

# Patient Survey to support the APPGBT Inquiry:

Pathway to a Cure – breaking down the barriers

October 2022



*"If you have hope you have life. If there's no hope then they will give up."*

**Loss of hope, devastation, depression, frustration and desperation. Just some of the feelings patients and carers used to describe the lack of treatment options for those diagnosed with a brain tumour.**

*"Gut wrenching, heart-breaking, demoralising, worrying, impacts negatively on all aspects. Scary frightening. When you continue to have options, you can continue to have hope."*

*"Sad it's like brain tumours don't exist. People are unaware. The amount of times I'm told by family just get up, you're fine, is pretty sad. There is no understanding of the affects it has on our lives."*

*"The treatment my son received was largely the same as Astronaut Neil Armstrong's daughter was given in 1962, being chemotherapy and radiotherapy. How many new drugs for treating brain tumours have been developed since the turn of the century?"*

**In October 2022, Brain Tumour Research conducted a patient survey on its digital media channels and through its networks to support the All-Party Parliamentary Group on Brain Tumours Inquiry: Pathway to a Cure.**

**The survey aimed to understand the experiences and thoughts of UK brain tumour patients and their families on the clinical pathway. Responses were received from and on behalf of 276 patients, many of whom had sadly died from this devastating disease.**

*"I think the prognosis for most brain tumour patients is incredibly bleak. Being told you have an incurable illness is devastating and robs the patient of perhaps the most important thing of all – hope."*

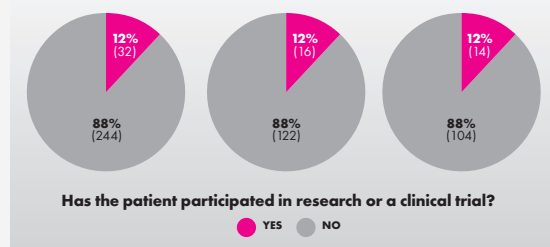
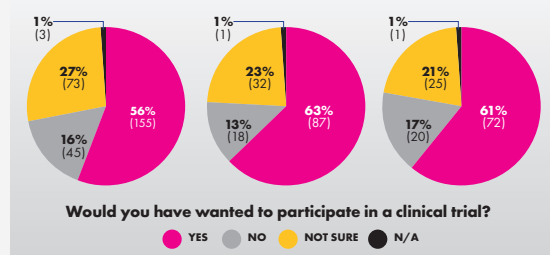
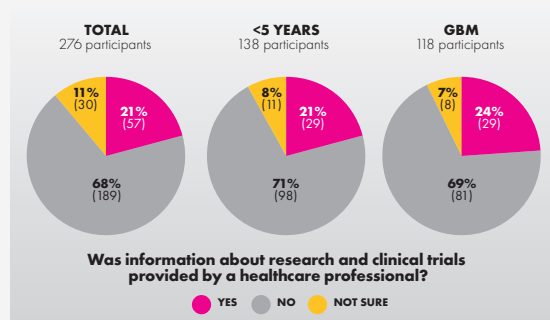
*"... my treatment options are still the same as 10 plus years ago. It doesn't give much hope."*

*"Disappointed, for her 21 years living with cancer there was no real advances other than more targeted radiotherapy."*

**We discovered an overwhelming feeling of doom from patients and their families, with death and reducing quality of life ahead of them. What's more, the lack of new treatment options was found to be detrimental to mental health, leaving families feeling abandoned and angry.**

*"Detrimental to mental health. You know there's nothing to be done, just living with this ticking time bomb that's slowly eroding who you are, you may as well not be alive at all."*

**Responses revealed that only 21% were provided with information about research and clinical trials by their healthcare professionals, with 72% indicating that they would have considered participating, but only 12% taking part in a trial.**



continued over

# Patient Survey to support the APPGBT Inquiry:

Pathway to a Cure – breaking down the barriers

October 2022



**Of the 138 diagnosed more recently in the last five years (2018-2022) just 21% were provided with information and a higher 76% would have considered participating, and still only 12% took part in a trial, demonstrating no improvement in recent years.**

*"Disgusted. Let down. Traumatized. My life is ruined. I'm waiting to die to be with my son, but here for my other two children."*

*"It's appalling!! Behind the times and behind progress made in other cancer types. It feels as though no one cares."*

**Those diagnosed with a glioblastoma (GBM), the most lethal of brain tumours, represented 118, or 43% of respondents. A slightly higher 24% were given information and more of these patients at 78% thinking about participating, yet still only 12% took part in a trial.**

*"A diagnosis of GBM is a death sentence, there are no hopeful conversations, just a 12-month prognosis and a suggestion to go out and make memories. We should be making the advances seen in breast cancer and leukaemia treatment and offering hope."*

*"Patients have less time with their loved ones. Treatment is harsh on their body as the same medication has been used for more than 10 years."*

**The survey found that 10% of patients travelled abroad to get their treatment, whilst others cited affordability as a reason why they didn't travel for treatment.**

*"More deaths and heartbreak – having to crowdfund and beg strangers for help."*

*"We obtained medication from abroad as not available in the UK. Nor were any trials of that being done here in the UK."*

*"It's traumatic, disheartening and for some, patients give up the fight early because there's not enough treatment options and they aren't able to go abroad. In some cases, brain tumours are found too late."*

**Responses on behalf of 25 children revealed that 28% were enrolled on trials, with two patients obtaining medication not available in the UK from abroad and three citing receiving treatment in Germany.**

*"It's devastating and living with a time bomb in your head. Just keep going on chemo getting sicker. My young son would have been more proactive and tried anything offered to have the chance to live a life. He had his whole life ahead snuffed out. It is heart-breaking."*

**Overwhelmingly 84% believed that the Government doesn't allocate enough funding to brain tumour research.**

*"Appears poor in comparison to other countries like the USA and Germany."*

*"Not very good. Plenty of studies and research without producing anything significant or effective to treat brain tumours. Good results from the US and Europe but it takes too long for them to be adopted here in the UK."*

*"It's slow. As a mother who has lost two children and a mother to cancer, two of them with brain tumours, I believe more funding for research will result in more effective treatment and even one day a cure."*

*"I feel the activism and the brain tumour family has created momentum that has opened channels to seek answers from those that make decisions around funding such as APPG, the noise made is being heard more. Sadly, it often takes a high-profile public figure to suffer or lose their fight to really bring the subject to a head. Tiny steps but at least steps."*

**Just 1%**  
**of the national spend on cancer research has been allocated to this devastating disease**

**Together we will find a cure**