

Tessa Jowell Centre Designation Application Form

Introduction

Tessa Jowell Brain Cancer Mission

Dame Tessa Jowell led a call to action for lasting change for all brain tumour patients. She asked for all patients to benefit from “the latest and greatest science” and called to focus on “living well with cancer, not just dying from it”. In response to her call, the Tessa Jowell Brain Cancer Mission (TJBCM) was founded to provide a national convening body for all stake holders engaged in glioblastoma research, treatment and patient advocacy. Since its inception, the TJBCM has pursued its mission to unite professional, patient, charity and government groups to share information, and establish transformative programmes that will lead ultimately to a cure for brain tumours.

Built initially around four Strategic Programmes, the TJBCM has made great progress in supporting its member organisations to promote: national research efforts; innovation in treatment and clinical trials (e.g. Tessa Jowell [BRAIN-MATRIX](#)); the first national clinical training scheme for clinicians seeking to focus on brain tumours; and patient advocacy. To provide an academic and clinical ‘home’ for these Strategic Programmes, embedded in the heart of the NHS and aligned Academic Health Science Centres and therefore of immediate visibility to patients, the TJBCM launched its Tessa Jowell Centre of Excellence Strategic Programme in November 2019.

Tessa Jowell (TJ) Centre of Excellence

It is well evidenced that the concentration of expertise in specialised centres and knowledge sharing between centres can contribute to better outcomes, improved patient satisfaction and access to research for rare diseases. In line with this vision, TJBCM aims to recognise and congratulate centres that offer a high standard of care by awarding them the Tessa Jowell Centre of Excellence designation. For UK neuro-centres, designation as a Tessa Jowell Centre of Excellence will serve as a national recognition of their staff going above and beyond. For patients, getting treatment in a designated centre will mean that they can be confident that they receive the highest standard of care under the NHS. Our aim is to enable and encourage as many centres as possible to achieve centre of excellence designation, so that we collectively raise the bar and set an example across the cancer community on how we can lead in treating rare cancers.

To define this high standard of care, The TJBCM has appointed a TJ Centre committee consisting of clinicians, academics and patients to identify the best services and innovations currently seen in the UK from which we believe every UK patient deserves to benefit. Based on their search for excellence and work previously done within TJBCM, the committee has defined high standards in five key areas:

1. Offer excellent clinical practice in surgery, pathology, imaging and oncology
2. Emphasise patient quality of life and offer a well-defined level of holistic care
3. Offer clinical trials and collaborate with other hospitals to encourage patient participation and recruitment
4. Offer good training opportunities for staff
5. Act as a site for excellence and innovation in translational and basic brain tumour research.

These standards in many cases go above and beyond existing guidelines and are aimed at both offering clinical excellence as well as having a strong emphasis on patient quality of life. The standards and accompanying assessment process have been developed in collaboration with NHS England, Department of Health and Social Care, NCRI and our partner charities Cancer Research UK, The Brain Tumour Charity, Brain Tumour Research, Brainstrust and Brain Tumour Support. Participation in the assessment process is completely voluntary and the application process has been piloted in four NHS Trusts.

Importantly, the TJ Centre committee aims to amplify our voice as a brain tumour community by providing thematic feedback to the NHS Commissioning team and DHSC: e.g. if there are certain areas that suffer from structural underfunding across all Trusts the committee will highlight and discuss these. Therefore, participating in the assessment process is extremely helpful, as it will put us in a strong position to give detailed feedback and advocate for appropriate resourcing.

TJBCM is now inviting all UK Neuro-Oncology Centres to join us in responding to Tessa's call to action by applying to become "Tessa Jowell Centre of Excellence Designated".

Centres obtaining designation will receive an invitation to a celebratory reception in the House of Lords where a Tessa Jowell Centre of Excellence plaque and certificate for display in the centre will be handed out. TJBCM will also put out press releases to celebrate and congratulate the centres achieving designation. Irrespective of the outcome of the application process, all centres who have applied are invited to become part of the Tessa Jowell Academy - a network of sharing best practices across Trusts. The academy will be launched with a one-day symposium to facilitate knowledge sharing.

Centres who have applied but who have not yet achieved designation will benefit from the sharing of best practices for areas that need further development and receive detailed feedback on where enhancements could be made. All centres will be encouraged to reapply in the next round opening early 2021.

