

FACTBASE: WHAT NEEDS TO CHANGE?

#BeyondBrainTumours

June 2023

FACTBASE introduction

Intro:

- Our community-created Factbase details the evidence that has helped create our “Living longer and better” strategy. This was created under ‘Phase 2: Mapping the need’ during the strategy development.

Purpose:

- The Factbase summarises a range of surveys, publicly available brain tumour reports and literature papers to identify unmet needs and sector insights.

Contents:

- Sources of information
- Summary unmet need
- Summary of SWOT (strengths, weaknesses, opportunities, threats)

PLEASE NOTE

- This Factbase has been verified. It details the evidence that has helped create our “Living longer and better” strategy. We are grateful for our working group of volunteers that have helped put this document together.
- 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. This document 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.)

Factbase: sources



Community Unmet Needs: Sources

- Community 'What must change' survey
- 'What must change' workshops on key issues
- Cancer landscape review
- Tessa Jowell Centres of Excellence insights
- Improving Brain Tumour Care survey results
- 'Life with a brain tumour' reports
- Fighting for a Faster Diagnosis
- Research strategy insights
- Brain tumour statistics

UNMET NEEDS
(Pages 6-16)

Factbase: sources



Sector insights: sources

- Market analysis (PESTLE)
- Key charity players
- Key research players
- App landscape review
- Data sharing survey

**Summary SWOT
(Pages 17-20)**

Unmet needs 1: Impact and awareness of brain tumours

Brain tumours are not getting a fair share of investment given burden:

- **~88,000 living with** a brain tumour in UK
- **13%** of adults diagnosed with brain cancer **survive five years or more**
- 60% of childhood survivors **cannot live independently**
- **Reduces life expectancy more than any other cancer** (27 average years of life lost)
- Most people are diagnosed via **emergency presentation**, also associated with the poorest survival rates
- Wide-ranging, often severe impact on quality of life because **it's your brain**
- **Low public awareness** of signs and symptoms
- Research funding up 350% to £22.3m in UK but still **only 3.2%** of total for cancer

What people say



“

Not nearly enough funding into research for a cure for this deadly disease. Too many people are losing their lives to brain tumours.

Unmet need 2: New treatments & research

There is a historic lack of new treatments for brain tumours, with a translational gap in turning knowledge into treatments:

- Developing **new treatments** is a top community priority, including for tumour progression
- **Scale of investment** in research is a top community priority
- We must improve the **ease and speed** of conducting clinical trials
- Only **3 in 10** people say they **participated** in research
- **5 in 10** consider alternatives and/or complementary therapy
- Need improved knowledge of **basic biology**
- Demand for treatment pathways that deliver better **quality of life**

What people say



“

Research and treatment options are the only way forward to give sufferers a chance. It takes cash, will and organisation. It's worked for other cancers and COVID.

Unmet needs 3: Treatment pathway

Large inequalities and gaps in UK & globally in treatment by country, centre, ethnicity, gender, tumour grade etc:

- **Best care** for everyone is a top community priority
- **Earlier** detection and diagnosis is a top community priority, with delayed diagnosis for **3 out of 10**
- **Poor clinician communication** leads to poor understanding of treatment, prognosis and side effects e.g. **during diagnosis**
- **4 out of 10** lack CNS access (Clinical Nurse Specialist)
- Gaps in pathway exist, e.g. **neuro-rehabilitation**, neuropathology, palliative care, neuropsychiatrists, dedicated CNSs

