NHS Brain Cancer Healthcare and Research:

Does It Matter Where You Are Treated?

Key Findings and Recommendations from the Tessa Jowell Brain Cancer Mission Centre of Excellence Designation Programme

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Tessa Jowell
BRAIN CANCER MISSION

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Finally, we thank the **1500+ brain cancer patients** who, through the Brain Tumour Charity, provided invaluable feedback on their brain cancer journey.

Foreword

"As Tessa's daughter and founding member of the Tessa Jowell Brain Cancer Mission, the publication of this report is a profound moment of reflection for us all.

It marks five years since the Tessa Jowell Brain Cancer Mission (TJBCM) was formed when my Mum, who was dying from brain cancer herself, laid out her transformational vision for how NHS brain cancer treatment and care needed to change. Her vision created the blueprint for the TJBCM: to ensure that every patient of today has equitable access to excellence and innovation in their local hospital, whilst paving the way to making brain cancer treatable in the future.

After she died, the Mission spent two years strategising with a team of 80 partners to define how we could translate her vision into reality. The Tessa Jowell Centres of Excellence (TJCE) would be our way of working with every NHS brain cancer centre in the UK to identify excellence, challenges and variation in services and provide hospitals with bespoke support to develop their services, foster innovation, and share best practice within the NHS. We launched the initiative in 2020 and now have 17 NHS Centres that have been awarded the Centre of Excellence status, spanning the length and breadth of the UK, and are working with all remaining Centres to achieve the TJCE status in time.

Our Centres of Excellence are a national effort, harnessing the extraordinary humanity, passion and ambition of the front-line clinicians, nurses and AHPs at the heart of the NHS. We are united with the shared purpose and vision to change the course of this unspeakable disease, which is the biggest cancer killer of adults under 40 and children in the UK, and of course the cancer that killed my Mum. The data published in this report are the data collected on the services of every brain cancer centre in the UK that applied to become a TJCE. In its totality, it is one of the most comprehensive end-to-end datasets collected on NHS brain cancer services in the history of the NHS – which now gives the TJBCM a unique strategic overview of the variations, consistencies, challenges, and opportunities to drive change and innovation nationally. We now know exactly where and why there are challenges and which hospitals are ready to lead the charge with pioneering new innovations. In time, we can support the rest of the network to systematically address these challenges and adopt the latest innovations as best practice.

This report holds something completely unique in the UK: the details of the real current picture of NHS brain cancer services and, most excitingly, the potential of the picture of the future where, as my Mum dreamed, "the very best and latest science" will be available to all."

Jess Mills, Daughter of Tessa Jowell and Co-Founder of TJBCM

From left to right: Nicky Huskens, Richard Gilbertson, Katie Bushby, Camille Goetz, Jess Mills

Contents

Summary

The Tessa Jowell Brain Cancer Mission's (TJBCM) Centre of Excellence Designation Programme is a transformative national initiative which aims to identify, recognise, and support specialist NHS Centres to provide high quality brain cancer care and research. This report summarises key findings from this programme, providing insight into how brain cancer is diagnosed, managed, and researched by 28 applicant UK neuro-oncology Centres, and how these services and activities vary geographically.

As part of the Designation Programme, a Committee of experts reviewed activities of applicant Centres across areas of diagnosis, treatment, quality of life care, staff training, clinical trial capacity and research. Centres were assessed through an extensive application form, virtual site visit and patient feedback. They were reviewed against a set of standards established through an iterative process involving key leaders across the specialities involved in brain cancer treatment and research. Patient feedback was collected in collaboration with the Brain Tumour Charity through the online 'Improving Brain Tumour Care' surveys. Full analysis of patient feedback is presented elsewhere.[1]

The assessment identified three groups of Centres:

1. **"Tessa Jowell Centres of Excellence"** met or exceeded the standards in all areas and showed no major points of concern. These Centres demonstrated five key characteristics that drive an excellent service: local champions, excellent leadership support, seamless integration of services, research infrastructure support and an ethos of kindness and compassion.

2. **"Pending Designation"** Centres met or exceeded the standards in most areas, with one or two minor areas where the standards were not yet met. Standards of the service provided by these Centres were high, with many areas of excellence seen across the pathway.

3. **"To Further Develop"** Centres demonstrated a good service but with several areas that did not yet meet the standards. These Centres were recommended to reapply after addressing the challenges identified in the review process. Some of these Centres were smaller regional centres where some specialists were working single-handedly. All Centres in this group were on a clear upward trajectory and demonstrated good awareness of their areas for further development.

There are many "pockets of excellence" and innovations across the entire patient pathway: Each Centre demonstrated individual strengths which, if widely shared and implemented across all Centres, could elevate care and research for brain cancer patients across the UK. The process highlighted a hard-working and dedicated workforce who go 'above and beyond' for their patients, address challenges through innovative solutions, and are committed to service development as evidenced by their participation in the review process.

Consistencies between Centres were found across the patient pathway: Centres demonstrated good adherence to guidelines issued by specialty specific bodies. Centres adhered to recommended waiting times (with exceptions as a result of backlogs induced by COVID-19 surges); were committed to patient involvement in treatment decision-making; and conducted audits to evaluate and improve services.

All Centres demonstrated a commitment to clinical research, with every Centre hosting at least one trial. Most notably, staff demonstrated dedication and tenacity, whether through efforts to get patients into clinical studies, ensuring patients were expedited to the top of community services waiting lists, or supporting patients with completing forms for benefit requests.

Centres faced common challenges threatening service development and sustainability: Many Centres reported challenges with staff recruitment and succession planning and offered limited resources for staff learning and development. Centres were often unable to obtain the desired funding to resource allied healthcare professional (AHP)-led services. Key barriers to increased clinical study activity include lack of clinical trial staff and equipment. Lab-based research is heavily dependent on limited funding sources from three main funders, leading to uncertainty in planning long-term studies and employment in this sector.

There were several areas of significant variation between Centres: Variation among Centres reflected differences in patient demographic, geography, funding, and regional working practices. Centres varied most notably in: the extent and type of genomic testing and biobanking offered; nurse resourcing and specialisation; AHP-led pathways organisation; identification and assessment of patients; and trial readiness and research activity, with disparities in the number of open trials and research staff resourcing.

These findings build on prior reports of geographical variation in services that likely result from six drivers:

1. Dedicated neuro-oncology services are constantly evolving and the evidence base supporting some service models continues to mature and expand;
2. There are alternative ways to effectively meet specific patient needs;
3. Services evolve in alignment with existing regional infrastructure and patient demographic;
4. Services and pathways are shaped by the clinical and research interests of staff;
5. Variability may result from limited awareness or exposure;
6. Variability is driven by inequalities in income and local funding priorities.

While the first four may be seen as positive drivers, the last two causes are less desirable and should be addressed where possible.

Service development and addressing gaps will require a tailored approach on both an individual and national level: Each Centre, following the review process, received constructive tailored feedback focused on areas to improve, underpinned by the data described in this report, with the aim to further encourage and support local service development. Nationally, the data collected have the potential to play a key role in shaping brain cancer health policy by highlighting variations, inequalities, and common challenges. The TJBCM is committed to working with all key stakeholders including Centres, charities, and commissioning teams to collaboratively address these. To facilitate this, the TJBCM has founded the Tessa Jowell Academy. Through this national digital platform, the Mission supports Centres to further develop their services in four ways: (1) offering bespoke courses and workshops tailored to unmet needs, (2) national networks for peers to address specialty specific challenges and share best practice, (3) a Peer-to-Peer Connect service, and (4) individualised Centre support.

Does it matter where patients go for their brain cancer treatment? Based on the findings, patients being treated for brain cancers in any UK centre will be able to obtain an effective standard of care, delivered by a motivated team. Patients are most likely to experience variation in care due to their Centre in the following parts of the pathway: the genetic testing of their tumour samples, access to clinical studies, and the extensiveness of nurse and AHP-led care and support they receive. Importantly, Centres are on a clear upward trajectory and are engaging with senior hospital management and their Integrated Care Boards to further develop their service.

Recommendations from this Report

① **Share examples of innovation and “pockets of excellence”**

Each Centre possessed individual strengths which, if widely shared and implemented across all Centres, could level up the care of brain cancer patients across the UK.

② **Address the unique gaps and local challenges for each Centre**

Opportunities for improvement are evident in every Centre. To help facilitate Centres to achieve these, the Mission offers support through the Tessa Jowell Academy.

③ **Collaborate nationally to overcome common challenges**

Some challenges and sources of variation will require a national, co-ordinated response. We make the following recommendations:

1. **Make genetic testing more equitable by addressing current barriers.** The TJBCM has launched an “Equity in Genomics Task and Finish group” to address this;
2. **Improve access to clinical studies for patients from all geographical areas;**
3. **Build consensus on best practice in patient quality of life care and improve access to these services;**
4. **Explore opportunities to diversify brain cancer research funding income** and further engage with NIHR on accessing the £40million funding commitment made in 2018;[2]
5. **Work to address persistent staff shortages.**

Remit of the Centre of Excellence Designation Programme

The extent of the Programme’s remit was to review whether applicant Centres met the Tessa Jowell Excellence Standards outlined by the TJBCM. This was a voluntary review. The Care Quality Commission assesses the quality and safety of care in hospitals. The TJBCM does not audit hospitals to determine safety or patient outcomes. Limitations of the TJBCM review are further discussed in the Approach section.

Introduction

Brain cancer remains one of the hardest to treat cancers.[3] While life expectancy for patients with many types of cancer has increased significantly over the last three decades, survival from glioblastoma remains at an impasse with no curative treatments currently available.[4]

In the absence of a cure, several challenges can be overcome to improve patient outcomes. Understanding and correcting variations in patient care and access to research across the country are key contributors to improving national cancer outcomes and are an increasing focus for health policymakers and researchers.[5,6] These issues are particularly important for brain cancer, given the unique challenges faced by patients, clinicians and researchers tackling the disease.[4] Yet, beyond ad hoc testimony and some peer-review activity, little is known about variations in brain cancer patient care, hospital staffing, training, and research among UK Centres.

A diverse team with expertise in these areas was assembled by the TJBCM to review activity across UK neuro-oncology Centres. This assessment was an integral part of the Tessa Jowell Centre of Excellence Designation Programme (see **Box 1**), designed to identify, recognise, and support excellence in brain cancer treatment, care, and research. The programme was open to any hospital – individually or as a regional group – providing care for brain cancer patients along the entire patient pathway.

