over 120 different types of brain and CNS tumours – it is not one disease <sup>10</sup> .	2016	May 2023
Brain cancer reduces life expectancy on average by 27 years – the greatest reduction of any cancer or significant disease over 7 years more than any other cancer or significant disease of unmet need (eg Parkinson's, Alzheimer's, cardiovascular disease, stroke). <sup>11</sup>	2019	May 2023
The total cancer research spend, as recorded by the NCRI, has risen 32% in the past 10 years. However, total UK funding into brain tumour research has increased by 348% over the same ten years, from £6.4m to £22.3m - meaning that the proportion of total cancer funding spent on brain tumours has increased from 1.2% in 2010/11 to 3.2% in 2019/20. <sup>12</sup>	2020	May 2023

#### Unmet needs: summary insights from brain tumour statistics

- Brain tumours are the biggest cancer killer of our young.
- 13% of adults diagnosed with brain cancer survive five years or more compared to an average across all cancers of 52%. There is patient-reported and clinical evidence for the wide-ranging and often severe impact of brain tumours on quality of life because of their location.

<sup>4</sup> [CancerData](#)

<sup>5</sup> The Brain Tumour Charity 'Brain tumour statistics 2020' report, Page 23.. Prevalence has been estimated based on published survival rates and incidence from cancer registry data for England, Northern Ireland, Wales and Scotland.

<sup>6</sup> Based on 2019 ONS data for ages 0-39, <https://www.nomisweb.co.uk/>.

<sup>7</sup> Attainment of Functional and Social Independence in Adult Survivors of Pediatric CNS Tumors: A Report From the St Jude Lifetime Cohort Study.; <https://ascopubs.org/doi/full/10.1200/JCO.2018.77.9454>

<sup>8</sup> NCRI tables. Cancer Research Spend Data Package 2019 Final [Internet]. Accessed 2020. Available from: <http://www.ncri.org.uk/what-we-do/research-database/>

<sup>9</sup> ICR 'Clinical trials in cancer' report 2021

<sup>10</sup> WHO published a reclassification of CNS tumour codes in 2021

<sup>11</sup> Global Burden of Disease, <https://vizhub.healthdata.org/gbd-results/>

<sup>12</sup> UK funding source source: NCRI source: <https://www.ncri.org.uk/how-we-work/cancer-research-database/trends-in-disease-site-spend/> plus TBTC funding sourced from: <https://www.thebraintumourcharity.org/about-us/annual-report-and-accounts/>

- At least 88,000 children and adults are estimated to be living with a brain tumour in the UK currently.
- Brain cancer reduces life expectancy on average by 27 years — the greatest reduction of any cancer or significant disease (eg Parkinson's, Alzheimer's, cardiovascular disease, stroke).<sup>13</sup>
- The proportion of UK cancer research funding spent on brain tumour research is 3.2% (2019/20).
- 38.9% of patients were diagnosed with a brain tumour through emergency presentation, in comparison to 18% for all cancers. There has been a 348% increase in brain tumour research funding in the UK over the past ten years, from £6.4m to £22.3m.
- Life expectancy for those with brain cancer has increased by 4.6% over the past ten years, the second highest increase of any cancer or significant disease of unmet need.

## 5. Sector insights

### Source L: Brain tumour sector PESTLE

We carried out a PESTLE (Political, Economic, Socio-Cultural, Technology, Legal, Environmental) analysis of the brain tumour sector.

- The PESTLE was carried out with the intent of including perspectives from across the brain tumour sector.
- A review was undertaken of the key factors from a political, economic, socio-cultural, technological, legal and environmental perspective.
- The original PESTLE ([Source document](#)) was also built on by the wider Working Group, expanding the resulting list from the source document.
- The issues were then analysed with the resulting unmet needs, opportunities and threats determined below:

#### Strengths

- Universal access to the NHS for people in the UK.
- Progress of Tessa Jowell Centres of Excellence programme in recognising and spreading best practice.
- Improving Brain Tumour Care surveys show gaps in patient experience.
- Increased researcher willingness to collaborate and use new technology to improve outcomes.
- Numerous examples of individuals and charities (eg TBTC supporter groups, BTR member charities) working together to make progress.

#### Weaknesses

- Unequal access to care and support for disadvantaged groups and lack of data on these gaps.
- Lack of emotional support for brain tumours (and other diseases).
- Significant gaps in NHS provision and specialist staff (e.g. CNSs, neuropathology, neurorehabilitation, palliative care), which have worsened since COVID.

