

B13/S/a

**2013/14 NHS STANDARD CONTRACT  
FOR CANCER: BRAIN/CENTRAL NERVOUS SYSTEM (ADULT)**

**SECTION B PART 1 - SERVICE SPECIFICATIONS**

<b>Service Specification No.</b>	B13/S/a
<b>Service</b>	Cancer: Brain and Central Nervous System (Adult)
<b>Commissioner Lead</b>	
<b>Provider Lead</b>	
<b>Period</b>	12 months
<b>Date of Review</b>	

**1. Population Needs**

**1.1 National/local context and evidence base**

Primary central nervous system (CNS) tumours are uncommon. The most numerous involve the brain and account for only 1.5% of cancers in England. The variety of pathological primary tumour types is large. However, metastases to CNS from other sites are also common.

CNS tumours include all tumours inside the cranium or in the central spinal canal. They arise due to abnormal and uncontrolled cell division, either in the CNS itself, in the cranial nerves, in the meninges, skull, pituitary pineal gland, or spread from cancers primarily located in other organs (metastatic tumours).

Any CNS tumour can be inherently serious and life-threatening because of its expansive character in the limited space of the intracranial cavity and spinal canal. Brain tumours or intracranial neoplasms can be malignant or benign; however the definitions of malignant or benign neoplasms differ from those commonly used for other types of cancerous or non-cancerous neoplasms in the body. The danger level depends on the combination of factors like the type of tumour, its location, its size and its growth rate. Because the brain is well protected by the skull, the early detection of a brain tumour only occurs when diagnostic tools are directed at the intracranial cavity. Primary (true) CNS tumours are commonly located in the posterior cranial fossa in children and in the cerebral hemispheres in adults, although they can affect any part of the brain in either group.

The following four important characteristics of tumours in the CNS determine why

the terms 'malignant tumour' (often equated with 'cancer') and 'benign tumour' lack validity when applied to this clinical setting.

- The cranium, which surrounds the brain, is a rigid box, so that even a small, slowly growing tumour can cause severe symptoms and detrimental (even fatal) effects when it results in raised intracranial pressure.
- Slowly growing tumours in the brain can infiltrate extensively into adjacent normal tissue, which makes excision impossible.
- Retaining the vital functions of the brain, in which these tumours arise, poses a particular challenge during surgical excision.
- A slowly growing tumour may undergo progression and transformation to an aggressive tumour.

Therefore the tumours are graded I-IV by World Health Organisation (WHO), Grade I tumours being very slow growing and Grade IV tumours generally very rapidly proliferating. The grade of the tumour may increase over time.

The incidence rate for primary tumours of the CNS in England is 9.1 per 100,000 population for men and 6.7 per 100,000 population for women. 1-year relative survival estimates for primary cancer of the CNS is 41%. The incidence of metastases to or affecting the CNS remains to be established.

CNS tumours often have a poor prognosis. Both their anatomical position and pathology indicate prognosis and play an important role in decisions about the appropriate investigation and treatment. Sometimes, the risks of obtaining tissue for histopathological assessment are considered clinically unacceptable, and the patient is managed on the basis of a diagnosis made on neuroradiological features.

The anatomical location influences symptoms that include physical, cognitive and psychological components. These tumours can significantly impact on an individual's cognitive ability and this increases the need for access to psychological/psychiatric, social and physical support. One of the most important outcomes of treatment and care planning is to maximise an individual's quality of life.

- **Brain tumour** - the tentative diagnosis of a brain tumour is supported by findings following imaging of the brain with CT or MRI. The diagnosis is confirmed by surgical biopsy, which allows histopathological classification, although in a few cases biopsy is either not feasible or clinically inappropriate.
- **Primary tumours of the spinal cord** are rare. Tumours around the spinal cord, such as meningiomas, and nerve sheath tumours, often schwannomas, are more likely to grow slowly. Complete excision may result in a good prognosis, although their location may pose technical difficulties. Metastases involving the spine and meninges are not uncommon and are serious.
- **Pituitary tumours** may be functional, secreting hormones, or non-functional. The diagnosis of these tumours is primarily by imaging, although hormonal measurements are also important. Apart from any hormonal or medical treatment that may be required, the management of these tumours

may involve surgical resection, which can be undertaken by either the trans-sphenoidal or standard craniotomy approaches

- **Skull base tumours** - the term refers to multiple tumour types that can occur at this anatomical location, for example, acoustic schwannoma (a cranial nerve tumour), some meningiomas and invasive tumours from adjacent sites, such as nasal tumours. These tumours may cause specific symptoms because of damage to structures in the region, such as cranial nerves, resulting in palsies and difficulty with balance or hearing.

### **Local context**

### **Evidence base**

This specification draws its evidence and rationale from a range of documents and reviews as listed below:

#### **Department of Health**

- Improving Outcomes; a Strategy for Cancer – Department of Health (2011)
- Cancer Commissioning Guidance - Department of Health (2011)

#### **NICE**

- Improving supportive and palliative care for adults with cancer - NICE(2004)
- Improving outcomes for people with brain and other CNS tumours (2006)
- NICE clinical guidelines: Diagnosis and management of patients with metastatic spinal cord compression (November 2008)
- NICE clinical guidelines: Improving outcomes in children and young people with cancer (August 2005)
- Quality standard for end of life care for adults – NICE (2011)
- Quality standard for patient experience in adult NHS services – NICE (2012)

#### **National Cancer Peer Review**

- National Cancer Peer Review (NCPR) handbook – National Cancer Action Team (2011)
- Manual for cancer services: brain and CNS measures (2011)
- Manual for cancer services: acute oncology measures (April 2011)
- Manual for cancer services: chemotherapy measures (June 2011)

#### **Other**

- Chemotherapy services in England. National Chemotherapy Advisory Group (2009)

## 2. Scope

### 2.1 Aims and objectives of service

The aim of the specialist brain and CNS tumour service is to increase survival while maximising a patient's functional capability and quality of life, and to ensure ready and timely access to appropriate supportive care for patients, their relatives and carers.

