Tessa Jowell Standards of Excellence

May 2023

The Tessa Jowell Brain Cancer Mission

Tessa Jowell
Centre of Excellence
for children

Contents

Tessa Jowell Centre of Excellence for Children Designation Standards of Excellence

This document outlines the standards for the treatment, care, and research of children with brain tumours that applicant centres are expected to meet to obtain Centre of Excellence for Children status. The standards are based on insights gathered in the Evidence Base, recommendations from the designation committee, who have each sought to define "achievable excellence" in their area of expertise, and Tessa Jowell's vision and call to action: "bringing the latest and greatest science to the patient" and "Focusing on living well with cancer, not just dying from it".

This Standards of Excellence document is accompanied by the following documents which are available to download on our website:

- **Centre of Excellence for Children Evidence Base**: an overview of current landscape and challenges in paediatric neuro-oncology, collected through extensive discussions with experts in the field, academics, charities, and patient representatives.
- **Centre of Excellence for Children Application Form:** a set of questions which test the enclosed standards. The data gathered through the designation process will enable the recognition of excellence as well as opportunities for improvement in paediatric services across the UK and support centres to further develop their services.

The following standards are divided into six key sections:

1. Robust and defined shared care arrangements
2. Excellence in clinical treatment
3. Excellence in patient care and quality of life
4. Education, development and play therapy
5. Training opportunities, organisational resilience and staff wellbeing
6. Opportunities in research and clinical trials

The Tessa Jowell Centre of Excellence for Children Programme has received strategic input from its Joint Strategy Board partners:

Section 1: Shared care arrangements

Shared care arrangements

Each devolved nation's commissioning body and their relevant children's cancer networks are responsible for oversight of service provision and are expected to ensure service specifications are met and strategic planning for treatment delivery and clinical trial implementation are supported:

- Centres should be able to demonstrate robust and clearly defined treatment and care arrangements and evidence of transfer planning for key intra-organisational, intra-network and inter-network transition points.

Diagnosis

- Patients presenting with a suspected brain tumour with neurological signs should have prompt access to a paediatric hot clinic/opinion or similar within 48 hours in almost all cases.
- Networks are expected to demonstrate an effective pathway with rapid and safe transfer where patients are able to promptly access interventional management including neurosurgical and definitive care.
- Networks are expected to ensure appropriate and prompt diagnostic imaging of suspected brain tumour using agreed imaging protocols across the network, including review of imaging by the primary treatment centre (PTC) in timely manner, via WebPACS or similar system.
- PTCs are expected to notify the shared care centre/Paediatric Oncology Shared Care Units (POSCUs) teams and the child's GP of the diagnosis and treatment plan in a timely manner.

Communication

- Centres are expected to be able to demonstrate liaison between clinicians at POSCU and PTC multi-disciplinary team (MDT) to effectively facilitate bi-directional communication.
- PTC and POSCU teams are expected to regularly communicate on ongoing treatment plan and relevant changes in patient status.
- Relevant members of the POSCU teams are encouraged to participate in/join MDT meetings to discuss patients and receive relevant updates on patients in real time.
- PTC and POSCUs should have agreed escalation standard operating procedures (SOPs) and policies for unwell patients and service interruptions, including out-of-hours and weekends.

Treatment

- Centres are expected to have shared prescribing platforms in place which can be viewed and utilised by POSCU and PTC.
- PTC and POSCUs are expected to demonstrate evidence of a resilience strategy to respond to system interruption (for e-prescribing/CIVAS and temporary shortages of trained administrators)
- PTC and POSCUs should demonstrate the process whereby MDT decisions around implementation of chemotherapy are translated into practice, including recording and sharing of consent conversations.
- PTCs are expected to demonstrate robust referral pathways to ensure patients in shared care units have equitable access to clinical trials.

End of treatment

- Once patients have left PTC, if needed, centres should be able to demonstrate a documented plan for rehabilitation care and, where possible, organise referrals for AHP services.
- End of treatment summaries are expected to be clearly shared between all centres, including GPs.