<sup>13</sup> Global Burden of Disease, accessed 2021. <https://vizhub.healthdata.org/gbd-results/>

- Lack of joined-up or integrated care for people with brain tumours across journey and across community- and health-care.
- Lack of breakthroughs and significant new treatments for decades.
- Little research focus on recurrence, metastatic tumours, rehabilitation etc.
- Low public awareness in the UK and globally of the incidence and impact of brain tumours.
- Relatively rare cancer type and with high mortality, which limits sustainable pressure for change.
- Over reliance in UK society on the third sector to provide support and fill gaps in mainstream care and fund essential research.
- Brain tumour charity sector behind other sectors in long term investment areas such as legacies, research, awareness, campaigning.
- Not empowering people to join a strong global community forcing change on common issues.
- The majority of brain tumours are not preventable, so a greater demand is made of treatments as the underlying burden cannot be reduced.
- Looking globally there are large inequalities (especially for low and middle income countries) across support/wellbeing, treatment and access to research by ethnicity, tumour grade etc.

## Opportunities

- Change to a Labour government might prioritise NHS 'drug innovation'.
- Health & Social Care Levy including government £40m BT research commitment.
- New £50m research, innovation and collaboration fund could include brain tumour research.
- APPG inquiry on brain tumour research raising awareness.
- Closer brain tumour charity collaboration could bring opportunities.
- Increased need for charity services.
- Mandate for data use from brain tumour community (Caldicott P7).
- Increased focus on helping others post COVID.
- Potential for advances via equality, diversity and inclusion.
- New digital infrastructure could improve health and care access eg apps, telehealth.
- Growing use of AI accelerating research.
- New technology-based treatments emerging for brain tumours.
- Real-time, wearable health monitors to improve treatment and care.
- Tech firms targeting healthcare opportunities.
- Proposed social security systems reform could benefit those with brain tumours.
- Charities Bill 2021 makes collaboration easier.
- Employment working model improving around flexibility, benefitting carers.
- Medicines & Medical Devices Act 2021 an enabler for personalised treatments.
- Carbon footprint of the healthcare sector will drive changes, e.g. around clinical trials.
- Corporate attention on Net Zero targets.
- Climate change impact on health and healthcare inequality.
- Good level of UK support available for brain tumours from charities.
- Looking globally, we can increase worldwide access to basic support, and improve outcomes most and at lowest marginal cost for people diagnosed in low and middle income countries.
- We haven't yet uncovered and made a health economics case for greater investment in treatment and research into brain tumours.
- Opportunity to include metastatic as well as primary brain tumours within the scope of the sector, attracting more support from policy makers and the general public.
- Embrace diversity and involvement within UK charity sector organisations and their partners to improve outcomes.
- Hybrid working offers opportunity for much wider, more diverse participation in the third sector, including effective global collaboration.

- Growth opportunity for funding of brain tumours in UK and global markets given the numbers affected and relatively low current funding.
- Pooling clinical and patient reported data within countries and globally.

### Threats

- Impact of 'Black Swan' events on recovery and giving.
- Post-Brexit/Pandemic impact on recovery and giving.
- Donations impacted by cost of living crisis.
- 6m+ on NHS waiting lists affecting access to brain tumour treatment.
- Healthcare staffing constraints affecting brain tumour care.
- Brain tumour sector research is too small to attract Pharma interest.
- Poor visibility versus other more prevalent diseases, e.g. dementia.
- UK inequalities growing, including in health and digital access.
- Conflict of interest between health priorities and NHS Net Zero ambitions.
- Greater focus on healthcare inequalities in political agenda.
- Corporates have moved into 'purpose' and are competing with the charity sector for resource and awareness.
- Proliferation of founder charities and support groups continuously adds to fragmentation of the charity sector.
- Charity sector overall behind curve in digital technology and data skills, and challenged in attracting these specialist skillsets at charity salaries.
- Persistent failures of the market to direct funds according to unmet needs e.g. into new drug development for the paediatric and low grade tumour community.
- The huge cost burden of bridging the translational gap between early stage research and clinical trials.

## Source M: Review of key Charity players ([source document](#))

### Overview

- We carried out a review of the 'charity key players' in the UK and globally in the brain tumour sector, including those whose work does or might (within the UK) benefit those with brain tumours.

- The list is not exhaustive and there will be omissions:
  - **Completed:** UK and global brain tumour charities, UK neurological charities, apps for brain tumours cancer and long term conditions (See Source document O below)
  - **In progress:** Research teams (basic science, imaging, new treatments, QoL), Change forums & lobby groups, Data registries for cancers
  - **Not prioritised currently:** Big health data and AI, Public health and prevention bodies, Leading neuroscience centres, Best practice, governing & networking bodies, Funders and philanthropists, Pharmaceuticals/biotech/industry, Health Service commissioning and governance, Medical technology, Complementary therapies, Living well & mobility aids, Mental health, A&Es and trauma centres (and their trusts and CCGs), Primary care (opticians, GPs, community nursing), Health and wellbeing nutrition movements, Impairments charities, Support groups
- The information is publicly available and the summary overviews have been carried out in good faith and should be considered indicative, not definitive.