The specialist brain & CNS service is provided by the coordination and integration of a neuroscience brain & CNS multi-disciplinary team multidisciplinary team and a cancer network brain and CNS multidisciplinary team. The key to a high quality service is good communication between the individual multidisciplinary teams and support services.

Good communication is essential for the smooth and effective provision of services and to prevent fragmented and uncoordinated patient pathways. A clear communication framework should be in place as identified in the improving outcomes guidance to ensure an appropriate standard of care.

The service is required to agree the following areas with commissioners:

- Service configuration and population coverage.
- Referral criteria, clinical (planned and emergency) protocols and network policies and treatment pathways for each of the brain and CNS tumours, and local follow up protocols.
- Engagement with the local network groups and national cancer peer review for brain and CNS Tumours.

The objectives of the services are:

- To provide an exemplary and comprehensive service for all eligible referred patients with brain & CNS tumours that is delivered in line with the Improving Outcomes Guidance (IOG) and the cancer waiting times.
- To provide expert diagnosis of brain & CNS tumours utilising the most up-to-date validated diagnostic tools and knowledge.
- To provide expert management of patients with confirmed brain & CNS cancers through the use of the most up-to-date clinical protocols and surgical management.
- To ensure there is clinically appropriate consideration and provision of surgery within the brain & CNS tumours patient pathway.
- To carry out effective monitoring of patients to ensure that the treatment is safe and effective.
- To provide care that promotes optimal functioning and quality of life for each individual patient.
- To ensure that all aspects of the service are delivered as safely as possible, conform to national standards and published clinical guidelines and are

monitored by objective audit.

- To provide care with a patient and family centred focus to maximise the patient experience.
- To support local healthcare providers to manage patients with brain & CNS tumour whenever it is safe to do so and clinically appropriate.
- To provide high quality information for patients, families and carers in appropriate and accessible formats and mediums.
- To ensure there is accurate and timely information given to the patient's General Practitioner.
- To ensure that there is involvement of service users and carers in service development and review.
- To ensure there is a commitment to continual service improvement.
- To comply with national data returns and electronic data transfer, including information on cancer stage, to registries.
- To ensure compliance with peer review measures.
- To ensure compliance with Care Quality Commission (CQC) regulations.
- Assessment and onward referral for stereotactic radiosurgery/stereotactic radiotherapy

## **2.2 Service description/care pathway**

### **Multidisciplinary team structure**

Brain and CNS is a rare disease which benefits from multi-modality treatment. It is essential that all new cases are discussed at an appropriate neuroscience multidisciplinary team and this team has full membership. The nominated services are shown in Section 5.

The service will provide:

#### **Neuroscience brain and other CNS cancer multidisciplinary team:**

- Responsible for the diagnosis and initial management (both surgical and non-surgical aspects of care) of adult patients with CNS tumours.
- The neuro-science brain and CNS multidisciplinary team should meet weekly to review all new patients and review current management plans for all patients under treatment.
- The specialist brain & CNS multidisciplinary team service is likely to serve a population of 1-3million people or more.

#### **Pituitary, skull base, spinal cord & other rare CNS tumours multidisciplinary teams:**

- These are services where patients would benefit from sub-specialist multidisciplinary team (MDT). These teams will not exist at every neuroscience centre. They should only be commissioned where sufficient patient numbers can be demonstrated.
- The multidisciplinary team is responsible for the diagnosis and initial

management (both surgical and non-surgical aspects of care) of adult patients with pituitary, skull base, spinal cord & other rare CNS tumours.

**Cancer network multidisciplinary team:**

- Responsible for the implementation of the non-surgical aspects of the management plan produced by the neuroscience multidisciplinary team including chemotherapy, radiotherapy and coordination of supportive care.
- The cancer network multidisciplinary team will meet at least monthly to coordinate care of new patients and to monitor ongoing care of follow up patients.

The service is expected to agree with commissioners where patients with brain & CNS cancer should be treated and develop clear referral systems and pathways to ensure that responsibility for the management of every patient with brain & CNS is passed to the appropriate brain & CNS multidisciplinary team.

The neuroscience multidisciplinary team (including any pituitary, skull base, spinal cord & other rare CNS tumours multidisciplinary teams) is responsible for the following:

- Establish a diagnosis for the optimal clinical management of the patient.
- Develop management plans for patients with CNS tumours at first presentation, to include initial supportive care needs, diagnostic and surgical interventions, non-surgical oncology interventions, treatment of symptoms and follow-up.
- Nominate and record a key worker to act as point of contact for patients, their relatives and carers. This should be agreed with the patient, their relatives and carers.
- Agree who is responsible for implementing the next stage of the management plan.
- Inform the diagnostic clinician/team at the local referring hospital and GP of the management plan.
- Inform the cancer network multidisciplinary team of the management plan (usually via a representative who is a member of the neuroscience multidisciplinary team and also in writing).
- Review and advise on patients referred back from the cancer network multidisciplinary team on disease progression or relapse.
- Develop multidisciplinary team protocols, in collaboration with the cancer network multidisciplinary team, to define appropriate follow-up imaging requirements for patients with CNS tumours.
- Implement the national management protocols for CNS lymphoma, medulloblastoma, pineal tumours and optic gliomas.
- Act as an educational resource for local service providers.
- Develop and maintain evidence-based local management protocols covering all aspects of the patient pathway.
- Participate in regular site-specific group meetings to review care pathways and protocols.
- Introduce and maintain systems for data entry across the area of service provision including links to cancer registries.

