Tessa Jowell
BRAIN CANCER MISSION

Tessa Jowell Centre Designation Standards

This document sets out the underlying standards to the Tessa Jowell Centre Designation Application Form.

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

General information

- Hospitals should have a CQC rating of good or outstanding. If the hospital has scored 'requires improvement', the centre is invited to provide details on whether there were any comments in relation to the neuro-oncology unit. If any, the centre will be expected to present a plan that demonstrates how it will address these comments.
- Centres that regularly receive NHS referrals from other areas may indicate that the centre is known for a certain expertise. This is not an obligatory requirement e.g. some centres may be a regional hub for stereotactic radiosurgery.

A. Surgery

Brain tumour patients are operated on by surgeons specialised in brain tumours:

- Each centre should have a team of neurosurgeons sub-specialised in brain tumours. In addition, within this team there should be surgeons who are subspecialised in gliomas.
- Glioma surgeons should be trained in using 5-ALA (pink drink) which must be made available to all glioma patients and most meningiomas patients.
- Within the team there must be neurosurgeons who have attended a white matter dissection course.
- Centres must have neurosurgeons on their teams that are trained in performing awake craniotomy with language and other appropriate functional monitoring and expertise in intraoperative neurophysiological monitoring. All patients eligible for awake craniotomy must receive it (exceptions for emergencies).
- Brain tumour surgeons must be skilled in intraoperative image guidance.
- Centres must routinely perform post-operative scans for gliomas within 72 hours of surgery to assess the extent of resection.
- All centres must routinely use neuro-navigation for all glioma surgeries.
- Centres should be encouraged to aim to operate on Grade II Low Grade Glioma patients within the first year of tumour diagnosis, where it is technically feasible, and as part agreed shared care management with the patient.
- Exceptions to the above standards for emergencies and biopsies.

B. Pathology

Waiting for neuropathology results can cause delays in the patient pathway and anxiety for patients. Timely intra-operative results are necessary for intra-operative neurosurgical decisions. Timely brain biopsy results are needed for Multidisciplinary Team (MDT) discussions and treatment decisions.

- We expect an intra-operative neurosurgical result within 20 minutes of receipt within the laboratory.
- CSF cytology specimens should be diagnosed within 2 days of receipt.
- We expect average brain biopsy cases to have a morphological and immunohistochemical diagnosis within 2 days of receipt within the laboratory, and 5 days if special stains required.

Each centre should be aware of and have a strong relationship with their local Genomic Laboratory Hub (GLH), or the equivalent for Scotland, Wales and Northern Ireland, to facilitate genomic analysis of brain tumour samples. The seven GLHs in England are funded to provide genomic testing for all centres. (see National Genetic Test Directory for the relevant funded brain tumour services offered). We expect that each centre access these services for their relevant patients and to see a reasonable number of samples submitted each year for analysis (depending on centre size). The following tests are available: Gene panel ~500 genes, RNA sequencing (for gene fusions)

Furthermore:

- We expect genetic analysis results from GLHs within 10 working days after receipt.
- We expect the final integrated diagnosis (with genetic analysis results) within 14 days of genetic analysis request (28 days for outside referral).
- It is desirable, but not required for centres to offer through their partners, if possible, whole genome and/or RNA sequencing based on clinical indication.

We expect all brain tumour specimens to be processed within specialist neuropathology laboratory facilities which are UKAS accredited to internationally recognised standard ISO 15189.

We expect neuropathology reports to contain the minimum data sets as recommended by the Royal College of Pathologists and reported by specialist neuropathologists taking part in Neuropathology EQA.

C. Imaging

1. Diagnosis, tumour stratification and therapeutic planning

We expect centres to:

- Undertake timely MRI on state-of-the-art equipment using, at minimum, nationally recommended core protocols, including volumetric acquisition.
- Generate an expert neuroradiology report within two weeks of imaging, even for highly specialised cases.
- Have capacity to schedule and report MRI within a few days to aid urgent diagnosis and treatment planning.

We expect centres to have access to and training in advanced imaging techniques for tumour diagnosis, stratification and therapeutic planning. Centres should aspire to be trained in and have access to varying combinations of the following:

- Perfusion-weighted and permeability Imaging: DSC-MRI/ASL/DCE-MRI
- fMRI
- DTI
- Proton Magnetic Resonance Spectroscopy
- PET

One way to collect evidence for expertise in the above techniques is research or audit activity in this area. E.g. if the team publishes or participates in clinical trials involving these techniques.