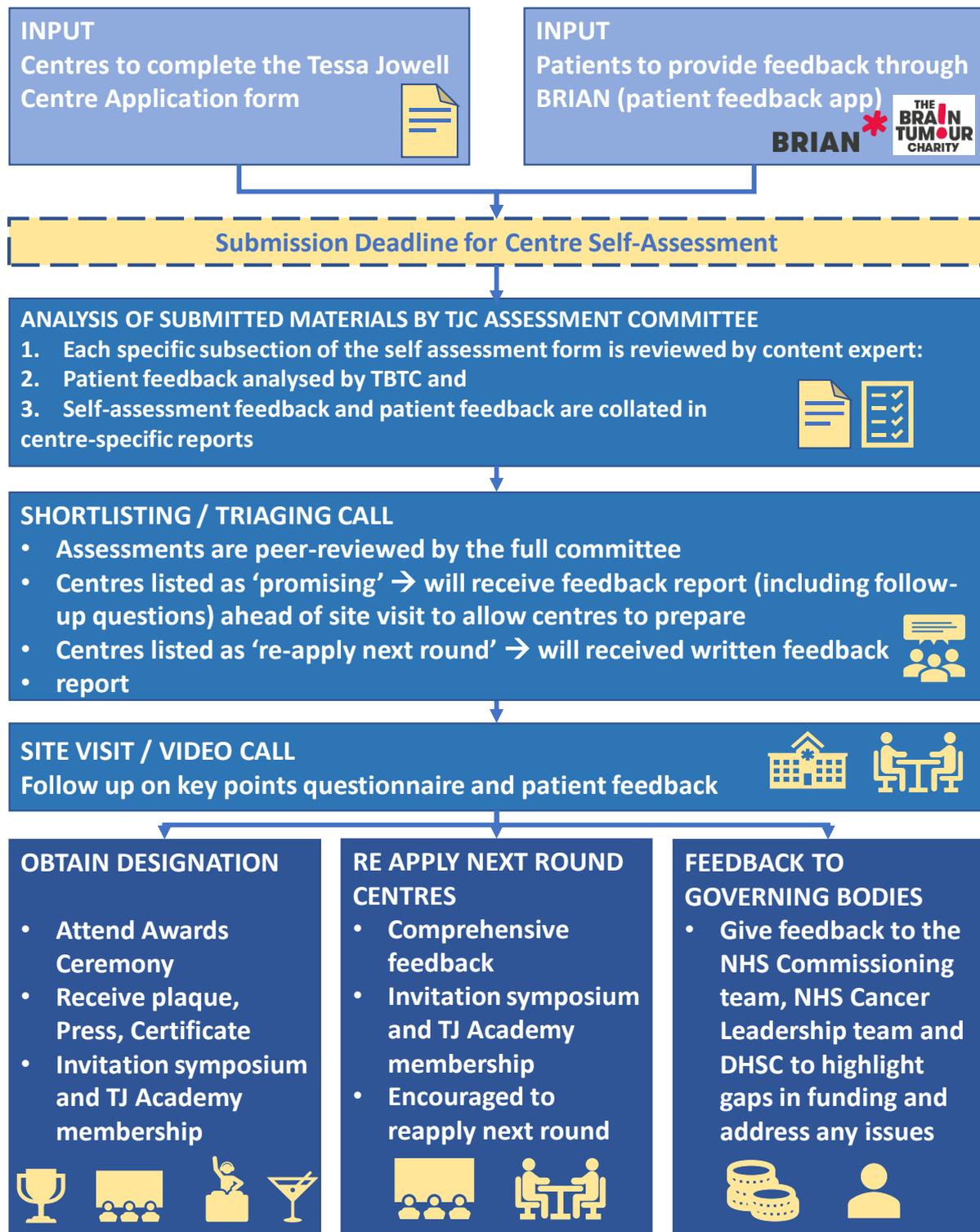
[Application process](#)

The TJBCM is delighted to invite you to become a 'Tessa Jowell Centre of Excellence'. To begin the application process, you will be asked to complete the below application form.

In parallel, the TJ Centre committee will use the [BRIAN web-based app](#) from the Brain Tumour Charity to collect patient feedback questionnaires and analyse how patients experience treatment and care received at your centre. As such, you are strongly encouraged to promote the use of the BRIAN app across your patient population. Please see the appendix for promotional material and patient information sheets.

Once completed, the submitted application forms will be reviewed by the TJ Centre committee. Centres who are likely to obtain designation will be invited to a face-to-face zoom call or site visit (contingent on COVID-19 regulation) to discuss a final set of queries based on the application forms and patient feedback. Centres will receive feedback ahead of this follow up to prepare answers and action plans. Centres who are not yet eligible for designation will receive feedback on their application with recommendations on how to implement enhancements and are encouraged to apply again. All applying centres will be invited to become part of the TJ academy where they can benefit from the collective expertise of member centres.