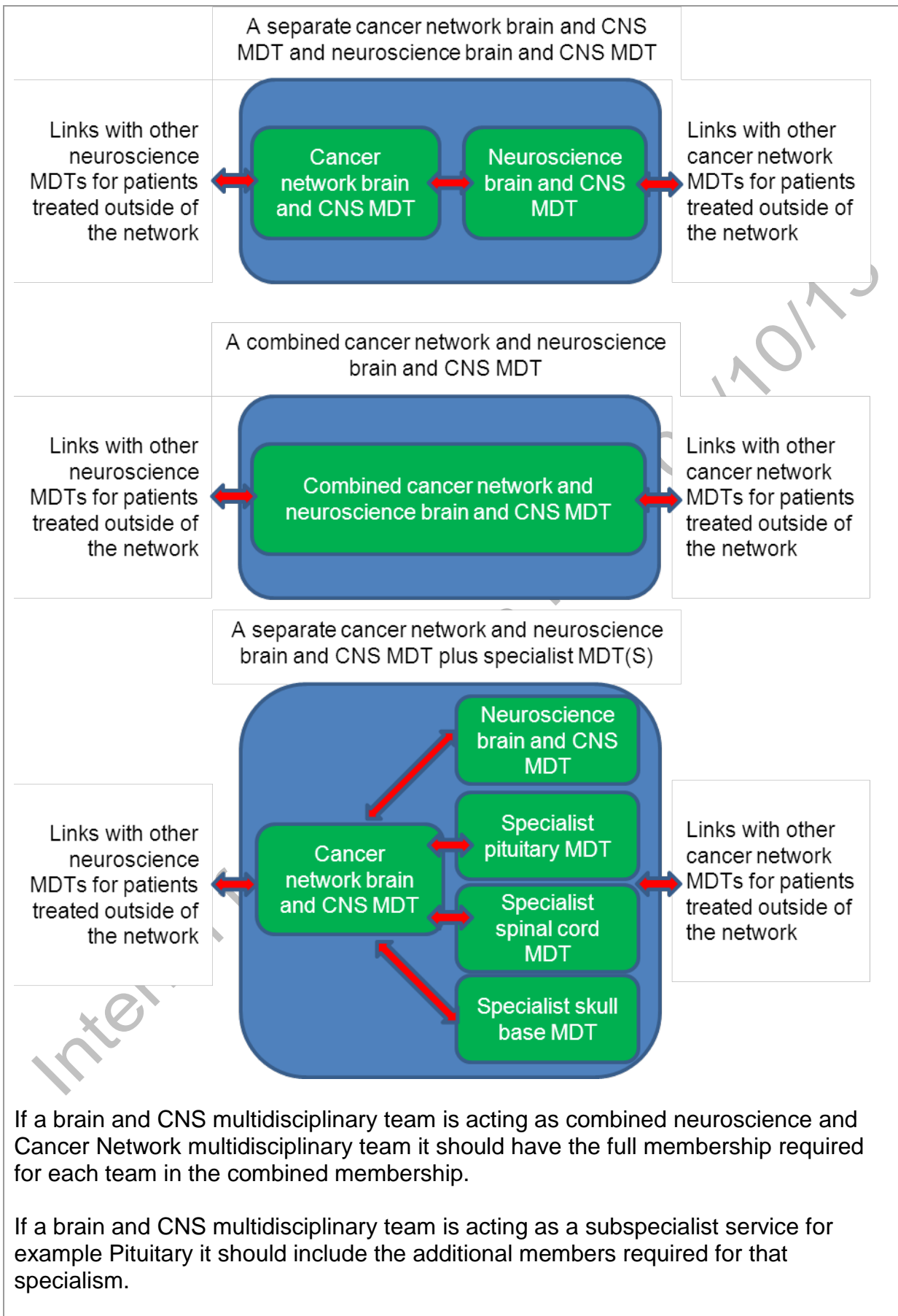
- Audit practice against this guidance and other national guidelines as they are published.
- Facilitate the entry of patients into appropriate National Cancer Research Network (NCRN) and local clinical trials.
- Liaise with the cancer network multidisciplinary teams

The cancer network multidisciplinary team is responsible for coordinating the nonsurgical management of adult patients with CNS tumours.