What people say



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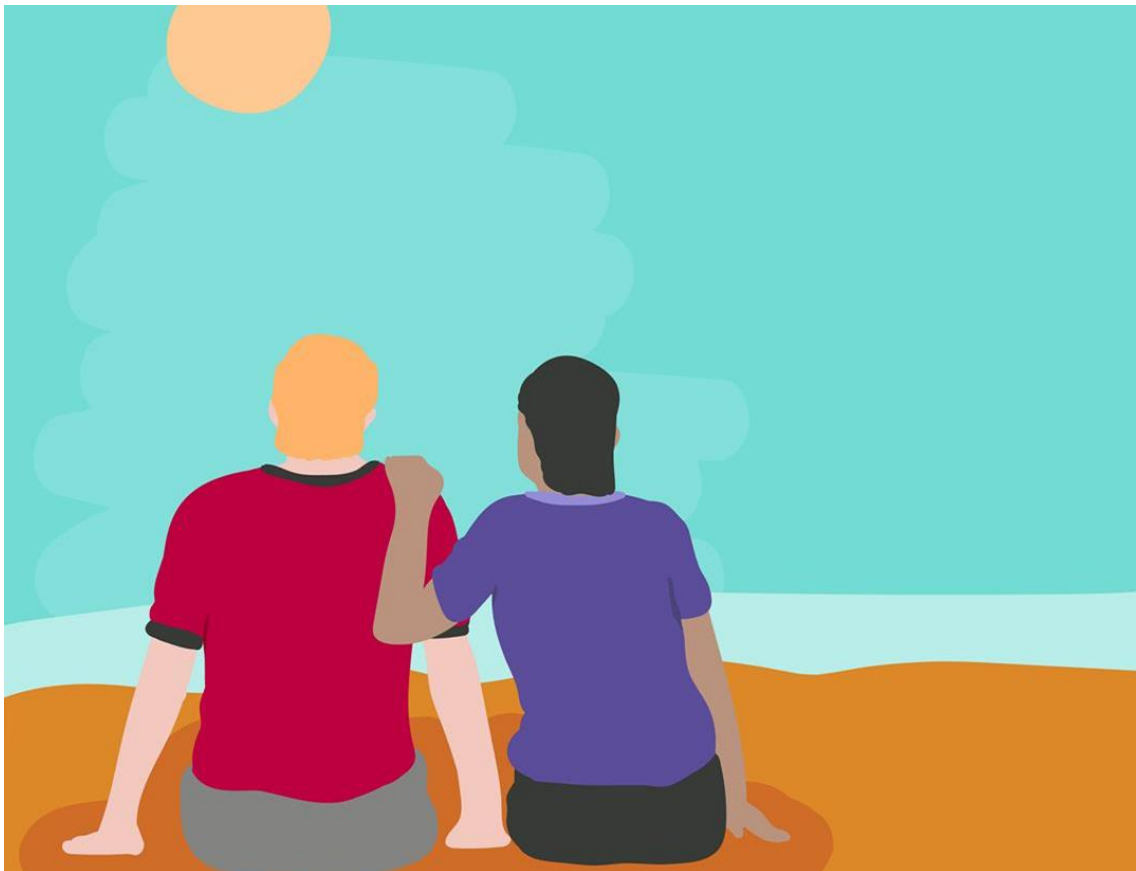
Collaboration is poor, there's nothing 'joined up' or streamlined [between] health care settings. It makes things very, very tough. Everything has to be repeated and must be constantly chased up.

Unmet need 4: Support and wellbeing

Significant inequalities, in UK & globally, in support and wellbeing by country, centre, ethnicity, tumour grade etc:

- **7 out of 10 have unmet needs**
- 9 out of 10 affects their **emotional or mental health**
- People have significant **impairments**, eg 1 in 3 visual, 1 in 2 memory
- People have significant **life changes**, eg 1 in 2 have financial difficulties
- **Gaps in understanding** of treatment, prognosis and side effects
- People **not told about support**, eg **7 in 10** not signposted to benefits
- **8 out of 10** don't have a personalised care plan
- End of life support lacking and not well integrated e.g. **6 out of 10** with terminal diagnoses **not given end of life care options**

What people say



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The mental impact of this has made my loved one consider suicide as a viable option, this shouldn't be the case and could be relieved with care offered at each stage.

Unmet need 5: Community & collaboration

- People expect **more collaboration** between charities, inside and outside the sector, based on potential for benefit.