Figure 1: Summary of the application process



Instructions for completion of the Application Form

When completing the application form, please keep the following in mind:

- Answer the questions based on your adult neuro-oncology service, both for malignant and non-malignant patients, with a focus on patients with a primary brain tumour.

- The committee recognises that in many cases there are differences in how services are named, organised and linked to each other. Please be assured that there is sufficient flexibility in the standards to allow for this.
- We understand that brain tumour care is sometimes offered in partnership with affiliated centres (e.g. surgery in one hospital and chemo / radio in another). Please list all centres that collectively cover the patient pathway as they will be designated as one group.
- To understand how your centre has collected the data to answer a question, you will at times be asked for details of an internal audit (if available).
- To understand if your centre meets a standard, we may ask for an example to highlight how your centre meets a standard.
- To understand the utilisation and accessibility of a specific service for brain tumour patients, you will at times be asked to provide an estimation of the proportion of your patients who have access to a certain service. Please explain to us how you estimated your patient numbers.

The application form has been piloted in four UK Neuro centres. Based on their experience completing the form they have made the following suggestions for completion:

- At the start of each section there is a suggestion as to who may be best positioned to complete the section.
- Consider appointing one person as application lead: they will assign relevant questions and sections to their colleagues and oversee timely answering of questions.
- The lead may make a final edit of the entire document to ensure answers are cohesive (please allow several hours over 2-3 days for the final edit).
- Some centres held weekly or fortnightly calls to coordinate form completion.
- Some centres opted for a shared google drive of the form, others preferred to copy paste relevant questions and send them over email.

Data Collection

The information provided to TJBCM through this form will be used solely for the purpose of Designation and periodic high-level reports without a reference to individual centres. Answers to questions will only be shared with the TJ Centre Committee members (membership will be available on TJBCM website). TJBCM will publish the names of all centres receiving designation and write periodic reports on the progress of the designation initiative. Any further use of data will be upon agreement of all contributing centres and additional permission will be sought on a case by case basis.

Next steps

Please return the completed form to Nicky.huskens@tessajowellbcm.org by the 19th of December.

This questionnaire has been developed in partnership with:



Application Form Completion

Please provide the names of the staff members who have led on the completion of the application form in the overview below.

1. Centres offer excellent practice in surgery, pathology, imaging and oncology	Section completed by: (Please write the name and profession of the person completing the section)
Surgery	
Imaging	
Radiotherapy	
Chemotherapy	
Pathology	
2. Centres will offer a well-defined level of care for patients:	Section completed by: (Please write the name and profession of the person completing the section)
MDT members, brain tumour clinic and access to allied health professionals	
CNS services and patient quality of life	
Rehabilitation services	
End of life support	
Collaboration with local support services	
Partnership with patient organisations	
3. Centres will act as a clinical trial hub for BRAIN MATRIX and other studies (Please write the name and profession of the person completing the section in the space below)	
4. Centres offer good training opportunities for their staff (Please write the name and profession of the person completing the section in the space below)	
5. Centres act as a site for excellence and innovation in brain tumour research (Please write the name and profession of the person completing the section in the space below)	
6. Tessa Jowell Centre Designation (Please write the name and profession of the person completing the section in the space below)	

Questionnaire

**Please do not provide any personal details of patients in your response to these questions*

Section 1: Excellence in surgery, pathology, imaging and chemoradiotherapy

General information (may be completed by one of the MDT-leads)

Questions	Answers
Name of NHS Trust and affiliated centres applying for designation	
Does your centre treat patients throughout the entire pathway or do you provide joint care with other hospitals/centres? If so, please explain how you ensure effective handover of care between different hospitals? <i>We will designate the entire group of hospitals as one.</i>	
How many new patients with a primary brain tumour did you treat in the last 12 months? <i>(please answer carefully as we will use this number to compare staff and resourcing)</i> Gliomas: Skull-based: Other:	
What is the hospital's most recent CQC rating (please provide the date)? Please describe if there were any comments with regards to the neuro-oncology unit.	
What is your average referral to treatment time for GBMs (please provide details of internal audit if available)?	
Do you regularly receive NHS referrals from other areas (nationally/ internationally)?	
Do you collaborate for complex cases (local/ national/international/networking or other arrangements for areas not covered internally)?	