The cancer network brain and other CNS tumours multidisciplinary team is responsible for the following:

- Implement the non-surgical aspects of the management plan produced by the neuroscience multidisciplinary team.
- Nominate and record a key worker to act as point of contact for patients, their relatives and carers. This should be agreed with the patient, their relatives and carers.
- Agree who is responsible for implementing the next stage of the management plan.
- Ensure that there are systems in place for the continuous assessment of the needs of patients, their relatives and carers, and provide or ensure provision of appropriate support.
- Re-refer patients to the neuroscience multidisciplinary team where appropriate, as defined in local protocols.
- Inform the local referring hospital and general practitioner of the current management plans.
- Involve the local referring hospital or community services in continuing, palliative and supportive care where appropriate, and provide specialist advice to local healthcare professionals when needed.
- Develop multidisciplinary team protocols, in collaboration with the neuroscience multidisciplinary team, to define appropriate follow-up imaging requirements for patients with CNS tumours.
- Act as an educational resource for local service providers.
- Develop and maintain evidence-based local management protocols covering all aspects of the patient pathway.
- Participate in regular site-specific group meetings to review pathways of care and protocols.
- Maintain data entry across the area of service provision.
- Audit practice against this guidance and other national guidelines as they are published.
- Facilitate entry of patients into appropriate NCRN and local clinical trials.
- Liaise with the neuroscience multidisciplinary team.

The specialist brain & CNS Cancer service must be compliant with one of the models shown in the figures below:





**N.B There should only be one cancer network/non-surgical team to co-ordinate treatment**

### **Multidisciplinary team membership**

**Neuroscience multidisciplinary team core membership includes:**

- Neurosurgeon(s) – who spends at least 50% of his or her clinical programmed activities in neurooncological surgery and is regularly involved in dedicated specialty clinics caring for these patients.
- Neuroradiologist(s) – who spends least 50% of clinical programmed activities spent in the practice of neuroradiology.
- Neuropathologist(s) - an accredited pathologist who is registered as a neuropathologist or histopathologist, has specialist expertise in neuro-oncology, and takes part in the national External Quality Assurance scheme for neuropathology organised by the British Neuropathological Society.
- Neurologist(s) - with expertise in neurooncology, epilepsy or neuro-rehabilitation.
- Clinical oncologist(s) - with a special interest in tumours of the CNS.
- Clinical nurse specialist(s) with specialist knowledge of CNS tumours.
- Specialist palliative care professional.
- Neuropsychologist(s) with a special interest in tumours of the CNS.
- Specialist AHP(s) including occupational therapy, physiotherapy, speech and language therapy, dietetics and others as appropriate, who have knowledge and experience in tumours of the CNS.
- Multidisciplinary team coordinator(s).
- Others as required (extended multidisciplinary team members).

Extended multidisciplinary team members includes (when required) representatives from:

- Ward nursing
- Community palliative nursing
- Neuropsychiatry/psychology.
- Epilepsy nurse specialists.
- Dietician.

### **Core membership of the cancer network brain and other CNS tumours multidisciplinary team**

- A neurologist with specified DCC PAs for the care of patients with the neurological consequences of a CNS tumour and of its treatment;
- Clinical oncologist(s) who takes responsibility for radiotherapy and who may take responsibility, in addition, for chemotherapy. If this clinical oncologist core member does not take responsibility for chemotherapy, another core team member should be named;
- Clinical nurse specialist(s);
- A healthcare professional who is a core member of a specialist palliative care team;

- An occupational therapist with time specified in their job plan for the care of patients with a CNS tumour;
- A speech and language therapist with time specified in their job plan for the care of patients with a CNS tumour;
- A physiotherapist with time specified in their job plan for the care of patients with a CNS tumour;
- A therapy radiographer;
- A MDT coordinator/secretary.

Extended multidisciplinary team members includes:

- A radiologist;
- A dietician;
- A clinical psychologist;
- A psychiatrist.

And may include

- Epilepsy nurse specialists.
- Representatives from ward nursing, community palliative nursing epilepsy nurse specialist, neuropsychology/neuropsychiatry.

#### **Core membership of the pituitary multidisciplinary team**

- A neurosurgeon with a practice in pituitary surgery or ear, nose and throat surgeon with practice in pituitary surgery.
- An endocrinologist with a practice in pituitary disorders.
- A neuroradiologist.
- Neuropathologist(s).
- A clinical oncologist.
- A clinical nurse specialist.
- An multidisciplinary team coordinator

#### **Core membership of the spinal cord multidisciplinary team**

- A neurosurgeon with a practice in spinal surgery or orthopaedic surgeon with practice in spinal surgery (at least 50% practice in spinal surgery).
- A neuroradiologist.
- Neuropathologist(s).
- An allied healthcare professional agreed as having responsibility for liaison with neurorehabilitation service.
- A clinical oncologist.
- A clinical nurse specialist.
- A multidisciplinary team coordinator.

#### **Core membership of the skull base multidisciplinary team**

- Surgeons-a combination which should fulfil the following:
  - Mandatory minimum core membership consists of a neurosurgeon with a practice in skull base surgery plus at least one, out of the following

(whichever are members, they should have a practice in skull base surgery), ear, nose and throat, maxillofacial, plastic surgeon;

- If not included as a core member, there should be ear, nose and throat, maxillofacial, and ophthalmic surgeons as mandatory extended team members;
- An allied health professional agreed as having responsibility for liaison with neurorehabilitation services;
- A neuroradiologist;
- Neuropathologist(s);
- An allied health professional agreed as having responsibility for liaison with neurorehabilitation service;
- A Clinical oncologist;
- A Clinical nurse specialist;
- An multidisciplinary team coordinator.

### **Patient experience**

The service should be patient centred and should respond to patient and carer feedback. Excellent communication between professionals and patients is particularly important and can avoid complaints and improve patient satisfaction.