Section 2: Excellence in clinical treatment

Imaging

Centres are expected to ensure every child has a pre-operative MRI which adheres to SIOP-E guidelines for imaging the brain and spine. The first scan is expected to be a diagnostic scan.

The first scan should be undertaken in a timely manner to prevent delays to surgery.

In extremis presentation for patients at risk of neurological failure:

- Patients should be scanned within one hour from trauma or within one hour of clinical stabilisation.
- A mechanism should be in place to allow for emergency bypass of MRI imaging (i.e., CT only) in cases of acute presentation requiring emergency surgery. In these instances, processes should be in place to ensure an appropriate MRI imaging dataset is acquired, when possible, e.g., post shunt or post biopsy or even post emergency debulking.

For urgent and acute presentations:

- The first scan should be undertaken within 24 hours from clinical concern that the child may have a brain tumour.
- An appropriate report should be returned within two hours of the scan being conducted. Reporting of scans should be conducted by radiologists with experience in paediatrics.

For non-urgent presentation:

- Centres are expected to adhere to a two week wait for patients who are referred from primary care with less urgent presentation of a possible underlying neuro-oncological pathology.

The follow-up scan should adhere to one of the following:

a. SIOP-E[1] guidelines used at first scan;
b. RAPNO[2] criteria for specific tumour types;
c. Specific tumour type scans (e.g., ependymoma as recommended by EMAG[3]).

Neurosurgery

- Centres are expected to have a team of neurosurgeons subspecialised in paediatric brain tumours.

[1] The European Society for Paediatric Oncology
[2] Response Assessment in Paediatric Neuro-Oncology
[3] Ependymoma Advisory Group

- Centres are expected to have a dedicated neurosurgeon who operates on a minimum of 10 paediatric patients/year.
- Neurosurgeons are expected to work with a neuro-surgically trained paediatric anaesthetist to support all surgeries.
- Neurosurgeons should actively engage with or participate in national and international associations, organisations and working groups (i.e., CCLG, BPNG, ISPNO, SIOP-E Brain Tumour Group).
- Neurosurgeons are expected to have time in their job plan to attend weekly MDT meetings.
- Neurosurgeons are expected to engage in national MDT/advisory panel for available tumour types.
- Neurosurgeons are expected to take part in the peer review process, including:
    - Regular mortality and morbidity meetings for the paediatric neurosurgery service
    - Regular mortality and morbidity meetings for the paediatric neuro-oncology service
- Neurosurgeons are expected to keep a database record of cases and outcomes, including complications, complete resection rates for relevant tumours, second-look and biopsy numbers.
- Centres are expected to aim to see most patients with newly diagnosed urgent brain tumour within 24 hours of presentation.
- Centres are expected to see most non-urgent cases in clinic within one week of presentation.

Neuropathology and genomics

Centres will vary in the diagnostic pathway according to local requirements; however, centres are expected meet national standards and certification:

- All brain tumour specimens should be processed within specialist neuropathology laboratory facilities and/or genomics laboratory hubs which are UKAS accredited to internationally recognised standard ISO 15189.
- All paediatric neuropathologists should take part in External Quality Assessment (EQA) schemes.

Histopathological, immunohistochemical and cytological examination are expected to be available within specified turnaround times:

- Intra-operative neurosurgical result **within 20 minutes** of receipt within the laboratory
- CSF cytology specimens should be diagnosed **within 2 days of receipt**.
- Diagnostic biochemical tests (AFP, HCG) should be available on the same working day, and always **within 24 hours of sampling.**
- Initial biopsy results (including immunostaining) should be available within **5 working days**.

Centres are expected to demonstrate robust and secure pathways for all tumour tissue, to optimise the process and minimise delays for diagnosis, molecular diagnostics, treatment, and research. The following standards are expected:

- Sufficient frozen tumour material for molecular analysis and adequate capacity to snap freeze samples. Centres are expected, where possible, to collect a sample size of 1cm x 1cm x 1cm.

