THE BRAIN TUMOUR CHARITY - JOINT APPG CATCH UP WITH CANCER SUMMIT CONSULTATION: SOLUTIONS TO THE COVID INDUCED CANCER BACKLOG

- **How large is the cancer backlog and what are the risks to patients?**

Between April 2020 and March 2021, 1836 fewer people in England have received an urgent referral for a suspected brain tumour compared to the same period in 2019/2020. Estimates indicate that roughly 1% of those urgently referred will receive a diagnosis of a high-grade brain tumour, suggesting a missed diagnosis of around 18 people.

Data from the NCRAS/PHE Rapid Cancer Registration Dataset (RCRD) shows the total number of people starting first treatment for high-grade brain and CNS tumours is comparable to previous years, providing some reassurance that many services were maintained during the COVID-19 pandemic. Further, RCRD also shows the number of surgical brain tumour resections undertaken dropped by around 2.5% compared to the same time the previous year (Jan-Nov 2020 vs 2019). This indicates a limited backlog for high-grade brain tumour surgery.

Despite the fact that the total number of people starting first treatment for brain and CNS tumours is comparable to previous years, the percentage of brain and CNS tumours presenting as an emergency rose from 39% to 55% between February and May 2020. This increase was mirrored by a drop in diagnoses via other routes. Although this has now returned to levels similar to those seen pre-pandemic, it is possible that rather than there being a backlog of undiagnosed high-grade brain tumours, the route to diagnosis for people diagnosed with a high- grade brain tumour may have changed. Given this data is only currently available until December 2020, we are very concerned that another backlog of people with an undiagnosed brain tumour may have built up over the lockdown of early 2021 and without rapid action we could see another increases in the emergency presentation.

Understanding the true scale of the backlog for brain tumours is extremely challenging and significantly more complex. Whilst the release of additional data has highlighted areas where a brain tumour backlog may exist, there is currently still a significant blind spot when it comes to quantifying this fully – particularly in understanding the backlog for those living with low-grade and non-malignant tumour, which account for up to 6,000 cases in the UK each year (more detail on this below).

We are concerned that COVID-19 may have created a significant backlog of people living with a low-grade or non-malignant brain tumour whose treatment will have been postponed and who are now in need of surgery as soon as possible. However there is limited data available on non-malignant brain tumours (more detail on this is below) meaning the *scale* of this backlog remains unknown.

Given our inability to quantify the scale of the backlog of brain tumours and its impact on the community, we are unable to accurately assess whether current funding and workforce provisions will be sufficient. Establishing this and working to ensure the needs of the community are met must be a priority for Government.

A lack of data for low-grade (non-malignant/benign) brain tumours

Representing roughly half of annually diagnosed brain tumours, low-grade brain tumours vary widely. Whilst many diagnosed with a low-grade tumour will be placed on a ‘watch and wait list’, some will receive intervention for their tumour such as surgery, chemotherapy and radiotherapy. Unfortunately, low-grade brain tumour can transform into malignant brain cancer.

Despite this, data for low-grade brain tumours is poorly recorded, collected and reported, with information lacking in many publicly available cancer datasets. Where included, poor coverage limits its utility. As a result, the currently collected data on the backlog of brain tumours does not reflect the whole community.

The Royal College of Surgeons' Clinical Guide to Surgical Prioritisation during the Coronavirus Pandemic placed the surgery of some low-grade brain tumours in priority category 4, to be undertaken within 3 months. During November and December 2020 surgeries below priority group 2 were cancelled or postponed across the UK. As a result, it is highly likely that the backlog of surgery for some low-grade brain tumours is yet be accounted for. Further, the Adult Neuro-Oncology Service Provision during COVID-19 outbreak, published in January 2021 by the British Society of Neurological surgeons and the British Society of Neuro-Oncology, recommends considering postponement of 'low surgical priority' tumours such as low-grade gliomas and recurrent or atypical meningioma. This is supported by a charity survey of 9 major neuro-oncology units across the UK between October 2020 – January 2021 which also highlighted delays to surgery and treatment for a range of low-grade brain tumours, particularly meningioma.

While there is limited evidence to demonstrate the impact delays like this could have on patients' long-term outcomes, a recent (2019) paper published in Neuro-Oncology demonstrated the significant improvement in 10-year survival for patients with low-grade gliomas (from 51.7% in 2006 to 95.8% in 2017) seen at the National Hospital for Neurology and Neurosurgery (UCL Hospitals NHS Foundation Trust) which was likely due to a shift in surgical practice with early surgical resection preferred over active monitoring.