Patient experience is reported in the national cancer patient survey. In this survey patients with access to a clinical nurse specialist reported much more favourably than those without on a range of items related to information, choice and care and commissioners may wish to ensure that enough clinical nurse specialists are in post. The national programme for advanced communications skills training provides the opportunity for senior clinicians to improve communications skills and all core multidisciplinary team members should have attended this.

### **Patient Information**

Every patient and family / carer must receive information about their condition in an appropriate format. Verbal and written information should be provided in a way that is clearly understood by patients and free from jargon. The information must cover:

- Description of the disease.
- Management of the disease within the scope of the commissioned service as described in the specification, clinical pathways and service standards.
- Diagnostic procedures.
- Treatment options and their effects (including potential adverse effects).
- Any discussion of predicted outcome with patients should take account of their requirements and requests around this information.
- Drugs and other treatments commissioned in the clinical pathway.
- Self-management and care.
- Dietary and nutrition information.
- Contact details of the patient's allocated key worker.
- Support organisations or internet resources recommended by the clinical team.

The service must also provide education to patients and carers on:

- Symptoms of infection.
- Wound healing problems.
- Contact in case of concern.

The useful reference is the Information Prescription Service (IPS) which allows users, both professional and public, to create information prescriptions (IPs) for long-term health needs. <http://www.nhs.uk/IPG/Pages/AboutThisService.aspx>

### **Referral processes and sources**

All referrals are to be managed within the Cancer Waiting Time thresholds.

NICE referral guidelines for suspected cancer make specific recommendations for the referral of patients with suspected brain or other CNS tumours. Implementation of these guidelines, as well as new stroke and transient ischaemic attack (TIA) pathways, should help professionals and agencies providing first contact care to identify those adult patients more likely to have a high-grade tumour. Such professionals and agencies include GPs, nurse practitioners, ophthalmic practitioners, out-of-hours services, NHS Direct and clinicians in A&E departments.

The advice for managing children and young people with these conditions has been addressed separately in the NICE guidance: improving outcomes in children and young people with cancer. Please also refer to the service specification for cancer in children and young people

Referrals are accepted by any qualified doctor from the specialist brain & CNS cancer multidisciplinary team where the patient has confirmed or suspected brain or central nervous system cancer including:

- Brain tumours and rarer CNS tumours.
- Pituitary tumours
- Skull base tumours
- Spinal cord tumours
- Primary neuroectodermal tumours (PNET)
- Optic tract gliomas.
- Primary central nervous system lymphomas.
- Pineal tumours

The receiving clinician at one of the providers may request the referrer to carry out further investigations to aid the proper diagnosis of the patient's condition.

The symptoms associated with brain tumours include headaches, seizures, changes of mental, psychological or mood states, unilateral deafness and progressive neurological deficit. All of these symptoms are common in general practice.

Specialist brain & CNS multidisciplinary teams should develop and agree network referral criteria and pathways in line with the NICE guidelines recommendations for the referral of patients with suspected brain or other CNS tumours published in: referral guidelines for suspected cancer. These local pathways are to detail explicit

advice and diagnostic test for GPs to access.

The service is required to develop and agree network intra-hospital guidelines for cross referral from other specialities and emergency departments.

### **Radiology and pathology**

The service must have adequate investigation and imaging capacity so that patients with suspected CNS tumours undergo assessment and treatment is undertaken in a timely way (in line with cancer waiting time national targets). This usually involves:

- Neuroradiological imaging and histopathological evaluation.
- Biopsy or tumour resection.
- Germ cell tumour markers and histopathological evaluation.
- Computed tomography (CT).
- Magnetic resonance imaging (MRI).
- Other imaging techniques, including MR spectroscopy, diffusion and perfusion imaging, single photon emission computed tomography (SPECT) and positron emission tomography (PET).

There should be rapid access for diagnostic imaging (e.g. MRI) and neurosurgical biopsy or resection services, including image localisation and stereotactic techniques. In addition the service should have an electronic image transfer system in place to ensure timely image transfer between the local hospital and neuroscience multidisciplinary team. Commissioners may wish to agree an appropriate turnaround time for communicating the results back to patients.

Neuropathology and neuroradiology services should be provided to a level that ensures practitioners in these specialities can deliver appropriate diagnostic investigations in a timely and efficient manner, complying with national cancer waiting times targets, and such that they can be involved in preoperative and postoperative management decisions and intraoperative diagnosis.

### **Diagnosis**

Multidisciplinary teams should agree local clinical guidelines for diagnostic investigations to detect brain and CNS cancer in all potential patient groups, the use of which should be audited throughout the network. These should deal with establishing the initial diagnosis, pre-operative assessment, assessment of emergency cases, follow-up procedures, and surveillance of patients at high risk (particularly those with known genetic susceptibility to brain and CNS cancer).

The use of molecular markers is important to supporting diagnosis, prognosis and prediction of drug response in gliomas and metastatic disease though not all molecular markers are in routine practice. Commissioners should work with the network tumour group to define and agree use of existing and new molecular markers.

Decisions on whether, or when, to carry out further investigations should be made by discussion between hospital specialists and patients. The specialist brain & CNS

multidisciplinary team should agree with their local cancer networks diagnostic protocols.

Emergency presentation of cancer is strongly associated with poorer survival. In brain and CNS cancer overall around 60 per cent of patients present as emergencies and so it is important to have good emergency systems in place.