2. Treatment response evaluation

Imaging schedules should include post-operative MRI within 72 hours and appropriate intervals after radiotherapy and chemotherapy.

Centres should have experience in established response criteria and be able to demonstrate a robust approach to therapeutic evaluation in cases of suspected pseudoprogression or radio-necrosis. To test for this, centres could have access to relevant advanced techniques (e.g. perfusion MRI, or PET).

D. Radiotherapy

We expect the waiting time for radiotherapy to not exceed six weeks.

We expect centres to be able to demonstrate a mechanism for peer review of radiotherapy treatment volumes. This is in line with the recommendation by the Royal College of Radiologists. The peer review:

- Can be carried out by a colleague with a similar specialisation within the individual centre.
- If sole practitioner, arrangements should be put in place with partner centre to aid in peer review.
- If centres do not have peer review mechanism in place, we expect them to have a plan in place to work towards this.

We expect centres to use Intensity-Modulated Radiation Therapy (IMRT) in a significant proportion of their cases in order to minimise normal tissue risk of radiotherapy. If not actively using, centres should be able to demonstrate a plan to do so for the next 12-18 months. It is desired that centres should be working towards IMRT for all of their cases.

We expect centres to have access to and refer for stereotactic radiotherapy treatment for selected metastasis and certain primary brain tumours.

Proton Beam Therapy (PBT) is offered in Manchester (April 2020) or abroad in Essen, Germany until the second NHS England site in London is opened in 2022. PBT is predominantly offered to paediatric patients, but young adults with rarer primary tumours and certain skull-based tumour types e.g. chondrosarcoma or chordoma of skull base also qualify. All UK centres have a referral pathway via the National Proton Beam Panel. We expect centres to be aware of the option to refer adults to these centres and would expect each centre to have referred suitable cases over the last 3 years.

E. Chemotherapy

- It is desirable for centres to provide access to therapies or drug combinations (e.g. bevacizumab) to treat radio-necrosis.
- We expect that that the oncologists discuss side effects of long-term corticosteroids and chemotherapy with patients and have a protocol in place for the mitigation and/or management of side effects.
- We expect that there is clear information available for patients (e.g. patient information sheets) on the proposed therapy they are receiving and what to do in case of emergency: e.g. chemotherapy patients developing a fever.
- We expect oncologists to involve their patients in the risk/benefit judgement of different treatment protocols
- We expect waiting time for chemotherapy to not exceed 31 days following agreement for the need of therapy
- For recurrence of the tumour we expect waiting time for chemotherapy to not exceed 31 days

Section 2: Well-defined level of care for patients

2A: Clinical care up to and exceeding the Integrated Multidisciplinary Care Model (IMCM)

1. Centres will offer excellent care for their brain tumour patients. They will implement the Integrated Multidisciplinary Care Model (IMCM) in the neuro-oncology service.

- The majority of brain tumour patients are referred to a pre-operative Multidisciplinary Team (MDT)
- All brain tumour patients are discussed by a group of experts before their treatment formally begins.
- The MDT should include relevant specialists, including:
    - Neurosurgeon
    - Diagnostic Neuroradiologist
    - Neuropathologist
    - Clinical Oncologist
    - Medical Oncologist (optional)
    - Neurologist
    - Neuropsychologist
    - Neuro-oncology Nurse
    - Palliative Care Specialist
    - Allied Health Professional (e.g. neuro-oncology physiotherapist, Occupational Therapist, Speech and Language Therapist)
    - Geneticist (desired, or access when relevant)
    - Consultant in Rehabilitation (desired, or access when relevant)
    - MDT Coordinator
- Exceptions for emergencies

Brain tumour patients should have access to a dedicated brain tumour clinic. All patients should:

- Be provided with a named healthcare professional with the responsibility for coordinating health and social care support for people with brain tumours and their relatives and carers, for example, a key worker (often a clinical nurse specialist or advance practitioner role).
- Receive their diagnosis in private and face to face for all tumour types.