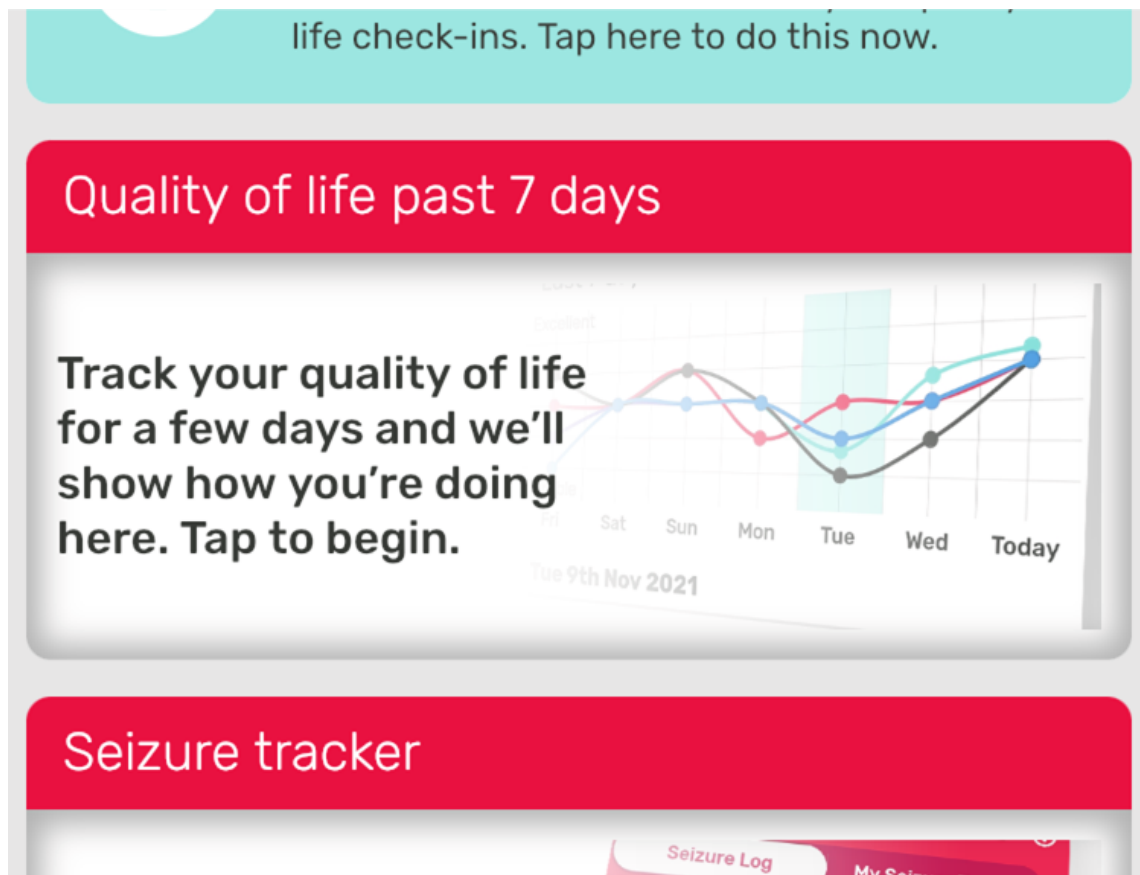
“The sector must collaborate and work together to make the best use of available resources to improve the lives of people living with a brain tumour. There is strength in numbers.”

Unmet need 6: Use of data

Strong community mandate to use health data to improve outcomes:

- Need large, **open-access database** of molecular, clinical, imaging and patient reported data
- Don't measure and **act on long-term outcomes** of everyone, including quality of life
- No universal **access to molecular** diagnosis
- Caldicott principle 7: duty to share information for improving care is as important as the duty to protect confidentiality.

What people say



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I feel very strongly that more progress is required as regards 'using clinical and patient reported data to improve care'. In fact, I haven't observed any real gathering of data to actually improve care.

Strengths of the sector

The UK brain tumour focus has grown considerably in the last decade across funding research, offering support and building awareness:

Impact and awareness of brain tumours

- There is strong motivation by those affected to drive change and improve outcomes, given the impact of brain tumours.
- There is a strong underlying UK propensity to give money and time, boosted by COVID.
- There is a healthy APPG on brain tumours.

New treatments and research

- There has been a 348% increase in research funding for brain tumours over 10 years to £22.3m in 19/20.
- The global research community is growing e.g. US now \$237m/year.
- The Brain Matrix programme creates a future platform for accelerated research.

Support, well being and treatment pathway

- A good level of UK support is available for brain tumours from charities.
- There is universal access to the NHS for people in the UK.
- The Tessa Jowell Centres of Excellence programme is making great progress in spreading best practice.
- The Improving Brain Tumour Care surveys show gaps in patient experience.
- COVID has accelerated adoption of digital health technology and telehealth.

