

**Written Evidence from OurBrainBank (UK) to the APPG on Less Survivable Cancers for their Mini Inquiry into Earlier Detection and Faster Diagnosis (5th May 2025)**

1 Introduction

This written evidence is submitted by OurBrainBank (UK), a patient-led charity dedicated to transforming outcomes for people diagnosed with glioblastoma (GBM), the most aggressive and least survivable form of brain cancer. Our mission is to accelerate improvements in treatment and care for GBM patients in the UK and ensure they do not miss out on the potential benefits of personalised cancer treatment and access to clinical trials.

We welcome the Mini Inquiry by All-Party Parliamentary Group (APPG) on Less Survivable Cancers into earlier detection and faster diagnosis. For many cancers, such a strategy promises improvement in survival rates. However, this principle does not apply equally to all cancers and the benefits of earlier diagnosis are not so marked in the case of GBM. The biology of GBM is exceptionally aggressive, with rapid progression and diffuse infiltration into brain tissue. Most diagnoses occur only after symptoms such as seizures, speech problems, or cognitive changes emerge—often when the tumour is already advanced. Therefore, in the case of GBM, earlier diagnosis is very difficult to achieve and though it may improve care planning and access to treatments and trials, it is unlikely to significantly extend survival or result in cures.

Median overall survival for GBM remains between 12 and 15 months, with fewer than 5% of patients surviving five years post-diagnosis. These figures have remained largely unchanged for two decades. Even with access to optimal NHS care—which comprises surgery, radiotherapy, and chemotherapy (the Stupp protocol)—most patients face a devastating prognosis. Whilst efforts to improve earlier diagnosis for all cancers are to be welcomed, OBB believes that to achieve substantial benefits for people with GBM the emphasis should be on improving the quality and detail of diagnosis through genomic sequencing. We argue for a fundamental shift in approach from treatment of tumours by body part to the use of genomic diagnostics, opening up the possibility of the integration of molecular oncology and personalised medicine.

OurBrainBank believes that the future of GBM care lies in tailoring treatment to the individual’s tumour biology. Advances in genomic sequencing allow for in-depth tumour profiling, offering potential avenues for targeted therapies and enrolment in clinical trials. Although cures remain elusive, these approaches can offer better-informed treatment plans, improved quality of life, and—very importantly—hope.

Our charity’s goal is to assist in transforming GBM from terminal to treatable, and for that we believe that the therapeutic pathway must be as personal as the tumour. With modern medicine standing on the brink of revolutionary changes—from genomics to precision oncology— personalised treatment is becoming a reality. To ensure current and future GBM patients benefit from the more precise and detailed diagnostics that make these innovations possible OurBrainBank urges health policymakers and practitioners to take three tangible steps:

• To provide comprehensive genomic sequencing for all GBM patients.

• To increase access to clinical trials that match patients to treatments based on tumour genetics.

• To institute personalised treatment planning – informed by molecular profiling, not based on generic protocols alone.

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In recent decades, the field of oncology has undergone a profound shift. The emergence of genomic sequencing and targeted molecular medicine has transformed treatment of several cancers—most notably breast, lung, and melanoma—by replacing generalised protocols with personalised approaches. These advances are especially critical for rare and less survivable cancers such as GBM, where conventional treatments offer limited and often short-lived benefit.

GBM is the most common and deadliest malignant brain tumour in adults. Classified as a grade IV glioma, it is known for its rapid growth, invasive behaviour, and resistance to standard therapies. The traditional tools of oncology—surgery, chemotherapy, and radiotherapy—have reached the limits of their effectiveness in GBM. The disease’s biological complexity, high degree of intratumoural heterogeneity, and its location in the ‘black box’ of the brain all contribute to poor outcomes. Innovation is urgently needed, and many of the most promising opportunities lie in the realm of personalised medicine.

OurBrainBank argues that genomic sequencing should become the standard and universal diagnostic tool for brain tumour patients. It provides a powerful window into the molecular architecture of individual tumours. This enables clinicians to identify specific genetic mutations, epigenetic changes, and signalling pathways that drive tumour growth. These insights can guide the use of targeted therapies, facilitate enrolment in molecularly stratified clinical trials, and even repurpose existing drugs. This approach has already improved survival in other cancers and holds great promise for GBM.

For GBM patients who undergo genomic testing, treatment options can expand significantly. While some may benefit from emerging immunotherapies or targeted drugs, others may be directed away from ineffective treatments. In all cases, care becomes more data-driven, rational, and potentially less harmful.

However, implementing this approach requires infrastructure—especially frozen tissue storage— skilled staff, defined clinical pathways, and timely access to sequencing results. It also demands cultural change, new regulatory frameworks, and investment in early-phase and platform trials. Above all, it needs new rights for patients to demand more choice and agency in relation to the care they receive.