- Formal arrangements with the VIVO/CCLG tissue bank to allow cases to undergo biobanking for research.
- Molecular analyses to include the methods below. Centres are expected to aim to process, analyse and report samples for diagnostic purposes within the timeframes below:
    - Methylation array 21 days
    - Gene panel + relevant fusions 14 days
    - Whole genome sequencing 42 days*
    - SNP Array 14 days
    - FISH 14 days
    - MLPA 14 days

**Turnaround time to return WGS data once sample has been received from genomics laboratory. Whole genome sequencing is not a current standard of care and extra consent should be obtained.*

The results of all diagnostic procedures are expected to be available for discussion at MDT within a clinically appropriate timeframe. For final integrated diagnosis, a genetic result if provided locally is expected within 10 days and a report within 14 days. If genetics are sent off site, a final integrated diagnosis in 28 days is expected.

Chemotherapy

All chemotherapy is subject to oversight by governance within the organisation and report to Trust-chemotherapy governance processes.

Prescribing and administering chemotherapy is expected to align with the relevant nationally agreed guidelines in each devolved nation (e.g. NICE Improving Outcomes Guidance).

- Centres are expected to demonstrate documented protocols and processes in place for prescribing chemotherapy.
- Centres should be compliant with chemotherapy administration protocols, including high-dose chemotherapy.
- Centres are expected to demonstrate compliance with current guidance on appropriate level of staffing and staff training for safe administration of chemotherapy, where possible.
- Where there is a staffing shortfall, centres will be expected to mitigate any risk; plans must be in place to correct any identified shortfall in appropriately qualified and trained staff within a short (1-2 months) interval.

Service infrastructure:

- Centres are expected to keep a record of bed-days and associated treatment delays.
- Centres are expected to document hospital-specific outcomes and review these on an annual basis. Outcomes could include survival, morbidity, administration errors and near misses, prescribing errors. Reports should be freely accessible to all staff members.
- Centres are expected to keep a record of patients who have received high-cost/novel medications.

Radiotherapy

Centres are expected to consider all radiotherapy and/or chemotherapy treatment options; options should be discussed in a paediatric MDT and with the patients and their families.

Discussions should include logistics, alternative options, and the financial support available for families.

Most curative radiotherapy in children where there is a reasonable 5-year survival expectation is currently commissioned to be delivered with proton beam therapy (PBT), provided the patient is fit to travel and be treated as an outpatient. The Christie in Manchester and UCLH deliver PBT as part of the national NHS Proton Beam Therapy service. Centres should aim for early referral to proton panel, with imaging and supporting documentation. This is particularly true for diagnoses such as medulloblastoma and ependymoma where treatment should start within defined timescales.

Centres are expected to ensure patients receive radiotherapy treatment at the earliest possible opportunity. Waiting times should not exceed:

- 42 days from surgery for medulloblastoma
- 6-8 weeks from last surgery for ependymoma

Patients should have access to specialist rehabilitation support services during radiotherapy, including physiotherapy, occupational therapy, speech and language therapy, and dietetics.

Centres are expected to offer all patients access to available trials at their own centre or via referral to a nearby centre e.g., SIOP Ependymoma II trial or the high risk medulloblastoma trial (HRMB).

Radiotherapy departments offering photon therapy are expected to staff or have access to:

- At least two clinical oncologists with paediatric sub-specialism
- Play therapist or youth support specialist
- Specialist paediatric anaesthetic service
- Specialist radiographer

Centres are expected to align with defined protocols for radiotherapy, CT/MRI planning scans and dose fractionation.

Prospective peer review, at least of target volume delineation, is expected for all paediatric radiotherapy given with curative intent (radical or adjuvant).

Patients should be reviewed at least once/week for toxicity and other adverse events.

Section 3: Excellence in patient care and quality of life

Centres are expected to demonstrate excellent patient care and support at all stages of the treatment pathway.

Multi-disciplinary team organisation

Treatment and care of brain tumours in children is expected to be delivered by a multidisciplinary team (MDT) of specialist health professionals in a flexible and relevant manner.

Patients are expected to be discussed at one or more MDT meetings attended by the relevant specialists involved in the children's' treatment and care.