Following a consultation process with experts in the field of brain cancer, a set of 'Excellence Standards' were designed (see **Supplementary Materials**), with Centres assessed in five key areas (see **Table 1**). These standards go above and beyond existing NHS guidelines and aim to capture the standard of care needed to attain clinical excellence, with a strong emphasis on patient quality of life.

Box 1: About Tessa Jowell Centre of Excellence Designation Programme

The data presented in this report were collected as part of the Tessa Jowell Centre of Excellence designation process, one of eight national portfolio programmes delivered by TJBCM. The transformational Centre of Excellence Designation Programme aims to identify, recognise and support specialised Centres providing high quality brain cancer care, through an application process, where Centres apply to be considered for 'Tessa Jowell Centre of Excellence' status. At the end of this process, Centres either attained 'Excellence' status, or were asked to re-apply in the future. All Centres received detailed feedback and further support to help attain future 'Excellence' status, through the other TJBCM programmes such as the Tessa Jowell Academy. For patients, the 'Excellence' status allows them to feel more confident that they are receiving excellent care under the NHS. For Centres, striving for this status encourages ongoing service improvement and raises treatment and care standards over time.

> **We know where things need improving and where excellence can be celebrated and shared […]**
>
> PROF RICHARD GILBERTSON

Table 1: Five Component Areas of the Designation Review

Area of Assessment	Description
1. Treatment	Core treatment pathway, including surgery, pathology, chemotherapy and radiotherapy
2. Patient Quality of Life Care	Nurse and AHP-led services, such as symptom management, rehabilitation and end-of-life care, with an emphasis on patient quality of life
3. Staff Training and Development	Training and development opportunities for their staff
4. Clinical Trials	Clinical trial opportunities, clinical trial readiness of Trust, patient participation and collaboration with other Centres
5. Brain Cancer Research	Links with brain cancer research, including basic and translational science

The assessment of each applicant Centre was informed by three components:

1. A set of over 100 questions, designed by a Committee of brain cancer specialists and self-completed by each Centre;
2. Input from over 1500 patients collected by the Brain Tumour Charity;
3. A 1.5-hour virtual site visit with each Centre to discuss their strengths and areas for improvement.

The data collected as part of the 'Centre of Excellence' programme have provided insight into brain cancer treatment, care and research across Wales, Scotland, and all regions of England. It is envisaged that these data will inform health service planning and policy for brain cancer, as well as the wider debate about geographical variations in care for other cancers and diseases.

This report presents an overview of the approach of the review process and the main findings, explaining how Centres scored against the standards. We discuss the key characteristics of three categories of Centres and examine the drivers behind a 'Centre of Excellence'. We describe the key consistencies, strengths, and characteristics of excellence for the 28 Centres. This is followed by an overview of the areas of variation between the Centres and the common challenges that services face. Finally, we set out three recommendations to drive progress in the treatment, research and care for patients with brain cancer and explain how some of these are already being addressed through the Tessa Jowell Academy. Detailed methods and the full results are accessible through the QR code at the end of the report.

Our Approach

Data Collection

Applications to apply for 'Centre of Excellence' status were open to UK neuro-oncology Centres, defined as a hospital, or network of hospitals, providing a complete care pathway from diagnosis to end-of-life care for patients with a brain cancer. A "Centre" can therefore be a single NHS Trust, or a group of NHS Trusts who together constitute a patient pathway.

Data were collected through two designation rounds, with 28 Centres responding out of 31 eligible to apply. Each Centre completed a self-reported application form that assessed performance in five areas of excellence (see **Table 1**). The application process was designed to collect quantitative and qualitative data. Questions were developed iteratively in collaboration with subject specialists.

Responses from Centres were reviewed by 18 experts, all NHS clinical specialists and often also leading academics in their specialty. Centres were additionally assessed using patient feedback collected through the Brain Tumour Charity questionnaire "Improving Brain Tumour Care".[1] Each application was then subject to peer-review by the Committee.

Following the Committee peer-review, virtual site visits were conducted with each Centre to clarify issues raised and gain further insight into service provisions. Finally, all data were reviewed and calibrated (where Centre scores were agreed and compared) by the Committee (see **Figure 1**).

Data Analysis

Numerical data were extracted to allow comparisons between Centres. Where Centres provided a range of data rather than an exact value, or provided data from their network sites, care was taken to define a representative score e.g. weighted average. We also noted when Centres provided estimates of numerical data.

Descriptive data were analysed thematically[7] to allow for the identification of common themes. In other cases, qualitative data were summarised narratively by selecting representative examples of common themes.

The results presented in this report rely on data extracted from application forms, in cross-reference with responses from the virtual site visits. Centres are anonymised throughout.

Limitations

- **Self-reported data:** Centres may have provided overly positive responses to questions or omitted critical information.
- **Free text elements in application:** variations may occur in the detail and content provided by Centres, resulting in perceived rather than actual differences in service delivery.
- **Many members completing the questionnaire:** certain questions may be completed by individuals not expert in the relevant content.
- **Quantitative data drawn from audits and staff estimates:** estimates are likely to be less accurate but are included to permit comparisons across Centres.

Please scan the QR code at the end of the report to view Extended Methods and Tessa Jowell Excellence Standards.

Figure 1: Application and Assessment Process.

Input

Review

Output

>1500 patients provided feedback through the Brain Tumour Charity

28 application forms completed by applicant Centres, answering 100+ questions

Expert Review of Each Section

A subject specialist reviews a specific section of every form – e.g. rehabilitation specialist reviews the rehabilitation section

Lead Review

One reviewer "owns" and reviews an entire form

Peer-review Day

All experts jointly discuss review outcomes and focus areas for each virtual site visit

TJBCM Review

Parallel review of all application forms by TJBCM

28 Virtual Site Visits

Interviews with Centres to clarify and provide further detail on application form responses

Designation Committee Final Review

Calibration of Centres against each other and the standards

National benchmarking dataset comparing Centres across England, Wales and Scotland

28 individual feedback reports for Centres comparing to national average

Centres awarded Excellence status; all Centres signed up to Tessa Jowell Academy

Findings

Figure 2: Growth of the Centres of Excellence over time.

March 2021: 9 Centres
22.5M people in catchment area
4200 new brain cancer patients per year

Dec 2021: 11 Centres
30M people in catchment area
5000 new brain cancer patients per year

March 2022: 17 Centres
40M people in catchment area
7300 new brain cancer patients per year

Outcome of the Centre of Excellence Assessment: The Network View

Following assessment of the 28 Centres who applied to the Tessa Jowell Centre of Excellence Designation Programme in the first two review rounds conducted in 2020-21, 11 Centres were awarded 'Centre of Excellence' status. A further six Centres were awarded 'Excellence' status upon reapplication in 2022, after having made improvements following Committee feedback.

During the assessment, Centres were graded in all areas of the treatment, care and research pathway as follows:

- Yellow indicates 'meeting the excellence standard'
- Light green indicates 'exceeding the standard'
- **Dark green** indicates 'exceeding the standard' in more than one way
- **Red** indicates that the standard is 'not met'

On the next page, **Figure 3** provides an overview of how the Centres scored in each step of the treatment and research pathway. Both excellence and issues to address were found across the pathway.

Figure 3: Heatmap of the 28 neuro-oncology Centres following the first two rounds of review, with Centres numbered across the top. Centres who reached excellence standards are labelled with a roman numeral, other Centres with letters.