2. Brain tumour patients should have access to consultants and allied health professionals (AHP) with experience in treating brain tumour patients. The Neuro-Oncology Team should include:

- Dedicated (diagnostic) neuroradiologist and neuropathologist
- Dedicated clinical oncologists
- Provide access to a neurologist, supportive care specialist and rehabilitation consultant who have experience with treating brain tumour patients.
- Provide access to dedicated occupational therapist, clinical psychologist, physiotherapist, speech and language therapist and dieticians with a dedicated specialism in neuro-oncology and or cancer rehabilitation.
- Provide access to specialist rehabilitation therapists at any point in the patient care pathway – diagnosis, treatment, post treatment, palliative and end of life care.
- Each specialist on the MDT should actively maintain and access relevant information and training within their specialised field. This can include attending conferences, expertise specific meetings and trainings. Centres should provide examples of these for each specialisation within their team. For example:

- Neurosurgeons should aim to attend the yearly BNOS meeting.
- Pathologist should aim to attend the BNP meetings.
- Team members may rotate these meetings, but each team should be represented each year.

3. Centres should aim to meet and exceed NICE improving outcomes guidance (2018 update)

- If centres do not meet NICE guidelines, they should have a plan in place to address this.
- It is desired for centres to exceed NICE guidelines in certain areas and highlight these to us as potential areas for sharing of best practice with other centres.

4. Centres should have an audit programme in place for their MDT activity

- This should be presented at an MDT AGM and for purposes of educating the team. Audits should be registered within the Trust audit portfolio.

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

1. Clinical nurse specialist (CNS) care

- CNS should create, together with the patient, a personalised care plan which has four main interventions as part of a recovery package:
  - (1) Holistic Needs Assessment and Care Planning
  - (2) Treatment Summary
  - (3) Cancer Care Review
  - (4) Health and Wellbeing Events.

  These elements form part of an overall support and self-management package for people affected by cancer. Patients should receive this at the time of diagnosis and at the end of treatment.
- If the personalised care package is not fully in place, we expect centres to offer at least a holistic needs assessment and provide a treatment summary. It is desirable to state an intent to work towards achieving all four points.
- Patients should receive an advanced care plan following diagnosis of an incurable brain tumour.
- We expect centres to have partnerships or close working relationships in place with organisations like MacMillan, Marie Curie or other local organisations.
- We expect CNS to be able to signpost to relevant charities for information, rehabilitation services and social care services to support patients personalised care needs.
- We expect CNS to be aware of and give information to patients about relevant clinical studies in their centres, other TJ centres or other centres in the UK.
- We expect CNS to offer guidance on benefits information or signpost to where this information may be found.

2. Measuring, managing and improving patient quality of life

- Centres should have a process in place to document and measure patient quality of life.
- Centres should be able to demonstrate that the holistic needs assessment leads to individualised care planning for patients.
- Centres should demonstrate a process in place for collecting patient feedback.
- Centres should be able to give an example of how feedback has improved current services.
- High grade brain tumour patients should be able to access:
  - a CNS telephone line 5 days a week
  - Specialist rehabilitation services from early in their pathway, if relevant.

3. Rehabilitation

- We expect centres to be able to refer eligible patients to rehabilitation services. Centres should demonstrate this by ensuring that they have:
    - A demonstrated referral pathway for rehabilitation in suitable cases e.g. spinal ependymoma with paraplegia post-surgery.
    - A specialist clinic is in place, in which staff receive brain tumour training.
    - Set patient specific goals and follow up on them.

4. Support services for low grade and non-malignant brain tumour patients

- Low grade and non-malignant patients should be able to access:
    - a CNS telephone line 5 days a week / named key worker
    - Specialist rehabilitation services
    - Support focussed on patient quality of life
    - Vocational rehabilitation as required through a central service or linked service

5. Supportive/palliative and end of life care

- Brain tumour patients should be offered a referral to supportive / palliative care early in their pathway (within 6 weeks of diagnosis of incurable disease), e.g. Enhanced Supportive Care (ESC) or an equivalent pro-active service. Centres should demonstrate this by explaining their referral pathway, service model and resourcing in the questionnaire.
- Centres should demonstrate an effort to ensure continuity of care and ensure an efficient transition to end of life care. Centres should ensure the patient is allocated a new main point of contact or key worker after the last line of treatment.
- Centres should demonstrate that they offer their patients the opportunity to discuss their goals of care through an advanced care plan close to the point of diagnosis of incurable disease.
- Centres should be able to demonstrate a clear pathway to offer support for inoperable patients.