The composition of the MDT(s) is expected to be appropriate to the patient's need at each stage of the treatment pathway. Relevant specialists in the MDT could include:

- Neurosurgeons
- Neuro-oncologists
- Neuro-radiologists
- Clinical oncologists
- Neuropathologists
- Neurologists
- Clinical Nurse Specialist
- Shared Care consultant and other team members (where relevant)
- Specialist Pharmacist
- Relevant Allied Health Specialists (Education Specialist, Physiotherapist, Speech and Language Therapists, Occupational Therapist, Dietician, Play Specialist, etc.)
- Neuropsychologists/Clinical Psychologists
- Social Worker
- Palliative Care Specialist
- Endocrinologists
- Ophthalmologists

Centres are expected to demonstrate clear communication pathways between members and/or specialty meetings, and pathways must ensure shared care arrangements are clearly communicated with all relevant team members.

Centres are expected to have clear second opinion pathways, including guidance on how second opinions should be managed outside the normal network arrangements.

Centres are expected to have a protocol in place to integrate genetic reporting into the MDT.

Nurse-led care

- Centres are expected to demonstrate availability of suitably trained ward nurses which meets the needs of the patients and supports the timely delivery of chemotherapy.
- Centres are expected to demonstrate that neuroscience and oncology nurses work collaboratively and are offered relevant clinical experience, e.g., through rotational posts.
- Centres are expected have a designated neuro-oncology CNS with specialist training. CNS are expected to be band 7 or above with formal degree level (or above) and qualification in children's cancer care or neuroscience. The CNS is expected to have level 3 specialist safeguarding training.

- Centres are expected to offer CNSs access to chemotherapy training.
- Centres are expected to offer the CNS team support and opportunities to develop their clinical expertise and national networking through attendance to conferences, relevant study days and CCLG or SIOP-E participation.
- Centres are expected to offer an appropriate and planned pathway of care, including support from CNS, for both low-grade and high-grade patients.
- Centres are expected to have a clear pathway in place of how to access CNS support during Monday-Friday office hours and how to access clinical support and advice outside CNS working hours.
- Centres are expected to ensure CNSs have protected time dedicated to appropriately support and care throughout the child's education. CNSs should contribute to special educational needs (SEN) assessment/Educational Health Care Plan (EHCP) and subsequent reviews to.
- The CNS is expected to work in collaboration with wider MDT, outreach and community teams, education services, neuropsychology, rehabilitation services, aftercare, palliative care and shared care.
- The CNS should remain a source of information and a signposting service for the child and family and other specialities until transition to adult services.

Rehabilitation

- Centres are expected to have clear communication pathways and agreed routes of referral for rehabilitation services.
- Centres should demonstrate robust and timely referrals to rehabilitation services.
- Centres are expected to assign each patient with a key worker during rehabilitation.
- Centres are expected to assess patients for rehabilitation needs at key time points and make a rehabilitation plan, throughout treatment and recovery including transition to community and long-term support.
- Centres are expected to provide families with sufficient information and access to resources, with clear guidance on managing rehabilitation needs until transition to adult services.
- Centres are expected to liaise with community services regarding the ongoing rehabilitation needs of a child.
- Centres are expected to liaise with cancer networks, other trusts, primary care trusts, local health boards and other agencies to support with robust rehabilitation strategies.

Psychological care

- Centres are expected to demonstrate dedicated funding or provision for both a qualified clinical psychologist and a clinical neuropsychologist (or a clinical psychologist experienced in neuropsychology).
- Standards below may be met by a clinical psychologist or a neuropsychologist depending upon service structure.

Clinical psychology

- Centres are expected to screen for mood and psychological difficulties at clinical appointments and to refer to clinical psychology where needed.
- Centres should demonstrate an ability to provide outpatient psychology appointments in a timely manner to provide complete psychological interventions for patients and their families.