A. Surgery (may be completed by a surgeon)

1. How many consultant neurosurgeons in your centre operate on brain tumour patients? Please also include how many surgeons operate on gliomas and are subspecialised in operating on gliomas:

Type	Number of consultant neurosurgeons
Brain tumours	
Gliomas	
Subspecialised in gliomas	

2. To understand how your neurosurgeons operating on brain tumour patients have been trained, please specify the following (please exclude emergencies and biopsies):

Training	Number of surgeons	% of eligible patients benefitting from skill
Consultant neurosurgeons with sub-specialisation in brain tumours		
Trained in 5-ALA (Pink Drink)		
Attended white matter dissection course		
Trained in awake craniotomy		
Skilled in intraoperative image guidance		

3. Does your centre routinely use image guided neuro-navigation for all gliomas? Please explain which cases qualify.

4. Do you offer surgery to most Grade II Low Grade Glioma patients within the first year of tumour diagnosis, where it is technically feasible and upon patient consent?

B. Pathology (may be completed by a neuropathologist)

1. To understand turn-around time for key tissue analysis, please fill in the table below:

Analysis	Average waiting time for results
Intraoperative result	
Cerebrospinal fluid (CSF) cytology	
Brain biopsies	
Brain biopsies with integrated genetics	

Please provide information on the source of the data and give a date (e.g. staff estimate or internal audit):

2. Please indicate which Genomic Laboratory Hub (GLH) (or equivalent Genomics Medicine Centre for Scotland, Wales and Northern Ireland) you are associated with (if any). Please provide an approximate estimation of yearly cases of adult brain tumour patients who have samples analysed by their local GLH, and which indications typically qualify. Services currently offered through the GLH are set out in the [National Genetic Test Directory](#)

3. Please indicate approximately how many samples per year are submitted for each of the following services:

Sequencing Service	Estimated samples/year submitted
Gene Panel Sequencing (provided by GLH for certain indications)	
Methylation Array	

Whole genome sequencing	
RNA sequencing	
Other	

Please provide information on the source of the data and give a date (e.g. staff estimate or internal audit):

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4. Please specify in the table below if you meet the following guidelines with yes / no answers. If your answer is no, please explain why and indicate if you have any plans in place to address this:

Analysis	Yes / No
Are tumour samples processed within specialist neuropathology laboratory facilities which are UKAS accredited to standard ISO 15189? <i>Please include date of accreditation</i>	
Do your neuropathology reports contain the minimum data sets as recommended by the Royal College of Pathologists?	
Are your pathology reports created by specialist neuropathologists taking part in Neuropathology External Quality Assessment (EQA)?	

In case of a 'no' in any of the above questions, please specify:

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C. Imaging (may be completed by a neuroradiologist)

Diagnosis, tumour stratification and therapeutic planning

1. Please specify the approximate waiting time for MRIs:

Type of MRI	Approximate waiting time
Routine outpatient MRI:	
Urgent outpatient MRI:	
Inpatient MRI:	

Please provide information on the source of the data and give a date (e.g. staff estimate or internal audit):

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2. Please specify your approximate average reporting time for MRIs:

Type of MRI	Approximate reporting time
Routine outpatient MRI:	
Urgent outpatient/inpatient MRI:	

Please provide information on the source of the data and give a date (e.g. staff estimate or internal audit):

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3. In the fifth week preceding receipt of this form, please provide the lead times from scan to report for the glioblastoma patients that underwent an MRI (please provide in number of days):

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4. Does your routine MRI brain tumour protocol conform with British Society of Neuroradiologists recommendations? (Yes/No)

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Please provide additional information:

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5. Please list the MRI equipment to which you have access in neuro-oncology practice:

MRI Equipment	Yes/No
1.5T MRI	
3T MRI	
Intraoperative MRI	
Other (please specify)	

6. To understand training in and access to advanced imaging techniques in your team, please fill in the table below:

	Access to equipment and software (or access route with partner centre) (Yes/No)	Number of staff members trained to report specialised imaging	Use of technique in clinical studies or have published research in this area (Yes/No)
Perfusion-weighted Imaging/DSC-MRI			
Arterial Spin Labelling			
Permeability-weighted Imaging/DCE-MRI			
Proton Magnetic Resonance Spectroscopy			
Diffusion Tensor Imaging			
fMRI			
PET			
Other (please specify)			

Treatment evaluation

1. Does your centre routinely perform post-operative MRI within 72 hours to assess extent of glioma resection? (Yes/No)

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2. At what time points do you routinely perform MRI after commencement of radio/chemotherapy?