		CENTRES																											
		I	II	III	IV	V	VI	VII	VIII	IX	X	XI	E	A	B	C	D	F	G	H	I	J	K	L	M	N	O	P	Q
CLINICAL CARE	Surgical service	🟨	🟨	🟨	🟨	🟨	🟩	🟨	🟩	🟨	🟨	🟢	🟥	🟨	🟩	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟢	🟨	🟨	🟨	🟥	🟥
	Pathology turnaround	🟢	🟨	🟢	🟢	🟢	🟨	🟩	🟩	🟩	🟨	🟨	🟨	🟥	🟢	🟢	🟩	🟨	🟨	🟥	🟩	🟥	🟨	🟨	🟢	🟥	🟨	🟢	🟥
	Pathology Genetics	🟩	🟢	🟩	🟩	🟨	🟢	🟢	🟩	🟢	🟨	🟨	🟢	🟨	🟢	🟨	🟩	🟨	🟨	🟨	🟩	🟨	🟨	🟢	🟨	🟨	🟨	🟨	🟨
	Imaging waiting times	🟩	🟨	🟢	🟨	🟩	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟢	🟨	🟨	🟨	🟨	🟨	🟢	🟢	🟥	🟥
	Imaging other	🟩	🟩	🟢	🟢	🟩	🟩	🟨	🟩	🟨	🟢	🟨	🟨	🟨	🟨	🟨	🟢	🟢	🟨	🟨	🟨	🟨	🟨	🟩	🟥	🟨	🟥	🟥	🟨
	Radiotherapy wait	🟩	🟨	🟨	🟨	🟨	🟢	🟨	🟨	🟨	🟨	🟨	🟢	🟨	🟨	🟥	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟢	🟢	🟨	🟨
	Radiotherapy other	🟢	🟢	🟨	🟢	🟢	🟩	🟢	🟨	🟩	🟨	🟢	🟨	🟨	🟩	🟨	🟨	🟩	🟨	🟩	🟥	🟥	🟨	🟨	🟥	🟥	🟨	🟨	🟨
	Chemotherapy	🟨	🟩	🟨	🟨	🟢	🟩	🟢	🟢	🟢	🟨	🟨	🟩	🟩	🟨	🟨	🟨	🟩	🟩	🟢	🟢	🟨	🟨	🟨	🟢	🟨	🟨	🟨	🟨
	Auditing Programme	🟩	🟩	🟩	🟢	🟨	🟩	🟩	🟨	🟢	🟨	🟩	🟢	🟢	🟩	🟨	🟢	🟩	🟨	🟢	🟢	🟢	🟨	🟢	🟨	🟨	🟥	🟥	🟥
PATIENT CARE	MDT & Clinic organisation	🟢	🟢	🟩	🟩	🟩	🟩	🟢	🟩	🟩	🟢	🟢	🟢	🟩	🟩	🟢	🟨	🟢	🟨	🟨	🟨	🟢	🟨	🟥	🟨	🟨	🟨	🟨	🟥
	CNS Care	🟩	🟩	🟩	🟩	🟩	🟢	🟢	🟩	🟩	🟨	🟢	🟩	🟢	🟨	🟩	🟨	🟩	🟩	🟨	🟩	🟢	🟨	🟨	🟨	🟨	🟩	🟩	🟢
	Rehabilitation (inpatient)	🟢	🟩	🟩	🟩	🟢	🟨	🟩	🟢	🟢	🟢	🟨	🟩	🟩	🟨	🟩	🟢	🟢	🟩	🟨	🟨	🟨	🟨	🟥	🟢	🟨	🟥	🟨	🟨
	Rehab (outpatient)	🟢	🟩	🟩	🟩	🟢	🟨	🟩	🟢	🟩	🟩	🟢	🟩	🟩	🟥	🟩	🟨	🟥	🟩	🟥	🟥	🟢	🟥	🟥	🟨	🟢	🟥	🟥	🟥
	Palliative and end-of-life care	🟢	🟩	🟨	🟢	🟨	🟢	🟩	🟢	🟨	🟢	🟨	🟢	🟢	🟨	🟢	🟥	🟨	🟩	🟢	🟢	🟢	🟨	🟨	🟢	🟨	🟩	🟥	🟥
	Low grade services	🟩	🟨	🟩	🟨	🟩	🟢	🟨	🟢	🟨	🟩	🟨	🟩	🟨	🟨	🟢	🟨	🟨	🟢	🟨	🟥	🟨	🟨	🟨	🟨	🟨	🟨	🟥	🟥
	Interaction with community services	🟢	🟩	🟢	🟩	🟢	🟢	🟩	🟨	🟩	🟢	🟨	🟢	🟩	🟢	🟩	🟢	🟢	🟩	🟨	🟨	🟢	🟩	🟥	🟨	🟢	🟨	🟩	🟥
	Collaboration with patient organisation	🟨	🟢	🟢	🟨	🟩	🟩	🟨	🟩	🟨	🟩	🟩	🟩	🟩	🟩	🟢	🟨	🟢	🟨	🟢	🟩	🟨	🟨	🟨	🟩	🟨	🟢	🟩	🟥
	Patient Centered Care	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟢	🟩	🟩	🟩	🟩	🟩	🟩	🟢	🟩	🟢	🟩	🟩	🟢
TRIALS	Clinical Trials	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟢	🟢	🟩	🟢	🟩	🟩	🟨	🟨	🟩	🟨	🟢	🟢	🟨	🟨	🟩	🟥	🟨	🟥	🟨	🟥
	Biobanking and sampling	🟩	🟩	🟩	🟩	🟢	🟢	🟩	🟩	🟢	🟢	🟢	🟩	🟩	🟨	🟢	🟩	🟢	🟥	🟢	🟩	🟨	🟥	🟩	🟥	🟥	🟥	🟩	🟥
TRAINING	Staff Development	🟨	🟩	🟩	🟩	🟩	🟢	🟩	🟢	🟩	🟩	🟩	🟢	🟢	🟨	🟩	🟨	🟩	🟨	🟨	🟢	🟨	🟨	🟨	🟨	🟥	🟨	🟢	🟥
	Succession and service sustainability	🟩	🟢	🟢	🟩	🟢	🟨	🟢	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟨	🟥	🟥	🟢	🟢	🟨	🟥	🟨	🟩	🟨	🟥	🟥	🟥
RESEARCH	Quality of research	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟢	🟩	🟩	🟨	🟢	🟩	🟨	🟢	🟩	🟨	🟨	🟩	🟨	🟨	🟨	🟩	🟨
	Grants	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟢	🟩	🟩	🟨	🟢	🟩	🟨	🟢	🟩	🟥	🟨	🟩	🟨	🟥	🟨	🟩	🟨

		I	II	III	IV	V	VI	VII	VIII	IX	X	XI	E	A	B	C	D	F	G	H	I	J	K	L	M	N	O	P	Q
TOTAL SCORES	**Flags**	0	0	0	0	0	0	0	0	0	0	0	-1	-1	-1	-1	-1	-2	-2	-2	-3	-3	-3	-4	-4	-5	-7	-8	-14
	Passes	4	5	5	6	5	5	6	6	7	9	10	4	8	11	11	13	7	14	10	7	14	19	11	13	14	7	7	8
	Exceeds	33	33	32	31	30	30	30	30	28	23	22	28	26	21	18	13	24	15	14	22	8	4	14	10	5	9	16	2

The assessment identified three groups (**Figure 4**):

① Centres who met or exceeded the standards in all areas and showed no major concerns. These were classified as “Tessa Jowell Centre of Excellence”.

② Centres who met or exceeded the standards in most areas, with a few areas where the standards were not yet met. These were classified as “Pending Designation”.

③ Centres with several areas which did not yet meet the standards were recommended to reapply after addressing the challenges outlined. These Centres were classified under “To Further Develop”.

Figure 4: The 28 applicant Centres were categorised into three groups according to how they met the ‘Excellence Standards’.

Group 1: “Designated”

Officially designated as
Centres of Excellence

Centre	Exceeds	Pass	Flags
I	33	4	0
II	33	5	0
III	32	5	0
IV	31	6	0
V	30	5	0
VI	30	5	0
VII	30	6	0
VIII	30	6	0
IX	28	7	0
X	23	9	0
XI	22	10	0

11 centres who met standards without a single flag

Group 2: “Pending Designation”

Reapply partially
in a year

Centre	Exceeds	Pass	Flags
A	27	4	-2
B	26	8	-1
C	24	7	-2
D	22	7	-3
E	21	11	-1
F	18	11	-1
G	15	14	-1
H	14	10	-1
I	14	11	-4
J	13	13	-1

10 centres who need to make minor changes in a few areas

Group 3: “To Further Develop”

Reapply in
two years

Centre	Exceeds	Pass	Flags
K	16	7	-8
L	10	13	-4
M	9	7	-7
N	8	14	-3
O	5	14	-5
P	4	19	-3
Q	2	8	-14

7 centres who need some changes across the service

Characteristics of ‘Centres of Excellence’

In addition to meeting every standard, these Centres generally demonstrated a breadth of innovative and excellent practice across treatment, care, research and staff training. The drivers behind the excellent service delivery by these Centres became especially apparent through the virtual site visits. Five drivers and attributes across all ‘Centres of Excellence’ were identified:

Local champions: A select group of two or three staff members who drive change to elevate care in their Centre. These included clinicians, nurses or AHPs who ensured their service would continue to innovate, sign up to trials, lead on audits, implement patient feedback or champion individual patients, helping them navigate through complex pathways.

Excellent trust leadership support: Several Centres reported productive and good relationships with their trust managers and commissioners. This ensured Centre leadership could argue for the required funding for their services and have productive discussions with management to keep the service up to date and well-staffed.

Seamless integration: Centres demonstrated strong links with colleagues in associated hospitals and community services as well as between the different specialties at a given site. Centres had systems in place to help services collaborate, for example software which shared patient data between clinical and community services.

Research support: Centres were strongly supported by their Trusts, associated academic research Centres and funding bodies in their research activity. They employed staff who proactively engaged in clinical studies and were involved in lab-based studies.

Centres embodied a human-centred culture of **kindness and compassion towards their patients**.

Based on the identified drivers, we have shared a checklist for Centre staff to use when further building on an environment and ways of working that foster excellence in **Box 2**.

Box 2: Proposed checklist to foster continuous service improvement

- **Champions:** Have I identified local champions in my teams and are we doing enough to empower those individuals to continue to innovate and improve the service? Are my local champions feeling valued?
- **Relationships:** How is the relationship with my Trust leadership and what could I do to further strengthen my working relationships?
- **Integration:** Is my service fully integrated? Are there any areas where patients might experience gaps, and are there any areas where I can improve communication and hand over to our affiliated Centres?
- **Links with research:** Can I strengthen my links with the local Clinical Trials Unit and/or neighbouring research Centres? Can we share biobanking facilities, collaborate on research projects or improve patient referrals to large studies in other Centres?
- **Human-centred kindness and compassion:** Does my patient feedback highlight any areas where we can improve? Are my patients involved in designing solutions to address these improvements? How do I share diagnoses, track evolving needs and thoughtfully transition patients to end-of-life care?

Characteristics of "Pending Designation" Centres

Applicant Centres which received "Pending Designation" were Centres that were able to meet or exceed the 'Excellence Standards' in most areas of review, but not all. The reviewers noted that the standards of the service provided by these Centres were high with many areas of excellence seen across the pathway. The areas where the Centres did not meet the standards were often challenges that could be addressed within a year of extra development, with some concerted effort from the team, additional funding or support from the TJBCM (with further details regarding support in the Tessa Jowell Academy section in the findings).

Characteristics of the "To Further Develop" Centres

Applicant Centres in the 'To Further Develop' groups were Centres which did not meet the standards in a number of areas and where the review Committee noted that the identified challenges may require more time to address. It should be noted that the level of care provided was good, safe and adhered to the various specialty standards.

Centres in this group showed fewer areas where they 'exceeded' standards compared with the other two groups. Notable excellence in several of the Centres in this group was in the areas of patient care, with enthusiastic and dedicated nurses and AHPs who provided patient care that went 'above and beyond', despite limited resources and complex geographies. It should be noted that all Centres in this group were on a clear upward trajectory and demonstrated good awareness of their areas for further development.

Some of the Centres in this group were smaller regional Centres where some specialists were working single-handedly. The Committee recommended improved networking with larger nearby Centres to jointly provide services and coverage to improve their performance in the next few years. These regional Centres are in the process of building up their research pathways and improving their clinical study capacity and readiness.