- Centres are expected to have the capacity and flexibility to respond to urgent or inpatient referrals to manage acute distress or behaviour that is challenging and the psychology team should particate in urgent MDT decision making or support.
- Psychologists should participate in integrated MDT working to gather clinical information, communicate formulations, facilitate interventions, meet training needs and contribute to MDT decision making.
- Centres are expected to provide support to staff via clinical supervision in line with level 3/4 practitioner guidance, reflective practice groups and debriefing, including supporting end of life care.

Neuropsychology

- Centres are expected to screen for cognitive difficulties at clinical appointments and to refer to neuropsychology where needed.
- Centres are expected to have structured service protocols to undertake gold standard cognitive assessments and follow-up at key defined intervals (e.g. time since diagnosis or key educational milestones).
- Centres should demonstrate integrated working between neuropsychology, clinical psychology, MDT colleagues and relevant third parties such as education services.
- Centres are expected to adapt neuropsychological care to the needs of each patient and to offer access to support between set assessment points where required.
- Centres are expected to provide proactive neurorehabilitation integrated with the MDT and third-party agencies including education.

Research

- Centres should demonstrate participation in clinical psychology and neuropsychology research, audits and service evaluation relating to improving quality of life and psychological wellbeing for children with brain tumours. This should include projects initiated within the centre and supporting wider multicentre trials designed to improve cancer care.

Supportive palliative and end of life care

Supportive care

- Centres are expected to discuss and offer specialist paediatric palliative care services to patients and their families at diagnosis/recognition of incurable disease. If the family initially declines palliative care support, centres are expected to demonstrate a process in place to proactively review patients and families, to offer referral to palliative care when they are ready.
- Patients and their families are expected to receive holistic palliative and end of life care that meets their physical, psychological, social and spiritual needs.
- All centres providing palliative care are expected to have access to specialist palliative care consultant support and a specialist nurse.
- The specialist paediatric palliative care team is expected to demonstrate good liaison and working partnerships with the neuro-oncology team, primary and secondary care, education, community and religious groups, where relevant.
- Access to specialist palliative care advice and support is expected to be available to the treating team (e.g., oncology) 24/7.
- Centres are expected to work collaboratively to provide continuity of care across all patient settings including hospital (PTC and POSCUs), primary care, home, school, and hospice.

End of life and bereavement

- At end of life, access to specialist palliative care advice and support is expected to be available 24/7 to the patient, family, carers and supporting teams.
- Centres are expected to demonstrate end of life and bereavement preparation support which may include input from allied specialities.
    - Patients approaching end of life should receive advanced and ongoing symptom management planning through a written symptom management plan that is anticipatory and includes anticipatory prescribing.
    - Patients with incurable disease should have advanced care plans in place (e.g., the established national template: CYPACP). These should be accessible to all relevant services, where appropriate (including primary care, A&E, and ambulance services).
- Centres are expected to demonstrate effective communication and access to equipment across geographical boundaries for at home end of life.
- Centres are expected to have dedicated resources and staff training, to support families in their preparation for end of life and bereavement.
- Bereavement support is expected to be provided either from the palliative care team or a named bereavement key worker/co-ordinator. This is expected to be accessible immediately following death and at later stages.
- Appropriate support is expected to be available for the healthcare team involved in the end-of-life care of a patient (including ward staff).

Collaboration with patient organisations

- Centres are encouraged to provide written information to patients on the services available provided by patient organisations and to signpost to these services in a timely manner.
- Centres are expected to have a named team member to coordinate patient and family support from external agencies and charities.

Audits

Every centre is expected to conduct audits on an annual basis, and these should be relevant for paediatric neuro-oncology MDT.

Section 4: Education, development and play therapy

Education

Education plays a central role in a child's treatment and care journey. Education for children with brain tumours can encompass:

1. Hospital-based education for children receiving treatment and care as inpatients.
2. Home-based education for children recovering at home.
3. School-based education for children once they finish treatments and reintegrate into the normal schooling system.
4. The teams that manage the child's schooling needs, are in contact with their school and are involved in planning their education.

Hospital-based education

- Centres are expected to assess patients at key transition points to understand the consequences of a brain tumour and treatment on cognitive development and therefore the educational needs.