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3. How many of your team are trained in the 'response assessment in neuro-oncology' criteria (RANO)?

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4. Please explain your centre's approach to imaging cases of suspected treatment-related effects (e.g. pseudoprogression or radionecrosis):

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D. Radiotherapy (may be completed by an oncologist)

1. Please state the approximate average waiting time for patients to obtain access to radiotherapy. How often does a patient have to wait more than 6 weeks?

Average waiting time	
Number of times patients wait >6 weeks	

Please provide information on the source of the data and give a date (e.g. staff estimate or internal audit):

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2. Does your centre have a peer review system in place to review radiotherapy treatment volumes? Please describe if the peer review is conducted by colleagues within the centre or if a partnership with a fellow centre is in place. Please also describe which cases are typically peer reviewed and an approximate estimate of the total % of cases that are peer reviewed.

Estimate of cases that are peer reviewed:

3. Does your centre offer Intensity-Modulated Radiation Therapy (IMRT)? If so, approximately what % of glioma patients treated last month received radiotherapy planned with IMRT? Please explain how you estimated patient numbers.

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4. Does your centre offer stereotactic radiosurgery? If so in which cases? If not, please describe the referral pathway for radiosurgery in suitable cases. How many patients accessed this service in the last 12 months?

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5. How many adult CNS patients with less common primary tumours have been referred to the National Proton Beam Panel in the last two years?

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Please provide information on the source of the data and give a date (e.g. staff estimate or internal audit):

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E. Chemotherapy (may be completed by an oncologist)

1. To treat radio-necrosis does your centre have access to bevacizumab or other drugs, and what is the funding route for that?

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2. Are there any treatments you would like to be able to offer to your patients, but struggle obtaining access to? Likewise, are there any treatments you are able to offer your patients that you would like us to know about?

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3. To understand how you navigate different treatment protocols with the help of patient input, please complete the table below:

Treatment Protocols	Protocol description
How do you involve patients in the risk/ benefit judgement of different treatment protocols? Please provide an example.	
Please describe the type of information patients typically receive to explain their treatment. (e.g. information sheets or websites)	
Does the patient receive information about steps to take in case of an emergency (e.g. developing a fever)? If so, please explain how you share this information (e.g. information pack)	
Please describe how you approach the discussion around the possible side effects of long-term corticosteroids and chemotherapy.	
Do you have protocols in place for the mitigation and/ or management of such side effects?	

Section 2: Well-defined level of care for patients

2A Clinical care up to and exceeding the Integrated Multidisciplinary Care Model (IMCM)¹ (may be completed by a core MDT member)

1. To understand how your MDT operates, please complete the table below to provide information on the MDT processes followed in your centre:

Specialties involved	Active participant in MDT? (Yes/No)	What is the referral pathway needed to access these services, if not part of your centre's MDT?
Neurosurgeon		
Diagnostic Neuroradiologist		
Neuropathologist		
Clinical Oncologist		
Medical Oncologist		

¹ IMCM, also known as the King's or Cambridge model of care as per <https://bmjopenquality.bmj.com/content/bmjqir/2/1/u201857.w981.full.pdf>

Neurologist		
Neuropsychologist		
Clinical Nurse Specialist		
Palliative Care Specialist		
Allied Health Professional: neuro-oncology physiotherapists, Occupational Therapists, Speech and Language Therapists		
Geneticist		
Consultant in Rehabilitation		
MDT Coordinator		
Other admin Staff		

When are patients typically discussed in an MDT? Pre-Surgery/Post Surgery/ Please give all time points.	
How frequently do you host MDTs in your unit?	

2. To understand in more detail how brain tumour patients are managed, please provide some information on how the clinics are organised for these patients:

	Further detail of services
Do you run a dedicated brain tumour outpatient clinic? Describe how these are organised (e.g. split by surgery / oncology or by tumour type / grades). Describe handover of services if between two different centres.	
How frequently do you hold this outpatient clinic?	
What specialties are involved in this clinic?	
Do you have dedicated administrative support for this clinic?	
Do you have dedicated clinical nurse specialists linked to these clinics? If so, please explain how many FTEs are part of the team and how they are organised (e.g. surgery / oncology, low grade / high grade). If more than one nurse, please explain how they cover the full patient pathway.	
Do you host any other specialist clinics for brain tumour patients?	
Please confirm how patients receive a neuro-oncology diagnosis (face to face, telephone or by letter), specify by tumour type or grade if relevant.	