Providers should:

- develop an algorithm to support decision-making in A&E or primary care
- set up an emergency communication alert system service for GPs/A&E/ Assessment Units/ clinicians to enable rapid specialty assessment and outpatient investigations

“Any patients presenting as an emergency to the local hospital with symptoms suspicious of brain/ CNS tumours should be investigated and managed based on the emergency referral pathway agreed between the hospital and the Brain and CNS MDT” This applies to patients admitted at night or during weekends, as well as those who are admitted during normal working hours.

### **Grading of Tumours**

Providers must include grading information in their cancer registration dataset (this will become mandated in the Cancer Outcomes Services Dataset from early 2013). This data is essential for directing the optimum treatment, for providing prognostic information for the patient and are also essential to the better understanding of the reasons behind the UK's poor cancer survival rates. Cancer stage is best captured electronically at multidisciplinary team meetings and transferred directly to cancer registries. Grading and other pathological data can also be extracted direct from pathology reports and sent to cancer registries. N.B. There is no staging for brain tumours equivalent to the tumour-node- metastasis (TNM) or other staging systems. However there are *4 grades of malignancy* in the WHO classification.

### **Treatment**

All possible management options should be discussed with the patients. The treatment each patient receives should be tailored to fit their individual values and situation, so it is essential that patients are actively involved in decision-making. This requires that they receive adequate and accurate information, both through meetings with members of the multidisciplinary team, and in published forms that they can study at home. Patients should be given sufficient time to consider all the options available to them.

Management of these tumours depends on their anatomical position and their pathological type. Tumours within the skull, but outside the brain, such as meningiomas, can often be completely excised with a very good prognosis. Tumours within the brain, such as gliomas, can rarely be completely removed because of their relation to critical structures and the infiltrating nature of the tumour. Depending on the type of tumour (for example, high-grade glioma) there may be benefits associated with treatment by resection, radiotherapy, including SRS/SRT, chemotherapy or a combination.

## **Chemotherapy and radiotherapy**

Chemotherapy and radiotherapy are important components in the treatment of some patients and should be carried out at designated centres by appropriate specialists as recommended by a specialist brain & CNS multidisciplinary team.

There should be a formal relationship between the specialist brain & CNS multidisciplinary team and the provider of non-surgical oncology services that is characterised by the agreement of network protocols, good communication, and well-defined referral pathways. This relationship should be defined in writing and approved by the Chair of the Neuro- Oncology Disease Site Group (NDSG) and the lead clinician in the specialist brain & CNS multidisciplinary team. Audits of compliance with these protocols will need to be demonstrated.

Refer to the following documents for more detailed description of these services:

- Adult systemic anti-cancer therapy (SACT/chemotherapy) service specification
- Radiotherapy model service specification 2012/13
- Stereotactic Radiation Therapy

## **Follow-up**

There should be an agreed follow-up policy for all patients. A clear communications framework should be in place as identified in the Improving Outcomes Guidance. Where patients have received specialist surgery outside their local hospital catchment the cancer network multidisciplinary team should take responsibility to ensure appropriate follow-up is given. This may require referral back to a neuroscience multidisciplinary team.

The Improving Outcomes Guidance series of documents made recommendations on follow-up care. Providers will need to adhere to cancer specific guidelines for follow up agreed through the NSSG and ensure patients have a follow up plan. The cancer specific guidelines will identify that some patients will need to continue receiving follow up from the specialised service but it is expected the majority will be able to receive follow up locally. The provider will need to ensure effective hand over of care and / or work collaboratively with other agencies to ensure patients have follow up plans appropriate to their needs.

## **Neuro-rehabilitation**

It is important that patients are supported from diagnosis through the entire pathway with appropriate neuro-rehabilitation support. The rehabilitation care pathways provide a model for this support and cover the acute, community and primary care settings. There should be appropriate assessment of patients' rehabilitative needs across the pathway and the provider must ensure that high quality neuro-rehabilitation is provided in line with the network agreed brain and CNS rehab pathway at:

Commissioners may wish to work with network tumour groups to define 'best practise' including a full neuro-rehab prescription that would determine what that patient needs (management plan) and what therefore must be commissioned from rehab providers, shared care services or local practises aiming to provide local services. Consideration should be given to neuro-rehab services for patients with high grade tumours where there may be a defined benefit and for patients with low grade tumours where neuro-rehab should ideally be available both before and after treatment.

### **Supportive and Palliative Care**

The provider shall give high quality supportive and palliative care in line with NICE guidance. The extended team for the multidisciplinary team includes additional specialists to achieve this requirement. Patients who are managed by a brain and CNS cancer multidisciplinary team will be allocated a key worker.

Each patient should be offered an holistic needs assessment at key points in their cancer pathway including at the end of primary treatment and the beginning of the end of life. A formal care plan should be developed. The nurse specialist(s) should ensure the results of patients' holistic needs assessment are taken into account in the multidisciplinary team decision making.

Patients who require palliative care will be referred to a palliative care team in the hospital and the team will be involved early to liaise directly with the community services. Specialist palliative care advice will be available on a 24 hour, seven days a week basis.

### **Survivorship**

The National Cancer Survivorship Initiative (NCSI) is testing new models of care aimed at improving the health and well being of cancer survivors. The new model stratifies patients on the basis of need including a shift towards supported self management where appropriate. In some circumstances traditional outpatient follow-up may be replaced by remote monitoring. The model also incorporates care coordination through a treatment summary and written plan of care.

