

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.

We welcome the opportunity to submit to this inquiry and are delighted to share some of the exciting research innovations that are happening in the sector. These include the Tessa Jowell BRAIN MATRIX, investigating DNA repair on a cell-by-cell basis in glioblastoma and understanding how immune cells block glioblastoma treatments.

### **1) What are the innovations with the greatest potential to transform cancer diagnosis and treatment in the short, medium and long term?**

Brain tumours by nature are difficult to treat and diagnose with symptoms usually being vague and non-specific. However, there are some exciting innovations that are under development that have the potential to transform patient pathways in diagnosis and treatment.

#### **Triage tests (Dxcover)**

Currently, MRI or CT scans are the only available option for brain tumour diagnosis. This means more often than not, patients with brain cancer are diagnosed in secondary and emergency care settings.

There is huge potential for triage tools to improve how brain cancers are detected and diagnosed. However, against the current context of resourcing and capacity strains across the NHS, there are some barriers to overcome. The impacts of the workforce crisis are seen in diagnosis staffing for MRI and CT machines. Moreover, due to the nature of brain tumour symptoms, primary care professionals face difficulties in knowing when to refer a patient for a scan purely based on the symptoms they present with. Finally, capacity of both primary and secondary care means it is challenging to refer everyone with non-specific symptoms for a scan.

To counter these challenges, one triage test in development is [Dxcover](#), which is a low-cost blood test. Recent trials have found that the blood test was able to [detect 96% of patients with brain tumours](#), and identified all patients with Glioblastoma Multiforme – the most aggressive type of brain cancer.

This liquid biopsy test may help improve the diagnostic pathway for patients with suspected brain tumours in the future as it will help GPs understand which patients should be prioritised for an MRI scan which could also help with capacity and staffing in radiology.

#### **Personalised Medicines and in particular, DCVax®-L**

The development of personalised medicines has huge long-term potential in transforming cancer treatment. [DCVax-L](#) is a type of immunotherapy known as a dendritic cell vaccine. It has been developed as a personalised vaccine made from each patient's own dendritic cells. The peer-reviewed phase III trial results were published in November 2022 and offered very promising results

The process of making this vaccine involves taking both tumour cells and blood from the patient. Immune cells are separated from the patient's blood and exposed to the tumour cells; it is through this process that dendritic cells learn to recognise the specific markers and proteins associated with the patient's tumour cells.

The "educated" dendritic cells are then injected back into the patient, where they go on to recruit and "teach" other anti-cancer immune cells, known as T-cells, to travel to the tumour site and attack the cancerous cells.

[Recent studies](#) have shown that using DCVax-L alongside temozolomide chemotherapy can prolong the lives of people diagnosed with a new or recurrent glioblastoma by nearly three months on average, compared to chemotherapy alone. The trial also found that DCVax-L doubled the five-year survival rate for those with a newly diagnosed glioblastoma and for those with recurrent glioblastoma, results saw the 30-month survival rate double.

### **Tessa Jowell BRAIN MATRIX**

Related to the long term potential of personalised medicine is [BRAIN MATRIX](#) clinical trial platform, which will be of benefit to the treatment of brain tumours. Funded by The Brain Tumour Charity, the study aims to fully understand a person's brain tumour using advanced diagnostic technology. By providing a platform for trialling precision medicines, the multi-centre "portal" recruits patients and will enable enrolment into biomarker driven trials.

Every person who is enrolled into BRAIN MATRIX will have their tumour tested in a lab to reveal its specific profile of genetic and molecular changes. This additional level of detail about individual tumours will allow people to be enrolled into clinical trials faster and could lead to more informed treatment options available to individuals. This project aims to pave the way for future drug treatments to be tested faster and, although it's being led from the UK, we also expect it to deliver global impact for brain cancer patients.

### **The BRIAN App**

The [BRIAN application](#), developed by The Brain Tumour Charity, is an innovation that is helping those affected by brain tumours with their treatment and care. BRIAN's tools, like the Benefits Checker and Clinical Trials Finder, offer information that may be otherwise difficult to find for individuals.

Furthermore, BRIAN allows patients to record their entire brain tumour experience in one place. The user is able to track and monitor their symptoms, treatments and side effects in the application, and allows the patient to share their data with anyone they trust, such as their Clinical Nurse Specialist or Neurosurgeon. This can ultimately help with tailoring care to people's individual needs.

Moreover, BRIAN records and collects anonymised data and the experiences of patients which can then be used by researchers so that they can better understand and improve people's quality of life. They can use the collective experiences of patients that have been tracked via the application to drive forward research into brain tumours and accelerate progress towards a cure.