Outcome of the Centre of Excellence Assessment: The Pathway View

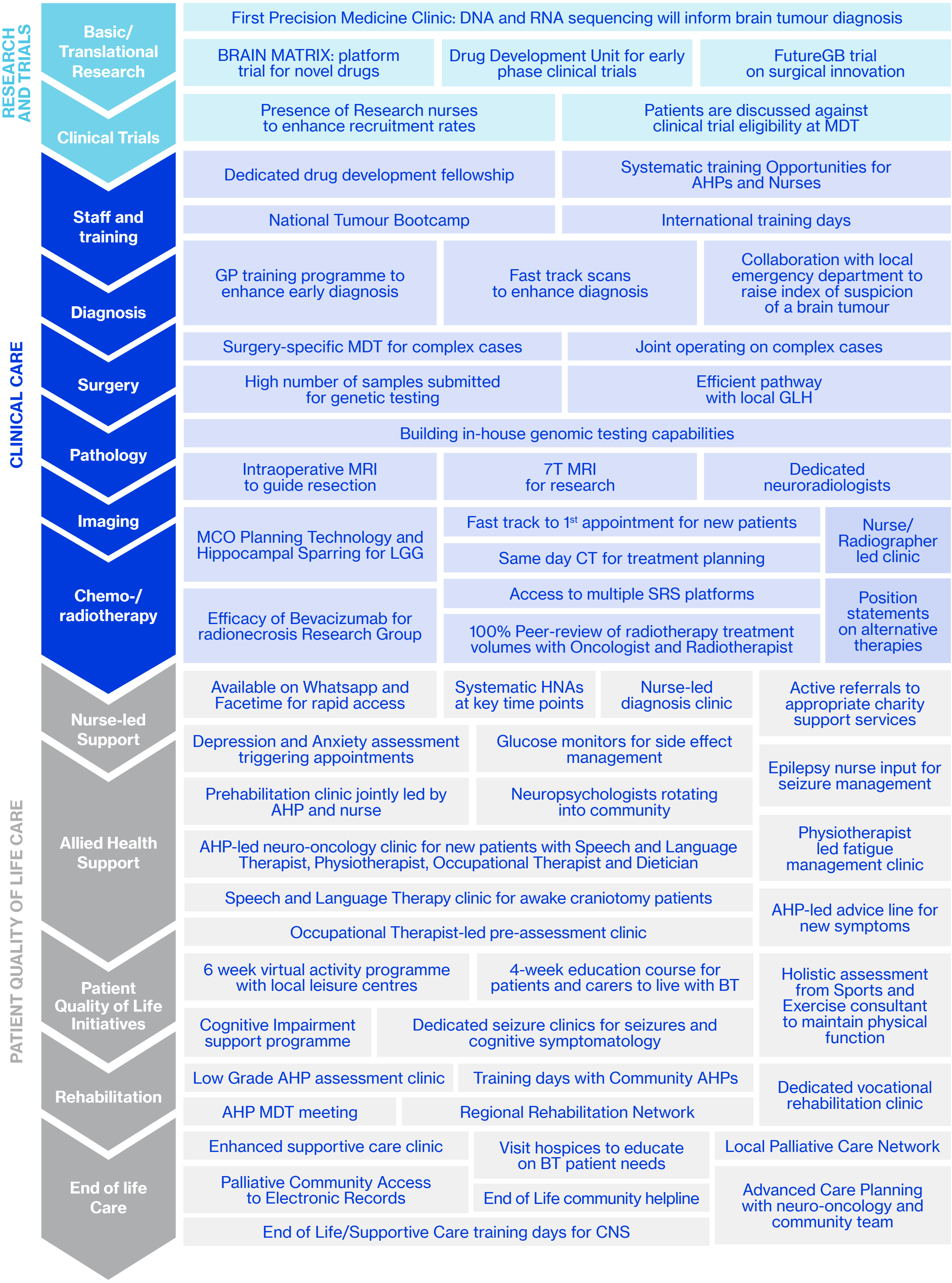
The data collected provide unique insights into the current state of the brain cancer field in the UK. Together, the data show a nuanced image of common strengths, with pockets of innovation and best practice, as well as widespread challenges and areas of significant variability in design, quality and extent of services provided. Possible determinants of variability are discussed in detail, accompanied by recommendations on how to address the areas of variability which cause vulnerabilities and inequalities in care. It is hoped that these findings will inform and contribute to the establishments of new standards of treatment and care for patients with brain cancers.

Consistencies, Strengths and Excellence

Notable areas of consistency were identified in many Centres

Our findings reveal important and reassuring consistencies between Centres. Basic patient safety and quality protocols were largely uniform across Centres, likely reflecting the high levels of standardisation in neurosurgery and neuro-oncology.[8] Additionally, outside of pandemic-related delays, waiting times for various treatment services were broadly within expected timeframes. All Centres complied with the British Society for Neuroradiologists' recommendations on MRI protocols for brain cancer patients. All Centres possessed UKAS accreditation for neuropathology laboratories, met the minimum guidelines set out by the Royal College of Physicians for datasets in pathologists reports, and took part in the Neuropathology External Quality Assessment (EQA). All Centres reported that they were broadly achieving NICE Improving Outcomes Guidelines and were actively working to meet these guidelines.

Figure 5: TJBCM's "Library of Excellence"; examples of best practices from UK Centres.



RESEARCH AND TRIALS

Basic/ Translational Research

Clinical Trials

First Precision Medicine Clinic: DNA and RNA sequencing will inform brain tumour diagnosis

BRAIN MATRIX: platform trial for novel drugs

Drug Development Unit for early phase clinical trials

FutureGB trial on surgical innovation

Presence of Research nurses to enhance recruitment rates

Patients are discussed against clinical trial eligibility at MDT

CLINICAL CARE

Staff and training

Diagnosis

Surgery

Pathology

Imaging

Chemo-/ radiotherapy

Dedicated drug development fellowship

Systematic training Opportunities for AHPs and Nurses

National Tumour Bootcamp

International training days

GP training programme to enhance early diagnosis

Fast track scans to enhance diagnosis

Collaboration with local emergency department to raise index of suspicion of a brain tumour

Surgery-specific MDT for complex cases

Joint operating on complex cases

High number of samples submitted for genetic testing

Efficient pathway with local GLH

Building in-house genomic testing capabilities

Intraoperative MRI to guide resection

7T MRI for research

Dedicated neuroradiologists

MCO Planning Technology and Hippocampal Sparring for LGG

Fast track to 1st appointment for new patients

Same day CT for treatment planning

Nurse/ Radiographer led clinic

Efficacy of Bevacizumab for radionecrosis Research Group

Access to multiple SRS platforms

100% Peer-review of radiotherapy treatment volumes with Oncologist and Radiotherapist

Position statements on alternative therapies

PATIENT QUALITY OF LIFE CARE

Nurse-led Support

Allied Health Support

Patient Quality of Life Initiatives

Rehabilitation

End of life Care

Available on Whatsapp and Facetime for rapid access

Systematic HNAs at key time points

Nurse-led diagnosis clinic

Active referrals to appropriate charity support services

Depression and Anxiety assessment triggering appointments

Glucose monitors for side effect management

Epilepsy nurse input for seizure management

Prehabilitation clinic jointly led by AHP and nurse

Neuropsychologists rotating into community

AHP-led neuro-oncology clinic for new patients with Speech and Language Therapist, Physiotherapist, Occupational Therapist and Dietician

Physiotherapist led fatigue management clinic

Speech and Language Therapy clinic for awake craniotomy patients

Occupational Therapist-led pre-assessment clinic

AHP-led advice line for new symptoms

6 week virtual activity programme with local leisure centres

4-week education course for patients and carers to live with BT

Holistic assessment from Sports and Exercise consultant to maintain physical function

Cognitive Impairment support programme

Dedicated seizure clinics for seizures and cognitive symptomatology

Low Grade AHP assessment clinic

Training days with Community AHPs

Dedicated vocational rehabilitation clinic

AHP MDT meeting

Regional Rehabilitation Network

Enhanced supportive care clinic

Visit hospices to educate on BT patient needs

Local Palliative Care Network

Palliative Community Access to Electronic Records

End of Life community helpline

Advanced Care Planning with neuro-oncology and community team

End of Life/Supportive Care training days for CNS

Our review of patient quality-of-life services revealed a consistent commitment to patient-centred care: reviewers noted many examples of NHS staff going above and beyond standard of care, putting patients and their families at the centre of service delivery. This is despite staff often operating in an under-resourced and under-funded environment. Seventy-five percent of Centres noted the existence of patient-centred care pathways as a key strength. All neuro-oncology Centres evidenced dedication to research, even if barriers prevented greater participation from staff and patients. Several staff members noted that they conducted research in their spare time in addition to their other duties. Furthermore, a common commitment to service improvement was identified, as shown by the engagement of Centres to ongoing improvement following the first round of applications. For example, six Centres which did not obtain designation in the first round made service improvements to obtain 'Excellence' status 18 months later. This is extremely encouraging and exemplifies the commitment of staff and Trusts to improve the care of patients.

There are many "pockets of excellence" and innovation across the entire patient pathway

Many examples of best practice and innovative models were identified. Specific areas of excellence were sometimes confined to single Centres and the underlying expertise, model of care, or components of the pathway would not be routinely shared with other Centres. As such, excellence could remain "trapped" within a single Centre. For example, some of the Centres with the most extensive neuro-rehabilitation opportunities were not necessarily aware that theirs were among the best developed in the UK. A list of examples of excellent and innovative practice across all areas of patient care was generated from the application process, including patient feedback. We have incorporated these into a "Library of Excellence" (**Figure 5**) as a resource to allow Centres to share and develop services, assisted by the Tessa Jowell Academy. A detailed description of the various areas of excellence can be found in the extended results through the QR code.

Challenges

Centres faced common challenges, with some notable exceptions

We identified three key areas of challenges impeding service improvement, with other notable areas summarised in **Box 3**.

Many Centres faced challenges staffing their services. There was a marked difference among Centres in overcoming staff recruitment and succession-planning issues. Some Centres showed effective ways of addressing these issues, for example, collaborating with neighbouring Centres to share technical expertise or providing holiday and sickness coverage.

Centres were often unable to obtain funding for well-resourced AHP-led services and staff. Clinical Nurse Specialists (CNS) were particularly overburdened in many Centres, potentially affecting the identification and meeting of patient needs. Many Centres were unable to offer repeated Holistic Needs Assessments and noted that the forms were not fit for purpose. This made the co-ordination of personalised care and support more challenging at times. A number of Centres also demonstrated a lack of insight into the need for long-term follow-up of patients referred to community services.

Further, heavy dependency on a small group of charitable funders for support for basic research was a significant weakness. The lack of funding diversity in this sector puts many studies and jobs at risk if research priorities were to change in this small group of funders. There were several other challenges shared by many Centres, which were often the reason that some Centres were not awarded 'Excellence' status (**Box 3**).

Box 3: Common areas where Centres failed to meet the standards set out by the TJBCM review Committee – and who were therefore not designated

Neurosurgery subspecialisation: A number of Centres reported that full subspecialisation of their neurosurgical services was still an ongoing process. These Centres mostly acknowledged the need for this, but entrenched ways of working undermined these efforts.