- Centres are expected to ensure appropriate provision of good quality education and support children's education from diagnosis to follow-up. Evidence of this support may be demonstrated with a comprehensive education, health and care plan (EHCP).
- Centres are expected to demonstrate knowledge sharing between key school staff, parents and hospital staff, to ensure continuity of education.
- Centres should have an appointed hospital education staff member to support children with special education and medical needs and whose responsibility it is to liaise with family and school staff.
- Centres are expected to have a SENDCo trained hospital teacher to liaise with schools and local authorities.
- All staff involved in hospital-based education are expected to have access to specialist training and resources for understanding the needs of children with acquired brain injuries. This may be provided through higher or specialist education or supplementary training.
- Centres could further support clinical team awareness of educational needs by offering access to training and resources on education requirements.
- Centres should demonstrate that the MDT is integrated with education and school involvement, with opportunities for educational staff to join MDT meetings.

School-based education

- Centres are expected to provide information and advice to schools for the return of the children to school. This should start from the first day of return to school.
- Centres should consider include all aspects of school reintegration and provide advice to schools on the following topics:
    - Movement around busy school environments
    - Involvement in physical education
    - Management and classroom support for fatigue, memory and recall, slow processing, literacy weaknesses and fine motor skills
    - Social, emotional and behavioural support including SALT
    - Medical requirements and arrangements
    - Appropriate timetable and homework deadlines

Play therapy

- Centres are expected to have access to at least one qualified play specialist trained with a degree in health play, level 3 training and a further qualification in neuro-oncology.
- Play specialists are expected to be supported through formal supervision, internal appraisals and psychological and well-being support.
- Play therapy teams are expected to be integrated with the MDT, in particular with radiotherapy teams, and attend relevant paediatric neuro-oncology MDT meetings.
- Centres are expected to demonstrate that children who are in hospital long-term have access to a dedicated play specialist and receive daily support.
- Centres are expected to have access to resources and toys for play therapy, including sensory resources and specialist resources for neuro-oncology patients.
- All centres should have access to a dedicated play space which can be adapted for use and suitable for children. This may include outdoor space.

Late effects and aftercare

- Centres are expected to have an aftercare service for patients with brain and spinal tumours.
- Centres are expected to offer continuity of care for patients within the service, provided by the MDT. An appropriate aftercare key worker should be assigned to each patient.
- Referral pathways for entry into the aftercare service should be clear for all patients.
- Centres are expected to draw up formal end of treatment care plans containing all key treatment and follow-up information. Follow-up care plans should:
    - Have input from a wide range of healthcare professionals from the MDT.
    - Be flexible and individualised, designed around the changing needs of the patient.
    - Be prepared in a timely manner.
    - Be discussed fully with patients and their families.
    - Be accessible by patients, primary care and all specialists involved in the provision of aftercare.
- At the end of treatment, patients and their families should be well-informed about next steps with clear signposting as to where and who to ask for support and what they can expect.
- Centres are expected to monitor patients at key transition points, to pro-actively identify unrecognised needs and respond to unmet needs, with timely escalation of issues. These should be considered at an early stage.
- Centres are expected to have active programmes to identify and manage problems early. This may include screening for:
    - Disease recurrence as appropriate
    - Second malignancy as appropriate
    - Psychological dysfunction
    - Developmental, mobility and neuro-psychological difficulties
    - Endocrine dysfunction, including early discussion regarding puberty and fertility.

  And/or:

    - Monitoring of body habitus (weight, height, BMI, metabolic syndrome), with intervention/ referral as required.

Teenagers, young adults, and transition of care

Teenagers and young adults have unique complex needs that differ from paediatric and adult patients.

- Centres are expected to demonstrate clearly defined pathways and bespoke transition plans during and after the transition (e.g., follow-ups) to TYA.

Section 5: Staff training, support, and organisational resilience

Staff training

Centres are expected to offer ongoing training and support for all staff members.