It will be important for commissioners to ensure that work from this programme is included and developed locally to support patients whose care will return to their more local health providers once specialist care is no longer required.

### **End of life care**

The Brain and CNS service should have clear pathways agreed for patients care at the end of life. This will include services within hospitals, community services and services in the voluntary sector. The provider should provide end of life care in line



with NICE guidance and in particular the markers of high quality care set out in the NICE quality standard for end of life care for adults.

### **Acute oncology service**

All hospitals with an A&E department should have an “acute oncology service” (AOS), bringing together relevant staff from A&E, general medicine, haematology and clinical/medical oncology, oncology nursing and oncology pharmacy. This will provide emergency care not only for cancer patients who develop complications following chemotherapy, but also for patients admitted suffering from the consequences of their cancer. For full details on AOS please refer to the service specification for chemotherapy referred to above.

### **Care pathways**

The local care pathway for brain tumour should be consistent with the national pathway on Map of Medicine. The process of producing the pathway and subsequent updates has been accredited by the National Cancer Action Team.

[http://eng.mapofmedicine.com/evidence/map/brain\\_tumour1.html](http://eng.mapofmedicine.com/evidence/map/brain_tumour1.html)

## **2.3 Population covered**

The service outlined in this specification is for patients ordinarily resident in England\*; or otherwise the commissioning responsibility of the NHS in England (as defined in who pays?: establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

\* - Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

Specifically, this service is for adults with a suspected brain or central nervous system cancer requiring specialised intervention and management, as outlined within this specification.

## **2.4 Any acceptance and exclusion criteria**

Designated clinicians at local hospitals should ensure the prompt referral of all patients who have a suspected or confirmed brain and CNS tumour to the specialist service. This includes all intrinsic and extrinsic primary and secondary tumours.

All referrals are to be managed within the cancer waiting time thresholds.

## **2.5 Interdependencies with other services**

The specialist brain & CNS Cancer multidisciplinary team service providers are the leaders in the NHS for patient care in this area. They provide a direct source of advice and support when other clinicians refer patients into the regional specialist services.

The specialist brain & CNS Cancer multidisciplinary team providers also provide education within the NHS to raise and maintain awareness of brain and central nervous system cancer and their management.

The neuroscience brain and CNS tumours multidisciplinary team, based at a neuroscience centre should work in a coordinated and integrated way to manage patients with suspect brain or CNS tumours with:

- Neuroscience centre, including specialist diagnostic imaging services
  - Neuroscience multidisciplinary team.
  - Pituitary multidisciplinary team.
  - Spinal cord multidisciplinary team.
  - Skull base multidisciplinary team.
- Cancer Network brain and CNS multidisciplinary team, including network diagnostic imaging services.
- Paediatric (including Paediatric Oncology) services.
- Primary care and local acute hospitals, including local diagnostic imaging services.
- Neuro-oncology disease site group brain & CNS tumours.

**The brain & CNS Cancer Network multidisciplinary team** should have rapid access to the following services through clearly agreed pathways, shared care protocols and joint treatment policies:

- Specialist neuropsychology and neuropsychiatry services
- Specialist neurorehabilitation services
- Radiotherapy and stereotactic/radio-surgery services
- Oncology centres
- Specialist palliative services

Co-located services – Intensive/critical care services may be required for some patients undergoing complex surgery and providers will be required to refer to the service specification for critical care.

### **Strategic Clinical Networks**

Strategic clinical networks will be in place from April 2013 located in 12 areas across England. They will be established in areas of major healthcare challenge where a whole system, integrated approach is needed to achieve a real change in quality and outcomes of care for patients. Cancer has been identified as one of the conditions that will be within this new framework. Strategic clinical networks will help commissioners reduce unwarranted variation in services and will encourage innovation. They will use the NHS single change model as the framework for their improvement activities.

Each Neuroscience Network will have a Disease Site Group covering brain and CNS tumours. This group is made up of clinicians across the network who specialise in brain and CNS tumours. It is the primary source of clinical opinion on issues relating to brain and CNS tumours within the network and is an advisor to commissioners locally. Each neuroscience multidisciplinary team or network multidisciplinary team will ensure they fully participate in the network systems for planning and review of services.

This group is responsible for developing referral guidelines, care pathways, standards of care and to share good practice and innovation. The multidisciplinary teams described above will should also collectively implement NICE Improving Outcomes Guidance including the use of new technologies and procedures as appropriate and carry out network and national audits.

Each network should agree an up-to-date list of appropriate clinical trials and other well designed studies for brain and CNS tumour patients and record numbers of patients entered into these trials/studies by each multidisciplinary team.

### **3. Applicable Service Standards**

#### **3.1 Applicable national standards e.g. NICE, Royal College**

Brain and CNS tumour services are required to achieve the two week wait for all patients where brain and CNS cancer is suspected. In addition the services are required to meet the following standards for all specialist brain and CNS cancer patients:

- 31 day wait from diagnosis to first treatment.
- 31 day wait to subsequent treatment.
- 62 day wait from urgent GP referral or screening referral or consultant upgrade to first treatment

Care delivered by the specialist brain & CNS multidisciplinary team service providers must be of a nature and quality to meet the CQC care standards. It is the Trust's responsibility to notify the commissioner on an exceptional basis should there be any breaches of the care standards.

Teams should as a minimum aim to achieve the median value for compliance with the cancer peer review measures, and if a team had immediate risks or serious concerns identified then remedial action plans should be in place. Further details are available at [www.cquins.nhs.uk](http://www.cquins.nhs.uk)

The provider is required to undertake annual patient surveys and develop and implement an action plan based on the findings.