Pathology turnaround times and testing capabilities: Several Centres did not have the infrastructure in place to turn around key analyses in a timely manner or routinely submit samples for genomic testing. Turnaround time issues were often related to Centres relying on neighbouring Centres for analyses, whereas the limited submission of genetic samples was influenced by a lack of infrastructure, resourcing or awareness.

Staffing: Centres experienced issues with insufficient staffing, whether due to national shortages or budget cuts. Many Centres were unable to demonstrate how they were adequately addressing these challenges to ensure sustainability of service in the case of retirement or staff losses.

Identifying and meeting patient needs: Patients reported a large number of unmet needs despite Centres' efforts to identify and meet these. This is partly due to issues in access (e.g. lack of hospital-based or community services, or insufficient signposting), capacity (overburdened staff unable to provide systematic Holistic Needs Assessments), and availability (e.g. waiting lists and insufficient staffing).

Co-ordination and oversight: Several Centres reported that it could be challenging to oversee patients, especially once they entered community services. Patients could get stuck on long waiting lists or have to rely on their GPs to access community services in a timely way.

Waiting times: Many Centres encountered issues with waiting times for AHP services. Community services often had long waiting lists and in-hospital services also struggled with this due to a lack of resourcing. This was particularly seen for neuropsychology.

Peer-reviewing: At least seven Centres were unable to peer-review at least 60% of their cases. This was primarily due to single-handed oncologists not having the capacity, or oncologists not having allocated time for peer-review in their job plan.

Tissue/biobanking: A number of Centres reported limited tissue and biobanking. This was due to underdeveloped infrastructure (e.g. freezer capacity) and limited clinical trial involvement.

Variations in Services

Certain elements of the design, quality and extent of brain cancer services and research vary substantially across Centres

While there were commonalities among Centres, reviewers noted a striking variation in many areas of services and research activities which can be summarised in the areas of treatment, patient quality of life, research and sustaining and developing the service.

Centres generally met required treatment standards with few variations in approach. Areas for further development included the subspecialisation of neurosurgical services, peer-reviewing of radiotherapy treatment volumes, and improving neuroradiology waiting times following pandemic-related delays. Significant differences in the staffing levels in hospitals (as shown by the proxy new glioma patient per surgeon) and in the attendance of subspecialities at multi-disciplinary meetings (MDMs) were also noted (**see Selection of figures below**). The most significant variation was observed in neuropathology, with differences in which patients were offered genetic testing and when, which staff members requested these tests (e.g. the oncologist or the pathologist) and if material was analysed locally or externally. This is despite the recognised importance of sequencing for identifying actionable targets in brain cancer,[9] as well as the fact that the introduction of Genomic Laboratory Hubs (GLHs) aimed to reduce social and regional inequality in access to genetic testing, simplifying patient pathways and "democratising" genetic testing.[10,11]

There was substantial variation in CNS and AHP deployment. There was limited standardisation of CNS staff organisation, subspecialisation, and engagement in, and leadership of, clinics. There was also striking variation in the quality, design and extent of AHP-led services dedicated to maintaining and improving patient quality of life. Many different models of rehabilitation services were identified. Services varied in the extent to which they provided hospital-based outpatient services or relied on community services. Patients across the country therefore could have differing levels of access to support.

Centres varied significantly in their participation in, and readiness for, clinical trials. Reported barriers to opening trials included limited research staff capacity. Similarly, support for preclinical research was concentrated in a few Centres, primarily those with links to large academic institutions.

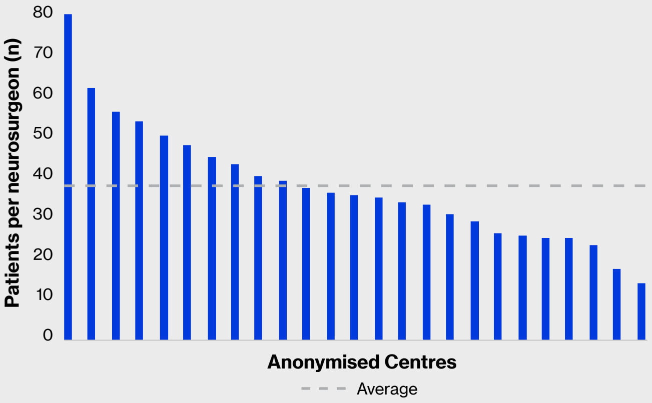
A selection of figures demonstrating the variations are highlighted in the boxes below.

Selection of figures demonstrating variation:

Surgery:

We divided the number of new glioma patients per year attending the Centre by the number of specialised neurosurgeons to get an approximation of the case load of different Centres. On average Centres operated on 38 new glioma patients per surgeon per year (range of 14 to 80 patients; **Figure 6**). Case load levels are not a direct representation of quality of care and are influenced by variables such as service organisation and resources.

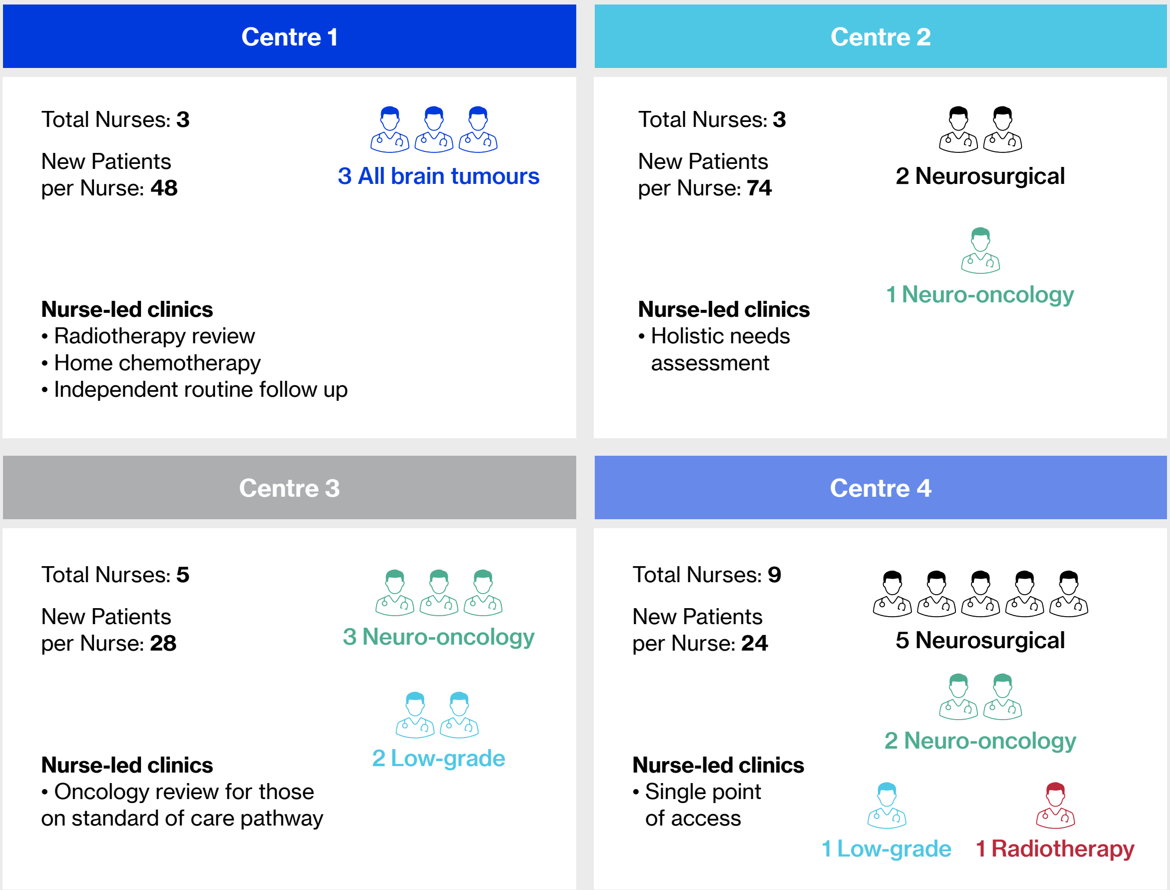
Figure 6: Ratio of new glioma patients per specialised surgeon in a 12 month period.



CNS resourcing:

Expertise and deployment varied among Centres. We identified four different models as highlighted by four example Centres: In Centre 1, nurses were deployed along the entire patient pathway for all brain cancers. In Centre 2, nurses specialised either in surgical or neuro-oncology care. In Centre 3, nurses specialised in low- or high-grade tumours. This was less common as few Centres deployed dedicated low-grade nurses. Centre 4 deployed a mixture of specialisation. Furthermore, Centres varied in how they involved nurses in clinics. Some Centres offered numerous nurse-led clinics, often including the Holistic Needs Assessment clinic, while other Centres reported only one nurse-led clinic.

Figure 7: Nurse staffing and deployment.



Centre 1

Total Nurses: **3**

New Patients per Nurse: **48**

3 All brain tumours

Nurse-led clinics
- Radiotherapy review
- Home chemotherapy
- Independent routine follow up

Centre 2

Total Nurses: **3**

New Patients per Nurse: **74**

2 Neurosurgical

1 Neuro-oncology

Nurse-led clinics
- Holistic needs assessment

Centre 3

Total Nurses: **5**

New Patients per Nurse: **28**

3 Neuro-oncology

2 Low-grade

Nurse-led clinics
- Oncology review for those on standard of care pathway

Centre 4

Total Nurses: **9**

New Patients per Nurse: **24**

5 Neurosurgical

2 Neuro-oncology

1 Low-grade

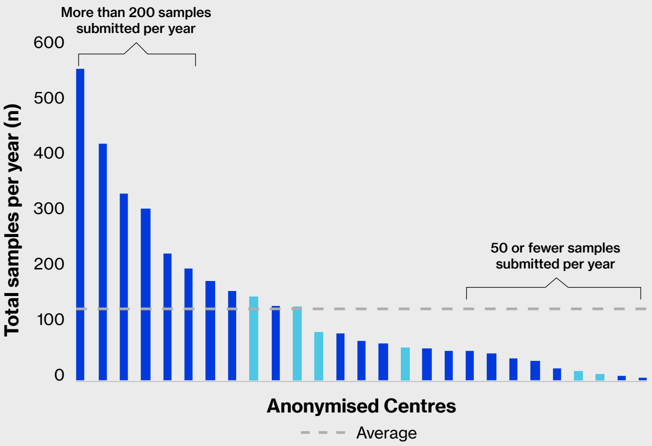
1 Radiotherapy

Nurse-led clinics
- Single point of access

Genetic testing:

We observed a striking variation in genetic testing between Centres. Six Centres submitted 200 or more samples, including gene panels, methylation array, whole genome, and RNA sequencing, while eight Centres submitted fewer than 50 samples (**Figure 8**). This variation existed even when normalised for the number of patients treated in each Centre. Only five (18%) Centres offered whole genome sequencing.

