

# THE MAJOR CONDITIONS STRATEGY CONSULTATION

## Submission from The Brain Tumour Charity

The Brain Tumour Charity is the world's leading brain tumour charity and the largest dedicated funder of research into brain tumours globally.

As a charity we provide support to the brain tumour community through the funding of new, innovative research, as well as through events, a dedicated support team, and advocating for necessary change to improve the lives of those affected by this disease.

The Secretary of State for Health, Steve Barclay, announced the government would be publishing a Major Conditions Strategy. One of the six major conditions outlined in the announcement is cancer. The evidence from this submission will be considered alongside submissions from the 10-Year Cancer Plan consultation.

We welcome the opportunity to submit to consultation inquiry and share some of the innovative ways that could help support patients with brain tumours.

### Question 1

The condition groups we are focusing on are often driven by preventable risk factors, with nearly half (42%) of ill health and early death being due to them. This includes tobacco, alcohol, physical activity, and diet-related risk factors. Action on preventable risk factors is also central to our work on tackling health disparities, since people living in more deprived areas are more likely to partake in these behaviours.

### How can we support people to tackle these risk factors?

We have submitted evidence to the 10-Year Cancer Plan consultation around the very small proportion (3%) of brain tumours that are linked to external risk factors: being overweight, and exposure to radiation. However, the current scientific consensus suggests that the vast majority of brain tumours are not preventable.

We are disappointed that this submission is limited in both the questions and word limits for cancers, particularly when there has not been significant change in the outcomes and experiences of patients with brain tumours.

Moreover, unlike some other major cancer types, even non-malignant tumours in the brain can have a major impact on the patient's long-term health and quality of life and can be life-threatening. We stress for the approximate 40% of the brain tumour community that have low-grade, benign tumours, facing serious, life-changing side symptoms, to be included within the Major Conditions Strategy.

Brain tumours do not have the same risk factors as other cancers. While there are no particular population groups that are at increased risk of having a brain tumour, there are groups who are likely to have a poorer experience and outcome than others. Not only are brain tumours a less survivable cancer, with a one-year survival rate of just 41.2%, there is major variation across the country – across Cancer Alliances the survival rate ranges from 49.4% to 37.2%.

The Tessa Jowell Brain Cancer Mission revealed shocking variation in brain tumour services across the UK, with disparities in the quality of treatment and experience of care pathways. For example, the report observed a significant variation across centres in the number of patients offered genetic testing (from 200 samples to fewer than 50 samples) despite the recognised importance of sequencing for identifying actionable targets in brain cancer. The postcode of patients diagnosed with brain tumours should not influence survival or experience of care. More action from the government is urgently needed to tackle the inequality in access and experience of care for all patients affected by brain tumours across the UK.

## Question 2

The cancer call for evidence published in 2022 provided useful insights that will shape the development of the major conditions strategy. We have published what we heard in the cancer call for evidence, which can be found at the end of this survey. However, if you wish to, we wanted to provide an opportunity to provide any further insights in this call for evidence.

## How can we better support those with cancer?

Outcomes for patients diagnosed with brain tumours have not improved in decades, despite being the largest cancer killer for under-40s. As The Brain Tumour Charity, we propose the following areas are central to the development of the Major Conditions Strategy:

**Faster diagnosis** – A high proportion of diagnoses are made in emergency care (41.6%%).

- Improved awareness in primary care is needed to understand the signs and symptoms brain tumours present. Our current campaign Better Safe than Tumour is helping to raise awareness, but more support from government is needed to reduce diagnosis waiting times.
- Faster roll out of the NHSE announcement of direct access to MRI imaging for GPs to speed up diagnosis routes.
- The development of clear targets addressing early detection for non-staged cancers, such as brain cancers (including proxy measures to monitor progress) are urgently needed.
- Investment in research to explore triage tools like the Dxcover liquid biopsy test for brain cancers, and some other less survivable cancers, as the evidence develops.

**Research** – Access to potentially life-prolonging clinical trials is varied across the UK.

- An action plan for utilising the £40m funding for research into brain tumours committed by the government in 2018 must be prioritised, as should improving patient participation in research.
- While there are innovative, albeit limited number of trials, including CAR-T cell therapy offering potential personalised medicine, only 5% of patients are accessing trials. The Improving Brain Tumour Care (IBTC) Survey also found only 24% of patients had been informed about potential research participation opportunities in clinical trials. In line with ensuring patients are offered personalised care, they should be informed of all options throughout their pathway.

**Person centred, integrated care** – access to Holistic Needs Assessments (HNA) and Clinical Nurse Specialists (CNS) is vital for ensuring person-centred, joined-up care, yet access is varied.

- The IBTC survey found 79% of participants were given access to a CNS or key worker, and only 40% were offered an HNA. Action to address the workforce shortage should be made a priority. The current 150k workforce gap stretches across multiple areas including medical oncologists and CNSs. A recruitment drive, to support multidisciplinary teams, dedicated researchers, early career researchers to specialise in neuro-oncology is needed.

**Address inequalities** – As outlined in the first question, brain tumour patients experience a postcode lottery in all stages of their pathway. These inequalities need to be formally recognised and addressed.

**Cancer and other conditions** – While some patients with a brain tumour make a full recovery, some are left with life-altering, long-term conditions that require aftercare and support for the rest of their lives.

- Signposting to after-care and support services, both for mental and physical health conditions, desperately needs improvement. There is a worrying lack of such services, leaving patients' needs unmet; only half of our survey respondents were signposted to emotional support post treatment.
- HNAs are the best chance for receive wrap-around care, yet we know this is not being consistently offered. Patients need a commitment that all patients are offered personalised HNAs.

### **Contact Details**

We greatly appreciate the opportunity to participate in this consultation. If you have questions about the innovations that have been mentioned, or the work of the Brain Tumour Charity, please reach out to our Policy team at [policy@thebraintumourcharity.org](mailto:policy@thebraintumourcharity.org).