The provider must be able to offer patient choice. This will be both in the context of appointment time and of treatment options and facilities including treatments not available locally.

The service will comply with the relevant NICE quality standards which defines clinical best practice.

#### 4. Key Service Outcomes

The service is expected to monitor the following clinical outcomes for tumours graded 2, 3 and 4 and Pituitary tumours:

- Neurosurgical complication rates
- One year, five and ten year survival rates separately reported for each grade. It would also be useful to have a separation for those treated with palliative intent, no surgery other than biopsy, short course radiotherapy.
- Quality of life for patients

#### Quality and Performance Standards

<i>Performance Indicator</i>	<i>Indicator</i>	<i>Threshold</i>	<i>Method of Measurement</i>	<i>Consequence of breach</i>
<u>Quality</u>				
	% of cases discussed at MDT	100%	Reported within national audit reports	
	Follow up ratios			
	Other quality measures	TBC	TBC	
	Percentage attendance by individual core members or their agreed cover at MDT	67%	Reported in peer review submissions	
	Attendance at advanced communications course  Links to specification point 3.1.10	100%.	Peer review	
Compliance with Peer Review	Compliance with all other peer review measures (other than where agreed with commissioners when the provider	National median compliance level		

	should have an action plan in place that has been agreed with the Commissioner			
<u>Performance &amp; Productivity</u>	The Provider should ensure that these targets are achieved for the part of the patient pathway that it delivers and that when the patient pathway crosses outside the locality border, appropriate scheduling of patients/activity supports achievement of the target by other providers in the pathway wherever possible, except when informed patient choice or clinical appropriateness mitigate against this.			
Waiting Time Compliance				
	62 day wait - % treated in 62 days from GP referral, consultant referral and referral from screening programme	>~86%	Reported on cancer waits database	
Aggregate Measures	14 day suspected cancer referral standard performance (A20)	93%	As above	
	31 day first treatment standard performance (A15)	96%	As above	
	31 day subsequent treatment (Surgery) standard performance (A16)	94%	As above	
	31 day subsequent treatment (Drugs) standard performance (A16)	98%	As above	
	31 day subsequent treatment (Radiotherapy) standard performance (A17)	94%	As above	
	31 day subsequent treatment (Other Treatments) standard performance	TBC	As above	
	31 day subsequent treatment (Palliative) standard	TBC	As above	

	performance			
	62 day standard from 14 day referral performance (A18)	85%	As above	
	62 day standard from screening referral performance (A19)	90%	As above	
	62 day standard from consultant upgrade performance (A19)	TBC	As above	
	Diagnostic Test Waiting Times	TBC	Some national data	

### Activity Performance Indicators

<i>Activity Performance Indicators</i>		<i>Threshold</i>	<i>Consequence of breach</i>
Audits (Specification Point 2.3.4)	Annual review conducted		
	Participation in National Audits	<b>100%</b>	
	Additional Audits undertaken	<b>N/A</b>	
Activity (Specification Point 3.1.4)	Threshold for number of procedures	Establish baseline cancer activity data for :- number of procedures for elective, day case, non elective emergency, outpatient follow-up attendance, outpatient follow-up, outpatient procedures all by speciality	
	Length of stay		
	Level of Admissions		
	Choice		
Service user experience	National cancer patient experience survey (ref A46 main contract)	National survey report when published	If the provider does not take part they will be required to meet with the commissioners to explain reasons for

			not doing so and activity planned to enable the information to be captured through alternative mechanism
	Improving service user experience	Of responses received 75% should express overall satisfaction with the service. Trust to evidence the measures it has taken to improve service user experience and outcomes achieved and numbers / percentages stratified	
	Addressing complaints	Trust to evidence the measures it has taken to address complaints and outcomes achieved	
	Patient involvement	Trust to evidence the actions it has taken to engage with patients and demonstrate where this has impacted	
Staff survey	Staff survey results		
Trial Activity (Specification Point 8.2.8)	Recruitment into trials	Patients eligible for an existing clinical trial should be offered to the chance to be treated in a clinical trial	
Outcomes (Specification	Post surgery mortality	Numbers and percentages baseline to be set	

Point 8.2.6)		in year	
	30 day mortality		
	One year survival		
	Five year survival		
	30 day readmission rates for cancer patients	Numbers and percentage baseline to be set in year	
Data Submission (Specification Point 8.2.6)	Registry dataset submission status	As required by Registry	
	DCOs		
	Staging data (Specification Point 2.3.4)	As required by Registry	

### ICD10 codes and cancer waiting times

Incidence rates and relative survival figures within this document have used the following codes from the international classification of diseases version 10 (ICD10) for malignant neoplasm of the brain and central nervous system:

C70: Malignant neoplasm of meninges – approximately 100 cases per year in England

C71: Malignant neoplasm of brain - approximately 3,800 cases per year

C72: Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system - approximately 100 cases per year.

### Cancer waiting times

Within cancer waiting times, Brain and central nervous system includes the following ICD10 codes:

C47: Malignant neoplasm of peripheral nerves and autonomic nervous system

C69: Malignant neoplasm of eye and adnexa

C70: Malignant neoplasm of meninges

C71: Malignant neoplasm of brain

C72: Malignant neoplasm of spinal cord, cranial nerves and other parts of central nervous system

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