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The rest of this submission presents a review of detailed evidence contained in two papers discussing the impact of developments in sequencing technology and associated advances in molecular oncology on patients with brain tumours.

1) OurBrainBank’s white paper, *GBM: The neglected disease in the cancer treatment revolution - A report on the state of care and therapies available to people diagnosed with GBM in the UK* (July 2023)

2) The Tessa Jowell Brain Cancer Mission paper, *Closing the Gap Report: A roadmap for equitable access to genomic testing and precision medicine trials for all patients with a brain tumour in the UK* (September 2024).

Taken together, the two papers make the case for bold investment in the systems, training, and policy changes necessary to revolutionise the diagnosis and care of patients and deliver personalised medicine for people living with brain tumours.

This submission sets out why OurBrainBank believes the NHS and government must act now to build this framework—not only to support people living with GBM today, but to advance treatments that will benefit future generations.

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2 Summary of the OurBrainBank White Paper on GBM (GBM)

2.1 OurBrainBank’s 2023 white paper was a patient-led, evidence-based exploration of GBM care in the UK. It reflected the lived experience of people with GBM and highlighted how the system fails to provide meaningful innovation for one of the most devastating forms of cancer.

Standard treatment, the NHS standard of care, often misleadingly described to patients as “the gold standard”, remains the Stupp protocol: maximal safe surgical resection, radiotherapy, and concurrent and adjuvant temozolomide chemotherapy. This protocol was introduced in 2005, and while it slightly improves median survival, it has not dramatically changed outcomes.

OurBrainBank’s white paper identified that while innovations such as 5-ALA (a surgical dye that helps neurosurgeons visualise the tumour more clearly) and awake craniotomies have improved some aspects of care, systemic shortcomings remain. These include a lack of access to genomic testing, slow progress in immunotherapy, and limited availability of clinical trials.

2.2 Genomic Testing and Personalised Treatment

One of the most critical failures is the underuse of genomic and molecular profiling. The white paper underscored that while the NHS formally funds Whole Genome Sequencing (WGS) for rare cancers through the Genomic Medicine Service, access to this testing for GBM patients remains low. At the time of the paper’s publication, it was estimated that fewer than 5% of patients received genomic sequencing. The reasons for this are largely structural: most hospitals do not store frozen tumour tissue, which is required for WGS. Others are unaware of the process or lack the infrastructure to transport tissue to genomic labs.

Without genomic data, GBM patients cannot benefit from personalised treatment plans, are often excluded from trials, and may receive ineffective therapies. The white paper stresses the importance of understanding the molecular heterogeneity of GBM, which includes key mutations such as IDH1/2, MGMT methylation status, EGFR amplification, and others. These can guide prognosis, treatment selection, and clinical trial eligibility.

2.3 Immunotherapy and Clinical Trials

The white paper also discussed the promise and limitations of immunotherapy. Unlike cancers such as melanoma or lung cancer, GBM has shown mixed results in response to checkpoint inhibitors or vaccines. Nevertheless, vaccine-based therapies like DCVax-L have shown some survival benefits and deserve further exploration. Unfortunately, trials into therapies like these are infrequent and often inaccessible to most UK patients.

OurBrainBank recommends a major increase in the number of UK-based or UK-accessible platform trials for GBM. These trials allow for the testing of multiple therapies simultaneously, based on tumour genetics, and could provide a crucial lifeline for patients who currently have few options.

2.4 Infrastructure Gaps

Even the most promising treatments are unreachable without appropriate infrastructure. The white paper revealed the shocking lack of frozen tissue storage in NHS hospitals—a prerequisite for modern genomic analysis. Most tissue is preserved using formalin-fixed, paraffin-embedded (FFPE) methods, which are unsuitable for comprehensive sequencing.

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OurBrainBank calls for universal frozen tissue storage at NHS hospitals treating brain tumour patients, with appropriate funding and training. A relatively modest investment in ultra-low temperature freezers could dramatically increase access to genomic testing.

2.5 Information and Advocacy

Patients and their families often describe a “fog of confusion” following diagnosis. The white paper called for clear, accessible information about the disease, including prognosis, treatment options, and trials. Many GBM patients are advised not to search online yet receive no alternative comprehensive resource. NHS websites are inconsistent, and often patients rely almost exclusively on support from the various brain tumour charities.

OurBrianBank’s white Paper made several recommendations:

• The provision of frozen tissue storage at all NHS sites conducting brain tumour surgery. • Universal access to genomic sequencing, including WGS and methylation profiling. • Improved patient information, accessible via the NHS and verified charity platforms. • An expanded portfolio of GBM clinical trials, especially those using adaptive or platform trial models.

• Faster translation of promising research into treatment, including reform of regulatory pathways and NICE evaluations.