6. Managing 'at risk' patients

- Centres should have measures in place to prepare for the deterioration of a patient's condition (e.g. emergency care plans or other initiatives) and should share them with the patient.

2C: Provide support to achieve patient identified goals

Centres should demonstrate through which mechanism / initiative they support patients in achieving their individual priorities. They should provide clear examples or can refer to answers in section 2B.

Good evidence could be given by referring to their Holistic Needs Assessment, rehab care plans, advanced care plans or by showing they act on patient feedback.

2D: Collaboration with local services

Centres should have collaborations in place with local support services that provide continuing care for brain tumour patients. This will ensure patients are kept out of the hospital or do not experience a big gap in care following their hospital discharge.
These collaborations **should** include strong links with:

- Community services (e.g. community nurses, or community MacMillan nurses, local hospices)
- Local council (Social workers)
- Primary care providers (GP)

These collaborations **could** include:

- Shared care arrangements
- Support/training events for community staff
- Initiatives to promote early diagnosis or improve referral pathways

2E: Partnering with patient organisations

Tessa Jowell Centres should have collaborations in place with patient organisations to ensure continued support and education for all brain tumour patients throughout their treatment. Collaborations should:

- Enhance the regional neuro-oncology network of the centre
- Lead to upskilling events
- Increase awareness of charities and their resources
- Potentially provide grant funding

Section 3: Clinical Studies

3A: BRAIN MATRIX membership

- It is desired for centres to be a member of or to be working towards BRAIN MATRIX membership and offer eligible patients the option to participate .

3B: Other clinical studies and trials

- Centres should have in place dedicated FTEs of medical staff, administrative staff and nursing staff to recruit and run clinical studies.
- Centres should have the infrastructure in place to offer brain tumour patients the opportunity to enrol in trials hosted in their centre or alternatively, be able to refer patients to trials at other centres. Instead, a smaller centre could demonstrate an awareness of open trials in other centres or have a link with a nearby larger teaching hospital.
- Centres should have at least one currently open clinical study, available locally or via referral.
- It is desired for centres to also be engaged in commercial studies.
- Centres should have pathways in place to collect and store snap frozen tissue.
- Centres should be able to work with patients to facilitate brain donation.
- Centres should have a pathway in place with a biorepository.
- It is desired that centres have contributed to the 100K Genome project.
- Centres should offer brain tumour patients information regarding biobanking and registry participation.

Section 4: Training and support for health professionals

4A: Hosting Tessa Jowell Oncology Fellows

It is desired for centres to be able to host Tessa Jowell Oncology Fellows. Centres should be able to:

- Host fellows and act as the primary fellowship training site by having access to either advanced neurosurgery / neuroradiology / molecular pathology / early and late phase clinical trials and specialist radiotherapy techniques.
- Demonstrate support for fellows: suitable working environment, administrative support and education and library resources.
- Submit a letter of support stating their commitment to the training and support of fellows.

4B: Training and ongoing training for staff members

Tessa Jowell Centres are expected to offer ongoing training and support for all staff members. Tessa Jowell Centres should:

- Demonstrate CDP opportunities for consultants and allied health professionals
- Offer other training opportunities to their neuro-oncology team to support and improve care
- Demonstrate plans for sustaining and developing their service.

Centres should be able to demonstrate brain tumour specific training / upskilling for their CNS staff. We appreciate that this training is not formalised, but we would like to see evidence that training within the centre is taking place. In addition, it is desirable that CNS have attended an advanced communication skills course (e.g. covering difficult conversations, and video sessions).

Centres should demonstrate that their Allied Health Care Professionals are appropriately trained.

4C: Sustaining and developing your service

Each centre should demonstrate that they have initiatives in place to ensure the continuous development of their staff and improvement of their services.

Centres should have initiatives in place to support work-life balance, workplace stress and mental health, for example counselling services.

Section 5: Brain Tumour Research

Research activity and collaboration

Each centre should participate in research either locally or through collaborations in order to encourage strong basic and translational science. Centres should demonstrate current research activity through:

- Current competitive grant funding
- Current peer-reviewed publications
- Current initiatives to engage basic scientists in brain tumour research
- Highlight / describe their own area of expertise within the centre.

Section 6: The Tessa Jowell Centre Designation Process

Centres should demonstrate a willingness / eagerness to work towards designation. Centres should demonstrate awareness of their strengths and recognise areas that may need further development.