A lack of brain tumour specific data

Whilst there are limitations to the data currently collected, more information about the brain tumour backlog must be made available to the brain tumour community. Cancer waiting time data for brain tumours is not currently available or accessible online. Information such as 31- and 62-day waiting time data would help policy makers and charities to identify the number of people waiting to start first treatment for a brain tumour, providing crucial insight into the treatment backlog. Further, data for the number of people receiving chemotherapy or radiotherapy is not currently accessible by cancer site. Information such as this would also be key to understanding how numbers of those treated has changed during the COVID-19 pandemic, compared to previous years.

Only a small percentage of people with a high-grade brain tumour start first treatment following an urgent referral for suspected cancer

Only 2-3% of people with a high-grade brain tumour are diagnosed and start treatment following an urgent referral for suspected cancer according to the Rapid Cancer Registration Dataset. This is compared to 40% of all cancer being diagnosed following an urgent referral on the two-week wait pathway.

As a result of this, we have an extremely limited understanding of how long the vast majority of those diagnosed with a brain tumour have been waiting to receive their diagnosis and start treatment. This is because 97% of people with a high-grade brain tumour are diagnosed through other referral routes like an emergency presentation or during an outpatient appointment. Here, they are not placed onto a formal cancer waiting time pathway until after their diagnosis has been made.

As a result, many of those who are currently waiting for their brain tumour diagnosis will not be on a defined cancer waiting time pathway, but will instead be elsewhere in the system, delayed due to backlogs in referrals, scans and outpatient appointments.

<u>Backlog in addressing the emotional and psychological impacts (and greater patient need) due to the pandemic support</u>

The psychosocial support needs of those whose diagnosis and treatment have been delayed as a result of COVID-19 must be assessed and appropriately managed. Numerous internal charity reports have highlighted the mental health and psychological difficulties that the brain tumour community have experienced as a result of COVID-19 and provisions must be put in place to ensure people personally affected by cancer are supported in any way possible.

The Brain Tumour Charity's 2020 'Improving Brain Tumour Care' survey highlighted the unmet need in several key areas of psychosocial support. 21% of people surveyed were not connected to any basic support by their healthcare team and only 44% signposted to counselling or emotional support (sample of 586 people undergoing diagnosis or treatment in the last 2 years). Further, just 21% of people reported having a 'good holistic needs assessments (HNA) and resulting personal support plan'. The survey also showed that 36% of respondent did not have 'good access' to a named clinical nurse specialist (sample of 690 people undergoing diagnosis or treatment in the last 2 years). A recent (May 2021) poll in our online support groups (sample: 96 people either living with a brain tumour or caring for someone living with) found 58% of respondents said that they did not have access to the psychosocial support services they needed and were impacted by this.

Additional risks include delays to treatment and diagnosis that may increase the risk of disease progression. Whilst evidence for disease progression because of delays caused by COVID-19 is anecdotal and demonstrating the impact of a delayed diagnosis would be extremely challenging, this is undoubtedly an area of significant concern in the patient community.

- **Has the current response of Government and NHS leaders to the COVID induced cancer backlog been sufficient?**
- **What policy recommendations should the APPGs make to the Government for tackling the Covid-induced cancer crisis.**

We urgently need Government and NHS bodies to establish scale of backlog of people living with low-grade tumours who are awaiting treatment they need and set out plan to address this.

Need to ensure sufficient resource is provided to address psychological impact and greater emotional needs of brain tumour patients whose care has been affected by pandemic – whether treatment disrupted or parents unable to be with paediatric patients while in intensive care due to hospital visiting restrictions.

The Brain Tumour Charity support the efforts of NHS England and Improvement and Public Health England in the release of new datasets to monitor the impact of COVID-19 and these have proven to be an invaluable resource in helping The Charity to understand more about the impact of the pandemic for our patient community and to inform the support and information we have offered to those affected by a brain tumour.

However, more needs to be done to ensure brain tumour data is collected and made available to the community. As discussed, we have a lack of understanding of the scale of the brain tumour backlog, particularly for low-grade brain tumours and urgent action is required by both the Government and by NHS leaders to build understanding in this area and support a response.

A House of Commons Petitions Committee Report from 2015 highlighted the lack of Government leadership for brain tumour awareness and recommended the inclusion of brain tumour specific symptoms in NHS campaigns, such as Be Clear on Cancer. We fully support the NHS's efforts to encourage people with concerning or 'red-flag' cancer symptoms to visit their GP through campaigns such as Help us to Help You, however - more still needs to be done to increase awareness of the signs and symptoms of brain tumours and encourage those with concerning symptoms to seek the advise of their GP.