All relevant MDT members are expected to have access to training appropriate for paediatric neuro-oncology. Specific examples could include:

- Medical:
    - Attendance at paediatric oncology conferences relevant to neuro-oncology, attendance at relevant courses (CCLG, RCPCH, RCS, RCPath, SIOP-E, SIOP, BNOS, RAPNO or other relevant sponsors).
    - Participation in the SIOP-E neuro-oncology working group or participation in the CCLG neuro-oncology specialist interest group.
    - Involvement in multi-centre clinical trials.
    - Specific in-house (local, cross-Trust or regional) training in neuro-oncology.
    - Training in fields relevant to neuro-oncology, such as paediatric endocrinology, rehabilitation, palliative care, paediatric neuro-oncology neuroimaging.
- Nursing:
    - A nurse educator or specialist CNS is expected to provide neuroscience and/or oncology training to the nursing team.
    - Access to a paediatric neuroscience degree/masters-level module and care of a child with cancer degree/masters-level module.
    - Sub-specialisation requirements for paediatric brain tumour specific upskilling.
    - Rotational opportunities between neuroscience and oncology wards.
    - Access to clinical supervision for CNS roles.
- AHPs:
    - Access to specific training, courses, and conferences relevant to paediatric oncology and neurorehabilitation.
    - Rotational opportunities into paediatric oncology and neurology teams.
    - Involvement of key members with CCLG or relevant groups within professional organisations.
    - Access to specialist neuropsychologists.
    - Access to online courses specific on acquired brain injury for teachers/hospital education staff.

Advanced communication skills courses (e.g., covering difficult conversations, and video sessions) are expected to be available for relevant MDT team members.

Centres are expected to demonstrate adequate study leave and funding for MDT members to attend relevant training.

Centres should demonstrate clinical supervision for all relevant roles (e.g., CNS, clinical psychology, AHPs).

Centres are expected to demonstrate evidence of regular training and updates for POSCU staff from PTC and national bodies; POSCU staff to demonstrate appropriate CPD and membership of national bodies (CCLG).

Organisational resilience and succession planning

- Centres are expected to demonstrate initiatives in place to ensure the continuous professional development of their staff and improvement of their services.
- Centres are expected to demonstrate awareness of the need for succession planning and demonstrate succession plans in place.

Staff support

- Centres are expected to offer clinical supervision and psychological support for all staff involved in the treatment and care of paediatric brain tumour patients.

- Centres are expected to demonstrate ongoing initiatives and support for staff to help manage work-life balance, workplace stress, mental health and bereavement.

Section 6: Opportunities in research and clinical trials

Clinical trials

- Centres are expected to have infrastructure and staffing in place to recruit and run clinical studies or have a pathway in place to enable patients to enrol in trials at other centres.
- Centres are expected to offer patients entry into available clinical trials if they meet the eligibility criteria.
- Centres are expected to offer early phase trials to patients locally at the treating centre or via referral to another institute.
- Centres are expected to have all late phase trials open within four months following trial launch or clear demonstration of working towards opening all late phase clinical trials.
- Centres should aim to submit tissue, CSF, and blood samples from at least 95% of patients eligible for biobanking.
- Centres are expected to engage with national networks including NCRI, CCLG, specialist interest groups, SIOP-E and ITCC.

Brain tumour research

Centres are expected to participate in research either locally or through collaborations to encourage strong basic and translational science.

Centres could demonstrate current research activity through:

- Current competitive grant funding.
- Current peer-reviewed publications.
- Current initiatives to engage basic scientists in brain tumour research.
- Initiatives to engage clinicians in basic and laboratory research. This could include medical student engagement and project supervision, engagement in NIHR training schemes (AFP, ACF, ACL, etc.), and research experience grants.
- Research teams with clinicians and scientists.
- Engagement with national networks including NCRI, CCLG, specialist interest groups, and SIOP-E.
- Active involvement in ECMC and/or ITCC (either as a centre or by links to an active centre for treatment).
- Leading role in national or international initiatives.
- Participation in or running of established registries.
- Non-medical research projects including nurse and allied health specialities research.

Section 7: The Tessa Jowell Centre Designation Process

Centres are expected to demonstrate a culture of continuous service development and improvement.

Centres should demonstrate awareness of their strengths and recognise areas that may need further development.