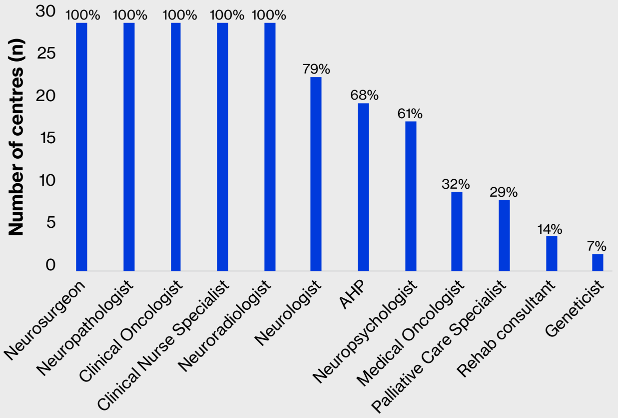
Figure 8: Total samples submitted during a 12 month period.



Multi-Disciplinary Team (MDT):

Cancer care is delivered by MDTs comprising of different specialists who work together to provide treatment. All Centres reported holding MDT meetings at least once weekly. Neurosurgeons, neuropathologists, clinical oncologists, and clinical nurse specialists, attended MDT meetings in all Centres. Four positions recommended as core MDT members by NICE Improving Outcomes Guidance[12] (neurologist, AHP, palliative care specialist and neuropsychologist) were not present in MDTs in all Centres.

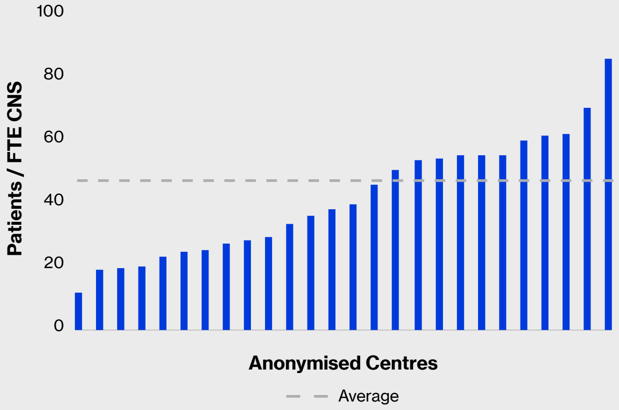
Figure 9: Attendance of specialties at MDT meetings.



Nurse-led care:

CNS support was calculated relative to the number of new glioma patients seen per year in each Centre. A nine-fold difference was observed in CNS capacity across Centres (**Figure 10**), varying between 13 and 95 patients/full time equivalent (FTE) nurse (average of 46 patients/FTE nurse).

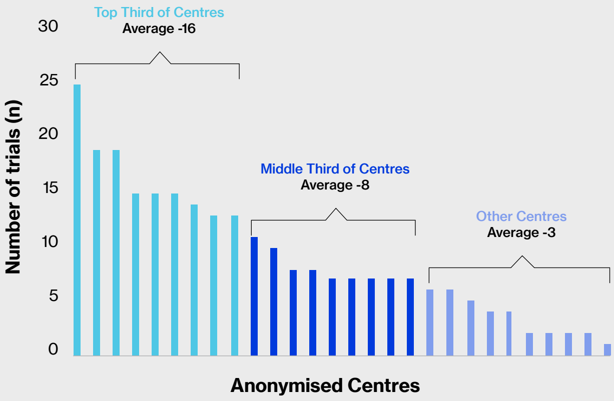
Figure 10: Number of new glioma patients per CNS in patients per full time equivalent.



Clinical studies:

While all Centres were participating in at least one open clinical study, the number of open studies in Centres ranged from 1-25 (**Figure 11**). Understandably, larger numbers of studies were observed in larger academic Centres.

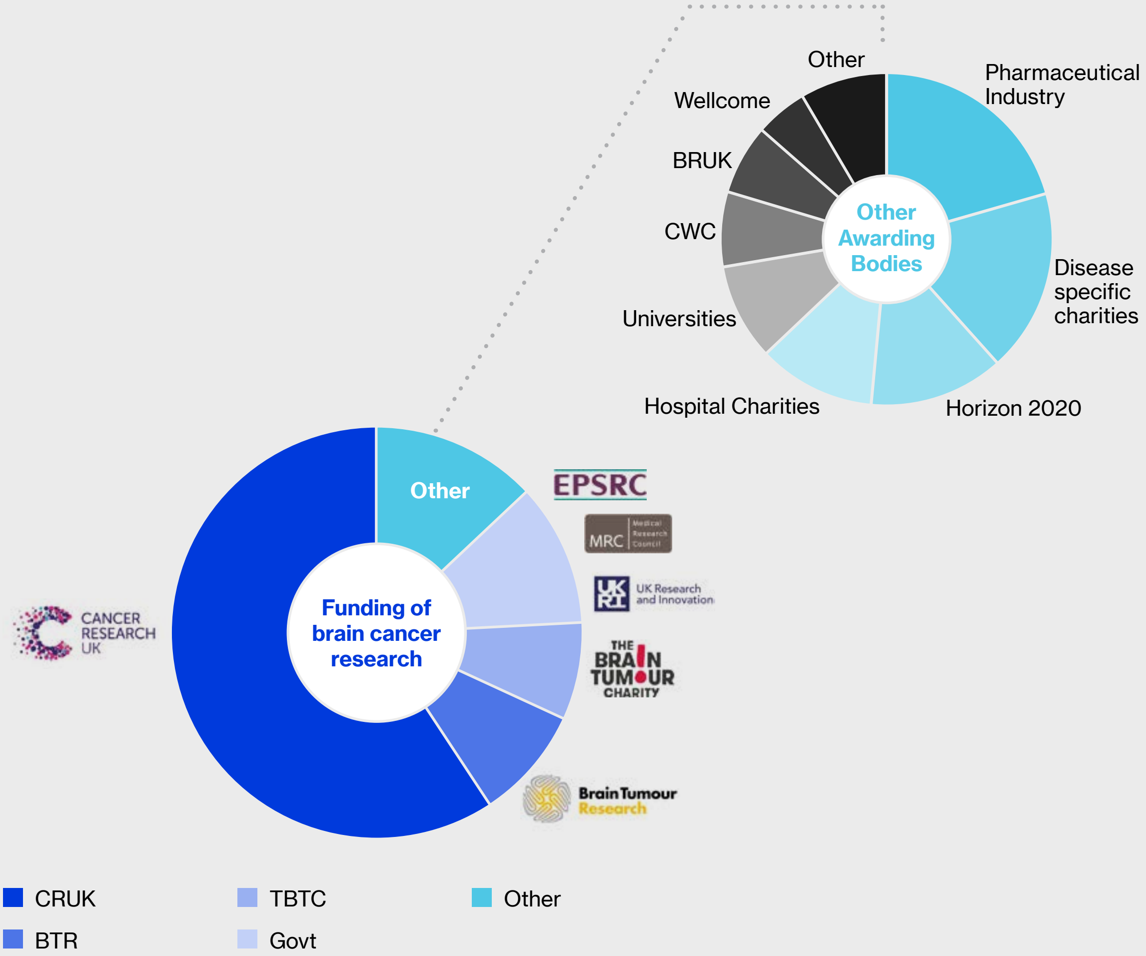
Figure 11: Number of clinical studies per Centre.



Laboratory-based research funding:

Centres reported ~£100 million of investments in brain cancer research between 2016 and 2020/21. Most of this funding was provided by Cancer Research UK (CRUK; **Figure 12**), with significant additional funding from Brain Tumour Research and the Brain Tumour Charity. Seventy-five percent of all research activity came from these three largest funders revealing a strong dependency on charitable funders. Eleven percent of funding originated from UK government sources (EPSRC, MRC, UKRI) and only 3% of basic and translational research funding was awarded by pharmaceutical companies. However, there was more pharmaceutical funding available for clinical studies (40.5% of all trials were commercially funded).

Figure 12: Funding of brain cancer research in UK brain tumour centres by funders (total ~£100million).



(Abbreviations: BRUK: Brain Research UK; CWC: Children with Cancer; EPRSC: Engineering and Physical Sciences Research Council; MRC: Medical Research Council; NIHR; National Institute of Health Research; UKRI: UK Research and Innovation).

Patient feedback

Patient feedback collected through the Brain Tumour Charity[1] highlighted challenges faced by patients. Seventy-four percent of respondents said they had unmet needs. This included needing more psychological support (41%) and symptom management (35%). Only half of patients reported being signposted to emotional support or counselling. Additionally, patient feedback found that only 35% patients reported participating in research. This ranged from 4% to 61% across Centres, demonstrating again striking variation. However, it is worth noting that this was a pilot study with a range of sample sizes per Centre, some of which were not large enough to be considered statistically powered.

	Patient feedback highlights
Diagnosis	**38%** did not understand their prognosis
Support	**41%** reported limited CNS access **74%** reported unmet needs **41%** needed more psychological support **79%** lacked needs assessment and plan
Research	**35%** participated in any research

The variation observed in brain cancer services likely originates from six drivers

While we noted significant variation between services provided by Centres, this variation can arise from a variety of positive, neutral or more negative drivers. Variability is to be encouraged when it drives up standards of treatment and care. In these cases, variations in care may represent genuine innovations, with lessons potentially to be learnt by other Centres. Other examples of variation may simply arise from differences in demographics or geography. However, it is important to recognise that some variation might reflect what has been called a “postcode lottery” of health services.[13,14] In these cases, the causes of variation need to be recognised, so that they can be addressed. Below we provide six potential drivers of variation, four of which are positive or neutral, and two are more unfavourable.

1. Services are constantly evolving

Neuro-oncology services are constantly evolving, and the evidence base supporting some service models continues to mature and expand. Further guidelines and evidence are likely needed for nurse- and AHP-led services, with a focus on symptom and quality of life management and rehabilitation. Some Centres reported that the limited evidence base for certain services led by AHPs had made it more difficult to obtain funding for such services. This has likely played a role in the significant variation in how these services are offered across Trusts. However, the need for these services is clear. Patient feedback survey responses consistently described the many unmet needs patients experience because of their diagnosis.

