

All-Party Parliamentary Group on Brain Tumours (APPGBT)
Tumour Treating Fields, Symptom Awareness and Inquiry Update

23rd November 2022 Portcullis House

Agenda

- Welcome from Chair, Derek Thomas MP
- Apologies received
- Matters arising from March/May meetings
- Introduction of Speakers
- Tumour Treating Fields – Hilary Duckworth, Novocure, Matthew Williams, Imperial College Healthcare NHS Trust
- Better Safe Than Tumour Signs and Symptoms Campaign Update – Stephanie Kleynhans and Kate Roberts, The Brain Tumour Charity
- APPGBT Inquiry update – Hugh Adams, Brain Tumour Research
- AOB
- Next meeting

Parliamentary attendees

- Derek Thomas MP – Chair
- The Lord Polak CBE - Officer
- Greg Smith MP – Officer
- Hilary Benn MP
- Virendra Sharma MP
- Ben Lake MP
- Nadia Whittome MP

Speakers

- Hillary Duckworth (Novocure)
- Matthew Williams (Imperial College Healthcare NHS Trust)
- Stephanie Kleynhans (The Brain Tumour Charity)
- Kate Roberts (The Brain Tumour Charity)
- Hugh Adams (Brain Tumour Research)

Discussion Summary

Derek Thomas MP (DT) opened the meeting by welcoming everyone and thanking them for their attendance. He proceeded to outline the background and purpose of the APPGBT, emphasising the importance and urgency of increasing awareness of brain tumours. **DT** also spoke about the need to hear people's stories and their experiences of living with this condition, including the need to increase public awareness of the symptoms of brain tumours.

Hillary Duckworth (HD) made her opening remarks in connection to **Novocure's** mission, emphasising it was to extend survival rates among patients with some of the most aggressive cancers. She noted that **Novocure** has developed a non-invasive approach to disrupting cancer cell division. This new technology is called Tumour Treating Fields (TTF). **HD** highlighted that **Novocure** are looking to start clinical trials of their product in December. She added that this new technology has a broad applicability, meaning that it can be used to treat various other tumours.

Matthew Williams (MW) emphasised that patients undergoing Tumour Treating Fields experience less side-effects from the treatment compared to conventional chemotherapy or radiotherapy. Moreover, Tumour Treating Fields do not require the patient to visit a hospital for their treatment – it can be done at home. This product can also be added to other cancer treatment modalities including chemotherapy and radiotherapy.

He highlighted that in the UK, around 3000 cases of patients with glioblastoma are registered each year. However, there has been no significant improvement in overall survivability outcomes in decades, despite the UK having some of the highest standards of care and care delivery.

MW noted that glioblastoma disproportionately affects children and younger people. It was agreed that the side-effects of traditional radiotherapy for brain tumours are unpleasant for patients that are undergoing treatment. **Novocure** aims to routinely offer patients with glioblastoma the opportunity to speak to them, and also give them an overview of the radiotherapy department in order to make them feel more comfortable – especially children.

Hilary Benn MP (HB) asked what the evidence of the impact is of wearing the TTF device. **MW** highlighted that the TTF device add an extra 5 months on average to a patient's lifespan. Median survival rate after radiotherapy is 3 months and the side-effects are usually much more unpleasant. The magnitude of benefit is roughly the same, but the treatment is less invasive and the most significant side effect is irritation to the skin. It was noted that the reason NICE has not yet approved the device is because they deem it as cost-ineffective, meaning that it does not pass the cost-benefit evaluation.

DT proceeded to introduce **Kate Roberts (KR)** and **Stephanie Kleynhans (SK)** from the **Brain Tumour Charity**, who presented their Better Safe Than Tumour – sign and symptoms campaign.

The goal of the campaign is to raise awareness of the symptoms of brain tumours – this includes information as to where patients can find help and how they can be supported. Speakers highlighted that they have introduced a symptoms checker on their website, which allows people to input data and produce a downloadable report. This can be taken to a GP and used as a tool for referral.

The campaign seeks to engage with healthcare professionals and improve their ability to spot the signs and symptoms of brain tumour disease, as many people often get misdiagnosed.

HB asked whether there is a different model that would enable tests to be done quicker, and how sustainable is the current set up in the healthcare system given the pressure on GPs. **KR** raised that they are working on developing policies on faster diagnosis, and on how research charities can support GPs to quickly refer people to the appropriate pathway for treatment. Specifically, they are working on developing a clinical decision tool to support GPs in recognising brain tumour symptoms. They will produce a report and write up policy recommendations based on the findings of the report.

Virendra Sharma MP (VS) asked that consideration has been given on the impact of brain tumours on different ethnic groups and demographics. **SK** responded by noting that the campaign is being targeted at people from all ages and backgrounds.

Jim Shannon MP (JS) asked if there is a role for optometrists for diagnosing people with brain tumours, and whether they can spot the signs and symptoms of brain tumours. **KR** highlighted that optometrists already work with research charities to make sure that they are aware of the signs and symptom of brain tumours, and that they are continuously seeking ways to involve them in health pathways.

The event proceeded with **Hugh Adams (HA)** from **Brain Tumour Research** who gave an update of the APPG's Inquiry. He pointed out that 5 years on from 2018, when the £40 million for brain tumour research was announced by the Government, much of this money remains unspent.

Inquiry oral evidence sessions with lab-based researchers have sought to understand how researchers can more effectively work and engage across the neurosciences. Some of the suggestions include bringing in researchers from other fields, and to widen the remit of the £40 million of funding. Moreover, it was agreed that the system around funding decisions needs to change.

The oral evidence session with industry highlighted the role of the Medicines and Healthcare product Regulatory Agency (MHRA). There are problems with the classical design of trials and big pharmaceutical companies have cut back or exited development of brain cancer medicines. The perception is that bigger industry partners do not want to be involved in drug repurposing.

The next steps for the inquiry will be to bring together the National Institute for Health and Care Research (NIHR) and the Medical Research Council (MRC) in the new year for a discussion on all of the abovementioned findings from the inquiry. The APPG on Brain Tumours has the evidence to write the report and provide policy recommendations.

It was agreed that the toxicity and invasiveness of treatments must be addressed and ensure there is better drug delivery. Moreover, it would be beneficial to bring other disciplines into brain tumour research, with a smaller focus on therapeutics and more focus on devices which could improve patient outcomes.

HA suggested that the APPG meet again in February 2023, with the topic of the meeting focusing on front line care.

DT thanked attendees for their time and closed the meeting.