### **Car-T Cell therapies – Immunotherapy**

[CAR-T cell therapy](#) is a type of Adoptive T-cell Therapy (ACT) that researchers are currently investigating for use on brain tumours, and it is a promising new way to get T-cells (immune cells) to fight cancer.

T-cells are removed from the patient's blood and genetically altered in the lab to have sensing proteins (receptors) on their surface. These receptors recognise specific proteins on the surface of tumour cells (like a key being used for a specific lock). The receptors on the T-cells are called chimeric antigen receptors, or CARs – hence the name CAR-T cell therapy.

The T-cells are then multiplied in the lab and given back to the patient, where they can now seek out the tumour cells in their body and launch a precise attack against them.

Presently, there are only a few CAR-T cell therapies approved for use for certain types of advanced, hard-to-treat leukaemia and lymphomas. Researchers are still improving how they make the T-cells in the lab and are learning the best ways to use them for different types of cancer. CAR-T therapy is being studied as a treatment for glioblastoma. Tests are ongoing, and have mixed results in treating solid tumours, such as brain tumours, where they have caused serious side-effects – some of which can be fatal. However, this is an ongoing innovation with huge potential. .

## Holistic Needs Assessment tool

The Brain Tumour Charity has developed an online Holistic Needs Assessment (HNA) tool that can be used by both the patient and their healthcare team. We know that too many people impacted by brain tumours do not have good access to a full and holistic assessment of their needs, whether that's emotional and psychological, physical or even financial. According to The Brain Tumour Charity's Improving Brain Tumour Care (IBTC) Survey, only 40% of respondents had said they were offered a HNA.

Hosted through the BRIAN app (see above), people are able to answer a series of questions assessing their different health, care and treatment needs which then their healthcare professional will be able to access. This provides for an open and honest conversation about which needs are being met appropriately and which are not. The tool also allows for signposting to other websites and resources where the patient can find out further information about what additional help can be provided externally.

The Brain Tumour Charity have developed this online tool alongside patients, carers and healthcare professionals and will be piloting it in different brain tumour centres around the country later this year.

## Nanopore Technology (nanoDX)

Nanopore technology has the potential to transform the accurate diagnosis and treatment of brain tumours with the technology reducing the time it takes to get diagnosis results.

There are currently studies around the [Methylation based classification of brain tumours using nanopore sequencing \(nanoDX\)](#): a prospective multi-centric evaluation.

The project aimed to reduce the time it takes to get diagnosis results, as well as improving access to the most cutting edge technology and use molecular testing to accurately diagnose and treat brain tumours. In major centres it takes around 14 – 28 days, or longer in smaller centres, for clinicians to receive molecular biomarker results for their patients. This is too long for people to have to wait to receive results, receive a definitive diagnosis and to begin potentially life-saving treatments. By using Nanopore technology, in this case nanoDX – a device the size of a mobile phone – gene alterations can be detected in a small amount of tumour DNA from biopsy. If this project is successful, the use of nanoDX will provide people around the world with access to state-of-the-art diagnostics which is not only faster at diagnosing but also cheaper than current methods.

## Tessa Jowell Centres of Excellence (TJCOE):

Announced in 2020, the [TJCOE](#) have been an excellent innovation for improving brain tumour care. Created as an award for UK centres who offer excellence in brain tumour treatment, aligned research and a strong focus on quality of life care – there are now 17 centres which have gained the award.

The Centres of Excellence award provides an opportunity for centres to be recognised for delivering an exemplary standard of care for brain tumour patients. Importantly, the award can highlight disparities in healthcare quality across the UK and has a vital role in ensuring that all centres are brought to the same level on every element of the various brain tumour pathways in terms of diagnosis and treatment. The award is available to all 30 UK Brain Tumour centres with 28 participating so far in the extensive review process, at the time of writing.

## 2) How best can innovations in diagnosing and treating cancer be transitioned into frontline clinical settings?

The utilisation of innovative tools such as BRAIN MATRIX is one of the best ways that diagnosing and treating cancer be transitioned into frontline clinical settings. As outlined above, BRAIN MATRIX will provide a platform for trialling precision medicines in the UK. It has a multi-centre "portal" protocol to

recruit patients and enable enrolment into biomarker-driven trials. This study will essentially pave the way for future drug treatments to be tested faster.

All participants in BRAIN MATRIX will have their tumour tested in a lab to uncover its molecular profile. In addition to the information about molecular changes in the tumour, imaging, treatment and other clinical data from each participant will be collected and analysed at a central hub.

By having molecular profiles ready-to-hand, future trials will be a step ahead and people will know sooner if the new experimental treatments could be appropriate for them.