Community, collaboration and data use

- There are many brain tumour focused charities covering most aspects of need, with some collaboration between them.
- The brain tumour community has a strong desire to share their data to help brain tumour treatment and care.
- There are many apps emerging to improve research and brain tumour patient care
- There are increasing examples of charities, groups and individuals working together effectively to drive change.

Weaknesses of the sector

Impact and awareness of brain tumours

- The brain tumour sector is too small to attract Pharma interest.
- There is low public awareness in the UK and globally of the incidence and impact of brain tumours.
- It is a relatively rare cancer type and with high mortality which limits sustainable pressure for change.

New treatments and research

- There has been a lack of breakthroughs, with no significant new treatments for decades.
- There is little research focus on recurrence, metastatic tumours, rehabilitation etc.
- As brain tumours are not preventable, more demand is made of treatments as the underlying burden cannot be reduced.
- Research funding for brain tumours has increased but is low compared with other cancers at only 3.2% of total cancer funding.
- No delivery on the £40m committed by the government to research into brain tumours after Tessa Jowell's death.

Support, well being and treatment pathway

- There is unequal access to care and support for disadvantaged groups and a lack of data on all these gaps.
- There is a lack of emotional support for brain tumours (and other diseases).
- There are significant gaps in NHS provision and specialist staff (e.g. CNSs, neuropathology, neurorehabilitation, palliative care)
- There is a lack of joined-up care for people with brain tumours across community and health-care systems.
- There is over-reliance in UK society on the third sector to provide support and fill gaps in care and essential research.

Community, collaboration and data use

- There is a lack of diversity in UK charity sector organisations.
- The brain tumour charity sector is immature compared to other cancers eg in research, awareness, legacies, campaigning.
- There are limits to global collaboration on healthcare and support given different healthcare systems.
- We don't measure and act on long term outcomes including quality of life.
- It is a fragmented sector in the UK and globally.
- We are not empowering people to join a strong global community forcing change on common issues.

Opportunities for the sector

Impact and awareness of brain tumours

- Given the relative impact of brain tumours, there is potential to increase the number of people driving change.
- We have yet to made a health economics case for greater investment in treatment and research into brain tumours.
- There is opportunity to include metastatic within the scope of the sector, attracting more support.

New treatments and research

- We can increase and coordinate research funding globally.
- There is a growth opportunity for funding of brain tumours in UK and global markets given the numbers affected and relatively low current funding.

Support, well being and treatment pathway

- Looking globally, there is real opportunity to increase worldwide access to basic support for people diagnosed in low and middle income countries.

Community, collaboration and data use

- Emerging use of AI, real-time monitoring, healthtech wearables, use of apps, should all enable joined-up personalised support and accelerate treatment/research capabilities
- Embrace diversity and involvement within UK charity sector organisations and their partners to improve outcomes.
- The shift to more flexible working benefits carers.
- There is opportunity in the UK and globally to grow the adoption of a common brain tumour app and data bank eg BRIAN.
- Hybrid working offers the opportunity for wider, more diverse participation including effective global collaboration.
- There may be benefits to collaboration by brain tumour charities, UK or globally, on research, influencing, support, data etc.
- There may be benefits to closer working with the neurological community on campaigning, research and quality of life.
- The Charities Bill 2021 makes collaboration easier.
- We have a duty to use data to improve outcomes, based on the community mandate and according to Caldicott Principle 7
- We can pool clinical and patient-reported data within countries and globally.

Threats to the sector

Impact and awareness of brain tumours

- 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
- There is a lower share of attention for brain tumours given the economy, wars/pandemics, climate change etc.
- There is lower attention for brain tumours compared to other diseases, given the ageing population and rapid growth in diseases like dementia.
- Corporate brands have moved into offering 'purpose' and social good, and are competing with the charity sector for resource and awareness.
- The charity sector overall is behind the curve in digital technology and data skills, and challenged in attracting these specialist skillsets at charity salaries.

New treatments and research

- There is a huge cost burden and time delay in bridging the translational gap between early stage research and clinical trials.

Support, well being and treatment pathway

- There are falling numbers of GPs in the UK - a decline of over 1400 since 2015.
- The NHS is under severe pressure which looks set to continue.
- There is increasing healthcare inequality in the UK and globally.

Community, collaboration and data use

- 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.
- Proliferation of founder charities and support groups continuously adds to fragmentation of the charity sector.