Are there any other ways in which you manage or coordinate the care of your out-patients that is not mentioned above?	
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If you do not run a specialist brain tumour clinic, please explain how you coordinate the care of you patients below.

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3. To understand which specialists in your unit provide care for brain tumour patients, please identify which specialists are members of your core team. Additionally, identify how each specialist within your team keeps up-to-date with the latest practice and developments within their field of expertise.

Specialist	Part of neuro-oncology team (Yes/No)	Number of these consultants on your team	How do specialists remain up to date on the latest developments within neuro-oncology?
Neurosurgeon			
Diagnostic Neuroradiologist			
Clinical oncologists			
Medical oncologist			
Neurologist			
Neuropathologist			
Supportive + Palliative care specialist			
Rehabilitation Consultant			
Other:			

4. To understand which allied health professionals provide care for neuro-oncology patients, please complete the table below, together with how they are accessed if not part of the core care team.

Specialist	Member of core team? (Yes/No)	Access route / referral pathway (if no)	How have they been trained in neuro-oncology?
Clinical nurse specialist			
Occupational therapist			
Clinical psychologist			
Physiotherapist			
Speech and language therapist			
Dietician			
Other:			

5. To understand how your centre is managing the NICE improving outcomes guidance (IOG) (2018 update), please explain how your centre is broadly meeting these guidelines.

	Description of activities

Is your centre broadly meeting the IOG within your existing service?	
Are there areas where further improvement may be needed? If so, are there any ongoing initiatives addressing that?	
What are the perceived challenges that prevent you from meeting the IOG?	
Are there areas where you are exceeding IOG? Give examples.	

6. Does your centre have an audit programme in neuro-oncology, and how is that programme delivered? Can you give any examples of improvements in the centre which have resulted from an audit?

7. Do you have areas for concern on waiting times? If so, please explain any delays and how they are currently being addressed. Please provide details of internal audit if available.

2B: Excellent Patient support at all stages of their treatment pathway

Clinical Nurse Specialist Care (may be completed by Clinical Nurse Specialist)

1. To further understand the support offered to patients and the resourcing of the CNS team, please fill in the table below:

Support	Offered Yes / No	Further detail of services
After initial consultation, do all of your patients get a 5-day point of contact for the centre? (specify by tumour grade or type if different). If not, please indicate % of patients have dedicated CNS support.		
Do you carry out a Holistic Needs Assessment on your patients? If so, please state when in the pathway		Percentage Diagnosis = Percentage EOT =
Are you able to refer to enhanced supportive / palliative care, rehabilitation and/or mental health services?		
Do you create an advanced care plan for patients with terminal tumours?		
Do you signpost to third party patient information (e.g. charities)?		
Are you able to refer patients to social workers?		
What partnerships do you have with charities (e.g. Macmillan and Marie Curie)		
How do you keep your team up to date with current open clinical studies in their centre?		
How do your patients find out about clinical research?		

How do you collect patient feedback (include any validated tool)? And do you have a local patient forum?		
How do patients find out about financial support?		
Do you offer help with filling in forms? (e.g. DS15 form to fast track benefits for terminally ill)		

Measuring, managing and improving patient quality of life (may be completed by Clinical Nurse Specialist)

2. To understand patient quality of life initiatives in your centre, please complete the table below:

Question	Further details of initiatives
How do you ensure that patient quality of life is assessed? (only <i>if any additional assessments not already mentioned in section 2B. Q1</i>)	
Please provide an example of the above measures (<i>if not already mentioned in 2B. Q1</i>).	
How do the results of such assessment affect care planning for individual patients?	
Are you currently collecting patient feedback? If yes, can you explain in what form and how this information is used?	
Could you give an example of how patient feedback has shaped or improved services that you offer?	
Do you run any patient support groups in your centre?	
Are there any aspects of care in your centre which you believe works particularly well, or are there any barriers to integrated care which you would like to highlight?	

3. To further understand the support offered to patients and the resourcing of the rehabilitation team, please fill in the table below (may be completed by physiotherapist or rehab therapist):

Question	Offered Yes / No	Further detail of services
Please give an estimate of the number of brain tumour patients referred for rehabilitation each year (<i>include inpatients, outpatients or community services</i>).		
Do you work with both high grade glioma patients or predominantly low grade or non-malignant patients?		
For all patients referred, do you carry out a holistic rehabilitation assessment of practical, psychological and physical support needs?		
Do you typically create individualised patient focused rehabilitation plans (that include meaningful patient goals)?		
If patients are referred to onward rehabilitation services to meet their needs/goals, do you follow up on their outcomes and progress?		