The white paper concluded that transforming GBM outcomes will not come from incrementally improving current therapies, but from radically embracing personalisation. Genomic profiling and data-driven medicine offer the most realistic route to improved outcomes. With adequate investment, patient-centred policies, and a commitment to innovation, there is hope that GBM could one day shift from terminal to treatable.

3 Summary of the Tessa Jowell Brain Cancer Mission Paper on Equity in Genomics

3.1 In September 2024, the Tessa Jowell Brain Cancer Mission (TJBCM) published a landmark report titled “Closing the Gap”, which examined disparities in access to genomic diagnostics and personalised treatments for brain tumour patients across the UK. The findings mirrored and reinforced OurBrainBank’s observations, offering a national view of systemic challenges and opportunities.

The report was grounded in data from the Tessa Jowell Centre of Excellence (TJCoE) programme and uncovered a troubling pattern: while the UK has world-class genomic infrastructure on paper, access for brain tumour patients—particularly those with GBM—remains unequal, inconsistent, and often underutilised.

3.2 Uneven Access to Genomic Testing

One of the most striking findings was the variation in genomic testing across NHS neuro oncology centres. While some hospitals regularly use WGS, methylation profiling, and targeted gene panels, others barely engage with these tools. In 2024, the paper estimated that only 10– 15% of glioma patients received WGS—a modest increase from 5% in 2023 but still leaving approximately 85% of patients without access to a service already (theoretically) funded by the NHS.

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Reasons for this disparity include logistical issues, such as a lack of frozen tissue infrastructure, and cultural factors, including clinician scepticism and/ or unfamiliarity with the utility of genomic data in clinical decision-making.

3.3 Infrastructural and Logistical Barriers

The report provided more detail on the widespread failure to use frozen tissue storage, which is essential for WGS. It found that many centres are ill-equipped. In the 2024 report the authors found that:

• 7 of 21 TJCoE hospitals froze fewer than 10 tumour samples per year.

• 2 centres froze none.

• Common barriers included lack of freezers, no provision for out-of-hours tissue processing, and difficulties in transporting samples to Genomic Laboratory Hubs (GLHs).

These gaps mean that even where WGS is available, many patients cannot benefit simply because their hospital cannot preserve tissue appropriately.

3.4 Delays in Diagnosis

Another significant concern is turnaround time for molecular diagnostics. While the Tessa Jowell Standards call for a maximum of two weeks to provide a final integrated diagnosis (histological and molecular), the report found that only 6 of 21 centres met this benchmark. In some cases, turnaround times exceeded 6 weeks, delaying treatment decisions at a time when every week matters.

Some centres reported delays of over 140 days to return WGS results—rendering the information irrelevant for many rapidly declining GBM patients.

3.5 Educational and Cultural Challenges

The report said that some clinicians reported a reluctance to use WGS, believing that the results do not alter clinical outcomes or justify the additional time and paperwork required. Others cited the lack of approved targeted treatments for GBM as a reason to delay implementing genomic analysis.

The report argued that these views are short-sighted. Even when immediate therapeutic benefits are limited, genomic data can direct patients into trials, provide prognostic clarity, and contribute to national and global research databases. It also lays the foundation for future drug development.

3.6 Policy Barriers in Devolved Nations

The report highlighted additional policy issues in Scotland, Wales, and Northern Ireland. In these national regions, patients are often dependent on sending tissue samples to England, incurring extra costs and delays. This further compounds inequality in access to personalised care.

3.7 Recommendations from the TJBCM Report

The Tessa Jowell Brain Cancer Mission report outlined several key recommendations: • Standardise genomic care pathways across all UK centres.

• Expand infrastructure for frozen tissue collection and processing.

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• Create multidisciplinary Genomic Tumour Advisory Boards (GTABs) to assist with complex cases.

• Support clinical education, especially for neuro-oncology multi-disciplinary teams (MDTs). • Provide clear, accessible information to patients and carers about genomic options. • Collect and monitor equity data to drive continuous improvement.

These recommendations strongly align with the priorities of OurBrainBank. Taken together the recommendations of both organisations argue that the challenges of delivering personalised GBM care are surmountable—with coordinated leadership, investment, and commitment to equity.

4 Update on the Genomics Picture in the UK 2025

Tessa Jowell Brain Cancer Mission continues to monitor the delivery of molecular and genomic testing across the UK’s adult neuro-oncology centres. They have not yet published data reflecting the position as of early 2025 but provisionally report that there has recently been significant growth in the use of genetic testing, although the increase has been highly variable and insufficiently inclusive. Whereas the OurBrainBank report from 2023 estimated fewer than 5% of GBM patients received WGS, estimates for the current year put the figure for all glioma patients at around 15% - a significant improvement, but nonetheless indicating that about 85% of brain tumour patients are not receiving diagnostic services that are of potential benefit to them.