2. Several acceptable pathways exist concurrently to meet a need

It is important to recognise that there are several valid ways to effectively meet a patient’s needs. Sometimes there is a lack of consensus on the best pathway due to lack of evidence. Variation was particularly observed in areas where an individualised approach may be preferable. For example, managing a patient’s emotional needs may differ based on the patient’s disposition. Centres reported several different ways in which a patient could receive supportive care and would differ on who would provide such care.

3. Services adapt to current infrastructure and geographical needs

Most services have evolved to align with existing infrastructure in their specific geographical area. Many brain cancer centres cover either a large geographical region or large population and need to operate in alignment with what different hospitals and community services can provide. Centres with access to an abundance of community services may develop models where handover to local care is desirable and effective. Conversely, Centres that serve areas with limited community services have opted to further develop hospital-based outpatient services. Centres have also evolved to suit their patient demographic. For example, one Centre with a particularly ethnically diverse population developed resources and ways of working to suit the specific cultural needs of their varied patient group. Centres designated as ‘Excellent’ demonstrate tailored and well-integrated models of care which work across a network of providers.

4. Services excel in areas that align with research interests of staff

Services and pathways have developed and matured in different ways based on the clinical and research interests of staff. A Centre may have a well-developed neuropsychology service or AHP-led symptom management clinic due to staff interest and strength. In these instances, Centres should be encouraged to disseminate their specialist expertise across the country. Adoption of innovations subsequently happens when other Centres learn about these at conferences and in scientific reports and have the capacity to start implementing these locally.

5. Limited awareness or exposure can limit service development

Variability may be the result of limited awareness or exposure. Centre staff may not have been exposed to certain innovations or models of care yet and have therefore not implemented these. This is particularly relevant in rapidly evolving fields such as genetic testing. Another frequently seen example is that Centres are not always aware of the support services provided by national and local charities.

6. Local funding priorities can inhibit service growth and maintenance

There is no doubt that variability is in part driven by income and local funding priorities. NHS trusts differ in their income, particularly when considering how much additional income they may be able to generate. Within Trusts there is a discretional difference in how much funding is allocated to brain cancer treatment versus other cancer services. Understaffing in some Centres was undoubtedly related to a lack of prioritisation by the Trust. Conversely, good staffing levels were often due to effective business case writing and business managers who would advocate on behalf of the team. Funding also differs between the devolved nations, with the Scottish, Welsh, and Northern Irish governments responsible for the distribution of funds in their respective countries.

Our findings align with and contribute to the wider literature on geographical variation in services

A core theme of the data is the significant variation across the country in many areas related to brain cancer. Regional inequalities in health care access and outcomes have become an area of increasing importance in UK health policy in recent years.[15–17] Differences in the provision and access to cancer services have been noted as a particular area of concern.[18] Studies have highlighted differences ranging from access to diagnosis[19] to provision of treatment,[6] with Chamberlain et al. finding evidence of a continuing “postcode lottery” of chemotherapy access.[20]

These findings add to this wider literature, by providing insight into the geographical variation in services across neuro-oncology Centres. Furthermore, while previous studies have mostly focused on synthesising national data from multiple sources,[20] or conducting audits on a restricted geography,[18] this study was large and systematic. Data were collected from Centres representing every region of England as well as Wales and Scotland. Our findings therefore expand upon previous studies on geographical variations in cancer services, while also providing some reassuring feedback on key consistencies in the sector.

Additionally, while previous studies have provided tentative explanations for geographical and regional variations in access to cancer services, from variations in patient pathways,[19] distance to services,[21] and local capacity and policy choices,[20] they have not reached any conclusive answers. Because our review was extensive and nationwide, it has permitted further exploration of some of the issues underlying variation, from Centres adapting to local needs, to regional or nationwide resourcing challenges as discussed above.

Three Recommendations Based on the Findings

Brain cancer patients face poor survival outcomes and significant long-term side effects when surviving.[4] There are no curative treatments for the most aggressive brain cancers; therefore, it is imperative that we raise standards in brain cancer treatment and research to optimise care. The findings outlined in this report have revealed several areas of geographical variation, as well as common challenges faced by many Centres. It is imperative that the brain cancer community works together in the coming years to address these challenges, delivering higher standards for patients and their families. Based on the findings of this report, we propose the following three recommendations on how the field can work together to address these common challenges and variations:

1. **Facilitate the dissemination of individual Centres' "pockets of Excellence" so that other Centres may adopt this**

   Each Centre has demonstrated individual strengths which, if widely shared and adopted, could make a great difference to how brain cancer patients are cared for. TJBCM will continue to co-host workshops and discussions and set up working-groups and events to facilitate this. TJBCM recommends that funders actively make funding available for the dissemination and evaluation of innovative practices.

2. **Centres should focus on addressing their unique gaps and challenges**

   In every Centre there is room for improvement in one or more areas. It is worth noting that while some aspects of service improvements require more costly investments (e.g. staff and infrastructure), others require minimal financial investment.

   On challenges that require minimal financial investments, neighbouring Centres can share established infrastructure and resources (e.g. biobanking); Centres can utilise remote working technologies to collaborate across networks (e.g. peer-reviewing for single-handed oncologists); directories can be drawn up for oversight of community services; and Centres can improve signposting to existing charitable services.

   To increase research activity, Cancer Research UK, The Brain Tumour Charity, and Brain Tumour Research have increased their outreach to scientists to advertise their open programmes and provide guidance on proposal writing.

   To further develop patient support, Centres could further strengthen links to the excellent services provided by Brainstrust, The Brain Tumour Charity, Brain Tumour Support and Macmillan, whose services have been created in response to extensive patient feedback.

   Unlocking further local funding to facilitate service growth remains challenging and time intensive. Maintaining a service is easier than growing a service. Through the Centre interviews it became apparent that while it was often possible to replace a staff member (e.g. a nurse) who left the service, it was much more challenging to justify growth and development. For example, obtaining funding for an additional staff member to launch a new service was not possible in many cases. Furthermore, we encountered several examples where Centre staff needed to work very hard to keep a post in place, and justifying renewal of a nurse or AHP position was challenging too.

   To achieve service growth, staff members need excellent business case writing skills to build strong relationships with senior management and to provide a strong evidence base for the new post or service.

3. **Collaborate nationally to address geographical variation and areas where Centres most commonly failed to meet the 'Excellence Standards'**

   For some challenges and certain areas of variation, a nationally co-ordinated effort is more likely to result in successful outcomes. There are many cases where variations can be addressed through targeted collaboration, including efforts in closing the genetic testing gap, improving trial readiness, widening access to neuropsychology, and addressing sustainability issues of the sector at the highest level (see **Box 4**).

Box 4: TJBCM recommends the following areas to be addressed nationally:

1. **Make genetic testing more equitable:** We strongly recommend reaching a consensus on when tests are ordered, which tests are ordered and what their clinical relevance / action is. Infrastructure barriers to genetic testing in individual Trusts should be addressed, including issues with freezer space, technician time and sampling capabilities. TJBCM has launched a national Task and Finish group to address this.
2. **Improve access to clinical studies for patients from all geographical areas:** To achieve this, the community should focus on:
    1. Increasing awareness of open studies and referring patients to other Centres where relevant;
    2. Shifting to a hub and spoke model for more trials, where regional "spoke" Centres can enrol patients, but with some of the specialised imaging and sampling to be outsourced to "hub" Centre(s). The BRAIN MATRIX is such a trial which has made notable progress in improving trial readiness of individual Centres;[22]
    3. Encouraging Centres to run their own small research projects and trials, with NIHR support and assistance, or linking to Biomedical Research Centres (BRCs).
3. **Build consensus on best practice in patient quality of life care and improve access to these services:** We noted substantial variation in patient support, symptom management and patient quality of life services. We recommend that consensus on these important areas are built, and that the community works to build an evidence base on effective models for patient care.
    1. Define nurse staffing levels and examine nurse specialisation and deployment;
    2. Examine design and delivery of AHP-led services, particularly rehabilitation support and define best practice;
    3. Improve access to neuropsychology, neurology and mental health support services in patient care;
    4. Develop and disseminate tools that help monitor and manage evolving patient needs;
    5. Develop and disseminate tools that track patients' transition to community services.
4. **Explore opportunities as a community to diversify brain cancer research funding income:** While funders such as Cancer Research UK, the Brain Tumour Charity and Brain Tumour Research provide vital grants to fund basic research, the community needs to ensure that income streams are diversified and not overly reliant on a few charitable funders. This includes further engagement with NIHR on accessing the £40million funding commitment made in 2018.[2]
5. **Work to address persistent staff shortages:** While not unique to the brain cancer community, staff shortages have proved a persistent challenge for Centres. The community should proactively work to assess, on a national level, the scale of shortages of key brain cancer specialty roles, and then use this data to develop recruitment and succession planning recommendations to be presented to the NHS leadership team.

Addressing These Recommendations: Tessa Jowell Academy

The Tessa Jowell Academy is a free national learning and networking digital platform, connecting all NHS brain cancer centres nationally. The platform is founded on the principles of specialised and accessible learning. Through the platform we aim to drive national equity and empower the NHS clinical workforce to mutually upskill each other, in line with the NHS People Plan ambitions.[23,24] The Academy was founded to specifically act on the recommendations in this report: addressing the variation and challenges identified by the Centre of Excellence initiative to elevate services while also driving innovative novel practice. The Academy is co-designed and delivered with the professional brain cancer community, dynamically responding to the evolving needs of these professionals as highlighted during the designation interviews and numerous focus groups. The platform, launched in February 2022, has over 800 active brain cancer professionals at the time of writing and provides four distinct services to address unmet needs and drive innovation:

1. Bespoke workshops and courses based on unmet needs

The platform offers regular Centre-led workshops and courses tailored to address unmet needs, both live and on-demand. After 12-months, there have been 32 workshops and over 1,200 attendees. Examples of courses include:

1. A CPD-accredited course for new nurses and AHPs to upskill on the fundamentals of neuro-oncology, taught by experts in the field.
2. A “show and tell” spotlight series where different Centres showcase their rehabilitation services so that they can discuss their challenges and excellence and learn from their peers.
3. Upcoming courses, including a ‘best supportive care course’ for all brain cancer professionals and ‘essentials research skills’ for aspiring nurse and AHP researchers to promote service development projects.