When referring a patient to a rehabilitation service, what is your approximate referral to treatment time?		
Do you provide regular updates on all patients to your local MDT or users' GPs regarding rehabilitation progress and plan?		
Do you run any dedicated rehabilitation programmes? Or signpost to any specific services (e.g. cancer or neuro rehab exercise services, early or late effect services, occupational rehab programmes, cognitive rehab or communication programmes)? If yes, please list.		

4. To understand support services for patients with non-malignant or low grade tumours, please fill in the table below (may be completed by a CNS):

Question	Further detail of services
Do your patients have access to a CNS (e.g. to leave a message if they experience new symptoms)? What does this access look like? How quickly are they likely to get a response?	
How are patients supported with the readjustment to their changed lives? (e.g. a survivorship programme)	
How do your patients access rehabilitation services? (as per table above)	
Do you run a dedicated rehabilitation clinic / service? If yes, please explain and list specialties involved. (if not covered above)	
Do you have access to a vocational rehabilitation team?	

Supportive, palliative and end of life care

5. To understand the scope of the supportive/palliative care offered and the transition to end of life care, please fill in the table below (may be completed by a palliative care specialist):

Question	Further detail of care services
When are high grade patients typically offered referral to supportive care / palliative care? What is the referral pathway and timeline for this? (e.g. Is this routinely within 6 weeks of diagnosis of an incurable disease?)	
Do you run a specialist palliative care clinic for brain tumour patients? E.g. Do your patients have access to enhanced supportive care or equivalent services? ² If yes, please list specialties involved and explain the model (e.g. separate clinic, shared clinic or MDT attendance)	

² ESC is a new initiative aimed at addressing more fully the needs of patients on active anti-cancer treatment in the context of a cancer centre. This proposal has been developed from a local pilot lead by The Christie NHS Foundation Trust and is currently implemented in > 26 cancer centres across the UK.

<https://www.england.nhs.uk/wp-content/uploads/2016/03/ca1-enhncd-supprtv-care-guid.pdf>

Do you have partnerships in place with local hospices / community services? If so, please list.	
How do you ensure timely and efficient handover between last-line treatment and end of life treatment?	
Do terminal inoperable patients receive the same standard of care?	

Managing ‘at risk’ patients (may be completed by an oncologist or CNS)

6. To understand how you are managing ‘at risk’ patients, please complete the table below.

Question	Description of risk management
Do you use emergency care plans? If yes, for which patients?	
Do you have other mechanisms for patients to be prepared for deterioration or emergency changes in their condition?	
Are your neuro-oncology patients who are at a high-risk of needing emergency care being added to the local ambulance service’s flagging system?	

2C: Provide support to achieve patient identified goals (may be completed by a MDT member)

1. Patients with a brain tumour diagnosis may have very different and individual priorities. How and by whom are these priorities identified in your centre and what measures are taken to ensure that this information is updated as circumstances change? Please refer to answers above if relevant. *Examples could include achieving this through: Holistic Needs Assessment, patient feedback, advanced care planning or CNS support.*

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2D Collaboration with local services (may be completed by a MDT member)

1. To understand your collaboration with local services, please explain the nature of your partnership and interactions with the following services and provide an example:

Services	Example of collaboration
Community services (e.g. community nurses)	
Local Council (e.g. Social workers)	
Primary care providers (e.g. GP)	

2. To understand how your centre collaborates with the local support services to provide continuing care for patients, please give two examples of how your centre currently works – or has worked since July 2017 with local services (e.g. current shared care arrangements, support/training events for community staff).

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3. Do you have any initiatives with local healthcare providers in place to promote early diagnosis of brain tumours or to improve referral pathways?

2E: Partnering with patient organisations (may be completed by a MDT member)

1. Provide one example of your centre's collaboration with patient organisations since July 2017, e.g. working together to organise an upskilling event or participating in your regional neuro-oncology network.

2. If you have a current grant from any patient organisation, explain how it contributes to the work of your centre.

3. To understand if you provide any signposting to charities and their resources, please explain how you collaborate with charities on distributing information (if any).