#### **UK key brain tumour players summary**

Based on a review of 22 UK not-for-profits who provide some service or benefit to those with brain tumours:

- There are multiple charities in the UK providing research funding, raising awareness and providing support to those with brain tumours.
- Many charities have used partnerships and collaborations to grow and there is some evidence of wider cross-sector collaboration.
- There are opportunities to explore the benefits of further collaboration within the sector, where it would benefit those with brain tumours.

#### **UK key neurological charities**

Based on a review of 12 charities where there may be learnings or benefits from closer collaboration:

- There are opportunities to learn from the breadth of collaboration within the neurological charity sector and success (and failures).
- Deeper partnerships with brain injury charities could provide opportunities to support quality of life initiatives and/or upweight campaigning and awareness efforts.
- Collaboration with Parkinson's/MS/ Stroke/Alzheimer's charities could help progress in advancing treatments, linking into cross-neuro community work already in progress.

#### **Key global players**

Based on a review of 46 not-for-profits who provide some service or benefit to those with brain tumours:

- Wide range of organisations internationally in terms of size and financial resources.
- In such a fragmented universe, likely that main opportunities for collaboration will be US/AUS
- Opportunity exists for pooling resources and knowledge sharing, as well larger charities acting as vanguard for smaller organisations.

#### **Source N: Review of key research players ([source document](#))**

We carried out a review of the ‘research key players’ in the UK, USA, Australia, and Canada. The source linked above summarises the key research establishments in each of these countries for the purpose of mapping the overall landscape of brain tumour research.

There are opportunities for:

- More collaboration amongst UK brain tumour organisations, driven by benefit.
- Opportunities for international collaboration for patient benefit eg USA/AUS
- More collaboration across neurological, cancer & other charities on common issues
- Increase and coordinate research funding globally
- Increase worldwide access to basic support
- Coordinate on healthcare advocacy and campaigning
- Pool patient-reported data

**Source O: App landscape review ([source document](#))**

We carried out a review of the apps and other support tools relevant to the brain tumour sector. The summary was developed from the perspective of our BRIAN app and we could make this a broader summary. From a BRIAN perspective, the follow insights can be drawn:

Strengths	Weaknesses
<ul style="list-style-type: none"><li>• Leader in BT-related apps currently available</li><li>• Wide range of content/functionality</li><li>• Provides data to medical researchers</li><li>• Links patients to clinicians</li><li>• Integration with health wearables (Apple, Fitbit, Google)</li><li>• Certified by ORCHA</li></ul>	<ul style="list-style-type: none"><li>• Limited awareness of app</li><li>• Still relatively low adoption by UK BT community (7k/88k)</li><li>• Active usage needs to grow</li><li>• Complex interface</li><li>• Rehab/wellbeing features could be enhanced</li><li>• English language only</li></ul>
Opportunities	Threats
<ul style="list-style-type: none"><li>• Extend usage of app in UK and global market eg multi-language</li><li>• Simplify check-ins and experience</li><li>• Developing current patient and clinical team offer</li><li>• More linking clinical &amp; patient reported data</li><li>• Potential to partner with complementary service providers to enhance content/functionality</li><li>• Wider integration with real-time monitors (sensors/wearables)</li><li>• Speed of innovation in IT likely to enable as yet unidentified step-change improvements in next 3-5 years</li><li>• UK 5G rollout provides platform for enhanced services</li></ul>	<ul style="list-style-type: none"><li>• Unidentified competitors may exist</li><li>• Existing apps, esp. cancer apps, could extend services/reach (e.g. ZOE)</li><li>• Other apps could compete on data collection and fragment the data set</li><li>• Entry to app market is relatively easy – new entrants could appear from UK/globally</li><li>• UK 5G rollout/adoption remains slow</li><li>• Limited resources/funding for further app development</li></ul>

- Use BRIAN as a showcase marketing tool for charity

## Source P: Data sharing survey ([source document](#))

In 2017, we carried out a data sharing survey to find out what the community felt about sharing their data, ahead of developing our app and databank. The summary results, which gave us a mandate to establish the patient-led app, were as follows:

- 97% were willing to share their medical and health data to help improve brain tumour treatment and care;
- 98.5% were willing to share this knowing that security breaches are not completely preventable; and
- 94.7% were willing to share this knowing that they could potentially be identified.

### Strengths

- The brain tumour community has a strong desire to share their data to help brain tumour treatment and care.

### Opportunities

- We have a duty to enable the responsible use of patient data to improve outcomes, based on this mandate and according to Caldicott Principle 7 (The duty to share information can be as important as the duty to protect patient confidentiality)