The BRIAN app is also an excellent way of bridging the gap between research and frontline clinical settings and vice versa. Not only does it help in providing information about clinical trials and research patients can become involved in, it also collects real-world patient data, which is invaluable to researchers. By providing a way to connect researchers and the patient, the BRIAN app is innovative in connecting the two.

### **3) What can be learnt about innovative cancer diagnosis and treatment from international examples of best practice?**

The [Sheri Sobrato Brisson Brain Cancer Survivorship Program](#) in the United States is an example of international best practice when it comes to the treatment and care of those affected by brain tumours. The programme offers those affected by brain tumours neurocognitive consultation and rehabilitation, exercise and wellness classes, education, support groups and peer support.

The programme's aims are to enhance the wellness and quality of life of patients with brain tumours through a collaborative, multidimensional approach focusing on emotional, physical and cognitive health. By taking some examples of the approach the programme has created in the United States, it could lead to better, more supportive care in the UK.

### **4) To what extent is workforce planning keeping up with innovations in the diagnosis and treatment of cancer?**

Workforce is the key limiting factor in bringing down waiting lists and restoring timely access to care. However the NHS is currently operating with [154,000 fewer staff than it needs](#).

There is a notable workforce gap in multiple areas including medical oncologists – especially around brain tumours. A recruitment drive needs to be undertaken to attract more dedicated researchers from other fields and encourage talent and breadth of knowledge in neuro-oncology research. Furthermore, there needs to be more of a dedicated focus on early-career opportunities for young researchers to specialise in neuro-oncology. This is an area that must be improved if we are to keep up to date with innovations in the diagnosis and treatment of specific cancers – such as brain tumours.

We are in desperate need for increased numbers of Clinical Nurse Specialists (CNSs) for brain tumour patients. CNSs play an important role in supporting people diagnosed with a brain tumour and delivery of high-quality cancer care which is why NICE clinical guidance (NG99) in England recommends that every brain tumour patient should have access to a CNS or a key worker. For those diagnosed with a brain tumour, access to a CNS can be vital especially around the coordination of specialised care and treatment as a result of how complex a condition brain tumours can be for the patient and their families.

Notably, The Brain Tumour Charity's IBTC survey revealed that 1 in 6 respondents were **not** given access to a CNS with a third (36%) of respondents who did have access, feeling unable to speak to their CNS as and when they needed to. These are worrying statistics and clearly indicate that more needs to be done to ensure the NHS provides the level of care brain tumour patients deserve.

The UK government previously committed to publishing an NHS long-term workforce plan. Such a plan should provide an opportunity to address continuing staff shortages and include a plan to increase

workforce supply. The workforce strategy needs to be published in full and include numbers of how many staff will be needed to keep pace with increased demand as a result of an aging population. As of yet, the plan has no publication date.

### **5) Is the impact of innovations in cancer diagnosis and treatment on health inequalities being sufficiently taken into account?**

It is important to recognise the impact on reducing health inequalities brain cancer innovations are having. As an example, the use of the innovative BRIAN app within the brain tumour community is tackling certain inequalities related to brain tumours.

The 'Insights' tool within the app enables the user to keep track of their treatment and their day-to-day wellbeing, this data can be shared with researchers and can provide a basis of further understanding on tracking the quality of life of those affected by brain tumours. This can contribute to research into reducing health inequalities and lead to a better understanding of how social demographics, geographical variations and inequalities contribute to differing levels of quality of life for brain tumour patients.

The application also provides a 'Benefits Clinic' where users can see what financial support they are entitled to. We know that those from lower socio-economic groups are more likely to have poorer health, so making sure people impacted by brain tumours do not miss out on any financial entitlements is key.

Furthermore, we know that there are geographical inequalities in terms of provision. A recent [report](#) conducted by the Tessa Jowell Brain Cancer Mission specifically looked into differences in brain cancer care across the country. The report found that importantly, brain cancer patients would get an effective level of care in any UK centre. However, the report added that patients are most likely to experience disparities in their care dependent on the Centre they are within. Especially around the following parts of the pathway: "the genetic testing of tumour samples, access to clinical studies, and the extensiveness of nurse and AHP-led care and support they receive".

This suggests that there remains room for improvement in different centres across the UK and that a postcode lottery continues to exist for brain cancer patients. However, the Tessa Jowell Centre's of Excellence award has been a fantastic innovation that is seeking to address some of the different standards of care that have been found in centres across the country by bringing them to an equally high level through the extensive awards process. As a result, we now have 17 centres out of 30 in the UK which have reached the highest awards level.

### **Contact Details**

We greatly appreciate the opportunity to participate in this inquiry and hope you have found the innovations and answers provided above to be of interest. We would also be happy to provide oral evidence in any session you are planning.

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).