2. National Networks and Working Groups

National networks are centralised member-led specialist peer support groups which examine challenges and variations in working practices. The networks aim to 1) address isolation for single-handed professionals working in highly specialised neuro-oncology roles, 2) promote and outline the responsibilities of these roles to develop consistency across the UK, and 3) develop specialist national guidelines where relevant. Networks to date include: Therapeutic Radiographers, Speech and Language Therapists and Allied Health Professionals (mixed specialties).

Working groups are solution-focused groups which jointly address and tackle systemic issues on a national level, informed by Centre of Excellence data. Groups may be a single specialty (e.g. neurologists) or a multidisciplinary approach (e.g. Equity in Genomic Testing).

3. Peer-to-Peer Connect

The ‘Peer-to-Peer Connect’ service is a centrally-facilitated support service for NHS staff members to obtain support or resources from peers in other Centres. Through this peer learning service, staff members obtain knowledge and expertise to further develop and improve their own role, or to set up, develop or improve services in their Centre. A member can put in a request regarding a local challenge, to then be matched by the Academy Manager with a peer who is highly experienced in this area. To date, 38 Academy members have requested support through this service. Many have shared feedback that the new connection has meaningfully contributed to addressing their challenges.

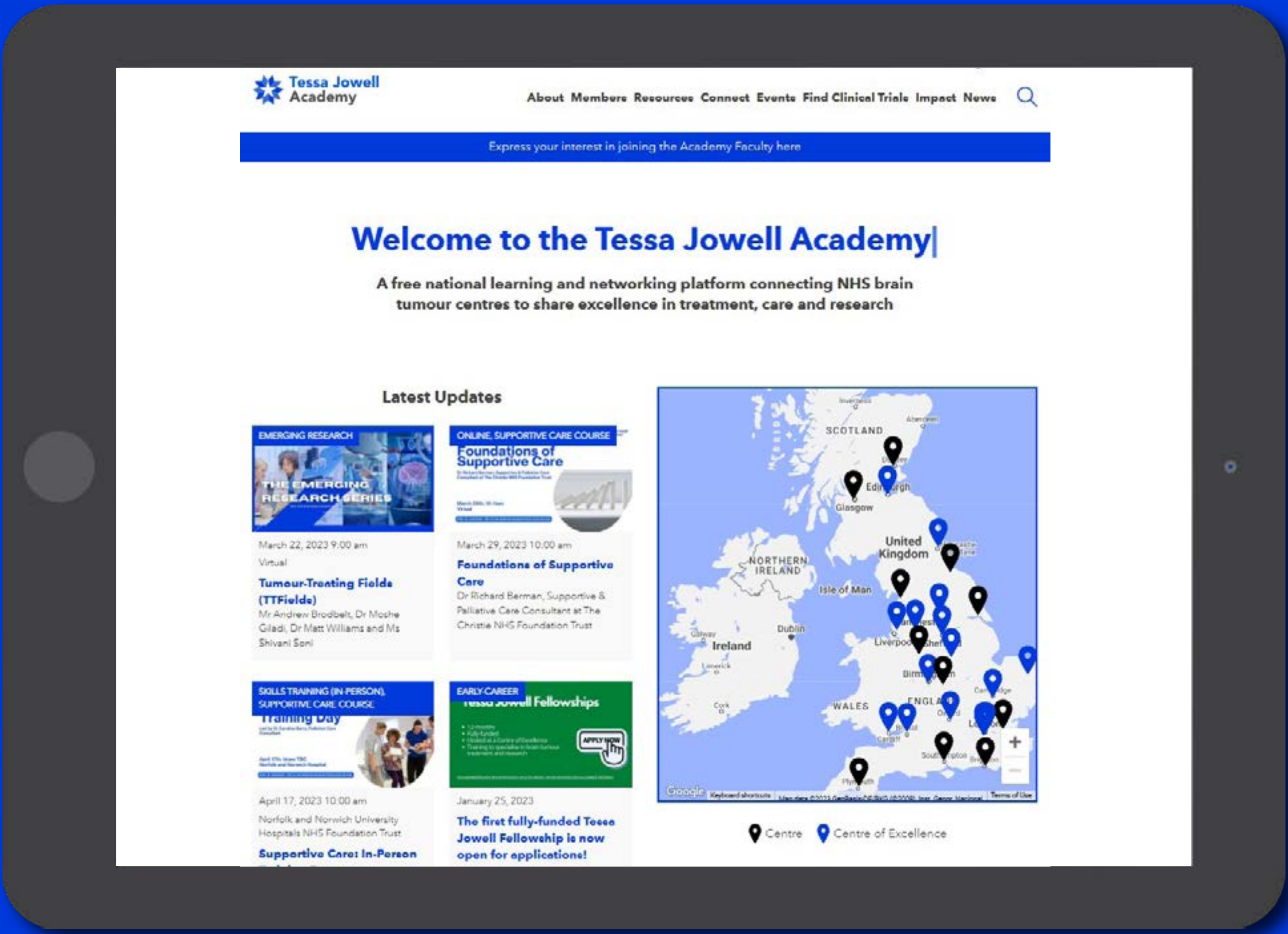
4. Individualised Centre Support

Centres can request tailored and individualised support from the TJBCM team. These requests are primarily focused on obtaining benchmarking data to allow for peer comparison while Centres are auditing their own services. Data have also been submitted as part of a business case to senior management in the Trust when asking for a new service or post. Examples have included data on pathology turnaround times, MRI waiting and reporting times, or details of services other Centres offer. Where relevant, the team has put Centres in touch with peer Centres who excel in the requested area of support or connected Centre staff with individuals in external organisations to discuss and address challenges (e.g. Macmillan to discuss nurse resourcing).

Finally, there have been requests for support to endorse the continuation of specialised roles. Where appropriate this endorsement has been given and has resulted in renewal of key posts across the UK.

Centres have already acted on the outcome of the designation review

The findings discussed in this report focus on data gathered in the first two review rounds of the Tessa Jowell Centre of Excellence Designation Programme. Since then, Centres not awarded "Centre of Excellence" status in the first round have had the opportunity to re-apply, provided they could demonstrate tangible service developments and improvements. Six were able to substantially transform their services and were awarded the "Centre of Excellence" status.



Welcome to the Tessa Jowell Academy

A free national learning and networking platform connecting NHS brain tumour centres to share excellence in treatment, care and research

Latest Updates

EMERGING RESEARCH
March 22, 2023 9:00 am
Virtual
Tumour-Treating Fields (TTFields)
Mr Andrew Brodbelt, Dr Moshe Giladi, Dr Matt Williams and Ms Shivani Soni

ONLINE, SUPPORTIVE CARE COURSE
March 29, 2023 10:00 am
Foundations of Supportive Care
Dr Richard Berman, Supportive & Palliative Care Consultant at The Christie NHS Foundation Trust

SKILLS TRAINING (IN-PERSON), SUPPORTIVE CARE COURSE
April 17, 2023 10:00 am
Norfolk and Norwich University Hospitals NHS Foundation Trust
Supportive Care: In-Person

EARLY CAREER
January 25, 2023
The first fully-funded Tessa Jowell Fellowship is now open for applications!

Conclusion and Next Steps

This report provides evidence of excellence in all UK brain cancer Centres and shows a clear upward trajectory of brain cancer treatment and research in the UK. It demonstrates significant variation in services, some driven by positive drivers, but several as a result of different local funding priorities that warrant addressing. The report also highlights important challenges that need to be addressed in a nationally co-ordinated way.

Based on the findings in this report, does it matter where patients go for their brain cancer treatment? All patients being treated for brain cancers in any UK Centre will be able to obtain an effective standard of care, delivered by a motivated team. Patients may experience variation depending on their Centre in some parts of the pathway: most notably in the genetic testing of their cancer samples, access to clinical studies, and the extensiveness of nurse and AHP-led care and support they receive. Importantly, all Centres are on a clear upward trajectory and are engaging with senior hospital management and their Integrated Care Boards to further develop the service.

The findings in this report confirm the need for the brain cancer field, and NHS policymakers more widely, to work towards a model that combines national standards and frameworks of support and oversight, with models of care tailored to local geographical and demographic needs. This has been a focus in UK health policy in recent years, with the establishment of Integrated Care Systems (ICSs) within NHS England. First trialled in 2017, and rolled out across England in 2022, ICSs have been designed to further "place-based" health decision-making, providing an oversight body where local health and care providers, local government and other stakeholders make decisions about a locality's health and care.[25–27] A similar approach to variation in brain cancer services would permit local innovation, while strengthening national guidelines and support to ensure that certain Centres are not falling behind.

The TJBCM, as a convening body for all key stakeholders in the brain cancer community, is well-positioned to drive this approach and facilitate acting on the findings of this report. The findings will act as a key resource for the TJBCM, informing and supporting the Mission to create bespoke solutions to provide support at a hospital, regional and national level. Through the Designation Programme and Tessa Jowell Academy we will continue to deliver on our strategy to transform treatment, care and research for brain cancer patients across the UK. This supports the NHS Long Term Plan (LTP) ambitions to improve cancer outcomes and services by reducing variation and inequalities, with a focus on improving the patient's quality of life.[28] The TJBCM will continue to track and report on Centres' service improvements and hopes that, in time, every Centre will be designated as 'Excellent'. Ultimately, the Centre of Excellence Programme aims to enable patients to be secure in the knowledge that Centres are providing an excellent service. It is hoped that, powered by ongoing data collection and collective learning and collaboration, the TJBCM can continue to constructively support Centres in their ongoing journey of service improvement.

Word of thanks

Finally, the TJBCM would like to express its deepest gratitude to all the Centres that have participated in the Centre of Excellence Designation Programme and who continue to demonstrate an undiminished commitment to service development.

Link to Supplementary Materials

To view the full extended results, please scan the QR code below or type the URL in your browser.

tessajowellbraincancermission.org/centreofexcellencereport

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About the Tessa Jowell Brain Cancer Mission

The Tessa Jowell Brain Cancer Mission (TJBCM) is a convening body which delivers transformative national programmes to improve brain tumour treatment, care and research in the UK. It designs and delivers a national portfolio of eight innovative programmes focused on accelerating research, advancing clinical trial infrastructure, improving care for today's patients, and connecting and training NHS staff.

The Mission's work is funded and supported by the government through the National Institute of Health Research, as well as eight influential cancer charities. Over 90 NHS doctors, nurses, allied health professionals and scientists from across the UK work daily with the Mission to design and deliver its programmes, which are jointly delivered with its partner organisations. TJBCM is a registered Community Interest Company.

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