Section 3: Clinical Studies

(may be completed by a MDT member who involved in clinical trials)

3A: BRAIN MATRIX membership

1. Is your Centre a member of the BRAIN MATRIX or working towards BRAIN MATRIX membership?

3B: Other Clinical studies and trials

1. In order to help us understand ongoing research and potential for research at your centre, please indicate how many of your staff have dedicated time for clinical research studies including trials in the following categories (**note: if you have recently completed the BRAIN MATRIX feasibility questionnaire you can skip this question**):

- Medical staff/ grade and role/ numbers of sessions/ funding source(s)
- Administrative staff/ grade and role/ number of FTEs / funding source(s)
- Nursing staff/ grade and role/ number of FTEs/ funding sources
- Other allied health professionals e.g. diagnostic and radiotherapy radiographers, medical physicists, therapists

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2. To understand the opportunities for patients, please list which clinical studies at your centre patients can participate in. We recognise that not all UK neuro centres are also part of a large clinical trial unit. Therefore, if clinical studies are not offered at your centre, please explain the process of referring patients for studies at other centres, or what you are able to do if a patient indicates a willingness to travel. What are the barriers to trial participation for patients at your centre?

Question	Further description of activities
Please list your current open studies to brain tumour patients	
Have you referred patients to studies in other centres? What is the referral process?	
What are your perceived barriers to trials participation?	

3. Please list the names of the national portfolio listed trials you are recruiting to.

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4. Is your centre engaged in commercial studies or other studies than indicated above? If yes, please list them.

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5. To understand opportunities for sampling and tissue collection for research purposes, please complete the table below

Research opportunities	Yes/no	Number of patients in last 12 months who used this service (if known)
Does your centre routinely collect snap frozen tissue? (Yes/No)		
Do you work with patients to facilitate brain donation at their request? (Yes/No)		
Do you have a systematic engagement with a biorepository? (Yes/No)		
How many samples have you contributed to the 100K Genome project?		
Are patients routinely asked and consented to participate in registries? (Yes/No)		

If you answered 'no' to any of the above questions, please elaborate below:

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Section 4: Training and support for health professionals

(may be completed by MDT member)

4A: Hosting Tessa Jowell Oncology Fellows

1. Has your centre been in conversation with the faculty of the fellowship programme to host Tessa Jowell fellows for a period of their 12-month training? If not, would you be open to exploring this option?

4B: Training and ongoing training for staff members

1. We would like to understand the access to CPD opportunities specific to neuro-oncology within your centre for both your consultants and allied health professionals. Please explain the extent of the opportunities.

2. How are you ensuring that your Clinical Nurse Specialists team is appropriately specialised in brain tumours? Please specify. Do your CNS attend any advanced communications skills courses (e.g. on delivering bad news)?

3. How do you ensure that Allied Health Professionals are trained to understand: (1) types of cancer treatments (2) tests and results commonly used (3) symptom management and side effects (4) knowledge of the recovery package or advanced care plans? Please explain and provide one example.

4. Please provide two concrete examples of training opportunities available to your centre's neuro-oncology team since December 2018 to support it in improving care. Please include the months, year and topic.

4C: Sustaining and developing your service

1. Please describe any problems you foresee in sustaining and developing your service e.g. reliance on charitable or short-term funding, or obstacles to succession planning. Have you performed a gap analysis?

2. Describe what steps your service is taking to ensure expansion of activities and/ or effective succession planning.

Support for staff

1. Does your centre or Trust offer access to counselling services for their staff? Please describe.

2. Are there any other ongoing initiatives or support for your staff to help manage work-life balance, workplace stress or mental health? Please describe.

Section 5: Brain Tumour Research

(may be completed by a MDT member who is involved in research activity)

5A: Research activity and collaboration

1. Describe the current relevant brain tumour research at your centre. Please indicate whether these are projects led by a group leader at your centre or a collaboration with other centres/institutes.

2. Please list the current competitive research grants (up to 10) at your centre for work relevant to brain tumours. Include the awarding body and value (note, clinical trials have been covered in previous section).

3. Please list the top relevant peer reviewed brain tumour publications from your centre since January 2018.

4. Are there any current initiatives in your centre engaging basic scientists on brain tumour research? If so, please provide an example.

Section 6: The Tessa Jowell Centre Designation

(may be completed by a MDT member who takes overall responsibility for completing this form)

1. Please provide in your own words why you believe your centre should be awarded the Tessa Jowell Centre of Excellence designation.

2. Please explain if there are any areas covered in this form where you feel you may need additional support to help meet the criteria and outline what kind of support you may need. Please also describe which barriers you are anticipating.

3. In which areas do you believe you provide excellence / best practice of care (e.g. are there any care models you have developed).

4. Who are the leaders within your brain tumour service who drive standards, introduce new approaches and help train others?

5. Please list the names and contact details of the key representatives of your unit to discuss the next steps of this application with.

Many thanks for completing the form!