

TEN MINUTE RULE MOTION – 28

FEBRUARY 2024

Key Messages

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

We know brain tumour patients, particularly those diagnosed with high grade or cancerous brain tumours, **are falling through the cracks of health and medicines policy**. With 12,000 people diagnosed with a brain tumour every year in the UK, we must do better.

We know that more treatments are absolutely necessary to improve survival and halve the harm for brain tumour patients and we are keen to work with industry to ensure that patients get access to more treatments as quickly and safely as possible. But there are barriers to overcome as [The Institute of Cancer Research Clinical Trials report](#) found that **brain tumour clinical trials had the lowest recruitment levels of all cancers from 2017-2021**.

Not only that but people are also not accessing the right support from healthcare professionals and **four in ten respondents to our [Improving Brain Tumour Care \(IBTC\) surveys](#) did not have good access to a CNS or key worker**. This is unacceptable and shows how important investment in our NHS workforce is.

This briefing outlines the work The Brain Tumour Charity is doing to try to overcome some of the barriers to drug development through its own funding but also what we are calling on government to do to improve the system for everyone.

We are recommending that:

- The government must implement the **recommendations made in the Lord O'Shaughnessy Commercial Clinical Trials Review in full**
- All people diagnosed with a brain tumour **should have access to a Clinical Nurse Specialist (CNS) or keyworker**, as recommended by NICE clinical guidance (NG99) in England, who **will also be able to provide information about clinical trial opportunities**
- The proposed shortening of training for medical students does **not compromise the high-quality training** they receive

Clinical Trials and Virtual Bio-Tech

We know brain tumour patients struggle to access appropriate trials. A key factor in ensuring research into brain tumours progresses to clinical trial stage is the financial incentive for pharmaceutical companies. Brain tumour drugs can be unappealing to pharmaceutical companies due to the relative rarity of brain tumours, so fewer people needing the drugs, and the highly aggressive and terminal nature of lots of the cancerous tumours, meaning people are taking the drug for less time. Two factors that do not create a good investment incentives for pharmaceutical industry.

In order for a piece of research to graduate out of the lab setting, it needs to be taken through large scale, drug discovery testing to ensure what's been proven in the lab is correct and that it isn't toxic to humans. It is only after this phase that drugs can be taken forward to the clinical trials process. But this costs money, and, if pharmaceutical companies are not financially motivated to invest, lots of research will never graduate out of labs. To make a start in countering this, **The Brain Tumour Charity is [funding new Translational Award](#), investing £2.2m over the next 3 years**, to take lab based

research through this large scale testing phase. **The aim is that more research will be taken all the way through to clinical trial**, rather than falling at the first hurdle.

Another way The Brain Tumour Charity is working to **improve clinical trial access is by funding and working to open our own trials**. Recently, a new glioblastoma clinical trial [named ARISTOCRAT](#) has opened with sites across the UK. The trial looks at whether cannabinoid-based drugs could help treat glioblastoma. **Lab-based research has shown that cannabinoid-based drugs may slow tumour growth**, particularly when used in conjunction with temozolomide, which is a chemotherapy drug. This is because glioblastomas have been shown to have receptors to cannabinoids on their cell surface.

We have also funded [the Tessa Jowell Brain Matrix](#), a pioneering study that will enable doctors to treat brain tumours with drugs that are more targeted than ever before. **By using genomic sequencing of gliomas, patients will have access to the most personalised treatments available and may fast-track access to appropriate clinical trials**. If they are not eligible for a current trial, patients may be given access to drugs, which have shown potential in gliomas, based upon their genomic sequencing.

On a systemic level, to ensure that industry is incentivised to open more clinical trials in the UK and to make drugs available for clinical trials, it is **essential that the [Lord O'Shaughnessy Commercial clinical trials in the UK review](#) recommendations are implemented in full**. It is also essential that the wider access environment is considered and that there is a clear and fair pathway to reimbursement for new treatments.

Workforce: Multi-disciplinary Teams (MDT) and Clinical Nurse Specialists (CNSs)

Having a fully staffed, effective and sustainable workforce is crucial for people with brain tumours to ensure an integrated and patient-centred pathway from symptoms all the way through to treatment and beyond. We know we also **need this workforce in order to ensure people are able to take part in research** as currently a barrier is that people are not being told about opportunities and staff do not have capacity to take on additional research work on top of their day jobs. [Cancer Research UK found in 2022](#) that **staff lacked capacity to dedicate time to research** with 64% of surveyed NHS staff working in research-inactive Trusts citing it as a barrier.

Once diagnosed, people should have access to a Holistic Needs Assessment (HNA) and care plan as outlined in the NHS Long Term Plan. They **should also have a named healthcare professional** to help put that personalised plan in place (as part of the [NICE Quality Standard NG99](#)) and **support to access potentially life-prolonging clinical trials**. But we know that people do not always get this access. Our [IBTC surveys](#) found that just 40% of respondents said they were offered a HNA. It also found that nearly one in six were not given access to a CNS or key worker.

The [Long-Term Workforce Plan](#) outlines that the NHS aims to **double the number of medical school training placements, to increase GP training** places in specialist areas and invest in the adult nursing workforce including **training places for CNS in oncology**. It is also promising to hear that there are plans in place for increased capacity for allied health professionals, including radiographers, and research nurses.

However, there are some areas in the Plan which fall short of detail. We need to make sure that the proposed increase in apprenticeship and shortening the curriculum for medical students **still guarantees high-quality training is provided**. Medical oncologists already do not receive mandatory training in neuro-oncology and the **proposed shortening of training could be concerning** if we want to ensure that every health and care professional is equipped with the knowledge of the signs and symptoms of brain tumours to get people a faster diagnosis.

Contact Details

For more information about The Brain Tumour Charity please contact the Policy & Campaigns team at policy@thebraintumourcharity.org.