Overall, the picture is that while some centres have embraced precision medicine, others still lack the capacity or commitment to offer it. In the last 5 years there has been progress in integrating genomics into brain cancer care. However, usage varies dramatically across NHS Trusts. Some hospitals submitted nearly 1,000 samples annually; others submitted just over 100. These disparities suggest a continuing postcode lottery.

5 Conclusion and Recommendations

GBM remains one of the most devastating diagnoses in modern medicine. It is not only a less survivable cancer—it is one of the least responsive to conventional treatment and among the most complex to manage. While early diagnosis and detection are powerful tools for many cancers, they offer only marginal benefit in the case of GBM, which typically presents at an advanced stage and progresses rapidly.

OurBrainBank argues that improvements in diagnosis for GBM should focus on ensuring universal genomic sequencing for all patients and that personalised medicine made possible by such sequencing represents the best hope for improving care and outcomes. Personalised treatment, informed by detailed genomic data and driven by clinical insight, can help ensure that each patient receives the most appropriate therapy available—whether that means enrolment in a trial, compassionate access to experimental treatments, or the avoidance of ineffective options.

This submission reflects evidence from patients, clinicians, and national reports. It shows that while progress is being made, many GBM patients in the UK remain cut off from genomic sequencing, targeted therapies, and innovation due to systemic, infrastructural, and cultural barriers.

We therefore recommend that as the All-Party Parliamentary Group on Less Survivable Cancers considers how to achieve earlier detection and faster diagnosis for such cancers it should incorporate the improvements and recommendations called for by OurBrainBank, The Tessa Jowell Brain Cancer Mission and others to transform GBM care including, crucially, the following:

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1) New Rights to Relocate



All patients diagnosed with GBM should be offered the choice of relocating to a hospital that is able to provide WGS if it is not provided by the hospital where it has been diagnosed. Patients may of course choose to stay with the diagnosing hospital if they believe the risks of delaying surgery outweigh the potential benefits of WGS.

2) Universal Frozen Tissue Storage

Ensure every NHS brain tumour centre has the capacity to collect and store frozen tissue samples. This relatively low-cost intervention is foundational to enabling genomic diagnostics. No patient should be denied WGS due to lack of a freezer.

3) Universal Whole Genome Sequencing (WGS) for GBM

WGS should be a standard part of the diagnostic pathway for all GBM patients, funded and implemented across the UK. Clinicians must be supported to facilitate consent and submission, and turnaround times must be standardised and monitored.

4) Investment in Platform Trials and Trial Access

The UK must increase the number of clinical trials open to GBM patients, including adaptive platform trials that match patients to treatments based on genomic markers. A national trial referral system should be developed to help clinicians and patients navigate available options.

5) Truly Personalised Treatment Planning

Treatment for GBM should be informed by molecular profiling from the outset. Neuro oncology MDTs should include access to genomic tumour boards and real-time decision making support, drawing on national and international expertise.

6) Training and Education for Clinical Teams

Neuro-oncology professionals should receive targeted training in genomic medicine to build confidence in interpreting results and applying them to care. Educational initiatives should be prioritised to overcome cultural resistance.

7) Public and Patient Information

Patients and carers should be given access to reliable, accessible information about genomic testing, clinical trials, and personalised treatment options. NHS websites and patient resources must be updated and expanded to include specific information about GBM. Most importantly, the Department should require all NHS Trusts to publish data on how many patients have been offered and received WGS at their hospital following a diagnosis of GBM.

8) National Equity Monitoring

Access to genomic diagnostics and personalised treatment must be audited regularly to ensure fair provision across regions and patient groups. Transparency and accountability are essential to drive sustained improvement.

The patients and carers OurBrainBank support and campaign for face a terrifying diagnosis. GBM often leaves them with enormous challenges, uncertain futures and limited time. Yet amid the

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difficulty, there is hope—hope grounded in science, innovation, and the determination to change what has long seemed unchangeable.

Transforming brain cancer care is not only a clinical necessity—it is a moral one. We believe that if the UK acts now, we can rapidly improve the state of brain cancer care in this country and join other countries such as Germany and the United States that are world leaders in personalised medicine for GBM, and other terminal brain cancers. In doing so, we will light a path forward for other rare and hard-to-treat cancers.

We urge policymakers to be bold. The tools exist. The insights are clear. The challenge now is to deliver on the promise of precision medicine—for those living with GBM today, and for all those who will face high grade brain cancers in the future.

Our message to policymakers is simple: Transform brain cancer care in the UK. Take tangible steps to ensure that the UK moves to the forefront of the personalised medicine revolution.

OurBrainBank (UK)

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